

# **The Identification of Clinically Relevant Indicators to Support Diagnostic Recognition of Adult Hip Dysplasia**

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## ABSTRACT

Acetabular hip dysplasia (AHD) is a treatable condition. Early referral for X-Ray evaluation and specialist treatment are pivotal for successful management. AHD is however, poorly recognised by clinicians including physiotherapists, and patients have been shown to wait unacceptable time periods before their AHD diagnosis is recognised. This delay is coupled with prolonged suffering of pain and increased severity of secondary osteoarthritis, which results in poor surgical outcomes.

An important role of first contact and musculoskeletal physiotherapists is management of patients with hip problems. The aim of this thesis was to identify clinically relevant indicators that would support diagnostic suspicion of AHD by these physiotherapists and accelerate appropriate referral.

The study comprised three pillars of investigation. Pillars 1 and 2 extend the understanding of AHD presentation through questionnaire surveys, which were used to collect the features of AHD experienced by those living with the condition (Pillar 1) and by those experienced in the relevant surgical correction (Pillar 2). Pillar 3 was an observational study that recorded the approach of musculoskeletal physiotherapists to the assessment of patients with hip problems. This identified whether opportunities were available for the identification of patients in whom AHD should be suspected.

The findings established that during patient assessment, physiotherapists successfully elicit information relevant to increasing the index of suspicion for AHD presence, but they do not recognise the relevance of that information nor the requirement for X-Ray referral. This indicates that the opportunity exists to inform practice and to apply new knowledge of AHD presentation.

In conclusion, this study offers extended understanding of potential AHD indicators as described by people living with the condition and those with expertise in its surgical correction. This knowledge should support diagnostic suspicion of AHD, and possibly accelerate referral for X-Ray evaluation and definitive diagnosis when appropriate.

## PUBLICATIONS AND CONFERENCE PRESENTATIONS

The following short paper and conference presentations were undertaken during the process of completing this study:

1. Evans E (2018) Acetabular hip dysplasia: the physio's role. *Frontline* 24(9): 28-29. ISSN: 2045-4910
2. Evans E (2021) Hip Dysplasia in Young People. *Children and Young People with Long Term Conditions Research Group* Platform Presentation Cardiff University [delivered online 12/3/21]
3. Evans E (2021) Hip Dysplasia Awareness. *Swansea Bay University Health Board Physiotherapy Training*. Platform Presentation [delivered online 20/4/21]
4. Evans E (2022) Hip Dysplasia Clinical Indicators. *Primary Care Physio* National specialist provider of primary care (first contact) physiotherapy services. In Service Training Presentation [delivered online 23/2/22]

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This thesis is dedicated to my wonderful, parents; my late father who I miss enormously and my adored mother. They inspired my curiosity for lifelong learning.

## GLOSSARY AND EXPLANATION OF TERMS AND ABBREVIATIONS

Throughout this thesis I have used terms and abbreviations, which I have endeavoured to define within the text. This glossary aims to support those definitions by providing further clarification and my interpretation of their use.

**First Contact Physiotherapists (FCPs)** are defined by the Chartered Society of Physiotherapy (CSP 2021) as musculoskeletal (MSK) physiotherapy specialists with an expertise in the clinical assessment, diagnosis and management of MSK conditions. FCPs work within primary care where they are the first point of contact for patients with MSK problems. They work with other primary care colleagues and with other parts of MSK system. Outpatient MSK physiotherapy services collaborate with FCPs in some geographical regions to ensure the services are complementary and to maximise referral management. In this thesis I have used the term 'First Contact' to refer to physiotherapists based in both primary care and MSK outpatient departments who provide the initial assessment of and early management decisions for patients' presenting with new episodes of hip problems.

The terms **Acetabular Hip Dysplasia (AHD)**, **Hip Dysplasia (HD)** and **Developmental Dysplasia of the Hip (DDH)** are used interchangeably in the literature. For the purposes of clarity, throughout the thesis, the condition, which is the focus of this study, is referred to as AHD. Where it is necessary to make a distinction (mostly age-related), reference is made to either infant DDH, adult AHD or where reference is made more generally to these conditions presenting at various ages, the broader term HD is used.

AHD	Acetabular Hip Dysplasia
CSP	Chartered Society of Physiotherapy
CDH	Congenital Dislocation or Dysplasia of the Hip (now known as DDH)
DDH	Developmental Dysplasia or Dislocation of the Hip
FABER	Flexion, Abduction, External Rotation test
FADDIR	Flexion, Adduction, Internal Rotation test
FAI	Femoroacetabular Impingement
FCP	First contact physiotherapist
GPs	General Practitioners
HD	Hip Dysplasia
JIA	Juvenile Idiopathic Arthritis
MSK	Musculoskeletal
NMR	Non-Medical Referrer
OA	Osteoarthritis
OHD	Occult Hip Dysplasia
PAO	Periacetabular Osteotomy
ROM	Range of Movement
RCoM	The Royal College of Medicine
THR	Total Hip Replacement

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# 1 Introduction

## 1.1 Isabelle's Story

Isabelle was a healthcare student whom I first met when she attended a lecture I was giving. At the time, she was hobbling around on crutches. As a physiotherapist, my curiosity regarding the cause of her altered gait compelled me to ask about her progress. She informed me that she was recuperating from total hip replacement (THR) surgery, yet she was still only 19 years old. Although I have seen how beneficial THR is in older adults, I was shocked to see the need in one so young. Isabelle had experienced hip pain since the age of 7 years that led to an 11-year search for a correct diagnosis. She had been a keen dancer and enjoyed sport, but the demands of these activities on her failing and painful hip resulted in a rapid decline in her participation in these pursuits. The loss of her native joint through THR reduced her pain, but the prosthetic joint will have consequences on her capacity to return to the high impact exercise she previously enjoyed, and which is normal for her age-group. Also, at the age of 19 years, Isabelle seemed uncomfortable with having had a procedure and related physiotherapy that have strong connotations with the elderly.

Isabelle's memories of her hip problem were that as an active, sporty seven-year-old she began to complain of a painful hip for which her parents sought a medical opinion. This marked the start of diagnostic considerations and various treatments that continued for 11 years. Isabelle received regular attention, being seen sometimes repeatedly, by more than seven different specialist consultants, various physiotherapists, and a range of other healthcare professionals. Numerous blood tests were involved, repeated X-Rays, MRI scans, ultrasound scans and eye tests along with joint aspiration procedures and arthrograms. Diagnosis was, however, consistently uncertain and clinicians repeatedly returned to the possibility of Juvenile Idiopathic Arthritis (JIA) being the cause of the problems. This diagnosis led to Isabelle being treated with methotrexate, a disease-modifying anti-rheumatic drug that can have unpleasant side-effects. At this stage, she was just 10 years old, and nothing appeared to be helping.

Isabelle provided me with her copious medical records and X-Rays. They showed that the details she and her parents presented had not, it seems, alerted clinicians to suspect

structural problems of the hip joint. However, a sudden episode of acute pain that limited her mobility, reduced her sports participation, and increased her need for medication, led to Isabelle being referred to a young persons' hip specialist. There, the features of her condition were quickly recognised as indicating the need for specific measurements to be applied to her plain X-rays and immediately the presence of acetabular hip dysplasia (AHD) was identified.

If diagnosed at an early stage in the disease trajectory, AHD can be surgically corrected through a procedure known as periacetabular osteotomy (PAO), which preserves the native hip joint. This is favoured by young adults because the alternatives, hip resurfacing or THR, restrict activity and have limited longevity. This may lead to the need for revision surgery, which carries the risk of joint failure (Bayliss et al 2017).

Isabelle recounted that over time, her hip joint had deteriorated and progressed into secondary osteoarthritis (OA). Evidence shows that pre-operative OA increases the risk of PAO surgical failure (Lerch et al 2017), hence the need for Isabelle to have a THR at her young age. Early diagnosis of AHD, before the onset of secondary OA, is therefore key to maintaining surgical options, but even though AHD is considered the leading cause of premature hip OA (Jacobsen and Sonne-Holm 2005), the identification of AHD presentation features, risk factors and its early detection have received little research attention (Nunley et al 2011; Pun 2016). Increased understanding of these factors might therefore accelerate AHD diagnosis, maintain surgical options, and improve treatment outcomes.

## **1.2 The Problem**

AHD is a treatable, mechanical disorder caused by a deformity of hip joint shape, position and structure (Nunley et al 2011). In healthy hips, joint stability is provided by a deep socket shaped acetabulum, which holds securely a congruent femoral head (Palastanga et al 1998). The stability is enhanced by a fibrocartilaginous labrum that has been shown to contribute 1-2% of total joint loading (Henak et al 2011). AHD, however, is recognised by a shallow acetabulum that can be abnormally orientated causing poor coverage of the femoral head and an unstable articular positioning (Troelsen 2012). This limits the area of articular contact between the acetabulum and femoral head causing increased joint loading (Troelsen 2012), instability and inefficient joint biomechanics. The acetabular labrum is forced into an extended role in the maintenance



of joint stability, exposing it to increased stress and potentially damaging forces (Henak et al 2011). This leads to joint degeneration and secondary OA (Jacobsen et al 2005). When patients initially present with the painful consequences of these issues, localising the cause of the problems can be challenging because the hip is composed of a myriad of deeply-positioned anatomical structures which ensure that the joint accomplishes the functional demands put upon it. A normal, healthy hip joint is capable of a wide range of movements and must also support the entire weight of the body whilst contributing to the stable transmission of weight during functional movements such as walking and running (Palastanga et al 1998). The hip must therefore have strength and stability whilst enabling mobility. To achieve this, the joint, as well as normally having a secure, congruent fit between the acetabulum and femoral head, has a strong joint capsule that is reinforced by related ligaments and muscles (Ng et al 2019). Distinguishing between these structures to identify the cause of a problem is therefore difficult. Yet, timely diagnosis of AHD is important because early recognition, before the onset of OA, facilitates successful corrective surgery and retention of the patient's native hip joint. Whilst there is copious evidence identifying the success of using THR to provide pain-free mobility in *older* adults with OA, the same surgery is also being applied to teenagers and young adults because of their *premature* OA; a condition that is often secondary to a frequently unrecognised AHD (Lever and O'Hara 2008; Wyles et al 2017). Whilst THR is effective in the treatment of serious pain, the procedure restricts activity and young patients can anticipate their life expectancy to exceed that of the prosthetic joint (Kennedy et al 2017) and the risk of multiple THR revisions over the course of a young person's life cannot be ignored (Bayliss et al 2017). Although a recent Lancet report pointed to a 25-year survival of primary THR in some 58% of cases, the authors considered typical patients undergoing THR to be more than 67 years old (Evans et al 2019). More generally, a 10-year implant survival rate is accepted as being the case for THR, although rates vary between the different types of fixations and bearings (National Joint Registry 2021). Hip resurfacing has an even higher failure rate of approximately 5% on average compared with less than 2% for THR over a 5-year period (Smith et al 2012). For older age groups, this is less of a concern than for younger patients who, along with expecting a greater number of life years following a THR, are also likely to have greater demands on their prosthetic hip and generally higher activity levels over decades of use (Nugent et al 2021). Younger age and higher activity levels have been shown to substantially increase the likelihood of subsequent revision surgeries (Bayliss

et al 2017). Unsurprisingly, therefore, in their study of young women adjusting to diagnosis of AHD and deciding on consequent treatment, Gambling and Long (2011) identified a strong desire in these young women to save their native joint. There is a consensus that for AHD, early surgical correction of the native hip joint via PAO can provide successful patient outcomes that delay or avoid the onset of premature secondary OA (Millis et al 2009; Troelsen et al 2009; Lerch et al 2017; Wells et al 2018). PAO improves joint stability through effectively three controlled fractures of the pelvis to reposition and increase the depth of the acetabulum, thereby increasing femoral head coverage (Ganz et al 1988). The procedure corrects the anatomical deficit and consequently improves joint biomechanics with the aim of relieving pain and preventing secondary OA. Evidence shows that there has been considerable success in the procedure first described by Ganz et al (1988) and since modified to introduce ongoing improvements (Mei-Dan et al 2019). Success has been measured in terms of years of native joint survival and the avoidance of conversion to THR (Millis et al 2009; Troelsen et al 2009; Lerch et al 2017; Wells et al 2018). Whilst studies have shown positive outcomes of PAO surgery, with evidence demonstrating a 30-year survival of hips (Lerch et al 2017), it has been established that a pre-operative reduction in joint space as seen in OA, joint incongruity and older age are associated with poor PAO surgical outcomes (Lerch et al 2017).

In cases of AHD, early diagnosis and referral to a specialist young persons' hip clinic are therefore key to effective management of the patient's problems. As highlighted in Isabelle's story however, positive management is not guaranteed. Research shows that for many patients initially presenting for clinical assessment of their hip problems, poor understanding of AHD physical presentation means suspicion of the condition can be overlooked and the patient fails to be referred for the required X-Ray measurements and definitive diagnosis. These delays are not trivial; Nunley et al (2011) showed that mean time from onset of symptoms to definitive diagnosis of AHD was more than 5 years (range 5 months to 29 years). Findings that are supported by Kennedy et al (2017) who identified that, following a mean of 14 months of hip pain, young patients attending their general practitioner (GP) waited on average more than a further 3.5 years before being assessed by a young persons' hip specialist. Consequently, the patient's condition deteriorates, secondary OA begins, and this presents an obstacle for successful PAO surgical outcomes (Isaksen et al 2019). In such cases, replacement of the joint through

hip resurfacing or THR are the only remaining surgical options for these young adult patients, some of whom will still only be in their teenage years (Kennedy et al 2017).

Knowledge of these threats justifies why early referral for the appropriate X-Ray measurements that determine femoral head coverage and acetabular depth, are pivotal to achieving the desired outcomes in the management of patients with AHD. Referring patients for X-Ray evaluation is part of physiotherapy practice and clearly within the scope of their profession. First contact physiotherapists (FCP), where patients can access physiotherapy directly without the need for referral, have been requesting imaging in this context as Non-Medical Referrers (NMR) for a number of years. Indeed, the Chartered Society of Physiotherapy (CSP 2021) states that diagnostic imaging, which is sometimes required for differential diagnosis, can be an important part of a comprehensive physiotherapy assessment. Research evidence continues to highlight, however, that the clinical presentation of AHD is complex and poorly understood (Clohisy et al 2008a; Nunley et al 2011; Ellsworth et al 2021), hence, physiotherapists and other first contact clinicians are not sufficiently informed of the features that should alert them to suspect AHD presence in relevant patients and to justify referral for hip X-Ray evaluation. This is important because, when patients with AHD seek help from an FCP or MSK physiotherapist, the ability of that physiotherapist to refer appropriately for X-ray evaluation, could considerably accelerate appropriate treatment, enabling the most successful outcomes to be achieved (Clohisy et al 2008b). Hence, clinicians need to know what features are associated with AHD presence so that they can be alerted to the need for relevant patients to receive early referral for specific X-Ray measurements and timely AHD diagnosis.

I felt passionately that Isabelle's experience of an 11-year search for correct diagnosis, during which she had many physiotherapy appointments, needed and deserved to be addressed. Firstly, I wanted to identify whether Isabelle's problems had been experienced by others. A brief Google search flagged up that hip dysplasia patient support groups were evident. Looking at the postings on these support groups, it was clear that many reflected Isabelle's story. The nature of these postings shone a light on the desperate search for diagnosis experienced by contributors. It also showed that having lived with hip dysplasia, often for years, AHD sufferers were not only seeking answers to questions but were also posting advice to each other in response to those pleas for help. This demonstrated a level of expertise on the condition, developed by

people with experience of living with hip dysplasia problems. Indeed, postings showed that these people could provide quite graphic accounts of the issues that characterised their condition.

As my interest developed, I became part of a study group who, with Economic and Social Research Council (ESRC) funding, ran a series of seminars for clinicians, researchers and patients with AHD. Seminars included presentations by young people with AHD who provided accounts of their search for diagnosis and the delays they had experienced; clearly, Isabelle's story was representative of others' experiences. In addition, the accounts highlighted frustration because people living with AHD expressed the feeling that the clinicians they consulted did not really listen to what they described. Through their accounts, I was aware that the details these young people reported about their AHD, regularly went beyond what might typically be included by a clinician during a patient assessment. From my own experience, I recognised that physiotherapists as well as other clinicians, focus on what they understand to be relevant to each patient assessment and therefore they direct their questioning to maintain this focus. I wondered, however, whether the detail offered by patients' lived experience of AHD could help to expand the knowledge and understanding of AHD and how it presents. I therefore considered the value of capturing the patient perspective.

Having spent time in young peoples' hip clinics, I had observed that when assessing a patient, surgical specialists view the patients' X-Ray images to evaluate the anatomical deficit and plan the surgery. In addition, these specialists investigate the patient's history and conduct a physical examination of the patient. I questioned whether collecting their knowledge of assessing patients with AHD could provide expertise from which other clinicians could learn.

Having identified that patients and specialist surgeons were key sources of knowledge on AHD presentation, I then considered how I could identify whether this knowledge could support physiotherapists' practice and how best it could inform patient assessment and diagnostic clinical reasoning. From my work as a lecturer in physiotherapy, my understanding of physiotherapy assessment is embedded in what we in the University teach BSc students about assessing patients. I wondered whether what we taught students was actually what was practiced by qualified physiotherapists, and I wanted to establish specifically, the type of data MSK physiotherapists at all levels of expertise and experience collect during the initial assessment of patients with hip problems. This, I

felt, would help me to merge knowledge of AHD presentation with physiotherapists' approach to patient assessment. By doing so, I could ensure that findings would directly and constructively inform education and thus practice and improve patient management with the purpose of accelerating AHD diagnosis. My overall plan for this PhD study was therefore to determine aspects of early AHD presentation that have not previously been recognised by firstly exploring the signs, symptoms and features experienced by those living with AHD. Secondly, I planned to identify what specialist surgeons' views were of AHD patients' history and physical assessment data and what features they considered relevant to the presence of AHD. Finally, I needed to identify the applicability of these AHD-associated features to physiotherapists' patient assessments to establish whether physiotherapists would be well placed to recognise them. I therefore needed to identify the content and type of data collected by MSK physiotherapists during the clinical assessment of patients with hip problems.

### **1.3 Scope of the Thesis**

This study set out to develop new understandings of features associated with AHD presentation that might support the assessment of patients with hip problems. The intention being to inform physiotherapists and other relevant clinicians of when to suspect AHD presence in patients with hip pain, alerting them to the need for X-Ray referral for definitive diagnosis. This thesis explains the justification for the study, the approach, and the findings. These are presented in 7 chapters, the first of which has provided an introduction that sets the scene for the study. The content of the remaining chapters is outlined in the subsections that follow.

#### **1.3.1 Diagnosis and Prevalence of AHD**

Research literature that supports current understanding of AHD diagnosis is dominated by investigations on the radiographic measurements that define AHD. These measurements are important because they identify the degree of anatomical deficit of femoral head coverage by the acetabulum, which establishes definitive AHD diagnosis. Because of this, the measurements play a key role in estimations of AHD prevalence (Engesaeter et al 2013; Tian et al 2017; Leide et al 2021). Following an explanation of the disease trajectory, Chapter 2 explains these measures and discusses the evidence upon which definitive diagnosis of AHD is determined and prevalence estimates are

calculated. This is of relevance to FCP and MSK physiotherapists because of the role they have in recognising when patient referral for X-Ray is required for differential diagnosis (CSP 2021). Chapter 2 goes on to consider the importance to surgical outcomes of timely diagnosis and how this relates to what is currently understood about physiotherapists' diagnostic clinical reasoning and differential diagnosis. It highlights how knowledge of patient presentation plays a key role in the process of physiotherapists' clinical reasoning.

### **1.3.2 Current Evidence of AHD Patient Presentation**

Although the occurrence of AHD is not uncommon, it has been identified as being poorly recognised and consequently it is often overlooked (Leide et al 2021) particularly in the early stages of patients' problems. This delays treatment and the effects can lead to limited surgical options. Other conditions of the hip such as OA, femoroacetabular impingement (FAI) and labral damage, appear to have a stronger presence in recent literature, which perhaps relegates the suspicion of AHD in favour of these alternative diagnoses. To establish what empirical evidence of AHD presentation is available to support its diagnostic recognition, Chapter 3 offers a systematic review of published studies to identify physical features associated with AHD. It provides an evaluation of the current position of evidence-based knowledge and understanding of symptomatic AHD presentation. Hence, the review determines the gaps in current knowledge that need to be addressed and that lead to the research question, aims and objectives of this thesis.

### **1.3.3 Building the Evidence**

Addressing the practical problem of poor AHD recognition, misdiagnosis and delayed treatment demands a practical solution that can be applied to the clinical assessment of patients with hip problems. A pragmatic approach was therefore appropriate. In Chapter 4, this pragmatic approach is explained as it justifies the research design and methodology for the investigation.

Logical diagnostic decision-making requires knowledge and understanding of a range of factors that include the pathology of a condition, identification of patients' signs and symptoms, and an ability to associate those signs and symptoms with a particular pathologic condition (Nordin 2000). This presents several problems to the timely diagnosis of AHD in that information detailing signs and symptoms of symptomatic AHD

is sparse (Nunley et al 2011). To address this, I considered it important to understand patients' experiences of the condition and identify how they describe their problems. In addition, I collected further insight from specialist PAO surgeons who have demonstrated expertise in correcting the problems associated with AHD because their understanding of pre-surgery AHD patient presentation was considered valuable. Building the understanding of AHD in this way can, however, only contribute to solving the problem of poor recognition and delayed diagnosis if it can be integrated into the decision-making of physiotherapists and other first contact clinicians involved in the assessment of patients (Nordin 2000). These considerations are discussed in Chapter 5 and lead to a description of the methods I applied to the collection of data for this study that involved three pillars of study. Firstly, in Pillar 1, I used patient surveys to identify the experiences of people living with AHD and determine how they describe their AHD-related problems. Secondly, in Pillar 2 I surveyed surgeons specialising in young peoples' hip correction to establish whether their surgical assessment procedures could uncover features of AHD presentation that would be helpful. Thirdly, I considered it important that both Pillar 1 and Pillar 2 surveys generated data that would inform clinical practice. Specifically, findings needed to support differential diagnosis of hip problems and assist physiotherapists and other relevant clinicians to recognise when referral for diagnostic X-Ray is indicated. For Pillar 3 therefore, I used an observational procedure to explore the content of physiotherapy assessment and evaluate whether opportunities are available for physiotherapists to apply this expanded knowledge of AHD presentation to their clinical reasoning.

### **1.3.4 Knowledge Progression and Contribution to Problem Resolution**

I present the results of the data collected from these three pillars of study in Chapter 6. Firstly, through thematic analysis of survey data from Pillars 1 and 2, I convey the array of features reported by people living with AHD and specialist PAO surgeons. Secondly, by providing the results of the physiotherapy patient assessment observations (Pillar 3), I highlight the type of data they collected, and the resulting patient management decisions made by these physiotherapists at the conclusion of their clinical assessment. I then discuss these results in Chapter 7 where I synthesise the findings across the three pillars of study and in conjunction with current literature. I follow this with a further discussion of the key findings in which I explain their implications to clinical practice. Here, I also address limitations of the study and provide recommendations for future

research that should continue to build on the understanding generated by this study. Finally, I offer a conclusion that summarises the thesis and its contribution to knowledge development.

In brief, the research questions this PhD addresses are: **What are the relevant clinical indicators that support diagnostic suspicion of adult acetabular hip dysplasia and how can they be incorporated into physiotherapy practice to signal the need for X-Ray referral and definitive diagnosis?**



## **2 Background**

### **2.1 Chapter Introduction**

Identifying the circumstances in which AHD should be suspected presents a challenge because there is currently no detailed clinical picture of the condition's physical presentation. This poses a threat to the recognition of AHD in patients with hip problems and risks under-estimation of AHD prevalence estimates. Poor recognition also impacts upon treatment outcomes, therefore, methods need to be found to improve the understanding of AHD patient presentation for accurate diagnosis. The purpose of this chapter is to firstly identify what is currently understood about defining AHD, the radiographic measures that are used to confirm the presence of the condition and the influence these have on prevalence estimates. Secondly, treatment methods are then outlined, highlighting how delayed diagnosis in AHD results in limited surgical options or poor outcomes.

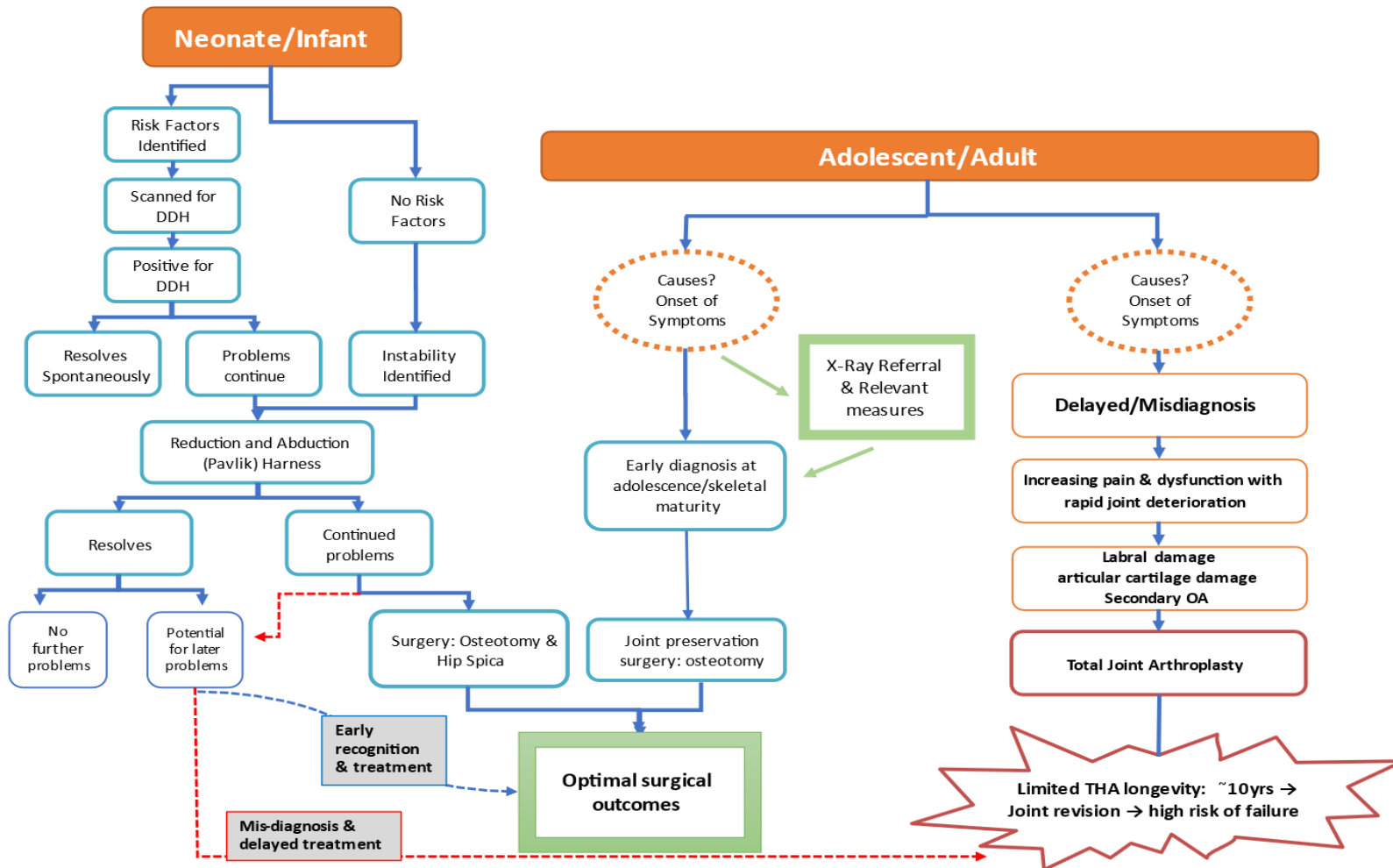
Physiotherapists are often the first clinicians to assess people with hip problems. They are therefore well placed to facilitate early diagnosis of AHD. This can only occur however if they understand how patients with the condition present and can distinguish AHD presentation from that of other hip conditions. The final part of this chapter therefore considers both the importance of knowledge to physiotherapists' diagnostic clinical reasoning and the differential diagnosis of patients presenting with hip problems.

### **2.2 AHD Disease Trajectory**

Abnormality of any hip joint structure results in altered biomechanics that predisposes the individual to intra-articular degenerative changes and secondary OA (Wyles et al 2017). In AHD, the shallowness of the acetabulum can result in chronic disability due to the joint being structurally unstable and at risk of dislocation. This, and the coexistence of altered joint stresses lead to premature secondary OA (Bullough 2004). AHD is therefore a pre-arthritic hip pathology that is considered a condition primarily of young people (Pun 2016). Surgical correction is directed towards reducing the risk of secondary OA by deepening the acetabulum and improving the stability of the femoroacetabular articulation. To optimise outcomes, the procedure needs to occur in the early or pre-arthritic stage, before the congruency of the joint surfaces alters, hence early recognition and diagnosis are essential (Nunley et al 2011). Clohisy et al (2008a)

report that at the Annual Meeting of the American Orthopedic Association (2007), delegates were surveyed to collect their perceptions of the quality of diagnostic evaluation and treatment of early and pre-arthritis hip disease. Fifty-seven percent stated that diagnosis and surgical care were deficient. The authors confirmed that improved management of these patients was indicated specifically the understanding of patient evaluation and selection for surgery. The obstacles to achieving this challenge include the fact that these young patients present with problems that can range from mild, barely detectable instability through to actual dislocation of the hip (Kose et al 2012) at any time from childhood to adulthood (Lee et al 2013). They may also present to a variety of different health professionals, which as well as physiotherapists and General Practitioners (GPs), can include specialists in sports medicine, orthopaedic, paediatric, adult hip joint and trauma surgery (Clohisy et al 2008a), adding to the difficulties of diagnostic standardisation and of knowledge dissemination. The challenges of establishing a clinical picture of AHD add to these diagnostic difficulties. For instance, whilst Isabelle's problems did not present until she was 7 years of age, hip dysplasia can present during infancy, when it is referred to as Developmental Dysplasia of the Hip (DDH). Additionally, a substantial number of cases do not present or are not diagnosed until adolescence or young adulthood. The link between these onset times, if indeed there is one, is not clearly understood. For instance, whilst some authors consider infant onset and later adolescent or adult onset to be on a continuum (Gala et al 2016), other authors have presented evidence to suggest cases where the two should be considered different conditions with different aetiologies (Lee et al 2013). The literature argues that two possible situations may lead to a later presentation. Firstly, early, infant anatomical deviations of the hip joint may remain clinically silent until adolescence or beyond (Pun 2016), or there might be a reoccurrence of infantile DDH in the young person for which they were previously diagnosed and possibly treated (Spence et al 2013). Secondly, patients may have had radiographically normal and stable hips as infants, but they develop dysplasia during skeletal maturation (Lee et al 2013). Different views exist, but onset at this later stage is considered by some to be a different aetiology from infant DDH (Lee et al 2013). I have summarised these views of onset times in Figure 2, which also includes a summary of the AHD trajectory that is explained in subsequent sections.

Figure 2.1 Onset Patterns of Infant DDH and Adult AHD and their Trajectory



Key: Developmental Dysplasia of the Hip (DDH); Osteoarthritis (OA); Total Hip Arthroplasty (THA)

The literature shows that infant DDH refers to a condition of the hip joint, in which the developing femoral head fails to articulate securely with the immature acetabulum due to abnormal laxity of the joint capsule (Okano et al 2015). By contrast, adult onset of the condition demonstrates a more skeletally mature acetabulum that is shallow and often abnormally orientated (Troelsen 2012) resulting in poor femoral head coverage.

Therefore, hip dysplasia at adolescence and adulthood reveals acetabular abnormalities, at which stage, the condition is distinguished from the infant form by being referred to as Acetabular Hip Dysplasia (AHD). The term is appropriate because it describes what is pictured and assessed radiographically. The literature, however, shows inconsistent use of the terminology, therefore, for the purposes of clarity throughout this thesis, the condition which is the focus of this study will be referred to as Acetabular Hip Dysplasia (AHD). Where it is necessary to make a distinction, reference will be made to either infant DDH, adult AHD or where collective reference is made more generally to conditions presenting at various ages, the term Hip Dysplasia (HD) will be used.

In infants, the urgency of early detection for affecting optimal treatment outcomes is well recognised and the clinical picture of infant DDH is well developed (Roposch et al 2011 and 2014; Williams et al 2016). As such, the condition is recognised by various professional disciplines including paediatricians and physiotherapists who routinely assess neonates for the condition (Wilkinson 2011). DDH risk factors have been established (Bache et al 2002), and evidence shows that these include: being female, breech delivery at birth, positive family history and being first-born (Ortiz-Neira et al 2012). In addition, specific physical assessment of neonatal hip stability, known as the Ortoloni and Barlow tests are applied (Sulaiman et al 2011; Perry and Paton 2019) and are used to identify infants requiring ultrasound imaging for diagnostic confirmation of DDH and severity assessment (Roposch et al 2011 and 2014; Williams et al 2016). Indeed, the level of understanding of infant DDH is such that some countries routinely screen all at risk infants (Pun 2016) to avoid diagnostic delay and provide early effective treatment. The same cannot be said for adult AHD. Dick et al (2018) point out that such hip problems affecting young adults predominantly between the ages of 16 and 50 years, fall between the far stronger research interests evident in conditions of young children such as DDH, Perthes and septic arthritis, and those of the elderly, which is principally OA. Hip conditions occurring between these two extremes, that is, in adolescents and young adults, therefore remain poorly understood and poorly recognised. The impact of this is inadequate rates of early AHD detection that risk

limiting surgical options with life-long consequences (Kennedy et al 2017). Clearly, there is a need for adult AHD to receive the same level of diagnostic understanding as that of infant DDH because early diagnosis is key to facilitating timely treatment and OA prevention (Nunley et al 2011). This is of relevance to MSK physiotherapists who are often the first clinicians to assess the patient's hip when problems present.

### **2.3 AHD Definitive Diagnosis**

AHD diagnosis requires the identification of clinical indicators and the application of radiographic measures (Wilkin et al 2017). Whilst it is the painful, often disabling symptoms that cause the patient to seek treatment, literature on diagnosis of AHD reveals that it is dominated by investigations into radiographic measurements. These quantify the anatomical deficit and provide an objective definition of the condition. Therefore, both definitive diagnosis of AHD and preoperative assessment for surgical treatment necessitate referral for X-Ray imaging of the pelvis and the application of specific measures that determine the severity of the structural abnormalities (Leide et al 2021). Anatomical deficits of AHD relate to the depth and the vertical orientation of the acetabulum (Troelsen 2012). These morphological features affect the amount of femoral head coverage offered by the acetabulum. A slight shallowness of the acetabulum alone causes joint instability whereas more severe acetabular insufficiency results in full dislocation (Beltran et al 2013) where the femoral head is not contained within the true acetabulum but instead sits in what is known as a false acetabulum (Kose et al 2012). The most commonly used acetabular depth measurement is applied to a conventional antero-posterior (AP) pelvic X-Ray image and is known as the Lateral Centre Edge Angle (CEA) of Wiberg (Figure 2.2). It reflects the containment of the femoral head within the acetabulum (Engesaeter et al 2013). The angle is formed by a perpendicular line drawn through the femoral head centre and a second oblique line from the same point to the lateral margin of the acetabulum (Nogier et al 2010; Beltran et al 2013). It is generally accepted that, whilst the angle alters during skeletal growth, in adults a CEA greater than 25° is normal, between 20° and 25° it is indicative of mild or borderline hip dysplasia and a measure of less than 20° indicates pathological AHD (Johnsen et al 2008; Clohisy et al 2008b; Troelsen 2012; Leide et al 2021).

*Figure 2.2 Measurement of Lateral Centre Edge Angle  
(Beltran et al 2013)*

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Some investigators couple measurement of lateral CEA with the anterior CEA of Lequesne (Figure 2.3), which assesses anterior coverage of the femoral head (Nogier et al 2010). It is measured in the false profile image of the hip joint where the patient is in a standing position with an angle of  $65^\circ$  between the pelvis and the film (Clohisy et al 2008b). The anterior CEA angle is then produced by a perpendicular line running through the femoral head centre and a second line from the centre of the femoral head to the anterior most aspect of the acetabulum (Nogier et al 2010). It is used to indicate femoral head under-coverage anteriorly, with pathologic AHD being recognised when measurements are less than  $20^\circ$ .

*Figure 2.3 Measurement of Anterior Centre Edge Angle  
(Beltran et al 2013)*

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*Key: Vertical-centre-anterior margin angle (VCA) indicating anterior femoral head coverage*

Acetabular Depth (AD) can be measured by applying a line drawn from the most lateral edge of the acetabulum to the ipsilateral upper edge of the symphysis pubis (Figure 2.4). A second perpendicular line is drawn from the deepest point of the acetabulum roof to meet the first line (DE). Measurement of this line is taken and values below 9 mm are considered to indicate AHD (Adanir and Zorer 2018).

*Figure 2.4 Measurement of Acetabular Depth  
(Daysal et al 2007)*

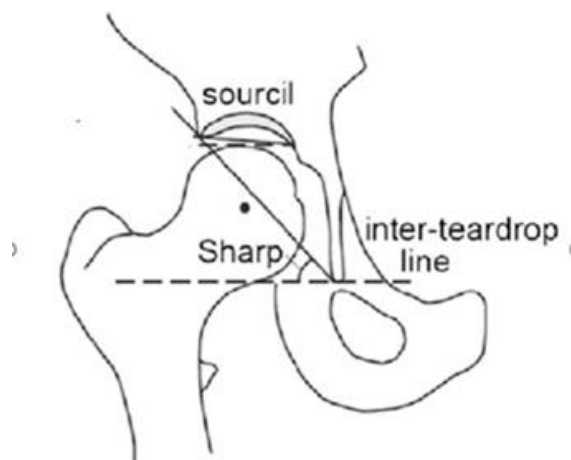
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*Key: ABC represents the Centre Edge Angle and acetabular depth is the distance between D and E.*

As well as the depth of the acetabulum, its position of inclination is also considered because this contributes to femoral head coverage. The acetabular inclination is

assessed using Sharp's Angle (Figure 2:5), which is measured by extending a horizontal line through the inferior tip of both the right and left pelvic tear drops (a radiograph feature marked 'inter-teardrop line' on Figure 2.5 below) and another line from the lateral edge of the acetabular roof to the horizontal line (Adanir and Zorer 2018). Angles between 33 and 38 degrees are considered normal with steeper angles greater than 42 degrees considered dysplastic (Mannava et al 2017).

*Figure 2.5 Sharp's Angle  
(Figure adapted from Laborie et al 2013 p.927 with acetabular roof angle of Tönnis removed)*



*Key: Sharp's angle is constructed by making a horizontal inter-teardrop line and a line connecting the inferior tip of the teardrop to the lateral acetabular rim.*

The consequences of acetabular depth and inclination are sometimes considered in terms of the resulting weight-bearing zone of the acetabulum because, in dysplastic hips, it is a reduction in this area that concentrates loading forces and contributes to the development of secondary OA (Jacobsen and Sonne-Holm 2005). The Tönnis angle (Figure 2.6) provides a measure of the acetabular 'roof' inclination and is reflective of the acetabular weight-bearing region (Beltran et al 2013). Also known as the Acetabular Index (AI) or horizontal toit externe (HTE) angle, it is calculated by the angle created from a horizontal line coming from the medial edge of the sourcil (a radiographic feature marked by an area of increased sclerosis and representing the weight-bearing area of the acetabulum) and a second line extending from the same point, running obliquely to the lateral edge of the sourcil (Figure 2.6).



*Figure 2.6 The Tönnis Angle  
(Beltran et al 2013)*

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Beltran et al (2013) consider normal Tönnis angles or AI values to be less than  $13^{\circ}$  whereas Clohisy et al (2008b), Troelsen (2012) and Ellsworth et al (2021) consider measures greater than  $10^{\circ}$  to indicate instability and dysplasia. Some controversy therefore exists regarding the exact cut-off points for what is deemed 'normal' but the greater the Tönnis angle the greater the inclination and hence, the bigger the risk of structural instability. By contrast, people with smaller Tönnis or AI values are at increasing risk of pincer type FAI (Clohisy et al 2008b) whereby over-coverage of the femoral head by the acetabulum causes abutment of the femoral neck against the acetabulum edge.

Radiographic imaging is also used to identify when the problem extends to femoroacetabular joint dislocation. A radiographic feature known as Shenton's line (Figure 2.7) curves from the lesser trochanter, along the femoral neck to connect with a line running along the inner margin of the pubis. The identification of a break in this line is used to identify femoral head dislocation as the femoral neck is seen to lie superior to the pubic line (Tian et al 2017).

*Figure 2.7 Shenton's Line  
(Popat et al 2020)*

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*Shenton's Line is normal on the right hip (marked in blue) and is interrupted on the left (marked in red) indicating a dislocated dysplastic hip*

The radiographic measures explained above are well accepted, traditional approaches to the evaluation of acetabular depth, orientation, and the position of the femoral head relative to the acetabulum. Due to the lack of specificity and understanding of AHD signs and symptoms, these radiographic measures form the cornerstones of diagnosis (Beaulé 2019). As with any measure, however, findings may be subject to variability due to several factors which influence both the repeatability of the applied measures and their diagnostic interpretation. Firstly, measurement errors can be caused by inaccurate patient positioning during the X-Ray imaging and the variability in the precision with which anatomical landmarks are identified (Beltran et al 2013). As Troelsen et al (2009) point out, this can cause a lack of agreement between clinicians on the diagnostic presence of AHD and its severity. In addressing this concern, Troelsen et al (2010) assessed the ability of 4 'raters', 3 of whom were orthopaedic surgeons and 1, a consultant radiologist, to diagnose AHD from their assessment of pelvic radiographs. The results demonstrated that repeatability of CEA and AI measures and raters' ability to diagnose AHD were greater when angles were drawn rather than only visually assessed as this missed between 10 and 20% of AHD diagnoses. The authors draw attention to the study's findings being limited by the fact that raters' awareness of AHD was heightened because they were asked specifically to assess whether AHD was present. The results may have shown even greater differences if assessment had reflected normal practice where raters evaluate X-Rays for a range of conditions.

In addition to inconsistencies in the application of X-Ray measures, there is no universal consensus on the cut-off points for the recognition of pathological AHD. When Wiberg first proposed the measurement of Lateral CEA in 1939, he defined a normal measure to be greater than 25°, a measure below 20° as being dysplastic and a measure between

20° and 25° as being “uncertain”. Scrutiny of more recent studies shows that whilst authors such as Engesaeter et al (2013) and Gala et al (2016) remain true to Wiberg’s 1939 proposed cut-off measures, other equally well-cited authors, including Nunley et al (2011) and Kappe et al (2012) apply a cut-off value of less than 25° to define pathological AHD. This inconsistent interpretation is less evident in the application of Anterior CEA where a measure below 20° is accepted by most authorities as demonstrating AHD (Nogier et al 2010; Nunley et al 2011; Beltran et al 2013; Gala et al 2016). Likewise, AHD is typically defined radiographically by an acetabular depth of less than 9mm (Adanir and Zorer 2018). Khobragade and Vatsalawamy (2017), however, demonstrated that acetabular depth was greater in males when compared with females and the differences were statistically significant. Moreover, Daysal et al (2007) suggest that acetabular depth correlates directly with vertical body dimensions, such as height and leg length. The indications are therefore, that pathologic acetabular depth measures probably vary and the determination of shallowness is likely to be relative to the individual’s anthropometric dimensions.

The interpretation of Sharp’s angle is also seen to vary between authors. Mannava et al (2017) define AHD as occurring where Sharp’s angle is greater than 42° whereas Welton et al (2018) apply a measure greater than or equal to 45° to identify the condition. Similarly, different cut-off values are applied when interpreting the Tönnis or AI angle. Beltran et al (2013) accept that Tönnis or AI values greater than 13° determine pathological AHD, but Clohisy et al (2008b), Troelsen (2012) and Ellsworth et al (2021) consider a measurement cut-off greater than 10° to indicate instability and dysplasia.

Whilst Mannava et al (2017) conclude that such measures become more accurate and reproducible with experience, the literature shows that other perspectives exist regarding the factors influencing the reliability and interpretation of X-Ray measures in the determination of pathological AHD. In highlighting that the condition is a multidirectional deformity, Bali et al (2020) describe the 3-dimensional nature of AHD. They point to the influence of various factors in the occurrence of AHD. These include acetabular and femoral version, neck shaft angle and soft tissues as well as roof inclination. Bali et al (2020) therefore establish the need for X-Ray evaluation to broaden diagnostic consideration beyond the findings of individual measures. LCEA, for instance, provides a well-accepted measure of lateral acetabular abnormalities only, hence anterior or posterior dimensions might be neglected. By questioning such traditional measures,

Wilkin et al (2017) developed the Ottawa Classification that defines 3 patterns of AHD. These are categorised as Global/Lateral, Anterior and Posterior instability. Recognition of these categories clarifies how a single measure such as LCEA, can easily miss other dimensions of dysplasia. Identification of each of these categories requires both quantitative radiological and qualitative clinical results. The use of qualitative findings such as anterior hip pain exacerbated by hip extension and external rotation for instance, adds greater meaning to the quantitative measure of LCEA in the context of the individual patient. This removes the need to establish whether the X-Ray measure qualifies as 'borderline dysplasia' because the functional consequences contribute to determining the practical meaning of any degree of shallowness. Therefore, through the application of lateral, anterior and posterior radiological measures alongside qualitative clinical evaluation, the Ottawa Classification can support the more meaningful recognition of AHD which traditional measures, such as the LCEA alone, might miss. Additionally, this classification system has been shown to have good intra and inter tester reliability (Bali et al 2020).

## **2.4 AHD Prevalence Estimates**

Prevalence estimations of hip dysplasia are generally mixed. Understanding infant DDH, whilst complex, offers reliable estimates because routine early diagnostic screening in newborns uses standard diagnostic indicators, which means clinicians actively seek out cases of infants with the condition. By contrast, patients with AHD can only be recognised after consulting with a clinician in response to their symptoms. At this point, the poor understanding of AHD presentation, uncertainty of both X-Ray referral thresholds and diagnostic cut-off points for radiographic measures, along with the generally poor recognition of the condition, means that AHD diagnosis is frequently overlooked or delayed (Nunley et al 2011; Leide et al 2021). Therefore, estimations of AHD prevalence are often based on what is understood about infant DDH alone with the assumption that AHD is simply persistent infant DDH. This is unlikely to provide an accurate picture because it disregards cases of adolescent or adult-onset AHD in individuals with no indications of hip instability or DDH as infants (Birrell et al 2003) and is challenged by authors who consider DDH and AHD to each represent distinct forms of hip dysplasia (Lee et al 2013).

The understanding of infant DDH prevalence is drawn together by Loder and Skopelja (2011), who provided an extensive systematic review of international English-language studies published between 1947 and 2010. The commonly cited review shows that the occurrence of infant DDH ranges widely from 0.06 per 1,000 live births in Africa to as many as 76.1 per 1,000 amongst Native Americans. The differing incidence amongst geographic locations shows a variation between racial groups, with cultural, familial and behavioural differences being identified as influencing DDH occurrence and indicates the detailed and global nature of current understanding.

By comparison, recognition of AHD prevalence is less straightforward. Although definitive diagnosis requires the application of relatively straight-forward X-Ray measures, because of the limited understanding of AHD presentation, clinicians struggle to recognise those patients requiring X-Ray referral (Leide et al 2021) and without radiographically confirmed AHD these patients are unlikely to be included in AHD prevalence estimates. Nogier et al (2010) suggest that in recent years there has been an increase in FAI diagnosis to the detriment of AHD recognition. They consider this to have occurred because of the elevated profile of FAI in current literature, coupled with the understanding that its treatment is less invasive than that of AHD. In terms of joint anatomy, FAI involves two distinctly different morphologies: the 'pincer' type that causes over-coverage of the femoral head and the 'cam' type that is recognised by the presence of excessive bone at the femoral head-neck junction (Langlais et al 2006; Dijkstra et al 2021). These two types of FAI can present individually or in combination (Anderson et al 2012). Similarly, cam-type FAI and AHD can present individually or in combination (Duncan et al 2015).

In acknowledging the suggestion that AHD is inadequately considered in the differential diagnosis of adults with hip problems, Nogier et al (2010) aimed to assess the prevalence of both AHD and FAI in a population of young French adults. The multicentred study considered the diagnostic conclusions of 5 assessors who were part of the French Arthroscopy Society, on 241 cases of hip pain in these young people. Diagnostic outcomes of the study's assessors that included physical assessment were compared with those made by an independent radiologist using only X-Ray assessment. The assessors' approach resulted in 42% of cases receiving a diagnosis of FAI and just 6% being diagnosed with AHD. X-Ray assessment by the independent radiologist confirmed, however, that FAI was present in 63% of cases and for AHD there was a 35% occurrence, 22% of whom also had a cam FAI. Although cases of FAI were high

overall (63%), findings were limited by a recruitment bias as 62% of the participants were male. This would likely impact on the results because FAI has been shown to be more common in males (Jung et al 2011; Polat et al 2018) and AHD, considerably more common in females (Kapron et al 2015). The study does however show that without radiographic confirmation, there is a proportionately greater propensity for diagnosis of FAI by physical assessment and the relative neglect of AHD diagnosis. Leide et al (2021) add to this in their observation that, whilst AHD may not be uncommon, there is a reluctance of radiologists to relate to AHD in their X-Ray reporting. Their retrospective study of 1,870 young adult patients, identified AHD presence in 98 cases (5.2%), but inspection of the original radiologists' reports showed that only 7 cases included any mention of the condition. In other words, 1 in 10 cases of AHD had not been reported to the referring clinician or patient. Clearly, these studies indicate a need for increased awareness of AHD amongst clinicians including radiologists. If this does not occur, prevalence estimates will remain unreliable. Like infant DDH, prevalence of AHD appears to vary between nationalities and geographical locations. Engesaeter et al (2013) recognised that in Norway the rate of THR's due to AHD (8%) was considerably greater than those of other Nordic countries (2%) indicating a higher Norwegian AHD prevalence. To test this suggestion, the investigators assessed the radiographic images of a population of 2081 Norwegian 19-year-olds (42% males) recruited from the register of all infants born at one University Hospital in 1989. Applying a CEA of less than  $20^{\circ}$  to diagnose AHD, Engesaeter et al (2013) identified an AHD prevalence of 3.3%. This is comparable with the findings of a Danish study of 4151 randomly selected 20–90-year-old Copenhagen residents (Jacobsen et al 2005). Using the same CEA cut-off measure of less than  $20^{\circ}$  to measure femoral head containment within the acetabulum, Sharp's angle (equal to or greater than  $45^{\circ}$ ) and several other measures reflecting hip joint instability, Jacobsen et al (2005) identified a Danish AHD prevalence of 3.4%, with approximately 2% of cases being unilateral and 1.4% bilateral. In concluding that AHD is not uncommon, the authors draw attention to AHD prevalence in Denmark as ranging from 3.5% to as much as 10.7% depending on the measure and radiological cut-off points applied. Concerns have been raised regarding the inconsistency of cut-off points used for radiographic AHD diagnosis as discrepancies between studies are evident. Whilst it is generally accepted that a CEA of less than  $20^{\circ}$  signals AHD (Beltran et al 2013), some authors have used the normally regarded 'borderline' CEA measure of less than  $25^{\circ}$  in their identification of AHD prevalence. By applying this measure of 20- $25^{\circ}$

as the CEA diagnostic cut-off, a 21% prevalence of borderline AHD was identified by Leide et al (2021) in a Swedish population. Even greater estimates were found in a UK study which, by recruiting 35 UK GPs who enrolled 195 patients presenting with a new episode of hip pain onto the study, and again applying the CEA cut-off for AHD of less than 25° and/or an acetabular depth less than 9mm, identified that 32% of patients had evidence of AHD (Birrell et al 2003). This high incidence possibly reflects the borderline measure of 25° CEA, which was applied but also, as with Nogier et al's 2010 study and Leide et al's 2021 study, rather than representing the general population, participants were those already presenting with hip symptoms thus providing prevalence estimates of symptomatic AHD only.

The studies showing a high AHD occurrence in patients presenting with mechanical hip pain (Birrell et al 2003; Nogier et al 2010 and Leide et al 2021) and the even higher occurrence of FAI (63%), found by Nogier et al (2010), provide findings of clinical value. This is because the morphological abnormalities of AHD and FAI have been shown to account for 95% of patients presenting with mechanical hip pain (Nogier et al 2010). In either case, radiographic imaging is required for definitive diagnosis. The findings therefore promote a strong message to clinicians regarding the importance of X-Ray referral for patients presenting with mechanical hip pain. This is key to identifying an accurate diagnosis, which is vital for gaining swift and correct patient management.

In summary, infant DDH prevalence is well understood but does not appear to accurately reflect the occurrence of adult AHD to which it is often applied. Limited recognition and reporting of AHD by clinicians highlights an apparent diagnostic reluctance to consider the presence of AHD. Greater understanding of FAI suggests that a risk of diagnostic bias might be evident in the differential diagnosis of young peoples' hip problems and whilst a high rate of AHD is associated with the presence of cam FAI, diagnostic emphasis draws attention more commonly to the cam FAI with a tendency to neglect the presence of AHD. This is likely to impact upon securing effective treatment.

## **2.5 Surgical Correction of Acetabular Hip Dysplasia**

The development of corrective surgical techniques has kept pace with the progress in understanding of both post-operative complications and the degenerative consequences of AHD (Mei-Dan et al 2019). Once diagnosed, surgical reconstruction of the dysplastic joint aims to correct the joint's biomechanics and stability, and thus normalise joint function (Sankar et al 2017). Reconstructive surgery is complex and typically uses the

PAO procedure to increase femoral head coverage by reorienting the acetabulum (Yasunaga et al 2017).

PAO involves a triple osteotomy, which is effectively 3 controlled pelvic fractures, the aims of which are to increase joint stability by acetabular augmentation and reorientation. By doing so, joint biomechanics are improved, reducing joint deterioration into secondary OA, which means that the need for THR can be avoided or at least delayed, often for decades (Kennedy et al 2017). Variations of femoral and acetabular osteotomies have been evident over the years (Salter et al 1961; Ganz et al 1988 Bayhan et al 2016), but in recent decades the Bernese PAO developed by Ganz et al (1988), has been favoured. It involves a series of osteotomies of the ischium, pubis and ilium, enabling the acetabular fragment to be repositioned in such a way as to increase the acetabular depth and enhance the angular orientation. The procedure results in improved femoroacetabular stability (Ganz et al 2008). The Bernese technique, which has been shown to provide decades of relief in more than 30% of patients (Steppacher et al 2008; Troelsen et al 2009; Lerch et al 2017), has benefitted from recent modifications. These have aimed to accelerate post-operative weight-bearing and functional recovery (Mei-Dan et al 2017), overcome the surgical recovery risk of ischial non-union (Mei-Dan et al 2019) and improve the reliability and reproducibility of patient outcomes (Mei-Dan et al 2017; Mei-Dan 2019).

Studies have identified however, the importance of patient selection for good outcomes of PAO surgery. In a systematic review, Clohisy et al (2009) identified that PAO did indeed provide good surgical outcomes for young people with AHD, but they also showed that there was an association of surgical failure with the presence of preoperative OA. Similarly, in their study of 63 patients (75 hips) receiving PAO, Steppacher et al (2008) demonstrated joint survivorship of 60% at 20 years. Pre-operative factors predicting a poor outcome included older age, a poor Merle d'Aubigne Postel score (that evaluates pain, gait and mobility), and an increased pre-operative OA or Tönnis classification score. These findings were reinforced when Lerch et al (2017) followed the same patient cohort a decade later to show a 29% hip joint survivorship at 30 years post-surgery and with the same factors as those identified in the earlier study (Steppacher et al 2008) being predictive of poor outcomes. Specifically, these included a pre-operative age greater than 40 years, a poor Merle d'Aubigné and Postel score and a Tönnis score greater than 1, that is joint degeneration that is worse than 'mild'. By contrast, however, van Stralen et al (2013) identified that beneficial results of triple



osteotomy, which included several types of procedures as well as the Bernese PAO, can begin to deteriorate after 15 years as OA develops. Although substantial pain reduction and improved function continued to be evident at 25 years follow-up, van Stralen et al (2013) reported an increase in OA between 15- and 25-years post-surgery, with more than 30% of patients ultimately requiring THR. The authors suggest that whilst triple osteotomy improves patient symptoms, it does not normalise hip joint biomechanics sufficiently to prevent OA from eventually developing. When, however, THA is required following PAO, it can be performed without additional complications (van Stralen et al 2013). The importance of PAO in preserving the proximal femur, clearly has valuable implications should a future hip arthroplasty or resurfacing be required (Ganz et al 1988) and avoiding or delaying THR is relevant. Langlais et al (2006) draw attention to the fact that THR restricts activity, which younger patients find difficult to accept. Importantly, in their study of 5 young women's postings on an online AHD patient support group, Gambling and Long (2011) highlight that following the shock of diagnosis, these young women endeavoured to save their native joints, favouring corrective surgery over THR. Careful patient selection for PAO is essential (Lerch et al 2017; Troelsen et al 2009) and for optimal surgical outcomes, early, pre-arthritis diagnosis and treatment are key (Lerch et al 2017). Awareness amongst clinicians of the importance of early AHD diagnosis and treatment, is recommended and it is therefore imperative that those who carry out initial hip assessments, understand the urgency of X-Ray referral (Kennedy et al 2017). To identify patients in this pre-arthritic phase, these clinicians need to have the tools to recognise those patients showing the potential for AHD. This includes them having knowledge of relevant physical features of patient presentation to inform their diagnostic clinical reasoning in order to recognise when referral for radiographic assessment, definitive diagnosis and surgical intervention are required.

## **2.6 Physiotherapists' Diagnosis and Clinical Reasoning**

First contact physiotherapy (FCP) was developed in the UK to facilitate patient access to orthopaedic physiotherapy expertise at the beginning of the management of MSK problems. The principle being, to ensure

*“...timely access to diagnosis, early management and onward referral if necessary. This benefits patients, primary care and the wider MSK system”*

(CSP 2021, para. 2)

Estimates show that MSK problems account for 17-30% of GP appointments, approximately one third of these are for the lower limb with hip pain contributing a significant proportion (Jordan et al 2010). Recently, there has been a drive to employ FCPs in primary care to reduce this workload burden on GPs and increase patient management capacity (Ingram et al 2021). Evidence suggests that this direct access to physiotherapy results in patients experiencing accelerated MSK care, having fewer work absences and with less medication. In addition, the approach has shown good support for safe, effective and economical patient management (Foster et al 2012). Through such initiatives, this element of healthcare redesign aims to enable people to get the right care at the right time (NHS England 2019).

Assessment and treatment of patients with MSK problems, in hospitals as well as GP surgeries, are considered fundamental to physiotherapy practice but possibly less so to the practice of GPs (Foster et al 2012). The approach to patient assessment that physiotherapists at all levels of expertise and experience use is a fundamentally routine procedure that is influenced by their knowledge and experience (Jones 1995). The procedure is typically composed of two parts, an assessment of the patient's history, and a physical examination. The patient's history is collected mostly from an interview procedure in which the physiotherapist asks the patient questions about their health problem, their general health and usual activities, their medical history and their family history. Details of the patient's history can also be drawn from medical notes and previous test results. The physiotherapist then uses these data to direct and inform the physical examination that follows (van Griensven and Ryder 2018) ensuring that it is individualised to the patient and their particular problems (Jones 1995). During this second part of the patient assessment, the physiotherapist may use observation, testing of functional movements plus muscle strength testing and palpation to explore the affected structures and the impact the patient's problems have on their function. This, along with specific measurements and testing procedures is used to verify and extend the findings of the patient's history and reach a conclusion about the patient's problems (Ryder and van Griensven 2018). The process has been shown to lead to a diagnosis that guides the physiotherapist's treatment and management plan and that is considered a key aspect of physiotherapists' patient assessment (Trede and Higgs 2009).

In 1978, Blaxter pointed out that the term 'diagnosis' is both a 'label', which clinicians attach to a recognised set of classified features, and the process involved in the

identification of that label. The acceptance of this definition continues to this day, but more recently profession-specific nuances of the term have been discussed in the literature. The purpose and concept of diagnosis in physiotherapy has been investigated by Spoto and Collins (2008). Their American survey of 253 physiotherapists with specific expertise in orthopaedics, identified three common and inter-related themes apparent in the process of their diagnosis. Theme 1 describes how, whilst physiotherapy diagnosis incorporates the medical diagnosis, it does in fact move beyond it to translate the medical diagnosis into the context of the individual patient's life. Theme 2 identified that physiotherapy diagnosis involves multiple levels or entities, such as different anatomical structures, the nature, and the stage of the pathology that establish the cause of the patient's functional limitations. Finally, Theme 3 referred to physiotherapists viewing diagnosis as being process-orientated, with the purpose of guiding treatment. Physiotherapy diagnosis therefore appears to be a "*means to an end*" (Spoto and Collins 2008 p 37) rather than it being *the* end of the process. These themes reflect Higgs and Jones' (2008) views of diagnostic clinical reasoning that they define as making decisions on patient management based on the evaluation of the individual's personal and clinical data.

Diagnostic clinical reasoning has received considerable attention in recent times, driven by two factors; firstly, the need to construct methods of teaching and assessing performance of clinical reasoning in student clinicians (Huhn et al 2019), and secondly to understand how diagnostic error occurs and how it can be prevented (Norman et al 2017). The understanding that has emerged, describes two broadly accepted approaches involved in the process of clinical reasoning; one being an intuitive process and another being analytical (Monteiro and Norman 2013). The intuitive, also known as System 1 processing or pattern recognition, involves immediate identification of a set of features that are known to represent a given condition, or 'label'. Heuristics, or mental shortcuts are involved (Norman et al 2017) and this system operates when the pattern of patient presentation is familiar to the clinician and hence involves recognition (Croskerry 2009). The use of System 1 has been criticised for its non-analytical approach that has been considered to risk error. But equally, every day, humans use this fast, intuitive approach to accept that a pen is a pen or that a particular person is, for instance, their son/their daughter/their spouse. With experience, knowledge and understanding, the fast, intuitive approach can be applied successfully to diagnosis and is, as Jones (2018) reminds us, quite simply, recognition.

Through their repeated experience of AHD patient data, specialists in young peoples' hip conditions might have developed the expert knowledge of patient presentation that they recognise as characterising the condition. Such experts can therefore apply this intuitive method of diagnosis with consistent success (Croskerry and Nimmo 2011) but, when experience is limited and understanding of the pre-existing set of categories of a specific condition is poor, faults in diagnosis occur (Balogh et al 2015).

By contrast, Edwards et al (2004) explain, how the hypothetico-deductive model of reasoning, also known as System 2 *analytical* approach, involves the clinician firstly drawing together information about the patient from various sources, including medical notes, patient accounts, history and test results. Elstein et al (1978) referred to this as 'cue acquisition'. From this they generate hypotheses of what diagnosis the data represent. Continued appraisal of patient data or 'cue evaluation' (Elstein et al 1978) then leads to the acceptance or rejection of hypotheses and identification of the patient's problems or diagnosis (Edwards et al 2004). Croskerry (2009) expands on this by explaining that this hypothetico-deductive method, requires an orderly, data dependent approach that takes time and resources. It does, however, provide a logical method of reasoning for novice practitioners whose lack of experience would prevent pattern recognition. Indeed, this approach to clinical reasoning has been favoured within the education of healthcare professionals as it has been assumed to provide a thorough and systematic approach to patient assessment and diagnosis (Sole et al 2019).

Whilst these two models of reasoning provide a theoretical differentiation between expert and novice reasoning, contemporary literature on their clinical application identifies an approach to clinical reasoning in which clinicians oscillate between the intuitive and the analytical systems (Yuen et al 2018). This enables the use of the rapid System 1 *intuitive* process for experienced practitioners or situations in which patient features are familiar, but when presented with an unfamiliar clinical picture, even expert practitioners can revert to the analytical System 2, hypothetico-deductive reasoning. Together these two systems form the dual-processing theory of clinical reasoning (Yuen et al 2018).

Croskerry (2009) cautions, however, that clinicians can be working in suboptimal circumstances where, for instance, busy clinics and overwork result in distractions, inadequate facilities, and fatigue. In such circumstances, the diagnostic reasoning process may suffer and short-cuts may occur leading to incomplete data collection and thus limited reasoning. Nevertheless, whilst the literature shows that there is general acceptance that physiotherapists like doctors use the dual processing model (Schwartz

and Kostopoulou 2018), it is clear that knowledge matters (Norman et al 2017). System 1 requires knowledge to intuitively recognise characteristics that represent a given condition. System 2 generates and analyses knowledge to develop and test hypotheses (Edwards et al 2004).

The hypothetico-deductive model of reasoning is rooted in the empirico-analytical research paradigm that assumes that reality, including truth or knowledge, is objective and measurable (Edwards et al 2004). This resonates with physiotherapy education where the understanding of biological sciences, such as anatomy, biomechanics, physiology and neuroscience is based on objective, measurable data (Higgs and Titchen 1995), and forms the foundation of students' clinical understanding. Mattingly (1991) however, sheds light on the role of the patient's 'story' during examination as it enables the physiotherapist to gain insight into the context (physical, emotional and behavioural) of the patient's problems. According to Edwards et al (2004), establishing this 'lived experience' of the patient, seeks to understand 'meaning' as opposed to 'measure'. Narrative reasoning comes from the interpretive research paradigm (Davies and Fisher 2018) and focuses on what patients say about their problems, providing the clinician with insight into the patient's interpretation of their experiences, their views and their self-management (Edwards et al 2004). Such knowledge is not something provided by the label attached to a designated condition. Rather, it perhaps provides the true and comprehensive picture of the patient's problems, uncovering a more accurate and meaningful solution as it accepts the context in which the problems exist in the lived experience of the patient. By studying the process of physiotherapy reasoning, Edwards et al (2004) describe how an "interplay" of strategies is applied by physiotherapists to identify not only the diagnosis (via System 1 and/or System 2), but also the problems the diagnosed condition has in the context of the patient's life as identified by the patient's story and through narrative reasoning.

Physiotherapists carry out patient assessment to direct treatment and to refer on for investigations or further opinion but notably, they have also been shown to continue the assessment process throughout treatment to maintain reasoning-directed treatment (Doody and McAteer 2002). Indeed, Doody and McAteer (2002) propose that this application of the reasoning process throughout the course of treatment might be a distinctive characteristic of physiotherapy that provides unique and enhanced opportunities to review and revise diagnostic hypotheses. Without evidence of how qualified physiotherapists actually assess patients in specific circumstances, however,

the acceptance of clinical reasoning theory as being the approach used universally by physiotherapists could risk assumption. This was an important consideration for the current study because such an assumption could lead to a potentially inaccurate understanding about the type of knowledge that could best support physiotherapy assessment and their patient management conclusions.

## **2.7 Physiotherapists' Knowledge**

During diagnostic assessment, the patient's account of their problems is directed by the nature of clinicians' questioning. Payton's (1985) pioneering study comparing clinical reasoning in physical therapists and doctors, indicated that a sequence of questioning is used that is similar for both professions. It tends to be confined to what the clinician considers clinically relevant and may risk a level of selectivity in what the clinician uses to formulate their diagnostic hypotheses. More recently, a systematic review by Huhn et al (2019) demonstrated that in physiotherapy as in medicine, the identification of what is clinically relevant is influenced by clinician's knowledge and their approach to clinical reasoning. The limits of the clinician's knowledge may result in a biased approach, where insufficient information is considered. Yuen et al (2018) define such biases, referring to the risk of both 'anchoring' where the clinician is preoccupied with certain aspects of patient presentation, ignoring other potentially relevant features and 'premature closure' where inquiry ends before the investigation is complete. Both types of bias risk incorrect conclusions. In the case of AHD therefore, the consequences of the patient's condition in the context of their lived experience are important for informing physiotherapy treatment. Additionally, knowledge of the signs, symptoms and features that indicate and define the diagnostic label of AHD, is required for correct recognition and overall patient management that could, for instance, include other forms of treatment such as surgery. This knowledge includes determining when referral is relevant because, in the case of AHD, X-Ray evaluation is required for accurate differential diagnosis. Establishing that a set of signs and symptoms presented by a patient represents a particular diagnosis can, however, be difficult because signs and symptoms can be representative of various diagnoses. To clarify this, the body of literature on differential diagnosis in patients presenting with hip problems was appraised to summarise current understanding.

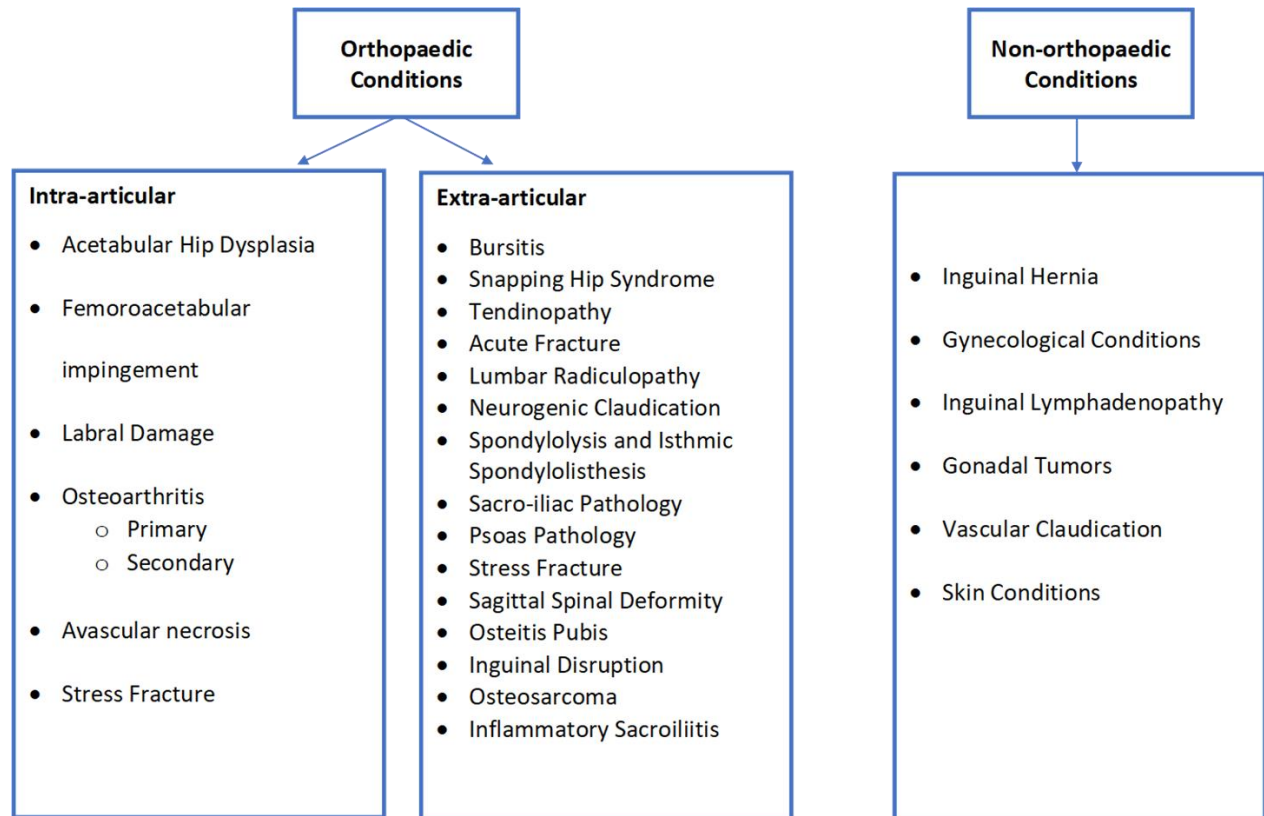
## 2.8 Differential Diagnosis

The process of diagnosing the presence of a pathology and distinguishing it from others is a complex, iterative, data-gathering procedure that aims to acquire a clear understanding of the patient's problems. Collected data are used to recognise diagnostic possibilities and eventually to make a data-informed diagnosis based on the recognition of clinical features that are indicative of a specific pathology (Balogh et al 2015). Diagnosis guides treatment and is a fundamental component of evidence-based practice (Spoto and Collins 2008). Diagnostic specificity however, particularly for pre-arthritis conditions of the hip in young adults is challenging because, isolating the cause of the problem within the complexity of the various structural and biomechanical features of the hip joint is difficult. Additionally, not only can referred pain be a diagnostic distraction but signs and symptoms can originate from a variety of hip pathologies (Clohisy et al 2008a). Understanding the nuances of the different pathologies is therefore important.

As Figure 2.8 summarises, the types of problems that can present as hip pain in young adults. These are grouped into non-orthopaedic and orthopaedic conditions (Dick et al 2018). Non-orthopaedic conditions presenting as hip pain may include systemic pathologies related to for instance, tumour and vascular claudication, pelvic and genitourinary pathologies (Martin et al 2010), and more rarely can include appendicitis and diverticulitis (Rao et al 2013). These problems can cause pain that is referred to the hip region and can often be distinguished from orthopaedic problems by the fact that the pain is typically unrelated to hip joint activity or position (Dick et al 2018). On the other hand, orthopaedic hip conditions are typically associated with activity related pain or altered movement (Martin et al 2010). These can be subdivided into firstly, extra-articular pathologies that occur adjacent to the hip joint. They include conditions of the surrounding soft tissues as well as the lumbar or sacroiliac joints that can cause pain to be referred to the hip (Kemp et al 2019). Secondly, those occurring within the joint itself that are known as intra-articular pathologies. These include morphological joint changes such as those of AHD, FAI, labral damage, femoral head necrosis or fracture (Hunt et al 2012). Although symptoms can be wide-ranging, pre-arthritis extra and intra-articular conditions can present in similar ways and both typically involve pain in the hip region that can be acute or chronic (Langlais et al 2006). Distinguishing between these two types of orthopaedic conditions is important because, apart from suspected fractures,

extra-articular conditions, which include tendinopathy, bursitis, iliotibial band syndrome, muscle injury, and piriformis syndrome are likely to benefit from physiotherapy assessment and intervention. By comparison, definitive diagnosis of intra-articular conditions often requires referral for X-Ray evaluation (Santiago et al 2016) to identify, for instance, joint dislocation or the severity of morphological joint abnormalities that may require surgery.

Figure 2.8 Groupings of Problems that can present as Hip Pain in Young Adults



### 2.8.1 Extra-articular Conditions

Extra-articular orthopaedic conditions are typically associated with trauma or increased and repetitive weight-bearing activities (Wilson and Furukawa 2014). Although these features may also be evident with intra-articular problems, often, the location of the pain on palpation can indicate that the problem stems from structures in that region. Osteitis pubis (pubic symphysis inflammation) for example, frequently presents as tenderness over the pubic symphysis joint (Angoules 2015); adductor tendinopathies as pain on palpation of the inner thigh in the region of the adductor musculature (Thorborg et al



2018), and trochanteric bursitis as lateral sided hip pain, which is increased when pressure is applied directly over the greater trochanter (Zibis et al 2018). Nonetheless, diagnosis should not be assumed on palpation alone as functional movements can also be informative. Iliopsoas bursitis, for instance, can present as anterior hip pain that typically occurs when the hip is extended from a flexed position; it can involve a catching or snapping sensation (Wilson and Furukawa 2014) and is often associated with athletic activity (Troum and Crues 2004). Hence, the history of the presenting condition can inform the characterisation of the problem.

## **2.8.2 Femoral Stress Fractures**

Femoral stress fracture can be intra-articular or extra-articular and typically occurs because of normal bone being exposed to abnormal stress (fatigue fracture) or an abnormality of the bone rendering it unable to tolerate normal stress known as insufficiency fracture (Harris and Chahal 2015). Femoral neck stress fractures (extra-articular) and femoral head stress fractures (intra-articular) are mainly reported in older adults as well as athletes and military populations who participate in repetitive distance running (Kim and Kim 2021) with diagnosis being rare in healthy children and adolescents presenting with hip pain (Bailie and Lamprecht 2001). Risk factors for insufficiency fractures include chronic renal or metabolic bone disease and bone tumours (Kim and Kim 2021). Sex-linked influences are also thought to increase risk status, with low bone mineral density, amenorrhea, and insufficient nutrition being threats, meaning that females are considered at higher risk (Ramey et al 2016).

Understanding of the factors that influence stress fracture location is limited, however, Kim and Kim (2021) carried out a comparison of extra-articular femoral shaft and intra-articular femoral head stress fractures that provides useful insight. These authors report on 37 male military recruits whose sudden surges in training intensity and duration make them a frequent population for stress fracture. The study found an association between femoral neck shaft angle (FNSA) and the location of the femoral stress fracture.

Femoral head stress fractures were evident in 26 of these recruits and femoral neck stress fracture in 11 recruits. The study found that FNSA greater than 135° (coxa valga) was related to femoral head stress fracture and that an FNSA less than 120° (coxa vara) was related to femoral neck fracture. These associations mean that FNSA could serve as a predictive factor for the risk of femoral stress fractures. The use of participants who were from a highly relevant population of regular femoral stress fracture sufferers and

were controlled for other known risk factors, add to the strength of the findings. However, the study had some limitations in that no normal comparison group was used. This limitation was somewhat mitigated by the fact that, of the recruits with unilateral stress fracture, the FNSA of each femur was compared, which provided good control of variables. The study could also be considered limited by the relatively small group of participants who were selected from within a very specific population. Nevertheless, if, as the authors suggest, the investigation is considered a pilot study, the findings justify a larger future study of the general population.

Physical symptoms of stress fracture have been reported as being an insidious onset of deep groin pain, hip or thigh pain, irritated by weight-bearing activity (Harris and Chahal 2015). The similarity of the symptoms to other intra-articular pathologies, means that the patient's history should contribute to differential diagnosis. Hence the intensity and usual duration of training and any noted changes to activities and form should be established (Harris and Chahal 2015). The onset of pain might also inform the direction of diagnosis in that, unlike other intra-articular conditions of the hip, stress fractures typically cause pain early in the weight-bearing activity that persists until a rest period intervenes (Harris and Chahal 2015). Physical examination can expose actions such as single-leg stance, squats and hopping as provoking pain, but importantly if stress fracture is suspected, physical assessment is cautioned to avoid potential fracture displacement (Harris and Chahal 2015).

### **2.8.3 Intra-articular Hip Conditions**

#### **NON-TRAUMATIC AVASCULAR NECROSIS OF THE FEMORAL HEAD**

For some of the intra-articular hip conditions, pain location is less helpful than with extra articular conditions. Anterior groin pain, for instance, can be evident in the presence of avascular necrosis of the femoral head (AVN), stress fracture, FAI, AHD and labral irritation (Dick et al 2018).

Without a history of hip surgery or trauma, useful diagnostic indicators for non-traumatic AVN (NT-AVN) are that it is typically bilateral, occurring in young to middle aged adults who might have a history of alcohol misuse, or treatment with chemotherapy, immunosuppression therapy or steroids (Narayanan et al 2017). A genetic predisposition for NT-AVN has also been proposed (Roth et al 2016). Based on a

comprehensive and international systematic review, guidelines for diagnosis and treatment for NT-AVN suggest that, as well as hip, thigh and/or groin pain, patients with NT-AVN may present with antalgic gait, and movement restricted by pain (Roth et al 2016). The guidelines also confirm the diagnostic importance of obtaining a history of the presenting condition and diagnostic radiographs, particularly when there appears no other cause. Hauzeur et al (2018) agree and, through their study of 88 patients attending a dedicated osteonecrosis clinic, they expand on this understanding. The main finding of their study was that AVN frequently produces normal findings from physical examination of the hip but often symptomatic problems of the spine and knee. These may result in misdirection of the problem's location and, as the authors state, could explain the inadequate diagnostic recognition of NT-AVN cases. Hauzeur et al (2018) grouped the data by bilateral and unilateral cases of NT-AVN as well as radiological stages 1–2 (pre-fractured), fractured stage 3 and stage 4, which includes joint space narrowing with secondary degenerative changes in the acetabulum. This lack of homogeneity in the patient groups may account for the authors concluding that no typical pattern of clinical features was evident. The recommendation coming from Hauzeur et al's (2018) study was however, that NT-AVN should be suspected in cases of symptomatic onset of pain in the pelvis, buttocks, groin and lower limbs.

As this overview of differential diagnostic features indicates, pain characteristics can be common to a number of hip pathologies, which highlights the challenges of differential diagnosis of hip symptoms. A summary of this overview is provided in Table 1 below, in which I list evidence-based distinguishing features that inform differential diagnosis of pathologies presenting as hip pain.

Table 1. Differential Diagnosis: Features of Conditions Presenting as Hip Pain

<p>Non-orthopaedic Conditions (Dick et al 2018)</p>		<ul style="list-style-type: none"> <li>• focussed medical history</li> <li>• physical examination: pain that is not triggered by hip activity or joint angle positioning</li> </ul>
<p>Extra-Articular Conditions (Wilson and Furukawa 2014; Angoules 2015; Zibis et al 2018)</p>		<ul style="list-style-type: none"> <li>• typically associated with trauma or increased and repetitive weight-bearing</li> <li>• pain location often indicative of the affected structures being in that region (eg tenderness over pubic symphysis joint indicative of pubic symphysis inflammation; inner thigh pain indicative of adductor tendinopathies)</li> </ul>
<p>Extra-articular/Intra-articular Conditions</p>	<p>Stress Fracture (Harris and Chahal 2015; Kim and Kim 2021; Ramey et al 2016)</p>	<ul style="list-style-type: none"> <li>• Cause: abnormal stress on normal bone or abnormal bone and normal stress</li> <li>• Wide age range</li> <li>• Risk factors: Repetitive distance running; Sex-linked influences (low bone mineral density, amenorrhea, insufficient nutrition); Sudden surges in training intensity and duration; Chronic renal disease; Metabolic bone disease and bone tumours</li> <li>• Typically, an insidious onset of deep groin pain, hip or thigh pain, irritated by weight-bearing activity with pain early in the weight-bearing activity that persists until a rest period intervenes</li> <li>• Pain provocation: single-leg stance, squats and hopping Importantly, if stress fracture is suspected, physical assessment is cautioned, to avoid potential fracture displacement</li> <li>• Coxa-valga associated with femoral head stress fracture</li> <li>• Coxa vara associated with femoral neck stress fracture</li> </ul>
<p>Intra-Articular Conditions</p>	<p>Non-Traumatic-Avascular Necrosis Femoral Head</p>	<ul style="list-style-type: none"> <li>• Typically, bilateral</li> <li>• young to middle aged adults</li> <li>• history of alcohol misuse, or treatment with chemotherapy, immunosuppression therapy or steroids</li> <li>• Possible genetic predisposition</li> </ul>

(Narayanan et al 2017; Roth et al 2016; Hauzeur et al 2018)

- hip, thigh and/or groin pain with antalgic gait, and movement restricted by pain
- Diagnostic radiographs recommended, particularly when there appears no other cause or diagnosis

Femoro-acetabular Impingement (FAI)

(Kappe et al 2012; Dick et al 2018; Ganz et al 2008; Polat et al 2018; Anderson et al 2012; Nogier et al 2010)

- Reduced hip internal rotation at 90° of hip flexion and reduced abduction
- A positive impingement test
- Significantly greater severity of symptoms related to sitting and when 'getting in or out of a car'.
- Typically, young adults (teens or twenties) involved in elite levels of sport or dance
- Or commonly in adults aged 30- 45 often affecting those who regularly take part in sport
- More common in men.
- Radiographic evaluation is essential to confirm the diagnosis and to exclude other pathologies that may be confused for or present with FAI

Labral irritation/damage (Klaue et al 1991;

- Localised sharp or pinching pain
- Typically aggravated by activity particularly repetitive twisting and pivoting movements of tennis, ballet, hockey and football

Reiman et al  
2014)

Acetabular  
Hip  
Dysplasia  
(AHD)

- Later stages can develop into cam FAI, labral damage and/or secondary osteoarthritis therefore symptoms can be very similar
- Specific Radiographic measures can determine femoral head coverage, acetabular depth and orientation

(Engesaeter  
et al 2013;  
Anderson et  
al 2012;  
Nogier et al  
2010)

*Key: Femoroacetabular Impingement (FAI)*

## **IMPINGEMENT, DYSPLASIA AND LABRAL INJURY**

FAI and AHD have been identified as the most common intra articular hip conditions presenting in young adults (Peters and Erikson 2006; Lankester and Gargan 2004; Langlais et al 2006). The potential for coexistence of cam-type FAI with AHD is highly relevant to the understanding of clinical assessment as it potentially increases diagnostic difficulty and draws even greater attention to the justification for detailed radiographic evaluation. By contrast, because pincer FAI describes femoral head over-coverage and AHD femoral head under-coverage, the two are incompatible for combined presentation (Nogier et al 2010). Yet diagnostic confusion between the conditions is not uncommon and whilst physical examination tests have been shown to be sensitive to the identification of hip problems, they lack specificity (Nepple et al 2013). Added to this, both FAI and AHD are structural pathologies that can lead to an irritated and damaged labrum because of repeated collision between the femur and acetabulum to which the labrum is attached (Anderson et al 2012). Labral damage symptoms are often described by patients as being localised sharp or pinching pain that can be aggravated by activity (Klaue et al 1991), particularly the repetitive twisting and pivoting movements of tennis, ballet, hockey and football (Reiman et al 2014). Hence symptomatically, when labral damage results, presentation of FAI and AHD can be similar. Unless treated, it is often this labral damage that, in AHD and cam FAI eventually leads to secondary OA (Wyles et al 2017). The femoral head over-coverage of pincer-FAI, however, has been shown to have a protective effect against OA onset (Agricola et al 2013).

Distinguishing between FAI and AHD in the early stages of presentation is key to securing effective patient management (Langlais et al 2006) because in cases of both cam and pincer FAI, surgical correction aims to restore impingement-free movement whereas corrective surgery for AHD aims to gain joint stability. Malviya et al (2016) highlight that due to the challenges inherent in recognising these conditions, patients experience significant delays in securing accurate diagnosis. The literature establishing nuances of each, identifiable during the physical examination of patients, is sparse and specifying differences is difficult. Investigators have, however, identified a limited number of characteristics, which has initiated the challenge of building a clearer picture of patient presentation for each condition.

By comparing the clinical presentation of 37 patients with FAI and 37 with AHD Kappe et al (2012) provide good indicative evidence of patients with FAI presenting with more

limited hip abduction and internal rotation than those with AHD ( $p=0.001$  and  $0.007$  respectively). In addition, analysis of individual item scores of the Western Ontario and McMaster Universities Osteoarthritis (WOMAC) index, showed that symptoms associated with sitting and difficulties of getting in and out of the car were more frequently reported in FAI patients than those with AHD. Nevertheless, the study highlights that most participants from both groups demonstrated a positive anterosuperior impingement test and they found no significant difference between the two groups for the WOMAC subscales of pain, stiffness, functionality and overall summed scores. Patient groups adequately represented the respective pathologies and those with evidence of anything greater than minimal hip OA were excluded, preventing presentation variables. The use of the WOMAC questionnaire, however, weakens the findings as it is a disease-specific measure of disability in OA (Whitehouse et al 2003). The authors defend their use of WOMAC by explaining that the known signs and symptoms reported by patients with AHD and FAI match those of the WOMAC items. Whilst this may be correct, WOMAC was validated using patients over 70 years old and therefore may not reflect problems of young, active individuals (Mohtadi et al 2011). This means that the study would be unlikely to recognise other and so far, possibly unknown or additional nuances of AHD and FAI in young age groups. Based on the strength of similarities in the presentation of these two conditions, Kappe et al (2012) emphasise the obligatory requirement for radiographic measures to confirm definitive diagnosis for both FAI and AHD.

Evidence suggests that age and activity patterns can provide some diagnostic guidance related to FAI presentation. There appears to be general acceptance in the literature that cam-FAI is more prevalent in young male patients, often in their third decade (Ganz et al 2008; Anderson et al 2012) whereas pincer-FAI is seen more commonly in middle-aged women (Ganz et al 2008). However, in their study of 2152 hips from 1076 asymptomatic young adults (mean age  $42.1 \pm 15.6$  years), Polat et al (2018) identified that of the 602 female and 474 male participants, 15.9% had radiologic evidence of cam-FAI, 10.6% had pincer-FAI, 3.1% had combined FAI and 9.3% had findings of acetabular dysplasia. They provide evidence showing that prevalence of both asymptomatic cam and pincer FAI was significantly greater in males (46%) in comparison to females (17%) in this Turkish population. Similarly, in an American study, Jung et al (2011) examined the computerised tomography (CT) scans of 419 randomly selected asymptomatic adult patients. The study showed that of the 215 male hips (108 patients), 13.9% of hips



(n=30) were defined as having a pathological cam deformity and among the 540 female hips (272 patients), 5.56% hips (n=30) were identified as having cam deformity. The cam deformity was evaluated by measurement of participants'  $\alpha$ -angle, which quantifies the anatomical deformity of femoral head-neck offset in FAI (Rakhra et al 2009). Males were shown to have significantly higher  $\alpha$ -angles than females in the corresponding age groups ( $p < 0.001$ ). In addition, the study showed that cam FAI was not rare among the asymptomatic population and was seen to be twice as frequent in men as in women (Jung et al 2011). Whilst the studies of Polat et al (2018) and Jung et al (2011) show evidence of greater prevalence of cam and pincer FAI in males, both studies investigated an asymptomatic population. The presence of a cam deformity does not therefore, seem to be necessarily related to a symptomatic pathology initially but the deformity may lead to the later development of OA (Jung et al 2011).

As with AHD, radiographic measures of FAI are not standardised and the definition in each of the studies varies. Acknowledgement of these discrepancies led to an expert panel being convened to gain multidisciplinary agreement on the diagnosis and management of patients with, what was termed, FAI syndrome (Griffin et al 2016). The resulting Warwick Agreement on FAI syndrome defined the condition as,

*“...a motion-related clinical disorder of the hip with a triad of symptoms, clinical signs and imaging findings. It represents symptomatic premature contact between the proximal femur and the acetabulum”.*

(Griffin et al 2016 p1170)

It was agreed that FAI syndrome composed either a cam or a pincer morphology that could present with symptoms of,

*“...motion-related or position-related pain in the hip or groin. Pain may also be felt in the back, buttock or thigh. In addition to pain, patients may also describe clicking, catching, locking, stiffness, restricted range of motion or giving way”.*

(Griffin et al 2016 p1171)

With respect to diagnosis, the Warwick Agreement stated that,

*“...symptoms, clinical signs and imaging findings must be present to diagnose  
FAI syndrome”*

(Griffin et al 2016 p1171)

By reporting on their understanding of FAI gleaned from their own surgical experiences, Dick et al (2018) accept that FAI is more common in adults aged 30-45 years, often affecting those who regularly take part in sport, however, they also point out that young adults involved in elite levels of sport or dance can be affected sooner, some as early as in their teens or twenties.

By contrast, it is well accepted that AHD is predominantly, though not exclusively, a condition affecting females (Engesaeter et al 2013; Sankar et al 2017). In a study limited to participants aged 18 and 19 years, Engesaeter et al (2013) assessed the radiographs of 2072 participants identified from normal records of infants born in 1989 from one Norwegian hospital. The study clearly demonstrated that AHD defined as radiographic centre-edge angle (CEA) of less than 20°, occurred almost twice as often in females as males with an incidence of 2.4% of men and 4.3% of women. In addition, women were shown to have more steeply sloping acetabular causing greater under coverage of the femoral head than men. More recently, Sankar et al (2017) add support to these findings by reporting on their study of 950 consecutive patients (982 hips) undergoing PAO for symptomatic AHD with an average age of 25.3 years. The cohort of patients was composed of 83% females and just 17% males. The considerable difference in the number of females compared with males reflects the greater incidence of symptomatic AHD in women. The study provides additional insight into the disease characteristics of this group of patients, identifying that AHD was seen to occur mostly in young, Caucasian females with normal Body Mass Index (BMI) and who had experienced symptoms for between 1 and 3 years prior to this surgery. This contrasts with the 62-month average wait for AHD diagnosis identified in Nunley et al's (2011) similar study of 57 adult patients treated with PAO surgery. The cohort of Sankar et al's 2017 study, however, included those who had received previous, failed surgery (15%) and who had a high prevalence of concomitant intra-articular pathology and labral damage. This could mean that symptoms were of greater severity in this group, demanding a quicker diagnostic response.

Importantly, these studies show that to secure diagnosis of both FAI and AHD and to exclude other pathologies that may be confused for or present with these conditions, radiographic evaluation is considered essential (Anderson et al 2012; Nogier et al 2010).

## **2.9 Chapter Summary**

Radiographically, AHD is recognised through the application of well-defined measures of acetabular depth and orientation. Evidence addressing differential diagnosis for patients presenting with hip pain shows that although the signs, symptoms and features outlined in the literature provide some insight into the nuances of the different pathologies, those that characterise AHD and that should indicate the need for X-Ray evaluation, are weakly defined and lack clarity. Poor understanding of AHD patient presentation means that clinicians, including physiotherapists who are often the first to assess these patients, do not have access to the knowledge required to recognise when the presence of AHD should be suspected. They are therefore unaware of the need to refer relevant patients for X-Ray evaluation. To inform their clinical reasoning and for their differential diagnosis, these clinicians require knowledge of the signs and symptoms associated with AHD. To clarify what current evidence is available to support this, Chapter 3 reports on a systematic review that I conducted to evaluate and draw together current understanding specifically of features that can be identified during routine physical assessment. These features are limited to those associated with pre-X-Ray patient presentation in AHD. This was deemed necessary to establish whether a synthesis of the existing evidence could inform the development of an AHD clinical picture that could signal the need for X-Ray referral. It also enabled me to identify the current gaps in evidence-based understanding of AHD patients' physical presentation.

### **3 Physical Indicators of Adult AHD: A SYSTEMATIC REVIEW**

#### **3.1 Chapter Introduction**

A systematic review was conducted to identify and critically evaluate empirical evidence that could answer the research question, what are the features associated with patient presentation of symptomatic AHD?

The review therefore had two objectives:

- (1) To identify and summarise evidence of the specific features, signs and symptoms that have been shown to occur in adolescent and adult patients with AHD.
- (2) To evaluate the level of evidence that supports identification of clinically relevant AHD presentation features, and that can be recognised or measured as part of a typical clinic-based physical assessment of young people with hip pain.

Hammersley (2020) explains how systematic reviews of medical research developed from the recognised need to promote the translation of research directly into patient care, enabling clinicians to exercise reliable evidence-based-practice (EBP) more readily. Hammersley (2020) highlights how this form of structured and methods-based review was created in the 20<sup>th</sup> century to summarise and synthesise the results from randomised control trials (RCTs), considered the 'gold-standard' of research methods. The traditional nature of RCTs involves the collection of numerical data and the use of statistical analysis. These characteristics may permit meta-analysis of studies' findings and is considered the strongest method of synthesising the results of multiple experiments to answer a research question (Nagendrababu et al 2020). Hence, systematic reviews of RCTs fit within a wholly positivist framework. In recent decades, however, the value of systematic review in the evaluation and synthesis of findings from a wider range of research methods has been recognised. Consequently, there has been growing interest in the development of synthesis methods which can be applied to the review of findings from studies using a variety of methods. In the case of this current review, a traditionally positivist approach was used to systematically search for and review relevant published studies that met specific inclusion criteria. This approach provides the opportunity for the same systematic review study to be repeated in the future should that be required. Due, however to the heterogeneity of the selected

studies, a narrative synthesis provides the details of the review's findings. This pragmatic approach to systematically reviewing then synthesising published literature is advocated by Gordon (2016) who explains that whilst the systematic review process has positivist elements that focus on data identification, extraction and quality assurance, synthesis techniques for reviews in which meta-analysis is inappropriate have not been fully established. Gordon (2016) therefore asserts that the method used for a systematic review and the synthesis which follows, should be treated as independent variables within a single research review. In detailing this further the author posits that for systematic reviews, a positivist method can be combined with a contrasting synthesis paradigm. The studies that were drawn together for this review were heterogeneous due to differing research aims, inconsistent definitions of AHD and various methods of measuring outcomes. These were not compatible with meta-analysis. Narrative synthesis was therefore deemed the best approach to presenting the evidence-based understanding because it provided a means of combining the results of multiple studies through the use of written text which both summarises and explains the review findings (Popay et al 2006).

## **3.2 Methods**

### **3.2.1 Protocol and search strategies**

A systematic review was completed in February 2018 in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al 2015; Moher et al 2009; Methley et al 2014). I searched five relevant health care databases: Scopus, Global Health, CINAHL, EMBASE and Medline via Ovid using the search strategy provided in Table 2 below. Prior to this, I had conducted a search that focussed on physiotherapy and AHD. This identified that publications addressed only infant DDH and post-operative physiotherapy treatment. Therefore, to directly address the objectives of this systematic review, key search terms were generalised to 'physical assessment' and 'physical examination' rather than limiting the search by including physiotherapy as a search term.

Citations were also tracked from key articles and major authors in the field. No date restrictions were applied. Included papers reported findings from empirical studies and written in the English language (there were no resources for translation). A combination

of keywords was used to guide the database searches, including for instance, hip dysplasia or acetabular dysplasia; hip assessment and physical examination; family history and medical history.

Table 2. Search terms used for Systematic Review

Number	Search Term
1	(hip* adj3 dysplasia)
2	(acetabular* adj3 dysplasia)
3	1 or 2
4	Exp Physical Examination/
5	Physical assessment*
6	Physical exam*
7	(hip* adj3 assess*)
8	(hip* adj3 exam*)
9	Family history*
10	Medical history*
11	4 or 5 or 6 or 7 or 8 or 9 or 10
12	3 and 11
13	Limit 12 to updaterrange

^The limits applied were: human studies; English Language.  
Keyword searches limited to: title, abstract, subject heading,  
keyword fields

Inclusion criteria were peer-reviewed quantitative study designs, including case series, retrospective and prospective observational studies and cohort studies; those reporting on features of patient history and/or preoperative physical assessment and involving patients with radiographically confirmed hip dysplasia (though thresholds of diagnostic measures may differ); patients with any severity of AHD; participants recruited from primary or secondary care and any geographical location. Exclusion criteria included: studies of infants; diagnosis only by radiographic assessment; patients who had received adolescent or adult surgery; studies using equipment unavailable for typical clinic-based assessment including primary care and/or physiotherapy practices (for

example, involving the use of movement analysis technology available in specialised laboratories) and editorials. This resulted in a final total of 10 papers (Figure 3.1).

### **3.2.2 Data extraction and Quality Assessment**

Data extracted included: study type, study location, subject details (diagnosis, age, gender), inclusion and exclusion criteria, outcome measures and key findings.

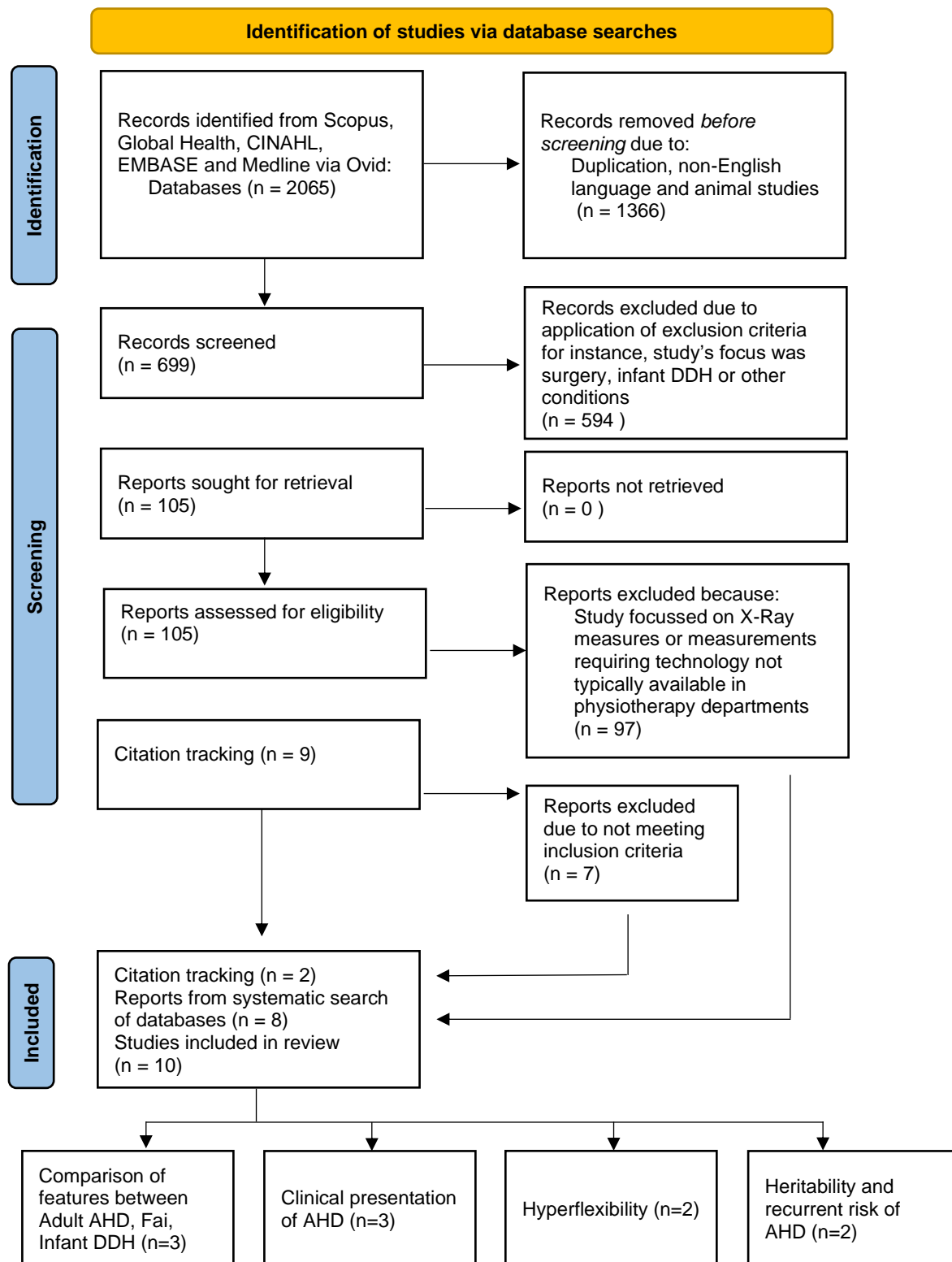
I carried out a two-stage critical assessment procedure that was reviewed for agreement by my PhD Supervisor, Dr Tina Gambling (TG). We firstly used a Critical Appraisal Skills Programme Cohort Study Checklist (CASP 2019) for the preliminary appraisal of each study and we each independently evaluated the quality and limitations of the studies. Disagreement and uncertainties at any stage of the process were discussed and resolved by a third reviewer, Professor Andrew Long (AFL) who was an advisor for the study.

Secondly, the National Institute of Health and Care Excellence (NICE 2012) quality appraisal checklist was utilised, grading the studies in terms of their overall quality. The three grades, (++, +, -) correspond respectively to the extent of the checklist criteria being fulfilled (all, some and few/none) and the likelihood of the study's conclusions to alter practice (very likely/likely, unlikely, very unlikely). Based on this, the quality of each study was evaluated by myself, TG and AFL each independently reading and reviewing the papers and applying the quality checklist independently. We then compared our assessments, checking potential differences in interpretations of the various elements of each paper, and arriving at a consensus view. The outcomes, which included the summary evaluative comments and the overall evidence quality rating, along with the data extracted from the papers, were then entered into an evidence table (Table 4).



Figure 3.1 Summary of Literature Search and Selection Results

(Adapted from: Page et al 2020)



### **3.3 Results**

The initial search generated 2065 potential articles for inclusion and a further 9 papers were identified through citation tracking (Figure 3.1). I screened each of these drawing only on the information contained in the title and abstract. The clear research question and robust inclusion criteria facilitated the approach and resulted in 699 potentially relevant articles. Following the removal of duplicates, animal studies, non-English language reports and studies focussing on other conditions, the full texts of the remaining 105 papers were then obtained. Together, TG and I reviewed each paper independently. This resulted in a blinded, double screening approach using the inclusion and exclusion criteria to complete the final selection of studies for the review.

Ten papers met the inclusion criteria and were included in the systematic review (Tables 3 and 4) as all investigated the association of specified features with adult AHD occurrence. I, along with TG and AFL, assessed each paper using the CASP Cohort Study Checklist (CASP 2019) approach and the NICE quality appraisal checklist (NICE 2012). To aid analysis and interpretation these studies were grouped into four thematic areas (Table 3), enabling discussion of the key clinical features that may contribute to the clinical picture of AHD.

*Table 3. Systematic Review Themes and Related Studies*

Theme	Authors	Year	Title
Theme 1: Comparisons of Features between Adult AHD, FAI and Infant DDH	Kappe et al	2012	Can femoroacetabular impingement and hip dysplasia be distinguished by clinical presentation and patient history?
	Lee et al	2013	Demographic Differences in Adolescent-diagnosed and Adult-diagnosed Acetabular Dysplasia Compared with Infantile Developmental Dysplasia of the Hip
	Duncan et al	2015	Are there Sex-dependent Differences in Acetabular Dysplasia Characteristics?
Theme 2: Clinical Presentation of Adult AHD	Nunley et al	2011	Clinical Presentation of Symptomatic Acetabular Dysplasia in Skeletally Mature patients
	Pranther et al	2018	Anxiety and Insomnia in Young and Middle-Aged Adult Hip Pain Patients With and Without Femoroacetabular Impingement and Developmental Hip Dysplasia
	Liu et al	2012	Changes of gluteus medius muscle in the adult patients with unilateral developmental dysplasia of the hip
Theme 3: Hyper- Flexibility	Samper et al	2015	Relationship between flexible flat foot and developmental hip dysplasia
	Bilsel et al	2016	Acetabular dysplasia may be related to global joint hyperlaxity
Theme 4: Heritability and Recurrent Risk of AHD	Li et al	2013	Heritability and sibling recurrent risk of developmental dysplasia of the hip in Chinese population
	Carroll et al	2016	The Occurrence of Occult Acetabular Dysplasia in Relatives of Individuals with Developmental Dysplasia of the Hip

### **3.3.1 Nature and Quality of the Evidence**

Having identified the four thematic areas, I then discussed the details of each study included in the systematic review with TG and AFL and produced an evaluation. Summaries of each study including the summary evaluative comments and overall evidence quality judgments are presented in Table 4. The predominant study type was a case-comparison study (n=6). The studies had a range of aims and objectives, from exploring questions of gender-specific differences in patients with symptomatic acetabular deformity to comparing the signs, patient history, symptom presentation, hip pathology, or sibling hereditary risk. Accordingly, a wide variety of outcome measures were utilised. Given the heterogeneity of study designs, study themes and outcome measures, a narrative synthesis of the evidence explains the findings.

Most studies (n=6) were of 'high' quality (++ rating), as rated by the NICE (2012) criteria and the remainder were of 'good' (+ rating) quality. Using only 'high' or 'good' quality papers adds to the credibility and potential significance of this systematic review.

Variation in quality was however evident by thematic area. The three studies in Theme One (clinical features of Adult AHD, FAI and Infant DDH) and the two studies in Theme Four (heritability and recurrent risk) were all 'high quality' (++). In Theme Two (clinical presentation), one was of 'high' quality and the other of 'good' quality (+). Both studies in Theme Three (hyper-flexibility), were judged to be of 'good' quality (+). All the studies had ethical approval from appropriate authorities.

Strengths of the high quality (++) rating) studies included: extensive detail of methods and measures used, a power calculation, adequate sample size and sound data analysis and interpretation. The good quality (+ rating) studies commonly had small sample sizes restricting generalisation and less extensive detail on, for example, the included subjects and/or source of control subjects. However, these studies had several strengths such as: clarity on measures, measurement procedures and expertise of those administering the measures, sound data analysis and interpretation.

### **3.3.2 Overview of Studies: Their Aims and Objectives**

In general, the overall aim of each study was to consider specific features that could signify predictors common to AHD or that could be identified in the presence of AHD. These specified features may present in a range of hip conditions, however, the purpose

of this systematic review was to identify whether the evidence could lead to establishing patterns of features that could collectively characterise an AHD clinical picture. Studies considered patterns of pain and dysfunction (Nunley et al 2011), changes in gluteus medius muscle size (Liu et al 2012) or anxiety and insomnia disorders (Pranther et al 2018). Others were prevalence studies that also considered whether specified features could distinguish between AHD and other conditions including infant DDH (Lee et al 2013) and FAI (Kappe et al 2012), or whether there were clinically important differences between male and female patients (Duncan et al 2015). Further studies explored the recurrent risk of hip dysplasia in the relatives of patients with the condition (Carroll et al 2016) and evidence of undiagnosed hip dysplasia in adult relatives of individuals with the condition (Li et al 2013).

### **3.3.3 Study Population**

A total of 1,158 heterogeneous subjects or participants with hip dysplasia were included in the ten studies investigated. These studies were undertaken predominantly in the USA (n=5) and Europe (n=2, Germany and Turkey); two studies were undertaken in China and one in Colombia.

### **3.3.4 Outcome Measurement**

The definition and approach towards measuring AHD was heterogeneous, reflecting the range of study aims. Recognition of AHD was predominantly by radiographic measures of anterior and lateral Centre Edge Angle (CEA) being less than either 20 or 25 degrees; Sharp's Angle (AA) greater than 42.2 degrees; Acetabular Index (AI) greater than 30 degrees; Tönnis Roof Angle greater than 12 degrees; Severin Score, used to radiographically evaluate results of operations performed for the treatment of infant DDH (Ward et al 1997); and Crowe Classification that classifies AHD according to the height of the pelvis, the medial head-neck junction, and the inferior margin of the acetabulum (Jaward and Scully 2011).

### **3.4 Exploration of Papers by Theme**

#### **3.4.1 Theme One: Comparisons of Features between Adult AHD, FAI and Infant DDH**

Three studies explored this theme (Lee et al 2013; Kappe et al 2012; Duncan et al 2015). The main objectives of these studies ranged from comparing the demographic features of infant-diagnosed patients with those patients diagnosed in adolescence or adulthood (Lee et al 2013) to determining whether there were clinically important sex-specific clinical, radiographic or other differences in patients undergoing PAO for adult AHD (Duncan et al 2015). Symptoms and history of patients with FAI were also compared with those of AHD to find valid differentiating signs (Kappe et al 2012). The findings presented in the studies, all of which were judged of 'high' quality using the NICE (2012) quality rating scale, provide indicative evidence of:

- FAI and AHD differences: Features of clinical presentation and patient history distinguishing between FAI and AHD. Specifically, hip abduction and internal rotation were more limited for those with FAI compared to patients with hip dysplasia alone. In addition, symptoms related to sitting were greater and there was a greater severity of reported problems for getting in and out of the car in those with FAI (Kappe et al 2012).
- Sex differences: Males with AHD having a greater prevalence of clinical, radiographic and intra-articular findings consistent with FAI and differences in Harris Hip Scores and University of California, Los Angeles (UCLA) Activity score (Duncan et al 2015).
- Sex differences: overall, significantly higher rates of females were affected in both infant DDH and adult AHD groups, but the proportion of males was significantly higher in the adult AHD group compared with the infant DDH group (Lee et al 2013).
- A significantly higher proportion of bilateral hip dysplasia in the AHD group compared with the infant DDH group (Lee et al 2013).

Overall, the studies identified potentially useful differences between adult AHD and FAI. In addition, interesting differences were demonstrated between infant DDH and adult AHD, which contribute to the suspicion that infant DDH and adult AHD could be considered as two different pathological entities.

### 3.4.2 Theme Two: Clinical Presentation of Adult AHD

Three studies explored this theme (Nunley et al 2011; Lui et al 2012; Pranter et al 2018). The objectives varied considerably between these studies, ranging from exploring clinical presentation (Nunley et al 2011), contractile muscle mass and change in length of the gluteus medius in skeletally mature patients with symptomatic AHD (Lui et al 2012), to investigating insomnia and anxiety in patients with hip pain (Pranter et al 2018). The one 'high' quality and two 'good quality' studies showed findings that provide indicative evidence of AHD presentation commonly associated with:

- An insidious onset of moderate to severe symptoms, mostly activity-related pain localised predominantly to the groin and to the lateral aspect of the hip, and less frequently to the anterior aspect of the hip or buttock (Nunley et al 2011).
- Pain characterised as sharp and dull (Nunley et al 2011).
- Common mechanical symptoms such as snapping, popping, or locking (Nunley et al 2011).
- Walking with a limp (Nunley et al 2011).
- Higher levels of insomnia and anxiety in young and middle-aged hip pain adults with and without symptomatic FAI and AHD hip deformity but with no more than minimal radiographic OA compared with pain-free controls (Pranter et al 2018).
- Significant reduction in the cross-sectional area, radiological density and length of gluteus medius muscle in the affected compared with the unaffected hip of patients with unilateral AHD (Lui et al 2012).

Overall, the findings provide good to high quality evidence of sleep and anxiety disorders in patients with FAI and AHD-associated hip pain. There is also high-quality evidence of patients with AHD receiving delayed diagnosis and definitive symptoms for patients with symptomatic AHD of moderate to severe pain and activity restriction diminishing pain.

The association of AHD with gluteus medius muscle changes was evident through measurement of its cross-sectional area and radiological density. Whilst such measures are beyond most clinic-based assessment, it is possible that alterations to gluteus medius, particularly when it is hypotrophied, are identifiable during physical assessment, when it may present as a positive Trendelenburg gait or eventually a loss of pelvic control and impaired mobility (Lui et al 2012).

### **3.4.3 Theme Three: Hyper-Flexibility**

Hyper-flexibility, also known as hypermobility or hyperlaxity, is defined in its simplest terms as relating to joints that have an abnormally large range of movement (Smits-Engelsman et al 2011). The condition has a broad range of presentations, and it is unclear if this variation reflects different disorders or discrete subgroups of hyper-flexibility (Di Mattia et al 2019). A spectrum of severity has, however, been described that varies from asymptomatic hypermobility, where localised joint movement is simply beyond normal range, through to the severe systemic effects of Ehlers-Danlos syndrome. This more severe condition is an hereditary disorder of connective tissue that is generally characterised by joint hypermobility and other structural weaknesses (The Ehlers-Danlos Society 2021).

Two studies explored an association between conditions in which hyper-flexibility was evident (Bilsel et al 2016; Samper et al 2015). These included AHD, with either recurrent shoulder instability or flexible flat feet. The findings presented in the studies, each of which were judged of 'good' quality, provide indicative evidence of:

- AHD being more frequent in patients with shoulder instability and hyper-laxity (Bilsel et al 2016)
- A higher prevalence of flexible flat foot in those with hip dysplasia (Samper et al 2015)
- Those with a history of hip dysplasia being five times more likely to present with flexible flat foot, compared to those without such a history (Samper et al 2015)

Overall, the findings provide good evidence of hyper-flexibility amongst those with AHD, either in the form of flexible flat foot, generalised joint hyper-laxity, or recurrent shoulder instability all of which can be determined during clinical assessment.

### **3.4.4 Theme Four: Heritability and Recurrent Risk of Hip Dysplasia**

Heritability refers to the strength of genetic influences in a population. Heritability studies aim to establish the power of genetics to predict disease, enabling recognition of the risk of a particular disease occurring within a family (Mayhew and Meyre 2017). Records of hip dysplasia occurrence from the early part of the twentieth century show that potential family links were identified through a study of 1,253 Indians from a North American settlement of Island Lake, Manitoba (Corrigan and Segal 1950). Diagnosis was



established of what was then termed, congenital dislocation of the hip (CDH), in some 6% of the population. Genealogical records suggested that the primary aetiologic factor for hip dysplasia was an hereditary one. Following this, Wynne-Davies (1970) studied 589 index patients with congenital dislocation of the hip and their families. The study findings suggested that two etiological groups with hip dysplasia exist, one in which predominantly late-diagnosed AHD was an inherited multiple gene and a second group with joint laxity which was considered responsible for a high proportion of the neonatal cases. Wynne-Davies (1970) presented persuasive evidence to show that infants with a late diagnosis of hip dysplasia, that is, normally months after the neonatal period, exhibited an inherited form of AHD. More recently, data from Stevenson et al (2009) indicate that there is indeed a genetic contribution to DDH as their study demonstrated a 12-fold increase in risk for first-degree relatives of individuals with the condition. Hence, genetic influences in hip dysplasia have long been suspected and these are still being investigated (Li et al 2013). These studies, however, focus on infant DDH and the risk of the same condition occurring in other infant relatives. Less attention has been given to the multifactorial nature of hip dysplasia or the onset of AHD that appears to occur in adolescence or adulthood and the potential for inherited characteristics to influence acetabular shape and hip joint stability. Two studies that have explored these factors and were deemed relevant for this review, therefore contributed to this theme (Carroll et al 2016; Li et al 2013). The main study objectives focused on the incidence of hip pathology phenotypic spectrum in family members with HD or estimating sibling recurrent risk and heritability of HD. The findings presented in the studies, both of which were judged of 'high' quality, provide indicative evidence of:

- Recurrent risk in siblings of probands with HD (that is, the individual serving as the starting point for the genetic or hereditary study of a family) was at least 10 times greater than in the siblings of non-HD families (Li et al 2013). The risk was 12 times higher for male siblings and 9 times higher for female siblings.
- A substantial percentage (27%) of first-degree and second-degree relatives of patients with infant DDH had unsuspected radiographic, and thus 'occult' HD (Carroll et al 2016)
- Those with occult HD were commonly aged under 30 years, after this age, many developed symptoms (Carroll et al 2016).

Overall, the studies provide high quality indicative evidence of the need to suspect HD in siblings of persons with the condition and to refer for radiographic screening, especially in families with a history of HD. Furthermore, there is a need for more research to identify the underlying predisposing genes in persons with DDH and occult HD (OHD).

Table 4. Evidence Table of Studies Included in the Review

(Table 4 continues from page 56-67)

Study	Main Study Objective	Study Type, Country & Recruitment Source	Participants (sample size, response rate, follow-up time) & Measures Used	Inclusion & Exclusion Criteria	Key Findings	Summary Evaluation Comments	Overall Evidence Quality Rating
<b>Duncan et al (2015)</b>	Determine whether there were clinically important gender-specific clinical, radiographic or other differences for patients undergoing PAO for AHD	Retrospective record review  St Louis, MO, USA  Patients on surgical database with symptomatic acetabular deformity and who had had a PAO.	N=180 patients, 203 hips)  Females: N=139; n=155 (76%) hips, mean age 26 years (range 9-49).  Males: N = 41; n=48 (24%) hips; mean age 27 years (range 12-44)  Demographic data (e.g. gender, height, weight,	<u>Included</u> if: <ul style="list-style-type: none"><li>Symptomatic acetabular deformity and who had had a PAO for whom non-operative treatment had failed,</li></ul> <u>Excluded</u> if: <ul style="list-style-type: none"><li>Had AHD secondary to Perthes-like deformities</li><li>Had acetabular retroversion</li></ul>	Found gender-specific disease characteristic differences particularly: males had greater prevalence of clinical, radiographic, and intraarticular findings consistent with concurrent FAI and instability and potentially a heightened risk of secondary FAI after PAO. Also, gender differences in the baseline Harris HHS (5 points) and UCLA Activity (1.0 point) scores between male	Study strengths include detail on methods and measures, power calculation for sample size (though authors query if sufficiently powered to detect any patient-reported outcome measures), clear pathway / description of follow-through of exclusion criteria, sound data analysis and clear data presentation. Ethical approval was given by Washington University School of Medicine.  The authors point to several limitations, including	<b>++</b>

**THEME ONE: COMPARISONS OF FEATURES BETWEEN ADULT AHD, FAI AND INFANT DDH**

BMI, age at the time of surgery).

Standard evaluation of bilateral hips, in the supine position and in flexion.

Maximal amount of motion for flexion and internal rotation of each hip without causing motion of the pelvis

Anterior impingement test

Self-reported, validated patient outcomes packet, from preoperative clinic visit. Included modified Harris hip score (HHS), Hip Disability and Osteoarthritis Score (HOOS), WOMAC, SF-12, and UCLA activity score.

- Had a previous ipsilateral osteotomy to the affected hip
- Digital radiographs not archived in the electronic medical record and could not be reviewed

and female patients, but only in the univariate analysis

incomplete intraarticular disease characterisation for all patients on the database (thus application and need for the exclusion criteria)

**Lee et al (2013)**

Assess demographic differences in patients diagnosed with DDH in infancy compared with those presenting as adolescents or young adults with AHD.

Retrospective case comparison study

Boston, USA

Online medical records review who had received PAO at the hospital

N = 421 questionnaires sent

Due to patient non-response and unavailable records, final dataset for analysis of N=311; age range, 9-51 years; 91% white European ethnicity; 50% in each group reported prior family history of DDH or AHD

Group DDH: Infantile DDH N=102; 98% female; 91% white ethnicity;

Group AHD: Adolescent/Adult diagnosed dysplasia: N=209; 88% female; 90% white ethnicity

Demographic and clinical data from

Included if:  
Patient had undergone PAO at the hospital between Aug 1991 and Jan 2008 under the care of one of the two senior authors

Excluded if:

- Syndrome or neuromuscular disorder predisposing to hip dysplasia

DDH group: patients had statistically significant higher rates of female gender, breech presentation at birth, and left hip involvement. There was also a higher, but not statistically significant % of first-born children in the DDH vs. AHD group.

For first-order family members of patients with DDH, there was a significantly higher likelihood that these family members had DDH compared with family members of patients with AHD.

In the AHD group there was a higher prevalence of male gender and bilateral hip involvement and a significantly higher rate of THA by age 65 years in 1<sup>st</sup> order relatives

Study strengths include detail on methods and measures, sound analysis and clear and appropriate data presentation. Useful and informative linkage of findings with other studies. Ethical approval was given by Boston Children's Institutional Review Board.

Authors point to several limitations including infantile DDH group restricted to those referred to the specialist children's hospital for treatment of residual dysplasia; members of the AHD group might have had infantile DDH which had gone undetected; and problems associated with retrospective record review and, for questionnaire data, retrospective patient recall. It is notable that the authors suggest ways to explore these limitations in other studies, for example, in locations where ultrasound infantile hip screening is undertaken, and/or use prospective database.

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			records (including diagnosis, side of surgery, gender, race, birth history, history of infantile hip dysplasia, family history of hip disease)				
			Patient questionnaire (demographic information and family history)				
			Chart review of outside records from referring providers, when available and documentation of radiographic measures				
<b>Kappe et al (2012)</b>	Compared symptoms and history of patients with FAI and AHD and WOMAC items, subscales and overall sum scores	Retrospective case comparison study  Ulm, Germany	FAI Group: N = 37; 16 women; 21 men; mean (SD) age 35.3 (10.1) years (range 17–56).  AHD / PO Group: N = 37; 27 women;	<u>Included</u> if: <ul style="list-style-type: none"> <li>Patients, selected consecutively, who had received either hip arthroscopy, minimally invasive anterior</li> </ul>	Similarities in clinical presentation between the two groups of patients (FAI or AHD / PO). Only statistically significant increased internal rotation at 90° flexion of AHD group; significantly higher mean score for 'getting	Study strengths include detail on methods and measures, consecutive selection of FAI and AHD / PO patients meeting the inclusion and exclusion criteria, sound analysis and clear and appropriate data presentation. Useful and informative linkage of	<b>++</b>

between these patients in order to find valid differentiating items

Hospital record review for either: adult patients receiving operative treatment for either AHD or FAI over a three-year period (Jan 2006 - Dec 2008); or patients receiving pelvic osteotomy (PO) for AHD during the same time span

10 men; mean (SD) age 27.8 (8.2) years (range 17–45)

Data on patient's hospital record including duration of symptoms, range of motion, incidence of a positive antero-superior impingement test and responses to the WOMAC questionnaire.

head neck offset reduction, or surgical hip dislocation for FAI

- Patients receiving PO for AHD

Excluded if:

- Hips with osteoarthritis more severe than grade one on Kellgren and Lawrence and/or Tönnis scale
- Patients with prior surgical treatment of the respective hip
- Patients with no pre-operative WOMAC questionnaire

in or out of a car'. No difference found in average symptom severity. Clinical examination showed that both FAI and PO patients frequently present with a positive antero-superior impingement test. Hip abduction and internal rotation more frequently limited in FAI than PO patients with AHD.

findings with other studies (and notes that patients with FAI or AHD have rarely been compared in the literature before). Ethical approval was given by the University of Ulm.

The authors point to some study limitations, in particular: the use of a questionnaire originally designed for osteoarthritis of the hip and knee, though its items have face validity for FAI and PO patients; differences in mean age in FAI and PO patient groups, gender and in clinical range of motion (the latter suggesting need for caution in any generalisation of the findings).

Note: same exclusion criteria for both FAI and PO patients

## THEME TWO: CLINICAL PRESENTATION OF AD

<b>Prather et al (2018)</b>	Describe level of insomnia and anxiety in young and middle-aged adults with hip pain and no more than minimal osteoarthritis compared to healthy persons	Prospective case-control study USA	N= 50 cases, aged 18-45, presenting for evaluation of hip pain at 2 tertiary university medical centres. 11 male and 39 female, mean (SD) age 31.2 (8.31) years. Mean (SD) height 66 (5.41) inches; mean (SD) weight = 158.3 (34.6) lbs. Duration of hip pain mean (SD) = 32.1 (52.61) months.	<u>Included if:</u> <ul style="list-style-type: none"> <li>• Hip Pain for ≥ 3 months</li> <li>• Pain distribution including groin and lateral hip</li> <li>• Minimum of 2 positive provocative hip test results on physical examination</li> <li>• Hip radiograph, Tönnis grade 0 or 1</li> </ul>	Cases slept significantly less ( $p < .001$ ) per night and experienced significantly greater insomnia ( $p < .0001$ ) and anxiety ( $p < .0001$ ) compared to controls.	No differences in insomnia and anxiety scores between hip pain patients or different types of hip deformity	Authors conclude that evidence of modifiable sleep and anxiety disorders, if recognized early on when cases first present.	Experienced clinicians undertook symptom-provocative hip tests; CT scans independently reviewed by a blinded radiologist. Good detail on measurement procedures. Good data presentation and analysis Ethical approval given by Washington University School of Medicine	+
			N = 50 healthy controls, matched by age and gender  Insomnia Severity Index (ISI) and the Pain Anxiety Symptoms Scale (PASS), measured on one occasion.	<u>Excluded if</u> <ul style="list-style-type: none"> <li>• Previous hip or lumbar spine surgery,</li> <li>• Inflammatory arthropathy</li> <li>• Pregnancy</li> <li>• Tumour</li> <li>• Fracture of the hip or spine</li> </ul>				However, no detail given on source of controls, only that they were 'symptomatic healthy controls. Also not indicated when patients were asked to complete measures of insomnia and anxiety.	
								In addition, as the authors observed small sample restricting generalizability, and single point in time measurement of insomnia and anxiety. Authors also point out that some of the patients may have responded to conservative treatment and some may have been referred for surgery.	



<b>Liu et al (2012)</b>	Compare loss of contractile muscle mass in, and change in length of, the gluteus medius in affected and healthy hip in AHD patients	Cohort, record-based study  Tertiary centre, AHD patients scheduled for total hip arthroplasty  China	N = 19 with unilateral AHD (7 males, 12 females). Mean age 47 years (range 35-61); mean weight, 55kg (range 50-69); mean height, 1.57m (range 1.55-1.70m);  CT scans made for morphological evaluation of the acetabular and proximal femur before total hip arthroplasty. Scans collected over a 3-year period.	No explicit <u>inclusion</u> criteria specifically mentioned. Likely to have been:  • Confirmed diagnosis of unilateral AHD and available CT scans for the 3 years.	CSA and RD of gluteus medius muscle were significantly reduced ( $p < 0.05$ ) in the affected hip compared to healthy hip. Length of the gluteus medius muscle was reduced by 8-11% ( $p < 0.05$ ), the gluteus medius activation angle significantly increased ( $p < 0.05$ ), and hip abductor moment arm was decreased ( $p < 0.05$ ).	Study strengths include the detail provided on the measurement procedures and their implementation and checks made on intra-observer and inter-observer repeatability, both of which were demonstrated. Good explanation is provided regarding gluteus medius and its importance to explore in patients with AHD.  However, it is a small study, restricting generalisability, and undertaken in one site. No indication is given of ethical approval (though, as it is based on available data, it might have appropriately been judged to focus on 'routine service development/monitoring').	+
<b>Nunley et al (2011)</b>	Determine the early clinical presentation of symptomatic AHD in skeletally	Cohort study  USA  Patients diagnosed with symptomatic AHD on basis of	N = 57 (41 female; 16 male); 65 symptomatic hips  Mean age 24 years  Patients followed up post-operatively	<u>Included if:</u>  • Confirmed diagnosis of AHD	Majority (77%) of the hips associated with moderate-to-severe pain daily. Pain commonly localised to the groin (72%) and/or the lateral aspect of the hip (66%). Activity-related hip pain was	Full detail given on design and clinical evaluation. Good level of detail provided about patient reported data; good data presentation and analysis. Ethical approval provided for the study.  As the authors observed, the study has several limitations.	++

mature patients

clinical history, physical examination, and radiographs

after PAO  $\geq$  2 years

Self-reported questionnaire data covering, *inter alia*, history, symptoms, including pain, demographics, aggravating factors and modes of relief, activity levels, and symptom onset.

Clinical evaluation: presence/absence of limping; Trendelenburg gait; and hip impingement test. Patients evaluated at follow-up visits at 6 weeks, 3 and 12 months and annually thereafter.

Clinical response to surgery assessed via Harris hip score

common (88%); activity restriction often diminished hip pain (75%). On examination, 31 hips (48%) associated with a limp, 25 (38%), with a positive Trendelenburg gait; and 63 (97%), with a positive impingement sign.

The mean time from symptoms onset to diagnosis of hip dysplasia was 61.5 months (range 5 months to 29 years). A mean of 3.3 healthcare providers seen prior to the definitive diagnosis.

Mean Harris hip score improved from 66.4 points preoperatively to 91.7 points at a mean of 29.2 months after the PAO

Authors appropriately conclude that the study demonstrates the need for greater clinical awareness of the condition, given likely

These include reliance on patients' recollections of onset of symptoms and their time course and impact; lack of a comparison group; and possibility that the same symptoms represent other co-existing extra-articular conditions.

impact of a delayed diagnosis and early and appropriate surgical treatment.

**THEME THREE: HYPER-FLEXIBILITY**

<p><b>Bilsel et al (2016)</b></p>	<p>Test the hypothesis that patients with recurrent shoulder instability accompanied by generalised joint hyper-laxity tend to have AHD</p>	<p>Retrospective case study  Istanbul, Turkey  Hospital records: pelvic radiographs of patients, from 2010 to 2013, with hyper-laxity &amp; shoulder instability, and with no history of hip joint trauma  Physician assessed AHD and generalized</p>	<p>N=26; 6 female and 20 male; mean (SD) age 26 (<math>\pm 8</math>) years (range 13-39 years) with shoulder instability and hyperlaxity  Generalised hyper-laxity assessed by Beighton criteria and score (range, 0-9); AHD by standard anteroposterior hip radiographs; pelvis; Central Edge Angle (CEA) measure by Wiberg method; MRIs to show SLAP-Bankart lesions (torn glenohumeral labrum of the shoulder).</p>	<p><u>Included if:</u></p> <ul style="list-style-type: none"> <li>• No previous hip joint injury, or previous hip surgery or hip joint disorders</li> <li>• No traumatic shoulder dislocation</li> </ul>	<p>88.5% of hips had AHD based on an AA above 42.2° and/or CEA under 22.6°.  Beighton score, mean (SD) 3.5 (<math>\pm 2.6</math>); 42.5%, severe; 15.4%, moderate.  In comparison with other prevalence studies of the Turkish population, average CEA and AA were significantly lower (<math>p &lt; 0.009</math>) than the average CEA and AA. For example, the mean (SD) CEA of the general Turkish population (Atkas et al 2000) was 33.8 (<math>\pm 5.6</math>)° (males: 34 (<math>\pm 5.5</math>)°; females 33.7 (<math>\pm 5.6</math>)°);</p>	<p>Study strengths include clear indication of measures used; appropriate statistical testing; good data presentation; Beighton scoring and radiographic measurements performed by one person; hospital ethical approval for the study.  There are some study limitations, including: need for greater detail on rationale and mode of selection of included patients, and if the study members were all patients who met the inclusion criteria in the selected time period; low subject numbers for a prevalence study; no scoring of function for hip and shoulders; MRI correlation not analysed due to ethical issues; and lack of power analysis. It is also</p>	<p>+</p>
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		joint laxity test scores			in the current study, CEA was 31.9 ( $\pm 5.1$ )°.	questionable how representative the study members were of persons with AHD (study had three times more male than female participants whereas AHD shown in other studies to be much more prevalent in females (ratio 3:1).	
<b>Samper et al (2015)</b>	Evaluate the possible relationship between flexible flat foot and AHD in children aged 6-15 years.	Cross-sectional, case-comparison study  Roosevelt Childhood Orthopaedics Institute, Bogota, Colombia	N=140 participants,  N=65; AHD/ Surgery group,  N=75 healthy controls	<u>Included</u> if: <ul style="list-style-type: none"> <li>For cases, patient undergone surgery for AHD or hip dislocation in previous 10 years</li> <li>For controls, child with no hip pathology history</li> </ul>	Prevalence of flexible flat foot in AHD cases was 61% compared with 12% amongst controls, with a prevalence ratio of 5.12 (95% confidence interval: 2.69---9.74). Thus, 5 times more likely for individuals with a history of hip dysplasia to present flexible flat foot compared to individuals without such a history.	Study strengths include valuable starting point to study relationship between flat foot and AHD in children; useful subgroup data analysis; ethical approval provided by authors' Institute; authors' suggestion of value of a prospective study with a longer follow-up to explore link between flat foot and AHD pathologies.	+
		Cases (Group A): recruited from those who had surgery for AHD or hip dislocation in the last 10 years.  Controls (Group B) recruited from a school	62% female, 38% male; age range 6-15 years  Both cases and controls evaluated using suggestive criteria for flexible flat foot, drawn from the international literature (e.g. flattening of the internal longitudinal arch, valgus of the	<u>Excluded</u> if: <ul style="list-style-type: none"> <li>For both case and control subjects, those with associated neuromuscular disorders</li> <li>Children aged &lt;6 years old or <math>\geq 15</math> years of age 6 (to represent AHD disease prevalence)</li> </ul>	Statistically significant gender difference was apparent: for the female cases, 63% prevalence rate of flexible flat foot (n = 36) vs. 13% (n = 4) in controls (p<.0001); for male cases, 50% prevalence rate (n = 4)	Limitations include small study, limiting generalisability; no matching of cases with controls indicated; not evident if study was sufficiently powered. Furthermore, as the authors observe, some of the current 'healthy' controls may be diagnosed with AHD later, for example, when 18-21 years old.	

population with no history of hip pathologies

talus and adequate subtalar mobility)

vs. 11% (n = 5) in controls (p<.007).

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#### THEME FOUR: HEREDITARY AND RECURRENT RISK OF HD

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<b>Carroll et al (2016)</b>	Determine the hip pathology, phenotypic spectrum of, and incidence in, family members of patients with DDH/AHD	Hospital and population database, diagnostic study  Salt Lake City Shriners Hospital for Children, Utah, USA, & Utah Population Database, using ICD-9 code for DDH	N=120 people from 19 families known to have at least one member with surgically treated DDH/AHD.  N=34 DDH/AHD; 19 probands (person serving as starting point for genetic study of the family) and 15 family members); & 86 family members with no DDH/AHD diagnosis.  N=15 family members with DDH (ten 1st degree & five 2nd	<u>Included if</u> <ul style="list-style-type: none"><li>• At least one member who had undergone treatment for DDH/AHD, bracing or surgery</li></ul> <u>Excluded if:</u> <ul style="list-style-type: none"><li>• Neurological condition</li><li>• Teratologic dislocations</li><li>• Aged ≤ 6 months old</li></ul>	The 120 subjects ranged from 1 to 84 years, 34 had orthopaedically treated DDH/AHD. Of the remaining 86 supposedly normal subjects, 23 (27%) had occult HD (OHD) as defined by centre edge angle (CEA) <20 and/or a Severin score of ≥ III. 60% of the 86 individuals were less than 30 years old, 74% of the OHD group were less than 30.  27% of 1 <sup>st</sup> and 2 <sup>nd</sup> degree relatives of patients with DDH/AHD had unsuspected radiographic AHD. Most of the subjects with OHD were younger than 30	Study strengths include use of tried and tested database approach for subject recruitment; clear and full description of methods; blinding of radiographers to DDH/AHD diagnosis; appropriate statistical analysis; informative data presentation. Ethical study approval from University of Utah Investigational Review Board.  Possible limitations include lack of detail over time frame and if all cases in that time period were included in the study; completeness of population databases; no power calculation for sample size,	<b>++</b>
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			<p>degree relatives of proband); N=86 family members with no prior history of DDH (50 1<sup>st</sup> degree and 36 2<sup>nd</sup> degree relatives of proband).</p> <p>Physical examination, radiographic assessment, and patient completion of functional outcome scores (HHS, AAOS, &amp; WOMAC)</p>		<p>years. After age 30, many of these patients developed symptoms.</p> <p>Authors appropriately suggest that radiographic screening of siblings of persons with DDH/AHD would be prudent in families with a significant history of DDH/AHD.</p>	<p>thus caveat over generalisability.</p>	
<b>Li et al (2013)</b>	Estimate the sibling recurrent risk and heritability of DDH	<p>Case-control study</p> <p>Qingfeng county area, Henan Province, China.</p> <p>Cases: referred subjects from a county-wide screening programme for DDH, 2002-2007.</p>	<p>N=429 DDH probands; N= 534 matched normal controls. Included 628 DDH (case) siblings in families of probands and 889 siblings in those of controls</p> <p>Questionnaire survey for proband's sibling information (e.g., number of siblings, birth order, gender,</p>	<p><u>Included</u> if:</p> <ul style="list-style-type: none"> <li>Case diagnosed in University Hospital between 2002 and 2007 – person first diagnosed was labelled as proband.</li> </ul> <p><u>Excluded</u> if:</p> <ul style="list-style-type: none"> <li>DDH secondary to other conditions (e.g. systemic</li> </ul>	<p>87 siblings (14%) in families of probands and 14 siblings (1.6%) in normal control families were diagnosed as DDH/AHD. Although the prevalence of DDH/AHF in female siblings was at least double that of male siblings, comparison with siblings in control group showed recurrent risk in siblings of probands was <math>\geq 10</math> times that in siblings of controls. Male sibling recurrent risk was about 12 times that of females,</p>	<p>The study has a number of strengths; first Asian case-control study on this topic; large sample sizes; subject recruitment carried out with no prior knowledge of their severity and details of DDH family history; good links with wider international literature, in introduction and situation of findings therein; matching of cases and controls; ethical approval by Medical Ethics Committee of the authors' institute.</p>	<b>++</b>

Controls: children who visited the clinic of the same hospital for DDH screening during the period of 2002–2007.

age at screening and screening results)

Radiological data to confirm screening results

Clinical examinations (e.g. limitation of abduction, Barlow's and Ortolani's test, following manipulation by experienced paediatric orthopaedic surgeon.

Radiographic records (to confirm DDH severity)

syndrome, neuromuscular diseases; pathological or teratological dislocation

- Families unable to provide accurate sibling screening records
- For controls, individual not included if one of their siblings was included in a proband family

and 9-fold in female siblings.

Authors soundly conclude that the study demonstrates a high probability of heritability of DDH/AHD and the need to identify underlying predisposition genes in future genetic studies.

The authors point to a number of limitations, including: inability, as case–control study, to compute incidence; family history first obtained by parents' report, which may lead to respondent bias (although data confirmed from hospital sources and clinical examination); cases and controls were recruited from the same hospital, but their siblings might have been screened at another hospital; possible selection bias as families unable to provide accurate sibling screening records were excluded from the study.

### 3.5 Discussion

The evidence presented in this systematic review, summarised in Table 4, demonstrates a multiplicity of approaches to study designs, all of which aim to contribute to the development of a clinical picture for AHD. Generally, the studies looked at specific defining features that could signify common predictors of AHD or that could be identified during clinical assessment as being present in patients with AHD. The findings are discussed within and across the four thematic areas in which the ten studies were categorised.

Studies in Theme One add to understanding clinical features of hip dysplasia and may be classified as potential indicators (Table 5) that could contribute to an AHD clinical picture. They present evidence about: demographic features of infant diagnosed DDH compared with adolescent or adult AHD (Lee et al 2013); differences in female and male AHD features (Li et al 2013); and features that distinguish between FAI and AHD, two very similar conditions (Duncan et al 2015; Kappe et al 2013). All the studies were rated high quality and therefore can be drawn upon to inform the development of a diagnostic picture.

Lee et al (2013) showed that there was an increased rate of female gender, breech presentation at birth and left hip involvement amongst those with infant DDH; by contrast, whilst a higher rate of females was also true for adult AHD there was a larger proportion of males and bilateral hip involvement in this group compared with infant DDH. This evidence challenges possible misconceptions that AHD is only a female condition. Duncan et al (2015) also found differences between males and females when exploring their hypothesis that FAI secondary to hip dysplasia was a known cause of poor PAO outcomes. They found that cam-type FAI substantially increases the risk for OA and is more frequent in male patients with adult AHD. Kappe et al (2012) also focused their attention on differentiating between FAI and AHD. They argued that whilst the antero-superior impingement test was almost always present in both FAI and AHD, internal rotation at 90° hip flexion was significantly less in patients with FAI. One further difference was that significantly more FAI patients presented with symptoms associated with sitting and getting in and out of a car than AHD patients.

Lee et al (2013) confirmed demographic differences between patients diagnosed with DDH compared to AHD, supporting the hypothesis that infant DDH and adult AHD may represent two distinct forms of dysplasia. In both, however, there is a familial tendency



toward hip disease with a higher incidence of early hip arthroplasty in adult AHD family members and a higher frequency of infantile dysplasia in families with an infant DDH history. This has implications for detecting AHD as many adults are not identified as having the condition unless they present with symptoms. Establishing details of family history may therefore inform and facilitate diagnosis. In addition, based on this, maternity services could consider collecting data routinely from pregnant women regarding their family history of hip conditions.

*Table 5. Theme 1: Comparison of Hip Dysplasia and Femoroacetabular Impingement*

Lee et al (2013)	Adult Acetabular Hip Dysplasia	Infant Developmental Dysplasia of the Hip
	Bilaterality more common	Breech delivery and left hip involvement more common
	Higher incidence of 1 <sup>st</sup> order relatives with Total Hip Replacement by age 65 years	Higher incidence of 1 <sup>st</sup> order family members with Developmental Dysplasia of the Hip
	Majority female but more males affected than Developmental Dysplasia of the Hip	Large majority female
Duncan et al (2015)	Sex-dependent Differences in Acetabular Dysplasia Characteristics	
	Males show less hip internal rotation at 90° hip flexion than females	
	Males show greater incidence of concurrent Femoroacetabular Impingement than females	
Kappe et al (2012)	Femoroacetabular Impingement	
	Less internal rotation and abduction	
	Symptoms more often associated with sitting and severity increased when getting in and out of a car	

Theme Two highlighted some specific early clinical findings (Table 6) and whilst these may not be isolated to AHD presentation alone, they may be helpful in building the clinical presentation of AHD when combined with other associated AHD features. The three studies provide evidence of changes in the gluteus medius muscle (Lui et al 2012); patterns of pain and dysfunction (Nunley et al 2011), and anxiety and insomnia disorders (Pranther et al 2018). The contribution of gluteus medius changes to the clinical picture

of AHD requires further consideration. Liu et al (2012) drew out the specific differences between an AHD joint and the normal, contralateral healthy joint in individuals with unilateral AHD. Hence the dependent variable of these gluteus medius measurements is accepted as being affected by the independent variable of AHD presence or absence. The authors accepted that similar gluteus medius changes can be evident in patients with advanced hip OA, but they argued that causes may differ. Liu et al (2012) explain that changes in gluteus medius in OA are associated with strategies to offload the problem hip, whereas in AHD, as well as offloading, the cause may also be related to the proximal displacement of the femoral head. This puts the femur in an abducted position; hence the abductor lever arm is reduced resulting in the gluteus medius activation angle being increased. Additionally, consideration needs to be given to the role that muscles and tendons acting across the joint have in maintaining hip joint stability. Whilst iliopsoas offers support to anterior stabilization, gluteus medius and minimus are important contributors to lateral stabilization, particularly in the maintenance of a level pelvis during single leg standing (Palastanga et al 1998). They are therefore likely to be exposed to greater demands in AHD to regain stability in an inherently unstable joint. Since completion of this systematic review, Jacobsen et al (2018) used sonography to demonstrate significant, though only weak to moderate correlations, between ultrasonic measures of iliopsoas and glutei abnormalities with pain location in patients with AHD. Although sonography is not readily available in most initial routine hip assessments, Jacobsen et al's 2018 findings offer support to those of Liu et al (2012). Jacobsen et al (2018) reason that the reduced weight-bearing of the shallow, steeply oriented joint in AHD increases anterior capsule and labral loading, raising the demands on iliopsoas because of its close proximity to the capsule-labral complex. Similarly, AHD joint limitations could have implications for gluteus medius and minimus as these hip abductors may need to work harder to achieve a level pelvis during ipsilateral swing phase of gait. Such extreme demands may result in fatigue or damage to the muscle tissue or tendons. This correlates with clinical reports of AHD-associated pain being located in the groin or lateral hip (Jacobsen et al 2018) and a Trendelenburg gait as identified in more than one-third of the symptomatic AHD patients of Nunley et al's 2011 study. As well as these indications of gluteus medius weakness, Nunley et al (2011) draw attention to sites of pain, mechanical symptoms and walking with a limp, emphasising the functional impairment that these patients experience.

In the final study of this theme, Pranter et al (2018) point to the value of the clinician exploring co-existing disorders related to chronic pain including insomnia and anxiety. They found young and middle-aged adults with hip pain and without radiographic moderate to severe hip arthritis, had insomnia and anxiety. Whilst these features are not limited to people with AHD and are apparent in hip pain patients generally, they should be included with other features identified in theme 2 studies as possible indicators that may offer an alert to physiotherapists and other first contact clinicians to the potential presence of AHD during early assessment of hip pain.

*Table 6. Theme 2: Clinical Presentation of Acetabular Hip Dysplasia*

Nunley et al (2011)	<ul style="list-style-type: none"> <li>• Insidious onset; moderate-severe, mostly activity-related, groin or lateral hip, sharp or dull pain</li> <li>• Mechanical symptoms such as catching, locking clicking</li> <li>• Limp</li> </ul>
Pranter et al (2018)	Higher levels of insomnia and anxiety in young and middle-aged hip pain adults
Lui et al (2012).	Reduction in size and density of gluteus medius muscle compared with the unaffected hip in unilateral Acetabular Hip Dysplasia.

Theme Three focused on the potential of joint hyper-laxity (Bilsel et al 2016) and flexible flat foot (Samper et al 2015) as being associated with AHD (Table 7). Bilsel et al (2016) found that AHD was more frequent in patients who had recurrent shoulder instability accompanied by generalised joint hyper-laxity. Samper et al (2015) found a relationship between flexible flat foot and HD in children between 6 and 15 years of age. Notably, 61% of the group with HD or hip dislocation also had flexible flat foot, compared to 12% in the healthy group. Thus, they recommend that patients who seek assistance for the first time because of a flexible flat foot condition should also be evaluated for indications of HD. Physiotherapy is the mainstay of treatment for patients with joint hyperlaxity (Kemp et al 2010) therefore, its identified association with AHD should contribute to alerting these clinicians to the possibility of AHD presence in people being assessed because of hip problems who also have hyperlaxity.

Table 7. Theme 3: Hyper-Flexibility

Bilsel et al (2016)	Evidence of an association between Acetabular Hip Dysplasia and general hyperlaxity with shoulder instability
Samper et al (2015)	Evidence of an association between hip dysplasia and flexible flat foot in children aged 6-15 years

The two studies of Theme Four (Carroll et al 2016; Li et al 2013) explored hereditary and recurrent risk factors (Table 8). Against a context where the aetiology of HD is poorly understood, although thought to be multifactorial (Carroll et al 2016), it is hypothesised that genetic as well as environmental factors may influence hip development. Several studies have investigated possible genetic links with hip dysplasia (Li et al 2013), but the focus for these investigations has been infant DDH and the findings are far from conclusive. To add to this evidence, with potential implications for AHD, Li et al (2013) explored the heritability of infant DDH in an Asian population and the recurrent risk of HD (DDH and AHD) in siblings of infant DDH probands, finding recurrent risk being at least 10 times greater for infant DDH siblings than healthy control siblings.

Carroll et al (2016) considered potential links between infant DDH with AHD, comparing the recurrent risk of undiagnosed adult AHD in the relatives of patients with infant DDH. They identified that 27% of 1st and 2nd degree relatives of patients with infant DDH had unsuspected adult AHD. Importantly, they demonstrated that in this so-called ‘occult’ AHD (OAD) group where individuals have an insidious form of AHD in which symptoms develop as they age, the majority (who were under 30 years of age) were ‘clinically silent’. The older members of the group (over 30 years) had indeed become symptomatic with age. Carroll et al (2016) suggest that this relatively high rate of OAD in families with a known history of infant DDH may explain why families with repeated incidence have an increased recurrent risk of OA in otherwise normal parents and grandparents.

Table 8. Theme 4: Heritability and Recurrent Risk of Hip Dysplasia

Li et al (2013)	<ul style="list-style-type: none"> <li>• High recurrent risk of Hip Dysplasia in siblings of individuals with infant Developmental Dysplasia of the Hip</li> <li>• High heritability</li> </ul>
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Carroll et al (2016)	<ul style="list-style-type: none"> <li>• Evidence of unsuspected or occult hip dysplasia in 1<sup>st</sup> and 2<sup>nd</sup> degree relatives of patients with hip dysplasia.</li> <li>• People with occult hip dysplasia commonly clinically silent until after aged 30 years</li> </ul>
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These findings support the hypothesis that an inherited predisposition to adult AHD occurs in otherwise healthy individuals and the likely cause of OA is unrecognised hip dysplasia. Adult AHD may also be part of a spectrum of hip dysplasia and an inherited condition. These findings emphasise the important role that clear, accurate family history-taking plays in the early diagnostic reasoning of young adult patients with hip pain. Indeed, Carroll et al (2016) suggest that radiographic screening of siblings of persons with infant DDH would be prudent in families with a significant history of infant DDH.

### 3.5.1 Implications for Clinical Practice

The implications for physiotherapy and other areas of clinical practice suggested by the ten papers, include paying attention to young, predominantly, but not exclusively, female patients who present with daily moderate to severe pain (Nunley et al 2011). Gluteus medius weakness or fatigue may be evident and may present as a Trendelenburg gait (Liu et al 2012) and a limp might also be evident (Nunley et al 2011). There might be evidence of hyper-flexibility (Bilsel et al 2016; Samper et al 2015) and clinicians should be aware that presentation could be bilateral (Lee et al 2013). Taking a clear family history, including asking patients about early onset of hip OA in family members (Carroll et al 2016; Li et al 2013), might also be valuable. However, whilst efforts have been made to identify features that characterise AHD presentation, the available evidence is not able to distinguish AHD presentation from other pathologies of the hip with confidence. Many of the features discussed in this systematic review are evident in a range of other conditions of the hip. Evidence generated by the systematic review does, however, provide insight into symptoms with which a person with symptomatic AHD might present but, differentiating the features that are attributable to hip dysplasia alone or to other painful hip conditions remains a challenge.

Although the range of evidence underlying the ten studies is of good to high quality, they fail to present a definitive clinical picture of AHD, rather, they suggest potential for guiding further research. Such research is much needed to inform practice interventions aiming to support recognition or at least, suspicion of AHD presence, sufficient to justify referral for imaging assessment. Looking across themes, the systematic review provided good indications of factors that form the foundations on which to build a clinical picture of adult AHD. The subtlety of these factors and the unknown reliability of their occurrence, however, confirms the need to add clarity to the findings. By doing so, the regularity of the indicators' occurrence amongst the AHD population might be identified, which would assist clinicians and enhance their index of suspicion for AHD presence in relevant patients. It would also prevent the typical diagnostic confusion between AHD and other conditions of the hip.

For infant DDH there are definitive, evidence-based risk factors (Ortiz-Neira et al 2012; Zamborsky et al 2019) and diagnostic criteria that provide reliable specificity that clinicians can utilise to accelerate diagnosis (Roposch et al 2011); this is not the case for adult AHD. Definitive risk factors and clinical indicators for AHD are not currently effective in reliably avoiding diagnostic delay.

### **3.5.2 Areas for Further Research**

Whilst the systematic review informs the foundations on which a clinical picture of adult AHD might be built, the nature of the findings points to several areas for further clinical research. Firstly, as Carroll et al (2016) argued, further study is needed to determine whether younger family members of patients with occult AHD should be screened and, if so, when, and building on what risk indicators and/or symptoms. Secondly, further study of the functionality of hip abductors, which are responsible for maintaining a level pelvis during locomotion would build greater understanding of the role of gluteus medius muscle changes in adult AHD patients. This should particularly investigate those patients with more minimal symptoms who are early in the disease trajectory, with a view to assessing its prevalence. Logical development of this finding would point to the recommendation that research is needed to develop specific post-operative rehabilitation programmes that target this muscle. Thirdly, as Li et al (2013) propose, further research is needed to explore the commonality of familial patterns and the supposition of AHD having a genetic link, to uncover any underlying predisposition genes. Fourthly, and the

stimulus for this PhD study, limitations in the evidence base regarding an AHD-specific clinical picture of physical presentation need to be addressed, giving consideration to the combination of presentation features in real time along with the history of onset of those features. Such features need to be recognisable during early assessment of patients with problematic hips.

### **3.6 Summary and Stimulus for this PhD Study**

The systematic review adds to the knowledge base by providing tentative evidence of indicators that begin to inform the development of a clinical picture of symptomatic AHD. These indicators are however, not limited to AHD alone as there remains confusion caused by the similarity of these symptoms to those of other hip conditions, which may lead to misdiagnosis (Nogier et al 2010; Lee et al 2018; Leide et al 2021). Further evidence is required to establish nuances of AHD that may support differential diagnosis. In addition, the review introduces the notion of potential indicators for selective screening of AHD in adults before troublesome symptoms present. It also provides preliminary evidence which supports the notion that infant DDH, and adult AHD could be viewed as two distinct conditions as risk factors, signs and symptoms differ. Further study is needed to establish a more recognisable and consistent clinical picture of AHD. There is a need to draw on the developing evidence surrounding the clinical presentation of AHD. Teasing out the symptoms of AHD from other hip conditions is particularly important to distinguish between those that would benefit from physiotherapy treatment and those requiring X-Ray referral and/or surgical correction. In addition, exploring, and further strengthening evidence of the regularity of occurrence of, for instance, hyper-laxity and the involvement of gluteus medius muscle in AHD would contribute to decision-making confidence. These are important to the understanding of how AHD might present, which is required to inform both diagnostic reasoning and patient management.

Further work is needed to identify clinical features that facilitate accurate suspicion of the condition's presence by physiotherapists and other clinicians who carry out early diagnostic assessment. This will enable patients to gain early referral to specialist young peoples' hip clinics and discuss treatment options at an early stage of the disease trajectory. When patients present with initial hip pain, the expertise of the clinician to

correctly suspect a diagnosis of AHD will be crucial to gaining quick X-Ray referral and early, effective outcomes.

In summary, supportive evidence is required to confidently confirm the findings of the systematic review and to address the remaining gaps in knowledge. The key aim of this PhD study is therefore to build on the understanding of AHD signs and symptoms and develop a clinical picture that will assist physiotherapists and other first contact clinicians to recognise potential indications of early, symptomatic AHD that will signal the need for X-Ray referral and definitive diagnosis.

The next chapter will explain the methodological approach to achieving this aim and the philosophical influence underpinning the study design.



## **4 Research Design and Methodology**

### **4.1 Chapter Introduction**

The overall aim of this PhD study was to build an understanding of pre-X-Ray clinical presentation of patients with AHD and explore how these insights might be integrated into physiotherapy practice. Therefore, having reported the findings of a systematic review, I now explain firstly, how that current, though limited understanding will be developed through achieving three study objectives. These objectives enabled me to achieve the overall aim. Secondly, I discuss the research framework in which these objectives were achieved and explain the rationale for each of the three pillars of study used to address them.

#### **4.1.1 Study Objectives**

In Chapter 1, I explained how online postings and seminar talks from people living with AHD had demonstrated their understanding and expertise regarding their hip condition. They also expressed feelings that information they offered clinicians during assessment of their hip, seemed to be ignored. From my own clinical experience, I was aware that patient reported information can go beyond what a clinician recognises as being relevant, but I recognised that this extended patient information might provide an opportunity that could help to expand the knowledge and understanding of AHD signs and symptoms. I therefore considered how best to collect the perspectives of people and patients living with AHD and to do so in a way that would enable them to account for their experiences without the restriction of heavily directed clinical-type questioning. This thinking informed the first objective of this study, which was to explore how patients with hip dysplasia describe their hip problems and experiences.

I also highlighted in Chapter 1 how, whilst specialist hip surgeons use X-Ray imaging to evaluate patients' anatomical deficits in the planning of corrective surgery, they also carry out an assessment of the patient's history and a physical examination of the patient and I wondered whether collecting their knowledge of assessing patients with AHD could provide insight from which other clinicians could learn. This, I felt, could provide an additional perspective of how patients with AHD present. This informed my

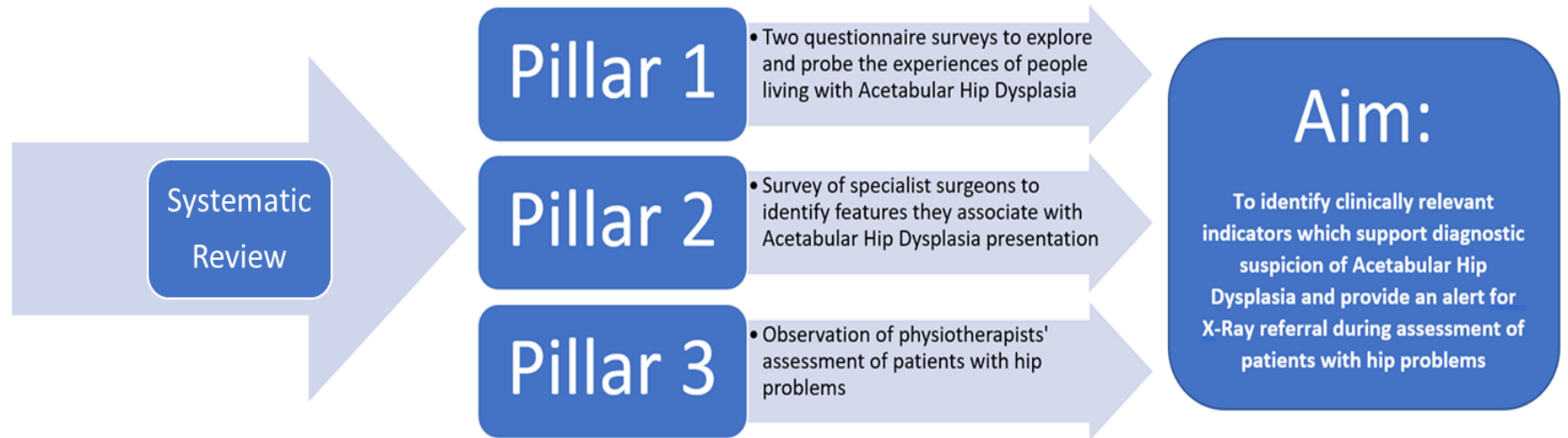
second study objective, to identify what surgeons who specialise in the correction of the condition consider to be the presenting features for suspecting hip dysplasia.

Additionally in Chapter 1, I questioned whether physiotherapists applied to their patient-assessments, the hypothetico-deductive reasoning they were taught during their pre-registration education. I was interested in knowing what patient data were collected during physiotherapists' clinical assessment and how they responded when patients presented with indications that were unfamiliar, or that related to AHD. Having considered how, during patient assessment, limited knowledge can cause clinicians to ignore potentially relevant features or end the enquiry before the investigation is complete (Yuen et al 2018), I wanted to know if, for instance, the biases of 'anchoring' and 'premature closure' that result from limited knowledge, were evident during physiotherapy assessment. This, I felt, would help me to merge extended knowledge of AHD presentation constructively with physiotherapists' approach to patient assessment. By doing so, I could identify whether findings from the experiences and expertise of people living with AHD and of specialist surgeons could intervene and inform physiotherapy clinical assessment with the ultimate purpose of improving patient management by accelerating AHD diagnosis. I considered this as being key to achieving the study's aim of building a clinical picture of AHD that would support physiotherapists' suspicion of AHD presence in relevant patients presenting with hip problems, alerting them to the need for X-Ray referral. My third objective therefore was to identify whether opportunities exist for the AHD signs, symptoms and features detected by this study to be applied to patient assessment in physiotherapy practice. People living with AHD, experts in the surgical correction of AHD and MSK physiotherapists involved in the early assessment of patients with hip problems, were therefore recognised as key sources of data for this study.

Each of the objectives was aligned to one of three pillars of investigation. Pillar 1 used two questionnaire surveys to explore and then probe the experiences of people living with AHD. Pillar 2 used a questionnaire approach to collect specialist surgeons' views of features evident in the presentation of patients with AHD. Finally, for Pillar 3, an observational approach was used to investigate the data collected by physiotherapists during their assessment of patients with hip problems and the patient-management decisions they made on conclusion of their initial assessment. Data analysis for all three pillars of study occurred concurrently enabling the structure and content of

physiotherapy assessment, verified by Pillar 3 observation findings, to inform the terminology and theme development used in the analysis of patient data (Pillar 1) and specialists surgeons' data (Pillar 2). Doing so ensured that the findings of Pillar 1 and Pillar 2 maintained relevance to physiotherapy assessment practices. Figure 4.1 provides an overview of the study aim, the systematic review which provided a preparatory investigation, and the 3 pillars of study used.

Figure 4.1 Overview of Study Pillars and Study Aim



## 4.2 Research Framework

As a physiotherapist and lecturer in physiotherapy, I understand professional practice to be underpinned by both natural science and social science (Trede and Higgs 2009). To manage patients' problems effectively, physiotherapists require the knowledge of natural sciences (for instance, anatomy, physiology, pathology) to recognise the named diagnosis and features of the patient's condition, as well as an understanding of the patient's illness experience, or the meaning of the health condition in the context of the patient's life (Mattingly 1991). Physiotherapists therefore draw on different kinds of knowledge to inform their practice.

AHD is a named diagnosis but the systematic review, supported by insight gained from patients, exposed that whilst the condition can be defined anatomically by X-Ray measurements, there is currently only a weak understanding of the physical and functional signs and symptoms which are associated with the condition. This means that it is difficult for clinicians to recognise those patients in whom AHD should be suspected and who would benefit from referral for X-Ray assessment in the first place. My aim was to address this problem by identifying indicators of AHD which would provide an alert for X-Ray referral. The systematic review which explored empirical evidence, used a positivist approach that identified an apparent lack of concrete evidence of signs and symptoms associated with AHD. A broader approach to the use of investigative research methods was called for. I therefore set out to establish what signs and symptoms are commonly evident in patients living with AHD. I also wanted to present these indicators in a way that would be relevant to clinicians, particularly physiotherapists, who are well placed to provide early referral for X-Ray *if* they are appropriately equipped to recognise when a suspicion of AHD is warranted. To achieve this, I firstly identified who would have relevant understanding. It was clear to me that people with AHD held valuable knowledge about the experience of living each day, often for years, with the condition. I also considered that specialist PAO surgeons might have a relevant understanding of how AHD presents through their experiences of assessing patients with AHD for corrective surgery. Having identified patients and surgeons as being key participants for this study, my second consideration was how I would access their knowledge. Through reading the online postings from the AHD patient support groups along with the ESRC seminar patient presentations and my discussions with patients, it was evident that these people could articulate their AHD experiences

coherently. Similarly, I wanted to ask surgeons to articulate their experiences of AHD patient presentation, the signs and symptoms they observed and that they associated with AHD presence. The collection of data based on exploring experiences, views and opinions, therefore required a qualitative approach designed using open enquiry. A qualitative approach provided the opportunity for collecting in-depth details of participants' experiences based on what they considered important and pertinent. Qualitative enquiry can produce data which are rich in detail and have the potential to drive and inform new understandings (Braun et al 2020). The richness of detail means that qualitative enquiry results in the production of large quantities of data which need to be summarised and synthesised in a theoretically and methodologically sound manner to create sensitive, insightful and trustworthy research findings (Nowell et al 2017). Thematic analysis provides a method in which data can be explored inductively to derive themes from the data that represent various dimensions or groupings of relevant content (Pistrang and Barker 2012). Braun and Clarke (2006) promote thematic analysis as a foundational method for identifying, analysing, describing and reporting themes identified within a set of data. This qualitative approach to analysis is considered to have the flexibility to be used across various epistemologies (Nowell et al 2017). I considered this flexibility a useful quality because as well as identifying what participants considered important about their experiences of AHD, it was also central to my study that I could describe the commonality of those experiences to establish signs and symptoms which characterise AHD more generally. My analysis would therefore demand on the one hand, a qualitative approach to identify the nature of participants' experiences and the signs and symptoms they associate with AHD. On the other hand, it would require a positivist approach with a more mathematical interpretation to evaluate how many times the same things were said by different people. Content analysis bridges the quantitative-qualitative divide by enabling the analysis of qualitative data using qualitative methods but in a way which provides an output which has clear quantitative traits (Pistrang and Barker 2012). This is achieved through the application of, for example, frequency counts. Words or themes which inform the research question, are generated from the data and their occurrence is then quantified (Pistrang and Barker 2012).

In essence, my approach to data analysis for each pillar of study began with the process of thematic analysis (adapted from Braun and Clarke 2006). This was extended by the quantification procedures of content analysis (adapted from Bengtsson 2016). The initial

thematic analysis enabled me to explore and categorise the features reported in the patient surveys (Pillar 1), the Surgeons' Survey (Pillar 2) and the observational fieldnote data (Pillar 3). Then, the quantification procedure of content analysis provided a systematic, objective means of drawing out valid inferences from the data to quantify specific features of interest related to my research question (Bengtsson 2016). The procedural stages used are detailed in the subsequent methods section for each pillar of study.

Hence, my approach to this study as a whole therefore employed a pragmatic paradigm. This posits that the investigator should design research methods based on what would be most effective in solving the research problem (Kaushik and Walsh 2019).

Epistemologically, pragmatism avoids deliberations on the nature of reality in favour of sensible solutions to real-life problems (Patton 2005). Therefore, whilst being consistent with qualitative investigation, pragmatism also embraces elements of numerical evaluation through the interrogation of the data to determine a rational contribution to problem-solution (Kelly and Condeiro 2020). For this PhD study, I recognised that whilst a qualitative approach was required for the collection of peoples' views, it needed to be coupled with a numerical consideration to identify how regularly patterns of presentation were similar between AHD patients and whether patterns of practice were similar between clinicians. This was important because I was interested, not only in what patients and clinicians with knowledge of AHD had to say about the condition, but also how often the same features were reported by different people. This would determine features which typically characterise the condition and would require numerical counts to be applied. In addition, the investigation needed to establish the practical applicability of the resulting AHD characterisation by verifying whether opportunities exist during physiotherapy assessment to employ the findings. The application of an observational approach to the physiotherapy assessment of patients with hip problems, identified whether opportunities were currently being overlooked for recognising patients in whom AHD should be suspected and if so, whether an opportunity existed to inform assessment practices and strengthen the index of suspicion for the presence of AHD in relevant patients by the application of new understanding.

A pragmatic framework was therefore considered appropriate for this investigation because it accepts the plurality of methods and the connection between the numerically bound characteristics of quantitative evaluation and the non-numerical life-world

approach of qualitative investigation (Kaushik & Walsh 2019). A pragmatic approach was clearly compatible with my study's goals, and it provided an effective platform through which I addressed this study's objectives.

#### **4.2.1 Pillar 1: Capturing Patients' Experiences of Acetabular Hip Dysplasia**

In recent decades, the value of listening to patients' stories for effective medical care was raised by Smith and Hoppe (1991) who developed an approach to acquiring patients' biopsychosocial history through integrated patient and physician-centred interviewing. This patient-centredness, they explained, was the objective of patient assessment encounters and has for a long time, been identified as an essential component of physiotherapy diagnostic reasoning (Jones 1995; Edwards et al 2004). Yet Balogh et al (2015) suggest that patients may feel a lack of engagement with the process of diagnosis. If the principle of patient-centredness means that patient input is collected during diagnostic assessment, their apparent feeling of lack of engagement raises questions possibly relating to how their input is used. In an interview on her 25-year nursing experience of end-of-life and palliative care, Sally Okun (2014), questions the issue of whether patients are genuinely used as partners in data generation, and she warns,

*"We listen to what patients say and we even capture it and put it in quotes and subjective assessments in our clinical documentation, but a lot of times, those data don't go anywhere"*

(Okun 2014 p31)

Such views highlight that people with AHD have a story to tell about their AHD experience that they feel has been neglected. I therefore recognised the need to develop a patient-centric approach to the collection and consolidation of data that would enable patients and people living with AHD to describe their experiences of their hip problems in their own way. This drove the design of Pillar 1 of this study: A survey of people living with AHD.

Through asking questions, I could explore how participants describe their AHD health condition, but I needed to do so in a way that maintained an opportunity for them to explain, without imposed limitations, what they considered important about their experiences of living with the condition. For Pillar 1, therefore, I began by evaluating



advantages and disadvantages of different methods of investigation. The popularity of interview was initially considered because the value of using a face-to-face approach offered the opportunity for in-depth questioning of participants. Interview would have also enabled me to be available to provide guidance if participants' understanding of questions was queried (Safdar et al 2016). Opposing this benefit was the fact that interview data are generated solely by interactions between interviewer and interviewee (Miller and Glassner 2019), and this might create the risk of me driving the agenda by the nature of my questioning or the style of my response to interview participants, which Frey (2018) refers to as interviewer bias. Interviews can also engender bias because participants can be tempted to give socially desirable responses in a face-to-face situation (Sadfar et al 2016), which might limit the accuracy or detail of their accounts. Importantly, the individual attention required of the interviewer meant that this method would be costly and time-consuming, limiting the number of interviews, which would conflict with my intention of collecting a wide range of responses to enable features reported repeatedly to surface.

Similarly, I considered the benefits of using focus groups as they enable the collection of spontaneous responses to questions and would provide the opportunity for clarification of areas lacking transparency. They are, however, restricted, not only by how many people would be willing to cooperate with appointments but also by how many could guarantee their readiness for talking (Queirós et al 2017). Focus groups take time to organise, and the resulting data are the product of group interactions that might constrain the views of some by being biased towards those who, for instance, speak loudest. Both interviews and focus groups therefore, not only have resource implications that inhibit the number of people involved in the data generation but crucially, such face-to-face methods were not well suited to my study because I was interested in collecting data from a large geographical reach of individual AHD patient experiences, to detect whether recurring patterns of important AHD presentation features were evident.

By contrast, questionnaire surveys provided an effective means of carrying out large-scale data collection. They were selected for the purposes of Pillar 1, because they provided a workable means of collecting information through recording the responses of individuals to questions of interest (Check and Schutt 2012). Questionnaire surveys have been traditionally associated with quantitative methods and used for the purposes of describing population variables numerically. These quantitative questionnaires have been identified as producing data lacking in depth and detail which can threaten

accuracy (Toepoel 2016). Indeed, such questionnaires have been criticised for their high risk of bias through both question design and overall questionnaire structure (Choi and Pak 2005). In addition, they are constrained by closed questions that restrict participants' responses to that which only the researcher deems relevant and that therefore, limit the opportunities for respondents to voice their thoughts and concerns (Kelly et al 2003).

On the other hand, I considered the open questions of qualitative questionnaire surveys to provide a workable means of shaping the understanding of AHD presentation, for which there may be a multiplicity of experiences and opinions (Jansen 2010). In doing so, they deliver data benefitting from advantages evident in both qualitative interviews and quantitative questionnaires because they provide a method of generating distinctive yet detailed data that can uncover new knowledge. Indeed, Braun et al (2020) point to the opportunity provided by responses to open-ended questions, of really hearing the respondent's voice by collecting details that the *respondent* deems important, and in language of *their* choice. Importantly, qualitative open-ended questionnaire-surveys have been shown to be effective where there is insufficient knowledge of how participants, influenced by a variety of contexts, perceive and describe a disorder (Bengtsson 2016), which strongly reflects the problem being tackled by this PhD study. Whilst open-ended response options mean that data are respondent rather than researcher driven (Züll 2016), they do require considerable effort from respondents as answers need to be formulated and articulated in their own words (Züll 2016). Online methods can, to some degree, ease this demand due to the avoidance of lengthy, labour-intensive activity of handwriting (Reja et al 2003) and when respondents recognise the relevance of the question topic and have a high degree of interest in it, such burdens are alleviated (Züll 2016). In addition, burden-easing can be accomplished by the provision of clear instructions regarding the information being requested and how the question should be answered (Aday and Cornelius 2006). Whilst these views of online survey methods are well supported in the literature, I considered what the potential limitations and inherent sociodemographic biases would be and how they may affect the findings. If, for instance, internet access and support group usage did not match the distribution of the AHD population, there would be a threat to the external validity of the data as it would mean that not every member of the population had an equal chance of being included in my sample. Andreeva et al (2015) investigated such issues in a French study of the population's nutritional attributes.

Sociodemographic characteristics of 122,912 individuals enrolled via the Internet were compared with those of corresponding national Census data. The results showed that internet enrolment provided distinct geographical and sociodemographic diversity that included participants from subgroups that are typically under-represented in traditional surveys (unemployed, immigrants, the elderly). However, it was also evident that for the internet-based study, there were a significantly greater number of women, well-educated and married or cohabiting individuals who responded compared with the corresponding national figures (all  $p < 0.0001$ ). The volunteer bias indicated by such findings along with limited internet access and literacy can jeopardise data generalisability which could in turn threaten the transferability of findings, weakening their clinical value. This is because, if sectors of the population are not included in a study, there is a risk that findings will not be applicable to them. I recognised, however, that whilst members of the AHD population who were technologically disadvantaged would likely be excluded from my study, access to the internet, along with internet literacy have considerably improved in recent years. Indeed, the Internet World Statistics (2022) shows that internet usage grew from 8.6% in April 2002 to more than 55% by June 2018. I also considered the conclusions of Andreeva et al (2015) who, having established the differences between sociodemographic characteristics in internet-based and traditional survey recruitment, also highlighted that internet-based research provides the means of acquiring very large and heterogeneous samples, including hard-to-reach subgroups of the general population. Added to this, I found it interesting to note that in a study exploring the factors which characterise childhood psychopathologies, Heiervang and Goodman (2011) found that the assumed limitations of online recruitment did not appear to affect measures of association between psychopathology and expected risk factors for acquiring the investigated conditions. The Norwegian study compared face-to-face interview of childrens' parents with online survey and paper questionnaire methods. The findings showed that whilst selective participation resulted in a reduced proportion of disadvantaged families taking part in the web-based survey, it did not generally affect findings of the characterisation of a pathology and the associated risk factors were not, in the case of Heiervang and Goodman's 2011 study, significantly affected by the different modes of data collection methods. An important influence on my decision-making was also that the biggest age group of active social media users (70% worldwide), who are therefore well practiced in online communications, are young adults in the 18–44-year-old age category (Statista 2020). This echoes the age at which the

largest proportion of people report their onset of AHD (Nunley et al 2011) and have hip surgery (Clohisy et al 2007 and 2009). This was important because ease of responding to online surveys is associated with respondents' familiarity with internet usage (Reja et al 2003). In addition, details about experiences of living with AHD can be very personal. Evidence suggests that after receiving a diagnosis of AHD, young women questioned aspects of their identity, disclosing how difficult they found it to talk to other people about their hip problems. Because of this, some explained how they found it easier to avoid discussion about AHD and to tell others that, for instance, their limp was due to an injury rather than a chronic condition (Gambling and Long 2011). This could explain why the anonymity offered by online AHD patient support groups has found popularity and draws attention to the value of online communications enabling people to reveal details about themselves that they might otherwise be unwilling to have associated with them. Indeed this form of communication has been shown to defuse the risk of participants' responses being influenced by reservations inherent in face-to-face encounters (Sadfar et al 2016). For example, participants may not be willing to tell others who may not understand, about their condition. The anonymity of online communication is therefore an asset particularly valued for this study as the primary purpose was to enable patients to describe their experiences of AHD in their own way. Therefore, whilst I accepted that the findings of an online survey might be limited to, for instance, technologically literate people who have internet and support group access, the benefits to my study of online usage included the opportunity to explore AHD characteristics using an international spread of hard-to-reach individuals, that would be faster and at a lower cost than other methods. I acknowledged that there would be an element of potential bias in this method of data collection, but on balance, I considered online survey methods a sensible approach to gathering information about features associated with AHD from a wide reach of people.

Overall, qualitative surveys were valued for the rich, deep, nuanced data they can capture which offer the potential for the development of new understandings (Braun et al 2020). Additionally, online methods were valued because they offer global access, that would provide the opportunity for capturing a wide breadth of diverse experiences and perceptions from a large population. I recognised that this could illuminate aspects of the topic not previously identified (Toerien and Wilkinson 2008). Online qualitative questionnaires for Pillar 1 therefore provided a pragmatic approach to the collection of

data from those living with AHD and avoided prohibitively high financial travel or postage costs associated with other methods of accessing geographically spread respondents.

Online methods have received some criticism because the lack of an interviewer is thought by some, to prevent an opportunity for probing respondents' answers. To mitigate this, two patient surveys were used. The first, patient survey-1 (PS-1), was exploratory, and was followed by a second more probing survey, patient-survey-2 (PS-2), which was not limited to PS-1 respondents. Safdar et al (2016), endorse the use of such a follow-up survey because it can deepen the investigation into issues identified from the first survey. PS-2 provided the opportunity to present respondents with questions arising from the analysis of PS-1 data, to gain greater detail, clarity and standardisation of response data

#### **4.2.2 Pillar 2: Collecting Expert Surgeons' Views of AHD Presentation**

Evidence-based knowledge of AHD presentation from specialist PAO surgeons is not currently accessible in a form from which others, uninvolved in the specialism, can learn. Notably, empirical evidence of these surgeons' experiences of assessing patients with the condition has not previously been analysed and documented. As this study aimed to support diagnostic recognition of AHD by characterising its presentation, it was logical to identify the features of patient assessment that these specialist surgeons use to inform their AHD diagnosis. This would provide knowledge from which physiotherapists and other relevant clinicians could learn. In planning how best to approach the collection of surgeons' views, I considered whether the findings of the systematic review could provide a starting point for gaining consensus between surgeons via a Delphi study. It is a method that has been used successfully in healthcare research to gain agreement on clinical understandings (Nasa et al 2021) and generate patient assessment measures (Singer et al 2016). However, the limited understanding of clinical criteria for pre-X-Ray AHD recognition, the lack of a universally accepted pre-X-Ray definition of AHD, and the uncertainty of the distinction between DDH and AHD meant that attempting to use a Delphi technique would be inappropriate. I needed to start at an earlier stage of enquiry to gain an increased understanding of and elicit relevant indicators for AHD recognition. Collecting surgeons' views and opinions through open questions was therefore considered a logical approach and questionnaire surveys provided a workable and

economical method of generating relevant data. Questionnaire surveys are well used in healthcare research as they have been shown to be effective in the collection of clinicians' experiences, practices and knowledge (van Geest et al 2007). They also offer an effective and efficient approach to accessing time-restricted surgeons with heavy clinical loads as they provide the convenience of completion in varying venues and at times that suit surgeons' busy schedule (Safdar et al 2016). Questionnaire surveys provide a greater reach than other methods because they are an ideal means of collecting data at spontaneous and opportune times, without the need for the pre-arranged appointments required by other methods such as interviews and focus groups. They also allow thinking time, which might overcome omissions of important information that the instant responses required of direct verbal questioning can risk (Fowler 2012). As with Pillar 1, questionnaire surveys for Pillar 2 were also favoured over other face-to-face methods because they are considered to enhance the honesty of responses (Safdar et al 2016). They achieve this by protecting the privacy of participants, safeguarding responses against reprisal and the judgement of others, which could be an issue when members of the same profession are giving their views and opinions. Questionnaire surveys can therefore encourage participants to reveal information that they might otherwise be unwilling to have directly associated with them (Coffelt 2018).

### **4.2.3 Pillar 3: Physiotherapy Patient Assessment**

The purpose of the third pillar of study was to identify the type of data physiotherapists collected during their assessment of patients with hip problems, and the resulting patient management decisions these physiotherapists made at the conclusion of their clinical assessment. Patients suspected of having structural problems of the hip benefit from early X-Ray evaluation as it can provide definitive diagnosis which is essential for establishing the appropriate treatment. In the UK, it is within physiotherapists' scope of practice to refer patients for X-Ray evaluation as part of their diagnostic clinical reasoning and differential diagnosis (CSP 2021). Physiotherapists' reasoning and referral decisions in the management of patients with hip problems, are therefore key to achieving successful treatment outcomes. I wanted to assess whether the features of AHD identified in Pillars 1 and 2 of this PhD study were evaluated during physiotherapy assessment of patients with hip problems. I also wanted to identify the contribution of these features to physiotherapists' readiness to provide relevant patients with a justified

referral for hip X-Ray. For Pillar 3 of this study I therefore examined the everyday work of MSK physiotherapists as they carried out their normal practice of assessing patients with hip problems. Specifically, I focussed on the data elicited during the patient assessment and the resulting decisions physiotherapists made regarding patient treatment and management. This enabled me to identify opportunities for and relevance of supporting and informing practice through the application of Pillars 1 and 2 findings. To achieve this, I needed to see first-hand what happens during physiotherapy assessment and record the events as they occurred in real time. This meant that the method used had to be observation as other methods, such as interview, focus groups or surveys would provide only post-experience opinions and would be subject to physiotherapists reporting what they think happened rather than what actually happened. Physiotherapists may also struggle to remember the detail of their patient assessment approach and report only those aspects of the patient assessment that they felt were suited to the research study. For Pillar 3 therefore, physiotherapists' assessment practices were investigated using observational methods.

Observational methods are recognised as being less intrusive than other methods such as interview and focus groups (Carnevale et al 2008) and are considered to gain richer, more accurate data than methods that rely on the self-reporting inherent in survey, interview and focus group methods (Morgan et al 2017) where participants can only report what they think is true. During patient assessment, physiotherapists perform a variety of tasks that, with repeated practice, can become so routine or automatic that they might find them difficult to explain (Harvey 2018). An observer may, however, be better placed to identify the step-by-step processes involved in conducting the task. In this sense, observing events and procedures is more effective in defining the components of well-practiced skills than asking the participants questions about the actions involved in such procedures (Harvey 2018). This means that as a research method, observation is effective for investigating how physiotherapists carry out their work activities and is particularly useful in exposing habits and actions that may not have been recognised by them. Consequently, observation was favoured over other methods that require participants to explain actions that they may conduct instinctively.

Observational methods have been described in several ways. Mulhall (2003) draws attention to both structured and unstructured approaches, describing a structured approach as being based within a positivistic paradigm. A priori, theory-based

classifications or categories are used to record what is said and done by those being observed. Unstructured observation, in contrast, differs by coming from an interpretivist or constructivist paradigm where the interest is in investigating cultural behaviours (Mulhall 2003). To address the objective of this pillar of study, my focus was to record physiotherapists' collection of patient data in a defined setting. This along with the essentially routine nature of physiotherapists' assessment procedures explained in Section 2.6, meant that I could use a semi-structured approach to the recording and analysis of their assessment practices, but still retain the exploratory nature of unstructured observation.

Direct observational research, where those being observed are aware of being watched, can produce results that are strong in validity because the researcher's data is a direct recording of the observed behaviour. They have, however, been criticised for inducing the risk of the Hawthorne effect where those being observed change their behaviour *because* they are being observed (Wickstrom and Bendix 2000). Nevertheless, this reaction has been shown to reduce as participants become accustomed to being observed. Importantly, the building of rapport and trust between the observer and the observed has been shown to mitigate the Hawthorne effect (Spano 2006). In relation to this, Harvey (2018) justifies the use of observational methods by drawing attention to an equal risk of similar reactions in interview and focus group research which, due to desirability or courtesy bias, risk participants saying what they think they should rather than what is real.

Throughout their education and in qualified practice, physiotherapists expect to be observed. Whether being examined for competence in the application of a skill or for the purposes of reporting, teaching, and learning, being observed is part of accepted physiotherapy practice. This acceptance supported the use of an observational method and presented a realistic and appropriate approach to establishing the content of physiotherapy assessment and the resulting conclusions regarding patient management. I wanted to know how the procedure of assessment played out in the real clinical situation of physiotherapists' management of a patient presenting with hip problems. By observing physiotherapists, the task I had set was to generate descriptions of different physiotherapists' assessment practices and to record the immediate patient management decisions generated by that assessment.



Observation as a non-experimental research method was therefore selected because it is the only method for accurately establishing what happens through the direct recording of what people do. Importantly, the real value of observation is that it helps to build an understanding of peoples' real-time actions and behaviours in their natural, rather than an experimental, environment (Mays and Pope 1995). This helps to establish the potential for intervention.

### **4.3 Chapter Summary**

To achieve the study's aim of building an understanding of pre-X-Ray clinical presentation of patients with AHD that might be integrated into physiotherapy practice, a pragmatic paradigm was applied. This approach to study design led to the formation of three objectives. The first of these was to explore how patients with hip dysplasia describe their hip problems and experiences. The second was to identify what surgeons who specialise in the correction of the condition consider to be the presenting features of AHD. The third was to identify whether opportunities exist for the signs, symptoms and features detected by the findings of objectives 1 and 2, to inform physiotherapy practice and support recognition of AHD during the clinical assessment of patients with hip problems. Each of these objectives was aligned with one of three pillars of investigation. The details of these pillars and the procedure for achieving each of them is explained in Chapter 5, which follows.

## 5 Methods

### 5.1 Chapter Introduction

The investigation was composed of three individual pillars of study that were aligned with each of three study objectives. This chapter clarifies my overall approach and, for each of the three pillars of study, participant recruitment, data collection tools and data analysis are explained. Details of the ethical approval gained for the investigation and the data management procedures are also provided.

### 5.2 PILLAR 1: Surveys of People Living with Hip Dysplasia

**Objective 1: To explore how people living with acetabular hip dysplasia describe their hip problems and experiences.**

#### 5.2.1 Pillar 1 Design

For this first pillar of study, the participants are referred to as patients to avoid any potential confusion with other individuals referred to throughout the account.

Pillar 1 had two parts: patient survey-1 (PS-1) and patient survey-2 (PS-2). A predominantly qualitative approach was used for the purposes of surveying patients living with AHD.

The use of two questionnaire surveys meant that the first, PS-1, explored patients' views with open questions that provided the opportunity for participants to describe their AHD experiences without restrictions. The second, PS-2, built on the findings of PS-1 by probing the responses, adding depth and breadth to the understanding. The Bristol Online Survey (BoS) platform (now known as Online Surveys) was used to administer the patient surveys because it facilitated the benefits of electronic completion and presented the survey responses in both spreadsheet and document form, which was useful for analysis.

#### 5.2.2 Patient Survey-1 (PS-1)

The purpose of PS-1 was to explore how patients with hip dysplasia describe their hip problems and to identify the language and terminology they typically use to explain their experiences. PS-1 was therefore designed to enable these patients to express what they considered important about AHD. This contrasted with previous studies that have

focused on investigating features of AHD that the researcher deemed important. For instance, what is currently known about AHD presentation is largely based on a study by Nunley et al (2011). The study used a questionnaire approach to collect responses from people with AHD about specific features related to their hip condition. Directed questions, pointed respondents to state whether or not they experienced a particular set of signs and symptoms. The restricted nature of this questioning meant that respondents may not have had the opportunity to explain broader features not listed in the questionnaire. This would limit the exploration of potential signs and symptoms. For this reason, attitudinal questions such as those which make use of, for instance, Likert scales, would have constrained participants into providing responses to only a limited number of topics with a limited choice of responses, the selection of which would have been made by me rather than by the participants. My aim, however, was to enable patients to provide details of their personal hip dysplasia experiences that they considered most relevant and troublesome. I wanted participants to describe *their* views in *their* own way so that features that may have been previously overlooked, could ultimately be investigated for diagnostic relevance. Open questions were deemed an effective means of achieving this.

PS-1 therefore used a qualitative questionnaire approach with open questions that encouraged patients to choose what to describe about their experiences and how to articulate those experiences (Sinkowitz-Cochran 2013).

For questionnaire-surveys to be credible and trustworthy, Groves et al (2009) advise that the design of both the individual questions and the overall questionnaire needs to ensure that content standards (questions on the pertinent issues); cognitive standards (questions on which respondents can and are willing to provide answers) and usability standards (questionnaires that can be completed as the researcher intended) are achieved. The choice of question-design for PS-1 was therefore driven by the research objective, which for Pillar 1 related to patients' description of their hip problems and experiences. This informed the selection and design of PS-1 questions as shown in Table 9 below.

Table 9. PS-1 Questionnaire and Question Design

	<b>Content Standards</b>	<b>Cognitive Standards</b>	<b>Usability Standards</b>
<b>Patients' Questionnaire</b>	Questions directed at respondents' experiences of AHD	Questions inviting respondents to share their understanding and their experiences of living with AHD	Clear, mostly open questions providing prompts for respondents to describe their personal experiences of AHD; tested by 3 AHD patients

Mindful that my objective for this pillar of study centred on drawing out clinical indicators of AHD from a potentially large assortment of patients' experiences, I needed the questionnaire to provide a broad funnel for the responses, to help patients communicate what could be years of AHD experiences into a written format. I therefore decided that questions should offer a prompt for these patients, to simply suggest an order in which they might choose to describe their experiences. I was aware that, because I brought to the study my own understanding of AHD and my professional knowledge of what is clinically relevant to physiotherapists, there was a risk that my selection of questions might be too directive at the expense of overlooking legitimate aspects of the participant's experience. I therefore involved people and patients living with AHD. Even though the UK standards for public involvement in research had not at this time been produced (National Institute for Health and Care Research 2019), I recognised the value of public and patient engagement. It provided insight which helped steer me towards an effective approach for collecting the signs, symptoms and features of AHD experienced by people with the condition and in a way that they found relevant. I had developed a group of contacts that comprised 2 staff and 2 student members from the University. They had all received a diagnosis of AHD and were highly motivated to be involved with my research. Their diagnoses had taken considerable time to be identified, and it was evident from their accounts, that the signs and symptoms they had reported to clinicians had not been readily associated with AHD presence. I consulted with these members in the following ways. Firstly, I met them individually face-to-face, and explained to them that I wanted to investigate the presentation of AHD to establish whether commonly occurring features could be identified that would characterise the condition. Through

discussion with them, they spoke positively about the possibility of exploring such features. It was also evident that they all considered questionnaire survey to be an effective method for the collection of patient accounts if it provided a structure that would be amenable to divergent responses. Members also agreed on the importance of having questions which acted only as a prompt for respondents to explain their experiences. I discussed with each member the nature of the questions that should be included. They highlighted that the opportunity should be available for survey respondents to account for any pre-onset features, experiences of problem onset, problem development over time, relevant concerns or features, and anything about diagnosis that respondents considered important. I used their recommendations to design the first draft of the questionnaire survey. On completion, I invited these members to pilot the draft questionnaire survey.

Additionally, I drew on Isabelle's story, the support group postings and the patient accounts presented at the ESRC funded seminars. These helped to shape the question design because they highlighted the experiences that these individuals had considered important. For instance, as well as demonstrating the variety and changing nature of their signs and symptoms over time, these individuals had also accounted for a range of features that they considered relevant to their hip problems such as their childhood physical abilities, issues related to reaching physical milestones during infancy and, following their onset of problems, the struggle they had in gaining diagnosis. I therefore considered it important to design prompting questions that would not only reflect these areas, but that would also enable participants to extend their accounts beyond the restrictions that direct questions might impose. To begin, however, demographic data were deemed necessary because quantitative analysis of these data would enable the relevant patient-respondent population to be described and would determine whether they represented the target population (Salkind 2010) of people living with AHD.

Questions for the initial section were therefore designed to collect data on respondents' country of residence, their age, hip involvement (right, left or bilateral), the date they received their first diagnosis of hip dysplasia and their current treatment status

In total, PS-1 comprised 5 sections. Section 1 asked participants to provide demographic information, sections 2 and 3 provided prompts for respondents to account for the history and current experiences of their hip problems and Section 4 prompted accounts of diagnostic experiences related to their hip problems. Finally, Section 5 provided the opportunity for respondents to add any other information about their hip

concerns that they considered important. Responses to questions 2-5 were designed for qualitative analysis.

### PS-1 PILOT STUDY

To test that the questionnaire survey met usability standards and for sense-checking, I conducted a pilot study which was used to identify and remedy features such as poorly positioned questions or vague, confusing questions. It was also used to check how a participant would perceive and react to the language used and to eliminate any unforeseen problems. Importantly, piloting ensured that the survey would display correctly online. Toepoel (2016) recommends that piloting should involve a small subset of the intended population who test the mode of data collection to be used in the actual study. To ensure that the individuals piloting the questionnaire survey represented the population of interest as recommended in the literature (Sadfar et al 2016), the staff and student members who I had engaged to advise on the initial questionnaire structure were invited to complete the draft questions. Three of the four members responded, and one member was unavailable. I deemed this number sufficient for testing the questionnaire survey for two reasons. Firstly, the feedback from these members clearly confirmed that the questions were easily understood and that the order and length of questions were satisfactory. Secondly, because those involved would not be participating in my main data collection, I considered it important to limit pilot testing to my personal contacts only so that I could avoid using my pool of potential patient-participants. I requested that these personal contacts completed the original draft of the survey, my intention being that their feedback on the survey’s readability, content validity and face validity would be used to refine the survey presentation. Their input resulted in a change to the order of questions and led to the agreed decision to organise the survey into the 5 sections tabled below (Table 10).

*Table 10. Organisation of PS-1 Questions*

Section 1:	Section 2:	Section 3:	Section 4:	Section 5:
Demographics; home country; age; hip involvement; date of 1 <sup>st</sup> diagnosis; treatment status	Earliest memories or understanding of Childhood hip related issues. Development of hip problems	Current Experiences; pain, problems, triggers and relievers; adaptations and life-impact	Experiences of getting a diagnosis	Any other information about the hip dysplasia experience considered important

The resulting data were analysed thematically as explained below (Section 5.2.6). The analysis led to the development of a second patient survey (PS-2) which probed aspects of the PS-1 findings. PS-2 was again qualitative in nature but because it aimed to extend the understanding of PS-1 findings, it used a more directed approach.

### **5.2.3 Patient Survey-2 (PS-2)**

The objective of this second survey was to build on and probe the findings of PS-1. As well as continuing to explore experiences and their descriptions, PS-2 was able to identify the similarity of those features amongst the patient group. PS-2 patients therefore benefitted from seeing and responding to questions addressing features highlighted by the PS-1 responses that they too may have experienced but may otherwise have not thought to describe. Hence, PS-2 used a more targeted approach as it aimed to extend the findings of PS-1 by clarifying and examining the commonality of patient-generated features. In addition, whilst PS-2 retained a qualitative approach, the closed questions enabled identification, categorisation and quantification of patterns of features that could contribute to the characterisation of AHD patient presentation. Using the categories of AHD-associated features identified through the PS-1 data analysis, levels of agreement and tick boxes were used for patients' responses to the closed questions. A Likert scale approach was used to achieve this. This approach uses an ordinal response scale to obtain participants' preferences or degree of agreement with a given statement. Typically, a 5-point scale is used to provide response options ranging from "Strongly Agree" through to "Strongly Disagree" with the alternative to "Neither Agree nor Disagree" in the middle. Each level on the scale is assigned a numeric value incremented by one for each level (Joshi et al 2015). These values can be summed to generate a combined score or, as in the case of PS-2, analysed individually to identify the degree of agreement between participants around a particular issue (Joshi et al 2015). For example, in relation to their current pain, PS-2 participants were asked to express their levels of agreement (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree) with each of the following statements:

- My pain is constant
- My pain occurs daily but is not constant
- My pain is intermittent, often occurring without any apparent cause
- I suffer from unpredictable weekly flare-ups of pain

- I suffer night pain sufficient to keep me awake

Responses for each option level were counted to produce percentage values of agreement between participants. To complete each topic of enquiry, participants were also asked to describe any other aspect of each topic which was not addressed by the given statements. These responses were analysed thematically as previously described.

PS-2 was structured in the following way.

Following demographic-related questions, PS-2 patients were asked closed questions to record whether they had experienced specific features. These features were generated by the results of the PS-1 analysis. Specifically, PS-2 probed aspects of:

- Family history
- Infant/Childhood problems
- Pain (development; triggers; relievers; location; intensity; severity)
- Hip sensations (other than pain)
- Characteristics of posture and gait
- Leg length discrepancy
- Hyper-flexibility/Hypermobility
- Hip instability
- Audible hip sounds
- Physical activity and function

In addition, 3 open questions were included to give respondents the opportunity to express issues on which they felt strongly. These were worded in the following way:

- Please list any aspects of your hip problem which you feel are important for clinicians to know about during their diagnostic assessment? Please rank this list (eg, from 1-10, with 1 as least important and 10 as most important) in order of importance starting with the feature you feel is most important.
- If there are any features or indications of your hip problem which you feel were ignored by the clinicians with whom you consulted, please list them here:
- Is there anything else you want to tell us about, which you feel describes the specific features of your hip dysplasia?

## **PS-2 PILOT STUDY**

A draft of the questionnaire was tested by those who had tested PS-1 and following their feedback the following refinements were made to the final version:



- i. The participant information sheet was included as part of the questionnaire rather than as a separate document. It introduced the questionnaire and provided potential respondents with details on the purpose of the study.
- ii. Following the information sheet, details of the overall design of the questionnaire and approximate time required for completion were added with a clear request for respondents who had already received surgery, to answer all questions in the context of their pre-surgery status.

#### **5.2.4 Participant Recruitment and Ethical Considerations**

Recruitment for PS-1 and PS-2 followed the same procedure. Details of the study and invitations to participate in each survey were posted on four online support groups. These groups were, STEPS Charity Worldwide, which is a charity supporting the most common as well as rare lower limb conditions; Adult Hip Dysplasia Support Group, set up by a physiotherapy student who had been diagnosed with hip dysplasia herself and wanted to learn from, help and support other adults with AHD; the PAO UK Based Group, for people with Hip Dysplasia and undergoing PAO surgery, and DDH UK which was set up to provide support for patients with hip dysplasia and their families. They were selected because, following an Internet search for hip dysplasia support groups, these were shown to be easily accessible and were sites that drew regular postings from those living with AHD. In addition, they did not require usernames or passwords and administrators were available for contact by email. The ability to contact administrators was considered important ethically, as I was aware that these online communities had been developed for the purposes of supporting people with hip dysplasia and that contributors used the facility to ask for and offer advice. Using the communities to access potential research participants may not have been considered by users when they joined the community. Therefore, to access the forum sensitively and with due courtesy, I corresponded initially with each forum's administrator. By providing them with study details and answers to their queries, I felt their acceptance for the promotion of my study on their forum provided an additional level of scrutiny regarding ethical issues and provided a degree of safeguarding for forum members.

To ensure informed consent, the postings to promote the questionnaire surveys began with an invitation to participate that included an information sheet entitled, "A project to

find out about your experiences of hip dysplasia” explaining the details of the study and what would be required of participation, (Appendix 3). Participants were then invited to ask and have answered any questions they may have had before being given access to the questionnaires. For this purpose, my name and contact details, along with those of my PhD Supervisor, were provided. Information sheets for PS-1 and PS-2 contained the same information but had appropriate titles to differentiate between the two.

Participants were advised that they could withdraw at any point during survey completion and if they chose to do so, their data would not be considered. If they chose to continue, the link to participate was presented and they were provided with the opportunity to complete the questionnaire immediately or to return to it later. On completion of the survey, a submission key was presented automatically, which provided a second opportunity to confirm participation. Consent for participation was therefore assumed by participants’ completion and final submission of the questionnaire. On completion and submission of the survey, participants were thanked for their time and effort via an automated response.

PS-1 questionnaire was posted in May 2018, and was followed 6 weeks later, by the posting of PS-2. Invitations to participate in PS-2 were not restricted to those who responded to the first survey, instead, invitations for both surveys were open to all forum users living with hip dysplasia. Methods for participation in both PS-1 and PS-2 followed the same procedure.

### **5.2.5 Data Processing**

For PS-1 and PS-2, the Bristol Online Survey (BoS) programme produced a word document of the responses. Identifiable respondent data, presented on separate pages from other responses, were removed to maintain anonymity and confidentiality.

Response data were also presented on an EXCEL spreadsheet and data processing included anonymising responses on the spreadsheet, by replacing respondents’ names and/or email addresses with a pseudonym in the case of PS-1 and a code in the case of PS-2.

## 5.2.6 Data Analysis

### 5.2.6.1 PS-1 and PS-2 Quantitative Data Analysis

Quantitative data were collected from the PS-1 and PS-2 for demographics. These were analysed using counts and frequency distributions to determine descriptive statistics of the respondents. Subsequent sections of PS-2 closed question data, also utilised simple counts and conversion to percentage representation to identify the commonality of respondents' experience of each of the commonly occurring coded items generated from PS-1 data.

### 5.2.6.2 PS-1 and PS-2 Analysis of Qualitative Data

A large volume of rich data was produced by Pillar 1 questionnaires (PS-1 and PS-2). The purpose of analysis was to provide an effective summary of these data, ensuring that it provided a meaningful response to the research question (Kelly et al 2003). According to Braun and Clarke (2006), an effective method of achieving this is through thematic analysis because the procedure provides flexibility and some theoretical freedom and can therefore be used within a range of epistemological positions. Thematic analysis is recognised as providing a pragmatic approach to analysing large quantities of data to produce knowledge formed by various individual experiences and perceptions from within an identified group (Nowell et al 2017). Braun and Clarke (2006) propose an approach to thematic analysis that is both well regarded in the social sciences, and well suited to my study. It required me to actively recognise relevant patterns within the data and from these, to generate appropriate themes. In this sense, I as the researcher became the '*instrument for analysis*' because of the element of subjectivity (Starks and Trinidad 2007 p.1376). This was required for making decisions about the data and how they would be organised when establishing categories of information and themes (Braun and Clarke 2006). In acknowledging the influence I had over the analysis I reasoned that because the purpose of this PhD study was to identify features of AHD patient presentation that would be relevant to physiotherapists, I, as a physiotherapist was well placed to understand how the features could be grouped together in a way that would provide that relevance for physiotherapists' assessment of patients with hip pain. This understanding had developed through my past clinical experience and the theoretical understanding of physiotherapists' diagnosis, clinical reasoning and knowledge. I therefore used what I understood to be of relevance to

physiotherapy assessment in the organisation and analysis of these data. This clearly influenced my decision-making throughout Pillar 1 data analysis in a way that I considered beneficial to the purpose of the study.

Credibility, confirmability and audit trails are amongst some of the essential features of a trustworthy thematic analysis (Nowell et al 2017). To address these, a six-phase procedure (Table 11) for conducting a thematic analysis that supports trustworthiness and facilitates transparency through its systematic approach, was utilised (Braun and Clarke 2006).

*Table 11. Phases of Thematic Analysis (Braun and Clarke 2006)*

<b>Phase</b>	<b>Description of the process</b>
1 Familiarization with the data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2 Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3 Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4 Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2) generating a 'theme map' of the analysis.
5 Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6 Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

Once the themes were established, content analysis of PS-2 responses then enabled the objectivity of the data to be considered (Bengtsson 2016). The benefit of this

approach was that, through a clustering of data codes into candidate themes, content analysis indicated the occurrence of feature similarities (data item codes) across the full data sets (Terry and Braun 2016). This was important for accurately characterising the entirety of the dataset because distinguishing data reported repeatedly by many respondents, in comparison with data for which only single reference was made, more accurately represented the data as a whole and indicated an importance or 'weight' value of features to the surveyed population. Aiming to develop an understanding of the changing nature of body image, Terry and Braun (2016) apply this notion to their data analysis by accounting for features that were "often" or "more often", evident, or refer to the fact that "many participants made statements similar to..."; "a large number of participants expressed..."; "half the participants [stated]...." or "...was common across the dataset". These were distinct from data that captured more unique values with the use of terms such as "key differences between participants..."; "... there was variation..." or "[X] was unusual amongst participants for describing....". This approach to data analysis, is recognised as providing a basic indication of shared views and opinions within a population and is particularly useful when searching for features that may characterise health conditions that are otherwise, poorly understood (Braun et al 2020) as is the case with AHD.

Using systematic data analysis in this way, enabled me to organise, describe and report the wide-ranging survey responses and to interpret the complex data clearly to report it accurately (Braun and Clarke 2006). It also facilitated an exploration of the wide range of perspectives provided by respondents from various contexts (Braun and Clarke 2006; Bengtsson 2016).

Qualitative data gained from responses to the open questions were therefore firstly thematically analysed following the 6-stage procedure adapted from Braun and Clarke (2006). This resulted in the identification of themes, each of which drew together units of information addressing the research question. These were labelled items of interest or codes. In accordance with Bengtsson's 2016 procedure of content analysis, all data sets were then re-examined to count how many respondents described the same coded item. This quantification procedure was performed on all open question response data for both PS-1 and PS-2. A description of the procedure follows.

### **PHASE 1: DATA FAMILIARISATION**

Thematic analysis of PS-1 qualitative data began with data familiarisation (Phase 1). I started this by reading and rereading each respondent's entire data set. This enabled me to recognise terms used repeatedly by various respondents and I generated a list of expressions such as 'pain'; 'instability'; 'family'; 'hypermobility' and their synonyms. These were identified as 'items' of interest. They formed the basis for phase 2; Initial Code Generation.

### **PHASE 2: INITIAL CODE GENERATION**

Highlighted items were coded as they represented a feature of interest for analysis. This important aspect of the analysis progressed into the systematic organisation of data items into meaningful coded groupings. As I was interested in establishing clinical indicators associated with AHD and with relevance to physiotherapy, the codes were units of information relevant to the research question. Specifically they were the signs, symptoms and features which respondents described. These were identified through a process of 'open-coding' (Maguire and Delahunt 2017) where codes were generated from the data as opposed to the application of pre-determined codes. At first, I used different colours to highlight repeated items (Table 12) but as each patient account was analysed the range of items grew in number and the colour-method became cumbersome. It had, however, enabled patterns of items to emerge. These patterns were sufficiently recognisable to form groupings of related items that established how items were to be coded. These were then managed on a spreadsheet. To accurately retain patients' terminology and prevent misinterpretation, sections of participant quotations were directly 'cut and pasted' from participants' data transcript and entered into the relevant column on a spreadsheet.

### **PHASE 3: THEME SEARCH**

On completion of the initial coding, phase 3, 'Theme Search', involved mapping the codes to consider their relationship. Codes addressing similar topics were drawn together to create candidate themes and subthemes (Table 13). The purpose of a 'theme' was to secure something important that is relevant to the research question (Maguire and Delahunt 2017). Theme development was guided by the identification of patterns of coded items that fitted together, and that captured possible clinical indicators of AHD. Links between coded items within themes were then scrutinised to identify related features; for example, within the 'Joint Features' theme, it was evident that

patients with hip instability also frequently reported joint clunking, clicking, popping or locking. The apparent association between such features contained within each theme, confirmed the suitability of all selected themes and their contents.

At the start of the initial coding, both I and my supervisor independently coded the data from one of the participants for comparison. This clarified the similarities of our resulting codes and confirmed consistency of approaches. Importantly, our discussion on coding and theme identification that followed, forced me to justify my approach and interpretation of data, which enabled me to continue coding expansion and collapsing along with the further theme search with consistency.

Having identified candidate themes and having populated them with the relevant item codes, I exercised a review procedure whereby each theme and its content were checked for possible repetition and redundancy. This involved ensuring that as new themes and items were generated, they were checked against those identified previously. This process of theme and item generation, checking, re-checking and confirmation drove the analysis.

On completion of phase 3, codes had been organised into candidate themes and subthemes. Using an extract from 'Anna's' data, Table 12 illustrates how the initial use of colour, highlighted features of interest from the raw data that were then transposed into early coding. Table 13 provides an example of how themes were generated from this item-coding.

Table 12. Phase 2: Colour-coding and Item Generation

Survey Questions	10. What are your earliest memories of having a hip problem?	11. Looking back on your childhood, were there any movements/activities you did differently from other people?	12. Please can you give a brief description of your symptoms, how they have developed since they first started and how they have changed over time?	13. What seemed/seems to trigger the symptoms?	14. What relived/relieves your symptoms?
Respondent Data	My mum was born with clicky hip and when I was born I used to cry when having my nappy taken off they took me to the GPs and they didn't say anything and wasn't concerned. Last year my hips started to sublux and pop out of place.	I was a very flexible child and used to sit in a w shape with my hips out	My hips sublux and can pop out of place and I have to manipulate them into position. The click and pop and make very loud noises. Most days I have a deep ache in my hips and groin other days it is sharp shooting pains which travel down my legs	Activity such as running, sex, sitting for too long	Rest standing whilst at my desk



Table 13. Phase 3: Initial Content of Candidate Themes

Theme	Family History	Infant/Childhood History	Joint Features	Pain
Data	mum was born with clicky hip	<p>when I was born I used to cry when having my nappy taken off</p> <p>I was a very flexible child</p> <p>used to sit in a w shape with my hips out</p>	<p>hips started to sublux and pop out of place. My hips sublux and can pop out of place and I have to manipulate them into position.</p> <p>The click and pop and make very loud noises.</p>	<p>Most days I have a deep ache in my hips and groin other days it is sharp shooting pains which travel down my legs</p> <p>[Trigger: Pain/problems]: running, sex sitting for too long</p> <p>[Pain relievers]: Rest standing whilst at my desk</p>

#### **PHASE 4: THEME EVALUATION**

Having organised coded items into named themes, I evaluated the first iteration of these themes to verify that the boundaries of each one were clear and explicit and to assess whether the data coding pertaining to each, conformed and supported the theme title or, whether new themes would be more representative.

At this stage, aspects of overlap were evaluated in terms of whether coded items were appropriately placed within the different themes. This highlighted where new, separate themes or subthemes were required. For example, coded items in the 'Pain' theme included the location of the pain (e.g., hip/groin); pain intensity (e.g. most days); nature of pain (e.g. deep ache or shooting pains); pain triggers (e.g. walking, sitting for too long) and pain relievers: (e.g. rest, standing whilst at my desk). These were recognised as being more appropriately managed as subthemes within the main theme of 'Pain'. By contrast, other related terms were collapsed together, for example, terms such as 'relative'; 'sister'; 'children' were included in the collective term 'family members.' Throughout this procedure of selecting, grouping and decision-making, my choice of themes and subthemes along with my decisions on the organisation of their content was driven by the overall study aim of identifying clinically relevant features of AHD that would alert physiotherapists to the need for X-Ray referral. Drawing on my knowledge and understanding of physiotherapy practice and patient assessment continued to ensure that the developing themes and subthemes would be clinically meaningful within physiotherapists' assessment of patients with hip problems. Expressions used by survey respondents, and which formed the coded items within each of the themes, were, however used verbatim.

The themes were reviewed by my PhD Supervisor who took a random sample of data subsets and placed them into one of the given themes. Agreement of theme definition verified that it was sufficient to ensure each feature (or coded item) was consistently placed into a particular theme, confirming repeatability.

#### **PHASE 5: THEME NAMING AND DEFINING**

A further refinement of the themes proceeded for Phase 5. Theme names were evaluated for descriptive clarity of what each addressed. I re-examined whether theme and subtheme titles reflected terminology that would be meaningful in the situation of a physiotherapy assessment. In doing so, I not only felt confident that the titles were appropriate but also, that each one accurately represented their content and that collectively, they captured relevant elements of respondents' data. In addition, the selected theme titles reflected those used in the AHD literature, enabling comparison of this study's findings with those of other studies.

Using systematic thematic analysis in this way facilitated an exploration of the numerous accounts provided by respondents from various contexts (Braun and Clarke 2006). At this point I extended the examination of data into a content analysis. I re-read every participants' data set, highlighting the occurrence of each coded item. This enabled me to then count how many data sets (or respondents) referred to each specific feature of interest. It provided me with an initial impression of the commonality of occurrence of the signs, symptoms and features which respondents associated with their AHD experiences. Through doing so, the results of PS-1 caused me to ask more questions. I was particularly curious to know whether items listed by only some PS-1 participants, were in fact experienced by others who did not think to describe them. Hence, PS-1 results informed the development of PS-2 which included closed questions, based on PS-1 themes. PS-2 also included open questions that provided participants the opportunity to describe any other features of their AHD that they wanted to include. These open questions were analysed using the same phased approach described above.

#### **PHASE 6: REPORT WRITING**

The findings of PS-1 and PS-2 were combined to achieve the final phase of analysis; Phase-6 'Report Writing'. Together they constitute the results section of Pillar 1 and are presented in the next chapter (Chapter 6 Results).

### **5.3 PILLAR 2: Survey of PAO Surgeons to Identify their Views of AHD Indicators**

**Objective 2: To ascertain the features of patient presentation that specialist PAO surgeons associate with AHD presentation.**

Specialist PAO surgeons were considered key informants for this study because they are experienced in assessing patients with AHD. Whilst their assessments benefit from the inclusion of X-Ray measures, they also consider the patient's history and conduct a physical assessment, and I was interested in identifying whether their views of these assessment findings could contribute to building a clinical picture of AHD presentation.

#### **5.3.1 Survey Design**

My aim was to draw from surgeons the clinical features that they considered important in the presentation of AHD. I did not want to restrict the content of responses by including heavily directed questioning, therefore, the survey was designed around open-ended questions that served only as prompts for surgeons' responses. Important to the survey design was that it

had to avoid being too onerous, as ease of response was considered important for encouraging completion by busy surgeons in a time-limited situation.

As with the patient questionnaire surveys, to build credibility and trustworthiness, the questionnaire design achieved content standards, cognitive standards and usability standards as advised by Groves et al (2009). The application of these to the surgeons' questionnaire is shown in Table 14 below.

*Table 14. Surgeons' Questionnaire and Question Design*

<b>Surgeons' Questionnaire</b>	<b>Content Standards</b>	<b>Cognitive Standards</b>	<b>Usability Standards</b>
	Questions directed at patient history and physical evaluation of diagnostic assessment of patients with acetabular hip dysplasia	Questions drawing on surgeons' recognised knowledge and expertise	Clearly worded, open, short unambiguous questions tested by 1 specialist hip surgeon and an academic researcher

Question design was informed partly by what I had observed during my visits to a young persons' hip clinic, which had provided some insight into the structure of the surgeons' assessments. I also considered the literature, which confirmed that whilst surgeons base their diagnosis of AHD on radiological parameters (Kappe et al 2012) they also refer to the patient history and physical assessment, which Lever and O'Hara (2008) explain is to evaluate patients for surgical planning and decision-making. Overall, the impression I gained from my visits to young peoples' hip clinics and from the literature was that although surgeons typically show a similar structure to their assessment of patients with hip problems, the information elicited varied, and the value placed on that information was unclear. The choice of question design for the surgeons' survey was therefore derived from the need to gain some clarity regarding the value of the various elements of their assessment. Importantly, the choice of questions was driven by the research objective for Pillar 2, which was to ascertain the features of patient presentation that specialist PAO surgeons identify as being present in patients with AHD.

The questionnaire involved 5 questions. The first four questions asked participants to list any aspects of Medical History; Family History; Physical Indicators and Special Test results that they considered to be associated with AHD presentation. A final, more directed question

enabled surgeons to include any features they considered important as it requested the following:

*“Please would you put in order of importance, the physical indicators and features of patient’s history which should alert clinicians to the possibility of hip dysplasia in adults (and prompt them to refer for X-Ray and/or referral to a specialist hip clinic)”.*

#### Pillar 2 Surgeons’ Survey Question 5

The survey design and wording of the questions were discussed with one internationally renowned PAO surgeon and my supervisor. Together they had been investigating hip dysplasia for some years before my study began; their focus being on outcome measures for young people undergoing hip surgery. Their feedback led to just one adjustment, which was that the front sheet of the questionnaire survey should include an illustration that summed up the purpose of the study on the principle that showing is more effective than describing. This, it was felt, would encourage surgeons to respond as it would provide an instant message of potential benefits that the study might provide.

### **5.3.2 Participant Recruitment**

Survey administration was conducted at The Royal College of Medicine (RCoM) Early Hip Intervention Conference (2018). The conference attracted attendance by UK-wide specialist PAO surgeons and was therefore a pragmatic approach to the recruitment of highly relevant surgeons.

Before inviting participation, I provided delegates with a short platform presentation to inform them of my study and the data collection procedure. Details were given regarding how response data would be used, how anonymity would be retained and how safe storage of the data would be ensured. Delegates were also informed that their voluntary completion and submission of the questionnaire survey would assume consent to participate. Following this, I invited surgeons’ participation, having provided the opportunity for them to ask and have answered, any questions they had.

Although the conference delegate list totalled approximately 50 surgeons who were due to attend, not all arrived and during questionnaire distribution, which occurred just before a break for lunch, fewer than 30 surgeons were present. I informed delegates that hard copies of the questionnaire were available on 5 large conference tables arranged at different points throughout the hall. Delegates were invited to collect a questionnaire with the suggestion that it was completed during the lunch break, at which time, I moved between tables offering further details of my study and answering any queries that were presented. I requested that

completed questionnaires be returned into a collection box that was placed near the hall's exit. This provided the opportunity for delegates to return the questionnaire without drawing the attention of others and supporting the principle of anonymity and confidentiality as it prevented others knowing the content of any of the responses. Four surgeons asked for the questionnaire be emailed to them for electronic completion as their involvement in the organisation of the conference day did not permit sufficient time for questionnaire completion and return. Their data were therefore successfully collected via e-mail.

### **5.3.3 Ethical Considerations and Data Protection**

Approval to administer the survey was given by the RCoM conference organisers. Knowing that the number of surgeons specialising in PAO correction was limited, I adopted practices that encouraged recruitment from a range of this restricted group. This included ensuring the survey design was straight-forward and brief. Also, as recommended by Jones et al (2006), I designed the platform presentation on survey requirements and participant information with sufficient detail to ensure that potential respondents made a properly informed decision regarding their consent to participate. I also made myself available throughout the conference day to answer any queries that potential respondents had. Sprague et al (2006) highlight the importance of ensuring the anonymity and confidentiality of participants and draw attention to consent being implied by the return of a completed survey. In addressing these issues, I ensured that in the collection of their data, responses could not be associated with the surgeon submitting the survey. In processing and transcribing respondent data, surgeons' personal details were removed and replaced with a respondent-code that was an individualised numerical identifier followed by 's', indicating surgeon, for example 110s. Data were exported into an EXCEL spreadsheet for analysis, and these were stored on the Cardiff University secured network. Hard copies of all returns were filed together and kept in a locked cupboard within a secured room and maintained in line with the Data Protection Act (2018).

### **5.3.4 Data Processing**

A total of 17 responses were received from specialist surgeons. Processing their data firstly involved removal and replacement of identifiable details with a respondent code as described above. Responses were then transcribed from the hard copy onto an EXCEL spreadsheet, verbatim.

### **5.3.5 Data Analysis**

Despite questions 1-4 being open-ended, responses were very brief with answers often involving only a short list of single word descriptors or a short statement. Consequently, responses to each question were clear and to the point, which facilitated comparison between surgeons' views and a straight-forward analysis. As with Pillar 1, the content analysis that was applied, firstly involved the identification of themes through an adapted version of Braun and Clarke's 2006 procedure for thematic analysis (Table 11) which was applied to surgeons' responses to questions 1-4. This procedure was then extended to establish the similarities between surgeons' listings of the signs, symptoms and features which they associated with AHD. I re-read every surgeons' data set, and listed each occurrence of items relevant to the research question. This enabled me to then count how many data sets (or surgeons) referred to each specific feature of interest.

The initial thematic analysis phase began during the transcription process as it provided me with the opportunity for reading and gaining initial familiarisation with the data. Details of each subsequent stage of the thematic analysis procedure follow.

#### **5.3.5.1 Qualitative Analysis**

##### **PHASE 1 DATA FAMILIARISATION**

During this stage, initial data familiarisation began as I conducted my first read-through of written responses during data transcription. Following this, a subsequent read-through of the data, involved me making notes on the overall impression of the responses, and I recorded whether all questions had been answered and whether the nature of each response addressed the intentions of each question.

##### **PHASE 2: INITIAL CODE GENERATION**

Repeated re-reading of the data led to Phase 2 of the analysis, which involved systematically identifying items that surgeons had listed in response to each question. The listed items directly fulfilled the requirement of coding as each one provided a feature of interest for this pillar of study, and each one clearly related to the specific topics of the survey questions.

##### **PHASE 3: THEME SEARCH**

As the intention of the questionnaire was to collect surgeons' views of the Medical History; Family History; Physical Indicators and Special Tests that they associated with the diagnosis of AHD, these topics of each survey question were accepted as themes for analysis. Clarke and Braun (2013) warn that using survey questions as named themes simply organises and summarises data, but the fact that surgeons' responses were single words or brief

comments that directly captured what was required from this pillar of study, meant that attempting any further analysis of the first 4 questions would not provide any additional benefits to the findings. Additionally, using the topic of each question as a theme enabled all responses for each question to be assembled and this aided recognition of similarities and differences between the surgeons' listing of items.

#### **PHASE 4: THEME EVALUATION**

Having confirmed the allocation of coded items into the named themes, checks were made on the fit of each coded item within the appropriate theme title. This also highlighted the value and relevance of the theme titles that directly addressed the aims of the study.

#### **PHASE 5: THEME NAMING AND DEFINING**

As it had been determined to use the topic of each survey question as individual theme titles, further naming was not required. Definition of each theme was reviewed to ensure that each one contained the correct and appropriate codes or items. At this point, I re-read every surgeon's data set, to identify the occurrence of individual items. I then counted how many surgeons had referred to each of these items. Through doing so, I established which items were most widely associated with AHD presentation by the surgeons and which were considered by only a minority as having an association with the condition.

#### **PHASE 6: REPORT WRITING**

The final stage of thematic analysis (Phase 6) involved an explanation of the findings supported by noteworthy extracts of surgeons' responses that validated or added clarification where needed to the data analysis findings. These are presented in the Results chapter that follows (Chapter 6).

##### **5.3.5.2 Question 5 Analysis**

Responses to Question 5, which asked respondents to assign an importance value to each feature listed, required additional analysis. Features, and their position of importance as listed by each surgeon were tabled (Table 15). Tabulating data in this way highlighted agreement and differences between surgeons' responses.



Table 15. Tabulation of AHD Features Importance Rating by each Surgeon

Feature	Surgeons' allocation of order of importance					
	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	6 <sup>th</sup>
(named) physical indicator/ feature	e.g., Respondent- code (1)  Respondent- code (2)	e.g., Respondent- code (3)				e.g., Respondent- code (4)

Respondent-codes were used to table each feature recorded by each surgeon and the position of importance they allocated for that feature. This, along with the full set of results for the pillar 2 investigation are presented in Chapter 6, Results.

#### 5.4 PILLAR 3: Observation of Physiotherapists' Patient Assessment

**Objective 3: To identify the content of physiotherapy assessment for patients with hip problems and to establish whether opportunities are being overlooked for identifying possible AHD presence**

Identifying the content and conclusions of physiotherapy assessment of patients with hip problems highlighted the type of data physiotherapists collect. It shone a light on opportunities for acting on data pertinent to AHD recognition that were offered by patients or identified during their clinical assessment. This informed the potential implementation of findings from Pillars 1 and 2, enabling effective use of new knowledge to support physiotherapists' assessment of patients with hip problems. This third pillar of study therefore used observation to identify the components of physiotherapy assessments, the type of patient data elicited during these assessments, and the patient management conclusions drawn by physiotherapists on completion of the assessment.

### 5.4.1 Study Design

Pillar 3 observations were carried out in two physiotherapy orthopaedic outpatient departments within one Welsh University Health Board (UHB). Access was organised through the physiotherapy triaging clinical specialist (Band 8 Physiotherapist) based at the main physiotherapy outpatient department. Data collection entailed 17 observations of 15 MSK physiotherapists as they carried out their initial assessment of patients with hip problems. Most physiotherapists in these departments were at Band 5 level (novice practitioners) and those with at least two-years post-registration experience at Band 6 level. Fewer Band 7 advanced or Band 8 specialist physiotherapists composed the orthopaedic outpatient physiotherapy staff in which this study took place. To ensure that my participant sample was representative of those working in these departments. I observed the practice of seven Band 5 physiotherapists; five Band 6 physiotherapists; two Band 7 physiotherapists and one Band 8 clinical specialist physiotherapist. It was important to observe practice across the grade range because experience and knowledge have been shown to influence the clinical reasoning procedure (Doody and McAteer 2002). Additionally, because I was interested in establishing whether opportunities were being overlooked for identifying possible AHD presence, it was important for me to recognise what occurred at all levels of physiotherapy assessment, not only those of experienced, senior physiotherapists. Novice physiotherapists are typically thought to apply a mostly hypothetico-deductive approach to their clinical reasoning. By contrast, in the dual processing approach to patient assessment, experienced or expert therapists have been shown to make greater use of pattern recognition or the rapid System 1 procedure in addition to the hypothetico-deductive reasoning (Doody and McAteer 2002). I was interested in identifying whether experience-related differences were evident in the type of patient data elicited and the assessment conclusions made by the physiotherapists. By realising this, I could explore whether an opportunity existed for physiotherapists to apply the understanding of AHD presentation developed by the previous pillars of study. Although patients were themselves not the focus of the observations, they had an inherent involvement in the procedure as it was the assessment of their hip problems that was observed. Patients were therefore identified from the referrals on the physiotherapy outpatient waiting list. These were limited to patients aged between 16 and 60 years and who indicated a complaint involving a hip problem. The upper age limit helped to reduce the number of patients with comorbidities or OA as their primary problem.

## 5.4.2 Participant Recruitment

Recruitment required me to enrol onto the study, the physiotherapists and the relevant patients. To do this, I firstly arranged a risk review meeting with the physiotherapy triaging clinical specialist and the out-patient administrator to establish the protocol for my observation study. The meeting confirmed that data collection set-up would require a 6-week lead time. All orthopaedic outpatient (MSK) physiotherapists would be invited to participate in the study. This would include novice grade practitioners (newly qualified Band 5) through to extended scope practitioners and clinical specialists (Band 8).

Due to the patient appointment arrangements, only 2 departments were used for the final data collection, however, invitations to participate were presented to physiotherapists in 3 different hospitals during prearranged meetings in each of the outpatient departments. During these, I explained to the physiotherapists the study, the type of information I was seeking, what would be required of them and requested their participation. I invited and answered questions from prospective participants and information sheets (Appendix 4) were distributed. These reinforced the study details that had been presented verbally and physiotherapists who were interested in participating were asked to complete, sign and return their informed consent (Appendix 6). These forms were available during the meeting and all participants submitted informed consent on the same day as the meeting. A collection box for the informed consent sheets was positioned on a plinth behind a screen enabling the physiotherapists to return the form privately, with those in attendance being unable to distinguish between physiotherapists who had signed their agreement to participate and those who had not. Confidentiality of those consenting to participate was therefore maintained, ensuring that the physiotherapy managers could not identify who had chosen not to participate. This aimed to reassure physiotherapists that their decision regarding participation would not be judged. The triaging clinical specialist and out-patient administrator were however, made aware of which physiotherapists consented as this was required for observation appointment bookings, and they treated this information with professional discretion.

The triaging clinical specialist identified referrals from the physiotherapy outpatient waiting list of patients who were between the ages of 16 and 60 years and who indicated a complaint involving a hip problem. In line with the normal practice of the outpatient department, the administrator then sent the patients listed, a 'partial booking' letter that invited the patient to confirm their continued requirement for an appointment with suggested appointment times included. For the purposes of the study, an invitation to participate in the

study and an information sheet (Appendix 5) were added to the partial booking letter for the patients to consider.

In line with the department's normal practice and in response to the partial booking letter, patients were requested to telephone the department to confirm they still required the appointment. On receiving the call, the administrator firstly confirmed the appointment date and time then asked the patient if they would be interested in taking part in the study. Those willing to do so were listed for me to observe their appointment.

The triaging clinical specialist agreed to organise three half days exclusively for these patient appointments, which enabled me to observe a number of assessments during each clinic session. In addition, I made myself available for relevant patients attending for appointments outside these 3 half days and they were also added to the observation list.

At the beginning of each relevant session and through discussion, I provided a reminder of the plan for the observations with each physiotherapist due to carry out patient hip assessments during that session. In addition, on arrival at clinic, listed patients were greeted by me and I again invited their involvement, answered any questions they had and collected their signed, informed consent sheet (Appendix 7). I then accompanied the patient into their appointment. No patient who, at the appointment-making stage had expressed their interest to participate in the study withdrew their consent, even though all were provided with an opportunity to do so.

### **5.4.3 Ethical Considerations**

I was aware that there may have been a risk of physiotherapists feeling under pressure to participate because of what others, including their managers, might think of them if they chose not to. My arrangements for collecting informed consent were therefore designed to mitigate this. Whilst details of the study and participatory requirements were presented to the staff group, collection of their informed consent was arranged to ensure privacy. In addition, whilst it was necessary for patient-booking arrangements for an administrator and the triage physiotherapist to know by name those who had consented, an agreement was made with them that participation would remain confidential.

Similarly, although patients were themselves not the focus of the observations, their informed consent was required as they were part of the observed event. This was addressed by the provision of two opportunities for them to consider the details of the study and what their involvement would require. They received an information sheet (Appendix 5) explaining these details at the initial stage of appointment booking and again on arrival at the department when they were also given the opportunity to ask and have answered any questions they had. At this later stage, their informed consent (Appendix 7) was collected

providing a second opportunity for them to withdraw their consent or not participate in the study if they so desired.

Approval to carry out these observations of physiotherapists, was received from the relevant Health Board's Research and Development Department Research Risk Review Committee (Appendix 8).

#### **5.4.4 The Observer (My) Role**

In planning my approach to the observations, I considered my relationship with the observed. As a physiotherapist myself, I have a professional association with those I planned to observe and, to some extent I considered them colleagues as, like me, most were involved in the education of undergraduate students. In this sense, the physiotherapists I observed could consider me an 'insider', which as Baker (2006) describes, is a member of the group being studied. I was not however, part of their department group, I was not employed by the UHB, and I was not involved in the treatment of their patients, therefore, in this sense, I was an outsider. The detachment of being an outsider can enhance objectivity but often the lack of interaction with participants can risk misconceptions of information-exchange and may not present the opportunity for asking questions or probing events as they occur (Baker 2006). By contrast, being an insider ensures access to the field of study, facilitating an accurate interpretation of the group's communication and terminology usage, which can engender an efficiency in data generation (Allen 2010). Being an insider in the observed activities is therefore useful in preventing disruption to the normal course of activities and in the development of potentially informative relationships with those being studied (Suzuki et al 2007). In analysing my position within these physiotherapy departments, I recognised combinations of these various elements were evident. Suzuki et al (2007) discuss the notion of the researcher being both an insider and an outsider due to various features such as ethnicity, class identity and profession that contribute to the researcher's identity. In my own case, my identity-position meant that, within the clinical department, physiotherapists might view me as an insider from a professional standpoint but as an outsider in terms of the management of their patients. In this sense, I was at an advantage from being able to understand the professional jargon and clinical procedures but might not be sufficiently involved in the department's 'group' to benefit from more social interactions in which challenges of patient encounters may be discussed within the clinical team. As a physiotherapist and regular visitor to the physiotherapy departments in which the study took place, I understand the community and the nature of the physiotherapists' roles and objectives. My professional role therefore positioned me as being neither or both an 'insider' and an 'outsider', which to some extent describes the complexity of reality. This

combination eased my access to the field of study and understanding, but I remained sufficiently outside the activities related to the management of patients coming into the department, to record events objectively (Suzuki et al 2007).

Next, I considered the nature of my participation in the activities being observed. Varying levels of observer participation have been identified, ranging from the researcher simply listening and watching, having no participation in observed activities, through to complete involvement where the researcher directly contributes to the activities being studied. Baker (2006) suggests that the decision on which role to use during an observational study is likely to be informed by features such as the investigator's association with the community of interest and the willingness of individuals to be observed. As an academic lecturer and clinical liaison staff member I had regular monthly meetings with the physiotherapists and was therefore a familiar sight to them. Most were used to being observed by me whether this was during their undergraduate education or during their supervision of students on clinical placements. Nevertheless, I was aware of the possibility that my presence as an observer of their current assessment practices could influence the physiotherapists' behaviour. However, in relation to this 'Hawthorne effect', behavioural reactions to being observed have been shown to dissipate as the observed become accustomed to being observed (Spano 2006). Additionally, I was mindful of the value of rapport and trust (Spano 2006), and I therefore spent time explaining to potential participants that the purpose of my observations was simply to understand what happens and not to judge or evaluate their individual skills. In response, I sensed an enthusiasm and willingness to support the study that was evidenced by the physiotherapists all consenting to participate. Therefore, in deciding on the role I would assume and how I would position myself in relation to the physiotherapists being studied, I drew on Baker's 2006 description of the 'complete observer' in which the investigator is present but unobtrusively and does not participate in activities. It is a passive role whereby the observer interacts with participants only minimally; the focus of the observer being on listening and watching (Baker 2006). This was appropriate for my study because, by focusing on the practices of physiotherapists as they carried out their patient assessments, I was able to record the events as they unfolded without influencing any aspect and with negligible alteration to normal practices. The arrangements for the observations, however, required me to interact with the patients. Although this interaction was minimal during the assessment procedure, I welcomed the patient on their arrival into the department as it provided the opportunity for me to recheck patients' willingness and consent to take part in the observations. I therefore felt it important to ensure a clinically professional image, and although I felt clinical uniform was not appropriate, by wearing the uniform colours of navy trousers, a white shirt and my university security lanyard, I reflected

my association with the physiotherapy profession, whilst maintaining my identity of being outside the clinical team.

Patient assessments were held either in screened cubicles or in individual examination rooms. I positioned myself in a discrete corner of the examination area and for each appointment, I checked with both the patient and the physiotherapist that my position was acceptable to them. I took no part in the physiotherapy assessment but, because I was interested in establishing the assessment practices of the physiotherapists, I recorded their questions, responses and actions via written field notes.

I began the written recording of assessment events as soon as the physiotherapist started to collect data for a patient. This could begin with the physiotherapist reading patient notes or referral sheets and in just one case, evaluating the patient's hip X-Ray. Others began their patient data collection at their first point of contact with the patient.

#### **5.4.5 Fieldnotes in Observational Study**

Qualitative observation requires the systematic recording of data to monitor exactly what happens during the events of interest (Mays and Pope 1995). Whilst various methods of recording are available, according to Marvasti (2014 p 359),

*“.....the simplest way to represent observations is to only describe them  
– write them down as you see them”*

In this sense fieldnotes transpose what is seen and heard into written text. Baker (2006 p183) supports this notion, confirming that,

*” Observational notes detail what the researcher actually saw....”*

However, in what is perhaps the most comprehensive guidance on fieldnote writing, Emerson et al (2011) highlight the variety of opinions that exist on the nature, style and purpose of fieldnotes. They explain how fieldnotes are considered by some to record the activities being observed, whilst others consider such records to take the form of a journal or diary that the observer uses to express their own thoughts and reactions to what is being observed. Emerson et al (2011) focus their text on ethnographic studies that involve gaining holistic understanding of cultures. For such studies, observation is just one part and other methods, which include for instance ethnographic interviewing, are used alongside insider observations to provide a variety of perspectives, where needed, into the cultural landscape of those being studied (Whitehead 2005). The nature of the research problem that I investigated through observation, however, was to identify the content of physiotherapy

assessment of patients with hip problems and to examine the physiotherapist's resulting conclusions regarding patient management and onward referral of the patients when relevant. Observation enabled me to recognise opportunities for physiotherapists to identify features associated with AHD and how best I could support practice by providing new and relevant knowledge. Therefore, my fieldnotes mirrored the procedural nature of the activity being observed and would therefore by necessity, follow the views of Baker (2006) and Marvasti (2014) in that they would quite simply record what I saw and heard in terms of the questions asked, the answers given, and the statements made.

Baker (2006) highlights how ensuring quality of fieldnote data is key to the success of an observational study and points to the application of three principles considered important in achieving the desired quality. These relate to how the language used in fieldnotes is recorded and highlights the importance of: 1) Clearly identifying what specific words were said by whom, as in direct quotations, and distinguishing these from those used for the purposes of description; 2) The use of a verbatim record, to clarify differences between terminology used by the observed compared with that of the observer and 3) The avoidance of generalisations or summaries, indeed the suggestion is that as much specific detail as possible is recorded. This was the approach I adopted as it was an effective way of capturing the details of the assessment content and the subsequent decisions the physiotherapists made regarding patient treatment or referral. In planning how to efficiently capture the volume of what was observed I prepared a basic recording sheet in table format (Table 16). At the top of each table, the date of the observed assessment was noted along with a coded identifier that documented the physiotherapist and their professional grade (Band 5, 6, 7 or 8) plus an anonymised patient code and their age. The design of the recording sheet distinguished between the physiotherapists' questions and comments and the patients' responses, questions and comments through the use of 2 columns with the heading 'Physio Questions' and 'Patient Response'. In addition, a section below the columns offered 5 further boxes titled Physical Test, Result, 'Outcome'; 'Diagnosis/Referral'; 'Further Tests'. These provided space to record the physiotherapist's decision for the next stage of patient management and was composed of the explanation given by the physiotherapist to the patient on conclusion of the assessment. Along with the questions asked, most responses were recorded verbatim where possible. Some terminology and sentences were abbreviated in the fieldnotes, but it retained the essence of what was said by the participants. This was straight-forward to do because physiotherapists' questions or statements and patients' direct responses, were clearly articulated and mostly concise, making these data easy to record. Some filtering of the entire conversation was applied however but this involved only condensing aspects of both repetition and the general, social



conversation used by each party in the development of polite rapport. Otherwise, all statements concerning the patient’s health, their related problems, expectations, views, opinions, and the contexts in which the health problems occurred, were recorded accurately. Similarly, the events occurring throughout the physical assessment were detailed as they occurred under the headings ‘Physical test’ and ‘Result’.

*Table 16. Fieldnote Recording of Physiotherapy Patient Assessment*

<b>Date:</b>	<b>Physio Code and Grade:</b>	<b>Patient Code:</b>	<b>Patient Age:</b>
<b>Physio Questions:</b>	<b>Patient Response:</b>		<b>Additional Comments</b>
<b>Physical Test:</b>	<b>Result:</b>		
<b>OUTCOME:</b>	<b>Diagnosis/Referral:</b>		<b>Treatment Plan:</b>

### 5.4.6 Data Processing

Field notes from each of the 17 observed assessments were transcribed within 2 days of each observation onto word documents for easy-reading and analysis. They remained in table format as shown in Table 16 with only minor alterations to the column titles, which aided analysis (Table 17). Firstly, the fieldnotes were recorded under two main headings: Subjective Interview and Physical Assessment. The subjective interview data captured the patient’s history and composed the questions asked by the physiotherapist and a summary of the patient’s response. The summary excluded only that information deemed irrelevant. Although this required me to make judgements on the value of what was being said, it was only repetition of explanations that were excluded. Removing these did not reduce the details or the meaning of what either the physiotherapist or the patient expressed. Fieldnotes for the physical evaluation component of the assessment recorded the nature of the test applied by the physiotherapist and what was expressed about the test result. In addition, a comments column was added to provide space for any notes I made during analysis. The boxes titled ‘Outcome’; ‘Diagnosis’; ‘Treatment’; ‘Referral’ and ‘Further Tests’ on the original recording form were abbreviated to one box titled ‘Diagnosis/Management

Plan. In total, the transcribed, word-processed notes for each observed assessment covered between 1 and 4 pages of A4 sheets.

*Table 17. Transcription Format for Observation Fieldnotes*

Date	Physio Code	Physio Band	Patient Code	Patient Age
<b>Subjective Assessment:</b>				
Physio Questions	Patient Responses		Comments	
<b>Physical Assessment:</b>				
Test	Findings			
<b>Diagnosis/Management Plan:</b>				

### 5.4.7 Data Analysis

Mays and Pope (1995) highlight how qualitative observational fieldnotes typically present the researcher with copious descriptions of the phenomenon of interest, hence some semblance of logic needs to be applied to and result from the analysis. Various analytical methods for doing so have been described but as Mays and Pope (1995) point out, methods such as inductive analysis or the constant comparative approach are fundamentally a content analysis involving an iterative process to generate categories of fieldnote data. Others describe the analysis of what was said as the recognition of patterns of meaning from the data collected (Maguire and Delahunt 2017). For the trustworthiness and plausibility of the observation findings for this Pillar 3 study, I used a systematic approach to content analysis that ensured that the evidence generated by the observations and resulting fieldnotes clearly endorsed the conclusions resulting from the analysis, as recommended by Mays and Pope (1995). To achieve this, my analysis followed a procedure adapted from the recommendations of Emerson et al (2011) that involved the following: systematic and analytical reading of fieldnote data; identification of features of interest of analytic dimensions or categories (open coding); the writing of analytic memos; selection or

confirmation of key themes and data-sorting; focused analysis and finally integrative report writing. In applying this approach, I focused on answering three questions:

- 1) What happens during physiotherapy assessment of patients with hip problems?
- 2) During the assessment, are features identified that are associated with AHD presentation?
- 3) If they are, what happens?

Gaining answers to these questions through my analysis directly addressed the objective for this pillar of study, and thus identified whether opportunities were being overlooked for identifying patients in whom AHD should be suspected. To achieve this, the application of the analytical procedure listed above was carried out in the following way:

### **SYSTEMATIC AND ANALYTICAL READING OF FIELDNOTES**

Firstly, each transcribed observation was read in its entirety to give due consideration to the recording of what had happened in each assessment. This included what the physiotherapist did, the patient information they elicited and the conclusions they drew on completion of the assessment. I highlighted on the transcribed fieldnotes all words and phrases that captured these events. As I did so, I began to make comparisons between observations, noting patterns and differences of recorded events.

#### **Open Identification of Features of Interest (Coding)**

For the next stage of analysis, I repeated the reading of each transcribed observation in line-by-line detail but this time I sifted through the initial features I had highlighted, reviewing and evaluating each one with its relevant portion of transcribed text. In doing so, I checked my interpretation and confirmed that I had not overlooked other details of possible interest. Using a questioning approach (Table 18), as recommended by Emerson et al (2011), this procedure of reading, evaluating and interpreting text enabled me to deepen my analysis and by doing so, I maintained my focus on establishing the patient features that had been identified by each physiotherapist during the assessment, and the conclusions that were drawn as a consequence. Emerson et al (2011) refer to this as 'open coding' where codes are designed to represent features of interest within lengthy portions of text. These observations, however, were composed of questions and responses that were brief enough to maintain their original terminology for analysis. The expressions used, captured relevant elements effectively, removing the need for specific codes to be introduced. Identifying these features of interest began to shape my thinking of how I could analyse assessment events and determine whether features associated with AHD were reported. If so, I could identify the impact such features had on subsequent conclusions and physiotherapists' patient management decisions.

Table 18. Questions Used to Identify Features of Interest (open coding)  
(Adapted from Emerson et al 2011)

What did the physiotherapists ask?
What did the physiotherapists do?
What do I see going on?
What did I learn from the fieldnotes?
Why did I include each feature of interest?
What is similar or different in each individual set of fieldnotes compared to the others?
What is the broad significance of each event or point of interest?

By applying the questions listed in Table 18, I maintained my focus of identifying *what* was happening during the physiotherapy patient assessments, which protected me from slipping into the temptation of looking for *why* certain events occurred. This was important because, rather than attempting to identify cause and effect, my interest for this study was on establishing the practical, pragmatic nature of physiotherapy assessment, the routine of their practice and possibly the automatic, habitual features that led to their conclusions and decisions.

For the early readings of the observation data, I concentrated on establishing answers to the first 4 questions listed in Table 18 as this provided a structured, systematic approach to the initial identification of features of interest for open coding. My response to each of these questions is shown in Table 19.

Table 19. Initial Open Coding

Questions asked of the data	Findings
What did the physiotherapists ask?	<ul style="list-style-type: none"> <li>• An opening/introductory question</li> <li>• Reactive questions in response to the information presented by the patient</li> <li>• Routine general health-check questions</li> <li>• Questions to check the accuracy of the physio's summary of the patient information</li> </ul>
What did the physiotherapists do?	<ul style="list-style-type: none"> <li>• Patient history evaluation, physical assessment, summary of findings and conclusion/decision-making</li> </ul>
What do I see going on?	<ul style="list-style-type: none"> <li>• Assessment took between 30-45 minutes</li> <li>• Physiotherapists provided the patient with the opportunity to describe the problems and in some cases to detail or elaborate these further as a result of reactive questioning.</li> <li>• The patient history evaluation appeared to elicit a considerable amount of patient data that extended beyond direct answers to physiotherapists' questions; these data included features associated with AHD</li> <li>• Conclusions/decisions were brief by comparison and included physio's diagnosis, the recommended treatment and the management plan</li> </ul>
What did I learn from the fieldnotes?	<ul style="list-style-type: none"> <li>• The structure of each physio assessment was very similar</li> <li>• Identification of the type and purpose of physiotherapy questioning was straight-forward</li> <li>• Physiotherapists' questions were mostly responsive to the type of information provided by the patient, but enquiry sometimes appeared to end unexpectedly</li> <li>• A number of patient-reported features were those which have been associated with AHD</li> <li>• There were omissions of questioning that I would have expected to see during this type of physiotherapy assessment.</li> <li>• Comparisons between each set of fieldnotes highlighted many similarities between physiotherapists' approaches but some differences in the assessments were also evident</li> </ul>

Key: Acetabular Hip Dysplasia (AHD)

With subsequent re-reads of the data and reviews of the features of interest, I then addressed the remaining 3 questions of the procedure adapted from Emerson et al's 2011 recommendations, which tested or justified my analysis. An overview of these and their findings is presented in Table 20.

Table 20. Checking and Reviewing of Initial Features of Interest

Questions asked of the data	Findings: Features of Interest (Coding) Review
Why did I include each feature of interest?	Each feature of interest (code) captured a relevant characteristic of the physiotherapist's enquiry and the patient information elicited. By identifying these events I tracked how the physiotherapist developed their understanding of the patient's problems and identified decisions made as a consequence.
What is similar or different in each individual set of fieldnotes compared to the others?	<p>All physiotherapists used a similar procedure and often very similar questions throughout the assessment of patients with hip problems.</p> <p>Differences in physiotherapists' approaches that were evident included:</p> <ul style="list-style-type: none"> <li>• The progression of questioning. This was unsurprising as questions were broadly in response to the information given by the patients who had their own unique set of problems.</li> <li>• Physiotherapists began their enquiry in different ways, for example, whilst some began by asking the patient opening questions, several considered data from the patient's medical records (e.g., X-Rays, Referral notes) prior to asking their opening question.</li> <li>• Different levels of enquiry were evident for instance, whereas a symptom such as pain received numerous levels of enquiry enabling the physiotherapist to gain deep understanding of the patient's pain features, a patient-description indicating joint instability received no further levels of enquiry to extend physiotherapy insight into the problem</li> </ul>
What is the broad significance of each event or point of interest (themes and codes)?	Broadly, the significance of the features of interest was that they captured how, during patient assessment, characteristics associated with AHD were identified. With this information, it was then possible to track the relationship of these characteristics with physiotherapists' conclusions and patient-management decisions that directly addressed the objective for the Pillar 3 study.

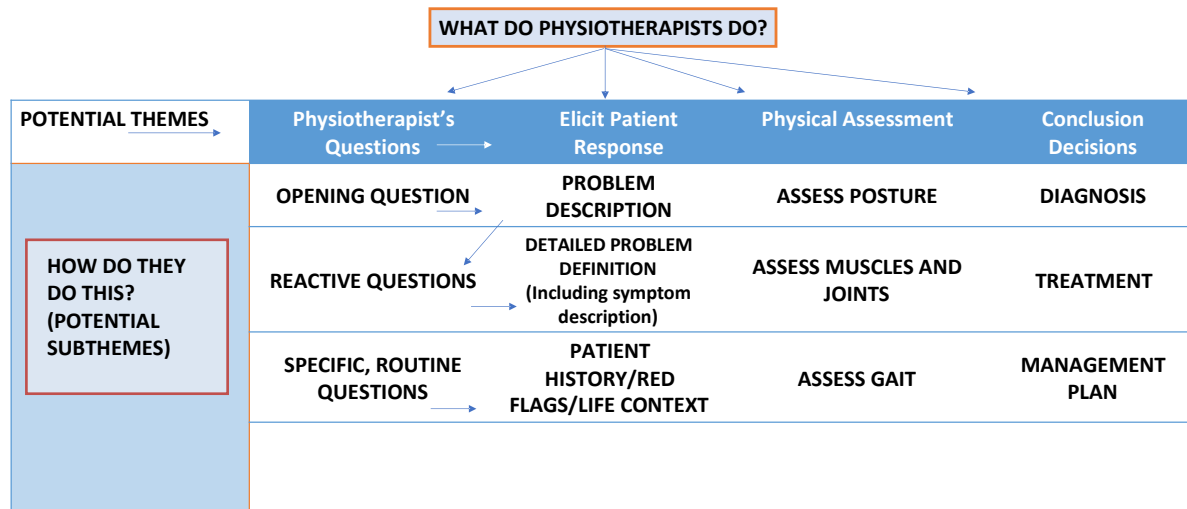
Key: Acetabular Hip Dysplasia (AHD)

#### Analytic Memos

Whilst addressing these questions I made notes that highlighted connections between features of interest. This note-making also recorded my thinking, which helped me to keep track of my decisions. As my analysis deepened, I became increasingly reflexive in this note-making. I began to include my own thoughts on the relationship between identified features of interest and I drew on my own professional understanding of physiotherapy assessment as well as the understanding of AHD that I had developed through the literature,

my previous surveys, and my earlier enquiries. My review of these notes enabled the connections and relationships of the observed events to be organised coherently, which generated initial themes and subthemes. (Figure 5.1). Fieldnote data were then sorted into these themes and subthemes.

Figure 5.1: Initial Mapping and Theme Development



#### Selection and Confirmation of Key Themes

The significance of identifying and sorting features of interest along with the memo-writing, began to demonstrate analytic dimensions that were relevant to pursue, and filtered out those that would not contribute to addressing the objective of this pillar of study. By reviewing these features, it became clear that they fitted appropriately within the initial themes and subthemes. Themes were confirmed as, Physiotherapists' Enquiry (Theme 1), composed of firstly, a condition-focused opening question, prompting the patient to begin the description of their problem. Following this, physiotherapists then used a number of reactive questions, which began by establishing the patient's general health. These questions were seemingly routine, standard enquiries that were similar in almost all the observed physiotherapy patient assessments. They drew from the patient, details of their past medical history, medication, 'red flag' issues, work or education and hobbies. Secondly, physiotherapy enquiry probed each element of the patient-reported problems. These sometimes quite focused lines of enquiry elicited patients' responses (Theme 2) which, through continued enquiry of more reactive questions, increasingly defined the patient's problems. Physiotherapists then carried out a physical assessment (Theme 3), which involved evaluating patients' movements and related function. Finally, in concluding the assessment, the physiotherapist reviewed their findings, stated their working diagnosis, their suggested management plan and treatment (Theme 4).

During the analysis of these themes and their content, I made constant comparisons between the features of each set of fieldnote observations, reviewing the themes in which I had grouped them. Doing so helped to draw out patterns and variations between observed assessments and identified where subthemes were necessary to capture all assessment elements. The procedure not only confirmed the appropriateness of the key themes, but it also began to frame the identification of potential links between the content of physiotherapy assessment, the information elicited regarding the patient's hip problems and the nature of the physiotherapist's response to those identified hip problems. At the end of this stage, I had the data from each set of transcribed observations sorted into the key themes and the related subthemes.

#### Sorting Fieldnotes into Themes and Subthemes

Data sorting was managed on a spreadsheet that enabled me to retain the structure of physiotherapists' assessment and establish what they were interested in finding out. Collecting each element of all assessments in this way allowed for straight-forward comparisons to be made between each of the observations. Tables 21-24 provide examples of data sorting into the themes and subthemes for patient RHKL1.



Table 21. Theme 1: Physiotherapists' Enquiry

Theme 1: PHYSIOTHERAPISTS' ENQUIRY					
Patient Code	Patient Age	Physio Band	Opening Enquiry (Subtheme)	Reactive Questions (Subtheme)	General Health and Content Questions (Subtheme)
RHKL1	24 years	5	What brings you here today?	Back pain? When is pain worse? And what's it like at night? What does it worsen with? Does hip limit anything? Does it lock? Are problems getting more frequent? Is pain weekly/daily? How much running do you do? Does popping/pain happen on standing?	Meds? General check questions <i>(Asthma? Blood pressure? Cholesterol? Diabetes? Epilepsy? Osteoporosis? Cancer? Recent fractures? Do you smoke? Drink alcohol? Any unexplained weight loss? Any allergies? Any immunity problems?).</i> Occupation? Who do you live with? Other sports/hobbies?

Table 22. Theme 2: Patient Responses

## THEME 2: PATIENT RESPONSES

Left hip locks since age of 14yrs; then pops and improves. Pressure/aching been worsening for a while. Am using trainers with insoles because of foot rolling

No, shooting pain through buttocks; Left leg pains, shooting – has started on Right too – to knee, but varies and is intermittent.

Returned from Australia in Feb (7mths ago) have had problems since then; might be caused by the long-time sitting or increased weight. I don't feel that shooting pain is connected to hip pain.

In the evening; Doesn't affect sleep

Being on feet all day; approx. 4hrs into shift – no other triggers. Thought running might worsen it but seems to feel worse when not running. Relieved by putting feet up.

Had X-Rays at 16 but nothing diagnosed

None

Weekend alcohol; nothing else

Natural hip or bone problem but scan showed nothing. Have never had an injury.

It's getting worse, what will it be like in 20 years?

Diagnosis and advice on how to manage it

Feel exhausted in evenings because of pain. Used to run but stopped for a while. Recently restarted running and hip improves. Really sociable; like to drink; extrovert but very worried.

Feels like hip "falls out". Had physio before; was told muscle grew at puberty but then went to Australia and didn't finish treatment

Yes, have to invest in shoes for better support; I wear insoles to stop foot rolling in.

Varies, sometimes daily for 2 weeks then nothing for a month. Seems no problem – not related to change in activities.

5K 2 or 3 times a week

Full time retail, on feet all day

Parents

Going out/drinking

During long shift on feet, hip feels wrong & can be painful – need to move in a particular way to unlock. Pain is a heavy, burning sensation relieved by putting feet up.

Now – no pain

Pain at work 4/10

Table 23. Theme 3: Physical Assessment

THEME 3: PHYSICAL ASSESSMENT		
Posture	Joints and Muscles	Gait
Not overtly assessed	In supine; knees to chest - No problem Abduction - OK but seemed weak Flexion, External Rotation - Left hip 'sensations' Palpation - No tenderness Flexion/Abduction/External Rotation (Right) - OK Flexion/Abduction/External Rotation (Left) - Hip feels a 'pull' & clicked on initial full flexion Straight leg raise (Left) - End range tightness Side lie: Hip Extension and Adduction (Left) - OK Hip Abduction (Left) - OK with resistance but hard work and weak	Not overtly assessed

[continued]

Hip Abduction (Right): Hard work, with resistance – difficult

Supine:

Bridging - OK

Slow lowering - OK

*Table 24. Theme 4: Conclusions and Decisions*

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THEME 4: CONCLUSIONS AND DECISIONS		
Physio Diagnosis	Management Plan	Treatment
Muscles weak, particularly stabilizers (Gluts/gluteal muscles)	Further assessment next time	Strengthen muscles Exercises: bridging and clams (hip abduction in side-lie) work until fatigue

Next, I reviewed the themes, subthemes and their contents to consider where data were similar, where they could be connected, where they differed and where elaboration was required. This required more focused analysis.

### **FOCUSED CODING**

The purpose of this phase of analysis was to further investigate each theme and its content. This enabled me to recognise whether any aspects of the subthemes, within each theme, were too general and whether it was necessary to further delineate these into subtopics that needed to be distinguished within the broader subtheme. Through this procedure the subtheme 'Reactive Questions' within Physiotherapists' Enquiry (Theme 1), was defined by a further breakdown into subtopics of:

- i. Pain,
- ii. Previous hip conditions and injuries,
- iii. Hip sounds and giving way,
- iv. Activities affected,
- v. Tests, X-Rays and Scans
- vi. Patients' views and opinions

These subtopics covered all aspects of the subtheme 'Reactive Questions' occurring in all assessments. Organising the data into these subtopics highlighted aspects of the assessment that the physiotherapists focused upon and aspects that received less attention. It also enabled me to establish the point at which the physiotherapists ended their reactive questioning of each patient-reported symptom. Table 25 provides an example of this data organisation.

Table 25. Focused Coding and Extended Subtheme Development

Patient Code	Physio Band	THEME1: PHYSIOTHERAPISTS' ENQUIRY						
		Opening Enquiry	Reactive Questions				General Health and Context Questions	
			i. Pain	ii. Previous hip conditions	iii. Clicking/popping/giving way	iv. Activities	v. Tests, X-Rays, Scans	vi. Patient's views & opinions
RHKL1	5	What brings you here today?	Back pain?	No enquiry	Does it lock?	Does hip limit anything?	No enquiry	No enquiry
		When is pain worse?			Does the popping/ pain happen on standing?	How much running do you do?		
		And what's it like at night?						
		What does it worsen with?						
		Is pain weekly/daily?						
		Are problems getting more frequent?						
								Meds?
								General check questions ( <i>Asthma?</i>
								<i>Blood pressure?</i>
								<i>Cholesterol? Diabetes?</i>
								<i>Epilepsy? Osteoporosis?</i>
								<i>Cancer?</i>
								<i>Recent fractures?</i>
								<i>Do you smoke? Drink alcohol? Any unexplained weight loss?</i>
								<i>Any allergies? Any immunity problems?).</i>
								Occupation?
								Who do you live with?
								Other sports/ hobbies?

Although I initially planned to concentrate on physiotherapists' questions, during this phase of focused coding, it became apparent that the questions alone did not adequately reflect the comprehensiveness of the data elicited via the patient history-taking. Whilst a range of possibly pre-planned questions was presented to the patient by the physiotherapists, the general feel of the assessments was that the spontaneity of the physiotherapist-patient interaction drew information from the patient that often extended beyond the physiotherapist's direct line of enquiry. This was relevant because to fulfil the objective of this pillar of study, I needed to establish if, during physiotherapy assessment, it was possible to identify features associated with AHD. Therefore, if the transcripts showed that such features were being identified, I wanted to understand how the physiotherapists responded to them. I therefore used a pragmatic approach and chose to also analyse what the patient reported as well as how the physiotherapist responded. To do this effectively, I returned to the original transcripts to view the patient responses in the context of their interaction with the physiotherapist. By doing so, I could identify which types of questions, asked by the physiotherapists, elicited information associated with AHD and could follow the relevant line of physiotherapy enquiry. For this focused coding phase, I re-read the transcribed observation fieldnotes and highlighted signs and symptoms described by the patient that have previously been associated with AHD. These are identified in bold underlined on the example provided in Table 26 below. I then made notes and memos about the physiotherapist's response to these signs and symptoms, an example of which is also shown in Table 26.

I applied this procedure to the transcription of every observation. On completion, I had identified patients' descriptions of each AHD-associated feature that had been reported and could track how the physiotherapist had responded. This, along with the previous exercise of drawing together physiotherapists' questions into the named subtopics, enabled me to establish features that received repeated attention and those that appeared to be disregarded or overlooked. In relation to this, I drew on Yuen et al's (2018) definition of biases, particularly 'anchoring' and 'premature closure' explained in Chapter 2 and recognised that they were evident. This helped me to make links between the signs and symptoms reported by the patient and the potential influence of bias on the physiotherapists' assessment conclusions. Similarities and variations of the detailed aspects of the physiotherapists' approach and assessment content were then compared between each observed assessment. This systematic reading, re-reading and focused coding concluded when no new features of interest could be identified and when lines of enquiry made by each physiotherapist for all relevant features of interest had been tracked.

Table 26. Focused Coding and Memo Writing

THEME 1: PHYSIO QUESTIONS	THEME 2: PATIENT RESPONSES	NOTES/MEMOS
What brings you here today? OPENING QUESTION	Left <u>hip locks</u> since <u>age of 14yrs</u> ; then pops and improves. Pressure/aching been <u>worsening</u> for a while. Am using trainers with insoles because of foot rolling	HIGHLIGHTED IN BOLD: signs reported by patients in Pillar1. Reactive questions show enquiry on pain and single questions on both locking and popping. Age 14 and no history of injury(?). PREMATURE CLOSURE?
Back pain? REACTIVE QUESTION	No, <u>shooting pain</u> through <u>buttocks</u> ; Left leg pains, shooting – has started on Right too – to knee, but <u>varies and is intermittent</u> . Returned from Australia in Feb (7mths ago) have had problems since then; might be <u>caused by the long time sitting or increased weight</u> . I don't feel that shooting pain is connected to hip pain.	Same problem beginning in other hip. Why? But no further questioning on this. ANCHORING?
When is pain worse? REACTIVE QUESTION	In the <u>evening</u>	
And what's it like at night? REACTIVE QUESTION	Doesn't affect sleep	
What does it worsen with? REACTIVE QUESTION	<u>Being on feet all day</u> ; approx 4hrs into shift – no other triggers. Thought running might worsen it but seems to feel worse when not running. <u>Relieved by putting feet up</u> . Had X-Rays at 16 but nothing diagnosed	No further questioning on this nor why decision was made to X-Ray or what was being looked for on X-Ray(?) PEMATURE CLOSURE?
Meds? GENERAL QUESTION	None	



General health and red flag questions

Weekend alcohol; nothing else

GENERAL QUESTIONS

What do you think it might be?

Natural hip or bone problem but scan showed nothing. Have never had an injury.

No injury – no further investigation into cause of initial problems and developing problem in other hip.

GENERAL QUESTION

PREMATURE CLOSURE?

What are your concerns?

It's getting worse, what will it be like in 20 yrs?

GENERAL QUESTION

What do you want from physio?

Diagnosis and advice on how to manage it

GENERAL QUESTION

Does hip limit anything?

Feel exhausted in evenings because of pain. Used to run but stopped for a while. Recently restarted running and hip improves. Really sociable; like to drink; extrovert but very worried.

No further questioning on this.

REACTIVE QUESTION

PREMATURE CLOSURE?

Does it lock?

Feels like hip "falls out". Had physio before; was told muscle grew at puberty but then went to Australia and didn't finish treatment

Why is this happening? No further questioning on this.

REACTIVE QUESTION

PREMATURE CLOSURE?

Are problems getting more frequent?

Yes, have to invest in shoes for better support; I wear insoles to stop foot rolling in.

Why is foot rolling in?  
PREMATURE CLOSURE?

REACTIVE QUESTION

Is pain weekly/daily?

Varies, sometimes daily for 2 weeks then nothing for a month. Seems no problem – not related to change in activities.

If not because of change in activities, what causes the problem?

REACTIVE QUESTION

PREMATURE CLOSURE?

How much running do you do?	5K 2 or 3 times a week
REACTIVE QUESTION	
Occupation?	Full time retail, on feet all day
GENERAL QUESTION	
Who do you live with?	Parents
GENERAL QUESTION	
Other sports/hobbies?	Going out/drinking
GENERAL QUESTION	

## REFLECTING AND REPORTING

I had set out to identify the content of physiotherapy assessment of patients with hip problems to establish whether opportunities were available to recognise when AHD presence should be suspected. Structuring the content of the observation fieldnotes into themes and subthemes enabled me to frame events in such a way that I could track the development of the physiotherapists' questioning, the information they elicited from the patient, and the conclusions they reached about the patient's condition along with the concluding patient-management decisions. The findings are reported in Chapter 6 and discussed in Chapter 7.

### 5.5 Ethical Approval

Ethical approval to conduct the PhD study was gained from the Research Ethics Committee, School of Healthcare Sciences, Cardiff University (Appendix 1) and Health and Care Research Wales (Appendix 2). These approved my initial plan which was to produce an assessment tool but meetings with senior physiotherapists regarding the arrangements for patient-assessment observations (Pillar 3) and in discussion with my original supervisory team, resulted in refinements being made which scaled back the aims. The Pillar 3 observation objective remained, but rather than using the data to produce an assessment tool, the data were used to establish opportunities for implementing into practice, the findings of Pillars 1 and 2. It was agreed that this should inform, alert and educate physiotherapists, enabling them to recognise the features of patient presentation which should increase the index of suspicion for AHD presence leading to consideration for X-Ray referral. The approach draws parallels with the 'Act F.A.S.T' campaign developed to increase public awareness of stroke symptoms. Early recognition of stroke symptoms and swift access to treatment have been shown to increase an individual's chance of receiving thrombolytic therapy and reduces the likelihood of infirmity (Wolters et al 2015). In a similar vein, a suitable alert tool would prompt physiotherapists to identify clinical indicators of AHD and trigger relevant referral for onward patient management. This early identification and rapid referral to relevant specialists would improve patients' opportunity for receiving timely surgical evaluation with the possibility of improving outcomes.

### 5.6 Data Management

To ensure that the study's procedures for managing data storage complied with Research Governance Framework for Health and Social Care in Wales (Welsh Assembly Government, 2009), the Cardiff University Research Integrity and Governance Code of Practice (2018) and the Data Protection Act (2018), all original hard copies of survey responses and

observation field notes were filed together and kept in a locked cupboard within a secured room. All signed informed consent sheets were stored in the same way.

Electronic data were retained on a university, password-protected server which only I and the School of Healthcare Sciences IT manager could access. Personal identifiable participant details were removed and replaced with a coded pseudonym on all analysis spreadsheets.

## **5.7 Summary of Methods**

Three pillars of investigation were used to address the research aim of identifying indicators of AHD that inform physiotherapists of when to suspect the presence of AHD in patients with hip problems, and that provide an alert for X-Ray referral and definitive diagnosis.

Pillar 1 involved Patient Surveys 1 and 2 (PS-1 and PS-2) and used a questionnaire survey approach. Apart from the demographics section, PS-1 employed a qualitative questionnaire, using open questions to explore patients' experiences of living with AHD. Thematic analysis enabled a wide range of features to be identified. PS-2 then employed a more circumscribed approach to identify whether PS-1 items listed by only some respondents, were in fact experienced by others who did not think to describe them. Analysis of PS-2 response data therefore included a qualitative approach alongside a numerical overlay. The purpose being to capture the commonality and the differences of reported features between a population of people living with AHD.

Pillar 2 also used a qualitative questionnaire survey approach to collect specialist surgeons' views on features they associate with AHD presentation. Finally, pillar 3 used an observational method to identify the approach of MSK physiotherapists to the diagnostic assessment of patients reporting a hip problem. This aimed to identify whether opportunities existed for intervening in and supporting practice, to strengthen diagnostic recognition of AHD.

The results of all three pillars of investigation are presented in Chapter 6 which follows. A synthesis of these results is then discussed in Chapter 7 where recommendations for practice, future research and study limitations are detailed.

## 6 Results

### 6.1 Introduction

This chapter presents the results of the study and is organised as follows: First I explain the results of the two Pillar 1 surveys used to initially explore and then probe the experiences of people living with hip dysplasia. Second, I detail the results of the Pillar 2 investigation, in which I surveyed surgeons to establish the features of patient presentation that these specialists in hip dysplasia surgery use to identify the condition in the context of surgical decisions. Finally, I describe the results of observing MSK physiotherapists as they conduct their initial assessment of young adult patients with hip problems. This was done to establish whether opportunities exist during these assessments, to improve recognition of hip dysplasia by applying the overall findings generated by this PhD study.

The presentation of these results is supported by respondents' direct quotations which also serve to illustrate and substantiate the interpretation of data. For the purposes of being concise and succinct, respondents' quotations are occasionally shortened as indicated using the expression [...]. The parts of the statements that have been removed were not thought to add anything to the content and meaning of the quotation and in every other respect, quotations are directly taken from respondents' original responses, therefore the examples of survey responses contain errors of spelling and grammar that remain untouched and uncorrected. For each pillar of study, the following method is used to maintain participants' anonymity. The results of Pillar 1 use fictitious names when referring to PS-1 respondents and to avoid confusion between the two pillar 1 surveys, when referring to PS-2 data, the respondent identifier is a numerical code. For Pillar 2, surgeons' names are replaced with a numerical code followed by the letter s to represent 'surgeon' (e.g., 110s). Pillar 3 participants and their patients are identified using coded letters and numbers.

### 6.2 PILLAR 1: Surveys of People Living with Hip Dysplasia

In this section I report on the results of the two patient surveys that were conducted via questionnaires. The objective of this pillar of study was to collect evidence on the features, signs and symptoms reported by people (patients) with AHD, and that they consider most important in their experience of living with the condition. I anticipated that this might enable currently undetermined diagnostic 'clues' to be uncovered. The initial exploratory survey (PS-1) also allowed me to attune to the language used by patients when they describe their hip problems, which was important because asking people to answer questions about their condition, parallels what patients are required to do during clinical assessment.

The use of a qualitative questionnaire method enabled those suffering from AHD to provide a commentary on their lived experiences of the condition, potentially revealing previously unrecognised clinically relevant features of the condition. The rich data collected via this exploratory first survey (PS-1), raised further questions that a second survey (PS-2) then built on.

### 6.3 Patient-Survey-1 (PS-1)

#### 6.3.1 Demographics

One hundred and three people responded to PS-1. Their ages ranged between 13 and 61 years (mean age = 36.7 years; mode = 34 years; median = 34 years). Details of age groupings, gender and nationality are presented in Table 27 below.

*Table 27. Patient Demographics*

<b>Current Age Groupings</b>	<b>No's</b>	<b>Gender (at birth)</b>	<b>No's</b>	<b>Country of Residence</b>	<b>No's</b>
Teens	8	Female (total from all age groups)	101	UK	75
20's	18			USA	20
30's	38			Canada	4
40's	21			Australia	2
50's	16	Male (both in 50's)	2	Honduras	1
60's	4			Slovenia	1

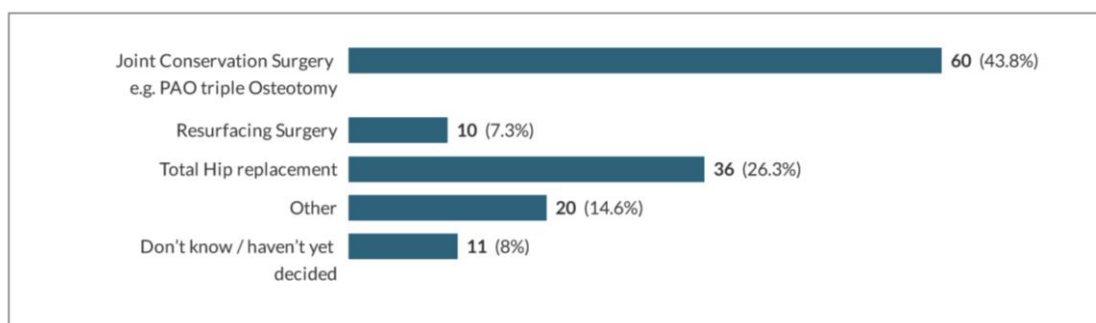
The gender distribution showed that 100 respondents were female, just 2 were male and 1 respondent was born female and is now male transgender. The high ratio of female to male respondents reflects the general incidence of AHD and infant DDH. Indeed, being female is considered a known risk factor for hip dysplasia (de Hundt et al 2012).

The treatment status of respondents was that 36 (35%) were over 12 months post-surgery, 15 (14.6%) were less than 12 months post-surgery, 18 (17%) were waiting for surgery and 13 (12.6%) were deciding on treatment options. In addition, a further 21 (20.4%) respondents described having had multiple surgeries or as recovering from recent surgery whilst waiting for or deciding on their next treatment option. For some, this was due to their

need for treatment on both hips indeed of the 103 participants, 70 reported having hip dysplasia bilaterally, with 18 having only left hip involvement and 15 having only right hip involvement.

Of the respondents who had already received surgery, their various procedures are shown in Table 28. As a number of respondents had received more than one surgical procedure and, on both limbs, the table accounts for 137 joint conservation procedures, resurfacing or hip joint replacement surgeries. Twenty ‘other’ procedures were reported that included hip arthroscopy, labral repair, ilio-tibial band release and knee surgery. A further 11 respondents reported being in the process of deciding on their surgery and treatment.

*Table 28. The Reported Surgical Treatment of PS-1 Participants*



Before receiving their AHD diagnosis, almost all participants reported having repeated appointments with a wide range of different clinicians. As well as their GP or physiotherapist, these included Radiologists, Orthopaedic Surgeons (Paediatric, Sports Medicine and Young Adult Hip Orthopaedic Surgeons), Paediatricians, Rheumatologists, Chiropractors, Osteopaths and Podiatrists.

### **6.3.2 Thematic Analysis**

The purpose of this analysis was to identify whether distinctive patterns of characteristics were evident that could provide clinically relevant indicators for the detection or suspicion of AHD. Two respondents chose to respond only to demographic questions, therefore the analysis that follows is of 101 responses.

The data of the respondents who provided the information requested were scrutinised systematically to identify physical and condition-related characteristics. As detailed in the Chapter 5 (Methods), a thematic approach was used, which generated items from the response data that were grouped into themes. To prevent any incorrect interpretation, the analysis included the actual terminology respondents used to describe these itemised characteristics. The volume and richness of the resulting data demanded an organised approach to the analysis, not least because respondents had chosen to provide great detail

on the challenges they had experienced in getting their hip condition recognised and the level of their frustration caused by the seemingly unhelpful responses of the clinicians they had consulted. Therefore, to address the aim of my study, I filtered out the reported physical features from this plethora of interesting and often emotional accounts. Additionally, although responses differed in structure, volume and detail, aspects of content were frequently similar in terms of the nature of what was described and, in the terminology used. Therefore, the number of respondents describing the same feature was recorded.

Mindful of the fact that during diagnostic assessment of patients' problems, clinicians typically ask the patient to describe how their problems began, I wanted to know what respondents described about the initial features of their hip problems. My analysis therefore begins by drawing out the early hip-related issues and any childhood characteristics that respondents described. These are then incorporated into the results of the overall thematic analysis, which follows.

### 6.3.2.1 Initial Experiences of Hip Problems

Before explaining their current problems, respondents were asked to describe their experiences of hip dysplasia by being prompted to detail firstly the earliest memories they had of how and when their hip problems began, and then how these problems developed. Preliminary reading of the data showed that the age at which respondents understood their initial hip problem to begin varied widely, from birth to middle age, hence respondents' accounts were likely to relate to quite different aspects of their life-stage and disease trajectory. Firstly, therefore, these onset ages were grouped (Table 29).

*Table 29. Ages of Initial Indications or First Diagnosis of Hip Problem*

<b>Age at which diagnosis/ initial indications occurred</b>	<b>Number within each age category</b>
Infant (birth- 2 years)	n=41 (x1 male)
Childhood (>2 years – 12 years)	n = 16 (x1 Male; x1 female-to-male transgender)
Teenage (13 years – 19 years)	n = 24
Twenties (20 years – 29 years)	n = 10
Thirties plus (30 years and older)	n = 10
Total	101

Of the 41 patients reporting an infant onset, 7 stated that they had received a diagnosis of actual dislocation, 17 received a diagnosis of DDH and a further 17 reported having indications of undiagnosed hip problems. Apart from the 24 respondents who received an actual diagnosis of infant DDH (dislocation or dysplasia before the age of 2 years), the remainder of the undiagnosed infant group, along with those reporting a later age for first



onset of hip problems, described receiving various diagnoses. These included, most commonly, 'growing pains', but also cartilage or labral damage; stress fracture; early OA; bursitis; back or knee problems and tendinitis. Some described being 'fobbed off' by the clinicians they consulted whilst others were told their hips were normal. Particularly concerning were reports of respondents being told that they were exaggerating their pain, that it was "in their heads"; self-induced; of no concern or that there was no arthritis.

Next, scrutiny of respondents' descriptions of their early signs of a hip problem drew out features that could be organised into seven groupings. Using the terminology of the patients' responses, Table 30 lists these groupings and their content. The groupings include the nature of the reported hip pain, the locations of the pain, factors that respondents reported as triggering the initial pain and other characteristics of both their hip joint and their gait.

Whatever the onset-age of their initial hip problems, whether during infancy or adulthood, respondents were then asked whether they had any childhood memories of hip-related characteristics that they felt were different from other children. Overall, 80% reported something related to their hips that they had been aware of during their childhood. These included characteristics such as hypermobility or increased flexibility (n=24); difficulty sitting cross-legged (n=23) or discomfort with prolonged sitting, standing, walking and running (n=17). Others listed activities that they preferred such as sitting in a 'W' or frog position (n=16), which describes an individual sitting on the floor with knees flexed, the medial surfaces of the knees in contact with the ground and with the bottom positioned between the feet, or activities they found particularly easy, for example doing the splits and gymnastics (n=16). Eleven respondents indicated an association between their early hypermobility or increased flexibility and their ease of doing gymnastics, the splits and/or 'W'- or frog-sitting. It is acknowledged that the accuracy of responses from those reporting past events such as neonatal, infant or childhood characteristics, is reliant upon individuals' memories as well as the quality of information that may have been reported to them by their parents or others. Responses are, however, analogous with taking a patient's history during clinical assessment, when the patient's perception of the history of their condition is normally recorded.

Table 30. Earliest Memories of Hip problems

Pain	Triggers	Hip clicks/locking	Gait	Posture	Hip instability	Miscellaneous Characteristics
<i>Pain Type:</i>	Pregnancy	'Clicky' hips	Trendelenburg or weak hip muscles	Poor posture	'Loose' hips	Hypermobility/very flexible
Sudden, severe	Childbirth	Snapping TFL		Odd, W- or frog-Sitting preferred	Painful 'giving-way' of hips	
Dull or achy	Monthly periods	Locking/sticking/cramping;	In-toeing			Asymmetrical hips
Intermittent	Excessive sport particularly: running; hiking; walking; gymnastics; football; dance; yoga	Position or exercise-related	Out-toeing	Couldn't sit X-legged	Could pop hips in and out at will	Odd leg movement in breaststroke
Twinges/shooting pain			Waddle			
Sciatic			Duck walk	Forward-lean (tight hip flexors)		
<i>Pain Location:</i>			Limp			Dragged leg when crawling
Hip or groin	Sitting					
Knee	Lying					
Back						
Leg tendons						

### 6.3.2.2 Symptom Development

Following questions on early experiences of their hip problems, PS-1 respondents were asked to describe their symptom development up until the point of any surgery they may have had. Participants were only loosely guided by open questions asking them to include features that triggered or aggravated their problems and methods they used to relieve these. They were also asked to describe activities that were particularly easy or noticeably difficult and to describe anything related to their posture and gait that they considered problematic or different from other people. Finally, respondents were asked to account for any other pre-surgery experiences of living with hip dysplasia that they felt were important.

These open questions led to a large volume of complex data and through the process of thematic analysis, I organised data into the following four salient themes that are discussed in subsequent subsections:

Theme 1: Pain

Theme 2: Posture and Gait

Theme 3: Joint Characteristics

Theme 4: Family History

### 6.3.2.3 THEME 1: PAIN

#### PAIN NATURE AND LOCATION

Pain in infancy was reported by respondents who described having undiagnosed infant hip problems. Whilst their young age meant that reports rely on what they were told about their problems, they cite examples of being unsettled as an infant. For instance, according to her mothers' account, Samantha, now aged 34, states,

*"I cried constantly as a baby so my mum took me to the doctors many times. They gave me sedatives to help me sleep".*

Whilst Anna, now 27 years and whose infant pain continued to develop into major hip problems in her early adulthood explains,

*"My mum was born with clicky hip and when I was born I used to cry when having my nappy taken off they took me to the GPs and they didn't say anything and wasn't concerned".*

Respondents' reports of pain during their adolescent or adult onset of hip problems, showed that it was universally the feature that caused them to consult with a doctor or physiotherapist. The reporting of pain indicates that it is the most troublesome feature and that it alone impacted on almost all areas of life, including education, career, participation in social and sporting activities and relationships. Pain also caused some respondents to use a walking aid or even a wheelchair, some from as young as their early twenties.

Most respondents from all age-onset groups described the nature of their pain as intermittent and often unpredictable at the start but developing into a constant pattern over time. Five respondents reported their initial problems to be a sudden onset of pain or initial 'nerve sensations', but commonly the descriptions were of pain beginning as an occasional dull ache that developed into more intense pain occurring with increased frequency and with no obvious cause. For some respondents, the initial pain was reported as being in the knee (n=10) or back (n=11), that was, they report, mostly manageable. For almost all these individuals, it was only when hip pain developed that the impact of the condition became particularly troublesome. There was no obvious consensus regarding the location of hip pain, but more participants described an onset of groin pain (n=27) some with associated buttock pain (n=8), and interestingly, groin pain was reported predominantly from respondents in the teens and adult-onset age groups (n=24). Others describe pain as occurring simply 'in their hip' (n=21), their thigh (n= 6) and the outside of their hip (n=2). A minority described painful shins (n=1) or muscle 'tightness' of their iliotibial band (n=2) or their psoas muscle (n=1). Mostly, however, respondents described their pain as becoming increasingly diffuse around the groin, hip and buttock region.

### **PAIN TRIGGERS AND CHALLENGING ACTIVITIES**

Within the accounts of their AHD experiences, respondents described the activities that triggered their symptoms or that they found more difficult or painful. Responses suggested two differing phases. The first was during childhood and the second occurred at late adolescence or young adulthood. During childhood, the problems predominantly related to difficulties sitting in the cross-legged position that respondents were required to do during their primary school years. Lily, now 18 provides a typical example in her description, stating that she...

*"First started noticing a problem in primary school where I couldn't cross my legs without being in discomfort.... I noticed that sitting cross legged, walking, horse riding and exercise triggered the pain".*

Sitting in this way was often reported as occurring during childhood when typically, school assemblies required pupils to sit cross-legged on the floor. It caused problems for a number of respondents during their primary-school years. Abbi, now aged 32 years states,

*“I could never sit cross legged at school, I used to dread story time at primary school as I found sitting on the floor unbearable. Physical exercise wise I was able to run/swim/play sports .... It wasn't until I looked back did I realise that my hips had not been normal”.*

Similarly, Sue, currently aged 38 years concurs, describing that...

*“I always found sitting in assemblies cross legged was painful and difficulty but never knew why”.*

By contrast, the problematic sitting positions reported in adolescents and adults were associated with deep hip flexion as required when sitting very upright in a chair. Other activities involving deep hip flexion such as squatting, or breaststroke swimming were also listed as being uncomfortably difficult. In her listing of activities that she found difficult, Holly, now aged 37 years provides an example of the activities that others also reported as difficult as she states,

*“...squatting, going from standing up to sitting down on the floor, and getting up again. Also lying on back and bringing my knees into chest. Standing and bringing my hip up further than 90 degrees”.*

Additionally, most accounts showed that the dominant activities that aggravated hip pain were prolonged walking, running, standing or sitting. Car journeys were also listed frequently as being uncomfortable with some reporting that the movements involved in clutch-use were problematic and that because of this, automatic cars were favoured. The prolonged sitting position of car journeys was also an uncomfortable problem for many and there were also reports of difficulties related to getting in and out of the car due to the confined space.

Almost one third of respondents listed shopping trips as being problematic. Most described that the prolonged walking time (often stated as more than a half to 1-hour), a slow, ambling walking pace and the demands of carrying their shopping, stimulated unbearable pain. Almost all mentioned having changed their shopping habits to now having online deliveries. Those who continued with occasional shopping trips had to plan them carefully, avoiding shops with stairs, working out where seating was available for rests and ensuring someone was available to accompany them to carry their purchases.

Those reporting a later onset of adolescent or adult AHD, whether or not preceded by childhood hip problems, could often describe specific activities that appeared to trigger the condition. Typically these included a rapid increase in the intensity of their activities. For instance, training for a marathon or half marathon was mentioned by a number of respondents, as Gemma, now aged 44 years, illustrates,

*“Had complaints of a clicky hip as a teenager (c. 16). Was seen at hospital but nothing was progressed. I am a very active person, enjoy running, and it was only when I was training for a half marathon when groin pain was first experienced”.*

Additionally, ten women reported an association of their hip pain with pregnancy and childbirth. Five respondents reported needing a C-Section because of their hip problems and Sharon explained that,

*“Aged 31 first born childbirth felt like hips were going to dislocate. By second child's birth aged 34 same pain but then my hips became a permanent problem. Had a rough forceps delivery. Had scans etc just a few months later but they missed the problem so was fobbed off.”.*

By contrast, 3 respondents explained how their hips improved post-pregnancy, but each reported rapid deterioration with subsequent pregnancies.

Other triggers of increased hip pain included reports of the cold, damp and/or humid weather that were reported by those whose initial onset occurred during adulthood. Paula, now 58, states, *“I think the weather affects the pain levels”.*

Other similar comments received in this older onset age-group included,

*“Cold, damp weather certainly made me feel it more (I became a field archaeologist, so I experienced plenty of cold, damp weather).” (Shelly, aged 52)*

Additionally, almost all of those reporting the uncomfortable effects of cold, damp weather were in the 41–58-year age group.

Whilst most respondents listed various specific activities that were difficult, 15% of participants stated that ‘all activities’ were challenging, as Shannon, aged 32 demonstrates,

*“I find most activities painful or uncomfortable, ...I can't walk without at least a crutch now and that is still difficult and painful”.*

## PAIN RELIEVERS

Medication was commonly used to relieve pain, with some respondents using potentially addictive drugs including cannabis, and strong opioids such as morphine and codeine. Less potent medication also appeared to be used but often in high doses and in various combinations. A number of respondents stated that various analgesics had been tried but with no or insufficient effect.

Rest was a commonly listed reliever of pain, though most respondents commented that too much rest also caused problems. Alex, now 31 years old explains how she managed her pain with,

*“Rest for some short periods of time and moving after long periods of rest”.*

Similarly, Carys (now aged 32 years) explains how, *“Resting between exercise helps”*. Interestingly regarding running, she goes on to explain how,

*“I know my hips more and know to take it easy between exercise sessions. Avoid long walks. Seem to affect me more than short runs maybe due to muscles not activating”.*

Whilst these strategies offered some temporary pain relief, some respondents clearly state that nothing at all helped; only surgery lessened, removed or changed the pain. Jean (now 51 years) confirms,

*“Tylenol and ice helped some. Sitting down and not moving was my best option. Before my THR nothing really helped”.*

Paula (58) agrees stating that her pain management involved,

*“pain killers warmth and rest and finally THR of both hips”*

Others detailed how their pain management involved considerable planning. Janet, aged 13 years, explains how,

*“...I have to factor it [hip dysplasia] into everything I do - school where I have to always have a chair which can be embarrassing when everyone is on the floor, and limited PE as contact sports and running/jumping cause me issues so I can't partake and teachers often don't know what to do with me instead - swimming, I am passionate about this and swim competitively but cannot train the same as everyone else as my left side tires easily - meeting friends/family days out always have to be planned with lots of rest opportunities or kept short otherwise I am in too much pain at present”.*

Similarly, Fifi states how,

*“Without realising you are doing it. you alter everything you do. I haven't been able to wear any shoes with a heel for years now, even a small heel. I plan journeys round shops, I think about where I can park and how much I can do in a day”*

Overall, respondents provided a clear picture of the considerable planning they applied to organising their lives around managing their pain. Potent, addictive medication or high doses and combinations of over-the-counter analgesia were used by some, whereas others found no benefit in their use. Several respondents also mentioned using brief periods of rest with heat or ice, in the management of their pain.

#### **6.3.2.4 THEME 2: POSTURE AND GAIT**

Postural abnormalities were reported by only 20 respondents. These abnormalities were due to back pain, scoliosis and lordosis with several specifically reporting a postural asymmetry.

A greater number of respondents believed they had changes to their gait (n=79) but not all of these provided details of how their gait had actually changed. A limp at some stage of their pre-surgery AHD experience was described by 44% of those reporting an abnormality and 15% reported an asymmetrical gait. Other gait difficulties were described by 15% as 'awkward' or as a waddle, hobble, stumble, shuffle or duck walk and 9 respondents described their gait as forward-leaning often, they commented, because of tight hip flexors. Altered gait was said by 9 respondents to be due to their leg-length difference whilst 24 respondents stated that their problems were due to weak hip muscles or they referred to having a Trendelenburg gait, and four respondents described their reliance on sticks and crutches, 2 of whom were younger than 35 years of age.

#### **6.3.2.5 THEME 3: HIP JOINT CHARACTERISTICS**

A range of similar terms were used to describe hip joint characteristics experienced by respondents. Comparable terms were grouped together and formed 3 distinct features relating to, joint hypermobility, hip instability, which was linked predominantly to the feeling of 'looseness' of the joint, hip dislocation or subluxation, and audible hip joint sounds. The detail on each of these characteristic features follows.



## JOINT HYPERMOBILITY OR HYPER-FLEXIBILITY

This feature was reported by some 25% of respondents who described it by using a variety of terms including 'hypermobility', 'hyper laxity', 'hyper-flexibility' or being 'very flexible'. It is clear from their accounts, that some respondents found their mobile joints initially beneficial in achieving gymnastic abilities or notable 'trick' movements. This was particularly evident in those who reported a pattern of hip problems featuring two onsets: an infant-onset of hip problems, that was followed by some years of problem-free hips, then a subsequent second onset of hip problems in adolescence or young adulthood. These respondents also reported favouring unusual or W-sitting positions during their childhood. Kirsten, for example, who, following diagnosis and treatment for infant DDH was free of hip problems until her mid-teens when she required corrective hip surgery, comments,

*"...I could however sit in some weird positions on the floor which my other classmates could not do (I however thought this was a party trick!!)".*

People reporting such features did not appear to be prevented from involvement in normal activities expected of their age; indeed, some even described themselves as high level athletes. It appears, however, that with the passage of time, participants associated their hypermobility with later hip pain. Gail, now 50 years explained,

*"I am hypermobile and was a competitive gymnast for years. I was able to do all three splits easily, among other things..... My three daughters ... are 20, 17, and 15. I'm sure all three are also hypermobile, and occasionally they have complained of mild, non debilitating hip pain".*

## HIP INSTABILITY

Another feature described by respondents was hip instability, dislocation, subluxation or the sensation of the hip 'popping out of the socket'. Anna now aged 27, describes how, having had her hip reports ignored throughout her childhood, her experience of getting the medical attention she needed involved a specific hip incident, she explains,

*"... Last year both my hips subluxed at work and an ambulance had to come and get me and that's when I was finally taken seriously."*

In another confirmed case of dislocation Janet, now aged 13 years describes how when she was 5, her....

*"... mother was convinced that a limp I had developed in the last few months was something more serious rather than something I would grow out of - xray revealed full dislocation of hip on the left side".*

Instability, sufficient to cause actual hip dislocation, was not unusual in the PS-1 responses and yet there were often reports of delays in its recognition. Sally (aged 18) explains,

*“I started having problems with my hips when I was 12 years old. I sought help for two years before being diagnosed .... I was misdiagnosed with bilateral torn labrums and bilateral impingement..... I actually had two anterior dislocations as a result of severe instability”.*

### **AUDIBLE HIP SOUNDS**

Throughout the respondents' commentaries, were recurring reports of hips producing audible sounds that included 'clunking', 'popping', 'snapping' and clicking. Mostly, these were closely associated with the reports of pain. Although respondents reported the troublesome nature of these symptoms, frequently during diagnostic assessment, they felt that the sounds were ignored, as Sue, now aged 38 years explains,

*“GP fobbed me off, consultant was nice, but wasn't expecting to be told that I had dysplasia now that was a shock. I was fed up of the pain and clicking and popping that's why I went to the GP in the first place”.*

Similarly, Brenda (age 28), states,

*“I noticed my hips clicked, and the amount they were clicking increased around the age of 22. I did not have any hip pain until 2014, at the age of 25.... First my hips would click every so often. Then they began clicking much more often but with no pain still. .... I first made an appointment with my family doctor to ask about my hips clicking. He wasn't concerned and said it was probably nothing”.*

The proportion of respondents who experienced these hip sounds was difficult to establish partly because of the range of terms used to describe the feature and because of the close association described by some respondents of hip sounds and pain. This made it unclear whether what they felt was actually what they could hear.

These findings of joint hypermobility, hip instability and audible hip sounds were highlighted as areas of particular concern by some, notably, and unsurprisingly, where they were associated with pain.

### **6.3.2.6 THEME 4: FAMILY HISTORY**

A recurrent issue in the data was a sense amongst the respondents that some understood hip dysplasia to have a familial association.

Sandra's comment illustrates her family concerns by explaining,

*"My younger sister is now experiencing worryingly similar symptoms to me and has been told her XR is 'clear'. I am now fighting for her for a second opinion given my own history".*

In struggling to gain her diagnosis, Fifi, who refers to infant DDH as congenital CDH, explains how,

*"I went many times to the Doctors with pain in my leg/hip/knee/groin but despite my eldest son having bilateral congenital CDH, it was never suspected with me. Eventually, after my 4th son also was born with one dislocated hip, I asked for my hips to be x-rayed."*

In addition, Freya states inherited-based fears that reflect those of several other respondents, stating,

*"I made sure our children were extensively tested for DDH as babies and young children, and, for my daughter in her teens, when she got hip pain. Both were OK, thankfully, but there is always that niggling anxiety in the back of your mind about whether you've passed anything on to your children".*

It is possible that these results represent a general understanding amongst those with AHD, of familial patterns increasing the risk of the condition. It is a useful finding as it draws attention to the potential diagnostic value of patients' perception of their condition and the information they volunteer.

### **6.3.3 PS-1 Results Summary**

In summary, thematic analysis of PS-1 drew together respondents' experiences of the features they associated with their AHD. Amongst these descriptions were similarities in some of the reported features. It was unclear however, whether the features described by some respondents were experienced by others who did not think to mention them. In addition, reported features generally lacked clarity in the description provided by respondents and often certain features were only vaguely mentioned. Pain, for instance, described by many as a major problem, was accounted for using descriptors that varied in terms of its nature and development, its triggers or aggravators. Similarly, whilst some 80% of respondents referred to alterations of their posture and gait, few commented on the detail

of how the changes presented. It was also unclear how the reported features developed over time and whether the earliest memories that respondents listed were features that they described at their initial clinical assessment. Additionally, although detail was lacking in their accounts, some respondents clearly associated their hip dysplasia with the occurrence or risk of the condition within their family. This dovetails with limited evidence in the literature. A positive family history can be a useful indicator for diagnostic assessment, but it seems that more needs to be understood about whether respondents have or would be likely to know about the possible history of family members regarding their experiences of hip conditions. Asking respondents directly whether they are aware of family members with similar hip problems might begin to answer this.

I wanted to probe such features further to see if common patterns could be determined between hip dysplasia sufferers because this could clarify more specifically, how hip dysplasia presents. For this reason, I developed a second survey to further investigate questions arising from PS-1 analysis. This second survey, PS-2, provided the opportunity to enquire whether respondents could describe what they reported initially to clinicians about their hip problems. It also provided the opportunity to address other questions that arose from PS-1 data analysis. These are listed in Table 31 below, which also indicates how PS-2 developed. This second survey was therefore more targeted than the first with the purpose of gaining greater clarification of issues raised by PS-1.

*Table 31. Key Findings of PS-1 that Informed PS-2 Development*

PS-1 Findings	Queries carried through to PS-2
Earliest memories of hip problems	Were these early problems described during respondents' first clinical assessment?
Theme 1: Pain	Is there agreement between AHD sufferers on the nature, triggers or aggravators and relievers of AHD pain?
Theme 2: Posture and Gait	How many respondents associate their AHD with abnormalities in their posture and gait and how many respondents agree with the terms used to describe these abnormalities?
Theme 3: Joint Characteristics of Hypermobility, Hip Instability and Audible Hip Sounds	Is it possible to determine the regularity of occurrence of these joint characteristics in people with AHD?
Theme 4: Family History	What proportion of AHD sufferers are aware of family members with hip problems, and could they state which family members had such problems?

## **6.4 Patient Survey-2 (PS-2)**

The clinical features elicited by PS-1 and organised into themes provided insight into a range of characteristics that might be associated with AHD. Some were described clearly and were seen to occur repeatedly by many respondents. Others required further investigation to establish firstly, whether various terms used by different PS-1 respondents, related to the same feature, and secondly, how commonly features occurred in patients with AHD. This was important because the study aimed to identify 'typical' as well as divergent features that characterise AHD. Further probing of reported features enabled more detail to be collected that contributed to building greater understanding of each theme item. Therefore, based on characteristics reported by PS-1 respondents and using a more directed approach, a second survey, PS-2, aimed to extend the findings of PS-1.

PS-2 was posted for 1-week on the same 4 patient-support fora as PS-1. Sixty-seven people responded and of these, 6 respondents had also participated in PS-1. Sixty-four of the PS-2 respondents were themselves hip dysplasia sufferers and 3 were mothers of infants with the condition who were included because they provided real-time data on their daughters' symptoms and experiences.

### **6.4.1 Demographics**

The current age range, age at diagnosis and country of origin of all PS-2 respondents, are detailed in Table 32. This shows that 65 respondents were female, and 2 respondents were male.

The current age range was greater across PS-2 respondents compared with PS-1 (infant – 60 years compared with PS-1 age range of 13-61 years) with a smaller proportion of respondents reporting initial diagnosis or indications of hip problems during infancy or childhood in PS-2 (39%) compared with those of PS-1 (55%).

Table 32. PS-2 Demographic Data

Current Age Groupings	No's	Gender (at birth)	No's	Country of Residence	No's	Age at initial diagnosis	No's
Infant	1	Female	65	Unknown	23	Infants	19
Children	2			USA	6	Childhood	7
Teens	2			England	24	Teens	2
Twenties	11			Wales	3	20's	10
Thirties	25	Male	2	Ireland	2	30's	29
Forties	19			Scotland	1		
Fifties	7			'UK'	8		

Treatment already received by respondents included osteotomy, resurfacing, labral repair, arthroscopy, joint replacement and joint revision surgery, pain medication, physiotherapy, hip spica, hip cast and hip-joint injection.

The treatment status for respondents' right and/or left hips is listed in Table 33.

Table 33. Treatment Status of PS-2 Respondents

Treatment Status	Left Hip (number)	Right Hip (number)
Deciding on treatment options	18	17
Waiting for surgery	10	13
Up to 12 months post-surgery	8	7
More than 12 months post-surgery	16	16

In line with PS-1 results, PS-2 respondents also reported having repeated appointments with their GP or physiotherapist when their hip problems began and that they consulted, sometimes repeatedly, with a similar range of other clinicians as those listed by PS-1 respondents. In addition, one PS-2 respondent reported being referred to a spinal specialist,

and one to a pain management team. There were also several reports of referrals to Gynaecology and 3 respondents who sought help from Health Visitors.

## **6.4.2 Data Analysis**

### **6.4.2.1 Problems Reported at Initial Clinical Assessment**

To begin PS-2, respondents were asked to describe what they reported to clinicians at their initial clinical consultation when they first sought help for their hip problem. Sixty-four respondents provided comments on what they recollected about their initial clinical assessment and a further 3 stated that they were too young to know what was reported at this early stage. Of the 64, most described the nature of their early symptoms in terms of both signs and painful symptoms (Table 34). These included a limp or abnormal gait (14%), which for some was during childhood; a leg length difference, knees turning inwards or a 'twisted leg', tired or weak legs and poor mobility. Hip clicks, clunks, popping or locking were said to be evident by 16% of respondents; hip instability that ranged from a feeling of instability or subluxation through to recurring hip dislocation was reported by 12.5% and a further 12.5% described muscular weakness, legs giving way and recurrent falls.

Those reporting an initial assessment during infancy or childhood described their delay in achieving walking milestones and of dragging their leg when crawling. Respondents described their early pain in a variety of ways that included a gnawing, grinding, aching, catching, locking, pinching, sharp, shooting or stabbing pain. The anatomical location that most respondents remembered this early or initial pain being was vaguely in the hip region, although 25% specified pain in the groin and others reported that initial pain was in their knee, low back and legs.

Initial aggravating factors were commonly reported as being prolonged walking (22%) but prolonged standing and sitting (including driving) were also listed. Pain triggered by running was reported by just 6% but any physical activity, including Pilates, flexing hip, and descending stairs, was also listed as triggers for respondents' early hip problems. Early signs and symptoms that were reported at respondents' initial clinical assessment are summarised in Table 34.

Table 34. Signs and Symptoms reported at Initial Clinical Assessment

Signs	Limp/abnormal gait	Leg length difference	Poor mobility
	Rotated legs	Hip clunks/clicks/popping	Hip instability
Symptoms	Pain (type):	Pain (location):	Aggravating factors
	<ul style="list-style-type: none"> <li>• Gnawing</li> <li>• Grinding</li> <li>• Aching</li> <li>• Catching/pinching</li> <li>• Shooting</li> <li>• Stabbing/ sharp</li> </ul>	<ul style="list-style-type: none"> <li>• Groin</li> <li>• Hip region</li> <li>• Knee</li> <li>• Low back</li> <li>• Legs</li> </ul>	<ul style="list-style-type: none"> <li>Prolonged walking</li> <li>Prolonged standing</li> <li>Prolonged sitting</li> <li>Running</li> <li>Physical activity</li> </ul>

The content of these responses is useful because it begins to build a picture of the early clinical presentation of patients with AHD and the initial hip issues they experienced, which provides insight into the history of the condition in these patients. The features reported also reinforce the findings of PS-1, but it is interesting to note that PS-2 respondents did not report mentioning features at their initial assessment such as hypermobility, difficulty with cross-legged sitting and a preference for W-sitting that PS-1 respondents had considered early features associated with their hip dysplasia. It is unclear whether this was because, at the stage of initial assessment, respondents were not aware of such features or whether clinicians' questioning at assessment did not provide the opportunity to report them.

#### 6.4.2.2 Symptom Development

#### 6.4.2.3 THEME 1: PAIN IN AHD

PS-1 results identified that pain was the most reported and troublesome feature of AHD but the exploratory and open design of PS-1 questions, resulted in widely varied descriptions. Whilst this generated rich detail of factors that respondents thought to include, the varying account styles and the different terms used to explain these accounts created an uncertainty about possible similarities of pain characteristics between AHD sufferers. PS-2 therefore presented more focused questions to determine details of the nature of the pain, its development, aggravators and relievers.



## Nature and development of pain

Beyond the features reported at initial assessment, PS-2 results showed that most respondents (81%) described how over time, hip pain that had started as a mild ‘niggle’, developed over time to intense pain and similarly, that pain changed from an occasional discomfort to a constant, debilitating problem (78%). Anna, now 34 years old explains,

*“I feel like the pain in my hip accelerated very quickly, from an annoying [s]hearing pain initially to a debilitating constant pain that was impacting on every day life. In the space of a few months my pain really intensified”.*

This reinforced the findings of PS-1 in which a similar development of pain was described. It confirmed the commonality of the experience of pain progression over time. As well as experiencing progressive pain, 67% also described suffering sudden, severe episodes of pain. Respondents additionally related to their pain in terms of abnormal sensations, describing how their responses to touch were disproportionately sensitive to the amount of pressure placed on the area. More than 30% identified that their hip often felt hot and almost 35% of respondents considered their hip to feel swollen. Some 72% of respondents agreed that they would describe the muscles around their hip as being uncomfortably tight. The characteristics of pain described by PS-1 and the further detail added through PS-2 results are summarised in Table 35.

*Table 35. Summary of Pain Characteristics identified in PS-1 and PS-2*

PS-1 Indicator	PS-2 Confirmation of symptom presence	PS-2 Additional Detail
Pain progression	Development from an occasional mild ‘niggle’ to constant, intense discomfort	Episodes of sudden, severe pain Disproportionate sensitivity to pressure on hip region Hip may become hot and swollen Muscles in hip region may become uncomfortably tight.

## Aggravating factors of pain

PS-1 responses included repeated reports of several characteristics of movement-related factors that respondents either found difficult to do or that aggravated their hip pain. These were investigated further in PS-2 to identify whether others had experienced such features

but had not thought to mention them. Through doing so, the finding from PS-1 that, during childhood, respondents found it difficult or were unable to sit cross-legged, was reinforced by PS-2 results. Almost half of PS-2 respondents (n=30) expressed problems with sitting cross-legged. Whilst this may not be a posture that many adults would relate to, young school-aged children are often required to sit cross-legged for prolonged periods during storytelling and school assemblies for instance. Paralleling the findings of PS-1, respondent 47's statement illustrates other's comments evident in PS-2, as she states,

*"I could never sit cross-legged and was given special permission to sit how I wanted (with legs in a W)."*

It was notable that PS-2 analysis goes on to show that the same number of respondents who reported an inability or discomfort in sitting cross-legged during childhood equates to the number reporting that although they had hip pain as a child, the problems were not a major issue until some years later (n=30). Indeed, the indications are that more problematic, persistent pain appears to begin well after childhood, with most respondents describing a reprieve from hip problems between their early or initial signs of hip issues and a later adolescent or young adult onset.

PS-2 questions asked respondents to be specific about physical activities that had been mentioned in various forms throughout the PS-1 responses. By drawing on the terminology used in the PS-1 responses, PS-2 questions provided the opportunity of checking whether these different terms had been correctly interpreted and, in some instances, whether they had been used to describe similar features, adding confidence to the accuracy of reported features. Doing so confirmed that factors that aggravated respondents' pain included prolonged standing (77%), prolonged sitting including long car journeys (73%) and prolonged walking (76%). These results serve only to confirm PS-1 findings but additionally, PS-2 findings showed that fewer respondents (61%) reported running as an aggravating factor compared with walking (76%), particularly in the early stages of the condition.

A small number of PS-1 respondents drew attention to the fact that their pain increased during cold, damp weather. The majority of those who did so were aged between 41 and 58 years. PS-2 respondents were asked directly about this to identify whether others related to the feature and whether those who did were also in the older age group. Of all the PS-2 respondents, 61% agreed that cold, damp weather worsened their pain symptoms but there was no consistent pattern of this being limited to the older age-group.

Other features considered to be triggers of hip pain that were evident in PS-1 responses, received further validation by the level of agreement recorded in the PS-2 results. The

majority of PS-2 respondents (84%) confirmed that exercise or 'over-use' increased their hip pain, with turning, twisting, pivoting or cutting manoeuvres causing problems for 78%. Additionally, lifting and carrying worsened pain for 60%, with ascending and descending stairs painful for 63% and 46% respectively. However, it was noted that a smaller proportion (30%) agreed that too little exercise was also a problem. It was clear from PS-1 results that prolonged sitting was considered a trigger of pain by many respondents, some of whom associated the problem with car journeys and the related difficulties of getting in and out of the car due to the confined space. PS-2 results confirmed that car journeys were a common issue as almost 75% of respondents agreed that the deep hip flexion and confined position of sitting in a car seat aggravated their hip problems.

A small number of PS-1 respondents indicated that swimming was problematic, reporting only that the pain it caused led to them giving it up, whilst others referred to their use of swimming as a reliever of their pain. PS-2 respondents were asked directly about the effects of swimming and, whilst the majority stated that the question was not relevant, presumably because they were not active swimmers, 14 reported that swimming helped in the management of their pain. However, a further 14 stated that they had stopped swimming because of the hip pain it caused.

Finally, because a number of PS-1 respondents had referred to childbirth or pregnancy as aggravating their hip pain, questions relating to these events were asked explicitly in PS-2. The result being that 30% of respondents agreed that pregnancy irritated their hip pain. One-third of these respondents also agreed that childbirth caused further problems with their hips. This reflects a high proportion of respondents given that almost 50% of respondents declared the question not to be relevant.

Pain triggers and difficult activities reported by PS-1 respondents are listed in Table 36 alongside a summary of the related PS-2 findings that serve to expand on the detail of these features and their occurrence amongst this population of AHD sufferers.

Table 36. Summary of PS-1 and PS-2 Reported Pain Triggers/Aggravators

PS-1 Indicator	PS-2 Confirmation of agreement and additional detail
Childhood difficulties of sitting cross-legged	Confirmed by those reporting childhood characteristics. For these, hip pain was not a major issue until late adolescence/adulthood
<b>Adolescent/Adult Pain Triggers:</b>	
Increased training intensity	Exercise/over-use confirmed as a trigger of hip problems
Pregnancy/childbirth	Pregnancy/childbirth as a trigger of hip problems confirmed by more than 50% of PS-2 respondents for whom it was relevant
Prolonged walking	Agreement demonstrated; Approximately $\frac{3}{4}$ of PS-2 respondents stated that walking, running, standing and sitting triggered hip pain.
Running	
Standing	
Sitting	
Car journeys	75% agreed that confined space and deep hip flexion of car seating aggravated hip problems
Clutch Use	
Getting in/out of car	
Sitting & moving in confined space	
Activities involving deep hip flexion	
Swimming	Swimming shown to be equally an aggravator of pain and a pain reliever
Cold, damp weather	Weather confirmed to be a common trigger for increased hip problems in PS-2 respondents. No apparent association with age

#### Pain Management

Some of the PS-1 respondents had listed powerful, addictive drugs that they used to relieve their pain. I therefore used PS-2 to understand more about the popularity of using medication in the management of AHD pain. Responses to PS-2 questions on medication usage strengthened the findings of PS-1. More than 65% of PS-2 respondents relied on medication, 36% of whom used opiates. Prescription and over-the-counter anti-inflammatory, analgesic and antidepressant drugs were also used but the notable factor was the combinations of medication that respondents used. Respondent 2 for instance, listed

having “Zomorph (slow-release morphine) Naproxen [and] Steroid injections” and respondent 12 listed “Naproxen, codeine, paracetamol, CBD”, which combines a medical form of marijuana with other opiates and anti-inflammatories. Others combined anti-depressants, commonly used for nerve pain, with anti-inflammatory medication.

In addition to medication, indications from PS-1 responses showed that the use of thermal methods was popular for pain management. Closer questioning showed that the application of heat and taking a hot bath was favoured by almost three-quarters of PS-2 respondents whereas fewer than one-third preferred to apply ice.

In their accounts of additional methods used to manage pain, whilst almost 20% stated that they favoured exercise, the majority of PS-2 respondents showed that the most commonly used approach was to rest (83%). For this, descriptions were given about the form of rest. Lying down was used by 70% and for those who agreed that sitting helped (25%), they were quite specific about the position required to provide relief. This mostly involved reducing hip flexion angle by sitting in a reclined or slouched position, as respondent 57 explains,

*“The only position in which I am moderately comfortable is lying down in bed or semi reclined in my recliner armchair”.*

Throughout PS-1 responses were indications that respondents used a considerable amount of planning to manage their pain. For some, that involved factoring in regular rest periods when exercising. Others described the need to plan their shopping trips in order to divide prolonged activities into manageable phases of walking and resting. The responses to direct questioning on this in PS-2 provided further insight into the importance to respondents of planning their activities. More than two-thirds of PS-2 respondents stated that their hip problem had a big effect on their social life, agreeing that only by planning could they be involved in activities. Planning involved ensuring that, wherever they were, they would have the opportunity to rest or to alter their position. Indeed, one-third of respondents stated that they were frightened to go out unless they could be guaranteed a seat. Planning this could be difficult and respondents stated that often it was easier to stay in and not take part. Alternatively, many respondents described how they were able to adapt activities in order to manage their hip pain. Respondent 18 for instance described how,

*“ The biggest adaptation I’ve had to make is to ensure I have an aisle seat when I got to a movie, concert, or play. I’ve also started taking planes whenever I travel, even if the bus is an option, because sitting for too long is painful”.*

Similarly Respondent 36 explained,

*“I have had to modify what I do, at what speed and how long for at work. I have to carefully select the type of bike I use to commute or use the train so I can take movement breaks”.*

For many, however, adaptations were not sufficient and their much-loved activities such as sport, dance, gardening and for some, even their education and career were severely impacted.

Table 37 provides a summary of the methods of pain management used by PS-1 and PS-2 respondents.

*Table 37. Summary of PS-1 and PS-2 Pain Management Methods*

PS-1 Pain Management Method	PS-2 Confirmation of agreement and additional detail
Medication	Commonly used combinations of opiates, anti-inflammatory, anti-depressant and steroid medication used to manage pain.
Thermal aids	Heat or hot baths used by approximately 75% Ice used by approximately 33%
Rest	Rest was confirmed as being one of the most popular methods for managing pain with most describing specifically a reclined sitting position or lying.
Activity modification (shopping)	Social activities that included shopping trips require considerable planning. Respondents emphasised the importance of planning (eg, breaks, seating, help to avoid lifting and carrying) when having to carry out these prolonged activities  Reduced participation or activity adaptations evident

#### Additional Pain-Related Comments

In response to the final questions of PS-2 that asked respondents to describe aspects of their AHD experiences that they felt important for clinicians to know, responses drew attention to the need for clinicians to understand the level of pain caused by hip dysplasia. Clearly the feeling amongst many was that this is neglected. As respondent 41 implores, *“Take me seriously when I say I'm in extreme pain”*. Such feelings are reiterated by others including respondent 14 who described her,

*“....struggle to be taken seriously by my GP resulting in being treated as though my hip dysplasia is a psychological manifestation.”*

Attention is also drawn to the emphasis respondents put on what they felt was an oversight to associate referred pain with their hip problems. Respondent 6 states that, "*Knee pain in adolescence could be related to the hip and not just knee*" she feels that her "*Chronic knee and lower leg pain as an adolescent that didn't respond to treatment*" was ignored by clinicians. In addition, respondent 7 reports that,

*"I had various problems with my hips knees and shins as a runner in my teenage years and always seemed to be told it was a pulled muscle or poor posture, on no occasion were further investigations carried out".*

#### **6.4.2.4 THEME 2: POSTURE AND GAIT**

PS-1 analysis showed that approximately 20% of respondents commented on their postural difficulties and more than 75% described the presence of gait abnormalities. I wanted to know whether others with AHD may also have experienced these problems but not thought to describe them. Through PS-2 questions, I aimed to verify how commonly postural and gait abnormalities were experienced in people with AHD because if such abnormalities were shown to occur commonly in this population, they could contribute to the characterisation of AHD presentation. To do this, I asked PS-2 respondents to express their level of agreement with characteristic descriptors of their gait and posture, using the terminology evident in PS-1 responses. Through this, the occurrence of postural changes was reported by most PS-2 respondents. Specifically, 72% of respondents agreed that their poor posture caused them to have back pain; 38% agreed that their altered posture included having an increased lumbar lordosis and 69% identified postural asymmetry, agreeing that they favoured one side when sitting. Comments associated with asymmetry and that respondents added, emphasised their avoidance of prolonged sitting and their discomfort when standing still. They described how, when they had to maintain these positions, some would fidget, put weight on one side or lean against a wall, whilst others described slouch-sitting or favouring a foot-raised position. They commented that these altered postures enabled them to take the pressure off their painful hip.

Most respondents agreed that their gait had noticeable changes, with 88% reporting a limp. Whilst pain and possible muscle weakness were likely to be the cause of a limp, 50% of respondents stated that they had a leg length difference that logically, may have resulted in a limp. Gait changes also included 77% who described having a waddle, hobble, shuffle or rolling gait and 64% saying that they walked with short, uneven steps. Fifty-nine percent also agreed that their pelvis dropped on one side when walking whereas a fewer number, less than 50%, listed recurrent falls and stumbling; a tendency to lean forwards because of tight hip flexors; thighs and knees feeling too close when running; toes turning inwards when

walking and inwardly rotated knees as being additional features of their gait. Table 38 provides a summary of these results.

*Table 38. Summary of Posture and Gait Characteristics*

PS-1 Posture and Gait Findings	PS-2 Confirmation of agreement and details of characteristics	Proportion of agreement
<u>Posture</u>	Poor posture causing back pain	72%
Reference to postural difficulties expressed but with limited if any description	Postural Asymmetry	69%
Reference to changes in gait	Walk with limp	88%
	Short, uneven steps	64%
	Waddle, hobble, shuffle or roll when walking	77%
	Pelvis drops on one side	59%
	Recurrently fall/stumble	47%
	Lean forward because of tight hip flexors	38%
	Thighs and knees too close when running	34%
	Toes turn in when walking;	23%
	Knees rotate inwards	34%

#### 6.4.2.5 THEME 3: JOINT CHARACTERISTICS

PS-1 highlighted that joint hypermobility, hip instability and audible hip sounds were features that many respondents related to their hip dysplasia experience. As with posture and gait, these are features of particular interest as they can be evaluated during physiotherapy assessment. Within the AHD sample population, the regularity of these features' occurrence was therefore recognised as being useful to explore in order to estimate the strength of their association with AHD clinical presentation.



### Hypermobility, Hyper-flexibility or Being Very Flexible

PS-1 showed that some 25% of respondents thought to include a description of their hypermobility as part of their AHD experience. Whilst some comments described benefits of this feature during childhood or adolescence in terms of, for instance, gaining their gymnastic ability, others linked hypermobility with their hip problems later in life. PS-2 drew on these findings and, by asking directly whether respondents considered themselves to be hypermobile or very flexible, insight was gained into the actual proportion of the AHD sufferers who might have the characteristic.

PS-2 data showed that 52% considered themselves to have very flexible or hypermobile joints. In relating to their hypermobility, 13 respondents described how, as children they could do box splits and side-to-side splits with ease, and their responses included examples of their abnormally wide joint range of movement. Closely linked with descriptions of their hypermobility were explanations of respondents' joint instability. Indeed, 10 respondents stated that, as a child or adolescent, they could make their hips dislocate at will. For example, in referring to her hypermobility, respondent 14 describes....,

*“Rotating my hips to make my feet face backwards. Ballet positions were always incredibly easy for me due to my ability to over rotate my hips outward, however painful”.*

In addition, respondent 47 explains how she happily,

*“... sat with my knees rotated inwards and my feet pointing outwards in a classic "W" shape. For my party trick I used to continue the rotation around, taking my left knee even further inwards and downwards, until my entire leg rotated and I could put my big toe in my mouth! (Yuk!) I now realise I was probably dislocating my hip each time I did it... I could do this until I was about 14 or so”.*

These features indicate considerable flexibility and with the high proportion of respondents describing themselves as being hyper-flexible, hypermobile, loose-jointed or double-jointed, the characteristic does appear to have a common association with AHD. Additionally, there were indications in the PS-2 responses that some related their hypermobility to hip joint instability and the following subsection discusses this further. Table 36 provides a summary of the PS-1 and PS-2 findings related to hypermobility.

*Table 39. Summary of Hypermobility reported in PS-1 and PS-2*

PS-1 Joint Characteristic	PS-2 Confirmation of agreement and details of characteristics	Proportion of agreement
Hypermobile or very flexible	Hypermobile, hyperflexible or very flexible	52%
	Hypermobility associated with gymnastic ability and ease of doing splits	20%
	Hypermobility linked with joint instability	15%

#### Hip Joint Instability

PS-1 respondents highlighted that hip instability, dislocation, subluxation or the sensation of the hip ‘popping out of the socket’ were areas of particular concern and were often associated with pain. To establish whether others experienced such features, the query was carried forward into PS-2.

Levels of agreement were used to identify the regularity of features that indicate joint instability and that respondents associated with their AHD. Most commonly, PS-2 respondents agreed that their hips felt unstable (77%) with 41% feeling that their hips repeatedly dislocated, subluxed, or moved out of the socket. Sixty-one percent also considered their hip region to look out of alignment.

Table 40 provides a summary of these findings.

*Table 40. Summary of Hip instability reported in PS-1 and PS-2*

PS-1 Joint Characteristic	PS-2 Confirmation of agreement and details of characteristics	Proportion of agreement
Hip instability	Hip instability	77%
	Repeated feeling of hip dislocation or subluxation	41%
	Hip appears out of alignment	61%

#### Audible Hip Sounds

It was evident in PS-1 results that audible hip sounds, which included ‘clunking’, ‘popping’, and clicking were frequently reported. Further support for a potential link between these sounds and AHD presence, is seen in PS-2 results in which almost all respondents agreed that audible hip sounds associated with their AHD were evident. Some 91% indicated that their hips clicked, cracked, clunked or locked. In addition, 38% of respondents reported that

as a child or adolescent, they were able to make their hips clunk, pop or click at will. In Respondent 14's description, below, it is clear how troubling the joint popping and clunking were and also the description shows how such symptoms are typically grouped together by respondents,

*“ As a baby and through to age 13, pain, leg length, popping, clunking and dislocation were all ignored, at 33 these and my mobility deterioration and deterioration of quality of life have been grossly ignored at many levels of care.”*

Table 41 provides a summary of the findings on the joint characteristic of audible hip sounds.

*Table 41. Summary of Audible Hip Sounds reported in PS-1 and PS-2*

<b>PS-1 Hip Joint Characteristic</b>	<b>PS-2 Confirmation of agreement and details of characteristics</b>	<b>Proportion of agreement</b>
Hip joint clunks, pops or clicks	Click, crack, clunk, lock	91%
	As child/adolescent could make hips clunk, pop or click at will	38%

#### **6.4.2.6 THEME 4: FAMILY HISTORY**

A small number of PS-1 responses referred to having family members who either had a history of diagnosed hip problems or who were planning to have diagnostic tests for hip dysplasia because of their concerns over an apparent familial pattern of hip problems. As with various other features highlighted in PS-1 results, I felt further investigation of family patterns of hip conditions was warranted because, if direct questioning could identify more details of familial links, the feature could provide a useful indicator for alerting clinicians to the possible presence of AHD. PS-2 respondents were therefore asked to provide information about any relatives who were known to have had hip problems. In response, although one respondent stated that she was adopted and had no information about her birth family, more than 48% named between 1 and 7 relatives with a known hip problem totalling 72 cases. Of these, 13 family members had a known diagnosis of DDH, 1 relative had a history of Perthes disease, a total of 24 relatives had received THR, 3 relatives had received hip resurfacing and although 45 were identified as having 'other' hip problems, only 18 descriptions were given regarding these 'other' hip problems that included those with a history of undiagnosed hip conditions. PS-2 responses to questions of family history are summarised in Table 42 below.

Table 42. Details of Family History of Hip Procedures and Problems from PS-2

Relative	THR	Hip Resurfacing	Other	Additional Comments (other)
Grandmother	7		4	Described only as severe &/or long-term hip problems; no named diagnosis
Mother	2		6	Of these, 2 were described as severe hip pain or lower limb problems; 1 had no specified diagnosis; 1 was having on-going physiotherapy. No further comments were made for the remaining relatives' problems
Aunt/Great-aunt	2		3	1 of these cases was diagnosed with DDH; 1 was described only as having hip nailing procedure and 1 with hip issues. No further information given for the remaining cases
Daughter		1	3	All from 1 respondent who described having 4 daughters with DDH; 1 was in harness & hips were monitored for 2 years and 1 had numerous pelvic/femoral osteotomies
Sister		1	6	Of the 6 'others' 1 was described as having severe hip pain, no diagnosis; and 1 mild dysplasia
Grandfather	5		2	No additional comments were included
Father	1	1	3	Of the 'others' just 1 was described as having recent hip pain, no diagnosis
Uncle	5		2	No additional comments were included
Son			4	1 respondent reported having 2 sons with DDH
Brother			3	1 respondent reported having a brother with confirmed diagnosis of Perthes disease
Cousin	2		5	'Other' included 1 report of a DDH diagnosis in female cousin
Grandchildren			2	2 respondents reported having grandchildren with DDH
Nephew			2	1 respondent reported having 2 nephews with CDH

Key: Total Hip Replacement (THR); Developmental Dysplasia of the Hip (DDH); Congenital dislocation/Dysplasia of the Hip (CDH)

## 6.5 Pillar 1 Summary

The findings of PS-1 and PS-2 patient surveys are summarised in Table 43 below. The results of PS-1 drew attention to features that people with AHD considered important in their experience of the condition. PS-2 was used to gain a better understanding of these features. Together, the findings indicated the following: Firstly, the early features of AHD identified by respondents in PS-1, did not match those that PS-2 respondents described to clinicians at their initial clinical assessment. This was notable because later questioning showed that PS-2 respondents had indeed experienced the same early features as those listed by PS-1 respondents. Specifically, both PS-1 and PS-2 respondents indicated that their hip problems began either in infancy and childhood or in adolescence and young adulthood. Whatever the onset age, a childhood history of hip-related features was often evident, and some respondents expressed a recognition that they had childhood memories of hip-related characteristics that they felt were different from other children. For instance, there were repeated reports of respondents being unable to sit cross-legged during childhood, preferring W-sitting positions, having an abnormal hip range of movement and in some cases, having the ability to seemingly dislocate their hip at will that some referred to as their 'party trick' in their early years. Respondents mostly related such features to their hypermobility or hyper-flexibility. PS-2 results showed, however, that during their initial clinical assessment, respondents either did not think to mention or were not given the opportunity to explain these childhood features.

Pain was universally the feature that caused respondents to seek medical help and the evidence suggests that the nature of the pain changed over time. PS-1 responses included a variety of accounts that described the differing perceptions of pain. Therefore, drawing together the range of expressions into a uniform set of terms, PS-2 was able to identify where there was agreement between respondents. This showed that most respondents experienced an initial onset of mild hip pain that, for some, was preceded by pain in the knee, legs or lower back and that developed from a minor niggle to a persistent, debilitating intense discomfort in the hip. Reports of sudden, severe episodes of pain in addition to the constant discomfort were also common.

In relation to the location of the pain, PS-1 findings identified that over time, groin pain developed for some but, more commonly, pain in the hip region was described. This description was confirmed by the PS-2 results. Additionally, PS-1 responses provided convincing statements that two particular events were considered by some to trigger the onset of hip problems. These were either a rapid increase in activity intensity such as training for a marathon, or pregnancy and childbirth. Clearly these features would be

relevant only to particular people, but consideration of their presence in young people reporting new hip pain appears useful.

Following PS-1 results, PS-2 responses achieved greater focus on factors that aggravated hip pain, confirming that prolonged walking, running, standing or sitting were listed by three-quarters of respondents as being activities that were problematic. With regard to sitting, PS-1 responses highlighted how sitting was reported as both triggering and relieving hip pain. Further investigation through PS-2 identified that whilst sitting in a reclined position, with an open hip angle (that is, a reduced hip flexion angle) was a position of ease that helped in the management of their hip pain, sitting in an upright or confined position, as in a car, caused pain. Indeed, throughout both surveys, respondents frequently referred to problems with any activity involving deep hip flexion, which as well as upright sitting included activities such as squatting, breaststroke swimming and lifting legs to the chest.

As well as reclined sitting, respondents described other methods of managing hip problems that involved adaptations and planning. PS-1 responses identified that a number of respondents described how their struggle with shopping trips led to some adapting to shopping online. PS-2 provided the opportunity to investigate this further to identify whether other approaches were used besides online shopping and to establish why shopping was difficult. Those who continued with shopping trips explained the need to plan. Working out where seating would be available and how to avoid stairs or uneven walking surfaces appeared vital and most explained the need to arrange for someone to be with them to lift and carry their shopping, as such actions were particularly troublesome. Planning activities in this way was also apparent in the PS-2 accounts of how respondents managed their social life, holidays and days out.

Other accounts of pain management, related to the many convincing suggestions that pain was most commonly activity-related and because of this, activities that had previously been enjoyed such as sport and social life, had been curtailed. Both PS-1 and PS-2 results identified that activity avoidance along with medication, was used by many to manage the pain of AHD. The medication listed in PS-1 results, showed that respondents mostly used combinations of medication that PS-2 findings confirmed. The medication included opioids or quite powerful combinations of analgesic, anti-inflammatory, anti-depressants and steroid medication. Even with such combinations however, some respondents stated that medication alone was insufficient. Medication history of this nature is useful for clinicians to know as it can provide an insight into the degree of pain the patient is having to manage.

Throughout the responses to PS-1 and PS-2, potential physical signs were evident. Altered posture was mentioned in a number of PS-1 responses and PS-2 established that almost

70% of respondents described having postural asymmetry that some attributed to their attempts to take pressure off their painful hip. Changes to gait were also revealed through PS-1 responses that referred to evidence of an awkward waddling, hobbling or shuffling gait. Some also described walking in a forward lean position due to their tight hip flexors, but the majority referred to the presence of a limp. This seemed to fit with their reports of a leg length difference, a noticeable weakness of the muscles around the hip region or even, as some specified, a Trendelenburg gait. In addition, respondents also related their limp to the need to off-load their painful hip. PS-1 responses were clear and uniform in their accounts of these gait features and PS-2 responses added no further details other than confirming how commonly these signs occurred amongst the population surveyed. It showed that as many as 80% reported having a limp and almost the same number (77%) described a waddling, hobbling or shuffling gait.

There were recurring indications amongst PS-1 respondents of their hypermobility or high flexibility. PS-2 results then went on to identify that more than 50% of respondents considered themselves to have hypermobile joints and that most linked this feature closely to their hip joint instability. Differing levels of hip instability were reported that included actual joint dislocation, subluxation or simply, that the hip felt it was popping out of its socket. Similarly audible hip sounds were reported by PS-1 respondents that were described as clicks, cracks, clunks and popping. PS-2 results confirmed that more than 90% of respondents agreed that hip sounds were a feature of their AHD experience.

Finally, a number of PS-1 responses included comments about relatives who had also experienced hip problems at a young age. Respondents seemed to accept that there was an association between the presence of hip conditions in their family and their own likelihood of having hip problems. PS-2, however, went on to identify that respondents were able to report relatives who had also experienced hip problems, such as hip dysplasia or OA and THR at a young age.

The findings of PS-1 and PS-2 listed above, describe what patients with AHD reported about their experience of living with the condition. While a number of these findings may be suggestive of AHD presence, some can also occur in other conditions of the hip, therefore individually, they may not be helpful in the recognition of AHD. Until each sign and symptom has been tested for its predictive value, they cannot be confirmed as being a sensitive diagnostic indicator. However, understanding the range of commonly occurring features experienced by AHD sufferers begins to create a clinical picture of the condition. This AHD clinical picture could help clinicians to recognise when a raised index of suspicion for the presence of AHD is justified and prompt X-Ray referral for definitive diagnosis. Table 43

summarises Pillar 1 findings, by combining PS-1 and PS-2 results. By developing the understanding of the AHD experiences, Pillar 1 provides an indication of potential signs and symptoms that might begin to distinguish AHD from other hip conditions and inform differential diagnosis. This is discussed in Chapter 7.

*Table 43. Summary of Pillar 1 Findings  
Features that characterise the experiences of people living with AHD*

Feature	Commonly Occurring AHD Signs and Symptoms
Childhood features:	<ul style="list-style-type: none"> <li>• Inability to sit cross-legged</li> <li>• Preference for W-sitting</li> <li>• Abnormal hip range of movement</li> <li>• Possible gymnastic ability and ease of doing splits in those with hypermobility</li> </ul>
<u><b>SYMPTOMS</b></u>	
Pain development:	<ul style="list-style-type: none"> <li>• Initially mild, intermittent hip niggle sometimes preceded by knee, leg or lower back pain, developing into persistent, intense debilitating hip pain</li> <li>• A possibility of sudden, severe episodes of pain in addition to consistent hip discomfort</li> </ul>
Pain location	<ul style="list-style-type: none"> <li>• Groin/hip region</li> </ul>
Pain triggers	<ul style="list-style-type: none"> <li>• Increased intensity of physical training, eg marathon training</li> <li>• Pregnancy/childbirth</li> <li>• Prolonged walking, running, standing or sitting</li> <li>• Sitting in confined space/getting in or out of car</li> <li>• Any activity involving deep hip flexion</li> </ul>
Pain management	<ul style="list-style-type: none"> <li>• Activity avoidance</li> <li>• Medication (opiates, anti-inflammatories, anti-depressants, steroids) Detail planning of activities to ensure availability of seating and avoidance of stairs, uneven surfaces, lifting and carrying</li> <li>• Reclined seating to balance rest with activities</li> </ul>
<u><b>SIGNS</b></u>	
Posture	<ul style="list-style-type: none"> <li>• Postural asymmetry</li> </ul>
Gait	<ul style="list-style-type: none"> <li>• Awkward waddle, hobble or shuffle</li> <li>• Forward lean walk due to tight flexors</li> <li>• Limp due to offloading weight from painful hip; leg length discrepancy; a Trendelenburg gait or weak hip muscles</li> </ul>
Joint Characteristics	<ul style="list-style-type: none"> <li>• Hypermobility or very flexible joints</li> <li>• Hip joint instability that might include full dislocation, subluxation or a feeling that the hip pops out of the socket</li> <li>• Audible hip sounds including clicks, cracks, popping and clunks</li> </ul>
Other notable features	<ul style="list-style-type: none"> <li>• Possible family history</li> </ul>



## **6.6 PILLAR 2: Survey of PAO Surgeons to Identify Their Views of AHD Indicators**

The purpose of Pillar 2 was to explore specialist surgeons' views of the features, signs and symptoms they associate with AHD patient presentation. These views could determine key aspects of AHD presentation that could contribute to the development of a clinical picture of the condition.

Seventeen orthopaedic surgeons who specialise in the assessment and treatment of the hip in young people responded to the survey. This represented more than 50% of the PAO specialist surgeons available at the RCoM, Early Hip Intervention conference described in Chapter 4. Estimates on the nationally representative nature of these 17 surgeons are difficult because PAO surgery is a developing speciality area, and, at the time of data collection, fewer than six UK surgeons were recognised through their publications and online profiles as having specialist PAO skills and knowledge (Mei-Dan et al 2017; Malviya et al 2016; Witt and Haddad 2017). Website searches and discussions with PAO surgeons indicate that recently there appears to be an increasing interest in orthopaedic surgeons undergoing specialist PAO training.

### **6.6.1 Demographics**

Surgical experience and institutional seniority details were available for 12 respondents who described themselves as being employed at Consultant Orthopaedic Surgeon level or above. The employment details of the remaining 5 respondents were not available. Other indicators of respondents' expertise included: 2 respondents who reported being faculty members at international hip meetings and orthopaedic courses, meaning that they are part of an academic group with specialist knowledge, and 4 who described themselves as being heavily involved in training orthopaedic surgeons of the future. In addition, several respondents described their involvement in research; one having had more than 40 published papers in various orthopaedic journals and 2 being reviewers for a range of orthopaedic journals, one of whom focusses their research on PAO surgery and other treatments for hip dysplasia. Of those providing information, their details are displayed in Table 44.

Table 44. Descriptive Details of Participating Surgeons

Time in Consultant post	More than 20 years n=3		More than 10 years n=2		More than 3 years n=7		
Title	Consultant in Charge n=1	Associate Clinical Professor in Trauma and Orthopaedic Surgery n=1	Post-doc researcher and Orthopaedic Surgeon n=1	Medical Director n=1	Director of young adult hip preservation programme n=1	Hip, Knee & Sports surgeons n=2	Specialists in hip and knee arthroplasty in young people n=4
Specialist skills/knowledge	Reconstructive or preservation hip and knee surgery in young people n=9		PAO surgery for hip dysplasia with minimally invasive approach n=4		Co-developer of UK-wide tertiary referral centre for young people with hip disorders n=1		Co-developer of Young Persons' Hip Services n=1

Key: Periacetabular Osteotomy (PAO)

## **6.6.2 Initial Impression of Surgeons' Responses**

The 5 survey questions asked surgeons to itemise features of patient presentation they associated with a diagnosis of AHD. Taken as a whole, the surgeons' responses included items that related to patients' history of their condition and the physical examination. Inconsistencies were evident in the way responses had been presented. Question 1 asked surgeons to list the features of medical, physical or functional history that they would associate with a diagnosis of AHD. Question 3 aimed to draw out the physical indicators that specialist surgeons considered indicative of AHD and the purpose of Question 4 was to identify specific tests for AHD used during physical assessment. The content of responses to these 3 questions were often repeated, or combined, and lacked a clear distinction between the topic areas. Therefore, analysis involved itemizing all features listed and decanting the 'features of history' and 'physical indicators' from the named 'special' tests. Similarly, whilst the purpose of Question 2 was to collect views on whether features of family history contributed to diagnostic decisions, surgeons occasionally referred to this topic when providing answers to other questions, hence these data were transferred to the appropriate list of features for analysis and are presented in Tables 45-48.

## **6.6.3 Qualitative Analysis**

### **6.6.3.1 Medical, Physical and Functional History**

In total, 12 surgeons listed at least one aspect of birth or childhood history that would increase their suspicion of AHD presence (Table 45). Of these simply "birth history" was listed by one surgeon, whereas others specified "first-born", "breech delivery" and "female". One surgeon also referred to the possible presence of an associated other system or foot abnormality. Also listed were a history of "double nappies or Pavlik" [harness], a history of DDH, a surgical history, being a late walker, favouring a W-sitting or figure-of-4 sitting position and any concerns with hip as an infant, as being possible features associated with AHD presence.

### **6.6.3.2 Family History**

Ten surgeons listed a family history of hip problems as being of possible relevance when suspecting AHD presence (Table 45), specifying family members with a congenital abnormality, HD, hip OA and hip problems or hip surgery. THR in a relative was specified by 8 surgeons with 7 of these stipulating a young age for the occurrence of these hip problems. One surgeon stated that a history of DDH in the patient's mother could be useful for the

patient's diagnosis and one surgeon also included anaesthetic complications and social circumstances as being part of her assessment of these patient's family history.

Table 45. Medical and Family History

Medical/Physical History		Family History	
<i>Birth History</i>	<i>Infant History</i>	Total Hip replacement (n=7)	At young age (n=7)
1 <sup>st</sup> born (n=2)	Any hip concern (n=1)	Hip OA (n=2)	
Breech delivery (n=2)	DDH/double nappies/Pavlik harness (n=3)	Dysplasia (n=4)	
Female (n=7)	Surgical History (n=2)	DDH in Mother (n=1)	
Associated abnormalities (n=1)	Late walker (n=1)	Congenital abnormality (n=1)	
	W or figure of 4 sitting (n=2)	Anaesthetic complications (n=1)	
		Social Circumstances (n=1)	

Key: Developmental Dysplasia of the Hip (DDH); Osteoarthritis (OA)

### 6.6.3.3 Physical Indicators

Pain was the most described feature related to diagnostic assessment for AHD, as it was listed by 13 out of the 17 surgeons. Descriptions of the nature of the pain included: a new, insidious onset of unrelenting, non-specific pain and more than 3 months of consistent pain post-sport that one surgeon described as having no clear cause. By comparison, one surgeon specified that pain could be “*activity related*” and one described pain that could be “*catching, sharp and intermittent with an intolerance of sudden angular movements*”.

The location of the pain was described by 6 surgeons; 5 of whom listed this as “*groin pain*” and 1 surgeon listing only “*lateral hip pain*”.

One surgeon stated that patients often report pain that is worse when: rising from a chair, accessing a car, sitting in confined spaces or during prolonged sitting upright, slouching or when there is restricted foot access. This surgeon also referred to pain affecting standing and walking and pointed out that females report decreased shopping stamina.

In total, 8 surgeons referred to elements of gait that they associated with AHD presence, 3 of whom listed a limp, 1 stating an “*in-toeing gait*” and 4 specifying a Trendelenburg gait. In addition to this latter feature, a further 3 listed weak or fatigued hip abductors that are known

to cause a Trendelenburg gait (Kendall et al 2013). Six surgeons also listed a leg length discrepancy as being commonly evident in patients with AHD and that this would be likely to affect gait.

“Young age” of the patient was listed by 6 surgeons and 3 surgeons listed “activity level” but gave no further details. Hip range of motion (ROM) was included in the lists of 5 surgeons, 3 of whom referred to an increased, free or normal hip ROM but by contrast, another surgeon described a “*decreased ROM*”. One surgeon listed only ‘ROM’ indicating neither an increase nor decrease. Hypermobility, however, was considered relevant by 3 surgeons, indicating a general increase in range of joint movements.

Other features listed by no more than 2 surgeons included: hip joint clunking/giving way; clicking/IT snapping; impingement; instability; stiffness and immobility. One surgeon also listed gait, spine examination, medication and anaesthetic history. All declared physical features are summarised in Table 46.

*Table 46. Physical Features Surgeons Associate with AHD Presence*

Pain nature n=13	Pain location n=6	Range of motion n=5	Gait n=8	Other (no descriptors included)
Descriptors				
New	Groin (c-shaped distribution)	Decreased due to pain	Limp	Young Age n=6 Activity level n=3
Chronicity more than 3 months	Lateral hip	Good, normal maintained	Leg length discrepancy	Instability n=2
Activity related		Increased	Trendelenburg/ weak or fatigued hip abductors	Impingement n=2 Stiffness & immobility n=1
No clear cause		Hypermobility/hyperflexibility	In-toeing	Clunking/ giving way n=1 Spine exam n=1 Pelvic asymmetry n=1 Medication n=1 Anaesthetic history n=1

*Key: C-distribution of pain describes a cupping of the patient’s hand around the anterior hip with their palm over the greater trochanter and fingers directed towards their groin*

#### 6.6.3.4 Special Hip Tests Used During Assessment of AHD

Various special tests and their uses during the assessment of patients with hip problems were listed by surgeons (Table 47). Two surgeons stated that these tests lacked specificity for AHD and one respondent commented that,

*“...I tend to do these tests but usually they don’t help me to diagnose or suspect DDH”.*

Seven surgeons stated that they carry out combined movement tests of the hip. These included the flexion-adduction and internal rotation (FADDIR) test used to identify intra-articular pathology or a likelihood of FAI or labral damage (Martin and Sekiya 2008). It also included the flexion-abduction-external rotation (FABER) test that is generally used as a pain provocation test as well as a test of range of motion in combined movements and the possibility of hip, lumbar or sacroiliac pathology (Pasic et al 2014; Bagwell et al 2016). Of the 7 surgeons using these tests, 4 commented that the tests are used to assess for the presence of a labral pathology, impingement or damage to the acetabular rim, any of which, they stated, can occur with AHD.

Six surgeons referred to their testing of hip rotation, with 2 stating that reduced internal rotation would add to their suspicion of AHD and 4 stating that increased internal rotation would be expected in the presence of AHD. Two surgeons also listed the combined movements of hip extension-adduction-external rotation, but no further details were provided on this.

*Table 47. Special Tests and their use during Assessment for AHD*

Test	Surgeons’ Comments	Listed by Respondents: (number(s) refers to respondent code)
Flexion-Adduction-Internal Rotation and/or Flexion-Abduction-External-Rotation tests	Reproduces Low groin pain specificity for AHD. Test used to identify AHD-related pathology	10s; 50s; 80s; 90s 130s; 150s; 160s;
Altered rotation	↓ internal rotation (n=2) ↑ internal rotation (n=4)	10s; 40s; 70s; 100s; 130s; 160s
Extension-Adduction-External Rotation		10s; 150s

*Key: Acetabular Hip Dysplasia (AHD)*

Table 48 draws together the information displayed in Tables 45, 46 and 47 to present an overview of all indicators listed in the surgeons' survey responses.

Table 48. Features Surgeons Associate with AHD Presentation

<b>INFANT/CHILDHOOD HISTORY</b>	<p>Congenital abnormality (n=1)</p> <p>Diagnosis of Developmental Dysplasia of the Hip (n=2)</p> <p>Surgery (pelvic) n=2</p> <p>'W' or 'figure of 4' sitting position favoured (n=2)</p>
<b>FAMILY HISTORY</b>	<p>Any family member with history of hip surgery or hip OA at a young age (n=11)</p> <p>Any family member with history hip dysplasia, hip or joint issue (n=8)</p>
<b>PHYSICAL INDICATORS:</b>	<p>Pelvic asymmetry (n=1); Slouching (n=1)</p> <p>Limp including Trendelenburg gait/weak hip abductors (n=8)</p>
<b>Posture and Gait</b>	<p>In-toeing gait (n=1)</p>
<b>Activity Level</b>	<p>Decreased (n=4); Decreased shopping stamina (n=1)</p>
<b>Muscles and Joints</b>	<p>Hip instability/positive apprehension test (n=6)</p> <p>Weakness and fatigue of hip abductors (n=3)</p> <p>IT band snapping (n=1)</p> <p>Range of movement (n=3)</p> <p>Good/normal range of movement (n=4)</p> <p>Decreased range of movement (n=4)</p> <p>Increased hip internal rotation (n=3)</p> <p>Decreased hip internal rotation (n=3)</p> <p>Clunking, clicking, locking, giving way at hip joint (n=5)</p> <p>Joint hypermobility (n=3)</p>
<b>Pain</b>	<p>Hip pain (n=6); more than 3 months of pain/chronicity (n=2)</p> <p>New pain onset at young age (n=7)</p> <p>Consistent pain post-sport (n=1)</p> <p>Pain that restricts movement/intolerant of angular movement (n=1)</p> <p>Worsening pain when rising from a chair, accessing a car, upright sitting or sitting in confined space (n=2)</p> <p>Groin pain, often activity related (n=7)</p> <p>Sharp, catching pain (n=2)</p>



	C-sign distribution of pain (n=2)
<b>Lower Limb</b>	Leg length discrepancy (n=6)
	Immobility (n=1)
	'Miserable mal-alignment' (n=1)
	Stiffness (n=1)
<b>SPECIAL TESTS:</b>	Used to assess for AHD-related pathology (low specificity for AHD alone):
<b>Combined Hip Movements</b>	Flexion/Adduction/Internal Rotation Test (n=6)
	Flexion/Abduction/External Rotation Test (n=5)
	Extension/Adduction/External Rotation Test (n=2)
<b>Altered hip rotation</b>	Decreased hip internal rotation (n=2)
	Increased hip internal rotation (n=4)

#### 6.6.4 Question 5: Features in Order of Diagnostic Importance

Question 5 asked surgeons to put features in order of importance for a diagnosis of AHD. Amongst the 13 surgeons who provided a response to this, there was much variation in terms of the features listed and their position within the order of diagnostic priorities. The number of features listed varied from 1 to 6. A list of these features is summarised in Table 49 where the allocation of the position of importance as rated by each surgeon is also indicated. This shows that not all the features that surgeons described in response to earlier questions as being associated with AHD (Table 48), were included in the order of their diagnostic importance listing. Overall, the features gaining greatest agreement in support of an AHD diagnosis were hip pain, problems with gait, leg length discrepancy, abnormalities of hip joint range of movement and a family history of hip problems. Several surgeons also included a positive impingement test, an altered rotational profile, stiffness, age of presentation, clunking/giving way, a positive birth history, pelvic asymmetry, and scars. The position of diagnostic importance for each of these features differed amongst surgeons, and some considered several features to be of equal importance, for example, one surgeon (identified as 40s) considered both a limp and a decreased walking distance to be the fourth most important assessment features for recognition of AHD.

This array of features and the different importance-rating placed on each by the different surgeons emphasises the equivocal nature of AHD presentation. However, a final statement provided by one surgeon (identified as 170s) provided a constructive headline message of

factors that were indicated but not overtly stated in other surgeons' responses by explaining that,

*"It is not normal for people of any age to have hip pain. ....In my pathways, significant and persistent hip pain in young patients should prompt early investigation with plain X-rays as the first step."*

This appears to offer useful direction for clinicians in terms of the response that should be taken when basic assessment findings are evident.

Table 49. Surgeons' Importance Rating of Features Indicating AHD Diagnosis

Feature:	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	6 <sup>th</sup>
Pain	40s 70s (early onset) 80s 90s 100s (and instability) 110s (new onset or C-distribution) 130s (groin or C-sign)	60s (trochanteric)	20s 30s	50s		10s (not responding to treatment; altered activity)
Gait Problems:					90s	
Limp		20s 30s		40s		
Trendelenburg Gait (+ve)		130s	50s 60s		10s	
Decreased walking distance				40s		
Immobility			90s			
Leg length discrepancy	30s (shorter) 50s (shorter)	10s	130s	60s		
Range of Motion (ROM)		50s (limited) 80s (restricted)	110s (good ROM)	20s (reduced) 30s (reduced)		
Family History	20s (hip) 60s (dysplasia)	70s (strong Family History)			40s	
Impingement Test (+ve)	10s		110s (not AHD specific)			
Rotational angle/profile			40s (altered) 100s			
Stiffness		90s				
Age of Presentation		100s				
Clunking/Giving Way		40s				
Positive Birth History			70s			
Pelvic Asymmetry				10s		
Scars				130s		

Key: Respondent codes identified by their number followed by 's' to indicate surgeon (e.g., 90s); Range of Movement (ROM); Acetabular Hip Dysplasia (AHD)

## **6.7 Pillar 2 Summary**

In summary, there were differences in surgeons' listings of the features considered important in the presentation of AHD (Tables 48 and 49). Not only were different features included by each surgeon, but notable variations were evident in the importance rating each one placed on the features they considered indicative of AHD diagnosis. Opposing views on hip range of movement and internal rotation (whether measures would be increased or decreased) were recorded and although there was some agreement in the use of specific special hip assessment tests, comments indicated that a positive test result indicated either the presence of other conditions associated with AHD or that they did not contribute to AHD diagnosis. Whilst it was difficult to identify consensus between surgeons, responses did provide some insight into a range of potential indicators of AHD.

## **6.8 Pillar 3: Observation of Physiotherapists' Patient Assessment**

The objective of these observations was to identify the content of physiotherapy assessment of patients aged between 16 and 60 years with a hip complaint. The upper age limit helped to reduce the number of patients with comorbidities or OA as their primary problem. By identifying the content of the assessments, these observations established whether opportunities were being overlooked for identifying patients in whom AHD should be suspected and if so, how new knowledge of AHD could inform practice for the benefit of patient management.

In presenting the results of the observations, I firstly provide a general description of the participants and an overview of the assessment procedures. I then explain the key themes that were generated by the fieldnote data, following which I summarise the findings and discuss their clinical application. Quotes are used to provide examples of the point being discussed and whilst both physiotherapist and patient quotes are provided, the identification code used relates to the particular patient assessment from which the quotes are taken

### **6.8.1 Demographics**

A total of 15 physiotherapists were observed during the completion of 17 assessments of patients with hip problems. Descriptive data of participating physiotherapists were considered in terms of their grade and experience. The least experienced physiotherapists were Band 5 (n=7) and with increasing experience were Band 6 (n=5), then Band 7 (n=2) and at Band 8, a clinical specialist in MSK physiotherapy (n=1).

The 17 patients involved in the observations ranged in age from 19 years to 60 years. Almost all expressed enjoyment in being active, as they referred to their participation in various sports ranging from distance walking through to ultramarathon running, football, jive-dancing, sailing, squash, netball and car rally driving. However, since the progress of their hip problems, they had limited or stopped their involvement in these activities. Although patients had all been referred to physiotherapy by their GP, they all indicated that they were receiving their first physical assessment for their current problems. Patients reported having had hip problems for between 3 months and more than 10 years with some describing longer term knee clicking, back pain or a childhood history of hip problems. The medical history of these patients showed that they had received previous diagnoses for past episodes of hip problems that included 3 patients who referred to childhood diagnoses of either slipped upper femoral epiphysis (SUFE), Scheuermann's disease (kyphosis during accelerated growth) or Osgood-Schlatter's disease (swelling and irritation of the tibial tuberosity). Others listed previous hip-related diagnoses received during adulthood as being

bursitis, fluid on the joint, OA in their back or contralateral hip, tight muscles and suspected prolapsed intervertebral disc (PID). One patient also stated that previously, their GP thought she was making up the hip problems she had described. Five patients stated that they had received hip X-Rays and of these, 2 were told that there were signs of early arthritic changes and 3 received confirmation that there was no evidence of OA. Additionally, 1 patient was awaiting the results of a blood test.

### **6.8.2 Assessment Procedure Overview**

The overall impression I gained during the observations was that for every patient-assessment, and with each physiotherapist, the overall approach was very similar. All physiotherapists used a standardised assessment record sheet (Appendix 9) that included 2 addressograph stickers providing details of the patient's NHS number, name, address and age. Although the assessment form appeared to guide aspects of the assessment and therefore likely contributed to the similarities evident between all the assessment procedures, it did not appear to restrict the assessment questioning or actions. Indeed, the physiotherapists' notes went beyond those framed by the assessment record sheet, continuing onto extra sheets when required. Each physiotherapist spent between 30 and 45 minutes on the assessment of the patients' hip problems and related issues. Assessment procedures appeared to follow the hypothetico-deductive model of reasoning (Croskerry 2009), whereby physiotherapists systematically drew together patient data from the referral, the patient-reported clinical history (during which they questioned the patient to elicit details of the hip issue), and the physical assessment (that evaluated joint movement and muscle strength). On conclusion of this data collection, physiotherapists explained their findings to the patient and suggested a diagnosis, treatment and management plan.

More than 50% of the examination time was used to investigate the patient's history and although this was guided by the physiotherapist's questions, it gave the patient the opportunity to describe various aspects of their hip problems and any related issues. The physiotherapists made a written recording of the problems and issues described, following which they used further questioning and physical assessment of the patient to collect more details. I recorded in my fieldnotes the physiotherapists' questions, the physical assessment techniques they applied and the conclusions they reached on completion of the assessment. The patients' responses throughout all aspects of their assessment were also included in my fieldnotes. These fieldnotes were then transposed and analysed to produce the results. My report of these results is presented under the headings of four themes. Each of the themes relates to a component of the assessment. Theme 1 firstly explains the physiotherapists' questions and the progression of enquiry into the patient's history. Theme 2 reports on

information elicited from the patients, highlighting where features associated with AHD were presented. Following this, Theme 3 lists the findings of the physiotherapists' physical assessment of the patient and Theme 4 reports the conclusions and treatment decisions made by each physiotherapist on completion of the patient's examination.

### **6.8.3 Theme 1: Patient History and Physiotherapists' Enquiry**

#### **6.8.3.1 Opening Enquiry**

In all 17 assessments, physiotherapists began their interaction with the patient with an opening question that drew from the patient the hip related problems they were experiencing. For 6 assessments, physiotherapists preceded their opening question by confirming the accuracy of the referral data or by asking the patient if they had received previous physiotherapy treatment. They then explained what was planned for this first appointment. In addition, one physiotherapist, the only Band 8 Clinical Specialist and most experienced of the observed clinicians, before seeing the patient, read the available patient notes and evaluated the patient's hip X-Ray, identifying and noting indications of cam FAI deformity. She also remarked that the patient had been referred from their GP with left hip pain, right knee pain and OA.

For all assessments, opening questions were mostly very similar, offering the patient the opportunity to describe any or all aspects of their hip-related concerns and experiences. Such opening questions were for example,

*"Tell me about your problem"* (for patients 6TP; 1NG; 4DW; 3SC)

*"How can I help you today"* (for patient 2LD)

*"Tell me what's been happening"* (for patient KL2D1)

These were sufficient to gain from the patient a basic outline of the hip issues they had experienced and the problems they were managing. None of the patients appeared to have any problems expressing their concerns and problems. Each physiotherapist made notes of the accounts given by the patient in response to the opening question. This information appeared to guide the physiotherapist's next level of questioning, identified here as 'reactive questions'.

#### **6.8.3.2 Reactive Questions**

Having listened to the patient's response to their opening enquiry, physiotherapists then asked reactive questions that drew from the patient further details about selected issues they

had reported that the physiotherapist deemed relevant for further follow up. The features common to almost all the observed assessments and that were the predominant features of the reactive enquiry were as follows:

### **i. Pain**

Most of the reactive questions focused on the patient's pain. Every physiotherapist asked pain-related questions repeatedly, which prompted the patient into describing the nature, severity, location and intensity of their pain, as well as factors that aggravated and relieved their pain, the frequency of their pain and the length of time they had experienced the pain. Pain-related questions asked during the assessment of patient 1NG included, for example,

*“Where is your pain?  
When did pain start?  
What specific activities trigger the problem?  
If 10 is worst pain possible, what would you score your back pain?  
What relieves pain?  
What activities have you had to stop because of the problem?  
How are you in the mornings when you first get up?”*

In all, following the patient's initial report of hip pain, physiotherapists went on to ask between 3 and 14 further levels of pain-specific questions, and pain-related enquiry often continued throughout the entire assessment. Overall, the enquiry appeared to provoke well-explained definitions of the pain, sufficient to serve as a marker for monitoring treatment outcomes.

### **ii. Previous Hip Conditions and Injuries**

More than half the observed assessments included physiotherapists questioning whether the patient had any related previous diagnoses. Patients SPSWH, PKES1 and TWTB1 were specifically asked if they had,

*“...any previous hip problems? Any childhood hip problems?”  
“Dysplasia or Perthes? Were you born with any hip problems?”*

Information received in response occasionally provided details of earlier diagnoses including those that patients had received as children. In addition, some patients extended their response without being prompted by explaining that their mother, sister or other relative had also been treated for hip problems at a young age. Interestingly, whatever response was received, no further questioning was apparent for this line of enquiry, therefore the purpose of the enquiry was unclear.

### **iii. Clicking, Popping, Locking or Giving Way**



Five patient assessments included enquiry on mechanical characteristics of the hip that addressed whether the hip felt or made an audible click or pop and whether the joint locked or gave way. This enquiry was mostly driven by the information provided by the patients in response to the opening question. In more than one assessment, the patient explained how their hip felt very loose as if it was going to ‘fall out’. For instance, patient SPSWH stated,

*“Feels like hip is loose, like muscles have stopped holding ball in socket  
Worried it’ll get really bad again”.*

Further examples are given in the Theme 2 section below (Information Elicited from the Patients) and, in each case, the physiotherapist responded by reassuring the patient that the hip could not ‘fall’ or ‘pop’ out because it was a very secure joint. The impression given was that they considered that hip joints cannot dislocate.

#### **iv. Effect of Hip Problems on Activities**

Eight out of the 17 assessments included specific physiotherapist questioning on the impact of the patient’s problem on their activities although most patients volunteered information on this before being asked. Questions included,

*“Are you as active as you were?”* (patient 1LGW1)

*“Does hip limit anything? How much running do you do?”*

(patient RHKL1)

*“Have you been running since? When did you stop running/jiving?”*

(patient 2LD)

Although further levels of reactive questions on this issue were rarely evident, the responses given by the patients regarding their activity and movement were followed up during the physical examination in all but one of the physiotherapy assessments.

#### **v. Hip-related Tests, X-Rays and Scans**

Patients often offered information about whether they had been referred for tests, X-Ray or scans of their hip. Where this information had not been readily volunteered, the physiotherapist made a direct enquiry to the patient. One patient explained that they were awaiting blood test results, and for this patient, the physiotherapist stated that the results would be considered at the next appointment. For the X-Rays, physiotherapists mostly referred to the radiologist’s report available in the patient’s notes. OA was the only pathology reported or referred to in the reports, otherwise, the hip image was deemed ‘normal’ and with no arthritis according to these reports. In one case, following the physical exam and without

viewing the X-Ray, the physiotherapist stated that the symptoms were probably indicating a degenerative hip joint, however, the radiologist's report had not appeared to agree, stating only that the hip appeared normal. With the exception of the Band 8 physiotherapist's approach who had viewed the patient's X-Ray and identified a cam-type FAI deformity, the other hip X-Ray reports were very similar in their focus on either hip normality or diagnosis of OA. The Band 8, however, had provided an interesting example of how, when physiotherapists extend their enquiry, they recognise the potential value of X-Ray evaluation to their patient assessment.

#### **vi. Patients' Views and Opinions**

All physiotherapists provided the patient with the opportunity to express their concerns and views about their hip problems. In 14 of the 17 assessments, physiotherapists asked specifically about the patient's thoughts on what they felt was causing their hip problem, the concerns they had and their expectations of treatment. The assessment of patient 1LGW1 provides an example of the wording used by most of these enquiries as the physiotherapist asked,

*"What do you think is causing it?"*

*"What are you worried about?"*

*"What are your expectations?"*

The similarity of the wording used for this line of enquiry was evident between all physiotherapists' assessments and provided the patient with an open opportunity to state any concerns they had. Typically, patient responses to these questions demonstrated apparent insight into their health condition that appeared to have the potential to be diagnostically informative. Interestingly, as Table 50 shows below, in each case, and in contrast to enquiry regarding patients' pain, the physiotherapist chose not to elaborate on the patients' answers and the line of enquiry ended after the response to initial questioning was received.

Table 50. *Contrasting Levels of Physiotherapy Questioning*

Patient	Physiotherapists' Question (initial level)	Patient Response	Physiotherapists' Continued Levels of Reactive Questioning
DSRGH	What triggers pain?	Turning...(points to joint) deep pain;...pain worse lying in bed	<p>How quickly did pain settle after initial pain? (<i>2<sup>nd</sup> level question</i>)</p> <p>Treatment (for pain)? (<i>3<sup>rd</sup> level question</i>)</p> <p>What triggers the pain? (<i>4<sup>th</sup> level question</i>)</p> <p>Is it worse in the morning? (<i>5<sup>th</sup> level question</i>)</p> <p>How long does it last? (<i>6<sup>th</sup> level question</i>)</p> <p>Does it wake you at night? (<i>7<sup>th</sup> level question</i>)</p> <p>What are you using to relieve it? (<i>8<sup>th</sup> level question</i>)</p> <p>In the morning, what do you do to help it? (<i>9<sup>th</sup> level question</i>)</p>
4DW	What are your thoughts on what caused the problem?	...family history of hip problems; cousin had hip problem as an infant;	No further enquiry
4DOB	What do you think causes the pain?	Mother had hip problems. My pain seems very similar to Mother's. It feels as though my hip pops out (Physio reassures that this would not be happening)	No further enquiry
3SC	Tell me about your problem	...Problems for 10 years but worse for 15 months..... Mother had the same; Sister had both hips and both knees replaced...Prolonged walking irritates it	No further enquiry

In most assessments, the physiotherapist asked a question about whether the patient had received previous treatments or consultations for hip problems and whether they had experienced any issues with their other or contralateral hip. There was also one enquiry about patients' sleep patterns and occasionally questions regarding whether the patient experienced unusual sensations or back pain.

#### **6.8.3.3 General Routine Questions**

These questions related to specific parameters of patient history that were mostly routine health questions aiming to gain clarification of the life-context in which the patient was experiencing their current problem. They included consideration of, for instance, the patient's medical history, general health, medication and red flag factors (warning signs that medical referral is warranted). The observed assessments showed that physiotherapists asked at least 4 such questions that in some cases, also included the collection of information regarding the patient's occupation, hobbies, sports and social history in addition to the above. The assessment of patient 1NG provides an example of the nature of this type of questioning as they were asked,

*“What is your job?  
Are you on sick leave?  
What activities have you had to stop because of the problem?  
Are you normally healthy?  
What current medication are you on?  
Do you smoke or drink alcohol?  
Who do you live with?  
What are your hobbies?”*

In addition, and in common with all other observations, patient 1NG was also asked questions on whether any problems had been experienced with their heart and lungs, blood pressure, cholesterol levels, weight loss and whether they had received surgery or any previous diagnoses of diabetes, epilepsy, thyroid issues, cancer, osteoporosis or fracture. This line of enquiry is reflective of questions asked as a matter of routine in all the observed assessments. The patients' responses were recorded but the purpose of collecting this information was not made obvious by the physiotherapist, although some questions could be associated with those identifying red flag indicators. If patients' responses to these influenced the physiotherapists' conclusions and decision-making, it was not apparent, and no medical referrals appeared to be required.

#### **6.8.3.4 Summary of Physiotherapists' Enquiry**

In summary, physiotherapists' enquiry showed three elements: an opening question, reactive questions and general routine questions. These provided the patient with opportunities for describing their health concerns and the issues they had experienced because of their hip-

related problems. In general, physiotherapists directed their reactive questions at collecting considerable detail about the patient's pain. This could be due not only to pain being the most troublesome feature for the patient, but also because pain can provide a marker for treatment outcomes (Beck et al 2019). Although evident and frequently identified as being apparent, there were fewer levels of enquiry into patients' previous hip-related conditions and hip history, or their reported hip clicks, clunks, popping and giving way. Additionally, enquiry was limited regarding the impact of the hip condition on the patient's activities and whether the patient had received any tests for their hip condition including X-Rays and scans. Almost all physiotherapists provided an opportunity for the patient to report any views or opinions they had about the nature and cause of their hip problems, but apart from pain, physiotherapists' reactive questioning to acquire detailed understanding of other features that patients reported, was not apparent.

#### **6.8.4 Theme 2: Information Elicited from Patients**

The nature of the physiotherapists' assessment enquiry provided patients with the opportunity to deliver substantial detail regarding their hip problems. When asked to expand on issues, patients did so freely and seemingly without hesitation, often reporting on features and issues that went beyond the physiotherapists' direct questioning. During the assessment, therefore, the patient provided a considerable amount of information about a range of issues that included their pain; hip joint clicks, locking and giving way; childhood problems; previous hip injuries and diagnoses; family history; activity changes, their worries and concerns. Details of each of these are explained in the following subsections.

##### **6.8.4.1 Pain**

As reflected by the pattern of physiotherapists' enquiry, pain was a major feature of the information elicited from the patient and guided by the physiotherapist's focused questions, patients provided details on the length of time they had experienced pain, how it had developed, the location, severity and the nature of their pain. Patients also described factors that both aggravated and relieved the pain as well as explaining the impact that pain had on their sleep. Patient 3SC for instance explained,

*"[problem is]...hips and knees... on buttock line..., constant niggling pain worsened by prolonged walking and getting in and out of car. Problems for more than 10 years but worse for 15 months. Work is painful... right leg is worse. Knee now getting bad, weather seems to affect it – winter months are bad. Painkillers make it bearable. Pain eases with movement*

*and tablets. Pain affects sleep every 3-4 hours. When sleeping, both hips are painful. Sleeping with pillow between knees helps hips..... [pain] at top of buttock sometimes 7 or 8/10"*

Repeated prompting by the physiotherapists' questions, led to most patients providing a similar level of detail to this example regarding the characteristics of their pain. Typically, pain was an issue that was thoroughly investigated by the physiotherapists and well-detailed by patients who gave sufficient descriptions at this initial assessment for changes to be monitored as treatment progressed.

#### **6.8.4.2 Hip Joint Instability**

Single statements provided information regarding a range of features relating to hip joint instability. Of particular note were comments made by patients that appeared to indicate episodes of hip joint subluxation or dislocation. Patient 4DOB provided a typical example of this by stating,

*"....feels like hip is popping out"*

Similarly, patient 6TP stated...

*"...cannot lie on my side;... feels like hip pops out then I drag my leg"*

Patient RHKL1 parallels these statements by reporting that, as well as the hip locking and popping, it

*"feels like hip falls out.....hip feels wrong.....need to move in a particular way to unlock"*

Others described their hip clunking, for instance patient JPCS1 described how they,

*"can feel hip 'clunk' when knee raised and lowered"*

Patients' concern about this issue was clear from their facial expressions and they seemed ready to discuss the point further but, in each case, further enquiry by the physiotherapist did not proceed. It was unclear how the patients' reporting of such features contributed to physiotherapists' conclusion and decision-making and, although there was no further enquiry, the physiotherapist provided reassurance that the joint would not, in fact, be popping out. This gave me the impression that the physiotherapist considered the patient's concerns implausible.

#### **6.8.4.3 Hip Sounds**

As well as the patient reporting their hip joint clunking or clicking in association with their hip joint instability, patients also described audible hip sounds that occurred during movement

but that they did not overtly associate with instability. Patient PKES1 for instance, explains how, inside their hip joint, it...

*“feels like pressure increases then clicks and improves but I can’t just make it click.... Sitting on floor increases feeling of pressure – click relieves it”.*

Others, such as patient ILGW1 associated clicking with pain, describing how they have,

*“pain in groin area and clicks – pain radiates to lumbar-spine area. Hip and knee click – worsened over time”.*

There was no further elaboration of these features, but they illustrate the various ways in which patients describe the hip sounds they experience and the associations they make.

#### **6.8.4.4 Childhood History**

In addition to responding directly to physiotherapists’ questions, patients also voiced other issues that they considered relevant. This drew out diagnoses or problems they had experienced during childhood. Patient TWTB1 for instance, explained that they had been diagnosed with left SUFE at the age of 11 or 12 years and although the physiotherapist asked about the patient’s family history, enquiring specifically whether there had been any family reports of Perthes or Dysplasia, no other enquiry was made in response to the information on SUFE. The patient also commented that there had been suspicion of a left FAI and that they were worried that the right hip might become like the left. Again, there was no further exploration of these points. Likewise, patient SPSWH described how they had experienced ‘clicky’ joints throughout childhood and patient 6TP reported having been diagnosed with Scheuermann’s disease as a child but in both cases, enquiry ended following these statements.

#### **6.8.4.5 Family History of Hip Issues**

Another feature on which patients often volunteered information without being questioned referred to their family members who had experienced hip issues similar to their own. Having described their concerns of her hip ‘popping out’, patient 4DOB, for instance stated that,

*“Mother had hip problems, my pain seems very similar to Mother’s”*

and patient 3SC also referred to the fact that their...

*“Mother had the same, ... Sister had bilateral hips and knees replaced”,*

Similarly, patient 4DW expressed her concern in relation to having a family history of hip problems. She reported that her cousin had infant hip problems and her father and uncle had hip replacements at a young age. In addition, her mother had chronic back problems. During a later conversation that I had with patient 4DW, I learned that the patient's cousin, who had been reported as having infant hip problems, was in fact treated with a frog plaster, indicating the presence of DDH. The volunteering of such information seemed to demonstrate the ease with which patients communicated their issues but they were not invited to expand on this information.

#### **6.8.4.6 Function**

Mostly without being prompted, patients reported functional issues caused by their hip problems. There were reports of hip pain being triggered by carrying items, which for some meant their activities, including their work, had to be adapted through for instance, the use of equipment. Others described how they struggled with activities involving deep hip flexion such as putting on tights or shaving their legs (patient 4DOB). Patients also referred to how they had reduced their distance for dog-walking (patient 4DOB) or were playing less netball and were motorcycling less often (patient PKES1). Additionally, they reported decreased episodes of running or sitting for long periods (patients JPCS1, TWTB1, 2LD, 4DOB). By contrast, however, patient RHKL1 explained that although they...

*“thought running might worsen it ..... [hip] seems to feel worse when not running... Recently restarted running and hip improves”*

Mostly, further enquiry by the physiotherapist on functional issues did not ensue. In just one case (patient 2LD), however, the physiotherapist did draw from the patient that running seemed to trigger hip problems and that because of this they had stopped both running and jiving. They were very keen to return to these activities and through discussion, this became an aim of the treatment.

#### **6.8.4.7 Summary of Information Elicited from Patients**

Overall, this theme showed that the information elicited from patients provided considerable detail about their pain, often in response to physiotherapists' questioning, and included details of their pain location, development, severity, nature, factors that aggravated pain and those that relieved it. In addition and often without prompting, patients reported their concerns regarding their hip joint instability and audible hip sounds, but they were not invited to expand on these issues. Patients also volunteered information about their childhood and family history. Although these issues appeared to be of considerable concern to the patient, the physiotherapist did not enquire further.



### 6.8.5 Theme 3: Physiotherapists' Physical Assessment

The physical assessment involved evaluating patients' movements and related function. Collection of these data are a routine part of physiotherapy patient assessment and aim to provide a measurable representation of the patient's physical status (Nicholls 1996). Typically, physical assessment is informed by the findings of the patient's history (Wright et al 2021) and for examination of the hip this could include, for instance, joint range of movement, lower limb strength, gait and postural measures. 'Special tests' can be a part of the physical examination that for hip joint assessment can include the FADDIR test for FAI (Martin and Sekiya 2008; Shanmugarai et al 2020) and the FABER pain provocation test, considered to reflect hip, lumbar or sacroiliac pathology (Bagwell et al 2016). No specific tests of AHD have yet received universal agreement. During the observations, one physiotherapist tested for joint hyperlaxity, which was negative, and one physiotherapist overtly identified a limp when assessing gait in patient SPSWH. Otherwise, the approach by all physiotherapists to the 17 physical assessments of patients was similar and there were no other distinctly obvious differences in content between the Banding grades other than one Band 5 who, rather than carrying out a physical assessment, simply asked the patient

*“do you get any odd sensations?.....are there any changes in the way you walk?”*,

This particular Band 5 did however, end the assessment by stating that more detail would be considered at the next appointment.

Throughout all physical assessments a clear pattern to the collection of information was evident and it was composed of five basic elements: visual evaluation, palpation, trunk and limb movements, special tests, and reflexes (Table 51). The findings from these assessment techniques centred on evaluation of any asymmetry and neurological deficits, the assessment of pain provocation and strength. During their visual evaluation, physiotherapists indicated that they were assessing patients' symmetry. Clear examples of this were seen in the assessment of patient ILGW1 where the physiotherapist assessed standing posture, noting an asymmetry of skin folds. Similarly, visual evaluation of patient PKES1 led to the physiotherapist to observe that the left knee was lower than the right, the left side of the trunk posteriorly, lacked side-flexor folds and the gluteal folds also showed some asymmetry. These observations were not investigated further. Two physiotherapists assessed the patient's ability to stand on tiptoe, which patient 3SC reported as being painful whereas no abnormality was identified for patient EL10B. Squatting was assessed in patient TWTB1 and was noted by the physiotherapist as causing pain and a forward leaning

posture. Similarly for patient DSRGH, squatting was confirmed as being limited and causing hip pain towards the groin area and patient 3SC was identified as favouring their left side throughout the squatting movement, possibly to offload the painful limb. By contrast, patients SPSWH and 4 DOB were deemed to show a normal ability to squat.

*Table 51. Physiotherapy Physical Assessment of Hip Problems*

Visual evaluation for symmetry	Palpation for pain	Trunk & Limb movements for range of motion (ROM) and strength	Special tests for pain, joint clicks and limitations of movement	Reflexes & Sensations for neurological deficits
Posture	Lower limb	Passive ROM	Flexion-Adduction-Internal Rotation test	Patella
1-leg standing	Back	Active ROM	Flexion-Abduction-External Rotation test	Ankle
Tip-toe standing		Resisted ROM	Modified Thomas' test	Lower limb sensations
Squat		Bridging		
Gait				

*Key: Range of Movement (ROM)*

Movements or postures that were abnormal, difficult or that caused the patient pain were also identified through the evaluation of the patients' ability to single-leg stand. This was identified as causing pain in the assessment of patient 4DOB, difficulties with balance for patient 3SC and a difference in the ease with which patient 4DW could weight-bear on their right leg compared with their left. Gait was overtly assessed by just 4 physiotherapists. During this, patient 3SC reported feeling uncomfortable when walking and that the discomfort increased as walking distance increased. Otherwise physiotherapists' findings were expressed as,

*"Gait – fine but currently no pain; limps when painful"* (patient SPSWH)

*"Can walk well when concentrating"* (patient 4DOB)

*"...difficult standing on left leg"* (patient 4DW)

Palpation was applied by most physiotherapists, albeit to different regions and seemingly for quite different purposes. Whereas the palpation of the back and hip region in the

assessments of patients JPCS1, RHKL and ILGW1 did not result in any observable reaction by the physiotherapists, in the assessment of patient ELI0B, the physiotherapist indicated that she suspected nerve irritation in the lumbo-sacral area and in the assessments of patients PKES1, TWTB1, 4DW, 2LD, 3AG and 4DOB, the physiotherapists noted the location of patients' back and hip regions that produced pain in response to varying levels of palpation pressure.

Trunk and limb movements were evaluated mostly by comparing the left and right sides. Passive movements, active-assisted movements, active and active-resisted movements as well as over-pressure were all evident in most of the observed assessments, but each physiotherapist appeared selective regarding which ones they used. The use of these various types of movements appeared to be for the assessment of the point during the movement that pain occurred. It was used for the purposes of identifying whether the movement could be deemed 'normal' or limited and to identify whether one limb was weaker or stiffer than the other. For example, when assessing patient DSRGH, the physiotherapist reported that passive hip flexion on the left limb was limited due to tightness and pain, and that passive lateral rotation on the left hip caused groin pain. Specific objective measurement of the range of movements with a goniometer for instance, was not apparent in any of the observed assessments, rather, general comments about range of movement were expressed, as shown in the assessment of patient EL10B, in which the physiotherapist noted:

*“In supine: Right leg – full range of movement. Left Leg – full range of movements but pain back of thigh. Left leg resisted movements – weaker with slight pain”*

The movement of bridging, which is a closed chain exercise in which the patient raises their pelvis from a crook-lying position, was also assessed in a number of patients. Both bilateral bridging (both feet contributing to weight-bearing) and unilateral bridging (only one foot contributing to weight-bearing) have been shown to preferentially activate gluteal muscles whilst minimizing tensor fascia lata muscle activation (Selkowitz et al 2013), hence difficulties with bridging could indicate gluteal muscle weakness. The physiotherapists' comments during this activity however, most commonly related to pain. For instance, the physiotherapist's observation of patient DSRGH's bridging was that it was limited because of back pain and similar pain-related comments were made by physiotherapists following attempts at the bridging exercise by patient ILGW1,

*“good but some pain, more difficult to do on left leg”*

and patient KL2D1,

*“increased lumbar pain; can go on one leg but pain increases”.*

The so named ‘special tests’, which were observed during these physiotherapy assessments included FADDIR, typically used to identify intra-articular pathology or a likelihood of FAI (Martin and Sekiya 2008), FABER which is generally used as a pain provocation test to indicate hip, lumbar or sacroiliac pathology (Pasic et al 2014; Bagwell et al 2016) and on just one occasion the modified Thomas test, which is considered to assess the extensibility of hip flexors (Vigotsky et al 2016). These tests would therefore seem diagnostically relevant. Physiotherapists’ comments during and after the application of each test related to either the point at which pain occurred, the apparent joint clicking that was evident in some patients and whether movement was limited. In the assessment of patient 3AG, for example, the physiotherapist provided the most detailed comment of all observed special tests stating,

*“Left passive external rotation increases hip pain; [following application of FADDIR] – right causes mild pain; Left causes more pain; [following application of FABER] – right caused click but OK; Left causes pain”.*

Other comments made following the application of these tests included the physiotherapist confirming that with patient 4DW the movements were *“uncomfortable”*; and for patient ILGW1 that they *“caused groin pain”*. In addition, for patient RHKL1 the test led to the physiotherapist’s commentary identifying that the *“hip feels a pull and clicked on initial full flexion”* and for patient 3SC that the right hip tests were *“painful, limited – Left [hip] ok”* and for the same patient the modified Thomas was said to be *“OK”* on the left and *“right: only uncomfortable”*.

Tendon reflex and sensation tests were carried out in just four assessments and in each case, the results were deemed ‘normal’. Two of these (patients 1NG and EL10B) were suspected of having either a prolapsed intervertebral disc with nerve compression or sciatic nerve irritation. By contrast, patient 3AG was thought to have back stiffness caused by hip problems and patient ILGW1,

*“...some impingement and some problems coming from the back”.*

#### **6.8.5.1 Summary of Physiotherapists’ Physical Assessment**

Overall, the physical assessment seemed to be informed by the findings of patient’s history and possibly, the physiotherapist’s developing hypotheses, which Wright et al (2021) consider is typical of clinical assessments. Physiotherapists were seen to use visual

assessment of posture to note asymmetry or balance problems, as well as gait assessment for any signs of a limp. Palpation was used for the evaluation of back and hip regions that identified nerve irritation and the location of pain during differing palpation pressures. Trunk and limb movements were compared between right and left sides and evaluated for strength symmetry, normal or limited ROM and the point during the movement that pain was elicited. Bridging, where the patient raises their pelvis from a crook-lying position, was also used with results expressed in terms of the patient's position when pain provocation was identified. The hip special tests were also applied and used mostly in the assessment of pain, additionally in one assessment the physiotherapist assessed the patient for hyperlaxity.

## **6.8.6 Theme 4: Physiotherapists' Conclusions**

### **6.8.6.1 Diagnosis**

Patients presented with a wide range of problems that included exacerbation of hip pain following ultramarathon training, hip locking since adolescence, hip pain with a history of SUFE at adolescence and back pain with neurological symptoms. Diagnoses emanating from the physiotherapists' initial assessment of these problems included hip tendinosis; hip joint problem; sciatic nerve irritation; back pain with OA, prolapsed intervertebral disc (PID) with nerve compression; and groin strain. Mostly, however, physiotherapists spoke predominantly about 'tight muscles'; 'weak muscles'; and impingement, using diagnostic terminology that was directly linked to the treatment. According to Spoto and Collins (2008), physiotherapy diagnosis differs from medical diagnosis in this way because it involves the assessment of movement dysfunction to establish how function should be restored. Physiotherapy diagnosis therefore informs and guides physiotherapy treatment, rather than it being the medicalised 'label' for a particular pathology. The findings from these observations would support that notion giving the impression that during patient assessment, physiotherapists were driven by identifying how their skills could help the patient, and less about determining the root cause of the patient's problems.

### **6.8.6.2 Treatment**

Overall, treatment centred on exercises to stretch tight muscles and strengthen weak muscles. These exercises were common to almost all observed treatment plans whatever the diagnosis (Table 52). In one case, (patient PKES1) facet joint mobilizations were also part of the planned treatment along with gluteal muscle strengthening to address back stiffness and hip tendinosis, whilst for patient DSRG, as well as exercises for strength and mobility, training to improve general health was also planned. Similarly, for patient SPSWH,

the physiotherapist explained that exercises aiming to keep the patient active and keep their weight down were to be provided. Overall, therefore, the variety of problems presented by patients during these observations were considerably greater than the variety of proposed treatments.

*Table 52. Patient Assessment: Treatment and Management Plans*

Patient Code	Diagnosis	Treatment and Management Plans
JPCS1	None given	Exercises
RHKL1	Weak muscles	Exercises and reassess at next appointment
KL2D1	Tight muscles	Exercises and assess more at next appointment
PKES1	Stiff back and hip pain	Exercises and mobilizations with recommendation for patient to wear insoles
ELI0B	Sciatic nerve irritation	Exercises, stretches and advice on application of heat
ILGW1	Query impingement	Exercises for strength and mobility
TWTB1	Impingement	Exercises and advice on pacing the exercises
DSRGH	Hip joint problems	Exercises for strength and mobility plus increase activity for general health and weight management. Next appointment target further exercises.
6TP	Hip OA and back pain	Exercises and look at back in more detail at next appointment
4DW	Muscle weakness	Exercises for mobilizing and strengthening and review in 2 weeks
1NG	PID/Nerve compression	Exercises and referral for exercise classes; aim for return to squash and running
3SC	Wear and tear of lumbar spine	Exercises; aim for return to sailing; see again in 2 weeks
1CD	Groin strain	Exercises and return in 2 weeks
2LD	OA	Exercises and gradual return to running; return in 2 weeks
3AG	Back stiffness caused by hip problems	Exercises
4DOB	OA/stiffness	Exercises and re-evaluate at next appointment
SPSWH	Degenerative (joint) condition	Exercises to keep active and keep weight down; review in 6 weeks unless pain returns

*Key: Osteoarthritis (OA)*

### **6.8.6.3 Management Plan**

All observed assessments led to physiotherapists providing exercises for the patient to carry out at home with most of these exercises targeting strength and mobility (Table 52). The longer-term aim for several patients was to return to their previous sporting activity and, as mentioned above, improvement in general health and weight management were also part of the overall plan for patients SPSWH and TWTB1. In nine cases, the physiotherapists recommended another appointment, which for most would be in 2 weeks and in 1 case in 6-weeks. For 6 of these patients (patients RHKL1, KL2D1, 6TP, 4DW, 4DOB and SPSWH), the physiotherapists explained that further assessment, review or re-evaluation would occur at this next appointment. In only one physiotherapist's management plan was a referral suggested and that was for exercise classes (patient 1NG). In at least 4 cases (patients ILGW; TWTB1; DSRGH and 3AG) the physiotherapist stated that the hip joint was causing the patient's problems, or that they suspected impingement (FAI), and joint degeneration was diagnosed in one patient, based only on signs and symptoms. The management plan for all patients however, including those with suspected structural problems of their hip joint, did not include consideration for X-Ray referral and evaluation.

## **6.9 Pillar 3 Summary**

Through the observation of 17 assessments of patients with hip pain by 15 physiotherapists, considerable detail was elicited regarding the patients' problems. Physiotherapists' initial enquiry encouraged patients to detail their hip-related problems and concerns. This was followed by the physiotherapists asking reactive questions, which led to an expansion of the patients' information. Patients' description of their pain received most attention, and often appeared to preoccupy the physiotherapist's enquiry leading to numerous questions and physical tests, which gained detailed understanding of the patient's experience of hip-related pain. Although patients readily volunteered information on a range of other features, some of which have been associated with AHD presence, physiotherapists' questioning on these was limited. Physiotherapists may have considered further details unnecessary, but enquiry appeared to end prematurely, particularly when compared with the levels of enquiry regarding patients' pain. Notably, physiotherapists' enquiry appeared to be driven by establishing how physiotherapy intervention could help, possibly at the expense of exploring concerns and features reported by the patient that may have related to the root cause of their problems and that may have benefited from further investigations. Information elicited from patients often included comments on hip joint instability, family history and their childhood history, each of which have been associated with AHD diagnosis, therefore



gaining further details of these issues would appear relevant in patients presenting with hip joint problems. In addition, although the physiotherapists enquired whether patients had received an X-Ray or scan of their hip, it was only the most experienced Band 8 physiotherapist who explicitly considered the available X-Ray image. Other physiotherapists who accepted the X-Ray report of OA or of no radiographic diagnosis seemed to lack consideration of broader diagnoses and no physiotherapist referred for X-Ray evaluation, even when their suspicion was of an unrecognised hip joint problem. Through her diagnosis of cam-type FAI, the Band 8 physiotherapist demonstrated that with the understanding of relevant signs and symptoms, physiotherapists' consideration of relevant X-Ray measures can verify hip joint deformities that could inform their overall patient management plan.

In brief, the observations showed that during the assessment of patients with hip problems, physiotherapists elicit considerable data on the reported features of the hip. Some of these features have, in the earlier pillars of this study and in previous investigations, been associated with the presence of AHD, but, with the exception of patient-reported pain, physiotherapists did not expand their enquiry on most of these features and did not appear to have knowledge of the association of these features with AHD. Apart from the Band 8 clinical specialist, physiotherapists did not appear to consider it necessary at this initial stage of assessment to gain verification of suspected hip joint abnormalities through referral for X-Ray imaging measures.

On completion of the Pillar 3 data analysis, the results and those of Pillars 1 and 2 were mapped, along with the findings of the systematic review (Appendix 10), to assess whether the type of patient data collected by physiotherapists during their assessments provided opportunities for identifying the features that this study has shown to be associated with AHD. This mapping and the resulting assessment are discussed in Chapter 7.

## 7 Discussion of Research Findings

### 7.1 Introduction

This final chapter draws together the findings from the systematic review and the 3 pillars of study that comprised the PhD investigation. Specifically, it provides a discussion of the key research findings and implications for practice. A conclusion that summarises the thesis is offered at the end of the chapter.

Whilst for some considerable time, AHD has been recognised as a likely cause of hip pain in young adults (Troum and Crues 2004), research evidence continues to highlight that the understanding of its clinical presentation, which is required for appropriate management and referral, is not only lacking, but is also distinctly complex (Clohisy et al 2008a; Nunley et al 2011; Ellsworth et al 2021). Definitive diagnosis is dependent upon X-Ray imaging to which specific measures are applied (Clohisy et al 2008b). The anatomical deficits, X-Ray measurements, pathology and the long-term consequences of AHD are well understood (Clohisy et al 2008b; Troelsen 2012), but research evidence highlights that the pre-X-Ray clinical presentation of early AHD is complex and poorly understood (Clohisy et al 2008a; Nunley et al 2011; Ellsworth et al 2021), hence, physiotherapists and other first contact clinicians may not be sufficiently informed of the features that should alert them to suspect AHD presence in relevant patients and justify referral for hip X-Ray evaluation. This is important because, when patients with AHD seek help from a physiotherapist, the ability of that physiotherapist to refer appropriately for X-ray evaluation could accelerate treatment and facilitate successful outcomes (Clohisy et al 2008b).

The first challenge this study tackled was to identify known features associated with AHD presentation. A systematic review of the evidence established that current understanding was limited. Therefore two pillars of study (Pillars 1 and 2) were employed to build on this limited understanding by showing that people with AHD and surgeons specialising in PAO correction of AHD, describe a multiplicity of features associated with the condition. Using thematic analysis, the data generated important findings that extend current understanding of AHD patient presentation.

The second challenge this study addressed was to establish whether opportunities exist during physiotherapy patient assessments to identify the signs and symptoms that compose this extended understanding of AHD presentation. The purpose of doing so was to establish how best to support and inform physiotherapy assessment practice for the improvement of AHD recognition in relevant patients. The observations of physiotherapists' patient assessments (Pillar 3) highlighted that physiotherapists do indeed elicit from the

patients information that, in relevant cases, could indicate the presence of AHD. However, contrary to expectations, the observations showed an emphasis on treatment selection and justification, with less attention directed at establishing the root cause or medical diagnosis of the patient's problems. This evidence suggests that with knowledge of AHD presentation, physiotherapists are well placed to recognise signs and symptoms associated with the condition.

To explain these findings, the discussion begins by clarifying how new knowledge generated by this study builds on current understanding of features associated with AHD. These features are organised into 5 categories namely, Patient Introductory Data; Patient and Family History; Pain; Hip Joint Characteristics; Posture and Gait. These developed from the features that were common to both Pillars 1 and 2 data, with some also being evident in the literature. The categories are discussed to explain and synthesise the evidence that supports their association with AHD presentation and includes evidence from the Pillar 3 observations that relates to the relevance of each feature to physiotherapy assessment. It also explains how knowledge and identification of the signs and symptoms within each category should increase physiotherapists' index of suspicion for the presence of AHD and prompt them to refer relevant patients for X-Ray evaluation and definitive diagnosis. The discussion then clarifies how the findings of Pillar 3 observations demonstrate opportunities for informing practice.

## **7.2 Features Associated with AHD and their Relevance to Physiotherapy Assessment**

### **7.2.1 Category 1: Patient's Introductory Data**

This category comprises four fundamental patient characteristics, identified through the literature and Pillars 1 and 2 of this study as being associated with AHD presentation. The first of these is the young age at which patients first experience hip problems. In Pillar 1, people with AHD described how they initially experienced the onset of problems in either infancy and childhood or at adolescence and young adulthood. Pillar 2 responses from surgeons in this study also referred to the young age of patient presentation, which they considered an alert to the possible presence of AHD. Importantly, the view of one of these specialist surgeons was that persistent hip pain in a young patient should prompt early investigation with plain X-Ray as an initial step. Although the systematic review did not provide evidence that directly confirms young age at presentation as an indicator of AHD, most investigations on the presenting features of AHD centred on young patient age groups (Nunley et al 2011; Bilsel et al 2016; Pranter et al 2018). Pillar 3 of the study went on to

show that the recording of patient age was a routine part of physiotherapy data collection, evident on the addressographs attached to the physiotherapy standardised assessment sheet (Appendix 9). As evidence from this study suggests a possible association of young age with AHD onset, this routinely collected data shows potential for contributing to the foundations of a clinical picture of early AHD.

There is general acceptance in the literature that both infant DDH and adult AHD affect a greater number of females than males (Engesaeter et al 2013; Kapron et al 2015; Sankar et al 2017). The systematic review provided evidence which showed that the sex distribution for DDH was 98% female and for AHD, 88% female (Lee et al 2013). In addition, a high female prevalence was indicated in a study of 180 patients undergoing PAO procedures in an American Department of Orthopaedic Surgery where 139 patients were female and 41 were males (Duncan et al 2015). The study went on to provide evidence that suggests sex-dependant differences, most notably that males with AHD have an increased risk of clinical and radiographic findings of concurrent cam-type FAI with the potential for secondary cam-type FAI following PAO. Coupled with this was the finding that males had reduced hip ROM, and, in comparison with females, this difference was strongly statistically significant for hip internal rotation at 90° flexion (Duncan et al 2015). Pillar 1 reflected the dominance of AHD in females as most patient respondents were female with only 2 being male born in both patient surveys. Recruitment bias may have been an influence as all participants were volunteers, recruited via patient support fora. It is possible that such fora or, indeed, participation in this study may appeal more to females than males, but there were no other indications to support this notion. Moreover, surgeons too described how they have a substantial index of suspicion for the presence of AHD in young female patients with a new onset of hip pain. Pillar 3 observations showed that gender was recorded during patient assessment, therefore, from evidence in the literature and from this study, the preponderance of female gender appears to be a useful contributor to the characterisation of AHD presentation that is relevant to physiotherapy assessment data.

In addition to indicating a greater prevalence of females in AHD, the systematic review also provided evidence to suggest that it is not uncommon for AHD to present bilaterally and that a significantly higher proportion of bilateral hip dysplasia is seen in AHD compared with infant DDH (Lee et al 2013). This high incidence of bilateral AHD was clear in Pillar 1 findings where the demographic data showed that of the 103 PS-1 participants, 70 reported having the condition bilaterally. Whilst this feature was not specifically listed by surgeons in the Pillar 2 survey responses, the potential for a condition to present bilaterally could be an important consideration during patient assessment. Typically, clinicians assessing the problematic lower limb use the contralateral limb for comparison (Gaskell 2013). Therefore

the potential for a condition to present bilaterally may confuse diagnosis as differences between limbs are likely to be less obvious than in the unilateral condition. This may explain why, as described by some respondents in Pillar 1, bilateral hip dislocation, clearly identifiable on X-Ray, had been overlooked during physical examination. Throughout Pillar 3 observations, physiotherapists were shown to use the contralateral limb for comparison of hip movements and strength. An awareness of the possible potential for AHD to present bilaterally, and thus risk masking abnormalities, would therefore be a relevant consideration that should inform their assessment of young patients with idiopathic hip issues.

Another feature evident in Pillar 1 findings was that patients reported having had repeated appointments with a range of different clinicians. Whilst these included GPs, physiotherapists and various secondary care specialists, patients reported that the appointments rarely led to long-term improvements in their hip condition, except for those who received THR. Only when the patient was referred to a young persons' hip clinic or PAO surgeon did they report receiving effective treatment. Then, in all cases, AHD diagnosis was confirmed. This is consistent with the findings of Nunley et al (2011) who found that patients could be evaluated by up to 11 healthcare providers before definitive diagnosis was established. Attention paid to the number and range of clinical appointments experienced by a patient, particularly where there has been little if any progress or improvement in their hip condition, may therefore provide valuable insight into the need for redirection of the patient for specialist referral. During Pillar 3 observations, it was evident that physiotherapy enquiry included verifying from the patient whether hip X-Rays or other tests had been carried out. Extending this enquiry to establishing the patient's record of previous clinical assessment appointments would appear possible and could provide useful insight into the diagnosis-related challenges experienced by the patient over time.

For this first category, four features of patients' introductory data have been identified by this study as being possible contributors to the characterisation of AHD presentation. Knowledge of these may be useful for informing physiotherapy patient assessment and based on this evidence, it is suggested that the features are considered by physiotherapists to contribute to their clinical reasoning. Table 53 summarises these features and their relevance to physiotherapy assessment.

Table 53. Mapping of Category 1: Patient's Introductory Data Associated with AHD

Characteristics/ALERTS	Features of AHD indicated by Systematic Review	Features of AHD experienced by Pillar 1 Patients	Features of AHD reported by Pillar 2 Surgeons	Pillar 3: Observations of Physiotherapists and resulting recommendations for AHD recognition
Young age	No specific links with young age established; association with young age only indicated by age groups studied in AHD investigations	Hip problems initially experienced in infancy, childhood, adolescence or during young adulthood	Young age of patients a distinct consideration in AHD	Data available and were routinely recorded. Consideration of young age within clinical reasoning is recommended
Female (predominantly)	Predominantly but not exclusively female. Males with AHD more likely to have cam FAI	Predominantly female respondents	Reference made only to females	Data available and were routinely recorded. Consideration of female gender within clinical reasoning is recommended
Bilaterality	Increased rates of bilaterality in AHD compared with infant DDH	Bilateral AHD reported by most Pillar 1 respondents	Nil reported	Possibility of bilaterality could inform evaluation during comparisons with contralateral limb. Consideration of bilaterality within clinical reasoning is recommended
Repetition of clinical appointments	Nunley et al (2011) reported patients could be evaluated by up to 11 healthcare providers before definitive diagnosis was established	Repeated appointments reported with a range of healthcare professionals including GPs, physiotherapist, Radiologists, Orthopaedic Surgeons (Paediatric, Sports Medicine, Young Adult Hip surgeons), Paediatricians, Rheumatologists, Chiropractors, Osteopaths and Podiatrists.	Nil reported	Details of patients' record of previous clinical appointments could be elicited and appear relevant. Consideration of past appointments/consultations within clinical reasoning is recommended.

## 7.2.2 Category 2: Patient and Family History

The background to this study (Chapter 2) explained that hip dysplasia is often described as representing a spectrum of hip abnormalities that range from infant DDH through to adult AHD and that, if left untreated, DDH continues into AHD (Ortiz-Neira et al 2012; Sewell and Eastwood 2011). The secondary OA that eventually results is considered the greatest reason for THR in females aged under 50 years (Sink et al 2014), yet 90% of AHD is thought to be unrecognised in young people (Price and Bramo 2012). A range of between 8% and 60% of patients with a history of treatment for DDH have been reported as having residual AHD at skeletal maturity (Okano et al 2015), yet evidence presented in the systematic review (Chapter 3) also suggests that AHD presenting for the first time at adolescence or early adulthood represents a different aetiology from infant DDH (Lee et al 2013).

Uncertainty is evident regarding the nature of a link between these two conditions, if indeed there is one. The results of Pillars 1 and 2 of this study indicate that AHD could be associated with a patient history of any infant or childhood hip concerns. This could include issues such as delayed walking or difficulties with crawling, hypermobile hips, a 'party trick' of popping their hip out of its socket, a preference for W-sitting and an inability to sit cross-legged, even when a later or adult first-onset of hip problems was reported. In addition, evidence from the systematic review as well as from the patients' and surgeons' surveys suggest that hypermobility may be evident in the childhood history of those with AHD (Samper et al 2015; Bilsel et al 2016).

The variety of features and the onset age of hip problems reported by Pillar 1 respondents suggest that multiple causes of AHD are likely including some that relate to a history of infant DDH, whether diagnosed and treated or undiagnosed and untreated. In addition, a new adolescent or adult onset of problems may be a different aetiologic entity from infant DDH. This is supported by the findings of Lee et al (2013) and Okano et al (2015) and whilst there is no clear agreement regarding hip dysplasia onset patterns, the literature does provide some suggestion that morphologic abnormalities of the hip joint that are labelled 'dysplasia' comprise aberrations of hip development. These can present in various ways and at various stages of skeletal growth and maturity (Okano et al 2015). Additionally, the literature highlights that like infant DDH, adult AHD is also recognised as a precursor of secondary OA (Agricola et al 2013; Morvan et al 2013; Wyles et al 2017), but unlike DDH, the poor recognition of adult AHD means that secondary OA, which limits surgical options, is less avoidable. Increased evaluation of patient's history of hip characteristics could therefore be important when assessing patients with hip problems as it may provide physiotherapists and other first contact clinicians with good reason to consider the possible presence of AHD as part of their differential diagnosis.

In addition to AHD indicators of the patient's physical presentation, it is possible that family patterns of the disorder may increase the AHD risk for an individual. As far back as 1950, Corrigan and Segal reported on the familial links evident in the high incidence of hip dysplasia in a North American settlement of Island Lake, Manitoba. Their findings suggested that the primary aetiologic factor for hip dysplasia was a hereditary one. The consequences of inbreeding in this settlement had resulted in increased numbers of individuals being descended from the same ancestor. This consanguinity supported the genealogical tracing of hip dysplasia occurrence and the restriction of the condition to certain families. Then in 1970, Wynne-Davies identified a shallowness of the acetabulum in the parents of infants with, what was then termed, congenital dislocation of the hip (CDH) and is now known as DDH. The study established that infants with a late diagnosis of hip dysplasia, that is normally months after the neonatal period, exhibited an inherited form of AHD. More recent evidence explained in the systematic review (Chapter 3), adds further support to the notion of heritability. Li et al (2013) showed that recurrent risk in siblings of probands with hip dysplasia, was at least 10 times greater than in the siblings of non-hip dysplasia families. Additionally, a study by Carroll et al (2016), demonstrated that almost one third of first-degree and second-degree relatives of patients with infant DDH had unsuspected radiographic, and thus 'occult' HD, most of whom were clinically silent until after the age of 30 years. Such findings are consistent with the results of this study's Pillar 1 patient-surveys that showed that a number of respondents recognised other members of their family as having experienced hip problems from a young age. Of the 64 PS-2 respondents, a total of 72 relatives were known to have hip problems. More than a dozen of these relatives were described as having had a confirmed diagnosis of AHD or infant DDH, whilst others had undiagnosed long-term hip problems that led to THR at a young age. Respondents appeared to raise this issue of recurrent family occurrence either because they felt it was a diagnostic indicator that should not be ignored, or because of their concern for heightened risk to their children's potential for hip problems and the desire to ensure timely diagnosis and early preventative treatment for them. Specialist surgeons in the Pillar 2 study agreed. Almost 60% listed family patterns of AHD, DDH or hip OA occurrence at a young age as being relevant to their assessment of patients with the condition. The features of patient and family history associated with AHD in this study's findings are summarised in Table 54 and their relevance to physiotherapy patient assessment is suggested.



Table 54. Mapping of Category 2: Patient and Family History Associated with AHD

FEATURE	Features of AHD indicated by Systematic Review	Features of AHD experienced by Pillar 1 Patients	Features of AHD reported by Pillar 2 Surgeons	Pillar 3: Observations of Physiotherapists and resulting recommendations for AHD recognition
<b>Infant/childhood History</b>	Indications of an association between childhood hypermobility and AHD	Reported history of: Infant hip problems/DDH Slow to walk or crawl Preference for W-sitting Hypermobility Gymnast/high intensity training Cross-legged sitting difficulties	Reported association of AHD with any infant hip concerns and altered joint ROM	<b>Infant/childhood history was not collected but consideration of this for clinical reasoning is recommended</b>
<b>Family History</b>	Indications of diagnostic relevance of having relatives with DDH or THR before age 65 years and record of siblings with OHD having onset of hip problems after the age of 30 years	Reports of relatives with DDH, AHD, OA/THR at a young age (pre-60 years old)	Reported association of AHD with other family members having a history of dysplasia	<b>Family history was not collected but consideration for clinical reasoning is recommended.</b>

Key: Acetabular Hip Dysplasia (AHD); Occult Hip Dysplasia (OHD); Developmental Dysplasia of the Hip (DDH) Osteoarthritis (OA); Total Hip Replacement (THR); Range of Movement (ROM).

Recognition of hereditary factors could provide direction for regular clinical checks, enabling earlier and therefore more effective management. Understanding the familiarity of a particular condition within a family can also provide the individual with lifestyle choices whereby behavioural or environmental factors that are habitual within a family and associated with the condition, can be avoided (Ruffin et al 2011). Establishing familial patterns of AHD would therefore offer guidance for ensuring regular clinical assessment for early diagnosis and provide the individual with choices. These may include encouraging the avoidance of factors that could be associated with accelerating the condition's destructive progress such as possibly, the reported 'party trick' of popping the hip out of the socket.

The evidence supporting an association of AHD with a positive family history of hip problems at a young age is compelling. It is important because the finding appears to provide a valuable contribution to the developing picture of clinically relevant indicators of AHD. Whilst more needs to be understood about possible genetic links, recognition of family traits can help to determine the risk to an individual of having the condition. This could enable these individuals to take steps to mitigate damaging effects and could provide a useful indicator for alerting physiotherapists to the possible presence of AHD in relevant patients.

### **7.2.3 Category 3: Pain**

Currently, what we know about AHD presentation is largely based on Nunley et al's 2011 study that followed 57 patients (65 affected hips) with symptomatic AHD. The findings identified pain as being the most reported feature of the condition. Pain onset was largely described as being insidious, with a moderate to severe, sharp or dull quality (Nunley et al 2011). This description reflects the features of pain reported by patients in Pillar 1 of this study, however, their reports as well as those of surgeons in Pillar 2, provide a greater level of insight. By expanding on current evidence, the results of Pillar 1 indicate that patients with AHD describe how the insidious nature of the mild occasional discomfort they had experienced initially, developed over time to more intense, constant, unrelenting and debilitating pain. For a large proportion of these patients, sudden, more severe episodes of pain were also experienced but only occasionally and for the majority, this severe pain led to the muscles around the hip feeling very tight. Similarly, Pillar 2 results show that specialist surgeons described how an insidious onset of unrelenting, non-specific pain lasting more than 3 months and with no clear cause contributed to an increased suspicion of AHD presence, particularly when those presenting with such pain were in the young-adult age bracket. The anatomical location of this pain was identified in the literature as being mostly in the groin but could also be sited on the lateral aspect of the hip or more rarely the anterior

aspect of the thigh or the buttock (Nunley et al 2011). Pillars 1 and 2 findings support this, but patient responses in Pillar 1 also showed that as well as the hip region, pain, particularly in the early stages of the condition, had been evident in the lower back or knee, and pain in these regions preceded more problematic hip pain. It is possible that this was either referred pain from the hip, or pain due to the overuse of soft tissues because of the postural readjustment caused by offloading the painful hip. It is also possible that, in later stages of AHD, the location of the reported pain can misguide diagnosis because of the presence of coexisting conditions. As previously mentioned, it is well accepted in the literature, and clinically, that any abnormality of the hip structure that changes the joint's mechanics is associated with secondary OA (Lever and O'Hara 2008; Wyles et al 2017). Also, during extremes of movement, abnormal contact between the proximal femur and acetabular rim caused by the dysplastic joint can lead to labral damage and cam-type FAI (Lever and O'Hara 2008), which is more common in males (Duncan et al 2015). Hence, it would be useful for clinicians to be aware that both pain nature and location of these conditions can mask features that potentially characterise AHD and that in such situations, AHD could, in fact, be the root cause of the problems. It would, however, be remiss not to consider the risk of over-investigating symptoms, particularly where those symptoms may indicate various diagnoses that may respond to conservative treatment. Nevertheless, as understanding of patient presentation builds, adequate evaluation and knowledge of signs and symptoms associated with AHD and other intra-articular abnormalities generally, should, as a Pillar 2 specialist surgeon suggests, signal the need for X-Ray evaluation to establish definitive diagnosis.

Further characterisation of pain, evident in both the literature and Pillars 1 and 2, shows that it is aggravated by activities such as prolonged walking, running, standing, pivoting manoeuvres and prolonged sitting. Expanding on this understanding, patient responses in Pillar 1 and surgeons' responses in Pillar 2 provide evidence that prolonged sitting includes car journeys due to problems related to sitting in confined spaces and driving manual cars because clutch use can be painfully challenging. In addition, because of the confined space, getting in and out of a car has also been described as increasing pain symptoms. Furthermore, shopping trips, climbing and descending hills and stairs as well as any movement involving deep hip flexion were all reported to aggravate pain for Pillar 1 patients.

The results of Pillar 1 provided further insight regarding previously unrecognised pain triggers that patients associated with their AHD. Of the PS-2 patient respondents, 30% agreed that pregnancy and childbirth considerably aggravated their hip pain. In an overview of the current knowledge of pregnancy-associated hip dysplasia problems, Simionescu et al's (2021) concluded that hip dysplasia is not associated with high-risk complications during

pregnancy or with increased difficulty in vaginal delivery, and that women with the condition can manage pregnancy and childbirth successfully. The study, however, largely centred on the influence of the women's previous surgical treatment for hip dysplasia, the resulting alteration to pelvic anatomy and the impact this might have upon the mechanism of birth. These findings are mirrored by advice given by the International Hip Dysplasia Institute (IHDI 2021) that it is not common for either AHD or its corrective surgery to cause problems during childbirth and normal delivery can be expected. This evidence and advice, however, revolve around the mechanism of delivery not the patient experience during delivery and the potential for longer term consequences. Research evidence on the patient experience is sparse, and it seems that only recently have potential difficulties been recognised, and then only briefly. In 2018, Jones et al discussed a case history of a 28-year-old female with borderline AHD. She had received several surgical procedures to address her hip problems including acetabuloplasty, osteochondroplasty and labral repair and had progressed well for 8 years. During pregnancy, however, she developed hip pain with continued deterioration of her hip that ultimately led to THR within 10 years. The authors concluded that the increased ligament laxity due to hormonal changes of pregnancy, caused hip joint instability that accelerated OA development. This might explain why a large proportion of the women surveyed in the Pillar 1 study for whom the feature was relevant, described how pregnancy or childbirth worsened their hip condition.

There has been nothing in previous literature to show what people with AHD find effective in relieving their pain symptoms but the study by Nunley et al (2011) did point to treatment options recommended by healthcare providers. These included nonsteroidal anti-inflammatory drugs (NSAIDs), opioids, physical therapy and surgery. Pillar 1 findings support the notion that the use of these treatment modalities is effective for some patients with AHD. However, these pain management methods appear to have much in common with those used in other conditions of the hip (Ahuja et al 2020) and do not therefore indicate features that contribute to distinguishing AHD from other hip conditions. They do, nevertheless, serve to confirm the severity of pain experienced by those with AHD.

A summary of all identified features of pain in AHD is provided in Table 55 and their relevance to physiotherapy patient assessment is suggested.

Table 55. Mapping of Category 3: Pain Characteristics associated with AHD

FEATURE/ALERTS	Features of AHD indicated by Systematic Review	Features of AHD experienced by Pillar 1 Patients	Features of AHD reported by Pillar 2 Surgeons	Pillar 3: Observations of Physiotherapists and resulting recommendations for AHD recognition
<b>Pain Development</b>	Limited evidence of an insidious onset of sharp or dull pain, mostly activity-related	Consistent reports of initially mild and intermittent ‘niggles’ becoming persistent, intense debilitating pain <u>at a young age</u>  Possibly preceded by knee, leg or lower back pain	A new, insidious onset of chronic, non-specific pain <u>at a young age</u> .  More than 3 months of consistent pain post-sport	<b>Pain development routinely assessed.</b>  <b>Consideration of pain development within clinical reasoning is recommended</b>
<b>Pain Location</b>	Groin  Lateral hip	Groin  Lateral hip  Hip region	C-distribution  Groin or lateral hip	<b>Pain location routinely recorded.</b>  <b>Consideration of pain location within clinical reasoning is recommended.</b>
<b>Pain Triggers/Aggravators</b>	Activity related: walking, running, standing, pivoting, sitting, standing from sitting	Increased intensity of sport/athletic training.  Pregnancy/childbirth.  Prolonged walking, running, standing, sitting.  Sitting in confined space (car).  Any activity involving deep flexion.	Persistent pain, particularly post-sport  Pain rising from a chair, accessing a car, restricted foot access or sitting in confined spaces	<b>Pain triggers and aggravators routinely recorded.</b>  <b>Consideration of pain triggers and aggravators within clinical reasoning is recommended.</b>

#### 7.2.4 Category 4: Hip Joint Characteristics

AHD is defined radiographically as a steeply oriented, shallow acetabulum causing femoral head under coverage (Troelsen 2012). This abnormal anatomy results in an inherently unstable hip joint, which Kuroda et al (2013) suggest is proportional to the degree of dysplasia. In their summary of symptoms associated with hip dysplasia in skeletally mature adults, Nunley et al (2011) listed the occasional presence of hip subluxation in relation to features of joint instability. The finding is consistent with those of the Pillar 1 patient responses that showed that although just 12.5% described a feeling of hip joint instability at their initial clinical assessment, at a later point in the trajectory of their AHD, that figure was elevated to 77% of patients experiencing hip joint instability. Additionally 41% recorded that such instability led to their hip joint repeatedly dislocating or subluxating. This is broadly supported by Bilsel et al (2016) who provide evidence that suggests an association of AHD joint instability with joint hyper-laxity or hypermobility. Several of the surgeons responding to the Pillar 2 survey agree, citing signs of joint instability and hypermobility as features that would increase their diagnostic suspicion of AHD presence. These findings may be explained by the fact that joint instability resulting from the structural changes that characterise AHD would be magnified by the ligamentous laxity of hypermobility. This is corroborated by Pillar 1 findings that show that hypermobility is often reported. In fact PS-2 results showed that more than 50% of the patient respondents described how, as children, they were very flexible or hypermobile, and for some, this was used to their advantage as it benefitted their gymnastic or athletic achievements. Indeed, many of the Pillar 1 respondents associated their hip problems with their previously high involvement with gymnastics, athletics, dance, hockey or football.

Hypermobility or hyper-flexibility is thought to be caused by a genetic predisposition affecting collagen structure which, due to the resulting joint laxity and instability, can lead to localised biomechanical overload and chronic soft tissue injury (Kuma and Lenert 2017). The more serious hyper-flexibility disorder often referred to as Ehlers-Danlos syndrome (EDS) is considered to have a prevalence of at least 3%, but it is poorly understood and therefore thought to be underdiagnosed (Kuma and Lenert 2017). Due possibly to their lax ligaments, people with such hyper-flexibility or hypermobility tend to have decreased muscle mass and strength. Hyperalgesia contributing to musculoskeletal pain, has also been reported in people with hypermobility along with reduced proprioceptive activity which, due to its influence on joint instability increases the risk of joint injury (Kuma and Lenert 2017). These features draw parallels with the hypermobility, abductor muscle weakness and joint instability problems reported by AHD patients in Pillar 1 and a possible association between hypermobility and AHD conditions is suspected (Bilsel et al 2016; Samper et al 2015).

Pillar 1 patients who describe their experiences of hypermobility indicate their feelings of concern about the lack of clinical attention the symptom appears to draw. Earlier examples of these Pillar 1 patient experiences explained in Chapter 6 illustrate the potential importance of hypermobility as a sign worthy of attention. For instance, Anna, who described herself as hypermobile, explained how this and her joint instability, which she felt were ignored by clinicians, resulted in bilateral hip joint subluxation that was severe enough for an ambulance to be called and her hip reports to finally be taken seriously. Greater diagnostic attention to hypermobility and hip joint instability appears to be indicated as an association of these features with AHD could be recognised.

As well as joint instability, some 90% of Pillar 1 patient respondents reported experiencing the audible hip sounds of clicking, cracking or clunking that they often described in association with pain and the sensation of hip joint locking. Whilst surgeon responses in the Pillar 2 study showed only minimal support for the contribution of these features to their suspicion of an AHD diagnosis, similarities between the Pillar 1 findings and those in the literature are evident. Nunley et al (2011) also described symptoms of hip joint catching, clicking and popping in 67% of their AHD patient cohort and joint locking in 23%. Based on these sources of evidence, there appears to be good reason to suspect audible hip sounds and hip joint locking as being associated with AHD. Although such features may present in various conditions of the hip, when present with other features associated with AHD, could contribute to the characterisation of the condition.

During the Pillar 3 observations, patients sometimes volunteered information regarding their hip joint sounds, their feeling of hip joint instability and their hypermobility and although physiotherapists were not seen to overtly assess patients for these characteristics during the physical assessment, the opportunity for physiotherapists to record such features was clearly shown. Therefore during patient assessment, the evidence suggests that the presence of such features should not be overlooked. Mapping of these hip joint characteristics and identifying their relevance to physiotherapy assessment are summarised in Table 56.

Table 56. Mapping of category 4: Hip Joint Characteristics Associated with AHD

FEATURE/ALERTS	Features of AHD indicated by Systematic Review	Features of AHD experienced by Pillar 1 Patients	Features of AHD reported by Pillar 2 Surgeons	Pillar 3: Observations of Physiotherapists and resulting recommendations for AHD recognition
<b>Hip Joint Instability</b>	Subluxation	Hip joint dislocation, subluxation and the feeling that the hip ‘pops out of it socket’ repeatedly reported	Hip joint giving-way Joint instability	<b>Opportunities evident for identifying the presence of hip joint sounds, hip joint instability and hypermobility during assessment. Consideration of these for clinical reasoning is recommended</b>
<b>Hypermobility</b>	AHD more frequent in patients with hyper-laxity/hypermobility	Hypermobility commonly reported often in association with gymnastic ability	Hypermobility may be present	
<b>Audible Hip Joint Sounds</b>	Snapping, popping or Locking	Clicks Clunks Popping Locking	Clunking, clicking, snapping	

Key: Acetabular Hip Dysplasia (AHD)



### 7.2.5 Category 5: Posture and Gait

Very few published studies provide evidence of why patients with AHD might experience changes to their gait, yet Nunley et al (2011) found that the most common functional loss reported by symptomatic patients with AHD was a limp, even during short walking distances. A limp is a frequent consequence of many lower limb pathologies and can be a compensatory response to prevent pain in the affected leg (Sawyer and Kapoor 2009). However, the evidence from Nunley et al (2011) suggests that in AHD, a limp is commonly associated with a Trendelenburg gait. Liu et al (2012) provide a possible explanation for this as they show that adults with AHD can have changes in the size, density and length of their gluteus medius muscle. This muscle, which is an abductor of the hip, has a key role in weight-bearing activities where it prevents the contralateral pelvis from dropping when the limb on that side is raised off the ground (Palastanga et al 1998). Hence, the reduced functioning of the muscle causes the pelvis to drop on the opposite side, and the characteristic Trendelenburg gait. The majority of Pillar 1 patients described their limping gait with almost 60% of PS-2 patient respondents relating to the fact that their pelvis drops on one side whilst walking. These alterations to gait were features evident in Pillar 2 responses where, as well as a limp, surgeons noted that in AHD, a Trendelenburg gait or weak, easily fatigued hip abductor muscles would be expected. Recently, in detailing current understanding of gluteus medius weakness and Trendelenburg gait, Gandbhir et al (2021) describe how a bilateral Trendelenburg can result in a waddling gait that they associated with hip dysplasia. This could explain why a number of Pillar 1 respondents reporting the presence of bilateral AHD, also described having a waddling, hobbling, shuffling or rolling gait. On the other hand, a limp could be caused by a leg length discrepancy and whilst published evidence investigating this is lacking, more than one third of the Pillar 2 surgeons listed leg length discrepancy as a possible feature of AHD. This is consistent with findings from Pillar 1 where 50% of patient respondents reported having gait problems because of their leg length discrepancy. During the Pillar 3 observations, physiotherapists assessed patients' posture and gait, they also evaluated muscle function and strength. Therefore, the contribution of a limp, a Trendelenburg gait and leg length discrepancy to their patient assessment and their clinical reasoning would appear valid and could provide an indication of where the patient's hip problem originates. The evidence also suggests good reason to add these features to the developing picture of AHD presentation.

Other alterations to gait reported, albeit less frequently, by Pillar 1 patients and Pillar 2 surgeons included the possibility of an in-toeing stride or inwardly rotated knees and a pattern of short, uneven steps. Biomechanical analysis using sophisticated technology has

shown that patients with AHD demonstrate decreased hip extension during walking with increased ankle pronation (Skalshøi et al 2015), which could explain the presence of these short, uneven steps. However, such abnormalities were only briefly reported by a minority of Pillar 1 respondents and further biomechanical analysis is required to understand the detail and possible occurrence of these changes to gait in patients with AHD. In addition, the technology required to measure such changes to gait is mostly unavailable in clinical physiotherapy departments at the present time.

Pillar 1 patients also referred to their experiences of recurrent falls or stumbles, and many described an awareness of their postural changes. One-third described having a forward-leaning posture that they felt was due to their tight hip flexors. Patients described managing their hip pain by resting in a reclined sitting posture, limiting the degree of hip flexion. It is conceivable that this reclined posture enhances pain relief by relaxing possibly overworked hip flexors. Evaluation of a patient's posture and gait is considered valuable during the physiotherapist's physical assessment as walking ability, and deviations from normal gait and posture inform therapeutic decision-making (Senden et al 2012). Posture and gait abnormalities that characterise AHD are therefore valuable to the clinical recognition of the condition and may contribute to the developing clinical picture of AHD that would be relevant to physiotherapists. Key features of posture and gait associated with AHD and identified in this study are summarised in Table 57, which also includes recommendations for physiotherapy assessment.

Table 57. Mapping of Category 5: Posture and Gait Characteristics Associated with AHD

FEATURE/ALERTS	Features of AHD indicated by Systematic Review	Features of AHD experienced by Pillar 1 Patients	Features of AHD reported by Pillar 2 Surgeons	Pillar 3: Observations of Physiotherapists and resulting recommendations for AHD recognition
<b>Posture</b>	Nothing reported	Postural abnormalities due to: back pain, scoliosis and lordosis  Postural asymmetry	Nothing reported	<b>Opportunities evident for identifying the presence of postural abnormalities during assessment. Consideration for clinical reasoning is recommended</b>
<b>Limp</b>	Limp [Bilateral Trendelenburg which can result in waddling type of gait and has been associated with hip dysplasia]	Waddle, hobble, shuffle or roll  Off-loading painful hip  Trendelenburg gait  Pelvis drops on one side/weak hip muscles  Associated with leg length discrepancy  Recurrent stumbles/falls  Forward-lean due to tight flexors  Toes and knees rotate inwards  Short, uneven steps	Trendelenburg gait  Weak or fatiguing hip abductors  In-toeing gait	<b>Opportunities evident for identifying the presence of gait abnormalities during assessment. Consideration for clinical reasoning is recommended</b>

### **7.3 Physiotherapy Assessment and Opportunities for Practice Intervention**

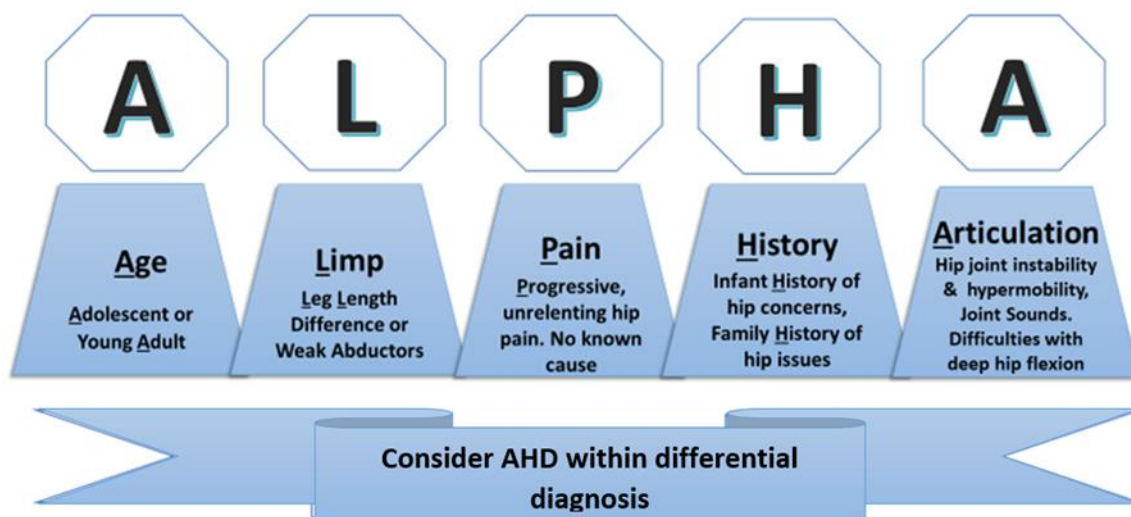
An obvious finding of the Pillar 3 observations was that physiotherapists were well placed to initiate early recognition of AHD in relevant patients, because they have the skills and use the lines of enquiry and assessment techniques required to collect the appropriate patient data. This could facilitate early referral for X-Ray and definitive diagnosis for relevant patients. However, the observations also support the findings of Payton's 1985 study that indicates that the sequence of questioning during patient assessment is confined to what the physiotherapist considers clinically relevant. Additionally, as Huhn et al (2019) state, the decision about what is clinically relevant is influenced by the physiotherapist's knowledge and their approach to clinical reasoning. Evidence to support understanding of AHD presentation has been lacking, making it difficult for physiotherapists and other clinicians responsible for assessing patients with hip problems to recognise when AHD should be suspected. This problem appeared to be evident during Pillar 3 observations, because physiotherapists elicited considerable information about patients' hip problems that included descriptions of the features that the results of Pillars 1 and 2 of this PhD study suggest are associated with AHD presence. However, further investigation by the physiotherapist into many of these features, such as hip joint instability, hypermobility, a positive family and childhood history was not forthcoming. By contrast, physiotherapists used repeated levels of enquiry and physical assessment techniques to gain a detailed understanding of the patient's pain and muscle weakness. In fact, the results of Pillar 3 observations suggest that during assessments of patients with hip problems, physiotherapists focussed overtly on patient symptoms amenable to physiotherapy intervention, seemingly to justify their treatment approach. This indicated that physiotherapists had a preoccupation with such symptoms that may have been at the expense of establishing the root cause of the patient's problem or diagnosis. Yuen et al (2018) refer to this as 'anchoring' which, along with 'premature closure' of an enquiry, is identified as being a bias evident in assessment that is due to a lack of knowledge that can lead to inaccurate conclusions. During Pillar 3 observations, broader consideration of diagnostic reasoning was evident in only one observed assessment, during which the physiotherapist firstly evaluated the patient's hip X-Ray before meeting the patient. Through doing so, she diagnosed the presence of cam-type FAI, which was shown to inform her overall management plan for the patient. The Band 8 physiotherapist was an experienced clinical specialist, and she demonstrated that with relevant knowledge physiotherapists can make constructive use of X-Ray to inform or support their assessment findings and, as this case demonstrated, to verify hip joint deformities. Providing physiotherapists with knowledge of the features that characterise AHD presentation should enhance their ability to identify when the condition ought to be

suspected. This could lead to accelerated referral for and constructive use of X-Ray assessment that might fast-track diagnosis, possibly before the onset of secondary OA.

### 7.3.1 Application of Study Findings for Differential Diagnosis

Early diagnosis of AHD before the onset of secondary OA is important but it poses a considerable challenge since features of AHD presentation can be subtle and poorly distinguishable from other conditions involving the hip. Therefore, physiotherapists and other relevant clinicians need firstly to ensure that they recognise when AHD should be considered within their differential diagnosis. To facilitate this, I have designed the Alpha memory aid shown in Figure 7.1, which uses key characteristics identified by this study as being associated with AHD. The purpose of the Alpha memory aid is to prompt clinicians into including AHD into their differential diagnosis and hypothesis testing when the relevant features are identified during patient assessment.

Figure 7.1 Alpha Memory Aid: An Acronym for AHD Awareness



Secondly, because some of the features associated with AHD are poorly distinguishable from other conditions involving the hip, establishing the nuances of their presentation in AHD is an important asset for differential diagnosis. To address this, the extended knowledge of AHD-associated signs and symptoms identified in this study were grouped into the following categories: 1) patient's introductory data, 2) patient and family history, 3) features of pain, 4) hip joint characteristics, 5) posture and gait. Next, the signs and symptoms contained within these five categories were listed and each characteristic was compared with those representing other conditions, which in Chapter 2 'Differential Diagnosis' were shown to present in a similar way to AHD. The listed signs and symptoms associated with these other conditions are not exhaustive, but those included in Table 58 aim to provide insight into how the AHD signs and symptoms identified and drawn together by this study, can collectively

contribute to distinguishing ADHD presentation from other pathologies with which it is commonly confused.

Table 58. Categories of AHD Features for Differential Diagnosis

**CATEGORY 1: PATIENT’S INTRODUCTORY DATA**      **Key: CAM Femoroacetabular Impingement (CAM FAI); Non-traumatic Avascular Necrosis (NT-AVN)**

AHD	FEATURES	Comparison with other Hip Conditions	
Initial problem: infancy/childhood or adolescence/young adulthood. Young age of patients a distinct consideration	<b>YOUNG AGE</b>	Most commonly, adults aged 30-45 years	CAM FAI
		Young to middle-aged adults	NT-AVN
		Wide age range	Stress Fracture
Predominantly affecting females Males with AHD more likely to have concurrent cam FAI	<b>FEMALE</b>	More common in men	CAM FAI
		Sex-linked influences e.g., low bone density of females	Stress Fracture
High rates of bilaterality – caution may obscure findings when comparing limb function	<b>BILATERALITY</b>	Typically, bilateral	NT-AVN
Repeated appointments with a range of healthcare professionals and no notable improvements	<b>REPEATED CLINICAL APPOINTMENTS</b>	Repeated appointments possibly associated with establishing focused medical history	Non-orthopaedic conditions
		Appointments associated with response to trauma	Extra-articular conditions
		Appointments due to management of possible renal disease; Metabolic bone disease or bone tumors	Stress Fractures

	Appointments possibly due to alcohol misuse; treatment with chemotherapy, immunosuppressants or steroid	NT-AVN
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CATEGORY 2: PATIENT'S HIP HISTORY AND FAMILY HISTORY

AHD	FEATURES	Comparison with other Hip Conditions	
Any infant hip concerns Hypermobility in childhood Preference for W-Sitting as a child Difficulties sitting cross-legged	<b>INFANT/ CHILDHOOD HISTORY</b>	Similar features may be evident in patients with Downs syndrome or hypermobility syndromes such as Ehlers-Danlos, but hip dysplasia is often seen to co-exist with these	
Relatives with DDH/AHD or Hip OA/THR at a young age	<b>FAMILY HISTORY</b>	Possible genetic predisposition	NT-AVN

CATEGORY 3: CHARACTERISTICS OF PAIN

AHD	FEATURES	Comparison with other Hip Conditions	



<p>Initially insidious onset of mild &amp; intermittent ‘niggles’ becoming persistent, intense debilitating pain <u>at a young age</u> lasting more than 3 months</p> <p>Hip pain possibly preceded by knee, leg or lower back pain</p>	<b>PAIN DEVELOPMENT</b>	Pain that is not triggered by hip activity or joint angle position	Non-orthopaedic Conditions
		May be associated with trauma or increased repetitive weight-bearing	Extra-articular conditions
		Typically, insidious onset; Associated with abnormal stress on normal bone or abnormal bone and normal stress	Stress Fracture
		Sudden onset sharp or pinching pain	Labral irritation/damage
Groin; Lateral Hip; C-sign Distribution of Pain; Hip Region	<b>PAIN LOCATION</b>	Location often indicative of the affected structures being in that region	Extra-articular Conditions
		Deep groin, hip or thigh pain	Stress Fracture
		Hip, thigh and/or groin pain	NT-AVN
		Localised pain	Labral irritation/damage
Increased intensity of training	<b>PAIN AGGRAVATORS</b> <i>[continued]</i>	Repetitive weight-bearing	Extra-articular Conditions
Pregnancy/childbirth		Repetitive distance running; sudden surges in training intensity and duration	Stress Fracture
Prolonged walking, running, standing, sitting		Pain early in weight-bearing	
Sitting in confined space (car)		Greater severity of symptoms related to sitting and getting in/out of car	Femoroacetabular Impingement
Any activity involving deep flexion			

		Activity particularly repetitive twisting and pivoting plus movements involved in tennis, ballet, hockey and football	Labral irritation/ damage
Medication: Opioids; anti-inflammatories; anti-depressants; steroids  Heat or ice  Rest – in reclined sitting  Planning of activities to avoid difficulties	<b>PAIN MANAGEMENT</b>	Strategies commonly used to manage pain caused by various musculoskeletal conditions	

CATEGORY 4: HIP JOINT CHARACTERISTICS

AHD	FEATURES	Comparison with other Hip Conditions	
Clicking, clunking, popping, locking	<b>AUDIBLE HIP SOUND</b>	Clicking possible	Extra-articular problems
Altered range of joint movements; often hypermobility reported	<b>HYPERMOBILITY</b>	Mostly, reduced range of joint movements associated with pain-provoking conditions	
Hip joint instability that may lead to dislocation, subluxation or the feeling that the “hip pops out of socket”	<b>HIP JOINT INSTABILITY</b>	No directly relevant or obvious comparisons	

CATEGORY 5: POSTURE AND GAIT

AHD	FEATURES	Comparison with other Hip Conditions	
<b>Asymmetrical</b>	<b>POSTURE</b>	Asymmetrical posture and limp are often evident in other pain-provoking conditions and are typically caused by the patient off-loading the painful weight-bearing joint; they are less likely to be caused by leg-length discrepancy or weak hip abductors evident in a Trendelenburg gait pattern	
<b>Waddle, hobble, shuffle or roll</b> <b>LIMP: Off-loading painful hip; Trendelenburg gait; Leg Length Discrepancy</b> <b>Recurrent stumbles/falls</b>	<b>GAIT</b>  <b>[continued]</b>		

Forward-lean due to tight flexors Toes & knees rotate inwards Short, uneven steps		
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Several characteristics of these categories warrant further explanation. The first category, patient's introductory data, lists nuances of AHD that could be useful for differential diagnosis. These include a young onset age, the predominance of females being affected, bilaterality and a record of repeated clinical appointments with limited benefits. The contribution of onset age to differential diagnosis requires clarification because similarities are evident between AHD onset and that of several other conditions of the hip. Like AHD, cam-type FAI and NT-AVN are considered to occur commonly during young to middle-age (Ganz et al 2008, Anderson et al 2012; Narayanan et al 2017) with stress fracture showing a wide-ranging onset age that could also overlap with that of AHD (Kim and Kim 2021). However, additional complexities of AHD onset age are apparent. Many authors relate the onset age of hip dysplasia to that which is understood about infant DDH and therefore assume that AHD is part of the same continuum (Gala et al 2016). For some patients, this may be true, however, data from Pillar 1 patients suggest that the third and fourth decade are most commonly reported as being when the onset of troublesome AHD symptoms begin. Yet these patients frequently described characteristic childhood physical features such as having had difficulty sitting cross-legged, a preference for W-sitting and often exaggerated joint flexibility or hypermobility. Such features can be evident in other conditions that demonstrate generalised hypermobility such as Ehlers-Danlos syndrome and Down's Syndrome, and in both these conditions, hip dysplasia is considered to commonly coexist (Clapp et al 2021 and van Gijzen et al 2019). Therefore, although not evident in all people with AHD, this association of childhood features with a later onset of hip problems appears to provide a useful indicator of AHD that may contribute to distinguishing it from other conditions of the hip. Additionally, in the mature skeleton, the radiographic hallmark of AHD is a shallow, steeply orientated acetabulum (Troelsen 2012) illustrating an inherently unstable hip joint. The consequences of this structural issue can be exaggerated by a laxity of the joint's soft tissues that is a feature of hypermobility. Evidence from the literature as well as from the findings of this current study indicates that these are common features of AHD, demonstrated physically in some patients by hip dislocation, subluxation or by the patient feeling that the hip 'pops' out of its socket. Other than traumatic dislocation or dislocation caused by an unstable THR, this problem could be a distinctive feature of AHD that, during Pillar 3 observations of physiotherapy assessments, was seen to be freely described by patients who appeared to recognise its relevance.

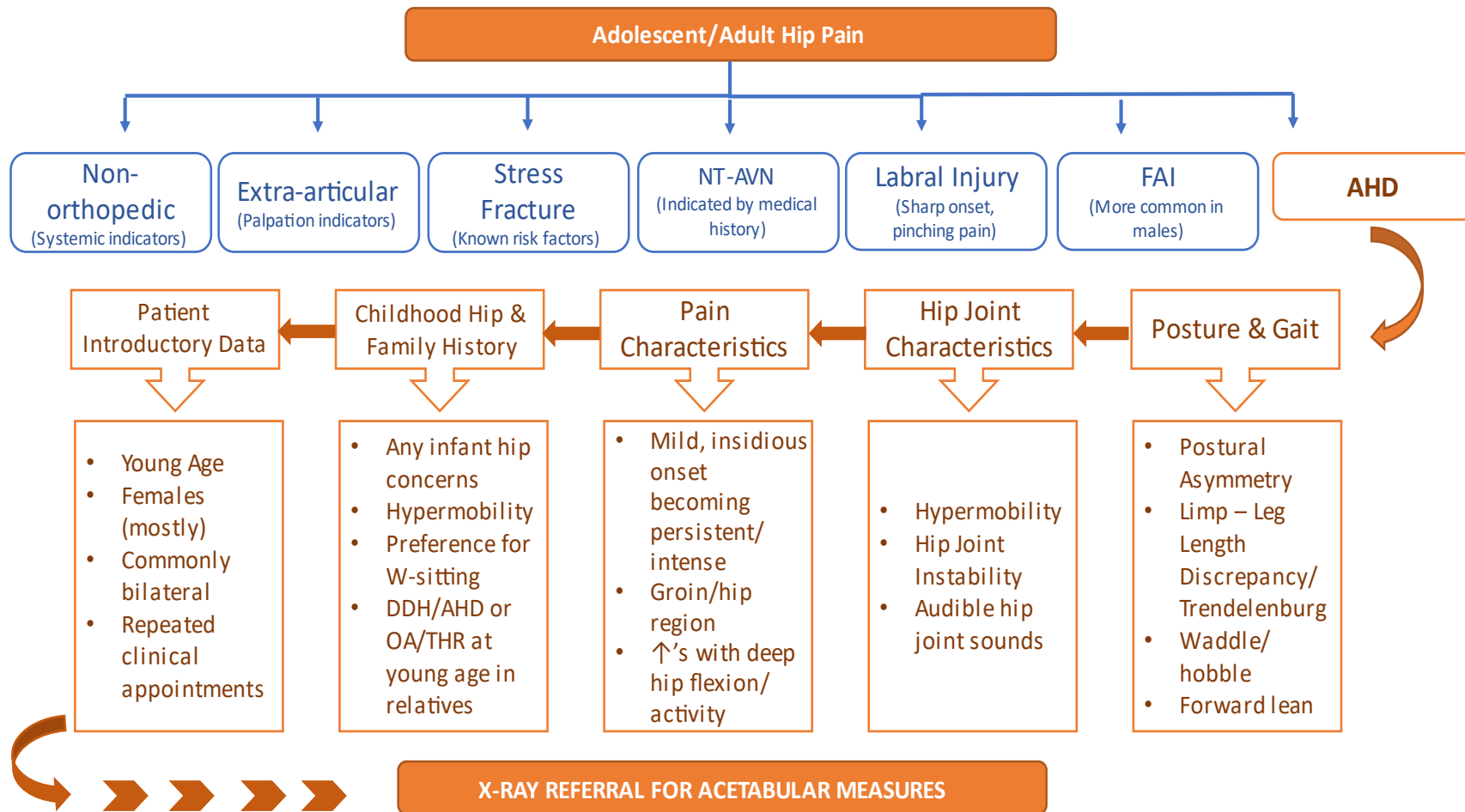
Evidence also suggests that hip conditions which show possible familial traits are thought to present in the individual as a tendency for the same condition to occur repeatedly within a family. For instance, where a patient has NT-AVN, a genetic predisposition for the same condition (NT-AVN) has been proposed (Roth et al 2016). In AHD however, evidence

suggests that the condition could be associated with familial patterns of relatives not only with DDH and AHD but also hip OA or THR at a young age. Hence, the presence of such features of family history could be useful for increasing the suspicion of AHD as the cause of the patient's hip problems. However, whilst the results of the systematic review along with those of Pillars 1 and 2 of this study offer tentative evidence to support this notion, bigger studies that establish the cause of familial traits or genetic influences are required before this feature can be applied with confidence in the differential diagnosis of AHD.

Pain is the feature that universally caused Pillar 1 patients to seek help from clinicians. It is therefore unsurprising that Pillar 3 observations highlighted that physiotherapists' questioning of the patient's history and the physical assessment, repeatedly focussed on determining a considerable level of detail regarding the patient's pain. Yet features of pain in AHD were overall difficult to distinguish from those of other hip-related conditions. However, patient reports of how their pain developed over time could conceivably provide characteristic traits unique to AHD. Of note are the repeated patient descriptions of an initial onset of mild, intermittent 'niggles' that developed over time to a persistent, debilitating, intense hip pain occurring at a young age and generally, with no obvious cause. Whilst this contrasts with the sudden, sharp pain characteristic of labral injury (Klaue et al 1991; Reiman et al 2014), later stages of both AHD and cam-type FAI can lead to labral irritation and damage because of repeated collision between the femur and acetabulum, to which the labrum is attached (Anderson et al 2012). Hence symptomatically, when labral damage results, presentation of cam-type FAI and AHD can be similar.

Finally, evidence from this study suggests that patients with AHD may present with an asymmetric posture and a limp; two features that occur commonly in a range of hip pathologies. The difference in AHD, however, may relate to their cause. Leg length discrepancy and weak or easily fatigued hip abductors often recognised as a Trendelenburg gait, are causes that have been reported frequently in association with AHD. A waddling, hobbling or shuffling gait that was reported by a number of Pillar 1 participants is thought to be a consequence of a bilateral Trendelenburg gait that Gandbhir et al (2021) also associated with AHD. Overall, the findings of Pillar 1 and Pillar 2 of this study, along with evidence in the literature, provide compelling evidence of features that characterise AHD. Figure 7.2 summarises these AHD-associated characteristics and organises them to highlight their potential value for differential diagnosis in young patients with hip problems.

Figure 7.2 Summary of AHD Characteristics for Differential Diagnosis



Whilst no individual sign, symptom or feature is sufficient to establish definitive presence of AHD, a combination of recognised characteristics summarised in Figure 7.2 begins to build a clinical picture of the condition. This contributes to distinguishing AHD from other conditions of the hip. The clinical picture can be used to inform physiotherapists and other clinicians of the possible presence of AHD in patients at the pre-X-Ray stage of their hip assessment. In offering a solution to the problems of delayed or misdiagnosis of AHD, the evidence generated by this study fosters a procedure for differential diagnosis of hip problems in young, particularly female individuals that involves addressing the following questions:

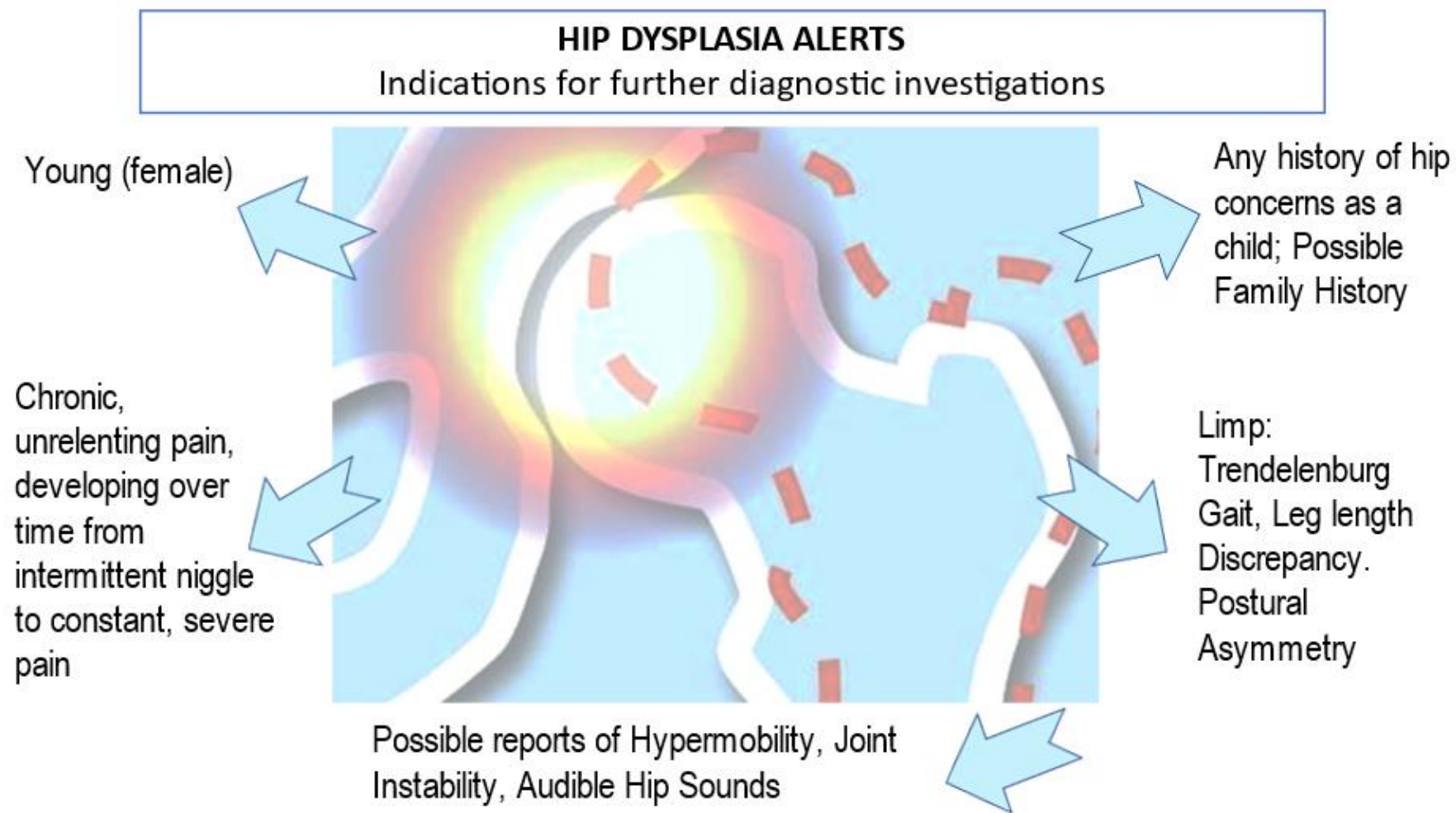
1. Does the patient have a history of hip concerns as an infant?
2. Does the patient have childhood memories of being unable to sit cross-legged and perhaps favouring a W-sitting position?
3. Was the patient a gymnast, hypermobile or very flexible as a child?
4. Does the patient have a family history of relatives previously diagnosed with DDH, AHD or hip OA/THR at a young age?
5. Is the patient's hip pain persistent and progressive?
6. Is the patient's hip pain aggravated by deep hip flexion and prolonged walking, running, standing, sitting or sitting in a confined space?
7. Does the patient provide any indications of hip joint instability, possibly with audible hip sounds and increased range of movements or hypermobility?
8. Does the patient have a postural asymmetry?
9. Does the patient demonstrate a Trendelenburg gait?
10. Does the patient have a leg length discrepancy?

The findings of Pillars 1 and 2 of this study, combined with published evidence indicate that people with AHD may demonstrate various combinations of affirmative answers to the above questions. Table 58 above, lists the features addressed by these questions and provides a comparison with known indicators of other conditions of the hip.

These findings hold implications for both undergraduate and postgraduate education. Students, educators and clinicians need to be provided with the opportunity to learn about the features of AHD patient presentation as understanding progresses. Inclusion of the findings of this study within the BSc Physiotherapy programme, submission of these findings to relevant journals and the provision of in-service training for clinicians will facilitate this. To conclude, Figure 7.3 provides an alert graphic that can be used as a teaching aid to inform physiotherapists and other clinicians responsible for diagnostic assessment of patients with hip problems, to the signs, symptoms and features indicating the possible occurrence of AHD and the need for X-Ray referral for definitive diagnosis.



Figure 7.3 Features Associated with AHD: An Alert Graphic and Teaching Aid



## 7.4 Limitations of this Study

Due to the nature of accessing specific groups of participants, this study has several limitations. Firstly, Pillar 1 participants were recruited from online hip dysplasia patient support groups. It is recognised that this involves inherent self-selection because of the requirement for participants to have access to the relevant technology and to be familiar with its use. Poor digital literacy and digital deprivation pose a threat to external validity as members of the AHD population may not have an equal chance of being included in the sample. This potential risk of bias has informed the recommendations for future studies generated from the findings of this investigation.

Additionally, as explained in Chapter 4, the biggest age group of active social media users (70% worldwide), are young adults in the 18–44- year-old age category (Statista 2020), which reflects the age at which people most commonly report their AHD onset (Nunley et al 2011) and have hip surgery (Clohisy et al 2007 and 2009). The use of these groups was therefore favoured and considered an effective method of recruiting appropriate participants. In addition, the value of using online methods enabled an international representation of AHD participants. It is recognised however, that people accessing patient support groups could be limited to those experiencing on-going or life-long problems related to their hip dysplasia. People with AHD who may have received timely and effective treatment with no prolonged issues, may therefore be omitted. The purpose of this PhD study was however, to address the problems patients have reported of delayed recognition of the condition and misdiagnosis. Details related to the chronicity of the problems from patients living with the consequences of delayed diagnosis of AHD and the pattern of symptom development over time were therefore important to identify. Hence, people living with long-term problems of AHD were considered key informants.

A second limitation was acknowledged in the recruitment of surgeons participating in Pillar 2 of this study as they were taken from the population of delegates attending only one UK conference. The conference was however, designed for people specifically specialising in corrective surgery for young people with hip problems. The surgeons attending were therefore from widespread geographical UK locations, representing various characteristics and levels of experience. It is possible that greater insight could have been achieved through recruitment of more internationally recognised expertise but funding for in-person meeting of an international nature was not available to achieve this. In-person methods were favoured because online approaches may have been insufficient to persuade participation.

Finally, Pillar 3 of the study used observation to determine the content of physiotherapists' assessment of patients with hip problems. A limitation of the approach used during this pillar of study was that the baseline knowledge of the physiotherapists in the diagnosis of AHD was not ascertained. There was, however, an ad hoc indication from several physiotherapists received before the study began that, although they were aware of AHD, the condition was not on their diagnostic radar.

Physiotherapists who were observed were from two different hospital departments of one UHB in Wales. Because all benefited from similar in-service training (IST) sessions, the possibility of limited representation of physiotherapists is acknowledged as the IST could enhance similarities between physiotherapists' clinical behaviours. These physiotherapists did, however, demonstrate a wide variety of clinical profiles that were likely to have influenced their practice. Such profiles included different institutions attended for their pre-registration education, variation in their post-graduate education and different clinical experiences gained from employment in a range of geographical locations. In addition, by ensuring that each seniority band was included, Pillar 3 provided the opportunity for representation of various levels of knowledge, experience and assessment approaches.

## **7.5 Recommendations for Future Research**

Future studies are required to determine how promoting this study's findings can improve the recognition of AHD in young patients with hip problems. For improvement to be measured, the baseline knowledge of FCP and MSK physiotherapists as well as GPs and radiologists in the diagnosis of AHD needs to be ascertained. Then, following the promotion of AHD alerts and the characterisation of AHD, timely referral for X-Ray evaluation for patients with suspected AHD can be measured by monitoring patients' diagnostic pathways. In addition, if accelerated X-Ray referral is established, potentially longer-term benefits could be measured. These would need to demonstrate an increase in young people retaining their native hip joint through improved management or corrective PAO surgery and a corresponding decrease in the number of young people undergoing THR surgery.

There could still be more to identify regarding patient presentation for the recognition of AHD. Importantly, because the external validity of this study's Pillar 1 findings is threatened by the risk that the level of internet penetration and literacy did not match the distribution of the AHD population, it is recommended that future studies check the generalisability of AHD characterisation established by this study, via face-to-face methods. These can be conducted in physiotherapy, orthopaedic and young peoples' hip clinics using people with a

verified diagnosis of the condition. This directed member-checking should seek to verify that the signs and symptoms reported to be associated with AHD presence via this study's online survey methods, find agreement with a broader population of those presenting with the condition and particularly those who, for various reasons, would be unable or unwilling to provide a response online. In addition, whilst this study offers a development to previous understanding of AHD presentation, the resulting clinical picture is comprised of a number of features, some of which can also occur in other conditions of the hip. Therefore, the combination of features suggested by this study as being indicative of AHD needs to be tested for its predictive value to strengthen diagnostic confidence in its use. However, promotion of this study's findings will increase awareness of the condition and will support clinicians to recognise when a raised index of suspicion for the presence of AHD should be considered, prompting further investigations.

As this understanding progresses further, current advances in technology that are becoming accessible to clinicians may offer greater diagnostic opportunities for accurate, detailed and objective biomechanical analysis. These may provide immediate identification of, for instance, kinetic and kinematic measures that might distinguish AHD from other conditions of the hip. Future investigations into such measures could provide further support for early suspicion of AHD presence before troublesome symptoms arise, ensuring that treatment choices remain available for at-risk individuals.

## **7.6 CONCLUSION**

Diagnosis of AHD is often overlooked or delayed, prolonging patients' problems of decreased function and increased pain due to the progressive deterioration of their hip joint. The implications of this can limit surgical options as corrective surgery needs to occur before the onset of secondary OA. Physiotherapists have the opportunity to accelerate the AHD diagnostic procedure if knowledge is available to them regarding the relevant features of patient presentation. This study set out to develop a clinical picture of AHD by identifying relevant signs, symptoms and features of the condition's presentation. A systematic review firstly established the current understanding of features associated with AHD. Secondly, Pillars 1 and 2 of this study built on the current understanding by identifying the problems that patients living with AHD and surgeons who specialise in correcting AHD associate with the condition. Through doing so, this study identified features of patient presentation at the pre-X-ray stage that could be applied to physiotherapy assessment to determine those patients in whom AHD should be suspected. The findings show that young, mainly female individuals with chronic, unrelenting hip pain for which there is no obvious cause should be

investigated further. A history of hip concerns as an infant or a possible family history of relatives with a record of hip problems at a young age, signal further concerns. Additionally, when these features present alongside a Trendelenburg limp or leg length discrepancy and hip joint characteristics of hypermobility, joint instability or audible hip sounds, the index of suspicion for the presence of AHD should trigger referral for X-Ray evaluation and definitive diagnosis.

I have explained throughout this thesis that AHD in young people is a chronic, painful and potentially activity-limiting condition, but good clinical management can provide effective and desirable patient outcomes. Growing evidence confirms the positive results of PAO corrective surgery which retains the patient's native hip joint. Increasingly, this evidence points to the reliance of successful surgical outcomes on early AHD diagnostic recognition. Timely diagnosis requires the clinicians involved in the assessment of patients with hip problems, to have knowledge of features evident in AHD patient presentation so that they recognise when X-Ray referral for definitive diagnosis is required. Such knowledge has been extended by the findings of this study and whilst these should be useful to GPs, radiologists, orthopaedic surgeons and other clinicians involved in the assessment of patients with hip problems, physiotherapists have an obvious opportunity for using this knowledge to enhance early AHD diagnosis. The unexpected findings of Pillar 3 observations, however, raise important questions regarding the purpose and extent of physiotherapy assessment in the management of young patients with hip pain. What physiotherapists displayed during these observations was firstly, that most used their assessment reasoning primarily to justify treatment, rather than establishing the root cause of the patient's problems or medical diagnosis. No matter what the cause of the patients' problems, taken collectively, the physiotherapists' conclusions were barely distinguishable with the majority aiming to strengthen weak muscles and increase range of movement where it was restricted. Secondly, physiotherapists displayed assessment biases of 'anchoring' and 'premature closure' that risk problems associated with incomplete or incorrect conclusions. This is considered to occur because of limited knowledge. By extending current understanding of the features associated with AHD and by providing relevant alerts to the possible presence of AHD in young patients presenting with hip pain, a potential solution to this problem is offered. Accordingly, whilst limitations to this study have been presented, the findings pave the way for future studies to evaluate the translation of this solution into practice. This would include measuring the impact that the suggested alerts have on facilitating early AHD diagnosis and increasing the opportunity for patients to benefit from PAO corrective surgery, reducing the reliance on THR for young people.

If management effectiveness of young peoples' hip conditions is to achieve parity with those of infants and of the elderly, the work to increase awareness of AHD must continue. Hence, training opportunities need to be designed that will strengthen the recognition of relevant signs, symptoms and features and enhance opportunities for early AHD diagnosis before the condition results in secondary OA and limited treatment options. This is not an issue for physiotherapists alone. Radiologists, GPs and orthopaedic surgeons may also need to strengthen their consideration of AHD presence during their differential diagnosis of young patients with chronic hip pain, and the findings of this study may also offer them support.

To the best of my knowledge, this study is the first to build on previously limited understanding of AHD presentation by drawing current literature together with data generated directly from those with first-hand experience of living with AHD and those treating patients with the condition. The findings of this study, which are summarised in the ALPHA memory aid (Figure 7.1) and an alert graphic (Figure 7.3) offer a solution to the poor recognition of AHD by extending the understanding of features associated with the condition. Their application to practice will enable physiotherapists and other clinicians to make more informed patient-management decisions for the benefit of young patients with chronic, unrelenting hip problems.

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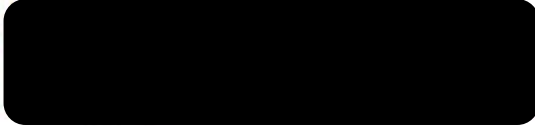


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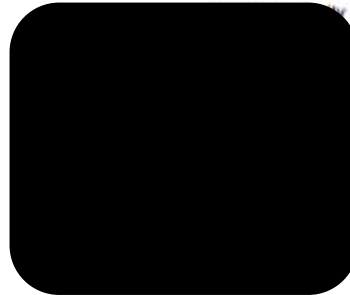
## Appendices

### Appendix 1: Research Ethics Committee Approval Letter (personal data redacted)

School of Healthcare Sciences



13 July 2017



*Liz Evans  
Cardiff University  
School of Healthcare Sciences*

Dear Liz

**Developing and evaluating an assessment tool for physiotherapists to improve and accelerate the diagnosis of adult hip dysplasia and fast-track patient treatment**

At its meeting of **11 July 2017**, the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

**Pass –and that you proceed with your Research in collaboration with your supervisor**

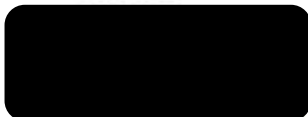
The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see attached and comment below from Committee.

Please e mail the information that has been requested by [redacted] today.

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely



Research Administration Manager

## Appendix 2: Health and Care Research Wales Approval (UHB and personal identifiers redacted)

RE: **Wales** – Ref **IRAS** 183604 – Study-wide Governance Checks Complete



Health and Care Research **Wales** - Research Permissions <Research-permissions@**wales**.nhs.uk>  
To: Elizabeth Evans



Fri 09/06/2017 15:03

From: Health and Care Research **Wales** - Research Permissions [<mailto:Research-permissions@wales.nhs.uk>]

Se

To:

Cc: ABB\_RandD1 <[ABB\\_RandD1@wales.nhs.uk](mailto:ABB_RandD1@wales.nhs.uk)>; Helen Falconer <[FalconerHE@cardiff.ac.uk](mailto:FalconerHE@cardiff.ac.uk)>; Tina Gambling <[GamblingTS@cardiff.ac.uk](mailto:GamblingTS@cardiff.ac.uk)>; Kirsten McEwan <[McEwanK@cardiff.ac.uk](mailto:McEwanK@cardiff.ac.uk)>

Subject: **Wales** – Ref **IRAS** 183604 – Study-wide Governance Checks Complete

Dear Mrs Evans,

**Re: Adult Hip Dysplasia: An assessment tool for early diagnosis v1 (IRAS 183604) – Study-wide Governance Checks Complete for Wales**

I am pleased to confirm that all the study-wide (global) governance checks for **Wales** have been completed for your study, however this does not constitute permission to proceed at research sites. When local governance checks are satisfied for a participating research site, the NHS organisation R&D office will issue a letter to confirm NHS research permission for that site.

The study-wide governance review was satisfied using the Research Protocol Version 1 dated 16 Apr 2016 that received REC favourable opinion on 03 Jun 2016. Please find attached a list of study-wide documents that have been approved.

The study is currently under review for NHS permission at Aneurin Bevan UHB.

**Please note that you cannot commence the study at a particular site until you have received written confirmation of NHS Research Permission for that site.**

All amendments made during your study, after NHS research permission has been gained, should be notified to your lead nation co-ordinating centre (Health Research Authority in England). Please see <https://www.myresearchproject.org.uk/help/hlpamendmentsresearch.aspx#Submitting-your-amendment> for further information.

Please contact [research-permissions@wales.nhs.uk](mailto:research-permissions@wales.nhs.uk) should you require any further information or assistance.

Kind regards,

[Redacted signature]

Permissions Service Coordinator / Cydgysylltydd y Gwasanaeth Caniatadau



Appendix 3: Pillar 1 Invitation to Participate and Participant Information Sheet (personal identifiers redacted)

HIP PAIN CARDIFF



**ARE YOU OVER 16 AND DO YOU HAVE HIP DYSPLASIA?**

**IF SO, IT WOULD BE WONDERFUL IF YOU COULD HELP US WITH OUR RESEARCH!**

**INTERESTED?**

Please read more [HERE](#)

*[Participant Information Sheet below]*

### **A project to find out about your experience of hip dysplasia**

#### **What is the purpose of this study?**

We want to find out about the features of hip dysplasia which you have experienced as well as your experience of gaining the diagnosis. This information will enable us to develop a clinical picture of hip dysplasia which will allow clinicians to recognise when other patients might have the condition. The study and its findings will raise the awareness amongst healthcare professions of the condition and thus lead to service improvements. It will also help us to develop an assessment tool which can be used in clinical practice enabling doctors and physiotherapists to recognise promptly when patients might have hip dysplasia.

#### **What will happen if I take part?**

You will be invited to respond to questions in writing on features of the pain, symptoms and triggers which alerted you to your hip problem. We will read both yours and others' experiences closely and identify the commonly occurring features which patients experienced. If we need further information or elaboration on parts of your account we will write to you and invite you to provide this. We would also like you to take part in the next stage of questionnaires which will develop from the first set of responses. This will provide an opportunity for you to see what others reported about their hip dysplasia and will help us to gain agreement between all participating patients, on what they consider to be the most important features of hip dysplasia. From this, we will establish a clinical picture of the condition which we will use to develop the assessment tool.

#### **What should I include in my answers of my life with Hip Dysplasia?**

We want to find out a little about you (how long you have had hip dysplasia, when you were diagnosed and at what age), how long it took for you to get a diagnosis, what you feel triggered your first hip problems, what signs and symptoms you have experienced since (up until any surgery you may have had), including the severity of your pain, the location of your pain and any movements or activities you were/are unable to do. We are also keen to know about any other features which you feel were caused by your hip dysplasia. In addition we want you to tell us about the impact of being diagnosed with hip dysplasia and how decisions were made about your treatment. To help you do this we have provided some specific questions which will be sent to you once we have received your signed consent form.

---

### **What happens to my story of my life with Hip Dysplasia?**

Your written experiences will first be anonymised by the research team to protect your identity so that your details cannot be recognised as belonging to you by anyone other than the research team. Your information will be read by members of the research team and may be used by others in the Cardiff University hip conditions research group, including students conducting data analysis. We will also use it to help us design an assessment tool which can be used in clinical practice to improve the recognition of hip dysplasia. We would also like to make parts of all the stories available in report form in publications and via the research project's web-site.

### **Will the information I give be kept confidential and securely stored?**

All information which is collected about you during the course of the research will be kept strictly confidential. All data collected will be anonymised and the stories will not be individually identifiable. Pseudonyms will replace your name and will be used in any oral or written reports or presentations from the study, including any direct quotations from your story.

All electronic data will be kept on a password-protected server at Cardiff University. Any paper-based material will be kept in a locked filing cabinet. The original data collection sheets will be kept under lock and key in accordance with the Data Protection Act and will only be accessible to the research team and regulatory authorities. Data will be kept for up to 15 years and then disposed of securely.

### **What happens if I change my mind about taking part in the study?**

You can withdraw your consent from the study at any time. Just let us know in writing. You do not have to give a reason. If you do decide at a later date to withdraw from the study, any data collected up to point of withdrawal will continue to be used within the study.

### **Who is undertaking this research project?**

The project is being undertaken by Liz Evans at Cardiff University as part of her PhD. [REDACTED] (Cardiff University) is supervising the PhD. She also has Hip Dysplasia and has undergone two major surgeries in her adult life.

### **How can I get further information?**

If you would like any further information to help you decide whether you will take part in the research, please contact Liz Evans who works in the School of Healthcare Sciences at Cardiff University [REDACTED]. She will call you if you include your phone number or follow up any query you raised in an e-mail, whichever you prefer.

**Who has reviewed the study?**

The study has been given ethical approval by the Research Ethics Committee of the School of Healthcare Sciences, Cardiff University. It is part of a bigger study which Liz is carrying out for her PhD. The bigger study involves specialist hip surgeons and physiotherapists. This clinical aspect of the study has been reviewed by Health and Care Research Wales and the Health Research Authority (England) via the Integrated Research Application System (IRAS 183804)

If having agreed to take part in the study you have a concern about any aspect of the study, you should in the first instance speak to Liz Evans, who will try to allay your concerns and answer your questions. If you remain unhappy and wish to complain formally, you can do this through Cardiff University Complaints Procedure. Details can be obtained from [REDACTED], [REDACTED], Director of Research Governance, School of Healthcare Sciences, Cardiff University, [REDACTED]  
Email: [REDACTED] Tel No: [REDACTED]

Appendix 4: Pillar 3: Participant Information Sheets – Physiotherapists (UHB Identifiers redacted).



## **PARTICIPANT INFORMATION SHEET**

### **(PHYSIOTHERAPISTS: Observations)**

#### **Preventing premature osteoarthritis: developing an assessment tool for non-specialists to improve and accelerate the diagnosis and treatment of Adult Hip Dysplasia (AHD)**

You are being invited to participate in a PhD research project, which aims to improve the care pathway for patients with hip dysplasia. The product of the research will be a diagnostic tool which will alert Physiotherapists to the potential for hip dysplasia in patients presenting with hip pain and guide them to providing an appropriate referral to specialist services. The research is being undertaken by Cardiff University and the XXXXXX University Health Board (XXXUHB)

We want to identify the features of physiotherapy hip assessments. We would like to observe your assessments of patients with hip pain. This information will enable us to identify how physiotherapists reach their diagnostic or referral decisions.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information below. If anything is not clear, or you would like more information, please do contact me – my details are at the bottom of this note.

#### **Do I have to take part?**

- No. It is up to you to decide whether or not to take part in this study.
- If you do decide to take part, you are still free to withdraw without giving a reason. You can withdraw once you have been observed, up until the beginning of the data analysis. Any data you have provided prior to your withdrawal will be used in the study. If you decide to withdraw, your decision will have no effect on your employment.

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

We would like to observe your assessment of patients to draw out the features of interest which enable you to make your expert diagnosis of, or referral decision for patients with hip pain. A meeting will be arranged when I will be able to answer any questions you may have, then if you are willing to take part, I will invite you to sign and submit to me the consent form included with this letter.

#### **Will the information I give stay confidential?**

Yes. All data will be treated in confidence. Participants in the research will not be identified by name in any publications. Quotations may be used in publications, but all personal information will be removed so that it is not possible to identify you. All information will be safely stored at Cardiff University on a password protected secure University server and/or in a locked filing cabinet for 15 years from the completion of the study, after which it will be disposed of securely. The information collected will only ever be used for research purposes. If, as part of our data collection, malpractice is observed, it will be reported to the senior clinician.



### **What will happen to the results of the research study?**

The research will help in the construction of a decision-making tool for physiotherapists who may not be experts in AHD, but who are frequently the first clinicians that patients consult when they have hip pain. The aim of providing such a tool is to accelerate definitive diagnosis of the condition by supporting early referral for radiographic imaging. This will assist in improving referral to specialist hip clinics and more timely and appropriate care pathways. The findings of this study will be presented at conferences and published in journals. A summary of the results of the study will be distributed to all individuals who participate in the research.

### **Sponsor**

The sponsor is Cardiff University. The University's Research Ethics Committee has reviewed and approved this study.

### **What happens if I decide not to participate in the study?**

Your decision not to participate in the study will have no effect on your employment and you will be under no pressure to participate.

**What happens if I change my mind about taking part in the study?** You can withdraw your consent from the study at any time. Just let us know in writing. You do not have to give a reason. If you do decide at a later date to withdraw from the study, any data collected up to point of withdrawal will continue to be used within the study.

### **Who is undertaking this research project?**

The project is part of a PhD study being conducted by **Liz Evans** who is your key contact. Others supporting this study include: [redacted] (Director of Post Graduate Studies Cardiff University), **Professor** [redacted] (School of Healthcare, University of Leeds), who has done extensive research within healthcare and [redacted] (Birmingham) who is a Consultant Orthopaedic Surgeon, his work includes paediatric orthopaedics and surgery addressing the consequences of childhood hip disease in young adults.

### **How can I get further information?**

If you would like any further information to help you decide whether to take part in the research, please contact - Tina Gambling or Liz Evans who work in the School of Healthcare Sciences at Cardiff University. They will either ring you back so that you do not have to pay for the telephone call or follow up any query you raised in an e-mail.

Dr [redacted]	Liz Evans:	[redacted]
Phone: [redacted]	Phone: [redacted]	[redacted]
E-mail: [redacted]	E-mail: [redacted]	[redacted]

If having agreed to take part in the study, you have a concern about any aspect of the study, you should in the first instance speak to the Chief Investigator, [redacted] or the key contact, Liz Evans, who will try to allay your concerns and answer your questions. If you remain unhappy and wish to complain formally, you can do this through contacting Dr [redacted], Director of Research Governance, School of Healthcare Sciences, Cardiff University, [redacted]

Email: [redacted] Tel No: [redacted]

### **What do I do now as I want to take part in the study?**

A meeting will be arranged in your department when I will answer any questions you may have about the study. I will then invite you to complete the consent form and return it to me.

Thank you for reading this information. We hope to have the opportunity of meeting you.

Liz Evans



## PARTICIPANT INFORMATION SHEET (Patients : Observation)

### **Preventing premature osteoarthritis: developing an assessment tool for non-specialists to improve and accelerate the diagnosis and treatment of Adult Hip Dysplasia**

You are being invited to participate in a PhD research project which is being undertaken by Cardiff University and XXXXX University Health Board (XXXUHB), focusing on the physiotherapy assessment for your hip pain.

This information will enable us to learn more about how a particular condition known as hip dysplasia (which you may or may not have) can be diagnosed more promptly and effectively. It will also help us to raise awareness of the condition within the medical professions and thus lead to improvements in services.

It is important for you to understand why the research is being done and what it will involve. Please take time to read the information below and discuss it with your friends and family if you wish, before deciding whether or not you would like to take part. If anything is not clear, or you would like more information, please do contact me – my details are at the bottom of this note.

#### **Do I have to take part?**

- No. It is up to you to decide whether or not to take part in this study.
- If you do decide to take part, you are still free to withdraw without giving a reason. But any data you have provided prior to your withdrawal will be used in the study.

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

If you are willing to take part, please inform the clinic receptionist by phone when you respond to your partial booking letter. Then, when you attend your physiotherapy appointment, you will meet one of the research team and have the opportunity to ask and have answered, any questions you may have. If you remain happy to take part in the study, we will invite you to sign a consent form.

Your participation in this phase of the study will simply involve having your physiotherapy appointment observed by a researcher. You may then be asked several questions by the researcher about your pain, symptoms and the impact of your hip condition.

If you are happy to participate, we may need to access your medical notes to check the details of your hip condition and to check whether you have any other condition that may impact upon your hip pain or movement.

#### **Will the information I give stay confidential?**

Yes. All data will be treated in confidence. Participants in the research will not be identified by name in any publications. Quotations may be used in publications, but all personal information will be removed so that it will not be possible to identify you. All information will be safely stored at Cardiff University on a password protected secure University server and/or in a locked filing cabinet for 15 years from the completion of the study, after which it will be disposed of securely. The information collected will only ever be used for research purposes.

### **Information unrelated to the project's data**

If, during my observation of your hip assessment or during the post-assessment interview, I am told or accidentally overhear, sensitive personal information, the information will not be included in the data collection and it will be removed from any recordings before data analysis takes place. I will not be seeking such information, nor will the questions I ask you be designed to elicit such information, therefore neither interviews nor questionnaires will intentionally include topics that might be sensitive, embarrassing or upsetting.

However, if you tell me information that indicates or alludes to poor care or you provide evidence of malpractice which contravenes XXXX University Health Board standards, it will be reported immediately to the senior physiotherapists at the physiotherapy out-patient clinic.

### **What will happen to the results of the research study?**

The results of this study will be shared with other clinicians and hip clinic staff in other hospitals. The research will aid diagnosis of hip problems in adolescence and adults with the aim of improving the patient experience, the care pathway and the treatment outcomes. The study will also aim to support the wider use of a diagnostic tool in clinical practice. The findings of this study and the resulting diagnostic tool will be presented at conferences and published in journals. A summary of the results of the study will be distributed to all individuals that participate in the research.

### **Sponsor**

The sponsor is Cardiff University. The University's Research Ethics Committee has reviewed and approved this study.

### **What happens if I decide not to participate in the study?**

Your decision not to participate in the study will have no effect on your treatment or the clinical care you receive.

**What happens if I change my mind about taking part in the study?** You can withdraw your consent from the study at any time. Just let us know in writing. You do not have to give a reason. If you do decide at a later date to withdraw from the study any data collected up to the point of withdrawal will continue to be used within the study. Your decision to withdraw from the study will have no effect on your treatment or the clinical care you receive.

### **Who is undertaking this research project?**

The project is part of a PhD study being conducted by **Liz Evans** who is your key contact. Others supporting this study include **Dr Tina Gambling** (Director of Post Graduate Studies Cardiff University), **Professor Andrew Long** (School of Healthcare, University of Leeds), who has done extensive research within healthcare and **Mr John O'Hara** (Birmingham) who is a Consultant Orthopaedic Surgeon, his work includes paediatric orthopaedics and surgery addressing the consequences of childhood hip disease in young adults.

### **How can I get further information?**

If you would like any further information to help you decide whether you will take part in the research, please let the physiotherapy department know when you phone them in response to the partial booking request and let them know if you are happy for them to give me your phone number. I will then give you a call. Or contact me directly - Liz Evans - or Dr [REDACTED] who also works in the School of Healthcare Sciences at Cardiff University. We will either ring you back so that you do not have to pay for the telephone call or follow up any query you raised in an e-mail.

Dr [REDACTED]

Phone: [REDACTED]

E-mail: [REDACTED]

Liz Evans

Phone: [REDACTED]

e-mail: [REDACTED]

Address:

HCARE, Cardiff University

[REDACTED]

If having agreed to take part in the study, you have a concern about any aspect of the study, you should in the first instance speak to [REDACTED] or Liz Evans, who will try to allay your concerns and answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Dr [REDACTED], Director of Research Governance, School of Healthcare Sciences, Cardiff University, [REDACTED]  
[REDACTED]

Email: [REDACTED] Tel No: [REDACTED]

**What do I do now as I want to take part in the study?**

If you would like to take part, please inform the clinic receptionist when you phone the physiotherapy out-patient clinic in response to your partial booking letter. When we meet you at the clinic, we will answer any questions you might have then ask you to complete a consent form.

Thank you for reading this information. I do hope to have the opportunity of meeting you.

Liz Evans MSc MCSP FHEA

Appendix 6: Pillar 3: Physiotherapist Consent Form (UHB Identifiers redacted)



**Consent to take part in the study (Physiotherapists: Observations)**

Preventing premature osteoarthritis: developing an assessment tool for non-specialists to improve and accelerate the diagnosis and treatment of Adult Hip Dysplasia

	Add your initials next to the statements you agree with
I confirm that I have read and understand the information sheet dated <u>March 2017</u> explaining the above research project and I have had the opportunity to ask questions about the project.	
I agree for the data collected from me to be used in the research study.	
I agree to take part in the above research project.	

I agree that members of the research team may observe some of my clinic appointments	
I agree to the use of direct quotes from my observed assessments in publications, on the understanding that I will not be identified and that my anonymity will be protected.	

Name of participant	
Participant's signature	
Date	
Name of key contact for this study	Mrs Liz Evans
Signature	
Date	

If you want to ask me any questions about the research study, you can contact me by telephone, email or letter:

Mrs Liz Evans  
HCARE  
Cardiff University

Telephone: [REDACTED]  
E-Mail: [REDACTED]



Appendix 7: Pillar 3: Patient Consent forms (UHB Identifiers redacted)



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
University Health Board



School of  
Healthcare Sciences  
Ysgol y Gwyddorau  
Gofal Iechyd

**Consent to take part in the study (Patients: Observation)**

Preventing premature osteoarthritis: developing an assessment tool for non-specialists to improve and accelerate the diagnosis and treatment of Adult Hip Dysplasia

	Add your initials next to the statements you agree with
I confirm that I have read and understand the information sheet dated <u>March 2017</u> explaining the above research project and I have had the opportunity to ask questions about the project.	
I agree for the data collected from me to be used in the research study.	
I agree to take part in the above research project.	
I agree to my physiotherapy out-patient consultation being observed	
I agree to being interviewed after my <u>physiotherapy assessment</u> if this is requested.	
I agree to the use of direct quotes from my interview in publications, on the understanding that I will not be identified and that my anonymity will be protected.	

Name of participant	
Participant's signature	
Date	
Name of key contact for this study	Mrs Liz Evans
Signature	
Date	

If you want to ask me any questions about the research study, you can contact me by telephone, email or letter:

Mrs Liz Evans  
HCARE  
Cardiff University

Telephone: [REDACTED]

E-Mail: [REDACTED]







GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
University Health Board

R&D Department  
Clinical Research &  
Innovation Centre

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**Research and Development Department  
Research Risk Review Committee**



Mrs Elizabeth Evans  
Senior Lecturer  
Cardiff University

8<sup>th</sup> June 2017

Dear Mrs Elizabeth Evans,

**Title:** Developing and evaluating an assessment tool for Physiotherapists to improve and accelerate the diagnosis of Adult Hip Dysplasia and fast-track correct patient treatment

**Chief Investigator:** Dr Tina Gambling

**Principal Investigator:** Mrs Elizabeth Evans

**ABHB R&D Reference Number:** RD/1527/17

**IRAS Number:** 183604

The [redacted] University Health Board Research Risk Review Committee at their meeting on the 5<sup>th</sup> April 2017 decided that overall the project does not appear to pose any risk to the University Health Board and can be approved.

The Chairman also noted that the project already has received favourable MREC/Local REC opinion.

The following documents have been reviewed and approved for use at this research site.

If you or any member or your team require a Research Honorary Contract or Letter of Access please contact the R&D Department at the above email address.

May I take this opportunity to wish you success with your study and remind you that the study team are required to do the following:

- a) Inform the University Health Board R&D Office if any external funding is awarded for this study in the future.
- b) Inform the R&D Office of any substantial amendments/changes to your protocol.
- c) Maintain a record of the number of research participants recruited into the study.

[continued]

- d) Complete any questionnaires sent to you by the University Health Board's R&D Office regarding this project.
- e) Comply fully with the Research Governance Framework , and co-operate with any audit inspection of the project files.
- f) Undertake the project in accordance with ICH-GCP and the University Health Board's Guidelines on Good Research Practice.
- g) Adhere to the protocol as approved by the Local Research Ethics Committee.
- h) Ensure that your research complies with the Data Protection Act 1998.
- i) Report any Serious Adverse Events to the R&D Office.
- j) Please note that approval lapses if the project does not commence within 12 months of approval.

If your study is adopted onto the Health and Care Research Wales Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that you will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the Health and Care Research Wales CRP, please go to <http://www.healthandcareresearch.gov.wales/get-your-study-on-the-clinical-research-portfolio/>

To upload recruitment data, please follow this link: <http://www.healthandcareresearch.gov.wales/uploading-recruitment-data/>

Uploading recruitment data will enable Health and Care Research Wales to monitor research activity within NHS organisations, leading to NHS R&D allocations which are activity driven. The uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact the [REDACTED] R&D office.

Yours sincerely

[REDACTED]

[REDACTED]

**Research and Development Director  
Research Risk Review Committee Chairman**



Appendix 9: Physiotherapists' Standardised Assessment Record Sheet (UHB Identifiers redacted)

**Body Chart / Medical Screening**

University Health Board Physiotherapy Service

Addressograph

Date:  
Page Number:

Medical Screening Questions	Tick if clear	Further Details	Lifestyle Screening Questions
Cough / sneeze			<b>Physical Activity</b> N/A <input type="checkbox"/> Discussed <input type="checkbox"/> ..... Intervention <input type="checkbox"/> (e.g. NERS) ..... Date:
Bladder/bowel			
Saddle area			
Gait			
Dizziness			
Nausea / vomiting			
Fainting / drop attacks			
Blurred / double vision			
Loss of hearing / tinnitus			
Speech / swallowing			
Loss of taste / smell			
Facial paraesthesia			
Cardiac			<b>Smoking</b> Non Smoker <input type="checkbox"/> Discussed <input type="checkbox"/> ..... Intervention <input type="checkbox"/> (e.g. SSW) ..... Date:
Respiratory			
BP			
Hypercholesterolaemia			
Diabetes			
Epilepsy			
R.A.			
Thyroid function			
History of cancer			
Osteoporosis			
Trauma / fractures			<b>Weight</b> N/A <input type="checkbox"/> Discussed <input type="checkbox"/> ..... Intervention <input type="checkbox"/> (e.g. AWM) ..... Date:
Smoker			
Alcohol use (quantity)			
Recent Infection / fever			
Immune suppression			
Weight loss			
Latex allergy			

<b>Surgical History</b>	<b>Drug History</b>
-------------------------	---------------------

Steroids	
Anticoagulants	

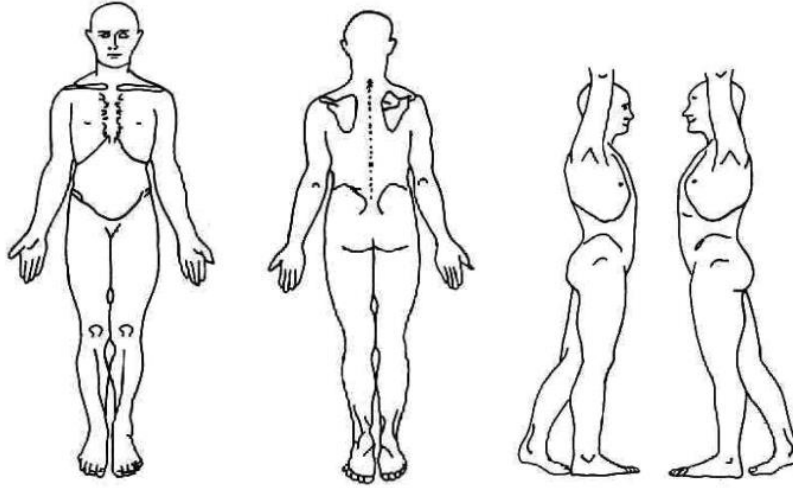
Physiotherapists Name: \_\_\_\_\_ Band: \_\_\_\_\_ Signature: \_\_\_\_\_

[continued]

Physiotherapy Service Body Chart

24hr

Sleep



Addressograph

Physiotherapist Name (Band):

Signature:

Date:

Page Number:

## Appendix 10: Mapping of Topics and Themes

	Systematic Review	Pillar 1: Patients Experiences	Pillar 2: Specialist Surgeons' Views	Pillar 3: Physiotherapy Observation
PAIN	Pain evident in almost all patients (Nunley et al (2011) and received the most detailed investigation/definition	Universally Pain was the feature which caused patients to consult with a doctor or physiotherapist.	Listed by 76% of surgeons, pain in AHD was described as new, chronic, non-specific with insidious onset	100% of physiotherapists elicited detailed accounts of patients' pain when assessing patients' hip reports. <u>Management aims included addressing pain which physiotherapists said was caused by OA, groin strain, muscle weakness, tightness or nerve irritation.</u>
Pain worsened by...	Stair climbing, weight-bearing, walking & bending (Kappe et al 2012); Walking, running, standing, impact, pivoting, sitting, stand from sitting (Nunley et al 2011)	Cold/damp weather (61%); Twisting/pivoting (78%); Lifting/carrying (61%); Stairs↑/↓ (71%); Exercise/over-use (86%); Under-use (18%); hip flexion greater than 90° (58%)	Individual comments of pain in AHD being 'activity-related' & a comment of sport being a pain trigger	Identifying triggers, regular part of the physio evaluation of patients' hip problems <u>but its contribution to patient management was unclear</u>
Pain location	Groin & lateral aspect of hip most commonly (Nunley et al 2011)	Groin (66%); lateral thigh (44%); pinpoint in hip region (36%); Knee (33%); Buttock (30%); Lower Back (25%); Radiating down leg (20%)	35% reported groin/C-sign distribution of pain & lateral aspect of hip in AHD.	Identifying pain location, part of regular physio evaluation <u>but its contribution to decision-making appeared to be linked to problems with OA, soft tissues or nerve irritation</u>

Pain Relievers	Rest (75%); NSAIDs (56%); Narcotics (8%); Positioning (42%) (Nunley et al 2011)	PS-1 indicated strong medication including cannabis and opioids used by some; high doses of analgesic and muscle relaxant combinations frequently used long term. Most described detailed methods of managing their pain including regular rest, ice & heat/hot baths.	Feature not listed	Identifying drug history, part of regular physio evaluation <u>No additional enquiry; role in physio decision-making not apparent</u>
Limp	Limp reported in 85% of hips (Nunley et al 2011)	83% of PS-2 respondents agreed that they had a limp	n=3 surgeons listed a limp as a feature of AHD gait	All physio's assessed patients' gait/limp; gait re-education part of management plan <u>but its role in diagnostic reasoning was unclear; appeared to relate only to OA, soft tissue or nerve irritation</u>
Gluteus Medius weakness/ Trendelenburg Gait	Reduced Gluteus Medius cross sectional area and radiological density (Liu et al 2012)	5 PS-1 respondents stated specifically that they had a Trendelenburg gait and n=1 stated 'abductors 'shut down'. 56% of PS-2 respondents agreed that their pelvis drops on one side	n=3 listed 'weak or fatigued hip abductors'	All physio's assessed patients' gait/limp; gait re-education and improving muscle strength generally, part of management plan.
GENDER: predominantly, but not exclusively female	Higher prevalence of females but greater proportion of males with AHD than diagnosed with infant DDH (Lee et al 2013). Males:	PS-1 & PS-2 responses show just 2 male-born in each respondent group	Feature listed by 41% of surgeons	Routinely recorded; <u>role in clinical reasoning and decision-making, unclear</u>

	greater prevalence of FAI & instability (Duncan et al 2015).			
FAMILY HISTORY	Recurrent risk of DDH proband siblings 10 times greater than siblings of non-DDH families (Li et al 2012). Increased risk of 1st & 2nd degree relatives of patients with DDH having 'Occult' HD with symptoms developing after age 30 years (Carroll et al 2016)	41% reported family members with hip problems	Listed by 59% of surgeons	Only asked in 1/17 assessments and <u>where patients offered the information, it did not prompt further questions.</u>
YOUNG AGE	Subjects in all studies were adolescents or young adults but most studies used purposive sampling	96% of PS-1 respondents and 100% of PS-2 respondents were under 60 years of age with most numerous being in the 20s - 40s age groups. All participants had initial indications of hip problems before the age of 40 years	More than 1/3 of surgeons stated hip pain at young age as an important feature with one stating <i>"In my pathways, significant and persistent hip pain in young patients should prompt early investigation with plain X-rays as the first step"</i>	Routinely recorded; <u>role in decision-making unclear</u>
AUDIBLE HIP SOUNDS	Snapping/popping (67%) /locking (23%) (Nunley et al 2011)	86% of PS-2 respondents agreed that their hips clunked/ clicked/ cracked or locked	n=1 mentioned hip clunking/giving way	Patients described their hip clunking or clicking without being questioned; <u>No additional enquiry; role in clinical reasoning or physio decision-making not apparent</u>
BILATERALITY	Statistically significant higher proportion of bilateral hip involvement within the adult	68% of PS-1 respondents described suffering from bilateral AHD	Bilaterality not listed	<u>Consideration of bilaterality not evident, though both hips were assessed.</u>

AHD group compared with infant DDH (Lee et al 2013).

**COMMONLY  
REPORTED BY  
PATIENTS**

PAIN TRIGGERS	No initial triggers listed; described only as insidious onset in 96.9% of hips; acute or traumatic in the remaining 3% (Nunley et al 2011)	Prolonged standing (70%), sitting (58%), walking (78%); Running (61%); High heels (50%); flip-flops (27%); X-Leg sitting: 42%;	Individual comments of an insidious onset with no clear cause; pain being 'activity-related' & 1/17 listed sport as a pain trigger	Identifying triggers, part of the evaluation but <u>its contribution to patient management related only to problems of OA, soft tissues or nerve irritation</u>
LEG LENGTH DESCREPANCY	No available evidence	50% of PS-2 respondents agreed they had a leg length difference	6/17 Surgeons listed leg length discrepancy as a feature	<u>Feature not evaluated</u>
PREGNANCY/ CHILDBIRTH	No available evidence	50% of participants for whom this question was relevant agreed that pregnancy/childbirth worsened their hip (Question not relevant for 50% of respondents)	Feature not listed	<u>Feature not evaluated</u>

**GOOD QUALITY  
PUBLISHED  
EVIDENCE**

HYPERFLEXIBILITY	Adult AHD more frequent in patients with hyper-laxity (Bilsel et al 2016)	48% of PS-2 respondents agreed that they were hypermobile	Just 3/17 surgeons included hypermobility as a feature	<u>Feature not evaluated</u>
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	A higher prevalence of flexible flat foot in those with DDH (Samper et al 2015)			
AHD versus FAI	Hip abduction and internal rotation more problematic for those with FAI compared with AHD alone	At least 10% of PS-1 respondents indicated the greater readiness their clinicians showed for a diagnosis of FAI and torn labrum, and that this delayed recognition of AHD which led to prolonged hip instability	Whilst 10 surgeons stated that hip movements were tested, most commented that there was no specificity for AHD; 1/17 did however state that they were done to rule out other pathologies	Physiotherapy assessment included evaluation of hip movements; 2/17 physiotherapy assessments <u>suspected FAI but that followed X-Ray evaluation</u>
<b>EVIDENT WITH MODERATE TO WEAK SUPPORT</b>				
INSTABILITY	22% reported hip subluxation (Nunley et al 2011)	Many reports of a 'looseness' of the hip joint and 38% reported that their hip repeatedly 'pops out'; 'goes out'; dislocates or subluxes	n=2 surgeons listed instability	Patients described their hip instability <u>without being questioned; n=1 physio stated that the hip would not be moving out of its socket</u>
<b>EVIDENT BUT LESS COMMONLY REPORTED BY PATIENTS</b>				
MONTHLY PERIODS	No available evidence	25% agreed that pain/instability worsened during monthly periods	Feature not listed	<u>Feature not evaluated</u>

