RAIRDA
Rare Autoimmune Rheumatic Disease Alliance

RARE CARE MATTERS: THE STRUGGLE TO ACCESS DIAGNOSIS AND CARE FOR RARE AUTOIMMUNE RHEUMATIC DISEASE PATIENTS

Rare Autoimmune Rheumatic Disease Alliance and Ipsos

April 2025

Sjögren's UK

VASCULITIS UK

SCLERODERMA & RAYNAUD'S UK

LUPUS UK

Contents

Foreword

As this report shows, across the UK, people with rare autoimmune rheumatic diseases (RAIRDs) are not getting the care they need. The evidence presented in this report 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.

Rare autoimmune rheumatic diseases are a group of conditions where the body's immune system becomes overactive and attacks healthy tissues, often in multiple organs throughout the body simultaneously. These conditions are often life-limiting and can be fatal.

Yet people with these rare conditions are left facing significant variations in their experiences of care and treatment: 30% of respondents to this survey waited for over five years for diagnosis.

Alarmingly, even after diagnosis many patients are facing poor care coordination, and difficulties accessing information and support. These challenges can lead to significantly poorer quality of life with 95% of respondents saying that their condition has had a negative impact on their lives.

RAIRDA is the first dedicated body bringing together patients and clinicians to advocate for better care and treatment for people living with Rare Autoimmune Rheumatic Diseases (RAIRDs). We work to develop evidence on the disparities in the quality of care and treatment received by people living with RAIRDs, and to drive change in health policy, with the aim of achieving better outcomes.

This survey builds on our previous work, including our 2018 and 2021 surveys, and the detailed recommendations made in our 2022 policy report, Resetting the Balance. While there are some areas of improvement, it is clear that the current healthcare system still falls short in addressing the needs of people living with rare autoimmune rheumatic diseases.

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 policymakers and the new Government do not lose sight of people living with rare diseases, including non-genetic conditions such as RAIRDs, so that these people from across the UK are not left feeling "totally alone with [their] disease," as one respondent told us.

We know that the current situation for people with RAIRDs can be improved. There are examples of excellent care and treatment across the UK, driving high patient satisfaction and better long-term outcomes.

Our recommendations provide a clear vision for improvement across key areas, which if taken on board by the government and NHS decision-makers, could change the landscape of care for people living with RAIRDs.

We are therefore 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 to support secondary care, and the completion and implementation of the first ever quality standard for rare diseases.

With the new government, and the upcoming 10-year health plan, there is a genuine opportunity to drive change and reduce inequalities for people living with rare disease. Access to vital care and treatment should not be a postcode lottery, and the prevalence of your condition should not determine the quality of your care.

The time for change is now. RAIRDA stands committed to driving these efforts forward, and we are calling on you to support our asks.

Sue Farrington
RAIRDA Co-Chair

Key Findings

This report presents the findings from a survey of over 1,300 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).

The survey set out to capture the current landscape of patient satisfaction with care, including what is working well, and areas for improvement.

Key findings from analysis of the survey data are as follows:

Diagnostic Pathways

- While a third of respondents (34%) were diagnosed within a year of symptom onset, 30% waited over five years for a diagnosis, with an average wait of 2.5 years.
- Longer waits for diagnosis are linked with poorer quality of life, with 86% of those who waited more than 5 years also reporting a negative impact on their ability to do day-to-day tasks.

Experiences of Care

- Over half of respondents (56%) reported that the different healthcare professionals (HCPs) caring for them worked well together, however a third (34%) felt they did not.
- How well HCPs worked together appears to be linked to respondents' emotional and mental well-being. Four in five respondents (80%) who felt the HCPs caring for them did not work well together, reported a negative impact on their mental and emotional well-being.
- Just 26% of respondents felt that they had confidence in their GP's understanding of their condition.

Access to support

- Just 15% of respondents were always able to access advice and support from their hospital within 48 hours, meaning that the majority of respondents experienced delays in obtaining timely advice.
- Furthermore, just 16% of respondents felt that they definitely had access to enough information and support.
- Those who felt they did not have access to enough information and support were more likely to report that their condition has had a negative impact on their emotional and mental well-being (83%) and that they were not managing well day-to-day (62%), compared to those who reported that they do have enough information.
- Just 28% of respondents had access to care from a specialist nurse – 79% of those patients who had access to a specialist nurse felt they had access to enough information and support, compared to just 58% of those who did not have access to a specialist nurse, suggesting that specialist nurses play a valuable role in patients feeling supported.

Impact on people living with RAIRDs

- The overwhelming majority of respondents (95%) reported that their condition has had a negative impact on their lives.
- 73% of respondents said that their condition had a negative impact on their psychological health.
- Two-thirds (66%) of working individuals state that their condition impacts their ability to perform their jobs effectively. This often necessitates adjustments to their working hours, as reported by 40% of these respondents.

Recommendations

RAIRDA has carefully considered the findings contained in this report alongside its own existing information base and policy recommendations. Based on this, RAIRDA has developed the following recommendations:

Reduce diagnostic delays:

- Create 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.
- Improve access to training for GPs to support them in their role in diagnosing and caring for people living with RAIRDs.
- Increase funding and support for research into the diagnostic pathway for RAIRDs, to include new and emerging technology such as AI.
- Provide funding for research into biomarkers of early disease activity, to support clinicians to identify 'red flag' signs of RAIRDs and speed up referrals to specialists.

Improve co-ordination of care:

- Ensure every person living with a RAIRD has a named person responsible for coordinating their care, to include coordinating an annual review of a patient's care, to be held in-person if possible.
- Ensure multi-speciality clinics are available, to ensure proper communication across specialities, well-coordinated care, and less travel and fewer appointments for the patient.
- Allocate resource for the development and ongoing management of specialised networks, including specialised rheumatology networks, to increase healthcare practitioner knowledge and expertise in supporting people with complex conditions such as RAIRDs.

Empower with greater knowledge and support:

- Recognise patient organisations as information partners with clear and ongoing lines of communication with named officials within each nation's health department, to ensure patients have access to all available support. Healthcare professionals in both primary and secondary care should be encouraged to engage with the wealth of materials provided by patient organisations – both as resources for their own practice, and for signposting to patients e.g. patient advice lines, information leaflets and support groups.
- Improve patient access to specialist nurses, by increasing opportunities and funding for training and recruitment for these roles, supported by the Department for Health and Social Care, and national health services.

Improve quality of life:

- Ensure patients have access to a good-quality, well-managed and well-staffed advice line, as a first point of contact for any issues which may arise, to prevent people in crisis going untreated, or forcing them to access less appropriate services.
- Ensure that patients with RAIRDs have access to holistic support, which must include effective psychological support, as well as nutrition and physical activity where appropriate.
- Assessment of welfare support for people with RAIRDs by policymakers must take into account the varied, often severe, impacts of these conditions when looking at how working people can be best supported.

About RAIRDA

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.

About RAIRDs

Rare autoimmune rheumatic diseases (RAIRDs) are a group of conditions where the body's immune system attacks its own healthy tissues. RAIRDs can affect many parts of the body (including joints, skin, lungs, kidneys and heart) and often require cross-specialty medical expertise. Unlike most rare diseases, these conditions predominantly occur in adult life.

Patients with RAIRDs face shared systematic challenges, including delays in diagnosis and lack of access to appropriate care. The chronic nature of RAIRDs, along with their potential for serious complications and organ damage, means that timely diagnosis, effective management, and ongoing research into this group of conditions, are crucial to improve the health and lives of those affected.

The following conditions are covered by this report:

Lupus

Lupus is a chronic autoimmune condition that occurs when the body's immune system attacks its own tissues and organs, causing inflammation and damage. This can impact various parts of the body, including the joints, skin, kidneys, heart, lungs, and brain. Symptoms vary widely but commonly include fatigue, joint pain, swelling, a butterfly-shaped rash across the face, chest pain, hair loss, mouth sores, and sensitivity to sunlight. Lupus can also present a significantly increased lymphoma risk.

Sjögren's disease

Sjögren's disease is a chronic autoimmune condition that primarily affects the body's moisture-producing glands, especially those responsible for tears and saliva. As a result, the hallmark symptoms are persistent dry eyes and dry mouth. These symptoms can have a significant impact on daily activities like eating, speaking, and reading.

Sjögren's can also affect other parts of the body. Individuals may experience joint pain, muscle aches, fatigue, dry skin, and even problems with organs like the lungs, kidneys, and liver, as well as a significantly increased risk of lymphoma.

Systemic sclerosis or scleroderma

Systemic sclerosis, also known as scleroderma, is a condition that causes the skin and connective tissues to harden and thicken. This happens because the body produces too much collagen, a protein that provides structure to these tissues.

The most noticeable symptom is skin changes, often starting with tightening and swelling in the fingers and hands, sometimes accompanied by itchiness. The skin may appear shiny and change colour, and small red spots called telangiectasia can appear on the hands and face. Systemic sclerosis can also impact internal organs like the lungs, heart, digestive system, and kidneys, leading to various complications.

Systemic vasculitis

Systemic vasculitis is a group of rare autoimmune conditions characterised by inflammation of the blood vessels. This inflammation can cause the blood vessels to narrow, reducing blood flow to organs and tissues, sometimes leading to organ damage.

Systemic vasculitis can affect any organ system and presents with a wide range of symptoms, making it challenging to diagnose. Common symptoms include fatigue, weight loss, fever, muscle and joint pain, and a rash. Depending on the organs affected, individuals may experience headaches, vision changes, numbness or weakness in the extremities, shortness of breath, chest pain, abdominal pain, or kidney problems.

Myositis

Myositis, or inflammatory muscle condition, is characterised by inflammation of the muscles. This inflammation causes muscle weakness, which can make everyday activities like climbing stairs, lifting objects, or even brushing hair difficult. Common symptoms include muscle weakness, fatigue, muscle pain and joint pain. Other symptoms may include difficulty swallowing, shortness of breath, and a rash, depending on the type of myositis.

Antiphospholipid syndrome (APS)

Antiphospholipid syndrome (APS), also known as Hughes syndrome, is an autoimmune disorder where the immune system produces abnormal antibodies that target proteins linked to fats in the blood, increasing the likelihood of blood clots.

The most common impact of APS is an increased risk of blood clots in arteries and veins, which can occur in various parts of the body, including the legs, lungs, and brain. These clots can lead to serious health problems such as deep vein thrombosis (DVT), pulmonary embolism, stroke, and heart attack. APS can also cause pregnancy complications like miscarriages, stillbirths, and pre-eclampsia.

Symptoms vary depending on where the blood clots form but can include leg pain or swelling, chest pain, shortness of breath, headaches, vision changes, and pregnancy complications.

Undifferentiated or Overlap Connective Tissue Disease

Undifferentiated or overlap connective tissue disease (UCTD) is a condition that presents with symptoms similar to other autoimmune connective tissue conditions like lupus, rheumatoid arthritis, or scleroderma, but doesn't fit the specific criteria for any of them. People with UCTD experience a range of symptoms, often including joint pain, fatigue, muscle weakness, and Raynaud's phenomenon (where fingers and toes change colour in the cold). Other possible symptoms include dry eyes and mouth, skin rashes, hair loss, and inflammation of the lining around the lungs or heart.

Raynaud's Disease

Raynaud's disease, also known as Raynaud's phenomenon or syndrome, is not considered a RAIRD; however, it is a condition commonly associated with RAIRDs. It is a condition that affects blood circulation, primarily in the fingers and toes. It is triggered by cold temperatures or stress, causing the blood vessels to narrow temporarily. During an episode, the affected areas may turn white or blue, feel cold and numb due to restricted blood flow. As blood flow returns, the areas may turn red, accompanied by tingling, throbbing, or a pins-and-needles sensation. Episodes typically last for minutes but can extend to hours.

1 Introduction

1.1 Background

RAIRDA is committed to improving the quality of care and treatment received by people living with RAIRDs. This research has been commissioned to build on RAIRDA's existing work, to develop RAIRDA's understanding of the key drivers of patient satisfaction with care, and to provide evidence to inform policy development and drive service change.

1.2 Survey method

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). It was designed in close collaboration between Ipsos, RAIRDA and their wider stakeholders. Respondents were also given the opportunity to complete a telephone interview (via a helpline) if they preferred.

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[1]

1.2.1 Questionnaire

The questionnaire had 40 questions and took an average of 14 minutes to complete. It included a mixture of closed and open-ended questions focussing on the following key themes:

- Diagnosis and accessing care
- Experience of care
- Access to drugs and monitoring
- Sources of support and ongoing management
- Day-to-day life and well being

1.2.2 Sampling and survey invitations

At the time of conducting the survey, there were no (known) centralised NHS lists of RAIRD patients that could be used to invite patients to take part in the survey. Therefore, RAIRDA distributed the online survey via an open link through their existing patient networks. This included:

- Member organisations
- The Eastern Network for Rare Autoimmune Diseases
- The National Rare Disease implementation groups
- Genetic Alliance and Beacon for Rare Diseases
- Rheumatology centres
- APS UK and Myositis UK
- Registration of Complex Rare Diseases – Exemplars in Rheumatology (RECORDER) group and associated patient groups

[1] Ethox Centre, Oxford University. For more information, please see their website, available at www.ethox.ox.ac.uk

The survey was launched just before the British Society for Rheumatology conference, an annual 3-day rheumatology conference attended by c.2000 delegates. Attendees include consultants, trainees, nurses and allied health professionals, as well as representatives from the third sector. Vasculitis UK shared the survey during their Special Interest Group session and the survey QR code was also shared in some presentations (e.g. by Vasculitis UK and scleroderma and Raynaud's UK, and at the Specialised Commissioning Special Interest Group Session). The survey link was displayed on the RAIRDA website, and shared on social media including Facebook and X. This approach aimed to reach a broad audience of individuals living with rare autoimmune rheumatic conditions.

1.2.3 Respondent profile

A total of 1,352 questionnaires were completed, with the breakdown by condition type shown in table 1.1. Forty five percent of respondents report having two or more autoimmune conditions, and length of time since diagnosis varied widely (45% since 2018, see appendix table 5.4 for full details). Overall, 91% were female, as expected, with more males amongst those with vasculitis (15%). Around four in five respondents were aged 45 or older (81%) and two in five were currently in paid employment (41% either full time or part time). Eighty-two per cent of respondents lived in England, 9% in Scotland, 5% in Wales and 2% in Northern Ireland. A full breakdown by demographics can be found in the appendices.

It is worth noting that this is a survey of people 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. Therefore, the experiences of people who have taken part in this survey might differ from those who are yet to receive a formal diagnosis.

Table 1.1: Number of respondents by condition

Condition	Number of respondents (1352)	Percentage
Antiphospholipid syndrome (APS)	151	11%
Form of systemic sclerosis or scleroderma	350	26%
Form of systemic vasculitis	287	21%
Lupus	398	29%
Myositis/inflammatory muscle condition	116	9%
Raynaud's disease	649	48%
Sjögren's disease	366	27%
Undifferentiated or overlap connective tissue disease	193	14%

Please note, respondents were able to select multiple conditions, therefore, the percentage total is greater than 100%.

Data processing and analysis

Following the fieldwork period, an analysis plan was created to determine how the data would be used. This included reviewing the answers to the open-ended question and developing a codeframe to code free text responses. The coded responses were integrated into the final data set.

Data tables were created for each survey question, summarising the overall findings and by key variables (e.g. condition, demographics, year of diagnosis, impact on life etc.). The list of key variables used to analyse each question was agreed in advance of table production. In addition, respondents' postcode information was used to append an Index of Multiple Deprivation (IMD) score to the dataset, to allow for analysis of socioeconomic factors.

Significance testing was applied to the data using two tailed t-tests. Where particular groups were tested against the overall sample (e.g. lupus vs overall sample), the test accounts for the correlation between testing variables.

Due to the lack of a pre-existing profile of patients with RAIRDs to use as a comparison, the data was not weighted.

1.3 About this report

When reading the report, please note the following points:

- Findings are not intended to be representative of the RAIRD population, they present a snapshot of the people who completed this survey. This means the survey findings may underrepresent certain groups (e.g. those from an ethnic minority background (8% of respondents) etc.)
- Findings are primarily reported at an overall level, rather than being disaggregated by each condition. Subgroup analysis is only presented where statistically significant differences are found between conditions.
- The abbreviation RAIRD in this report refers to "rare autoimmune rheumatic disease"
- The abbreviation HCP in this report refers to "health care professional"
- Quotes were taken from an open-ended question which invited respondents to share their experiences of their condition
- Numbers are always rounded and presented as "whole" numbers
- Percentages for response answers may not always total 100% due to rounding.

1.4 Comparisons to 2018

In 2018, RAIRDA conducted a survey to assess the experiences of people living with RAIRDs in the UK. The survey aimed to understand individuals' experiences with care, particularly in relation to the UK Strategy for Rare Diseases, published in 2013. The survey focussed on lupus, vasculitis and scleroderma, with a total of 2,101 responses achieved.

The 2024 survey used many of the same questions and it is useful to explore how experiences have changed over time. However, the 2024 survey was sent to respondents with a wider range of RAIRDS than 2018 (see Table 1.1 for the full list of RAIRDs). Therefore, any comparisons between the two surveys will focus on lupus, vasculitis and scleroderma/systemic sclerosis only (i.e. it is limited to the same conditions across surveys) to allow for more meaningful comparisons. Please note, that as neither the 2018 or 2024 dataset was weighted to a known population profile, differences in demographic profile may exist and therefore any comparisons should be considered indicative only.

Whilst these comparisons provide some nuance to how care might have changed, these comparisons should be treated with caution as these figures do not take into consideration other external factors which may have also changed since the survey was last conducted; e.g. advancements in treatment, changes in healthcare access, and the impact of the COVID-19 pandemic, which could influence patient experiences.

2 Diagnostic Pathways

2.1 Journey to diagnosis

The chronic nature of RAIRDs, along with their potential for serious complications and organ damage, means that timely diagnosis is imperative to prevent unnecessary disease progression and organ damage. However, the results of this survey show that patients face inconsistent, often substantial, lengths of time to diagnosis.

> ***"My experience of long waiting time[s] for diagnosis meant I was given incorrect and harmful advice."***
>
> Respondent with lupus, Sjögren's disease and Raynaud's disease

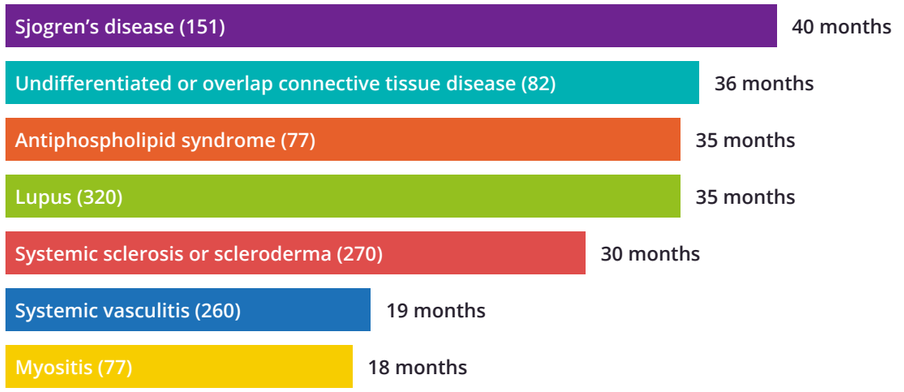
There was considerable variation in waiting times for diagnosis. The average time between first experiencing symptoms and receiving a diagnosis was approximately 2.5 years (31 months).[2] Yet whilst a third of respondents (34%) received a diagnosis for their primary rare autoimmune rheumatic condition within a year of symptom onset, three in ten (30%) reported that they experienced symptoms for more than five years before diagnosis.[3]

30%
waited over 5 years for a diagnosis

On average, from symptoms to diagnosis, respondents waited
31 months

As shown in Figure 2.1, the length of time between symptom onset and diagnosis varied considerably between conditions. For example, respondents with vasculitis experienced faster diagnosis times than other conditions – however, even with this relatively shorter diagnosis time, symptoms can worsen rapidly.

Figure 2.1: Average length of time experiencing symptoms before primary diagnosis by condition



Q9. How long before this diagnosis were you experiencing symptoms. If at all? Base: all participants (1352). Source: Ipsos.

[2] For "Q9. How long before this diagnosis were you experiencing symptoms, if at all?" Averages were calculated by identifying a middle-range for each answer code for how long people waited for diagnosis, for example, 'within 1 year' became 6 months '1-3 years,' became 24 months etc. For the answer category 'more than 5 years' a conservative estimate of 61 months was used. This means the final average wait time could potentially be higher than outlined in the report. Please note, the number of months has been rounded to the nearest whole number.

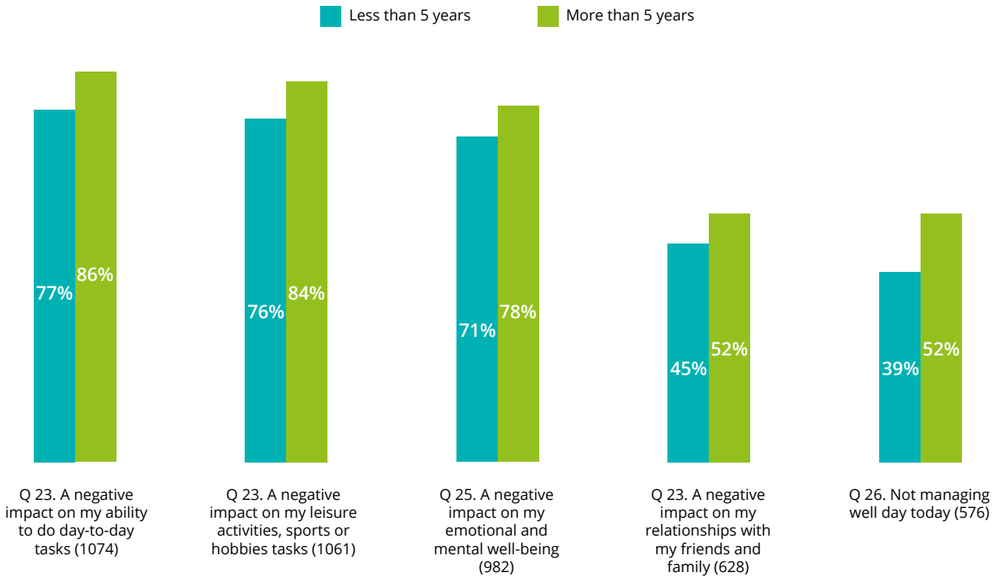
[3] See table 7.1 for detail.

Impact of length of time waiting for a diagnosis

Survey results show that respondents who waited for more than 5 years for a diagnosis were more likely to report their condition negatively affected their ability to do day-to-day tasks (86%), their leisure activities (84%), and their relationships with family and friends (52%), compared to those who report waiting less than 5 years for diagnosis.

Similarly, those who waited more than 5 years were more likely to report a negative impact on their emotional and mental wellbeing (78%) and that they are not managing well day-to-day (52%) (Figure 2.2).

Figure 2.2: Impact of length of time waiting for primary diagnosis



Q23. Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)? Base: All participants (1352).

Q25. To what extent have all of your rare autoimmune disease(s) Had a positive or negative impact on your emotional and mental well-being? Base: All participants (1352).

Q26. Over the last 12 months, how well, if at all, do you feel you have been managing day-to-day with all of your rare autoimmune disease(s)?

Base: All participants (1352). Source: Ipsos.

Misdiagnosis

A proportion of respondents (6%) spontaneously reported in the free text section of the survey that they were initially misdiagnosed[4].

> ***"The most difficult phase was prior to diagnosis when I was misdiagnosed several times."***
>
> Respondent with Sjögren's disease, systemic sclerosis/scleroderma, and Raynaud's disease

[4] Responses from the question "Is there anything else you would like to tell us about your experiences with your disease?".

2.2 Waiting times to see a specialist

The findings show that on average patients wait 5 months to see a specialist from time of referral; however, there is considerable variation across respondents.[5]

One in five respondents waited under a month to see a specialist (22%), but one in ten waited more than a year (9%).

Further, 10% of patients had to be diagnosed through an emergency or alternative route.

5 months
average wait time to see a specialist

Q10. How long did you have to wait to see a specialist for this diagnosis from the time of referral? Base: All participants (1352)

Despite the need for treatment to begin rapidly to prevent unnecessary disease progression, survey findings suggest that waiting times to see a specialist for lupus, sclerosis and vasculitis have worsened compared to the 2018 RAIRDA survey[6], which found that over half (54%) of respondents were seen by a specialist within 3 months of referral, compared with 50% in 2024.

Impact of waiting times to see a specialist

The length of time respondents waited to see a specialist appears to have an impact on their confidence in healthcare professionals. Those who were seen by a specialist within 4 weeks of referral were more likely to report being very confident in their specialist healthcare practitioners (48%) compared to those who waited for more than 4 weeks (31%).

Longer wait times are also linked to negative impacts on the personal lives of people with RAIRDs. Compared to those who report waiting less than 3 months for an appointment with a specialist, respondents who waited for more than 3 months to see a specialist were more likely to report experiencing extreme tiredness (86% vs 91%), and that their condition negatively impacts their day-to day tasks (77% vs 85%), job (41% vs 48%) or relationships with family and friends (45% vs 51%).[7]

Of those who waited more than three months to see a specialist

91%
have experienced extreme tiredness

85%
said their condition negatively impacts their day-to-day tasks

48%
said their condition negatively impacts their day-to-day job

51%
said their condition impacts their relationships with family and friends

[5] See Figure 7.2 for further detail.

[6] For the purpose of this analysis, data from the 2024 survey have been carefully filtered to match the criteria used in the 2018 report, which exclusively included respondents diagnosed with lupus, systemic sclerosis, and vasculitis. This approach ensures that any comparative analysis between the 2018 and 2024 datasets is conducted on a consistent basis, focusing only on these specific conditions. It is important to note that neither dataset has been weighted, which may result in demographic differences among respondent profiles. Therefore, any findings should be considered as indicative.

[7] See Figure 7.3 for more detail.

2.3 Access to private healthcare

One in five respondents (19%) used private healthcare to get a diagnosis, and around one in ten used private healthcare to see a specific doctor or consultant. A further one in ten (10%) used private healthcare because the waiting time in their area for appointments was too long.

A further one in ten (10%) used private healthcare because the waiting time in their area for appointments was too long.

> ***"I had to go to a health assessment (private) who then referred me to a private rheumatologist to get a diagnosis. I'm not sure how long it would have taken on the NHS. I feel lucky that I could afford to do that and that the earlier diagnosis probably saved me from further damage to my organs."***
>
> Respondent with vasculitis

2.4 Conclusion

As explored in this chapter, individuals with RAIRDs continue to face delays to diagnosis, and long waits to access specialist care, both of which are linked to negative impacts on respondents' quality of life and experiences of care.

Recommendations from RAIRDA:

- Create 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.
- Improve access to training for GPs to support them in their role in diagnosing and caring for people living with RAIRDs.
- Increase funding and support for research into the diagnostic pathway for RAIRDs, to include new and emerging technology such as AI.
- Provide funding for research into biomarkers of early disease activity, to support clinicians to identify 'red flag' signs of RAIRDs and speed up referrals to specialists.

3 Experience of Care

3.1 Care across multiple providers

Due to the complex nature of RAIRDs, many patients require care from a number of different specialists. Overall, two thirds of respondents (66%) reported they were accessing care from two or more specialists, and 43% were accessing care from 3 or more specialists.

Table 3.1: Specialities respondents report receiving care from

Specialty	Overall (1352)
Rheumatology	77%
Ophthalmology	26%
Respiratory	26%
Cardiology	21%
Gastroenterology	18%
Dermatology	16%
Renal	14%
ENT	12%
Oral medicine	12%
Neurology	11%

Q3. Thinking about all of your rare autoimmune disease(s), in the last 12 months, which of the following specialities have you received care from? Base: All participants (1352)

3.2 Number of hospital sites

Over half of all respondents (55%) said they visit two or more different hospital sites for treatment and monitoring, with 23% visiting three or more.

Further, 11% of respondents spontaneously reported in the free text section of the survey that their care was not joined up across the different hospital sites they receive care from.

In addition, the majority of respondents (70%) reported that they travel up to an hour to see their most frequently visited specialist (see appendix table 6.12 for more information).

The survey findings suggest that the number of respondents routinely attending multiple hospital sites has increased in comparison to the 2018 RAIRDA survey[8], which found that a third of respondents (33%) regularly attended multiple hospital sites, compared with 58% in 2024 (for lupus, systemic sclerosis/scleroderma and vasculitis).

[8] For the purpose of this analysis, data from the 2024 survey have been carefully filtered to match the criteria used in the 2018 report, which exclusively included respondents diagnosed with lupus, sclerosis, and vasculitis. This approach ensures that any comparative analysis between the 2018 and 2024 datasets is conducted on a consistent basis, focusing only on these specific conditions. It is important to note that neither dataset has been weighted, which may result in demographic differences among respondent profiles. Therefore, any findings should be considered as indicative.

> ***"My care is spread over several different hospitals with no one having the ultimate say in my treatment. This I find very frustrating at times. As I feel that I need someone to take the reins and take care of all of my various medical problems."***
>
> Respondent with APS, systemic vasculitis and Raynaud's disease

3.3 Healthcare professionals working together

Considering the proportion of respondents who access care across multiple sites and specialities, it is important that healthcare professionals can communicate effectively and work well together.

54% of respondents felt that the healthcare professionals caring for them work well together, either definitely, or to some extent. Over a third, 34%, of respondents felt that the healthcare professionals responsible for their care did not work well together at all.

54%
of respondents felt that the healthcare professionals caring for them work well together

34%
felt that the healthcare professionals caring for them did not work well together at all

Q13. Thinking more generally about your primary diagnosis, how confident or not are you that the specialist healthcare professionals you engage with understand your disease and needs? Base: All participants (1352).

This was also reflected in comments from patients completing the survey:

> ***"I would like to see more of a joined-up approach from health specialists, ophthalmologists, dermatologists, rheumatologists, GP and maybe even dentist, to get an all-round idea of the individuals' condition, symptoms and healthcare needs."***
>
> Respondent with lupus

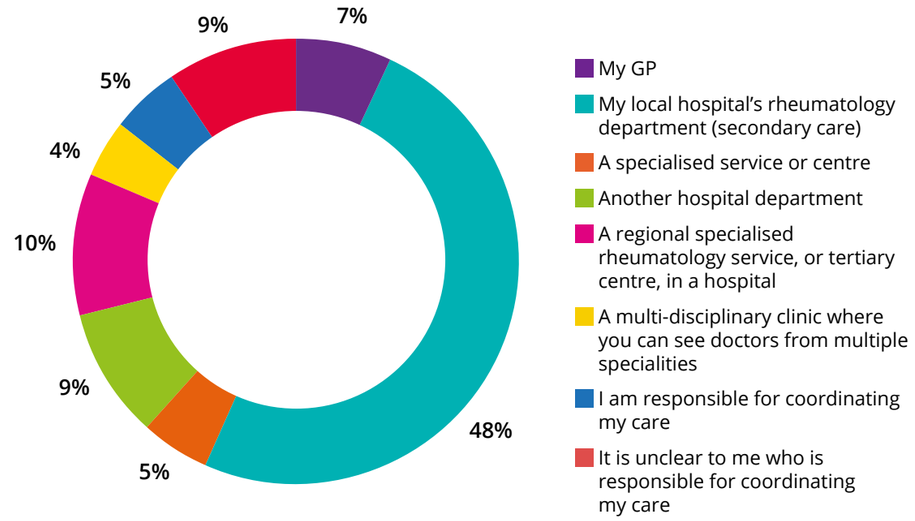
> ***"I really wish someone would coordinate between all my different consultants, I'm sure it would improve the level of care – and at the same time save the NHS money."***
>
> Respondent with systemic vasculitis and Raynaud's disease

These findings echo RAIRDA's 2018 survey findings, where 32% of respondents felt their care was not well coordinated among the healthcare professionals caring for them, suggesting that there has been no improvement in patient satisfaction with coordination between healthcare professionals.

3.4 Responsibility for care

Figure 3.1: Service/ team responsible for care for primary diagnosis

48% of respondents reported that their local hospital's rheumatology department is responsible for their care for their primary condition, while just 4% of patient reported that their care was coordinated by a multi-speciality clinic, where there are doctors from multiple specialities, and similarly, just 15% of patients reported that their care was coordinated by a specialised service or centre.



Q11. Still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease? Base: all participants (1352). Source: Ipsos.

Concerningly, 1 in 10 respondents reported that it was unclear to them who was responsible for coordinating their care, whilst 1 in 20 reported that they were responsible for coordinating their own care.

> ***I would find it helpful if all my different consultants could liaise with each other about my care as sometimes one condition impacts on another. I find it frustrating that I am the one running info between consultants, so my treatments don't clash."***
>
> Respondent with lupus

> ***"I don't have a clear structure of who will be responsible for my continuing care. I would have preferred to receive specific information of my type of vasculitis with details of who is the main care provider."***
>
> Respondent with systemic vasculitis

Impact on patient satisfaction

Survey results showed that respondents were more likely to report that healthcare professionals worked well together regarding their care, when their care is overseen by a multi-specialty clinic (75%), regional specialised rheumatology service (72%) or their local rheumatology department (63%).

By contrast, fewer respondents reported healthcare professionals working well together regarding their care where their GP is responsible for coordinating their care (37%), where the respondent is responsible for coordinating their care (26%), or where they were unclear about who was responsible for coordinating their care (12%).

Percentage of respondents who felt that all the different healthcare professionals caring for them work well together

75%
of respondents with care overseen by a multi-speciality clinic

63%
of respondents with care overseen by their local rheumatology department

37%
of respondents with care coordinated by their GP

26%
of respondents who are responsible for coordinating their own care

Q15. Do all the different health professionals caring for you work well together to give you the best possible care and support for this diagnosis? Base: all participants (1352).

Impact on mental and emotional wellbeing

Respondents who felt that the HCPs responsible for their care do not work well together were more likely to report their condition has a negative impact on their emotional and mental well-being (80%), compared to 68% of people who felt HCPs did work well together on their care.

Similarly, 59% of respondents who felt that the HCPs responsible for their care do not work well together reported they were not managing well day-to-day, compared to 34% of those who felt that HCPs did work well together on their care.

3.5 Confidence in general practitioners

Respondents were asked about how confident they were that the medical staff they engage with understood their condition and needs.

Just 26% of respondents felt that they had confidence in their GP's understanding of their condition.[9]

Further, almost one in five respondents (19%) spontaneously reported a lack of knowledge and understanding from GPs.

26%
felt confident in their GP's understanding of their condition

Q12. How confident or not are you that your GP understands your primary diagnosis and your needs for this diagnosis? Base: all participants (1352).

[9] See Figure 7.4

> ***"I don't think GPs and the general medical profession understand my condition or how it affects me."***
>
> Respondent with a form of systemic sclerosis or scleroderma and Raynaud's

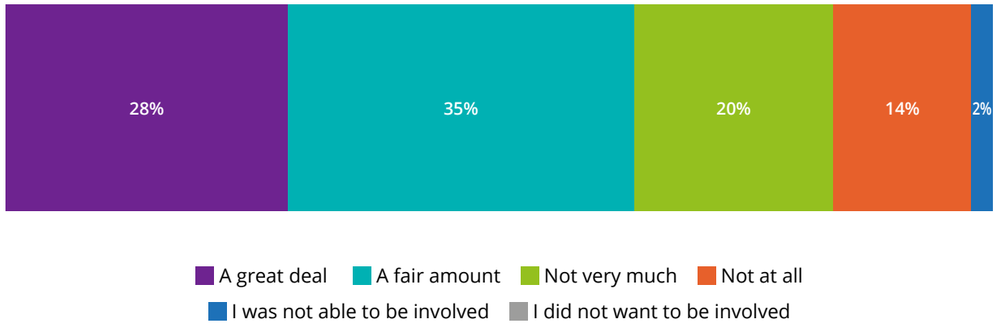
These findings suggest confidence in GPs understanding of patients' conditions and needs may have declined since the 2018 RAIRDA survey[10], which found more than half (55%) of respondents felt either not very or not at all confident in their GP's knowledge of their condition, compared with 62% of respondents in 2024 (for lupus, systemic sclerosis/scleroderma and vasculitis).

3.6 Involvement in agreeing care plans

As RAIRDs are a rare, life-altering and potentially life-threatening group of conditions, it is key that people living with RAIRDs feel that they can be involved in their care and treatment planning, as much as they want to be.

Overall, 34% of respondents said that they were either not very much, or not at all, involved in developing a plan for their care for their primary diagnosis with specialist healthcare professionals. Just three respondents told us that they did not want to be involved in planning for their care.

Figure 3.2: Involvement in agreeing a care plan



Q14. To what extent do the specialist healthcare professionals you engage with for this diagnosis involve you in agreeing a plan for your care and treatment? Base: all participants (1352).

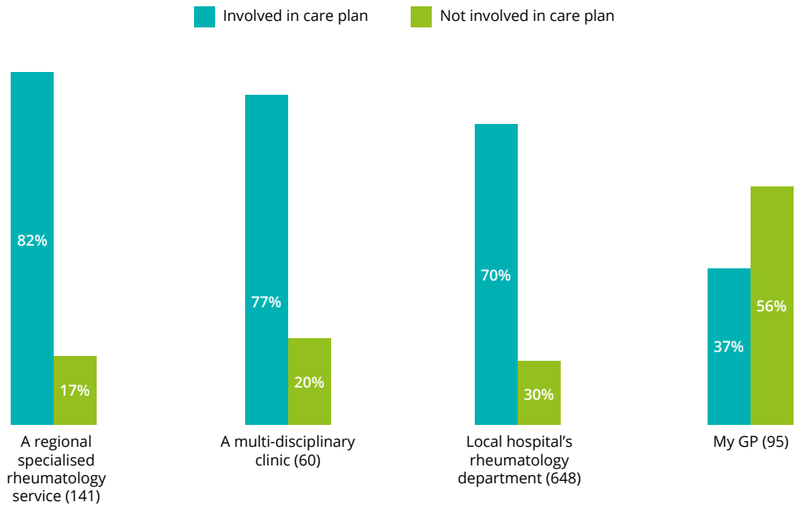
Responsibility for care

Respondents who reported that their GP is responsible for their care were far less likely to report being involved in care planning, than those who reported that multi-speciality clinics or rheumatology services are responsible for their care (Figure 3.3).

[10] For the purpose of this analysis, data from the 2024 survey have been carefully filtered to match the criteria used in the 2018 report, which exclusively included respondents diagnosed with lupus, sclerosis, and vasculitis. This approach ensures that any comparative analysis between the 2018 and 2024 datasets is conducted on a consistent basis, focusing only on these specific conditions. It is important to note that neither dataset has been weighted, which may result in demographic differences among respondent profiles. Therefore, any findings should be considered as indicative.

Figure 3.3: Impact of responsibility of care on agreeing a care plan

Q11. Still thinking about your primary diagnosis, from your understanding, which service or team is mainly responsible for the care of your disease? Base: all participants (1352). Source: Ipsos.



3.7 Impact of involvement in care planning

Respondents who reported that they were involved in agreeing a plan for their care and treatment were significantly more likely to report that they *'definitely'* had access to enough information and support about their condition (50%) compared with those who said they were not involved at all (3%). This highlights the importance of including patients in planning for their care and treatment where they would like to be, to ensure that they feel supported and have sufficient information.

Further, respondents who reported that they are involved as much as they want to be in their care are more likely to report that they are managing well day-to-day with their condition – 83%, compared to 65% of those who did not feel they were as involved in their care planning as they would like to be.

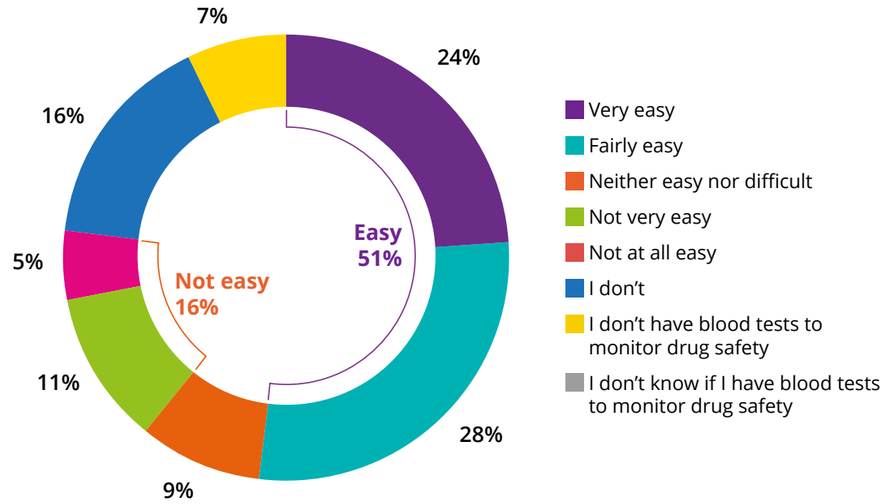
3.8 Monitoring of medication

Blood tests to monitor drug safety can be an important part of disease management for people with RAIRDs.

Half of all respondents (51%) reported that they find it easy to access blood tests for drug safety monitoring; however, 16% find this difficult.

Of respondents who reported that they have blood tests to monitor drug safety, 22% find it difficult to access them.

Figure 3.4: Ease of access to blood tests to monitor drug safety



Q17. How easy or not do you find it to access blood test to monitor your drug safety?
Base: all participants (1352). Source: Ipsos.

3.9 Conclusion

As outlined in this chapter, people with RAIRDs do not always feel confident that their healthcare professionals work well together on their care.

Respondents feel more positive about how healthcare professionals work together, when they receive care from a multi-speciality clinic, a specialised service, or their local hospital's rheumatology department, compared to when care is coordinated by a GP, or by patients themselves. Further, there are some particularly acute concerns about GPs' understanding of these rare conditions.

Most patients with RAIRDs want to be involved with planning for their care, and actively involving patients in developing their care plans appears to contribute to respondents coping better with their condition. However, it appears that patients cannot always be as involved in their care planning as they would like to be.

Recommendations from RAIRDA:

- Ensure every person living with a RAIRD has a named person responsible for coordinating their care, to include coordinating an annual review of a patient's care, to be held in-person if possible.
- Ensure multi-speciality clinics are available, to ensure proper communication across specialities, well-coordinated care, and less travel and fewer appointments for the patient.
- Allocate resource for the development and ongoing management of specialised networks, including specialised rheumatology networks, to increase healthcare practitioner knowledge and expertise in supporting people with complex conditions such as RAIRDs.

4 Information and Support

4.1 Access to information and support

As RAIRDs are rare, often debilitating conditions, it's key that patients can access timely, reliable information and support for their conditions. However, survey findings show that this need for information is not being met for all respondents.

> ***"Much of my disease management is through my own research… I worry about those less able to do this research for themselves."***
>
> Respondent with lupus, Raynaud's disease, undifferentiated or overlap mixed tissue disease

Just 16% of respondents to the survey felt that they definitely had access to enough information and support about their condition, although a further 48% said that they did, at least to some extent.

Around one in three (35%) reported they definitely did not have access to enough information and support.

> ***"There has been no emotional/mental support at all, I did ask for it."***
>
> Respondent with lupus

Impact of access to support and information

Respondents who felt they did not have access to enough information and support were more likely to report that their condition has had a negative impact on their emotional and mental well-being (83%) and that they are not managing well day-to-day (62%), compared to those who felt that they did have enough information.

4.2 Sources of information and support

Over three in five respondents (64%) have accessed information and support via their consultant during an appointment, and almost half (47%) have used patient organisations for information and support.

A large number have utilised online resources: two thirds (67%) have done an internet search; half have used social media (50%) and one in three (33%) have used online support and discussion groups.[11]

Specialist nurses

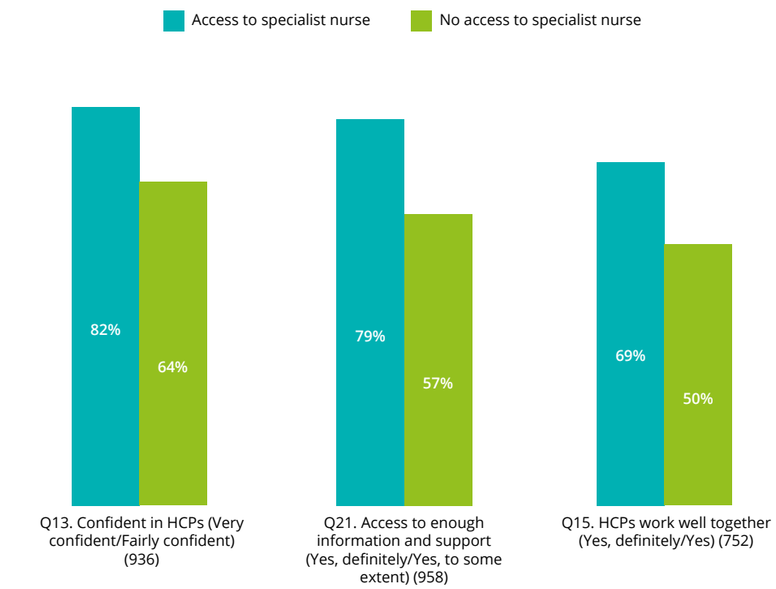
Just 23% of patients had accessed information and support via hospital-based advice lines, and 28% through a specialist nurse, despite the important role a specialist nurse with expert knowledge can play in supporting patients and their families with RAIRDs.

Respondents with access to a specialist nurse were more likely to report that they had access to enough information and support about their condition (78%), they were confident in their HCPs understanding of their condition and needs (82%), and that they felt HCPs caring for them work well together (69%), compared to those who did not have access to a specialist nurse (Figure 4.1).

[11] See Figure 7.5

> ***"I think ready access to specialist nurses really helps me to cope with chronic illness since any concerns can be raised quickly allowing me to focus on day-to-day life rather than my illness."***
>
> Respondent with Sjögren's disease, systemic vasculitis and Raynaud's disease

Figure 4.1: Impact of access to specialist nurses



Q13. Thinking more generally about your primary diagnosis, how confident or not are you that the specialist healthcare professionals you engage with understand your disease and needs? Base: all participants (1352).

Q15. Do all the different health professionals, caring for you all work well together to give you the best possible care and support for this diagnosis? Base: all participants (1352).

Q21. Do you feel you currently have access to enough information and support about your disease(s)? Base: all participants (1352). Source: Ipsos.

Further, access to specialist nurses seems to have declined for lupus, systemic sclerosis and vasculitis since the 2018 RAIRDA survey, which found that 37% report that their care is supported by a specialist nurse, compared to 32% in 2024 (for those with lupus, systemic sclerosis and vasculitis).[12]

Where respondents had accessed a specialist nurse, over three in five (63%) found it easy to contact them; however, one in five (20%) found it difficult. While the numbers using specialist nurses by condition type are very small and should be treated with caution, respondents with vasculitis who had used a specialist nurse (26%) were particularly likely to report they found it easy to contact them (74%).

[12] For the purpose of this analysis, data from the 2024 survey have been carefully filtered to match the criteria used in the 2018 report, which exclusively included respondents diagnosed with lupus, systemic sclerosis, and vasculitis. This approach ensures that any comparative analysis between the 2018 and 2024 datasets is conducted on a consistent basis, focusing only on these specific conditions. It is important to note that neither dataset has been weighted, which may result in demographic differences among respondent profiles. Therefore, any findings should be considered as indicative.

4.3 Access to advice from hospitals

Timely advice is particularly important for people living with RAIRDs, who are likely to experience flare-ups in their condition and may need support and treatment at short notice. However, the survey highlights considerable variation in experience when respondents try to access advice from their hospital.

24% of respondents reported that they were never, or almost never, able to access advice from their hospital within 48 hours when experiencing an issue. Just 15% of respondents could access advice and support within 48 hours when experiencing issues with their disease or treatment.

Just 15% of respondents could access urgent advice and support within 48 hours

Q20. How often are you able to get advice within 48 hours from your hospital when you experience issues with your disease(s) or treatment between appointments? Base: all participants (1352).

> ***"I never have access to get hold of any consultant / nurse if I need help, it's email to a central location that probably won't be looked at for 3/5 days then, they don't reply, same with telephone numbers, leave a message no one calls back."***
>
> Respondent with lupus, APS and Raynaud's

4.4 Access to support with diet and nutrition

Both exercise and dietary modifications can play a role in managing RAIRDs[13], as well as the general health and wellbeing of a person living with a chronic condition. Yet despite the importance of information on exercise and nutrition, over three quarters of respondents (77%) report that they haven't received any support in these areas.

Concerningly, the number of respondents receiving support on exercising appears to have declined since the 2018 RAIRDA survey[14], which found that 23% had received advice on exercising, compared to 6% in 2024 (for those with lupus, sclerosis and vasculitis).

Similarly, the number of respondents receiving support on nutrition and diet management also appears to have declined since 2018, with 13% receiving this support in 2018, compared to only 7% in 2024.

[13] Levy, B., 'Exercise Energizes Patients With Autoimmune Disease,' from NIH Intramural Research Program, I Am Intramural Blog (February 2023), available at: https://irp.nih.gov/blog/post/2023/02/exercise-energizes-patients-with-autoimmune-disease.

[14] For the purpose of this analysis, data from the 2024 survey have been carefully filtered to match the criteria used in the 2018 report, which exclusively included respondents diagnosed with lupus, sclerosis, and vasculitis. This approach ensures that any comparative analysis between the 2018 and 2024 datasets is conducted on a consistent basis, focusing only on these specific conditions. It is important to note that neither dataset has been weighted, which may result in demographic differences among respondent profiles. Therefore, any findings should be considered as indicative.

4.5 Conclusion

Respondents were keen to access information and support for their condition and were proactively accessing information and support through a variety of channels including formal, informal and online resources.

However, over a third of respondents reported that they do not have access to enough information and support, and access to specialist nurses or advice on diet and nutrition was limited.

This lack of information appears to be linked to a negative impact on respondents' emotional and mental well-being, and whether they are managing well day-to-day, emphasising the importance of ensuring adequate information and support for all RAIRD patients.

Recommendations from RAIRDA:

- Recognise patient organisations as information partners with clear and ongoing lines of communication with named officials within each nation's health department, to ensure patients have access to all available support. Healthcare professionals in both primary and secondary care should be encouraged to engage with the wealth of materials provided by patient organisations – both as resources for their own practice, and for signposting to patients e.g. patient advice lines, information leaflets and support groups.
- Improve patient access to specialist nurses, by increasing opportunities and funding for training and recruitment for these roles, supported by the Department for Health and Social Care, and national health services.

5 Quality of Life

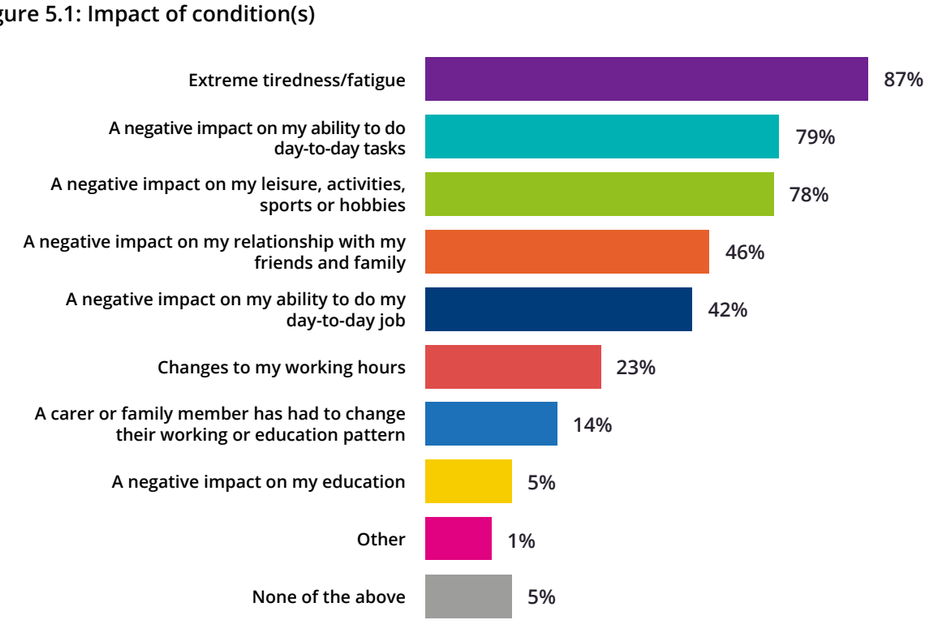
5.1 Overall impact of having a RAIRD

Almost all respondents (95%) reported that their RAIRD has negatively affected their life in some way over the last 12 months. On average, respondents highlighted four areas where their condition had negatively impacted them.

Extreme tiredness (87%) was the most reported issue, closely followed by a negative impact on their ability to do day-to-day tasks (79%) and a negative impact on leisure activities, sports or hobbies (78%) as shown in Figure 5.1. RAIRDs affect personal relationships for many (46%), particularly for those in the middle age groups (55% aged 35-44 and 58% aged 45-54).

> ***"It is just very difficult to get anybody to understand fully the impact Lupus fatigue has on the body and lack of sleep that effects your day-to-day living. That in itself without anything else going on has a major effect on quality of life and coping with it all."***
>
> Respondent with lupus and Raynaud's disease

Figure 5.1: Impact of condition(s)



Q3. Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)? Base: all participants (1352). Source: Ipsos.

The majority of respondents (73%) reported that their RAIRD negatively affects their emotional and mental well-being, with three in ten (31%) reporting a very negative impact.[15]

[15] See figure 7.6

95%
reported their condition had a negative impact on their life

Q23. Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)?
Base: All participants (1352)

73%
reported a negative impact on their emotional and mental wellbeing

Q25. To what extent have all of your rare autoimmune disease(s) had a positive or negative impact on your emotional and mental well-being?
Base: All participants (1352)

> ***"I think the mental health aspect and diet/exercise is not ever covered or mentioned. The social and personal impact of these diseases are not considered... it is the everyday, the mundane stuff that really gets you down."***
>
> Respondent with systemic vasculitis and undifferentiated or overlap connective tissue disease

We know from previous chapters that good care can have a significant impact on quality of life for people living with RAIRDs. Those who see a consultant quickly, have well-coordinated care across multiple providers, are involved in decisions about their care, and have access to specialist nurses, typically report more positive outcomes in terms of impact on their life and their ability to manage their condition day-to-day.

5.2 Managing day-to-day with their RAIRD(s)

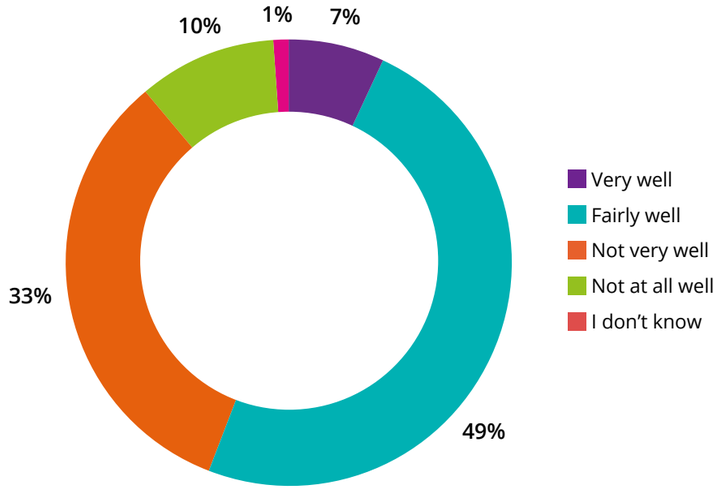
43%
reported they were not managing well

Despite almost all respondents reporting their RAIRD had negatively impacted their life over the last 12 months, over half (56%) reported they were managing well day-to-day with their condition (Figure 5.2).

However, this leaves a large group of respondents (43%) who were not managing well, of whom 1 in 10 (10%) reported they are not managing at all well. These findings are echoed in the free text section of the survey, where almost one in ten (8%) spontaneously reported that they feel they have been left to cope alone and need more support in managing with their condition(s).

> ***"[I] Need more help in managing day-to-day."***
>
> Respondent with a form of systemic sclerosis or scleroderma and Raynaud's disease

Figure 5.2: How well respondents are managing day-to-day with their conditions

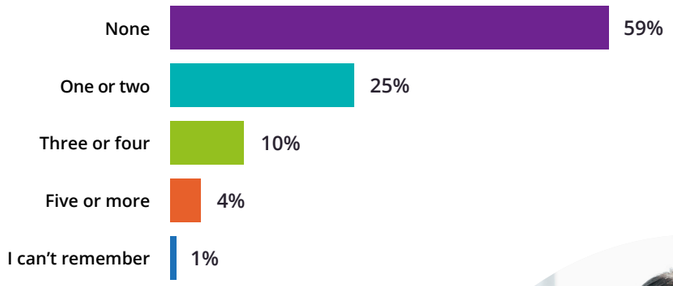


Q26. Over the last 12 months, hell, well, if at all, do you feel you have been managing day today with all of your rare autoimmune disease(s)? Base: all participants (1352). Source: Ipsos.

5.3 Unplanned hospital visits

There was a wide range of experiences for unplanned hospital visits. While three in five (59%) respondents have not had any unplanned hospital visits, 14% of respondents reported having had three or more visits in the last year (Figure 5.3).

Figure 5.3: Unplanned hospital visits in the last year



Q24. Thinking specifically about all of your rare, autoimmune disease(s), how many unplanned hospital visits have you made in the last year? Base: all participants (1352). Source: Ipsos.

5.4 Impact on people of working age

Over two thirds of survey respondents (69%) were of working age (aged 16-64). While over half of this group (55%) reported they are currently in full-time or part-time work, over a quarter (27%) were unable to work due to long-term sickness or disability (Table 5.1).

The proportion who were unable to work varied by condition; those with lupus (31%), systemic sclerosis (29%) and vasculitis (26%) were amongst the most likely to say they were unable to work due to long-term sickness or disability (see appendix table 6.8 for more information).

Table 5.1: Working status of respondents of working age

Working status	Overall (938)
In full-time/ part-time work	55%
Unable to work due to long-term sickness or disability	27%
Fully retired from work	9%
Other (Education, unemployed, looking after family/ home, other)	9%

Respondents in full-time and part-time work

Many working people reported that their RAIRD has impacted their work in some way. Almost two in three (66%) reported a negative impact on their ability to carry out their day-to-day job and two in five (40%) reported they have made changes to their working hours because of their condition.

66%
of working individuals said their condition affects their ability to perform their job effectively

40%
of working individuals have made changes to their working hours due to their condition

Q23. Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)? Base: Respondents of working age in full-time/ part-time work (516).

Respondents unable to work due to long-term sickness or disability

It is clear that for some people with RAIRDs, the impact on their life can be significant. The respondents who were most severely affected by their condition were also the most likely to say that they were unable to work. For example, almost all (98%) of those unable to work due to long-term sickness stated their condition had negatively contributed to extreme tiredness and fatigue.

This group were also more likely to report a negative ability to do day-to-day tasks (96%) and their relationships with friends and family (73%) compared to those who did not report they were unable to work due to long-term sickness or disability.

> ***"I have just given up my job as a teacher as I cannot cope physically anymore."***
>
> Respondent with systemic vasculitis and Raynaud's disease

The findings also suggest that a delayed diagnosis may be linked to an individual's ability to work; a third (32%) of those who waited more than 5 years for a diagnosis reported being unable to work due to health reasons, compared to a quarter (24%) who were diagnosed in under 5 years.

5.5 Conclusion

The majority of respondents reported that their condition had negatively impacted their life over the last 12 months. Tiredness, an impact on the ability to carry out day-to-day tasks and leisure activities are the most commonly cited issues.

For working people, their condition has often led to a change in working hours, along with a reduction in their ability to carry out their day-to-day job – this was exacerbated for those who experienced a long period of time between first experiencing symptoms and receiving a diagnosis.

Recommendations from RAIRDA:

- Ensure patients have access to a good-quality, well-managed and well-staffed advice line, as a first point of contact for any issues which may arise, to prevent people in crisis going untreated, or forcing them to access less appropriate services.
- Ensure that patients with RAIRDs have access to holistic support, which must include effective psychological support, as well as nutrition and physical activity where appropriate.
- Assessment of welfare support for people with RAIRDs by policymakers must take into account the varied, often severe, impacts of these conditions when looking at how working people can be best supported.

6 Appendix A

Table 6.1: Primary Diagnosis

Primary diagnosis	Number of respondents (1352)	Percentage
Antiphospholipid syndrome (APS)	77	6%
Form of systemic sclerosis or scleroderma	270	20%
Form of systemic vasculitis	260	19%
Lupus	320	24%
Myositis/inflammatory muscle condition	77	6%
Raynaud's disease	115	9%
Sjögren's disease	151	11%
Undifferentiated or overlap connective tissue disease	82	6%

Please note, this table outlines the primary diagnosis of all respondents. In cases where a respondent has more than one condition, they were asked to select which they would consider to be their primary diagnosis. By primary diagnosis, we mean the rare autoimmune disease respondents receive the most care and support for.

Table 6.2: Secondary Diagnosis

Secondary diagnosis	Number of respondents (709)	Percentage
Antiphospholipid syndrome (APS)	42	3%
Form of systemic sclerosis or scleroderma	50	4%
Form of systemic vasculitis	8	1%
Lupus	44	3%
Myositis/inflammatory muscle condition	16	1%
Raynaud's disease	383	28%
Sjögren's disease	116	9%
Undifferentiated or overlap connective tissue disease	50	4%

Please note, this table outlines the secondary diagnosis of respondents with two or more conditions. After a respondent with 2 or more conditions selected their primary condition, their secondary condition was assigned randomly out of the remaining conditions.

Table 6.3: Combined diagnosis

Combined diagnosis	Number of respondents (1352)	Percentage
Antiphospholipid syndrome (APS)	151	11%
Form of systemic sclerosis or scleroderma	350	26%
Form of systemic vasculitis	287	21%
Lupus	398	29%
Myositis/inflammatory muscle condition	116	9%
Raynaud's disease	649	48%
Sjögren's disease	366	27%
Undifferentiated or overlap connective tissue disease	193	14%

Please note, this table outlines the combined diagnosis of all respondents and includes all the different conditions respondents report that they have been diagnosed with. Respondents were able to select multiple conditions, therefore, the percentage total is greater than 100%.

Table 6.4: Year of diagnosis

Year of diagnosis	Number of respondents (1352)	Percentage
2024	55	4%
2022 – 2023	249	18%
2020 – 2021	161	12%
2018 – 2019	144	11%
2016 – 2017	131	10%
2011 – 2015	236	17%
2006 – 2010	109	8%
2001 – 2005	72	5%
1991 – 2000	115	9%
1981 – 1990	31	2%
1980 or before	20	1%

Please note, this table outlines the secondary diagnosis of respondents with two or more conditions. After a respondent with 2 or more conditions selected their primary condition, their secondary condition was assigned randomly out of the remaining conditions.

Table 6.5: Gender

Gender	Number of respondents (1352)	Percentage
Man	120	9%
Woman	1228	91%
Non-binary	2	<1%

Table 6.6: Age

Age	Number of respondents (1352)	Percentage
16-24	23	2%
25-34	76	6%
35-44	150	11%
45-54	271	20%
55-64	418	31%
65-74	292	22%
75-84	112	8%
85 or over	10	1%

Table 6.7: Working status

Working status	Number of respondents (1352)	Percentage
Employed, including self-employment	550	42%
In full-time education at school, college or university	17	1%
Looking after family or home	42	3%
Retired	431	32%
Unable to work due to long-term sickness or disability	272	20%
Unemployed	13	1%

Table 6.8: Working status by condition

Condition	Number of respondents (1352)	Unable to work due to long-term sickness	Retired	Other (education, unemployed, looking after family/ home, other)
Antiphospholipid syndrome (APS) (68)	151	35%	3%	7%
Form of systemic sclerosis or scleroderma (153)	350	29%	10%	8%
Form of systemic vasculitis (195)	287	26%	8%	6%
Lupus (254)	398	31%	8%	9%
Myositis/inflammatory muscle condition (53)	116	13%	19%	11%
Raynaud's disease (68)	649	16%	6%	12%
Sjögren's disease (73)	366	23%	15%	8%
Undifferentiated or overlap connective tissue disease (71)	193	32%	7%	13%

Table 6.9: Ethnicity

Ethnicity	Number of respondents (1352)	Percentage
White (inc. white minorities)	1230	91%
Ethnic minorities (exc. white minorities)	114	8%

Table 6.10: Country

Country	Number of respondents (1352)	Percentage
England	1112	82%
Northern Ireland	29	2%
Scotland	117	9%
Wales	71	5%

Table 6.11: Index of Multiple Deprivation (IMD) Quintile:

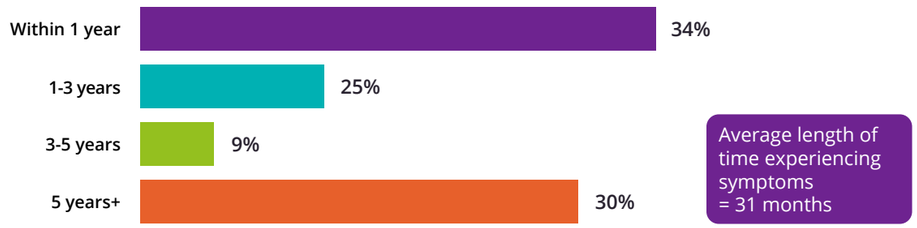
IMD Quintile	Number of respondents who provided postcode information (1158)	Percentage
1	116	9%
2	173	13%
3	270	20%
4	304	22%
5	295	22%

Table 6.12: Travel time to see a specialist

Travel time	Number of respondents (1352)	Percentage
Under 30 minutes	401	30%
31 minutes to 60 minutes	540	40%
61 minutes up to 90 minutes	169	13%
91 minutes up to 2 hours	61	5%
Over 2 hours, up to 3 hours	36	3%
Over 3 hours	39	3%
My appointments take place virtually	21	2%

7 Appendix B (charts)

Figure 7.1: Length of time experiencing symptoms before primary diagnosis



Q9. How long before this diagnosis were you experiencing symptoms, if at all? Base: all participants (1352). Source: Ipsos.

Figure 7.2: Wait time between referral and appointment with specialist

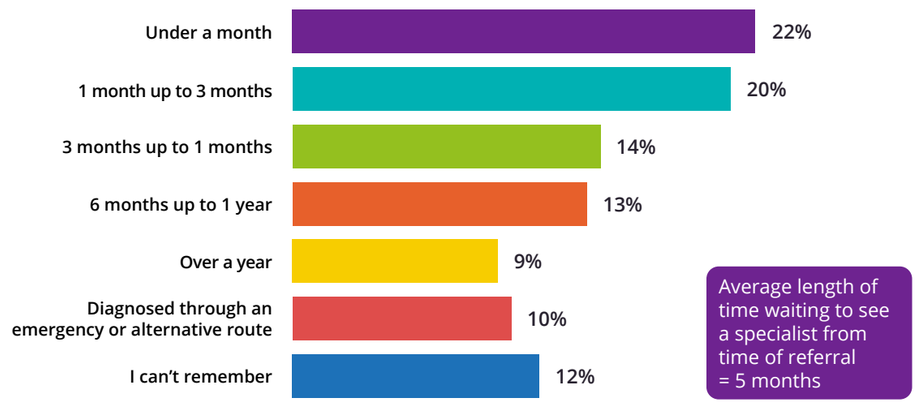
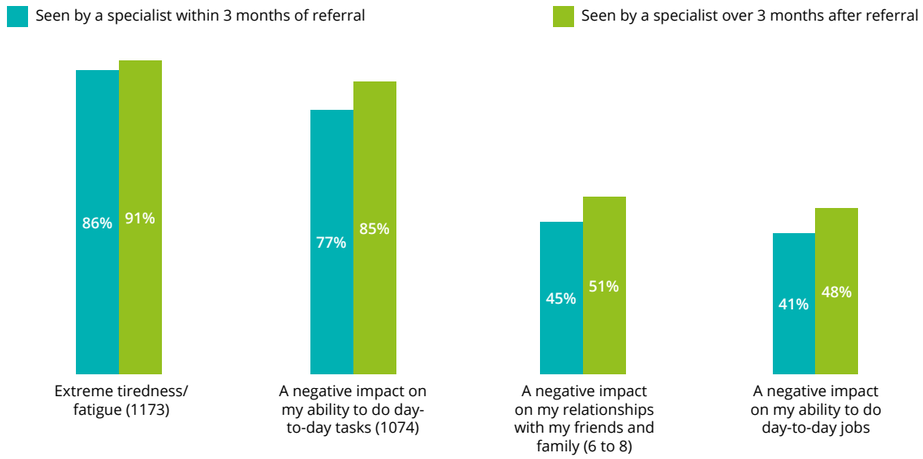
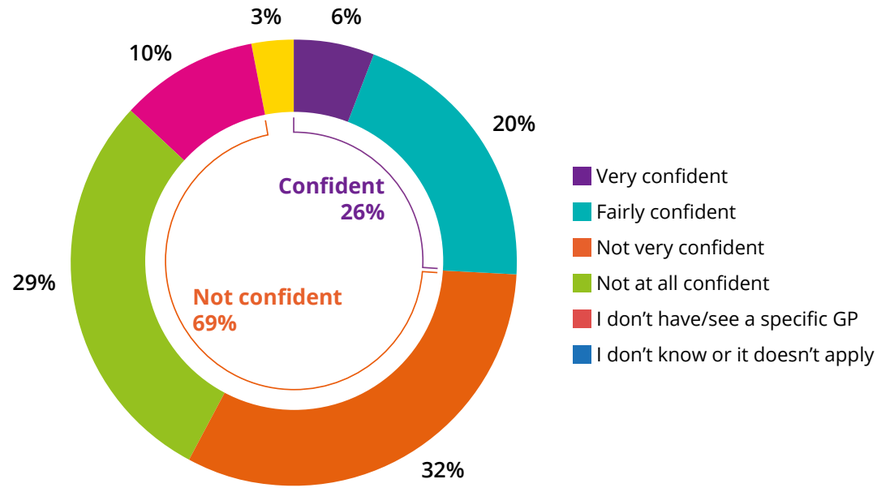


Figure 7.3: Impact of waiting times to see a specialist



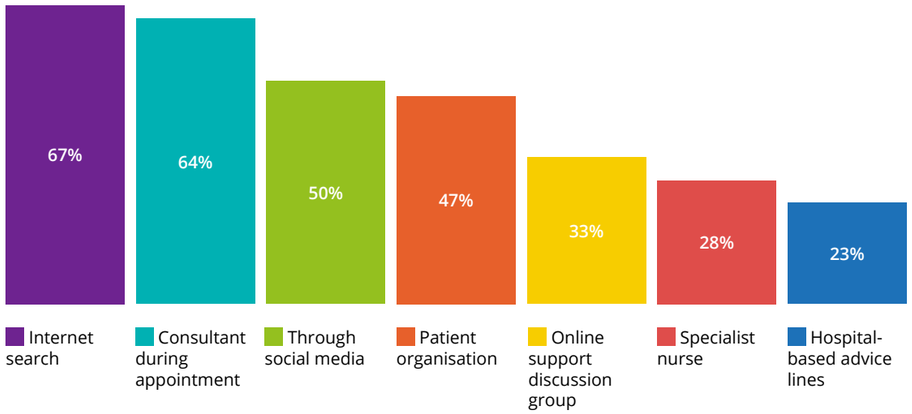
Q23. Which of the following, if any, have you experienced in the last 12 months as a result of your rare autoimmune disease(s)? Base: all participants (1352). Source: Ipsos.

Figure 7.4: Respondent confidence in GPs



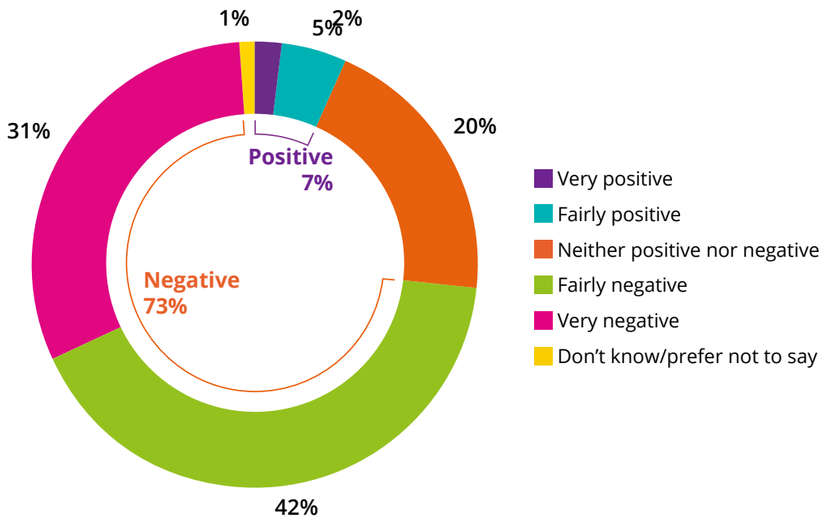
Q12. How confident or not are you that your GP understand your primary diagnosis and your needs for this diagnosis? Base: all participants (1352). Source: Ipsos.

Figure 7.5: Ways respondents have accessed support



Q12. How confident or not are you that your GP understand your primary diagnosis and your needs for this diagnosis? Base: all participants (1352). Source: Ipsos.

Figure 7.6: Impact on emotional and mental wellbeing



Q25. To what extent have all of your rare autoimmune disease(s) had a positive or negative impact on your emotional and mental well-being? Base: all participants (1352). Source: Ipsos.

RAIRDA
Rare Autoimmune Rheumatic Disease Alliance

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 Board members

Sue Farrington - SR UK (RAIRDA Co-Chair); **Bridget Griffiths** (RAIRDA Co-Chair); **Caroline Olshewsky** - Lupus UK; **Pat Wolstenholme** - Sjögren's UK; **Zoi Anastasa** - Vasculitis UK; **Dr Peter Glennon**; **Dr Peter Lanyon**; **Dr Elizabeth Price**.

RAIRDA member organisations

Sjögren's UK

LUPUS UK

VASCULITIS UK

SCLERODERMA & RAYNAUD'S UK