What is the average time to diagnosis for axial spondyloarthritis in the UK?

First results from a new audit
September 2023

Aspiring to Excellence
Driving improvements in axial SpA care

About the National Axial Spondyloarthritis Society

Our purpose:

To transform the diagnosis, treatment, and care of people with axial SpA so everyone can live well with it.

Our cause:

Axial SpA is an inflammatory condition of the spine and joints. It works silently, leaving people in increasing pain and exhaustion.

What we do:

We campaign to transform diagnosis and treatment.
We provide support to empower people living with the condition.

Aspiring to Excellence; Driving Improvements in Axial SpA Care

People with axial SpA often experience delayed diagnosis, and quality of care is inconsistent despite a national guideline being in place. This means patients can spend years in pain with no answers and feel unheard and dismissed as they navigate diagnosis and treatment.

This needs to change.

Aspiring to Excellence was established to ensure that every patient, gets the best care, every time.

Working with the NHS Transformation Unit, we partner with rheumatology teams to catalyse improvements in their departments and the wider NHS.

We offer these teams protected time so that they can work on projects that will improve patient experiences.

We create a learning environment with service improvement experts on hand to propel projects towards success.

And we build a powerful network of healthcare professionals who can collaborate and support each other through change.

Together, we will drive improvements in axial SpA care.

Find out more by visiting: **www.nass.co.uk/aspiringtoexcellence**

Time to Diagnosis Key Figures

8.5 Years to diagnosis is NOT OK. Time to act.

8.29 years

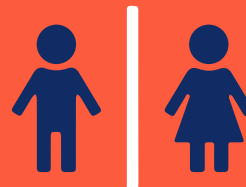Average (mean) time to diagnosis on NASS time to diagnosis audit

325

325 patients' data submitted so far

33

Aspiring to Excellence
Driving improvements in axial SpA care

Patients from 33 Trusts and Health Boards inc all *Aspiring to Excellence* teams

175/150

46% female vs 54% male

76%/ 24%

Majority of responders (76%) identify as white British

4.89 years

Median time to diagnosis

32.18 years

Average age at symptom onset

Data as at 31st July 2023, for anyone with a diagnosis since January 2021

"Aged 17, I saw a rheumatologist. I had been in pain for five years, and I was exhausted. I could see no life beyond this struggle but now I'm a successful journalist, living my best life."

Bethany

www.actonaxialspa.com

Photograph by: Jonathan Blackham

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act on Axial SpA

"This diagnosis doesn't mean your ambitions and goals have to disappear. With the right medication, and if you build healthy habits with exercise, it's possible to live the life you want to lead."

Max

www.actonaxialspa.com

Photograph by: Jonathan Blackham

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"Now I've got the right diagnosis I can run around with my children, I'm building a successful business and I can be the person I want to be again."

Mel

www.actonaxialspa.com

Photograph by: Jonathan Blackham

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act on Axial SpA

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What is the average time to diagnosis for axial Spondyloarthritis in the UK?

Foreword - NASS

The average UK time to diagnosis for axial SpA is 8.5 years. It has not improved over time[1, 2] and is longer than the international mean of 6.7 years.[3] There are significant benefits to timely diagnosis, not least a reduction in pain and distress for those experiencing symptoms. In addition:

- **Diagnostic delay costs the UK economy £18.7 billion p.a.[4] Reducing time to diagnosis to one year would save an average patient £167,000.**
- **Reducing delay improves functional impairment and quality of life.[5]**
- **Reducing delay alleviates pressures in primary care and secondary care[2] if patients are identified on first presentation and referred to rheumatology.**

Most of the published data on time to diagnosis come through audits in individual rheumatology departments as well as from the National Early Inflammatory Arthritis Audit (NEIAA). However, NEIAA only covers England and Wales. The number of patients included in NEIAA is much lower than incidence estimates would suggest and NEIAA reports do not provide granularity of data to understand where on the pathway to diagnosis the delays are typically occurring; a new iteration of NEIAA began in April 2023 which should address this latter deficit. Such an understanding is crucial to focusing improvement activities to achieve timely diagnosis.

In 2019, NASS created a quality improvement programme called *Aspiring to Excellence*. Designed to encourage and recognise service improvement in axial SpA care, it provides tailored, expert support provided by our partner, the NHS Transformation Unit, and is delivered through a multi-site learning environment, team coaching and webinars. Now with 19 departments involved, the programme's focus in 2022 to 2023 is on reducing diagnostic delay.

To measure the programme's performance, a group of participating clinicians worked with us in the summer of 2022 to create a new audit tool. Our aim was to measure at each site: time from symptom onset to presentation in primary care; time from first presentation to referral; time from referral to first appointment in rheumatology; and time from first appointment in rheumatology to diagnosis. We decided that the audit tool should be completed by the patient (not by the clinician which is the case for NEIAA) and should include patients diagnosed since January 2021. The audit went live in 2023. On the back of early success in recruitment, and in discussion with our group of clinicians, we decided in April 2023 to make the audit tool available to any rheumatology department in the UK.

This report presents the initial results of the first four-nation UK audit of time to diagnosis in axial SpA. We don't yet have a comprehensive picture across the UK, and the numbers of patients per department are small overall. Thus, we cannot with confidence refer to the results in the report as providing a baseline position. Nevertheless, this is already the largest current data set in the UK on diagnostic delay.

We have demonstrated that it is possible to create, at pace, a nimble audit tool that can provide the granularity of data needed to support service improvement and pathway development. We hope that the audit will continue to grow to provide a comprehensive picture across every region and nation in the UK.

The data indicate a mean time to diagnosis from symptom onset of 8.29 years (median of 4.89 years). Fewer than 5% of those patients surveyed received a diagnosis in under 12 months, whilst 19% waited over 15 years. If this picture does represent the national average, then we have yet to see a significant reduction in time to diagnosis at national level, although pockets of excellence are beginning to emerge. However, against a backdrop of the Covid-19 pandemic, it may be encouraging that diagnostic delay did not lengthen.

The results of this first audit should galvanise efforts to drive reduction in diagnostic delay and create debate on what we should aspire to, so that nobody has to live for long periods with debilitating and painful symptoms and no agreed diagnosis and treatment path.

Dr. Dale Webb,
FRSA, FRSPH
CEO NASS

Foreword - Dr Marian Chan

Despite better treatments and more developed imaging techniques including MRI, which was recognised by the Assessment of SpondyloArthritis International Society (ASAS) in 2009 as classification criteria, there has been no improvement in the time to diagnosis in the UK.

With our mean delayed time to diagnosis at Luton and Dunstable hospitals of 7.1 years,[6] we were keen to improve and understand the areas contributing to our patients' time to diagnosis. We were successful in joining the third cohort of the NASS *Aspiring to Excellence* programme and have been thrilled to learn and share experiences with fellow participating centres, including engaging with their expertise and successful solutions in tackling diagnostic delays in axial SpA.

This new audit tool - enabling patients to share their diagnostic journey and key steps in that journey - has revalidated our understanding that the majority of our delay is within primary care. We have used this intelligence as our focal point for educating and empowering our primary care teams (physiotherapists, general practitioners, chiropractors etc) in recognising and referring patients early as per NICE (NG65, 2018) and GIRFT (2022) recommendations.

The audit tool has not only furthered our understanding of where our unmet needs are but will allow us to continue measuring the impact of change, tracking this more quickly and efficiently, locally, and nationally.

It has been a whirlwind journey and there is a lot of work to be done. We believe we can achieve this as we are truly inspired by our *Aspiring to Excellence* colleagues in tirelessly continuing to improve even in very challenging times.

Dr Marian Chan,

Consultant Rheumatologist and Clinical lead Axial SpA services Bedfordshire Hospitals NHS Foundation Trust

Foreword - Will Gregory

The case for change with regards to the unacceptable delay to diagnosis in axial SpA in the UK is well laid out in both this document and other publications from NASS [4, 7, 8]

The question facing health care professionals (HCPs) around this case for change must be: *"but what can I do?"* The data presented in this early report provide some answers to this question. With delays lying across multiple components of the healthcare landscape, there are now targets for each of us to consider.

It strikes me, as a physiotherapist, the role our profession might have in decreasing time to diagnosis. Our pilot, two-site survey of patient-reported time to diagnosis in axial SpA[9] showed that more than 60% of those awaiting an axial SpA diagnosis had seen a physiotherapist. The early data presented in this audit report confirms this high percentage exposure to physiotherapists in the journey of those seeking an axial SpA diagnosis. In addition, this report highlights the average length of delay from first HCP presentation to referral to rheumatology, often involving multiple interactions with their general practitioner, a physiotherapist, or other HCPs. Whilst axial SpA can be subtle in its early presentation, with slow progression and an intermittent nature, there is a clear remit from these audit data to increase awareness of presenting factors to both the general public and the HCPs who might see axial SpA prior to diagnosis. We need to ensure axial SpA signs and symptoms are identified earlier and referred for potential diagnosis more rapidly – this is a call to action for all HCPs involved in the assessment of musculoskeletal medicine across primary care, private provision, and more traditional rheumatology triage settings.

From a British Society for Rheumatology (BSR) point of view it is great to see this drive for change being led by NASS. As the BSR NEIA audit moves into its sixth year and expands to collect data from more rheumatology presentations it is useful that NASS offer a condition-specific audit to help guide potential national changes that could facilitate the identification and treatment of rheumatology conditions more rapidly. The BSR have already been working with NASS to explore opportunities for collaboration on this programme in the future.

The team at NASS, the *Aspiring to Excellence* teams and all rheumatology services contributing to this audit must be congratulated on the creation, at speed, of a nimble audit tool that is proving an effective way to explore where the delays in diagnosis of axial SpA lie across the UK and through multiple health care providers. Having data to support the broader musculoskeletal workforce answer the question of *"but what can I do?"* is vital as we seek to decrease delay to diagnosis and hence improve quality of life for those living with axial SpA.

Will Gregory,

Consultant Physiotherapist and Clinical Governance Lead, Rheumatology, Salford Royal Hospital, and Vice President of the British Society for Rheumatology

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Acknowledgements

Executive Summary

We have found it possible to create, at speed, a low, tech and nimble method for data collection that has secured engagement from clinicians and patients through a patient completed survey tool.

There are opportunities to use the data in the future to explore where the delays exist, to monitor responses to quality improvement (QI) initiatives and to see what role health inequalities play in driving diagnostic delay. We will continue to collect data and strive for system-wide change.

From a total sample of patient submissions of 465, we extracted those diagnosed since January 2021 for analysis, n=325 to provide a contemporary picture.

Mean time to diagnosis from symptom onset was 8.29 years, with a median of 4.89 years. Less than 5% (n=15) of those surveyed received a diagnosis in under 12 months, whilst 19% waited over 15 years.

Patients reported that they consulted health care professionals (HCPs) on multiple occasions with their axial SpA symptoms prior to diagnosis, suggesting that opportunities for earlier identification and referral are being missed. 66% (n=214) of the sample saw physiotherapists multiple times, 63% (n=206) consulted GPs on numerous occasions - sometimes with more than 10 visits. 20% (n=63) visited chiropractors and osteopaths (n=64) more than once.

Females waited longer to receive their diagnosis 4.95 vs 4.16 years, taking almost six months longer once they first saw a rheumatologist (1.18 years versus 0.51 years) than men.

Mean time to diagnosis across the patient journey was as follows:

2.69 years
(32% of average time to diagnosis) from experiencing symptoms to seeking help from a GP.

4.35 years
(56%) from first GP appointment to rheumatology referral.

0.44 years
(5%) spent waiting for a first rheumatology appointment following referral.

0.81 years
(9%) for the time from first appointment to formal diagnosis.

Figure 1 - Proportion of time to diagnosis by section of the patient journey.

- **Symptom onset to GP appointment** — 32%
- **GP appointment to referral** — 56%
- **Referral to rheumatology appointment** — 5%
- **Rheumatology appointment to diagnosis** — 10%

From left to right: Sian Bamford (Royal Free), Natasha Banya (Royal Free), Will Gregory (Salford), Dr Aisling Coy (Salisbury), Kristi Hutton (Barkering, Havering & Redbridge), Dr Arumugam Moorthy (Leicester); Prof. Hasan Tahir (Royal Free), Fiona Glover (Leicester) and Dr Ameen Jubber (Leicester)

Introduction

This report provides initial data from a new audit tool that measures time to diagnosis for axial spondyloarthritis (axial SpA). In the UK, the average time to diagnosis (TTD) is approximately 8.5 years.[1, 3]

In 2021 - following a national consultation process - NASS proposed a routemap to ensure that everyone with axial SpA is diagnosed within 12 months of symptom onset, thereby minimising future complications, improving quality of life, and commencing appropriate treatment and self-management at the earliest opportunity.[8]

In our QI programme *Aspiring to Excellence*, 19 rheumatology departments are working on improving TTD. To measure TTD, clinicians from those departments worked with NASS to create an audit tool in the summer and autumn of 2022. *Aspiring to Excellence* forms part of a broader set of initiatives led by NASS which aim to ensure the widespread implementation of the 2017 NICE Guideline (NG65) on Spondyloarthritis.[10] The audit is therefore critical in estimating the effectiveness of our collective efforts to achieve timely diagnosis at local and national level.

Methods

The data collection followed a simple process where rheumatology teams shared with patients posters or leaflets with a QR code, encouraged them to complete the survey, and the patient - often in the waiting room - clicked the QR code and answered the questions before submitting their data. We excluded, from a total sample of 465, those patients diagnosed prior to January 2021, partly to minimise recall bias but also to provide a baseline position for our Gold Standard routemap which was published in July of that year.

We need your help
Measuring time to diagnosis for axial SpA

NASS

What am I being asked to do?

We're inviting you to take a quick survey about your healthcare journey. You are being asked to answer a few questions about your experiences from symptom onset to diagnosis. We also would like some basic demographic information, this does not include anything that could personally identify you. If you are unsure about how to answer a question, please consider asking a member of the rheumatology team.

Why are we asking you to do this?

You have recently been diagnosed with Axial Spondyloarthritis (axial SpA) or Ankylosing Spondylitis (AS). **Right now, people wait an average of 8.5 years to receive a diagnosis for AS or axial SpA.** The National Axial Spondyloarthritis Society (NASS) are working to reduce this time from 8.5 years to one. Our rheumatology teams are working with NASS to understand whether measures being taken to reduce diagnosis times are working.

Scan the QR code to access the survey

By completing the survey you are giving your consent for the use of the information supplied

What is axial SpA?

- Axial SpA is an inflammatory condition of the spine and joints. Inflammation where muscles attach to the bones causes extreme pain. If left untreated it can permanently fuse bones together. It works silently, leaving people in increasing pain and exhaustion.
- **1 in 200 people (approximately 220,000)** in the UK live with axial SpA. It's more common than MS and Parkinson's combined.

How will we use your data?

- NASS and the hospital will use the information you give to campaign to transform diagnosis and treatment of axial SpA.
- The data will help us measure if we are **reducing the 8.5 year time to diagnosis.**

In partnership with   Sponsored by

BRITSpA   TU   abbvie   Biogen   Lilly   NOVARTIS   Inspired by patients. Driven by science.

Aspiring to **Excellence**
Driving improvements in axial SpA care

Limitations of the survey

We identify the following limitations:

Selection bias: the survey was completed on an opt in basis from a limited number of sites so may not be a representative sample of patients. As our sample size increases and includes patients from a larger range of locations, hospitals, and communities this bias should reduce.

Recall bias: As the survey is asking patients to recall events potentially going back many years, there could be errors in their recall. This is particularly likely for patients that have been going through a very long wait. To mitigate this, we are using the data only for those with relatively recent diagnoses, in this case since January 2021.

Data validation: In the majority of cases the process of data collection did not provide an opportunity for clinical validation of the data entered by patients. In some cases, the patient will complete the survey in clinic with an HCP giving guidance. This is partly mitigated by removal of any submissions that appear to have obvious data errors, such as a negative part or whole journey, where diagnosis date is earlier than symptom onset date.

Change lag: Change and particularly system-wide change will take a long time to work through a system. In addition, improved public awareness of axial SpA is likely to result in more people who have been living with symptoms for a long time getting diagnosed. Thus, in the short term we may see an increased average TTD. To balance this impact we are assessing a range of metrics including the % of people diagnosed within one year of symptom onset.

Results, comment and analysis
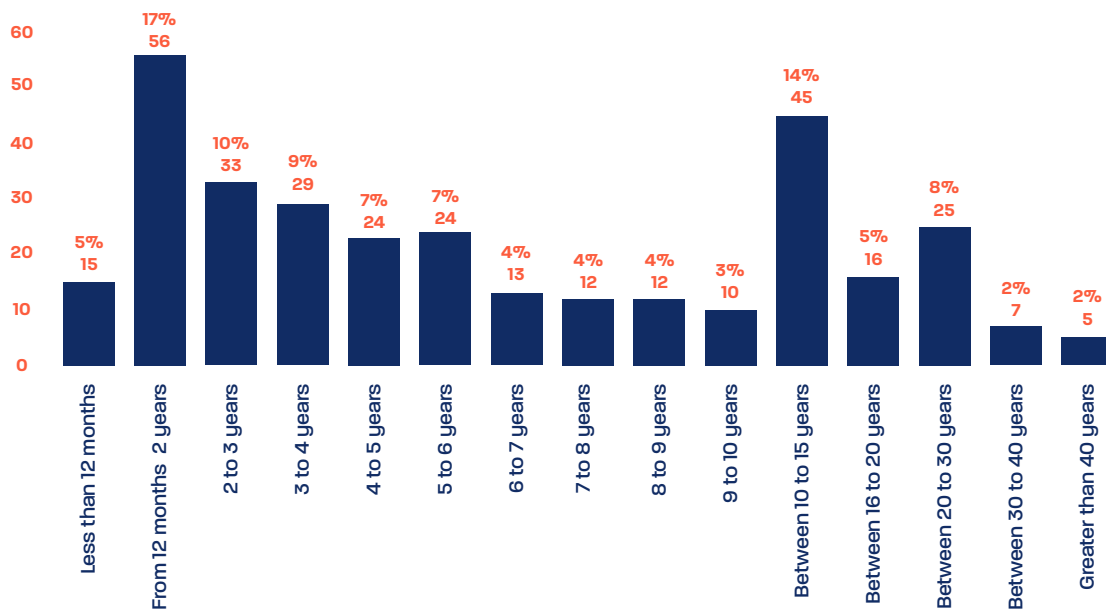
Time to diagnosis

Mean time to diagnosis from symptom onset was 8.29 years; the median was 4.89 years. Fewer than 5% (n=15) of those surveyed received a diagnosis in under 12 months, whilst 16% had waited over 15 years.

If representative, this would imply that the time to diagnosis remains in line with previously published data. Against a backdrop of the Covid-19 pandemic, it may be encouraging that diagnostic delay did not lengthen.

Figure 2 below shows the distribution of patient time to diagnosis in years. It highlights that 5% were diagnosed within the Gold Standard of less than 1 year.

A quarter (27%) are diagnosed between 12 months and 3 years from symptom onset, a further quarter (27%) wait between 3 and 7 years. With over a third (37%) waiting longer than the 8.5 year average time to diagnosis

Figure 2 - Distribution of years to diagnosis – showing the number of patients that wait each year. This is based on the total time to diagnosis

Distribution of year to diagnosis (total)

Where in the patient journey to diagnosis are the delays?

Mean time to diagnosis across the patient journey was as follows:

- 2.69 years (32% of average time to diagnosis) from experiencing symptoms to seeking help from a GP.

- 4.35 years (56%) from first GP appointment to rheumatology referral.

- 0.44 years (5%) spent waiting for a first rheumatology appointment following referral.

- 0.81 years (9%) for the time from first appointment to formal diagnosis.

These results highlight that primary care is the most significant delay in the patient's journey and that up to 88% of the delay is experienced prior to a referral into rheumatology.

Figure 3 - Proportion of time to diagnosis by section of the patient journey

32%

56%

5%

10%

- Symptom onset to GP appointment
- GP appointment to referral
- Referral to rheumatology appointment
- Rheumatology appointment to diagnosis
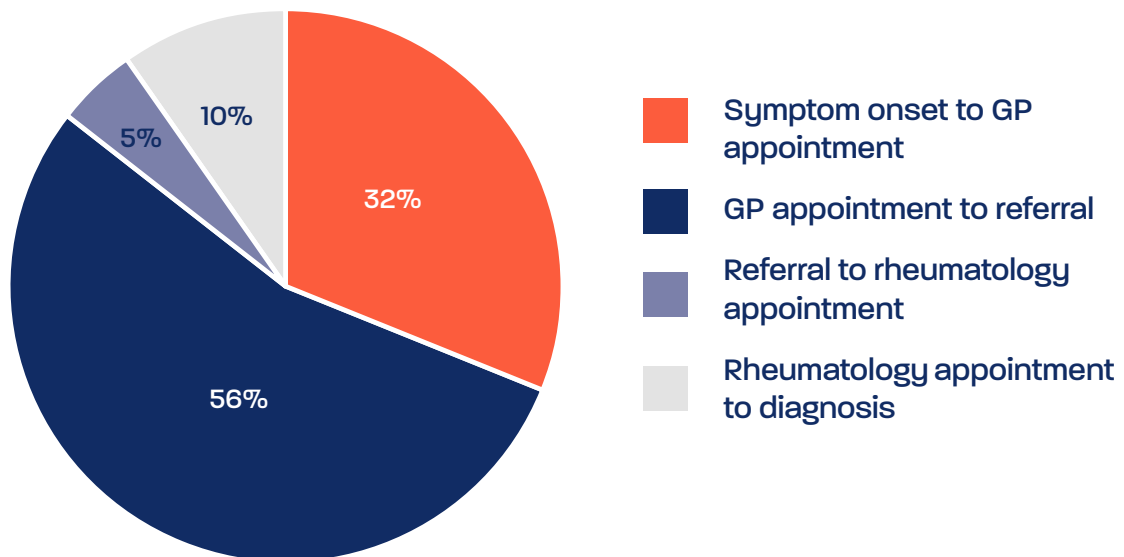
Proportion of total time to diagnosis by part of pathway

How often are patients being seen by health care professionals during their diagnosis journey?

One of the drivers of a delay to diagnosis is a failure to suspect inflammatory back pain and possible axial SpA at first or early presentation to health care services. This leads to patients seeing their GP and other primary care HCPs multiple times before they eventually receive a diagnosis. For example, a recent survey by two NHS rheumatology services[9] found that across the two sites, 89% of patients saw a general practitioner (GP) prior to diagnosis, of whom 68% of patients saw a GP one to five times, 16% five to ten times and 13 more than ten times. Many patients also saw other HCPs multiple times.
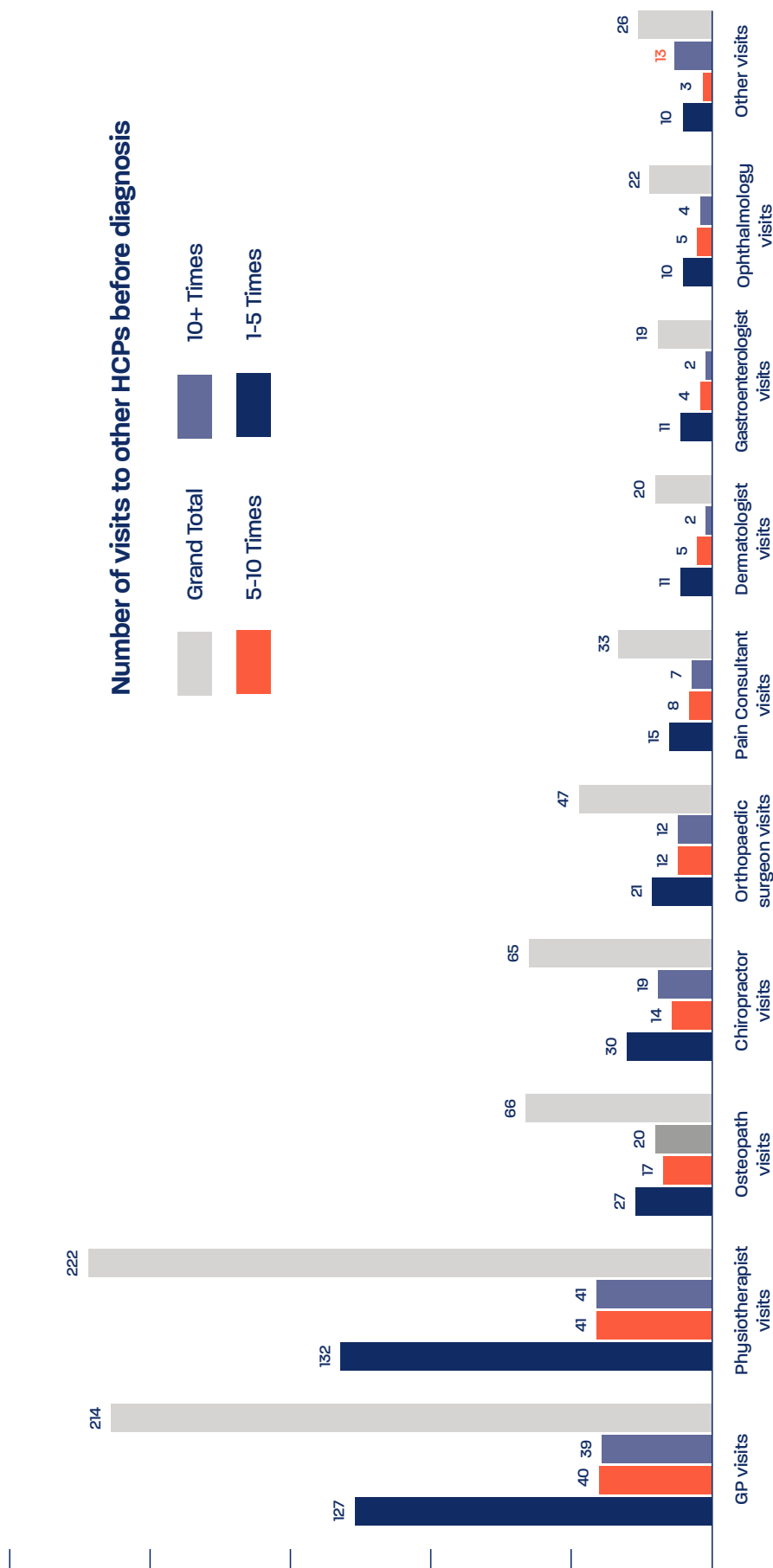
We also found in our national consultation for the *Act on axial SpA* campaign that approximately 40% of people with

axial SpA also report seeking treatment pre-diagnosis from osteopaths, chiropractors, musculoskeletal (MSK) community physiotherapists and private physiotherapists, some of whom may not have specialist knowledge of recent developments in axial SpA. [11, 12, 13] This can often be at the expense of those patients paying for private services. The costs of these appointments are a key driver in the high financial cost to individuals.[3]

The audit shows that patients reported consulting clinicians multiple times with their axial SpA symptoms prior to diagnosis, suggesting that opportunities for earlier identification and referral are being missed. 66% (n=214) of the sample saw physiotherapists multiple times, 63% (n=206) consulted GPs on numerous occasions, sometimes with more than 10 visits. 20% (n=63) visited chiropractors and osteopaths (n=64) more than once.

Figure 4 – Number of visits to other HCPs before diagnosis and an estimate of how often they consult these professionals.

Number of visits to other HCPs before diagnosis

Legend:
- Grand Total
- 10+ Times
- 5-10 Times
- 1-5 Times

Category	1-5 Times	5-10 Times	10+ Times	Grand Total
GP visits	127	40	39	214
Physiotherapist visits	132	41	41	222
Osteopath visits	27	17	20	66
Chiropractor visits	30	14	19	65
Orthopaedic surgeon visits	21	12	12	47
Pain Consultant visits	15	8	7	33
Dermatologist visits	11	5	2	20
Gastroenterologist visits	11	4	2	19
Ophthalmology visits	10	5	4	22
Other visits	10	3	13	26

These results confirm previous studies and testimonials that patients often 'bounce around' primary care and community services, both NHS and private, before they receive a formal diagnosis by a rheumatologist.

Of concern is that nearly 2 in 3 of patients that have received a diagnosis of axial SpA are seen multiple times by GPs and physiotherapists.

Discussion

There is a significant appetite amongst the rheumatology clinical community to generate data to support quality and service improvement.

Within eight weeks of gathering the group of HCPs to assess how we could generate delay to diagnosis data, we were ready with a patient survey audit tool that could simply collect the data needed. This shows that it is possible to develop at pace a scalable data collection tool. By taking a pragmatic approach to data collection and having a simple online form for patient-led completion we have been able to implement the audit at pace with a low burden on busy clinical teams.

The audit has enabled us to confirm that the greatest blocker in the patient journey is in primary care, which emphasises the importance of our *Champions in Primary Care* programme. These data support an upcoming manuscript looking at the role of primary care in ending the delay. The data set has also supported us in the co-creation of various tools to help HCPs that can be found on our act on axial SpA website.

Next steps

Having generated proof of concept and a baseline position from which to measure, we are confident that over time we will be able to:

- identify where the blockers in the pathway are located.

- support rheumatology teams to understand where to focus their improvement activities for the biggest impact.

- identify the factors such as gender, age, ethnicity, location that have the greatest effect on patients' time to diagnosis.

- shape our future agenda for policy, campaigning, and parliamentary engagement, and

- measure changes in time to diagnosis.

Future analysis will identify the impact of health inequalities, patient characteristics, access, and location on diagnostic delay. This will be focussed on areas that we are aware have an impact on axial SpA diagnosis. This will enable targeting of future QI initiatives, policy interventions and campaigning. Following our proof of concept we continue to run the audit on an ongoing basis and will encourage more rheumatology teams and HCPs to engage in the audit and support patients to submit their data. This will help build the national picture but also help drive local improvements.

Annex one – What is axial SpA?

Axial spondyloarthritis (axial SpA) is a form of inflammatory arthritis that most commonly affects the spine and sacroiliac joints. It is a painful and progressive long-term condition for which there is no cure. There is currently an 8.5-year average time to diagnosis[1].

Axial SpA is not rare and affects an estimated 1 in 200 of the adult population[14] in the UK (approximately 220,000), which is twice the prevalence of multiple sclerosis (MS) (1 in 600 of whole UK population or 107,000)[15]. The disease is characterised by painful flares and fatigue.

People with the condition can also have a range of complications and co-morbidities:

- 26% of people will have uveitis[16]
- 9% will have psoriasis[17]
- 7% will have inflammatory bowel disease[18]
- 25% of people will have irreversible spinal fusion[19]
- There is a close association with osteoporosis[20]
- 59% report suffering a mental health issue at some point.

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What is the average time to diagnosis for axial Spondyloarthritis in the UK?

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NASS

Axial SpA works silently.
We don't.