

Flash Report

Network of Expertise on Long COVID under the Expert Group on Public Health

18 September 2023

The Network of Expertise on Long COVID under the Commission Expert Group on Public Health held a virtual meeting, chaired by DG SANTE. The representatives of 11 Member States plus Iceland and the United States of America attended the meeting.

EU Survey outcomes and Mapping Study

Member States had been surveyed earlier in the year to gain an overview of the actions already taken to address the challenges of Long COVID. The **outcomes of the survey** indicate that multidisciplinary care pathways of Long COVID patients are implemented or planned in all the responding countries, as are rehabilitation programmes and national guidelines for diagnosis and treatment of Long COVID. On the contrary, none of the responding countries had implemented screening and early detection programmes for Long COVID. The identification of research needs and gaps relating to Long COVID and the sharing of guidelines and intelligence on diagnosis and treatment were considered priority topics by all of the responding organisations. The EC tasked the EUHealthSupport Consortium with conducting a **mapping study**, which will: (1) provide an overview of existing definitions of Long COVID; (2) map existing guidelines and intelligence on Long COVID diagnosis and treatment within EU Member States and beyond; and (3) provide an overview of surveillance systems used to monitor Long COVID patients.

Cohorts Coordination Board: Working Group on Long COVID

Members were updated on the Working Group on Long COVID, which currently meets monthly and includes 27 representatives from various European projects. The primary goal is to share findings related to Long COVID, with the aim of facilitating mutual learning and fostering collaborative partnerships. The ultimate objective is to enhance the quality of data, promote interoperability, and work towards the establishment of standardised data collection methods. This, in turn, will result in a more precise definition of Long COVID, contributing to better prevention and care strategies. The Working Group is currently drawing up an initial draft of a Master Protocol for Observational Cohorts to provide empirically driven guidance for conducting robust observational research into post-viral syndromes, using Long COVID as an illustrative case.

ORCHESTRA Project

NELC members were informed of the H2020 project ORCHESTRA (connecting European cohorts to increase common and effective response to SARS-CoV-2 pandemic). The project groups 37 partners from 15 countries and aims at establishing an international large-scale-cohort to generate rigorous evidence for the management of SARS-CoV-2 infection. In particular, the ORCHESTRA work package 2 linked six prospective cohorts from 56 centres in five countries (France, Italy, the Netherlands, Spain, and Argentina) to define the post-COVID syndrome by periodically assessing clinical, virological, biochemical, and immunological aspects and quality of life from diagnosis of SARS-CoV-2 infection up to two years follow-up. Determinants could be explored from different perspectives including medical history, concomitant treatments, acute infection characteristics, variants of concern, and variation in time of serology and biochemistry patterns. A revised definition of post-COVID-19 syndrome was proposed, including the reasoning behind it.

Presentation of US action on Long COVID

Member States were informed of activities taking place in the USA related to tackling long COVID by the Office of Long COVID Research and Practice. The working definition at the

federal level was shown, including highlighting the key differences from the definition of the WHO Europe. The timeline of the US government response was identified and explained, followed by the domains of the national research action plan. Members were informed of the RECOVER initiative – Researching COVID to Enhance Recovery – a flagship initiative, which has so far been funded with over 1 billion USD. The Initiative adopts a multipronged approach to reach the research questions underlying Long COVID. To conclude, members were pointed to a series of both scientific and lay documents.

Presentation by the WHO Europe on their work on Long COVID

The WHO informed members of their activities both at the global level and in Europe. WHO Europe provides country support to identify health system approaches on Post COVID-19 condition through country deep-dives; shares models and approaches across the region; supports developing medium-term Post COVID-19 condition management plans in countries; provides resources for rehabilitation; and hosts events. The WHO Europe stressed that cross-border and international collaboration is key. The WHO pointed specifically to the WHO Tool¹ for collecting country information on the management of patients with post COVID-19 condition.

Discussion and establishment of NELC actions

Members discussed potential actions for the NELC to guide the workplan for the coming years. Initial suggestions included supporting the exchange of best and promising practices and experiences – including those of patients - across Member States; presenting relevant EU level studies and evidence, including implementable results from research projects; facilitating exchanges between Member States about relevant experiences (e.g. identifying clusters of countries sharing or having overcome similar challenges). The development of guidelines, clinical recommendations and good clinical practice on Long COVID was considered relevant, as was providing support to patients, including education programmes.

Conclusions and AOB

Member States were encouraged to indicate² particular ideas for future meetings of the network. The Chair then thanked everyone for their attention and comments and told participants of the next virtual meeting currently planned for December 2023.

¹ [The WHO Global Clinical Platform for COVID-19](#)

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