

# The patient journey to diagnosis for axial Spondyloarthritis (axial SpA) - The challenges in primary care and the positive impact of specialist (axial SpA) services

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**Axial SpA works silently. We don't.**

## INTRODUCTION / AIM

The mean time to diagnosis (TTD) in the UK for axial SpA is currently 8.29 years. However, it should be possible to ensure diagnosis within 12 months of symptom onset (or a time to diagnosis of 12 months) to optimise clinical outcomes and patient quality of life. Current evidence suggests significant variability in the patient journey, particularly within primary care, where patients have repeat consultations for axial SpA related symptoms before being referred onward to rheumatology.

The National Axial Spondyloarthritis Society (NASS) TTD patient survey assesses where in the pathway patients experience most delays and the factors that may be driving these pinch points.

## METHOD

In the summer of 2022, we developed a patient self-administered post-diagnosis axial SpA survey with a group of clinicians, adapting a local example from 2 UK sites. The survey consists of 5 demographic questions and 5 questions related to the patient diagnosis journey.

To support roll out patient information leaflets and posters were developed, local governance approval sought by participants and QR codes directing patients to the survey given out in clinic.

The survey was launched in October 2022 and in the first two years we have had 54 departments sign up and submit patients.

Data were collected from 534 patients diagnosed with axial SpA since January 2021.

## RESULTS

The average time from first GP appointment to rheumatology referral was the longest wait (see figure 1) at 4.33 years (53% of the total delay). Mean time between other elements of the pathway were (% shown in brackets):

- 2.49 years (31%) from experiencing symptoms to seeking help from a GP,
- 0.39 years (5%) waiting for a first rheumatology appointment following referral,
- 0.88 years (11%) for the time from first appointment in rheumatology to formal diagnosis.

Patients also reported seeing healthcare practitioners multiple times pre diagnosis (see figure 2). Physiotherapists (66%, n=353) and GPs (63%, n=337) were seen most frequently, with chiropractors (19%, n=103) and osteopaths (17%, n=93) seeing around a fifth of patients repeatedly.

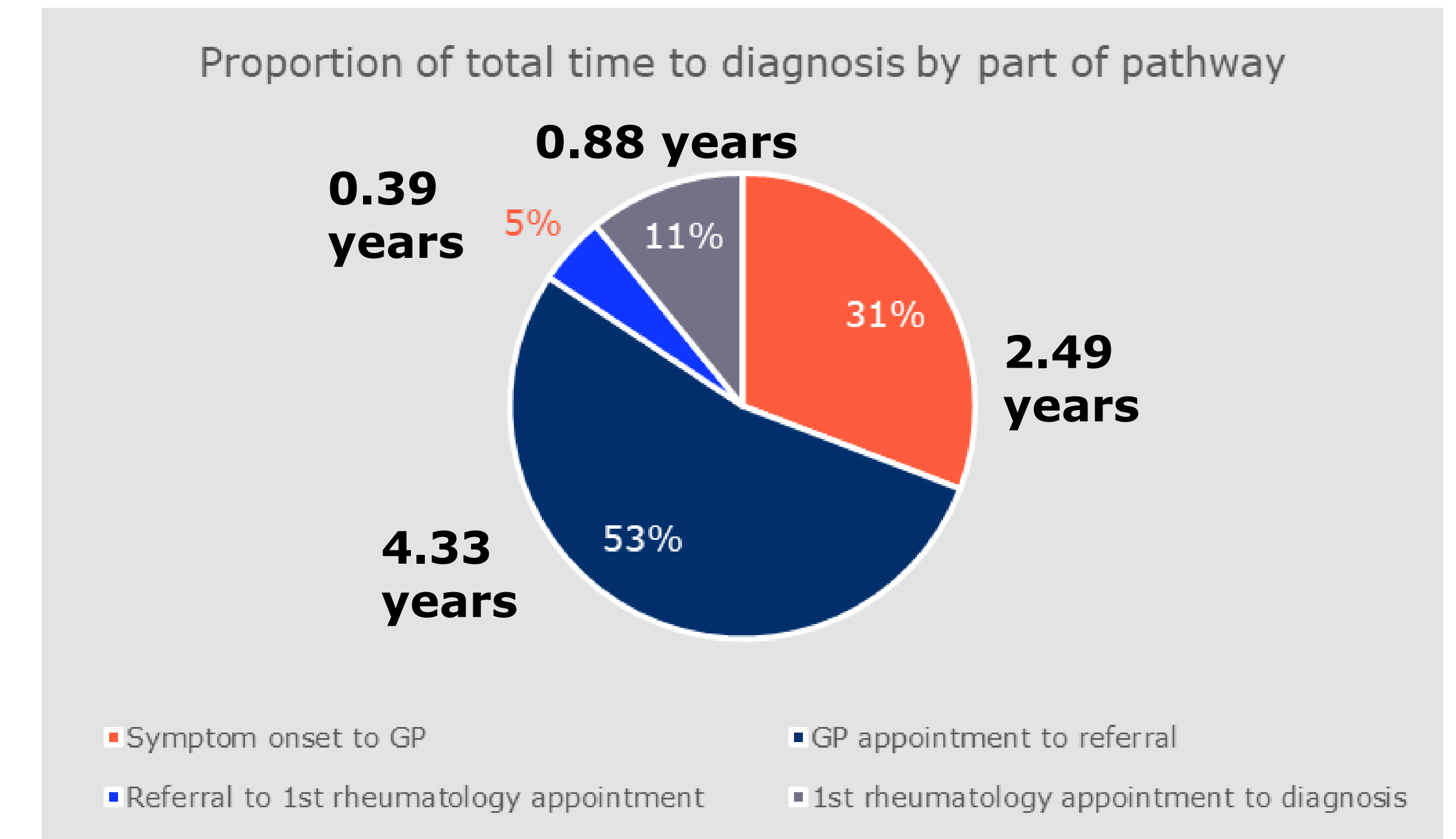
Patients diagnosed within a specialist axial SpA service - rather than in general rheumatology clinics - experienced a quicker diagnosis overall in years (7.21 vs 10.04), lower waiting times (0.31 vs 0.64) and quicker diagnosis once they were within rheumatology (0.64 vs 1.99). See figure 3.

## CONCLUSION

Our findings highlight that the key area of focus to drive down diagnostic delay is in primary care. A lack of awareness of the condition, low confidence in identifying symptoms, lack of a definitive diagnostic criteria and complex clinical presentations lead to possible missed opportunities for onwards referral to rheumatology. Solutions may involve increasing awareness, ongoing education and standardised referral processes, practices and pathways. Greater patient awareness can ensure that appropriate patients present sooner.

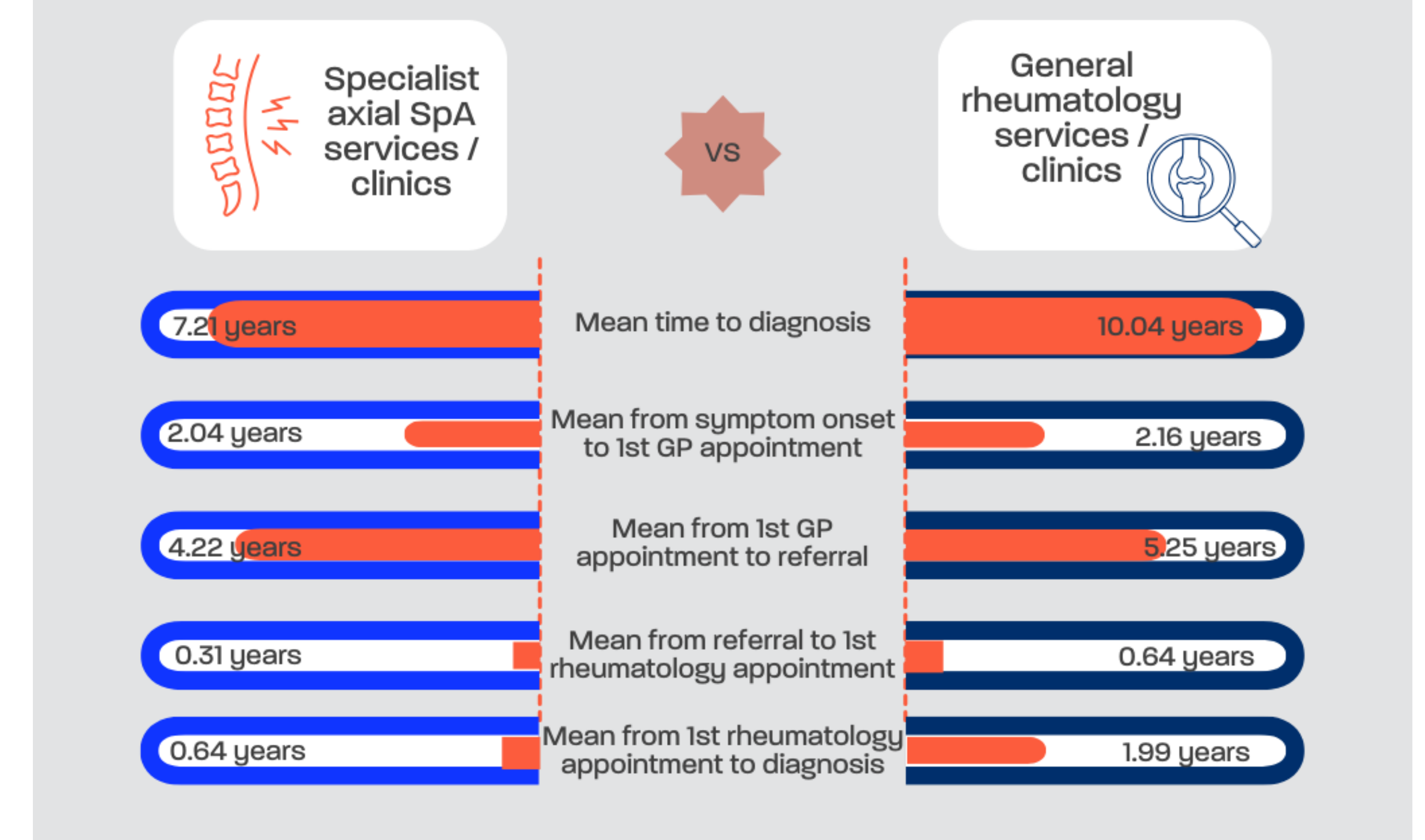
The findings also highlight the importance of having specialist axial SpA services and inflammatory back pain clinics in rheumatology. Whilst specialist clinics are not possible everywhere, patients in these settings get a quicker diagnosis due to increased expertise, greater access to co-located MSK radiology services and expedited triage out of general rheumatology pools.

Symptoms starting slowly  
Pain in the lower back  
Improves with movement  
Night time waking  
Early onset (under 40)

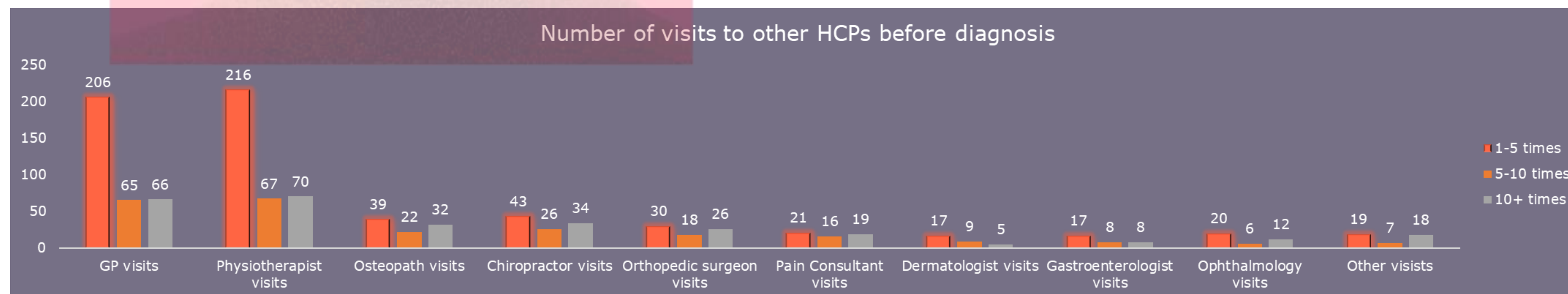


**Figure 1:** Proportional split of average (mean) time to diagnosis by pathway

**Figure 3:** Comparison of time to diagnosis for specialist axial SpA services versus general rheumatology (based on patients place of diagnosis)



**Figure 3:** Comparison of time to diagnosis for specialist axial SpA services versus general rheumatology (based on patients place of diagnosis)



**Figure 2:** Number of visits to other Health Care Professionals (HCPs) before receiving a formal diagnosis

8.5

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