TITLE

Developing an alternative care pathway for emergency ambulance responses for adults with epilepsy: A Discrete Choice Experiment to understand which configuration service users prefer. Part of the COLLABORATE project

AUTHORS

Emily Holmes,[1,2] Pete Dixon,[3] Amy Mathieson,[3,4] Leone Ridsdale,[5] Myfanwy Morgan,[6] Alison McKinlay,[5,7] Jon Dickson,[8] Steve Goodacre,[9] Mike Jackson,[10] Deborah Foster,[10] Kristy Hardman,[10] Steve Bell,[10] Anthony Marson,[2] Dyfrig Hughes,[1,2] Adam J. Noble[3]*

1. Centre for Health Economics & Medicines Evaluation, North Wales Medical School, Bangor University, UK.
2. Department of Pharmacology and Therapeutics, University of Liverpool. UK.
3. Department of Public Health, Policy and Systems, University of Liverpool, Liverpool, UK
4. Centre for Primary Care and Health Services Research, University of Manchester, UK
5. Department of Basic and Clinical Neuroscience, King's College London, London, UK
6. Institute of Pharmaceutical Science, King's College London, UK.
7. Centre for Behaviour Change, Research Department of Clinical, Educational and Health Psychology, University College London, UK
8. Academic Unit of Primary Medical Care, University of Sheffield, UK.
9. School of Health and Related Research, University of Sheffield, UK.
10. North West Ambulance Service NHS Trust, Bolton, UK.

* Corresponding author.
Dr Adam Noble BSc (Hons), CPS, PhD
Department of Public Health, Policy and Systems, Institute of Population Health Sciences,
The Whelan Building, Ground Floor, University of Liverpool, L69 3GL
E-mail: adam.noble@liv.ac.uk; Tel: +44 (0)151 794 5993; Fax: +44 (0)151 794 5537

ABSTRACT

Introduction: To identify service users' preferences for an alternative care pathway for adults with epilepsy presenting to the ambulance service.

Methods: Extensive formative work (qualitative, survey and knowledge exchange) informed the design of a stated preference discrete choice experiment (DCE). This hypothetical survey was hosted online and consisted of 12 binary choices of alternative care pathways described in terms of: the paramedic's access to medical records/ 'care plan', what happens next (described in terms of conveyance), time, availability of epilepsy specialists today, general practitioner (GP) notification and future contact with epilepsy specialists. DCE scenarios were described as: (i) typical seizure at home. (ii) typical seizure in public, (iii) atypical seizure. Respondents were recruited by a regional English ambulance service and by national public adverts. Participants were randomised to complete 2 of the 3 DCEs.

Results: People with epilepsy (PWE; n=427) and friends/family (n=167) who completed the survey were representative of the target population. PWE preferred paramedics to have access to medical records, non-conveyance, to avoid lengthy episodes of care, availability of epilepsy specialists today, GP notification, and contact with epilepsy specialists within 2-3 weeks. Significant others (close family members or friends) preferred PWE experiencing an atypical seizure to be conveyed to an Urgent Treatment Centre and preferred shorter times. Optimal configuration of services from service users' perspective far out ranked current practice (rank 230/288 possible configurations).

Discussion: Preferences differ to current practice but have minimal variation by seizure type or stakeholder. Further work on feasibility of these pathways in England, and potentially beyond, is required.

KEYWORDS

Epilepsy, Seizure, Ambulance, Care Pathway, Preference, Discrete Choice Experiment.

HIGHLIGHTS

1. Alternatives for adults with epilepsy presenting to ambulances – user preferences
2. Discrete choice experiments with n=427 people with epilepsy and n=167 friends/family
3. Experiments captured their care preferences for 3 different seizure scenarios
4. Users' preferences are similar for the scenarios but diverge from current practice
5. People with epilepsy prefer to avoid conveyance to an emergency department

Abbreviations

A&E	Accident & Emergency Department
ASM	Anti-seizure medication
CP	Care Pathway
DCE	Discrete Choice Experiment
Dx	Diagnosed
ED	Emergency Department
GP	General Practitioner
IQR	Interquartile Range
NASH	National Audit of Seizure Management in Hospital
NHS	National Health Service
NWAS	North-West NHS Ambulance service
PWE	People with epilepsy
Rx	Prescribed
UK	United Kingdom
UTC	Urgent Treatment Centre

INTRODUCTION

Emergency care use, epilepsy and alternative care pathways

Ambulances often attend to people with epilepsy (PWE).[1-4] According to the way care in the UK is configured, most (~70%) attendances result in the person being conveyed to a hospital emergency department (ED).[2, 5] Up to 20% of PWE in the UK attend ED each year;[6-8] ~60% multiple times.[9] Most (~65%) have not seen an epilepsy specialist in the prior 12 months.[10, 11] Whilst expensive,[12, 13] ED visits for PWE typically have little benefit – most have established (rather than new) epilepsy, present with a non-emergency state (e.g., an uncomplicated seizure), and the visit does not instigate ambulatory care improvements.[2, 10, 11, 14-17] Other countries report similar issues.[18, 19]

The current situation, together with a policy drive to reduce clinically unnecessary ED visits,[20] has created a momentum for paramedics to have access to some form of alternative care pathway (CP) that could, when safe, be used by paramedics to divert adults with epilepsy away from EDs, whilst also bringing them to the attention of an epilepsy specialist.

There is no definitive evidence showing an alternative CP for epilepsy works.[21, 22] There are, however, reasons to suspect it could. Firstly, paramedics express a willingness to take on additional responsibility for seizures; [23] secondly, there is positive evidence in favour of alternative CPs for other presentations,[24-26] including data linkage that shows most non-transported patients did not have subsequent health events;[27] and, thirdly, evidence is available on the barriers to non-conveyance.[28, 29] They include a lack of alternatives to ED.[30, 31] Other notable ones include pressures on how long paramedics can 'spend on scene' and their limited access to the medical records or 'care plans'[i] of person being seen.[34]

A variety of alternative CP configurations are being considered for epilepsy [35] and their development is not being coordinated. The CPs differ with respect to where the person is taken, who is eligible, who does the caring, whether they could stimulate ambulatory care improvements and how long this would take. Arguably, the optimal configuration is one that is both acceptable to patients

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[i] 'Care plan' does not have a universally agreed definition. Within England, guidelines state all adults with epilepsy should have an agreed and comprehensive written epilepsy 'care plan'. 32.National Institute for Health and Care Excellence. *Epilepsies in children, young people and adults*. 2022 [cited 2023 14/11]; Available from: https://www.nice.org.uk/guidance/ng217/resources/epilepsies-in-children-young-people-and-adults-pdf-66143780239813.One section should include information on "first aid, safety and injury prevention at home and at college or work". 33. National Institute for Health and Care Excellence. *Quality statement 4: Epilepsy care plan*. 2013 [cited 2023 14/11]; Available from: https://www.nice.org.uk/guidance/qs26/chapter/Quality-statement-4-Epilepsy-care-plan. For some it is sometimes called a 'seizure action plan' or similar. In the UK, 'care plans' – or pertinent information derived from them – are not routinely accessible to urgent and emergency care staff in England for people with seizure disorders.

from the target population (and significant others to whom care decisions can be delegated) and feasible for delivery within the National Health Service (NHS).[36]

The COLLABORATE project

Our multicomponent COLLABORATE project [37] sought to identify the optimal alternative CP for adults with epilepsy. A key method was the use of stated preference discrete choice experiments (DCEs).[38]

What are DCEs and why did we use them?

DCEs are a reliable method of quantitatively measuring peoples' preferences, underpinned by behavioural economic theory [39, 40] and extensively used in healthcare evaluation,[19, 38] including epilepsy.[41-43] Survey respondents choose between hypothetical, but realistic alternatives, described in terms of attributes (e.g., where the ambulance takes you) characterised by specific levels (e.g., Home, ED). By varying the attribute levels that are presented, across a series of choice-sets, the importance of the attributes and the extent to which they drive preferences can be estimated. When a DCE is designed well, preferences expressed within them show good congruence with real-world behaviour. [44-47]

The aim of the current DCE study was to identify attributes of post-seizure care that PWE and their significant others (close family members or friends) consider important, measure their preferences for post-seizure care, and to estimate the 'utility' of different CP configurations. A second study, reported in our accompanying article (see accompanying submission), then used knowledge exchange methods to share the DCE evidence with a wider range of stakeholders and develop a consensus on which CP configuration represented the optimal balance between user preference and feasibility.

METHODS

Overview

As per guidelines,[48, 49] a multidisciplinary panel used mixed-methods to develop a DCE to elicit preferences for three seizure scenarios, where opportunities for increased non-conveyance exist [50, 51]. Namely, a person with established epilepsy who has experienced: i) a seizure at home that is in line with their usual presentation; ii) a seizure in public that is in line with their usual presentation; and iii) a seizure that has self-terminated, but which is different in some way to their 'normal' seizure/s (See Supplementary File 3 for full descriptions of these scenarios).

Attributes and levels

Attributes and levels were derived from extensive formative work (Supplementary File 1), including: qualitative interviews and ranking exercises conducted with patients and significant others;[52] and, a survey of England's ambulance services, neuroscience and neurology centres, and EDs to determine parameters of the alternative CPs for epilepsy under consideration.[35] Draft attributes, levels and scenario vignettes were then refined based on feedback from a workshop involving n=13 ambulance staff and epilepsy professionals.

The same 6 attributes were selected for each scenario/experiment (Figure 1). Attribute labels were supported by a brief description and levels by symbols. The number of levels per attribute ranged from 2 to 4.

Experimental design

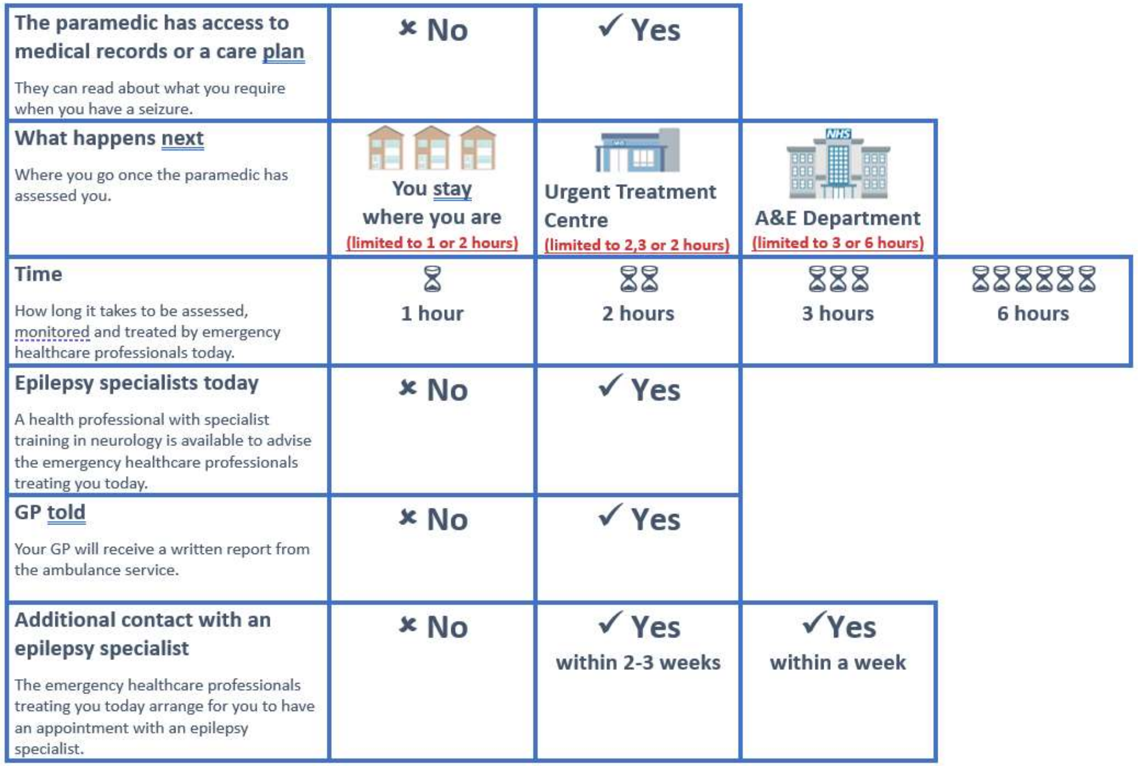
The 6 attributes and their levels resulted in 288 possible CP configurations. This was reduced to 24 using Ngene software (Choice Metrics, 2018, Ngene 1.2.1), which created 12 pair-wise forced choices.

To ensure plausibility, the levels for the attribute 'Time' were conditional on the level that the attribute 'What happens next' took. It captured care location. Thus: for '…stay where you are', levels were 1 or 2hrs; Urgent Treatment Centre (UTC), 2,3, or 6hrs; Accident & Emergency [A&E] Department, 3 or 6hrs (see Figure 1 'Notes' for details on UTCs and comment on the terms A&E and ED).

Survey design

DCEs were administered via an online survey on the XM Qualtrics platform that included the DCEs and additional questions (Supplementary File 2). To minimise participant burden, each participant was randomised to complete DCEs for 2/3 scenarios. For each scenario, the DCE involved the participant being presented with a vignette (Supplementary File 3) and asked them to state which of two, unlabelled CP options they would prefer (Figure 2). This binary choice task was repeated 12 times for each scenario (each participant completed 24 in total). The phrasing of the scenario and attribute descriptions/levels were modified in the version completed by significant others. The noted additional questions secured information on participants' characteristics, experiences, views and supported subgroup differences to be explored.

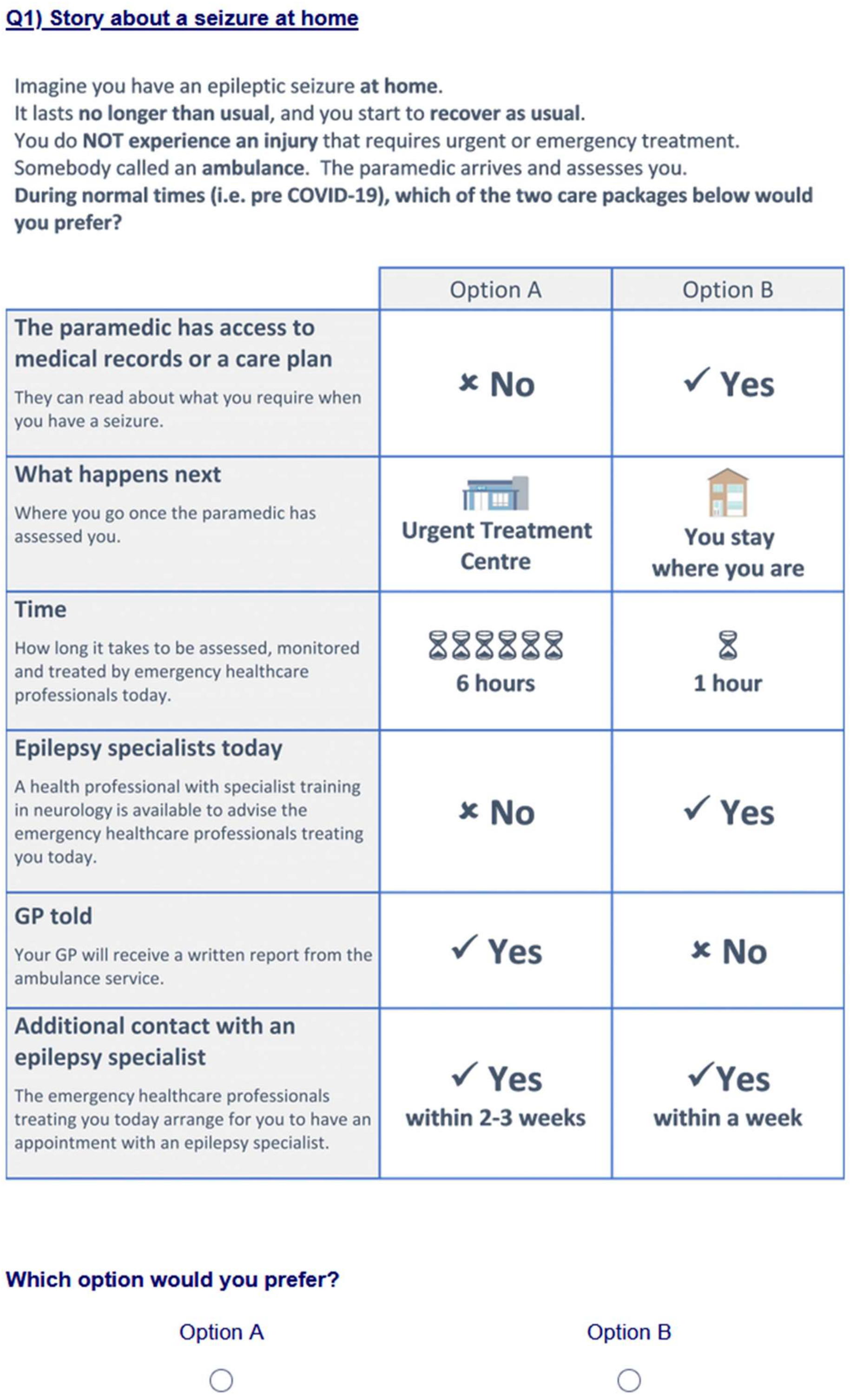
An animated video provided participants with instructions of how to complete the DCEs (Supplementary File 4). For significant others it said they should express *their* preferences for the care of the PWE they knew. As the study occurred in 2020, it also included advice to make



The paramedic has access to medical records or a care plan They can read about what you require when you have a seizure.	✗ No	✓ Yes		
What happens next Where you go once the paramedic has assessed you.	You stay where you are (limited to 1 or 2 hours)	Urgent Treatment Centre (limited to 2,3 or 2 hours)	A&E Department (limited to 3 or 6 hours)	
Time How long it takes to be assessed, monitored and treated by emergency healthcare professionals today.	⧗ 1 hour	⧗⧗ 2 hours	⧗⧗⧗ 3 hours	⧗⧗⧗⧗⧗⧗ 6 hours
Epilepsy specialists today A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today.	✗ No	✓ Yes		
GP told Your GP will receive a written report from the ambulance service.	✗ No	✓ Yes		
Additional contact with an epilepsy specialist The emergency healthcare professionals treating you today arrange for you to have an appointment with an epilepsy specialist.	✗ No	✓ Yes within 2-3 weeks	✓Yes within a week	

FIGURE 1 Six attributes used to describe all the CP configurations within the Discrete Choice Experiments along with the levels they could assume

Notes: The language used for the attributes was changed in the significant others version of the survey to ensure focus on the person with epilepsy that they knew (e.g. “What happens next: Where you go once the paramedic has assessed you” became “What happens next: Where the person with epilepsy you know goes once the paramedic has assessed them”); ‘Urgent Treatment Centre’ (UTC) is the label that, following the Urgent and Emergency Care Review, has been given to most English walk-in centres, minor injuries units and urgent care centres.[53] They are open at least 12-hours a day, be GP-led, staffed by GPs, nurses and other clinicians and have access to simple diagnostics, e.g. urinalysis, ECG and in some cases X-ray. In the UK terms “Accident and Emergency Department”/ “A&E” and ED are often used interchangeably. “Accident and Emergency”/ “A&E” are common within lay parlance and so were used within the DCEs rather than ED.



Q1) Story about a seizure at home

Imagine you have an epileptic seizure **at home**.
It lasts **no longer than usual**, and you start to **recover as usual**.
You do **NOT experience an injury** that requires urgent or emergency treatment.
Somebody called an **ambulance**. The paramedic arrives and assesses you.
During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer?

	Option A	Option B
The paramedic has access to medical records or a care plan They can read about what you require when you have a seizure.	✗ No	✓ Yes
What happens next Where you go once the paramedic has assessed you.	Urgent Treatment Centre	You stay where you are
Time How long it takes to be assessed, monitored and treated by emergency healthcare professionals today.	⌛⌛⌛⌛⌛⌛ 6 hours	⌛ 1 hour
Epilepsy specialists today A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today.	✗ No	✓ Yes
GP told Your GP will receive a written report from the ambulance service.	✓ Yes	✗ No
Additional contact with an epilepsy specialist The emergency healthcare professionals treating you today arrange for you to have an appointment with an epilepsy specialist.	✓ Yes within 2-3 weeks	✓Yes within a week

Which option would you prefer?

Option A	Option B
○	○

FIGURE 2 Example of a pair-wise choice question used within the Discrete Choice Experiment survey (for a participant who had epilepsy themselves)

Notes: The DCE for each seizure scenario contained 12 such choice questions. For these, the attributes in the grey shaded left-hand column stayed constant, but the levels (i.e., the descriptions for Option A and Option B) varied.

choices based on preferences for care outside of the pandemic. The survey was piloted with an external sample of n=12 PWE aged ≥18-years recruited from the Epilepsy Action Research Volunteer Network; cognitive interview techniques helped identify refinements.

Participants

Eligibility criteria and recruitment

PWE aged ≥18-years, self-reporting a clinical diagnosis of epilepsy, prescribed anti-seizure medication, seen by the ambulance service in the prior 12 months and able to provide informed consent and independently complete the survey in English. Significant others needed to be aged ≥16.

Participants were recruited by two routes: (i) North-West NHS Ambulance service (NWAS) searched their records for eligible PWE who they attended between October 2018 and October 2019; (ii) via national public adverts (required as the COVID-19 pandemic disrupted the first route). Supplementary File 5 provides further details on the routes, eligibility and ethical approvals.

Analysis

Sample size

The protocol used a 'rule-of-thumb' [59] in advance of the finalised DCE design. It indicated a requirement of complete data from 84 participants for each scenario. As participants were randomised to complete DCEs on 2/3 scenarios, 126 participants would be needed.[37] This was further increased to 150 to allow for variation in the actual number of choice tasks and levels used in the finalised DCE.

Data quality checks and curation

Participants whose responses to characteristic questions indicated ineligibility were excluded. Index of Multiple Deprivation (IMD) 2019 [54] was calculated for each participant using their home postcode. Multiple imputation was performed for those with incomplete/invalid postcodes.[55]

Participant characteristics

Sample 'representativeness' was evaluated by comparing it to evidence from the UK's 2019 National Audit of Seizure Management in Hospital (NASH-3). It captured the characteristics of persons with established epilepsy prescribed antiseizure medication attending UK EDs.[11]

Base case analysis

Random effects logit regression models [56] determined the importance of the attributes and their effect direction for each scenario by participant type. Subject to a test of linearity for the only continuous attribute 'Time', the base case model was specified as:

$Ui = \beta0 + \beta1$ (care plan) $+ \beta2$ (no convey) $+ \beta3$ (convey UTC) $+ \beta4$ (convey ED) $+ \beta5$ (time) +
$B6$ (epilepsy specialist today) $+ \beta7$ (GP told) $+ \beta8$ (no future specialist) $+ \beta9$ (2-3 week specialist) $+ \beta10$ (1 week specialist) $+ \varepsilon$
Ui= utility derived by individual
$\beta0$= constant term
βi= estimated coefficient for each attribute (variable)
ε= error term (assumed to vary by seizure scenario)

The reference level of effects coded attributes (e.g., what happens next: stay at home) were calculated as: -1* (sum ß of other levels). Confidence intervals (95%) were determined by 1,000 bootstrap replications.

All analyses were conducted in STATA, V13 (StataCorp LP, College Station, TX).

Subgroup analysis

Preference heterogeneity was assessed using log likelihood ratio tests of the restricted model (base case) versus unrestricted models (defined by subgroups). Four a-priori characteristics of interest were specified. Namely: (i) whether participant had visited ED or not in the prior 12-months for epilepsy; (ii) had contact with an epilepsy specialist within the prior 12 months; (iii) reported an intellectual disability; and (iv) their IMD quintile.

During the formative work (Supplementary File 1) we identified five further subgroups that may influence preference. Specifically, whether the participant had: (v) experienced prior problems accessing specialist epilepsy services; (vi) a seizure 'care plan'; (vii) familiarity with seizure scenario; (viii) particular views and experiences of COVID-19; and finally, (ix) their recruitment route.

Subgroup analyses occurred when sufficient cases existed (i.e., ≥30 participants). Alpha for the post-hoc analyses was adjusted for multiple comparisons.

Ranking of CP configurations according to preference

The expected 'utility' to participants of the 288 configurations in each seizure scenario was calculated by summing the coefficients (β) from the respective regression models and ranking them (1= highest utility). Ranks were constructed separately for each seizure scenario and participant type. Thus, 6 sets of ranks were generated.

To support knowledge exchange around feasibility of implementing the most preferred CP (see accompanying submission), we estimated the uptake of the six "top rank" configurations, by seizure and participant type, using: $P = \exp(\text{utility } CP_i)/\Sigma \exp(CP_j)$. The configuration best approximating current care was also presented alongside the most highly ranked to allow for descriptive comparison of how well current care aligns with users' preferences.

RESULTS

Recruitment

Recruitment via route 1 began on 31st July 2020 when NWAS sent invitations to n=981 individuals it deemed eligible. The time between the incidents that led these persons to be cared for by NWAS and invitation ranged from 10 to 21 months.

Recruitment via route 2 commenced on 13th July 2020. Major patient organisations circulated adverts via newsletters and on social media between 20th July 2020 and 16th November 2020 and they appeared in newspapers between 9th and 16th October 2020.

All recruitment routes closed on 25th November 2020.

Participants

Responses

Eligible, useable survey submissions were received from n=594 participants (n=427 PWE; n=167 'significant others') (Figure 3). Most (81.1%; n=358 PWE, n=124 'significant others) were recruited via route 2. Of the 1188 DCEs allocated to these participants, 88% were complete.

Participant characteristics, representativeness and familiarity with seizure scenarios

Combining participants from the two recruitment routes created a sample more like the target population, albeit still slightly younger than expected and reporting more recent epilepsy specialist contact (Table 1).

Median age of the PWE taking part (or being represented) was 35 years (IQR 26-48), 66.7% were female and median years diagnosed was 12 (IQR 4-26). Most (74.4%) had 1 to 3 contacts with the ambulance service in the prior 12 months for epilepsy. Significant others were predominantly a parent (59.4%) or spouse/partner (24.4%) to the PWE. Participants were recruited from across England. Most (71.4%) participants reported they (or the PWE they knew) had "often" or "sometimes" been in each of the DCE scenarios (Supplementary File 6).

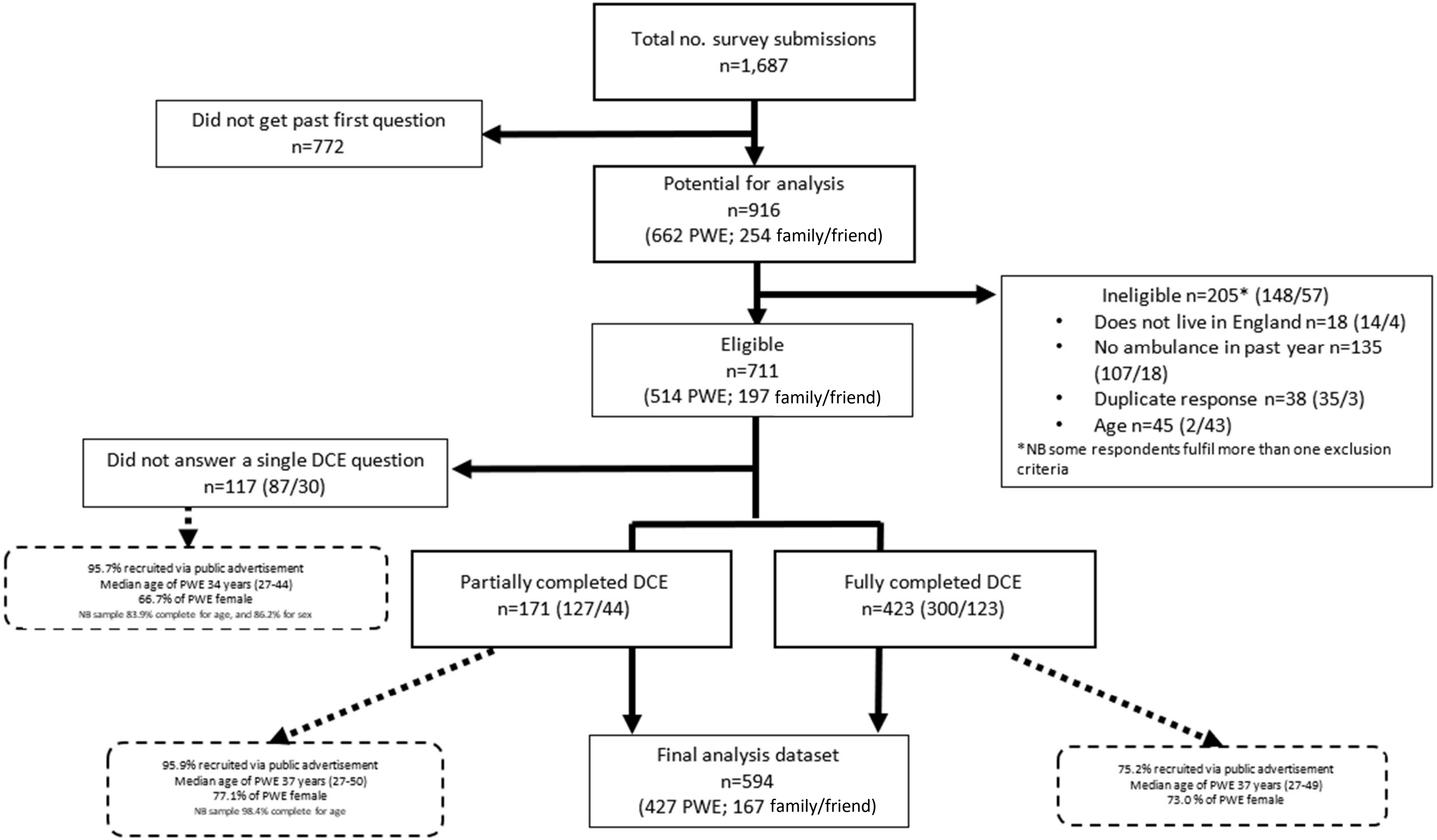


FIGURE 3 Responses to survey by participant type, recruitment pathway and extent of completeness of response to Discrete Choice Experiments

Notes: DCE, Discrete choice experiment; PWE, person with epilepsy; A member of the research team (PD) screened out any persons submitting a survey response that included any answer/s indicating they were ineligible (e.g., <18 years old, did not live in England, insufficient contact with the ambulance service). Persons who did not submit sufficient responses to DCE (defined as completion of at least one choice task from one of the DCEs) were also excluded.

TABLE 1 Headline characteristics of samples recruited by the two routes and their representativeness individually and when combined

	Route 1 **Via** **ambulance service**	**Route 2** **Via** **public advert**	**Combined**	**NASH-3**
Analysis dataset	**N=112**	**N=482**	**N=594**	**N=1,676**
***Participant type**, n (%)*				
Person with epilepsy (PWE)	69 (61.6%)	358 (74.3%)	427 (71.9%)	1,676 (100%)
Significant other	43 (38.4%)	124 (25.7%)	167 (28.1%)	
***Age of PWE,** Median (range)*				
Reported by people with epilepsy	36 (26-51)	37 (27-49)	37 (27-49)	
Reported by significant other participants	32.5 (26-46)	28 (23-39)	29 (24-41)	
Combined	34 (26-49)	35 (26-48)	35 (26-48)	43 (29-58)
Missing	1	45	46	
***Sex of PWE,** Female n (%)*				
Reported by people with epilepsy	37 (53.6%)	280 (78.2%)	317 (74.2%)	
Reported by significant other participants	20 (47.6%)	30 (37.0%)	50 (40.7%)	
Combined	57 (51.4%)	310 (70.6%)	367 (66.7%)	783 (46.8%)
Missing	1	43	44	

	Route 1 Via ambulance service	**Route 2 Via public advert**	**Combined**	**NASH-3**
Analysis dataset	**N=112**	**N=482**	**N=594**	**N=1,676**
Intellectual disability in PWE, *Yes n (%)*				
Reported by people with epilepsy	7 (11.1%)	27 (11.4%)	34 (11.4%)	
Reported by significant other participants	18 (42.9%)	19 (23.5%)	37 (30.1%)	
Combined	25 (23.8%)	46 (14.5%)	71 (16.8%)	297 (17.8%)
Missing	7	165	172	
PWE' Index of Multiple Deprivation, *n (%)*				
Reported by people with epilepsy				
Quintile 1	24 (38.1%)	60 (25.5%)	84 (28.2%)	517 (30.9%)
Quintile 2	12 (19.1%)	56 (23.8%)	68 (22.8%)	395 (23.6%)
Quintile 3	11 (17.5%)	40 (17.0%)	51 (17.1%)	304 (18.1%)
Quintile 4	13 (20.6%)	44 (18.7%)	57 (19.1%)	292 (17.4%)
Quintile 5	3 (4.8%)	35 (14.9%)	38 (12.8%)	168 (10.0%)
Missing	6	124	129	

	Route 1 Via ambulance service	**Route 2 Via public advert**	**Combined**	**NASH-3**
Analysis dataset	**N=112**	**N=482**	**N=594**	**N=1,676**
PWE seen epilepsy specialist in prior 12 months, *Yes n (%)*				
Reported by people with epilepsy	48 (76.2%)	205 (87.2%)	253 (84.9%)	
Reported by significant other participants	36 (85.7%)	76 (93.8%)	112 (91.1%)	
Combined	84 (80.0%)	281 (88.9%)	365 (86.7%)	815 (48.6%)
Missing	7	166	173	

Notes: N, number; PWE, person with epilepsy; NASH-3, National Audit of Seizure Management in Hospitals, audit round 3.

Compared to PWE who took part themselves, the PWE known by significant others were more often male, younger, had an intellectual disability, prescribed a rescue medication, had more ambulance and ED contact and had greater experience of the 'Atypical seizure' scenario (Supplementary File 6).

Utility model Specification: Testing for non-linear effects

The preference weight on 'Time' was not linear across all 6 seizure/respondent contexts (Supplementary File 7). The base case model was therefore respecified with 'Time' as a categorical attribute.

Statistical significance of attributes and direction of their influence on preference

Preferences of people with epilepsy

Across the 3 scenarios, PWE consistently preferred a CP where the paramedic had access to their medical records or a 'care plan' (Table 2). They wanted the 'Time' it took to be assessed, monitored and treated to be <6-hours, for an epilepsy specialist to be available to advise their emergency healthcare professional, for their General Practitioner (GP) to be notified and they wanted the CP to initiate a future appointment with an epilepsy specialist. They did not have a significant preference as to whether this appointment occurred within 1-week or two- to three-weeks of the incident.

There was slight divergence across the scenarios when it came to preference for 'What happens next'. For an 'Atypical seizure', none of the levels reached statistical significance. For 'Home typical seizure' and 'Public typical seizure', PWE significantly prefered to stay where they were and avoid ED. For 'Home typical seizure', PWE also expressed a preference to avoid conveyance to a UTC.

Preferences of significant others

Significant others, like PWE, had a consistent preference for a CP that involved the paramedic having access to the patient's medical records or 'care plan', for an epilepsy specialist to be available to advise the emergency healthcare professionals, for the patient's GP to be notified and for a future appointment to be arranged with an epilepsy specialist (Table 2). They also did not have a preference as to when this appointment occurred.

When it came to 'Time', significant others also consistently wanted it to be <6-hours. Uniquely, for 'Home typical seizure', they also expressed a significant preference for the time it took to be two-hours.

With regards 'What happens next', for a 'Public typical seizure' or an 'Atypical seizure' none of the attribute levels reached statistical significance. For a 'Home typical seizure', like PWE, significant

TABLE 2 Regression models for people with epilepsy and significant others (with 'Time' treated categorically)

Attribute [level]	**Seizure scenario**								
	Atypical Seizure			***Home typical seizure***			***Public typical seizure***		
	ß coeff	*95% CI*[a]		*ß coeff*	*95% CI*[a]		*ß coeff*	*95% CI*[a]	
Regression models for participants with epilepsy (with 'Time' treated categorically)									
Access to medical records / care plan (0=no; 1=yes)	**0.460***	0.346	0.653	**0.539***	0.410	0.783	**0.565***	0.435	0.435
Convey [no – stay where you are]^	0.067	-0.290	0.400	**0.543***	0.230	0.984	**0.407***	0.134	0.748
Convey [urgent treatment centre]	0.044	-0.148	0.257	**-0.259***	-0.497	-0.064	-0.097	-0.291	0.078
Convey [emergency department]	-0.111	-0.293	0.062	**-0.284***	-0.516	-0.109	**-0.310***	-0.518	-0.147
Time [1 hour]^	0.164	-0.610	0.970	0.295	-0.572	1.179	0.080	-0.649	0.791
Time [2 hours]	0.284	-0.088	0.716	0.192	-0.240	0.665	0.135	-0.249	0.559
Time [3 hours]	0.079	-0.425	0.549	0.175	-0.348	0.743	0.331	-0.090	0.806
Time [6 hours]	**-0.526***	-0.738	-0.416	**-0.662***	-0.921	-0.558	**-0.545***	-0.754	-0.449
Epilepsy specialist advises today (0=no; 1=yes)	**0.591***	0.536	0.751	**0.372***	0.298	0.529	**0.353***	0.283	0.487
GP told (0=no; 1=yes)	**0.426***	0.367	0.557	**0.261***	0.189	0.397	**0.268***	0.199	0.390
Epilepsy specialist in future [no]^	**-0.277***	-0.401	-0.208	**-0.290***	-0.427	-0.213	**-0.187***	-0.305	-0.114
Epilepsy specialist in future [2-3 weeks]	0.163	-0.126	0.470	0.153	-0.136	0.499	0.127	-0.121	0.393
Epilepsy specialist in future [within 1-week]	0.114	-0.116	0.371	0.137	-0.127	0.398	0.060	-0.149	0.277
Constant	-0.021			-0.099*			-0.042		
Number of observations	2817			2692			2733		

Number of groups	258			239			252		
Observations per group – min	1			1			1		
Observations per group – average	10.9			11.3			10.8		
Observations per group – maximum	12			12			12		
Wald chi^2(10)	374.67			582.64			435.33		
Log likelihood	-1687.92			-1443.0			-1604.31		

Regression models for significant other participants (with ‘Time’ treated categorically)

Attribute [level]	**Seizure scenario**								
	Atypical Seizure			***Home typical seizure***			***Public typical seizure***		
	ß coeff	*95% CI*[a]		*ß coeff*	*95% CI*[a]		*ß coeff*	*95% CI*[a]	
Access to medical records / care plan (0=no; 1=yes)	**0.456***	0.261	0.779	**0.360***	0.035	0.710	**0.584***	0.344	0.937
Convey –no - stay where you are]^	-0.376	-0.977	0.125	**0.729***	0.039	1.684	0.311	-0.323	1.037
Convey [urgent treatment centre]	0.275	-0.041	0.644	-0.194	-0.760	0.258	-0.023	-0.448	0.385
Convey [emergency department]	0.101	-0.177	0.391	**-0.535***	-0.993	-0.223	-0.288	-0.667	0.017
Time [1 hour]^	0.844	-0.307	2.149	-0.174	-2.490	1.564	0.060	-1.790	1.454
Time [2 hours]	0.295	-0.305	0.928	**0.833***	0.152	2.183	0.509	-0.178	1.395
Time [3 hours]	-0.370	-1.168	0.309	0.265	-0.842	1.514	0.228	-0.648	1.270
Time [6 hours]	**-0.770***	-1.172	-0.575	**-0.924***	-1.380	-0.736	**-0.797***	-1.210	-0.573
Epilepsy specialist advises today (0=no; 1= yes)	**0.826***	0.727	1.104	**0.356***	0.200	0.606	**0.551***	0.408	0.822
GP told (0=no; 1=yes)	**0.354***	0.249	0.549	**0.303***	0.145	0.567	**0.336***	0.203	0.549
Epilepsy specialist in future [no]^	**-0.381***	-0.574	-0.268	**-0.219***	-0.448	-0.075	**-0.263***	-0.463	-0.139

Epilepsy specialist in future [2-3 weeks]	0.395	-0.031	0.873	0.171	-0.636	0.837	0.163	-0.462	0.686
Epilepsy specialist in future [within 1-week]	-0.014	-0.378	0.366	0.048	-0.497	0.803	0.100	-0.326	0.661
Constant	-0.143*			0.031			-0.071		
Number of observations	1139			1108			1044		
Number of groups	105			97			96		
Observations per group – min	1			1			1		
Observations per group – average	10.8			11.4			10.9		
Observations per group – maximum	12			12			12		
Wald chi^2(10)	170.31			327.38			184.02		
Log likelihood	- 662.46			-512.11			-575.86		

Notes: ß coeff, Beta Coefficient; CI, confidence interval; [a]CIs generated by 1,000 bootstrap replications; ^omitted level calculated as -1* (sum ß of other levels); ***p<0.05** others expressed a statistically significant preference for the patient to stay where they were and avoid ED.

Ranking of care package configurations by preference

Highest ranking care package configurations

The top ranked configurations for the scenarios were similar to one another (Table 3). Indeed, for three scenarios the top CP was identical, there after they only varied by 'What happens next' and 'Time'. With respect to 'What happens next', none of the top-ranked configurations featured conveyance to ED.

How current care positioned within rankings

The CP representing current care was amongst the least favoured across the 6 seizure contexts (Table 3). The highest rank it achieved across them for PWE and significant others was 230/288 and 220/288 respectively.

Subgroup analysis

A-priori analyses

For PWE there were sufficient cases to complete 8/12 a-priori subgroup analyses for PWE (Supplementary File 8). The only statistically significant finding was that for the 'Home typical seizure' scenario, those who had visited ED in the prior 12 months had a significant preference to avoid conveyance to ED.

No a-priori subgroup analysis could be completed for significant others.

Post-hoc analyses

All 15 post-hoc analyses could be completed for PWE (Supplementary File 8). Two could be completed for significant others.

Familiarity with the seizure scenario, presence of a 'care plan' and recruitment route were not related to preference. Willingness to access different types of health services during the pandemic only had an impact on preferences when PWE considered a 'Home typical seizure'. Experience of problems accessing specialist services also had an impact on preferences of PWE. When considering an 'Atypical seizure', PWE reporting no problems had a significant preference for assessment, monitoring, and treatment lasting two-hours, and additional epilepsy specialist care within 1-week. In contrast, participants who had experienced problems preferred to be conveyed to a UTC and spend less time (1-hour). For 'Public typical seizure', those who reported no previous access problems had a

TABLE 3 Probability of selection top-ranked configuration and current care configuration by seizure context

		People with epilepsy			**Significant others**			**CP configuration approximating current practice**
		Atypical seizure	***Home typical seizure***	***Public typical seizure***	***Atypical seizure***	***Home typical seizure***	***Public typical seizure***	
	Top ranked configuration	'A'	'B'	'C'	'D'	'A'	'A'	
Attribute levels	The paramedic has access to medical records or a care plan	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✗ No
	What happens next	Stay where you are	Stay where you are	Stay where you are	Urgent Treatment Centre	Stay where they are	Stay where they are	A&E Department
	Time	⧖⧖ 2 hours	⧖ 1 hour	⧖⧖⧖ 3 hours	⧖ 1 hour	⧖⧖ 2 hours	⧖⧖ 2 hours	⧖⧖⧖ 3 hours
	Epilepsy specialists today	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✗ No
	GP told	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
	Additional contact with an epilepsy specialist	✓ Yes within 2-3 weeks	✓ Yes within 2-3 weeks	✓ Yes within 2-3 weeks	✓ Yes within 2-3 weeks	✓ Yes within 2-3 weeks	✓ Yes within 2-3 weeks	✗ No
Seizure context		**Proportion estimated to select different care package configurations**						
Participant type	***Seizure scenario***	***A***	***B***	***C***	***D***	***Same as CP A***	***Same as CP A***	***Current CP (rank out of 288)***
People with epilepsy	Atypical seizure	27%	24%	22%	23%			4% (248)
	Home typical seizure	27%	30%	27%	13			3% (247)

	Public typical seizure	26%	24%	31%	15%			4% (230)
Significant other	Atypical seizure	15%	26%	8%	50%			1% (253)
	Home typical seizure	47%	17%	27%	7%			2% (220)
	Public typical seizure	34%	22%	25%	16%			3% (239)

Notes: GP, general practitioner.

The single CP deemed to best approximate current care configuration was selected and informed by evidence from the literature and the workshop conducted as part of the formative work (Supplementary File 1). England has 10 regional ambulance services. Whilst there is some variation between regions, the information secured and available indicates it is typical that the ambulance crew managing a persons with a seizure disorder will not have access to relevant information about the person's medical history and most (~70%) would ultimately be conveyed to ED. The time being cared for in ED would be ~3-4 hours. The person's GP would typically be notified of the event by letter, but the person will not be seen by or referred on to an epilepsy specialist (such as an epilepsy nurse or neurologist).

significant preference to avoid going to the ED, compared to those who reported problems, where none of the options for 'What happens next' made a statistically significant contribution to preference.

DISCUSSION

Main findings

The DCEs provided novel insights into the post-seizure care preferences of PWE and their significant others. The findings reveal that for the seizure scenarios explored, most PWE and significant others want a configuration of care markedly different from what is currently offered.

In all instances, the DCEs show service users want: the paramedic to have access to the patients' medical records or 'care plan'; for a health professional with specialist training in neurology (e.g., an epilepsy nurse, neurologist) to be available to advise their paramedic; for the time it takes to be assessed, monitored and treated to be less than 6-hours; and for the incident to result in appointment arrangement with an epilepsy specialist (be it within 1 week or two to three). In terms of 'What happens next', there is a pattern of preferring to avoid ED and for the patient to remain where they are, or in one instance to go to a UTC. The only attribute in the preferred CP configurations that aligns with current care is that users want their GP to receive a report from the ambulance service regarding the incident.

Implementing findings

Whilst there were some differences in the care preferences of people for the different seizure scenarios, the main message was that substantial commonality exists across them. This, along with the finding that care preferences do not appear to be profoundly different for key subgroups means a *single* CP configuration might, if deemed appropriate by stakeholders, be deployable for all seizure contexts.

Interestingly, the slight differences that existed between seizure scenarios in preferences holds face validity. For instance, participants ascribed most value to paramedics having access to medical records or 'care plans' for seizures in public – i.e., when the call for an ambulance is often made by a bystander and when they are less likely to be accompanied by someone who can share medical history to contextualise the presentation.[57-59] They also expressed a stronger preference for a specialist to be able to advise paramedics and for their GP to be notified when the seizure was atypical.

Only a few differences existed between PWE and significant others in their preferences. This is noteworthy given we asked significant others to express *their* preferences for the care of the PWE (even if they differed from the patients). This lends further support to the potential of a single CP configuration.

The differences that did exist between PWE and significant others in their preferences may be attributable to the unique profile of the PWE that significant others knew. Specifically, for the attribute 'Time' when considering 'Home typical seizure', significant others prefered for the time it took to be cared for to be 2 hours, rather than 1 like PWE. Their desire for more time in the presence of a paramedic could be because the patients that significant others knew were often prescribed rescue medication and more likely to have an intellectual disability. Benzodiazepines are associated with longer recovery times [60, 61] and intellectual disability means it can take longer to know whether someone is returning to their baseline and so safe to be left.[62]

For the attribute 'What happens next' when imagining an 'Atypical seizure', significant others preferred conveyance to a UTC, rather than 'Stay where they are' like PWE. As well as more often being prescribed rescue medication, the patients that significant others knew were reported to have had more contact with the ambulance service. Consequently, the significant others might have been aware that conveyance to a health facility after benzodiazepine treatment is recommended (unless a 'care plan' states otherwise).[63]

Which attribute changes to prioritise?

Delivering one of the preferred configurations in its entirety might not immediately be within the capability of ambulance services and their partners. Which configuration/s strikes the optimal balance between service user acceptability and NHS feasibility is addressed in our accompanying article (see accompanying submission). Nevertheless, it is reassuring that the DCE data indicates even limited (i.e., single attribute) changes could improve the situation. Attributes with the most consistent, strong and positive influence were having a specialist able to advise paramedics on the day and providing paramedics with access to medical records or 'care plans'.

Strengths and potential weaknesses

A key strength of the DCE was the breadth and depth of the formative work informing it. Whilst novel, it aligns with good practice [48, 49, 64] and provides a 'worked example' for those interested in developing CPs.[65]

The COVID-19 pandemic disrupted original recruitment plans. One consequence was it increased the time between a person's contact with the ambulance service and invitation. This likely accounts for the low response from that recruitment route (~12%). Despite this, usable preference data was secured from a broadly representative sample of ~600 service users from across England. This is the largest study of the target population.

The sample size achieved was sufficient to permit an examination of the preferences for all seizure scenarios and participant types. It was not sufficient to allow all subgroup analyses of interest. Those that could be completed showed no significant differences in existed in the care preferences of participants recruited by the two routes. Moreover, we did not find evidence that COVID-19 dramatically affected care preferences.

Sample representativeness was a strength. However, we do acknowledge that the online nature of participation could have excluded an important, less privileged minority of people [66] (96% of UK households have internet access [67]). It may also help explain why our sample was ~8-years younger than expected.

One notable difference between our sample and the target population was its higher contact (86%) with epilepsy specialists in the prior 12 months. NASH-3 found 52% of PWE attending ED had such contact.[11] The difference may be attributable to how we obtained this information. We asked participants whether *"they had seen or spoken to a doctor or nurse that specialises in epilepsy?"*. NASH, in contrast, relied on what was recorded within ED records. The higher contact might also because of when we recruited. During the initial months of COVID-19, some specialists initiated contact with PWE in their communities to inform them of care delivery changes.

CONCLUSION

For the three common seizure scenarios investigated, PWE and significant others want a care configuration markedly different to current provision. There is a pattern of preferring to avoid conveyance to ED and for the patient to remain where they are. Not all elements of the care pathways preferred by service need to be offered to improve things from the users' perspective. The elements likely to have most predictable benefit are having a specialist available to advise paramedics on the day and providing paramedics with access to patient medical records/ 'care plan'.

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DECLARATIONS OF INTERST

None.

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Supplementary File 1: Formative research to develop Discrete choice experiment

OVERVIEW

A range of issues require attention when developing a Discrete Choice Experiment (DCE). Chief amongst these is the need ensure the attributes used are those which are pertinent to the target audience, capable of being 'traded', and, in the current context, plausible characteristics of an alternative care pathway (CP). There is a natural limit to the number of attributes and levels that can be used within a DCE. The more there are, the more complex the choice task becomes and the potential for participant burden and missing data increases.

We therefore undertook an extensive, sequential body of formative work informed by best practice recommendations.[1, 2] To help better understand users' decision calculus, attributes of importance to them were first identified via a ranking exercise (Step 1). These were then refined and plausible levels for them developed via a Knowledge Exchange event with service providers (Step 2). A draft DCE survey was then developed and piloted with service user representatives (Step 3).

The process were overseen by a multidisciplinary DCE design panel who considered the evidence from them different steps and refined the DCE accordingly. The panel included expertise in DCEs (EH, DH), emergency medicine (SG), neurology (AGM), paramedical science (MJ), general practice (JMD) and psychology (AN), as well as having service user representation. We describe the steps below.

STEP 1 - RANKING EXERCISE

Design

Part of COLLABORATE [3] involved face-to-face semi-structured interviews being conducted with people with epilepsy (PWE) from the target population, and, where possible, a significant other. Full details of these, including their ethical approval, is described by McKlinay et al.[4] Key to the current discussion is that towards the end of the interviews, PWE were invited to complete a ranking exercise (Table S4.1). It involved participants being presented with five care attributes potentially relevant to the choice of CP, identified by the research team based on findings from previous studies, policy and clinical experience. These were printed on 'show cards', along with brief descriptors. Participants were asked to consider these and state whether they felt anything important was missing; the qualitative interviewer

Table S4.1 Guide for ranking exercise used

***Ranking exercise**	**We are keen to understand what type of care people would prefer when they have a seizure.** **Here are some factors** that you have mentioned / or we think may be important …** *Interviewer displays show cards in a random order in front of the participant.* Looking at these cards: 1. **Is there anything missing?** Are there any other factors what would affect your choice? *Interviewer writes additional factors on blank cards and places them alongside the pre-defined cards in front of the participant.* ***Record any self-nominated factors on the interview record sheet*** 2. **Which are the most important factors in your opinion?** Can you pick up all the cards that would most likely affect your decision? *Explain that these factors can have been experienced, or not; and include any that were self-nominated in this exercise. Clear the remaining cards from the table.* **3. Now, can you rank these in order of most important to least important?** *Check the order the interviewer places the cards is i.e. So, you think 'X' at the top is the most important? Encourage the participant to "think aloud" and explain their ranking. If participants find it hard to rank certain factors, or align them side by side, explore why.* ***Record the rank scores on the interview record sheet.***

Show cards for ranking exercise

Where the ambulance takes you
Where the ambulance takes you (e.g. A&E, Urgent treatment centre).

Care provider
The healthcare professional responsible for your care when you get there.

Waiting time
How long you have to wait before you see the healthcare professional.

Tests
The type of tests the health professional could carry out immediately if needed

Follow-up
Referral to see a health professional with specialist training in epilepsy

Ranking exercise interview record sheet
Participant ID: _ _ /_ _ / _ _
Interviewer ID _ _

Factor*	Rank Results (insert 1-5) 1 = most important 5 = least important X = not selected
Anything Else? **Write here:**	
Anything Else? **Write here:**	
Anything Else? **Write here:**	
Anything Else? **Write here:**	
Anything Else? **Write here:**	
Anything Else? **Write here:**	
Where the ambulance takes you	
Care provider	
Waiting time	
Tests	
Follow-up	

Notes: In study documentation and interview guides, we used the term "Accident and Emergency", as it is often the term used to describe EDs in the UK. Similarly, the term "paramedic" is often used interchangeably to describe ambulance staff, including advanced paramedics and first responders Where possible, we used participants' own description of ambulance staff.

(AMc) helped participants recall characteristics they mentioned during their interview and wrote them onto spare 'show cards'. The five pre-defined attributes were:

1) '*Where the ambulance takes you',*
2) 'The health care responsible for care when you get there',
3) 'How long you have to wait before you see that healthcare professional',
4) 'Tests that can be carried out immediately'
5) 'Number of people who are referred on to a health professional with specialist training in epilepsy'.

Participants were asked which of those on display were the most important in their view and would likely most affect their choice of care post-seizure. To then help reduce the number of care attributes to a number manageable for a DCE and improve face validity, participants were asked to rank those selected in order of importance, from most to least important. Participants were encouraged to "think aloud" when making their choices. The choices were recorded by AMc, as was the corresponding dialogue (which was subsequently transcribed verbatim).

Interim analysis of the ranking scores was completed to identify any areas that required further exploration within the subsequent interviews to assist with the assessment of attributes for use within the DCE.

Approval for this work was provided by the King's College London Psychiatry, Nursing and Midwifery Ethics Committee (LRS-18/19-10353).

Analysis

All ranked attributes were analysed quantitatively in Excel by EH using standardised rank scores for each attribute.

Rank score = (#attributes – rank + 1) / n

Where:

rank = rank position (1 = most important)
n = number of attributes selected by the participant

Additional attributes nominated by individuals were categorised according to a thematic framework by EH and assessed against a set of pre-defined criteria (Table S4.2) to determine their suitability as a potential attribute for the DCE. The framework was developed by EH, with assistance from AMc and the wider research team.

Table S4.2 Pre-defined criteria used to determine which attributes were suitable for use

Inclusion	**Exclusion**
Attribute is: • Important to patients and policy makers; • Plausible; • Capable of experimental manipulation / being traded (e.g., tangible characteristic rather than a viewpoint).	*Attribute is:* • Too close to the latent construct (i.e., utility derived from the CP); • Intrinsic to personality; • Overlapping with alternative attribute (if so, consider combining attributes); • A characteristic of the seizure scenario itself; • Independent of CP or need for emergency care.

Notes: Criteria were adapted from Coast et al.[1]

Results

Twenty-five people with epilepsy were interviewed and their characteristics are described by McKinlay et al. Of them, 23 completed the ranking exercise. Five had a significant other present when completing it.

In addition to the pre-specified attributes, the 23 participants together nominated 13 additional attributes for consideration (Table S4.3). Four of these were nominated by more than one participant.

When asked to select the most important to choices regarding post-seizure care, the average number of attributes selected was 4.84 (range 3 to 5). Waiting time was the most selected (n=20). Care provider had the highest rank score of the pre-defined attributes (3.68), whilst safety was the highest ranked self-nominated attribute.

Table S4.3 Attribute ranking exercise results

Pre-defined Attributes	**Count selected**	**Mean score**
Care provider	19	0.67
Where the ambulance takes you / Location of care	19	0.63
Waiting time	20	0.63
Tests	18	0.47
Follow-up	19	0.39
Self-nominated attributes	**Count nominated**	

Reassurance	3	-
Contacting next of kin	2	-
Safety	2	-
Linked communication*	1	-
Care plan awareness*	1	-
Education	1	-
Check over	1	-
Right equipment	1	-
Going home	1	-
Training	1	-
Immediate help	1	-
Trust	1	-
Patient group/support	1	-

Notes: Mean score = mean rank score (max 1 = most important). *Following interim analysis and qualitative exploration with participants, 'Linked communication' and 'Care plan awareness' were grouped together as they were deemed to represent the same attribute.

Decisions and reflections of DCE design panel to Step 1 findings

DCE panel decisions and reflections following interim analysis

The interim analysis of the ranking scores led the DCE design panel to request further qualitative exploration with subsequent participants of: (i) the types of tests they were considering as important; (ii) how they understood reassurance as a construct of care being provided; (iii) what their understanding was of the term 'linked communication', and (iv) what overlap there was between the nominated attribute 'care provider' and location of care (where the ambulance takes you).

i) Types of tests people were considering

For some people, being in a place that has access to tests '*just in case needed'* was reported as important. For other participants they wanted the tests for monitoring of their condition and for the information from them to assist with their own self-management or for discussion with their routine care providers. The tests mentioned as being valued most frequently included: magnetic resonance imaging; 'brain scans' more broadly; laboratory tests/ blood tests; electrocardiogram and blood pressure checks.

Whilst it was acknowledged that the type of tests health professionals could carry out immediately if needed was important to patients, the design panel considered it implausible as an independent characteristic of a CP. Essential tests would be provided based on clinical necessity and were intrinsic to the emergency care episode, thereafter desirable tests or equipment would be restricted by location of care and therefore overlap with the other attribute *“what happens next”*

ii) ‘Reassurance’ as a construct of care being provided

Participants described how *reassurance* was derived from various actions, including the ability for “someone” (be it the paramedic or another healthcare professional) to: instruct the significant other what to do, intervene to stop recurrent seizures, monitor vital signs or provide immediate care in case of injury.

The design panel considered that this evidence indicated *reassurance* represented the utility derived from receiving emergency care, and so excluded this additional attribute from the selection process.

iii) Understanding of the term ‘linked communication’

Upon questioning, people reported *reassurance* (also self-nominated) when they were cared for by one health service and found the records from their usual service were also available to the healthcare team there. One participant expressed this as meaning he “felt less alone and there was a team of people supporting” him. The term ‘linked communication’ was also interpreted by some participants as a characteristic of decision-making, with some saying they wanted their healthcare professionals to involve them more in the process of their healthcare.

Based on the above evidence, the design panel determined that ‘linked communication’ would need to be specifically described in the DCE to ensure the survey measured preferences for a tradable characteristic of a CP, rather than ‘experience’ of accessing specialist services/decision-making. It was noted, however, that the findings of a service of providers also completed for COLLABORATE [4] found regional variation regarding linked communication/ access to medical records.

The DCE design panel, therefore, proposed defining the attribute as: *Access to care plan / medical notes,* and proposed further discussion at the Knowledge Exchange Event to gain a clear understanding of the importance and plausibility of this characteristic.

iv) Overlap between attributes

Overlap was noted as existing between the predefined attributes ‘care provider’ and ‘follow-up’. Participants reported that an important aspect of ‘care provider’ was them being someone *"with specialist training in epilepsy"* and when considering follow-up people wanted to ensure that this was by *“someone who is connected to a neurologist “.* Pre-defined attributes were also combined with self-nominated care characteristics by one participant: *"care provider" (safe), Waiting time (monitoring), Tests (reassurance).*

DCE panel decisions and reflections following completion of entire ranking exercise

Attributes selected

Based on the evidence from the ranking exercise and discussions of these findings, the panel requested 6 attributes described as version 1.1 in Table S4.4 be taken forward for discussion at the Knowledge Exchange event for potential use within the DCE. The panel's decision was based on the following.

All five pre-defined attributes were selected within the ranking exercise at least once by participants. However, after considering the findings from further qualitative exploration, the panel excluded the pre-defined attributes '*Care provider*' and *'Tests'* from use within the DCE since they overlapped with the predefined attribute *'Location of care'* and as such were not independent characteristics of a CP.

The panel noted that the attribute '*Location of care'* would require detailed introduction at the beginning of the DCE experiment to ensure respondents understood the names and features of the potential level for this attribute (e.g., what an 'Urgent Treatment Centre' was).

The panel also recommended that the attribute '*Waiting time*' be modified to the more neutral term '*Time',* and the prose accompanying it expanded to include time spent being assessed, monitored, and treated since some PWE expressed value in being in a safe location, monitored by a health care professional.

The attribute '*Follow-up'* was identified as being a broader construct than initially described and so was separated to create 3 attributes. One relating to immediate specialist care at the time of the incident, one to future specialist care, one to non-specialist/primary care involvement.

With regards the 12 self-nominated attributes, the panel considered that only one of them – namely '*Access to care records'* – satisfied the eligibility criteria for use within the DCE.

Attribute levels

Based on findings from COLLABORATE's survey of service providers,[4] as well as their own expertise and clinical experience, the design panel generated draft levels for the V1.1 attributes (Table S4.4) and asked for these to also be considered at the Knowledge Exchange event for potential use. In generating the levels, the panel sought to ensure the levels accounted for relevant major anticipated changes in the future – such as longer emergency department waiting times and more integration of services and sharing of patient records. Potential interactions, properties of the experimental design (e.g., number of choice sets) and

Table S4.4 Overview of attribute selection and refinement process

V1.0	V1.1	V1.2	V1.3	V1.4
Attributes presented in or emerging from ranking exercise	***Attributes presented at Knowledge Exchange Event***	***Revised Post 1c for use at DCE Development Panel***	***Presented at Cognitive Interviews***	***Final Used in WP2b***
Where the ambulance takes you Where the ambulance takes you (e.g., A&E, Urgent treatment centre)	**Location of care** Where you are assessed and treated. *Levels (3):* • *At home / on the scene* • *Urgent Treatment Centre* • *Emergency Department.*	**What happens next** Where you go once the paramedic has assessed you. *Levels (3):* • *You remain at home/ at the scene (<2 hours)* • *You are taken to an Urgent Treatment Centre (2-3 hours)* • *You are taken to a hospital A&E department (4+ hours)*	**What happens next** Where you go once the paramedic has assessed you *Levels (3):* • *You remain at home / the scene* • *Urgent Treatment Centre* • *A&E Department*	**What happens next** Where you go once the paramedic has assessed you. *Levels (3):* • *Stay where you are* • *Urgent Treatment Centre* • *A&E Department*
Care Provider The healthcare professional responsible for your care when you get there				
Tests The type of tests the health professional could carry out immediately if needed				
Waiting time How long you have to wait before you see the healthcare professional	**Time** The time you spend being assessed, monitored and treated *Levels (3):* • *1-hour* • *2-3 hours* • *4 hours +*		**Time** How long it takes to be assessed, monitored and treated by emergency healthcare professionals today *Levels (4):* • 1-hour • 2-hours • 3-hours	**Time** How long it takes to be assessed, monitored and treated by emergency healthcare professionals today. *Levels (4):* • 1-hour • 2-hours • 3-hours;

			• 6-hours	• 6-hours
Follow-up Referral to see a health professional with specialist training in epilepsy	**Involvement of Specialist Services** Involvement of a health professional with specialist training in epilepsy *Levels (3):* • *None;* • *Within 24-hours by phone;* • *Involved in care episode at location of care (by telephone if home).*	**Involvement of Specialist Services** Involvement of a health professional with specialist training in epilepsy *Levels (3):* • *No* • *Yes: Someone with specialist training is involved in your care (by telephone if home / at the scene)* • *Yes: Someone from an epilepsy team in your area (by telephone if home / at the scene)*	**Involvement of Specialist Services** Involvement of a health professional with specialist training in epilepsy *Levels (3):* • *No* • *Yes: Someone with specialist training is involved in your care (by telephone if home / at the scene)* • *Yes: Someone from an epilepsy team in your area (by telephone if home / at the scene)*	**Epilepsy specialists today** A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today *Levels (2):* • No • Yes
	Follow-up How long you have to wait for follow-up by epilepsy specialist services after this episode *Levels (4):* • *Not referred;*	**Future contact with an epilepsy specialist.** Length of time between the paramedic attending and contact with an epilepsy doctor or nurse. *Levels (3):* • *Within 5-working days*	**Future contact with an epilepsy specialist.** Length of time between the paramedic attending and contact with an epilepsy doctor or nurse. *Levels (3):* • *Within 5-working days*	**Additional contact with an epilepsy specialist.** The emergency healthcare professionals treating you today arrange for you to have an appointment with an epilepsy specialist. *Levels (3):* • *No* • *Within a week*

	• *Within 5-days by telephone;* • *2-4 weeks;* • *4 weeks +*	• *2-3 weeks* • *Over 4 weeks*	• *2-3 weeks* • *Over 4 weeks*	• *2-3 weeks*
	Contact with your GP. The paramedic attending will contact your GP to inform them of the care you have received *Levels (2):* • *No* • *Yes*	**Contact with your GP.** Your GP will be notified that an ambulance was called out to you *Levels (2):* • Yes • No	**Contact with your GP.** Your GP will be notified that an ambulance was called out to you *Levels (2):* • Yes • No	**GP told.** Your GP will receive a written report from the ambulance service. *Levels (2):* • Yes • No
Self-nominated during ranking part 1: ***"Awareness of care plan"*** ***"Linked communication"***	**Access to care plan.** The paramedic attending is able to access your care plan (and record the care you receive) in your epilepsy case notes *Levels (2):* • *No access to care plan* • *Yes access to care plan.*	**The paramedic has access to your [a] care plan** The paramedic attending is able to access a plan that explains what you require when you have a seizure. *Levels (2):* • No: access to care plan • Yes: access to care plan	**The paramedic has access to a care plan or medical records** They can read about what you require when you have a seizure. *Levels (2):* • No • Yes	**The paramedic has access to medical records or a care plan.** They can read about what you require when you have a seizure. *Levels (2):* • No • Yes

implications for analysis (e.g., continuous/categorical levels) were also discussed when deliberating the levels.

Three attributes (i.e., Location of care, Time, and Involvement of Specialist Services) were assigned 3 levels, two attributes (i.e., ‘Contact with your GP’, ‘Access to care plan’) were binary, and one (i.e., ‘Follow-up’) had 4 levels.

STEP 2 - KNOWLEDGE EXCHANGE EVENT

Design

A face-to-face Knowledge Exchange (KE) event with service provider representatives was run in London in October 2019. It involved representatives attending a one-day, in-person, workshop and being asked to use their clinical experience and expertise to help further refine the draft attributes, ensure the levels specified for them were plausible and provide feedback on the vignettes. The team had successfully used this approach for a previous DCE project.[5]

Approval for this formative work was provided by the Health Research Authority and the National Research Ethics Service Committee West Midlands–Solihull (19/WM/0012).

Recruitment

To take part, representatives needed to be able to provide informed consent, be aged ≥18 years, live in the UK, work within the ambulance service (front-line or managerial role) or as a neurologist or epilepsy nurse specialist and be able to be attend and participate in the scheduled event.

Representatives were identified from those services that took part in COLLABORATE’s survey of service providers [4] and said they and/or their service wanted to be informed about future parts of the project. A total of n=69 respondents expressed an interest. A sampling framework was created to support the recruitment of representatives from different regions of England.

Using the framework, invitations were posted and/or emailed to designated contacts at n=10 ambulance services and n=10 neurology services. It was possible for recipients to pass the invite onto someone they considered more suitable for participation within their organisation. Recipients could respond to the invitation by using an enclosed response slip or by contacting the team by phone or email.

To help ensure the voice of service users was present in all formative discussions, a representative from Epilepsy Action was also present during the meeting.

All those participating provided written informed consent and representatives were reimbursed for travel.

Process

Discussions were, at different time points, facilitated by AN and EH. In advance of the event, participants had been sent an agenda for the day.

On the day, participants first heard short presentations from the research team (AN, AM, AMc, EH). These covered the project's background, an introduction the DCE method and summary of the findings from the formative research conducted to date. Participants were then presented with the V1.1 attributes.

For each attribute, participants were asked to verify the attribute represented a characteristic of a CP, whether the levels were plausible and described using appropriate language (i.e., how they might describe the attribute to patients). During discussion, EH enquired about the experimental potential of the attributes to ensure the utility function was adequately described and that attributes were capable of being traded. Finally, participants were asked for their views on the scenario vignettes.

Field notes were taken and the session audio-recorded for subsequent full transcription and analysis.

Results

Participants

Fifteen of those invited confirmed a willingness to take part and were booked to attend; 13 ultimately attended the workshop. Attendees comprised: n=6 paramedics, n=4 consultant neurologists, n=2 epilepsy nurse specialists and n=1 user group representative. All came from different organisations and there was wide geographical spread as planned. The event lasted 6 hours, with a comfort break and lunch period included.

Feedback from participants on draft attributes and levels

Participants agreed the 6 candidate attributes were all characteristics of an alternative CP. Overall, the attributes were considered likely pertinent to patients (and health professionals and policy makers), plausible, capable of being traded and suitable for inclusion in the DCE.

Participants had the following specific feedback for the different attributes.

1) Access to care plan

KE participants advised that based on their experience service users might be unfamiliar with the term 'care plan'. It was highlighted that many people do not have one. Moreover, the content of any such plan may vary between regions.

2) Location of care

Concern was raised that the attribute, as presented, might incorrectly raise an expectation amongst DCE participants that all treatment forms could be delivered at all three attribute levels. It was also considered that what treatment could be provided would depend on the role and experience of the attending ambulance clinician and where the patient was located geographically since infrastructure varies.

For these reasons, participants suggested the attribute be refined to ‘What happens next’, that any reference to ‘treatment’ be removed and that within the attribute description it be stated that ‘What happens next’ refers to the period *after* the patient has been initially assessed by the attending ambulance clinician (since an alternative CP would only be appropriate if the attending clinicians has deemed this to be clinically safe).

The participants also had important feedback relating to the proposed levels. Ambulance representatives stated that whilst it was identified as possible via the survey of service providers,[4] transporting a patient home who had had a seizure in public, rather than conveying them to ED was not widely offered or feasible. Thus, they recommended changing the level ‘At home /on the scene’ to ‘Stay where you are’.

In the context of an atypical seizure presentation there was some discussion as to whether all three levels for the attribute were plausible. One epilepsy specialist was of the view that after an atypical seizure conveyance to ED was *always* necessary, not least because they believed it should mean they receive input into their care from an epilepsy specialist. For them, using the levels of ‘Stay where you are’ and ‘Urgent Treatment Centre’ were not inappropriate for the atypical seizure scenario.

3) Time

KE participants advised restricting the level used for this attribute to 2-hours when the attribute ‘Where next’ took on the level of ‘Stay where you are’ and to 3-hours when it took on the level of ‘Urgent Treatment Centre’. When ‘Where next’ took on the level of ‘ED’, the representatives said “4-hours +” should be used. These changes they said would make the attribute levels more feasible and realistic. They did acknowledge though that there might be instances during periods of “‘winter pressures’” when these times might not be achievable for various reasons.

4) Involvement of specialist services

Views as to the feasibility of the different levels for this attribute varied, partly reflecting the different extents to which it was part of current practice in different regions. Participants from the ambulance service highlighted how the challenge of them contacting specialist services varied depending on the locality that they were operating within. Participants from epilepsy specialist services wanted to emphasise that working hours and capacity needed to be accounted for within the levels for this attribute. The level “Within 24-hours by phone” was not considered plausible by all epilepsy specialists.

5) Follow-up

It was highlighted that the patient may be accessing the CP in a different geographical area to the one that their specialist epilepsy service was located in. Clarity on this being future contact with the patient’s specialist service (rather than that of the emergency care region) was important, as some people may not be aware that there is a local service. It was advised that the description should focus on the length of time between the emergency episode and contact with an epilepsy doctor or nurse.

6) Contact with your GP

Participants form the ambulance service described how what happens at present in regards this comprises more of a notification to the patients GP of the incident, rather than a full ‘report’ of the care received. It was recommended that the attribute by reworded to reflect this.

Decisions and reflections of DCE design panel following Knowledge Exchange exercise

The panel welcomed the KE participants’ feedback. They accepted most but not all their suggestions. The changes served to create V1.2 of the attributes in Table S4.4. The details are as follows:

1) Access to care plan

Based on the KE participants feedback, the panel agreed the DCE would require an introduction that provided a detailed explanation of the term ‘care plan’ to participants and what they can contain. They also stated that the care plan attribute would need to explicitly refer to access to medical records since this is an aspiration for current practice and for many this is what ‘care plan’ in an emergency comprises.

2) Location of care

The panel, with input from clinicians within the research team, endorsed all the changes recommended by the KE participants. The exception to this was the comment from one epilepsy specialist that suggested the level ‘Stay where you are’ should not be used for the atypical seizure presentation. The reasons for the panel declining that last suggestion were as follows.

Firstly, the parameters of the atypical seizure presentation to be used within the DCE were restrictive. The presentation as described does not meet the requirements for ED care on clinical grounds (i.e., it was an epileptic seizure in a person with established epilepsy from which they had recovered from, but which was different in some way to their usual experience. No injuries were incurred).

Secondly, the DCE was only asking for a person's care preferences in a hypothetical situation. It was not making recommendations as to the suitability of the approach.

Finally, one reason the representative expressed a need for all atypical seizure presentations to visit ED was based on the view that not going to ED would deprive the person from input from an epilepsy specialist. This does not though reflect clinical reality. Whilst NICE guidelines [6]suggest this should happen in some form, most people with established epilepsy who visit ED are not seen by a specialist at the time, nor are they followed up by one.[7] Moreover, within the DCE it was still possible for a person to stay where they were or be conveyed to a urgent treatment centre and *still* receive specialist follow-up.

3) Time

The panel accepted the recommendations of the representatives and noted that the experimental design would need to allow for conditions between 'Time' and 'Location of Care' to ensure the choices remained plausible.

4) Involvement of specialist services

On reflection the panel said this attribute should be refined to focus on specialist advice *during* the care episode, thus minimising overlap with the other attribute 'Follow-up'.

5) Follow-up

The panel accepted the KE participants feedback and agreed that the attribute should not indicate that health professional with specialist training in epilepsy would be known to the patient.

When presented to the KE participants the attribute 'Follow-up' had 4 draft levels (i.e., Not referred; Within 5-days by telephone; 2-4 weeks; and 4 weeks +). The panel on reflection stated that the level for this attribute of "Not referred" be removed given the earlier noted NICE recommendation of follow-up in all cases. The panel also suggested collapsing the remaining levels to help reduce the size of the experiment to a more manageable number of choice-sets.

6) Contact with your GP.

The language used for this attribute was amended in line with the participants suggestion.

STEP 3 - PILOTING AND FINALISING SURVEY

EH, AM and AN developed a draft version of the DCE survey and a standardised set of instructions for piloting. The instructions explained the context of the DCE survey to participants, introduced them to the attributes and their levels. Participants were asked to use their imagination as best they could if they (or the person with epilepsy they know) had not found themselves in one of the seizure scenarios used in the DCE.

To maximise engagement, accessibility and reduce reading burden,[8] a 7-minute professionally produced animated video was developed that relayed most of the instructions. Participants were to be requested to watch it before completing the survey. The animation was narrated and included subtitles and developed with the input of service users, researchers and clinicians.

Pilot interviews

Design

The pilot involved working closely with persons from the target population to iteratively refine the DCE survey. It sought to identify any changes required to ensure survey length was acceptable and that participants completed the task as intended.

Pilotees were asked to complete the draft of the online DCE survey in the presence of a research associate (AM). Using the cognitive interview technique, pilotees were encouraged to ‘think aloud when making their choices. They were also asked to consider their preferred presentation of the attributes (e.g., use of text, pictograms). Interviews were audio recorded and field-notes taken.

Recruitment

Pilotees were identified from the Patient and Public Involvement (PPI) group that was established for the project with the support of Epilepsy Action. Persons on it were all aged ≥18 years and either had epilepsy or were a significant other to someone with epilepsy. Beyond being willing and able to independently serve on such a group in English, no other eligibility criteria were applied. Recruitment continued until data saturation was achieved.

Results

Pilotees

Twelve PPI members were enrolled and provided feedback on the DCE survey. Saturation in terms of feedback was occurring after around 6 pilot interviews. However, to verify the refinements made to the DCE based on their feedback were sufficient, an additional 6 PPI members completed the DCE.

Feedback received and changes made to DCE survey

The survey was well received by the PPI members and their understanding of the majority of the DCE and wider non-DCE was as intended. Respondents did nonetheless request some important changes which the panel made. The changes served to create the finalised attribute set which is labelled V1.4 in Table S4.4.

The changes made based on PPI feedback were as follows. Firstly, to ensure clarity of meaning for the two attributes describing current and future involvement of a health professional with specialist training in epilepsy, PPI members requested that ‘Involvement of specialist services’ be changed to ‘Epilepsy specialist today’, whilst ‘Future contact with an epilepsy specialist’ be changed to ‘Additional contact with epilepsy specialist’.

There was variation in how the PPI members interpreted the two ‘yes’ levels for the attribute ‘Involvement of specialist services today’. Consequently, the panel decided to simplify this to a single ‘Yes’ level.

PPI members also challenged the levels used for the attribute ‘‘Additional contact with epilepsy specialist’. They had commonly experienced ‘No’ follow-up following instances of urgent care and so requested that this level be included to help ensure face validity. The panel made this change. Finally, following the recommendation of PPI members, *Contact with GP* was simplified to *GP told.*

In addition to the above changes requested by PPI members, the DCE panel also decided it was necessary to amend the survey in view of the COVID-19 which started to impact the UK whilst piloting was occurring. At this point, government requests to ‘socially distance’ were emerging and changes in the way people were using emergency services were becoming evident.[9] Therefore, respondents were asked to make their choices based on their preferences for care outside of the pandemic, termed ‘normal times’ in the survey. Feedback was specifically received on this amendment to wording from the pilotees who received this amended version of the DCE. The animation was also updated and the close of the survey was updated to include a signpost to information on COVID-19 and Epilepsy.

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Supplementary File 2 Non-DCE questions asked of participants by survey in order of appearance

Number		Question	Answer Options
People with epilepsy	Significant others		
1	1	*Are you doing this survey because you have epilepsy or because you know someone who has epilepsy?*	• I am a person with epilepsy; • I know someone with epilepsy
2	2	*Please tell us your date of birth*	• Free text
3	3	*Are you male or female?*	• Male; • Female
4	4	For PWE: *Here are some types of epileptic seizure. Which have you ever experienced?* *(You can select more than one. Please select the one(s) that come closest to what you have experienced)* For ‘significant other’: *Below are some different types of epileptic seizures. Which type(s) do you think the person with epilepsy that you know has ever experienced.* *(You can select more than one. Please select the one(s) that come closest to what you believe they have experienced)*	• Seizures where I am/they are aware of what is happening (such as focal seizures); • Seizures where I am/they are confused or only partially aware (such as complex focal seizures); • Seizures where I/ they briefly lose consciousness (such as absences; tonic; atonic seizures); • Seizures where I/ they lose consciousness and jerk or convulse (such as tonic clonic seizures)

Number		**Question**	**Answer Options**
People with epilepsy	Significant others		
5	5	Presented if >1 type selected for Q4) For PWE: *In the past 2 years, which of these types of epileptic seizures would you say is your usual type(s)? By usual, we mean what some people call their "normal", "run of the mill" type of seizure (You can select more than one.)* For 'significant other': *In the past 2 years, which of these types of seizure would you say is their usual type(s)? By usual, we mean their "normal", "run of the mill" type of seizure of seizure. (You can select more than one)*	• Seizures where I am/they are aware of what is happening (such as focal seizures); • Seizures where I am/they are confused or only partially aware (such as complex focal seizures); • Seizures where I/ they briefly lose consciousness (such as absences; tonic; atonic seizures); • Seizures where I/ they lose consciousness and jerk or convulse (such as tonic clonic seizures)
6	6	(Presented if >1 type also selected for Q5) For PWE: *Which one of these types is mostly likely to lead you to have contact with the emergency health services? (Select just one)* For 'significant other': *Which one of these seizure types would mostly likely lead the person you know with epilepsy to have contact with the emergency health services? (Please select only one)*	• Seizures where I am/they are aware of what is happening (such as focal seizures); • Seizures where I am/they are confused or only partially aware (such as complex focal seizures); • Seizures where I/ they briefly lose consciousness (such as absences; tonic; atonic seizures);

Number		Question	Answer Options
People with epilepsy	Significant others		
			• Seizures where I/ they lose consciousness and jerk or convulse (such as tonic clonic seizures)
7-18	7-18	DCE questions for first scenario randomised to (see Table 9 for scenarios)	• 12 DCE binary choice questions
19-30	19-30	DCE questions for second scenario randomised to (see Table 9 for scenarios)	• 12 DCE binary choice questions
31	31	*What is your home postcode?* *(If you do not know it, please type in your address, including the area, village or town name. You do not need to tell us your house or flat name or number.)*	• Free text
-	32	For 'significant other': *How do you know the person with epilepsy that led you to take part in this study?* *The person I know is my …*	• Brother or Sister; • Daughter or Son; • Wife, Husband or Partner; • Other, please specify
-	33	For 'significant other': *How old is the person with epilepsy that you know?* *(If you do not know exactly, please give us your best guess)*	• Free text
	34	For 'significant other': *Are they male or female?*	• Male; • Female
32	35	For PWE: *Do you have a learning disability?*	• • Yes;

Number		Question	Answer Options
People with epilepsy	Significant others		
		For 'significant other': *Do they have a learning disability?*	• No
33	36	For PWE: *How old were you when you were first diagnosed with epilepsy?* *(This might be different to when you had your first seizure)* For 'significant other': *How old were they when they were first diagnosed with epilepsy?* *(If you do not know exactly, please give us your best guess. The answer might be different to when they had their first seizure)*	• Free text (- years old)
34	37	For PWE: *Have you ever been diagnosed with non-epileptic attack disorder (NEAD)? (even if the diagnosis might have proved to be wrong). (Other names used are non-epileptic seizures (NES), non-epileptic events, psychogenic seizures, functional seizures, dissociative seizures, pseudoseizures or pseudoepileptic seizures)* For 'significant other': *Have they ever been diagnosed with non-epileptic attack disorder (NEAD)? (even if the diagnosis might have proved to be wrong). (Other names used are non-epileptic seizures…)*	• Yes; • No; • I don't know
35	38	For PWE: *Are you prescribed an emergency rescue medicine for your epilepsy?* *(This would be a medicine that you or someone close to you carries around and uses during or straight after a seizure)* For 'significant other':	• Yes; • No; • I don't know

Number		Question	Answer Options
People with epilepsy	Significant others		
		Are they prescribed an emergency rescue medicine for their epilepsy? (This would be a medicine that they or someone close to them carries around and uses during or straight after a seizure)	
36	39	For PWE: *In an emergency situation, do you have some way of letting health care professionals know what care and support you need? (For example, you might have a "care plan" that they can see, have a way of sharing your medical records with them or you might carry instructions personal to you)* For 'significant other': *In an emergency situation, do they have some way of letting health care professionals know how to care and support them? (For example, they might have a "care plan" that they can see, have a way of sharing their medical records with them or carry instructions personal to them)*	• Yes; • No; • I don't know
27	40	For PWE: *How many epileptic seizures (of any type) have you had in the past 12 months?* *(If you are unsure, please give us your best guess)* For 'significant other': *How many epileptic seizures (of any type) would you say they have had in the past 12 months?* *(If you do not know exactly, please give us your best guess)*	• None, 1, 2, 3, 4, 5, 6, 7, 8, 9, Ten or more
28	41	For PWE: *In the past 12 months, how many times have you been to a hospital emergency department because of your epilepsy? (If you are unsure, please give your best guess)*	• None, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, Other, please specify

Number		Question	Answer Options
People with epilepsy	Significant others		
		For 'significant other': *In the past 12 months, how many times have they have been to a hospital emergency department because of epilepsy? (If you are unsure, please give your best guess)*	
29	42	For PWE: *In the past 12 months, how many times has an emergency ambulance come to you because of epilepsy? (Please include even those times when the ambulance was not called by you or someone you know)* For 'significant other': *In the past 12 months, how many times has an emergency ambulance come to them because of epilepsy? (If you are not sure, please give us your best guess. Please do include any times as well when an ambulance might have been called for by someone else)*	• None, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, Other, please specify
30	43	For PWE: *In the past 12 months, have you seen or spoken to a doctor or nurse that specialises in epilepsy? (such as a neurologist or epilepsy nurse specialist)* For 'significant other': *In the past 12 months, have you or the person you know with epilepsy seen or spoken to a doctor or nurse that specialises in epilepsy? (such as a neurologist or epilepsy nurse specialist)*	• Yes; • No; • I don't know
31	44	For PWE: *Do you ever have problems accessing the epilepsy specialist services in your area?*	• Yes; • No;

Number		Question	Answer Options
People with epilepsy	Significant others		
		For ‘significant other’: *Do you know whether they ever have problems accessing the epilepsy specialist service in their area?*	- I don’t know
32	45	For PWE: *Do you believe you have had enough support so you and those close to you know what to do when a seizure happens?* For ‘significant other’: *Do you believe they have had enough support so that they and those close to them know what to do when a seizure happens?*	- Yes; - No
33	46	For PWE: *How long would you be prepared to wait to see a doctor in an NHS Urgent Treatment Centre?* For ‘significant other’: *How long would you yourself be prepared to wait with the person you know with epilepsy to see a doctor in an NHS Urgent Treatment Centre?*	- 1 hour, 2, 3, 4, 5, 6, More than 6 hours
34	47	For PWE: *How long would you be prepared to wait to see a doctor in a NHS hospital Emergency Department?* For ‘significant other’: *How long would you yourself be prepared to wait with the person you know with epilepsy to see a doctor in the NHS hospital Emergency Department?*	- 1 hour, 2, 3, 4, 5, 6, More than 6 hours
34	48	*When it comes to caring for someone after a seizure, do you think the following sentence is true or false“:*	- True; - False

Number		**Question**	**Answer Options**
People with epilepsy	Significant others		
		"If a person with epilepsy has a simple, uncomplicated seizure, there is no need to call a doctor or ambulance"	
35	49	For PWE: *How often have you found yourself in the situations below“* *"You have an epileptic seizure in a public place and an ambulance comes. The seizure lasts no longer than usual and you recover as usual. You have NOT experienced an injury that requires urgent or emergency treatment"* For ‘significant other’: *How often would you say the person you know with epilepsy has found themselves in the situations below? (If you are not sure, please give us your best guess“* *"They have an epileptic seizure in a public place and an ambulance comes. Their seizure lasts no longer than usual and they recover as usual. They have NOT experienced an injury that requires urgent or emergency treatment"*	• Never been in this situation; • Often been in this situation; • Sometimes been in this situation
36	50	For PWE: *"You have an epileptic seizure at home and an ambulance comes, The seizure lasts no longer than usual and you recover as usual. You have NOT experienced an injury that requires urgent or emergency treatment"* For ‘significant other’: *"They have an epileptic seizure at home and an ambulance comes, Their seizure lasts no longer than usual and they recover as*	• Never been in this situation; • Often been in this situation; • Sometimes been in this situation

Number		Question	Answer Options
People with epilepsy	Significant others		
		usual. They have NOT experienced an injury that requires urgent or emergency treatment"	
37	51	For PWE: *"You have an epileptic seizure (or seizures) that is different to what you usually experience. An ambulance comes. The seizure (or seizures) has stopped. You have NOT experienced an injury that requires urgent or emergency treatment"* For 'significant other': *"They have an epileptic seizure (or seizures) that is different to what they usually experience. An ambulance comes. The seizure (or seizures) has stopped. They have NOT experienced an injury that requires urgent or emergency treatment"*	• Never been in this situation; • Often been in this situation; • Sometimes been in this situation
38	52	For PWE: *Thinking about all the times an emergency ambulance has come to you for epilepsy, how often have you been with someone you know who could help?* For 'significant other': *Thinking about all the times an emergency ambulance has come to them for epilepsy, how often have they been with someone they know who could help? (If you are unsure, please give your best guess)*	• Never; • Rarely; • About half the time; • Most of the time; • Always
39	53	For PWE: *When an emergency ambulance has come to you for epilepsy, who has been most likely to call for it?* For 'significant other':	• Me/ Themselves; • A family member or friend/ A family member or friend (this might be you); • A member of the public;

Number		Question	Answer Options
People with epilepsy	Significant others		
		When an emergency ambulance has come to them for epilepsy, who has been most likely to call for it?	• Other
40	54	*Do you think the Coronavirus (COVID-19) has changed your willingness to access/ your willingness for the person with epilepsy to access NHS services? Please read each of the statements below and indicate to what extent you agree or disagree.* For PWE: *I am less willing to go to A&E following a seizure, due to the Coronavirus.* For 'significant other': *I am less willing for them to go to A&E following a seizure, due to the Coronavirus.*	• Strongly agree; • Somewhat agree; • Neither agree nor disagree; • Disagree; • Strongly disagree
41	55	For PWE: *I am less willing to go to an Urgent Treatment Centre following a seizure, due to the Coronavirus.* For 'significant other': *I am less willing for them to go to an Urgent Treatment Centre following a seizure, due to the Coronavirus.*	• Strongly agree; • Somewhat agree; • Neither agree nor disagree; • Disagree; • Strongly disagree
42	56	For PWE: *I am less willing to go to an outpatient appointment, to see an epilepsy specialist, due to the Coronavirus.* For 'significant other': *I am less willing for them to go to an outpatient appointment, to see an epilepsy specialist, due to the Coronavirus.*	• Strongly agree; • Somewhat agree; • Neither agree nor disagree; • Disagree; • Strongly disagree

Number		Question	Answer Options
People with epilepsy	Significant others		
43	57	<u>For PWE:</u> *I am less willing to go to see my GP following a seizure, due to the Coronavirus.* <u>For 'significant other':</u> *I am less willing for them to go to see my GP following a seizure, due to the Coronavirus.*	• Strongly agree; • Somewhat agree; • Neither agree nor disagree; • Disagree; • Strongly disagree
44	58	*Do you believe you have had the Coronavirus (COVID-19)?*	• Yes; • No; • Don't know
45	59	*Do you believe someone close to you has had the Coronavirus (COVID-19)?*	• Yes; • No; • Don't know

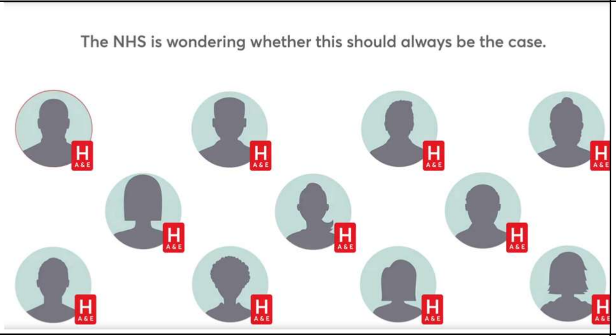
Notes: PWE, people/person with epilepsy; Table excludes introductory text, staging text and 'debrief' materials.

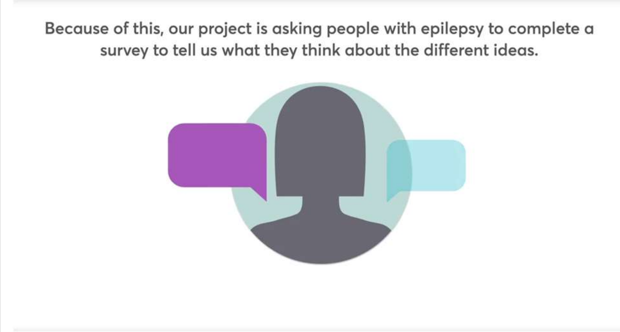
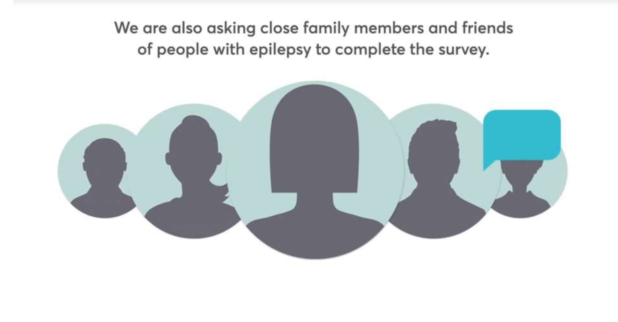
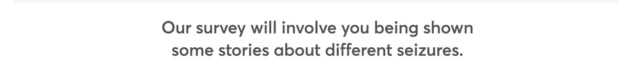
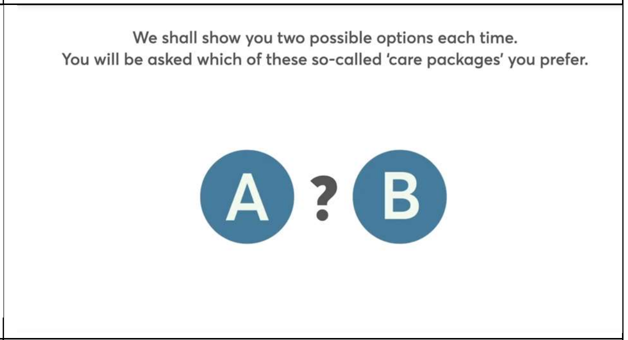
Supplementary File 3: Vignettes for seizure scenarios used in DCEs for different participant types

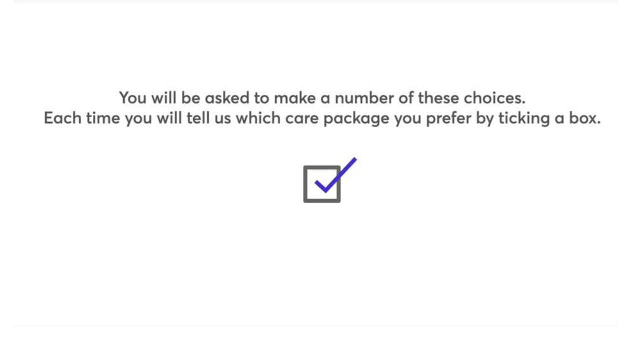
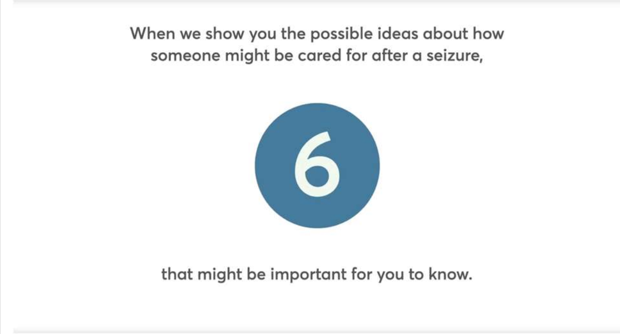
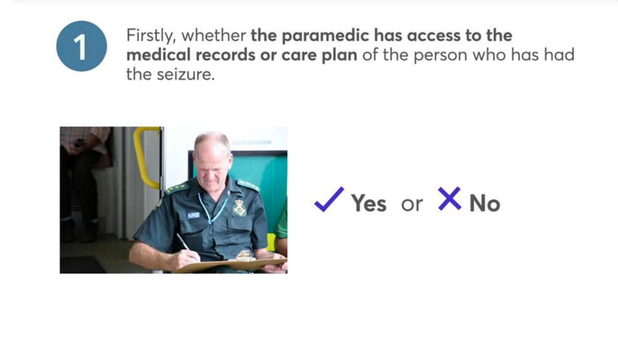
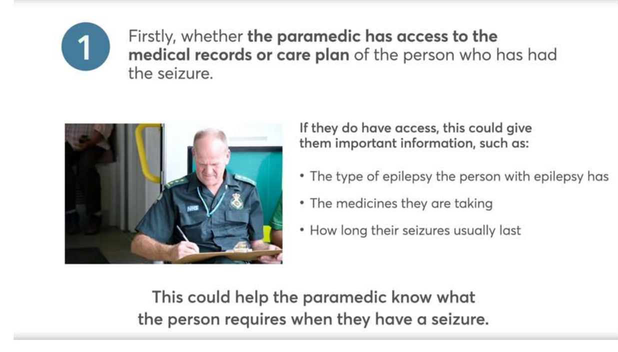
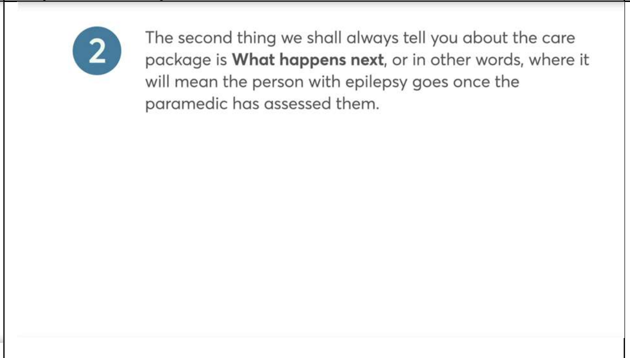
	Participant type	
Scenario	***People with epilepsy***	***Significant others***
Atypical seizure	Story about a seizure different to usual Imagine you have an epileptic seizure (or seizures) that **is different** in some way to what you usually experience. For example, it might start differently, last longer, or be a different type. The **seizure (or seizures) stop**. You do **NOT experience an injury** that requires urgent or emergency treatment. Somebody called an **ambulance**. The paramedic arrives and assesses you. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer?**	Story about a seizure different to usual Imagine the **person you know** has an epileptic seizure (or seizures) that **is different** in some way to what they usually experience. For example, it might start differently, last longer, or be a different type. The **seizure (or seizures) stop**. They do **NOT experience an injury** that requires urgent or emergency treatment. Somebody called an **ambulance**. The paramedic arrives and assesses them. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer them to get?**
Home typical seizure	Story about a seizure at home Imagine you have an epileptic seizure **at home.** Its last **no longer than usual**, and you start to **recover as usual**. You do **NOT experience an injury** that requires urgent or emergency treatment.	Story about a seizure at home Imagine **the person you know** has an epileptic seizure **at home.** Its last **no longer than usual**, and they start to **recover as usual**. They do **NOT experience an injury** that requires urgent or emergency treatment.

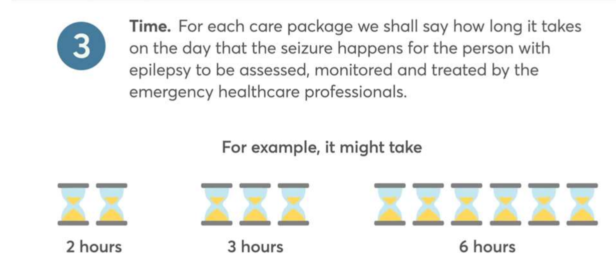
	Somebody called an **ambulance**. The paramedic arrives and assesses you. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer?**	Somebody called an **ambulance**. The paramedic arrives and assesses them. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer them to get?**
Public typical seizure	Story about a seizure in public Imagine you have an epileptic seizure **in public.** Its last **no longer than usual**, and you start to **recover as usual**. You do **NOT experience an injury** that requires urgent or emergency treatment. Somebody called an **ambulance**. The paramedic arrives and assesses you. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer?**	Story about a seizure in public Imagine **the person you know** has an epileptic seizure **in public.** Its last **no longer than usual**, and they start to **recover as usual**. They do **NOT experience an injury** that requires urgent or emergency treatment. Somebody called an **ambulance**. The paramedic arrives and assesses them. **During normal times (i.e. pre COVID-19), which of the two care packages below would you prefer them to get?**

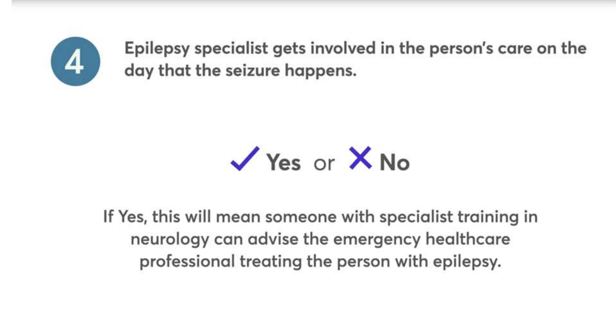
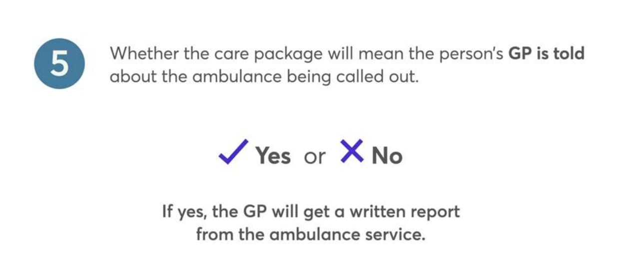
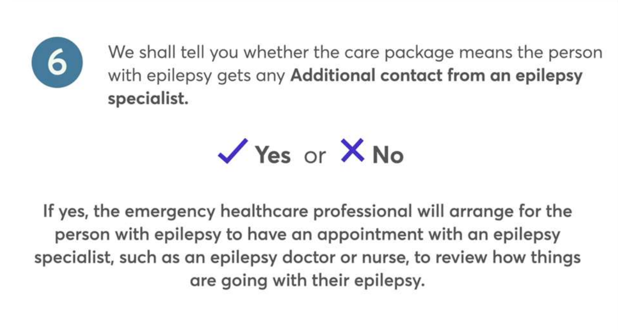
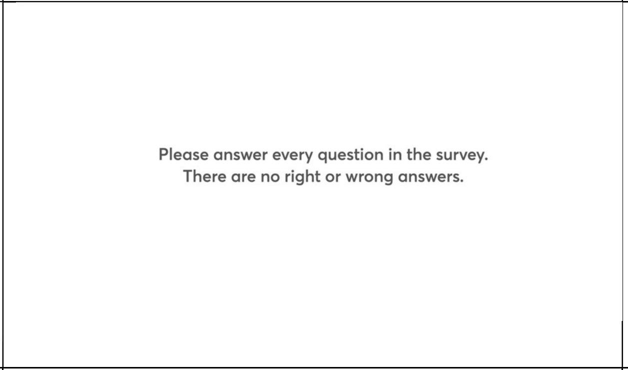
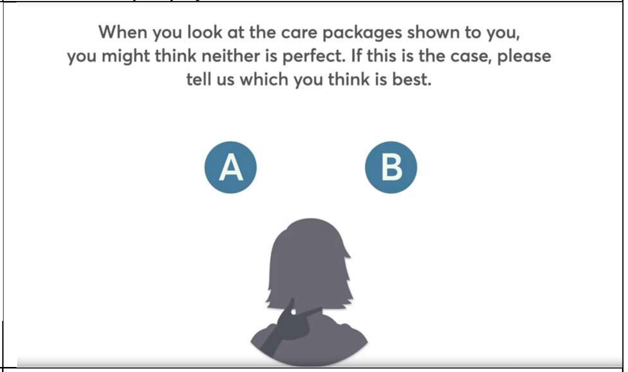
Supplementary File 4 Screenshots from animation along with accompanying narration (for full animation see https://www.youtube.com/watch?v=T3TU4tZ46Ik)

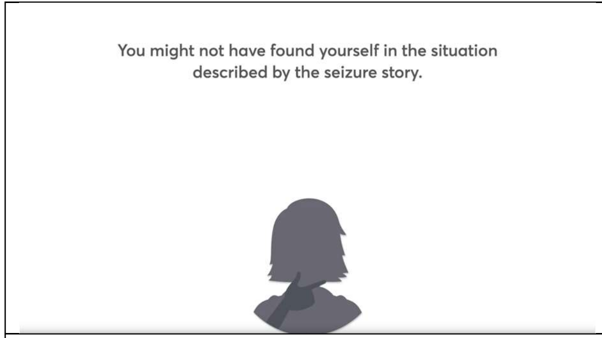
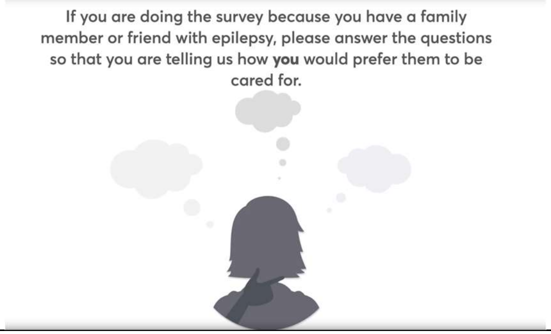
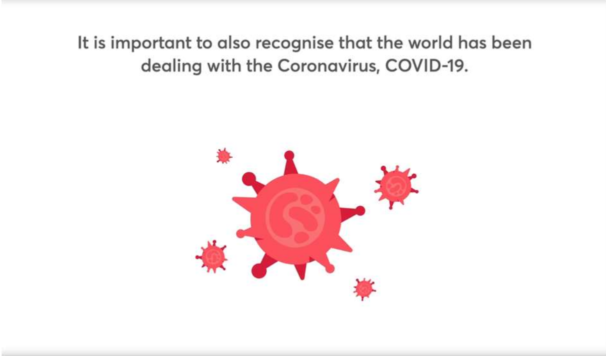
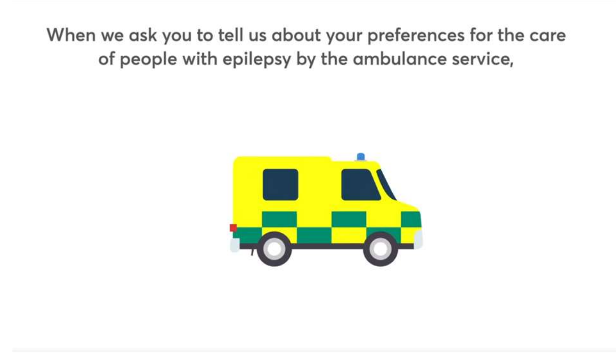
 Emergency care for epilepsy can be important, even life-saving, and the person will need to be taken to a hospital Accident & Emergency department.	 However, at other times a person with epilepsy who has had a seizure might not, from a doctor's point of view, always need to go to a hospital Accident & Emergency department, or A&E.	
"Emergency care for epilepsy can be important, even life-saving, and the person will need to be taken to a hospital Accident & Emergency department."	*"However, at other times a person with epilepsy who has had a seizure might not, from a doctor's point of view, always need to go to a hospital Accident & Emergency department, or A&E."*	*"The NHS has recently been thinking about whether it needs to change the type of care that people with epilepsy get when an ambulance comes to help them. At the moment, most people with epilepsy who are seen by an ambulance are taken to a hospital A&E department."*
 The NHS is wondering whether this should always be the case.	 There are lots of ideas for other ways that people could be cared for by the ambulance service.	 Some of these would mean the person is not taken to an A&E department when the ambulance crew do not think it is needed.
"The NHS is wondering whether this should always be the case."	*"There are lots of ideas for other ways that people could be cared for by the ambulance service."*	*"Some of these would mean the person is not taken to an A&E department when the ambulance crew do not think it is needed."*

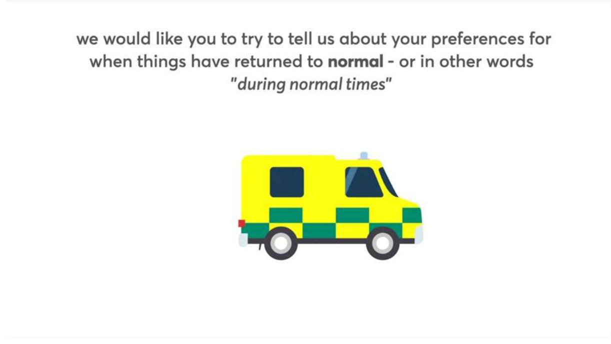
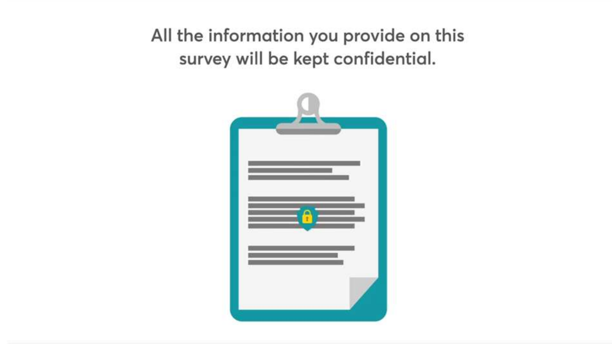
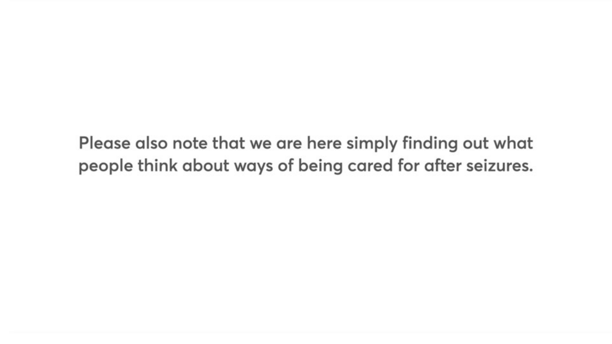
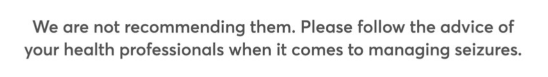
 It is important to find out if people with epilepsy think any of these ideas might be helpful. We can then share this information with the NHS to make sure the views of people with epilepsy are heard.	 Because of this, our project is asking people with epilepsy to complete a survey to tell us what they think about the different ideas.	 We are also asking close family members and friends of people with epilepsy to complete the survey.
"It is important to find out if people with epilepsy think any of these ideas might be helpful. We can then share this information with the NHS to make sure the views of people with epilepsy are heard."	*"Because of this, our project is asking people with epilepsy to complete a survey to tell us what they think about the different ideas."*	*"We are also asking close family members and friends of people with epilepsy to complete the survey."*
 Our survey will involve you being shown some stories about different seizures.	 The story will ask you to imagine that you, or the person with epilepsy that you know, have had a certain type of seizure. You will be told the paramedic has arrived and done an assessment.	 We shall show you two possible options each time. You will be asked which of these so-called 'care packages' you prefer.
"Our survey will involve you being shown some stories about different seizures."	*"The story will ask you to imagine that you, or the person with epilepsy that you know, has had a certain type of seizure. You will be told the paramedic has arrived and done an assessment."*	*"The survey will then show you some possible ways that you, or the person with epilepsy that you know, could be cared for. We shall show you two possible options each time. You will be asked which of these so-called 'care packages' you prefer."*

 You will be asked to make a number of these choices. Each time you will tell us which care package you prefer by ticking a box. ☑	 When we show you the possible ideas about how someone might be cared for after a seizure, 6 that might be important for you to know.	 1 Firstly, whether **the paramedic has access to the medical records or care plan** of the person who has had the seizure. ✓ **Yes** or ✗ **No**
"You will be asked to make a number of these choices. Each time you will tell us which care package you prefer by ticking a box."	*"When we show you the possible ideas about how someone might be cared for after a seizure, we shall describe them according to 6 things that might be important for you to know."*	*"Firstly, whether the paramedic has access to the medical records or care plan of the person who has had the seizure. Yes or No."*
 1 Firstly, whether **the paramedic has access to the medical records or care plan** of the person who has had the seizure. **If they do have access, this could give them important information, such as:** • The type of epilepsy the person with epilepsy has • The medicines they are taking • How long their seizures usually last This could help the paramedic know what the person requires when they have a seizure.	 2 The second thing we shall always tell you about the care package is **What happens next**, or in other words, where it will mean the person with epilepsy goes once the paramedic has assessed them.	 2 **The care package might mean the person with epilepsy:** • stays where they are • that they are taken to an Urgent Treatment Centre • or that they are taken to an A&E department
"If they do have access, this could give them important information, such as: the type of epilepsy the person with epilepsy has; the medicines they are taking; and, how long their seizures usually last. This could help the paramedic know what the person requires when they have a seizure."	*"The second thing we shall always tell you about the care package is what happens next, or in other words, where it will mean the person with epilepsy goes once the paramedic has assessed them."*	*"The care package might mean the person with epilepsy: stays where they are; that they are taken to an Urgent Treatment Centre; or that they are taken to an A&E department."*

 A&E and Accident and Emergency Department. They deal with genuine life-threatening emergencies.	 **Urgent Treatment Centres** NHS run centres for people who need urgent medical attention, but their condition isn't life threatening.	 **Urgent Treatment Centres** Most are open from 8am till 8pm, some longer.
"You will be familiar with terms like A&E and Accident and Emergency Department. They deal with genuine life-threatening emergencies."	*"You might not though, be familiar with the term Urgent Treatment Centres. Urgent Treatment Centres are NHS-run centres for people who need urgent medical attention, but their condition isn't life threatening."*	*"Most are open from 8am till 8pm, some longer."*
 Around half are located on the same hospital site as a traditional A&E.	 The other half are located in community hospitals which do not have an A&E or are in specially designed health centres.	 3 **Time.** For each care package we shall say how long it takes on the day that the seizure happens for the person with epilepsy to be assessed, monitored and treated by the emergency healthcare professionals. For example, it might take 2 hours 3 hours 6 hours
"Around half are located on the same hospital site as a traditional A&E."	*"The other half are located in community hospitals which do not have an A&E, or are in specially designed health centres."*	*"The third thing we shall tell you about is time. For each care package we shall say how long it takes on the day that the seizure happens for the person with epilepsy to be assessed, monitored and treated by the emergency healthcare professionals. For example, it might take: 2 hours; 3 hours; 6 hours."*

 4 **Epilepsy specialist gets involved in the person's care on the day that the seizure happens.** ✓ Yes or ✕ No If Yes, this will mean someone with specialist training in neurology can advise the emergency healthcare professional treating the person with epilepsy.	 5 Whether the care package will mean the person's **GP is told** about the ambulance being called out. ✓ Yes or ✕ No If yes, the GP will get a written report from the ambulance service.	 6 We shall tell you whether the care package means the person with epilepsy gets any **Additional contact from an epilepsy specialist.** ✓ Yes or ✕ No If yes, the emergency healthcare professional will arrange for the person with epilepsy to have an appointment with an epilepsy specialist, such as an epilepsy doctor or nurse, to review how things are going with their epilepsy.
"The fourth thing we shall tell you about the care package is whether it means an Epilepsy specialist gets involved in the person's care on the day that the seizure happens. Yes or No. *If Yes, this will mean someone with specialist training in neurology can advise the emergency healthcare professional treating the person with epilepsy."*	*"The fifth thing is whether the care package will mean the person's GP is told about the ambulance being called out: Yes or No.* *If yes, the GP will get a written report from the ambulance service."*	*"Finally, we shall tell you whether the care package means the person with epilepsy gets any Additional contact from an epilepsy specialist: Yes or No.* *If yes, the emergency healthcare professional will arrange for the person with epilepsy to have an appointment with an epilepsy specialist, such as an epilepsy doctor or nurse, to review how things are going with their epilepsy."*
 How soon this appointment happens after the seizure will vary. For example, it could be within 1 week within 2-3 weeks	 Please answer every question in the survey. There are no right or wrong answers.	 When you look at the care packages shown to you, you might think neither is perfect. If this is the case, please tell us which you think is best. A B
"How soon this appointment happens after the seizure will vary. For example, it could be: within 1 week or within 2-3 weeks."	*"Please answer every question in the survey. There are no right or wrong answers."*	*"When you look at the care packages shown to you, you may think neither is perfect. If this is the case, please tell us which you think is best."*

 You might not have found yourself in the situation described by the seizure story.	 If this is the case, we would ask you to use your imagination.	 If you are doing the survey because you have a family member or friend with epilepsy, please answer the questions so that you are telling us how **you** would prefer them to be cared for.
"You might not have found yourself in the situation described by the seizure story."	*"If this is the case, we would ask you to use your imagination."*	*"If you are doing the survey because you have a family member or friend with epilepsy, please answer the questions so that you are telling us how you would prefer them to be cared for. It is possible that what you would prefer to happen might be different to what they would say themselves."*
 It is important to also recognise that the world has been dealing with the Coronavirus, COVID-19.	 This has led to some restrictions on NHS services and people's movements and requests for us to distance ourselves from one another.	 When we ask you to tell us about your preferences for the care of people with epilepsy by the ambulance service,
"It is important to also recognise that the world has been dealing with the Coronavirus, COVID-19."	*"This has led to some restrictions on NHS services and people's movements and requests for us to distance ourselves from one another."*	*"When we ask you to tell us about your preferences for the care of people with epilepsy by the ambulance service"*

 we would like you to try to tell us about your preferences for when things have returned to **normal** - or in other words *"during normal times"*	 All the information you provide on this survey will be kept confidential.	 Please also note that we are here simply finding out what people think about ways of being cared for after seizures.
“we would like you to try to tell us about your preferences for when things have returned to normal - or in other words ‘during normal times’”	*“All the information you provide on this survey will be kept confidential.”*	*“Please also note that we are here simply finding out what people think about ways of being cared for after seizures.”*
 We are not recommending them. Please follow the advice of your health professionals when it comes to managing seizures.	 This project is supported by; NHS National Institute for Health Research epilepsy action	
“We are not recommending them. Please follow the advice of your health professionals when it comes to managing seizures.”	*“This project is supported by the National Institute for Health Research and by the charity, Epilepsy Action.”*	

SUPPLEMENTARY FILE 5 Further details on recruitment routes and eligibility

OVERVIEW

The supplement provides further details on the eligibility criteria for persons to participate in the Discrete Choice Experiment (DCE) survey and on the two recruitment routes.

Table S5.1 DCE survey participant inclusion and exclusion criteria and ethical approval for different routes

Route 1: Via Ambulance Service		**Route 2: Via Public adverts**	
People with epilepsy	***Significant others***	***People with epilepsy***	***Significant others***
Aged ≥18 years (no upper limit)	Aged ≥16 years (no upper limit)	Aged ≥18 years (no upper limit)	Aged ≥16 years (no upper limit)
Lives in North West England (within 30 miles of Liverpool city centre)	Lives in North West England	Lives in England	Lives in England
Able to provide informed consent and independently complete a questionnaire in English	Able to provide informed consent and independently complete a questionnaire in English	Able to provide informed consent and independently complete a questionnaire in English	Able to provide informed consent and independently complete a questionnaire in English
Dx. epilepsy, Rx. ASM	Close family member or friend to person with Dx. epilepsy, Rx. ASM, aged ≥18 years	Dx. epilepsy, Rx. ASM	Close family member or friend to person with Dx. epilepsy, Rx. ASM, aged ≥18 years
Any syndrome or seizure type	Any syndrome or seizure type	Any syndrome or seizure type	Any syndrome or seizure type
Been seen by ambulance for epilepsy in prior 12 months (conveyed or not) (checked against medical record)	Person with epilepsy been seen by ambulance for epilepsy in prior 12 months (conveyed or not) (checked against medical record)	Been seen by ambulance for epilepsy in prior 12 months (conveyed or not) (self-reported)	Person with epilepsy been seen by ambulance for epilepsy in prior 12 months (conveyed or not) (self-reported)

Ineligible: ► Severe current psychiatric disorders (e.g. acute psychosis) ► Life-threatening medical illness ► Resides within a care or nursing home or has no fixed abode ► Registered 'opt out' for contact for research purposes with NHS.	Ineligible ► Severe current psychiatric disorders (e.g., acute psychosis) ► Life-threatening medical illness	Ineligible: ► Severe current psychiatric disorders (e.g., acute psychosis) ► Life-threatening medical illness ► Resides within a care or nursing home or has no fixed abode	Ineligible ► Severe current psychiatric disorders (e.g., acute psychosis) ► Life-threatening medical illness
Ethical approval for this recruitment route was provided by the Health Research Authority and the National Research Ethics Service Committee West Midlands–Solihull (19/WM/0012). Each person completing the survey had the option of providing their personal details to the research team to receive a £20 shopping voucher.		Ethical approval for this route was provided by the University of Liverpool's Health and Life Sciences Research Ethics Committee (Ref: 7766). Participants completing the survey had the option of providing their personal details so they could be entered into a prize draw to win one of four £50 shopping vouchers.	

Notes: Dx, diagnosed; Rx, prescribed, ASM, anti-seizure medication.

ROUTE 1: FROM ENGLAND'S MERSEYSIDE AREA VIA THE NORTH-WEST NHS AMBULANCE SERVICE (NWAS)

Background on how NWAS codes incidents they manage

Emergency calls to NWAS are handled by an emergency operations centre. At the time of the study, NWAS used the Advanced Medical Priority Dispatch System (AMPDS) to code the reason for the call. The AMPDS system prompts trained, but non-clinical call handers to ask standard questions. The callers' responses to the questions yields 'determinant descriptors' which are used to assign a specific subcode to the call and determine the nature and priority of response.

When a call is received regarding what is described as a suspected seizure then AMPDS Protocol 12 is activated. The caller handler assigns these calls one of 16 possible subcodes. One of the standard questions that caller handlers endeavour to ask when managing a call via Protocol 12 is whether the patient for whom the call is about has a diagnosis of epilepsy (i.e., "Is s/he an epileptic?"). As most (~70%) calls for suspected seizures are made by a relative, friend or carer it is anticipated most callers can answer this question in an accurate way. When a call for suspected seizure is confirmed as relating to a person with a history of epilepsy then the subcode given to the call is given an 'e' suffix.

How NWAS identified ostensibly eligible individuals for the DCE survey

NWAS acted as a 'Participant Identification Centre'. It involved them first completing an electronic search of the emergency calls they had received in the prior 12 months to identify incidents coded under Protocol 12 and assigned the 'e' suffix. Persons with 8 of the 16 possible Protocol 12 subcodes were eligible (Figure S5.1).

The eligible codes were selected by a consultant neurologist (AM) and consultant paramedic (SB) and captured 79% of the suspected seizure incidents managed by NWAS in 2017/18 that were assigned suffix 'e' (S Bell, North West Ambulance Service, 29/7/2019). The restriction on subcodes was necessary due to ethical concerns about the possibility of inadvertently sending an invitation letter to someone who had died. It was also an attempt to screen out incidents unrelated to epilepsy (e.g., acute symptomatic seizures, preeclampsia, hypoglycaemia).

NWAS also restricted their search to only identify persons aged ≥18 years and living within ~30 miles of Liverpool city centre. Figure S5.2 provides a map of the catchment area. Approximately 4.1M people reside within this area. The restriction with regards where the person lived was necessary for several reasons. The main one being that prior to COVID-19 disrupting recruitment, it was our intention that a researcher would be able to travel to any participants that wished to participate via a face-to-face appointment (including those without internet access).

Based on prior health DCEs [1] and work with the target population,[2, 3] we anticipated 30-60% of the PWE invited by NWAS might participate. To determine how many individuals NWAS needed to invite we used the lower estimate of 30% and applied this to the target sample sizes for PWE who had (i.e., n=150) and had not experienced conveyance to ED following ambulance attendance (i.e., n=150). We also accounted for a need to potentially accommodate for ~15% of participants that (based on prior epilepsy DCEs) might have insufficient data for inclusion in the analyses. [4-6]

This indicated NWAS needed to invite n=580 people who had not been conveyed to ED following attendance and n=580 people who been conveyed to ED following attendance. As conveyance and non-conveyance to ED do not occur at the same rate, the time periods that NWAS would need to search within to identify sufficient persons from these two groups was permitted to differ.

Having completed the electronic search, two NWAS research paramedics (DW; KH see acknowledgements) reviewed the ambulance report (called then Patient Report Form, [PRF]) for each of the identified incidents by hand to exclude persons ineligible. Those who remained had their status checked against the NHS ‘Spine’ service to exclude any persons who had died and/or who had ‘opted-out’ from contact for research. At the time of the project, when crews were ‘on scene’ they did not use an electronic recording system, rather they completed standardised ‘Patient Report Forms’ (PRFs) by hand and these were subsequently ‘scanned in’.

Persons who continued to be eligible were posted an invitation pack by NWAS. This included a covering letter – signed by NWAS’ chief consultant paramedic – informing them about the study. A repeat invite was sent ~3 weeks later.

To identify significant other participants, invite recipients were asked to identify a significant other to take part with should they wish this to happen and to pass on recruitment documents to them that were also contained within the invitation pack.

PWE and significant others interested in participating were asked to visit the survey page. A short, simple web address was provided. They could also contact the research team by phone, email,

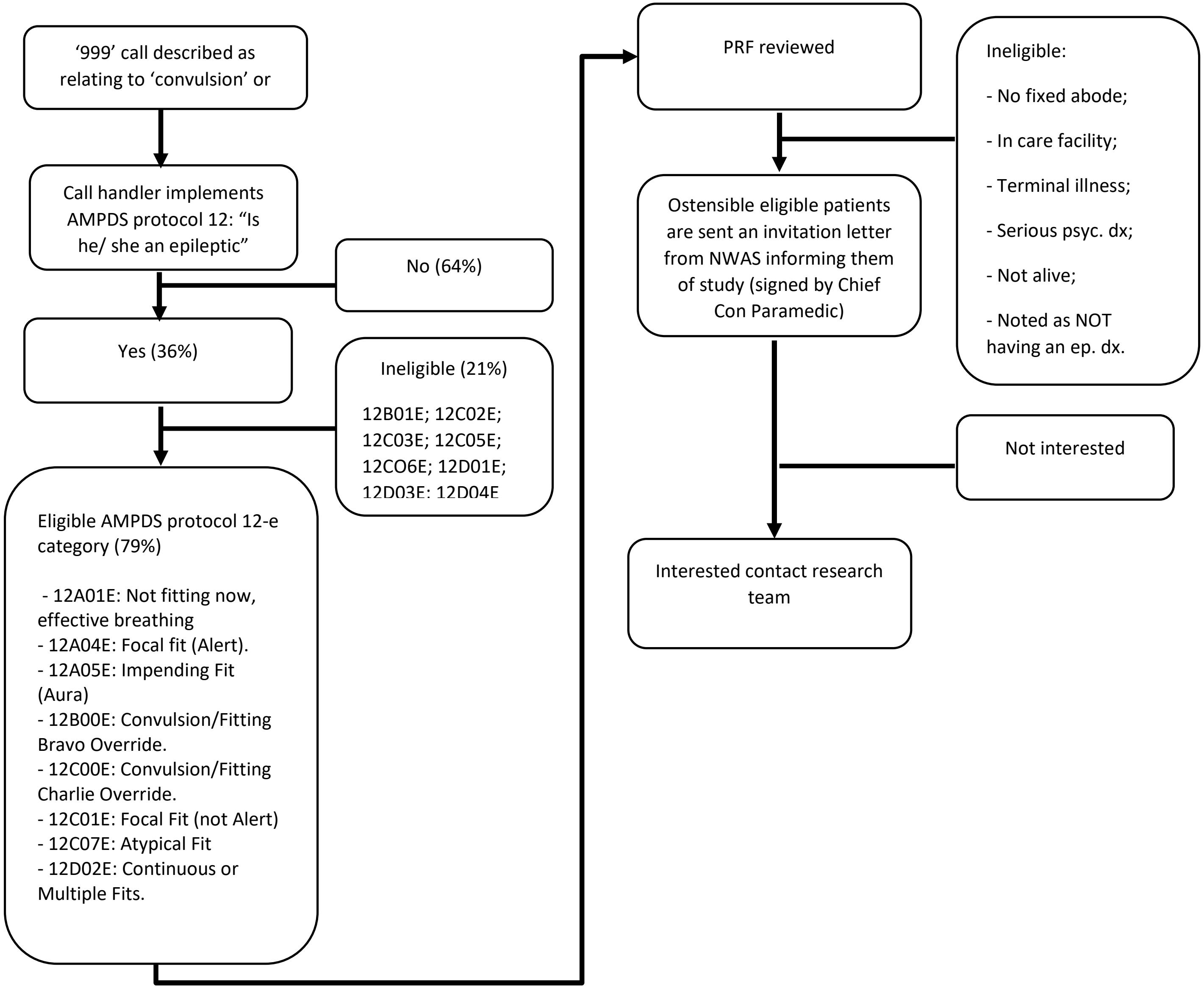


Figure S5.1 Flow chart of screening process and identification of individuals for invitation via ambulance service

Notes: AMPDS, Advanced Medical Priority Dispatch System; dx, diagnosis; ep, epilepsy NWAS, North-West Ambulance Service NHS Trust; PRF, Patient-report form; psych., psychiatric diagnosis; 12B01E, Fitting with effective breathing (not verified), Epileptic or previous diagnosis of fitting, <35 years; 12C02E, Fitting during pregnancy – epileptic or previous diagnosis of fitting; 12C03E, Diabetic Patient Fitting – Epileptic or previous diagnosis of fitting; 12C05E, History of stroke or brain tumour – epileptic or previous diagnosis of fitting; 12C06E, Overdose/ poisoning (ingestion) – epileptic or previous diagnosis of fitting; 12D01E, Not breathing (after Key Questioning) – epileptic or previous diagnosis of fitting; 12D02E, Fitting agonal/ineffective breathing – fitting history; 12D04E, Fitting effective breathing (not-verified) – epileptic or previous diagnosis of fitting >35.

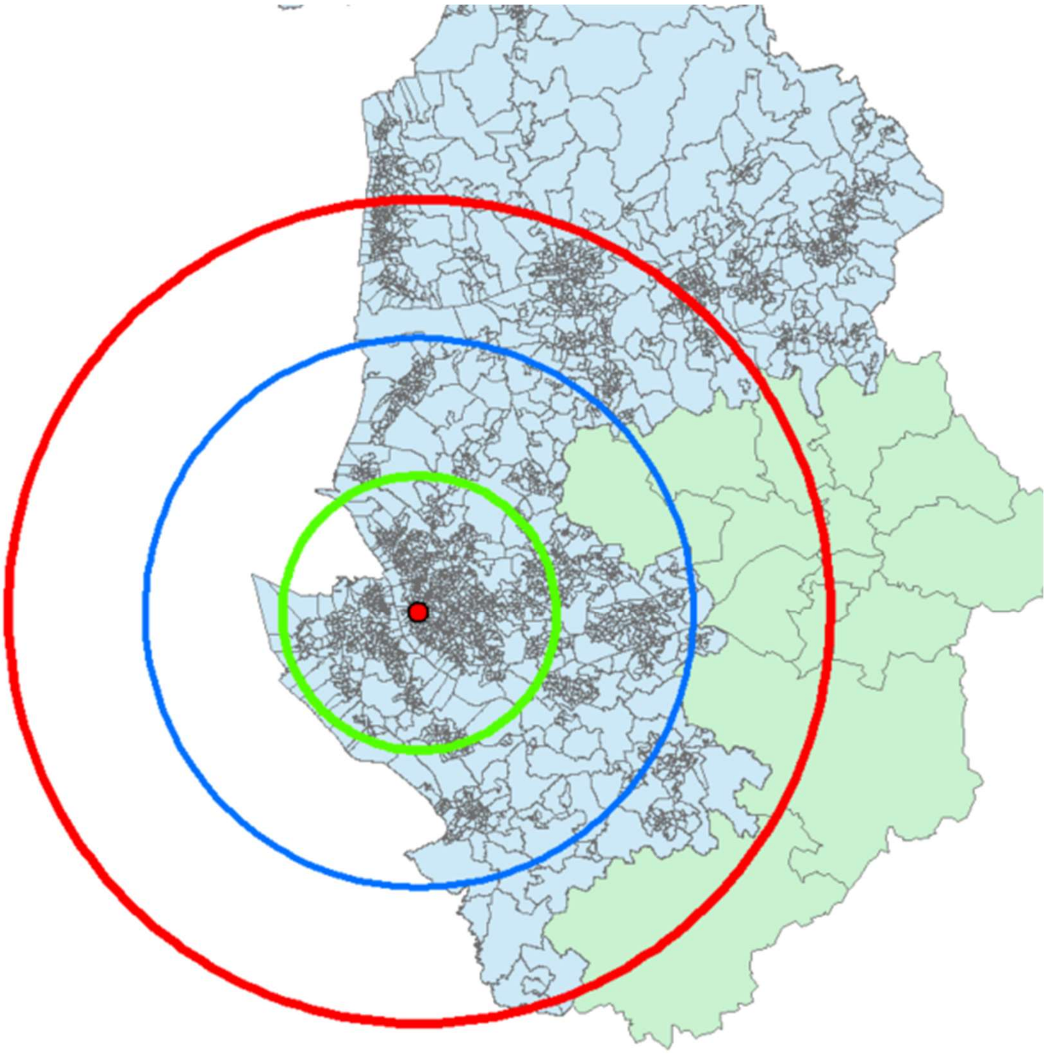


Figure S5.2 Catchment area for search by NWAS

Notes: Red dot indicates Liverpool city-centre; green circle indicates 10 miles from Liverpool city centre; blue circle indicates 20 miles; red circle indicates 30 miles. Noted that not all persons whose residence was within the red circle were eligible for identification as they did not reside within the footprint of the North West Coast NIHR Clinical Research Network who reimbursed NWAS for the time they spent identifying participants. Those areas that were eligible are those that are coloured light blue and which are contained within the red circle. The areas coloured light green are within the footprint of another funder, namely, the Greater Manchester NIHR Clinical Research Network.

or by using a FREEPOST return slip included in their invitation pack. Those wanting to access the survey and take part were asked to provide – via the survey page –eConsent.[7]

g

Who NWAS ultimately identified and invited

NWAS screened N=2634 incidents and identified n=981 individuals for invite. Of these, n=456 (46.5%) people were identified because of an incident that resulted in conveyance to an emergency department (ED) and n=525 (53.5%) individuals were identified due to an incident that ended with non-conveyance. To identify enough people following a conveyed incident, NWAS needed to search within 5 months of incidents (i.e., June 2019 to October 2019). To identify the non-conveyed individuals, NWAS needed to search within 11.5 months of incidents (i.e., October 2018 to October 2019).

As shown in Figure S5.3, the leading reason for an incident not resulting in a person being identified for invite was that the individual had already been identified based on an earlier incident (25.7%). This exclusion is labelled 'duplicate' in the figure. Other key reasons included that the person resided within a care facility (19.8%) and that the person was not noted on the PRF completed by the ambulance crew at the time as having diagnosed epilepsy (18.4%). In 14.7% of cases the PRF for the incident could not be retrieved or the writing was illegible.

The time between the incidents that had led these persons to contact NWAS and them being sent an invitation ranged from 10 to 21 months. The wide range reflects the different periods of time needed to identify enough persons for invite who and had not been conveyed to ED. Not only is non-conveyance a rarer outcome, but a high proportion of those who had not been conveyed were found to reside within a care facility.

Having been sent an invitation pack, n=18 persons informed the research team they were unable to complete the survey online. A further n=4 persons informed the team they were ineligible.

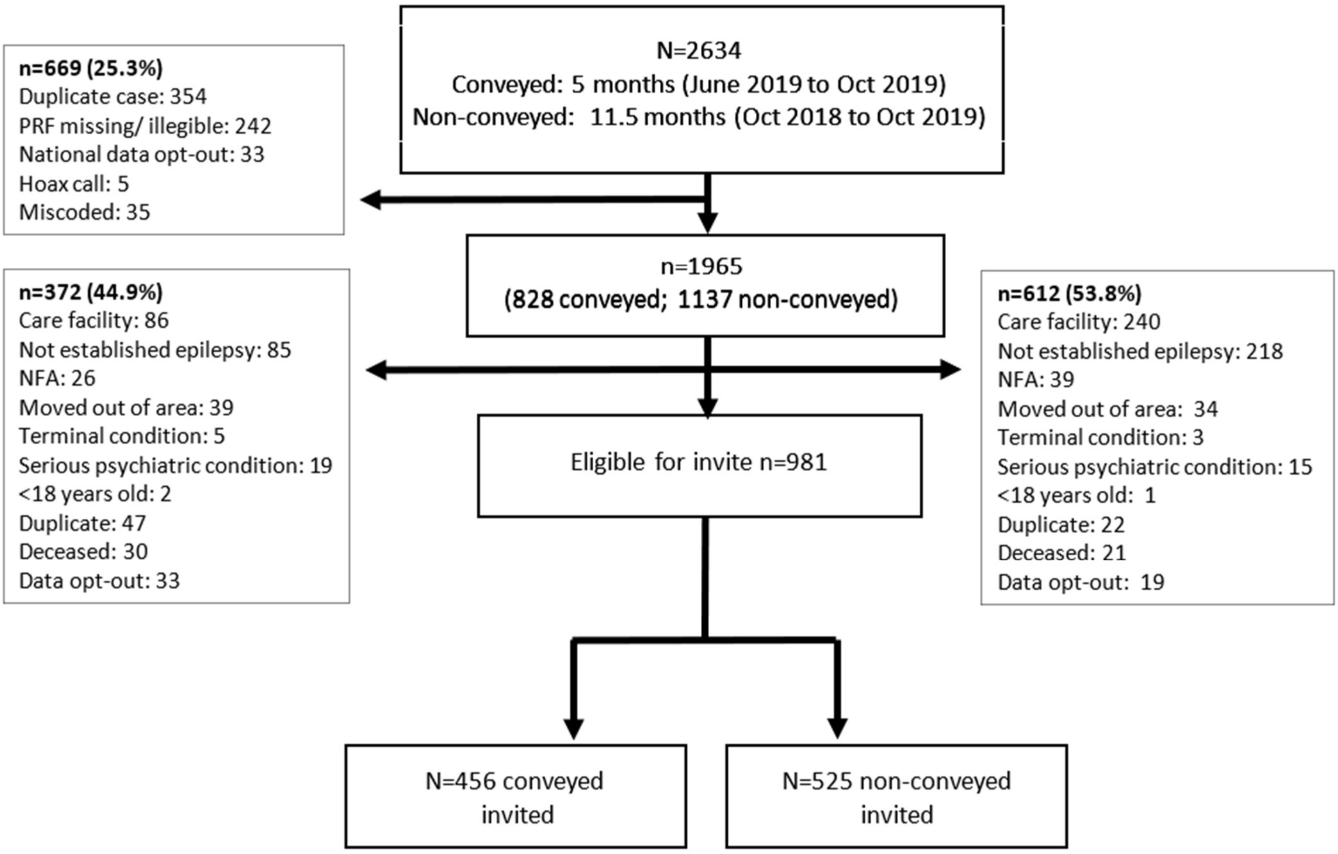


Figure S5.3 Flow chart of screening process and identification of individuals for invitation via ambulance service

Notes: N, number; NFA, no fixed abode; PRF, Patient Report Form.

ROUTE 2 – VIA PUBLIC ADVERT

A range of participant advertisements were created for distribution via different platforms. The dates on which major recruitment interventions were made are shown in Figure S5.4 relative to responses to the survey. The specifics are as follows.

Between 9th and 16th October 2020, colour advertisements (17cm x 3 columns wide) appeared in the print and online versions of 15 of England's largest regional newspapers operated by Reach PLC (Table S5.2). The papers had a median circulation of 13,000 (interquartile range [IQR]= 12,000 to 18,000). The median page number the adverts appeared on was 9 (IQR= 5 to 19). An advert appeared in at least one newspaper for each of England's local government region, except for London (due to cost).

In addition, between 20th July and 16th November 2020, major service user organisations affiliated in some way with epilepsy circulated the adverts within local meetings and via newsletters and on social media. This included Epilepsy Action utilising Facebook's paid advertisement feature to increase the visibility of their posting of the advert.

Persons interested in participating were directed via the adverts to a duplicate version of the survey page that had been created for those recruited via route 1. This permitted us to be able to differentiate how participants were recruited. Within electronic adverts, a hyperlink to the survey page was provided, whilst within paper versions of adverts, the link was a 'tinyURL'.

Table S5.2 Details of regional newspapers public adverts appeared in

Region	**Publication**	**Date of advert**	**Page number**
East of England	Cambridge News	09/10/2020	3
East of England	Essex Chronicle	15/10/2020	8
North East	The Chronicle	09/10/2020	20
North East	Evening Gazette	16/10/2020	15
Yorkshire & The Humber	Hull Daily Mail	09/10/2020	5
Yorkshire & The Humber	Grimsby Telegraph	16/10/2020	4
East Midlands	Leicester Mercury	09/10/2020	8
East Midlands	Derby Telegraph	16/10/2020	31
North West	Liverpool Echo	09/10/2020	12
North West	Manchester Evening News	16/10/2020	9
West Midlands	Stoke Sentinel	09/10/2020	9
West Midlands	Birmingham Mail	16/10/2020	22

South East England	Surrey Advertiser	09/10/2020	18
South West England	Western Morning News	09/10/2020	5
South West England	Western Daily Press	16/10/2020	19

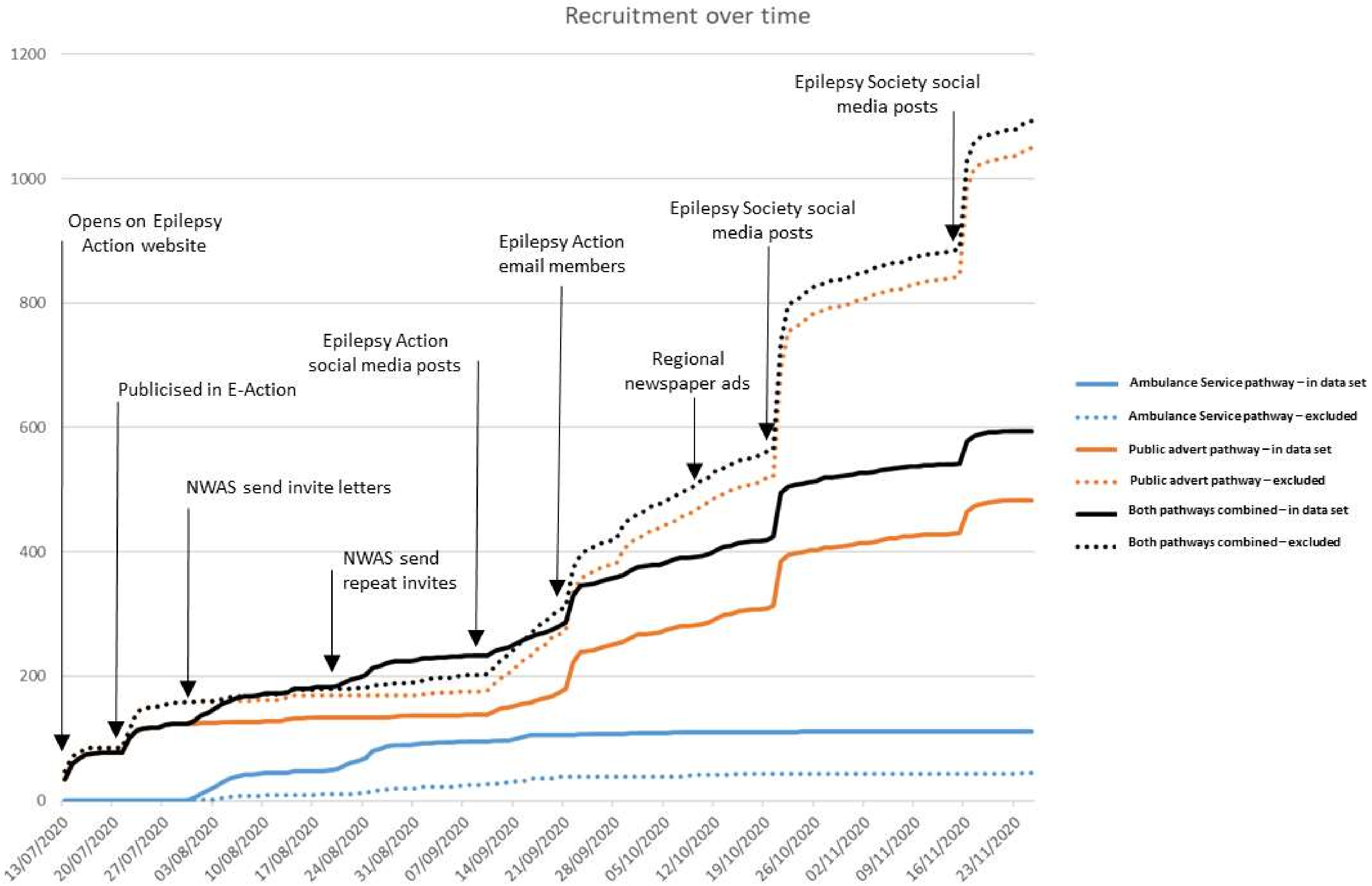


Figure S5.4 Recruitment graph by source

Notes: NWAS, North-West Ambulance Service.

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1. Watson, V., F. Becker, and E. de Bekker-Grob, *Discrete Choice Experiment Response Rates: A Meta-analysis.* Health Economics, 2017. **26**(6): p. 810-817.
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3. Ridsdale, L., et al., *Can an epilepsy nurse specialist-led self-management intervention reduce attendance at emergency departments and promote well-being for people with severe epilepsy? A non-randomised trial with a nested qualitative phase.* Health Services and Delivery Research, 2013. **1**(9).
4. Wijnen, B.F., et al., *Eliciting patients' preferences for epilepsy diagnostics: a discrete choice experiment.* Epilepsy & Behavior, 2014. **31**: p. 102-9.
5. Powell, G., et al., *Pharmacogenetic testing prior to carbamazepine treatment of epilepsy: patients' and physicians' preferences for testing and service delivery.* British Journal of Clinical Pharmacology, 2015. **80**(5): p. 1149-1159.
6. Lloyd, A., E. McIntosh, and M. Price, *The importance of drug adverse effects compared with seizure control for people with epilepsy: a discrete choice experiment.* Pharmacoeconomics, 2005. **23**(11): p. 1167-81.
7. Medicines and Healthcare products Regulatory Agency and Health Research Authority. *Joint statement on seeking consent by electronic methods*. 2018 [cited 2021 13 August]; Available from: https://www.hra.nhs.uk/documents/1588/hra-mhra-econsent-statement-sept-18.pdf.

Supplementary File 6 Detailed description of DCE participants’ demographics, epilepsy characteristics, geographical location and familiarity with seizure scenarios

Table S6.1 Characteristics of DCE participants by recruitment route and when combined

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Participant type, *n (%)*			
Person with epilepsy (PWE)	69 (61.6%)	358 (74.3%)	427 (71.9%)
Significant other	43 (38.4%)	124 (25.7%)	167 (28.1%)
Age of PWE, *Median (range)*			
Reported by people with epilepsy	36 (26-51)	37 (27-49)	37 (27-49)
Reported by significant others	32.5 (26-46)	28 (23-39)	29 (24-41)
Combined	34 (26-49)	35 (26-48)	35 (26-48)
Missing	1	45	46
Sex of PWE, *Female n (%)*			
Reported by people with epilepsy	37 (53.6%)	280 (78.2%)	317 (74.2%)
Reported by significant others	20 (47.6%)	30 (37.0%)	50 (40.7%)
Combined	57 (51.4%)	310 (70.6%)	367 (66.7%)
Missing	1	43	44
Significant others relation to PWE, *PWE is… n (%)*			

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Partner/spouse	15 (35.7%)	15 (18.5%)	30 (24.4%)
Sibling	1 (2.4%)	7 (8.6%)	8 (6.5%)
Child	21 (50.0%)	52 (64.2%)	73 (59.4%)
Other	5 (11.9%)	7 (8.6%)	12 (9.8%)
Missing	1	43	44
Intellectual disability in PWE, *n (%)*			
Reported with people with epilepsy	7 (11.1%)	27 (11.4%)	34 (11.4%)
Reported by significant others	18 (42.9%)	19 (23.5%)	37 (30.1%)
Combined	25 (23.8%)	46 (14.5%)	71 (16.8%)
Missing	7	165	172
Years since PWE' diagnosis, *Median (range)*			
Reported with people with epilepsy	12 (4-23)	12 (4-28)	12 (4-27)
Reported by significant others	12 (4-25)	13 (6-23)	12 (6-25)
Combined	12 (4-24)	12 (4.5-27)	12 (4-26)
Missing	7	166	173
PWE' Index of Multiple Deprivation, *n (%)*			
Reported with people with epilepsy			
Quintile 1	24 (38.1%)	60 (25.5%)	84 (28.2%)
Quintile 2	12 (19.1%)	56 (23.8%)	68 (22.8%)
Quintile 3	11 (17.5%)	40 (17.0%)	51 (17.1%)
Quintile 4	13 (20.6%)	44 (18.7%)	57 (19.1%)
Quintile 5	3 (4.8%)	35 (14.9%)	38 (12.8%)
Missing	6	123	129

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Significant other' Index of Multiple Deprivation, *n (%)*			
Quintile 1	16 (38.1%)	16 (20.0%)	32 (26.2%)
Quintile 2	6 (14.3%)	16 (20.0%)	22 (18.0%)
Quintile 3	9 (21.4%)	13 (16.3%)	22 (18.0%)
Quintile 4	6 (14.3%)	21 (26.3%)	27 (22.1%)
Quintile 5	5 (11.9%)	14 (17.5%)	19 (15.6%)
Missing	1	44	45
Seizures in prior 12 months			
Reported by people with epilepsy			
0-3	18 (28.6%)	66 (28.1%)	84 (28.2%)
4-6	10 (15.9%)	28 (11.9%)	38 (12.8%)
7-9	10 (15.9%)	11 (4.7%)	21 (7.1%)
10 or more	25 (39.7%)	130 (55.3%)	155 (52.0%)
Missing	6	123	130
Reported by significant other participants			
0-3	9 (21.4%)	17 (21.0%)	26 (21.1%)
4-6	5 (11.9%)	14 (17.3%)	19 (15.5%)
7-9	5 (11.9%)	11 (13.6%)	16 (13.0%)
10 or more	23 (54.8%)	39 (48.2%)	62 (50.4%)
Missing	1	43	44
Combined			
0-3	27 (25.7%)	83 (26.3%)	110 (26.1%)
4-6	15 (14.3%)	42 (13.3%)	57 (13.5%)
7-9	15 (14.3%)	22 (7.0%)	37 (8.8%)

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
10 or more	48 (45.7%)	169 (53.5%)	217 (51.5%)
Missing	7	166	173
Types of seizures PWE had ever experienced, *n (%)*			
Reported by people with epilepsy			
One type only	29 (42.0%)	113 (31.6%)	142 (33.3%)
Multiple types	40 (58.0%)	245 (68.4%)	285 (66.7%)
Reported by significant other			
One type only	20 (46.5%)	47 (37.9%)	67 (40.1%)
Multiple types	23 (53.5%)	77 (62.1%)	100 (59.9%)
Combined			
Multiple types	63 (56.3%)	322 (66.8%)	385 (64.8%)
Missing	0	0	0
'Usual ED' seizure type p/2 years**, *n (%)*			
Reported by people with epilepsy			
Focal type (…aware of what is happening)	5 (7.3%)	12 (3.4%)	17 (4.0%)
Complex partial type (…confused or partially aware)	7 (10.1%)	31 (8.7%)	38 (8.9%)
Absences, tonic, atonic (…briefly lose consciousness)	5 (7.3%)	39 (10.9%)	44 (10.3%)
Tonic clonic (…lose consciousness & jerk or convulse)	52 (75.4%)	276 (77.1%)	328 (76.8%)
Reported by significant other participants			
Focal type (…aware of what is happening)	1 (2.3%)	2 (1.6%)	3 (1.8%)
Complex partial type (…confused or partially aware)	0 (0.0%)	8 (6.5%)	8 (4.8%)

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Absences, tonic, atonic (…briefly lose consciousness)	0 (0.0%)	11 (8.9%)	11 (6.6%)
Tonic clonic (…lose consciousness & jerk or convulse)	42 (97.7%)	103 (83.1%)	145 (86.8%)
Combined			
Tonic clonic	94 (83.9%)	379 (78.6%)	473 (79.6%)
Missing	0	0	0
PWE seen epilepsy specialist in p/12 months, *Yes n (%)*			
Reported with people with epilepsy	48 (76.2%)	205 (87.2%)	253 (84.9%)
Reported by significant other participants	36 (85.7%)	76 (93.8%)	112 (91.1%)
Combined	84 (80.0%)	281 (88.9%)	365 (86.7%)
Missing	7	166	173
Rescue medication prescribed, *Yes n (%)**			
Reported by people with epilepsy	17 (27.0%)	62 (26.4%)	79 (26.5%)
Reported by significant other participants	16 (38.1%)	33 (40.7%)	49 (39.8%)
Combined	33 (31.4%)	95 (30.1%)	128 (30.4%)
Missing	7	166	173
Ever diagnosed with NEAD, *Yes n (%)**			
Reported by people with epilepsy	14 (22.2%)	51 (21.7%)	65 (21.8%)
Reported by significant other participants	8 (19.1%)	13 (16.1%)	21 (17.1%)
Combined	22 (21.0%)	64 (20.3%)	86 (20.4%)
Missing	7	166	173

	Via ambulance service	Via public adverts	Combined
Analysis dataset	**N=112**	**N=482**	**N=594**
Ambulance contacts in p/12 months, *Median (range)*			
Reported by people with epilepsy			
1-3	43 (68.3%)	187 (79.6%)	230 (77.2%)
4-6	15 (23.8%)	26 (11.1%)	41 (13.8%)
7-9	5 (7.9%)	8 (3.4%)	13 (4.4%)
10 or more	0 (0.0%)	14 (6.0%)	14 (4.7%)
Missing	6	124	130
Reported by significant other participants			
1-3	29 (69.1%)	54 (66.7%)	83 (67.5%)
4-6	5 (11.9%)	16 (19.8%)	21 (17.1%)
7-9	4 (9.5%)	4 (4.9%)	8 (6.5%)
10 or more	4 (9.5%)	7 (8.6%)	11 (8.9%)
Missing	1	43	44
Combined			
1-3	72 (68.6%)	241 (76.3%)	313 (74.4%)
4-6	20 (19.1%)	42 (13.3%)	62 (14.7%)
7-9	9 (8.6%)	12 (3.8%)	21 (5.0%)
10 or more	4 (3.8%)	21 (6.7%)	25 (5.9%)
Missing	7	166	174
ED contacts in p/12 months, *Median (range)*			
Reported by people with epilepsy			
0-3	50 (79.4%)	187 (79.6%)	237 (79.5%)
4-6	12 (19.1%)	29 (12.3%)	41 (13.8%)
7-9	1 (1.6%)	10 (4.3%)	11 (3.7%)

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
10 or more	0 (0.0%)	9 (3.8%)	9 (3.0%)
Missing	6	124	130
Reported by significant other participants			
0-3	33 (78.6%)	60 (74.1%)	93 (75.6%)
4-6	4 (9.5%)	11 (13.6%)	15 (12.2%)
7-9	1 (2.4%)	4 (4.9%)	5 (4.1%)
10 or more	4 (9.5%)	6 (7.4%)	10 (8.1%)
Missing	1	43	44
Combined			
0-3	83 (79.1%)	247 (78.2%)	330 (78.4%)
4-6	16 (15.2%)	40 (12.7%)	56 (13.3%)
7-9	2 (1.9%)	14 (4.4%)	16 (3.8%)
10 or more	4 (3.8%)	15 (4.8%)	19 (4.5%)
Missing	7	166	173
PWE correctly answering seizure first aid question, *Yes n (%)*	47 (74.6%)	192 (82.1%)	239 (80.5%)
Missing	6	124	130
Significant other participants correctly answering seizure first aid question, *Yes n (%)*	39 (92.9%)	71 (87.7%)	110 (89.4%)
Missing	1	43	44
When ambulance comes, how often is PWE with someone who could help, *n (%)*			
Reported by people with epilepsy			

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Never	1 (1.6%)	21 (9.0%)	22 (7.4%)
Rarely	10 (15.9%)	40 (17.1%)	50 (16.8%)
About half the time	12 (19.1%)	49 (20.9%)	61 (20.5%)
Most of the time	27 (42.9%)	78 (33.3%)	105 (35.4%)
Always	13 (20.6%)	46 (19.7%)	59 (19.9%)
Missing	6	124	130
Reported by significant other participants			
Never	1 (2.4%)	1 (1.3%)	2 (1.7%)
Rarely	4 (9.5%)	8 (10.1%)	12 (9.9%)
About half the time	7 (16.7%)	11 (13.9%)	18 (14.9%)
Most of the time	10 (23.8%)	29 (36.7%)	39 (32.2%)
Always	20 (47.6%)	30 (38.0%)	50 (41.3%)
Missing	1	45	46
Mostly likely to call for ambulance, *n (%)*			
Reported by people with epilepsy			
PWE themselves	2 (3.2%)	9 (3.9%)	11 (3.7%)
Family or friend	47 (74.6%)	149 (63.7%)	196 (66.0%)
Member of public	9 (14.3%)	61 (26.1%)	70 (23.6%)
Other	5 (7.9%)	15 (6.4%)	20 (6.7%)
Missing	6	124	130
Reported by significant other participants			
PWE themselves	0 (0.0%)	2 (2.5%)	2 (1.7%)
Family or friend	33 (78.6%)	57 (72.2%)	90 (74.4%)
Member of public	5 (11.9%)	14 (17.7%)	19 (15.7%)
Other	4 (9.5%)	6 (7.6%)	10 (8.3%)

	Via ambulance service	**Via public adverts**	**Combined**
Analysis dataset	**N=112**	**N=482**	**N=594**
Missing	1	45	46

Notes: ED, emergency department; n, number; NEAD, non-epileptic attack disorder; PWE, person with epilepsy; **Seizures description and labels presented to participant to choose from were as follows: “Seizures where you/they are aware of what is happening (such as focal seizures)”, “Seizures where you/they are confused or only partially aware (such as complex focal seizures)”, “Seizures where you/they briefly lose consciousness (such as absences, tonic, atonic seizures)”, and “Seizures where you/they lose consciousness and jerk or convulse (such as tonic clonic seizures)”. If multiple types were reported, the one listed is the one the person identified as typically leading to emergency health service contact; Please note that the n=594 participants did not all fully complete the non-DCE questions. Moreover, the order in which the non-DCE questions appeared in the surveys for PWE and significant others differed.

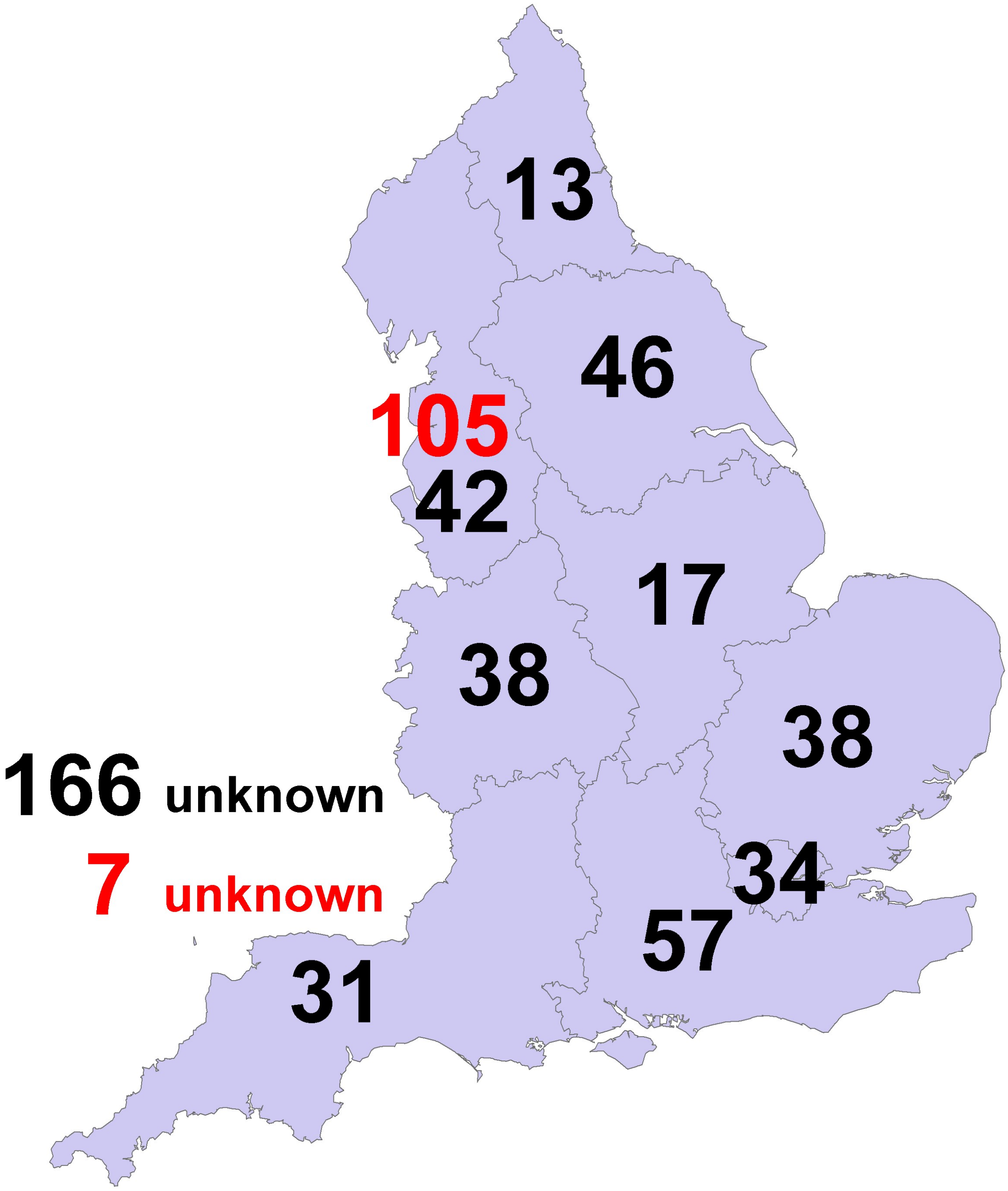


Figure S6.1 Distribution of participants in the final analysis dataset by English region that they reside in

Notes: Map separates England into local government region. The figures in red relate to individuals recruited via the ambulance service route, whereas figures in black indicate individuals recruited via the public advert route. Participants were recruited from across England's regions with persons from the North West overrepresented due to the two recruitment routes operating there. Postcodes for 173 individuals (n=166 from public advert route; 7 from the ambulance route) were partial and did not permit confidence in determining local government region.

Table S6.2 Familiarity to participants of seizure scenarios used within DCEs

	Recruitment route		
	Via ambulance service	**Via public adverts**	**Combined**
People with epilepsy participants	**n=69**	**n=358**	**n=427**
Public typical seizure scenario, n (%)			
Never been in this situation	14 (22.2%)	70 (29.9%)	84 (28.3%)
Often/ sometimes been in this situation*	49 (77.80%)	164 (70.1%)	213 (71.7%)
Home typical seizure scenario, n (%)			
Never been in this situation	19 (30.2%)	73 (31.2%)	92 (31.0%)
Often/ sometimes been in this situation*	44 (69.8%)	161 (68.8%)	205 (69.0%)
Atypical seizure scenario, n (%)			
Never been in this situation	14 (22.2%)	65 (27.8%)	79 (26.6%)
Often/ sometimes been in this situation*	49 (77.80%)	169 (72.2%)	218 (73.4%)
Missing	6	124	130
Significant other participants	**n=43**	**n=124**	**n=167**
Public typical seizure scenario, n (%)			
PWE I know has never been in this situation	17 (40.5%)	25 (31.3%)	42 (34.4%)
PWE I know has often/ sometimes been in this situation*	25 (59.5%)	55 (68.8%)	80 (65.6%)
Home typical seizure scenario, n (%)			
PWE I know has never been in this situation	11 (26.2%)	29 (36.3%)	40 (32.8%)
PWE I know has often/ sometimes been in this situation*	31 (73.8%)	51 (63.8%)	82 (67.2%)

***Atypical seizure scenario**, n (%)*			
PWE I know has never been in this situation	11 (26.2%)	11 (13.8%)	22 (18.0%)
PWE I know has often/ sometimes been in this situation*	31 (73.8%)	69 (86.3%)	100 (82.0%)
Missing	1	44	45

Notes: n, number; DCE, Discrete choice experiment; PWE, person with epilepsy; * Answer options were “Never been in this situation”, “Sometimes been in this situation”, and “Often been in this situation”.

Table S6.3 Comparison of the characteristics and epilepsy profile of the people with epilepsy taking part in or being represented in the survey

	Reported by PWE themselves (n=427)	**Reported by significant others (n=167)**
Age of PWE, Median (range)	37 (27-49)	29 (24-41)
Missing	2	44
Sex of PWE, Female %	74.2%	40.7%
Missing	0	44
PWE has an intellectual disability, Yes %	11.4%	30.1%
Missing	128	44
Rescue medication prescribed to PWE, Yes %	26.5%	39.8%
Missing	129	44
Ambulance contacts in p/12 months, %		
1-3	77.2%	67.5%
4-6	13.8%	17.1%
7-9	4.4%	6.5%
10 or more	4.7%`	8.9%
Missing	129	44
ED contacts in p/12 months, %		
0	15.3%	8.9%
1-3	64.5%	66.7%
4-6	13.6%	12.2%
7-9	3.7%	4.1%
10 or more	3.0%	8.1%
Missing	129	44

	Reported by PWE themselves (n=427)	**Reported by significant others (n=167)**
When ambulance comes, how often is PWE with someone who could help, %		
Never	7.4%	1.7%
Rarely	16.8%	9.9%
About half the time	20.5%	14.9%
Most of the time	35.4%	32.2%
Always	19.9%	41.3%
Missing	130	46

Notes: n, number; p/12 months, past 12 months; ED, emergency department; PWE, person with epilepsy

Supplementary File 7 Testing for non-linear effects of time

Table S7.1 shows the results of testing the linearity of the attribute ‘Time’. Model A uses a continuous specification for Time, in which the results would be interpreted as linear. However, Model B suggests that when Time is categorised, the size/direction of the coefficients moving between levels is not as expected (not linear). The most pronounced example is for significant others responding to the ‘Home typical seizure’ scenario. This indicates preferences of 2-hours > 3-hours > 1-hour > 6-hours+. A linear relationship would assume 1 > 2 >3 > 6.

Visual inspection of plots of the effects coded coefficients illustrates this deviation from the linear assumption by seizure contexts (Figure S7.1).

Table S7.1 Regression coefficients for time (linear) and time (categorical)

	People with epilepsy			**Significant others**		
Model statistic	***Atypical seizure***	***Home typical seizure***	***Public typical seizure***	***Atypical seizure***	***Home typical seizure***	***Public typical seizure***
Number of observations	2817	2692	2733	1139	1108	1044
Number of groups	258	239	252	105	97	96
Model A (time continuous)						
β coefficient of Time [continuous]	-.172*	-.237*	-.214*	-.217*	-.279*	-.263*
Model B (time categorical)						
β coefficient of Time [1 hour]^	0.164	0.295	0.080	0.844	-0.174	0.060
β coefficient of Time [2 hours]	0.284	0.192	0.135	0.295	0.833*	0.509
β coefficient of Time [3 hours]	0.079	0.175	0.331	-0.370	0.265	0.228
β coefficient of Time [6 hours]	-0.526*	-0.662*	-0.545*	-0.770*	-0.924*	-0.797*

Notes: Coefficients for time reported only. ^omitted level calculated as -1* (sum β of other levels); *$p<0.05$. Full model specification: xtlogit pref care_plan urgent_treatment_centre, emergency_department, time | time_two time_three time_six, specialist_today, GP_told, specialist_2to3weeks, specialist_5days

Figure S7.1 Testing for non-linear effects of time: plot estimated coefficients for time by scenario and sample

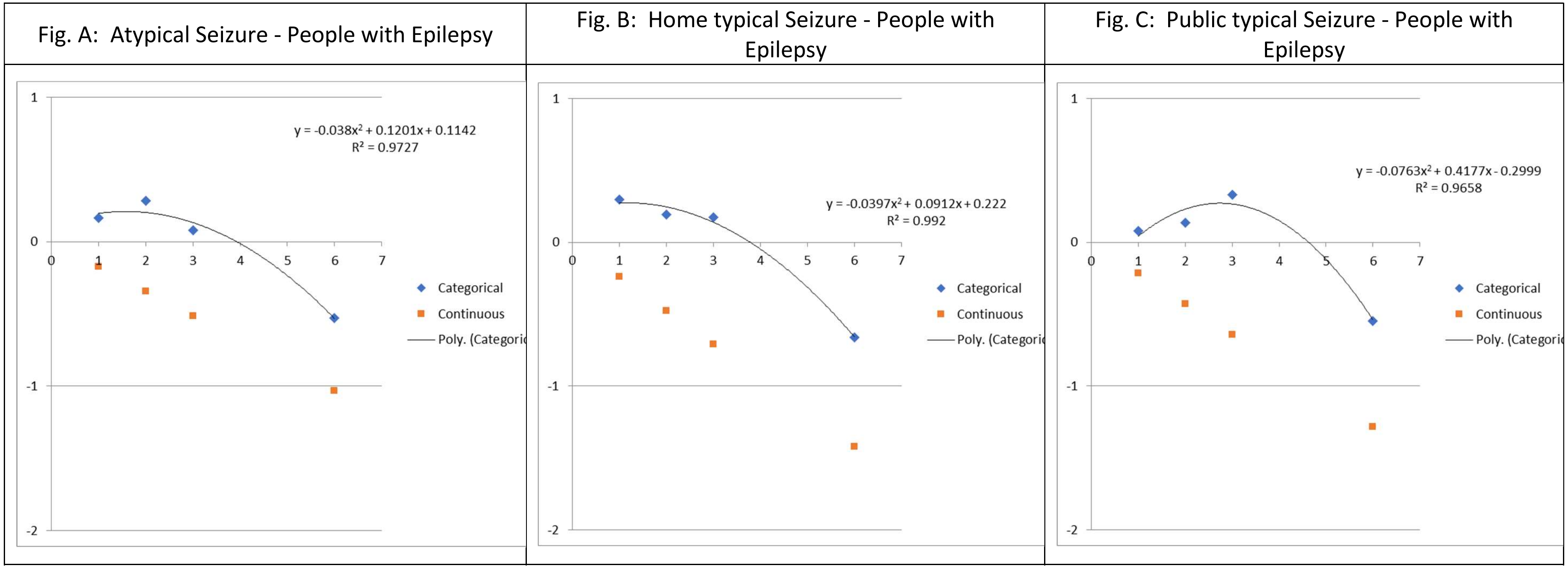


Fig. A: Atypical Seizure - People with Epilepsy

Fig. B: Home typical Seizure - People with Epilepsy

Fig. C: Public typical Seizure - People with Epilepsy

Fig. D: Atypical Seizure – Significant Other

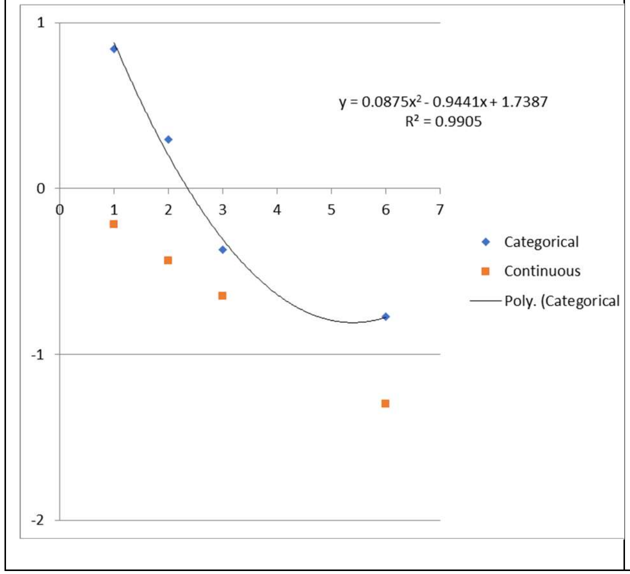


Fig. E: Home typical seizure – Significant Other

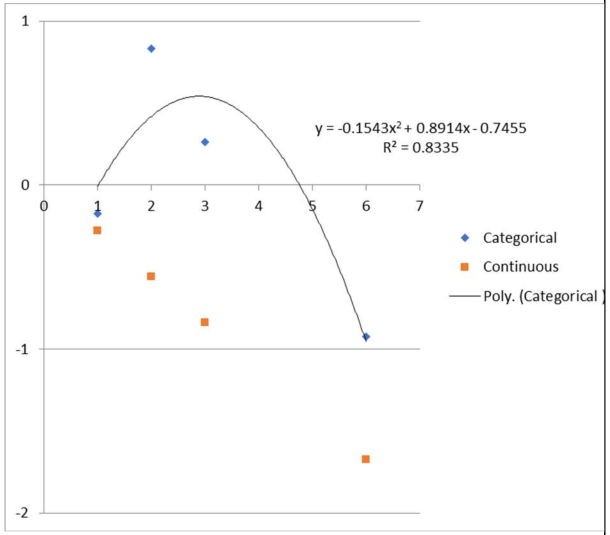
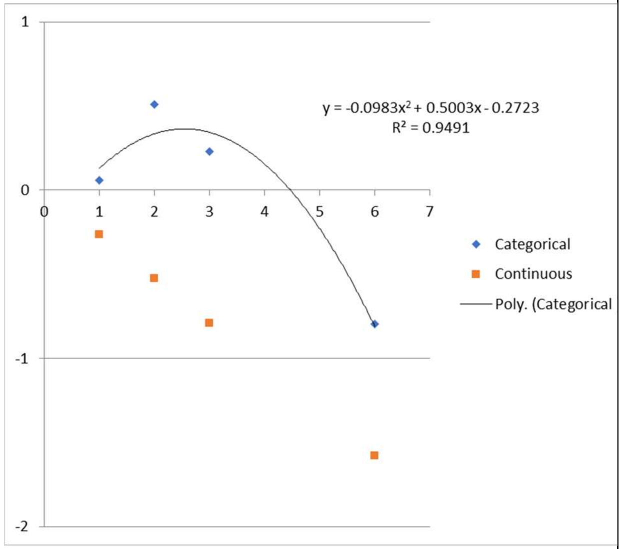


Fig. F: Public typical Seizure– Significant Other



Supplementary File 8 Results from DCE subgroup analyses

TABLE S8.1 Summary of subgroup analysis to explore preference heterogeneity

		Seizure scenario											
		Atypical Seizure				***Home typical seizure***				***Public typical seizure***			
		m1 n	m2 n	m3 n	LLR p-value	m1 n	m2 n	m3 n	LLR p-value	m1 n	m2 n	m3 n	LLR p-value
Planned subgroup analysis (PWE)													
(i) Any visits to ED in past 12-months (No=m2; Yes=m3)		204	32	172	0.3102	198	31	167	**0.0030***	194	29	165	N/A
(ii) Social deprivation (IMD decile 1-4=m2; IMD decile 5-10=m3)		205	101	104	0.5308	198	97	101	0.3708	193	94	99	0.4478
(iii) Contact with epilepsy specialist in past 12-mths (No=m2; Yes=m3)		204	22	182	N/A	198	37	161	0.0476	194	31	163	0.0552
(iv) Intellectual disability (No=m2; Yes=m3)		205	182	23	N/A	199	169	30	0.0434	194	179	15	N/A
Post-hoc analysis (PWE)													
(v) Problems accessing specialist services (No or don’t know=m2; Yes=m3)		204	106	98	**0.0033***	198	111	87	0.1221	194	111	83	**0.0056***
(vi) Care plan (No or don’t know=m2; Yes=m3)		204	133	71	0.8565	198	131	67	0.4481	194	122	72	0.1814
(vii) Familiarity of scenario (Never=m2; Often or sometimes=m3)		2	56	147	0.5956	197	60	137	0.1244	194	50	144	0.0164
(viii) Recruitment route (Ambulance=m2; Public advert=m3)		258	48	210	0.3575	239	40	199	0.1393	252	44	208	0.6919
(ix) Willingness to access healthcare during COVID-19 pandemic (Strongly agree/somewhat agree	…. A&E	170	104	66	0.8947	171	109	62	0.4294	163	103	60	0.4605
	… UTC	168	93	75	0.7671	165	100	65	**0.007***	161	95	66	0.9519
	… OPD	143	58	85	0.7459	143	62	81	0.5417	142	54	88	0.817

=m2; Neutral, Disagree/Strongly disagree=m3)	… GP	157	61	96	0.7105	149	58	91	0.3456	153	55	97	0.7544
Post-hoc analysis (Significant Others)													
(viii) Recruitment route (Ambulance=m2; Public advert=m3)		105	30	75	0.2474	97	28	69	N/A	96	28	68	N/A
(ix) Willingness to access healthcare during COVID-19 pandemic (Strongly agree/somewhat agree =m2; Neutral, Disagree/Strongly disagree=m3)	…. A&E	75	50	25	N/A	66	47	19	N/A	65	39	26	N/A
	… UTC	75	43	32	0.0298	66	43	23	N/A	66	36	29	N/A
	… OPD	64	26	38	N/A	60	22	38	N/A	54	22	32	N/A
	… GP	66	21	45	N/A	59	19	40	N/A	57	20	37	N/A

Notes: m:model; m1: restricted, m2: subgroup=0, m3:subgroup=1; N/A, Not applicable i.e. not LLR test performed due to n<30; IMD, Index of Multiple Deprivation; A&E, Accident and emergency department; UTC, Urgent treatment centre; OPD, outpatient department; GP, General Practice; Bonferroni correction for post-hoc analysis applied, significance level **p< 0.001**.

TABLE S8.2 Summary of regression models for subgroups reaching statistical significance

	Home typical seizure - PWE				**Atypical seizure - PWE**				**Public typical - PWE**				**Home typical seizure - PWE**			
	(1) Any visits to ED in past 12-months				*(5) Problems accessing specialist services*				*(5) Problems accessing specialist services*				*(9) Willingness to access UTC during coronavirus pandemic*			
	No		Yes		No/don't know		Yes		No/don't know		Yes		Agree		Neural/disagree	
Attribute [level]	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value	β-coeff	p-value
Access to medical records / care plan	0.770	0.060	0.499	0.000	0.440	0.000	0.600	0.000	0.587	0.000	0.559	0.000	0.464	0.003	0.531	0.002
Convey [UTC]	-11.22	0.992	-0.152	0.189	-0.220	0.187	0.371	0.013	-0.050	0.726	-0.067	0.655	-0.188	0.247	-0.460	0.023
Convey [ED]	-7.726	0.991	-0.244	0.032	-0.335	0.016	0.013	0.923	-0.378	0.004	-0.149	0.297	-0.227	0.188	-0.525	0.004
Time [1 hour]^	-41.02		0.507		-0.847		1.114		0.256		0.180					
Time [2 hours]	16.42	0.992	0.203	0.381	0.722	0.032	-0.136	0.614	0.207	0.453	0.129	0.667	0.116	0.724	0.597	0.151
Time [3 hours]	24.78	0.992	0.011	0.968	0.689	0.077	-0.411	0.225	0.196	0.569	0.280	0.440	-0.333	0.433	0.889	0.069
Time [6 hours]	-0.188	0.487	-0.721	0.000	-0.564	0.000	-0.567	0.000	-0.659	0.000	-0.589	0.000	-0.884	0.000	-0.513	0.001

Epilepsy specialist advises today	2.398	0.990	0.402	0.000	0.547	0.000	0.771	0.000	0.331	0.000	0.448	0.000	0.471	0.000	0.315	0.001
GP told	2.226	0.990	0.306	0.000	0.530	0.000	0.395	0.000	0.277	0.000	0.341	0.000	0.241	0.003	0.344	0.000
Epilepsy specialist in future [2-3 weeks]	-14.60	0.992	0.226	0.172	-0.190	0.423	0.536	0.006	0.184	0.360	0.165	0.436	0.400	0.092	-0.256	0.385
Epilepsy specialist in future [within 1 week]	14.95	0.992	0.084	0.539	0.433	0.039	-0.221	0.166	0.041	0.803	0.076	0.658	0.029	0.882	0.425	0.095
Constant	1.750	0.992	-0.154	0.006	0.007	0.917	-0.113	0.101	-0.096	0.152	0.007	0.919	-0.212	0.011	-0.079	0.392
Number of observations	372		2004		1272		1176		1332		996		1200		780	
Number of groups	31		167		106		98		111		83		100		65	