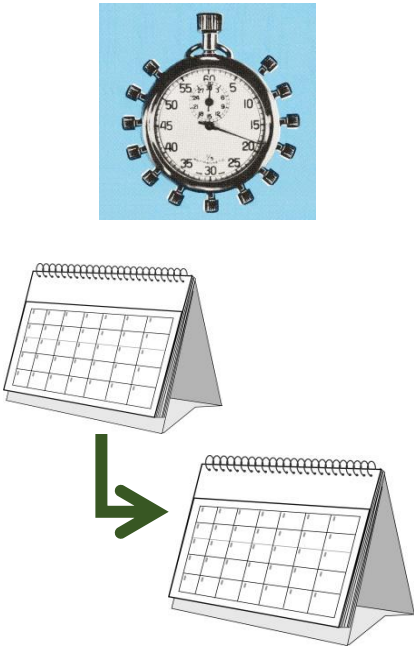
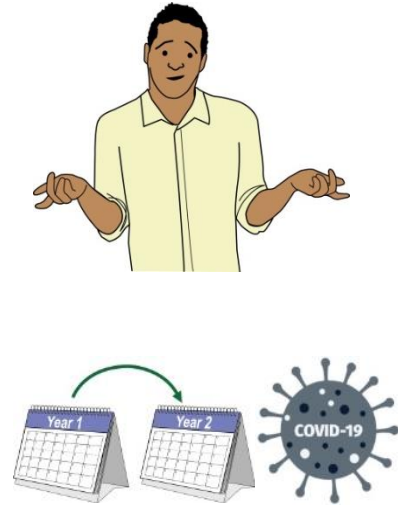


# Long COVID and People with Learning Disabilities March 2022



## Our final findings...

 A stopwatch is shown at the top left. Below it are two desk calendars, one labeled 'Year 1' and one labeled 'Year 2', with a green arrow pointing from the first calendar to the second.	<p>There are two stages to long COVID:</p> <ol style="list-style-type: none"><li>1. Ongoing symptomatic COVID-19 – symptoms that last 4-12 weeks</li><li>2. Post-COVID-19 syndrome – symptoms that last for more than 12 weeks and can't be explained by another diagnosis</li></ol>
 An illustration of a man with dark hair and a mustache, wearing a light yellow shirt, with his hands outstretched in a questioning or explanatory gesture. Below him are two desk calendars, one labeled 'Year 1' and one labeled 'Year 2', with a green curved arrow pointing from the top of the 'Year 1' calendar to the top of the 'Year 2' calendar. To the right of the calendars is a dark blue, spherical icon representing a COVID-19 virus with several spikes protruding from its surface.	<p>It was very difficult to find people with learning disabilities, who knew about Long COVID or had been diagnosed with Long COVID. For example, a Strategic Liaison Nurse told us that only one patient was registered with Herts Valley CCG with a learning disability and/or Autism that had been diagnosed with Long Covid.</p>

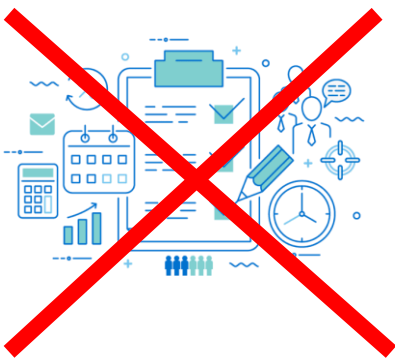


We were surprised by some of the narratives as to why this might be.

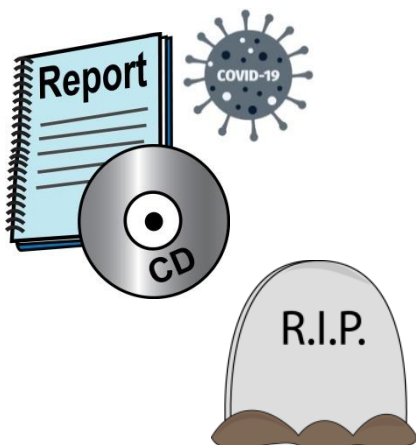
For example, a researcher suggested that people with learning disabilities didn't get Long COVID.



Other health professionals we spoke to said that people with learning disabilities had difficulty in recognising symptoms of Long COVID.



Also, there was no national data about the incidence of Long COVID in people with a learning disability whether or not the person was admitted to hospital with COVID infection.



A [Public Health England study](#) in 2020, reported that England death rates for people with learning disabilities was up to 6 times higher from coronavirus than the general population.



We do not know whether people with a learning disability are disproportionately affected by Long COVID, as they are not self reporting or being diagnosed and there is limited data available.



Because of the reported statistics for people with learning disabilities and COVID-19, it is extremely likely that people with a learning disability will be experiencing Long COVID.

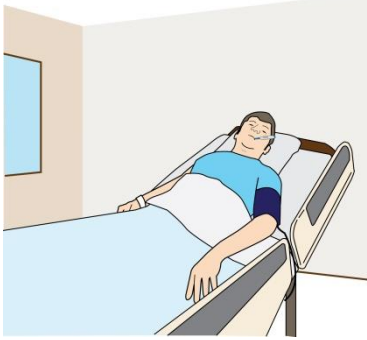
### Summary of main issues:



There was no accessible easy read information for people with learning disabilities about what Long COVID is and its symptoms.



Many people with learning disabilities have lost some or all of their support towards independent living. They are more isolated with less support to understand important health information.



Many people with learning disabilities admitted to hospital with COVID experienced a level of trauma not least of all because of the threat of DNR notices.



People with learning disabilities told us that they are still worried and scared about going into hospital.



People with learning disabilities have found it difficult to articulate vague symptoms of Long COVID. It may also be difficult for carers to recognise the symptoms if these cannot be communicated.



Many of the symptoms are similar to the side effects of the medication that many people are on which also adds to the complex picture that people with learning disabilities experience.



Diagnostic overshadowing: when 'symptoms of physical ill health are attributed to a mental health/behavioural problem.



There are not many spaces for people with learning disabilities to talk to each other about Covid-19 and Long COVID.



Mainstream groups and online communities are not accessible to people with learning disabilities.

Digital exclusion has been a barrier during the pandemic.



People with learning disabilities in Assessment and Treatment Units, Forensic Units and care homes experienced blanket restrictions and limited access to family, friends, and general health care.

## Connections and influence:



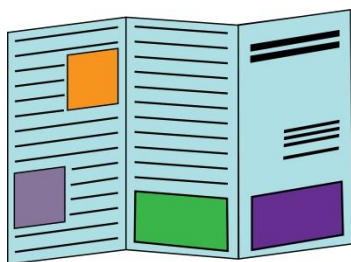
During the project we made contact with the University of Birmingham who are developing a diagnostic tool for Long COVID. They told us that there are more than 200 symptoms associated with Long COVID.



Researchers from Leeds University made contact regarding the COVID-19 Yorkshire Rehabilitation Screening Tool. Funding is being sought to create an accessible version of the tool.



We made contact with [Long Covid Support](#) about a survey to collect information on the patient experience of health care and other support services for Long Covid. We discussed how to make this accessible for people with learning disabilities.



We connected with Herts People First and NHS East and North Hertfordshire CCG and used this as a pilot area to do more focused research. We gathered information about reported cases of Long Covid in people with learning disabilities, we found out about available information and communications, plans to develop a Long Covid pathway. We also provided guidance on the development of Long COVID easy read leaflet.

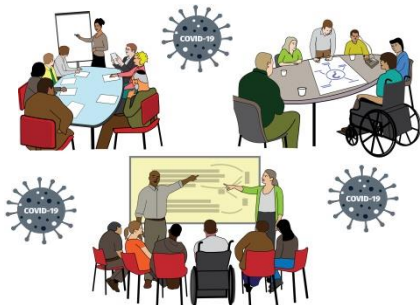


We are providing guidance to the Royal College of GP's to develop an accessible survey to send to people with learning disabilities about COVID, being hospitalised, and ongoing symptoms.

## Conclusion



Based on the primary finding about the lack of Long COVID accessible information and communications, we have been raising awareness and speaking with a range of people and organisations about how to improve this.



We have run sessions for self advocate's to talk about Long COVID and increase understanding.



We have sent out information about the project and our findings in our members' newsletter.



NHS England and NHS Improvement



We have raised the issues at the national NHSE Learning Disability and Autism Partners meetings.

We have asked that Long COVID symptoms are included in the Annual Health Checks.



We have spoken to the mainstream Long COVID organisations about how they can be more inclusive of people with learning disabilities.

We have also produced a 'Guidelines for Inclusion – For Organisations' document to support out work with mainstream organisations.

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**Date:** June 2022

**People First**

a voice for people with learning difficulties