Versus Arthritis welcomes the opportunity to provide input to the Scottish Government’s work on the impacts of COVID-19 shielding.

This is an initial assessment and we welcome opportunities to continue working with the Scottish Government as it considers longer-term policy development in relation to COVID-19 shielding.

This initial assessment includes responses to the following stakeholder survey questions requested by the Scottish Government:

1. **Please briefly describe how your organisation’s work is connected with Shielding.** (i.e. are you involved with one or more of the specific clinical categories? Or a specific demographic of people within the shielded group? What kinds of support do you provide?)

2. **Do you have any data or information about the sociodemographic make-up of your shielding client group?** (We are particularly interested in numbers of people likely to return to work; numbers of shielding children or families with children in the household; numbers of people living alone; numbers who may rely on carers for support.)

3. **What challenges are your client group likely to be experiencing as a result of shielding (physical health, mental health, wider social and economic challenges, etc.)?**

4. **What support needs do you think your client group will have as lockdown eases?**

5. **Do you think your shielding client group would welcome increased flexibility in the shielding guidance so that they could better decide for themselves which measures to follow?**

Data used to inform Versus Arthritis’ response to the stakeholder survey

- Whilst we are unable to provide an exact estimate of the number of people with arthritis and musculoskeletal conditions who are currently shielding in Scotland, Versus Arthritis has carried out a number of data and information gathering exercises in relation to the impact of COVID-19 and shielding.

A) **Versus Arthritis survey of shielding population in Scotland**

- In response to this request from the Scottish Government to provide information on the impact and demographics of the shielding population in Scotland, Versus Arthritis carried out a short survey amongst our Campaign Network in Scotland.¹ This is a group of approximately 900 people in Scotland who support our campaigning and influencing work.
• The survey was launched on 9th June 2020, and the data below is from 114 people who responded by 10am 11th June. The survey will remain live for the time being and additional data and analysis can be supplied as required.

• **Note that the initial survey question asked participants to select one of the following options, and therefore ensure only those actively shielding responded:**
  - I am shielding and am answering these questions from my own experience (n = 113)
  - I am answering these questions on behalf of someone I care for who has been asked to shield (n = 1)

• All available data from this survey is presented in **Annex A**

**B) Versus Arthritis survey of COVID-19 impact (UK wide)**

• Versus Arthritis carried out a UK-wide survey about experiences during the pandemic which was distributed to both existing and new supporters of the charity at the beginning of April 2020. Pain and pain management was used as an overarching theme, but there were specific questions asking how people’s lives were being affected by COVID-19. The survey remains open until the end of June.

• Analysis of the data from the month of April and May has been carried out on both the total sample (n = 5,882 including 561 respondents from Scotland) and a sub-set who selected the option: 'I've been advised to self-isolate for 12 weeks' (n = 1,958 including 164 respondents from Scotland). Note that further analysis of additional data for June will be carried out and made available when possible.

• All available data from this survey is presented in **Annex B**.

**C) Versus Arthritis insight from our engagement channels**

• Versus Arthritis receives communication from our community through channels including our helpline, on-line virtual assistants, on-line community etc. (see Question 1 below).

• Versus Arthritis has a listening panel which is an independently recruited and managed panel of around 50 people with arthritis. From 27th April the charity had weekly discussions with 8 members to understand in detail the impact of COVID-19 on their lives. A number of these members reported they were shielding.

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**1. Please briefly describe how your organisation’s work is connected with Shielding. (i.e. are you involved with one or more of the specific clinical categories? Or a specific demographic of people within the shielded group? What kinds of support do you provide?)**

• Versus Arthritis is the largest charity supporting people with musculoskeletal conditions in the UK and we represent over 1.5 million people in Scotland with arthritis or other musculoskeletal conditions. It was formed from the merger of Arthritis Research UK and Arthritis Care, including Arthritis Care Scotland, in September 2018.

• Musculoskeletal conditions are the leading cause of long-standing illness in Scotland. As outlined in responses below, a significant proportion of people with
arthritis are vulnerable during the COVID-19 pandemic and are, or are likely to be, in the shielding category – see Box 1.

**Box 1: COVID-19 shielding and musculoskeletal conditions**

- Some types of arthritis are caused by the immune system becoming overactive and attacking healthy parts of the body, such as the joints. Treatments for these conditions work by dampening or suppressing the body's immune system to prevent damage to healthy joints. However, this also means that certain treatments make those taking them more vulnerable to picking up infections, such as COVID-19.
- The British Society of Rheumatology (BSR) has worked with NHS England and national experts to identify which groups of people with rheumatic conditions need to shield. This guidance has been applied to adults, children and young people regardless of age. Versus Arthritis provided feedback on this risk scoring system to inform the Scottish Government’s shielding advice to people with rheumatic conditions.
- In Scotland, patients in shielding group 5 (‘People on immunosuppression therapies sufficient to significantly increase risk of infection or who have had their spleens removed’) were identified by cross-referencing information provided by secondary care on prescription of biologic drugs and other secondary care prescriptions with primary care and other centrally held data, using an algorithm similar to the BSR stratification guide.

- In Scotland Versus Arthritis engages and supports people with arthritis and musculoskeletal conditions in a variety of ways, including those who are shielding. Our activity during the COVID-19 pandemic is summarized in **Table 1**.

**Table 1.** An overview of how Versus Arthritis is supporting people with arthritis in Scotland who are shielding

<table>
<thead>
<tr>
<th>Area</th>
<th>Versus Arthritis activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>INFORMATION: Providing accurate information and advice on shielding for people with arthritis and musculoskeletal conditions.</td>
<td>• Developed website resources and information in collaboration with professional bodies so people can identify their relative risk and advice on shielding.&lt;br&gt;• Developed Scotland-specific resources on COVID-19 which includes specific guidance on shielding.</td>
</tr>
<tr>
<td>IMPROVING ACCESS: Providing range of contact options for people with arthritis who are shielding.</td>
<td>• We provide a free Helpline which provides advice on shielding. During the COVID-19 pandemic queries have increased by 80%.&lt;br&gt;• We also provide email, social media and online forum support to people who are shielding.&lt;br&gt;• We launched COVA our COVID-19 chatbot which provides 24/7 advice including on shielding.</td>
</tr>
<tr>
<td>SELF-MANAGEMENT: Offering support to self-manage musculoskeletal pain to those who are shielding.</td>
<td>• COVA-chatbot provides information on staying active and mentally healthy during the pandemic.&lt;br&gt;• Offering live-streaming of Tai Chi for arthritis in groups to existing and new beneficiaries.&lt;br&gt;• Working with partners to roll-out our online self-management toolkit.&lt;br&gt;• Offering telephone support including welfare checks and soft self-management skills. Currently exploring providing a ‘telephone befriending</td>
</tr>
</tbody>
</table>
service’ to tackle isolation faced by those who are shielding.
- Soon launching our online offer for physical activity resources for those with musculoskeletal pain and/or shielding.

| YOUNG PEOPLE: Supporting young people with arthritis who are shielding. | • Launched new ‘Arthritis Tracker’ for teens and young adults with arthritis to help manage their symptoms, talk to health and care providers and get support.
• Moved delivery of our activities to online platform for young people. |
| LOCAL SUPPORT: Keeping in touch with people with arthritis who are shielding. | • Launched ‘Keeping Connected’ newsletter for people in Scotland during the COVID-19 pandemic. |

2. Do you have any data or information about the sociodemographic make-up of your shielding client group? (We are particularly interested in numbers of people likely to return to work; numbers of shielding children or families with children in the household; numbers of people living alone; numbers who may rely on carers for support.)

Key points:
- Our survey data indicates that a large number of people (approximately half) with musculoskeletal conditions in Scotland who are shielding may be doing so without having received a ‘shielding letter’ from the Government (Graph 3).
- The number of people with musculoskeletal conditions in Scotland who are shielding increases with age. About half of those shielding are of working-age (Graph 5).
- Whilst clinical advice on shielding focuses predominantly on those with inflammatory or autoimmune forms of arthritis, our surveys have revealed the majority (approximately two-thirds) of people shielding report more than one musculoskeletal condition (Graph 6). Pre-existing research also indicates the shielding group is likely to have other long-term conditions including diabetes, a cancer diagnosis, lung or cardiovascular disease which may increase their risk of COVID-19 infection or wider vulnerability.
- Whilst specific data on the socioeconomic status of those with musculoskeletal conditions who are shielding is not available, it is likely that a larger proportion of this group will be in the most/more deprived quintiles in Scotland (see below).

Demographics of shielding population amongst those with arthritis and musculoskeletal conditions in Scotland
- Those on certain immunosuppressant therapy to manage inflammatory forms of arthritis may be advised to shield as per the Scottish Government’s guidance (see Box 1 for further detail).
- In Scotland approximately 37,000 adults have rheumatoid arthritis and it is estimated that approximately 1,000 young people have some form of juvenile arthritis in Scotland. Note that not all of these people will be ‘at risk’.
- It should also be noted that poor musculoskeletal health is often accompanied by other long-term conditions such as type 2 diabetes, cardiovascular disease, lung disease and cancer, with prevalence of one or more additional morbidities increasing with age. This
is relevant as the Scottish Government’s guidance highlights those with rheumatic conditions are at increased risk if they: ‘also have heart disease, lung disease, kidney disease, diabetes or are aged over 70 years.’

**Socioeconomic profile of arthritis and musculoskeletal conditions in Scotland**

- Musculoskeletal conditions are more prevalent in the most deprived communities in Scotland compared to the least deprived areas.  
- In Scotland there is a 20% ‘employment gap’ between the number of people with arthritis in work and those with no health condition. A third of people with rheumatoid arthritis will have stopped working within two years of onset and half are unable to work within 10 years. 
- Unpublished data in a report from YouGov commissioned by Versus Arthritis estimated that in 2018 approximately 27% of people with musculoskeletal conditions in Scotland reported reliance on formal or informal care, with reporting significantly higher amongst those in lower (C2DE) socio-economic groups compared to higher groups (ABC1). 

3. **What challenges are your client group likely to be experiencing as a result of shielding (physical health, mental health, wider social and economic challenges, etc.)?**

**Key points:**

- Arthritis and related musculoskeletal conditions often limit people’s mobility and dexterity and so stop people being able to do activities of everyday life. People with these conditions often experience pain and fatigue; for many people, a musculoskeletal condition can result in a loss of independence, isolation and reduced quality of life.

- Our survey of people with musculoskeletal conditions who were asked to self-isolate indicates that a large proportion of respondents (around half) reported difficulties getting their shopping and other deliveries or said they were feeling more lonely or isolated than usual or had appointments for their arthritis cancelled (Graph 9).

- Our data also indicates that the majority (more than two-thirds) of those asked to self-isolate felt they would get support from family, friends or neighbours, with only a minority expecting to receive support from local health and social care or voluntary services (Graph 10).

- Thematic analysis of insight gathered by the charity and from free-text responses to our survey of people with musculoskeletal conditions who are shielding revealed:
  - A feeling of being ‘overlooked’ and left out of health conversations.
  - Impacts on physical mobility and health, with an increase in painful symptoms of their condition, including barriers to exercise as they cannot get outside.
  - A marked impact on mental health, with feelings of isolation and loneliness exacerbated by shielding. It should be noted that many appreciated having the support of their family. As time has progressed, there has been anxiety about the inability to plan for the future and increased reporting of fears of being vulnerable as activities return to ‘normal’.
  - A support ‘gap’ for practical help around the home, for example broken appliances and a fear of both being perceived as a burden or people entering their home.
• Issues around access to both medical (e.g. GP, rheumatology blood testing) and personal care (e.g. massage, podiatry) appointments.

• Problems around work and employment with people reporting challenges working from home and employer understanding. Several people highlighted that the necessity of working from home because of shielding, actually improved their relationship with work.

Further insight and case studies:

• Versus Arthritis has put forward a series of case studies in the media to illustrate the impact of COVID-19 and shielding on people with arthritis. A list of these is included below for reference:
  o BBC Radio 4 Today - You can listen to the Today programme report about shielding, featuring the Versus Arthritis case study Sinead Fitzgibbon, at 1:36:56 (available for 15 days)
  o The Telegraph - People shielding from coronavirus ‘feeling left behind’ as lockdown measures ease
  o i News - Coronavirus: high risk people feel ‘left behind’ as lockdown eases

• The charity has also recently published a blog on the impact of COVID-19 and shielding on our beneficiaries in Scotland with the ALLIANCE: https://www.alliance-scotland.org.uk/blog/opinion/pain-colours-everything/#expanded

4. What support needs do you think your client group will have as lockdown eases?

Key points:

• Please see results below (Graph 1) from Versus Arthritis’ survey which highlights the key support needs of people with musculoskeletal conditions in Scotland who are shielding. We asked: ‘How could your experience of shielding be improved going forward?’

• These results highlight that most people who are shielding would appreciate a range of additional support, from support to return to ‘normal’ physical activity to help to manage their painful symptoms. Many respondents also expressed a desire to retain access to priority deliveries and phone or video appointments with their health care services.

Graph 1: Future support needs requested by participants of Versus Arthritis’ shielding survey in Scotland
• For those who are working, the majority requested support to help agree a safe plan to return to work with their employer. Approximately 40% of the shielding population in Scotland are likely to be in employment and expecting to return to work. It should be noted that few in the UK survey reported support from their employers to work from home. Given the existing barriers to employment faced by people with musculoskeletal conditions in Scotland it is likely that some in the shielding population may face challenges re-entering the workforce.

• For many people with arthritis, lockdown is an everyday reality of living with persistent pain. The agony of arthritis can take away your ability to leave the house, see your family and friends or go to work even under ‘normal’ conditions. This means that for many with arthritis who are shielding, there is anxiety about the return to ‘normal’ as they feel they have benefitted from the changes that have come about due to COVID-19 and harbour concerns that their needs will once again be overlooked.

“More support needs to be given to those of us with multiple health conditions and there needs to be clarity when it comes to letting us know what the dangers are for those of us who are very ill but are not classed by the Government as vulnerable. I feel very vulnerable because of my conditions and find it incredible that those of us with arthritis etc. are classed as being fit to do our own shopping etc. whereas our immune systems are virtually non-existent. It makes me feel as though I am disposable” -Anne, Ross and Cromarty

“My employer was not putting my safety first although they were aware I am vulnerable. I was relieved to receive the government’s letter and know from their update that shielding is extended. My anxiety is the lowest it’s been in years. I’ve been struggling with RA in my part-time job for years and this has taken huge pressure off me physically. My joints are actively flaring but the quality of my life has improved significantly during this time shielding.” -Anonymous, Midlothian

“Mental health support as my previous agoraphobia has returned and I am frightened to go outside at all, even into the garden.” -Anonymous, Lanarkshire

5. Do you think your shielding client group would welcome increased flexibility in the shielding guidance so that they could better decide for themselves which measures to follow?

Key points:

• As illustrated by the data in Graph 1, a large proportion of those shielding said they would welcome specific information targeted towards their own situation. Indeed, a number of comments from survey participants supported a more flexible approach, with some caution expressed around ensuring any decision-making prioritises the safety of those who are at risk:

“I find the one-size-fits-all shielding advice frustrating. I understand why it is given and that it wasn’t possible to make bespoke advice available but lack of exercise has had a negative effect on mental health of many, especially those who are fighting to maintain mobility.” -May, Ayrshire

“I don’t think there is a one size fits all for shielding but understand at the beginning it had to be implemented urgently. Surely a risk matrix should now be used going forward to indicate a score on impact and possibility of contracting the virus per individual. I mentioned above that I don’t know for sure why I am shielding as I wasn’t advised the reason and when I asked my GP surgery they could not tell me why!” -Annette, Stirlingshire
“Shielding has been essential for many of us to be made safe but somewhere along the way we disappeared from the daily briefing and eventually we became invisible. It’s a lonely and frustrating place to be left in, especially when the weather is poor! Everyone has differing vulnerabilities and health needs but blanket coverage needs to be removed and assessments of individual health risks identified so the pathway out of Shielding is not anxiety led to reduce fear.” -Caroline, Inverness-shire

“It’s absolutely essential that lockdown, shielding and assistance to do so *not* be removed prematurely, despite the difficulties it brings. I’d far rather be housebound and safe than outside and at risk. I’d also like to thank all the volunteers who have provided invaluable support for myself and others like me; without their help we simply wouldn’t be able to continue living.” -Anonymous, Ayrshire

- However, respondents to our survey and insight gathered by the charity in relation to shielding has highlighted the importance of clear communication of any new guidance – see Graph 2. Most respondents were positive about both the Scottish Government’s communication of guidance and updates, however there is a clear desire for specific information for people who are shielding.

![Graph 2: Communication needs on shielding](image)

- On Thursday 28th May, Versus Arthritis co-signed a letter with 50 other charities (including Macmillan and National Voices) which highlighted our concerns about the UK Government’s shielding process to date and made a number of recommendations for improvement which may be of interest to the Scottish Government as decisions are approached on changes to shielding guidance:
  - There needs to be urgent and direct communications from Government with those who are vulnerable, especially those who have been advised to shield.
  - There will also need to be clear communications with charities, health and care professionals and local government to ensure consistency of advice given to those who are vulnerable.
We recommend the creation of a cross-Government advisory panel and a named lead Minister to develop a detailed strategy to protect the quality of life of people who are vulnerable to COVID-19, coordinating consistent Departmental policy on support to those that are shielding or are clinically vulnerable. This should have strong input from medical professionals, charities and those who are being advised to shield or staying home. We also believe SAGE should include expertise on disability, psychology and psychiatry.

- Notably, differences in shielding guidance between each of the UK Government’s has led to some confusion, and ideally a more coordinated approach would be favoured by both people with arthritis and Versus Arthritis. We note that NHS England has recently raised the prospect of a new risk stratification tool, which the Government expects to be available in/from September. Hence, if the Scottish Government is developing its own approach to risk stratification for people who are shielding it would be welcomed if Governments could work across nations to agree a shared approach before publication.

- It should also be noted that an evidence-based tool to assess worker’s vulnerability to Covid-19 has also been developed.11 This tool summarises vulnerability for combinations of risk factors including age, sex and ethnicity and various health problems, and translates the risk associated with each risk factor into years which are added to (or subtracted from) an individual’s actual age.

- Furthermore, Recent evidence from Public Health England’s report that indicates that the risk factors for COVID-19 are similar to the risk factors for musculoskeletal conditions. This evidence demonstrated that a number of risk factors related to increased admission and mortality for COVID-19 are common to both musculoskeletal conditions and those reporting chronic pain in England.12 Specifically, age, race, socioeconomic factors, obesity and co-morbidities shared between these three groups should be considered as part of any changes to shielding risk guidance.

- As illustrated throughout our response, people with musculoskeletal conditions in Scotland who are shielding were already facing challenges before the pandemic. Therefore, to ensure any future changes to shielding guidance are suitable, realistic and acceptable, it is essential that the Scottish Government involve people with arthritis directly, and indirectly through organisations such as Versus Arthritis.

Dr James O’Malley, Policy Manager, Versus Arthritis June 2020

e: jomalley@versusarthritis.org t: 020 7307 2260 m: 07484 904201
Annex A: Versus Arthritis survey of shielding population in Scotland

• In response to this request from the Scottish Government to provide information on the impact and demographics of the shielding population in Scotland, Versus Arthritis carried out a short survey amongst our Campaign Network in Scotland. This is a group of approximately 900 people in Scotland who support our campaigning and influencing work.

• The survey was launched on 9th June 2020, and the data below is from 114 people who responded by 10am 11th June. The survey will remain live for the time being and additional data and analysis can be supplied as required.

• Note that the initial survey question asked participants to select one of the following options, and therefore ensure only those actively shielding responded:
  o I am shielding and am answering these questions from my own experience (n = 113)
  o I am answering these questions on behalf of someone I care for who has been asked to shield (n = 1)

Shielding letter data

Shielding with/without a letter from the Scottish Government: Survey participants were asked: ‘Have you received a letter from the Government instructing you to shield?’ Surprisingly, almost half of those who said they were shielding were doing so in the absence of a shielding letter from the Scottish Government. The majority of those shielding who had received a letter were doing so because they were on immunosuppression therapy or were advised to shield by their GP or consultant. Similarly, a large proportion of those shielding who had not received a letter reported they had decided to shield for these two reasons. However, it should be noted that about one-third of people shielding in the absence of a letter reported either ‘I don’t know’ or ‘I believe I am in the ‘at risk’ group’.

Graph 3: Percentage of respondents who had received a shielding letter from the Scottish Government

Yes 51%
No 49%
Graph 4: Reasons given for shielding by those who received a letter and those who had not.

Demographic data
Age range: The majority of those shielding in Scotland were aged 41 years or older.

Graph 5: Age-range of those who participated in the survey.
Musculoskeletal conditions: The most reported condition amongst those shielding was inflammatory or autoimmune disease (36%) with significant, but smaller numbers reporting osteoarthritis or chronic or long-term/ongoing joint pain.

Graph 6: Musculoskeletal conditions reported by survey participants (note they could select more than one option)

Work and employment: Approximately 40% of the shielding respondents in Scotland were in work and expected to return to work.

Further results will be available from this survey over time, and from a wider population.
Annex B: Versus Arthritis survey of COVID-19 impact (UK wide)

- Versus Arthritis carried out a UK-wide survey about experiences during the pandemic which was distributed to both existing and new supporters of the charity at the beginning of April 2020. Pain and pain management was used as an overarching theme, but there were specific questions asking how people’s lives were being affected by COVID-19. The survey remains open until the end of June.

- Analysis of the data from the month of April and May has been carried out on both the total sample (n = 5,882 including 561 respondents from Scotland) and a sub-set who selected the option: ‘I’ve been advised to self-isolate for 12 weeks’ (n =1,958 including 164 respondents from Scotland). Note that further analysis of additional data for June will be carried out and made available when possible.

Demographic data from the total (i.e. UK wide) ‘self-isolating’ sample

Age range: The majority of those ‘self-isolating’ were aged 41 years or older.

![Graph 7: Age-range of those who participated in the survey](image)

Multimorbidity: The majority of those ‘self-isolating’ reported having more than one musculoskeletal condition.

![Graph 8: Number of musculoskeletal conditions reported by survey participant](image)
**Musculoskeletal condition:** The most prevalent condition reported amongst those ‘self-isolating’ was inflammatory arthritis or autoimmune disease (37%), however large numbers also reported osteoarthritis (24%) and chronic or long-term/ongoing joint pain (28%).

![Musculoskeletal condition chart]

**Graph 7:** Musculoskeletal conditions reported by survey participants (note they could select more than one option)

**Work and employment:** NOTE: This data is for April only.
Approximately one-fifth (17.5%) of those ‘self-isolating’ reported they were now ‘working from home’. There were several positive outcomes reported in relation to working from home amongst the ‘self-isolating’ group, including benefits for physical and mental health, however only one-fifth (20%) said their employer had been supportive.

![Work and employment chart]
**Graph 8:** Percentage of respondents ‘now working from home’ who agreed/strongly agreed with the statements

**Issues experienced by those asked to ‘self-isolate’**

![Graph showing issues experienced by those asked to 'self-isolate'.](image)

**Graph 9:** Percentage of respondents who reported issues

![Graph showing percentage of respondents who reported issues.](image)

**Graph 10:** Percentage of how those ‘self isolating’ expected to source additional support

![Graph showing percentage of how those 'self isolating' expected to source additional support.](image)

*Further results will be available from this survey over time, and from a wider population.*
References

2 https://action.versusarthritis.org/page/58110/survey/1?ea.tracking.id=stakeholders
14 https://action.versusarthritis.org/page/58110/survey/1?ea.tracking.id=stakeholders