CVDR/S6/23/3/2

COVID-19 Recovery Committee

3rd Meeting, 2022 (Session 6), Thursday, 9 February 2023

Long COVID – Awareness and recognition

At this meeting Members will hold an evidence session with representatives of:

- Long Covid Scotland
- Long Covid Support Group: Scotland
- The ALLIANCE
- Covid Action Scotland
- Long Covid Kids

Background

The Office for National Statistics recently reported that the there is an estimated 175,000 people in Scotland with self-reported symptoms of long COVID. This represents 3.3% of the population.

There are many symptoms associated with long COVID these can include respiratory, cardiovascular, neurological and musculoskeletal symptoms. The Office for National Statistics reported that fatigue continued to be the most common self-reported symptom of long COVID (71%), followed by difficulty concentrating (52%), shortness of breath (48%) and muscle ache (47%).

As a proportion of the UK population, the prevalence of self-reported long COVID was greatest in people aged 35 to 69 years, females, people living in more deprived areas, those working in social care, those aged 16 years and over who were not working and not looking for work, and those with another activity-limiting health condition or disability.

SIGN (the Scottish Intercollegiate Guidelines Network) in conjunction with NICE (the National Institute for Health and Care Excellence) has published a guideline on managing the long-term effects of COVID-19. This includes recommendations on assessment, investigation and referral, planning care, management, rehabilitation and research.

The Scottish Government published a paper on Scotland's Long COVID Service in September 2021. This notes that its approach is based on four elements:

1. supported self-management
2. primary care and community-based support
3. rehabilitation support
4. secondary care investigation and support.

The Scottish Government has also established a National Strategic Network. This was established in March 2022 to provide national support to building the capacity, capability and co-ordination of health and social care services for people with long-term effects of COVID-19.

The Strategic Network structure is composed of:

- a strategic oversight board
- a steering group
- a clinical and subject matter expert group
- a service planning group
- a lived experience planning group.

The services available for people with long COVID in Scotland varies by health board. The Scottish Government said:

> "funding has been made available to NHS Boards and partners to respond to the needs of people with long COVID in their areas. NHS Boards are using the resource to develop pathways which aim to support early intervention and improved co-ordination of support and services for people with long COVID. For example, many Boards are introducing a single point of access for assessment and co-ordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person's needs."

The Committee launched a call for views, which closes on the 10 February. The published submissions received, to date, can be viewed online. The Committee also wrote to the Cabinet Secretary for Health and Social Care and the response can be read here.

Themes

Members may wish to discuss the following themes with witnesses. These are based on the questions in the public call for views.

Theme 1: Public awareness of risks of long COVID

In Scotland's Long COVID Service, the Scottish Government committed:

- £40,000 to deliver a targeted long COVID marketing campaign in conjunction with community pharmacies across Scotland.
- Develop and distribute a communications toolkit for primary care teams, NHS Boards and other partners. The toolkit will include key messages, campaign assets and relevant information on long COVID ensuring clarity and consistency of information available.

The Scottish Government's Long COVID Awareness Campaign highlights the symptoms, has information on self-management and information on sources of support.

The majority of written submissions highlighted a low level of awareness of long COVID. A number of submissions highlighted the potential benefits of a public awareness campaign around the risks of catching COVID-19 and long COVID.

> "A public awareness campaign is required to educate the general public on the risks posed by covid."
>
> "Advertising campaigns on the number of people out of work, the financial impact of being unable to work, the complete lack of financial support for long covid patients, the total lack of medical assistance, the poor/unknown medical prognosis for patients etc. Should also highlight that it's not only patients with comorbidities that are vulnerable to long covid (something the government seemed keen to spread) and that contracting covid leaves lots of people with comorbidities."

Members may wish to ask:

- **What more could / should be done to raise public awareness and recognition of long COVID?**
- **Do you think the Scottish Government's current approach for managing COVID-19 pays sufficient attention to the risks of long COVID?**
- **Do witnesses consider that enough is being done to encourage people with long COVID to seek help? What is the level of unmet need?**

Theme 2: Awareness of long COVID in primary care.

A number of submissions also commented on a reluctance of GPs to diagnose long COVID. Concerns were also raised around lack of knowledge and attitudes of some healthcare professionals.

> “My experience has been with my GP who was keen to diagnose the menopause rather than 'label' my symptoms as Long Covid.
> I used to be a GP and I know the medical model struggles with an diagnosis for which there is no definitive treatment. I would have found it helpful to discuss my symptoms and how they were affecting me knowing that there was no 'cure' but this didn't seem possible.”

> “I found a real reluctance among the doctors I saw to even use the term "long covid". I had to explicitly ask "is this long covid" for them to say "it sounds like it might be" - which made me feel awful and like I was just being dramatic rather than a helpful diagnosis which could have led to support and treatment options.”

Concerns were also raised in relation to accessing primary care:

> “I have not be[en] referred to any other service & it is impossible to get GP appointments. Feel incredibly abandoned & just have to cope. I don't know what services are available.”

Members may wish to ask:

- **Is there enough awareness and recognition of long COVID by primary care professionals?**
- **What was the experience of witnesses when seeking help with long COVID from their GP or other healthcare provide?**

Theme 3: Training on long COVID

In relation to training. Some respondents considered that more training on long COVID should be provided to GP’s, human resources professionals, local authority employees and health board staff.

> “Better training of the healthcare workforce. There are pockets of best-practice, but these are not being recognised and taken advantage of.”

> “There should be appropriate training for staff, however this is near impossible as staff don’t have the time for CPD”

> "GPs are trying their hardest but are limited with options. It's a lottery if you have a GP that has read enough to understand. There are new theory's evolving and difficult for people to stay on top of."
>
> "Providing primary care providers with regular bulletins on new developments plus actual clinical training would be helpful as well."

The RCGPs has a eLearning course on the long term effects of COVID-19 and Post-COVID-19 syndrome, although some people consider this needs to be updated. This aims to teach people how to describe the various presentations of Post-COVID syndrome, understand the current guidance and understand the impact on patients.

Members may wish to ask:

- **What training on long COVID do you think would be beneficial for medical professionals and public sector employees?**
- **Are witnesses aware of examples of good practice?**

Theme 4: Stigma

In a recent study of people with long COVID found that 95% of people reported experiencing stigma related to their condition. A number of respondents to the Committee's call for views also highlighted issues around the stigma that exists around long COVID.

> "With long covid being an invisible illness/disability, there can often be a stigma from medical professionals or the general public that you are not or should not be entitled to the support you need and often it is a true fight to have your struggles be recognised."
>
> "Not sure you can educate the public about a variable and invisible illness, but if the government avoid stigmatisation of disabled people and the 'scrounger' rhetoric loved by some in politics, that would help."
>
> "Making employers aware & protecting those with LC as myself & the other 2 others I personally know affected by LC have felt stigmatized at work when we speak about our issues with LC".

This issue has been discussed in the BMJ The stigma is real for people living with long covid. This commented:

> "Stigma drives people underground and away from health services, contributes to psychological distress and mental illness, and by doing so compromises long term physical health outcomes. Non-engagement with health services and ill health are further stigmatized, perpetuating a vicious cycle of further stigma and sickness. Research on long covid stigma is still

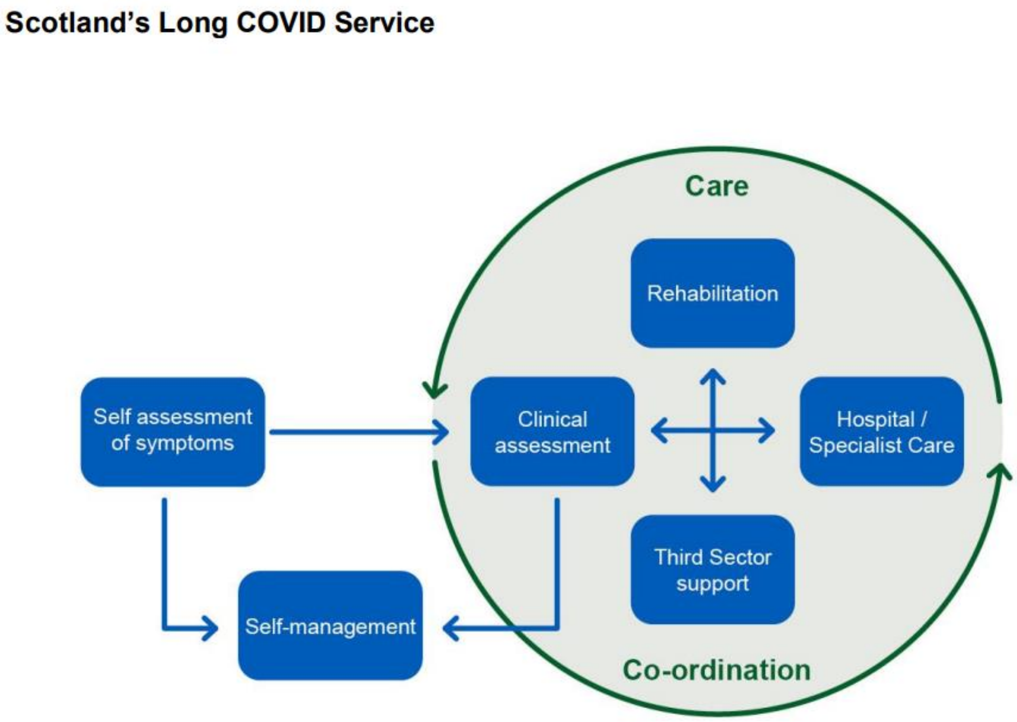
> lacking, but emerging testimonies point to two important facets: institutional discrimination and internalised stigma."

Members may wish to ask:

- **Have witnesses experienced discrimination as a result of their long COVID?**
- **What can be done to reduce stigma around long COVID?**
- **What impact does the health service have on the stigma associated with long COVID?**

Theme 5: Long COVID services

In Scotland's Long Covid Service the Scottish Government outlines the importance of following components:



In its letter to the Committee the Scottish Government stated:

> "It is for each NHS Board to develop and deliver the best models of care for assessment, diagnostic tests, and support for the treatment or management of symptoms, tailored to the needs of their local population. This may involve strengthening the co-ordination of existing services, or establishing dedicated services where appropriate. While none of the services being delivered by NHS Scotland Boards are termed 'long COVID clinics', initiatives being supported by the funding include key elements of care that are also offered by

> post COVID assessment clinics elsewhere in the UK, including pathways providing assessment and co-ordinated access to relevant support and services in line with individual patient need”.

From the submissions to the call for views it appears that people’s experiences of accessing health care support for long COVID is mixed. Concern were raised about workforce issues, access to primary care, availability of off-licence medicines and availability of diagnostic tests.

> “These need to be standardised and staffed appropriately. AHP staff are fantastic however, they need to be supported but doctors who can prescribe medication as appropriate. There are off licence medications that do help people and these need to be looked at. Involve Dr Claire Taylor at a strategic level, She seems to be the only available long covid specialist. There needs to be access to doctors who specialise in neurology, cardiology and respiratory to provide specialist knowledge of how covid affects the body. There needs to be access to testing as required (MRI, CT, CXR, VQ, ECG, 24 hour tape) while not everyone needs this some do. It shouldn’t be a battle and wait for these tests, we have waited long enough. Many of these clinics seem to be physio and OT only, and that is not enough, and they are not going to work.”

> “Long covid assessment clinics would be amazing if they actually did valid tests (checking for presence of blood clots, measuring endothelial function, assessments for POTS, knowledge of MCAS, able to offer imaging diagnostics etc). Assessment clinics that purely talk about 'managing' your condition, palm it off as anxiety, or encourage 'exercising through it', would be a total waste of resources and the time and energy of long covid sufferers.”

> “There is not enough money allocated for services and not the right mix of professionals involved. There is no support for people with long covid and it feels as if we have been abandoned”

> “In both Edinburgh and Ayrshire I have failed to get anywhere with a doctor/NHS and have instead paid privately for treatment, supplements and looked online for community support.”

> “I would like to see proper MDT long Covid assessment clinics across Scotland. By MDT I don’t mean just physios and staff from psychiatric/psychology services. They should have input from physicians, nurses, AHP and where appropriate mental health professionals. Access to investigations- eg scans (eg. MRI, CT, VQ), wider range of blood tests, etc. Ability to refer on to appropriate specialist teams where required.”

Members may wish to ask:

- **What has been witnesses experience of accessing specialist care?**

- **What would be the benefits to people with long COVID of a quick diagnosis?**

- **Are witnesses aware of any inequalities in long COVID care?**

Theme 6: Support for people with long COVID

Many written submissions highlighted the need for people with long COVID to access support. One respondent said that the following support was needed:

- Financial support
- Respite and psychological support
- Flexibility from employers

Many people highlighted problems continuing with work.

> “There needs to be financial support for those unable to return to work as a result of long covid. People shouldn’t lose their jobs because of COVID”
>
> “Employers are not able to support such a complex condition effectively also adding to stress & anxiety of sufferers.”

The Faculty of Occupational Medicine has published Guidance for managers and employers on facilitating return to work of employees with long-COVID. The Chartered Institute of Personnel and Development have also developed a number of guides to help support employees with long COVID. Other resources are available from Long Covid Work – Supporting people with Long Covid to stay in, return to, or leave work well.

A number of respondents commented that long Covid should be recognised as a disability and people with long COVID should be able to get appropriate benefits. A person is disabled under the UK’s Equality Act 2010 if they have a physical or mental impairment that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities. Only three conditions are specifically included in the Act: cancer, multiple sclerosis (MS) and HIV infection. If long COVID has this effect on an individual they would meet the definition of disability in terms of the Equality Act 2010.

People who have long COVID that affects their everyday life may be eligible for a number of benefits such as: Adult Disability Payment, Attendance Allowance, Universal Credit – limited capacity to work, Child Disability Payment. The daily living part of Adult Disability Payment maybe available to people who need help with: preparing food, eating and drinking, managing therapy or monitoring a health condition, washing and bathing, managing toilet needs or incontinence, dressing and undressing, communicating verbally, reading and understanding signs, symbols and words, engaging socially with other people face to face and making budgeting decisions.

One of the written submissions highlighted problems when applying for Adult Disability Payment noting: “I received a response of "there is not enough know about long COVID to use as evidence"”.

The submission from long COVID kids noted:

> “A rapid survey of families in our Scottish support services found that over 60% of families had not applied for Child Disability Payment because the form was too complicated and the lack of clarity from policymakers, professionals and advisers made it virtually impossible to receive the support necessary.”

Disabled people can get extra support to understand and apply for benefits from Social Security Scotland through the Independent Advocacy Service.

Carers of people who receive certain disability benefits may be eligible for Carer's Allowance and Carer's Allowance Supplement.

Members may wish to ask:

- **How should support for people with long COVID be co-ordinated?**
- **What areas should be prioritised?**

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