

National Rheumatoid Arthritis Society Survey 2006



ARMA Standards of Care: patients' experiences



Meeting the Standards of Care for people with Inflammatory Arthritis. A national pilot survey of NRAS members.



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National Rheumatoid Arthritis Society

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Introduction

Ailsa Bosworth, Chief Executive, NRAS

In 2004 the Arthritis and Musculoskeletal Alliance (ARMA) published Standards Care for people with inflammatory arthritis. This was the culmination of over two years' work, and a project in which we at NRAS had played a leading role from the outset.

From the time NRAS was launched in October 2001, we were aware of the serious inequities in people's access to services around the country. Soon after we became members of ARMA, in spring 2002, we found that their thinking on what action was needed (but as part of a broader framework including other musculoskeletal conditions) was in line with our own.



Ailsa Bosworth - Chief Executive

We agreed that the way forward was to work together, with other patient organisations and health professionals, to develop Standards of Care: these would set out what good quality care should be and provide medical professionals with a clear way of auditing their services.

We at NRAS contributed to the development of the Standards over the next two years, and I was happy to take the role of co-ordinating the working group on inflammatory arthritis, together with Professor David L Scott of King's College, University of London.

In the year following the publication of the Standards of Care, NRAS has also helped to develop the tools for rheumatology units to use in auditing the Standards. In particular, we have helped to create a tool specifically to measure patients' experiences of their services. We worked closely on this together with a group of health professionals and other patient groups, with Wendy Garwood, Project Manager of the Early Rheumatoid Arthritis Network (ERAN), who chaired the audit group.

We decided that our annual survey of NRAS members in 2005 would take the form of a pilot of this new patient questionnaire. We felt this would be a valuable addition to the formal pilots, whose work ARMA was co-ordinating, taking place with smaller patient samples. Our survey would, in effect, be a national pilot and provide a broad-based view of how services are meeting the requirements of the Standards. This report sets out what we found.

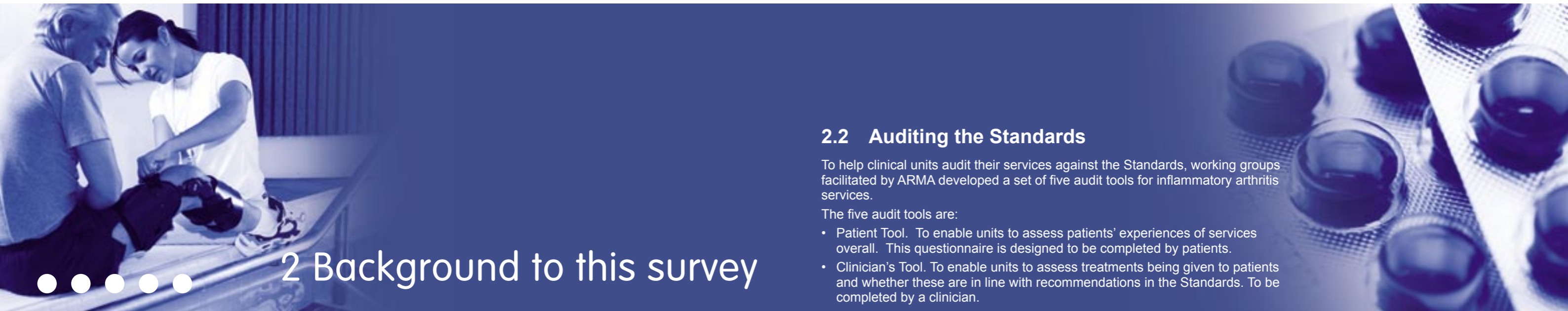
We have been encouraged by some of the findings. When patients do have access to a full multidisciplinary team, for example, they are generally very positive about the team and the care they receive. We were also glad that over three quarters of people said they are involved in decisions relating to their treatment – this would not have been the case 15 to 20 years ago.

However, there are also some areas of concern, including cardiovascular risk assessment and monitoring, access to the full multidisciplinary team and how people's pain management and social and emotional needs are addressed.

We hope that NRAS's annual surveys are a resource for health professionals working in the field of rheumatology. Our purpose in publishing them is to give up-to-date, concise information about the experiences of people with RA, of their care and treatment in both secondary and primary care.

We aim to highlight where changes are needed, to give feedback on patients' positive experiences of healthcare systems, and to improve patient care and education overall.

We hope that the findings of this survey will provide professionals with valuable insights into patients' experiences, and a practical benchmark to help healthcare units around the country evaluate their services.



2 Background to this survey

2.1 About the Standards of Care for people with Inflammatory Arthritis

The term 'inflammatory arthritis' describes a range of conditions, which includes rheumatoid arthritis (RA), ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis (JIA). These conditions affect over 700,000 adults and children in the UK.

They are progressive conditions, which vary greatly between individuals in their pattern and severity. For a minority of people, symptoms may be mild and easily manageable; for others their disease causes damage to a number of joints and has a severe impact on their quality of life. The costs to individuals, to their families, to the NHS and to the national economy are considerable.¹

While we know that swift access to services, at an early stage, improves the outlook for people with inflammatory arthritis², people around the country have vastly different experiences when it comes to the quality of their care.

The *Standards of Care for people with Inflammatory Arthritis* set out recommendations for good quality healthcare services for people living with these conditions. They are intended to support people of all ages in leading independent and healthy lives. Based on available medical evidence, the Standards define what services are appropriate at all stages of people's experience, including their first symptoms, diagnosis, self-management, ongoing treatment and support. The Standards were developed by an expert group that included people with inflammatory arthritis, representatives of user organisations, experienced service providers and medical and healthcare professionals.

They form part of a broader set of Standards: others cover osteoarthritis, back pain (these two were also published in 2004), bone disease, regional musculoskeletal pain and connective tissue disorders (these three are forthcoming).

The Standards have been widely welcomed by clinicians, healthcare professionals and government, including the then Secretary of State for Health, John Reid. The Standards have also informed the development of a new Musculoskeletal Services Framework, to be published by the Department of Health.

¹ ARMA, *Standards of Care for people with Inflammatory Arthritis*, 2004, p1.

² *ibid.*, p2.

2.2 Auditing the Standards

To help clinical units audit their services against the Standards, working groups facilitated by ARMA developed a set of five audit tools for inflammatory arthritis services.

The five audit tools are:

- Patient Tool. To enable units to assess patients' experiences of services overall. This questionnaire is designed to be completed by patients.
- Clinician's Tool. To enable units to assess treatments being given to patients and whether these are in line with recommendations in the Standards. To be completed by a clinician.

- Primary and Secondary Care Resources Tool – to enable units to assess the range of rheumatology services available in their area. To be completed by a health professional, with reference to other managers including those in primary care, secondary care, physiotherapy, occupational therapy and orthopaedics.
- Referral times (Patient) Tool. To enable units to find out whether they are achieving referral from primary care to first consultant appointment within 12 weeks. To be completed by patients.
- Referral times (Team) Tool. Also designed to audit the target 12-week referral time, this is completed by a member of the professional team and captures additional information about key points in the referral process.

This report outlines the findings of a national pilot amongst NRAS members of one of these tools; the Patient Tool. The pilot was undertaken by NRAS as their annual membership survey in 2005.

A group of 10 Rheumatologists at Training (RATs) have run formal pilots of the tools in rheumatology units and clinics, co-ordinated by ARMA. Involving a total of 10 locations around the country, this process has incorporated pilots for each of the five tools and began at the end of October 2005. The tools are to be finalised during April 2006 and will be available on the ARMA website www.arma.uk.net from May 2006. Additional audit tools for the Standards of Care on Osteoarthritis and Back Pain will be developed in the future.

2.3 The survey methodology

The survey had two aims:

1. To provide information from patients' perspectives on how rheumatology services are meeting the requirements of the Standards of Care.
2. To pilot and refine the format and usability of the survey questionnaire, to complement its pilot by rheumatology units, which was co-ordinated by ARMA.

NRAS carried out the survey in November 2005. It took the form of a postal questionnaire, sent to 706 people with inflammatory arthritis, who were all members of NRAS. The response was excellent: NRAS received 414 responses, a response rate of 59%. NRAS recorded the results and sent the data to the Early Rheumatoid Arthritis Network (ERAN) for analysis.



3 Key findings

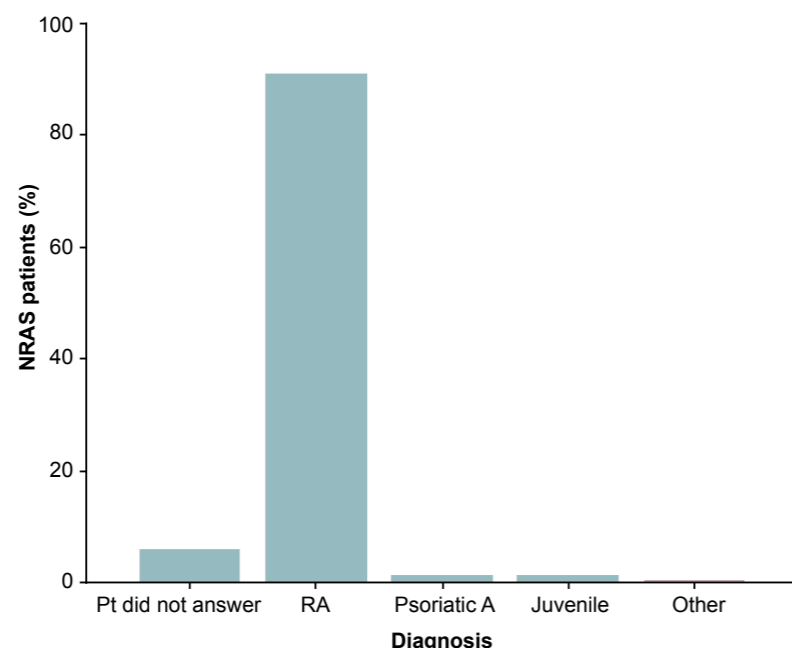
3.2 Care plans

Standard 7 states: People should be offered an individualised care plan for ongoing care.³

3.1 The patient group

Of the 414 respondents, 377 had rheumatoid arthritis (RA), 5 had psoriatic arthritis (PA), 6 had juvenile idiopathic arthritis (JIA), 2 had other forms of inflammatory arthritis and 24 did not describe their condition.

Figure 1. What arthritis do you have?



As this was a pilot survey of NRAS members, the majority of respondents (91%) had RA and the results therefore predominantly reflect the experiences of people with RA.

380 people with RA or JIA gave information about the length of time they had had the disease. The mean length of disease duration was 11.27 years. Of these people, 64 people had had their diagnosis for two years or less.

As all the respondents were members of NRAS, it is reasonable to assume that they represent a group of patients who are comparatively well-informed about and involved in the management of their condition.

78% of respondents said they had been involved in decisions about their treatment. This is encouraging, as there will always be a minority who do not want to be or are not capable of being involved in such decisions.

However, it is a concern that only 10.8% of respondents said they had ever been given a written care plan.

Calls to NRAS's helpline confirm that many patients experience considerable confusion about their care. Many have received little information about their current treatment, what to expect, and what their options will be if the current treatment fails. Many would benefit from better support in the form of education, ongoing access to information, and a written 'map' or care plan. These would help to inform people, reduce their anxiety and stress and educate them to better manage their condition.

We appreciate that many units are under-resourced and that health professionals may understandably feel they do not have sufficient time to provide this support. We suggest that a standardised care plan, for local adaptation, could help in this respect – see the section 'Conclusions and the way forward'.

3.3 Opportunities for patients to comment on services

Standard 9 states: Healthcare organisations should involve people with inflammatory arthritis in the planning and development of services. Only 21.6% of respondents – whose average disease duration was over 11 years – said they had been asked to give feedback on the services they had received.

Both medical teams in NHS Trusts and managers in Primary Care Trusts need reliable ways of assessing how well they are meeting their patients' needs and of measuring improvements to their services. For them to achieve this, patients need to have opportunities to give feedback. If a service is to be patient-focussed, it needs to have patients' own views at its centre.

Patient audits are a valuable source of information for all professionals involved in planning and delivering services. While methods for collecting feedback must be sensitively designed – to ensure, for example, that patients' comments remain anonymous – these practical considerations should not be obstacles to undertaking such questionnaires.

³ ARMA, *Standards of Care for people with Inflammatory Arthritis*, 2004.

“I have been seen by OT and physio but largely off my own efforts, through my GP”

3.4 Comprehensive annual review

Standard 12 states: People with inflammatory arthritis should be offered a comprehensive, annual specialist review.

The survey findings indicate that the requirement of a comprehensive annual review, as set out in the Standards, is not being achieved everywhere (see Table 1).

	number of replies	annually	more often	less often	don't know
rheumatologist/doctor	N=382	68 (17.8%)	285 (74.6%)	24 (6.3%)	5 (1.3%)
nurse specialist	N=312	18 (5.8%)	160 (51.3%)	97 (31.1%)	37 (11.8%)
physiotherapist	N=280	4 (1.4%)	18 (6.5%)	193 (68.9%)	65 (23.2%)
occupational therapist	N=289	13 (4.4%)	18 (6.1%)	198 (68.5%)	60 (21%)
podiatrist	N=293	15 (5.2%)	41 (13.9%)	170 (58%)	67 (29.9%)
dietician	N=269	3 (1.1%)	4 (1.5%)	172 (63.9%)	90 (33.5%)

Table 1

It is encouraging that 92% of patients reported their arthritis was reviewed by their rheumatologist or doctor annually or more frequently. However, the results give some cause for concern about patients' access to other key professionals in the multi-disciplinary team.

Of our respondents, nearly a third (31.1%) had their disease assessed by their rheumatology nurse less frequently than once a year. For nearly 70%, a review with a physiotherapist or occupational therapist took place less frequently than once a year. Many respondents commented that they had to ask to be referred to different members of the team when they needed it. This relies on patients being aware of the services that should be available to them – and many are not.

NRAS's own contact with people who have arthritis (primarily rheumatoid arthritis), from our helplines and correspondence, confirms that many people are unaware of the full range of professionals whose support they should be able to access. For example, people may not know that they should be able to get splints for their hands or wrists, or an evaluation of their workplace by an occupational therapist – support which could make the difference between them being able to continue working or not.

“Have had RA for 7 years, but only just had contact with our nurse specialist, so things can only get better”

“Not yet seen a physio/ occupational therapist even though I have deteriorated over the last 18 months”

3.5 Monitoring cardiovascular risk

Standard 12 states: People with inflammatory arthritis should be offered a comprehensive, annual specialist review that includes cardiovascular health checks such as blood pressure and a cholesterol test, in accordance with the British Society for Rheumatology (BSR) Guidelines.

It is well researched and documented that people with RA are at greater cardiovascular risk than the general population; indeed, the risk is higher than in patients with type 2 diabetes.⁴ Specific research to explore cardiovascular risks for other forms of inflammatory arthritis has not to date been carried out, and further research is needed to examine whether these cardiovascular risks can be assumed to be similar for different inflammatory arthritis conditions. However, while this data is awaited, it is reasonable to consider that the inflammatory component seen in RA results in a similar cardiovascular risk for people with other types of inflammatory arthritis.

It is a serious concern that most respondents to our survey reported that monitoring of their cardiovascular health was infrequent (see Table 2).

measure	number of replies	always	sometimes	never
blood pressure	N=381	100 (26.2%)	152 (39.9%)	129 (33.9%)
cholesterol	N=375	33 (8.8%)	100 (26.7%)	242 (64.5%)
smoking status	N=342	26 (7.6%)	71 (20.8%)	245 (71.6%)
weight	N=371	40 (10.8%)	75 (20.2%)	256 (69%)
blood tests	N=384	258 (6%)	70 (18.2%)	56 (14.6%)

Table 2

Over a third of those replying said that their blood pressure was never monitored between rheumatology outpatient visits. Nearly two thirds (64.5%) also said this about their cholesterol levels and over two thirds (69%) about their weight. Only a minority said that their blood pressure and cholesterol levels were always monitored between outpatient visits.

Although research has clearly established the higher risk of heart disease in people with RA, GPs are not offered the same contractual incentives to monitor their cardiovascular risk factors as they are, for example, in people with diabetes.⁵

⁴ British Society for Rheumatology & British Health Professionals in Rheumatology, *Guideline for the Management of Rheumatoid Arthritis (The first two years)*, 2005.

⁵ Hall FC & Dalbeth N, Disease Modification & Cardiovascular Risk Reduction: 2 Sides of the Same Coin, *Rheumatology* 2005; Vol 44 p1473-1482; Symmons D & Bruce I, Reports on the Rheumatic Diseases, *arc leaflet series 5 – Hands On Management of Cardiovascular Risk in RA and SLE*, Feb 2006 No 8.

“My ‘MD team’ are my consultant and specialist nurse; any other discipline has been at my request through info from other RA sufferers”

“Specialist nurse is very kind but always very rushed”



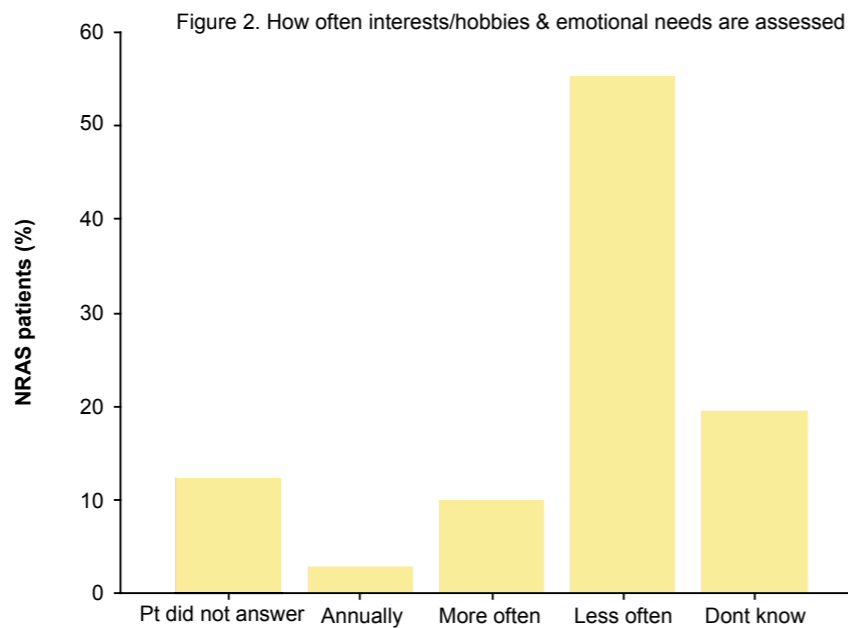
3.6 Assessment of social and emotional needs

Standard 12 states: People with inflammatory arthritis should be offered a comprehensive, annual specialist review that ... should also assess psychosocial support needs.

The Standards of Care recognise that inflammatory arthritis can affect every aspect of a person’s life, including their emotional health and the ability to continue with interests that contribute to their enjoyment and sense of purpose. People’s psychosocial needs may change over time and with the course of their disease, so regular assessment is important.⁶

“My nurse/physio treats you as a person with opinions and feelings”

“My nurse specialist is fantastic and I know I can rely on her to help me but her ever increasing workload means that it is becoming more difficult to get an appointment”



It is discouraging that only 12.8% of respondents said their emotional needs, interests or hobbies were assessed annually or more often (see Figure 2). Research has shown that inflammatory arthritis has a huge impact on many aspects of daily life. NRAS’s research, for example, found that RA had a significant impact on people’s self-esteem, relationships and sexual activity, and that over 60% of people with RA believed they had suffered from depression.⁷ We are concerned that the increasing demands on rheumatology nurses’ roles and under-resourcing are reducing the time available to assess and support patients’ social and emotional needs.

⁶ Oberai B and Kirwan JR, Psychological factors in patients with chronic rheumatoid arthritis, *Annals of Rheumatic Diseases* 32:969-971, 1988; Fitzpatrick R, Newman S, Lamb R, and Shipley M, Social relationships and psychological well being in RA, *Social Science and Medicine* 27:399-403, 1988.

⁷ NRAS, *Beyond the Pain. The social and psychological impact of RA*, 2004.

3.7 Assessment of pain

Standard 5 states: On diagnosis people should have a full assessment of their disease, general health, psychosocial and pain management needs.

Standard 6 states: People with inflammatory arthritis should have access to safe, evidence-based care and management strategies, with appropriate monitoring arrangements.

Over 65% of respondents said that their pain was assessed annually or more often. This may at first seem encouraging, but it suggests that the questionnaire fails to address the most important question: while it asked how often pain was assessed and whether respondents had received support, it did not also ask about the effectiveness of that support or how pain management advice or treatment was reviewed and modified.

75% of respondents said they used painkillers or anti-inflammatories to manage their pain, indicating a high prevalence of pain amongst this group. Over a quarter (28.1%) said they had received practical advice, and respondents cited a wide variety of other strategies they used to manage pain. These included exercise, steroid injections, hydrotherapy, TENS and patient support programmes; and also alternative therapies such as acupuncture, reflexology and reiki. We suggest that the wide range of therapies being tried is additional evidence of the importance of pain management for people with inflammatory arthritis.

We propose that consideration is given to including, in future audits, questions about how pain is managed and how effectiveness can be monitored and evaluated. The evidence from NRAS’s helpline, correspondence, this survey and previous research⁸ is that managing pain is a critically important issue for patients.

“The GPs do not know how to go about treating rheumatoid arthritis. No idea. No idea of pain questions. I could go on”

“Initial consultation... was terrible. No help, no advice, said it wasn’t RA, dismissed the pain and made me feel worse”

⁸ *ibid.*

3.8 The multi-disciplinary team

Standard 10 states: People with inflammatory arthritis should have ongoing access to the local multi-disciplinary team, whether this is based in secondary care or in the community.

Respondents were invited to make any additional comments about their multi-disciplinary team. 55% of respondents did so, contributing a wide range of views. Comments were rarely neutral and tended towards the very positive or negative, indicating that there is a wide variation in people’s experiences of care. Some key themes emerged.

“I was exhausted, but I couldn’t sleep for the pain”

3.8 The multi-disciplinary team (cont.)

- Where people said they had access to a multi-disciplinary team, the vast majority of comments were positive.

“They are my lifeline”

“I feel support by the team – when RA has flared I have been seen promptly and RA brought under control”

“They work closely together. I feel confident I am getting the best care”

- A number of respondents highlighted the fact that referrals and access to other services were not smooth, or that services were not easily available when they needed them. Some also suggested that they would welcome more information about available services.

“Often as a patient I have to be proactive to ask and get what I want or need. If I didn’t insist then things wouldn’t always happen”

“It would be nice to have access to physios, podiatrists, occupational therapists, without having to be referred to one because by the time you get an appointment the flare up has receded”

“Never been offered any additional services except drugs and painkillers”

- A sizeable minority (over one tenth) of those commenting said that they did not have a multidisciplinary team, with some saying that they did not know such a team existed.

“I have no ‘Multidisciplinary Team’”

“What ‘Multidisciplinary Team’ – I asked to see a dietician, physio and psychiatrist but not forthcoming”

“What exactly is this – it hasn’t been made clear to me who is involved in this”

“I have never had any kind of team look after me or tell me what to do or give me advice even after my joint operations. I did once get physio after one operation”

- Where people had access to rheumatology specialist nurses, it was clear that they valued their support.

“Basically my nurse specialist is brilliant”

“The Rheumatology Nurses in particular are helpful and knowledgeable and can be reached by phone at any time if I need to discuss anything”

“My specialist nurse is a ‘life saver’. She is the key person to me, as the consultants only have limited time”

- The difficulties most frequently mentioned stemmed from under-resourcing: e.g. long waits for appointments and long waiting times at clinics.

“I had to wait very long periods between appointments despite being in constant pain and very debilitated by the condition”

“General hospital too many people to see, no time for in depth consultation”

“There is a time limit due to number of patients. Feel that I should not take up too much time at appointments”

- A number of respondents said that the lack of continuity affected the quality of their care.

“It would be good to see the same doctor more than once”

“I only see a hospital doctor every six months and then it is usually someone I’ve never seen before, so I never feel that they are very interested in my condition, I find this very frustrating”

“I never, or rarely, see the same rheumatologist, specialist nurse, twice so therefore cannot build up a relationship”

4 Piloting the survey questionnaire

The survey highlighted some aspects of the questionnaire design and wording that could be refined to improve the quality of information received. We identified the following points:

- Questions on patients’ pain could be refined, to collect information on how effective pain management advice and review is perceived to be. Achieving effective pain relief is a major factor in patients’ ability to manage their condition and to cope with daily life.
- Some specific instructions and signposting needed to be clearer, to prevent respondents from misreading them. For example, one section was to be completed only by people who had been diagnosed for less than two years, but a number of other respondents also completed this.
- Respondents wanted the option of answering ‘never’ to some questions about the frequency of assessments.
- A question about surgery elicited comprehensive medical histories; rephrasing this to focus on respondents’ most recent operation would provide clearer data.
- It may be helpful to ask whether respondents are receiving private treatment. It was apparent from free response answers that this applied to a small number of respondents.



5 Conclusions and the way forward

This pilot survey has identified some key issues about care and treatment from patients' perspectives. We would like to highlight these for consideration by all professionals involved in providing and planning services for people with inflammatory arthritis.

- **Opportunities for patients to comment** on the services they receive provide valuable first-hand information. We encourage rheumatology units to offer these opportunities, for example through an annual audit of a sample of patients (e.g. using this audit tool). We suggest annually as we recognise that resources are limited and teams are operating with a considerable workload.
- We propose that consideration is given to developing **a standard format for a patient care plan** that rheumatology units could adapt for local use. This would make it more achievable to provide a written plan for all patients following their diagnosis and being established on treatment. We suggest that a multi-disciplinary group, if possible facilitated by ARMA, would be the most appropriate forum for developing a standard care plan, and we would welcome the opportunity to contribute.
- We are concerned that some people with RA are at risk because **cardiovascular risk assessment and monitoring** is not taking place everywhere as frequently as the Standards of Care recommend. The most appropriate setting for monitoring is an issue currently under some debate; however the overriding concern of patients is that it should take place regularly, irrespective of the setting. NRAS is of the opinion that GPs would be well placed to provide such risk assessment and monitoring as they already do this for other patients. However, currently there is no mention of arthritis in the Quality Outcomes Framework and therefore no incentive or remuneration for GPs to do this work. As a consequence, NRAS believes it should remain the responsibility of the rheumatology team to ensure that this risk assessment and monitoring is done in accordance with best practice.
- We are concerned that lack of resources means there is insufficient **support for patients in regard to the social and emotional impacts of their disease**, which can affect all aspects of daily life. The support of specialist nurses and other health professionals is of huge importance in this respect to patients with long term conditions like inflammatory arthritis. However, these specialist roles are currently at risk of being made redundant or facing non-renewal of contracts, in NHS Trusts that have overspent and we know of specific instances where this has happened. We are concerned that this further threatens patients' access to much-needed support and urge Trusts to give priority to keeping these vital posts.

6 More information

6.1 About NRAS

The National Rheumatoid Arthritis Society (NRAS) is the only patient-led national charity specifically for people with rheumatoid arthritis (RA), their families and carers. Established in 2001, we have rapidly become the campaigning voice in the UK for people with RA. Our aims are:

- to provide information, advocacy and support on all aspects of the disease.
- to raise public and government awareness of rheumatoid arthritis.
- to campaign for more funding and better use of existing resources in the treatment of RA.
- to facilitate the networking of patients and encourage self-help.

Our national helpline 0845 458 3969 operates Monday to Friday from 09.30am to 4.00 pm.

Our website www.rheumatoid.org.uk covers every aspect of the disease, treatments and the impact of living with RA.

We work with national networks of consultant rheumatologists, clinical nurse specialists and allied health professionals, and can refer to them for expert advice.

Our national network of trained volunteers, all of whom have RA, are available on the phone for any person with RA who needs them.

6.2 About the Standards of Care

Visit ARMA's website, www.arma.uk.net:

- for more information about the Standards of Care project.
- to download a copy of the Standards of Care for people with Inflammatory Arthritis.
- to download a copy of any of the audit tools, including the patient tool.

Or contact ARMA at:

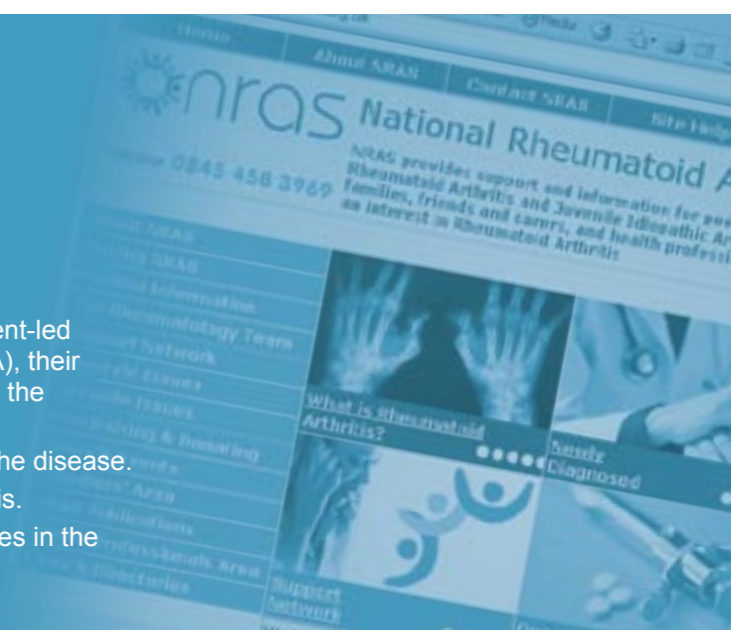
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6.3 Thank you

Our thanks to ARMA for the use of their audit tool for this our fourth Annual Survey. Thank you to all our members who gave their time and their views in this survey. We would also like to thank Cathy Mayes, Project Officer and Wendy Garwood, Project Manager of the Early Rheumatoid Arthritis Network (ERAN) for their valuable assistance in analysing the survey data and creating the charts.

Editorial: Kate Wilkinson

Design and print: AIT Marketing Associates Ltd





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APR06/0043