Rapid Exchange Forum – Special Edition

"Harmonising advances in Long COVID research: Uniting European actors for solutions"

October 9, 2023 9:00 – 10:00 a.m.

Attendees:

Ales Korosec (Slovenia), Alessandro Cozzi Lepri (UK), Alexei Yavlinsky (UK), Ana Abecasis (Portugal), Andreas Tofarides (Cyprus), Anina Chileva (Bulgaria), Anita Gottlob (Austria), Astrid Lavens (Belgium), Barthélémy Moreau de Lizoreux (Belgium), Björn Jensen (Germany), Branka Horvat (France), Bruno Ciancio (ECDC), Caroline Steigenberger (Austria), Chantal Britt (Long COVID Europe), Christian Brander (Spain), Claudia Habl (Germany), Csaba Kiss (Hungary), Daniel Naumovas (Lithuania), Diego Castanares Zapatero (Belgium), Stephanie Durand (France), Edita Strumiliene (Lithuania), Edoardo Pizzioli (France), Elizabeth Berghuis-Mutubuki (The Netherlands), Fabienne Van Aelst (Belgium), Filippo Chiabrando (Italy), Florian Röthlin (Austria), Francesca Bai (Italy), Graziano Onder (Italy), Greg Owsianik (European Commission), Hanna Tolonen (Finland), Henk Hilderink (The Netherlands), Janis Misins (Latvia), Johannes Weiss (Austria), Jon Schoorlemmer (Spain), Jose Penalvo (Belgium), Dovile Juozapaite Vuhsk (Lithuania), Laura Planells (Belgium), Laurence Geebelen (Belgium), Lilja Parkkali (Finland), Luigi Palmieri (Italy), Luis Lapao (Portugal), Michal Rosen-Zvi (Israel), Marc Bardou (France) Marco Floridia (Italy), Maria Francesca Greco (Italy), Maria Preschern (Austria), Mariana Peyroteo (Portugal), Marilia Silva Paulo (Portugal), Marina Giuliano (Italy), Marlies Laethem (Belgium), Menno Kok (EIT Health), Merike Rätsep (Estonia), Miriam Saso (Belgium), Neville Calleja (Malta), Nienke Schutte (Belgium), Oliver Cornely (Germany), Patricia Urban Lopez (European Commission), Richard Pentz (Austria), Robert Lang (Hungary), Sarah Moreels (Belgium), Sasha Milbeck (Belgium), Shany Biton (Israel), Stefan Schreck (European Commission), Tal Kozlovski (Israel), Veerle Bos (The Netherlands), Yishai Shimoni (Israel), Yvan Devaux (Luxembourg), Gabriella Scarlatti (Italy), Gunter Maier (Austria), luc Nicolas (EHTEL), Olivier Robineau (France)

Aim of the meeting:

The goal of the Rapid Exchange Forum – Special Edition is to bring awareness to international activities already in place that exchange information on public health measures that require rapid actions. We hope this meeting will bring attention to various expert groups and organizations involved in Long COVID research and advocacy, and promote collaborative efforts across Europe.

Welcome by Nienke Schutte - PHIRI

The Population Health Information Research Infrastructure (PHIRI) arranges a Rapid Exchange Forum (REF) every two weeks, where participants and speakers address urgent public health questions. PHIRI has done this since the start of COVID-19, but we see that the REF is still relevant especially when discussing the long-term consequences of COVID, of which Long COVID is one of them. PHIRI also arranges a Rapid Exchange Forum – Special Edition every trimester, where we exchange experiences in the field, share activities that are already ongoing to prevent duplication of work, and stay informed of each other's activities. Today we are focusing on Long COVID. We have various experts from different organisations, from research to advocacy, and we will see what they have been up to, whether there are synergies in their activities and how we can promote collaboration among players in the field of Long COVID.

Stefan Schreck – European Commission (DG Sante)

In the area of public health policy, the Commission has established the Network of Expertise on Long COVID (NELC). The network's participants are from institutions that have been nominated by the ministries of health of member states (MS), and within this network of expertise, we want to make sure that all relevant MS institutions are aware of activities other MS are doing, what the latest

research is, best practices that different countries might want to implement, and anything that may have European-wide value. The network is quite new, but has already met twice this year, and is planning a third meeting in December. The Commission acknowledges that other countries and institutions are working on Long COVID, and hope to call upon their expertise, and integrate their work through the Network of Expertise.

While the NELC is a closed group (where you have to be nominated by your government or your member state to participate), the Commission also wants to create an open stakeholder group that anyone who is interested can join. They hope to create this either this year, or early next year.

Additionally, the NELC has already conducted a survey to see what member states have already done, and what they consider a priority in the realm of Long COVID. The replies from 8 MS indicated that of those who replied, 7 MS have established multidisciplinary care pathways for Long COVID patients; 7 MS established rehabilitation programs for patients; 6 MS have national guidelines for treatment; 6 MS have specialized clinics. Replies from specific countries reported that Spain has indicated a surveillance system for Long COVID, Ireland has worked on the prevention of Long COVID, and Germany has established an interagency coordination to educate the public on the impact of Long COVID. Additionally, all 8 MS who replied to the survey indicated the need to have more unified European guidelines, visions and definitions on diagnosis and treatment. The NELC is thus focusing their work on the key priorities identified by MS.

Nienke Schutte: Thank you, Stefan. It is great to see how many member states have already indicated their priorities and willingness to participate in the network. This could also serve as a call for action to other member states to share their best practices and to indicate to other member states what their expertise centres are. This can be really helpful for other countries to learn how to set up and address this issue.

Richard Pentz – Austrian Public Health Institute

During the pandemic, The Austrian Public Health Institute produced many rapid evidence syntheses for the Ministry of Health to answer pressing policy questions. This has continued after the pandemic, considering questions on Long COVID.

One of these evidence syntheses focuses on the question of which interventions are effective in the treatment of Long COVID. For our evidence base, we conducted very rapid literature searches on the databases Pubmed and the COVID L.OVE repository (created by Episetemonikos), searching for the term "Long COVID" and looking specifically at systematic reviews, meta-analyses and syntheses. From the 600+ articles found, we searched for "therapies" and "treatment" in the title, screened the abstracts for relevance, and then identified 20 systematic reviews that we used for analysis. Due to many of these reviews focusing on very narrow and specific interventions, we decided to focus on a specific large, regularly updated and ongoing systematic review published by the Pan-American Health Organisation (PAHO) on therapeutic options for Long COVID.

After analysing the quality of RCTs included in the PAHO SR, we found that the methodological quality of the RCTs is quite low and there is low certainty of evidence for the interventions studied and the effectiveness. They are of low methodological quality, have small sample size, and are very heterogenous in their definitions of Long COVID and standard of care.

Our main research finding is that there have been many different interventions that have been studied for Long COVID, but there is very low certainty of evidence and the available evidence is of limited use for physicians, patients ,or researchers. Better quality studies are needed to produce better evidence.

Nienke Schutte: Thank you very much, Richard. It is quite interesting to see how there are still heterogeneous definitions of Long COVID, and this is indeed a call for better quality studies and more research groups focusing on this.

Sarah Moreels – Sciensano

The Primary Care Unit at Sciensano has conducted a study that focuses on caring for patients with Long COVID. To offer some background - Long COVID cases are seen in non-hospitalized patients

with mild-acute COVID-19 symptoms, and it is recommended that patients with persistent symptoms are treated within the primary health sector. General Practitioners (GPs) hold a key role in the treatment, but unfortunately, healthcare professionals have found it difficult to properly treat and manage patients with Long COVID. Our study aims to investigate the knowledge, perception, and experience of GPs on Long COVID care, specifically in Belgium.

The study was a cross-sectional design, where all GPs in Belgium were targeted. An online voluntary questionnaire was created, and distributed during Spring 2022 in Belgium through established national GP networks and newsletters of various GP associations in Belgium. In total, 105 GPs responded to the survey, and the sample can be comparable with all GPs in Belgium. Specific questions focused on the scientific knowledge and perception on Long COVID, criteria implemented by GPs to make a Long COVID diagnosis, and GPs experience on Long COVID care. As there a variety of definitions of what constitutes "Long COVID care", we did not include an official definition in the questionnaire.

The GPs indicated in their survey responses that they have insufficient scientific knowledge, and a lack of reliable information and educational material on Long COVID diagnosis and treatment. We also found that the majority of GPs provided care to Long COVID patients, and this was independent of the GPs' practice type, gender, or age. We found that there were about 2 Long COVID patients per 1000 active patients in Belgian general practice, which gives us an estimation that around the timing of our study, there were about 22,000 Long COVID patients in Belgium who went to GPs for their Long COVID care. Our main research findings are that GPs take a central role in the multidisciplinary care for Long COVID patients in Belgian primary health care, especially because GPs frequently provide care to Long COVID patients. GPs also use similar diagnosis criteria for identifying patients, but identified some barriers in how to properly deal with Long COVID care.

Identified barriers were specifically tackled in Belgium, because after the study from July 2022 onwards, there was the establishment of the care trajectory "post-COVID-19" which gives reimbursement for primary care patients. And, in November 2022, there was a publication of a Long COVID evidence-based guideline in Belgium, which was useful for primary health care professionals, and in stimulating the multidisciplinary care cooperation between various healthcare providers in Belgium.

Moreover, we also did a cross-country validation and launched an English version of our survey in Malta in the summer of 2022. We compared the results of Malta with Belgium, and identified that in both countries, most GPs take care of Long COVID patients, similar diagnostic criteria was applied in both countries, and barriers mentioned were quite similar. It is important to stress that in Europe there is a need to unify uniform evidence-based guidelines and scientific support especially in primary care to help GPs in treating Long COVID patients.

Nienke Schutte: Thank you so much Sarah. It is great to hear highlights, especially about the role of GPs in caring for Long COVID patients, but also the need for more evidence-based guidelines for primary care. Belgium is definitely not the only country where this is a concern now.

Gunter Maier: Do you have ICD-10 diagnostic data from GPs respectively the outpatient sector?

Sarah Moreels: Unfortunately, in Belgium, we currently don't have ICD-10 diagnostic data from primary care.

Gunter Maier: Thank you – we have the same problem in Austria (which will hopefully be resolved soon). Therefore I would be very interested in the methodological approach of Spain in their Long-COVID surveillance system.

Chantal Britt – Long COVID Europe

Long COVID Europe (LCE) is a Belgium-based NGO, and is a partner of the WHO Regional Office in Europe. It consists of a network of international and national Long COVID patient groups from 15 European countries including UK and Switzerland. Our main activities are raising awareness, having campaigns, and advocating for support and research funding for Long COVID. Most of the people active in LCE are also active nationally and are representing patient groups. We try to get the patient

view in guidelines and policies, and also address varying country views and needs when it comes to Long COVID.

I will start with some facts on Long COVID. 36 Million people are affected, and it is by no means a rare condition. According to our observations and recent studies, 75% of patients with chronic symptoms (after 6 months) don't recover. Most of the patients are around 45 years of age, and women have double the risk of men. Children and elderly are also affected, but it is not as common. No treatment is available – all available treatments are meant to alleviate symptoms, and since there are no objective biomarkers, this is a problem for insurance. Many patients struggle with stigma, medical gaslighting, and psychologization of symptoms, and it is an underfunded chronic condition.

In regards to challenges, there is a lack of recognition, relevant data and research. It is a hugely underfunded condition, and the existing data and research is inexistent, incomplete, and irrelevant. For most of the research that exists, we as patients would not pick those topics. There is a lack of knowledge still, and a lot of training is needed on the social security and on the medical side. There is also lack of patient involvement. Especially for a chronic condition like this, patients should be involved in all the research to make sure that the research and results are relevant for them. Problems in research and recognition are also elevated by the a large overlap with chronic fatigue (ME/CFS), and fragmentation between health systems in countries.

For our recommendations, recognition, standardized definitions, and adequate care pathways are needed. The fact is that patients are not getting better, and what we currently have in regards to research and therapies is inadequate. There are also no European-wide statistics, data coordination and harmonization which makes it really difficult for us to have proof about the numbers affected and the progression of the disease. We observe that people are not getting better, but we need the proof for it. There should also be coordination and support for the research efforts, which is currently very fragmented. LCE has requested public funding – currently, Charité Fatigue Clinic is one of the only centres in Europe which really knows something about the condition, but has to get private funds to run the clinic. It is crazy that we are not taking this disease seriously enough, even after 3.5 years. More research is also needed into medicine, therapies, burden, and the socio-economic impact of not only Long COVID, but related conditions like ME/CFS which many Long COVID patients are now developing. And, we need patient involvement to ensure that the research and policies are really in the interest of patients.

Nienke Schutte: Thank you, Chantal. It is great that we also have the patient perspective in this, because it stresses the importance of picking the right research topics, and having the evidence to base our interventions and policies on.

Claudia Habl: Thank you, Chantal. What would be the 2 most priority research questions?

Chantal Britt: The top research questions from patients would be: "What existing drug therapies effectively and safely treat the top symptoms, which are exertion intolerance, post-exertional malaise, cognitive dysfunction." More importantly, what we do not need is more studies on the effectiveness of physiotherapy (graded exercise, training, etc.) and cognitive behavioural therapy. The second question would be on defining a set of biomarkers to diagnose Long COVID and ME/CFS.

Claudia Habl: Thank you for sharing dear Chantal.

Marc Badou: At least in France, patients' representatives are involved in the selection of topics to be addressed in research programmes.

Graziano Onder - Università Cattolica del Sacro Cuore

Since the end of 2021, the Italian Ministry of Health has funded activities related to Long COVID. First of all, we have estimated the impact of Long COVID on healthcare resource use in 3 Italian regions. Since the definition of Long COVID is very heterogenous, we thought it would be a good idea to rely on use of resources (hospitalizations, diagnostics, visits, etc.), which are more objective measures. We understand by this analysis that the severity of COVID-19 infection is the strongest predictor of resource use in the twelve months after acute infection. In the beginning of 2022, we also performed a survey of around 150 Long COVID centres in the country. As there were many centres that arose after the pandemic, they were providing very heterogenous care, and we thought it might be a good idea to study

the differences. We proved a huge level of heterogeneity in the care provided, which allowed us to make recommendations for the country on how to provide and organize care for people with Long COVID. Lastly, also through the umbrella funding of the Ministry of Health, we aimed to provide information to citizens on Long COVID. We developed webpages outlining the different centres where people can seek care, and also established different programs such as E-learning courses for healthcare professionals. To wrap up my pitch, I will specify that while all of these national projects are great, there is still a need to have broader projects on a European-wide level involving more countries.

Nienke Schutte: Thank you very much Prof. Onder. As we have seen from the previous speakers as well, the definition of Long COVID is still very heterogeneous, so looking at healthcare resource use could be a really good way to research this condition.

Olivier Robineau – University of Lille

At the beginning of the crisis, France set up an emergency research program called CAPNET to perform studies quickly. In regards to Long COVID, this program financed studies on the long-term follow-up of hospitalised patients, but also a study in the French general population on non-hospitalised patients with Long COVID. Subsequently, AMRS-MIE is the French national agency, where along with Marc Badou, I coordinate the group on research on Long COVID. We had two calls – one in 2021 and one in 2022, to study different aspects of Long COVID. Since then, a total of 46 different national projects have been financed, with focus on pathophysiology, social sciences, and clinical management and interventions. Work has been published on the epidemiological existence of post-COVID condition, risk factors of symptoms in acute phases, and evidence of the neuroendocrine effects of the condition. In parallel, the French Federal Health Institute, Santé Publique France, has developed two large transversal studies to demonstrate the impact of Long COVID in France, the different definitions of the condition, and prevalence estimates based off definition. Clinical research remains complex, but it seems to us that research on the implementation of existing treatment and the multi-dimensional patient pathway is really important to support patients.

Nienke Schutte: Thank you so much, Olivier. I think it is quite important that you show us, quite again, the consequences of the heterogeneous definition of Long COVID, and how the incidence varies depending on what definition you use. This is really important to take into account.

Discussion

Luc Nicolas: Are there any studies that have been made with the support of electronic patient health records?

Olivier Robineau: Electronic health records have been widely used for studies on Long COVID, especially in Great Britain. We also did this in France with 3 longitudinal studies, but these types of surveys have high levels of bias. So it is important to have longitudinal follow-up using this sort of data, but also to have cross-sectional survey to have a representative sample that is not biased by the survey.

Yvan Devaux: I have a call for participants. I am from the Luxembourg Institute of Health and we have been working on Long COVID projects since the beginning of the pandemic through projects with the European Commission and also Long COVID Europe. We would like to also set up a COST Action Proposal to bring together expertise on Long COVID and merge our competencies. If anyone is interested in joining this COST Action Proposal, please send me a message here: yvan.devau@lih.lu

Nienke Schutte: Thank you, Yvan. I think this really shows the importance of European collaboration on this topic. As we also heard a lot about fragmentation, these initiatives by the Commission and involvement in the network, and also a COST Action can be really helpful in sharing best practices and do network activities on the topic. It is very much needed!

Gunter Maier: It is interesting for me, because in Austria, there was an obligation to test for COVID, but now there is no obligation anymore, so our ability to identify the potential Long COVID patients is nullified as of now. Because we do not have the means to identify COVID patients, as they cannot

access COVID tests, there is no record that they had COVID. So Long COVID is often not diagnosed. So it is interesting for me to know, if there is an obligation to test for COVID in other countries.

Olivier Robineau: No obligation to test in France. This strongly raises questions on how to monitor the epidemiology of Post-COVID condition.

Sarah Moreels: In Belgium, there is also no obligation to test, so it is really difficult to monitor and identify people with Long COVID if they don't have an official COVID infection. And I think this is a problem in many European countries.

Oliver Cornely: In Germany, we are setting up an adaptive platform trial, FPI planned for January, with close involvement of 2 patient organisations in trial design.

Chantal Britt: Milo Puhan in Zurich has a cohort with 2-year data just published.

Sarah Moreels: In Belgium, there are also publications by Smith et al on a cohort study.

Concluding remarks

Today we have heard about the fragmentation across countries, the heterogeneity in defining Long COVID, the need for evidence-based guidelines, and also new and relevant studies from a more longitudinal perspective. I would like to thank the speakers and the audience for their participation, and close the Rapid Exchange Forum – Special Edition.

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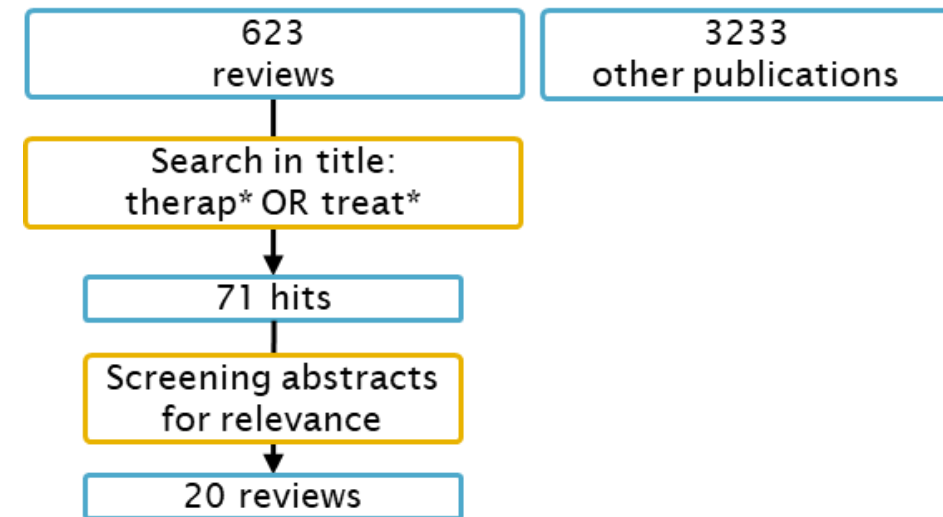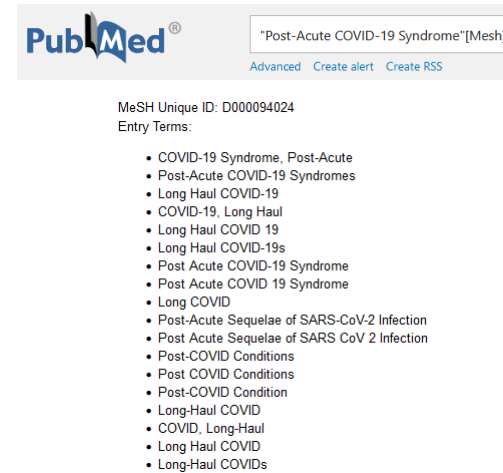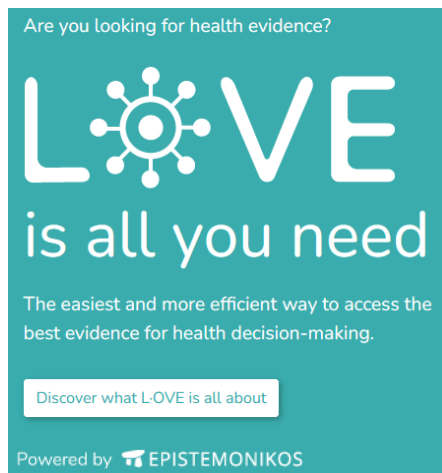# Rapid evidence synthesis: Interventions to treat long COVID

Richard Pentz, Austrian Public Health Institute (GÖG)

09.10.2023

Evidence base

24.08.2023

- PubMed: MeSH term „post-acute COVID-19 syndrome "
  - Filter: systematic reviews / meta-analyses / reviews
- Epistemonikos COVID L.OVE: category "Post COVID-19 condition"
  - Tags: systematic reviews / broad syntheses

Overview of systematic reviews

author	year	month	type	Included symptom groups	included interventions	included study designs	N RCTs
PAHO	2023	6	living SR	any	any	RCTs	65
Bonilla	2023	3	NR	any	pharmacological	interventional	1
Ceban	2023	3	SR	any	COVID-19 vaccine	any	0
Chandan	2023	2	SR	any	non-pharmacological	any	1
Fawzy	2023	1	Scoping Review	any	any	interventional	n.r.
Gawey	2023	6	SR	any	complementary and alternative medicine	any	0
Leng	2023	3	NR	neurocognitive	any	any	1
Rinn	2023	4	Scoping Review	any	digital interventions	any	1
Ceban	2022	1	Scoping Review	any	any	any	11
Chee	2022	11	SR	any	pharmacological	interventional	3
Fernández-Lázaro	2022	12	SR	respiratory physical fitness	therapeutic exercise	any	2
Linnhoff	2022	12	NR	cognitive fatigue	non-invasive brain stimulation	any	1
Luo	2022	9	protocol	any	TCM	RCTs	N/A
Mazza	2022	1	NR	depression	any	any	0
Gogoll	2021	10	NR	respiratory	any	any	0
Nna	2021	2	protocol	any	any	observational	N/A
Vollbracht	2021	3	SR	fatigue	vitamin C	any	0
Yong	2021	4	NR	any	any	any	0

N/A: not applicable; n. r.: not reported; NR: narrative review; RCT: randomised controlled trial; SR: systematic review; TCM: traditional Chinese medicine

PAHO living SR

LIVING SYSTEMATIC REVIEW OF THERAPEUTIC OPTIONS FOR POST-ACUTE AND POST-COVID19 CONDITION

June 16 2023

- Search: Epistemonikos COVID L.OVE, last search 16.06.2023

- Inclusion:
  - study design: RCT
  - population: long COVID patients
  - intervention: any
  - comparisons: placebo / no intervention / head-to-head
  - outcomes: mortality / HrQL / specific symptoms

- Quality assessment: Cochrane RoB 2.0

- Synthesis:
  - meta-analysis, risk ratios
  - GRADE approach
  - MCID thresholds (1 % for mortality; 2 % for HrQL; 5-10 % for symptoms)

766 446 records identified as potentially eligible in the COVID-19 L·OVE platform

94 276 records excluded based on population or type of article criteria

672 200 fulfilling definition of type of article included in COVID-19 L·OVE

323 750 records not corresponding to a primary study

348 450 primary studies

348 385 records not fulfilling inclusion criteria

65 RCTs included

Source: PAHO 2023; https://iris.paho.org/handle/10665.2/57104

Focused research question

- Excluded from PAHO results:
  - prophylaxis
  - PIMS-TS
  - head-to-head comparisons
- Included from PAHO results:
  - 50 RCTs
  - studying 34 individual interventions (> 50 % medicines, plant-based remedies or food supplements)
  - all comparing to "standard of care"
  - 7 symptom groups:
    - Asthenia / Fatigue (27 RCTs studying 19 interventions)
    - Respiratory symptoms (15 RCTs studying 7 interventions)
    - Neurocognitive symptoms (8 RCTs studying 8 interventions)
    - Olfactory / gustatory symptoms (11 RCTs studying 8 interventions)
    - Cardiovascular symptoms (1 RCT studying 1 intervention)
    - Psychologic symptoms (1 RCT studying 1 intervention)
    - + HrQL and/or AEs in some RCTs

AE: adverse event; HrQL: health-realted quality of life; PIMS-TS: Pediatric inflammatory multisystem syndrome associated with SARS-CoV-2; RCT: randomized controlled trial

Results

- RCTs included in PAHO SR*:
    - **methodological quality (very) low** in almost all available RCTs → high risk of bias
    - sample size (too) low in most RCTs (median n = 52.5; min 12 / max 444)
    - most interventions studied in only 1 or just few RCTs of low quality → low certainty of evidence
    - **limited evidence of effectiveness for 13 of 34 studied interventions**
    - moderate certainty of evidence that **respiratory training** improves respiratory outcomes and HrQL
    - low certainty of evidence for:

- additional RCTs**:
    - 1 RCT, n = 120, medium risk of bias: positive effects of telerehabilitation on asthenia, respiratory symptoms, HrQL
    - 1 RCT, n = 96; medium risk of bias: positive effects of ivermectin nasal spray on olfactory function

Asthenia / Fatigue
Actovegin
Respiratory training
AXA1125
ImmunoSEB + ProbioSEB CSC3
CBT
Physical training
Plant extracts
Telerehabilitation
tDCS

Respiratory symptoms
Treamid

Neurocognitive symptoms
Actovegin

Olfactory / gustatory symptoms
Palmitoylethanolamide + Luteolin

Psychological symptoms
VR information video

HrQL
Hypobaric oxygen
Physical training
Plant extracts
tDCS

Adverse events
Treamid

HrQL: health-realted quality of life; RCT: randomized controlled trial; tDCS: transcranial direct current stimulation
* certainty of evidence assessed using GRADE; ** certainty of evidence not assessed

Summary

Limitations:

- of RCTs / PAHO SR:
  - low quality
  - small sample size
  - heterogeneous definitions of long COVID (time since acute COVID between 14 and 180 days)
  - heterogeneous definitions of "standard of care"
- of GÖG rapid evidence synthesis:
  - limited search strategy (depending exclusively on MeSH term / tags)
  - no formal quality assessment of PAHO SR

Conclusions:

- high number of different interventions has been studied…
- …to produce almost exclusively low certainty evidence
- available evidence of limited use for patients, doctors or decision-makers
- better quality studies are needed, focusing on select interventions

Thank you for your attention

Dr. Richard Pentz

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Background

As most Long Covid cases are in non-hospitalized patients with a mild acute COVID-19 infection, **caring for patients with persistent COVID-19-related symptoms** is recommended to take place **in primary health care with general practitioners (GPs)** taking up a **key position.**

However …

➢ healthcare professionals have been uncertain as the most effective ways to manage Long Covid

➢ little is known about the diagnostic criteria used by GPs to identify patients with Long Covid

➢ limited knowledge on care provided for people with Long Covid symptoms in primary health care
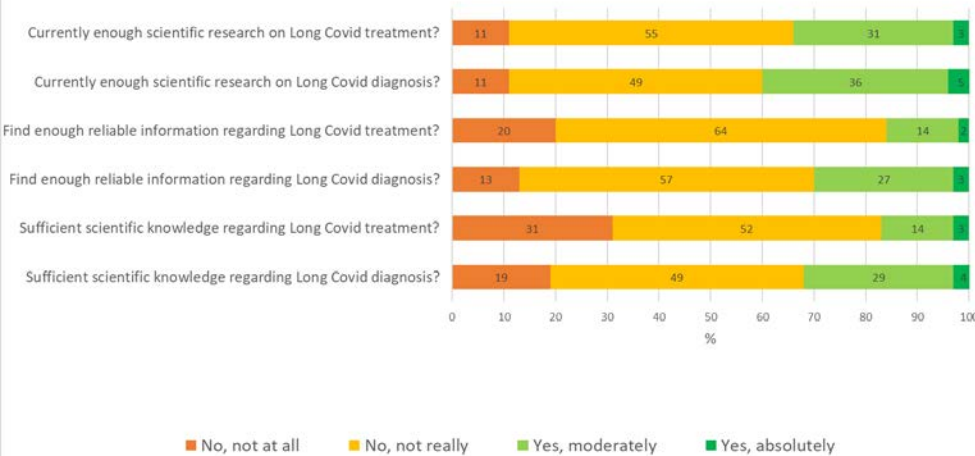
Aim of study: to gain **insight in** the **knowledge, perception and experience of GPs on Long Covid care**, in Belgium

Methods & participation

- Cross-sectional study design

  - ➢ Study population: all Belgian GPs

  - ➢ Survey (based on literature review, validated by experts)

- Online questionnaire

  - ➢ Spring 2022, voluntary participation

  - ➢ Distributed through established national GP networks (Sentinel General Practitioners network, Belgian GP associations: Domus Medica and SSMG)

  - ➢ Questions on (1) scientific knowledge and perception on Long Covid, (2) criteria implemented by GPs to make a Long Covid diagnosis, (3) GPs' experience on Long Covid care + practice and GP demographic characteristics

  - ➢ No definition included (as variety in definitions of post Covid-19 condition)

- Total response of 105 GPs

  - ➢ responding GPs are comparable with all Belgian GPs

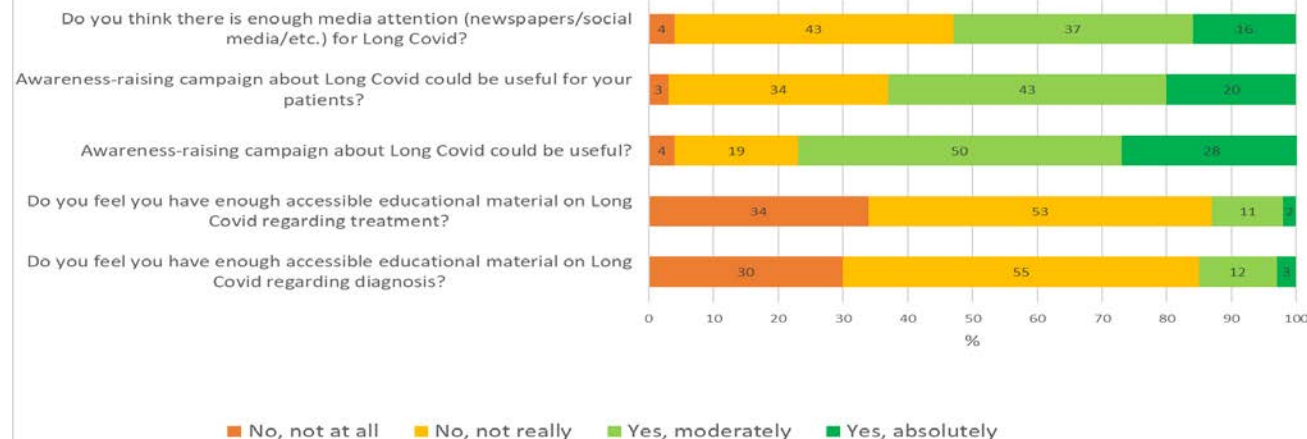# Results – GPs' knowledge and perception on Long Covid in Belgium

GPs' statements on scientific knowledge and available information on Long Covid

Statement	No, not at all	No, not really	Yes, moderately	Yes, absolutely
Currently enough scientific research on Long Covid treatment?	11	55	31	
Currently enough scientific research on Long Covid diagnosis?	11	49	36	5
Find enough reliable information regarding Long Covid treatment?	20	64	14	
Find enough reliable information regarding Long Covid diagnosis?	13	57	27	
Sufficient scientific knowledge regarding Long Covid treatment?	31	52	14	
Sufficient scientific knowledge regarding Long Covid diagnosis?	19	49	29	4

Legend: ■ No, not at all ■ No, not really ■ Yes, moderately ■ Yes, absolutely

Insufficient scientific knowledge + lack of reliable information on Long Covid diagnosis and treatment

Limited accessibility to educational material + awareness-raising campaign (for GPs and patients) is merited

GPs' statements on educational material and awareness campaigns for Long Covid

Statement	No, not at all	No, not really	Yes, moderately	Yes, absolutely
Do you think there is enough media attention (newspapers/social media/etc.) for Long Covid?	4	43	37	16
Awareness-raising campaign about Long Covid could be useful for your patients?	3	34	43	20
Awareness-raising campaign about Long Covid could be useful?	4	19	50	28
Do you feel you have enough accessible educational material on Long Covid regarding treatment?	34	53	11	
Do you feel you have enough accessible educational material on Long Covid regarding diagnosis?	30	55	12	

Legend: ■ No, not at all ■ No, not really ■ Yes, moderately ■ Yes, absolutely

Results – Caring for Long Covid patients

- **Majority of GPs** (75%) **provided care** to Long Covid patients (independently of practice type, GPs' gender or age)

- Estimation of 2 Long Covid patients per 1000 active patients (median) in Belgian general practice

- **Central position of GPs** in the coordination of care for Long Covid patients:

  - Follow-up for half of these patients (52%) by GP/GP colleagues

  - 33% by multidisciplinary cooperation

  - 15% solely by another healthcare provider / healthcare institution

  - GPs were consulted biweekly (18%), monthly (48%) or every few months (19%) by these Long Covid patients

- A **multidisciplinary approach is preferred** by 93% of GPs

  - multidisciplinary care for Long Covid patients was less organized than preferred by GPs at timing of the study

Results – Caring for Long Covid patients

- **To assess Long Covid in primary health care:**

  ➢ Duration of persistent symptoms (from 4 weeks to 5 months) as main criterion for identifying Long Covid patients

  ➢ GPs mainly applied diagnostic criteria by themselves (46%)

  ➢ 60% stated that a positive COVID-19 test result is required

- Long Covid patients suffered mainly from fatigue (95%), concentration/memory problems (75%), breathing difficulties (68%), impairment in daily functioning (67%) and brain fog (46%)

Long Covid symptoms in primary care, Belgium
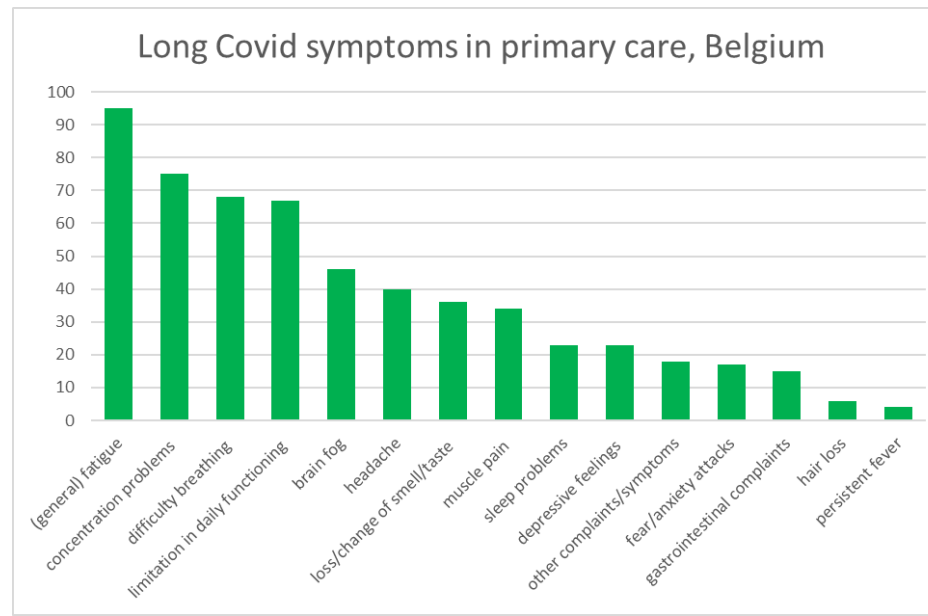
Conclusion

GPs take a key role in the (multidisciplinary) care for Long Covid patients in Belgian primary health care

- ➤ GPs frequently provide care to Long Covid patients

- ➤ similar diagnostic criteria used by GPs

- ➤ Barriers mentioned by GPs (at timing of study – Spring 2022)

    - ➤ establishment of the care trajectory 'post-Covid-19' for primary care patients since July 2022

    - ➤ publication of a Long Covid evidence-based guideline for primary healthcare professionals in November 2022

Cross-country validation:

- ➤ English version of survey distributed in Malta (Summer 2022)

- ➤ In both countries: most GPs care for Long Covid patients, similar diagnostic criteria were applied and same barriers mentioned by GPs

    => **Need for uniform evidence-based guidelines, scientific support and training for GPs** to help in their approach towards Long Covid **across Europe**

Long COVID Europe

Chantal Britt, Long COVID Europe (LCE)

PHIRI Rapid Exchange Forum on Long COVID research
9 October 2023, Zoom

Long COVID Europe (LCE)

- **Belgium -based NGO**
- non-state actor **accredited by WHO** Regional Office for Europe
- **Network of international/national Long Covid patient groups** from 15 European countries incl. UK and Switzerland

LCE activities

- Raise **awareness**, advocate for support, research funding
- **coordinate** efforts, **exchange** information and good practice examples, **support** members (differences)
- **represent patient views and needs** in advisory boards, government working groups, research steering committees, guideline drafting teams (WHO/national), conferences, education programmes

What is Long Covid? – facts and figures

- **36 million people affected** – in WHO Europe region in 3 years, 1 in 30 in the overall population (prevalence 3%)
- **75% don't recover** – of people with chronic symptoms impacting daily activities (after 6 months) only 25% fully recover.
- **~45 years old, women with double the risk** (men more at risk for less frequent acute Covid), children/elderly also affected
- **No treatment available, no objective biomarkers**
- **Stigma, medical gaslighting, psychologisation**
- **Underfunded chronic condition**

Main challenges

- **Lack of recognition** (complex, subjective, lazy or crazy)
- **Lack of (relevant) data** (medical: prevalence, subtypes, associated (post-infectious) conditions, therapy effect & safety, social/eco impact
- **Lack of (relevant) research** funding, coordination, harmonization, (underfunded) basic research (inexistent, incomplete, & irrelevant)
- **Lack of knowledge** (healthcare system, medical training, social security)
- **Lack of PPI** – set research priorities & fulfil needs (patient-centered)
- **Overlap with ME/CFS ; costs EUR40 billion/year in Europe** (ex Covid)
- **Fragmentation** – heterogenous **national economies and healthcare systems** across Europe

Recommendations

- **Recognition**, **standardized definitions, adequate care pathways** (also children)
- **Europe-wide statistics/data coordination & harmonisation** – registries for long Covid & ME/CFS case numbers & progression
- **Europe-wide coordination and support of research efforts**
- **Support structures** for healthcare, research, social security, labour
- LCE requests >**EUR 500 mln in (public!) funding** for **patient-centered** research (Charité fatigue clinic privately funded)
- **Research into medicine, therapies, burden, socio-economic impact** of long Covid and ME/CFS
- **Patient and public involvement in policies, healthcare & research**

Thank you for your attention.

Long COVID Europe (LCE), Chantal Britt, Co-Chair

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