North-east COVID-19 observatory: issue 11.

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2020

North-East COVID-19 Observatory

Issue 11—26th October 2020

Welcome

Welcome to our eleventh issue of the Observatory. This will now be issued monthly, with each month having a dedicated theme. We include news, professional matters, and relevant professional and light reading. Each issue has one or two guest contributors with a specialist interest in the chosen theme. This month we have a very new theme - **Long Covid** - and, because of this, we are delighted to have **Colin MacLean**, Liaison Librarian Research Support at Robert Gordon University as our guest writer. Colin is also a member of the editorial team of the Observatory - so we are grateful for his extra input into this new and evolving phenomena. As ever, we value any feedback and encourage people to request themes or to send in resources that others might find interesting.

Theme: Long Covid

For many people, the experience of Covid-19 will go beyond being a respiratory illness that they will recover from in two or three weeks but instead manifest as several confounding syndromes with long term impacts on health. Post-viral fatigue is often experienced as a consequence of viral disease but that, added to the aftermath of intensive care treatment, creates a physically and mentally challenging set of potentially long term conditions. Such is the severity of the disease that many will emerge on the other side with organ damage too. Knowledge about the disease and its outcomes is emerging through the global research effort and the rapid publication and sharing of research papers.

Last week (19 to 25 October 2020) was International Open Access Week, an annual event celebrating the Open Access phenomenon. The research papers that we have highlighted in each issue of North East Covid-19 Observatory were chosen as being pertinent to each theme but it was considered of equal importance, in offering our selections, that they were openly accessible to our readership.

Making the content of research papers from academic journals accessible to all is one of the main goals of Open Access, to counter those situations where readers arrive online at a publisher website and are able to access the abstract of a paper but not the full text, without making a payment. Affiliates of a university or health service might be able to get through the paywall by offering up suitable credentials, but most people would not be in such a position. Given that most research and therefore the published outputs of research are backed by public funds, this situation is clearly wrong and Open Access addresses it directly.

Adapting the business models of academic journal publishers to Open Access however is one of the challenges of our times. In the journey towards understanding the coronavirus, aspects of the impact of Covid-19 and

Long Covid, and in achieving a vaccine, a super abundance of research papers have appeared. For-profit publishers have set aside commercial interests and stepped up and made much of the research available and free to read for the common cause. Notably, as an immediate response to the WHO announcement of the global epidemic of coronavirus, the International Association of STM Publishers (STM = Scientific, Technical and Medical) issued this communiqué, about their commitment to combating Covid-19 by extending immediate access to resources. You can see what is provided from the list available here: https://www.stm-assoc.org/coronavirus-2019-ncov/

This list of free to read resources is a welcome development but nevertheless a challenging one to negotiate for anyone unfamiliar with academic publishing portfolios. Again, most people do not have access to research databases that render these resources discoverable. However there are several open access tools that serve the purpose, which I highlight here:

***PubMed Central**: Pubmed Central is a research database of full text academic papers developed by the United States National Library of Medicine. Free to access.*

***PubMed**: Also from the US National Library of Medicine is a comprehensive research database of the medical and biomedical journal literature that incorporates the full text of PubMed Central.*

***Google Scholar**: Google Scholar is a search engine developed by Google to enable users to search across scholarly literature specifically and identify accessible sources of academic papers.*

***Dimensions**: Dimensions is a product of Digital Science. Publication data is free to access and search and open access content is clearly labelled. A subset of Dimensions is aimed at Covid-19 resources.*

***CORE**: CORE is a free to access searchable database of entirely Open Access resources built by harvesting the content of open data providers across the world, such as institutional repositories, open access and hybrid journal publishers. The technology is delivered by the Open University and JISC, the organisation providing digital infrastructure and skills support for FE and HE in the UK.*

Open Access more widely goes further than being about publications alone but also extending access to sharing and reuse of research findings through open licences, text mining and the research data itself. Publications and discovery tools such as PubMed Central and Google Scholar are nevertheless core components of research infrastructure.

Long Covid: the Story so Far?

On January 30th 2020 the World Health Organisation declared the global outbreak of Covid-19 January a public health emergency of international concern. At that time, few people in the United Kingdom (UK) had heard of Covid-19, the disease caused by the Coronavirus strain Sars-Cov-2.

By the end of March 2020 the UK went into lockdown to try and contain the spread of Covid-19, which soon became a term everyone knew because it affected everyone's lives in very many different ways. Figures to date state that over 34 million cases of Covid-19 have been diagnosed globally, with just over 23 million people reported to have recovered.

For some people, recovery has not been swift and they continue to suffer from a wide range of symptoms. This period of protracted illness following diagnosis has been termed Long Covid. This term was coined by patients - you can read about why and how the term came into common parlance here. Although difficult to define with precision, some sources state that over 60,000 people in the UK are thought to have Long Covid.

Tim Spector, Professor of Epidemiology at King's College London and who is leading the Covid Symptom

Study App, told BBC Radio 4's *File on 4* that data from the app shows that around 300,000 people have reported symptoms lasting for more than a month. According to **Professor Trisha Greenhalgh** and colleagues, this is termed "post-acute Covid-19" and with 60,000 having reported symptoms for more than three months, 'Long Covid'. As the number of cases increase and as time moves on, these figures will of course change.

Paul Crisp, Director of the Centre for Guidelines at the National Institute for Health and Care Excellence (NICE), states that there is growing evidence to suggest Covid-19 is a multi-system disease that for many people involves persistent symptoms with longer-term impacts on their health. Whilst there is no authoritative definition, Long Covid is the term used to explain the lasting effects of COVID-19. According to a report by the NiHR (cited in an article by **Elisabeth Mahause** in the *British Medical Journal*), the term may actually cover different syndromes. These syndromes of Long Covid are thought to be:

- Permanent organ damage to the lungs and heart
- Post-intensive-care syndrome
- Post-viral fatigue syndrome
- Continuing Covid-19 symptoms

People who are suffering or who have suffered from the effects of Covid-19 have formed a pressure group, and (as you will read later) now have a Facebook and Twitter presence. The pressure group is in the form of a UK Support Group called Long Covid Support. This is an active and vocal group, and the website can be accessed at https://www.longcovid.org/. In August, members of longcovid.org and their partners sent a letter to **Jeremy Hunt**, Chair of the Health and Social Care Committee, which Health Secretary **Matt Hancock** publicly acknowledged in September. The letter called for the UK Government to assemble a multi-disciplinary Long Covid taskforce to consider the following:

1. Improvements to (continuing) professional education
2. More and better research
3. Quality psychosocial and mental health services
4. Better public health programmes
5. Help for NHS and social care workers to return to work safely
6. Funding for patient-led support groups.

On September 23rd a UK Parliament Select Committee commissioned work on Long Covid. This resulted in a very interesting report by **Professor Trisha Greenhalgh and colleagues** on *Long Covid: Evidence, Recommendations and Priority Research Questions*, which provides written evidence in response to this Government inquiry. It is an essential read for those of you wanting to know more about Long Covid and the suggested tier approach for a Long Covid service. It defines Long Covid as:

> *A distinct condition affecting approximately 60,000 people in the UK, and characterised by persistent and fluctuating fatigue, breathlessness, cognitive blunting ("brain fog") and pain. The cause is unknown but it is likely to be due at least partly to an inflammatory reaction. Many cases remain undiagnosed, since clinicians may incorrectly require a positive test for Covid-19.*

This paper uses the definition in an earlier BMJ paper (also by Greenhalgh et al.), which differentiates between post-acute Covid-19 and chronic Covid-19. This defines post-acute Covid-19 as symptoms lasting 3-12 weeks and chronic Covid-19 as symptoms beyond 12 weeks. The authors go on to state that "some people

whose initial Covid-19 was mild (and who were never hospitalised) may go on to develop chronic symptoms, and vice versa." According to the authors, patients with Long Covid fall into three groups, broadly speaking:

A. People who were very ill (perhaps on ITU) with acute Covid-19 and who now have significant long-term organ damage (e.g. lungs, heart, brain, kidneys), along with weakness and debility.

B. People who were not so ill in the acute stage but who also now have some evidence of long-term organ damage.

C. People who have persistent symptoms after Covid-19, but who don't have persisting organ damage.

We have pulled the definitions out of this paper, but strongly recommend that those interested in Long Covid should read it in full, because it outlines the need for urgent interdisciplinary services to be organised and managed in a four-tier system.

Persistent Symptoms After COVID-19: This qualitative study of 114 Long Covid patients, with draft quality criteria for services, can be read here.

Personal Stories of Having Long Covid

Two stories from the Long Covid Support Group: The Group asked for two personal stories to be shared widely. The first is from a 22 year-old mental health nurse from London and the second is from a 46 year-old from Ohio.

Report from the NiHR: The NiHR have published an online resource called *Living with Covid-19*. This document is a dynamic review of the evidence around ongoing Covid-19 symptoms (Long Covid). This is a very informative paper and gives the results of focus groups carried out with people who have Long Covid. It also makes recommendations for services needed to help those with the long term effects of this disease.

The Effects of Long COVID: a Physician and Patient's Perspectives: Patient Safety Movement's Dr Donna Prosser is joined by Dr Steven Deeks (Professor of Medicine at the University of California, San Francisco) and Dr Jake Suett (Staff Grade Anaesthetist and Intensive Care Doctor, UK), to discuss the long-term implications of COVID-19 from clinical and personal perspectives. Dr Deeks shares the research around long COVID-19 symptoms and Dr Suett provides a personal anecdote of his experience with symptoms that have lasted months. Dr. Suett also shares information about the COVID symptom study, which consists of an international mobile app to track COVID-19 symptoms over time. You can view the recording here.

Social Media

Social media is a useful forum for finding out about current thinking, but please note that it does not guarantee that the evidence is robust!

Facebook: There is a Facebook group who could not understand why they were not recovering from Covid. It was set up by Diana Berrent, who started the group in March. At the time of writing (October 2020) the group has 80,000 members worldwide. This is a closed group and only for people with Long Covid. So researchers, clinician and interested people are advised to contact info@longcovid.org if they would like more information.

Twitter: People with Long Covid, who sometimes refer to themselves as "long-haulers", have a Twitter account (@long_covid) and hashtag (#LongCovid).

Wikipedia: A sign of the growing interest and knowledge concerning Long Covid is demonstrated in that Wikipedia now has a page dedicated to this condition.

Media Resources

Podcast: Dr Jake Suett, an intensive care doctor, talks to Dr Ava Easton about his experience of getting Covid -19 and the lasting effects of the infection that he is still experiencing. This resource is from the Encephalitis Society and you can listen to it here.

BBC Radio 4 Scientifically: This resource gives some interesting information on Long Covid, and is entitled "Four things we've learned about Long Covid":

- It's not all about the lungs: People with long Covid are experiencing a wide variety of symptoms associated with multiple organs.
- There might be a storm brewing: A cytokine storm caused by over-reaction of the immune system, which can cause organ failure.
- It can get into your head: More than post-viral anxiety – many reported psychiatric and neurological conditions might be biological.
- There's still a long way to go: How to tease the data apart will decide how countries across the globe fight against the disease.

Your Covid Recovery: This is an online resource from NHS England, which offers support and advice to people during their period of recovery from Covid-19. It contains some very useful information and is suitable for use throughout the UK.

Guidelines

NICE and the Scottish Intercollegiate Guidelines Network (SIGN) announced on October 5th 2020 that they would work with the Royal College of General Practitioners (RCGP) to develop a guideline on persistent effects of Covid-19 (Long Covid). The guideline will address, among other things, a formal definition of the disease, how to identify on-going symptoms, and a definition of best practice investigation and treatment options to support the management of the condition across diverse communities. It is expected that the guideline on the longer term patient impact of Covid-19 will be published by the end of the year. The announcement referenced the same written evidence from the House of Lords' inquiry that was referred to earlier in this newsletter, so we would presume that the recommendations of a four tier service design will be considered. You can read the press release about the forthcoming guidelines here.

Educational Resources

The NiHR have published a report entitled *Brain and Nerve Complications are More Common Than Expected in Younger Patients with Severe COVID-19*. Questions about how a pandemic virus causes neurological complications have been around since the Spanish flu in 1918. This paper shows the volume and the breadth of potential neurological complications. People aged under 60 who are hospitalised with COVID-19 are more likely than expected to experience severe psychiatric symptoms. Research found that altered mental states such as psychosis are being reported in these younger patients. It confirmed that strokes and other neuro-

Logical symptoms are common in severe COVID-19.

An initial study included 153 cases reported by stroke physicians, neurologists and psychiatrists in the UK in April 2020. It found that most strokes occurred in people aged over 60. But about half the cases of altered mental state such as psychosis or swelling of the brain (encephalitis) were in younger people. These complications may reflect damage to the brain and nervous system caused by the coronavirus. In the study, 'altered mental state' included any sudden change in personality, behaviour, thinking abilities, or consciousness. Neurological symptoms included any symptoms involving the nerves or muscles. Strokes included blood clots or bleeds in the brain. Further research may help researchers work out how the virus causes these complications. This in turn may help them develop appropriate treatment pathways.

Attributes and predictors of Long COVID: analysis of COVID cases and their symptoms collected by the COVID Symptoms Study App (Sudre et al., 2020): The authors analysed data from 4182 incident cases of COVID-19, the symptoms of which were logged prospectively in the COVID Symptom Study App. 558 (13.3.%) had symptoms lasting more than 28 days; 189 (4.5%) for more than 8 weeks; and 95 (2.3%) for more than 12 weeks. Long COVID was characterised by symptoms of fatigue, headache, dyspnoea and anosmia, and was more likely with increasing age, BMI and female sex. Experiencing more than five symptoms during the first week of illness was associated with Long COVID. The authors suggest that this model could be used to identify individuals for clinical trials, to reduce long-term symptoms, and to target education and rehabilitation services. You can access the report here.

NHS England will offer specialist centres for people suffering with Long Covid symptoms. Speaking at the NHS Providers conference on October 7th, NHS chief executive Sir Simon Stevens announced that £10 million is be invested this year in additional local funding, to help kick start and designate Long Covid clinics in every area across England, to complement existing primary, community and rehabilitation care. Sir Simon said this new network will be a core element of a five-part package of measures to boost NHS support for Long covid patients:

1. New guidance commissioned by NHS England from NICE by the end of October on the medical "case definition" of Long Covid. This will include patients who have had Covid, but who may not have had a hospital admission or a previous positive test.
2. *Your Covid Recovery* - an online rehab service providing personalised support for patients. Over 100,000 people have used the online hub since it launched in July, which gives people general information and advice on living with long Covid.
3. Designated Long Covid clinics (above). This will involve each part of the country designating expert one-stop services in line with an agreed national specification.
4. National Institute for Health Research (NIHR) funded research on Long Covid, working with 10,000 patients to better understand the condition and refine appropriate treatment.
5. The NHS's support will be overseen by a new NHS England Long Covid taskforce, which will include Long Covid patients, medical specialists and researchers.

You can access the announcement here.

Long Covid Support: This group was mentioned earlier in the Observatory, but we feel that it is worth repeating under the Educational Resources section. This group has a very informative website with personal testimonies, resources, media assets and contact information.

Research Funding

NHSG Endowment Trust: The Trustees are very keen to support applications for funding. They state that "the emphasis should be on social research and particularly the effects of COVID-19, people with long-term conditions, prevention, inequalities and projects which informed improvements in care and support." The grants are for up to £12k.

CSO Funding: Applied Research on Longer-Term Effects of COVID-19 Infection: CSO are launching a call for applied research proposals that are designed to improve understanding of the longer term effects of COVID-19 infection on physical and mental health and wellbeing in Scotland, and/or for research with the aim of developing effective clinical interventions to support recovery and rehabilitation from COVID-19 infection.

Studies within remit would include: the epidemiology of, or clinical evaluation of 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 sequalae.

This call is not to support: hypothesis-generating basic research on the molecular, cellular and/or physiological mechanisms underlying long COVID; nor is it to support wider research relating to COVID-19 such as into the impacts of social distancing/lockdown measures on health and wellbeing.

The funding available for individual projects is for up to £300,000 at 80% full economic cost. Projects should be up to 24 months in duration, although longer projects will be considered on an exceptional basis if clinically/scientifically justified. CSO expects to be in a position to fund around 6 such projects through this call. CSO standard terms and conditions of grant and applicant eligibility criteria apply.

Cross-disciplinary collaborative proposals are welcomed, as are studies that build on or extend existing studies in Scotland. Funded applications will need to start within 3 months of the award. Applications should be submitted along with a letter of support from the host institution, confirming that the research can be conducted within this timeframe and, where support of the NHS for use of resources is required, the research can be supported by the territorial Health Board(s) or special Health Board(s) involved. Applications that are within remit of this current call are not eligible for consideration by the CSO response mode committees' January 2021 application round. These committees will accept other COVID-19 related research applications that are within their individual remits, but out with the scope of the current call. Applications should take into account other research currently underway on the long-term effects of COVID-19 infection and CSO will liaise with other funders to ensure duplication of effort is avoided. You can access the application form here.

Pre-Announcement of NIHR/UKRI Call: Long-Term Effects of COVID in Non-Hospitalised Individuals: This is a pre-announcement that the NIHR and UKRI will be advertising a joint research call in late October, for projects starting in the New Year. The primary aim of the call will be to fund ambitious and comprehensive research into the longer term physical and mental effects of COVID-19 in non-hospitalised individuals. Funded projects will be expected to start in early 2021. Find out more here.

COVID-19 Library

The topic is new and information is growing all the time. We have done our best to access the most interesting resources for you to read—with three academic articles and six pieces of light reading that we hope you will enjoy.

Academic Reading

Callard, F. and Perego, E., 2020. How and why patients made Long Covid. Social Science and Medicine, 7 October, article 113426. https://doi.org/10.1016/j.socscimed.2020.113426

Morley, J.E., 2020. COVID-19 — The Long Road to Recovery. Journal of Nutrition Health and Aging, 5 October. https://doi.org/10.1007/s12603-020-1473-6 and https://rdcu.be/b8yEg

Marshall, M., 2020. Covid-19's lasting misery. Nature, 585, 17 September. https://media.nature.com/original/magazine-assets/d41586-020-02598-6/d41586-020-02598-6.pdf

Light Reading

Reynolds, M., 2020. They never officially had Covid-19. Months later they are living in hell. Wired, 11 September. https://www.wired.co.uk/article/coronavirus-long-haulers-negative-tests-Covid-19

BMA, 2020. Doctors with Long Covid. [online]. London: BMA. Available from: https://www.bma.org.uk/news-and-opinion/doctors-with-long-Covid

Witvliet, M.G., 2020. I'm a Covid-19 long-hauler and an epidemiologist. Here's how it feels when symptoms last for months. The Conversation, 11 August. https://theconversation.com/im-a-Covid-19-long-hauler-and-an-epidemiologist-heres-how-it-feels-when-symptoms-last-for-months-143676

Mukherjee, M., 2020. My tête á tête with Covid: a patient's perspective. The Physician, 6(2), https://doi.org/10.38192/1.6.2.27

Conte, R.L., 2020. Covid-19 long haulers: meaning, symptoms, support groups. [online]. Covid.us.org. Available from: https://Covid.us.org/2020/07/12/Covid-19-long-haulers-meaning-symptoms-support-groups/

A short article in the Guardian concerning those deemed to be at the greatest risk of Long Covid can be read here.

Your COVID-19 Observatory

We hope you are enjoying the Observatory, which will now be issued monthly. The next issue will be circulated on **Monday 30th November**.

The Editorial Team

We are a small team from the School of Nursing, Midwifery and Paramedic Practice at Robert Gordon University (RGU). Angela Kydd (Clinical Professor in Nursing RGU / NHSG) is the editor, Colin MacLean is the librarian and Rahul Oza provides technical support.

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