

# CHRONIC CRISIS

**The impact of COVID-19 on  
people with rare autoimmune  
rheumatic diseases**

# About this report

Rare autoimmune rheumatic diseases (RAIRDs) are characterised by a person's immune system becoming dysfunctional and attacking its own healthy cells, leading to inflammation and damage in tissues and organs which is often irreversible and can be potentially fatal. These conditions can affect many parts of the body (including joints, skin, lungs, kidneys and heart) and often require cross-specialty medical expertise. Unlike the majority of rare diseases, these conditions predominantly occur in adult life and do not have a simple genetic link. They also disproportionately affect women – for example women make up 80% of people who have lupus. The impacts of these conditions varies from person to person depending on the organ or organs affected but they can be severely life-limiting and potentially life-threatening. Around 9,000 people will be diagnosed with one of vasculitis (including Behçet's), scleroderma, lupus or primary Sjögren's syndrome every year in the UK.

From April 27<sup>th</sup> to May 15<sup>th</sup> 2020 we conducted an online survey of people with RAIRDs. This online survey was publicised through member charities' mailing lists and via social media channels. As well as being asked a set of multiple-choice questions, respondents were asked to comment on any issues that they felt were important to them. Overall, 1,383 responses to the survey were received, 1,110 from England, 168 from Scotland, 87 from Wales and 28 from Northern Ireland. The majority of respondents had lupus (479), scleroderma (325), Sjögren's syndrome (376) or a form of vasculitis (387). Other conditions featured included mixed and undifferentiated connective tissue disease and antiphospholipid syndrome. These figures include people who have diagnoses for multiple conditions. The number of respondents is roughly proportional to these conditions' comparative prevalence.

## About RAIRDA

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

## RAIRDA member organisations



June 2020

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## Summary

**54%** of respondents to the survey were currently shielding.

**80%** of people with these conditions had experienced a change in their care and treatment.

**37%** of these people said that their ability to manage their condition had been affected as a result. Virtual or telephone appointments can be helpful, but on their own they are insufficient to give all these patients the care they need.

**33%** of people with RAIRDs say the pandemic has adversely impacted their household finances compared to 23% of the general public.

**34%** of people with RAIRDs said that advice from the health service or the government was “unclear and contradictory”.

Some people raised concerns about accessing healthcare due to not wanting to add to the burden on the NHS or fears of infection with COVID-19. However, many more commented that they felt ‘**abandoned**’ due to a lack of clear information about their level of risk or the way their care plan had been changed.

# Foreword

As RAIRDs are characterised by a dysfunctional immune system and are treated using medications which suppress the immune system, we feared that people with these conditions would be disproportionately impacted and concerned by COVID-19. Findings from RAIRDA's 2018 report *Reduce, Improve, Empower*<sup>1</sup> also indicated that the health service was not organised to effectively support these people, let alone in a time of crisis, with patients feeling their care lacked coordination and GPs lacked knowledge of their condition. We now understand that the potential impacts can go beyond personal susceptibility to the virus and include the effect of shielding, the disruption to care, and the hit to peoples' employment and incomes.

To better understand the issues impacting people with RAIRDs we opened an online survey from the end of April until mid-May 2020 for all people with rare autoimmune rheumatic diseases in the UK. This report is based on more than 1,300 responses that we received to this survey including hundreds of detailed comments written by people about their experiences.

Our previous survey in 2018 showed that, even before the current crisis, over half of people were not confident with their GP's knowledge of their condition and over 60% did not feel there was a coordinated plan for their care. This survey further confirms these findings, with people feeling guidance was far clearer when they spoke to hospital specialists rather than GPs.

What is most concerning about the comments in this survey was the number of people who said they felt 'abandoned' by the health service and the rest of society in general. This came across in comments about people seeking guidance and information on their level of risk, seeking to raise issues such as a worsening of symptoms from their RAIRD and trying to understand how their care has been impacted by COVID-19.

80% of respondents experienced a change in their care with over a third of these people saying such changes impacted their ability to manage their condition. This shows a very different picture from the Office for National Statistics report on all shielding patients collected in late May which shows less than a third have experienced a change in their care<sup>2</sup>. Comments and survey responses from some patients, as well as what we know about the medical need for monitoring tests, indicate that virtual appointments alone can be insufficient to support these people. Some respondents reported intervals between monitoring tests which could allow time for asymptomatic, but irreversible damage to their organs to accrue. Whilst this survey clearly could not collect information from people in the middle of their diagnostic journey, which we know can take many years for these conditions, we know this period will only have lengthened as services are so disrupted. Delays to starting treatment, unmanaged side-effects and uncontrolled disease course can all lead to organ damage. These outcomes are not only devastating to people with RAIRDs but increase the cost to the health service of supporting people in the long-term.

This survey also shows that many people with RAIRDs have faced difficulties with regards to work and personal finances during this pandemic. Comparing the results of this survey with polling of the general population, people with RAIRDs are more likely to experience financial hardship due to the pandemic. This is partly because those people with RAIRDs in employment are more likely to have been furloughed due to their need to shield. In addition, a small group who are shielding have experienced a significant loss of income because they have been placed on statutory sick pay rather than being furloughed.

This pandemic has caused severe disruption for people with these chronic conditions. But the crisis is also "chronic", in the sense that many of these issues with care or support have their roots in problems which were present long before this crisis. If we do not get our response to these issues right, the consequences will be long-lasting.

# Advice and communication about risk from COVID-19

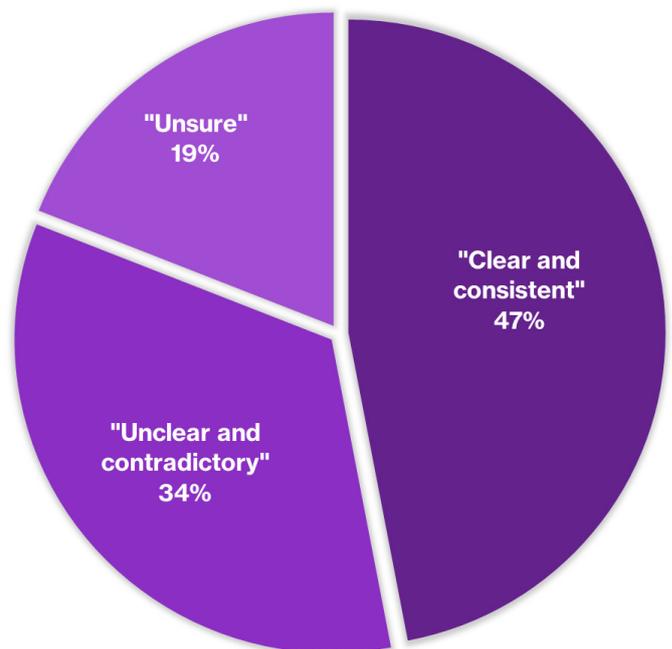
## Clarity in communication of health protection advice

COVID-19 is a new virus and our understanding of who is most at risk from infection is still developing. This was even more true at the time guidance was developed on who was most at risk from COVID-19, and therefore needed to self-isolate or shield. Factors which put someone at higher risk from COVID-19 and therefore in a higher risk category included taking certain immunosuppressive drugs and organ involvement in pre-existing conditions<sup>3</sup>. Given both of these are relatively common for people with RAIRDs, this suggests that a high number of RAIRD patients would be at risk from infection.

The fact that RAIRDs vary in severity, along with the extent to which major organs are affected, means that the degree of potential risk from COVID-19 infection also varies significantly. This meant there was a need to communicate with patients about their own individual level of risk in addition to deciding which category of risk patients fell into.

This exercise needed to happen at a time when UK health services started to reassign clinical resources to deal with COVID-19. Additionally, prior to COVID-19, people living with RAIRD conditions reported issues with their care and felt that it was often fragmented and lacked coordination. The current crisis appears to have compounded these difficulties.

**Which of these best describes the advice you have received from clinicians, the health service and the government**



<i>Advice received from health service</i>	<i>Says advice they have received is 'Clear and consistent'</i>	<i>Says advice they have received is 'Unclear and contradictory'</i>	<i>Says they are 'Unsure' about how clear the advice is</i>
<b>All respondents</b>	<b>47%</b>	<b>34%</b>	<b>19%</b>
<b>Has received no advice or information</b>	<b>7%</b>	<b>54%</b>	<b>39%</b>
<b>Told to shield</b>	<b>75%</b>	<b>18%</b>	<b>7%</b>
<b>Told at higher risk but not to shield (also called 'moderate risk')</b>	<b>38%</b>	<b>47%</b>	<b>15%</b>
<b>Told at no extra risk</b>	<b>38%</b>	<b>45%</b>	<b>17%</b>

Only 47% of respondents said that the advice they received was “clear and consistent”, with 34% saying the advice they received about their level of risk was “unclear and contradictory”.

However, as the chart on the previous page shows, people’s views on how clear the advice had been depended on what advice they had received. For example, amongst people who reported they had received no personalised information or advice, only 7% said the guidance from the government and health service was “clear and consistent”. Amongst people who reported that they had been told they were either at “no extra risk” or at “higher (moderate) risk but did not need to shield” only 38% considered that the advice they received was clear and consistent.

Whilst we might expect people who had received no advice to feel that instructions have been unclear, the fact those who were told they were at no extra risk, or at what NHS guidance currently calls ‘moderate’ risk, felt there was a lack of clarity indicates a need to communicate more clearly to everyone.

***“I feel completely abandoned and confused about what I can or cannot do. I’m on two lots of immunosuppressants and my conditions are not under control but I’ve had no advice from anyone for several months.”***

***“As a health professional I knew that I was very high risk and took necessary measures to protect myself but it took about 6 weeks for me to be identified by my GP surgery as a very high-risk patient and I still have not heard anything from my rheumatology team.”***

***“I was not initially included in government shielded list and took two weeks to find relevant information (via charity website), later confirmed by letter from hospital.”***

***“The letter informing me of my vulnerability didn’t arrive until five weeks into lockdown.”***

The effect of unclear and delayed communications cannot be overstated as it impacts on other areas of people’s lives, such as their employment and work. Some patients reported receiving shielding letters as late as May.

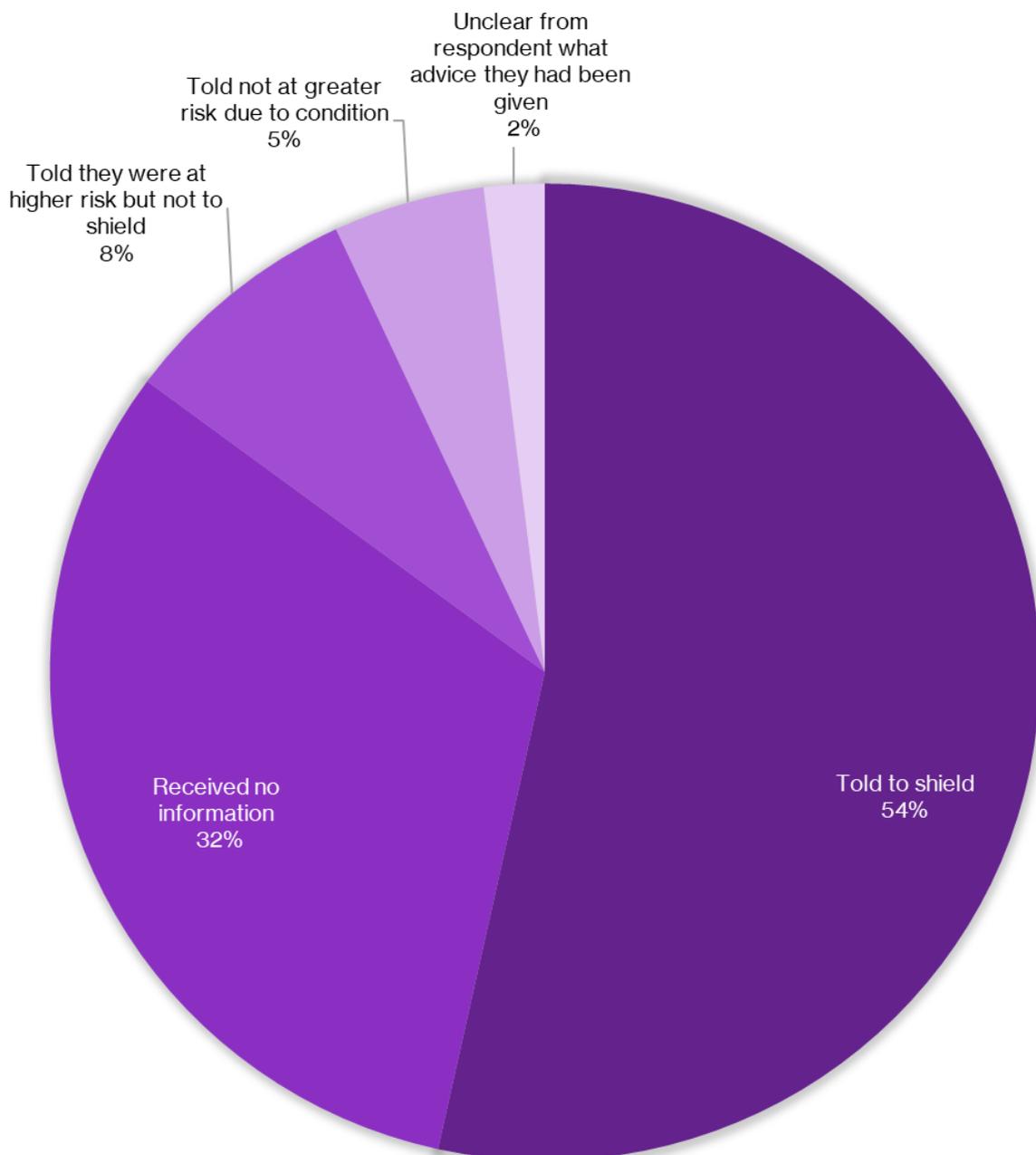
***“I’ve had no contact from my rheumatology team. I’ve assumed that means I’m not at increased risk but it’s not clear. I received a letter last week to say I should shield but it’s not clear if this is because of my condition or medication. I understand that services are incredibly busy and other people are at much higher risk than myself, but it was too late. I had already had COVID-19 and been off work for six weeks by then.”***

***“My GP and hospital contradict on shielding advice.”***

## Proportion of people with RAIRDs who are clinically extremely vulnerable and shielding

Overall, 54% of respondents to the survey had been told to shield, reflecting the high degree of risk of poor outcomes from COVID-19 amongst these conditions, for the reasons highlighted above. The need for shielding is likely to proportionally affect people with RAIRDs compared to other musculoskeletal conditions. The proportion varies by individual condition: 77% of respondents with a form of vasculitis have been told to shield, compared to 49% for lupus.

### Advice given to respondents



## The impact of unclear, contradictory, or delayed communication about risks

The effect of unclear and delayed communications is of vital importance as it impacts on other areas of peoples' lives, such as their employment.

*"I wasn't issued with my letter from the hospital until mid-April and my employer would only offer to put me on SSP [statutory sick pay] and not furlough me. As I cannot work from home I had to continue to work as I could not afford to go home. Once I got my letter, I was furloughed on 80% pay."*

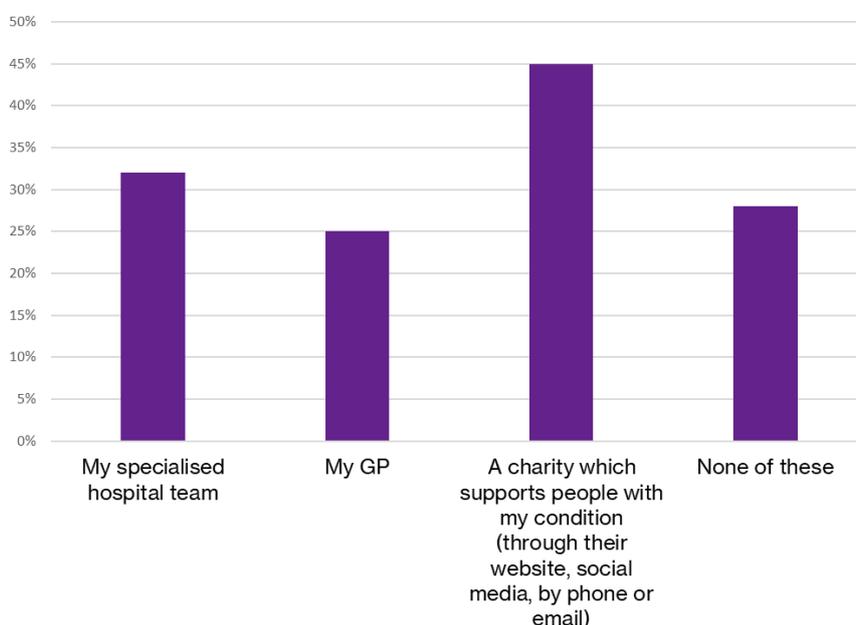
*"I believe there are lots of people who still haven't received the shielding letter and this is causing problems with employers. Both my GP and consultant were unsure as to who would actually be issuing letters. It has been a worrying time."*

## Sources of advice consulted

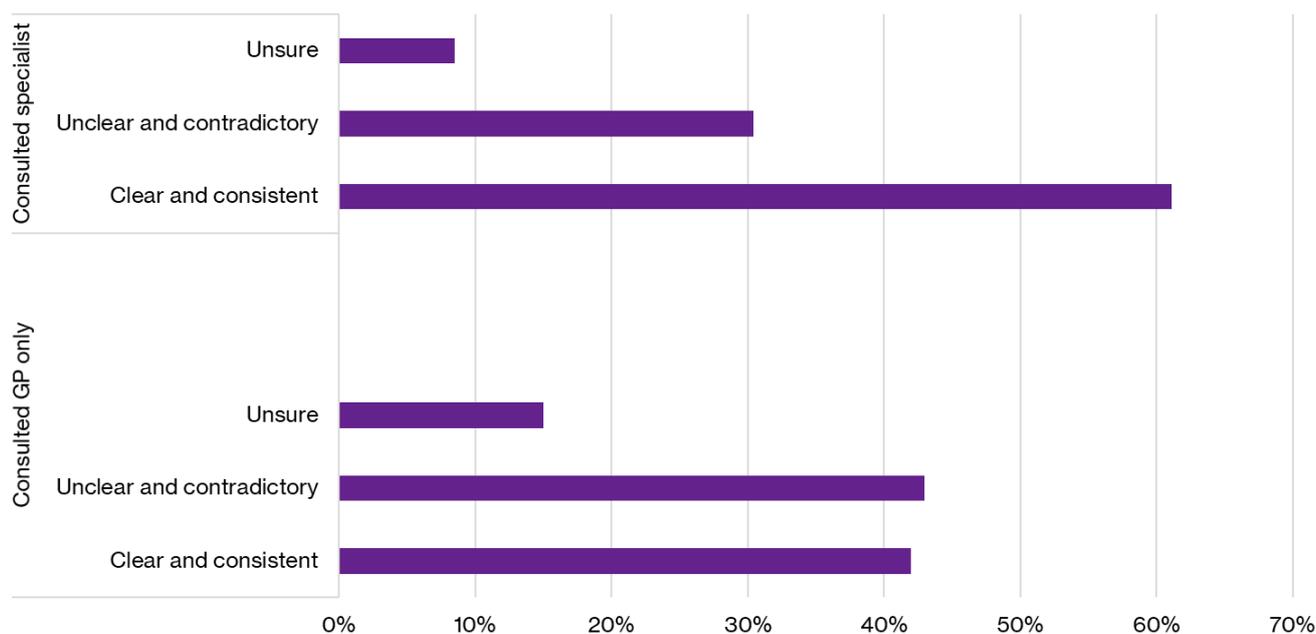
Charities were the source of advice and information consulted the most by respondents. People were slightly more likely to consult a charity if they felt that advice from their clinicians, the health service and the government was unclear or if they had received no personalised advice or information. In their comments, some respondents stated charities had been unable to clarify their queries whilst others stated that charities had been an essential and useful source of information.

People who had consulted or received advice from their hospital specialist were more likely to say the advice from the health service had been clear compared to those who had only consulted their GP. This, as well as comments from respondents at the end of the survey, suggested GP knowledge and ability to support patients with RAIRDs varies considerably. This was also seen in RAIRDA's 2018 report *Reduce, Improve, Empower* which showed that 55% of patients were "not at all" or "not very" confident in their GP's knowledge of their condition. Responses to this survey highlighted examples where their GP and hospital team had advised different levels of risk. This shows the need for greater coordination, and standardisation between healthcare settings for the way these decisions are made.

### Sources of advice consulted by patients



## How people categorised advice, by clinician consulted



## Recommendations

- There needs to be greater clarity and consistency in the communication of individual health protection advice, particularly to subgroups identified as being at high risk of poor outcomes, such as people with RAIRD conditions.
- The process and criteria for identifying people who are at higher risk needs standardisation across the NHS, informed by greater knowledge of impact of COVID-19 on people with RAIRD conditions during the pandemic.
- To avoid contradiction and confusion, these criteria need to be applied consistently across all healthcare settings and specialties.
- Registration of people with RAIRD conditions with Public Health England's rare disease registration service (NCARDRS) would facilitate their identification and risk assessment to support future health protection advice for this vulnerable subgroup of the population.
- The survey results highlight the challenges faced by people living with RAIRD conditions stemming from fragmentation of care. Solving this requires greater coordination across healthcare settings.

# Personal impact of shielding

The high percentage of shielding people with RAIRDs means the impact of shielding is an extremely important issue to this community.

When respondents were invited to comment on issues not raised in the survey that they thought were important many raised issues around mental health, particularly around shielding.

***“It’s frightening to have to keep in and completely isolate myself. It’s damaging to my mental health with many really difficult days.”***

***“Logistical, physical and practical healthcare arrangements were put in place quickly. There has not been a lot of mental health support”***

***“My mental health is getting worse due to not being able to get out & about as much.”***

***“My mental health is suffering greatly, I have been prescribed a maximum dose of Prozac, my moods are very low and although I am trying my hardest to control this, I’m finding it increasingly difficult.”***

***“Mental health worse, have days of crying due to loneliness. Getting worried about when I can go out, will I want to go out?”***

Some respondents expressed frustration at the lack of support for people who were shielding and said they felt they had been abandoned. Many cited specific issues with getting essentials such as groceries and medication delivered.

***“I feel like I’m being punished for having a medical condition that is out of my control and I think the government needs to be doing more to allow highly vulnerable people some freedom, while still protecting them. I understand that the measures are in place to protect us in the short term, but being trapped in your own home is not sustainable in the long term and at the moment I feel abandoned.”***

RAIRDA’s 2018 report *Reduce, Improve, Empower*, identified the impact of peoples’ condition on their mental health and wellbeing. More than half (52%) of people said they felt isolated or lonely at least once a week as a result of the effects of their condition, with one in five (21%) feeling that way every day. The current crisis has increased this sense of isolation and further highlights the need for access to emotional and psychological support for this group of people.

## Recommendations

- **Access to emotional and psychological support is essential to help people with RAIRDs to better manage these life-limiting conditions, and the isolation and loneliness that is often experienced.**
- **UK governments should adhere to the principles of the ‘Nothing About Us Without Us’ statement from National Voices<sup>4</sup>. UK governments should actively engage with those most impacted by changes that affect their lives. Two million people who are shielding and the millions more who have been told they are at higher risk should be the prime consideration in decisions made by UK governments about easing lockdown measures.**
- **As the lockdown is eased, support for shielding groups must be continued, including support with grocery shopping and mental health, in recognition that many will still have concerns about their safety and prolonged isolation may have a long ‘after-effect’ on a person.**

# The impact of COVID-19 on care for people with RAIRDs

The demands on the health service of dealing with COVID-19 patients and the need for potentially vulnerable people to minimise their potential exposure to the virus have led to changes in the provision of healthcare for people with RAIRD conditions, including disruption to usual treatment pathways, alterations in care processes and monitoring schedules for immunosuppressive drugs. However, this disruption could lead to serious complications for people living with these conditions: Regular monitoring tests (clinical assessment, blood and urine monitoring) is required to accurately assess disease activity and damage which might otherwise be undetected and for which rapid diagnosis and treatment is needed.

80% of respondents said they had experienced a change in how their care has been provided.

Out of all respondents:

- 40% have had a telephone or virtual appointment when they would normally have had one in person.
- Nearly half (46%) of people have had an appointment cancelled.
- One in four (24%) have already had a reduction in the frequency of blood monitoring tests.

Across the UK nearly 37% of respondents who have reported a change in their usual care felt it had impacted on their ability to manage their condition. The percentage of shielding patients who had experienced a change in care, and the proportion who felt this had affected their ability to manage their condition was similar to the overall figure. Whilst the sample size per UK nation is small and so findings should be used with caution, in Wales, the proportion of people who reported a change in care who said it had impacted their ability to manage their condition is significantly higher than other UK nations at nearly 50%.

Some patients reported that home visits had meant that they had still been able to have essential blood tests taken without attending hospital.

***“Have had my monthly blood test moved to a home visit and all my medication is now automatically ordered for a month at a time for the next six months. Very organised by my surgery.”***

We know that some tests, such as urinalysis, cannot as yet be carried out through home testing. It is also clear that not every area has been able to implement home testing.

Concerns about virtual appointments were repeated in comments by other patients concerned about the lack of physical tests they normally have.

***“I have just been offered telephone consultations but no arrangements for blood tests that are normally arranged for the week before my appointment so that results can be discussed during the time with the consultant. I’m not sure what’s going to be achieved over the phone!”***

***“I am waiting on lung tests which have been postponed so I have no idea if I have lung involvement. I therefore have no idea if my condition is getting worse or if this means I am at high risk from COVID-19.”***

***“Currently experiencing a significant flare up of my disease. Although I feel fully supported by my rheumatology team from a distance, I do wonder how differently my flare up would be managed if COVID-19 restrictions were not currently in place.”***

Of the 556 people who said they had a virtual or telephone consultation, 195 (35%) still said changes to their treatment regime had affected their ability to manage their condition. This was better than the 46% of people who had experienced a cancellation who said their ability to manage their condition had been affected as a result of treatment changes. However, many people who had virtual appointments still felt their ability to manage their condition had been affected. Alongside comments from respondents this shows that virtual appointments alone are insufficient to support many people with RAIRDs.

Therefore, whilst virtual appointments can save people with RAIRDs time, money and the stress of travelling, and people with RAIRDs continue to value helplines staffed by nurses, it is important to remember that they cannot be a substitute for physical appointments when these involve vital monitoring tests.

Most concerning of all were the people who felt 'abandoned' or had been left without a check-up for their condition for nearly a year. It was also clear from comments that a lack of communication about changes to care was a major issue for patients.

***“My next appointment is now one year away and I have had no contact from my specialist team. They do not offer telephone appointments and have not contacted me despite my being extremely unwell.”***

***“I think that patients with long-term chronic illnesses have been forgotten. We have been left to just manage while in some cases getting sicker because our medication has been restricted. Or been left on medication doses that are incorrect due to a scheduled appointment being put back. Another factor is not being able to get vital scans or tests to check our medical conditions.”***

***“I feel abandoned by my three specialists, all appointments cancelled by letter with no follow-up. I have had one telephone appointment with my GP, at my request, to discuss blood tests whilst shielded.”***

***“As I have only recently been diagnosed, I feel I don't know enough about my treatment and condition to know whether it is being monitored. The hospital has passed my care to the GP so I am now going to contact them as I believe I should be having regular blood tests.”***

***“My treatment by one hospital department has been exemplary, the communication from another department at the same hospital has been terrible.”***

***“My consultant has told me about the importance of regular and annual check ups but these have stopped and I have had no notification of future appointments.”***

Annual check-ups and regular monitoring tests are vital to monitor disease course and any potentially damaging side-effects from medication as these can often be asymptomatic and so not noticed by patients or picked up by a virtual consultation. This added need for physical monitoring tests means the needs of people with RAIRDs are distinct from those with many other rheumatology conditions.

***“Reduced blood tests for monitoring medication mycophenolate means that early warning signs for potential serious side effects will not be picked up. Also, a telephone consultation with a specialist will not pick up any asymptotic changes or deterioration which could be serious. Also six monthly bloods tests have not been carried out. By the time I have my next appointment in six months it will be over a year meaning I could have late kidney damage before it was detected.”***

The more people these tests are interrupted for, the more people could suffer unnecessary complications. This will not only have consequences for patients, but also the health service's long-term costs as these complications will require more complex and expensive treatments.

Some people reported that they had cancelled appointments themselves due to fears of COVID-19 infection; however, this seemed to be outweighed by the number who commented that they felt support was unavailable rather than that they were reluctant to access it. People who had attended appointments acknowledged and seemed reassured by steps taken to protect them and reduce the risk of infection, such as healthcare staff wearing PPE (personal protective equipment) and minimising the time spent in waiting areas. Therefore, communicating the steps being taken to protect patients seems a sensible strategy to encourage attendance.

## Recommendations

- **The National Institute for Health and Care Excellence (NICE) has advised clinicians to take steps to protect vulnerable patients during physical visits. Clinical teams can reassure patients and help to ensure attendance by communicating and discussing these steps with patients in advance of appointments.**
- **Unacceptable interval times between blood monitoring and urinalysis need to be avoided. Plans for named coordinators to support the care of people at high risk of COVID-19 and upskilling NHS staff to deliver more support during a single home visit are welcome and we hope these will benefit people with rare autoimmune rheumatic diseases.**
- **Safety-netting exercises will be important to prevent people experiencing unsafe intervals between hospital appointments and making sure undiagnosed or recently diagnosed patients start treatment promptly.**

# Access to vital medication

Without the medication they need to control their conditions, people with RAIRDs can experience a flare of their disease. This can be a serious situation requiring hospitalisation, increasing the burden on the health service. Securing supplies of these medications is therefore an important way of keeping these people safe and reducing the load on the health service.

In late March one of our member charities was inundated with calls from people unable to collect their normal prescription of hydroxychloroquine, after this was “talked up” as a potential treatment for COVID-19, particularly in other countries. Since then we have seen these issues resolved in the short-term and the government has issued welcome reassurances about measures being taken to ensure medicine which is in demand reaches patients who need it.

Thirty-one percent of respondents reported a new or unusual issue had arisen in obtaining their regular medication. However, 74% of this group said these issues had now been resolved, leaving 8% of all respondents saying they had experienced a new issue which had not been resolved yet. A slightly higher proportion of people with lupus experienced issues obtaining their medication which might be expected given the high proportion prescribed hydroxychloroquine. At the same time, the difference was small, suggesting that these issues were not confined to one medication and that not all people receiving hydroxychloroquine had experienced issues.

## Recommendations

- **Actions taken so far to ensure medication in demand in the UK cannot be subject to parallel export and can only be prescribed for those with a relevant clinical need are welcome. As many medicines people with RAIRDs rely on are produced abroad, industry and government will need to work together to ensure global supply chains remain robust.**

# Employment and income

A small number of people with RAIRDs have experienced difficulties with employment and faced a choice between their financial security and keeping themselves safe. Overall, the pandemic has had a greater financial impact on people with RAIRDs than the general public.

Of those in employment and believing themselves to be at high or very high risk from COVID-19, over 50% had been able to keep working from home or work in a way which reduces their contact with other people, 27% have been furloughed, 6% are self-employed and not able to work. A small group (4%) say their employer has not been supportive in taking steps to reduce their contact with other people. Some of this group have taken unpaid leave to keep themselves safe. A final group consisting of 6% of respondents have been placed on statutory sick pay (SSP), despite employees who are shielding being eligible for being put on furlough. SSP is only £95 a week or just under £5,000 pro-rata and represents a huge difference to the furlough scheme which gives employees 80% of their salary.

Respondents commented on how the guidance for employers was open to interpretation, and many were concerned about being pressured to return to work in conditions which might put them at risk. This is an issue for people who have been told they are at higher risk from COVID-19 but not judged to need to shield, as well as for those who are shielding.

***“Guidance for employers isn’t specific enough when it comes to furloughing the extremely vulnerable/shielding category, I qualify for furlough but my workplace aren’t putting me on it - meaning I have to live off of SSP for three months***

***“The importance of clear guidelines is crucial as we need to inform our employers. Inconsistent messages have made it very difficult for a clear dialogue to happen. Chronic illness impacts on work anyway and employers can be unsympathetic due to lack of knowledge and understanding they perceive us being lazy or moaning.”***

***“Whilst the advice to me has been clear I think the advice in general is being interpreted by employers.”***

***“I am concerned about how long I will need to shield for and if my employer will continue to be supportive. My role is not really suited to home working.”***

***“My manager has been very unkind and I have been left feeling incredibly guilty and worried about my employment”***

***“I’m worried that the restrictions are going to get lifted too soon and people like me will have to go back into an office or closed environment where they are at risk.”***

Another important consideration is that needing to shield has an impact on the whole household.

***“My husband may be asked to return to his office-based work, my children to college/further studies. However, if they are still required to shield me it puts us all in an impossible situation.***

Overall, out of all respondents to our survey, 33% said their household’s financial situation had already worsened as a result of the pandemic. This is significantly higher than the 23% of the general public who said the pandemic was affecting their household finances in a poll conducted by the Office for National

Statistics (ONS) at a similar time as this survey<sup>5</sup>.

This difference might be expected given that a greater percentage of people with RAIRDs will have been furloughed compared to the general public, due to them being more likely to shield. Given the disproportionate financial impact on people with underlying health conditions of the pandemic, UK governments need to take steps to ensure people are able to access financial support, such as the furlough scheme, and do not feel pressured to return to workplaces which might put them at undue risk. The fact that 27% of respondents were on furlough through the UK government's job retention scheme before including those being paid SSP means that a slightly higher proportion of people with RAIRDs were furloughed than the general population<sup>6</sup>. As people with RAIRDs seem to be over-represented among furloughed employees, this means that as the job retention scheme is scaled back so that employers need to make contributions, these changes may have a disproportionately negative impact on people with RAIRDs.

## Recommendations

- **All employees who have been advised to shield should receive 80% of their salary, rather than employers being able to choose between placing them on SSP and furloughing them.**
- **The government should reopen the furlough scheme to new entrants, as fluctuations in people's health conditions and changes in medication will mean some people will fall into the shielding category after the deadline.**
- **People who are shielding and on furlough should be excluded from the government's recent deadline for new additions to the furlough scheme.**
- **Those at higher risk from COVID-19 should be at the forefront of considerations around 'reopening' the economy and not be pressured to return to work before it is safe to do so.**
- **The government should act to minimise the degree to which guidance is open to interpretation by employers.**

# Conclusion

Over 50% of people with RAIRDs are shielding across the UK. This may have been a necessary step to protect these people from COVID-19, but it has had a knock-on impact on these people's mental and physical health and wellbeing.

The need to protect these people from COVID-19, as well as disruption to the health service from COVID-19, has led to changes in care for the vast majority of people with RAIRDs. This, and the confusion about which patients should be shielding, has been exacerbated by issues with the care of these patients before COVID-19. This cannot be wholly accounted for by patients being reluctant to present to health services with issues or attend appointments due to their concerns about COVID-19. When patients commented in their own words about their experience of the health service during this period, the word 'abandoned' came up repeatedly. Better communications could help resolve this issue. Virtual or telephone appointments can be and have been helpful for people with RAIRDs, but they cannot replace or substitute for physical monitoring tests.

It is vital that people with RAIRDs do not lose out in the labour market due to the need to protect themselves. Future shielding guidance must bear this in mind and prevent any pressure being put on people to return to work before it is safe to do so. Not only are people with RAIRDs more likely to lose out financially due to the fact that many of them have been furloughed to allow them to shield, but some have lost out substantially by being put on SSP by their employer instead of receiving 80% of their normal salary. Decisions about whether to furlough someone or put them on SSP should not be at employer discretion.

These issues represent a crisis in how people with these chronic conditions access healthcare, support themselves and their families and live their lives. Even if the threat from COVID-19 can be eliminated within the very near future, the health service faces a substantial challenge in surmounting the backlog of appointments for care which has been delayed and supporting the increased number of people with mental health needs.

When COVID-19 does recede as a public health concern, these conditions will still be with us. The testimony of people with RAIRDs in this report shows the need to improve the way these people are cared for and communicated with.

# Recommendations

## Advice and communication about risk from COVID-19

- There needs to be greater clarity and consistency in the communication of individual health protection advice, particularly to subgroups identified as being at high risk of poor outcomes, such as people with RAIRD conditions.
- The process and criteria for identifying people who are at higher risk needs standardisation across the NHS, informed by greater knowledge of impact of COVID-19 on people with RAIRD conditions during the pandemic.
- To avoid contradiction and confusion, these criteria need to be applied consistently across all healthcare settings and specialties.
- Registration of people with RAIRD conditions with Public Health England's rare disease registration service (NCARDS) would facilitate their identification and risk assessment to support future health protection advice for this vulnerable subgroup of the population.
- The survey results highlight the challenges faced by people living with RAIRD conditions stemming from fragmentation of care. Solving this requires greater coordination across healthcare settings.

## Personal impact of shielding

- Access to emotional and psychological support is essential to help people with RAIRDS to better manage these life-limiting conditions, and the isolation and loneliness that is often experienced. Adequate resourcing for mental health services is vital to support people who are shielding or have been shielding.
- We support the principles of the 'Nothing About Us Without Us' statement from National Voices. UK governments should actively engage with those most impacted by changes that affect their lives. Two million people who are shielding and the millions more who have been told they are at higher risk should be the prime consideration in decisions made by UK governments about easing lockdown measures.
- As the lockdown is eased, support for shielding groups must be continued, including support with grocery shopping and mental health, in recognition that many will still have concerns about their safety and prolonged isolation may have a long 'after-effect' on a person.

## The impact on care for people with RAIRDS

- The National Institute for Health and Care Excellence (NICE) has advised clinicians to take steps to protect vulnerable patients during physical visits. Clinical teams can reassure patients and help to ensure attendance by communicating and discussing these steps with patients in advance of appointments.
- Unacceptable interval times between blood monitoring and urinalysis need to be avoided. Plans for named coordinators to support the care of people at high risk of COVID-19 and upskilling NHS staff to deliver more support during a single home visit are welcome and we hope these will benefit people with RAIRDS.
- Safety-netting exercises will be important to prevent people experiencing unsafe intervals between hospital appointments and making sure undiagnosed or recently diagnosed patients start treatment promptly.

## Access to vital medications

- Actions taken so far to ensure medication in demand in the UK cannot be subject to parallel export and can only be prescribed for those with a relevant condition are welcome. As many medicines people with RAIRDs rely on are produced abroad, industry and government will need to work together to ensure global supply chains remain robust.

## Employment and income

- All employees who have been advised to shield should be furloughed and receive 80% of their salary, rather than employers being able to choose between placing them on SSP and furloughing them.
- Those at higher risk from COVID-19 should be at the forefront of considerations around 'reopening' the economy and not be pressured to return to work before it is safe to do so.
- The government should reopen the furlough scheme to new entrants, as fluctuations in peoples' health and changes in medication will mean some people will fall into the shielding category after the deadline.
- People who are shielding and on furlough should be excluded from the government's recent deadline for new additions to the furlough scheme.
- The government should act to minimise the degree to which guidance is open to interpretation by employers.

# References

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While there are inherent limitations to survey data, including self-selection of participants, the strength of the survey results are the large number of respondents, and the opportunity for people with a broad range of experiences to contribute. Some quotes used in this report were edited for concision.