Level of, and Factors Affecting, Adherence to Prescribed Exercise in People with Spondyloarthritis

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Abstract

Background: Spondyloarthritis is a group of chronic inflammatory musculoskeletal diseases for which exercise is considered an essential part of their management. Adherence is a primary determinant of the effectiveness of any intervention and can be influenced by multiple factors. The World Health Organisation proposes that when studying adherence, an approach where adherence is determined by interplay of factors relating to five construct; socioeconomic, healthcare, condition, treatment and patient-related can be used. Currently the level of adherence and factors affecting adherence to prescribed physiotherapy programmes in people with SpA is unknown.

Objectives: The aim of the research within this thesis was to investigate the level of, and factors affecting, adherence in people with SpA.

Methods: Three studies were undertaken. Firstly, a systematic review of the current literature investigating adherence to prescribed exercise in SpA. Secondly a cohort study to investigate the level of, and factors affecting, adherence to a web-based physiotherapy programme in patients with axial SpA (axSpA), the prototypic SpA condition. Finally, a survey of physiotherapists in the United Kingdom (UK) delivering prescribed exercise programmes to people with SpA, investigating the factors they perceive as affecting adherence and barriers to adopting methods to improve adherence.

Results: The systematic review identified and included ten studies with a total of 690 participants. Rates of adherence ranged from 51% to 95%, and in the main were poorly reported. The interventions and measurement of adherence varied across studies, making comparisons difficult. Two studies identified that adherence was improved following educational programmes and one study indentified that higher disease severity and longer diagnostic delays were associated with higher adherence rates. One study indicated supervised group exercise increased adherence to HEP whilst another found no difference. Three linked studies by the same authors with the same participants demonstrated that adherence reduced over time. No study within the systematic review measured adherence to a web-based physiotherapy programme.

The cohort study found adherence to web-based physiotherapy exercise in people with axSpA was 27.6% of all sessions for all participants over 12-months. When participants started a session, they were likely to complete all the individual exercises within the session (74% versus 26% of the time). Adherence reduced over the course of the intervention. No quantitative factors were found to influence adherence, however participant interviews found that disease symptoms, getting into a routine and support have an important role in influencing adherence.

The online survey identified that physiotherapists believe that adherence to prescribed exercises can be low. There were high levels of agreement of the factors affecting adherence to exercise. Within the WHO-proposed healthcare-related construct, good access to physiotherapy and effective medication for symptom control were perceived to improve adherence. Within the disease-related construct, concurrent mental health problems, high disease symptoms and multiple co-morbidities were consided to reduce adherence. Within the socio-economic domain, support increased adherence, while social deprivation reduced adherence. Within the person related construct, the belief the exercise would help and being physically active improved adherence, whilst lack time, interest or confidence and low self-efficacy reduced adherence. Within the treatment related construct, several strategies such as individualising the intervention, including goal setting, providing patient education, could increase adherence. Time was the most common barrier to physiotherapists implementing strategies to improve adherence.

Conclusions: This thesis has provided data that adherence to prescribed exercise in people with SpA can be variable, often low and reduces over the course of interventions. This thesis has identified multiple interacting factors within the five constructs suggested by the WHO adherence model which may influence adherence. When prescribing exercise, physiotherapists should consider which factors are potentially affecting adherence within each WHO domain and address key modifiable factors in order to optimise adherence for that individual. Further research is required to compare rates of adherence across different modes of programmes, identifying which factors are most important in influencing adherence on a group level. Finally improving and standardising the

measurement of adherence is crucial to facilitate progress and comparisons in this field.

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Publications:

Paul, L., Coulter, E.H., Cameron, S., McDonald, M.T., Brandon, M., Cook, D., McConnachie, A. and Siebert, S., (2016). Web-based physiotherapy for people with axial spondyloarthritis (WEBPASS)–a study protocol. *BMC musculoskeletal disorders*, *17*(1), pp.1-8.

McDonald, M.T., Siebert, S., Coulter, E.H., McDonald, D.A. and Paul, L., (2019). Level of adherence to prescribed exercise in spondyloarthritis and factors affecting this adherence: a systematic review. *Rheumatology international*, *39*(2), pp.187-201.

Coulter, E.H., McDonald, M.T., Cameron, S., Siebert, S. and Paul, L., (2020). Physical activity and sedentary behaviour and their associations with clinical measures in axial spondyloarthritis. *Rheumatology International*, *40*(3), pp.375-381.

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McDonald, M.T., Siebert, S., Coulter, E.H., Cameron, S., Brandon, M., Cook, D., McConnachie, A. and Paul, L. (2016) WEBPASS Physiotherapy for patients with Axial Spa, The association of physical activity and sedentary behaviour with disease measure in

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Marie Therese McDonald

Definitions/Abbreviations

AS:	Ankylosing Spondylitis
ASAS:	Assessment of SpondyloArthritis International Society
ASQoL:	Ankylosing Spondylitis Quality of Life
axSpA:	axial spondyloarthritis
BASDAI:	Bath Ankylosing Spondylitis Disease Activity Index
BASFI:	Bath Ankylosing Spondylitis Functional Index
BASMI:	Bath Ankylosing Spondylitis Metrology Index
BMI:	body mass index
CI:	Chief Investigator
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
CRP:	C-reactive protein
CV:	cardiovascular
DMARD:	Disease modifying anti-rheumatic drug
EAQ:	exercise attitude questionnaire.
EMBASE:	Excerpta Medica Database
ESSG:	European Spondyloarthropathy Study Group
EULAR:	European League Against Rheumatism
HCP:	Health Care Professional
HEP:	home exercise programme
IBD:	inflammatory bowel disease
LTF:	lost to follow up
MeSH:	medical subject headings
MRI:	Magnetic Resonance Imaging
MSK:	Musculoskeletal
NHS GGC:	National Health Service Greater Glasgow and Clyde
NASS:	National Ankylosing Spondylitis Society
NHS:	National Health Service
NSAIDs:	non-steroidal anti-inflammatory drugs
nr-axSpA:	non-radiographic axial Spondyloarthritis
OA:	Osteoarthritis
PIS:	Participant information sheet
PhD :	Doctor of Philosophy
PsA:	Psoriatic Arthritis

PRISMA:	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RA:	Rheumatoid Arthritis
RCT:	Randomised Control Trial
reA:	Reactive Arthritis
SD:	standard deviation
SpA:	Spondyloarthritis
TNF:	Tumour Necrosis Factor
UK:	United Kingdom
uSpA:	undifferentiated spondyloarthropathy
VAS:	visual analogue scale
WEBPASS:	Web-based Physiotherapy for People with Axial Spondyloarthritis
WHO:	World Health Organisation

1 Chapter: Introduction

1.1 Introduction & Problem Statement

This chapter introduces Spondyloarthritis and provides an introduction to rationale for the body of work contained within this thesis. This chapter presents the overarching aim and investigations central to the thesis. The organisation of the thesis and the original contribution of the work to existing knowledge will be presented.

Spondyloarthritis (SpA) is a group of chronic inflammatory musculoskeletal diseases. The prevalence of SpA varies across countries and is estimated to be between 0.4-2.4% with an incidence rate of 1-16.4/100000 within Europe (Sieper., et al. 2006). The aetiology of SpA is unclear, however, interactions between genetic, immune and environmental factors are thought to contribute to the development of SpA (Dougados and Baeten, 2011).

SpA is characterised by inflammation of the joints and spine, resulting in progressive musculoskeletal damage, enthesitis, dactylitis and extra-articular manifestations such as uveitis, psoriasis, and cardiovascular (CV) disease (van der Horst-Bruinsma and Nurmohamed, 2012). The physical limitations of SpA are known to affect employment, leisure activities, mood and interpersonal relationships (Strand and Singh, 2017). People with SpA suffer from joint pain, swelling, stiffness, loss of bone density, fatigue, and functional limitations in performing daily tasks. The economic impact of work limitations related to SpA is substantial. As symptoms commonly start when a person is young, normally within the second or third decade of life, and continue over a person's lifetime, work productivity is affected over the long term (Strand and Singh, 2017). SpA is associated with an increase in all-cause mortality compared with the general population. This is predominantly related to osteoporotic fractures and CV disease (Molto & Nikiphorou, 2018).

SpA can be classified as axial or peripheral SpA depending on the dominant clinical musculoskeletal manifestation (Rudwaleit et al., 2009). Axial spondyloarthritis (axSpA) predominantly affects the spine and/or sacroiliac joints. Whilst peripheral SpA predominantly involves the peripheral joints. Subtypes of SpA include ankylosing spondylitis (AS), psoriatic arthritis (PsA), non-

radiographic axSpA (nr-axSpA), reactive arthritis (reA), enteropathic arthritis, and historically undifferentiated spondyloarthropathy (uSpA) (Dougados and Baeten, 2011, Reimold and Chandran, 2014). AxSpA itself is a spectrum, incorporating AS and nr-axSpA. AS is the most commonly described of the SpA conditions and is considered the most severe and potentially disabling of the SpA group (Zochling and Smith, 2010). Apart from when referring to the specific condition, AS and axSpA are used interchangeably throughout this thesis.

The optimal management of SpA requires a combination of pharmacological and non-pharmacological treatments. Pharmacological treatment of SpA includes non-steroidal anti-inflammatory medicines (NSAIDs), disease-modifying anti-rheumatic drugs (DMARDs) and biologic drugs including tumor necrosis factor (TNF) blocking agents (Zochling et al., 2006). NSAIDs can be effective in reducing symptoms such as pain, and morning stiffness as well as potentially reducing structural damage associated with SpA. However, gastrointestinal toxicity is a well-known adverse effect of NSAIDs and can contribute to co-morbidities within SpA (Wanders et al., 2005). NSAIDs alone are not sufficient or effective therapy for a significant number of people with more severe disease. Conventional synthetic DMARDs, such as sulfasalazine and methotrexate, are less studied and potentially less effective in SpA compared with rheumatoid arthritis (RA) (van der Horst-Bruinsma et al., 2002). They are generally not considered effective for spinal disease (Haibel et al 2007). Biologic therapy is indicated in cases of persistent high disease activity and when insufficient response to NSAIDs or conventional DMARDs are recorded (Braun et al., 2011). Biologic therapies used in SpA include the TNF inhibitors infliximab, etanercept, adalimumab, certolizumab and golimumab. They have demonstrated efficacy in the control of disease activity in 60–70% of patients with axSpA (van der Heijde et al., 2005, 2006, Inman et al., 2008). Secukinumab, a biological DMARD that targets IL-17A, has also been shown to be effective for axSpA and is included in recently published treatment recommendations (van der Heijde et al., 2017, NICE 2017). Although drug management continues to evolve, people with SpA still experience impaired health-related quality of life due to the symptoms and clinical manifestations of SpA, and a significant percentage of people do not respond to any currently available medications (Strand and Singh 2017).

Non-pharmacological strategies include exercise therapies, education, lifestyle and behavioural changes and self-management. Physiotherapy treatment includes prescribed exercise programmes, which are important aspects of the care for people with SpA (NICE 2017). Physiotherapists prescribe exercises to improve and/or maintain clinical outcomes and symptoms. The existing literature suggests that exercise can be effective in improving physical function, disease activity, pain, stiffness and CV fitness. However, the majority of published literature has examined exercise in AS populations so generalising to SpA should be done with caution (O'Dwyer et al., 2014a, NICE 2017). Exercise programmes require to be individualised taking into consideration assessment findings, goals and lifestyle (Dagfinrud et al., 2004, O'Dwyer et al., 2014a, 2014b, Reimold and Chandran, 2014, Millner et al., 2016, Regel et al., 2017). Prescribed exercise programmes are predominantly provided as home exercise programmes (HEPs) or in supervised sessions. These programmes commonly include flexibility, CV fitness, strengthening and balance exercise. The chronic nature of SpA requires ongoing, regular exercise throughout the person's lifetime (Millner et al., 2016, Nice 2017, Regel et al., 2017).

Due to the life-long, chronic nature of SpA, adhering to prescribed exercise programmes is challenging for individuals with SpA and the professionals supporting them. Adherence refers to the extent to which a person's behaviour corresponds with the recommendations from a healthcare provider (HCP) (Sabete et al., 2003). A person's adherence to their prescribed exercise programme can determine the efficacy of the programme (Sabete et al., 2003). Improved clinical outcomes are reported in other conditions in those who adhere to their exercise programmes in comparison to those who do not (Pisters et al., 2010, Peek et al., 2016). The extent to which people with SpA adhere to prescribed exercise programmes is currently not known.

Adherence to physiotherapy prescribed exercise programmes is determined by the interplay of multiple factors. The World Health Organisation (WHO) proposes that when studying adherence, a multidimensional approach could be undertaken where adherence is determined by the interplay of factors relating to five constructs; socioeconomic, healthcare, condition, treatment and patient-related (Sabate et al., 2003). The WHO (2003) suggest this approach could be used as a starting point to study factors within these constructs; however, the

factors within these constructs relating to the behaviour of adherence to prescribed exercise within SpA are currently unknown.

Delivering physiotherapy using a web-based approach may be a feasible alternative to traditional physiotherapy for people with SpA. Web-based physiotherapy programmes can be individualised, with progressive exercise programme provided online with the physiotherapist remotely contactable. Physiotherapy programmes delivered in this manner, may help support people over the longer term who may struggle to engage with traditional physiotherapy due to travel or lifestyle (Laver et al., 2020). People with SpA are commonly diagnosed in the second or third decade of their life, when employment and family commitments have the potential to be demanding. Web-based programmes have the advantage of being flexible and available 24 hours per day and so may be a more feasible alternative intervention to traditional face to face physiotherapy and support adherence in the long term (Paul et al., 2014).

1.2 Overall aim and investigations central to this thesis

The overall aim of this research was to investigate the level of, and factors affecting, adherence to prescribed exercise programmes in people with SpA.

1.3 Organisation of thesis

This thesis comprises three studies. First, a systematic review was conducted to assess adherence to prescribed exercise in people with SpA (Chapter 3). Secondly, a cohort study assessed adherence over one year to a prescribed web-based combined physiotherapy-led and patient choice programme and measured a range of factors affecting adherence in people with axSpA (Chapter 4). Finally, an online survey of physiotherapists delivering prescribed exercise programmes to people with SpA in the United Kingdom (UK) was conducted to investigate the factors they perceived as affecting adherence and barriers to adopting methods to improve adherence (Chapter 5). Overall conclusions and recommendations for each study and the collective body of work are presented in Chapter 6.

The three studies (Chapters 3-5) form a coherent and progressive programme of work. The systematic review found no studies had investigated adherence to an online physiotherapy programme, thus, a cohort study measuring adherence to online physiotherapy was devised. The cohort study and systematic review identified limited information on the factors affecting adherence, thus a survey of physiotherapist was devised.

Individually the three studies may be of interest to a number of specific audiences including health professionals, academics, service providers and users, third sector organisations and exercise scientists. To help facilitate this, the first study, the systematic review, has already been published (McDonald et al., 2019); however, this thesis will offer greater detail than presented in the published work.

1.4 Original contribution of work to knowledge

Each of the studies in this body of work has contributed original knowledge to the current literature of physiotherapy for people with SpA. The systematic review was the first to evaluate the level of adherence and factors affecting adherence in people with SpA. The cohort study addressed a gap in the literature, as it was the first study to measure the level of adherence to a web-based programme and investigate new factors affecting adherence in people with axSpA. This study was part of, and extended the work of the Web-based Physiotherapy for people with axSpA (WEBPASS) study, which was funded by Versus Arthritis (previously Arthritis Research UK) (20874). The PhD student (MTM) was a qualified physiotherapist, who specialised in rheumatology. The PhD student was a grant applicant, and was involved in the design of the study, recruitment, provision of the physiotherapy, data analysis and write up of the study. This PhD study extended the work of the Versus Arthritis study by completing a more in-depth study and analysis of adherence.

Finally, the online survey was the first to explore what physiotherapists perceived as the factors which affected adherence and the interventions for axSpA, which may address the barriers to implementing these interventions.

2 Chapter: Literature Review

This chapter will present the epidemiology of SpA. It will then go on to outline the different subsets of the disease, the pathophysiology, and the diagnostic criteria. The clinical features and symptoms of SpA and pharmacological treatments available will be discussed. The effect of SpA on employment and the economy will next be presented. Physiotherapy interventions and treatment will be discussed in relation to SpA, with particular focus on prescribed exercise programmes. Adherence will be defined and examined in the context of adherence to physiotherapy prescribed exercise programmes and the aims and objectives of this thesis will be outlined. An individual justification for each of the three studies undertaken in this PhD will be at the start of each of the respective chapters.

2.1 Spondyloarthritis

SpA describes a group of interrelated inflammatory arthritides which share common genetic, pathophysiological and clinical features (Dougados & Baeten 2011, Bengtsson et al., 2017). SpA conditions include AS, nr-axSpA, reA, enteropathic arthritis, PsA and historically uSpA (Dougados & Baeten 2011, Reimold & Chandran 2014).

2.2 Epidemiology & Prevalence of Spondyloarthritis

SpA as a group are as common a diagnosis as RA (Haglund et al., 2011) with approximately 1 in every 200 people in the UK having an axSpA (Hamilton et al., 2015). A systematic review investigated the epidemiology of SpA from 16 studies worldwide and reported the prevalence varied from 0.01% in Japan to 2.5 % in Alaska (Stolwijk et al., 2012). In western Europe the prevalence is estimated to be between 0.3 and 2.5% with an incidence of 1-16.4/100000 (Sieper et al., 2006). However, there are variable definitions and delays in the diagnosis of SpA

which impact on the reported prevalence for SpA and potentially account for the variation between studies, in addition to geographic variation. It is anticipated that with better recognition and diagnosis of SpA the reported prevalence will increase. There is a need for further studies into the prevalence of axial and peripheral SpA in the general population, and to estimate the prevalence of SpA in developing countries (Stolwijk et al., 2012).

2.3 Pathophysiology of SpA

The pathogenesis of SpA is not fully elucidated. However, it is believed SpA is the result of a complex interaction between genetic risk factors and environmental triggers that leads to the activation of an auto inflammation response (Reveille and Arnett, 2005).

Susceptibility to SpA can be partially attributable to genetic factors, with documented familial aggregation and a concordance rate in identical twins (Reveille and Arnett, 2005). The gene HLA-B27 is an important genetic factor in the development of SpA (Dougados and Baeten, 2011). HLA-B27 is found in up to 95% patients of European ancestry with AS, as well as in 70% with reA, 60% with psoriatic spondylitis, 25% with peripheral PsA (although no association with cutaneous psoriasis itself), 70% with spondylitis associated with inflammatory bowel disease (IBD) (but no association with IBD itself), and 50% with acute anterior uveitis occurring without other stigmata of SpA (Serrano et al., 2017). However, HLA-B27 is also present in the general population. With geographic variation, only 7–8% of HLA-B27 carriers go on to develop AS. Therefore, HLA-B27 can only explain part of the risk for SpA, other genes alongside environmental triggers may play a role, but are not yet fully understood (de Koneing et al., 2018). Genome-wide association studies have identified a number of non-HLA susceptibility genes, several of which implicate the IL-23/IL-17 cytokine pathway (Reveille & Arnett, 2005). In common with other inflammatory rheumatic conditions, inflammatory cytokines have been implicated in the pathogenesis of SpA. The focus in SpA, and related extra-articular conditions such as psoriasis and IBD, has increasingly been on the key role of the IL-23/IL-17 axis, leading to numerous therapeutics targeting this (Siebert et al., 2020).

The role of abnormal intestinal microbiota and infections in the development of SpA have been suggested. In reA, symptoms typically develop a short-time after a gastrointestinal or genitourinary infection (Carter and Hudson, 2009). Evidence that gut bacteria are important in SpA includes findings in animal models of SpA. Seminal work reports that rats and mice develop SpA-like clinical and pathologic features when housed in a regular laboratory environment, but not when raised in a germ-free environment (Taurog., et al 1994). Findings on changes in gut microbiota in humans with SpA are emerging, with much unknown, such as how and when the microbiome influences disease. However, there appears to be a general expectation that abnormal intestinal microbiota and infections play a role, which may allow for therapeutic intervention in future (de Koneling et al., 2018).

The role of mechanical stress in inflammation and bone formation is increasingly recognised as associated with the pathogenesis of SpA but remains poorly understood (Ronneberger et al., 2011) The 'synovio-entheseal complex' represents an integration between ligament or tendon insertions and the adjacent synovium. Fibrocartilage at these insertions is prone to micro damage and in people who are susceptible, tissue repair can produce tenosynovitis or synovitis due to the synovium being rich in immune cells and able to undergo hyperplasia and vessel ingrowth (Schett et al., 2017). While acute lesions may resolve with chronic inflammatory lesions, resolution of the process results in fat metaplasia and bone formation. In axSpA this leads to bony bridges within the spine called syndesmophytes which limit spinal mobility, or boney projections at entheseal sites called enthesiophytes (Vieira-Sousa et al., 2015).

2.4 Clinical Features of SpA

Common shared clinical features of SpA include inflammatory back pain, sacroiliitis, peripheral arthritis, enthesitis, dactylitis. Non-articular manifestations such as uveitis, psoriasis, IBD and CV disease are also reported (van der Horst-Bruinsma and Nurmohamed, 2012). These clinical features are further discussed below.

2.4.1 Enthesitis

The enthesis is the site of insertion of ligaments, tendons, joint capsule, or fascia into bone. Enthesitis is defined as the inflammation of the enthesis origin and is the hallmark of SpA (Taniguchi et al., 2013, Sen et al., 2020). The most common site of enthesitis is the Achilles tendon insertion into the heel (see fig 2-1) but iliac crests, cost chondral junctions at the sternum, the greater trochanters, and the tibial plateaus can also be affected. Enthesitis produces tenderness on palpation of these sites and occasionally also swelling of superficial sites such as the Achilles tendon insertion (Rudwaleit et al., 2011).

Figure 2-1. Enthesitis at insertion of Achilles Tendon into calcaneus in right heel (arrow). Reproduced from ASAS http://slides.asas-group.org/app/slides/search?q=

2.4.2 Inflammatory Back Pain & Sacroiliitis

Inflammatory back pain is a major symptom of axSpA (Braun and Inman, 2010). It is distinct from mechanical back pain as it is characterised by persistent back pain that worsens with periods of immobility, such as during the night, but improves with light exercise. It is associated with morning stiffness and pain can radiate to the dorsal spine or pelvis. Sacroiliitis can manifest as alternating left-right gluteal region pain. The cervical spine, and less frequently the thoracic spine, can also be affected, especially in AS, with loss of range of motion

(Deodhar et al., 2016). Spinal enthesitis has been suggested as the cause of inflammatory back pain and sacroiliitis (Braun, et al., 2000)

2.4.3 Peripheral Arthritis

Peripheral arthritis is a common characteristic of SpA. This often involves the lower extremities, especially knees and ankles, and is associated with pain, stiffness and joint swelling. The pattern is normally acute, non-erosive, asymmetrical, and oligoarticular (Fragoulis et al., 2019).

2.4.4 Dactylitis

Dactylitis is the global inflammation of fingers and toes, which can make them look like sausages (Figure 2-2) (Olivieri et al., 2006). It can be acute, with inflammatory signs, or chronic and often not painful. Dactylitis can affect one or more fingers and/or toes asymmetrically (van der Horst-Bruinsma and Nurmohamed, 2012).

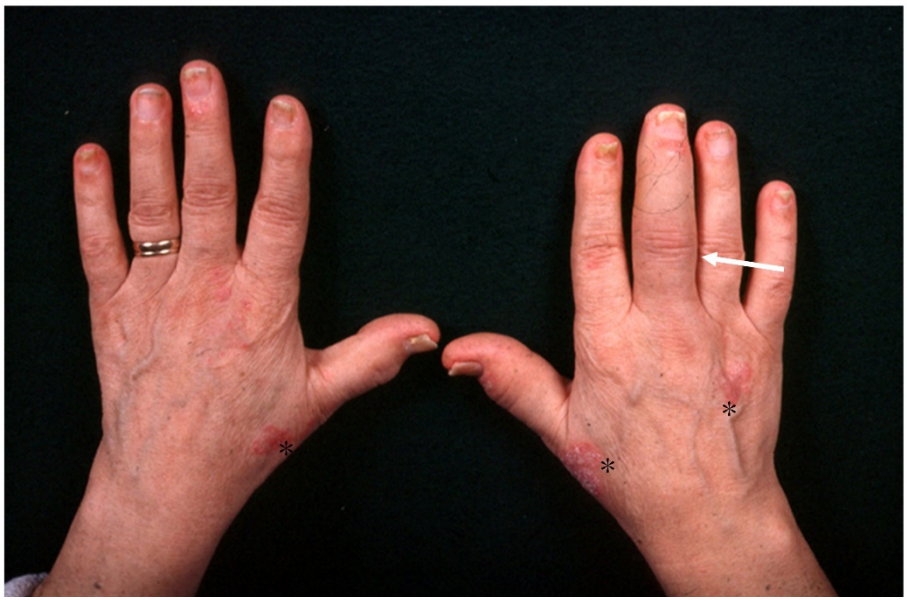


Figure 2-2. Dactylitis of the third digit (arrow) on right hand.
Reproduced from : http://slides.asas-group.org/app/slides/search?q=

2.4.5 Extra-Articular Features

Acute unilateral anterior uveitis is a common symptom of SpA, especially in HLA-B27 positive patients, and may be the presenting feature (Gupta, 2018). Uveitis is an eye condition where inflammation affects the uveal tract such as the iris, ciliary body, and/or choroid. Anterior uveitis is the most frequently observed extra-articular manifestation of SpA and can be seen affecting up to 40% of patients (Gupta, 2018). Approximately 10% of people with SpA have concurrent IBD, such as Crohn's disease and ulcerative colitis (van der Horst-Bruinsma and Nurmohamed, 2012). Psoriasis is an inflammatory skin condition which causes skin to become red, scaly and crusty and is present in 10-20% of people with SpA and characteristic of PsA (van der Horst-Bruinsma and Nurmohamed, 2012).

Other less common non-articular features include aortic insufficiency, nerve conduction abnormalities, neurological manifestations secondary to spinal fractures or atlantoaxial subluxation, amyloidosis, and osteoporosis (Sieper et al., 2006).

2.4.6 Symptoms

Individuals with SpA commonly complain of fatigue, stiffness, and frequent flares. These symptoms are variable but for a proportion of individuals with SpA these will be intense, frequent and disabling (Sieper et al., 2006, Atzeni et al., 2014, Jacquemin et al., 2017). As a result of clinical features and new bone formation, people with axSpA suffer with spinal immobility, pain and loss of function (Jacques and McGonagle, 2014).

2.5 Types of Spondyloarthritis

SpA conditions include AS, nr-axSpA, reA, enteropathic arthritis, PsA and historically uSpA (Figure 2-3) (Dougados & Baeten 2011, Reimold & Chandran 2014). SpAs can be classified according to their clinical presentation as predominantly axial or peripheral SpA, with some overlap between these two subtypes (Rudwaleit et al., 2009) (Figure 2-3). AxSpA is characterised by

predominant involvement of the spine and/or sacroiliac joints. AS, nr-axSpa, certain forms of PsA and reA with axial involvement, and enteropathic arthritis can present as axSpA. These conditions are all part of the same spectrum of axSpA and, apart from when referring to the specific condition, AS and axSpA are used interchangeably throughout this thesis. In peripheral SpA, peripheral joint arthritis, enthesitis and/or dactylitis dominate in the clinical presentation (Rudwaleit et al., 2011). ReA, PsA, enteropathic arthritis and certain forms of undifferentiated SpA can present as a peripheral SpA (Figure 2-3).

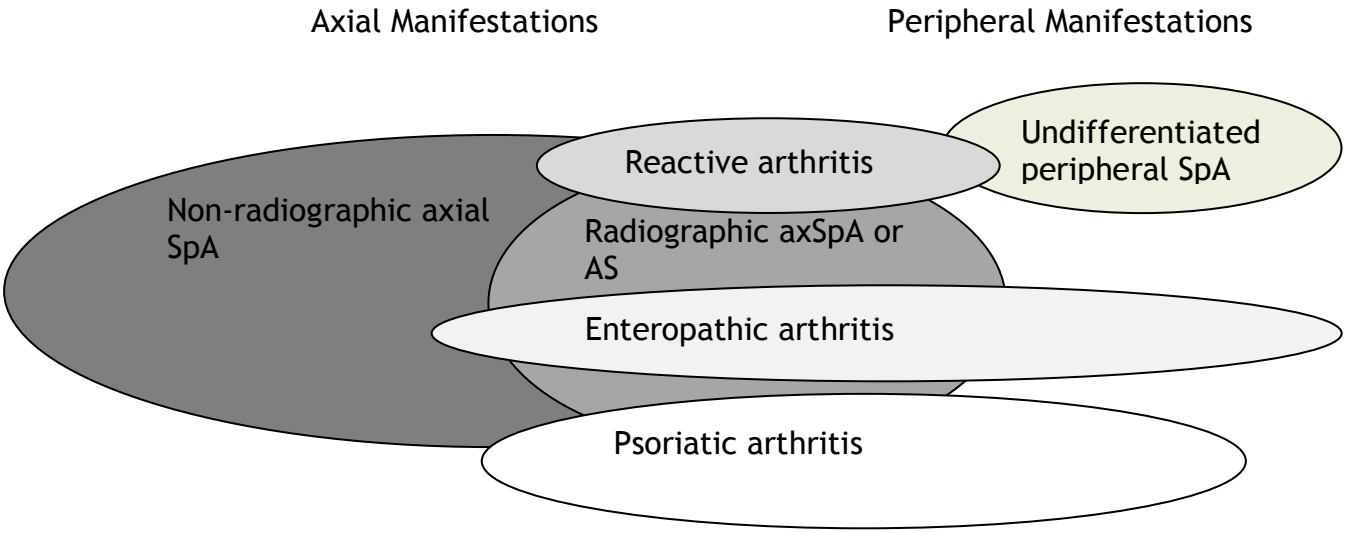


Figure 2-3. Family of Spondyloarthritis conditions.
Modified from Proft et al., 2018. Therapeutic Advanced Musculoskeletal Disorders.

The following sections describe the clinical features of each specific condition in more detail.

2.5.1 Ankylosing Spondylitis (AS)

AS (also known as radiographic axSpA) is the prototypic and best described of the axSpA conditions, and is considered the most severe and potentially disabling of the SpA group (Zochling and Smith, 2010). AS is traditionally distinguished from nr-axSpA by the presence of radiographic changes of the sacroiliac joints, fulfilling the modified New York criteria (van der Linden et al., 1984), although both conditions fall on the axSpA spectrum. People with AS

suffer from inflammatory back pain, which is worse in the morning and is associated with stiffness but improves as the day continues (Rudwaleit et al., 2006). Inflammatory back pain is present in 70–80% of patients with axSpA, is chronic (present > 3 months) and typically has insidious onset before the age of 45 years. Inflammation in AS typically occurs at the entheseal sites, the spine and sacroiliac joints. Persistence of disease leads to progressive joint and structural changes throughout the spine, mainly as a result of new bone formation (Zochling and Smith, 2010). This includes the ossification of spinal ligaments and the appearance of bony outgrowths, known as syndesmophytes, which are classic radiographic features of AS. In the most severe cases, this ultimately results in complete fusion of the vertebrae (ankylosis, often referred to as "bamboo spine"), which causes limited spinal mobility, and fixed curvature of the spine which gives the individual the characteristic posture and gait (Figure 2-4) (Braun and Sieper 2007). There can also be peripheral joint involvement, particularly of the hips, and extra-articular manifestations, including uveitis, psoriasis and IBD.

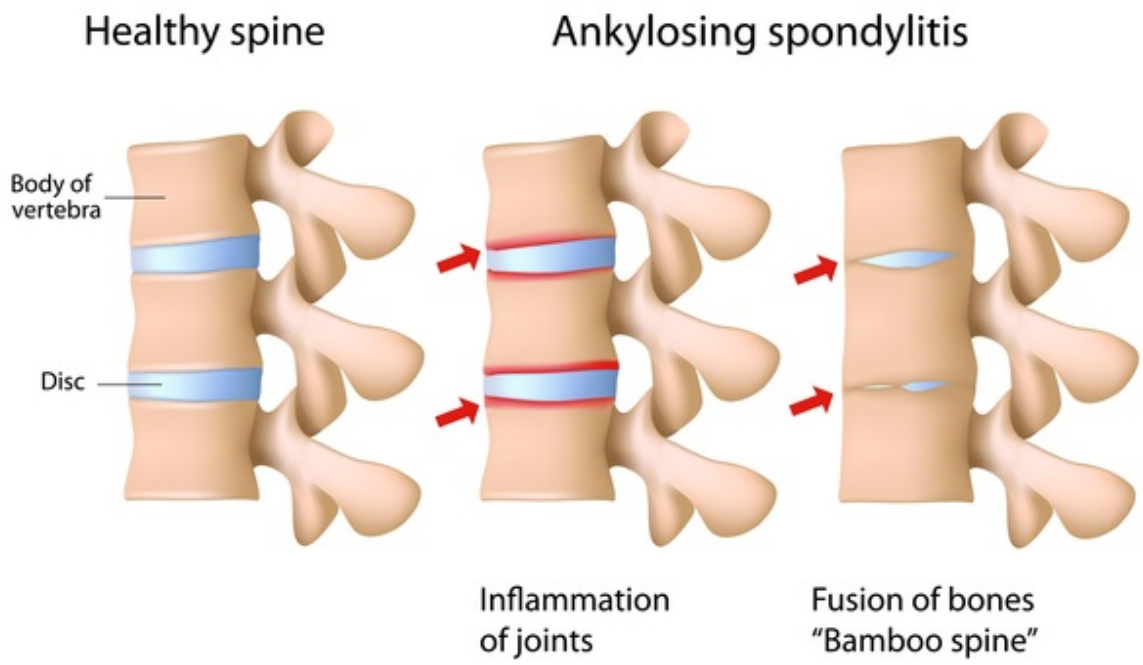


Figure 2-4. Schematic of changes in the spine in Ankylosing Spondylitis. Reproduced from: https://ghr.nlm.nih.gov/condition/ankylosing-spondylitis

2.5.2 Non-Radiographic SpA

Nr-axSpA and AS are part of the spectrum of axSpA, with similar burden of disease (Rudwaleit et al., 2009). The clinical features of nr-axSpa are the same as, with people presenting with chronic inflammatory back pain and stiffness predominantly of the pelvis and the lower back which improves with movement. Peripheral arthritis and enthesitis of the lower limbs are the most common peripheral manifestations. In nr-axSpA there is spinal inflammation on magnetic resonance imaging (MRI) and/or evidence of inflammation (eg raised CRP) but no new bone formation on x-ray, whereas in AS radiographic changes have occurred in the sacroiliac joints (Ludwaleit et al., 2009). Modern imaging modalities especially MRI have allowed earlier diagnosis of axial inflammation in patients who suffer from inflammatory back pain (Rudwaleit et al., 2009, Poddubnyy and Sieper, 2018). However, nr-axSpA is not considered as a precursor to AS the majority of patients will not develop radiographic progression despite clinical and MRI imaging of spinal inflammation (Poddunbnyy et al., 2011).

2.5.3 Reactive Arthritis

ReA is an inflammatory arthritis that arises after certain types of gastrointestinal or genitourinary infections (Carter and Hudson, 2009). Musculoskeletal symptoms begin a few days to 6 weeks after infection. The typical pattern of ReA is an asymmetric, mono- or oligoarthritis, predominantly of the lower extremities including knees, ankles and feet. In addition, inflammatory back pain, sacroiliitis and enthesitis can occur. Non-articular manifestations include conjunctivitis and urethritis (Kim et al., 2009). This type of SpA is self-limiting over 2-3 months in the majority of patients but a proportion of people, as high as 40%, will develop chronic ReA, with a small number going on to develop AS (Kaavela et al., 2009).

2.5.4 Psoriatic Arthritis

PsA is a heterogeneous condition associated with cutaneous psoriasis. People with PsA may have a number of musculoskeletal presentations, including

peripheral polyarthritis, mono/oligoarthritis, dominant enthesitis, dactylitis or sacroiliitis/spondylitis (Akgul, 2011).

2.5.5 Enteropathic Arthritis

Enteropathic arthritis is an SpA which occurs in people with IBD such as Crohn's Disease or ulcerative colitis (Peluso et al., 2013). Similar to other subtypes of SpA, people with EA can have axial symptoms and/or peripheral arthritis, enthesitis or dactylitis (Peluso et al., 2013).

2.5.6 Undifferentiated SpA

Undifferentiated SpA is a poorly described subgroup that fulfils SpA criteria but cannot be classified in one of the other subtypes (Paramarta et al., 2013). uSpA may develop into other forms of SpA such as AS or PsA (Paramarta et al., 2013) and has largely fallen out of favour and been replaced by nr-axSpA with the availability of MRI imaging allowing identification of sacroiliitis.

2.6 Diagnosis and Classification Criteria for SpA

Traditionally AS was the most commonly diagnosed subtype of SpA and classification was based on the modified New York criteria, which required the presence of both clinical and radiographic features (van der Linden et al., 1984). However, structural changes identified on conventional radiographs can often take up to 10 years to develop, while it was clear that a large proportion of patients with classic symptoms and clinical features did not fulfil the imaging criteria required for AS (Feldtkeller et al., 2000). The modified New York criteria therefore excluded the possibility of diagnosing nr-axSpA within the axSpA spectrum. The advent of MRI scanning, which can detect both acute inflammation and chronic damage within the spine and sacroiliac joints, has provided a means for the better detection of inflammatory changes.

To classify the whole spectrum of SpA, not only axSpA, the European Spondyloarthropathy Study Group (ESSG) and Amor criteria were developed in the early 1990s (Amor et al., 1990; Dougados et al., 1991). They both cover the

whole spectrum of SpA including axial and peripheral manifestations and gave weighted scores to non-articular features associated with SpA. However, it has been suggested that these criteria lack sensitivity (Collantes et al., 2000). To facilitate the diagnosis of nr-axSpA the new Assessment of the SpondyloArthritis international Society (ASAS) classification criteria for axSpA was introduced (Rudwaleit, 2010). The ASAS, incorporates the use of MRI evidence of sacroiliac inflammation, with criteria for both axial and peripheral forms of SpA (Figure 2-5). (Rudwaleit et al., 2009a, Rudwaleit et al., 2009b). Furthermore, some patients do not have obvious x-ray or MRI changes, so the ASAS classification criteria includes a clinical arm, although in clinical practice, c-reactive protein test (CRP) is the main non-imaging feature used to support a diagnosis of nr-axSpA. This relatively new criterion was studied in a population of 975 and reported a sensitivity of 79.5% and a specificity of 83.3%, which overall in terms of sensitivity is superior to the Amor which reports sensitivity of 59% and specificity of 86% and ESSG criteria which reports sensitivity of 58% and specificity of 90%. Therefore the ASAS classification criteria are now commonly used in SpA research and also to support clinical practice, although classification criteria on their own are not intended for diagnostic purposes (Rudwaleit et al., 2011). By enabling the identification of patients with nr-axSpA, patients may have access to more effective treatment sooner in the disease course.

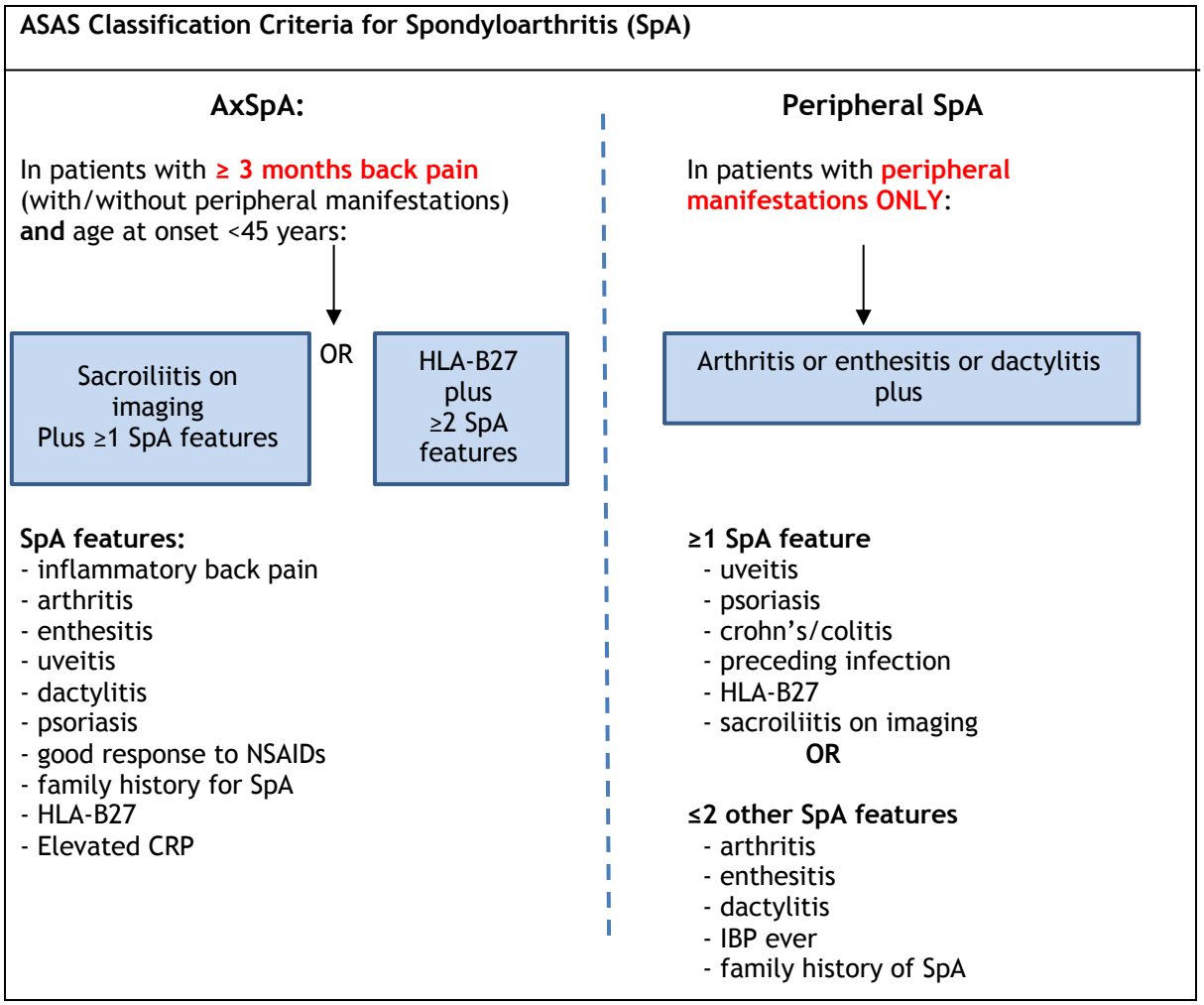


Figure 2-5. ASAS classification criteria for axSpa (left column) and peripheral SpA (right column).

Adapted from Rudwaleit et al., (2011)

2.7 Disease course of SpA

With the exception of some forms of ReA, SpA is a chronic long-term condition with no known cure. The clinical course of SpA is characterised by periods of remission and flare-ups of the disease. Identification and treatment of SpA at an early stage can affect disease course and outcomes although it still remains unclear within axSpA whether this will translate to reduced radiographic progression (Baraliakes et al., 2014). Furthermore, not all patients with axSpA develop radiographic changes; in those that do develop new bone formation at the spine and sacroiliac joint, this can progress to spinal fusion or ankylosis of the spine, reducing spinal mobility and function (Dougados and Baeten, 2011) (Figure 2-4).

There is an increase in all-cause mortality in SpA compared with the general population predominantly related to osteoporotic fractures and CV disease (Bremander et al., 2011). CV disease is consistently found as the leading cause of mortality in patients with SpA, ranging from 30 to 50% of all-cause mortality in this population (Moltó and Nikiphorou, 2018).

2.8 Employment in Spondyloarthritis

Participation in employment with a long term chronic condition such as Spa/axSpA can be challenging, compounded by the fact that the symptoms of axSpA commonly start when a person is in their 20-30s when people are establishing their careers and work productivity is high (Strand and Singh, 2017). The physical limitations, such as reduced spinal mobility, and high disease activity leading symptoms such as pain, stiffness and fatigue of SpA can affect the ability to carry out certain tasks and therefore may negatively affect employment (Strand and Singh, 2017). Employment levels among people with SpA may be lower than the general population. A study in the Netherlands found that people with AS were 14.4% less likely to be employed in comparison to the general population after adjustment for age, gender and education (Webers et al., 2018). People with AS can struggle to meet the various demands of their job, which can lead to higher rates of withdrawal from employment, sick leave (absenteeism) and impairment while at work (presenteeism) compared with the general population (Booneen et al., 2001).

Furthermore, individuals in work may experience work instability, which is a mismatch between an individual's functional abilities and the demands of their job (Fabreguet et al., 2012). If the mismatch is not resolved, it can threaten continued employment. Work instability within the working population of SpA is common. A study evaluated work instability in 156 patients with SpA, the mean age of participants was 41 (SD 11) years and the mean disease duration 15 (SD 11) years. The results demonstrated high or moderate work instability as assessed by the ankylosing spondylitis work instability scale in 40% of individuals (Fabreguet et al., 2012). To combat work instability, people with SpA may switch to a less physically demanding job, and/or retire early because of the condition (Fabreguet et al., 2012). Within the UK, survey data from 570 people

with AS found that, AS had a significant effect on their ability to work with 43% of people of working age either unemployed or retired early and ≥70% citing AS as the cause (Cookey et al., 2015)

2.9 Economic Impact of Spondyloarthritis

SpA incurs an economic burden to individuals diagnosed with the condition, their families, the health service and society. This burden includes medical costs, such as medications, visits to outpatient clinics, hospital admissions, physiotherapy, and care (Cooksey et al., 2015). Indirect costs can also be incurred which includes reduced earnings, modifications to home or car, and transport. There are also societal costs with decreased tax receipt to the economy and increased receipt of disability benefits.

Costs vary between countries and the majority of research has investigated the economic impact of AS. Within the UK the total cost of AS including indirect and medical costs in the UK is estimated at £19016 per patient per year. This was calculated to include GP attendance, administration costs and hospital costs derived from routine data records, plus patient-reported non-NHS costs, out-of-pocket AS-related expenses, early retirement, absenteeism, presenteeism and unpaid assistance costs. The majority of these costs (>80%) were work-related costs. (Cooksey et al., 2015).

2.10 Pharmacological Management of SpA

Pharmacological treatment options for people with SpA have broadened considerably over the past several years. Pharmacological treatments of SpA include; NSAIDs, DMARD and biologic agents including TNF and IL-17 inhibitors (Zochling et al., 2006).

NSAIDs are the first-line therapy in axSpA, and can rapidly reduce pain and stiffness associated with inflammation in axSpA (Zochling and Smith, 2010). While two studies had suggested that continuous or high dose NSAID use in AS was associated with less radiologic progression (Wanders et al., 2005, Kroon et al., 2012), a subsequent randomised trial of continuous versus on-demand

diclofenac did not demonstrate a significant difference in radiographic progression (Sieper et al., 2016). Furthermore, potential long-term gastrointestinal and CV toxic effects of NSAID therapy remain a concern, especially in patients who are recognised as having more comorbidities than the general population (Dougados and Baeten, 2011).

DMARDs, such as sulfasalazine are generally not considered to be effective for axial symptoms in axSpA (van der Horst-Bruinsma., et al 2002). However, DMARDs have a role in treating peripheral SpA, including in patients with axSpA peripheral joint involvement (Sieper and Poddubnyy, 2016). The efficacy of DMARDs for enthesitis or dactylitis remains to be determined, with several studies within a review article suggesting no significant efficacy (Sieper and Poddubnyy, 2016), while other studies have indicated some efficacy in peripheral SpA, including PsA (Mease et al., 2019).

Biologic therapy is indicated in cases of persistent moderate to high disease activity and insufficient response to NSAIDs (or conventional synthetic DMARD in cases of peripheral arthritis) (Braun et al., 2011). TNF and IL-17 inhibitors are the currently licensed for patients with active axSpA, including those with nr-axSpA. Improvements in clinical symptoms, inflammation levels and MRI-detectable inflammation in the spine have been observed for infliximab, etanercept, adalimumab, golimumab and certolizumab pegol for AS and TNF blockers; adalimumab, certolizumab pegol, etanercept and golimumab in patients with nr-axSpA (Sieper and Poddubnyy, 2016). Secukinumab, an IL-17A inhibitor, has been shown to be effective for both AS and nr-axSpa (Sieper, 2016). The choice of treatment should be made after discussion between the clinician and the patient about the advantages and disadvantages of these treatments (van der Heijde et al., 2016, NICE 2017).

Treatment options are likely to expand, with the development of other biologics and targeted synthetic DMARDs. However, people with SpA still experience significant impaired health-related quality of life and unmet need due to the symptoms and clinical manifestations of SpA, and a percentage of people do not respond to medication (Strand and Singh 2017).

2.11 Non-Pharmacological Management of SpA/axSpA

The optimal management of SpA requires a combination of pharmacological and non-pharmacological treatments (Nice 2017). The two most common non-pharmacological managements are educational programmes, which aim to improve understanding of the condition and treatments and exercise programmes (Regel et al., 2017). Hydrotherapy is recommended as an adjunctive to manage pain and maintain or improve function in people with axSpA (NICE 2017, McCrum, 2019). Less commonly used are manual therapy and electrotherapy, which may be due to the lack of evidence base for these interventions (Reimold and Chandran., 2014, McCrum, 2019).

2.12 Exercise in SpA

Exercise is a planned, structured, and repetitive bodily movement completed to improve or maintain physical fitness (Caspersen et al., 1985). Exercise programmes are an important part of non-pharmacological management of SpA and have been described as a cornerstone of management of axSpA (Dagfinrud et al., 2004). Within the UK, exercise programmes are a part of routine care for people with SpA where physiotherapists prescribe exercise programmes to improve or maintain symptoms and disease outcomes for individuals with SpA (O'Dwyer et al., 2014a, Poddubnyy and Sieper, 2018).

2.12.1 Evidence for Exercise in SpA

The majority of evidence for exercise programmes has focussed on AS populations and predates the ASAS classification criteria (Landewe & van Tubergen 2015, NICE, 2017). There is little evidence on physiotherapy management of peripheral SpA (McCrum, 2019).

A systematic literature review examined the safety and efficacy of the non-pharmacological management of axSpA (Regel et al., 2017). For the efficacy of exercise, this review focused on five papers which had an unclear or low risk of bias (Kjeken et al., 2013, Neidermann et al., 2013, Rodriguez-Lozano et al., 2013, Dundar et al., 2014, Sveaas et al., 2014). Four papers considered exercise

interventions and one paper considered education in addition to exercise. The five RCTs included heterogeneous interventions including: aqauatic exercises versus land based exercises (Dundar et al., 2014), Nordic walking plus flexibility exercises compared to flexibility exercises and attention control (Neidermann et al., 2013), endurance exercises and strength training compared to no exercise (Sveaas et al., 2014), education and exercises (including flexibility, strength, deep breathing and advice for exercises in the pool) compared with standard care from a rheumatologist (Rodriguez-Lozano et al., 2013) and a rehabilitation programme versus standared care (Kjeken et al., 2013). The exercise interventions lasted between 3-12 weeks (Kjeken et al., 2013, Neidermann et al., 2013, Dundar et al., 2014, Sveaas et al., 2014), whilst the study which combined exercise and eduction lasted for 24 weeks (Rodriguez-Lozano et al., 2013). Cohen's effect sizes were calculated to determine the combined effect on disease activity, function, spinal mobility and pain. Cohen's effect sizes are the mean change in score divided by the baseline standard deviation, with Cohen's effect sizes <0 meaning worsening, 0–0.49 a small positive effect (i.e. an improvement), 0.5–0.79 a moderate effect and ≥0.8 a large effect (Cohen, 1988).

This review found for disease activity, as measured by the BASDAI, the majority of the effect sizes (n=3/6) fell into the small bracket (0–0.49). These small effect sizes were found in an intervention group which included flexibility exercises and Nordic walking and a control group of flexibility exercises and attention control (Neidermann et al., 2013), and an intervention group of education plus exercise (Rodriguez-Lorano et al., 2013). Two effect sizes were moderate (0.5–0.79), for an aquatic exercise intervention and the control group of land based exercise over 4 weeks (Dundar et al., 2014). A large effect size (1.43) was found for an intervention of a 12-week strength and endurance exercises (Sveaas et al., 2014).

Regel et al., 2017, also considered effect sizes for function, as measured by the BASFI. A worsening Cohen's effect size (-0.07) for the intervention group of Nordiac walking and flexibility exercises over 12 weeks was calculated (Neidermann et al., 2013). The majority of the effect sizes were small (n=4/6) (0-0.49). These small effect sizes were found in the control group of flexibility exercises and attention control (Neidermann et al., 2013), the intervention

group of aquatic execise and the control of land based exercise (Dundar et al., 2014,) and the intervention group of education and exercise (Rodriguez-Lorano et al., 2013). A moderate effect size (0.5) for the intervention group of a strength and endurance intervention was calculated (Svaas et al., 2014).

Regel et al (2017) also calculated effect sizes for spinal mobility as measured by the BASMI. Three RCTs found small positive Cohen's effect sizes of between 0.07 (Neidermann et al., 2013) and 0.48 (Dundar et al., 2014). The smallest effect size (0.48) was found within the flexibility control group of Neidermann et al., 2013) and the largest in the aquatic exercise group of Dundar et al.,(2014). Sveass et al 2014 also reported a small effect of their strength and endurance exercise intervention.

Regel et al (2017) also calculated effect sizes for pain. They reported one small effect size for an intervention of exercise and education over 24 weeks (0.27) (Rodriguez-Lorano et al., 2013), one moderate effect size (0.57) for land based exercises over four weeks (Dundar et al., 2014) and one large effect size (0.96) for an aquatic exercise intervention over four weeks (Dundar et al., 2014).

Overall, therefore, this review concluded that regular exercises can improve disease activity, pain, function and spinal mobility however, the effects were usually small (Regel et al., 2017). It is unclear from the evidence presented within this review if one particular type of exercise is superior to others. The review informed the European League Against Rheumatism (EULAR) guidelines and subsequently, exercise was identified as key and was incorporated in the EULAR/ASAS treatment recommendations which stated:

'*Patients should be educated about axSpA and encouraged to exercise on a regular basis and stop smoking; physical therapy should be considered'.* (van der Heijde et al., 2017).

Although Regel et al (2017) focussed on non-pharmacological management it also included the safety and efficacy of NSAIDs, they did not compare exercise with NSAIDs. Regular exercise is considered to be of nearly the same importance as NSAIDs in the first-line therapy of axSpA (Braun et al. 2011). However, no study has directly compared the effect of NSAIDs with the effects of exercise.

Within SpA a systematic review was undertaken on the effectiveness of physiotherapy interventions including, exercise programmes in people with SpA and to inform the NICE guidelines, as previously the majority of the evidence relates to AS (NICE, 2017). Fourteen RCTs were included, these studies were divided into; unsupervised structured home exercises versus standard care, supervised individual structured exercise (inpatient) versus standard care, supervised structured group exercise versus unsupervised structured home exercise and supervised structured group exercise versus standard care. Quality was assessed using the GRADE tool: grading of recommendations, assessment, development and evaluations. The grade tool states RCTs are initially rated as high quality and then can be downgraded or not from this initial point. For non-RCT evidence these are initially rated as low quality and the quality of the evidence can further downgraded or not from this point.

When comparing unsupervised structured home exercise with standard care, NICE (2017) found high quality evidence for improved quality of life (1 RCT, n=756), reduced finger to floor distance (1 RCT, n=48), and improved BASFI score (5 RCTs, n=1034) favouring the unsupervised structured home exercise group and from low to moderate quality evidence, no significant difference in BASDAI score (5 RCTs, n=1034) and BASMI score (2 studies, n=104).

NICE (2017) also compared supervised individual structured outpatient exercise with standard care. They reported from very low quality evidence that there was no significant difference in finger-floor distance (2 RCTs, n=80), or BASMI score (2 RCTs, n=68) or pain (2 RCTS, n=38).

Supervised individual structured exercise (in-patient) were compared to standard care. NICE (2017) report, from moderate quality evidence (one RCT, n= 95), that there was no significant difference in BASDAI, BASMI, and BASFI scores.

NICE also compared supervised structured group exercise with unsupervised structured home exercise low to moderate quality evidence found no significant difference in BASFI score or stiffness (1 RCT, n=45), finger-floor distance, or pain (2 RCTs, n = 91).

Furthermore, NICE (2017) found when supervised structured group exercise was compared with standard care, from low to moderate quality evidence, 2 RCTs,

(n=97) an improvement in BASDAI score and BASFI score in those receiving structured supervised group exercise compared with standard care. Very low to moderate quality evidence (2 RCTs, n=97) found no significant difference in BASMI score or quality of life in those receiving structured supervised group exercise compared with standard care.

From this evidence, NICE (2017) recommended referring people with axSpA to a specialist physiotherapist to start an individualised, structured exercise programme. NICE (2017) did not specify if this should be within a group, or supervised. This programme should include stretching, strengthening, postural exercises, deep breathing, range of motion exercises for the spine and aerobic exercise (NICE, 2017). International guidelines similarly recommend exercise within the management of AS (Zochling, 2006; Ozgocmen et al., 2012; van den Berg et al., 2012; Rohekar et al., 2015) and SpA (Wendling., et al 2014). A recent article published since these systematic reviews has found that high intensity exercises improved pain, fatigue and stiffness in people with axSpA in general (Sveaas et al., 2020). Furthermore, exercise may also have a role in attenuating a systemic anti-inflammatory response, and improving CV fitness (Millner et al., 2016).

2.12.2 Content of Exercise Prescription

Although the clinical guidelines and evidence support the use of exercise in axSpA, the optimum delivery strategy remains unclear. Traditionally, improving spinal mobility has been the focus of exercise programmes, however, there is an increasing recognition that exercise programmes should also aim to maintain or improve strength, CV health, function and quality of life (Reimold and Chandran, 2014). Each exercise programme should be tailored for the individual that it is prescribed for, taking into account the physiotherapist's assessment, and the goals and lifestyle of the patient (O'Dwyer et al., 2014a, Reimold and Chandran, 2014, Millner et al., 2016).

2.12.3 Frequency, Duration and Course of Exercise Programmes

There is a high level of variation in terms of the frequency and duration of prescribed exercise programmes for people with SpA in the published literature, with most studies limited to AS. Two systematic reviews reported that the frequency of exercise programmes in studies ranged from twice daily to once weekly (Dagfinrud et al., 2011, O'Dwyer, et al, 2014a). Recommendations from a consensus statement which used a modified Delphi technique from 11 physiotherapists specialising in AS and a rheumatologist asked the question: 'In adults with AS, what dosage of exercise is beneficial for pain, mobility, disease activity and function?' and suggested aiming for long term maintenance and high frequency five or more times per week (Millner et al., 2016). Thirty minute sessions have been reported as being optimum in one paper (Santos et al. 1998), but exercise programmes should be tailored for each individual and therefore, 30 minutes should be an aim but not compulsory. Therefore, people with SpA, in particular, axSpA should exercise frequently from diagnosis over the course of this life-long chronic condition (Millner et al., 2016). It is important to recognise long term participation in exercise programmes is likely to be challenging for people with SpA and the exercise professionals supporting them.

2.12.4 Delivery of Exercise Programmes

Exercise programmes can be done at home or supervised individually by a physiotherapist or within a group. Home-based exercise programmes have been shown to effectively improve clinical outcomes and health-related quality of life in people with AS (Yigit et al., 2013, Sollini et al., 2015). A Cochrane review reported that both home and supervised exercises were beneficial for people with AS, but concluded that supervised exercise programmes were more effective than home exercises (Dagfinrud et al., 2004). More recently, it has been suggested that improvements from exercise undertaken in a supervised group setting are more likely to be due to higher adherence and higher exercise dosage rather than purely from the supervision alone (Millner et al., 2016). The authors conclude an exercise programme should be based on personal preference, local availability of physiotherapy and adequate dosage rather than only considering supervised exercise (Millner et al., 2016).

Participating in regular prescribed exercise over the longer term is important if the beneficial effects of the exercise are to be realised. For optimum clinical outcomes people with SpA then require regular (high frequency) life long exercise. Within finite resources and increasing patient numbers it is not feasible for people with SpA to receive ongoing physiotherapist supervised sessions through the NHS. In addition, for many it is not possible for them to attend face to face exercise sessions due to eg time, transport, caring responsibilities. Therefore, new approaches in the delivery of prescribed exercise programmes should be investigated in people with axSpA for efficacy and adherence.

Web-based physiotherapy approaches are a newer form of delivery of physiotherapy exercise programme. In a web-based approaches the programme can be remotely monitored with the physiotherapist contactable if and/or when required and carried out asynochronously. These remotely delivered approaches may be an alternative to traditional HEP and/or supervised exercise programmes (Laver et al 2020). Web-based interventions are becoming a more feasible option due to the increasing number of people with access to the internet and the required computer skills. The Office of National Statistics (2018) reported that 90% of the UK adult population used the internet, with most adults being regular users.

Web-based tailored, individualised exercise programmes have been shown to be feasible for people with chronic conditions such as multiple sclerosis and spinal cord injury (Paul et al., 2014, Coulter et al., 2017). Furthermore, web-based interventions have demonstrated increased engagement, satisfaction and motivation to exercise in other long term health conditions including osteoarthritis (OA) and RA (Dahlberg et al., 2016, Brennan and Barker, 2008). They have the advantage of being available 24 hours a day, giving users flexibility to choose when and where to exercise, which may be particularly useful for the younger axSpA population, who are likely to be in employment and have family commitments. This flexibility may allow people with SpA to engage with the programme when is it suitable for them, for example in the evenings where work and family commitments may be less, improving adherence to the programme. Flexibility may improve adherence in the long-term as the

programme is available without the need for referral back to physiotherapy or group exercise programmes. Furthermore, for some people participating it is probable that exercise without social interaction like group exercise, or supervised exercise may be preferred. Web-based physiotherapy provision for people with SpA has not previously been examined.

2.13 Adherence

Adherence is defined as the extent to which a person's behaviour corresponds with the recommendations from a HCP (Sabete et al., 2003). The term adherence takes into consideration that individuals have a choice about whether they act on the recommendations from a HCP. Traditionally the term 'compliance' has been used to describe the extent a person's behaviour corresponds to HCP recommendations; however, compliance implies that an individual does not have a choice (Taube, 2016). Therefore, compliance is a term to be used when there is no choice, such as laws or rules. When considering exercise prescription, physiotherapists recommend a structured exercise programme, and often prescribe the frequency, duration, and type of exercises. Individuals have a choice about whether to participate in these exercise programmes and therefore the correct term to use in this context is adherence (Segal 2007). Adherence is not a binary concept; individuals can adhere to only some of the recommendations or only some of the time.

2.13.1 Level & Effect of Adherence

The evidence presented in the above sections indicates that exercise improves clinical outcomes in axSpA. Even if the optimal dosage and frequency of exercise in SpA was known, the outcomes will also depend on how much of this recommended exercise the individual does. As it is an individual's choice whether they will follow the recommendations given by the physiotherapist, the level of adherence is important to consider.

Adherence to exercise programmes helps realise the benefits from the exercise programme. Broadly, within long term conditions the WHO recognise poor adherence to long-term therapies compromises the effectiveness of treatment

(Sabete et al., 2003). The literature in other musculoskeletal conditions has reported better outcomes for those who adhere to exercise programmes, compared to those who do not (Pisters et al., 2010, Peek et al., 2016). In addition to better treatment outcomes, increased adherence has been reported to reduce waiting times and the cost of care in long term conditions (Vermeire et al., 2001, Hayden et al., 2005).

The level of adherence to physiotherapy prescribed exercises is unclear. A systematic review in a mixed population (musculoskeletal conditions, urinary incontinence, haemophilia, post orthopaedic surgery and chronic lung disease) reported an average rate of adherence to physiotherapy prescribed exercise programmes across 12 studies of 67% (Peek et al., 2016). Sluijs et al (1993) used questionnaires to ask 1,206 physiotherapy service users who had various pathologies including neck & back pain, about their adherence over a one-week period with and reported that adherence could be as low as 30%.

The demands of the exercise programmes may be higher in people with SpA as programmes are likely to be prescribed in the long term and with high frequency. Therefore, it is possible adherence may be lower due to these high demands. Two quantitative cross-sectional surveys have gathered data on the extent of exercise participation in AS. Passalent et al (2010), surveyed 61 people in Canada finding that 34.4% of participants self-reported exercising on a daily basis, 57.4% 3 times per week and 26.2% less than once a week. More recently Sang et al (2020), surveyed 259 people in China finding only 20.5% of the sample exercised 30 minute, 5 times per week. Neither Chan et al, or Passalent et al, provided an exercise intervention and therefore it was not clear if people participating in the study had previously seen a HCP and asked to adhere to exercise of specific parameters. Although these surveys suggest a gap between general recommendations to exercise and participation in exercise, without including recommendations from a HCP this cannot be defined as adherence. Therefore, there is a gap in the knowledge of the level by which people with SpA, and axSpA adhere to exercise interventions. The level of adherence to prescribed exercise have not been reviewed in SpA.

The literature investigating the effectiveness of exercise programmes on disease outcomes in axSpA, calls for more monitoring of adherence within research and further study to gain understanding (Dagfinrud et al., 2011, Millner et al., 2016, Passalent et al., 2010). Further study into the level of adherence to the recommended exercise would be of benefit, to gain a greater understanding of the extent of adherence in people with SpA.

2.13.2 Measurement of Adherence

Adherence to exercise has been measured using self-reported home diaries, self-reported questionnaires, clinician reported questionnaires, and objective measures, such as accelerometers (Bollen et al., 2014, Hall et al., 2015, McLean et al., 2017, Newman-Beinart et al., 2017). The approach chosen depends on what aspect of adherence is being measured. For example, adherence to physical activity guidelines may be measured using electronic devices, such as accelerometers and pedometers, giving a measure of steps taken and sedentary time. However, these approaches would not capture whether the individual undertook specific exercises and therefore would not be suitable to measure adherence to HEPs (Newman-Beinart et al., 2017). A further measurement approach is for the clinician to assess adherence through direct behavioural observations, such as attendance at exercise sessions, or clinician-reported questionnaires such as the Sports Injury Rehabilitation Adherence Scale (Kolt et al., 2007). This approach may be suitable for measuring adherence to attendance at supervised exercise sessions but is not suitable or appropriate to measure adherence in an unsupervised HEP (Bollen et al., 2014).

Researchers recognise that accurately measuring adherence to HEP is difficult (Bollen et al., 2014, Hall et al., 2015, McLean et al., 2017). Self-reported adherence questionnaires such as the Adherence to Exercise Scale for Older Patients (Hardage et al., 2007), the Community Health Activities Model Program for Seniors (Stewart et al., 2001), the modified Rehabilitation Adherence questionnaire (Shin et al., 2010) and the Rehabilitation over Adherence Questionnaire (Podlog et al., 2013) have been used. However, McLean et al (2017) found no evidence of content or face validity, precision and score interpretation for any of the above questionnaires. Therefore, adherence

to HEP is most commonly measured using a self-reported diary method, although there is currently no standardised diary used across research studies (Newman-Beinart et al., 2017). Self-reported HEP diaries are far from ideal as they can be influenced by participants' attitudes and beliefs, poor recall, and participants providing a perceived desired response rather than an accurate one (Bollen et al., 2014, Newman-Beinart et al., 2017).

The issues of measuring adherence are recognised and acknowledged by the WHO (2003), who advised using the best measurement strategy to obtain an approximation of adherence appropriate for the specific setting. Researchers should also consider the convenience and acceptability of the method for the user (Vitolins et al., 2000).

There is no gold standard for defining 'good' versus 'satisfactory' versus 'poor' adherence across health behaviours (Vitolins et al., 2000). Some exercise studies have defined good adherence as having completed or performed 50% (Wing et al., 1996) or 75% of all planned sessions (van Het Reve et al., 2014). Other studies have considered full adherence as 100% and partial adherence as approximately 67% (Jansons et al., 2016).

2.13.3 World Health Organisation Five Interacting Dimensions Affecting Adherence

Whether a person adheres or not to the recommendations from their HCP can depend on a number of factors. The WHO proposes that when studying adherence, a multidimensional approach should be undertaken where adherence is determined by the interplay of factors relating to five constructs; socioeconomic, healthcare, condition, treatment and patient related (Sabete et al., 2003). The WHO (2003) approach can be used to study factors within these dimensions to any regime for example taking medicine appropriately, obtaining immunisations and executing behavioural modifications that address personal hygiene, self-management, smoking, unhealthy diet and insufficient levels of physical activity/exercise (Sabete et al., 2003) (Figure 2-6).

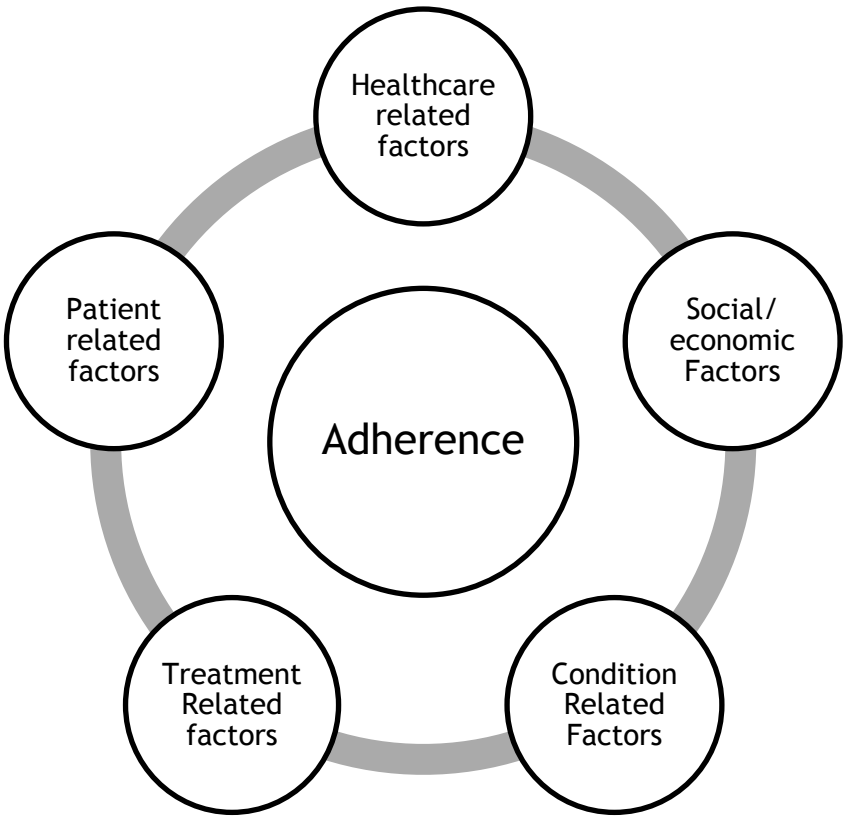


Figure 2-6. The World Health Organization Five dimensions of Adherence, Sabete et al (2003)

The factors which influence adherence to exercise programmes have been studied in other patient populations (Jack et al., 2010, Jordan et al., 2010, Beinart et al 2013, Picorelli et al., 2014, Kampshoff et al., 2014, Ezzat et al., 2015, Peek et al., 2016, Nicolson et al 2017, Room et al 2017, Essery et al., 2017).

Six systematic reviews have investigated treatment-related factors related to exercise adherence (Jordan et al., 2010; Beinart et al 2013; Ezzat et al., 2015; Peek et al., 2016; Nicolson et al 2017; Room et al 2017). A Cochrane review in adults with chronic musculoskeletal pain reported interventions with supervised exercise components, individualised exercise programmes and self-management programmes had a positive effect on adherence to exercise (Jordan et al., 2006). Peek et al (2016) found in a mixed population of adults (musculoskeletal conditions urinary incontinence, haemophilia, post orthopaedic surgery and chronic lung disease) that interventions which used activity monitoring and feedback, written instructions and booster sessions may be effective in promoting exercise adherence. Ezzat et al (2015) reported limited evidence in

an arthritis population that patient education supported adherence. Nicolson et al (2017) concluded that booster sessions could improve exercise adherence for those with osteoarthritis, and motivational approaches improved adherence for those with chronic low back pain. Beinart et al (2013), reviewed adherence to home based exercises in a chronic low back pain population, finding adherence was supported using motivational strategies and supervision. Room et al, (2017) reviewed effectiveness of interventions to improve adherence in older people finding that interventions which included feedback and monitoring techniques supported adherence but there was insufficient evidence to recommend their use. No participants with SpA were included within any of these reviews.

Four systematic reviews investigated other factors such as patient-related/socioeconomic and adherence to exercise (Jack et al., 2010, Picorelli et al., 2014, Essery et al., 2017, Kampshoff et al., 2014). Jack et al (2010) reviewed barriers to exercise adherence in a musculoskeletal population. There was evidence that poor treatment adherence was associated with low levels of physical activity at baseline or in previous weeks, low in-treatment adherence with exercise, low self-efficacy, depression, anxiety, helplessness, poor social support/activity, greater perceived number of barriers to exercise and increased pain levels during exercise. Picorelli et al (2014), reviewed older adults' adherence to exercise programmes and found a number of factors were found to be associated with greater adherence rates. These included higher socioeconomic status, living alone, fewer health conditions, better self-rated health, taking fewer medications, better physical abilities, better cognitive ability, and fewer depressive symptoms. Essery et al (2017) reviewed adults' adherence to self-managed home based physical therapy and found evidence that intention to engage, self-motivation, self-efficacy, previous adherence to exercise-related behaviours and social support increased adherence. Kampshoff et al (2014) reviewed exercise adherence in people who previously had cancer and found that exercise adherence was supported when a person had previously exercised.

There was no evidence of which health-care related factors affect adherence to physiotherapy exercise literature as noted by Jack et al 2010, and subsequently by Babatunde et al 2017.

An understanding of the factors in relation to these five WHO dimensions which influence adherence to prescribed exercise in SpA is important so that physiotherapists can assess who is most likely to benefit, explore with the individual how to change any modifiable factors and consider optimal interventions to improve adherence. The factors which influence adherence to exercise in SpA have not been reviewed, so there is no data about the condition-related factors, while data for the other WHO domains is only available from other conditions. The characteristics of SpA and demographics of people with axSpA differ from other conditions and thus, while some factors which influence exercise adherence may be the same, it is likely that some of the factors will be different; this is currently unknown.

2.14 Gaps in the Literature

SpA is a group of common inflammatory arthritis conditions with no known cure (Rudwaleit et al., 2009). The evidence indicates that exercise improves clinical outcomes in axSpA. As part of their management, people with SpA, and axSpA in particular, are advised to perform lifelong regular exercise over the course of their condition, which commonly starts in their early 20s, making it difficult to adhere to this component of their management. It is therefore likely that the level of adherence with exercise will impact on clinical outcomes in axSpA. The main gaps in the literature when the work within this thesis started were:

1. There was no systematic review of the level of adherence and factors affecting this adherence in people with SpA.
2. Limited evidence existed in terms of measuring adherence to novel interventions such as online delivered physiotherapy for axSpA.
3. There was no data on the views of physiotherapists who prescribe exercise programmes for people with SpA, regarding factors which influence adherence, strategies used to improve adherence and the barriers to implementing these strategies.

2.15 Aim of the thesis

The overall aim of this research was to investigate the level of, and factors affecting adherence to prescribed exercise programmes in people with SpA. This

was addressed by systematically evaluating the current literature to explore adherence to prescribed exercise programmes. Secondly, by conducting a cohort study measuring adherence to a 12-month five times per week web-based physiotherapy programme. And finally through a survey of physiotherapists delivering prescribed exercise programmes, investigating the perceived factors affecting adherence, the interventions and strategies to support adherence and the barriers to implementing these.

3 Chapter: Systematic Review

This chapter presents the first study in the thesis, a systematic review of the level of adherence to prescribed physiotherapy programmes in people with SpA and investigated factors affecting this adherence. This study was published in Rheumatology International in January 2019 (McDonald et al., 2019). The published paper had five authors, Marie Therese McDonald (MTM), Stefan Siebert (SS), Elaine Coulter (EC), David McDonald (DM) and Lorna Paul (LP). LP and SS are the PhD students' (MTM) supervisors. All authors contributed to the formation of the research question. MTM conducted the search, which was reviewed by DM. MTM extracted the data. EM, LP and MTM quality assessed the articles. MTM drafted the manuscript with all authors reviewing and commenting on the draft. This chapter also contains an update on the search summarising relevant papers published since the 2019 paper and a more detailed discussion on the findings of the review than the published article.

3.1 Justification

As described, SpA describes a group of inter-related but distinct inflammatory conditions including AS, nr-axSpA, reA, enteropathic arthritis, PsA and historically uSpA (Dougados and Baeten, 2011, Reimold and Chandran, 2014).

Exercise is essential in the management of SpA, and axSpA in particular, to maintain or improve mobility, strength, CV health, function, quality of life and to limit spinal deformity (Reimold and Chandran, 2014, Regel et al 2017) and is included in the ASAS-EULAR recommendations for the management of axSpA (van der Heijde et al 2017). It is recommended that people with axSpA should exercise frequently at every stage of their condition (Dagfinrud et al., 2011, Millner et al., 2016). Most of the literature evaluating exercise in SpA is in people with AS, the prototypic form of axSpA, and predates the ASAS classification criteria, so generalising to SpA as a whole should be done with caution (O'Dwyer, et al, 2014a, Landewé and van Tubergen, 2015). However, in order to capture the widest range of published literature on adherence to prescribed physiotherapy programmes, the search criteria for this systematic review used SpA and all the specific conditions covered by this.

In order for any intervention like exercise to be successful, participants need to perform the required intervention. Adherence refers to the extent to which a person's behaviour corresponds with the recommendations from a HCP (Sabete et al., 2003). The level of adherence to physiotherapy programmes in other conditions is reported to be as low as 30% (Sluijs., et al 1993, Peek et al., 2016). Survey data where no exercise interventions was provided, reports participation in exercise within an AS population may be as low as 20% (Passalent et al 2010, Sang et al 2020).

Adherence to exercise programmes may be influenced by multiple inter-related factors (Sabaté et al., 2003). These factors have been studied in other patient populations including people with musculoskeletal complaints, OA, older people and people recovering from cancer (Jack et al., 2010, Jordan et al., 2010, Kampshoff et al., 2014, Picorelli et al., 2014, Ezzat et al., 2015, Peek et al., 2016, Essery et al., 2017, Room 2017). However, the factors which influence adherence to exercise in SpA have not been reviewed.

The aim of this systematic review was therefore to examine the rates of adherence to prescribed exercise and the factors reported to influence adherence in people with SpA conditions. The objectives of this review were to systematically review, appraise and synthesise quantitative literature in order to examine adherence levels and factors affecting adherence to prescribed exercise within studies.

3.2 Methods

3.2.1 Search Strategy

The present systematic review follows the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines (Moher et al., 2009). A search was performed 1st of August 2018 by two reviewers MTM and DM using five databases: The Cochrane library, CINAHL (1982 to March 2018), EMBASE (1989 to March 2018), MEDLINE, and Web of Science Collections. The searches were saved on the database and updated on 1st of August 2020 by MTM alone. The search included specific keywords and combined Medical Search History

(MeSH) headings were exploded for greater depth (Table 3-1). Date of publication was not restricted. Reference lists of relevant articles were also hand searched.

Table 3-1. Keywords used for the literature search.

1.	Enteropathic arthritis
2.	Reactive arthritis
3.	Seronegative spondyloarthritis
4.	Ankylosing spondylitis
5.	Axial Spondyloarthritis
6.	Spondyloarthritis
7.	Psoriatic arthritis
8.	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9.	Exercise
10.	Muscle Strength
11.	Flexibility exercise
12.	Physical therapy modalities
13.	Exercise therapy
14.	Physical activity
15.	Resistance training
16.	Physical fitness
17.	Sport
18.	Movement therapy
19.	Stretching
20.	Educational Programme
21.	Walking
22.	Yoga
23.	Hydrotherapy
24.	9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23
25.	Adherence OR patient adherence OR guideline adherence
26.	Concordance OR patient concordance OR guideline concordance
27.	Compliance OR patient compliance OR guideline compliance
28.	25 OR 26 OR 27
29.	28 OR 24 OR 8

3.2.2 Inclusion/Exclusion criteria

In order to assess the level of, and quantitative factors affecting adherence to prescribed exercise in adults with SpA, articles were included if they were quantitative papers with participants who were over 18 years old and had SpA or any of the specific SpA conditions, including AS, axSpA, ReA, PsA or enteropathic arthritis, or if the study had a mixed population where the data related to the SpA population could be extracted; they were published in English; the intervention involved a prescribed exercise or educational programme to increase exercise participation. Prior to the systematic review, a small scoping review by the PhD student (MTM) found little evidence of qualitative studies, therefore, due to insufficient literature to bring together in a review, qualitative studies were excluded from the search.

There is no gold standard way of measuring adherence therefore any measurement of adherence to exercise, including self-report, was included. Articles were excluded if they were case studies, testimonies or editorial opinions in order to reduce an over estimation of the level of adherence and factors affecting adherence from single sources. Reviews, books or discussion papers, unpublished data, published theses and conference abstracts were also excluded as these were deemed lower level evidence (McAuley et al., 2000)

3.2.3 Data Extraction and Synthesis

For included studies the following data were extracted: study design, overall aim of the study, characteristics of participants, intervention details (duration and frequency of the exercise intervention), control group, measures of adherence, dropout rates, adherence data, other outcomes included in the studies, and overall conclusions of each study. Where no % adherence rate to the intervention was provided, this was calculated by MTM where data were available to do so. Correlations of ≥ 0.3, ≥ 0.5, and ≥ 0.7 were considered small, moderate and large, respectively (Pett, 1997). Due to the heterogeneity of exercise interventions of the studies within the review, the data were synthesised using a descriptive narration (Higgins et al 2019). The descriptive narration synthesis grouped and compared the following; quality of studies, study design, characteristics of participants, characteristics of interventions,

measurement of adherence within the studies and level and factors affecting adherence; grouping together similar interventions where possible.

3.2.4 Quality Assessment

There is no one method for assessing methodological quality of articles within a systematic review. The quality of a study refers to measures of internal validity, external validity and statistical criteria, i.e whether calculations can be made and conclusions can be drawn (Higgins et al., 2019). There are several different quality assessment tools, however, there are no commonly used tools which allow different study designs, such as cohort studies and RCT studies, to be examined using one tool to give a single score. Therefore, a less commonly used quality assessment tool, consisting of 20 criteria, which has been developed and modified from previous tools and used within previous reviews proposed by Davie-Smith et al., (2017), was chosen (Table 3-2) (Scholten-Peeters et al., 2003, Poorolajal el al., 2011, Davie-Smith et al., 2017). For this review, the quality criteria were based on representative study population, type of study, use of standard and validated outcome measures, appropriate statistical tests, control for confounding variables, consideration of non-response bias, and data presentation of relevant outcome measures. Davie-Smith et al (2017) also considered evidence of limitations, bringing the quality assessment in line with the Strengthening Reporting of Observational Studies in Epidemiology guidelines. The standard of information required to meet each criterion was set a-priori. The maximum quality assessment score is 38 points (100%), based on three sub-categories: (1) the source population (11%), (2) study population characteristics (42%) and (3) methodological characteristics (47%). Each article was independently scored by two of three reviewers (LP, MTM, EC) and when agreement could not be met, the third assessor was consulted to ensure consensus was reached.

Table 3-2. Quality assessment criteria and scores used to rate the articles. Adapted from Davie-Smith et al., (2017).

Category	Criteria	Scores
(1) Source Population		
A	Description of source population	Not available (0) Ambiguous (1) Available (2)
B	Description of inclusion/ and or exclusion criteria	
(2) Study population characteristics		
C	Age	Not available (0) Partially available (1) Available (2)
D	Gender	
E	Education	
F	Employment Status	
G	Marital Status	
H	Comorbidity	
I	Economic Status	
J	Data presentation of relevant O/M	
(3) Methodological characteristics		
K	Representative population	Not clear (0) Partially (1) Yes (2)
L	Study design/study type	Not clear (0) Cross sectional design (1) Retrospective / mixed design (2) Prospective design (3)
M	Population selection	Non randomised (0) Randomised / NA (1)
N	Instruments used	Non validated (0) Partially validated (1) Validated (2)
O	Statistical methods for O/M	Non appropriate (0) Partially appropriate (1) Appropriate (2)
P	Control for confounding variables	Not considered (0) Partially considered (1) Fully considered (2)
Q	Response Rate vs. Drop outs	<60%/not mentioned (0) 60-80% (1) >80% (2)/ NA (2)
R	Characteristics of drop outs	Not reported (0) Reported (1)/NA (1)
S	Relevant O/M	Not well defined(0) Well defined (1)
T	Limitations	Not considered (0) Partially considered (1) Fully considered (2)

3.3 Results

3.3.1 Outcome of the Search

In August 2018 the literature search produced 813 articles, including 91 duplicate articles which were removed (Figure 3-1). The titles and/or abstracts of articles were screened initially by two reviewers (MTM and DM) which resulted in a further 667 being excluded. The two reviewers (MTM and DM) then examined the full texts of the remaining 55 articles and a further 46 articles were excluded. Reasons for exclusion at each stage are provided in Figure 3-1. In August 2020 the search was updated and produced 189 further articles, including 2 duplicate articles which were removed (Figure 3-2). The titles and/or abstract of articles were screened at this point by MTM which resulted in 184 being excluded. The full text of the three remaining articles were read by the MTM which resulted in a further 2 articles being removed. Reasons for exclusion at each stage are provided in Figure 3-2. This resulted in ten full text articles for review and assessment, nine from the august 2018 search and one from the august 2020 search (Figure 3-1, Figure 3-2).

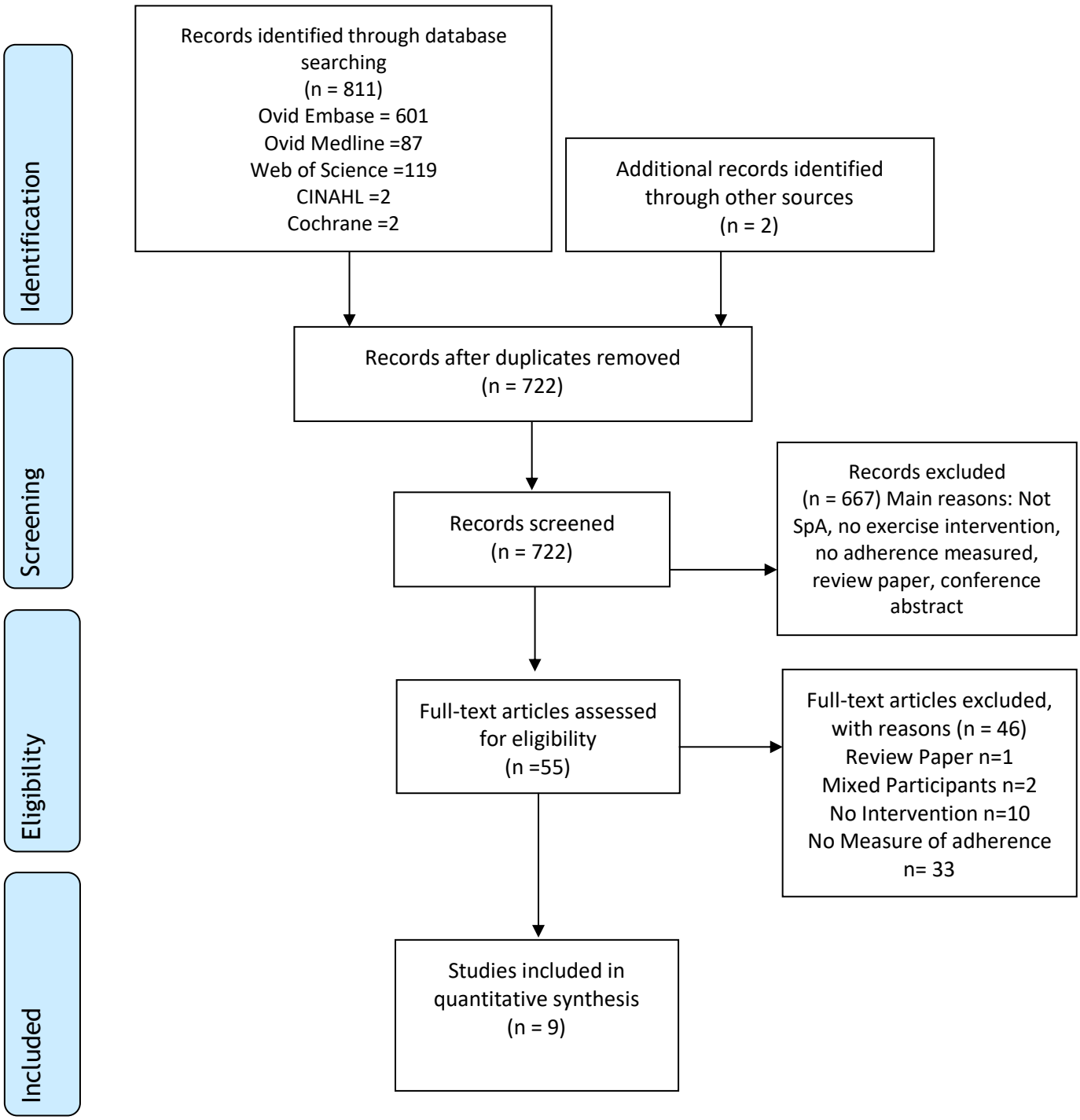


Figure 3-1. PRISMA flowchart of screening and inclusion process of included trials conducted in August 2018.

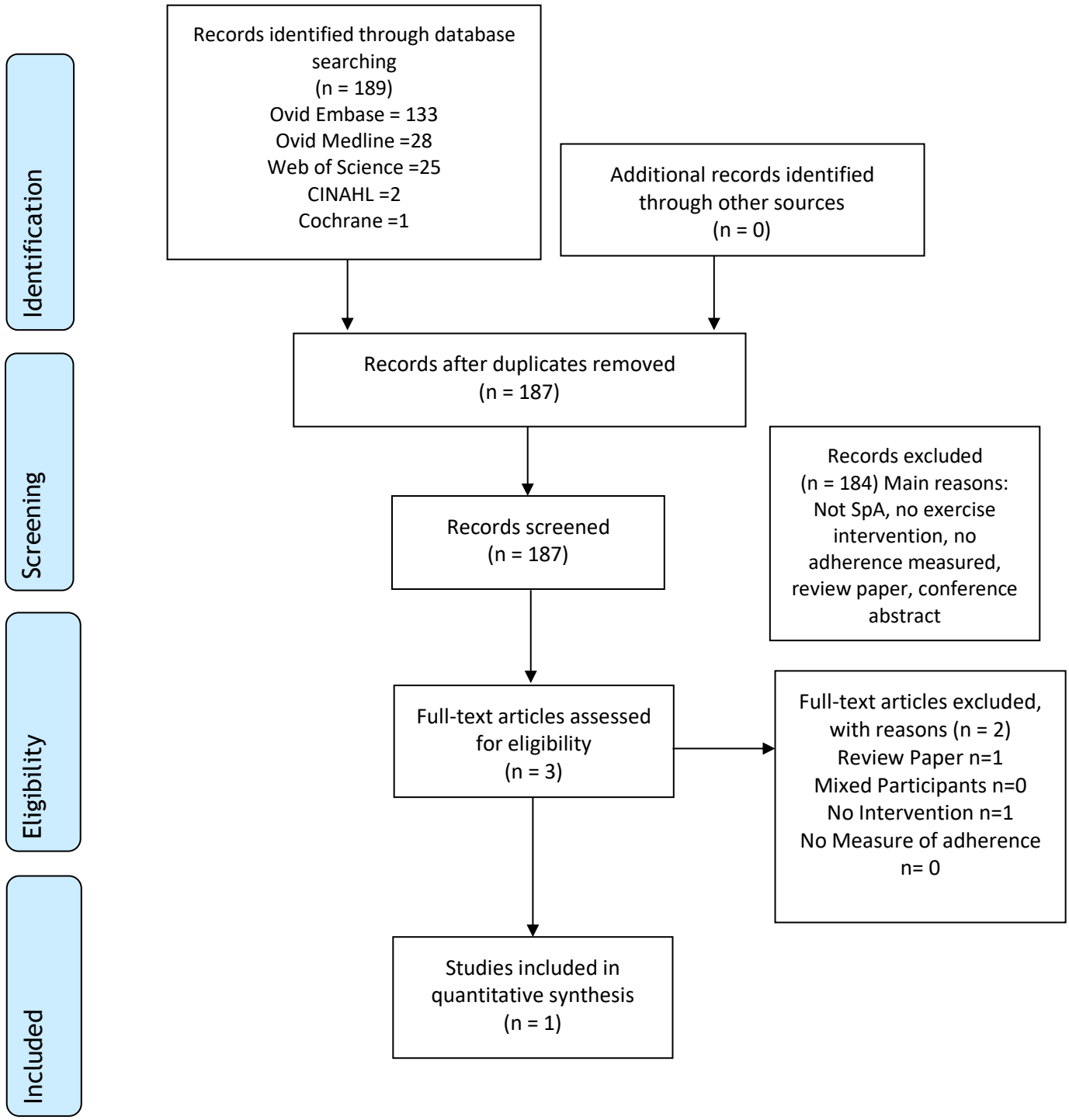


Figure 3-2. PRISMA flowchart of updated screening and inclusion process of included trials conducted in August 2020.

3.3.2 Quality Assessment and Risk of Bias

Quality assessment scores for the remaining ten papers ranged from 47% to 81%. The majority (n=7) of the included articles were rated as good quality, scoring greater than 60% (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Niedermann,

et al., 2013, Sveaas et al., 2020) (Table 3-3). Gross & Brandt (1981) had the lowest score (47%) due to a small convenience sample (n=18) and attribution bias with an average of only three participants attending the weekly intervention. Two studies scored 50% due to poor reporting of study population characteristics (Barlow & Barefoot 1996, Chimenti et al., 2014).

Three studies ran consecutively using the same participants (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994). This may have led to a repeated sample effect where a positive bias was created by the participants learning what was required in relation to the outcome measures. In the first study, participants (n=144) all received supervised exercise and a HEP for six weeks (Hidding et al., 1993a). For the second study, the participants were then randomised into two groups, an intervention group (n=68), who received supervised exercise and a HEP, and a control group, who received only a HEP (n=76) for nine months (Hidding et al., 1993b). In the third study, the intervention group from the second study (n=68) was divided further into two groups; one group undergoing group supervised exercise and a HEP while the second group continued a HEP only for a further nine months (Hidding et al., 1994).

Table 3-3. Quality assessment of included articles, shown in descending order of overall quality score (based on the quality assessment tool proposed by Davie-Smith et al 2017)

Study	Source Population				Study Population Characteristics										Methodological Characteristics												Quality Scores	
	A	B	Total	%	C	D	E	F	G	H	I	J	Total	%	K	L	M	N	O	P	Q	R	S	T	Total	%	Overall total	%
Hidding et al (1993a)	2	2	4	100	2	2	2	1	2	0	2	2	13	81	2	3	1	1	2	1	2	0	1	1	14	78	31	81
Svaas et al (2020)	2	2	4	100	2	2	0	2	2	0	0	2	10	62	2	3	1	2	2	1	2	0	1	2	16	89	30	79
Hidding et al (1993b)	2	2	4	100	2	2	2	1	2	0	2	2	13	81	2	3	0	1	2	1	0	1	1	1	12	67	29	76
Hidding et al (1994)	2	2	4	100	2	2	2	1	2	0	2	2	13	81	2	3	1	1	2	0	2	0	1	0	12	67	29	76
Niedermann et al (2013)	2	2	4	100	2	2	0	0	0	0	0	2	6	37	2	3	1	2	2	2	2	0	1	2	17	94	27	71
Fernandez-de-las-Penas (2006)	2	2	4	100	2	2	0	0	0	0	0	2	6	37	2	3	1	2	2	0	1	0	1	2	14	78	26	68
Sweeny et al (2002)	2	1	3	75	2	2	0	0	0	0	0	2	6	37	2	3	1	2	2	0	1	0	1	2	14	78	23	61
Chimenti et al (2014)	1	1	2	50	2	2	0	0	0	0	0	2	6	37	1	3	1	2	2	0	1	0	1	0	11	61	19	50
Barlow and Barefoot (1996)	1	2	3	75	1	2	0	0	0	0	0	2	5	31	1	3	0	2	2	0	1	0	1	2	12	67	19	50
Gross and Brandt (1981)	1	0	1	25	2	2	0	0	2	0	0	1	7	44	2	3	0	0	2	0	2	1	0	0	10	56	18	47

3.3.3 Study Design & Characteristics

The main findings of each of the ten included studies are presented in a summary table (Table 3-4). The majority of included studies were randomised control trials (RCTs) (n=6) (Niedermann et al., 2013, Hidding et al., 1993b, Hidding et al., 1994, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Sveaas et al., 2020), while the remaining trials were prospective cohort studies (n=2) (Hidding et al., 1993a, Chimenti et al., 2014,) and quasi-experimental studies (n=2) (Gross & Brandt 1981, Barlow & Barefoot 1996). Of the six RCTs; Svaeaas et al (2020) compared a combination of supervised and unsupervised high intensity exercise with usual care, Neidermann et al (2013) compared supervised Nordic walking and an unsupervised CV session with a discussion of mindfulness, Fernandez-de-las-Penas et al (2006) compared two different types of HEP for one year following a 12-week supervised exercise programme, Hidding et al (1993b) & (1994), compared supervised exercise plus a HEP with a HEP only and Sweeny et al (2002) compared a home based self-care programme, which consisted of an educational programme and a HEP, with no intervention. Of the two prospective cohort studies; Chimenti et al (2014) investigated a HEP only and Hidding et al (1993) supervised exercise and a HEP. The quasi-experimental studies compared self-management courses with no intervention (Gross & Brandt 1981; Barlow & Barefoot 1996).

3.3.4 Participant Characteristics

A total of 690 individual participants (taking into account the three Hidding et al 1993a, 1993b, 1994 used the same participants), of which 66% were male, with a mean age range of between 41-50 years were included across the ten studies. Eight trials included only participants with AS; 560 participants with a range of mean disease duration of between 4-28 years (Gross, Brandt 1981, Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Barlow & Barefoot 1996, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Niedermann et al., 2013). One trial included 100 people with axSpA; with 70% of this axSpA population having AS (Sveaas et al 2020), and the remaining trial included 30% participants with PsA (Chimenti et al., 2014). Overall across all ten studies within this review AS participants made up 91% (630 participants), nr-axSpA 4.5% (30 participants) and PsA 4.5% (30 participants) of all participants (Gross, Brandt

1981, Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Barlow & Barefoot 1996, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Niedermann et al., 2013, Chimenti et al., 2014, Sveaas et al 2020).

3.3.5 Characteristics of Interventions

Exercise duration ranged from six weeks (Hidding et al., 1993a) to 12 months (Fernandez-de-Las Penas et al., 2006) across the ten studies. Frequency of exercise sessions varied from daily (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al. 1994) to once weekly (Fernandez-de-Las-Penas et al., 2006), with an individual session duration ranging from 30 minutes (Chimenti et al., 2014) to 3 hours (Hidding et al., 1993b & Hidding et al., 1994). The exercise interventions included hydrotherapy, Nordic walking, supervised and unsupervised exercise programmes, aerobic and flexibility exercises (Gross, Brandt 1981, Barlow & Barefoot 1996, Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Niedermann, et al., 2013, Chimenti et al., 2014, Sveaas et al., 2020). All but two studies Hidding et al., 1993b, Hidding et al., 1994,) used exercise interventions of varying length and frequency (Table 3-4).

Educational programmes varied between two days to four weeks, with individual sessions ranging from 90 minutes (Gross & Brandt., 1981) to 12 hours (Barlow & Barefoot 1996).

3.3.6 Measurement of Adherence

Adherence to prescribed exercise was the primary outcome in three studies which all evaluated the effect of educational programmes that included advice on exercise (Gross & Brandt 1981, Barlow & Barefoot 1996, Sweeney et al., 2002). The remaining studies recorded adherence as a measure of fidelity to the exercise intervention (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Fernandez-de-Las-Penas et al., 2006, Niedermann, et al., 2013, Chimenti et al., 2014, Sveaas et al., 2020). The main aim, included outcomes and conclusions of each study are displayed in Table 3-5.

In three studies the supervised exercise component was recorded by attendance at the session (Hidding et al., 1993b, Hidding et al., 1994, Sveass et al., 2020). Seven studies measured adherence using patient-reported home exercise diaries with limited information provided about the diaries (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Sweeney et al., 2002, Niedermann et al., 2013, Chimenti et al., 2014, Sveaas et al., 2020). Four of these six reported the minutes of exercise per week, (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Sweeney et al., 2002). One study asked participants to tick a box to record that the prescribed exercises had been completed (Chimenti et al., 2014) and two studies provided no details of the home exercise diary (Niedermann et al., 2013, Sveaas et al., 2020). The three remaining studies measured adherence by asking participants to retrospectively record their adherence at different time periods; namely, whether they had completed their exercises the previous day (Gross & Brandt 1981), the frequency and volume of exercises in one week (Barlow & Barefoot 1996), and how often the exercises had been completed over the past year (Fernandez-de-Las-Penas et al., 2006). No study included the home exercise diary for closer evaluation.

3.3.7 Level of, and factors affecting, adherence to Combined Supervised Exercise and HEP Interventions

The summary adherence results for the studies are shown in Table 3-4. Five high quality studies combined supervised exercise and a HEP (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Niedermann et al., 2013, Sveaas et al., 2020). Sveaas et al (2020) reported adherence to a 3 times per week high intensity exercise programme over three months, finding 38 (76%) of participants followed more than 80% of prescribed sessions (≥29 of 36 sessions) while four participants (8%) discontinued after a few sessions. No data was provided for the remaining participants meaning a percentage adherence rate could not be calculated (Sveaas et al 2020). Nierdemann et al (2013) reported (calculated rate) 75% of sessions were completed of a three times per week intervention of which two sessions were supervised and one session was a HEP over 12 weeks (Niedermann et al. 2013). Hidding et al (1993a) combined a two weekly supervised session and daily HEP and reported 86% (calculated rate) to the daily 30-minute HEP. No data was provided on adherence to the supervised sessions

(Hidding, et al. 1993a). In the follow-on studies, Hidding et al (1993b and 1994) reported mean adherence rates, reported as percentage of prescribed minutes of exercise, of 63% (calculated rate) and 51.4% (calculated rate) for the participants receiving a HEP over nine months with some of the participants receiving supervised exercise in addition to a HEP. Hidding et al (1993b) reported no difference between the groups but within Hidding et al (1994) the group with a supervised component spent significantly longer on their HEP (mean duration 1.9 versus 1.2 hours per week, $p < 0.05$). In addition to adherence rates for the HEP, Hidding et al (1993b) reported 74% and Hidding et al (1994) reported 62% of supervised sessions attended over nine-months.

The three linked studies by Hidding et al demonstrated, from high quality evidence, that adherence to a HEP reduced over time, with 86% of prescribed minutes of exercise completed in the first six weeks (Hidding et al., 1993a), reducing to 63% over the following nine months (Hidding et al., 1993b), and 51% over the subsequent nine-month period (Hidding et al., 1994). Similarly, adherence to the once weekly supervised exercises reduced over time from 74% attendance at sessions in the first nine months to 62% in the second nine-month period studied (Hidding et al., 1993b; Hidding et al., 1994)

3.3.8 Level of, and Factors Affecting, Adherence to Interventions of HEP only

Two studies reported adherence to a HEP only. Fernandez-de-las-Penas et al (2006) reported 95% adherence (sessions completed, calculated rate) in participants with AS to a once weekly HEP for one year. Chimenti et al (2014), was considered poorer quality evidence and reported 100% adherence of completers with PsA to prescribed sessions and exercises during a 12 week, twice weekly HEP but reported that 23.3% of participants dropped out of the programme and so their overall calculated adherence for those starting the study was 76.7%. Chimenti et al (2014), also reported that adhering to a HEP in participants with PsA was not affected by age, gender, body mass index, blood pressure or heart rate. Fernandez-de-las-Penas et al, did not report any factors affecting adherence.

3.3.9 Level of, and Factors Affecting Adherence to Exercise following an Educational Programme which includes Advice on Exercise

The three remaining studies measured adherence to exercise, as primary outcome, following an educational programme which included advice on exercise or prescribed exercise but did not set the dose of exercise and therefore percentage adherence could not be calculated. Barlow and Barefoot (1996), reported an increase in the number of completed exercises (from 4.5 per week to 9 per week, $p=0.004$) and frequency (from 2.5 per week to 6 per week, $p=0.002$) of HEP three weeks after a 12-hour, two-day educational programme which included information on AS, exercises in the hydrotherapy pool, posture and exercise motivation sessions. The number and frequency of exercises significantly decreased at six months (9 per week -7 per week, $p=0.04$ and 6 per week to 1.5 per week, $p=0.007$ respectively). The authors also reported a moderate but statistically significant correlation of higher disease severity (as assessed by an earlier form of the BASDAI) with higher adherence to the number of exercises ($r=0.35$, $p=<0.001$) and weak but statistically significant correlation higher disease severity with frequency of therapeutic exercises ($r=0.28$, $p<0.05$), and longer diagnostic delay with adherence to a greater number ($r=0.28$, $p<0.05$) and frequency of home exercise activities ($r=0.27$, $p<0.05$).

Gross & Brant (1981) reported no significant increase in exercise participation following a four week, once weekly, 90-minute educational session. However, they reported that four people improved their 'compliance' with exercise programmes, while compliance remained the same in five and one person had reduced compliance. Of note, the studies by both Gross & Brant (1981) and Barefoot & Barlow (1996) were considered poorer quality evidence.

Sweeny et al (2002) found that participants who received an educational video with an exercise regime, a booklet and wall chart to encourage adherence to regular exercise did significantly more 'AS exercise' ($p<0.05$) (55 mins/week before the intervention and 99 mins/week following the intervention,) and aerobic exercise (67 mins/week before the intervention and 85 mins/week following the intervention $p<0.001$ than a control group which received no intervention (AS specific exercise increased by 5 minutes from 50 mins to 55

mins over the six month study duration and aerobic exercise reduced from 72 mins to 55mins).

3.3.10 Frequency of Exercise

There was no clear relationship in the studies between the frequency of the exercise and adherence with 95% adherence reported for a once weekly intervention (Fernandez-de-las-Penas et al, 2006), 77% reported for twice weekly (Chimenti et al., 2014), 75% reported for three times per week (Niedermann et al., 2013) and 86% (Hidding et al., 1993a), 63% (Hidding et al., 1993b) and 51.4% reported for daily HEP (Hidding et al., 1994).

Table 3-4. Characteristics of study, participants, interventions and adherence outcomes of the studies included in the review (shown in chronological order).

Study author(s) Characteristics	Participants	Drop outs (number)	Was adherence considered an Outcome?	Intervention & control groups (where applicable):	Measurement of adherence & time points:	Adherence & calculation of adherence (if relevant)	Factors affecting adherence
Gross and Brandt 1981, quasi-experimental	18 AS patients Intervention: n=11 (n=5 female, n=6 male) Mean age 46 Mean disease duration 28 years Control n=7 (n=7 male) Mean age 49 mean disease duration 19yrs	n=0	yes	Two groups; **Intervention Group**: 90-minute educational support group which encouraged exercise. No details of the exercise programme given. 1 x weekly for 4 weeks **Control**: no intervention	Self-reported questionnaire at week 0 and week 4 previous day recall of how often exercise.	Adherence reported as the number of people who had changed adherence to exercise: **Group 1** (no of people) Attendance at educational support group: mean 3 sessions Improved n=4/11, unchanged n=5/11, deteriorated n=1/11 no data n=1/11 **Group 2:** (no of people) Improved n=1/7 Unchanged n=3/7 Deteriorated n=2/7 no data n=2/7 No significant difference in groups.	The intervention with educational group increased adherence although not significant
Hidding et al 1993a, Cohort	144 AS patients (n=31 F, n=113 M) mean age 43 yrs median disease duration 4 years	n=0	No	One group: **Individualised supervised exercise sessions**: 30mins 2 x per week for 6 weeks and daily 30 mins HEP	Self-reported home exercise diary over 6 weeks	Average reported to HEP only: 3 hours on HEP *86% (adherence calculated by 180 actual mins/210 possible mins x 100 =86%)	None reported
Hidding et al 1993b RCT	N=144, AS patients'	Total N=9	No	All participants: Daily 30 minute HEP	Exercise class register of attendance for	Group 1:	Supervision does not increase

	continuation of Hidding 1993a Group 1: (group PT) n=68 (n=18F, n=50M) mean age 43.7 Disease duration 5 years Group 2: (no group PT) n=76 (n=13F, n= 63 M) mean age 41.5 Disease duration 4	Group physiotherapy n=1 No group physiotherapy n=8		Two groups: **Group 1**: group physiotherapy 1 x week, 3hours (1hour physical training, 1-hour sporting activities and 1-hour hydrotherapy) for 9 months **Group 2**: no group physiotherapy	Group 1 for group exercise Self-reported home exercise diaries for both groups over 9 months	Average class attendance was 73.5% over 9 months During 9 months both group 1 & 2 spent 2.2 hours (median 1.9 reported with mean of 2.2 reported in Hiding 1994) on HEP *63% adherence (calculated by 132 actual mins/ 210 possible mins x 100 =63%)	adherence: No significant different between groups.
Hidding et al 1994, **RCT**	N=68 AS patients (follow up of group 1 of the Hidding 1993b study, group 1 of the Hidding 1993) Group 1: (group PT) n=30 (n=7 F & 23 M) mean age 42.3 disease duration 7.9 Group 2: (no group PT) n=34 (n=10 F, n= 24 M) mean age 44.3	Total n=8 Group 1 n=4 Group 2 n=4	No	All participants HEP daily for 30mins and assigned to two groups: **Group 1**: supervised group physiotherapy 1 X week, 3 hours (1-hour physical training, 1hour sport and 1-hour hydrotherapy) for 9months **Group 2**: no group physiotherapy for 9 months	Exercise class register for attendance of supervised group physiotherapy for Group 1. Both Group 1 & 2 adherence to HEP measured with self-reported exercise diary over 9 months.	Group 1: Mean 62% attendance at supervised group physiotherapy over 9 months Both Groups: average 1.8 hour of HEP per week *51.4% adherence to daily HEP over 9 months. (calculated by 30mins x 7=210 possible minutes of exercise per week, 1.8 hours = 108 actual minutes of exercise, 108/210 x100 =51.4%)	Supervision increase adherence: Mean duration of 1.9 hours for supervised group and 1.2 hour per week for HEP group with supervised exercise versus group with HEP only $p<0.05$.

	disease duration: 6.8						
Barlow & Barefoot,1996 Quasi-experimental	N=52 AS patients Intervention group: n=24 (n=10 female n=14 male) mean age 42.6 disease duration 16.9 years Control: n=28 (n=12 female n=16 male) mean age 42.6 disease duration of 17.9	Total n=3 group n=3 control n= 0	yes	2 groups: **Intervention**: 2 days' self-management course, education, exercise, hydrotherapy, motivation. Given a guidebook with exercise but no information on dose. **Control**: No intervention	Self-reported questionnaire measured the range in number of individual home exercise, and frequency of exercise sessions per week in the past week. At baseline, 3 weeks and 6 months	Group 1: Median exercise frequency Baseline: 2.5x/week 3 weeks: 6x/week 6 months: 1.5x/week Range (Individual exercises): Baseline: 4.5x/week 3 Weeks: 9x/week 6 Months: 7x/week Group 2: Exercise Frequency Baseline: 3x/week No 3 week data 6 months: 2x/week Range (Individual exercise) Baseline: 5.5x/week 6 months 5.5x/week Rise in range home exercise activity: baseline- 3 weeks post intervention group (p=0.004) and increase in frequency of home exercise sessions (p=0.0023) Change in exercise range and frequency 3 weeks post intervention (p=0.04)	Disease severity (an early form of BASDAI) positively associated with exercise range and frequency of exercise (r=0.35, P<0.001 and r =0.28, P<0.05) Longer diagnostic delay associated with performance of a great range (r=0.28, P<0.05) and frequency of home exercise activities (r=0.27, P<0.05) Between group difference in adherence in short term in favour of intervention groups with educational programme.

						6 months: decreased significance (p=0.007)	
Sweeny et al 2002, RCT	N=200 AS patients Intervention n=100 (n=30 female n=70 male) mean age 47 disease duration 22.3 Control: n=100 (n=32 female, n=68 male) mean age 47 yrs disease duration 21.1 yrs	Total n=45 Group 1: n=20 Group 2 n= 25	yes	Two Groups **Intervention**: exercise video, exercise booklet, exercise progress wall chart and stickers. **Control**: no intervention	Self-reported minutes of exercise (AS specific exercise & aerobic exercise) at baseline and six months.	Intervention 1: Baseline: 55 mins per week AS exercise, 67 mins per week aerobic exercise 6 months: 99 mins per week AS exercise, 85mins per week aerobic exercise Control 2: Baseline: 50 mins per week for AS exercise, 72 mins per week for aerobic exercise 6 months: 55 mins per week each for AS and aerobic exercise	Between group difference significant between group differences at 6 months for aerobic ($p \leq 0.001$) and AS ($p \leq 0.05$) specific exercise. Possible that education group increases adherence
Fernandez-de-las-Penas (2006) RCT	N=40 AS Group 1 n=20 (5 F, 15 M) Mean age 45 Disease duration 8 years Group 2: n=20 (n=4 F, n=16 M) Mean age 46	n=0	No	Two Groups: **Group 1** 15 x 1 hour sessions of conventional supervised exercise over 4 months **Group 2** 15 x1 hour sessions of global posture re-education supervised over 4 months.	Adherence measured for all participants exercising independently unsupervised for 1 year. Verbally asked participants at the end of the year follow up.	80% of participants (*n*=32) had done every week for the year. 20% of participants (n=8) did a mean of 3.25 sessions per month. *95% adherence (total possible number of sessions for all participants over the year=2,080, 32 people did each week for a year= 1,664 sessions.	No factors reported

	mean disease duration 7.6 years			Both groups asked to continue regime individually unsupervised once per week for 1 year.		8 people did 3.25 per month = over the year =312 sessions (312 +1664)/ 2080 x 100= 95% adherence)	
Niedermann et al 2013 **RCT**	N=106 AS Group 1: n=53 (n=19 F, n=34 M) Mean age 50.1 Mean disease duration 9 yrs Group 2: n=53 (n=19 F, n=34 M) Mean Age 47.6yrs Disease duration: 8yrs	Total n=7 Group 1 n=4 Group 2 n=3	No	Two Groups: **Group 1**: 12 weeks, 30 minute CV Supervised Nordic walking &, flexibility class, and one unsupervised CV activity such as Nordic walking or biking, 1 hour flexibility class **Group 2**: Monthly (3 in total) X 2.5 hour psychology led discussion on mindfulness and 1 hour flexibility class	Self-reported exercise diary over 12 week programme.	Adherence reported to CV training only Group 1 *n*=40 did mean of 3 CV training per week *n=8* did not perform at least 1 CV per week. *75% adherence rate (total available sessions 12 X 3 X 53 = 1908 completed sessions 40 x 12 x 3 =1440 1440/1908 x100 =75%)	no factors reported
Chimenti et al 2014 **Cohort Study**	N=30 PsA (no details if axial or peripheral symptoms) n=12 female n=18 male mean age 50.8	Total n=7	Yes	**One Group**: HEP for 40 mins twice per week for 12 weeks.	Patient reported exercise diaries over 12-week programme. Frequency of individual exercise completed.	23 participants completed 100% of the programme 7 participants who dropped out taken at 0% adherence. Overall adherence 76.6%	Adherence to HEP not affected by age, gender, body mass index, blood pressure or heart rate

Sveaas et al 2020 RCT	100 patients axSpA (70% AS) Intervention group: n=50 (n=25 women, n=25 male, n=38 with AS and n=12 with nr-axSpA) Mean age 45 years disease duration not reported Group 2: n=50 (n=22 male, n=28 female, n=32 AS, n=18 nraxSpA) Mean age 47.2 Disease duration not reported	Total n=3 intervention group n=2, control group n=1	no	12 weeks: **Intervention Group**: 3 X per week; 2 x weekly supervised high intensity cardiorespiratory & strength exercises, and 1 X unsupervised cardiorespiratory session **Control**: standard care and instructed to maintain physical activity levels as normal.	Exercise Adherence measured by supervising physiotherapist to completed sessions and as self-reported exercise diary over 12 weeks.	Intervention Group: 38 (76%) of participants followed more than 80% of the prescribed exercise protocol (more than 29 of 36 sessions) 4 (8%) of participants discontinued. No details given for the rest of the participants. Adherence rate not possible.	No factors reported

Key: AS: Ankylosing Spondylitis, axSpA: Axial Spondyloarthritis, BASDAI: Bath Ankylosing Spondylitis Disease Activity Index, CV: Cardiovascular, F: female, HEP: Home Exercise Programme, M: male, Mins: minutes, n: number, nraxSpA: non Radiographic Axial Spondyloarthritis, PsA: Psoriatic arthritis, PT: Physiotherapy, RCT: randomised controlled trial, yrs: years

Table 3-5. The overall aims, outcomes and conclusions of the studies included in the review.

Author, date	Overall aim of study	All outcomes and time points	Study conclusions
Gross and Brandt 1981, quasi-experimental	To evaluate if a support group helps people cope with their disease and increases their knowledge and compliance with treatment	Questionnaire on coping with AS, family relationships and knowledge of their condition, compliance (adherence). 0, 4 weeks	Improvements in knowledge of disease. Compliance with prescribed exercise programmes improved but not significantly
Hidding et al 1993a, Cohort	To study the relationship between disease duration and the effects of physical therapy	Outcomes: Spinal mobility, physical fitness, function and pain. 0-6 weeks	Short-term supervised individual therapy is effective in AS, improving mobility, fitness and function irrespective of disease duration
Hidding et al 1993b RCT	To study the effects of adding supervised group physical therapy to unsupervised individual therapy in AS	Outcomes: Spinal mobility, physical fitness, function, self-reported global health. 0,3,6,9 months	Group physiotherapy was superior to HEP in improving spinal mobility, fitness and self-reported global health
Hidding et al 1994, RCT	To evaluate if beneficial effects with supervised group physiotherapy continue when supervised group exercise is stopped	Outcomes: Spinal mobility, physical fitness, function, self-reported global health. 0,3,6,9 months	Global health and function are sustained or improved if group physical therapy is continued
Barlow & Barefoot,1996 Quasi-experimental	To examine the effect of group education on self-efficacy, psychological well-being and performance of home exercise	Outcomes: Self-efficacy, psychological well-being, home exercise activities performed (adherence)	Group patient education course improved self-efficacy, psychological well-being at 6 months. Improvement in adherence to home exercises but not maintained at 6 months
Sweeny et al 2002, RCT	To evaluate the effect of a home based self-care package.	Outcomes: function, disease activity, well-being, self-efficacy. 0, 6 months	An exercise intervention package to promote self-management significantly increases self-reported levels of exercise, self-efficacy for exercise and a trend for improvement in function
Fernandez-de-las-Penas (2006) RCT	To evaluate the long-term effect of two exercise interventions on function and mobility in AS	Outcomes: Spinal Mobility, function, disease activity. 0, 4 months, 1 year	Global posture re-education offers short and long term promising results in management of AS
Niedermann et al 2013 RCT	To evaluate moderate intensity CV training & flexibility programme on fitness and perceived disease activity in AS	Outcomes: Disease activity, function, spinal mobility, global health, physical activity, anxiety and depression	CV training and flexibility exercises increased fitness and reduced disease activity

Chimenti et al 2014 **Cohort Study**	To evaluate the effect of an exercise programme on disease activity and quality of life in people with PsA (no information if axial or peripheral symptoms)	Outcomes: Disease activity, quality of life, physical activity, adherence	Self-reported health outcomes improved in those who completed the study
Sveaas et al 2020 **RCT**	To investigate the effectiveness of high intensity exercises on disease activity in patients with axSpA	Outcomes: Disease activity, function, physical fitness, inflammation levels, muscle mass and body weight. 0, 3 months	High intensity exercise reduced disease activity, inflammation and improved function and physical fitness

Key: AS: Ankylosing Spondylitis, axSpA: Axial Spondyloarthritis, CV: cardiovascular, F: female, HEP: home exercise programme, M: male, Mins: minutes, PsA: Psoriatic arthritis, RCT: randomised controlled trial.

3.4 Discussion

This is the first systematic review to explore the level of, and the factors affecting, adherence to prescribed exercise in people with SpA. Ten papers were identified that addressed adherence to prescribed exercise in SpA, of which eight studies included participants with AS, one study with axSpA participants where the majority of participants included had AS, and a single small study of participants with PsA. Adherence was not the primary outcome in the majority of studies. Adherence rates were reported, or able to be calculated, in six of the ten papers, finding percentage adherence rates to prescribed exercise interventions programmes ranging from 51 – 95% (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Fernandez-de-Las-Penas et al., 2006, Niedermann et al., 2013, Chimenti et al., 2014). The exercise interventions differed in terms of frequency, type, intensity, length and in the measurement of adherence. Therefore, any direct comparison should be interpreted with caution. While the majority of these studies did not report factors affecting adherence rates, inclusion of education programmes and supervision, disease severity and delays in diagnosis were identified in single studies, as affecting adherence there was no consensus across studies (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Niedermann et al., 2013, Chimenti et al., 2014). There was general agreement however that adherence to prescribed exercise appeared declined over time.

3.4.1 Level and Measurement of Adherence

Adherence was poorly reported within the studies. The level of adherence reported in the studies varied from 51-95% in six papers (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Fernandez-de-Las-Penas et al., 2006, Niedermann et al., 2013, Chimenti et al., 2014). Three studies did not provide parameters for the exercise prescription therefore adherence could not be calculated (Gross & Brandt 1981, Barlow & Barefoot 1996, Sweeny et al., 2002). One study did not provide information on adherence for all participants (Svaas et al., 2020). No study provided full details of the adherence to each parameter of the prescribed exercise programme, instead reporting one aspect of adherence such as the number of sessions completed or the minutes of exercises completed. Better reporting of adherence within research studies investigating

physiotherapy prescribed exercise interventions studies would aid fuller understanding of the level of adherence to these programmes.

Evaluating and improving adherence is limited by the absence of a gold standard measure of adherence to prescribed exercise programmes. Self-reported HEP diaries, used by six of the studies within this review, may be influenced by participants' attitudes and beliefs, poor recall, and giving a perceived desired response rather than an accurate one (Stone et al., 2003, Prince et al., 2008, Bollen et al., 2014). The highest rate of adherence within the included studies was 95% for a once weekly HEP (Fernandez-de-Las-Penas et al., 2006). Poor recall potentially influenced this rate as participants were asked about adherence after one year. Class attendance registers, used in all supervised components within this review do not take into consideration adherence to the actual exercises within the attended exercise session (Hidding, et al., 1993b, Hidding et al., 1994,). Developing a standardised measure of adherence which addresses the limitations of self-reported measures and fully measures adherence such as minutes/sessions/intensity to prescribed components, would improve the ability to meaningfully assess adherence rates and make comparisons across studies.

Two cross sectional surveys have gathered data on the extent of exercise participation in AS. Passalent et al (2010), surveyed 61 people with AS in Canada finding; 34.4% of the sample reported exercising on a daily basis, 26.2% exercised less than once a week, and 57.4% of patients reported engaging in at least 1 form of exercise 3 times per week. More recently Sang et al (2020), surveyed 259 people with AS in China finding only 20.5% of the sample exercised 5 times per week for 30 minutes of exercise. It is unclear if participants within the study had been prescribed an intervention by a HCP at any point, and therefore were adhering to the recommendations of the HCP. The rates found in this review were mostly higher than those found by Passalent et al (2010), and Sang et al (2020). This might reflect adherence to the interventions (of lower frequency) and not general participation in exercise, however it should be noted that people who volunteer for research studies may be more motivated or interested. Therefore, adherence rates in research studies may be higher than

adherence rates within routine clinical practise. Measuring adherence rates as part of research studies limits generalisability.

Due to the small sample within this review, and the poor quality of three of the studies (Gross & Brandt 1981, Barlow & Barefoot, 1996, Chimenti et al., 2014), it remains unclear as to the extent of adherence to prescribed exercise in people with SpA. However, no study within this review reported full adherence to a prescribed exercise programme. Therefore, HCPs should be aware that SpA patients, with the majority of evidence for people with AS, are unlikely to fully adhere to an exercise programme, impacting the effectiveness of the intervention.

Future research should consider what level of adherence or dose of exercise is necessary for prescribed exercise in axSpA to be effective in terms of beneficial outcomes; for example, is there a minimum amount of exercise required to achieve outcomes? Is there a level of exercise beyond which additional gains are minimal or is it a linear relationship? Understanding this would enable more targeted focus on adherence to ensure the required levels of exercise are achieved.

3.4.2 Factors Affecting Adherence

As discussed in the previous chapter (Section 2.13.3), the WHO proposes that when studying adherence, a multidimensional approach should be undertaken where adherence is determined by the interplay of factors relating to five constructs; socioeconomic, healthcare, condition, treatment and patient related (Sabete et al., 2003). Adherence to prescribed exercise was the primary outcome in only three studies, therefore the majority of studies did not report on factors that influenced adherence rates. The review found two disease characteristics influenced adherence; severity of AS disease and delay in diagnosis. However, this was reported in only one study, with limitations and assessed as poorer quality, and the correlations were moderate to weak and thus this should be interpreted with caution (Barlow & Barefoot, 1996). A review and meta-analysis including 27 studies across a broad number of conditions and treatment regimens including medication, exercise and diet similarly found that

greater disease severity was reported to be associated with better adherence (DiMatteo et al., 2007). Prescribed exercises have the potential to reduce disability and/or improve function, and may increase motivation for people with higher disease severity, however on the other hand symptoms for people with high disease severity has the potential to reduce adherence. This issue needs further investigation. Longer diagnostic delays may increase adherence to adhere to recommended exercise interventions but again more information is required to explore why this might be the case.

Patient-related factors are another domain of the WHO approach to studying adherence. One small study, with limitations, and assessed as poor quality, within this review found completing a HEP was not affected by age, gender, body mass index, blood pressure or heart rate (Chimenti et al., 2014). It is probable that other patient-related and condition characteristics influence adherence, for example those discussed in chapter 2 that have been found in other conditions in SpA (section 2.13.3) but no further information was found within this review.

Treatment factors can also affect adherence (Sabete et al., 2003). This review found limited evidence that interventions which include supervised components and educational programmes increase adherence to exercise in SpA. Two of the three studies within this review, which included an educational component, found an increase in adherence following an educational programme incorporating exercise prescription (Barlow & Barefoot 1996, Sweeney et al., 2002). The third found only a trend towards improvement, although poor participant attendance at the educational programme could account for this result (Gross & Brandt 1981). The three studies were rated poorer quality from the appraisal, which further reduces the conclusions that can be drawn from these studies. However, a review investigating adherence to medicine in chronic conditions similarly found support groups, which included educational support, increase adherence (Ganguli et al., 2016). Two linked studies within this review compared a combined a supervised component and HEP with HEP alone (Hidding et al., 1993b, Hidding et al., 1994), with the latter reporting that participants who were supervised for part of their programme spent significantly longer performing HEP. The magnitude of the influence of supervision and educational

programmes on adherence is unknown, but it is probable that they have some effect. A Cochrane review found supervised programmes in people with chronic musculoskeletal pain reported better adherence to exercise programmes than unsupervised exercise (Jordan et al., 2006). A Cochrane review of physiotherapy interventions for people with AS has shown that supervised programmes improve spinal mobility and overall wellbeing more than individualised HEPs (Dagfinrud et al., 2008). As these exercise programmes are otherwise similar, it is possible that improved adherence may in part account for this, although regular contact with the physiotherapist and possibly the group if the supervision is in a group setting, in the supervised programmes may also have additional benefits beyond the exercise intervention itself.

There are likely more treatment factors which could facilitate adherence, but no more information was found within this systematic review. Designing interventions which are underpinned by behavioural change theory such as social cognitive theory, or which incorporate behavioural change techniques may have the potential to improve adherence (Jansons et al., 2017). Self-efficacy refers to the magnitude of a person's belief in their ability to undertake a task and achieve a desired goal (Room et al., 2017). Improving health knowledge and self-efficacy are integral to initiating and maintaining behaviour change within social cognitive theory (DiMatteo et al., 2007).

Intervention types within this review included hydrotherapy, nordic walking, aerobic and flexibility exercises. It was not possible to draw any conclusions in terms of the superiority of any particular type of exercise at improving adherence as there were no studies which compared exercise interventions on adherence rates. In addition, within the limited information found in this review there was no clear relationship between the frequency of the session and adherence. Therefore, it could not be concluded whether the type of exercise prescribed or the frequency of the session affected adherence. Enjoyment and perceived benefit of types of exercise have been shown to be facilitators to regular exercise in middle aged women (McArthur et al., 2014). An individualised approach could be considered where the physiotherapist and person with SpA reflect on how often an individual realistically thinks they can carry out their prescribed exercises, which type of exercise they would prefer and prescribes

exercise on this basis (Taube, 2016). Furthermore, interventions which include agreed goals and explores barriers to change could help improve adherence on an individual basis and have been shown to improve adherence in other health conditions (Farrance et al., 2016, Hill et al., 2011). There was health-care related factors affecting adherence found within this review.

3.4.3 Adherence over Time

As axSpA is a lifelong condition, long term adherence to exercise is a crucial part of management. This review found adherence to exercise in axSpA generally declined over time following an educational programme, from one poor quality study (Barlow & Barefoot 1996), and declined following an exercise programme in three high quality studies (Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994). This concurs with the wider field of adherence literature (Pisters et al., 2010, Spink et al., 2011, Jansons et al., 2017). Continued adherence has been shown to depend on the ability to accommodate exercises within everyday life and the perception that exercise is effective in improving unpleasant symptoms (Campbell et al., 2001). Self-regulation is the ability to monitor and regulate behaviour, such as exercise. Self-regulatory skills could be improved through the use of goal setting, self-monitoring, self-reinforcement, stimulus control, and cognitive restructuring strategies which may help to maintain adherence to prescribed exercise over time. Previous systematic reviews in other conditions have found these strategies to be effective in maintaining adherence (Room et al., 2017, Jordan et al., 2006) but have not been investigated in SpA.

3.4.4 Limitations

This review has a number of limitations. Firstly, only papers available in English were included as there were no resources for translation. This potential publication bias may influence the generalisability of the review. It was also limited by the heterogeneity of the study designs included. As mentioned previously, adherence was not the primary outcome in the majority of studies, while interventions and measures of adherence varied. Due to the variety of outcome measures used, it was not possible to conduct a meta-analysis. Three

studies within this review used the same participants; this may have led to a repeated sampling bias effect.

Only 4.5% of patients within this review were diagnosed with PsA & nr-axSpA with the 91% of participants diagnosed with AS. No studies examined adherence to exercise programmes in people with the other specific SpA conditions or SpA in general. While nr-SpA is considered to be on the same spectrum as AS, with shared clinical and functional features, the results from AS cannot be assumed to apply to nr-axSpA as people with the latter are more likely to be younger or female (Wright et al., 2020). Therefore, the limited evidence base to date is predominantly in relation to people with AS.

3.4.5 Future Research

Future research should investigate a range of personal, condition (disease), socioeconomic, and healthcare that may influence adherence and consider which ones best predict adherence or which can be modified to increase adherence. Understanding who is likely to adhere to prescribed exercise can allow physiotherapists to predict who is most likely to benefit from their interventions and to ensure resources are targeted to those who require them most.

A variety of treatment factors may support adherence and should be investigated. Interventions which include education to improve health knowledge, provide information and support at key points and/or in novel ways, such as through web-based exercise, could facilitate adherence, especially in the longer term when adherence declines and warrant further investigation (Paul et al., 2014).

3.5 Conclusion

The aim of this systematic review was to examine the rates of adherence to prescribed exercise and the factors reported to influence adherence in people with SpA. The review found adherence was poorly reported within the included studies and the heterogeneity of the studies included meant comparison between studies was difficult. Adherence rates were reported from 51%- 95%

suggesting that patients do not fully adhere. Treatment factors identified within single studies as possible influencers were supervision, inclusion of education programmes. Higher disease severity and delays in diagnosis were associated with higher adherence although these were within single, poor quality studies. The full picture of adherence levels and factors affecting adherence to prescribed exercise in SpA remains unclear. Future research should aim to measure adherence to prescribed exercise, including novel programmes such as web-based physiotherapy programmes over the longer term and consider multiple personal, disease, healthcare and treatment factors which could potentially influence adherence in SpA.

4 Chapter: Web-based Physiotherapy: A cohort study (WEBPASS)

The role of exercise as an intervention in SpA is best characterised and established in axSpA, as seen in the systematic review in Chapter 3 and the clinical guidelines (Regel et al., 2017). This chapter reports a cohort study measuring adherence to a web-based physiotherapy programme over one year in axSpA. This study was part of, and extended the work of, the Web-based Physiotherapy for people with axSpA (WEBPASS) study, which was funded by Versus Arthritis (previously Arthritis Research UK, 20874) (Paul et al., 2016).

4.1 Study Team and Role of the PhD Student

The study research team consisted of Lorna Paul (LP) chief investigator (CI), and co-investigators Stefan Siebert (SS) clinical academic Rheumatologist, PhD student Marie Therese McDonald (MTM), Elaine Coulter (EC), Sara Cameron (SC), Debbie Cook (DC), Mhairi Brandon (MB), and Alex McConnachie (AM).

The PhD student (MTM) was a qualified physiotherapist, who specialised in rheumatology in general and axSpA in particular. The PhD student was a co-applicant on the grant, and was involved in the development and design of the study, and the application for ethical approval. The PhD student picked and filmed the exercises for the exercise catalogue. The PhD student was responsible for recruitment, assessing each individual at the baseline visit and providing them an individualised prescribed exercise programme. The PhD student monitored each participant and changed the exercise programme accordingly. The PhD student carried out all the semi-structured interviews and data analysis pertaining to the adherence of the study apart from the data analysis for adherence over time which was analysed by the Robertson Centre for Biostatistics at the University of Glasgow.

The aim of the Verus Arthritis-funded study was to assess the feasibility of the web-based physiotherapy intervention, including efficacy and adherence over time. The work presented in this PhD extended this to a more detailed examination and analysis of adherence to the exercise programme. This included

examination and analysis of overall sessions each participant engaged with, comparing patient choice and prescribed exercise components, analysing individual exercises within each prescribed session and explored associations of the overall sessions completed with participants' baseline characteristics.

4.2 Justification

As described in Chapter 2, exercise programmes are essential in the management of axSpa and are prescribed to improve disease outcomes (Regel et al., 2017). Adherence refers to the extent to which a person's behaviour corresponds with the recommendations from a HCP (Sabete et al., 2003). The level of adherence to an exercise programme will affect how successful exercise programmes are in achieving improved disease outcomes (Pisters et al., 2010).

The systematic review described in Chapter 3 found the rates of adherence to supervised and unsupervised exercise interventions of hydrotherapy, nordic walking, aerobic and flexibility exercises ranged from 51-95% in people with SpA, with the majority of evidence in people with AS (Gross & Brandt 1981, Hidding et al., 1993a, Hidding et al., 1993b, Hidding et al., 1994, Barlow & Barefoot 1996, Sweeney et al., 2002, Fernandez-de-Las-Penas et al., 2006, Niedermann et al., 2013, Chimenti et al., 2014, Svaas et al., 2020). Interventions which incorporated supervision and an educational programme potentially improved adherence. Higher disease severity and delays in diagnosis were positively associated with adherence whilst age, gender, body mass index, blood pressure and heart rate were not found to affect adherence. These factors were found often in single, low-quality studies with minimal consensus between studies (fig 4-1). Therefore, the majority of factors affecting the WHO model of adherence for exercise programmes in axSpA remain unknown (fig 4-1). Furthermore, the systematic review in Chapter 3 observed adherence reduced over time. Short term adherence appears higher than long-term adherence. However, long-term adherence to exercise is recommend and required in conditions such as axSpA (Regel et al., 2017)

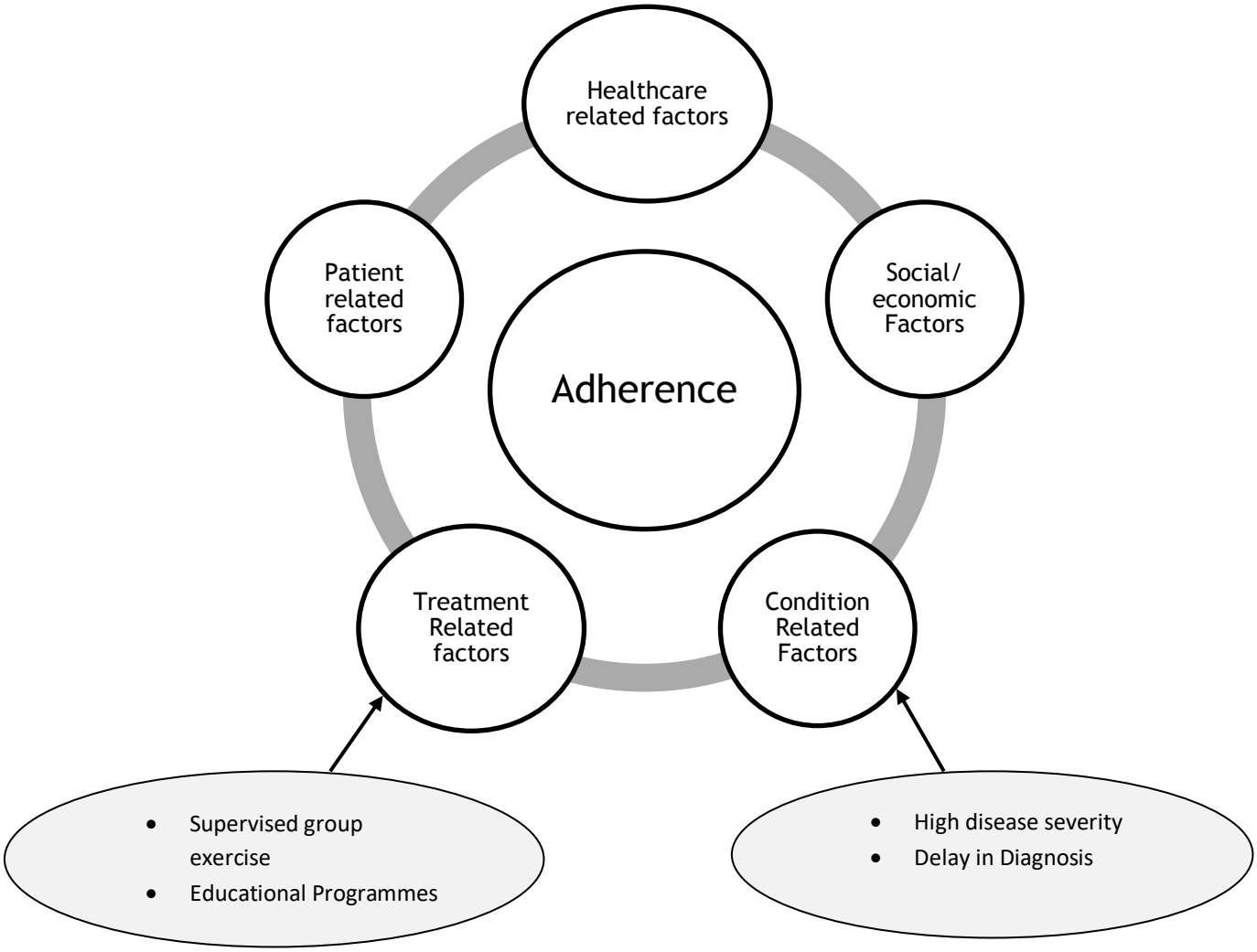


Figure 4-1. WHO model of dimensions of adherence (Sabete et al., 2003) with possible factors identified in the systematic literature review in Chapter 3 (shown in shaded ovals).

Furthermore, no study within the systematic review investigated and reported the level of, and factors affecting, adherence to a web-based based physiotherapy programme. Web-based exercise programmes are becoming a more feasible option due to the increasing number of people with regular access to the internet and skills to use it (Laver et al., 2020). Web-based programmes can be individualised and progressed with the physiotherapist being remotely contactable and with digital interactions between therapist and user being incorporated. Advantages of web-based physiotherapy approaches include the flexibility of being available without the need for travel and having the ability to choose when and where to exercise. This can be useful for those who struggle to engage with traditional physiotherapy due to other commitments such as work and family (Brennan and Barker 2008). The need for remotely delivered and

monitored therapies has also been highlighted by the coronavirus pandemic in 2020.

Web-based exercise may be a particularly beneficial strategy for people with axSpA. People with axSpA are commonly diagnosed with this chronic lifelong condition in the second or third decade of their life (Rojas-Vargas et al., 2009), so many will need to start exercise in young adulthood so this means exercising over the long term, which is likely to be hard to maintain. With the advent of effective drug therapies, the majority of people with axSpA remain in employment and also have family and lifestyle commitments which make it difficult for them to attend traditional, scheduled face to face physiotherapy sessions (Webers et al., 2018). Adherence has been shown to be adversely affected by exercise regimens which are inconvenient, or not tailored to a person's situation or daily routine (Sluijs et al 1993). Therefore, investigating adherence to a web-based physiotherapy approach in axSpA is warranted.

Investigating adherence to exercise is hampered by the lack of a standardised approach to measurement allowing limited comparisons to be made between studies (Bollen et al., 2014, Hall et al., 2015, McLean et al. 2017). In the systematic review (Chapter 3), adherence to HEPs was usually measured using patient-reported home exercise diaries (McDonald 2019). The majority of these studies measured only one aspect of adherence to the prescribed programme, for example the minutes of exercise or the number of sessions completed. Measuring more than one aspect of the prescribed exercise components, such as the number of sessions and the number of exercises completed within the session and over an extended time period, has the potential to give a more complete understanding of the adherence to HEPs in axSpa.

Therefore, to address the issues outlined from the published literature, this second study within the PhD aimed to explore adherence to a 12-month web based programme. Focusing in detail on adherence levels through; sessions and exercises completed, comparing adherence to participant choice and physiotherapy prescribed components, adherence over time and to consider

factors which may affect adherence. In addition, qualitative data from semi structured interviews conducted as part of the WEBPASS study that specifically related to adherence were analysed.

The following research questions were identified:

At the individual level, what was the adherence to a 12-month programme web-based physiotherapy programme for people with axSpA. Specifically;

1. How many sessions did each participant engage with (total number and percentage of maximum of 5 per week X 52 weeks)?
2. How many participants had good adherence (pre-defined as engaging with at least 3 sessions per week)?
3. Did participants adhere differently to the prescribed component or the patient-choice component.
4. For each prescribed exercise session did participants complete all individual exercises presribed?
5. What were the weekly adherence rates (sessions engaged with and percentage of participants with good adherence) to the 12-month physiotherapy programme and how did the weekly rates change throughout the 12-month period?
6. Were there any associations between participants' demographics, disease measures and adherence (in terms of number of sessions engaged with)?

4.3 Research Methodology

Within the field of research there are two main poles of research methodology; quantitative and qualitative, each with distinct epistemological paradigms with strong philosophical underpinnings (Crossan, 2003). From a quantitative perspective collecting objective data which are measurable and eliminating confounding variables allows the researcher to derive cause and effect or association from the relationship under investigation (Leavy et al., 2014). In contrast, qualitative research uses small, purposeful samples of respondents to provide important information, not because they are representative of a larger group but to gain a deeper understanding of the lived experience of a

participant (Reid, 1996). Punch (2013) recommended careful consideration of the research questions and ensuring the correct and most appropriate methodology is used to answer the questions. It was determined that a predominantly quantitative methodology would best answer the research questions posed but an additional qualitative programme evaluation would add a deeper understanding of the lived experience of participants' adherence to the programme.

4.4 Methods

4.4.1 Study Design and Ethical Approval

A prospective, interventional cohort study was undertaken. The primary aim of WEBPASS study was the feasibility, including efficacy and adherence each week to a web-based physiotherapy programme. Favourable ethical opinion was obtained from the West of Scotland Research Ethics Committee (Ref: 15/WS/0229) (see Appendix 1) and approval from NHS Greater Glasgow and Clyde (NHS GGC) Research and Development prior to any study related procedures being performed. The study sponsor was NHS GGC Health Board.

4.4.2 Study population

The population of interest were 50 adults with inclusion criteria of axSpA (diagnosed by a rheumatologist), with disease duration of longer than one year and who had access to the internet. There was no reliable data in the literature to inform sample size calculations for this study, so 50 was chosen as a convenience sample that was felt to be both feasible for recruitment and sufficiently large to assess adherence to the exercise programme. As adherence was the primary outcome, any drop outs during the study would be captured as part of this. The disease duration of longer than one year was chosen as the exercise programme was intended as a maintenance programme. Key exclusion criteria were already exercising regularly (three or more times per week), any joint replacement within the past six months and any other significant comorbidities that could be considered as contraindications to exercise.

4.4.3 Description of the Intervention

The intervention was a physiotherapy prescribed programme delivered using a web-based approach and a patient choice component. The website used was www.webbasedphysio.com (now www.giraffehealth.com). This consisted of a home page, exercise page, exercise diary and an axSpA-specific advice/ information section with links to relevant external websites. The website could be accessed via a personal computer, tablet, smartphone or television, via a personal login provided to each participant. This online platform had been used to deliver online exercise programmes in people with multiple scelorsis and spinal cord injury with promising results in terms of feasibility (Paul et al., 2014, 2019, Coulter et al., 2015, 2017).

The website contained a catalogue of exercises with different levels of difficulty, as well as a warm up and cool down. Each exercise was demonstrated using a video, text explaining the exercise, an audio description of the exercise and a timer (fig 4-2, fig 4-3). The exercise catalogue was expanded by the PhD student in conjunction with the wider research team to include axSpA-specific exercises based on the Back to Action programme (http://nass.co.uk/back-to-action) developed by the National Ankylosing Spondylitis Society (NASS) in conjunction with specialist rheumatologists and specialist physiotherapists for people with axSpA.

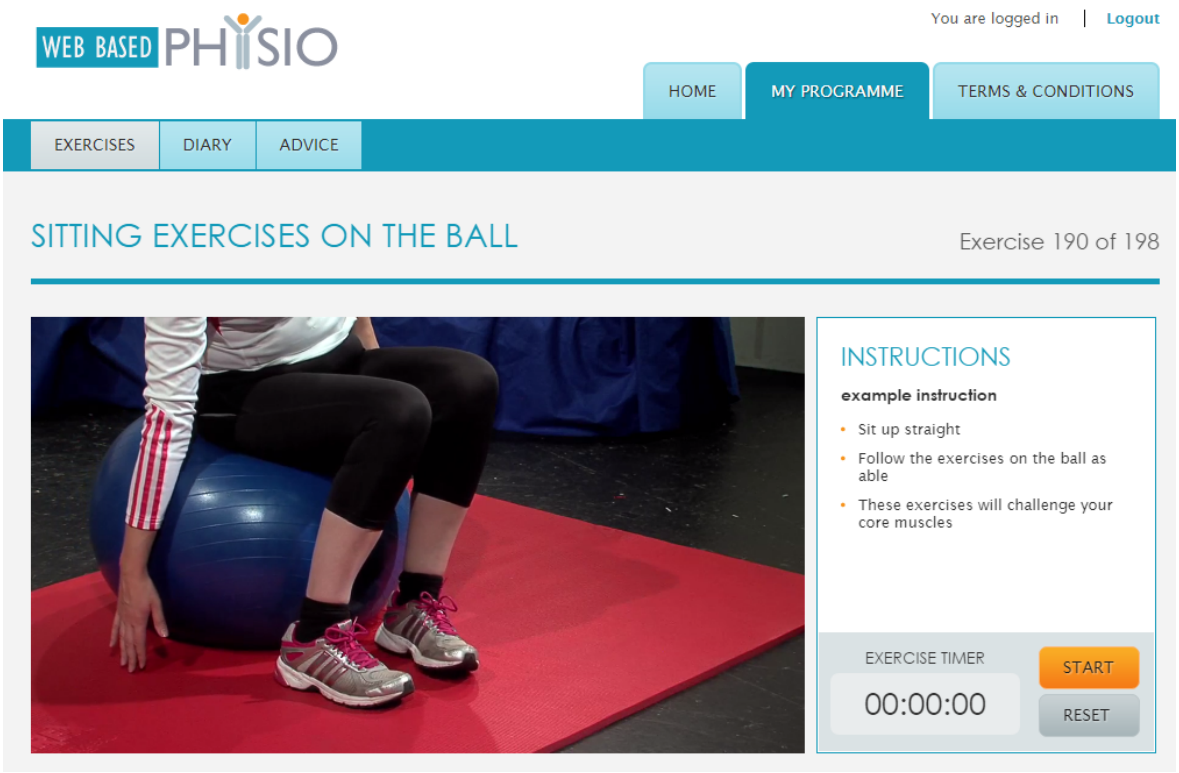


Figure 4-2. Example of a seated exercise used in WEBPASS.

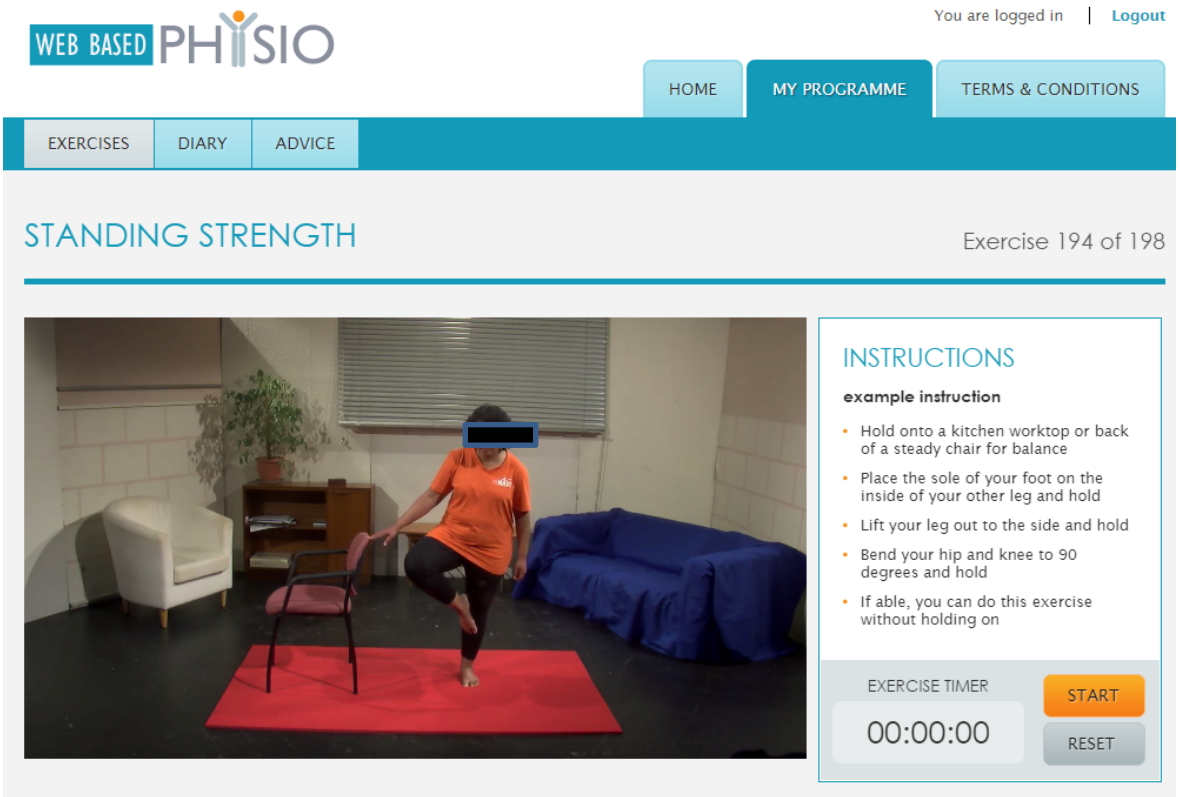


Figure 4-3. Example of a standing exercise used in WEBPASS

An exercise programme to maintain or improve spinal mobility, function, quality of life and CV fitness is recommended in axSpA (Dagfinrud et al. 2004, O'Dwyer et al. 2014a, O'Dwyer et al. 2014b, Reimold and Chandran 2014, Millner et al. 2016, Regel et al., 2017). Exercise programmes should be tailored to the person's assessment findings, goals and lifestyle (Milner et al., 2016). Therefore, in WEBPASS, participants were initially assessed by a physiotherapist (MTM, PhD student) and specific personal goals, including mobility, flexibility and CV goals, were agreed, between the physiotherapist and participant. Participants were then provided with a tailored, prescribed exercise programme based on the assessment findings and agreed goals. Although there is no agreed recommendation with regards to how often and for how long people with axSpA should exercise, the limited available research and consensus advises to aim for high frequency such as five or more times per week for around 30 mins (Dagfinrud et al., 2004, O'Dwyer et al., 2014a, 2014b, Reimold and Chandran 2014, Millner et al., 2016). In WEBPASS the five exercise sessions per week were composed of the prescribed individualised exercise programme three times per weekly and, in order to enable participants the choice to incorporate other exercise and physical activities, participants were also asked to choose their own exercise twice per week. As part of these patient choice sessions, participants were encouraged to participate in a NASS run group class or a recreational swim, walk, or any other exercise of their choice. Participants were asked to record this as 'other exercise'. The programme was amended throughout the year by the PhD student based on feedback from each participant as described in section 4.4.9.

The website incorporated behaviour change techniques. Behaviour change techniques are observable and replicable components of interventions and can be used alone or in combination with other behaviour change techniques (Michie et al., 2011). The following behavioural change techniques were incorporated into WEBPASS; goals and planning, feedback and monitoring, shaping knowledge, natural consequences, comparison of behaviours, repetition, substitution and antecedents. These behavioural change techniques have been shown to be

successful in promoting and maintaining exercise behaviour (Webb et al., 2010, Michie et al., 2011). Feedback was incorporated into the programme by displaying each individuals progress by the percentage of the programme they had completed. This was displayed using a graph, which users saw each time they logged on to the website (Figure 4-4).

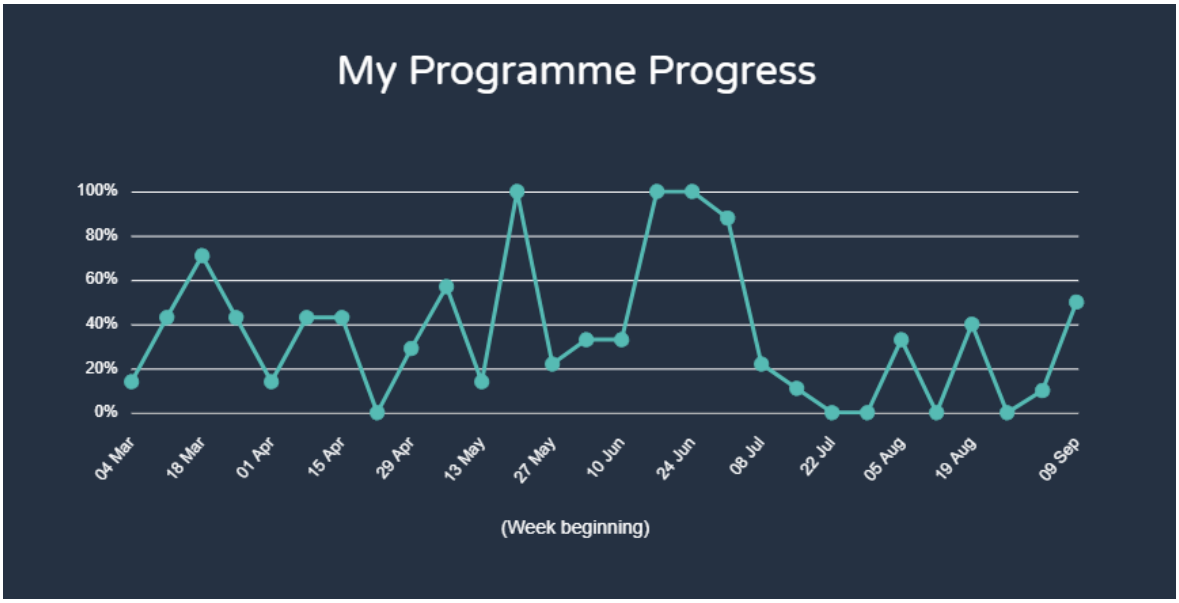


Figure 4-4. Screenshot of an example of a participant's progress.

4.4.4 Study Conduct

All members of the research team undertook Good Clinical Practice training and these principles were adhered to throughout the study. A trial steering committee comprising an independent chair, independent clinical experts, the CI, grant co-applicants, a statistician and two patient representatives oversaw all aspects of the project to monitor progress and to help ensure the aims and objectives were achieved. All adverse events were recorded and discussed. For serious adverse events, the CI notified the project sponsor in line with regulatory requirements.

4.4.5 Recruitment

A convenience sample, of up to 50 people, of participants with axSpA were recruited from specialist axSpa clinics and related physiotherapy departments across NHS GGC between 1st of Dec 2015 and 1st of Dec 2016. The study was also promoted through local NASS branches, the NASS website and newsletter, the University of Glasgow website and social medial twitter account and using posters in the waiting areas of axSpA clinics. Rheumatology consultants and registrars, physiotherapists and other HCPs involved in the care of people with axSpA were informed about the study and they were asked to discuss the study with their patients and identify interested patients. The PhD student regularly attended these clinics and spoke directly with potential participants or ones who were referred by HCPs. The purpose of the study was explained to potential participants, each interested participant had the opportunity to ask questions, they were given the participant information sheet (PIS) and a week to consider the study before deciding whether to take part. The study PIS is shown in Appendix 2.

4.4.6 Screening, consent and baseline assessment (Visit 1)

The initial visit took place at the participants' local hospital within NHS GGC. The purpose of the study was again explained to the participant and they were given an opportunity to ask any further questions. This first study visit was undertaken by the research assistant (SC). Participants provided written informed consent to participate in the study and for their GP to be informed of their participation; they then underwent screening for eligibility as per the inclusion and exclusion criteria (section 4.4.2).

If the participant passed the screening, the following outcome measures were taken as baseline assessment; Bath ankylosing spondylitis functional index (BASFI), Bath ankylosing spondylitis disease activity index (BASDAI), the work productivity and impairment questionnaire (WPAI:AS, the ankylosing spondylitis quality of life questionnaire (ASQoL), the EuroQol 5 dimension scale (EQ5D-5L), exercise attitude questionnaire (EAQ), Bath ankylosing spondylitis metrology

index (BASMI), and the six minute walk test (6MWT). These outcome measures are validated, widely used in clinical and research practice and are explained in more detail in Section 4.5. If required, assistance was provided with scribing for the self-reported outcome questionnaires. The 6MWT and BASMI were supervised by the research assistant using standardised methodologies. Each participants weight and height was measured so a body mass index (BMI) could be calculated.

Physical activity was measured with an activPAL activity monitor (PAL Technologies, Glasgow) which was attached to the participant's thigh using a Tegaderm waterproof dressing and participants were asked to undertake their usual activity for seven days. The participant was asked to fill in a diary for the days on which they wore the activPAL, recording when they slept and woke each day, so that sleep time could be subtracted from sedentary time.

Participants were informed that the programme was intended as a maintenance programme and that they could access any HCPs, including physiotherapists, as usual if any specific health care problems arose. There were no other changes to routine clinical care or treatment, which continued as per local practice.

4.4.7 Randomisation and Blinding

As this was a cohort study in which all participants received the intervention, randomisation and blinding were not relevant or required.

4.4.8 Visit 2

Participants were asked to return one week after the baseline visit for an appointment with the PhD student (MTM). The activPAL and sleep diary were returned. The participant was assessed by the physiotherapist by reviewing the outcome measures taken at visit 1. By using this information, and discussing each individual's lifestyle and preferences, specific exercise goals (including mobility, flexibility, and CV health) were agreed between the physiotherapist and participant. An exercise programme was then devised by the physiotherapist & PhD student (MTM) to address these goals and this tailored exercise

programme was set up on the web platform. Participants were advised on how to use the website and taken through their personal online exercise programme.

Participants were asked to tick a box on each exercise page when they had completed that exercise so that adherence to the programme could be recorded. Participants were informed that the online exercise diary should only be completed on the day on which the exercises were undertaken.

4.4.9 Remote Monitoring and Programme Alterations

After visit 2, participants received weekly phone calls from the PhD student (MTM) or the first two weeks of the programme. The purpose of these phone calls was to ensure the participant was able to log onto the website and to follow the exercise programme. Thereafter, the PhD student (MTM) reviewed the exercise diary of each participant remotely every two weeks and altered the participant's exercise programme online, as appropriate, by changing any combination of exercises, level of difficulty and/or number of repetitions based on feedback from the participant. Participants were informed of any changes by email. Participants could also contact the PhD student (MTM) directly to request a change in their programme should they feel this was required or if a problem arose.

4.4.10 Visit 3

Visit three was undertaken 6 months (± two weeks) after the visit 2. All outcome measures done at the baseline visit were repeated under the direction of the research assistant (SC) or PhD student (MTM) and the participant was given the opportunity to ask any questions. A new activPAL was attached and, as at baseline, the participant was advised to undertake their normal activities for seven days. The participant was again asked to fill in the sleep diary and asked to return the diary and activPAL in the post after the seven days. Of note, the PhD work presented here does not report the outcome measures taken at this visit.

4.4.11 Visit 4

Visit four was undertaken 12 months (± two weeks) after visit 2. All outcome measures were repeated under the direction of the research assistant (SC) or PhD student (MTM). A new activPAL was attached and as before the participant was advised to undertake their normal activities for seven days. The participant was again asked to fill in the sleep diary and was asked to return the diary and activPAL in the post after a week. A visual summary of the participant journey through the trial is provided in Figure 4-5. Similar to visit 3, this PhD work does not report the outcome measues taken on this visit.

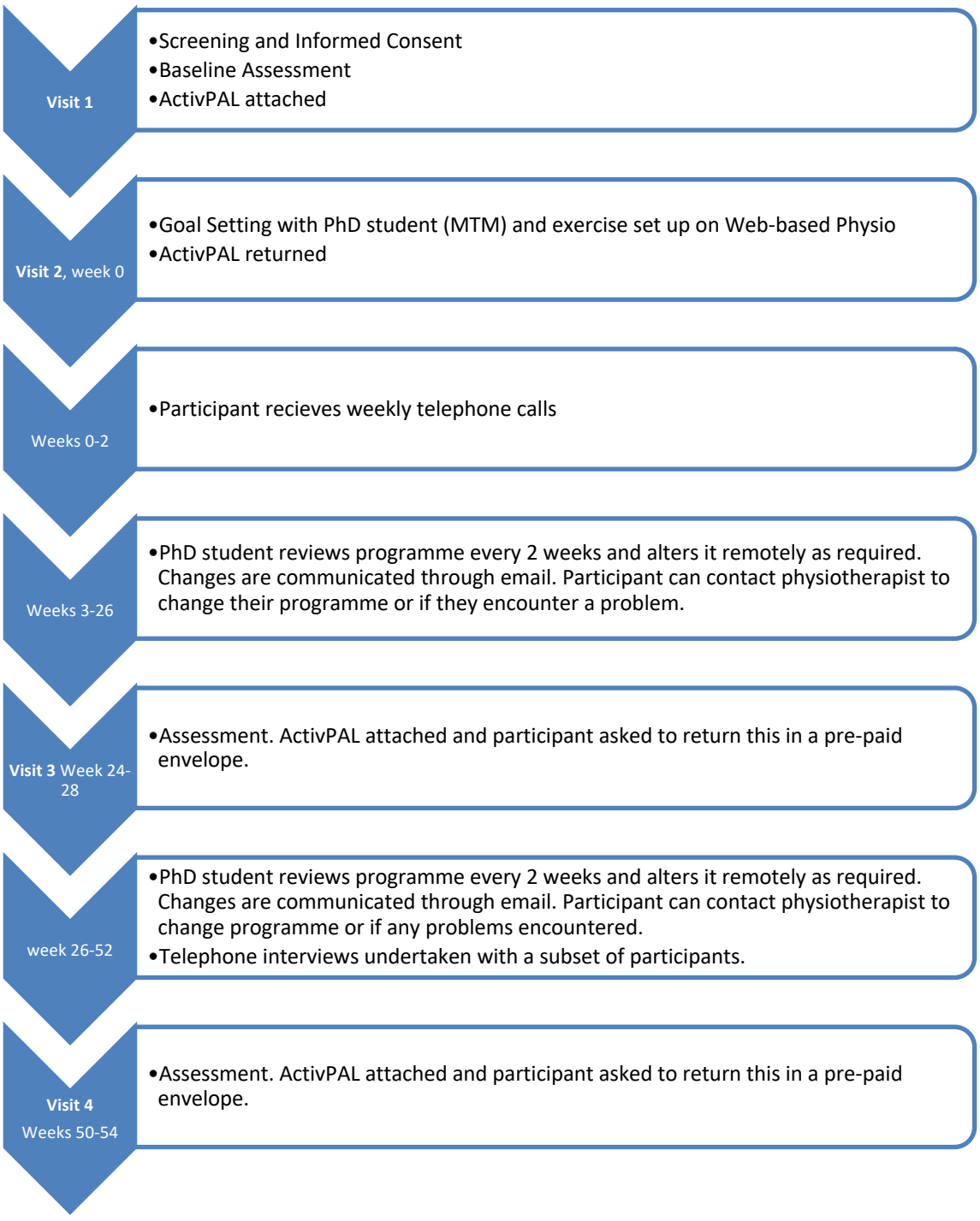


Figure 4-5. Participant journey and summary of study visits.

4.4.12 Telephone Interviews - Qualitative Data Evaluation

To explore participants' views and adherence to the programme, telephone interviews were conducted with participants between 6 months and 12 months of the study. Telephone interviews were chosen as the CI found in previous studies that these were most convenient for the participants. A topic guide was developed, which contained the main and prompt questions (Appendix 3). The interview questions were piloted by the PhD student within the research team in order to determine the most logical order of the questions.

A sample of 10 participants, 20% of all participants, was purposely selected to ensure data was collected from participants who did, and who did not, adhere to the programme, by looking at their total sessions adhered to, in order to gain a maximum variation sample. Participants were selected by the research assistant (SC) and the PhD student looking at the adherence data between 0-6 months, purposely selecting participants with different adherence rates, thereby attempting to collect data from participants across the adherence ranges. Selected participants were asked at their six-month assessment if they would be willing to participate in interviews and, if agreeable, a time of the participant's choosing was arranged for the PhD student to phone the participant. The PhD student (MTM) performed the interviews using the previously developed questions. The interviews were audio-recorded and then transcribed.

4.5 Outcomes

4.5.1 Adherence

As described in Chapter 2, there is no gold standard measurement of adherence, with adherence to HEPs most commonly measured using a self-reported diary method, although, even then, there is currently no standardised diary used across research studies (McLean et al., 2017). The World Health Organisation advises using the best measurement strategy to obtain an approximation of adherence appropriate for the setting (Sabete et al., 2003). Researchers should also consider the convenience and acceptability of the method for the user

(Vitolins et al., 2000). Self-reported diaries are convenient and provide an approximation of adherence; therefore, self-reported exercise diaries were utilised in WEBPASS.

Electronic diaries are thought to be more accurate than paper diaries as individuals using paper diaries may retrospectively fill multiple entries at one time, possibly recording their adherence inaccurately. Electronic diaries can be completed in real time and so have the potential to be more accurate (Stone et al., 2002). The web based physio platform also included an inbuilt electronic self-reported exercise diary which was felt to be the most convenient for the patient to record adherence as they would already be accessing their physiotherapy programme on the website. In an attempt to improve accuracy participants were asked to complete this self-reported exercise diary on the day they completed their exercise programme. They were not able to retrospectively or prospectively complete exercise diaries.

Participants logged onto www.webbasedphysiotherapy.com (now www.giraffe.com) and after each exercise ticked a box if the exercise was completed; participants were also able to leave a comment for the physiotherapist (Figure 4-6). A session of web-based physiotherapy was counted when the session of physiotherapy had been engaged with, with any of the individual exercises within the session completed. There was a maximum possible of 5 sessions per week. The exercise plan had two components; prescribed exercise sessions three times per week, and participant choice twice per week. To assess if the exercises within each session of prescribed exercise; the session was deemed as *complete* if all prescribed exercises had been ticked and was deemed i*ncomplete* if any prescribed exercise in that session was not ticked. For the participant-choice component, the participant was asked to tick 'other exercise' and use the comment box to give further details on what exercise they had performed.

The exercise diary for each participant was copied into an Excel spreadsheet and the number of sessions completed for each participant was manually counted

and recorded. For each session of the prescribed component, the 'exercises completed' were compared with the 'total number prescribed' and the session was deemed 'completed' if all exercises were completed or 'incomplete' if any exercise within the session was not completed. This information was then recorded.

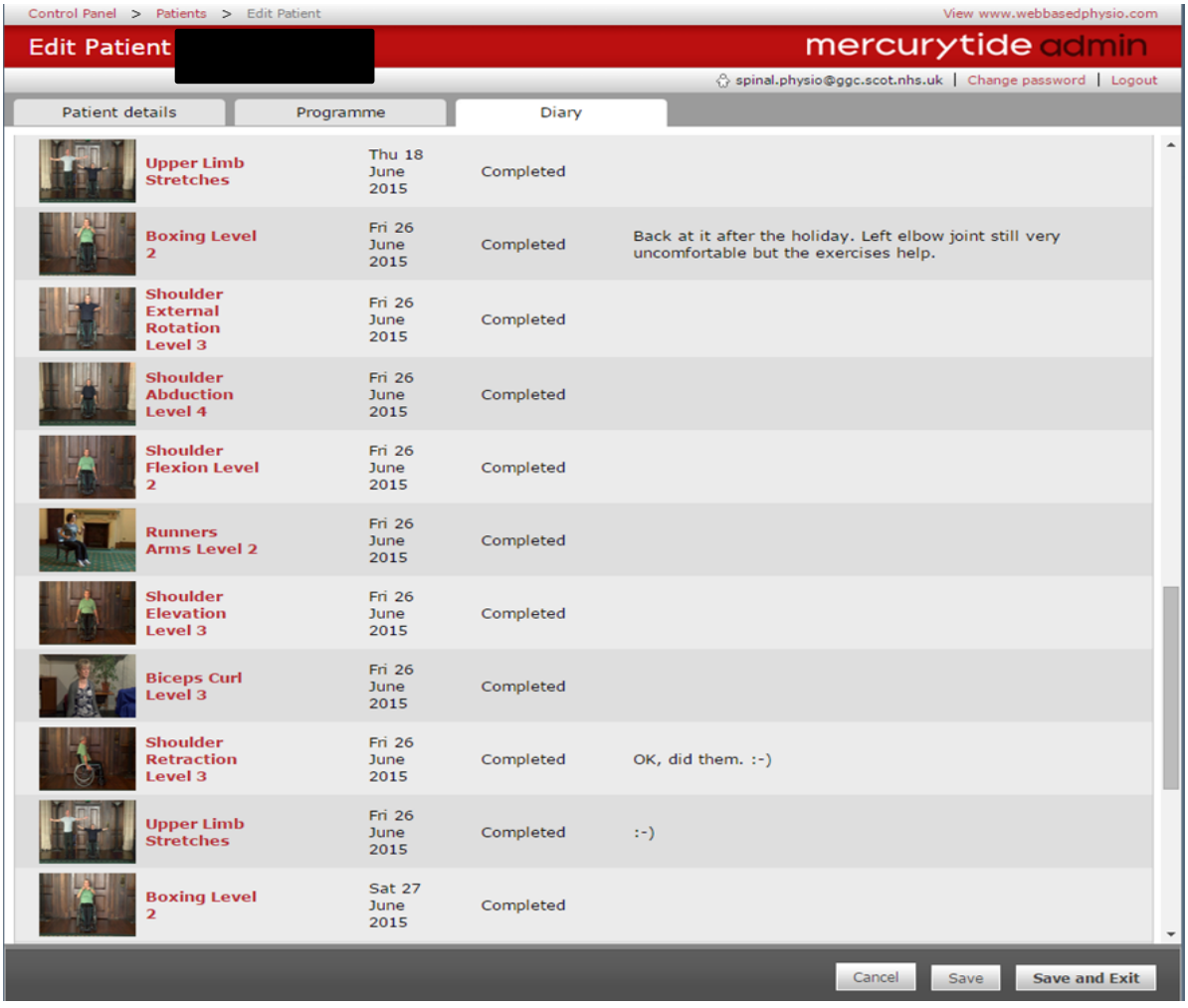


Figure 4-6. Physiotherapist's view of a participant's exercise diary, showing comments from the participant and that all exercises have been completed

4.5.2 Defining Good Adherence

As described in Chapter 2 there is no gold standard for defining 'good', 'satisfactory' or 'poor' adherence across health behaviours (Vitolins et al. 2000). In the absence of a consensus, good adherence was pre-defined in this study as the participant having engaged with an average of three exercise sessions per

week (i.e. 60%) or an average of three exercise sessions per week averaged across the programme.

4.5.3 Outcome measures used for correlations

4.5.3.1 Function

Function was measured using the BASFI. The BASFI is a set of 10 questions designed to determine the degree of functional limitation in those with axSpA. It is measured using visual analogue scales (VAS) ranging from 0 (easy) to 10 (impossible) with questions focused on the person's ability to perform specific functional tasks over the *past week* (Calin et al., 1994). The first 8 questions consider activities related to functional tasks, such as putting on socks with or without help and climbing steps with or without using a handrail. The final two questions assess the patient's ability to cope with everyday life.

The BASFI has been shown to have high levels of validity and reliability when measuring functional ability in AS. Calin et al (1994) compared the BASFI to the Dougados Functional Index within a sample size of 163 AS patients. They demonstrated that the BASFI score covered 95% of the available range in contrast to 65% with the Dougdas Functional Index. Furthermore, superior sensitivity was noted with the BASFI over a three-week period when compared to the Dougdas functional index ($p=0.004$).
The BASFI has become the standard functional questionnaire in clinical practice. The questionnaire was developed with patient input, ensuring the questions are relevant to those with AS (Calin et al., 1994). It is quick and easy to complete, reliable and sensitive to change across the whole spectrum of disease. A final total score out of ten is given by adding up the answer to each question and then dividing by ten. A higher overall score indicates more functional impairment. The minimal clinically important improvement of the BASFI is 0.6 (Kviatkovky et al., 2016).

4.5.3.2 Disease Activity

Disease activity was measured using the BASDAI (Garrett et al., 1994). The BASDAI uses a 10cm VAS to answer 6 questions pertaining to the 5 major symptoms of AS within the past week; fatigue, spinal pain, joint pain/swelling, areas of localised tenderness and morning stiffness. The VAS lines are anchored with the labels 'none' and 'worst ever' at either end of the first five questions, and with '0 hours' and 'two hours' at either end of the additional question on duration of morning stiffness. The two scores for morning stiffness are added and divided by two, giving a single mean count for morning stiffness. The final score is the mean of the five items, giving a score between 0 and 10. A BASDAI score equal to or above 4 is considered to indicate active disease (Kviakovky et al., 2016). The BASDAI is a quick and simple validated index, taking between 30 seconds and 2 minutes to complete and therefore widely used in routine clinical practice to assess disease activity. The minimal clinically important improvement of the BASDAI is 1.1 (Kviatkovky et al., 2016). Test–retest reliability was good when assessed for inpatients over a 24-hour period (r 0.93, P <0.001), and when assessed by postal survey in 162 AS patients who reported no change on an AS-specific health transition question over a 1-week period (intraclass correlation coefficient of 0.87 (95% confidence interval [95% CI] 0.83–0.91) (23). In terms of content validity, the measure was developed by experts in the field with patient input, reflecting items relevant to both patients and clinicians. For construct validity, the BASDAI correlated well with the earlier Bath Disease Activity Index, with no significant differences in score distribution, reproducibility, or sensitivity. There is good correlation with the ASQoL questionnaire (Pearson's correlation coefficient 0.79) and BASDAI scores are significantly higher in AS patients unable to work due to ill health (P < 0.01) (Zochling 2011).

4.5.3.3 Spinal Mobility

In addition to pain and stiffness, axSpA is associated with reduced spinal mobility, especially in long-standing disease. Spinal mobility was measured using the BASMI, which is validated and widely used in routine clinical practice

(Jenkinson et al, 1994). The index includes five clinical measurements: cervical rotation, tragus to wall distance, lumbar side flexion, modified Schober Test, and intermalleolar distance. For cervical spine rotation, tragus to wall and lumbar spine flexion, the mean of the left and right measurements is taken, according to the instructions. The BASMI measurements take around 7 minutes to perform.

There are two tables for calculating the BASMI scores from the measurements obtained. A table with three scores (0, 1, 2) for each measure was used in the original BASMI description by Jenkinson et al, (1994); this table was subsequently expanded to allow ten scores (0-10). This table is more sensitive to change and now more commonly used in research and practice (van der Heijde et al 2008). The 10-step table was used in WEBPASS. Each clinical measure has an individual score, which are then added together to give a total score out of 50, which is then divided by 5 to give a final score out of 10. Scores range from 0 to 10 and the higher the BASMI score the more severe the patient's limitation of spinal movement due to their AS.

The BASMI is accurate, reproducible and sensitive to change. Zochling et al (2011) report that comparisons between three physiotherapists showed good interrater reliability for cervical rotation of r 0.98, (P <0.001), tragus to wall of r 0.99 (P < 0.001), lumbar side flexion of r 0.94 (P < 0.001), lumbar flexion as measured by the modified Schober's method of r 0.99, (P <0.001), and intermalleolar distance r 0.98, (P < 0.001). Intraobserver reliability for the same three physiotherapists on consecutive days showed similarly high values: cervical rotation (r 0.99, P < 0.001), tragus to wall (r 0.99, P <0.001), lumbar side flexion (r 0.98, P < 0.001), lumbar flexion as measured by the modified Schober's method (r 0.99, P < 0.00 1), and intermalleolar distance (r 0.99, P < 0.001) (Zochling et al., 2011). Inter and intra- rater operator reliability has been reported with repeated measurements differences of 1.0 or less are within the bounds of error (Martindale et al, 2012). In terms of content validity, the initial instrument development was based on an extensive literature review and a panel of clinicians and research associates with a special interest in AS. In terms

of construct validity, the BASMI has been shown to discriminate between patients with and without radiographic change due to AS. The BASMI does not correlate strongly with changes in functional outcomes, as measured by the BASFI (r 0.44, P < 0.001). Spinal mobility, as measured by the BASMI, correlates with radiographic change as measured by the Stoke Ankylosing Spondylitis Spine Score (Spearman's 0.6). For criterion validity, the comparison between the five BASMI measures and total scores of 20 clinical measurements (total metrology score) was good (r 0.92, P< 0.001) (Zochling, 2011)

4.5.3.4 Quality of Life

Disease-related quality of life was measured using the ASQoL questionnaire (Doward et al 2003). This is a self-reported questionnaire which takes around 4 minutes to complete. The ASQol has 18 items which address the physical and psychological impact of the disease, including items relating to mood, coping, relationships, social life and activities of daily living. Scores range from 0-18, with a higher score reflecting worse quality of life. This questionnaire has been shown to be valid and reliable in AS (Doward et al., 2003). The Spearman rank correlation coefficient for the test-retest reliability of the 18 item ASQoL was 0.92 (n=129), indicating that the measure has excellent reliability, with low levels of random measurement error. Intraclass correlation coefficients were 0.92. Evidence of construct validity was provided by examining the levels of association between the ASQoL and the comparator instruments. Moderate to high correlations were found between the ASQoL and all the comparator instruments (Doward et al., 2003).

Health related quality of life was also measured with the EQ-5D-5L, which consists of a questionnaire and VAS (Brazier el al., 2016). It is short and easy to use, encompassing both positive (well-being) and negative (illness) aspects. The EQ-VAS records the subject's perceptions of their own current overall health status and can be used to monitor changes over time. The questionnaire is a self-reported description of the subject's current health in 5 dimensions i.e., mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

The participant is asked to grade their current level of function in each dimension into one of three degrees of disability (severe, moderate or none). The maximum score of 1 indicates the best health state (Brazier et al., 2016). The EQ_5D is commonly used across a number of health conditions. A cross-sectional study investigated the validity and realiability of the EQ_5D in people with axSpA in an Asian tertiary hospital from 2017 to 2018 (Seng et al., 2020). Construct validity was evaluated by testing 22 *a priori* hypotheses with other patient-reported outcomes measures. Cronbach's alpha was used to estimate the internal consistency of the EQ-5D-5L, while its test-retest reliability was assessed using weighted kappa and the intraclass correlation coefficient (ICC). The EQ-5D-5L demonstrated good internal consistency with a Cronbach's alpha of 0.79. The test-retest reliability of the EQ-5D-5L was good, with a weighted kappa of ≥0.61 for mobility, self-care, usual activities, and anxiety/depression; the ICC was 0.92 and 0.99 for the EQ-5D-5L index and VAS scores, respectively. The weighted kappa for the EQ-5D-5L pain/discomfort was moderate [0.53, 95% CI: 0.41–0.60]. This study supports EQ-5D-5L as a valid and reliable instrument for assessing health-related quality of life in people with axSpA (Seng et al., 2020).

4.5.3.5 Employment and Productivity

Employment and productivity were measured using the self-administered WPAI:AS which measures work productivity loss due to general health or a specified health problem. This questionnaire has been shown to be a valid, reliable and responsive tool for assessing work productivity for people with AS (Reilly et al., 2010). The WPAI:AS consists of six questions to determine employment status, hours missed from work due to AS and other reasons (absenteeism), hours actually worked, the degree to which AS affected work productivity while at work (presenteeism) and the degree to which AS affected activities outside of work. Four scores are derived: percentage of absenteeism (time off work), percentage of presenteeism (reduced productivity while at work), an overall work impairment score that combines absenteeism and

presenteeism and the percentage of impairment in activities performed outside of work. Higher scores indicate greater work impairment. Questions related to absenteeism and presentism are applicable to employed participants only. A study was carried out to determine the validity, reliability and responsiveness of the WPAI:SpA. Baseline and week-24 data from a randomized, double-blind study of adalimumab in patients with AS were used. The discriminative validity of WPAI:SpA absenteeism, presenteeism, overall work productivity loss and activity impairment scores was assessed relative to patient-reported outcomes: BASDAI, ASQOL, Short-Form 36 Health Survey, Physical and Mental Component Summaries and Health Utilities Index Mark 3. Responsiveness of the WPAI:SpA instrument was assessed for patients meeting the minimum clinically important differences for ASQOL and BASDAI (i.e. quality of life and clinical responders, respectively) and quantified with standardized response mean calculations. Two hundred and five people with AS were included. Patients with more severe AS (BASDAI > median) showed significantly greater impairment in work and daily activities than patients with lesser disease severity ($P < 0.001$). This trend was consistent for ASQOL, Short-Form 36 Physical Component Summary, Short-Form 36 Mental Component Summary and Health Utilities Index Mark 3. There were significant differences in WPAI:SpA scores for patients achieving BASDAI clinical response and ASQOL quality of life response compared with non-responders. For responders, standardized response mean calculation were large for work presenteeism, overall work impairment and activity impairment (0.86 to 1.29 for BASDAI; 0.89 to 1.18 for ASQOL) and small for absenteeism (0.25 for BASDAI; 0.31 for ASQOL). Therefore, it was deemed the WPAI:SpA is a valid, reliable and responsive tool for assessing work productivity for patients with AS.

4.5.3.6 Attitude to exercise

The participants' attitude to exercise was measured using the EAQ (Manigandan et al., 2004). This self-reported questionnaire contains three different components of attitude: affective, behavioural and cognitive. Each question is scored from 1 ('don't agree at all') to 4 ('agree very much'). A higher score indicates a positive attitude to exercise. This questionnaire was constructed using a Delphi technique by sampling physiotherapists and occupational

therapists with a minimum of 2 years' working experience at the Christian Medical College, Vellore (Manigandan et al., 2004). In terms of content validity, 21 therapists took part in this phase of the study. Eighteen specific questions based on the experts' opinion were selected. The questionnaire was also piloted on a small (no number given) group of patients. Therefore, the EAQ-18 was deemed a validated questionnaire which represents participants' attitudes towards exercise (Manigandan et al., 2004).

4.5.3.7 Exercise Capacity/Fitness

Exercise capacity or fitness was assessed using the 6MWT which measures the total distance walked in six minutes on a hard flat surface (Enright, 2003)). The participant is instructed to walk around two cones positioned 10m apart for six minutes. They are permitted to slow down or rest when necessary and to use walking aids as required. Although not specific to axSpa, this test is a well-recognised and validated outcome measure of exercise capacity across a range of chronic conditions (Enright, 2003). The validity and reliability of the 6MWT has not been tested on people with axSpA. A study conducted by Pankoff et al., (2000) used the 6MWT as a tool to assess cardio-respiratory fitness in people with fibromyalgia. Twenty-six subjects (27–59 years of age) performed three walk tests over consecutive days before and after a 4-week treatment programme. Reliability was determined using a one-way repeated measures analysis of variance and the intraclass correlation coefficient (ICC2,1). Reliability of the 6MWT was excellent, both at program intake (ICC2,1 = 0.91) and programme completion (ICC2,1 = 0.98), and a significiant correlation between the 6MWT and VO2 max ($P<0.001$) was found.

4.5.3.8 Physical Activity

Physical activity level was measured with an activPAL activity monitor. The activPAL, is a small, single unit device that contains a tri-axial accelerometer that responds to gravitational acceleration as well as acceleration resulting from segmental movement (Edwardson et al., 2016). From the inclination of the thigh, posture can be classified as sitting/lying, standing or walking. The

activPAL was attached at each assessment using a Tegaderm waterproof dressing and participants were asked to undertake their usual activities for seven days.

Wearing an activPAL monitor for five consecutive days has been shown to be a valid and reliable method of measuring physical activity in a healthy population with this data being representative of an individual's activity (Grant et al., 2006, Dahlgren et al., 2010). No study has measured the validity of the activPAL in axSpA; however, in rheumatoid arthritis it has been reported to be a valid measure of time spent in sedentary, standing/light activity and walking behaviours when compared to direct observation (Larkin et al., 2016). This study compared activPAL with direct observation of the time spent in sedentary, standing/light activity and walking behaviours, with correlation analysis revealing that activPAL step counts were strongly correlated with direct observation values (r=.94; 95% CI=.86, .98). However, paired t test revealed no significant difference (P=0.57) between the activPAL activity monitor and direct observation for time (total number of seconds) spent in sedentary behaviour or between the activPAL activity monitor and direct observation for time (total number of seconds) spent in standing or light activity behaviour for the total testing session (p=0.08) (Larkin et al., 2016).

4.5.4 Handling of data

Participants were assigned an individual study number with all information relating to their participation coded using this unique identifier. All study specific information and all subsequent data analysis, reports and potential publications were anonymised. Data were collected, managed and stored in accordance with the Data Protection Act (1998), which was the relevant Act at the time of the study. Data were entered into a database by the research assistant (SC) or physiotherapist (MTM). All participant data were anonymised and any data which identified a participant were stored separately in a locked filing cabinet in a locked room in the University of Glasgow. Anonymised data were stored on a secure password protected drive on a University server. Only the research team had access to the data collected. The data will be destroyed five years after completion of the study.

4.5.5 Statistical Analysis

4.5.5.1 Quantitative data analysis

Adherence data was calculated for each session and whether the exercise session was complete or incomplete. This data was inputted into Excel initially, as the exercise diaries could not be cut and pasted into SPSS and then transferred to SPSS by the PhD student. Descriptive statistics were used to explore adherence to the number of sessions and exercises completed within the session. In addition, comparisons were made between the two components of the exercise programme; prescribed and participant choice.

Participants who completed the study, i.e attended their 12-month appointment were divided into those who had good adherence, as defined by averaging at least three sessions per week over the course of the 12 months, or not good adherence, averaging less than three sessions per week over the course of the year, by counting all sessions throughout the year and dividing by 52.

Data analysis for adherence over time was calculated by the Robertson Centre for Biostatistics, as part of the WEBPASS grant, but was also included within this PhD. This was recalculated by the PhD student, as one participant was subsequently removed from the analysis because she did not meet the criteria to be included in the study.

All demographic and outcome data were tested for distribution using the Kolmogorov–Smirnov test (Razali and Wah, 2011). Where a normal distribution was noted, mean and standard deviation were used and where data were not normally distributed, median, range and inter quartile range were used. To compare the adherence rates between the prescribed and participant choice component of the programme, a Wilcoxon Signed Ranks statistical test was used with the statistical significance defined as $p<0.05$ (Cohen, 1988).

The relationship between the total completed sessions of the intervention and age, duration of disease, BASFI, BASMI, BASDAI, ASQOL, PA data and 6MWT was assessed using Pearson correlation coefficient, if data were normally distributed, and Spearman's Rho correlation, where data were not normally distributed. Correlations of ≥0.30, ≥0.50 and ≥0.70 were considered small, moderate and large, respectively (Pett et al 1997). For the correlation analysis, the Bonferroni correction was applied to control for type I error from multiple comparisons and the statistical significance was pre-defined as $p<0.025$.

4.5.5.2 Qualitative data analysis

The telephone interviews were recorded and transcribed. Data were analysed using thematic analysis according to the six-phase method of identifying and analysing patterns in qualitative data described by Clarke and Braun (2013) using a general inductive approach. Initially, the transcripts were read and re-read in order for the CI and PhD student to become familiar with the data. Observations were noted on the transcriptions, as appropriate, during this stage and relevant codes were generated along with appropriate data extracts. The next stage of analysis involved the CI and the PhD student independently considering and collating the codes by hand, and making note of meaningful patterns in the data that were relevant to the research questions. Themes and sub-themes were generated and reviewed, discussed and agreed by the CI (LP) and the PhD student (MTM).

Themes and subthemes were then presented using pseudonym quotes, with participant age and number of completed sessions from the prescribed number of exercises, to illustrate the participant view.

Rigour was enhanced during the process by ensuring an audit trail of the process. The CI and PhD student (MTM) were involved in reviewing each of the themes and subthemes. The principles of credibility, transferability and dependability were followed throughout. Credibility was ensured by triangulating the themes from a number of participants. Dependability was ensured by having both the CI and the PhD student check the themes and transferability by recruiting a

maximum variation sample of those who adhered and did not. Reflexivity was promoted by completing a reflexive diary and regularly meeting with the research team to try minimise the bias this would bring to interpretation of the data.

4.6 Results of WEBPASS Cohort Study

Within this section the results of the PhD work relating to adherence within the interventional WEBPASS cohort trial are presented. This work aimed to explore adherence to the 12-month web based physiotherapy programme in more detail than in the main Versus Arthritis funded WEBPASS study, focusing on adherence levels; sessions and exercises completed, good adherence (defined as adhering at least three times per week), comparing adherence in the participant choice and physiotherapy prescribed components, adherence over time and evaluating factors which may affect adherence. In addition, data from the WEBPASS interviews related to adherence were analysed. The CONSORT flow diagram (Moher et al (2010) of participants' progress through the different phases of the study (enrolment, intervention, 6- and 12-month follow-up) is shown in Figure 4-7

4.6.1 Participants

In total, 166 people were invited to participate in the study, with 139 invitations made directly at dedicated axSpA clinics, 9 people expressed an interest in participating after seeing the project published on posters, twitter and the NASS newsletter and 18 participants were referred by a doctor or physiotherapist. Of these 166 people, 116 were excluded for the following reasons: not interested in the study (n=32), already exercising more than three times per week (n=23), no access to the internet (n=14), significant co-morbidity that precluded exercise (n=5), joint replacement surgery less than six months ago (n=5), axSpA diagnosis less than one year ago (n=5), no axSpa diagnosis (n=4) or no information/reason given (n=28) (See Figure 4-7).

Fifty participants met the inclusion criteria, were willing to participate in the study, and underwent screening and baseline measurements. Four participants withdrew prior to the six-month assessment for the following reasons: health issues (n=2), work commitments (n=1) and unable to access the programme (n=1), while four participants did not attend for their six-month appointment and therefore were lost to follow up (LTF). Between the six month and 12-month visits, a further 5 participants were LTF, one of these participants lost to follow up subsequently contacted the PhD student to advise that her diagnosis was revised from axSpA to chronic non-specific low back pain, although this participant's data is included in the baseline data her data was removed from the subsequent adherence analysis. Thirty-eight participants (76%) completed their 12-month assessment.

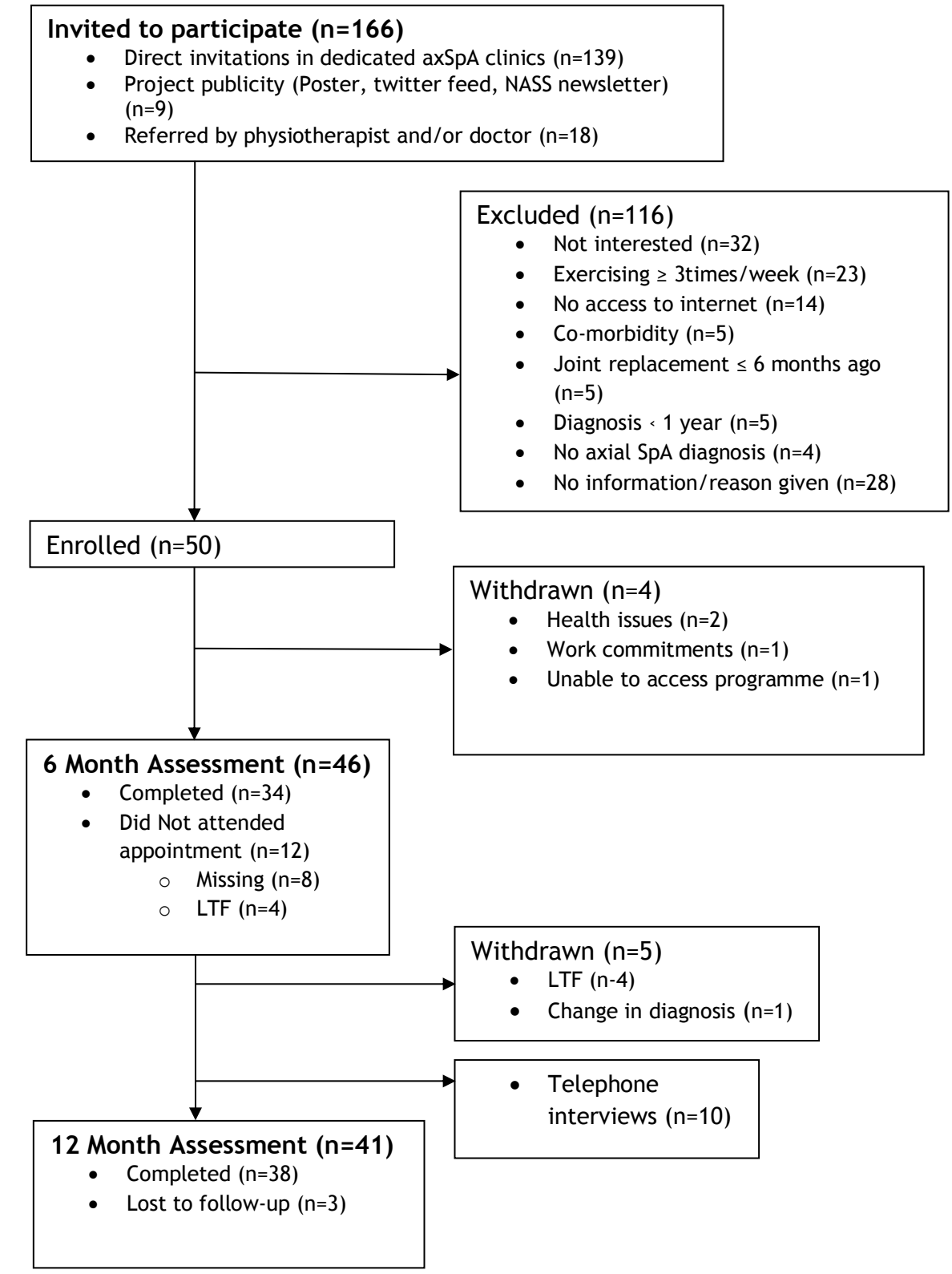


Figure 4-7. Consort diagram for WEBPASS.

4.6.2 Demographics and baseline characteristics

The cohort of 50 participants comprised of 23 males (46%) and 27 females (54%) (Table 4-1). The mean age was 50 years (SD 11.7) and mean time since diagnosis was 16.2 years (SD 11.9). All participants had a diagnosis of axSpa at baseline, 48 (96%) participants had a subset diagnosis of AS and only two (4%) participants had a subset diagnosis of nr-axSpA. The mean Body Mass Index (BMI) across the sample was 27.2 kg/m^2 (SD 5.58) with a range of 17-42kg/m^2; 19 participants were of normal weight (BMI 18.5-25kg/ $m^{2,}$), 14 people were overweight (BMI 25-30kg/m^2) and 11 participants were obese BMI >30kg/$m^{2,}$), with missing weight and hence BMI data for 6 participants (NICE 2014). Twenty-one participants (42.1%) had no co-morbidities, 18 participants (36%) had one co-morbidity, eight participants (16%) had two co-morbidities and three participants (6%) had three or more co-morbidities. The most common co-morbidity was hypertension.

The majority of participants (68%) were currently employed, with 30 working full-time and 4 part-time. Three participants were unemployed, one was a student, two were off work and 10 were retired. Forty-six participants (92%) walked with no aids while four (8%) participants walked with the aid of a stick.

The mean baseline disease activity (BASDAI) was 4.6 (SD 2.27; range 0.4-8.7), with 58% with a BADAI score ≥4, indicating high disease activity and 42% with BASDAI <4 indicating low disease activity. The mean baseline function score (BASFI) was 4.5 (SD 2.6), which is below the reported patient-acceptable symptom state for the BASFI for this age-group and disease duration (Kviatkovsky et al., 2016). The mean spinal mobility for the cohort, as measured by the BASMI, was 3.7 with a higher score indicating more restricted spinal mobility. The mean baseline ASQoL (quality of life) score was 9.6 (SD 5.8) out of a possible 18, with a higher score indicating poorer quality of life. Health related quality of life, as measured by the mean ED-5D was 0.7, where the maximum score of 1 indicates the best health state.

Exercise capacity was measured using the 6MWT, and participants walked for a mean of 406.5m (SD 112.2) during the baseline test. This is lower than 571±90 m

which was reported for 444 health subjects (238 males) from seven countries (10 centres) ranging 40–80 yrs of age (Casanova et al., 2011). The mean score for attitude to exercise at baseline was 60.9 out of a possible 72, with a higher score indicating a positive attitude to exercise.

Table 4-1. Participant baseline characteristics.

	n (%)	Mean ± SD (range)
Demographics		
Age (years)		50 ± 11.7
Gender (M:F)	23:27 (46:54)	
Disease duration since diagnosis (years)		16.2 ± 11.9
Weight (kg)		76.9 ± 18.2
Type of axSpA		
AS	48 (96%)	
nr-axSpA	2 (4%)	
No of Co-morbidities		
0	21 (42%)	
1	18 (36%)	
2	8 (16%)	
3	3 (6%)	
Work status & Impairment		
WPAI		42.4 ±27.9 (0-100)
Paid Employment	34 (68%)	
Retired/medically retired	10 (20%)	
Unemployed	3 (6%)	
Off work	2 (4%)	
Student	1 (2%)	
Disease activity/mobility/function		
BASDAI (0-10)		4.6 ± 2.3 (0.4-8.7)
Low disease activity (BASDAI <4)	21 (42%)	
Active disease activity (BASDAI ≥4)	29 (58%)	
BASMI (0-10)		3.7± 1.76 (0.4-7.5)
BASFI (0-10)		4.5 ± 2.6 (0.4-9.3)
Exercise capacity		
6 minute walk test (m)		406.5 ± 112.2 (121-622)
Mobility		
Mobility with aid (stick)	4 (8%)	
No aid required	46 (92%)	
Attitude		
Exercise Attitude Questionnaire (n=48)		60.9 ±11.4
Quality of Life		
EQ-5D (n=50)		0.7 ± 0.35
EQ-5D VAS (n=50)		65.5 ±15.7
ASQoL (n=50)		9.6 ± 5.8
Current Treatments		
Anti-TNF	25 (50%)	
NSAIDs	30 (60%)	
Analgesics	22 (44%)	
Currently attending Physio/exercise class	4 (8%)	

4.6.3 Characteristics of Participants Completing and Not Completing Study.

In order to determine whether participants who completed the study (to 12 months) were different to those who did not complete the study, baseline characteristics of these two groups were compared (Table 4-2). Compeletors of the study were those participants who attended their 12-month appointment (n=38). Non completors were those participants who did not attend their 12-month appointment (n=12). There was no statistically significant difference in terms of demographics, work status, disease activity/mobility/function, exercise capacity, exercise attitude and quality of life between those who completed or did not complete the study.

Table 4-2. Baseline demographics of participants completing or not completing 12-month follow-up.

	n (%)	Mean ± SD (range)	Completers (n=38)	Non-completers (n=12)	p value
Demographics					
Age (years)		50 ± 11.7	Mean 50.8 ± 11.31	Mean 47.5 ± 12.96	0.35
Gender: Male	23 (46%)		17 (44.7%)	6 (50%)	
Female	27 (54%)		21 (55.3%)	6 (50%)	
Disease duration since diagnosis (years)		16.2 ± 11.9	17 ± 12.4	13.5 ± 10.3	0.73
Type of axSpA					
AS	48 (96%)		36	12	1
nr-axSpA	2 (4%)		2	0	
No of Co-morbidities					
0	21 (42%)		16	5	0.85
1	18 (37%)		14	4	
2	8 (16%)		6	2	
3	3 (5%)		2	1	
Work status & Impairment					
WPAI		42.4 ± 27.9 (0-100)	40.5 ± 30.9	48.3 ± 14.7	0.4
Paid Employment	34 (68%)		25	9	0.75
Retired/medically retired	10 (20%)		7	3	
Unemployed	3 (7%)		3	0	
Off work	2 (4%)		2	0	
Student	1 (2%)		1	0	
Disease activity/mobility/function					
BASDAI (0-10)		4.6 ± 2.3 (0.4-8.7)	4.9 ± 1.6	4.4 ± 2.45	0.53
Low disease activity (BASDAI <4)	21 (42%)				
High disease activity (BASDAI ≥4)	29 (58%)				
BASMI (0-10)		3.7± 1.76 (0.4-7.5)	3.87 ± 1.74	3.6 ± 1.78	0.82
BASFI (0-10)		4.5 ± 2.6 (0.4-9.3)	3.87 ± 1.74	3.6 ± 1.78	0.82
Exercise capacity					
6MWT(m)		406.5 ± 112.2 (121-622)	406 ± 91	406 ± 119	0.86
Motivation/ Attitude					
Exercise Attitude Questionnaire (n=48)		60.9 ±11.4	54.6 ± 8.2	62.6 ± 11.5	0.30
Quality of Life					
EQ-5D VAS (n=50)		65.5 ±15.7	66.34 ± 16.4	62.91 ± 13.3	0.288
ASQoL (n=50)		9.6 ± 5.8	13 ± 4.02	8.47 ± 5.9	0.27

4.6.4 Baseline Exercise Level

Participants were only eligible for the study if they self-reported that they were not exercising ≥3 times per week. Twenty-eight participants (56%) self-reported that they did not exercise at all at baseline. Twenty-two participants (44%) self-reported that they did some form of exercise; eight participants exercised once per week, eight participants exercised twice per week, four participants reported exercising three times a week and two participants initially reported exercised more than three times per week. On further questioning, the two participants who self-reported exercising three or more times a week, were in fact describing physical activity, such as walking to work, rather than exercise, so these participants were included in the study. The mean number of self-reported exercise sessions for the cohort at baseline was 2.1 sessions per week (SD 1.4).

4.6.5 Adherence to Number of Sessions over 12 months for all Participants

To answer how many sessions of web-based physiotherapy individuals engaged with, adherence to the number of sessions in the exercise programme was assessed by calculating the number of sessions for each individual and then the percentage of exercise sessions over 12 months (number of sessions engaged in divided by maximum 260 based on five exercise sessions per week over 52 weeks). The data for all participants is shown in Table 4-3. Note that totals only add up to 49 as the participant (study number 43) whose diagnosis changed during the trial was excluded from all calculations.

Table 4-3. Adherence to prescribed sessions of exercise all participants (n=49) – shown in order of ascending percentage adherence.

Participant Number	Total Possible Number of Sessions	Actual Total Number of Sessions	% Adherence (Actual/possible)	Completed Trial
48	260	0	0	no
21	260	0	0	no
15	260	0	0	yes
30	260	0	0	no
8	260	0	0	yes
39	260	0	0	yes
36*	260	0	0	yes
27	260	1	0.4	yes
29	260	1	0.4	yes
20	260	2	0.8	no
16	260	4	1.5	no
3	260	8	3	no
13	260	9	3.5	yes
42	260	11	4.2	yes
9	260	13	5	no
44*	260	19	7.3	yes
35	260	19	7.3	yes
32	260	17	6.5	no
25*	260	28	10.8	yes
38	260	33	12.7	yes
10	260	36	13.8	yes
14	260	38	14.6	no
28	260	42	16.1	yes
17*	260	43	16.5	yes
22	260	46	17.7	no
18	260	46	17.7	yes
23	260	46	18	no
5*	260	52	20	yes
19	260	78	30	yes
50	260	80	30.8	yes
4	260	92	35.4	yes
49	260	96	36.9	yes
11*	260	105	40.4	yes
2*	260	106	40.8	yes
24*	260	108	41.5	yes
7	260	109	41.9	yes
46	260	116	44.6	yes
45	260	134	51.5	yes
26	260	135	51.9	yes
47	260	144	55.4	yes
6	260	145	55.8	yes
1*	260	151	58.1	yes
41	260	168	64.6	yes
34	260	169	65	yes
37	260	176	67.7	yes
33*	260	181	69.6	yes
31	260	225	86.5	yes
40	260	227	87.3	yes
12	260	260	100	yes
Total	**12,740**	**3519**	**27.6%**	

* indicates participants who participated in interviews.

The percentage of sessions undertaken ranged from 0-100%. Overall 3519 out of a total of 12,740 potential exercise sessions (27.6%) were completed. Seven participants did not initiate their exercise programme, engaging in zero sessions. Only one participant engaged in all 260 sessions.

4.6.6 Adherence to Sessions for Participants Who Completed and Did Not Complete the Study

In order to illustrate differences in adherence rates between participants who completed the study, (as determined by attending their 12-month appointment) and did not complete the programme and also to compare participants who initiated the exercise programme and did not, Table 4.4 presents the adherence to sessions (number and percentage) as a group for participants who did and did not complete the study, and who did and did not initiate the exercise programme.

Table 4-4. Adherence for participants who completed (completers) and did not complete (non-completers) the study.

Number of Participants	Total number of sessions (participants x 260)	Total Completed Number of Sessions	Percentage (SD)
Completers (n=38)	9,880	3345	33.8 (± 28.6)%
Completers removing those who did not start (n=34)	8,840	3345	37.8(± 28.3)%
Non-completers (n=11)	2869	174	6.1(+7.8)%
Non-completers removing those who did not start (n=8)	2080	174	8.3 (+7.2)%

For those participants who completed the study (n=38), overall their percentage adherence was higher than those who did not complete the study (n=11), 33.8% versus 6.1%. Furthermore, for participants completing the study when removing those who did not initiate any sessions of web-based physiotherapy, the overall adherence rate rises to 37.8%.

For participants who did not complete the study they represent low adherence rates overall, 6.1% which rises to 8.3% when removing those who did not initiate any sessions of the WEBPASS study.

4.6.7 Adherence for Participants

In order to illustrate the range of adherence to sessions over the 12-months for participants, the results are presented by box plots (Figure 4-8).

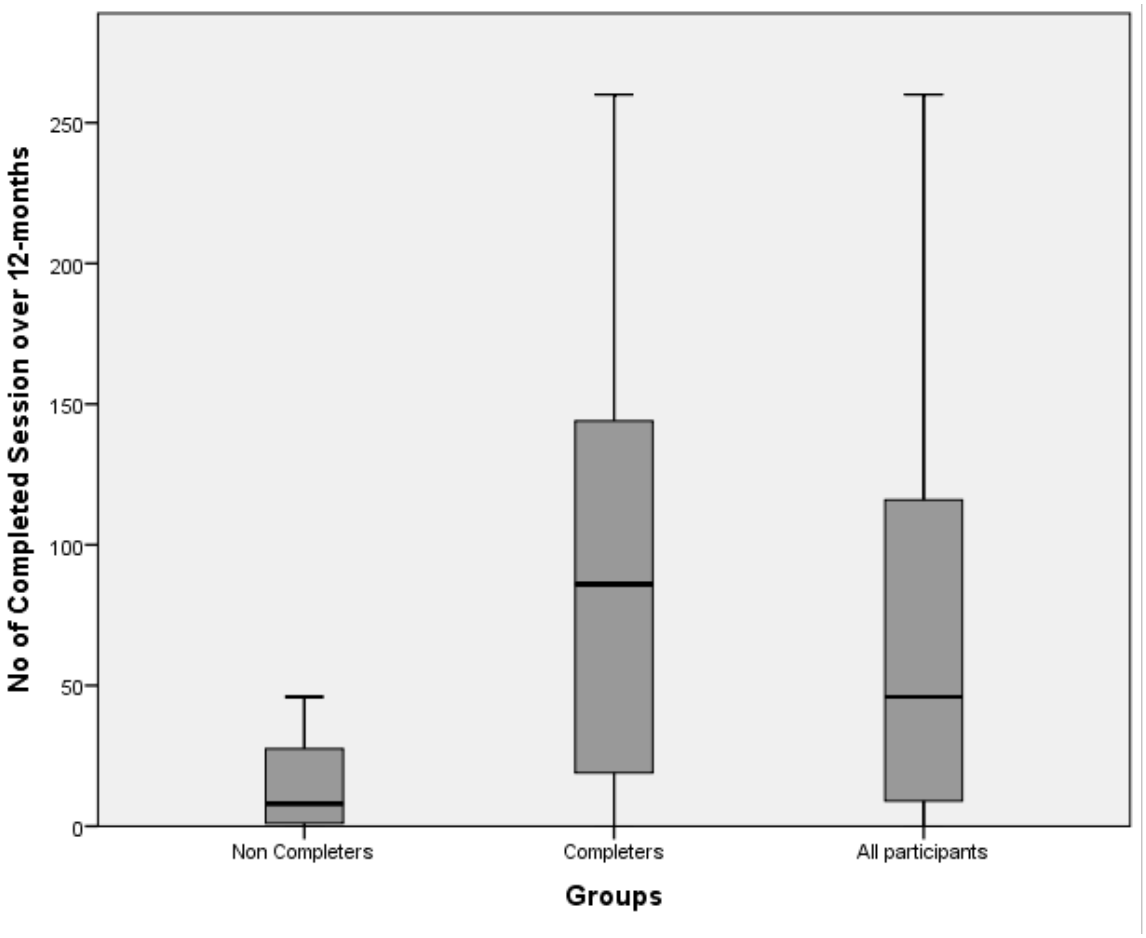


Figure 4-8. Boxplots showing the number of sessions completed over the 52 weeks for all 49 participants, and for completers and non-completers of the study.

The maximum number of sessions was 260 over the year for each participant. The first box plot from the left represents participants (n=11) who did not complete the study. For these participants the range of sessions completed was between 0-46, median of 8 sessions, 25th percentile of 0 sessions and 75th

percentile of 38 sessions. The second box plot represents participants who completed the study (n=38). For these participants the range of sessions was between 0-260 with a median of 86 sessions, 25th percentile of 19 sessions and 75th percentile of 144 sessions. The final box plot represents all participants. For these participants the range of sessions was between 0-260, the median of 46 sessions completed, the box indicates the 25th percentile of 8.5 sessions and 75th percentile of 125 sessions.

Although adherence overall to the exercise programme was low, for those completing the trial the adherence to sessions was much higher.

4.6.8 Participants with Good Adherence

Good adherence was defined as being met if the participant completed an average of at least three exercise sessions per week throughout the 12-month programme (at least 156 sessions out of the overall possible total of 260). Considering the 38 participants who completed the study, only seven participants (18.4%) met the pre-defined criteria for good adherence for the year. Thirty-one participants who completed the 12 months of the study adhered to less than 156 sessions overall (Table 4-3).

4.6.9 Adherence to Prescribed and Participant Choice Components

The participants' weekly exercise programmes consisted of two components: a prescribed component (3 times per week, 156 possible sessions per participant, 7,644 sessions for all participants) and a participant choice component (2 times per week, 104 possible sessions per participant, 5,096 sessions for all participants). In order to assess whether adherence differed, the adherence rate (percentage of completed sessions) was assessed for each component, for all participants (n=49) (Table 4-5). The adherence to each component for each individual participant is shown in appendix 4.

Table 4-5. Adherence rates for the prescribed and participant choice components of programme (n=49).

	Total number of Available Sessions)	**Total number of Sessions Completed**	**% Completed (SD)**
Prescribed Exercise Component	7,644	2515	32.9 (± 31)%
Participant Choice Component	5,096	1004	19.7 (± 24.8)%

Overall the participants' adherence rate was higher for the prescribed component of the exercise intervention (32.9% of all sessions completed) than the patient choice component (19.7% of all sessions completed).

A Wilcoxon signed ranks test found that adherence with the prescribed exercise component was significantly higher than the patient-choice exercise component in this study ($p<0.001$).

4.6.10 Adherence to Content of Prescribed Component of Exercise

Previous sections have described adherence across the programme and across exercise sessions as a whole. However, it is also important to consider adherence within each prescribed exercise session. If all prescribed exercises within an exercise session were carried out, the session was considered as "complete", whereas if any prescribed exercise in the session was missed, the session was defined as "incomplete". Table 4-6 below shows the summary of complete and incomplete prescribed exercise sessions. Only prescribed exercise sessions that were initiated (2515) were analysed to investigate whether all the exercises that were prescribed within the session were completed. Appendix 5 presents the individual data for each participant.

Table 4-6. Number of initiated prescribed exercise sessions that were complete or incomplete.

	Sessions Complete	Sessions Incomplete
Total Number of sessions (n=2515)	1850	665
Percentage of total sessions	74%	26%

The data shows that when exercise sessions were initiated, the majority (74%) of these sessions were completed fully, with approximately a quarter (26%) of initiated sessions incomplete. Once participants initiated an exercise session, most of the time they completed each exercise within the session.

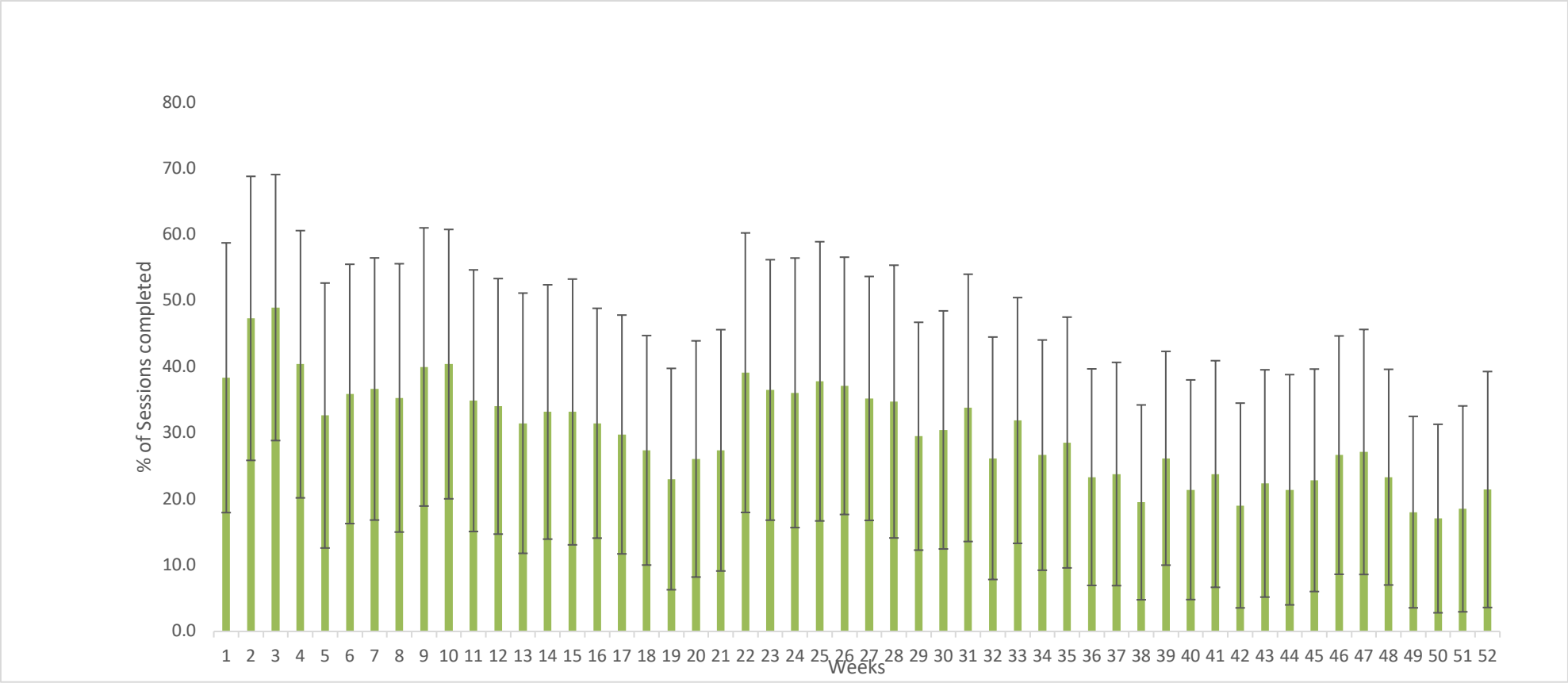
4.6.11 Adherence over Time

Adherence to any activity or lifestyle programme is not constant but is likely to change over time. In order to evaluate how adherence to this exercise programme changed over time, adherence each week within the 12-month intervention was analysed.

4.6.11.1 Adherence over time: Sessions

Adherence over time was first calculated as the percentage of sessions for each week for all participants adjusting for when participants withdrew or were lost to follow up (Figure 4.9). Thirty-eight participants completed the trial (3 participants were lost to follow up at the last (12 month) study visit, 8 participants withdrew or were lost to follow up before the last (12 month) study visit). (Figure.7)

Figure 4-**9. Percentage of Completed Exercise Sessions each Week for All Participants, adjusting for when withdrew and lost to follow-up. Error Bars show SD**



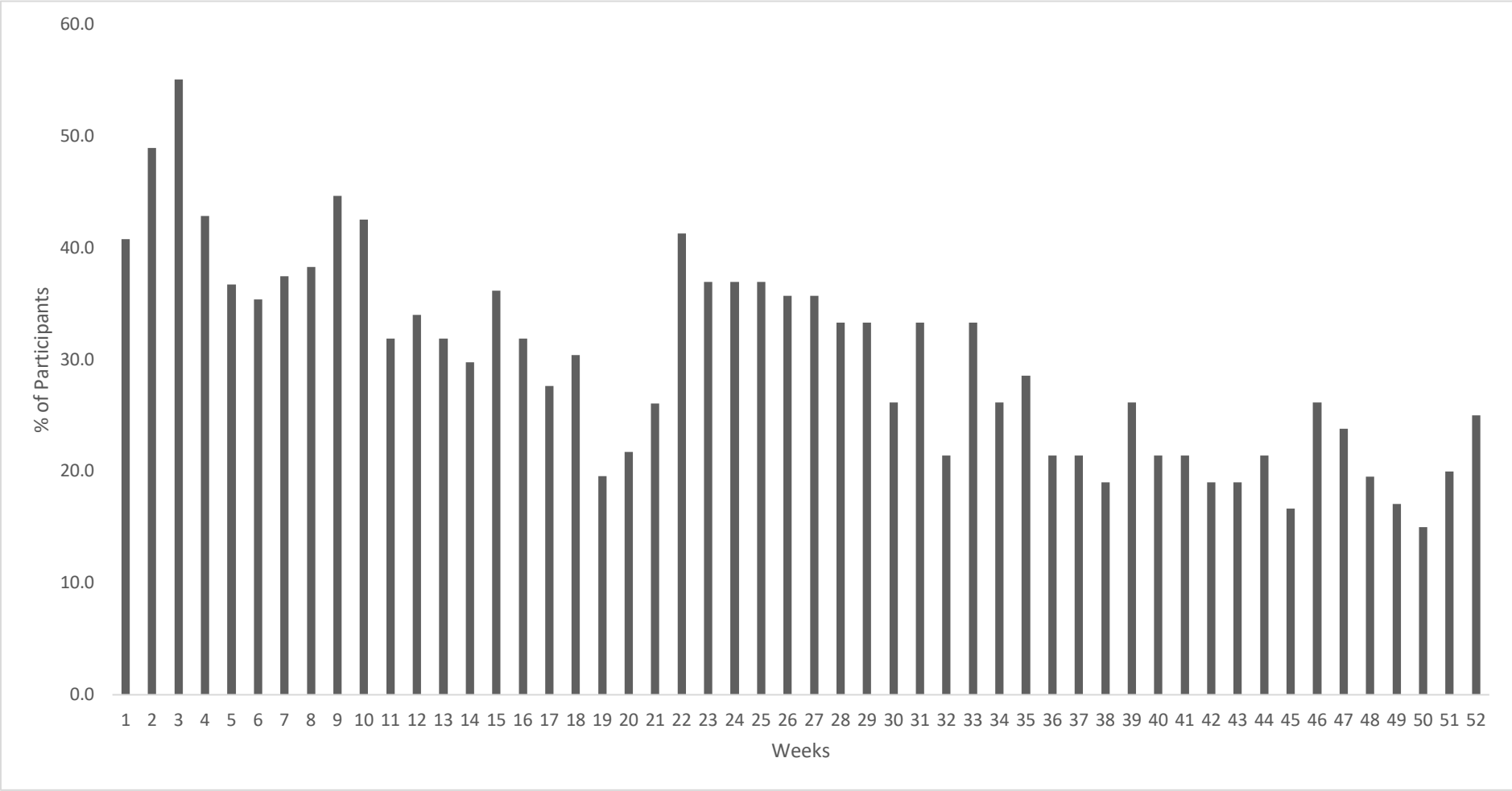
The weeks with the highest percentage of sessions engaged with were early in the study, with 47% and 49% of all sessions for weeks 2 and 3, respectively. These weeks coincided with when the PhD student contacted the participant by phone. A few participants had trouble logging on to their programme, which explains the relatively lower adherence in week 1 in comparison to week 2. A general downward trend is observed from week 3 (49%) until week 19 (23%), apart from a small temporary increase in adherence at weeks 9 and 10 (40% and 40.4% respectively).

Around the six-month mark, the adherence level increased (from 23% in week 19 to 39.1% in week 22), and was sustained above 34.8% until week 28. This increased adherence coincided with attendance for the third study visit (6 months ± 2 weeks). A further gradual downward trend is then seen, with occasional spikes, from week 29 (29.5%) until week 36. After this, adherence plateaus between 17.1% and 27.1% until the end of the study, with the nadir at week 50 and peak at week 47, when the final study visit was being arranged.

4.6.11.2 Adherence over Time: Good Adherence

Good adherence was defined if participant engaged with an average of at least three exercise sessions per week throughout the programme. The percentage of participants who had good adherence for each week of the 12-month study period was calculated, again adjusting for participants who withdrew or were lost to follow up as per the consort diagram (Figure 4-7).

Figure 4-10. Percentage of Participants with Good Adherence Each Week, adjusting for when participants Withdrew of Were lost to Follow Up.



The overall trend for good adherence rates (Fig 4-10) was similar to that for adherence to weekly sessions (Fig 4-9). Good adherence was highest at the start of the study, peaking during weeks 2 and 3 with 49% and 55% of all participants achieving good adherence, respectively. The relatively lower adherence in week 1 compared to week 2 is again likely due to difficulties logging on to the programme. Good adherence was lowest at the end of the trial, with only 15% of all participants achieving good adherence. Overall the first 10 weeks of the trial had higher rates of good adherence (35.4%- 55.1%of participants), with a second increase between weeks 22-29 (33%-41.3 %of participants), which coincided with the six-month assessment.

4.6.12 Factors Associated with Adherence

To determine which factors were associated with higher adherence, the associations between a number of baseline demographic and disease measures and the number of sessions of exercise completed were explored. These baseline measures were chosen, based on previous literature and plausible associations, to explore if any would be associated with adherence. The results are shown in Table 4-7.

Table 4-7. Baseline variables associated with adherence in terms of Total Sessions Completed.

Category	Variable	Sessions Completed
Demographics	Age (n=49)	*r* 0.17 *p* 0.46
	BMI (n=43)	*r* -0.118 *p* 0.44
	Disease Duration (n=49)	*r* 0.50 *p* 0.733
Work	Work Impairment (WPAI) (n=48)	*r* -0.227 *p* 0.12
Disease Measures	Spinal Mobility BASMI score (n=49)	*r* -0.17 *p* 0.243
	BASFI (n=49)	*r* -0.218 *p* 0.132
	BASDAI (n=49)	*r* -0.138 *p* 0.35
Physical Activity Measures	Baseline Number of steps taken as measured by activPAL (n=44)	*r* r=0.017 *p* 0.914
	Baseline Standing time as measured by activPAL (n=44)	*r* -0.06 *p* 0.698
Quality of Life Measures	Quality of Life (measured by ASQoL) (n=49)	*r* -0.28 *p* 0.052
	Pain subset of EQ5D (n=49)	*r* -0.14 *p* 0.34
	Mobility subset of EQ5D (n=49)	*r* -0.106 *p* 0.466
	Self-care subset of EQ5D (n=49)	*r* -0.66 *p* 0.65
	Usual activities subset of EQ5D (n=49)	*r* -0.263 *p* 0.068
	Anxiety/depression Subset of EQ5D (n=49)	*r* -0.125 *p* 0.39
	Total health score – EQ5D (n=49)	*r* 0.2 *p* 0.2
Attitude to exercise	Attitude (total score from the Exercise Attitude Questionnaire) (n=49)	*r* 0.2 *p* 0.2
Fitness	Exercise Capacity (measured with six minute walk test) (n=49)	*r* 0.235 *p* 0.104

There were no significant associations (P>0.025) between baseline demographics, disease measures or any of the other measures and exercise sessions completed.

4.6.13 Adverse events and complications

While exercise is established as a key component in the management of axSpA and adherence with the web-based exercise programme was the primary outcome, the safety of this approach also needs to be considered. There were 4 serious adverse events and 15 adverse events recorded during the study (Tables 4-8 and 4-9). None of the serious adverse events were deemed to be related to the study intervention or any study procedures.

In terms of adverse events, there were three adverse skin reactions due to the waterproof dressing used to attach the ActivPAL physical activity monitor. There were five musculoskeletal reactions (three axSpA disease flare ups and two with increased localised pain in neck/knee) that were considered possibly related to the exercise intervention. These axSpA flares ups occurred early in the study on commencing the exercise programme and, as there was some concern this was related to too rapid increases in exercise intensity, the exercise programmes were amended so that exercises were introduced more gradually for subsequent participants. There were also three episodes of axSpA flare ups that were not considered related to the study intervention as these occurred in people who were not exercising (not adhering) to the exercise regime, or who had been exercising at their current exercise level with no change in their programme and occurred during concurrent infections. An increase in hip pain was recorded but this was deemed not related to the trial as the participant was known to have an old hip replacement, which needed revision. There were three further adverse reactions of pins and needles, kidney stones and drug reaction, which were assessed as being not related to the intervention.

Table 4-8. Serious Adverse Events.

Serious Adverse Events	Assessment of relationship to study
Breast cancer (n=1)	Not related to intervention
Fractured humerus (n=1)	Not related to intervention
Lung Cancer (n=1)	Not related to intervention
Hospital stay for headache (n=1)	Not related to intervention

Table 4-9. Adverse Events.

Adverse event	Assessment of relationship to study
Skin reaction to activity monitor waterproof dressing (n=3)	Related to study procedure (activPAL)
Generalised axSpA flare (n=3)	Possibly related to intervention
Infection and axSpA flare (n=3)	Not related to intervention
Increased neck pain (n=1)	Possibly related to intervention
Increased knee pain (n=1)	Possibly related to intervention
Increase hip pain (n=1)	Not related to intervention
Pins and needles (n=1)	Not related to intervention
Kidney stone (n=1)	Not related to intervention
Drug reaction* (n=1)	Not related to intervention

.* Specific drug and type of reaction not recorded

4.6.14 Telephone interview results

Twenty percent of participants (10 out of 50) were interviewed as part of the qualitative component. There was an equal gender split with five male and five female interviewees, age range of 47-79 years. Eleven participants were invited to interview, with one participant (p12) unable to commit to the telephone interview due to work commitments. This participant was the only participant with full adherence (p12, p 103). The number of sessions adhered to by this group ranged between 0 and 181 sessions, as illustrated by * in Table 4-3. To allow comparison between responses from the same participant and between different participants, each participant was given a pseudonym. Participant demographics and pseudonyms are shown in Table 4-10. Only Sophie, met the criteria for good adherence.

Table 4-10. Demographics of the Participants completing Telephone Interviews.

Participant Pseudonym	**Participant Number**	**Gender**	**Age (years)**	**Total number of sessions engaged in**
Sophie	33	Female	55	181
John	1	Male	79	151
Mary	24	Female	60	108
Laura	11	Female	50	105
Robert	2	Male	54	106
Fred	5	Male	52	52
Gary	17	Male	47	43
Fay	25	Female	79	28
Peter	44	Male	49	19
Hannah	36	Female	61	0

4.6.14.1 Themes from Qualitative Data Evaluation

From the qualitative programme evaluation, two key themes were identified from the data. The first theme was views on the web-based physiotherapy approach with three sub-themes identified; content, accessibility and usability. The second theme was adherence to the programme with four sub-themes; starting and maintaining the programme, symptoms, getting into a routine and support.

For the first theme identified: the participants' views on the web-based physiotherapy approach, a sub-theme related the specific content of the web-based physiotherapy programme emerged. This included aspects such as the behaviour change techniques incorporated into the programme. The most frequently reported aspect of the website that participants found helpful were the exercise videos. The behavioural technique of comparison of behaviours and repetition were provided in the form of exercise videos, which also included written and spoken instruction. Four participants commented that they used the exercise videos to compare their own exercise technique to the technique showed in the videos. This increased confidence levels that they were performing their exercise correctly. The exercise videos were felt to be superior to an exercise sheet or leaflet.

'(previously) a physio gave me some sheets to study and I found it difficult because I didn't know if I was doing it properly and eh, lets be honest, you don't always do it! So for me the web-based was very good because you could actually watch people doing it so you could follow and know how to do it..yeah I think for me watching somebody do something is much better than a leaflet' (P2 Robert, age 54, 106 sessions)

'What I do find is the web-based one, em, you know exactly what to do because someone is doing it in front of you and you're following it, copying them. So you know you're doing the exercise correctly' (P11 Laura, age 50, 105 sessions)

'Its good having the videos to go back to it check if you're still doing it right' (P33, Sophie, age 55, 181 sessions)

'I think it's good because well you know you've, cos of the little video' (P5 Fred, aged 52, 52 sessions)

The content sub theme within the views of the web-based programme also included individualised nature of the content (i.e. the exercise programme).

Each individual was assessed by a physiotherapist and the programme was prescribed based on assessment findings and relevant to their condition. This was reported to be of benefit, with two participants commenting on this aspect of the programme:

'The good thing is with this programme is that it's recommended by you [physiotherapist], so you're telling me what to do for my condition. So I'd hate to do something off YouTube or a DVD and discover that I'm doing it wrong or causing more damage' (P2, Robert, age 54, adhered to 106 sessions)

Another participant compared the programme to other apps and online resources:

'The unfortunate thing with that [other apps/resources] is that it's not specifically for myself' (p11, Laura, age 48 105 sessions)

It was noted that these two participants had relatively good adherence, therefore individualising the intervention may be an important aspect in adherence.

The second sub-theme of the views of the web-based physiotherapy theme was accessibility. This related to the participants' views on convenience when accessing the programme and resource. The opportunity to choose when and where to access the website was reported as an advantage of the web-based physiotherapy approach. Five participants reported a preference for exercising in the privacy of their own home as it was more convenient, avoided the embarrassment of exercising in front of others and fitted in with other daily activities.

'It's great [exercising at home] You're more likely to do it ….but as far as I'm concerned it's perfect doing it in the house. It's much more convenient and I'm much more likely to do it. …and after a while you look forward to it. … I think it's great' (P1, John, age 79 adhered to 151 sessions)

'I prefer to do it in my own home because I get a bit embarrassed being in amongst other people sometimes' (P11 Laura, age 50, 105 sessions).

'Oh I'm happy with that [exercising at home]. I wouldn't dream of exercising in a group, that's not my character' (P25, Fay, aged 79, adhered to 28 sessions)

'it's very good because you can do it in your own time which is good and so obviously do it when you want to. Personally I'd rather do it at home, I wouldn't want to do it in a group, I don't really like group activities and I think a lot of people would rather do it. Well it's up to the individual, some people like doing group activities, some people might get embarrassed but eh, for me, I'd rather do it on my own' (P2 Robert, age 54, adhered to 106 sessions)

'I think it actually makes it easier because you just do it when you've got time whereas if you've got to go to a gym or a community you need to then, there is extra effort' (P5, Fred, aged 52, adhered to 52 sessions)

In contrast, two participants reported missing the social interaction and social aspects of exercising with others.

'if I had been in a group, that might have helped but it was lonely' (P36, Hannah, aged 61, 0 sessions)

'for me there is no substitute for going to a class which was led by a physio……just being around people that have the same thing, you can relax' (p44, Peter, aged 49, 19 sessions)

Participants who preferred exercising at home appeared to complete more sessions although P28 Fay did not, illustrating there were some exceptions.

The third sub-theme within the views on the web-based programme was usability. This was the ease at which participants were able to use the web-based physiotherapy programme. Three participants commented that the programme was easy to use:

'it was simple and straight forward…. I thought it was very easy to use and user friendly. It was a nice format, easy to use, I think' (P44, Peter, aged 49, 19 sessions)

'I think it's easier to follow in some ways, you can d o it in your own time and can be – it's well laid out' (P5, Fred, aged 52, 52 sessions)'

'it's good and it's certainly made me remember a lot more. I have no criticisms at all and I think it's been so far a good thing for me' (P24, Mary, aged 60, 108 sessions)

However, it was noted that although the participants found it easy to use, this did not always translate into higher adherence.

However, one participant also found accessing the programme on their device difficult:

'My problem was that, I've got internet in the house but my tablet, I had problems with my tablet so that caused a bit of trouble… cos I'm not good with computers so I struggled initially. Sometimes it wouldn't upload and sometimes it would, eh, I couldn't get volume on it. And then later it was ok' (P2 Robert, age 54, adhered to 106 sessions)

Not being able to record some exercise sessions appeared to be a problem for two participants as the programme at that time did not allow people to retrospectively complete exercise diaries.

'So a few times, or quite a lot of times I've not put it in but I've done all the exercises… it's a bit frustrating' (P24 Mary, aged 60, 108 sessions).

Therefore, in this participant's case her adherence may be higher than that recorded.

'really frustrating because you can't go back. That's one of the things that's annoying about it because you can't go back and do it. you've done your

exercises, you want to tell someone you've done them and get brownie points for it and you've not got the connection you can't do it, so that's definitely an issue' (p33 Sophie, age 55, adhered to 181 sessions)

The second theme was adherence to the programme. This highlighted some challenges that individuals faced, even when they intended to adhere to the programme. The subthemes identified here were: starting and maintaining the programme, symptoms, getting into a routine and support.

Two participants found it difficult to start the programme;

'A lot of people maybe have the inclination to do it. I'm afraid I'm just a bit lazy when it comes to things like that… I've great intentions that never really materialise' (P44 Peter, aged 49, 19 sessions)

'it took me a couple of weeks to get into it' (P5, Fred, aged 52, 52 sessions)

Three participants noted difficulty in maintaining the programme. Their adherence reduced over time, even though they intended to adhere to the programme, with some commenting on life events getting in the way of their intention to exercise:

'well started off very good ….And we looked forward to doing it and I think it was about November that we fell away. A lot happened with my aunt being unwell and then we had a holiday and after that it just got on top of me and I didn't get it done. Right and it wasn't because I didn't want to do it' (P2 Robert, age 54, 106 sessions)

'Over the year… I think… I think I attended more at the beginning of the course and it just kind of tail off. I was ashamed to say' (P44, Peter, aged 49, 19 sessions)

'you can be really enthusiastic about something when its new and then it tails of a bit' (p33 Sophie, age 55, adhered to 181 sessions)

Symptoms was a sub-theme of adherence. When individuals noticed an improvement in symptoms, such as feeling better or if they experienced less pain, this would help them adhere to their exercise programme:

'because I find it works…. because it makes me feel better' (P25 Fay, aged 79, 28 sessions)

It is worth noting that this participant did very few sessions even though she had noted that exercise improved her symptoms.

'I don't want to be stiff. And now I'm much more supple I'm enjoying it and I don't want to take pain killers if I am sore, so obviously exercise is simple, it's like a tablet isn't it, if you take it you aren't going to be sore. And now I know that if I do get a flare up and I'm sore, maybe a bit of exercise can be the answer' (P2 Robert, age 54, 106 sessions)

'I feel better, I feel em, I feel I'm achieving something (P11 Laura, age 50. 105 sessions)'

'feeling good (helps do the programme)' (P1, John, age 79 adhered to 151 sessions)'

In comparison, one participant commented that if symptoms weren't too troublesome, then they didn't feel the need to exercise

'because my condition is really quite good now between getting the new hips and the good medication, I just don't feel a great need for it, going to the class but the big thing is that if my condition deteriorated, then I would need to, I would really need to look at a web based thing where I have to do it in the house. If my condition was bad it would have motivated me to do more but because I'm good I taken my foot off the pedal, the gas' (P44, Peter, aged 49, adhered to 19 sessions)

The perceived lack of need for exercise for his condition may explain the low number of sessions completed by this participant.

In contrast, if an individual noticed troublesome or increased symptoms when exercising, such as pain or fatigue, they reported they were less likely to stick to their exercise programme:

'if you feel the pain is worse then you don't do as much as you should' (P25 Fay, aged 79, 28 sessions)

'when I had an off day where my hip was sore or my shoulder was inflamed and I found it hard. Also my neck flared up and even though they say it helps it, it was just that I wanted to just lie down and sleep to get over it. It's the fatigue that gets you because you're tired and also when you do exercises you can actually make bits sorer and it can last for days' (P36, Hannah, aged 61, adhered to 0 sessions)

Of note with the above comments is the low number of sessions completed in those who commented their symptoms were troublesome.

Finding a routine, was identified as a sub-theme of adherence. Adherence appeared to improve if an individual was able to find a routine with their exercises:

'the main thing is to get into a routine and then you actually enjoy it. Look forward to it. In fact, you miss it if you don't do it. Routine is one of the main but also feeling good' (P1, John, age 79, 151 sessions)

'it's, see I've got into the habit of well, cos I've now got into the routine of the exercises' (P5 Fred, aged 52, adhered to 52 sessions)

In contrast, social pressures, such as Christmas or family, were identified by participants as a barrier to adhering to their exercise programme:

'There is occasional days when there's so much family stuff going on that I'm just too tired to do them all. I do some of them every day but I don't do them all every day. Phases when I was especially busy before Christmas and things

and more tired and I wasn't able to do as much and just wee phases when I've been having a flare as well' (P24 Mary, aged 60, adhered to 108 sessions)

'coming near to the holiday time it sort of dropped a wee bit and then during the holiday sort of got back' (P5 Fred, aged 52, 52 sessions)

'before Christmas I had a bad cold and there's lots of stuff going on and I kind of didn't do as much in the run up' (P33 Sophie, age 55, 181 sessions

Support was identified as being important in terms of adherence to the exercise programme. In the study, support was included the PhD student being in regular contact and checking participants' exercise diaries:

'it's good, I need people to see I'm doing it right, I need pushed to do things.. Like when you say to me you want to check it [the exercise diary], I mean that's good' (P17, Gary, age 47, 43 sessions)

'over the years I've had personal programmes and things over year, you know to follow. And I did go through stages where I would do it and be really good and then I would fall away from it again. But I wasn't as, so this time em I've been finding that I have been kinda sticking to it. Probably cos I know someone's, you know, kinda checking it as well you know' (P11 Laura, age 50, 105 sessions)

Support could also be from family.

'.. I think summer time I did a wee bit more as well plus I was going to ____ [holiday] so I thought I better get out and do something ...looking in the mirror sometimes and getting encouraged to do it. My partners on my case so I better do it (laughs)' (P17, Gary, age 47, 43 sessions)

'I could look at my diary and discover like ok I'll do that day and that day but my wife is very good and she forces me into doing it … so we both done it together so she was good at saying you've got to do it but eh yeah. You can't fall by the way side, its good someone else doing it with you because they give you encouragement' (P2 Robert, age 54, 106 sessions).

4.7 Discussion

This PhD study aimed to explore adherence in the Versus Arthritis WEBPASS cohort study. The PhD study measured adherence levels and factors affecting adherence to a 12-month web-based physiotherapy programme. The programme consisted of an individualised exercise programme three days per week and patient choice of exercise two days per week. To explore adherence to the WEBPASS programme a number of different methods were investigated. Firstly, the number of sessions participants engaged with (doing at least one exercise within the session) was measured. Secondly, how many participants had good adherence (pre-defined as engaging in a mean of at least three sessions a week over the year) was calculated. Thirdly, a comparison between adherence levels of the patient choice and the prescribed component of the programme was examined. Fourth, to measure if all individual exercises completed within the prescribed sessions were completed. To consider adherence over the course of the intervention, the number of participants who had good adherence each week of the intervention and the number of engaged sessions were calculated. The baseline factors affecting adherence were also investigated. Finally, qualitative data from the WEBPASS interviews specifically relating to adherence were interpreted.

4.7.1 Adherence to Sessions Engaged with

Firstly, the PhD study measured the number of sessions that participants engaged with. The results of this study found that overall participants in the study adhered to 27.6% of all available sessions. This is notebaly lower than the 51%-95% rates of adherence reported in the systematic review (Chapter 3) (McDonald., 2019). The types of exercise interventions, characteristics of the participants and differing measures of adherence potentially account for the differences in adherence rates between the WEBPASS cohort study and the studies included within the systematic review.

Within Chapter 3 the duration of interventions ranged from 6 weeks (Hidding et al. 1993a) to 12 months (Fernandez-de-Las-Penas et al. 2006). Only one included

study within the systematic review reported an intervention of longer than 9 months with 95% adherence to a once weekly exercise session at 12 months. This adherence rate is open to reporting bias as participants were only asked about adherence once, at the end of the study. Therefore, poor recall may have affected this result (Fernandez-de-Las-Penas et al. 2006). McPhate et al (2013) suggest that the longer the duration of any given intervention, the lower the level of adherence. Five of the studies included in the systematic review had interventions that lasted for 12 weeks or less with two of the studies reporting adherence rates of 76.6% and 75% (Gross & Brandt 1981, Barlow & Barefoot 1996, Niedermann et al., 2013, Chimenti et al 2014, Svaass et al., 2020). In the first 12 weeks of the WEBPASS cohort study, the percentage adherence of sessions engaged in was notably higher than the last 12 weeks of the study (33% - 49% first 12 weeks versus 17 -27% last 12 weeks). However, the longer duration of the WEBPASS intervention may only partly explain the lower adherence rate, the frequency of session may have also played a role. Other possible factors include participants in the WEBPASS study had high disease duration (mean 16.9 years), high disease activity, low baseline exercise levels and the method of measuring adherence.

Within WEBPASS, participants were required to do exercise sessions five times per week, while the number of weekly exercise sessions in the studies reported in Chapter 3 ranged from once to daily. The highest rate of adherence reported in the systematic review (Chapter 3) was 95% for a once weekly intervention over 12 months. However, as mentioned this rate may be biased due to the measurement of adherence of asking participants once at the end of the 12-month intervention (Fernandez-de-Las-Penas et al., 2006). Three linked studies, using the same participants in the systematic review reported adherence to a daily HEP, with some participants receiving an additional supervised component and reported 86% (12 weeks), 51% (nine months) and 63% (nine months) of minutes of the prescribed HEP completed, higher than the overall 27.6% reported to a less frequently prescribed HEP than in WEBPASS (Hidding et al., 1993, Hidding et al., 1993, Hidding et al., 1994). Differences in how adherence was defined and measured may have contributed to the different adherence results, while it also possible that people who agree to participate in a series of linked studies may be more motivated than those who sign up for a single study.

This possibility is supported by the unusual lack of any drop-outs over the 20 months of these three studies. Furthermore, within the Hidding et al studies, the participants were relatively newly diagnosed (less than 8 years see Fig 3-4, chapter 3) compared to the cohort within WEBPASS who had a mean diagnosis of 16.2 years. Therefore, the WEBPASS cohort may represent an older population who have become less motivated to exercise having had the condition for several more years. It is also possible that the addition of supervision of the exercise sessions for some of the participants in the Hidding et al studies also contributed to higher adherence.

Troublesome symptoms such as pain and fatigue may reduce adherence (Jack et al., 2010), this is fully discussed in the factors affecting adherence section (4.7.7). Of note 58% of participants within WEBPASS were classed as having high disease activity, which potentially reduced adherence. Furthermore, the low baseline exercise activity of the participants in the present study is likely to be an important factor, discussed below.

In order to demonstrate change in activity levels, the WEBPASS study was designed to recruit axSpA patients who were not currently exercising. The WEBPASS cohort study inclusion criteria required that people should not be exercising more than three times per week, whereas no such inclusion criteria on baseline exercise were noted for studies within the systematic review. Research has shown that people who are physically active are more likely to adhere to HEPs (Schoo et al., 2005, Jack et al., 2010). However, the majority (n=28) of participants who were recruited to the WEBPASS cohort study were not exercising at all. Therefore, this may account for the lower overall adherence figures in WEBPASS in comparison with the studies within Chapter 3.

It is standard practice for all patients with axSpA in the local health board, NHS GGH to be regularly informed of the need to exercise as part of their standard care. It is therefore likely that participants would have been informed of the importance of exercise before joining the study, although if they had retained this knowledge was not formally assessed as part of this study. Despite the probability of having the knowledge of the importance of exercise the majority of participants within WEBPASS were not exercising. Changing behaviours in the

form of initiating and then maintaining exercise participation is challenging (Meade et al., 2019). Individuals can know the benefits of exercise but have no intention of starting or continuing with an exercise programme, described in the literature as the knowledge-behaviour gap (Connell et al., 2016). It could be argued that our participants had the intention of exercising, as they volunteered for the study, although it is also possible they felt they should participate or felt encouraged to do so by the physiotherapist; without the intention, commitment or ability to actually do this. When intentions do not translate into desired action, this is commonly referred to in behaviour change literature as the intention-behaviour gap (Kersten et al., 2015). Evidence suggests that, within the general population, intentions are only translated into action between 20-50% of the time (Kersten et al., 2015, Bassett, 2015). The overall adherence rate of 27.6% of exercise sessions completed concurs with intentions translating into action 20-50% of the time and therefore is consistent with what is expected in changing behaviour (Kersten et al., 2015).

The measurement of adherence most probably played a role in the lower adherence rate found in WEBPASS in comparison to the previously published literature. In WEBPASS an electronic diary was utilised which only allowed participants to complete their exercise diaries measuring adherence on the day of exercise. This may have resulted in an underestimate of the adherence for participants who carried out their programme but did not fill in the diary due to either internet connection issues or forgetfulness and is discussed in section 4.7.8.

4.7.2 Good Adherence

The PhD study aimed to find out the number of participants with good adherence. Seven of the 49 participants in the WEBPASS trial did not initiate the exercise intervention, completing no sessions at all. For those who provided adherence data for the 12-months (n=38), only 18% (7/38) achieved good adherence according to our pre-defined cut-off. This indicates difficulties for some people in initiating an exercise programme, whilst for others maintaining the WEBPASS exercise programme was the issue. Overall adherence to sessions was higher in those who initiated the exercise programme. These issues were

also identified in the telephone interviews where two participants with low adherence (19 and 52 sessions) commented that they found it difficult to initate the programme, and three participants, again with low adherence (19, 55,106 sessions) found that their adherence tailed off throughout the year.

Although pre-defining good adherence illustrated the small number of participants who achieved 'good' adherence over the study and highlighted the difficulties in maintaining the programme it should be recognised that there is no standard measure of what constitutes good adherence (Vitolins et al. 2000). Although research in OA shows a link between the clinical outcomes achieved and adherence (Pisters et al 2010), no such link exits for people with SpA. Future research could link adherence to outcomes in SpA and a cut-off point of what constitutes good adherence could be linked to this. It may be that any adherence improves outcomes and therefore labelling good adherence may not be helpful.

4.7.3 Adherence to Prescribed and Patient Choice

The PhD study aimed to compare the prescribed component of the exercise (three times per week) with the patient choice component (two times per week). Participants adhered significantly more to the prescribed exercise component than the patient choice component. The patient choice component was included to give participants flexibility in their programme; for example, to allow them to attend a NASS exercise class or go for a recreational swim. The participants ticked the box named 'other' on the website. It is possible that participants forgot to enter their other exercise as these were not being completed at the same time as the online diary was completed, whilst for the prescribed contact they may have accessed their prescribed exercises and diary, resulting in under-reporting of patient-choice exercise element of their overall programme. Furthermore, for those participants who did tick the other box, most did not provide details about the activity that was undertaken. Therefore, this data could not be analysed further, beyond a binary completed or not. The characteristics of the intervention and participants may have played a role in the higher adherence for prescribed component and are explored below.

Behaviour change techniques are observable and replicable components of interventions and can be used alone or in combination with other behaviour change techniques (Michie et al., 2011). Published literature suggests that interventions that incorporate greater number of behaviour change techniques have a larger effect in changing behaviour than interventions that incorporate fewer techniques (Webb et al. 2010). WEBPASS incorporated the following behaviour change techniques reported to be important in facilitating adherence: goals and planning, feedback and monitoring, shaping knowledge, natural consequences, comparison of behaviours, repetition, substitution and antecedents (Michie et al., 2011). While these behavioural change techniques may potentially have influenced adherence to the prescribed component in WEBPASS, the impact of this could not be ascertained as there was no control arm without these techniques. However, in the interviews, several individuals commented positively on the benefit of the exercise videos on the website. The behavioural techniques of comparison of behaviours and repetition were provided in the form of exercise videos, which also included written and spoken instructions.

Individualising exercise interventions has the potential to improve adherence and could account for higher adherence in the prescribed exercise component. Participants may have believed that the prescribed exercises provided by the physiotherapist would be more efficacious or less likely to cause harm than their own choice of exercises. Quotes from two participants who were interviewed concurred that the fact that the programme was individualised to their own particular needs and that it was prescribed by a trained physiotherapist were important to them and helped empower them to participate in the programme. This is consistent with a qualitative study investigating adherence to physiotherapy prescribed exercise in people with persistent musculoskeletal pain, which reported that exercise adherence increased where there was a collaboratively developed, tailored and individualised exercise prescription (Escolar-Reina et al., 2010). A systematic review investigating adherence to falls programmes also found higher levels of adherence in physiotherapy-led programmes compared to exercise instructors (Simek et al., 2012), suggesting that confidence in the instructors' expertise is important for patients who are asked to exercise.

Self-efficacy may be important when considering adherence and may account for the higher adherence within the prescribed component in comparison to the patient choice component. Self-efficacy is the belief in one's own ability to perform a task within a given context (Bandura 1997, Bassett, 2015). Self-efficacy is situation specific, with people feeling efficacious about doing some activities, but not others, and being able to do some tasks in some situations but not others (Bassett, 2015). Self-efficacy was not measured in WEBPASS, therefore the self-efficacy of the participants is unknown, but it is possible the cohort may have had higher levels of self-efficacy, in terms of performing the prescribed exercises, where they had clear direction, fixed instructions, demonstrations, support and guidance but had lower self-efficacy about choosing their own exercises.

Therefore, physiotherapist led, individualised exercise programmes incorporating behavioural change techniques may support adherence. However, developing participants' skills and self-efficacy to participate in their own choice of exercise programme is also important and may help with long-term maintenance of healthy physical activity and exercise lifestyles. Physiotherapists should consider strategies such as educational programmes or self-management programmes to achieve this and future research should investigate ways to encourage people with axSpA to choose and participate in their personal choice of activities.

4.7.4 Adherence within Each Prescribed Session

Whilst it is important to consider the number of sessions engaged in, it is also important to investigate if the exercises within each session were completed. In the WEBPASS study, participants were prescribed individualised exercise programmes containing different exercises to complete three times per week for the 12-month intervention. All sessions which were started were analysed (n=2515) and results demonstrated that when these exercise sessions were started the participants were likely to complete the session (74% fully completed sessions versus 26% of sessions incomplete). One similarly study within the sytematic review (chapter 3) measured individual exercises in patients with PsA

and found that over 12 weeks all exercises in the sessions were completed (Chimenti et al, 2014). Similarly, Chan and Can (2010) measured adherence to individual exercises within a physiotherapy session (no information given on conditions) and measured short term adherence (over the past week) using a questionnaire, with 74.4% of patients doing the prescribed number of exercises and all the repetitions (Chan & Can, 2010). This is the first study to investigate adherence to exercises within sessions over a longer time period (12months). Although there is limited data on within session adherence to exercise, studies concur that there are high levels of adherence to individual exercises within sessions. Taken together, this study and shorter-term studies indicate that physiotherapists should concentrate particularly on strategies to encourage service users to initiate exercise sessions in the knowledge that they will likely complete all the exercises within the designated session. This also applies to maintenance of adherence over the longer term, where getting people to initiate the exercise session appear to be key to developing routine and increasing long-term adherence rates.

4.7.5 Adherence over Time

As adherence fluctuates, the PhD study also considered adherence over the course of the 12-month invervention. Overall, the findings from the WEBPASS cohort study show that adherence to sessions declined over the 12-months. The weeks with the highest percentage completion were early in the study, with adherence to sessions increasing around the predetermined study visits (6 and 12 months ± 2 weeks), suggesting that the contact to arrange these visits acted as a prompt or incentive to do the exercises.

As far back as the 1980s, researchers reported difficulties for participants in maintaining adherence to exercise programmes. Ice (1985) reported dropout rates of between 30-50% of a cohort of cardiac rehabilitation patients within 12 months of initiation. More recently, Simek et al (2012) reported that approximately 48% of older adults ceased exercising altogether within six months of initiating an exercise programme to prevent falls. Similarly, Pisters et.al. (2010), reported 75% adherence at 13 weeks and 59% adherence at 65 weeks following individually tailored exercise prescription and behavioural-graded

activity programmes for people with osteoarthritis. Reducing adherence over time has also been demonstrated in studies exploring the efficacy of exercise programmes delivered using the internet in people with long-term conditions (Akinci et al., 2018, Paul et al., 2019, Tallner et al 2016, Motl et al 2011, Conroy et al 2018). Akinci et al., (2018) examined the impact of a web-based exercise intervention over 8 weeks in people with type two diabetes and reported that 52% of participants were non-adherent, defined as failing to complete three sessions for three consecutive weeks. Paul et al., (2019) examined the impact of a web-based exercise intervention prescribed twice weekly for six months in people with multiple sclerosis and reported that 63% of participants completed 75% or more of their programme during the first four weeks which reduced to 40% during the last four weeks. Similarly, Tallner et al 2016, investigated adherence to an online exercise programme in people with MS delivered over six months, three times per week. They reported that 73% of participants completed 80% or more of their programme during months 1-3 which reduced to 36% during months 4-6. Motl et al (2011) investigated a 12 week varied frequency online programme in people with multiple sclerosis and reported 96% of participants logged on to the website in weeks 1-2 which reduced to 52% at week 8, while Conroy et al (2018) investigated a six month telerehabilitation exercise intervention in people with multiple sclerosis and reported only half of participants adhered to their programme and almost one quarter completed no exercise diaries at all.

Of note, three studies reported in the systematic review for SpA ran consecutively using the same participants, allowing assessment over time, the first was a 12-week intervention, followed by a nine-month intervention, followed by a further nine-month intervention (Hidding et al. 1993a, Hidding et al. 1993b, Hidding et al. 1994, McDonald et al., 2019). These linked studies show that adherence to a daily HEP reduced from 86% to 51% and in the supervised sessions from 74% to 62%. Similar to the results in the WEBPASS cohort study, the adherence rates in these studies reduce over time.

Good adherence to exercise (at least three times per week) over time was also considered. The pattern of participants with good adherence over the 12-month study period was similar to that for sessions engaged with, the number of

participants with good adherence was highest early in the study and declining over the course of the study, with peaks around the study visits.

Physiotherapists should be aware of reduced adherence over the course of an intervention and should consider strategies and time points to support people with axSpA. Future study could identify the optimum or helpful strategies such as phone calls, text, and the cost effectiveness of these measures.

4.7.6 Online Programmes & Adherence

Although adherence in the WEBPASS cohort study was lower than other axSpA studies in the systematic review Chapter 3, no other study reported adherence to an online physiotherapy programme over 12-months. Web-based programmes have many theoretical advantages, including accessibility, flexibility and asynchronous use, which may be useful for people in employment or with other commitments. Interestingly 8% of people who were approached about the WEBPASS study did not have access to the internet therefore this approach is not suitable for all. The same web-based physiotherapy platform has been examined for individuals with multiple sclerosis and show promising results with adherence rates (average 1.3 logs in per week of a possible 2) (Paul et al., 2014). A study involving participants with a range of musculoskeletal conditions, showed adherence was better with online HEP compared to a paper handout, but this intervention was limited due to the short duration of four weeks and therefore to be interpreted with caution (Lambert et al., 2017). There is other emerging evidence that digital interventions, such as the use of apps, can support adherence to exercise programmes although this is in its infancy (Argent et al., 2018). Web-based programmes can be more cost effective than standard treatment which is an increasingly important consideration for all healthcare interventions (Paul et al., 2019). Web-based programmes are of increasing importance in response to the 2020 coronavirus pandemic where, many people with long term chronic conditions were unable to assess face to face physiotherapy services.

People with axSpA gain most benefit from exercise programmes of high frequency and over longer term (Millner et al., 2016). Web-based programmes

should theoretically aid people to exercise in the long term. However, from the results within this study it is important to note that some individuals do not initiate their programme. For others, adherence reduces over the course of the intervention. Therefore, careful consideration of strategies to support both initiation and maintenance of adherence should be considered. A blended approach with face to face physiotherapy and online physiotherapy may be appropriate, especially for people with axSpA who are not exercising regularly and may help overcome some obstacles of 'getting going' and 'keeping going'. Further research should compare adherence rates between web-based programmes, HEP and a blended approach, to investigate if the delivery of the intervention affects adherence. Personal preference is a key factor and it is likely that no single approach will be appropriate for all people. Availability of a selection of options may be the most effective strategy.

4.7.7 Factors Affecting Adherence

This PhD study also aimed to investigate the factors which affected adherence to a web-based 12-month exercise programme in people with axSpA. Associations between age, weight, disease duration, steps/day, standing time, quality of life, pain, health related quality of life, attitude to exercise, spinal mobility, function, disease activity, fitness and work impairment and completed WEBPASS exercise sessions were explored. There were no statistically significant associations found; this may be due to the small sample size or because these were not associated with adherence in this cohort.

The qualitative data from the semi structured interviews provided insight into the factor's participants perceived as influencing adherence. Four sub themes of adherence were explored; initiating and maintaining the exercise programme, symptoms, getting into a routine and support. The themes of initiating and maintaining the exercise programme are considered in good adherence (section 4.7.2). As expected in patients being asked to exercise for their underlying condition, the symptoms a person experiences as a result of an intervention have the potential to positively and negatively influence adherence to that intervention. Participants reported that when exercise positively impacted on their axSpA symptoms this increased their adherence to the exercise

programme. This is consistent with the health belief model, where the expected benefits of a health behaviour are key factors in influencing participation in that health behaviour (Stretcher and Rosenstock 1997). Drawing from this theory, if participants in the current study believed that the exercise programme was an effective means of reducing symptoms, for example pain or joint stiffness, then they would be more likely to adhere. Increasing adherence to exercise associated with symptom reduction was also reported in a qualitative study investigating adherence to physiotherapy exercises in people with OA (Campbell, 2001). However, it is possible for those people whos baseline symptoms were not troublesome, then there would be less to be gained from the intervention and this could potentially negatively affect adherence. One participant in WEBPASS commented that he did not feel the need to adhere to his exercise programme as his symptoms were not sufficient to affect his quality of life.

In contrast, new or worsening symptoms, such as pain or fatigue, experienced as a result of exercising have the potential to reduce adherence. Three individuals reported their pain and fatigue increased when doing their exercise programme and as a result, they adhered less to the programme. This is consistent with a systematic review investigating adherence to exercise in people with musculoskeletal complaints which found evidence that higher pain levels experienced during exercise was a barrier to adherence (Jack et al., 2010). Lower adherence with high symptoms, has implications for people with SpA, many of whom have active disease, frequent flares and fatigue as part of their condition which if troublesome when exercising may reduce their adherence. Therefore, for this cohort of participants, a more gradual increase in exercise dose (intensity, time) to help minimise their symptoms as they start an exercise intervention is required. Further support and contingency plans for how to adapt their exercises in the event of worsening symptoms would also be beneficial. A small number of participants in WEBPASS experience an increase in symptoms in the early stages of the exercise programme which were recorded as AE. Future study could further develop the knowledge of how symptoms affect adherence to exercise programmes.

Getting into a routine was identified from the WEBPASS interviews as improving adherence. This was also identified by Campell et al (2001) when investigating

adherence to a prescribed, individualised physiotherapy exercise programme of three-month duration in participants with OA. As mentioned previously, web-based physiotherapy programmes offer flexibility and reduce the need for travel. However, the web-based platform did not include regular scheduled times for exercises and it was left to the individual decide when to do them. Strategies to address this could include the physiotherapists encouraging them to incorporate their exercises into their everyday routine, for example at work or at set times throughout the day. It could be that web-based programme of physiotherapy-tailored exercises together with regular scheduled prompts to schedule exercise sessions would provide the optimal balance of flexibility and routine. This is particularly important for people with axSpA who are encouraged and required to exercise throughout the course of their lives.

Social support was also identified in the interviews as important in improving adherence. Support can be from friends and family members as well as from HCPs. Several qualitative comments pointed to the social support network of the participant having a positive effect on adherence. Studies investigating adherence to sport injury rehabilitation programmes found that social support and emotional support from friends and family can improve adherence in both the clinic and home setting (Levy et al., 2008). Furthermore, two systematic reviews report evidence that social support can predict adherence to exercise in people with RA and other musculoskeletal conditions (Jack et al., 2010, Essery et al., 2017).

Support can also be in the form of group exercise. Qualitative data from two participants, neither of whom adhered to the programme, refers to preferring to exercise in groups. In a previous systematic review in people with dementia or cognitive impairment, a group format was identified as supporting adherence by most of the participants (van der Wardt et al., 2017). Whilst this may not be directly applicable to people with axSpa within the systematic review (Chapter 3) one study found that adherence was higher in supervised groups exercise in axSpA (Hidding et al., 1994). Although it is not clear whether this increased adherence could be attributable to the supervision or the social support within the group, a Cochrane review of physiotherapy interventions for people with ankylosing spondylitis has shown that supervised group programmes improve

spinal mobility and overall wellbeing more than individualised home exercise programmes (Dalfinrud et al., 2008). As people with axSpA are required to exercise regularly and frequently in the longer term, support in terms of HCP supervision and/or group exercise is not always feasible. Therefore, physiotherapists should encourage service users to build their own support networks into their exercise regimes to support adherence. The NASS exercise groups link (www.nass.co.uk) are popular with people with axSpA and offer peer to peer support and contact while exercising in groups, physiotherapists could encourage people with axSpA to attend these groups (NASS, 2020). Future research should aim to incorporate more social contact, group and supervision within web-based physiotherapy interventions and consider a blended approach.

Within WEBPASS adherence rates increased around the time of study visit appointments suggesting that support or contact with a HCP is important to help facilitate adherence. Similarly, regular consultation with a physiotherapist, compared to use of a brochure, has previously been found to be associated with increased adherence to a HEP in adults (Simek et al., 2012). However, it is possible that increased adherence around these study visits represents that the service user feels indebted to adhere around these times and motivation was stimulated through pleasing the physiotherapist (Frey, 1994). Adherence rates increased less at the end of the study than the six-month study visit (Fig 4-9 & 4-10) suggesting that this increased adherence at the time of study visits, also reduces over time.

4.7.8 Measurement of Adherence

Comparing adherence rates between studies is hampered by differences in the measurement of adherence. There is no standardised manner in which adherence is measured (Newman-Beinart et al., 2017). Most commonly adherence to a HEP is measured with a diary, albeit with no standardised diary or timeframes for filling in the diary (Frost et al., 2016). Adherence to HEPs in SpA was usually measured using self-reported paper home diaries (McDonald et al 2019). Over-estimating adherence is a common problem with self-report diaries as participants do not accurately recall or report their behaviour. They may record what they perceive the HCP desires rather than a true appraisal of

their behaviour, or may report multiple entries at a given time (Bollen et al., 2014, Newman-Beinart et al., 2017). In WEBPASS we utilised an electronic diary which only allowed participants to complete their exercise diaries measuring adherence on the day of exercise. This mitigated for poor recall and multiple retrospective entries but did not mitigate against participants giving the desired response rather than an accurate one. It may have however underestimated adherence for participants who carried out their programme but did not fill in the diary due to eg. internet connection issues or forgetfulness. This was confirmed in the participant interviews where two participants stated this was the case and therefore may have accounted for the lower adherence rate in WEBPASS. Since this study was undertaken, the online physiotherapy platform has been upgraded to allow people to retrospectively complete their exercise diaries. A robust, standardised measure of adherence that is used across studies would greatly improve the ability to compare between studies and interventions.

4.7.9 Limitations

There are several limitations of this study. As this was a cohort study with no control arm, the adherence rate could not be compared with usual care HEP, such as a leaflet or a brochure. Comparing adherence rates within an RCT would allow for a more meaningful comparison of adherence between interventions of similar content, frequency and length using different modes of delivery. Furthermore, the small sample size and lack of power meant it was not possible to ascertain the baseline factors which influence adherence. Two different assessors were involved in taking the outcome measures at baseline, 6-months and 12-months, although both assessors followed standardised procedures this could affect the reliability of the measurements.

The activities that participants did as part of their ‘other’ patient-choice exercises were not captured and therefore could not be analysed. As indicated, the requirement for same day reporting in the electronic diary used in WEBPASS may have under-reported adherence. Further work is required to establish a standardised and clinically relevant measure of adherence for HEP.

The low level of baseline exercise level of the participants within WEBPASS limits the generalisability of this study to those not currently exercising or doing very little exercise.

Lastly, the research physiotherapist (PhD student), who was well known to participants, carried out the telephone interviews. Therefore, participants might have felt that they should comment positively. However, all participants were informed that negative comments would help to improve future work. They were also assured that the outcomes of the interviews would not affect the progress of the PhD student or their care. Member checking, or respondent validation, is a technique used to enhance trustworthiness of qualitative findings in which qualitative results are sent back to participants to check for accuracy (Burnard et al., 2008). In this study, findings were not sent back to participants due to time constrains for both participants and the CI. However, to enhance trustworthiness the analysis was verified and discussed with a supervisor (LP). Both PhD student and supervisor also commented on the final emerged themes.

4.7.10 Adverse events

The most common intervention-related adverse event within this trial was patient reported flares, which are a common feature of axSpA. A study investigating the prevelance of flares in 170 people with axSpA reports that on any given week around 30% of people with axSpA will self-report a flare (Jacquemin et al., 2017). In WEBPASS there were five musculoskeletal reactions (three axSpA disease flare ups and 2 increased localised pain) that were considered possibly related to the exercise intervention as they occurred on commencing the exercise programme. There was some initial concern this was related to rapid increases in exercise intensity. Therefore, the exercises were increased more gradually for subsequent participants with no further flare ups reported. There were also three episodes of axSpA flare ups that were not considered related to the study intervention as there were no coinciding factors, i.e. these participants had either not been adhering to their programme or had been exercising with no change in the level of exercise but had concurrent infections which were the likely triggers for these episodes. The three remaining adverse reactions were not related to the intervention. Therefore, web-based

exercise for people with axSpA appears to be a safe intervention, provided this is started gradually in people with low baseline exercise levels.

4.7.11 Generalisability of Findings in Relation to Sample

The majority of participants within this study (n =48, 96%) had AS, while only (n=2, 4%) had nr-axSpA, therefore the evidence from this study is mostly generalisable to those with AS. Furthermore, the participants within this study had been diagnosed for a mean of 16.2 years (±11.9 years), so it cannot be assumed that people who are newly diagnosed would show similar patterns of adherence. The inclusion criteria for this study stated that the participants should not be exercising more than three times per week, therefore the findings of this study may only be generalisable to those people with axSpA with similar exercise behaviours. As discussed this low level of exercise levels may partially account for the lower adherence rate found in the WEBPASS cohort study in comparision to studies within the systematic review (Chapter 3). Participants were recruited from NHS GGC, which sees patients mostly from urban locations; furthermore, Glasgow in known to have high poverty rates, higher rates of excess mortality and chronic illness than other similar urban areas (Walsh et al., 2017). People in lower socio-economic groups are less likely to meet the current PA target than the rest of the population and therefore this could have impacted on the adherence rates found in the WEBPASS cohort study (Schmidt et al., 2008).

4.7.12 Implications for clinicians

This trial adds to the body of evidence of non pharmalogical management in the management of axSpA by (Regel et al 2017) contributing new long-term data about adherence to an online exercise intervention in people with axSpA. Furthermore, due to the inclusion/exclusion criteria this trial has provided an insight into adherence of patients with low baseline exercise levels despite longstanding disease. However due to the relatively small sample size the generalisability of the study results to the wider clinical axSpA population warrants further investigation.

The study also identified issues with getting people to initiate exercise sessions, with encouraging data that when initiated, most sessions are completed. Thus indicating initiation of exercise programmes should be a key focus for HCPs. The study also indicated that exercise programmes can be individualised and supported using this model of physiotherapy-assessment and online delivery. The use of embedded exercise videos and other strategies reported within the study were deemed beneficial by participants. Physiotherapists should employ strategies to get people with axSpA initated on their exercise programme, as although some participants will struggle to maintain the programme, others will demonstrate good adherence.

A number of key lessons were identified for future strategies and interventions for improving adherence such as scheduling exercise as part of daily routine and engaging the support of family, friends and HCPs.

Clinicians should be aware that no single programme will work for all people with axSpA, with multiple inter-related factors that may influence adherence. HCPs should explore individual key barriers and facilitators with their patients.

4.7.13 Recommendations for future research

While the optimal study design for comparing interventions are large scale RCTs, these are often not feasible for complex interventions such as exercise particularly when this is already part of routine clinical care in axSpA. Other strategies and indirect comparisons are therefore likely to be required.

In order to progress to improve the understanding of adherence this field urgently requires agreed and robust measures of adherence, which would allow comparison between different interventions.

There are several models of exercise interventions worthy of study in axSpA, including comparing adherence rates between online programmes, standard HEPs, traditional physiotherapy-led supervised interventions and blended approaches. In addition to effectiveness and adherence, these studies should also include evaluation of cost-effectiveness and patient preferences.

Such studies should investigate the key factors which may affect long term adherence to different types of exercise interventions in axSpA. This would enable physiotherapists to identify those who may benefit from specific interventions and better tailor interventions for those who need greater support.

Further research should investigate how different components of interventions, such as how specific behaviour change techniques are operationalised and impact on adherence to prescribed exercise programmes and when is the best time point to offer these.

4.7.14 Conclusion

The aim of this cohort study was to measure adherence, and factors affecting adherence, to 12-month web-based exercise intervention.

Adherence to exercise sessions engaged with in the WEBPASS cohort study was 27.6% of all sessions. Due to differences in participant characteristics, length and frequency of intervention and differing measures of adherence it is difficult to directly compare this level of adherence to other interventions in people with axSpA. More research is required to compare adherence rates between different modes of delivery of exercise interventions.

Online programmes, have many advantages such as lower costs, more flexibility and availability, as well as being able to capture adherence on the same system. Individualised online exercise programmes are a viable option for some people with axSpA, particularly due to the long term and frequent exercise required in this condition, so are an option that physiotherapists should consider as part of their management of axSpA. However, it is clear that, like all interventions, this is not effective for all and strategies to identify those most likely to benefit from these methods are required, as are strategies to improve adherence with this programme.

When participants started a session, more often than not they completed all the individual exercises within the session. Physiotherapists should therefore

concentrate on strategies to encourage participants to start sessions. Similarly, higher adherence was found in those who initated the programme, so getting started with exercise programmes and each session appears to be a cruicial to facilitate adherence.

Adherence reduced over the course of the intervention. Physiotherapists should consider when adherence reduces and instigate strategies to improve adherence.

The factors which influence adherence remain unclear, but symptoms, getting into a routine and support may play a role in influencing adherence. Physiotherapists should encourage service users to build support networks, and incorporate exercises into their daily routine.

5 Chapter: Physiotherapists' Perceptions of Adherence to Exercise in People with Spondyloarthritis

This chapter presents the third study within this thesis, a national survey of UK physiotherapists' perceptions of patient adherence to exercise in people with SpA.

5.1 Justification

As previously discussed, exercise is essential in the management of SpA .This is paramount within axSpA patients to maintain or improve mobility, strength, CV health, function, quality of life and to limit spinal deformity (Reimold and Chandran, 2014). Evidence supports that exercise improves clinical outcomes in people with AS, therefore they should exercise frequently at every stage of their condition (Regel et al., 2017) .

Earlier within this thesis, the level of and factors that may affect adherence to exercise programme in people with SpA were investigated. The systematic review (Chapter 3) demonstrated adherence rates of 51% -95% across a range of physiotherapy prescribed interventions for people with SpA. It also highlighted single studies, with limitations, that identified severity of disease and delay in diagnosis increased adherence and reported that age, gender, body mass index, blood pressure or heart rate did not influence adherence. Interventions which had a supervised component and which incorporated education programmes may increase adherence in people with SpA. However, there was no consensus between these studies which limited the conclusions that could be drawn from current evidence. Furthermore, it is probable that there are other factors that could affect adherence that have not been investigated.

The cohort study of web-based physiotherapy (WEBPASS) (which combined unsupervised web-based physiotherapy three times per week and patient choice exercise twice per week) for people with axSpA (Chapter 4) found adherence levels of 27.6% of all sessions over 12 months. It investigated a wider range of potentially related factors. However due to the small sample size, it was not possible to quantitatively identify any patient or disease-related factors associated with adherence to exercise in SpA. Participants of WEBPASS with

axSpA adhered significantly more to the prescribed exercise component. This was individualised and contained behavioural change techniques and adherence was greater than the patient choice component. The qualitative evaluation in the WEBPASS cohort study identified that current symptoms, getting into a routine and support all affected adherence.

Whilst the WEBPASS study (Chapter 4) and the systematic review (Chapter 3) added a number of potential factors affecting adherence, when this evidence is considered together there remains uncertainty about the factors which affect adherence in SpA and with a number of factors and domains, such as health care, not investigated (A summary of the key results related to the WHO model is shown in Figure 5-1).

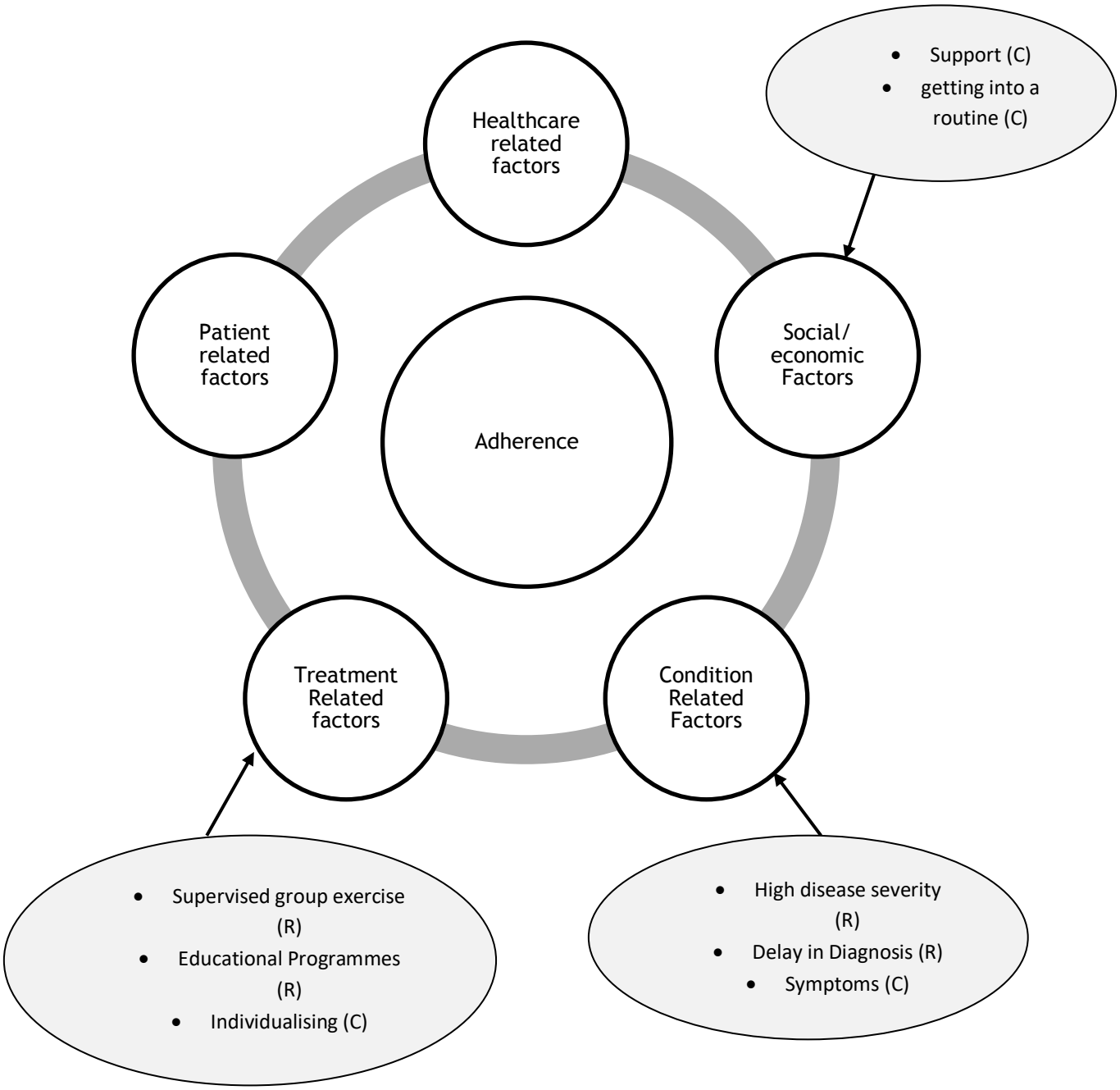


Figure 5-1. WHO model of adherence (Sabete et al., 2003) with possible factors from the systematic literature review and WEBPASS Cohort Study added in ovals. Factor labelled with R if found from review and C if found from the cohort study.

The beliefs held by physiotherapists may influence their approach to considering adherence. Older research suggests that physiotherapists do not always consider how adherence to their prescribed exercise programmes affects the achievement of clinical outcomes (Turk and Rudy 1991). If there are no improvements in clinical outcome from the exercise prescription, physiotherapists may think the exercises prescribed are at fault and modify the programme (Turk and Rudy, 1991). A more recent survey of physiotherapists'

perceptions of patient adherence to prescribed self-management strategies in MSK conditions (not including SpA), suggests that physiotherapists now consider the impact of adherence to the exercise programmes on the achievement of clinical outcomes (Peek et al., 2017). As stated previously, physiotherapists are at the forefront of exercise management for people with SpA. Therefore, it is imperative to have a clear understanding of their beliefs and perceptions regarding adherence to exercise in SpA.

It is also important to consider the views of physiotherapists specialising in exercise prescription for people with SpA as they may themselves be aware of factors influencing adherence. To date no study has ascertained what patient-related, condition specific, socio-economic, treatment and healthcare factors physiotherapists perceive as affecting adherence to prescribed exercise programmes for people with SpA. Understanding the factors which physiotherapists consider as impacting on adherence and discuss with their patients or use to tailor their support would be valuable.

Furthermore, understanding the unique challenges and issues facing physiotherapists in adopting interventions and strategies to improve adherence to prescribed exercise is an essential key step to facilitate improved exercise adherence in people with SpA. To date no study has looked at what barriers are faced by physiotherapist when adopting methods to improve adherence.

5.2 Aims and Research Questions

Therefore, to address the gaps in the current literature relating to the view of physiotherapist an online survey was performed to explore the beliefs and perceptions of physiotherapists specialising in prescribing exercises to people with SpA. The following specific research questions were formulated;

1. What are the methods of prescribing exercise currently used by physiotherapists?
2. Do physiotherapists believe that patient adherence is important to improve patient outcomes in people with SpA?

3. What factors do physiotherapists perceive affect adherence to prescribed exercise in people with SpA?
4. What strategies and interventions do physiotherapists perceive increase patient adherence to prescribed exercises in SpA?
5. What are the barriers to employing these interventions to aid adherence?

5.3 Methods

5.3.1 Study Design and Ethical Approval

A cross-sectional web-based survey was carried out between 1 July 2019 and the 30 September 2019. Ethical approval was obtained from the College of Medical, Veterinary and Life Sciences Ethics Committee, University of Glasgow in June 2019 (Appendix 6).

5.3.2 Participants and Recruitment

It is unknown how many physiotherapists within the UK regularly assess and treat people with SpA, with no central register of UK physiotherapists who specialise in this condition held. Therefore, snowball sampling (TenHouten, 2017) was chosen as a way of identifying the target population. Several different dissemination routes were utilised. The AStretch committee, a group of 11 physiotherapists who specialise in promoting best practice in treatment and assessment of people with axSpA in different areas within the UK, in conjunction with the NASS charity, were first asked to complete and forward the survey on to other physiotherapists who regularly assess and treat patients with SpA. Thereby identifying local networks of physiotherapists within each area. NASS, the UK charity for people with axSpA and provider of resources to HCPs working with people with axSpA, was asked to advertise the study, via email to all physiotherapists from their database and advertise the survey on twitter and Facebook with a link to the survey. In the introduction to the survey, there was a request for participants to forward the survey on to other eligible physiotherapists.

The following inclusion criteria were used:

- qualified physiotherapists who specialise in the assessment and treatment of adults with SpA within the UK
- adults making up 80% of caseload
- seeing adults with SpA at least each month and
- willing to participate
- Had not already completed the survey.

5.3.3 Survey Development and Content

A survey method was used in preference to focus groups or interviews in order to capture the views of a nationally representative sample of physiotherapists. An electronic survey was chosen for the study as research has shown electronic surveys to be superior to paper surveys in terms of response rates, completion rates and the representativeness of the sample from which the data are collected (Denscombe, 2006). This survey was informed by a previous survey which had been developed to capture physiotherapist perceptions of patient adherence to self-management strategies, which included exercise, orthotics, advice and braces, in various MSK conditions but did not include people with SpA (Peek et al., 2017). Google Forms was chosen as the platform to base the electronic survey due to the ease of use by both participant and researcher and as it is widely accessible and freely available.

The survey included a participant information paragraph at the start of the survey explaining the purpose of the survey and informing each participant there were no known risks or benefits to completing the survey (Appendix 7). Consent was assumed if the survey was completed. Only submitted surveys could be viewed and included.

The survey included screening questions confirming whether adults made up 80% of the physiotherapist's workload, if they regularly saw patients with SpA (at least every month) and if they practised in the UK. If they answered 'no' to any of these questions they were thanked for their participation and informed they had completed the survey, as per the inclusion criteria.

The main survey (Appendix 8) consisted of 10 questions which took approximately 10 minutes to complete. Socio-demographic data questions were asked pertaining to where in the UK the physiotherapist was based and for how many years the physiotherapist had been qualified.

In order to understand physiotherapists views on the importance of adherence to prescribed exercises, participants were asked how important they considered adherence to prescribed exercise to be in improving outcomes in people with SpA. Specifically, physiotherapists were asked to indicate the extent to which they agreed or disagreed with the statement 'Treatment outcomes in Spondyloarthritis can be positively affected by patients adhering to physiotherapy prescribed exercise programmes'. Physiotherapists responded using a five point Likert scale (strongly agree; agree; neither agree nor disagree; disagree; strongly disagree).

In order to evaluate the current methods of prescribing exercise in SpA. Physiotherapists were provided with a list of possible ways of prescribing exercise and asked to tick all that apply. In addition, a free text box was provided for physiotherapists to list any other ways in which they prescribed exercise.

To evaluate the factor which physiotherapists perceive affect adherence, physiotherapists were provided with a list of factors, selected from the literature and previous phases of the PhD, that may affect patient adherence, including patient characteristics, disease characteristics, healthcare and social factors. Physiotherapists responded using a six point Likert scale (frequently increases adherence; sometimes increases adherence; does not affect adherence; sometimes reduces adherence; frequently reduces adherence; don't know). A free text box was provided for physiotherapists to list any additional factors which they felt influenced adherence.

In order to understand the methods physiotherapists employ to improve patient adherence, physiotherapists were provided with a list of possible methods to improve adherence and they responded using a four point Likert scale (Yes frequently increases a person's adherence; yes sometimes increases a person's

adherence; has no effect on a person's adherence; not sure/have no experience of this). A free text box was provided for physiotherapists to list any other methods that they use that helps increase patient adherence to prescribed exercise programmes.

To understand the barriers physiotherapists perceived to in employing methods to aid patient adherence, physiotherapists provided with a list of statements such as 'I don't have enough time to assess patient adherence' and I have limited knowledge/skills in assessing patient adherence'. Physiotherapists were asked to indicate the extent to which they agreed or disagreed with these statements using a five point Likert scale (strongly agree; agree; neither agree nor disagree, disagree, strongly disagree). The survey can be found in Appendix 8.

The survey was piloted for acceptability and feasibility by two qualified physiotherapists before the final survey was sent to participants; no changes were required from this pilot test.

5.3.4 Data Collection

The electronic survey was available for a period of three months between July 2019 and September 2019. The participant was asked to complete the survey once.

5.3.5 Statistical analysis and handling of data

The data were downloaded to a spreadsheet (google sheets) on a password protected computer. Data were analysed using descriptive statistics. The responses from the physiotherapists were grouped into the following five constructs proposed by the WHO multidimensional model of adherence; socioeconomic, healthcare, condition, patient and treatment factors (Sabete et al., 2003). Answers to each question were presented descriptively in tabular form. Free-text data was analysed using thematic content analysis.

5.4 Results

5.4.1 Survey response

Fifty-two physiotherapists responded to the survey in the allocated three-month period. Levels of missing data were extremely low with only one missing response to one question from one respondent.

5.4.2 Socio-demographic Information

Whilst there was variation in terms of years qualified as a physiotherapist, 71% of physiotherapists were qualified for greater than 10 years and 44% over 20 years (See Table 5-1). Over half of the physiotherapists were from England (n=29, 56%), with the remainder from Scotland (n=20, 38%) and Wales (n=2, 4%). missing data (n=1, 2%). No physiotherapists from Northern Ireland completed the survey.

Table 5-1. Years Since Graduating as Physiotherapist.

Years since Graduating	Number of Physiotherapists (%)
0-2	2 (4%)
3-5	2 (4%)
6-10	5 (10%)
11-15	9 (17%)
16-20	11 (21%)
21-30	11 (21%)
31+	12 (23%)

5.4.3 Perceived Importance of Patient Adherence and Methods of Prescribing Exercise

Almost all respondents (96.1%) agreed that adhering to physiotherapy prescribed exercise was important to positively influencing patient outcomes (n= 38 strongly agree, n=11 agree). Only 2 respondents disagreed (3%).

The most common method of prescribing exercise in SpA was signposting to NASS exercise groups (n=50, 96.2%). NASS run group exercise classes branches in Scotland, England, Wales and Northern Ireland. Physiotherapists surveyed commonly prescribed exercises using demonstrations of the exercise (n=48, 92.3%) and written instructions (n= 47, 90.4%). Slightly less commonly used were group exercise (n= 41, 78.8%) and digital resources such as apps or online exercise programmes (n=39, 75%). Hydrotherapy and residential programmes were reported by two physiotherapists.

5.4.3 Physiotherapists Perceptions of Factors Which Influence Patient adherence

Physiotherapists were presented with a list of factors from previous research and asked whether each factor could increase, decrease or did not affect adherence. Physiotherapists could also indicate if they did not know or had no experience of the factor. Physiotherapists were asked to provide any further factors not listed.

In addition to the specific factors listed in the survey, there were free text responses. The responses from the physiotherapists were grouped into one of the following four constructs proposed by the WHO multidimensional model of adherence; socioeconomic, healthcare, condition, and the patient factors (Sabete et al., 2003). The fifth construct - treatment factors was considered in a later question.

The factors which were perceived by physiotherapists to affect adherence are presented in Table 5-2. Factors which predominately increased adherence are coloured green, those factors which were predominantly perceived to reduce adherence coloured red. The free text responses were categorised into the

corresponding WHO construct. If a free text response contained more than one construct the quote was broken down into each corresponding construct, however the exact words were kept. Free text comments are presented in Table 5-3 below.

Table 5-2. Physiotherapists' Perceptions of Patient, Condition, Socio-economic, Healthcare-related factors which negatively (red shading) or positively (green shading) Influence Patient Adherence to Physiotherapy Prescribed Exercises. Values shown are the number and % of physiotherapists who indicated each response.

	Frequently Increases Adherence	Sometimes Increases Adherence	Does not Affect Adherence	Sometimes Decreases Adherence	Frequently Decrease Adherence	Don't know
Condition-related factors						
Concurrent mental health condition(s) such as anxiety or depression.	1 (2%)	1 (2%)	0	17 (33%)	**32 (62%)**	1 (2%)
High disease symptoms, such as pain, fatigue, stiffness, frequent flares.	2 (4%)	0	1 (2%)	18 (35%)	**31(60%)**	0
Multiple comorbidities	1 (2%)	0	0	**35 (67%)**	15 (29%)	1(2%)
Patient-related factors						
Lack of time	0	0	0	21 (40%)	**31 (60%)**	0
Being Afraid of Exercise	1 (2%)	1 (2%)	0	18 (35%)	**30 (58%)**	2 (4%)
Lack of interest	0	0	0	24 (46%)	**27 (52%)**	1(2%)
The person believes the exercises will not improve the symptoms or outcomes	0	0	2 (4%)	**25 (48%)**	23 (44%)	2(4%)
Low confidence or Self efficacy in ability to exercise	2 (4%)	1 (2%)	0	16 (31%)	**32 (62%)**	1 (2%)

High motivation	**45 (86%)**	7 (13%)	0	0	0	0
The belief that exercises will help.	**40 (77%)**	9 (17%)	1 (2%)	0	2 (4%)	0
Enjoying the exercises that have been prescribed.	**38 (73%)**	10 (19%)	1 (2%)	1 (2%)	1(2%)	1(2%)
Already being physically active.	**36 (70%)**	10 (19%)	1 (2%)	4 (8%)	0	1(2%)
Socio-economic factors						
Lack of support from friends, family, work or a charity.	1 (2%)	0	2 (4%)	**28 (54%)**	21(40%)	0
High levels of social deprivation.	1 (2%)	1 (2%)	4 (8%)	**21(40%)**	**21(40%)**	4 (8%)
Support from friends of family, work or a charity.	**27 (52%)**	22 (42%)	2 (4%)	0	1 (2%)	0
Healthcare-related factors						
Good Access to physiotherapy	**28 (54%)**	18 (35%)	2 (4%)	3 (6%)	0	1(2%)
Receiving effective medicine for symptoms of spondyloarthritis	**21 (40%)**	**21 (40%)**	1 (2%)	8 (15%)	0	1 (2%)

Table 5-3. Free Text Comments from the physiotherapist survey, relating to Patient, Condition, Socio-economic, Healthcare-related factors from the WHO construct which affect adherence.

Theme	Comments
Condition/disease-related	'If they feel their condition/symptoms are controlled with meds they may not see the importance of exercise therefore adherence can be decreased (p5)'
Patient-related	'Lack of education and understanding of their condition can decrease adherence (p2)' 'Decreases: family history of poor outcome despite exercise (p15)' 'Some people put off NASS class due to age range, extent of disease progression of regular members (p45)' 'Lack of understanding of condition and evidence base for exercise and condition management (p48)' 'Increases: family history of SpA with poor outcomes (i.e. don't want to end up like dad) (p15)' 'Enjoyment (p19)' 'Limited health literacy- reduces adherence (p22)' 'Understanding their condition (p37)' 'Understanding their condition, their medical management being able to take on responsibility for managing aspects of their condition (p38)'
Socio-Economic	'Financial limitations - even services such as Live Active/Vitality are charged (p14)' 'Increases: peer support, being part of a NASS group, having an active hobby or work role, previous or current employment in the military (p15)' 'Contact with peer group e.g. NASS increases adherence (p23)'
Healthcare-related	'Attending an immersive inpatient programme, which has the patient exercising in a group setting nearly every day for the duration of the programme, demonstrates the cumulative value of daily exercises. I believe this increases adherence (p8)'

	‘Variety (p19)’ ‘Ease of access time wise and physically to relevant/preferred exercise environment Patients don’t believe that the community gym based staff understanding their conditions enough to be able to help them safely (p38)’ ‘Access to hydrotherapy (currently only NASS class) (p23)’ ‘Using rheumatology physiotherapists to take classes in leisure facilities to increase adherence using a group and someone they trust to advise suitable exercises. Finding the activity that they enjoy and using a personal outcomes based approach to facilitate increase adherence and initiation of exercise (p48)’ ‘Availability of class at time that suits family life or work may increase either way (p32)’

5.4.3.1 Condition-related Factors

Condition-related factors were generally perceived (>90% agreement) to have a negative impact on adherence. High disease activity, concurrent comorbidities and mental health conditions were all reported by the physiotherapists to reduce an individual patient's adherence to exercise. One physiotherapist commented that if symptoms were controlled with other treatments, then individuals did not feel the need to exercise.

5.4.3.2 Patient-related Factors

Physiotherapists perceived that adherence was reduced (>92% agreement) in people with SpA who lack the time or interest or who believed the exercises were not beneficial in improving symptoms and/or outcomes. Conversely, adherence was perceived to be increased in individuals who believed that the exercises would improve symptoms and/or outcomes (96% agreement). High motivation, enjoying the exercises and already being physically active were all perceived (>89% agreement) to increase adherence to prescribed exercises.

Free text comments were provided by eight physiotherapists who remarked that adherence could be affected positively by having a greater understanding of the condition and reduced by poorer understanding. Free text comments also highlighted family history of SpA as being important in adherence.

5.4.3.3 Socio-economic Factors

Physiotherapists perceived that socio-economic factors could affect an individual's adherence. 80% of physiotherapists indicated that high levels of socio-economic deprivation reduced adherence (40% frequently and 40% sometimes). The level of support from work, family, friends or a charity was perceived to increase adherence and that it was reduced where there was lack of support.

Additionally, two physiotherapists commented that the support of a peer group, such as a NASS exercise group, helped increase adherence. Financial limitations in relation to having to pay for community programmes were reported by one physiotherapist to reduce adherence.

5.4.3.4 Healthcare-related

Healthcare-related factors were also perceived to play a role. Good access to physiotherapy services (89% agreement) and receiving effective medication (80% agreement) to relieve symptoms were perceived by physiotherapists to increase adherence.

Free text comments relating to the availability of healthcare were made by six respondents. Access to hydrotherapy, in-patient programmes, or community programmes were perceived to increase adherence. Furthermore, having a variety of programmes available at times that suited the individuals with SpA and with suitability qualified staff, such as physiotherapists, was perceived to increase adherence.

5.4.4 Treatment factors to Improve Patient adherence to Physiotherapy Prescribed Exercises.

The content and delivery of interventions have potential to affect adherence to prescribed exercise programmes. As this is the component that the physiotherapists have the most direct control over, this aspect is considered separately in more detail. The physiotherapists were presented with a list of components of interventions and interventions with different methods of delivery, taken from previous research, and asked to indicate their opinions on the impact of these on adherence. The results are shown in Table 5-4. The physiotherapists were also asked to add any additional methods not listed, with the ten free text responses presented in Table 5-5.

Table 5- 4. Physiotherapists' Perceptions of Interventions/Treatment-related factors to Improve Adherence. The commonest response for each item is shown in bold text.

	Frequently improves adherence	Sometimes improves adherence	Has no effect on adherence	Not sure or have no experience of this
Individualising the exercise programme to the person	**37 (71%)**	15 (29%)	0 (0%)	0 (0%)
Goal Setting with person	23 (44%)	**27 (52%)**	1 (2%)	1 (2%)
Providing patient education of importance of exercise	**29 (56%)**	21 (40%)	2 (4%)	0 (0%)
Providing patient education on the expected outcomes or consequences	21 (40%)	**29 (56%)**	1 (2%)	1 (2%)
Practicing the exercises within the consultation	**36 (69%)**	14 (27%)	2 (4%)	0 (0%)
Physiotherapist communication skills	**32 (62%)**	18 (35%)	2 (4%)	0 (0%)
Providing patient education: supportive material	21 (40%)	**29 (55%)**	2 (4%)	1 (2%)
Discussing the barriers and facilitators to adherence	**25 (48%)**	24 (46%)	1 (2%)	2 (4%)
Addressing the general health of the patient, including referral to GP or AHP colleagues	13 (25%)	**34 (65%)**	3 (6%)	2 (4%)
Involvement of the patient's support person	14 (27%)	**32 (62%)**	1 (2%)	5 (10%)
Monitoring of patient adherence	20 (38%)	**24 (46%)**	1 (2%)	7 (13%)
Novel digital interventions	13 (25%)	**31 (60%)**	2 (4%)	6 (11%)
Motivational Interviewing	13 (25%)	**27 (52%)**	6 (11%)	6 (11%)

Table 5-5. Free Text Responses from the physiotherapist survery relating the the treatment-related domain which affect adherence.

Theme	Comments
Treatment/ Interventions	'Identify what the outcome will be and advise I will challenge it next time, i.e. your goal we discussed is X which with compliance you will be able to do next time so let's start with that (P4)'
	'Weekly access to the stretch class (p16)'
	'Signposting to group exercise such as NASS or community programmes (p19)'
	'Encourage to come to NASS class (p23) & (p45)'
	'Exercise groups for social support (p48)'
	'Intensive exercise programme at Highland Rheumatology unit for 2-week inpatient stay (p23)'
	'Combining exercises into activities of daily living (p34)'
	'Intensive input of education and guided exercise practice (p36)'
	'The main one is keeping things real for the patient being fully aware of what is preventing them from exercising and looking to work towards overcoming any identified factors. Making things as easy and 'seamless' as possible p38)'

All physiotherapists surveyed had experience of, and agreed that individualising the exercise programme to the person increased adherence, with 71% of physiotherapists believing that it frequently increased adherence and the remaining 29% believing that it sometimes increased adherence. There were high levels of agreement (equal to or above 96% of all physiotherapists surveyed) that providing; patient education on the importance of the exercise and the expected outcomes or consequences, practicing the exercises within the consultation with the patients and physiotherapist communication skills increased adherence. There was lower agreement regarding motivational interviewing and providing novel digital interventions, although this was still high with 77% and 85% of physiotherapists agreeing that this improved adherence. However, 11.5% of physiotherapists felt motivational interviewing did not have an effect on adherence, with 11.5% of physiotherapists having no experience or not sure of these interventions.

There were nine free text comments from physiotherapists which highlighted the need for social support, group exercises, intensive inpatient programmes and incorporating exercise into everyday life (Table 5-5).

5.4.5 Barriers to Employing Interventions and Strategies to Improve Adherence.

Acknowledging the unique challenges and issues facing physiotherapists in adopting methods to improve adherence to prescribed exercise is an essential step to facilitating and improving exercise adherence in people with SpA. The barriers to the adoption of strategies to improve adherence were explored by providing the physiotherapists with a list of common barriers in employing interventions. Physiotherapists could also add free text responses. These barriers are presented in Table 5-6 and the free text responses in Table 5-7.

Table 5-6. Barriers to Employing Interventions and Strategies to Improve Adherence. The commonest response for each item is shown in bold text.

	Strongly Agree	Agree	Disgree	Strongly Disagree	Don't know/no experience of this
I do not have enough time to assess patient adherence with prescribed exercise	4 (8%)	14 (27%)	**25 (48%)**	9 (17%)	0
I have limited knowledge/skills in assessing patient adherence	0	4 (8%)	**25 (48%)**	23 (44%)	0
I do not have enough time to provide adherence aiding strategies	2 (4%)	16 (31%)	**26 (50%)**	8 (15%)	0
I am uncomfortable discussing adherence with patients.	1 (2%)	5 (10%)	17 (33%)	**28 (54%)**	1 (2%)
I have limited access to resources such as patient educational materials	1 (2%)	9 (17%)	19 (37%)	**22 (42%)**	1 (2%)
There can be a lack of continuity of care; patients often see different physiotherapists	1 (2%)	10 (19%)	**23 (44%)**	17 (33%)	1 (2%)
I don't believe that I can alter patient adherence - either patient adhere or they don't.	0	2 (4%)	**25 (48%)**	24 (46%)	1 (2%)
I don't believe that adherence is a problem with my patients	0	8 (15%)	**24 (46%)**	20 (39%)	0
I don't believe that improving patient adherence is relevant to physiotherapy practice	0	0	16 (31%)	**34 (65%)**	2(4%)

Table 5-7. Free Text Responses from the physiotherapist survey relating to Barriers to Employing Interventions and Strategies to Improve Adherence.

Theme	Comments
Barriers	'A generally poorly run rheumatology service with lots of referrals from consultants to Physio (p5)'
	'No access to hydrotherapy (p16)'
	'Lack of technology and training in using it (p32)'
	'Lack of facilities available in the hospital, closing our hydro pool not being allowed to issue pulleys etc, and sporadic facilities in the community with very poor hospital community. Interface/communication/bridges to give patients the confidence that any sports/gym based professional understands their conditions enough for the to be in safe hands (p38)'
	'No time given to develop the service, resource etc (p43)'
	'Non-attendance (p45)'
	'The readiness of the patient to change and other stressful factors in their life at the time and mental health issues (p48)'
	'Lack of consistency in Physiotherapy service provision/ evidence based pathway in NHS [health area] for AS patients. Often influenced by consultant clinics staffing and facilities by sector (p49)'

Almost all physiotherapists (96%) reported that improving patient adherence was relevant to their clinical practice. However, fewer (85%) respondents believed that patient adherence was a problem with their patients and the majority (94%) believed that they could alter a person's adherence. However, only 65% reported that they had time to assess adherence and similarly only 65% reported they had time to use methods to aid adherence. A high percentage (92%) reported they had sufficient knowledge/ skills in assessing patient adherence. The majority of respondents had access to patient education material (72%) and reported that their patients received continuity of care (77%).

There were eight free text comments from physiotherapists. The majority of the barriers to physiotherapists employing strategies to improve adherence were health system based. These related to poor access to, or between services, poorly managed service and local variation. One physiotherapist identified a perceived barrier in terms of patient factors relating to adherence and one highlight lack of training in technology.

5.5 Discussion

The aim of this survey was to explore UK physiotherapists' who specialise in rheumatology views on the importance of patient adherence to physiotherapist-prescribed exercise. To explore this in detail the following areas were considered: which factors affect adherence to prescribed exercise in people with SpA, which interventions physiotherapists perceived increased patient adherence and which barriers are perceived in employing these interventions to aid adherence. In addition, the physiotherapists were asked about which methods they currently use to prescribe exercises.

Traditional methods of prescribing exercises such as signposting to charities, providing demonstrations and written instructions were more commonly used than digital resources, such as apps or online exercise programmes (90%+ of physiotherapists versus 75%). Group exercises were slightly less common than providing demonstrations, which may reflect the availability of a group exercise format (78.8% versus 90%). Additional methods suggested by two physiotherapists were prescribed hydrotherapy exercises and through a residential programme which may not be available in all areas.

The first requirement in changing behaviour and improving outcomes is awareness of the issue. Almost all physiotherapists (96.1%) agreed that adhering to physiotherapy-prescribed exercise was important in positively influencing patient outcomes. Demonstrating that UK physiotherapists who regularly assess and treat people with SpA do consider the influence of adherence to their prescribed exercise programmes. This is in contrast to older research which reported that physiotherapists may wrongly assume exercise programmes are ineffective rather than considering lack of adherence with the programme (Turk and Rudy, 1991). This awareness provides a good starting point for physiotherapists to assess adherence in their patients and take steps to improve it.

In order for physiotherapists to act on their awareness of the importance of adherence and the issues positively or negatively impacting these, they require to be identified. As previously discussed, the WHO proposes that when studying

adherence, a multidimensional approach could be undertaken where adherence is determined by the interplay of five domains: condition related, patient related, socioeconomic, health and therapy/intervention related (Sabete et al., 2003). Therefore, this approach has been used as the framework in this thesis and in this study it was utilised to garner participants understanding across the domains. These are explored further in Section 5.5.1 – 5.5.5 below.

5.5.1 Condition-related Factors Affecting Adherence

In the WHO model of adherence condition-related factors affect adherence (Sabete et al 2003). This survey identified concurrent mental health conditions, high disease symptoms and multiple comorbidities as condition-related factors perceived by physiotherapists in this survey to reduce adherence to prescribed exercise programmes.

Concurrent mental health conditions, such as depression and anxiety were identified by respondents as factors that may reduce adherence to prescribed exercise in SpA patients. These findings concur with research in MSK and mixed population of adults receiving physiotherapy which similarly report that the presence of anxiety and depression reduced adherence to physiotherapy prescribed exercise programmes (Jack et al., 2010, Essery et al., 2017). Whilst depression and anxiety are prevalent within the general population (Global Burden of Disease Study 2013 Collaborators, 2015), having a long term chronic condition increases the likelihood of an additional depressive or anxiety disorder (Meesters, et al., 2014). Within SpA, survey data demonstrates that greater than half of people with SpA are affected with concurrent mental health conditions (Redeker et al., 2018, Shen et al., 2016). Adherence to medicine is more widely studied than adherence to exercise, where a meta-analysis has identified depression as a strong predictor of patient non-adherence. Non-adherence has been identified as being 27% higher in those with depression compared to those without (DiMatteo et al., 2000). The symptoms of depression include low mood, and loss of interest or pleasure in activities that were previously enjoyable. These symptoms may contribute to reduced likelihood of adhering to a regular prescribed exercise programme (Sobin & Sackeim 1997). Symptoms of anxiety may include excessive worry, avoidance, chest palpitations or pain, shortness of

breath, and gastrointestinal distress (Dreskin, 2018). These may make adhering to regular exercise difficult, particularly if the person also has concerns that the exercise could worsen their SpA or pain. Therefore, it is important for physiotherapists to recognise these symptoms of depression and anxiety in their patients. Future research should investigate whether routine use of screening questionnaires for anxiety and depression can improve adherence to exercise programmes by identifying and onwards referral for those who would benefit from mental health interventions. Such an approach is recommended and routinely employed within weight management programmes (NICE, 2014).

High levels of disease symptoms were identified by respondents as another common factor that could reduce an individual's adherence to prescribed exercise. The clinical presentation of SpA varies between individuals. Characteristic manifestations such as inflammatory back pain, oligoarthritis, and enthesitis lead to stiffness and pain that can make it difficult for an individual to do exercises. Furthermore, individuals with SpA commonly complain of fatigue. These symptoms are usually variable but for a proportion of individuals with SpA these will be intense, frequent and disabling (Sieper et al., 2006, Atzeni et al., 2014, Jacquemin et al., 2017). These findings are in contrast to the systematic review within Chapter 3 (section 3.3.9) which found that individuals with high disease severity had increased adherence. However, this was the result of a single study with moderate to weak association between disease severity and adherence (Barlow & Barefoot 1996). Similarly, a qualitative study investigating the perspectives of adults with AS found signs and symptoms of AS, principally pain, stiffness, and fatigue, were significant barriers to physical activity by the majority of participants. When symptoms increased during flare-ups, many regarded these as insurmountable barriers to exercise (O'Dwyer et al., 2016). Conversely, one physiotherapist within this survey commented that if SpA symptoms were well controlled patients may not see the importance of exercising. Interestingly, one participant in the WEBPASS interviews (p44, Peter Section 4.6.14.1) reported that they did not exercise due to the absence of significant symptoms. The relationship between adherence to exercise and symptoms is therefore likely to be complex. On the one hand, severe symptoms or flare ups may make it difficult for patients to perform exercises due to the symptoms themselves or concerns about "doing harm", while on the other hand,

very mild disease may mean patients do not see the need or value to do exercises. These condition-related factors overlap with patient-related factors which are discussed in more detail in the following section. Physiotherapists should be aware that disease activity levels in SpA fluctuate and may impact on an individual's adherence to exercise, thus need to be taken into consideration. Patient education about the role of exercise in SpA and contingency plans for flare-ups may help with adherence in these situations. Patient education is a suggested intervention to improve adherence and is discussed in Section 5.5.5.

In addition to the disease itself, the physiotherapists identified multiple comorbidities as factors that could impact negatively on adherence. There is a higher risk for comorbidities for individuals with SpA than in the general population, particularly for cardiovascular and osteoporosis conditions (Moltó et al., 2016). Multimorbidity is defined as the coexistence of two or more chronic diseases in an individual (Wong et al., 2014). In an observational study investigating comorbidities in people with SpA across 22 countries, at least 1 comorbid condition was found in 51% of patients, while 9% had ≥3 comorbidities, in addition to their SpA (Moltó et al., 2016). In the present survey, 96% of physiotherapists agreed that multiple comorbidities reduced adherence to prescribed exercise. The existing literature also suggests a possible link between multimorbidity and reduced adherence (Dekker et al., 2019) but no quantitative studies were identified that investigated the effect of multimorbidity on adherence to exercise. However, a study of 3866 people in China reported that multimorbidity was associated with poorer medication adherence (Wong et al., 2014). The reasons why multimorbidity reduces adherence are not clear, there may be a high burden of managing each disease for example following medical regimes and attending multiple appointments (Mair & Gallacher, 2017). Therefore, as multimorbidity is prevalent in people with SpA, physiotherapists should be aware that this may reduce their adherence to exercise.

5.5.2 Patient-related Factors affecting Adherence

In this survey, there were high levels of agreement from UK physiotherapists that lack of time (100%), being afraid of exercise (92%), lack of interest (98%),

belief that the exercises will not help symptoms or outcomes (92%) and low self-efficacy (92%) were patient-related factors that reduced adherence to prescribed exercise. There was also a high level of agreement that high motivation (100%), belief that the exercises would help (94%), enjoyment of the exercises (92%) and already being physically active (88%) increased adherence.

Motivation can be defined as the energisation of behaviour towards positive stimuli, such as objects, events, possibilities, or in this case toward the prescribed exercise (Elliot, 2006). All physiotherapists within this survey agreed that high motivation would increase adherence. However, lack of time, interest, self-efficacy, lack of enjoyment, have the potential to reduce motivation and ultimately adherence to exercise. While the belief that the exercises will help symptoms or outcomes may increase motivation toward exercise and therefore, ultimately adherence to exercise (Woodard and Berry, 2001, Teixeira et al., 2012).

This survey found that all respondents perceived that lack of time reduces an individual's adherence. Lack of time is frequently reported as a barrier to physical activity and exercise (Reichert et al., 2007). In a general population survey of 320,000 individuals in Brazil, 31.5% reported lack of time as a barrier to physical activity. Those 31.5% who reported lack of time as a barrier to physical activity had significantly less self-reported leisure time in comparison to those who did not report time as a barrier, therefore lack of time appears to be a real barrier and does not just represent lack of motivation (Reichert et al., 2007). Similarly, a qualitative study of 17 people with AS investigating physical activity and exercise perspectives of adults reported that the participants expressed difficulty finding time to exercise, with time spent with family, working and studying being prioritised over exercise (O'Dwyer et al., 2016). Given these findings, it is important for physiotherapists to discuss and evaluate time constraints with individuals for whom they prescribe exercises and help them to develop strategies to mitigate against lack of time.

Self-efficacy is an individual's belief in their ability to complete specific tasks (Oshotse et al., 2018). Low self-efficacy was perceived by 92% of physiotherapists within this survey to reduce adherence to exercise. People with

low self-efficacy typically stop the task if they encounter problems such as understanding the regime, being physically unfit, busy or tired. In contrast, those with high levels of self-efficacy, do their best to improve skills and overcome the obstacles (Bandura, 2004). Therefore, the belief and confidence that a person can exercise, even given constraints, different situations and impediments such as feeling tired or being busy is associated with a greater likelihood of completing it (Bandura, 1997). Self-efficacy is situational and may be one possible reason for the reduced adherence to the patient choice element in comparison to the prescribed component in the WEBPASS cohort study (Section 4.7.3). Therefore, physiotherapists should explore each individual's self-efficacy toward the exercise prescribed and consider the impact of self-efficacy on adherence and, if appropriate, implement interventions which may improve self-efficacy (See Section 5.5.5).

This survey found that 94% of physiotherapists perceived individuals who believed the exercises would help symptoms or outcomes would have increased adherence and 92% of physiotherapist perceived individuals who did not believe the exercises prescribed would improve symptoms or outcomes would have reduced adherence. This relates to, and overlaps with, the condition-related factors identified in Section 5.5.1 as it is both the level of the symptoms and the patient's perception of the impact of exercise on these that is likely to impact on adherence to exercise programmes in these situations. This is supported by the four free text comments in the survey which highlighted that physiotherapists believe the patient's degree of understanding of the condition as being important, where lack of understanding reduces adherence and greater levels of understanding improves adherence. Physiotherapists should be aware that the beliefs the patient holds regarding the possible outcomes achieved from exercise may influence adherence to the programme. Physiotherapists should explore this with their patients, and consider interventions which may influence their belief and therefore their adherence. The interventions which include patient education to improve adherence are discussed in Section 5.3.5.

In the survey, 93% of the physiotherapists agreed that individuals who enjoyed the exercises that had been prescribed would have increased adherence. Enjoyment can be described as a positive affective state that

reflects feelings such as pleasure, liking, and fun (Hu et al., 2007). There is a recognition of the importance of enjoyment in positively influencing participation in exercise (Hagberg et al., 2009). This is supported by the results by O'Dwyer et al (2016) from a qualitative study investigating barriers and facilitators to exercise in AS, which indicated that enjoying the programme improved participation (O'Dwyer et al., 2016).

In contrast, lack of interest in exercise was reported by 98% of the surveyed physiotherapists to reduce adherence. Lack of interest in physical activity and exercise is a significant challenge and common within the general population in Europe (Carraça et al., 2018). Physiotherapists should consider that lack of interest reduces adherence and that enjoyment increases adherence and incorporate strategies to optimise these. For example, physiotherapists could explore the goals of rehabilitation and the type of exercise that is likely to interest and be enjoyable to the individual and prescribe based on this premise. Furthermore, fun activities within group exercise could be incorporated. This is discussed further in the therapy-related Section 5.5.5. Even if an individual's lack of interest in exercise cannot be changed, recognising this and the fact that these individuals are less likely to adhere to exercise, can still be helpful in understanding poor outcomes and determining where limited physiotherapy resources can best be focussed.

Already being physically active was a patient-related factor perceived by 89% of physiotherapists to increase adherence to prescribed exercise. Already being physically active may support adherence as individuals do not have to initiate as great a behaviour change in comparision to those who aren't active. For those who aren't active, physiotherapists could consider the readiness of each individual to change their behaviour. A simple method of doing this would be for physiotherapists to ask, on a scale of 0-10 how ready are you to change your behaviour, this would allow physiotherapists to gauge the likely success of interventions (Royal College of Nursing 2019). On the other hand, interestingly, 8% of physiotherapists perceived that already being physically active could reduce an individual's adherence to prescribed exercises. The reasons for this could not be determined from the survey but it is possible this is due to the individual already exercising and therefore not being motivated, or seeing the

need, to do further or different exercises prescribed by a physiotherapist. This apparent contradiction does again highlight the complex and multiple interactions affecting adherence to exercise.

5.5.3 Socio-Economic Factors affecting Adherence

In the WHO (2003) model socio-economic factors are identified as factors that may also influence adherence. In this survey there were high levels of agreement from UK physiotherapists that support that social deprivation had an effect on adherence.

The majority (94%) of physiotherapists agreed support from friends, family, work or a charity would increase adherence and lack of support would reduce adherence. Two free text comments by physiotherapists specifically highlighted the importance of social support in the form of group exercises, such as those provided by NASS. The WEBPASS cohort study also highlighted the importance of support, which was identified as a theme from the participant interviews (Section 4.6.14.1). Similarly, support has been identified by two systematic reviews to be important in supporting adherence to physiotherapy prescribed exercises in other mixed musculoskeletal conditions, and mixed population receiving physiotherapy (Jack et al., 2010; Essery et al., 2017) and within a qualitative inquiry with people with AS (O'Dwyer et al., 2016), where participants highlighted the importance of support in the form of friends, family, team or club mates, other adults with AS, as well as from exercise instructors and HCP including physiotherapist. Therefore, support appears to be an important factor in influencing adherence to prescribed exercise and physiotherapists should be aware that the level of support that an individual has may influence their adherence to prescribed exercise. Support can be built into interventions and is discussed in the therapy-related Section 5.5.5

Social deprivation may reduce adherence to exercise. A high proportion (80%) of physiotherapists agreed that high levels of social deprivation reduced adherence to exercise, while 4% of physiotherapist perceived that it increased adherence and the remainder (16%) were not sure or had no experience of this. To the author's knowledge, no study has directly investigated the effect of social

deprivation on adherence to physiotherapy-prescribed exercises; however, people in lower socio-economic groups are less likely to meet the current PA target than the rest of the population (Schmidt et al., 2008). A free text comment from a physiotherapist within the survey highlighted that financial limitations reduced access to services, such as community based rehabilitation classes which charge a fee for taking part. The overall solution to deprivation will be at a societal and government level including reducing inequalities. However, physiotherapists should be aware that people with high levels of social deprivation may be less active and less likely to adhere to prescribed exercise programmes, so should specifically enquire about these aspects and discuss potential solutions, such as free classes or online resources with their patients.

5.5.4 Healthcare-related Factors affecting Adherence

In this survey there were reasonably high levels of agreement from UK physiotherapists that good access to physiotherapy increased adherence, as did receiving effective medication for the symptoms of SpA. There is considerable overlap with effective medication within the health-care construct and symptoms within the condition characteristic construct of the WHO multi-dimensional model, again highlighting the complexity of these inter-related factors.

The perception of effective medication being important for good adherence is supported by a multi-site quantitative study investigating the impact of effective medication on exercise behaviour among individuals with A. It concluded that effective pharmacological management of symptoms improved motivation to exercise and enabled participants to recommence, or further engage with, prescribed exercises and PA (Stockdale, et al, 2014). However, 15% of the physiotherapy survey respondents felt that receiving effective medication could reduce adherence, with a follow up free text comment stating that if a person's symptoms were controlled with medication, then they might not see the importance of exercising. As discussed within the condition related Section 5.5.1, this sentiment was echoed by one participant in the WEBPASS interviews who felt that his symptoms were not sufficient to warrant exercise (Peter p44, Section 4.6.14.1.2). Therefore, simply assessing adherence levels in isolation

may be a poor measure of success and should be combined with other disease and health-related QoL outcomes. Therefore, while it is possible that effective pharmacological and non-pharmacological management may, in many cases, help increase adherence to exercises, for some individuals this will mean their symptoms may not be sufficient to motivate them to exercise. Physiotherapists should explore this with individuals, review medicines and refer onto other HCPs if symptom control is poor. They should also explain the additional benefits and rationale for exercise, particularly in those with good symptom control. This is further strengthened by 65% of physiotherapists within this survey agreeing that adherence to exercise could be increased by addressing the general health of the patient for example referral onto a GP.

5.5.5 Intervention and Treatment-related factors to Support Adherence

Once physiotherapists have considered the multiple potential factors influencing an individual's adherence to exercise in each of the above four WHO constructs of personal, condition, socio-economic and healthcare-related factors described above, the next step is to consider interventions and strategies to improve adherence with a particular emphasis on addressing the factors from the constructs identified within the assessment. As prescribers of the exercise interventions, this is the domain where the physiotherapists can have the most direct influence on their patients' adherence. In the survey there were high levels of agreement for different interventions and strategies to increase adherence, including individualising the intervention, using novel digital interventions, providing education, using communication to improve adherence (for example by goal setting, discussing barriers and facilitators, and/or motivational interviewing), addressing the general health of the patient, and including support in the intervention (such as practicing the exercises, monitoring patient adherence, involving a support person).

All physiotherapists in this survey agreed that individualising the exercise programme improved adherence, with 71% perceiving that individualising the exercise regime frequently increased adherence. This concurs with the findings of the WEBPASS cohort study, where individualising the intervention was one

possible reason why participant's adherence to the prescribed component was deemed to be greater than the patient choice component, as also highlighted in the participant interviews (Section 4.6.14.1). Individualising the exercise programme to the needs and capability of participants has been reported as being important. O'Dwyer et al reported that most participants with AS felt that individualised exercise prescriptions were preferable to generic programmes (O'Dwyer et al., 2016).

One physiotherapist commented in the survey that variety could also promote adherence. Sylvester et al (2016) undertook a cross sectional survey of 499 adults and reported a positive relationship between perceived exercise variety and self-reported exercise behaviour. Variety may support adherence by reducing boredom. Physiotherapists have knowledge about pathology, exercise prescription and clinical reasoning skills, so are well placed to individualise and include variety within programmes based on their assessment findings (Taylor et al., 2007). Within individual programmes, enjoyment and variety could be built in.

Patient education can be defined as a planned learning experience to influence a patient's knowledge and health behaviour (Schrieber and Colley, 2004). Patient education can take different forms and have different aims, such as a better understanding of the condition or the treatment, or understanding the potential outcomes and consequences with and without the treatment (Rosemann et al., 2007). This education can take place in a group or on an individual basis. It may also involve supportive material. In this survey, 96% of the physiotherapists agreed that providing education regarding the importance of exercise would improve adherence, while the remaining 4% believed it would have no effect on adherence. Furthermore, 96% agreed providing education on the expected outcomes or consequences of not exercising would increase adherence, with only one respondent believing it would have no effect on adherence. Similarly, 96% of the physiotherapists agreed that providing patient information in the form of supportive material would increase adherence.

Studies using solely education in this field are few and far between, with the majority of interventions which involve patient education doing so in

combination with exercise to form a self-management plan, which is common in clinical practice (Argent, et al 2018). Two out of three studies in the systematic review (Chapter 3) reported an increase in adherence following an educational programme which also incorporated exercise prescription (Barlow and Barefoot, 1996; Sweeney, et al, 2002). The third found only a trend towards improvement, although poor patient participation with the educational programme could account for this result (Gross and Brandt, 1981). Two further systematic reviews of physiotherapy prescribed exercises in MSK conditions (with no participants with SpA) suggested that adding educational components increased adherence (Ezzat et al., 2015, Peek et al., 2016). At present there is no evidence to suggest the optimum format of educational programmes although tailoring the support for each individual is suggested to be beneficial (Argent, et al, 2018). As the addition of education programmes has the potential to improve adherence physiotherapists should consider using education programmes in, or alongside their exercise interventions to improve adherence. Again this over laps with the patient construct of the model, where poor understanding of condition may reduce adherence, therefore education could be an intervention to help with this.

Communication is an essential component of exercise prescription, both for informing patients about their regimens and then encouraging and supporting them in performing these programmes (Zolnierek and Dimatteo, 2009). This survey found 96% of physiotherapist agreed that the communication skills of the physiotherapists could increase adherence, with only 4% stating this had no effect on adherence. There is interest in examining the relationship between the HCP and patient, with a positive association noted between a good working relationship with a HCP and a patient's ability to manage and cope with a variety of illnesses and adhere to the HCP's recommendations (Hall et al., 2010; Bennett et al., 2011).

The HCP-patient relationship includes verbal and non-verbal communication, effective questioning and transmission of information, expressions of empathy and concern, partnership and participatory decision-making (Zolnierek and Dimatteo, 2009). Research in adherence to medication has indicated that patient adherence can be aided by using a frank, non-judgmental and open

approach to asking about adherence. The HCP should acknowledge how common non-adherence is, then explore barriers and facilitators to adherence, tailor communication to suit the patient's preferences for the quantity and style of communication and use a patient-centred approach with shared decision making. The HCP should recognise that the patient's decisions may ultimately not be in accord with medical recommendations (Cairns, 2006, Butow and Sharpe, 2013). The best method of communication within online delivery of exercise programmes, such as WEBPASS (chapter 4), is unclear, but a 'keeping in touch' session could be built in to web-based interventions, and could be as straight forward as adding in a phone call, or a message through the web-based platform. Physiotherapists could aim to improve their communication skills, to aid adherence, through training and reflection. Further research could investigate the success of communication training and 'keeping in touch' sessions within web-based interventions.

There was a high level (94%) of agreement that discussing barriers and facilitators with each individual would increase adherence. Physiotherapists could act collaboratively with each person to discuss their personal barriers and facilitators to undertaking an exercise programme, and then consider which are modifiable and focus on these. This process may include motivational interviewing (discussed below) or goal setting.

Goal setting is the social interaction where goals are shaped during a conversation between a HCP and service user (Schoeb et al., 2014). Goal setting can be used to direct the prescribed exercise intervention towards a specific outcome or outcomes and can be used to evaluate the success of rehabilitation interventions (Wade, 2009). Goal setting is collaborative between a HCP and the patient and/or their family. Almost all physiotherapists (96%) agreed that goal setting could increase adherence. This concurs with a systematic review of physiotherapy prescribed exercises in other conditions (Peek et al., 2016). Goal setting has been suggested as a strategy to improve self-efficacy (Sacomori et al., 2015). Low self-efficacy was noted by physiotherapists to reduce adherence, in the patient related construct, therefore goal setting may be a strategy to improve adherence through improving self-efficacy, however further research should assess how effective this is. Similarly, physiotherapists agreed within this

survey that practicing the exercises within the intervention with the patient would increase adherence. Again practising the exercises could improve self-efficacy, which in turn could improve adherence.

In this survey, 77% of the physiotherapists perceived that motivational interviewing increases adherence to prescribed exercise, and 11% felt motivational interviewing had no effect on a person's adherence. The remaining 11% of respondents had no experience of this. Motivational interviewing is a strategy that aims to help individuals articulate and resolve their ambivalence regarding a behaviour, such as exercise, and encourages them to find their own individualised solutions (Palacio et al., 2016). It can encompass communication, discussion of barriers and facilitators and goal setting. MI involves the HCP listening, showing empathy and acknowledging an individual's barriers toward exercise with understanding and acceptance, rather than as a fault. The HCP then provides encouragement and helps the individual set realistic goals and instils confidence that the individual will be able to successfully cope with lapses and setbacks (Hettema, et al, 2005). Motivational Interviewing was initially used in clinical settings almost exclusively by clinical psychologists and is not typically part of traditional physiotherapy training or practice (McGrane et al., 2015), which may account for the 11% of physiotherapist who were not sure or had no experience of this intervention. A systematic review found adherence to exercise was improved with the addition of motivational interventions to traditional physiotherapy (McGrane et al., 2015). Furthermore, a systematic review concluded that motivational interviewing improves adherence to medicine (Palacio et al., 2016). Physiotherapists should consider training in and using motivational interviewing as another strategy to increase adherence to their prescribed exercise programmes.

As highlighted previously, within the socio-economic section, support of family and friends appears to be an important factor in adherence. Support can also be built into interventions, again highlighting the overlapping complexity of the adherence model. Physiotherapist could identify existing support mechanisms and encourage new support networks such as HCPs, family, work colleagues, carers and group exercise opportunities. Members of the support network could be invited to participate in the physiotherapy session, alongside the individual

with SpA, and taught the prescribed exercises and encouraged to either exercise together or to' check' in with each other to promote adherence. Within WEBPASS (Chapter 4) two participants (p17 Gary & p2 Robert, Section 4.6.14.1) noted that their partners either encouraged them to exercise or they exercised together which they felt improved their adherence, this highlights the benefits of including a person's support network within the exercise session.

In group exercise the support can come from the physiotherapist and the other people within the group. Physiotherapists from this survey agreed that interventions which provided support would increase adherence; this could be through monitoring adherence, involving the patients support team, through addressing the general health of the patient and through practicing the exercises within the consultation. It is interesting that 10% of physiotherapists had no experience of including support networks and this may be an area to include in interventions to increase adherence.

5.5.6 Physiotherapists' Barriers to Employing Interventions and Strategies to Improve Adherence

To improve patient adherence to prescribed exercise, physiotherapists need to be supported in their efforts to assess and promote patient adherence (Babatunde, et al, 2017). Time is consistently highlighted by physiotherapists and other professions as a constraint to providing patient care (McMahon and Connolly, 2013). In this survey, the majority of physiotherapists (65%) did not perceive that a lack of time was a barrier to assess adherence and provide interventions to aid adherence, although for a third (35%) this was seen as a barrier.

An encouraging finding of this study is that limited knowledge about adherence (8%), inability to discuss adherence (12%), lack of continuity of care (21%) or limited resources (19%) were not perceived by the majority of respondents as being barriers to implementing methods to aid adherence. For those who did perceive these as barriers, training and support could help physiotherapists with providing interventions and communication skills to discuss with adherence with patients.

Almost all the physiotherapists (96%) perceived that adherence is relevant to physiotherapy practice. However, given that the majority of physiotherapists (85%) surveyed also responded that adherence is a problem with their patients, further research is required to determine methods and strategies to improve adherence to exercise in people with SpA.

Free text responses indicated perceived barriers were mainly related to service provision, such as facilities and providing hydrotherapy, which are largely out of the direct control of the individual physiotherapists.

5.5.7 Overall Physiotherapist Perceptions of Factors Affecting Adherence in People with SpA

It is encouraging that physiotherapists perceive adherence important as part of their practice, most but not all thought adherence was a problem in their patients, however, evidence from the WEBPASS study and in other existing literature suggests adherence to exercise programmes is low (Sluijs et al., 1993, Peek et al., 2016). It may be that some physiotherapists underestimate the level of adherence of their patients to prescribed exercises. Robust measurement of adherence and including routine measurement of adherence within clinical practice may help with this.

Physiotherapists who prescribe exercises for people with SpA believe they can improve adherence, therefore should aim to determine the relevant factors affecting adherence for each individual and design personalised interventions. While factors in each WHO construct should be considered, the physiotherapist's focus should be on those factors that they can modify. Physiotherapists, especially those within the NHS, have very little control over health care related factors such as the access to services.

5.5.8 What this study adds to the existing literature

The findings of this national survey provides new evidence that physiotherapists believe that adherence to prescribed physiotherapy exercise is important in

improving clinical outcomes in people with SpA and that patient adherence to prescribed exercise is problematic.

There were high levels of agreement between therapists of a number of new factors affecting adherence to exercise in people with SpA. Within healthcare related construct good access to physiotherapy and effective medication for symptom control improved adherence. Within the disease related construct, concurrent mental health problems, high disease symptoms and multiple co-morbidity reduced adherence. Within the socio-economic domain, support increased adherence, while social deprivation reduced adherence. Within the patient related construct the belief the exercise would help and being physically active improved adherence, whilst lack time, interest or confidence and low self-efficacy reduced adherence. Within the treatment related construct, individualising the intervention, including goal setting, providing patient education, practicing the intervention, discussing barriers and facilitators, addressing the general health of the person, monitoring the intervention, providing and/or facilitating support, including digital interventions, and motivational interviewing could increase adherence.

The survey found that lack of time, contingency of care and poor service provision were barriers to implementing interventions to improve adherence.

5.5.9 Limitations

The main limitations of this study is related to sampling methods. While every effort was made to reach a large sample of physiotherapists working with people with SpA, no physiotherapists from NI responded. The physiotherapists who responded were also mostly experienced practitioners who are likely to have specialist insights into adherence and the condition; while this had the advantage of capturing expert insights, these views may not be representative of younger or more recently qualified physiotherapists. In contrast, the latter may have more insights into digital resources or motivational interviewing. Furthermore, this survey was limited by snowball sampling in that physiotherapists who see people with SpA as part of other services such as MSK services or private practitioners may not have been known to networks of

physiotherapists. The results of this survey are therefore generalizable to those physiotherapists' who are experienced and specialising in SpA. This survey was limited by its cross-sectional design, meaning that it was not possible to draw causality between any variables from the results or understand how the factor interacted.

A further limitation of this study is that respondents answered questions of factors affecting adherence that were proposed by the PhD Student. Although these factors were informed by the previous literature, this may have prompted the respondents to respond to factors which they would not have considered had these not been proposed.

Another limitation of this study was that the specific diagnoses within the SpA spectrum of conditions that the physiotherapists assessed and treated was not collected, so it was not possible to evaluate whether the perceptions of physiotherapists differed between those treating mainly axial versus peripheral SpA.

5.5.10 Future Research

This study has identified a number of factors which physiotherapists believe may determine adherence. Future studies could investigate these factors in more detail, with particular emphasis on determining the most important and the weighting of factors in terms of their impact on adherence. This would help identify the factors where changes could lead to the greatest impact.

Future research should consider how physiotherapists can easily measure adherence within every day practice.

Further research could focus on the extent to which physiotherapists address patient adherence to prescribed exercise during routine patient consultations to investigate if there is consistency between the perceptions of physiotherapists as reported in this study and what physiotherapists actually do in practice. There was a high level of agreement of interventions and strategies to aid adherence demonstrated in this study, but there is a need to examine the extent to which

such methods are effective in physiotherapy practice, and whether or not they are used routinely by physiotherapists. There is also a need to examine which factors are modifiable and which are non-modifiable by physiotherapists.

Future research should determine the training needs for physiotherapists to build adherence management into daily practice such as through improved communication skills and training in interventions to support adherence and evaluate if this translates into improvements in adherence rates and subsequent patient outcomes.

5.5.11 Conclusion

The aim of this survey was to explore the beliefs and perceptions of physiotherapists specialising in prescribing exercises to people with SpA on adherence to exercise programmes, focusing on the five domains in the WHO adherence model; the methods of prescribing exercise, the beliefs of the importance of patient adherence, the factors which affect adherence, the strategies and interventions to increase adherence and the barriers to employing these strategies and interventions.

This study identifies multiple factors within the five constructs of the WHO adherence model which may interact with each other to determine an individual's adherence to prescribed exercise, highlighting the complexity and heterogeneity of this issue. This survey adds that physiotherapists believe that adherence to prescribed exercise can be low.

This study identified that time was the commonest barrier for physiotherapists to implement strategies to improve adherence.

Physiotherapists should consider the factors potentially affecting each individual's adherence to exercise and aim to implement strategies to effectively address these issues, improving adherence and importantly resultant clinical outcomes.

Future studies should consider how physiotherapist measure adherence within every day practice and consider which factors best predict adherence and which interventions are most successful in improving adherence.

6 Chapter: General discussion, conclusion and recommendations

6.1 Study summaries

The overall aim of this research was to investigate the level of adherence and factors affecting adherence to prescribed exercise programmes in people with SpA. The aim was formulated after an extensive literature review to address important gaps in the literature. To meet the aims of this thesis, three studies were conducted.

The first study in this thesis was a systematic review of 10 studies investigating adherence to prescribed physiotherapy exercise programmes in people with SpA. The outcome of the systematic review showed that rates of adherence ranged from 51% to 95%. There was significant heterogeneity between studies, including in how they defined adherence and the types of exercise intervention being investigated, making comparisons difficult. Two studies identified that adherence improved following educational programmes and one single study found higher disease severity and longer diagnostic delays were associated with higher adherence. One study indicated supervised group exercise increased adherence to HEP whilst another found no difference. Three linked, consecutive studies by the same research group reported that adherence reduced over time and a further study found adherence reduced after an educational programme. From the SLR, it was therefore not possible to reach any definitive conclusions about adherence to prescribed physiotherapy programmes in people with SpA. No study within the systematic review measured adherence to an online physiotherapy programme in SpA.

The second study within the PhD study evaluated adherence to a 12-month web based programme in people with axSpA. As people with this condition are required to exercise frequently from diagnosis (commonly in their 20s or 30s) over the course of this lifelong chronic condition, online programmes have advantages in being flexible and available 24/7, without the need for travel, which may potentially benefit long term adherence. The PhD focused in detail on adherence levels of participants in the WEBPASS study in terms of: sessions engaged in and completed, levels of pre-defined good adherence, comparison of

adherence to participant choice and physiotherapy prescribed components, adherence over time and evaluation of factors which may affect adherence. In addition, interview data specifically related to adherence were analysed. This study found that the adherence rate in the WEBPASS trial was 27.6% of all sessions engaged in overall for the 12-months. It is difficult to compare this result directly to the published literature of adherence to exercise interventions in SpA due to differences in participant characteristics, length, frequency and type of intervention and differing measures of adherence. Seven of the 49 participants in the WEBPASS trial did not initiate the exercise intervention, completing no sessions at all. For those who provided adherence data for the 12-months (n=38), only seven achieved good adherence according to our pre-defined cut-off. Finding the link between how adherence affects outcomes may help understand the level of adherence required to gain the desired outcomes. This study also found that when participants started an exercise session, they were very likely to to complete the session. The study also found adherence reduced over time but not in a strictly linear fashion, with increases in adherence levels around the time of contact with the physiotherapist for study visits. Online programmes, have many advantages such as lower costs, more flexibility and availability, as well as being able to capture adherence on the same system. Individualised online exercise programmes are a viable option for some people with axSpA, particularly due to the long term and frequent exercises required in this condition, so are an option that physiotherapists should consider as part of their management of axSpA. However, it is clear that, like all interventions, this is not effective for all and strategies to identify those most likely to benefit from these methods are required, as are strategies to improve adherence with this programme. The factors which influence adherence remain unclear but from the patient view-point, symptoms, getting into a routine and support appear to play a role in influencing adherence to this intervention. Physiotherapists should encourage service users to build support networks, and incorporate exercise into their daily routine, with online exercise platforms one option to consider.

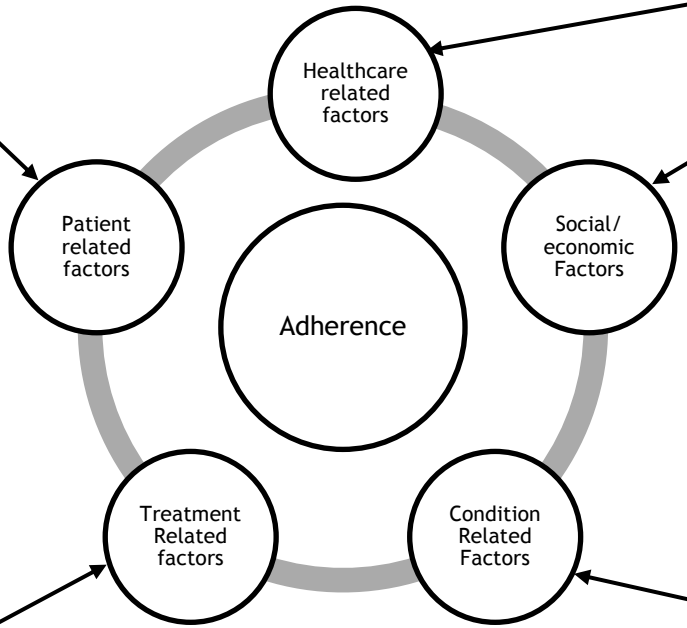
The third study within the PhD study explored the beliefs and perceptions of UK physiotherapists specialising in prescribing exercises to people with SpA, using the WHO model of adherence and focusing on: the methods of prescribing

exercise, the beliefs of the importance of patient adherence, the factors which affect adherence, the strategies and interventions to increase adherence and the barriers to employing these strategies and interventions. The findings of this national survey indicate that almost all physiotherapists believe that adherence to prescribed physiotherapy exercise is important in improving clinical outcomes in people with SpA, relevant to their practice and that they, as physiotherapists, could employ strategies to alter a person's adherence levels. However, not all physiotherapists felt that adherence to exercise was a problem in their patients and only two thirds reported that they had sufficient time to assess adherence or implement measures to address this. There were high levels of agreement of the factors affecting adherence to exercise. The healthcare related factors found were: good access to physiotherapy, effective medication for symptom control improved adherence. The disease related factors found were: concurrent mental health problems, high disease symptoms and multiple co-morbidity reduced adherence. The socio-economic factors found were: support increased adherence, while social deprivation reduced adherence. The patient-related factors found were: the belief the exercise would help and being physically active improved adherence, whilst lack time, interest or confidence and low self-efficacy reduced adherence. The treatment-related factors found were, individualising the intervention, including goal setting, providing patient education, practicing the intervention, discussing barriers and facilitators, addressing the general health of the person, monitoring the intervention, providing and/or facilitating support, including digital interventions, and motivational interviewing could increase adherence. There was some overlap between the constructs.

The survey found that lack of time, contingency of care and poor service provision were barriers to implementing interventions to improve adherence.

These three studies have contributed to a model of adherence for physiotherapists to use and is presented in fig 6-1.

Figure 6-1. Model of adherence for Physiotherapists to Consider in exercise programmes for People with SpA. Adapted from the WHO (2003) with possible factors added from this thesis investigation (R = factor from review, C=factor from cohort and S = factor from survey)



Patient-related:

- Lack of time (S)
- Lack of interest, (S)
- being afraid of exercise, (S)
- low self-efficacy & low belief exercise will help may reduce adherence. (S)
- Enjoyment, (S)
- being physically active, (S)
- believing exercise will help may increase adherence (S)

Healthcare-related:

- Good access to physio may increase adherence (S)
- Effective medication may increase adherence (S)

Socio-Economic:

- Good support may increase and lack of support may reduce adherence (C) (S)
- High levels of social deprivation may reduce adherence (S)
- Getting into a routine may increase adherence (C)

Treatment Related: Interventions that may increase adherence:

- goal setting (S)
- individualising (S) (C)
- education (S) (R) (C)
- practising exercises, (S)
- discussing barriers and facilitators (S)
- Support (C) (S)
- addressing person's general health (S)
- motivational interviewing (S)
- supervised group exercise (R)
- Digital interventions (C) (S)

Consider barriers in implementing interventions;

- lack of time, (S)
- lack of continuity of care, (S)
- service provision difficulties (S)

Condition-related:

- Concurrent mental health problems may reduce adherence (S)
- Conflicting evidence, high disease symptoms may reduce adherence or increase adherence (S) (R)
- Delay in diagnosis may increase adherence (R)
- Multiple co-morbidities may reduce adherence (S)

6.2 Contribution to knowledge

All three studies make an original contribution to knowledge in the field of adherence to exercise prescription in people with SpA. The systematic review reported in Chapter 3 was the first to assess the available literature investigating adherence to prescribed exercise in people with SpA and has been published (McDonald et al., 2019). The WEBPASS cohort study provided new evidence on the level of adherence to an individualised web-based physiotherapy programme and added to the limited knowledge of adherence to exercises in axSpA and is the first online intervention in axSpA. The online survey found new evidence that physiotherapists specialising in prescribing exercise in people with SpA knew the importance of adherence in achieving clinical outcomes, largely recognised that adherence to prescribed exercise is problematic and identified a broad range of factors which may contribute to adherence, strategies and interventions that may support adherence and barriers to implementing them. All three studies contribute to the model of adherence presented in fig 6-1 which provides physiotherapists with a suggested model for adherence to consider for each person for whom they prescribe exercises.

6.3 Recommendations for clinicians

Physiotherapists should be aware that adherence to prescribed exercise in people with SpA is variable, can be low and reduces over time, with multiple factors in several domains influencing this. Physiotherapists could use the model in fig 6-1 with each individual they prescribe exercise to in order to consider potential factors affecting adherence and to develop strategies and interventions to improve adherence, focusing on those they can alter, while being aware of other external factors that may be beyond their control, in order to optimise the chances for good adherence, and therefore improved clinical outcomes, in their patients with SpA.

6.4 Public and Patient Involvement in the Thesis

Patient and public involvement in research is recognised as best practice, to ensure that research is relevant to user needs and hence more likely to have beneficial impacts (Gray-Burrows et al., 2018). Two patient representatives sat on the WEBPASS steering group for the cohort study described in Chapter 4, who commented on the process of the study, and Debbie Cook who was the current chief executive of NASS was a co-applicant on the WEBPASS grant. Furthermore, the survey, Chapter 5, was piloted with two qualified physiotherapists prior to dissemination. However, more patient involvement in the development of research questions within the survey and the systematic review within Chapter 3 and how best to link the three research studies may have further improved the research ensuring the research was relevant to service users.

6.5 Recommendations for future research

Further research is recommended

- to find a standardised measure of adherence so meaningful comparisons between studies can be formed.
- to compare adherence across interventions.
- to better understand the link between adherence and clinical outcomes (such as pain, function, disease activity) in people with SpA.
- to confirm the factors affecting adherence as identified by physiotherapist within this thesis.
- to find which factors best predict adherence in people with SpA and which are most amenable to intervention.
- to consider the extent to which physiotherapists address patient adherence to prescribed exercise during routine patient consultations.

6.6 Conclusion

This thesis has provided preliminary data that adherence to prescribed exercise in people with SpA can be low, is variable and reduces over time. Web-based programmes appear safe and have advantages. Comparing adherence rates across different deliveries of programmes is difficult due to the heterogeneity of the interventions, participants and measurement of adherence. Once a person starts an exercise session more often than not, they complete all the exercises within the session, therefore physiotherapists should concentrate on strategies to get people started on their session. This thesis identified several new factors which possibly affect adherence. Physiotherapists could consider and discuss these factors with each patient, and problem solve with each individual to modify any factors which negatively affect adherence and can change, and maximise factors such as support networks which improve adherence. Furthermore, physiotherapists could consider several of the strategies and interventions such as goal setting and individualising interventions which might improve adherence. Overall further research is required to strengthen or confirm the findings. As such, the work contained within this thesis should be viewed as the groundwork to be built upon for further research.

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Appendix 1 Ethics for Webpass Cohort Study

WoSRES

West of Scotland Research Ethics Service

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Study title: WEB-Based Physiotherapy for People with Axial Spondyloarthritis: A Cohort Study (WEB-PASS)
REC reference: 15/WS/0229

IRAS project ID: 186902

The Research Ethics Committee reviewed the above application at the meeting held on 21 October 2015. Thank you for attending to discuss the application, along with Mrs McDonald.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Sharon Macgregor, WoSREC5@ggc.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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

Conditions of the favourable opinion

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting

Social or scientific value; scientific design and conduct of the study

The Committee asked what treatment patients would normally receive.

Dr Paul advised that there is no standard usual care. Patients would see a physiotherapist once and be given an exercise programme to do at home. They may or may not see a physiotherapist again.

It was not clear whether the website will record who is using it.

Dr Paul confirmed that patients will log on to the website and tick a box to say that they have done the exercises. They can also add comments (for example – whether they are having difficulty with a particular exercise) and the physiotherapist will see this and take the necessary action.

Informed consent process and the adequacy and completeness of participant information

It was noted in page 2 of the Participant Information Sheet that the section explaining what will happen at the first appointment also mentions what will happen at three of the visits. (ie wearing the activPAL). This information is then repeated in the "Visits 3 and 4" section and was a little confusing.

The researchers agreed to look at these sections and amend them as appropriate.

However, after the researchers left, the Committee agreed that the Information Sheet was satisfactory as this was only a minor point and that no changes are required.

Suitability of supporting information
It was not clear when the diary would be used and what information will be recorded. The Committee were not sure if compliance would be maintained if the diary had to be completed for the duration of the study.

The researchers confirmed that the diary will only be completed while the ActivPAL is being worn. Only the times when the patient goes to bed and gets up will need to be recorded.

Other general comments
It was noted that there were several places where information had still to be added ("ZZZZZZ" and "version x, dated xx.xx.xx") in the information sheet, consent form and interview schedule. However, it was presumed that this information will be completed before the documents are issued.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster]		14 August 2015
Covering letter on headed paper [Covering Letter]		29 September 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter]		12 August 2015
GP/consultant information sheets or letters [GP letter]	V1	16 July 2015
Interview schedules or topic guides for participants [Exit Telephone Interview]	1	14 August 2015
Letter from funder [Letter of Award from ARUK]		20 May 2015
Letters of invitation to participant [Invitation Letter]	V1	16 July 2015
Other [Telephone Interview]	1	17 August 2015
Other [WPAI Questionnaire]		
Other [BASFI Questionnaire]	V1	18 September 2003
Other [BASDAI Questionnaire]		
Other [EDQ5 Questionnaire]		
Other [Exercise Motivations Questionnaire]		

Other [Exercise Adherence Questionnaire]		
Other [Activity Diary]	V1	14 August 2015
Participant consent form [Consent Form]	V1	21 September 2015
Participant information sheet (PIS)	V1	21 September 2015
REC Application Form [REC_Form_07102015]		07 October 2015
Research protocol or project proposal [Protocol]	V1	21 September 2015
Summary CV for Chief Investigator (CI) [Lorna Paul CV]		23 January 2015
Validated questionnaire [ASQoL]		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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

After ethical review

Reporting requirements

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

Notifying substantial amendments
Adding new sites and investigators
Notification of serious breaches of the protocol
Progress and safety reports
Notifying the end of the study

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

User Feedback

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

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WS/0229	**Please quote this number on all correspondence**

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

Yours sincerely

for
Dr Stewart Campbell
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Dr Maureen Travers, NHS Greater Glasgow and Clyde

West of Scotland REC 5

Attendance at Committee meeting on 21 October 2015

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Stewart Campbell	Consultant Physician & Gastroenterologist **(CHAIR)**	Yes	
Dr Roddy Chapman	Consultant Anaesthetist	Yes	
Dr James Curran	GP	Yes	
Dr Gillian Harold	Consultant Radiologist	No	
Mrs Naomi Hickey	Research Nurse	Yes	
Dr Gillian Kerr	Consultant Physician	Yes	
Dr Ahmed Khan	Consultant Psychiatrist	Yes	
Professor Eddie McKenzie	Statistician	Yes	
Canon Matt McManus	Parish Priest (Vice-Chair)	Yes	
Ms Janis Munro	Key Account Manager	Yes	
Mrs June Russell	Retired (Research Chemist)	Yes	
Mr Charles Sargent	Retired	Yes	
Dr Marcel Strauss	Consultant Radiologist	Yes	
Mrs Liz Tregonning	Retired (Special Needs Teacher) (Alternate ViceChair)	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Dr Judith Godden	Scientific Officer/Manager
Mrs Sharon Macgregor	Co-ordinator
Diane Murray	Staff Nurse

Appendix 2 Patient Information Sheet from Webpass Study

Participant Information Sheet

For the study entitled: WEB-based Physiotherapy for People with Axial Spondyloarthritis (WEB-PASS)

Why have I been approached about this study?

We are inviting you to participate in this study as you have ankylosing spondylitis or axial spondyloarthritis ("axial SpA" is used to refer to both from here on) and have been identified by your healthcare professional as someone who requires a long-term exercise and physiotherapy programme, so would be suitable for inclusion in this study. This study is a collaboration between NHS Greater Glasgow and Clyde and the School of Medicine at the University of Glasgow; it is funded by Arthritis Research UK.

Before you decide whether or not to take part it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

You will need to have internet access to participate in this study. Thank you in advance for taking the time to read this information leaflet.

What is the purpose of the study?

Regular exercise is a core part of the management of axial SpA, as we know that exercise can increase mobility, flexibility, strength, physical activity, pain, mood and quality of life in this condition, in addition to the more general health benefits of regular activity. However, it is not easy for people to take part in exercise regularly over the longer term for a variety of reasons such as work and family commitments, motivation, and lack of resources and supervision. There is therefore a need to develop and study new ways of delivering exercise for conditions such as axial SpA. The internet offers the potential to deliver personalised physiotherapy programmes under the supervision of a trained

physiotherapist and has shown potential in a number of other chronic conditions. This study will investigate the effectiveness of, and adherence to, a one year web-based exercise programme specifically developed for axial SpA.

Do I have to take part?

No; taking part in research is entirely voluntary; therefore it is up to you to decide. You should read this information leaflet and if you are interested in taking part you should phone the research team on the contact details at the bottom of this information leaflet and we will arrange your 1st appointment. When you attend that appointment you will be screened to make sure it is safe and suitable for you to take part in the study. If you wish to go ahead you will be asked to sign a consent form to show that you agree to take part. You would still continue to receive your medications and treatments under the care of your rheumatology team as per standard clinical practice.

If you decide to take part you are still free to withdraw at any time and without giving a reason. Your decision will not have any effect on the standard of care you receive.

What will happen to me if I take part?

There are a total of four study appointments over one year which will take place at your local hospital physiotherapy department. The first visit should take approximately 90 minutes, while the other 3 visits should take no more than 1 hour.

*At your **first appointment**, you will be asked some questions to ensure you are eligible to take part in the study. If you are eligible and wish to take part, you will be asked to provide written informed consent and baseline study assessments will be completed. This will involve completing a walking test and five questionnaires, an assessment of your posture and movement of your spine. At 3 of the visits you will also be given a small physical activity monitor to wear (attached to one thigh) which will measure your walking activity for one week while you will be asked to keep an activity diary during this same week.*

*At the **second visit** (approximately one week after the first visit) your specific exercise goals and programme will be devised. Your physical activity monitor will be removed and you will be provided with an individualised web-based physiotherapy exercise programme.*

***Between visits**: You will use a computer, laptop or tablet device in your own home to access your exercise programme via the internet. You will be asked to logon to your exercise programme on the study web-site five times per week in order to perform your exercises (approximately 30 minutes at a time) and complete the brief online exercise diary. Your physiotherapist will provide you with information on how to use the website and how to follow your exercise programme. The exercise programme will include the standard exercises recommended for axial SpA which will have been tailored to your personal goals and ability. Your physiotherapist will phone you once a week for the first 2 weeks; after this the physiotherapist will review your programme every two weeks and will contact you by email with any changes.*

In addition, if you agree to be contacted about this, you may be asked to take part in a telephone interview during the project. During this interview we will ask you about your adherence to your exercise programme, reasons why you complete or find it difficult to complete your online exercise programme and what other activities or exercise you do. This telephone call will be recorded, anonymised and transcribed by a member of the research team.

***Visits 3 and 4:** You will be invited back to repeat the assessments carried out at your first assessment after 6 and 12 months. At these assessments you will also be given an activity monitor attached to the front of your thigh using a waterproof dressing for one week, after which you will remove it and post back to the research team in a pre-paid envelope.*

What are the possible disadvantages or risks of taking part?

There are no major risks in taking part in this study. Regular exercise is key part of the management of axial SpA and is recommended for all people with these conditions. Some people may feel breathless while completing the exercises and may notice some muscle soreness or tiredness which is generally short lasting. A small number of people may find wearing the activity monitor causes a minor skin irritation. This is rare but should this be the case, we would advise participants to remove the activity monitor and to contact us.

What are the possible benefits of taking part?

We hope taking part in the study will improve your health and condition as the existing evidence suggests regular exercise is helpful for these, however we cannot promise that the study will help you personally. The information obtained from this study may help improve the treatment of other people with axial SpA.

What about expenses or payments involved with taking part in the study?

The exercise programme will be free; however you will be required to have a computer, tablet device or smart phone and internet access to take part (unfortunately we are unable to cover these costs). You will not be paid for participating in the study, but we have funding to help contribute to your travelling expenses (£10 per study visit). You will not have to pay postage for sending back the activity monitors (pre-paid postage).

What happens when the research study stops?

These exercise programmes are designed to give you an individualised exercise programme to help you exercise at home along with advice on how to exercise in the long term and self-manage your condition. After taking part in this research project you should continue exercising on your own independently. You will still be allowed access to the website when the study finishes.

Will my taking part in this study be kept confidential?

Yes, all information collected from you during the study will be kept strictly confidential and treated with normal ethical and legal practice for data collection. With your permission we will inform your own GP about your involvement in this study. In addition representatives of the Sponsor NHS Greater Glasgow and Clyde, may access your medical notes where they relate to the study in order to monitor that the study is being carried out properly.

What happens if new information becomes available?

Sometimes new treatment information becomes available. Although this is unlikely for this study, but should this happen during the study the research team will tell you and discuss whether you should stay in the study. If you decide not to continue, this will not affect your care in any way. If you decide to continue you will be asked to sign an updated consent form.

What will happen if I don't want to continue in the study?

You can withdraw at any time without giving us any reason. However, as one of the aims of this study is to find out what sorts of things affect the use of this programme, we would ask to complete a brief telephone interview with you to understand the reasons why you withdrew from the project. This will help us understand the difficulties people may have with completing a web-based exercise programme over 12 months. If you do withdraw we would also encourage you to keep in contact with us and let us know your progress. Any information collected prior to your withdrawal will still be used.

What If there is a problem?

Should you have a concern about any aspect of the study, in the first instance you should contact the research physiotherapist, using the contact details below, who will do their best to answer any questions. If this does not resolve the issue, and you would like to formally complain you can do this through the NHS Complaints Procedure, details can be obtained from the Patients, Relations and Complaints Office in Scotland and the Patient Advice and Liaison Service in England.

Independent advice about the study can be obtained from Jim Woodburn, Professor of Rehabilitation, tel: 0141 3318483.

What happens to the results of the research study?

It is intended that the results of the study will be published in medical literature and/or presented at healthcare conferences. All data will be anonymised before this and no-one will be able to identify you. Should you wish to know the results of the study then we will send you a summary of the main findings once the research is complete.

Who is organising funding the research?

This study is funded by Arthritis Research UK.

Who has reviewed this study?

All research in the NHS is looked at by the Research Ethics Committee, an independent group of people who aim to protect patient safety, rights, well being and dignity. This study has been reviewed and given favourable opinion by the West of Scotland Research Ethics Committee.

Participation, further information and contact details.

Should you wish to take part in this study or if you require any further information about this research study please contact:

Marie Therese McDonald
Advanced Physiotherapist
Therapy Department,
Queen Elizabeth Hospital
1345 Govan Road,
Glasgow
G514TF

Tel: **01413303734**
Email: **M.McDonald@nhs.net**

Thank you for taking the time to read this information leaflet

Appendix 3 Interview Schedule for the Qualitative Programme Evaluation for Web-pass

WEBPASS: Telephone Interview Schedule

Topic	Questions
Section 1: Introduction	My name is xxxx and I'd like to ask you some questions about the web-based physio research study that you have been taking part in. This should take about 10-15mins, is that ok? I would also like to record our conversation, is that ok?
Section 2: Access & exercising at home	How do you access the website? Did you use a computer, laptop, tablet or phone? Have you had any issues accessing the website? What do you think about web-based physio? What is good or not good about the website? Sometimes we are criticised for not exercising in a group or the community. What are your thoughts about following an exercise programme on your own, in your own home?
Section 3: Diagnosis and exercise history	How long have you been diagnosed with AS/axial SpA? Do you think it is important to exercise with your condition? If so what do you think the benefits are? Before participating in the study, had you been advised by your doctor or physiotherapist that you should exercise? If so what kind of exercise? What exercise have you done in the past for your AS/axial SpA? Have you followed exercises on the internet (eg. YouTube) for your AS/axial SpA diagnosis? Have you followed the exercise programme from NASS? Have you received an exercise programme from a physiotherapist for your AS/axial SpA diagnosis? [If so, what?] What are your thoughts about following an exercise programme over the internet? How does this web-based physio exercise programme compare to exercise programmes you have followed in the past?

Section 4: Adherence	Roughly how often did you do your web-based exercise programme every week? You said you did your programme X times per week. How did you fit that into your day? Were there times when it was difficult to exercise X times a week? If so what circumstances made it difficult? So when it was difficult what did you do to try and get your programme done? Could we have done anything to have supported you to exercise X times a week more often? (prompts could be added depending on what people say) Do you think being in a research study has affected how often you complete your exercise programme? Have you noticed any benefits since taking part in the exercise programme? If so, what? Have you noticed any increased pain since starting the exercise programme? If so, where is the pain? Throughout the last six months did the amount you did your exercises change? What would help/helps you do regular exercise? Do you do any other exercises as well as the web-based programme? If so, what do you do? [How often/where/with who?] Do you log on to the website each time you do your exercise programme? If no, why not? Do you tick the box to say that you have done your exercises each time you do them? If no, why not?
12 month time point only Section 5: Future plans	Thanks for your comments; they are really useful to us. And now that the official period of the project is finished, do you have any plans to continue with your web-based exercise programme?

	If you were offered web-based physio again would you take it up?
Section 6: Closing	That is all my questions for you now, is there anything else that you would like to feedback to us? Well thank you very much for taking part in the study and for taking the time out to speak to me today as your feedback is really useful.

Appendix 4 Adherence to prescribed Exercise component and Patient Choice Component for Each Participant

Participant Number	Total Possible Number of Prescribed Exercise Sessions	Number of Prescribed Exercises Sessions Completed	% of Prescribed exercises completed	Total Possible Number of Patient Choice	Number of Sessions of Patient Choice Completed	% of Patient Choice Exercises Completed	Completed study?
1	156	93	59.6	104	58	55.8	Yes
2	156	72	46.2	104	34	32.7	Yes
3	156	7	4.5	104	1	1	No
4	156	88	56.4	104	4	3.8	Yes
5	156	21	13.5	104	31	29.8	Yes
6	156	95	60.9	104	50	48.1	Yes
7	156	79	50.6	104	30	28.8	Yes
8	156	0	0	104	0	0	Yes
9	156	9	5.8	104	4	3.8	No
10	156	35	22.4	104	1	1	Yes
11	156	70	44.9	104	35	33.6	Yes
12	156	156	100	104	104	100	Yes
13	156	8	5.1	104	1	1	Yes
14	156	22	14.1	104	16	15.4	No
15	156	0	0	104	0	0	Yes
16	156	4	2.6	104	0	0	No
17	156	43	27.6	104	0	0	Yes
18	156	38	24.4	104	8	7.7	Yes
19	156	64	41	104	14	13.5	Yes
20	156	2	1.3	104	0	0	No
21	156	0	0	104	0	0	No
22	156	32	20.5	104	14	13.5	No
23	156	26	16.7	104	20	19.2	No
24	156	81	51.9	104	27	26	Yes
25	156	20	12.8	104	8	7.7	Yes
26	156	102	65.4	104	33	31.7	Yes
27	156	0	0	104	1	1	Yes
28	156	36	23.1	104	6	5.8	Yes
29	156	1	0.6	104	0	0	Yes
30	156	0	0	104	0	0	No
31	156	147	94.2	104	78	75	Yes
32	156	15	9.6	104	2	2	No
33	156	134	85.9	104	47	45.2	Yes
34	156	101	64.7	104	68	65.4	Yes
35	156	11	7	104	8	7.7	Yes

36	156	0	0	104	0	0	Yes
37	156	117	75	104	59	56.7	Yes
38	156	30	19.2	104	3	2.9	Yes
39	156	0	0	104	0	0	Yes
40	156	144	92.3	104	83	79.8	Yes
41	156	118	75.6	104	50	48.1	Yes
42	156	8	5.1	104	3	2.9	Yes
43	Excluded						
44	156	10	6.4	104	9	8.65	Yes
45	156	100	64.1	104	34	32.7	Yes
46	156	83	53.2	104	33	31.7	Yes
47	156	137	87.8	104	7	6.7	Yes
48	156	0	0	104	0	0	No
49	156	86	55.1	104	10	9.6	Yes
50	156	69	44.2	104	11	10.6	Yes

Appendix 5 Prescribed Component Fully Completed or Incomplete

Participant	Total Number of Physio Prescribed Exercises Adhered to.	Were all exercises within the session adhered to (number above sessions fully adhered to number below sessions unfinished)
1	93	86
		7
2	72	65
		7
3	7	7
		0
4	88	63
		25
5	21	16
		5
6	95	22
		73
7	79	77
		2
8	0	-
		-
9	9	0
		9
10	35	29
		6
11	70	17
		53
12	156	150
		6
13	8	8
		0
14	22	2
		20
15	0	-
		-
16	4	0
		4
17	43	3
		40
18	38	17
		21
19	64	29
		35

20	2	1
		1
21	0	-
		-
22	32	29
		3
23	26	5
		21
24	81	48
		33
25	20	9
		11
26	102	97
		5
27	0	-
		-
28	36	33
		3
29	1	1
		0
30	0	-
		-
31	147	147
		0
32	15	6
		9
33	134	118
		16
34	101	93
		8
35	11	1
		10
36	0	-
		-
37	117	98
		19
38	30	26
		4
39	0	-
		-
40	144	78
		66
41	118	105
		13
42	8	6
		2
43	Exclude	0
		0
44	10	8
		2
45	100	0
		100
46	83	68

		16
47	137	133
		4
48	0	-
		-
49	86	82
		4
50	69	67
		2

Appendix 6 Ethical Approval for survey in Chapter 5

University of Glasgow

19th June 2019

MVLS College Ethics Committee

Project Title: Exploring Physiotherapist Perceptions of what Affects patient adherence to Exercise in people with Spondyloarthritis

Project No: 200180170

Dear Dr Siebert,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End April 2020
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

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Glasgow
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Appendix 7 Participant Information Sheet at Start of Survey Chapter 5

Dear Physiotherapist,

You are invited to take part in this study by answering a survey regarding your experiences of patient adherence to physiotherapy prescribed exercise in spondyloarthritis. It is up to you to decide whether or not to take part. There are no risks involved in taking part and you will remain anonymous. If you decide to start the questionnaire you are free to stop at any point. Filling in the questionnaire completely or in part indicates consent to take part in this study. The questionnaire will normally take 10 minutes to complete and we ask you complete this only once.

The results will contribute to a doctoral project with the purpose of finding out if physiotherapists believe clinical outcomes can be influenced by adhering to prescribed exercises in people with spondyloarthritis, factors which might affect a person's adherence, methods which can be employed by physiotherapists specialising in spondyloarthritis to increase patient adherence and what barriers physiotherapists may face in employing these methods.

There are, at this time, no known benefits for you to take part in this survey.

We would appreciate if you could forward this survey onto any other physiotherapists within the UK who regularly see people with spondyloarthritis.

The researcher will be happy to answer any questions about this study please email on:

Appendix 8 Copy of Survey Questions used in Electronic Survey of Physiotherapist in Chapter 5

Do you work as a rheumatology physiotherapist seeing patients with spondyloarthritis regularly (at least every month)? *(Circle your response below).*

Yes
No. **Thank you, you have now completed the survey.**

Do adult patients make up more than 80% of your clinical case load? *(Circle your response below).*

Yes
No. **Thank you, you have now completed the survey.**

Please circle the range that best describes the number of years since you graduated as a physiotherapist.

0-2
3-5
6-10
11-15
16-20
21-30
>30

Please indicate the country you currently practice physiotherapy.

Scotland
Northern Ireland
Wales
England
Rest of the world. **Thank you, you have now completed the survey.**

The following questions relate to patient adherence to physiotherapist prescribed exercises in spondyloarthritis. For this study:

'Adherence' is defined as the extent to which a patient follows the prescribed exercises by you, their physiotherapist. This term is often used inter-changeably with 'compliance'.

Please indicate the extent to which you agree or disagree with the following statements by placing a cross within the box which best corresponds to your answer.

Treatment outcomes in Spondyloarthritis can be positively affected by patients adhering to,	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
Independent exercise programs (e.g. specific exercises you have prescribed verbally or in writing)					

How do you prescribe exercise programmes in SpA. Tick all which apply:

I use digital resources such as apps, or youtube videos	
I give written instructions such as physio tools or exercise sheets	
I provide demonstrations	
I encourage people to exercise in a group.	
I direct people to the NASS website or booklets	
Other please specify	

In your experience, in people with spondyloarthritis, do these factors affect adherence to prescribed exercise?

	Frequently **Increases** Adherence	Sometime **Increases** Adherence	**Does not** affect Adherence	Sometimes **decreases** Adherence	Frequently **decreases** Adherence	Don't Know
Being afraid of exercise						
Low self-confidence or self-efficacy in ability to exercise						
The person believes the exercises will not the symptoms or outcomes						
Lack of time						
Lack of interest						
High Motivation						
Multiple Co-morbidities						
Disease symptoms such as pain, fatigue, stiffness, frequent flares						
High levels of Social Deprivation						
The belief that the exercises will help						
Support from friends, family, work or from a charity						
Lack of support from friends, family, work or from a charity						
Con-current mental health condition(s) such as anxiety or depression						
Enjoying the exercises that have been prescribed						

The patient receives medicine that is effective in relieving the symptoms of spondyloarthritis						
Already being physically active						
Good Access to Physiotherapy						

What methods have you found physiotherapists can use to improve patient adherence to physiotherapist-prescribed exercise? Please indicate the extent to which you agree or disagree with the following statements.

	Yes frequently Increases a Persons Adherence	Yes sometimes increases a person's adherence	Has no effect on a persons adherence.	Not sure or have no experience of this
Individualising the exercise programme to the patient (e.g. reduction in complexity, tailoring to patient lifestyle, modification for pain response, individually tailored information)				
Goal Setting with the patient				
Providing patient education (either printed or verbal) of the importance of the exercise.				
Providing patient education (either printed or verbal) on the expected outcomes or consequence.				
Providing patient education in the form of supportive material or links to additional material, links to charities				
Practicing the exercises within the consultation including physiotherapist demonstration, patient practice and feedback, checking the patient understands the instructions				
Motivational Interviewing				
Discussing the barriers and facilitators to adherence and discussing ways to overcome the barriers				
Monitoring of patient adherence, including use of reminders, follow up (face to face or via telephone), use of exercise diaries and feedback to the patient on their adherence				

Addressing the general health of the patient, including referral to GP or Allied Health colleague regarding issues which may impact on adherence such co-morbidities, medication or diet				
Involvement of the patient's support person, e.g. including them in the consultation such as exercising alongside the patient				
Physiotherapist communication skills, including active listening and being more empathetic or persuasive with the patient				
Novel Interventions, such as web-based interventions exercises delivered over internet, or apps, or you-tube videos of exercises				
Other please specify				

Do any of the following barriers prevent you from employing methods to improve patient adherence to a self-management strategy? Please indicate the extent to which you agree or disagree with the following statements which best describes your response to a-j below.

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know/ have no experience of this.
I do not have enough time to assess patient adherence with prescribed strategies					
I have limited knowledge/ skills in assessing patient adherence					
I do not have enough time to provide adherence aiding strategies					
I am uncomfortable discussing adherence with patients					
I have limited knowledge/ skills in providing adherence aiding strategies					
I have limited access to resources such as patient educational materials					
There can be a lack of continuity of care; patients often see different physiotherapists					
I don't believe that I can alter patient adherence-either patients adhere or they don't					
I don't believe that adherence is a problem with my patients					
I don't believe that improving patient adherence is relevant to physiotherapy practice					
Other please specify					

Thank you for completing this survey, your time and views are greatly appreciated