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# Service users' preferences and feasibility – which alternative care pathway for adult ambulance users achieves the optimal balance? Workshops for the COLLABORATE project

Adam J. Noble[a,*], Beth Morris[a], Pete Dixon[a], Amy Mathieson[a,b], Leone Ridsdale[c], Myfanwy Morgan[d], Jon Dickson[e], Steve Goodacre[f], Mike Jackson[g], Dyfrig Hughes[h,i], Anthony Marson[i], Emily Holmes[h,i]

[a] *Department of Public Health, Policy and Systems, University of Liverpool, Liverpool, UK*
[b] *Centre for Primary Care and Health Services Research, University of Manchester, UK*
[c] *Department of Basic and Clinical Neuroscience, King's College London, London, UK*
[d] *Institute of Pharmaceutical Science, King's College London, UK*
[e] *Academic Unit of Primary Medical Care, University of Sheffield, UK*
[f] *School of Health and Related Research, University of Sheffield, UK*
[g] *North West Ambulance Service NHS Trust, Bolton, UK*
[h] *Centre for Health Economics & Medicines Evaluation, North Wales Medical School, Bangor University, UK*
[i] *Department of Pharmacology and Therapeutics, University of Liverpool, UK*

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## ABSTRACT

*Introduction:* Adults presenting to the ambulance service for diagnosed epilepsy are often transported to emergency departments (EDs) despite no clinical need. An alternative care pathway (CP) could allow paramedics to divert them from ED and instigate ambulatory care improvements. To identify the most promising CP configuration for subsequent testing, the COLLABORATE project surveyed people with epilepsy and family/friends who had recently used the English ambulance service to elicit preferences for 288 CP configurations for different seizures. This allowed CPs to be ranked according to alignment with service users' preferences. However, as well as being acceptable to users, a CP must be feasible. We thus engaged with paramedics, epilepsy specialists and commissioners to identify the optimal configuration.

*Methods:* Three Knowledge Exchange workshops completed. Participants considered COLLABORATE's evidence on service users' preferences for the different configurations. Nominal group techniques elicited views on the feasibility of users' preferences according to APEASE criteria. Workshop groups specified the configuration/s considered optimum. Qualitative data was analysed thematically. Utility to users of the specified CP configurations estimated using the COLLABORATE preference survey data.

*Results:* Twenty-seven participants found service users' preferences broadly feasible and outlined delivery recommendations. They identified enough commonality in preferences for different seizures to propose a single CP. Its configuration comprised: 1) patients staying where they were; 2) paramedics having access to medical records; 3) care episodes lasting <6 h; 4) paramedics receiving specialist advice on the day; 5) patient's GP being notified; and 6) a follow-up appointment being arranged with an epilepsy specialist. Preference data indicated higher utility for this configuration compared to current care.

*Discussion:* Stakeholders are of the view that the CP configuration favoured by service users could be NHS feasible. It should be developed and evaluated.

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*Abbreviations:* APEASE, Acceptability, Practicability, Effectiveness, Affordability, Side-effects, and Equity; CP, Care Pathway; DCE, Discrete Choice Experiment; ED, Emergency Department; GP, General Practitioner; KE, Knowledge Exchange; NGT, Nominal Group Technique; NHS, National Health Service; PPI, Patient and Public Involvement; PWE, People with epilepsy; UTC, Urgent Treatment Centre.

* Corresponding author.
*E-mail address:* adam.noble@liv.ac.uk (A.J. Noble).

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## 1. Introduction

### 1.1. *Emergency care use, epilepsy and alternative care pathways*

Studies from around the world show ambulances frequently attend to adults with epilepsy and convey them to hospital emergency departments (EDs) [1–4]. In England, suspected seizures are the 7th most common presentation to the ambulance service; [2,5] ~70 % are conveyed to ED. The population attending ED for a suspected seizure is mixed and includes people with varying needs. For some, attendance at ED will be important, potentially lifesaving. Having said this, ED attendance for most seen by ambulance for a suspected seizure will offer minimal benefit since most have established (rather than new) epilepsy; present with a non-emergency state (e.g., uncomplicated seizure); and the attendance does not instigate improvements in ambulatory care [2, 6–11]. Clinically unnecessary attendances can though, harm the patient [12,13] and, by restricting ED capacity, also others [14].

There is momentum therefore for paramedics to have access to some form of alternative care pathway (CP) that could, when appropriate, be used to divert adults with established epilepsy away from ED, whilst bringing them to the attention of an epilepsy specialist for subsequent review. Barriers to increased non-conveyance have been identified [15, 16] and a lack of alternatives to ED is one.

An alternative CP for epilepsy could though, take various configurations [17]. It is important that the strongest candidate/s are implemented. The wider literature indicates low uptake upon implementation is a real possibility [18–20]. One potential reason for this is a failure to develop a CP in partnership with those expected to deliver or receive it. Our COLLABORATE project, whose protocol is available elsewhere [21], thus engaged with stakeholders to identify the optimal alternative CP configuration for epilepsy that should be prioritised for implementation and evaluation.

### 1.2. *Understanding which care pathway configuration would be acceptable to service users*

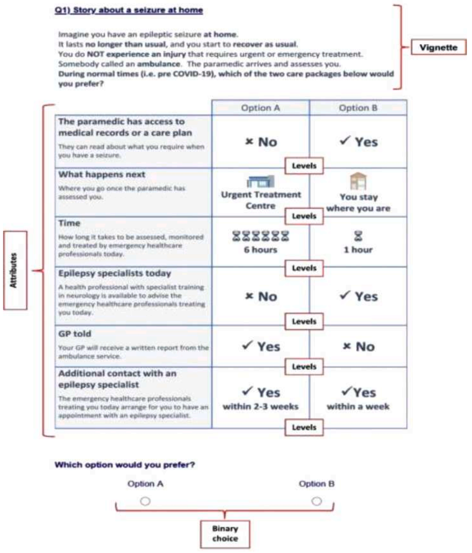
In our accompanying article [22] we reported how one element of COLLABORATE involved using Discrete Choice Experiments (DCE) to understand what configuration of post-seizure care people with epilepsy (PWE) from England prefer. DCEs are an attribute-based survey method capturing an individual's stated preferences. Table 1 provides an overview of the method and our use of it.

In brief, COLLABORATE's DCEs reported in our accompanying article involved PWE being presented with vignettes describing seizure scenarios and making choices to indicate which CP configurations, described according to 6 attributes, they preferred. Table 2 describes the attributes and levels. The scenarios were 'Home typical seizure', 'Public typical seizure' and an 'Atypical seizure'. Significant others (e.g., close family, friends) to PWE also completed the DCEs.

Stated preference data was ultimately secured for 6 different contexts (3 scenarios*2 participant types) and allowed us to estimate users' preference for 288 possible CP configurations.

The DCEs revealed: the target population wants a configuration of post-seizure care markedly different from that currently offered[1]; that they are open to non-conveyance to ED; and that their care preferences for the 6 contexts are similar. Fig. 1A details the attribute levels preferred by service users. In terms of the attribute 'What happens next',

**Table 1**
Overview of discrete choice experiments.

| **Discrete Choice Experiments (DCE)** | **Annotated example of one DCE used in COLLABORATE project** |
|---|---|
| • DCEs are a attribute-based survey methodology to assess stated preferences [23,24].<br>• Underpinned by random utility theory [25]. State that any 'good', including a health care package, can be described by its characteristics ('attributes') and the extent to which an individual prefers a good will depend on the 'levels' these attributes take [26].<br>• DCEs elicit stated preferences by presenting hypothetical scenario and participant chooses which 'good' they prefer. Each 'good' is described according to the same attributes, but the levels vary.<br>• Changing the levels these attributes take (using an experimental design), produces profiles of goods that respondents choose between (choice sets).<br>• By observing how participants change their responses, DCEs permit inferences about which attributes and levels drive preference, the direction of effect (e.g., want more or less), and how respondents 'trade-off' level changes. |  |
| **DCEs use in COLLABORATE project** | |

**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**<br>They can read about what you require when you have a seizure. | × No | ✓ Yes |
| **What happens next**<br>Where you go once the paramedic has assessed you. | Urgent Treatment Centre | You stay where you are |
| **Time**<br>How long it takes to be assessed, monitored and treated by emergency healthcare professionals today. | 6 hours | 1 hour |
| **Epilepsy specialists today**<br>A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today. | × No | ✓ Yes |
| **GP told**<br>Your GP will receive a written report from the ambulance service. | ✓ Yes | × No |
| **Additional contact with an epilepsy specialist**<br>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 ○

(continued on next page)

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[1] England has 10 regional ambulance services. Whilst there is some variation between regions, it is typical that the ambulance crew managing a person 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).

**Table 1** (*continued*)

| Discrete Choice Experiments (DCE) | Annotated example of one DCE used in COLLABORATE project |
|---|---|
| • DCEs created for three hypothetical seizure vignettes (home typical seizure, public typical seizure, atypical seizure).<br>• For each, participants were asked to respond to 12 forced, pairwise choices.<br>• Each involved them saying which of two unlabeled care pathway (CP) options was preferred (Option A, Option B).<br>• CP options were described according to 6 attributes. Levels per attribute ranged from 2 to 4 (Table 2).<br>• $N = 427$ people with established epilepsy aged ≥18 seen by the English ambulance service in the prior 12 months and $n = 167$ friends/family of such persons, completed the DCEs online.<br>• Wording was adjusted to suit versions completed for people with epilepsy and significant others.<br>• See Notes of this table for all seizure vignettes. For an atypical seizure it was *“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.*<br>• Adjacent image presents an annotated example of a choice task for the scenario ‘home typical seizure’. | |

*Notes* CP, care pathway; DCE, discrete choice experiment.
Vignettes for different seizures scenario were as follows: Public typical seizure, *“Story about a seizure in public…Imagine you have an epileptic seizure* ***in public****. Its lasts* ***no longer than usual****, and you start to* ***recover as usual****. You do* ***NOT experience an injury*** *that requires urgent or emergency treatment.”*; Home typical seizure, *“Story about a seizure* ***at home****…Imagine you have an epileptic seizure at home. Its lasts* ***no longer than usual****, and you start to* ***recover as usual****. You do* ***NOT experience an injury*** *that requires urgent or emergency treatment.”*; 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.”* Wording differed in the versions completed for significant others.

there was a pattern of preference to avoid conveyance to ED and for the PWE to remain where they were.

Importantly, the sample providing this data was broadly representative of the target population. This is noteworthy as persons who attend ED for epilepsy differ from the wider epilepsy population. Some studies have found they have lower epilepsy knowledge, report more clinical anxiety, report greater perceived epilepsy stigma and are more likely to live in a socially deprived area [30–33]. Up to 20 % have an intellectual disability [34]. Outside of the UK, there is also evidence that being of black and aboriginal ethnicity is associated with ED use [35].

### *1.3. Understanding which configuration/s favoured by service users are feasible*

The DCEs provided crucial design information. However, in seeking to identify which configuration/s should be prioritised for implementation and evaluation, factors related to feasibility within the National Health Service (NHS) also need consideration. Michie et al.’s [36]‘APEASE’ framework, described in Supplementary File 1, highlights the factors. They include expected affordability, practicability, effectiveness, side effects, equity and acceptability to providers [36].

We therefore here report on ‘Knowledge Exchange’ (KE) workshops we completed with people whose professional positions meant they could fund, implement or support an alternative CP for epilepsy. We asked them to consider the DCE findings and use their expertise and experience to judge which configuration represented the optimal balance between user preference and feasibility.

## 2. Methods

### *2.1. Design*

Three KE workshops were completed. Their design (Fig. 2), described under ‘Procedure’, was relatively novel, as DCE projects often stop upon experiment completion (e.g., [37–40]). It was informed by Wilkins and

**Table 2**
Six attributes used to describe all the care pathway configurations within the DCE.

| | Attribute | Levels | *Commentary* |
|---|---|---|---|
| 1. | **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):*<br>• No<br>• Yes | 'Care plan' does not have a universally agreed definition. Guidelines in England state all PWE should have an agreed and comprehensive written epilepsy 'care plan' [27]. One section should include information on "first aid, safety and injury prevention at home and at college or work". [28] In some geographical areas, this part is sometimes called a 'seizure action plan' or 'emergency care plan'. The varied ways in which the term 'care plan' is used led to the specific phrasing for this attribute and the accompanying prose. It was piloted. [22] |
| 2. | **What happens next** Where you go once the paramedic has assessed you. | *Levels (3):*<br>• *Stay where you are*<br>• *Urgent Treatment Centre*<br>• *A&E Department* | 'Urgent Treatment Centre' 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 [29]. They are open at least 12 h a day, 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, the terms "Accident and Emergency"/ "A&E" and ED are often used interchangeably. "Accident and Emergency"/ "A&E" is common within lay parlance and so was used to describe EDs within the DCE. |
| 3. | **Time** How long it takes to be assessed, monitored and treated by emergency healthcare professionals today. | *Levels (4):*<br>• 1-hour<br>• 2-hours<br>• 3-hours<br>• 6-hours | To ensure plausibility, the levels for the attribute 'Time' were conditional on the level that the attribute 'What happens next' took. 'Stay where you are', time restricted to 1 or 2 hrs; Urgent Treatment Centre (UTC), time restricted to 2,3, or 6 hrs; Accident & Emergency [A&E] Department, time restricted to 3 or 6 hrs. |
| 4. | **Epilepsy specialists today** A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today | *Levels (2):*<br>• No<br>• Yes | – |
| 5. | **GP told.** Your GP will receive a written report from the ambulance service. | *Levels (2):*<br>• Yes<br>• No | – |
| 6. | **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):*<br>• *No*<br>• *Within a week*<br>*2–3 weeks* | – |

*Notes:* A&E, accident and emergency; DCE, discrete choice experiment; ECG, electrocardiogram; ED, emergency department; GP, general practitioner; UTC, Urgent Treatment centre.
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").

Cooper's [41] definition of KE as a two-way exchange between researchers and research users. It goes beyond just telling people things and should be seen as a process of listening and interaction, with a goal to generate mutual benefit.

For reasons outlined by Black [42], a group, rather than individual approach was preferable. We had planned face-to-face workshops; however, the COVID-19 pandemic meant smaller, online workshops were necessary.

Reporting conforms with the Standards for Reporting Qualitative Research [43].

## 2.2. *Participants*

### 2.2.1. *Eligibility criteria*

Participants needed to be aged ≥18 years, live in the UK, be able to provide informed consent, participate independently in English and represent one of the following groups: paramedic, epilepsy specialist (neurologist, epilepsy nurse specialist [ENS], neuropsychiatrist) or commissioner. For each workshop we also sought to have ≥1 service user representative present as an active participant.

With regards composition, at each workshop we planned to have persons from each group represented [44] and persons from different ambulance regions. England has $n = 10$ such regions [45]. They have varied in non-conveyance rates [46] and potentially have different infrastructure relevant to alternative CPs [47].

### 2.2.2. *Recruitment*

Clinical representatives were recruited from organisations participating in a national survey completed for COLLABORATE [17]. Commissioners were recruited by the National Ambulance Commissioners Network and the Association of Ambulance Chief Executives circulating adverts. Service users were recruited by inviting members from COLLABORATE'S patient and public involvement group. It included 12 adults with epilepsy and significant others.

Supported by a sampling matrix, 50 people were ultimately sent invitations. We sought to over-recruit by ~30 %, to accommodate nonattendance [48]. Invitees willing to participate were asked to inform the research team and complete an e-consent form.

Approval was received from the Health Research Authority and West Midlands–Solihull NHS Ethics Committee (19/ WM/0012). Service user participants were offered a £20 voucher.

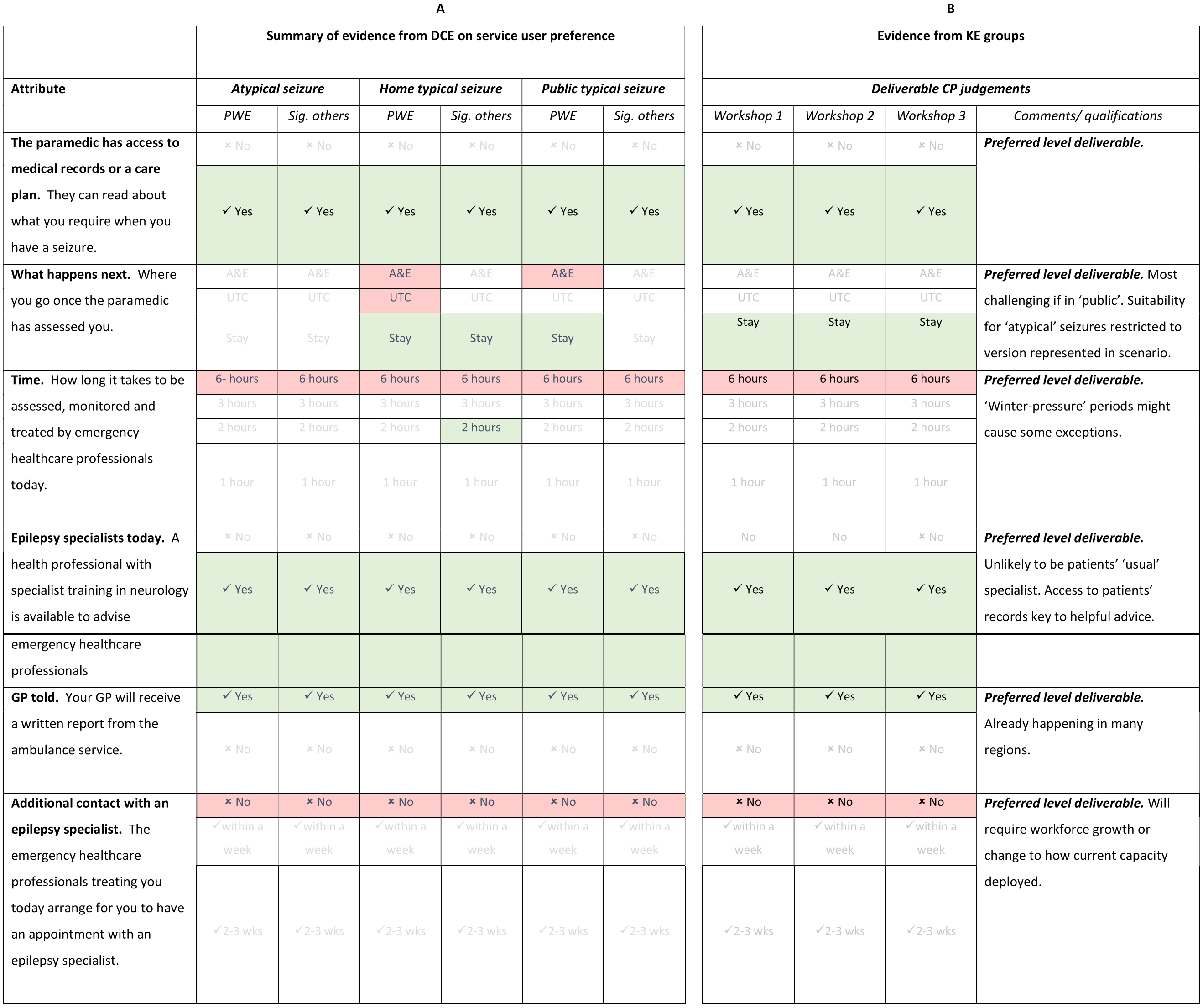
## 2.3. *Procedure*

### 2.3.1. *Overview of structure and facilitation*

Workshops had three-parts and were facilitated by BM, a qualitative health services researcher. EH was present to assist with DCE questions and AN to offer support. With participants consent, workshops were audio-recorded and transcribed verbatim. Participants did not review transcripts.

### 2.3.2. *Part 1*

Participants were shown two pre-recorded presentations. The first introduced APEASE. The second shared detailed, yet distilled DCE findings (Supplementary File 2). To familiarise participants with the DCE approach, in advance of the workshops they were sent a practice version.



| | A | | | | | | B | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Summary of evidence from DCE on service user preference | | | | | | Evidence from KE groups | | | |
| **Attribute** | ***Atypical seizure*** | | ***Home typical seizure*** | | ***Public typical seizure*** | | ***Deliverable CP judgements*** | | | |
| | *PWE* | *Sig. others* | *PWE* | *Sig. others* | *PWE* | *Sig. others* | *Workshop 1* | *Workshop 2* | *Workshop 3* | *Comments/ qualifications* |
| **The paramedic has access to medical records or a care plan.** They can read about what you require when you have a seizure. | × No | × No | × No | × No | × No | × No | × No | × No | × No | ***Preferred level deliverable.*** |
| | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | |
| **What happens next.** Where you go once the paramedic has assessed you. | A&E | A&E | 🟥 A&E | A&E | 🟥 A&E | A&E | A&E | A&E | A&E | ***Preferred level deliverable.*** Most challenging if in 'public'. Suitability for 'atypical' seizures restricted to version represented in scenario. |
| | UTC | UTC | 🟥 UTC | UTC | UTC | UTC | UTC | UTC | UTC | |
| | Stay | Stay | 🟩 Stay | 🟩 Stay | 🟩 Stay | Stay | 🟩 Stay | 🟩 Stay | 🟩 Stay | |
| **Time.** How long it takes to be assessed, monitored and treated by emergency healthcare professionals today. | 🟥 6- hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | 🟥 6 hours | ***Preferred level deliverable.*** 'Winter-pressure' periods might cause some exceptions. |
| | 3 hours | 3 hours | 3 hours | 3 hours | 3 hours | 3 hours | 3 hours | 3 hours | 3 hours | |
| | 2 hours | 2 hours | 2 hours | 🟩 2 hours | 2 hours | 2 hours | 2 hours | 2 hours | 2 hours | |
| | 1 hour | 1 hour | 1 hour | 1 hour | 1 hour | 1 hour | 1 hour | 1 hour | 1 hour | |
| **Epilepsy specialists today.** A health professional with specialist training in neurology is available to advise | × No | × No | × No | × No | × No | × No | No | No | × No | ***Preferred level deliverable.*** Unlikely to be patients' 'usual' specialist. Access to patients' records key to helpful advice. |
| | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | |
| emergency healthcare professionals | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 | |
| **GP told.** Your GP will receive a written report from the ambulance service. | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | 🟩 ✓ Yes | ***Preferred level deliverable.*** Already happening in many regions. |
| | × No | × No | × No | × No | × No | × No | × No | × No | × 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. | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | 🟥 × No | ***Preferred level deliverable.*** Will require workforce growth or change to how current capacity deployed. |
| | ✓within a week | ✓within a week | ✓within a week | ✓within a week | ✓within a week | ✓within a week | ✓within a week | ✓within a week | ✓within a week | |
| | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | ✓2-3 wks | |

**Fig. 1.** (A) Summary of DCE evidence on attribute levels preferred by service users for different contexts and (B) attribute levels specified by Knowledge Exchange workshop groups as representing optimal balance between NHS feasibility and service user preference *Notes:* A&E, Accident and Emergency department; CP, care pathway; UTC, Urgent Treatment Centre; Sig. Other, significant other; wks, weeks; For columns presenting 'Summary of evidence from DCE': a green cell indicates an attribute level the respondents significantly preferred for the care pathway to have in that scenario; a red cell means an attribute level that respondents significantly preferred to not have in the care pathway for the scenario; white cells indicate those that did not reach statistical significance.

### *2.3.3. Part 2*

Nominal Group Technique's (NGTs) secured participants views on the DCE findings and feasibility of users preferred attribute levels. NGTs are well established [49] and adaptable [50]. The approach we used involved a 2-minute period of silent 'reflection' for participants to consider the findings, followed by a 'round robin' phase that provided each participant with a protected opportunity to share their views. When considering feasibility, participants were asked to have a timeframe of the next 5–10 years in mind. A 'clarification' phase finally occurred during which participants could discuss matters openly and respond to each other.

Discussions were supported by a topic guide (Supplementary File 3).

### *2.3.4. Part 3*

This part sought to identify participants' views on the optimal CP configuration, accounting for user preference and feasibility.

Each workshop group was asked whether they would recommend the development of one or more CPs for use with the different seizure scenarios. A summary slide was presented of the variation in preferences by context (Supplementary File 4). Having made their decision, the group was asked to create as many CP configurations as they deemed necessary, specifying the attribute levels for the different scenarios that they considered to represent the optimal balance. Their choices were recorded 'on screen' by AN within a table.

## *2.4. Analysis*

To understand participants views on the attribute levels preferred by users and their justification for the CP configuration/s they recommended, qualitative data from Parts 1–3 was thematically analysed using an approach informed by Braun and Clarke [51].

It was conducted deductively with identification of pre-existing themes underpinned by previous research and inductively with the identification of themes grounded in the data. BM generated codes through open coding and categorized these thematically. AN reviewed these and suggested alternative interpretations until consensus was achieved. Quotations, with minor editing to preserve anonymity, are presented to illustrate themes.

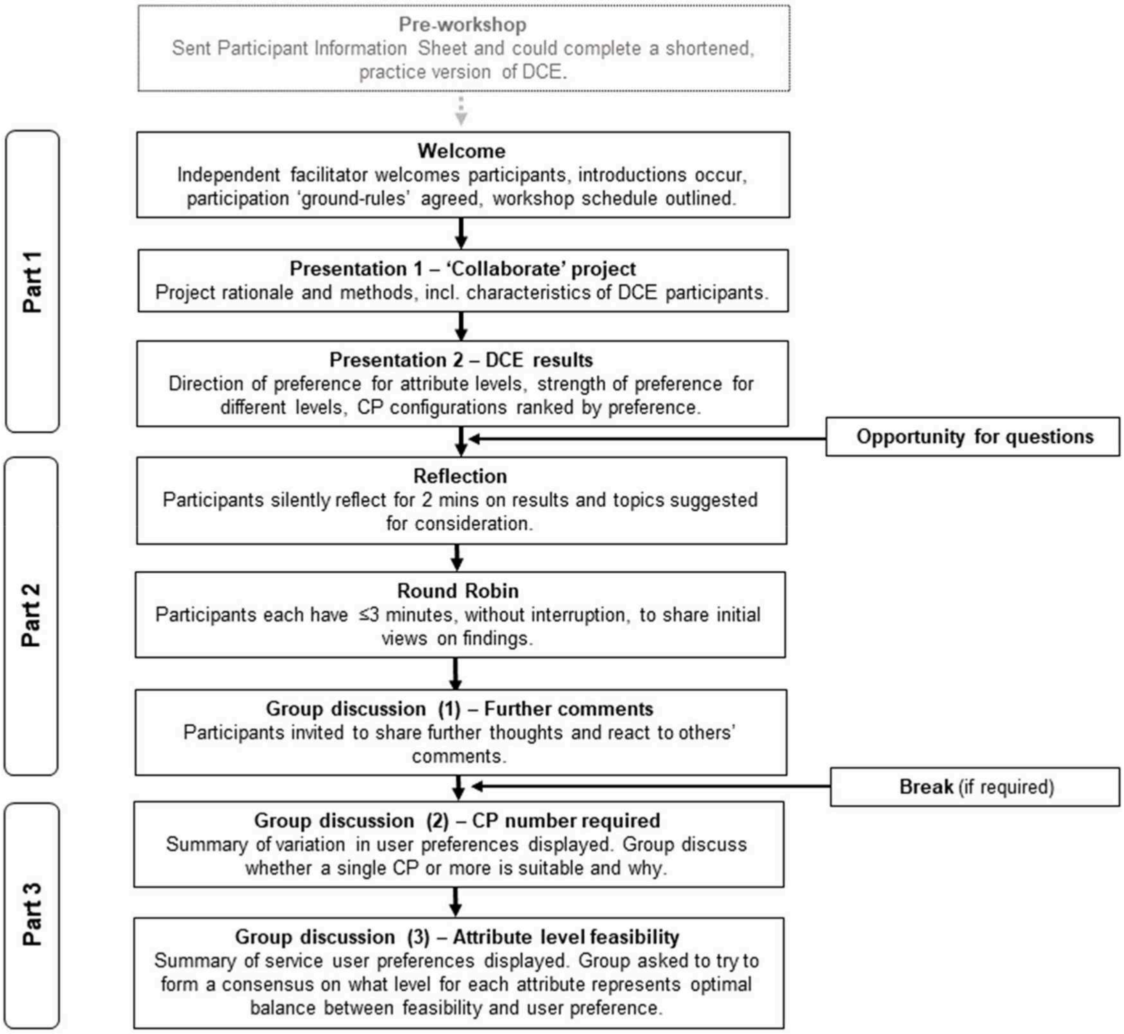


**Fig. 2.** Structure of Knowledge Exchange workshops. *Notes:* CP, care pathway; DCE, Discrete choice experiment; incl., including.

The CP configurations that the different workshop groups specified as representing the optimum during Part 3 are presented in a table. Using the findings from the DCE (see [22]), the rank positions of the configurations specified by the groups was determined and is described. To contextualise their positions, the ranking of the configuration representing current care in the same contexts was determined.

## 3. Results

### 3.1. Participants

Twenty-seven representatives attended the workshops (10 paramedics; 8 epilepsy specialists; 5 commissioners; 4 service users). Paramedics came from 7 of England's different regional ambulance services. The workshops occurred between April and May 2021. The composition of the groups at them is shown in Fig. 3. It also reports the job titles of the participants.

### 3.2. Themes

Transcript analysis provided insights into the extent to which the DCE evidence aligned with the representatives' experience and the perceived feasibility of the preferred attribute levels. These are expanded upon in the following sections. Supplementary File 5 provides additional illustrative quotes.

#### 3.2.1. Reactions to DCE findings

Some participants said the DCE findings aligned with their clinical or 'lived' experience. For others, the evidence was revealing. All said the findings indicated a need to change service provision:

> *"I thought it was…quite sobering that…patients…presenting to us with epilepsy don't…really kind of want what we're currently doing…clearly a burning platform…for us to…change"* (Paramedic;F;1)

Participants were keen to highlight that the extent to which any alternative CP is ultimately used by a clinician will need to be based on clinical judgement at the time, saying it would not be appropriate or wise to mandate use when implementing it.

*Feasibility of service users' preferred attribute levels and number of CP configurations required* Participants believed the attribute levels preferred by users were broadly feasible. Moreover, they considered one CP for all 6 seizure contexts justifiable. They believed there was sufficient commonality in users' preferences and that a single CP would be simpler from an administrative and commissioning perspective.

> *"There are some challenges for ambulance staff in terms of quality* versus *performance…but er, I think for a lot…of ambulance services it's* [the preferred CP configurations is] *probably not that, that far of a stretch…"* (Paramedic,M;1)

The workshop groups believed the optimal CP configurations comprised of: ambulance clinicians having access to medical records;

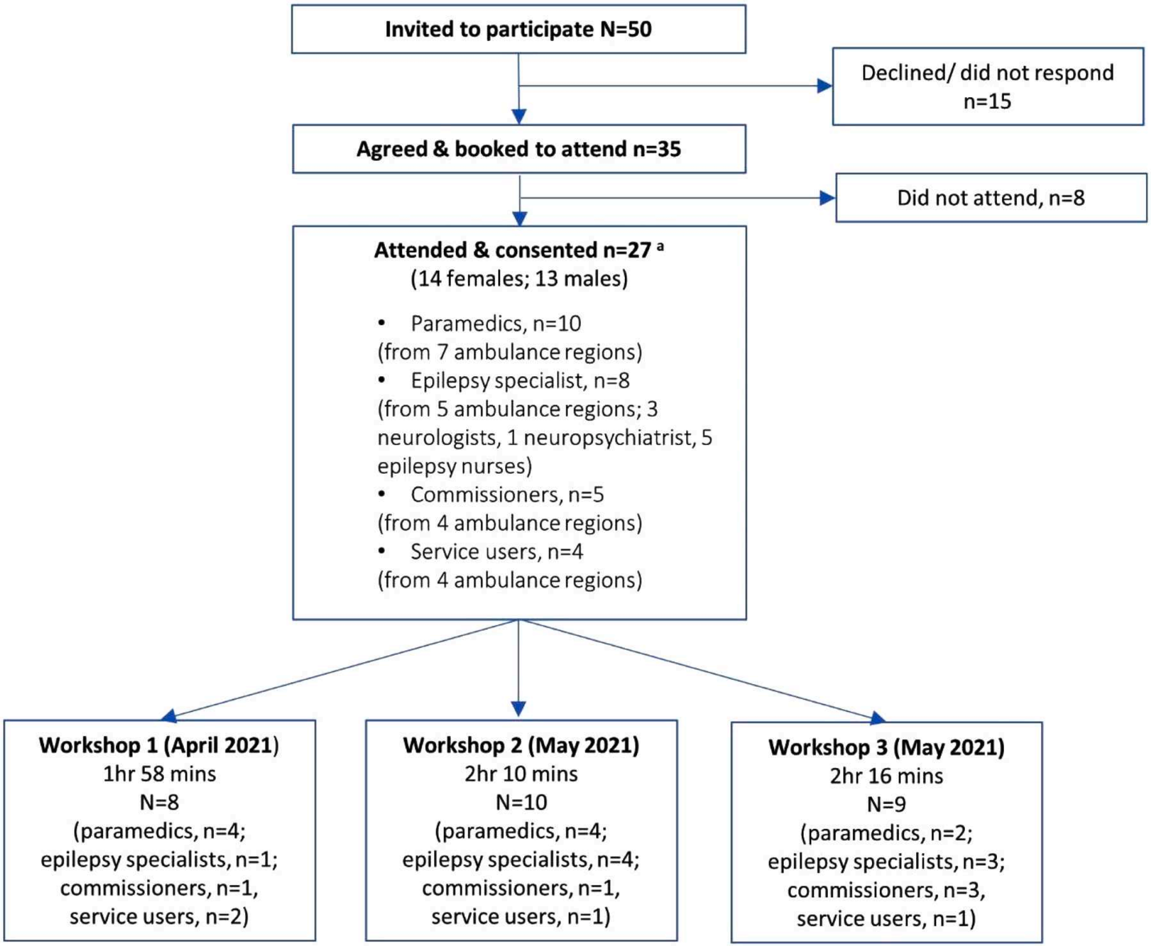


**Fig. 3.** Recruitment flow diagram, participant characteristics and workshop details. *Notes:* hr, hour; mins, minutes; N/n, number. [a] Training pathways for the different stakeholder groups are not equivalent. Moreover, there can be variation within some of them. To provide an indication of their seniority whilst also maintaining anonymity, below are the job titles/ roles of participants.
Ambulance service participants: Consultant paramedic*4; Advanced paramedic*2; Lead Paramedic*1; Community specialist paramedic*2; Deputy clinical director*1.
Epilepsy specialist participants: Consultant neurologist*2; Consultant neuropsychiatrist*1; Neurology registrar*1; Epilepsy Nurse Specialist*2; Consultant Epilepsy Nurse*1; Epilepsy Nurse Lead*1.
Commissioning participants: Regional commissioning lead*1; Regional director of services*2; Care pathway director*2.

the person typically staying where they were; the time taken being less than 6 h (whether it was 1, 2 or 3 h was not specified); for crews to be able to be advised by a specialist on the day; for the GP to be notified; and for the incident to result in an appointment being made for the patient to have a follow-up appointment with an epilepsy specialist (whether it was within 1 or 2–3 weeks was not specified) (Fig. 1B). Using these attribute levels, the number of CP configurations for consideration reduced from 288 to 18. Their estimated utility is discussed later.

### *3.3. Feedback on feasibility of individual attribute levels preferred by users*

*Attribute 1: The paramedic has access to medical records or a care plan (Level options: Yes, No)*

The consensus amongst participants was that ambulance clinicians having access to medical records, or a care plan was achievable in the next 5–10 years, if not sooner. Their justification being that in some regions, mechanisms were already in place for sharing more rudimentary versions of a person's medical record with crews (e.g., "NHS Summary Care Records"). It was acknowledged though, that there was work to be done by usual care providers to ensure PWE had a care plan to share:

> "*I don't have a care plan, and I do wonder how many other people with epilepsy don't really have a care plan.*" (PPI;F,2)

Participants believed access to medical records, or a care plan could support non-conveyance by increasing crews' confidence to identify persons suitable for consideration:

> "[It could] *give them that bit of reassurance*…[paramedics] *don't work in an ED department where there's somebody on hand to…get that second opinion…for me, it doesn't have to be that physical person, it can be that well documented care plan that will give them the confidence to make that decision.*" (Paramedic, M,3)

Participants also offered views as to what such plans should contain. They were united in stating that crews needed access only to pertinent information and that it should be presented and accessed in a consistent way between geographic areas to maximise utility:

> *"…in the heat of the moment to kind of trawl…years of clinic letters or hand-written medical notes is…only half useful…The development of a very specific document…a care plan is where…significant gains can be had."* (Neuroscience doctor;M,1)

They said it should cover "*the baseline for that patient as an absolute minimum*" and have "*some representation of that patient's wishes"* (Paramedic;M;6). As ambulance clinicians can differ in their training and experience [52,53], participants emphasized the information needed to be written in an accessible language.

*Attribute 2: What happens next (Level options: ED, UTC, Stay where you are)*

Participants were mostly in agreement that it was feasible to follow service users' preferences to stay where they are for 'Home typical seizure', saying this was already becoming more common practice:

> "*…do we think this is feasible…patients with diagnosed epilepsy with a typical seizure presentation – 100 %….been the best option for a while* [stay at home] *and paramedics are gaining confidence in that in their current practice."* (Paramedic;F,2)

Participants were more circumspect in their support for the preference of PWE to not be conveyed to ED following an 'Atypical seizure'. It was noted how this would represent a major change in practice:

> *"…with atypical seizure presentations, most of us have quite low thresholds to take patients to ED.*" (Paramedic;F,2)

Much discussion was had about the *range* of possible presentations that can be captured by the term 'atypical' and how the CP preferred by services users might be suitable for some, but not all. They acknowledged the parameters of the 'Atypical seizure' scenario used in the DCE and agreed that for this variation, the patient staying where they were should be feasible.

Because of the potentially elevated risk of atypical seizures, participants highlighted consideration will, in due course, need to be given to which grades of ambulance clinician would be permitted to use an alternative CP for them. They noted this would be particularly pertinent during periods of high demand when ambulance services are sometimes supported by voluntary staff and private services.

*Attribute 3: Time (Level options: 1, 2, 3, or 6 h)*

Participants believed a CP that reflected users' preference to avoid being assessed, monitored and treated by an emergency health care professional for more than six hours was feasible, as was significant others preference for the time be two hours for a 'Home typical seizure'.

> "*…absolutely achievable and probably for the most par…that is something that we achieve with… cases already.*" (Paramedic;M,4)

> "*where would you allow them* [people who have had a seizure in public] *to recover safely...One thought was in the back of an ambulance…*" (ENS;F,3)

Nonetheless, participants did highlight how feasibility might reduce during periods of high demand (e.g., 'winter pressures'). Also, they noted how there might be operational challenges and indirect pressure from performance targets if crews are asked to stay with persons with long-recovery times, rather than conveying them to ED and becoming available to respond to other incidents:

> "*…there will always be tensions between…call volumes…some days it would be possible to…maintain that kind of stance* [i.e., wait with PWE for 2 h], *but on other days…it just may not always be possible…*" (Commissioner;F;2)

*Attribute 4: Epilepsy specialists today (Level options: Yes, No)*

Participants believed it feasible within the next 5–10 years for a CP to reflect service users' preference for emergency health care professionals to have access to a health care professional with specialist training in neurology for advice. What consensus was lacking on though, was *who* this specialist should be.

Some epilepsy specialist said that for the person to offer meaningful advice, they needed to be *personally* familiar with the patient. With existing capacity, they stated this was not feasible. They were of the view that the priority should therefore instead be on developing and giving ambulance crews access to high-quality care plans personalised to the patient:

> *"…if they've got a seizure care plan, if they know their treatment plans and it's all written out, actually they* [crews] *won't need this…they don't need the specialist advice.*" (Neuroscience doctor;F,1)

Ambulance clinicians, however, were keen to emphasise that they work in an isolated way and that any advice from a specialist – whether they know the patient or not – would be welcomed. They also explained the technological infrastructure was in place in many areas to accommodate this since they already use it to access advice from different specialists for other presentations.

*Attribute 5: GP told (Level options: Yes, No)*

There was a consensus amongst participants that users' preference for GPs to receive a written report from the ambulance service was feasible. Participants noted that in regions where crews' complete records electronically, it was already happening:

> "*When we discharge someone on the scene, the GP is automatically emailed a…as long as we can trace the patient on the* [system]. *So yeah absolutely…achievable...*" (Paramedic; M,3)

*Attribute 6: Additional contact with an epilepsy specialist (Level options: No, within a week, 2–3 weeks)*

Overall, participants believed users preference for the emergency health care professional treating them on the day to arrange for them to have a follow-up appointment with a specialist was feasible. Ambulance clinicians said they already arrange follow-up appointments for other presentations, whilst epilepsy specialists said other parts of the urgent and emergency care system (e.g., ED staff) can already instigate epilepsy follow-up appointments and so extending it to ambulance crews was viable. They did note that some specialist services were struggling to meet wait time standards for referrals from more traditional sources. However, they did not deem this to be an insurmountable barrier, believing the attribute level could be achieved by an expansion in capacity or alternatively by deploying existing capacity differently:

> *"…we've looked at the way we run our services and made…a radical change… we're not booking routine follow up appointments…they can contact us…that's allowing more capacity…that's now our mission – that we get back to calls* [from ambulance crews and PWE] *within the day because they're, they're patients or health care professionals that really need to speak to us."* (ENS;F,2).

### 3.4. Estimated utility to service users of CP configurations identified as optimal

The attribute levels specified by participants as representing the optimum, permitted 18 CP configurations to be created. Table 3 shows the median ranking of this set of configurations for each seizure context (with a rank of 1 being the CP most preferred by users). For each context, the set included the service users most favoured configuration. Moreover, all 18 configurations were estimated to hold more utility than offered by the configuration representing current care.

Participants noted two situations in which the optimal levels might be harder to achieve (Fig. 1B). The first was when an epilepsy specialist was not available to advise paramedics on the day. Amending the CP to reflect this reduced the ranking of the CPs, however, estimated utility of the 18 remained above that of current care

The second situation was during periods of heightened pressure on the NHS when the preferred level for 'Time' and users' preferences for non-conveyance might not be possible (due to greater reliance on clinicians who are not qualified paramedics); the median ranking of the CPs configuration reduced substantially in this circumstance, with 7 of the configurations now holding less expected utility to service users than current care.

**Table 3**
Restricted attribute levels based on participants' feedback, the number of care pathway configuration that could be constructed using them and descriptive statistics of their expected utility.

| | **BASECASE**<br>*Optimal & Feasible* | **Scenario One**<br>*Specialist advice not available today, advice in care plan assumed to be sufficient* | **Scenario Two**<br>*'winter pressures' / times of strain of NHS resources.* | |
|---|---|---|---|---|
| **Attributes** | | | | |
| *The paramedic has access to medical records or a care plan* | Yes | Yes | Yes | |
| *What happens next* | Stay, UTC, ED | Stay, UTC, ED | Stay, UTC, ED | |
| *Time* | 1,2,3 | 1,2,3 | 1,2,3, **6+** | |
| *Epilepsy specialists today* | Yes | **No** | Yes, **No** | |
| *GP told* | Yes | Yes | Yes | |
| *Additional contact with an epilepsy specialist* | 2–3 weeks, 1-week | 2–3 weeks, 1-week | 2–3 weeks, 1-week | |
| **Count of CP configurations** | 18 | 18 | 12 | |
| | Median rank (range) | Median rank (range) | Median rank (range) | Current care* configuration rank |
| ***People with epilepsy*** | | | | |
| Home typical seizure | 42.5 (1 to 60) | 86 (10 to 107) | 183.5 (59 to 236) | 247 |
| Public typical seizure | 30.5 (1 to 71) | 74 (10 to 136) | 158.5 (49 to 240) | 230 |
| Atypical seizure | 9.5 (1 to 19) | 66.5 (34 to 99) | 139.5 (70 to 210) | 248 |
| ***Significant other*** | | | | |
| Home typical seizure | 47.5 (1 to 162) | 79 (4 to 205) | 219.5 (91 to 264) | 220 |
| Public typical seizure | 15 (1 to 61) | 64.5 (12 to 144) | 180 (88 to 247) | 239 |
| Atypical seizure | 28 (1 to 138) | 97 (15 to 231) | 167.5 (67 to 261) | 253 |

*Notes:* CP, care pathway; ED, emergency department; GP, general practitioner; Stay, "Stay where you/they are"; UTC, urgent treatment centre. Rank 1= most preferred; 288= least preferred. * Based on evidence presented by Mathieson et al. [17], the configuration chosen to represent 'current care' was, according to the 6 attributes and levels, comprised of: i) 'The paramedic has access to medical records or a care plan': No; 'i) 'What happens next': A&E; iii) 'Time': 3 h; iv) 'Epilepsy specialists today': No; v) 'GP told': Yes; and vi) 'Additional contact with an epilepsy specialist': No.

## 4. Discussion

### 4.1. Main findings

Three KE workshops were conducted with stakeholder groups. Participants were broadly of the view that the configuration of care which service users want to receive after common seizure presentations is feasible within 5–10 years. There was also consensus that there was sufficient consistency in users care preferences to warrant implementing and evaluating a single alternative CP.

Across the workshops, the CP configurations which participants said should be prioritised comprised of ambulance clinicians having access to medical records, the person largely staying where they are, the time being less than 6 h, for crews to have access to specialist advice during the episode, for the GP to be notified of the incident, and for the episode to generate a follow-up appointment with an epilepsy specialist. Based on this judgement, 18, marginally different CP configurations are possible, with our preference evidence (see [22]) indicating all would be expected to be more favourable to service users than current care.

That participants considered users' preferences to be feasible may be attributable to the extensive formative work we completed for the DCEs [22]. It ensured the attribute levels and combinations presented within the DCE were within the bounds of realism and likely safe.

One of the 18 CPs configurations should now be developed and evaluated for its efficacy. An evaluation should consider both short and longer-term outcomes. A cluster-randomised controlled trial would likely provide the most robust evidence. However, as pressures on EDs continue to increase, a faster evaluation approach may be needed to support service change.

### 4.2. Granular information regarding implementation

As well as helping identify the optimal CP, stakeholders provided insights that could help with its implementation. This included a need to consider what grades of clinicians might use it, how best to 'brand' it to promote use, how not conveying people who have had an atypical seizure will represent a significant shift in practice and how ambulance performance measures might need to continue to evolve to focus on care and outcomes (rather than response time) to ensure they facilitate the CPs use. Paramedics have previously described how performance targets mean they can feel able to spend limited time 'on scene' and perversely encourage conveyance [52].

Stakeholders also identified the attribute levels requiring work for them to become a reality – namely, how best to use existing epilepsy specialist capacity and developing and providing access to care plans (or what others might refer to as 'seizure action plans' or 'emergency care plans'). Their views align with the wider evidence. For instance, tensions are known to exist regarding how best to utilise the UK's finite specialist resources (it has fewer neurologists per head than other developed nations [54] and only ~55 % of acute trusts have access to an epilepsy nurse [55]). We also know many PWE do not have care plans [52].

With respect to feasibility, we asked participants to consider and share any logistical factors which might challenge the deliverability of the favoured CP configurations. We also asked them whether implementing the favoured CP configurations would serve all PWE equally. Participants did not identify the extent to which a person was in a rural or urban location as a challenge [53], nor did they highlight the known differences in the characteristics of persons with epilepsy seeking ambulance care. Nonetheless, it is important to continue to be mindful of their potential influence to ensure any implemented CPs meets the needs of all from the target population.

### 4.3. Periods when optimal levels might not be possible and implications

Stakeholders offered other insights which further underlined the value of the exercise. Specifically, they noted circumstances during a calendar year when optimal attribute level might be harder to achieve, and so flexibility might be required to maintain deliverability. To support implementation discussion, we estimated the impact on utility. Of most concern was the potential increase in 'Time' for assessment, monitoring and treatment during periods of 'winter pressure'. It was sufficient to mean 7 of the possible CPs could be perceived as 'worse' than current practice by service users. Service providers should be cautious about offering or permitting a CP that assumes this level.

### 4.4. Strengths and potential weaknesses

We developed and used a novel approach to KE. It permitted us to work efficiently and collaboratively with stakeholders (during a pandemic). Strengths included (i) the standardised approach by which we shared DCE evidence; (ii) workshop group composition; and, (iii) use of the NGTs which allowed participants to share and discuss views openly and constructively [56].

Potential limitations include the online nature of the workshops that restricted participant numbers. It meant we did not seek representation from other stakeholder groups that might have insights into supporting the target population. This includes, general practice, emergency medicine, and addiction and mental health services. Evidence does though, suggest that the disciplines we recruited from are most likely to be instigating CPs [17]. With regards sampling, the job titles of the participants indicate most, whilst clinically active, were in mid-to-senior level positions within their discipline. It might have been favourable to also include more persons in more junior positions since potential differences in their experience, attitudes and training [57] might have meant they had additional insights on the ideal CP configuration, for instance, with regards acceptability to ‘front line’ staff.

The ambition of our project was to identify the strongest CP configuration for subsequent testing and evaluation for use in England. It remains to be seen therefore what alternative CP configuration would be considered most favourable in other countries. Some adjustments may be required due to nuances in how different care systems operate. The approaches COLLABORATE used and transparently reported, could provide a template by which to find out.

Finally, we would note that our project sought only to draw on the stated preferences of users and the expertise of stakeholders to identify the strongest CP configuration for subsequent testing and evaluation. Stakeholders were asked to account for various factors such as practicability, effectiveness, cost-effectiveness, and affordability. Ultimate judgement on how well any CP can actually deliver against these outcomes requires formal evaluation.

## 5. Conclusions

By working collaboratively with stakeholders, this study has identified a refined set of alternative CP configurations for use by the ambulance service for epilepsy. The configurations are those deemed to hold the most potential to be acceptable to service users and feasible. At least one should now be implemented and evaluated.

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## Declaration of Competing Interest

None.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2024.04.010.

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