NASS

Axial SpA
works silently.
We don't.

Strategy 2025 – 2029

Introduction

NASS is proud to be the oldest patient organisation in the world supporting people affected by axial spondyloarthritis – or axial SpA. For almost 50 years we have led the way in helping people to make sense of and manage their condition.

The period 2020 – 2024 saw a step change in our work and impact upon which this new strategy builds.

First, our campaign to drive down the time to diagnosis - *Act on Axial SpA* - has subverted any normalising of lengthy diagnostic delay. It reached 5,000,000 people and helped thousands start their journey to diagnosis. Our work engaged hundreds of healthcare professionals and a core of rheumatology departments, stimulating new healthcare improvement projects. We created a new dataset showing both localised reductions in time to diagnosis and a possible reduction at UK level. *Act on Axial SpA* has reached a tipping point and in the next five years we will propose and monitor national improvement goals for time to diagnosis and publish new resources to support the NHS and private providers to implement our recommendations. We will create demonstration projects showing how to accelerate reductions in diagnostic delay and publish our data in order to shape clinical practice and inform healthcare policy. We will support patients in the year after their diagnosis to help them make sense of and manage their condition.

Second, we created the world's largest healthcare quality improvement (QI) programme in axial SpA. *Aspiring to Excellence* supported 23 rheumatology departments with QI teaching and coaching and a national learning network to share their experience and data. The programme nurtured improvement projects across the pathway covering diagnosis, physiotherapy services, employment, self-management programmes, flare clinics and the setting up of specialist axial SpA clinics. We published research that established what people with lived experience need and value from their axial SpA diagnosis and care and used this to inform new work led by NASS which aims to establish a gold standard approach to treatment and care, integrating patient and clinical insights. Over the next five years we will complete this work by publishing a gold standard that covers the treatment pathway, we will support its implementation and propose a national NHS minimum data set to monitor service quality.

Our third step change was in supported self-management. Born out of the circumstances resulting from the COVID pandemic, we created a large body of new resources and approaches to help people manage their condition. First, we created *My AS, My Life* which helps those who already have some level of confidence in managing their conditions, ran 129 webinars and created a library of videos that were viewed 400,000 times. Next, we collaborated with 48 rheumatology departments to reach 1,600 patients with tailored on-line education and peer support. More recently we focused on those who are newly diagnosed or who struggle to manage their condition, creating *Your SpAce*, offering bite-sized, engaging information and lived experience content. Our evaluation data indicate that we have proof of concept. Over the next five years we will strengthen our impact data so that we can continue to learn and adapt our approach, as well as pilot different content and delivery mechanisms and create new projects across the four nations to maximise our reach.

The final step change was in our work to influence and advocate for a greater awareness and understanding of axial SpA in healthcare policy. We created The All Party Parliamentary Group for Axial Spondyloarthritis as a mechanism to ensure oversight of the implementation of the NICE Guideline 65 on spondyloarthritis. It published multiple enquiries that led to Parliamentary debates and Ministerial meetings. We supported healthcare professionals through *Act on Axial SpA* and *Aspiring to Excellence*, created new fora to provide peer support and were more visible and engaged than ever before at healthcare professional conferences. We will sustain our work in this area, as well as support new work within NHS Wales and prioritise opportunities in Scotland and Northern Ireland as they arise.

Meanwhile, we continued to offer a comprehensive confidential information and support service. We doubled our opening hours to respond to the unprecedented demand for our services created by COVID and over the last five years we helped 27,000 people. Our benefits advice service provided critical assistance to those seeking welfare benefits and helped people secure £5,000,000. Our national network of volunteer-led branches adapted to the challenges imposed by the pandemic, providing online support to help people stay well and connected to each other. After the pandemic our local branch committees showed great resilience and tenacity in negotiations with hospitals and other venues, with the majority able to return to sessions. Week in, week out, they provide physiotherapy, hydrotherapy and peer-support to thousands of people across the UK. We will continue to offer our information and support service at its current level, ensure that NASS branches are well supported and build more NASS affiliated groups.

We created a new visual identity as well as sub-brands for *Act on Axial SpA* and *Aspiring to Excellence*, developed a much stronger story-led approach to our marketing and communications and extended the range of social media channels we used.

Membership of NASS is now at its highest level with 21% growth over the last five years - a very good indicator of the health of our organisation and how it is perceived by our community. We aim to grow membership over the next five years by 30% with more exclusive, curated content for members, more face to face events and more tailored membership journeys.

Finally, the last five years have been very challenging financially for patient organisations as a consequence of the negative impact on our fundraised income of the pandemic and cost of living crisis. Nevertheless, we achieved a 21% growth in income, mainly through new partnerships with pharmaceutical companies and an increase in donations and grants. Our income generation plan for the next five years will deliver the resources we require through new income streams, digitally mature fundraising and the effective leverage of donor data. Our financial management is strong, and we will continue to maintain cost efficiency, improve financial processes, manage our assets effectively and ensure that we have adequate reserves.

In 2026 we will celebrate the 50th anniversary of NASS. We are immensely proud of what we have achieved and feel that we have much to celebrate. We are confident that we can be even more impactful in the next five years. We thank all of those who have supported and partnered with us, we look forward to strengthening our work together and to welcoming new people into the NASS family.

Our Vision:

A future with timely diagnosis and holistic care, supported by a united axial SpA community.

Our Mission:

Transforming axial SpA futures: creating a social movement for change and an empowered community.

We do this by:

- Putting people with axial SpA at the heart of what we do, and leading the debate about the future of axial SpA care and support.
- Raising awareness and educating people about axial SpA through public awareness campaigns and healthcare professional education.
- Supporting people to live well with their condition through specialist support and advice.
- Generating evidence to demonstrate that improvements in diagnosis time, care and self-management are possible through research, pilots and demonstration projects.

Goal One: To ensure that people with axial SpA are diagnosed within twelve months of symptom onset and receive the information and support they need

Our work in 2020 - 2024

Delayed diagnosis impacts negatively on people with axial SpA, the NHS and the economy. It results in worse outcomes for patients and affects their quality of life.

In 2021, following a national consultation process, we launched *Act on Axial SpA*. Its long-term goal is that people with axial SpA across the UK are diagnosed within twelve months of symptom onset. The programme includes research and audit, public awareness campaigns, education and training for healthcare professionals (HCPs), quality improvement interventions, and policy and Parliamentary activity. It seeks to test and then spread interventions and promotes an integrated approach that follows the person from symptom onset to diagnosis in rheumatology.

Since 2021, we have created the conditions for improvement by:

- ***Formulating a clear vision*** through our route map[1] and then communicating it through scientific meetings, Parliamentary meetings and events, presentations at regional axial SpA network meetings, social media and through a bespoke campaign website.
- ***Creating a sense of urgency*** – by commissioning research into the full economic costs of axial SpA, arrangements for MRI, internal referrals, and the knowledge and practice within gastroenterology and ophthalmology. We worked with Parliamentarians to bring our data to light through two Parliamentary debates and a Ministerial meeting. We

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[1] 1 Webb D, Swingler L, Barnett R, Sengupta R, Marshall L, Hamilton J, Zhao S & Gaffney K. Act on axial SpA: A Gold Standard time for the diagnosis of axial SpA (2021). London: National Axial Spondyloarthritis Society

started publishing our approach and findings in scientific journals and presented at scientific conferences in the UK and abroad.

- ***Establishing a guiding coalition*** of clinical collaborators, rheumatology teams and primary care professionals.
- ***Establishing an improvement team*** comprising of NASS, the NHS Transformation Unit and our principal clinical collaborators.
- ***Putting in place a measurement system*** through a UK-wide patient-completed time to diagnosis survey, recruiting 57 NHS Trusts and Health Boards and collecting data from almost 600 patients diagnosed since January 2021. We influenced the National Early Inflammatory Arthritis Audit to strength its data collection in this area.
- **Working with innovators /early adopters to test out our ideas**. This includes the 23 rheumatology departments involved in our sister programme *Aspiring to Excellence*, the 10 participants in our *Champions in Primary Care* programme, and a new peer to peer network of more than 160 HCPs. We supported the trialling of a primary care pop-up alert, one of our *Champions* worked with Ardens to refresh the MSK template and another worked with Fourteen Fish which manages the appraisal process for GP trainees. We made awards to our first 23 *Changemakers* to acknowledge publicly the work of our early adopters.

We reached 5,000,000 people through our social media campaigns and 300,000 people visited our website www.actonaxialspa.com. Crucially, 36,000 people completed our online symptom checker, with more than 70% meeting the threshold for referral to rheumatology. The time to diagnosis survey established, for the first time, a UK-wide data set that disaggregates the journey from symptom onset to diagnosis. It indicates that the average time to diagnosis in 2024 is 7.4 years. Data generated by *Aspiring to Excellence* rheumatology teams show localised improvements in the time to diagnosis.

In summary, our work has created new momentum in the UK and a palpable sense of a community working together to reduce diagnostic delay. We have tested interventions and now have an emerging set of best practices / tested change ideas that are ready to be spread, underpinned by a compelling theory of change which we can evidence.

We are at a key moment in the campaign, a tipping point. We now seek to sustain the gains we have made, extend our reach, support patients to self-management in the year following their diagnosis, and embed our approach within the NHS.

Our vision

Our long-term vision remains the same - diagnosis within 12 months of symptom onset to optimise clinical outcomes, patient quality of life and economic productivity. To do this we need:

- A significant increase in awareness of the condition among HCPs and the general public.
- A critical mass of clinical leaders who will drive up health care performance in axial SpA.
- Widespread use of technology to ensure that axial SpA is higher within clinical reasoning and to support diagnosis.
- Routine use of pathways to ensure that patients are referred directly to rheumatology for assessment.
- Consistent use of agreed national protocols for imaging.
- Improved information and support to people in the year following their diagnosis.

Above all, we must continue to win hearts and minds, build further a social movement of people who want to work with us to create change, and scale up ideas that have shown demonstrable proof of concept.

How we will achieve this in 2025 - 2029

With the benefit of a new national data set on the current time to diagnosis we are in a position to set **two national improvement goals for the next five years** to inform policy development in the four UK nations and drive local service improvement:

- *To achieve a reduction in the average UK time to diagnosis for axial SpA from 7.4 years to 5 years by 2029.*
- *To improve the number of UK axial SpA patients diagnosed within one year from symptom onset, from 1 in 25 in 2024 to a minimum of 1 in 4 by 2029.*

To encourage widespread adoption of our ‘gold standard’ approach we will:

- **Create a ‘playbook’ for NHS organisations** to help them implement our approach and embed it within NHS systems and improvement programmes.
- **Create demonstration projects** that will implement the full package of activities in a co-ordinated way at local level, underpinned by a rigorous measurement framework. They will serve as exemplars in accelerating reductions in time to diagnosis and help NHS organisations make the case at local level for appropriate investment.
- **Strengthen our focus on data and scientific publications** to make the case for change to HCPs and policy makers.
- **Extend the programme’s focus and provide supported self-management to guide those newly diagnosed through the first 12 months after diagnosis.** We will help capacitate rheumatology departments to design and deliver supported self-management for their patients through place-based demonstration projects as well as through a core set of online resources.
- Continue with national campaigning, awareness raising, and influencing work.

Goal Two: To create and embed a gold standard approach to treatment and care, integrating lived experience and clinical perspectives

Our work in 2020 - 2024

There is a growing body of evidence showing variation across the UK in the quality of treatment and care for people with axial SpA, including that generated by the All Party Parliamentary Group (APPG) on Axial Spondyloarthritis which we established in 2019. These variations can impact on people's capabilities in managing their day to day lives.

In 2019 we created *Aspiring to Excellence*, the first at-scale quality improvement (QI) programme in rheumatology in UK, and to our knowledge the largest axial SpA QI programme in the world. Working with our technical partners at the NHS Transformation Unit, we delivered learning and coaching for multidisciplinary teams from around the country to work on local improvement projects, creating a locus and visibility for quality improvement in axial SpA.

Key achievements are as follows:

- We recruited 23 departments from around the country working on a wide range of projects covering diagnosis, physiotherapy services, employment, self-management programmes, flare clinics and the setting up of specialist axial SpA clinics.
- The network met quarterly throughout the last four years and our technical partner delivered coaching and webinars to teams and individuals to move their projects forward.
- NASS and the participating departments presented at the annual conferences of the British Society for Rheumatology (BSR), the British Society for Spondyloarthritis (BRITSpA) and the European Alliance of Associations for Rheumatology (EULAR), published research papers relating and gave oral evidence to the APPG on Axial Spondyloarthritis.

- We developed additional QI resources to allow those rheumatology departments not involved in the programme to be able to access QI support in axial Spa locally.
- We produced a first season of a Podcast series called *Rheum for Improvement*, which featured six episodes focussing on the achievements of the teams.
- We developed a blog series looking at individual projects and used these to encourage teams to share their data.
- All of our teams developed scientific posters which were displayed and discussed at an annual Celebration Event.
- We commissioned research called *What do patients need and value in the diagnosis, treatment and care of axial spondyloarthritis?*, which surveyed 900 people and we launched the report in the Houses of Parliament. We used the results to establish a set of values-based standards and a corresponding toolkit to help HCPs to implement them.

Our vision

Everyone with axial SpA receives an equitable standard of treatment and care, can have their treatment and care delivered in a way that suits them, and are supported to live their day to day lives by the healthcare system and wider community.

To do this we will:

- Establish what we mean by a Gold Standard in Treatment and Care, going beyond the existing clinical guidelines and standards.
- Ensure that the needs of people with axial SpA, their families and carers are well considered.
- Support HCPs to deliver the best service they can without increasing workload, and helping to streamline their offering.
- Establish regional and national co-operation and support to implement the Gold Standard.

How we will achieve this in 2025- 2029

Our approach will need to be multifaceted working at local, regional and national level:

- ***Create a Gold Standard in Treatment and Care for Axial Spondyloarthritis*** across the entire pathway following diagnosis, taking into account every element of life with axial SpA that should be covered within the healthcare system.
- ***Develop recommendations for the collection of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMS).***
- ***Run a national public consultation on the draft Gold Standard*** to ensure that the views of people living with axial SpA and health care professionals are considered.
- ***Publish a Gold Standard in Treatment and Care in formats applicable to different audiences*** such as people with lived experience, NHS managers/commissioners and those HCPs working at local level to improve axial SpA services.
- ***Support the implementation of the Standard*** by creating a toolkit and measurement tool for implementation to support departments, recognising the pressure that they are under, including the development of business support templates.
- ***Consider piloting a place-based intervention*** along the treatment and care pathway, partnering with an external organisation to deliver it.
- ***Propose a national minimum data set for axial SpA***.

Goal Three: To support and empower people to live well with axial SpA and feel part of a supportive community

Our work in 2020 - 2024

Information and support service

One of the main aims of NASS since its inception has been to provide guidance, advice and information for people affected by axial SpA, including families, carers and employers. Providing credible, reliable information in the right way at the right time allows people to understand their symptoms, the reasons for any tests or examinations, their management plan and how they should self-manage. This also enables patients to be fully engaged during consultations, playing an essential part in shared decision-making.

Everyone’s axial SpA journey is different, and we aim to provide information to help people during every step of their journey in a variety of formats. Someone looking for a diagnosis or who has just been diagnosed may never have heard of the condition or met anyone else with it. Our information needs to be simple, easily accessible, warm and empathetic.

After diagnosis, people may only see a member of their rheumatology team once a year. Additionally, their GP may know little about the condition. In order to self-manage effectively, it is imperative that people affected by axial SpA develop a good understanding of the condition and how they can manage it through medication, exercise and self-management techniques.

We have provided personalised support through our Helpline service since 2010 and in 2020 we doubled our opening hours. Each year we support 5000+ people this way. This includes support for people with axial SpA who want to claim disability benefits, with access to detailed guides for NASS members and personalised impact letters. We provide guidebooks, a magazine to members, a website. Our resources are also available on a YouTube channel, with subscribers growing by 258% during 2020-2024.

Self-management support

In 2020 - following a consultation process and in response to the COVID pandemic - we created the first phase of a supported self-management programme to ensure that everyone affected by axial SpA has the skills, confidence and knowledge to manage their condition optimally. The programme aimed to empower people to live well with the condition, connect patients with their local rheumatology team and reduce isolation.

We consolidated our early resources by setting up *My AS, My Life*, aiming to enable people to learn practical ways to manage their condition, as well as reduce isolation, by asking experts questions live and sharing their experiences. We ran 129 webinars live-streamed across social media, with 424,000 views and created a video library on the NASS website and YouTube channel. 74% of those surveyed found *My AS, My Life* very or quite useful.

In the next phase of the programme we worked with 48 rheumatology departments to run 60 regional online supported self-management sessions, reaching 1,600 people. Designed in collaboration with local HCPs, we designed these sessions to provide tailored education and peer support. This approach worked well during the pandemic when access to healthcare was limited. 92% of attendees surveyed found it helpful to meet others with axial SpA, 75% found the gaps between clinic appointments isolating and appreciated meeting their HCPs in the sessions, and 80% of attendees reported they understood more about managing their condition as a consequence of their participation.

Next, to support those who are newly diagnosed or who struggle to manage their condition, we established *Your SpAce* in 2023. It offers bite-sized, engaging information and lived experience content, with 22 videos and 10 downloadable resources. We sent promotional packs to 190 NHS hospitals to signpost their patients to Your SpAce. The webpages were viewed 38,000 times, videos watched over 21,000 times, and resources downloaded over 1700 times.

87% of people surveyed felt the *Your SpAce* videos helped them understand more about their condition, 80% reported having more practical skills, and 78% said they felt less alone after watching the lived experience videos. We additionally ran 21 *Your SpAce* online peer support meetups, with over 610 attendees. 65% of attendees had never met anyone else with axial SpA before attending a meetup and 96% reported feeling less alone afterwards.

We presented our work at national and international conferences and received an award by EULAR.

NASS branches

For over 40 years NASS has supported people to exercise confidently and safely through our NASS branch network. During the COVID pandemic all our branches had to close. Branches adapted and learned to run online sessions, supported local members through group communications such as WhatsApp and met up outdoors when regulations allowed. After the pandemic our local branch committees showed great resilience and tenacity in negotiations with hospitals and other venues, with the majority finally being able to return to sessions.

NASS membership

NASS has had a membership programme since our inception. By joining as a NASS member, thousands of people living with axial SpA can connect with each other, ask and answer questions and share advice. As a member, they are joining us in our mission to improve care and drive down the delay to diagnosis.

Our members' benefits include access to our thriving members forum, an annual copy of *AS News* magazine, free copies of our guidebooks, guides to claiming PIP and ESA benefits and an invitation to our annual Members Day where they can meet other members, vote in our AGM and influence the direction of the charity, and receive the latest advice on living well with the condition.

During 2020 – 2024 we achieved a 21% in growth in membership numbers despite some discontinuity of staffing and internal cost reductions. We had a programme of member engagement including periodic surveys and focus group consultations and encouraged branches to ensure that attendees also became members. We launched a membership campaign in 2020 which was hampered by the pandemic. We started to offer more exclusive content for members including webinars that were very well attended. We resolved problems with our website, recruiting hundreds of members as a consequence.

Our vision

We want people with axial SpA across the UK to understand their diagnosis and management, confidently navigate the NHS and be active partners in decisions about their treatment and care.

We want members to feel part of an engaged and supportive community, actively contribute to it, and feel well supported by NASS.

How we will achieve this in 2025 - 2029

Information and support service

We will continue to provide personalised support through our Helpline service and help those seeking to claim disability benefits, including access to detailed guides for NASS members and personalised impact letters. We know it can be difficult for people to reach out to a Helpline and we want to be more proactive in encouraging people to make contact. We will continue to provide credible and user-friendly information resources in a wide range of formats.

Self-management

In the first phase of our self-management programme we established some level of proof of concept. We will strengthen our impact data so that we can continue to learn and adapt our approach, pilot different content and delivery mechanisms as well as promote it to others. We will:

- Work with an academic partner to evaluate our work.
- Build in a validated outcome measures to evaluation activity.
- Co-produce and pilot new ways of delivering online supported self-management.
- Create a final *Your SpAce* module on activity and exercise.
- On the basis of positive evaluation results, promote it as a best practice example of online support for people recently diagnosed with axial SpA
- Continue growing and supporting our community through online *Your SpAce* peer support meetups.
- Continue running ad hoc *My AS, My Life* webinars to maintain an up-to-date video library.

NASS branches

We will support and motivate people to exercise confidently and safely, both independently and through our NASS branch network. We will:

- Ensure branches feel supported by NASS. Our branches are run by volunteers and we want to make the work they do enjoyable and stress-free. We will regularly reach out to branches asking them to let us know if we can help in any way, especially in terms of promoting the sessions to local people with axial SpA and helping them navigate difficulties with members, physiotherapy provision or venues.
- Maintain and expand the branch network.
- Work to develop more NASS affiliated groups.
- Continue to offer a diverse range of materials to help people exercise confidently and safely and develop new and updated exercise resources to meet the needs of our diverse population of patients.

We will continue to build an axial SpA community through regular online meetups, sessions, webinars and our NASS branch network. We want everyone to feel welcome in our community.

Membership

We aim to grow membership numbers over the next five years by 30% and will:

- ***Review our membership offer*** to maximise recruitment, retention and satisfaction.
- ***Develop a membership recruitment campaign***, with new collateral demonstrating its features and benefits.
- ***Reduce membership attrition*** by continuing to improve the members area of the website and create four sets of tailored membership journeys – new members, one year plus members, five years plus and lapsed members.

- ***Encourage members to make regular use of the NASS online forum***, as well as connect through social media, and share their stories to inspire and relate to other people living with axial SpA.
- ***Offer more exclusive member webinars*** following on from a successful pilot webinar in 2024.
- ***Run more face-to-face community events across the UK*** to engage and support our members.
- ***Review membership support platforms*** to ensure that we provide an optimal experience.

Goal Four: To influence, advocate and educate for axial SpA

Our work in 2020 - 2024

Axial SpA is not a rare condition, and yet awareness amongst a range of stakeholders is low including HCPs outside of rheumatology, policy makers and Parliamentarians. Greater awareness is critical to achieving earlier diagnosis and improved treatment, as well as social and work outcomes. Colleagues in rheumatology and beyond should feel supported by NASS to deliver the best possible information and support to their patients. Establishing and building relationships is a key part of our influencing work and helps to build our credibility in the rheumatology, musculoskeletal and wider health care environment.

Our work with HCPs outside rheumatology has grown significantly in the past five years, most recently as part of the *Act on Axial SpA* campaign. We:

- Set up a new Peer to Peer Network, made up of 160 HCPs from a range of backgrounds, providing monthly webinars on different topics and an opportunity to share ideas and issues.
- Delivered bespoke educational sessions to specific groups, working with other organisations, such as the Royal College of Chiropractors, Physio First and MIMS.
- Delivered locality Peer to Peer meetings for groups of HCPs working in a specific area.
- Developed a toolkit for the diagnosis of axial SpA, as well as template presentations that can be used by HCPs to educate their peers.
- Established the *Changemaker* Awards to recognise those who are working to reduce the time to diagnosis.

We strengthened key relationships and extended our reach within the broader rheumatology and MSK community:

- We maintained relationships with key stakeholders including the British Society for Rheumatology, the Chartered Society for Physiotherapy, the British Society for Spondyloarthritis, Primary Care in Rheumatology, the Royal College of Chiropractors, the Institute of Osteopathy, and the MSK Partnership.
- We were actively involved in regional axial SpA and rheumatology networks.
- We significantly improved our presence at HCP conferences.
- Professional bodies and regional networks helped to raise our profile amongst new audiences and professionals early in their career.
- We showed support for colleagues in the NHS at a time when it is under significant pressure.
- We co-created regional self-management sessions and helped to build stronger relationships locally between rheumatology departments and NASS branches.

We lobbied and campaigned at national level:

- We set up an All Party Parliamentary Group on Axial Spondyloarthritis in 2019 and ran 11 meetings.
- We published two national inquiries looking at the provision of axial SpA services measured against the National Institute for Health and Care Excellence Spondyloarthritis Guideline (*NG65: Spondyloarthritis in over 16s: diagnosis and management*).
- We also published a hydrotherapy manifesto, a set of minimum service specifications and an article in *The Lancet Rheumatology.*
- The Chair of the APPG secured an adjournment debate in the House of Commons on delayed diagnosis and a Westminster Hall debate on World Arthritis Day.
- The Health Minister cited our economic analysis in a second Westminster Hall debate covering musculoskeletal health and work.

- We met with two Health Ministers to discuss the time to diagnosis and hydrotherapy provision following the pandemic.
- After the 2024 General Election we held a parliamentary roundtable to shape a NASS response to the newly formed government’s 10-year plan for the NHS and to help inform our future Parliamentary activity.
- We supported work with NHS Wales through its new Musculoskeletal Network. We worked closely in the early stages with the national leads, and contributed to the MSK Framework which will form the basis of the work going forward.

Our general communications evolved over the last five years:

- We created a new visual identity as well as sub-brands for *Act on Axial SpA* and *Aspiring to Excellence*, developed a much stronger story-led approach and extended our of social media channels.
- We embraced new channels including Instagram and WhatsApp to widen our reach and engage new audiences.
- We secured coverage in the national press, providing case studies for stories around diagnosis and living with axial SpA.
- We appeared on a national television news programme to discuss the delay to diagnosis and living with axial SpA.
- We ensured a strong presence on specific themed days, including World AS Day, World Arthritis Day and Bone and Joint Week.
- We supported our sister charities, umbrella bodies and professional organisations with their national campaigns including osteoporosis, health inequalities and home care services.

Our vision

We want axial SpA to be recognised by a broad range of health care professionals and healthcare policy makers to embed axial SpA in national guidance and standards in order to ensure timely diagnosis and holistic care.

How we will achieve this in 2025 - 2029

Health care professional education and awareness - we will:

- Deliver HCP education across all four nations, including in primary care, rheumatology, other secondary care services such as ophthalmology, and private practice (physiotherapy, osteopathic, chiropractic).
- Support professional bodies and Royal Colleges to develop core rheumatology training, ensuring axial SpA is embedded and considered at both under-graduate and post graduate level.
- Ensure that the *Act on Axial SpA* Toolkit is up to date, easy to access and focussed on the most critical tools.
- Run national and locality online peer to peer meet ups that bring together a variety of HCPs working across, primary care, secondary care and private practice with educational webinars and discussion on topics important to diagnosing and treating axial SpA.

Health care professional engagement and support - we will:

- Work closely with professional bodies to gain their endorsement, confidence and help NASS to strengthen our credibility.
- Promote our work to HCPs at national and international conferences and events, providing speakers and leading sessions.
- Showcase examples of good practice and achievements through the *Changemaker* Awards.
- Help already engaged HCPs to develop further improvement work.
- Support research projects by providing patient and public involvement centrally and through our members.
- Support our branch physiotherapists to deliver their sessions by connecting them with AStretch and help them to attend axial SpA specialist physiotherapy courses.

At a national policy and parliamentary level - we will:

- Establish a network of MPs in England who are seen to be key influencers in health, with the possibility of re-establishing the All Party Parliamentary Group on Axial Spondyloarthritis.
- As the Musculoskeletal and Rheumatology Networks gather momentum with NHS Wales, seek support within the Senedd.
- Maintain and grow engagement with the Cross Party Group for Musculoskeletal Conditions and Arthritis in Scotland.
- In England: Work towards national implementation of the *Act on Axial SpA* 'Playbook' & contribute to the NHS 10-year plan consultation.
- In Wales: Work towards national implementation of the 'Playbook' as part of NHS Wales Executive MSK Network & collaborate on all relevant pathways.
- Prioritise opportunities in Scotland and Northern Ireland as they arise.
- Contribute to national consultations from government and arm's length bodies to make sure the voices of people with axial SpA are represented.

Communications - we will:

- Build on our social media presence with a continued move from broadcast to social mode with the aim of building our online community.
- Keep up to date with new developments and channels in social media to ensure we keep our audiences engaged.
- Use the stories of people living with axial SpA to demonstrate the day to day realities.
- Form a Communications Board, made up of volunteers who are members of the NASS communities and professionals in the field, to ensure that we have a strategic focus.
- Continue to work with other organisations to support their campaigns, and maintain our presence on key dates such as World AS Day, World Arthritis Day and, Bone and Joint Week.

Goal Five: To ensure that NASS is able to deliver its ambitious programmes

Our work in 2020 - 2024

Income generation and financial management

Over the last five years we generated £4,468,654. The main areas of income growth were industry funding (£1.7m), fundraising (£437k), donations (£424K) and trusts (£405K). Legacy income generated £518,000 overall, with lower income in 2022-2024. However, the number of people who pledged to leave a gift in their will increased.

We made significant improvements to our fundraising systems, processes and resources, including: an updated website; new and updated fundraiser on-boarding and stewardship processes for challenge event fundraisers, community fundraisers and legacy pledgers; the integration of our Customer Relationship Management system with multiple fundraising and donation platforms; new and updated branded online portals and platforms to facilitate specific fundraising opportunities; a new fundraising board; and an updated pipeline of prospects and template applications and impact reports for core funding from charitable trusts.

We strengthened financial management, developing clear, easy-to-understand financial reports and analysis. Better historical data now enable more effective forecasting and progress tracking. We established collaborative budgeting with project managers and introduced stronger financial controls, including double approval and consistent expenditure coding. These improvements provide a solid foundation for our growth.

Recent years have been challenging for the fundraised income of charities with the double impact of the COVID pandemic and the cost of living crisis.

However, the most recent annual status of fundraising report[2] gives some cause for greater optimism. Intention to give is at its highest level since 2020 with 78% of the public intending to give. The report emphasises that a strategy to diversify fundraising income is crucial to growth, and that being digitally mature can ‘significantly enhance performance by enabling charities to better navigate the increasingly digital-first landscape’. It also stresses that effective data management is key to income growth.

Another recent sector report warns of the potential for ‘digital moats’ whereby large charities dominate in fundraising through their use of Artificial Intelligence (AI), unless the sector as a whole moves towards rapid, safe adoption of AI[3].

Therefore, a key priority for our future fundraising work is to embrace the predictive analytic potential of AI and use it to create well-targeted digital-first campaigns.

Data, insight and research

Over the last five years we created large-scale programmes each of which produced a range of data. In order for our work to be credible to HCPs and policy makers our results need to be robust, defensible and published in scientific journals. We have made good progress in the last three years in publishing some of this work, but now need to accelerate progress. In addition, our data, insight and research foundations need to be strengthened in multiple ways across the organisation if we are to create maximally robust results and use them to make the case for better diagnosis, treatment and supported self-management.

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[2] *The Status of UK Fundraising: 2024 Benchmarking Report*, Blackbaud

[3] *Charity Fundraising Trends, 2024*: Charity Excellence Framework

Information technology

NASS operates with a client/cloud infrastructure design. There are no internal servers - all services are provided by trusted cloud providers (Microsoft, Sage & Salesforce). Modern devices are managed through Microsoft 365's InTune and Connectwise RMM (provided by third-party IT Support). The current infrastructure is well-suited to our needs. We have a policy for regular device replacement cycle as hardware ages or fails. Overall, there is a strong foundation of cloud-based services that support both office and remote working.

Staffing and ways of working

Over the last five years we have recruited specialist staff to manage new programmes. We developed our communications capability and capacity to strengthen our brand, messaging and marketing, but had to make cost reductions in 2022 and 2023 because of the negative impact of the macro-economic environment on our income. Recently, we employed a full-time research fellow. We established a staff charter which sets out of our ways of working and set up internal and external project boards to create a consistent approach to programme management. We established remote and hybrid working for staff.

Our vision

A financially sustainable organisation that generates the income required for full delivery of the strategic plan, manages its assets effectively, meets its financial obligations and follows best practice and regulation in financial management.

A data-driven organisation, able to harness its insights and results to inform healthcare policy and practice, with the depth and breadth in staffing and programming capabilities and internal systems to continue to deliver substantial, impactful work.

How we will achieve this in 2025 – 2029

Improving our fundraising capability

Leverage donor data effectively - we will use an AI system to develop predictive analysis to inform fundraising campaign development, grow our regular givers, reactivate lapsed donors, as well as offer a higher degree of donor personalization. It will also free up staff time for additional membership and fundraising activity.

Ensure digitally mature fundraising - we need to become digitally mature in fundraising and build in specialist capability to design and deliver more effective digital marketing. Doing so will enable us to grow income in the areas of donations and community and events fundraising. With new marketing strategies and collateral including compelling case studies and impact data, a clear and compelling vision and consistent communication.

Delivering income growth

With enhanced fundraising capability and capacity, we will grow our income by a minimum of 6% per annum. With inflation estimated at 2-3% p.a., this represents around 3% real growth p.a.:

- We aim to sustain industry funding at current levels, but will seek to grow the number of industry partners
- We will grow income from fundraising by 10% p.a.
- We will grow income from donations by 20% p.a., broadening our donor base, growing the number of committed givers to maximise sustainable income, and enhancing gift value and frequency of gifts
- We aim to sustain trust income at current levels. However, we have been successful in recent years in securing larger grants. With a growing track record in delivering impactful larger programmes (and having more robust data to demonstrate impact) there is scope for further growth.

- We will grow membership income by 30%, reducing attrition and attracting greater numbers of new members
- We aim to sustain legacies at current levels, given the unpredictability of this income stream. We will continue to grow the number of people making legacy pledges and ensuring that we continue to cultivate warm relationships with those who have made a pledge to NASS
- We will grow trading income by 25% by introducing a monthly lottery.
- We will introduce a corporate membership scheme aimed at pharma and other corporates

Financial management

Ensure compliance in financial reporting and controls - we will review all financial policies on a biennial basis, incorporating changes to regulatory compliance from the Charity Commission, Office of the Scottish Charity Regulator and the Fundraising Regulator.

Continue to maintain cost efficiency – we will regularly review current suppliers to ensure we are getting competitive rates and ensure that there is clear guidance with regard to financial thresholds for open and limited tendering.

Continue to improve financial processes – we will streamline or automate financial processes to increase efficiency and accuracy and conduct a biennial review of financial procedures.

Strengthen financial management - we will further improve our budgeting and forecasting through better use of historical data, scenario planning and working closely with budget holders. We will continue providing clear financial reports tailored for our trustees, funders, and regulators.

Maintain cash reserves at appropriate levels – free cash reserves will be maintained at a minimum level of 6-9 months of operating costs. Fixing reserves at this level reflects the facts that some of our income is unpredictable and many of our costs are fixed. We will create a procedure for actions when reserves fall outside of these levels.

Ensure effective asset management - reserves in excess of six months will be held in fixed-term savings account. We own two apartments which will continue to be rented out at market rates. We will ensure that the Intellectual Property for all work undertaken by NASS is owned by NASS.

Ensure that staff and trustees have appropriate finance training – we will provide financial management training which will include financial roles and responsibilities for budget holders, basic financial literacy training to help everyone understand our financial reports and processes and specific training for trustees on their financial oversight responsibilities.

Data, insight and research

To maximise the potential for our work to make the case for specific changes in axial SpA care we will focus on the following:

- **Stay abreast of the latest research in axial SpA** in order to shape our strategy and business development, inform our policy work and undergird fundraising proposals.
- **Ensure that all of our work is data-driven.** We will build a data strategy into the design of each new programme, so that study designs meet the standards for publication in scientific journals and survey instruments will allow a range of sub-analyses. We will build a research strategy for the use of our symptom checker data and journey to diagnosis of people once they have completed the checker. We will grow the time to diagnosis audit and build a portfolio of publications from it. We will create partnerships with academic organisation and seek research funding to evaluate our work wherever we can.
- **Harness insights across our work** including metrics relating to our social media channels, websites, members, fundraisers and supporters.

- **Our research and data will be used to inform NHS health policy and clinical practice**, with a publications strategy and portfolio of studies published from across our work.
- **We will create an organisational culture that is research and insight literate**, introducing data deep dives, a research journal club, and providing training to relevant staff to ensure competent use of our systems.

Information technology

We will maintain and optimise our current cloud-based systems rather than making major changes. We will ensure our existing technology remains secure, up-to-date, and efficient through regular updates and staff training. We will embrace new technologies – including those based on AI – where they clearly benefit our work. We will ensure access to research software to enable literature searching, reference management and statistical analysis.

Staffing and ways of working

We will periodically review our team charter and continue to work through project boards for our larger programmes. We aim to build new staffing capability in the areas of data and insight, volunteer management, communications and, policy and public affairs as our finances improve. We will continue to review all HR policies on an annual basis. We will build a volunteer management plan.

Governance

We will review Board level governance against Charity Commission guidelines. New trustees will continue to receive an induction. Trustees will be encouraged to contribute the work of NASS outside of committee meetings and will be supported to do so. We will introduce a new risk management framework.