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How a long COVID rehabilitation intervention works: refining its programme theory through a realist-informed qualitative study

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Abstract

Background Although the majority of individuals infected with SARS-CoV-2 recover without treatment, some individuals experience persistent symptoms (long COVID), which may negatively affect their activities and roles of everyday life, leaving them with a profound rehabilitation need. In response to the emergence of long COVID patients, a Danish municipality developed and implemented a structured, out-patient long COVID rehabilitation intervention (*The Long COVID Rehabilitation Intervention)*. To understand how, why and for whom the intervention works, and its functioning, an exploration of the underlying programme theory is required. We thus aimed to explore the interactions between the intervention mechanisms of change, the implementation context and the expected outcomes of *The Long COVID Rehabilitation Intervention* to confirm or refine the initial programme theory.

Methods We conducted a qualitative study from a realist perspective. Data comprised 12 individual interviews with patients participating in the intervention, a focus group interview with the health professionals delivering the intervention, and an individual interview with the manager of the rehabilitation centre. Transcripts were coded and analysed using a realist analytical approach, enabling for refinement of the initial programme theory expressed with context-mechanism-outcome configurations.

Results We demonstrated a close interconnectedness among the context-mechanism-outcome configurations, with identity transformation as central to the intervention functioning supported by a person-centred rehabilitation approach, patient education, and peer support. Moreover, we identified acceptance as an overarching mechanism across all context-mechanism-outcome configurations, facilitating a reconceptualisation of beliefs, values, and roles. This empowered the patients to navigate and participate in daily life despite ongoing long COVID symptoms.

Conclusion Overall, the initial programme theory was confirmed but required refinement to contexts and mechanisms. The theorisation of *The Long COVID Intervention* clarified how, why, and for whom it worked, informing the development of future long COVID and post-viral rehabilitation interventions.

Keywords Long COVID, Rehabilitation, Health service, Programme theory, Realist evaluation

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Background

While most people infected with SARS-CoV-2, the causative agent of COVID-19, recover without requiring treatment, some individuals experience persistent and debilitating symptoms, such as fatigue, cognitive impairment, muscle pain, and dyspnoea, lingering for months after the acute phase of COVID-19 [1–5]. Persistent or newly developed symptoms occurring within three months after infection with SARS-CoV-2 and with a duration of minimum two months are defined by the World Health Organisation (WHO) as post COVID-19 condition, also called long COVID [6]. Yet, long-term symptoms after viral infection are not a new phenomenon [7–9]. However, knowledge of Post-Viral Syndromes, especially their management and rehabilitation, remains limited and urgently needed [6, 10–12]. Thus, long COVID presents a unique case for addressing this knowledge gap.

Although estimates for patients experiencing long COVID vary widely, ranging from 5% to 45% in recent studies involving hospitalised, non-hospitalised patients, or general populations, long COVID continues to pose a global health challenge [13–17]. Long COVID is known to impact work ability and activities of daily living of the affected individuals from months to years after infection with SARS-CoV-2 [18–20]. Likewise, studies have demonstrated that long COVID may negatively alter affected individuals' self-perceptions and ability to carry out their usual roles at work and at home, hindering their recovery process [21, 22].

NICE and the WHO highlighted the need for rehabilitation for individuals with long COVID early in the COVID-19 pandemic [6, 12]. Despite a growing body of evidence on the effects of long COVID rehabilitation, several systematic reviews indicate that studies evaluating rehabilitation for patients with long COVID are heterogeneous and based on small and selected cohorts of mainly previously hospitalised patients, leaving a pressing need for further research [23–25]. In a recent framework of research priorities in COVID rehabilitation, O'Brien et al. (2024) highlighted the need for enhancing our understanding of safe rehabilitation of post-infectious conditions, such as long COVID [26].

In Denmark, municipalities are responsible for rehabilitating patients with long COVID. However, specific guidelines for developing and conducting these rehabilitation interventions are lacking [27]. In response to the emergence of patients with long COVID in the Summer of 2020, a large Danish municipality developed a structured out-patient rehabilitation intervention called *The Long COVID Rehabilitation Intervention*. Given the novelty of long COVID and the urgent need to develop the intervention based on clinical experience and rehabilitation principles from other patient groups, the effectiveness and functioning of the intervention remain uncertain. Understanding the effectiveness and functioning of such interventions requires exploration of their underlying programme theories and intervention mechanisms [28]. Realist evaluations are found promising in exploring the underlying programme theories and context-mechanism-outcome configurations (CMOCs) to understand the functioning of the interventions [29]. Therefore, this study employs a realist approach to gain a deeper understanding of the programme theory, specifically how, why, for whom, and under which circumstances *The Long COVID Rehabilitation Intervention* may work. We aim to explore the interactions between the intervention mechanisms of change, the implementation context and the expected outcomes of *The Long COVID Rehabilitation Intervention* to confirm or refine the initial programme theory. To address this aim, we formulated the following research questions:

1. How and why do patients perceive the mechanisms of *The Long COVID Rehabilitation Intervention* to contribute to the expected outcomes?
2. How and why do health professionals perceive the mechanisms of *The Long COVID Rehabilitation Intervention* to contribute to the expected outcomes?
3. Under which contextual circumstances do these mechanisms operate?

Intervention

Ahead of detailing the study's methods, a description of the intervention and the initial programme theory is provided, as this is essential for understanding the methods employed in this study. The study's methods are detailed in the following section (Sect. 3 Methods).

Intervention components

The Long COVID Rehabilitation Intervention was offered to patients with long COVID, delivered at an out-patient rehabilitation centre specialised in neurological rehabilitation in a Danish municipality from 2020 until 2023. The intervention is illustrated with a general logic model (Fig. 1) and described in detail using a TIDieR template [30] (see Additional file 1) which were developed by the research team alongside the initial programme theory (see Sect. 2.2) prior to initiating the present study.

Patients could participate in the intervention via referral to rehabilitation from a long COVID outpatient clinic at a large Danish university hospital or their general practitioner. The intervention, delivered by a team of physiotherapists and occupational therapists, had a minimum duration of three months and was tailored to patients' needs. It comprised a combination of individual and group sessions, typically initiated with individual

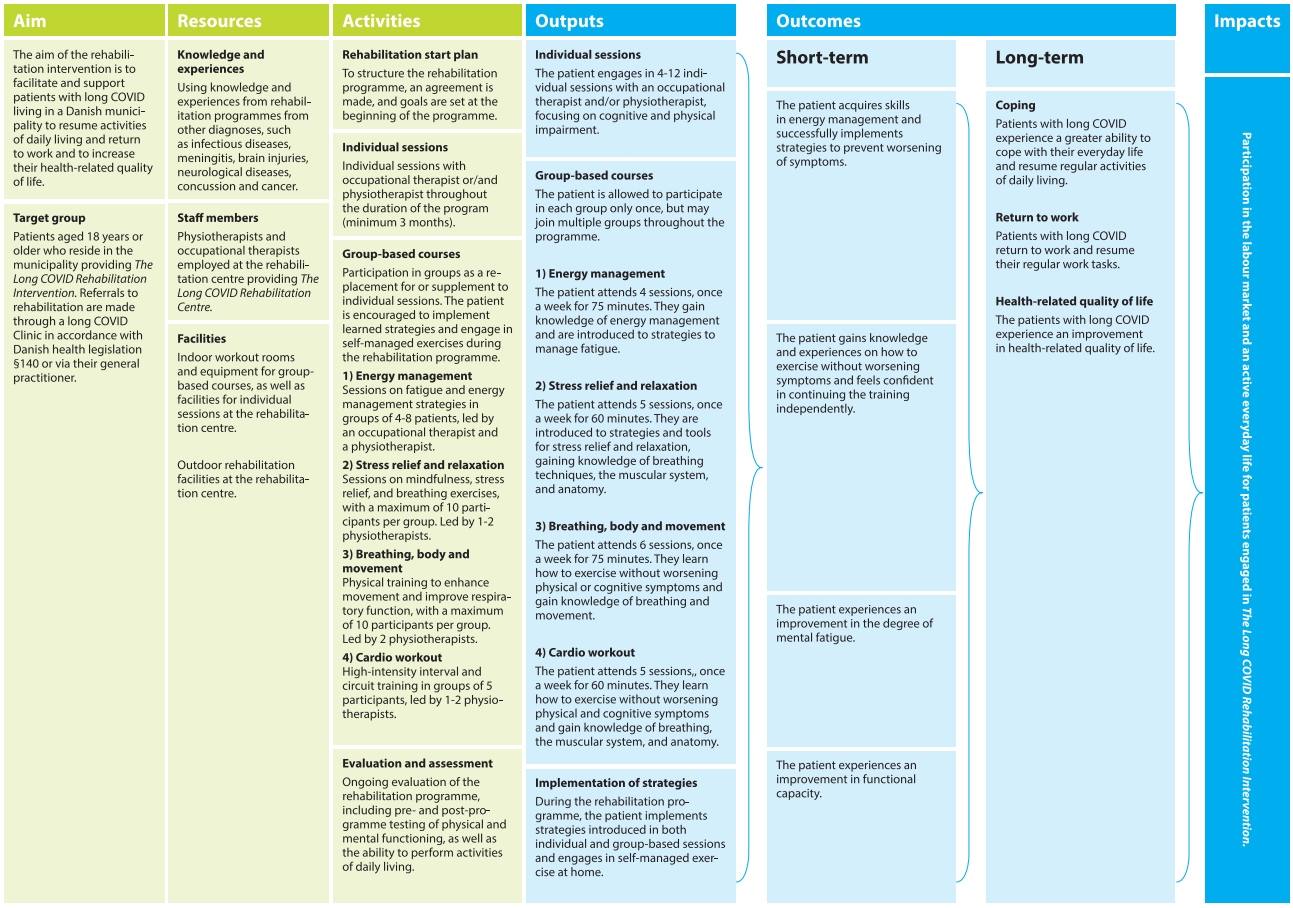

Fig. 1 General logic model illustrating the components and structure of the Long COVID Rehabilitation Intervention. This model was developed by the research team before the study commenced, to depict the intended content and structure of the intervention. It was not derived from study data

consultations, followed by group courses, and concluding with individual sessions. Sessions were initially held weekly or biweekly and were later spaced out, with some patients receiving monthly follow-ups. The content included energy-management strategies, advice and strategies for managing and balancing daily activities across home, work and leisure, peer support, breathing techniques, and physical exercises. Due to changes nationally and politically in the management of patients with long COVID, and therefore also in the organisation of *The Long COVID Rehabilitation Intervention*, the intervention was delivered in this form until June 2023. From July 2023, the group sessions changed from only including patients with long COVID to also involving patients with neurological diagnoses. The other elements remained the same.

Initial programme theory

The Long COVID Rehabilitation Intervention was initially developed by health professionals from the rehabilitation centre using a practise-based, experience-informed approach. Knowledge from rehabilitation programmes from similar diagnoses, such as meningitis, brain injuries, neurological diseases, cancer and concussions, was drawn upon, as no theoretical framework for long COVID was available. The theorisation of the intervention expressed with the initial programme theory was developed in parallel with the general logic model prior to the current study by the research team and was based on observations, written materials and informal meetings with the health professionals delivering the intervention and the manager of the rehabilitation centre. The initial programme theory is described below and listed in Table 1 as the initial programme theory hypotheses expressed with Context-Mechanism-Outcome configurations (CMOCs), showing how the contexts of the intervention interact with and influence the mechanisms and patterns of outcomes produced in the intervention [29]. In this article, we refer to programme theory hypotheses as CMOCs.

The Long COVID Rehabilitation Intervention aimed to improve the patients' functioning, quality of life, and ability to perform and resume daily activities at home, at work and during leisure time. Building on the theory

Table 1 Initial programme theory hypotheses expressed with CMOCs

CMOC title	CMOC description
Identity transformation	The Long COVID Rehabilitation Intervention encompassing patient education and skill building, individual and in-group sessions with other patients with long COVID and delivered through a person-centred rehabilitation approach (**C**), collectively fostered a reconceptualisation of beliefs, values, and roles (**M**) which led to an identity transformation among patients with long COVID, enabling a shift in the patients' occupational choices, self-perception, and improved engagement in meaningful activities (**O**).
Person-centred rehabilitation approach	The person-centred rehabilitation approach encompassing multidisciplinary collaboration and active involvement of the patients throughout the rehabilitation course (**C**) empowered the patients to take on active roles in their rehabilitation process (**M**). These mechanisms led to a more coherent rehabilitation course and strengthened commitment and engagement in the rehabilitation intervention among the patients (**O**).
Patient education	Individual sessions delivered by occupational therapists and physical therapists and group sessions with other patients with long COVID fostered a supporting space for individual and peer learning (**C**), equipping the patients with essential skills and knowledge. The acquired skills and knowledge empowered the patients, and they experienced an increase in self-efficacy in relation to managing their symptoms and implementing the strategies in their everyday life (**M**). As a result, the patients would experience increased, improved symptom management, better planning of daily activities and participation in meaningful activities (**O**).
Peer support	Within the context of The Long COVID Rehabilitation intervention, participation in group sessions in a supportive and empowering environment, where patients could support each other emotionally without judgement (**C**) created a sense of belonging and a safe space for patients to openly discuss their challenges and concerns (**M**). These mechanisms contributed to increased self-efficacy and strengthened commitment to implementing the strategies and reduced feelings of isolation and stigma (**O**).

C = context, *M* = mechanism, and O = outcome

of transformative learning and identity by Illeris (2014) [31], it was anticipated by the researchers that through participation in the intervention and interacting with health professionals and other patients with long COVID, the patients might reconceptualise their beliefs, values, and roles, leading to an identity transformation, a shift in how the patients perceived themselves and their roles, and a change of occupational choices. The intervention emphasised a person-centred, biopsychosocial, and multidisciplinary approach, in which professionals aimed to actively involve patients and flexibly adapt the delivery within the overall framework. These principles were aligned with the person-centred rehabilitation model by Jesus et al. (2022) and rehabilitation principles and definitions described by Wade (2023) and Meyer et al. (2020) [32–34]. Another important element of the intervention was patient education, consistent with rehabilitation principles emphasising education and learning as fundamental processes in rehabilitation [32, 34, 35]. Patients received psychoeducation on long COVID and were introduced to principles of energy management, which was expected to equip them with necessary skills, empower them, and increase their self-efficacy to implement the strategies and participate in meaningful activities at home, work or leisure. By practising and sharing experiences with other patients with long COVID during the group sessions, the patients were expected to learn from each other, thereby highlighting peer learning as a key element of the patient education. Additionally, the group settings and interaction with other patients with long COVID provided a safe environment for openly sharing emotions and experiences without judgement, fostering peer support. Although the effectiveness of peer support for patients with long COVID is not known, Mullard et al. (2023) highlight the relational and social potential of peer support for patients with long COVID, as it is described as promising in reducing social isolation, improving well-being, and increasing self-efficacy among patients with other chronic disorders [36].

Methods

Design

The study used a qualitative design guided by Pawson and Tilley's (1997) realist evaluation framework, rooted in critical realism [37]. A realist evaluation aims to test and refine the underlying programme theory of the intervention by exploring the interaction between the contexts, mechanisms and outcomes illustrated with the CMOCs. In this study, we adopt Greenhalgh and Manzano's (2022) understanding of context as encompassing more than just things or people but also the psychological, organisational, economic, and technical relationships - forces that interact and influence each other [38]. Additionally, when referring to mechanisms, we define them as both the resources provided by the intervention and the individuals' reasoning in response to these resources and the context, as outlined by Dalkin et al. (2025) [39]. The study followed the realistic evaluation cycle [29], by 1) describing the initial programme theory and CMOCs, 2) collecting qualitative data about the intervention, consisting of interview data with patients, the health professionals and the manager, 3) analysing the data and testing the CMOCs based on the data, and 4) refining the proposed initial CMOCs.

Setting

The study was conducted from September 2023 to April 2025 alongside a process evaluation and effectiveness evaluation exploring the implementation processes and effectiveness of *The Long COVID Rehabilitation Intervention* (ClinicalTrials.gov ID: NCT06544382, registration date: 9 August 2024). Participants were recruited from a rehabilitation centre delivering *The Long COVID Rehabilitation Intervention* in a Danish municipality with a population of more than 350,000 citizens. Approximately 450 patients participated in the intervention between summer 2020 and summer 2023.

Data collection

The data was collected through a focus group interview with the health professionals delivering the intervention, a semi-structured individual interview with the manager of the rehabilitation centre, and semi-structured individual interviews with patients who had participated in the rehabilitation intervention. The interviews were conducted between November 2023 and June 2024. Interview guides were developed for each data collection method (see Additional file 1). The interview style for all interviews was inspired by a realist interview approach and the teacher-learner-cycle used to introduce elements of the programme theory on which the informants could reflect about their perspectives on the elements of the programme theory [40].

According to patient preference, the interviews took place either at the patient's home, at the research unit in charge of the study, at the rehabilitation centre delivering *The Long COVID Rehabilitation Intervention*, online or by phone. To accommodate symptoms of fatigue, breaks were incorporated into the interviews when needed. The interviews with the health professionals were performed at the rehabilitation centre, and the interview with the manager was conducted online at the manager's request. All interviews were audio recorded except for one, as a patient declined recording of the interview. For this interview, notes were taken by the interviewer during the interview and all thoughts and reflections were noted immediately after the interview to ensure a record of as many details as possible.

Participants and recruitment

Participants for the patient interviews were recruited at the rehabilitation centre providing *The Long COVID Rehabilitation Intervention*. The physiotherapists and occupational therapists delivering the intervention distributed study information and a contact form to their patients. Patients interested in participating were contacted by the principal investigator, who explained the study and invited them to the interviews. The interviews were performed after the modifications to the group sessions following national changes to the long COVID management schemes. To ensure the recruitment of patients who had participated in the intervention prior to the changes, patients who commenced their rehabilitation course before the changes were initiated were prioritised as informants. Yet, to gain enough patient perspectives, patients who had commenced their intervention during fall 2023 were also included. Based on this initial sampling, ten females were recruited from November 2023 until March 2024. To ensure gender diversity, and variation in age and the period of participation in the rehabilitation course, additional male participants attending the rehabilitation course in 2022 were purposely sampled from May to June 2024. Invitations were sent to ten men via a secure digital post service, requesting their response by mail or phone. The number of participants was not predetermined; purposive sampling continued until additional interviews did not contribute substantively new perspectives on the CMOCs.

The health professionals were recruited to participate in the focus group interview in collaboration with the manager of the rehabilitation centre. They were all health professionals that were or had been part of the long COVID rehabilitation team from Summer 2020 until inclusion. The focus group interview was conducted in December 2023. Likewise, the manager of the long COVID team, who oversaw the development and implementation of the intervention, was invited to participate in an individual interview, taking place in January 2024.

Data analysis

Interview data was transcribed verbatim and analysed in NVivo (version 15) inspired by the realist analytical approach by Gilmore et al. (2019) [41]. The data was prepared for analysis by listening to and reading each interview transcript. The voices of patients, health professionals and the manager were given equal weight and value in the data analysis. For each initial CMOC, a code was created with linked memos describing the initial CMOC. An initial coding of each interview enabled exploration of additional themes during the analysis, which were used in the refinement of the initial CMOCs or creation of new CMOCs. The adjusted or newly developed CMOCs were presented in a figure, illustrating the refined programme theory of *The Long COVID Rehabilitation Intervention*.

Results

Informants

A total of 12 patients (10 females, 2 men; aged 20–80 years) completed interviews lasting approximately one hour. One interview was split into two to accommodate fatigue. Prior to their long COVID diagnosis, all patients except three (who were retired) were employed

or studying. At the time of the interview, three were working or studying, four were on sick leave (part-time and full-time), and five were unemployed or retired.

Nine patients participated prior to the adaptation of the group courses in August 2023. This group included two men who had completed the programme in 2022 and seven females who commenced in spring 2023; all attended the original form. Three patients participated after the adaptation. One attended only individual sessions due to a language barrier, as the groups were offered exclusively in Danish. The remaining two attended mixed-diagnosis groups, which was the only deviation from the original intervention.

The focus group consisted of two physiotherapists and three occupational therapists. All, except for one physiotherapist who joined in May 2021, had been involved in the development and delivery of the intervention from summer 2020. The manager oversaw the long COVID team throughout the whole period.

Refinement of CMOCs

The following sections introduce the findings in relation to each initial CMOC. The results show a

close interconnectedness between the CMOCs and point toward identity transformation as central to the functioning of the intervention, reinforced by the other three CMOCs. The refined programme theory is illustrated in Fig. 2

Identity transformation

Generally, the identity transformation CMOC was supported by the interviews with the patients and health professionals. The health professionals highlighted that change of identity and roles were of focus throughout the rehabilitation, helping the patients to understand their new situation and teaching them strategies to overcome the challenges caused by the long COVID symptoms.

> *Because it's life-changing […]. It's the whole life that has changed. Fatigue and everything else that comes with it changes everything. So, it's a life transformation. Occupational therapist 1*

As they were no longer able to perform their usual activities at home, at work or during leisure time, or to carry out their ordinary roles, the patients had to see themselves in a new perspective, accept their situation and learn to manage their symptoms. As patient 3 expressed, she had to *"learn to live with it".* Likewise, patient 10 described how she had to accept that the rehabilitation of her long COVID condition was a long process with *"no magic fix"*, and as patient 5 expressed: "*That's also what the rehabilitation has been about: a greater acceptance that it probably won't just go away"*. Besides the process of acceptance, the interviews with the patients indicated how a process of reconceptualisation of values, beliefs, and roles was occurring throughout the rehabilitation course. Several patients expressed that their limited amount of energy forced them to constantly value one activity over the other to prioritise the most important one.

> *[T]hat's what you have to do when you suddenly go from having many resources to having very, very few. You have to redefine yourself and figure out what you actually want to use the few resources you have for. What do you want to spend them on? I think about that every time Patient 7*

The patients also highlighted how meeting and interacting with the health professionals and other patients with long COVID changed their attitudes towards the most important daily activities. For instance some shifted from prioritising work to recognising the importance of social activities, thereby facilitating the process of reconceptualisation of values and beliefs, as demonstrated in the quote below.

> *[I]t's also something that has surprised me quite a bit. That they [health professionals and peers] don't support me in just pushing through as I usually do. Everyone, across the board, has really emphasised that your social life is just as important as your work life. Patient 8*

This reconceptualisation enabled them to better prioritise their daily activities and implement the learned strategies. This reconceptualisation was reflected in the patients' own values and beliefs of what mattered most to them, but it was also influenced by sociocultural context in terms of the norms of society and the roles which were expected of them, for example at home or work. The health professionals described a general societal norm contrasting to the purpose of the intervention:

> *Anyone who has been physically ill just thinks, well, it's about getting up and doing a little, then doing more and more, and then you get better. And then we're standing here saying, actually, you should do less and less and less, right? Occupational therapist 2*

This impacted the health professionals' way of working and shifted their focus from curing the patients to helping them to manage and cope with their symptoms. In particular, the physiotherapists had to accept that these patients required a larger focus on energy management and not necessarily on improving their physical function

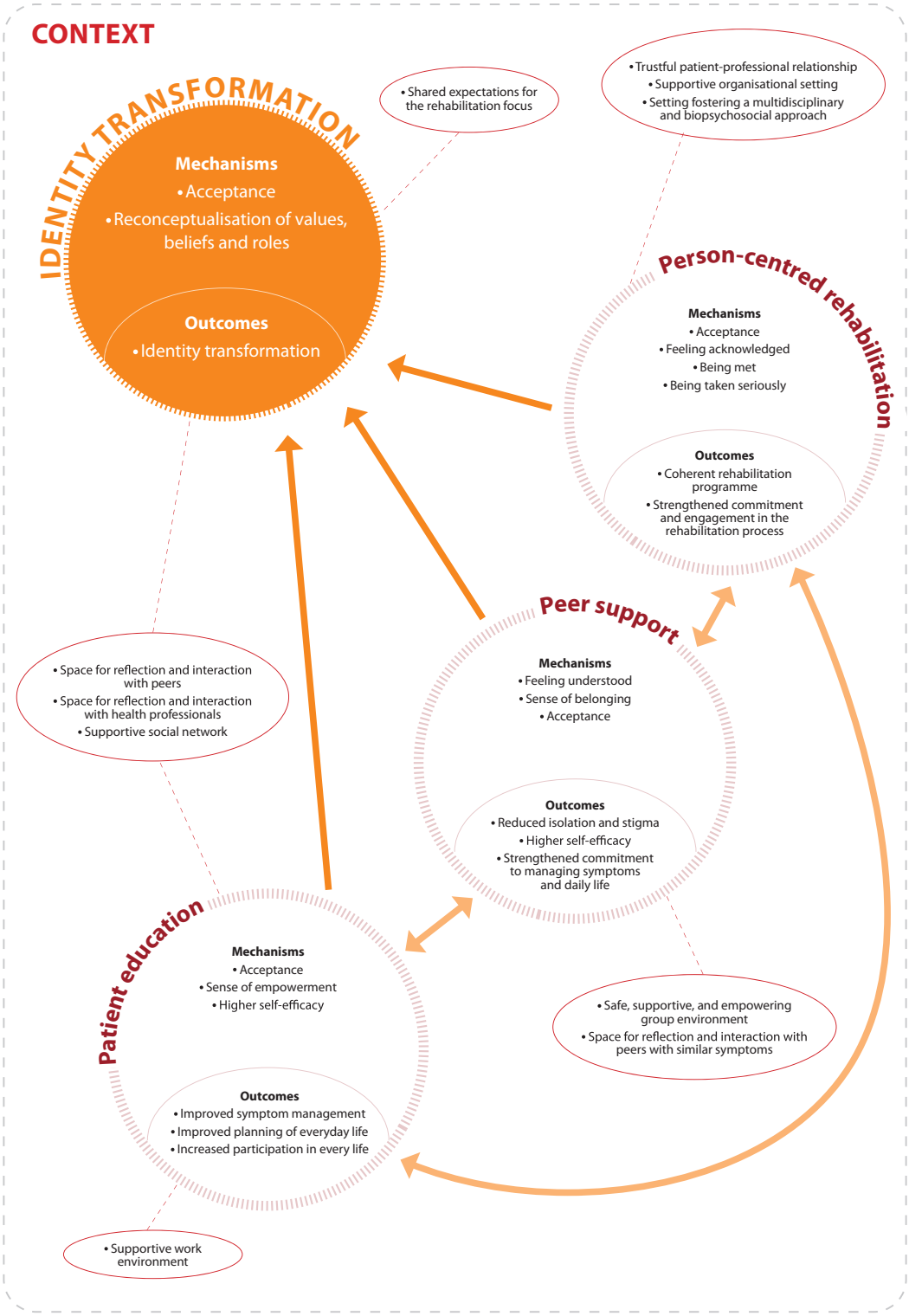

Fig. 2 The refined programme theory of *the long COVID rehabilitation intervention*

as they were used to with other patient groups. Likewise, several of the patients, particularly patients with physical symptoms such as muscle and joint pain and respiratory symptoms, expected a larger focus on the physical functioning and support to return to their prior exercise capacity before entering the rehabilitation course. They expressed generally more frustration and non-fulfilled needs in relation to managing their physical symptoms.

This may indicate that the general understanding and expectations of what rehabilitation should encompass, such as a focus on improving the physical functioning through exercising, acted as a sociocultural contextual barrier for health professionals and the patients. Another sociocultural contextual barrier related to a lack of support and understanding from family and relatives. For some patients, long COVID challenged their relationships with their family and friends, as the patients could no longer carry out their usual roles, which made them question their rights to feel ill.

> *But it just hit me a bit that it's my own sister who hasn't understood [the full extent of my fatigue], even though she's heard about it, understood it, and seen me be tired. But you can't maintain … What should I say? It's not guilt or shame, but there's this right to feel bad that's hard to hold on to. Patient 4*

A lack of support and understanding from relatives may be a constraining contextual factor in terms of activating the mechanism of acceptance of the situation and condition. On the contrary, when the patients experienced a supportive social network, it reinforced the process of acceptance of their situation and implementation of the strategies. Hence, the analysis suggests that the processes of acceptance and reconceptualisation of values, beliefs and roles were not just based on the patients themselves but was highly influenced by the sociocultural context in which they were part of, indicating that the reconceptualisation of values, beliefs and roles and identity transformation transcended the rehabilitation course.

Based on the analysis, the CMOC on identity transformation is refined as follows:

- If *The Long COVID Rehabilitation Intervention* is built on shared expectations regarding the rehabilitation focus, provides the patients with a space for reflection alongside health professionals and peers, and the patients experience a supportive social network (**C**), then the patients are likely to experience increased acceptance of their situation and undergo a reconceptualisation of values, beliefs and roles (**M**), leading to an identity transformation reflected in a shift in occupational choices, improved self-perception, and engagement in meaningful activities (**O**).

Person-centred rehabilitation approach

As highlighted in the initial programme theory, multidisciplinary collaboration is an important factor in a person-centred rehabilitation approach. The collaboration was described by the health professionals as evolving over time, as they got more experienced with the patient group:

> *And we also started to cross into each other's professional areas. And when we had been in contact for 9 months anyway, it became, like,'how's the energy management going?', and things like that. It just became completely natural, yes. Physiotherapist 1*

The collaboration involved the integration of the disciplinary fields of physiotherapy and occupational therapy. For example, occupational therapists incorporated breathing exercises into their individual sessions and energy management strategies, while physiotherapists focused on energy management before introducing physical exercises and instructing patients on increasing their physical activity levels. Patients generally highlighted the multidisciplinary collaboration as a strength of the rehabilitation intervention, as it fostered a coherent rehabilitation process and made them feel seen and supported throughout their rehabilitation:

> *But I knew that [name of physiotherapist] had been involved in the energy management group. I mean, she knew what had been said, and I had the individual sessions with [name of occupational therapist] alongside it as well. And they've just communicated with each other. I mean, it's been really good. Patient 5*

The relationship with the health professionals was highlighted as another key aspect of the intervention. Many patients had previously felt misunderstood and unsupported by society and their social networks. A trustful relationship with health professionals can be seen as an essential part of the context, providing patients with a safe space to share feelings and concerns and supporting them in following advice on symptom management and the prioritisation of daily activities. This trustful relationship also allowed for addressing psychological and social aspects of the patient's life, in line with a person-centred and biopsychosocial approach. When the patients experienced this trust, they felt acknowledge and experienced enhanced acceptance of their situation, which facilitated strengthened commitment and engagement in the rehabilitation intervention. Similarly, the health professionals emphasised the importance of a person-centred approach within the context of the intervention. The health professionals described how the intervention was tailored to each patient's individual needs and circumstances, guiding decisions on when to offer physiotherapy or occupational therapy, the selection of relevant group courses, the frequency of sessions (e.g. weekly or monthly individual sessions) and the overall duration of

the rehabilitation course. The patients expressed how it made them feel heard and included in the rehabilitation intervention:

> *It meant that I felt seen, acknowledged, helped and supported. And that's why I believe the one-on-one sessions were better. The ones that have made the biggest difference to me are those, because they [health professionals] were so skilled. They were able to step in and pinpoint what this patient needed help with, and what they didn't need help with. Patient 4*

Through the interviews with the manager and the health professionals, the organisational context was highlighted as an important factor for facilitating the patient-centred approach. According to the manager of the rehabilitation centre, having to navigate in the context of a new disease resulted in a situation where *"[W]e were all out of our depth. But we were out of our depth together"*. The manager actively involved health professionals in the development and implementation of the intervention, encouraging a trial-and-error approach that enabled them to iteratively develop, test, and adjust components based on shared experiences. The health professionals generally described this approach in positive terms and highlighted how it motivated them and provided them with greater influence than usual. Moreover, it enabled them to work closer together and adjust the intervention to each patient, facilitating the patient-centred approach described above.

Based on the analysis, the CMOC on person-centred rehabilitation approach is refined as follows:

- If patients with long COVID participate in *The Long COVID Rehabilitation Intervention*, delivered by a multidisciplinary team using a biopsychosocial and patient-centred approach, with whom they share a trustful relationship, and if the intervention is implemented in an organisational setting supporting the person-centred approach (**C**), then the patients will experience a feeling of being met, taken seriously and acknowledged, and an acceptance of their situation (**M**). This will lead to a more coherent rehabilitation course and strengthened commitment and engagement in the rehabilitation intervention (**O**).

Patient education

According to patients and health professionals, psychoeducation and learning new strategies was a focus of the rehabilitation course. The health professionals expressed that teaching the patients about the symptoms and energy management concepts and providing them with tools and strategies to use when needed were an important element of their work. These perspectives were supported by findings from the patient interviews. Generally, the patients described how they gained new knowledge on breathing techniques, taking breaks and planning and prioritising daily activities, which enabled them to get through a whole day and perform more activities at home, at work and during leisure time throughout the day without or with fewer symptom relapses, supporting the outcomes described in the initial programme theory on patient education. However, the interviews with the patients also suggest that the way they were guided and encouraged to apply the strategies was a pivotal element in building the skills and gaining the knowledge necessary to achieve the outcomes.

> *But for me, it has really meant a lot that there have been some people with whom I could reflect. So it's not just knowledge. It's also the interaction with people themselves. Patient 2*

The quote illustrates how the collaboration with the health professional created a space for reflection, enabling patients to learn the strategies through continuously practising them in their daily life. By having someone to discuss the strategies and implementation of these in the patient's everyday life, the rehabilitation was centred around the patients and their everyday lives, supporting the initial CMOC on the person-centred approach. The patients also pointed towards the collaboration with the health professionals as a supporting factor for practising and implementing the strategies.

> *We've made some agreements, and then I've come back, and it's kept me grounded. I've really had periods where I had almost no energy at all. But because of the fact that you kind of had to meet with someone, you end up having to try it out Patient 7*

As the quote shows, the regular meetings with the health professionals and possibility to discuss the applied strategies and knowledge supported the patients to stay on track and keep on practising the strategies despite the symptom burden. Learning from and being inspired by the other patients' strategies was also highlighted by the patients as an important factor for managing the symptoms and increasing their self-efficacy in terms of performing previously challenging daily activities. Additionally, some patients highlighted how they could use the gained knowledge and support from health professionals and other patients as a foundation for standing up for their needs and use it as an argument for saying no to certain tasks, for instance at work, if they were too demanding:

> *It's a knowledge and a standpoint that I need to take with me into my everyday life. And I wouldn't have had the strength to do that if I … Now, I suggested myself that they could have just given me a leaflet, and then I might have understood it, but it wouldn't have given me the resilience to actually go to work and say, no, I still can't attend the meetings. Patient 4*

Gaining knowledge and support transformed the reasoning and perspectives of the patients in terms of what they needed and thereby empowered them to stand up for their rights and needs, which enhanced their acceptance of their situation. Likewise, an occupational therapist highlighted how changing the patients reasoning and providing them with confidence to apply the strategies under different circumstances was central to the rehabilitation intervention. Thus, the findings indicate that an important mechanism may be a feeling of empowerment and self-efficacy from applying the strategies and skills in the everyday life, which supports the initial CMOC on patient education.

In the analysis of identity transformation, patients' relatives were identified as a sociocultural contextual factor, influencing the mechanisms of acceptance and reconceptualisation of beliefs and values. Likewise, the support from relatives was necessary to succeed in implementing the energy management strategies. When the patients experienced resistance from their relatives, it made it more difficult for them to accept their situation and to implement the strategies and skills they learned. Another important contextual factor was the patients' work situation. Several of the patients described how the flexibility of work tasks and support from colleagues and managers influenced their ability to practise and incorporate the strategies at work. This was highly influenced by the work industry and type of position, and by the cultural and social norms of the work. For example, patient 10 highlighted how the flexibility of her work tasks and having a supporting manager allowed her to take breaks at work, which she found helpful in managing her energy levels and limiting the symptom burden. Other patients with more rigid positions and tasks and with sociocultural expectations from managers and colleagues in terms of fulfilling their usual roles before getting ill were left in a dilemma, as they were aware of the necessity of implementing the strategies. Yet, their work context did not allow it. Instead, they had to *"hang in there"* while being at work and assign lower priorities to activities at home or spend their spare time to *"refuel"* and *"recharge the battery"*, as expressed by patient 3, indicating that a rigid work setting influenced by the legal and sociocultural context required more flexibility in other aspects of the patients' lives.

Based on the analysis, the CMOC on patient education is refined as follows:

- If patients with long COVID participating in the rehabilitation intervention have opportunities for reflection with health professionals and other patients with long COVID, and experience supportive social and work environments (**C**), they will experience a greater acceptance of their situation, higher self-efficacy and a stronger sense of empowerment to practise and implement the strategies in their everyday life (**M**). By doing so, the patients are expected to achieve an improvement in symptom management, better planning of daily activities, and increased participation in their everyday life (**O**).

Peer support

The CMOC on peer support is described in relation to all the group courses offered in the rehabilitation intervention. Although not all interviewed patients had participated in all the different group courses, the findings indicate that it was primarily in the energy management group that the proposed CMOC on peer support was evident. In the relaxation and respiration group and the cardio workout group, the focus was directed towards the individual and their own experiences with physical exercises and not on interaction with the other participants, creating a feeling of distance to the other participants.

> *It felt very much like it [red.: the cardio workout group] was tailored to the individual. I mean, the other person who was there had to do some exercises that were different from the ones I was doing. […] It wasn't such a personal meeting, at least. It was a bit distant. Patient 11*

On the contrary, most of the patients described how participating in the energy management group and meeting other patients with long COVID enhanced understanding and acceptance of their symptoms and situation. As many patients had previously experienced a lack of understanding from wider society and their relatives, finally meeting other patients with long COVID made them feel less alone with their condition. Engaging with the other participants in the energy management group also helped the patients to recognise their own progress and to stay committed to the rehabilitation process:

> *So it's also about mirroring. Yes, you mirror each other for better or worse. And everyone has been aware of that. And now I actually feel a little better than last time, but that doesn't mean I'm better than you or anything. I mean, using each other in*

that way and being able to see something positive in it Patient 3

Although the energy management group generally was described as positive in terms of meeting other patients with long COVID creating a sense of belonging and reduced feelings of stigma, the data suggest this mechanism was influenced by several contextual factors. In particular, the epidemiological context seemed to influence the peer support mechanisms.

I think it was a bit difficult for me [ed.: to be able to reflect myself in the others in the energy management group]. I might have felt like I was the one who was doing the worst. I mean, that feeling of 'wow, I'm really hit hard by this.' That was a bit hard for me. Patient 7

Thus, if the patients experienced severe fatigue, it made it difficult for them to engage and interact with the other patients in the group. Additionally, having more physical-related symptoms instead of fatigue also seem to influence the mechanisms behind the peer support.

Especially those muscular symptoms, and they weren't very prominent in anyone else. I mean, many others had much more the brain-related issues, or what should I say, which I had less of. So in that way, there wasn't really anyone I could directly reflect myself in within that group. Patient 2

The quotes illustrate that when the patients perceived symptoms other than fatigue as their primary or most severe symptom, such as more physically related symptoms, the content and discussions with the other patients in the energy management group felt less relevant to them. This may have hindered the activation of the mechanisms of peer support, as it made it difficult for some patients to relate to those with more fatigue-related symptoms. As a result, severe fatigue or the experience of other primary or worse symptoms may act as an epidemiological contextual barrier to engaging in peer support. This contextual factor could hinder activation of the mechanisms related to feeling less alone and understood, as outlined in the initial CMOC on peer support, potentially leading to unintended outcomes, such as increased isolation and stigmatisation, if patients continue to experience a need for meeting others who share similar long COVID symptoms.

Based on the analysis, the CMOC on peer support is refined as follows:

- If patients with long COVID participate in group sessions with a safe, supportive and empowering environment which facilitates interaction with patients with similar long COVID symptoms (**C**), then the patients will experience a sense of belonging, feeling understood, and acceptance of their situation (**M**), which may lead to reduced feelings of isolation and stigma and higher self-efficacy and strengthened commitment to managing their everyday life and symptoms (**O**).

Summary of analysis and refined programme theory

While the initial CMOCs were largely confirmed, they required refinement to their contexts and mechanisms. The analysis demonstrated the interaction between these elements within all four CMOCs, revealing an interconnectedness among them. Acceptance was identified as an overarching mechanism across all CMOCs, playing a fundamental role in how the intervention facilitated change. Moreover, identity transformation was identified as central to the functioning of the intervention, supported by the CMOCs on person-centred rehabilitation, patient education, and peer support. Rather than focusing on patients returning to their functional level prior to long COVID, the intervention facilitated a process of acceptance and reconceptualisation of beliefs, values, and roles, which empowered the patients to navigate daily life and engage in meaningful activities at home, at work and during leisure time despite the ongoing presence of symptoms. The central role of identity transformation, alongside the overarching mechanism of acceptance and the interconnectedness of the CMOCs, differs from the initial programme theory and serves as an essential element in understanding the functioning of the intervention.

Discussion

The aim of the study was to understand how, why, for whom, and under which circumstances *The Long COVID Rehabilitation* worked by exploring the interaction between the contexts, mechanisms, and outcomes of the intervention. Generally, the initial CMOCs were confirmed but they all required refinement to their contexts, mechanisms, and outcomes. We demonstrated an interconnectedness between the CMOCs and identified acceptance as an overarching mechanism, with identity transformation playing a central role in the functioning of the intervention. In the following, we discuss the main findings mentioned above in relation to existing literature, the strengths and limitations, and the implication for future long COVID rehabilitation practises.

Discussion of main results

To our knowledge, this is the first study to explore the programme theory and CMOCs of a long COVID rehabilitation intervention. Although existing studies

evaluating long COVID rehabilitation interventions primarily focus on the effects of the interventions instead of how and why they work, our results align with findings and rehabilitation recommendations in other studies. One of our main findings concerning the interconnectedness of the CMOS is illustrated with the refined programme theory in fig. 2 The analysis of each CMOC shows similarities between the hypotheses, such as contextual factors, including space for reflection with peers and health professionals, and supportive social networks, as well as acceptance as an overarching mechanism, all of which were present across multiple CMOCs. While Pawson and Manzano-Santaella (2012) argue that *'programmes never offer up a single theory'* [42], we suggest that the interconnectedness of the refined CMOCs demonstrates the complexity of the programme theory and that the intervention possesses several theories and hypotheses, all adding to the overall functioning of the intervention. Another main finding concerns identity transformation as central to the functioning of *The Long COVID Rehabilitation Intervention*. Change of identities and roles in relation to long COVID have been highlighted in several studies [18, 21, 22, 43, 44], underscoring the need for focusing on identities and roles in long COVID rehabilitation. In a recent paper, Harrison, Rhodes and Lancaster (2024) analysed the concept of recovery among patients with long COVID and discussed how the process towards feeling well was unpredictable and for some required a process of working towards a new version of oneself [44]. While it was not in relation to a rehabilitation programme, it supports our findings on identity transformation as being central to the functioning of the rehabilitation intervention. In our study, reconceptualisation of beliefs, values, and roles was identified as a key mechanism in relation to identity transformation. This finding is consistent with findings of a qualitative interview study by Gerlis and colleagues (2022), exploring patient experiences of a rehabilitation programme for post COVID-19 symptoms. They highlighted a shift in values to prioritise own well-being during recovery and rehabilitation [43], which aligns with our findings of the reconceptualisation of beliefs, values, and roles as a central mechanism in the CMOC on identity transformation.

We identified the patients' acceptance of their situation as an overarching mechanism across all CMOCs and as a key mechanism in the CMOC on identity transformation. This aligns with studies in the field of rehabilitation highlighting acceptance of illness and symptoms as a key aspect in the rehabilitation of chronic conditions, with reported associations to improved emotional functioning, reduced pain intensity, and lower levels of depression [45–47]. Likewise, the role of acceptance has been addressed in studies on long COVID. For instance, Raunkiaer et al. (2022) explored the experiences of a combined in- and outpatient rehabilitation programme in a qualitative study [48]. Although the context and intervention differ from the intervention of focus in our study, the interventions possess similar components, such as energy management and psychoeducation. Raunkiaer and colleagues (2022) showed how their intervention generally contributed to a better recognition, understanding and acceptance of the individual's situation with long COVID, which supports our findings. Likewise, they found that social and work contexts, such as flexible working conditions and supportive social networks, facilitated participation in the rehabilitation course, which is consistent with our findings. Similarly, another qualitative study by Leggat et al. (2024), conducted as part of the co-production of a self-management intervention for persons with long COVID in the UK, highlighted how acceptance together with hope enabled their participants to focus on learning, carry out their strategies and manage their day-to-day symptoms [49]. While Leggat et al. (2024) focused on self-management strategies, our findings suggest that mechanisms of acceptance also play a role within a structured and supervised rehabilitation setting, indicating a broader applicability of these mechanisms.

Moreover, our findings showed how meeting and interacting with peers and health professionals throughout the rehabilitation course was an important contextual factor in several of the CMOCs, facilitating mechanisms of acceptance, being met, and understood. Gerlis et al. (2022) demonstrated similar findings, highlighting validation and assurance from staff and peers, and shared reflections and experiences enabled through the rehabilitation course. They discussed how this was important for their cohort who experienced long COVID early in the pandemic, as they may have been poorly understood due to limited knowledge of the disease [43]. However, the patients in our study primarily participated in the rehabilitation course in 2023, suggesting that these mechanisms may be valid in general for patients participating in long COVID rehabilitation and not just for patients who experienced the symptoms early in the pandemic. This highlights the importance of developing long COVID rehabilitation interventions that ensure meeting and interacting with peers and health professional to facilitate mechanisms of acceptance, being met and understood.

National and political changes in the management of patients with long COVID, resulting in closing of long COVID clinics and a decline in patients referred to rehabilitation, influenced the study. In response to the decline in referrals and fewer economic resources, the rehabilitation centre made changes to the intervention in Summer of 2023. Although the changes were expected to only change the intervention components, such as offering fewer groups with mixed diagnoses, it may have

influenced the function of intervention regarding peer support, as the patients were not guaranteed to meet and interact with other with the same condition. The refined programme theory implicitly takes this into account, as meeting patients with similar symptoms was highlighted as an important contextual factor in peer support. Therefore, these organisational changes are expected to primarily have influenced the components and not the function of the intervention.

Although return-to-work and health-related quality of life were included as outcomes in the initial logic model, they are not explicitly represented in the refined CMOCs. The identity transformation, facilitated by acceptance of the situation and a reconceptualisation of beliefs, values and roles may contribute directly to improvements in health-related quality of life and engagement with valued activities across home, work and leisure domains, regardless of whether patients fully resumed previous activities. However, the intervention was not designed as a vocational rehabilitation programme and was delivered within a neurological rehabilitation setting. While return-to-work is an important goal for many patients, it is a complex process requiring additional mechanisms and support, as highlighted by Ottiger et al. (2024) in a systematic review and meta-analysis on work ability and return-to-work of patients with post-COVID-19 [19, 50]. Future studies should examine how CMOCs identified here might complement such targeted interventions.

Strengths and limitations

Using a realist perspective to develop and test CMOCs permitted identification of how the intervention may work, for whom and under which circumstances, which is considered a strength of the study. The study was conducted in a single centre, which may limit the transferability of the findings to other contexts. Yet, exploring the underlying programme theories of an intervention and understanding the contextual contingencies have been highlighted by Skivington et al. (2021) to facilitate increased transferability across settings, and produce evidence and understanding of the intervention [28]. Hence, the findings of the present study remain relevant to explore and test in other settings as well. Despite recommendation of using mixed methods in realist evaluations [29, 37], we only applied qualitative methods to address the aim. The study was originally planned as a mixed-methods study to test the programme theory and explore the implementation process of the intervention. However, it was decided to divide the study into two, leaving room for a more in-depth analysis of the data. Therefore, the findings of the present study will be used in a future evaluation of the implementation process, using both qualitative and quantitative data.

With 10 of 12 patient participants being female, the study had an overrepresentation of females as informants. To address this, a second sampling was conducted retrospectively and purposively to recruit men who had previously participated in the rehabilitation intervention, yet only two responded and agreed to participate. The overrepresentation of females in studies examining the incidence and prevalence of long COVID is well documented [1, 3], which likely contributed to the recruitment challenges and the lower number of male participants. In terms of age and employment status, the sample (aged 20–80 years, including patients in work or study, on sick leave, or unemployed) broadly reflects the variation observed in a larger cohort of patients diagnosed with long COVID in the same setting, of whom some were referred to the rehabilitation intervention, as described in our previous study [18]. However, the lack of complete data on all patients referred to the intervention limits the precision of this comparison. Future studies should examine the sociodemographic characteristics of the full rehabilitation population to enable a more precise assessment of representativeness.

Evaluating an existing intervention that adapted over time in response to national and political changes in the long COVID management scheme necessitated a pragmatic recruitment approach. Recruitment continued until no new perspectives on the CMOCs emerged, supporting the adequacy of the sample size for the study's aims. This approach may nonetheless have limited diversity in other sociodemographic characteristics, including ethnicity, and introduced potential selection bias. Furthermore, the patients were recruited at different stages of their rehabilitation courses and after the implementation of the changes; hence, some reflections of the participants may have been influenced by recall bias. The focus group interview with health professionals was conducted after the changes to the intervention had been applied, potentially causing recall bias in this group as well. Yet, the social dynamics during the focus group interview facilitated reflection and discussions on previous events and experiences, minimising recall bias. Likewise, the manager was potentially influenced by recall bias, but since they mainly provided perspectives on the context, this bias is considered minimal. As described in the method section, the study applied a theory-driven realist interview approach and a teacher-learner-cycle to test the programme theories. However, due to the novelty of the disease and limited knowledge of rehabilitation interventions for this patient group, the investigators made sure that the interview style would leave room for the participants to present other perspectives on the intervention, supporting the gleaning theory phase of a realist interview [40], strengthening the findings of the study.

Implications

The focus of the study is consistent with long COVID rehabilitation research priorities highlighted by O'Brien et al. (2024), pointing towards the need for identifying and examining safe approaches to rehabilitation and examining the role, implementation, and impact of models of COVID rehabilitation care [26]. Likewise, the components and organisation of *The Long COVID Rehabilitation Intervention* align with those described in the scoping review of rehabilitation care models for long COVID by Décary et al. (2022), including multidisciplinary teams, patient-centred care, patient education, and patient support groups, which relate directly to the content of the intervention [51]. However, our findings do not merely confirm the relevance of these components; they expand the current state of knowledge by providing a theoretically informed understanding of *how* such components may function in practice, through refined CMOCs, thereby offering insights into the development and delivery of future long COVID rehabilitation interventions. Based on our findings on identity transformation being central to the functioning of the intervention and acceptance as an overarching mechanism, we believe that long COVID rehabilitation interventions may benefit from incorporating a focus on the identity transformation of the persons in rehabilitation and on facilitating acceptance through providing contexts enabling these mechanisms, as suggested in our refined programme theory. Yet, as contexts vary across settings and the mechanisms in long COVID rehabilitation interventions may come in to play differently, we recommend that the refined programme theory is tested in the corresponding settings to ensure transferability of our findings to other long COVID and post-viral rehabilitation contexts.

Conclusion

In this qualitative interview study, we explored the functioning of *The Long COVID Rehabilitation Intervention*. While the initial programme theory was largely confirmed, refinements were needed regarding contexts and mechanisms for each CMOC. We developed a theoretical understanding of the intervention, highlighting identity transformation as central to its functioning, facilitated by a person-centred rehabilitation approach, patient education, and peer support. Furthermore, we identified acceptance as an overarching mechanism and demonstrated strong interconnectedness between the CMOCs. This theoretical understanding of *The long COVID Rehabilitation Intervention* is essential in evaluation and development of future long COVID rehabilitation interventions.

Abbreviations

COVID-19	Coronavirus disease 2019
CMOC	Context-Mechanism-Outcome configuration
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

Conceptualisation: T.B.N., L.G.O., J.H., C.V.N., S.L., C.H.L., and D.S. Project administration: T.B.N., L.G.O. and D.S. Formal analysis: T.B.N. and D.S. Writing – original draft preparation: T.B.N., L.G.O. and D.S. Writing – review and editing: T.B.N., L.G.O., J.H., C.V.N., S.L., C.H.L., and D.S. All authors have read and agreed to the published version of the manuscript.

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Data availability

The datasets supporting the conclusions of this article are not publicly available in order to protect participants' privacy in accordance with the European General Data Protection Regulation and the terms of informed consent. Data may be available from the corresponding author upon reasonable request and subject to appropriate ethical approvals.

Declarations

Ethics approval and consent to participate

The study was approved by Research Ethics Committee at VIA University College, Denmark (J.no.: A23-73802) and by the Regional Data Protection Agency (J.nr. 1–16-02–655-20). Informed written consent was obtained from all participants. The study was carried out in accordance with The Declaration of Helsinki.

Competing interest

JH works for the Centre for Development, Evaluation, Complexity and Implementation in Public Health Improvement (DECIPHer), which is funded by Welsh Government through Health and Care Research Wales.

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