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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

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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.

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1. Introduction

1.1. 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'[1] 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 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].

1.2. 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].

1.3. 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 [48], 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.

2. Methods

2.1. Overview

As per guidelines [49,50], a multidisciplinary panel used mixed-methods to develop a DCE to elicit preferences for three seizure scenarios, where opportunities for increased non-conveyance exist [51, 52]. 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).

2.2. 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 [53]; 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 (Fig. 1). Attribute labels were supported by a brief description and levels by symbols. The number of levels per attribute ranged from 2 to 4.

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[1] '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]. One section should include information on "first aid, safety and injury prevention at home and at college or work" [33]. 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.

Fig. 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 [54]. 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.

2.3. 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 2 h; Urgent Treatment Centre (UTC), 2,3, or 6 hrs; Accident & Emergency [A&E] Department, 3 or 6 h (see Fig. 1 'Notes' for details on UTCs and comment on the terms A&E and ED).

2.4. 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 (Fig. 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 choices based on preferences for care outside of the pandemic. The survey was

piloted with an external sample of $n = 12$ PWE aged $\geq$18-years recruited from the Epilepsy Action Research Volunteer Network; cognitive interview techniques helped identify refinements.

2.5. Participants

2.5.1. Eligibility criteria and recruitment

PWE aged $\geq$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 $\geq$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.

2.6. Analysis

2.6.1. Sample size

The protocol used a 'rule-of-thumb' [55] 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.

2.6.2. Data quality checks and curation

Participants whose responses to characteristic questions indicated

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 ○

Fig. 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.

ineligibility were excluded. Index of Multiple Deprivation (IMD) 2019 [56] was calculated for each participant using their home postcode. Multiple imputation was performed for those with incomplete/invalid postcodes [57].

2.6.3. 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].

2.6.4. Base case analysis

Random effects logit regression models [58] 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:

$U_i = \beta_0 + \beta_1$ (care plan) $+ \beta_2$ (no convey) $+ \beta_3$ (convey UTC) $+ \beta_4$

(convey ED) + β5 (time) +

B6 (epilepsy specialist today) + β7 (GP told) + β8 (no future specialist) + β9 (2–3 week specialist) + β10 (1 week specialist) + ε

Ui= utility derived by individual

β0= 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 1000 bootstrap replications.

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

2.6.5. 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.

2.6.6. 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 [48], 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.

3. Results

3.1. 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.

3.2. Participants

3.2.1. Responses

Eligible, useable survey submissions were received from $n = 594$ participants ($n = 427$ PWE; $n = 167$ 'significant others') (Fig. 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.
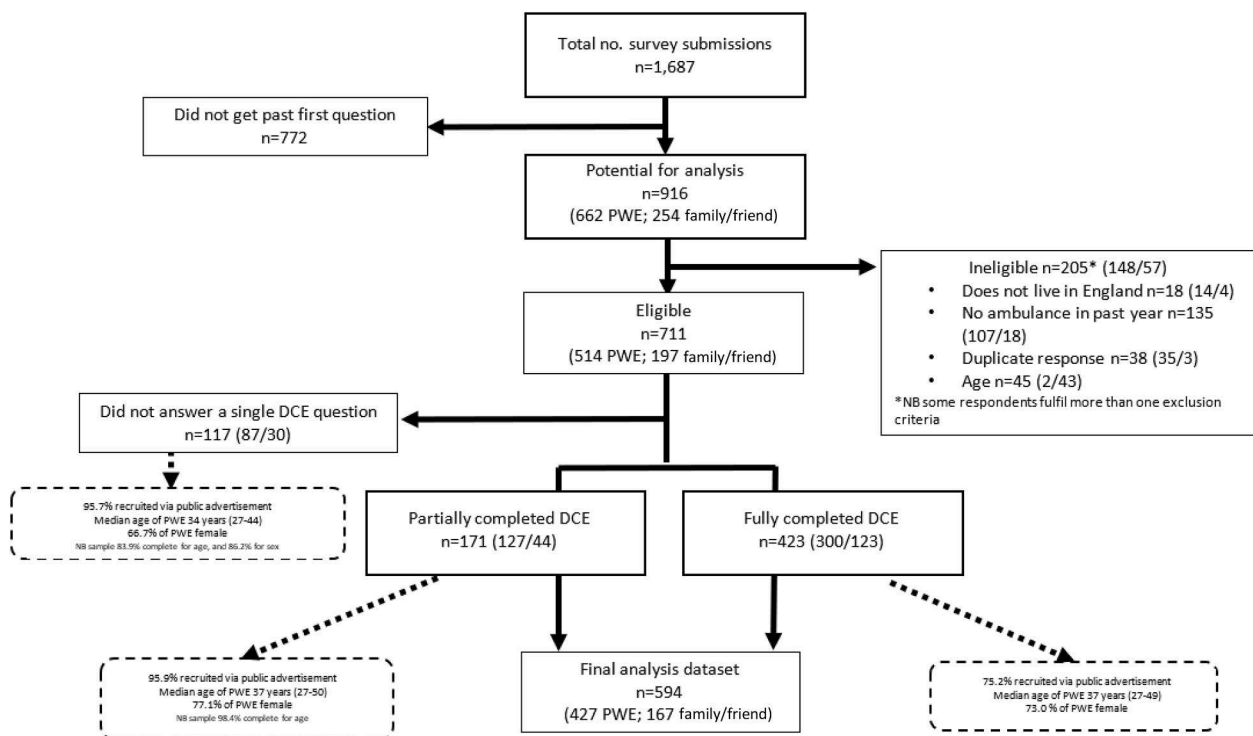
Fig. 3. Responses to survey by participant type, recruitment pathway and extent of completeness of response to Discrete Choice Experiments

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.

3.2.2. 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

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* = 1676**
***Participant type,* n (%)**				
Person with epilepsy (PWE)	69 (61.6 %)	358 (74.3 %)	427 (71.9 %)	1676 (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	
***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	
***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.

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).

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).

3.3. 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.

3.4. Statistical significance of attributes and direction of their influence on preference

3.4.1. 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.

3.4.2. 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 . others expressed a statistically significant preference for the patient to stay where they were and avoid ED.

3.5. Ranking of care package configurations by preference

3.5.1. 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.

3.5.2. 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

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*		
	β coeff	*95 % CI[a]*		*β coeff*	*95 % CI[a]*		*β 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 h]	0.284	−0.088	0.716	0.192	−0.240	0.665	0.135	−0.249	0.559
Time [3 h]	0.079	−0.425	0.549	0.175	−0.348	0.743	0.331	−0.090	0.806
Time [6 h]	**−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*		
	β coeff	*95 % CI[a]*		*β coeff*	*95 % CI[a]*		*β 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 h]	0.295	−0.305	0.928	**0.833***	0.152	2.183	0.509	−0.178	1.395
Time [3 h]	−0.370	−1.168	0.309	0.265	−0.842	1.514	0.228	−0.648	1.270
Time [6 h]	**−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 1000 bootstrap replications; ^omitted level calculated as −1* (sum ß of other levels); ***p < 0.05.**

across them for PWE and significant others was 230/288 and 220/288 respectively.

3.6. Subgroup analysis

3.6.1. 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.

3.6.2. 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 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.

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 h. 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).

4. Discussion

4.1. 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 h; 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.

4.2. 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 [55,59,60]. 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 preferred for the time it took to be cared for to be 2 h, 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 [61,62] and intellectual disability means it can take longer to know whether someone is returning to their baseline and so safe to be left [63].

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) [64].

4.3. 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 [48]. 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'.

4.3.1. 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 [49,50,65] and provides a 'worked example' for those interested in developing CPs [66].

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 [67] (96 % of UK households have internet access [68]). 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.

5. 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'.

Declaration of competing interest

None.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2024.04.008.

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