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**A Gold Standard in Treatment and Care for Axial Spondyloarthritis**

**Evidence template for people with lived experience**

Please return this form to aspiringtoexcellence@nass.co.uk no later than Friday 26 July 2024.

**About You**

**Name (not compulsory):**

**Email address (not compulsory):Telephone number (not compulsory):**

**I am a (tick one):**

[ ]  A person with axial spondyloarthritis (including ankylosing spondylitis)

[ ]  A carer, family member or friend of someone with axial spondyloarthritis (including ankylosing spondylitis)

[ ]  Other (please specify)

[ ]  I would prefer to be contacted by email or telephone to have conversation about my experiences.

[ ]  I am happy to complete the form below to share my experiences.

**Are you happy to be contacted to discuss your evidence in more detail?**

[ ]  Yes – you can contact me by email

[ ]  Yes – you can contact me by telephone

[ ]  No

*If you have said yes we will need your email address or telephone number.*

**About your experience**

We now want to know briefly about your experiences. If you have more than one example please do share them all here. Please keep this to around 50 words per example.

We would mainly like to hear about your positive experiences. Tell us about examples of best practice you have experienced, what worked well for you and why.

However if you think there are specific lessons that could be learned from your negative experiences, and have suggestions on how they could have been improved, we are also happy to hear about those.

**Can you tell us what you were offered? For example group exercise, help with dealing your mental health, work advice, information on the condition, help to manage fatigue, help with symptoms other than joint issues such as bowel, eyes, skin.**

**Why were you offered this? For example you find motivating yourself to exercise alone difficult, you were struggling with anxiety following diagnosis, you were considering how best to fit work into life with axial SpA, it is just standard practice for everyone to be offered a formal education session when they are diagnosed.**

**When were you offered this? Was it before you were diagnosed, at diagnosis, in the year or two following diagnosis, or maybe a long time since your diagnosis.**

**Your evidence in more detail**

We now want to know a bit more detail about the treatment and care you received by answering the questions below. The more detail you can give the better.

**How would you describe what you were offered?**

**Was it individual or group?**

**Where was it delivered? For example at a hospital, in a community setting, at home.**

**Who delivered it? For example one of your health care team such as your rheumatologist, physiotherapist, occupational therapist. Or maybe it was someone you saw privately like an osteopath, or even a gym instructor. It could be that you attended an event hosted by a charity like NASS.**

**How was it delivered? For example, was it online or in person.**

**How often and for how long?**

**Did your axial SpA improve and/or quality of life and/or emotional wellbeing improve? Tell us how. For example you may have increased ability to work, ability to self-manage flares, seen improvements in your bowel, skin, eye problems, increased energy or improved relationships and social activity.**

**Were you asked to report back about your experiences and the impact on your axial SpA?**

**How, did you share your experiences and impact on your axial SpA? For example, you may have completed a survey, or taken part in a focus group, or asked to feedback to the person who delivered the service.**

**Understanding our audience**

Now we are going to ask you a few questions about who you are. You don’t have to answer these, but it does help us to understand who we are reaching and who found what helpful.

1. **Where in the UK or British Isles are you based?**

[ ]  England

[ ]  Northern Ireland

[ ]  Scotland

[ ]  Wales

[ ]  Channel Islands

[ ]  Isle of Man

[ ]  I am based elsewhere (please tell us where):

1. **Do you identify as:**

[ ]  Male

[ ]  Female

[ ]  Non-binary

[ ]  Prefer not to say

[ ]  I prefer to use another term (please state):

1. **Is your gender identity the same as you were assigned at birth?**

[ ]  Yes

[ ]  No

[ ]  Prefer not to say

1. **Please choose your age bracket**.

[ ]  Under 18

[ ]  18-24

[ ]  25-34

[ ]  35-44

[ ]  45-54

[ ]  55-64

[ ]  65+

1. **What is your religion or belief?**

[ ]  Buddhist

[ ]  Christian (all denominations)

[ ]  Hindu

[ ]  Humanist

[ ]  Jewish

[ ]  Muslim

[ ]  Sikh

[ ]  Nothing in particular

[ ]  Atheist or agnostic

[ ]  Prefer not to say

[ ]  Other (please specify):

1. **What is your ethnic group?**

[ ]  Arab

[ ]  Asian (Indian)

[ ]  Asian (Pakistani)

[ ]  Asian (Bangladeshi)

[ ]  Asian (Chinese)

[ ]  Asian (other)

[ ]  Black (African)

[ ]  Black (Caribbean)

[ ]  Black (other)

[ ]  Mixed (black and white)

[ ]  Mixed (Asian and white)

[ ]  Mixed (other)

[ ]  White (English, Welsh, Scottish, Northern Irish or British)

[ ]  White (Irish)

[ ]  White (Gypsy or Irish Traveller)

[ ]  White (Roma)

[ ]  White (other)

[ ]  Prefer not to say

[ ]  Other (please specify):

1. **The Disability Discrimination Act as incorporated in Equality Act 2010 defines a person as disabled if they have a physical or mental impairment which has substantial and long term (i.e. has lasted or is expected to last at least 12 months) adverse effect on their ability to carry out normal day-to-day activities.**

**Adverse effects may arise from external barriers experienced by people with impairments. When you answer the question, you should not take into account the effect of any medication or treatments used or adjustments made (for example at work or at home) which reduce the effects of impairments. Instead, you should think about the effect the impairment would have if these were not being used or made.**

**Taking this into account, do you consider yourself to be a disabled person**?

[ ]  Yes

[ ]  No

[ ]  Prefer not to say

1. **What is your sexual orientation?**

[ ]  Bisexual

[ ]  Gay or lesbian

[ ]  Heterosexual / straight

[ ]  Prefer not to say

[ ]  I prefer to use another term (please state):

1. **Do you consider yourself to be from a low-income household? That is £15,000 a year income before tax or less.**

[ ]  Yes

[ ]  No

[ ]  Prefer not to say

