Improving Axial Spondyloarthritis Time to Diagnosis and Access to Treatment – Royal Free London NHS Foundation Trust

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BACKGROUND

Barnet Hospital is part of the Royal Free London NHS Foundation Trust which is situated in North London. Historically, there was no specific referral pathway for patients with suspected axial Spondyloarthritis (axSpA) and as such, patients with suspected axSpA were assessed and managed within general rheumatology clinics.

Professor Tahir joined the Rheumatology team at the Royal Free London NHS Trust in 2019 and had previously set up a specialist axSpA service in East London which had successfully reduced delay to diagnosis to 3 years [1]. Professor Tahir wanted to establish a specialist service at the Trust involving a range of healthcare professional including physiotherapists, nurses, pharmacists, spinal surgeons, radiologists, ophthalmologists, dermatologists and gastroenterologists.

A weekly specialist axSpA clinic was set up in March 2020 involving a Consultant Rheumatologist and an Advanced Practice Physiotherapist in Rheumatology. The axSpA team at Barnet Hospital were selected to join cohort two of the National Axial Spondyloarthritis Society (NASS) *Aspiring to Excellence* programme with an aim of providing a world class axSpA service and reducing delay to diagnosis to within 12 months.

OBJECTIVES

The literature reports an 8.5-year delay to diagnosis in axSpA in the United Kingdom and the long-term aim of our project is to improve the time from symptom onset to diagnosis to within 12 months, which is in alignment with the NASS Gold Standard. We also aimed to improve access to treatment.

We planned to achieve these aims through multiple work streams including the development of an inflammatory back pain pathway in North Central London and by improving public, primary and secondary care awareness of axSpA. We also wanted to improve patient's access to treatment once diagnosed.

METHODS

Baseline Data

Firstly, we collected baseline data regarding the delay to diagnosis in our axSpA patient group. We conducted a survey to ascertain I) the time of symptom onset to referral for a rheumatology opinion and II) the time taken to be given an accurate diagnosis. Patients were asked to document the different healthcare professionals that they had seen and the number of consultations they had had with each professional. 60 Royal Free London NHS Trust patients completed the survey and the median delay to diagnosis was 6.09 years. The initial survey was carried out in conjunction with Salford Care Organisation, Northern Care Alliance NHS Foundation Trust [2] The survey has now been adopted by NASS and is used nationally among the *Aspiring to Excellence* sites to capture data regarding delay to diagnosis. We are using this data to evaluate the effectiveness of our various work streams in reducing delay to diagnosis.

A driver diagram was developed and identified four main drivers to achieve our aim of reducing delay to diagnosis to within 12 months (figure 1). The various interventions are discussed below.

Public Awareness

Advertising banners have been designed and are displayed in our Trust to alert the public to the symptoms of inflammatory back pain and how they can access our specialist service. The banner design incorporates the NASS axSpA symptom checker. Members of the team were present at Barnet Hospital on World arthritis day October 2022 to discuss back pain with members of the public, patients and staff. Over the next year we plan to run awareness events in the community.

Primary Care

Within primary care, we have carried out multiple education sessions for health care professionals including GPs, first contact practitioners, physiotherapists, osteopaths and chiropractors to assist in the identification, referral, and management of patients with inflammatory back pain. The sessions have been well received with 100% of participants likely to recommend the training and 97% of participants likely to change their practice as a result of the sessions. We have set up an online education resource for primary care colleagues. We have set up a monthly virtual primary care rheumatology MDT meeting where primary care clinicians can discuss cases and get advice regarding patient management. Colleagues report that they have found it 'really helpful to have the rheumatology MDT and have access to the expertise of Professor Tahir'. They felt there was 'a very open atmosphere and all questions were welcome' and that 'the MDT helps give clinicians greater confidence managing rheumatological patients. We also offer a specialist axSpA opinion to primary care colleagues via the Consultant Connect service.

There are two GP champions working with the team to promote awareness of axSpA and help streamline referrals to secondary care.

We engaged with a team developing a primary care "pop up tool" to prompt clinicians to consider an inflammatory cause for symptoms when consulting patients with back pain. Unfortunately, despite facilitating discussions and meetings amongst teams, the tool was not adopted by any sites.

Currently, there is a review of MSK services being conducted in North Central London and we are involved in discussions regarding the development of an inflammatory back pain pathway to facilitate prompt referral to rheumatology for patients with suspected AxSpA.

Secondary Care

An internal referral pathway within secondary care for patients with suspected inflammatory back pain has been established. Research projects have been initiated to evaluate the prevalence of inflammatory back pain in people diagnosed with inflammatory bowel disease, psoriasis or anterior uveitis and to explore whether they have been referred for a rheumatology opinion. A 22-question patient survey was created to identify the burden of back pain in patients attending a specialist uveitis clinic. Participants were recruited when attending their clinic appointments. The Berlin Criteria was used to identify the presence of inflammatory back pain and participants were asked whether they had a previous diagnosis of axSpA. The survey also asked whether individuals had ever seen any healthcare professionals regarding their lower back pain and the number of consultations they had had. The results from the study have recently been published and education sessions with the ophthalmology team are being organised [3].

The team have developed and delivered a radiology teaching programme for radiologists and rheumatologists to improve identification of the radiological features of axSpA and influence delay to diagnosis. These sessions have been well received with positive feedback from participants.

Rheumatology

Over the past three years, we have been successful in establishing a specialist axSpA service within the rheumatology department at the Royal Free London NHS Trust. We currently provide 1 consultant and 2 advanced practice physiotherapist sessions per week and new patients are referred to the service via choose and book.

AxSpA patient experience surveys have been conducted in 2021 and 2022 to gain insight into their experience of the service and highlight any areas for improvement.

We have recently embarked on a remote patient monitoring project which aims to monitor patient function and disease activity via a selection of patient reported outcomes and blood monitoring. It has been very challenging to get the project up and running and there have been multiple hurdles to overcome, however we are planning to integrate the data captured into our patient initiated follow up pathway to optimise patient access to treatment and enable the service to be more responsive to patients needs especially when in flare.

Weekly rheumatology radiology meetings and virtual biologic meetings are now established with an aim of improving time to diagnosis and treatment.

Patient education material including a Q&A booklet and patient podcasts have been developed alongside a monthly virtual patient education session involving a consultant rheumatologist, physiotherapist and a patient representative. In the next few months, a clinical psychologist will also be joining the sessions to offer patients further information and guidance regarding the psychological impact of axSpA.

Within the outpatient physiotherapy department, a new axSpA pathway has been developed which includes access to a newly designed evidence-based exercise group to improve patient access to treatment. Patients are provided with written documentation and access to recordings of the exercises covered in the sessions to help support long term management of their condition.

RESULTS

Time to diagnosis

100 Royal Free London patients have now completed the NASS national time to diagnosis audit. Our current delay to diagnosis from symptom onset to diagnosis is 5 years which is a reduction in 1.09 years in comparison to our baseline data taken at the start of the programme in 2021.

The time from onset to diagnosis run chart (figure 2) demonstrates that since joining the *Aspiring to Excellence* programme, the time to diagnosis among our cohort of patients is still quite variable. There are a number of factors that will be impacting on this including the Covid pandemic, the post covid backlog and more recently the NHS strikes. Our various public, primary care, secondary care and rheumatology department improvement activities have been plotted on the run chart. It does not appear that any of the improvement activities have had a direct impact on delay to diagnosis. Around the time of our various primary care education events the variation in delay to diagnosis reduced with delays being nearer to the median.

Our specialist axSpA service has now been running for 3 years with 2 clinics per week in 2020 and 3 clinics per week from 2021. The run chart evaluating our time from referral to rheumatology services to diagnosis (figure 3) since setting up our specialist service and our team being involved in the *Aspiring to Excellence* programme does not show any special cause variation in relation to our improvement activities but the variation from the median does seem to be reducing over time.

50 uveitis patients completed our 22-question patient survey to identify the burden of back pain in patients attending a specialist uveitis clinic. 40% of participants (20) reported that they had experienced back pain for more than 3 months and 12% of participants (6) had an established diagnosis of axSpA. Of the remaining 14 participants (28%) who had back pain and were not diagnosed with axSpA, 9 participants (18%) fulfilled the Berlin criteria for IBP. Two individuals within this subgroup had a previous diagnosis of psoriasis and two participants had a previous diagnosis of inflammatory bowel disease. Only eight of the 20 respondents that had experienced back pain for longer than three months had seen a rheumatologist. This study highlighted the fact that IBP is going unrecognised and underdiagnosed in patients with uveitis which leads to a delay in referrals to secondary care rheumatology services and increases the time to diagnosis and treatment. As a result of this work, we are planning some education sessions with our ophthalmology colleagues to increase awareness of axSpA which will assist in identification and onward referral and ultimately reduce the delay in diagnosis.

Patient experience

AxSpA patient rheumatology clinic experience surveys have been carried out in 2021 and 2022. Each year, 50 patients have completed a paper questionnaire. On a 0-10 numerical rating scale, in 2021, 70% of patients rated 10/10 when asked if they would recommend the rheumatology service to their family and friends. A further 4% of respondents answered 9/10 and 20% 8/10. In 2022, there was an improvement in the results with 85% of patient answering 10/10 when asked if they would recommend the rheumatology service to their family and friends and 5% answering 9/10 and 5% 8/10.

Patients were also asked to rate their consultation overall. In 2021, 48% of respondents rated their overall consultation as outstanding, 17% excellent and 30% very good. In 2022, the results again improved with 73% of respondents rating their overall consultation as outstanding, 20% as excellent and 5% as very good.

When asked if there was anything particularly good about the consultation one patient commented that the clinician was "very professional and had good knowledge about condition". Another patient stated that "the clinician was kind, compassionate and realistic" and one patient was "very impressed from start to finish". When asked about things that could have been improved, one patient mentioned the lack of appointment availability. We are hoping that this is something that can improve with our new remote patient monitoring project and the integration of remote monitoring in the PIFU pathway.

For the past year, the virtual patient education sessions have been taking place on a monthly basis. There has been an improvement in pre and post session scores when asking participants how well they understand their condition, how confident they are in managing flare ups and how confident they are to exercise regularly and independently. In the post group questionnaire, all patients report they are aware of resources regarding the management of their condition and how to contact the team if they have any issues. Patients have commented that they were given 'clear information and it was nice to hear other people's experiences with axSpA'. They also 'thought the session was superb and it's great to have professionals to talk to.'

CONCLUSION

Over the past three years we have been successful in setting up a specialist axSpA service at the Royal Free London NHS Foundation Trust. When joining the *Aspiring to Excellence* programme in 2021, our aim was to improve time to diagnosis to within one year in line with the NASS gold standard. There has been some improvement in our median delay to diagnosis from a baseline of 6.09 years to a current 5 year delay. Our data does show some improvement in the time from referral to rheumatology to diagnosis however we need to continue to improve healthcare professionals' awareness and identification of inflammatory back pain in order to reduce the delay from symptom onset to referral to rheumatology. The lack of engagement with the primary care 'pop up tool' was disappointing as we feel this had the potential to have a positive impact on the identification of inflammatory back pain in primary care, but we plan to run further healthcare professional education events and continue to host our virtual primary care MDT meetings and consultant connect service.

The results of our uveitis survey were in line with findings from other centres and have facilitated discussions with our opthalmology colleagues. We plan to run some education sessions with the opthalmology team and carry out similar surveys with a cohort of psoriasis and inflammatory bowel disease patients. Working collaboratively with our secondary care colleagues will increase awareness of AxSpA and therefore influence delay to diagnosis. Progress in establishing an inflammatory back pain pathway within North Central London has been limited but this has largely been due to an MSK review being undertaken. The team have been involved in discussions regarding pathways and current issues so hopefully there will be some positive developments in the coming year.

The service offered to our axSpA patients has been developed over the past 3 years with the setting up of a specialist clinic, the production of a variety of educational resources and the redesign of the physiotherapy service provision for axSpA patients. Our patients report high levels of satisfaction with the service they receive in the rheumatology clinic, our virtual education sessions and physiotherapy service. A patient commented regarding a lack of appointment availability, and this is something we hope to influence via our new remote patient monitoring and PIFU project.

Being part of the *Aspiring to Excellence* programme has provided the opportunity for the team to have dedicated time to focus on our service and develop ideas for improvement. Utilising some of the quality improvement methodology covered on the programme has helped to structure and measure our improvement ideas. Over the past 2 years of programme there has been some improvement in our delay to diagnosis, but we have not achieved our aim of improving time to diagnosis to within one year. Going forward, we will continue to use quality improvement measurement tools to monitor and inform our service improvement work.

References

1 Adshead R, Donnelly S, Knight P, Tahir H. Axial Spondyloarthritis: Overcoming the Barriers to Early Diagnosis-an Early Inflammatory Back Pain Service. Curr Rheumatol Rep. 2020 Aug 17;22(10):59. doi: 10.1007/s11926-020-00923-6

2 Gregory W J, Bamford S, Tahir H. A Survey of Diagnostic Delay in Axial Spondyloarthritis Across Two National Health Service (NHS) Rheumatology Services. Cureus 14(3): e23670. doi:10.7759/cureus.23670

3 Bamford S, Tahir H, Ladan Z, Hanumunthadu D. Patient Survey Exploring the Burden of Inflammatory Back Pain in Patients with Uveitis. Cureus 15(4): e37473. doi:10.7759/cureus.37473

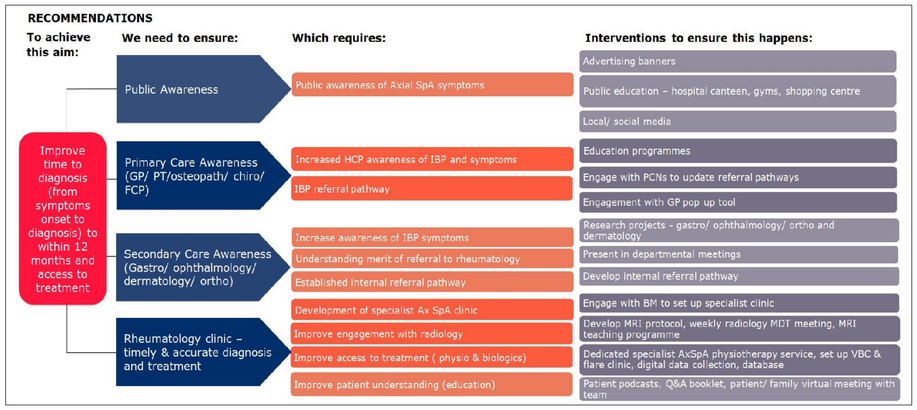

Figure 1 – Driver diagram - Improving time to diagnosis to within 12 months

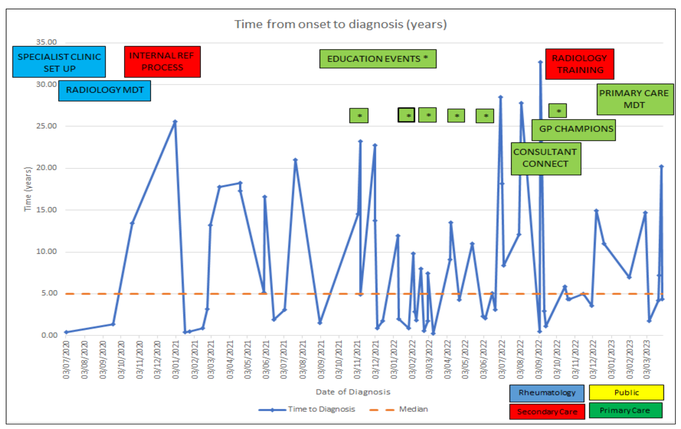

Figure 2 – Run chart – Time from onset to diagnosis

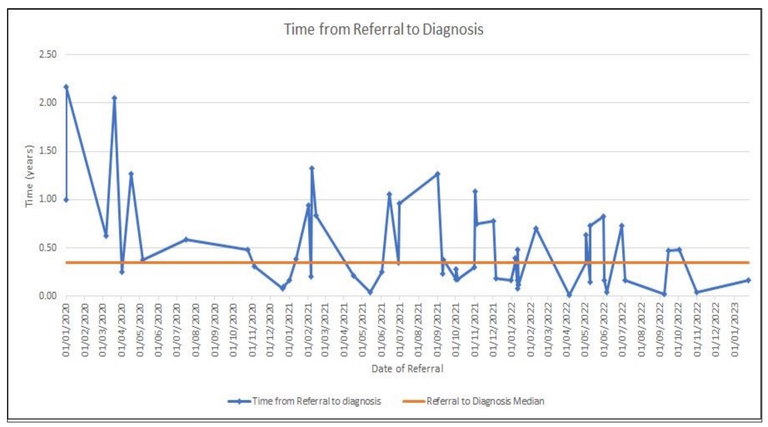

Figure 3 – Run chart – Time from referral to diagnosis

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