

Long Covid Cross Party Group 8th June 2022 Minutes

Present:

MSPs:

Jackie Baillie
Alex Cole Hamilton
Sandesh Gulhane
Beatrice Wishart

Invited Speakers:

Helen Goss,
Sheena Al Alami

Non-MSP meeting members:

Dorothy Elder,
Amy Small,
Callum O'Dwyer,
Cass Macdonald,
Freja Lundberg,
Helen Gibson,
Jackie Baxter,
Barbara Melville,
Dave Blane,
Edward Duncan,
Bruce Watson,
Ellie Bates,
Emma Miller,
Esperanza Miyake,
Fiona Armour,
Hannah Tweed,
Joan Rowley,

Karen Jeffrey,
Kate O'Donnell,
Kate Stott,
Leanne Quinn,
Lesley Walker,
Moirra Newiss,
Nicola Hendry,
Nick Sculthorpe,
Peter Kelly,
Risga Summers,
Shaben Begum,
Sheila Trachsler,
Lesley MacNiven,
Terri Lloyd,
Alison Love,
Catherine Hughes
Jane Omerod
Chris White

Agenda Item 1: Introductions-

The meeting was opened by Jackie Baillie MSP who explained that Jane Ormerod of Long Covid Scotland unfortunately could not be present. She welcomed the Parliamentary debate that took place on Long Covid since the last CPG on the 19th May despite the lack of progress on the issue and briefly spoke of the current status and trajectory of the disease. She welcomed the opportunity to discuss this issue further with the valuable contributions of patients suffering from the illness, noting that this CPG would have a specific focus on people's experiences with accessing relevant healthcare services.

Agenda Item 2: Previous meeting's minutes-

The minutes of the previous Long Covid CPG, held on 9th March 2022, can be accessed online [Previous CPG Minutes are available online](#)

Agenda Item 3: The experience of accessing healthcare and services for people

a) Chris White highlighted the results of a survey carried out on 220 people currently suffering from Long Covid which is in its final analysis stage. He spoke of peoples' common experiences in navigating health services and describes the frustration shared in the lack of responsiveness from certain GPs. He states that the Scottish Government's rejection of the specialist clinic route is having negative outcomes and doctors limited knowledge on the issue needs to be addressed in a more systematic way.

b) Helen Goss echoed Chris's sentiments and noted her disappointment at the lack of action taken. She cited certain stories of families/individuals resorting to informal experimentation in the desperate effort to find some relief. Helen also pointed out the way in which accountability is being avoided from various actors and institutions. She went on to tell various personal stories of sufferers, particularly children.

c) Sheena referred to the poor quality of life and dismal employment prospects that people with Long Covid have been subjected to. She made a series of recommendations that could potentially instruct government on how to alleviate some of the difficulties faced by patients including an Occupational Health Scheme and the need to incorporate self-employed people into this issue. Sheena explained the reality of the social support system in that sick pay schemes are being exhausted

and many people with Long Covid are having to leave work and seek unemployment benefit.

Agenda Item 4: Update from MSPs: Long Covid Treatment Pathways

Sandesh Gulhane MSP: noted the reality of medical practice with regard to Long Covid treatment, stating that many doctors are very limited in their ability to meaningfully help Long Covid sufferers right now. Specialist clinics highlighted as an obvious solution therefore disappointment expressed at the lack of enthusiasm from government.

Alex Cole Hamilton MSP: 1/30 Scots now suffering from Long Covid therefore pathology must be advanced and essential for a holistic approach to be developed. Political and public unity described as critical in this area.

Beatrice Wishart MSP: Sadness expressed at the rapid development of this disease and the lack of solutions, especially for children.

Jackie Baillie MSP: Regret at the lack of substantial funding and the pace of rollout. Research targets also highlighted as too slow paced. Noted that while political discussions are important, peoples' real lived experiences and stories must be used to bring about improvement. Steps outlined to call for reform of the system.

Agenda Item 5: Discussion

Various meeting members spoke of their experiences including parents, young people and healthcare workers citing rural isolation, employment law, psychological ramifications and the use of the media as significant factors in dealing with Long Covid.

Agenda Item 6: AOCB-

Close