

Policy Brief

Health and Social Care Professionals: Imagining Better Futures of Healthcare for People with Energy Limiting Conditions (ELC)

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Artists and creative practitioners: Khizra Ahmed, Khairani Barokka (Okka), Julian Gray, Mish Green and Louise Kenward.

Project Partners: [Chronic Illness Inclusion](#), an organisation of people living with energy limiting chronic illnesses; [Healing Justice London](#), a community-led health and justice organisation; [The Lantern Initiative](#), a social enterprise raising awareness of mental health issues in the Muslim community.

KEY INFO

Research question: What would better health and social care involve, for people with ELCs*?

Policy area or themes:

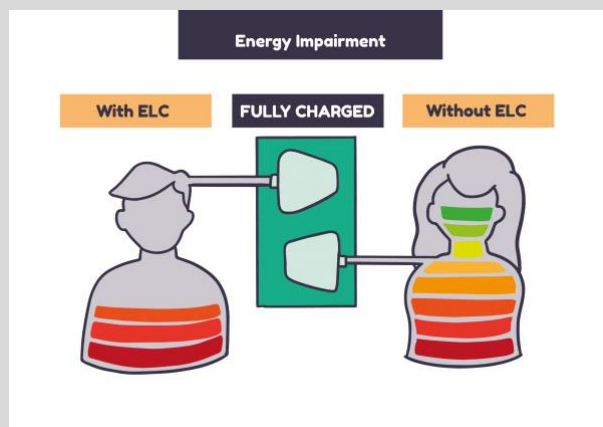
- Health and Social Care
- Equality, Diversity and Inclusion

Methods: Online workshops with 14 medical and allied health care professionals facilitated by Healing Justice London. The wider project included a series of creative workshops for women and people of marginalised genders, with ELC. Synchronous and asynchronous options were available for all workshops.

Geographical area: UK-wide

Research stage: Completed

***About Energy Limiting Conditions**



*Energy Limiting Conditions (ELCs), also called Energy Limiting Chronic Illnesses (ELCI), include neurological, musculoskeletal and auto-immune diseases, ME/CFS, fibromyalgia and Long Covid, amongst others.

They involve energy impairment and debilitating fatigue that affect every part of people's lives.

Image by Nifty Fox for Chronic Illness Inclusion, used with permission.

Summary of the research

Our collaborative research project asked 49 participants with ELC and 14 medical and associated health care professionals to imagine a better future of health and social care for people with ELC. Our [previous research](#) has shown that many people with ELC experience barriers to getting the support they need from health and social care services. Disbelief and disregard of lived experiences is often central to these problems. Sexism, racism, homophobia, transphobia, Islamophobia and other forms of oppression also limit access to equitable and effective health and social care. We want to dismantle these barriers and help improve services for people with ELC.

We facilitated a series of online artist-led workshops for people of marginalised gender (women, trans men, non-binary, intersex and gender nonconforming people) who live with ELC. Dedicated workshops were held for Muslim women, and for LGBTQIA+ people. Workshop participants and artists co-created new work including a podcast, comic books, zines, art and creative writing.

We also held online workshops with 14 medical and allied health care professionals (subsequently referred to as healthcare professionals/HCPs): 4 doctors in a range of specialities, 2 medical students, 1 NHS mental wellbeing practitioner, 3 trainee counsellors, 1 dietitian, 1 physiotherapist, and 2 alternative health practitioners. These workshops explored participants' experiences of supporting patients with ELC and their suggestions for service improvement. This policy brief draws on this work with HCPs, though many of the recommendations are similar to those suggested by people living with ELC.

Key findings

HCPs we spoke to are committed to providing the best possible care for all their patients, including those with ELC. However, they identified a number of structural and attitudinal barriers to providing good care:

1. A lack of time and continuity in primary care meaning HCPs can only deal with the immediate issue rather than seeing this in context of chronic conditions:

“As a GP I'm still assigned 10 min appointments for all my patients. ... And there's not a lot of continuity. And if I want to take the time and take a minute to find out who that patient is, for somebody that has a lot of history around their own illness already, ...it takes more than a minute to really unpick that and develop that understanding of a person's life and how things impact them. ...There's a paucity of time throughout, across the board, particularly in primary care, particularly in general practice, which is often the first place of contact that people with energy limiting conditions come to.” (GP)

2. HCPs acknowledged that they may act as a barrier or gatekeeper to NHS (limited) resources. Medical education and training often prioritises conditions with an 'objective' measure as the basis for a clear diagnosis and treatment pathway. HCPs often want to help but don't know how to. They are not routinely trained to manage illness / experiences that can't be measured, and don't always feel comfortable dealing with uncertainty. An emphasis on “fixing” can come at the expense of listening to, supporting and advocating for patients who live with poorly understood complex chronic conditions and co-morbidities. The desire for a solution, or cure, needs to be challenged in medical education to train HCPs to recognise the value of validation and understanding in the absence of treatment for people with ELC. One GP told us:

“My experience of the medical profession is that it's quite judgmental. ... It's designed to be very objective about an entirely subjective human experience of life. We have very clearly defined boxes, and we have observations that we use as parameters to measure things But we're not good in the things that we can't measure, or we don't know how to investigate. And personally, I find it very frustrating, and I almost feel a sense of incompetency to some extent, as a healthcare professional.

... But the more I practice, the more I recognize that what I can offer patients isn't necessarily a medicine ... care comes in in lots of forms, in terms of listening skills and meeting a patient where they're at, you know, finding out what it is that's going on for the patient at that moment in time." (GP)

3. Medical education also reproduces ingrained attitudes that encourage HCPs to disbelieve patient's accounts if there aren't corresponding biomarkers. Conditions that are rare, hard to diagnose or are chronic in nature represent a challenge to these conventions:

"medicine is so geared towards critical analysis of people's narratives and kind of a disbelief. And there's kind of positivism, ... if there's nothing on a scan, then it's not real, you know, that kind of history. ... When we get taught to take histories, there's a very particular way in which we expect people to structure what information they give us. And then, if they don't give it in that way, they get labelled things like an unreliable narrator, you know, or an unreliable historian. ... if there's not a matching investigation that explains the condition then it just doesn't exist. Basically, if we can't see it, it's not real." (Doctor, psychiatrist)

4. Long delays in diagnosis and dismissal of symptoms can lead to distrust and there is a need for additional time in secondary, as well as primary care to rebuild relationships.

"the people that I see in clinic, quite often they've been through years and years and years of investigations and going around different doctors, and by the time they get to [my specialist] clinic where we are kind of taking what we do is kind of integrative approach, ... they are so frustrated, they're so sad. And quite often I've had people just not expect that I will listen to them because they're so used to it." (Specialist doctor)

5. The HCPs in our workshops recognised that the health system can be difficult to navigate with lots of bureaucratic barriers compounded by administrative delays within the NHS itself. This exacerbates the problems of disconnected care. One person said that the "health system is designed for healthy people". Missing an appointment due to fatigue, lack of transport, caring responsibilities or because of poor communication from the NHS can mean losing access to other services and if someone disengages with services, the 'fault' is often assumed to be with the patient rather than the system:

"There's just so many hurdles, and I think if you've actually got, other pressures in your life which many people do, precarious work or caring commitments, and energy limiting conditions, the chances of actually managing to get through all the hoops is almost impossible. Which is ironic, the health service is basically designed for healthy people, it's not designed for anyone who's actually got an impairment. But instead of kind of saying, 'Oh, wow! We need to kind of do things differently', the tendency is, if someone then doesn't engage, it's kind of on them. It's like, Oh, well, we can discharge them now, they're not interested in the help we've tried to offer them, we did our best." (Doctor, psychiatrist)

6. Whilst there is recognition that patients with chronic conditions need to be supported to find ways to live well with those conditions, participants reported that CBT (Cognitive Behavioural Therapy) has often become the only therapy patients can access through the NHS. Contracts are often given to services who employ people trained only in CBT only, meaning if other forms of therapy might be better suited for the patient, that is not possible to provide. There is recognition this is not always appropriate for people with ELC and can actually cause harm. This is frustrating and demoralising for those having to deliver these services. Shortages in resourcing and funding means additional training isn't available:

"We're trained in CBT, and I think there are potential limitations that CBT can offer people with ELC or Long Term Conditions in general. Especially when it comes to a lot of the thought work we do in CBT, it's a lot about like cognitive, restructuring, thought challenging, which can come across as being

invalidating like saying, 'have you tried thinking of it a different way?' And in the sessions you can hear yourself potentially sounding, invalidating. And you're like, 'wait, am I, am I gaslighting you right now?' But like it's the only kind of tool we have in the toolbox. I know there's a lot of research looking at how great or how much better acceptance and commitment therapy (ACT) is for people with long-term health conditions. And I have often thought or fed back that it would be so great if we could get some training on ACT in relation to chronic health conditions, but the funding's not really there to make that happen." (NHS mental wellbeing practitioner)

7. Despite the shortcomings of CBT mentioned above, patients are often referred back to the service multiple times, because it is the only option. Targets set for patient recovery mean that patients who don't 'recover' become a 'risk to the service's data' and are discharged or encouraged to seek help privately elsewhere. People in most need are therefore not 'held' by services and can be labelled as 'revolving door patients':

"Because the service needs to show that they are meeting a certain recovery rate to be able to get funding from the Clinical Commissioning group if someone keeps getting referred back to us, you know, maybe even multiple times in the same year, and we're so limited in what we can offer people ... at a point we just we just stop offering it. ... we might say, OK, we have to accept this referral, but can you encourage this client after 2 sessions to going for some low-cost counselling instead, because, it doesn't make sense to keep them on our books. And from the patient's perspective, we could say 'this isn't working for you, so why should we keep trying to make it work for you because it's a waste of your time as well', but it is awful at the same time to get rid of people in that way." (NHS mental wellbeing practitioner).

8. HCPs recognised that it is essential to have an intersectional understanding of how healthcare operates. Systemic and historical racism, Islamophobia, misogyny, homophobia, fatphobia, transphobia and other assumptions can all impact patients' experiences. One participant told us: "medicine operates within society and everything that is wrong with society is wrong in medicine." However, they also said that education for HCPs doesn't train them in how to consider intersectional forms of marginalisation that patients may be facing. In this context, some HCPs we spoke to said that the NHS's approach to reaching marginalised people can be quite exploitative and top down, rather than co-operative, properly resourced and led by communities:

"NHS professionals go let's do a focus group. No, let's not do a focus group, actually, let's not do that. Why don't you give us the money that you want to spend on a focus group, us being the community, the stakeholders in the community. We'll create the space and we'll invite you to come and listen. How about we do it that way around." (Trainee counsellor)

9. The HCPs we spoke to said that often the problems people are experiencing are problems related to housing, care, and poverty and that a much more integrated and multidisciplinary approach to health and social care is needed to address these problems and support people with ELC to live as well as is possible given their condition:

"I want to start moving away from medicine being the only thing that people feel like they can turn to when they have energy limiting conditions. ... There are so many other parts of someone's life that are interconnected with how their body feels. ... You should have access to the highest quality research and specialists, but they're also not the only specialist that exists. There are specialists in social care, there are specialists in physiotherapy and specialists in mental health and all the other things that sort come along with that experience, in housing and all of these things." (Final year medical student)

Policy recommendations

- **Advocate for more resources** including more time for GPs to spend with patients and more specialist staff and services to support people with ELC. Continuity of care is also important and needs resourcing. An intersectional approach should always be taken which recognises individual differences and barriers to health and social care services.
- **Education and Training** around ELC is vital, and should be included at all levels of training, including medical school curriculums and professional development. Modelling of listening and believing patients by senior doctors to junior and training doctors should be part of this. Expertise and awareness should be shared through staff networks and clinical leads interested in ELC.
- **Patient Involvement** should be built into the system throughout. Consider how people with lived experiences of ELC can meaningfully contribute to medical education and patient liaison groups. There is a need to acknowledge a breakdown of trust and a clear intention to build understanding around ELC.
- **Move away from purely biomedical modules.** Conceptualisation of ELC needs to change because there is not always a known identifiable organic cause for symptoms. There is a need for a paradigm shift away from “fixing” and curing” to supporting quality of life for people with ELC. Build a culture that can deal with uncertainty and values listening and advocacy not just a quick fix.
- **Specialist services** need to be developed for people with ELC. There needs to be clear information and guidelines around what support can be provided to people with ELC. This should include a range of appropriate therapies and not rely solely on CBT or graded exercise therapy which does not work for all.
- **A Multidisciplinary approach**, alongside those specialist services, will provide the best support. We need to work to develop a joined-up approach for people with ELC involving health and social care alongside housing, welfare and third sector services working. There should also be recognition that employment is not always possible and benefits should not be contingent on economic activity.

Further information

- Project website: <https://disbeliefdisregard.uk/ahrc-project/>
- Policy Briefs and Reports from previous project, including one on including people with ELC in patient and public engagement / involvement: <https://disbeliefdisregard.uk/resources/#policybriefs>
- A medical evaluation toolkit for use in training: <https://disbeliefdisregard.uk/resources/>

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