

“IT’S A MOVING TARGET”: PACING AS STRATEGY TO REDUCE SYMPTOM EXACERBATION

RESULTS FROM AN INTERNATIONAL
COMMUNITY-ENGAGED STUDY WITH ADULTS
LIVING WITH LONG COVID

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WHAT IS PACING?

- Pacing is a strategy and rehabilitation approach that **balances rest and activities** in daily life, to manage symptoms such as fatigue and post-exertional symptom exacerbation (PESE)*.
- Multiple potential **goals** of pacing and **types** of pacing**.
- Important to **consider and select the most appropriate types of pacing and energy management strategies for the patient population**. For example, pacing strategies with the goal to increase activity may not be safe or appropriate for people with Long COVID**.

*Goudsmit, Ellen M., Jo Nijs, Leonard A. Jason, and Karen E. Wallman. Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: a consensus document. Disability and rehabilitation; 2012; 34 (13): 1140-1147.

**World Physiotherapy. World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy; 2021.

Scan to learn more
about pacing:



STUDY PURPOSE AND AIMS

- To explore **experiences with pacing** from the perspectives of adults living with **Long COVID** from Canada, Ireland, United Kingdom, and United States.
 - To describe the **perceived role of pacing** as a rehabilitation intervention with adults living with Long COVID;
 - To explore **knowledge about pacing** as a rehabilitation intervention for adults living with Long COVID; and
 - To explore **experiences utilizing, engaging, and adopting pacing** for adults living with Long COVID.

METHODS

STUDY DESIGN: Community-engaged qualitative descriptive study involving one-on-one online interviews.

PARTICIPANTS: Adults living with Long COVID in CAN, IRE, UK, and US.

DATA COLLECTION FROM DEC 2021-MAY 2022 :

- Online Interview, demographic questionnaire, visual illustrations.
- Episodic Disability Framework was the scaffold for the interview guide (dimensions of disability; contextual factors, including living strategies such as pacing; and triggers)
Example Q: Did you adopt any other **living or coping strategies** to help you deal with the health challenges and ups and downs of disability living with Long COVID?

ANALYSIS:

- 2ndary data analysis with aim to address research questions on pacing.
- Group-based analysis using directed content analysis techniques.



**PATIENT-LED
RESEARCH
COLLABORATIVE**



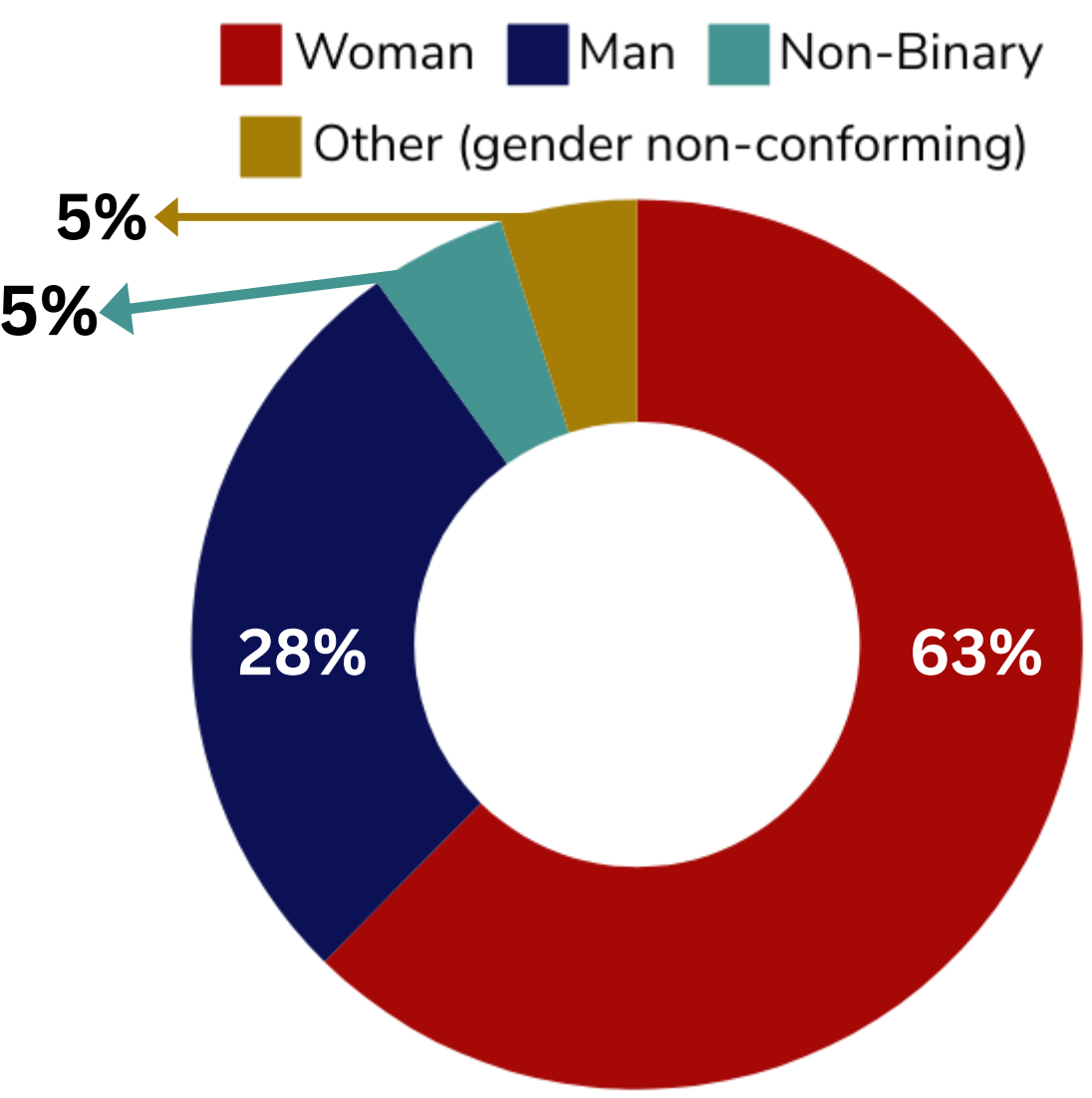
Scan to read more
about the **Long
COVID and Episodic
Disability Study:**



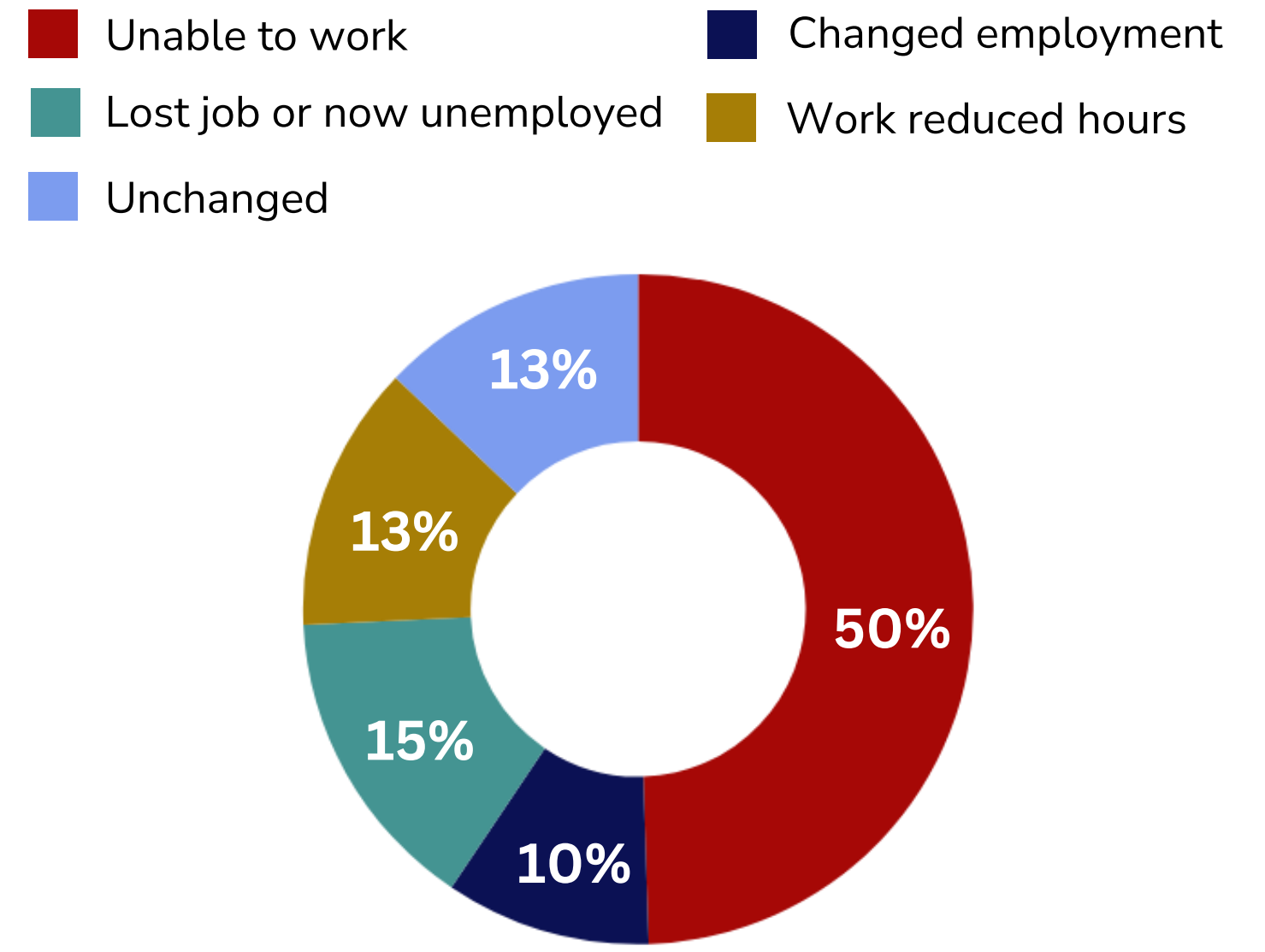
PARTICIPANT CHARACTERISTICS (n=40)

MEDIAN AGE (IQR): 39 years (32-49)

GENDER



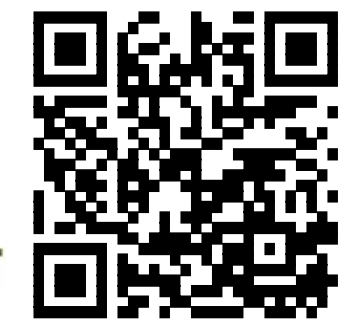
EMPLOYMENT STATUS AFTER LONG COVID



83%
of participants were living with Long COVID >1 year

93%
of participants spoke about pacing or concepts related to pacing

Scan for more info on characteristics:



PACING: EXPERIENCES OF ADULTS LIVING WITH LONG COVID

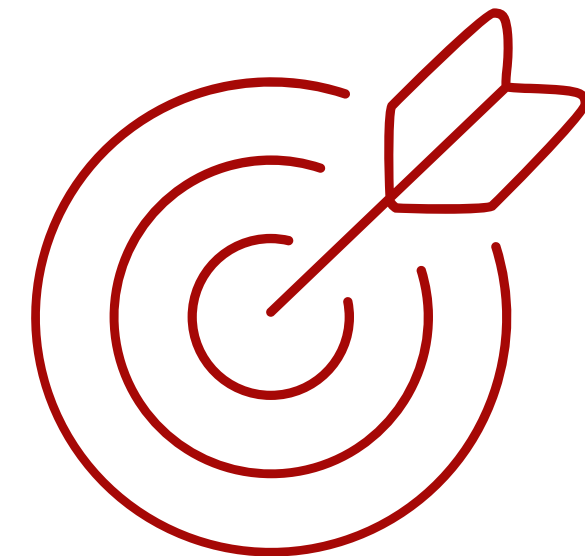
CHARACTERISTICS OF PACING

LEARNING HOW TO PACE

ANALOGIES USED TO DESCRIBE PACING

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

P24, US



CHARACTERISTICS OF PACING

PACING IS A HELPFUL LIVING STRATEGY BUT IT IS NOT A CURE FOR LONG COVID

- Pacing was described as a **living strategy** and was **widely adopted** by the participants.
- Participants implemented pacing to:
 - Manage symptoms.
 - Avoid crashes.
- **Pacing was not described as treatment or cure for Long COVID.**
 - Pacing was described as **requiring ongoing effort and implementation** to reduce or avoid symptom exacerbation.

I've understood more as time's gone on about pacing... I would say it's a smoother ride now, but that's not because my symptoms are getting better. It's because I'm understanding more about my limitations and how much I have to pre-empt my body. P19, UK

CHARACTERISTICS OF PACING

PACING MITIGATES OR PREVENTS MULTIDIMENSIONAL HEALTH CHALLENGES

- Participants described different dimensions and factors that had to be considered when pacing, **beyond just pacing physical activities (including emotional, cognitive activities).**

It seems to be a three-pronged thing. Like it's physical and mental but also emotional. If you use a lot of emotional energy, there's a lot of stuff going on around you... That can take a lot from you as well... if I used up a lot of energy yesterday... if I went shopping yesterday... I might not be as able to do this today. It's just knowing those things... you start learning that's the way it is. P9, IRE

- Effective pacing required finding a **balance** between different types of exertion.



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LEARNING HOW TO PACE

- Pacing was described as a **learned skill** with many challenges, requiring **time, effort, and trial and error** to implement effectively.
- Many participants learned about pacing through their own investigation of the available management options for Long COVID (**online resources including community-support groups**).
- Participants described **parallel strategies and skills that they developed to support their success with pacing**.
 - Planning and prioritization.
 - Mindfulness, chunking activities, organizing, resting, and adapting activities/using equipment or aids.

The more I read about [pacing], it is the way to get through this kind of a thing because it's the way people have been doing it for years with CFS and ME is pacing and then they are living their lives... P10, IRE

LEARNING HOW TO PACE: CHALLENGES WITH PACING

Some people are making choices that aren't choices because... they don't have the income or the freedom in any way whether it be to take time off work because they just can't or just working... They've been told to rest... Also, if I don't work I'm going to not eat, so I'm going to work... They're not going to get better at all because they're overdoing it constantly... **If you're going to choose between that and losing your home, you're going to work. I think you have to be careful about choices and a lot of people don't have them.** P14, CAN

- Learning about pacing, energy conservation, and the benefits of rest vs. activity through **trial and error**.
- **Lack of social support** for pacing from friends, family, and health care providers.
- Adopting pacing as a living strategy requires an **emotional and psychological adjustment**.
- Pacing requires **sacrifice**.
- **Unexpected obstacles** – You cannot plan and pace everything in life.



LEARNING HOW TO PACE: CONSEQUENCES OF NOT PACING

RELAPSE / CRASH / SYMPTOM EXACERBATION

- Encompassing physical, mental-emotional, cognitive domains. Ex: headache, nausea, brain fog, etc.
- Multiple participants referred to “**suffering**” if they were unable to pace or ‘overdid it’.

LOSS OF FUNCTION / PRODUCTIVITY / INCOME

- Some participants described crashes where they would be temporarily bed-ridden, or “physically paralyzed”.
- There were consequences for their ability to engage in employment and other activities in their lives.

I lost like \$10,000 of my salary because of choices I had to make because I had to manage long COVID... There's a pressure to maintain wellness, to keep well because I can't afford to not be well... That can be a bit of a pressure but it also helps to have a bit more discipline and pace in myself to try to stay well. P1, UK



ANALOGIES USED TO DESCRIBE PACING

ENERGY ENVELOPE



[Pacing is] just trying to remain with as few symptoms as possible through pacing, through **staying within** like what's called the energy envelope. P37, IRE

BUDGETING ENERGY



If I'm going to an event... I have to conserve energy and pace myself. It's like I'm putting money in my bank. I'm giving myself 2,000 euros which I wish I had and then I have to take all that out and I only have like -10. P6, IRE

SPOON THEORY



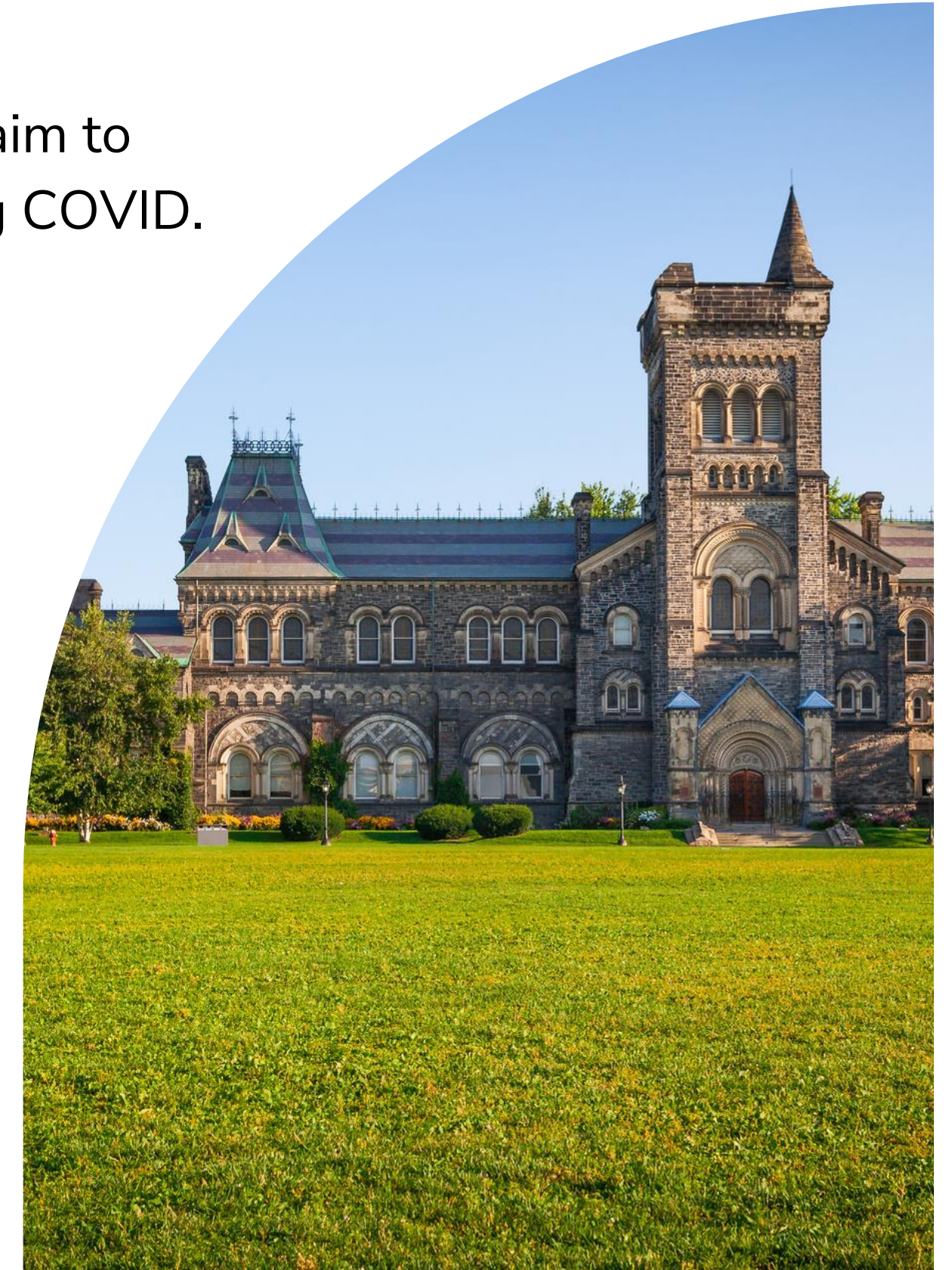
I'm timing things so that I'm doing my cooking more on the weeks when I don't have my kids or I'll do all the cooking on the weekend and then it's just getting through the weekday and relying on leftovers. **It's trying to do my pacing and my planning so that I don't run out of spoons, especially before the week is through and I'm not borrowing from my future self. My future self needs the spoons too.** P25, CAN

POINTS FOR CONSIDERATION

- This was a **2ndary data analysis**. The primary objective of the interviews was not to describe pacing. However, there was a considerable amount of rich data on the experiences of adults living with Long COVID with pacing from the interviews.
- The participants were from 4 countries (CAN, IRE, UK, US).
- The participants were recruited through community support groups and networks and were knowledgeable about Long COVID and supports that existed for people living with Long COVID.
 - There may be many adults living with Long COVID who do not know about pacing or who have relatively little experience with pacing.

SUMMARY

- Pacing was characterized as a **helpful living strategy** with the aim to mitigate or prevent multidimensional health challenges of Long COVID.
- Pacing is **not a cure** for Long COVID.
- Pacing is a '**moving target.**' It is a learned skill with many challenges, requiring time, effort, trial and error to implement effectively.
- Participants used many **analogies** to conceptualize and communicate pacing.
- Rehabilitation providers should **consider the complexity of pacing and work collaboratively with patients to implement this strategy**, when appropriate.





THANK YOU - ACKNOWLEDGMENTS



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QUESTIONS?



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MORE RESOURCES ON PACING:

