

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

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Rare Autoimmune Rheumatic Disease Alliance (RARDA)



RAIRDA – Health and Social Care Committee consultation response: supporting people with chronic conditions

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Submitting evidence on behalf of: The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA)

Evidence does not need to be held as confidential, and RAIRDA gives permission for its name to be published alongside its evidence.

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) is asking the Committee to consider in the scope of its inquiry into chronic illness how best the health and social care systems can support people living with rare autoimmune rheumatic diseases (RAIRDs).

RAIRDs are chronic, incurable conditions, and currently, issues such as late diagnosis, and poor care and treatment, mean that people living with them experience reduced quality of life, and preventable poor outcomes including, in some cases, premature mortality.

About RAIRDA and RAIRDs

RAIRDA is the first alliance linking clinical and patient organisations to campaign for improved care for people living with RAIRDs in the UK. RAIRDA is comprised of LUPUSUK, Vasculitis UK, Scleroderma and Raynaud's UK, and the British Sjögren's Syndrome Association.

RAIRDs are a range of conditions in which the body's immune system damages its own tissues, often in multiple organs throughout the body simultaneously. This can lead to tissue or organ damage, which can be fatal. RAIRDs can affect many parts of the body, including joints, skin, lungs, kidneys and the heart. They can be split into two groups: connective tissue disorders (lupus, scleroderma, myositis, primary Sjögren's syndrome) and systemic vasculitis (ANCA-associated vasculitis, giant cell arteritis, Takayasu's Arteritis and Behçet's disease).

In the UK, there are over 170,000 people living with RAIRDs, and an estimated 3.5 million people living with rare diseases. Individually, the conditions are rare, but overall, rare disease affects a significant proportion of the population.

Yet there is no specialised centre in Wales for people with RAIRDs. A patient responding to our 2021 survey demonstrated how poor the experiences of some patients are in parts of Wales: *“Patients with chronic ill health are being failed in Wales. There is no support, no monitoring, no bloods taken, no medication. I worked hard in my career. For the past eleven years I have become incapacitated by my illness. I have lost my career and am now unable to afford private care.”*

NHS and social care services

Whilst the UK Rare Diseases Framework (2021) has been a significant step towards improving care for rare diseases, there are gaps in the framework which mean that people with RAIRDs are still at real risk of preventably poor health, and are experiencing widening health inequalities compared to those with common conditions. [The Wales Rare Diseases Action Plan 2022-2026](#) has identified relevant areas for improvement. However, the plan appears to be heavily focused on genetic conditions. Going forward it would be good to see the Welsh rare disease policy have a greater focus on conditions which are predominantly non-genetic, such as RAIRDs. RAIRDA’s policy paper, [Resetting the Balance](#) (2022), outlines a roadmap for better care and treatment for people with RAIRDs.

The readiness of local NHS and social care services to treat people with chronic conditions within the community

NHS services remain focused on common conditions, with an increasing focus on high volume, low complexity conditions, exacerbated by the backlog caused by the COVID-19 pandemic. This is often at the expense of rare diseases, which means the current system is preventing some people with rare disease from experiencing an achievable level of good health. This UK-wide issue is especially acute in Wales, as there are various factors which mean that rare disease services are stretched, including a small population, geographic distribution of rare disease patients, and the availability of providers. These factors mean that it may not always be possible or practical to treat rare diseases within the community, and that it may be necessary to gain specialist expertise from elsewhere. However, systems for rare disease treatment should recognise and facilitate this, rather than allowing this to act as a barrier to people receiving good care.

Support available to enable effective self-management where appropriate, including mental health support

Patients with RAIRDs in Wales have expressed that they struggle to effectively self-manage their conditions, due to services such as helplines or their single point of contact, proving ineffective and at times difficult to access. In Wales, fewer respondents to our 2018 survey had access to a specialist nurse than anywhere else in the UK, and of those who did, Welsh patients reported the most difficulty in contacting their specialist nurse.

Poor self-management support can lead to people with RAIRDs experiencing avoidable disease progression, as well as unnecessary distress. Our 2018 survey showed that in Wales, 62% of respondents said they weren't confident in their GP's understanding of their condition. In 2021, one Welsh patient told RAIRDA: *"I went privately as I didn't know who to contact during a flare. The consultant explained it will be due to COVID that the rheumatology nurses don't answer the phone, or reply to messages left."* The lack of availability of information for patients during a flare-up of their disease is a barrier to self-management which can lead to escalation of the flare-up, preventable A&E attendance or as above, patients being forced to spend money they may not have on private care.

If the Committee were to look at issues faced by people with rare diseases in local NHS care, it could encourage engagement with people with lived experience, patient organisations and clinicians to consider how best to improve experience and outcomes. Further, RAIRDA is currently calling for the development of a NICE quality standard for rare disease and has had productive discussions with policy-makers across the four nations. A quality standard could outline standards for training as well as targets for diagnosis, referrals and access to helplines for people with RAIRDs, creating an incentive for change at a local level.

Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people

Workforce pressures in Wales mean that people with rare disease are facing serious barriers to accessing essential services and ongoing treatment. This also exacerbates the inequality faced by people with rare disease: the shortage of rheumatologists, in particular, is disproportionately affecting people with RAIRDs. Patients accessing Vasculitis UK's helpline have reported waiting six to nine months to see a specialist rheumatologist, even when their symptoms are suggesting their vasculitis is progressing at a dangerous rate. The many unfilled vacancies in rheumatology in Wales are evidenced in this report by the [British Society for Rheumatology](#).

The care and treatment inequalities faced by people living with RAIRDs exacerbate existing medical and societal inequalities. As a group of conditions, RAIRDs predominantly affect women, and some RAIRDs, such as lupus, are more common amongst people of Black African, Caribbean and Asian ethnicities.¹

It is understood that the nature of rare disease, along with Wales's population size and geographic distribution means that specialists may not always be available in a patient's area, or even in their nation, making it necessary for cross-border NHS referrals to the rest of the United Kingdom.

However, Vasculitis UK's helpline in Wales has found that NHS cross-border referrals are currently extremely complicated, and due to funding issues they are often unsuccessful – despite the fact that this is the necessary pathway of care for the patient. Even when a shared care collaboration has been established with a hospital in England, RAIRDA have received reports of breakdowns in communication which have had serious impacts on the welfare of patients – in the worst cases, leading to serious adverse outcomes and even increased morbidity.

In 2018, in Wales, 38% of patients told RAIRDA that they had accessed private healthcare for their condition compared to 28% in the rest of the UK. This indicates that in Wales, fewer patients are able to get the care they need through the NHS. This may in part be due to the fact that NHS patients in Wales do not have the same statutory right of “patient choice” as in England – wherein if you are not satisfied with your treatment or your consultant or your hospital, you can ask your GP to refer you to another consultant and/or hospital of your choice, without having to ask permission of your current consultant.

One patient reported to our 2021 survey that *“I feel the Welsh NHS has abandoned me, I'm fortunate I can pay to access treatment and consultation in England, but there is a desperate need for a centre in Wales to treat patients like myself with specialist care.”* The increased rate of RAIRD patients in Wales accessing private care means that people with chronic conditions who can't afford to access private healthcare are being left behind by the NHS, facing a serious inequality where those who can pay, are treated, and those who can't, sometimes cannot access specialist treatment at all.

If the Committee were to focus on the availability of essential services and treatment for people with rare disease, this might encourage policy makers to address these issues. For example, RAIRDA have called for a specialised, tertiary centre (or centres) for RAIRDs to be formally commissioned in Wales by the Welsh Health Specialised

¹ RAIRDA, [Resetting the Balance](#) (November 2022), p.4.

Services Committee. This could help close the gap between Wales and the rest of the UK.

Multiple conditions

The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation

The nature of RAIRDs mean that they often involve multiple organs throughout the body – often joints, skin, lungs, kidneys and the heart. This means that multi-disciplinary working is key to providing effective care to people with RAIRDs.

However, our 2018 survey showed that there is a disparity in access to multidisciplinary care in Wales, compared to the rest of the UK. 9% of respondents living in Wales reported they had been able to access care at a joint clinic with doctors from multiple different specialties, compared to 17% across the rest of the UK. This is despite the fact that 93% of UK survey respondents reported seeing clinicians from multiple specialties. The NHS is not responding effectively to individuals with multiple conditions which interact, or to those whose chronic conditions require treatment from multiple specialties.

The interaction between mental health conditions and long-term physical health conditions

Further, the impact of chronic conditions on mental health and wellbeing is significant. Yet, in our 2018 survey, just 9% of respondents in Wales reported being offered psychological support to help them manage the impact of their condition. The rest of the UK sat at 15% – a figure which, although still poor, suggests that Wales is behind the other nations in addressing the impact of chronic illness on the mental health of people with RAIRDs.

The development of a NICE quality standard for rare disease would establish targets for both multidisciplinary working and psychological support. Further, the development of a specialised tertiary centre (or centres) for RAIRDs in Wales would improve access to both multidisciplinary care, and psychological support. If patients feel well supported clinically, this can have an immensely positive impact on how they cope with chronic illness, and their wellbeing in general.

Impact of additional factors

The impact of the pandemic on quality of care across chronic conditions

The pandemic has had a significant impact on care across the NHS, but this has disproportionately impacted people with rare conditions. RAIRDA's June 2021 survey asked patients to evaluate the impact of the pandemic on their care – 41% said it had a major negative impact, whilst 29% said it had a minor negative impact. The unprecedented situation in the Welsh NHS means that due to workforce pressures combined with the pressure applied by the COVID-19 backlog, patients are waiting far longer for treatment than is clinically advisable.

One patient stated to RAIRDA in 2021: *“I had my rheumatology appointment cancelled during March 2020. I have not heard anything more from the hospital since. I am unwell and was hoping to start a new treatment for the conditions I've had diagnosed. I feel there is no help whatsoever and as if I have fallen off the radar completely. Just left in pain and forgotten about.”*

Services in Wales do not currently have the capacity to meet demand, and unless action is taken, the inequalities in access to care and treatment for people with rarer conditions like RAIRDs will only increase. For example, if a NICE quality standard for rare disease was in place with diagnosis targets, it would ensure that people are seen before their condition reaches a critical point, preventing future adverse outcomes which also place strain on NHS resources. Thus, prevention policy should include provisions for creating parity in the care and treatment received by those with both common and rare conditions.

Prevention and lifestyle

Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating)

RAIRDs, unlike many rare diseases, are predominantly non-genetic diseases, so no specific action e.g. genetic testing can prevent initial onset, or give an early indication that the disease will occur. While they may not be explicitly preventable, issues such as late diagnosis, and poor care and treatment, mean that people living with them experience preventable poor outcomes including, in some cases, premature mortality.

Specifically, RAIRDs can be life threatening and significantly life-altering, yet prevention of these adverse outcomes through early diagnosis, priority access to preventative vaccinations and treatment, care coordination, access to specialist support and effective monitoring has not been given appropriate investment and attention, creating a significant inequality for people living with RAIRDs.

Recent reports from RAIRDA's member charities suggest that some patients in Wales are being left for months without drug monitoring or regular blood tests for disease activity. In 2021, one patient reported that "*The rheumatology department is vastly understaffed, and the waiting list for clinics are long. Therefore, conditions deteriorate and end up needing more intensive intervention, making the rheumatologist's job much more difficult and burdening the waiting list more.*" Workforce issues must be addressed so that healthcare professionals are able to deliver the quality care which they aim to, as soon as possible. The longer people with RAIRDs are left without effective diagnoses, treatment or monitoring, the more severe both the impact on the patient, and the knock-on effect on NHS resources and capacity.

Scrutiny from the Committee would help highlight current inequalities in aspects relevant to prevention and encourage action to address them. If the Committee were to include preventing avoidable disease progression and mortality for people with rare diseases on its agenda for the inquiry, it could encourage the NHS and policy makers to address this area.

Conclusion

RAIRDA is grateful for the opportunity to feed into this important inquiry and hopes that supporting people with RAIRDs and other rare diseases will form part of the Committee's agenda when looking at supporting people with chronic conditions. RAIRDA is happy to provide any additional evidence required by the inquiry.