



**nras**  
National Rheumatoid  
Arthritis Society



# **Shaping NRAS' Three Year Plan; Our Survey Findings**

Report of the survey findings

TwoCan Associates

November 2024

## **Thanks**

We are very grateful to all the people who generously gave their time to complete the survey.

We would also like to thank the Steering Group members who helped throughout the project, particularly with reaching out to the NRAS community:

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## Executive Summary

The National Rheumatoid Arthritis Society (NRAS) is developing its next three-year strategy will start in 2025. To ensure the strategy is built on the needs and views of the people it serves and its supporters, NRAS commissioned TwoCan Associates to conduct a survey of people with lived experience of Rheumatoid Arthritis (RA) and Juvenile Idiopathic Arthritis (JIA) and health professionals.

665 people completed the survey and 89% of respondents were people living with RA/JIA.

When asked what NRAS was doing well, the majority reported that the information, support and advice that the organisation provides are very high quality and much valued.

When asked what could be improved in terms of what NRAS does currently, the respondents suggested that NRAS could do more to:

- Raise awareness of RA/JIA
- Raise the profile of NRAS
- Campaign on healthcare for people with RA/JIA
- Educate health professionals
- Make NRAS resources more accessible to different audiences

When asked what more NRAS could do in future to help people with RA/JIA, the respondents identified new areas of activity in the following areas:

- Advocacy support for individuals
- Campaigns
- Information resources
- Research
- Local groups
- Tailored support
- Engaging younger people
- Fundraising

Some of the suggestions related to work already underway, emphasising the importance of these projects. Some suggestions for new information resources actually already exist, highlighting the need to raise awareness of the full set of resources available.

The remaining suggestions will be considered alongside the findings of similar consultation exercises carried out with other stakeholders e.g. staff and volunteers. The combined views will help decide priorities for action in the final strategy, which will be shared widely in Spring 2025. NRAS is committed to continuing to work with people affected by RA/JIA, carers and health professionals in the activity that follows to implement the strategy.

# Introduction

## Aims of the project

1.1 The National Rheumatoid Arthritis Society (NRAS) is the only UK patient organisation that specifically focuses on supporting people living with Rheumatoid Arthritis (RA) and Juvenile Idiopathic Arthritis (JIA). The organisation's next three-year strategy will start in Spring 2025. NRAS wanted to ensure the strategy is built on the needs and views of the people it serves and its supporters. This included:

- People living with RA or JIA
- Families and friends supporting people with RA or JIA
- Health professionals caring for people with RA or JIA
- Volunteers

1.2 NRAS therefore commissioned TwoCan Associates, a small consultancy specialising in patient and carer involvement ([www.twocanassociates.co.uk](http://www.twocanassociates.co.uk)), to conduct a survey of people with lived experience and health professionals. The survey asked people's views on:

- What NRAS does well
- Where NRAS could improve what it does currently
- What more NRAS could do in future to help people with RA and JIA

## Background

1.3 The work that NRAS currently does includes:

**Information & Support** through services, such as helpline, free booklets, websites, support groups, online community platforms and videos on their YouTube channel.

**Disease & Lifestyle Education** through SMILE-RA (self-management teaching sessions) and online webinars, which are used by patients, carers and healthcare professionals.

**Advocacy, Policy & Campaigning** through representing the voice of people living with RA or JIA in national policy decision making.

**Research & Innovation** through supporting a wide range of health research and working with technology developers to improve the lives of those living with RA or JIA.

**Raising awareness** through campaigns that aim to increase the public's understanding of RA and JIA.

**Fundraising** through donations, grants, fundraising events and legacies.

## **About this report**

- 1.4 This report summarises the responses to the survey. These were categorised and the findings written up by an independent researcher from TwoCan. The discussion was written with input from the Steering Group to reflect on where the suggestions build on the work that NRAS already does.
  
- 1.5 The report will be published and shared widely. The findings will be considered alongside feedback from other consultations with staff, volunteers, NRAS's professional advisory board, health commissioners and service leads. The final strategy will be published in Spring 2025 and shared with everyone with an interest in the work of the organisation.

## 2. Methods

- 2.1 A Steering Group of NRAS staff, including the Chief Executive, helped to shape the whole project. They considered examples of similar surveys used by other health charities and designed a draft survey relevant to the RA/JIA community. This draft was piloted with 15 people with experience of RA or JIA, who were volunteering at NRAS. Their feedback was included in the final version of the survey and their responses included in the findings.
- 2.2 In order to reach as wide a range of people as possible, the survey was made available online and on paper via the post. The online version of the survey was sent out via NRAS email, NRAS social media, NRAS HealthUnlocked, NRAS Members and Healthcare Professional's eNews and other professional societies. Paper copies and emails were sent to people who had been active in the last two years, based on information on NRAS's database. This included people who were members or volunteers, people who had used a service, ordered a publication or merchandise, or been involved with any NRAS event. To ensure that the paper survey reached a diverse range of people, invites were sent to people who were selected on the basis of diagnosis, age, gender and location in the UK. NRAS survey data and the national census data were used to determine the appropriate proportion of different characteristics to include amongst those on the list.
- 2.3 The survey was open between September 4th and October 6th 2024. In the final week, analysis of the characteristics of the respondents showed that few men, people under the age of 45 and ethnic minority groups had responded. Social media posts were therefore aimed at these groups to encourage them to take part.
- 2.4 As a consultation of people's views on NRAS's services and resources, the survey is better considered as a 'brainstorm of ideas', rather than research on people's views. The responses have been categorised to look for common themes, where people have had similar ideas or expressed similar opinions. Direct quotes from survey respondents have been included to illustrate the topics raised. These are attributed to the perspective of the person being quoted: person with RA/JIA, carer of a person with RA/JIA, or healthcare professional.

### 3. Findings

3.1 This section first describes (a) who took part in the survey, and then reports on the findings under the three main questions asked in the survey:

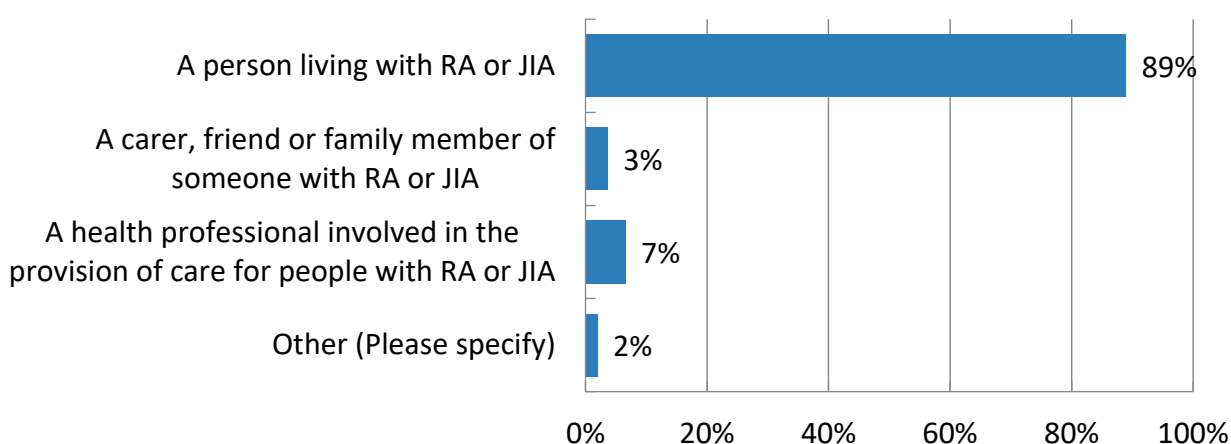
(b) What is NRAS doing well

(c) What is NRAS currently doing that could be improved

(d) What more could NRAS do in future

#### (a) Who took part in the survey

3.2 The vast majority (89%) of survey respondents (n=665) were people living with RA or JIA (Fig. 1). This was expected as the survey had been sent to people who had recently used NRAS services.



**Fig 1. Percentage of respondents with different perspectives on RA or JIA**

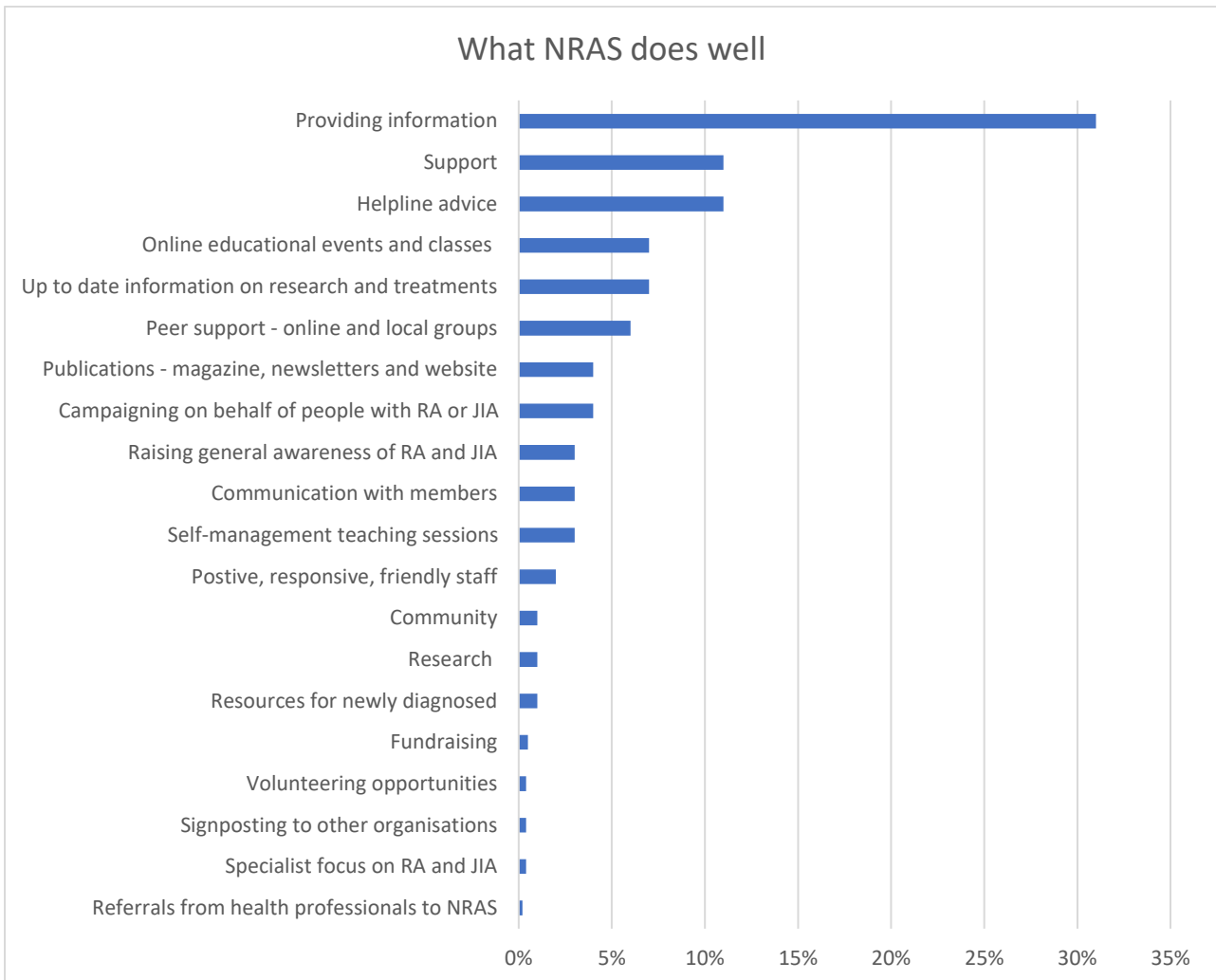
(the total is more than 100% as some respondents belonged to more than one category)

3.3 All respondents were asked about their location in the UK. People with lived experience of RA/JIA were also asked questions about their age, number of years with RA/JIA, ethnic background, and gender. Carers were asked about their ethnic background and gender, while health professionals were asked about their professional background. The characteristics of the respondents can be found in the Appendix. Two responses from staff were not included in this analysis but passed to the Steering Group for information.



## (b) What is NRAS doing well

3.4 The percentage of survey respondents that described different areas of NRAS's work as being done well is shown in Figure 2.



**Fig 2. Percentage of survey respondents who identified different areas of NRAS's work as being done well**

3.5 The majority of respondents highlighted NRAS's information resources as being very high quality. Many emphasised that they especially valued being kept up to date on the latest research and treatment developments.

Your information about the disease is clear, accurate and detailed enough to be useful but not in overwhelming medical jargon. Plain English & accessible. It was a calm reassuring source of information when I was first diagnosed and

whenever I have needed to revisit for information about different treatments.

**Person with RA/JIA**

The printed guides are super useful – we shared them with many people/practitioners at our school – very well presented and explained, child friendly etc **Carer**

The information resources for children, young people and their families are very informative and written in a way that is easy for families to understand. **Health professional**

Keeping the members up to date with the latest news regarding research, drugs therapies etc. **Person with RA/JIA**

- 3.6 Many stated that the advice offered through the helpline, and the support provided by NRAS are also very much valued:

NRAS has given me sound advice when I have contacted them with a query. The person giving me the advice has been understanding and taken the time to answer my query. **Person with RA/JIA**

You're there at the end of the phone when it matters most. **Person with RA/JIA**

- 3.7 The self-management resource SMILE-RA was described as being very informative and useful:

Feedback from patients has been very positive, they found the SMILE RA helpful. **Health professional**

I have learned far more about RA from NRAS in a few years than from my NHS team in almost three decades! **Person with RA/JIA**

- 3.8 Some respondents described the magazine as 'excellent':

It is full of inspiring stories about people living with RA & JIA. It's informative about latest research covering a whole range of treatment options... It's layout, which is attractively presented, makes it easy to quickly find & focus on topics.

**Person with RA/JIA**

- 3.9 Overall, the many different ways to obtain information and support, the friendly and supportive staff, the opportunities to network with other people with RA/JIA and as well as a wide range of experts, makes people feel they are part of well-connected community.

My work as an Occupational Therapist specialising in rheumatology would be so much harder without NRAS. **Health professional**

NRAS is a very important to me. I feel I'm not alone. I tell everyone how brilliant NRAS is and that it's great to have an organisation to talk to with a real understanding of the disease. Incredibly beneficial to both my physical and mental health. **Person with RA/JIA**

## **(c) What is NRAS currently doing that could be improved**

3.10 The four main areas where respondents thought there was room for improvement were all long-term activities which often take many years to achieve change. These activities always need continual effort and included:

- Raising awareness of RA/JIA
- Raising the profile of NRAS
- Campaigning on healthcare for people with RA/JIA
- Educating healthcare professionals
- Making NRAS resources more accessible

These will be discussed in turn.

### **Raising awareness of RA/JIA**

3.11 Many respondents described the problems they experienced in day-to-day life because the people around them do not understand their condition. For this reason, they suggested that further work be done to raise awareness of RA and JIA amongst the general public and suggested ways to do this using general broadcast media.

Educate lay people about what this disease is. It has been nothing short of difficult explaining this disease to people who are not healthcare professionals... I think there needs to be bigger promotion for RA awareness week. Go on TV shows like Breakfast News, a feature on The One Show, interview celebrities with it... We need to move away from the mindset that RA is 'just a bit of wear and tear in the joints' and 'you get some pain in your joints.' **Person with RA/JIA**

Spread more awareness of the condition, since my son was diagnosed at 3 years old. I always get told "he's too young to have arthritis". **Carer**

3.12 Others suggested key audiences to target with awareness-raising, in particular those people who may be making decisions about the lives of people with RA/JIA without fully understanding the condition: especially employers, health professionals and benefit assessors.

Raising the profile and awareness of RA amongst employers... Once my RA was under control, the worst aspect of my life was trying to explain the residual effects to others. They aren't interested or don't believe me, because I look fine. Even health professionals don't take fatigue seriously. The impact on me has been enormous.

**Person with RA/JIA**

Need to give DWP (Department of Work and Pensions) more information on how it affects people's lives and not just pain. **Person with RA/JIA**

## Raising the profile of NRAS

- 3.13 Having received the benefits of NRAS's support, many respondents wanted to ensure other people with RA/JIA would be told about the organisation, particularly at the time of diagnosis. They suggested increasing publicity more generally, especially on social media. They also suggested creating relationships with rheumatology departments and RA/JIA specialists to encourage them to alert their patients.

Perhaps we could work on developing a higher profile with GPs and consultants. I have never been referred to NRAS in any of my appointments... I wish I had, especially when I was on a waiting list for six months to see a consultant before I was first diagnosed. **Person with RA/JIA**

Increase awareness among healthcare professionals in rheumatology of NRAS activities especially referral for patients' education at diagnosis. Work more closely with specialist nurses. **Health professional**

So many people who have come to our Group meetings found us by chance and wished they'd had more info at the beginning of their RA journey. Most info given out by their teams is from Versus Arthritis. **Person with RA/JIA**

- 3.14 Some hoped that by raising its profile NRAS would also have greater weight in its campaigning and lobbying.

## Campaigning on improvement to healthcare for people with RA/JIA

- 3.15 Although some people described receiving high quality healthcare, many were concerned that this is not generally the case across the UK. They wanted NRAS to continue campaigning to end 'the postcode lottery' in standards of care and to continue to lobby for free prescriptions. They also wanted a more holistic approach to care including routine psychological support:

Lobby for services including mental health, nutrition and physical activity support as standard when part of rheumatology clinic. **Person with RA/JIA**

Advocate for more psychological support. **Health professional**

Advocate more standardised facilities throughout the country e.g. access to podiatrists/ occupational therapists working with Rheumatology teams. **Person with RA/JIA**

Campaign for timely appointments with RA consultants and other health professionals. **Person with RA/JIA**

Given the often, slow process of getting a diagnosis during which time people are often in significant pain and distress, is there any way the NRAS could be involved to help speed this process? **Carer**

- 3.16 One or two people commented that they would like to know more about which campaign areas are being prioritised, what has been achieved and what more they could do to help.

### **Educating healthcare professionals**

- 3.17 Others were concerned that healthcare professionals might vary in their knowledge and understanding of the condition, leading to differences in the level of care provided. They suggested that NRAS could do more around healthcare professional briefing and training.

Educate GPs better about how to spot signs early, refer early and diagnose, particularly in sero-negative cases... **Person with RA/JIA**

Offer 'top up' training to NHS specialist nurses, who often appear unaware of complications of RA. **Person with RA/JIA**

Help health care professionals get this research and attend up to date events easily and more frequently. **Health professional**

Educate rheumatology consultants to be a bit more holistic as RA causes other conditions but they seemingly do not consider overall effect of RA if your numbers are fine, you can't be suffering. **Person with RA/JIA**

### **Making NRAS resources more accessible**

- 3.18 Some respondents suggested ways to increase the reach of NRAS's publications by making them available in other formats or adapting the content to meet the needs of diverse communities. These suggestions included:

- Producing information in multiple languages
- Large print leaflets
- Ensuring all information is available in print for people who can't download or print the information themselves

- Tailoring information to people who are neurodiverse or have learning difficulties

3.18 Others suggested doing more to reach people who don't have access to the internet or may need support to access online information and events.

3.19 Some people commented that it can be difficult to find the information they are looking for on the NRAS website and would find an online set of FAQs helpful.

I find navigating your website frustrating at times, unable to find what I am looking for quickly. **Person with RA/JIA**

3.20 One of the specific resources people wanted was a searchable library of NRAS talks and videos. They wanted to be able to find recordings of events that had already happened as well as being able to make an informed choice about the videos on offer.

I like the free-to-join video sessions but feel they could be better listed, advertised and recapped upon - maybe as an archive - so that they are more instantly accessible and accessible for longer. Some kind of catalogue introduced, maybe?  
**Person with RA/JIA**

I would like to see more online taster sessions available for different exercise classes. I found these very helpful in deciding which types of exercises were suitable (or could be easily adapted) for me to take part in. **Person with RA/JIA**

3.21 Others suggested making access to NRAS resources at different times, particularly the helpline and online events. This would broaden their reach.

Weekends are always my difficult time when I need a question answered, and Dr Google isn't a good place to start looking. It would be good if your helpline could be open for a short time over the weekend. **Person with RA/JIA**

I have only just found you and tried to call the helpline today at the only time when I could make a call confidentially, but you were not available. If you are only available in working / school run hours it will always be difficult for me to call.

**Person with RA/JIA**

The zooms of online conferences etc could be repeated during day? I am not an evening person, especially since commencing treatment. **Person with RA/JIA**

3.22 Some suggested that NRAS could do more to reach people who may not feel comfortable with contacting a health charity, in particularly men aged 60+ and people from underserved communities.

Improve the image of NRAS. It seems to be aimed at the middle class, super comfortable who can afford private health care and gym membership. I don't feel like I "belong" to the organisation. **Person with RA/JIA**

- 3.23 While many respondents said that they found the Health Unlocked forum a very useful way to be able to talk to other people with RA/JIA, some thought that the discussions might need stronger moderation, to ensure the advice given is accurate and to strike a better balance between positive and negative experiences.

It appears that a small group of people, who seem to know each other, can sometimes be off putting for someone new. I understand this is difficult to manage. It can be very off putting but there are also lots of kindness too. **Person with RA/JIA**

Some members use it as a vehicle to vent their anger and problems on innocent others. It is not bad at present, but has been awful. Many members left or became silent.

**Person with RA/JIA**



## **(e) What more could NRAS do in future**

3.24 The survey respondents identified many potential areas of new activity for NRAS falling into the following areas:

- Advocacy support for individuals
- Campaigns
- Information resources
- Research
- Local groups
- Tailored support
- Engaging younger people
- Fundraising

These will be discussed in turn.

### **Advocacy support**

3.25 The survey respondents identified a number of areas where individuals might need expert advice and support through advocacy, including where people with RA/JIA are experiencing:

- discrimination or unfair treatment at work
- difficulty in obtaining benefits they are entitled to
- uncertainty in preparing for interviews with occupational health/ employers
- poor quality care from the NHS

I recently had a flare and my medication was changed. When I came to getting another script I chased for a month and got no reply from my RA nurse and the GP said it was still with consultant. Advice to patients on what to do would be helpful.

#### **Person with RA/JIA**

It would be good if NRAS could have local advocates who could go with people with RA, as I spoke to a woman who had been 'undiagnosed' when she moved health authorities and had a consultant who didn't believe seronegative RA was real. It took her a year to get back on medication and it stopped her being able to work. **Person with RA/JIA**

### **Campaigns**

3.26 Ideas for new areas of campaigning for NRAS included:

- a public health campaign on the importance of early diagnosis and intervention in order to achieve best outcomes. This could include a reintroduction of the 3S campaign in primary care. **Health professional**
- identifying and promoting best practice for people with JIA moving from paediatric clinics to adult clinics **Health professional**
- identifying and promoting good practice when supporting people with RA/JIA to enter employment or stay in work, ensuring that both employers and employees understand the condition and the support required. **Carer**

## Information resources

3.27 Some respondents suggested developing information and advice to help people with RA/JIA deal with the common challenges they face. This included producing information about RA/JIA for others, so that those people can better understand and support the person with the condition.

How to get people to support someone with RA. Educate the supporters. Or create a booklet on how to help someone with RA – that would be amazing. I would gladly help offer some ideas on what this could look like. **Person with RA/JIA**

Perhaps there could be more support directed towards family and friends of people living with RA or JIA – helping them to better understand the how the condition can impact, even if the affected person looks well, and practical suggestions for good ways to encourage mutual support within the family unit. **Health professional**

Help raise awareness of travel companies e.g. airlines, airports, railways, taxi companies etc **Person with RA/JIA**

Advice on how to deal with some/many people's ignorance of RA and its symptoms in relation to people with RA, how to explain to people what you're going through without causing offence. **Person with RA/JIA**

Supply an immuno-suppressed credit card style plastic card. **Person with RA/JIA**

3.28 Another common challenge is navigating the health system and knowing how to get the most out of appointments with hospital consultants. All parties thought there could be benefits from information and advice on this. People with RA/JIA expressed a wish for health professionals to be more responsive to the problems they can experience, whereas health professionals wanted their patients to better understand who to ask about different aspects of care. Some suggested that NRAS meet this need directly by employing healthcare staff on the helpline.

Discuss with patients their treatments and advise them how people to monitor efficiency and effectiveness of their treatments and who to go when things don't work out. **Person with RA/JIA and a healthcare professional**

Provide and promote information for patients about how to navigate the NHS system, such as where to go to get the right help e.g. don't waste your valuable time in the rheumatology consultation time, asking about things that should be dealt with at your GP, optician, pharmacy, podiatry, or other specialist clinic. I am often not able to help, so signpost elsewhere and as a result have less time to deal with the rheumatology issues, that I can make a difference with. **Healthcare professional**

I sometimes feel not listened to at my appointments... I know my body and live with it every day... I wish our health care professionals would listen more, instead of ticking boxes, as we are all different. And sometimes feel dismissed. Would be good to give feedback to the consultants, to listen to their patients more. **Person with RA/JIA**

NRAS can and does play an important role in encouraging patients to 'come forward' and not always wait for appointments if they have problems. **Person with RA/JIA**

- 3.29 A number of people with RA and adults with JIA reported needing more information and advice on the issues that affect them after many years of living with the condition.

As a person who has had Rheumatoid disease for many years, I have seen and done most of the RA experience. What I lack, and what does not seem to be in the magazines is coping with the very end stage of the disease process - when the drugs have failed and most joints are bone on bone with only replacements as an option. Many newer diagnosed members hopefully will not reach my stage. Modern drugs came too late for me. Being older, I seem to be overlooked often by health care professionals and end up having to pay to get help or treatments. I had to give up driving and many hobbies and am now living a very isolated life. Whilst there is a great need to fund raise, I physically cannot do the many things on offer. I am not great with IT and have not taken to zoom so many things are missed. Friends and family give up on disabled people like me so I have become lonely and isolated. Depression and anxiety are big things that need discussing. I used to be a psychiatric nurse and should have skills to cope - but these are gone. The effects of a disabling disease plus disability and age are a toxic combination and need to be discussed. **Person with RA/JIA**

As a long term sufferer of RA, I have found some if the information not really geared up to my age and condition. Maybe consider older people's circumstances. **Person with RA/JIA**

There is nothing about JIA adults. 40 years is a long time. It is not the same as RA. **Person with RA/JIA**

- 3.30 Some respondents also highlighted the value of balanced information that reports on 'the good and the bad' to avoid some people feeling isolated. However, this needs to be managed sensitively and with care, as not everyone will wish to access information about all the potential risks in the future.

One of the leaflets was extremely negative. My Wife destroyed it! It listed all the health issues RA could lead to. **Carer**

A more rounded view of RA good and bad tales so people don't feel they are not the norm if things not easy and life takes a drastic turn i.e. work gone. **Person with RA/JIA**

Talk about what happens as the disease progresses. What happens if the meds just don't work or don't work well enough. It happens and it's a lonely place when you can't get any reliable info on what to expect. **Person with RA/JIA**

More information about the worries of being on JAKs/biologics after 65.

**Person with RA/JIA**

More about RA and cardiovascular risks. **Person with RA/JIA**

- 3.31 Similarly, people with RA said they would like to know more about the risks of developing other autoimmune diseases. They wanted to get help with managing these other conditions especially as some are rare conditions. It would be helpful if this information was all in one place. Some suggested that NRAS make links with other relevant charities to collaborate on producing joint resources.

You could usefully focus your work on people like me with a number of co-morbidities... there must be a large number of people with RA who have another autoimmune disease. I have had to join other charities for my Crohns, uveitis, ankylosing spondylitis, hepatitis etc. This is overwhelming and there is very little literature about it.

**Person with RA/JIA**

Link up with charities and support networks for diseases/ailments that often affect those with RA... It would be good to, for example, be able to click on a button within the NRAS website to say eg I have RA and COPD (chronic obstructive pulmonary disease) so this is the lifestyle/ diet/ support access options available to me.

**Person with RA/JIA**

3.32 A number of respondents said they would like more information on how to stay well long-term, particularly through diet and lifestyle choices. They wanted to know how to include complementary approaches and whether this helped some people to manage their RA without taking medication.

I'd like to see more of the 'functional medicine' type approach being promoted...there are natural approaches to minimising flare-up intensity (relaxation, nutrition, good sleep, meaningful connection with other people) that our clinical specialists tend to gloss over. **Person with RA/JIA**

3.33 Some women with RA/JIA said they would like more information on women's health, in particular:

- how to prepare in advance for the changes that will happen in peri-menopause and menopause, especially how this might affect the control of RA symptoms and medication
- how the menstrual cycle may affect symptoms and how to cope with them
- preparing for pregnancy

3.34 Finally, a number of topics were mentioned briefly by people with RA/JIA or carers as being potentially useful information resources. These included:

- current research on any new drugs and on basic biology aiming to understand the mechanism of RA
- an easily accessible explanation of the mechanism of the disease to explain the symptoms and how the treatments work
- other rare types of inflammatory arthritis
- rare symptoms of RA
- details of side-effects of treatments and how to manage them including impact of medication on skin (photosensitivity and risk of skin cancer)
- treatment options for people who have not found a drug that works for them or are unable to tolerate the newest drugs
- surgery choices
- impact of RA on relationships / sexual advice
- what to do in the summer when joints are increasingly more uncomfortable and swollen
- advice on footwear, gadgets and technology that could help people in their daily lives

- where to find financial support e.g. for bathroom adaptations
- employment rights

## Research

- 3.35 Some people with RA/JIA suggested that NRAS do more to publicise opportunities to participate in research and support recruitment to current studies.

Maybe get more involved in research... it helps to publicise some existing research and by contacting members find potential candidates to participate. **Person with RA/JIA**

Provide more details on research and clinical studies that are ongoing and recruiting patients. **Person with RA/JIA**

### Local groups

- 3.36 Many of the survey respondents described their disappointment at not having a local group near them, or finding that the only group in their area is a long drive away. Others had made the effort to attend groups, but had not found them as useful as they hoped.

My local one is run by very elderly ladies, well meaning, but it has little bearing on modern RA treatments. And is frankly a bit boring. **Person with RA/JIA**

I went to one local group and we all had to sit around a boardroom table... it was very formal. Apart from a coffee midway which was not a social time, it was I am afraid quite dire. I had taken an afternoon off work to go. I didn't go back. So sorry **for the negative comment, but these groups might be someone's only lifeline.**  
**Person with RA/JIA**

- 3.37 Some people with RA/JIA asked whether NRAS could be more proactive in supporting the development and running of local groups and suggested the following:

- give support to people who would like to help run a local group but feel daunted by the task or lack confidence
- provide resources for groups, "oven ready" packages – information resources, videos to watch and discuss etc
- suggest speakers
- identify and connect people locally who would like to join a group

- help local groups to connect with their local hospital
- NRAS staff to go out on road shows and meet with local groups

3.38 Some people with RA/JIA and carers also suggested that either in-person or online groups might be useful to set up for people with specific interests. These could be held at times and locations to suit people's needs and the content focused on issues directly relevant to the group. These included:

- Children and young people
- Young adults moving from children's to adult services
- People of working age with RA/JIA
- Long-term carers of people with RA/JIA
- People who are newly diagnosed

#### Tailored support

3.39 Some survey respondents were concerned that not all people with RA/JIA are able or keen to attend a group and suggested alternative ways of providing support. This included:

- Mentors for newly diagnosed people
- Befrienders for people who are housebound
- Buddying up schemes for people who do not like groups
- Peer-led information sessions in Rheumatology Clinics

3.40 One or two carers and people with RA/JIA emphasised the psychological challenges of living with RA and its toll on people's mental health. They suggested that NRAS provide more forms of psychological support.

3.41 Health professionals also suggested some forms of emotional support as well as practical support for patients including:

- short-term counselling where necessary
- bursary funds for attending appointments, particularly for people who have to attend a specialist centre which may be many miles away
- supporting people to make lifestyle choices that are likely to reduce their chances of getting worse

- 3.42 One or two suggested that NRAS should aim to provide more support to people with RA/JIA directly by funding RA specialist nurses who could visit patients in their own home.

## Engaging younger people

- 3.43 Some of the survey respondents suggested that information resources could be developed to better meet the needs of children and young people.

Produce an animated cartoon for children to understand more about their injection treatments and blood tests. **Health professional**

I was very young when I was diagnosed and to be honest I found the site boring so I think it would be great if you could have an area based on stages of life. i.e. school ages, start of career, start of a family life and progress through the stages

**Person with RA/JIA**

Offer literature for younger people - topics around working, challenging careers with an autoimmune condition, going to university / college etc. There is not enough information for people going from adolescent to adult life. **Person with RA/JIA**

- 3.44 Others suggested that the branding and presentation of information might need to be improved to engage younger people.

Image/branding needs to focus on younger people with arthritis. Maybe a younger/fitter ambassador e.g. Sports person? **Person with RA/JIA**

More youthful presence on social media, Instagram and TikTok **Health professional**

Look at how you deal with the changing generations - your services are great for silver surfers... **Person with RA/JIA**

## Fundraising

- 3.45 One or two people with RA/JIA had suggestions for how to improve fundraising, including:

- an easier donation system (like Amazon) where one click does it all
- a full gift catalogue available all year round, not just a few cards at Christmas
- a shop where people could buy useful gadgets

I'd prefer to buy it from the NRAS so it goes towards your cause. **Person with RA/JIA**



- 3.46 Finally, it is important to note that many respondents (about 1 in 10) stated that they could not think of anything NRAS needed to improve either now or in the future.

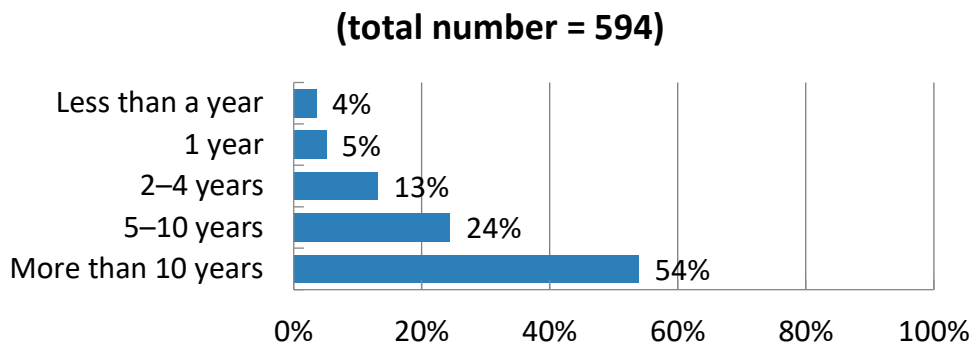
I have known NRAS for 10 years and you have not let me down or disappointed me at all – so I do not think it could be better. **Person with RA/JIA**

## 4. DISCUSSION

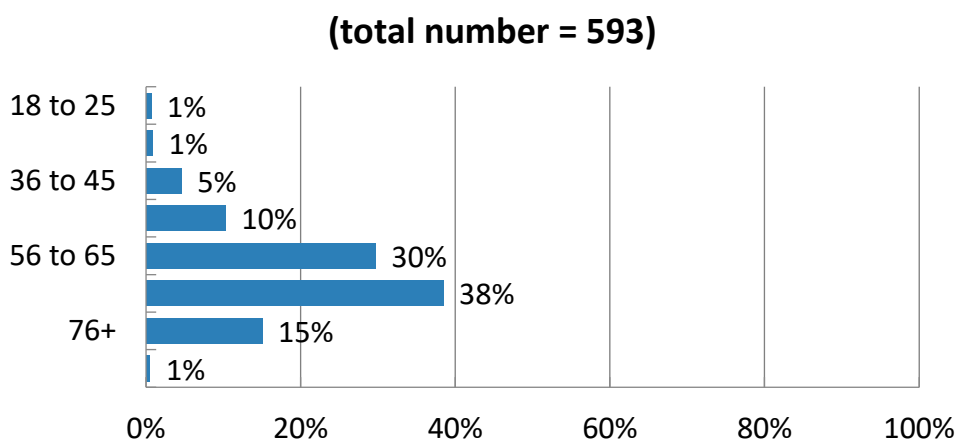
- 4.1 Overall, the findings from the survey have confirmed that many people highly value NRAS's work, especially the information and support it provides. The responses have also given a clear picture of areas where people with RA/JIA, carers and health professionals believe there is potential for new developments and improvements.
- 4.2 Some of the suggestions link to work that is already underway in NRAS, e.g. improving the search function of the website. This report will help to prioritise and strengthen commitment to these projects.
- 4.3 Some of the suggestions for new resources in fact already exist e.g. information about RA/JIA for workplaces. The fact that people are still asking for this information, shows that more work needs to be done to raise awareness of the full range of resources that are available.
- 4.4 Other suggestions will be considered alongside the results from other consultation exercises that have been carried out in parallel, with staff and other stakeholders. It is of note that the survey has confirmed views that have been heard elsewhere e.g. from volunteers. The final organisational strategy will take all of these views on board to agree a set of priorities for action over the next three years. The strategy development is ongoing until Spring 2025, when NRAS aims to launch the final strategy. This will be shared widely.
- 4.5 As the work continues, both to make improvements and to raise awareness of the resources already on offer, NRAS is committed to working in partnership with people affected by RA/JIA, carers and health professionals. This will ensure their views will continue to help shape the design, delivery and dissemination of NRAS's services and resources.

## Appendix: Characteristics of the people who responded to the survey

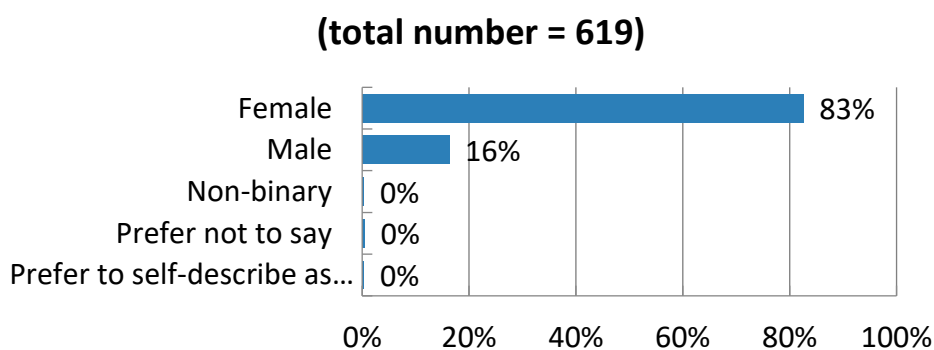
In each of the figures below the total number of respondents is the total number of people who answered this question. Not all respondents were asked every question.



**Fig 2. Percentage of respondents living with RA/JIA for different numbers of years**

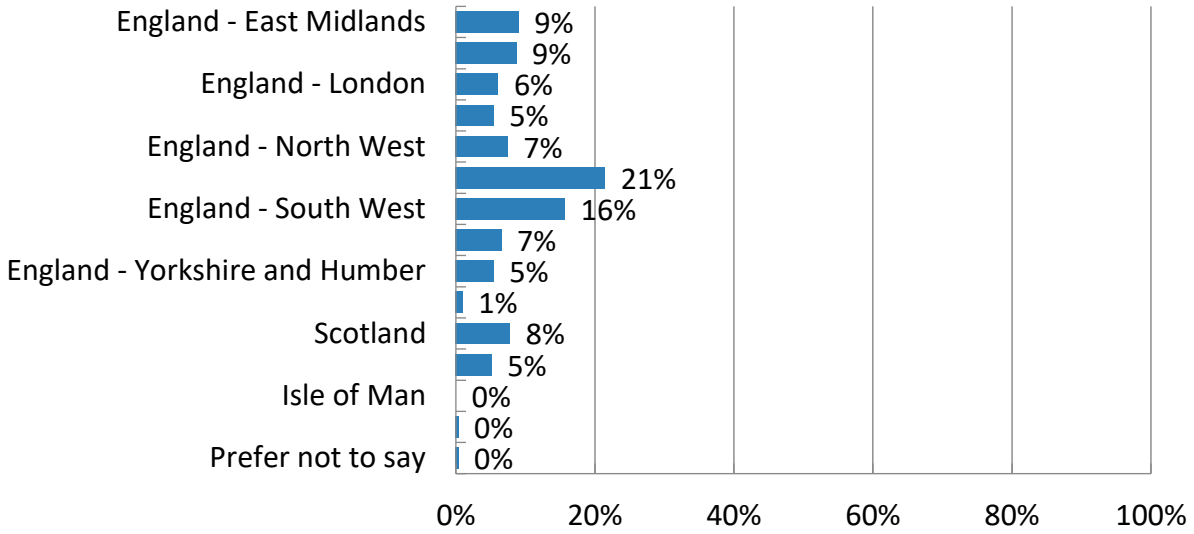


**Fig 3: Percentage of people with RA/JIA at different ages**



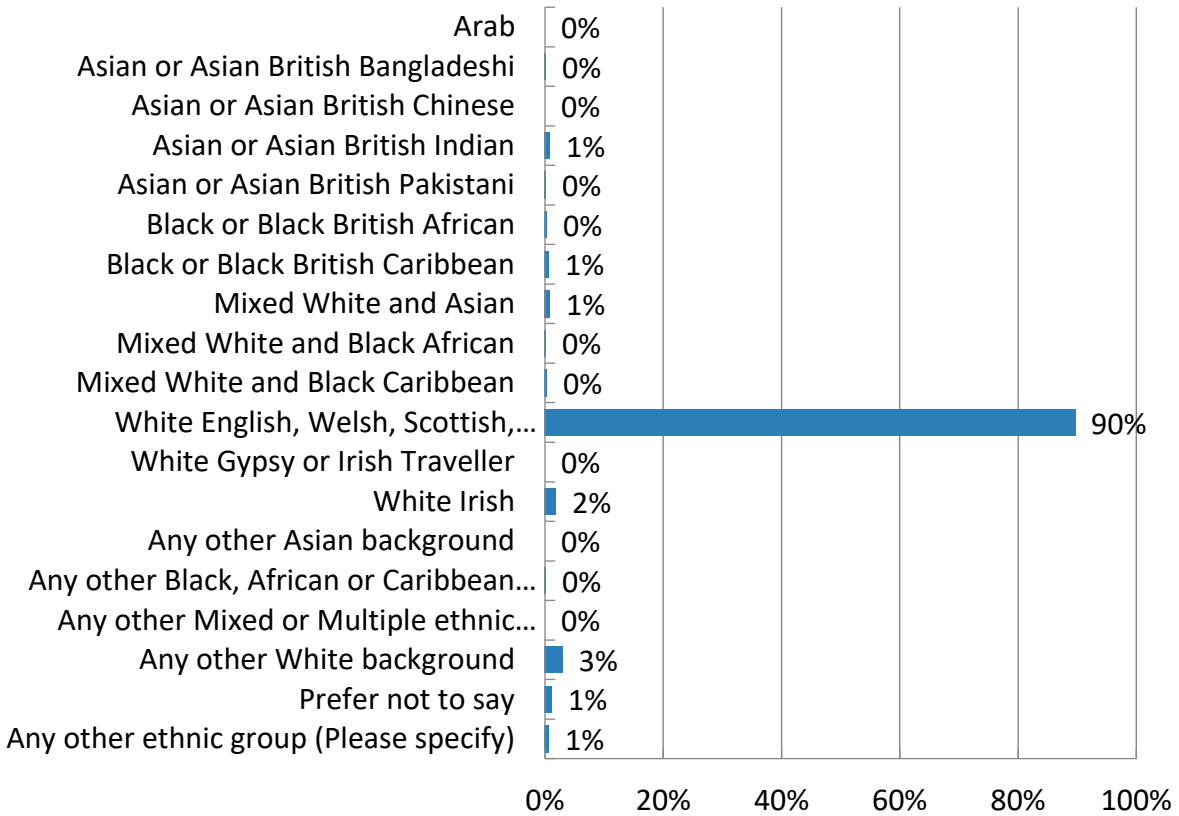
**Fig 4: Percentage of people with RA/JIA and carers with different genders**

(total number = 645)



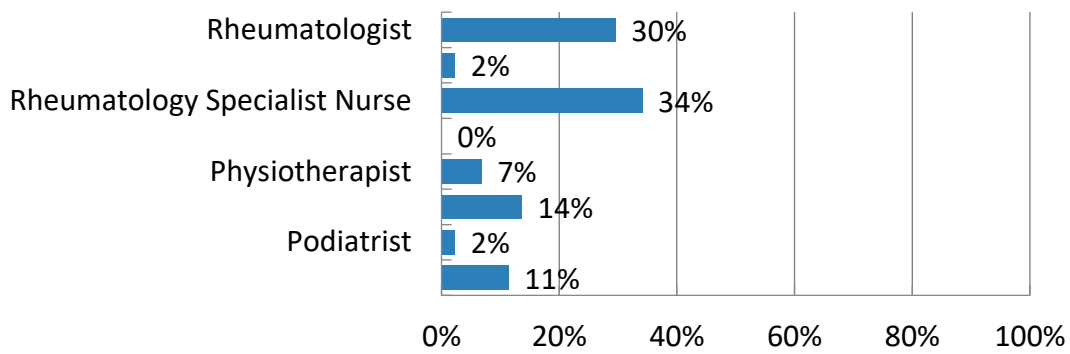
**Fig 5. Percentage of people living in different geographical locations in UK for all respondents**

(total number = 600)



**Fig 6: Percentage of people with RA/JIA and carers with different ethnic backgrounds**

**(total number =44)**



**Fig 7: Percentage of health professionals with different professional backgrounds**