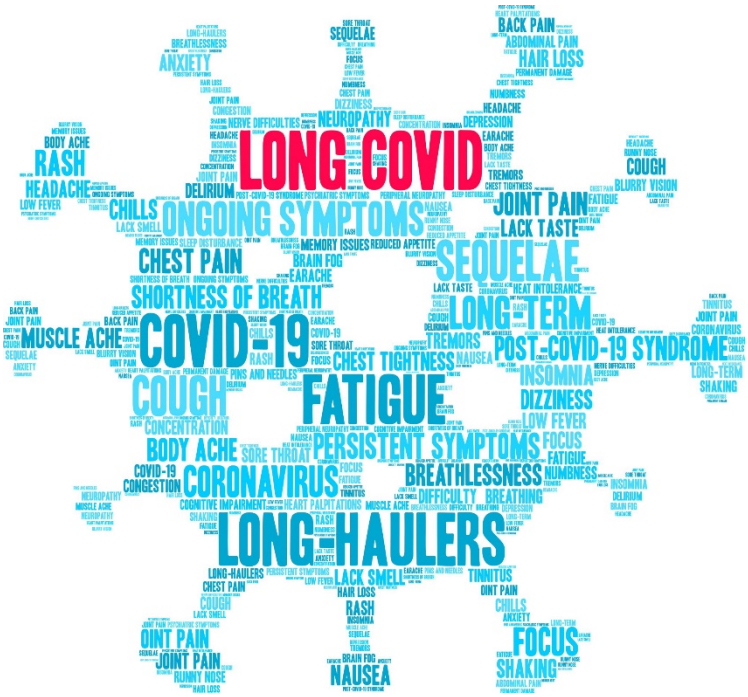
STUDY

Requested by the COVI Committee

European Parliament

Workshop on long COVID

Workshop Proceedings



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Workshop on long COVID

Workshop Proceedings

Abstract

These proceedings summarise the presentations and discussions of the workshop on 'long COVID' organised for the European Parliament's Special Committee on the COVID-19 pandemic on 9 March 2023. The six presentations touched, *inter alia*, upon the current state of knowledge on the disease's clinical profile, potential causes and underlying mechanisms, impacts on patients and society, and lessons to be learned from post-acute infection syndromes and chronic diseases. The speakers and Members could discuss the urgent actions and financial support needed from the EU to close gaps in scientific knowledge, to raise awareness on long COVID, and to develop treatments which could improve patients' condition.

This document was prepared for the Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (COVI), of the European Parliament by the Policy Department for Economic, Scientific and Quality of Life Policies.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
COVID-19	Coronavirus Disease 2019
EBV	Epstein-Barr Virus
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
ECR	European Conservatives and Reformists Group
EMA	European Medicines Agency
EPP	Group of the European People's Party
EU	European Union
EUR	Euro(s)
GBP	Great-Britain Pound(s)
Greens/EFA	Group of the Greens/European Free Alliance
HIV	Human Immunodeficiency Virus
ID	Identity and Democracy Group
ME/CFS	Myalgic encephalomyelitis/chronic fatigue syndrome
PAIS	Post-Acute Infection Syndrome
POTS	Postural orthostatic tachycardia syndrome
Renew	Renew Europe Group
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
S&D	Group of the Progressive Alliance of Socialists and Democrats
US	United States of America
USD	United States Dollar(s)
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

The workshop was organised on 9 March 2023 in Brussels at the request of the Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (COVI). The workshop convened leading epidemiologists, immunologists and clinicians, involved in the research on long COVID and treatment of patients, as well as the chair of the European level long COVID patients' association.

Aims of the Workshop

The workshop provided the European Parliament with an overview of the European and global situation on long COVID, the current state of understanding of underlying biological mechanisms of the disease, the state of advancement on treatments and therapies for patients, and lessons that can be drawn from dealing with other post-acute infection syndromes and chronic diseases.

Main discussions

Epidemiology and symptomatology of long COVID

Long COVID has concerned **17 million people** in the WHO European Region in 2020-2021 alone, and an estimated 65 million worldwide. Forecasts estimated that 20 million Europeans will suffer from long COVID by March 2023. On average, at least **10% of persons infected with SARS-CoV-2** will develop the disease.

The disease is defined by a history of confirmed or probable SARS-COV-2 infection, with symptoms occurring usually three months from the onset of COVID-19 lasting for at least two months. Symptoms include fatigue, shortness of breath, cognitive dysfunction, but many other symptoms can arise, with a demonstrated reduction of the quality of life. The symptoms can have a new onset or continue since the COVID-19 infection and cannot be attributed to any alternative diagnostic.

Several **personal and environmental factors influence the prevalence** of long COVID in the European population. Regarding individual factors, there is a prevalence of long COVID among women, in the age range of 25 to 69, and for persons hospitalised for an infection with SARS-COV-2. Socio-economic factors also play a role and residents of deprived areas, economically inactive persons and those suffering from activity-limiting health conditions appear more affected. On the other hand, **vaccination** appears to reduce the risk of developing long COVID by 15 % to 50%.

Long COVID may **affect all organ systems**, including the heart, lungs, kidneys, spleen, liver, pancreas, the immune system, the gastrointestinal tract, the neurological system, the blood vessels, and the male and female reproductive systems. This multisystemic character makes the research even more complicated.

Costs of long COVID on societies

It is estimated that long COVID represents respectively an **economic cost** of USD 3.7 trillion (over 5 years) and GBP 2.5 billion (per year) in the US and the UK.

Workplaces and labour markets are impacted, and workers fall out of employment. There is a lack of standardised concepts for the workplace. Social security support for long COVID patients varies considerably from one Member State to another, in some cases requiring workers to go back to work despite severe symptoms.

Children seem to be affected by Long COVID in a way similar to adults, manifesting itself especially in high rates of school dropouts and anxiety.

Current state of understanding of the disease

There are a number of different hypotheses currently investigated as possible **causes of long COVID** including: persistence of the virus in the body, response of the immune system, mitochondrial dysfunction, dysfunctional neurological signalling, affection of the autonomous nervous system, endothelial dysfunction, EBV reactivation, or blood clotting). A better understanding of the causes of long COVID is crucial for developing optimal patient treatment and care.

Long COVID can be compared with similar '**post-acute-infection syndromes**' (PAIS), caused by viruses such as Ebola, dengue, Epstein-Barr virus (EBV), MERS-CoV, SARS-CoV-1, or influenza. Synergies can be drawn with research on these post-acute-infection syndromes. The unprecedented scale of long COVID creates a momentum for the research on PAIS.

Symptoms similar to long COVID have been identified following the **vaccination**, which is a rare but real threat for patients. The spike protein found on SARS-CoV-2 and in the vaccines appears to be central in the research on long COVID.

Finally, the **chronic fatigue syndrome** (myalgic encephalomyelitis/chronic fatigue syndrome - ME/CFS), a severe and chronic disease characterised by post-exertion malaise and triggered by various infections, has been identified in a large proportion of long COVID patients. Similarities with long COVID include misdiagnosis, lack of knowledge and understanding by GPs, as well as a high cost for society and health and care systems.

Care and treatments provided to patients

Persons affected by long COVID are often confronted with **scepticism** from their family and work circles and are oftentimes misdiagnosed by the medical professionals. As there are no biomarkers yet available for routine diagnosis, the diagnostic of long COVID relies up to now mostly on clinical examinations.

Currently, the management of the disease is **costly and complex**. The current treatments are only individual- and **symptoms-based**. As the medical knowledge about long COVID is still emerging, adequate treatments are not always provided to patients and counterproductive therapies are still sometimes indicated by medical professionals.

Conclusions and recommendations

The invited experts provided the following common conclusions:

- Long COVID is a **severe somatic disease** with biological causes. It is *not* a psychosomatic disease.
- **Various symptoms** affect patients' organ systems in a **multisystemic** way. The most common symptoms are extreme fatigue, insomnia, shortness of breath, cardiovascular problems, and difficulties to focus. Long COVID is also characterised by **exertion intolerance**, meaning that physical or intellectual efforts or stress worsen the symptoms.
- Long COVID is a **chronic disease** lasting for several months or years, and the convalescence is characterised by **fluctuations** including phases of relapse.

- The **main prevalence factors** of long COVID are female sex, age-range (25-69 years old) and hospitalisation after infection with SARS-CoV-2. While the vaccines may cause complications in some cases, vaccination against COVID-19 appears to clearly reduce the prevalence of long COVID.
- The **underlying causes** of long COVID have not yet been fully elucidated and several hypotheses are currently being investigated.
- The **current treatment** of long COVID is symptoms-based and not curative. A number of medicinal products are currently being investigated.

Experts' policy recommendations for the European Parliament:

- **Specific fundamental and translational research and clinical trials must be urgently organised and massively funded** (Long COVID Europe demands EUR 500 million; the United States earmarked more than USD 1 billion in long COVID research). This should focus on investigating the cause(s) of long COVID, testing already approved medicinal products, and finding new drugs and treatments for patients. Large-scale multi-country studies with correspondingly large study populations are essential. Cooperation with the pharmaceutical industry could support the rapid development of treatments.
- **The design of studies and clinical trials** must be collaborative, based on robust scientific principles, allow comparability across Member States and provide robust data to draw clear conclusions. Facilitating multi-country studies is crucial for achieving larger cohort sizes. Patient participation should be ensured in all steps of the studies. Studies should also include socioeconomic aspects and implications for long COVID patients.
- **European reference centres on long COVID** should be established. Synergies could be achieved by the creation of outpatient care structures for PAIS in general, including long COVID.
- Steps towards a **coordinated and harmonised approach to long COVID** could bring added benefits for patients across the EU. This includes coordinated decision-making but also the approach by the medical community, or health insurance and social security systems. More specifically, harmonised diagnostic criteria are needed.
- **European research networks** should be established. European-level (online) collaborative research platforms could help research results to be disseminated, analysed and pooled.
- **Large-scale awareness-raising actions on long COVID** are necessary in order to reduce the stigmatisation of people affected with Long COVID within their social circles, help them receive adequate medical care and treatments, and to accommodate their working or study conditions to the disease.
- **Thorough training of medical professionals** would allow better care for patients and avoid delayed diagnostics or inappropriate treatments.
- **Long COVID should be recognised as an (occupational) disease** for patients to benefit from social security benefits and, if necessary, early pension. In addition, worker and student rehabilitation policies should be a priority.

1. BACKGROUND ON LONG COVID

Long COVID, also known as post-COVID syndrome or long-haul COVID, refers to the persistent symptoms that some people experience after recovering from COVID-19, the illness caused by the SARS-CoV-2 virus. The WHO was able to develop a **clinical case definition** of this condition in October 2020, stating that the post-COVID-19 condition *'occurs in individuals with a history of probable or confirmed infection with SARS CoV-2, usually 3 months after the onset of COVID-19 with symptoms that last at least 2 months and cannot be explained by an alternative diagnosis. The most common symptoms are fatigue, shortness of breath, cognitive dysfunction (commonly known as "brain fog")*[1] *and others and usually impact on daily functioning. Symptoms may be of recent onset after the initial recovery from an acute episode of COVID-19 or may persist since the initial illness. Symptoms may also fluctuate or relapse over time'*.[2]

This definition has been added to the International Classification of Diseases 11 (ICD-11) in October 2020 to "document or flag conditions that occur in the context of COVID-19". As of now, more than 200 symptoms, including chest pain, speaking difficulties, anxiety or depression, muscle aches, fever, loss of smell, and loss of taste, have been recorded by patients[3]. The ECDC's systematic review and meta-analysis on the post COVID-19 condition of October 2022 brings further insights. The condition brings about an extremely wide range of physical and psychological symptoms, the most prevalent being fatigue, shortness of breath, depression, headache and dizziness.

Despite extensive scientific research in this area, there is currently no medical treatment to cure long COVID.[4] According to a modelling published in September 2022 by the WHO, 17 million people have been affected by long COVID in the EU. WHO data also shows that the condition affects more women than men, particularly when they have experienced severe COVID-19 which required hospitalisation. According to these findings, one in three women versus one in five men are likely to develop long COVID[5]. In addition, the European Commission pointed out that children are also susceptible to long COVID[6].

Thus, in order to reduce the significant mental and physical health impacts of long COVID, the WHO has recommended that States increase investment in this area. For example, during the 72nd WHO Regional Committee for Europe held on 12-14 September 2022, Dr Hans Henri P. Kluge, WHO's Regional Director, emphasised the urgent need to ensure greater investment, analysis and, above all, solidarity with those suffering from this physical condition[7]. In order to promote the development of scientific research on long COVID and the possible rehabilitation, WHO Europe has decided to collaborate with Long COVID Europe, a European network of COVID patient organisations from several Member States

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1 BMJ 2022; 376:o158, Baraniuk C., Covid-19: How Europe is approaching long COVID, 20 January 2022, https://www.bmj.com/content/376/bmj.o158.

2 WHO, A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021, https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1.

3 WHO, Science conversation episode #47 - Post COVID-19 condition, 30 July 2021, https://www.who.int/emergencies/diseases/novel-coronavirus-2019/media-resources/science-in-5/episode-47---post-covid-19-condition?gclid=Cj0KCQiA1ZGcBhCoARIsAGQ0kkp-FWba9gslCTUQ7YM_7W7jOUDSlCNTx-Y_jXIk1QZmVUIrzRVshxYaAkTCEALw_wcB.

4 CNN, Gumbrecht J., Paxlovid reduces risk of long COVID, Veterans Affairs study finds, 6 November, 2022, https://edition.cnn.com/2022/11/06/health/paxlovid-long-covid-va-study/index.html.

5 Politico, Collis H., WHO urges action as 17M long COVID cases estimated in Europe region, 13 September 2022, https://www.politico.eu/article/who-urges-action-as-17m-long-covid-cases-estimated-in-europe-region/; See also the study published in the International Journal of Infectious Diseases, Characteristics of long-COVID among older adults: a cross-section study, Vered Daitch, 30 September 2022, https://www.ijidonline.com/article/S1201-9712(22)00535-5/fulltext.

6 Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, 2 September 2022, COM(2022) 452 final, EU response to COVID-19: preparing for autumn and winter 2023, https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52022DC0452.

7 WHO, At least 17 million people in the WHO European Region experienced long COVID in the first two years of the pandemic; millions may have to live with it for years to come, 13 September 2022, https://www.who.int/europe/news/item/13-09-2022-at-least-17-million-people-in-the-who-european-region-experienced-long-covid-in-the-first-two-years-of-the-pandemic--millions-may-have-to-live-with-it-for-years-to-come.

such as Austria, Belgium, France, Greece, and Cyprus. This network aims to raise awareness about long COVID.

Health Commissioner Stella Kyriakides called on Member States to "gather evidence on post-COVID condition and to improve health workforce training to recognise it". At EU level, the EU Strategy on COVID-19 therapeutics includes the allocation of EUR 90 million under Horizon Europe for population studies and clinical trials in order to identify links between risk factors and health outcomes, and to design evidence-based public health policy and clinical management, including for long COVID patients.

Moreover, the Commission tasked the Expert Panel on effective ways of investing in health (EXPH) to submit an opinion, on the impact of long COVID on health systems, and to provide expert guidance on how to develop appropriate health services for patients with this condition. The opinion, published end of 2022, focusses on 6 areas: potential treatments, health systems that need to embed research on long COVID at all levels of care (including rehabilitation), efforts to reduce transmission (including vaccination), investment on models of care that are co-ordinated in primary care and on establishment of coordinated programmes of surveillance systems[8].

With regard to the impact of COVID-19 and post-COVID at work (occupational health and safety), SARS-CoV-2 has been recognised as a biological agent in the Directive on Biological Agents at Work early during the pandemic in June 2020, and COVID-19 has been included in the European schedule of occupational diseases in November 2022. The European Agency for Safety and Health at Work (EU-OSHA) has published a discussion paper on 9 June 2022 on the impact of post-COVID condition on workers and workplaces. It points out in particular that, considering the estimated size of the long COVID population and the fact that most of this group are workers, the impacts of long COVID go beyond public health, and present a substantial challenge for employers, as key workers could meet difficulty in returning to their normal jobs within usual timescales[9]. As a matter of fact, most workers recovering from long COVID will require a gradual phased return to work, beginning with a small amount of work every day and every week, and progressively extending working hours over a period of one to two months or longer.

[8] Opinion of the Expert Panel on effective ways of investing in health (EXPH), Facing the impact of post-COVID-19 condition (long COVID) on health systems, 2022, https://health.ec.europa.eu/system/files/2022-12/031_longcovid_en.pdf; See also the webinar organised by the European Observatory on Health Systems and Policies on 2 March 2021, https://eurohealthobservatory.who.int/news-room/events/item/2021/03/02/default-calendar/preparing-for-long-covid-covid-19-and-health-systems-strengthening.

[9] See the article KFF, "What are the Implications of Long COVID for Employment and Health Coverage?", Alice Burns, 1 August 2022, https://www.kff.org/policy-watch/what-are-the-implications-of-long-covid-for-employment-and-health-coverage/.

2. WORKSHOP PROGRAMME

The workshop consisted of two parts with a total of six presentations:

Part 1

Long COVID: an emerging global challenge
Prof. Dr. Peter Piot (Professor of Global Health at the London School of Hygiene and Tropical Medicine, Special Advisor on COVID-19 to the President of the European Commission and EU Chief Scientific Advisor Epidemics)

Long COVID: definition, epidemiology and symptoms
Prof. Dr. Dominique Salmon (President of the Working Group on Long COVID at the French National Authority for Health, Professor at Paris Descartes University)

Potential underlying mechanisms, diagnostics and treatments
Prof. Dr. Clara Lehmann (Infectiologist, German Centre for Infection Research, University of Cologne)

Part 2

Post COVID
Prof. Dr. Bernhard Schieffer (Cardiologist, Philips University Hospital Marburg)

Chronic Fatigue Syndrome as part of Long COVID
Prof. Dr. Scheibenbogen (Immunologist, Charité University Hospital Berlin)

Long COVID patients' assessment of the current situation and needs
Ann Li (Chair, Long COVID Europe)

3. SUMMARY OF THE PRESENTATIONS

The workshop was chaired by **MEP Michèle Rivasi**, Vice-Chair of the Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future.

Opening remarks

MEP Michèle Rivasi underlined the particularly high interest of citizens in the topic of the workshop, in particular patients feeling misunderstood and isolated. eLong COVID appears multifactorial, and no treatment is currently available. Vice-Chair Michèle Rivasi set the scene by asking the following questions to be explored in the workshop:

- What is long COVID?
- How does the disease affect patients in Europe?
- What are the potential causes of long COVID?
- What are the best strategies to combat the symptoms?
- What should policymakers undertake to respond to the challenges of long COVID?

3.1. Long COVID: an emerging global challenge (Prof. Dr. Peter Piot)

The first presentation was given by **Prof. Dr. Peter Piot,** Professor of Global Health at the London School of Hygiene and Tropical Medicine, Special Advisor on the COVID-19 pandemic to European Commission President Von der Leyen, and EU Chief Scientific Advisor Epidemics.

3.1.1. Long COVID exists!

Prof. Piot underlined the significance of the topic for him, not only as an **epidemiologist** and expert in infectious diseases, but also as a **patient** affected by Long COVID since the early days of the pandemic. With this experience in mind, he immediately dismissed the misconception that long COVID does not exist.

Long COVID is a **combination of symptoms**, including extreme fatigue, insomnia, shortness of breath (incl. serious chronic pneumonia), cardiovascular problems (e.g. tachycardia), difficulties to focus. In Prof Piot's personal case, long COVID occurred after hospitalisation. The convalescence took between 3 to 4 months. In the beginning, he experienced a difficulty to convince physicians of the reality of long COVID.

3.1.2. Scale of long COVID

Long COVID is a big problem. The COVID-19 pandemic is not over in Europe and hundreds of people die from it still today. However, the severity of the disease and mortality rates have now subsided thanks to vaccination and natural immunity. Currently, Europe is entering a new phase of the pandemic with now and then waves of COVID, particularly in colder months.

Even if SARS-Cov-2 would disappear, people suffering from the long-term consequences of acute infections would remain. The most reliable estimates indicate that **65 million people worldwide** currently suffer from long COVID (January 2023)[10], including **17 million in the WHO European Region**.

[10] Davis, H.E., McCorkell, L., Vogel, J.M. et al. Long COVID: major findings, mechanisms and recommendations. Nat Rev Microbiol 21, 133–146 (2023). https://doi.org/10.1038/s41579-022-00846-2.

The prevalence of long COVID is the highest amongst persons aged 25 to 69 and women. It also appears that **socio-economic risks factors** play a role: residents of deprived areas, economically inactive persons and those suffering from activity-limiting health conditions appear more affected[11].

The economic costs are enormous. Estimates from the US and from the UK highlight respectively a cost of USD 3.7 trillion[12] (total cost over 5 years) and GBP 2.5 billion (per year) to national economies[13]. The **labour market** is affected by persons falling out of employment due to long COVID: 4 million workers in the US alone, for an estimated USD 170 billion in lost wages per year[14].

On average, about **10% of persons affected by COVID-19** will develop long COVID. Vaccination appears to reduce the risk of developing long COVID by 15% to 50%. This is a relevant finding in support of vaccination of young people who are less at risk of having an acute infection but can nevertheless develop long COVID.

3.1.3. Symptoms of long COVID

Long COVID affects about every organ system in the human body but also people's minds. The complexity is reinforced by the fact that not everybody has every symptom, and that subgroups of patients may require different approaches in care. General practitioners are at the frontline.

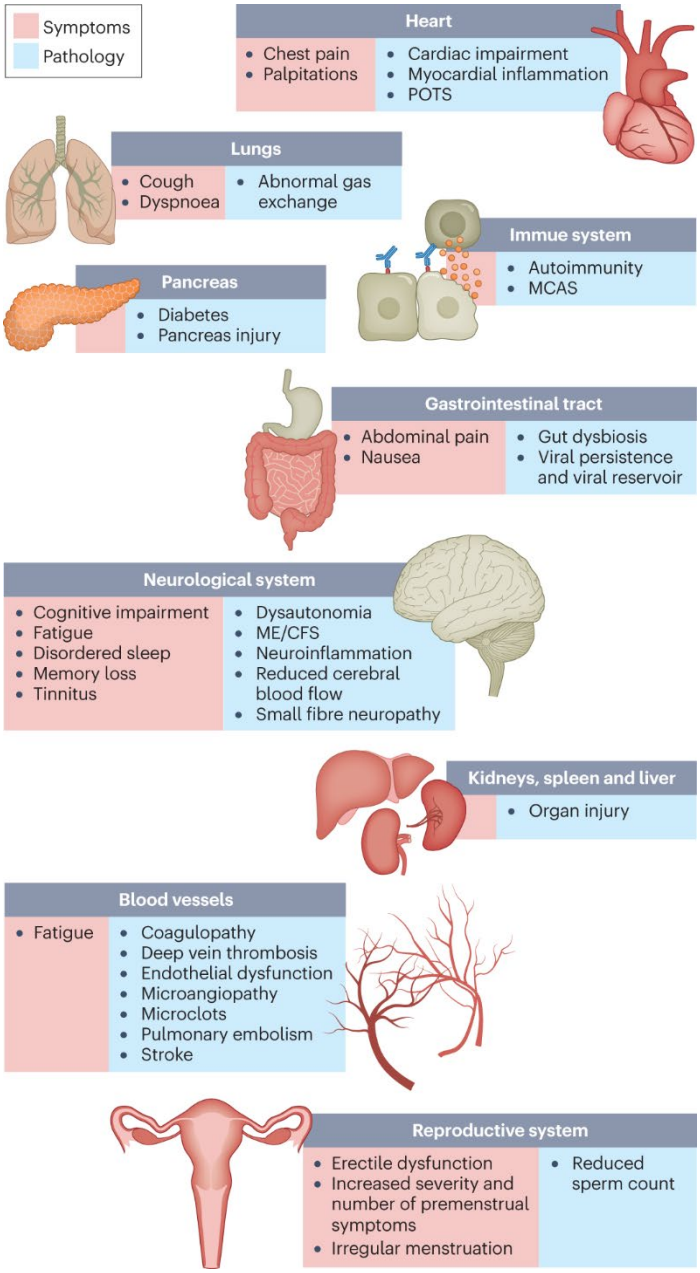
[11] United Kingdom, Office for National Statistic, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 3 November 2022.

[12] Cutler, D. M., The Economic Cost of Long COVID: An Update, July 16, 2022, Harvard University.

[13] Metro, Long Covid 'could cost UK around £2,500,000,000 a year', https://metro.co.uk/2021/02/10/long-covid-could-cost-uk-around-2500000000-a-year-14050266/.

[14] Bach, K., New data shows long Covid is keeping as many as 4 million people out of work, August 23, 2022, Brookings.

Figure 1: Long COVID symptoms and the impacts on numerous organs with differing pathology.



Source: Davis, H. E., *et al*, Long COVID: major findings, mechanisms and recommendations, Nature Reviews Microbiology, 21, 133-146 (2023).

The symptomatology of **long COVID is not unique**: other viral infections, in particular respiratory viral infections, can produce similar symptoms (e.g. influenza, MERS-CoV, SARS-CoV-1), and certain persons still suffer from the consequences of the SARS-CoV-1 epidemic of 2003. The uniqueness with long COVID is that **billions of people have been infected with SARS-CoV-2** within a short time. Therefore, the scale of long COVID is much larger than anything seen before.

This represents therefore at the same time a major opportunity for advancing our understanding about people suffering from **other post-acute infections** and chronic issues such as the chronic fatigue syndrome, as the science progresses, as the clinical management, treatment, and the prevention progress.

The cause of long COVID is not fully elucidated yet. There are several hypotheses (e.g. persistence of the virus in the body, response of the immune system, dysfunctional neurological signalling, or blood clotting). Elucidating the cause of long COVID is not only a scientific question but also constitutes the basis for patient treatment and care.

A large number of potential **treatments** or **experimental therapies** are currently being tested. However, trials are oftentimes very small, and it will thus be difficult to draw very robust conclusions. **Collaborative research on large patient groups is needed**.

The EU is now addressing the issue after some hesitation, and many initiatives run in parallel. Last December, an EU-US conference was organised by the EC's Directorate General for Health and Food Safety to discuss the impact of long COVID on health systems and patient care. The European Commission financially supports several large cohort studies, to understand, diagnose, and treat long COVID (e.g. via Horizon 2020). In addition, the EU Strategy on COVID-19 therapeutics of May 2021 includes the development of treatments against long COVID.

This type of **study necessarily involves large amounts of money** for the EU, as they necessarily must involve large populations over long periods of time. But things must be put in perspective: the US National Institute of Health opened funding for a research project on long COVID for USD 1.15 billion[15].

Some EU Member States have a **registry for long COVID** but not all of them. This is an important tool for knowing what exactly is going on in national populations.

The challenges to be addressed include **scientific questions**, in particular: clinical spectrum of long COVID, diagnosis, epidemiology, risk factors, causes of long COVID (aetiology and pathogenesis), treatment, prevention, social and economic impact. Furthermore, the **society's attention is shifting away from COVID-19** although the pandemic is not over, and the symptoms of long COVID patients are often not taken seriously enough (fatigue, brain fog).

To overcome these challenges, it is important to **involve people with long COVID in research and policy**; and to **build awareness** that there are long-term effects of the pandemic through which it continues to affect the lives of millions.

3.2. Long COVID: epidemiology, clinical profile and outcome (Prof. Dr. Dominique Salmon)

A **clinical case definition of the post COVID condition** has been issued by the WHO in October 2021, following a Delphi consensus process (methodology to obtain expert consensus). The elements of the definition are:

- There is a history of **confirmed or probable SARS-CoV-2 infection**.
- **Symptoms occur usually 3 months from the onset** of COVID-19.
- The symptoms **last for at least 2 months**.
- There is **no alternative diagnostic**.
- The **main symptoms** include fatigue, shortness of breath, cognitive dysfunction, but many other symptoms can arise. They have a demonstrated impact of patients' quality of life.
- The symptoms can have a **new onset or continue** since the COVID-19 infection.

[15] National Institutes of Health, 'NIH launches new initiative to study 'Long COVID', Feb 23 2021.

A specific definition for children has recently been drafted based on the above definition with a few nuances, tanking into account that long COVID in **children** is often associated with **school dropout** and **anxiety**.

3.2.1. Prevalence and epidemiology of long COVID

The prevalence of long COVID varies across studies but is generally situated between 15 and 30% of persons infected with SARS-CoV-2, at months 4 to 6 after infection. Two national examples were given:

- The National Office for Statistics of the United Kingdom conducted a study in 2021 on more than 20 000 participants: at Week 12, around 12% of participants still had symptoms. The population affected is thus estimated at 2.8% of the population, i.e. **1.8 million people in the UK**.[16]
- In France, a 2022 study on more than 25 000 adults showed that 30% of participants still had post-COVID symptoms at 3 months and 20% at 18 months. The estimation is that long COVID affected 4% of the adult population, i.e. **2.06 million people in France**.
- In the United States of America, similar results have been obtained.[17]

When comparing international studies, big differences in prevalence appear between countries[18].

With regard to individual factors, a common conclusion is that long COVID is **more frequent among persons hospitalised for a COVID-19 infection**. In this sense, COVID-19 patients with more severe or more individual symptoms are more prone to developing long COVID[19]. In addition, **female sex** is associated with occurrence of long COVID[20].

Environmental or behavioural factors also appear to play a role. The initial **COVID-19 variants** (Alpha) were more associated with long COVID compared to Delta and Omicron variants[21]. In addition, **pre-infection vaccination** is protective against long COVID[22]. A posteriori vaccination however does not provide significant benefits. Despite these differences, persons still can develop long COVID even with 3-shots of vaccination and with the Omicron variant.

3.2.2. Clinical profile: symptoms of long COVID

The symptoms of long COVID affect persons in many ways but have common characteristics. They are:

- **multisystemic**, i.e. they affect several organs;
- have a **prolonged duration**;
- **fluctuate**, i.e. the general state of a person can change significantly; and
- are **exacerbated after exertion** (effort).

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16 National Office for Statistics (UK). Prevalence of ongoing symptoms following COVID-19 infection in the UK, 2 Sep 2021.

17 Santé Publique France, 'Post-COVID-19 affection (also called long COVID) in France, Update on 21 July 2022'.

18 Chan, C., *et al*, Global Prevalence of Post-Coronavirus Disease 2019 (COVID-19) Condition or Long COVID: A Meta-Analysis and Systematic Review, J Infect Dis. 2022 Nov 1;226(9):1593-1607.

19 Augustin et al, 2021; Sudre et al, 2021; Mirfazeli et al, 2021; Durstenfeld et al; Ford et al, 2022; Han et al, 2022.

20 Augustin et al, 2021 ; Sudre et al 2021; Evans et al 2021; Mirfazeli et al 2021; Ford et al, 2022; Marra et al. 2022; Wynberg et al, 2022; Han et al, 2022.

21 Durstenfeld et al, 2022; Marra et al, 2022.

22 Byambasuren et al, 2022; Brannock et al, 2022; Marra et al, 2022.

Fluctuations in the significance of symptoms occur especially as a function of **physical or intellectual effort**, **stress**, **emotion**, menstrual **periods** or even **meals**.

Symptoms found in 75% of patients include **fatigue** (physical and mental), **cognitive and neurological** symptoms (concentration, memory, attention, balance disorders, dizziness, paraesthesia, headache, dysautonomic symptoms, difficulty finding words), and **cardio-respiratory** symptoms (dyspnoea, cough, tachycardia, chest pain, malaise). Additional symptoms found in around 30% of patients include Ear-Nose-Throat (ENT) symptoms, emotional affections, sleep disorders, myalgias/arthralgias, menstrual/libido disturbances, ocular symptoms, fever/shivering, digestive and/or cutaneous/vascular symptoms. **Almost all organs are affected**.

A majority of symptoms appear suggestive of a moderate to severe **autonomic dysfunction**, i.e. an affection of the autonomous nervous system. The autonomous nervous system is responsible for all automatic functions (respiratory, cardiac, digestive)[23]. A hypothesis, which remains to be scientifically demonstrated, is that SARS-CoV-2 crosses the cribriform plate[24] to **reach the deep brain**.

3.2.3. Perspectives of long COVID

In year 1, around 70% of patients see an improvement of their state. However, this **improvement is incomplete** and around 85% of patients report a persistence of symptoms[25]. 10 to 15% of patients are still affected by serious **disabling symptoms**. The limitation of patients' social life and the lack of prospects of recovery can lead to suicidal thoughts.

According to the most recent figures from January 2023, a positive trend can be observed: the share of persons who recovered from long COVID increases while the share of persons currently affected declines. Long COVID may become a chronic disease for certain patients.

3.2.4. Conclusions and recommendations

Prof. Salmon ended her presentation with key characteristics on long COVID and recommendations:

- Long COVID is a **new, multisystemic, fluctuating and non-visible disease**, which becomes chronic for some patients. Its management is complex and not codified.
- Long COVID has a **high cost** for health care systems and puts high demands on medical staff. Long COVID patients often do not stay in hospitals (ambulatory care), which limits visibility.
- The **scepticism** on the disease is still too frequent, including in the medical profession. This creates risks of **discrimination** and delay **in the provision of care** for long COVID patients.

In the EU, it is essential that:

- Long COVID be treated as a **severe somatic disease**, and not as psychosomatic one.
- **Special funds** be allocated to specialised management of the most severely affected patients.
- Patients with a chronic disease be **supported and socially integrated** (e.g. in relation to work, e.g. to allow part-time employment).

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[23] Nicholas W. Characterization of Autonomic Symptom Burden in Long COVID: A Global Survey of 2,314 Adults, medRxiv 2022.04. 25.2227 4300.

[24] This bone, the cribriform plate, transmits the olfactory nerves that carry the sense of smell.

[25] Tran VT, et al, Course of post COVID-19 disease symptoms over time in the ComPaRe long COVID prospective e-cohort, Nat Commun. 2022 Apr 5;13(1):1812.

- **European research networks** be established and promoted to gather epidemiological data, in particular for children, adolescents and to ensure long-term follow-up.
- **Prevention and communication campaigns** be implemented, with involvement of patients.

3.3. Long COVID: Potential underlying mechanisms, diagnostics and treatment

This presentation was given by **Prof. Dr. Clara Lehmann** (University of Cologne, German Institute for Infection Research).

3.3.1. Post-acute infection syndromes

SARS-CoV-2 is not the first chronic post-acute infection syndrome (PAIS). There is a great number of PAIS that arise after a post-acute (viral) infection, for instance, the **post-Ebola syndrome**, which had severe consequences in Africa, the **post-dengue syndrome**, or the **Epstein-Barr** virus, which causes severe post-infection syndromes.[26]

Today, SARS-CoV-2 and long COVID create the opportunity to **understand more about the pathomechanisms of PAIS**, as until now, they are still under-researched, as a sort of "black box" of medicine.

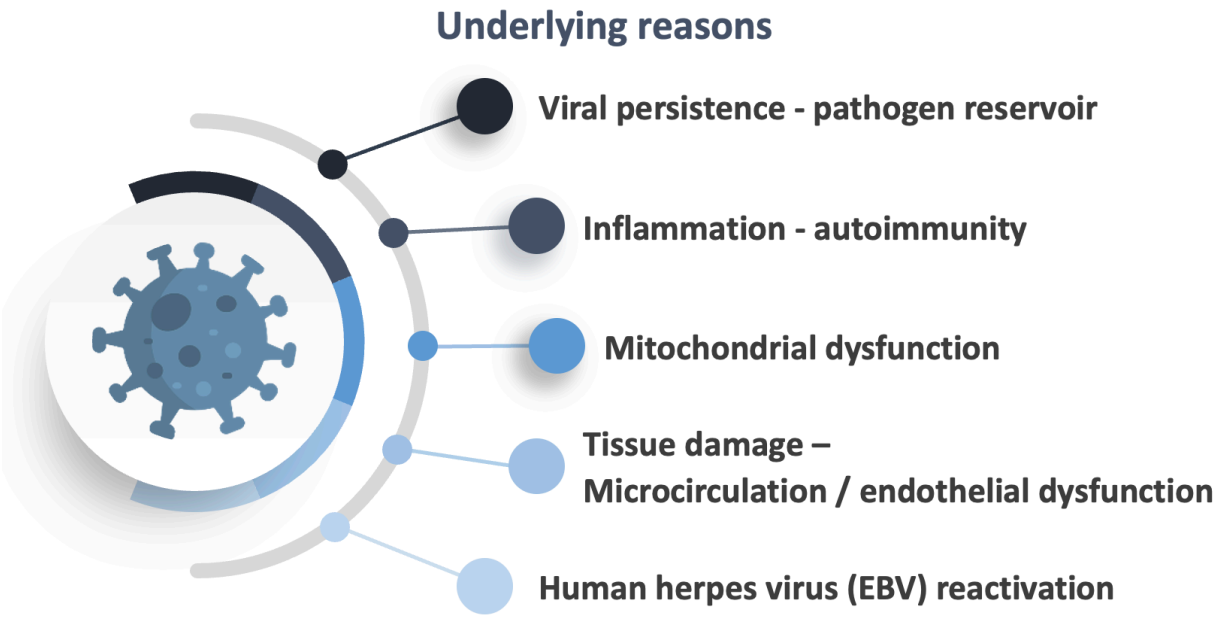
What symptoms are actually due to an infection with SARS-CoV-2? The differentiation of long COVID *stricto sensu* from other issues, i.e. persistent symptoms of COVID-19 infection, biological correlates, or psychosocial stress generated by the pandemic, is fundamental for researchers and for patients. However, the differentiation and isolation of long COVID is made even more difficult by the **absence of biomarkers of long COVID**.

3.3.2. Pathophysiology: Underlying mechanisms of long COVID

A variety of mechanisms which could explain the physiopathology of long COVID are currently discussed. These mechanisms are not mutually exclusive and are even complementary.

[26] Hung, T. M., et al.,Trends Parasitol. 35, 673–676 (2019). PREVAIL III Study Group et al. N. Engl. J. Med. 380, 924–934 (2019). Choutka J et al., Nature Medicine, Vol. 28, May 2022, 911–923.

Figure 2: Long COVID - underlying reasons



Source: Prof. Clara Lehmann's presentation.

Looking specifically at these mechanisms:

- **Viral persistence**: the virus needs a specific receptor (ACE2) to enter the cells. This receptor is very present in the intestine. This could explain why persistent virus components or protein fragments are found in the intestine.
- **Autoimmunity and persistent activation**: these mechanisms are very often and prominently observed in patients but not in all of them. A lot of research is conducted on this mechanism.
- **Mitochondrial dysfunction**: a recent publication has shown a correlation between mitochondrial oxidative stress and neuropsychological disorders.
- **Reactivation of the human herpes virus (Epstein-Barr virus)**: research has shown that SARS-CoV-2 can lead to a reactivation of the Epstein-Barr virus. However, many other diseases lead to a reactivation of the Epstein-Barr virus, without causing a disease.

3.3.3. Treatment approaches

What can be offered to a long COVID patient today?

This is a new situation for doctors, as no treatment can be easily determined and prescribed. The treatment is **individual,** and **symptoms based**. Treatment approaches are also **multimodal**, for instance:

- **physiotherapy** (e.g. respiratory therapy, physiotherapy on the apparatus, pacing, individual therapy), to treat physical symptoms,

- **neuropsychological and occupational therapy** (brain power therapy [27], psychological-functional therapy[28]), to treat cognitive symptoms, or
- **speech therapy** (voice, speech and language therapy; swallowing therapy), to treat communicative symptoms.

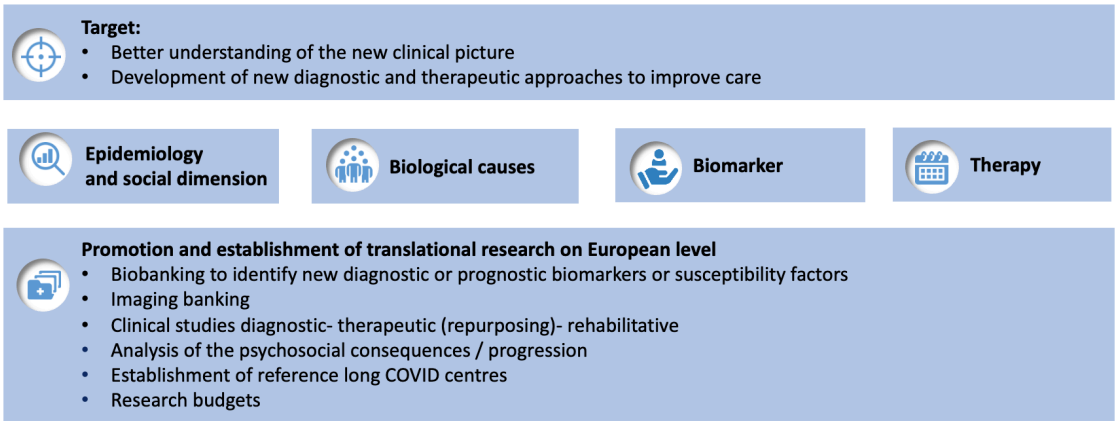
These symptomatic therapies work well but not for all patients. A number of patients, after one year of therapy, are still affected by symptoms, and an improvement is not always a given.

Targeted therapies and **clinical studies** are **urgently needed** for the management of long COVID. A certain number of clinical studies are currently ongoing. In this regard, it is essential that clinical studies are **properly conducted** according to scientific principles to increase the community's knowledge. For this purpose and to obtain **robust results**, enough time must be dedicated to design and implement studies.

3.3.4. Urgent needs

Prof. Dr. Lehmann outlined the following urgent needs of medical professionals and researchers, to ensure a better care for patients:

Figure 3: Long COVID - urgent needs



Source: Prof. Clara Lehmann's presentation.

3.4. Post COVID (Prof. Dr. Bernhard Schieffer)

This presentation was given by **Prof. Dr. Bernhard Schieffer** (Marburg University Hospital, Philipps University Marburg). He offered his perspective as a cardiologist and clinician, in direct contact with patients.

3.4.1. General observations on long COVID

The spike protein is found both in SARS-CoV-2 and in the vaccines. Symptoms similar to long COVID have been identified following the vaccination, which is a **rare but real threat for patients**. The same antigen found in SARS-CoV-2 is used in vaccines, thus, there are difficulties in selecting patients for the

[27] The following areas, among others, are specifically promoted: memory (long-term memory and short-term memory), memory skills, attention and concentration, endurance, spatial cognitive and constructive skills, orientation skills (to space, time, place, situation and person), visual and auditory perception.

[28] Targeted therapy on disease-related disorders of the psychosocial and socio-emotional functions and the resulting ability disorders.

study populations. A refinement of study population selection criteria is a major reason why additional studies and selection programmes are needed.

The **post-infection syndromes** are well known and occur following viral and bacterial infections. The **spike protein** seems to be the key which needs further fundamental research.

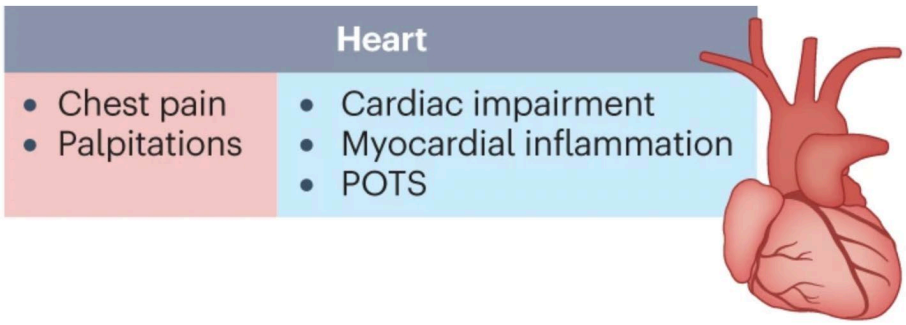
The WHO estimates that long COVID will impact approximately **20 million people** in the European Region in March 2023.

3.4.2. Impact of post-COVID on the cardiac system

The everyday clinical work is the following: long COVID affects every organ, which makes it extremely difficult to select patients for clinical trials, for specific drugs or for the search for niches where the spike protein or virus particles or vaccine particles may hide.

There is a certain probability that specific organ functions are affected. Cardiologists see a tremendous number of **patients suffering from cardiac symptoms**, i.e. cardiac impairment, postural orthostatic tachycardia syndrome (POTS) and myocardial inflammation, particularly smouldering myocarditis, a threat for certain cardiac deaths.

Figure 4: Long COVID symptoms and the impacts on heart



Source: Davis, H. E., *et al*, Long COVID: major findings, mechanisms and recommendations, Nature Reviews Microbiology, 21, 133-146 (2023).

In the absence of knowledge of the underlying mechanisms, cardiologists do not know how to handle the symptoms. Therefore, **multinational trials** and the **collection of data on how to treat patients** are needed. In Germany, for many doctors, long COVID patients appear as psychiatric patients due to their neuro-emotional disorders, which may be caused by a smouldering neuroinflammation.

Prof. Schieffer advocated for a **European-level research platform** where everyone could contribute (with clinical charts of patients), as has been done in Israel. This type of platform provides the opportunity, with the support, e.g., of AI algorithms, to obtain clinical algorithms to help clinicians and patients develop new strategies against the post-COVID symptoms, either induced by the vaccine in rare cases or SARS-CoV-2.

3.5. Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) as part of long COVID (Prof Dr Carmen Scheibenbogen)

The presentation was given by **Prof. Dr. Carmen Scheibenbogen** (Charité University Hospital Berlin). The speaker is a clinician and researcher, in charge of patients with chronic fatigue syndrome for more than a decade. More recently, the unit has been taking care of long COVID patients.

3.5.1. Compared overviews of long COVID and ME/CFS

The special situation of ME/CFS as part of long COVID (on the post-COVID spectrum): Prof. Scheibenbogen started by giving an **overview of the post-COVID disease**. Post COVID patients suffer from diseases known for a long time, e.g. cardiovascular, pulmonary diseases, autoimmune diseases, psychiatric, or neurocognitive diseases. The more specific post-COVID symptoms are fatigue and exertional intolerance, cognitive pain, and/or vertigo, shortness of breath, or others.

At Charité, an **observational study** was initiated in Summer 2020 to learn **if ME/CFS is triggered by COVID**[29]. **The diagnostic of ME/CFS patients** can be made based on diagnostic criteria (e.g. ME/CFS based either on the Canadian Consensus Criteria (CCC) or US Institute of Medicine (IOM) criteria; or POTS and orthostatic hypotonia). Looking at younger patients (not hospitalised for COVID-19 infection) suffering from severe or at least moderate fatigue and exertional intolerance for at least six months, with no evidence of organ impairment or other diseases, the results are that **ME/CFS was identified among 50% of patients** according to the (stricter) Canadian Consensus Criteria. The two-year follow-up of patients additionally showed that the symptoms-based treatments of ME/CFS do not allow a clear improvement of the symptom severity.

Prof. Scheibenbogen went on to present the **overview of myalgic encephalomyelitis / chronic fatigue syndrome** (ME/CFS). It can be triggered by COVID-19 but also by various other infections (e.g. EBV, enterovirus, influenza). The main symptom is not fatigue but **exertion intolerance** (i.e. daily activities lead to aggravation of all symptoms – **post-exertion malaise, which can last for days**). Other symptoms include brain fog (neurocognitive impairment), pain, sleep disturbances, orthostatic problems and severe hypersensitivity. The diagnostic relies on the diagnostic criteria abovementioned but also on measurement of the muscle fatigue or of orthostatic intolerance.

3.5.2. The underdevelopment of knowledge, care and research on ME/CFS

In addition, ME/CFS is a **severe chronic disease with no curative treatment**. The WHO classifies ME/CFS as a neurological disease and about 50% of patients are unable to work. 25% of patients are housebound, and in the most severe cases, can be bedbound.

Patients affected by ME/CFS are in a **difficult care situation** all over Europe. The symptoms can lead to the use of a wheelchair, as for **multiple sclerosis**. The two diseases have a **similar prevalence** in the population (pre-pandemic), the same **overrepresentation of women** (2:1), with **early age onset**, and the **quality of life in ME/CFS is comparable but worse** than for multiple sclerosis[30]. However, there are only 2 **specialised clinics** on ME/CFS in Germany, compared to 217 for multiple sclerosis, and 0 **drugs licensed** against ME/CFS compared to 16 against multiple sclerosis.

The reasons for the difficult care situation are that the disease was long **misdiagnosed** as a psychiatric disease (e.g. "epidemic hysteria")[31]. Until today, some physicians and general practitioners (GPs) have a lack of knowledge and still claim that ME/CFS and long COVID are psychosomatic diseases. This attitude has slowed down research and clinical development of therapies in Europe and worldwide.

> *"Disbelief and lack of knowledge and understanding of ME/CFS among GPs is widespread, and the resultant diagnostic delays constitute a risk factor for severe and prolonged disease. Failure to*

[29] Kedor, C., Freitag, H., Meyer-Arndt, L. et al. A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity. Nat Commun 13, 5104 (2022).

[30] Falk Hvidberg M, et al. The Health-Related Quality of Life for Patients with ME/CFS. PLoS One. 2015.

[31] McEvedy CP, Beard AW. Royal Free epidemic of 1955: a reconsideration. Br Med J. 1970 Jan 3;1(5687):7-11. doi: 10.1136/bmj.1.5687.7. PMID: 5411611; PMCID: PMC1700894.

diagnose ME/CFS renders problematic attempts to determine its prevalence, and hence its economic impact".

Pheby, D., *et al*, A Literature Review of GP Knowledge and Understanding of ME/CFS: A report from the Socioeconomic Working Group of the European Network on ME/CFS (EUROMENE), *Medicina*, Dec. 2020.

The **cost of the disease** is estimated at **EUR 40 billion per year** to health services and society[32]. This pre-pandemic estimation must be read in light of the doubling of ME/CFS cases during the pandemic.

The priorities to address post-infectious syndromes and ME/CFS are:

- **Care structures**, with outpatient clinics for post-infectious syndromes (ME/CFS, POTS, among others), integrated into **post-COVID networks** for synergies.
- For the less severely ill who can remain in employment: **rehabilitative structures with pacing** (to learn how to cope with the disease) instead of activation programmes (in light of the exertion intolerance).
- For the bedbound: in-patient diagnostic structures and **home-care structures**.
- **Translational research funding**.
- **Clinical trials**: no medicinal products are currently available for ME/CFS or post-COVID. Currently, the treatments are symptom-based but not curative.
- **Cooperation with the pharmaceutical industry** for rapid development.
- **Harmonised diagnostic criteria**.

3.6. Long COVID patients: Assessment of the current situation and needs (Ann Li)

The presentation was given by **Ann Li** (Long COVID Europe), to represent the millions of people with long COVID in Europe, three years after the onset of the pandemic in Europe.

3.6.1. Long COVID Europe (LCE)

Ann Li started by describing her own experience of long COVID. Despite an improvement, return to work is difficult and many symptoms of the disease are still present. The situation is worse for some, and many patients with long COVID are still bedbound.

National and regional initiatives gathering long COVID patients were initiated in 2020. Long COVID Europe, the European umbrella organisation was founded in February 2021, to improve the **coordination of national approaches to the disease**. Now, long COVID Europe consists of 24 organisations from more than 15 European countries. It is an official non-state actor accredited by the WHO Regional Office for Europe.

The work of the organisation is hampered by the fact that certain members of the organisation are too exhausted to participate in the work because of their own long COVID. In addition, member organisations from Eastern European countries face difficulties due to the political situation in their countries. The Chair of Long COVID Europe regretted the big **disparities between the Member States** of the EU and the impact on the **health and quality of life** of the patients. She strongly called on the

[32] Pheby, D., *et al*., The Development of a Consistent Europe-Wide Approach to Investigating the Economic Impact of Myalgic Encephalomyelitis (ME/CFS): A Report from the Euroepan Network on ME/CFS (EUROMENE), *Healthcare (Basel)*, 2020.

Members of the European Parliament to **clearly recognise that long COVID is a real disease** and **not to politicise long COVID**.

The association includes experts, e.g. healthcare professionals and researchers. Ann Li called on MEPs to make use of this first-hand medical and scientific expertise, and to **ensure patients' participation in decision-making**.

Long COVID affected 17 million persons in 2020-2021 alone (in the WHO European Region). This represents more than the population of Belgium or the Netherlands. These figures should not hide the tragic heart-breaking individual stories: European citizens losing everything, and broken family relationships.

A central message is that **post-acute infectious syndromes** (PAIS) should not only be considered in the acute phase, but the **chronic phase is at least as important**. After three years, many long COVID patients are still in the chronic phase.

3.6.2. Assessment of the care for long COVID patients in Europe

Medical practitioners are generally unaware of the adequate diagnosis, treatment and safe rehabilitation methods, despite existing tools. **Symptoms-based treatments** (incl. medicinal products) **are available** but not being prescribed due to the lack of knowledge. However, contrary to the UK's National Institute for Health and Care Excellence (NICE) guidelines and WHO guidelines, graded exercise therapy (GET) and cognitive behavioural therapy (CBT) are still commonly prescribed for long COVID subgroups with post-exertional malaise (PEM), although described as ineffective and potentially harmful, increasing the risk for severe chronification of the disease.

Here again, **too much depends on individual sheer luck** (doctor consulted, country of residence and its care system, health insurance). The quality, affordability and access to good care should not depend on luck or coincidence.

3.6.3. Socio-economic impact of long COVID

On the **socio-economic level**, long COVID has become the leading cause of inability to work. In the UK, one year ago, it has been estimated that more than **2 million working days were lost** due to long COVID. **Essential workers and female workers** were the most affected by the infection at the beginning of the pandemic. Currently, better **coordinated efforts to tackle long COVID** are urgently needed. Finally, chronic long COVID creates **substantial risks for patients' financial stability**, with risks of falling below the poverty line.

Children can get long COVID as well. This is not due to hysterical parents, or depressed children. They have the same symptoms as adults. The impact on children should be carefully monitored, as they may lose decades in education and quality of life.

The demands of the patients on the socio-economic level are:

- **Recognition of long COVID as an (occupational) disease**, including for disability benefits and early pension.
- Establishment of standardised concepts for **workplace/education (re-) integration** of people with mild/moderate long COVID.
- **Social security support structures** for all patients, with special attention to severely affected (house- and bed-bound).

- Improved **collection of health and economic data** about the outcomes for long COVID patients.

3.6.4. Long COVID patients' demands

With regard to **biomedical research**, no targeted treatments are yet available, and the management of the condition is inadequate (limited to symptom relief). The assessment of LCE is that there is a **severe lack of funding for basic research and clinical trials** on already approved medicines and interventions. Research is characterised by a **lack of coordination** at the European level but also national level, and the research priorities are not always aligned with patients' needs due to the **absence of involvement of the patients**.

The central demands of Long COVID Europe to improve medical knowledge and guarantee access to adequate treatments are:

- **Funding for research**. LCE calls on EU Member States to allocate a minimum of **EUR 500 million in emergency funding** (only around EUR 1 per citizen of the EU) for biomedical research and clinical trials on long COVID, in patients of all ages. In comparison, the dedicated budget in the US is more than USD 1 billion.
- In addition, LCE calls for the establishment of **national platforms for large multi-centre studies** (see National Clinical Study Group at Charité in Berlin).
- LCE also calls for **meaningful, high-quality patient involvement** at all stages of long COVID research (from funding calls to project design, implementation and data evaluation).

With regard to **awareness**, LCE calls for:

- **Large-scale public awareness campaigns** on the existence of long COVID as a serious disease (to reduce the stigma of patients, e.g., from families, medical sector, and colleagues), but also how to prevent long COVID during and following an acute SARS-CoV-2 infection, on how to adequality manage the symptoms and reduce the risk for severe chronification.
- **Targeted educational programmes in the medical sector**, utilising existing competencies from the field of post-infectious conditions (e.g. ME/CFS).

European policymakers must create the legal and policy framework in which these actions are possible: time, funding, and personnel, to coordinate all these efforts.

4. DISCUSSIONS AND Q&A

Members of the European Parliament and participants to the workshop could raise questions to the expert speakers during two Q&A sessions.

Following the first round of presentations:

- Remarks and questions from MEP Radan KANEV (EPP)

MEP Radan KANEV recalled the European Parliament's work on chronic fatigue syndrome (CFS), and the contacts of MEPs with patients and patients' organisations. It is a poorly studied disease, and the causes are unclear. However, there are similarities in symptoms with long COVID and both diseases could overlap. While working on the extension of the ECDC's mandate, the ENVI Committee wanted to provide more resources on the interconnection between chronic and contagious diseases. Question: MEP KANEV asked the speakers whether the mutualisation of knowledge based on the study of ME/CFS and of long COVID could help in understanding more about the causes of CFS.

Prof. Piot confirmed that research on long COVID will support the understanding of CFS, and both conditions may spring from the same well. It is a casual benefit of researching long COVID. When researching HIV/AIDS, researchers learned a lot about the treatment of other viruses. It needs to be clearly and loudly stated that long COVID is not a psychosomatic disease, but it has a biological cause. According to **Prof. Salmon**, long COVID is a PAIS. Until today, PAIS only concerned 0.3 to 0.9% of the population (e.g. EBV infections, etc.). The difference with long COVID is that 30% of the population is concerned. All the **research on long COVID will be useful for all PAIS**, in particular on the underlying mechanisms (e.g. persistence of viral fragments identified in Zika and Ebola patients).

- Remarks and questions from MEP Karsten LUCKE (S&D)

MEP Karsten LUCKE thanked Prof. Piot for his clear statements that the COVID-19 pandemic is not over, that 17 million persons are affected by long COVID, that long-term costs will be incurred, and that long COVID has over 200 symptoms. Question: MEP LUCKE recalled Prof. Dr. Lehmann's statements on the lack of scientific knowledge on post-acute infection syndromes and asked about the possibility of establishing a **European PAIS-Strategy**, in line with those for cancer or mental health, for Europe to be equipped for the future with the appropriate toolbox. The second question was addressed to Prof. Salmon, to confirm that long COVID is not a psychosomatic disease, but a **serious multidimensional disease**. The third question was addressed to Prof. Dr. Lehmann about the existence of **treatments** and **diagnostic tools**.

Prof. Salmon underlined that **long COVID is indeed a biological disease, not** a psychosomatic disease, although it has psychological consequences (anxiety, lack of optimism, etc.). **Prof. Dr. Lehmann** underlined that research on **post-viral syndromes**, i.e. the connection between virus infection and its long-term consequences, is highly important and urgently needed to prepare for future pandemics. For instance, a connection between EBV infections and multiple sclerosis has been established in recent publications. Regarding **biomarkers**, as of today, no specific readily accessible laboratory values unconditionally indicate long COVID, and they can only be used as indicators (e.g. antibodies).

- Remarks and questions from MEP Max ORVILLE (Renew)

MEP Max ORVILLE explained that in his region of origin, the common infectious diseases (e.g. Zika, Chikungunya, Dengue) have almost identical symptoms as those of COVID-19, and that there have been the same long-term consequences (PAIS). Question: MEP ORVILLE asked whether researchers used the research in the regions affected by the abovementioned infectious diseases to prepare or

better recognise long COVID and if yes, what conclusions could be drawn for the development of specific treatments against COVID and long COVID.

Prof. Dr. Lehmann remarked that only little research has been done so far on PAIS and their pathomechanisms, including on Zika and Ebola. Based on insight gained with the Ebola epidemic, research conducted by **Prof. Salmon** at the Pasteur Institute (in France) revealed that traces of SARS-CoV-2 remained in the olfactory clefts. According to **Prof. Piot**, research on long COVID is currently ongoing in South Africa, Uganda and Senegal.

- Remarks and questions from MEP Tilly METZ (Greens/EFA)

Question: MEP Tilly METZ wondered what could be done by the European Parliament to raise **awareness on PAIS**, and specifically long COVID; and whether the action plan or strategy called for on long COVID could go beyond long COVID. Regarding **treatments**, it appears that many pharmaceutical companies are developing therapeutics targeting long COVID symptoms (e.g. immune system, blood clots, or COVID fragments) under the guidance of the EMA, and key trials are expected. She asked about the state of advancement regarding these treatments. Regarding **epidemiology**, MEP METZ asked whether the reasons why women were more affected by long COVID were known. The fourth point raised was about the specific need for **training of doctors and general practitioners** to address long COVID. The final question was whether **good practices for the rehabilitation** of long COVID patients could be identified.

Prof. Dr. Lehmann highlighted the importance of discussing PAIS in general and not only in the context of long COVID. The current development of medicines and treatments for long COVID patients are based on specific underlying mechanisms (e.g. persistence of viral fragments, auto-antibodies, etc.). She recalled the importance of properly conducting studies and clinical trials, without time pressure, to obtain valid results and data. The timing for the rollout of medicines relies on the results of studies. **Prof. Piot** confirmed the need to have large studies with significant numbers of participants. He regretted that Europe is not well equipped for **multi-country studies**, mainly because of bureaucratic and administrative obstacles. Regarding the higher **prevalence of long COVID among women**, a great number of infectious diseases show that women are more affected by men, which can be explained by pathophysiological differences, but these differences between the biological sexes and the differentiated effectiveness of therapies remain insufficiently researched. Urgent European-level research and action could bring added value. According to **Prof. Salmon**, women have different biology and long COVID symptoms appear to be affected by menstrual periods. Women also generally have more autoimmune diseases. This could be explained by a different reaction to the spike protein. **Prof. Salmon** also highlighted the benefits of allowing a slow rehabilitation and re-education path for long COVID patients. Regarding treatments, Prof. Salmon recalled the importance of time for research and trials, citing as comparison the development of antiviral treatments against AIDS.

- Remarks and questions from MEP Virginie JORON (ID)

MEP Virginie JORON thanked the experts and spared a thought to all patients who contacted MEPs prior to the workshop. She started by recalling that the ECDC has recorded tens of thousands of **side effects of COVID-19 vaccines**. The vaccination against COVID-19 does not appear to protect persons from long COVID. The question addressed to Prof. Piot was the following: Has the prevalence of long COVID been impacted by the vaccination? MEP JORON regretted the lack of research on the impact of vaccination on long COVID, i.e. long COVID as a side effect of vaccination. She evoked the **exclusion of the responsibility** for pharmaceutical companies in procurement contracts, for the compensation of the 1.6 million cases of side effects recorded by the ECDC. The last question concerned whether the EC intends to establish a **compensation fund** for the victims.

Prof. Salmon observed a few cases of patients with post-vaccination symptoms reminiscent of long COVID. In light of the billions of persons having received a vaccination, these cases are rather exceptional. The benefits of vaccination are far greater than the risks. However, research should be conducted on these cases. She regretted the total exclusion of pharmaceutical companies' responsibility. **Prof. Piot** recalled that almost all epidemiological and clinical studies on long COVID record the vaccination status of patients. From these studies, there is very strong evidence that vaccination offers some protection, albeit not 100%, against the development of long COVID, which is an additional rationale for vaccination, especially for younger people. Regarding the financial compensation for the side effects of vaccines, there are national rules, and the EMA can provide data on side effects. **Prof. Salmon** confirmed the benefits of pre-infection vaccination against long COVID. However, the effects of post-infection vaccination against long COVID are inconclusive. The rollout of vaccination in 2021 was correlated with a decrease in the number of long COVID cases.

- Remarks and questions from MEP Margarita DE LA PISA CARRIÓN (ECR)

MEP Margarita De la Pisa Carrión thanked the speakers. Long COVID clearly is a PAIS, and the diagnosis is a difficult process. What can be done to improve the understanding of factors influencing long COVID (e.g. vaccination)? The role of the spike protein produced by RNA vaccines in the incidence of long COVID is unclear. A lot of data and records with individual factors (infections with SARS-CoV-2, reinfections, vaccination or not, other treatments, etc.) is available. The question is whether speakers think more substantive in-depth research is needed to help understand exactly what is happening at cellular or molecular levels, and to have a better understanding of human immunity.

Prof. Salmon recalled that many factors influence long COVID. At the European level, meta-cohorts should be put in place, for researchers in epidemiology to share data (as was done for HIV and hepatitises). **Prof. Lehmann** highlighted that a lot of clinical data is available in a variety of countries, but the quality of the clinical data is very different across different studies. To conduct a proper comparative analysis, the quality of data must be more comparable.

- Remarks and questions from MEP Ivan Vilibor SINČIĆ (NA)

MEP Ivan Vilibor SINČIĆ asked about the methods for the **diagnostic of long COVID** in absence of biomarkers, and about the differentiation from e.g. long flu or other diseases. The second question concerned the differences of prevalence of **long COVID across Member States** and the way statistics are conducted. The last question was about the existence of data on the vaccination and treatment status of long COVID patients.

Prof. Salmon described medical practitioners' method to diagnose long COVID, i.e. referring back to the WHO definition of long COVID. There are no biomarkers already available for routine diagnosis, and PCR tests and serology are not helpful.

- Remarks and questions from Vice-Chair MEP Michèle RIVASI (Greens/EFA)

MEP Michèle RIVASI recalled that funding research on PAIS is very important, both for long COVID and for other viruses. In the **EP draft resolution**, it is highlighted that funding of research is fundamental, that European registries must be created, that patients must be recognised and that medical professionals need to be trained. MEP RIVASI subsequently compared the symptoms of long COVID with the side effects of vaccines against COVID-19 (e.g. troubles with menstrual cycles, digestive, cutaneous, cardiovascular troubles, etc.). On this basis, she raised the question as to whether the combined research on the side effects on the one hand and symptoms of long COVID on the other hand, could help understand the underlying mechanisms of the virus, in particular regarding the **spike protein**, found both in the virus and vaccine. Finally, she addressed a question to Prof Piot on which

body is responsible in Europe for **declaring and ending pandemics** (i.e. either 'pandemic' via WHO or 'public health emergency' at the EU level), and the criteria to initiate or halt the state of emergency.

Prof. Piot added that cross-border high-quality clinical trials for the development of therapeutics need to be facilitated. He believes that the possibility for the EU to declare 'epidemic emergencies' is a very good development, as an increase in epidemics is likely to happen at the regional level. The African Union has taken the same decision, with the support of the African Centre for Disease Control (ACDC). Regarding the criteria used in Europe to declare an epidemic, the long list of criteria of the WHO can be used and evaluated by a committee of experts to be established. The COVID-19 pandemic has not come to an end (still hundreds of people dying every day in Europe), but the pandemic is much less acute. The suggested committee of experts should therefore also advise on the criteria to declare the end of the pandemic, based on a consensus. Designing these mechanisms prior to a potential future pandemic is therefore essential. Regarding the training, **Prof. Salmon** highlighted the importance of awareness-raising and in-depth training of medical practitioners.

Following the second round of presentations:

- Remarks and questions from MEP Pascal ARIMONT (EPP)

MEP Pascal Arimont thanked the speakers, in particular Prof. Dr. Scheibenbogen for her presentation on ME/CFS as part of long COVID. ME/CFS is initiated by infections and patients often do not receive a correct diagnosis. The European Parliament has written a resolution on ME/CFS although relatively little has happened since. The funds dedicated by the European Commission to the research on ME/CFS under Horizon Europe are not sufficient to conduct in-depth research. There is no strategic support for the research or awareness-raising on this disease, despite the sharp increase in the number of persons concerned due to the COVID-19 pandemic. It is estimated that the number of patients affected has doubled, from two to four million during the pandemic. Long COVID patients report symptoms very similar or even identical to ME/CFS. According to MEP Arimont, who is in direct contact with patient organisations, the EU *must* unlock research funds and he will write amendments to the COVI Committee resolution to give specific attention to ME/CFS, as research on ME/CFS is also research on long COVID.

- Remarks and questions from MEP Karsten LUCKE (S&D)

MEP Lucke agreed that ME/CFS, long COVID and post-vaccination syndrome should be altogether better integrated into the COVI draft report. MEP Lucke addressed his first question to **Prof. Dr. Schieffer**: in light of the absence of biomarkers, what is the consequence and what is currently possible in concrete terms for patients? The second question was addressed to **Prof. Dr. Scheibenbogen**: could more be said about therapies for ME/CFS patients? The final question to Ms. Ann Li is what can be said about how children are affected by long COVID and what is needed for them.

Prof. Scheibenbogen stated that patients experience a very specific form of fatigue, and that ME/CFS and long COVID patients mostly get worse when they do too much. Therefore, pacing is very important, i.e. they should not over-exert. Pacing is however not a therapy; it is just disease management. Numerous drugs are already licensed, which need to be urgently tested in clinical trials. Some trials are already ongoing worldwide, but more is needed. **Prof. Schieffer** stated that research could focus on the niches in the human body which may be used as a hideaway for vaccine or SARS-CoV-2 particles. Drugs that target these niches should be tested in clinical trials. Urgent and immediate funding is necessary for translational research and clinical structures, as well as for outpatient management. Long COVID patients do not have time, as long COVID is a dynamic process. In particular, children are particularly at risk not to recover at all.

- Remarks and questions from MEP Max ORVILLE (Renew)

He reminded that initially it had been thought that COVID did not affect the youngest, however, a certain number of studies show that long COVID affects them as well. The COVID-19 pandemic has had adverse consequences on children and the lockdowns had, among others negative impacts on mental health. The addition of long COVID could have terrible consequences on their intellectual, social or physical development. According to Renew, this requires an early screening of children, via the establishment of efficient and trained prevention services in schools. It is also necessary to improve the care and to recognise long COVID as a long-duration disease.

MEP Orville addressed his question to Ms. Ann Li, as to whether the above proposals are coherent and desired. If yes, how should they be put in place?

Ms. Ann Li stated that children have the same symptoms as adults. Fewer children have long COVID than adults, because it is more prevalent in persons between 30 and 50 years old. However, children can have long COVID, and **symptoms are not less severe**. Instead of discussing whether children can have long COVID, it would be more important to find solutions for them.

- Remarks and questions from MEP Jutta PAULUS (Greens/EFA)

MEP Paulus validated the suggestion of Prof. Dr. Schieffer to establish a European-level research platform, as Europe has a large amount of data. She wondered what is required for such a platform / EU cohort study to be established (e.g. funding, coordination, EU agency in the lead).

Regarding Prof. Dr. Scheibenbogen's presentation, she raised the question as to what can be learned from the approach to multiple sclerosis, in terms of engagement from the Member States, to improve the condition and quality of life of ME/CFS patients.

She asked Ms. Ann Li what else the European Parliament could do or push for, in addition to demands formulated already, in particular with regard to social security. There have been difficulties among German citizens to have their disease acknowledged to receive social security as they are no longer able to work.

Ann Li reiterated her demand that long COVID should be recognised as an occupational disease, for disability benefits and early pension. There are persons with long COVID who are not getting any state benefit at all and are forced to go back to work although they do not have the energy or health. There should also be standardised approaches for the workplace, and HR staff should be educated about the reintegration of people with mild symptoms, as long COVID patients can relapse. The symptoms have an up-and-down pattern, and the evolution of the disease is not a linear improvement. Social security structures are needed for all patients and with special attention to house- or bed-bound patients.

Essential workers and persons living in poor conditions have been highly exposed to acute infection with SARS-CoV-2, and this could be reflected in persons affected by long COVID. It is important not to push them further into poverty.

Prof. Dr. Scheibenbogen stated that the comparison allows the following conclusion: funding is crucial, for ME/CFS and for long COVID. Specific funding must be directed to these diseases, and not to neurological diseases in general.

Prof. Dr. Schieffer remarked that biomarkers are important, particularly when looking at post-vaccine and post-infection long COVID. Clustering these patients is important: certain age groups within the population respond differently to virus or spike protein stimuli.

- Remarks and questions from MEP Virginie JORON (ID)

MEP JORON addressed her question to Prof. Dr. Schieffer. She believes that post-vaccination long COVID symptoms should be investigated more closely. What are the symptoms and severity of post-vaccination long COVID, on the 350 patients reported by Prof. Dr. Schieffer? She also suggested to also take into consideration data from outside the European Union, e.g. from Nigeria, where MEP JORON met Prof. Babalola and asked about the cases of COVID and long COVID.

Closing remarks

Vice-Chair MEP Michèle Rivasi closed the workshop by thanking all the speakers for the very interesting discussions. She hoped to see a lot of suggestions raised during the workshop in the final report of the Special Committee on the COVID-19 pandemic and clearly stated the following points:

- Long COVID does exist.
- Training is needed for all medical professionals.
- Funding for research and clinical trials is essential.

SHORT BIOGRAPHIES OF THE SPEAKERS

Prof. Dr. Peter Piot

Professor London School of Hygiene & Tropical Medicine, Commission's advisory panel on COVID-19

Prof. Dr. Peter Piot MD PhD is the Handa Professor of Global Health and former Director of the London School of Hygiene & Tropical Medicine. He is Special Advisor on COVID-19 to the President of the European Commission, and EU Chief Scientific Advisor Epidemics, as well as visiting professor at the Rega Institute, KU Leuven, the University of Antwerp, and the National University of Singapore.

He was the founding Executive Director of UNAIDS and Under-Secretary-General of the United Nations. He co-discovered the Ebola virus in 1976 and led pioneering research on HIV, women's health and infectious diseases. He trained at the University of Ghent (MD) and the Institute of Tropical Medicine/University of Antwerp (PhD) and has held positions at the Institute of Tropical Medicine, Antwerp; the University of Washington, Seattle; the University of Nairobi; Imperial College London; the College de France, Paris, and the Gates Foundation.

He is a member of the Belgian, American, British, and French National Academies of Medicine, and the German National Academy of Sciences Leopoldina. He is Chair of the Scientific Committee of the Institut Pasteur de Dakar, Vice-Chair of GHIT Fund, Tokyo, and was a founding Board Member of CEPI, as well as of the Global Fund to fight AIDS, TB, Malaria. In 1995 he was made a Baron in his native Belgium, and in 2016 received a UK Knighthood. His awards include the Canada Gairdner Global Health Award, Robert Koch Gold Medal, Prince Mahidol Award, Hideyo Noguchi Africa Prize, and Nelson Mandela Award for Health and Human Rights. He was a 2014 TIME Person of the Year. He has published over 600 scientific articles and 16 books, including his memoir, No Time to Lose, available in 5 languages.

Prof. Dr. Dominique Salmon

Professor of Infectious Diseases at Paris Descartes University Paris, President of the Working Group on long COVID at the French National Health Authority

Prof. Dr. Dominique Salmon is currently Professor of Infectious and Tropical Diseases at Paris Descartes University in Paris and was until September 2022 a Hospital Practitioner in Infectious Diseases and Immunology Department of COCHIN HOTEL DIEU Hospital in Paris. Her clinical sub-specialties are HIV/AIDS, viral hepatitis, bone and joint infections and antimicrobial stewardship and since 2020 COVID, especially long COVID. She coordinates an out-patient management platform for the patients with prolonged manifestations of COVID (long COVID). She is also involved in partnership with research units at Pasteur Institute or at INSERM in the clinical studies on the pathophysiology of long COVID.

She works as an expert for the French National Authority for Health for the national recommendations of care for long COVID patients. She is the principal investigator of the national prospective French cohort of patients coinfected with HIV and hepatitis C (ANRS CO13 HEPAVIH Cohort) for the French Agency for research on emerging infectious diseases (ANRS | Maladies infectieuses émergentes). Her teaching activities include teaching at the medical faculty of the Paris Descartes University, in Infectious and Tropical Medicine. She is supervising Master and PhD students.

Prof. Dr. Clara Lehmann

Professor and Senior Physician, University of Cologne

Prof. Dr. Clara Lehmann is a Senior Physician and is the Head of the Infection Control Center of the University of Cologne, Faculty of Medicine and University Hospital Cologne, Department of Internal Medicine. In addition, she is Medical Head of the Vaccination Center of the University Hospital of Cologne since 2021. She is a graduate of a Medical school at the University of Cologne, Germany and the University of Paris V, France. During her professional career primarily focused on infectious diseases, she has been granted several awards, including a research award in 2014 from the German Society of Infectious Diseases.

Her research focuses on infectious diseases, vaccines, HIV and sexually transmitted diseases, and long COVID. She is part of the Scientific Advisory Board of the German Medical Association "Long Covid Syndrome" since 2022, which she co-founded.

Prof. Dr. Bernhard Schieffer

Professor and Senior Physician, Gießen/Marburg University Hospital

Prof. Dr. Schieffer is an interventional cardiologist, Director of the Clinic for Cardiology, Angiology and Internal Intensive Care Medicine at the University Hospital Gießen/Marburg (UKGM). His work focuses on the causes and consequences of long COVID symptoms, after SARS-COV-2 infections and post-vaccination, a symptomatology similar to long COVID. Prof. Dr. Schieffer heads an interdisciplinary post-COVID outpatient clinic at the University Hospital Gießen/Marburg.

Prof. Dr. Carmen Scheibenbogen

Acting Director of the Institute of Medical Immunology, Charité University Hospital Berlin, Germany

Prof. Dr. Carmen Scheibenbogen is an Internal Medicine physician and hemato-oncologist, ME/CFS doctor, Professor for Immunology and Acting Director of the Institute of Medical Immunology at *Charité Universitätsmedizin* in Berlin, Germany. She is co-founder of the COST-funded European network for ME/CFS EUROMENE, the Charité Fatigue Centre, and the Post COVID Network Charité.

Her research focuses on chronic fatigue syndrome (ME/CFS), Post Covid Syndrome, immune monitoring, immunodeficiencies, and immunotherapy and she has published more than 200 peer-reviewed papers. Since 2020 she has received funding from the German Government for the joint research project IMMME (immune mechanisms of ME/CFS), for a German "ME/CFS patient registry and biobank", for the interdisciplinary and intersectoral care study CFS CARE and the National Clinical Study Group, a clinical trial platform for ME/CFS and Post Covid.

Ann Li
Chair of Long COVID Europe

Ann Li coordinates projects on chronic diseases in primary care. In her healthcare region in Belgium, she was one of the people who coordinated the primary care reform of 2016. She has been working on integrated care and innovative ways of multidisciplinary collaboration in primary care. Since 2020 she has been a freelance editor of the scientific magazine for the Flemish professional association of general practitioners and since August 2022 has been working on the implementation of primary care psychologists in Flanders.

In 2020, Ms. Li founded the Flemish Long COVID patients' association. She is part of the Belgian consortium drafting the guidelines for managing long COVID in primary care, and member of the working group designing the Belgian care pathway for people with long COVID. Ms. Li is the patient representative in a couple of scientific research groups. She has been the chair since the foundation of Long COVID Europe in the summer of 2021.

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 organisations were struggling with the same issues. LCE creates economies of scale by sharing relevant resources, know-how, and contacts with its members.

WORKSHOP SLIDES:

1. Long COVID: an emerging global challenge, by Prof Peter Piot (London School of Hygiene and Tropical Medicine, European Commission's Advisory Panel on COVID-19)

2. Long COVID - Epidemiology, clinical profile and outcome, by Prof Dominique Salmon (Paris Cité University, Working Group on Long COVID French National Health Authority)

3. Long COVID - Potential underlying mechanisms, diagnostics and treatment, by Prof Clara Lehmann (German Center for Infection Research, University of Cologne)

4. Post COVID, by Prof Dr Schieffer (University Clinic Gießen/Marburg, Philips University Marburg)

5. Myalgic encephalomyelitis / Chronic fatigue syndrome (ME/CFS) as part of Long COVID, by Prof Dr Scheibenbogen (Charité University Hospital Berlin)

6. Long COVID patients – Assessment of current situation and needs, by Ann Li (Long COVID Europe)

DEDICATED WEBPAGE:

Special Committee on the COVID-19 pandemic – Workshop on Long COVID:

https://www.europarl.europa.eu/committees/en/long-covid/product-details/20230201WKS04921

These proceedings summarise the presentations and discussions of the workshop on 'long COVID' organised for the European Parliament's Special Committee on the COVID-19 pandemic on 9 March 2023. The six presentations touched, inter alia, upon the current state of knowledge on the disease's clinical profile, potential causes and underlying mechanisms, impacts on patients and society, and lessons to be learned from post-acute infection syndromes and chronic diseases. The speakers and Members could discuss the urgent actions and financial support needed from the EU to close gaps in scientific knowledge, to raise awareness on long COVID, and to develop treatments which could improve patients' condition.

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