

Advocating for Long COVID Rehabilitation Support in Manitoba: An Environmental Scan

Manitoba Academic Rehabilitation Sciences COVID Interest Group
(MARSCI)

RFHS / College of Rehabilitation Sciences

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Table of Contents

Executive Summary	iii
Long COVID: Background	1
What is Long COVID?	1
How prevalent is Long COVID?	1
What are the signs and symptoms associated with Long COVID?	1
What is rehabilitation for individuals with Long COVID?	2
Long COVID Management Policies in Canada	4
Objective	4
Methods	4
Findings	4
Learning From Those Living with Long COVID	6
Our approach	6
Extraction of information	6
Findings	7
Interpretation and future recommendations	10
Current Services Manitoba: Long COVID	11
Overview	11
Findings	11
Opportunities and current resources	17
Conclusion	18
References	19

Executive Summary

Many individuals (10-30%) experience persistent and/or new symptoms beyond the acute COVID-19 infection, which can present regardless of initial infection severity. Commonly referred to as “Long COVID” among public advocacy groups, this post-COVID condition affects multiple body systems and is thought to reflect persistent inflammation, thrombosis, and an autoimmune reaction. The most consistent complaints of Long COVID are fatigue, shortness of breath, muscle pain and difficulty concentrating. Many with Long COVID experience loss of income, or struggle to fulfill family duties. Given that there have been over 117,000 PCR-test confirmed COVID-19 cases in Manitoba, it is likely that thousands of Manitobans are affected by Long COVID. Emerging international guidance recommends that policy makers address Long COVID through a multidisciplinary approach, including interprofessional rehabilitation services.

With this in mind, we conducted an environmental scan to support and make recommendations for Long COVID management in Manitoba. Our objectives were to 1) identify policy for management of Long COVID, 2) learn about the concerns and advocacy priorities of people with lived experiences of Long COVID, and 3) gather information on current Long COVID services in Manitoba. We conducted web searches in July-September 2021 for a) provincial/territorial government policies related to Long COVID, b) peer-reviewed evidence syntheses and original studies about Long COVID, and c) Long COVID public advocacy groups. We collected information on current, publicly-funded Long COVID rehabilitation services in Manitoba, by consulting with service providers, managers and researchers with knowledge of the Manitoba health system.

Our policy search identified frameworks for managing Long COVID in just two provinces (Alberta and Saskatchewan); both frameworks incorporate integrated, interprofessional care. We were unable to identify Long COVID policy in any other jurisdiction, and four jurisdictions indicated that Long COVID will be managed using existing programs or global budgets. Public advocacy groups consistently raised the lack of recognition, let alone care, for Long COVID. Concerns about accessibility to appropriate health services were consistently expressed by advocacy groups because established services may not be equipped to address the needs of people with Long COVID. Advocacy groups argue for specialized team-based clinics, with rehabilitation as one of the main components of Long COVID management. Our scan of existing Manitoba services indicated that current rehabilitation services are not designed for the needs of people with Long COVID. Major gaps include Long COVID rehabilitation services for children and youth, and accessible community-based interprofessional care for young and middle-aged adults. Long COVID rehabilitation programs are being developed, but are not yet funded.

Almost two years into the COVID-19 pandemic, Manitoba lacks interprofessional rehabilitation and other services to meet Long COVID population needs. We recommend:

1. Decision-makers ensure patient needs and equity concerns are the central focus of Long COVID management by actively engaging with Manitobans living with Long COVID;
2. Shared Health and other health authorities coordinate to improve access to rehabilitation specialists, and create referral processes to an integrated system of care for Long COVID that includes team-based rehabilitation programs;
3. Decision-makers allocate additional funding and resources to service delivery organizations to establish appropriate and equitable services, at primary and secondary care levels for Long COVID.

Long COVID: Background

What is Long COVID?

It is becoming increasingly apparent that many people experience persistent, disabling signs and symptoms and/or new signs and symptoms beyond the initial illness of acute COVID-19 [1-6]. This condition, which has been termed “Long COVID,” can present in individuals who were severely ill with COVID-19, but also occurs in those who experienced relatively mild signs and symptoms during the initial period of acute infection [4]. Current data suggest that while the development of Long COVID is not linked to the severity of the initial COVID-19 infection, it is associated with middle age, the number of symptoms in the acute phase, greater body mass index, and being female, among other factors [7]. Long COVID encompasses both “ongoing symptomatic COVID-19” (symptoms persisting 4-12 weeks since acute onset) and “post-COVID-19 syndrome” (symptoms persisting for more than 12 weeks that cannot be explained by an alternative diagnosis) [4]. The condition affects multiple body systems and the mechanisms involved are thought to include persistent inflammation, thrombosis, and autoimmunity [7]. Symptoms reported by patients experiencing Long COVID are highly variable and relatively little research has been conducted to date, however, emerging data suggest that the most consistent persistent complaint is fatigue, and that shortness of breath, muscle pain and difficulty concentrating are also common [1-6, 8]. People who suffered severe acute COVID-19 illness and required admission to the intensive care unit, may also have prolonged effects related to post-intensive care syndrome and/or permanent organ damage. The World Health Organization (WHO) proposed a clinical definition of post COVID-19 condition that was released on Oct 6, 2021: “Post COVID-19 condition occurs in individuals with 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 and 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” [9]. The WHO International Classification of Diseases (ICD)-ICD-10 code U09.9 Post COVID-19 condition, unspecified was approved for implementation effective October 1, 2021.

How prevalent is Long COVID?

Current data suggest that 10-30% of people infected with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) develop Long COVID [7, 8, 10]. It has been noted that it is especially difficult to track prevalence of Long COVID in those who recovered from the initial infection without requiring hospitalization, and that processes for gathering and updating data are just now being developed [1-3, 7, 11]. Preliminary data indicated that in Manitoba approximately 21% of 55,467 post COVID-19 patients reported persistent symptoms four weeks or more after infection in June 2021 [12]. Given that there have been over 61,000 cases of COVID-19 in Manitoba (as of Oct 9, 2021, see <https://www.gov.mb.ca/covid19/updates/cases.html#maps>), we expect that thousands of Manitobans could be affected by Long COVID.

What are the signs and symptoms associated with Long COVID?

Our understanding of Long COVID is still evolving, but it is apparent that the condition can be very debilitating. Almost all body systems may be involved including the heart, lung, brain and

gastrointestinal tract [7]. Long COVID is associated with a wide range of overlapping and fluctuating symptoms that include extreme fatigue, shortness of breath, chest and muscle pain, cognitive dysfunction, brain fog, gastrointestinal complaints, palpitations, dizziness, anxiety and depression, insomnia, persistent fever, and more [1-4, 7, 8]. Persistent (chronic) fatigue describes overwhelming tiredness or exhaustion that is not relieved by rest and is not proportional to exertion – this is common with Long COVID [7, 13-15]. Comparisons have been made between Long COVID and other post-viral conditions, including severe acute respiratory syndrome (SARS) and Middle East respiratory syndrome (MERS), [3, 16, 17] and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [13, 14, 18]. Patients with these conditions may experience post-exertional symptom exacerbation (also known as post-exertional malaise), which presents as worsening of symptoms and substantially reduced function after even relatively low intensity physical, cognitive or emotional activity is attempted [19, 20]. Patients experiencing extreme fatigue and post-exertional symptom exacerbation with Long COVID are often severely disabled, finding it difficult to complete even simple activities of daily living [15]. Many of these individuals have been unable to return to work, which has serious economic as well as personal consequences [2, 6, 7].

Existing guidelines suggest that the initial management of Long COVID should be in primary care [7]. Health authorities must organize services to provide tools for self-management, access to individual rehabilitation specialists and processes for referral to integrated interprofessional rehabilitation programs to support the large number of individuals affected by this debilitating condition [4].

What is rehabilitation for individuals with Long COVID?

Rehabilitation is a “set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” [21]. Health conditions may include disease, such as Long COVID, injury, disorders and/or trauma [21]. Rehabilitation aims to help individuals with health conditions be as independent as possible in their lives and everyday activities [21, 22]. Additionally, rehabilitation strives to enable participation in education, work, recreation, and meaningful life roles [22].

Specific to Long COVID, rehabilitation interventions may be delivered by a multidisciplinary team of health professionals employed in primary care including but not limited to, physical therapists (PTs), occupational therapists (OTs), speech-language pathologists, respiratory therapists, and rehabilitation assistants [23, 24]. An individual’s family may be an important contributor to the delivery of rehabilitation as well [24].

The rehabilitation interventions provided for individuals with Long COVID will depend on the individuals’ presenting signs and symptoms, impairments, activity and participation restrictions related to Long COVID. The presentation of Long COVID and responses to rehabilitation interventions can be variable [1-4]. As such, it is important that rehabilitation interventions consider a person-centred approach, [15] that is rehabilitation should be individualized and tailored to meet the evolving needs of individuals, consider the interactions of the biological, physical and social aspects of individuals, and actively involve people in the rehabilitation process [25]. Rehabilitation interventions for people with Long COVID may include education such as self-management, energy conservation, healthy lifestyles, behavior modification and resuming physical activity [26]. Furthermore, pulmonary rehabilitation interventions including breathing, coughing and respiratory muscle exercises are suggested [26]. Aerobic, resistance,

range of motion, flexibility, balance and gait re-training exercises are also recommended [26]. The Canadian Thoracic Society recommends that patients start with low intensity aerobic exercise that is conservatively progressed with the gradual introduction of resistance training [27]. Close monitoring is required to prevent post-exertional malaise [27]. Lastly, psychological support and interventions, such as cognitive behavioral therapy, may be a necessary component of an individual's rehabilitation secondary to Long COVID [26].

Long COVID Management Policies in Canada

Objective

This section reports findings from an environmental scan that aimed to identify publicly available provincial/ territorial policies on Long COVID management across Canada.

Methods

We defined policies as any written evidence of law, regulation, procedure, administrative action, incentive or voluntary actions of provincial/ territorial governments or departments (cdc.gov/policy/analysis/process/definition.html). One investigator conducted a web search for publicly available policies for each province/ territory (n=13) using search terms provided in appendix 1. Where policies were not identified from the web search, we emailed individuals in relevant roles to inquire if policies were available. Policies were identified, if available. If no policy was available, relevant information on programs was extracted and filed for reference. During the search we also identified relevant frameworks or guidelines and policy documents from outside of Canada, which were saved for reference. Along with this, policy exemplars were also highlighted.

Findings

No provincial/ territorial policies on Long COVID management were identified (0/ 13). Four jurisdictions (NWT/ Yukon/ ON/ NU) noted that patients with Long COVID will be seen in existing programs, arrangements, or within existing global budgets. Five jurisdictions (QC/ NB/ NS/ PEI/ NL LAB/ MB) had no mention of Long COVID anywhere.

Alberta is the furthest ahead wherein Alberta Health Services (AHS) has established 11 Strategic Clinical Networks (SCN), one of which is Neurosciences, Rehabilitation and Vision (NRV SCN). Each SCN brings together individuals from AHS and partners (research, operations, patients, families) to “address the most pressing healthcare challenges of our time” [28]. AHS has a tollfree Rehabilitation Advice line (9-5, M-F). Despite the lack of a specific policy, we noted with interest that in March 2021 the NRV SCN published a Post COVID-19 Rehabilitation Response Framework which “provides necessary pathways, tools, and supports that enable care providers to appropriately and systematically determine the level of functional impairment, and corresponding rehabilitation required, of patients with Post COVID-19 Syndrome” [29]. The Framework lists 19 recommendations: 2 for Screening, 9 for Assessment to Determine Rehabilitation Needs, 3 for Discharge and Transition Planning, and 5 for Long-Term Implications. The Framework document also contains in the appendices recommended pathways and resources as well as two screening tools and links to resources for patients and health care providers.

It is not clear if AHS has accepted all the recommendations of the NRV SCN, there is a [MyHealth.Alberta.ca](https://myhealth.alberta.ca) webpage for persons recovering from COVID-19 entitled “After COVID-19: Information and Resources to Help You Recover” [30] that provides accessible and comprehensive information containing links to resources on the following topics: Symptoms, Self-Care, Brain Health and Mental Health, Returning to Work or School, Exercising and Being Active, Resources, Rehabilitation Advice Line.

In British Columbia, no formal policies nor frameworks were found but a Post-COVID-19 Interdisciplinary Clinical Care Network has been established to coordinate care, research and education for recovery [31]. BC Provincial Health Services Authority has established four Post-

COVID-19 Recovery Clinics, all in the Greater Vancouver area. The clinics are reported to be “interdisciplinary, integrated with primary care providers, and based on a model of supportive care co-designed by clinicians and survivors of COVID-19” [32]. In addition to the clinics, there are links to information videos, symptom management fact sheets, and clinical care resources.

We also identified that Saskatchewan has recently published a Long COVID framework with eight recommendations that address a model of care, role of primary care providers, interdisciplinary teams (includes OT, PT, RT), quality standards, education for care providers and public, universal access to care, coordination of care [33]. However, there is no evidence on the Saskatchewan Health Authority website that the recommendations have been adopted.

Beyond Canada, we identified strong exemplars developed by the governments in Wales and Scotland. In Wales, we identified *Rehabilitation: a framework for continuity and recovery 2020 to 2021: A framework to help organisations plan rehabilitation services following the coronavirus pandemic* [34]. “This Framework will assist service planning for the anticipated demand for rehabilitation and recovery for people affected by COVID-19, including those presenting with Long COVID and non-COVID-19 populations in adults and children” [34]. It will identify growing evidence of the impact of the pandemic for the following four discrete population groups:

- Rehabilitation needs of people recovering from COVID-19
- Rehabilitation needs for people awaiting paused planned care
- People who avoided accessing services during the pandemic who are now at greater risk of disability and ill health
- People who were socially isolated or shielded

The Welsh framework also recognizes economic impact for the wider society; loss of usual societal participation and loss of family and friends; impact on frontline health and social care workers. It also includes additional resources, including Developing a rehabilitation modeling resource [35], Rehabilitation Post COVID-19 evaluation guidelines [36]; and Covid-19 Planning and Response Rehabilitation Task and Finish Group [37].

In Scotland we identified the *Framework for Supporting People through Recovery and Rehabilitation during and after the COVID-19 Pandemic* [38]. “This Framework specifically focuses on the priorities and objectives for COVID-19 rehabilitation and is underpinned by principles to support planning to meet this increasing demand. It aims to build on good practice and capacity within the existing system and to explore innovative models, adopting a multi-disciplinary and multi-agency approach, to help us secure both timely and flexible delivery of care and support” [38].

Along with this, in December 2020 the National Institute for Health and Care Excellence (NICE) in Scotland published guidelines for managing the long-term effects of COVID-19 and includes recommendations for service models [4]. Overall, there was very low-quality and limited evidence from narrative descriptions of service models. Four guidance recommendations were: i) provide access to multidisciplinary services, led by a physician with appropriate specialist support; ii) provide integrated multidisciplinary rehabilitation services based on local need and resources; iii) share knowledge, skills and training between services to help practitioners in community settings; and iv) agree local, integrated referral pathways between primary and community care, multidisciplinary rehabilitation services, specialist services, multidisciplinary assessment clinics and specialist mental health services.

Learning From Those Living with Long COVID

Our approach

We opted to listen to people living with Long COVID by seeking out and learning from online advocacy groups. This enables us to hear public voices, recognized by CIHR and Health Canada as crucially important to coming to consensus on problems in our health services systems [39, 40]. Our objective was to identify public advocacy groups for people experiencing Long COVID in Canada, and review their key concerns and advocacy focus. Here, we share what organized groups understand as problems, and the solutions they are advocating for, which is arguably most important at this early stage to align future services with client-centred approaches.

We searched for English-language Long COVID support and advocacy groups online, first in Canada, and then other wealthy countries with universal health care system (i.e., excluding the USA). To be included, they needed to be led/co-led by people with Long COVID. We opted to not search explicitly for provincial advocacy groups at this time. In terms of groups from countries outside of Canada, we found sites in only in the United Kingdom countries and Ireland.

Extraction of information

A team member identified potential groups in early July 2021; a research assistant completed extraction by the end of August 2021.

We extracted the following information, when available, from the websites of the eight groups identified:

1. Name, country, website, date accessed
2. Group description
3. Advocacy documents
4. Health services experiences and needs from the point-of-view of those with lived experience of Long COVID
5. Rehabilitation-related concerns and content

Some descriptions of Facebook groups linked to a website. We extracted only from websites, not the Facebook group itself, to respect the privacy of participants in the groups, as well to comply with requests posted, in some cases.

Many groups include web links or direct publication of personal stories of living with Long COVID. Our rapid review focuses not on individual stories, but documents outlining common problems across individual experiences.

After summarizing the content of each group, we completed a content analysis, searching for similarities and differences in extraction categories 4 and 5 across groups, first comparing those within Canada, and then with groups from other countries.

Table 1: Advocacy groups included in the analysis

Name	Country	Website
COVID Long-Haulers Support Group Canada	Canada	https://www.covidlonghaulcanada.com/
Long Covid Canada	Canada	https://longcovidcanada.ca/

Long Covid Cases Ireland	Ireland	https://www.longcovidcases.ie/
Long COVID Kids	UK	https://www.longcovidkids.org/
Long COVID Physio	UK/global	https://longcovid.physio/
Long COVID SOS	UK	https://www.longcovidsos.org/
Long COVID Support	UK	https://www.longcovid.org/
Long COVID Scotland	Scotland	https://www.longcovid.scot/

Findings

The consistency across groups, both within and outside of Canada, is striking. The primary differences reflect contextual variations, such as income supports available and health care systems, which vary by country.

1. **Definitional concerns**

The definition of Long COVID is still debated, including the time frame at which the term applies. Minimum duration of symptoms tends to be listed as either four weeks, or 12 weeks for the term to apply. Manifestations vary widely, including multiple body systems (neurological, cardiac, respiratory, skin and immune system), and impacting cognitive and physical abilities. Advocacy groups emphasize that Long COVID affects a wide range of persons, including those with and without pre-existing chronic health conditions, and both children and adults. Long COVID Kids refers to the condition as a relapsing and remitting condition.

Long COVID SOS, in a letter to NICE in 2020, advocates for the use of the term Long COVID, instead of Post-Covid19-Syndrome [41]. We have chosen to use the term Long COVID for this reason (herein LC).

In Manitoba, as of July 13, 2021, CTV reported that Shared Health acknowledged that over 12,490 people experienced persistent symptoms 4 weeks after infection with COVID-19 – almost 22% of all those infected in the province to that date [42]. These numbers are similar to those shared with us by Carla Loeppky, Director of Epidemiology and Surveillance Information Management and Analytics with Manitoba Health, for an earlier date (Jun 22, 2021).

2. **Health care access issues**

2.a *Lack of access to diagnosis*

Both Canadian groups flag issues with initial lack of diagnosis of COVID-19, due to both restrictions on access to diagnostic tests in early 2020, or where testing was completed too late to be reliable. Canadian groups note that the solution to this, to date, has been the use of a 'presumptive diagnosis', which creates problems described below. Groups in Ireland, Scotland, and the UK broadly (SOS) echoed this problem.

2.b *Not being believed by gatekeepers to services, and other problems accessing care*

Both Canadian LC groups, and those in UK and Ireland, report that many people seeking care for their LC symptoms have received little practical help, or are even dismissed by clinicians. Some clinicians note the lack of a positive COVID-19 test blocks diagnosis, have told their patients that symptoms do not last for more than two weeks, or diagnosed the person with mental health challenges, such as anxiety. They describe physicians sending them home to manage their symptoms, without ongoing support or referral to more specialist services.

2.c *Impacts of these health care access and definitional challenges*

Both Canadian groups flag how diagnostic problems, including presumptive diagnoses, can limit access to clinical help, including rehabilitation care. Long COVID Canada reports some resort to repeatedly visiting emergency departments for heart, neurological, or breathing problems, while others turn to alternative wellness care and/or peer support to fill the void. Those with presumptive diagnoses are often excluded from participation in research studies.

More generally, the groups reported both very limited health care support overall, and sometimes inappropriate, harmful care. Graded exercise, in particular, was flagged as contraindicated for some with LC, yet some clinicians are still recommending it. Both physical and psychological support was limited.

The impacts spill outside of health care to lack of access to sick or disability leave from employers or to federal income supports (e.g., the Canada Emergency Response Benefit). And in their personal lives, both children and adults find themselves unable to participate in usual activities, which generates uncertainty about the future. Both financial uncertainty and decreased abilities to resume normal activities affects their families more broadly; for example, Long COVID Canada lists a Facebook group that offers caregiver peer support.

Groups from countries outside of Canada listed similar difficulties:

- Not receiving appropriate care due to diagnostic reasons (presumptive rather than confirmed COVID-19 infection), lack of timely services (either from no referral to specialized care, or long wait lists for such services), and inappropriate care (e.g., graded exercise)
- Dismissal of LC; misdiagnosis of anxiety or other mental illnesses
- Financial and employment impacts in their lives (including inability to access disability supports; inability to return to work; relapse after attempted return to work; loss of job because of inability to return)
- Increased utilization of primary care and emergency departments

In addition, some groups identified other health system problems, such as inconsistent care (Long COVID Ireland), and need for self-advocacy for tests and treatment (Long COVID Support; Long COVID Scotland). In England, after release of the NICE/SIGN/RCGP guidelines and establishment of LC clinics, a survey shared by Long COVID Support found that of the 128 people with LC surveyed between Dec 18/20 and early Feb 2021, only 23 were successfully referred, and six were seen in the specialty clinics. In contrast, 95 were refused referral, which 87 participants reported was the result of either GP lack of knowledge about the LC clinics or disbelief that the person has LC. Of note, Dec 18/20 was the date of the announcement of the existence of 60 LC clinics in England, which offer physical, cognitive, and psychological assessments, with potential referral to other specialized services (including pulmonary or cardiac specialists, rehabilitation, and mental health services, among others).

Several groups mentioned various interpersonal forms of stigmatization (Long COVID Ireland) and discrimination (Long COVID Scotland), pressure to return to work (Long COVID Ireland) or returning to work too soon (Long COVID Physio), and general lack of understanding and support (Long COVID Ireland; Long COVID Scotland).

3. Advocacy focus

The advocacy focus of the organizations aligns with the problems flagged in the systems influencing the lives of those experiencing LC. Both Canadian groups argue for the creation of awareness strategies, as well as an inclusive approach to systems of care and

financial/employment supports for those with Long COVID, including those with only presumptive diagnoses of COVID-19. We detail their specific calls for action, before speaking to similarities with groups in other countries.

More specifically, less than four months into the pandemic, Long COVID Canada published an open letter dated Jun 30, 2020, signed by 52 people [43]. The letter addressed the chief medical and public health officers at the federal and provincial/territorial levels. They advocate for the establishment and coordination of research into long-term illness causes, the implementation of “effective standards for presumptive diagnosis of COVID-19”, updated public health guidelines, ensuring awareness of LC by physicians, policy makers, employers, and the general public (to the latter point, to encourage those with ongoing problems to seek care). Dr. Bonnie Henry’s response, written in her role as Chair of the Council of Chief Medical Officers of Health on behalf of the Federal-Provincial-Territorial Special Advisory Committee on COVID-19, fails to address most of their substantive concerns about long-term illness and lack of awareness. Instead, the response outlines general federal investments and recommending that those with long-term symptoms seek care from their regular provider or via a telehealth service.

COVID Long Haulers Canada have an open Change.org petition [44], where they advocate for “interdisciplinary, targeted research” inclusive of all manifestations of LC, a change of reporting on COVID-19 cases (where ‘recovered’ is changed to ‘non-infectious’ for those with ongoing symptoms, and ‘recovered’, for those whose symptoms have resolved), and “a network of inclusive rehabilitation, dedicated explicitly to recovery needs to be put in place. These clinics must be accessible to everyone suffering from Long COVID and clinically diagnosed people must not be discluded [sic]. People are going to need physical, cognitive, psychological, and financial integrated care centres to be able to get back to work and to a meaningful life.”

Awareness and better diagnosis, research, health care, and income supports were raised by Canadian advocacy groups. Groups in other countries advocated for similar initiatives; groups listed for each may not be exhaustive:

- Awareness and better diagnosis
 - Acknowledgement of the existence of LC, and dissemination of accurate information via governmental channels (Ireland; Support)
- Health Care
 - Multidisciplinary, accessible clinics for LC care for assessment, treatment, and rehabilitation (Ireland; SOS; Support; Scotland)
 - Creation and distribution of care pathways and guidelines (Ireland; SOS)
 - Guidance for primary care clinicians for LC, ensuring both recognition and consistency of treatment (Ireland; SOS; Support)
 - Public involvement development of health system models (Scotland)
- Financial and employment supports
 - Guidance for employers re: fair treatment for those with LC (Ireland; SOS)
 - Adequate financial support (Ireland)
 - Consider economic implications of inaction, and provide long-term sick leave (SOS)
 - Clarity on eligibility and entitlement to adequate financial support (Ireland)
- Research
 - On the cause(s), treatments, risk factors for Long COVID (LC Support)

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- Includes participatory, co-design approaches that include research on the actions already being taken (Long COVID Scotland)
- Integrates the medical humanities, anthropology, and the arts (Long COVID Scotland)
- Long COVID taskforce to address the above, plus funding for patient-led support groups (LC Support)

Of note, the advocacy work of several UK based groups is more advanced than that described on the Canadian groups' websites. Some examples: Long COVID Scotland hosted a National Summit in July 2021, and has connections with universities. Long Covid Physio collaborated with World Physiotherapy to produce a briefing paper on safe rehabilitation, facilitating discussion across many groups to do so (including Long COVID SOS and Long COVID Support). Long COVID SOS started the 'message in a bottle campaign', a short video translated to at least 6 languages, which led to a meeting with the WHO's COVID Technical Lead and Director of Clinical Care on Aug 21, 2020.

4. Rehabilitation-related content

Most groups, but not all, specifically advocate for rehabilitation supports in particular, though some remain at the more general language of 'medical' or 'health care' for LC. For example, COVID Long Haulers Canada advocates for 'inclusive rehabilitation at accessible clinics, focused on recovery needs' (Change.org petition). Long COVID Physio and Long COVID SOS highlight rehabilitation as one of the three core pillars of response to LC; recognition and research are the remaining two pillars. Long COVID Physio argues for universal access to services tailored to the specific symptom presentation and the goals of the individual. Long COVID Cases Ireland and several of the UK-based groups argue for multidisciplinary, accessible clinics for Long COVID care. In these, Ireland argues for occupational and physical therapy, nutritionists, and counselors, while the Scottish group names physiotherapy, occupational therapy, and psychology.

Interpretation and future recommendations

To borrow the words of Long COVID Support, public voices in Canada, the UK, and Ireland amplify the concerns about 'inconsistent, inequitable, and inadequate health care services'. For some, access is inequitable due to disbelief by clinicians, who act as gatekeepers to other services. Lack of diagnosis due to lack of COVID-19 testing early in the pandemic adds a level of complication. Long COVID may be understood as a new "illness you have to fight to get", due to the medical and political uncertainties about the condition [45]. Recognition of the condition is crucial but insufficient. Concerns about over-reliance on self-management, with a general lack of assessment, tailored treatment, and support services are repeated across countries and groups. These experiences, common across countries, can be interpreted as both interpersonal and structural forms of stigmatization in health care settings, in ways that affect work and family life.

Based on what we have read, we recommend active public engagement with Manitobans living with Long COVID, to support health services planning and evaluation, ensuring their needs and equity concerns are the central focus throughout, as the Manitoban health system decides how to respond to the new need for services.

Current Services Manitoba: Long COVID

Overview

This section contains a scan of services being offered in Shared Health and the Winnipeg Regional Health Authority. The scan was conducted between July 1, 2021 and October 1, 2021 and covers services offered between mid-April 2021 and October 1, 2021. We used the following sources to gather this information (please see contributor list at end of document for information on specific contributors):

- Occupational Therapy Primary Care Community of Practice meetings
- Ad hoc Long COVID Clinician Interest Group hosted by the Occupational Therapy Primary Care Community of Practice. Representation includes Access Centres, My Health Teams, The Health Outreach and Community Support (HOCS) program, the Pulmonary Rehabilitation Program (Deer Lodge Centre), some community centres such as Nine Circles Community Health Centre, the Community Stroke Care Service, and the University of Manitoba. Disciplines represented included dietitians, occupational therapy, pharmacy, physical therapy, respiratory therapy, and social work.
- Environmental scan conducted by Haley Thorne and Laura Parsons and supervised by Sheena Warkentin as a part of Haley and Laura's Master of Occupational Therapy Advanced Fieldwork Placement at Deer Lodge Centre.
- Reaching out via email, personal communication to front line service providers, managers, and researchers not included in the above groups.

Findings

1. *Current services/programs for Long COVID*

Table 1 provides list of health services/programs that currently provide service to people living with Long COVID in Manitoba. The table also lists identified gaps for each program/service.

Table 1: Health services/programs for people living with Long COVID

Program/Service	Population	Current Long COVID referrals	Gaps
Pulmonary Rehabilitation Program (DLC, Misericordia, Seven Oaks/Wellness Institute)	Initially served all adults with Long COVID. In September, changed criteria to people with prolonged interstitial changes in the lungs to remain in line with evidence on pulmonary rehabilitation effectiveness.	134 Long COVID referrals since December 2020 out of 407 all-cause referrals [46]. Wait time is one to two months as of August 2021.	<ul style="list-style-type: none"> – No occupational therapist or social worker on teams. Consultative OT services provided at DLC by OT from another service in July/August identified many OT needs such as executive functioning assessment and intervention. OT services no longer available to team. – Not able to meet cognitive and psychosocial needs of this population with current PRP staffing model. Large need for executive function assessment and strategy development. – People without lung interstitial changes not eligible for program as many referred have Long COVID symptoms but not lung changes. – Those too impaired for the pulmonary rehabilitation program with post-ICU and Long COVID combined.
Geriatric Day Hospitals	Adults 65 and over who require two or more disciplines for assessment and intervention. Adults 60 and over if recovering from COVID19. During pandemic, those recovering from COVID19 have been prioritized.	Day hospitals had reduced services during the pandemic. Group programs were closed for a period until September 2021.	<ul style="list-style-type: none"> – Only for older adults. – Designed for people with functional impairment impeding activities of daily living rather than impairment in productivity activities like employment.

Program/Service	Population	Current Long COVID referrals	Gaps
Health Sciences Centre Long COVID service	In planning phase. Was hoping to start service for adults with Long COVID fatigue in September.	n/a	Was planning to start with physiotherapy services, but not yet started due to lack of funding approval. Vision is for an interprofessional team (PT, OT, SW, dietitians) but no funding has been allocated yet.
Wellness Institute Long COVID program	<ul style="list-style-type: none"> - Adults who have had COVID-19 and are unable to return to work due to ongoing physical, mental, and emotional effects. - Physical therapist does intake and makes referrals to other clinicians (OT, social work, dietitian). 	Seen about 35 clients to date since mid-April 2021.	<ul style="list-style-type: none"> - None of the clinicians are full time in the program. - No interdisciplinary intake. - Fee for service model results in people not being to access the OT and social work component even if deemed necessary by the PT intake assessment.
My Health Teams	Typically adults. Pediatrics often referred to other services.	<p>No system in place to determine referral rate.</p> <p>Concern from clinicians that there is no screening process to identify individuals with Long COVID at the first point of contact.</p> <p>Comorbidities and social complexities make people with Long COVID hard to identify.</p> <p>Current wait time all clients in St. James 2 months.</p>	<ul style="list-style-type: none"> - Inadequate resourcing for long term one-on-one assessment and intervention for chronic disease. My Health teams were designed as a consultative model. - Not all teams have all disciplines represented (occupational therapy physical therapy, respiratory therapy). - Lack of resourcing to take on additional community care needs that have arisen due to Long COVID (increase in mental health needs, people with poorly managed chronic disease that is a result of COVID but may or may not be related to Long COVID diagnosis).

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Program/Service	Population	Current Long COVID referrals	Gaps
			<ul style="list-style-type: none"> - Client needs to be connected to physician with my health team partnership. On review of 108 charts of patients with Long COVID who attended the Deer Lodge Pulmonary Rehabilitation Program, 59 were discharged and not connected to team-based care in community and eight did not have a Primary Care Provider identified nor was there any evidence that they were matched to one prior to discharge. - Clinicians addressing high patient need and referral loads post multiple COVID-19 re-deployments.

Program/Service	Population	Current Long COVID referrals	Gaps
Community Therapy Services	<ul style="list-style-type: none"> – Adults who require health services or assistance with activities of daily living, require service to remain safely in their home and require more assistance than available from existing supports and community resources. – Clients who require OT and/or PT assessment and short-term intervention(s) and where home and community is the best environment to address client needs and short-term intervention(s). 	<p>1 to 2 referrals per week with long COVID usually in combination with other health conditions. Fatigue, weakness, and activity intolerance are common referral issues.</p>	<ul style="list-style-type: none"> – Short-term only (typically one or two visits) and more appropriate for adults who are also receiving home care services in the home. – Claudine Lafond (Director, Community Therapy Services) reports that many referrals that do not meet their criteria are offered alternatives but that for many referrals, there are no appropriate alternatives that can be recommended to the client.
Priority Home Team	Adults with severe deficits from Long COVID who may be on trajectory for long term care.	Uncertain	<ul style="list-style-type: none"> – Only serves a high needs population. – Would not typically provide services to individuals who were not hospitalized.

2. Tools currently available

WRHA Post COVID Symptom Referral Pathways document was created and released in March 2021 identifying services / clinics based on specific referral criteria. The document identifies that the suggested pathways 'do not take the place of local resources that the reader feels may be more appropriate'. Community and primary care services are not included on this pathway, and it is out of date since its development in spring 2021.

3. Strengths in current Long COVID care

Occupational therapy students conducting a project on Long COVID in conjunction with DLC interviewed a small number of people affected by Long COVID. The students reported in their presentation of findings that the patients who were hospitalized while acutely ill reported feeling supported by current resources available to them (Thorne & Parsons, 2021). However, it is important to note that these clients were currently receiving post-hospital care and this finding cannot be generalized to the entire Long COVID hospitalized population. However, it is logical that people who were hospitalized would be more likely to be identified and referred for hospital follow-up services through the multidisciplinary assessment that is often provided in-hospital for discharge planning. In contrast, people who are not hospitalized may not be identified as requiring Long COVID care.

4. Gaps in care for Long COVID in Manitoba

Generally, Long COVID is not being identified by the health system as a separate issue requiring unique services. Existing services are expected to absorb the need, though existing services are not necessarily able to provide specific services for this population.

4.a Population Gaps

- Rural and remote populations. Existing or developing services for Long COVID are primarily situated in Winnipeg leaving a gap in rural and remote areas of Manitoba
- Pediatric population. According to sources accessed in this environmental scan, no public programming exists, or is in the planning phases in our province for children and adolescents who are experiencing or will develop Long COVID.
- People with primarily mental health repercussions of COVID-19.
- People with no positive COVID test. These individuals are less recognized as requiring referrals and supports.
- Those with phenotypes that could be serviced by primary care teams may not be able to access these services in primary care due to waiting lists and/or lack of connection with a My Health team and/or lack of recognition of service need.
- Adults requiring interprofessional team care who are under 65 years of age.
- People who are unable to access services online or who require their service very close to home due to issues with transportation, etc.
- People with respiratory and autonomic symptoms with no lung changes on imaging.

4.b Service Design Gaps

- Services that are available outside of working hours since the largest volume of patients with Long COVID are working and middle aged.
- Mental health service integration:
 - Lack of coordination between mental and physical health services for chronic disease care that requires biopsychosocial approach like Long COVID.
 - Lack of recognition of the mental illness symptoms (e.g. anxiety, depression) in individual with Long COVID by service providers resulting in lack of service provision.
- Lack of publicly available return-to-work rehabilitation services.
- Lack of full population access to primary care teams with rehabilitative professional services.

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- Lack of community rehabilitation model that covers all the of the population that goes beyond consultative services.
- Lack of supports for people with access barriers like transportation, and long-standing structural marginalization.

4.c Tools and Resources

- Screening tool to identify Long COVID in community and primary care settings. There is concern from clinicians and patients with lived experience that there is a lack of knowledge of Long COVID symptoms/presentation and how to screen for Long COVID in primary care and community settings which impedes service access.
- Referral pathways and other system navigation tools for providers.
- System navigation for patients: Lack patient knowledge of Long COVID making it difficult for them to accurately identify their own symptoms and advocate/communicate re: their care needs, particularly those not hospitalized for COVID-19. Information gained from triaging for the pulmonary rehabilitation program indicated that many patients did not know where to go for help and felt unsupported before they were connected with the pulmonary rehabilitation program.
- Adults with different phenotypes require different care that needs to be considered in the pathways that are developed.

Opportunities and current resources

- Primary care rehabilitation (OT, PT, RT) and other allied health clinicians are interested in delivering a Long COVID self-management support and education program virtually to community dwelling adults. While they recognize that this will not address many of the gaps in Long COVID care, this is seen as a feasible task that could be done by sharing resources between the pulmonary rehabilitation clinicians and the My Health Teams. There is potential to transition the “Coping with COVID” virtual group developed during the pandemic into a “Living with Long COVID” group.
- The Family Doctor Finder is prioritizing patients who are receiving Virtual Outpatient Covid Monitoring (VCOP) and patients with Long COVID requiring a primary care provider. This may support links to My Health team rehabilitation services for people with Long COVID.
- The respiratory therapist with the Respiriology Clinic at the Health Sciences Centre could potentially support referrals to other services for Long COVID support.
- Collaboration with Worker’s Compensation to address gaps in return-to-work service for people with Long COVID.
- Occupational Therapy [47] and Physiotherapy [48] have Private Practice Directories that can support navigation to services for people with private insurance.
- Chronic Disease Collaborative in Shared Health. Collaboration may provide the opportunity to provide input into the development of provincial Long COVID services. It may also allow for the consideration of Long COVID in relation to many other chronic diseases requiring biopsychosocial approach and symptom-based approaches in community.
- Primary care clinicians indicated that primary care community facilitators could potentially take a role for pulling together resources on community supports available for people Long COVID.
- Primary care clinicians suggested that linking to Healthy Aging Resource Team (HART) teams should be explored for identifying people with Long COVID and supporting people to get supports.
- Our pediatric sources suggest that the Provincial Lyme Disease program could potentially be used as a template for a multidisciplinary approach for this condition.

Table 2: Services for Long COVID care that could be provided in community through interdisciplinary team-based care

– Support self-management and recovery	– Nutritional Counselling
– Fatigue (Energy conservation and pacing)	– Cognitive Assessment and assessment including support for “brain fog” and developing cognitive strategies
– Return to activities of daily living	– Support around polypharmacy
– Return to work assessment and support	– Teaching and education inhaler use
– Mental Health with special focus on anxiety (e.g. Mindfulness, processing grief, acceptance therapy, CBT)	– Lung recruitment and coughing assist strategies
– Social support and financial needs addressed- those marginally housed, needing financial services such as application to long term disability, Worker’s Compensation, etc.	– Pain management
– Sleep hygiene	– Functional assessments and home visits
– Functional reablement/restoration focusing on ADLS and IADLS	– Sensory assessment and intervention

Conclusion

Current Manitoba services for Long COVID care are fragmented and uncoordinated with major gaps in service provision. The coordination or development of formal pathways locally, regionally and provincially that take into account the varying populations and presentations of Long COVID are essential. As is, the development of services that address major gaps in care, such as team-based rehabilitative care for community-dwelling adults.

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