



Remote researchers

Learning from experts-by-experience in digital inclusion

“Thank you so much for creating this place where we could listen and be heard.”

Focus group participant

Introduction

This guide explains the research practice of the Chronic Illness Inclusion Project (CIIP). We did research within our own community of disabled people living with energy limiting chronic illness (ELCI). We adapted the process to meet our needs and circumstances, as participants as well as researchers. The practice we developed was an extended online focus group.

The chronic illness community is invisible to society and to policy makers - the people who make decisions about our lives. The purpose of our research was to give our community a voice, by sharing and promoting our knowledge and experiences. The CIIP was part of a research programme called DRILL¹, which put

¹ DRILL stands for [Disability Research into Independent Living and Learning](#).

disabled people in the lead of research about how to improve our lives². The report from our research is [here](#).

To have our voice heard, we needed to reach and involve people who could not participate in traditional face-to-face focus groups. Our research practice had to adapt so that participants could take part from home. Therefore, it took place entirely online, through the Internet.

We hope that sharing our practice will help other researchers to make their research more inclusive of people with ELCI. Most importantly, we hope this will create more opportunities for people with ELCI to have their voice heard, be involved in policy and decision-making processes in future, as well as become peer researchers themselves.

The “digital-by-default” world we now live in excludes and discriminates against many disabled people. But new digital technologies are also providing opportunities for the inclusion of disabled people who have historically been excluded from involvement and participation. The online focus group software we used was one such example.

This focus group software, as well as other digital communication technologies such as videoconferencing are now widely available. Organisations and institutions have a duty to use them so that we are not unnecessarily excluded from society.

Our extended online focus group practice could be used, not just for research, but for a variety of engagement, involvement, and co-production activities.

The ELCI community

Our community is generally known as the chronic illness community, or sometimes, the “spoonie” community³. It is found

² The three disabled researchers involved in this project have extensive lived experience of energy limiting chronic illness.

³ For an explanation of the term “spoonie” and “spoon theory” see https://en.wikipedia.org/wiki/Spoon_theory

online, through social media networks like Facebook and Twitter, and blogging platforms. It is mostly made up of people who have lost some, or all, of their face-to-face networks and friendships because leaving their home is impossible, or very difficult, due to the impairment that results from chronic illness. Many of us use the term “housebound” to describe these circumstances.

Our research found that one of the main experiences we share in the chronic illness community is energy impairment. Energy impairment is what makes it difficult or impossible to leave our home, among many other limitations.

“Energy impairment” is a new term that we developed with the chronic illness community. We also know that the term “housebound” is rejected by many disabled people, for very valid reasons. To make sense of our research practice we need to explain both of these terms and why we use them.

What is ELCI?

Energy Limiting Chronic Illness (ELCI) is a long-term condition characterised by a debilitating mix of physical fatigue, cognitive fatigue, and pain, alongside other diverse or fluctuating symptoms. The overall impact of our condition is significantly reduced energy for essential everyday activity. Living with ELCI means having to carefully ration limited energy in order to accomplish basic tasks and avoid aggravating symptoms.

What is energy impairment?

Energy impairment is a term we have developed to convey the experience of energy limitation as a type of impairment or disability. Energy impairment is the main feature of ELCI but it may also be experienced by people with other impairments or health conditions as a secondary feature. Energy impairment is a form of hidden impairment.

Why are face-to-face activities difficult with ELCI?

For people with ELCI, energy impairment is a global impairment. That means it affects nearly everything about how our bodies and brains work. ELCI affects mobility (walking), cognition (eg thinking, reading, communicating), in fact nearly every kind of activity, as well as our body's response to sight, sound and smell and temperature. A sub-group of us also have multiple chemical sensitivities.

It is more difficult to accommodate the global impairment with ELCI than to accommodate a single impairment. Adjustments and support may help with one aspect of our impairment, but not enough to mitigate the overall impact.

Going out to a meeting or event requires many units of energy. Getting ready to leave the house, travelling to the venue, interacting with other attendees, listening to and processing what's being said, speaking up, sitting upright, sustaining concentration, coping with background noise and artificial lighting, then travelling home again – all of these individual tasks or challenges are a drain on our very limited reserves of energy. When we do them all in a sequence they can result in a “**crash**”, or in days or weeks of “**payback**” (see Glossary).

For people with moderate or mild energy impairment, adjustments such as travelling by taxi, having supportive seating, or being able to lie down for a rest could make a meeting or event accessible. But for others, no amount of adjustments or support can make an in-person event accessible. This also holds if we have already used up our daily or weekly energy budget on other activities like household management or a social activity.

Therefore many of us use the term “housebound”, and why we wanted to create a research practice that our participants could take part in from home or bed. [See appendix/link to website for more explanation of why we identify as housebound]

Some people with ELCI say they are completely housebound. Others say they are not completely housebound but taking part

reliably in activities outside their home is difficult because of fluctuation and **payback**, which are two key features of ELCI.

Accessibility issues with ELCI

Some disability scholars have thought about making sure focus group research includes all forms of impairment or disability.⁴ But this work still does not take account of disabled people who are unable to access face-to-face settings.

We designed our focus group to be as inclusive and accessible as possible to people with ELCI, based on our lived experience of the challenges it creates. As well as being sometimes or always housebound, ELCI also involves:

- **Cognitive difficulties** – for example, problems with concentrating, finding words, difficulties with reading and writing due to severe mental fatigue. This means it can take us much longer to do an activity that involves thinking, and we may have to break it up into chunks with rests in between.

“I have struggled to answer the questions only because it’s been so long since anyone wanted my opinion and the brain fog that comes with my illness making it difficult to remember the right words.”

- **Fluctuation** – symptoms and energy levels can vary a great deal over months, weeks or within a single day. Often people with ELCI can’t predict or control this variability. The fluctuation may be caused by our condition itself. It may also be a consequence of having already used up our available

⁴ Olsen, J. (2019). The Nominal Group Technique (NGT) as a Tool for Facilitating Pan-Disability Focus Groups and as a New Method for Quantifying Changes in Qualitative Data. *International Journal of Qualitative Methods*, 18,

energy for the day or week on other essential activities, as this participant explained:

Every task from "basic" personal care to filling in forms, dealing with people, housework etc takes energy and for each event there are days worth of payback where I'm not able to do very much at all.

Ethical issues in online research

Our research practice was also designed to address some of the ethical challenges in doing research online. Research councils refer to this way of doing online research as "internet-mediated research" (IMR). We addressed some of the known ethical challenges associated with IMR. We also highlighted ethical challenges relating to the chronic illness community that were not already identified in the existing literature on IMR. [See our Ethics Review](#) for more detail.

The ethical challenges we considered included:

Privacy - especially the risk of intrusion to an online forum by outsiders.

Confidentiality – especially the ambiguity between public and private information in online spaces

Difficulty of safeguarding participants when discomfort or distress that may arise within the research process is not visible to researchers.

Establishing trust - trust-building is an essential part of collecting and sharing in-depth experiences and opinions. In face-to-face settings this is helped by contextual information such as visual cues, facial expressions. This contextual information is absent in an online forum.

Higher risk of mental distress: living with ELCI often entails a high degree of social isolation. Internet and social media interactions bring benefits of social connectedness, peer support, information-sharing and empowerment. However, this form of communication also brings greater risk of emotional and psychological harm from interpersonal conflict – whether perceived or real (See [Ethics Review](#)).

Health risk from over-exertion

Many people with ELCI experience worsening of their health and impairment when they go beyond their own safe level of activity. For some people, the mental effort of taking part in a focus group, even if they really want to, could damage their health. For this reason we only selected participants who said they were able to safely use a computer for more than five hours per week.

Technical solutions

We used online focus group software from a small company called focusgroupit.com. Focusgroupit.com offered a simple, easy-to-use platform for text-based discussion and interaction. It was affordable and involved very little learning for either researchers or participants.

Focusgroupit.com is designed for commercial market research within a short time frame, e.g. one week. However, it proved to be suitable for social research that was extended over a longer period. Giving participants more time to engage with the focus group and submit their answers made it much more accessible.

Focusgroupit.com offered solutions to our impairment challenges as well as to ethical challenges:

Ensuring privacy and anonymity

Our participants were already familiar with, and active in, social media platforms such as Facebook. Facebook allows for private discussion groups, and we wanted to replicate this familiar social experience for the purposes of our research. However, even

private Facebook groups pose a problem for privacy and anonymity. Participants might find themselves in a Facebook group alongside people whose identity was known to them already from their external social media networks.

Focusgroupit.com encouraged participants to adopt a pseudonym (a different name) unrelated to their identity “In Real Life”, or on Facebook, Twitter or Instagram. This allowed for a greater level of anonymity and confidentiality. Focusgroupit.com also offered better security than free-to-use discussion platforms such as Google Groups. Giving greater protection against intrusion.

Adjusting for fluctuation and cognitive fatigue

Our online focus group allowed participants to take part and interact with others at a time of their choosing, within a two-week window. This is called an “asynchronous” discussion group. A “synchronous” discussion group is when participants are all online at the same time and interacting in real time. Synchronous discussion groups require activity at a set time and tend to require fast processing of information and response. These features make synchronous discussion groups less accessible to people with ELCI because of unpredictable fluctuation in energy levels and cognitive fatigue and difficulties.

Unbiased responses

The focusgroupit.com platform was designed to get “unbiased” answers to questions from participants. This means their response was not influenced by what other people in the focus group were saying. Participants had to post their response to a question before they could see, or respond to, other participants’ responses. This was another advantage of focusgroupit.com over a Facebook group.

Our research process

Our extended online focus group took place over an eight-week period. We initially recruited 25 participants. 19 of them were active throughout the research period.

Participants accessed the focus group through the focusgroupit.com website using their username and password. Researchers had to approve their registration to the site at the start to allow them access to the forum and safeguard the forum from intruders.

Over the eight-weeks, a new “topic” was posted to the focus group every two weeks. Each topic had a short introduction, and between one and three questions to answer. Participants could choose to skip one or more questions and move onto the next. Occasionally there were additional materials such as a video to watch. There was also a “poll” half-way through where participants voted on which terms they preferred for describing chronic illness.

Once they had answered the initial question(s) participants could read other participants’ answers and respond to them. In this way participants could have a discussion with each other as if they were in a room together.

Participants received an email when a new topic had been posted, which gave them a link to access the latest topic. This helped to remind them to take part over the eight weeks. They could also select to have an email alert when someone had posted a new comment, or had replied to their comment. In this way they had control over how involved they wanted to be once they had answered the initial questions.

Three researchers were active during the focus group period. Two were “moderators”, meaning they posted the topics and questions and replied to participants. Sometimes they asked participants to explain their answers in more detail. Sometimes they asked follow-up questions. One researcher was an “observer”, meaning they did not take part in discussion but read and summarized discussions. The observer also looked out for any disagreements between participants that could have escalated to conflict.

The design of our research practice was new and experimental. We did not know how much or how little our participants would

say in the online focus group, or how long they would remain engaged with it. We were surprised at how intense the discussion was, how much trust and solidarity developed between participants, and how honest and revealing the information they shared was. The focus group generated over 38,000 words of discussion. Some participants built bonds of peer support and friendship that they chose to carry over into their online networks beyond the life of the focus group.

We had originally planned for the focus group to last for six months. However, after eight weeks of intensive discussion it was clear that neither participants nor researchers could sustain this level of activity. We concluded that eight weeks was the best time frame.

Safeguarding participants and establishing trust

Why was our online focus group successful in establishing trust and generating interesting discussion?

All three researchers belonged to, and were active in, chronic illness communities online before the research. We believe our shared lived experience with participants was an important factor in gaining their trust. Our own experiential knowledge shaped the questions we asked and the way we responded to participants' answers. We were conscious of the need to maintain personal boundaries and not introduce our personal biases into the discussion. But we managed to share enough information about ourselves to make clear that we understood and shared many of the experiences and opinions reported by participants.

How did we safeguard participants against emotional distress?

All participants had to consent to a code of conduct within the focus group. The guidelines asked them to be aware of the greater potential for misinterpretation and misunderstanding within text-based communication, and to be respectful of the diversity of experiences and opinions in the group.

However, the extended and asynchronous format (meaning it was “open” at all times) of our focus group made it ethically more risky. It was not always possible for three researchers living with ELCI themselves to moderate discussion over an eight-week period. There was no solution to this problem. No interpersonal conflict that we were aware of arose between participants during our research practice but this may have been more due to luck than design.

If we were to repeat our research practice we would make participants fully aware of the risks of interpersonal conflicts to ensure their consent was informed.

On balance we feel the benefits of our research practice, both for the participants themselves and the chronic illness community generally, significantly outweighed the risks.

“I have really appreciated this opportunity and think it has great potential... I do hope it continues in some way as it is imperative we chronic illness folk have a platform to air our opinions and experiences; and I hope to work with you all in the near future.”

Focus group participant

Housebound vs Trapped at Home

We believe there is a crucial difference between being housebound (or bedbound) due to severe energy impairment, and being trapped at home, or in bed, due to a failure of independent living support or access provisions.

Some disabled people reject the term “housebound”, for very important and valid reasons. Disabled people have been labelled as housebound when they could in fact access the community if external barriers were removed, and appropriate accessibility measures and assistance were put in place. The term housebound has been used to justify the exclusion and institutionalisation of disabled people against their will.

However, many people with severe ELCI claim the term “housebound”; (and/or “bedbound”) to capture a crucial and defining aspect of our identity and experience that cannot be addressed by removing social barriers, or having personal assistance.

Energy impairment is a global form of impairment. It affects physical, cognitive as well as sensory function. This means that for people with severe ELCI, no amount of personal assistance, technological support or other adjustments are enough to mitigate the impact of their impairment and enable them to leave their home and participate in society.

Identifying ourselves as “housebound” does not mean we don’t need or want assistance and adjustments to have lives of equal value as participate as much as possible. It means the support and adjustments we need in are different. They often involve access and participation from home, or bed.

Making the distinction between disabled people who are housebound and those who are trapped at home allows us to place the needs of both groups on an equal footing and fight for equality and inclusion together.

Some people with ELCI say they are completely housebound. Others say they are not completely housebound but taking part reliably in activities outside their home is difficult because of **fluctuation** and **payback**, which are two key features of ELCI.

Because there is no better word to describe these experiences, we use the term housebound to include people who are not completely housebound, but have difficulty participating in activities outside their home because of ELCI.

Glossary of ELCI terms

Crash

Noun - A state of body-mind shutdown, resulting from over-exertion and/or exposure to stressors (e.g. environmental, emotional, deregulation of eating or sleeping, unexpected event).

Verb – to become incapacitated through dramatic energy deficit. Experienced as pulling the plug out, blowing a fuse, hitting a wall, or a computer crashing from having too many apps open or running out of battery power.

A crash is when we can no longer push through symptoms. A crash can happen during activity or event once our energy budget is spent, as a result of not pacing, conserving or recharging energy as needed. A crash can happen the next day or days following over exertion or can be immediate.

Payback

The increase in symptoms and/or loss of function that results from spending energy outside of our energy budget.

Some of us are able to “borrow” energy from tomorrow to use today, but we have to “pay it back” afterwards. We may choose to incur payback for an activity or event that is valuable to us. Or

we may judge that an activity or event is not worth the payback that follows.

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