

Blood Cancer UK briefing – changes to the COVID-19 shielding scheme

June 2020

Overview

In March, the four governments of the UK introduced shielding for over two million people who were extremely clinically vulnerable to COVID-19. This meant they had to stay at home and have minimal contact with the people they lived with and no contact at all with people outside their household. The governments put support in place to help the shielding population through this difficult period which gave them the freedom to shield. However, it is clear that the last three months have been extremely challenging for people in this group, including the 200,000+ people with blood cancer.

Pausing of shielding and the potential effect on people with blood cancer

Shielding is to be 'paused' for everybody currently shielding on 31 July in England, Northern Ireland and Scotland if the COVID-19 infection rate remains low. It will be paused in Wales on 16 August. This is not the 'more nuanced' approach as was promised on 12 June by the Westminster Government¹ which stated:

As the Government learns more about the disease and the risk factors involved, it expects to steadily make the risk-assessment more nuanced, giving confidence to some previously advised to shield that they may be able to take more risk; and identifying those who may wish to be more cautious. The Government will need to consider both risk to self, and risk of transmitting to others.

We are particularly concerned because emerging data shows that people with blood cancer are more likely to die than people with most other health conditions if they catch COVID-19². **So even though infection rates are lowering, COVID-19 is still active in the community and the risk of a poor outcome if someone with blood cancer becomes infected is unchanged.** It's likely that many people with blood cancer will either be advised to continue shielding by their doctors or will choose to do so because they haven't been given enough evidence to feel safe.

Shielding currently treats everyone including people with blood cancer as a single group, but we know there are differences in their risk of becoming seriously unwell or dying if they were to become infected with COVID-19. There is an opportunity to release some people with blood cancer from needlessly being asked to shield now or in the future. But this requires an evidence-based pathway out of shielding, that people with blood cancer can understand and trust: grounded in clinical evidence, developed by the doctors who treat people with blood cancer and with the involvement of people with blood cancer.

Prior to the lifting of shielding, the UK Governments must:

- Re-commit to the policy announced on 12 June to develop a more nuanced approach to shielding that can be adopted if shielding needs to be re-introduced.

¹ <https://www.gov.uk/government/publications/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy/our-plan-to-rebuild-the-uk-governments-covid-19-recovery-strategy>

² Aries et al, Clinical outcome of coronavirus disease 2019 in haemato-oncology patients; British Journal of Haematology; first published 18 May 2020; <https://doi.org/10.1111/bjh.16852>

Shah et al, Poor outcome and prolonged persistence of SARS-CoV-2 RNA in COVID-19 patients with haematological malignancies, King's College Hospital experience; British Journal of Haematology; first published 11 June 2020; <https://doi.org/10.1111/bjh.16935>

The OpenSAFELY Collaborative; "OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients"; medrxiv.org, posted 7 May 2020; <https://doi.org/10.1101/2020.05.06.20092999>

- Commit to including more detailed guidance for blood cancers in that approach, so that people with blood cancer who are at lower risk of serious illness can be safely excluded from future shielding guidance and people at highest risk receive clear information and support to help guide their choices about how to avoid infection.
- Commit to reviewing the available evidence on outcomes of COVID-19 infection for people with blood cancer as part of this process and to ensure both haematologists and people with blood cancer are included in the development of guidance.
- Publish the infection rate at which people might be asked to shield again and confirm whether this can happen regionally or locally.

If formal shielding support is to be lifted, the UK Governments must:

- Re-open the furlough scheme to enable people whose clinicians advise them to continue shielding and/or where their employer cannot create a COVID-free workplace, to claim 80% of their salary therefore ensuring they don't have to return to work risking their health.
- Ensure everyone newly diagnosed with blood cancer continues to be added to the shielding list.
- Commit to re-introducing the full support package if people are asked to shield again if the infection rate increases.

What is shielding and how many people with blood cancer are shielding?

Governments across the UK announced in late March that millions of people at high-risk of developing severe complications from coronavirus should protect themselves from all contact for 12 weeks – a process known as 'shielding'.

The English group – 1.5 million people in total - were written to from Monday 23rd March and told that they should shield themselves until at least 15 June. The letter also enables recipients to:

- Receive statutory sick pay as a result of not going into work³
- Get preferential access to supermarket delivery slots⁴
- Qualify for free food and other services via the 'clinically vulnerable' service⁵

³ <https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19/guidance-for-employers-and-businesses-on-coronavirus-covid-19#sick-pay>

⁴ <https://deframedia.blog.gov.uk/2020/03/21/daily-update-on-the-coronavirus-response/>

⁵ <https://www.gov.uk/coronavirus-extremely-vulnerable>

There are at least 164,000 people with blood cancer who have been asked to shield in England⁶, 21,000 in Scotland⁷, an estimated 12,000 in Wales and 7,000 in Northern Ireland⁸. However, people newly diagnosed since March with blood cancer should also have been asked to shield. This means that the above figures are an underestimate.

People with blood cancer are at increased risk of both catching COVID-19 and dying from it

There is growing evidence that people with blood cancer are at greater risk of both catching COVID-19 and dying from it if they do catch it. We note the findings of a recent paper by Goldacre *et al*, which examined factors associated with COVID-19-related hospital death. The authors found that those with a history of haematological malignancy were at more than three times increased risk up to five years from diagnosis, and nearly double the risk thereafter⁹.

It's therefore crucial that Governments across the UK do not end the shielding scheme unless there is robust evidence that people with blood cancer are not at a higher risk of catching the coronavirus and dying from it, as the emerging data suggests.

People with blood cancer value the shielding scheme and are concerned about rapid changes to it

Blood Cancer UK conducted a survey of people affected by blood cancer, performed in part to understand their perspectives on key aspects of the UK Governments' policy responses to the coronavirus pandemic. It is noteworthy that people with blood cancer are highly supportive of shielding and are concerned about the easing of lockdown restrictions. In particular:

- 75% of survey respondents told us they were worried about the potential easing of the lockdown
- 98% of survey respondents told us they were following shielding guidance 'very strictly' or 'quite strictly' – this is a stark contrast to recent Office for National Statistics survey data, which suggested fewer than 60% of people shielding were complying with guidance
- When shielding patients were asked how long they could stand to continue shielding for, 7% of respondents told us they couldn't stand to shield for more than an additional month and approximately 25% responded 1-3 and 3-6 months. Strikingly, 22% of respondent said they were willing to continue shielding indefinitely.

Qualitative responses also show that people with blood cancer are using their judgment when leaving the house for limited exercise, by maintaining strict social distancing from others and exercising at quiet times of the day:

'...We live in a valley where only a very few walkers and cyclists exercise. Usually we only pass (at a safe distance) a couple of cyclists and/or walkers when we do a 40-minute walk.'

'I am following everything except that early every morning I go for a 30-minute walk from my door. I feel it is good for my mental wellbeing and I also feel it is important to keep as fit as possible to make sure I am in the best possible state of fitness in case I do become infected.'

⁶ <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-04-27/40578/>

⁷ Parliamentary Answer given to Miles Briggs MSP by Jeanne Freeman MSP, Cabinet Secretary for Health and Sport: <https://www.parliament.scot/S5ChamberOffice/20200608.pdf>

⁸ Some people with chronic blood cancers have been asked to shield in England but not in Scotland. Omissions in the way blood cancer is defined by UK Governments also mean that people with some types of blood cancer, such as myeloproliferative neoplasms are not included in the shielding population.

⁹ <https://www.medrxiv.org/content/10.1101/2020.05.06.20092999v1.full.pdf>

Given the evidence above that indicates people with blood cancer are at increased risk of both contracting and dying from COVID-19 and their reticence about the relaxation of lockdown measures, it is highly likely that many people with blood cancer will seek to shield for the foreseeable future.

People with blood cancer explain that even in June, when incidence of COVID-19 is falling, they are still taking additional steps to protect themselves and their families from avoidable contact:

'I'm self employed so that's been tricky and I've moved my counselling business all online. My younger son should be starting college in September, and my consultant has already said that it will be a safer option for me if he can move in with his dad. He lives nearby but that is going to be emotionally challenging'

'I'm very lucky I can continue to work full time from home so employment issues haven't been a problem for me, but I imagine many vulnerable people will be facing an impossible choice between their job and their health.'

Access to food and medicine

People with blood cancer have also benefited hugely from priority access to supermarket delivery slots and help with food and prescription that prevents them from needing to go in-person to shops.

Survey data shows the scale of concern from people with blood cancer over access to food and medicine amidst the pandemic. We note that 15% of survey respondents listed 'picking up groceries and prescriptions' as one of their major concerns of the COVID-19 pandemic.

It is noteworthy that the ONS' own survey data shows that when asked 'what support, if any, has helped you to shield yourself at home?' 57% said food deliveries and 59% prescription deliveries¹⁰.

We welcome the Westminster Government's commitment to ensuring that priority access to supermarket delivery slots and the support of the NHS volunteer scheme is maintained, to ensure they can continue to protect themselves if necessary. However, it is crucial that all UK Governments make this same commitment.

Employment support for those who choose to continue shielding

We are also aware of small numbers of people with blood cancer who are of working age, that are unable to work from home because of the nature of their roles. For these people, the shielding scheme and the eligibility for sick pay as a result has been crucial in protecting them from COVID-19.

Anna, who has AML and works in a pharmacy explains: *'My employer was reluctant to give me sick pay for 12 weeks, so receiving a shielding letter was a lifeline for me. It's meant that I can protect myself from COVID-19. If shielding ends, I'll have to choose between going back to work and risking my health or staying at home and potentially facing unemployment.'*

It is therefore crucial that people with blood cancer who do not feel confident to return to work, or who are advised to continue shielding by their clinician should have the flexibility to be furloughed by their employer.

¹⁰ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland>