



# **Long COVID, Episodic Disability and Labour Force Participation**

**Calls to Action  
for Government, Employers, Human  
Resource (HR) Professionals, Insurers  
and Benefit Providers:**

**Canada, Ireland, United Kingdom (UK),  
United States of America (USA)**

**September 2024**

# ACKNOWLEDGEMENTS

Funding for this policy paper was provided by the Ontario Strategy for Patient Oriented Research (SPOR) SUPPORT Unit, which is supported by the Canadian Institutes of Health Research (CIHR), the Province of Ontario, and partner Ontario hospital foundations and institutes.

This Long COVID and Episodic Disability Study was supported by the Canadian Institutes of Health Research (CIHR) Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (Funding Research Number #: GA4-177753), 160 Elgin Street, Ottawa, Ontario, Canada, K1A 0W9. Kelly K. O'Brien & Angela Cheung were supported by a Canada Research Chair from the Canada Research Chairs Program.

We thank the community organisations who collaborated in this work including Long COVID Physio, Patient-Led Research Collaborative (PLRC), COVID Long-Haulers Support Group Canada, Long Covid Support and Long COVID Advocacy Ireland. Thank you to the participants of the Long COVID and Episodic Disability Study for their contributions to this study providing the foundation to this work.



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**Recommended Citation:** Habitus Consulting Collective & Long COVID and Episodic Disability Study Team (O'Brien KK, McCorkell L, Malli N, McDuff K, Chan Carusone S, Cheung A, Goulding S, Kelly M, O'Hara M, O'Connell S, O'Donovan I, Thomson C, Wei H, Stokes R, Fay J). (2024). Long COVID, Episodic Disability and Labour Force Participation: Calls to Action for Government, Employers, Human Resource (HR) Professionals, Insurers and Benefit Providers: Canada, Ireland, United Kingdom, United States of America.

### Source Papers:

O'Brien KK, Brown DA, et al. (2022). Long COVID and episodic disability: advancing the conceptualisation, measurement and knowledge of episodic disability among people living with Long COVID—protocol for a mixed-methods study. *BMJ Open*, 12(3), eO6O826.

<https://doi.org/10.1136/bmjopen-2022-O6O826>

O'Brien KK, Brown DA, et al. (2023). Conceptualising the episodic nature of disability among adults living with Long COVID: a qualitative study. *BMJ Global Health*, 8(3), eO11276.

<https://doi.org/10.1136/bmjgh-2022-O11276>.

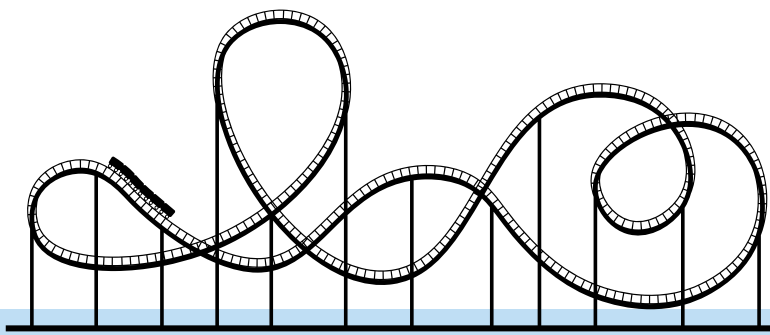
O'Brien KK, Brown DA, et al. (2024). Conceptual framework of episodic disability in the context of Long COVID: Findings from a community-engaged international qualitative study. *MedRxiv Preprint*, 2024.05.28.24308048. <https://doi.org/10.1101/2024.05.28.24308048>

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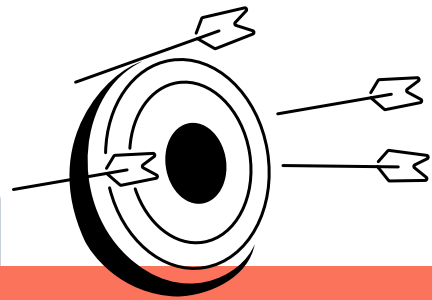
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'I liken it to a rollercoaster ride and you're like up and down... there are good days and bad days.'

-Research Participant (P16)



'I feel like it's a moving target. I'm still trying to figure out, two years later, what I'm capable of... sometimes I feel like I plateau and how much is getting better versus just better at pacing...'

- Research Participant (P24)

# Context

Since the start of the COVID-19 pandemic, the World Health Organization (WHO) reported over 775 million cases and 7 million deaths resulting from COVID-19 [1]. The wide-ranging impacts of this global health crisis have affected global economies, exacerbated social inequities, and exposed major gaps in policies, infrastructure, and government responses [2].

Post COVID-19 condition, referred to as Long COVID, has impacted millions of people across the globe [3]. An estimated 10-45% of COVID-19 survivors experience unresolved symptoms months to years after acute infection [4], although accurate prevalence rate estimates are challenging due to the variation in identifying and reporting of Long COVID [5].

The World Health Organization (WHO) defines Long COVID as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection with symptoms lasting for at least 2 months with no alternate diagnosis. The National Academies of Sciences, Engineering, and Medicine (NASEM) further defined Long COVID as an 'infection-associated chronic condition that occurs after SARS-CoV-2 infection and present for at least 3 months, as a continuous, relapsing and remitting or progressive disease state that affects one or more organ systems' [6]. People living with Long COVID report a **wide range of health symptoms that impact their work, daily life, and social engagement**, some of which fluctuate and change over time, and others that remain persistent and long-term [7].

Many individuals with Long COVID experience **episodic disability**, characterized by physical, cognitive, or mental-emotional health challenges, difficulties with day-to-day activities, challenges to social inclusion (including within employment), as well as uncertainty about the future which may fluctuate on a daily basis or over months or years living with the condition [8].

Long COVID has a large impact on the working age population (17-69 years) [9]. As a result, millions have lost jobs, are struggling with reduced functional capacity, and have a reduced ability to work full time [10]. This amounts to billions of dollars in cost, not only for individuals in terms of lost wages and savings, but also for governments and employers from increased health care costs and labour market shortages [11].

[1] World Health Organization, 2024.

[2] Cutler & Summers, 2020; Human Rights Watch, 2022; Statistics Canada, 2021; The Lancet, 2023; The World Bank, 2022; Vu & Malli, 2020.

[3] Al-Aly et al., 2024; Chen et al., 2022; Davis et al., 2021; Hanson et al., 2022; The Lancet, 2023; World Health Organization, 2022.

[4] Bull-Otterson et al., 2022; Ceban et al., 2022; Chen et al., 2022; Ford et al., 2024; Groff et al., 2021; Hanson et al., 2022; Kuang et al., 2023; National Center for Health Statistics, 2024; Office for National Statistics, 2024; O'Mahoney et al., 2023; Taquet et al., 2021; Woodrow et al., 2023.

[5] Faghy et al., 2022; Woodrow et al., 2023.

[6] Soriano et al., 2022; World Health Organization, 2022.

[7] Al-Aly, Xie, & Bowe, 2021; Ashton et al., 2022; Bowe et al., 2021; Bull-Otterson et al., 2022; Ceban et al., 2022; Cha & Baek, 2024; Davis et al., 2021; Taquet et al., 2021; Tran et al., 2022; Xie & Al-Aly, 2022; Xie, Xu, & Al-Aly, 2022; Xie et al., 2022.

[8] O'Brien et al., 2023, 2024; Realize Canada, 2022.

[9] Bach, 2022; Reuschke & Houston, 2022.

[10] Bach, 2022; Cutler & Summers, 2020; Hsu, 2022; National Centre for Health Statistics, 2024; Perlis et al., 2023; Reuschke & Houston, 2022; Solve Long Covid Initiative, 2022; Stelson et al., 2023; Voruz, Assal, & Peron, 2022.

[11] Bach, 2022; Cutler, 2022; Solve Long Covid Initiative, 2022; Waters & Wernham, 2022.

Research on Long COVID is still in its nascency and more needs to be done to identify biomarkers, diagnostic tests, mechanisms, and therapeutics to understand its long-term impact [12]. Given its **complexity and unpredictability**, many gaps exist in understanding Long COVID and persons living with Long COVID can often face uncertainty, dismissal, epistemic injustice, and gaslighting, all creating unique challenges for managing their treatment [13]. It is **critical for public, medical, and policy sectors to be educated on Long COVID and understand its impact o and understand its impact on employment.**

**Urgent, evidence-informed action is required by governments, healthcare providers, employers, insurers, benefit providers, and Human Resource (HR) professionals to build accountable policies and practices.** Involvement of **persons living with Long COVID can offer crucial knowledge and expertise** that can help develop solutions to address the impacts of Long COVID [14].

In this policy paper, **we identify evidence-informed actions that governments, employers, HR professionals, insurers, and benefit providers can take to support people living with Long COVID** in maintaining their health and participating in the labour force. Grounded in the context of experiences of people living with Long COVID from four jurisdictions, Canada, UK, USA, and Ireland, the aim is to offer actions that can be transferred and implemented in other contexts related to Long COVID, employment, and labor force participation [15].

This policy paper builds on findings from the **Long COVID and Episodic Disability Research Study that highlighted the experiences of episodic disability of people living with Long COVID and their impact on overall health and labour force participation** [16]. The research team involved people living with Long COVID, clinicians, researchers, and representatives from community organizations across four jurisdictions: Canada, Ireland, the UK and the USA [17].

The policy paper highlights **13 calls to action** for governments, employers, benefit providers, HR professionals, and insurers to create conditions that facilitate better outcomes for people living with Long COVID and their employers. This policy paper also includes four national spotlights to feature policies in the context of the countries involved in the Long COVID and Episodic Disability research study, namely Canada, UK, Ireland, and the USA [18]. This is meant to be a living document that will evolve as evidence continues to advance in the context of Long COVID and its effects on employment and labor force participation.

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[12] The Lancet, 2023.

[13] O'Brien et al., 2023; Russell et al., 2022; The Lancet, 2023.

[14] Brown et al., 2020; Gorna et al., 2021; O'Brien et al., 2023; Skilbeck, Spanton, & Paton, 2023; Von Nordheim et al., 2024.

[15] O'Brien et al., 2023, 2024.

[16] O'Brien et al., 2022, 2023, 2024.

[17] O'Brien et al., 2022, 2023, 2024.

[18] O'Brien et al., 2023, 2024.

'Fluctuations, it's unpredictable really... last year I was going through a period where I thought I was improving and I thought I was on like an upward trajectory and I was, I suppose, until a certain point.

So I got to a stage where I was able to go walking, go on walks for like up to an hour without crashing... And then it got to a point where the walk, going for a walk, was making me crash the next day... I've kind of just been down.

I don't know if ... I'm stable or going towards a downwards trajectory. It's hard to tell really... I really don't know what caused that shift from like improving to losing that.'

-Research Participant (P37)

# The Issue

- **Labour force exclusion:** Millions of people living with Long COVID globally have **lost their jobs or are unable to fully participate in work** [19]. People living with Long COVID have shared difficulties engaging in work due to **physical and cognitive symptoms** [20]. Exclusion from the workforce impacts the financial, emotional, and wellness benefits of gainful employment of individuals living with Long COVID [21].
- **Employers face many challenges:** Employers have varied experiences and knowledge of Long COVID, and are faced with the **need to design accommodations for workers with episodic health challenges** [22]. They may need to adapt staffing and workflow needs to the potentially fluctuating and unpredictable nature of episodic disability [23]. While providing more comprehensive and long-term disability benefits is costly, losing skilled employees as a result of poor accommodations affects productivity and morale, diversity in the workplace, and training costs for new employees [24].
- **Poor understanding and recognition of Long COVID: Recognition of Long COVID as a disability varies within and across jurisdictions,** holding implications for what is provided in terms of **benefits, social supports, and insurance coverage** [25]. This results in variability in how employers implement policies, practices, and procedures, as well as how they allocate resources to respond to the needs of people with Long COVID [26].
- **Inadequate accommodations:** Employers and insurers are **not responding to the episodic and fluctuating nature of Long COVID** with adequate accommodations, benefits, and policies [27]. This makes it **difficult to sustain long-term employment** for individuals living with Long COVID and creates uncertainty about the future (i.e., finding and keeping work, financial instability) [28]. Many who are caring for those living with Long COVID may also be lacking adequate accommodations and benefits.

[19] Ayoubkhani et al., 2024; COVID-19 Longhailer Advocacy Project, 2022; Cutler, 2022; Perlis et al., 2023; Reuschke & Houston, 2022; Trades Union Congress (TUC) & Long Covid Support, 2023.

[20] Davis et al., 2021; Kerkisiek et al., 2023; Kokolevich et al., 2022; Lunt et al., 2024; Nielsen & Yarker, 2023; O'Mahony et al., 2022; Perlis et al., 2023; Reuschke & Houston, 2022; Realize Canada, 2022.

[21] O'Mahony et al., 2022; Reuschke & Houston, 2022.

[22] Cohen & Rodgers, 2024; Job Accommodation Network, 2024; SunLife, n.d.

[23] Cohen & Rodgers, 2024; DeMars et al., 2022; O'Brien et al., 2023.

[24] Job Accommodation Network, 2024; SunLife, n.d.

[25] Dorfman & Berger, 2023; Government of Canada, 2023; Office for Civil Rights, 2021; Office of the Chief Science Advisor of Canada, 2022; UK Department of Health, 2021.

[26] Dorfman & Berger, 2023; Lunt et al., 2024; Nielsen & Yarker, 2023.

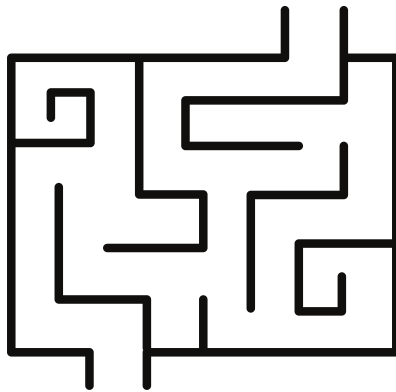
[27] Lunt et al., 2024; McNabb et al., 2023; Nielsen & Yarker, 2023; Stelson et al., 2023.

[28] Nielsen & Yarker, 2023; Perlis et al., 2023; Stelson et al., 2023; Voruz, Assal, & Peron, 2023.



- **Lack of implementation of recommendations for return to work:**

Recommendations for supporting return to work for persons with Long COVID exist [29]. However, **implementation of these recommendations by governments and employers has been infrequent and inconsistent** [30]. There is also no clear accountability mechanism to ensure people living with Long COVID are supported in the labour force [31].



- **Negative impact on economy:** Long COVID has a staggering impact on the global economy with respect to costs and productivity loss, with **labor shortages in many industries, including within key sectors such as health care and services sectors** [32].
- **Disproportionate impacts on certain population groups: Women are at a higher risk of Long COVID** which is likely to produce compounded impacts on women's employment trajectories [33]. Individuals at older age [34], as well as from certain racial groups [35], can be impacted more than others. Given Long COVID impacts individuals in their prime working age, which is often the career building phase of life, there are wide-ranging economic impacts affecting individuals' broader life trajectory including retirement planning [36]. Policies and practices should be tailored to support these groups that are disproportionately impacted by Long COVID.

[29] DeMars et al., 2022; Realize, n.d.a, n.d.b.; SunLife, n.d.

[30] Lunt et al., 2024; McNabb et al., 2023; Prevost-Manuel, Foxcroft, & Common, 2021.

[31] Lunt et al., 2024.

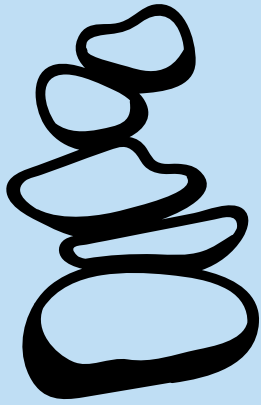
[32] COVID Long-Haulers Support Group Canada & Viral Neuro Exploration (Vinex), 2021; Cutler, 2022; Cutler & Summers, 2020; Ham, 2022; Lunt et al., 2024; Reuschke & Houston, 2022; Solve Long Covid Initiative, 2022; Voruz, Assal, & Péron, 2023.

[33] National Center for Immunization and Respiratory Diseases (NCIRD), 2024; Song & Giuriato, 2023.

[34] Song & Giuriato, 2023.

[35] Cohen & Rodgers, 2024; Khullar et al., 2023; National Center for Immunization and Respiratory Diseases (NCIRD), 2024.

[36] Bach, 2022; Lunt et al., 2022.



Over

'How will you know you're ready to return to work? [I've been told that] you have to be able to get through the basics of your own day to day life and be fully functional at it with capacity to spare before you can try and put your toe back into the working world... I'm not in a stable enough place for that to be a realistic goal.'

-Research Participant (P25)

'I can only do maybe a max of 10 hours a week [of work], if that. But through all that I'm still trying... It's taken a long time to find things...[so] that I can earn that little bit of extra income because... feeling useful in society... and helpful to people...  
I haven't given up...'

-Research Participant (P38)



'If I had capacity to work, then I would. So I just don't want people to think that I have like some sort of entitlement thing just because I have a disability.'

-Research Participant (P38)

# Calls to Action

The following calls to action for governments, employers, HR professionals, insurers, and benefit providers have been created over ten months through research, review of literature, and with direction from people living with Long COVID. They pertain to supporting labour force participation, income support, and maintaining or returning to paid employment among people living with Long COVID. These calls to action are not listed in order of importance and are grouped according to the target audience, namely: Government, and Employers, HR Professionals, Insurers, and Benefit Providers, although the suite of recommendations should be considered for a holistic and coordinated response.

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## For Government

### 1 **Develop national guidelines and policies that explicitly recognize Long COVID as a disability.** This will require that:

- Medical professionals **formally recognize Long COVID as a medical condition and disability** that may require benefits through work (e.g., to support rehabilitation, employment protections, work accommodations, financial supports) [37]. For example, Long COVID was added as a recognized condition under the Americans with Disabilities Act (ADA) in the USA [38].
- The medical system creates or provides **clear diagnostic criteria** that includes clinical practice guidelines for standardized assessment, and interventions for Long COVID based on globally recognized definitions. This includes using clear case definitions [39], as well as clear direction on the use of standardized medical coding (e.g. International Classification of Diseases (ICD)) [40].

### 2 **Direct health professional regulatory bodies to mandate foundational training and build capacity among health providers about Long COVID** [41]. Specifically, training should include information on:

- Understanding Long COVID as an episodic disability and how it impacts work and workplace accommodations.
- Writing medical notes for employees requesting time off work and/or accommodations from their employer.

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[37] DeMars et al., 2022.

[38] Americans with Disabilities Act, n.d.; Office for Civil Rights, 2021; U.S. Department of Health and Human Services, 2022b.

[39] Soriano et al., 2022.

[40] Dorfman & Berger, 2023; Johns Hopkins Medicine, 2022; Office of the Chief Science Advisor of Canada, 2022; Pfaff et al., 2023.

[41] Jamieson et al., 2024; Nielsen & Yarker, 2023.

## Calls to Action

**3** Ensure employers (including Human Resource professionals), insurers, and benefit providers provide information and are held accountable for implementing guidance offered by the government for Long COVID workplace policy. This will require:

- Employers investing in resources to educate employees about the rights and benefits afforded to them through national guidelines and policies for Long COVID. Having employees living with Long COVID educated and aware of their rights is a crucial accountability mechanism to ensure uptake and sustained implementation of workplace supports.
- Training of managers and employees on Long COVID related policies and practices to ensure accountability [42].

**4** Mandate a minimum number of days of paid sick leave or disability leave for employees living with Long COVID, recognizing the episodic nature of the illness [43]. This will require:

- Supporting people living with Long COVID who do not qualify for disability benefits to take leave in order to rest or pace their activity [44].

**5** Provide training and education to employers on the legal obligation to accommodate people with episodic disability including the impact, reasoning, benefits, and how to effectively implement accommodations [45]. This includes:

- Directing employers to educate their labor force on accommodations, aligning with any national guidelines, and reviewing benefit packages for employees living with Long COVID.

**6** Invest in research and encourage research collaboration to address issues of Long COVID employment policies, practices, and procedures in a way that accounts for the chronic, multidimensional, unpredictable, and episodic nature of Long COVID [46]

[42] Automatic Data Processing (ADP), 2023; Chartered Institute of Personnel and Development (CIPD), 2022a, 2022b; DavidsonMorris, 2023; Kohn et al., 2024; Realize Canada, 2022; U.S. Department of Labor, 2022.

[43] Automatic Data Processing (ADP), 2023; DavidsonMorris, 2023; Jamieson et al., 2024; Job Accommodation Network, n.d.a, n.d.b.

[44] Automatic Data Processing (ADP), 2023; Job Accommodation Network, n.d.a, n.d.b.

[45] Automatic Data Processing (ADP), 2023.

[46] McCorkell & Peluso, 2023; Public Health Agency of Canada, 2021, 2023a; Office of the Chief Science Advisor of Canada, 2022; U.S. Department of Health & Human Services, 2022a.

### For Employers, Human Resource Professionals, Insurers, and Benefit Providers

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#### **7** Develop and implement employment policies and practices that are responsive to the needs of people living with Long COVID [47]. This will require:

- Reviewing the **Episodic Disability Framework** [48], as well as other recommendations and up-to-date research on Long COVID, and frameworks and recommendations to inform the development of policies and practices within workplaces [49].
- Engaging with Long COVID advocacy groups and listening to people living with Long COVID [50], ensuring that involvement of people living with Long COVID is carefully supported (including with adequate compensation).

#### **8** Improve access to occupational health and counseling services to facilitate professional advice on whether a person can continue work, in what form, and with what specific accommodations [51].

#### **9** Provide individualized workplace accommodations to meet the needs of persons living with Long COVID [52]. This will require:

- Recognition of the differences in the experiences of Long COVID and varied contexts of work (e.g., industry/sector, type of role, cognitive or physical health demands) to make appropriate accommodations.
- Offering accommodations to all employees irrespective of employment status (e.g., temporary or permanent).
- Identifying employee competencies and capacities, rather than limitations, to create accommodations that prioritize employee strengths.

[47] Automatic Data Processing (ADP), 2023; DavidsonMorris, 2023; Job Accommodation Network, n.d.a, n.d.b.

[48] O'Brien et al., 2023, 2024.

[49] Chartered Institute of Personnel and Development (CIPD), 2022a; DeMars et al., 2022; Job Accommodation Network, n.d.a, n.d.b; Office of the Chief Science Advisor of Canada, 2022; Stelson et al., 2023.

[50] Brown et al., 2020; Chartered Institute of Personnel and Development (CIPD), 2022a; Gorna et al., 2021; Long COVID Families, n.d.; National Institute for Health and Care Excellence (NICE), 2024.

[51] Chartered Institute of Personnel and Development (CIPD), 2022a; Kohn et al., 2024; Nielsen & Yarker, 2023; SunLife, n.d.

[52] Advisory, Conciliation and Arbitration Service (ACAS), 2024; DeMars et al., 2022; Job Accommodation Network, n.d.a; n.d.b; Long COVID Families, n.d.; Nielsen & Yarker, 2023; Realize Canada, 2022; University of Bristol, 2021; Varagur, 2021.

## Calls to Action

### **10 Offer flexibility in working conditions for those with Long COVID [53], including:**

- Flexibility to work from home or remotely;
- Reduced physical and cognitive workloads;
- Frequent breaks or breaks at times that meet the employees' needs;
- Changes to job roles or responsibilities;
- Prolonged or phased return to work;
- Fewer meetings (especially when these require video/screen time).

### **11 Build contingency plans for employees living with Long COVID in case they experience sudden and unexpected episodes of disability that impact their ability to work:**

- Since persons living with Long COVID can face unpredictable relapses, it is important to have contingency plans in place to ensure they have supported coverage at work so they can rest and pace activity.

### **12 Allocate resources to support accommodations and flexibility to ensure sustainability of supports for persons living with Long COVID:**

- Supporting employees living with Long COVID may require additional resources and funds that employers may need to consider as they plan annual budgets.

### **13 Avoid asking for medical notes and recognize the often 'invisible' nature of episodic disability with Long COVID.**

- If needed, ask health professionals to provide information on employees' functional capacities and limitations as opposed to the official diagnosis.
- Many individuals living with Long COVID face challenges in accessing health providers who correctly diagnose their condition. It is important to trust employees who ask for accommodations in good faith.

[53] Chartered Institute of Personnel and Development (CIPD), 2022a; Cutler, 2022; DeMars et al., 2022; Job Accommodation Network, n.d.a, n.d.b; Realize Canada, n.d.a.; Stelson et al., 2023; U.S. Department of Labor, 2022.

# National Spotlights

The following section spotlights four countries that were a part of the research study. These spotlights include nation-specific personal experiences, employment contexts, and policy approaches towards Long COVID. Statistics and definitions are not always directly comparable across nations, but illustrate exemplars of shared challenges and potential solutions.



# National Spotlight: United States of America

***“There’s just this notion that ‘oh I must not be trying hard enough’.... I don’t necessarily think of it as a stigma as much as ignorance or dissonance. I mean, I think people don’t want to think about people like me. People don’t want to think that a viral infection can disable you perhaps for the rest of your life. I mean, you had the flu and now you’re disabled; that’s it?” (P15, USA Resident) [54]***

*Grace is living with Long COVID [55]. She knows there are laws and guidelines to protect her at work but in reality, it simply isn’t enough. She experiences stigma and deeply ingrained stereotypes daily. She is alone in having to challenge her employer’s poor practice. Every day she has to research her rights and fight, on top of dealing with the symptoms of Long COVID. She is doing everything within her power to keep her job.*

Grace is one of over 16 million people in the USA aged 18–65 who have Long COVID [56]. Grace’s Long COVID can be recognised as a disability under the Americans with Disabilities Act (ADA) if symptoms are causing impairment that “substantially limit” major life activities [57]. However, it does not guarantee her access to federal benefits programmes.

Support is needed for the 2–4 million Americans [58] who are out of work as a result of Long COVID. Individuals with Long COVID are 10% less likely to be employed relative to those without a prior SARS-CoV-2 infection and on average work 50% less hours than individuals without a prior SARS-CoV-2 infection [59]. When the anticipated costs of missed income, savings, and healthcare bills for the entire population of persons with Long COVID are compiled, it is estimated that the cost of Long COVID-related disability in the USA since the pandemic started until January 31, 2022 has exceeded \$386 billion [60].

In addition to the USA’s acknowledgement of Long COVID as a disability has come as part of a whole-of-government response. The National Institutes for Health (NIH) created the RECOVER Initiative, creating a research network with a mission to address the impacts of Long COVID by taking a large-scale, multidisciplinary approach where people with Long COVID, their families, and caregivers take a role [61].

[54] O’Brien et al., 2023, 2024.

[55] Grace’s story represents a combination of research participant and lived experience groups’ contributions.

[56] Bach, 2022; National Center for Health Statistics, 2024.

[57] Americans with Disabilities Act (ADA), n.d.

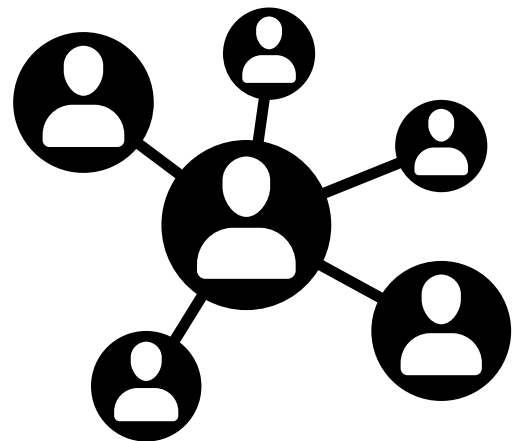
[58] Bach, 2022; National Center for Health Statistics, 2024.

[59] Ham, 2022.

[60] Solve Long Covid Initiative, 2022.

[61] Assistant Secretary for Public Affairs, 2023; RECOVER (Researching COVID to Enhance Recovery), 2024, n.d.

American members of the Long COVID and Episodic Disability Study working group shared that while individuals are entitled to accommodations at work, there is a lack of enforcement. Further, they shared that employers are under informed with respect to Long COVID and are influenced by misinformation and stigma, which pose substantial barriers for remaining in or re-entering the workforce.



# National Spotlight: United Kingdom

*“There were so many times I just felt like giving up. The emotional or psychological trauma when you are not believed, when you know that something is wrong. You felt like you were going to die every night and then people are just dismissing you” (P1, UK Resident) [62]*

*Norma is highly qualified and experienced [63]. Before Long COVID, she was thriving in her health sector career. Now, Norma can't find an employer or a position that provides the flexibility she needs for the episodic symptoms she experiences. Norma is part of the 7% (2.9 million) of the United Kingdom working age population who have had, or still have, Long COVID [64]. Norma, like 79% of those with Long COVID in the UK, has been negatively impacted in her daily functioning [65].*

The number of working-age individuals who experienced employment exclusion as a result of long-term sickness increased by 120,900 people from 2019–2021, contributing to the growing labour shortage in the United Kingdom [66]. In the same timeframe, an estimated 80,000 persons in the United Kingdom (0.3% of the workforce) have lost their jobs as a result of Long COVID, of whom 43% worked in occupations such as farming, construction, cleaning and security (occupations at high risk of job insecurity) [67].

Long COVID Support (England and Wales) together with the Trade Union Congress have put forward recommendations for Long COVID to be categorized as a disability under the Equality Act (2010), increasing the statutory sick pay, overhauling the benefits system, providing universal access to occupational health, and providing access to disablement benefits to individuals with Long COVID [68]. The UK Department of Health and Social Care stated that existing benefits can be accessed for individuals with Long COVID [69]. However, assessment processes require many administrative steps with applications for access to benefits often unsuccessful without appeal [70], which can be highly cognitively and physically demanding for individuals living with Long COVID.

[62] O'Brien et al, 2023, 2024.

[63] Norma's story represents a combination of research participant and lived experience groups' contributions.

[64] Reuschke & Houston, 2022.

[65] Office for National Statistics (ONS), 2023.

[66] UK Office for National Statistics Annual Population Survey as cited in Reuschke & Houston, 2022.

[67] UK Office for National Statistics Annual Population Survey as cited in Reuschke & Houston, 2022.

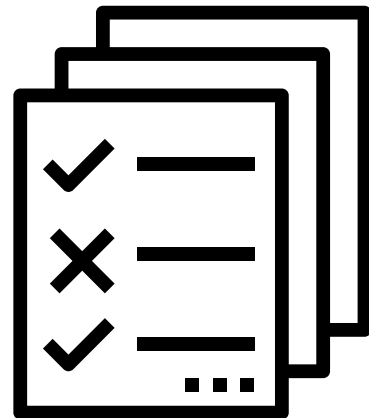
[68] Trades Union Congress (TUC) & Long Covid Support, 2023.

[69] UK Department of Health and Social Care, 2021.

[70] UK Department for Works and Pensions, 2021.

In preparing this policy paper, Long COVID Support members expressed the importance of employers' support in keeping them in their job role to prevent the need for unemployment support. It is also felt that there are currently few roles flexible enough to accommodate fluctuating states in health: ***"I have relapses all the time... the name like episodic disability is actually ...the best description that I've heard of it because that's exactly how it feels"*** - Long COVID Support member, Working Group Session, November 2023).

The UK experience has shown that when organizations come together, including people living with Long COVID, unions, and academic institutions, clear guidance and evidence can be created and shared. This policy paper highlights how various jurisdictions can learn from one another with shared collective actions applicable in all.



# National Spotlight: Canada

***“Some people might think it’s like handouts and stuff like that. But honestly if we could work, we would work. We need some support and we need support that actually gives us the ability to afford everything that we need. Like, again, I’m not looking for handouts but I do know that I need help.” (P38, Canadian Resident) [71]***

*Seema feels the stigma of living with Long COVID [72]. That stigma is felt through the looks and treatment she gets from her managers and colleagues and the ‘employment processes’ she goes through that seem to create further barriers to doing the work she is trained to do. It is hard not to internalize that stigma and feel that it is her fault for not ‘recovering fast enough’. This is compounded by the confusion and difficulty in finding support she is eligible for in the rural location where she lives. By the end of 2022, Seema was one of 1.4 million Canadian adults (5% of all Canadians) who had or have experienced Long COVID symptoms three months after infection [73].*

Across Canada, among those who were in school or employed, Long COVID resulted in more than 20% missing school or work, with 24 missed days on average [74]. Making claims for disability benefits can also be complex, with patients requiring a multidisciplinary team to make individual claims with claims often being unsuccessful, apart from cases of severe disability.

A multidisciplinary task force was established in 2022 by Canada’s Chief Science Advisor to understand and advise on ways to address Long COVID conditions [75]. The task force put forward an integrated framework to respond to people living with Long COVID in Canada with recommendations that take into consideration literature, as well as experiences of providers and people living with Long COVID [76]. These advancements were impacted by the advocacy, education, and campaigning work of organisations including *Realize Canada* [77] and COVID Long-Haulers Support Group Canada [78]. These groups work together to combine the experiences of people living with Long COVID with academic expertise and evidence.

[71] O’Brien et al, 2023, 2024.

[72] Seema’s story represents a combination of research participant and lived experience groups’ contributions.

[73] Statistics Canada, 2022.

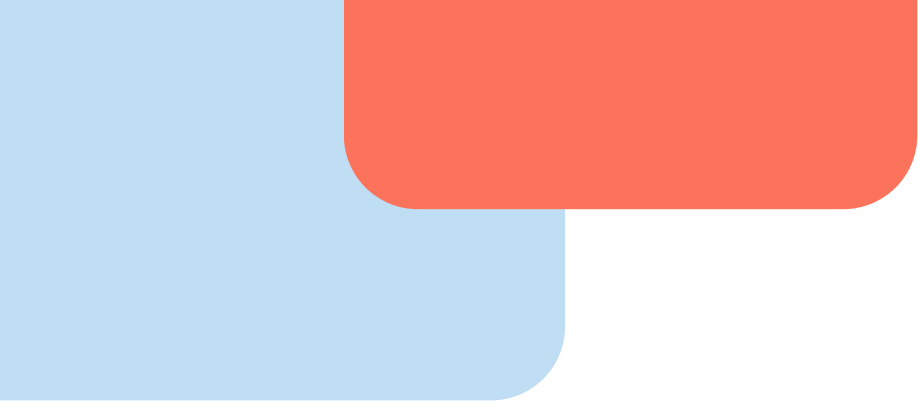
[74] Statistics Canada, 2023.

[75] Office of the Chief Science Advisor of Canada, 2022.

[76] Office of the Chief Science Advisor of Canada, 2022.

[77] Realize Canada, n.d.c.

[78] COVID Long-Haulers Support Group Canada, n.d.; Office of the Chief Science Advisor of Canada, 2022.



As part of this policy paper, COVID Long-Haulers Support Group Canada members shared that a lack of enforcement, direct guidance, as well as legislative power were major challenges impacting individuals with Long COVID. They also pointed out the variability of funding and programming for Long COVID support that currently exist across Canadian regions, provinces, and territories. This variability introduces additional complexity that makes it difficult to navigate matching the right services for the right person in the right place.

Navigating this maze is incredibly complex and can be further challenging for those trying to access services who are experiencing cognitive impairment living with Long COVID.

Canada has been a leader in creating guidance for employers and government in relation to Long COVID [79]. These insights have been critical in the formulation of calls to action within this policy paper. Formalizing these recommendations into policy will help to foster and ensure broad implementation.

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[79] DeMars et al., 2022; Realize Canada, n.d.a, n.d.b.

# National Spotlight: Ireland

*“I suppose I’m on sick pay at the minute. That’s rumoured now to be stopping because I work in the public service and that’s supposed to be stopping now in June of this year. So I have no idea what’s going to happen then at that stage. Actually, that’s a big worry.” (P37, Irish Resident) [80]*

*Aisling still has symptoms of Long COVID [81]. She has been part of the advocacy community for Long COVID in Ireland for the past 18 months. She has her own issues with her employer but she gets invaluable support from her peers through the Long COVID community. She is one of the approximately 230,559 people in Ireland reported to have Long COVID symptoms (5% of the population), of whom 36,889 are impacted significantly in their daily activities by symptoms [82]. Aisling is by no means alone in her experience. Nor is she alone in feeling frustrated with her government for their lack of involvement of people living with Long COVID in the formation of recommendations, policy, or planning.*

Based on the 2023 report from the Department of Social Protection, Long COVID was determined not to meet the statutory criteria for recognition under the Occupational Injuries Benefit Scheme [83]. However, according to a survey of individuals living with Long COVID in Ireland, thirty-eight percent (38%) of people reported that their symptoms had a severe impact on their ability to work, with another 33% reporting a moderate impact [84]. Because of their Long COVID symptoms, 22% of participants had received social welfare support or pandemic unemployment payment (PUP) before it ended in March 2022 [85].

A motion regarding Long COVID was put forward in the Dáil Éireann for private members [86]. The impacts of Long COVID were discussed, including the rolling out of specialist services for individuals who have been unable to make a full recovery from the virus [87].

These achievements, in part, are occurring because of the tireless efforts of patient-led organisations, such as Long COVID Advocacy Ireland [88], who provide support, education, and advocacy services to all Long COVID patients in Ireland.

[80] O’Brien et al., 2023, 2024.

[81] Aisling’s story represents a combination of research participant and lived experience groups’ contributions.

[82] Naughten, 2023.

[83] Irish Department of Social Protection, 2023.

[84] O’Mahony et al., 2022.

[85] O’Mahony et al., 2022.

[86] House of the Oireachtas, 2022.

[87] House of the Oireachtas, 2022.

[88] Long Covid Advocacy Ireland, n.d.

Members of these groups have shared the importance of a localised approach to gathering insight and recommendations for implementation, especially for a smaller country like Ireland where key messages from neighbouring larger countries can create confusion in employees' rights and access to support.

The impact of other legislation is also key. In April 2023, Ireland passed the Work Life Balance and Miscellaneous Provisions Act, that gives employees a legal right to seek remote work and specifies when and how often companies must agree to grant or when they can deny such requests [89]. Issues such as data security, fees, and staff turnover had to be addressed when passing the Bill [90]. This new Act may have a positive impact on the lives of people living with Long COVID, as employers are required under the Bill to have a formal policy on remote employment [91]. Temporary schemes for paid leave for public health service employees unfit for work post COVID-19 infection were also enacted [92].

Although the legislation is imperfect as employers in most cases are free to refuse a working from home request, Ireland still holds a unique example of legislation that may have an important impact on the accessibility of work for those living with Long COVID [93]. The calls to action in this policy paper similarly include the importance of accommodations within the workplace.



[89] Government of Ireland, 2024; Workplace Relations Commission, 2023.

[90] Inverarity, 2022.

[91] Inverarity, 2022.

[92] Hoey, 2022.

[93] Workplace Relations Commission, 2023.



# Appendix 1: Glossary of Terms

**Disability:** An umbrella term used to describe *impairments*, *activity limitations*, and *participation restrictions*, where: an *impairment* is a problem in body function or structure, an *activity limitation* is a difficulty encountered by an individual in executing a task or action, and *participation restriction* is a problem in the involvement in life situations [94].

The nature of disability is complex and is an interaction between an individual's bodily and mental states and the environment or society in which an individual resides [95]. A disability can occur at any time in a person's life, can be permanent, temporary or episodic, steadily worsen, remain the same or improve, and can be mild to severe [96].

Disability can also be the cause, as well as the result, of other diseases, illnesses, or injuries [97]. While the traditional, biomedical approach views disability as a medical or health problem that prevents or reduces a person's ability to participate fully in society, the social approach views disability as a natural part of society while examining the attitudes, stigma, prejudices, and inaccessible environments that hinder the full and effective participation of persons with disabilities in society on an equal basis with others [98].

**Episodic Disability:** A condition causing episodes of disability varying in severity and duration and may occur with advance warning or come on unexpectedly [99]. Episodic disabling conditions or diseases are often lifelong and chronic, but unlike permanent or progressive disabling conditions [100], they present as waning episodes of disability. Episodic disability can both be defined as a health condition, or as a health-related consequence of a condition [101].

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[94] World Health Organization, n.d.

[95] Human Resources and Skills Development Canada, 2013; World Health Organization, n.d.

[96] Human Resources and Skills Development Canada, 2013.

[97] Human Resources and Skills Development Canada, 2013.

[98] Human Resources and Skills Development Canada, 2013.

[99] Episodic Disabilities Network, n.d.; Palmer, Egan, & Popiel, 2024.

[100] Episodic Disabilities Network, n.d.; O'Brien et al., 2023, 2024; Palmer, Egan, & Popiel, 2024.

[101] Episodic Disabilities Network, n.d.; O'Brien et al., 2023, 2024; Palmer, Egan, & Popiel, 2024.

**Episodic Disability Framework:** The Episodic Disability Framework is a conceptual framework that characterizes the multidimensional and episodic nature of health challenges experienced by persons living with a chronic condition [102]. The Framework includes three components: 1) dimensions of disability (physical, cognitive, mental-emotional health challenges, difficulties carrying out day-to-day activities, challenges to social inclusion, and uncertainty or worry about the future); 2) contextual factors that interact with and can exacerbate or alleviate dimensions of disability, including extrinsic factors (e.g., support from employers, insurers, income and benefits providers; stigma and epistemic injustice) and intrinsic factors (e.g., living strategies and personal attributes) and; (3) triggers (e.g., exertion) that can exacerbate an episode of disability [103].

**Labour Force:** The term includes both those who are unemployed and employed. The employed are persons having a job or business, whereas the unemployed are without work but are available and actively seeking work [104].

**Persons living with Long COVID:** Refers to individuals with lived or living experiences of Long COVID.

**Long COVID:** Long COVID (also referred to as Post-COVID-19 condition [105]) is multidimensional, episodic and unpredictable, characterized by 'clusters of symptoms' that can overlap, fluctuate and change over time, and often described as relapsing and remitting [106]. Long COVID is defined by the World Health Organization as a health condition that occurs in children and adults with a history of probable or confirmed SARS CoV-2 infection, present at 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 [107]. Symptoms may be of new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness [108]. In June 2024, the National Academies of Sciences, Engineering, and Medicine further defined Long COVID as an 'infection-associated chronic condition that occurs after SARS-CoV-2 infection and present for at least 3 months, as a continuous, relapsing and remitting or progressive disease state that affects one or more organ systems'. [109]

[102] O'Brien et al., 2008, 2009, 2023, 2024.

[103] O'Brien et al., 2008, 2009.

[104] Statistics Canada, 2010.

[105] Office of the Chief Science Advisor of Canada, 2022.

[106] Brown et al., 2020; Brown & O'Brien, 2021; Davis et al., 2021; Gorna et al., 2021; Greenhalgh et al., 2020; Nalbandian et al., 2021; Rayner, Lokugamage & Molokhia, 2020; Soriano et al., 2022; Ziauddeen et al., 2022.

[107] Soriano et al., 2022; World Health Organization, 2022.

[108] Soriano et al., 2022; World Health Organization, 2022.

[109] National Academies of Sciences, Engineering, and Medicine (NASEM), 2024.

# Appendix 2: Approach

This policy paper was derived from a combination of sources including: 1) empirical research exploring experiences of episodic disability among adults living with Long COVID [109], 2) an evidence review including existing disability-related policies and recommendations for return to work across four jurisdictions; and 3) ongoing consultation and co-creation among a team of people living with Long COVID with policy and employment expertise in the context of Long COVID.

## 1) Empirical Research - The Long COVID and Episodic Disability Study

This policy paper draws from empirical research, specifically an international community-engaged qualitative study to explore the experiences of episodic disability from the perspectives of adults with Long COVID [110]. The “Long COVID and Episodic Disability Research Study” involved an international team of people living with Long COVID, clinicians, researchers, and representatives from community organizations across four countries: Canada, Ireland, the UK and the United States of America [111].

Forty (n=40) participants living with Long COVID were recruited from community partner organizations in Ireland, Canada, Ireland, the United Kingdom and the United States of America. The team used purposive sampling to recruit participants diverse in age, gender, ethnicity, sexual orientation, and duration since initial presentation of COVID-19. Interviews were conducted online between December 2021 and May 2022. The team asked questions about experiences living with Long COVID, the health-challenges experienced, and how this impacted their overall health [112].

Findings from the study highlight the episodic and multidimensional nature of disability experienced among adults living with Long COVID. These episodes can be hard to predict in terms of severity and duration, with symptoms not easily measurable with readily available diagnostic tests in standard clinic practice. These episodes can lead to a sense of uncertainty, as individuals may be uncertain of the severity, duration, and consequences of an episode of disability, as well as the long-term impact on their overall health and ability to engage or return to work.

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[109] O'Brien et al., 2023, 2024.

[110] O'Brien et al., 2023, 2024.

[111] O'Brien et al., 2023, 2024.

[112] O'Brien et al., 2023, 2024.

The study recommends that clear recognition and diagnostic criteria of episodic disability associated with Long COVID. This will help, not only to recognize the health challenges experienced with Long COVID but also increase access to timely treatments, safe rehabilitation services, as well as disability justice and employment rights. Knowledge on Long COVID and episodic disability can further support employers, insurers, and policy makers to inform equitable and person-centered approaches to models of service delivery for people with Long COVID [113].

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[113] O'Brien et al., 2023, 2024.

## 2) Evidence Review

Habitus Collective, in partnership with the Long COVID and Episodic Disability Study team, conducted an evidence review that was steered and informed by people living with Long COVID. The review included up-to-date evidence collected until June 2024 from academic journal articles, national statistical data, national government white papers, as well as community studies and policy papers pertaining to employment, Long COVID, and its impacts from Canada, Ireland, UK and the USA.

## 3) Co-Creation among a Core Team of People living with Long COVID

Members of the Long COVID and Episodic Disability study team attended four working group sessions (August and November 2023; February and March 2024) with people living with Long COVID with representation from all four countries in which the original study was based (between 6-12 team members attended each meeting). The focus of these meetings was to discuss the Long COVID and Episodic Disability study findings as they related to the context of labour force participation and income support, and implications for policy.

The writing team comprised of policy experts, researchers, community members, clinicians, and academics who included:

- People with Long COVID from Canada, Ireland, the United Kingdom, and USA.
- Clinicians and researchers in the field of Long COVID.
- Long COVID organisations and community networks including:
- Long-COVID Physio, a global peer support network for physiotherapists living with Long COVID [114]
  - Patient-Led Research Collaborative [115]
  - COVID Long-Haulers Support Group Canada [116]
  - Long Covid Support (England and Wales) [117]
  - Long COVID Advocacy Ireland [118]

Members provided evidence on policies related to employment and labour force in their jurisdictions, interpreted the research evidence related to employment and income support, and used the data from the Long COVID and Episodic Disability research study to guide the policy design, calls to action, and recommendations. They shared their experiences, leadership, and insights to co-develop this policy paper.

[114] Long COVID Physio, 2023.

[115] Patient-Led Research Collaborative, n.d.

[116] COVID Long-Haulers Support Group Canada, n.d.

[117] Long Covid Support, n.d.

[118] Long COVID Advocacy Ireland, n.d.

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