

The research is organized by the School of Medicine at Swansea University and being funded by the Medical Research Council (MRC)

AS in Wales

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What is the purpose of the study?

Ankylosing Spondylitis (AS) is the second most common form of inflammatory arthritis. But, there is a lack of research into the condition. This study will help us to better understand the condition. We will be looking at why some people develop severe AS. We would like to identify patients who could benefit from early use of intense therapy in order to prevent the development of severe AS. We want to examine the impact and cost of AS in order to better estimate the cost of new treatments, so that hopefully they are made available sooner for people with AS. The study can therefore help improve care for people with AS. For more information please see the study website <http://www.asinwales.swan.ac.uk/>

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Welcome to the first newsletter for the Population-based Ankylosing Spondylitis (PAS) cohort in Wales study. This will be a regular feature to keep you informed of new developments and progress of the study, as well as important results from the study. We are grateful for all your participation and completed questionnaires which are already yielding important information about AS. We hope you will all continue to contribute, as without participants like you, this study would not be possible.

Quotes from people participating

"I feel the main cost of my AS is borne by my wife and (very grown up) 12 year old son. Dealing with somebody who can be the most miserable sod in the world (it just comes on for no apparent reason). We are getting better at dealing with it, but it's never easy, they can both pick up now quite quickly when dad's not feeling too good, and also them understanding that sometimes I am just too exhausted to join in with normal family activities. Without their help, love and understanding I could never deal

"AS has had a lot of effect on my working life, because of difficulty in movement of neck and shoulders."
(72 year old man)

"I would value free admission to my local swimming pool/gym which would help encourage my self-help programme."
(56 year old man)



"The emotional cost is vast based on the restrictions of physical movement which has affected the sport I played, the vehicles I drive and the personal relationships."
(63 year old man)

"I am unsure as to whether my ongoing participation in this study will be of any use to you. While in my late teens and 20s I was virtually crippled by AS, I am now virtually symptom free. For example I used a walking stick at 19. Yesterday at 58, I ran 10 miles. Please excuse the boastfulness. I am just so delighted that I can."
(58 year old man)

"I have had hip surgery twice this year. I have had resurfacing of both hips. I do not think the long term use of medication i.e. arcoxia helped my condition which I have been on for a period of 4 years."
(49 year old man)

Characteristics of study participants

- The average age of people participating is 54 years old (youngest person is aged 20 and the oldest person is aged 100).

- There are 238 men and 84 women (3 males to every 1 female) participating.

- Average age of first symptoms is 25 years and the age of first diagnosis is on average 34 years with a resultant delay in diagnosis of an average of 9 years.

- 26 people in every 100 have a close family member who also has AS.

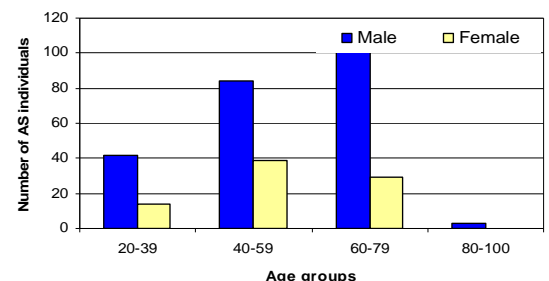
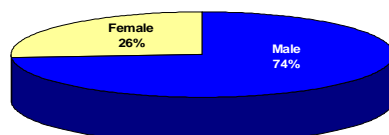
- 18 people in every 100 also have inflammatory bowel disease (IBD), 14 in every 100 also have psoriasis (inflammation of the skin) and 37 in every 100 have iritis (inflammation of the eye).

- 42 people in every 100 have seen their GP in the past month, with an average number of 1.5 visits per month.

- 46 in every 100 people are working (the majority of non-working participants are retired or not looking or work).

- People with AS retire 10 years earlier (9 years earlier for men and 11 years earlier for females) compared to those without AS in their profession.

- People with AS have a Work Productivity Loss of 7%. Consequently, improved treatment may improve work productivity and time remaining in work, thus offsetting some of the cost of anti-TNF treatment.





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What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with AS. We hope that in future results from questionnaires relating to disease severity measures (such as disease activity and functional levels) will be entered into your records held by your rheumatologist. Scores from your existing X-rays or MRI scans can also be entered into the computer system for your rheumatologist to see and use. Therefore, they can have a more full picture of your AS when you have an appointment.

What will happen to the results of the research study?

The findings from the study will be sent to the National Ankylosing Spondylitis Society to go in their newsletter. We will send regular summaries of the findings to you by post with your questionnaires or as quoted on the front page of this Newsletter. Findings will be published on the AS research website. As well as this we will submit findings to be presented at national and international conferences and in peer reviewed journals. No participants in the study will be identified in any reports/publications.

National Ankylosing Spondylitis Society (NASS)

The National Ankylosing Spondylitis Society is a national charity providing help and information for people with AS. We have a range of factsheets and booklets to help patients that we are increasing steadily, whether newly diagnosed or have had AS for a longer time.

In Spring 2010 we are hoping to hold a regional conference for people with AS with a focus on the issues that patients face in Wales. More details will follow on our website www.nass.co.uk and our newsletter.

NASS currently has 6 branches in Wales that provide regular hydrotherapy and exercise sessions for members and are supported by physiotherapists:



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