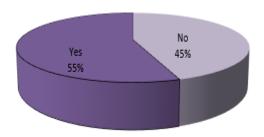


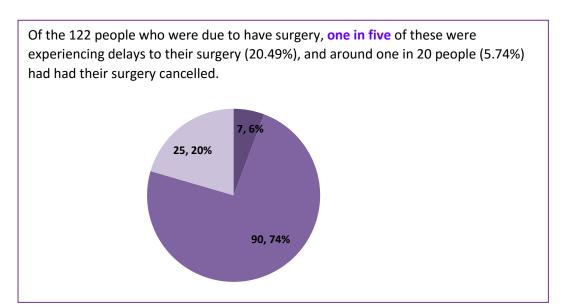
# ARMA survey on restrictions on access to treatments and services

The Arthritis and Musculoskeletal Alliance (ARMA) carried out a survey between 12<sup>th</sup> November 2015 and 15<sup>th</sup> January 2016. The survey was open to people with musculoskeletal (MSK) conditions and asked them if they had experienced any restrictions to accessing treatment and/or services.

Of the 478 people who responded to whether they had experienced restrictions in accessing treatment or services, 264 (55.23%) said they had.



Half of all people surveyed had experienced restrictions – with many saying they had difficulty in getting referrals to Rheumatologists and Physiotherapists. Once referred, many experienced long waits to access these specialists.



One in two people felt that the restrictions, delays and/or their condition had a negative impact on their life.

### Survey respondents said:

'Judgement & a lack of interest, understanding, tolerance and concern. Fighting to be heard, understood and treated'.

'Very long wait to see specialists, lack of GP knowledge.'

'People don't understand because they can't see an illness.'



## **Key findings:**

- Lack of understanding within primary care GPs had limited knowledge of conditions and the impact of MSK conditions on people's lives
- Lack of referrals to specialists. This is especially important for people diagnosed with Inflammatory Arthritis who should receive specialist treatment within 3 months.
- Inconsistent services across England, with some areas having no facilities such as Hydrotherapy pools or pain clinics available.
- People who do not live near specialist clinics or health care hubs find it hard to access high quality care.
- Lack of ongoing care and support for chronic conditions.
- People described feeling dismissed, that their symptoms were not taken seriously.
- Often only painkillers or anti-depressants were prescribed, not specialist medication.
- People do not understand because they cannot see the condition ('invisible illness').
- Lack of awareness of the disruption caused by delayed/cancelled operations (upon work/ family/childcare) – "life on hold".
- Reliant upon charities rather than statutory care.
- No help with accessing pain management courses.

#### **Key recommendations:**

- All Health Care Professionals treating people with MSK conditions should be sufficiently equipped to offer quality care and refer as appropriate.
- Commissioners to ensure the right services are provided for the needs of the local population. See ARMA's Key messages for commissioners document.
- People with chronic conditions to have continuity and coordination of care
- Health professionals should refer people with MSK conditions to patient-led organisations
  which are capable of providing additional information and support (e.g. .helplines, peer
  support, self-management courses) as a matter of course. Please refer to ARMA's
  membership page for more information.



### Case study

My last appointment with the Rheumatologist for my Ankylosing Spondylitis (AS) was 4 months overdue meaning I had to wait 16 months between appointments. I wasn't given any explanation for this delay. I cannot remember the last time I received any physio, it was years ago. It has also been years since I had Hydro therapy and have had no other treatments since. There has been no explanation of why I can no longer access such services.

I am on medication for my AS and if prescribed any new medication have to check that this will not impact on another condition I have. If I do change meds and there are any problems, my G.P. puts me back on the previous medication until my next visit to the consultant.

Over the years I have felt that my care is the bare minimum. Having said this, I attended the clinic in April this year, and was amazed to find that I was with the Consultant for almost half an hour. I had a brief examination (the first for years.) I have had x-rays and am now awaiting an MRI scan. This is the first positive consultation I have had in many years.

I attended the NASS conference last year and heard the keynote speaker, a consultant from a Rheumatology Department, speaking about the multi discipline approach offered in her dept. to patients with AS. It really did confirm to me that our local department is lacking in so many ways with no liaison between Rheumatology and other departments in the hospital.

Anna, Hull and East Riding\* name changed

For more information see arma.uk.net or email projects@arma.uk.net