



PHIRI

Population Health Information
Research Infrastructure

Covid-19 impact on population's Mental Health

Task 8.4:

NATIONAL ACTION PLAN ON POSTVIRAL /
POSTINFECTIOUS SYNDROMES

- LONG COVID INITIATIVES

– Róbert Láng (HU)

REF meeting
5th June, 2023





Agenda

- Long COVID Europe
- RECOVER Initiative
- Long COVID Physio





Long COVID Europe

Long COVID Europe (LCE) is a European network of Long COVID patient associations run by (current and former) Long COVID patients.

LCE was founded because many Long COVID patient organizations were struggling with the same issues.

LCE creates economies of scale by sharing relevant resources, know-how, and contacts with its members.



What Do They Do?



Mission statement

- offer unique expertise as a patient network, helping third parties cover their patient-centric blind spots
- gather information concerning Long COVID to curate and share with Long COVID stakeholders

What Do They Hope to Achieve?

- **Recognition** of Long COVID as an impactful pandemic within the COVID-19 pandemic that urgently needs to be addressed by governments and the healthcare sector, with physical causes, also affecting young people.
- **Research and knowledge distribution** via extra funding for patient-centric Long COVID research in multi-disciplinary networks, with an urgent focus on trustworthy diagnostics and ways to eliminate hurdles for patient rehab.
- **Rehabilitation** based on medical needs using a multi-disciplinary approach, freed from counterproductive administrative and financial hurdles, with sufficient support for those with little or no access to informal care.

Via Extra Funding for Patient-centric Long COVID Research

- LCE urges the scientific community to investigate the mechanisms and conditions causing Long COVID
- ask for substantial and immediate increases in the funding of Long-COVID-specific, multi-disciplinary patient-centric research
- research needs to be co-designed and co-produced with Long COVID patient organisations, acknowledging their expertise.

RECOVER Initiative: Researching COVID to Enhance Recovery



To better understand, prevent, and treat PASC, the National Institutes of Health created the **RECOVER Initiative: Researching COVID to Enhance Recovery.**

RECOVER seeks to answer questions

- What does recovery from SARS-CoV-2 infection look like among different groups?
- How many people continue to have symptoms after acute infection?
- How many people develop new symptoms after acute infection?
- What causes these health effects?
- Why do some people develop these health effects while others do not?
- Does SARS-CoV-2 infection trigger changes in the body that increase the risk of other conditions, such as chronic lung, heart, or brain disorders?

The Consortium collaborates with patients, caregivers, and community representatives across all levels of the initiative, including in national leadership roles and within local communities in study locations.

Recover and RTI

- The RECOVER Initiative is using the best science to make progress toward understanding recovery from the long-term effects of COVID.
- RECOVER is a prime example of how RTI supports translational research and science that require complex research networks. It brings together researchers from across the Nation, referred to as the RECOVER Consortium, who are leading cohort studies related to PASC.
- RTI (Research Triangle Institute) serves as the Administrative Coordinating Center (ACC) for the RECOVER Initiative. In this capacity, we partner with NIH to develop and oversee the Consortium.

Long COVID Physio



- Long COVID Physio is an international peer support, education and advocacy, patient-led association of Physiotherapists living with Long COVID and allies.
- They work internationally across advocacy, policy, guideline development and research.
- Their education outputs are for anybody living with Long COVID and people wanting to learn more.

Since 2020

- Long COVID Physio was founded in November 2020 by Physiotherapists living with Long COVID from the United Kingdom (UK) and United States (US).
- The founding objective for Long COVID Physio is to provide **peer support** for physiotherapists, support workers and other allied health professions (AHPs) living with Long COVID.

Expanding objectives for Long COVID Physio

- provide and participate in **education** on Long COVID, disability and rehabilitation.
- provide patient and public involvement (PPI) in **research**, participate in establishing research agendas, and engage in research outputs.
- provide community driven **advocacy** in Long COVID from the voices of physiotherapists living with and affected by Long COVID.
- engage in regional, national and international **policy** and **guidelines** on Long COVID.
- engage in regional, national and international implementation of **healthcare models** for Long COVID rehabilitation.

Long COVID Physio partners with organisations as strategic alliances



www.phiri.eu



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317