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## "Long Covid" and access to the right to health

Report<sup>1</sup> Committee on Social Affairs, Health and Sustainable Development Rapporteur: Ms Carmen Leyte, Spain, EPP/CD

Summary

The report highlights the socio-economic impact of "long Covid", a chronic disease that persists for at least three months after infection with covid-19. Characterised by a variety of symptoms, such as chronic fatigue, brain fog and neurological disorders, this condition affects millions of people worldwide and in Europe, and compromises the quality of life and professional abilities of those who suffer from it.

To date, its definition remains unclear and access to healthcare is limited. Patients, often faced with inadequate care and stigma, struggle to obtain an accurate diagnosis and appropriate treatment.

Encouraging States to adopt a human rights-based approach in the fight against "long Covid", the Parliamentary Assembly calls for coordinated public policies, sufficient funding for biomedical research to establish a definition and effective treatment, and recognition of "long Covid" as a disability. Raising public awareness, training healthcare professionals, and setting up transdisciplinary centres are essential to meet the medical, social and economic needs of those affected and to guarantee their fundamental rights.

<sup>&</sup>lt;sup>1</sup> Reference to committee: <u>Doc 15416</u>, Ref. 4623 of 24 January 2022

### A. Draft resolution<sup>2</sup>

1. The Parliamentary Assembly notes that "long Covid", characterised by the continuation of symptoms or the appearance of new symptoms three months after the initial infection with SARS-CoV-2 (which caused the Covid-19 pandemic) and the persistence of these symptoms for at least two months without any other explanation, affects a large and growing number of people throughout Europe and the world, and has considerable impacts on public health, the economy and the quality of life of those affected.

2. This disease, which manifests itself through a variety of symptoms such as chronic fatigue, neurological disorders and other physical and mental complications, can in some cases be comparable to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). It causes major physical and mental challenges, affects social and professional relationships, and leads to increased psychological distress. Patients are often confronted with a limited understanding of their condition by the medical community and those around them, making their experience even more difficult.

3. The Assembly expresses its concern about the socio-economic impact of this disease which can be massively disabling for millions of people and manifests itself with visible or invisible disabilities. With policymakers and the healthcare sector focused initially on containing, and then preventing a recurrence of the Covid-19 pandemic and today with other new health issues emerging, the millions of patients suffering from "long Covid" have become a huge blind spot.

4. The Assembly is disappointed that, to date, there is no single, consensual definition of "long Covid", although most countries broadly adhere to international guidelines. A clearer and more disaggregated definition of "long Covid" could help to improve clinical management and better target policies.

5. The Assembly also regrets that no solution as yet has been identified to ensure patients' recovery and cure, as research is still in its infancy to understand the causes and consequences of the disease.

6. The Assembly is concerned about the limited access to healthcare for people with "long Covid", resulting from insufficient investment in biomedical research and weakened healthcare systems. It points out that Article 11 of the <u>European Social Charter</u> (<u>ETS No. 35</u> and <u>revised ETS No. 163</u>) enshrines the right to health protection.

7. The Assembly recalls its <u>Resolution 2373 (2021)</u> "Discrimination against persons dealing with chronic and long-term illnesses" in which it urges member States "to strengthen capacities for screening and prevention with respect to chronic and long-term illnesses and to adopt a holistic approach, which is regularly reviewed and adjusted and involves all sectors of the administration to promote the well-being of individuals, fight against inequalities and take vulnerabilities into consideration. The authorities must fight against diagnostic delays so that, after a certain period, which should not be longer than one year, each patient is able to exercise their rights again without hindrance".

8. Recognising the need to adopt a human rights-based approach in the fight against "long Covid", the Assembly calls on member States to:

8.1. ensure sufficient funding for biomedical research so that a common definition and terminology are established, and effective treatments are available to ensure an adapted, safe and sustained recovery that reduces long-term disability;

8.2. adopt public policies coordinated at national level and defined in collaboration with people suffering from "long Covid" to meet their medical, social and professional needs;

8.3. set up transdisciplinary centres of expertise for diagnosis, treatment and prevention in order to facilitate access to care for people suffering from "long Covid";

8.4. work with the health sector to disseminate information and specific training for medical staff on "long Covid";

8.5. to run, in partnership with civil society, awareness-raising campaigns on "long Covid" aimed at the general public, aiming to ensure understanding which will in turn protect the possibility for those

<sup>&</sup>lt;sup>2</sup> Draft resolution adopted unanimously by the Committee on 6 December 2024

affected by this disease to enjoy as normal a life as they can, free from stigmatisation and with their rights and freedoms fully respected and facilitated;

8.6. to recognise that "long Covid" should fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in order to allow access to social security, disability benefits and compensatory aids;

8.7. to ensure equitable access to healthcare for people suffering from "long Covid", in particular children and young people, and for the States Parties to the Convention on Human Rights and Biomedicine (ETS No 164, Oviedo Convention) to take the necessary measures to give effect to the provisions of Article 3;

8.8. promote flexible policies for patients with "long Covid", both in the workplace and in educational establishments, to ensure that the patients concerned are able to continue their work and education under appropriate conditions;

8.9. encourage international cooperation in the fight against this disease.

9. Finally, the Assembly also reiterates its strong encouragement to those Council of Europe member States which have not yet ratified the revised European Social Charter to do so as soon as possible.

Doc. ...

#### Β. Explanatory memorandum by Ms Carmen Leyte, rapporteur

#### 1. Introduction

1. The Covid-19 pandemic has as of today so far caused the deaths of around 7 million people<sup>3</sup> and has had unprecedented human and financial costs. While for many, Covid-19 is nothing more than a bad memory, for at least 22 million people in Europe, it remains a daily nightmare. Ever since they were infected with SARS-CoV2, they have been suffering from debilitating symptoms that doctors are largely powerless to deal with. These people are suffering from "long Covid", a chronic disease whose causes are undeniably biological, but whose definition is still vague and whose mechanisms are not well understood. The lives of these chronically ill people are destroyed: it affects their family and social lives, often they are no longer able to work, and their access to adequate support can be limited due to a lack of recognition of the disease.

As far back as 2022, the Director-General of the World Health Organisation (WHO), Dr Tedros 2. Adhanom Ghebreyesus, warned of the devastating effects of "long Covid" on the lives and livelihoods of tens of millions of people<sup>4</sup>. In 2023, the WHO's Regional Director for Europe, Dr Hans Henri P Kluge, released a public statement in which he said that ""long Covid" remains a glaring blind spot in our knowledge, that urgently needs to be filled". Unfortunately, even today, the definition of "long Covid" is not clear, and those affected suffer and remain helpless.

On 9 September 2021, the Committee on Social Affairs, Health and Sustainable Development held a 3. public hearing in a hybrid manner with the participation of two former French members of the Committee, Ms Martine Wonner (ALDE) and Ms Laurence Trastour-Isnart (EPP/CD); Mr Risto O. Roine, Professor of Neurology, Turku University Hospital & Chair of the Board, Finnish Brain Council, and Mr Daniel Altmann, Professor of Immunology, Imperial College London. The minutes of the hearing were declassified.<sup>5</sup>

On 2 December 2021, a motion for a resolution on ""Long Covid" and access to the right to health" 4. was tabled by my former colleague Ms Trastour-Isnart with the support of several members of our Assembly.<sup>6</sup> It was referred to the Committee on Social Affairs, Health and Sustainable Development for report and Ms Romilda Zarb (SOC), was appointed rapporteur in December 2022. I took over her work on 25 March 2024.

This report takes stock of advances in research and the existing needs of patients. It is based on 5. research and expert hearings held in Lisbon in September 2024: Mr Juan Soriano, Epidemiologist, Department of Pneumology, Hospital Universitario de la Princesa - UAM, Madrid and Ms Chantal Britt, Long Covid Europe (European network of patient organisations affected by "long Covid"). The minutes of these hearings should be declassified at the committee's next meeting on 6 December 2024.

#### 2. What is "long Covid"? - the definition remains unclear

On 7 December 2022, the WHO adopted the following definition of "long Covid": the continuation or 6. development of new symptoms three months after the initial Sars-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation.

In its factsheet<sup>7</sup>, WHO provides a more comprehensive definition of the syndrome. According to this 7. definition, Post Covid-19 condition occurs in individuals with a history of probable or confirmed Sars-CoV-2 infection, usually 3 months from the onset of Covid-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction, but also others, which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute Covid-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. WHO also points out that a separate definition may be more relevant to children. Beside post Covid-19 condition, other terms are also used, such as "long Covid", chronic Covid-19 syndrome and post-acute sequelae of Covid-19, however, there are differences.

8. The clinical picture of "long Covid" is still vague. It has nevertheless been recognised in the US, Europe and other countries as a chronic disease. It is often debilitating, with characteristics common to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (CFS/ME). It often results in depression and fatigue, in addition to more than 200 other identified symptoms.8

 <sup>&</sup>lt;sup>3</sup> The Guardian, 12 October 2022, <u>The data is clear: long Covid is devastating people's lives and livelihoods</u>.
<sup>4</sup> The Guardian, 12 October 2022, <u>The data is clear: long Covid is devastating people's lives and livelihoods</u>.

<sup>&</sup>lt;sup>5</sup> Public hearing on long, held, hybrid covid, Thursday 9 September 2021, <u>AS/Soc (2021) PV 08 add.</u>

<sup>&</sup>lt;sup>6</sup> Doc 15416.

<sup>&</sup>lt;sup>7</sup> WHO Factsheet on Post Covid-19 condition.

<sup>&</sup>lt;sup>8</sup> The Guardian, 27 April 2021, "Long Covid is very far from 'all in the mind' - but psychology can still help us treat it".

9 The British newspaper The Guardian has published a series of articles dedicated to "long Covid". In the England and Scotland alone, about 2 million people are reported to be experiencing "long Covid".9 The illness remained largely unrecognised at the beginning because of the multiplicity of its symptoms. Even if some symptoms can be spotted with MRI scans, there is for the time-being no test for "long Covid". It is a "catch-all term" used to describe the condition of people recovering from the coronavirus. Researchers have been able to empirically list some observations: older people appear to have a slightly higher risk; people who were hospitalised with Covid-19 are probably more at risk to develop the syndrome; women are more exposed; being vaccinated and/or treated (e.g., with the antiviral medication Paxlovid) may reduce risks. They have also discovered that patients suffering from certain comorbidities are more likely to experience "long Covid" than others: for the following reasons among others, presence of RNA viruses; type 2 diabetes; Epstein-Barr virus; autoantibodies<sup>10</sup> and hypermobility.<sup>11</sup> Though some Australian researchers have recently suggested that the term "long Covid" should be "retired", as it might lead to hypervigilance, other experts have pointed out that it is still important to bring awareness to the situation considering the large number of people affected.<sup>12 13</sup>

According to CovidTracker<sup>14</sup> almost 700 million people have contracted Covid-19 and approximately 10. 7 million individuals have died (though these are just the official figures of reported deaths; unofficial estimates stand at over 20 million deaths so far). WHO has assessed that 10% to 20% of the survivors have been left with long-term symptoms. In addition, it cannot be excluded that some initially asymptomatic patients are experiencing symptoms of "long Covid" after an infection.

Mr Juan Soriano, who has been working on the definition of "long Covid" within a WHO working group, 11. presented the results of his work to the Commission. Taking the example of HIV, for which research has taken several decades, he reminded us how much time and resources research needs to define the contours of a disease in order to establish an effective treatment.

12. To this day, the definition of "long Covid" remains unclear. There is still no threshold or biomarker to define what we mean by this disease. Despite thousands of academic articles on the subject, many clinicians still do not know how to assess and manage people suffering from a post-Covid-19 state. The lack of consensus on a definition and even a name (for example, in France the Haute Autorité de Santé (HAS) uses the term "prolonged symptoms following Covid-19") partly reflects the confusion about the underlying pathological processes and the natural history of the disease.

#### 3. Understanding the effects of the "long Covid" - Various symptoms leading to isolation

More than 200 distinct symptoms have been reported by sufferers of "long Covid". Many aspects of 13 patients' daily lives are affected, with physical, mental and social repercussions. It appears that 60% of sufferers experience not only fatigue, but also "brain fog", an inability to multi-task, anxiety and depression, while 35% report shortness of breath<sup>15</sup>. This chronic fatigue often limits the ability to carry out simple tasks, necessitates frequent breaks and therefore affects productivity. In addition, sufferers have reduced physical capacity, making it difficult to exercise or even travel on a daily basis. Cognitive problems affect memory, concentration and the ability to process information, making it difficult to perform intellectual work or tasks requiring prolonged attention. Lastly, a symptom common to patients suffering from "long Covid" is disruption of the immune system. It has been confirmed that the coronavirus can persist in tissues at the level of genetic material after infection, so it can trigger a chain of symptoms throughout the body.

These physical and mental limitations often lead to social isolation, as patients can no longer take part 14. in the usual social activities or work, which increases feelings of loneliness and frustration. The result is often a deterioration in mental health. Patients often suffer from anxiety, depression and post-traumatic stress, due to the uncertainty surrounding their recovery and the loss of their former quality of life.

15. "Long Covid" is a disease that profoundly affects the quality of life of sufferers. It imposes major physical and mental challenges, impacts on social and professional relationships, and leads to increased

<sup>&</sup>lt;sup>9</sup> The Guardian, 25 April 2024, <u>"About 2m people have long Covid in England and Scotland, figures show"</u>.

<sup>&</sup>lt;sup>10</sup> The Guardian, 12 October 2022, "The astounding impact and reach of long Covid, in numbers and charts".

<sup>&</sup>lt;sup>11</sup> The Guardian, 19 March 2024, "People with hypermobility may be more prone to long Covid, study suggests".

<sup>&</sup>lt;sup>12</sup> The Guardian, 15 March 2024, "Time to stop using term 'long Covid' as symptoms no worse than those after flu, Queensland's chief health officer says". <sup>13</sup> The Guardian, 23 March 2024, <u>"long Covid may be nothing unique in the future – but its effects today are still very</u>

real".

<sup>&</sup>lt;sup>14</sup> https://Covidtracker.fr.

<sup>&</sup>lt;sup>15</sup> The Irish Examiner, 21 October 2022, "Life with long Covid: 'I'm not the person I was'".

psychological distress. Faced with these symptoms, and in the absence of recognition, patients often find that the medical community and those around them have little understanding of their condition, which makes their experience even more difficult.

16. During the public hearing before the Committee, Ms Britt, Long Covid Europe (European Network of Organisations of Patients Affected by Long Covid), who herself suffers from "long Covid", emphasised the extent to which patients are powerless and desperate in the face of the non-recognition of the disease from which they suffer and the medical uncertainty with which they are faced. "A large proportion of healthcare staff do not have sufficient skills or knowledge when it comes to "long Covid". Very often, diagnoses are wrong and prescriptions are therefore also erroneous, resulting in ineffective treatments that only make symptoms worse. This neglect has an impact on patients' lives (loss of work, inability to go to school, social isolation, lack of perspective)". She pointed out that only 1% of doctors treat long-standing Covid, and that in the absence of transdisciplinary centres of expertise to establish a correct diagnosis, patients are passed from one specialist to another without any cure.

17. For the time being, there is no solution to ensure the recovery and cure of patients, as research is still in its infancy to understand the causes and consequences of "long Covid". There is not enough data available to know whether the symptoms encountered will be permanent or not, as the national authorities have only collected data over four years. It could be that there will be waves of people becoming disabled - with a visible disability or not. The "long Covid" could be an "event with massive disabling consequences" that will require strong political responses.

# 4. Limited access to healthcare - *insufficient investment in scientific research and weakened healthcare systems*

18. In 2021, the NIH, the US National Institutes of Health, has decided to invest 1 billion dollars to study long-standing Covid and its mechanisms. The US National Institutes of Health then launched the RECOVER initiative<sup>16</sup>, the aim of which is to gain a better understanding of the disease and improve the recovery of patients suffering from it. The European Union has committed 50 million euros and EuCare<sup>17</sup> has been set up, although it does not yet cover all its Member States.

19. A research project carried out in Hong Kong has demonstrated the role of vaccination in protecting against "long Covid". Vaccination against Covid-19 proved to be "effective in reducing the risk of health consequences<sup>18</sup>.

20. WHO is committed to learning more about the impact of "long Covid" and exploring means to improve the lives of persons affected by the syndrome in the short, medium and long-term. In September 2022, WHO/Europe partnered with the NGO *Long Covid Europe* to develop 3 goals – the 3 Rs<sup>19</sup>: Recognition, Research and Rehabilitation. They called upon governments and health authorities to focus attention on post "long Covid" and those affected by it through greater: 1. recognition and knowledge sharing, where all services are adequately equipped, and no patient is left alone or having to struggle to navigate a system that is not prepared, or not capable of, recognising this debilitating condition; 2. research and reporting through data gathering and reporting of cases, and well-co-ordinated research, with full participation of patients needed to advance understanding of the prevalence, causes and costs of "long Covid"; and 3. rehabilitation which is based on evidence and effectiveness, and is safe for both patients and carers.

21. Epidemiological studies have shown that certain demographic groups (such as women aged between 35 and 50 or socio-economically disadvantaged people), people suffering from particular pathologies (such as asthma, chronic lung disease, heart failure or chronic kidney disease), people who have suffered from a more serious acute illness, people with a high BMI and unvaccinated people are at greater risk than others of suffering from "long Covid" and are more likely to present serious symptoms. Particular attention must therefore be paid to vulnerable people, especially children.

22. Indeed, although children and young people were initially less affected by Sars-CoV-2, an analysis of medical records revealed that children under the age of five, suffering from certain pathologies, as well as

<sup>&</sup>lt;sup>16</sup> RECOVER Covid" initiative <u>https://recovercovid.org/</u>

<sup>&</sup>lt;sup>17</sup> HOME - EuCARE (eucareresearch.eu).

<sup>&</sup>lt;sup>18</sup> *Nature*, 26 February 2024, <u>"Persistence in risk and effect of Covid-19 vaccination on long-term health consequences after Sars-CoV-2 infection".</u>

<sup>&</sup>lt;sup>19</sup> WHO, Increasing Recognition, Research and Rehabilitation for Post Covid-19 Condition (long Covid).

those who had had a serious infection, were at risk of suffering from "long Covid"<sup>20</sup>. Although it appears that the prevalence of the post-Covid-19 condition is lower than in adults,<sup>21</sup> for the time being, there is insufficient information to demonstrate that "long Covid" cannot have permanent effects on children. Some children have not recovered after more than two years. The increase in cases of Paediatric Inflammatory Multi-Systemic Syndrome (PIMS)<sup>22</sup> in children is also linked to Sars-CoV-2 infection. Some children have been unable to return to school for the past two years due to extreme fatigue or "brain fog".23

23. Numerous studies have shown that women are more likely to develop prolonged symptoms after infection with Covid-19, and these symptoms can persist for several months. Women are therefore disproportionately affected by "long Covid" and this is combined with the frequent minimisation of their symptoms when declaring "long Covid". Women have frequently faced scepticism from the medical profession, a phenomenon which is sometimes referred to as "medical misogyny" and is unfortunately not new. The surge of "long Covid" could be an opportunity to explore the gender-parsed consequences of previous pandemics such as Polio, Ebola, Sars and also to fill gaps in the research about conditions that affect only women such as endometriosis.24

Generally, the effects on vulnerable people are difficult to measure, not least because of the lack of 24. statistics. Socioeconomic factors play a role, as this category of the population does not have the same access to healthcare as others. For this reason, it is necessary to review the action taken by the public authorities, to ensure that no one is left behind and that an appropriate attention and response is given to all individuals and groups of sufferers.

25. Research into "long Covid" is progressing, but still faces major challenges, particularly in terms of diagnosis and specific treatments. The accumulation of long-term data and progress in understanding the mechanisms of this disease should make it possible to gradually meet patients' needs.

In addition to the lack of effective treatment, access to healthcare remains a problem, as health 26. systems have been so weakened. The negative impact of the pandemic on healthcare systems has been dramatic, and they have not yet fully recovered. They do not therefore always have sufficient capacity to address "long Covid" after having been so severely affected by the different waves of variants. Existing healthcare systems are not yet sufficiently equipped to follow the trajectory of "long Covid" over time.

27. To date, not all countries have centres specialising in "long Covid" with transdisciplinary skills that provide patients with a one-stop shop. Only 22 OECD countries have set up such specialist clinics. However, as demand exceeds supply, waiting times are long and not all patients have access to them.

#### 5. Adopting a human rights-based approach in the fight against "long Covid"

The Sars-CoV-2 infection and the "long Covid" phenomenon represent an unprecedented challenge 28. for national authorities in protecting human rights in a health crisis - a challenge that requires continuous, rapid and coordinated action. Despite the progress that has been made, there are still many challenges that need to be tackled, always from the point of view of a human rights-based approach.

To begin with, it seems vital that access to care should be guaranteed, and to achieve this, the disease 29. must be recognised. This requires a common definition and appropriate treatments, as well as awarenessraising campaigns to ensure that as many people as possible are informed about the disease and to reduce stigma. Multidisciplinary centres should be set up in all Member States, with sufficient capacity to monitor patients.

Furthermore, given that "long Covid" could have disabling consequences, it should be recognised as 30. a disability. In this respect, it is necessary to continually keep under consideration and modernise the way in which society views people with disabilities, and in particular people with "invisible" disabilities. In this context, I would like to recall the 2021 report of my former colleague, Ms Wonner, on "Discrimination against persons dealing with chronic and long-term illnesses". <sup>25</sup> I believe that "long Covid" should fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and involve obligations on the

<sup>22</sup> Evelina Hospital London, Paediatric multisystem inflammatory syndrome.

<sup>&</sup>lt;sup>20</sup> JAMA Network, 22 August 2022, "Clinical Features and Burden of Post-acute Seguelae of Sars-CoV-2 Infection in Children and Adolescents". <sup>21</sup> New York Times, 07 February 2024, <u>"New Report Raises Concerns About Long Covid in Children".</u>

<sup>&</sup>lt;sup>23</sup> ApresJ20 (patient association in France), paediatric long Covid (french only).

<sup>&</sup>lt;sup>24</sup> The Guardian, 18 October 2022, "They can't ignore us any more': five women on long Covid and medical misogyny".

<sup>&</sup>lt;sup>25</sup> Resolution 2373 (2021) adopted on 21 April 2021.

part of the States parties to this convention. On this point, I recall the Convention on Human Rights and Biomedicine (ETS No 164, Oviedo Convention) and the principle of equitable access to health care (article 3).

31. "Long Covid" may drastically reduce people's ability to work. Socioeconomic rights are at stake, and it is necessary to acknowledge that a large number of persons are still suffering from the effects of Covid with an on-going effect on their socioeconomic status and rights. In his Op-ed for The Guardian,<sup>26</sup> Greg Frey recalled the weight of stress, anxiety and depression even before the pandemic, and called for an opening a debate on the four-day workweek, in part to take into consideration the condition of the people suffering from "long Covid". This could be one approach to ensuring that people suffering from "long Covid" can continue to work according to an adapted working hours schedule.

32. Over and above the medical costs, "long Covid" has a significant cost. Even excluding the direct costs of health care, "long Covid" is likely costing OECD countries as much as \$864 billion -\$1.04 trillion USD per year due to reductions in quality of life and labour force participation<sup>27</sup>, or around 1% of their GDP. "Long Covid" may be reducing the workforce by nearly 3 million workers across OECD countries, amounting to an economic cost of at least \$141 billion USD from lost wages alone. Governments therefore need to invest in research now to reduce these long-term economic effects.

33. Investment in research is still insufficient. The US has already invested \$1.5 billion in public funds since 2021 for research, and an additional investment of \$515 million was recently announced.<sup>28</sup> But European countries are lagging behind, particularly the UK and France, which have invested £50 million<sup>29</sup> and only €25 million<sup>30</sup>, respectively in this area.

Europe should play its role in combatting "long Covid" and consider the threat seriously. Civil society 34. continues to call on the European Commission to release €500 million to fill the research gap on "long Covid".<sup>31</sup> In September 2024, the European Commission launched a €2 million project to combat "long Covid" (EU4Health), which is managed by the World Health Organisation (WHO) and the Organisation for Economic Cooperation and Development (OECD). Health Commissioner Stella Kyriakides acknowledged that "Our understanding of "long Covid" is now far greater - and yet we still need to better understand its complexity and how to treat it effectively".

35. Patients are uniting everywhere in the world physically and on social networks to give voice to their concerns about their lives with "long Covid". Long Covid kids<sup>32</sup> has developed many tools to raise awareness on the condition of children and help parents to find answers. Long Covid Europe brings together patient associations fighting similar problems. Survivors have set up support groups<sup>33</sup> to defend their rights. The number of people living with the syndrome is significant and continues to grow. These people must not be forgotten. As an organisation playing a leading role in defending human rights on the European continent, the Council of Europe has a duty to keep the issue on the agenda of the authorities, to support initiatives on our continent to help sufferers and make their voices heard, to restore their confidence in the system, and raise awareness amongst the population of this continuing effect on many citizens of the pandemic which hit our societies a few short years ago.

36. It is up to public authorities to coordinate their efforts at European and international level to provide a comprehensive response aimed at developing effective treatments, rehabilitating patients and protecting their rights including the right to health, and their full participation. The human rights-based approach promoted by the Council of Europe should be the starting perspective in preparing the response of national authorities. The latter should set aside the necessary resources to devise and provide guidance to all relevant stakeholders on the best policy responses, taking due account of the complexity of "long Covid" and in full consultation with those who are experiencing.

<sup>&</sup>lt;sup>26</sup> The Guardian, 29 July 2023, "Could Long Covid lead to the rise of a four-day workweek?".

<sup>&</sup>lt;sup>27</sup> Espinosa Gonzalez, A. and E. Suzuki (2024), "The impacts of long Covid across OECD countries", OECD Health Working Papers, No. 167, OECD Publishing, Paris, https://doi.org/10.1787/8bd08383-en

<sup>&</sup>lt;sup>28</sup> National Institutes of Health, 13 February 2024, "NIH to bolster RECOVER long Covid research efforts through infusion of \$515 million".

 <sup>&</sup>lt;sup>29</sup> Claire Duddy, House of Commons Library, 29 February 2024, <u>"Coronavirus: long Covid".</u>
<sup>30</sup> European Investment Bank, 07 March 2023, <u>"France: EIB and GeNeuro sign €25 million credit line backed by InvestEU</u> to support clinical development of treatments for long Covid".

<sup>&</sup>lt;sup>31</sup> EU Commission, 13 December 2022, Online EU-US conference on Long Covid.

<sup>&</sup>lt;sup>32</sup> Long Covid Kids Charity.

<sup>&</sup>lt;sup>33</sup> India Covid Survivors (Twitter), Beth - LongCovidLife (TikTok), Covid Survivor Indonesia (Instagram).