

# NASS Update

Debbie Cook, Chief Executive



# About NASS



- Only registered charity dedicated to AS
- Formed 1976
- 6 members staff
- 4,000+ members
- 95 branches



# Supporting people affected by AS

[www.nass.co.uk](http://www.nass.co.uk)



- 250k+ sessions in past 12 months
- Mobile optimised Easter 2016

## News

## Research

# Campaigning



## Getting My Diagnosis



## Just Diagnosed



## Living Well with AS



## Exercises for AS

# AS one



- New initiative for young people with AS
- Website currently being developed
- Focus on transitional stage of life (18 – 35)
- A place to exchange experiences and ideas – use of social media
- Launch early 2017
- 2017 – activity weekends, formal launch party, raising awareness





# Social media



@NASSexercise (3,000+)

@NASSchiefexec (3,200+)

Facebook (11,000)

NASS Forum (2,000)



# Publications

Guidebook

Anti TNF Guide

Managing your AS at Work

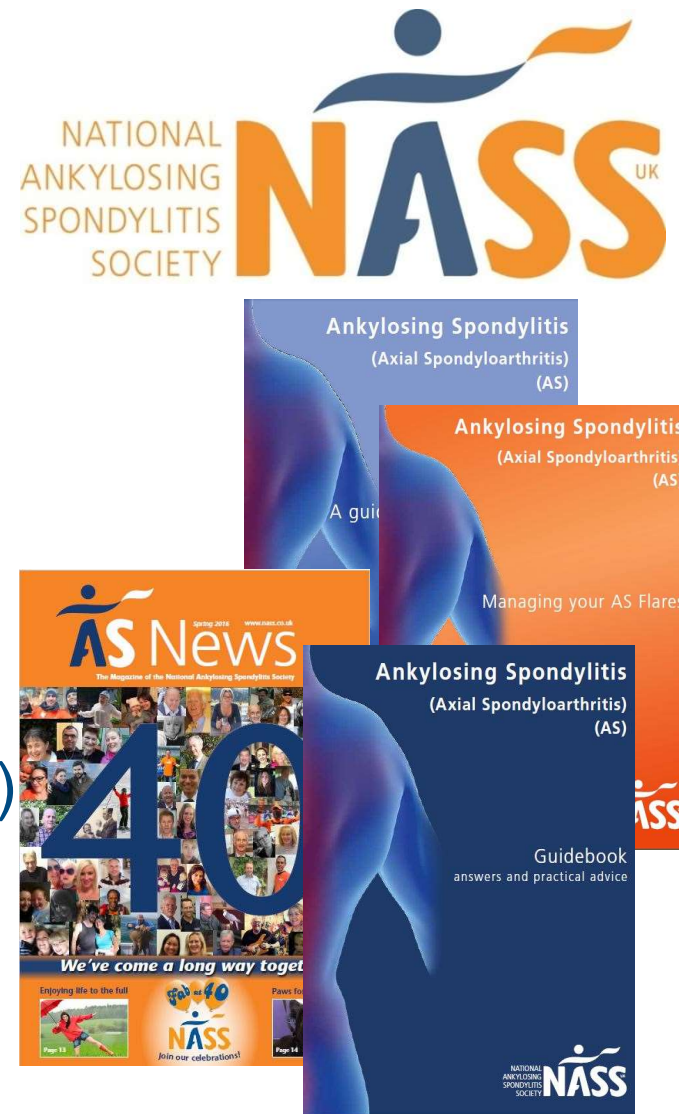
Managing AS Flares

Factsheets (Driving, Fatigue, Uveitis)

AS News

Benefits guides

My plan for life with...'



# Helpline



- 5,000+ contacts a year
- Medication, benefits (supporting letters), diagnosis, exercise
- 020 8741 1515 – Mon–Fri – 0900–1200
- Supported by Medical Advisory Board





# Exercise guides



## Exercising safely in a gym with AS

Part 1 available as pdf, app and book

Part 2 just released – Gym balls & free weights

Fight Back DVD ideal for more advanced AS



**BACK TO ACTION**



**BACK TO ACTION**

Part Two: Free Weights & Gym Balls



# Back to Action Part 2



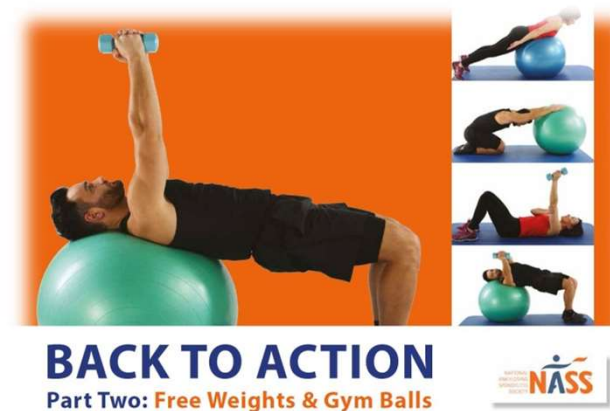
## Gym Balls & Free Weights

40 new exercises

Free copies sent to 400 physiotherapy departments

Free copy to every NASS branch

App being updated – videos & voiceovers for every exercise



# NASS Branches



- 95 branches across UK
- Meet for supervised physiotherapy sessions
- Most meet in hospital gyms and hydro pools
- 'NASS Near You' webpage
- Always developing new branches



# Members' Day



- Once a year at weekend
- Different location every year
- Presentations from HCPs, practical sessions, chance to meet others
- 2017 will be focussed on managing flares



# Giving patients a voice



# Giving patients a voice



- Important role of NASS is to give people living with AS a voice
- Listen to patients informally via social media, NASS Helpline, Members' Day
- Listen more formally through surveys



# State of the Nation 2016



**2000 respondents**

**56% Male**

**44% Female**

**30% Under 44**

**48% 45-64**

**22% 65+**

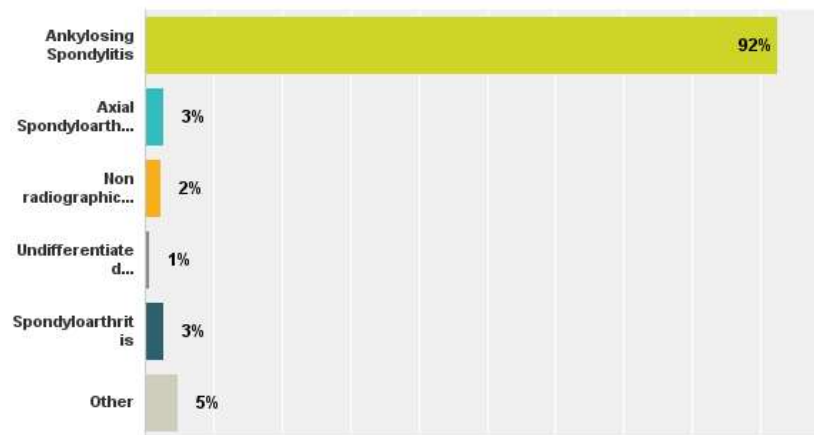
**From across UK**



# Nomenclature

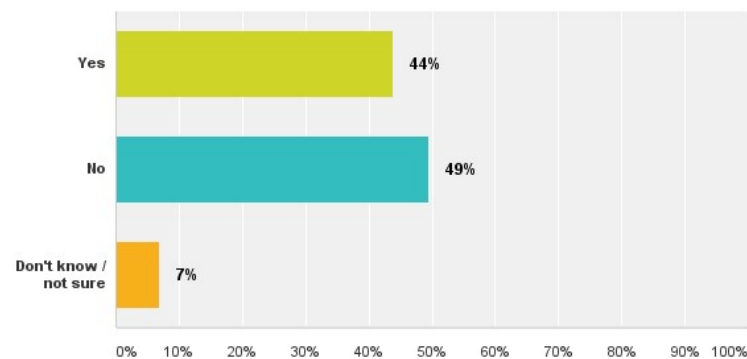
## Q4 What diagnosis have you been given?

Answered: 1,989 Skipped: 11



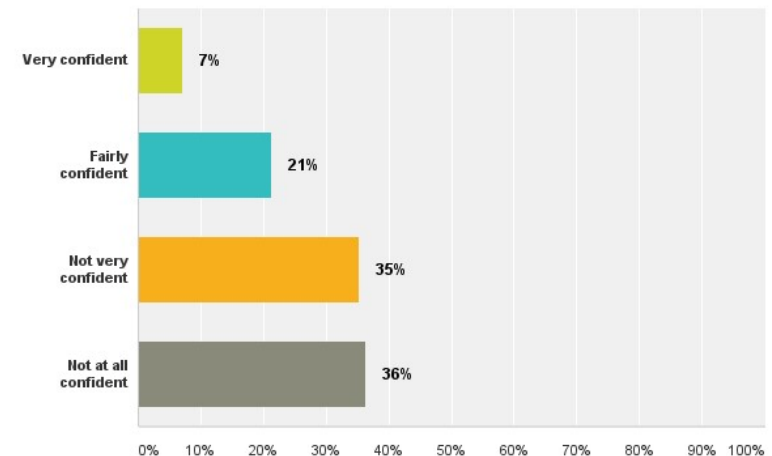
## Q5 Have you previously heard of the term axial spondyloarthritis?

Answered: 1,980 Skipped: 20



## Q6 And how confident would you say you feel about the meaning of the term axial spondyloarthritis?

Answered: 1,962 Skipped: 38

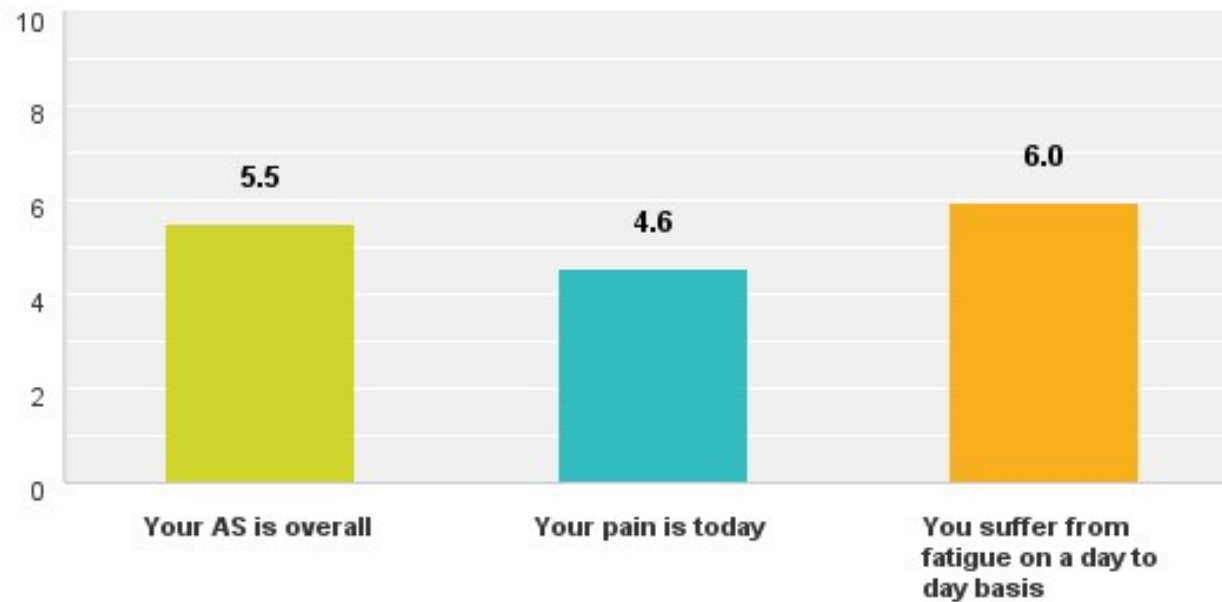


# Severity of disease



**Q14 On a scale of 1 to 10 how would you estimate....**

Answered: 1,941 Skipped: 59

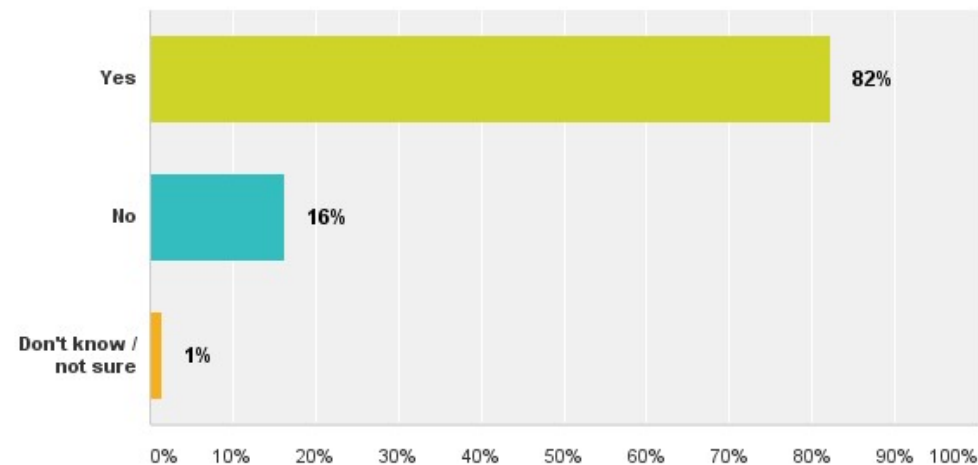


# Are patients reaching secondary care?



**Q15** Are you currently under the care of a rheumatologist for your AS?

Answered: 1,941 Skipped: 59



↑70% in 2010 and 78% in 2013

BUT recent study from University of Aberdeen indicates just one third of patients under care of rheumatologist

SO is there a NASS effect?



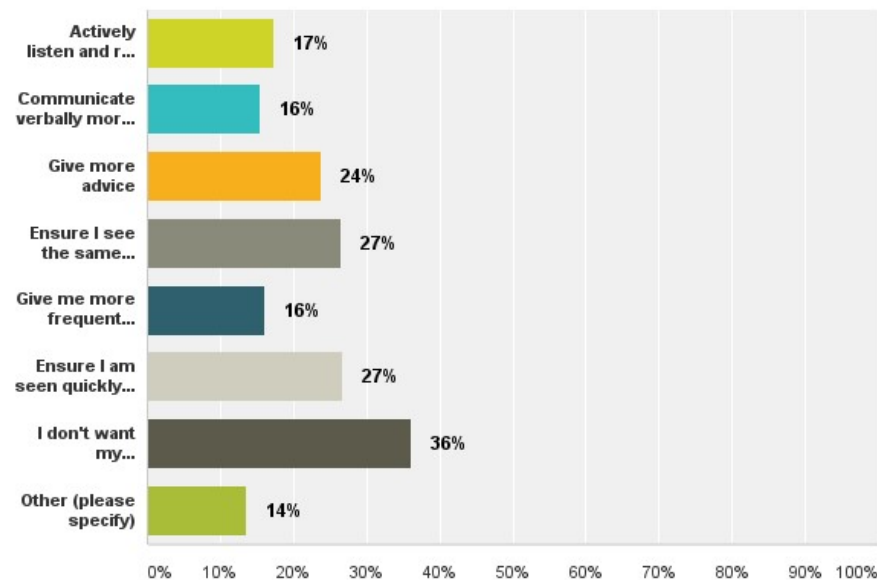
# Satisfaction with rheumatologist



Satisfaction rating with rheumatologist of 4.02 out of 5 (4.09 in 2013)

**Q19 Which of the following, if any, would you like your rheumatologist to do differently....**

Answered: 1,532 Skipped: 468

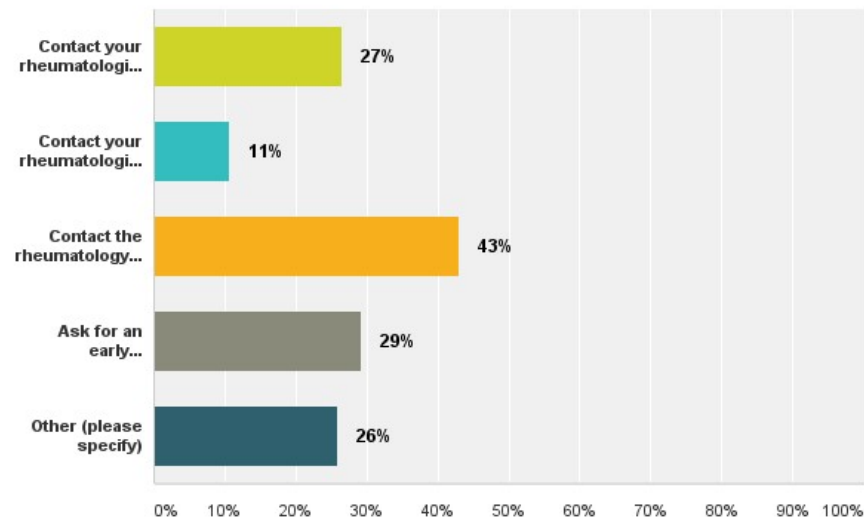


# Access to help during a flare



**Q21 If you suffer from a flare up of your AS are you able to....**

Answered: 1,473 Skipped: 527



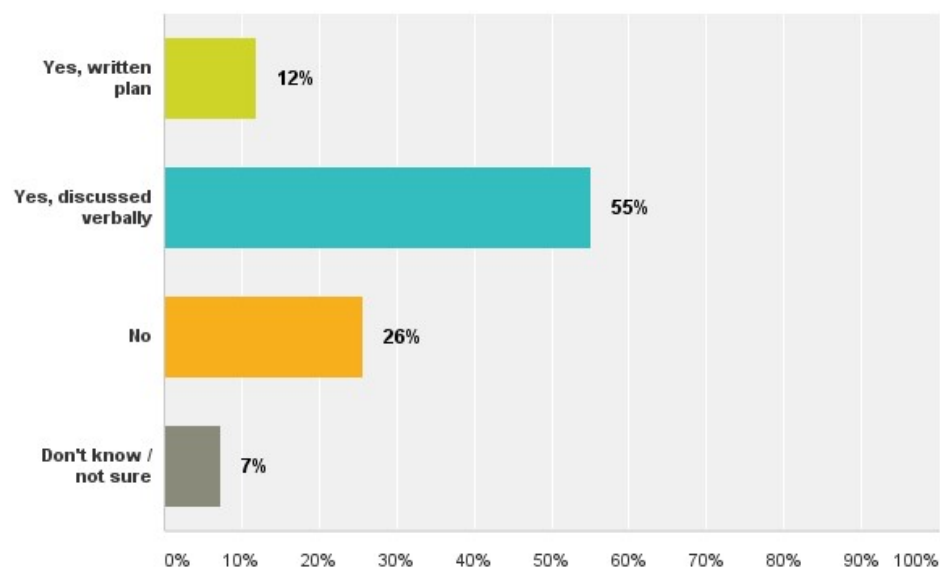
- Satisfaction with help and advice from rheumatology department during a flare 3.51 out of possible 5
- 20% not very or not at all satisfied

# Management Plan



**Q26 Has your rheumatology department provided you with an agreed treatment or management plan to help you manage the symptoms of your AS?**

Answered: 1,527 Skipped: 473



Worked with other organisations to develop My Plan for Life

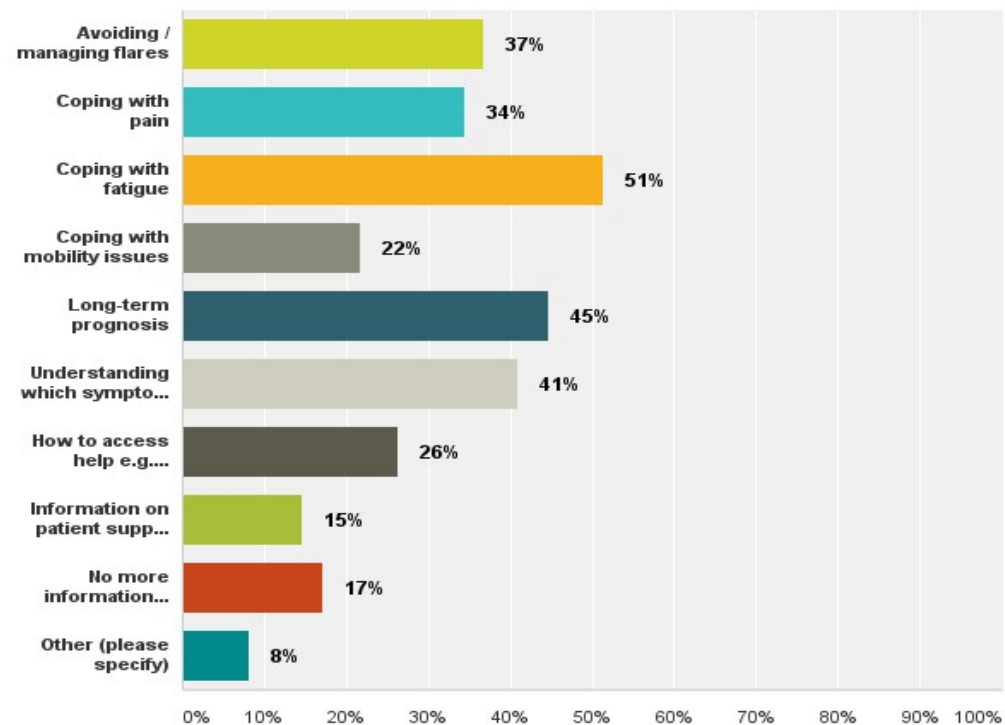
# Information



**77%** feel they have received all or most of the information they need from their rheumatology team

**Q28 And which of the following, if any, would you like more information on?**

Answered: 1,383 Skipped: 429



# Access to physiotherapy



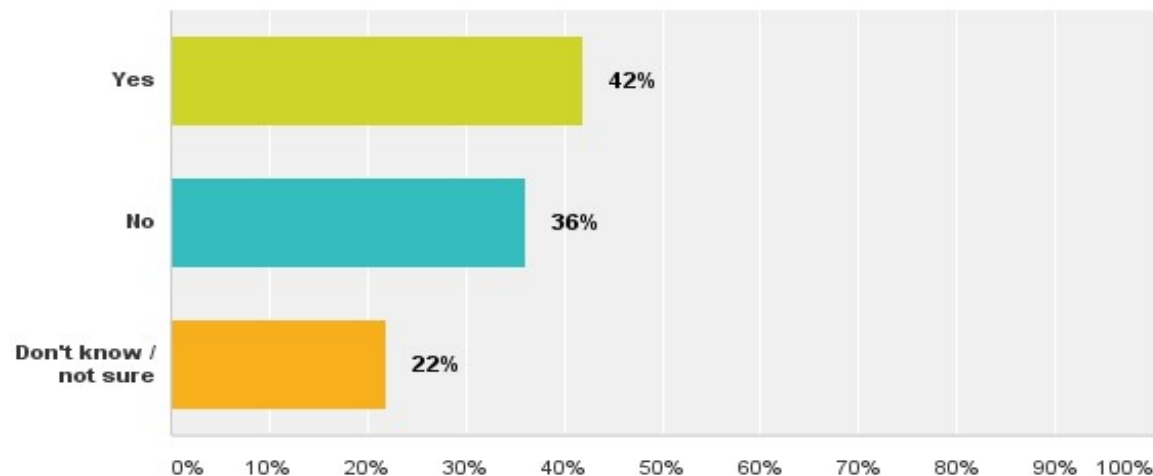
46% have seen a physiotherapist in the past 12 months

↑ from 39% in 2013

Only 27% of those seeing a physio were aware they could self refer during a flare

## Q40 Would you like to see a physiotherapist for your AS?

Answered: 988 Skipped: 1,012

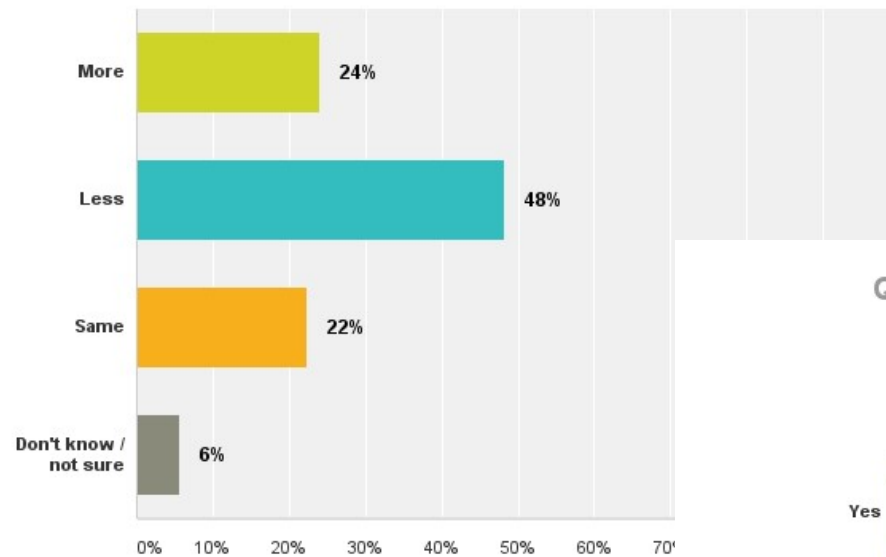




# Exercise levels

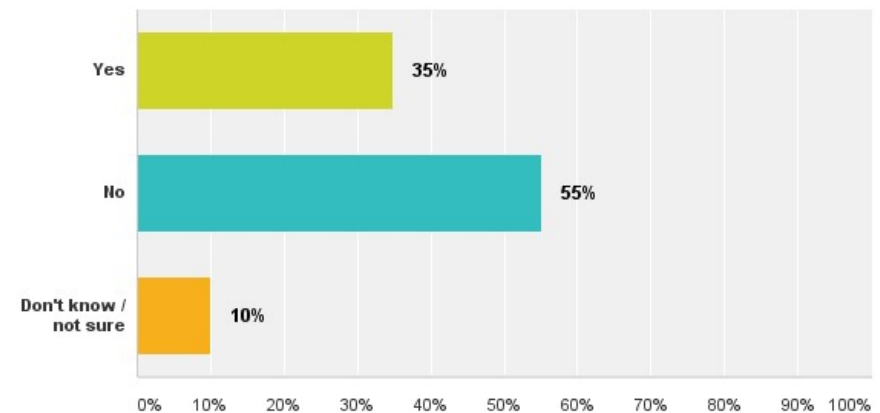
**Q48 Overall would you say that you are physically more active, less active or about as active as other people your age?**

Answered: 1,801 Skipped: 199



**Q49 Overall, do you feel you take enough exercise for your AS and your general health and wellbeing?**

Answered: 1,798 Skipped: 202



# Barriers to exercise



**Q50** What, if any, would you say are the biggest barriers to exercising for you?

Answered: 1,583 Skipped: 417

Family Age Flare Ups Children Knee Problems Neck  
Condition Walking Laziness Stiffness  
Weather Fatigue Spine Pain Life  
Exercise Gym Motivation Pool Mobility  
Access Tiredness Job Tired Health Issues Energy

# Improving awareness and understanding



RCGP Learning

Essential CPD for primary care

NATIONAL  
ANKYLOSING  
SPONDYLITIS  
SOCIETY



## Delay to diagnosis remains at 8.5 years

- Over past 5 years reached more than 25,000 GPs
- Now working with RCGP on two eLearning modules
  - Diagnosing axial spondyloarthritis
  - Managing axial spondyloarthritis
- Hope to launch at end 2016
- Have potential to reach 50,000 HCPs

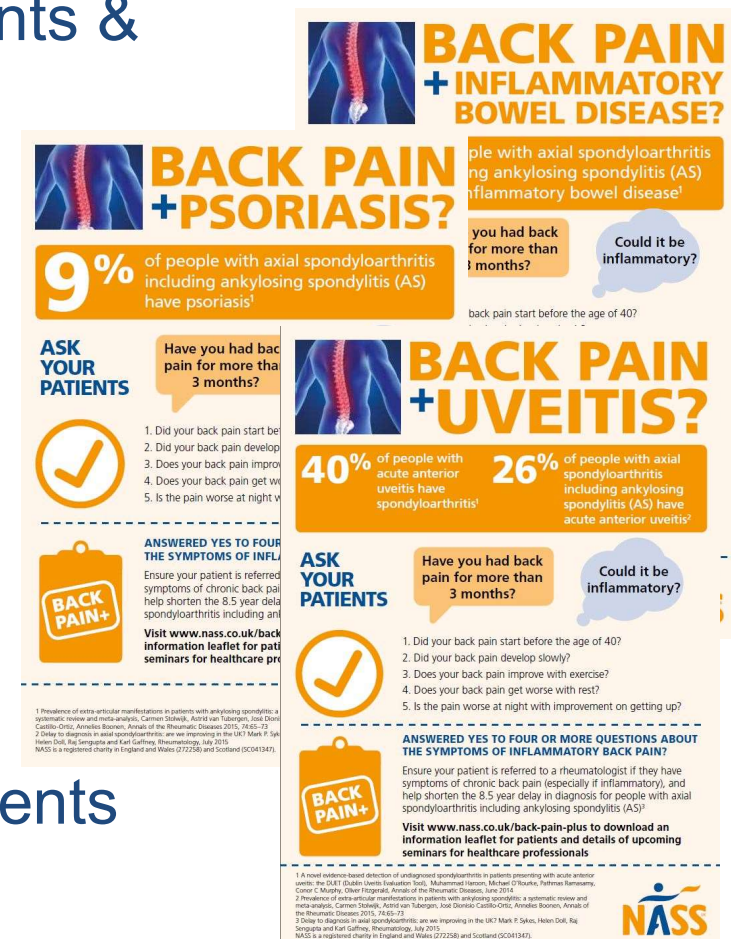
# Back Pain Plus

Awareness campaign aimed at  
Ophthalmologists  
Dermatologists  
Gastroenterologists

- 40% with acute anterior uveitis have spondyloarthritis
- 9% of people with AS have psoriasis
- 7% of people with AS have inflammatory bowel disease







# Research Fund



**Launched January 2015**

6 projects funded

- Diet (Aberdeen)
- Fatigue (Warwick)
- Mindfulness (Swansea)
- Physiotherapy course (Cardiff)
- Quality of Life Experiences of Bangladeshi patients (London)
- Lower Back Pain & Psoriasis (Stoke on Trent)

3 Educational bursaries awarded relating to physiotherapy



# AS Clinic Near You



## Patients want to choose a rheumatologist with an interest in AS

- 2017
- Area on website similar to NASS Near You
- Approach all Rheumatology Departments for information
- Would you like built in feedback?

Enter your postcode or your nearest town

Your postcode

Search

# Patients' Choice Awards

Recognising great care



Thank you  
[@NASSchiefexec](#)