Response from the Royal College of Physicians of Edinburgh to the Covid Recovery Committee's Long COVID call for views questions

Awareness and recognition

Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?

The Royal College of Physicians of Edinburgh (RCPE) is pleased to respond to this call for views and welcomes the Committee's interest in long Covid.

The RCPE understands that currently there are more than 2.1 million people living in the UK (3.3% of the population) with long COVID (symptoms continuing for more than four weeks after the first confirmed or suspected coronavirus (COVID-19) infection and not explained by something else).

Hence, there is an increasing awareness of "long COVID" and the myriad of presentations in patients and a recognition that in many cases this dissipates after a year which is encouraging. Indeed, it appears that many people self-report long COVID. We are aware that fatigue is the most common symptom reported as part of individuals' experience of long COVID (70%), followed by difficulty concentrating (45%), shortness of breath (42%) and muscle ache (42%). Other symptoms are not recognised by many patients and medical professionals such as the relationship to myocarditis for example.

A major concern is that the prevalence of long COVID is greatest in particular population groups, namely people aged 35 to 69 years, females, people living in more deprived areas, those working in social care and in particular those with another activity-limiting health condition or disability.

Our understanding of the pathophysiology and mechanisms underlying it remains primitive with ongoing research. Treatment in general is limited. The general public and indeed many medical professionals mislabel clinical disorders for long COVID such that in increase in the education and awareness of the disorder is required.

NHS England has produced useful information on its website but it is not clear how easily this is accessed or known by the public.

https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid

We previously welcomed the useful NICE/SIGN guideline on long Covid that was published in 2022 (Guideline COVID-19 rapid guideline: managing the long-term effects of COVID-19 (nice.org.uk))

We are aware of concerns that policy makers in Scotland are behind the progress made in England with the funding towards research and specialist centres to deal with long COVID. However, we are also aware of fears this has come at the expense of other valuable services rather than an addition to current services.

What more could / should be done to raise awareness and recognition of long COVID?

The RCPE supports the use of more simple literature and messaging on long COVID and its presentations. Again, we also recognise the risk of adding to health anxieties among some people and the risk of misdiagnosis of other important pathologies as currently it is very much a clinical diagnosis in many cases with no specific diagnosis test available.

What are your thoughts on the use of long COVID assessment clinics?

In other parts of the UK these are up and running and appear to have had some benefit but we understand some remain overwhelmed and under resourced, again similar to many other NHS services. We consider that it would be extremely helpful to see the data from England on their outcomes to make an informed evaluation about whether they may be an appropriate development here but we do believe their establishment merits serious consideration.

Therapy and rehabilitation

Do you consider that the correct mix of services are in place to help people who have long COVID?

In England we believe there are sufficient services. However, again there is also a hidden iceberg of people with possible long COVID who may benefit from these services but are not currently accessing them. Many of these patients are seen in general speciality clinics such as cardiology, respiratory, physiotherapy which overburdens these services.

What support could or should be available for people who are supporting or caring for people with long COVID?

We believe this can be split into four areas:

1. Education of the condition and how to manage it from a simplistic perspective.
2. Support remotely from specialists and therapists to advise.
3. Access to face-to-face services and resources.
4. Access to additional funding to allow changes in homes and purchase of equipment such as chairlifts etc.

Study and research

What should be the main priorities for study and research into long COVID?

We believe that there are a number of important areas which require study and research, including understanding the mechanisms leading to long COVID and potential drugs which may impact quality of life.

It is welcome to see that, to date, more than £50 million of government funding has been invested in long COVID research projects with over £39 million funding 19 NIHR projects. Indeed these 19 studies are examining the underlying mechanisms of long COVID, investigating symptoms such as 'brain fog' and breathlessness, and testing possible treatments.

They are also exploring whether NHS services, such as long COVID clinics, meet people's needs, and looking at what people can do to optimise their own recovery.

We are heartened to see the breadth of research in this area and the publication of results at pace to improve our understanding of long COVID.

Is sufficient data publicly available on the prevalence of long COVID in Scotland?

We are aware of the Long-CISS (Covid In Scotland Study) which found that 1 in 20 people who took part in the research had not recovered from having COVID-19 at their most recent follow up – between six and 18 months following infection with SARS-CoV-2. (Hastie, C.E., Lowe, D.J., McAuley, A. et al. Outcomes among confirmed cases and a matched comparison group in the Long-COVID in Scotland study. Nat Commun 13, 5663 (2022). https://doi.org/10.1038/s41467-022-33415-5)

This study also demonstrated that using NHS health data records, they were able to examine all Scottish adults who had a positive COVID-19 test, as well a sample of people who tested negative for the disease. Again, the concerning feature was the association with female sex, deprivation, respiratory disease, depression and multimorbidity.

However, data on the prevalence is not easily available to the general public.