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# Barriers and facilitators of healthcare access for long COVID-19 patients in a universal healthcare system: qualitative evidence from Austria

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## Abstract

**Background** Long COVID-19 challenges health and social systems globally. International research finds major inequalities in prevalence and healthcare utilization as patients describe difficulties with accessing health care. In order to improve long-term outcomes it is vital to understand any underlying access barriers, for which relevant evidence on long COVID-19 is thus far lacking in a universal healthcare system like Austria. This study aims to comprehensively identify access barriers and facilitators faced by long COVID-19 patients in Austria and explore potential socioeconomic and demographic drivers in health and social care access.

**Methods** Applying an exploratory qualitative approach, we conducted semi-structured interviews with 15 experts including medical professionals and senior health officials as well as focus groups with 18 patients with confirmed long COVID-19 diagnosis reflecting varying participant characteristics (age, gender, urbanicity, occupation, education, insurance status) (July–Nov 2023). Data were analysed following a thematic framework approach, drawing on a comprehensive ‘access to health care’ model.

**Results** Based on expert and patient experiences, several access barriers and facilitators emerged along all dimensions of the model. Main themes included scepticism and stigma by medical professionals, difficulties in finding knowledgeable doctors, limited specialist capacities in the ambulatory care sector, long waiting times for specialist care, and limited statutory health insurance coverage of treatments resulting in high out-of-pocket payments. Patients experienced constant self-organization of their patient pathway as stressful, emphasizing the need for multidisciplinary care and centralized coordination. Facilitators included supportive social environments, telemedicine, and informal information provided by a nationwide patient-led support group. Differences in patient experiences emerged, among others, as women and younger patients faced gender- and age-based stigmatization. Complementary health insurance reduced the financial strain, however, did not ease capacity constraints, which were particularly challenging for those living in rural areas.

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**Conclusions** The findings of this study indicate a call for action to improve the long COVID-19 situation in Austria by empowering both providers and patients via increased information offerings, strengthened interdisciplinary treatment structures and telemedicine offerings as well as research funding. Our insights on potentially relevant socioeconomic and demographic drivers in access barriers lay the necessary foundation for future quantitative inequality research.

**Keywords** Long COVID-19, Post COVID-19 syndrome, Barriers, Facilitators, Healthcare access, Socioeconomic, Demographic, Inequalities

## Introduction

Timely access to relevant health and social care for all is essential to ensure good population health and health equity. However, different access barriers prevail across population groups and particularly among socioeconomically disadvantaged groups and minorities [1]. Consequently, it is essential to understand those barriers and how to potentially tackle them. People with chronic conditions often have to overcome multiple barriers when trying to access healthcare, delaying or ultimately preventing required treatment and putting an additional burden on patients [2, 3]. A growing body of research indicates that this is also the case for those suffering from the comparatively novel, post-viral condition long COVID-19 (LC) [4–13].

While the prevalence of LC is difficult to reliably determine due to the lack of a uniform definition, highly heterogeneous study results, and poor quality of conducted studies [14], an international meta-analysis published in 2023 reported an average prevalence of 45% of all COVID-19 patients [15]. In comparison, the Austrian National Public Health Institute estimates a prevalence of 10–20% for complaints over six weeks and 2–5% for complaints over twelve weeks in Austria, Germany, and Switzerland [14]. Based on over 750 million COVID-19 cases to date globally [16], applying even conservative estimates would result in a substantial number of (previously) affected individuals.

Identified risk factors to develop the condition in the first place include female sex, younger age, belonging to an ethnic minority, socioeconomic deprivation, comorbidities, severity of the acute disease, and obesity [17–19]. LC patients suffer from a heterogeneous range of physical and psychological symptoms including post-exertional malaise (PEM), postural orthostatic tachycardia syndrome (POTS), mast cell activation syndrome (MCAS), or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [15, 20–23]. These lead to productivity losses due to sick leaves, reduced productivity when working, or reduced working hours [24, 25], as well as increased healthcare needs and corresponding utilization [19, 26, 27].

To support clinicians and patients, many countries such as Austria, the United Kingdom (UK), Germany, and Canada designed clinical pathways and guidelines for

LC, determining the intended care for patients [28–30]. Most commonly, general practitioners (GPs) and primary care were designated to be the first point of contact and foreseen to conduct an initial assessment based on the provided guidelines, followed by targeted specialist care and rehabilitation as necessary [28, 29, 31]. Considering the higher LC risk of severe COVID-19 cases, the UK, the US, and the Netherlands also provided a direct entry to the care pathway for hospitalized COVID-19 patients via specialist follow-ups after discharge [28, 29]. In addition to leveraging existing resources, at least 22 OECD countries introduced specialised, usually multidisciplinary clinics for LC patients to account for the complexity of the disease [28, 31]. Moreover, countries like Belgium and France dedicated resources to coordinate patient pathways and most countries developed guidelines for self-management [28]. Many countries also set up mechanisms such as ongoing trainings for doctors to be able to disseminate newly available information effectively and actively involved patients in developing their LC response to inform the underlying assessment and ensure patient-centred approaches [28].

Nevertheless, exploratory international evidence on the general experiences of LC patients suggests difficulties in accessing required healthcare services [4–9]. Described challenges include limited availability of appropriate services and expertise [4–7], a wide range of varying symptoms making it hard to accurately navigate the system [4, 8], financial stress resulting from care expenses and reduced income [7] as well as experienced stigma and medical scepticism [5–9]. Building on this research, further studies focusing explicitly on access barriers confirmed those findings and further identified barriers such as bureaucratic requirements [12], appointment logistics including waiting times and transportation [10, 11], affordability of services [10], insufficient communication across service providers [13], and a lack of continuity in care [13]. By contrast, facilitators to access healthcare included multidisciplinary, patient-centred approaches, persistence and self-management by patients as well as feeling taken seriously [10, 11, 13].

It is still unclear whether these existing barriers and facilitators are encountered by all LC patients equally or if there are inequalities in line with – or beyond – the abovementioned risk factors to develop LC or symptoms

of LC (e.g., due to myocarditis or ME/CFS) [17–19]. So far, only few studies investigated relevant barriers and facilitators to assess potential inequalities [10–13]. While a German focus group [12] and Canadian interview [10] study provide first insights in this regard, they solely focus on the patients' perspectives while omitting expert (e.g., healthcare professionals) viewpoints. Also, first exploratory research on the experiences of GPs with LC has recently been conducted and published as a preprint [32]. Baz et al. [11] and Turk et al. [13] complement their patient interviews with healthcare professional interviews, however, these data were collected in the UK where the healthcare system uses GPs as gatekeepers, single access point, and main treatment coordinator [33]. Consequently, a research gap remains regarding the comprehensive identification of access barriers and facilitators involving both LC patient and expert perspectives in a universal healthcare system without such a gatekeeping system in place.

Austria is an interesting example in this regard, operating a two-tier universal healthcare system with 99.9% of the population covered by statutory health insurance [34] and no formal gatekeeping mechanism to access specialist care [35], placing the Austrian healthcare system 4th best regarding unmet needs for medical examination due to financial, geographic or waiting time reasons among the EU27 in 2020 [36]. Nonetheless, healthcare service provision also includes a sizeable private for-profit sector: 38% of the population have private complementary health insurance covering additional services/treatments or appointments with (private) doctors not contracted by statutory health insurance [37, 38]. This is also reflected in recent developments in the provider landscape. While the number of non-contracted doctors increased by more than 40% to around 11,300 between 2011 and 2023, the number of contracted ones decreased by roughly 2% to 8,300 [39], putting pressure on the public system.

However, when comparing Austria to the three health systems investigated in the studies outlined above (Table 1), Germany [12], the UK [11, 13], and Canada [10], Austria still has the highest number of generalist medical practitioners per capita and substantially more specialists than the UK and Canada [40]. It also offers an above-OECD-average number of hospital beds per capita, reflecting a tendency to conduct procedures in an inpatient rather than ambulatory care setting similarly to Germany [41–43]. Spending around 11% of its GDP on health expenditure, Austria also commits substantially more resources than the OECD average of 9.2% although marginally less than Germany and Canada [44, 45]. Overall, the Austrian health system could be considered as having been well equipped to take on the complex challenges posed by LC. Building on above-average available health resources, Austria like the three other countries

developed a clinical guideline putting GPs in the centre, introduced specialist LC clinics, and involved patients to identify challenges such as lacking coordination of care and inform priorities such as expansion of specialist clinics [14, 23, 28]. However, other than Canada it did not report introducing a specific mechanism to quickly disseminate LC information to doctors but rather relied on already existing channels and the five-year cycle in which doctors need to meet ongoing training requirements [28, 46]. Austria also committed substantially less funding for dedicated LC research than the other countries at approximately €0.10 per capita compared to €0.80–1.00 and drastically less than the United States at almost €4.60 per capita [47–52]. A detailed comparison of selected indicators for the four countries and the OECD average can be found in Table 1, highlighting Austria's comparatively advantaged structural starting point for responding to LC.

To date, Austrian research has not yet examined the access barriers and facilitators encountered by LC patients. However, differences in health services utilization by socioeconomic and demographic characteristics were previously investigated irrespective of disease [53–56]. In these studies, lower income, lower education, and having a migration background were found to be associated with a worse health status and health behaviour [57] – which is in contrast to the Austrian health targets stating the goal “to promote fair and equal opportunities in health, irrespective of gender, socio-economic group, ethnic origin and age” [58]. Research on general barriers to healthcare access in Austria has been conducted for specific sub-populations [59, 60] and chronic conditions [3]. Identified barriers included stigmatization, discrimination, insufficient health literacy, insufficient service availability and capacity, language barriers, and inflexible healthcare structures [3, 59, 60].

Against this background, this study aims to answer two research questions:

1. *What are system- and patient-related barriers and facilitators of healthcare access encountered by LC patients from the onset of healthcare needs all the way to healthcare consequences in a universal healthcare system without gatekeeping?*
2. *Which socioeconomic and demographic patient characteristics are potentially driving inequalities in LC healthcare access?*

We use Austria as an empirical example and adopt a qualitative approach drawing on both patient and expert perspectives, thereby providing the necessary foundation for future quantitative inequality studies.

**Table 1** Fact sheet general and long COVID-19-specific health system indicators in OECD comparison

Indicator	AUT	GER	UK	CAN	OECD	Year (latest available)	Source
Life expectancy at birth	<b>81.6</b>	80.7	80.4	81.6	80.3	AUT 2023, GER 2022, UK 2020, CAN 2021, OECD 2021	[74, 75]
% of population in the same age with a good or very good perceived health status	<b>69.2</b>	65.5	72.9	n/a	69.8	AUT 2023, GER 2023, UK 2020, OECD 2021	[76, 77]
GDP per capita in €, purchasing power parity converted at current prices	<b>66,480</b>	62,500	53,104	55,578	53,204	2023	[78]
Health expenditure in % of GDP	<b>11.0</b>	11.8	10.9	11.2	9.2	2023, OECD 2022	[44, 45]
thereof government/compulsory schemes	<b>8.5</b>	10.1	8.9	7.9	7.0	2023, OECD 2022	
thereof voluntary/out-of-pocket	<b>2.5</b>	1.7	2.0	3.3	2.2	2023, OECD 2022	
Committed research funding to long COVID-19 in million €	<b>1.0</b>	81.0	59.0	30.9	n/a		[47–50]
per capita in €	<b>0.1</b>	1.0	0.9	0.8	n/a		[52]
Number of hospital beds per 1,000 capita	<b>6.9</b>	7.8	2.4	2.6	4.3	2021	[41]
% of cataract surgeries carried out in ambulatory setting	<b>91.5</b>	88.0	99.3	99.8	93.8	2021	[42]
% of tonsillectomies carried out in ambulatory setting	<b>0.7</b>	15.2	70.2	75.2	40.0	2021	[43]
Number of medical practitioners per 1,000 capita generalist	<b>1.4</b>	1.1	0.8	1.3	n/a	AUT 2023, GER 2022, UK 2023, CAN 2022	[40]
specialist	<b>3.1</b>	3.5	2.5	1.5	n/a	AUT 2023, GER 2022, UK 2023, CAN 2022	
% of population satisfied with the availability of quality health care in the area where they live	<b>84.0</b>	85.0	67.0	56.0	66.8	2022	[79]
Cycle length for doctors to prove meeting of ongoing training criteria in years	<b>5.0</b>	5.0	5.0	5.0	n/a	2024	[46, 80–82]
% of population covered by government/compulsory health insurance	<b>99.9</b>	99.9	100.0	100.0	97.9	AUT 2022, GER 2022, UK 2022, CAN 2023, OECD 2021	[83]
voluntary health insurance	<b>38.1</b>	27.3	10.9	69.0	40.8	AUT 2022, GER 2022, UK 2022, CAN 2023, OECD 2021	[84]
% of population reporting unmet healthcare needs due to waiting times	<b>0.1</b>	0	n/a	n/a	1.4	2021	[85]
costs	<b>0.1</b>	0.1	n/a	n/a	0.8	2021	
distance	<b>0</b>	0	n/a	n/a	0.1	2021	
% of population skipping the following due to costs consultation	<b>5.2</b>	3.5	4.6	5.2	7.8	AUT 2019, GER 2020, UK 2020, CAN 2020, OECD 2021	[87, 88]
medical tests, treatment or follow-up	<b>n/a</b>	4.2	3.5	5.7	7.8	2020, OECD 2021	
prescribed medicines	<b>3.3</b>	6.2	5.6	9.3	4.0	AUT 2019, GER 2020, UK 2020, CAN 2020, OECD 2021	

Note Austria (AUT), Germany (GER), United Kingdom (UK), Canada (CAN), Organization for Economic Co-operation and Development (OECD) as average, gross domestic product (GDP), n/a (not available)

## Methods and data

### Study design

This study applies an exploratory, qualitative design based on semi-structured interviews and focus groups to address the outlined research questions. Participants were recruited to provide insights from three relevant perspectives: (i) provider perspective, (ii) non-provider expert perspective, and (iii) the patient perspective. Perspectives (i) and (ii) were collected in individual interviews whereas patients took part in focus groups of up

to four participants. Focus groups were chosen as the direct exchange between participants enables them to remember, confirm and challenge details of their own experience when mentioned by others [61]. Moreover, we thereby were able to minimize the burden of participation and allow participants to take breaks and only contribute to certain questions, so focus groups posed the most appropriate data collection method for these study participants. The study was reported following the Standards for Reporting Qualitative Research (SRQR) [62]

and the corresponding checklist can be found in supplementary material A1.

**Conceptual framework**

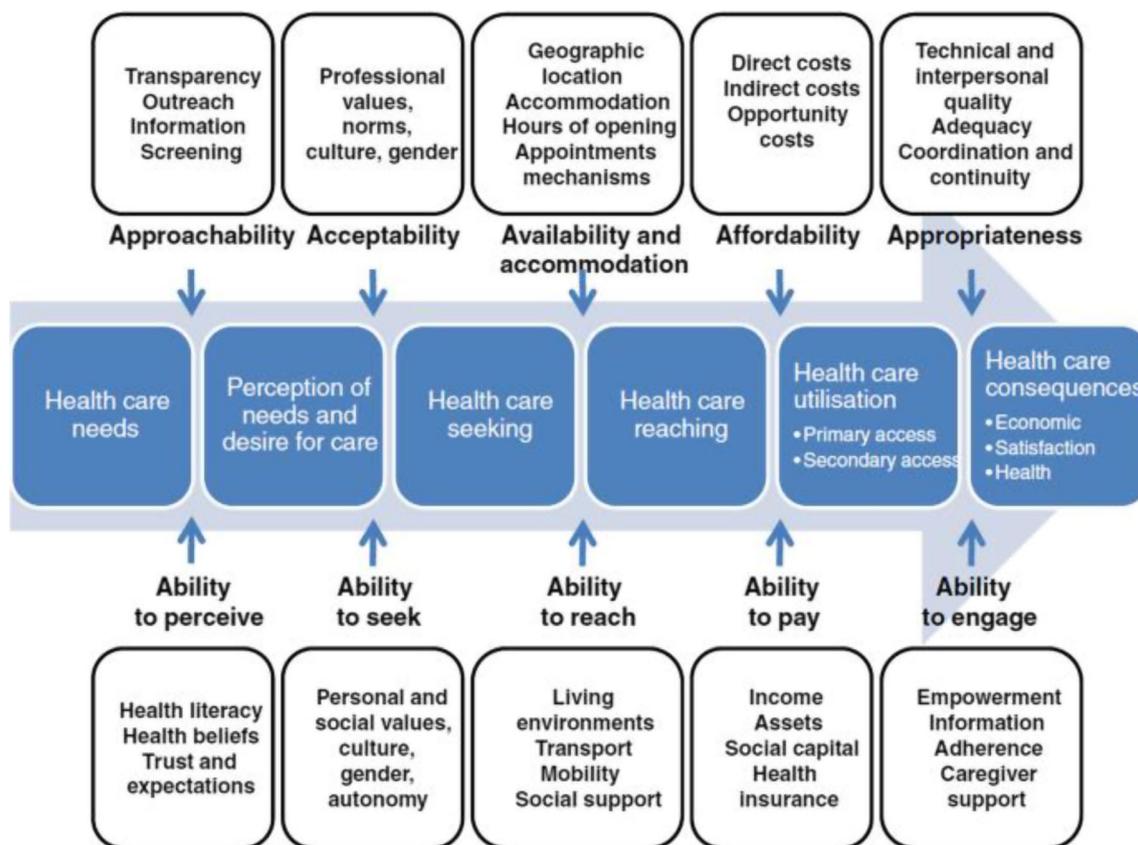
We applied a codebook thematic analysis following Braun and Clarke [63, 64], using a framework analysis approach to analyse all transcripts [65]. The framework employed in this study was developed by Levesque et al. (2013), aiming to comprehensively assess access to healthcare and was previously applied in empirical inequality research [3, 66]. As visualized in Fig. 1, the framework considers five dimensions of healthcare access from healthcare need to healthcare use and consequences including health, economic, and satisfaction. Each dimension combines the characteristics of healthcare systems including providers (upper part) and the characteristics/abilities of populations including persons, social, and physical environments (lower part) [67]. A more detailed summary of the model's dimensions can be found in the supplementary material A2.

**Recruitment**

Recruiting of (non-)provider experts (perspectives i and ii) was conducted via purposive and subsequent snowball sampling. Purposive sampling refers to selecting

participants based on their knowledge on the topic of interest, which was particularly necessary given the novelty of LC at the time of study initiation in early 2023. Interview participants were identified via initial referrals by experts on LC within the Medical University of Vienna and subsequently via recommendations by interviewed experts [68]. The official Austrian guideline on postviral conditions including LC relevant to this study follows the LC definition developed by the UK National Institute for Health and Care Excellence (NICE) [23]. It distinguishes acute COVID-19 (up to four weeks), ongoing symptomatic COVID-19 (from four weeks up to 12 weeks), and post-COVID-19 syndrome [30]. The latter refers to symptoms developed during or after a COVID-19 infection that “continue for more than 12 weeks and are not explained by an alternative diagnosis” [30]. The often used term “long COVID-19” was initially coined by patients [69] and picked up in the NICE definition, referring to both ongoing symptomatic COVID-19 and post-COVID-19 syndrome [30].

In total, 32 experts on LC in Austria were contacted, of which 15 agreed to participate. Expert recruiting continued until all major stakeholder perspectives were covered, namely primary and specialist care clinicians of different LC-relevant disciplines as well as senior health



**Fig. 1** Access to healthcare framework by Levesque et al. [67]. Permission to use this conceptual visualization was obtained from Jean-Frederic Levesque

officials such as public policy experts, statutory health insurance managers, and leading members of LC scientific associations advising the ministry of health. Moreover, theoretical saturation was evaluated on a rolling basis and achieved with the initial sample. In an effort to also derive insights on the LC situation of the most socioeconomically deprived patients, we contacted three providers of medical services to homeless and uninsured people in Austria to enquire potential expert interview partners. While one provider did not get back to us, the other two turned down the invitation, arguing that LC was not typically diagnosed in their patients due to many and often severe pre-existing medical conditions. The main participant characteristics of interviewed experts are presented in Table 2.

Patients (perspective iii) were recruited following a convenience sampling approach. The study details were shared in the patient-led *Long COVID Austria* support group on Facebook and with the research team's personal networks. The latter also resulted in recommendations of patients not part of the support group, thereby complementing the sample. Eligible patients had to be at least 18 years of age, Austrian residents, conversational in either German or English, and give informed consent to participate. Patients either had to be suffering from acute LC or had to have recovered no longer than three months prior to data collection. No proof of LC was required, yet all participants stated they had received a formal diagnosis.

**Table 2** Characteristics of interviewed experts

Participant	Gender	(Medical) expertise	Region
E1	Female	Specialist and health authority	Nationwide
E2	Female	General practice, scientific society, and scientific advisory body	Nationwide
E3	Male	Statutory health insurance	Nationwide
E4	Female	Specialist and scientific society	Nationwide
E5	Female	Advocacy group	Nationwide
E6	Female	Advocacy group	Nationwide
E7	Male	General Practice	Vienna
E8	Male	General Practice	Vienna
E9	Male	Specialist	Nationwide
E10	Female	Specialist	Tyrol
E11	Female	Specialist and scientific society	Nationwide
E12	Male	Specialist, scientific society, and scientific advisory body	Vienna
E13	Male	Specialist and scientific advisory body	Vienna
E14	Male	Specialist and scientific advisory body	Vienna
E15	Female	Specialist and scientific society	Nationwide

Twenty-six patients initially agreed to participate, however, eight dropped out or stopped responding to the research team. This resulted in 18 patients ultimately participating in 7 focus groups. A summary of the recruiting process is presented in Fig. 2.

Prior to scheduling, all patients completed five brief questions on their socioeconomic and demographic background via email. Relevant characteristics were derived from previous research on either LC contraction [17, 18, 70] or inequalities in healthcare utilization [54, 71, 72]. Questions covered age, gender, urbanicity, occupation, education, employment and complementary health insurance status. Focus groups were subsequently scheduled based on availabilities and, as feasible, selected socioeconomic and demographic characteristics, leading to four all-female, two all-male, and one medical occupation group.

Patient recruitment prior to scheduling continued until all relevant socioeconomic and demographic characteristics were represented in the sample. Theoretical saturation regarding the derived insights was evaluated on a rolling basis and achieved with the initial sample. Out of 18 participating patients, 13 (72%) were female, one (6%) had already recovered from long COVID-19, and six (33%) were 30 years of age or younger. Patients started developing persistent symptoms as early as November 2020 and got infected with COVID-19 in various waves of the pandemic as displayed in Fig. 3. Detailed patient characteristics are presented in Table 3.

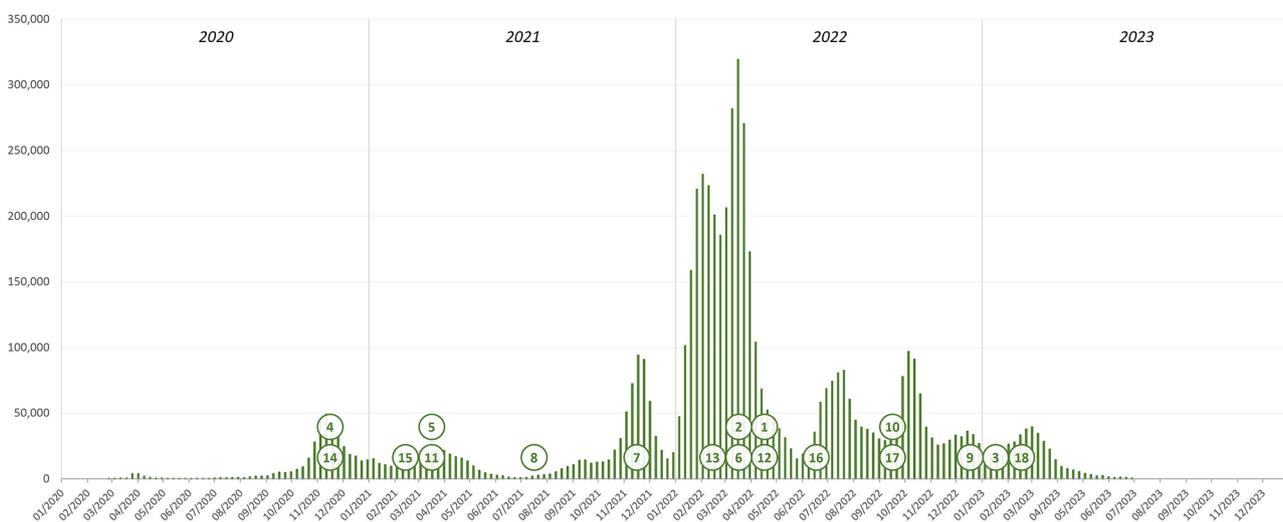
### Data collection

Data was collected in a semi-structured format to give participants sufficient space to share their experiences and – in the case of focus groups – interact with each other. A set of predetermined, open-ended questions was used, complemented by questions arising over the course of the interview [73]. Guiding questions for experts (perspectives i and ii) focused on the LC patient pathway including potential barriers and facilitators, existing health and social care infrastructure, and socioeconomic and demographic patient characteristics. For patients (perspective iii), the focus was on the respective experiences along their patient pathway, including barriers and facilitators faced in access to health and other relevant care. The guiding questions (in English) can be found in the supplementary material A3-5.

Interviews and focus groups were conducted either in person or virtually via WebEx as per participant's preference. All patients decided to participate in the focus groups virtually. Indeed, they were appreciative of the option as some would have been prevented from participating otherwise due to their health status and/or geographical location. Individual interviews lasted 20–30 min, focus groups 50–60 min. Participants were



**Fig. 2** Overview of the recruitment process



**Fig. 3** New weekly COVID-19 cases in Austria and participants' COVID-19 infection dates [89]

**Table 3** Socioeconomic, demographic, and long COVID-19 characteristics of patients

Participant	Gender	Age	Region	Rural/urban	Education	Currently working	Reduced working hours	Complementary health insurance	Long COVID-19 duration	Recovered
P1	Male	21–25	Upper Austria	Rural	Matura (A-level equ.)	No	-	No	1.5 years	No
P2	Female	36–40	Vienna	Urban	Matura (A-level equ.)	No	-	No	1.6 years	No
P3	Male	51–55	Styria	Rural	Matura (A-level equ.)	No	-	No	0.8 years	No
P4	Female	56–60	Burgenland	Rural	Vocational training	Yes	Yes	No	2.9 years	No
P5	Female	56–60	Upper Austria	Rural	University	No	-	No	2.6 years	No
P6	Female	36–40	Vienna	Urban	Matura (A-level equ.)	No	-	No	1.6 years	No
P7	Female	26–30	Vienna	Urban	University	No	-	No	1.9 years	No
P8	Male	36–40	Upper Austria	Rural	Vocational training	No	-	No	2.3 years	No
P9	Male	56–60	Vienna	Urban	Matura (A-level equ.)	Yes	No	No	0.8 years	No
P10	Female	26–30	Vienna	Urban	University	Yes	Yes	No	1.1 years	No
P11	Female	41–45	Styria	Rural	Matura (A-level equ.)	No	-	No	2.6 years	No
P12	Female	46–50	Tyrol	Rural	Matura (A-level equ.)	Yes	No	Yes	1.5 years	No
P13	Female	31–35	Vienna	Urban	University	Yes	Yes	No	1.7 years	No
P14	Female	41–45	Lower Austria	Urban	University	Yes	No	No	2.9 years	No
P15	Male	26–30	Lower Austria	Rural	Vocational training	No	-	No	2.7 years	No
P16	Female	31–35	Vienna	Urban	University	Yes	Yes	Yes	1.3 years	No
P17	Female	26–30	Vienna	Urban	University	Yes	Yes	No	1.1 years	No
P18	Female	21–25	Vienna	Urban	University	Yes	No	No	0.5 years	Yes

Note Long COVID-19 duration calculated until either recovery or time of focus group participation and numbers are rounded. All focus groups took place in October 2023

offered the option to take breaks or leave the interviews/focus groups anytime, however, no one took up the offer. For their participation, patients received a compensation of 30€ in the form of vouchers. The first interviews and all focus groups were jointly led by PG and SM. Following feedback by SM, PG led the remaining interviews. Data collection was conducted in German and took place between July and November 2023.

### Analysis

Recordings were transcribed verbatim by a professional provider contracted by the Medical University of Vienna and transcripts subsequently quality-checked by PG and independently at least one other member of the research team (SM, AŁ). Following the thematic framework analysis approach [63, 64], themes and sub-themes were deductively developed based on the previously introduced framework by Levesque et al. [67] visualized in Fig. 1. Furthermore, additional sub-themes were developed inductively, for example psychosomatic diagnoses, ignored expertise of doctors, and experienced sexism as sub-themes for *Acceptability*. Potentially relevant socioeconomic and demographic characteristics were initially

identified based on the patient focus group transcripts and patient background information as well as cross-checked with the expert interviews.

All transcripts were double-coded by PG and SM or AŁ. Disputed coded segments were discussed and decided on in the research team (PG, SM, AŁ, SK) as ultimately were findings and interpretations in light of the respective socioeconomic and demographic participant background. Quotes included in this manuscript were translated to English by PG and checked by SM and AŁ. Data analysis was conducted using the qualitative analysis software MAXQDA 24.

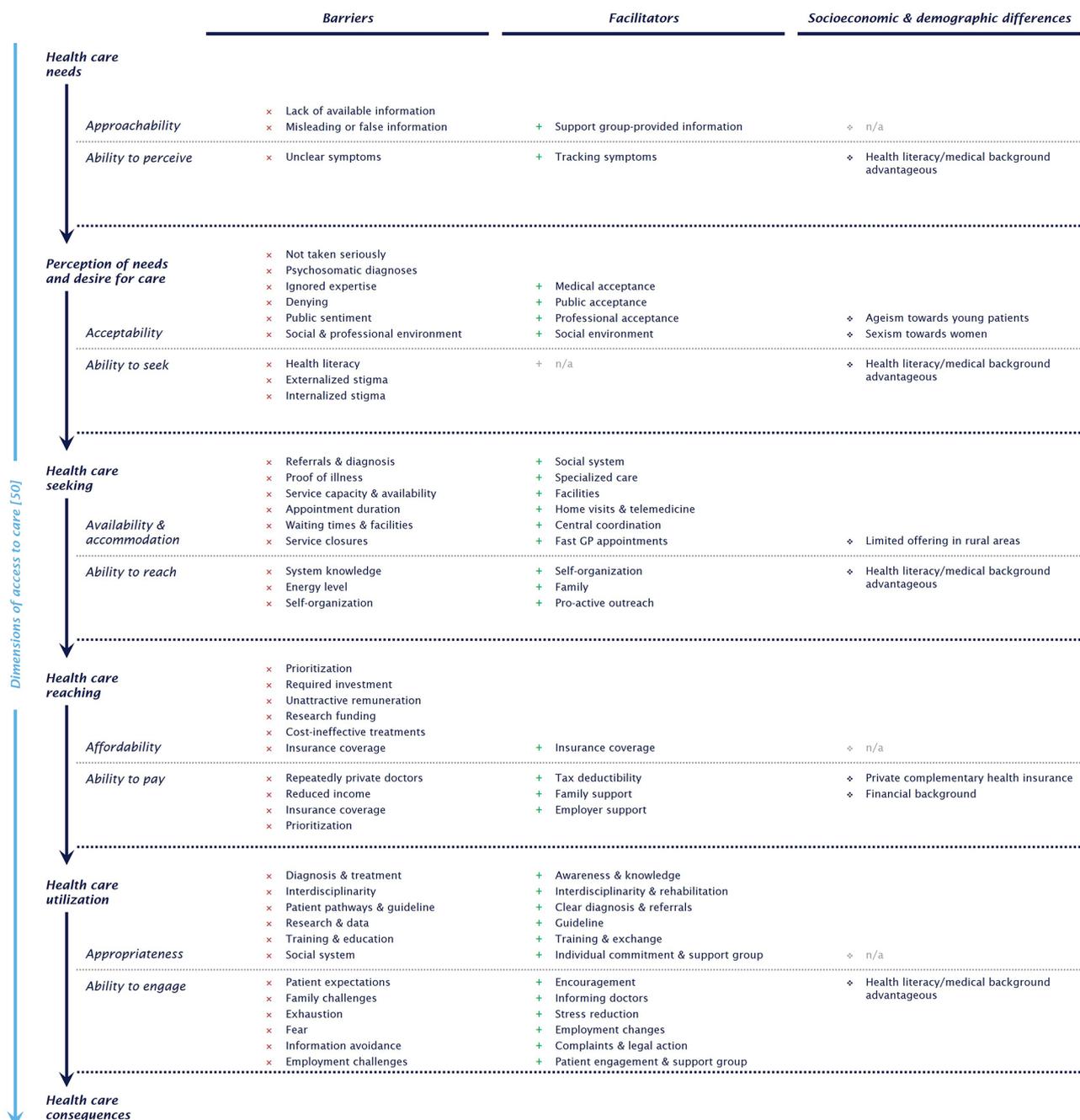
### Reflexivity

PG has extensive professional experience in conducting expert interviews and SM was trained in qualitative methods and previously conducted, analysed and published qualitative research in an academic context. In addition, both PG and SM completed specialized qualitative training courses including thematic analysis to prepare for this study. Both interviewers PG and SM are academic researchers. PG is a male PhD candidate in health economics and public health and works as a senior

scientist whereas SM is a female associate professor holding a PhD in socioeconomics. The research team did not have any prior relationship with any of the participants at the time of data collection except for two clinical experts who are acquaintances of PG. They were not involved at any stage of this study other than their own interviews. Neither the research team nor any person close to them have been diagnosed with LC at the time of data collection.

### Results

Following the framework by Levesque et al. [67], findings are presented along the ten steps of the ‘access to health care’ model, supported by expert (E) and patient (P) quotes. A condensed summary of the key results is presented in Fig. 4. Further selected quotes are listed in supplementary material A6-7.



**Fig. 4** Summary of identified barriers, facilitators, and socioeconomic and demographic differences organized in Levesque et al.'s framework [67]

### Approachability

After symptom onset, patients reported a lack of available and easily accessible information on relevant services as well as medical information on symptoms and the condition, particularly by health authorities. In some cases, available online information was perceived as misleading or eventually turned out to be incorrect and GPs themselves did not know where to refer patients. As a result, patients required substantial effort to initially find appropriate services.

*"I found the main difficulty was to know what offers there are, what can I do, what is available at all? This information is not really easily accessible. You have to do an insane amount of research and [...] I find it very, very difficult that there isn't a list of contacts you can trust. There is also a lot of nonsense circulating and you have to be able to differentiate." (P5).*

*"It is basically impossible [for patients] to find out quickly and easily where to go for long COVID." (E9).*

Clinical experts working as GPs confirmed the patient perspective and added that they also felt left in the dark regarding the exact requirements and procedures conducted at specialist LC outpatient hospital departments.

In response to scarce official information, the patient-founded and -led support group *Long Covid Austria* curated a list of specialized services and made it available to members, which patients deemed extremely helpful. Moreover, patients informally exchanged referrals and selected media coverage by traditional outlets incorporating scientific evidence was seen as helpful to learn more about the condition itself and available services such as rehabilitation.

### Ability to perceive

Barriers in the ability to perceive healthcare needs were experienced twofold. Patients described having difficulties attributing unspecific symptoms to the condition and resorted to self-track vital signs such as heart rate or blood pressure. Experts observed a split pattern in this regard: On the one hand, patients showed a low awareness of LC as a condition. On the other hand, patients displayed an increased sensibility towards symptoms and tended to self-diagnose. Having a medical background and therefore presumed high health literacy turned out to be a relevant socioeconomic patient characteristic in this regard, improving patients' ability to perceive and assess their symptoms. Subsequently, it was difficult for patients to accept their diagnosed or suspected condition and the limitations and consequences that came with it. In this context, patients also found it challenging to actively communicate those limitations in either professional or private settings.

*"When I got home, I really didn't want to know anything about doctors and Long COVID anymore and thought to*

*myself, 'no.' I couldn't actually quite believe that I might have POTS [postural orthostatic tachycardia syndrome] although I recognised the signs, and I thought to myself, okay, that's probably what it is, but I still thought, no, I still don't feel like that." (P17).*

### Acceptability

Patients had to deal with scepticism by medical professionals as well as in their personal and professional environments. Encounters with medical professionals turned out to be a major challenge to patients and many had to switch doctors multiple times before they felt like their condition was finally accepted as such. Experiences ranged from symptoms not being taken seriously and downplayed over unsubstantiated psychosomatic diagnoses all the way to denial of the existence of LC. This gave patients the impression that they constantly had to justify themselves.

*"Then I went to the GP. He said, well, if I got to the 2nd floor by foot, then it can't be that bad. Then I thought to myself, 'no, sorry, I went ski touring for 1,000 meters in January' and I felt better than I do now on the 2nd floor, just as a comparison. Unfortunately, he didn't take me seriously at the beginning." (P13).*

In this regard, demographic characteristics significantly affected patients' experiences and were highlighted by patients and experts alike, as women described not being taken seriously by medical personnel and being subject to inappropriate insinuations and diagnoses.

*"I was also accused by a neurologist, i.e. a contracted neurologist, that I was depressed because I was 27, didn't have a partner at the time and of course wanted to have a child and because I don't have a husband or a child now at 27, I'm imagining it all and I should go on dates and go on vacation and when I come back I'll see that half of my imaginary symptoms are gone." (P7).*

Moreover, age was of relevance as younger patients also reported not being taken seriously as their symptoms seemingly did not fit the picture of a previously healthy and young person.

*"When my mum came to get me, [the doctors] said her son should live a life that befits his age." (P15).*

Patients and experts alike were frustrated as medical professionals such as specialists or medical assessors at courts or insurance funds ignored the expertise of their peers. It was also reported that vaccinations as a potential trigger of LC symptoms were initially rejected by some medical personnel. However, patients also reported positive experiences with individual medical professionals who took them seriously and friends and family often showed sympathy as well, being considered the biggest support by patients. However, expectations regarding magnitude and duration of the associated limitations sometimes nonetheless were in contrast to patients'

actual abilities and energy levels, causing frustration up to domestic violence.

*“Especially in my immediate environment, my family, etc. Understanding, yes, but. ‘Yes, we understand everything, but can you still go shopping for this and that, can you still do this and that?’ So, between understanding and then also, every bit of protection, every pacing I give myself is hard-won, because the demands from outside are still there. You function as a mother and a wife.” (P5).*

In the professional context, patients described very stigmatizing but also supportive reactions, depending on the individual employer, superior, and colleagues. Negative experiences personally and professionally were connected to general scepticism towards and a lack of knowledge about the condition, particularly in non-medical environments. By contrast, one affected nurse described not being taken seriously by her colleagues for being unvaccinated.

Both patients and experts acknowledged that ongoing LC media coverage and increasing evidence of the condition is improving overall acceptance. However, experts cautioned that the public and political sentiment could be affected by an increasing fatigue towards the pandemic and any COVID-19-related topics.

#### **Ability to seek**

Barriers hindering patients’ ability to seek care regarding a perceived healthcare need were limited health literacy and experienced stigma. Health literacy in this case was concerned with knowledge about the condition and consequently which specialists to consult as patients described not being able to pinpoint symptoms and experts added that often the connection of symptoms to certain medical disciplines was not apparent to patients, for example immunology. Patients with a presumed high health literacy again reported fewer difficulties in this regard.

Nonetheless, unfamiliar symptoms and limitations in combination with the abovementioned external stigma led patients to question themselves and their perception of symptoms, effectively inducing internalized stigma.

*“At some point you don’t understand your own body anymore because it suddenly works completely differently to how you’re used to and then I really thought to myself, ‘what if he [the doctor] is right?’ And then I simply questioned every symptom that I had and asked myself the question all the time, am I imagining it or do I really have it?” (P17).*

#### **Availability and accommodation**

Participants highlighted multiple barriers to reach services due to lacking availability and accommodation. Considering the breadth and heterogeneity of LC symptoms, patients usually had to see multiple different

specialists to rule out alternative diagnoses and treat specific symptoms. In response, authorities across Austria introduced specific LC outpatient (hospital) departments as early as 2021. The federal state of Tyrol moreover set up a central coordination unit for LC patients to determine the most dominant symptoms and guide them to the related outpatient departments. However, this approach was not adopted by other Austrian federal states.

When making appointments at ambulatory specialists, patients had to provide referrals and in case of said specialized LC outpatient hospital departments, additionally had to have specific symptoms to be admitted. Furthermore, statutory health insurance funds requested regular proof of illness and medical reports by specialists in order to continue sick pay.

*“If you don’t hand in a specialist’s report pretty much immediately, they [statutory health insurance] come knocking and then turn off the money tap.” (P16).*

Some services and benefits such as rehabilitation, recognition as work-related condition, or disability pension required formal applications including medical reports. Patients experienced those formalities as time-consuming and stressful despite some statutory health insurance funds offering assistance with the submission of applications. Patients particularly feared the application for a disability pension as they were aware of a very low success rate due to the experiences of others shared on social media.

Specialists in the ambulatory care setting with LC-specific expertise and specialized LC outpatient hospital departments were scarce and consequently confronted with high demand for their services, leading to capacity constraints and many either not accepting any new patients at all or at waiting times for appointments of multiple months up to a year. By contrast, primary care including GPs was highlighted for short waiting times for appointments or even drop-in sessions. Interestingly, having complementary private insurance did not seem to affect waiting times as capacities were overall scarce and patients paying out of pocket frequented private doctors as well.

*“I actually don’t have any capacity. In this respect, you can’t really talk about waiting times because it’s not guaranteed that you’ll get an appointment at all. I have a notice on my homepage for a few months now saying that there is an admission freeze. So fewer people wrote or called, but at the end of the day, a lot of people still call or email me. I probably get five to ten enquiries a day. Or even more.” (E9).*

This was even aggravated in rural areas which were highlighted to have very limited service offerings in an acceptable proximity and only few specialists offered teleconsultations, restricting access particularly regarding

ambulatory specialist care and pointing at urbanicity as a relevant socioeconomic factor affecting experiences.

Moreover, many specialized outpatient hospital departments across Austria were shut down in 2023, allegedly due to a lack of demand. This was criticised by patients and experts alike, emphasizing the continuous demand and the benefits of those departments as interdisciplinary offers. Waiting times on the day of the appointment could be up to multiple hours, particularly in the specialized outpatient hospital departments. Those were notably challenging to patients in case facilities were not catering to their limitations such as an increased light sensitivity or inability to wait in an upright position for an extended period of time and waiting areas were bright, noisy, or did not offer any possibility to lie down. To counteract these challenges, some patients proactively communicated their requirements before appointments so providers could accommodate. Appointments themselves were often kept short which patients felt did not reflect their needs in light of their condition. This problem was especially prevalent in the public sector whereas non-contracted doctors were pointed out to offer longer appointments.

#### **Ability to reach**

The patients' ability to reach services was hindered by multiple barriers. A lack of system knowledge and guidance by GPs was particularly challenging for those patients who previously had not yet been regular users of the healthcare system and were not familiar with the different mechanisms regarding referrals, applications, claims, and insurance coverage limitations. They often felt abandoned by GPs not offering any tangible guidance and described difficulties understanding suggested referrals as well as figuring out how to find knowledgeable ambulatory specialists.

*"I'm not familiar with medical specialists either. It was the first time for me. Getting a referral, going to a specialist. [...] Also rehab, what do I need from who, where do I go, I think you were pretty much left on your own."* (P6).

Again, patients with a medical background were able to better navigate the system and look for services in a targeted manner, highlighting the impact of health literacy on the barriers encountered by patients.

Patients had to take matters in their own hands, navigating the system and self-organizing their patient journey with little to no perceived support by authorities or the primary care sector. This included proactively finding the required services and, due to the abovementioned capacity constraints, persistently scheduling appointments often requiring repeated outreach.

*"I wrote a specialist an email every fortnight for six months, always the same thing, copy/paste, hoping that he*

*would read it at some point. And thank goodness he did."* (P8).

This organizational effort was experienced as very exhausting, stressful and time-consuming. Moreover, physically getting to services often was a barrier as patients' mobility including the ability to drive often was impaired by their symptoms. By contrast, the main facilitator to reach services explicitly highlighted by patients was support by their social environment, mostly partners and families who assisted with the organization effort, daily chores and transportation. Moreover, some doctors offered telemedicine or home visits if necessary.

#### **Affordability**

Particularly in the early stages of the pandemic, LC was considered a minor concern compared to the acute disease according to interviewed experts. Consequently, resource allocation saw a prioritization of the latter, leading to insufficient structures being developed to tackle the arising challenge of persistent symptoms. As described before, patients felt like they lacked guidance and therefore deviated from the aspired patient pathway, for example by directly consulting with ambulatory specialists without a prior referral. Experts pointed this out as rather cost-ineffective.

Experts also emphasized that while there has been some improvement regarding statutory health insurance coverage of services specifically required by LC patients, overall coverage was still limited and examinations essential to diagnose LC such as the Schellong test were not included. Especially the time-intensity of LC patients was criticised as not being properly reflected in the remuneration of newly introduced services, such as a one-time in-depth consultation for suspected LC, resulting in high opportunity costs for doctors. Moreover, the offered remuneration was deemed insufficient to incentivise doctors to build up knowledge and treat patients.

*"The outpatient sector tends not to have any additional available resources for multiprofessionalism and multidisciplinary. I would say this is certainly an aspect that represents a barrier, an organisational one and in connection with this also the reimbursement, if you like. [...] After all, if a detailed and very time-consuming clarification of complex clinical presentations in the outpatient sector is remunerated in the same way as everything else, not much will happen."* (E12).

Accordingly, more resources were demanded to strengthen treatment structures to accommodate for the condition's heterogeneity and multitude of symptoms as well as dedicated research funding. One noteworthy positive example of sufficient resources was multidisciplinary rehabilitation nationwide, for which capacity constraints were negated by experts and patients, and co-payments

were minimal due to coverage by statutory health insurance and even waived in case of low income.

### Ability to pay

Patients mostly had to resort to the private, non-contracted healthcare sector when looking for ambulatory specialists with LC experience and also struggled with limited statutory health insurance coverage of recommended treatments.

*“All the things that help me are hardly or not at all covered by [statutory] health insurance and my savings have melted away very, very, very much in the last year and a half.” (P13).*

Due to the condition's chronic nature, patients had to consult those specialists repeatedly, which was further fuelled by the statutory health insurance funds' requirements of regular medical assessment reports in order to uphold eligibility of sickness pay. Consequently, some patients had to consult specialists even more often than medically necessary.

As a result, patients reported incurring substantial medical bills in stark contrast to the core principles underlying Austria's universal healthcare system. Moreover, patients voiced frustrations that they felt left alone by statutory health insurance despite having paid considerable insurance contributions before. Some financial relief was offered by existing mechanisms in the health and social system such as tax deductibility of medical expenses and a capped annual prescription fee, however, the main financial burden was put on patients often accumulating several thousand Euros in expenses over time. Partly, the patients' financial situation additionally came under pressure due to reduced income. While some patients were on extended sick leaves and only received sick pay lower than the regular salary, others had to reduce their working hours due to their symptoms. As a consequence, some patients prioritized their treatments according to their budgets, extending intervals between appointments for, e.g., physical therapy, or even purchasing medical equipment themselves in an effort to save money. Again, family and employer support were pointed out by patients to be vital in easing the financial pressure, at least to some extent.

*“At some point, I talked to my family, my mum and my sisters. If it goes on like this, they said, do what helps you, we'll work together, that's fine. But that's not really how it's supposed to be and what always frustrated me so much was that I write my statutory health insurance contribution on my invoices every month, I know how much I pay in and then sometimes I get 13.74 euros of it back every month, which is a major blow every time, where you think to yourself, I would really need this [money] right now.” (P13).*

In terms of socioeconomic characteristics, private complementary insurance and financial background determined the patients' experience on the one hand directly, as it eased the financial burden. On the other hand, it had an indirect impact as private complementary insurance can be seen as a proxy for higher income, which in turn minimized the financial pressure.

### Appropriateness

Patients and experts alike described several encountered barriers concerning the appropriateness of health and social care. The main driver was the novelty of the condition, leaving providers, policy makers, and patients struggling to find appropriate solutions while simultaneously facing an ongoing pandemic. Particularly in the early stages of the pandemic, patients had difficulties to get a diagnosis by a medical professional, with some of the reasons related to the findings presented with regards to *Acceptability*. Some clinical experts emphasized the complexity of diagnosing LC in the absence of a clear biomarker, leading to late, alternative, or no diagnosis at all, complicating the patients' journeys.

*“It always gets complicated where it's difficult to see, when you can't take a picture and the disorder comes to light, but when there are much more complex needs for examination, but in reality, you might not be able to make a technical medical diagnosis. Or almost none. In case of brain fog, you take an MRI, but you don't see any fog in the brain.” (E13).*

However, other experts disagreed, stating clear indications and rather pointed in the direction of premature diagnoses without proper assessment as many patients seeking help had a prior COVID-19 infection and unspecified symptoms. Subsequently, initiating appropriate treatment proved equally difficult and frustrating to both providers and patients, as little scientific evidence was available and most importantly no cure yet, limiting treatment to tackling symptoms rather than the condition itself. Clinical experts in this context described feeling helpless in their inability to help patients. While some treatments simply did not yield the desired results, others turned out to be even counterproductive according to the experts. One commonly mentioned example was rehabilitation not adjusted for LC patients, setting them back on their road to recovery due to uncompromising mandatory schedules including physical exercises, no opportunity to take breaks, and facilities not fit for purpose.

By contrast, some patients described very positive rehabilitation experiences as providers adapted and tailored their offerings to the needs of LC patients. Patients benefitted from continuous multidisciplinary care unavailable in any other setting and being able to solely focus on their condition and how to handle the connected impairments. Multi- and interdisciplinary care as

offered in rehabilitation was emphasized as desirable but currently lacking by experts and patients. They described the current system as rather isolated treatment of different symptoms by different disciplines, resulting in inefficiencies and an administrative burden to patients. Even on paper interdisciplinary LC outpatient hospital departments were always led by and located within a single discipline such as neurology or pulmonology.

*“There should be truly interdisciplinary outpatient hospital departments, because it’s now often the case that they are sent to the neurology long COVID clinic, neurology does a routine neurological assessment, finds nothing and says okay, we’re not responsible because we can’t find anything. And that’s the end of the matter.” (E9).*

Moreover, experts highlighted the lack of institutionalized exchange between disciplines, leaving the networking and interdisciplinary exchange to individual voluntary commitment. Particularly in the beginning of the pandemic, this commitment by experts in their respective fields to jointly develop guidelines and drive national and international exchange to improve treatment as well as outreach to patient support groups was praised. This early cooperation resulted in the Austrian guideline on the diagnosis and treatment of LC as well as the recommended patient pathway [23]. While the speed and cooperation to develop this multidisciplinary guideline and a corresponding web tool was deemed very positive, clinical experts voiced concerns about the practicality. They criticised the guideline as too long although they acknowledged the challenge of being concise regarding such a complex condition.

In the Austrian guideline, the recommended patient pathway put GPs at the centre, asking them to coordinate patient journeys with targeted referrals to specialists depending on symptoms. However, patients often deviated, directly seeking appointments at ambulatory specialists as not all GPs were able to provide sufficient guidance. This resulted – according to experts – in uncoordinated doctor hopping between specialists from different disciplines.

While patients and experts observed a positive trend in LC expertise, they emphasized a prevailing lack of knowledge on the topic by GPs and specialists as well as hesitance or a lack of capacity by doctors to keep up to date with the latest findings and recommendations. Patients already considered it a positive experience if their GPs followed specialist recommendations and provided referrals and prescriptions.

*“So the feeling I always have is that every doctor thinks they are omniscient, but particularly on this topic [LC] there are only a handful of doctors who actually have expertise.” (P1).*

This is in line with the experts’ calls for an inclusion of post viral conditions in the curriculum of medical

degrees and training offers to medical personnel to build up expertise and exchange best practices. Moreover, a current lack of dedicated research into fit-for-purpose diagnostics and treatments has been highlighted by experts, who also pointed out a lack of available Austrian data on LC. The ongoing development and incorporation of LC-specific codes to the Austrian health data ecosystem was considered a long overdue necessity. Unavailable data also complicates arguing any policy changes in the social system. Patients and experts emphasized that the current system was not designed to provide for LC patients, to give them the time they need to appropriately recover, and to gradually re-enter the workforce. While returning to work initially part time was subsidized and well received by patients, employers had to agree to participate and there was no legal entitlement to it.

#### **Ability to engage**

Patients’ ability to engage was impeded by the balancing act between pacing and giving a true impression of the symptom load. Conscious of their impairments, patients would reduce their daily activity before appointments to make the most out of them just to be told that they appeared to be as healthy as ever.

*“It’s often so frustrating with doctors as you make an effort, sleep in so you’re fit, come in with a list of questions and then they say, yes, it’s fine. You’re more or less prepared, you’ve somehow asked reasonable questions, you seem healthy and you haven’t actually worked for two days beforehand so you can attend this appointment that you pay for yourself - because you don’t get a contracted appointment for anything – but still you’re sometimes not even taken seriously.” (P13).*

In this context and against the barriers outlined in the *Acceptability* section, patients found it very helpful if specialists or GPs encouraged them in their self-perception and emphasized the legitimacy of LC. Moreover, being taken serious by medical experts also empowered patients to share their experiences with susceptible doctors – often the respective GPs – in an effort to improve their own care and allow other patients a better experience.

Experiences in this regard differed notably by presumed high health literacy based on patients’ medical background, as those patients had a better understanding of diagnoses and recommended treatments, empowering them in discussions with medical personnel. In our patient sample health literacy was approximated based on the profession of participants. Experts independently identified it as a potentially relevant socioeconomic factor as also pointed out by patients themselves.

*“I’m quite sure that simply having this medical expertise and at least knowing a bit of the terminology has helped*

*enormously and that so many people simply don't have it." (P17).*

Clinical experts on the other hand described increased patient expectations that they could only partially live up to due to a lack of medical evidence and options. In case patients felt like they were not taken seriously, complaints sometimes helped to change that and some took legal action when being denied sickness benefits. However, their ability to engage was hampered by low energy levels. Patients were exhausted due to their condition and additionally constant administrative tasks, particularly regular medical reports required by statutory health insurance to uphold sick pay. Moreover, the many negative experiences left their marks and patients described being in fear for future appointments.

*"Everyone in this round just nodded in agreement, this fear of these expert assessments and of this burden, what is coming next and these discriminatory statements that you hear again and again." (P4).*

Nonetheless, patients were eager to improve conditions for others and help each other. This also led to the establishing of the *Long Covid Austria* support group on Facebook which was highlighted as very helpful not only for information but also exchanging experiences and having a sense of community. In addition, patients were trying to raise awareness in their local environments, for example by founding further support groups and organizing charity events. By contrast, some patients did not join the Facebook group on purpose as they wanted to avoid the first-hand reports by other LC patients for the sake of their own mental health.

Employment-related changes such as switching to home office or subsidized part-time reintegration helped patients cope with their symptoms. Yet, there also were negative examples such as layoffs during sick leaves or patients going back to work again too soon, impeding recovery. Lastly, while the close social environment posed a major facilitator to patients, constantly providing support for a loved one also took a toll and some significant others had to reduce their working hours due to caring responsibilities or developed physical issues themselves.

### **Socioeconomic and demographic differences in health and social care access**

Overall, five socioeconomic and demographic characteristics which are potentially driving differences in experienced access barriers emerged in the data analysis. These included urbanicity, health literacy, gender, complementary private health insurance or financial background, and age as potentially relevant socioeconomic and demographic characteristics. We found that those LC patients living in rural areas, those with low health literacy, women, those without complementary health insurance or an advantaged financial background, and

those deemed not old enough to have a chronic disease at a disadvantage in healthcare access. Four out of the five characteristics were proactively pointed out by patients as having affected their own experience, while age additionally emerged in the analysis. All five characteristics were independently highlighted by experts.

### **Discussion**

This study finds that long COVID-19 patients in Austria experience a wide range of barriers to access appropriate healthcare. Our study also provides first insights into potential inequalities in healthcare use as well as potentially relevant socioeconomic and demographic characteristics acting as catalysts in this regard. These barriers exist in spite of the comparatively well-equipped Austrian health system and active patient involvement starting as early as January 2022 [14]. At the time this study took place, i.e. over one and a half years later in summer and fall 2023, the policy priorities patients had raised back then still were not implemented. These included the expansion of specialist LC clinics and a nationwide roll-out of the central coordination of patient pathways introduced in the province of Tyrol [14].

Following Levesque's conceptualization of 'access to care' [67] to answer the first research question on barriers and facilitators encountered by LC patients, particularly system-related issues were identified as barriers. Relevant barriers were related to *Acceptability* such as not being taken seriously, *Availability and accommodation* such as long waiting times for appointments, as well as *Appropriateness* such as limited LC knowledge by doctors. The main identified facilitators such as individual commitment and support by the patient's social environment emerged in response to those barriers. In terms of the second research question on socioeconomic and demographic characteristics potentially driving healthcare access inequalities, we find that women and younger patients experienced sexism and age-based scepticism, respectively, patients with a medical background observed advantages in engaging with health professionals and navigating the system, those living in rural areas were restricted in service offerings, and a strong financial background or complementary health insurance eased the financial burden, thereby facilitating access. Interviewed experts also identified those characteristics as relevant to patient experiences.

Looking at previously identified access barriers and facilitators to LC patients internationally, our findings not only confirm related research [3–13] but comprehensively extend and complement it. Schmachtenberg et al. and Brehon et al. identified barriers similar to our results experienced by LC patients in Germany and Canada respectively such as stigma, financial precarity, lack of specialized care, and bureaucratic hurdles [10,

12]. However, as they solely focused on the patient perspective, we additionally provide insights on the barriers faced by practitioners such as high patient expectations and incorrectly diagnosed LC.

Our abovementioned findings also complement the ones by Turk et al. [13] and Baz et al. [11] who included health professionals in their studies. While we largely confirm their other results such as limited knowledge about LC by healthcare professionals and required self-management by patients, we find that in Austria there seem to be no capacity constraints or substantial waiting times for GPs whereas both UK studies established over-subscribed GPs as a barrier [11, 13]. This is most likely due to the gatekeeping role of GPs in the UK. While the official Austrian LC guideline [23] expects GPs to be the first point of contact for patients and to coordinate patient treatment via targeted referrals, patients are free to deviate from the intended LC pathway. In our study, LC patients indeed often did so, as also observed in other Austrian research [55]. In contrast to the Austrian LC guideline [23], LC patients reported reliance on self-management as they felt that their GPs were often overwhelmed with their condition. This finding was confirmed by interviewed GPs who felt left alone and lacking clear guidance for referrals, potentially leading to these deviations. Lastly, the barriers identified by Schwarz et al. for patients with specific chronic diseases (e.g., chronic back pain) in Austria generally also seem to hold true for LC [3]. However, especially aspects related to LC's novelty as a disease such as limited medical expertise and need for further clinical research are new in our findings.

Three of the abovementioned international studies [10, 11, 13] also identified facilitators to healthcare access such as multidisciplinary care and individual commitment by doctors as well as the opportunity to connect with fellow LC patients online. Our findings confirm these results except for those facilitators emerging in response to barriers not encountered by the participants included in our sample such as capacity constraints at GPs. Moreover, we identified facilitators specific to Austria such as tax deductibility of medical bills, prescription fee exemptions, and government-subsidized programs to gradually re-enter the workforce after extended sick leaves, which could be applicable to other countries.

Our findings for LC patients contrast the OECD concluding not only a generally very low level of unmet healthcare needs due to financial, geographic, or waiting times reasons in Austria, but also a comparably low difference between low and high income populations in this regard, implying good and equal accessibility [36]. Another OECD report [56] assessing income-related inequalities in health service utilisation confirms equal utilization of GP services across countries including Austria, however, pro-rich inequalities prevail for specialist

visits. While Austria was not included in the recent OECD analysis of specialist visits due to insufficient data, our findings point in the same direction [56]. Our findings of differing experiences by gender, age, and financial background or complementary health insurance status are in line with those studies although they did not cover LC. We additionally identified urbanicity and having a medical background as relevant characteristics in the context of LC. Particularly the latter complements the Austrian studies [53, 54, 57] which find the level of education – considered a proxy for health literacy – to matter. However, in our sample rather the medical background such as working as a nurse or veterinarian made a difference.

The absence of a cure for specific LC conditions such as post-acute infection syndromes like PEM, POTS, MCAS, and ME/CFS as well as its unclear prevalence emphasize the public health and inequality relevance of our research. While there currently are a wide range of access barriers to healthcare for all patients due to the comparative novelty of the condition, our findings suggest differing experiences related to socioeconomic and demographic patient characteristics. Future research should investigate potential inequalities in access drawing on a representative sample and look into language barriers hindering access, as non-LC research in Austria [60] points in this direction and this dimension was not addressed in this study. Also, health system indicators such as number and qualifications of health professionals should be assessed as to whether they properly reflect the ability of health systems to appropriately respond to emerging complex health challenges.

Our results constitute an urgent call for action to improve access to healthcare for LC patients in Austria. Some of the identified barriers could also be applicable to other chronic conditions characterized by very heterogeneous symptoms such as ME/CFS and multiple sclerosis. Selected policy implications include empowering patients by providing clear, easy to understand information on available services, extending relevant statutory insurance coverage and limiting bureaucratic requirements, and ultimately ensuring a safe, paced return to work. Moreover, LC care should be strengthened by providing appropriate trainings and guidelines to medical personnel, investing in dedicated interdisciplinary resources, case management structures, as well as tools such as telemedicine and digital health solutions, and increasing research funding to drive interdisciplinary clinical research.

### Strengths and limitations

This study provides comprehensive evidence building on both expert and patient experiences and differentiates between multiple dimensions of access to care as conceptualized by Levesque et al. [67]. However, some

limitations prevail. First, the patient sample largely consisted of comparably severe, currently affected LC patients, both in terms of daily impairment due to experienced symptoms and in terms of illness duration. As we followed a convenience sampling approach, this could have been the case since those hit hardest by the condition may be the ones keenest to share their experiences. For example, a recovered patient cancelled their participation after initial agreement as they wanted to find closure. Second, we did not collect aetiological information of participants. Rabady et al. distinguish three causes of LC: A prolonged acute COVID-19 infection, the worsening of a pre-existing disease as a result of a COVID-19 infection, and the recurrence of post-COVID syndrome as a manifestation of a post-acute infection syndrome [23]. Experiences might differ as the underlying diseases are known for the first two causes but not for the third. Lastly, while we achieved a predominantly female sample, reflecting the higher prevalence of LC among women, we did not collect any information regarding migration background of participants. Consequently, we could not assess a potential impact on experienced access barriers in this regard. Based on prior Austrian research by Kohlenberger et al. [60] it could be expected that language barriers play a role particularly among those with migration background. This study, however, in light of resource constraints was solely conducted in German. Kohlenberger et al. [60] also identified other barriers such as waiting times and lack of system knowledge [60], yet, those were considered not exclusive to people with migration background so it was decided not to collect the according background data during recruitment. This allowed to minimize the number of questions patients had to answer prior to scheduling and thereby the participation effort. Moreover, this approach aimed to avoid potential dropouts as this personal information could be considered as sensitive by some.

## Conclusions

Our research finds a wide range of barriers to healthcare access for LC patients in Austria and outlines multiple potential action points such as more information to both patients and service providers including on definition and differentiation between aetiologies, strengthened truly interdisciplinary treatment structures, improved telemedicine offerings as well as dedicated research funding. Our research points at socioeconomic and demographic drivers of LC healthcare access. Further quantitative research is necessary to test the findings in a large population sample in light of the considerable public health relevance of long COVID-19.

## Abbreviations

GP	General Practitioner
LC	Long COVID-19

MCAS	Mast cell activation syndrome
ME/CFS	Myalgic encephalomyelitis/chronic fatigue syndrome
PEM	Post-exertional malaise
POTS	Postural orthostatic tachycardia syndrome

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12939-024-02302-4>.

Supplementary Material 1

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## Author contributions

SM and AŁ conceptualized the overall study; SM, AŁ, JS secured resources; PG, AŁ, and SM conceptualized the analysis; SK advised on the study design; KH provided expert contacts; PG and SM conducted the data collection; PG, SK, AŁ, and SM conducted the data coding and analysis; PG prepared the first draft of the manuscript; all other authors (SK, AŁ, KH, JS, SM) provided feedback on the manuscript; all authors (PG, SK, AŁ, KH, JS, SM) approved the final manuscript.

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## Data availability

The qualitative data generated and/or analysed during the current study are not publicly available due to confidentiality obligations but are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Ethics Committee of the Medical University of Vienna (EK 1228/2023). All participants provided informed consent to participate.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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