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Investigating care outcomes and experiences of adults with Long COVID through patient-reported indicators (PROMs and PREMs) in Belgium

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Abstract

Background Long COVID, with its multisystemic manifestations, poses a substantial burden on health systems. Nevertheless, evidence regarding Long COVID patients' perspectives, perceived health outcomes and care experiences in Belgium remains limited.

Methods OECD's Patient-Reported Indicator Surveys (PaRIS) collected patient-reported outcome and experience measures (PROMS and PREMs) from individuals aged 45 + with chronic conditions. In Belgium, 4,687 primary care patients provided self-reported data between March 2023 and January 2024. This study explores the associated clinical and sociodemographic factors, care outcomes and experiences of adults with Long COVID in Belgium, by comparing COVID-19 positive respondents with and without Long COVID. Multivariate models were used to examine the clinical and sociodemographic determinants of Long COVID, and mixed-effects models were applied to compute the 10 key PROM and PREM indicators following the PaRIS10 methodology, accounting for the hierarchical structure of the data (patients nested within GP practices).

Results Overall, 50% (N=2,359) had a previous COVID-19 infection diagnosis, and over one in four (26%, N=605) of them reported Long COVID-related symptoms lasting two months or longer after COVID-19 infection (12.9% Long COVID prevalence among primary care users aged 45 years and older in Belgium). Female sex, age 45–54 years, lower educational level, multiple chronic conditions, and higher BMI were associated with having Long COVID. Primary care patients aged ≥45 years with Long COVID reported significantly lower PROM scores for general health, wellbeing, physical and mental health compared to non-Long COVID respondents. Those with Long COVID symptoms lasting at least one year reported even poorer outcomes, particularly in general health, wellbeing and physical health. PREMs showed no significant differences between Long COVID and non-Long COVID respondents overall. However, trust in healthcare system and person-centred care was significantly lower when Long COVID patients still had these long-term symptoms at survey time.

Conclusions In Belgium, adults with Long COVID aged ≥45 years using primary care service report poorer health outcomes and less positive care experiences compared with those without Long COVID. These findings point to the substantial burden associated with Long COVID and the need for more tailored, person-centred care in primary care for Long COVID. Strengthening dedicated care pathways, improving coordination across

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services, and ensuring clear communication and support for patients will be essential to better address the needs of people living with Long COVID.

Keywords Long COVID · Primary health care · Patient-reported indicators · PROM · PREM · Belgium

Background

Long COVID (also known as post-acute sequelae of COVID-19) is a multi-systemic condition comprising persistent symptoms following the acute SARS-CoV-2 infection [1]. Long COVID is characterized by a wide range of symptoms that vary in nature and intensity, commonly including chronic fatigue, cognitive impairment ("brain fog"), respiratory difficulties, musculoskeletal pain, and cardiovascular issues [2, 3]. Individuals living with Long COVID experience a significant reduction in quality of life, affecting physical, mental and social health, causing disability and reduced productivity [2, 4, 5]. Moreover, recovery from Long COVID remains uncertain for millions of patients worldwide [1, 5].

Worldwide, people living with Long COVID have large healthcare needs, leading to increased healthcare utilization, additional healthcare and disability spending [2, 4]. The impact of Long COVID extends beyond individual patients and challenges the capacity of healthcare systems. Services for Long COVID vary widely within and between healthcare systems. Furthermore, over the past years, Long COVID has raised growing concerns among healthcare professionals [1, 6]. Primary care is at the forefront in caring for Long COVID patients and general practitioners (GPs) take up a key position as they are typically the first point of contact for patients experiencing persistent Long COVID symptoms [7]. As Long COVID symptoms may persist for months, multidisciplinary approach to diagnosis and treatment is required [5, 6]. Unfortunately, due to the variability in Long COVID services, most people with Long COVID describe them as insufficient, and barriers to healthcare access, diversity in quality and equity of care have been identified [6, 8, 9]. A few countries, such as Belgium, France and Germany, have reported a national care trajectory for Long COVID with various level of implementation [10]. In Belgium, since July 2022, diagnosed Long COVID patients included in the post-COVID-19 care trajectory can benefit from reimbursement of rehabilitation-related costs when consulting (mainly primary care) healthcare professionals [11].

In this regard, capturing Long COVID patients' perspectives on perceived health outcomes and care experiences using patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in primary care is an important approach [12]. Patient-reported measures (PROMS, PREMS) are important for monitoring the quality of care and developing policies and practices in countries. Integrating patients' perspectives in the approach to Long COVID enriches the understanding of care experiences and inform patient-centred care models.

As evidence on the perceived health outcomes and care experiences of people with Long COVID remains scarce in Belgium, this study aims to address this knowledge gap by investigating care outcomes (PROMs) and experiences (PREMs) of adults living with Long COVID and using primary care services in Belgium.

Methods

Study design, sampling and participant selection

OECD's Patient-Reported Indicator Surveys (PaRIS) is a cross-sectional survey capturing patient-centred outcomes and experiences for individuals aged 45 years and older living with chronic conditions [13]. The PaRIS patient questionnaire (PaRIS-PQ) used in this study has been published and is publicly available on OECD's

website [14]. As part of this initiative, self-reported data were obtained from primary care patients from March 2023 to January 2024 in Belgium.

All active Belgian GPs ($N = 11,734$) were invited by email to participate in this study. Eligible patients were aged 45 years or older, living in the community, and had at least one registered contact with their general practice during the six months preceding sampling. As no national or regional patient registry was available in Belgium, patient sampling was conducted using the electronic medical records (EMRs) of participating practices. In total, 59 participating practices provided a patient sample by generating a list of eligible patients from their EMR systems following a standardized procedure. In total, 14,603 eligible patients were included in the final sample [15].

A total of 4,687 patient survey responses (59.7% completed online, 40.3% on paper) were collected. Despite the low practice response rate (< 5%) compared to other participating countries [13], the regional GP representativity was good for Belgium [15]. Furthermore, the 33.4% patient response rate observed in Belgium is consistent with response rates reported in recent international patient-level surveys [13]. Non-response bias could not be formally assessed due to the lack of data on non-respondents (this limitation will be examined in future PaRIS rounds).

The core analysis of this study includes 2,359 participants (50.3%) who answered 'yes' to the question: 'Have you ever tested positive for COVID-19 (using a rapid point-of-care test, self-test, or laboratory test) or been told by a doctor or other health care provider that you have or had COVID-19?'. When answering 'yes' on the former question, respondents received additional questions related to Long COVID. These COVID-related questions were based on those of the US Pulse household survey [16]. On the question 'Did you have any symptoms lasting 2 months or longer that you did not have prior to having coronavirus or COVID-19?' *(Long term symptoms may include: tiredness or fatigue*, *difficulty thinking*, *concentrating*, *forgetfulness*, *or memory problems (sometimes referred to as "brain fog"*, *difficulty breathing or shortness of breath*, *joint or muscle pain*, *fast-beating or pounding heart (also known as heart palpitations)*, *chest pain*, *dizziness on standing*, *menstrual changes*, *changes to taste/smell*, *or inability to exercise')*, respondents could indicate the persistence of symptoms by choosing (1) Yes, symptoms lasted between 2–3 months, (2) Yes, symptoms lasted between 3–6 months, (3) Yes, symptoms lasted between 6 months – 1 year, (4) Yes, symptoms lasted at least 1 year, (5) No and (6) Not sure. When answering (1) to (4) on the Long COVID question, participants could indicate if they still have symptoms at survey time ('Do you still have these long-term symptoms?') by answering (1) Yes, (2) No and (3) Not sure.

Of the 2,359 COVID-19 positive respondents, those reporting 'not sure' for Long COVID-related symptoms ($n = 146$) and those with missing outcome ($n = 20$) were excluded (to avoid misclassification bias), leading to a final sample of 2,193 respondents (see Fig. 1).

Measures

This study investigates differences in care outcomes and healthcare experiences between adults living with and without Long COVID in Belgium. The primary dichotomous outcome variable was the Long COVID status, i.e. whether or not people self-reported Long COVID-related symptoms lasting two months or longer after COVID-19 infection.

In addition, the following collected sociodemographic characteristics and risk factors were included as covariates in the analysis: age, gender, educational level, Body Mass Index (BMI) and number of chronic conditions.

To assess Belgium's healthcare performance through a patient-centred lens, the ten key indicators from the PaRIS10 Dashboard were used. These indicators are based on internationally recognised measurement instruments (PROMIS, WHO-5 Well-being Index and P3CEQ) and are applicable to the general population (for specifications, see table in national report) [15]. The PaRIS10 Dashboard includes five PROMs that capture essential aspects of health: physical health, mental health, social functioning, well-being and general health. In addition, five PREMs offer insight into critical interactions with healthcare services: confidence to self-manage, experienced care coordination, person-centred care, experienced quality of care and trust in health system.

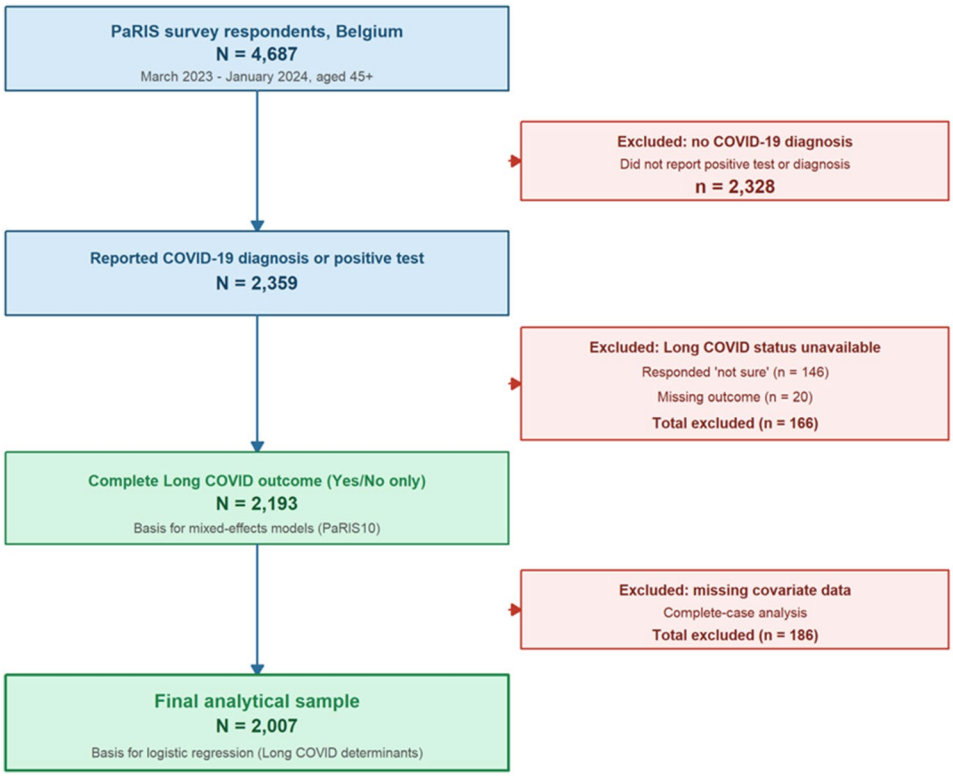


Fig. 1 Flowchart of selection of respondents in this study

Data management and informed consent

Data were collected through both an online survey platform provided by Ipsos and paper questionnaires distributed by a third-party provider (TTP). Participants were encouraged, via the invitation letter, to complete the online survey. Those who preferred a paper version could request one by mail or by phone, or use the paper questionnaire included in the second reminder mailing. Informed consent was obtained from all participants included in the study. All methods were carried out in accordance with the declaration of Helsinki.

Statistical analysis

Descriptive statistics were conducted to summarize respondents' characteristics and key outcome variables. Data are presented as absolute numbers and percentages for categorical variables, and as mean with standard deviation (SD) for continuous variables. Descriptive analyses of all variables were evaluated with Pearson's chi square test and mean values were compared by Student's T-test. Missing data for the primary outcome were minimal ($N=20$, 0.8%) and missingness in covariates was low (<7%, see Table 1 for reporting of missing data per variable).

To strengthen the representativeness of the results and achieve consistency with OECD PaRIS methodology [13], the standardization variables (age and gender) in all models were rescaled to align with the 2023 Belgian population (aged 45+), using data retrieved from the Belgian national statistical office (STATBEL) [17].

Association between COVID-19 positive participant's sociodemographic characteristics and risk factors, and the Long COVID status was assessed through a multivariate logistic regression model. Complete-case analysis was applied ($N=2,007$), excluding 186 individuals with missing values on covariates (missingness was found to be at random). Model assumptions were assessed and a random intercept was initially included to account for potential clustering within GP practices. However, as the random intercept variance indicated no meaningful clustering, the random intercept was further excluded and a standard logistic regression was used. Odds ratios (OR) and 95% confidence intervals (95% CI) were reported. A p-value <0.05 was considered statistically significant.

Table 1 Sociodemographic and clinical characteristics of COVID-19 positive participants ($N=2,359$)

		COVID-19 positive ($N=2,359$)	
		N	%
Socio-demographic characteristics			
Age categories			
	45–54 years old	669	28.4
	55–64 years old	841	35.7
	65–74 years old	614	26.0
	75 + years old	227	9.6
	Missing	8	0.3
Gender			
	Female	1318	55.9
	Male	977	41.4
	Other	6	0.3
	Prefer not to say	12	0.5
	Missing	46	1.9
Level of education			
	No education, primary or lower secondary education	533	22.6
	Higher secondary education	654	27.7
	Higher education	1145	48.5
	Missing	27	1.1
Risk factors			
Body mass index (BMI) - WHO classification			
	Underweight (< 18.5)	26	1.1
	Normal (18.5–24.9)	867	36.8
	Overweight (25–29.9)	914	38.7
	Obesity (≥ 30.0)	398	16.9
	Missing	154	6.5
	BMI continuous (mean + SD)	*26.4*	*4.5*
Number of chronic conditions			
	0	526	22.3
	1	781	33.1
	2	534	22.6
	3	296	12.5
	4	117	5.0
	5	42	1.8
	6	7	0.3
	7	2	0.1
	8	2	0.1
	Missing	52	2.2
Clinical characteristics			
If yes on previous COVID-19 diagnosis: Long COVID-related symptoms			
	Yes, symptoms lasted between 2–3 months	320	13.6
	Yes, symptoms lasted between 3–6 months	99	4.2
	Yes, symptoms lasted between 6 months − 1 year	68	2.9
	Yes, symptoms lasted at least 1 year	118	5.0
	No	1588	67.3
	Not sure	146	6.2
	Missing	20	0.8
If yes on Long COVID-related symptoms: symptoms at survey time? ($n=605$)			
	Yes	165	27.3
	No	352	58.2
	Not sure	77	12.7
	Missing	11	1.8

Multilevel models were conducted, taking into account the hierarchical structure of the data (GP practices – patients). Following the OECD PaRIS methodology [13], missing covariate values were handles by creating a separate missing category for each affected covariate, retaining all COVID-19 positive respondents with complete Long COVID outcome (N=2,193) in the analysis. For each indicator, mixed-effects regression models with a random intercept for GP practice were fitted (only a random intercept was included, as random slope did not improve model fit). Depending on the nature of the dependent variable, linear (continuous outcomes) or logistic (dichotomous outcomes) mixed-effects models were constructed. All models were adjusted for age, gender and number of chronic conditions. These mixed-effects regression models were applied to compute the ten key PaRIS PROM and PREM indicators (PaRIS10), in which values differing significantly (p<.05) from the reference group (participants without Long COVID among COVID-19 positive respondents) were indicated. Model-based adjusted predicted probabilities (binary indicators) or adjusted predicted mean scores (continuous indicators) derived from the fitted models are presented, and 95% CI were used for identification of statistical significance. Positive outcome criteria (e.g. a score of 42 or higher is considered to indicate good physical health) are reported in the results table. A p-value of <0.05 was considered statistically significant. To assess whether additional adjustment affected the findings, we performed a sensitivity analysis additionally including educational level and BMI. Results were broadly consistent with the overall findings (i.e. direction and magnitude of associations were preserved), highlighting the robustness of our models (see Supplementary Table S1).

Data management and analysis were performed in R version 4.4.1 and above.

Results

Half of respondents (50.3%; N=2,359) reported having tested positive for or being diagnosed with COVID-19. Compared to all PaRIS study participants (N=4,687), COVID-19 positive participants were younger (<65 years) and higher educated (see Supplementary Table S2).

The sociodemographic and clinical characteristics of the COVID-19 positive respondents (primary care users aged 45+) are presented in Table 1. Among these study participants, 55.9% were women, 64.1% were between 45 and 64 years old and 48.5% had a higher education. Of all respondents, 55.6% were overweight or obese, and 22.3% had no chronic condition.

Among those who had experienced COVID-19, over one in four (25.6%, N=605) reported Long COVID-related symptoms beyond two months and 5.0% (N=118) reported persistent symptoms beyond 12 months. Among participants who had experienced Long COVID-related symptoms (N=605), about one in four (27.3%, N=165) reported still experiencing symptoms at the time of the survey, with 58.8% of these reporting symptoms that had lasted at least one year (p<.001).

The logistic regression results show several important associations with Long COVID (Fig. 2). Being male was associated with a 37% lower odds of having Long COVID compared to females (OR=0.63, p<.001). Age was also a significant factor, with older age groups showing progressively lower odds of Long COVID: 26% lower odds for 55–64 years old adults (OR=0.74, p<.05), 42% lower odds for adults aged 65–74 years (OR=0.58, p<.001), and 62% lower odds for 75+'ers (OR=0.38, p<.001), compared to the youngest age group 45–54 years old. On the other hand, having more chronic conditions increased the odds: each additional chronic condition was associated with a 28% higher odds of Long COVID (OR=1.28, p<.001). Compared to respondents with lower education, those with higher education had 54% lower odds of having Long COVID (OR=0.46, p<.001). BMI was also linked to Long COVID, where each unit increase in BMI was associated with a 3% higher odds of Long COVID (OR=1.03, p<.05).

Table 2 presents the results for PaRIS10 indicators by Long COVID status and patient-reported persistence of symptoms. Adults with Long COVID aged≥45 years using primary care service reported significantly lower PROM scores for general health, wellbeing, physical and mental health compared to respondents without Long COVID. When symptom duration was taken into account, a strong physical health impact among all individuals

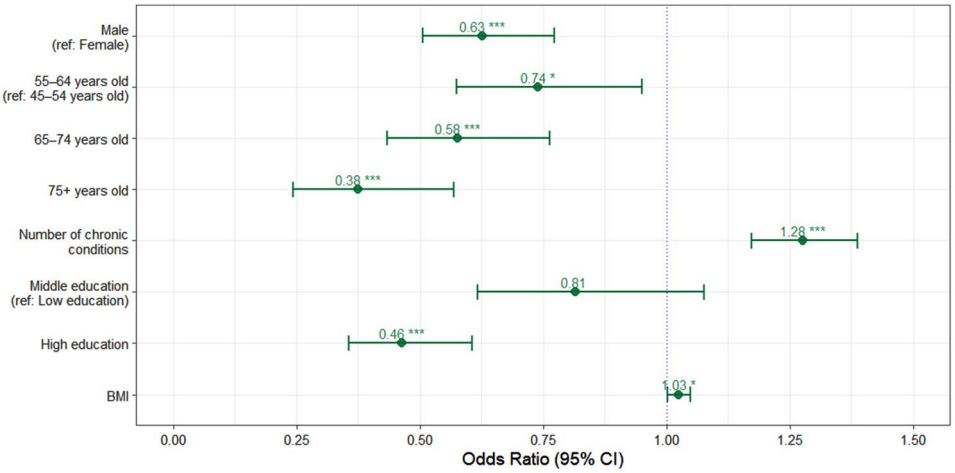


Fig. 2 Association between clinical and sociodemographic characteristics and Long COVID among COVID-19 positive participants (N=2,007). Adjusted odds ratios (OR) with 95% confidence intervals (CI) for the association between participants' sociodemographic characteristics, risk factors, and Long COVID status. Estimates come from a multivariate logistic regression model, standardized for age and sex to the 2023 Belgian population (aged 45+). The vertical line at OR = 1 indicates no association. Asterisks denote statistical significance (* p < .05, ** p < .01, *** p < .001)

Table 2 Adjusted estimated PaRIS10 indicator values (from mixed-effects regression models) by Long COVID status (N=2,193)

Long COVID (LC)	Patient-reported outcome measures (PROMs)					Patient-reported experience measures (PREMs)				
	General health (%)	Well-being (/100)	Physical health (16.2–67.7)	Mental health (21.2–67.6)	Social functioning (%)	Experienced quality of care (%)	Confidence to self-manage (%)	Trust in healthcare system (%)	Experienced coordination (/15)	Person-centred care (/24)
Positive Outcomes	Good, very good, excellent	≥50	≥42	≥40	Good, very good, excellent	Good, very good, excellent	Confident, very confident	Agree, strongly agree	≥7.5	≥12.0
No Long COVID (n=1,588)	81.7	64.5	48.3	47.9	90.6	96.8	69.5	73.7	9.27	18.3
Long COVID (n=605)	71.3*	56.5***	43.9***	45.7***	86.1	96.1	64	64.6	8.69	17.4
LC, symptoms lasted between 2–3 months (n=320)	71.2*	56.8***	43.9***	45.2***	85.5	95.4	63.5	64.2	8.76	17.7
LC, symptoms lasted between 3–6 months (n=99)	80.1	58.4	45.7*	46.6	86.5	98.2	63.8	72.2	8.65	16.9
LC, symptoms lasted between 6 months – 1 year (n=68)	68.6	57.2*	43.5***	45.7	89.7	94.2	56.1	65	8.51	16.7
LC, symptoms lasted at least 1 year (n=118)	65.7*	53.6***	42.8***	46.4	85.1	97.1	69.9	58.8	8.59	17.2
LC, long-term symptoms at survey time (n=165)	60.2**	50.2***	40.7***	45.4***	82.4	95.3	63	57.2***	8.29	16.5***

Asterisks denote levels of statistical significance (* p < .05, ** p < .01, *** p < .001) relative to the reference category (No Long COVID among COVID-19 positive respondents)

Results are adjusted for age, gender & number of chronic conditions, taking into account the hierarchical structure of the data (random intercept for GP practice)

Data is weighted using STATBEL 2023>=45 years old

with Long COVID was observed. Respondents mentioning short-term Long COVID symptoms (two to three months) indicated a clear impact on general health, wellbeing, physical and mental health. Wellbeing was significantly lower for those with symptoms lasting six months to one year, and individuals with symptoms persisting at least one year reported even poorer outcomes, particularly in general health, wellbeing and physical health. Moreover, participants reporting persistent Long COVID symptoms at the time of the survey reported significantly lower scores across all care outcomes, with the exception of social functioning.

Self-reported experience measures (PREMs) showed no significant differences between Long COVID and non-Long COVID respondents overall (Table 2). However, trust in healthcare system and person-centred care was significantly lower when adults with Long COVID still had these long-term symptoms at survey time.

Discussion

Key findings

In this study, the primary care-based survey of PaRIS was used to provide estimates of the impact of Long COVID in the general population using primary care services. COVID-19-positive participants were generally younger and more highly educated than the overall PaRIS study population, consistent with previous Belgian population-based research on SARS-CoV-2 seropositivity [18].

In Belgium, among primary care adults aged 45 years and older who have been infected with COVID-19, more than one in four (25.6%) reported persistent Long COVID-related symptoms beyond two months and for 5.0%, symptoms persisted beyond a year. For Belgium, a Long COVID prevalence of 12.9% among primary care 45 + adults with chronic conditions is estimated. When applying the stricter WHO case definition (i.e. persistence of symptoms from three months after initial COVID-19 infection) [19], Long COVID prevalence in primary care is 6.1% for Belgium. A survey among the general Belgian population (not focusing on individuals living with chronic conditions in contact with healthcare) estimated the overall prevalence of Long COVID among people aged 15 years and older on 4.2% when symptoms persisted at least 3 months [20]. Based on data from 16 OECD countries collected through the PaRIS survey, Long COVID prevalence (persistent symptoms beyond three months) is estimated at 7.2% of the primary care population aged 45 years and older, with Belgium presenting comparable estimates to our surrounding countries (France, Netherlands) [10].

This study shows that adults with Long COVID using primary care service were more likely to be female, aged 45–54 years old and with a lower education level. Although severe acute COVID-19 outcomes are more common among older men, prior studies have consistently shown a higher prevalence of Long COVID among women and middle-aged adults [21, 22], suggesting that the determinants of persistent Long COVID symptoms may differ from those associated with acute disease severity. Potential explanations include sex-related differences in immune responses, healthcare-seeking behaviour, symptom reporting, and social or occupational exposures [1, 23]. Having multiple chronic conditions and a higher BMI were also associated with having Long COVID, in line with findings from previous studies [24, 25].

Through patient-reported indicators, care outcomes and experiences of primary care patients aged 45 years and older with Long COVID in Belgium could be investigated. In this study, substantial differences in self-reported care outcomes were found between Long COVID and non-Long COVID respondents. Adults living with Long COVID reported poorer health outcomes for general health, wellbeing, physical and mental health. These results are in line with the study of Smith et al. [26] who reported a significant decline in health-related quality of life three months after SARS-CoV-2 infection among adults with Long COVID. Brus et al. [27] found that respondents three to six months post-acute infection had the worst health outcomes, with the lowest health-related quality of life, the highest fatigue level and highest proportion with a likely depressive disorder. The study of Scott et al. [28] confirmed this in a longitudinal study over two years by concluding that participants with Long COVID

exhibited the worst health-related quality of life and mental well-being compared to non-Long COVID groups. The physical health impact of Long COVID for adults has been confirmed in various studies [26, 29–31].

By taking into account symptoms' persistence reported by people living with Long COVID, the study also explored differences in perceived burden across symptom-duration groups. Participants reported a strong overall health impact both during the onset of Long COVID symptoms (first two to three months) and when symptoms had persisted for a year or longer. The study by Tran et al. [32] observed a U-shaped trend in the perceived impact of Long COVID on patient's lives, with a worsening around six months after onset that the authors hypothesized may reflect patients' realization that persisting symptoms might be chronic rather than temporary. Our findings are broadly consistent with poorer outcomes in general health, wellbeing and physical health among participants with symptoms persisting for at least one year. However, because our study is cross-sectional, we cannot infer individual trajectories over time or conclude that patients follow a U-shaped course.

Adults with Long COVID aged≥45 years using primary care service with Long COVID symptoms at the time of the survey expressed lower trust in the healthcare system and reduced scores on person-centred care compared to non-Long COVID respondents. Compared to Belgian patients with chronic conditions [15], the scores for trust in the healthcare system and person-centred care were particularly low among people with Long COVID. This observation is consistent with the possibility of Long COVID-specific care gaps in Belgium. These results align with the study of Brus et al. [8] who encountered help-seeking barriers, issues in availability of care and financial barriers among people with Long COVID. Former studies also confirmed that people feel that Long COVID care doesn't align with their patient needs and preferences, and many patients still face neglect, stigma and inadequate support [9, 33–35]. This is also the case in Belgium where patients with Long COVID report unmet needs among others in care delivery, support, and access to inclusion in the Long COVID care trajectory [36, 37]. Moreover, as the majority of our study respondents were at survey time confronted with severe Long COVID symptoms (i.e. persistent symptoms for at least one year), these adults had higher care needs and service use, encountered higher care barriers and major health and life disruptions, including absenteeism from work or school [38]. Over the past pandemic years, Long COVID patients are not the only one reporting challenges navigating healthcare. Healthcare professionals also echo the need for a clear case definition, specific clinical guidelines, diagnostic tools and interdisciplinary support for Long COVID management [2, 6, 39]. The need for coordinated and integrated primary and secondary care for Long COVID, also recognized among Belgian GPs [40] may explain these lower scores in our study.

Strengths and limitations

Strengths of this study are OECD's design of the PaRIS study, the use of standardised validated measures (PROMS and PREMS) and focus on ten study key indicators (the PaRIS10). This study has a population-based approach as the PaRIS survey concentrates exclusively on primary care users. Given the overrepresentation of capitation-funded practices relative to their share within the Belgian primary care system [15], socioeconomically vulnerable populations may be more adequately represented in this study. Moreover, patient-reported indicators were collected on numerous adults with self-reported Long COVID ($N>600$) in Belgium. Although multiple comparisons were conducted across several PaRIS indicators and symptom-duration subgroups, sensitivity analysis showed that the observed associations were generally consistent in direction and magnitude across related indicators, supporting the plausibility of the overall findings despite the potential influence of multiple testing and ceiling effects.

This study has several limitations. The main limitation is the selection bias due to the design of the study. The sampling frame was limited to patients registered in participating practices, covering only a small proportion of the eligible Belgian population and potentially limiting representativeness. Patients from culturally and linguistically diverse backgrounds may also have been underrepresented due to lower participation of highly diverse practices and limited use of translated questionnaires. Adults with chronic conditions were overrepresented in our sample which limits generalizability. Moreover, Long COVID status was self-reported and measured as

patient-reported persistence of symptoms, without confirmation based on medical records or diagnosis. Information related to several potentially important confounders (such as time since acute COVID-19 infection, severity of the acute infection, vaccination status, etc.) was not collected in the PaRIS-PQ, which may influence observed associations. The lack of data on the precise timing of SARS-CoV-2 infection and symptom onset limits the interpretation of findings, as participants may have experienced different pandemic phases, viral variants and different healthcare scenarios [41]. Furthermore, symptom status reported at the time of the survey may reflect heterogeneous stages of disease progression and recovery, reducing comparability across respondents. Moreover, the observed patterns may reflect differences in health seeking behaviour, symptom reporting and diagnostic practices across demographic groups [42], and should therefore be interpreted with caution. At last, adults who recovered quickly or did not self-identify as having Long COVID may be missed in this study.

Conclusion

This study provides a deeper understanding of care outcomes and experiences of adults with Long COVID in Belgium, through the collection of PROMS and PREMS among people aged 45 + consulting primary healthcare. This study found that adults living with Long COVID report poorer health outcomes and less positive care experiences compared to those without Long COVID, especially when symptoms persisted beyond one year. These findings point to the substantial burden associated with Long COVID and suggest the presence of potential care gaps that warrant further attention within the Belgian healthcare system.

Capturing healthcare through the eyes of people suffering from Long COVID enriches our understanding of care experiences and may help inform patient-centred care models and health policy. The study findings underscore the need for more tailored, person-centred care models in primary care for complex diseases such as Long COVID. Moreover, the findings suggest that dedicated care pathways, interdisciplinary collaboration and coordinated management may warrant further consideration in the care of people with Long COVID. In addition, adequate training and support for healthcare professionals in primary and secondary care, as well as the development and monitoring of integrated care pathways for the long-term management of Long COVID could contribute to improving healthcare experiences. Future research is needed to evaluate the effectiveness of such approaches in improving care for adults with Long COVID in Belgium.

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Author contributions SM, RE and DA designed the study. RE and DA collected the data. SM and RE performed the analysis and interpretation of the data. SM drafted the manuscript and RE, PS, NS, SB, RD and DA critically revised the manuscript. All authors approved the final version of the manuscript.

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Data availability The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

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