CVDR/S6/23/6/1

COVID-19 Recovery Committee

6th Meeting, 2022 (Session 6), Thursday 9 March 2023

Long COVID inquiry

Introduction

1. This inquiry will focus on diagnosis, treatment and current support available to those with long COVID. The aim of the inquiry is to scrutinise what action the Scottish Government is taking to address long COVID and post COVID syndrome. The inquiry will focus on the following three main themes—

   - Awareness and recognition
   - Therapy and rehabilitation
   - Study and research

2. This is the fourth and penultimate formal evidence session of the inquiry, in which the Committee will focus on study and research into long COVID. The Committee will take evidence from the following panel of witnesses—

   - Euan Dick, Head and Professor Dame Anna Dominiczak, Chief Scientist (Health), Chief Scientist Office;
   - Dr Janet Scott, Consultant in Infectious Disease (NHS Highlands) and Affiliate Senior Clinical Lecturer, MRC-University of Glasgow Centre for Virus Research;
   - Professor Kay Cooper, Clinical Professor of Allied Health Professions, Robert Gordon University and NHS Grampian;
   - Professor Edward Duncan, Nursing Midwifery and Allied Health Professions Research Unit, University of Stirling;
   - Professor Chris Robertson, Professor of Public Health Epidemiology, University of Strathclyde.

Background

3. In July 2021, SPICe published a blog on long COVID which set out what long COVID is, how many people were affected at that time, and how it is being treated

and managed in Scotland. In February 2023, SPICe produced an updated blog, Long COVID: where are we now? for this inquiry.

Scottish Government position

4. In advance of launching the inquiry, the Committee wrote to the Scottish Government seeking an update on its current position regarding long COVID. The Committee requested information on the following—

- Further information on the £2.5 million supported nine research projects commissioned by the Scottish Government into long COVID;
- Details of funding allocations of the £10 million long COVID support fund to date and future investment plans for addressing long COVID;
- Further details on the £370,000 supported national programme of improvement work led by National Strategic Network
- An update on the implementation of the recommendations of the National Strategic Network on the initial priority areas for improvement in relation to long COVID
- Details of those people who have accessed Chest, Heart and Stroke Scotland's 'long COVID support services'
- Clarification on its position on long COVID clinics and information on which, if any, health boards have established them;
- Further details on the expert group set up to identify the capacity needs of NHS Boards and staff in supporting people who have long COVID;
- Whether the Scottish Government believes long COVID should be treated as a disability under the Equality Act 2010;
- How the Scottish Government is meeting the recommendations of NICE around long COVID service provision

5. The Scottish Government's response has been published on the website.

6. Following this response, the Committee then wrote to health boards, the Thistle Foundation and NHS National Services Scotland seeking further information in relation to long COVID services provided by their organisation, including—

- details on the current services available including information on how the Scottish Government funding has been used;
- any barriers to service development and provision;
- any examples of good practice; and
- details of future plans for long COVID service provision in the short and medium term.

7. Responses received have been published on the Committee's inquiry webpage.

Engagement

8. The Committee was keen to speak to people with lived experience of long COVID at the outset of the inquiry. On 12 January 2023, the Committee spoke with

participants, who were contacted through Long Covid Scotland as part of the launch of its inquiry into long COVID. A note of the discussion and a briefing paper from Long Covid Scotland can be found on the website. On 2 February, the Committee held an informal online discussion with participants from Long Covid Kids, a note of the discussion can be found on the website.

Evidence

Oral evidence

9. At its meetings on 9 and 23 February, the Committee took evidence on the first two themes of the inquiry on awareness and recognition and therapy and rehabilitation respectively. On 2 March, the Committee then took evidence on comparative approaches to long COVID services across the UK. The papers and transcripts from those meetings can be found on the website.

Written evidence

10. The Committee issued a call for views on 12 January 2023, which ran until 10 February 2023 and was then extended until 19 February 2023. The Committee received more than 500 responses which can be read on the website. The Committee's call for views asked the following 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?
    - What more could / should be done to raise awareness and recognition of long COVID?
    - What are your thoughts on the use of long COVID assessment clinics?

    Therapy and rehabilitation
    - Do you consider that the correct mix of services are in place to help people who have long COVID?
    - What support could or should be available for people who are supporting or caring for people with long COVID?

    Study and research
    - What should be the main priorities for study and research into long COVID?
    - Is sufficient data publicly available on the prevalence of long COVID in Scotland?
    - Do you have any other comments?

11. A summary of the responses to the call for views has been published on the website and an extract on study and research is attached at **Annexe A**.

12. **Annexe B** includes written evidence provided by the following witnesses—

- Chief Scientist Office;
- Dr Janet Scott.

Next steps

13. The Committee will conclude its oral evidence taking on the inquiry at its meeting on 16 March when it will take evidence from the Scottish Government.

Committee Clerks
March 2023

ANNEXE A – Extract from the call for views summary of responses

Study and research

Individual respondents called for more research into the causes of long COVID and for biomedical research into diagnosis possible treatments. For example, Sarah McDonald said identifying potential treatment targets and testing therapies should be priorities for research and study. She said—

> "There is already sufficient evidence to justify initial studies on treatments for mast cell activation (H1 and H2 antihistamines), anticoagulants (in some cases) and treatments for autonomic dysfunction. There is potential to better understand known conditions and their treatment. For example there is some evidence available for POTS but it has major gaps, particularly when it comes to early intervention and potential resolution given average time to diagnosis pre-covid for patients with POTS was 5 years. By this time 85% of patients had been told their symptoms were caused by anxiety so the attrition rate of patients who either recovered before diagnosis or gave up seeking help is likely high. Given the massive increase in POTS patients post-covid and the fact most are early in their illness or currently undiagnosed there is potential to learn about early intervention and track recovery in a way that has not been possible before."

There were many suggestions of areas for future research and study, for example, Dr Janet Scott suggested the following areas for further study and research into developing diagnostic techniques and imaging e.g., Xenon Gas MRI and ImmunoPET and into treatment strategies.

Some of these points were also raised by the ALLIANCE who highlighted that respondents to its survey felt that there was not enough research or clinical trials being done to explore medical interventions for Long COVID, and called specifically for biomedical research and clinical trials to take place.

A number of individual respondents called for research into the parallels between other conditions, often displayed in long COVID patients, such as ME/ CFS/ PVFS/MCAS. #MEAction Scotland commented that emerging research suggests that more than 40% of people with long COVID are meeting the criteria for ME.

There were a number of calls from individuals for specific research into the presence of microclots in patients with long COVID and pointed to research being carried out in other countries including Germany. CHSS said—

> "As the largest organisation in Scotland supporting people living with chest heart and stroke conditions, we are also aware of research into long term implications of microclots. This includes potential links to stroke, pulmonary embolisms and ischaemic heart disease. More research into what this association looks like is essential if we are to best support people living with Long Covid, and if necessary mitigate their future risk of disease."

There were also calls for further research into understanding the effectiveness of rehabilitation services. RCPE also called for more research into understanding the mechanisms leading to long COVID and potential drugs, which may impact quality of life.

There were a number of calls for further research into the impact of long COVID on children and young people. Stirling University suggested this could include a comparison of experiences by age, gender, social class and ethnicity to identify where interventions could be focussed.

NHS Fife and RCOT also identified a lack of research or guidance on the impact of long COVID on children and young people. This point was echoed by Long Covid Kids who recommended '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.' COSLA and SWS also commented on this saying—

> "Further research is required to determine the long-lasting effects of the condition on young people, however, common symptoms relate to fatigue, anxiety and depression. Long COVID could result in loss of education through extended absence and impact on mental health welfare during this time. This may impact on local authorities' educational services, including mental health support and funding requirements for in-school counsellors, if those with long COVID require additional support."

A number of respondents spoke of the prevalence of long COVID in women including #MEAction Scotland and University and College Union Scotland. The Scottish Women's Convention said that as women are more likely to be carers for those people with Long COVID there should be more research into the gendered aspects of long COVID saying—

> "Due to the prevalence of women working in health and social care, as well as making up the majority of retail and hospitality workers, women were more likely to contract the COVID-19 virus. It is, therefore, vital that future study and research into the impact of COVID considers the gendered element of the virus, and if women are more likely to experience long COVID as a result."

NASUWT also commented on the fact that women aged between 35 and 69 are most likely to experience Long COVID and that some racial or ethnic minority groups and people with disabilities can also be at greater risk for developing post-COVID conditions. It said—

> "Counter-intuitively, the ONS figures show a much lower prevalence rate in non-white populations, which is illogical, given the higher impact the virus has had on Black people. This suggests significant underreporting in Black people. It is essential that study and research into Long COVID takes an intersectional approach and considers impact by protected characteristic."

Stirling University called for further research in a number of areas including how experiences of Long COVID vary by factors such as ethnicity, socioeconomic status, gender and age, and exploring how inequalities can be addressed through

interventions.

Dr Aileen Grant and Dr Nicola Torrance called for further research into the impact of health inequalities and deprivation on people effected by long COVID. They said—

> "…these people were disproportionally affected during the pandemic: relative deprivation was associated with higher rates of infection and mortality due to Covid-19. Evidence suggests there is likely to be unmet need in more deprived areas."

NHS Fife also called for further study into understanding impact of co-morbidity and inequalities.

British Association for Counselling and Psychotherapy (BACP) called for more analysis of the psychological impacts of Long COVID, upon both those with Long COVID and their families and support networks.

Jill Austin suggested research into the co-occurrence between long COVD (and ME/CFS) and neurodiversity (ADHD/autism) and research into the link between long COVID and menopause. The need for research into the overlap between symptoms of menopause and perimenopause and Long COVID was also highlighted by Claire Jones.

ANNEXE B – Written evidence provided by witnesses

Chief Scientist Office – Scottish Government

Overview of the Chief Scientist Office (CSO) research call on the longer-term effects of COVID-19 infection.

February 2023

Within the Scottish Government, the Chief Scientist Office (CSO) has policy responsibility for health research, development and innovation.

As part of the Scottish Government's response to the pandemic CSO launched a funding call in October 2020, seeking applications for research to investigate the longer-term effects of COVID-19 infection. The call particularly 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.

CSO received 35 applications by the call closing date of 9th November 2020. These applications were reviewed by 2 independent panels with expertise in the wide range of methods and specialisms covered by the applications and from a range of research institutions both in and outside Scotland and including lay members. Both panels were chaired by Professor Jon Nicholl, Chair of Health Services Research at the University of Sheffield. The panels met remotely on 2nd December 2020 (Panel A) and 4th December
2020 (Panel B). For each panel the same operational procedures were adopted. CSO's approach was to fund the top 3 ranked applications from each of Panels A and B. The remaining applications from both panels were then ranked together to enable the funding decision process to be completed.

The process followed by CSO was assessed by Professors John Savill (University of Melbourne and Chair of CSO's Strategic Advisory Board) and John Iredale (University of Bristol and Chair of Main Panel A Research Excellence Framework 2021) who were asked to give an independent view on the process followed by CSO together with Professor Nicholl. They concluded that the process followed and criteria used were appropriate, and had allowed robust review of the applications submitted. Furthermore, the outcome was a programme of projects meeting the aim of establishing a broad Scottish programme of high quality research on long-COVID-19 that could inform policy and clinical practice on responding to this aspect of the pandemic.

A total of 9 projects were funded with a total funding commitment of £2.466 million. Details of these projects are provided as Annex A.

In the wider UK research funding landscape, two long-COVID specific calls were launched in 2020 from:

(1) National Institute for Health and Care Research (NIHR) / UK Research and Innovation (UKRI)
(2) National Institute for Health Research (NIHR).

Both calls were open to applications led from Scotland. The NIHR/UKRI call announced in February 2021 that 4 projects funded totalling £18.5m had been funded. The NIHR call announced in July 2021 that 15 projects funded totalling £19.6m had been funded. 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

In normal times, CSO considers research applications through its two grant funding committees. These each meet twice per year and their role is well known among the health and care research community.

The Health Improvement, Protection and Services Research Committee (HIPS) considers applications for research aimed at improving or protecting population health or improving the quality, safety and/or effectiveness of healthcare in Scotland. https://www.cso.scot.nhs.uk/grant-funding/response-mode-funding-schemes/healthhttps://www.cso.scot.nhs.uk/grant-funding/response-mode-funding-schemes/health-improvement-protection-and-services-research-committee/improvement-protection-and-services-research-committee/

The Translational Clinical Studies Research Committee (TCS) considers applications for research aimed at improving treatments and / or diagnostic approaches for conditions of clinical importance to the population of Scotland. https://www.cso.scot.nhs.uk/granthttps://www.cso.scot.nhs.uk/grant-funding/response-mode-funding-schemes/translational-clinical-studies-research-committee/funding/response-mode-funding-schemes/translational-clinical-studies-research-committee/

Both the above committees welcome applications from across the entire clinical spectrum, including on long-covid.

Annex A: Overview of project funded through the Chief Scientist Office research call on the longer-term effects of COVID-19 infection.

COV/LTE/20/04
Amplifying the voices of people with lived experience to improve understanding, support, treatment and education. Share-to-improve: Long Covid experience (COv-VOICES) Study **University of Stirling**
Professor Kate Hunt
£299,883

COVID-19 is a new virus. Media stories often talk about the numbers of people who die from COVID-19, or about people who are hardly affected and recover quickly. We will conduct a study of the experiences of people who have a range of symptoms

that sometime last for months after catching COVID-19. This is called ‘Long Covid’. We will use our findings to produce a reliable online resource with practical information and support for people with Long Covid and their families and carers, and information that can be used to train doctors, nurses, social care and other healthcare workers.

In our detailed interviews with people with Long Covid, we will ask them about their symptoms, the services they used, the information, support and care needs they have, and how Long Covid has affected their lives. Our findings, with video, audio and written clips from the interviews, will be freely available on a website (www.healthtalk.org/), which has won many prizes for being a source of patient experiences of health and illness that people can trust. We will also be able to compare the experiences of people in our studies with people who live in other countries, and with other studies.

Details of Papers Published to date

Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy: https://pubmed.ncbi.nlm.nih.gov/36507117/

COV/LTE/20/06
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
University of Glasgow
Professor Jill Pell
£299,562

Most people with COVID-19 recover within three weeks, but some don’t. Our study will identify how many people continue to be unwell, their symptoms, and how it their lives. Scottish adults who had a positive COVID-19 test, and a negative test comparison group, will be sent an SMS message inviting them to take part in the study. If they agree, they will use an app to answer questions about their health before and after COVID-19, and any effect on their lives. They will answer the questions again 12, 18, and 24 months after testing. Their health records will tell us if they have been in hospital or taking medicines. This can be done without us knowing their name or speaking to them. They will be asked if they agree to be contacted directly. Some who agree will have one-to-one interviews to discuss, in more detail, the impact of COVID-19 on their health and relationships. We will also ask for their suggestions on what help they need. Anyone can refuse to take part, or withdraw from the study, at any time. Patients with lived experience of COVID-19 symptoms will be members of a steering group providing advice during the project.

Details of Papers Published to date

Outcomes among confirmed cases and a matched comparison group in the Long-COVID in Scotland study: https://pubmed.ncbi.nlm.nih.gov/36224173/

Do we need consent to obtain consent? Public and participant feedback to using personal health data for: https://pubmed.ncbi.nlm.nih.gov/35672086/

COV/LTE/20/08
COVID-19: Tracking Persistent Symptoms in Scotland (TraPSS)
University of the West of Scotland
Professor Nicholas Sculthorpe
£239,358

We know that people respond very differently if they become infected with COVID-19. Some people need to be admitted to hospital, while others have no symptoms at all. After treatment, some people find that their symptoms can carry on for a long-time, even if their initial symptoms were mild. Research into this effect, often called 'long-COVID' has found that it affects very different numbers of people in different studies. This means that in order to help Scottish patients recovering from COVID-19 infection, we need to study long-COVID in Scotland. Therefore, this project aims to improve our understanding of Long-COVID in the Scottish population, and particularly in people whose original symptoms were relatively mild. We will review the current evidence describing the types of symptoms other studies have reported, and we will survey people at different stages of recovery to find out what kinds of persistent symptoms they have. Finally we will follow people who have recovered from a COVID-19 infection for 9 months to see how many people have long term symptoms, what symptoms persist, and for how long.

Details of Papers Published to date

More Than 100 Persistent Symptoms of SARS-CoV-2 (Long COVID): A Scoping Review:
https://www.frontiersin.org/articles/10.3389/fmed.2021.750378/full

COV/LTE/20/10
Prevention and early treatment of COVID-19 long term effects: a randomised clinical trial of resistance exercise **University of Glasgow**
Professor Colin Berry
£286,660

Many people have long-lasting symptoms after COVID-19, such as breathlessness, fatigue and chest pain. So far, research studies of treatments for COVID-19 have focused on the life-threatening acute illness; few studies look at treatments to improve long-term health after COVID-19. COVID-19, particularly when this requires a hospital admission, can lead to weight loss and muscle wasting, contributing to worse outcomes. Muscle strengthening (resistance-based) exercise could improve outcomes in the long-term.

We are looking to do two things:

1) To undertake a research trial of pragmatic resistance-based exercise for 220 people recovering from COVID-19.

2) Create a platform for rapid trials of new treatments after COVID-19. This will cut the costs of doing future trials and allow more patients the opportunity to contribute to medical research that will improve outcomes for people recovering from COVID-19.

Our team is multidisciplinary, multi-ethnic, gender-balanced and drawn from across NHS Scotland, and the University of Glasgow. We are currently leading the CISCO-19 study, funded by the CSO, in the West of Scotland, using medical imaging of the hearts, lungs, and kidneys of patients, to understand the impact of COVID-19. We have consulted with members of the public, including people with COVID-19, in designing this study.

Details of Papers Published to date

Prevention and early treatment of the long-term physical effects of COVID-19 in adults:
design of a randomised controlled trial of resistance exercise—CISCO-21:
https://pubmed.ncbi.nlm.nih.gov/35971155/

The Janus of COVID-19: from registry data to prospective studies:
https://pubmed.ncbi.nlm.nih.gov/34166487/

COV/LTE/20/15
Developing and validating a risk prediction model for long COVID-19
University of Edinburgh
Professor Aziz Sheikh
£189,659

Most patients with coronavirus disease 2019 (COVID-19) recover within a few weeks. However, around 10-20% of people continue to have symptoms that last for many weeks or months. These ongoing symptoms can involve different parts of the body, including the heart, lungs, nervous system and they may also result in mental health problems. It is still unclear which patients will develop these long-term problems also sometimes known as
“long-COVID”.

Our team has been involved in developing a calculator for the UK and Scottish Governments to identify people at risk of serious COVID-19 that results in hospital admission or death. We now plan to build on this and develop the world’s first calculator to identify who is at greatest risk of developing long-COVID. We will do this by analysing data from a unique COVID-19 data platform that we have created, which securely holds information on 5.4 million people (~99% of the Scottish population). We will work with the Scottish Government and NHS leaders to make this calculator available for routine clinical use, which will offer opportunities for the more focused and efficient targeting of resources to reduce the long-term risk of disability and death from COVID-19

Details of Papers Published to date

Deriving and validating a risk prediction model for long COVID-19: protocol for an observational cohort study using linked Scottish data: https://pubmed.ncbi.nlm.nih.gov/35793922/

Symptoms and signs of long COVID: A rapid review and meta-analysis: https://pubmed.ncbi.nlm.nih.gov/35596571/

COV/LTE/20/26
Clinical phenotyping to enable targeted treatment of persistent cognitive symptoms after COVID-19
University of Edinburgh
Professor Alan Carson
£290,941

People with 'Long Covid' describe memory and concentration problems. Studies examining how people perform on memory and intelligence tests have found that patients who have had COVID-19 perform worse than those who have not. But to date, we don't know why they have poorer cognitive function.

Memory and concentration symptoms in 'Long Covid' are likely to have different causes in different people. Some may have had direct infection or inflammation of the brain, or blockages to blood vessels in the brain. In others, underlying brain disease may have been 'unmasked' by COVID-19. Some may have functional cognitive disorders, where memory and concentration problems are the result of changes in the brain's 'software'. In others, anxiety, low mood or fatigue may contribute to their symptoms. Each of these conditions has a different outcome and treatment.

This study aims to closely examine 100 people with persisting cognitive symptoms after COVID-19, assessing the cognitive problems as well as markers of brain damage, inflammation, and underlying degenerative brain disease.

Details of Papers Published to date

'What is Brain Fog?': https://jnnp.bmj.com/content/early/2022/12/06/jnnp-2022-329683

Structural epitope profiling identifies antibodies associated with critical COVID-19 and long COVID: https://www.medrxiv.org/content/10.1101/2022.07.11.22277368v2

Functional cognitive disorders: clinical presentations and treatment approaches: https://pn.bmj.com/content/early/2022/12/08/pn-2022-003608

COV/LTE/20/28
Longer term impact of COVID-19 infection people with diabetes
University of Glasgow
Dr Robert Lindsay

£295,201

People with diabetes have suffered greater adverse consequences of COVID-19 in the acute phase of infection during the pandemic. Whether they also have increased susceptibility to longer term sequelae is unknown. Such knowledge is critical to public health approaches to management of the pandemic in these populations. We will build on the excellent available surveillance of the population of people with diabetes in Scotland using the existing SCIdiabetes platform, used already to accurately detail short-term outcomes.

Current research during the COVID crisis has highlighted that to the end of July 2020, 2724 people with diabetes had Covid-19 (positive test, admission or death certificate) of whom 988 had unfortunately died. This means more than 1736 people with diabetes in Scotland may be living with the consequences of Covid-19. Assessment of the long term holistic impact on people with diabetes cannot be approached using routine data collated from electronic health records and so we propose to use the resources of the Scottish Diabetes Research Network (SDRN) to collect information through questionnaires and clinical examination on a range of outcomes in people with diabetes compared to the general population of people with diabetes.

COV/LTE/20/29
Evaluating emerging models of community rehabilitation for people experiencing the effects of long-COVID to inform responsive service delivery across Scotland
Robert Gordon University
University of Stirling
Professor Kay Cooper (RGU)
Dr Edward Duncan (UoS)
£296,545

Studies estimate that 10–35% of people with COVID-19 experience disabling clinical symptoms following the acute phase of their illness (long-Covid). Scottish Government figures estimate that there are already 5,330-18,655 citizens with long-Covid, many of whom are likely to require support to recover. Community rehabilitation, delivered by physiotherapists, occupational therapists and other health professionals, is a well-established approach to enabling people to maximise their quality of life and recovery. However, community rehabilitation for people with long-Covid is in its infancy.

There are considerable differences in how community rehabilitation for people with longCovid is currently delivered across Scotland. We want to assess which models of community rehabilitation are most appropriate, in which circumstances. We will evaluate the delivery and outcomes of four different models of community rehabilitation for people with long-Covid currently being delivered in Scotland. This will help us to identify which models are more suitable, for which patient groups and in which contexts. We will then hold online workshops with community rehabilitation mangers, service leads and others from across Scotland.

During the workshops, we will present our findings and support participants to develop evidence-based action plans to improve their local long-Covid community

rehabilitation services.

Details of Papers Published to date

A national survey of community rehabilitation service provision for people with long Covid in Scotland: https://pubmed.ncbi.nlm.nih.gov/33953912/

COV/LTE/20/32
Lived experience of long term COVID-19 on NHS workers in health care settings in Scotland:
a longitudinal mixed methods study
Robert Gordon University
Dr Nicola Torrance
Dr Aileen Grant
£294,605

Many NHS workers have greater occupational risk of exposure to COVID-19 than the general population. UK studies found the risk of healthcare workers testing positive for COVID-19 was seven times higher than for non-essential workers. In Scotland healthcare workers and their households contributed to a sixth of cases admitted to hospital.

This study aims to establish the nature and extent, and lived-experiences long COVID on the health and well-being on a self-identified cohort of professional and ancillary staff in NHS Scotland. We plan to use a longitudinal mixed methods approach, collecting data over a oneyear period. A rapid review of the literature on the longer-term effects of COVID-19 will guide the development of an online questionnaire survey which will be used to examine selfreported health status, working lives, and other key factors in affected individuals. Subgroups of NHS workers will then be invited to take part in qualitative interviews designed to capture their narrative accounts of living with long COVID. Stakeholder workshops, where we will share emerging findings, will engage with occupational health and human services, professional bodies and training establishments.

The findings will help to inform policy, practice and research recommendations, including NHS workforce planning needs.

Dr Janet Scott

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?

Recognition is difficult to gauge. I live and work in an environment which is very aware of long COVID, although attitudes to it vary. Patient groups report frustration at not being believed by their GPS and 'gaslighting' . This may reflect the lack of current treatment options and referral pathways open to GPs.

The relapsing nature of long COVID is acknowledged by the WHO but formal study is currently lacking. This type of pattern, together with the uncertainty of prognosis makes return to work planning difficult

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

Although each patient will have to be assessed on a case-by-case basis, specific guidelines on return-to-work policies would be helpful. Some patients may be long-term disabled - in which case, recognition under the Equality Act 2010 would be helpful and allow them to seek assistance via Access to Work funds and justify reasonable adjustments in the workplace.

Such recognition would assist in legitimising suffering.

Having named long COVID specialists in long COVID clinics would also help. At present the primary care and therapy-led rehabilitation teams could be useful, but are unlikely to cure anyone.

What will help are a small group of consultants (and GPS) who can really learn clinically about the condition, be research curious, action new research swiftly, and participate and enrol patients in appropriate clinical trials.

Please see my response below

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

Part of mine:

"I attended the Westminster Conference on Long COVID on 31st January 2023, where the many benefits of having integrated long COVID assessment clinics in England were discussed by several groups.

There is £224 mil in ring-fenced funding, and funding has been renewed for 2023/2024.

This has led to properly integrated clinics, training modules, access to research studies and evaluation of outcomes.

Dr. Emma Tucker, who leads the service in Oxford lists the following benefits of dedicated service:

"-Allow us to deliver safe care whilst learning more about the condition.

-Mechanism to provide integrated care for this new multisystem disease. Successful elements of us have been:

-Increased involvement of GPs into care management.

-Gathering of a broader multidisciplinary therapy team to meet therapy needs such as new speech and language of petrol therapy, physiotherapy, and nursing.

-Integrated psychology: delivering physical health and psychological health strategies concurrently.

-Access to arrange specialist input in management without need for multiple onward referrals.

-Improved capability to identify other causes of symptoms. Quality triage and prioritisation.

-Vocational rehab, working age cohort return to work is the key goal of intervention.

-Involvement of the voluntary sector with social prescribing, and the development of a suite of self-management resources

-Importantly, there was discussion of the stimulator development of clinical networks to share learning quickly and encourage training, which will soon be leading to a long Covid clinical society for sharing best practice."

In all of this, the lack of long Covid clinics in Scotland has left both are clinicians and our patients behind.

Recruitment into research is a very important aspect of the clinics, especially in this new condition. We were unable to participate fully for example in the PHOSP covid study, and I have yet to set up recruitment for STIMULATE- CP. UK national research funding is going into the studies and it is important to facilitate access for Scottish patients.

I previously set up a clinic of Ebola Survivors in Sierra Leone. Arguments against such clinics were similar to those that have been arguing against long COVID clinics in Scotland specifically, that patients should present and be managed by their primary care providers. Survivors like, long, Covid patients, where gaslit, with even well-known international experts suggesting their symptoms could be caused by a hard life in west Africa. Without going into the clinical details of post-Ebola syndrome, this is very obviously not the case, and this has subsequently been born out by my research and that of others.

Having a dedicated service, diagnosing correctly (long COVID is frequently misdiagnosed), learning, engaging and legitimising long COVID, and engaging in research is essential for providing optimum care in my opinion.

Therapy and rehabilitation

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

Most services have yet to open. I have been advising the NHS GGC team. I think the therapies will be very useful. I might like to see the more active participation of interested GPs, and I think a link to secondary care is missing and is needed.

The integrated model used in England has really broken down the primary/secondary care barriers, and would be worth emulating the best examples of this.

Clinicians for example with expertise in POTs and Sleep disturbances would be helpful.

Secondary care services, such as respiratory need to be funded to see long COVID patients, so that onward referrals are possible where appropriate.

Research in imaging and biochemical markers is moving quickly and we may need to implement some of these tests clinically soon to offer the best service, which will also have a cost implication.

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

Care needs to be judged on the level of individual disability, just as with any other disability. Of course, this can be kept under review as a patient may recover. We cannot assume that patients will fully recover (although we hope they will). My research with Prof. Jill Pell, in the CSO-funded project COVID In Scotland Study (CISS), indicated that after the first 6 months, very few people saw improvement and 11% deteriorated.

It is a relapsing, fluctuating disease - so a patient may improve, get back to work, and subsequently relapse.

Study and research

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

1. understanding the aetiology of long covid: eg. persistent virus, autoimmune

2. developing diagnostic techniques and imaging e.g. Xenon Gas MRI and ImmunoPET

3. 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.

4. True Prevalence and the impact of vaccination may also be useful

I do not think further work on characterising long COVID or mapping services is a good use of resources.

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

True prevalence is in fact quite a tricky thing to calculate. With Prof. Pells group we are working on that right now, and will publish soon.

We would be delighted to have results widely known.

Do you have any other comments?

Thank you for conducting this enquiry. I know Scottish long COVID patients feel left behind.

I think adding long COVID speciality clinics into an integrated service would give this disease the champions and experts it so badly needs.

We also need to consider UK or Scotland-wide clinical trials to quickly find solutions to the problem.

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