



Deposited via The University of Sheffield.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/id/eprint/206486/>

Version: Published Version

Article:

Blenkinsop, S., Wardrope, A., Willis, J. et al. (2024) Climate change: attitudes and concerns of, and learnings from, people with neurological conditions, carers, and health care professionals. *Epilepsia*, 65 (1). pp. 95-106. ISSN: 0013-9580

<https://doi.org/10.1111/epi.17824>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here:

<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

RESEARCH ARTICLE

Climate change: Attitudes and concerns of, and learnings from, people with neurological conditions, carers, and health care professionals

Stephen Blenkinsop¹  | Alistair Wardrope^{2,3}  | Joseph Willis⁴  | Sanjay M. Sisodiya^{4,5} 

¹School of Engineering, Newcastle University, Newcastle Upon Tyne, UK

²Sheffield Institute for Translational Neuroscience, University of Sheffield, Sheffield, UK

³Department of Neurology, Sheffield Teaching Hospitals National Health Service Foundation Trust, Sheffield, UK

⁴Department of Clinical and Experimental Epilepsy, University College London Queen Square Institute of Neurology, London, UK

⁵Chalfont Centre for Epilepsy, Bucks, UK

Correspondence

Sanjay M. Sisodiya, Department of Clinical and Experimental Epilepsy, University College London Queen Square Institute of Neurology, London WC1N 3BG, UK.

Email: s.sisodiya@ucl.ac.uk

Funding information

Epilepsy Society; Health Education England/NiHR Academic Clinical Fellowship; Natural Environment Research Council, Grant/Award Number: NE/R01079X/1

Abstract

Objective: Concern about climate change among the general public is acknowledged by surveys. The health care sector must play its part in reducing greenhouse gas emissions and adapting to a changing climate, which will require the support of its stakeholders including those with epilepsy, who may be especially vulnerable. It is important to understand this community's attitudes and concerns about climate change and societal responses.

Methods: A survey was made available to more than 100 000 people among a section of the neurological community (patients, carers, and clinicians), focused on epilepsy. We applied quantitative analysis of Likert scale responses supported by qualitative analyses of free-text questions with crossover analyses to identify consonance and dissonance between the two approaches.

Results: A small proportion of potential respondents completed the survey; of 126 respondents, 52 had epilepsy and 56 explicitly declared no illness. The survey indicated concern about the impact of climate change on health within this neurological community focused on epilepsy. More than half of respondents considered climate change to have been bad for their health, rising to 68% in a subgroup with a neurological condition; over 80% expected climate change to harm their health in future. Most (>75%) believed that action to reduce greenhouse gas emissions will lead to improved health and well-being. The crossover analysis identified cost and accessibility as significant barriers.

Significance: The high level of concern about climate change impacts and positive attitudes toward policies to reduce greenhouse gas emissions provide support for climate action from the epilepsy community. However, if policies are implemented without considering the needs of patients, they risk being exclusionary, worsening inequalities, and further threatening neurological health and well-being.

KEYWORDS

extreme weather, global warming, heat waves, neurology

Stephen Blenkinsop and Alistair Wardrope contributed equally to this work.

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Epilepsia* published by Wiley Periodicals LLC on behalf of International League Against Epilepsy.

1 | INTRODUCTION

The climate emergency is undermining human health, directly—through more frequent and more severe extreme weather events, rising sea levels, and droughts—and indirectly, through biodiversity loss, food and water insecurity, and resulting socioeconomic pressures.^{1,2} Human activity has resulted in warming.³ The UK experienced its warmest year on record in 2022,⁴ seeing mean summer temperatures 1.1°C higher than the 1991–2020 average and a new record UK temperature of 40.3°C⁵ during a 16-day period recording 2227 excess deaths.⁶

In 2019, the UK government⁷ set a legally binding target for at least 100% reduction of greenhouse gas emissions (compared to 1990 levels) in the UK by 2050.⁸ In 2020 the UK National Health Service (NHS) declared its intent to reduce carbon emissions to net zero by 2040 for the emissions it controls directly, and 2045 for those it has the ability to influence.⁹ These targets require significant effort from patients, health care providers, and NHS suppliers; such engaged action necessitates understanding current stakeholder views around climate change and potential responses.

Nervous system diseases are a leading cause of disability and death, contributing significantly to societal inequalities worldwide.¹⁰ Climate change may pose a particular risk for people with neurological diseases.^{11–13} We present the results of a survey aimed at people with neurological conditions, their carers, and health care professionals, to gain an understanding of current perceptions of climate change, its impacts, and potential responses among these stakeholders.

2 | MATERIALS AND METHODS

2.1 | Questionnaire development

To benefit from a population normative sample, we obtained permission to use the Department for Business, Energy, and Industrial Strategy (BEIS) survey on Climate Change and Net Zero: Public Awareness and Perceptions,¹⁴ which we modified, removing questions of less relevance to our target population, and incorporating validated questions from previous surveys of patient/physician attitudes toward climate change and health.^{15–19} All questions identified in our review, and details of those that were included and that were excluded, are summarized in Appendices S1 and S2.

We piloted the draft survey among a group of clinicians, carers, and patients, following which questions were edited for relevance and intelligibility, and sought postdistribution feedback on usability from a subset of

Key Points

- People with neurological conditions, focusing on epilepsy, are concerned about climate change
- Most survey respondents believe climate mitigation actions will lead to improved health and well-being
- Care is needed to ensure climate actions do not aggravate health-related inequalities
- Lived experience of people with epilepsy may inform adaptation for broader populations, for example, managing with public transport only

respondents with expertise in different neurological conditions (see Section 4 below).

2.2 | Respondents

The survey was anonymous, with all answers hosted on a secure university account. We made the survey available online to staff and student members of the UCL Queen Square Institute of Neurology, linked neurological charities, and social media accounts of the UK Epilepsy Society and the International League Against Epilepsy, with an estimated circulation across these groups of >100 000. The survey was open from June 13 to August 9, 2022, encompassing the record-breaking temperatures in the UK. In total, 126 survey responses were received.

2.3 | Analysis

2.3.1 | Quantitative analysis

Most questions elicit 5-point Likert scale responses. Accumulated percentage totals are reported for each question for overall "negative/low" (responses 1, 2), "neutral/medium" (response 3), or "positive/high" (responses 4, 5) outlooks. Total percentages may not sum to exactly 100% due to rounding.

2.3.2 | Qualitative and crossover analysis

We performed qualitative analyses for three free-text questions: "What do you think will be the biggest risks of climate change for people with your neurological condition, or that of the people you care for?" (Appendix S1; Q13); "If you said that you oppose the net zero target, in a few words please tell us why you are opposed?" (Q18);

and “What do you think the biggest effect of society's response to climate change will be for people with your neurological condition, or that of the people you care for?” (Q33). The first two, inviting shorter answers about specific concerns, underwent relational content analysis, exploring the frequency and relationship between issues raised. Acknowledging our existing theoretical prefiguration derived from extant climate and health literature, we conducted a directed analysis with initial content labels from previous studies, with iterative revision in light of data.²⁰ The last question invited more open responses, studied using thematic analysis,²¹ identifying themes within a reflexive and contextualist framework.

To integrate our qualitative and quantitative data, we conducted quantitative-dominant crossover analyses. This process involves “quantizing” qualitative data by mapping free-text content or themes to answers in the quantitative survey questions, and counting the occurrence of these survey question answers within the qualitative responses. Counts of responses endorsing items in qualitative and quantitative questions can then be compared, looking for consonance and dissonance. We performed qualitative-dominant crossover analyses by treating survey responses qualitatively, considering all the questions themselves as qualitative data. This allows identification of what content or themes in the free-text qualitative answers are not present in quantitative responses, identifying quantitative silence of the survey to address issues of concern to respondents.²²

2.4 | Ethical and regulatory approval

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

The work was undertaken as part of an approved, registered NHS service evaluation at University College London Hospital (62-202122-SE). The survey posed minimal informational and psychological harms to participants; following best practices, it did not require external ethical review.²³

3 | RESULTS

Respondents could optionally provide additional personal/demographic information by responding to 11 questions, listed in Appendix S1 and summarized in Figure S1. Due to limited sample sizes, we only segmented results based on whether respondents reported having a long-standing illness (Question 11: “Do you have any long-standing illness, disability, or infirmity that limits your normal day-to-day activities?”). We opted to use the self-defined “illness,”

rather than specific medical disease diagnosis, because (1) the reference BEIS survey used this question; and (2) the focus of this project is on the personal and social sequelae of climate change and policy on people's lives; for this, “illness”—the subjective lived experience of poor health—is more relevant than “disease”—the description of bodily phenomena in terms of biological dysfunction.²⁴ Sample sizes were insufficient to analyze further specific subgroups of this community, for example, comparing the responses of patients, carers, and clinicians separately using responses to Question 1 (“I am...”); see Table S1 for details of responses. Quantitative survey responses were therefore only analyzed for the whole sample and for the two subsamples (“Do you have any long-standing illness...?": “yes or no”). In all, 63 of 126 respondents reported a long-standing illness; of those, 57 of 63 indicated explicitly that they were referring to a neurological condition, most commonly epilepsy (52 respondents; see Appendix S2 for a full breakdown of diagnoses), with six respondents providing no response. Of those identifying themselves as having a long-standing illness, therefore, 83% explicitly referred to epilepsy, and so the responses of this subsample primarily represent this community. Of those who did not report a long-standing illness or disability (63/126), 56 explicitly reported no long-standing illness and seven preferred not to say. We present results for these three groups referred to as All, Illness, and No-illness; the results discussed reflect the All population, unless differences between Illness/No-illness subgroups are substantial, in which case these are explicitly presented.

3.1 | General attitudes to climate change

Respondents considered that climate change is occurring (Q1), only one respondent disagreeing. Respondents expressed concern about current climate change (Q4), 90% reporting a high and 3% a low level of concern. As in previous surveys,¹⁴ climate change was perceived to be affecting other countries more than respondents and their locality (Q2); 56% agreed/strongly agreed that climate change is affecting “You and your family,” rising to 93% for “People in other countries” (Figure 1). However, when asked whether climate change will affect “You and your family” (Q3), 88% responded affirmatively, indicating perceived increased future risk.

3.2 | Health risks

3.2.1 | Quantitative

Most respondents were worried about climate change's health effects (Q5: 78%). More than half considered climate

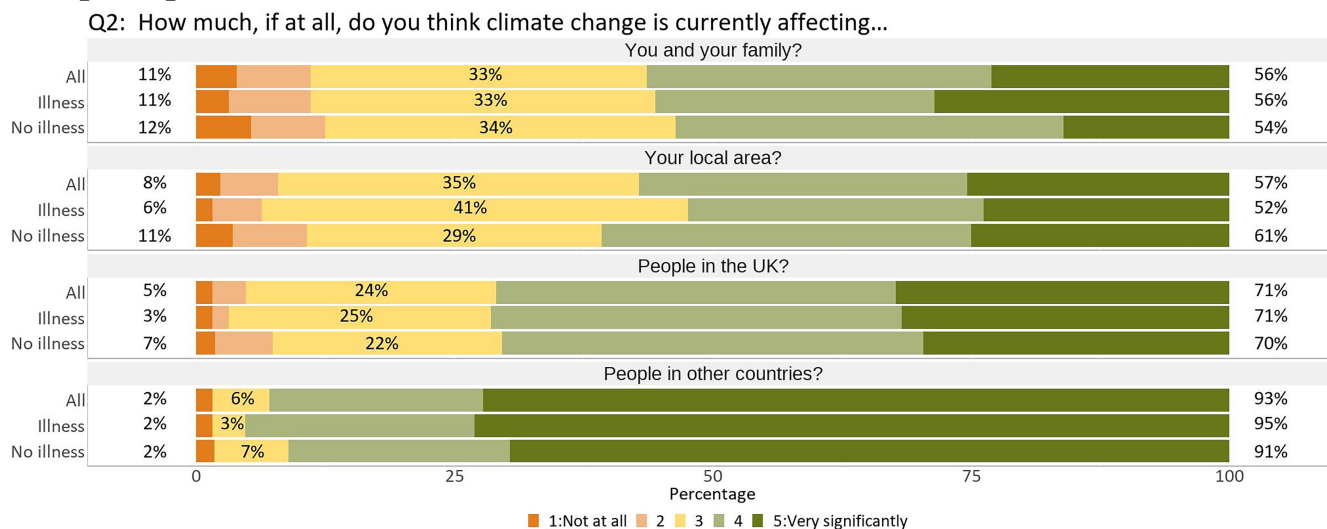


FIGURE 1 Responses to the question, "How much, if at all, do you think climate change is currently affecting...." The number of responses for each subquestion was 126, 126, 124, and 126 (all responses, top to bottom panels).

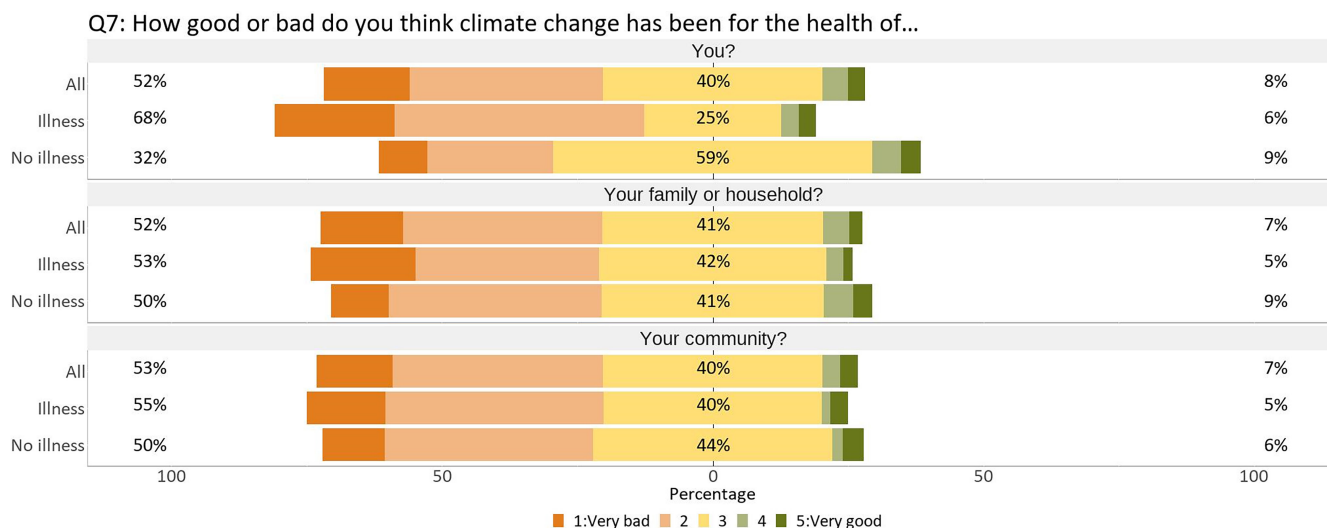


FIGURE 2 Responses to the question, "How good or bad do you think climate change has been for the health of...." The number of responses for each subquestion was 126, 125, and 121 (all responses, top to bottom panels).

change to have been bad for their/their community's health (Q7; Figure 2); this figure was 68% in the Illness group compared with 32% in No-illness. Fewer than 10% believed climate change to have positive health impacts. However, only 16% reported discussing effects of environmental issues on their health with their doctor (Q6), slightly higher in Illness versus No-illness (21%/13%). The proportion who thought climate change would have a negative effect on health in the next 5–10 years rose to ~80% (Q8; Figure 3), consistent with the Intergovernmental Panel on Climate Change (IPCC)'s summary that there are very few examples of beneficial health outcomes from climate change.²⁵

Respondents were asked to what extent they thought nine different effects of climate change might impact

on people's health in general (Q11) and, in particular, the health of people with neurological conditions (Q12; Figure S2). For all nine effects, most respondents identified a big or very big impact for both questions, especially for changes in extreme weather and illness due to extreme heat. Focusing on those with a long-standing illness resulted in a slightly higher proportion of respondents identifying a big or very big impact on access to health care and medicines. More than three quarters considered there to be an above-moderate likelihood that their health or that of their family will be harmed by heat waves in the next 5 years (Q9; higher in the Illness than No-illness group: 84%/70%), broadly consistent with concern about the effects of heat waves (Q10; Figure 4).

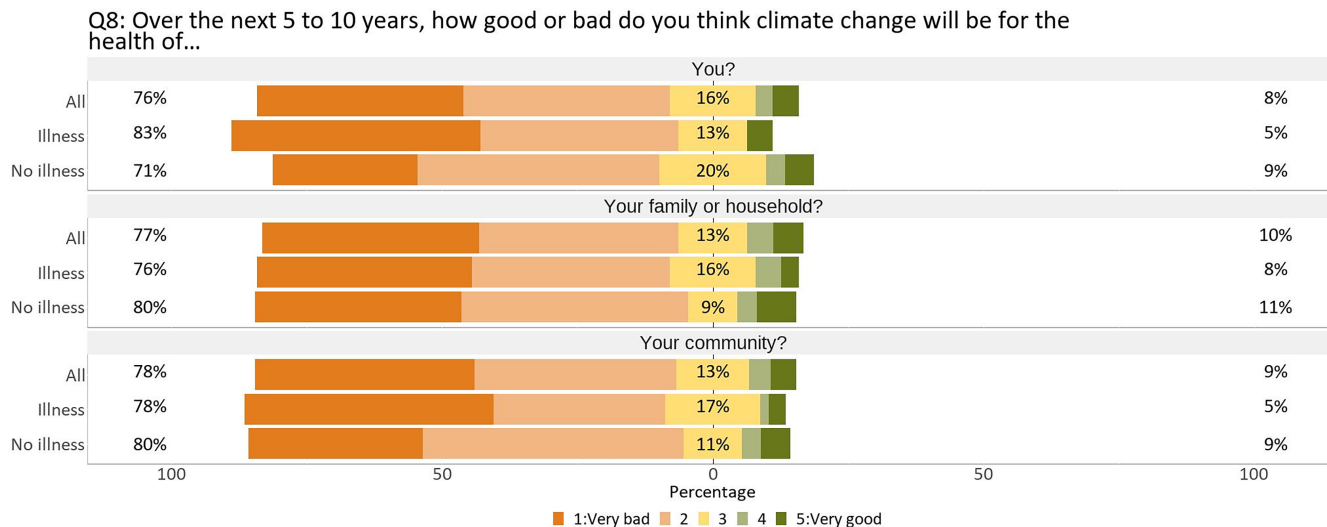


FIGURE 3 Responses to the question, "Over the next 5 to 10 years, how good or bad do you think climate change will be for the health of..." The number of responses for each subquestion was 126, 125, and 126 (all responses, top to bottom panel).

3.2.2 | Qualitative

We asked "What do you think will be the biggest risks of climate change for people with your neurological condition, or that of the people you care for?" There were 91 answers. Respondents expressed concern about a range of specific health concerns (e.g., effects of extreme heat [40 respondents], access to health care [18 respondents], or medicines [14 respondents]), related to a range of neurological and psychiatric conditions such as epilepsy (26 respondents), mental health disorders (seven respondents), and multiple sclerosis (two respondents). Respondents were more concerned that climate change would worsen control of existing neurological disease (35 respondents) than cause new disease (two respondents). Three respondents rejected links between climate change and health in general, or in the UK context.

3.2.3 | Crossover analysis

There was consonance between qualitative and quantitative results, the highest rated concerns being extreme heat and access to medicines and health care, with only a small minority reporting no or minimal health risk posed in the UK by climate change.

Qualitative responses highlighted areas of silence, respondents identifying threats such as health risks posed by forced migration or of enforced climate adaptation strategies. Several respondents identified the potential for climate change to exacerbate preexisting vulnerabilities, such as heat waves differentially affecting those with impaired thermoregulation, or interacting with other homeostatic mechanisms or diurnal rhythms. The

quantitative questions did not highlight how climatic and nonclimatic factors may interact synergistically to leave some people especially vulnerable (e.g., a person with impaired thermoregulation who has limited access to environmental temperature control due to poverty, and limited options to move to cooler environments due to impaired mobility, is particularly vulnerable to heat waves from the combination of these factors in a way that is likely more significant than the sum of the individual factors), nor interactions between different health threats.

Table 1 gives illustrative quotations from the qualitative responses that elaborate on, or demonstrate silence of, quantitative data.

3.3 | Policy responses to climate change

3.3.1 | Quantitative

Fifty-three percent of respondents indicated a high level of knowledge about the net zero concept (Q14), with most supporting the UK's net zero target (Q17: 86%). Most considered it unlikely, however, that the NHS would achieve its net zero target by 2045 (Q15; 53%; ~40% considered this neither likely nor unlikely). Q19 and Q20 both indicate recognition that all parts of society have a responsibility to reduce carbon emissions, but that government and business/industry bear most responsibility; for Q19, 80% indicated a high score for the general public, rising to 95% and 96% for government and business/industry, respectively.

Approximately one third agreed substantial lifestyle changes are needed to address climate change, with more

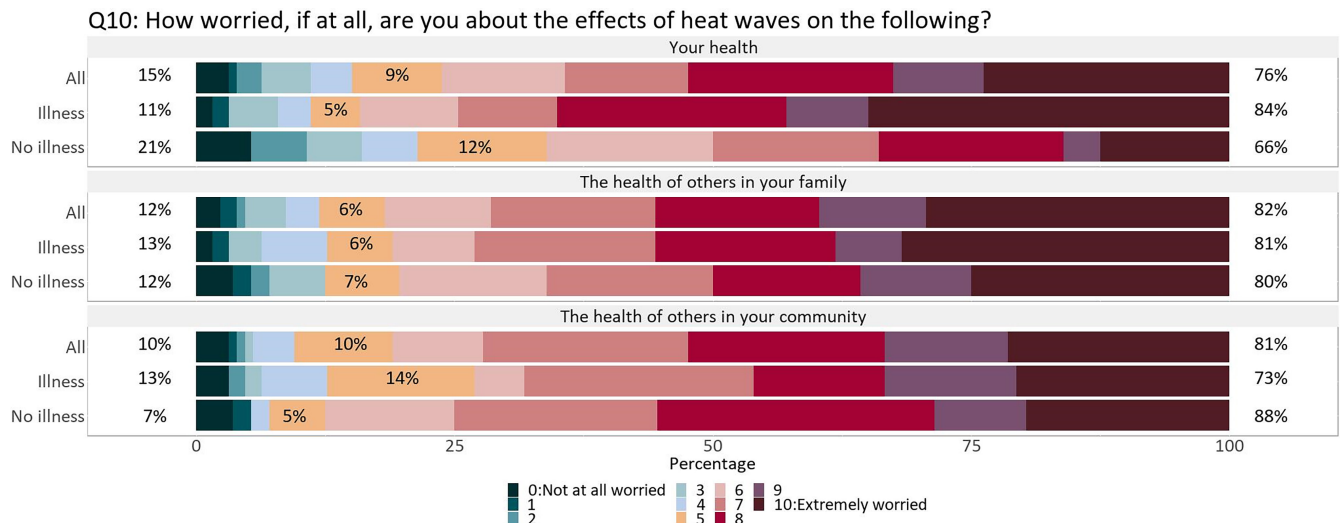


FIGURE 4 Responses to the question, "How worried, if at all, are you about the effects of heat waves on the following?" The number of responses for each subquestion was 126 (all responses). Note the use of an 11-point scale for this question.

than one half disagreeing (Q21), according with lesser responsibility allocated to the general public (Q19, Q20). Respondents were more unsure about roles for technology, with approximately one quarter agreeing it will help reduce most of our emissions, whereas >40% disagreed; approximately one third neither agreed nor disagreed. Sectors rated as contributing most heavily to UK emissions (Q22) were transport (87%) and heating/cooling of homes/commercial buildings (75%). Surprisingly, given previous questions (Q19, Q20), a majority (53%) gave a low score to manufacturing industries. When asked to select up to three responses to tackle climate change (Q23), the most common related to transport; ~20% of selected options were to use alternatives to car travel and ~15% to avoid/minimize air travel. Respondents viewed most carbon mitigation policies positively (Q27); only greener diets (49%) and greener industry (59%) produced higher proportions of negative than positive responses.

Respondents considered improved energy efficiency the most likely of offered actions to happen over the next few decades (Q24) and were less likely to expect changes related to food, either reduced meat consumption or reduced food waste. In the next 6 months (Q25), a majority of respondents were likely to adopt lifestyle mitigation changes, except "buy an electric car" and "switch from gas central heating to an alternative," decisions influenced most by cost and availability/accessibility options (Q26).

3.3.2 | Qualitative and crossover

We asked opponents of net zero targets to explain their reasons. Sixteen answered. Consonant with quantitative results, most reasons related to skepticism regarding the

ability of UK policy to achieve its goals (10 respondents), rather than opposition to the objective (six respondents). Reasons for direct opposition included economic cost, including opportunity cost (three respondents); direct harmful effects of certain technologies, including disproportionate burdens placed on people with disabilities (two respondents); and lack of positive effects of net zero policy (two respondents).

Consonant with quantitative data (Q15), respondents were pessimistic about net zero policy because of concerns regarding likelihood of success, due to inadequate technology (three respondents), or government/industry failure (six/two respondents, respectively) to adhere to targets; and because of belief that the net zero target was insufficiently ambitious or stringent (three respondents). In the quantitative survey, people assigned greater responsibility to industry than to government failure, but in response to this question more reference was made to inadequate government action, an apparent dissonance explained by the respondents' highlighting the interrelationship of the actions of these two parties, respondents believing that government regulation is a necessary step to achieve business action on climate change.^{26,27}

Illustrative quotations are given in Table 1.

3.4 | Health effects of climate change mitigation policy

3.4.1 | Quantitative

Most respondents perceived benefits of achieving net zero for health and well-being (Q16), with >70% thinking it would produce improvement. Although 57% also

TABLE 1 Illustrative quotations from content analysis of Q13 and Q18, demonstrating points of dissonance with or silence of quantitative survey data.

Question	Content	Illustrative quotation
Q13. What do you think will be the biggest risks of climate change for people with your neurological condition, or that of the people you care for?	Worsening of existing disease	People with damage to myelin around their nerves (such as myself) can be effected [sic] quite badly by increases in temperature, such as heat waves. High temperatures have always been a trigger for my seizures. Possible seizure due to lack of sleep ... Extra worry ... causing stress which may cause a seizure.
	Causing new disease	Increased risk of developing neurological condition.
	Rejection of association between climate and health	The usual cold damp weather and dark winter days in the UK have been and will always be a bigger risk to people's health than a few extra warm days in summer.
	Health risks of climate adaptation	The built environment needs to be adapted for greater ventilation and cooler buildings; however, circulating fans also trigger my seizures.
Q18. If you said that you oppose the net zero target, in a few words please tell us why you are opposed?	Specific vulnerabilities and intersectional risks	People with neurological conditions sometimes cannot regulate their temperature properly, this means that climate change, which causes temperature/weather to be more extreme can have a huge impact on them, and unless they are being cared for they may not be able to do anything about it.
	Disproportionate burdens placed on people with disabilities	Disable [sic] people need some things that aren't climate friendly.
	Opportunity cost	National Grid have estimated that decarbonizing the grid in the UK will cost 2 trillion pounds over 30 years. If the goal is to improve people's lives there are almost certainly better things the money could be spent on.
	Lack of positive effects	Even if the UK hits the target it will have approaching zero impact on what is a global problem.
	Government regulation needed to drive industry change	Action should have been taken earlier with more stringent requirements on business.

perceived a benefit to the economy in achieving net zero, a larger proportion considered it would have a negative economic effect (14%) than negative health effect (7%). Respondents overwhelmingly expressed desire to see more action on global warming to protect people from health problems (Q28), by business and industry (>95%) and the general public (87%). In all cases, >50% of respondents expressed the opinion that all groups should be doing much more. Typically, most respondents felt their neurological condition did not affect their ability to take actions against climate change (Q30), and a majority felt it made alternatives to driving easier (55%), which is important because some people with neurological conditions are not permitted to drive. Most also felt taking most of these actions would not affect their neurological condition

(Q31). They indicated that of actions taken across society to reduce emissions, most would have a positive health consequence (Q32). Two actions were, however, considered to have a negative effect—more eco-friendly land use (61%) and more greenhouse gas removal technology (59%)—which are more difficult to explain.

3.4.2 | Qualitative

We asked respondents, “What do you think the biggest effect of society’s response to climate change will be for people with your neurological condition, or that of the people you care for?” We received 76 responses. Through contextualist thematic analysis—preinformed by existing

TABLE 2 Thematic analysis of responses to question on biggest effects of response to climate change on people with neurological conditions.

Theme	Subthemes	Examples
Harm prevention		Positive impact on global warming, fewer climate-related issues such as heat waves, improved air quality. ^a
Health co-benefits	Transport	I hope that there will be much more public transport options, which will benefit those with epilepsy who are unable to drive. ^b
	Diet	Especially with neurological conditions we should look to the connections between the gut and the brain more, and consider what we consume, the quality of what we consume and so encourage individuals to eat organic/free-range produce that is within this country, therefore lower carbon footprint and also better for ourselves. ^b
	Mental health	A reduction in climate-related anxiety and allowing limited resources to be available for more people in need. ^a
Harmful side effects	Transport	The expectation to cycle/walk everywhere would mean epilepsy sufferers would need to change lifestyle to accommodate that extra physical stress on the body on top of everyday activities including daily exercise. ^b
	Built environment	I am also being increasingly excluded from society and all public spaces. ^b
	Cost	The additional cost of making changes may mean that they do not have money for other things to support their health. That the additional stress of money will then in turn impact their health. ^a
	Diet	Plant-based food 75 different ingredients a lot of it is GM-based no thank you. ^a
	Loss of access to resources	Harder to access/use medical appliances and products like hoists and single use products. ^b
(In)equity	Social	Society's response may work for the general public, but would most likely forget about people with any type of chronic condition/disability. ^b
	Economic	We need better wealth distribution for any of this to help. It's all good speaking about the general public but it is the richer, more plane-using few who are causing the biggest issue. ^a
Pessimism		Apathy will lead to zero change and worse outcomes. ^a

^aResponses concerning population-wide effects.

^bResponses concerning effects specific to people with certain neurological conditions.

conceptualizations of health and climate change among clinicians and academics¹ we identified five themes, with additional subthemes (Table 2). Two cross-cutting themes ran through all; some respondents focused on disease-specific health effects, whereas others were concerned with more general effects; and some emphasized personal responsibility or mitigation and adaptation action, whereas others focused on structural determinants of climate policy.

3.4.3 | Crossover

Qualitative responses were largely consonant with quantitative questions, with low expectations for the possibility of technological solutions, and a greater emphasis on lifestyle changes. The biggest barriers to participation in mitigation actions were considered to be cost (seven responses) and accessibility (nine responses). Qualitative answers elaborated on the reasons, suggesting people with disabilities or diseases may not be able to participate

in carbon-reduction behaviors to the same extent (e.g., through needing to use consumables such as single-use medical devices, or greater dependence on high-carbon transport). Respondents highlighted that some people with neurological concerns have specific dietary requirements (e.g., ketogenic or modified Atkins diets); this may provide a tension with a move to plant-based diets, consonant with the greater skepticism regarding switching to plant-based diets in the Illness group in Q22.

A recurrent concern from the qualitative responses, regarding which the quantitative survey was relatively silent, is that of equity and intersectional threats posed by climate change and climate policy. Respondents noted mitigation policies might support people with neurological conditions, or further exclude them from social participation. They also noted that different threats may combine—for example, rising temperatures combined with public transport dependence might create conditions less hospitable for some people with long-term conditions.

4 | DISCUSSION

The effects of climate change are pervasive. An editorial published simultaneously in 2021 across 233 medical journals around the world raised concerns about impacts on health and biodiversity, calling for urgent action,²⁸ with further recent calls for neurologists to educate themselves about climate change.^{11,29,30} Although we must strive to limit climate change as our primary goal, we are already committed to changes in the global climate; it is therefore imperative that adaptation to a changed climate occurs alongside accelerated mitigation efforts. Learning about climate change, research into climate impacts, and actions to take in relation to neurological diseases now form part of the neurological community's duty of care. Building support for climate action requires understanding current attitudes and concerns. Our results highlight deep concern about the impacts of climate change on neurological conditions among people with such conditions (primarily epilepsy in our targeted study), carers, and neurological professionals, with considerable thought about appropriate, feasible responses and their consequences. To respond to climate change and avoid aggravating existing inequalities, such views must be taken into account in management strategies and future policy formulation, especially given that neurological conditions are the leading cause of reduced disability-adjusted life-years and second leading cause of death.

Our results show this community desires widespread action, especially led by government and industry; however, there is also concern about unintended consequences of climate policy. Concerns are greater when people report their attitudes toward future impacts of climate change. A particular worry from the survey, requiring additional exploration, is heat waves—acute manifestations of climate change, which are already affecting the population of the UK³¹ and in Europe are known to cause thousands of excess deaths, disproportionately among those with vulnerabilities such as chronic illnesses.^{32–34}

High levels of concern over climate change are broadly consistent with those found in surveys of the general public. In the UK, 83% expressed concern over a similar period to our survey³⁵ and a survey in EU member nations over 2021–2022³⁶ showed 81% thought climate change and its consequences were the biggest challenges for humanity in the 21st century. The UK survey³⁵ indicated that 48% know "a lot or fair amount" about net zero, concordant with 53% in our survey, although a larger proportion in the former survey (41%) indicated knowing "little or hardly anything." Questions on the perceived effects of net zero produced similar responses to those in the European survey,³⁶ where 56% believed that policies to fight climate change would be beneficial for the economy (57% in our

survey), with both indicating a higher proportion believing it would lead to improved quality of life.

Behaviors thought to have the biggest impact on tackling climate change in the UK were walking/cycling as a substitute for using a car, using low carbon heating in homes, and minimizing home energy use,³⁵ consistent with responses to Q22 and Q25. More respondents across Europe³⁶ also considered changes in individual habits were the best way to fight climate change compared with technological innovation (52%/41%), in line with our results (55%/42%). The value of individual action is supported by the IPCC Sixth Assessment Report.³⁷

Our survey, in contrast to previous surveys,^{35,36} focused on the neurological community, specifically those with epilepsy, allowing additional points to be considered. The specific needs of this community are important to note in future policies; for example, better public transport provision may help many with neurological diseases, whereas inequality may be aggravated by enforced shifts to electric vehicle usage without addressing affordability. We did not, however, explicitly investigate needs in relation to adaptations to climate change, for example, retrofitting homes to cope with heat waves. People with neurological illness should not feel additionally guilty from necessary use of strategies that could be considered intrinsically less sustainable (such as single-use devices). The qualitative responses to the survey repeatedly emphasized an intersectional approach to climate change and health, highlighting that climate mitigation policy could present an opportunity to improve health and social access for people with neurological conditions, and that such policies if implemented blindly and without proper consideration of different needs and effects risk being exclusionary, and threatening neurological health and well-being.

Some people with neurological illnesses already have to live lives adapted to certain difficulties, including having exclusively to use public transport, or to avoid high temperatures. Mutually informative dialogue between those with neurological illnesses and professionals may be needed not just to determine and institute the best mitigation and adaptation strategies, and not only to inform policymaking, but also to address climate anxiety, and to learn from people with neurological illnesses who may already experience, for example, heightened adverse outcomes on exposure to higher temperatures and humidity. There is potential for the broader population to learn from communities of (lived) expertise, akin to "reverse innovation" in developed countries, whereby learning from necessarily frugal innovation in developing countries is adopted in better-resourced environments.³⁸

Our limited sample sizes preclude drawing out many differences that may exist between those with neurological illnesses and those otherwise involved with such illnesses.

There were some noteworthy differences, however (e.g., Q6, Q7, Q9); more people with existing illness thought climate change had already affected their health, and had already consulted their clinicians in this regard, and were more worried about the future effects on health of climate change, than people without neurological illness.

Several limitations should be noted. As highlighted in the Materials and Methods section, the context of this survey was a period of extreme heat in the UK that included record-breaking temperatures. Previous work has noted that personal experience of natural hazards can influence perceptions of climate change and risk,^{39,40} and this may be reflected in people's responses here, particularly to questions relating to heat waves. Heat waves are particularly relevant manifestations of climate change, associated with excess mortality, and are therefore a valid area for study. Ongoing monitoring of this community's attitudes toward climate change and extreme weather over time is therefore recommended.

The small sample size limits generalization of our findings. We specifically included in the population to which the survey was made available the staff at the lead institution and the International League Against Epilepsy, both organizations with active climate change programs, which may have biased responses. Only a small proportion of the total circulation provided responses; the limited number of respondents indicates the need to continue to raise awareness of climate change in this community. The survey distribution pattern focused responses toward those living or working with epilepsy, represented in the diagnoses and expertise reported by respondents, and to those with Internet access and familiarity. Feedback on the survey from people with expertise in certain neurological conditions (motor neuron disease, dementia) suggested the survey's length and language might impede participation for people with these conditions; this provides a rationale for further work in these patient groups using abbreviated, plain-language versions. Despite the limitations described, these responses should give pause for thought, as people with neurological illness may represent the vanguard of health concerns related to climate change. The results suggest their already-lived experience should be heeded and further explored in subsequent research.

Our survey results point to the value of pursuing early signals; specifically, people within the neurological community who may be especially vulnerable, focusing on epilepsy, are concerned about current and future impacts of climate change, especially heat waves, and are keen for both individual and governmental actions to be taken. Many are already taking actions; but there is also concern that adaptations and policies risk aggravating illness-related inequalities unless systems thinking is applied. Climate change will affect us all; some people may be affected earlier and to a greater extent. We must better

understand the needs of the neurological community, and we may all learn important lessons for the future from such endeavor.

AUTHOR CONTRIBUTIONS

All authors contributed to the design of the work, data acquisition, analysis, and writing. *Study conception and supervision:* Sanjay M. Sisodiya. All authors provided references and edited the text. All authors approved the final version for publication. All authors are in agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGMENTS

We thank the many organizations that helped circulate the survey, including the Epilepsy Society, National Brain Appeal, International League Against Epilepsy, and MS Society. We thank BEIS for permission to use the Public Attitudes Tracker (Wave 37; <https://www.gov.uk/government/statistics/beis-public-attitudes-tracker-wave-37>).

FUNDING INFORMATION

J.W. and S.M.S. are supported by the Epilepsy Society. S.B. is funded by the NERC FUTURE-STORMS project (NE/R01079X/1). A.W. is funded by a Health Education England/NIHR Academic Clinical Fellowship.

CONFLICT OF INTEREST STATEMENT

A.W. is a member of Medact, a health workers' campaigning organization campaigning on issues of health and social justice, including climate justice. None of the other authors has any conflicts to declare.

ORCID

Stephen Blenkinsop  <https://orcid.org/0000-0003-0790-6545>

Alistair Wardrope  <https://orcid.org/0000-0003-3614-6346>

Joseph Willis  <https://orcid.org/0000-0002-6766-363X>

Sanjay M. Sisodiya  <https://orcid.org/0000-0002-1511-5893>

REFERENCES

- Romanello M, Di Napoli C, Drummond P, Green C, Kennard H, Lampard P, et al. The 2022 report of the lancet countdown on health and climate change: health at the mercy of fossil fuels. *Lancet*. 2022;400(10363):1619–54.
- Kovats S, Brisley R. Health, communities and the built environment. In: Betts RA, Haward AB, Pearson KV, editors. The third UK climate change risk assessment technical report. London: Climate Change Committee; 2021.
- IPCC. Summary for policymakers. In: Masson-Delmotte V, Zhai P, Pirani A, Connors S, Péan C, Berger S, et al., editors. Climate

- change 2021: the physical science basis contribution of working group I to the sixth assessment report of the intergovernmental panel on climate change. Cambridge, United Kingdom and New York, NY, USA: Cambridge University Press; 2021. p. 3–32.
4. Met Office. 2022 provisionally warmest year on record for UK. 2022. Available from: <https://www.metoffice.gov.uk/about-us/press-office/news/weather-and-climate/2022/2022-provisionally-warmest-year-on-record-for-uk>
 5. Met Office. Seasonal Assessment—Summer 2022. 2022. Available from: https://www.metoffice.gov.uk/binaries/content/assets/metofficegovuk/pdf/weather/learn-about/uk-past-events/summaries/uk_monthly_climate_summary_summer_2022.pdf
 6. Office for National Statistics. Excess mortality during heat-periods: 1 June to 31 August 2022. 2022. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/excessmortalityduringheatperiods/englandandwales1juneto31august2022>
 7. Department for Business Energy & Industrial Strategy. UK becomes first major economy to pass net zero emissions law. 2019. Available from: <https://www.gov.uk/government/news/uk-becomes-first-major-economy-to-pass-net-zero-emissions-law>
 8. Priestley S. Net zero in the UK. London: House of Commons Library; 2019. Report No.: CBP8590.
 9. NHS. Delivering a ‘net zero’ National Health Service. London: NHS England; 2022.
 10. Feigin VL, Vos T, Nichols E, Owolabi MO, Carroll WM, Dichgans M, et al. The global burden of neurological disorders: translating evidence into policy. *Lancet Neurol.* 2020;19(3):255–65.
 11. Louis S, Carlson AK, Suresh A, Rim J, Mays M, Ontaneda D, et al. Impacts of climate change and air pollution on neurologic health, disease, and practice: A scoping review. *Neurology.* 2023;100(10):474–83.
 12. Ruzskiewicz JA, Tinkov AA, Skalny AV, Siokas V, Dardiotis E, Tsatsakis A, et al. Brain diseases in changing climate. *Environ Res.* 2019;177:108637.
 13. Hurley D. Mounting evidence on the effects of climate change on neurologic disorders. *Neurol Today.* 2022;22:1–17.
 14. Demski C, BEIS, DEFRA. Climate change and net zero: public awareness and perceptions. HM Government. 2021; Report No.: 2021/034. Available from: https://assets.publishing.service.gov.uk/media/60d48d5d8fa8f50ab1d011fa/Climate_change_and_net_zero_public_awareness_and_perceptions_summary_report.pdf
 15. Temte JL, McCall JC. Patient attitudes toward issues of environmental health. *Wilderness Environ Med.* 2001;12(2):86–92.
 16. Boland TM, Temte JL. Family medicine patient and physician attitudes toward climate change and health in Wisconsin. *Wilderness Environ Med.* 2019;30(4):386–93.
 17. Howe PD, Marlon JR, Wang X, Leiserowitz A. Public perceptions of the health risks of extreme heat across US states, counties, and neighborhoods. *Proc Natl Acad Sci U S A.* 2019;116(14):6743–8.
 18. Kotcher J, Maibach E, Miller J, Campbell E, Alqodmani L, Maiero M, et al. Views of health professionals on climate change and health: a multinational survey study. *Lancet Planet Health.* 2021;5(5):e316–23.
 19. Leiserowitz A, Maibach E, Roser-Renouf C, Feinberg G, Rosenthal S, Marlon J. Public perceptions of the health consequences of global warming: October, 2014. New Haven, CT: Yale University and George Mason University; 2014.
 20. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277–88.
 21. Terry G, Hayfield N, Clarke V, Braun V. Thematic analysis. In: Willig C, Stainton Rogers W, editors. *The Sage handbook of qualitative research in psychology.* SAGE: United Kingdom; 2017. p. 17–37.
 22. O’Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ.* 2010;341:c4587.
 23. Whicher D, Wu AW. Ethics review of survey research: a mandatory requirement for publication? *Patient.* 2015;8(6):477–82.
 24. Hofmann B. On the triad disease, illness and sickness. *J Med Philos.* 2002;27(6):651–73.
 25. Cissé G, McLeman R, Adams H, Aldunce P, Bowen K, Campbell-Lendrum D, et al. Health, wellbeing, and the changing structure of communities. In: Pörtner H-O, Roberts D, Tignor M, Poloczanska E, Mintenbeck K, Alegría A, et al., editors. *Climate change 2022: impacts, adaptation and vulnerability contribution of working group II to the sixth assessment report of the intergovernmental panel on climate.* Change Cambridge, UK: Cambridge University Press; 2022. p. 1041–170.
 26. Berrone P, Fosfuri A, Gelabert L, Gomez-Mejia LR. Necessity as the mother of ‘green’ inventions: institutional pressures and environmental innovations. *Strateg Manag J.* 2013;34(8):891–909.
 27. Cai X, Zhu B, Zhang H, Li L, Xie M. Can direct environmental regulation promote green technology innovation in heavily polluting industries? Evidence from Chinese listed companies. *Sci Total Environ.* 2020;746:140810.
 28. Atwoli L, Baqui AH, Benfield T, Bosurgi R, Godlee F, Hancocks S, et al. Call for emergency action to limit global temperature increases, restore biodiversity, and protect health. *N Engl J Med.* 2021;385(12):1134–7.
 29. Gulcebi MI, Bartolini E, Lee O, Lisgaras CP, Onat F, Mifsud J, et al. Climate change and epilepsy: insights from clinical and basic science studies. *Epilepsy Behav.* 2021;116:107791.
 30. The Lancet Neurology. Neurology and the climate emergency. *Lancet Neurol.* 2022;21(1):1.
 31. World Weather Attribution. Without human-caused climate change temperatures of 40°C in the UK would have been extremely unlikely. 2022. Available from: <https://www.worldweatherattribution.org/without-human-caused-climate-change-temperatures-of-40c-in-the-uk-would-have-been-extremely-unlikely/>
 32. Robine J-M, Cheung SLK, Le Roy S, Van Oyen H, Griffiths C, Michel J-P, et al. Death toll exceeded 70,000 in Europe during the summer of 2003. *C R Biol.* 2008;331(2):171–8.
 33. Robine J, Cheung S, Le Roy S, Van Oyen H, Herrmann F. Report on excess mortality in Europe during summer 2003. EU; 2007. Available from: https://ec.europa.eu/health/ph_projects/2005/action1/docs/action1_2005_a2_15_en.pdf
 34. Fouillet A, Rey G, Laurent F, Pavillon G, Bellec S, Guihenneuc-Jouyau C, et al. Excess mortality related to the august 2003 heat wave in France. *Int Arch Occup Environ Health.* 2006;80(1):16–24.
 35. BEIS. BEIS public attitudes tracker: net zero and climate change summer 2022. UK: BEIS; 2022.
 36. European Investment Bank. The EIB climate survey—citizens call for green recovery. Luxembourg: European Investment Bank; 2022.

37. IPCC. Summary for policymakers. In: Shukla P, Skea J, Slade R, Al Khourdajie A, van Diemen R, McCollum D, et al., editors. *Climate change 2022: mitigation of climate change contribution of working group III to the sixth assessment report of the intergovernmental panel on climate change*. Cambridge, UK: Cambridge University Press; 2022. p. 48.
38. Bhatti Y, Taylor A, Harris M, Wadge H, Escobar E, Prime M, et al. Global lessons in frugal innovation to improve health care delivery in the United States. *Health Aff.* 2017;36(11):1912–9.
39. Diakakis M, Skordoulis M, Savvidou E. The relationships between public risk perceptions of climate change, environmental sensitivity and experience of extreme weather-related disasters: evidence from Greece. *Water.* 2021;13(20):2842.
40. Wachinger G, Renn O, Begg C, Kuhlicke C. The risk perception paradox—implications for governance and communication of natural hazards. *Risk Anal.* 2013;33(6):1049–65.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Blenkinsop S, Wardrope A, Willis J, Sisodiya SM. Climate change: Attitudes and concerns of, and learnings from, people with neurological conditions, carers, and health care professionals. *Epilepsia.* 2023;00:1–12. <https://doi.org/10.1111/epi.17824>