



Resetting the Balance

Improving care and outcomes for
rare autoimmune rheumatic diseases

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1. About RAIRDA

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) brings together patient organisations as a strong voice to campaign for improved care for people living with rare autoimmune rheumatic diseases (RAIRDs), raise the profile of this group of conditions, influence policy and guide future research.

RAIRDA member organisations



2. About rare autoimmune rheumatic diseases

Rare autoimmune rheumatic diseases (RAIRDs) encompass a range of conditions in which the body's immune system damages its own tissues. These conditions, which include vasculitis, and connective tissue diseases like lupus, scleroderma, and Sjögren's syndrome can be life-threatening and are significantly life-altering for many living with them. Treatments aim to suppress the immune system to mitigate the damage these diseases can do. However, these treatments need to be balanced against the potential side effects and the potential for diseases to flare, making responsive, coordinated care essential. There are over 170,000 people living with rare autoimmune rheumatic diseases such as vasculitis, lupus, and scleroderma in the UK.¹

There are 18 different types of vasculitis, many of which have a significant impact on life expectancy

Despite their differences, these conditions have commonalities. Generally, patients with these conditions receive some care from rheumatologists but often require other specialities and departments too, particularly nephrologists, dermatologists, respiratory physicians and cardiologists. Due to their complex and rare nature, some patients will need care from a specialised hospital, as well as their local hospital. Unlike other rare diseases, 80% of which are genetic and the majority of which affect children, RAIRDs lack a simple genetic cause, and generally start in adulthood.

Examples of rare autoimmune rheumatic diseases

Lupus

In lupus, autoantibodies attack the body's own tissues. The majority of people living with lupus are women, and the condition is more common amongst people of Black African, Caribbean, and Asian ethnicity. Two major symptoms of lupus are extreme fatigue and joint and muscle pain. However, there are many others including: rashes, depression, anaemia, feverishness, headaches, possible hair loss, mouth ulcers and kidney disease.

Sjögren's syndrome

Sjögren's is a relatively common, but under-recognised condition. It predominantly affects adults. It may occur alone, when it is often referred to

as primary Sjögren's, or in association with another rheumatic disease such as rheumatoid arthritis or lupus. Sjögren's causes inflammation within the secretory glands, leading to reduced secretions and sicca (dryness). Common systemic features include joint pain and fatigue. More serious complications, such as lung or renal involvement, are seen in a minority.

Scleroderma

Scleroderma can be divided into two types, localised (affecting the skin) and systemic (which also affects internal organs). The disease causes stiffening of the body's tissues and can be fatal if there is severe lung, heart or kidney involvement.

Systemic vasculitis

Vasculitis is a collective term for a group of autoimmune diseases that cause inflammation of the lining of the blood vessels, leading to restriction of blood flow which can result in tissue and vital organ damage. There are 18 different types of vasculitis, many of which have a significant impact on life expectancy. Vasculitis has the highest mortality of any RAIRD. For example, of people who are diagnosed with the subtype ANCA-associated vasculitis, approximately 15% will die within the first year.

1 Peach, E. et al (2020) Risk of death among people with rare autoimmune diseases compared with the general population in England during the 2020 COVID-19 pandemic. *Rheumatology* 60(4), pp.1902-1909. This paper cites a figure of 168 691 people with a recorded diagnosis of RAIRD alive on 1 March 2020. Which can lead to the assumption that there are more than 170,000 people with a diagnosis across the UK.

3. Foreword

RAIRDA was established with the aim of bringing together patients and clinicians to campaign for improved care for people living with rare autoimmune rheumatic diseases. Since we were formed, our work, including our previous reports, has shown considerable disparities in the quality of care and treatment received by people living with rare autoimmune rheumatic diseases.² It is vital we have equality of care and treatment for this group: prevalence should not be the determinant of outcomes for patients.

As the evidence presented and the personal stories shared in this paper highlight, there is a need to urgently address the care and treatment of people living with these rare conditions. Like many other rare diseases, RAIRDs can be very serious. Late diagnosis and inadequate care can significantly reduce a person's life expectancy and have a major impact on their quality of life.³ The clinical vulnerability of this group has been demonstrated through the devastating impact of COVID-19, with people with RAIRDs at 54% increased risk of COVID-19 infection and more than twice the risk of COVID-19-related death compared to the general population.⁴

To date, people living with rare conditions have too often been forgotten when it comes to policy or investment in health services. NHS services remain too focused on common conditions, with an increasing focus on high volume, low complexity conditions. This is something that has been exacerbated by the backlogs created due to the pandemic and presents a real risk that rarer conditions will be forgotten in the race to reduce long waiting lists.

The UK Rare Diseases Framework, published at the beginning of 2021, is an important step forward in increasing the focus on rare conditions. However, at present, this framework, and its nation-specific action plans have gaps in terms of addressing the explicit needs of people living with

rare autoimmune rheumatic diseases (RAIRDs). This is, in part, because this group of diseases differ from other rare diseases in that they are predominantly non-genetic and present later in life than other rare conditions. These differences mean that many of the umbrella measures included in the UK Rare Diseases Framework are less relevant for RAIRDs.

This paper presents a roadmap for improvement across six important areas, where policy and system changes could transform the care and treatment of people living with RAIRDs across the UK. Within these areas there are some 'quick wins', whereas others may take longer to implement in full. However, what is important is that there is commitment from across the board - patient groups, clinicians, NHS bodies, and policymakers in England, Wales, Scotland, and Northern Ireland to work collaboratively to implement the changes that are urgently needed.

As we begin to emerge from the pandemic it feels like a pivotal moment to refocus on improving care and addressing inequalities in provision for people with rare diseases, driving home the message that the prevalence of a disease should not determine the care you receive. RAIRDA and its member charities are committed to playing our role in implementing the recommendations in this paper and we urge others to join us in this important task.



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2 RAIRDA (2018), 'Reduce, Improve, Empower', Addressing the shared needs of rare autoimmune rheumatic diseases.

3 Ibid.

4 Rutter, M. et al. (2021), COVID-19 infection, admission and death among people with rare autoimmune rheumatic disease in England: results from the RECORDER project, *Rheumatology*.

4. Executive summary

Rare autoimmune rheumatic diseases (RAIRDs) differ from many other kinds of rare diseases in that they are predominantly non-genetic. They can also be hard to diagnose and cause very severe and potentially life-threatening illness. People living with these conditions face further challenges in that they have limited treatment options, and often experience fragmented and variable care depending on where they live in the UK.⁵

44%

of respondents reported that they waited more than three years from the first symptoms to receiving their correct diagnosis.

61%

of respondents were not confident that there was a coordinated plan in place for their care.

40%

say that they don't feel that they have enough information and support from their hospital about living with their condition.

Only 46%

of respondents report having access to a telephone advice line when they have a question about their condition.

Only 37%

said that their care is supported by a specialist nurse.

In RAIRDA's 2018 report 'Reduce Improve Empower', we reported on the findings of a survey of 2,000 people with vasculitis, lupus, and scleroderma.⁶ Patients across the UK reported issues with their care.

Research by RAIRDA has shown that the pandemic has exacerbated these issues. A survey undertaken by RAIRDA in April and May 2020 found that since the onset of the pandemic, 80% of people with these conditions had experienced a change in their care. This finding has been strengthened by research from others. Recently published research on rheumatology patients, including those with RAIRDs, shows a reduction in the percentage of patients agreeing they were medically supported from 74% pre-pandemic to 40% during-pandemic.⁷

This makes it all the more important to act now to improve policy and services for people with RAIRDs. In terms of policy, rare diseases have too often been missed out with national level strategies, plans and initiatives focused on more common conditions. A notable exception being the 'Getting It Right First Time: Rheumatology' (GIRFT) report which included several important recommendations on RAIRDs.⁸

The UK Rare Diseases Framework seeks to address this, however at present its

Since the onset of the pandemic, 80% of people with these conditions had experienced a change in their care

strong focus on genomics means it lacks recommendations for conditions such as RAIRDs which are predominantly non-genetic. Addressing this current imbalance in the framework could be a major driver of improved care across the UK, both for RAIRDs and for other predominantly non-genetic rare conditions. Many of the recommendations below could be co-ordinated through the ongoing work of the framework, which would ensure impact across all four nations.

RAIRDA is calling for government, the NHS, and other relevant bodies to take action in the following areas:

Our recommendations:

Protection against the ongoing threat of COVID-19 and other viruses

- **Priority access to vaccines and treatments:**
Eligible people with RAIRDs should continue to have priority access to vaccines and treatments, which includes having their eligibility consistently recorded across primary and secondary care records.
- **Improved communication:**
Governments in each nation need to ensure there is improved communication between people with RAIRDs, and professionals who they engage with, to ensure people are aware of their right to access vaccines and treatments. Patient organisations should be treated as information partners and be able to have clear and ongoing lines of communication with officials within each nation's health department or NHS oversight body.
- **Better coding for RAIRDs:**
NHS Digital and equivalent bodies in other nations must address the need to develop accurate and up-to-date digital coding of NHS records to rapidly and reliably identify RAIRD patients. This should include considering the need for more extensive coding in outpatients, and the need to make it easier for practitioners in primary and secondary care to change codes when they are inaccurate.

Quicker and more effective processes for diagnosis

- **Quicker diagnosis:**
A need for more measurable and realistic targets for referral, and initiation of treatment. These targets should highlight specific time periods within which referral should

happen. They should be developed by National Institute for Health and Clinical Excellence (NICE), or Health Improvement Scotland (HIS), in collaboration with patient groups and other experts, and included in a quality standard so their importance is recognised, and they can be audited to show improvement. The creation of a standard could incentivise investment in ways to improve diagnosis – such as better access to diagnostic tests.

- **More effective diagnosis:**
This could be achieved by better training alongside the development of new technological tools for GPs and other primary healthcare professionals. This would better enable them to recognise the signs of RAIRDs and initiate rapid referral to a specialist for investigations, diagnosis and treatment. In the longer term there is also a need to develop biomarkers of early disease activity, incorporate them into clinical pathways, and educate professionals on their use.
- **Research into the diagnostic journey:**
There remain uncertainties about the diagnostic journey that are currently barriers to improving diagnosis. There is a need for further research into this area to inform future policy and action.

Better access to treatments – including new and innovative drugs across the UK

- **A joined-up approach to increasing treatment availability:**
The UK Rare Diseases Framework, as part of its vision of 'improving access to specialist care, treatments and drugs' should facilitate discussion between the constituent bodies in each nation as to how to improve access to drugs for rare diseases – including new treatments, but also re-purposing old ones.

In the longer term there is also a need to develop biomarkers of early disease activity, incorporate them into clinical pathways, and educate professionals on their use

5 RAIRDA (2018) 'Reduce, Improve, Empower' Addressing the shared needs of rare autoimmune rheumatic diseases.

6 Ibid.

7 Sloan, M. et al, 2022, Will 'the feeling of abandonment' remain? Persisting impacts of the COVID-19 pandemic on rheumatology patients and clinicians. *Rheumatology*.

8 Kay, L. Lanyon, P. and MacGregor, A. (2021) *Rheumatology, GIRFT Programme National Specialty Report*.

Better co-ordination of care

- **Access to multi-disciplinary clinics:** Given the complex needs of people with RAIRDs, and often the need for treatment by multiple specialities, there needs to be increased availability of multi-disciplinary clinics to address the complex needs of these patient groups.
- **Universal access to key components of co-ordinated care:** Commissioners in all four nations should ensure all patients with RAIRDs have access to three core aspects of co-ordinated care:
 - A comprehensive in-person (unless requested otherwise) annual review coordinated by the service responsible for their care.
 - Access to a good quality, well-managed and well-staffed advice line as point of call for unexpected issues.
 - A named person responsible for co-ordinating their care.

This should be clearly articulated in a quality standard and service specifications where applicable.

Improving access to specialist care and knowledge within the workforce

- **The development of specialist networks:** The national Rare Disease Framework Action Plans being developed for Scotland, England, Northern Ireland, and Wales should describe how health

services will invest in, and support, specialised networks for rare diseases, including specialised rheumatology networks. Joint working through the vehicle of the UK Rare Diseases Framework should also be encouraged to facilitate knowledge sharing on how best to undertake this in each nation.

- **Upskilling health professionals:** Health services should upskill and develop enhanced roles for nurses and allied health professionals involving caring for people with RAIRDs. This should include better training in caring for people with RAIRDs within rheumatology teams.

Reducing inequalities in access to high quality care and treatment

- **Development of a quality standard for RAIRDs:** To underpin many of the above recommendations, a quality standard for RAIRDs, or one that includes RAIRDs, should be developed, including statements on core components of care set out in this report, such as diagnosis and co-ordination of care.
- **Regular audit of services:** The NHS in partnership with relevant professional and patient organisations, should plan to regularly audit services for RAIRDs in line with these proposed quality standards, to highlight inequalities and areas of the service where there is a need for improvement.

5. Protection against ongoing threat of COVID-19 and other viruses

RAIRDA's 2020 report showed that COVID-19 had impacted people living with rare autoimmune rheumatic diseases (RAIRDs) in a variety of ways - in terms of their physical and mental health, but also financially.⁹ The survey was conducted in April and May 2020, when the shielding guidance was in place.¹⁰ Some key findings from that report were:

54%

of respondents to the survey were currently shielding.

80%

of people with these conditions had experienced a change in their care. **37%** of these people said that their ability to manage their condition had been affected as a result.

33%

of people with RAIRDs say the pandemic has adversely impacted their household finances compared to **23%** of the general public.

In addition to this, other research has shown the impact that COVID-19 has had on the morbidity and mortality of people with RAIRDs. Research from the RECORDER project in March-July 2020 showed that people with RAIRDs had a 54% increased risk of COVID-19 infection and more than twice the risk of COVID-19-related death compared to the general population.¹¹

Vaccines and anti-viral treatments

Research has also shown that many people living with these conditions have a poor response rate to vaccines. The OCTAVE study, looking at the percentage of people who generated antibodies after two doses of the COVID-19 vaccine, found that people with rheumatic conditions were considerably less likely to generate antibodies.¹²

This is likely in part due to the need for treatment with immunosuppressing drugs, such as rituximab. For those with rituximab-treated ANCA-Associated Vasculitis, 87% responded less well than the baseline of healthy subjects.

This low response rate to vaccines means that many of this patient population were eligible for a third primary dose of the COVID-19 vaccine, and a subsequent booster three months after. However, a survey by RAIRDA, with support from other charities, in November 2021 found significant issues with the rollout of the third primary dose to people with rheumatic conditions.¹³ At that point, two months after the Joint Committee on Vaccinations and Immunisation (JCVI) had issued their guidance, around one-quarter (22%) of those who responded to the survey had not been able to access a third primary dose, and for those who had, nearly half (44%) said that it was much more difficult to access than their previous doses.¹⁴

In March 2022 RAIRDA conducted another survey to determine how easily people with RAIRDs were accessing fourth doses of the survey and anti-viral treatments.¹⁵ The survey showed that people were finding accessing fourth doses easier than third doses, with 62% of respondents saying that accessing their fourth dose was 'very easy'.

9 RAIRDA (2020) Chronic Crisis: The Impact of COVID-19 on people with rare autoimmune rheumatic disease.

10 From April 27th to May 15th 2020 we conducted an online survey of people with RAIRDs. We received over 1,300 responses from across the UK.

11 Rutter, M. et al. (2021) COVID-19 infection, admission and death among people with rare autoimmune rheumatic disease in England: results from the RECORDER project, *Rheumatology*. 61(8), pp. 3161-3171.

12 National Institute for Health and Care Research (2021). OCTAVE trial: Initial data on vaccine responses in patients with impaired immune systems. [online] www.nihr.ac.uk. Available at: <https://www.nihr.ac.uk/news/octave-trial-initial-data-on-vaccine-responses-in-patients-with-impaired-immune-systems/28529>.

13 Survey supported by the National Axial Spondyloarthritis Society (NASS), National Rheumatoid Arthritis Society (NRAS) and Arthritis and Musculoskeletal Alliance (ARMA).

14 GOV.UK (2021). Joint Committee on Vaccination and Immunisation (JCVI) advice on third primary dose vaccination. [online] GOV.UK. Available at: <https://www.gov.uk/government/publications/third-primary-covid-19-vaccine-dose-for-people-who-are-immunosuppressed-jcvi-advice/joint-committee-on-vaccination-and-immunisation-jcvi-advice-on-third-primary-dose-vaccination>.

15 An online survey launched between 24 March and 7 April 2022, which received 526 responses from England, Scotland, Wales and Northern Ireland.



However, it suggested that there are considerable issues in terms of access to anti-viral treatments:

- 40% of respondents who would class themselves as eligible for COVID-19 antiviral treatments reported they had no form of contact from the NHS about the treatments.
- 13% of people had identified themselves as testing positive for COVID-19 since the treatments became available.
- From this cohort, over half (62%) weren't automatically contacted by a Covid Medicines Delivery Unit (CMDU) to be assessed for treatment after testing positive and 50% found the process to get referred to a CMDU by their GP/consultant to be 'very difficult'.

This suggests that there continue to be issues with correctly identifying and communicating the vulnerability of COVID-19 to this group.

Communication and information

Our member charities have also reported consistent issues with health professionals, often in primary care, not being aware of people with RAIRDs' eligibility for priority access to vaccines and treatments. This has caused issues for patients who know they are eligible, but then struggle to get the acknowledgement they need from GPs.

Our member charities' helplines are often the first port of call when people have questions or issues about accessing vaccines or treatments. However, the charities have often struggled to navigate government health departments and NHS bodies to obtain clear answers to questions about frequently changing information relating to eligibility or processes for accessing vaccines and treatments. Having designated people, or closely monitored emails, within relevant government or NHS bodies could help improve this access and the information that is available for people with RAIRDs.

"To improve the quality of information available for service planning and benchmarking, we recommend that diagnoses should be coded for outpatients as part of routine activity"

Coding

Timely and clear communication about eligibility for priority vaccines and treatments, as well as whether individuals should be encouraged to shield, can be triggered by having the correct codes on individual health records. Codes are used to record the conditions that patients have and are then used by primary care to determine who is most at risk for viruses such as COVID-19 and flu, and as a result who should be eligible for vaccination. Throughout the current pandemic, and previously in terms of vaccines for flu, people with RAIRDs have experienced vaccine access issues as they don't have the right code, as in the example of Anna opposite.

The GIRFT national specialty report for rheumatology has also highlighted the importance of coding, as in the majority of NHS Trusts, diagnoses are not routinely recorded in the outpatient record, which is where most rheumatology patients receive their treatment. Their recommendation was "to improve the quality of information available for service planning and benchmarking, we recommend that diagnoses should be coded for outpatients as part of routine activity. Wherever possible, this should be part of an electronic record, which, if linked to electronic prescribing for outpatients and day cases, has the potential to create a powerful dataset to drive improvement."¹⁶

There is a need to review how patients with RAIRDs are coded throughout the NHS, to ensure they can be notified quickly and accurately as needing additional protection from infection, be it flu, COVID-19 or something else.

Case study

Anna, 52, was diagnosed with MPO ANCA vasculitis 4 years ago.

At the beginning of the pandemic in March 2020, she received information from the government that she should shield. For three to four weeks, she separated herself entirely from the rest of her family as her husband's job required him to still meet people. The messages she received at this time, including being asked to pack a hospital bag, only increased her anxiety and fear of COVID-19.

As the pandemic progressed, she became aware that vital treatment for her vasculitis (rituximab) could result in a poor antibody response to the vaccine. In response to this, she decided to undergo antibody testing which found that she had no antibodies.

Given this fact, Anna was pleased to hear towards the end of 2021 that new COVID-19 treatments were available for people who are most vulnerable to the virus. However, despite being eligible, she wasn't contacted or sent the priority PCR test. What followed was weeks of calls to her GP, specialist, and even NHS England to try and get this mistake rectified. All the while, she was extremely anxious about whether she would be able to access the treatments if needed within the five-day timeframe. She eventually discovered that she did not have the necessary code on her GP notes to trigger priority access to tests. This has now been added, but it has had a considerable impact on her mental wellbeing.

"It was really frustrating and time-consuming being passed back and forth. My GP practice said that the only code they knew about was already on my notes, and to try various other people who also couldn't help. I found various letters online but nothing that said what code was needed. I have to say I have lost trust in the system, and I don't understand why the people I was signposted to didn't have information about the code."

Recommendations

Protection against the ongoing threat of COVID-19 and other viruses

Priority access to vaccines and treatments: Eligible people with RAIRDs should continue to have priority access to vaccines and treatments, which includes having their eligibility consistently recorded across primary and secondary care records.

Improved communication: Governments in each nation need to ensure there is improved communication between people with RAIRDs, and professionals who they engage with, to ensure people are aware of their right to access vaccines and treatments. Patient organisations should be treated as information partners and be able to have clear and ongoing lines of communication with officials within each nation's health department or NHS oversight body.

Better coding for RAIRDs: NHS Digital and equivalent bodies in other nations must address the need to develop accurate and up-to-date digital coding of NHS records to rapidly and reliably identify RAIRD patients. This should include considering the need for more extensive coding in outpatients, and the need to make it easier for practitioners in primary and secondary care to change codes when they are inaccurate.

"It was really frustrating and time-consuming being passed back and forth. My GP practice said that the only code they knew about was already on my notes, and to try various other people who also couldn't help"

¹⁶ Kay, L. Lanyon, P. and MacGregor, A. (2021) Rheumatology, GIRFT Programme National Specialty Report.

6. Quicker and more effective processes for diagnosis

Diagnosing, and therefore treating, rare autoimmune diseases early can help patients avoid serious complications and, in some cases, as these conditions can be life-threatening if not treated, death. However, nearly half of respondents to our 2018 survey reported a wait from symptom onset until diagnosis of over 3 years. 70% of people living with systemic lupus erythematosus are initially misdiagnosed.¹⁷ A study in the USA of over 4,000 patients demonstrated the benefits of early diagnosis for people with lupus, finding that it could lead to fewer flares and rates of hospitalisation that were 20% lower than those diagnosed later.¹⁸



Specific targets for diagnosis and referral

There is likely to be significant benefit for RAIRDs in creating targets for referral from primary care, waiting times to be seen in secondary care, and commencement of treatment. Such targets have led to significant benefits for other more common conditions such as rheumatoid arthritis. The 2013 NICE quality standard for rheumatoid arthritis (updated in 2020) set how long it should take for someone with suspected arthritis to be referred and start treatment, as well as mandating access to rapid support and annual reviews of their condition. The National Early Inflammatory Arthritis Audit, led by the British Society for Rheumatology, has shown steady improvement in services in England and Wales against this standard, and the statements within it, as shown in the tables adjacent.^{19 20 21 22}

Quality statement 1:

patients with early inflammatory arthritis referred within three days (%)

2015	2016	2019	2020
17	20	41	47

Quality statement 2:

patients seen by rheumatology services within 3 weeks of referral (%)

2015	2016	2019	2020
38	37	38	48

Quality statement 3:

patients treated with disease modifying drugs within 6 weeks of referral (%)

2015	2016	2019	2020
53	68	54	64

17 Kent, T. et al (2017), Burden of illness in systemic lupus erythematosus: results from a UK patient and carer online survey, *Lupus*, 26(10), pp. 1095-1100.

18 Oglesby, A. et al (2014), Impact of Early Versus Late Systemic Lupus Erythematosus Diagnosis on Clinical and Economic Outcomes. *Applied Health Economics and Health Policy*, 12(2), pp.179-190.

19 British Society for Rheumatology (2015), A patient and public guide to the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

20 British Society for Rheumatology (2016), A patient and public guide to the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

21 British Society for Rheumatology (2019), National Early Inflammatory Arthritis Audit, Patient and Public First Annual Report (NEIAA).

22 British Society for Rheumatology (2021), National Early Inflammatory Arthritis Audit, Patient and Public First Annual Report (NEIAA).

Access to diagnostic tests

Access to diagnostic tests can be an issue. In February 2020, through the British Society of Rheumatology, RAIRDA conducted a survey of rheumatologists asking about access to key diagnostic tests for RAIRDs. 54 responses were received, covering all regions of England, Scotland and Northern Ireland. Just under half had access to a CT-PET scan on-site, with 20% needing to wait longer than three weeks to have the test done. A delay in diagnosis can delay the start of treatment and cause longer term issues, especially in patients with major organ involvement. The GIRFT national specialty report for rheumatology identified similar issues. It found that out of 101 responses, only 7 trusts are currently achieving the 1-day turnaround target for ANCA tests, used to help diagnose ANCA-associated vasculitis.²³

Diagnostic journey

These diseases are rare and complex, and difficult to diagnose. Many of the delays stem from the fact there is no single diagnostic test for any of them, their presentations are complex and symptoms are non-specific and as such, they require expertise to diagnose. A lack of knowledge of these conditions among GPs can also impact on diagnosis. These delays are often also the result of issues along someone's diagnostic journey, this can include issues such as:

- Delays to patients presenting to their GP with symptoms.
- Patients being misdiagnosed and then treated for the 'wrong' condition by their GP.
- Time taken up if patients are referred to the wrong speciality.
- The time taken waiting to see a specialist, generally a rheumatologist.
- Any delays in diagnostic testing.

It is important that further research is done to understand more about these barriers to early diagnosis, to identify ways to address them, and to improve the speed and experience of diagnosis

23 Kay, L. Lanyon, P. and MacGregor, A. (2021) Rheumatology, GIRFT Programme National Specialty Report.

for people with RAIRDs. Alongside this, work needs to be done to investigate ways technology could be harnessed to support diagnosis, such as through the development of diagnostic tools for primary care.

Case study

Georgina, now 36, noticed the early symptoms of scleroderma at the age of 25, when she developed Raynaud's and problems with her hands, followed by breathing difficulties. Despite visiting her GP on several occasions, it took over 18 months to reach a diagnosis.

"I had been back and forth to my GP with many symptoms - starting with Raynaud's in my hands, then swollen fingers, sore and aching wrists, painful joints, and hip pain. I also got excruciating pain when it was cold, and I could barely lift my legs to walk. Later came the breathing problems - shortness of breath... Finally, digital ulcers developed and curling, stiffness in my hands and my fingers got worse very quickly by the end."

At the age of 27, Georgina visited family in Poland, and decided to seek a diagnosis whilst she was there. It was then that she learned she had diffuse systemic sclerosis, and that her now severe respiratory issues were caused by associated interstitial lung disease; or scarring within the lungs that affects their ability to absorb oxygen.

"When I was first diagnosed, I felt very overwhelmed; I couldn't really process it to begin with. I was very much in denial and angry. I was adamant to fly back to the U.K. and get back to work and carry on as normal. My family had to intervene and almost force me back to hospital in Poland where I started treatment and ended up staying for the following year."

"When I was first diagnosed, I felt very overwhelmed; I couldn't really process it to begin with"

Since her diagnosis, Georgina's condition has progressed and she has been forced to give up her career as a beauty therapist, as well as the active social life that she used to enjoy. She firmly believes that if this disease had been detected earlier, she could have received effective treatment sooner and her life would not have changed to such a dramatic extent.

"Getting a diagnosis was very difficult. When I went to Poland, they were shocked at how far I had gone without any intervention. My GP saw all the symptoms but did not connect the dots. Even if they had spotted something and sent me to a specialist it would have helped. I just kept being sent away with no answers. If it had been found sooner, there would have been a chance to reverse some of the permanent damage, and things would not have got so bad, but I was diagnosed too late."

"(My condition) has impacted my life hugely, I had to leave my job and put my career as a beauty therapist behind me. Physically I can no longer use my hands the way I used to, and chronic fatigue is a big issue and affects what I can do every day. Small things people take for granted like getting out of bed, brushing teeth, having a shower and cooking are all incredibly difficult. I've had to adapt a lot and learn to accept help from family and friends in order to get things done."

"Getting a diagnosis was very difficult. When I went to Poland, they were shocked at how far I had gone without any intervention. My GP saw all the symptoms but did not connect the dots"

Recommendations

Quicker and more effective processes for diagnosis

Quicker diagnosis: A need for more measurable and realistic targets for referral, and initiation of treatment. These targets should highlight specific time periods within which referral should happen. They should be developed by National Institute for Health and Care Excellence (NICE), or Health Improvement Scotland (HIS), in collaboration with patient groups and other experts, and included in a quality standard so their importance is recognised, and they can be audited to show improvement. The creation of a standard could incentivise investment in ways to improve diagnosis - such as better access to diagnostic tests.

More effective diagnosis: This could be achieved by better training alongside the development of new technological tools for GPs and other primary healthcare professionals. This would better enable them to recognise the signs of RAIRDs and initiate rapid referral to a specialist for investigations, diagnosis and treatment. In the longer term there is also a need to develop biomarkers of early disease activity, incorporate them into clinical pathways, and educate professionals on their use.

Research into the diagnostic journey: There remain uncertainties about the diagnostic journey that are currently barriers to improving diagnosis. There is a need for further research into this area to inform future policy and action.

7. Better access to treatments – including new and innovative drugs across the UK

Lack of treatments for RAIRDs

Treatment options for many RAIRDs at present are limited, and where they do exist, they may not be suitable for all patients. For example, rituximab, a treatment commissioned by NHS England, is an effective treatment for some patients with lupus, but in others it isn't tolerated and can provoke an allergic reaction. A research study found that in 125 patients, 17.6% experienced adverse infusion reactions to rituximab. 35.7% of these infusion reactions were severe enough to require cessation of the treatment.²⁴

There are potential new treatments in the pipeline for RAIRDs as well as the potential for existing treatments to be repurposed. However, there are often challenges in showing the efficacy of new treatments when they are evaluated for use on the NHS, due to factors such as few complete trials, or trials against a relevant comparator.²⁵ When these treatments are being appraised patient groups have a voice in demonstrating the value of these treatments to patients, however it is unclear how much impact their contributions have in comparison to other evidence, such as that of health economists.

Changes to current processes

At present, there are several schemes or policies in development that could address some of these barriers and improve access to treatments. In England these include the Innovative Medicines Fund, which was launched in June 2022, and the Medicines Repurposing Programme. There is potential for these schemes to improve access to treatments for RAIRDs, either in their current form, or with some adjustments. For example, the inclusiveness of the Medicines Repurposing Programme could be strengthened by the provision of funding for stage two clinical trials for promising treatments.

However, there is a need for alignment of all these processes, and for relevant bodies in each nation, such as NHS oversight bodies and those responsible for evaluating medicines, e.g. NICE, Scottish Medicines Consortium (SMC), to work together with charities and experts to find ways to improve treatment options for RAIRDs.

There are potential new treatments in the pipeline for RAIRDs as well as the potential for existing treatments to be repurposed



²⁴ Hennessey, A., et al (2019). Adverse infusion reactions to rituximab in systemic lupus erythematosus: a retrospective analysis. *BMC Rheumatology*, 3(32).

²⁵ NICE (2021) Belimumab for treating active autoantibody-positive systemic lupus erythematosus, Technology appraisal guidance [TA752]. Published: 15 December 2021

Case study

Abbie was diagnosed at 19 with lupus. Initially, her lupus was stable but then for a long time she struggled to get medications to settle it down. She tried several combinations, including rituximab, and in 2019 was offered access to belimumab after her consultant put a case together for her to receive it. Being on the drug has put her disease back on hold, reduced her pain, and the impact the disease has on her daily life.

“Within six months of being on belimumab I was seeing sustainable change; change I could really rely on. Consistently, day by day, I was feeling better. Other people were also seeing a real difference in my energy levels. It is the most stable my lupus has been in years and means I am able to work and haven’t had to take any extended leave.

I experienced far fewer side effects with belimumab than rituximab, and as the time required to receive the drug in hospital is much shorter, it is much easier to manage around work. The immune response to the COVID-19 vaccine also seems to be stronger when on belimumab, so I am thankful I have been able to access this treatment.

I was fortunate that I had a consultant that fought for me to be able to access it. I was part of a NICE health appraisal and saw how hard it can be to build a case with the right data to enable everyone who needs to, to access these drugs.”



Recommendations

Better access to treatments - including new and innovative drugs across the UK

A joined-up approach to increasing treatment availability. The Rare Disease Framework, as part of its vision to ‘improving access to specialist care, treatments and drugs’ should facilitate discussion between the constituent bodies in each nation as to how to improve access to drugs for rare diseases - including new treatments, but also re-purposing old ones.

“Within six months of being on belimumab I was seeing sustainable change; change I could really rely on. Consistently, day by day, I was feeling better”

8. Better co-ordination of care

Why is this needed?

These conditions are characterised by the body’s own immune system becoming overactive and attacking healthy tissues, often in multiple organs throughout the body simultaneously. They can also affect many parts of the body (including joints, skin, lungs, kidneys, and heart). This rare and complex nature of RAIRDs means that they are primarily managed by specialists and often require cross-speciality expertise from multiple teams across different hospitals. In 2018, 55% of people with RAIRDs told us they lacked confidence in their GP’s knowledge of their condition, underlining the importance of specialist care. These conditions can also change rapidly and without the ability to raise issues, such as flares and side-effects, in an early and timely manner, patients’ conditions can worsen unnecessarily. These factors mean that access to co-ordinated and responsive care is therefore vital for patients.

Impact of the pandemic

RAIRDA’s 2018 report highlighted several problems in this area. For example, less than half (46%) of respondents reported having access to a telephone advice line to contact a hospital department when they have an issue with their condition. Recent research suggests that issues in this area have only been exacerbated during the pandemic.²⁶ One report found that 57% of rheumatology patients felt it was difficult or very difficult to contact their rheumatologist compared with before the pandemic. Other recently published research on rheumatology patients, including those with RAIRDs, has also shown a reduction in the percentage of patients agreeing they were medically supported from 74% pre-pandemic to 40% during-pandemic.²⁷

What good looks like

Delivering co-ordinated care is not an easy undertaking, especially in the context of a pandemic. However, there are several core components that, when in place, should ensure people with RAIRDs feel better supported and able to access the care they need. These include having access to an advice line or email inbox with staff confident in supporting people with their condition and a named person responsible for co-ordinating their care across specialties and hospitals. Having a named person can help mitigate the challenges of navigating the system and reduce stress. Also, given the complex needs of this group of conditions, there is a need for everyone to have a comprehensive annual review. The review needs to cover mental health, as well as physical needs. Factors such as having to shield for long periods of time during the pandemic and ongoing anxieties around lack of immunity to COVID-19 make the requirement to consider mental health needs even more pressing.

Remote vs face to face

The pandemic has proliferated, through necessity, the use of remote options for consultations and patient monitoring. This can have many benefits for patients, reducing the need to travel and enabling multi-disciplinary meetings with health professionals in different locations to happen more easily. It has also led to innovations such as the creation of the PASTUL (Patient self-Assessment of Skin Thickness in Upper Limb) questionnaire to remotely monitor skin activity in scleroderma.²⁸ It is important that these innovations continue, to benefit patients now, but also to ensure high quality patient care could continue in any future pandemics. However, at the same time, it is important that patients have the option to meet in person with their specialists, if that is their preference, and that steps are taken to guard against the potentially negative impact of remote consultations. Sloan et al. (2022) have shown for rheumatology patients that these can include a negative impact on doctor-patient relationships and less disclosure of symptoms, particularly relating to mental health.

²⁶ Wincup, C., Amarnani, R. and Giles, I. (2021) Evaluating the impact of COVID-19 on patient access to rheumatology services, medication and future care: a nationwide study of more than 2,000 patients. *Rheumatology*. 60 (Suppl 1)

²⁷ Sloan, M, et al, (2022), Will ‘the feeling of abandonment’ remain? Persisting impacts of the COVID-19 pandemic on rheumatology patients and clinicians. *Rheumatology*.

²⁸ Spierings, J., Ong, V. and Denton, C.P. (2021). PASTUL questionnaire: a tool for self-assessment of scleroderma skin during the COVID-19 pandemic. *Annals of the Rheumatic Diseases*, [online] 80(6), pp.819-820. doi:10.1136/annrheumdis-2020-219775.

Case study

Susie, 71, shares some of her experiences of living with Sjögren's Syndrome

"So far, I've seen specialists from 6 different areas of expertise, as well as my rheumatologist who diagnosed it, and my GP who has been great. I've also seen an optician, dietician, physiotherapist, dentist and counsellor. Sometimes, I've found it difficult to know which one to prioritise, so that Sjogren's doesn't end up dominating my whole life."

Susie has developed hearing loss, intermittent balance disturbance, extreme fatigue, disrupted sleep, dry mouth with sporadic ulcers, and a dry throat which makes swallowing difficult sometimes. She has also had to cope with episodes of 'restless legs', and 'brain fog', which in her case, accompanies exhaustion.

"One of the hardest things is the constant uncertainty. For me, every morning when I wake up, I wonder what kind of day it will be. Will I have a muzzy head and brain fog, and have to move slowly and carefully? Will I have enough stamina to do what needs to be done? I've had to slow down a lot and learn how to pace myself. To work out priorities. If I get overly exhausted, I feel miserable and hopeless. That's horrible. I work hard to keep out of that state."

She describes Sjögren's as a lonely condition. None of her friends or family had heard of it. She wanted to be able to explain it a little, so has read a bit about it from a variety of sources. Being part of a local support group, under the umbrella of the British Sjögren's Syndrome Association (BSSA) charity, has been helpful in connecting her with other Sjögren's people.

A significant aspect of having Sjögren's, perhaps common to any chronic disease, has been the psychological adjustment Susie has been through.

"I think there's a whole grieving process to go through when you're told you've got a chronic disease, whatever it is. There are losses. For me, the biggest loss is spontaneity. No more rushing out the front door, without first stopping to think through my check list - eye drops, lip salve, hand cream, sunglasses, sunhat, water bottle and so on. It's a palaver, but I'm getting used to it now. I work hard to keep a positive outlook on life. I listen to healing meditations, I read the "Action for Happiness" website, I write "3 Things to Be Thankful For" as many days as I can. I think it all helps."

Recommendations

Better co-ordination of care

Access to multi-disciplinary clinics: Given the complex needs of people with RAIRDs, and often the need for treatment by multiple specialities, there needs to be increased availability of multi-disciplinary clinics to address the complex needs of these patient groups.

Universal access to key components of co-ordinated care: Commissioners in all four nations should ensure all patients with RAIRDs have access to three core aspects of co-ordinated care:

- A comprehensive in-person (unless requested otherwise) annual review coordinated by the service responsible for their care
- Access to a good quality, well-managed and well-staffed advice line as point of call for unexpected issues
- A named person responsible for co-ordinating their care.

This should be clearly articulated in a quality standard and service specifications where applicable.

One of the hardest things is the constant uncertainty. For me, every morning when I wake up, I wonder what kind of day it will be. Will I have a muzzy head and brain fog, and have to move slowly and carefully?

9. Improving access to specialist care and knowledge within the workforce

The value of specialist networks

RAIRDs often need specialist care. Unfortunately, specialised centres for the care of RAIRDs can be located long distances away from some patients. Whilst ideally local hospitals would be able to deliver care to the same standards, this may not be the case in practice. An audit of lupus care found that dedicated clinics for RAIRDs were more likely to adhere to certain guidelines such as blood pressure recording and urine monitoring for patients.²⁹

RAIRDA's 2018 report suggested closing the gap between specialised and nonspecialised care through the use of coordinated networks between specialist centres and local providers. Implementing these networks effectively could give patients the best of both worlds: relatively local care, supported by specialists further away. They could also bring benefits for diagnosis, by pooling expertise, and improve care coordination by setting up common pathways across regions.

The GIRFT national specialty report for Rheumatology identified several key principles for the effective functioning of networks.³⁰ These include the importance of properly including network roles in job planning and ensuring that there is sufficient administrative support to coordinate the network. This shows the importance of investment to reap the benefit of networks.

Variation in development of networks

In England, the commissioning of specialised rheumatology services since 2013 has been a key step in improving care for these conditions. However, the GIRFT Rheumatology report found considerable variation in the strength of specialised rheumatology networks between regions. For example, in the East of England, 94% of trusts say they are in a network, compared to only 26% in London and 33% in the North-West.³¹

The Eastern Network for Rare Autoimmune Disease Video Case-Conference Service is an exemplar of best practice in this area (see below), as recognised by a Best Practice Award in 2018 from the British Society of Rheumatology.

In Scotland, a National Managed Clinical Network for Vasculitis was launched in early 2020. It is undertaking work to map and understand vasculitis services and care as they currently exist before moving on to addressing variation in care. This network is condition-specific, and does not include other RAIRDs, but could improve care for vasculitis.

The UK Rare Diseases Framework could be a vehicle to share best practice between regions and nations about the value of networks, how to adapt them to different regions and nations, and steps that can be taken to successfully implement them.

Case study

Eastern Network for Rare Autoimmune Diseases (ENRAD) Video Case-Conference Service (VCC)

The Eastern Network for Rare Autoimmune Diseases (ENRAD) is a network of clinicians across the East of England with an interest in Connective Tissue Disease and Vasculitis (CTDV) formed in 2016. The ENRAD Video Case Conference (VCC) is a series of meetings held twice monthly via video conference to discuss their complex cases of CTDVs in the region. The forum stands as an opportunity to share advice and knowledge regarding the diagnosis and management of RAIRDs in the East of England, and for clinicians to discuss their complex cases to review with regional experts.

The collaborative working approach adopted by the ENRAD VCC enables quicker diagnosis of complex CTDV patients. It improves the quality of patient care across the region and reduces the need to refer some patients for additional consultations in specialist centres. It also has the benefit of highlighting gaps in current national guidelines or protocols due to recurring scenarios of unclear diagnoses brought to the VCC. These act as a catalyst for the development of new pathways

²⁹ Pearce, F et al, 2021, 'BSR guideline on the management of adults with systemic lupus erythematosus (SLE) 2018: Baseline multi-centre audit in the UK', Rheumatology (Print), vol. 60, no. 3, pp. 1480-1490.

³⁰ Kay, L. Lanyon, P. and MacGregor, A. (2021) Rheumatology, GIRFT Programme National Specialty Report.

³¹ Ibid.

by ENRAD that benefit future clinical practice more widely. The activities of the ENRAD VCC have also resulted in improvements in the process of access to High Tariff Drugs (HTDs), enabling a more efficient and standardised decision-making process for patients in the East of England.

It has also provided a number of financial benefits, such as reduced HTD use for inappropriate cases, reduced non-elective admissions due to better management of patients' disease activity, and reduced clinic appointments when patients can be managed locally with ENRAD VCC guidance. This has resulted in estimated savings of £937,065 over 18 months³²

Upskilling of the workforce around RAIRDs

The workforce crisis in the NHS, and particularly rheumatology, could have a big impact on care for RAIRDs. Whilst other specialities are involved in caring for RAIRDs, they often rely on rheumatology to lead and coordinate care. RAIRDA supports the recommendations of BSR's Rheumatology Workforce: A Crisis in Numbers' report – particularly on the need to increase the number of consultant posts and specialist nurses.³³

However, alongside this and considering the time it might take to address these shortages, there is a need to upskill existing health professionals in caring for people with RAIRDs. This is the case particularly within rheumatology teams, so they can feel confident in supporting people with rare autoimmune rheumatic diseases. Nurses in particular can also support someone with the wider impacts of their condition. A recent study of scleroderma care suggests that patients find it easier to discuss certain issues like the impact of their condition on work and family life with nurses than physicians.³⁴ The British Society for Rheumatology has called for health services to develop enhanced roles for nurses, pharmacists and other healthcare professionals, and it should be considered that some of these could be focused on supporting people with RAIRDs.³⁵ This could ease consultant workload and incentivise more healthcare professionals to specialise in rheumatology by increasing opportunities for career advancement.

32 British Society for Rheumatology (2018), *BSR Best Service Evaluation Report*.

33 British Society for Rheumatology (2021) *Rheumatology workforce: a crisis in numbers*.

34 Denton, C.P., Laird, B., Moros, L. et al. Things left unsaid: important topics that are not discussed between patients with systemic sclerosis, their carers and their healthcare professionals—a discourse analysis. *Clinical Rheumatology* 40, 1399–1407.

35 British Society for Rheumatology (2021) *Rheumatology workforce: a crisis in numbers*.

Recommendations

Improving access to specialist care and knowledge within the workforce

The development of specialist networks:

The national Rare Disease Framework Action Plans being developed for Scotland, England, Northern Ireland, and Wales should describe how health services will invest in, and support, specialised networks for rare diseases, including specialised rheumatology networks. Joint working through the vehicle of the UK Rare Diseases Framework should also be encouraged to facilitate knowledge sharing on how best to undertake this in each nation.

Upskilling health professionals: Health services should upskill and develop enhanced roles for nurses and allied health professionals involving caring for people with RAIRDs. This should include better training in caring for people with RAIRDs within rheumatology teams.

10. Reducing inequalities in access to high quality care and treatment

Quality standards

To systematically address inequalities, we believe clear standards should be set for the core aspects of care. Specifically, the creation of National Institute for Health and Care Excellence (NICE) quality standards could be a useful tool to drive improved outcomes for RAIRDs. NICE develops quality standards to set out priority areas for quality improvement in health, public health and social care. They highlight areas with identified variations in current practice which need to be addressed to improve outcomes. Each standard is comprised of a set of statements to help improve quality and information on how to measure progress. They can be used by anyone responsible for commissioning or delivering services.

Whilst NICE quality standards would only apply in England, the standards NICE has created for some conditions have also been adopted by health boards in Wales.

In Scotland, a similar standard could be created by Health Improvement Scotland, as part of their standards programme.

Audits against standards

Having clear standards gives a framework which an audit can be performed against to identify variations in care. An example of this is the British Society of Rheumatology Audit for National Early Inflammatory Arthritis (NEIAA), which uses quality standard measures to identify changes in care. Audits of care against these standards have shown steady improvement of services in England and Wales. For example, the most recent British Society for Rheumatology, NEIA Audit (2020) showed that the proportion of people with early inflammatory arthritis who started on a disease-modifying antirheumatic drug (DMARD) within 6 weeks of referral increased from 54% in 2019 to 64% in 2020.³⁶



To systematically address inequalities, we believe clear standards should be set for the core aspects of care

36 British Society for Rheumatology (2021). National Early Inflammatory Arthritis Audit (NEIAA).

UK Rare Diseases Framework

The UK Rare Diseases Framework and its nation-specific action plans are an important step toward improving care and outcomes for people with rare diseases. The action plans that are currently being drafted include several significant recommendations, however, there are gaps in terms of incentives to encourage commissioners and providers to focus on improving outcomes for rare diseases, such as RAIRDs. The creation of quality standards for collections of rare diseases such as RAIRDs, or one for all rare diseases, could fill this gap. Some of the areas identified in this report, such as targets for diagnosis and key aspects of co-ordinated care, could be included in a quality standard.

Case study

Variation in care

In 2018 RAIRDA conducted a survey of people living with RAIRDs in England, Scotland, Wales and NI. The survey received 2229 responses. The majority were from England, however 244 were from Scotland, 125 from Wales, and 53 from NI. Although some of these sample sizes are small the results indicated that there is considerable variation in care across the UK. Overall the results also show that there is a significant need for improvement in all nations, in a number of areas vital to good treatment and care.

Nation	Waiting for a specialist for 6 or more months	Able to access care at a joint clinic with doctors from multiple different specialties	Psychological support received
England	23%	19%	16%
Scotland	28%	17%	15%
Wales	35%	9%	9%
Northern Ireland	43%	14%	8%

Recommendations

Reducing inequalities in access to high quality care and treatment

Development of a quality standard for RAIRDs: To underpin many of the above recommendations, a quality standard for RAIRDs, or one that includes RAIRDs, should be developed, including statements on core components of care set out in this report, such as diagnosis and co-ordination of care.

Regular audit of services: The NHS, in partnership with relevant professional and patient organisations, should plan to regularly audit services for RAIRDs in line with these proposed quality standards, to highlight inequalities and areas of the service where there is a need for improvement.

11. Conclusion

This paper presents compelling evidence and clear recommendations for how to improve care and services for people living with rare autoimmune rheumatic conditions across the UK. Partnership across all sectors will be key to transforming outcomes for this patient group and RAIRDA and its member charities are keen to lead the way in facilitating and driving joint working.

We hope that the next few years will see the development of more policy that reflects the needs of people living with RAIRDs, and real breakthroughs in important areas such as improving diagnosis and creating and accessing new treatments. We also hope that the experience of living with a RAIRD is dramatically improved as care and treatment reaches parity with other more common conditions. Finally, we hope this progress happens across the UK, with the treatment a person gets no longer being determined by which nation or region they live in.

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