Invitation to Tender

The emotional impact of axial spondyloarthritis

Introduction

Tenders are invited to undertake qualitative research with a sample of people who have axial spondyloarthritis (referred to here as axial SpA (AS)). The research findings will be used for two principal purposes:

- to inform our campaign Every Patient, Every Time which aims to improve the quality of NHS care for people with AS
- to inform the development of NASS's support to people with AS who have poor emotional well-being.

We intend to publish materials based on the research (including the full report).

This document provides background information, describes the research questions, offers some initial thinking about potential sampling and summarises key tasks, available budget and timescale.

Background to axial SpA (AS)

Axial SpA (AS) is a painful, incurable inflammatory arthritis. It mainly affects the spine but can also affect other joints in the body, including the hips, knees, feet, shoulders, elbows and hands. Additionally, it can affect:

- The eyes. 30-40% will have an attack of uveitis at some time in their life. This is an eye condition caused by inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens
- The gut. 7% will develop inflammatory bowel disease including Crohn's Disease and Ulcerative Colitis
- The skin. 9% will develop psoriasis

People with axial SpA (AS) will be living with daily pain, stiffness and high levels of fatigue.

Axial SpA (AS) is a condition that affects young people. Symptoms start in late teens to early twenties, with the average age of onset being 24. It is managed through medication to reduce the inflammation and regular exercise. However, it lasts a lifetime and is characterised by regular flare ups of the disease.

An estimated 1 in 200 of the adult population in the UK have axial SpA (AS).

The current average delay to diagnosis from when symptoms start is 8.5 years, by which time irreversible damage to the spine may have occurred. During this time, people are living with uncertainty and pain.

Axial SpA (AS) and emotional wellbeing

Anecdotally, we know that people with axial SpA (AS) often have poor emotional wellbeing, as they often experience fatigue, social isolation, guilt, concerns about their body image and anxiety about having flares. For younger people, these feelings can be amplified, and there is some research suggesting that rates of depression are higher among younger people with AS.

Prevalence studies indicate that up to 59% of people with axial SpA (AS) have depression – this is significantly higher than both the general population and other musculoskeletal conditions. Factors associated with moderate-severe depression include disease related factors (higher disease, greater functional impairment), socio-economic and smoking status. People with axial SpA (AS) have increased risk of developing depressive disorders following their diagnosis. People with axial SpA (AS) and poor mental health are also more likely to have other co-morbidities.

Therefore, we have a large population of people with axial SpA (AS) and poor emotional well-being who are likely to require treatment and support. We don't know the extent to which relevant clinicians are recognising and treating appropriately but suspect care may be sub-optimal.

Research questions

1) What is the emotional impact of:

- ***Living with the symptoms before diagnosis***. What's it like to live for an average of 8.5 years without a diagnosis? How does this delay impact on people's long-term emotional wellbeing?
- ***Getting a diagnosis.*** What is the impact of receiving a diagnosis of axial SpA (AS)? How do initial feelings develop over the first few months after diagnosis?
- ***The first year*** of living with axial SpA (AS)
- ***Working.*** Did it impact on their chosen career, did they have to change jobs, lost opportunities? What was the emotional impact of that?
- ***Relationships.*** Did it cause relationship break downs, difficulties in their relationships. What was the emotional impact of that?
- ***Family life.*** Did it stop them having a family, cause worries or anxieties, make family life hard? What was the emotional impact of that?
- ***Social life?*** What was the impact on their social life? What was the emotional impact of that?

2) Throughout we want to understand whether people have suffered with any mental illness such as depression or anxiety

3) What are people's coping strategies, the experiences they have had of (not) being supported by primary and secondary care. What gets in the way? What helps?

4) What are their support needs and how should these be provided?

5) What do they need from NASS in this regard?

Target audience

Our target audience is people diagnosed with axial SpA (AS) who self-report as having poor emotional well-being. We have access to this target audience and will recruit the sample once the sampling frame is agreed. We would like your input and advice on how our target audience should be segmented. We might consider:

- Age
- Time since diagnosis
- Gender
- Location within the UK

Research approach

Whilst there have been quantitative studies on emotional wellbeing and axial SpA (AS) there has been a paucity of qualitative studies on the emotional impact, service experience and unmet needs. Thus, we are proposing a qualitative approach to the present study.

We welcome your views about the most appropriate methods to use, whether focus groups, mini groups, trios, duos etc.

Key tasks for the contractor

- Carry out a literature review
- Get ethical approval
- Meet with NASS to design the discussion guide and agree the sampling frame
- Conduct all fieldwork (NASS will recruit the sample and take care of all logistical considerations)
- Conduct all analysis
- Write final report based on feedback from NASS and peer review.
- Write and submit a paper for publication in a peer-reviewed journal on the study's key themes, in collaboration with a rheumatologist and
- an academic associated with NASS.
- Prepare an abstract for oral / poster presentation at conference

Available budget

A budget of between £15,000 and £18,000 is available, inclusive of VAT and all costs.

Timescale

We would like proposals in by Friday 14 June 2019. Please send your proposal to Sally Dickinson by email.

We would like advice on achievable timescales, starting ASAP

Contact details:

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