

Gender disparity in axial spondyloarthritis diagnosis where is the unconscious bias?

Results from the National Axial Spondyloarthritis Society (NASS) patient survey



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INTRODUCTION

UK mean time to diagnosis (TTD) for axial spondyloarthritis (axial SpA) is currently 8.29 years. However, it should be possible to ensure diagnosis within 12 months of symptom onset to optimise clinical outcomes. Current evidence suggests a gender gap in TTD, with women waiting between one and four years longer on average (mean) internationally for a diagnosis. A survey tool was created by NASS and UK rheumatology teams to evaluate the national performance in TTD and the factors impacting diagnosis.

METHODS

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 was sought by participating hospitals and QR codes directing patients to the survey were 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.

As well as looking at the global results we analysed data submitted according to patient gender and location of diagnosis. To reduce any recall bias we removed any patients with a reported diagnosis date of earlier than January 2021.

RESULTS

- Data were collected from 523 patients diagnosed since January 2021 to July 2024, with 46% women and 54% men.
- While the overall mean TTD was similar for both genders at 8.20 years (women) and 8.08 years (men), the median average showed a discrepancy, with 5.03 years (women) compared to 4.39 years (men).
- Women sought help quicker after symptom onset (2.21 vs. 2.73 years) and had a slightly faster referral following the first assessment by a GP (4.30 vs. 4.43 years).
- However, women experienced 33% longer waiting times (0.44 vs. 0.33 years) once in rheumatology.
- The mean time from first assessment to diagnosis was 113% longer for women than for men (1.25 vs. 0.59 years).
- Additionally, women spent a higher proportion of their diagnostic journey in rheumatology (21% or 1.70 years) compared to men (11% or 0.92 years).
- 73% of their journey occurs after they seek help, compared to 66% for men. See figure 1.

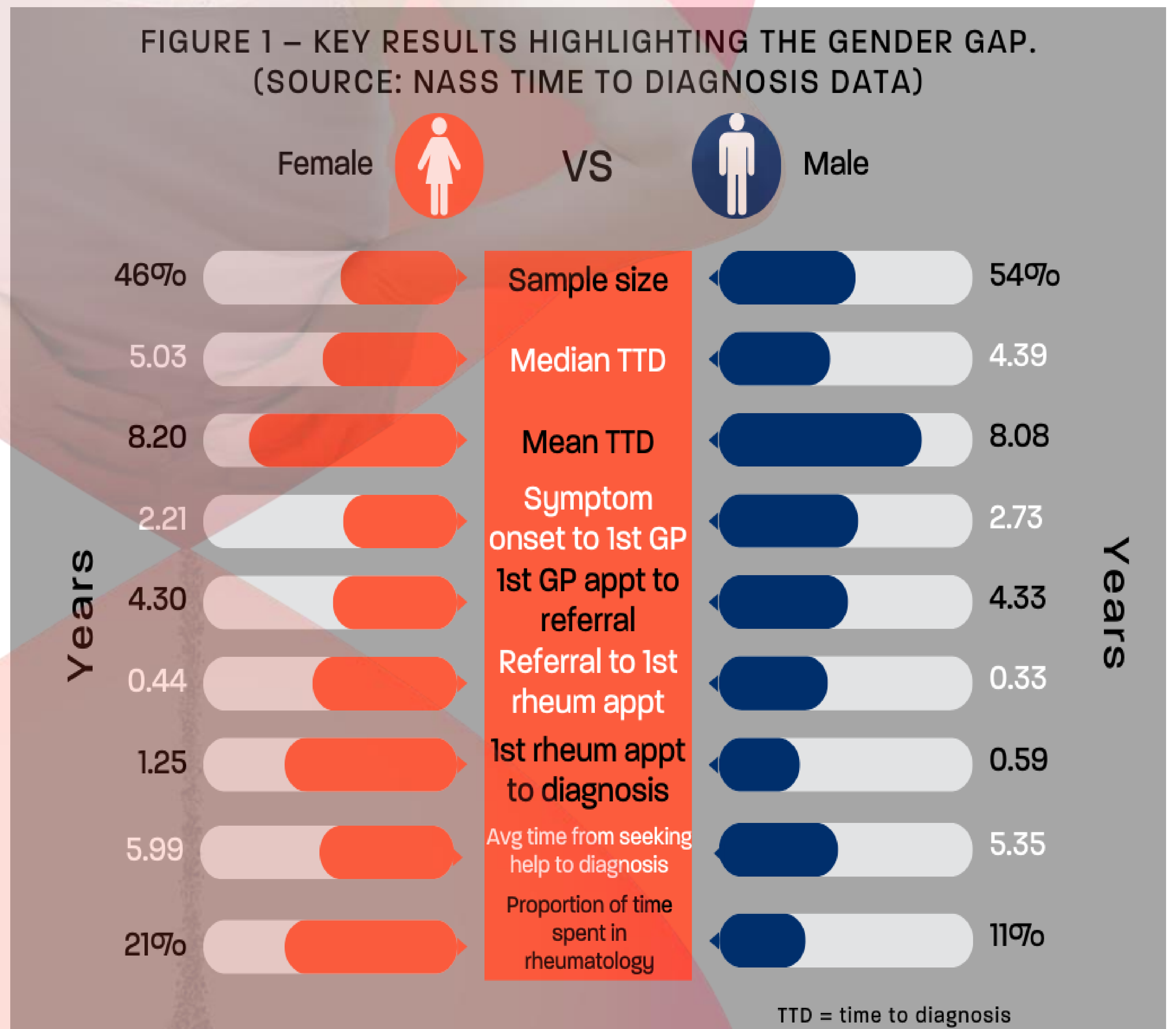


Figure 1: Key results highlighting the gender gap. (Source: NASS time to diagnosis data)

CONCLUSION

Our findings highlight a gender gap in TTD, particularly for women when they reach rheumatology. Despite seeking help earlier, women face greater barriers, beginning in primary care and exacerbated in secondary care.

Solutions may involve awareness, education, referral improvements, and addressing clinical complexities. There are also opportunities for further research into why women face these longer waits and the systemic issues relating to gender bias, particularly those within rheumatology.



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