NASS

Driving Improvements in Axial SpA Services

Building Strong Foundations Through *Aspiring to Excellence*

In partnership with

BRITSPA
British Society for SpondyloArthritis

Sponsored by

abbvie Biogen Lilly NOVARTIS ucb Inspired by patients. Driven by science.

About NASS

We are the National Axial Spondyloarthritis Society (NASS) and we transform the diagnosis and care of people living with axial spondyloarthritis (axial SpA).

It's an invisible and misdiagnosed condition, often leaving people feeling powerless, in increasing pain and extreme exhaustion.

So we campaign policy makers for early diagnosis and better services. We work with the NHS to get axial SpA identified and diagnosed quickly and we're determined that everyone receives effective care.

We make sure people with axial SpA get the latest information and the support they need to tackle living with this condition.

And we build an active community, online and through our local branches across the UK.

Axial SpA works silently. We don't.

Together we are stronger

Each year at NASS we help thousands of people live well with axial SpA by:

- Campaigning to end the unacceptable 8.5 year delay to diagnosis
- Providing information, videos, guides and resources to help people tackle the challenges of living with the condition
- Campaigning policy makers and building political pressure to ensure axial SpA gets the attention it deserves
- Working with the NHS to ensure people get effective care and access to vital healthcare services
- Building communities, through our branches across the UK, through our network of members and online, so no one need feel alone with the condition.

NASS receives no statutory funding and relies on the generosity of our fundraisers, donors and corporate partners to fund our life-changing work.

Go to www.nass.co.uk to find out more.

Acknowledgements

NASS would like to thank all of the rheumatology staff who shared their reflections about their participation in the *Aspiring to Excellence* programme during interviews in August and September 2021. The rheumatology teams work at:

- **Chapel Allerton Hospital, Leeds Teaching Hospitals NHS Trust**
- **NHS Fife**
- **Newcastle upon Tyne Hospitals NHS Foundation Trust**
- **Royal Berkshire NHS Foundation Trust**
- **Sheffield Teaching Hospitals NHS Trust**
- **University Hospital Southampton NHS Foundation Trust**

We're especially grateful to all of the teams for remaining engaged with the programme despite the many challenges of the coronavirus (COVID–19) pandemic.

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Contents

Introduction

This report summarises the progress of six rheumatology teams in the first year of their participation in *Aspiring to Excellence*, a quality improvement programme led by NASS.

Aspiring to Excellence is designed to encourage and recognise service improvement in axial spondyloarthritis (axial SpA) care, and is a strategic partnership between NASS, BRITSpA and sponsoring companies AbbVie, Biogen, Lilly, Novartis and UCB. Through a competitive award process, *Aspiring to Excellence* provides tailored, expert support delivered by the NHS Transformation Unit and a multi-site learning environment, to help rheumatology teams catalyse improvements within their departments. This national network of participating centres explores novel approaches to care, with the aim of informing, encouraging and supporting national changes in axial SpA service provision.

The programme 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[1]. In 2019 we worked with Parliamentarians to create an All–Party Parliamentary Group on axial SpA to create national oversight of the Guideline implementation. So far we have published two national inquiries with robust sets of recommendations which led to Parliamentary Questions and a debate. In 2021 we launched Act On Axial SpA with the aim of reducing diagnostic delay and achieving a Gold Standard time to diagnosis of one year[2]. As part of the implementation of Act On Axial SpA, in 2022 we will launch a primary care clinical champions programme and an educational initiative aimed at secondary care (non–rheumatology) services, as well as publish new research into the full economic costs of delayed diagnosis. Together, these initiatives use multiple change levers – system focussed and people focussed; top down and bottom up – to improve axial SpA diagnosis and treatment.

Aspiring to Excellence is happening at a very challenging time for the NHS generally and rheumatology specifically. The COVID–19 pandemic has resulted in significant stress to the NHS and its staff. It led to the temporary redeployment of rheumatology teams, the reduction of services and even closure of departments. The recent Getting it Right First Time (GIRFT) Rheumatology report[3] paints a picture of fragility in current service provision nationally, including an imbalance between capacity and demands in many NHS Trusts, a failure to meet quality standards

[1]National Institute for Health and Care Excellence. Spondyloarthritis in over 16s: diagnosis and management NICE guideline [NG65]. 2017.

[2]National Axial Spondyloarthritis Society. Act on axial SpA: A Gold Standard time to diagnosis. 2021. [Available from: www.actonaxialspa.com]

[3]Kay L, Lanyon P, Macgregor A. Rheumatology: GIRFT Programme National Specialty Report. 2021.

for early assessment and treatment of inflammatory arthritis, lack of widespread referral management systems and significant workforce challenges.

Yet despite these challenges, there is reason for optimism. Our case study interviewees report significant adaptability, resilience and teamwork in the face of the unexpected challenges that COVID–19 brought. They were able to turn adversity into opportunity – harnessing digital solutions and innovative new ways of working – in rapid response to the pandemic.

Above all, our first six participating departments have demonstrated an impressive ability to stay engaged with the programme despite the pandemic, and implement many of their planned improvement initiatives.

They have:

- **Trained community–based physiotherapists, leading to improved rheumatology referrals**
- **Implemented an inflammatory back pain (IBP) pathway from primary care**
- **Introduced an MRI spine IBP protocol to reduce variation in imaging**
- **Established a tertiary referral service which has improved time to diagnosis**
- **Implemented mental health interventions for patients which have reduced the percentage of patients with abnormal Hospital Anxiety and Depression Scale scores**
- **Established a pathway for physiotherapy self–referral and reduced physiotherapy Did Not Attend (DNA) rates**
- **Used audit to make the business case for an extended scope practitioner.**

Our approach

Background to *Aspiring to Excellence*

The first six teams started their *Aspiring to Excellence* journey at the end of 2019. During their first year, despite a multitude of challenges caused by the COVID-19 pandemic, each team has adapted and collaborated to implement ambitious projects within their services.

Programme design

The programme design is underpinned by the following:

- **A framework for management grounded in systems theory:** W. Edwards Deming's System of Profound Knowledge[4]
- **A learning system that brings healthcare organisations together:** the Institute for Healthcare Improvement's (IHI) Breakthrough Series (BTS) Collaborative[5]
- **An approach and set of tools to develop, test and implement changes leading to improvement which is based on Deming's theoretical framework:** the Model for Improvement (developed by the Associates in Process Improvement) [6]

Deming's System of Profound Knowledge

Deming's System of Profound Knowledge contains four component parts which *Aspiring to Excellence* covers over the first year of the programme:

- **Appreciation for a system:** an organisation is composed of interrelated connections and interactions rather than discrete and independent departments governed by chains of command. The root cause of most problems lies within the system, so the most effective way to improve care is to improve the system.
- **Knowledge of variation:** common cause variations are natural variation in processes and outcomes, whereas special cause variation is unusual behaviour caused by factors affecting the system in a non–random way. Distinguishing the differences, and understanding their cause, is key to improving performance.
- **Theory of knowledge:** how do people think and act, based on what they believe to be true? We learn better when we predict, which forces us to think ahead to the proposed outcomes.
- **Psychology:** people are primarily motivated by their 'intrinsic' needs such as working with others to achieve goals and taking pride in their work, rather than just monetary reward.

Our aim is to develop participants' understanding that the application of the System of Profound Knowledge to their axial SpA subject matter expertise will unlock knowledge for improvement.

The Breakthrough Series (BTS) Collaborative model

The BTS Collaborative model was first designed in 1994 and has been successfully tested/implemented across various healthcare sectors internationally. It provides a structured programme that brings together organisations to work on a specific topic area. It is made up of a mixture of learning events where teams learn improvement theory and apply that directly to a project in their environment, and action periods where teams test their change ideas. Teams in such Collaboratives have achieved wide ranging improvements for health and care services, with the IHI citing improvements in reducing waiting times by 50%, reducing worker absenteeism by 25%, reducing Intensive Care Unit costs by 25%, and reducing hospitalisations for patients with congestive heart failure by 50%[7].

The Model for Improvement

The Model for Improvement provides a simple but effective approach to applying the fundamentals of quality improvement (QI) and testing change within a project. Participants first seek to clarify the problem they are trying to solve by utilising root cause tools and collecting baseline data, before clearly articulating their QI aim. Clear measurement–for–improvement plans are created with change ideas developed through qualitative and quantitative analysis, before tests of change are planned and implemented utilising the Plan–Do–Study–Act (PDSA) cycle methodology.

PDSA cycles are based in scientific method and moderate the impulse to take immediate action with the wisdom of careful study[8]. Through this rigorous structured approach, *Aspiring to Excellence* teams are confidently able to implement tested change ideas that respond to the root cause of the problem.

The programme also builds upon principles identified through lessons learnt from the application of QI in the NHS, including ensuring senior support for participation in the programme, organisational support for teams to have time freed up to deliver their projects and attend events, and appropriate time for improvements to be developed and implemented[9].

[4]Deming WE. The new economics for industry. Government, Education, Massachusetts Institute of Technology, Cambridge, MA. 1993;1:235.

[5]Institute for Healthcare Improvement. The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement. 2003.

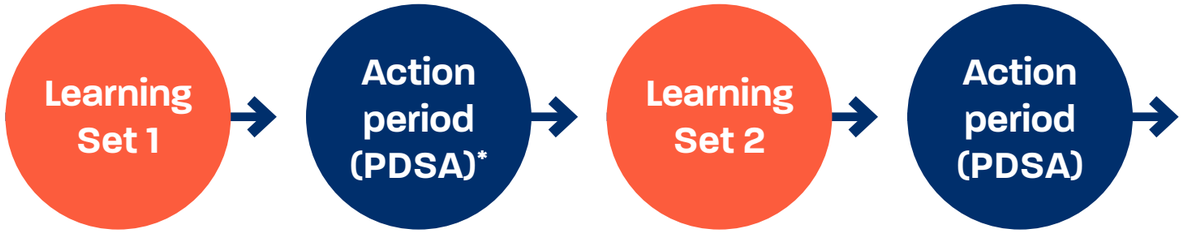
[6]Langley GJ, Nolan KM, Nolan TW, Norman L, Provost LP. The improvement guide. San Francisco: Jossey–Bass. 1996.

[7]Institute for Healthcare Improvement. The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement. 2003.

[8]NHS England and NHS Improvement. Quality, Service Improvement and Redesign Tools: Plan, Do, Study, Act (PDSA) cycles and the model for improvement. 2021. [Available from: www.england.nhs.uk/wp-content/uploads/2021/03/qsir-plan-do-study-act.pdf].

[9]The Health Foundation. Building the foundations for improvement: How five UK trusts built quality improvement capability at scale within their organisations. 2015. [Available from: www.health.org.uk/publications/building-the-foundations-for-improvement].

Our programme structure, in line with the IHI design, is shown below

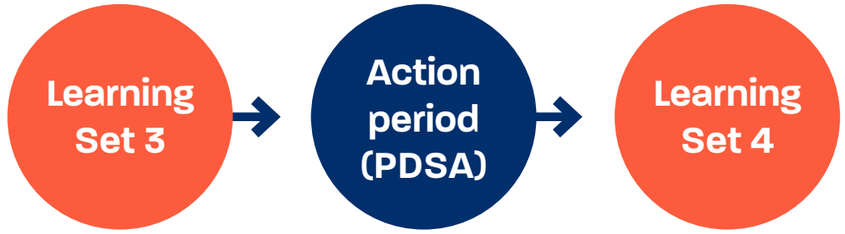


1. Learn about your **fellow teams**
2. Understand the basics of the **model for improvement**
3. **Your project** – aims, changes you can make, measures of success
4. **Plan** for Action Period 1

1. Collect your **baseline data**
2. Become crystal clear on the **problems** you are trying to solve

1. **Share** successes and lessons learnt
2. Think creatively about how to **solve your problems**
3. Develop your **change ideas** and how to test them
4. **Plan** for Action Period 2

1. **Test** your first change ideas
2. Collect the **data** to know if it's been successful



1. **Share** successes and lessons learnt
2. **Analyse** tests of change
3. Plan next steps – how can you **sustain & spread** your changes?
4. Present data in **accessible ways**
5. **Plan** for Action Period 3

1. **Implement** new tests of change
2. **Scale up** successful tests

1. **Celebrate** successful changes and articulate benefits
2. **Share** lessons learnt

*PDSA: Plan-Do-Study-Act

Programme delivery

Aspiring to Excellence utilises four component elements to support QI skill development and service improvement. The first three elements relate to the Learning Events and the fourth to the Action Period.

The first approach is **educational input;** whereby teams meet as a group four times a year and the NHS Transformation Unit provides QI content for the teams to apply to their own services. Working examples of how the theoretical framework can be used in practice are also provided.

The second is, critically, to provide **protected project time** for teams to work on their projects. *Aspiring to Excellence* provides teams with precious time away from their clinical and operational roles, applying the QI methodology to a project that will make a difference for patients and for staff.

The third approach is to provide **networking opportunities** (both facilitated and unfacilitated). The teams have so much knowledge that time to share this and learn from each other is vital. We celebrate success and learn when things don't go as we expect. It is a well–recognised QI saying that there is no such thing as failure when you are testing improvement ideas, you have simply learnt more about your system.

The fourth approach takes place in the Action Periods between the Learning Sets where the NHS Transformation Unit meets with each team for a 1:1 **Improvement Coaching** session. This can take many different forms, from the team presenting the work to date and discussing pitfalls and recognising progress, to tackling a specific challenge or issue. Our role here is to be a critical friend, a champion of the team, a supporter, QI expert and a facilitator.

Key lessons from the first year of *Aspiring to Excellence*

Background

Team members from each of the six organisations were interviewed in August 2021 to gain a deeper understanding of their motivation for applying to the programme, the steps they took to drive QI in their axial SpA service, and the impact that they had on the service. Each organisation was also asked to provide some advice for other organisations and key lessons, which are now summarised in this report.

The theory works: Having a tried and tested transferable theoretical framework provides a strong basis to build improvement work

Although some of the participants had QI experience or knowledge prior to the programme, what they found valuable is that *Aspiring to Excellence* formalised and solidified that knowledge. It provided a structured, logical, transferable framework to work from and apply to their improvement projects. Participation provided critical time to strengthen their QI knowledge and skills and build their foundations for improvement. They reported confidence in applying this knowledge beyond the programme and into other areas of rheumatology. Marjorie Godfrey (MS, RN) of The Dartmouth Institute for Health Policy and Clinical Practice once said that "Improvement in healthcare is 20% technical and 80% human". Providing a framework through *Aspiring to Excellence* ensures technical capability is developed in a standard way to support consistency and sustainability in delivery.

Recognition is important: Being part of an acknowledged, competitive programme creates a sense of accountability and motivation

The badge of participating in a national, competitive programme was reported to be useful – providing acknowledgement for the work and to demonstrate to colleagues and patients that the team is committed to QI. We also know that this can facilitate wider support for programmes of change for senior organisational leaders, which is often vital to the success of planned change programmes[10].

Apply the tools: Take the time to utilise QI tools such as PDSA cycles and driver diagrams, to understand fully the problem and then construct improvement aims

The teams were positive about the usefulness of driver diagrams and PDSA cycles to understand fully the problems in their service, and break down the larger overall aims into logical, digestible, structured smaller projects and goals – key to developing an efficient, achievable, and successful work plan. Having broken the problems down, the teams could then set aside small, regular chunks of time to work on their QI goals as a team.

Measurement is essential: Understand the baseline and set–up efficient processes to collect further data to demonstrate change

Interviewees spoke about the importance of ongoing data collection to make the case for change and demonstrate that it had happened – to develop powerful stories to use with patients, with managers and in clinical work. It was important to get data collection set up early on to collect a baseline position, demonstrate the problem, adapt solutions accordingly and ensure efficient processes down the line to reduce burden on already busy, under–resourced staff. Data interpretation can also be used to provide evidence for much needed investment in additional resources – as demonstrated for physiotherapy services in Sheffield, whereby the extended scope practitioner role was made permanent, in part due to data collected through *Aspiring to Excellence* demonstrating a need for such a role. Measurement is one of the key parts of the Model for Improvement, ensuring change is evidenced and improvements are identified.

> **"All improvement will require change, but not all change will result in improvement[11]"**

[10]Kaplan HC, Provost LP, Froehle CM, Margolis PA. The Model for Understanding Success in Quality (MUSIQ): building a theory of context in healthcare quality improvement. BMJ Quality & Safety. 2012;21(1):13-20.

[11]Langley GJ, Nolan KM, Nolan TW, Norman L, Provost LP. The improvement guide. San Francisco: Jossey–Bass. 1996.

"You're always keen to get going, however allowing yourself the time and space to make a plan, ensure that you are collecting appropriate outcome measures/ data, and being efficient is really important. Although inevitably, the data that you need to collect often becomes more obvious as you go through and will likely be more accurate in your second, third cycles."

Dr Ben Thompson, Consultant Rheumatologist

The importance of team and structure: Build in regular contact & project updates to maintain momentum/enthusiasm and ensure clarity of project aims – perhaps even more so in trying times

Prioritising or formalising (e.g. through regular MDT meetings) the time to talk with colleagues, both local and national, was identified as critical to success – to learn from each other, engage colleagues and brainstorm ideas. Making the time for face–to–face meetings away from the hospital was seen to be beneficial because, with virtual meetings, there is always the temptation not to attend if you are extremely busy. Face–to–face meetings means that the time is ringfenced/ formally booked off, to get away from the usual clinical setting and be more motivated and engaged in other discussions. Keeping an updated, running record of everything you have done and when you did it, within a single document, was also seen as useful to reflect upon in these meetings – important for tracking progress and further motivating the team.

Engagement is key: Collaborate with wider team members and other stakeholders

Improvement projects provide a way of enthusing trainees to get involved, to be engaged with spondyloarthritis and be enthused about having this as their sub–specialty in rheumatology. Collaboration with service managers, administrative staff, occupational therapy, gastroenterology, radiology etc. should happen early to explain the improvement goals and their value.

"It's an incredible opportunity to be part of this three–year national programme; to have the support from QI experts and learn tools to help make changes in the way we deliver care for our patients and then test and re–test these changes through regular PDSA cycles. I am looking forward to moving into year two of the programme and seeing what further changes we can make to benefit the service and our patients with axial SpA."

Jacqui Tomkins, Rheumatology Specialist Physiotherapist

Improving time to diagnosis through community–based physiotherapy

Newcastle upon Tyne Hospitals NHS Foundation Trust

Setting the scene

The multidisciplinary SpA team at the Freeman Hospital run a specialist axial SpA physiotherapy self–referral and self–management programme. They were keen to expand this into their community–based physiotherapy and intermediate care service called TIMS (Tyneside Integrated Musculoskeletal Service) which recently replaced their in–hospital physiotherapy team.

They therefore joined *Aspiring to Excellence* with the following aims:

- To improve the ability of TIMS to identify axial SpA within the community; to improve the quality of referral and the time from referral to diagnosis
- To improve the overall health of patients with axial SpA by implementing an annual review, as well as reviewing the methods for delivering services and investigating innovative ways of working.

Why did they get involved in the programme?

The team had clear goals to work on and were inspired by the opportunity to collaborate with NASS on these ambitions, while pooling resources with other teams interested in axial SpA. The programme offered the opportunity to focus and drive their work forward, and help the team to work smarter and more effectively. They wanted to feel motivated as part of a formal programme, to improve outcomes through a QI approach, and have a sense of being both supported and held accountable.

What did they do?

The team created driver diagrams to guide their service changes and then used PDSA cycles to implement their improvement projects. The patient journey was mapped, identifying the referral source of patients with suspected axial SpA. Training of TIMS community–based physiotherapists was then implemented, including a briefing on the importance of identifying axial SpA and a recommendation to use screening criteria – specifically, the Assessment of Spondyloarthritis International Society (ASAS) Expert Criteria for Inflammatory Back Pain (IBP) Assessment. The quality of referral from TIMS was then assessed, as well an assessment of the use of the ASAS Expert Criteria. Delays in time from referral to first appointment in the extended scope physiotherapist IBP clinic were assessed. Other work within year one included the development of Newcastle's existing annual review process so that it could be integrated into the new electronic patient record, with collated information on comorbidities and additional health checks. Innovative ways of working were explored, including a hybrid virtual/in–person model of care and use of ePROMs – the process much accelerated as an inevitable response to the COVID–19 pandemic.

"The driver diagrams have been really helpful to write down and will permeate the way that we work throughout the rest of our careers. But also, just to realise that the way to get things done within the NHS is to demonstrate the change. These are really powerful stories that you can use with patients, with managers, and in your clinical work."

Dr Ben Thompson, Consultant Rheumatologist

What impact have they had?

Axial SpA referrals from TIMS have improved

Relationships with TIMS have been strengthened, with a monthly pathway meeting implemented to maintain and continue service improvements. TIMS have been equipped with the knowledge and skills to identify and refer IBP patients. An effective method of screening by TIMS physiotherapists has also been implemented, resulting in timely, appropriate referrals into Newcastle Rheumatology.

Service redesign and innovative new ways of working have been achieved

Over the challenging past year, the team have maintained an accessible, safe, comprehensive service for people with axial SpA, including a strengthened telephone advice line and a re-organisation of the service. The team has been further enhanced through recruitment of an additional Consultant Rheumatologist and the wider involvement of healthcare assistants.

Innovative new ways of working have been achieved, with the launch of web-based physiotherapy – an online, interactive, remote monitoring, personalised exercise programme. A hybrid model of care was also implemented rapidly; with the opportunity for most patients to be seen remotely and face-to-face when required.

Improving time to diagnosis through the development of a referral pathway and reduced variation in imaging

University Hospital Southampton NHS Foundation Trust

Setting the scene

The Southampton axial SpA service has been in existence for five years and is driven by a small team who are passionate about engaging patient perspectives to drive improvements in care. The team were acutely aware of the need to improve delays in axial SpA diagnosis, to facilitate earlier treatment and ultimately improve patient outcomes.

They joined *Aspiring to Excellence* with the following year one aims for their service:

- Reduce time from presentation of axial SpA in primary care to rheumatology
- Reduce variation in use of imaging to diagnose axial SpA.

Why did they get involved in the programme?

The team knew that they wanted to improve aspects of their axial SpA service but had struggled to enact change previously. *Aspiring to Excellence* offered a badge behind these aspirations in terms of a national programme that could nourish and energise those ideas with motivation and external support, while networking and participating in shared learning with national colleagues. The programme also offered the opportunity to raise the profile of the department and show patients a formal commitment to improving services. This acknowledgement and dedication to consistent improvement/service evolution also aligned with the wider hospital values.

What did they do?

The team began by developing two driver diagrams.

Figure 1: Reduce time from presentation of axial SpA in primary care to rheumatology

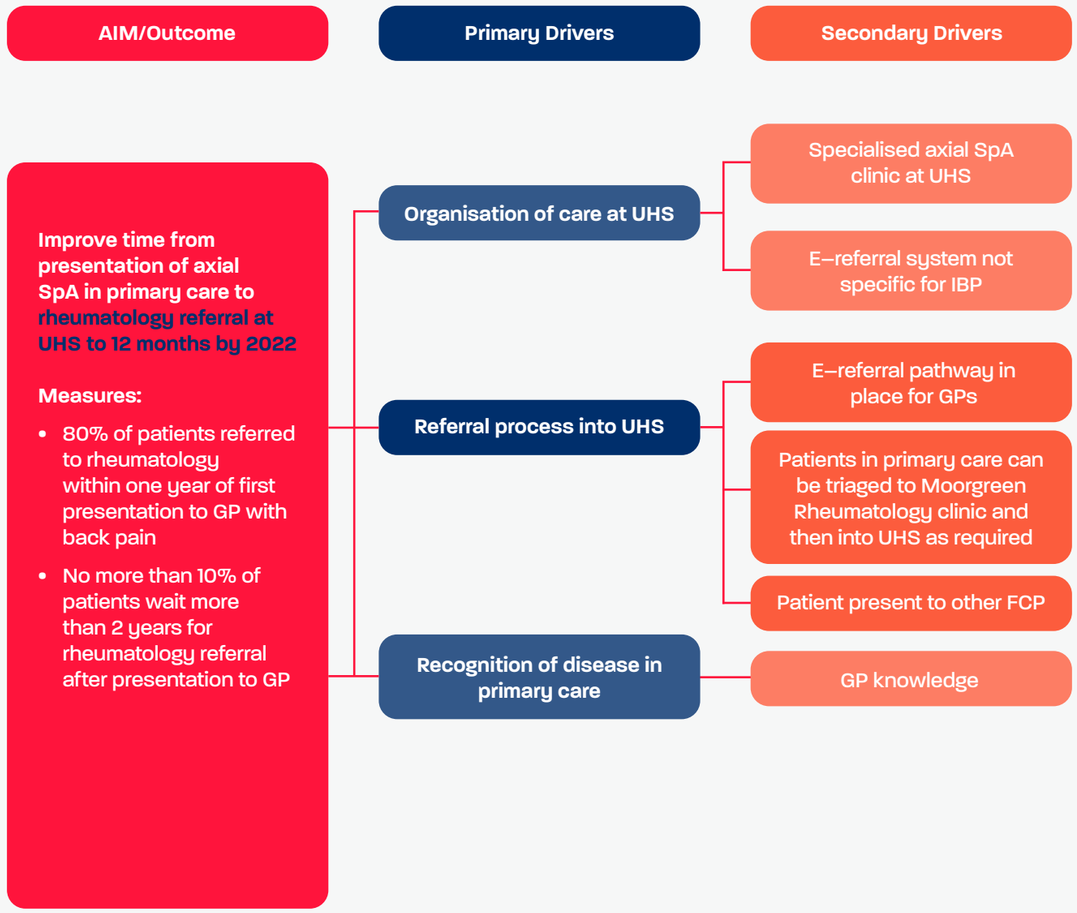
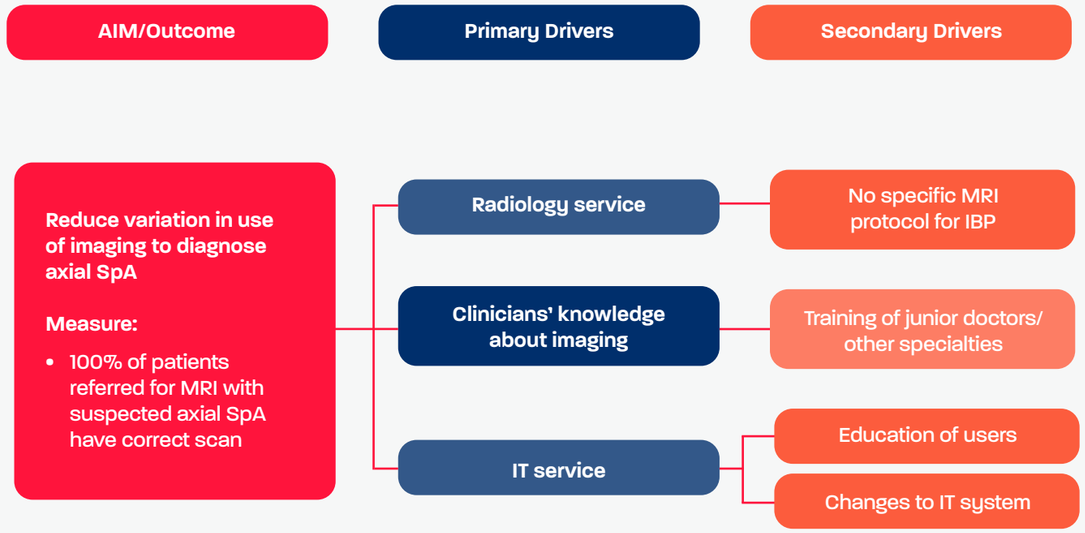


Figure 2: Reduce variation in use of imaging to diagnose axial SpA



From this they utilised PDSA cycles, and the SMART (specific, measurable, achievable, relevant and time bound) framework to envision deliverable aims and break these into structured components to create a work plan.

The e–referral pathway to the axial SpA service was mapped to identify key stakeholders and to understand the current process for referring to rheumatology. The team audited the referral time of patients presenting with IBP to rheumatology, and telephone interviews were conducted with patients who had a delay of over 8 years to diagnosis, to understand the context of this delay. They designed a survey to determine how GPs use the e–referral system and their confidence in diagnosing axial SpA.

The improvement team engaged key stakeholders (rheumatology and gastroenterology consultants and trainees, radiologists and radiographers) to audit imaging practices and explore the current request system.

"One of the key QI tools that helped us to explore our goals and aims was the driver diagram that breaks up your goals into primary and secondary drivers... Things that you think you know already, but putting it down in a diagram and dissecting it a bit further than you would otherwise was helpful."

Dr Dinny Wallis, Consultant Rheumatologist

What impact have they had?

The Southampton axial SpA team have made significant headway in achieving both of their year one aims, with impressive changes implemented throughout the diagnosis pathway.

An IBP referral pathway from primary care is in place, and an educational resource for GPs has been created

After identifying a lack of IBP pathway within the e–referral system, the team developed a referral pathway. Although suggested investigations were present in the system for rheumatoid arthritis, there was no advice for IBP and service booking criteria were poorly defined. Axial SpA was removed from irrelevant referral pathways, and a new IBP pathway added, including an educational resource for GPs listing IBP criteria, and suggested further investigations to determine likelihood of axial SpA.

Audit data suggests median time from first healthcare professional contact to first rheumatology appointment is one year, with a range of 0–14 years

An audit of 73 patients diagnosed with axial SpA within the last three years suggested a mean of 5.6 years (median one year, range 0–34 years) between first symptom recalled and seeing a healthcare professional. Six interviews were conducted with patients who had between 8–20 years delay from onset of symptoms to diagnosis. Key themes are presented in Figure 3.

Figure 3: Key themes: context of diagnostic delay reported by patients with axial SpA

"Mechanical back pain is so common"

"If you can touch your toes, you don't have it"

"You don't look like someone who has AS"

"I'm young I'll get over it"

"...because I was young and a woman"

"Felt embarrassed explaining why I thought I might have AS"

"Am I being a baby about it?"

"She thinks I must be putting it on"

"She indicated that what I felt was almost in my head"

"No one ever believed me"

"People don't know enough about it"

Collaboration with radiology has strengthened and led to the implementation of a novel, shorter MRI spine IBP protocol

With regards to imaging variation, anecdotal evidence suggested frequent use of incorrect scanning protocols for MRI acquisition, resulting in excessive time in the scanner and increased burden on radiology resources. This was supported with evidence from an MRI audit, with 16% (7/43) of rheumatology or gastroenterology IBP scans conducted utilising incorrect sequences. The idiosyncratic imaging request system was identified as the root cause of this variation in protocol. The team therefore implemented a change of protocol, creating a novel, shorter protocol for "MRI spine inflammatory back pain". This included an informative button with indication and sequences, and updates and induction packs were disseminated to the gastroenterology and rheumatology teams. Two novel audits are now underway to explore usage of the updated IBP e–referral pathway and MRI spine IBP protocol in practice. Initial results suggest that further re–education is needed, plus a re–audit of services.

Improving time to diagnosis through tertiary referral, and improving patient flow

Chapel Allerton Hospital, Leeds Teaching Hospitals NHS Trust

Setting the scene

The large, well–established Leeds Specialist Spondyloarthritis Service has a multidisciplinary, multispecialty approach to SpA care, working closely with dermatology and gastroenterology departments to deliver joint clinics.

Having grown rapidly over the last five years, the team joined *Aspiring to Excellence* with the following aims:

- Develop a regional multidisciplinary team network
- Improve patient flow and ways to rationalise clinic demand and waiting lists
- Implement electronic data capture.

Why did they get involved in the programme?

Delivering high quality, multidisciplinary care, involving multiple specialities, is becoming increasingly challenging. The team had a clear vision of what they wanted to achieve – to improve the quality of care for people using their service by maximising responsiveness to patient needs and facilitating communication between specialties including tertiary referrals. In addition, the team was keen to reduce costs by reducing unwarranted variations in care and addressing possible treatment misuse.

The team was mindful of the ambition of their aims, which included an upgrade of their Trust electronic data capture system to help deliver care to the right patient at the right time (Getting It Right First Time) in a more efficient fashion and working across specialities. They applied to the programme in order to develop the skills and capabilities to understand QI and develop a consistent and coherent approach to take their projects forward.

What did they do?

The team employed QI techniques including driver diagrams and PDSA cycles to plan their work and break down their high–level overall aims into a logical set of underpinning, digestible goals and projects.

The creation of a regional MDT network was fully actioned during the first month of the COVID–19 pandemic. An electronic SpA MDT referral form was created together with a dedicated email address to capture these referrals. In order to facilitate access to the MDT for tertiary referring centres, an electronic portal was created through the Trust website.

The following driver diagrams set out the team's approach to improving patient flow and ensuring electronic data capture.

Figure 4: Improve patient flow and clinic rationalisation

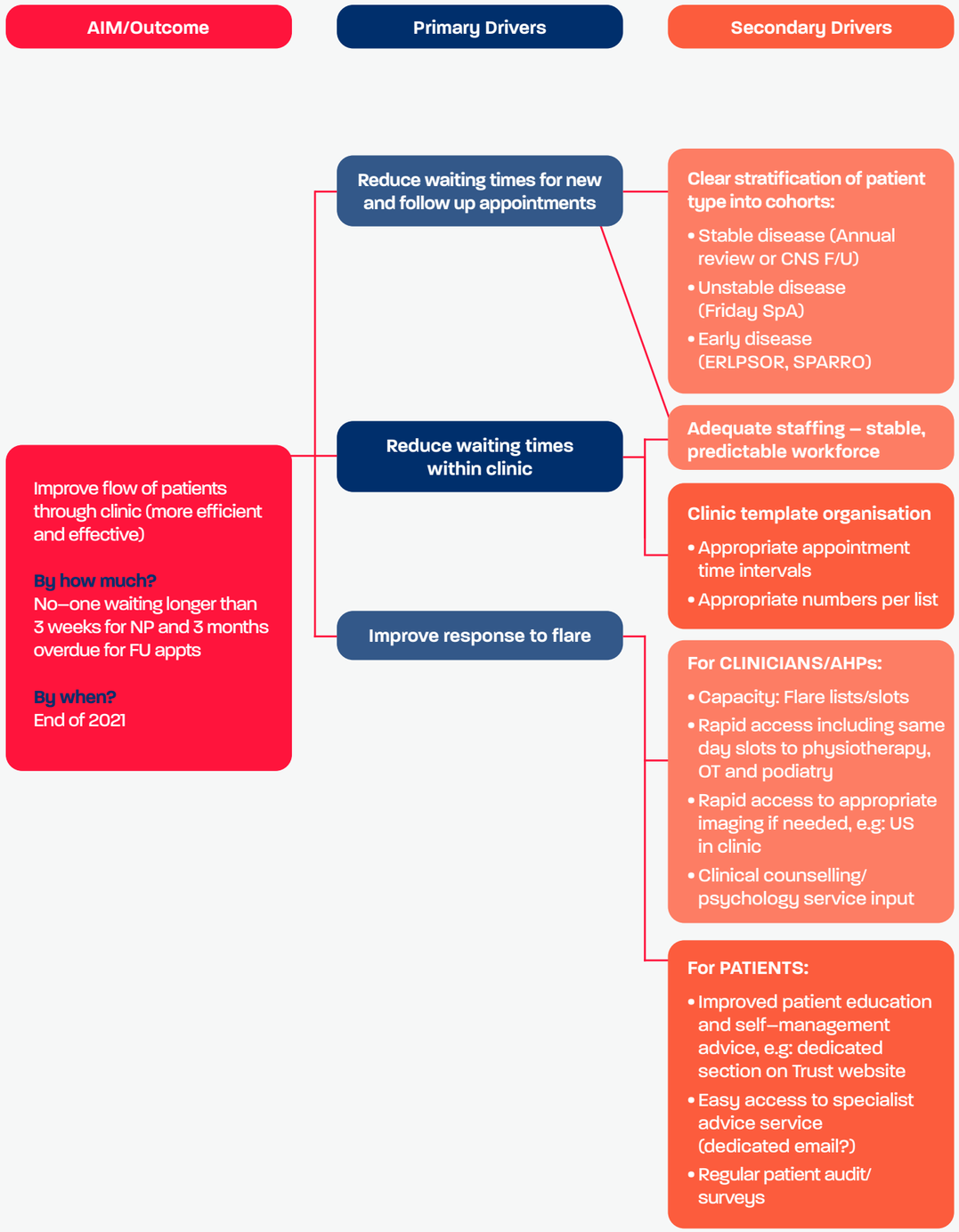
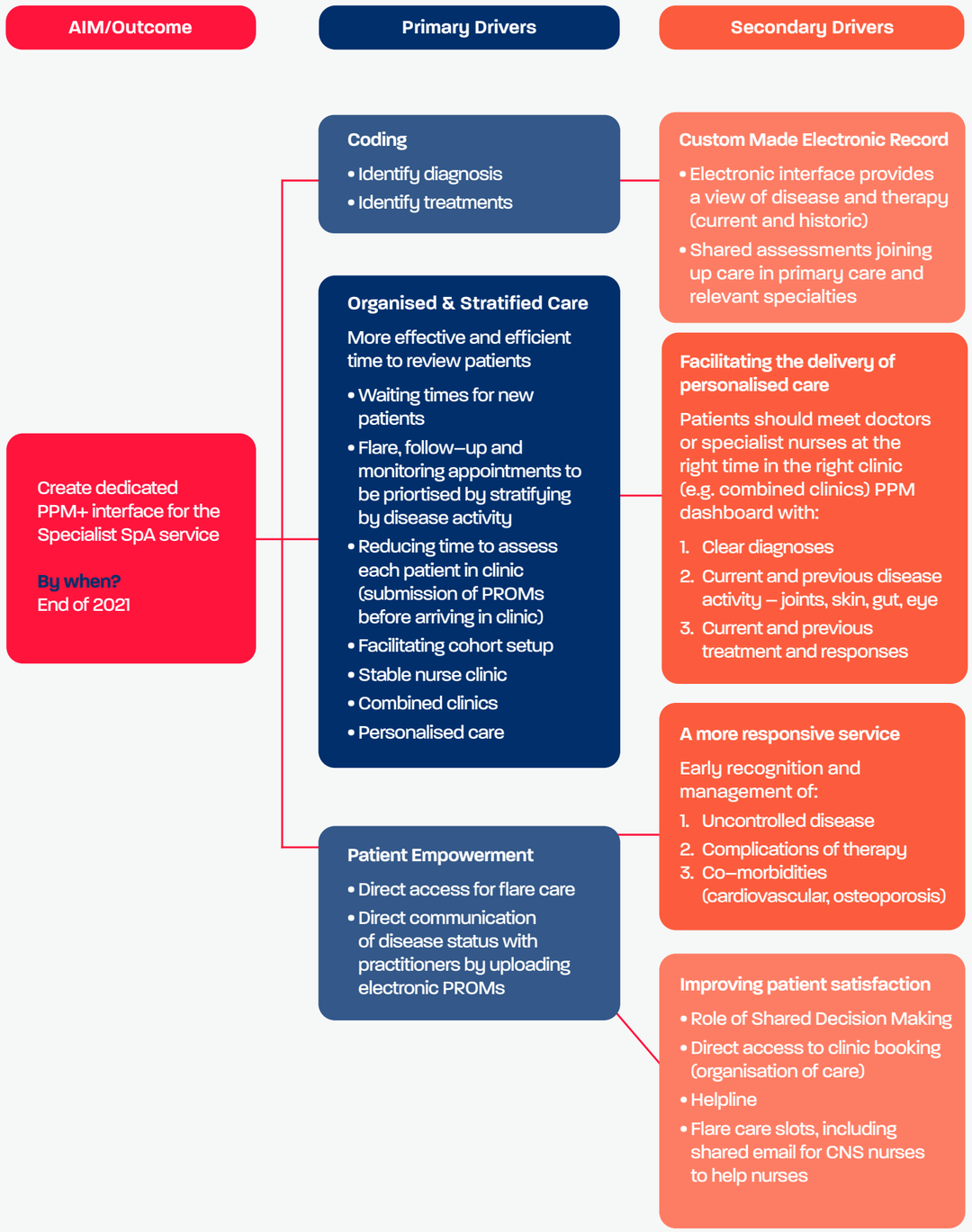


Figure 5: Implement electronic data capture



What impact have they had?

A regional MDT network infrastructure has been established

Since the launch of the online SpA MDT referral form in July 2020, there have been ten tertiary referrals – with an improvement in mean time to resolution from four months to just five working days.

Online resources and patient education have been improved

The Leeds team have created a dedicated SpA website link from the Leeds Teaching Hospitals NHS Trust webpage, including signposts to relevant resources and information on axial SpA. They have also taken steps towards improved patient education and self–management, for example through implementing online self –request blood monitoring forms.

Funding has been secured for an electronic data capture project

This project will involve the creation of a dedicated SpA service interface on the unique, secure Leeds Teaching Hospitals NHS Trust electronic health record system – a secure virtual health and social care record system, called PPM+. This should ultimately facilitate the development of an integrated care pathway, to allow quick identification and treatment of flare, prioritisation of patients based on disease activity, patient–initiated follow–up, and improved efficiency in clinic.

"*Aspiring to Excellence* has made us aware of our capability, not only of our limitations. There is no magic bullet here. Transforming a massive organisation's IT system may seem like an impossible enterprise, but by sharing responsibility and involving our managers and stakeholders we are confident that we will achieve our goals, however long it may take! After all, this all about improving patient care."

Dr Helena Marzo–Ortega, Consultant Rheumatologist and Associate Professor

Improving mental health and self–management

Royal Berkshire NHS Foundation Trust

Setting the scene

Since completing an audit against the NICE Spondyloarthritis guidelines (NG65) and Quality Standards (QS170) two years ago, the multidisciplinary Royal Berkshire rheumatology team have been passionate about improving axial SpA patient care and experience in their service on the whole patient pathway.

They joined *Aspiring to Excellence* with the following aims in their first year:

- To improve the management of mental health issues in axial SpA patients
- To improve patients' ability to self–manage and reduce workload on the advice line through facilitating direct access to a physiotherapy service for axial SpA patients, while simultaneously reducing waiting time to see a physiotherapist.

Why did they get involved in the programme?

The team realised the opportunities provided by the programme and had the enthusiasm for it. They were keen to undertake formal QI training and mentoring to learn how to make improvements in a structured, systematic way. The networking aspect was also particularly appealing – to have the opportunity to engage, collaborate and learn from other axial SpA teams.

What did they do?

In the first year, the team first created driver diagrams to create a shared view of the components that would be needed to contribute to the achievement of their goals.

Figure 6: Improve management of mental health issues in axial SpA patients

Figure 7: Improve patients' ability to self–mange and reduce workload on the advice line through facilitating direct access to a physiotherapy service for axial SpA patients, while simultaneously reducing time to see a physiotherapist

They then undertook PDSA cycles with individual projects within the driver diagrams.

The team asked patients attending clinic to complete the Hospital Anxiety and Depression Score (HADS). In collaboration with the team's psychologist, they created a self–help video on managing anxiety and depression and disseminated it to all patients who completed the HADS. They signposted patients to online mental health resources and self–management programmes. A re–audit of HADS was then completed at follow–up.

The QI team developed a self–referral physiotherapy form and QR code for patients with SpA which was uploaded to the Trust website. They created a bespoke nhs.net email address to receive self–referral forms from patients. The staff undertook an audit to determine the number of advice line contacts and time from physiotherapy referral to the appointment, since implementation of online self–referral.

What impact have they had in their first year?

Fewer patients have higher scores on the Hospital Anxiety and Depression Scale

- From January to March 2020, 45 axial SpA patients completed the HADS; 31% scoring 0–7 ("normal"), 20% scoring 8–10 (borderline abnormal) and a concerning 48.9% scoring >11 (abnormal); indicating a critical need for improved mental health support for axial SpA patients.
- All 45 patients viewed the self–help video and 38% participated in an online self–management programme delivered by NASS – indicating a considerable engagement with mental health resources, when provided.
- Following COVID–19 lockdown (March to May 2021), follow–up HADS were collected and showed a significant reduction in the number of patients with an abnormal HADS >11 (27%), and a trend towards lower HADS (42% 0–7, 31% 8–10).

This programme is now being embedded within the service to improve the mental health of patients.

Despite the impact of COVID–19, the team has established a pathway for physiotherapy self–referral

- The staff undertook an audit of flares in axial SpA patients which demonstrated that this group of patients often suffer flares but try to self–manage despite potentially requiring physiotherapy input to manage flares or recover from flares.
- They then publicised a physiotherapy self–referral service to axial SpA patients at their Rheumatology clinic appointment which seems to have been met with satisfaction and enthusiasm by patients.
- The QI team will re–audit flares and the use of advice line/contact with the administrative team. Now the pathway is in place the team will be able to complete their PDSA cycle once it has had some time to embed into their service and pathway.

"The *Aspiring to Excellence* programme has given us structure and focus to build on our work to achieve the best standard of care in axial SpA. We have embedded new practices into our axial SpA patient pathway that have both spread and sustainability. This will ensure there is continuous improvement in our service long after we have completed the programme for the benefit of our patients."

Dr Antoni Chan, Consultant Rheumatologist

Improving patient engagement and self–management of flares

Fife Rheumatic Diseases Unit, NHS Fife

Setting the scene

The spinal team at Fife Rheumatic Diseases Unit is large and multidisciplinary with a strong person–centred, holistic approach to care. Their overall aim for year one was to improve patient engagement and self–management of axial SpA flares.

They hoped to:

- Improve patients' knowledge of axial SpA
- Improve the availability and ease of access of physiotherapy appointments
- Improve communication within the team via a virtual MDT review appointment
- Inform the rheumatology team of the care pathway for flares.

Why did they get involved in the programme?

The team knew that they wanted to make improvements to their general clinic; however, they had tried to make changes in the past without much success. They were acutely aware that the clinic had a high did not attend (DNA) rate, and that there was poor engagement both with the clinic and physiotherapy appointments. The service felt disorganised and unsatisfactory, and the team were passionate about making improvements. *Aspiring to Excellence* offered an opportunity for deeper reflection on the service and to try to understand the problem more completely, in order to devise more effective solutions.

> **"I think we were very solution focused – what's the problem, what can we do about it, instead of really picking the problem apart and looking at it in more detail before then implementing changes."**
>
> Paula Dowie, Clinical Specialist Physiotherapist

What did they do?

The team utilised PDSA cycles and driver diagrams to reflect on the issues in their current service, focus ideas and devise a structured work plan.

Figure 8: Improve patient engagement and self- management of flares

The team updated a selection of PROMS and ensured a consistent approach to their collection. They are now reviewed via remote consultation, rather than being sent in the post, whereby previously often incorrect or duplicate forms were sent, or patients would not complete.

They changed the pathway for physiotherapy appointments – from an opt–in service, to ensuring that all axial SpA patients were given an appointment. Similarly, all axial SpA patients calling the advice line are directed to physiotherapy, with self–referral encouraged by the nurses and administration staff. The physiotherapist sees all newly diagnosed patients in clinic, explains the importance of physiotherapy and instructs patients to reach out via new physiotherapy contact cards if they need advice or assessment.

A new format to spinal clinics has been restarted post–COVID–19 lockdown.

What impact have they had?

The service has been redesigned and led to improvements in DNA rates and physiotherapy participation

Despite immense challenges faced during the pandemic, the Fife team have over the past year managed to redesign their service and make positive, tangible changes in the way that they deliver patient care. The clinic and physiotherapy DNA rate has improved and participation in physiotherapy has improved. The new service allows time for education and reflection, for patients to understand that physiotherapy is just as important as medication.

Patients are more engaged and proactive in their care and self–management

Improved patient education is now provided at the first appointment, engaging patients with a treatment plan much earlier on, and empowering them to self–manage and take steps towards improving their condition, before even their first formal physiotherapy appointment. The rheumatology team has noted a significant difference in the way that patients self–manage, and report that more people proactively contact the advice line or physiotherapy looking for help.

Face to face clinics feel less chaotic and more enjoyable

The department has now implemented a novel, hybrid model of virtual/in–person care ensuring that only those patients who need/want to be seen in person attend face–to–face.

Ringfencing time for collaboration has strengthened team relationships and engaged colleagues

A regular MDT review meeting has been implemented every two weeks, to discuss complex cases in a more efficient, structured way. This also provides a platform for sharing ideas and engaging the physiotherapists and junior doctors.

"We have done small projects before in the department and you just get so tied up with day-to-day work, you just don't have time to focus. I think this programme has allowed us time to do the learning, to then be able to implement things and change our thinking and to gain that confidence and that knowledge."

Dr Sarah Hailwood, Consultant Rheumatologist

Improving the referral of patients in flare to physiotherapy

Sheffield Teaching Hospitals NHS Trust

Setting the scene

The Sheffield rheumatology team is primarily based at the Royal Hallamshire Hospital, and established a dedicated axial SpA service ten years ago. The team currently provides innovative young adult services and monthly axial SpA multidisciplinary team clinics, which are well received by patients. Their overall aim when joining *Aspiring to Excellence* was to improve equity of care across rheumatology for all axial SpA patients, including those both within and outside of the dedicated axial SpA MDT service.

The aim for year one was:

- 100% of axial SpA patients in flare to be referred to physiotherapy for acute management.

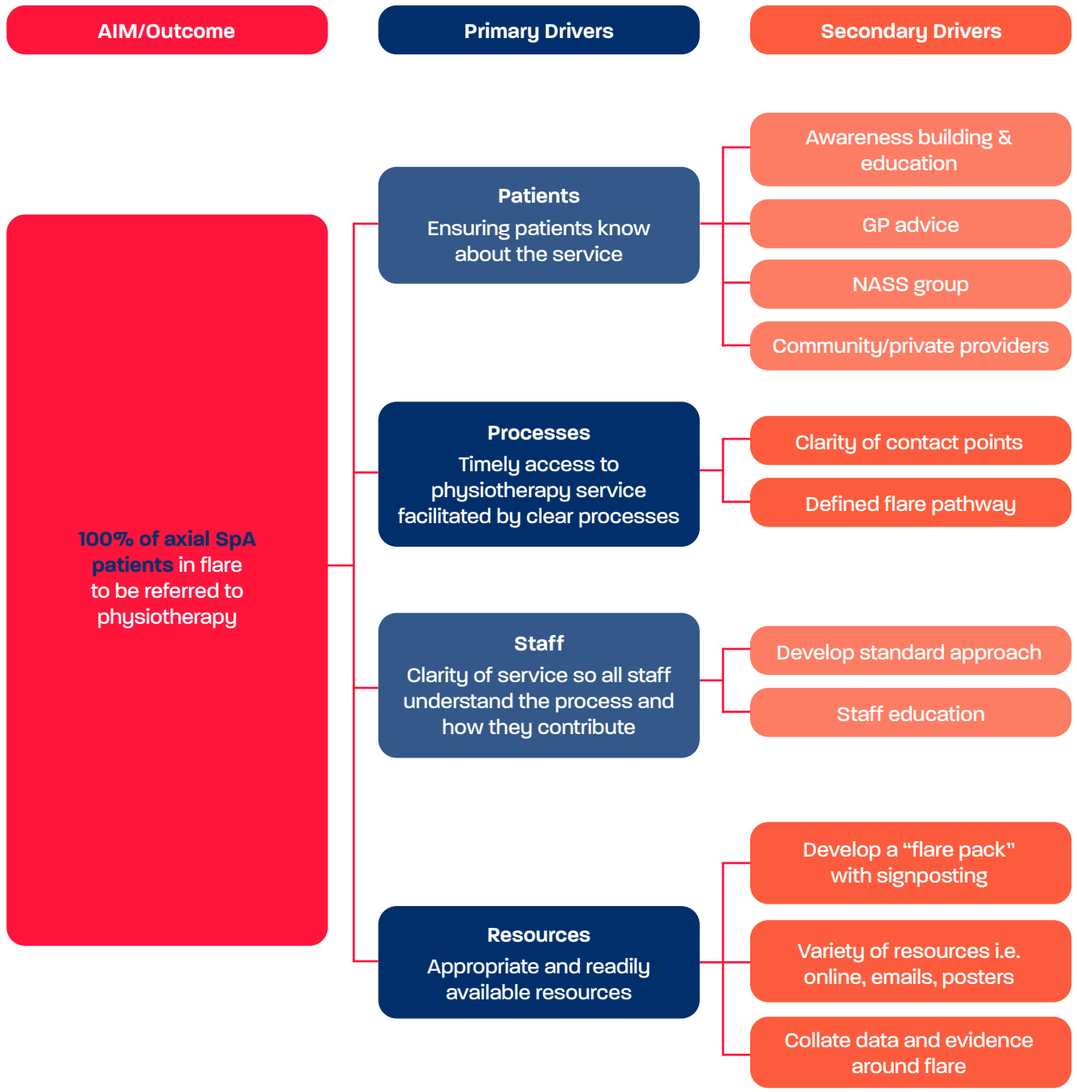
Why did they get involved in the programme?

Since the creation of the axial SpA service ten years ago, the team has been inspired with ideas for improvement and aware of the need to evolve over time. The launch of *Aspiring to Excellence* provided the unique opportunity to understand their own service better, while simultaneously networking, learning from others, and sharing knowledge from their own experiences. Furthermore, participation in a planned, competitive programme would allow the team to ringfence that time and make service improvements a priority; while using an evidence–based, theoretical QI framework to work in a standardised, methodological manner.

What did they do?

The team used driver diagrams and fishbone diagrams to dissect their aims and formulate a structured work plan, from which PDSA cycles were implemented.

Figure 9: 100% of axial SpA patients in flare to be referred to physiotherapy



An audit of department notes was carried out to improve understanding of the current service/ treatment pathways and to facilitate prospective data collection and completeness.

Data were collected on:

- The number of axial SpA patients treated within and outside of the specialist MDT service
- The percentage of patients on biologic treatment
- The percentage of patients referred to physiotherapy
- The number of axial SpA outcomes recorded (BASDAI, BASFI, cardiovascular risk etc.)
- Percentage of patients referred to physiotherapy while in flare

From this data it became clear that those patients treated within the specialist service were much more likely to have had outcomes measured and acted upon. Some patients in flare were simply having their biologics switched, and a proportion had never been referred to physiotherapy – indicating a need to make referral expectations and treatment guidelines more explicit.

On the basis of this analysis the department's axial SpA flare management referral guidelines were updated, with all axial SpA patients in flare to be sent for specialist physiotherapy triage and acute management. An adapted annual review form was developed (in collaboration with Newcastle), with a section to prompt referral of all patients in flare to physiotherapy. General expectations for physiotherapy referral were also outlined in the form: including when/how often to refer. There was also a switch to electronic triage, and vast expansion of the MyPathway remote management app.

What impact have they had?

Data collection has facilitated a deeper understanding of the current service and helped to make a business case for an extended scope practitioner (ESP)–led axial SpA clinic

Audit data have shone a spotlight on how many patients there are and that capacity does not meet demand, with only 47% (258/550) of all axial SpA patients seen within the specialist MDT service – forcing much needed investment in time and resources. Evidence supported the critical need for a permanent ESP role within the axial SpA service which has now been recruited. This ESP role is now noticeably more visible in the service, with consultant colleagues naturally referring axial SpA patients for specialist physiotherapy triage.

The profile of axial SpA patients has been raised among MDT colleagues

Remote reviews, patient education, support and ePROM collection has been significantly expanded both in scope and patient coverage.

An updated audit is now underway to explore flare management and physiotherapy referral, following implementation of the novel annual review form

"Peer learning and support is possibly the most important part of the programme. The community of us made it fun, and it is always helpful to meet people within the same specialty – there are the same or similar barriers in every service. It is useful to understand how to overcome them/ not overcome them, and to have the peer support of knowing you are not alone."

Dr Lisa Dunkley, Consultant Rheumatologist

Annexe One:

List of case study team members

Royal Berkshire NHS Foundation Trust

- Dr Antoni Chan – Consultant Rheumatologist and Associate Medical Director
- Elena Papadopoulos – Specialist Rheumatology Physiotherapist
- Kathryn Rigler – Specialist Rheumatology Physiotherapist
- Jennifer Salisbury – Specialist Occupational Therapist
- Shirley Lee – Rheumatology Lead Nurse
- Helen Wheeler – Rheumatology Specialist Nurse
- Jayne Honnor – Rheumatology Specialist Nurse
- Habib Wardak – Lead Rheumatology Pharmacist

Fife Rheumatic Diseases Unit, NHS Fife

- Dr Sarah Hailwood – Consultant Rheumatologist
- Paula Dowie – Clinical Specialist Physiotherapist
- Nicola Thomson – Rheumatology Nurse
- Stephanie Hart – Admin

Chapel Allerton Hospital, Leeds Teaching Hospitals NHS Trust

- Dr Helena Marzo-Ortega – Consultant Rheumatologist
- Dr Andrew Barr – Consultant Rheumatologist
- Dr Jane Freeston – Consultant Rheumatologist
- Dr Claire Vandevelde – Consultant Rheumatologist
- Charlie Davies – Clinical Nurse Specialist
- Jason Ward – Clinical Nurse Specialist

Freeman Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust

- Dr Ben Thompson – Consultant Rheumatologist
- Dr Lesley Kay – Consultant Rheumatologist
- Dr Ejaz Pathan – Consultant Rheumatologist
- Maureen Motion – Extended Scope Practitioner in Physiotherapy
- Gemma O'Callaghan – Specialist Occupational Therapist
- Michelle Rutherford – Clinical Nurse Specialist
- Dr Rachel Duncan – Consultant Rheumatologist
- Lesley Tiffin – Clinical Nurse Specialist

Sheffield Teaching Hospitals NHS Trust

- Dr Lisa Dunkley – Consultant Rheumatologist
- Zoe Cox – Clinical Specialist Physiotherapist & ESP (Extended Scope Physiotherapy Practitioner)
- Liz Byrne – Anti–TNF specialist nurse

University Hospital Southampton NHS Foundation Trust

- Dr Dinny Wallis – Consultant Rheumatologist
- Jacqui Tomkins – Rheumatology Specialist Physiotherapist

Annexe Two:

Background to 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 delay to diagnosis[12].

Axial SpA is not rare and affects an estimated 1 in 200 of the adult population[13] 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)[14]. 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 acute anterior uveitis[15]**
- **9% will have psoriasis[16]**
- **7% will have inflammatory bowel disease[17]**
- **25% of people will have irreversible spinal fusion[18]**
- **There is a close association with osteoporosis[19]**
- **59% report suffering a mental health issue at some point**

[12]Sykes MP, Doll H, Sengupta R, Gaffney K. Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? Rheumatology. 2015;54(12):2283-4.

[13]Hamilton L, Macgregor A, Toms A, Warmington V, Pinch E, Gaffney K. The prevalence of axial spondyloarthritis in the UK: a cross-sectional cohort study. BMC Musculoskeletal Disorders. 2015;16.

[14]MS Society. MS in the UK. 2016. [Available from: www.mssociety.org.uk].

[15]Stolwijk C, van Tubergen A, Castillo-Ortiz JD, Boonen A. Prevalence of extra-articular manifestations in patients with ankylosing spondylitis: a systematic review and meta-analysis. Annals of the Rheumatic Diseases. 2015;74(1):65-73.

[16]Ibid. 15.

[17]Ibid. 15.

[18]S, Graham D, Little H, Rubenstein J, Rosen P. The natural disease course of ankylosing spondylitis. Arthritis & Rheumatology. 1983;26(2):186-90.

[19]Wang DM, Zeng QY, Chen SB, Gong Y, Hou ZD, Xiao ZY. Prevalence and risk factors of osteoporosis in patients with ankylosing spondylitis: a 5-year follow-up study of 504 cases. Clinical and Experimental Rheumatology. 2015;33(4):465-70.

Annexe Three:

Glossary of terms

- **Act on Axial SpA –** campaign to reduce the current 8.5 year time to diagnosis to a gold standard time of one.
- **Acute anterior uveitis (AAU) –** Acute anterior uveitis is an eye condition caused by inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens. It is also sometimes referred to as iritis.
- **All Party Parliamentary Group –** All–Party Parliamentary Groups (APPGs) are informal cross–party groups that meet, relatively informally, to discuss a particular issue of concern
- **BASDAI –** The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) disease activity questionnaire contains six questions regarding subjective symptoms during the week prior to answering the questions.
- **BASFI –** Bath Ankylosing Spondylitis Functional Index is made up of 10 questions that are related to activities of daily living and are scored with a rating scale, used to measure functional impairment.
- **Biologic treatment –** a product that is produced from living organisms or contain components of living organisms
- **BRITSpA –** British Society for Spondyloarthritis, a group of professionals working in the UK with a commitment to advancing knowledge and treatment of spondyloarthritis
- **DNAs –** did not attends
- **Driver diagram –** Driver diagrams are structured charts of three or more levels. They translate a high level improvement goal/ aim into a logical set of high level factors (primary drivers) that you need to influence in order to achieve your goal. They also show the specific projects/activities that would act on these high level factors.
- **e–PROMS –** electronic patient reported outcome measures
- **Extended scope practitioner (ESP) –** An extended scope practitioner is a physiotherapist who has gone on to do extra or specialist training.
- **Flares –** a period of increased pain and fatigue
- **Getting it Right First Time (GIRFT) Rheumatology –** Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS by reducing unwarranted variations.
- **Hospital Anxiety and Depression Scale –** commonly used by doctors to determine the levels of anxiety and depression that a person is experiencing. The HADS is a fourteen item scale that generates: Seven of the items relate to anxiety and seven relate to depression.
- **IBP –** inflammatory back pain
- **Inflammatory bowel disease (IBD) –** Inflammatory bowel disease (IBD) is a term mainly used to describe two long–term conditions that involve inflammation of the gut: ulcerative colitis and Crohn's disease.
- **MDT –** multidisciplinary team
- **Multiple sclerosis –** Multiple sclerosis (MS) is a condition that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance.
- **NASS –** National Axial Spondyloarthritis Society
- **NHS Transformation Unit –** NHS Improvement & Strategic Transformation agency specializing in large –scale Clinical services, Healthcare consulting and Change management
- **NICE Guideline and Quality Standard –** Evidence–based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders
- **Parkinson's disease –** Parkinson's disease is a brain disorder in which parts of the brain become progressively damaged over many years.
- **Plan–Do–Study–Act (PDSA) cycle methodology –** PDSAs are based in scientific method and moderate the impulse to take immediate action with the wisdom of careful study
- **PROMs –** patient reported outcome measures
- **Psoriasis –** Psoriasis is an inflammatory skin condition that causes red, flaky, crusty patches of skin covered with silvery scales.
- **QI –** quality improvement
- **QR code –** a machine–scannable image that can instantly be read using a Smartphone camera.
- **Rheumatology –** discipline specialising in immune–mediated disorders of the musculoskeletal system, soft tissues, autoimmune diseases, vasculitides, and inherited connective tissue disorders

National Axial Spondyloarthritis Society

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Facebook: **@NationalAxialSpondyloarthritisSociety**
Instagram: **@NASS_exercise**

NASS is a registered charity in England and Wales (1183175) and Scotland (SC049746)