

**A Gold Standard Time to Diagnosis   
in Axial Spondyloarthritis**

Consultation Questions

The National Axial Spondyloarthritis Society invites your input into an important new consultation that we have launched to help inform the development of a ‘Gold Standard Time to Diagnosis’ in axial spondyloarthritis (axial SpA), including ankylosing spondylitis (AS).

As you may be aware, axial SpA is a form of inflammatory arthritis that most commonly affects the spine. It is a painful and progressive long-term condition affecting approximately 220,000 people in the UK[[1]](#footnote-1) (1 in 200 adults), for which there is currently no cure. It currently takes on average 8 ½ years for someone living with axial SpA within the UK to be diagnosed, during which time people can experience significant amounts of pain, physical disability and anxiety. In short, those affected pay a heavy physical and psychological price for this delay.

Despite the current system pressures resulting from COVID-19, we think however that there is real scope for significantly reducing this delay in the coming years, ­and we ultimately believe that axial SpA can, and should, be diagnosed on average within a year from the onset of symptoms. Achieving this is within our gift and would have the effect of delivering transformative health and wellbeing improvements for all those affected by axial SpA. It would also support the NHS to become a world leader in axial SpA service delivery in the process.

To help identify the key barriers and opportunities for achieving this vision, NASS and leading national axial SpA clinical experts have identified four key reasons for the delay in diagnosis, alongside the corresponding solutions to overcoming them. These high-level delays and solutions are included within ‘annex 1’ of this document, with more detailed tactical suggestions for delivering change provided within ‘annex 2’. Further detail and supporting rationales for all of these areas are included within the corresponding consultation proposal document that has also been shared with you.

As a next step, we are now seeking to engage a broad range of key stakeholders involved in the national and local organisation and delivery of axial SpA services on these proposals, as well as those living with the condition. Consultation questions are included overleaf, responses to which will help inform our scope and how we look to move forward in the months ahead. We know we will only be successful in this journey if we are to work collaboratively. We would therefore be hugely grateful for your time in responding to these questions, which should take around 10-15 minutes to complete.

For any further information, please contact [goldstandard@nass.co.uk](mailto:goldstandard@nass.co.uk)

**Consultation Questions**

(questions can also be answered via SurveyMonkey, at the following link: <https://www.surveymonkey.co.uk/r/Gold-Standard-NASS-Consultation>

1. Which of the following best describes the capacity in which you are responding to this consultation?

|  |  |
| --- | --- |
| Commissioner |  |
| Healthcare practitioner involved in the management of  axial spondyloarthritis |  |
| Individual living with axial spondyloarthritis |  |
| National policymaker |  |
| Parliamentarian |  |
| Professional body representative |  |
| Third sector representative |  |
| Other (please provide further details below) |  |

Please mark the most appropriate answer below

1. Please provide your name, organisation (if applicable) and contact details below. Please note that we are asking for contact details in the event that we feel it would be helpful to discuss elements of your response further.   
   All contact details collected will be handled in accordance with GDPR requirements and will not be shared more widely.
2. Would you be happy for your consultation response to be published?

Please mark the most appropriate answer below:

|  |  |
| --- | --- |
| Yes |  |
| No |  |

1. Are you supportive of the principles behind developing a Gold Standard Time to Diagnosis in axial SpA?

Please mark the most appropriate answer below:

|  |  |
| --- | --- |
| Yes |  |
| No |  |

Please insert any further information on your response in the below comment box.

1. Do you agree with the four key barriers we have identified contributing to the current 8 ½ year average delay in axial SpA diagnosis? Within your answer, please include any additional barriers that you believe should be considered.

Please provide your feedback in the below comment box

1. Do you agree with the four key solutions we have identified for addressing the current 8 ½ year average delay in axial SpA diagnosis? Within your answer, please include any additional solutions that you believe should be considered.

Please provide your feedback in the below comment box

1. What do you think represents realistic implementation timelines for achieving a Gold Standard Time to Diagnosis in Axial SpA across the UK?

Please provide your feedback in the comment boxes below

What should we realistically be looking to achieve within 1 year of an implementation programme?

What should we realistically be looking to achieve within 2 years of an implementation programme?

What should we realistically be looking to achieve within 4 years of an implementation programme?

1. How well do you think the proposed activity areas set out in our implementation plan (annex 2 and supporting document) will help us achieve our first identified solution: ‘Help the person with inflammatory back pain to recognise that it might be axial SpA’? Are there any other areas that you think should be considered?

Please provide your feedback in the below comment box

1. How well do you think the proposed activity areas set out in our implementation plan (annex 2 and supporting document) will help us achieve our second identified solution: ‘Ensure swift identification of potential axial SpA in primary care’? Are there any other areas that you think should be considered?

Please provide your feedback in the below comment box

1. How well do you think the proposed activity areas set out in our implementation plan (annex 2 and supporting document) will help us achieve our third identified solution: ‘Ensure direct referral to rheumatology’? Are there any other areas that you think should be considered?

Please provide your feedback in the below comment box

1. How well do you think the proposed activity areas set out in our implementation plan (annex 2 and supporting document) will help us achieve our fourth identified solution: ‘Ensure that patients get a timely diagnosis from the rheumatologist’? Are there any other areas that you think should be considered?

Please provide your feedback in the below comment box

**Additional questions for those responding on behalf of an organistaion**

1. What role do you think you/your organisation can have in supporting the proposed Gold Standard Time to Diagnosis in axial SpA?

Please provide your feedback in the below comment box

1. Is your organisation currently undertaking any activity, or has planned activity, that you think is relevant (positively or negatively) to the vision of achieving a Gold Standard Time to Diagnosis in axial SpA?

Please provide your feedback in the below comment box:

1. Would your organisation potentially be interested in endorsing the development of a Gold Standard to Diagnosis?

Please mark the most appropriate answer below:

|  |  |
| --- | --- |
| Yes |  |
| No |  |

Please insert any further information on your response in the below comment box:

**Annex 1: Identified delays and solutions to achieving a Gold Standard Time to Diagnosis**

**Identified delays to timely axial SpA diagnosis**

* Delay 1: People do not know that axial SpA may be a cause of their chronic back pain
* Delay 2: General practitioners (GPs) may not recognise features of axial SpA
* Delay 3. People may be referred to non-rheumatologists who may not promptly recognise axial SpA
* Delay 4. Rheumatology and radiology teams may not optimally request or interpret investigations

**Identified solutions to timely axial SpA diagnosis**

* Solution 1. Help the person with inflammatory back pain to recognise that it might be axial SpA
* Solution 2. Ensure swift identification of potential axial SpA in primary care
* Solution 3. Ensure direct referral to rheumatology
* Solution 4. Ensure that patients get a timely diagnosis from the rheumatologist

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**Annex 3: A Gold Standard Time to Diagnosis in Axial Spondyloarthritis: Consultation Proposal Authors**

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**About Gold Standard Time to Diagnosis**

Gold Standard Time to Diagnosis is led by National Axial Spondyloarthritis Society (NASS) in partnership with Norfolk & Norwich NHS Foundation Trust and RUH Bath NHS Foundation Trust.

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1. Louise Hamilton, Alexander MacGregor, Andoni Toms, Victoria Warmington, Edward Pinch, Karl Gaffney, The prevalence of axial spondyloarthritis in the UK: a cross-sectional cohort study, Biomed Central Musculoskeletal Disorders, December 2015 [↑](#footnote-ref-1)