

Date

By email only to:

Dear ...,

Re. PPI - (name of study)

Congratulations on your success in obtaining funding for your study on Long Covid.

Long Covid Support (<https://www.longcovid.org/>) is an international peer support and advocacy group for people with Long Covid. We comprise a core group of 40-50 people with Long Covid working across numerous work streams including advocacy, support, research involvement and campaigning.

Long Covid Support was formed by a group of people struggling to recover from Covid-19, who found each other online and have been campaigning in the UK for recognition, rehabilitation and research into treatments since May 2020.

Our international Long Covid Support Facebook Group is an inclusive space for people experiencing the diverse, debilitating and alarming symptoms of Long Covid in which to share information and access peer support. Also on Facebook is our 'Covid-19 Research Involvement Group', a group where investigators can make connections with patients for involvement, participation and engagement in research into Covid-19.

We would like to be part of patient involvement in your study to help ensure the patient voice remains at the heart of the research as we believe that proper patient involvement is crucial to the development and success of effective research, innovations and services.

We have been instrumental in providing patient and public voices to all responses to Long Covid across the four nations of the United Kingdom, including with the NHS England Long Covid Task Force, Lord Bethel's Long Covid Round Table, the NIHR, Parliamentary debates, the Westminster Forum, the BMJ, The Society of Occupational Medicine and the Independent SAGE. Internationally we have worked with the World Health Organisation, the International Severe Acute Respiratory and Emerging Infection Consortium and The Global Research Collaboration for Infectious Disease Preparedness. We have also contributed to several scientific publications and a huge number of specialist reports, media articles and appearances. A list of publications to date is given at the end of this letter.

We have a wide view and experience of the needs of not only ourselves but many others with Long Covid and are thus ideally positioned to collaborate with organisations such as yourself in a way that amplifies the contribution of the individual patient recruited through traditional PPI initiatives. We can:

- Facilitate recruitment of participants, including from diverse and inclusive groups, through our Facebook groups;
- Participate as members of study governance committees;
- Advise on the development of research questions, surveys, interpret study results and promote knowledge translation activities;

- Advise on study design to ensure that it is free from hidden stigma and inequality;
- Advise on how your work can inform a broader international coordinated response to the long-term impact of Long Covid;
- Help identify the needs of people with Long Covid and ensure that their experiences are captured;
- Facilitate networking with the other major UK and International research teams investigating Long Covid;
- Provide input on ways in which study findings may be used more broadly in the Long Covid community, clinical and research settings;
- Provide training in Patient and Public Involvement in Research for both patients and members of your study team;
- Be involved in ongoing integrated knowledge translation (iKT) with members of the global Long Covid community through mechanisms such as the Community of Practice via our [Long Covid Support website](#), social media and educational materials that are accessed globally by community members and healthcare providers.

We are embedded in the international community of Long Covid patient-led groups and we have several sister and affiliate groups that focus on particular areas: Long Covid Kids, Long Covid Scotland, Long Covid Wales and Long Covid Physio.

Our social media reach and network spans the following:

- Long Covid Support Group (Facebook): 42k members (in 100 countries and territories, principally from the UK and US);
- Long Covid Support public page (Facebook): 10k followers;
- @long_covid Twitter account: 13k followers;
- Long Covid Instagram: 4k followers.

We look forward to hearing from you, and to working together.

Warm regards,

Margaret O'Hara on behalf of Long Covid Support Research Sub-Group

Email: research@longcovid.org

Publications Co-Authored with Members of Long Covid Support

May-20	Janet Bettger	COVID-19: maintaining essential rehabilitation services across the care continuum	BMJ Global Health
Jul-20	Darren Brown	Six Lessons for COVID-19 Rehabilitation From HIV Rehabilitation	Physical Therapy and Rehabilitation Journal
Sep-20	Nisreen Alwan	From doctors as patients: a manifesto for tackling persisting symptoms of covid-19	BMJ Letters
Oct-20		NIHR Themed Review 1 - Living with Long Covid	evidence.nihr
Dec-20	Melina Michelin	Characterising long-term covid-19: a rapid living systematic review	medrxiv
Dec-20		Covid 19 rapid guideline :Vitamin D- NICE Guideline(NG187) - 17.12.2020	NICE.org
Dec-20		COVID-19 rapid guideline: managing the long-term effects of COVID-19	NICE.org
Jan-21	Samuel Lipworth	From SARS and MERS to COVID-19: a review of the quality and responsiveness of clinical management guidelines in outbreak settings	medrxiv
Feb-21	Alice Norton	Long COVID: tackling a multifaceted condition requires a multidisciplinary approach - The Lancet Infectious Diseases	The Lancet Infectious Diseases
Feb-21	Whelehan	Leadership through crisis: fighting the fatigue pandemic in healthcare during COVID-19	BMJ Leader
Feb-21	Darren Brown	Physical Therapists Living With Long COVID. Part 1: Defining the Indefinable	Journal of Orthopaedic and Sports Physical Therapy
Feb-21	Darren Brown	Physical Therapists Living With Long COVID. Part 2: When "Keep Pushing" Isn't the Answer Feb 2021	Journal of Orthopaedic and Sports Physical Therapy
Feb-21	Robin Gorna	Long COVID guidelines need to reflect lived experience	The Lancet
Mar-21	Nida Ziauddeen	Characteristics of Long Covid:findings from a social media survey	medrxiv
Mar-21	Gail Carson	Research priorities for Long Covid: refined through an international multi-stakeholder forum	BMC Medicine
Mar-21	Danilo Buonsenso	Clinical Characteristics, Activity Levels and Mental Health Problems in Children with Long COVID: A Survey of 510 Children	preprints.org
Mar-21		NIHR Themed Review 2 - Living with Long Covid	evidence.nihr
Apr-21	Simon Decary	Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome	Journal of Orthopaedic and Sports Physical Therapy
Apr-21		Rehabilitation of adults who are hospitalised due to acute Covid-19 or long Covid: physiotherapy service delivery	Chartered Society of Physiotherapists
Apr-21	Manoj Sivan	Fresh evidence of the scale and scope of long covid	BMJ Editorial