

Ankylosing Spondylitis:

Hard to say, hard to see,
time to hear

May 2014
Gail Beer
Matt James



♥2020
HEALTH
WELLBEING
RESPONSIBILITY

This research was made possible by an unrestricted educational grant from AbbVie Ltd for which we are very grateful. The views expressed in this document are those of the authors and do not necessarily reflect those of any representative organisation. All facts have been cross-checked for accuracy as far as possible.

abbvie

Contents

Foreword	3
About the authors	4
Executive summary	5
Introduction	8
Project objectives	9
Methodology	9
Background	10
Taking action	12
Awareness	14
Understanding	16
Action	23
Medication	24
Exercise	25
Occupational therapy and health	26
Lifestyle advice	27
Active life	30
Conclusion	33
Appendices	34
Steering Group members	34
Workshop participants	35
References	36

Foreword

Ankylosing spondylitis. It's not the easiest of names to say, nor does it lend itself to devising catchy media headlines or health campaigns. If it's hard to say, it's equally hard to see. A lack of awareness of the condition, including among GPs and clinicians, only helps to compound the problem. AS is often overlooked, misdiagnosed or diagnosed late as a condition. "You don't look ill" is a common response from friends, family and employers alike who, noticing no visible condition, are commonly inclined to question what is actually wrong!

But for the 200,000 people with this condition - roughly twice the number who have Parkinson's disease or multiple sclerosis – it is a very real and serious issue. AS is a condition which causes great pain, restricting mobility and the ability to perform every day tasks such as washing your hair, opening a car door or pouring water into a kettle. The daily pain and fatigue can simply wear you down.

Every single person with AS will have a different experience, but here is mine. I, like many others, was diagnosed very late in life. As a teenager I was very active and sporty, playing cricket and rugby and tennis, and competing in badminton in county and national competitions. I began to experience real stiffness and soreness in the neck and the spine after matches. As the years went by, the stiffness became more routine and more painful, and progressively the flexibility in my spine and my neck grew less and less.

By my late twenties, the stiffness and the pain were periodically debilitating, and affecting my sport and my general health. As it got worse, I tried everything, including various "alternative" therapies and mail-order remedies. Direct steroid injections into painful, swollen joints weren't helping any more. It wasn't until I was in my late 30's that I finally had blood tests, visited a rheumatologist, and first heard of the condition called ankylosing spondylitis. Much of the damage to my joints had been done, but this diagnosis was finally the start of a coherent programme of treatment involving appropriate physiotherapy and anti-TNF injections.

The diagnosis and appropriate treatment may have come late for me, but it has been transformative. My working, family and social life are so much more manageable and enjoyable. I won't be playing rugby for Wales (there was never much chance of that anyway, though the ambition of every Welsh dad!) – but along with the right medication and exercise I now live largely without pain, without fatigue, and I am as active and productive as I've ever been. With that first hand experience of living with AS, I want the Government to help other people with AS, now and in the future, to get the best care so that they can stay active and in work for longer, affording them a good quality of life. That is why I welcome this report by 2020health as it aims to not only raise awareness of AS but also rates of diagnosis and the quality of long term care and treatment patients receive. By identifying best practice we must strive to increase the participation and responsibility of patient, professional and policy maker in AS care and treatment. The recommendations and proposals set out in this report help to initiate this process.

AS may be hard to say and hard to see but it is certainly time to hear about it, loud and clear.

Huw Irranca-Davies MP

About the authors

Gail Beer

Director of Operations, 2020health

Gail worked in the NHS for over 30 years, latterly as an Executive Director at Barts and the London NHS Trust. She trained as a general nurse at St Bartholomew's Hospital before undertaking a course in Renal Nursing at the Royal Free Hospital. After a number of senior nursing posts within London she moved into management, taking a Masters in Health Management at City University, before becoming Director of Operations at BLT. Since leaving Barts and the London NHS Trust she has worked as an independent consultant in healthcare in both the NHS and the private sector. Gail's main interests are in creating a society that values the contribution older people make, compassion in caring and preventing disease caused by poor lifestyle choices.

Matt James

Research Fellow, 2020health

Matt has a particular interest in the intersection of values, health, technology and public policy. As an independent consultant, he has a wide ranging portfolio of expertise which spans the arenas of public policy, academia and the third sector, including working in Parliament as a parliamentary researcher for a MP and shadow minister. Skilled in research, administration and new media development, Matt has convened numerous series of public symposia which have brought together key stakeholders to discuss the ethical, social and legal implications of new technologies and health. Matt has an undergraduate degree in political history and sociology as well as a Master's degree in bioethics and medical law. He was recently elected as a Fellow of the Royal Society of Arts and Commerce (FRSA).

Executive Summary

Spondyloarthritis (or spondyloarthropathy; SpA) is the name given to a family of inflammatory rheumatic diseases. Axial spondyloarthritis or axial SpA (often abbreviated to axSpA) refers to a particular form of spondyloarthritis in which the predominant symptom is back pain.

This report focuses primarily on ankylosing spondylitis (AS), a defined disease of axSpA. AS is a chronic spondyloarthropathy that primarily involves the spine. The cause of AS is unknown but there is a strong genetic component and prevalence is estimated to be up to 0.2–0.5 percent of the adult Caucasian population (Braun, Bollow & Remlinger 1998). Although twice as many people suffer from AS as multiple sclerosis, more people are aware of the latter as a condition.

There have been many good initiatives developed over the past couple of years around spondyloarthropathies which have helped to raise the profile of the condition, but there is still more to be done. Further work is needed to clearly communicate the value of early diagnosis to patients, professionals, Health and Wellbeing Boards, NHS England and CCGs, as well as to those developing quality standards such as National Institute for Health and Care Excellence (NICE), the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) and Quality and Outcomes Framework (QOF).

Recognising these initiatives and the identified forms of best practice, this report compliments existing work and focuses on the sustainable application of recommended standards. In so doing the hope is to increase the participation and responsibility of patient, professional and policy maker in AS care and treatment.

By reviewing the literature this report has developed a pathway for the patient to follow through the stages of diagnosis, referral and treatment (see Figure 1). Four themes have been identified which cut through key sections of the pathway and summarise the main issues requiring specific attention and response at that particular point.

The four key themes are:

- **Awareness**
- **Understanding**
- **Action**
- **Active life**

Executive Summary

Practical and sustainable solutions are offered in response to help to improve patient experience and treatment. Based upon this review a series of key recommendations are offered:

	Recommendation	Action to be taken by:
	Awareness	
1	Adoption of AS patient pathway as an algorithm for AS diagnosis and treatment.	NHS England CCGs
2	A national awareness campaign to create greater understanding of AS and enable early diagnosis and referral. Heightened awareness of AS as a cause of back pain so it is more readily considered as a default diagnosis.	Health & Wellbeing Boards Public Health England NHS England CCGs
	Understanding	
3	Action the introduction of clinical guidance for spondylorthritis.	NICE
4	Improve GP awareness of AS diagnosis and early intervention, including education in AS and inflammatory back pain.	Royal College of General Practitioners CCGs
5	Explore the development of shared care models using best practice.	CCGs
6	Review MRI capacity within the NHS to maximise efficiency and deliver value for money.	CCGs Acute trusts
7	Train all radiologists in SpA MRI interpretation. The British Society of Skeletal Radiologists should provide national guidelines to ensure these SpA MRI protocols have their endorsement.	Royal College of Radiologists British Society of Skeletal Radiologists Health Education England
8	AS and IBP to be recognised in the national back pain pathway with clear and robust clinical guidance for diagnosis and treatment.	NICE

Executive Summary

	Recommendation	Action to be taken by:
	Action	
9	A Quality Standard for axSpA to be swiftly developed, including clear criteria for the holistic care of patients with axSpA.	NICE
10	Preferential and reduced rates to gyms to be made available to those with AS to aid access to exercise facilities. Exercise prescriptions to be made available where appropriate.	Health and Wellbeing Boards CCGs Public Health
11	Occupational therapy to become a recognised part of the primary care clinic.	Health & Wellbeing Boards CCGs
12	Every person diagnosed with AS to receive an annual appointment with a specialist for a review of their condition. Key aspects to include review of medication; range of movement; impact on work and social activities; co-morbidities and mental health.	CCGs
13	Application and promotion of technology-based solutions to help empower patients to manage their own conditions.	NHS England CCGs
	Active Life	
14	Clear and practical guidance on how to manage inflammatory back pain in the workplace to form part of the Government's health, work and wellbeing initiative.	Department of Health
15	Employers to develop strategies for getting people back into work. Small businesses to work with larger organisations to exchange ideas and best practice.	Occupational health Health & Wellbeing Boards Employers
16	Every patient to be directed to, and put in contact with, an appropriate patient support group.	GP Health and Wellbeing Boards

Introduction

Spondyloarthritis (or spondyloarthropathy; SpA) is the name given to the family of inflammatory rheumatic diseases. Axial spondyloarthritis or axial SpA (often abbreviated to axSpA) refers to a particular form of spondyloarthritis in which the predominant symptom is inflammatory back pain. The term 'axial SpA' is increasingly being used among rheumatologists and other medical professionals with the publication of the new classification criteria, recently developed by the Assessment of SpondyloArthritis International Society.

The diagnosis of axSpA is primarily based upon inflammatory back pain, which is associated with inflammation to an area of the lower back called the sacroiliac joints. Inflammation of the sacroiliac joints, also named sacroiliitis, can be detected on x-ray by a rheumatologist. Given that it may take considerable time (sometimes more than a decade) for these changes to show up on x-ray, sacroiliitis may or may not be present in a diagnosis of axSpA. Therefore, within the axSpA group, there are two subgroups:

- **Ankylosing Spondylitis (AS):** the diagnosis when the x-ray changes indicative of sacroiliitis are clearly present
- **Non-radiographic axial spondyloarthritis (nr-axSpA):** the diagnosis when x-ray changes are not present but changes on MRI scans or typical clinical symptoms occur in the presence of a positive blood test for a gene marker called HLAB27

This report will primarily address issues concerning AS, a chronic spondyloarthropathy which mainly involves the spine. The cause of AS is unknown but there is a strong genetic component and prevalence is estimated to be up to 0.2–0.5 percent of the adult Caucasian population.

Although twice as many people suffer from AS as multiple sclerosis, more people are aware of the latter as a condition. This is reflected in the average length of time it takes for a diagnosis of AS to be made. Between onset of the disease and correct diagnosis there is a delay of between 8.5 – 10 years, although in some cases the delay can be up to 30 years or more. A contributing factor may be the lack of any visible clinical signs particularly in the early stages of this disease.

There have been many good initiatives developed over the past couple of years around spondyloarthropathies, including 'Looking Ahead' (AS), 'Talking AS' and 'Forgotten conditions'. These have helped to raise the profile of the condition but there is still more to be done, including clear communication of the value of early diagnosis to patients, professionals, Health and Wellbeing Boards, NHS England and CCGs, as well as to those developing quality standards such as National Institute for Health and Care Excellence (NICE), the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) and Quality and Outcomes Framework (QOF).

Introduction

Project objectives

Recognising the initiatives that have set out forms of best practice, this report focuses on sustainable applications of recommended standards. In doing so, the hope is to increase the participation and responsibility of patient, professional and policy maker in AS care and treatment. The key objectives are to:

- Address the weaknesses and obstacles encountered in the provision and delivery of care within current restraints
- Identify practical and sustainable actions and solutions for the future which incorporate the latest best practice and recommendations

Methodology

A selection of research methods were employed to gather evidence and perspectives for the project. The work was undertaken between June and September 2013 and consisted of two key strands:

- **Desk-based literature review and research** – Reviewing and evaluating the range and variation of recommendations and ‘best practice’ guidance for AS care and treatment. This research was used to inform the stakeholder workshop.
- **Stakeholder workshop** – Identifying key obstacles and hindrances to patient education and referrals. Space was given for open dialogue and the exchange of ideas to help develop practical and realistic solutions to these issues.

The project has benefited from the support of an external steering group of unpaid experts. 2020health discussed the emerging themes and recommendations from the research with these experts in a number of meetings.

2020health is also grateful to the input of Dr Jane Martindale and the Patient and Public Involvement Group at Wrightington Wigan and Leigh NHS Foundation Trust, who kindly reviewed and offered comments on the patient pathway diagram.

Background

Ankylosing spondylitis (AS) is a form of arthritis and one of its main symptoms is inflammatory back pain (IBP), affecting the spine, including muscles and ligaments. Those who have AS can experience deformity and disability throughout their adult years, with symptoms such as back pain and stiffness.

To minimise both the effects of disease progression and complications, the following three key actions are required:

- **Early recognition**
- **Prompt appropriate treatment**
- **Careful long term monitoring**

AS: The Key Facts

AS is an inflammatory condition of the spine.

'Ankylosing' means fusing together. 'Spondylitis' means inflammation of the vertebrae. Ankylosing spondylitis describes the condition where some or all of the joints and bones of the spine fuse together.

AS is part of the group of rheumatic conditions known as spondyloarthropathies (SpA). The four sub-groups of the SpA family are:

- (a) Ankylosing spondylitis (AS)
- (b) Psoriatic arthritis (PsA)
- (c) Reactive arthritis
- (d) Enteropathic arthritis – an arthritis associated with the occurrence of inflammatory bowel disease.

Usually beginning in adolescence or early adulthood, AS is a chronic progressive disease characterised by periods of fluctuating intensity and leading to slowly increasing spinal and peripheral joint damage.

People with AS can experience repeated episodes or flares of inflammation at different sites of the spine.

With repeated episodes of inflammation and recovery, extra bone or 'ankylosis' may form where the inflammation has occurred.

Prevalence of AS is estimated to be between 0.2 – 0.5% of the adult Caucasian population.

The outlook of patients with AS has improved significantly over recent years with many able to maintain an active life.

Background

Prevalence

AS affects 2–5 adults per 1000 in the UK (Braun, Bollow and Remlinger et al, 1998). It is likely that some 200,000 people suffer from AS in the UK, around twice the number of people with multiple sclerosis (NASS 2010a: 6). Fifty percent of people with AS also experience inflammation and damage in other parts of their body, particularly in the hip, eye and gut.

Symptoms

While there are common symptoms characteristic to AS, GPs and other primary care professionals can sometimes find it difficult to distinguish these from other more common kinds of spinal pain. The key symptom in early forms of AS is inflammatory back pain (IBP), with gradual onset of back pain especially at night and following periods of immobility. Sleep is therefore disturbed for many, who feel the need to get out of bed and move about to reduce the pain and stiffness.

In general, AS causes lifelong spinal pain and restriction and limits affected individuals' ability to work, rest, socialise and exercise. Symptoms start in the late teens and early 20s and can often be present for a long time before the diagnosis is made. Findings from research studies carried out into AS indicate a delay of between 8.5 – 10 years from the onset of symptoms to actual diagnosis. This period can be longer in women than in men (NASS 2010a: 6). Generally, most people with AS live a normal lifespan, however there is an increased risk of premature death from cardiovascular disease. In a recent research project involving 150 patients (73 with AS, 71 with PsA and six with other SpA types), patients with spondyloarthritis were found to be at greater cardiovascular risk owing to a higher prevalence of smoking and a higher rate of inflammatory change of the arterial walls (Papagoras et al 2013).

Taking Action

The low profile of AS as a medical condition is at the root of the reason why good quality care is not always available. As the National Ankylosing Spondylitis Society (NASS) has highlighted, the results of this are:

- A lack of patient awareness. People who develop symptoms have no familiarity with the disease.
- A lack of awareness among general medical practitioners and health care providers. When someone presents to a non-back pain specialist with symptoms of AS, the medical professional may not consider AS as a possible diagnosis.
- An under investment in specialist services. The lack of awareness means that specialist services are not always in place for those with AS. This also leads to considerable variance in quality of AS care across the country. While there are many good rheumatology departments in the UK, it is important to spread the learning and best practice found in these departments across the whole of the country.

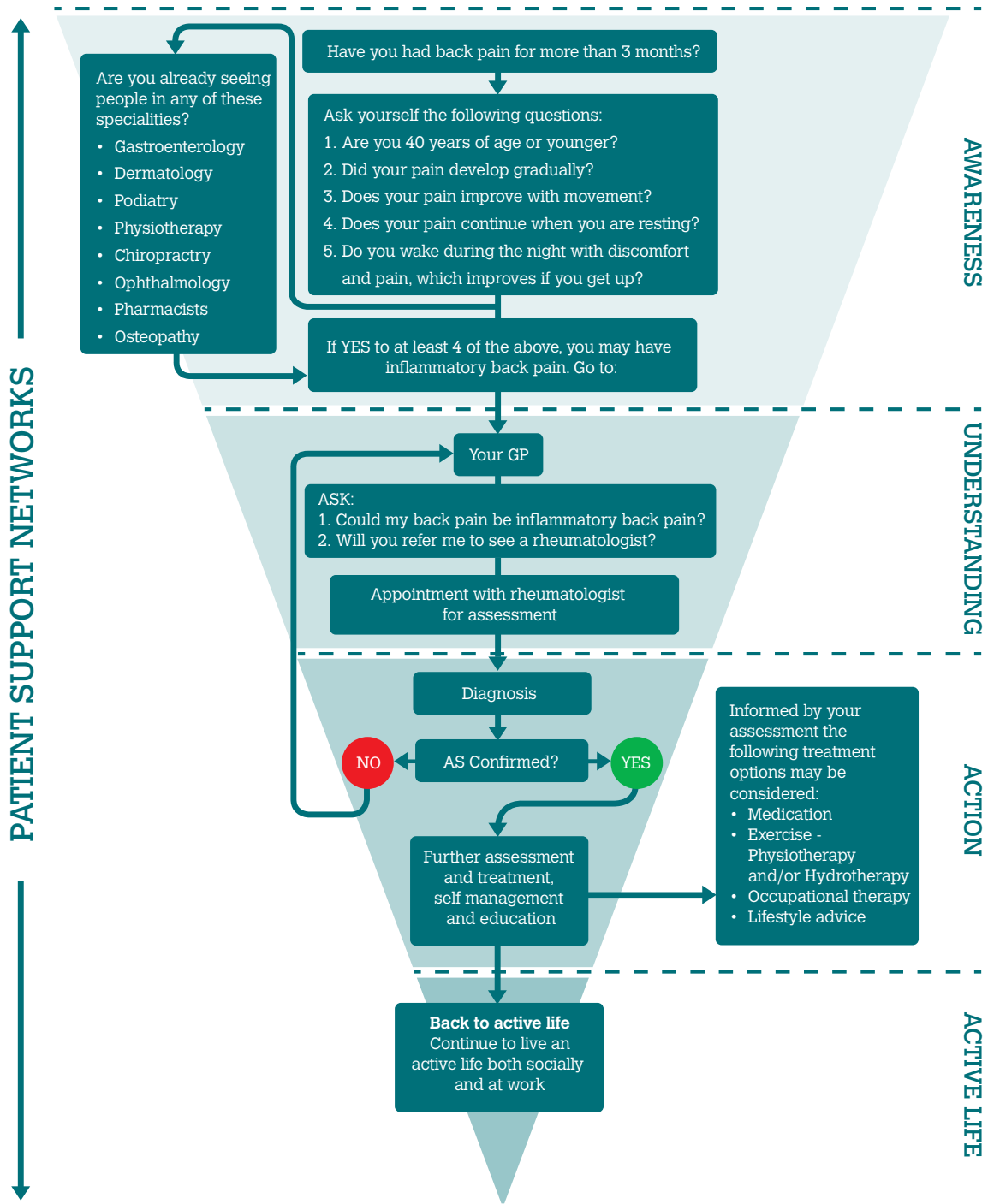
Recent initiatives have aimed to improve the lives of people with AS and their families by identifying best practice and providing a benchmark for the effective care and treatment of AS patients. Building on this work, this report has developed a pathway for the patient to follow through the stages of diagnosis, referral and treatment (see Figure 1). Four themes have been identified which cut through key sections of the pathway and summarise the main issues requiring specific attention and response at that particular point. Practical and sustainable solutions are offered in response in order to help to improve patient experience and treatment.

The four key themes:

- **Awareness**
- **Understanding**
- **Action**
- **Active life**

Taking Action

Figure 1



Taking Action

Awareness

Given the low profile of AS amongst both the medical profession and the general public, the key challenge is raising awareness of the condition in order to provide a good level of universal care to people with AS. Until very recently AS was perceived to be 'a relatively mild disease' (NASS 2010a: 8) with few treatment options and little research being undertaken into the condition and its effects. This is changing as the profile of the condition begins to increase, but more clearly needs to be done to raise awareness and understanding.

It is vitally important for AS to be diagnosed early and identified correctly as a form of inflammatory back pain. More than 30 percent of GP consultations are for musculoskeletal conditions, with low back pain the second most common reason (after upper respiratory problems) for visiting a GP (Deyo & Weinstein 2001). On average people with AS go undiagnosed for 8.5 years.

The informed patient

Improving the numbers of 'informed patients' looks to be one of the more effective means by which to improve awareness and early diagnosis of AS.

Back pain is very common in the UK. A survey published in 2000 found that almost half of the UK's adult population (49 percent) report low back pain lasting for at least 24 hours at some time in the year (Backpain 2013). Despite this, among the UK population there is a general lack of awareness of the causes of back pain. This could be due to the fact that it is very difficult to identify a single cause for back pain, leading people to think that nothing can be done to alleviate the pain. Many endure the discomfort thinking it will eventually ease. This situation needs to be remedied. Key to this will be to make people aware of the distinction between mechanical back pain and inflammatory back pain. A national campaign could encourage the public to question the kind of back pain they are experiencing, by using the following five questions (also given in the pathway diagram – see Figure 1):

1. Are you 40 years of age or younger?
2. Did your pain develop gradually?
3. Does your pain improve with movement?
4. Does your pain continue when you are resting?
5. Do you wake during the night with discomfort and pain, which improves if you get up?

Aiming for the 'informed patient' is a good place to start and educating people is always beneficial, but it will be impossible to ensure that everyone is aware of AS. Therefore there is also a need to increase awareness among healthcare professionals.

Taking Action

The informed professional

There are a number of healthcare specialities, spanning primary and secondary care, where individuals may present with symptoms of inflammatory back pain. These include:

- Gastroenterology
- Dermatology
- Ophthalmology
- Orthopaedic surgery
- Podiatry
- Physiotherapy
- Chiropracty
- Pharmacists
- Osteopathy
- GPs

It is important to raise awareness among these healthcare specialists so they consider AS as a possible diagnosis. This will expedite referral to the appropriate services and support the patients require.

Raising awareness of AS among primary care healthcare professionals, such as GPs and physiotherapists, working in the field of back pain management is particularly important. While good progress is being made in the development of back pain assessment pathways and the introduction of musculoskeletal triage services, there is still scope to improve the identification and recognition of inflammatory back pain, which is often not understood sufficiently. Primary healthcare professionals often lack a comprehensive understanding of the natural course of AS, resulting in a missed opportunity to give an early diagnosis and assessment of the patient's condition (NASS 2010a: 18). People with back pain problems often go to the chemist to request painkillers, therefore giving this group of professionals the opportunity of early intervention.

Recommendation	Action to be taken by:
Adoption of AS patient pathway as an algorithm for AS diagnosis and treatment.	NHS England CCGs
A national awareness campaign to create greater understanding of AS and enable early diagnosis and referral. Heightened awareness of AS as a cause of back pain so it is more readily considered as a default diagnosis.	Health & Wellbeing Boards Public Health England NHS England CCGs

Taking Action

Understanding

Inflammatory back pain is not a prime area of expertise for most GPs and others in the primary care setting; it is one of the main areas of specialisation of rheumatologists.

GP awareness

The key problem is therefore how to realistically improve understanding of AS in order to aid early diagnosis. No single action will suffice so there is a need to create a suite of mechanisms and actions that can improve diagnosis and early intervention. Part of this suite must include improving GPs' understanding of AS because this is where people will present with unresolved backpain. However GPs cannot be expected to appreciate and recognise the subtleties of inflammatory back pain, given the fact they may only see one or two cases of AS a year in contrast with many cases of mechanical back pain. Nevertheless, while GPs cannot be trained to be expert diagnosticians, they can be trained and equipped to:

- Be familiar with a range of possible diagnoses
- Recognise the signs of inflammatory back pain
- Know where to refer the patient for more specialised treatment and help

The National Institute for Health and Clinical Excellence (NICE) has committed to introduce a Clinical Guideline for Spondyloarthritis in 2014. Based on the best available evidence, clinical guidelines are recommendations on the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. These guidelines are urgently required to help deliver the best possible care for those with AS. NICE must not delay in introducing this guidance and must be encouraged to meet its commitment. Linked with this guideline, it is also necessary to introduce a better education programme for GPs on inflammatory back pain so that GPs can identify suspected cases and refer on to a rheumatologist for a full diagnosis.

Recommendation	Action to be taken by:
Action the introduction of clinical guidance for spondylorthritis.	NICE
Improve GP awareness of AS diagnosis and early intervention, including education in AS and inflammatory back pain.	Royal College of General Practitioners CCGs

Adopting this approach could lead to concerns about rheumatologists being overloaded with referrals, which is something that needs to be monitored. However, it is felt that it is better to have an increase in referrals, and those suffering with AS diagnosed earlier, than miss the opportunity of diagnosis entirely. While referrals to an AS specialist may incur higher costs initially, the potential savings made in the long term through early diagnosis and averting the need for extensive intervention is a significant point to consider.

Taking Action

Specialist physiotherapy

The role of specialist physiotherapy forms the cornerstone of effective management of AS, helping to improve physical functioning and reducing physical pain. The physiotherapist helps to care for and treat the AS patient by:

- Devising an individual treatment programme specifically for the needs of the patient. This can include exercises to maintain or improve range of movement as well as strengthen muscles to help maintain good posture.
- Advising on self-managed exercise
- Supporting the patient in the self management of their AS
- Performing annual assessments to monitor the patient's range of movement and posture
- Giving advice and education on AS
- Functioning as part of the MDT

The input of specialist physiotherapy allows a person living with AS to maximise opportunities to live an active and independent life. It is therefore highly recommended that everyone sees a physiotherapist for an assessment when they are first diagnosed with AS and continues to be seen by one on a regular basis. NASS conducted a survey in September 2013 of 1,630 UK patients with an AS diagnosis: 60 per cent of those surveyed had not received any physiotherapy in the previous 12 month period. Easy access to specialist physiotherapy must therefore form a key element in any care model for AS. How this could be realised is shown in Box 2.

Shared care versus secondary care

While it is recognised that everyone with AS should have access to timely and optimum treatment, it is important to consider the best location for the delivery of that treatment. The future delivery of health care shifts the emphasis from acute hospitals to primary care, thus bringing services closer to the patient and allowing them to remain in their community. If this is the model to be adopted, then how this model could assist those with AS needs to be carefully assessed, with consideration given to the following:

1. A phased programme: Given the current lack of capacity in primary care, a shift to a shared model of AS care would need to be carried out in phases. It is not practical to shift responsibilities from secondary to primary care in the short term.
2. Patient empowerment: As with many other long term conditions, a model for AS care should focus on helping patients to manage their condition
3. Location: The best location needs to be found for the delivery of optimum levels of care without undue inconvenience to the patient
4. Specialist services: Specialist services are vital to the treatment of AS and need to be involved appropriately

The model of care could be consultant led or involve partnerships between primary and secondary services to form a shared care approach. There are potential benefits and risks associated with each, as set out in Table 1 on the next page.

Taking Action

Table 1 - Models of care comparison

	Consultant Led	Shared Care
POTENTIAL BENEFITS	<ul style="list-style-type: none"> • Optimum levels of care provided by specialist services • Patients attend specialist centres with appropriate equipment and facilities • Enhances opportunity for multi-disciplinary learning between different specialist teams • Early identification of secondary diseases • Ready access to diagnosis and treatment • Early referral to other specialist as required • Easy access to diagnostics tests • Early access to clinical trials and involvement in research programmes • Support of patient groups (important not least because confidence in primary care may have been eroded due to delayed diagnosis) 	<ul style="list-style-type: none"> • Builds GP capacity of AS in terms of understanding and awareness • Collaboration and knowledge exchange between primary and secondary services, allowing input from specialised services (such as specialist physiotherapy) into primary care and enabling specialised services to focus on complex cases • Helps empower patients to manage their own conditions, supported by both their GP and specialist services closer to home • Improved long term follow up and management of co-morbidities • Aids regular monitoring and assessment to help inform best procedure for each individual patient, drawing upon expertise of specialist physiotherapy. • Better levels of communication, exchange of patient notes, speed of referrals between specialists • Enhances levels of confidence in the system between patient and professional • Minimises waste of resources and time • Helps to demonstrate the NHS QIPP (Quality, Innovation, Productivity, Prevention) framework of quality of care

Taking Action

	Consultant Led	Shared Care
POTENTIAL RISKS	<ul style="list-style-type: none"> • Awareness and understanding of AS remains low in primary care • Demands on specialist services increase • Increased risk of communication breakdown between primary and secondary care • A cumbersome referral system with patients still needing to be referred back to GP for referring on to other specialists • Duplication of work and time wasted spent in resolving communication breakdown issues • Reduced continuity of care 	<ul style="list-style-type: none"> • Division of responsibilities are not clearly understood, resulting in substandard care • Increased risk of communication breakdown between primary and secondary care • Inadequate diagnoses of other health issues due to a lack of awareness and understanding of the nuances of AS and related complications • Delayed access to diagnostic testing • Continuity of care breakdown due to changes of clinician

There are a number of ways in which the two models of care may work. Boxes 1 and 2 offer some possible examples of each.

Box 1

Consultant Led Model

Integrated approaches to running clinics

- (a) Parallel to other clinics (such as gastroenterology or dermatology), making it convenient for patients to attend and assisting the smooth exchange of patient notes and speed of referrals
- (b) Combined specialist approach, allowing for joined up care and review of patients, quicker decision making and enhanced learning for staff

Taking Action

Box 2

Shared Care Model

Physiotherapy/Nurse-led clinics

- Allows for combined and coordinated care, drawing upon the skills of a multidisciplinary team (MDT)
- Allows for closer interaction and input from GPs (with appropriate training) in helping to manage care of AS
- Requires specialist physiotherapist or extended scope practitioner involvement
- Physiotherapists to receive the necessary training in medications including analgesics and NSAIDs, building upon the independent prescribing rights conferred to them in 2013. Nurse practitioners with prescribing rights or a GP with a special interest could also prescribe
- Helps to ensure that patients have access to appropriate care in an efficient manner
- Clinics could be based within a community, primary or secondary care setting

Specialist clinics run in GP's surgery

- Rheumatologists could run AS clinics within the GP's surgery
- A weekly clinic brings treatment closer to the patient and helps normalise the condition
- Opportunity for first hand experience to be gained by the GP (as well as other healthcare staff) to increase and enhance their understanding of AS

Educating physiotherapists in primary care to recognise AS and IBP

- Rheumatologist-led short course for physiotherapists covering the enhanced skills and training they need to identify inflammatory back pain
- Provided as post-graduate training course
- Rheumatologist could have the authority to certify a physiotherapist as competent to make a referral of inflammatory back pain to a rheumatologist

Recommendation

Explore the development of shared care models using best practice.

Action to be taken by:

CCGs

Taking Action

Consideration needs to be given to how these changes affect current limits of contractual responsibilities. A patient-friendly referral system is needed, permitting referrals from one consultant to another without the need for the patient to be passed back to the GP for referring on, so avoiding unnecessary delays and inefficient use of resources.

Contractual responsibilities

Tariff responsibility has recently shifted from the Department of Health to Monitor and NHS England. Both bodies have recently undertaken consultations on the key principles that will underpin the new National Tariff that comes into effect in April 2014. Among these key principles is a focus on allowing for flexibility in service redesign and innovation, particularly around models of integrated care that will benefit patients. These developments are to be welcomed but clearly need to be outworked in a tangible way. By offering more freedom and flexibility to develop new service models, any changes and improvements should have the needs of the patient firmly at the centre and not just focus on savings and efficiency. For the AS patient this presents the opportunity to ensure access to the appropriate specialist for treatment and reassessment at the right time without unnecessary delay.

MRI scans in assisting diagnosis

Making an accurate early diagnosis of AS is challenging because ‘clinical assessment of the spine is difficult and there are no confirmatory diagnostic signs’ (NASS 2010a: 13). It has recently been found that MRI can help demonstrate both acute inflammation and chronic damage in the skeleton, which is particularly relevant to nr-axial SpA. Delay in AS diagnosis is 8.5 years on average. Classification of early AS highlighting the value of MRI has been laid out in the ASAS criteria. Defining AS MRI sacroiliitis has also been set out in an international consensus document so that a standardised approach can be adopted in implementing these criteria.

The availability of MRI units has increased rapidly in most European countries over the past two decades. Nevertheless a report by the National Audit Office in 2011 concluded that in the UK, NHS trusts do not have the means to know if they are making best use of their high value equipment (NAO 2011:9). Levels of activity vary significantly between trusts and so it is difficult to assess efficiency and best practice. This point is further raised in a report by the Department of Health’s NHS Improvement & Efficiency Directorate (Department of Health 2011: 10).

Comparative summary of key data on MRI and CT

	MRI (Magnetic Resonance Imaging)	CT (Computed Tomography)
Total number of machines in the NHS (2010)	Total: 304 267 installed in the last 10 years	Total: 426 376 installed in the last 10 years
Life years of a machine	7–10	7–10
Average life of existing machines	6.3 years	6.2 years
Number of MRI Units (2010)¹	5.9 per million population	8.2 per million population
European average²	10.3 per million population	20.4 per million population

(Source: NAO 2011; OECD 2012: 75)

1. Any equipment in the private sector is not included.
2. The EU average does not include countries which only report equipment in hospital.

Taking Action

While MRI has become the preferred method of investigation in SpA, concerns have been raised over the issue of cost effectiveness of this technology. There is the perception that MRI scanning is expensive and should only be used in exceptional cases. Some radiologists have presented the case that this is actually cost neutral. Developed in conjunction with consultant rheumatologists for imaging diagnosis in Leicester, a standardised 40-minute MRI protocol has been devised which allows specific imaging sequences of the whole spine and the lateral spinal joints, allowing for early and specific diagnosis of axSpA. The protocol has been disseminated throughout parts of England and in different centres in Europe and North America. The impact of the protocol can be seen in a number of ways:

- Improved and speedy diagnosis in a difficult-to-diagnose disease.
- Cost saving. Local protocols developed in Leicester have indicated that patients who do not demonstrate MRI changes do not receive high-cost drug therapy, thereby reducing cost (Rennie 2013). This warrants further investigating and auditing.
- Time saving. Scans four body parts in the time usually taken to scan one, due to specific protocols and sequences, saving MRI scanner time.
- Streamlined pathway from Consultant Rheumatologists to Consultant Radiologists and ‘intelligent booking’ of patients.
- Trialled and measured with two audit cycles. 100 percent uptake in adoption of the protocol by consultant rheumatologists in 2009–10 and adoption across Leicester at multiple sites.

This standardised MRI protocol developed by the team in Leicester, and the corresponding findings of the National Audit Office, helps to make the salient point that the use of MRI needs to be maximised in order to aid diagnostics and achieve value for money. For the AS patient, the maximised use of MRI assists in the prompt diagnosis of axSpA. The earlier a MRI scan can take place and a diagnosis of axSpA made, the more likely it is the person can stay in work (with appropriate support) which brings with it obvious economic benefits.

Recommendation	Action to be taken by:
Review of MRI capacity within the NHS to maximise efficiency and deliver value for money.	CCGs Acute trusts

The lack of training in SpA MRI interpretation can lead to significant under recognition of the condition. It is important that radiologists are trained to read results and that this extra resource is used efficiently. While musculoskeletal radiologists are well placed to do this, in order to improve patient treatment and service, all radiologists should be trained to read and interpret MRI results.

Taking Action

Recommendation	Action to be taken by:
Train all radiologists in SpA MRI interpretation. The British Society of Skeletal Radiologists should provide national guidelines to ensure these SpA MRI protocols have their endorsement.	Royal College of Radiologists British Society of Skeletal Radiologists Health Education England

Back pain pathway

All of these issues point to the need for a back pain pathway supported by robust algorithms. In cases of suspected AS there needs to be early and swift referral from GP onto a rheumatologist and MRI scan. Good communication is needed between members of the primary care team so that patients can easily follow the correct pathway and assist in achieving early diagnosis.

It is understood that most clinical commissioning groups (CCGs) are currently developing a back pain pathway, so it is crucial that AS is addressed and incorporated into this. Creating a separate pathway dedicated to AS is not perceived to be as effective as incorporating AS into a recognised back pain pathway. Far from diminishing the importance of AS, including AS in this way would help bring the condition to the attention of GPs more readily so that they recognise it as a possible diagnosis in a patient presenting with back pain.

Recommendation	Action to be taken by:
AS and IBP to be recognised in the national back pain pathway with clear and robust clinical guidance for diagnosis and treatment.	NICE

Action

Once AS has been diagnosed the patient should have access to the full range of treatment and care they require, whether that is for disease, disease flares, disease complications or late-stage skeletal damage.

For effective treatment to take place, the patient needs to be at the centre of the treatment process, with approaches to care and treatment being designed in response to individual needs. The key care and treatment areas for those with AS are:

- Medication
- Exercise
- Occupational therapy and health
- ^a Lifestyle advice

Taking Action

Medication

Those who suffer from AS often endure long-standing symptoms and are commonly not aware of the therapeutic options available to them. Some underplay the true extent of their symptoms, and as a result they are unaware of either their suitability or eligibility for medication (NASS 2010a: 16). There are a number of treatment options which are known to be effective for AS, for example:

- Non-steroidal anti-inflammatory drugs (NSAIDs) – Conventional drug treatment of spinal disease
- Anti-TNF therapy drugs – A relatively new form of treatment offering substantial improvements in symptom control

NICE have noted that the benefits of NSAIDs and other disease-modifying anti-rheumatic drugs (DMARDs) in treating AS are variable, indicating that these drugs may be more beneficial in treating peripheral joint involvement, but not spinal symptoms (NICE 2008:6). Despite this, clinicians sometimes use these less effective options in spinal disease such as AS and nr-Axial SpA, which does not help to improve outcomes for patients.

The benefits of anti-TNF therapy for symptom control, which in turn help to improve lifestyle and capacity to work, have now been demonstrated. Recent research indicates the clinical efficacy and safety of anti-TNF therapy in patients with active AS over seven years of continuous treatment. After seven years, more than half of the treated patients remained on anti-TNF therapy, and one-third were in partial remission (Baraliakos et al 2013). Moreover, in its report which looked at how AS affects the working lives of those living with the condition, NASS found that 56 percent of patients strongly agreed that anti-TNF had impacted positively on their working life, versus just 23 percent on NSAIDs (2010b:12).

The need for biologic therapy must be assessed on more than just the basis of controlling symptoms; it must also take into consideration:

- Work instability
- Progressive restriction of the spine
- Onset of co-morbidities

Despite national guidance clearly setting out the appropriateness of anti-TNF therapy, there is still disparity between guidance and practice. NASS report that this is largely due to the need for considerable administrative and clinical support, and CCGs approving therapy on an individual basis. This situation is further compounded by the historical perception of many clinicians that AS is either of modest severity or is largely untreatable, and so regular clinical follow up is not actively pursued (NASS 2010a: 16).

Taking Action

NASS cite several blocks to the free availability of the right treatment at the right time for those with AS (2010a: 16). They are:

- Poor understanding of the disease
- Limited therapeutic expectations
- Prescribing restrictions
- Funding constraints for provision and support of biologic therapies

Recommendation	Action to be taken by:
A Quality Standard for axSpA to be swiftly developed, including clear criteria for the holistic care of patients with axSpA.	NICE

Exercise

Exercise and physiotherapy are central components for the treatment of AS. Engaging in effective exercise can help those with AS to maintain flexibility and good posture, as well as generally help to manage their pain. In particular, hydrotherapy is beneficial. Exercising in warm water can help to protect joints and allows the body to be exercised in a way which would be more difficult out of water. The NHS may offer only short term access to hydrotherapy sessions due to cost restraints and the limited availability of hydrotherapy facilities.

Given the importance of exercise in treating AS, offering exercise prescriptions to people with AS would be an effective way of increasing provision. Local gyms need to be prepared to support the delivery of a programme like this. Often gym instructors and fitness trainers work in a self-employed capacity, so funding arrangements for exercise prescriptions, redeemable at gyms and leisure centres, need to be clearly understood, with systems in place to ensure the adequate provision of appropriately trained staff, services and facilities. There is scope here to make effective use of personal health budgets in order to allow those with AS to determine the services they wish to have access to, at a time and place convenient for them.

Recommendation	Action to be taken by:
Preferential and reduced rates to gyms to be made available to those with AS to aid access to exercise facilities. Exercise prescriptions to be made available where appropriate.	Health and Wellbeing Boards CCGs Public Health

Taking Action

A good exercise regime can also help to reduce fatigue bringing many positive benefits including an improved sense of wellbeing. Fatigue is common among people with AS. Chronic or long term fatigue in AS is not like 'normal' tiredness and can last for several days or weeks at a time. There are a range of different factors which may well contribute to this sense of fatigue:

- **Inflammatory back pain:** The underlying inflammatory process in AS can lead to fatigue
- **Anaemia:** This condition is often found alongside inflammation
- **Long term pain:** This kind of pain is known to contribute to exhaustion and lead to disturbed periods of sleep
- **Sleep disturbance:** Pain and stiffness can lead to broken periods of sleep
- **Medication:** Certain drugs used to treat arthritis can cause drowsiness, affecting concentration, which may worsen fatigue
- **Muscle weakening:** Where this does occur, it obviously takes more effort to perform certain tasks which can contribute to fatigue
- **Distress and uncertainty:** As with any long term condition, fear and uncertainty surrounding the future can lower mood and trigger episodes of anxiety, depression and fatigue

Once more, the involvement of a specialist physiotherapist can prove invaluable in giving exercise advice and supporting the patient in the self management of their condition. Equally important is recognising the need for periods of rest and for the individual to pace themselves accordingly.

Drugs prescribed to help control inflammation in AS can also bring the benefit of reducing fatigue. In cases where medication may contribute to drowsiness and loss of concentration, alternatives may be prescribed (NASS 2011).

Occupational therapy and health

This is an essential part of treatment for those with AS, as it is often the means by which they can stay in work and maintain a normal and active life. Occupational health experts can offer useful advice and suggestions on patterns of work, job responsibilities and support mechanisms that can create a more conducive work environment for someone with AS. This input benefits both employers and employees but it is often not available.

Recommendation	Action to be taken by:
Occupational therapy to become a recognised part of the primary care clinic.	Health & Wellbeing Boards CCGs

Taking Action

Lifestyle advice

There are many aspects of lifestyle that can have an effect on symptoms of AS. While there is nothing to suggest that specific foods affect AS, it is important nonetheless to ensure that joints in the body are not put under extra pressure. Consequently advice on diet, obesity and exercise is useful to minimise any aggravation of the symptoms of AS. Research indicates that those with AS are at an increased risk of cardiovascular disease, heart attacks and strokes (Papagoras et al 2013). Therefore, advice on blood pressure, cholesterol and smoking are valuable to the reduced risk of cardiovascular disease. Smoking is known to worsen AS: stopping smoking is perhaps the single most important piece of lifestyle advice that can be given to AS patients (Chung et al 2012).

Multidisciplinary involvement

Provision of the right treatment at the right point in time requires expert input and skill. To this end there is the need for multidisciplinary team (MDT) input to identify what is best for each AS patient and devise a treatment plan. Primary and secondary care services (such as occupational therapy, physiotherapy, cardiology, gastroenterology) need to be involved and work closely together to help provide the appropriate services.

Long term follow up

To date, the long term monitoring of people with AS has been highly variable. Whether through poor patient experience, limited awareness and understanding of the condition, or service expediency, many become lost in the system with no proper follow up and follow through care. For many, progression of the condition is relentless, albeit slow and characterised by relatively modest and unchanging symptoms – see Box 3.

Box 3

Effects of AS

Common direct effects of AS

- Inflammation of parts of the body, especially within the spine, where tendons or ligaments insert into the bone (known as enthesitis)
- Arthritis
- Spinal osteoporosis
- Involvement of soft tissue organs – such as the eye and heart

Indirect effects of AS

- Respiratory difficulty
- Toxic effects of treatment – renal impairment, hypertension and gastrointestinal disturbances

Taking Action

Given these effects, it is important that effective and ongoing disease monitoring occurs in order to track the progression of AS and introduce appropriate interventions. The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) is the recommended instrument to assess disease activity, with function usually assessed using the Bath Ankylosing Spondylitis Functional Index (BASFI). Other criteria have also been identified as key elements of regular expert assessment of AS patients – see Box 4.

Box 4

Key elements to regular expert assessment

- Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)
- Bath Ankylosing Spondylitis Functional Index (BASFI)
- Bath Ankylosing Spondylitis Metrology Index (BASMI)
- Progression of skeletal changes through the modified Stoke Ankylosing Spondylitis Spine Score (mSASSS)
- Assessment of peripheral joint lesions, enthesitis, fatigue, sleep quality, spinal pain

Access to urgent clinical review or advice via telephone, email or other online forms, in instances of disease flare up and other serious complications, is an essential part of the care patients with AS require. This could be provided by a rheumatology physiotherapist or specialist nurse.

With this model of care in place and to aid long term management of their condition, patients should also be offered an annual appointment during which a holistic review can be undertaken. Key aspects to this review would include:

- *Review of medication*
- *Assessment of range of movement and posture, i.e. metrology assessment.*
- *Impact on work and social activities*
- *Mental health*
- *Co-morbidities.*

Recommendation	Action to be taken by:
Every person diagnosed with AS should receive an annual appointment with a specialist for a review of their condition. Key aspects to include review of medication; range of movement; impact on work and social activities; co-morbidities and mental health.	CCGs

Taking Action

Self management

Having the necessary healthcare professional administer tests and assessments, such as BASDAI, is an important part of the process, but empowering the patient to help them manage their own care is also crucial. Patients want to know and understand their condition so to be part of the decision making process (Department of Health 2012:2). The Government acknowledges that in order to create a patient-centred NHS, policies will work on embedding care planning, shared decision-making and providing the information and support necessary to enable people to manage their own conditions, where they wish to do so (Department of Health 2012: 26).

Use of app based technology¹ to help keep patients informed, but also in terms of generating data collection and monitoring, could be particularly useful for those with AS. This is a growing area particularly among the young. Early forms of this kind of technology have already been developed outside of the NHS and utilise BASDAI, BASFI, as well as the Work Productivity and Activity Impairment Questionnaire (WPAI). One of the benefits of this type of technology is that it diminishes the need for telephone appointments. Patients can log-in and complete the assessments; the information and outcome data is stored for the clinician to assess, review and then discuss with the patient at the consultation, helping to maximise consultation time. To date, however, roll out has not been on a national basis. There is also scope to further increase the amount of data that could be captured through such an app. Nevertheless, it is a good start and serves as an early indicator as to what can be done.

Developing technology-based solutions that assist data capture and monitoring could be fed in to the national NHS Choice Framework. This framework sets out clear expectations for NHS England commissioners about the choices patients ought to be able to make, and ensures that patients have clarity over what choices they can reasonably expect to have about where they go and who they see for treatment (Department of Health 2012: 30).

Obstacles identified include the NHS's general approach to IT. The cost of infrastructure can be prohibitive and the use of third party software can be problematic due to firewall restrictions. It is anticipated that as the opportunities are taken up more widely, with growing momentum surrounding telehealth solutions and the use of technology in healthcare, these obstacles will be resolved, but more needs to be done to drive this forward.

Recommendation	Action to be taken by:
Application and promotion of technology-based solutions to help empower patients to manage their own conditions.	NHS England CCGs

1. A piece of software accessed through the internet, desktop PC, laptop, smart phone or tablet device.

Taking Action

Personal health records

A further aspect of patient empowerment would be the introduction of electronic personal health records. Patients do not like their time being wasted through notes being incomplete or lost and MDTs not communicating with one another. This in turn can lead to a break down in trust and confidence between the patient and clinician, which can take time to rebuild. Best practice points to the fact that doing things right first time not only increases quality but also drives down cost.

The NHS's Information Strategy sets out the vision of patients being able to access and share their own health and care records, thereby empowering the patient to make decisions in partnership with professionals (Department of Health 2012: 25). Based on nationally set information standards, the strategy is a way to encourage fully joined-up systems, facilitating the sharing and communication of information and data in an efficient and swift manner across the health and care system.

Linking this with the discussion above concerning app-based technology solutions, there is scope to connect elements of telehealth and app-based technology with electronic personal health records. Bringing the two together could be a powerful combination, enabling the patient to manage their own lifestyle by recording and tracking their own progress. Data could be submitted electronically, helping to populate the personal health record with real time information, thus saving time in appointments with clinicians. As a result of up to date and relevant data being available to hand, time taken in face-to-face appointments is more useful and focused.

Active life

Research carried out by NASS indicates that around one third of people with AS give up work before retirement age, and of those who are in work (either full or part-time), a quarter (26 per cent) said that their AS had affected their career progression. Thirty percent said that were worried about losing their job (2010b). Furthermore employers, noticing no visible condition, are commonly inclined to question what is actually wrong with the person with AS, since he or she 'doesn't look ill'.

Rather than considering the diagnosis or treatment of AS as the end of the pathway, returning to active life and work needs to be recognised as a legitimate clinical outcome. It needs to be more widely realised that despite having AS, people are still able to live fulfilling and active lives. To illustrate the point, the pathway diagram in Figure 1 is based on a funnel design as a way of identifying the return to active life as the key outcome.

For many people with AS the issue is not simply being employed or unemployed; it is more to do with how being in employment helps to build self esteem and dignity. Being employed (full or part-time) helps to engender a sense of productivity, making career progression, paying the mortgage, access to pension rights and providing for the family all possible. NASS's survey on work found that those with a lower BASDAI score (or reporting less disease severity), or patients on treatments considered effective, were more likely to be in full or part-time employment (2010b: 11). Given that a typical diagnosis for AS currently takes a long time, people often have to give up work before they are fully diagnosed. Once they receive their diagnosis, they not only have to learn how to manage their condition, but also have to address the challenge of returning to work. Levels of self-confidence are likely to have been reduced as a result of going through the diagnosis process, which further contributes to the challenge of returning to work. One way in which 'return to work' initiatives in this area could specifically help those with AS is by making it a requirement for GPs to think about employment as an outcome for patients.

Taking Action

It is acknowledged that in recent years, following Dame Carol Black's Review of the Working Age Population, the Government is already taking active steps to prioritise funding to help strengthen the relationship between health and work. This is in the early stages of development and requires ongoing support and involvement so that joined up policy approaches, designed to keep more people in work, make a lasting impact.

The Chartered Society of Physiotherapy (CSP) is working on a pathway which has 'returning to work' as the main outcome. The CSP is suggesting that cognitive behaviour therapy (CBT) forms a key component of the pathway. Even with recovery from a physical injury, the individual may still have mental health issues, such as anxiety and depression, when faced with the prospect of returning to work while managing a chronic condition like AS with the unpredictability of flare ups. Consideration is also being given as to how to develop a non-medical model of what is going to keep people healthy and in work. To successfully return to work, those with AS require appropriate support in place to deal with the effects they experience.

Recommendation	Action to be taken by:
Clear and practical guidance on how to manage inflammatory back pain in the workplace to form part of the Government's health, work and wellbeing initiative.	Department of Health

The role of employers

Rather than employers being dismissive of complaints about back pain or viewing them with suspicion as an excuse for poor performance, it is important for them to seek to improve the working lives of people with long term conditions so that they remain in work. Key areas for employers to give greater attention to are:

- Providing appropriate training for co-workers so that they better understand how they can support those employees with long term conditions, and respond positively. Understanding the distinction between mechanical back pain and inflammatory back pain is important.
- Adapting a flexible approach to job design and responsibilities for those with AS. This may include introducing flexible working hours, amended job descriptions and adopting inclusive recruitment policies and procedures. Allowing employees with AS to take regular short breaks from work to stretch out and exercise can be extremely beneficial.
- To proactively engage with and draw upon the advice and support of appropriate healthcare professionals (such as GPs and occupational health) when an employee notifies them of their condition, so that the individual is able to remain an effective member of the workforce without feeling isolated.

Recommendation	Action to be taken by:
Employers to develop strategies for getting people back into work. Small businesses to work with larger organisations to exchange ideas and best practice.	Occupational health Health & Wellbeing Boards Employers

Taking Action

Age related response

Consideration needs to be given as to how best to support those with AS, given that it is a chronic disease and affects most stages of life.

It is also often harder to encourage younger patients to self manage, as they are often not aware or not ready to acknowledge that they may have AS. There is a need to think about how younger patients can be supported in their diagnosis.

People from disadvantaged backgrounds tend to be worse off with AS. Certain support services (such as hydrotherapy) can often be more easily accessed by those with their own transport, or even those in a position to pay for them (as not all are provided by the NHS). As discussed earlier, the adoption of exercise prescriptions, use of personal health budgets and partnerships with local gyms and sports centres are options to consider in response to this.

As the retirement age rises, an increasing number of people will be working who have musculoskeletal problems, including AS. Enabling these people to stay in work will be of clear economic benefit.

The role of patient support groups

Given the life-long implications of AS, access to the right information, at the right time in the right format, is vitally important. Specialists and the MDT need to be the primary conduit for this information in light of their expertise and knowledge, but with collaborative links with primary care to help dissemination. However, in parallel to this is the need for reliable and approved sources of information from patient support groups and which run the length of the pathway given in Figure 1.

Recommendation	Action to be taken by:
Every patient to be directed to, and put in contact with, an appropriate patient support group.	GP Health and Wellbeing Boards

Valuable work and support is already provided by the third sector and voluntary organisations in this area. This should continue to be championed and supported, focusing on key areas such as:

- Setting up and strengthening physical peer support groups or helping to initiate virtual online support forums, providing valuable opportunity for individuals to meet with others in a similar position and draw strength and support from one another
- Providing reliable sources of information and education so that the patient understands their condition and is empowered to take an active role in the management of their care

Conclusion

Despite the prevalence of AS and other axSpA, it is clear that there remains a lack of awareness of the condition, both among the public and the health service in general. While improving rates of diagnosis is a necessary step, it is also important that following diagnosis, patients are supported with the appropriate long-term care and treatment. The challenge is to see both the patient and health professional educated and empowered so they can work together to achieve the best possible outcome – the patient returning to active life.

From reviewing the literature we have identified the following key issues which effectively address this challenge:

- **The informed patient** – Increasing the number of ‘informed patients’ looks to be one of the more effective means by which to improve awareness and early diagnosis of AS.
- **AS diagnosis** – Raising awareness of AS among non-back pain health professionals so that they consider AS as a possible diagnosis. This will aid early diagnosis by helping ensure patients can be referred to the appropriate services and support they require.
- **Shared care model** – In light of the current shift to primary care from the acute hospital setting, building up capacity in primary care as part of a shared model of care is important. This allows for combined and coordinated care to take place, drawing upon the skills of a multidisciplinary team (MDT), and in turn helps ensure that patients have access to appropriate care in an efficient manner.
- **The role of specialist physiotherapy** – This forms the cornerstone to effective management of AS, helping to improve physical functioning, reducing physical pain and supporting patients in the self management of their condition.
- **Self-management** – Empowering the patient is important so that they understand their condition and can play a key part in the process of managing their care.
- **Focus on the long term** – Patients should have an annual appointment with a specialist during which a holistic review of their condition can be undertaken. Key aspects to this review would include review of medication, range of movement, impact on work and social activities, mental health and comorbidities.
- **Engaging in active life** – Returning to active life needs to be recognised as a legitimate clinical outcome. It needs to be more widely realised that despite having AS, people are still able to live fulfilling and active lives.
- **Role of employers** – More needs to be done to encourage employers to support the working lives of people with long term conditions so that they are able to remain in work.

Given the life-long implications of AS, access to information remains a key necessity for those with AS. This information needs to be reliable and come from approved sources so that it can be of maximum benefit to patients. Consequently an invaluable role is to be played by patient support groups, which can provide information and support at every point along the patient pathway.

Appendices

Steering Group members

Chaired by Dame Helena Shovelton DBE

Name	Position	Organisation
Gail Beer	Director of Operations	2020health
Ross Carroll	Senior UK Government Affairs Manager	AbbVie Ltd
Debbie Cook	Director	NASS
Trish Cornell	Senior Rheumatology Practitioner	Poole Hospital National Health Service Foundation Trust
Jo Cumming	Head of Information	Arthritis Care
Claire Harris	Physiotherapist	Northwick Park Hospital
Huw Irranca-Davies MP	Shadow Minister for Environment, Food and Farming	
Matt James	Research Fellow	2020health
Dr. Andrew Keat	Consultant Rheumatologist	Northwick Park Hospital
Dr. Jane Martindale	Clinical Specialist Physiotherapist in rheumatology	Lancaster University and Wrightington Wigan and Leigh NHS Foundation Trust
Dr. Helena Marzo-Ortega	Consultant Rheumatologist and Honorary Senior Lecturer	Leeds Musculoskeletal Biomedical Research Unit
Charlotte Morris	Research Assistant	2020health
Dr. Raj Sengupta	Consultant Rheumatologist	The Royal National Hospital for Rheumatic Diseases, Bath and the BMI Bath Clinic, Bath
Dame Helena Shovelton DBE	Chair	2020health

Appendices

Workshop participants

Name	Position	Organisation
Gail Beer	Director of Operations	2020health
Colin Beevor RN	Clinical Nurse Specialist for Rheumatology Services and Matron/ Service Manager	Musculoskeletal Services Portsmouth Hospitals NHS Trust
Stephen Bevan	Director, Centre for Workforce Effectiveness	The Work Foundation
Ross Carroll	Senior UK Government Affairs Manager	Abbvie Ltd
Jo Cumming	Head of Information	Arthritis Care
Leonie Dawson	Professional Advisor	Chartered Society of Physiotherapy
Sally Dickenson	Information Officer	NASS
Laura Guest	Chief Executive	British Society of Rheumatology
Claire Harris	Chair / Senior Physiotherapist	AStretch / Northwick Park Hospital
Huw Irranca-Davies MP	Shadow Minister for Food and Rural Affairs	
Matt James	Research Fellow	2020health
Claire Jeffries, BSc Hons, MCSP, SRP	Solent Healthcare's Physiotherapy Manager and Clinical Specialist in Hydrotherapy and Rheumatology	Solent NHS Trust
Professor Peter Kay	National Clinical Director for musculoskeletal conditions	NHS England
Dr. Andrew Keat	Consultant Rheumatologist	Northwick Park Hospital

Appendices

Workshop participants (continued)

Name	Position	Organisation
Dr. Jane Martindale PhD, BA, Grad Dip Phys	Clinical Specialist Physio-therapist in rheumatology.	Lancaster University and Wrightington Wigan and Leigh NHS Foundation Trust
Dr. Helena Marzo-Ortega	Consultant Rheumatologist and Honorary Senior Lecturer	Leeds Musculoskeletal Biomedical Research Unit
Charlotte Morris	Research Assistant	2020health
Dr. Winston Rennie MB, MSc, FRCR, MFSEM	Consultant Musculoskeletal Radiologist	Leicester Royal Infirmary

References

Backpain 2013. Facts and Figures <http://www.backcare.org.uk/factsandfigures>

Baraliakos, X., Haibel, H., Fritz, C., Listing, J., Heldmann, F., Braun, J., Sieper, J. 2013. 'Long-term outcome of patients with active ankylosing spondylitis with etanercept-sustained efficacy and safety after seven years'. *Arthritis Res Ther.* 2013 Jun 20;15(3):R67. <http://www.ncbi.nlm.nih.gov/pubmed/23786760>

Braun, J., Bollow, M., Remlinger, G. et al. 1998. 'Prevalence of spondylarthropathies in HLA-B27 positive and negative blood donors'. *Arthritis Rheum* 1998; 41:58-67.

Chung, H.Y., Machado, P., van der Heijde, D., D'Agostino, M.A., Dougados, M. 'Smokers in early axial spondyloarthritis have earlier disease onset, more disease activity, inflammation and damage, and poorer function and health-related quality of life: results from the DESIR cohort'. *Ann Rheum Dis.* 2012 June;71(6):809-16. doi: 10.1136/annrheumdis-2011-200180.

Department of Health NHS Improvement & Efficiency Directorate, Innovation and Service Improvement. 2011. *Innovation Health and Wealth, Accelerating Adoption and Diffusion in the NHS.* <http://www.institute.nhs.uk/images/documents/Innovation/Innovation%20Health%20and%20Wealth%20-%20accelerating%20adoption%20and%20diffusion%20in%20the%20NHS.pdf>

Department of Health. 2012. *Liberating the NHS: No decision about me, without me.* London: Department of Health. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf [accessed 13th August 2013]

Deyo, R.A., Weinstein, J.N. 2001. 'Low back pain'. *N Engl J Med* 2001; 344: 363-70.

NASS. 2010a. *Looking Ahead: Best practice for the care of people with ankylosing spondylitis (AS).* London: NASS.

Appendices

NASS. 2010b. Working with ankylosing spondylitis: NASS Society Survey 2009. London: NASS.

NASS. 2011. 'What is fatigue?'. NASS website. May 2011. <http://nass.co.uk/about-as/managing-my-as/fatigue/>

National Audit Office. 2011. Managing high value capital equipment in the NHS in England: Report by the Comptroller and Auditor General HC 822 Session 2010-11. <http://www.official-documents.gov.uk/document/hc1011/hc08/0822/0822.pdf>

NICE. 2008. Adalimumab, etanercept and infliximab for ankylosing spondylitis. NICE technology appraisal guidance 143. London: NICE. <http://www.nice.org.uk/nicemedia/live/11992/40761/40761.pdf>

OECD. 2012. 'Medical technologies: CT scanners and MRI units', in Health at a Glance: Europe 2012. OECD Publishing. <http://dx.doi.org/10.1787/9789264183896-31-en>

Papagoras, C., Markatseli, T.E., Saougou, I., Alamanos, Y., Zikou, A.K., Voulgari, P.V., Kiortsis, D.N, Drosos, A.A. 'Cardiovascular risk profile in patients with spondyloarthritis', *Joint Bone Spine*, 1 June 2013, <http://dx.doi.org/10.1016/j.jbspin.2013.03.019>. (<http://www.sciencedirect.com/science/article/pii/S1297319X13000985>)

Rennie, WJ. 2013. 'MRI in SpA Standardised Local Protocols'. In: UK Radiological Congress (UKRC) 2013, 10-12 June, ACC Liverpool. <http://www.ukrc.org.uk/assets/Speaker%20presentations%202013/Wednesday/H6%20Arthritides/H6%20-%20MRI%20in%20SpA%20standardised%20local%20protocols,%20Thariq%20Hajamohideen.pdf>

US PsA Working Group. 2013. Outside In: Joint Advances in Rheumatology and Dermatology: A best practice guidance document for the care of people with Psoriatic Arthritis (PsA). <https://www.psoriasis-association.org.uk/silo/files/Joint-Advances-2013-Abbvie.pdf>

2020health's mission

Making health personal

2020health is an independent, social enterprise think tank whose purpose is to both improve individual health and create the conditions for a healthy society, through research, evaluation, campaigning and relationships.

2020health research and activity includes the following workstreams

Fit-for-school:

To create a holistic picture of wellbeing and what children need in order to thrive at school, and identify ways of enabling more children to flourish and break the cycle of failure.

Fit-for-work:

To continue looking at the importance of work for health and health for work, and ensure that those who experience illness receive timely and appropriate support, understanding that worklessness impacts on economies and society as a whole.

Fit-for-later life:

To look from active retirement, to increasing dependency and end-of-life care and consider new models of provision, raise the status of caring, embed respect for ageing and ensure inclusion.

Forgotten conditions:

To ensure that people with rare or unusual health conditions have their needs met by the NHS.

"Passionate about patient power and won't flinch from promoting their interests."

Dr. Mark Britnell, Chairman and Partner,
Global Health Practice, KPMG

Integration:

To promote integrated care that uses technology to empower people and enable management of their healthcare and wellbeing.

International:

To ensure that we continue to share our knowledge of healthcare and learn from those countries that care for people better than we do.

Innovation:

To ensure that people have access to innovation in all of its forms and keep the UK at the forefront of R&D.

Social Care:

To find sustainable solutions to ensure people's vulnerable or final years are the best they can be.

"Always striving to keep people's needs at the centre of what the NHS delivers."

Dr. Johnny Marshall, GP, Head of Policy,
NHS Confederation



2020health.org
Devon House,
171-177 Great Portland Street,
London W1W 5PQ
T 077 2020 6910
E admin@2020health.org

Published by 2020health.org
© 2014 2020health.org
Price £00

ISBN 978-1-907635-24-3

