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WEBINAR: Hearing of the Expert Panel on effective ways of investing in health on the opinion: Facing the impact of post-COVID-19 condition (Long COVID) on health systems

Brussels, 18 October 2022 (virtual meeting)

Aim and objectives

The Expert Panel on effective ways of investing in health (EXPH) is an interdisciplinary and independent group established by the European Commission in 2012 to provide non-binding independent advice on matters related to effective, accessible and resilient health systems in the form of opinions.

The aim of this hearing was to provide stakeholders with an opportunity to share their views on the draft opinion of the Expert Panel on '*Facing the impact of post-COVID-19 condition (Long COVID) on health systems*'. The draft opinion was made available on the Expert Panel's website prior to the hearing.

Panel members and drafting group - speakers

Panel members: Prof. Jan De Maeseneer (Chair of the hearing), Dr. Dionne Kringos (Chair of the drafting group), Dr Jelka Zaletel, Prof. Pedro Pita Barros (Rapporteurs)

In total 80 participants attended the hearing. Slido was used for live polling of the audience and the results can be found at the end of this report.

Presentation of the draft Opinion

Professor De Maeseneer opened the hearing and presented the Expert Panel on effective ways of Investing in Health as well as the drafting group that dealt with this opinion. Dr Kringos introduced the mandate of the opinion. The Panel was requested to provide a concise policy-oriented opinion with analysis and recommendations on the following points: 1. Make an overview of current state-of-the-art on what post-COVID-19 condition is, its probable causes and symptoms, using the available literature to date, including the work carried out by the ECDC in this area. 2. Provide an analysis of the main knowledge, organisational and resource requirements for healthcare systems to design and develop appropriate health services for post COVID-19 condition. 3. Provide guidance on how public health surveillance should be adapted to measure the impact of post-COVID-19 condition on the population.

The rapporteurs presented the key points of the draft opinion during the meeting.

1. Current state-of-the-art

Professor Pita Barros presented the overview of the current state-of-the-art. He explained the shortcomings of the current knowledge about the factors and probable causes triggering long-term health damage, as well as about the models of care and the recovery tracks. Acute covid-19 infection is a complex multi-system disease affecting many body systems, implying that the post-COVID-19 condition (Long COVID) also affects different parts of the body. The condition can cause long-term damage through several mechanisms (lung damage, risk of blood clotting with multi-organ damage implications, etc.) This has many implications for knowledge, learning and health systems. He pointed out the different existing definitions of the post-COVID-19 condition (Long COVID) and said that the drafting group decided to use the current World Health Organization definition.

When discussing how many people may be affected by it, Professor Pita Barros underlined the different biases in current measurements. One worldwide estimate gives 3.69% of all covid-19 infections resulted in post-COVID-19 condition (Long COVID), thus millions of people suffer from it. From those that have Long COVID, a significant subset of people have symptoms that adversely affect their day-to-day activities.

The probable causes of post-COVID-19 condition include a previous COVID-19 infection, as well as other factors triggering long-term damage. Professor Pita Barros underlined the incomplete state of knowledge on this issue. However, the following multiple, non-mutually exclusive mechanisms included:

- Direct effects of the acute illness resulting in organ damage and tissue injury;
- Remnants of the viral material;
- Persistent inflammation;
- Auto-immunity;
- Formation of hyper-activated platelets and micro clots;
- Interactions with the host's microbiome.

The symptoms identified by the panel include episodic and multisystem symptoms such as fatigue, headache, cognitive impairment, difficulty breathing, post exertional symptom exacerbation, muscle aches, joint pains, chest pains, palpitations, dizziness, sleep disturbance, joint pain. Any combination of these symptoms can manifest, and this list is not exhaustive.

There is evidence that symptoms cluster into systems, which is an aspect requiring further attention. They may disappear temporarily and reappear, and this complicates the way to identify this condition.

Knowledge about recovery from the post-COVID-19 condition (Long COVID) is limited due to lack of research, with an uncertainty about the definition and characterization of the recovery process and challenges. Two challenges were identified:

- The recovery seems to produce “economic scars”, meaning that people experiencing the condition are substantially less likely to remain in employment and, if they do, they have reduced hours of work.

- People living with poorly understood health conditions experience health-related stigma. This is due to the uncertainty of the symptoms associated with the condition which leads to misattribution of symptoms on the one hand, or ignorance of the symptoms and their link to the post-COVID-19 condition (Long COVID) on the other hand.

2. Models of care for patients with post-COVID-19 condition (Long COVID)

Professor Pita Barros presented three core components. First, there is a need for a wide range of skills and expertise in multidisciplinary rehabilitation teams, to identify and treat the condition. Second, the continuity and coordination of care are central to improve knowledge and treatment capacity. Third, treatment and care should be people-centered with shared decision-making.

He underlined that there was a high degree of uncertainty about the nature, progression and management of the condition, therefore patients need to have a co-creation role along the clinical pathways. He presented a number of obstacles that need to be tackled in order to create pathways of care. These include administrative, financial and professional barriers as well as differences in operating methods in different organisations.

3. A health systems approach to long COVID

Professor Pita Barros continued by presenting a health system approach to the post-COVID-19 condition (Long COVID). The drafting group approached this question using the WHO health systems framework. In terms of service delivery, he highlighted the need for specialised knowledge as well as special training for primary care professionals and teams involved in the patient coordination role at primary care level (as first point of contact). The guidelines on treating the condition should be revised frequently as knowledge on the matter evolves very quickly. For rehabilitation, the WHO guidelines should be used. Moreover, there needs to be awareness about unexpected or emerging inequities.

He outlined specific challenges for the health workforce, including the need for specialist training, clinical management system with an enhanced role for the patient in the process, training requirements for a variety of health professionals.

Health information systems need to adapt to face the needs of patients, to ensure that appropriate data are collected, collated, synthesized and transmitted to those who need them at all levels of the health system. An international harmonization would be necessary on the minimum dataset. Health information systems should support the research needed to further the knowledge on the post-COVID-19 condition, in order to allow for international benchmarking and efficient knowledge sharing.

4. Guidance on public health surveillance

Professor Pita Barros presented the final part of the draft opinion regarding public health surveillance. He underlined the need for an effective surveillance with data collection, analysis and interpretation of data, and a mechanism to ensure follow up actions. An outreach programme, tailored to the population, would alleviate biases and help identify the causes of the symptoms, their prevalence, and the rates of cases where patients do not seek treatment.

He suggested that a standardized survey in the European Economic Area as well as a EUROSTAT data collection on health services utilization could provide a solution to detect more serious manifestations of the post-COVID-19 condition (Long COVID). He added that there was an opportunity for an EU dimension to tackle the issue by establishing a consistent surveillance system for Long COVID in the European Union.

5. Recommendations

Dr Zaletel presented the recommendations of the Expert Panel:

- Research on post-COVID-19 condition should as far as possible be explicitly co-produced with people living with the condition, with co-creation of potential therapeutic interventions, as well as a targeted consideration of the clinical pathways so that research findings can achieve impact;
- Research on post-COVID-19 condition and especially on potential treatments needs to be done at sufficient scale to provide definitive answers that take account of any heterogeneity within the population.
- Health systems need to embed research on post-COVID-19 condition at all levels of care including rehabilitation, identifying incentives that can be applied and barriers that can be removed to facilitate the developments of health facilities as settings for research.
- As COVID-19 infection is the cause of post-COVID-19 condition, measures to prevent it, including vaccination and reducing transmission, must remain a priority;
- Post-COVID-19 condition is to be recognized as one of many complex chronic conditions that, in many patients, will co-exist with others. This calls for models of care that are coordinated in primary care, with mechanisms to ensure rapid referral to specialist teams while avoiding placing patients in “Long COVID siloes”;
- A coordinated programme of surveillance systems should be established, including data from each member state using consistent case definitions and methodologies, and encompassing the impact of this condition on health, employment and the economy.

Open discussion: participants' views

An academic at the University of Leeds raised concerns about using a single definition of the post-COVID-19 condition. She added that she will send further comments in writing. **Dr Kringos** replied that the use of the definition facilitated discussion, and comments on the definition were welcome. **An academic from Lund University** asked if the post-COVID-19 condition can be defined based on time and severity of disease. The external expert of the drafting group, **Dr Alwan** added that the definition should still be worked on, and it should evolve over time.

Long COVID SOS, a UK-based charity, partnered with “Long COVID Europe”, intervened to salute the work done in the opinion. She asked the next steps and the way to implement the recommendations at the Member States level. How can patient groups be involved further in order to develop these action points? **Dr Zaletel** replied that the opinion could be used as a basis to direct

research along the recommendations. She suggested that civil society should keep the debate moving and check on developments. It was important that the solutions are co-created.

The German Medical Association asked whether a European harmonized curriculum / learning track on the post-COVID-19 condition could be implemented. **Professor De Maeseneer** replied that it could be detrimental to have a specific learning track for one disease. Specific considerations for the post-COVID-19 condition should be built into existing learning tracks. However, he warned that a disease specific curriculum could lead to inequity by disease. **Dr Zaletel** added that task shifting could be considered to meet specific challenges.

The European Medicines Agency (EMA) pointed out that that EMA has several platforms for interaction with patients and stakeholders. She underlined that EMA could help with questions on Long COVID.

A **primary care worker from Barcelona** mentioned that her organization had regional guidelines for coordination with hospitals. Due to the difficulties in the definition of Long COVID, specifically detection and coordination, it was difficult to put an integrated care approach in practice. There can be a proper follow-up with a longitudinal view in primary care, and task shifting could alleviate some of the burden of cooperation.

Conclusion

Prof. De Maeseneer, Chair of the public hearing, underlined that challenges differed in every country and some degree of harmonisation as well as a multidisciplinary approach was needed to face the post-COVID-19 condition (Long COVID). He thanked all attendees for their active participation (also via the chat) and invited them to submit written comments by 30 October.

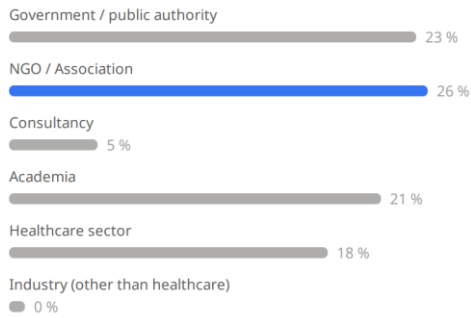
Slido poll results

In a live poll conducted during the hearing, 26% of respondents said they represented NGO/Associations, 23% government/public authority, 21% academia/think tanks, 18% healthcare sector and 5% consultancies.

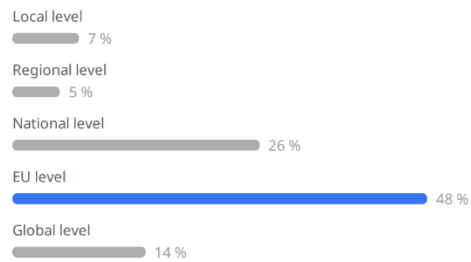
When asked about their capacity in dealing with post-COVID-19 condition, 45% of respondents identified themselves as researchers, 32% as post-COVID-19 condition patients, 20% as healthcare providers, 16% as policy makers and 7% as pharma/medical technology specialists or developers.

In a poll asking participants to rank the Panel's recommendations in order of importance, the recommendation to combat and prevent the spread of COVID19 infections was ranked as No.1, followed by the recommendations to recognise post-COVID-19 condition as a multi-factorial chronic condition and to establish a coordinated programme of surveillance systems to include data on post-COVID-19 condition.

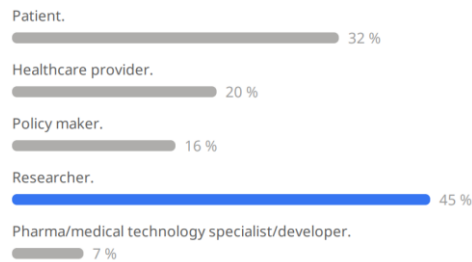
What type of organisation do you represent? 0 3 9
(1/2)



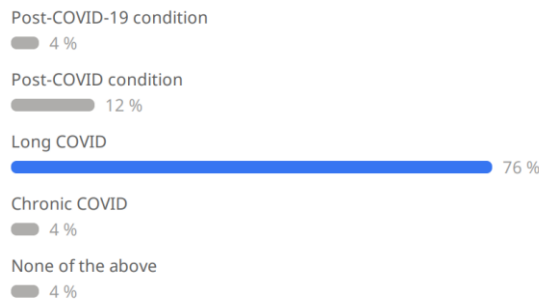
Which level describes best your organisation's impact? 0 4 2



In what capacity do you deal with the post-COVID-19 condition. 0 4 4
(1/2)



What term should be used to refer to the condition? 0 2 5



How would you prioritise the recommendations of the Expert Panel. Please rank from most important/urgent at the top to least important/urgent at the bottom. 0 2 3
(1/2)

1. Combat and prevent the spread of COVID-19 infections. 4.96
2. Recognize PC as a multi-factorial chronic condition while avoiding placing patients in "PCC siloes". 3.78
3. Establish a coordinated programme of surveillance systems to include data on PCC. 3.35
4. Co-create research on PCC diagnosis and treatment with patients. 3.30
5. Embed research on PCC at all levels of care in the health system. 2.96
6. Scale up research on PCC recognizing the variation in the presentations of PCC and to cover heterogeneity in the population. 2.65