The Scottish Report

A Scotland-wide survey of people with immune mediated inflammatory diseases to gather their experiences of accessing NHS services, treatment and healthcare.

SPRING 2026

nras National Rheumatoid Arthritis Society

JIA at NRAS

CROHN'S & COLITIS UK

Lupus UK

NASS Axial SpA works silently. We don't.

psoriasis association

ABOUT NRAS

The National Rheumatoid Arthritis Society (NRAS) is the only patient-led charity in the UK focusing specifically on rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA), including adult JIA. We provide information and support services for those affected by RA and JIA, their families, friends, carers and health professionals and are supported by an advisory board of medical and healthcare professionals.

We were pleased to join forces with Crohn's & Colitis UK, Lupus UK, National Axial Spondyloarthritis Society and the Psoriasis Association to undertake this Scotland-wide survey of people with immune mediated inflammatory disease. All 5 organisations contributed to developing the survey and had input to the final report.

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Introduction

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Following the publication of our survey of people with inflammatory arthritis across Wales in Spring 2025 , we felt it was important and the timing was right to do a major survey of people with inflammatory arthritis across Scotland. We were delighted that Crohn's & Colitis UK, Lupus UK, National Axial Spondyloarthritis Society and the Psoriasis Association all agreed to collaborate in this survey so that we could extend the reach to include the common immune mediated inflammatory diseases.

Our joint report is timely as the Scottish Government published a Population Health Framework in June 2025. The Population Health Framework sets out the Scottish Government's and the Convention of Scottish Local Authorities' (COSLA's) long-term collective approach to improving Scotland's health and reducing health inequalities for the next decade. The framework goes hand in hand with The Service Renewal Framework outlining a long-term strategy to reshape how health and social care services are planned, delivered, and experienced. The interim publication of the consultation response to the Long-Term Conditions Consultation published end of last year is also very relevant to the results of this survey.

National patient organisations and local community organisations have a pivotal role to play, alongside health professionals, in supporting people with IMIDs. In our survey, it is clear that the majority of respondents want greater access to education about their disease as well as being signposted to sources of supported self-management services and resources.

All patient organisations involved in this survey know how hard health professionals are working, appreciate their commitment, and understand the challenges the NHS is dealing with. Our goal is to support and work with health professionals as well as our respective beneficiaries. On behalf of the organisations who collaborated on this survey, we look forward to working with all stakeholders in the IMID community to improve the lives of people in Scotland living with these life-long conditions.

Foreword

Iain McInnes
University of Glasgow
NRAS Scottish Patron

"If you want to go fast, go alone; if you want to go far, travel together."

This African wisdom reminds us of the critical role of partnership and the necessity for a bold, common vision if one seeks transformational change. This is especially the case if one desires to positively inform and impact the delivery of health care, and thereby of wellness, to people with immune-mediated inflammatory diseases. In this spirit, it is a particular pleasure to offer a foreword to "The Scottish Report".

Immune-mediated inflammatory diseases (IMIDs) comprise a broad range of chronic disorders that together affect up to 10% of the population. As such, they are amongst the commonest causes of chronic disease at the global level. IMIDs lead to substantial disability and loss of quality of life and impose a costly burden on afflicted individuals, their families, health care systems ('The NHS') and wider society. They are more common in the most economically disadvantaged in society and contribute thereby to health inequalities. Until recently they were considered primarily as isolated entities – only by bringing together the collective burden of disease imposed by this broad range of disorders can their true impact and importance be properly realised.

IMIDs are united by common cause – literally and figuratively. They share pathogenetic causative mechanisms causing clinical features, often following a remitting relapsing pattern characterised by apparently inexorable decline. They include conditions such as rheumatoid arthritis, axial spondyloarthritis, systemic lupus erythematosis, psoriatic disease, diabetes, Crohn's Disease, ulcerative colitis amongst many others. IMIDs arise in different organs when the immune system acts abnormally to promote inflammation – in essence, the immune system turns its attention from its essential role of defence again infection and cancer, towards attack wrought against our own tissues. This causes damage and often irreversible functional loss.

In the last two decades, the treatment of IMIDs has been revolutionised by the advent of new classes of medicines that target the 'unbalanced immune system' with exquisite specificity. These remarkable therapeutics reduce inflammatory symptoms and signs, protect vital organs from damage and in many cases, their use can lead to substantial functional improvements for individuals, and even long-term remission. Appropriately utilised and supervised, therapeutic immune modification can transform lives. Universally, optimal treatment of IMIDs in the 21st century requires input from many disciplines – with specialists across traditional 'ologies' now working together to maximise the outcomes for affected people. Expert teams comprise doctors, nurses, other health professionals and social care experts working in a team surrounding the most important person of all – those with IMIDs. This begs the obvious question, namely the extent to which an already pressed NHS has adapted to these opportunities to deliver the care and possibility conferred upon people with IMIDs by extraordinary, science-driven therapeutic advances?

Just as the clinical community has recognised the value of coming together around the IMIDs, so too, this coalition of disease relevant charities, catalysed by NRAS, is a welcome invention. Bringing together the convening power of several charity voices to collective advocacy, enquiry and interrogation of the provision of services is compelling and reminds us of the value of including patient organisations in the team surrounding the patients. The exciting result is 'The Scottish Report'. This document presents the voice of the IMID patient with resonance and clarity. Challenges clearly emerge around delays in diagnosis and the provision of consistent long-term disease care. Unmet needs in patient education and self-management are highlighted which the patient organisations are well placed to support. These require attention and due consideration. This report should not be perceived however, as a 'Scots' lament'. Rather it is a call to action to ensure that the opportunities engendered by extraordinary scientific, clinical and strategic advances in the IMIDs deliver a vision that transforms the outcomes for people affected by these pervasive disorders.

Summary

A total of 1,339 individuals responded to the survey, and of those, 1,256 were eligible and completed all relevant questions.

Delays to diagnosis

- 55% of people had more than 3 visits to GP before a referral was made.
- 68% of referrals were delayed waiting for test results.
- More than a quarter of respondents are being seen and treated outside of the 18-week Referral to Treatment (RTT) standard of NHS Scotland.
- Of those reporting RA as their main condition, only 29% reported being seen by secondary care within 6 weeks.
- Of the 7% of people who chose a private appointment for an initial diagnosis, 56% said it was due to long waiting times in the NHS.

Patient support and education

- 45% of people were not referred to any patient organisations and 9% can't remember whether they were or not.
- 65% would welcome further education about their condition (although this jumps up to 76% if we filter people diagnosed within the last 5 years).
- For those diagnosed with in the last 5 years, there has been an increase in GPs referring patients for physio whilst they await secondary care appointment: >5 years 8% and <5 years 33%.

Disease management

- 65% feel their condition is either unstable or has room for improvement.
- 73% of people feel their condition impacts their quality of life 'a moderate amount' or 'a great deal'.
- 53% of people feel their condition reduces their ability to carry out day-to-day activities every day or at least a few days a week.
- 33% reported that they did not have access to the wider members of the Multi-Disciplinary Team (MDT) ; especially, for people living in more rural areas.
- Only 11% of people diagnosed with RA, reporting annual/ periodic reviews with health professionals.
- Only 8% of people report being on a PIR pathway.

Self-management skills

- Only 25% of people diagnosed in the last 5 years consider themselves to be 'very' or 'completely' confident in their ability to self-manage their condition.
- 47% of all people said biggest barrier to self-management is lack of knowledge.
- 82% of respondents said that they did not undertake any kind of tracking or self-monitoring of symptoms or their condition more widely.

Background and Aims

Immune Mediated Inflammatory Diseases (IMIDs) is an umbrella term which includes a wide group of autoimmune conditions which share common inflammatory pathways, meaning that people with one IMID are at higher risk of developing another. Overall, there are more than 80 different IMID conditions affecting around 10% of the population and they can be wide ranging in their symptoms and impact. The chronic systemic inflammation involved in IMIDs where the immune system is triggered into attacking healthy tissue, can lead to eventual tissue damage and disability.

Most of these conditions are whole system diseases, which means that skin, joints and organs can be affected, involving distinct specialities such as Rheumatology, Gastroenterology, Dermatology and Ophthalmology. The economic cost of IMIDs is high: both to the individual but also in healthcare resources and lost productivity. There is significant unmet need in terms of clinical outcomes and patient satisfaction for people living with these complex conditions, which have a major impact on quality of life.

The National Rheumatoid Arthritis Society (NRAS) led this Scotland-wide descriptive survey and collaborated with other IMID organisations: Crohn's and Colitis UK, Lupus UK, the National Axial Spondyloarthritis Society and the Psoriasis Association. The aim was to survey people living with the range of conditions outlined in Appendix 1, to gather their experiences of the NHS services, treatment and healthcare they are receiving. We also wanted to understand if they were being signposted and referred to the wide-ranging support on offer to people from the patient organisations involved or others. For full details of the different forms of IMID conditions included in our survey, please see Appendix 1.

Survey

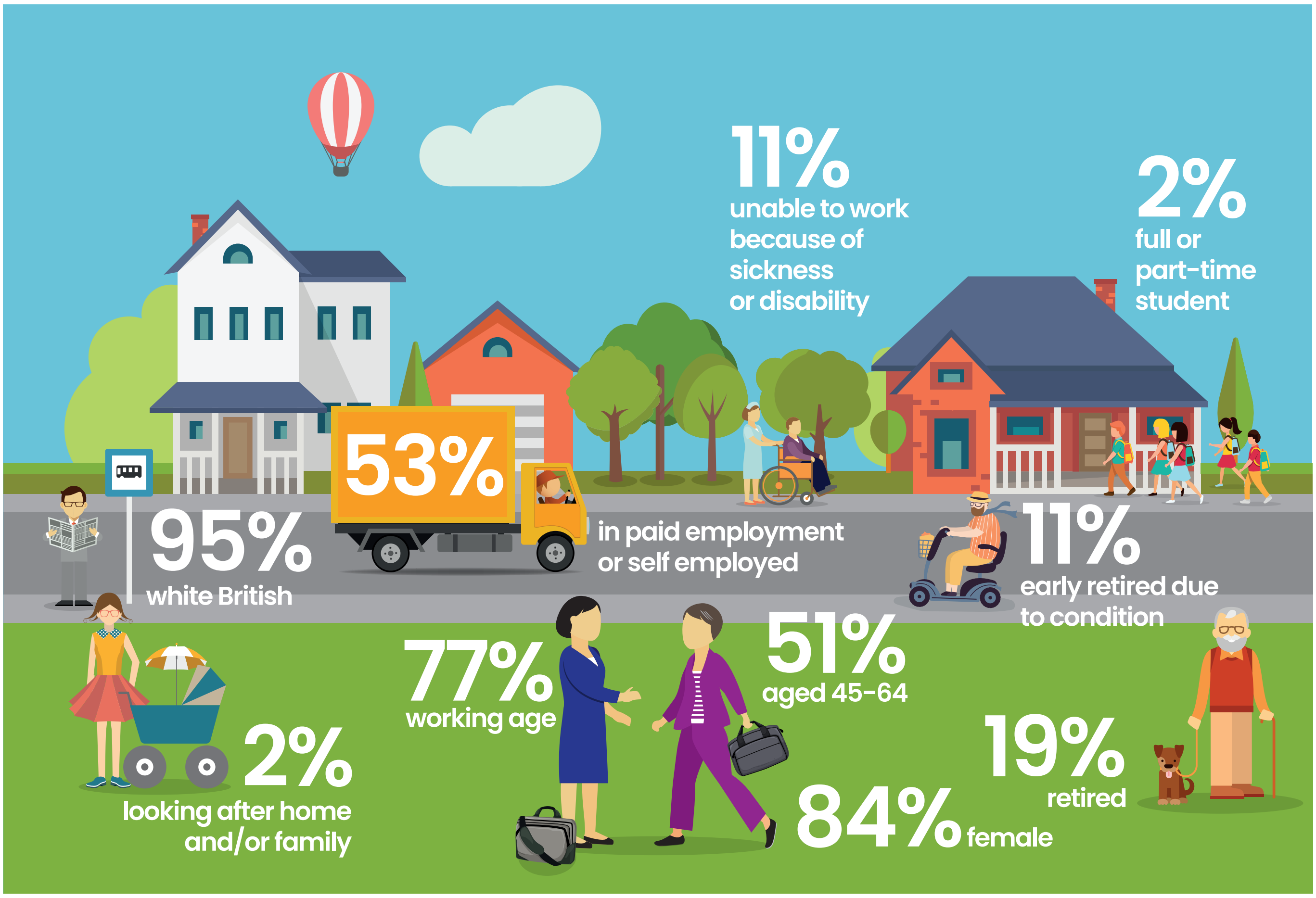
The survey asked questions about people's experiences of being diagnosed and the ongoing management of their Immune Mediated Inflammatory Disease (IMID) comprising 7 main sections:

1. Eligibility
2. About you/r condition
3. Diagnosis to Treatment
4. Supported self-management
5. Ongoing Care
6. Condition Specific Questions
7. Additional Information and Demographics.

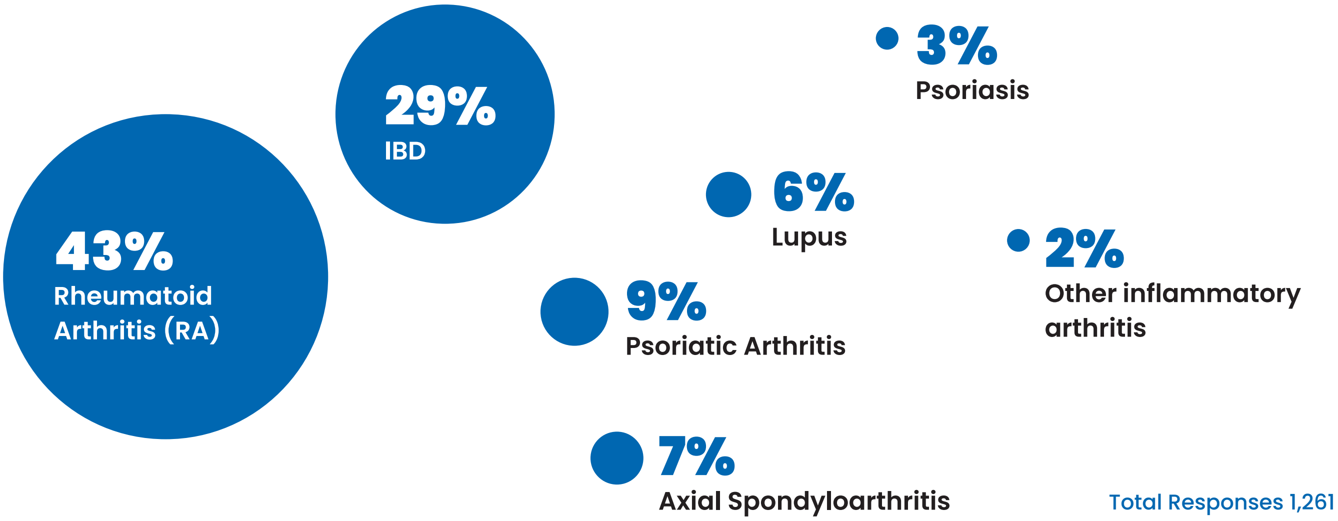
Participants

1,256 eligible participants completed all relevant questions.

Most of the respondents were female (n=1057, 84%), White British (n=1198, 95%) and aged between 45-64 years (n=645, 51%). This percentage split was expected as many of the conditions are more prevalent in women. 77% of participants were of working age and 53% were in paid employment. 22% were unable to work due to sickness/disability or had retired early due to their disease. Further demographic breakdown is available on request.



The number of different IMID reported by participants was:



A detailed list of all conditions involved can be found at Appendix 1. Most individuals had a disease duration of over 5 years (n=852, 68%) with only 7% being diagnosed for 1 year or less.

All Health Boards across Scotland were represented, with NHS Lothian and NHS Greater Glasgow and Clyde having the highest percentage of responses, which is expected given their population density and geographical location. A comparably smaller response was received from the Western Isles, Shetland and Orkney which is in keeping with the rurality of these areas and lower population density.

Key findings and recommendations

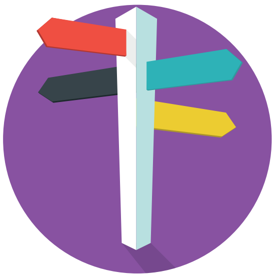
When analysing the results, 5 areas emerged as significant themes for participants in the survey.

Patient delay in accessing services

Diagnosis

Ongoing care and support

Education and supported self-management



Referral and signposting to patient organisations

Delay in accessing services

Just over a third of individuals (n=441, 35%) waited more than 3 months before seeing their GP following their symptom onset. This increases to 41% of respondents waiting more than 3 months amongst those who were diagnosed more recently (within the last 5 years).

A major area of delay, which has been broadly recognised, starts with the person themselves. Almost irrespective of the condition, people often don't recognise that the symptoms being experienced could be something serious which requires urgent medical investigation. We asked specific questions for those with inflammatory bowel disease as to whether they had ever attended emergency services prior to diagnosis. **Nearly a third of people diagnosed with inflammatory bowel disease visited accident and emergency services with symptoms: (n=110, 30%,) with 47% of those individuals having visited A&E more than twice before their condition was diagnosed.**

The group of individuals who waited longer before obtaining their first appointment with the GP, more than 3 months, were also more likely to report having more than 3 appointments with their GP before a referral to secondary was made.

Most people reported that getting an appointment with a GP was easy or fairly easy (n=986, 79%) when they started experiencing symptoms. However, the results indicate that those living in more rural or island communities found it more difficult to obtain a GP appointment compared to those living in urban communities.

> "I personally feel that Inflammatory bowel disease is only diagnosed when it's bad enough to warrant going to accident and emergency."
>
> *Respondent, aged 18-24, living with Ulcerative Colitis*

> "There is also a dearth of knowledge within primary care which leads to underdiagnosis and inadequate disease support. For example despite my Crohn's diagnosis and presenting at GP's with severe back pain, I was not referred to Rheumatology or diagnosed with Axial SpA for a further decade from my IBD diagnosis, which resulted in undertreatment and erosion in my spine."
>
> *Respondent, aged 45-54 living with Crohn's and Axial SpA*

What can be done?

The quicker individuals get a confirmed diagnosis and start treatment, the better their outcomes are likely to be and the more likely that some may be able to achieve remission sooner. This is often referred to as a 'window of opportunity'. The symptoms of autoimmune inflammatory diseases can often be attributed to other, less critical health issues. **Raising awareness of the symptoms of autoimmune inflammatory diseases is widely considered a significant public health issue.**

It is vital to raise awareness of the importance of *early* presentation with symptoms of immune mediated inflammatory diseases to a GP. A funded campaign with all stakeholders using common assets and a common message to raise greater awareness could make a real difference. (All five of the organisations represented in this report work hard to raise awareness of their respective diseases and three of them have 'Symptom Checkers' on their websites and the other two have symptom lists which are being used by people on a monthly basis.)

Part of any campaign needs to include upskilling primary care professionals in recognising key symptoms and red flags in IMIDs (eg: First Contact Practitioners and new teams employed to help GPs) as they frequently add to the delay in people being referred in line with best practice. Many of the free text comments in this survey reinforce this.

We acknowledge the difficulty in targeting messaging to the general public who have not yet engaged with a GP but who may be experiencing symptoms which they are dismissing for a variety of reasons. Greater collaboration between the patient organisations and the Scottish Societies for Rheumatology, Gastroenterology, Dermatology and the Royal College of GPs Scotland, would be very beneficial in generating such a public awareness campaign.

> "Between the receptionist - not able to grasp my enquiry(s)... The doctor (once an appointment had been made), deciding to cancel it, and refer me to a prescribing practitioner..... who openly admitted she could do nothing, and only the doctor could. Then having to go back into the system.
>
> It took a month for me to be seen."
>
> *Respondent, aged 65-74 living with Crohn's*

If you are interested in working with any of the organisations represented in this report, to help us create a public awareness campaign so that more people seek help at an earlier stage, please contact any of organisations involved.

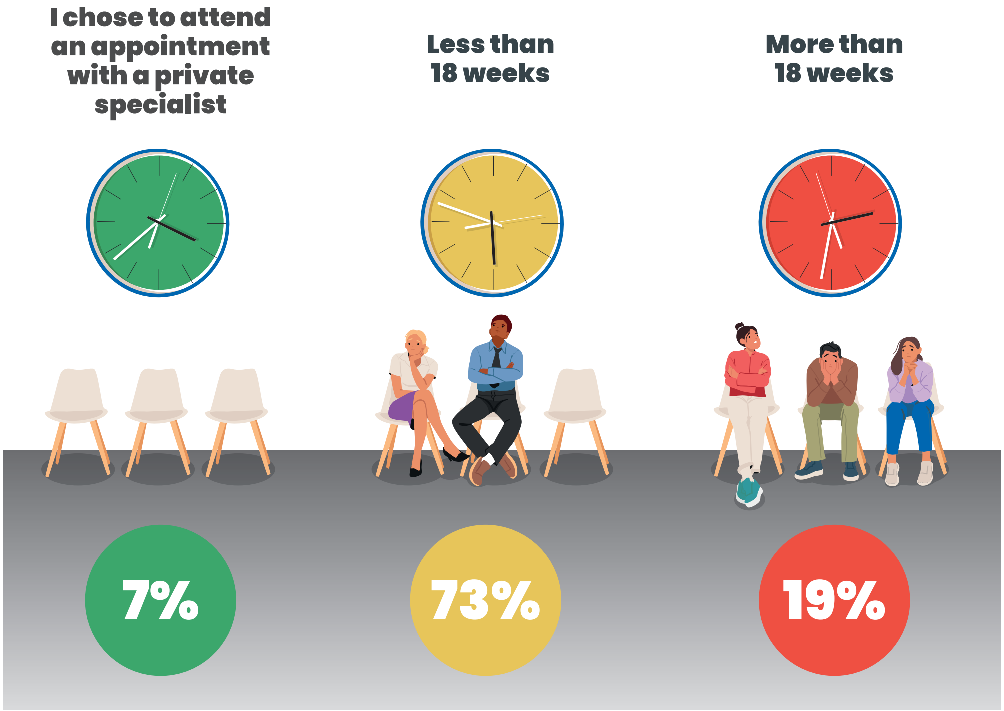
Diagnosis

This survey showed that **50% of individuals require 3 or more GP appointments before referral was made.**

The majority of respondents reported that they were seen by a secondary care specialist within the 18-week Referral to Treat (RTT) standard of NHS Scotland (n=919, 73%). However, 19% recorded that they were seen outside of this 18-week target. When looking at individuals diagnosed more recently, i.e. within the last 4 years, those reporting that they were seen outside of the 18-week target increases to 22%. This increases to 25% if you look at those diagnosed just within the last 12 months.

> "Was initially told by GP after multiple blood tests I did not have arthritis. Until I could no longer walk. Then after many months got a referral to rheumatology. To find out I was sero negative. But GP did not seem to know about this."
>
> *Respondent aged 55-64, living with Rheumatoid Arthritis*

Following your referral to an NHS specialist by your GP, how long did you wait until your first appointment?



We have benchmarked waiting times against the Scottish Government's 18-week target, which requires that 90% of patients should been seen within 18 weeks. However, all of these IMIDs have recommended referral to treatment times of much less than 18 weeks. Typically, the recommendation is that people should be seen in specialist care within 6 weeks. If we apply a 6-week threshold to the whole dataset, **less than a third (32%) were seen and treated within 6 weeks of referral.**

7% of all respondents decided to go privately for their first specialist care appointment and if we just look at the last 2 years, this rose to 13%. The most common response as to why they chose to attend privately was due to long waits in the NHS followed by the fact they had private insurance. 94% of people who attended an initial private appointment have since been referred back to specialist services in the NHS for ongoing care.

What can be done?

Data is absolutely key to driving quality improvement initiatives. It would be beneficial to patient outcomes **to have nationally collected audit data on key performance indicators across Scotland**, benchmarking healthcare teams against national guidelines and/or quality standards in inflammatory autoimmune conditions. **Continuous audit is known to improve performance over time.** This is evident in England and Wales; for example, from latest data from the National Early Inflammatory Autoimmune Diseases Audit.

> It was very upsetting to know in myself that something was wrong but GP kept dismissing my concerns. Rheumatology team in xxxxx are great, it was getting to see them in the first place that was the biggest problem.
>
> *Respondent, aged 45-54 living with Undiffereniated Arthritis*

In relation to all the IMID conditions considered in this survey, **there is a 'window of opportunity' whereby the sooner people are diagnosed and treated, the better their outcomes are likely to be** (around 3 months from symptom onset). Raising greater awareness of the window of opportunity as part of a national campaign around earlier diagnosis for IMIDs would help.

This survey showed that half of respondents required three or more GP appointments before being referred, highlighting the need for greater GP awareness and support, as well as improved training for other primary care professionals such as first contact practitioners, community pharmacists, and physiotherapists. In addition, because many individuals return to their GP with new symptoms that they may not recognise as connected to previous concerns, there may be value in exploring whether GP software could include a 'connect the dots' prompt to the GP to flag repeated presentations with seemingly unrelated symptoms that could, in fact, indicate an underlying inflammatory autoimmune disease.

Many specialist teams have insufficient numbers of consultants, nurses and allied health professionals (AHPs) to serve their populations and this impacts their ability to:

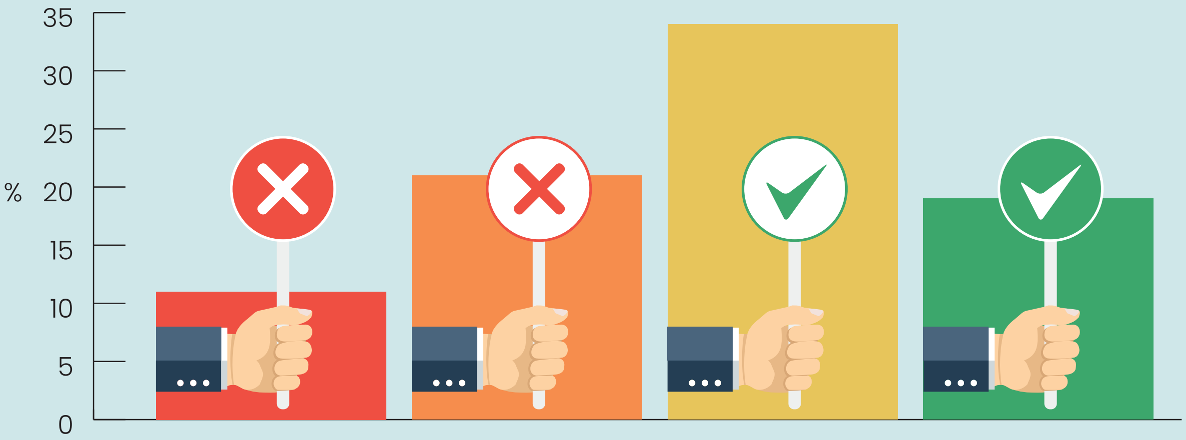
- see patients referred within best practice guidelines
- train and mentor resident doctors, nurses and AHPs
- succession plan for retiring consultants, nurses and AHPs

Workforce shortages across specialist teams must be addressed by the Scottish government if some of the delays to diagnosis are to be effectively addressed.

Ongoing Care and Support

High quality ongoing care is essential if you live with a life-long, invisible and unpredictable disease. We asked what access to services individuals had, how well they thought their disease was managed, how long it took to get to their hospital appointments and other questions about clinic visits, technology and prescriptions. Here's what they said:

Disease Management



11% feel their condition is *unstable and not well controlled.*

21% reported their condition was *inadequately managed and has a lot of room for improvement.*

34% said their condition was *adequately managed but has some room for improvement.*

Only 19% felt their condition was very well managed and had minimal constraints on day-to-day life. A small percentage of people (7%) reported to be in remission either on treatment or drug free.

n=1256

Getting in touch with your team

Over 80% of respondents confirmed that they could contact their specialist team via telephone or email/message. A small but important percentage of respondents, 8% (n=103) reported not being able to contact their specialist team outside of appointments and 37 of those (3%), stated that there used to be a helpline which has since been closed.

From recent national surveys (UK wide) about access to nurse-led advice lines , it is clear that the pressures on workforce to manage this service are significant, which is why some advice lines are closing or reducing their available hours. It is therefore extremely important that people can get in touch with their GP when they need help with their IMID condition, and therefore noteworthy that **a significant 43% (n=537) of respondents report that once diagnosed, they find it difficult to get through to their GP or to book a timely appointment.**

60% of all respondents report that their GP surgery undertakes blood monitoring under shared care agreements.

Time between appointments

39% (n=484) of respondents stated that they felt they needed more frequent planned appointments with their specialist team for management of their condition, irrespective of time since diagnosis or type of IMID they have.

The percentage of people wanting more planned appointments increased for those in rural communities:

- 50% of those living in the NHS Highland Health Board
- 57% of those living in NHS Shetland Health Board
- 58% of those living in the NHS Ayrshire and Arran Health Board

Access to the wider MDT

A third of respondents(n=413) report that they were not offered access to any other members of their specialist team (including, but not limited to, specialist nurses, physiotherapists, occupational therapists, podiatrists).

People living in rural areas with longer to travel were, once again, more likely to report having less access to the wider MDT.

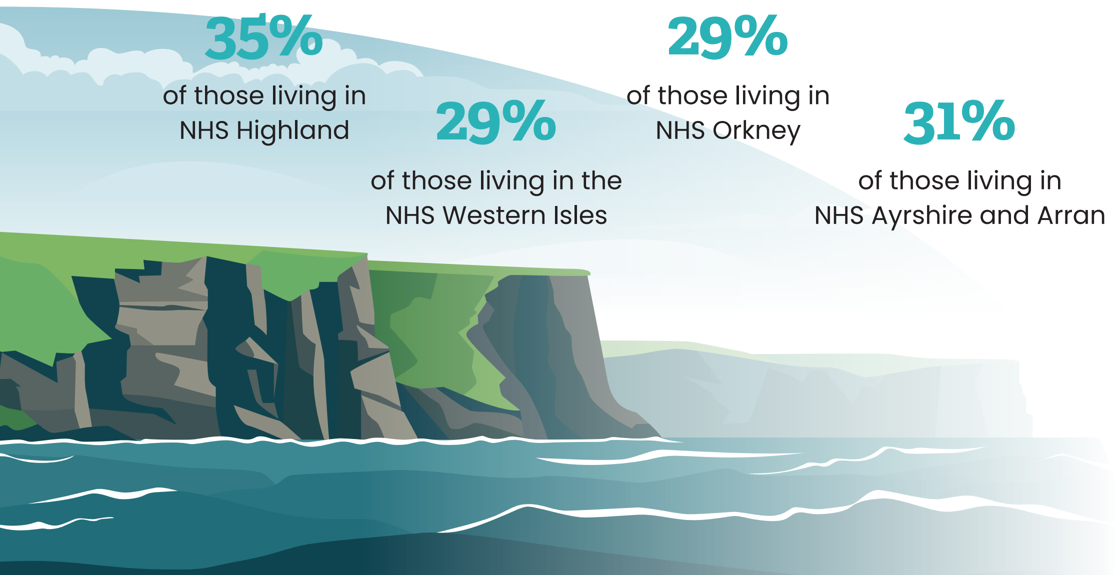
Patient Initiated Review (PIR)

We had expected to see an increase in the use of Patient Initiated Review (PIR) to explain some of the long waits between appointments but the majority (n=1045, 83%) report that PIR has not been discussed with them and this statistic remains static at 83% across all respondents and lengths of diagnosis.

83% of all respondents across all lengths of diagnosis and conditions report that no one has spoken to them about PIR.

Rural communities

Where people live is important in regard to ongoing care and support, as those living in the more rural areas in Scotland were significantly more likely to report that they **have not been seen within the last 12 months** and this includes:



35%
of those living in
NHS Highland

29%
of those living in the
NHS Western Isles

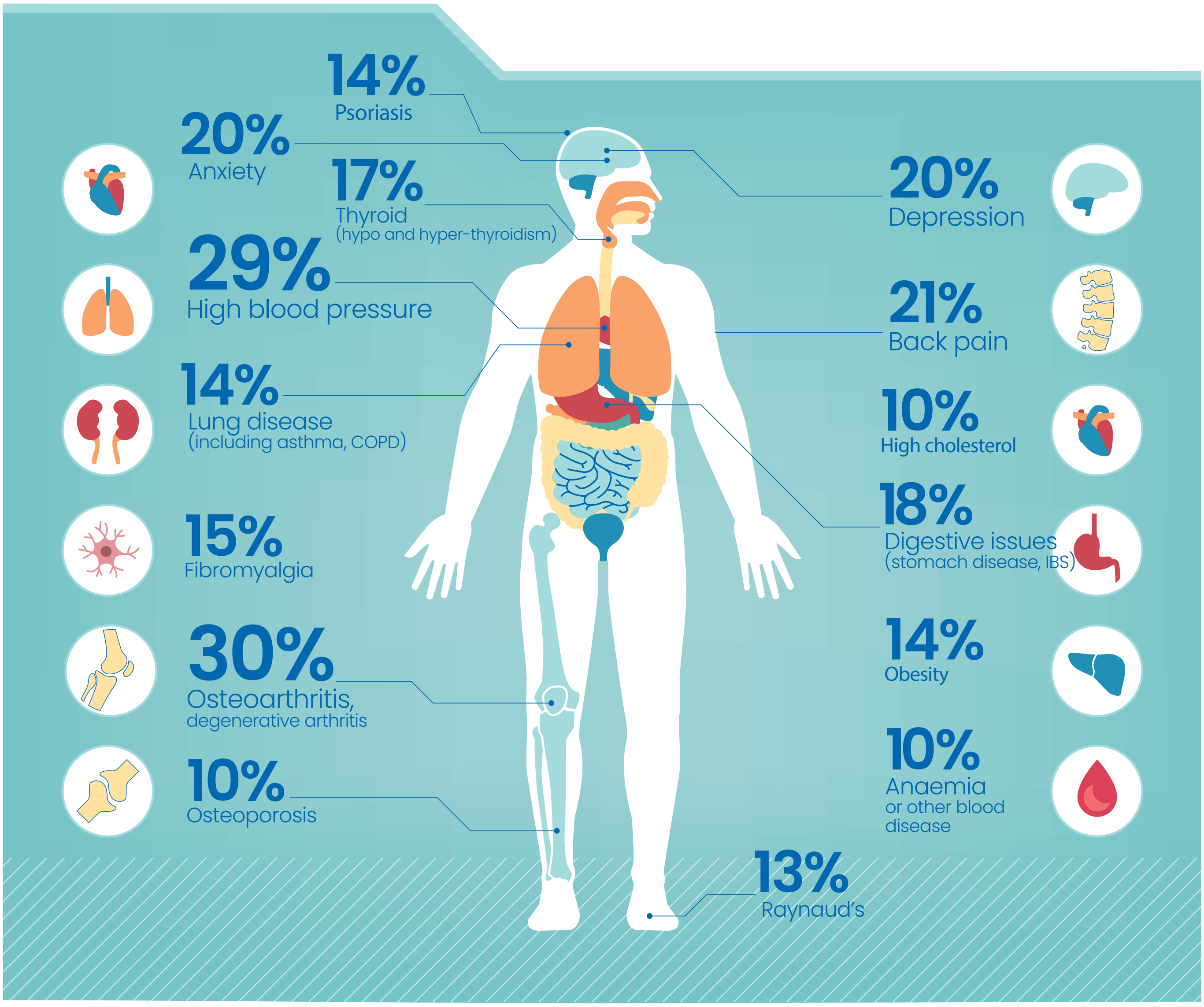
29%
of those living in
NHS Orkney

31%
of those living in
NHS Ayrshire and Arran

22% of all respondents report having to travel more than 1 hour to attend their specialist service. 71% of those living in NHS Orkney report having to travel more than 2 hours to attend their specialist service. This increases the burden of cost of disease for those in rural areas, potentially significantly.

Comorbidities and their risk assessment/management

Across all the conditions, prevalence of comorbidities (other conditions in addition to the main one) is high. 67% (n=839) of all respondents reported on average 3.5 conditions in addition to their main diagnosis (839 individuals reporting 2973 conditions). **The most commonly reported were osteoarthritis, hypertension, back pain, anxiety and depression.** The 15 most commonly reported conditions are represented below:



> "In the past year, I have seen various consultants based in different hospitals but none of them talk with each other or share information or updates on my conditions… they don't share information case notes or my progress with each other and treat each condition separately and I feel they are uninterested in my other conditions."
>
> *Respondent, aged 55-64 living with Rheumatoid Arthritis*

Coordination of care

Around half of those who have more than one additional diagnosed condition 46%, (n=382) report that their care is not very well or not at all coordinated.

What can be done?

Addressing workforce shortages across rheumatology, gastroenterology and dermatology (and more broadly across all specialties) by the Scottish government is essential if access to earlier diagnosis and ongoing care is to be improved.

Access to digital solutions can be a way to assist many individuals with ongoing care. For example, **82% of people in the survey said they did not undertake any kind of remote monitoring of their disease.** It is well established from research that trying to recall how you have been over a long period of time (for example over the past 6-12 months) is problematic for people. Lack of recall can therefore make reporting back to your healthcare team more challenging, and issues may be missed as a result.

Given the percentage of people who feel their disease is not well managed or has room for improvement, **when selecting people suitable for Patient Initiated Review (PIR) pathways, shared decision-making and patient education must be part of the process. Remote monitoring of IMID patients on PIR pathways, by whatever means, should be in place to enable better longer-term outcomes. PIR, when implemented with care, can reduce the burden of regular appointments on secondary care services.**

Specialist teams should ensure that **periodic health reviews** including assessing risk of major comorbidities such as heart disease, osteoporosis, diabetes, eye health and mental health are routinely undertaken. Primary care is well placed to undertake health checks like this.

As mentioned earlier **continuous audit is known to improve performance over time and access to better outcome data will be essential to be able to improve patient lives over the long term.**

Nurse-advice lines are the most common way to enable people to contact their healthcare team. National surveys have demonstrated that although telephone advice lines are provided by experienced specialist nurses, high demand is impacting on their wellbeing. **Having designated training could equip nurses with additional skills to manage increased capacity and monitor their own wellbeing.**

Patient organisations can and do support people to become better informed about their condition and better able to self-manage their disease and risk of developing comorbidities. **It is essential that patients are signposted to relevant information and patient organisations.**

"Rheumatology is an oversubscribed specialty, with approximately 66% of consultant rheumatology applicants unable to secure a post. Vacancies and shortages are due to a lack of appropriate workforce planning, which must be matched to the needs of the rheumatology population and provide access to the right specialist training and education opportunities for nurses, pharmacists, psychologists and allied health professionals."

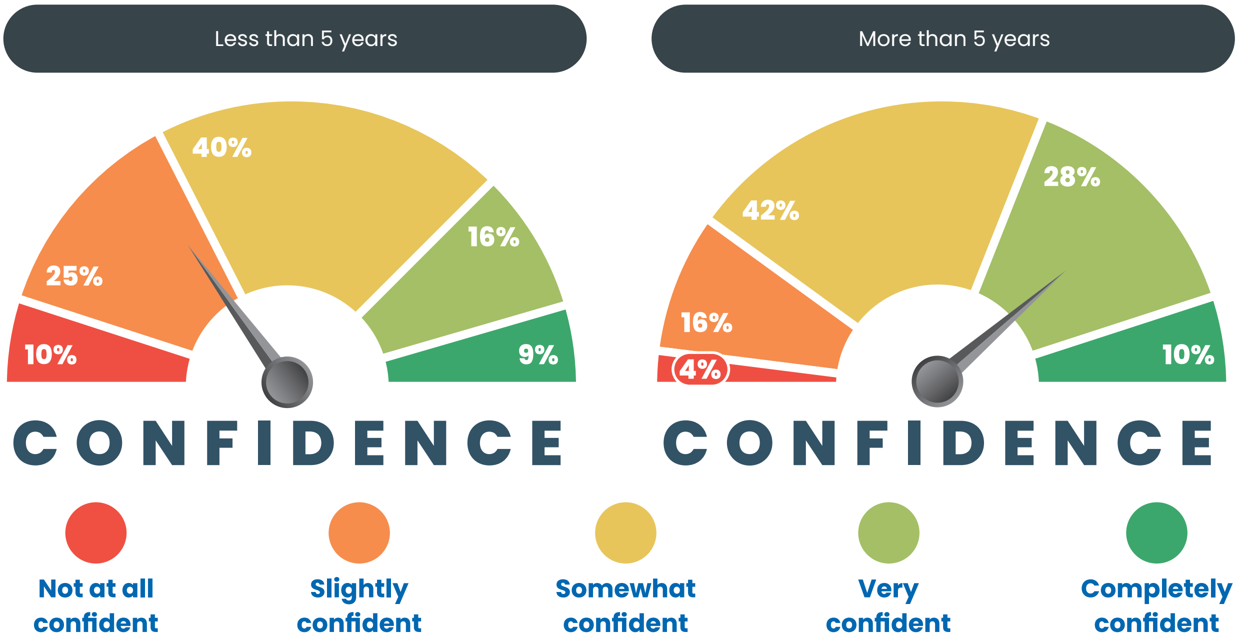
From British Society for Rheumatology Workforce research briefing, 'The People We Need" June 2023

Education and Supported Self-management (SSM)

With increasing waits between appointments and the introduction of Patient Initiated Review in some areas, it is now more critical than ever that people are given the confidence and knowledge to self-manage with the right support. We asked respondents how confident they felt about their ability to self-manage their condition between appointments. **Approximately a third, 34% of individuals, reported that they felt very or completely confident to manage their condition. In Lupus, only 19% said they felt 'very' or 'completely' confident about managing their condition.**

Those diagnosed for longer than 5 years appear more confident to manage their condition than those who are more recently diagnosed (within the last 4 years) as shown by the graph below.

How confident do you feel about your ability to self-manage your condition(s) between appointments?



38% of people recall being provided with written information about their drug treatment or living with their condition. Only 15% reported that they had received information either 1:1 or in a group session about managing their condition from either a nurse or member of the MDT. **A significant minority of respondents, 22%, said they had not been given access to or signposted to any materials or resources.**

People who were less confident to manage their condition were also less likely to have been offered education and access to supported self-management resources.

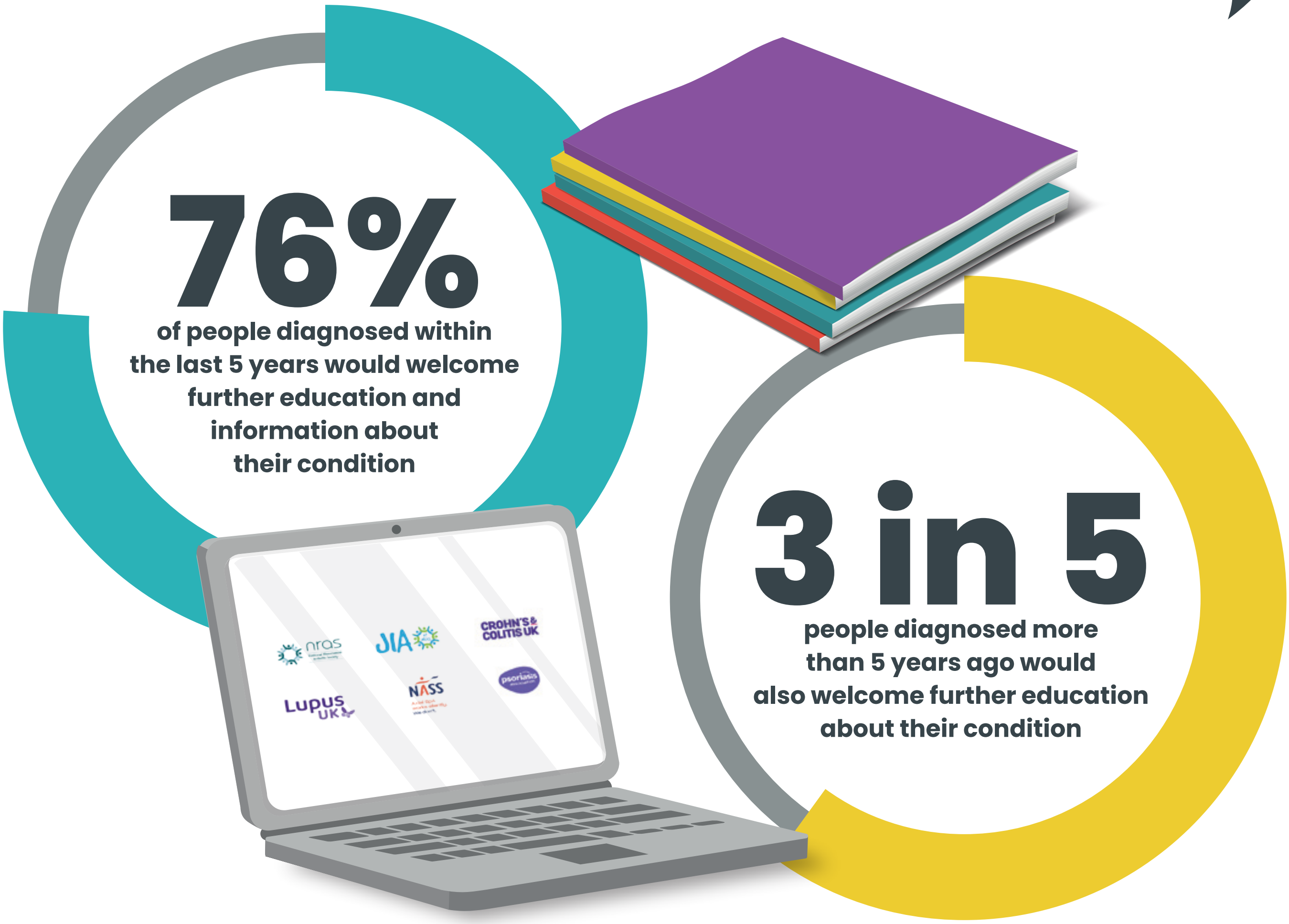
Over half of respondents (52%), said that they had not had any opportunities for ongoing educational activities and a further 20% reported that they had received initial education but no ongoing education. **Ongoing education in long term conditions is extremely important for people's understanding and management of their condition over their lifetime and as circumstances change**.

Barriers to learning about supported self-management included lack of support and difficulty accessing services. Only just over one fifth of respondents reported no barriers.

We asked whether respondents would welcome access to educational and supported self-management resources. The answer was an overwhelming yes as can be seen below.

> "I feel alone with my condition and left to get on with it myself and find my feet with it as not many others in my area have it or even heard of it!"
>
> *Respondent aged 35-44, living with Axial Spondyloarthritis*

Would you welcome further education and information about your condition through access to supported self-management (SSM) resources?



76%

of people diagnosed within the last 5 years would welcome further education and information about their condition

3 in 5

people diagnosed more than 5 years ago would also welcome further education about their condition

Referral and signposting to patient organisations

From the graph below, 45% of respondents had been referred to a patient organisation. When this group is segmented by length of time since diagnosis, there is an upward trend of more people being referred to patient organisations in recent years. However, there is still a significant proportion of people not being referred or signposted to any organisation, so they are missing out on receiving prompt access to the wide range of support available to them.

At diagnosis, or when you started treatment, were you referred or signposted to any of the patient charities listed below

Crohn's & Colitis UK

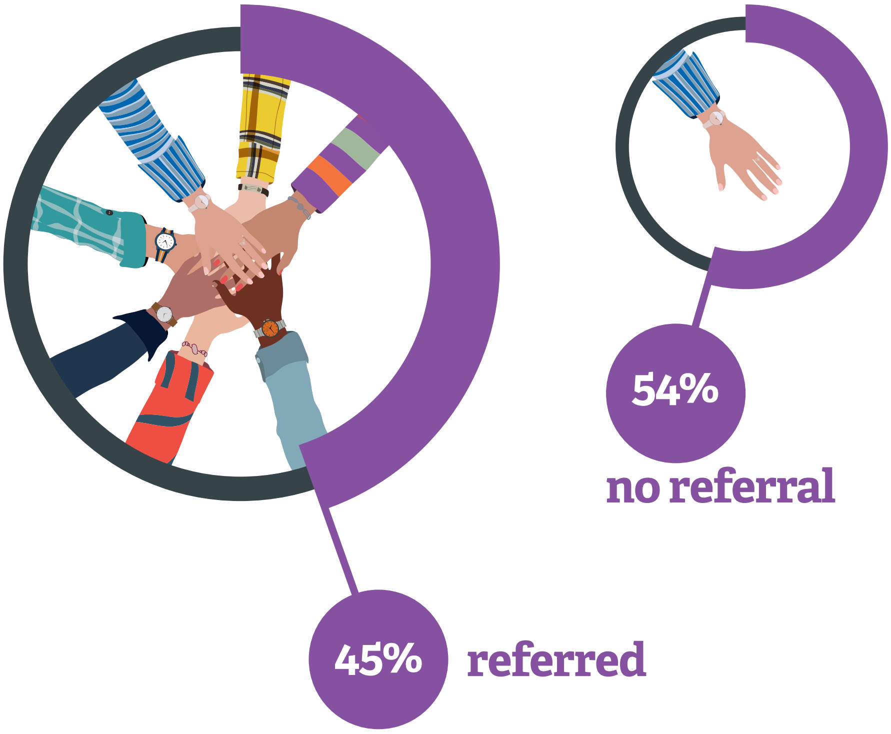
Lupus UK

National Axial Spondyloarthritis Society

National Rheumatoid Arthritis Society

The Psoriasis Association

Versus Arthritis



The 73% who said their disease impacted their life a great deal, were also more likely to have reported that their disease had room for improvement or was not well managed.

Just over a third also reported that their disease impacted daily life and activities with 19% saying it had an impact a few days a week and 13% reporting a few days a month.

People only see their healthcare team for a tiny amount of time in the space of a year and for over 99% of their time they are alone and managing things themselves. This is one of the main reasons why patient organisations are therefore so important, because they can be there to support the individual when they need information or support that doesn't need clinical intervention.

Patient organisations have a very wide range of evidence-based educational and supported self-management (SSM) resources to suit different learning styles and different levels of health literacy. **Patient organisations play a key role in delivering education and supporting learning around self-management strategies.** There is a clear correlation between those people who had been referred to a patient organisation and reported that they had a better understanding of SSM.

These resources are readily available and free to people including being able to provide them to Health Boards and trusts to hand out to their patients. All the organisations have national helpline services and can provide empathetic and expert information, and this can include supporting low mood and anxiety.

What can be done?

Multidisciplinary teams in all Health Boards should incorporate automatic referral to relevant patient organisations in the early stages of diagnosis so that patients know where to go for general education, information, support and advocacy.

All patient organisations have patient leaflets and posters that can be handed out and put up in clinic areas and will provide these free to hospitals on request.

Surveys over time amongst health professionals have indicated that often HCPs are unaware of the broad range of services and resources provided by patient organisations. They are generally aware of helplines, booklets and community groups but often are less aware of many of the other services provided which might benefit their patients. **All the organisations involved in this survey see themselves as part of the MDT and want to work in partnership with professionals to support and benefit patients.**

Free Text Responses

387 individuals provided an answer to this question giving 53 A4 pages of information about their experiences of access to services and care. Some consistent themes in this survey are similar to the findings in the NRAS Welsh Survey:

- Long waits for care.
- Delayed diagnoses.
- A majority not being referred to patient organisations for help and support.
- A lack of joined-up communication between GPs and specialists and between different specialties.
- The "postcode lottery" is a recurring concern, with significant differences in access to care across health boards.

Yet, there are also experiences reported of shorter waiting times, excellent care and effective treatment—highlighting the variability of access to healthcare.

"Not just a postcode lottery - but a doctor lottery"

Respondent aged 35-44, living with Psoriatic Arthritis

"I had an urgent NHS referral in Jan 24 but did not get an appointment until Aug 24."

Respondent aged 45-54, living with Rheumatoid Arthritis

"I feel very isolated with lupus; rely on online groups and would appreciate more help with lifestyle management."

Respondent aged 65-74, living with Lupus (SLE)

"The best care I ever received was living in the Highlands. My consultant was amazing."

Respondent aged 35-44, living with Crohn's

Always very well supported by my consultant and her team, she is very approachable which makes dealing with my condition so much easier.

Respondent aged 55-64, living with Ulcerative Colitis

"Transition from paediatric to adults service is poor. Not the same care offered in adults."

Respondent aged 18-24, living with Crohn's

"I felt abandoned, like deer in headlights, I didn't fully understand what was happening to my body, I was directed to Crohn's and Colitis website for support."

Respondent aged 55-64, living with Ulcerative Colitis

Discussion

The results from this survey indicate delays in people seeking help and then delays in referral and diagnosis impacting the ability to achieve best outcomes for people presenting with Immune Mediated Inflammatory Diseases. Also, once in the system, for many, the access to NHS services and care delivered to people living with IMID conditions in Scotland is not routinely meeting their needs or expectations. A significant proportion of people report that their condition impacts their quality of life and day to day activities frequently and significantly. There is an appetite to learn more about their condition and how to self-manage but the main barrier to this is a lack of knowledge and difficulties in accessing education and supported self-management resources. Around one third of respondents said that they did not have access to the wider team including nurses, physiotherapists, occupational therapists, podiatrists. This was especially true for those living in rural communities and for whom the cost and burden of travel to appointments was significantly higher than people in urban locations.

Around half of all survey participants were not signposted or referred to relevant patient organisations and whilst this number is improving in recent years, many people are missing out on the benefits of the wide ranging support provided by patient organisations. The EULAR Recommendations for the Implementation of Self-Management Strategies in Inflammatory Arthritis published in 2021 stated that “The ability to self-manage in inflammatory arthritis (IA) represents an essential component of care that goes beyond drug therapy and which supports the patient in managing the practical, physical and psychological impacts of disease” and recommend that “HCPs should encourage patients to become active partners of the team and make them aware of HCPs and patient organisations involved in all aspects of the care pathway.” Patient organisations provide high quality, evidence-based sources of support, information, education and supported self-management programmes/resources, with the ability to improve both physical and mental/emotional health and wellbeing.

All organisations involved in this survey are committed to improve the lives of people living with IMID conditions in Scotland. Better patient outcomes that are meaningful to people living with IMIDs together with improvements to service pathways and access to care more broadly is more likely to be achievable through better collaborative working. The patient organisations represented in this report are ready to play their part in this endeavour.

> “It’s been, and continues to be, my pleasure to be involved with NRAS. It’s the positive that has come out of having RA. My life is a lot richer for being an active member of NRAS. Thank you for having me!”
>
> *NRAS Volunteer. Hertfordshire*

Linking to the Strategic Direction of the Scottish government and NHS Scotland

An interim analysis to the Long-Term Conditions Framework for Scotland has been published . However, whilst finalisation and implementation of this framework is likely to be interrupted by the Scottish elections in May, we hope that whichever party is elected will commit to working with third sector partners who are keen to collaborate to improve delivery of care and patient outcomes.

Value-based healthcare has gained importance in recent years in managing chronic conditions and prioritising patient-centred outcomes over service volume. This approach is especially relevant for patients with IMIDs, whose complex and many different needs require a coordinated, multidisciplinary care model. Existing clinical service models usually focus on single specialty management and often provide fragmented care, especially where workforce issues continue to be problematic, with delays to treatment plans and lacking preventive care when it comes to managing comorbidities and people with more than one co-existing IMID.

This siloed approach may not always adequately address the range of impacts on the person living with an IMID as can be seen from this survey. These issues have prompted a movement in some places towards more collaborative cross-specialty care, with the potential to share knowledge and resources with more effective use of available time for clinical consultation and early recognition and treatment of co-occurring IMIDs. This is reflected in the consultation response to the Long-Term Conditions Framework:

"From the responses, 80% agreed that the Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long-term conditions alongside *condition-specific* work. The benefits of this were deemed to be:

- Whole-system, person-centred, holistic, and integrated models of care;
- Equitable and sustainable access to care, treatment, and support;
- An increased focus on prevention and early intervention; and
- A unified approach could be easier to communicate"

Further, responses to consultation questions were often framed in terms of the valuable role of the third sector in providing support to people with long-term conditions. Points frequently raised in responses included:

- the historic **under-recognised value and contribution of third sector services** outside of medical care in helping people to manage long-term conditions
- the **role of the third sector in bridging gaps in public sector provision**
- sustainable and longer-term funding for the third sector – **equal partners in care delivery for people living with long-term conditions**
- workforce recruitment and retention challenges

The Population Health Framework sets out Scottish Government's and COSLA's long-term collective approach to improving Scotland's health and reducing health inequalities for the next decade. One of the key priorities it embeds in its aims over the next 10 years is **prevention**. This must go further than reducing primary prevention of conditions such as heart disease, cancer and type 2 diabetes and address secondary prevention of comorbid conditions which are major risks for people with existing long-term conditions to reduce the burden on the health and social care systems.

The third sector has a major role to play in supporting and influencing pathways of care, embedding referral and signposting to relevant patient organisations at point of diagnosis where education, supported self-management resources and emotional support can be a catalyst to improving outcomes for people diagnosed with life-long and life-altering conditions as those included in this survey.

Mental health support is urgently required for people with chronic long-term disease, and we understand the difficulty faced by governments across the UK to provide the increasing levels of care which are needed. Whilst serious mental health conditions and clinical depression need urgent medical intervention, many people find that the support and information they get from patient organisations including access to peer support can alleviate low mood and anxiety which can lead to depression. This is perhaps not sufficiently appreciated or understood. In this survey 28% of people reported depression, anxiety or both.

We hope to work collaboratively with health professionals, health boards and the Scottish government to improve the physical and emotional care and outcomes of all those living in Scotland with immune mediated inflammatory conditions.

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Appendix 1

Condition list

Inflammatory Arthritis:

- ○ Rheumatoid Arthritis (RA)
- ○ Adult Juvenile Idiopathic Arthritis (AJIA)
- ○ Axial Spondyloarthritis (axial SpA including ankylosing spondylitis)
- ○ Undifferentiated Arthritis
- ○ Palindromic Arthritis

Psoriasis & Psoriatic Arthritis

- ○ Psoriasis
- ○ Psoriatic Arthritis

Inflammatory Bowel Disease:

- ○ Crohn’s disease
- ○ Ulcerative colitis
- ○ Microscopic colitis

Lupus

- ○ Systemic lupus erythematosus (SLE)
- ○ Cutaneous lupus (lupus of the skin - CLE)
- ○ Both SLE and CLE (lupus)
- ○ Lupus but unsure which type
- ○ Undifferentiated Connective Tissue Disease (UCTD)
- ○ Mixed Connective Tissue Disease (MCTD)

Appendix 2

Have your say on inflammatory autoimmune care in Scotland!

Do you live with?

- Rheumatoid Arthritis
- Axial Spondyloarthritis
- Inflammatory Bowel Disease
- Lupus
- Psoriatic Arthritis/ Psoriasis

We want to find out about the experiences of NHS care for people living with one or more of the inflammatory conditions listed above. If you are **over 18** and get your care from **NHS Scotland**, we want to hear from you!

Please take part in our survey

nras.org.uk/scottishsurvey

Scan me

This survey will be closing on 10th Oct.

National Rheumatoid Arthritis Society (NRAS) is a registered charity in England and Wales (1134859) and Scotland (SC039721).

The Scottish Report

A Scotland-wide survey of people with immune mediated inflammatory diseases to gather their experiences of accessing NHS services, treatment and healthcare.

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