High-level Meeting on Post-COVID Conditions (Long COVID)
A virtual meeting hosted by the WHO Regional Office for Europe
Abstract:
This was the first meeting on post-COVID conditions, also known as long COVID, held by the WHO Regional Office for Europe. It provided a vehicle for Member States of the WHO European Region to share country experiences on data, burden, management and health systems' response to post-COVID conditions. WHO stands ready to support Member States to revisit and improve their national monitoring and evaluation capacity, to develop national guidance to manage patients with post-COVID conditions, and to support their health systems to adapt to post-COVID conditions.

Keywords:
COVID-19, LONG COVID, POST-COVID CONDITIONS, REHABILITATION
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This report summarizes the contributions of presenters at the meeting.

**Setting the scene**
Hans Henri P. Kluge, WHO Regional Director for Europe

**Background to post-COVID conditions**

**Clinical manifestations**
Dina Pfeifer, Medical Officer, Infectious Hazard Management, WHO Regional Office for Europe

**Rehabilitation**
Satish Mishra, Technical Officer, Disability, Rehabilitation, Palliative and Long-term Care, WHO Regional Office for Europe

**The impact on health systems**
Tomas Zapata, Regional Advisor for Health Workforce and Service Delivery, WHO Regional Office for Europe

**An aid to policy**
Martin McKee, Research Director, European Observatory on Health Systems and Policies

**Country experiences**

**Austria:** Reinhild Strauss, Ministry of Health  
**Denmark:** Line Riddersholm, Deputy Director, Primary Health Care  
**France:** Marc Bardou, speaking on behalf of the Health Ministry  
**Georgia:** Tamar Gabunia, First Deputy Minister for Internally Displaced Persons, Health and Social Affairs  
**Italy:** Graziano Onder, National Institute of Health  

**Kazakhstan:** Azhar Giniyat, Deputy Minister, Ministry of Health  
**Netherlands:** Ines Mogami, Policy Officer, Infectious Diseases, Ministry of Health, Welfare and Sports  
**Poland:** Jan Szczegielniak, National Consultant in the field of Rehabilitation, Government of Poland  
**Portugal:** Ana Luisa Gomes, Directorate-General of Health  
**Sweden:** Judith Bruchfeld, Senior Consultant, Infectious Diseases, Karolinska University Hospital

**Closing**
Hans Henri P. Kluge, WHO Regional Director for Europe

**Moderation**
Dorit Nitzan, Regional Emergency Director, WHO Regional Office for Europe

Natasha Azzopardi Muscat, Director, Division of Country Health Policies and Systems, WHO Regional Office for Europe
This was the first meeting on post-COVID conditions, otherwise known as long COVID, held by the WHO Regional Office for Europe. It provided a vehicle for Member States of the WHO European Region to share country experiences on data, burden and management of post-COVID conditions.

Dorit Nitzan, Regional Emergency Director of the WHO Regional Office for Europe, invited Hans Henri P. Kluge, the WHO Regional Director for Europe, to make some opening remarks. He noted that it has become clear that COVID-19 disease can result in a set of sequelae that extends beyond the typical post-viral recovery period. Recognition and understanding of post-COVID conditions, also termed long COVID by patient groups, is growing. Post-COVID conditions can adversely affect physical, mental and social functions, with a predominant symptom of fatigue, among others.

Many question need to be answered. Who is at risk? What is the range of symptoms? Which diagnostic tests are required? Can it be prevented? How should it be treated? How should health services be readied to provide the needed care? This meeting sets out to understand which decisions countries have made in the process of finding answers to such questions.

We will not be able to say that we have defeated the virus or ended the pandemic without addressing post-COVID conditions.

Hans Henri P. Kluge, WHO Regional Director for Europe
Background to post-COVID conditions

Clinical manifestations
Some COVID-19 patients experience post-intensive-care syndrome; others, however, have a clinical picture that is more like post-infection syndromes, such as post-viral fatigue syndromes or myalgic encephalomyelitis. Guidance on management on these syndromes is available.

Post-COVID conditions, which can arise irrespective of disease severity and may even affect asymptomatic cases, presents as a range of signs and symptoms. While some hypotheses have been posited, understanding of the pathophysiology, pathogenesis, immunogenesis and clinical characterization is limited.

Affected patients may access a number of medical specialties and come away without a definitive diagnosis. Recognition and understanding of post-COVID conditions is limited among medical professionals, hindering their ability to diagnose, especially in the absence of a positive SARS-CoV-2 test (possibly because the patient was unable to access such a test). Advanced diagnostic technology may be required in some instances to demonstrate the damage the person’s body has suffered. Lack of access to such technology means that only limited progress has been made on treatment and management. Large cohorts of patients will need to be followed for a number of years in a quest to find affordable pharmacological and non-pharmacological interventions and effective approaches to managing this sometimes life-changing condition.

Well designed research using existing harmonized data-collection tools and research protocols recommended by WHO will need to involve virtually every health-professional discipline. Evidence-based research findings will translate into guidance and standard operational procedures to support health-care staff to manage their patients.

We should avoid losing time and resources by generating poor-quality evidence [on post-COVID conditions]. A massive and coordinated research effort is needed.

Dina Pfeifer, Medical Officer, Infectious Hazard Management, WHO Regional Office for Europe

Rehabilitation
Growing evidence indicates that rehabilitation services will be key to physical, emotional and economic recovery from COVID-19. The Regional Office has produced the hugely popular leaflet, Support for rehabilitation self-management after COVID-19-related illness (1), to support countries in their COVID-19 response. The leaflet is for those who are self-managing their COVID recovery at home and presents basic therapeutic interventions and advice. Other WHO guidance documents and tools have also been developed (2). Most recently, a policy brief on post-COVID conditions was launched by the European Observatory on Health Systems and Policies (see below), and WHO is working on a patient toolbox for post-COVID-19 rehabilitation.

Post-COVID conditions will need long-term health system solutions. WHO has been working with countries to implement the Rehabilitation in health systems: guide for action tool (3), the primary objective of which is to provide practical guidance on how countries can use health system building blocks for the provision of accessible and quality rehabilitation services. A rehabilitation competency framework that
The impact on health systems
Currently, it is difficult to state the impact of post-COVID conditions on health systems. The prevalence of post-COVID conditions is unknown at this stage, and while WHO has started work on formulating the case definition, there currently is no consensus on case definition. Countries need to capture more, and better, data on post-COVID conditions. WHO has released relevant ICD10 and 11 codes and is providing country support to train coders to address this. Countries can perform rapid assessments on health information and surveillance systems to better capture these data.

Post-COVID conditions will have service delivery implications. They will create new health needs to which health services and health workforces will have to adapt. Well coordinated care, based on a unified multidisciplinary pathway and on multidisciplinary teams, will be critical in responding to post-COVID conditions. Primary care services should be supported to adopt a coordination role and ensure they can provide (or refer to) the range of services required by people with post-COVID conditions (including mental health support, social and welfare advice, support for self-care and specialized care). Having a single point of assessment and one-stop diagnostics will be central for patients with the most complicated manifestations, who need to be referred to hospital. Country context will be critical in tailoring the health system response.

All this will have implications for the health workforce. The number of patients with post-COVID conditions who require interventions will translate into an increased workload for health-care workers. Countries need to start planning for this, alongside their ongoing planning to address the current pandemic, while also continuing to provide other essential health services. Health workers will require new knowledge and skills to manage people with post-COVID conditions. In-service training and continuing professional development activities will be needed to help them acquire these skills and knowledge. Multidisciplinary teams will be important in addressing the multiple health needs of patients with post-COVID conditions.

Primary care will have to be supported to provide well coordinated care based on a unified multidisciplinary pathway through which multidisciplinary teams respond to the multiple health needs of patients with post-COVID conditions.

Tomas Zapata, Regional Advisor for Health Workforce and Service Delivery, WHO Regional Office for Europe

An aid to policy
The policy brief, In the wake of the pandemic: preparing for long COVID (5), developed jointly by the European Observatory on Health Systems and Policies and the WHO Regional Office for Europe, tries to bring together what is currently known about this complex condition (or, more accurately, range of conditions) in one place.

It addresses the issue of what health systems need to do in the face of post-COVID conditions, or long COVID. Health systems in countries should:

- ensure systems are in place to gather data on those who are affected; countries should establish cohorts of patients who have had COVID-19 and follow them up over time to
develop understanding of the natural history of post-COVID conditions;

- listen to people who are affected by the condition – people with post-COVID conditions say they feel they are not being listened to; there is much evidence that co-production leads to services that are more acceptable to health professionals and patients and are based on trust and mutual respect;

- include health professionals with different types of expertise and skills in the response; post-COVID conditions affect many systems in the body, so the response must involve multidisciplinary teams;

- recognize that much of the care for patients with post-COVID conditions will be provided in primary care; general practitioners (GPs) need to have the necessary knowledge and the skills, including guidance on when to refer and to whom; and

- make sure that there are really good links between clinical practice and research.

Only a few countries have clinical trials whereby patients are involved in the design. With so little known about post-COVID conditions, every patient should be given the fundamental opportunity to participate in clinical trials. The consequence of not doing so is that many patients may be given treatments that are ineffective or even dangerous.

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It’s basic good practice in the 21st century that no health service should be developed without listening to the voices of patients.

Martin McKee, Research Director,
European Observatory on Health Systems and Policies
Countries were invited to share their experiences, and representatives from Austria, Denmark, France, Georgia, Kazakhstan, the Netherlands, Poland and Portugal related their experience in relation to a number of key themes of post-COVID condition management.

Guidelines/protocols
Country representatives provided descriptions of guidelines, protocols, data collection and other measures put in place to support the response to post-COVID conditions at national and regional levels.

Denmark published its first national guidelines for managing the long-term effects of COVID-19 in November 2020, calling for every region in the country to establish post-COVID conditions clinics in hospitals to enable patients with severe symptoms to access multidisciplinary assessment and treatment. Patients with milder symptoms are managed through the country’s strong primary health care system. Revised guidelines were published in March 2021 (6), further clarifying the concept of post-COVID conditions and reflecting current evidence following advice from an interdisciplinary group of primary- and secondary-care specialists.

So-called rapid action guidelines were issued in France in February 2021 (7). The guidelines build on the current state of knowledge on how best to describe, treat and prevent post-COVID conditions. They reflect the uncertainties around the condition, but have been issued to provide physicians and others with some support.

The Family Medicine Association of Georgia has developed a protocol that defines the recommended interventions for two groups of patients: those who experienced mild COVID-19, and people who experienced severe symptoms and had to be treated in emergency units. The protocol determines that patients in the former group are mainly monitored by primary care providers, while those in the latter may require referral for specialist support. Georgia is currently working with WHO on developing a long-term rehabilitation strategy that will include post-COVID-19 rehabilitation.

All COVID-19 patients in Kazakhstan receive care based on treatment protocols. Evidence-based clinical protocols focus on treatment for adults, children and pregnant women. Much attention is given in the protocols to prevention of post-COVID complications. A series of clinical recommendations developed in the country reflect issues around the detection of patients with post-COVID conditions and self-management.

In its guidance, WHO has highlighted the importance of rehabilitation in preventing complications, optimizing functioning and reducing new disability from COVID-19. Poland has taken the lead in developing standards for physiotherapy for post-COVID-19 patients. Patients who have recovered from COVID-19 are given the WHO Support for rehabilitation self-management after COVID-19-related illness leaflet (1), which the Polish professional organization of physiotherapists has translated and adapted to the Polish context. The leaflet is for those who are self-managing their COVID-19 recovery at home and suggests basic exercises and advice for those who have been unwell due to the virus.

Portugal currently is developing a national guideline for post-COVID-condition management focusing on multidisciplinary management in primary care settings.

Patient representation
Several of the countries represented at the meeting currently do not have measures in place to ensure patient representation in the response to post-COVID conditions, although most have aspirations to develop such measures. There are exceptions, however. France, for instance, conferred with
patient representative groups when developing its rapid action guidelines. Sweden works in close collaboration with the COVID-19 National Patient Association, and COVID-19 patient associations have a strong voice in determining approaches in Austria.

The representative from the Netherlands reported on some very dynamic online initiatives underway in the country that involve patients and their representatives. One of them is called the “Long-form Corona Line”, a platform focusing on COVID-19 patients who have chronic problems post-COVID. Through this platform they can share their experiences with other patients with similar symptoms and access experts such as nurses and doctors from different fields for guidance and advice. Another platform, which translated into English is called “Support around Corona”, is a collaboration involving a public health institution and the ARQ Centre, which specializes in psychotraumatology. This platform is available to the public and health professionals, helping users to find support for mental health issues.

The C-Support organization in the Netherlands is built on an integrative support model that addresses patient needs in relation to post-COVID symptoms. It is neither a patient organization nor a provider of medical care; rather, it offers advice and information to support patients with post-COVID conditions through access to ethical, medical and legal advice. People with symptoms that have lasted longer than three months can apply for support, and around 2700 have done so since the launch in October 2020. First results from C-Support show that patients feel supported, find a place where they feel good and are guided along the process through a multidisciplinary approach.

There were strong expressions of support from several country representatives to WHO's inquiry into interest in the development of an umbrella group at regional level to represent the views of patient groups.

**Health system and treatment approaches**

It was clear from presentations by country representatives that responses to post-COVID conditions at national level primarily are primary-care based, with specialist support being provided by secondary-care services, and that rehabilitation approaches comprise the main intervention.

France has positioned GPs as the gatekeepers for COVID-19 patients. GPs are essential in managing these patients but need to have reliable access to specialist advice and support when needed. Treatment approaches tend to focus on physiotherapy delivered through outpatient units for those whose symptoms are less severe, and access to rehabilitation centres for those with more intractable problems.

Georgia is creating a rehabilitation programme for post-COVID patients. A facility once used to treat tuberculous patients has been converted into a pulmonary rehabilitation centre. It provides a special programme of pulmonary rehabilitation for post-COVID patients, who can receive up to 21 days’ treatment in the centre. It is too early to evaluate the effectiveness of the programme, but patient satisfaction is reported to be very high and they value the opportunity to engage with the programme.

The development of treatment options for post-COVID conditions is, understandably, raising patient expectations of what can be delivered. Georgia has experienced, for example, high expectations among some patients that they should have regular CT scans to monitor their condition. Having a very clear protocol around this, educating patients and providing training and support for physicians is very important.

The necessary measures for early rehabilitation of post-COVID patients in Kazakhstan is provided at hospital level through inpatient and outpatient routes. GPs are the portal through which patients are referred to rehabilitation services at hospital level.

A multidisciplinary COVID follow-up clinic was set up in Sweden in May 2020. The clinic, which is linked to various research projects, assesses patients whose symptoms suggest multi-organ involvement and the need for individual assessment. The range of disciplines and professions on offer at the clinic means that patients do not have to be referred elsewhere – they can access the services they need from a single site.
Research
A wide range of research activity was reported by country representatives.

A cohort of hospitalized patients was established at the very beginning of the COVID-19 pandemic in France, with patients being followed for up to 18 months after being admitted to hospital because of COVID-19. A cohort study is also being developed in Georgia, where the main centre for managing and alleviating COVID-19-related complications and introducing best practice recommendations in the country aims to follow around 500 post-COVID patients over a period to understand better the complications and how they can be treated.

Research among cases in Kazakhstan has identified some of the major manifestations of post-COVID conditions, which include immune deficiency conditions, cognitive disorders, progression of atherosclerosis and exacerbation of hypertension. The country’s guidelines and clinical protocols are based on these observations. The National Cardiovascular Centre, which provides care to post-COVID patients, launched a special project in December 2020 looking at post-COVID conditions in 400 patients (100 of whom are under the age of 18) who are enrolled for rehabilitation.

Pilot projects focusing on post-COVID-19 patients have been implemented in Poland with the engagement of the Foreign Office, Ministry of Interior and National Health Fund. The programme was launched officially on 1 September 2020, supported by a regulation of the Minister of Health. The goal of the programme is to identify the needs for rehabilitation in patients who continue to experience symptoms or develop additional disorders or complications post-COVID. The programme will also evaluate the outcomes of the rehabilitation model developed in the country.

Clinical experience collected so far with 600 patients and findings from the pilot projects make it very clear that the rehabilitation programme in Poland is very effective with patients who have post-COVID symptoms. They stress that clear eligibility criteria is vital, and that the rehabilitation model needs to be tailored to the individual’s needs and capabilities.

Researchers at the multidisciplinary COVID clinic in Sweden have followed up around 550 hospitalized patients who had been critically ill with respiratory failure during the first two waves of the pandemic in the country. Around 80% are males with previous comorbidity. Twenty per cent are over 65 years of age, with a mean age of 53 years. The clinic started receiving referrals for non-hospitalized patients from the summer of 2020 and has assessed around 180, with more than twice that number currently awaiting attendance at the clinic. Criteria for referral are that patients are more than three months post-COVID and have multiple symptoms affecting their ability to work by 50% or more. Most of this group (around 80%) are female; they are also younger and often have previously been physically active and healthy (see Box 1 for some details of the research being done in Sweden).

The National Institute of Health of Italy is working with several academic centres on implementing post-COVID assessments through a multidimensional approach that focuses on clinical, psychological and neurological factors. More than

Box 1. Interesting research findings from Sweden
Researchers in Sweden have found a high degree of dysautonomia among patients with post-COVID conditions, including postural orthostatic tachycardia syndrome (PoTS). PoTS has been recognized since the 1990s but is not common. It predominantly affects younger women (80% of those diagnosed are women) who exhibit non-specific symptoms such as palpitations, dizziness, headache, fatigue (including post-exertion and malaise), chest pain and discomfort. Around 50% have a post-viral debut and the long-term prognosis is that around 50% will recover within one to three years. The researchers have now called this condition post-COVID PoTS and have presented a case for publication in the Journal of the American College of Cardiology. Twenty-one patients have been diagnosed with PoTS, around 70 with suspected PoTS are undergoing investigation and new referrals are arriving at the rate of 10 every week. The researchers believe this is an important differential diagnosis in the post-COVID syndrome.

Prospective studies are needed to further characterize the symptoms and quantify their burden. It is important to assess the response to existing and other potential therapies.
1000 post-COVID patients have been assessed using a very comprehensive and detailed protocol that allows information to be gathered on different elements of post-COVID conditions.

A multi-centre study following up severe COVID patients in their first, third and sixth month after discharge has been conducted in Austria. The study, which is ongoing, has found that long-term symptoms are common but that early rehabilitation can improve and often reverse the worst damage.

**Surveillance data and registration**
Collecting surveillance data and creating registries related to post-COVID conditions will be central to developing better understanding of the condition and its prevalence. Countries are putting in place systems to collect this vital information.

**Georgia**, for instance, has taken steps to harmonize data collection and create registries around COVID. A register of all post-COVID patients is in place, and attempts are made to track patients through co-indicators, mostly related to financial needs. Re-hospitalizations among COVID patients and hospitalizations of post-COVID patients are tracked. Consideration is being given to defining a critical data set for the country to follow.

**Sweden** uses harmonized data on the ICD code for post-COVID, but while **Portugal** has a robust surveillance and data-collection system in place, it is not yet fully adapted to the post-COVID situation.
Hans Henri P. Kluge closed the meeting by reiterating that WHO stands ready to support Member States to revisit and improve their national monitoring and evaluation capacity, and to strengthen them in developing national guidance to manage patients with post-COVID conditions.

Defined by patient groups, the priority areas where action is needed to respond to post-COVID conditions can be categorized in three words:

- **recognition**: all services must be adequately equipped and no patient should be left alone or struggle to navigate through a system that is not prepared to, or not capable of, recognizing this very debilitating condition;

- **research**: data gathering and sharing, and well coordinated research with full participation of patients, are needed to advance understanding of the prevalence, causes and costs; and

- **rehabilitation**: this cost-effective intervention is an investment in building back healthy and productive societies.

Health systems will have to adapt to respond to the new needs of patients with post-COVID conditions.
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1. All weblinks accessed 13 April 2021.
The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

**Member States**
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Armenia  
Austria  
Azerbaijan  
Belarus  
Belgium  
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Bulgaria  
Croatia  
Cyprus  
Czechia  
Denmark  
Estonia  
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