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Almost one-third of UK rare rheumatic patients face a five-year wait for diagnosis

Today, a new report reveals that some individuals with rare autoimmune rheumatic diseases (RAIRDs) in the UK encounter major barriers in accessing care and treatment. The findings are concerning: nearly one-third of patients had to wait more than five years to get a proper diagnosis, and the average wait time was still a hefty two and a half years.

RAIRDs are a group of conditions, such as Lupus, Sjögren's, Vasculitis, Scleroderma, and Raynaud's, where the immune system attacks the body's own healthy tissues. These conditions often affect multiple organs at once and can be life-limiting or even fatal. Despite the seriousness of these diseases, many patients face poor care coordination and struggle to find the right support or information. As a result, the quality of life for many patients takes a serious hit. In fact, almost all (95%) of those surveyed said their condition has a negative impact on their lives.

Key findings from *Rare Care Matters: the struggle to access diagnosis and care for rare autoimmune rheumatic disease patients* by Ipsos and the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) highlight even more challenges:

- 86% of people who waited over five years for a diagnosis said it negatively affected their ability to do everyday tasks.
- Nearly three-quarters (73%) reported that their condition worsens their mental health.
- And for those who are working, two-thirds (66%) said their disease makes it harder to do their job effectively.

This report shines a spotlight on the urgent need for better awareness, faster diagnosis, and more support for those living with these rare and often debilitating diseases.

RAIRDA is the first dedicated body bringing together patients and clinicians to advocate for better care and treatment for people living with RAIRDs. The report is the result of a survey of over 1,300 people living with RAIRDs across the UK and aims to seek support from the Government to reduce inequalities for people living with rare diseases.

The Mixed Experiences of Care for People with Rare Autoimmune Diseases

When it comes to receiving care for rare autoimmune diseases, people's experiences in the UK seem to vary widely. Some patients are lucky enough to have a smoother journey, while others face frustration and a lack of support.

For a third (34%) of those surveyed, things went pretty well. They were diagnosed within a year of noticing symptoms, which is a relief considering the long wait times many face. Over half (56%) of patients said that the healthcare professionals involved in their care worked well together, making the whole process feel more coordinated and manageable.

But not everyone had such a positive experience. Around a third (34%) of respondents said that their healthcare team didn't seem to be on the same page, leaving them to feel unsupported. When it comes to trusting their GP's knowledge about their condition, just over a quarter (26%) felt confident in their doctor's understanding. Even more concerning, only 16% of patients felt they had enough access to information and support, which can make all the difference in managing such complex and often life-altering diseases.

In short, while some patients feel like they're getting decent care, many others are left struggling with communication gaps, a lack of trust in their doctors, and difficulty finding the information they need. There's clearly a lot of room for improvement in how people with rare autoimmune diseases are treated and supported.

RAIRDA's report lists a set of policy recommendations from RAIRDA, which include the creation of measurable, realistic targets for referrals to specialists and commencement of treatment for RAIRDs to be included in each nation's health and care guidance body and implemented by the NHS. It outlines the need of every person living with a RAIRD to have a named person responsible for coordinating their care. In addition, it urges the Government to provide increased funding and support for research into the diagnostic pathway for RAIRDs.

Sue Farrington, Co-Chair of The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA), said: *"As this report shows, across the UK, people with RAIRDs are not getting the care they need. The evidence echoes the stories we hear every day from our patient communities – the UK's health system is not working for people living with RAIRDs, and they are falling through the cracks.*

These findings are perhaps not unsurprising, in a system where there has been an increasing focus on major and common conditions. The UK Rare Diseases Framework and subsequent action plans have enabled a significant

step for rare conditions, but more is needed. It is imperative that the new Government does not lose sight of people living with RAIRDs, especially given the recent changes in the English health and social care system, including the abolition of NHS England. People living with RAIRDs should not be left feeling “totally alone with [their] disease,” as one respondent told us.”

Dr Bridget Griffiths, RAIRDA Co-Chair, said: *“Whilst there are examples of excellent care and treatment across the UK, the situation for people with RAIRDs can be improved. We are calling on decision-makers and politicians to use the insights in this report to drive improvements in provision, such as the expansion of specialised networks to share knowledge and improve access to expert care and treatment, and the creation and implementation of the first ever quality standard for rare disease. Access to vital care and treatment should not be determined by the prevalence of your condition. The time for change is now.”*

Rosie McQueen, who is 73, lives in South Wales and has Sjögren’s disease, said:

“Sjögren’s is a systemic disease with a highly significant impact on many of us. Because it can, and often does, have an effect on several different bodily systems, we are frequently juggling medical appointments with different specialists, while trying to ensure they are coordinated with each other. It is very hard work being your own medical coordinator. This hard work comes on top of trying to balance normal living requirements with debilitating chronic fatigue and the brain fog that too often comes with it.

It is a condition that requires constant re-evaluation and mental agility, and is ever-changing, involving an ongoing grieving process as each loss hits home. The findings of this report reflect how important it is that care and support for people living with rare autoimmune rheumatic conditions is improved, to ensure we are given informed care and appropriate reassurance, which reflects the reality of these conditions.”

Peter Dowd MP, Chair of the APPG on Rare Diseases said:

“This report highlights the challenges faced by the 170,000 people living with rare autoimmune rheumatic diseases (RAIRDs) in the UK and the need for

continued improvement in our healthcare system. The UK Rare Diseases Framework is an important step forward, and we must build on this progress to ensure that no one with RAIRDs is left behind. By strengthening support and care pathways, we can create a system that works for everyone."

About the RAIRDA Patient Survey

This report presents the findings from a survey of 1,352 people living with Rare Autoimmune Rheumatic Diseases (RAIRDs) across the UK, conducted by Ipsos in 2024 on behalf of the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA). An online survey was conducted between 22nd April and 31st May 2024 of individuals aged 16 and over living with rare autoimmune rheumatic disease(s).

Survey respondents were those who have received a formal RAIRD diagnosis and does not include people who suspect they have a RAIRD or are still on their journey to diagnosis.

The methodology:

Patients were eligible to take part in the survey if they had a diagnosis of any of the following conditions: lupus, Sjögren's disease, systemic vasculitis, systemic sclerosis (scleroderma), myositis, antiphospholipid syndrome (APS), Raynaud's disease, and undifferentiated or overlap connective tissue disease (UCTD).

All elements of the survey approach, questionnaire content and survey materials underwent ethical review and approval by the Ethox Centre at Oxford University.

About RAIRDA

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) is a UK-based alliance of patient organisations and clinicians. RAIRDA came together in 2016 to provide a clear voice to drive improvement in the care and treatment of individuals living with rare autoimmune rheumatic conditions (RAIRDs). RAIRDA's member organisations are Lupus UK, Scleroderma & Raynaud's UK (SRUK), Vasculitis UK and Sjögren's UK, and RAIRDA has four member clinicians.