

# Clare Jacklin Chief Executive



# The Value of Patient Organisations

- Far more than just 'local support'
- Patient Organisations contribute to national policies; service redesign; healthcare professional education; support and conduct research
- We can influence health beliefs and unhelpful behaviours
- We tell everyone about the importance of effective supported self-management
- Educate patients by providing access to information and resources
- **We reinforce your clinical advice**



# Patient Organisations' crucial role in supporting GIRFT recommendations



## Rheumatology

GIRFT Programme National Specialty Report




## Recommendations: Improving early management of inflammatory arthritis

Recommendation	Actions	Owners
9. Management of suspected early inflammatory arthritis (EIA) should be improved through clearer referral criteria, effective triage systems and adequate resourcing to meet patient needs and comply with the audited National Institute for Health and Care Excellence (NICE) quality statements.	a Develop standard nationally agreed referral criteria for suspected EIA, to support effective triage and evaluate them over time.	GIRFT, BSR
	b Liaise with primary care networks to review local referral rates/yield and refine referral processes in line with 9a to ensure patients are assessed within the three week target set by the audited NICE Quality Statement 2.	Trusts, PCNs, BSR audit
	c Model demand and ensure there is adequate dedicated clinical resource to meet local patient needs, including dedicated EIA clinics where possible.	Trusts
	d Interrogate the audited NICE Quality Statement 3 performance data to assess and address root causes of delays in patients initiating treatment once diagnosed.	Trusts


*"Following diagnosis I phoned the NRAS helpline and spoke to someone who was very supportive and helped me to process this devastating news. This was then followed up with "peer to peer support". This telephone conversation with someone my own age with the same condition was again very helpful with helping me come to terms with this illness."*



**nras**  
National Rheumatoid  
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# My AS, My Life

### Helping you build the skills and confidence to take control of your AS and your life

On average you might spend 2 hours each year with a health professional discussing your axial SpA (AS). That leaves 8,758 hours where you have to manage your condition on your own.

My AS, My Life helps you build the confidence and skills you need to self-manage your axial SpA (AS). It includes guides, videos, blogs and links to a whole range of issues covering both your physical and mental health.

If you'd like to chat to someone about any of the issues in this section, the [NASS Helpline](#) are there for you.

#### Upcoming Sessions

Our next sessions are:


- Thursday 14 October, 13.00: How axial SpA can affect your feet with Dr Lindsey Cherry, Senior Clinical Academic at the University of Southampton & Solent NHS Trust
- Wednesday 20 October, 12.00: Pilates 'Improver' session with Ruth Larkin, Sports Therapist and Pilates teacher
- Tuesday 26 October, 10.00: Relaxation session with Ali Potter, Health & Mindset Coach and Osteopath
- Wednesday 3 November, 13.00: Acupuncture for pain with Ian Appleyard, Research & Policy Manager, British Acupuncture Council

#### Watch Live

To watch live, visit our [Facebook page](#) at the time of the live session. If you can't see the video, refresh your page.

#### Session Library

Watch previous sessions, read blogs and download resources on the following topics:



[Living with Arthritis](#)
[How we Help](#)
[Membership](#)
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## Pain Management

### Arthritis Pain

People with arthritis can experience both acute and chronic pain.

Those with inflammatory types of arthritis such as Rheumatoid Arthritis can experience sudden 'flare-ups' which are felt as sudden sharp pain in one or two joints. This can last a few days and be accompanied by redness and swelling around the joint. The person may feel unwell and fatigued. Underlying this can be long term chronic pain associated with permanent tissue damage.

Those with osteoarthritis tend to experience more chronic pain that can range from slight stiffness in the morning to severe pain, particularly on movement.

### Managing Arthritis Pain

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# VERSUS ARTHRITIS ACTIVE LONDONERS PROGRAMME

[Information and support](#)
[How you can help](#)
[Healthcare professionals](#)
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## Healthcare professionals

We know you work hard to support people with or are risk of osteoporosis - so we're here to support you.

We work with healthcare professionals and providers in primary and specialist care to help improve services and standards, so that people with osteoporosis receive the treatment they deserve.

Whether you use us to help address your patients' questions or as a source of expertise in the development of your own career, we are committed to keeping you up to date and informed.

### Our free Helpline is for you, too

Get in touch to discuss osteoporosis and bone health with one of our specialist nurses:

**0808 800 0035**

[nurses@theros.org.uk](mailto:nurses@theros.org.uk)

### Osteoporosis video resources for your patients

Send your patients to [theros.org.uk/newly-diagnosed](https://theros.org.uk/newly-diagnosed) for videos that answer common questions about osteoporosis and bone health.



Versus Arthritis Active Londoners pilot is a service for people with arthritis and related musculoskeletal (MSK) conditions who want more lives. Created by Versus Arthritis and funded by the Mayor of London, the programme is designed to support people to get a variety of tailor-made movement sessions, expert tips and advice. To attend one of our free activity sessions tailored for people in London Boroughs of Camden, Southwark and Merton [please complete all the fields below and submit the form](#). Once we receive one of our members of staff will contact you within 10 working days to confirm your service with us. Please note: **You will need to access our pilot.**

you'll receive:

activity sessions tailored to your needs and led by a qualified instructor champion.



# nrras

National Rheumatoid Arthritis Society

## Reducing delays in switching to biosimilars

Recommendation	Actions
<b>19.</b> Trusts and departments should continue to be supported to make rapid switches to use of best value biologic medicines, including biosimilars, where clinically appropriate.	<p><b>a</b> Develop national approaches to the choice of best value biologics, similar to the national initiative for switching to biosimilar adalimumab. This should include appropriate commissioning levers including reference pricing to support the costs of clinical changes.</p> <p><b>b</b> Continue to use Model Hospital (and future Model Health system) to monitor the uptake of best value biologic medicines.</p> <p><b>c</b> Continue to monitor patient safety and optimal clinical outcomes to support future choices around best value biologics.</p>

# Collaborating with NHS England & other patient organisations to develop resources for you



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## Adalimumab resources to use with patients

**Ben Rehman**, Assistant Head (Medicines Optimisation), Specialist Pharmacy Service · Published 18 September 2018

Topics: [Adalimumab](#) · [Biosimilars](#) · [RMOG recommendations and resources](#)

These resources have been put together by the NHS England Pharmacy Communications team. They are designed for professionals to use with patients to support introduction of biosimilar adalimumab.

### Attachments

 [Adalimumab Patient FAQ Final - updated 19 September](#) · PDF · 274 KB

 [Adalimumab Template Patient Letter - Final - 9 August](#) · Word · 32 KB

 [Adalimumab-Article-for-Patient-Newsletters-Final-Oct-2018\[1\]](#) · Word · 100 KB





# EULAR Recommendations

## EULAR Recommendations for the implementation of self-management strategies in patients with Inflammatory Arthritis (IA)

### Objectives:

To develop EULAR recommendations for the implementation of effective self-management strategies facilitated by health professionals in IA concurrently with and complimentary to the delivery of standard routine medical care which will have tailored care planning and shared decision making at its centre:

- To enable all members of the rheumatology multi-disciplinary team to be able to provide and signpost a continuous and appropriate measure of support to enable better RA patient self-management.
- To improve overall patient experience, disease outcomes and quality of life.



**6**  
OPEN ACCESS

**2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis**

Elena Nikiforou<sup>1,2</sup>, Eduardo José Ferreira Santos<sup>3,4</sup>, Andrea Marques<sup>5,3,4</sup>, Peter Böhm<sup>6,3</sup>, Johannes WJ Bijlsma<sup>6</sup>, Claire Immediato Daen<sup>7</sup>, Bente Appel Esbensen<sup>8,9</sup>, Ricardo J O Ferreira<sup>10</sup>, George E Fragoulis<sup>10</sup>, Pat Holmes<sup>11</sup>, Hayley McBain<sup>12</sup>, George S Metsios<sup>13,14</sup>, Rikke Helene Moe<sup>15</sup>, Tanja A Stamm<sup>16</sup>, Annette de Thurah<sup>17,18</sup>, Condruța Zabalán<sup>19</sup>, Loreto Carmona<sup>20</sup>, Ailsa Bosworth<sup>21</sup>

**Handling editor** Dimitris T. Sotiropoulos

**Additional supplemental material** is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/eularands-2021-220249>).

**For numbered affiliations** see end of article.

**Correspondence** to Dr Elena Nikiforou, Rheumatology Department, King's College London, London SE5 8RL, UK; [enikiforou@gmail.com](mailto:enikiforou@gmail.com)

EJS and AM contributed equally.

LC and AB are joint senior authors.

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**To cite:** Nikiforou E, Santos EJ, Marques A, et al. A multi-disciplinary taskforce of 18 members from 11 European countries was convened. A systematic review and other supportive information (survey of healthcare professionals (HCPs) and patient organisations) were used to formulate the recommendations.

**Results:** Three overarching principles and nine recommendations were formulated. These focused on empowering patients to become active partners of the team and to take a more proactive role. The importance of patient education and key self-management interventions such as problem solving, goal setting and cognitive behavioural therapy were highlighted. Role of patient organisations and HCPs in promoting and signposting patients to available resources has been highlighted through the promotion of physical activity, lifestyle advice, support with mental health aspects and ability to remain at work. Digital healthcare is essential in supporting and optimising self-management and the HCPs need to be aware of available resources to signpost patients.

**Conclusion:** These recommendations support the inclusion of self-management advice and resources in the routine management of people with IA and aim to empower and support patients and encourage a more holistic, patient-centred approach to care which could result in improved patient experience of care and outcomes.

**Check for updates**

**INTRODUCTION**

In people living with inflammatory arthritis (IA), as well as other rheumatic and musculoskeletal diseases (RMDs) and chronic conditions, an important aspect of care is the ability to understand the disease and deal with the practical, physical and psychological impacts that come along with

**What is already known on this subject?**

- The ability to self-manage in inflammatory arthritis (IA) represents an essential component of care that goes beyond drug therapy and which supports the patient in managing the practical, physical and psychological impacts of disease.
- Self-management is a multicomponent complex intervention that represents an unmet need in the care of people with IA.

**What does this study add?**

- These recommendations, based on evidence and expert opinion, confirm the beneficial effects of different components of self-management and provide guidance on embedding self-management interventions into the routine clinical care of people with IA.
- This work highlights the value of patient organisations in providing support and structured guidance for people with IA and the need to demonstrate and document the effectiveness of specific self-management interventions.

**How might this impact on clinical practice?**

- Adherence to these recommendations will lead to improved patient care and outcomes in people living with IA and will encourage a more active patient role in the management of disease.

**is.<sup>1,2</sup> This extends beyond drug therapy and places emphasis on the ability to self-manage as an essential component of care.<sup>3</sup> Comorbidity including cardiovascular disease and common mental health conditions represent important, yet often poorly addressed aspects of IA despite their impact on disease outcomes.<sup>4,5</sup> Addressing physical as well as psychological comorbidities is therefore crucial and more likely to be achieved if more holistic approaches to patient care are adopted, including**

**BMJ** [eular.bmj.com/](http://eular.bmj.com/) <https://doi.org/10.1136/eularands-2021-220249>



## RECOMMENDATION 1

Healthcare professionals should encourage patients to become active partners of the team and make them aware of healthcare professionals and patient organisations involved in all aspects of the care pathway.

## RECOMMENDATION 2

Patient education should be the start-point and underpin all self-management interventions.



## RECOMMENDATION 3

Self-management interventions that include problem solving and goal setting and, where relevant to the individual and available, cognitive behavioural therapy, should be incorporated into routine clinical practice to support patients.

## RECOMMENDATION 4

Healthcare professionals should actively promote physical activity at diagnosis and throughout the disease course.



## RECOMMENDATION 5

Lifestyle advice based on evidence should be given to better manage common comorbidity and patients should be guided and encouraged by their healthcare team to adopt healthy behaviours.



## RECOMMENDATION 6

Better emotional wellbeing leads to better self-management, therefore, mental health needs to be assessed periodically and appropriate intervention made if necessary.



## RECOMMENDATION 7

Healthcare professionals should invite discussion with patients about work and signpost to sources of help where appropriate or where needed.

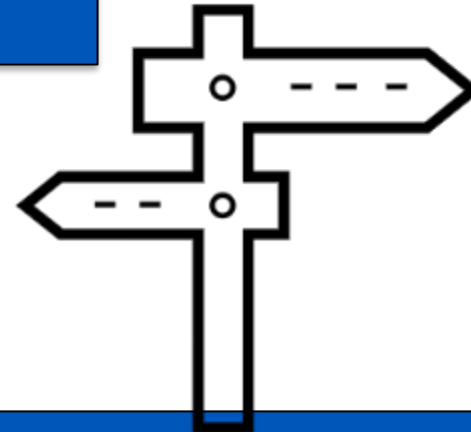
## RECOMMENDATION 8

Digital healthcare can help patients to self-manage and should be considered for inclusion in supported self-management where appropriate and available.

### Disease Activity Score (DAS)



Download App



## RECOMMENDATION 9

Healthcare professionals should make themselves aware of available resources to sign-post patients to, as part of optimising and supporting self-management

**NRAS can help you to provide high quality evidence-based patient education and access to a range of supported self-management resources for your RA patients**



# Right Start Service



## The NRAS New2RA Right Start

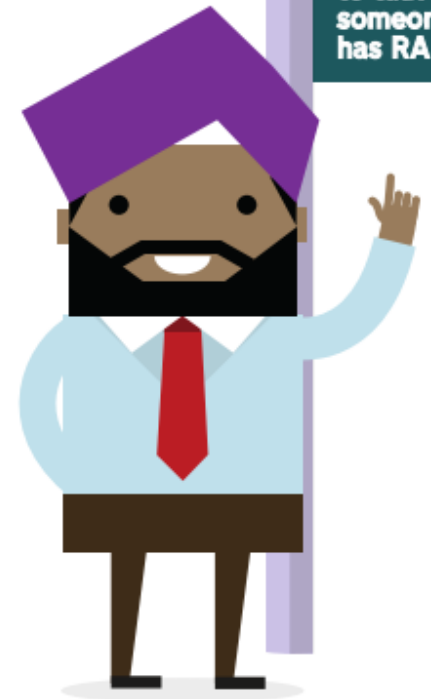


Step 1  
Referral to  
Right Start

Step 2  
NRAS  
Helpline call

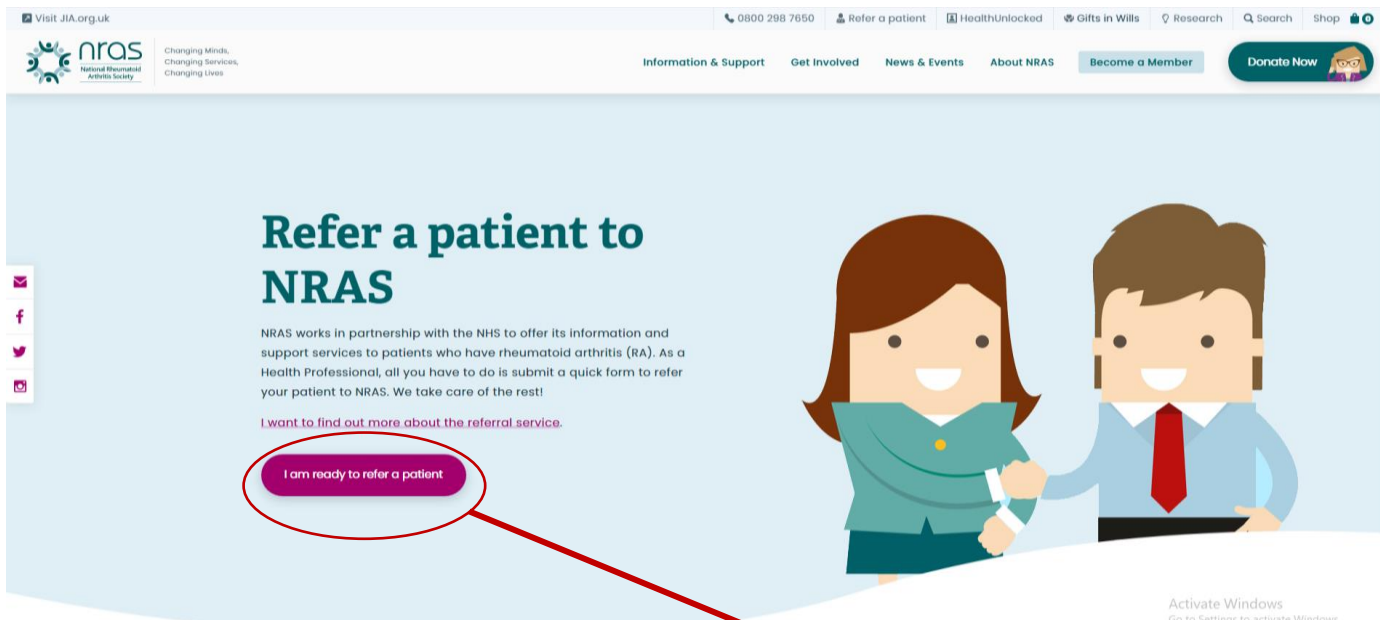
Step 3  
Tailored  
Information  
pack

Step 4  
A chance  
to talk with  
someone who  
has RA



# Referral to New2RA Right Start

## Step 1



When you are ready to refer, click on the button







**Step 1**  
Referral to Right Start

**Step 2**  
NRAS Helpline call

**Step 3**  
Tailored Information pack

**Step 4**  
A chance to talk with someone who has RA

## Rheumatoid Arthritis?

Access the **New2RA Right Start** Service

Ask your healthcare provider to refer you to the **New2RA Right Start** service.

[www.nras.org.uk/rightstart](http://www.nras.org.uk/rightstart)

Helpline: 0800 298 7650  
General: 01628 823 524  
e: [helpline@nras.org.uk](mailto:helpline@nras.org.uk)  
w: [www.nras.org.uk](http://www.nras.org.uk)

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4 Switchback Office Park  
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JIA-at-NRAS is a part of the National Rheumatoid Arthritis Society

## Rheumatoid Arthritis?

Access the **New2RA Right Start** Service

[www.nras.org.uk/rightstart](http://www.nras.org.uk/rightstart)



# NICE - Rheumatoid arthritis in over 16s

## Quality standard [QS33]

Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management. (2013, updated 2020)



**NICE** National Institute for Health and Care Excellence

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**Coronavirus (COVID-19)**

For information on how NICE is supporting the NHS and social care, view our new [rapid guidelines and evidence summaries](#). Learn about the [government response to coronavirus on GOV.UK](#).

Close

Home > NICE Guidance > Conditions and diseases > Musculoskeletal conditions > Arthritis

The NRAS New2RA Right Start Service – a comprehensive and tailored support service for people newly diagnosed with rheumatoid arthritis

### Shared learning database

Organisation: National Rheumatoid Arthritis Society (NRAS) and King's College Hospital NHS Foundation Trust

Published date: February 2020

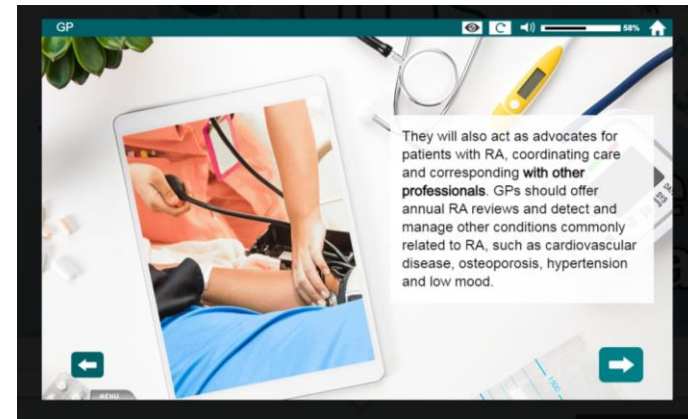
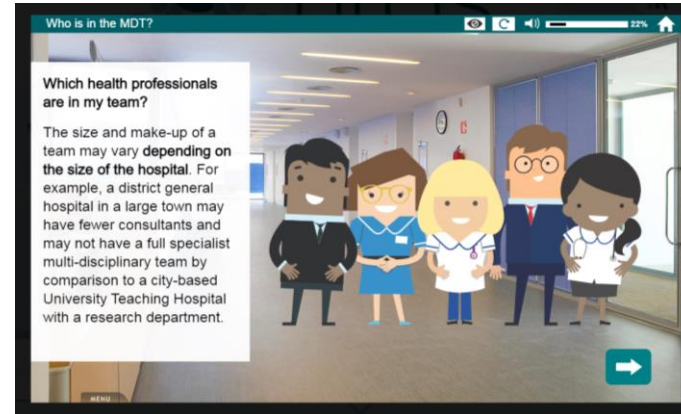
The National Rheumatoid Arthritis Society (NRAS) follows best practice, evidence-based standards in all we do. Whilst huge strides have been made in the diagnosis and treatment of Rheumatoid Arthritis (RA), the impact on quality of life can be significant and for many RA remains hard to come to terms with.

NRAS has contributed to NICE Guidelines and Quality Standards since the first RA guideline in 2009. We promote adherence to the Guideline and Standards.

Active  
Go to 54


# SMILE-RA

- Programme is intuitive, interactive, uses quizzes and contains video contributions from patients, health professionals, NRAS staff
- 4 modules built, one more in progress.
  - Medication & Treatment
- Advisory panel & input from patients and HCPs involved in each module




# Modules – Netflix like Display

Latest Releases



NRAS Learning



- Foundation
- Newly Diagnosed
- Meet the Team
- Managing Pain and Flares
- Medication and Treatment

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NRAS Foundation

Category: NRAS Learning  
Status: completed  
Type: e-learning

Start Here  
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Overview Details

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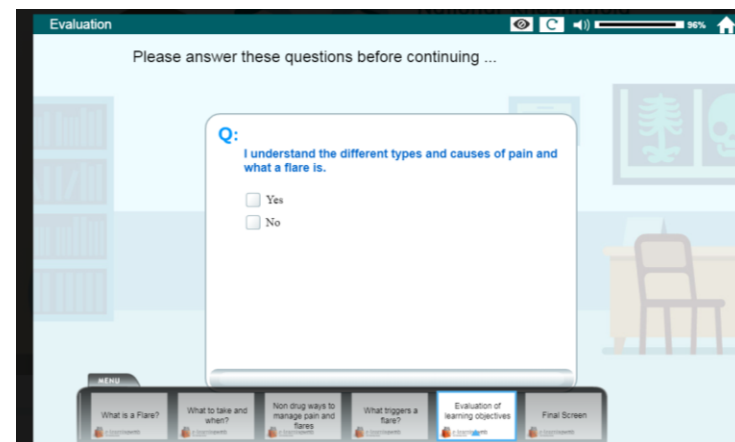
nras E-Learning  
Smile-RA  
Self-Management  
Individualised Learning Environment

Foundation

# Evaluation



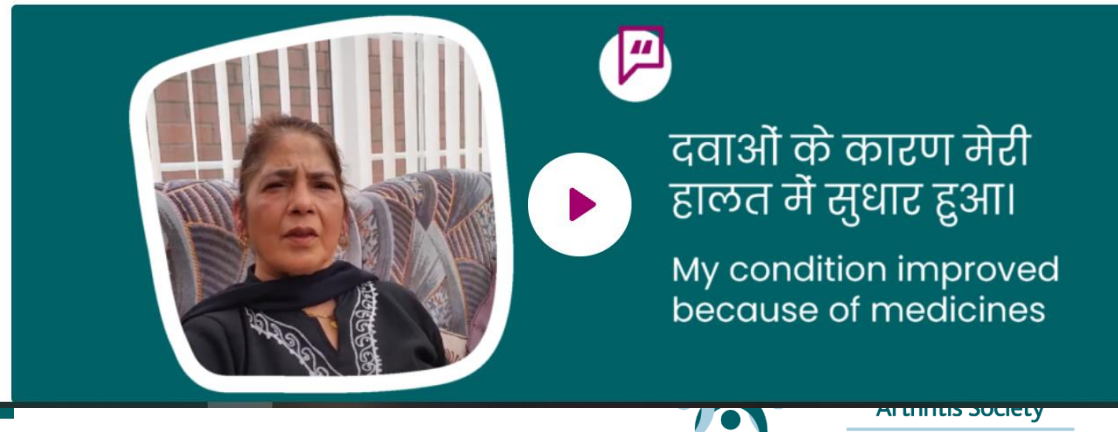
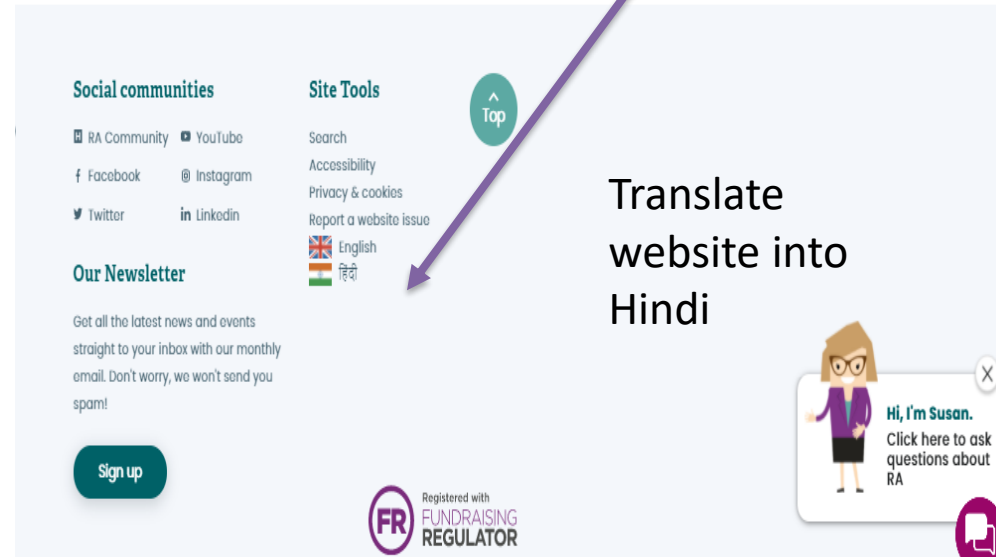
- Each module has **learning objectives** at the start and 3-4 questions at the end to establish learning objectives have been met
- The Foundation Module **includes 3 questions + the RA Impact of Disease Questionnaire** (7 domains)
  - Pain
  - Functional Disability Assessment
  - Fatigue
  - Sleep
  - Physical Wellbeing
  - Emotional Wellbeing
  - Coping
- **Baseline RAID taken** following registration and at further time points to be decided upon.





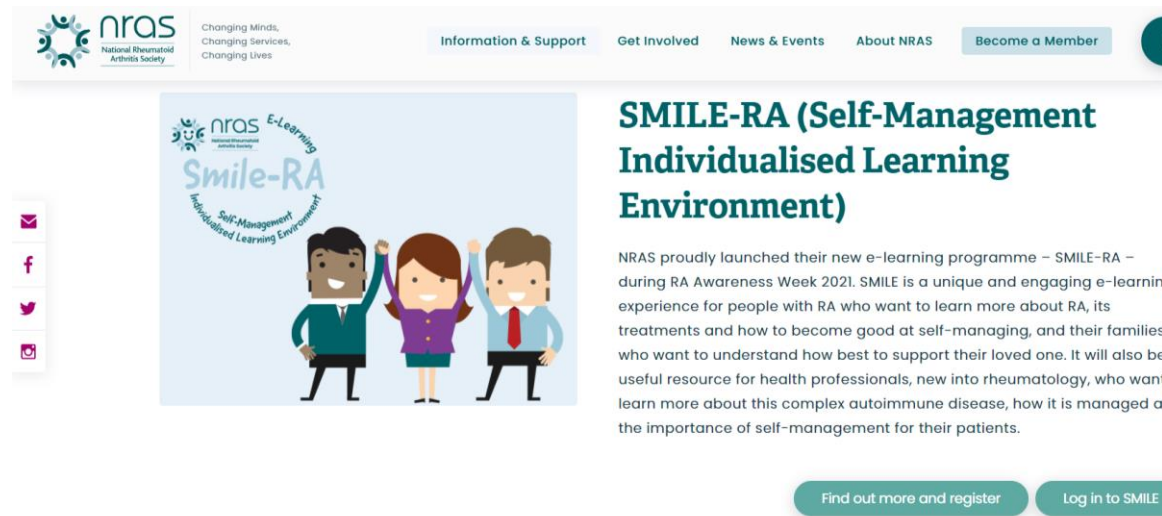
# Information for South Asian population

## Apni Jung अपनी जंग



# Re-cap of what NRAS & most patient organisations can offer your patients

- Wellbeing sessions
- NRAS Here For You - peer support
- Free publications
- **Helpline 0800 298 7650**
- NRAS **New2RA Right Start**/Living with RA
- NRAS **SMILE-RA**
- Largest global online RA community (HealthUnlocked)
- RheumZooms, Facebook Lives with expert speakers
- Evidenced based informative websites full of resources



The screenshot displays the NRAS (National Rheumatoid Arthritis Society) website. The header includes the NRAS logo, tagline 'Changing Minds, Changing Services, Changing Lives', and navigation links: 'Information & Support', 'Get Involved', 'News & Events', 'About NRAS', and a 'Become a Member' button. A vertical sidebar on the left contains social media icons for email, Facebook, Twitter, and Instagram. The main content area features a large graphic for 'Smile-RA' with the text 'nras E-Learning', 'Self-Management', and 'Individualised Learning Environment'. The graphic depicts three diverse people (two men and one woman) in business attire, smiling and raising their hands in a celebratory gesture. To the right of the graphic, the heading 'SMILE-RA (Self-Management Individualised Learning Environment)' is followed by a paragraph: 'NRAS proudly launched their new e-learning programme – SMILE-RA – during RA Awareness Week 2021. SMILE is a unique and engaging e-learning experience for people with RA who want to learn more about RA, its treatments and how to become good at self-managing, and their families who want to understand how best to support their loved one. It will also be a useful resource for health professionals, new into rheumatology, who want to learn more about this complex autoimmune disease, how it is managed and the importance of self-management for their patients.' At the bottom right, there are two buttons: 'Find out more and register' and 'Log in to SMILE'.








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