



UKHSA
Nobel House
17 Smith Square
London
SW1P 3JR

21 April 2023

Dear Dame Jenny Harries,

We are writing to you as a coalition of charities representing immunocompromised people regarding the UK Health Security Agency's decision to pause the Office for National Statistics (ONS) Coronavirus (COVID-19) Infection Survey (CIS).

Last month, UKHSA announced an indefinite pause to the survey while it reviewed its approach to COVID-19 surveillance going forward. As the pause came into effect, further announcements were made drastically reducing symptomatic testing in England and Wales and detailing the upcoming closure of the NHS COVID-19 app.

The [statement](#) announcing the pausing of the ONS CIS describes it as an effort to 'ensure our surveillance activities remain proportionate and cost effective with the move to Living with COVID-19.' However, in the Government [guidance](#) for Living with COVID-19, it states that 'UKHSA will maintain scaled down critical surveillance capabilities including the COVID-19 Infection Survey (CIS) population level survey, genomic sequencing and additional data.'

Many immunocompromised people do not receive the same level of, if any, protection from vaccinations and so [continue to be at high risk](#) from COVID-19. Whether they are transplant recipients or living with long-term medical conditions such as cancer, these individuals continue to need information and support to protect them from developing severe COVID-19 and to help them make informed choices about behavioural precautions they follow.

In current Government [guidance](#), people with weakened immune systems are advised to 'try to avoid contact with people who have symptoms of COVID-19'.

We have heard from many vulnerable people we support that having knowledge of the scale of COVID-19 infections across the UK and in their local area empowers people with weakened immune systems to better understand their personal level of risk and make an informed decision. Without this knowledge, immunocompromised individuals' confidence in mixing with others and re-starting activities, including returning to the

workplace, will be undermined. There is also a mental health impact for patients with such uncertainty about their safety.

Without the data from the ONS CIS, or an appropriate alternative, immunocompromised people are not only being left behind with the Living with COVID-19 plan, but they are being left in the dark.

'I'm post transplant and I have been relying on the ONS survey to make choices about what I do (which isn't much even when the figures are at their lowest). Finding that the publication of ONS figures has been culled has made it worse. I don't know what to do - I already spend most of my time indoors.' – Kidney transplant recipient, via Kidney Care UK.

'As I am immunocompromised and vulnerable to serious COVID disease, I really appreciated the ONS study to inform me of level of local community COVID infection on weekly basis. I was able (with caution) to do more with family and friends when levels were lower. It was great. Without this information I feel I am struggling to make informed decision of level of COVID infection and as a result I am now doing less mixing and feeling more anxious.' – Immunodeficiency UK patient representative.

We are also concerned that with reduced testing and available data, without the CIS, it will be harder to identify and predict the incidence of future COVID-19 variants of concern. This risks the ability to reintroduce key protective measures, such as mass vaccination and testing, in an emergency, and may potentially delay or prevent the provision of effective antiviral, therapeutic and pre-exposure prophylactic treatments to those at high risk of severe COVID-19.

We would be grateful if you could share with us the following information as a matter of urgency:

- What is the timeline for the UKHSA review of COVID-19 surveillance? When will a final decision be made?
- What alternative surveillance is being considered? Is resuming the CIS an option?
- Will people with weakened immune systems or organisations representing these groups be invited to provide input?
- Once the current review is complete, in what scenarios will UKHSA consider an urgent review of COVID-19 surveillance?

We look forward to hearing from you and would be very happy to meet to discuss further.

Yours sincerely,

Louise Wright
Chief Executive, Action for Pulmonary Fibrosis

Henny Braund MBE
Chief Executive, Anthony Nolan

Helen Rowntree
Chief Executive, Blood Cancer UK

Mark Oakley, Nikola Brigden & Prof. Martin Eve
Evusheld for the UK

Dr Susan Walsh
Chief Executive, Immunodeficiency UK

Paul Bristow
Chief Executive, Kidney Care UK

Sandra Currie
Chief Executive, Kidney Research UK

Fiona Hazell
Chief Executive, Leukaemia UK

Andrea Brown
Chief Executive, National Kidney Federation

Clare Jacklin
Chief Executive, National Rheumatoid Arthritis Society (NRAS)

Nick Moberly
Chief Executive, MS Society

Ceinwen Giles
Co-Chief Executive, Shine Cancer Support