

DISBELIEF AND DISREGARD: GENDERED EXPERIENCES OF HEALTHCARE FOR PEOPLE WITH ENERGY LIMITING CONDITIONS

“NOTHING ABOUT US WITHOUT US”

BRIEF
6

MAKING PUBLIC AND PATIENT INVOLVEMENT/ ENGAGEMENT (PPIE) MORE INCLUSIVE OF PEOPLE WITH ENERGY LIMITING CONDITIONS

Introduction and Recommendation

One of the key recommendations from this research is:

Inclusion in research and policy decisions:

People with Energy Limiting Conditions (ELC) must be part of conversations about policy and practice that affect them and equal partners in research on ELC. The accessibility of patient and public involvement frameworks must be improved to ensure the inclusion of people with ELC. This might, for example, include asynchronous and remote modes of participation.

In this brief, we set out why we are making this recommendation and some suggested ways to make public involvement and engagement more inclusive of people with ELC. For more information on the background and methodology used in this research, see brief 1.

The Need for More Accessible Modes of Engagement

Many of our participants told us that more research about ELC is sorely needed. This refers to a need for both more biomedical studies, and more qualitative research about the lived experience of ELC. This research must involve people with ELC and be used to influence conversations and decisions about healthcare policy, service development and practice.

People with ELC must be involved throughout the research process - from the conceptualisation and design stage, through to the analysis and dissemination of findings. One participant highlighted this need for more co-production of research:

“Women need to be involved in every step of research processes - not just included as participants, but actively involved in designing the study processes. Without this, research will continue fail the people it is most meant to serve.” Participant 68: age 25-34, white, bisexual, woman, England.



Patient and Public Involvement/Engagement (PPIE) is seen as a mechanism to promote greater inclusion, equality, and diversity in research. It is increasingly a key requirement of research funders when awarding grants. Our participants recommended involving people with ELC in patient engagement fora and ensuring their inclusion in wider conversations about healthcare policy and practice, in ways that enable their full participation. Some participants suggested establishing “experts by experience” panels where people with ELC could share their experiences with healthcare professionals, with a view to informing policy and practice. One participant explained:

“I would like to see panels set up where people...with different healthcare issues and needs (ones which are poorly met at the moment, like mine) can discuss their experiences and feedback the improvements they would want to ideally see, to the relevant authorities.” Participant 235: age 55–64, white, heterosexual, woman, England.

Another participant described the need for a “cultural shift” to ensure that diverse lived experience is given a higher priority within the research agenda:

“We need a huge culture shift in women’s healthcare...investing in research for women’s health and drawing on women from all walks of life and actually listening to what they have to say.” Participant 477: age 25–34, white, bisexual, woman, England.

There also remains a need to improve the accessibility of existing PPIE activities for people with ELC. Some of our participants explained that current PPIE activities are not accessible as they are too physically and/or cognitively demanding for people living with energy limitation and chronic pain, for whom cognitive fatigue is a common symptom.

Recommendations to Make PPIE More Accessible to People With ELC

Understanding of ELC

Embed understanding within PPIE of the unique challenges and barriers faced by people with ELC.

Prioritising accessibility

Establish a supportive culture by prioritising accessibility and adapting involvement and engagement activities to take account of energy impairment. This may include (but is not limited to): online remote participation; shorter meetings with regular breaks; supporting people who need to participate with cameras off, or from darkened rooms; using accessible platforms and forms of communication.

Asynchronous participation

Introduce asynchronous participation options. Even with access provisions in place, some people with severe ELC may not be able to participate in synchronous PPIE activities. Asynchronous activities enable people to contribute in their own time, over extended periods of time, as and when fluctuating conditions allow, taking into account the need to pace engagement.

Minimising cognitive fatigue

Simplify tasks and provide clear written and recorded instructions to mitigate cognitive fatigue where possible.

Financial support for participants

Budget time and resource to support the inclusion of people with ELC in PPIE. This includes reimbursement for participants’ time, covering costs for those who need the support of a personal assistant or carer, and advice about how payments for participation might have an impact on benefits.

Further information about improving access for people with ELC is available via Chronic Illness Inclusion here: chronicillnessinclusion.org.uk/wp-content/uploads/2021/04/remote-revolution-to-reasonable-adjustments.pdf

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Cognitive Fatigue