

# COVID-19 Recovery Committee

## Informal engagement session

### Note of discussion

Thursday, 12 January 2023

#### Committee member attendees

Siobhian Brown MSP (Convener)

Murdo Fraser MSP (Deputy Convener)

Jackie Baillie MSP (Committee substitute)

John Mason MSP

Brian Whittle MSP

Apologies were received from Jim Fairlie MSP and Alex Rowley MSP.

#### Discussions

As part of the launch of its inquiry into long COVID, the Committee spoke with 4 participants, who were contacted through Long Covid Scotland, with experience of long COVID. 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.

Participants also provided a written submission, which is reproduced at the end of this note.

## **Awareness and recognition**

- There is a lack of awareness and recognition of long COVID
- There is not enough knowledge and understanding among employers and the medical profession of the condition
- More GP training needed
- Issues around work and financial implications for people with long COVID
- NICE and WHO guidelines are being used for diagnosing long COVID although it was felt that people often had to go to private health care clinicians to get a formal diagnosis
- Public messaging of the risks associated with COVID and long COVID is inadequate
- There is no long COVID strategy
- There should be more focus on prevention and messaging around public health safety which should include an ongoing campaign on the risks of long COVID
- It is not clear where lived experience contributes to the policy making in relation to long COVID

## **Therapy and rehabilitation**

- Wrong and harmful approaches are often adopted, such as graded exercise therapy and cognitive behavioural therapy, due to a lack of understanding of the condition
- A more holistic approach to treating long COVID should be adopted where people with long COVID should be involved in developing treatments
- There are problems with diagnosing long COVID given the symptoms and lack of any test to identify long COVID
- There are risks associated with misdiagnosis with other conditions such as ME and the menopause

- There can be an over emphasis on support and rehabilitation without proper assessment and diagnosis in the first instance
- There is insufficient use of accredited assessment and diagnostic tools
- Long COVID conditions become worse if not treated which puts more pressure on health services and health professionals which exacerbates the current health crisis
- Approaches to long COVID services varies across health boards and a more systematic approach across Scotland is required regarding long COVID assessment and diagnostics
- Feedback on the use of long COVID clinics in England is mixed
- There is a lack of connectivity between primary care and secondary care
- Having a central place to go for assessment and diagnosis and a clear referral pathway is essential
- There are difficulties and costs associated with setting up long COVID 'one stop shops' across all health boards although this should not preclude adopting a strategic approach across Scotland
- There is no long covid clinical pathway – there is a need for a consistent approach
- Often those with long COVID become experts on their own care
- There is no interconnectivity between learning and treatment with health boards not using treatments such as respiratory physiotherapy
- It is not clear how clinical models are being linked to ongoing research
- There is a lack of sharing best practice on long COVID treatment practices

- It is not clear how the Scottish Government's budget has been allocated to health boards, how these budgets are being spent and the extent to which health boards have used all their funding allocation
- There were problems across health boards recruiting the right staff in the current climate which could explain underspends
- Often patients turn to private care for treatments that do not appear to be offered on the NHS such as respiratory physiotherapy which can lead to health inequalities.
- Not enough use is being made of long COVID assessment apps and their development, where patients can record their symptoms, and these shared with the health boards.
- There is a need to treat interconnected symptoms rather than treating individual symptoms
- There is a lack of service provision for children with long COVID
- Often NHS resources on long COVID are out of date and not fit for purpose
- Impact on mental health

## **Study and research**

- There are international models on how to assess and treat long COVID although lessons do not seem to be being learned from these models
- Patients and people with lived experience should be involved with ongoing studies and research
- There is no evidence of people with lived experience being involved in current education being undertaken by NHS Education for Scotland and Dundee University
- Need for more studies on treatments to take place in Scotland

- Lessons should be learned from rest of UK and other countries, particularly around data collection



**LONG COVID**  
**SCOTLAND**  
[www.longcovid.scot](http://www.longcovid.scot)

## **Manifesto and Key Information**

### **Long Covid Inquiry Launch - Thursday 12th January**

#### **What is Long Covid?**

Long Covid (or Post-Covid Syndrome) refers to prolonged and debilitating COVID-19 experiences. The typical profile includes young, previously healthy adults, who were often active and hard-working prior to becoming unwell. Long Covid also has a significant effect on children and adolescents, as identified by the Long Covid Kids campaign.

The Office of National Statistics estimate 2.1 million people in the UK are living with the condition, which equates to over 187,000 people in Scotland. Given Long Covid goes uncounted and misdiagnosed, the true figures could be higher.

#### **People with Long Covid experience the following:**

**Severe and serious symptoms.** Long Covid can affect the entire body. Cases vary greatly, with symptoms including but not limited to: breathing difficulties, chest pain, numbness, fatigue, tachycardia, and allergies, often in a relapsing and remitting pattern. The impacts upon activities of daily living are considerable.

**Difficulties accessing care.** Despite serious cardio-respiratory and neurological symptoms, most people with Long Covid cannot access primary or secondary care investigations and treatment. Some describe health practitioners who are sympathetic but are unsure how to help, whereas others describe being dismissed and exhausted at having to research and advocate for themselves.

**Receiving inappropriate and dangerous advice.** Some are prescribed interventions such as Graded Exercise Therapy, which was recently removed from the NICE Guidelines for similar conditions. GET is contraindicated for fatigue symptoms and can exacerbate symptoms of cardiac injury, which is found in approximately 30% of Long Covid cases.

**Psychological trauma.** Experiencing a serious infection, prolonged illness, and in many cases invalidation from family, peers and even health practitioners, can lead to complex trauma and even suicide. Understandably, people may be reticent to ask for help, and those

who do ask may not get what they need.

**Difficulties working, studying and being a carer.** Many with Long Covid are unable to work, study or carry out caring responsibilities. Those who do return to work, study or care often push through out of necessity, to the further detriment of their health. Some struggle due to disbelieving and unsupportive employers and lecturers.

**Financial problems.** Many with Long Covid experience considerable financial difficulties from being unable to work, and/or from having to pay for private investigations and support. Despite meeting the criteria, many are being refused disability benefits.

**Discrimination.** People with Long Covid are discriminated against due to lack of testing or negative tests, not having been hospitalised, and for pre-existing inequities such as socioeconomic status, race, gender, and disability. This is exacerbated by health practitioners and researchers having more power than patients and carers.

## What do people with Long Covid need?

### AWARENESS & RECOGNITION

**Knowledge education and support for health professionals:** Health professionals must be adequately informed and supported in their roles. Comprehensive patient-informed guidelines for GPs, specialists, and other health professionals, including strategies to mitigate common medical bias, are essential for diagnosis and treatment.

**Public health awareness of COVID-19 and Long Covid:** While Long Covid has become better known, it is not understood. The dominant narratives suggest young people experience 'mild' disease, and that children do not get ill or transmit the virus - these are falsehoods. Public understanding of morbidity is pivotal in reducing the spread of COVID-19.

**Information for employers, unions and universities.** People with Long Covid who work or study may have difficulties that are hard for their employers or lecturers to understand fully. Employers, unions and universities need information, informed by patients, on how to support people returning to or starting work and study.

**Formal Recognition of Long Covid as a disability.** Despite the debilitating, long-term nature of the condition, many with Long Covid are told they do not have a disability, preventing them from accessing appropriate services and support. This must be rectified.

**Recognition for other chronic conditions.** While our lived experience is Long Covid, we recognise its overlap with conditions such as ME, PoTS and MCAS, which historically have been stigmatised and under-researched. People with other chronic conditions bring essential knowledge, and should benefit from research and services developed.

## THERAPY & REHABILITATION

**Fully funded and informed care:** The current funding from Scottish Government amounts to around £16 per person. To meet needs across Scotland, services for investigations, care, and safe rehabilitation must be funded, and co-produced with people with Long Covid. This is urgent, as many people with Long Covid are unable to access basic support, including for severe and serious symptoms.

**Multi-disciplinary support:** Care cannot fall solely on the shoulders of GPs. Fully funded multi-disciplinary support, including time with consultants and organ-damage screening, would reduce time pressures, allow for the needed investigations, allow better communication between health professionals, and offer opportunities for research in action.

**Long Covid care strategy:** There is currently no national strategic framework or guidelines to support health boards. A patient-informed model based on good practice to date would ensure consistency where possible and prevent duplication of work. Boards could then tailor the model where required.

**Occupational therapy and practical support:** People also need social care support for managing at home, especially caregivers and people who live alone, yet people with Long Covid struggle to get referred.

**Psychological support:** High-quality mental-health support is essential and must be patient-led, and given people report feeling isolated, not dependent on leaflets or online self-help measures. Peer support can continue but should be recognised and funded as a secondary source of support.

## STUDY & RESEARCH

**Equitable patient and public involvement (PPI):** People with Long Covid are assets to researchers. As with the design of medical services, they need to be involved in research from its onset, regardless of background, test status, and hospitalisation status.

**Epidemiological and mechanistic studies:** While ONS statistics are a start, Long Covid must be better counted in populations to determine incidence and risk factors across all age groups. Long Covid must also be studied at the biological level to understand the unique footprint of the disease. Though research has begun, there is still a way to go.

### How was this information collected?

These recommendations are informed by high-quality journal research, and patient-led research, including surveys and focus groups. Key points are also confirmed by formal research and undertaken by various institutions and health agencies in the UK and Scotland.