

## **Supplementary written evidence submitted by Inclusion London (CVD0037)**

I am writing on behalf of Inclusion London, the Pan-London Disabled People's Organisation, to raise concerns brought up in the media and by some of our member organisations about the refusal by multiple NHS Trusts to issue adequate supplies of anti-bacterial/anti-viral filters to users of home ventilators.

These anti-bacterial/anti-viral filters are essential pieces of equipment used by disabled people with conditions such as Muscular Dystrophy and other progressive muscular and respiratory conditions, and there can be dangerous, or even deadly consequences to the person if they do not have all the parts needed to operate their ventilator safely. Furthermore, the anti-bacterial/anti-viral filters are now, more than ever, crucial due to the Coronavirus pandemic, which home ventilation users are extremely clinically vulnerable to. Considering many of these home ventilation users will use social care support and will have staff working in their homes who are not shielding, it is extremely important that all measures are taken to reduce the likelihood of transmission of Covid-19.

Part of the reason for the refusal or increased rationing of anti-bacterial/anti-viral filters is that NHS Trusts are having to wait three or more months for the filters to be shipped from China to the UK, and on arrival they must be re-tested to see if they meet British standards – as they may not be fit for purpose. In the meantime, home ventilator users have been told that they cannot have adequate supplies of the filters needed for their machines because the limited stock should be directed to patients with Covid-19. Home care ventilators users prior to the pandemic had been told by their doctors that they should be changing their anti-bacterial/anti-viral filters weekly (and in some instances, daily), and indeed, in the manuals for home ventilator systems, similar guidance on the use of filters is advised. Disturbingly, even before the pandemic, some home ventilator users were told that there was only enough supply for filters to be changed monthly, even when the doctor acknowledged that they become ineffective after 24 hours – in this particular case, the home ventilator user has had all supply of anti-bacterial/anti-viral filters stopped.

At a time where increased hygiene measures are being advocated by the government during a global pandemic, it must be asked why a group of people deemed “extremely clinically vulnerable” have been refused the essential equipment needed in order to maintain the good hygiene of their home ventilators.

The continuing shortage of filters, and the refusal or increased rationing by NHS Trusts to home ventilator users must be addressed by this inquiry. It also prompts larger questions around the devaluing of disabled lives, inequalities in accessing and receiving health care and supply chains of equipment to the NHS.

Why have disabled patients been disproportionately put at risk of Covid-19 by the government not having emergency supplies in place for the pandemic?

Whilst the general population has been told of the necessity of maintaining good hygiene and other personal protective practices, why have home ventilator users' lives been put at increased risk through the decision by NHS Trusts to refuse or ration the supply of anti-bacterial/anti-viral filters needed to use their machines safely and protect the user from infection?

Why is the government not having these filters produced in the UK, or at least ordering the filters they know have been produced to British standards, in order to stop the risk to both Covid-19 patients and home ventilator users?

Why has the Government put hospitals in the intolerable position where they have to stop or ration vital medical supplies to all but inpatients due to chronic under funding of respiratory departments?

Further reporting and quotes from home ventilator users on this issue can be found in the Disability New Service articles:

<https://www.disabilitynewsservice.com/nhs-trust-tells-people-with-muscular-dystrophy-were-keeping-your-ventilator-filters-for-patients-with-coronavirus/>

<https://www.disabilitynewsservice.com/coronavirus-second-nhs-trust-accused-of-respiratory-roulette-discrimination/>

I hope you understand the importance of including these questions within your inquiry, and seek to address the larger issues of healthcare discrimination and the inequality disabled people are facing during the pandemic.

Please do not hesitate to get in touch with me if you have any questions relating to this letter, or any of Inclusion London's other work.

*July 2020*