

What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis? **Final Project Report Headstrong Thinking Limited** December 2022

















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Foreword

Much is made of the concept of patient-centredness, of ensuring that patients' needs and values guide clinical decisions. But to what extent are axial spondyloarthritis (axial SpA) services patient-centred?

More fundamentally, do we really know what people with axial SpA value and need from such services? To date, our answers to those questions have been partial and based on anecdote.

Services for the diagnosis and treatment of axial SpA clinical care are informed in the UK by NICE Guideline 65 (2017) and Quality Standard 170 (2018), and internationally by the European Alliance of Associations for Rheumatology (EULAR) Recommendations (updated in 2022) and the Assessment of Spondyloarthritis Society (ASAS) Quality Standards (2020). Whilst there was some patient input into the development of these documents, they express a predominantly clinician-based view of what should be provided in diagnosing and managing axial SpA.

This is a significant deficit that NASS has sought to address. As part of our *Aspiring to Excellence* quality improvement programme, we commissioned Headstrong Thinking Limited to undertake independent research with a sample of more than 900 people living with axial SpA. The study aimed to identify the needs and values of people living with axial SpA in diagnosing and managing the condition and to assess the extent to which these are reflected in people's experiences of services.

The results are striking. Respondents reported feeling disbelieved by health care professionals when seeking a diagnosis. Some didn't feel listened to or valued, and sometimes the clinicians seemed to lack empathy and understanding of their pain and anxiety. A significant proportion had to pay privately to get their diagnosis, with those on higher incomes more likely to have done so. Respondents felt that there was a lack of joined up thinking about different specialisms when it came to getting their diagnosis. Once diagnosed they lamented

the dearth of support and information available from the NHS immediately after receiving a diagnosis and many reported not feeling involved in decisions about their care. There was a discrepancy between what people expect of their health care providers and the care they received, with many feeling that they should have been provided with care that was not forthcoming. Nearly half of respondents reported paying for additional care. Many reported that there is a lack of tailored care, and a sizeable minority told the researchers that they were not self-managing very well. Of concern to us, those groups that were most likely to have had negative experiences of NHS services were women, younger people, those on lower incomes and those with a more recent diagnosis.

Whilst we recognise that there are areas of good practice and we acknowledge that the NHS is under considerable strain in the current climate, the overall message from the study is that people with axial SpA do not think that they are receiving high quality care. At the same time, it is clear that people with axial SpA know very well what they do want.

Drawing on the research findings, we have developed the first ever set of Patient Quality Standards which we will launch in Spring 2023. We will be pressing NICE, EULAR and ASAS to integrate them into their existing guidelines and standards, as well as working with our 19 Aspiring to Excellence rheumatology departments and others to incorporate them into routine clinical practice. Every patient, every time deserves clinically effective, patient-centred care.

D.C ____

Dr. Dale Webb, FRSA, FRSPH CEO, NASS



Introduction

This is the final report of a major qualitative and quantitative research study, conducted for the National Axial Spondyloarthritis Society (NASS), in 2021-2022.

The aim of the research was to determine the values and needs of patients in the diagnosis and management of axial spondyloarthritis (axial SpA).

At the time of commissioning the research, (Spring 2021), an All-Party Parliamentary Group for axial SpA had recently conducted a national inquiry, supported and published by NASS. This inquiry sought to bring to the attention of parliamentarians and policy

makers the application of the National Institute for Health and Care Excellence Guideline for Spondyloarthritis. The guideline largely focusses on clinical outcomes rather than person-centred holistic care. Headstrong Thinking's research study was designed to complement those findings, bringing in the lived experience, needs and perspectives of people with axial SpA, so that a more rounded and balanced picture could emerge.

The research considered the nine "Assessment of Spondyloarthritis International Quality Statements", as detailed by the BMJ in figure 1⁻¹.

Figure 1 - Summary of nine Assessment of Spondyloarthritis International Society quality statements (QS)

Non-rheumatology care

Clinical Symptoms

OS 1 Referral: People with suspicion of axial SpA are referred to a rheumatologist for diagnostic assesment within 3 working days.

Rheumatology care

Diagnosis/ Differential diagnosis	OS 2: Time to Special People with suspicion of axion are assessed by a rheumat within 3 weeks after refe	al SpA ologist	People have t	S 3: Assessment with suspected axial SpA heir diagnostic work-up bleted within 2 months.
Treatment	OS 4: Monitoring Disease Activity Disease activity of people with axial SpA is monitored under the supervision of a rheumatologist with validated composite scores at least twice a year.	OS 5: Disea In people wi and active dis conventional the escalation wil discu	th axial SpA sease despite erapy, treatment th biologics is	QS 6: Non pharmacological Treatment People with axial SpA are informed about the benefits of regular exercise.
Management	OS 7: Education and Self-management People with axial SpA are offered education on the disease including self-management within two months of diagnosis.	QS 8: Rap Patients with a disease flare or related side et advice within days of cor rheuma	axial SpA and possibly drug- ffects receive in 2 working ttacting the	OS 9: Annual Review People with axial SpA have a comprehensive annual review by the rheumatologist.

¹https://ard.bmj.com/content/79/2/193.long

The research design and content took a patientcentred, rather than clinician-centred, perspective, to complement these quality standards.

The research objectives, methodology and sample recommendations ensured that the researchers could also explore other aspects of patient experience, which NASS believed had not been identified and evaluated in terms of their contribution to patient perceptions of "quality care."

Fieldwork and analysis were conducted by an independent research and marketing consultancy, Headstrong Thinking, and its partner, Community Research.

About Axial SpA

Axial SpA is a painful, progressive form of inflammatory arthritis. It mainly affects the spine but can also affect other joints, tendons and ligaments. Axial SpA is an umbrella term for:

- 1. nr-axial SpA (non-radiographic axial SpA)
- 2. Radiographic axSpA also known as ankylosing spondylitis (AS)

The former can be shown on MRI as it will show inflammation of the spine and sacroiliac joints. The latter can be detected on an X-ray as it will show bone fusion and growth. Initial and ongoing inflammation can cause bones to wear down and then when the inflammation subsides, the bone grows again, and this may cause spine fusion and certainly causes lack of mobility, pain and discomfort.

'25% of people will have spinal fusion as well as fusion in other parts of the body including the ribs, causing problems with breathing, the feet, causing problems with walking and hips, leading to the need for hip replacement surgery.' ²

Versus Arthritis (2019) The State of Musculoskeletal Health 2019. Arthritis and other musculoskeletal conditions in numbers

The purpose of the research study was for NASS to understand the values and needs of patients, to enable them to inform health care professionals (HCPs) and providers about the values and needs of patients in terms of their treatment and care and for NASS to integrate powerful patient quality standard messages into its public and professional campaigns.

² Versus Arthritis (2019) The State of Musculoskeletal Health 2019. Arthritis and other musculoskeletal conditions in numbers

Executive summary

The research was conducted by Headstrong Thinking Ltd for NASS between September 2021 and April 2022.

The objectives of the research were shaped by NASS's desire to provide patient-centred definitions of quality care, to complement existing clinical definitions.

The research comprised a literature review, a small-scale qualitative study (n=12) and a larger-scale quantitative survey (n=939).

The literature review pinpointed gaps in current understanding of the impacts on psychological, emotional, cognitive and practical experience of living with axial SpA. NASS was particularly keen to better understand the impact of a delayed diagnosis - which is often a feature of the experience of an individual with axial SpA and can exacerbate both the psychological and physical aspects of living with the condition.

The qualitative phase of the research provided a range of insights and hypotheses that the quantitative research was used to validate and quantify:

- This phase uncovered a rich understanding of the impacts on psychological, emotional, cognitive and practical aspects of life with axial SpA
- Patients were keen to stress that living with axial SpA is what happens between appointments and there is so much of that time and so little time in an appointment
- A detailed picture of a wide range of clinical, psychological and practical adverse impacts around delayed diagnosis emerged
- It provided an in-depth understanding of these experiences across sex, gender and a range of life stages, socioeconomic groups, diagnosis status, years of living with axial SpA and co-morbidities
- The qualitative findings confirmed the nuanced complexities and impacts on physical and psychological health, and the quality of life, of those living with axial SpA

 It indicated that individuals' experiences within the NHS created strong views about what quality care should look like.

This comprehensive feedback was used to develop a quantitative questionnaire covering all aspects of care using the output and language of people with axial SpA.

The quantitative phase of the research largely validated the conclusions and confirmed the extent of some of the issues uncovered in the qualitative research:

- It found that the average time it takes for people to get a diagnosis from the onset of symptoms is 12.4 years, which is longer than found in previous studies (although please note that the respondents to this survey may not be representative of the wider axial SpA community, as discussed on page 32)
- Respondents often reported feeling disbelieved or that they were not listened to by HCPs when seeking a diagnosis, which meant it took even longer than it needed
- A delayed diagnosis was seen to have had a negative impact on many, both in terms of the progression of the condition itself and on people's ability to manage it
- A significant proportion of respondents got their diagnosis privately, with those on higher incomes more likely to have done so, indicating that where people have the financial means, they will pay for a speedier diagnosis
- There was a sense that there was a lack
 of joined up thinking across different
 specialisms, both when it came to joining
 up the dots to make a diagnosis, and when
 it came to the ongoing management of
 people's different symptoms
- There was felt to be a dearth of support and information immediately after receiving a diagnosis, but when people do receive the support and information they need, they are largely satisfied with it, indicating that the problem isn't with the quality of provision, it's with the lack of access to it

- When it comes to people's satisfaction in the care they receive for their condition, views were mixed. While overall, the research found a mean score of 6.4 out of 10, this disguised some of the outlying views – nearly a fifth were not satisfied but well over a third were very satisfied – as well as the differences by subgroup
- There was a discrepancy between what people expect of their health care provider and the care they received, with many feeling that they should have been provided with care that was not forthcoming. Nearly half of respondents reported paying for additional care
- The sense that people reported in the qualitative research of not being made to feel like individuals was further borne out in the quantitative research, where many feel that there is a lack of tailored care provided
- Although most said that they were selfmanaging quite well, there was a sizeable minority who were not. Additional support with fatigue management, pain management and physical activity would be most welcomed
- The groups that were most likely to have had negative experiences on their journeys with axial SpA were women, younger people, those on lower incomes and those with more recent diagnoses.

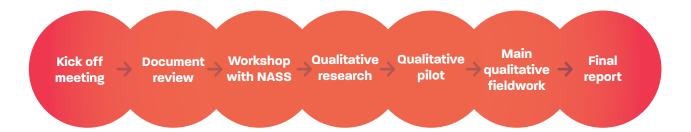
Taken as a whole, this research process has uncovered some profound findings, which should be of concern for everyone involved in the diagnosis and treatment of axial SpA:

- The current guidelines do not fully align or include the patient perspective on what constitutes quality in the diagnosis and treatment of axial SpA
- People with axial SpA are able to clearly articulate what they want and need from HCPs in the diagnosis and ongoing treatment of their condition

- They are equally clear that, for the most part, they are not receiving "quality care" as they define it, with significant gaps between expectation and patient experiences
- Most patients reported that they prefer to work as a team with HCPs, and make active decisions about how to manage their axial SpA; yet, a consistent picture emerged of patients not being listened to, or believed, when they sought diagnosis, of being treated as a collection of symptoms, rather than as a whole person; of a lack of join-up both between HCPs and along the patient journey; and of a lack of tailored advice for how they could manage their condition more effectively
- Worryingly, there were significant disparities across the sample, with women, lower income groups and those on benefits consistently reporting they were less likely to receive quality care. Members of ethnic minorities may also have experienced poorer care (note: small sample size)
- There was a suggestion that the quality of care, as defined by patients, is getting worse, not better, with more negative experiences being reported by the more recently diagnosed (within the past five years)
- The research suggests that there is a need for greater understanding of the patient perspective in designing diagnostic and care pathways for people with axial SpA, particularly with those living outside of the South of England; from minority ethnic groups; and from the LGBTQ community.

Project approach

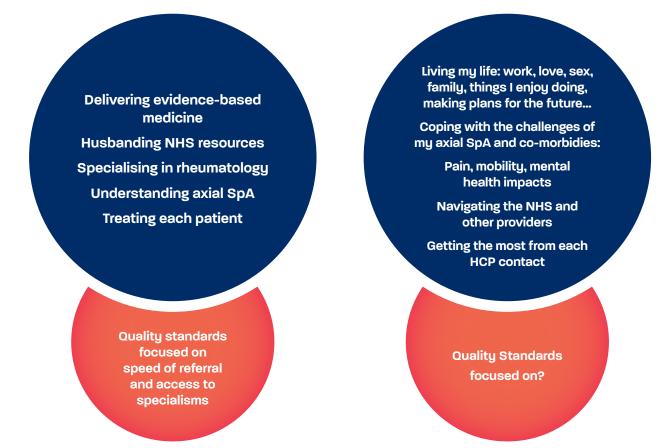
This project spanned ten months, and was divided into seven stages, set out below. The project began in July 2021, with a meeting with key NASS personnel at which the scope and scale of the project were agreed, and key milestones and a timetable confirmed.



Pre-fieldwork workshop

A workshop was convened on September 23rd, 2021, at which NASS and Headstrong Thinking agreed a detailed approach to the research study. One output of the workshop was the following diagram, which captured an initial hypothesis about the key differences in the clinician versus patient perspective on quality of care for people with axial SpA:

Figure 2 - The clinician vs. the patient perspective?



The workshop participants agreed the following objectives for the project:

- To understand more about the diagnostic pathway, specifically where people get lost, and the gaps where people were not getting adequate support
- To inform the next phase of the APPG inquiry
- To aid in writing submissions to Government and to NICE, including a set of quality standards to mirror those produced by ASAS
- To compliment the information and support NASS itself was able to offer people with axial SpA
- To understand how people's attitudes and world view impact on how they see their condition and what they want from services
- To understand how people would like to be involved in decision making around their care and levels of patient activation
- To enable NASS to speak to clinical audiences and cut through the dry language currently used with something which better captured the day-to-day language and experiences of real people
- To provide NASS with a dataset of relevant statistics to support their lobbying and awareness raising campaign activities

Literature review

Headstrong Thinking conducted a literature review for NASS in October 2021. The full list of sources consulted is appended. The review was used in part to highlight the gaps in existing patient-centred research into axial SpA. These specific findings are reported here to provide the rationale for the focus and content of the subsequent research. The full literature review, which also included sections on symptoms, medication, employability and patient access to health care, is appended.

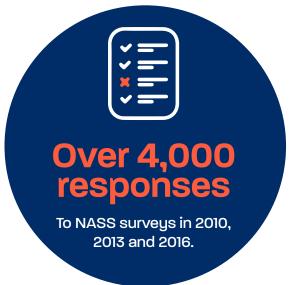
The literature review concluded that the existing knowledge base contained little robust information about the psychological and emotional impact of axial SpA, for example, there was little understanding of the lives of

those behind a headline figure - of the elevated risk of depression in axial SpA patients.

Nor did the literature cover the impact of axial SpA on the individual in the wider context of their life, life stage or personal relationships

Understanding what quality of care meant to patients in the context of their interactions with HCPs and the (NHS) health care system was also missing a person-centred research approach.

The researchers proposed a range of areas for exploration in the qualitative phase of the project. These were informed by a review of a number of NASS resources, and the openended feedback from surveys undertaken by NASS in 2010, 2013 and 2016. The total number of responses to these surveys combined was over 4000.



The areas proposed for further insight were as follows:

- Daily living, transport and travel
- Relationships including parenting, sex and intimacy and partners/family as carers
- · Work and benefits
- Social life and social recognition, ableism and lack of awareness/understanding of axial SpA in the population
- Mental health, wellbeing, physical health and exercise
- Experience of the NHS good and bad interactions; navigating the system; unmet needs.

The focus of the research questions was on the following areas, identified as gaps in the literature review:

- The patient pathway, and specifically, the journey to diagnosis (with sections on primary care and rheumatology), early days, and long-term management
- Interpersonal aspects of patient care, including the organisation of care and the technical aspects of care (for example, monitoring disease activity).

In relation to the NHS health care system:

 How patients would rank some key statements in terms of importance (in relation to their perceptions of "good quality care")

- Establishing unmet needs in relation to what people see as effective patient-centred communication from HCPs
- Daily living, in the context of selfmanagement and conversations with HCPs, for example, to what extent do people value being able to talk to their health care provider about activities of daily living.

Detailed demographic information was collected, to allow for the fullest range of subgroup analysis. NASS also asked the researchers to use the recently developed NHS Patient Activation Measure³, to devise a question pinpointing the needs of different kinds of axial SpA patients.

Overall research approach

The research programme was conducted in three phases.

The first phase was a small scale, qualitative study, conducted in November and December 2021. This provided in-depth feedback on the everyday lives and experiences of health care provision, amongst twelve individuals with axial SpA. Its additional role was to provide a detailed array of relevant questions, couched in everyday language, for the subsequent quantitative questionnaire. It also provided insight into the key demographic and attitudinal measures to collect, for use in sub sample analysis of the quantitative sample data.

The second phase of the research was a small scale, cognitive testing phase. Five individuals with axial SpA were invited to test the proposed questionnaire and feedback in a conversation with one of the researchers. The questionnaire was refined in the light of their comments.

The third phase was a quantitative survey, completed by over 900 individuals. The link to the quantitative questionnaire was launched by NASS, using the agreed social media and marketing channels in February 2022. The survey remained open until 4 April, 2022,

to allow the maximum number of people to contribute.

Qualitative research

Research objectives

The specific objectives of the qualitative research phase were agreed after consideration of the literature review. They were articulated as follows:

- To provide insight into the sample characteristics and variables we need to identify and collect to allow for meaningful analysis of the quantitative survey data
- To collect in-depth data based on lived experience to ensure the survey can ask about "quality health care provision"
- Establishing more about what makes a "positive interaction" or a "negative interaction" with an HCP and how trust and perceptions of "quality" care can be built or undermined
- How patients would rank some key statements in terms of importance (in relation to their perceptions of "good quality care")

³ https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/pamlearning/

- Establishing unmet needs in relation to what people see as effective patient-centred communication from HCPs
- The impact of axial SpA on mental health as well as physical health
- The experiences of those with recent diagnosis as well as those who have lived with axial SpA for longer, and impact of a delayed diagnosis
- The parts of life/life stages/diagnostic stages where people might need tailored resources from NASS and what their needs would be.

Qualitative research sample and methodology

Twelve individuals were recruited to take part in an online or telephone interview, lasting one hour, which took the form of a discussion rather than a structured interview questionnaire. This approach ensured that individuals could add elements of their experience of living with axial SpA, which the interviewers had not necessarily anticipated in deciding on the range of questions. These individuals were chosen to represent different types of patient, in terms of whether they had a diagnosis of axial SpA and, if so, how long ago they had received it. They also differed in terms of age, sex, gender, employment status, living situation and presence or absence of comorbidities relating to their axial SpA. The intention was to cover as many sample variables as possible, to aid understanding of which might prove important in the analysis of the data from the larger, statistically significant, quantitative survey.

Participants were approached by NASS to take part, drawing on a database of individuals who had consented to contact for research purposes. Once these agreed to further contact, their details were passed to the researchers and held securely. Individuals gave their informed consent to take part in the interview and to the collection and storage of their personal information by the researchers under GDPR regulations. They were told that their interview would be confidential and that any findings used in reporting would be anonymised. They were given the opportunity to opt into further specified usage of their data: namely that we could audio record the interview for analysis purposes and that their data could be used in the development of anonymised case studies. They also consented to a potential approach by NASS, to provide audio or filmed accounts based on their interview. NASS would use these to further understanding of axial SpA amongst HCPs; patients; prospective patients and the general public. They were told that they could withdraw consent at any point including during the interview. In the event, all twelve interviews were concluded successfully.

Sample achieved

The following tables detail the characteristics of the twelve individuals recruited for the qualitative research. The first table covers demographic information and the second, the detail of symptoms associated with axial Spa and other health issues for each participant. These data illustrate the variability and complexity of issues and symptoms – both physical and psychological - that an individual could experience with a diagnosis of axial SpA.

Participant demographics - Table 1

Age	Gender	Diagnosis	Employment status	Family status
59	Male	Waiting for	Full time	Lives alone
24	Female	Waiting for	Student	Lives with partner
19	Female	Last five years	Gap year: hopes to go to uni	Lives with parents
22	Female	Last five years	Full time	Lives with parents
ल	Female	Last five years	Part time	Married 2 children (and pregnant)
30	Female	Last five years	Full time	Recently separated
બ	Male	Last five years	Student	Lives alone
M M	Female	Last five years	Made redundant and unable to work	With husband
55	Female	Last five years	Retired at 50: no longer able to work	Lives with husband
23	Male	Over five years ago	Part time	Lives alone
26	Male	Over five years ago	Full time	Lives with partner
74	Male	Over five years ago	Retired	Lives with partner

Participant symptoms and comorbidities - Table 2

Age/	Diagnosis	Physical symptoms	Comorbidities or other axial SpA	Other issues/conditions
Male, 29	Awaiting diagnosis	Low back pain, stiffness (A.M)	Insomnia, depression, weight loss	·
Female, 24	Awaiting diagnosis	Back, shoulder, neck pain, difficulty walking	Fatigue	Endometriosis, mild sco- liosis
Female, 22	<5 Years	Weak/stiff hands, knees, sore shoulder "crunching" jaw	Peripheral joint involvement	Developing back pain
Female, 55	<5 Years	Chronic pain and stiffness (all body)	Microvascular angina, eyes, fatigue	Bechet's syndrome, anxiety, depression
Female, 31	<5 Years	Lower back	Fatigue	New "sharp" shoulder pain
Female, 30	<5 Years	Joint pain (all body)	Fatigue	Hypermobility spectrum disorder
Female, 33	<5 Years	Lower back pain, shoulder blades and rib cage	Fatigue, focusing and processing info	Anxiety
Male, 31	<5 Years	Back pain, pain and stiffness in other joints (moving location)	Fatigue	Feet (mobility) insomnia
Female, 19	< 5 Years	Back pain, leg tremors and spasms		brain cyst, non-epileptic seizures, urinary infections?
Male, 53	> 5 Years	Back pain, joint pain, failing eyesight, inability to walk, mild crohn's	Podiatry, gastroenterology, orthopaedics, ophthalmology	Depression (family loss and he was a carer)
Male, 74	> 5 Years	Uveitis, back pain feet have "collapsed completely" Osteoarthritis (knees and hips) and neck is mostly fused	Chronic kidhey disease, angina.	Diabetic
Male 56	> 5 Years	Fatigue, stiffness, back pain, increasing knee pain	Stomach (side effect of anti- inflammatory medication)	Periods of insomnia

were used to illustrate each theme identified by the two researchers who had conducted the interviews. The themes were then used in the final The findings of the interviews were analysed using a thematic approach. All interviews were transcribed and direct quotes from participants presentation of findings, to ensure the research debrief met the agreed objectives of the research.

Detailed qualitative research findings

This research uncovered a rich understanding of the impacts on psychological, emotional, cognitive and practical aspects of life with axial SpA.

A detailed picture of a wide range of clinical, psychological and practical adverse impacts around delayed diagnosis emerged.

More detail is provided below, specifically on: participants' experiences of symptoms of axial SpA; the first year after diagnosis; and living longer term with axial SpA (including the impact on psychological and emotional health).

Then interactions with the NHS are reported on, including patient-centred perceptions of quality care.

Symptoms of axial SpA: The patient experience

Participants explained that the word "symptoms" did not fully capture the nature of their experience when recounting the time during which they eventually got a diagnosis for axial SpA. Individuals did experience symptoms (as the chart in the previous section outlining the profile of each participant shows).

However, in their search for a diagnosis these symptoms could be discounted by GPs as factors of age, lifestyle or unrelated conditions. A diagnosis of "growing pains" or the likely consequence of an active sporting lifestule were given as initial or repeated explanations. Some participants were told that their symptoms may be related to psychological rather than physical health conditions and prescribed medication accordingly. Others were sent to specialists such as orthopaedics or neurology to investigate individual symptoms with a lack of further referrals if results came back negative. It was difficult for GPs or individual clinicians to take an overview and recognise the whole picture that might suggest axial SpA. Mindful of their gatekeeper role, participants felt GPs could be reluctant to refer patients for further investigations which would use expensive or scarce resources.

"I do find going to the GP is an absolute nuisance. They don't really look into things as such, they ask you what's wrong and then basically just ply you with painkillers or medication, you have to keep going back, keep going back... (in A&E) I've basically just been sitting there in pain for hours on end and not been seen. Basically, just give up and go home."

Male, 29, works full time seeking diagnosis

Some participants believed that, because they were young, they were not taken seriously by the GP who would often resort to stereotypical or stigmatising explanations. Young women felt they were more likely to be judged if they became upset during appointments and that this could exacerbate a tendency to offer a mental health rather than physical diagnosis.

Getting a diagnosis

Participants were asked about their experience of getting a diagnosis. They explained that the period of life prior to, and when seeking, a diagnosis was often long and drawn out. Each individual had a different experience, but a number of possible stages to diagnosis were outlined. It is important to note that progress through these "stages" was not always linear and that individuals did not see them as "stages" in the sense that they were not always logical, predictable or even tangible, except in hindsight.

They are better described as experiential touch points and the following list describes each of them:

- Accepting GP initial response at face value.
 The person presenting wanted it to be nothing
- Repeated and intensifying pain/stiffness or other physical symptoms. A growing belief something physical is wrong

- Feeling fobbed off, disbelieved, dismissed by the GP
- A strong belief that repeat attendance can count against you
- Some individuals were told that they might be suffering from myalgic encephalomyelitis (ME), fibromyalgia, depression or just "attention seeking." These diagnoses tended to stall progress towards an accurate diagnosis of axial SpA or a referral to appropriate secondary care
- Not feeling believed, accepted or understood often led to self-doubt. It felt hard to assert oneself especially as a young person. It was difficult to challenge an authority figure
- A minority of individuals recognised that they employed an avoidance strategy when they were questioning themselves and found it too upsetting and/or stressful to keep visiting the GP. If they moved around the country as young people often do, this avoidance period could be rationalised as difficulty organising a new GP to consult
- Referrals to a rheumatologist came, sometimes prompted by consultations with osteopaths, chiropractors or physiotherapists with some knowledge of axial SpA
- For others, referrals to other specialists came first and sometimes individuals' progress was made more complex by parallel investigations into other conditions or comorbidities, which were not recognised as such at the time
- Over time a few individuals found ways to be more assertive with clinicians taking their notes and scan results to appointments to reduce what they perceived as the "fobbing off" risk
- Getting a final accurate diagnosis.

As a result of these factors, getting a diagnosis could take a number of years. The following two case studies also illustrate the impact of how well resourced the individual is on their ability to influence their path to diagnosis.

The first year after diagnosis

Because getting a diagnosis could be a long process, a number of individuals found the initial period after that point very unsettling. The diagnosis appointment was a relief, but could be

treated by the consultant as an end in itself. The news was delivered; leaflets might be given out; the patient possibly referred to physiotherapy and medication advice given.

"He looked at my cycle helmet and said, 'well you're obviously active, keep it up' and that was that but he didn't say what or how much and I don't want to make things worse...I definitely didn't get the closure or the clarity that I was hoping for."

Male, 31, student diagnosed <5 years

Individuals described that taking in the news was difficult and that it was only when the impact dawned later that their important questions surfaced. For some, this was a period of denial or a decision to take each day as it came. For others, they worried about whether they were doing the "right thing" in terms of exercise or diet. There were concerns about daily life – employment, benefits, the advisability of planning to have a child or going to university. Some described the impact on their mental health, feeling grief that they had lost many years getting to a diagnosis and now faced an uncertain future, not knowing the best or worst case scenario.

Most reported that they had invested a great deal in the diagnosis appointment and found it extremely hard afterwards, when they had to wait for further opportunities to discuss their emerging concerns. Getting accurate information was difficult; waiting until the next annual appointment felt far too long. Participants would have welcomed an opportunity to have a further, in-depth, conversation. For some, this would have been a chance to map out the possible course of the disease and the options they might have for medication, especially if they researched the role of biologic drugs (biologics). For others, it was more a question of 'what can I do to help myself and feel like I am in control, rather than losing a sense of control?' Others needed practical help to inform their workplace and educate their employer about reasonable adjustments.

Well resourced female seeking a diagnosis

- Female aged 24; student; living with partner
- Impact on uni studies pt. time; breaks; selfstudy and now finally full time student after five years
- Uni requires specialist consultant's letter to underwrite "reasonable adjustments"
- Paying for upcoming private specialist as rheumatology appt. to confirm diagnosis
- Trying to get diagnosis for 5/6 years.
 Complicated by parallel process with endometriosis (& meningitis attack)
- "Dismissed;" "passed around," treated with scepticism; young woman: – self doubt
- Fibromyalgia? ME? Depression?
- Carries notebook with "8 main symptoms"
 + copies of test results/scans to all appts
- Search for diagnosis supported by family and friends with medical knowledge + emotional support from counsellor + paid for physio.

"I remember bringing it [axial SpA] up to a rheumatologist I saw in 2017 and being dismissed quite quickly as well it didn't fit this very neat box and so that couldn't be it. Are you on painkillers? Are you on antidepressants? I kept saying "well I'm not depressed, I'm a very, happy, positive person, I'm just in a huge amount of pain."

Female, 24, student seeking diagnosis

Isolated male with lower educational attainment: seeking a diagnosis

- Aged 29, lives alone, dyslexic, only has mum, who is seriously ill
- Skilled manual worker, employed (but layoffs due to condition couldn't pay for car repairs, couldn't afford subscription tv channels at those times)
- · Symptoms for 9 years
- Severe back pain causing insomnia, weight loss associated with depression (diagnosed by GP)
- Presented several times at A&E due to pain but left after several hours unseen
- Workplace adjusted his work & paid for chiropractor who finally got GP to refer for x -ray and bloods

 Waiting for MRI scan. He does not know what the problem might be and does not understand what he has been told to date.

"I'm no wiser at the moment.

Basically, said a lot of posh words but not giving me much diagnosis or treatment."

Male, 29, lives alone seeking diagnosis

Living long term with axial SpA – daily life

Participants described very challenging experiences when talking about living with axial SpA. The researchers noted that, for some participants, the act of telling an outsider about their lives made them realise how difficult each day could be. They were so used to weighing up how they could preserve their energy each day, or planning what they needed to do to sit less painfully in a restaurant with friends, it had all become second nature.

The day-to-day challenges faced were many:

- Reducing expectations of the self how many daily housework chores can I do today if I want to do some tomorrow
- Managing flare-ups, which occur suddenly and disrupt family and work life, and can necessitate a period of total inactivity
- Getting to know the patterns of pain, for example, leaving tasks until later in the day if stiffness is a chronic issue first thing
- Debilitating exhaustion of pain, making it hard to sleep well, think clearly or remain positive
- Adjusting expectations of life and coming to terms with assumptions about what being a parent can mean, or settling reluctantly for a different job or career path, or losing a job
- Pressure on relationships, as a partner might have to become a carer and/or a (sole) source of income
- Giving up independence for example not being able to drive or needing a car which has been adapted
- Loneliness and isolation living alone and/or living alone in a "fog of pain."

"I think in terms of relationships as I mentioned before, myself and my partner of eight years, only separated a few months ago. And I think about the strain that my health has put on our relationship. The fact that, ultimately, a lot of the time in terms of my physical needs, he has had to do a lot of things for me in terms of helping with stuff around the house or helping me get dressed or helping on those longer journeys, where maybe I can't drive on holiday or things like that. And I don't think I realised just how much that was having to happen until he's not here. And now, I'm realising actually, I really struggle with daily tasks like getting the washing out the washing machine."

Female, 31, employed full time diagnosed < 5 years

Living long term with axial SpA – impact on emotional and mental health

Participants described a wide range of impacts on their emotional and mental health of living with axial SpA. They reported a clear interaction between their physical symptoms and mental health. Individuals were usually in great pain some or all of the time. Many had poor sleep patterns and were exhausted. They experienced the psychological stress of not being able to plan and manage life in a predictable manner, because of physical pain, stiffness and/or poor strength or mobility. Unpredictable flare-ups exacerbated these stresses.

In addition, a range of external factors also impacted an individual's mental health. Many had economic worries as a result of not being able to work or work efficiently. Others described the "traumatic" effect of having to navigate the benefits system and the assessments for disability related benefits such as Personal Independence Payments, that this necessitated. Being a parent, or partner, and being able to do your "fair share" might become difficult or impossible. Encountering a lack of awareness or understanding of axial Spa in the wider world impacted participants, who reported a range of difficult emotions this caused for them. Friends and family were not always able to understand the individual's inability to act spontaneously or attend events and social lives could fade away. The fact that, for many, their major symptoms were not visible, contributed to a lack of understanding in others. All in all, having to adapt to a life not planned or anticipated was hugely stressful. This was often described as "surviving and trying to cope" rather than living and thriving.

The specific range of psychological and emotional issues mentioned could be categorised as follows:

- Depression and/or anxiety
- Emotional isolation
- · Grief and loss
- Poor self-esteem and loss of sense of personal identity
- Cognitive impairment, or "brain fog" as it is often described

Individuals described days when they would catastrophise about the future or be unable to do anything but cry. Others felt too anxious to go out or struggled to motivate themselves or interact with others. Two individuals reported a loss of appetite and a lack of desire to look after their health, which resulted in them losing weight.

Being in pain could create a sense of existing alone and a withdrawal from the world. Individuals censored what they told family and friends about how bad the pain was. Not being believed by medical professionals while trying to get their diagnosis could impact on their ability to trust themselves and others – leading, in turn, to a further withdrawal and a "going inside myself".

"Yes, ...I managed to find other young people who also have AS..... I think before, especially when I got diagnosed, at the same time I lost those friends, I felt so alone. I felt like I was the only one. I know it's not true, but I felt like I was the only person in the world that was going through what I was going through."

Female, 22, working full time and living with parents diagnosed <5 years

Participants described a large amount of grief and loss, often combined with self-blame and guilt, when describing how they could not contribute to family life in the way they wanted to or could not have the same carefree lifestyle as their (young) peers, or lead the life they had planned.

Having a chronic disease impacted on individuals' sense of self — who they were and how they were seen by others. They reported fears that they were not believed and seen as lazy. Those relying on others and/or receiving benefits felt that this was not "who they were." A loss of confidence, and a sense of agency, were frequent issues in lives that could feel unpredictable and out of control. Not feeling confident, or at ease with who they were, led some people to find it hard to assert themselves with HCPs - encumbered by worries that they would be judged, or dismissed, or not seen as worthy of further support.

"I think it's also important that people understand that there's grief in getting a diagnosis, but there's also grief in the people around that person because everyone's got expectations of how relationships or friendships or what you want from your children from their life and for something like AS to come along and some of those dreams and hopes are changed or taken away, and that is difficult and that does affect a lot of people in different ways."

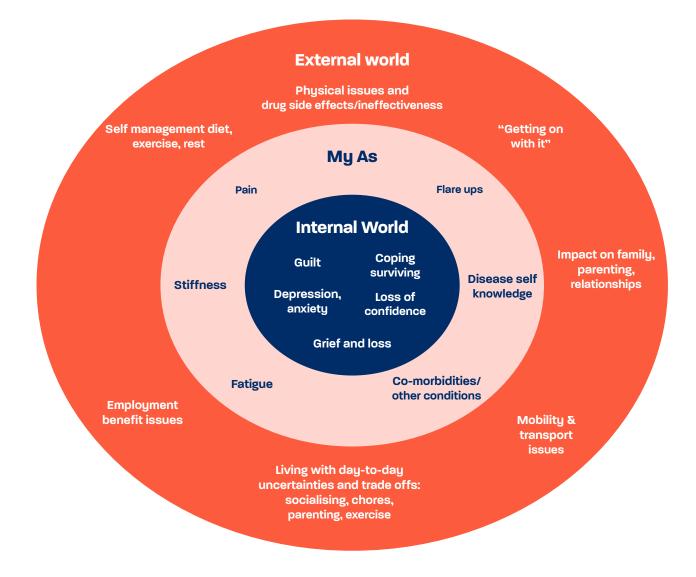
Female, 31, not working

diagnosed <5 years

"Brain fog" meant that individuals reported being unable to concentrate for long periods of time, or found it hard to remember things, or focus. For some, there were reports that their inability to focus or concentrate was further exacerbated by fatigue caused by insomnia and/or the impact of chronic pain. "Brain fog" alone or this combination of impacts led to some participants to report an inability to prioritise or carry out the simplest tasks, which in turn led to frustration and self-blame.

Summarising life with axial SpA

The following diagram sums up the complexities of living day to day with axial SpA and highlights the fact that life with this disease is not just a series of medical appointments. Rather, it was explained as a life of internalised battles, full of learned strategies to make day-to-day tasks possible; challenges to one's sense of identity; fear of judgment and psychological and emotional health struggles. Each individual said they had become a reluctant expert by experience in what it meant for them to have axial SpA.



Axial SpA and the NHS

The twelve participants had a wide range of experiences of interactions with the NHS in relation to their axial SpA. Two were still seeking a confirmed diagnosis; seven had received that diagnosis within the last five years and three had received it over five years ago, (one of whom had received it over twenty years ago). The sample was designed in this way, to ensure that the research would add to NASS's existing understanding of the impact of axial SpA on those recently diagnosed and waiting a number of years for diagnosis. This diversity of sample served to illustrate the wide range of experiences within the NHS that the researchers were able to capture and quantify in the subsequent largescale survey.

Types of interaction with the NHS

Patient interactions with the NHS ranged from repeated attempts to get an initial diagnosis through GP appointments, right through to support for a complex range of axial SpA comorbidities, which developed over time and became more severe. Most individuals had received their diagnosis from a rheumatology consultant, although some had initially been referred to orthopaedic or neurology consultants. A minority had had their diagnosis hastened by the intervention of an NHS physiotherapist, private chiropractor or osteopath, who had suspected axial SpA and written to the individual's GP to support their request for a consultant rheumatologist appointment.

Each now relied upon an annual rheumatologist appointment post-diagnosis, with occasional mention of the support of a specialist rheumatology nurse or an additional consultant appointment. Those with developing comorbidities saw other consultants specialising, for example, in podiatry, ophthalmology, or neurology only one individual felt that his care was centred round him, with good communication between hospitals or Trust departments within the NHS, and a specialist approach to his axial SpA care from each consultant. Others mentioned a more "siloed" approach, with a frequent need for patients to update individual

practitioners on their notes at each appointment. These individuals learned to question issues such as drug interactions or side effects of being prescribed different drugs for different comorbidities at the same time.

These reports began to speak to the concept of what quality of care in interactions within the NHS might look like for individuals with axial SpA. The fieldwork took place during the Covid-19 pandemic, in the autumn of 2021, when lives had been affected in the UK since March 2020. The researchers felt it important to acknowledge this, and to point to a number of factors which individuals felt were affecting their care. These had either manifested for the first time as a result of Covid-19, or were seen to exacerbate existing issues with accessing quality care as an axial SpA patient.

Reported impacts of Covid-19 on perceived quality of NHS care

Individuals reported a range of issues that adversely affected their NHS experience. Some factors, such as the withdrawal of hydrotherapy or the requirement to access a physiotherapist online or by phone rather than in person, were consequences of the pandemic. Other issues were seen as longer term and made more severe by the onset of Covid-19. Individuals mentioned:

- Waiting longer for "annual" consultants' appointments
- Lack of continuity of consultants and/or appointments, with more junior medical staff who changed between patient appointments, or telephone appointments with clinicians whom the patient had never met
- Access confined to short telephone appointments, which did not enable patients to see their notes or update their clinician on other emerging issues
- Difficulty with the obtaining or dispensing of repeat prescriptions and/or test results.

"A lot of the time it just feels like I'm getting passed on between different people. It's sad that that's become the norm, like ever since I got diagnosed, it's just been like over two years of trying to find the right person to contact and then ensuring that they contact me and give me what I want. Even then, there's been so many things that have fallen under the radar because I'll go to the GP, the GP will tell me to go to the rheumatologist and then I will message the rheumatologist and they will say okay... I'll mention it to the helpline, and I'll speak to the nurse, and they'll say, 'We'll discuss this with the rheumatologist' and no one gets back to me."

Female, 22, full time diagnosed <5 years

Patient-centred perceptions of "quality" care

A number of consistent themes emerged from the interviews about what axial SpA patients saw as overarching principles of quality care. They wanted:

- To be believed, seen and heard and respected for their own knowledge of their body and their axial SpA
- To experience a purposeful, consistent pathway of care underpinned by effective administration and communication - not a series of care "snapshots"
- To help them know what they could do to help themselves at home "help me make a plan"

It is important to note that these principles emerged as important for patients over time – that they were often looking back to diagnosis, and pre-diagnosis, when they reflected on these themes. For those in the thick of the early stages of living with axial SpA, putting these principles into practice would have made a great difference to their experience

of genuine quality care. However, at that time, most felt they lacked the clarity, understanding, experience or emotional resources to engage with axial SpA and identify the care they needed and could ask for.

The realities of care

Research participants understood the system challenges faced by the NHS, especially during the interview period in Covid-19. They saw for themselves the challenges faced by GPs and NHS Trusts/Health Boards trying to maintain adequate staffing levels and husband scarce resources. They saw the logistical challenges of being unable to offer face-to-face appointments and collections.

They also wanted those delivering their care to understand much more about living with axial SpA day in day out and how that might shape better person-centred care. Living with axial SpA is what happens between appointments and there is so much of that time and so little time in an appointment. Some individuals wondered about what was being measured in their rheumatology consultant appointments and how that related to decisions about care and their own ability to understand and manage their axial SpA.

"They just ask you questions like it's very much quantitative data, like on a scale of 1-5, how difficult do you find getting out of bed? On a scale of 1-5, how difficult do you find this? Then they just put that into the computer and then I think my understanding is, in six months' time, they'll ask me the same questions. It's like I don't really understand what the point really is because you're not getting any improved care."

Male, 31, student diagnosed <5 years They also found being asked how well they were managing, a difficult question. Often, they felt that they were managing an uncertain, unpredictable daily life in which flare-ups might set them back temporarily or adjustments they were making hid the scale of the impact of the disease on their quality of life. If they were managing to shrink their world and limit what they could do – were they managing better or just surviving?

Often, it was the small things that patients noticed that they considered to be quality care:

- A GP genuinely trying to get to the bottom of the issues for them with a determined plan which they took time to explain to the patient
- An HCP who asked how axial SpA was affecting being a parent, or decisions about pregnancy or difficulties getting to work
- An HCP who understood that crying at an annual appointment might just be the relief of having the appointment, or a reaction to difficult news, rather than an indication of mental illness or weakness
- A consultant who had read all the notes and offered a proactive discussion about medication changes or the pros and cons of different biologics
- A 'go to' rheumatology consultant who coordinated the referrals and results of patient visits to other consultant departments with good knowledge of axial SpA
- Confidence in follow up and effective administration about appointments
- An HCP who listened to a patient's own intimate experience of his or her comorbidities, medication interactions and side effects and assessment of advances in the disease.

"I do have fears, that I don't think
I could physically cope with the
demands of carrying a child or
all of the things that... I have big
fears about what would happen if
I needed to get them into the car?
What would happen if I needed to do
this? Would I be able to cook? Would
I be able to clean? So, I think there's
a lot around fears of being a parent
and also different medications."

Female, 32, works full time diagnosed <5 years

Hygiene factors – getting the basics in place

Participants mentioned a number of basic "hygiene" factors, that any quality customer care provision would be expected to deliver. These would be:

- · Reliable appointment making and call backs
- Maintaining the progress of tests, scans and result reporting to patients and GPs in a proactive manner, without leaving them "in limbo". Communication of future appointments and interventions and their purpose in the overall care plan
- Awareness, at each consultant or specialist nurse appointment, of the content of a patient's notes, scans and test results including impact of comorbidities and medications
- Recognition of the importance of face-toface physiotherapy appointments for a condition like axial SpA
- Working with the patient on a plan to support themselves between appointments, e.g., accurate advice around the importance of exercise, tailored to axial SpA.

A summary: providing quality care by stage of patient diagnosis

Table 3 sets out the important types of intervention patients said they needed to take account of the stage of the patient journey from diagnosis or ongoing management of the disease. It also presents this input from a patient-centred perspective and is built on the insight gained from individual patient stories.

Table 3

Diagnosis	Post diagnosis: immediate aftercare	Ongoing clinical response post diagnosis
Increase GP/secondary sector awareness of axial SpA especially in young patients and women	Get referral for physio support and consistent advice regarding realistic and safe axial SpA exercise options	Respond to changing needs. Axial SpA is a moving picture of adaptation and loss
"Join the dots": both in terms of symptoms and building a picture of the person	Book follow up appt with rheumatologist and provide information on medication options	Focus and respond to what is important to the patient now - life and loss in their daily life and provide self-management advice
Believe the person and don't penalise or stigmatise repeat attendance by scepticism, judgment or pathologising	FAO for post diagnosis phase - allow for initial period of confusion and denial before questions crystalise for the person with axial SpA	Medication reviews, biologics and consistent regular, consultant, physio care, and hydrotherapy Listen to the person who has become their own expert
Timely blood tests, referrals, and follow up/call backs	Explicitly acknowledge and support mental health without pathologising	Explicitly acknowledge and support mental health without pathologising
Act as a team and as the patient's ally and "get to the bottom of it"	Tailored information/ support for daily exercise, dietary and work challenges	Tailored information/ support for daily exercise, dietary and work challenges

Demographic and attitudinal information

In exploring feedback from individual participants, the researchers noted demographic factors which impacted participants' experience of living with axial SpA and which also influenced their perceptions of quality care. It was recommended that the following demographic information be collected in the quantitative research phase to allow for in depth analysis of the sample:

- Age (bands and exact)
- Gender
- Sex
- Working status
- Employment status
- Household: (living with)
- Presence of children under 16 (who are the participant's responsibility)
- · Claiming benefits
- · Needing care support
- Driving licence/current car driver

NASS subsequently added other demographic characteristics to the list which supported their strategic needs when campaigning and developing services and resources for people with axial SpA.

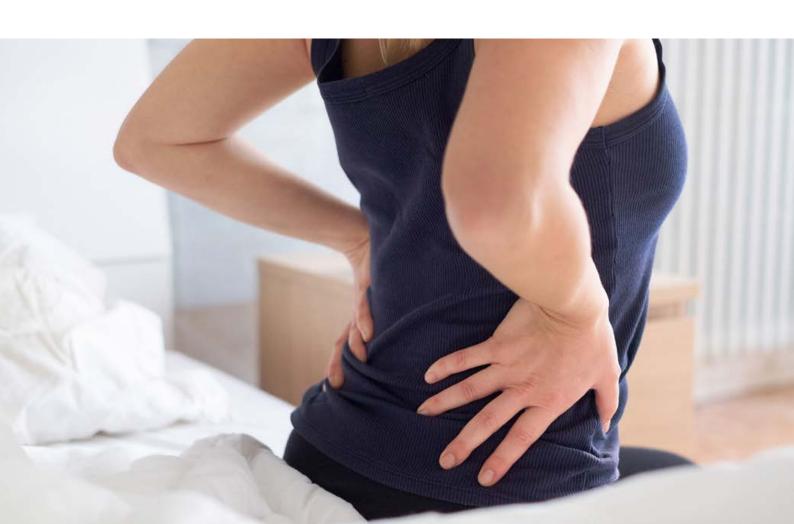
The researchers also stressed the importance of being able to analyse results by the following variables relating to experience of getting an initial diagnosis

- Number of years with symptoms
- Number of years to diagnosis
- · Number of years since diagnosis
- Age of person at diagnosis

A form of words was tested with the twelve participants, which attempted to capture their attitudes to living with axial SpA and their preferred style of relating with NHS HCPs. This had been useful in previous patient research, when understanding the difference in responses to survey questions amongst different patient "types." The statements were as follows.

- "I tend to leave all the decisions about my treatment and day to day management of axial SpA to my GP and/or consultant and/ or other health professionals I see about my axial SpA."
- "I do some research and thinking about axial SpA myself but on balance I leave it up to the doctors/nurse and/or other health care professionals to advise me about treating and managing my axial SpA, day to day."
- "I do a lot of my own research and thinking about my axial SpA and am largely confident/ happy to make my own decisions about how to manage it day to day (with or without support from health care professionals.)"
- "I do some research and thinking about axial SpA myself but I prefer to work with my health professionals and feel that we make decisions about my care and day to day management of my axial SpA together."

These options were considered in the light of the recently introduced Patient Activation Measure (ibid). The final statements used in the quantitative questionnaire were amended to allow for the results to be mapped onto the Patient Activation Measure more effectively.



The quantitative survey

About the survey

The online survey was in field between the 4th February and 4th April 2022 and was circulated to people on the NASS e-news mailing list, as well as being advertised via Facebook, Twitter and Instagram. As discussed above, the questionnaire design was informed by the qualitative research, and was made up of four sections:

- Section 1 captured respondents' demographics and details of their condition and treatment
- Section 2 explored respondents' experiences of seeking a diagnosis of axial SpA
- Section 3 explored their experiences immediately after receiving a diagnosis
- Section 4 explored their experiences of living with axial SpA and their ongoing health care.

The questionnaire consisted largely of closed questions, where respondents were able to choose their answers from a list of possible responses. There were some open-ended questions which allowed respondents to detail their experiences in their own words, and examples of these verbatim responses are included as quotes to illustrate some of the findings.

About this section of the report

The analyses reported here come from an achieved sample of 939. However, those who had not yet received a formal diagnosis only answered the first section of the survey; the majority of the data are taken from the responses of the 913 people who had received a diagnosis.

Since a sample, rather than the entire population of people living with axial SpA (c.200,000 people), has taken part, all results are subject to sampling error.

For random samples, this can be measured. For a question where 50% of the sample responds with a particular answer, the chances would be 95 in 100 that this result would not vary more than + or -3.2% from the result that would have been obtained from a census of the entire population of people with axial SpA (i.e., a confidence level of 95%). It should be noted that these tests apply only to random samples. The sample for this project was not random and was entirely self-selecting. However, it is accepted statistical and industry practice to treat the sample as random and apply the confidence interval tests described as a rule of thumb with regard to likely sample error. It should also be noted that the margins of error for smaller sub-samples (e.g. demographic sub-groups) will be higher. Sub-groups within a sample (e.g., men and women) may have different results for the same question. A difference must be of a certain size, in order to be statistically significant though. Throughout the analysis of the survey data, the researchers tested if a difference in results between two sub-groups within the sample was a statistically significant one, at a 95% confidence level. Where differences are not significant at this level they have not been drawn out within the findings. Again, strictly speaking, the tests for significance apply only to random samples, but in practice they are used as a helpful rule of thumb to decide whether findings should be highlighted or not. Any sub-group differences highlighted within this report have been tested as statistically significant at a 95% confidence level or greater.

Percentages which derive from base sizes of less than 100 respondents should be regarded as indicative.

Where percentages do not sum to 100, this may be due to respondents being able to give multiple responses to a question or to computer rounding.

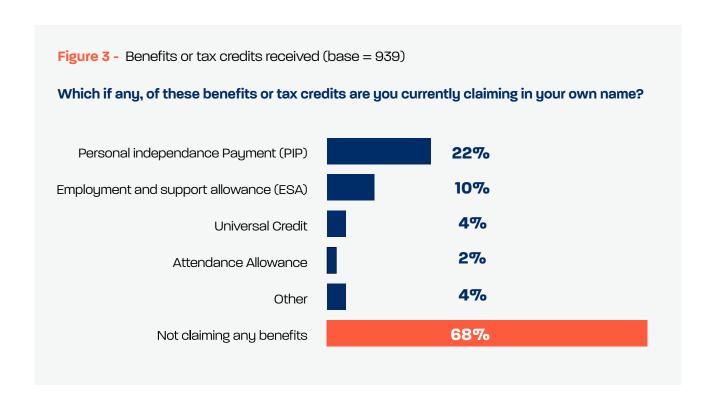
Findings

Details on sample

The questionnaire asked for people's demographic details, in order that responses could be analysed by sub-group. The full sample breakdown can be found in the appendices of this report. As the sample was self-selecting it cannot be said to be fully representative of the population of people living with axial SpA; it should be noted that women skewed younger and men skewed older in the sample; this means that any differences by gender or age may be overlapping. The sample was also made up of primarily people from white ethnic backgrounds and was

concentrated in the South of England (37% of respondents were based in the South East or South West compared to 22% of the UK population).

The survey asked about people's income, working status and whether they were in receipt of benefits. As can be seen in Figure 3, most (68%) did not receive any benefits or tax credits. Just over a fifth (22%) of respondents received Personal Independent Payments. This rose to 44% amongst those whose household incomes were under £25,000 a year (compared to 7% of those whose incomes were over £50,000), and 32% amongst those who were not currently working (compared to 13% of those who were working).

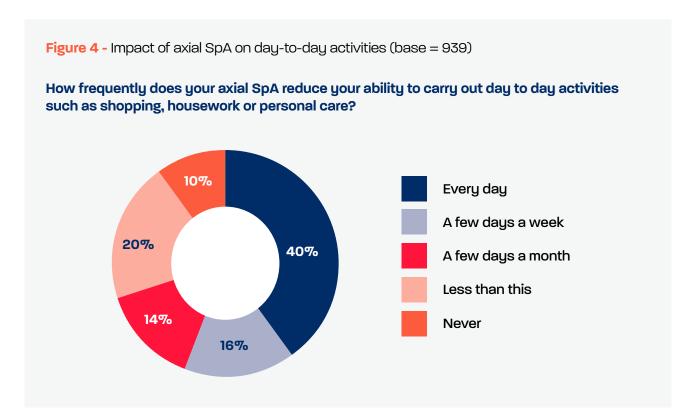


Details on condition and treatment of axial SpA symptoms

When asked, over half of respondents (55%) in the survey considered themselves to be a disabled person. This was lower amongst older people (just 47% of those aged 65+ considered themselves to be a disabled person compared

to 57% of 35-64 year olds and 60% of 18-34 year olds in the sample).

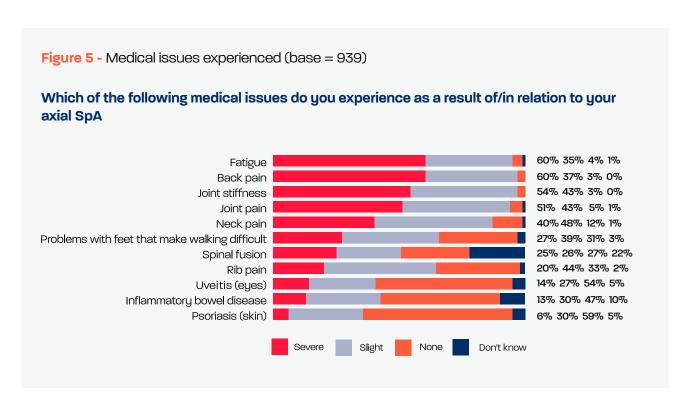
As shown in Figure 4, the vast majority of respondents said that their axial SpA reduced their ability to carry out day to day activities, such as shopping, housework or personal care, with 40% saying it reduced their ability to carry out daily activities every day.



Amongst the 90% of respondents who said their ability to carry out day to day activities was reduced, most said they needed support, 63% from friends or family members, and 2% from professional or voluntary carers.

Respondents were asked from a prompted list which medical issues they experienced as a result of, or in relation to, their axial SpA. As shown in Figure 5, the most common medical issues experienced by respondents were fatigue and

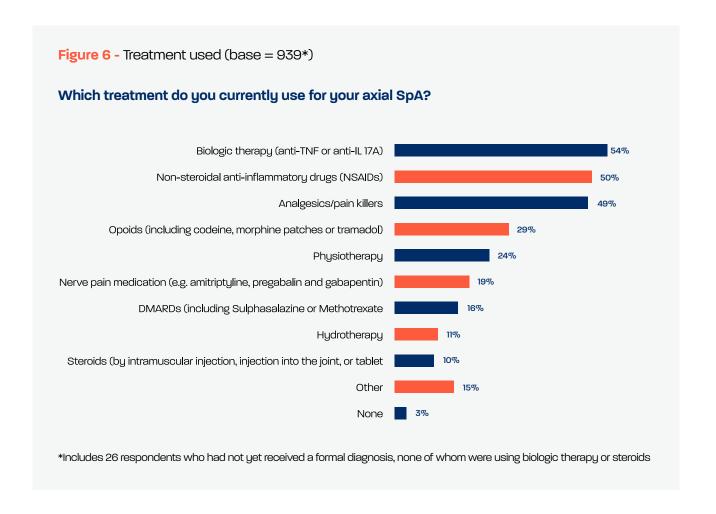
back pain, with 60% saying they experienced each of these severely, with women and younger respondents more likely to have experienced them. Just over half (54%) said they experienced severe joint stiffness and 51% severe joint pain. 40% said they experienced severe neck pain. The issues that were less common were uveitis, inflammatory bowel disease and psoriasis (14%, 13% and 6% respectively said they experienced these issues severely).



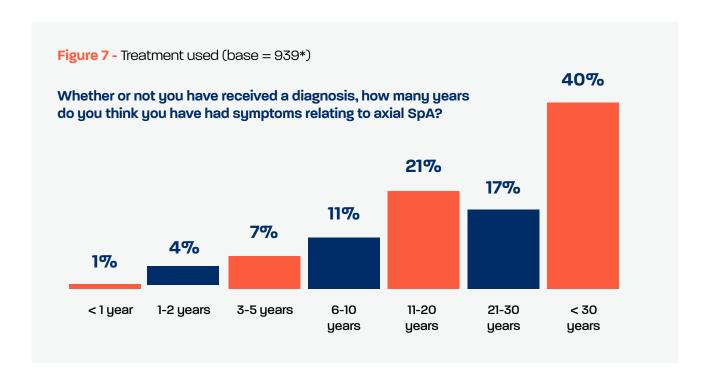
Respondents were asked if they experienced any other issues as a result of their axial SpA. The most common issues that were mentioned were hip issues / hip pain, with 6% saying they experienced this severely and 2% slightly; depression / anxiety (5% severely, 4% slightly); and sleep issues (5% severely and 3% slightly).

As shown in Figure 6, the most common treatment used by respondents for their axial SpA was biologic therapy (54%), non-steroidialsteroidal anti-inflammatory drugs

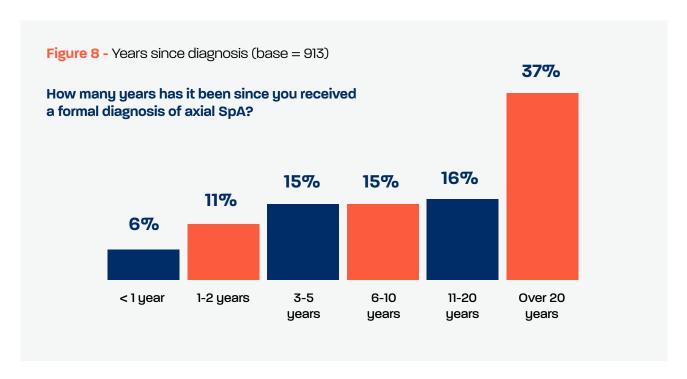
(50%), and analgesics (49%). Younger respondents were more likely to use biologic therapy (66% of those aged 18-34 did so, compared to 41% of those aged 65+), and women were more likely to use NSAIDs (55% vs 44%), analgesics (53% vs 44%) and opioids (33% vs 25%) than men. The use of opioids was significantly higher amongst those who had not yet received a diagnosis (50%, compared to 26% of those diagnosed in the past five years and 30% of those diagnosed over five years ago).



Most respondents in the survey had been living with their condition for a long time. Less than a quarter said they had symptoms relating to axial SpA for ten years or less, while 40% had symptoms for over thirty years.



Likewise, a large proportion had received a formal diagnosis a long time ago; 37% received one over twenty years ago, and a further 16% received one 11-20 years ago. Almost a third (32%) had received their diagnosis within the past five years.



Men were significantly more likely than women to have had symptoms for longer (54% said they had had symptoms for over 30 years, compared to 31% of women) and to have been diagnosed a longer time ago (56% said they were diagnosed over 20 years ago compared to 24% of women); however, this is likely to be as a result of the fact that it was also the case that men within the sample tended to be older.

Journey to diagnosis

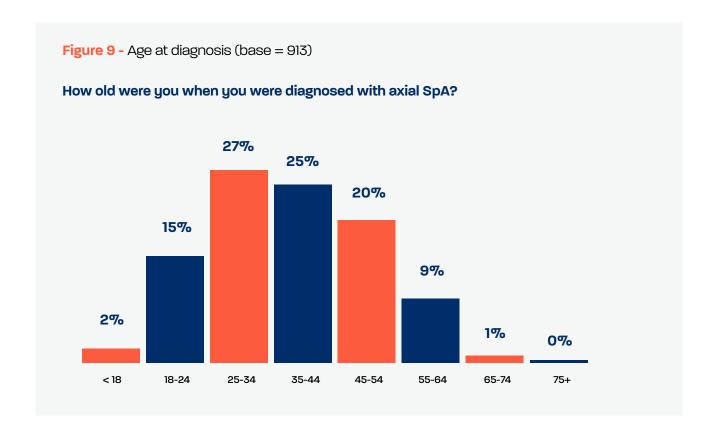
The first main section of the survey focussed on respondents' experiences of seeking a diagnosis for axial SpA.

Respondents were asked how many years it had taken them to get a formal diagnosis of axial SpA, from when they had started experiencing symptoms and then from when they had gone to see a doctor about those symptoms. The average (mean) number of years since starting to experience symptoms was 12.7 and since seeing a doctor, was 9.4. However, within this, there was of course a range of experiences: over a quarter (26%) received a diagnosis within two years of seeing a GP; by contrast 15% waited 20 or more years. (Please note that the median number of years to diagnosis from the onset of symptoms was 10 years, and the median number of years from seeing a doctor was 6 years, indicating that some outliers whose diagnosis took a particularly long time may have pushed this average up.) Across both measures, the average length of time was about two years higher for women than for men. The same 2-year longer average diagnosis time was seen for people who had a household income of under £25,000, compared to those with an income of over £50.000.

Previous research conducted by NASS found that the average time from the onset of symptoms to diagnosis was 8.5 years; significantly less than the 12.7 years average in this research. The fact that the length of time was longer for those who were diagnosed more recently (14.1 years for those diagnosed within the past five years compared to 12 years for those diagnosed over five years ago) supports the hypothesis that delays diagnosis are getting worse, not better (possibly exacerbated by the pandemic). The average time between the onset of symptoms to seeing a doctor appears to have been longer amongst those who were diagnosed within the last five years compared to those who were diagnosed over five years ago (4.41 years compared to 2.76 years⁴). This suggests that some people have delayed seeing a GP either through choice or lack of access. Although the overall amount of time to get a diagnosis was higher for women, there was no difference between genders in the time between the onset of symptoms and seeing a doctor.

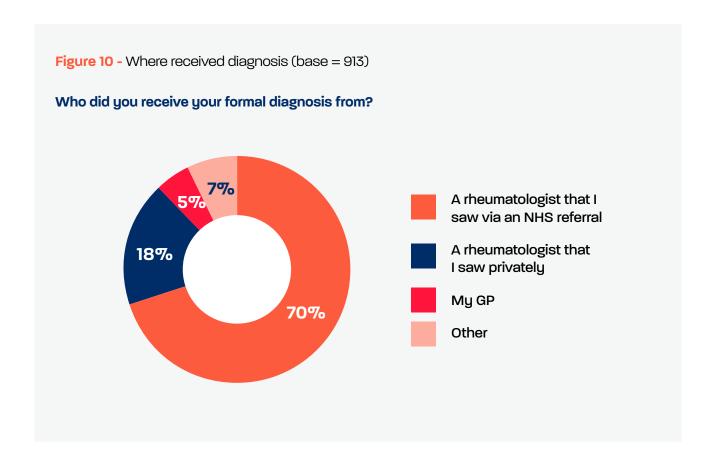
The age at which respondents received a diagnosis varied, as shown in Figure 9: many were diagnosed between the ages of 25 and 34 (27%), 35 and 44 (25%) and 45 and 54 (20%); however, 10% were over the age of 55, and 17% were under 25 when diagnosed.

⁴ This was not asked directly of respondents, but calculated by looking at the difference between the average number of years to receive a diagnosis from the onset of symptoms and seeing a doctor.



Most respondents (70%) received their diagnosis from a rheumatologist that they saw via an NHS referral, as shown in Figure 10. However, a sizeable minority (18%) received their diagnosis from a rheumatologist they saw privately, with women significantly more likely than men to have done so (21% compared to 14%). Perhaps an indication of recent pressures on the NHS, those who had received their

diagnosis within the past five years were more likely to have gained their diagnosis via a rheumatologist they saw privately compared to those who were diagnosed more than five years ago (28% compared to 14%). Those with incomes of over £50,000 pa were also significantly more likely to have received a diagnosis privately (27% compared to 10% of those on incomes of under £25,000).



Respondents were asked the extent to which they agreed or disagreed with a series of statements related to seeking a diagnosis. Figure 11 shows the proportion of people who agreed or disagreed with the different statements relating to some of the issues experienced when seeking a diagnosis and backs up many of the stories heard in the in-depth interviews.

Confirming the qualitative research findings, one of the most significant issues was that HCPs had not connected people's different symptoms: 80% of respondents agreed or strongly agreed with the statement 'I wish health professionals had joined up the dots of my different symptoms sooner', and this was significantly higher amongst women (84%) than men (73%).

"If someone had put all my symptoms together sooner I would have been diagnosed years ago instead of thinking I must be a hypochondriac. When I saw a doctor I was only allowed to speak about the one thing but could have done with showing them a list."

Female, 45-54

For many the issue was not being believed, with over half (53%) agreeing or agreeing strongly with the statement 'I didn't feel believed by health professionals when I was trying to get my diagnosis'. Again, this was significantly higher for women (61%) than for men (43%).

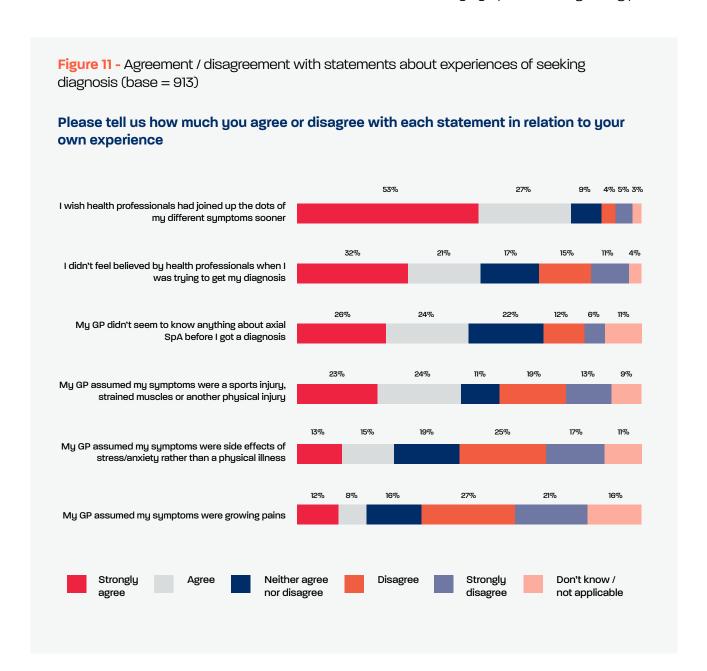
"I was dismissed by multiple GPs telling me it was in my head. I was told I was too young to have something wrong."

Female, 25-34

Half (50%) agreed or agreed strongly with the statement 'my GP didn't seem to know anything about axial SpA before I got a diagnosis'.

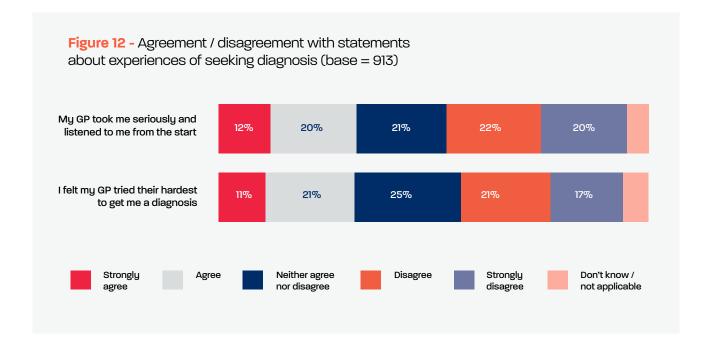
Related to this, a sizeable minority agreed that their GP had assumed that they were presenting with something else:

- 48% agreed or agreed strongly with the statement 'my GP assumed my symptoms were a sports injury, strained muscles or another physical injury',
- 28% agreed or agreed strongly 'my GP assumed my symptoms were side effects of stress / anxiety rather than a physical illness';
- 20% agreed or agreed strongly 'my GP assumed my symptoms were growing pains'.



There was a sense amongst many that their GP's attitude had left something to be desired, as shown in Figure 12. Although 32% agreed or agreed strongly with the statement 'my GP took me seriously and listened to me from the start', more disagreed (42%) than agreed with

this. Similarly, 38% disagreed or disagreed strongly with the statement 'I felt my GP tried their hardest to get me a diagnosis', compared to only 32% who agreed / agreed strongly. For both statements, women were more likely to disagree and less likely to agree than men.



It is clear that the delay in getting a diagnosis is seen to have had a negative impact, as shown in Figure 13. The vast majority (69%) agreed / agreed strongly with the statement 'I feel that the time it took to get my diagnosis impacted on my ability to quickly get to grips with managing my axial SpA' and 66% agreed / agreed strongly that 'I feel that the time it took to get my diagnosis impacted negatively on the progression of my axial SpA'. Those who were on lower incomes and those in receipt of benefits were significantly more likely to agree with these statements.

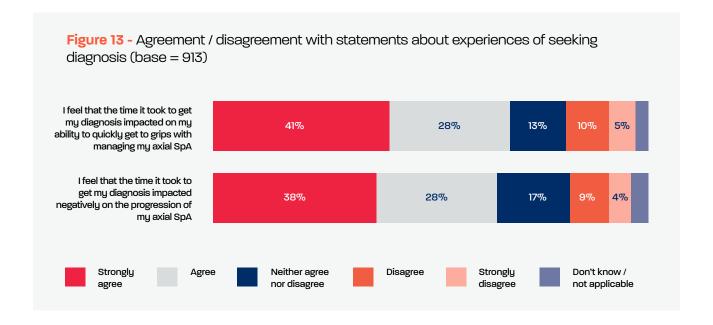
The verbatim quotes that follow illustrate the negative impact a delayed diagnosis can have:

"Connecting the dots on all the symptoms I was experiencing. Then I may have received a faster diagnosis and stopped the permanent and irreversible damage to my knees and weakened bones due to prolonged use of steroids. My rheumatologist at the time did not connect that my swollen knee joints were related to the back pain and bad neck I was suffering from. Axial spondyloarthritis was never mentioned. It took 14 years to get a diagnosis, by which time a lot of permanent damage had been done. In the end I paid to see a private rheumatologist, and received a diagnosis of axial SpA within 24 hours. I am now on biologics that have turned my life around. I just wish I could have been on them earlier."

Female, 35-44

"I wish the doctor and consultant had listened to my descriptions of pain and changes in joints more. As they didn't believe me, it caused them to deny I had anything wrong and telling me 'it's all in my head' and refusing to do any further scans. Only when I got issues with my eyes did anyone join the dots but a lot of damage had been done by that point By listening to the patient and trying to do something other than prescribing painkillers (physio, hydrotherapy) that would make a huge improvement to the patient."

Male, 35-44



Respondents were asked to imagine they could give health professionals one piece of advice about how to improve people's experience of getting a diagnosis of axial SpA and to say in their own words what advice they would give. Figure 14 shows all the responses mentioned by 5% or more of respondents. The most commonly given advice, suggested by around a fifth of respondents (19%) was that HCPs should 'listen to their patients', and a further 6% said that they should 'treat patients with respect / believe them'. Reflecting their own experiences, 11% wanted HCPs to 'consider all the symptoms when doing a diagnosis / join the dots'. One in ten (10%) felt that there should be 'more training and awareness for GPs / health care professionals'.

"Your patient knows their own body far better than you do. Please listen to them and don't make assumptions such as it is just wear and tear.

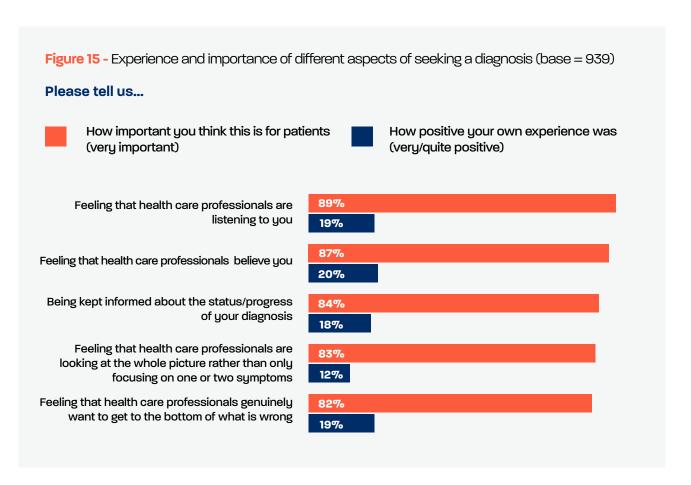
There are no rules with axial SpA, no age limits, weight limits, activity related limits, lifestyle influences etc. Patients with axial SpA will not fit every box and some times won't tick any boxes. Every one is different."

Female, 45-54



Respondents were asked about some of the different aspects of getting a diagnosis and rated them each, firstly with regard to how positive their own experiences had been, and then based on how important they thought they were for patients. Figure 15 shows the

disparity between what respondents rated as important and what they themselves had experienced, with only a fifth or less saying they had had a very or quite positive experience of these aspects.



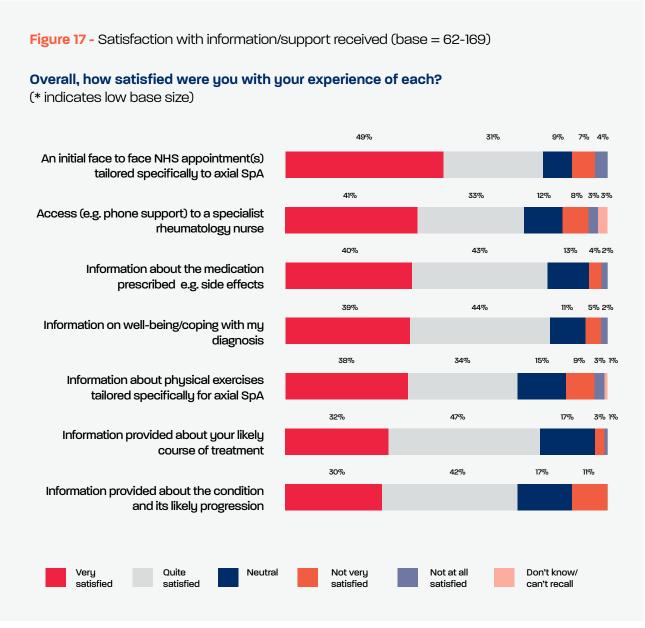
Post diagnosis experience

The middle section of the survey focussed on respondents' experiences immediately after having received their diagnosis.

Those who had been diagnosed in the previous five years were asked what support and information (from a prompted list) they had received in the first year after being diagnosed. As shown in Figure 16, the provision of support and information was variable. Over half of respondents said that they received access

(e.g. phone support) to a specialist rheumatology nurse (57%); information about the medication prescribed e.g. side effects (57%); and information about the likely course of treatment (51%). However, one in six (17%) said that they did not receive any of the types of support or information on the list. Across the board, younger respondents (those aged 18 to 34) were more likely than their older counterparts to have received these different forms of information and support following diagnosis.

Figure 16 - Support / information received post diagnosis (base = 294) As far as you can remember, which of the following did you receive from NHS health professionals in the first year of getting your diagnosis of axial SpA? Access (e.g. phone support) to a specialist 57% rheumatology nurse Information about the medication prescribed e.g. 57% side effects Information provided about your likely course of 51% treatment Information provided about the condition and its 45% likely progression Information about physical exercises tailored 40% specifically to axial SpA An initial face to face NHS physio appointment(s) 38% tailored specifically to axial SpA Information on well-being with my diagnosis 21% None of the above 17%

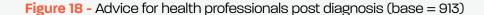


Those who had received support or information were asked how satisfied they had been with their experience of each; the vast majority said they were very or quite satisfied, as shown in

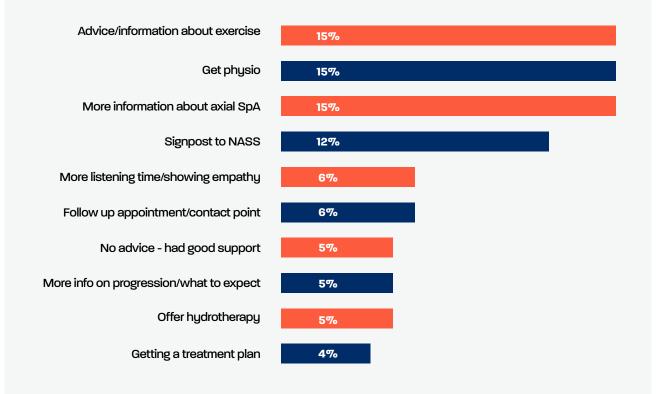
Figure 17.

All respondents were asked what advice they would give HCPs about how to improve people's experience of the initial period following a diagnosis of axial SpA. As shown in Figure 18, many felt that physical exercise is important – 15% each said 'advice / information about exercise' and 'get physio'. Those who were more confident to manage their condition themselves were significantly more likely to see 'advice / information about exercise' as helpful

(this response was given by 20% of those who identified most strongly with the statement 'I do a lot of my own research and thinking about my axial SpA and am largely confident/happy to make my own decisions about how to manage it day to day (with or without support from health care professionals)', compared to 9% of those who identified with the statement 'I do some research and thinking about my axial SpA but on balance I would prefer to leave it to health care professionals to advise me about treatment and management'. A further 15% thought that 'more information about axial SpA' was important, with women particularly supporting this (18% compared to 10% of men), and 12% of respondents said 'signposting to NASS'.



What advice would you give? What did you find most helpful or wish you had received in the first few months?



"I wish I'd been told how important it was to keep doing physio exercise. Exercise was never a big part of my initial diagnosis."

Female, 55-64

"After my first diagnosis, it would have been very helpful if I'd had a proper explanation of what the diagnosis meant, rather than just prescribing anti inflammatory drugs, and told you'll be sent an appointment in 12 months."

Male, 65-74

As in the previous section of the survey, respondents were provided with a list of things that might be considered important for people in the early days after receiving a diagnosis and asked to say how positive their own experience had been of each aspect, and then how important they thought it was for patients. As shown in Figure 19, there was a divergence between what people thought was important, and what their own experiences had been, although the contrast was slightly less extreme than it had been at the stage of seeking a diagnosis. Less than half said they had a positive experience of any aspects of care post diagnosis (except in relation to 'information about physical exercises that might help with axial SpA' where 54% had a positive experience). The greatest discrepancy was in relation to managing pain levels and flare ups.

It was seen as very important by 82% to get advice on how to manage pain levels and very important to get information on how to manage a flare up by 81%; however, only 39% and 29% respectively had a positive experience in these areas themselves. As had been the case when it came to seeking a diagnosis, women were significantly less likely than men to have had a positive experience across all aspects of care after receiving a diagnosis.

Despite the fact that only 42% said 'advice about the impact of axial SpA on starting a family' was very important, this rose to 49% amongst women and 50% amongst those aged 18-34. Those aged 18-34 were significantly more likely to say their own experience was negative (39% compared to 18% for those aged 35-64 and 17% for those aged 65+).

Figure 19 - Experience and importance of different aspects after receiving a diagnosis (base = 913) Please tell us... How important you think this is for patients How positive your own experience was (very important) (very/quite positive) 82% Advice on how to manage pain levels 39% 81% Information about how to manage a flare-up 29% 81% Information about physical exercisers that might help with axial SpA 54% 78% Having someone to go back to with questions 40% Advice about how to manage impact of axial 77% SpA on day to day life 33% Information about possible side effects of 73% medication to treat axial SpA 42% A detailed explanation from a doctor about treatment plans for different stages of the condition 30% 69% Information about organisations and groups that support people with axial SpA 49% Having an assessment of my emotional 13% wellbeing/mental health Advice about the impact of axial SpA on starting a family 10%

Living with axial SpA

The final part of the survey focussed on respondents' experiences of living with axial SpA.

Respondents were asked on a scale of 1 to 10, how satisfied they were with the care they received for their axial SpA specifically. Figure 20 shows the spread of responses, indicating a wide range of experiences from the very positive to the very negative.

Overall, respondents were broadly satisfied: the mean score was 6.3 out of 10, and 38% of respondents scored their care at 8, 9 or 10 out of 10. However, a sizeable minority (18%) were not satisfied (scored their care at 1, 2 or 3 out of 10).

Satisfaction was significantly lower amongst the following groups:

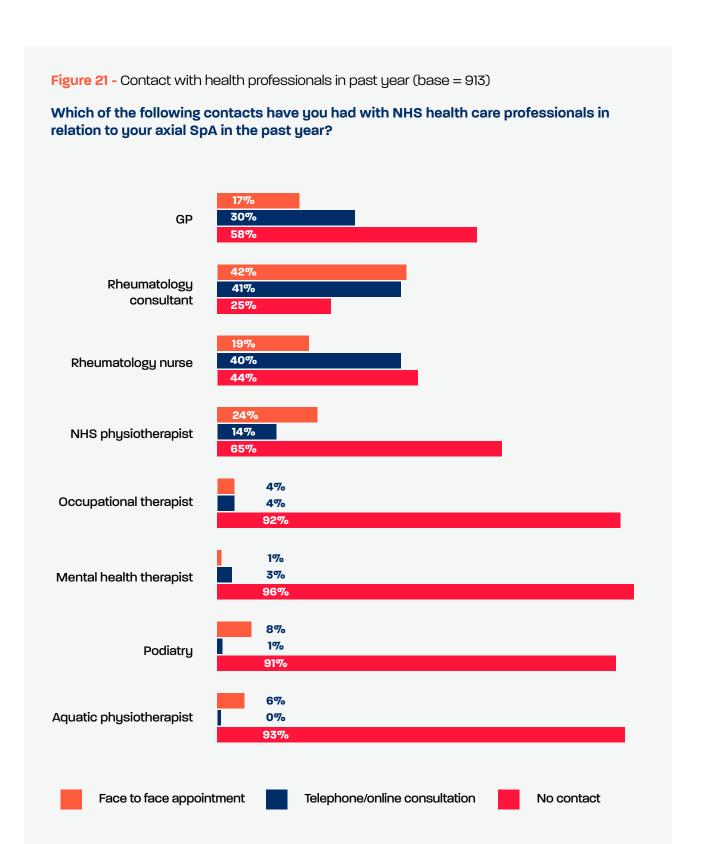
- Women (20% scored it at 1, 2 or 3 compared to 15% of men)
- People earning less than £25,000 (23% scoring 1, 2 or 3 compared to 16% of people earning £25,000 or more)
- People who consider themselves to be disabled (21% scoring 1, 2 or 3 compared to 15% of people who do not).



Respondents were asked which HCPs - from a list - they had been in contact with in the past year, in relation to their axial SpA either via a face-to-face appointment and/or via a telephone or online consultation. As Figure 21 shows, well over half (58%) said they had no contact with a GP in the past year, and only 17% had a face-to-face appointment (with 30% having had a phone or online consultation). More people had than had not seen a rheumatology consultant, 42% face-to-face and 41% remotely (25% had not), and over half had seen a rheumatology nurse (40% remotely, and 19% face-to-face), though 44% had not. Around a third had seen a physiotherapist

(24% face-to-face and 14% online or on the phone). The vast majority (over 90%) had not seen an occupational therapist, mental health specialist, podiatrist or aquatic physiotherapist in the past year.

Those who had been more recently diagnosed were more likely to have had contact with HCPs in the past year than those who were diagnosed longer ago. For example, 53% of those who were diagnosed within the past five years had contact with a GP (compared to 37% of those who were diagnosed over five years ago), and 83% had seen a rheumatology consultant (compared to 71%).



Respondents were asked in relation to four different types of HCPs (GP, rheumatology consultant, rheumatology nurse and NHS physiotherapist) to say what their expectations were in terms of the care they might provide in different areas – whether they expected to receive that type of care, and if so whether they received it. Figures 22 to 25 below show the results for each type of professional, and indicate the mismatch between the care patients expect and the care they actually receive. Across the different types of care and the different types of HCPs a pattern emerged where those who had been diagnosed more recently (within the past five years) were more likely to have expected to be provided with care that they had not received than those who were diagnosed longer ago. Whether this is about expectation management or if the care received by more newly diagnosed patients is lacking is not possible to assess.

When it came to GPs, larger proportions of respondents said they were not currently receiving care that they would expect to receive, than said they were. This was particularly the case for advice / support in relation to their mental health, where only a fifth (20%) said they received this from their GP compared to the 59% who said they expected to, but did not, receive it (this rose to 70% amongst 18-34 year olds compared to 49% of those aged 65+). Similarly, just 10% said they received information on organisations that support people living with axial SpA, compared to 51% who said that they expected to but did not receive it. Although overall 50% said they would not expect GPs to provide advice about the day-to-day management of their condition, expectations differed by age, with the proportion dropping to 36% amongst 18-34 year olds (compared to 57% of those aged 65+). These results are shown in Figure 22.

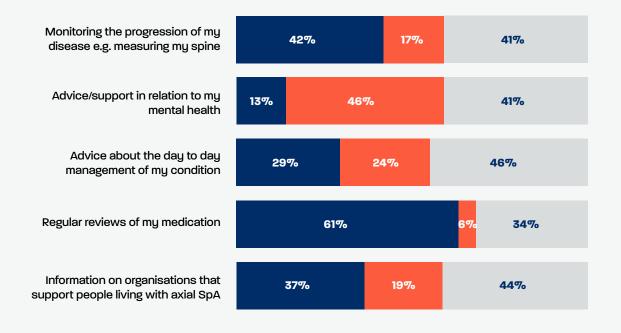
Figure 22 - Preferred care from GP (base = 913) Thinking about the care you are looking for on an ongoing basis, please say what your preference would be - GP Monitoring the progression of my 68% 25% disease e.g. measuring my spine Advice/support in relation to mu 20% 22% 59% mental health Advice about the day to day 8% 50% 42% management of my condition Regular reviews of my medication 32% 32% 36% Information on organisations that 10% 39% 51% support people living with axial SpA I expect this health care professional to provide this care, and I do currently receive it I would not expect this type of care to be provided by this health care professional I expect this health care professional to provide this care, and I do not currently receive it

As shown in Figure 23, the pattern was slightly more positive when it came to people's experiences with their rheumatology consultant, in that a greater proportion were getting the care they expected to receive, for example 61% received regular reviews of their medication.

However, there were still some discrepancies when it came to expectations, for example, 76% expected to receive advice about the day-to-day management of their condition from their rheumatology consultant, but only 29% did so, compared to 46% of respondents who did not.

Figure 23 - Preferred care from rheumatology consultant (base = 913)

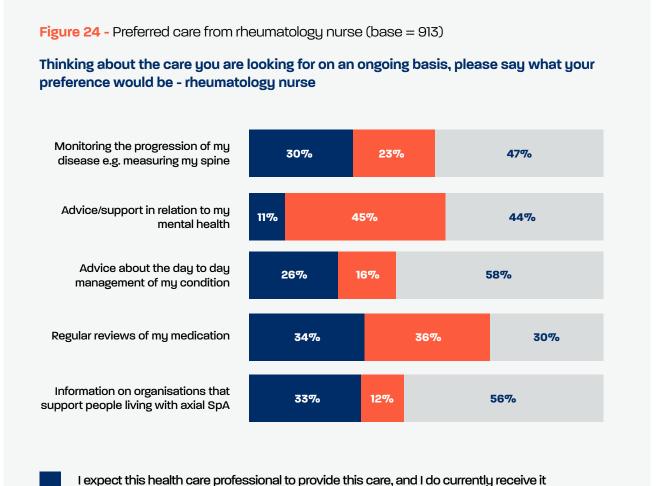
Thinking about the care you are looking for on an ongoing basis, please say what your preference would be - rheumatology consultant



- I expect this health care professional to provide this care, and I do currently receive it
- I would not expect this type of care to be provided by this health care professional
- I expect this health care professional to provide this care, and I do not currently receive this

There were similar discrepancies with people's experiences of their rheumatology nurses, with over half expecting to receive advice about the day-to-day management of their condition but not receiving it (58% compared to 26% who did receive this). The vast majority (88%) expected

information on organisations that support people living with axial SpA to be provided by their rheumatology nurse, but only 33% received this, compared to 56% who did not. These results are shown in Figure 24.

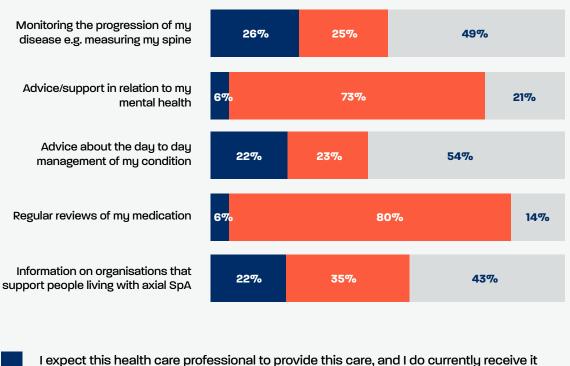


I would not expect this type of care to be provided by this health care professional

I expect this health care professional to provide this care, and I do not currently receive this

Figure 25 - Preferred care from NHS physiotherapist (base = 913)

Thinking about the care you are looking for on an ongoing basis, please say what your preference would be - NHS physiotherapist



respect this health care professional to provide this care, and no currenting receive it

I would not expect this type of care to be provided by this health care professional

I expect this health care professional to provide this care, and I do not currently receive this

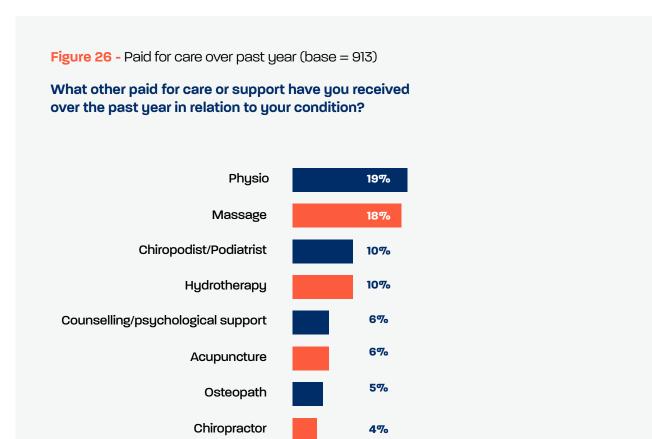
As Figure 25 shows, the areas where respondents were most likely to expect NHS physiotherapists to provide care were in relation to monitoring the progression of their disease and advice about the day-to-day management of the condition, and in both areas they were seen to be falling short. Only 22% received

advice about the day-to-day management of their condition, compared to 54% who did not, and 26% said their NHS physio monitored the progression of their disease, compared to 49% whose did not.

Nutritionist

None of the above

Other



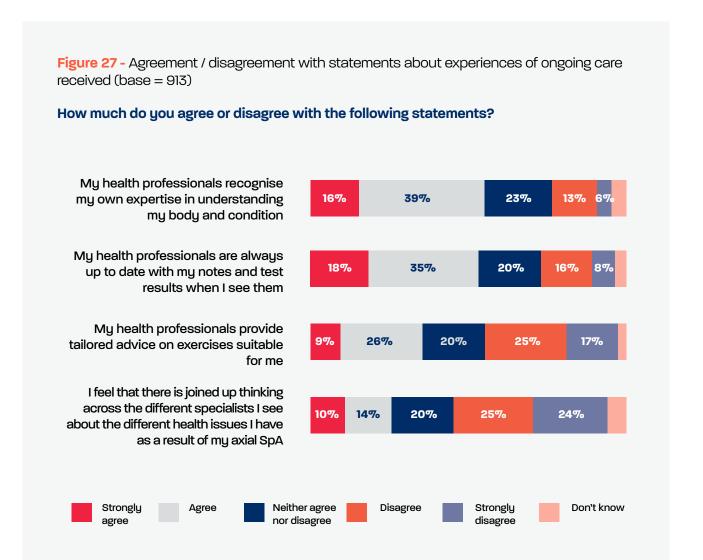
2%

6%

55%

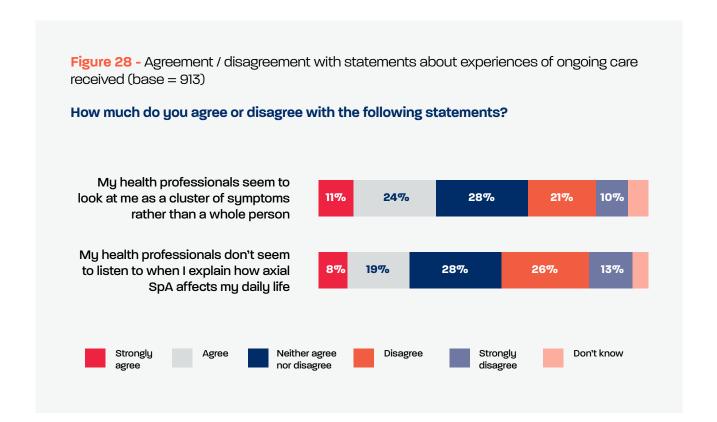
As shown in Figure 26, just under half of respondents had paid for other care or support for their axial SpA over the past year, with physiotherapy (19%) and massage (18%) being the most common types of support paid for. A further one in ten paid for a chiropodist / podiatrist or hydrotherapy. Women were significantly more likely than men to have paid

for additional care or support (65% of men did not pay for anything, compared to 49% of women), as were those who were more recently diagnosed (59% of those diagnosed over five years ago had not paid for any other care, compared to 48% of those who were diagnosed in the past five years).



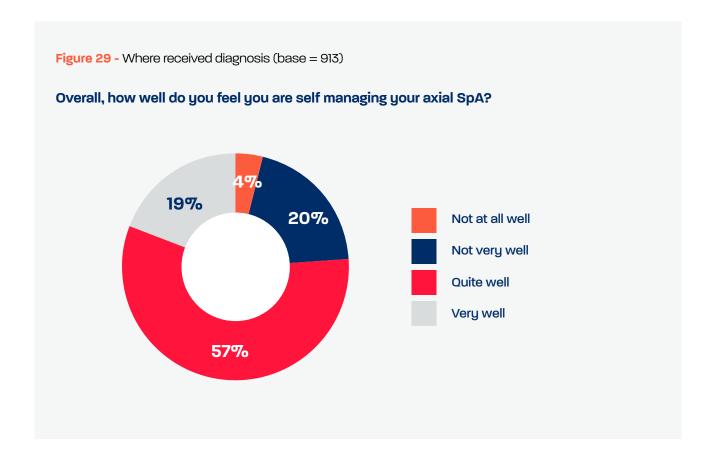
Respondents were asked the extent they agreed or disagreed with a series of statements relating to the care they received from their HCPs. As Figure 27 shows, most agreed/agreed strongly with the statement 'my health professionals recognise my own expertise in understanding my body and condition' (54% agreed) and 'my health professionals are always up to date with my notes and test results when I see them' (53% agreed). By contrast more people disagreed than agreed with the statement 'My health professionals

provide tailored advice on exercises suitable for me' (42% disagreed compared to 35% who agreed), and nearly double the amount of people disagreed/disagreed strongly as agreed/agreed strongly with the statement 'I feel that there is joined up thinking across the different specialists I see about the different health issues I have as a result of my axial SpA' (49% compared to 25%). Across the board women were significantly more likely to disagree with these statements than men.



A slightly higher proportion of respondents agreed / agreed strongly (35%) than disagreed / disagreed strongly (30%) with the statement 'my health professionals seem to look at me as a cluster of symptoms rather than a whole person' (see Figure 28). However, more disagreed/ disagreed strongly (40%)

than agreed/ agreed strongly (27%) with the statement 'my health professionals don't seem to listen when I explain how axial SpA affects my daily life'. Again, for both statements, disagreement was significantly higher amongst women than men.



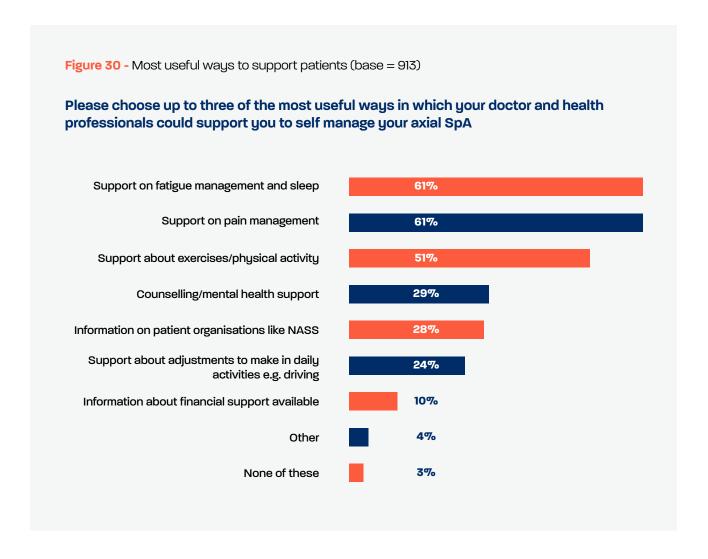
When asked how well they thought they managed their condition outside of their medical appointments, 76% of respondents felt that they were self-managing their condition well (19% thought they were self-managing very well, and 57% quite well) – see Figure 29. However, nearly a quarter said they were not self-managing well.

The groups that were more likely to consider they were self-managing well were:

- Men (79% compared to 73% of women)
- Older respondents (87% of those aged 65+ compared to 66% of those aged 18-34)
- Those in higher socio-economic groups (79% of ABC1s compared to 70% of C2DEs)
- Those on higher incomes (81% of those earning over £50,000 compared to 65% of those earning under £25,000)
- Those without children under the age of 16 living at home (78% compared to 65% of those with children)

- Those who are not from minority ethnic groups (77% of white British respondents compared to 54% of those from minority ethnic groups)
- People who don't consider themselves to be disabled (91% compared to 64% of those who do)
- Those who were diagnosed over five years ago (80% compared to 66% of those who were diagnosed five years ago or less).

Although most respondents said that they felt they were self-managing their condition well, the qualitative results indicated that this did not necessarily mean that they were thriving; rather that they were 'coping', all things considered. For example, 29% of those who said they were self-managing well said that their axial SpA reduced their ability to carry out day to day activities such as shopping, housework or personal care every day. While this was much higher amongst those who felt they were not self-managing well (71%), the fact that nearly a third of respondents who thought that they were self-managing well still had their life impacted by their condition on a daily basis does imply that this definition is a relative one.



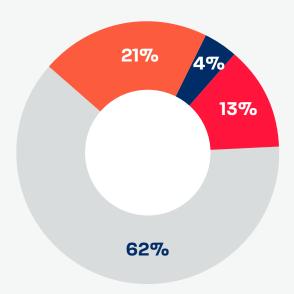
When asked to choose from a prompted list the most useful ways in which HCPs could support them, a clear picture emerged as shown in Figure 30. Almost two-thirds (61%) of respondents said they wanted support on fatigue management and sleep, and the same again wanted support on pain management, with women much more likely to be seeking this support than men. Half (51%) wanted support about exercises / physical activity; by contrast, this was more the case for men (55% compared to 47% of women).

As outlined earlier, respondents were asked from a series of statements that can be mapped to the Patient Activation Measure which best fit their attitude to managing their axial SpA. As Figure 31 shows, most (62%) said that they would like to work as a team with their HCPs and make decisions about the care and day to day management of their axial SpA together, and a further 21% said they were largely confident to make their own decisions about how to manage it day to day.

Men were more likely than women to want to leave it to HCPs: 8% said they would prefer to leave HCPs in charge of decisions about treatment and day to day management of my axial SpA (compared to 2% of women), and 17% said that on balance they would prefer to leave it to HCPs to advise them about treatment and management (compared to 10% of women).

Figure 31 - Attitude to managing axial SpA (base = 913)

Which of the following statements best fits you and your attitude to managing your axial SpA on a day to day basis



- I do a lot of my own research and thinking about my axial SpA and am largely confident to make my own decisions about how to manage it day to day
- I would prefer to leave health professionals in charge of decisions about my treatment and day to day management of my axial SpA
- I do some research and thinking about my axial SpA but on balance I would prefer to leave it to health professionals to advise me about treatment and management
- I would like to work as a team with my health professionals and make decisions about the care and day to day management of my axial SpA together

Worryingly, those respondents who identified with the statement 'I would like to work as a team with my health professionals and make decisions about the care and day-to-day management of my axial SpA together' (who were by far the largest cohort) were more likely to answer that they expected specific types of care from HCPs but were not receiving them, and to have lower levels of satisfaction with their care generally.

Conversely, respondents who identified with the statements 'I would prefer to leave health professionals in charge of decisions about my treatment and day-to-day management of my axial SpA' or 'I do some research and thinking about my axial SpA but on balance I would prefer to leave it to HCPs to advise me about treatment and management' seemed to have had a better experience with healthcare professionals, and were more satisfied with their care.

People who identified with the statement 'I do a lot of my own research and thinking about my axial SpA and am largely confident to make my own decisions about how to manage it day to day' were significantly more likely to say that they were self-managing well compared to the other groups. They were also less likely to have had contact with HCPs in the past year.

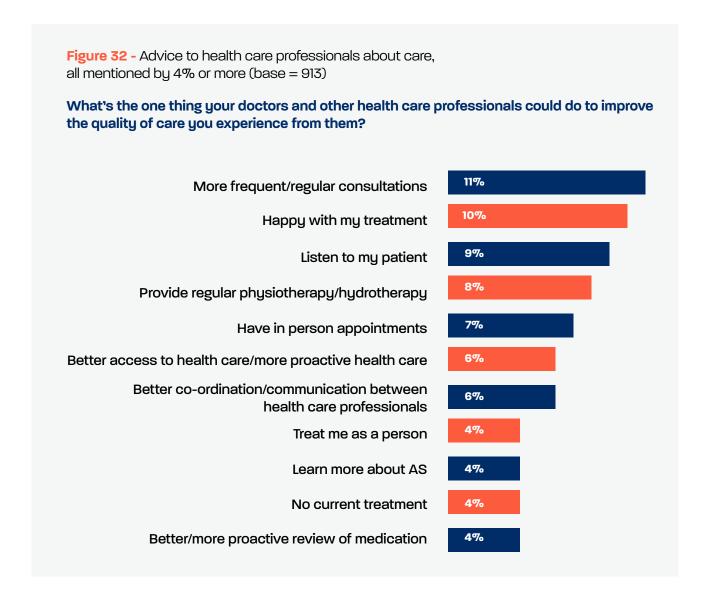
Finally, respondents were asked to think about the current treatment they were receiving for axial SpA and to say what advice they would give to HCPs about how to improve the quality of care they experienced.

The most common advice, given by 11% of respondents, was that there should be more frequent / regular consultations which is something that also came up often in the qualitative interviews. One in ten (10%) said they had no advice as they were happy with their treatment, rising to 15% of those aged 65+.

However, 9% of respondents wanted HCPs to listen to them as patients more, particularly women (11% compared to 6% of men); whilst 8% wanted more access to specific treatment, saying that regular physiotherapy / hydrotherapy should be provided. The most common suggestions for advice (suggested by 4% or more) are shown in Figure 32.

"The pandemic has made the situation worse. I saw the physio in November last year for the first time in 2 years and now cut back to seeing her every 2 years and if I am lucky the rheumatologist once a year whereas I used to see them both once a year."

Female, 65-74



Demographic differences

Some of the key differences by different groups have been highlighted within the findings, but the recurrent patterns that have emerged are also summarised here.

- Throughout their journey, from seeking diagnosis to living with axial SpA, women reported a less positive experience than men. For example, it took them longer to get a diagnosis, they were less likely to feel believed / listened to by their HCPs, and more likely to report a negative experiences in relation to their ongoing care / treatment. They were also less likely to feel that they were self-managing their axial SpA well, although generally keener to work in partnership with their HCPs then men
- By contrast, older people were more likely to report a positive experience throughout their journey (this may be driven by the fact that men were more likely to fall into the older age brackets)
- Those on lower incomes and those in receipt of benefits were more likely to have experienced a delayed diagnosis and to feel that this delay had a negative impact on the progression of their condition and their ability to get to grips with it. They were also less satisfied with the care they received

- Given the small sample size, most of the differences between White British respondents and those from minority ethnic groups were not statistically significant.
 However, there were indications that people from minority ethnic groups may have had less positive experiences and / or found it harder to live with their condition
- Although they were more likely to have had recent contact with HCPs, those who had received their diagnosis of axial SpA within the past five years were more likely to say they had not received the type of care they were expecting, compared to those who received their diagnosis over five years ago. They also experienced a longer delay in getting a diagnosis in the first place
- Looking at differences by statements relating to respondents' preferred style of relating with NHS HCPs, it may be that people who say they prefer to make decisions themselves or with their HCPs (as opposed to leaving the decision making to them), have been 'forced' into this as a result of having had more negative experiences with HCPs.

Conclusions

The current guidelines do not fully align or include the patient perspective on what constitutes quality in the diagnosis and treatment of axial SpA.

People with axial SpA are able to clearly articulate what they want and need from HCPs in the diagnosis and ongoing treatment of their condition: they want to be listened to and believed; to be treated as a whole person, rather than a collection of symptoms; to experience a joined up and purposive care pathway, rather than a series of care snapshots; and to be helped to know what they can do to help themselves.

They are equally clear that, for the most part, they are not receiving "quality care" as they define it, with significant gaps between expectation and patient experiences.

Most patients reported that they prefer to work as a team with HCPs, and make active decisions about how to manage their axial SpA; yet, a consistent picture emerged of patients not being listened to, or believed, when they sought diagnosis, of being treated as a collection of symptoms, rather than as a whole person; of a lack of join-up both between HCPs

and along the patient journey; and of a lack of tailored advice for how they could manage their condition more effectively.

Worryingly, there were significant disparities across the sample, with women, lower income groups, disabled people and those on benefits consistently reporting they were less likely to receive quality care. Members of ethnic minorities may also have experienced poorer care (note: small sample size).

There was a suggestion that the quality of care, as defined by patients, might be getting worse, not better, with more negative experiences being reported by the more recently diagnosed (although it is important to acknowledge that the fieldwork for this study took place in a time of exceptional pressure on the NHS).

The research suggests that there is a need for greater understanding of the patient perspective in designing diagnostic and care pathways for people with axial SpA.

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- NASS: Dr Dale Webb, Jill Hamilton, Sally Dickinson, Zoë Clark and Liz Marshall

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Appendices

Appendix 1

Literature review sources

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Appendix 2

NASS: Qualitative research discussion guide

1. Research objectives and comment

The purpose of this qualitative research phase is to inform the subsequent quantitative research which will provide NASS with a robust picture of the daily physical and emotional lives of those with AxSpA and the drivers of their perceptions of quality of care and trust (or lack of it) in the "system"

Specifically, the qualitative research objectives are as follows:

- Understand the day-to-day impact of the condition and how it is diagnosed experienced, treated and managed.
- Ensure that we do not inadvertently overlook any element of lived experience which could be considered part of the "patient journey" and therefore might impact on perceptions of quality. We do not know what we do not know.
- Get the question coverage and colloquial language right for the development of an engaging and accessible quantitative questionnaire.
- Inform decision making about possible discrete quotas/analysis subsamples for the quantitative study.

If we were conducting a standalone qualitative study we might develop a discussion guide that asked a range of questions about very specific topics – almost in a semi structured manner – to ensure full coverage of what we thought to be the key issues. In this case we propose to do some of that but will place equal emphasis on first inviting an open ended set of responses from participants to ensure we privilege their own experiences, language and issues they feel are relevant to understanding their attitudes and behaviours. How we then proceed to use this discussion guide in each individual interview will be shaped by those unique first responses and by the knowledge that we are deliberately

seeking to recruit individuals who represent different points on the AxSpA spectrum. Each interview will take around one hour on Zoom or by phone.

2. Introduction for participants

Explain to the participant that the interview for NASS is confidential and will be anonymous, unless they have agreed otherwise in which case we will check here and use their information in accordance with what they have explicitly agreed in advance of the interview (re case studies; use of video and or audio transcription and future contact with NASS for research purposes). The interview is one hour long and they will be given £40 as a thank you for their participation. If at any point they do not wish to continue this is absolutely fine and if there is anything in the questioning they do not wish to answer that will also be respected.

The purpose of the study of to fully understand how AxSpA impacts their lives in the widest sense – physical, emotional, in terms of relationships and practical considerations such their individual circumstances around travel, work, money and anything else. Importantly it is also to understand how they feel about the health care they need; how confident they are about the people in the health care system they deal with; whether they get the care they need; examples of good and bad practice – whatever that means to them and what the HCPs don't "get," if anything.

3. Background to life and to AxSpA

Could you just tell me briefly about your age, family circumstances in terms of who you live with if anyone, whether you work or not and anything else that covers the background to our discussion?

Also, briefly some details about your AS. First of all, what do you call it -is "AS" the term you use. If not, please let's use the term you do use. Have you been diagnosed with AS (or other term) or not? If so, how long ago and how long did it take you to get a diagnosis? If not, where are you with getting a diagnosis – if you are seeking one – where are you on that journey

and what has prompted and persuaded you to think about getting the diagnosis? We will come to hear more about your contacts with GP/hospitals, physios etc if they are relevant later in our discussion.

4. Life with axial SpA

(Assume we would use whatever term they use, for each interview)

In your own words just tell me what you think I should know about life with AS? There are no right or wrong answers here and we would welcome honest answers from you as NASS are really keen to understand the reality. If we could leave the discussion about your specific experiences of the NHS, hospitals, physio etc to a bit later in our conversation that would be useful but I appreciate there may be overlap here.

At this stage please just cover all and everything in your daily life and your physical and mental/emotional health (and that of your family if they come into the picture too) that you feel is impacted and affected by having AS?

Prompt after the participant has described their experiences and circumstances just to make sure we have covered (as relevant) money, benefits, work, pressure on relationships with partners, children, other family members, family as carers, sex life, impact on travel and mobility—to appointments and generally, holidays.

Also acknowledging and building on any discussion of physical pain and specific/wideranging AS symptoms. Also, importantly their assessment of their own mental and emotional health now and at points during the time they have had AS. Whether they feel this has changed over the time they have had AS – how and why. How was this prior to diagnosis, on diagnosis and afterwards in whatever timeframe is relevant to them. How often do they think or talk about their mental health and how they feel? What stops them, what encourages them, if anything?

5. Their health care experience

Please could you tell me first of all which of the following people we will call "health care professionals or HCPs" you have any contact with? GP; rheumatology consultant; rheumatology nurse; NHS physio; NHS hydrotherapist. How often might you see each of them in relation to your AS?

Are there any other hospital specialist consultants and/or specialist nurses that you have contact with as a result of other symptoms of your AS — for example for your eyes ,skin or bowels? Do you buy any support or treatment privately for help with AS? For example, physio, hydrotherapy or alternative treatment practitioners such as acupuncture etc.

What and how many medications, if any, are you taking which you feel relate to you having AS — either that you have to buy yourself over the counter and/or those on prescription. Check for Anti TNF drugs. Again, do you take any so-called alternative medicines for your AS?

For those who have "meaningful" current interactions with the named HCPs:

Thinking about the HCPs you do interact with, tell me what if anything works well for you in relation to the HCPs you see on the NHS and/ or privately. What, if anything do you appreciate or have been pleasantly surprised by or commented on positively to others in relation to your care — in the widest sense? This can be anything — practical or about how they treat you or their manner towards you — anything that sticks in your mind as going or having gone well. At this stage, do not prompt.

And what has worked less well or has been a really bad experience or experiences - we might cover minor or major niggles here as well as things in your interactions with HCPs that have proved disastrous, if any and why?

(Prompt if necessary and relevant on the efficiency, access to, timeliness and sensibleness of administrative issues around appointments - planned or crisis/unforeseen, the manner and behaviours/attitudes of the HCPs seen, how well that HCP appears to know them and avoid them having to go over the same information again, how involved and consulted they feel about the medication they take or possible changes in that, how well coordinated their care is to cover all the different hospital specialties they might need to see, how consistently they see the same people, whether they see all the HCPs they feel they need. Cover physios, hydrotherapists, specialist nurses as appropriate etc.)

6. Impact of perceived quality of care (ask all but adapt to their circumstances in relation to who they see and how often)

What has been the impact on your physical or mental/emotional health of the things that have worked well or not worked well in relation to seeing HCPs about your AS, when you have done this? Please just explain this in your own words and if you can think of specific examples to illustrate what you mean on a day to day level, that would be helpful too?

If you could write a fully honest letter or talk to your GP and/or your hospital consultant or consultants that are treating your AS, to explain to them what you feel they could do to improve the quality of the care you experience from them:

What would be the ONE thing it feels most important to let them know that could make the biggest difference to you:

- For your physical health
- · For your mental/emotional wellbeing
- For your ability, if you feel this is relevant, to help you better manage your AS yourself and/or you mental or emotional wellbeing as someone with AS

And what other things would you suggest, however small? Things that might affect your quality of life, confidence, family circumstances, relationships or the whole experience of attending appointments with HCPs.

And how do you feel specifically about being called a "patient" in and outside the health care system? Why do you say that?

7. Self-care and self-management of AS (ask all)

Do you feel that you are able to manage your AS yourself – either with or without the help of HCPs?

What does this phrase "self-management" or "selfcare" mean to you if anything? What do you do that might fall under this umbrella, if anything and how helpful is it?

Is it a phrase you recognise, like, relate to, reject, find irritating, irrelevant, unhelpful?

Did you/have you had to figure this out for

yourself — i.e., things that might help you? What do you feel is the attitude of your GP/nurse/physio/consultant/hydrotherapy (as appropriate) to helping you to manage your AS. Do they mention that? Encourage it? Does it feel to you as if they think it's not part of their remit with you? What gives you that impression?

What sources, if any, have you used to get any information and support in helping you deal better with your AS – how hard was it to find them and which ones, if any do you find helpful. This can be anything from different types of support groups, blogs, podcasts, YouTube, websites, social media etc. (If NASS mentioned is, follow up. If NASS not mentioned, just check what, if anything, they know about NASS at the end of this section)

Is self-care something that positively impacts your mental/emotional or physical health living with AS? What specific benefits if any in these areas have you noticed?

8. Attitudes to managing AS

Which one of these three statement best fit you and your attitudes to managing your AS (or if none of them do, tell me what a better summary is of how you feel?)

- "I tend to leave decisions about my treatment and day to day management of AS to my GP and/or consultant and/or other health professionals I see about my AS"
- "I do do some research and thinking about AS myself but on balance I leave it up to the doctors/nurse and/or other health care professionals to advise me about treating and managing my AS, day to day"
- I do do some research and thinking about AS myself but I prefer to work with my health professionals and feel that we make decisions about my care and day to day management of my AS together"
- "I do a lot of my own research and thinking about my AS and largely make my own decisions about how to manage it day to day (with or without support from health care professionals)"

9. The future?

And can you just tell me how you would sum up your feelings about your future with AS and why you feel as you do? And anything else you would like us to know?

10. Ending the interview

At the end of the interview, we will check in with participants to see if they need additional support from NASS via the helpline (and give details) or elsewhere they have access to after the interview and encourage them to seek it now or in the next days if they feel they want to. Administer the thank you and check how that should be paid to them.

Appendix 3

Detailed sample for the quantitative research

The table below shows the full demographic breakdown of the final sample.

Respondent demographics

Table 4

	Number	%
	Gender	
Male	391	41.6%
Female	548	58.4%
	Age	
18-24	2	0.2%
25-34	72	7.7%
35-44	146	15.5%
45-54	221	23.5%
55-64	247	26.3%
65-74	175	18.6%
75+	76	8.1%
Soc	cio-economic group	
Α	165	17.6%
В	271	28.9%
C1	165	17.6%
C2	76	8.1%
D	39	4.2%
E	223	23.7%

Location		
South East	201	21.4%
South West	144	15.3%
East Anglia	91	9.7%
London	85	9.1%
North West	72	7.7%
Scotland	70	7.5%
Yorkshire & Humberside	67	7.1%
East Midlands	58	6.2%
West Midlands	53	5.6%
North East	38	4.0%
Wales	38	4.0%
Northern Ireland	16	1.7%
Isle of Man	5	0.5%
Channel Islands	1	0.1%
Presence of children under 16		
Yes	173	18.4%
Aged 0-3	30	17.3%
Aged 4-5	26	15.0%
Aged 6-9	60	34.7%
Aged 10-15	112	64.7%
No	766	81.6%
Presence of other adults in household		
I live on my own	148	15.8%
My partner/spouse	709	75.5%
My child/children (16 or over)	152	16.2%
My parent/parents	36	3.8%
Other relatives (aunts, uncles, nephews, nieces, grandparent etc)	17	1.8%
My friend / friends	3	0.3%
A lodger/s or housemate/s	7	0.7%
Someone who cares for me professionally	1	0.1%

Highest level of education attained		
Higher Education & professional/vocational equivalents	482	51.3%
Other Higher Education below degree level	145	15.4%
A levels, vocational level 3 and equivalents	120	12.8%
GCSE A*-C Grade/ O Level /Trade Apprenticeships	103	11.0%
Lower level qualifications	47	5.0%
Other qualifications	14	1.5%
No qualifications	28	3.0%
Employment status		
Self-employed	89	9.5%
Employed, full-time	249	26.5%
Employed, part-time	135	14.4%
Not employed, looking for work	9	1.0%
Not employed, not looking for work	27	2.9%
Student	7	0.7%
Retired	291	31.0%
Not able to work	120	12.8%
Other	12	1.3%
Annual household income		
Below £10,000	42	4.5%
£10,000 - £24,999	190	20.2%
£25,000 - £49,999	270	28.8%
£50,000 - £74,999	139	14.8%
£75,000 - £99,999	59	6.3%
£100,000 or more	73	7.8%
Prefer not to answer	166	17.7%

Benefits claimed		
Personal Independence Payment (PIP)	208	22.2%
Employment and support allowance (ESA)	97	10.3%
Universal Credit	41	4.4%
Attendance Allowance	20	2.1%
Other	42	4.5%
Not claiming any benefits	641	68.3%
Ethnic group		
White (English, Scottish, Welsh, Northern Irish or British)	842	89.7%
White (other)	41	4.4%
Prefer not to say	15	1.6%
White (Irish)	10	1.1%
Asian (Indian)	6	0.6%
Asian (Pakistani)	5	0.5%
Other (please state)	4	0.4%
Mixed (Asian and other)	3	0.3%
Asian (other)	2	0.2%
Black (African)	2	0.2%
Black (Caribbean)	2	0.2%
Mixed (black and white)	2	0.2%
Mixed (other)	2	0.2%
White (Gypsy or Irish Traveller)	2	0.2%
Arab	1	0.1%
Sexual orientation		
Heterosexual or straight	840	89.5%
Bisexual	27	2.9%
Gay or Lesbian	20	2.1%
Prefer not to say	47	5.0%
Prefer to use another term	5	0.5%

Appendix 4: Quantitative survey questionnaire

Intro

This research is being conducted on behalf of the National Axial Spondyloarthritis Society, NASS (www.nass.co.uk), with people who already have or are actively seeking, a diagnosis of axial spondyloarthritis. Throughout this survey we are using axial SpA as an umbrella term to cover both ankylosing spondylitis (AS) and non-radiographic axial spondyloarthritis.

The survey should take no longer than 15 minutes to complete.

All information received is strictly confidential, and will be dealt with in accordance with the Market Research Society Code of Conduct.

Your details will not be passed to any third party and you will receive no marketing material as a result of completing this questionnaire.

If you are happy to continue, please click below.

Screening question

Which of the following best describes your current situation? SINGLE CODE

I have talked to my GP about my symptoms but a referral to rheumatology has not yet been offered	1	
I am waiting for my first appointment with a rheumatology consultant	2	
I received a diagnosis of axial SpA (AS) in the past five years	3	
I received a diagnosis of axial SpA (AS) over five years ago	4	
None of the above	5	CLOSE

THOSE WHO ANSWER I OR 2 TO COMPLETE ALL OF SECTION I, AND Q1 AND Q6-Q9 ONLY AFTER THAT.

Section 1: Demographic questions (ASK ALL)

To start with, we'd like to find out a bit about you and your circumstances.

D1. Which of the following describes how you think of yourself? SINGLE CODE

Male	1
Female	2
Non-binary	3
I prefer to use another term (please specify)	4
Prefer not to say	5

D2. Can you please tell us your age? SINGLE CODE

Under 18	1	CLOSE
18-24	2	
25-34	3	
35-44	4	
45-54	5	CONTINUE
55-64	6	
65-74	7	
75 +	8	

D3. What is the occupation of the MAIN INCOME EARNER in your household? If now retired, please select the most appropriate option that fits the job performed prior to retirement. If currently unemployed for under 6 months, please select the most appropriate option that fits the job performed prior to becoming unemployed. SINGLE CODE

Higher managerial/ professional/ administrative e.g. established doctor, Solicitor, Board Director in a large organisation (200+ employees, top level civil servant/public service employee)	1
Intermediate managerial/ professional/ administrative e.g. Newly qualified (under 3 years) doctor, Solicitor, Board director in a small organisation, middle manager in a large organisation, principle officer in civil service/local government	2
Supervisory or clerical/junior managerial/ professional/ administrative e.g. Office worker, Student Doctor, Foreman with 25+ employees, salesperson.	3
Skilled manual worker e.g. Skilled Bricklayer, Carpenter, Plumber, Painter, Bus/ Ambulance Driver, HGV driver, AA patrolman.	4
Semi or unskilled manual work e.g. Manual workers, all apprentices to be skilled trades, Caretaker, Park keeper, non-HGV driver, shop assistant, pub/ bar worker.	5
Full time education	6
Full time homemaker	7
Unemployed for over 6 months	8
Disabled or too ill to work or medically retired	9

D4. Where do you live (country/ region)? SINGLE CODE

East Anglia	1
East Midlands	2
Greater London	3
North East England	4
North West England	5
Northern Ireland	6
Scotland	7
South East England	8
South West England	9
Wales	10
West Midlands	11
Yorkshire & Humberside	12
Channel Islands	13
Isle of Man	14
Other	CLOSE

D5a. Do you have any children under 16 living in your household? SINGLE CODE

Yes	1	CONTINUE
No	2	MOVE TO D6

D5b. What ages are your children? MULTICODE

Aged 0-3	1
Aged 4-5	2
Aged 6-9	3
Aged 10-15	4

D6. Which, if any, other adults live in your household? MULTICODE

I live on my own	1
My partner/ spouse	2
My child/ children (16 or over)	3
My parent/ parents	4
Other relatives (aunts, uncles, nephews, nieces, grandparent etc)	5
My friend/ friends	6
A lodger/s or housemate/s	7
Someone/ people I care for professionally	8
Someone who cares for me professionally	9

D7. What is the highest level of education you have attained? SINGLE CODE

Higher Education & professional/ vocational equivalents

(including Degree or Degree equivalent, and above, Higher degree and postgraduate qualifications, First degree (including B.Ed.), Postgraduate Diplomas and Certificates (including PGCE), Professional qualifications at degree level (e.g. graduate member of professional institute, chartered accountant or surveyor, NVQ or SVQ level 4 or 5)

1

Other Higher Education below degree level

(including Diplomas in higher education & other higher education qualifications, HNC, HND, Higher level BTEC, Teaching qualifications for schools or further education (below Degree level standard), Nursing, or other medical qualifications not covered above (below Degree level standard), RSA higher diploma)

2

A levels, vocational level 3 and equivalents

(including A level or equivalent, AS level, SCE Higher, Scottish Certificate Sixth Year Studies or equivalent, NVQ or SVQ level 3, GNVQ Advanced or GSVQ level 3, OND, ONC, BTEC National, SCOTVEC National Certificate, City & Guilds advanced craft, Part III (& other names), RSA advanced diploma)

3

GCSE A*-C Grade/ O Level/ Trade Apprenticeships

(including GCSE/O Level grade A*-C, vocational level 2 and equivalents, NVQ or SVQ level 2, GNVQ intermediate or GSVQ level 2, RSA Diploma, City & Guilds Craft or Part II (& other names), BTEC, SCOTVEC first or general diploma, O level or GCSE grade A-C, SCE Standard or Ordinary grades 1-3)

4

Lower level qualifications

(NVQ or SVQ level 1, GNVQ Foundation level, GSVQ level 1, GCSE or O level below grade C, SCE Standard or Ordinary below grade 3, CSE below grade 1, BTEC, SCOTVEC first or general certificate, SCOTVEC, RSA Stage I, II, or III, City and Guilds part 1, Junior certificate)

5

Other qualifications

(including other vocational or professional or foreign qualifications)

6

No qualifications

7

D8. Which of the following best describes your employment status? SINGLE CODE

Self-employed	1
Employed, full-time	2
Employed, part-time	3
Not employed, looking for work	4
Not employed, not looking for work	5
Student	6
Retired	7
Not able to work	8
Other	9

D9. Please tell us about the total annual income of your household (before tax and deductions, but including any benefits/ allowances). SINGLE CODE

Below £10,000	1
£10,000 - £24,999	2
£25,000 - £49,999	3
£50,000 - £74,999	4
£75,000 - £99,999	5
£100,000 or more	6
Prefer not to answer	7

D10. Which, if any, of these benefits or tax credits are you currently claiming in your own name? MULTICODE

Employment and support allowance (ESA)	1
Personal Independence Payment (PIP)	2
Attendance Allowance	3
Universal Credit	4
Other	5
Not claiming any benefits	6

D11. What is your ethnic group? Choose from one option that best describes your ethnic group or background. SINGLE CODE

Arab	1
Asian (Indian)	2
Asian (Pakistani)	3
Asian (Bangladeshi)	4
Asian (Chinese)	5
Asian (other)	6
Black (African)	7
Black (Caribbean)	8
Black (other)	9
Mixed (black and white)	10
Mixed (Asian and other)	11
Mixed (other)	12
White (English, Scottish, Welsh, Northern Irish or British)	13
White (Irish)	14
White (Gypsy or Irish Traveller)	15

White (Roma)	16
White (other)	17
Prefer not to say	18
Other (please state)	19

D12. What is your sexual orientation? SINGLE CODE

Bisexual	1
Gay or Lesbian	2
Heterosexual or straight	3
I prefer not to say	4
I prefer to use another term (please state)	5

D13. The Disability Discrimination Act as incorporated in The Equality Act 2010 defines a person as disabled if they have a physical or mental impairment which has substantial and long-term (i.e. has lasted or is expected to last at least 12 months) negative effect on their ability to carry out normal day-to-day activities.

Taking this into account, do you consider yourself to be a disabled person? SINGLE CODE

Yes	1
No	2
Prefer not to say	3

D14a. How frequently does your axial SpA reduce your ability to carry out day-to-day activities such as shopping, housework or personal care? SINGLE CODE

Every day	1	CONTINUE
A few days a week	2	CONTINUE
A few days a month	3	CONTINUE
Less than this	4	CONTINUE

Never 5 GO TO D15

D14b. What support, if any, do you need to carry out day-to-day activities on these occasions? MULTICODE

No outside support needed	1
Support from friends / family members	2
Support from professional or voluntary carers	3

D15a. Which of the following medical issues do you experience as a result of / in relation to your axial SpA? (If you suffer from flares, please indicate the issues you experience during these flare ups). MULTICODE

	Severe	Slight	None	Don't know / not sure
Back pain	1	1	1	1
Neck pain	2	2	2	2
Spinal fusion	3	3	3	3
Fatigue	4	4	4	4
Uveitis (eyes)	5	5	5	5
Psoriasis (skin)	6	6	6	6
Inflammatory bowel disease	7	7	7	7
Joint pain	8	8	8	8
Joint stiffness	9	9	9	9
Problems with my feet which make walking more difficult	10	10	10	10

D15b. Which other severe issues do you experience? OPEN END

D15c. Which other slight issues do you experience? OPEN END

None

D16. What treatment do you currently use for your axial SpA? MULTICODE

Analgesics / pain killers	1
Opioids (including codeine, morphine patches or tramadol)	2
Non-steroidial anti-inflammatory drugs (NSAIDs)	3
Steroids (by intramuscular injection, injection into the joint, or tablet)	4
DMARDs (including Sulphasalazine or Methotrexate	5
Biologic therapy (anti-TNF or anti-IL 17A)	6
Nerve pain medication (e.g. amitriptyline, pregabalin and gabapentin)	7
Physiotherapy	8
Hydrotherapy	9
Other (please state)	10
None	11

Section 2: Your journey to diagnosis

We'd like to explore your experience of seeking and receiving a diagnosis of axial SpA. We'll move onto your experience of living with the condition later on in the survey; for now, please just think about your experience leading up to your diagnosis.

1. Whether or not you have received a diagnosis, **how many years do you think you have had symptoms** relating to axial SpA? SINGLE CODE

Less than 1 year	1
1-2 years	2
3-5 years	3
6-10 years	4
11-20 years	5
21-30 years	6
Over 30 years	7

THOSE WHO ANSWERED I OR 2 TO SCREENING QUESTION [NOT YET DIAGNOSED] SKIP TO Q6.

2. How many years did it take you to get a formal diagnosis

a. From when you first experienced the symptoms of axial SpA? If you can't remember the exact figure, please give your best estimate. OPEN END (ONLY ALLOW DIGITS)

b. From when you first saw a GP about your symptoms? If you can't remember the exact figure, please give your best estimate OPEN END (ONLY ALLOW DIGITS)

Not applicable / I did not see a GP

3. And **how many years has it been since you received a formal diagnosis** of axial SpA? If you can't remember, please give your best estimate. SINGLE CODE

Less than 1 year	1
1-2 years	2
3-5 years	3
6-10 years	4
11-20 years	5
Over 20 years	6
4. How old were you when you were diagnosed with axial SpA? SINGLE CODE	
Under 18	1
18-24	2
25-34	3
35-44	4
45-54	5
55-64	6
65-74	7
75+	8
5. Who did you receive your formal diagnosis from?	
A rheumatologist that I saw via an NHS referral	1
A rheumatologist that I saw privately	2
My GP	3
Other, please state	4

6. Here are some things that other people have told us about their experience of getting a diagnosis of axial SpA. Please tell us how much you agree or disagree with each statement in relation to your own experience. RANDOMISE STATEMENT ORDER. SINGLE CODE.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know/ not applicable
My GP didn't seem to know anything about axial SpA before I got a diagnosis						
I didn't feel believed by health professionals when I was trying to get my diagnosis						
My GP took me seriously and listened to me from the start						
My GP assumed my symptoms were side effects of stress / anxiety rather than a physical illness						
My GP assumed my symptoms were a sports injury, strained muscles or another physical injury						
My GP assumed my symptoms were growing pains						
I feel that the time it took to get my diagnosis impacted negatively on the progression of my axial SpA						
I feel that the time it took to get my diagnosis impacted on my ability to quickly get to grips with managing my axial SpA						
I felt my GP tried their hardest to get me a diagnosis						
I wish health professionals had joined up the dots of my different symptoms sooner						

ALTERNATIVE Q6 FOR THOSE WHO HAVE NOT YET RECEIVED A FORMAL DIAGNOSIS ONLY

Here are some things that other people have told us about their experience of seeking a diagnosis of axial SpA. Please tell us how much you agree or disagree with each statement in relation to your own experience. RANDOMISE STATEMENT ORDER. SINGLE CODE.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know/ not applicable
My GP didn't seem to know anything about axial SpA before I got a diagnosis						
I didn't feel believed by health pro- fessionals when I was trying to get my diagnosis						
My GP took me seriously and listened to me from the start						
My GP assumed my symptoms were side effects of stress/ anxiety rather than a physical illness						
My GP assumed my symptoms were a sports injury, strained muscles or another physical injury						
My GP assumed my symptoms were growing pains						
I feel that the time it took to get my diagnosis impacted negatively on the progression of my axial SpA						
I feel that the time it took to get my diagnosis impacted on my ability to quickly get to grips with managing my axial SpA						
I felt my GP tried their hardest to get me a diagnosis						
I wish health professionals had joined up the dots of my different symptoms sooner						

Feeling that health care professionals genuinely want to get to the bottom of what is wrong

7. Imagine you could give health professionals one piece of advice about how to improve people's experience of getting a diagnosis of axial SpA. Thinking back to when you were seeking your diagnosis, what advice would you give? Please provide as much detail as possible about what you found helpful or would have liked to have experienced. OPEN ENDED							
ALTERNATIVE WORDING FOR	THOS	SE WHO HA	VE NOT YE	Γ RECEIVED	A FORMAL	DIAGNOSIS	3
Imagine you could give healt experience of getting a diagr diagnosis, what advice would have found helpful or would I	nosis c d you	of axial SpA. give? Pleas	. Thinking at se provide a	oout your o s much det	wn experiei ail as possi	nce of seek	ing a
8. Here are some things that SpA. For each of these pleas you think this is for patients.	e tell ı	us: a) how p		•		-	
	a)	Very positive	Quite positive	Neutral	Quite negative	Very negative	Don't know / can't recall
	b)	Very important	Quite important	Neutral	Not very important	Not at all important	Don't know
Feeling that health care professionals are listening to yo	u						
Feeling that health care professionals believe you							
Being kept informed about the status / progress of your diagno	osis						
Feeling that health care profess als are looking at the whole pict rather than only focussing on o or two symptoms	ure						

9. And what is most important overall? SINGLE CODE

Feeling that health care professionals are listening to you	1
Feeling that health care professionals believe you	2
Being kept informed about the status / progress of your diagnosis	3
Feeling that health care professionals are looking at the whole picture rather than only focussing on one or two symptoms	4
Feeling that health care professionals genuinely want to get to the bottom of what is wrong	5
Something else – please state	6

CLOSE FOR THOSE WITHOUT A DIAGNOSIS

Section 3: Learning to live with axial SpA

We'd now like to explore your experiences in the initial period after receiving a diagnosis of axial SpA. By this we mean the first year after diagnosis.

10. ONLY ASK THOSE WHO ANSWERED 1,2 OR 3 AT Q3 [DIAGNOSED WITHIN LAST 5 YEARS]. As far as you can remember, which of the following did you receive from NHS health care professionals in the first year of getting your diagnosis of axial SpA? Please tick all that apply. MULTICODE

IF ANSWERED 1 AT Q3 [DIAGNOSED WITHIN LAST YEAR] CHANGE QUESTION WORDING TO: Which of the following have you received from NHS health care professionals since getting your diagnosis?

An initial face-to-face NHS physio appointment(s) tailored specifically to axial SpA	1	
Information about physical exercises tailored specifically to axial SpA	2	
Access (e.g. phone support) to a specialist rheumatology nurse	3	
Information provided about the condition and its likely progression	4	
Information provided about your likely course of treatment	5	
Information about the medication prescribed e.g. side effects	6	
Information on well-being / coping with my diagnosis	7	
None of the above	8	GO TO Q12

11. ONLY ASK THOSE WHO ANSWERED 1,2 OR 3 AT Q3 [DIAGNOSED WITHIN LAST 5 YEARS]. Overall, how satisfied were you with your experience of each? PIPE THROUGH ALL RESPONSES TICKED IN Q10.

	Very satisfied	Quite satisfied	Neutral	Not very satisfied	Not at all satisfied	Don't know / can't recall
An initial face to face NHS physio appointment(s) tailored specifically to axial SpA						
Information about physical exercises tailored specifically to axial SpA						
Access (e.g. phone support) to a specialist rheumatology nurse						
Information provided about the condition and its likely progression						
Information provided about your likely course of treatment						
Information about the medication prescribed e.g. side effects						
Information on well-being / coping with my diagnosis						
12. Again, imagine you were giving a experience of the initial period follo What did you find most helpful or v	wing a diagr	nosis of axia	al SpA. Wh	at advice w	ould you gi	ve?

13. Here are some things that other people have said are important in the early days after receiving a diagnosis of axial SpA. For each of these please tell us: a) how positive your own experience was, and b) how important you think this is for patients. RANDOMISE ORDER. SINGLE CODE

	a)	Very positive	Quite positive	Neutral	Quite negative	Very negative	Don't know / can't recall
	b)	Very im- portant	Quite im- portant	Neutral	Not very important	Not at all important	Don't know
A detailed explanation from a doc about treatment plans for differer stages of the condition							
Having someone to go back to wing questions	ith						
Information about how to manage a flare-up	Э						
Information about physical exerc that might help with axial SpA	ises						
Information about possible side eff of medication to treat axial SpA	ects						
Advice on how to manage pain le	vels						
Advice about how to manage imp of axial SpA on day-to-day life	act						
Advice about the impact of axial on starting a family	SpA						
Information about organisations and groups that support people with axial SpA							

Having an assessment of my emotional wellbeing / mental health

And what is most important overall? SINGLE CODE

A detailed explanation from a doctor about treatment plans for different stages of the condition	1
Having someone to go back to with questions	2
Information about dietary changes that might help with axial SpA	3
Information about physical exercises that might help with axial SpA	4
Information about possible side effects of medication to treat axial SpA	5
Advice on how to manage pain levels	6
Advice about how to manage impact of axial SpA on day to day life	7
Advice about the impact of axial SpA on starting a family	8

Section 4: Long term management

The next section is about your day-to-day experience of living with axial SpA and the care you currently receive.

Overall, on a scale of 1 to 10 where 1 is not at all satisfied, and 10 is extremely satisfied, how satisfied are you with the care you currently receive for your axial SpA specifically? SINGLE CODE. 10 POINT SCALE.

16. Which of the following contacts have you had with NHS health care professionals in relation to your axial SpA in the past year? MULTICODE

	Face-to-face appointment	Telephone/ online consultation	No contact
GP			
Rheumatology consultant			
Rheumatology nurse			
NHS physiotherapist			
Occupational therapist			
Mental health specialist			
Podiatry			
Aquatic physiotherapist			

- 17. Thinking about the care you are looking for on an ongoing basis from different types of health care professionals, for each of the following, please say what your preference would be. SINGLE CODE
- a. Monitoring the progression of my disease e.g. measuring my spine
- b. Advice/ support in relation to my mental health
- c. Advice about the day-to-day management of my condition (e.g. diet, physical activity etc)
- d. Regular reviews of my medication

professional

e. Information on organisations that support people living with axial SpA

	GP	Rheumatology consultant	Rheumatology nurse	NHS physiotherapist
I expect this health care professional to provide this care, and I do currently receive this				
I expect this health care professional to provide this care, and I do not currently receive this				
I would not expect this type of care to be provided by this health care				

18. What other paid for care or support have you received over the past year in relation to your condition? MULTICODE

Physio	1
Osteopath	2
Chiropractor	3
Counselling/ psychological support	4
Hydrotherapy	5
Acupuncture	6
Nutritionist	7
Massage	8
Chiropodist/ podiatrist	9
Other (please state)	10
None of the above	11

19. How much do you agree or disagree with the following statements? RANDOMISE STATEMENTS. SINGLE CODE.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
My health professionals seem to look at me as a cluster of symptoms rather than a whole person						
My health professionals recognise my own expertise in understanding my body and condition						
ASK ONLY OF THOSE WHO ANSWER 'SEVERE' FOR 5, 6 or 7 IN D15a [HAVE CO-MORBIDITIES] I feel that there is joined up thinking across the different specialists I see about the different health issues I have as a result of my axial SpA						
My health professionals are always up to date with my notes and test results when I see them						
My health professionals don't seem to listen when I explain how axial SpA affects my daily life						
My health professionals provide tailored advice on exercises suitable for me						

20. We'd like to understand how well you feel you manage your condition outside your medical appointments. Overall, how well do you feel you are self-managing your axial SpA? SINGLE CODE

Not at all well	1
Not very well	2
Quite well	3
Very well	4

21. Please choose up to three of the most useful ways in which your doctor and health professionals could support you to self-manage your axial SpA. MULTICODE UP TO 3

Support on pain management	1
Support about exercises / physical activity	2
Support about adjustments to make in daily activities e.g. driving	3
Support on fatigue management and sleep	4
Counseling / mental health support	5
Information about financial support available	6
Information on patient organisations like NASS	7
None of these	8
Other, please state	9

22. Which of the following statements best fits you and your attitude to managing your axial SpA on a day-to-day basis? Don't worry if none of them fit exactly – just tell us which one comes closest to your attitude. SINGLE CODE

I would prefer to leave health professionals in charge of decisions about my treatment and day-to-day management of my axial SpA	1
I do some research and thinking about my axial SpA but on balance I would prefer to leave it to health professionals to advise me about treatment and management	2
I would like to work as a team with my health professionals and make decisions about the care and day-to-day management of my axial SpA together	3
I do a lot of my own research and thinking about my axial SpA and am largely confident to make my own decisions about how to manage it day to day	4

23. Finally, thinking about the current treatment you are receiving for your axial SpA, what's the one thing your doctors and other health care professionals could do to improve the quality of care you experience from them? OPEN ENDED

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