Patient-centred approaches to long COVID

Webinar report

On 2 March 2023, the COVIRNA project hosted the webinar '*Patient-centred approaches to long COVID*' with the participation of Dr Tomas Zapata, Programme Manager in the Division of Country Health Policies at WHO Europe; Dr Yvan Devaux, Head of the Cardiovascular Research Unit at the Luxembourg Institute of Health (LIH) and Coordinator of the COVIRNA project; Prof Nisreen Alwan, Associate Professor of Public Health at the University of Southampton; Ms Ann Li, Chair of the Long COVID Association; and Prof Dr Thomas Lüscher, President-Elect of the European Society of Cardiology, Director of Research, Education & Development and Consulting Cardiologist at the Royal Brompton & Harefield Hospital Trust, and Professor of Cardiology at the Imperial College London. The webinar presented the burden of long COVID, discussed how to make long COVID care more patient-centric, and highlighted how innovative solutions such as the COVIRNA toolkit can be integrated into existing care pathways.

Long COVID and its burden on health systems

According to the World Health Organisation's definition, "*post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time*" (WHO, 2021). Post-COVID condition (PCC) or long COVID affects a large portion of the global population. **Dr Tomas Zapata** reported that globally, 45% of COVID-19 patients experience a range of unresolved symptoms at around 4 months post-infection. In the WHO European region alone, at least 17 million individuals may have experienced PCC in 2020 and 2021.

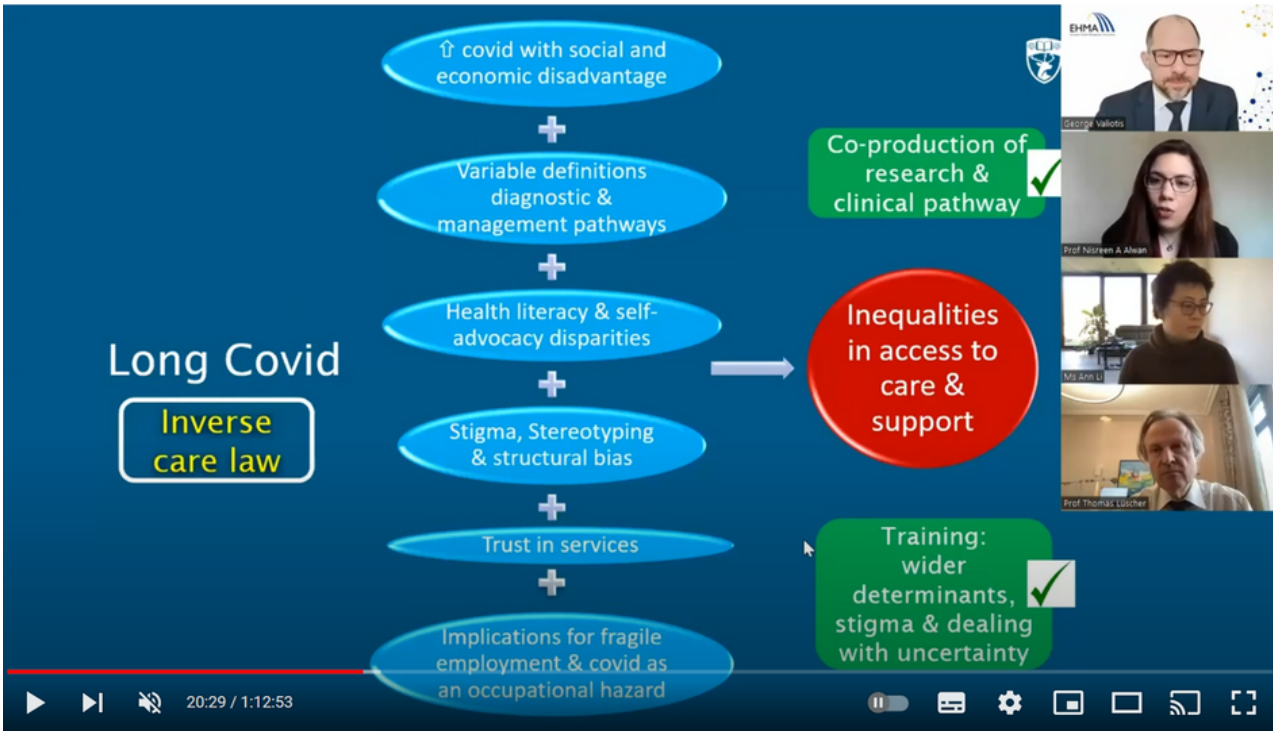
According to **Dr Zapata**, while there is not yet a complete understanding of the burden on health systems, long COVID also contributes to the economic downturn as it limits people's ability to participate in work and community life. The paper '*Call for action: health services in the European region must adopt integrated care models to manage Post-Covid-19 Condition*' offered recommendations to reduce the burden of PCC, including how to build capacity for early identification and recognition of symptoms, which aligns with the objectives of the COVIRNA project. The paper also recommended to strengthen primary care to manage PCC – when medically indicated – and to be the point of referral for more severe cases. The paper acknowledged the need for individualised long-term rehabilitative care and underlined the importance of strengthening health systems to provide an individualised multidisciplinary care pathway in which patients' multi-system needs are assessed and managed, informed by real world outcome data and patient experience.

Long COVID challenges: patients and health systems' perspectives

Ms Ann Li highlighted several challenges that patients face. This includes lack of knowledge on adequate diagnosis, treatment and rehabilitation for long COVID. Inadequate treatments are still commonly prescribed, such as graded exercise and cognitive behavioural therapy, which are contrary to the National Institute for Care and Excellence and WHO guidelines, because they increase the risk of developing severe chronic conditions. More education is therefore needed on PCC and available symptom-based treatments. Furthermore, long COVID patients bear a considerable socio-economic impact because of their inability to work, which puts them

at higher risk of being driven into poverty. Finally, **Ms Li** underlined the need for adequate biomedical research to reach a pharmaceutical cure for long COVID.

Prof Nisreen Alwan explained how the '*inverse care law*' applies to long COVID. According to the inverse care law, for certain conditions, those who are most in need of accessing healthcare are least likely to access it and vice versa. There are underlying factors to inverse care law, such as the variable definitions, diagnostics and management pathways for long COVID patients. There are also issues around health literacy and advocacy, as people who can advocate for themselves and have a higher health literacy tend to get more out of the health system. The stigma and stereotypes associated with long COVID equally affect healthcare and trust in services, causing people to refrain from reaching out for help. Besides the inverse care law, another challenge is the difficulty to separate treatment and diagnosis of long COVID from the prevention of COVID, because the most effective way to reduce the burden of PCC is by preventing people from getting COVID in the first place.



Current approaches and clinical management of long COVID patients

According to **Prof Dr Thomas Lüscher**, currently there is no treatment for long COVID, primarily because the disease is not yet fully understood. There are some symptom-based treatments which have become more and more common, but these treatments are eminence-based – meaning that they rely on the opinion of healthcare professionals – rather than evidence-based. The most complicated problem to address amongst long-COVID patients is fatigue and loss of performance. In these cases, echoes, pump function and lung function measurements are usually normal. Hence further research using randomised controlled trials is needed to get an in-depth understanding of the disease process. A special focus should be given on immune responses. COVID-19 activates the immune system, but somehow this activation does not disappear in patients with a severe course of the disease. However, the difficulty with such studies is that long COVID is usually a fluctuating episodic illness. All participants agreed on the importance of patient involvement in research since the very early stage of the setup and design. Long COVID patient organisations and associations would play an important role in recruiting appropriate patients for these studies.

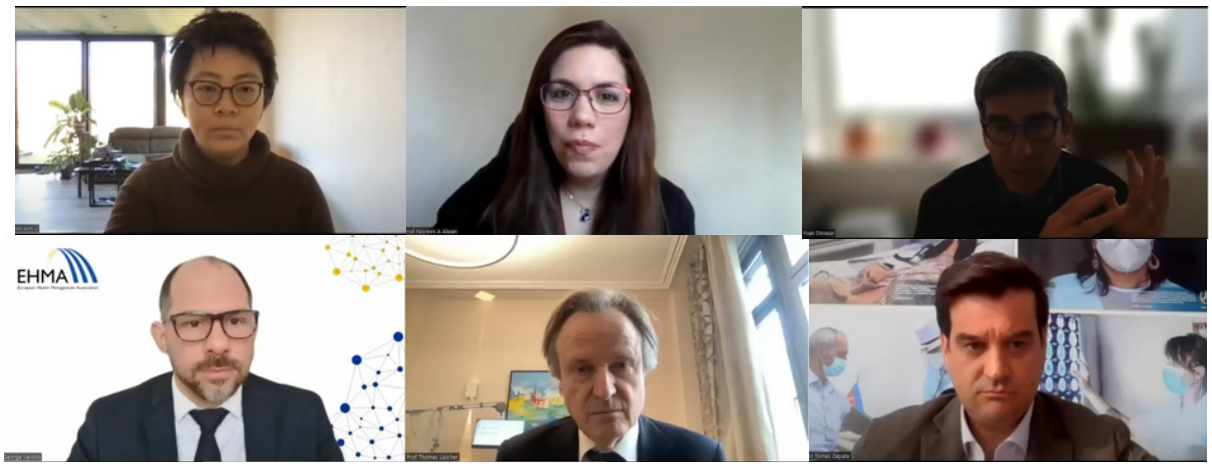
Nowadays, patients suffering from long COVID can, in many countries, go to specialised clinics where they are diagnosed and treated by physicians who are actively engaged and have read the most up-to-date literature on the topic. There are also dedicated patient pathways followed in hospitals. **Dr Zapata** presented case studies commissioned by the WHO to better

understand how health services have adapted to respond to the needs of patients with PCC. Catalonia put primary care at the centre, creating a long COVID primary care reference group where all patients are referred. They also have priority tracks for referral to hospital services. In Italy, two tracks are available depending on the complexity of long COVID. When the complexity is high, patients are referred to specialised centres in hospitals that adopt multidisciplinary approaches and have one-stop services *[1],* including rehabilitation. When the complexity is lower, it is dealt with at primary care level. In Israel, patient management is done through primary care, but also supported by referrals to long COVID clinics at the hospital level, and strong rehabilitation services in primary care. Co-production with patients could help inform the development of more universal pathways.

The role of COVIRNA in addressing long COVID challenges

Dr Yvan Devaux described COVIRNA as a translational research project that would allow for the development of tools to be used in hospital to satisfy unmet clinical needs. The aim of the project is to build on the available knowledge on RNA molecules and create a prognostic tool to identify COVID-19 patients at high risk of developing cardiovascular complications. If patients are detected at an early stage, their treatment and care can be personalised, better managed and monitored, and health professionals can ensure that they are referred appropriately. This will decrease the risk of developing severe heart problems and other PCC consequences. The importance of having tools like COVIRNA was further supported by **Dr Zapata** who explained that having access to a reliable prognostic test will be critical to define patients' pathways and provide appropriate care to those patients. **Ms Li** stated that the use of a prognostic tool will improve the identification of risk factors and allow health practitioners to act sooner, helping patients get their lives back.

Additionally, **Ms Li** stated that one of the biggest problems is to clearly understand the number of people who have long COVID and the impact of clinically ill individuals on the economy. With accurate figures and an understanding of the financial impact of this condition, budget could be more easily allocated to research on long COVID. **Prof Lüscher** proposed the use of an application that would allow for long COVID patients to report on how and whether they are working, as well as how much they are working. This would give a good insight on the economic impact of COVID-19. However, patient screening alone is not enough. **Prof Alwan** urged to use the data to enable long COVID patients to follow different pathways than those of regular cardiovascular patients.



[1] One-stop services provide their patients with initial consultation, diagnosis and treatment plan within a single visit. They include a variety of staff and specialists to meet all the potential needs of visiting patients.

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