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RESEARCH ARTICLE

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Towards consensus: The need for standardised definitions in Long (post) COVID care in 34 European countries

Raquel Gomez-Bravo[a,b*], Sandra León-Herrera[c*], Marina Guisado-Clavero[d], Ileana Gefaell[e,f], Xenia Wostmann[g], Nathalie Wössner[h], Shlomo Vinker[i], Francesca Vassallo La Ferla[j], Erva Kırkoç Üçüncü[k], Georgi Tsigarovski[l], Péter Torzsa[m], Kadri Suija[n,o], Aleksander Stepanović[p], Theresa Sentker[q], Anna Segernäs[r], Bohumil Seifert[s], Marta Sánchez-Castro[t], Jochen G. Schneider[t], Anna Repovská[g], Ferdinando Petrazzuoli[u], Davorina Petek[p], Abel Perjes[m], Naldy Parodi López[v,w], Ana Luisa Neves[x,y], Katarzyna Nessler[z], Jean Muris[aa], Achim Mortsiefer[bb], Sarah Moreels[cc], Tatjana Meister[m], Pekka Mäntyselkä[o], Liubovė Murauskienė[dd], Heidrun Lingner[q], Anna Krztoń-Królewiecka[ee], Milena Kostic[ff], Büsra Çimen Korkmaz[gg], Snezana Knezevic[hh], Stylianos Kazakos[ii], Vasilis Karathanos[jj,kk], Ivanna Shushman[ll], Oksana Ilkov[mm], Kathryn Hoffmann[nn], Bruno Heleno[oo,pp], Miroslav Hanževački[qq,rr], Dragan Gjorgjievski[ss], Thomas Frese[tt], Marta Fournier[uu,vv], Louise Fitzgerald[ww,xx], Sabīne Feldmane[yy], Marina Dotsenko[zz], Philip-Richard Domeyer[aaa], Daniel Croucher[bbb], Vojtech Cerny[ccc], Jako S. Burgers[ddd], Elena Brutskaya-Stempkovskaya[eee], Carmen Iliana Busneag[fff,ggg], Nicola Buono[hhh], Sherihane Bensemmane[cc], Sabine Bayen[iii], Maria Bakola[jjj], Radost Assenova[l], Limor Adler[i], Sara Ares-Blanco[kkk,lll*] and María Pilar Astier Peña[mmm,nnn*]

[a]CHNP, Rehaklinik, Ettelbruck, Luxembourg; [b]Research Group Self-Regulation and Health, Institute for Health and Behaviour, Department of Behavioural and Cognitive Sciences, Faculty of Humanities, Education, and Social Sciences, Luxembourg University, Esch-sur-Alzette, Luxembourg; [c]Department of Psychology and Sociology, University of Zaragoza, Zaragoza, Spain; [d]Investigation Support Multidisciplinary Unit for Primary care and Community North Area of Madrid, Gerencia Asistencial de Atención Primaria, Servicio Madrileño de Salud, Madrid, Spain; [e]Federica Montseny Health Centre, Gerencia Asistencial de Atención Primaria, Servicio Madrileño de Salud, Madrid, Spain; [f]Fundación de Investigación e Innovación Biosanitaria de Atención Primaria (FIIBAP), Research Network on Chronicity, Primary Care and Health Promotion–RICAPPS-(RICORS), Bilbao, Spain; [g]Executive Board of the SVLS/SGPS./Spoločnosť všeobecných lekárov Slovenska/Society of General Practitioners of Slovakia, Department of General Practice Faculty of Medicine, Comenius University Bratislava, Bratislava, Slovakia; [h]Altea Long COVID Network, Zürich, Switzerland; [i]Department of Family Medicine, Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel; [j]Mater Dei Hospital, Msida, Malta; [k]Egil District State Hospital, Diyarbakir, Turkey; [l]Department of Urology and General Practice, Faculty of Medicine, Medical University of Plovdiv, Plovdiv, Bulgaria; [m]Department of Family Medicine, Semmelweis University, Budapest, Hungary; [n]Institute of Family Medicine and Public Health, University of Tartu, Tartu, Estonia; [o]Institute of Public Health and Clinical Nutrition, School of Medicine, Faculty of Health Sciences, University of Eastern Finland, Kuopio, Finland; [p]Department of Family Medicine, Faculty of Medicine, University of Ljubljana, Ljubljana, Slovenia; [q]Department of Medical Psychology, Hannover Medical School, Hannover, Germany; [r]Primary Health Care Centre in Ekholmen and Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden; [s]Department of General Practice First Faculty of Medicine, Charles University Prague, Prague, Czech Republic; [t]Department of Life Sciences and Medicine, University of Luxembourg, Belvaux, Luxembourg; [u]Department of Clinical Sciences in Malmö, Centre for Primary Health Care Research, Lund University, Malmö, Sweden; [v]Department of Pharmacology, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden; [w]Department of Clinical Pharmacology, Sahlgrenska University Hospital, Gothenburg, Sweden; [x]Department of Primary Care and Public Health, Imperial College London, London, UK; [y]RISE-Health, University of Porto, Porto, Portugal; [z]Department of Family Medicine, Uniwersytet Jagielloński–Collegium Medicum (UJCM), Krakow, Poland; [aa]Department of Family Medicine, Maastricht University, Maastricht, The Netherlands; [bb]Chair of General Practice II and Patient-Centredness in Primary Care, Institute of General Practice and Primary Care (IAMAG), Faculty of Health, Witten/Herdecke University, Witten, Germany; [cc]Health Services Research (Primary Care Unit), Department of Epidemiology and Public Health, Sciensano, Brussels, Belgium; [dd]Department of Public Health, Institute of Health Sciences, Faculty of Medicine, Vilnius University, Vilnius, Lithuania; [ee]Department of Family Medicine, Andrzej Frycz Modrzewski Krakow University, Krakow, Poland; [ff]Health Center 'Dr Đorđe Kovačević', Lazarevac, Belgrade, Serbia; [gg]Van Gürpınar District Public Hospital, Van Gürpınar, Turkey; [hh]Department of Medical Sciences, Academy of Applied Studies Polytechnic, Belgrade, Serbia; [ii]Family Medicine, General Health System Cyprus, Larnaca, Cyprus; [jj]Laboratory of Hygiene and Epidemiology, Medical Department, Faculty of Health Sciences, University of Ioannina, Ioannina, Greece; [kk]GHS, Larnaca, Cyprus; [ll]Internal Medicine Department, Medical Faculty 2, Uzhhorod National University, Uzhhorod, Ukraine; [mm]Department of Family Medicine and Outpatient Care, Medical Faculty 2, Uzhhorod National University, Uzhhorod, Ukraine; [nn]Department of Primary Care Medicine, Medical University of Vienna, Vienna, Austria; [oo]Comprehensive Health Research Center, NOVA Medical School, Universidade Nova de Lisboa, Lisbon, Portugal; [pp]USF das Conchas, Regional Health Administration Lisbon and Tagus Valley, Lisbon, Portugal; [qq]Department of Family Medicine 'Andrija Stampar' School of Public Health,

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CONTACT Raquel Gómez Bravo raquelgomezbravo@gmail.com Centre Hospitalier Neuro-Psychiatrique (CHNP), Rehaklinik, 17, avenue des Alliés, B.P.111, L-9002 Ettelbruck, Luxembourg.

*These authors contributed equally to this work.

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School of Medicine, University of Zagreb, Zagreb, Croatia; [rr]Health Centre Zagreb West, Zagreb, Croatia; [ss]Faculty of Medicine, Ss. Cyril and Methodius University, Skopje, North Macedonia; [tt]Institute of General Practice and Family Medicine, Medical Faculty, Martin-Luther-University Halle-Wittenberg, Halle/Saale, Germany; [uu]NOVA Medical School, Universidade Nova de Lisboa, Lisbon, Portugal; [vv]USF Ajuda, Regional Health Administration Lisbon and Tagus Valley, Lisbon, Portugal; [ee]Member of Irish College of General Practice (MICGP), Dublin, Ireland; [xx]Member of Royal College of Physician (MRCSI), Dublin, Ireland; [yy]Department of Family Medicine, Rīga Stradins University, Riga, Latvia; [zz]Department of Infectious Diseases, Belarusian State Medical University, Minsk, Belarus; [aaa]School of Social Sciences, Hellenic Open University, Patra, Greece; [bbb]DaVinci Health Hospital, Birkirkara, Malta; [ccc]Institute of General Practice, 1st Faculty of Medicine Charles University, Prague, Czech Republic; [ddd]Dutch College of General Practitioners, Utrecht, The Netherlands; [eee]Radiation Diagnostics and Radiation Therapy Department, Belarusian State Medical University, Minsk, Belarus; [fff]'Spiru Haret' University, Bucharest, Romania; [ggg]Occupational Health Expert, Bucharest, Romania; [hhh]National Society of Medical Education in General Practice (SNAMID), Caserta, Italy; [iii]Department of General Practice, University of Lille, Lille, France; [jjj]Research Unit for General Medicine and Primary Health Care, Faculty of Medicine, School of Health Science, University of Ioannina, Ioannina, Greece; [kkk]Federica Montseny Health Centre, Gerencia Asistencial Atención Primaria, Servicio Madrileño de Salud, Madrid, Spain; [lll]Research Network on Chronicity, Primary Care and Health Promotion–RICAPPS-(RICORS), Spain, Instituto de Investigación Sanitaria Gregorio Marañón, Madrid, Spain; [mmm]Universitas Health Centre, Public Health Care Service of Aragon, Zaragoza, Spain; [nnn]GIBA-IIS-Aragón, Chair of Patient Safety Working Party of semFYC (Spanish Society for Family and Community Medicine) and Quality and Safety in Family Medicine of WONCA World (Global Family Doctors), Board Member of WONCA World and SECA (Spanish Society for Healthcare Quality)

ABSTRACT

Background: The COVID-19 pandemic has significantly impacted global healthcare systems, leading to challenges in managing Long COVID. Variations in definitions and diagnostic criteria across Europe hinder recognition and treatment efforts. This study aims to analyse and compare the definitions of Long COVID used in 34 European countries.

Methods: A retrospective descriptive study was conducted involving key informants from 34 European countries, utilising an online questionnaire to gather data on Long COVID definitions. Quantitative and qualitative analyses were employed to assess the variability of definitions and challenges in managing Long COVID.

Results: The study found significant variation in Long COVID definitions among the participating countries; the most frequent definition was the other definition (n: 17, 50.0%), followed by the World Health Organisation's definition (n: 16, 47.0%) and the CDC definition (n: 11, 32.3%). Half of the countries reported using multiple definitions simultaneously, indicating a lack of standardisation. Qualitative analyses highlighted challenges such as difficulties in standardising terminology, variability in clinical criteria, and issues with implementing diagnostic codes.

Conclusion: The findings underscore the need for a unified, yet adaptable, definition of Long COVID. Such a definition would support general practitioners (GPs) by simplifying diagnostic processes, improving continuity of care, and facilitating equitable patient access to multidisciplinary resources. The current lack of consensus complicates patient care, data collection, and resource allocation, impacting health policy development. Future efforts should focus on achieving agreement on definitions to ensure equitable treatment and effective healthcare responses to Long COVID.

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Primary health care; COVID-19; post-acute COVID-19 syndrome; diagnosis; clinical coding; Europe

Introduction

The COVID-19 pandemic has posed an unprecedented challenge to global healthcare systems, which now have to deal with its long-term consequences [1]. Among these, the management and treatment of Long COVID (LC) stands out as an emerging condition that affects a significant number of patients after overcoming the acute phase of the disease [2].

Individuals suffering from LC, also known as prolonged COVID-19 or post-COVID, experience a wide range of symptoms, including extreme fatigue, difficulty breathing, cognitive problems, and various physical and mental disorders that deteriorate their quality of life [3]. The lack of a standardised definition and consistent diagnostic criteria has complicated the recognition, research, and effective treatment of this condition across Europe [4–6].

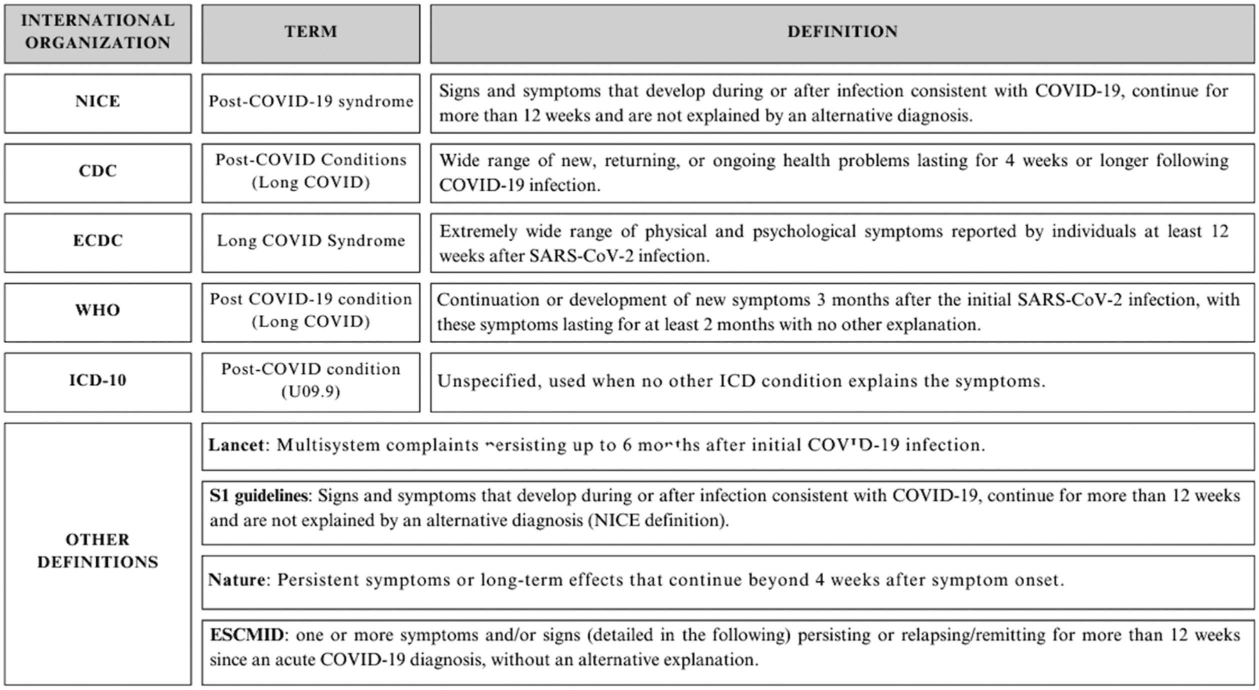
In March 2020, the European Centre for Disease Prevention and Control (ECDC) recommended the rapid identification and monitoring of SARS-CoV-2 cases, developing a contingency plan for primary health care (PHC), hospitals, and long-term care facilities [7]. However, the recognition and management of LC have not received the same coordinated attention, leading to significant variations in how this condition is defined and treated across different European countries [5,6].

PHC, characterised as the first accessible, continuous, comprehensive, and person-centred point of contact, played a pivotal role during the COVID-19 pandemic. PHC not only provided the initial care of the patients, but also managed follow-up during the acute phase [8]. In the long term, PHC remains critical in early recognition, comprehensive evaluation, and coordinated management of LC patients, ensuring access to specialised services as needed [6]. Additionally, PHC educates patients about the prolonged nature of COVID-19 and provides continuous support for managing persistent symptoms to promote their recovery and enhance their quality of life [9].

The management of LC poses an emerging challenge for European healthcare systems, which must face a complex condition without consistent diagnostic criteria and whose definition varies significantly among different countries and health organisations [10]. None of the proposed definitions is entirely precise. Each has strengths and weaknesses, differing in aspects such as the most suitable name for identification, the timeframes from onset (3, 4, 12, 24 weeks), or the symptoms and signs to include [11]. For example, the Centres for Disease Control and Prevention (CDC) officially labelled the condition 'Long COVID', describing it as a term adopted by patients themselves, broadly defined as signs, symptoms, and conditions that appear or persist for 4 weeks or more following the initial infection with SARS-CoV-2 [12]. On the other hand, the World Health Organisation (WHO) designated the condition as 'Post COVID-19 condition', delineating it as the persistence or development of new symptoms 3 months after the initial infection with SARS-CoV-2. According to this definition, these symptoms could endure for at least 2 months without other alternative explanations [13]. Additionally, the National Institute for Health and Care Excellence (NICE) in Great Britain adopted the nomenclature 'Post COVID Syndrome', defining it as signs and symptoms manifested during or after COVID-19, persisting for more than 12 weeks without an alternative diagnosis [14]. Also, diagnostic codes are crucial for patient follow-up within the healthcare system, as well as for monitoring and identifying populations. Figure 1 details the consensus terms and definitions for LC.

Exploring the various definitions of LC in use across several European countries is essential for understanding the variations in its clinical and epidemiological management [5,15]. This study also highlights the potential benefits of establishing a common definition, which could standardise and improve the management of this complex condition, enhance data comparability, improve clinical care, and better support patients on their path to full recovery [16].

The aim of this study, therefore, was to analyse and compare the various definitions of LC used in 34 European countries and assess the feasibility of creating a standardised definition that optimises clinical care for these patients within PHC.



INTERNATIONAL ORGANIZATION	TERM	DEFINITION
NICE	Post-COVID-19 syndrome	Signs and symptoms that develop during or after infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.
CDC	Post-COVID Conditions (Long COVID)	Wide range of new, returning, or ongoing health problems lasting for 4 weeks or longer following COVID-19 infection.
ECDC	Long COVID Syndrome	Extremely wide range of physical and psychological symptoms reported by individuals at least 12 weeks after SARS-CoV-2 infection.
WHO	Post COVID-19 condition (Long COVID)	Continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.
ICD-10	Post-COVID condition (U09.9)	Unspecified, used when no other ICD condition explains the symptoms.
OTHER DEFINITIONS	**Lancet**: Multisystem complaints persisting up to 6 months after initial COVID-19 infection.	
	S1 guidelines: Signs and symptoms that develop during or after infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis (NICE definition).	
	Nature: Persistent symptoms or long-term effects that continue beyond 4 weeks after symptom onset.	
	ESCMID: one or more symptoms and/or signs (detailed in the following) persisting or relapsing/remitting for more than 12 weeks since an acute COVID-19 diagnosis, without an alternative explanation.	

Figure 1. Consensus terms and definitions for Long COVID.
NICE: National Institute for Health and Care Excellence; CDC: Centres for Disease Control and Prevention; ECDC: European Centre for Disease Prevention and Control; WHO: World Health Organisation; ICD-10: International Classification of Diseases-10; ESCMID: European Society of Clinical Microbiology and Infectious Diseases. Note: The official sources for the development of the survey can be found in Supplementary File 1.

Methods

Study design

This research was a retrospective descriptive study conducted in 34 European countries, forming part of the larger Eurodata study, which examines the role of primary healthcare (PHC) during the COVID-19 pandemic in Europe [17].

Employing an online self-administered ad hoc questionnaire, the study gathered comprehensive data on the definitions of LC used in different European countries.

Participants

Structure of the research consortium

The research consortium is structured around a core team comprising four specialists in family and community medicine, including one with a specialisation in public health (PH).

National researchers serve as key informants at the national level. Most researchers are affiliated with the World Organisation of Family Doctors in Europe (WONCA Europe), which includes 47 member organisations and a network of over 90,000 family doctors throughout Europe. WONCA Europe also hosts the European General Practice Research Network (EGPRN) that serves as a periodic meeting point for these researchers [18,19].

Study participants

The participants were key informants from 34 countries (Figure 2), selected based on the following criteria: being a general practitioner (GP) or having a background in general practice, practicing in Europe during the COVID-19 pandemic; and proficiency in English. They were affiliated with international networks such as WONCA Europe and the European General Practice Research Network (EGPRN), which serve as platforms for ongoing professional collaboration and research dissemination. Their selection was based on their recognised expertise and familiarity with national-level guidelines and practices in their countries.

Participant recruitment. Before the study, national collaborators were invited to attend two informational webinars and one in-person meeting, all of which were optional. Nevertheless, all participants received detailed written materials and formally consented to participate in the study. Those who expressed interest in participating were designated as national key informants. To formalise their participation, they were required to confirm their involvement in the Eurodata project and sign an informed consent form. This approach ensured that all participants, regardless of webinar or meeting attendance, were adequately informed and formally enrolled in the study

Survey development and data collection. The survey was developed through a collaborative process, incorporating information from official sources (Supplementary File 1). An initial version of the questionnaire was distributed, feedback was gathered, and a revised version was created to achieve consensus among the researchers. Definitions related to healthcare services and professionals are provided in Supplementary File 2.

The use of the definitions in Figure 1 was queried in the questionnaire. Respondents were also asked about other definitions that may be in use in their respective countries.

The survey was administered to key informants between June and July 2024, with two reminder emails sent to ensure timely responses.

Two members of the core research team for quality assurance reviewed the collected data. Any unclear responses were followed up with key informants for clarification and additional information. In cases of discrepancies, these were discussed within the core team and with the key informants to reach consensus. Furthermore, countries provided supporting links and sources for their responses (available in Supplementary File 3).

Data analysis. To evaluate the variation in LC definitions and practices across participating countries, both quantitative and qualitative analyses were conducted. Quantitative data were gathered from 34 countries and analysed to determine the distribution of LC definitions. Frequencies and percentages were calculated for each definition. The analysis was performed using STATA 16.

To assess the extent of variability in definitions, we computed the proportion of countries using multiple definitions simultaneously.

For qualitative data, thematic analysis was employed to identify key challenges reported by key informants regarding the definition and management of LC. Responses were categorised into themes, and direct quotes were included to illustrate these challenges.

By combining the quantitative data with qualitative insights, we gained a comprehensive understanding of the inconsistencies and challenges in the global approach to LC.

Results

This study gathered responses from 34 countries, providing a broad view of the definition and management

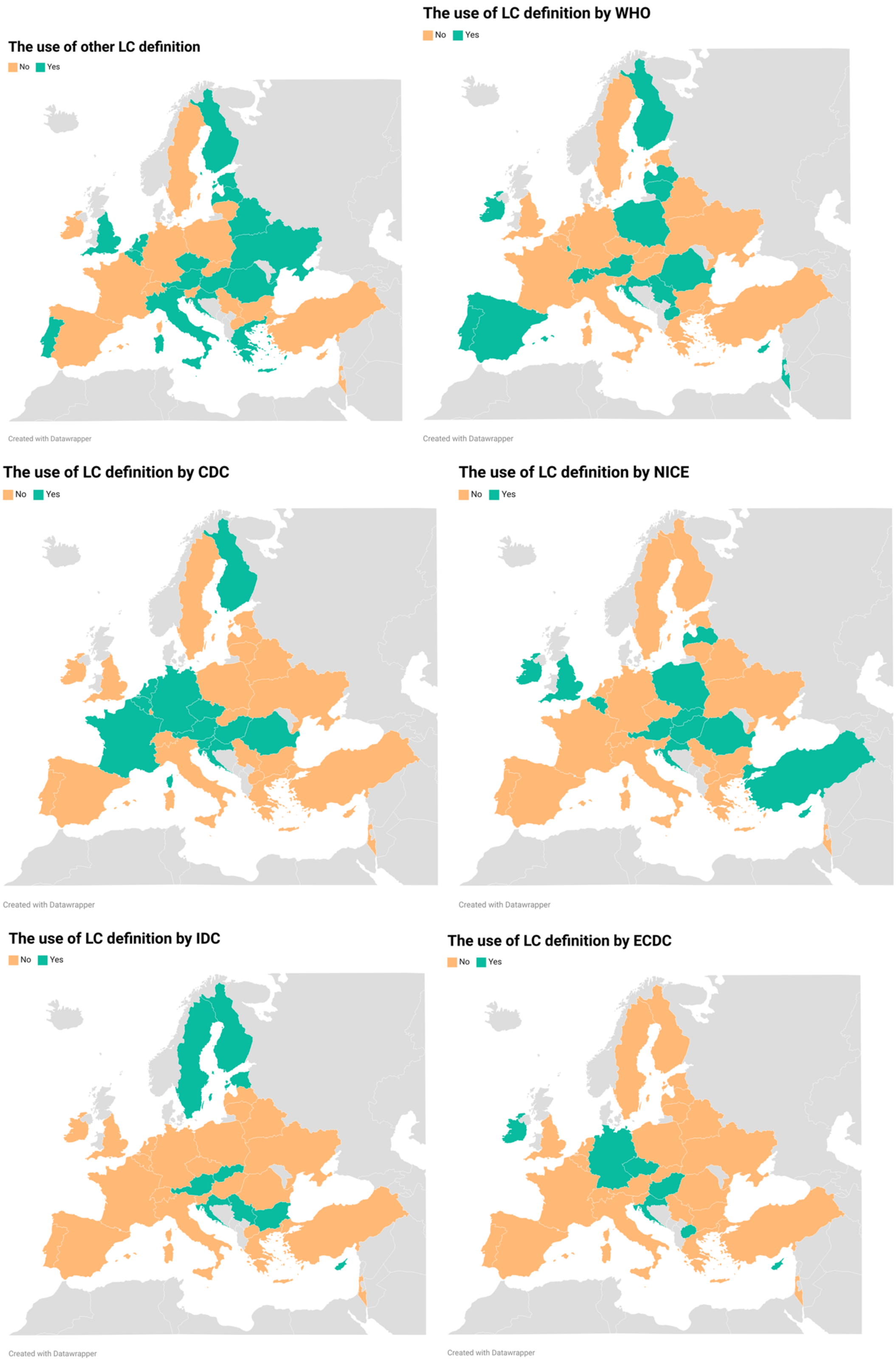


Figure 2. Participating countries in the study and type of definition in each country.

of LC worldwide. The map below (Figure 2) illustrates the participating countries, highlighting the global reach of the study. This extensive participation underscores the study's relevance and its ability to offer a representative perspective on the practices and challenges associated with LC across different regions.

Quantitative results

The responses from the 34 participating countries regarding the definitions of LC were analysed (Supplementary File 4). The results highlighted considerable variation in the definitions used, with key findings presented in Table 1. Notably, 18 countries (52.9%) adopted multiple definitions simultaneously (Figure 2), reflecting a lack of standardisation in the terminology used to describe this condition. The most commonly preferred definition was an alternative definition, followed by the WHO, NICE and CDC definitions.

Qualitative results

The qualitative analysis of open-ended responses provided valuable insights into the challenges faced by different countries in managing and defining LC. Several key themes emerged:

Challenges in standardising terminology

In several countries, multiple definitions of LC are used simultaneously, complicating the diagnostic and treatment (Supplementary File 3). Some countries, like Bulgaria and Malta, lack an officially accepted definition. While various definitions have been proposed, they have yet to be recognised by Ministries of Health or relevant scientific societies.

One key informant from Belgium noted: '*Here we use both the NICE and CDC definitions, but it is not always clear which is the most appropriate in each case*'.

Similarly, the participant from Hungary stated: '*The variability of the definitions used makes it difficult to implement a consistent framework for managing LC*'.

Table 1. Distribution of Long COVID definitions used across participating countries (N: 34 countries).

Definition	N (%)
Other definition (S1 guidelines, Lancet, ESCMID, Nature)	17 (50.0%)
WHO definition	16 (47.0%)
CDC definition	11 (32.3%)
NICE definition	12 (35.2%)
ICD-10 definition	9 (26.4%)
ECDC definition	7 (20.5%)

NICE: National Institute for Health and Care Excellence; CDC: Centres for Disease Control and Prevention; ECDC: European Centre for Disease Prevention and Control; WHO: World Health Organisation. ICD-10: International Classification of Diseases-10; ESCMID: European Society of Clinical Microbiology and Infectious Diseases. Note: The total number of countries exceeds 34, as some countries are counted under more than one definition. The official sources for the development of the survey are found in Supplementary File 1.

Variability in clinical criteria

In several countries, healthcare professionals are not consistently following the criteria for diagnosing LC, leading to confusion in patient care.

A key informant from Austria commented: '*Although there are clear guidelines, doctors do not follow them adequately, which creates difficulties in daily clinical practice*'. Similarly, the key informant from Estonia shared a similar experience: '*Doctors do not consistently adhere to diagnostic guidelines of LC, making the management of cases irregular*'.

Problems in implementing diagnostic codes

Despite the availability of diagnostic codes for LC in some countries, they are not routinely applied in outpatient settings.

The key informant from Austria mentioned: '*Diagnostic codes are not widely used in the outpatient sector, making it difficult to adequately track patients with LC*'. Similarly, the key informant from Estonia noted: '*Despite the existence of diagnostic codes for LC, they are not used routinely in practice, which significantly complicates clinical care*'.

Discussion

This study provides a novel perspective on the variability in the definition and management of LC across European countries, addressing the research question of how the various definitions of this syndrome are defined and applied at a European level. The preferred terms were other definitions, followed by the WHO definition, and NICE definition, along with the CDC definition. By comparing how definitions are adopted and used institutionally, the findings illustrate the heterogeneity and fragmentation in current practices. These variations have significant implications for clinical care, research comparability, and health policy development.

Use of various and multiple definitions

The observation that more than half of the countries resort to multiple definitions of LC reflects the syndrome's inherent complexity and the clinical uncertainty surrounding it [20]. This simultaneous use of various definitions may stem from the need to adapt them to specific clinical or research contexts. One key differentiator among definitions is the timing, as only the CDC specifies a short duration of symptoms for diagnosing LC.

While the incubation period and duration of initial-phase symptoms are well-documented for most diseases, the persistence of symptoms beyond the initial phase is not clearly defined for most viral infections, except for conditions like Epstein-Barr virus, cytomegalovirus, and herpes zoster. The prolonged nature of symptoms poses not only a challenge for patients but also a significant public health issue. If symptom persistence is considered to last 4 weeks, as suggested by the CDC, this increases the likelihood of a larger patient population eventually improving, but also raises the risk of overdiagnosis. Adopting stricter definitions, such as considering 12 weeks as the cut-off point, would allow for a more accurate diagnosis in line with current knowledge [21,22].

However, the lack of standardisation complicates international data comparisons, hindering global research and the development of health policies. For example, while ICD U09.9 offers a defined classification for LC, whereas the ICPC2 code A77 encompasses a broad range of cases, including both acute and LC, without clear differentiation. This discrepancy complicates monitoring efforts and creates inconsistencies across case definitions. Harmonised diagnostic codes are essential for identification, accurate patient follow-up and effective population-level monitoring [23]. Without alignment, discrepancies in case definitions can undermine the ability to respond to patient needs in a consistent and timely manner. A more uniform approach could improve data comparison and support more coherent policy-making, benefiting both research and clinical practice [24].

WHO definition

Our findings show that the WHO's definition of LC is the most widely adopted, used by 46.8% of the participating countries. This suggests the WHO has played a significant role in standardising the concept. However, the WHO's definition is designed to evolve with new evidence and a deeper understanding of COVID-19's long-term effects [25]. This flexibility, while important, may have contributed to the emergence of alternative definitions. In our study, nearly 60% of countries use other definitions or combinations of definitions. Factors such as clinical practices, available resources, healthcare systems capacity and the integration of emerging research likely influence this variability. Further research into the reasons behind this choice and its impact on clinical practice and research would be valuable [26].

Variety in the use of definitions

The lack of universal consensus around the definition of LC highlights the challenge of defining a condition that is still evolving and under intense investigation [13]. Although multiple definitions offer different perspectives, the absence of a common framework can hinder communication, clinical management, and data integration. Moving towards a widely accepted-yet adaptable-definition could simplify the diagnostic process and promote more consistent care pathways [27].

Emerging definitions

The emergence of new definitions, such as those proposed by the S1 guidelines, Lancet, ESCMID, and Nature (Supplementary File 1), illustrates the dynamic and contested nature of LC as a clinical entity. While these efforts can generate valuable insights, they also risk contributing to further fragmentation of knowledge and practice. Advancing towards a more unified, evidence-informed definition is essential for ensuring consistency in identifying and treating the syndrome [28].

Consequences for the patient

The lack of a unified LC definition can significantly impact patient care [29]. Inconsistent definitions contribute to fragmented global data, hindering the much-needed data linkage across countries to enhance research on therapeutic approaches. Additionally, this lack of standardisation has socio-economic repercussions, potentially affecting health insurance coverage and creating inequities in access to care across regions. Without reliable epidemiological data and a coherent definitional framework, many patients may fall through the cracks—particularly those whose experiences do not align neatly with rigid criteria. This makes it difficult to advocate for targeted care pathways and healthcare strategies.

Strengthening definitional alignment would help ensure that care is based on clinical need rather than administrative interpretation, improving consistency in both diagnosis and access to services [29]. Moreover, patient perspectives have played a central role in naming and advocating for the recognition of Long COVID. These lived experiences should inform the development of definitions and care strategies, ensuring that diagnostic criteria are inclusive and ethically grounded [29]. Activism has also been pivotal in bringing visibility to Long COVID—challenging institutional inertia and catalysing changes in policy, research funding, and public awareness. This grassroots mobilisation has reshaped public discourse and conferred epistemic authority to patients' experiences, which must be acknowledged in any serious effort to define and address the condition.

Consequences for the healthcare system

The absence of unified definitions also complicates the efforts to assess LC's impact on public health and health systems [5,6,30]. Although the COVID-19 pandemic led to advancements in unified health policies within the European Commission—such as coordinated epidemiological surveillance by the ECDC, hospital bed allocation, and vaccination strategies—implementation has varied widely at the national level. Similar inconsistencies exist in the adoption of LC criteria. For example, while the ECDC has published comprehensive guidance, many member states have yet to translate this into national policies or guidelines.

Reports from the European Commission and the OECD [5,6] highlight the lack of standardisation in defining LC and allocating resources for patients. To improve coordination and support, it is essential to enhance the implementation of ECDC recommendations and consider establishing a centralised European body – similar to the NICE in the UK – to develop common clinical practice guidelines. These efforts must include patient input and reflect the realities in the frontline practice [6]. Such a model could promote equity, strengthen surveillance systems, and enable more effective allocation of financial and professional resources. This approach would support uniform standards across the EU, reduce disparities in patient care, and ensure equitable access to necessary services. For GPs, standardised definitions would directly facilitate clearer clinical decision-making, improve diagnostic coding accuracy, streamline referrals to specialists, and justify patient access to multidisciplinary services, thereby directly improving patient care and equity. Without a clear, unified definition, effective resource planning, healthcare provider training, diagnostic accessibility, and the strategic allocation of funds for LC patients and their treatment remain hindered.

Biopsychosocial complexity and the role of the initial infection

Persistent symptoms following COVID-19 share features with other post-infectious syndromes, such as those following Epstein-Barr virus, cytomegalovirus, or influenza. This broader context highlights the need for a biopsychosocial approach to LC, recognising that persistent symptoms may arise from overlapping biological, psychological, and social mechanisms [31]. The relevance of the initial infection (e.g. confirmed SARS-CoV-2 infection) must be carefully considered, especially as widespread and reliable testing declines. In the absence of a definitive biomarker for LC, there is a growing risk of misattributing persistent symptoms either to or away from COVID-19.

This diagnostic uncertainty has important implications for clinical care. Symptom-based and functional assessments may be more relevant than strict virologic confirmation in guiding treatment. Multidisciplinary care models should therefore focus on the patient's current health status and functional limitations, rather than on the specific nature or timing of the initial infection [32–34]. This approach could also support the development of more inclusive and effective care pathways for individuals suffering from post-infectious or unexplained persistent symptoms, regardless of their origin.

For general practitioners—the first point of contact for most patients with persistent symptoms—a standardised definition is particularly important. It enables consistent diagnostic coding, facilitates communication with specialists, and helps justify access to services or referrals within constrained healthcare systems. In the absence of centralised guidelines or training, GPs often operate in isolation. A shared definition, even if provisional, would support clearer clinical pathways, reduce uncertainty in decision-making, and provide a foundation for equitable care and professional advocacy.

Future directions

To advance the recognition and management of LC, comparative studies are needed to evaluate the effectiveness, inclusivity, and clinical utility of different definitions. This effort should aim for a consensus that allows for more consistent identification and equitable treatment of LC. While diverse interpretations and approaches are inevitable and understandable in a rapidly evolving field, definitional fragmentation should not delay care or research.

Efforts towards standardisation must remain responsive to emerging scientific evidence and be informed by those most affected—patients, clinicians, and public health professionals. Embracing a biopsychosocial framework that recognises the multifactorial nature of persistent symptoms will also be key to addressing the broad spectrum of LC experiences.

Conclusion

The results underscore the need for a standardised LC definition to improve clinical care and support research efforts. The results underscore the need for a standardised yet adaptable LC definition to improve clinical care, enhance research comparability, and inform health policy. Given the ongoing uncertainty surrounding LC's clinical characteristics and biological mechanisms, any definition should remain provisional and be regularly updated through transparent processes involving frontline clinicians, public health experts, and patients themselves. The absence of a unified definition complicates patient management, data collection, and resource distribution, ultimately influencing health policy.

Our findings highlight the urgent need for a more standardised definition of LC to enhance clinical care, enable consistent data collection, and inform equitable health policy and resource allocation across Europe. However, defining LC is not solely a technical exercise—it reflects broader uncertainties in clinical understanding, institutional capacity, and the responsiveness of health systems to complex, evolving conditions.

The current variability in definitions poses significant challenges, yet we acknowledge that premature or overly rigid standardisation may risk excluding patients or misrepresenting clinical realities. Definitions must serve as tools to guide—not constrain—clinical reasoning and must be responsive to both scientific evidence and patient experiences. Given the absence of a validated biomechanism for LC, any definitional framework must remain provisional and responsive to new evidence. A premature fixed definition may obscure rather than clarify the condition's clinical diversity.

Looking ahead, any consensus should emerge from an inclusive and transparent process, rooted in evolving research and shaped collaboratively by those most affected: patients, frontline clinicians, and public health professionals. A dynamic, co-produced definition has the potential to bridge gaps in care and advance both science and solidarity in the management of LC.

Disclosure statement

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ORCID

Raquel Gomez-Bravo http://orcid.org/0000-0002-3786-8626
Sandra León-Herrera http://orcid.org/0000-0002-1200-5904
Marina Guisado-Clavero http://orcid.org/0000-0002-8448-2929
Ileana Gefaell http://orcid.org/0000-0002-1635-1003
Shlomo Vinker http://orcid.org/0000-0001-9804-7103
Péter Torzsa http://orcid.org/0000-0002-8148-4961
Theresa Sentker http://orcid.org/0000-0003-1162-310X
Bohumil Seifert http://orcid.org/0000-0002-6881-8840
Marta Sánchez-Castro http://orcid.org/0000-0002-1028-9608
Jochen G. Schneider http://orcid.org/0000-0003-2139-0602
Ferdinando Petrazzuoli http://orcid.org/0000-0003-1058-492X
Davorina Petek http://orcid.org/0000-0002-0151-4463
Abel Perjes http://orcid.org/0000-0002-7176-1275
Naldy Parodi López http://orcid.org/0000-0001-6367-9389
Ana Luisa Neves http://orcid.org/0000-0002-7107-7211
Katarzyna Nessler http://orcid.org/0000-0001-9869-7923
Jean Muris http://orcid.org/0000-0002-8780-476X
Liubovė Murauskienė http://orcid.org/0000-0002-6625-8843
Heidrun Lingner http://orcid.org/0000-0003-2074-0367
Büsra Çimen Korkmaz http://orcid.org/0000-0001-7224-5734
Snezana Knezevic http://orcid.org/0000-0001-9137-2122
Vasilis Karathanos http://orcid.org/0000-0003-1144-7302
Oksana Ilkov http://orcid.org/0000-0002-0923-0596
Kathryn Hoffmann http://orcid.org/0000-0001-8760-4250
Bruno Heleno http://orcid.org/0000-0002-3943-1858
Dragan Gjorgjievski http://orcid.org/0000-0003-1817-7632
Louise Fitzgerald http://orcid.org/0009-0009-8039-3097
Philip-Richard Domeyer http://orcid.org/0000-0003-4594-1202
Jako S. Burgers http://orcid.org/0000-0002-6040-4221
Elena Brutskaya-Stempkovskaya http://orcid.org/0009-0008-1820-7962
Carmen Iliana Busneag http://orcid.org/0000-0001-5611-4312
Nicola Buono http://orcid.org/0000-0001-8797-477X
Sabine Bayen http://orcid.org/0000-0002-3334-9394
Maria Bakola http://orcid.org/0000-0002-9016-9322
Radost Assenova http://orcid.org/0000-0003-2158-5792
Sara Ares-Blanco http://orcid.org/0000-0002-4984-8788
María Pilar Astier Peña http://orcid.org/0000-0002-3192-7672

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