

## **Developing the NASS Self-Management Programme** **Improving health outcomes among axial SpA patients**

### **Background**

Axial spondyloarthritis (axial SpA) affects 1 in 200 people in the UK. Inflammation, where muscles attach to the bones, cause extreme pain, exhaustion and limited movement. Axial SpA is an invisible and often misdiagnosed condition, and on average, it takes over eight years to receive a diagnosis. **If left untreated, and if symptoms are not managed, axial SpA can permanently fuse the bones.**

Symptoms typically start in a person's late teens or early twenties, and these symptoms can have a significant impact on daily life. These symptoms can make it hard to do everyday activities, like putting on shoes, driving a car, or looking after children. Consequently, many people feel cut-off from their social and working lives, which can lead to depression<sup>1</sup>.

Axial SpA is a complex condition, and it is not enough to rely on medication to manage the symptoms or long-term effects. Patients must self-manage their condition through daily exercise, pain management techniques and modifying activity to manage fatigue.

Despite the considerable impact axial SpA has on lives, patients are not routinely offered condition education programmes, as you might find for conditions such as diabetes. On average, a fortunate patient might spend 2 hours each year with a healthcare professional, which leaves 8,758 hours where they must manage their symptoms on their own. Many people with axial SpA report feeling isolated and have never met anyone else with the condition.

When the pandemic hit, rheumatology departments closed or were left with a skeleton service, and routine medical appointments became unavailable. Many people had to shield, were unable to work, and newly diagnosed patients experienced long wait times to start treatment.

**As the Covid-19  
pandemic hit, people  
needed our support  
more than ever.**

NASS is the only charity in the UK dedicated to transforming the diagnosis and care of people living with axial SpA. During 2020, we doubled our Helpline opening hours and increased the number of staff on the Helpline. The number of enquiries that we responded to rose by 300% in the first six months of the pandemic, and over 12 months, we helped 5,600 people who were struggling with issues related to axial SpA. Our Facebook Live self-management videos were watched over 135,000 times, supporting people with axial SpA through the Covid-19 pandemic and beyond.

The impact of Covid-19 on rheumatology services is significant, and accessing care continues to be a challenge for many axial SpA patients. Disruption to services is estimated to continue impacting support services for at least the next two years.

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<sup>1</sup> Imke Redeker, Falk Hoffmann, Johanna Callhoff, Hildrun Haibel, Joachim Sieper, Angela Zink, Denis Poddubnyy, Determinants of psychological well-being in axial spondyloarthritis: an analysis based on linked claims and patient-reported survey data, *Ann Rheum Dis.* 2018 Jul; 77(7): 1017–1024

## **Bridging the gap: A new self-management education programme**

Our new self-management education programme aims to bridge this gap and equip axial SpA patients with the skills and tools they need to help them confidently manage their symptoms and live well with the condition.

In 2020, we held consultations with patients and medical professionals, which identified the need for group education sessions to learn new skills and tools to help them confidently manage their axial SpA.

The consultations identified three key self-management education areas; pain, managing flares, and fatigue, and that a new programme should deliver the following key objectives:

**1. Empower patients with axial SpA to live well with their condition.** Content will be developed and delivered by NASS Self-Management Programme Officer Zoë Clark, a healthcare professional who lives with axial SpA. Patients will learn new skills and tools to help them confidently manage their symptoms and feel able to take charge of their condition and make decisions right for them. Each session will have time for gentle exercises and facilitated group discussion.

**2. Connect patients with their local rheumatology team.** Hospital staff will identify patients to invite and will be part of delivery so that patients feel closer to their healthcare team.

**3. Reduce isolation.** Each session will have time for patients to share their experiences with healthcare professionals. Meeting others with axial SpA will help reduce isolation among patients. We wanted to reach patients who had never previously attended an axial SpA self-management session through their hospital.

**4. Be co-designed with people living with axial SpA and healthcare professionals.** We will establish the need and desire for an axial SpA Self-Management Programme from both patients and clinicians. Content will be monitored and evaluated through feedback from patients to ensure that their experiences shape the programme and that topics and methodology are pertinent and effective.

**5. Be easily accessible.** Sessions should be no more than two hours long and limited to a maximum of 45 people to encourage group discussion. All sessions will be delivered using digital technology to reduce the barriers to attending among patients who may be shielding or otherwise have to travel long distances.

**6. Leave a legacy.** At the end of the programme, patients will have a suite of resources and tools to continue their self-management pathway. We will provide rheumatology teams with content and resources to run future sessions with new patients.

## Pilot programme delivery

Thanks to funding from the **Postcode Neighbourhood Trust**, we were able to run a pilot self-management programme with patients from six NHS Trusts, identified through our network of healthcare professionals. These Trusts were: the Royal Berkshire Hospital, Salford Royal Hospital, Great Western Hospital (Wiltshire), Royal Hallamshire Hospital (South Yorkshire), Norfolk and Norwich Hospital, and Salisbury District Hospital.

We intentionally chose centres with varied axial SpA services. Some departments had a multi-disciplinary team in place, while others had a single clinician for the service. One centre was setting up a new axial SpA service. **In total, we held ten pilot sessions across the six locations.**

Our initial consultation meetings with rheumatology healthcare professionals and people living with axial SpA helped to determine the initial structure and topics for sessions. NASS Self-Management Programme Officer, Zoë Clark, then developed the content for each initial pilot session. These sessions covered pain, fatigue, flares, exercise and emotional wellbeing.

To test this content, we held two pre-pilot sessions with NASS Branches in Reading and Cambridge.

Zoë then tailored content to each patient group to include presentations from Zoë and local medical professionals, facilitated group discussions, time for group exercises and stretches, Q&As with medical teams, and interactive polls.

Follow up sessions provided an opportunity for patients to explore other self-management topics in greater depth and were guided by patient feedback. Topic areas at follow up sessions included: medication, exercise, night pain, sleep, and managing stress.

## Demographics of Attendees

Patients were invited to attend by their rheumatology department via letter or email. NASS Self-Management Programme Officer invited local NASS Branches and members.

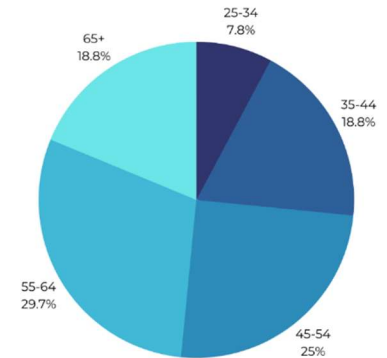
In total, 266 patients booked onto our Self-Management Pilot Programme, across the six sites.

**“Good turnout, very good level of engagement from the participants, lots of enthusiasm to build on this with future sessions.”**  
Specialist Physiotherapist

### Reaching an older audience

There was an even split among male and female patients (45% and 55% respectively). We were encouraged that 27% of attendees were aged under 45.

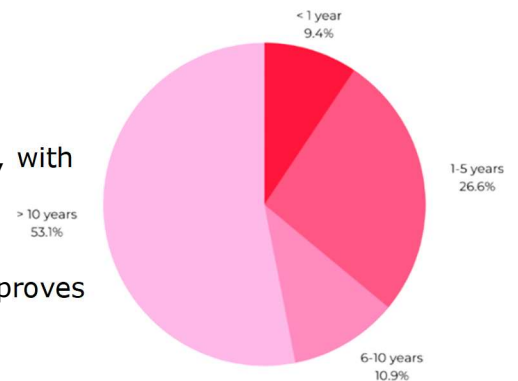
Over half of patients had been diagnosed with axial SpA more than ten years ago, which would indicate that most of attendees had lived with symptoms of axial SpA for a large part of their adult lives.



### Reaching recently diagnosed patients.

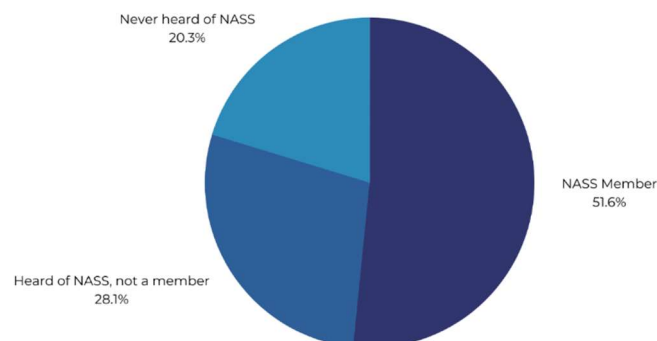
However, just over a quarter of patients were newly diagnosed, with nearly 10% having received a diagnosis within the past year.

This is particularly important because good management of axial SpA reduces the risk of long-term effects of the condition and improves patient quality of life.



### Reaching new audiences

Length of diagnosis ranged from less than one year to more than ten years, with the latter being the most common. Of the attendees, half had never heard of NASS, while the other half had heard of NASS but weren't members.



## Measuring the impact

To measure the impact of our pilot programme against our key objectives, we collected qualitative and quantitative feedback from attendees through pre- and post-training surveys and emails. We also facilitated discussion groups with patients and healthcare professionals. To maintain patient confidentiality, we did not record sessions.

### 1. Empower patients to live well with their axial SpA.

At the end of the sessions, **86%** of attendees reported that they felt they understood more about managing their axial SpA, with 80% feeling more confident managing their pain and 75% feeling more confident about managing their flares.

**“The information session was really useful and I came away feeling much more confident about the condition”** Patient

### 2. Connect patients to their local rheumatology team.

In total, **83%** of attendees reported finding the gaps between clinic visits isolating and appreciated the opportunity to meet their healthcare team in the online session. Seven in ten attendees described feeling closer to their rheumatology team following the session.

**“I find the gaps between clinic visits quite isolating and appreciate the forum for discussion and ideas”** Patient

At the end of sessions, **75%** of attendees reported feeling more confident about approaching their rheumatology team for advice and being clearer on how they can self-refer to the team.

### 3. Reduce the isolation among people living with axial SpA.

Nearly all attendees (**95%**) reported finding it helpful to meet other people with axial SpA and share their experiences in the online sessions.

Patients valued meeting their local rheumatology team, and it was essential to allow time for questions and group discussions. After the programme, **78% of attendees reported feeling more comfortable discussing their emotional wellbeing with their healthcare team.**

**“Great session and very interesting to hear from others with the condition - I have never met anyone else with it since being diagnosed.”** Patient

No attendees had previously been invited to an axial SpA self-management session by their hospital.

#### 4. Be co-designed with people living with axial SpA and healthcare professionals.

Throughout the delivery of the pilot sessions, content and delivery were continually reviewed and improved using feedback from patients and healthcare professionals.

While 86% of patient attendees thought that the content of sessions was suitable for patients at all stages of their axial SpA journey, **87% of attendees identified an additional need** for training specifically for newly diagnosed patients (within the last two years).

In addition, **83% said they would value small, interactive sessions** with rheumatologists and patients from their local hospital, compared to 59% who would prefer larger, regional sessions. Finally, **92% of patients said they would benefit from an e-learning self-management course.**

All the healthcare professionals involved in the online sessions reported they were beneficial for their patients and expressed an interest in holding future sessions. All found the preparation time just right and found the draft content extremely helpful.

**"I'm very thankful to NASS for working with us to improve the care offered to patients with axial SpA."**  
Consultant Rheumatologist

Areas identified as particularly positive were the breakout rooms, the length of sessions, facilitation by NASS team members, a chance to speak with their patients and the use of features to encourage attendee interaction.

#### 5. Be accessible.

The online platform was effective and accessible for attendees, with **98%** of attendees reporting they found it easy to attend and **100%** of attendees feeling confident about attending a future session using the same technology. In addition, **86% of attendees found it more convenient** than attending an in-person event.

**"Attendance was great (to capacity) and engagement really good. Patients who I wasn't expecting to attend, did. Moreover, patients who I know would be anxious speaking in public, contributed to the discussion."**  
Consultant Rheumatologist

#### 6. Leave a legacy.

At the end of the programme, we emailed patients links to further resources and local services to continue their self-management pathway. Patients were also directed to their local NASS branch, and invited to continue discussions on the NASS Members forum and social media pages.

In addition, we continue to support patients through weekly Facebook Live sessions on various topics to help them manage their axial SpA symptoms. These sessions are free to access on the My AS My Life section of the NASS website.

We will continue to review the results of the pilot sessions in consultation with attendees, people living with axial SpA, NASS Trustees, the NASS Medical Advisory Board and healthcare professionals, to enable us to plan future sessions.

**"I think NASS are amazing and have enjoyed working with you. Last night gave me insight in how I can run similar sessions locally and confidence to get on and do this."**  
Consultant Rheumatologist

## Next steps: Developing the Self-Management Programme for axial SpA patients across the UK.

Now our pilot programme has concluded, we have ambitious plans to deliver the programme to axial SpA patients across the UK. We are currently undertaking a programme of applications to carefully selected funders to help raise the funds required to deliver and develop this programme from September 2021.

At the time of writing, we have already received expressions of interest from 35 hospitals to deliver our self-management programme to their patient cohorts. Plans are in place to extend our call for expressions of interest later in the year.

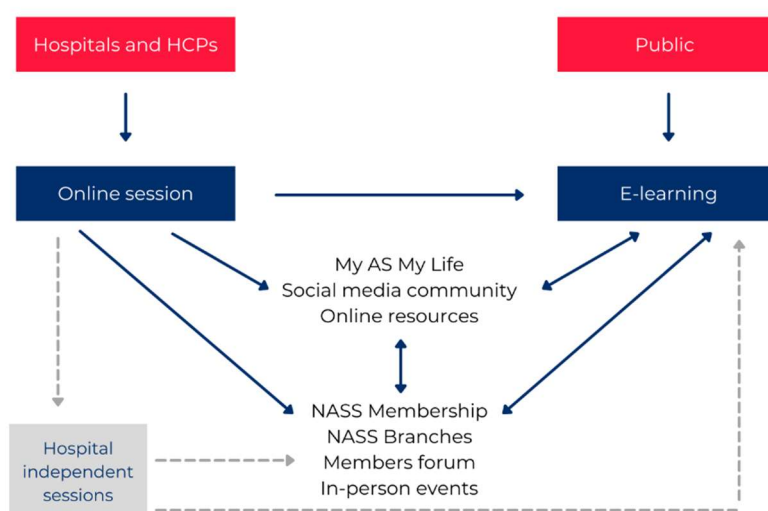
Findings from our pilot programme highlight areas of development such as resource libraries to support hospital staff, NASS branches and healthcare professionals to run sessions independently at a high, consistent standard ('sessions in a box'), and a self-management e-learning course for independent learning.

### 1. Resource libraries – leaving a legacy.

We can work with centres to create a library of resources they can utilise for independent self-management sessions. This will reduce preparation time for healthcare professionals and ensure that sessions across the UK are at similarly high standards with reliable and up-to-date information. We can work with NASS Branches to create resources for shorter self-management 'sessions in a box'. For example, short presentations, conversation prompts, worksheets. This will support Branch physiotherapists to lead short sessions on different aspects of self-management, ensuring a consistently high quality of information across the Branch network.

### 2. E-learning platform – supporting independent learning.

The NASS Self-Management Programme Officer would develop an e-learning platform in collaboration with patients and healthcare professionals. E-learning modules will cover various self-management topics and will include a module specifically for newly diagnosed patients. These sessions would be self-directed, independent learning, utilising text, videos, quizzes, exercise breaks and text areas for users to create their care plans.



An e-learning platform will have increased accessibility for users and offer a different approach for learning self-management techniques. It will be routinely offered to our self-management programme attendees and will be suitable if a patient cannot attend their local Branch or hospital session.