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National Rheumatoid Arthritis Society

MANCHESTER 1824
The University of Manchester



NRAS Right Start Service Evaluation

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Right Start
Patient Referral Service

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Right Start
Patient Referral Service

New2RA nras National Rheumatoid Arthritis Society RIGHT START

Executive Summary

The NRAS New2RA Right Start Service (Right Start) is a tailored service to support people living with Rheumatoid Arthritis (RA), delivered following a diagnosis or at any point when additional support is needed. The service focuses on early emotional support, education and supported self-management, helping individuals understand their diagnosis, adjust behaviour and lifestyle, and take practical first steps towards managing their condition.

An independent service evaluation was conducted in partnership with the University of Manchester between April 2022 and December 2024 across four rheumatology units in England. Analysis was completed at the end of 2025 to allow for 12-month follow-up of participants.

NRAS was responsible for the delivery and operational management of the service. The University of Manchester led the evaluation elements, including analysis of the patient-reported outcome measures (PROMs), site staff surveys and qualitative interviews. The full anonymised site-level report authored by Dr Charlotte Sharp is included in the appendices.

Key Findings

The evaluation found meaningful improvements across several domains that are central to the aims of the Right Start service.

Clinicians reported:

- The service **met expectations**
- They were reassured that patients were receiving **high-quality education**
- The referral process **did not increase clinical workload**
- A **reduced workload** where referral rates were good
- Feedback from patients was **overwhelmingly positive**

Patients reported:

- Improved **education and understanding** of rheumatoid arthritis
- Increased **confidence in self-management and coping**
- Improved **sleep** with a reduction in fatigue
- Increased participation in **social activities**
- A reduction in **perceived illness impact**

Recommendation: to embed Right Start within care pathways

Although follow-up numbers were small ($N \approx 25$), the pattern of statistically significant changes supports the acceptability and effectiveness of embedding enhanced Right Start within care pathways for newly diagnosed RA.

Right Start Service Evaluation

Background

The National Rheumatoid Arthritis Society (NRAS) follows best practice and evidence-based standards, consistently promoting adherence to the National Institute for Health and Care Excellence (NICE) guidelines and quality standards, which NRAS has contributed to developing since the first RA guideline was published in 2009.

Although diagnosis and treatment of RA have improved dramatically, the impact on quality of life remains significant. Right Start aims to improve outcomes by providing early emotional support, normalising fears and anxiety, giving education about RA and its treatments, and offering supported self-management resources tailored to individual need. While most referrals relate to newly or recently diagnosed people, a person can be referred at any stage. Referral also supports health professionals to meet NICE Quality Standard 33, Statement 3 ("Adults with rheumatoid arthritis are given opportunities to take part in educational activities that support self-management throughout the course of their disease.") and improve people's experience of care.



A new diagnosis can be devastating with anxiety and depression occurring as common comorbidities in early RA. NRAS' experience of supporting people with RA across the UK indicates that timely emotional and educational support can help people to adjust, improve confidence and coping, support adherence, and strengthen supported self-management.

Right Start was developed with UK consultant rheumatologists during 2017–2019, informed by earlier signposting approaches and an audit of the NRAS helpline. It launched in April 2019 with a General Data Protection Regulation (GDPR) compliant online referral process and supporting materials for use in clinic. Referrals increased steadily, leading to this independent service evaluation.

At the time of developing the Service Evaluation Protocol, NRAS already had 71 rheumatology units referring some of their patients to Right Start and Living with RA (equivalent programme for people with existing disease which ran at that time), and it was hoped and anticipated that the results of this service evaluation would encourage many more rheumatology units across the UK to refer their patients to the NRAS Right Start service so that more people could benefit from our resources and support.



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Evaluation Partner

A protocol to carry out a service evaluation process was developed in collaboration with our academic partners, University of Manchester (UoM). They recommended suitable patient-reported outcome measures (PROMs), as well as the design of staff surveys and qualitative interviews with each of the pilot sites. Four hospitals across England took part.

Dr Charlotte Sharp, Consultant Rheumatologist at the Kellgreen Centre & Honorary Senior Clinical Lecturer UoM, was responsible for collecting and analysing the site data and her full, anonymised site report is included at Appendix 3 to this Report. Suzan Verstappen, Professor of Epidemiology in the Centre for Musculoskeletal Research, School of Biological Sciences, UoM recommended the individual PROMs used and was responsible for analysing the patient data detailed later in this report.

Research Design

Please refer to the appendices for comprehensive and detailed information regarding the longitudinal study design, including PROMs and data analysis.

Key Aims for the Service Evaluation

System Related

1. **To integrate the Right Start referral within the RA care pathways** of the rheumatology units participating in the service evaluation, maximising use of evidence-based NRAS resources.
2. **Linking of the Right Start service directly to the NICE Quality Standard** on education and self-management meant that we were not only providing high-quality education and support but also enabling health care professionals (HCPs) to meet their obligations under NICE Quality Standard 33 – domain 3. Rheumatology teams are being audited against these standards within the National Early Inflammatory Arthritis Audit.
3. **To provide economical and evidence-based access to education and supported self-management** resources through NRAS. Many healthcare professional-run, in-hospital educational programmes have stopped due lack of resources; this was exacerbated during the pandemic.
4. **To give health professionals confidence** that they are providing their patients with access to excellent educational and supported self-management resources, which also align with the EULAR (European Alliance of Associations for Rheumatology) Recommendations for the Implementation of Self-management Strategies in Inflammatory Arthritis published later in 2021.
5. **To demonstrate the value of close collaboration** between NRAS (and patient organisations more widely) and (rheumatology) health professionals.

Patient Related

- **To demonstrate that formal integration of the service** within an RA care pathway so all members of the team are involved, increases the referral numbers, leading to many more newly or recently diagnosed patients with RA having access to tailored self-management resources, education and support.
- **To improve both the physical and mental health outcomes** of patients who are newly/recently diagnosed.
- **Encourage better long-term adherence** to medication.
- Ability to **raise awareness** of the value and importance of acquiring **self-management skills** with people at an early point in their RA journey.



Results Summary with Evidence

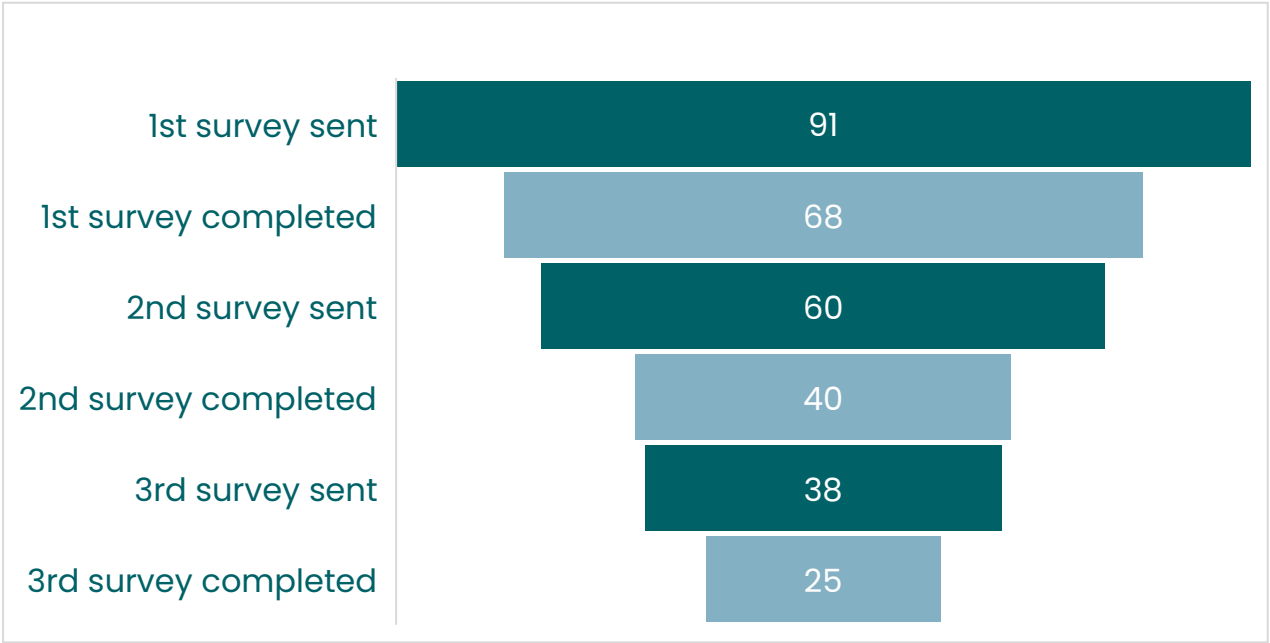
Data (including p-values) and clinical interpretation can be found in appendices 2 and 3.

Right Start participants showed reliable improvements across education and understanding, confidence in self-management, sleep and fatigue, functional participation (social activities), and reduced perceived illness impact.

- Several gains were evident within 3 months
- Broader and sustained improvements within 12 months
- Work and daily activity measures strengthened by 12 months
- Mood and anxiety remained stable
- Adherence to medication remained high

Despite small follow-up numbers who completed all three surveys, (N≈25), the pattern of statistically significant changes supports the acceptability and effectiveness of embedding Enhanced Right Start within care pathways for newly diagnosed RA.

Total number of surveys sent and returned at each stage:



1. Understanding, Confidence and Control

Key message: Patients reported clearer understanding of RA and their treatments, felt more confident managing their symptoms, with a stronger sense of control. The gains were statistically reliable.

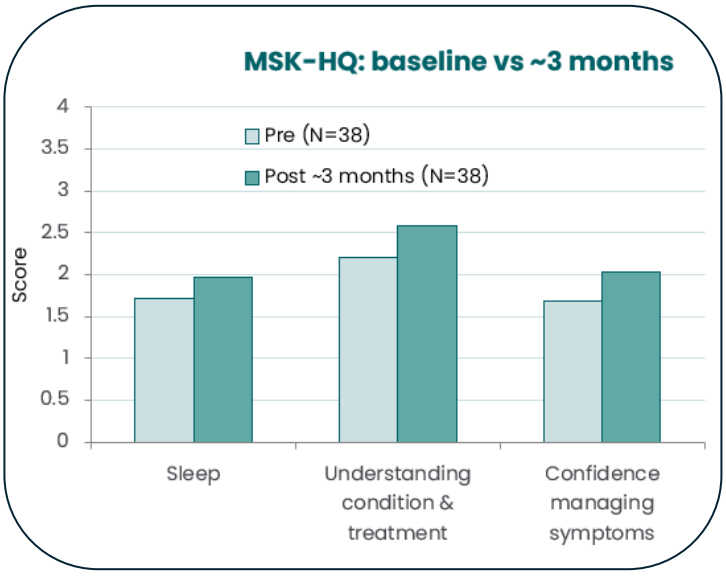
Evidence: Musculoskeletal Health Questionnaire (MSK-HQ), Rheumatology Attitudes Index (RAI) + Brief Illness Perception Questionnaire (BIPQ) results

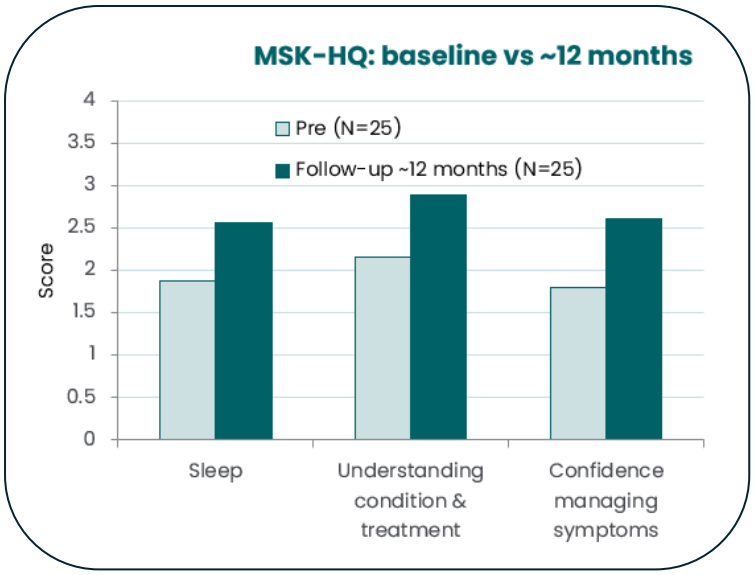
2. Daily Functioning, Fatigue and Sleep

Key messages:

- Sleep improved and continued to improve over the year.
- Participants also reported returning to daily activities and hobbies.
- Over 12 months, participants reported less fatigue.

Evidence: MSK-HQ results





3. Work, Productivity and Activity

Key message: By 12 months, participants reported no absence from work (median 0 days) and reported less disruption to daily activities. Improvement was stable across the whole group.

Evidence: Work Productivity and Activity Impairment (WPAI) results

4. Emotional Wellbeing and Medication Adherence

Key messages:

- Mood and anxiety remained stable with no significant deterioration
- Medication adherence remained high throughout

Although these outcomes were not statistically significant, they are reassuring results in the context of early RA, a time typically associated with distress.

Evidence: Patient Health Questionnaire (PHQ – 2), Generalised Anxiety Disorder Scale (GAD – 2), Medication Adherence Report Scale (MARS – 5) results

For more detail on patient data including p-values, see Appendix 2.

5. Staff Feedback

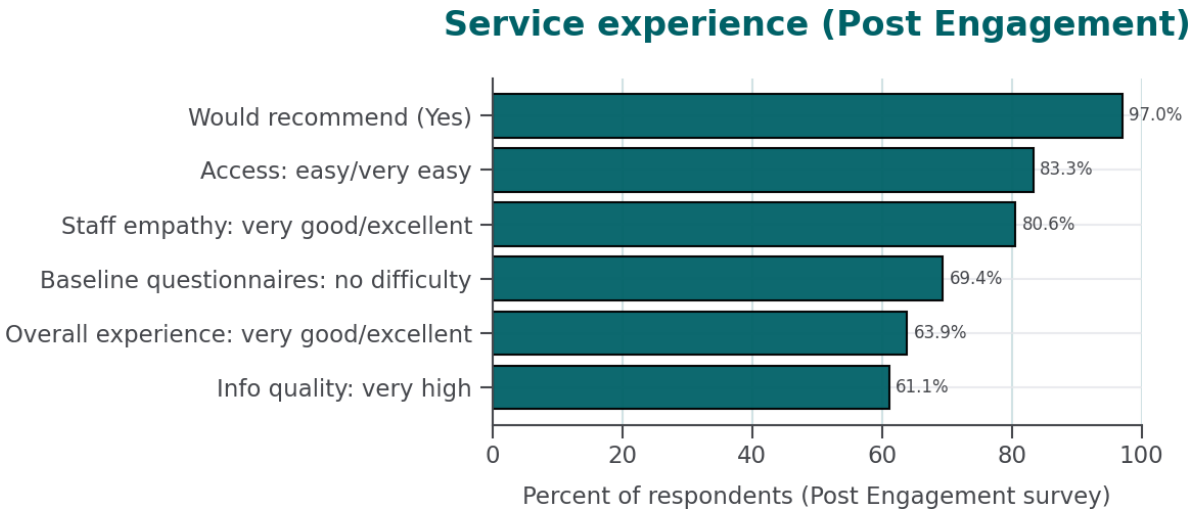
Key message: Clinicians felt reassured that patients were receiving high-quality education and support. There were no reported increases to workload; some sites saw reduced workload due to improved patient understanding.

Evidence: (see appendix 3 for Dr Sharp's report)

6. Patient Service Experience

Key message: 97% of patients would recommend Right Start, with over 80% confirming NRAS staff empathy to be very good or excellent and information quality to be very high.

Evidence: Post Engagement Survey results



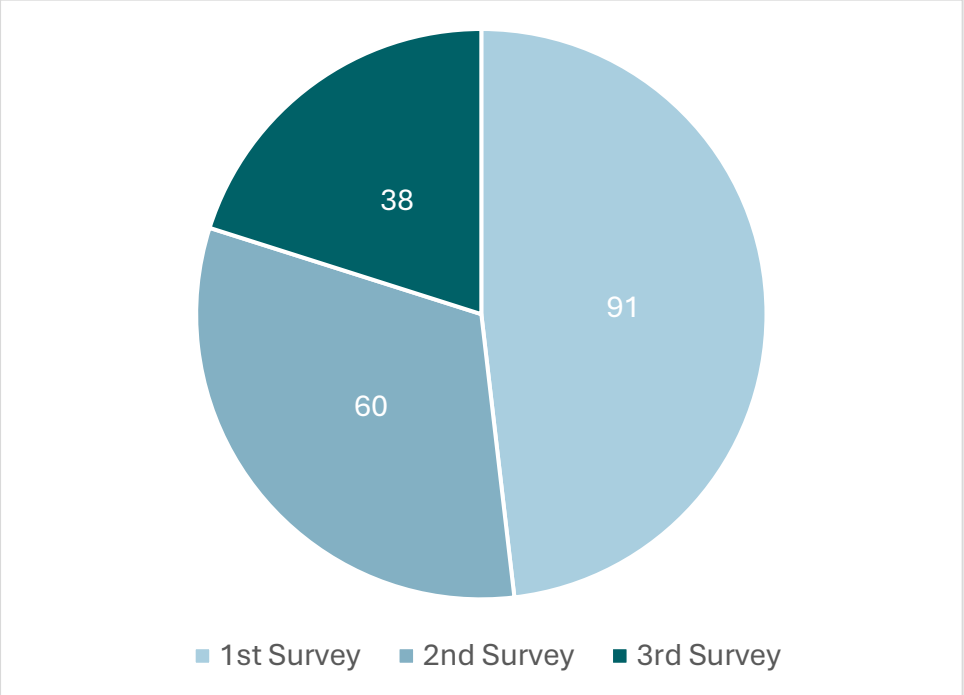
Overall Summary:

Right Start delivers **meaningful improvements** in understanding, confidence and daily functioning, and **greater perceived control over RA.**

Even with small sample sizes, the consistent pattern of change supports Right Start as a valued and effective component of early RA care.

We are not claiming that the patient-reported data is entirely due to the Right Start intervention as we understand that there are many variables which impact a person's experience and outcomes, including medication and support from the rheumatology team. However, we have focused on reporting in greater detail those domains reported by patients which align more with the aims of the Right Start service, such as understanding of their condition, acquiring greater confidence to self-manage, coping, and adherence to medication.

The total number of surveys sent out at each stage:



Status of the Right Start Service as of March 2026

NRAS has acted on feedback from the pilot sites and continues to refine Right Start to improve uptake and accessibility. This includes online booking for helpline appointments (with coordinator support for those who prefer not to book online), interpreting services for bookable telephone appointments, and online translation of website information (excluding videos) into multiple languages in addition to English.

NRAS continues to promote Right Start to rheumatology teams and support adoption within clinical pathways. Current referral and funding information is summarised below.

Recommendations from Dr Sharp's Site Report

1. Remove the requirement to enter the patient's address; NRAS could collect this later.

NRAS response

The address is useful in the absence of response from email. It also enables contact rather than a digital-only approach which improves accessibility for some. In addition, if there is a phone number, a call or text can be made before writing.

2. Reassure sites that the referral is quick and easy, and their workload is unlikely to be increased in any way as a result of patients engaging with NRAS; in fact, they will be better educated which may result in fewer helpline calls.

NRAS response

We will be focusing on RS again at BSR 2026 and will use this opportunity to engage with health professionals to reinforce this message. As of autumn 2025, NRAS have employed a Health Engagement Manager whose remit is to engage with rheumatology units and support their adoption of Right Start into their RA clinical pathways. We will be testing self-referral via a health professional within 12 months (directive signposting).

3. Provide leaflets and posters for sites to display and consider supplying copies of paper referral forms for sites who have administrative support to help clinicians make referrals.

NRAS response

We already provide posters and patient leaflets to all units. We are producing a QR code which HCPs can have on their desk and patients can scan as it takes them direct to the referral form.

4. Encourage more activity from local NRAS sites to help promote the service.

NRAS response

This is part of our peer support strategy deliverable over the next 3 years.

5. Consider having a league table or benchmarking system to allow sites to see where their recruitment rates fall in comparison with other sites. [Note that sites may not wish for this to identify their sites to others, but may wish to see where their performance lies in comparison with others]

NRAS Response

We are planning to implement a top ten referrers, which will be published direct to all referring units on a quarterly basis.

Other suggestions were as follows:

- Sites to share how they had successfully increased referral numbers - Adopted for inclusion in our healthcare engagement strategy
- Quarterly reminder emails from NRAS - Adopted for inclusion in our healthcare engagement strategy
- Posters and leaflets supplied by NRAS - Already exist, can be ordered from NRAS
- NRAS to provide a 'smart phrase' for easy inclusion in patient records and communications – NRAS are looking into this
- More representation from NRAS from ethnically diverse groups to encourage greater uptake from those groups – We will look at this as part of our EDI strategy and as we have interpreter services for all booked calls, please do refer any patients whether English is their first language or not.

Accessibility

From the end of March, Interpreting Services will be implemented within our Information and Support Team for bookable telephone appointments. Online information on our website (excluding videos), can be translated into 16 languages in addition to English. For the South Asian populations in the UK, there is a specific web area called Apni Jung (which means 'our fight' against RA) in Hindi. In this area, we have a wide range of educational videos in Hindi, Punjabi and Urdu.

Current Stats (as of March 11, 2026)

- 231 unique Units referring patients to RS
- Total number of patients referred to RS is >3,000

Funding

NRAS gets no statutory funding. The Right Start Service Evaluation was funded by NRAS. We are grateful to the National Community Lottery Fund for partially funding our Right Start service over 3 years from 2025-2028.

Right Start is directly supporting the NHS and, in our view, should be funded by the NHS. It costs NRAS £5,000 per day to provide the high level of support we do on behalf of people with RA and JIA and to support HCPs.



Appendix I

Research Design

The Evaluation Sites

The protocol was finalised in early 2022 and the first patients were referred in April 2022. Referrals could be made at any point within twelve months of diagnosis. NRAS project managed delivery and collected demographic data; completed, de-identified PROM surveys were transferred securely to the University of Manchester for analysis in line with the Data Sharing Agreement. The University of Manchester also administered staff surveys and interviews and undertook thematic analysis.

Ethics

This work comprised service evaluation, rather than research, according to the Health Research Authority 'Defining Research' guidance; it did not require HRA approval or NHS REC ethics approval. The University of Manchester proportionate review process was applied for and gained. The ethics reference number is: UoM REC 2022-13072-21696.

Data Sharing

A formal Data Sharing Agreement between NRAS and the University of Manchester was signed at the end of March 2022.

Consent

A paragraph on consent was included in the patient surveys and participation implied consent. Staff participants provided written informed consent for their survey and interview data (including anonymised quotations) to be used in reports and any publications arising from the project.

Evaluation design (Longitudinal study with a follow-up duration of 12 months)

The Evaluation involved two parts:

The evaluation comprised (1) patient-reported outcome measures collected at baseline (before the first helpline call), at the end of the intervention

(approximately 3 months) and at 12 months, with demographic data collected at baseline; and (2) staff insights via online surveys at baseline and 9 months, with qualitative interviews conducted at 18 months, due to delays in site data collection.

PROMs used

Brief Illness Perception Questionnaire (BIPQ), Musculoskeletal Health Questionnaire (MSK-HQ), Patient Health Questionnaire 2-item Depression (PHQ2), Generalized Anxiety Disorder 2-item questionnaire (GAD2), Worker Productivity and Activity Index – RA (WPAI-RA), Medication Adherence Report Scale 5-item (MARS-5), and Rheumatology Attitude Index (RAI). The NRAS PREM (experience measure) was administered immediately after the intervention only.

Patient Data

The baseline survey (before the first helpline call) captured demographic data and PROMs. Follow-up surveys were completed at approximately 3 months (post intervention) and at 12 months; the 3-month survey also included the NRAS PREM (experience measure). Demographic data included age (categories), gender, ethnicity and work status.

Data Analysis

Patient journeys were tracked from referral through the intervention. On receipt of referral, participants were allocated a code and identifiable data were removed from survey responses prior to analysis. PROMs were issued via the NRAS survey platform (Sogolytics) at the stated time points, and completed de-identified surveys were transferred securely to Manchester in line with the Data Sharing Agreement. NRAS held the limited demographic data and shared only anonymised essential demographic information for analysis.

Implementation at the pilot sites was evaluated through staff surveys and follow-up interviews, exploring barriers and enablers, fidelity to plans, perceived impact, workload implications and improvement opportunities.

Appendix 2

Patient Data *(For full details of the site data see Dr Sharp's report, Appendix 3)*

Total number of patients referred during the period of evaluation (April/May 2022 to end 2025, which was the final 12-month follow-up time point) was 179. Key numbers at each time point (baseline, 3 months (post intervention) and at 12 months) are detailed below. Interpretation of the patient-reported outcome measurements analysis by Prof. Suzan Verstappen is summarised in this section.

Patient Evidence Data *(If you would like to see the patient data tables, please contact research@NRAS.org.uk)*

1. Understanding, Confidence and Control

- MSK-HQ: Clearer understanding of RA and treatments by 3 months (p=0.0175), even stronger by 12 months (p=0.0003). Confidence to manage symptoms improved at 12 months (p=0.0005). Overall impact improved at 12 months (p=0.0131).
- RAI: RA controlling life decreased at 12 months (p=0.0196). Coping effectively improved at 3 months (p=0.0458) and 12 months (p=0.0117). RAI - Total improved at 12 months (p=0.0222).
- BIPQ: Total BIPQ score decreased (better) at 3 months (p=0.0409) and further by 12 months (p=0.0002). Specific items improved by 12 months: control over illness (p=0.0053), understanding illness (p=0.0011; also improved by 3 months p=0.0003), emotionally affected (less) (p=0.0004), concern about illness (less) (p=0.0015), and illness affects life (less) (p=0.0366).

2. Daily Functioning, Fatigue and Sleep

- MSK-HQ: Better sleep by 3 months, sustained at 12 months (p=0.0014 at both points). Social activities/hobbies improved at 12 months (p=0.0365). Fatigue improved at 12 months (p=0.0082).

3. Work, Productivity and Activity

- WAPI: Ability to perform normal daily activities improved at 12 months (p=0.0176). Zero median absenteeism at 12 months with tighter interquartile range, IQR (p=0.0154).

4. Emotional Wellbeing and Medication Adherence

- PHQ – 2: Depressive symptoms were mild at baseline and remained stable over time, with no statistically significant short- or long-term change (all p-values > 0.05).
- GAD – 2: Anxiety symptoms were mild at baseline and did not change significantly at either 3 or 12 months following engagement (reported p-values ≥ 0.185).
- MARS – 5: Medication adherence was already high at baseline, and no statistically significant improvement or deterioration was observed at either 3 months or 12 months following engagement (all p-values > 0.05).

Status of Referrals

- Total number who did not, for whatever reason, wish to participate in the study or people NRAS were unable to contact after 3 attempts: **88**
- Total number of people who did not continue (those who agreed to participate and filled out the relevant questionnaires at baseline, but did not continue at one of the survey time points): **66**
- Total amount of participants remaining after the 3rd survey who completed all three surveys at relevant time points: **25**

Breakdown of the reasons the 88 who either did not wish to engage with RS or who NRAS were unable to get in touch with (and therefore were not sent the first survey) is as follows:

- Number of people NRAS were unable to contact after 3 attempts: **38**

Reasons for opting not to receive RS survey	Number of People (50)
Struggling with mental health issues	1
Found too much information overwhelming	1
Did not want the service yet	1
Did not think she would benefit as the hospital provided her with all the details she needed	1
Did not want to speak to anyone but requested that a pack of information be sent to her	1
Opted out and no specific reason was given	12
Felt were doing well and well supported by their respective medical team	6
Felt they were doing ok	5
Inappropriate referrals	4
Did not want to take part in the survey (no reasons given)	10
Had no email address	4
Not approached due to being too busy to speak	4

It's important to note that we have reduced the number of people who either do not want to engage with RS at the time they are offered it or who we are unable to contact due to improving the referral process in line with the recommendations in Dr Sharp's site report and by implementing further features to improve the booking experience. Where we are currently with RS referrals is summarised at the end of the report.

Appendix 3

Report from Manchester of the data from Staff Evaluation

Evaluation of the Enhanced National Rheumatoid Arthritis Society Right Start Pilot

By Dr Charlotte Sharp

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National Rheumatoid Arthritis Society Enhanced Right Start Service Evaluation

Background:

The National Rheumatoid Arthritis Society (NRAS) is a UK national charity whose aim is 'supporting people living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA)'. In 2019, NRAS launched 'The New2RA Right Start' Service (Right Start). The aim of Right Start is to improve outcomes of people who are newly diagnosed with RA through a provision of emotional support, normalisation of fears and anxiety, education about RA and its treatments and a range of supported self-management resources tailored to individual need.

In 2021, the service had received referrals from over 70 rheumatology units across the UK, numbering in excess of 360 patients newly or recently diagnosed with RA. The 'standard' Right Start service provided a GDPR-compliant online referral process to which any UK rheumatology service could refer a newly or recently diagnosed patient with RA, without necessarily embedding the process formally within their RA care pathway.

In 2021, NRAS proposed to pilot an 'Enhanced Right Start' scheme, offering the same support, but formally integrating referrals into participating sites' RA patient care pathways, aiming for the service to be offered to all suitable patients. This evaluation was commissioned to assess the success of that Enhanced Right Start pilot, in particular to understand the acceptability and feasibility of the scheme for clinical sites. Patients agreeing to the pilot scheme also needed to agree to complete additional patient-reported outcome measures (PROMs) to inform this evaluation.

NRAS anticipated that sites would refer 3-4 patients per month to the scheme, which over six months, was hoped to result in 90-120 referrals. The evaluation was planned to take place across five sites; in the end four sites signed up to the programme; one site dropping out due to service pressures.

Referral process:

Patients could be referred by their healthcare professional (HCP) at any point within twelve months of diagnosis. Patients identified by the pilot sites as suitable were informed about the scheme and offered the opportunity to participate either at that point or a little later, dependent on their individual circumstances and feelings. They were given a patient information leaflet about Right Start and an NRAS information sheet about the pilot scheme. Sites were asked to explain the benefits, enabling the individual to make an informed decision as to whether they wish to participate.

Once patients provided verbal consent, sites referred consenting patients to NRAS using the minimum data set required by their online portal: https://nras.tfaforms.net/5047247

For further patient and healthcare professional information for referral into NRAS Right Start via the NRAS website: https://nras.org.uk/refer-a-patient/

Aim:

To evaluate the implementation of the NRAS Right Start Pilot Scheme.

Objectives:

- To explore the barriers and challenges to implementation
- To explore enablers to implementation
- To compare expectations and plans for the programme with practice (fidelity)
- To explore perceived impact of the programme

Methods:

Four sites across the UK, selected and agreed by the NRAS team.

Surveys of staff at baseline and 6 months plus one semi-structured interview with a health professional from each unit at 12 months.

Questions focussed on the experiences of staff implementing the scheme across participating NHS sites, in particular regarding:

- details of the sites and their service
- how sites went about approaching patients for participation
- acceptability of the scheme for staff
- perceived barriers and enablers to patients agreeing to participate
- perceived benefit for patients
- perceived benefit for their services
- perceived challenges associated with implementing the service
- whether the service met their expectations
- whether there was perceived change in workload at the NHS site (along with collection of any data to support this)
- how the scheme might be improved in future
- perceived challenges relating to scale-up and spread

The initial project was planned to take place over 12 months, so the planned timeline for evaluation of implementation of the NRAS Enhanced Right Start Service was for a health professional(s) at each site (n=4) to be invited to complete baseline surveys at 0 and 6 months, and an interview at 12 months. Because the recruitment to the pilot was extended to 18 months, an amendment to the protocol was implemented which resulted in sites being invited to baseline surveys at 0 and 9 months, and an interview at 18 months.

Consent to complete the online survey was gained through a tick-box at the top of the online surveys, which were conducted via the secure, University of Manchester approved supplier, Qualtrics. Staff completing the surveys were assigned a unique identifier, which they will be asked to enter into the survey to enable longitudinal linking of both surveys and the interview.

Formal written consent for interviews was obtained prior to the interviews taking place, which included consent for audio recording. Interviews were carried out via the online platform Zoom. Recordings were transcribed 'intelligent verbatim' by a University of Manchester approved supplier, 1st Class Secretarial. Transcripts were checked with the recordings, and any potentially identifiable information (e.g. geographical location, name of healthcare setting) redacted.

A thematic analysis was conducted across the surveys and interviews, seeking to: a) understand barriers, challenges and enablers to implementation, b) compare expectations of the service with practice and c) explore the perceived impact of the service.

This work comprises service evaluation, rather than research, according to the Health Research Authority 'Defining Research' [available at http://www.hra-decisiontools.org.uk/research/, accessed 28/07/2021], and therefore did not require HRA approval or NHS REC ethics approval. The University of Manchester required all service evaluation projects to undergo proportionate review, which was approved (Proportionate University Research Ethics Committee Reference: 2023-13072-27293).



Results:

Four sites participated in the study. All sites were urban, with three being secondary care sites, and one a tertiary care site. Respondents were either consultant rheumatologists or rheumatology specialist nurses.

Baseline survey:

Representatives from all four sites contributed to the baseline survey.

None of the sites expressed any concern about participating in the scheme. Levels of anxiety, health literacy, time since diagnosis and age were factors felt to be most likely to influence whether a patient would participate. Respondents expected that patients would experience improvement in: understanding (n=4), self-management (n=3), mood (n=2), change in health beliefs (n=2), disease control (n=2) and concordance with medication (n=1). Respondents expected that staff would experience: Reduced time spent answering phone calls (n=4), Improved communication between patients and clinical team (n=3), and Improved disease control leading to reduced service pressures (n=2).

9-month survey:

Representatives from three sites contributed to the 9-month survey. The fourth site was sent reminders in line with the protocol but did not complete the survey. One of the sites entered the incorrect anonymous code, which meant that it was not possible to associate responses with a particular site during the analysis.

One of the three sites reported that patients were not as keen to participate as they had anticipated; the other two did not report any problems. The same patient factors were felt to influence the likelihood of a patient taking part as they had in the initial survey. Two sites reported experiencing resistance from colleagues participating in the scheme, with one elaborating that this was because they forget.

Table 1 shows whether respondents agreed / disagreed with the following statements:

Table 1. Sites' reporting of whether the service met their expectations

The scheme has met my expectations regarding:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Improving patient understanding of RA	2	1			
Improved self-management	2	1			
Improved mood	1	1	1		
Tighter disease control		2	1		
Improved concordance with medication		2	1		
Change in unhelpful health beliefs		2	1		
Reducing staff time spent on helpline calls		3			
Improved communication with team	1	2			
Reducing the volume of helpline calls		2	1		

One site reported that "Patients feel empowered to self-manage their condition" and that staff "feel reassured there is excellent information out there".

Semi-structured interviews:

Representatives from three sites took part in interviews. The fourth site was invited and sent reminders in line with the protocol, but declined to take part in an interview due to service pressures.

All members of the MDT are able to refer patients into the NRAS Right Start scheme and responsibility for this differed across sites. This was most effective

when led and performed predominantly by specialist nursing staff. One of the sites already referred patients into the NRAS Right Start Scheme, and so the service was already embedded within every day practice. For the remaining three sites this was a new intervention, requiring adoption amongst the team.

Sites where the responsibility for NRAS Right Start lay with consultants had consistently low referral rates. The scheme was discussed at departmental meetings and following QI interventions, leading to *"a flurry of referrals and then it would drop off again." [R2]*. Another reported that *"I think the main barrier is I don't think clinicians remember" [R3]*, despite intentions to refer being *"good".*

One respondent found it difficult to get buy-in from the specialist nursing team. They wondered *"whether the specialist nurses felt that it could be in any way a threat to their service" [R2].* They stressed that this was just a hunch, but they struggled otherwise to understand the relatively low levels of engagement.

The NRAS referral portal was described as being simple and easy to use. One site suggested that the mandated address field for patients may have provided a barrier to recruitment. This is because it led to concern about the extent of data sharing for patients, and added burden of data entry for HCPs. Their suggestion for improvement is to remove this field and have NRAS collect these data with patients' consent, as part of the initial contact with NRAS. Another suggestion was to provide patients with a link for them to refer themselves.

Identifying patients was felt to be straightforward because of the clear criteria of being newly diagnosed with RA. Patients were identified as being suitable at the time of diagnosis, and offered the opportunity to take part at that point. They were provided with information leaflets; some sites had posters up in the waiting areas.

Staff across sites identified that offering Right Start at the point of diagnosis was often seen to be providing too much information for patients, on top of a new diagnosis and medication. This was understood by staff, but felt to result in a risk that the opportunity may not be offered to patients later on in their journey,

because staff might not remember to offer it at subsequent engagements. One site *"felt that we were offering a lot of the support internally that patients needed in the initial stages. So, it might not necessarily have been valued added at that stage". [R2]*

One site was able to estimate that about a quarter of patients declined to engage with Right Start. Others were not able to quantify this, or the number of patients they had referred during the pilot recruitment period. Patients whose RA became rapidly under control with initial treatment were felt less likely to need the support offered by NRAS. Staff felt that patient factors such as older age, not having English as a first language, and coming from particular ethnic groups might contribute to an increased likelihood that patients would decline the offer. Reasons for patients to decline the offer included concern and suspicion about data sharing, a lack of confidence and familiarity with the required IT processes, and a sense of overwhelm with the number of apps and websites they are asked to engage with as part of their healthcare:

"You've got your NHS App, you've signed up for that for your GP. We really want you to sign up to [the hospital portal] and this is how you contact us. And when you're going to use our advice line, as well, and here's lots of information, oh and there's another service as well that we want you to get. That they are genuinely, I think, quite overwhelmed and that's the hard thing is for people to prioritise well actually what, you know, what is right for me." [R2]

From a service perspective, all respondents referred to the very heavy workloads that they were experiencing, which influenced their capacity to refer patients into the scheme. Sites with recent large-scale service changes, such as the introduction of a new electronic patient record, reported that the integration of Right Start had to wait until staff had become used to operating in new ways.

"It was probably at quite a challenging time as well because, like a lot of services, the pressure is on to be seeing the patients, getting through the clinics, lots of external pressure because we've been, sort of, chronically understaffed, mainly from a nursing point of view. That's it's, like, another…oh no, another thing I've got to think about" [R2].

Clinicians reported that the service met their expectations in terms of what was delivered for patients, with staff feeling reassured that patients were getting high quality education. No one reported any dissatisfaction either from patients or staff with what NRAS offered. *"I would say it might improve capacity, so that you have more time in clinic to spend on issues that might not be able to be discussed by NRAS. Giving confidence to patients and giving them more autonomy, getting them to be able to self-manage the condition, rather than relying on other people. And just, and generally taking control" [R1].*

There were no reported increases in workload, although this had been a concern for one or two sites before the scheme started. Services who had good referral rates reported that it had led to a reduced workload and was *"just been an absolute godsend to us, especially when we're restricted with time" [R1].* Another said the impact on workload had been *"neutral" [R3].* It was felt to be of benefit for providing reliable information, including supporting patients to trust the medical advice about taking medications.

Feedback from patients to staff members had been overwhelmingly positive. Only one respondent reported a single patient having denied providing consent for the referral once NRAS had got in touch.

Factors which contributed to consistent referrals included having paper copies of the referral forms available in the clinic rooms, use of admin support to enter the data for clinical staff. Those clinicians who received the recruitment rates in comparison with other sites involved in the Enhanced Right Start pilot, said this was helpful to motivate them to bolster their own recruitment.

Potential improvements to help encourage referral included more discussion amongst the whole MDT on a regular basis, to remind colleagues to refer. NRAS presenting to sites, engaging with all members of the MDT, rather than nominated key contacts, was felt likely to have a favourable effect on teams' engagement. It was stressed that this activity should focus on *"how you refer patients" [R3]* [rather than being told what NRAS as a charity does]. A more active local NRAS group to support patients who were newly diagnosed and to encourage them to take up the offer of being referred, were also suggested.

Other suggestions were as follows:

- Sites to share how they had successfully increased referral numbers
- Quarterly reminder emails from NRAS
- Posters and leaflets supplied by NRAS
- NRAS to provide a 'smart phrase' for easy inclusion in patient records / communications
- More representation from NRAS from ethnically diverse groups to encourage greater uptake from those groups



Recommendations

1 Remove the requirement to enter the patient's address; NRAS could collect this later

2 Reassure sites that the referral is quick and easy, and their workload is unlikely to be increased in any way as a result of patients engaging with NRAS; in fact they will be better educated which may result in fewer helpline calls

3 Provide leaflets and posters for sites to display, and consider supplying copies of paper referral forms for sites who have administrative support to help clinicians make referrals

4 Encourage more activity from local NRAS sites to help promote the service

5 Consider having a league table or benchmarking system to allow sites to see where their recruitment rates fall in comparison with other sites. [note that sites may not wish for this to identify their sites to others, but may wish to see where their performance lies in comparison with others]

For responses to the above suggestions and recommendations, please see main body of report on pages 11 and 12

End of Report from Dr Sharp

Acknowledgements

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*"Since the introduction of **Right Start** there has been **a definite improvement in patient-reported outcome measures** as patients seek to self-manage, supported by the resources provided by **NRAS.***

*In addition to patient satisfaction, the resource has been of huge benefit to my colleagues and myself, especially when there is **limited time in clinic with newly diagnosed patients** to go through all their diverse needs in a short period of time.*

It is so reassuring to know that those patients who are referred will get such an excellent service from NRAS.

*As I, and all my colleagues, have to take part in the NEIAA audit, the Right Start service has helped us achieve some of the requirements that are needed. **It's a great and beneficial service** to our patients and most definitely **enhances their journey**."*

Quote from a nurse specialist from one of the 4 pilot sites (this quote was received outside of the service evaluation, and they are one of our high-volume referrers).