

CVDR/S6/23/6/2

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An t-Ionad Fiosrachaidh

## **COVID-19 Recovery Committee**

**6th Meeting, 2023 (Session 6), Thursday,  
9 March 2023**

### **Long COVID – Study and research**

At this meeting Members will have an opportunity to discuss research into long COVID. Members will hear from:

**Professor Dame Anna Dominiczak, Chief Scientist (Health) and Euan Dick, Head of Chief Scientist Office**

The Chief Scientist Office's has funded nine projects in Scotland looking at the longer-term effects of COVID-19.

**Professor Chris Robertson, Professor of Public Health Epidemiology, University of Strathclyde**

Professor Chris Robertson is an applied statistician with interests in the application of Statistics over a wide variety of disciplines, including the statistical modelling of infectious diseases and in epidemiological studies.

**Professor Kay Cooper, Clinical Professor of Allied Health Professions, Robert Gordon University and NHS Grampian; and  
Professor Edward Duncan, Nursing Midwifery and Allied Health Professions Research Unit, University of Stirling**

Professor Kay Cooper and Professor Edward Duncan are involved in the LOCO-RISE study: [developing sustainable models of rehabilitation for long-term effects of COVID-19 in Scotland](#). This study aims to assess which models of community rehabilitation for people with long-covid are most appropriate, in which circumstances. It will evaluate the delivery and outcomes of four different models of community rehabilitation for people with long-covid currently being delivered in Scotland.

**Dr Janet Scott, Clinical Lecturer in Infectious Disease, Centre for Virus Research Glasgow**

Dr Janet Scott is a Clinical Lecturer in Infectious Disease at the MRC-University of Glasgow Centre for Virus Research. Dr Scott is interested in post viral sequelae focusing on long COVID. She is involved in a number of long Covid studies; understanding relapsing remitting Long COVID, Wellcome Trust and [defining and understanding the longer-term effects of COVID-19](#): A mixed methods study exploring the frequency, nature, and impact of 'long COVID' in the Scottish population.

The Committee launched a call for views on the inquiry. [The published submissions can be viewed online](#). The Committee also wrote to the Cabinet Secretary for Health and Social Care at the start of the inquiry and [the response can be read here](#).

SPICe [published an updated blog on long COVID](#) on 09 February 2023.

## Background

[The Chief Scientist Office's launched a funding call for applications for research into the longer-term effects of COVID-19](#). Applications were invited for Scottish-led applied research proposals, designed to improve understanding of the longer-term effects of COVID-19 infection on physical and mental health and wellbeing in Scotland, and/or research with the aim of developing effective clinical interventions to support recovery and rehabilitation from COVID-19 infection. [Nine projects received funding](#) and are currently taking place.

Other research has been funded by the [National Institute of Health Research](#) into long COVID. The NIHR's research portfolio aims to examine the underlying mechanisms of long COVID, investigate symptoms such as 'brain fog' and breathlessness, and tests possible treatments. It explores whether NHS services, such as long COVID clinics, meet people's needs and looks at what people can do to optimise their own recovery.

Members may wish to discuss the following themes with witnesses.

## Themes

### Theme 1: Long COVID research in Scotland

As part of the Scottish Government's response to the pandemic the Chief Scientists Office launched a funding call in October 2020, seeking applications for research to investigate the longer-term effects of COVID-19 infection. The call welcomed applications on diagnostic, prognostic and precision medicine approaches to long COVID-19 (defined as not recovering for several weeks or months following the start of symptoms); development and evaluation of treatment and rehabilitation strategies; research to increase the knowledge base around lived experience of long-term COVID-19 infection.

Nine projects were funded:

1. Amplifying the voices of people with lived experience to improve understanding, support, treatment and education. Share-to-improve: Long Covid experience (COV-VOICES) Study
2. Defining and understanding the longer-term effects of COVID-19: A mixed methods study exploring the frequency, nature, and impact of 'long COVID' in the Scottish population
3. COVID-19: Tracking Persistent Symptoms in Scotland (TraPSS)
4. Prevention and early treatment of COVID-19 long term effects: a randomised clinical trial of resistance exercise
5. Developing and validating a risk prediction model for long COVID-19
6. Clinical phenotyping to enable targeted treatment of persistent cognitive symptoms after COVID-19
7. Longer term impact of COVID-19 infection people with diabetes
8. Evaluating emerging models of community rehabilitation for people experiencing the effects of long-COVID to inform responsive service delivery across Scotland
9. Lived experience of long term COVID-19 on NHS workers in health care settings in Scotland: a longitudinal mixed methods study

In the evidence session on 02 February, Dr Melissa Heightman told the Committee that research trails into treatments for long COVID are lacking at the moment, and that this void puts patients at risk – as they may seek experimental treatments abroad.

Dr Heightman also told the Committee to have good research there is the need for an established clinical pathway.

**Members may wish to ask:**

- **What are the emerging findings from the research funded by the Chief Scientists Office?**
- **To what extent do the projects funded by the Chief Scientists Office focus on diagnostic, prognostic and precision medicine approaches to long COVID-19? Are there any gaps in the areas of research?**
- **Have there been any issues regarding the involvement of Scottish research sites/ NHS Boards in UK wide studies?**
- **How is research embedded in long COVID services in Scotland?**

## Theme 2: Future research

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 included a section on recommendations for research, this listed the following areas for research:

### Interventions for post-COVID-19 syndrome

- What are the most clinically effective interventions (including social prescribing and structured community support) for managing post-COVID-19 syndrome?
- Does effectiveness vary for different population groups (for example, sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with a learning disability)?
- Do any symptoms of post-COVID-19 syndrome predict the need for specialist intervention?
- Are there clusters of symptoms that identify response to interventions in post-COVID-19 syndrome?
- What is the clinical effectiveness of different service models of multimodality/multidisciplinary post-COVID-19 syndrome rehabilitation in improving patient-reported outcomes (such as quality of life)?
- What is the clinical effectiveness of exercise interventions for people with post-COVID-19 syndrome? Does effectiveness vary for different population groups (for example, sex, age, socioeconomic group, black, Asian and minority ethnic group communities or people with a learning disability)?
- Does early exercise rehabilitation assist in improving symptoms of post-COVID-19 syndrome?

### Prevalence of post-COVID-19 syndrome

- What is the prevalence and incidence of post-COVID-19 syndrome in people who have received single, double or boosted doses of the approved vaccinations in the UK? Does this vary across different population groups (for example in black, Asian and minority ethnic group communities)?

### Other recommendations for research

#### Prognostic markers of developing post-COVID-19 syndrome

- What is the clinical effectiveness of D-dimer and other blood tests and clinical features as prognostic markers of developing post-COVID-19 syndrome?

#### Presentation of post-COVID-19 syndrome in children, young people, pregnant women and older people

- What symptoms do children, young people, pregnant women and older people with suspected post-COVID-19 syndrome present with?

### **Clinical course of post-COVID-19 syndrome**

- What is the natural history of post-COVID-19 syndrome?
- What pathophysiological mechanism(s) underlie the most common presentations of post-COVID-19 syndrome? For example, generalised fatigue, breathlessness and ‘brain fog’?

### **Validated tools for screening for post-COVID-19 syndrome**

- Develop and validate new and existing screening tools (including physical, psychological and psychiatric aspects) for post-COVID-19 syndrome in a UK population.
- What tools are validated for screening for post-COVID-19 syndrome, which are the most accurate at identifying post-COVID-19 syndrome in a UK population and what is their effectiveness in guiding management?

At the meeting on 10 November 2022, the Committee heard from Professor McCartney, referred to the long COVID guideline. He said:

“It lays out a really clear research agenda of answerable questions that need to be looked at, and if resource were to be allocated towards research in this area, it would be a very good starting point. We need to understand how to diagnose, assess and treat long Covid; there will be a range of different options and inferences from other conditions that might or might not work, but it all needs to be tested. We need an evidence base for this, because at the moment we are under pressure to act in the absence of evidence, and that can do more harm than good. It can, for example, create a lot of iatrogenic harm—that is, harm from healthcare treatments—so we need an evidence base and an experimental context in order to learn more about this.”

Dr Janet Scott, in her written evidence, told the committee that the main priorities for study and research into long COVID should:

- understanding the aetiology of long covid: eg. persistent virus, autoimmune
- developing diagnostic techniques and imaging e.g. Xenon Gas MRI and ImmunoPET
- Treatment strategies - swift, prioritised national trials to rule in and rule out treatment options. Stimulate\_CP has been set up for this but is struggling with prioritisation and recruitment.
- True Prevalence and the impact of vaccination may also be useful

Other [suggestions for research](#) from the call for views included:

- The implications of long COVID for NHS workers in the longer-term
- The impact of health inequalities and deprivation on people effected by long COVID – these people were disproportionately affected during the pandemic
- The experiences of people caring for someone with long COVID, the impact on their health, quality of life and any economic implications.
- The clinical management and treatment pathways for long COVID

Many written submissions also called for research into treatments for long COVID:

“Treatment trials need to start NOW with existing medications that may show promise in the treatment of long covid”.

“Any research funding for long COVID must be directed into relevant biomedical research and not studies based on the now debunked idea that post viral illness is somehow psychological. Chronic illness is complex and will benefit from ongoing collaboration among researchers from across the globe to better understand the underlying disease mechanisms and ultimately find treatments and cures”.

A number of written submission also called further research into the impact of long COVID on children and young people. NHS Fife and the Royal College of Occupational Therapists also identified a lack of research or guidance on the impact of long COVID on children and young people. Long Covid Kids suggested:

“Investment into high quality biomedical research in children and young people to better understand the underlying pathology and mechanisms that cause Long Covid, so as to develop appropriate treatment protocols to improve health and wellbeing outcomes”.

Annexe A is a word cloud shoeing the frequency of words used in response to the question in the call for views on research priorities.

In oral evidence Jane Ormerod, Long COVID Scotland, told the Committee:

“In 2020, nine research projects were funded in Scotland, but there has not been any further funding for Scottish research projects since then. There are a lot of opportunities for further research. I would like to know what the future plan for that is”.

Members may wish to ask:

- To what extent is work being undertaken in the UK which focuses on the recommendations for research set out in the [guideline on managing the long-term effects of COVID-19](#)?
- Are there any plans for commissioning further research into long COVID in Scotland?
- How should the focus of research be prioritised?

### Theme 3: Funding research

As outlined earlier the Chief Scientists Office funded nine projects with a total funding commitment of £2.466 million. In the wider UK research funding landscape, two long-COVID specific calls were launched in 2020. The National Institute for Health Research (NIHR) funded 15 projects. Two of these 15 projects were Scottish-led:

- Activity tracking and just-in-time messaging to improve adaptive pacing: a pragmatic randomised control trial – Prof. Nic Sculthorpe – University of the West of Scotland
- ReDIRECT – Remote diet intervention to reduce Long-COVID symptoms trial - Dr Emilie Combet and Dr David Blane – University of Glasgow

As well as suggesting areas where further research is needed a number of written submissions also made suggestions of where research was not needed or did not contribute to developing improved services. For example, one respondent said:

“There should be no more precious research money thrown at digital apps, symptom monitoring (we know them!), self-management or any approaches that psychologise the condition.”

They went on to say:

“New research studies need to NOT duplicate work already done or in progress and there needs to be oversight of all research so there is a joined up approach. It does feel there has been no oversight, co-ordination or direction for research funding and a lot of studies still ongoing in Scotland have been overtaken by work elsewhere and won't add anything to the evidence base.”

Dr Janet Scott told the committee she did not believe that “further work on characterising long COVID or mapping services is a good use of resources”.

**Members may wish to ask:**

- **What oversight has there been on how has research funding across the UK has been allocated?**
- **What level of research funding for long COVID is needed in the short to medium term?**
- **Are witnesses aware of any additional (ongoing) funding streams for long COVID research?**

## **Theme 4: Evidence based policy making**

NHS England's [national commissioning guidance for post COVID services](#) recommends that post COVID services support new and ongoing research. Noting that:

“Due to the paucity of information surrounding long COVID, there is an urgent need for data to inform clinical management and health access for those disproportionately impacted by COVID-19. Data is used to support funding, operational decisions and research, and data quality is a key component of the commission for post COVID services”.

The NHS plan for improving long COVID services states:

“Since July 2021, NHS England has maintained a national registry for patients attending post COVID services. This includes data linkage across multiple NHS data sources, including demographic, inpatient and outpatient activity, diagnostic imaging, COVID testing and vaccination data. It has enabled insight into the natural history of long COVID and the journey for patients with long COVID, supporting equitable service. NHS England will further develop the long COVID registry and harness registry data, including by working with NIHR research programmes, to generate insights that add to the evidence base on long COVID and inform future service planning, treatment and care for people with long COVID.”

In its letter to the Committee in relation to evidence and innovation the Scottish Government said:

“The Strategic Network is facilitating the exchange of regular updates to clinical and service planning colleagues to ensure they have access to up to date and evidence-based information to inform practice and planning, including relevant information from CSO funded studies on the long-term effects of COVID-19.”

Jane Ormrod, Long Covid Scotland told the Committee:



“We want research here to be linked to British and international research. It is said that the time between an initial idea for research and that research producing something that leads to guidelines or treatment can be as long as five to 10 years. Things move pretty slowly.”

In [oral evidence on 10 November](#), Professor Sir Aziz Sheikh told the Committee:

“In Scotland we have absolutely phenomenal data sets in the health space: no other country in the world has the data that we have. How do we now deploy the data beyond questions about whether vaccines are working? That would be a relatively straightforward move.”

When asked why is that not happening? He said:

“It is because we do not have permissions, at the moment, and we do not have instruction to do that. We are able to do what we are doing in relation to Covid because the Cabinet Secretary for Health and Sport at the time, Jeane Freeman, asked us to do it and everything fell into place. Therefore, we need high-level instruction that the work is to be done. There is the wider question whether we can move to whole-system intelligence for NHS Scotland. That will be absolutely crucial if we want to improve services and begin to bend the cost curve. There is also the question about bringing health data—which are so rich—together with economic data, which could be done. Major investments have been made but, again, somebody senior needs to instruct the country to move in that direction.”

**Members may wish to ask:**

- **What data linkage is taking place in Scotland in relation to long COVID? Could this be improved and are there any areas of focus that would be particularly insightful?**
- **How are findings from long COVID research being used to inform decisions about service provision and delivery? How could this be facilitated?**
- **Is the long COVID service provision in Scotland based on best practice identified in the long COVID research?**
- **How is international research in long COVID disseminated in Scotland?**
- **How is the impact of long COVID research being monitored?**

**Lizzy Burgess, Senior Researcher, SPICe**

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## Annexe A: Word cloud of responses to the call for views question “What should be the main priorities for study and research into long COVID

