What Patients Want from a Rheumatology Service

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Trustee, National Rheumatoid Arthritis Society
My talk will cover

- Impact of delayed diagnosis
- How people come to a diagnosis
- Patient Activation - Partners in our care?
- Variation in pathways/access to care
- What does good look like?
- Results of a poll on social media
- Getting help *when you need it*
- Influence of depression in early RA
- Lifelong medication
- Biologics and biosimilars - switching
- Work - a health outcome?
- Don’t ignore our feet – difficulty of accessing specialist podiatry
- Annual Reviews
Delays in Diagnosis

NAO Report 2009

- People with RA visit a GP on average 4 times before being referred to a specialist for diagnosis, and 18 per cent of patients visit more than 8 times.

HQIP Early IA/RA Audit – 1st & 2nd year data

- Only 17%/20% of people were referred by a GP within the recommended period in NICE QS1
- Only 38%/37% of people referred were seen in specialist care within 3 weeks, NICE QS2
- Average time from symptom onset to starting DMARDs 6 months (ERAN data) – 68% yr 2 within 6 weeks
- Raising public awareness of the impact of Rheumatoid and inflammatory arthritis is key – S Factor posters available
- Talking about ‘arthritis’ in umbrella terms doesn’t help public understanding of the difference in types of arthritis
Have you got... The $S$ factor?

- **Stiffness**: Early morning joint stiffness lasting over 30 minutes
- **Swelling**: Persistent swelling of one joint or more, especially hand joints
- **Squeezing**: Squeezing the joints is painful in inflammatory arthritis

This could be inflammatory arthritis

See your doctor now!
Delay can cause long term disability
For more information, see www.nras.org.uk
Issues around coming to a diagnosis

- Shock
- Anger
- Relief
- Why me?
- Grieving
- Loss
- Anxiety
- Sadness
- Impact on job
- Impact on family
- I don’t do drugs
- Future dreams and ambitions
- Ability to understand health issues – Patient Activation

National Rheumatoid Arthritis Society (NRAS)
Patient Activation Measure

Level 1
Disengaged and overwhelmed
Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor. Their perspective: “My doctor is in charge of my health.”

Level 2
Becoming aware, but still struggling
Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals. Their perspective: “I could be doing more.”

Level 3
Taking action
Individuals have the key facts and are building self-management skills. They strive for best practice behaviors, and are goal-oriented. Their perspective: “I’m part of my health care team.”

Level 4
Maintaining behaviors and pushing further
Individuals have adopted new behaviors, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus. Their perspective: “I’m my own advocate.”

Increasing Level of Activation

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Partnership working

You might be a Dr. but I’m an expert in ‘me’ and ‘my life’
Results of a poll on social media

Big Poll Question on HealthUnlocked

Which three things would matter most to you about access to a rheumatology service?

385 Voters

292 Getting access to the treatments and care I need when I need it
226 Knowing I can get help when I need it
191 Having trust in my team
189 Treating me as an individual, not just my disease
149 Getting access to members of team when I need it, e.g. physio, occupational therapist
58 Getting a holistic annual review
38 Getting access to research studies and trials
33 Getting access to counselling or talking about therapies if needed

Big Poll Question on Facebook

Amogst the options below, what would matter most to you in a rheumatology service?

224 Voters

- Getting access to the treatments and care I need when I need it
- Knowing I can get help when I need it
- Having trust in my team
- Treating me as an individual, not just my disease
- Getting access to members of team when I need it, e.g. physio, OT
- Getting access to counselling or talking about therapies if needed
- Getting a holistic annual review
- Getting access to research studies and trials
Variation in practice and access to care

There is significant variation in the way care is delivered across the UK
HQIP, Kings Fund and NAO Reports, State of Play in UK Rheumatology

- Impact on individuals of variation in practice is apparent on on-line forums
- It’s clear from calls and contact to our helpline
- Access to structured self-management programmes is very limited
- People don’t know what they don’t know or what good looks like if they’ve never experienced it!
- It’s pot luck where you happen to live, some get great care, others don’t always
- Some units do a DAS every visit, others don’t, some do T2T some don’t
- A few do holistic annual reviews, most don’t (well, not in line with NICE guidelines!)
- Primary and secondary care teams are more integrated in some areas than others
- Clinicians interpret guidelines differently, even within the same unit!

Result for patients: Confusion, anxiety

Our Goal is to be there at the start of everyone’s journey with RA and whenever they need us along the way, to reduce that confusion and anxiety.
What does ‘good’ look like?

- Clear referral protocols for primary care
- Early Arthritis Clinic, reducing time to diagnosis
- A team who buy into the principles of Shared Decision-making, care planning and supported self management
- Access to right treatment at the right time from a well-resourced MDT
- Confidence and trust in the team
- Access to research trials, programmes/studies
- Being sign-posted to NRAS and other organisations who can help at point of diagnosis
- A team who operate T2T and tight control in line with best practice guidelines
- Being given clear instructions on how to get help when you need it - access to Nurse-led helpline
- Monitoring in the community – shared care
- Proper holistic annual reviews
- Work – a health outcome
Help when you need it

- Learning how, when and where to get help early on is key for patients

- Access to education/self management = better use of NHS resources

HQIP Audit
People with RA should receive advice within 1 working day of contacting the rheumatology service

96%/92% of patients had access to urgent advice within 1 working day

59%/67% of patients offered structured patient education and self-management service within 1 month of diagnosis
Impact and influence of Depression in early RA - 1

Depression affects up to 40% of patients
Many studies indicate improved outcomes with intensive T2T strategies but impact on psychological co-morbidity unknown

In a recent cross-sectional study in O/P – 2013 - first 24 months of care
98 patients filled in HADS, ASES, Pain scale and team had access to clinical info incl DAS for 65% of these patients

- 42% were anxious
- 32% were depressed
- 24% both anxious and depressed
- Further analysis of HADS score indicated 6.1% severely depressed
Impact and influence of Depression in early RA –2

Results:
• Strong correlation between mood disturbance and patients’ SE scores
• Same found with pain scores
• Higher levels of depression associated with higher DAS – specifically the subjective elements, *tender joints and patient global*
• Number of swollen joints and ESR did not correlate with depression
• Time since diagnosis does not correlate with either depression or anxiety

Implications/conclusions
• Low self-efficacy is therefore a risk for developing co-morbid depression and anxiety
• Since DAS calculation scores are used by clinicians to evaluate need for RA therapies including use of biologics/biosimilars, depression may be impacting on clinicians’ decisions to use such therapies when patients may be better treated with psychotherapy/talking therapies
Lifelong medication

• Impact of having to take strong drugs for life can be huge and scary
  • We can help with telephone peer support
  • We can and do reinforce your key messages
  • Importance of adherence
• We’re developing a new booklet on all RA medications
• Introduction of biosimilars – switching
  • For a copy of our new position statement email Nicola@nras.org.uk
What about my job?

- 75% of people are of working age when diagnosed with RA
- Over 70% of people recruited to the national audit were under 66 years of age
- The audit reported that one in eight patients (12%) need frequent time off work or are not working because of their arthritis
- 35% of 239 who answered the question in a recent survey across Wales were not working due RA

The HQIP audit asked patients if they recalled ever being asked by their rheumatology team about their work

- Only a small number of patients completed this questionnaire but 42% of those who did said that they had been asked about their work
- 19% said it had not been discussed while the rest did not answer the question

It’s vitally important for health professionals to ask the question!
Annual Reviews

The needs of patients with long standing disease are different to the newly diagnosed. Given pressure on resources should there be some prioritisation of patients for holistic annual reviews?

- DMARDS
- DAS score/HAQ
- QRISK2
- FRAX assessment for osteoporosis
- Steroid Hx
- Smoking/alcohol,
- Screening questions for OT, podiatry, physiotherapy referral
- Anything that the patient wants to discuss – work? QoL?

“Gave me the feeling that something was being done about my condition”
Annual Review – Freeman audit results

35 patients total (Nov/Dec 2015):
• 6 patients - DEXA scan.
• 9 patients already had pre-existing CVD so were excluded from QRISK2
• Of the remaining 26 patients, 10 were found to have a QRISK2 >20%, resulting in a referral to their GP about commencing statins.
• 1 patient on NSAIDS without PPI cover, - > referred to GP.

8 other referrals were made, including Podiatry (3), Occupational Therapist (3), Osteoporosis specialist nurse (1), and a Consultant (1). Other interventions included medication changes (2), steroid injections (1), blood tests (4), and fasting glucose (1).
Don’t ignore our feet

Our information on foot health

Foot health online course

Our information on foot health

Foot health

Rheumatoid Arthritis can have a huge impact on Foot Health. Often people have told us it is difficult to find the right information at the right time about foot issues. In this section you will find information about protecting your feet (prevention is always better than cure), foot surgery, footwear, and much, much more.

Foreword by Ailsa Bosworth, CEO, NRAS

Something like 90% of people with Rheumatoid Arthritis experience pain and problems with their feet and footwear is a huge issue for many. As a consequence, we have decided to create this new foot health area on our website to give a real focus to feet and footwear, which we hope you will find really helpful. We’d also like to get input and feedback from you if you have found a service or brand of footwear for example, that has really helped you or solved a problem for you so that we can add to our links in this section for the benefit of everyone.

It’s important to note here however, that today, with earlier diagnosis and more aggressive treatment from the outset, less foot and ankle damage and deformity is likely by comparison to people diagnosed between 20 and 30 years ago when treatment regimens were very different and of course we didn’t have the biologics available that we have today. So, today, being diagnosed with RA, one can be much more positive about the future and be able to lead a relatively normal life. Of course the earlier you are diagnosed and treated, the better and the more chance you have of
How can NRAS help you to help your patients?

- Newly diagnosed packs from NRAS including ‘10 Healthcare Essentials’, FOC
- NRAS membership for you and your team – FOC
- Regular health professional e-bulletins
- Business cards for your Nurse Specialists to hand out with our free helpline details
- Peer to Peer telephone support service
- 50 groups across the UK supporting you too
- Informative website/publications and Self-Management programmes
- Rheum2Talk HCP training
- Booklets on work related issues for employees and employers, support to remain in work
- Videos on early diagnosis/exercise and more
- Just launched an area for South Asian patients www.nras.org.uk/apnijung
- Service for families and CYP www.jia.org.uk

‘NRAS has changed my life. You don’t realise how much you have done for me. I only found out about NRAS 2 years ago and my life has changed completely as a result of becoming a member’.
Thank you!

Questions?

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