

COVID-19 Recovery Committee
Informal engagement online session
Note of discussion
Thursday, 2 February 2023

Committee member attendees

Siobhian Brown MSP (Convener)

Murdo Fraser MSP (Deputy Convener)

Jim Fairlie MSP

John Mason MSP

Brian Whittle MSP

Apologies were received from Alex Rowley MSP.

Invited participants

As part of its inquiry into long COVID, the Committee spoke with five parents of children who have long COVID. The participants were identified through Long Covid Kids.

Discussion

The following summary is intended to provide an overview of the main themes that emerged from the discussion. The discussion was based around the key themes contained in the call for views namely: awareness and recognition; therapy and rehabilitation; and study and research.

Awareness and recognition

Parents and children

- There is a lack of awareness and recognition of long COVID in children
- More public messaging on long COVID in children is needed
- More needs to be done to educate the general public, health professionals and educators and schools on long COVID and the debilitating nature of the symptoms
- Parents feel very let down by the medical profession and the Scottish Government regarding the lack of help and support in diagnosing children with long COVID and providing appropriate treatment and support
- Children suffering from long COVID feel left behind and isolated from their peers
- Many parents are struggling to juggle work and caring for their children
- Long Covid Kids supports around 12,000 families worldwide. Roughly 50-60% of those 12k are UK based with over 200 families who reside in Scotland.
- It is expected that the number of families affected by long COVID is much higher
- Parents do not always identify long COVID in their children and therefore do not receive support from organisations such as Long Covid Kids
- Parents have had to become an expert on the condition, in order to support their children and obtain appropriate treatment because many clinicians do not appear familiar with the relevant NICE guidelines

Policy makers and health professionals

- There is not enough knowledge and understanding among the medical profession of the condition

- It is extremely difficult to get a long COVID diagnosis for children, often taking years
- Getting a long COVID diagnosis on the NHS is very difficult due to the varying and vast number of symptoms and some clinicians were reluctant to diagnose long COVID in children
- Long COVID has had a huge detrimental impact on the mental health of children with long COVID, leading many to develop depression and other mental health conditions
- More funding for NHS staff for training on long COVID assessments, diagnostics and treatments should be made available for NHS staff who should be supported in their learning activities
- There should be a long COVID implementation plan detailing what steps the Scottish Government plans to take to help support and treat those children with long COVID and their parents
- Policy makers and the medical profession should act on the advice and learning from lived experience

Educators

- Many children have missed two or three years of their education with potentially significant consequences for their future
- Approaches taken by schools regarding offering support to children with long COVID varies across Scotland
- Due to long absence periods, more could be done to support children's learning where possible. Suggestions could include home visits, accessibility solutions within schools, rest breaks and alternative digital solutions

Therapy and rehabilitation

- Patients need to be treated in a holistic way looking at the interconnectedness of symptoms

- Many parents felt they had no option than to seek private healthcare, often abroad, and acknowledged that this was not an option for all parents
- There are issues diagnosing long COVID in children, given myriad of symptoms
- Although treatments for some of the symptoms of long COVID are available – these are not always offered to children with long COVID as a result of lack of knowledge and awareness by GPs
- A clinical diagnosis is extremely helpful for children and parents as, although there is no cure for long COVID, it is helpful in identifying the appropriate treatment for the individual's symptoms
- Concern was raised regarding inappropriate treatments such as graded exercise being suggested for children – despite this not being recommended in the NICE guidelines
- Concern was raised for those children going through their late teens and falling in between children's and adult's health services and not being able to access either appropriately
- Often simple and inexpensive treatments such as anti-histamines can improve the quality of life for children with long COVID once diagnosed
- It was acknowledged that not every GP and medical professional can be an expert on long COVID. Therefore, to have a clinic staffed with long COVID experts across multi disciplines would offer far more support for families than is currently the case
- There was a general consensus that having long COVID clinics across Scotland would be a useful step
- Concern was expressed that children do not have access to the long covid clinic in NHS Lanarkshire as this is an adult service

- Access to paediatric care is often very difficult involving long waiting times
- The approach to long COVID clinics in England was said to be a positive step and it was felt that Scotland was 'behind the curve' on its approach to long COVID medical services provision.

Study and research

- It was noted that the Scottish Government has not funded study or research projects that include children's experience of long COVID. This has created a gap in knowledge and understanding.
- More data needs to be gathered on long COVID in children, in order to understand the scale of the problem
- Scotland should learn from international examples of good practice in relation to assessing and treating children with long COVID
- More funding should be made available for medical research into long COVID in children
- Parents and children with lived experience should be involved with ongoing studies and research
- Lessons should be learned from rest of UK and other countries