

MINISTERIAL ROUNDTABLE ON LONG COVID

23 SEPTEMBER 2021 1330-1430

HIGH LEVEL SUMMARY OF DISCUSSION	
1	Welcome and introductions
	<p>Secretary-of-State, Rt Hon Sajid Javid MP, welcomed and thanked the group for attending. He thanked Lord Bethell for his work as Parliamentary-under-Secretary for Innovation and introduced Maria Caulfield, Parliamentary under Secretary for Primary Care and Patient Safety, as the Minister leading on long COVID policy.</p>
2	ONS update
	<p>Name Redacted went through the latest long COVID prevalence estimates from ONS. He reminded attendees that all results are experimental and subject to change as ONS makes improvements to data collection and analysis.</p> <p>NR explained that the report used 3 different approaches to estimate prevalence. Each approach has its own benefits and limitations, and therefore have produced slightly different estimates.</p> <p>NR noted that some findings reflect those reported previously – notably that prevalence of long COVID at 12+ weeks post-infection was highest among women, middle-aged people, and people with existing illness.</p> <p>NR stated that ONS are reviewing the 12 physical symptoms used to collect long COVID data in the COVID Infection Survey and these may be updated.</p> <p>Secretary-of-State asked if ONS has learnt anything from other countries that are measuring long COVID prevalence in their populations?</p> <p>NR said that the UK are ahead of the curve on prevalence data reporting. Most international studies have been of limited quality and size. ONS are discussing potential international links.</p>
3	NHSEI update
	<p>Cathy Hassell provided an update on NHSEI’s progress in response to long COVID.</p> <p>CH stated that NHSEI published their 5 Point Plan in October 2020 and have subsequently published a further, more detailed plan in June 2021 which outlined 10 key actions.</p> <p>CH noted that 5 of these 10 key actions have been completed so far. There is more work to be done but NHSEI is making progress.</p> <p>CH said that based on data from September, there were 6,000 referrals to the assessment services over a 4-week period. 88% of these referrals were accepted. This rate of referrals is only around 30% of what was anticipated which may mean many people are not coming forward.</p> <p>CH said that an early case study from Leeds assessment services found that people on rehabilitation programmes reported improvement in all 5 measured outcome areas. NHSEI will continue to measure the impact of long COVID services.</p> <p>CH outlined NHSEI’s next steps:</p> <ul style="list-style-type: none"> • Understanding future demand • Addressing geographic variation

NR explained that she was from Manchester, one of the 6 most deprived areas in England, and had caught COVID-19 early on in the pandemic. She was disbelieved by her GP, who dismissed her illness. Months later, still suffering with debilitating symptoms that affect her daily life, she received an antibodies test which confirmed she had previously contracted COVID.

NR noted that while she has now been referred to NHSEI's long COVID services, she often has to travel to multiple different hospitals for her appointments. This model of service is not accessible for many people who live on a low income or are disabled.

NR said she has set up a local long COVID online support group and regularly hears from people who are being disbelieved by their GPs.

NR received a good level of support from his GP and hospital when he contracted COVID-19. Since then, he has had an inconsistent experience with accessing treatment pathways.

NR is able to advocate for himself and navigate the healthcare system, but fears that many people would not be capable of understanding how to get the help they may need due to various barriers to access.

NR stated that misinformation is a huge issue. Current public messaging and the support available should be reviewed and made more accessible.

5 General discussion

Secretary-of-State invited patient support group representatives to speak.

NR said that she would like to see more effort to prevent cases of long COVID and recommended updating the COVID-19 symptoms list. She recommended NHSEI and the Government advise anyone who feels unwell takes a PCR test, to improve funding for isolation, and to continue to encourage people to work from home.

Name Redacted agreed that prevention was important. She stated that many people are concerned about England's high rate of infection. The previous Secretary-of-State had emphasised the need for treatments for long COVID at a previous roundtable. Currently, many patients are self-medicating.

Name Redacted raised concerns about children and schools. She recommended a return to mandatory mask-wearing in schools, as the return of in-person education has increased infection rates. She suggested that a public awareness campaign highlighting the effects of long COVID on children may help people to understand the risks and change their habits.

Melissa Heightman noted that research into treatments is very important. Currently patients are using treatments off-licence and clinicians are finding themselves in difficult positions.

NR said she has had a positive experience with the NHSEI services in Oxford. Her condition is improving and the NHS are doing good work. She expressed hope that more people would have positive stories about accessing services in future and also concern at patients self-medicating, as this can become dangerous.

NR emphasised that updating the symptoms list is important, as are treatments. NHSEI have delivered excellent work but the quality of services must be a priority, not just