1. Definition – What is Long COVID?

- 1.1 How long it takes to recover from coronavirus (COVID-19) is different for everyone. For most people symptoms will resolve by 12 weeks, but some people have symptoms that can persist for longer than 12 weeks and may change over time and new symptoms may develop.
- 1.2 Clinical case definitions to identify and diagnose the long-term effects of COVID-19 by NICE guideline [NG188]¹
 - Acute COVID-19: signs and symptoms of COVID-19 for up to 4 weeks
 - Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 weeks up to 12 weeks
 - Post COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.
 - In addition to the clinical case definitions, the term 'Long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12weeks) and post-COVID-19 syndrome (12 weeks or more).
 - The likelihood of developing Long COVID is not considered to be linked to the severity of their acute COVID-19 (including whether they were hospitalised).
- 1.3 A clinical case definition of post COVID-19 condition by a Delphi consensus, World Health Organisation (WHO)²
 - Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. A separate definition may be applicable for children.

2. Symptoms/Signs of Long COVID

2.1 Symptoms after acute COVID-19 are highly variable and wide ranging. The most reported symptoms include but are not limited to the following:

| Table 1 Common symptoms after acute COVID-19 | Table | 1 Common symptom | s after acute | COVID-19 | 1 |
|--|-------|------------------|---------------|----------|---|
|--|-------|------------------|---------------|----------|---|

| System | Symptom | System | Symptom |
|----------------|-----------------|------------------|---------------------|
| Respiratory | Breathlessness | Gastrointestinal | Abdominal pain |
| symptoms | Cough | symptoms | Nausea and vomiting |
| Cardiovascular | Chest tightness | | Diarrhoea |
| symptoms | Chest pain | | Weight loss and |
| | - | | reduced appetite |

¹ COVID-19 rapid guideline: managing the long-term effects of COVID-19. NICE guideline [NG188]; Updated 11 November 2021. https://www.nice.org.uk/guidance/ng188

² A clinical case definition of post COVID-19 condition by a Delphi consensus. World Health Organisation; 6 October 2021. https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1

| System | Symptom | System | Symptom |
|--------------|---------------------------------|---------------------------|--------------------------|
| | Palpitations | Musculoskeletal | Joint pain |
| Generalised | Fatigue | symptoms | Muscle pain |
| symptoms | Fever | Ear, nose and throat | Tinnitus |
| | Pain | symptoms | Earache |
| Neurological | Cognitive impairment | | Sore throat |
| symptoms | ('brain fog', loss of | | |
| | concentration or | | |
| | memory issues) | | |
| | Headache | | Dizziness |
| | Sleep disturbance | | Loss of taste and/or |
| | | | smell |
| | Peripheral neuropathy | | Nasal congestion |
| | symptoms (pins and | | |
| | needles and | | |
| | numbness) | | |
| | Dizziness | Dermatological | Skin rashes |
| | Delirium (in older populations) | symptoms | Hair loss |
| | Mobility impairment | Psychological/psychiatric | Symptoms of |
| | Woomity impairment | symptoms | depression |
| | Visual disturbance | | Symptoms of anxiety |
| | visual disturbance | + | Symptoms of post- |
| | | | traumatic stress order |
| | | | tradifiatio stress order |

The following symptoms and signs are less commonly reported in children and young people than in adults: • shortness of breath • persistent cough • pain on breathing • palpitations • variations in heart rate • chest pain

2.2 The Office for National Statistics³ listed the most common symptoms self-reported as part of individuals' experience of Long COVID: fatigue (50%), followed by shortness of breath (37%), loss of smell (37%), and loss of taste (28%).

3. Prevalence – How common is Long COVID?

- 3.1 National context
- 3.1.1 Estimates of the prevalence of self-reported Long COVID
 - As of 2 January 2022, an estimated 1.3 million people (565,000 males, 767,000 females) living in private households in the UK (2.1% of the population were experiencing self-reported Long COVID (symptoms persisting for more than four weeks after the first suspected COVID-19 infection which were not explained by something else (Figure 1), including around 117,000 children aged 2-16 and around 107,000 people between 17 and 24 years old.
 - Of people with self-reported Long COVID, 947,000 people (71%) first had (or suspected they had) COVID-19 at least 12 weeks previously, and of those 554,000 (42%) first had (or suspected they had) COVID-19 at least one year previously.

³ Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK. ONS; 3 February 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 2 January 2022

1,500

Thousands

1,000

4 Apr to 2 May 2021

8 Aug to 5 Sept 2021

6 Dec 2021 to 2 Jan 2022

Figure 1 1.3 million people were experiencing self-reported Long COVID as of 2 January 2022

Source: Office for National Statistics – Coronavirus (COVID-19) Infection Survey (CIS) **Note**: The estimates presented 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. Study participants were asked to respond to the following questions: "Would you describe yourself as having 'long COVID', that is, you are still experiencing symptoms more than 4 weeks after you first had COVID-19, that are not explained by something else?"

- 3.1.2 Case rate of Long COVID symptoms after lab-confirmed infection⁴
 - Of 20,565 study participants who tested positive for COVID-19, 11.4% continued to report any of 12 symptoms for at least five weeks after infection, falling to 3.0% for at least 12 weeks (Figure 2). The corresponding estimates in the control group were statistically significantly lower, at 2.2% for at least five weeks and 0.5% for at least 12 weeks.

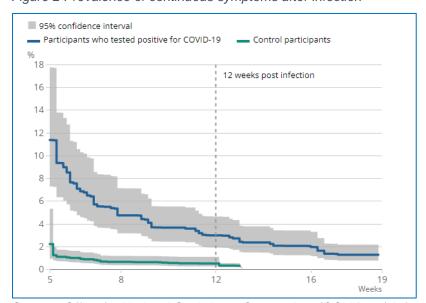


Figure 2 Prevalence of continuous symptoms after infection

Source: Office for National Statistics - Coronavirus (COVID-19) Infection Survey (CIS)

⁴ Technical article: Updated estimates of the prevalence of post-acute symptoms among people with coronavirus (COVID-19) in the UK: 26 April 2020 to 1 August 2021. ONS; 16 September 2021.

Note: The 12 symptoms comprise: fever, headache, muscle ache, weakness/tiredness, nausea/vomiting, abdominal pain, diarrhoea, sore throat, cough, shortness of breath, loss of taste, and loss of smell.

- Among study participants who tested positive for COVID-19, 14.1% were estimated to be experiencing self-reported Long COVID of any severity four weeks after infection, falling to 11.7% at 12 weeks (Figure 3). The estimated prevalence of self-reported Long COVID resulting in at least some limitation to day-to-day activities was at 9.3% at four weeks after infection and 7.5% at 12 weeks. Self-classification may better account for range and recurrence of symptoms.

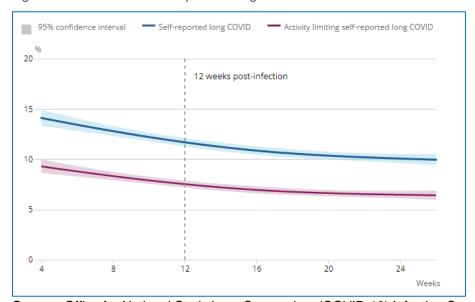


Figure 3 Prevalence of self-reported Long COVID

Source: Office for National Statistics – Coronavirus (COVID-19) Infection Survey (CIS)

3.2 Local context

- The post-acute COVID-19 model on COVID-19 Situational Awareness portal presents real-time data driven (10-12 weeks) forecast of post-acute COVID overall and new cases of post-acute COVID that require support from a service. For modelling purposes, the definition of post-acute COVID has been defined as signs and symptoms that develop during or after an infection consistent with COVID-19, which continue for more than 12 weeks and are not explained by an alternative diagnosis. This is in line with the NICE definition (Section 1.2).
- Based on positive PCR cases extracted from UKHSA second generation surveillance system since 30 August 2020 as community testing had reached sufficient levels (lateral flow tests also included since 1 December 2021), it was estimated that there were 10,280 post-acute COVID (12 weeks+) in Tower Hamlets (Figure 4), and 1,950 would require services (Figure 5).

Figure 4 Post acute COVID (12 weeks+), new cases by UTLA (latest update: 26 January 2022)

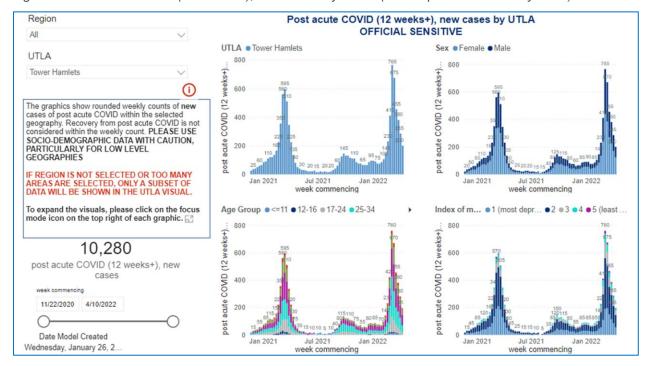
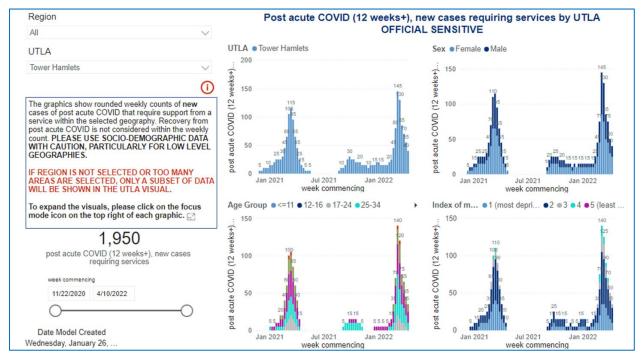


Figure 5 Post acute COVID (12 weeks+), new cases requiring services by UTLA ((latest update: 26 January 2022)

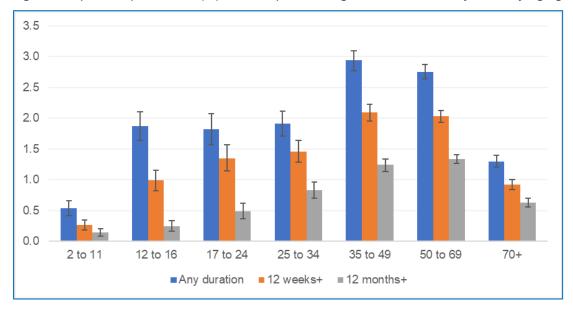


4. Risk factors – Does Long COVID affect everyone equally?

4.1 According to ONS estimates³, prevalence of self-reported Long COVID was highest among people aged 35 – 69 years, females, people living in more deprived areas, people working in health and social care sectors, or teaching and education, as well as those with another activity-limiting health condition or disability.

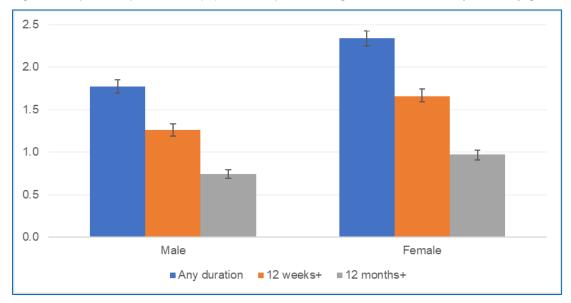
4.2 **Age Group** (Figure 6): The prevalence of self-reported Long COVID was highest among people aged 35 – 49 years (2.94%) or 50 to 69 years (2.75%).

Figure 6 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by age groups



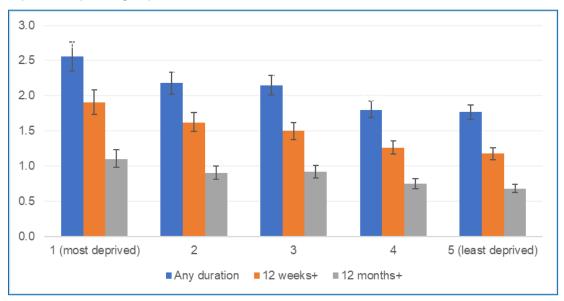
4.3 **Gender** (Figure 7): The prevalence of self-reported Long COVID was significantly higher in females (2.34%) than in males (1.77%).

Figure 7 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by gender



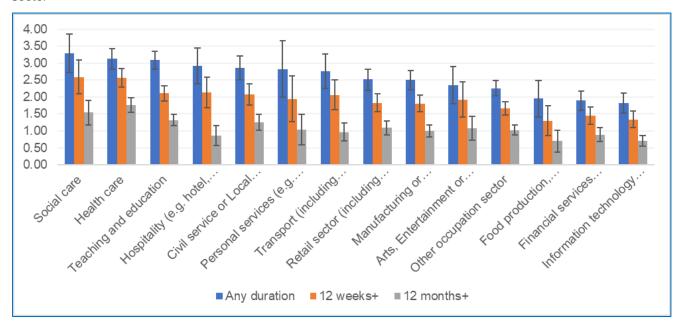
4.4 **Area deprivation** (Figure 8): There is a social gradient in the experience of Long COVID with the prevalence being higher in the most deprived areas (2.56%) compared to that in the least deprived areas (1.77%).

Figure 8 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by area deprivation quintile group



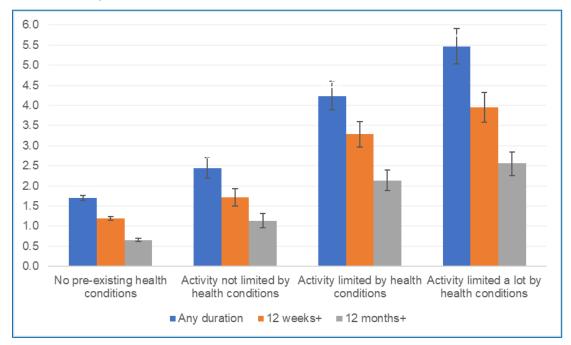
4.5 Employment sector (Figure 9): Health and social care workers experienced the highest prevalence rates of self-reported Long COVID (3.13% and 3.30% respectively), followed by teaching and education sector (3.09%). This was largely explained by other (non-employment) socio-demographic characteristics such as age, sex and location, and the risk of initial infection.

Figure 9 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by employment sector



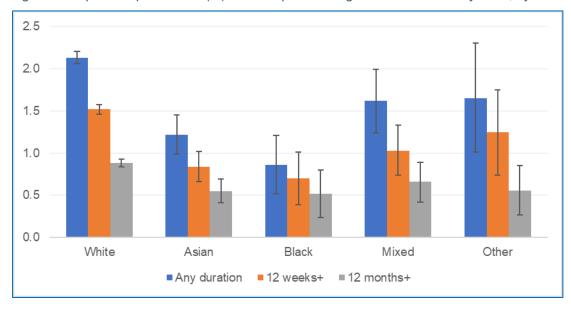
4.6 **Pre-existing health conditions** (Figure 10): Long COVID appears more prevalent among people with pre-existing health conditions, limiting their day-to-day activities (5.47%) compared those with no pre-existing health conditions (1.70%).

Figure 10 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by self-reported health/ disability status



4.7 **Ethnicity** (Figure 11): The picture on ethnicity is mixed. ONS estimates suggested that Long COVID was more prevalent among people in the white ethnic group.

Figure 11 Population prevalence (%) of self-reported Long COVID at 2 January 2022, by ethnic group



5 Possible mechanism – What causes Long COVID?

5.1 Further research is required for exploring pathophysiological mechanism(s) underlie the most common presentations of post COVID-19 syndrome.

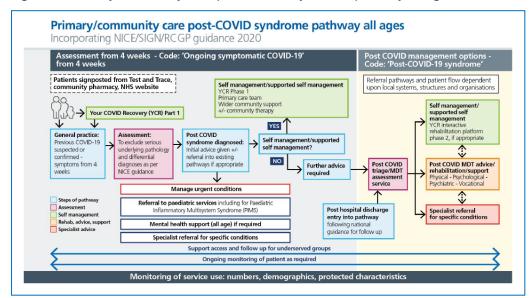
- 5.2 The British Society for Immunology has suggested the underlying immune mechanisms that contribute to people experiencing longer-term health issues post COVID-19 infection⁵:
 - Direct effects of viral infection and tissue damage
 - Collateral damage from excessive inflammation
 - Post-viral autoimmunity
 - Consequences of thrombotic complications
- 5.3 The NIHR has suggested that there may be grounds to understand Long COVID as up to four syndromes, with different underlying causes and treatment needs⁶:
 - Post-ICU syndrome
 - Long-term organ damage e.g. heart and lungs
 - Post-viral syndrome
 - An entirely novel syndrome, separate from the others such that it could be more specifically and uniquely identified as 'Long COVID'

6 Care pathways – How can Long COVID be treated?

- 6.1 Three principles of care for Long COVID':
 - Personalised care
 - Multidisciplinary support and rehabilitation
 - Supporting and enabling self-care

6.2 Post-COVID syndrome pathways

Figure 12 Primary/community care post-COVID syndrome pathway all ages



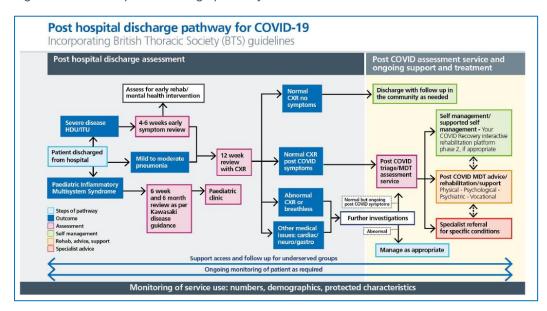
https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/

⁵ Report: Long-term immunological health consequences of COVID-19. British Society for Immunology; 13 August 2020. https://www.immunology.org/coronavirus/immunology-and-covid-19/report-long-term-immunological-health-consequences-covid-19

⁶ Living with Covid19 – Second review. NIHR; 16 March 2021.

National guidance for post-COVID syndrome assessment clinics. NHS; 26 April 2021. https://www.england.nhs.uk/coronavirus/publication/national-guidance-for-post-covid-syndromeassessment-clinics/

Figure 13 Post hospital discharge pathway for COVID-19



- The pathways (Figure 12, Figure 13) are designed to help the NHS improve people's physical, psychological and cognitive outcomes and to signpost to social support (for all ages). This is through offering a holistic, needs-based, person-centred, integrated care approach which has access to a clinical assessment or intervention as required.
- It is important that an early holistic medical assessment is performed in children and young people (CYP) with suspected Long COVID to identify those in need of further specialist input and management for organ impairment, as well as offering appropriate support for other wide-ranging symptoms that may significantly affect quality of life.

6.3 Self-management and supported self-management

- People with people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome are given advice and information on self-management, starting from their holistic assessment. This should include:
 - ways to self-manage their symptoms, such as setting realistic goals
 - who to contact if they are worried about their symptoms or they need support with self-management
 - sources of advice and support, including support groups, social prescribing, online forums and apps
 - how to get support from other services, including social care, housing and employment, and advice about financial support
 - information about new or continuing symptoms of COVID-19 that the person can share with their family, carers and friends.
- The <u>Your COVID recovery website</u> has been highlighted as a potential source of reliable, up-to-date information and support.

7 Impacts – What might Long COVID have impacts on individuals and society?

7.1 Daily living

- As well as clinical needs, the functional impairment seen in some people with Long COVID may result in community and social care needs.
- Of 1.3 million people with self-reported Long COVID³, the experienced symptoms adversely affected the day-to-day activities of 836,000 people (63%), with 244,000 (18%) reporting that their ability to undertake their day-to-day activities had been "limited a lot".

7.2 Return to work

- There have been ongoing concerns on employers' sickness and absence policies, and there have been calls to recognise Long COVID as an occupational disease.
- The Faculty of Occupational Medicine has published the guidance for healthcare professionals on return to work for patients with Long COVID, and the guidance for managers and employers on facilitating return to work of employees with Long COVID⁸.
- NHS has published guidelines for supporting NHS people affected by Long COVID, to help line managers and leaders understand what Long COVID is and how they can support colleagues who are experiencing its symptoms⁹.
- Supporting people with Long COVID return to work requires first understanding of their symptoms, and how these would impact their work. Adjustments could include reduced hours, flexitime, or special equipment.

7.3 Social impacts¹⁰

Data collected from the Opinions and Lifestyle Survey (OPN) between 7 April and 13 June 2021 found that 6.2% of the adult population (aged 16 years and over) in Great Britain may have experienced Long COVID at some point in the pandemic. 'Long COVID' here refers to adults who self-reported on the OPN that they had had a positive test or believed they have had COVID-19 and also responded 'yes' or 'not sure' to the question 'Have you experienced 'Long COVID'?'

7.3.1 Impact on life of Long COVID (Figure 14)

Among those who answered 'yes' to experiencing Long COVID:

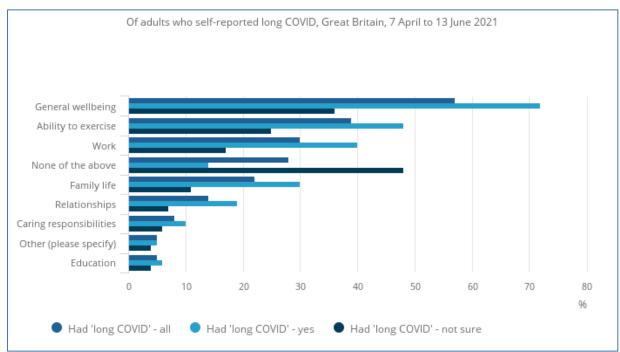
- Over 7 in 10 (72%) said this had negatively affected their general wellbeing
- Around half (48%) said it had negatively affected their ability to exercise
- 4 in 10 (40%) said it had negatively affected their work, and this rose to 5 in 10 (50%) while considering working adults only

⁹ Guidelines for supporting our NHS people affected by Long COVID. NHS; 1 February 2022. https://www.england.nhs.uk/publication/guidelines-for-supporting-our-nhs-people-affected-by-long-covid/

¹⁰ Coronavirus and the social impacts of 'long COVID' on people's lives in Great Britain: 7 April to 13 June 2021. ONS; 21 July 2021.

⁸ Guidance: updated guidance on post-COVID syndrome. Faculty of Occupational Medicine; updated 9 February 2022. https://www.fom.ac.uk/covid-19/guidance-updated-guidance-on-post-covid-syndrome

Figure 14 Impact on life of Long COVID



Source: Office for National Statistics – Opinions and Lifestyle Survey

7.3.2 Well-being and Long COVID

- Of those who may have experienced long COVID, personal well-being levels (mean scores) across all four personal well-being indicators were worse compared with those who reported they'd not had COVID-19 (in any form):
 - anxiety (4.6 for long COVID, 3.8 for not had COVID-19)
 - life satisfaction (6.4 for long COVID, 7.1 for not had COVID-19)
 - feeling that the things done in life were worthwhile (6.9 for long COVID, 7.4 for not had COVID-19)
 - happiness (6.5 for long COVID, 7.1 for not had COVID-19)
- Of those who may have experienced Long COVID:
 - 3 in 10 (30%) reported experiencing moderate to severe depressive symptoms in the last 2 weeks compared with 16% of those who had not had COVID-19
 - A quarter (25%) were likely to have some form of anxiety compared with 15% of those who had not had COVID

7.3.3 Household finances and Long COVID

- Those who may have experienced Long COVID (22%) were more likely to have had their household finances affected by the pandemic than those who have not had COVID-19 (13%).
- The most frequently reported reason for finances being affected by the pandemic regardless of COVID-19 status was having reduced income.
- Of those who may have experienced Long COVID, they more frequently reported a range of reasons, compared with those who had not had COVID-19:
 - Struggling to pay bills (26% for those with Long COVID, and 18% for those who had not had COVID-19)
 - Struggling to pay housing costs (e.g. rent or mortgage) (15% and 7%)

- Struggling to pay school expenses (e.g. uniforms, supplies or equipment)
 (8% and 4%)
- Less money available to spend on food (23% and 17%)

8 COVID-19 Vaccination and Long COVID – Does COVID-19 vaccination protect against developing Long COVID?

- 8.1 An ONS study¹¹ analysed the relationship between COVID-19 vaccination and self-reported Long COVID in a sample of UK adults aged 18 to 69 years based on data to 30 November 2021.
 - It found that receiving two doses of a COVID-19 vaccine at least two weeks before a first test-confirmed COVID-19 infection was associated with a 41.1% decrease in the odds of self-reported Long COVID at least 12 weeks later, relative to socio-demographically similar study participants who were not vaccinated when infected.
 - There was no statistical evidence that the relationship between vaccination status at the time of infection and the likelihood of subsequently reporting long COVID symptoms differed by vaccine type i.e. whether participants received adenovirus vector (Oxford/AstraZeneca) or mRNA (Pfizer/BioNTech or Moderna) vaccines.
 - Longer follow-up time is required to assess the impact of booster doses and the Omicron variant.
- 8.2 The UK Health Security Agency (UKHSA) has undertaken a rapid evidence review¹² of the effects of vaccination against Long COVID or post-COVID symptoms, including 15 UK and international studies up until January 2022.
 - Seven studies examined whether vaccination before infection reduced the symptoms or incidence of Long COVID, seven studies examined whether vaccination in people with Long COVID reduced or cleared the symptoms of Long COVID, and one study examined both. All studies were observational, and there was large heterogeneity between studies in the definition of Long COVID.
 - There is evidence that:
 - Vaccinated people who are subsequently infected with COVID-19 are less likely to report symptoms of Long COVID than unvaccinated people, in the short term (4 weeks after infection), medium term (12 to 20 weeks after infection) and long term (6 months after infection)
 - Two doses of the COVID-19 vaccination provide a high level of protection against long COVID, compared to one dose or no doses
 - Unvaccinated people with Long COVID who were subsequently vaccinated had reduced Long COVID symptoms
 - Unvaccinated people with Long COVID who subsequently vaccinated reported fewer Long COVID symptoms than those who remained unvaccinated

9 Key unknowns

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¹¹ <u>Self-reported long COVID after two doses of a coronavirus (COVID-19) vaccine in the UK</u>. ONS; 26 January 2022.

¹² The effectiveness of vaccination against long COVID: A rapid evidence briefing. UKHSA COVID-19 Evidence Team; 2022. https://ukhsa.koha-ptfs.co.uk/cgi-bin/koha/opac-detail.pl?biblionumber=64359

- The impact of specific variants on the risk of developing Long COVID in Long COVID. There are uncertainties due to the spared of the Omicron variant.
- The effect of boosters against Long COVID
- Clear mechanisms underlying Long COVID phenotypes, which would inform efficient diagnostic pathways or specific treatments
- The symptom groups or syndromes more debilitating, which should be prioritised for treatments
- Prognosis including outcomes and effectiveness of current care pathways
- Long COVID in children and young people
- Long-term impacts on economy, society, and health inequalities

10 Government action on Long COVID

- 10.1 In October 2020, the NHS announced <u>a 5-point plan to support Long COVID patients:</u>
 - Advice for clinicians and information for patients: NICE published the case definition in November 2020 and clinical guidance on managing the longterm effects of COVID-19 in December 2020 (updated in November 2021)
 - NHS England and Improvement committed to provide post COVID assessment clinics: 90 clinics have been established in England to offer multi-disciplinary assessments
 - The creation of the '<u>Your Covid Recovery</u>' an online rehab service to provide personalised support to patients
 - National Institute for Health Research (NIHR) funded research projects across the UK
 - The establishment of the NHS England Long COVID taskforce
- 10.2 In June 2021, the NHS announced a further support package of support for Long COVID for 2021/22. <u>The Long COVID Plan 21/22</u> builds on the five-point plan and outlines 10 key next steps to be taken to support those suffering from Long COVID:
 - Invest £30 million in the rollout of an <u>enhanced service for general practice</u> to support patients to be managed in primary care, where appropriate
 - Invest a further £70 million to expand Long COVID services to add to the £24 million already spent on Post-COVID Assessment Clinics
 - Care coordination to ensure care is joined up and prioritized based on clinical need
 - Establish 15 Post-COVID paediatric hubs across England in order to coordinate care for children and young people across a range of services
 - Develop standard rehab pathway packages to treat the commonest symptoms of Long COVID
 - Extend the use of the Your COVID Recovery online rehab platform
 - Collect and publish data to support operational performance, and clinical and research activities
 - Focus on equity of access, outcomes and experiences
 - Promote good clinical practice through the national learning network on Long COVID for healthcare professionals
 - Support NHS staff suffering from Long COVID by offering a package of comprehensive support for health and wellbeing

10.3 In its <u>COVID-19 Response</u>: <u>Autumn and Winter Plan 2021</u>(September 2021) and <u>COVID-19 Response</u>: <u>Living with COVID-19</u> (February 2022), the Government reiterated its commitment to supporting Long COVID research and expand NHS services.

11 Resources

11.1 National

- Find help and support if you have long COVID GOV.UK (www.gov.uk)
- Long-term effects of coronavirus (long COVID) NHS (www.nhs.uk)
- Long-term effects of COVID-19 (nhsinform.scot)
- Your COVID Recovery | Supporting your recovery after COVID-19
- Long COVID (sign.ac.uk)

11.2 Local

- Long COVID in Newham and Tower Hamlets | North East London Health & Care Partnership (eastlondonhcp.nhs.uk)
- Coronavirus support for residents
 Support for residents (towerhamlets.gov.uk)
- Financial and benefit advice
 - <u>Financial and benefits advice (towerhamlets.gov.uk)</u>; <u>Benefits</u> (towerhamlets.gov.uk)
 - Benefits and financial support (towerhamlets.gov.uk) (Inc. additional support during COVID19 pandemic)
- Employment advice
 - THTT-EA Covid19 Employment Advice V1 (pagetiger.com)
- Housing advice
 - Housing (towerhamlets.gov.uk)
 - Coronavirus housing advice (towerhamlets.gov.uk)
- Tower Hamlets Talking Therapies
 - <u>Tower Hamlets Talking Therapies | Making a positive difference through Talking Therapies</u>
- Bereavement support
 - Deaths and funerals during coronavirus (towerhamlets.gov.uk)
- Diet and shopping support
 - Shopping and meals (towerhamlets.gov.uk)
- Healthy living services
 - Maintaining a healthy weight <u>Managing your weight | Tower Hamlets Connect</u> Smoking cessation support <u>Smoking | Tower Hamlets Connect</u>
- Voluntary and community organisations support
 - Voluntary and community organisations that can help (towerhamlets.gov.uk)
- Social prescribing
 - Services Social Prescribing (gpcaregroup.org)