Long COVID notes for ASPHER COVID-19 Task Force

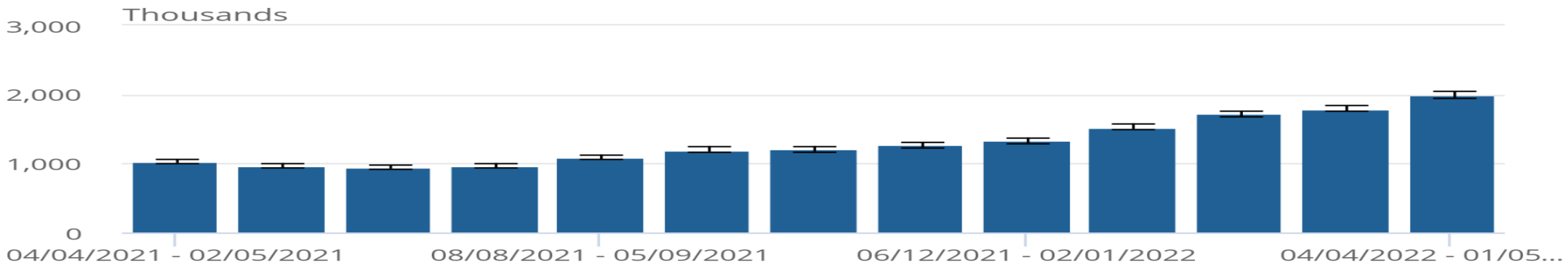
9TH JUNE 2022

J REID

ONS 1st June 2022 reported

Figure 1: 2.0 million people were experiencing self-reported long COVID as of 1 May 2022

Estimated number of people living in private households with self-reported long COVID of any duration, UK: four-week periods ending 2 May 2021 to 1 May 2022



Office for National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: Report 1st June 2022

Estimates of the prevalence of self-reported long COVID and associated activity limitation, using UK Coronavirus (COVID-19) Infection Survey data. (my highlighting)

An estimated **2.0 million people living in private households** in the UK (3.1% of the population) were experiencing self-reported long COVID (symptoms persisting for more than four weeks after the first suspected coronavirus (COVID-19) infection that were not explained by something else) as of 1 May 2022 (see Figure 1).

Of people with self-reported long COVID, 442,000 (22%) first had (or suspected they had) COVID-19 less than 12 weeks previously, **1.4 million people (72%) at least 12 weeks previously**, 826,000 (42%) at least one year previously and 376,000 (19%) at least two years previously.

Of people with self-reported long COVID, 593,000 (30%) first had (or suspected they had) COVID-19 before Alpha became the main variant; this figure was 239,000 (12%) in the Alpha period, 427,000 (21%) in the Delta period, and **619,000 (31%) in the Omicron period**.

Long COVID symptoms adversely affected the day-to-day activities of 1.4 million people (71% of those with self-reported long COVID), **with 398,000 (20%) reporting that their ability to undertake their day-to-day activities had been "limited a lot".**

ONS report 1st June 2022- continued

Fatigue continued to be the most common symptom reported as part of individuals' experience of long COVID (55% of those with self-reported long COVID), followed by shortness of breath (32%), a cough (23%) and muscle ache (23%)

As a proportion of the UK population, prevalence of self-reported long COVID was greatest in **people aged 35 to 49 years, females, people living in more deprived areas, those working in social care, teaching and education or health care, and those with another activity-limiting health condition or disability**.

The estimates presented in this analysis relate to self-reported long COVID, as experienced by study **participants who responded to a representative survey, rather than clinically diagnosed ongoing symptomatic COVID-19 or post-COVID-19 syndrome in the full population.**

ONS dataset 1st June 2022 by age group and sex (% reporting with 95%CI

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/alldatarelatingtoprevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk

25 to 34	2.17	1.94	2.40
35 to 49	3.25	3.08	3.41
50 to 69	3.10	2.99	3.22
70+	1.58	1.47	1.69
Male	1.85	1.76	1.93
Female	2.59	2.50	2.68

ONS dataset- Younger adults and children (% reporting)

Age 2 to 11	0.41	0.31	0.51
Age 12 to 16	1.47	1.27	1.67
Age 17 to 24	1.59	1.35	1.82

ONS data 1st June 2022

Estimated percentage of people living in private households with self-reported long COVID who first had (or suspected they had) COVID-19 at least 12 weeks previously, UK: four week period ending 01 May 2022

Health/disability status	No health conditions	1.76	1.69	1.82
Health/disability status	Activity not limited by health conditions	3.27	2.96	3.57
Health/disability status	Activity limited a little by health conditions	4.77	4.41	5.13
Health/disability status	Activity limited a lot by health conditions	5.91	5.48	6.34

ONS dataset released 1st June 2022 for Index of Multiple Deprivation quintile group

Most deprived	1	**2.87**	2.65	3.09
	2	**2.37**	2.21	2.53
	3	**2.25**	2.11	2.39
	4	**1.95**	1.84	2.07
Least deprived	5	**1.86**	1.75	1.97

ONS dataset by Ethnic group (%)

White	**2.28**	2.21	2.34
Asian	**1.67**	1.36	1.98
Black	**1.64**	1.08	2.19
Mixed	**1.58**	1.18	1.99
Other	**1.79**	1.15	2.43

ONS dataset by region

England	**2.26**	2.19	2.33
North East	**2.86**	2.49	3.22
North West	**2.64**	2.44	2.85
Yorkshire and the Humber	**2.77**	2.51	3.04
East Midlands	**1.95**	1.72	2.17
West Midlands	**2.23**	1.99	2.47
East of England	**2.29**	2.08	2.51
London	**1.69**	1.56	1.83
South East	**2.27**	2.09	2.45
South West	**2.15**	1.91	2.38
Wales	**2.20**	1.92	2.49
Scotland	**1.97**	1.76	2.18
Northern Ireland	**1.77**	1.45	2.09

ONS 1st June dataset by employment sector

Teaching and education	**3.42**	3.14	3.71
Health care	**3.55**	3.23	3.86
Social care	**3.87**	3.27	4.47
Transport (including storage, logistic)	**3.07**	2.55	3.59
Retail sector (including wholesale)	**2.88**	2.53	3.23
Hospitality (e.g. hotel, restaurant)	**2.29**	1.87	2.71
Food production, agriculture, farming	**2.59**	1.95	3.23
Personal services (e.g. hairdressers)	**3.15**	2.28	4.02
Information technology and communication	**2.09**	1.77	2.40
Financial services (including insurance)	**2.11**	1.81	2.41
Manufacturing or construction	**2.48**	2.20	2.77
Civil service or Local Government	**3.11**	2.74	3.49
Arts, Entertainment or Recreation	**2.42**	1.81	3.03
Other occupation sector	**2.52**	2.28	2.75

ONS survey notes 1st June 2022 report

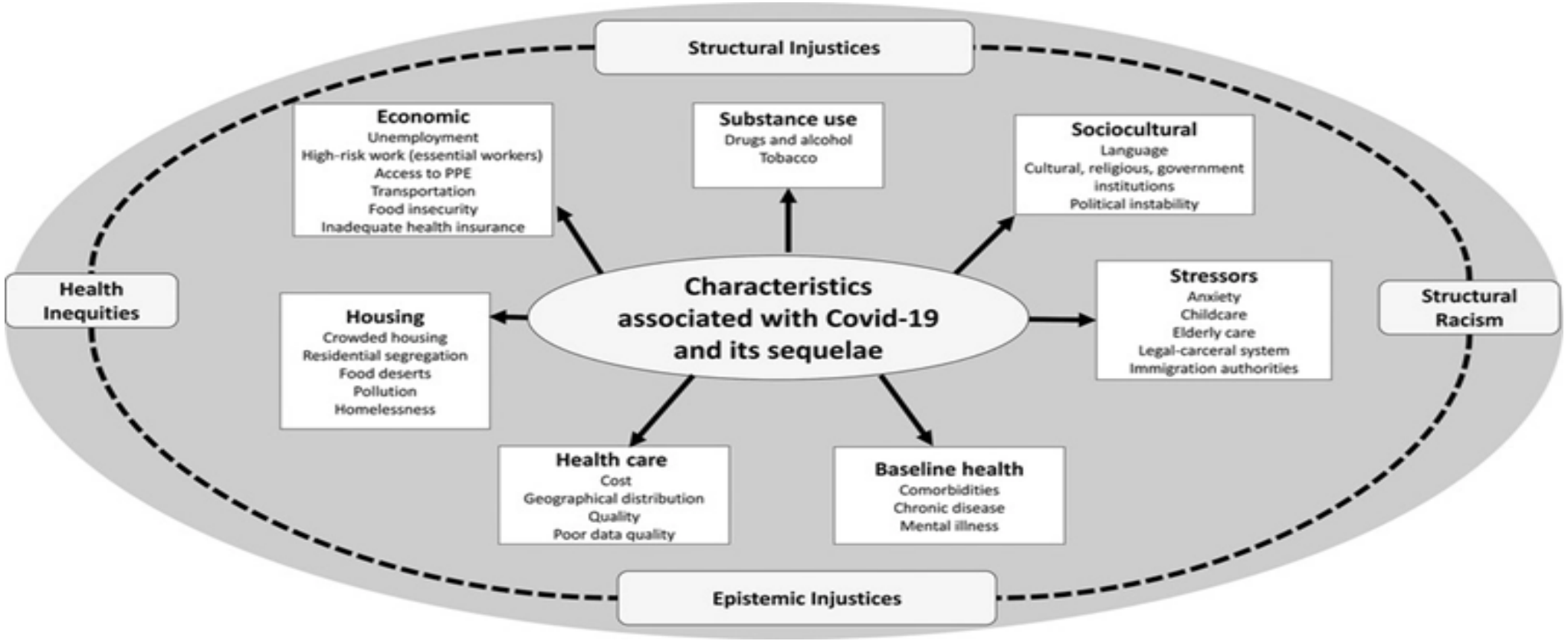
Coronavirus (COVID-19) Infection Survey (CIS)

This analysis was based on 296,868 responses to our Coronavirus (COVID-19) Infection Survey (CIS) collected over the four-week period ending 1 May 2022, weighted to represent people aged two years and over living in private households in the UK. **Self-reported long COVID was defined as symptoms persisting for more than four weeks after the first suspected COVID-19 infection that were not explained by something else.** Parents and carers answered the survey questions on behalf of children aged under 12 years.

draft ASPHER Report 09/06/2022 – 1. Introduction

1. **We explore the scope of Long COVID starting from various definitions used and addressing the link between epidemiology and inequalities from higher exposure and the greater adverse outcomes. We can view Long COVID-19 as a cluster of different complex syndromes.**
2. **The epidemiology of Long COVID does not readily mirror severity of acute illness, and it can affect those infected independently of their age and sex.**
3. **Focuses on childhood post-acute and persistent infection syndromes and provide specific consideration of children living through the pandemic as forms of adverse childhood experiences.**
4. **An example of an underlying analytical public health framework is shown below, to acknowledge that there are many levels of assessing sequelae and wider determinants of health, including for COVID-19 infection and Long COVID.**
5. **The intersectionality of different determinant mechanisms should alert us to the seriousness of Long COVID's threat to health inequalities in the next decade.**

Relationship Between Structural Inequalities and COVID-19, from: Berger Z, Altiery DE Jesus V, Assoumou SA, Greenhalgh T. Long COVID and Health Inequities: The Role of Primary Care. *Milbank Q*. 2021;99(2): 519-541. doi:10.1111/1468-0009.12505



2. Definitions - examples

Long COVID

Post-Acute COVID syndrome (PACS)

Post COVID condition (WHO)

Post COVID syndrome

Also note other syndromes such as -**post-ICU syndromes (PICS)**

3. Long covid in children and young people

- Special focus needed given **many different problems** experienced by children during the pandemic
- Given the large number of children and adolescents infected with SARS-CoV-2, **the impact of even a low prevalence of persistent symptoms would be considerable.**
  - Molteni and colleagues' results highlighted that COVID-19 in children is usually of short duration with low symptom burden, even if some children experience prolonged illness duration. **Symptoms recover usually within two months.**
  - Some children who tested negative for SARS-CoV-2 also had persistent and burdensome illness. However, to date, **few studies explore the epidemiology, assessment and treatment of long COVID in children and young people**[39].
  - In addition, there may be **emerging or hitherto unrecognised syndromes or disorder's** where COVID-19 infection plays a role.

4. Managing Long COVID and other enduring sequelae of infection

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European countries have responded differently to this new challenge, focusing on supplying healthcare services rather than defining long term plans and investing in Long COVID research

Specialist Long COVID clinics are reported to be operating in Belgium, France, Germany, UK, and Spain, and guidance for healthcare professionals has been provided in Italy, Norway, Estonia, and Sweden. **However, additional resources need to be allocated to research, treatment development and the identification of services for the assessment, treatment, rehabilitation and practical support** to address the burden of disease from long COVID and related conditions

Need to **provide protections for individuals with disabilities** to allow for full and equal access to civic and commercial life – needing statutory protections

5. Strengthening the focus on inequalities

Post-COVID symptoms, in particular fatigue, have forced many affected **people to take days or even weeks off from work, causing a negative impact on their economic conditions**.

In addition to being at a greater risk of acute COVID-19, **essential workers also face an increasing burden of Long COVID**

Accessibility of care should be considered. People living in medically underserved areas, who include predominantly Black and minority ethnic groups, may have inadequate access to primary care. Yet vulnerable groups also have more comorbidities and hence a greater need for care

Addressing all of the inequities, including inequity in access to specific COIVID related prevention, treatment and care, evaluate services, undertake longitudinal research into the life course and quality of life impacts and develop teaching materials - all in partnership with the communities at increased risk as well as people experiencing long COVID and those who have living experience of other chronic multisystem disorders.

6. Mitigating the risk of Long COVID

The fragmented perspectives in addressing long COVID weakens the ability to manage all the different dimensions of the problem. While sustaining the efforts on strategies for the primary prevention of infection, because **preventing SARS-CoV-2 infection appears to be the most effective way to prevent long COVID and its innumerable complications**, **mitigation measures are far more complex**.

More studies are needed to clarify the incidence of long COVID in partially and fully vaccinated people and additionally **whether vaccination protects people from Omicron-induced Long COVID**. We also need to know about any impact of repeated infections in generating Long-COVID as more people experience recurrent episodes of Omicron on top of previous variants.

There are many related **broad social policy issues of equitable access to education and work** that can be explicitly addressed in legislation and guidance for human rights and systems supporting social wellbeing and inclusion

7. Conclusions

Long COVID should be **classified as a preventable condition**, and we should set down a marker for the requirement for internationally agreed diagnostic coding of disease, treatments and inclusion in amenable mortality lists.

Because of the complexity of COVID-19 infection and Long COVID, efforts must be focused on **engaging a broader and renewed collaboration among public health stakeholders**. These should take a broad, multidisciplinary approach identifying particularly vulnerable groups.

Health services must be improved in proportion to the rapidly growing need, including new specialized training programs, care pathways for citizens and patients, and training for physicians.

Better use of resources is also needed to **ensure equitable access and distribution of health care**, at the global, national, community, and individual levels, to address health inequities

Recommendations – 1-5

1) Surveillance and tracking of all Long COVID cases, including data on their pre-existing health inequalities and clinical vulnerabilities should be promoted, with regular reporting through from local government to national levels and with sharing across countries.

2) Research into Long COVID should look at comparative incidence and prevalence across those already experiencing health inequalities and in various vulnerable groups or settings.

3) Cross-cutting policies to address the deeper issues related to inequalities should be implemented. This will need to include attention to occupational, housing, social care, educational and financial impacts on cases, those close to them and their disadvantaged communities.

4) Educational and support programs should be created for affected Long COVID patients, their carers and their wider communities, ensuring the sustainability of funding, effective interventions and evaluation over time.

5. We should work to increase the awareness of inequality, vulnerability and need for transparent equity in all interventional approaches, aimed at public health professionals, physicians and rehabilitation professionals, while also linking awareness-raising with those who live with and offer lay care for Long COVID patients

Recommendations 5-9

6. **Any uncertainty about role of vaccines in offering protection against Long COVID should be a major international research priority, particularly given that vaccine hesitancy and inequitable access to vaccines is evident in excluded groups.**
7. There needs to be a **special interest in child health regarding any Long COVID syndromes and other pandemic sequelae**. This should be an area of epidemiological aetiological and interventional research, and also ensure evaluation of optimal outcomes for already disadvantaged and with anticipated associated poorer prospects for long term health status.
8. There are uncertainties about the eventual range of post covid conditions, and **an open and flexible model should be promoted** that allows care and support to all who will need it, in whatever ways appropriate to the condition.
9. The **primary prevention of Long COVID is an underlying pre-requisite by reducing exposure of populations, especially those unvaccinated, and if newer variants have worse sequelae.** Those who assess the pandemic severity largely on the basis of severity of acute infections will underestimate the pandemic's severity and the appropriate intensity of any upcoming countermeasures.

As we face a winter with fewer non-vaccine protections against respiratory viruses, we should consider those already disadvantaged and most vulnerable to Long COVID in