TITLE:

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

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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 hours; 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.

KEYWORDS

Epilepsy, Seizure, Ambulance, Care Pathway, Preference, Feasibility.

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

INTRODUCTION

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.

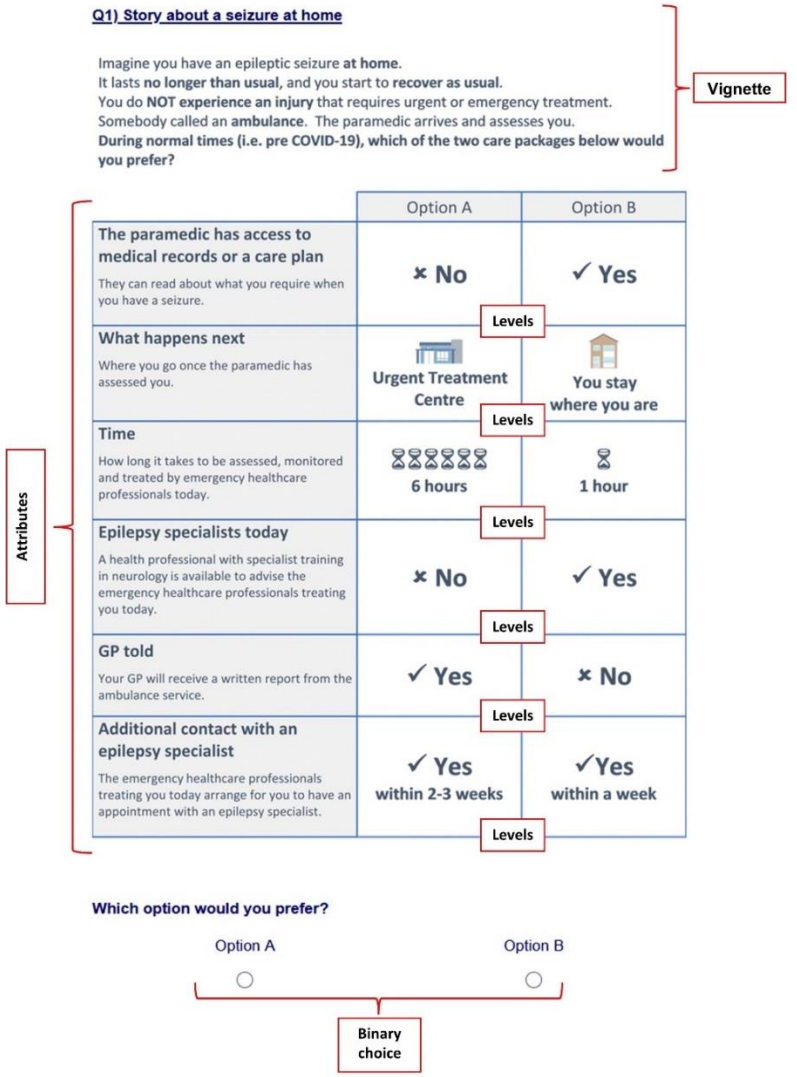
Understanding which care pathway configuration would be acceptable to service users

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.

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] • 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] • 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. • Changing the levels these attributes take (using an experimental design), produces profiles of goods that respondents choose between (choice sets). • 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	
• DCEs created for three hypothetical seizure vignettes(home typical seizure, public typical seizure, atypical seizure). • For each, participants were asked to respond to 12 forced, pairwise choices. • Each involved them saying which of two unlabeled care pathway (CP) options was preferred (Option A, Option B). • CP options were described according to 6 attributes. Levels per attribute ranged from 2 to 4 (Table 2). • 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. • Wording was adjusted to suit versions completed for people with epilepsy and significant others. • 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.* • 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.

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):* • No • 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):* • *Stay where you are* • *Urgent Treatment Centre* • *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 hours 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**	*Levels (4):* • 1-hour	*To ensure plausibility, the levels for the attribute 'Time' were conditional on the level that the attribute 'What happens next'*

	How long it takes to be assessed, monitored and treated by emergency healthcare professionals today.	• 2-hours • 3-hours • 6-hours	*took. 'Stay where you are', time restricted to 1 or 2hrs; Urgent Treatment Centre (UTC), time restricted to 2,3, or 6hrs; Accident & Emergency [A&E] Department, time restricted to 3 or 6hrs.*
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):* • No • Yes	-
5.	**GP told.** Your GP will receive a written report from the ambulance service.	*Levels (2):* • Yes • 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):* • *No* • *Within a week* *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").

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. Figure 1A details the attribute levels preferred by service users. In terms of the attribute 'What happens next', 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]

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.

METHODS

Design

Three KE workshops were completed. Their design (Figure 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 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.

[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).

	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	

FIGURE 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.

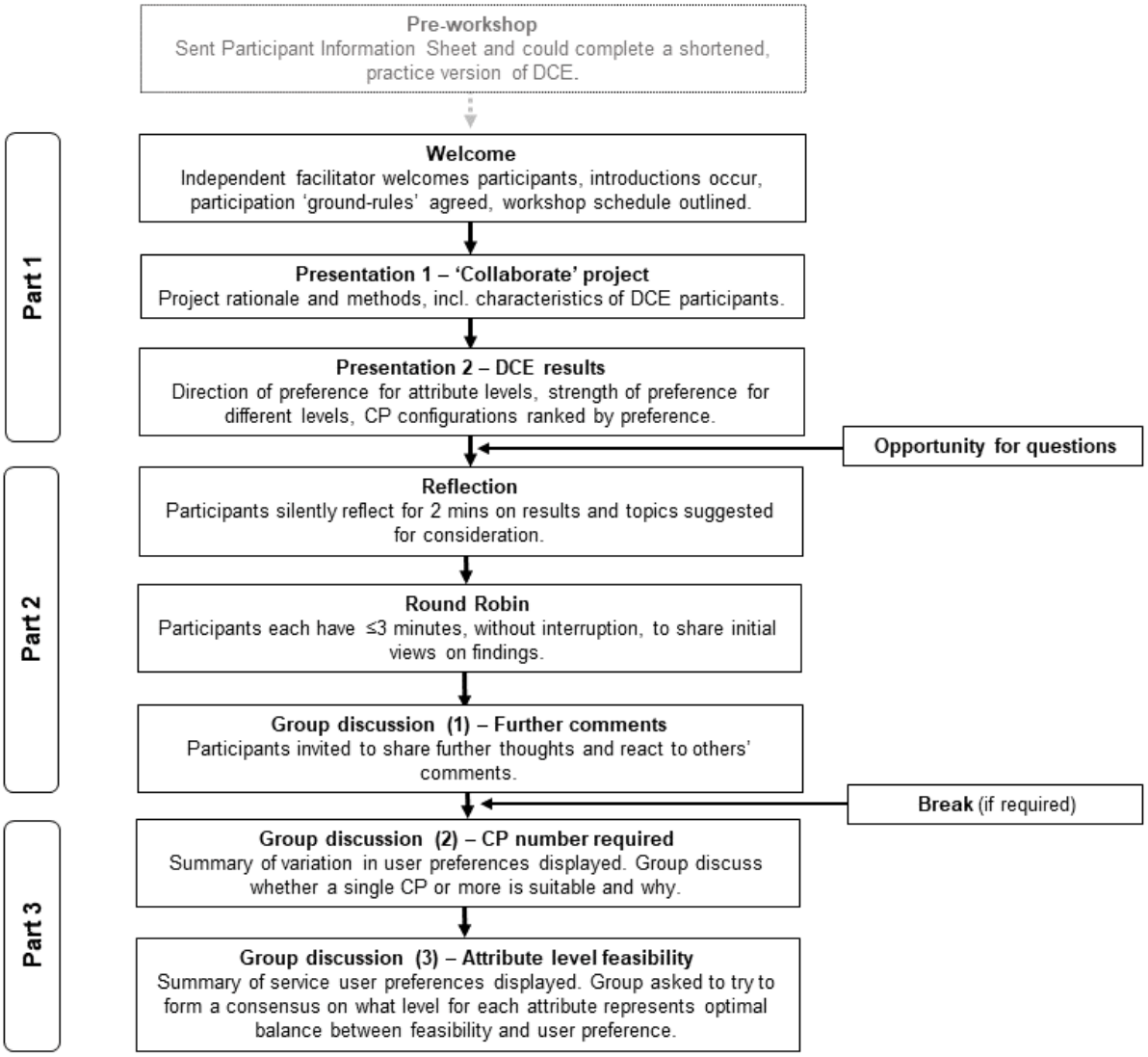


FIGURE 2 Structure of Knowledge Exchange workshops

Notes: CP, care pathway; DCE, Discrete choice experiment; incl., including.

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]

Participants

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]

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 .

Procedure

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.

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.

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).

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.

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.

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.

RESULTS

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 Figure 3. It also reports the job titles of the participants.

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.

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

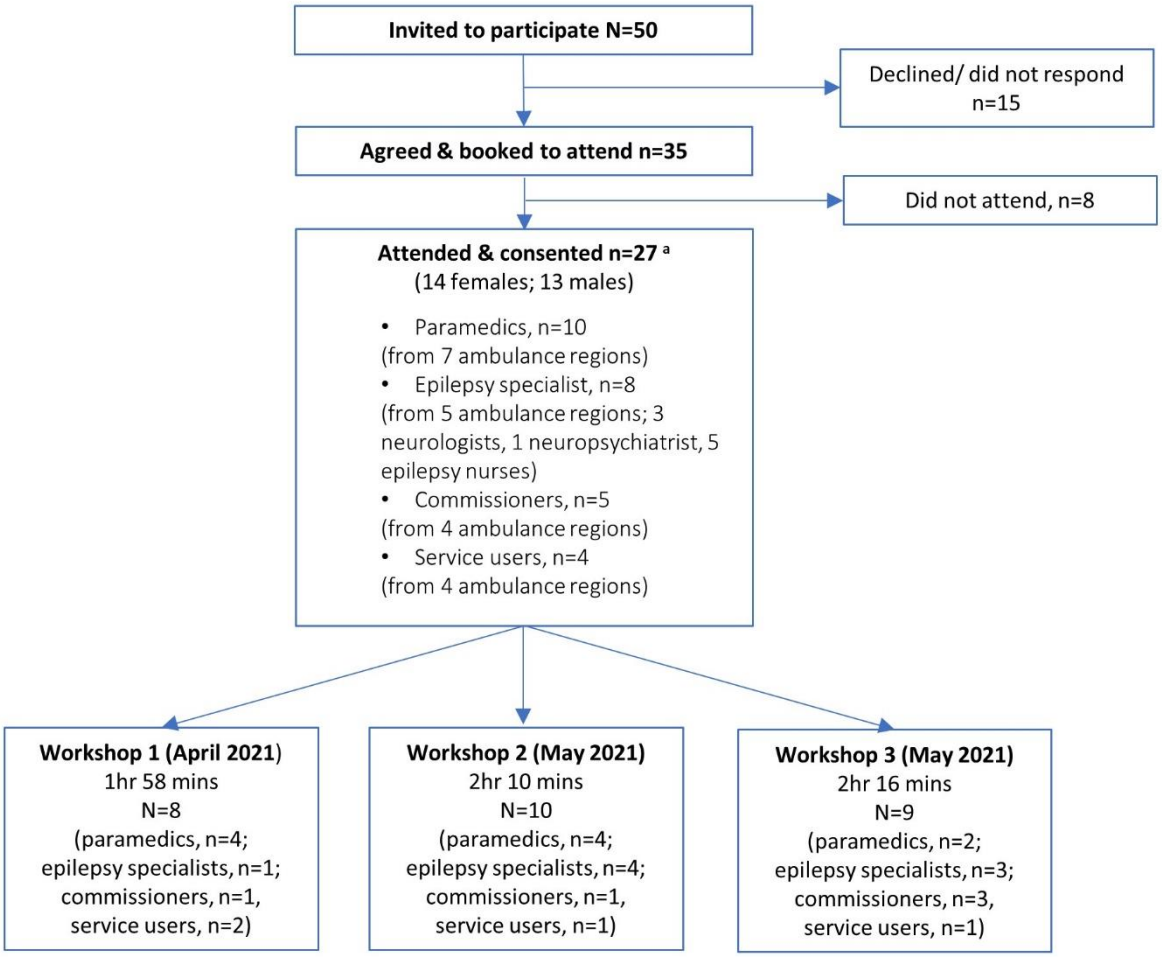


FIGURE 3 Recruitment flow diagram, participant characteristics and workshop details

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.

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; the person typically staying where they were; the time taken being less than 6 hours (whether it was 1, 2 or 3 hours 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) (Figure 1B). Using these attribute levels, the number of CP configurations for consideration reduced from 288 to 18. Their estimated utility is discussed later.

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 hours)

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 hours], *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).

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 (Figure 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.

DISCUSSION

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 hours, 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

.

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	**Scenario One**	**Scenario Two**	
	Optimal & Feasible	*Specialist advice not available today, advice in care plan assumed to be sufficient*	*'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 hours; iv) ‘Epilepsy specialists today’: No; v) ‘GP told’: Yes; and vi) ‘Additional contact with an epilepsy specialist’: No.

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.

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.

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.

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.

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.

ACKNOWLEDGEMENTS

We thank the people who so generously participated in this study. We also acknowledge the support and guidance we received from our study's steering committee [Professor Tom Quinn (chairperson), Mr Trevor Baldwin, Mrs. Jayne Burton, Prof. Verity Watson, Mr. Nigel Rees, Mrs. Juliet Bransgrove, Mr. Sam Burton and Professors Dan Horner and Khalid Hamandi] and Patient and Public Involvement volunteers.

FUNDING

This project is funded by the National Institute for Health Research's Health Services and Delivery Research Programme (HS&DR Programme) (project number 17/05/62). Professor Anthony Marson was further supported by the National Institute for Health Research Applied Research Collaboration North West Coast (ARC NWC). The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the University of Liverpool, the HS&DR programme, the NIHR, the NHS, or the Department of Health and Social Care.

DECLARATIONS OF INTEREST

None.

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Supplementary File 1 The APEASE criteria for determining the potential of different interventions

The Table outlines Michie et al.'s [1] so-called APEASE criteria for determining the potential of different interventions. It highlights key factors that can, to differing extents, be important in determining promise and has been used by a range of bodies to help select interventions (e.g.,[2]). These include affordability, practicability, effectiveness, acceptability, side-effects and equity.

Table SF 1. APEASE criteria

Item		**Detail**
A	Affordability	Interventions often have an implicit or explicit budget. It does not matter how effective, or even cost-effective it may be if it cannot be afforded. An intervention is affordable if within an acceptable budget it can be delivered to, or accessed by, all those for whom it would be relevant or of benefit.
P	Practicability	An intervention is practicable to the extent that it can be delivered as designed through the means intended to the target population. For example, an intervention may be effective when delivered by highly selected and trained staff and extensive resources but in routine clinical practice this may not be achievable.
E	Effectiveness (and cost-effectiveness)	Effectiveness refers tot eh effect size of the intervention in relation to the designed objectives in a real world context. It is distinct from efficacy which refers the effect size of the intervention when delivered under optimal conditions in comparative evaluations. Cost-effectiveness refers to the ratio of effect (in a way that has to be defined, and taking account of differences in timescale between intervention delivery and intervention effect) to cost. If two interventions are equally effective then clearly the most cost-effective should be chosen. If one is more effective but less cost-effective than another, other issues such as affordability, come to the forefront of the decision making process.
A	Acceptability	Acceptability refers to the extent to which an intervention is judged to be appropriate by relevant stakeholders (public, professional and political). Acceptability may differ for different stakeholders.

Item		Detail
		For example, the general public may favour an intervention that restricts marketing of alcohol or tobacco but politicians considering legislation on this may take a different view. Interventions that appear to limit agency on the part of the target group are often only considered acceptable for more serious problems.
S	Side-effects/ safety	An intervention may be effective and practicable, but have unwanted side-effects or unintended consequences. These need to be considered when deciding whether or not to proceed.
E	Equity	An important consideration is the extent to which an intervention may reduce or increase the disparities in standard of living, wellbeing or health between different sectors of society.

Notes: Reproduced with permission.

To expand further, is the intended intervention likely to be acceptable to all those involved – including to those expected to deliver it and their employing organisations? The latter will, for instance, need to be willing to assume any potential risks and consequences that may occur from the intervention if something goes wrong.

Is the envisioned intervention practicable – can the service wanted by the intended users be implemented in the NHS? Is there the required capacity and information sharing resources? Thirdly, how effective and cost-effective is/ or is it anticipated that the service will be in achieving the desired objectives? Fourthly, can it be afforded within budget? It arguably does not matter how acceptable or preferred an intervention is if it cannot be afforded. On a related point, if responsibility for commissioning an intervention is shared by different groups, will it be possible to get them all to agree to fund it? Fifthly, how far does one anticipate that the intervention might lead to unintended adverse outcomes? And finally, equity. How far is the intervention likely to increase or decrease known differences between the more advantaged and disadvantaged in our society?

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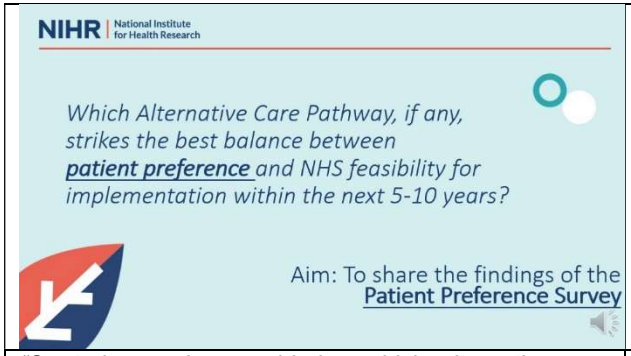
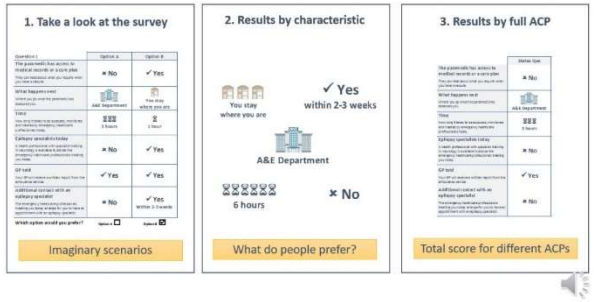
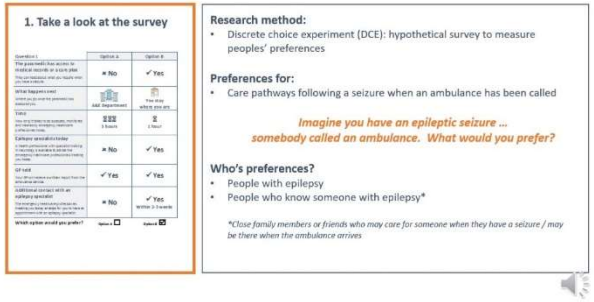
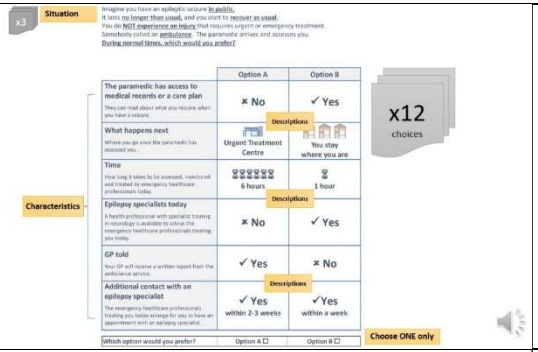
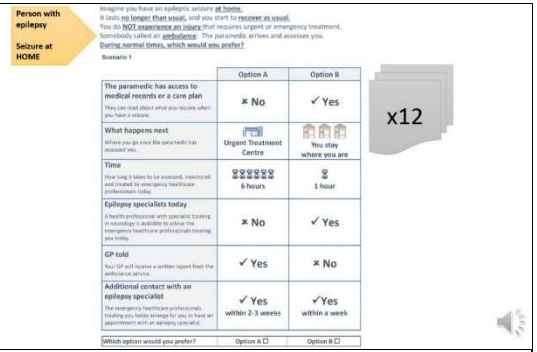
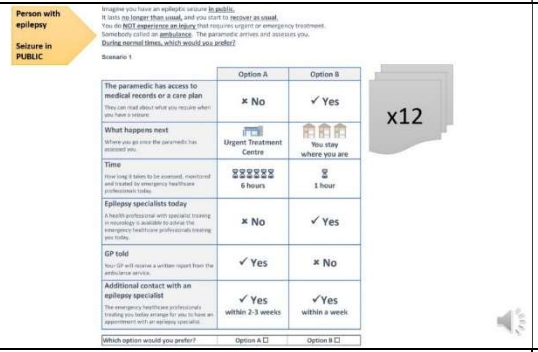
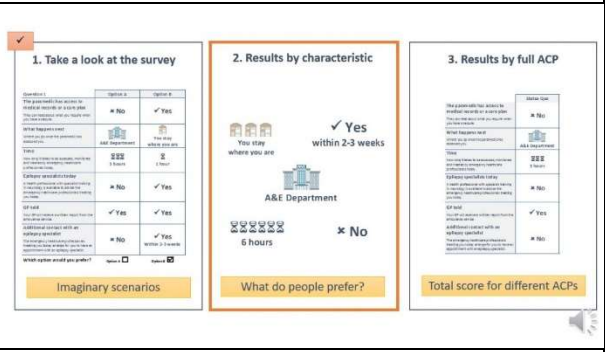
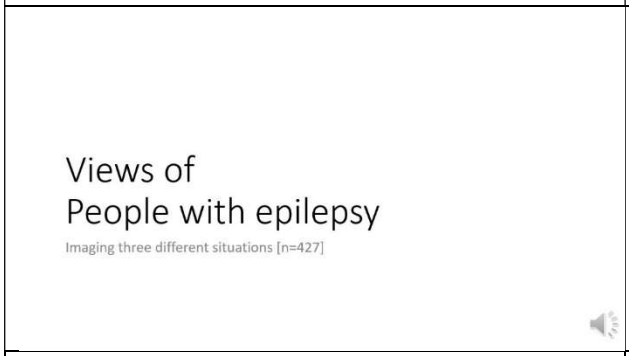
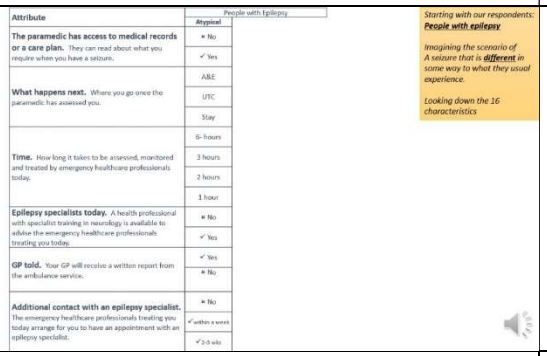
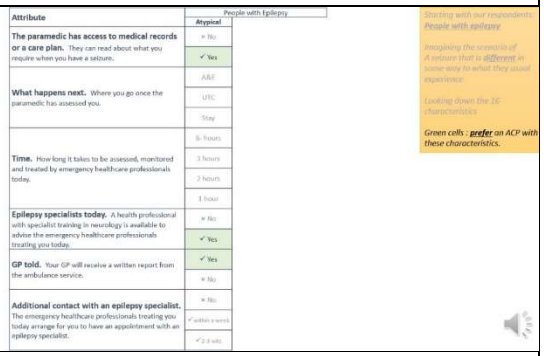
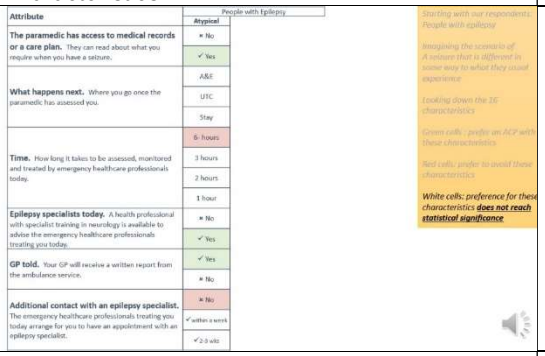
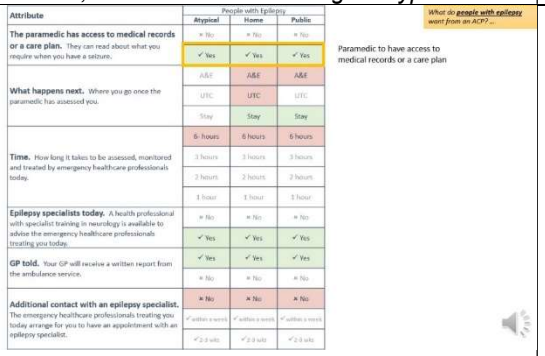
Supplementary File 2 Screenshots and narration from presentation shown to Knowledge Exchange workshop participants on the results from the DCE survey

		
"So today you're considering which alternative care pathway, if any strikes, the best balance between patient preference and NHS feasibility for implementation within the next 5 to 10 years and the aim of this presentation is the share patients views from our patient preference survey."	*"The presentation is in three parts. First, we will take a quick look at the survey 'hen we'll look at peoples' preferences for individual characteristics for alternative care pathways before looking at patient preferences for full alternative care pathways or combinations of those characteristics."*	*"So, starting with the survey we used Discrete choice experiments. It is a hypothetical survey to measure'people's preferences. We were measuring preferences for care pathways following a seizure when an ambulance had been called. We asked people to imagi'e 'you've had an epileptic seizure somebody called an ambulance what would you prefer' and we measured the preferences of people of epilepsy and people who know someone with epilepsy."*

	,	
"I'm going to give you a quick tour of our Discrete choice experiment. So if we start at the top of the screen you can see that we describe the situation that we want the respondent to imagine. So here they are imagining they have an epileptic seizure in public. We give a description and then we ask 'which option would you prefer'. Every option is described in terms of the same 6 characteristics and they vary by their description. The respondent is asked to choose between Option A or Option B and to just choose one option. Each of these choice tasks is repeated 12 times."	*"We have three different scenarios for each set of respo–dents - so an atypical seizure that is different normal."*	*"A typical seizure at home."*
		
"And a typical seizure in public. Friends and family were asked to imagine the person they knew in the same three scenarios."	*"The same six characteristics were used in every experiment'and it's important consider the wording of the options for these.* *So 'the paramedic has access to medical records or a care–plan' - they can read about what you require when you have a seizure – 'Yes' or 'No'.*	*"So now to move the results of the Discrete choice experiment and we consider which individual characteristics of an alternative CP people preferred."*

	'What happens next' – 'where you go once the paramedic has assessed' – 'you stay where you are', conveyed to an 'urgent treatment centre' or conveyed to an A&E department. *In terms of 'time' we were reflecting on how long it takes to be assessed monitored and treated by emergency healthcare professionals today and that can range from one hour to six hours.* *'Epilepsy specialist today' referred to a health professional with specialist training in neurology was available to advise the emergency healthcare professionals that were treating you today so within the current episode – 'yes' or 'no'.* *GP notification, so whether your GP will receive a written report from the ambulance service – 'yes' or 'no'.* *And then, 'Additional contact with epilepsy specialists' in the future. So an emergency healthcare professionals treating you today arranges for you to have an appointment with an epilepsy specialist in the future – 'no' t'ey don't make the appointment or 'yes' they arrange an appointment within two to three weeks or within a week.* *All of our discussions today focus on these characteristics only.*	
		
"We are starting with the views of people of epilepsy. We had 427 complete responses across the three imaginary scenario'."	*"I'll talk you through the presentation of the results before we summarise the findings. So down the left hand side of this ta'le you'll see the six characteristics. Then in column 'wo you'll see the respondents – so here people with ep–lepsy - followed by the hypothetical scenario –*	*"If the cells are in green then it means that the respondents preferred a CP with these characteristics in that particular scenario."*

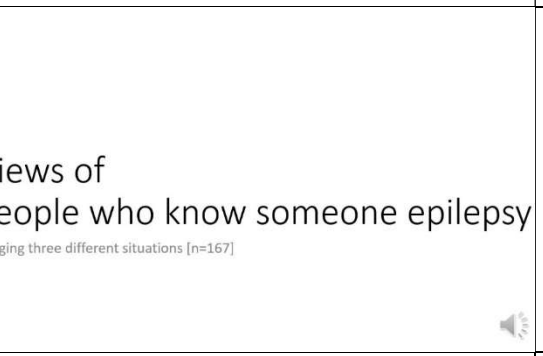
	an atyp–cal seizure, a seizure that was different to normal. And then as we look down that column, we see the 16 –haracteristics."	
		
"If they are red, it means that they prefer to avoid these characteristics in that scenario."	*"And where the cells remain white, preference for these characteristics does not reach statistical significance so'we can't say with certainty that they would influence preferences for a CP. These results are repeated for each scenario, so here we are loo king at atypical."*	*"And then we have a typical seizure at home."*
		
"And a typical seizure in public."	*"OK, so what do people with epilepsy want from a CP. Well consistently they want the paramedic to have 'access to medical records or a care plan."*	*"They want the 'time' to be assessed monitored and treated to be less than six hours."*

"They want the 'epilepsy specialists available to advise emergency healthcare professionals today'."

"And they want their GP to be notified."

"They also want a future appointment with an epilepsy specialist be arranged for them today but t'ey don't have a significant preference as to wheth'r that's within a week or within two to three weeks."

"Significance of preference varies for 'what happens next'. For a typical seizure at home or in public, people of epilepsy want to stay where they are. They also want to avoid being conveyed to the A&E department. Those who are at home also want to avoid being conveyed to an urgent treatment centre."

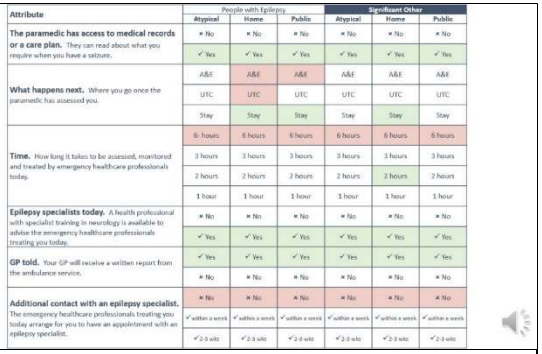


"Now to the views of people who know someone with epilepsy."

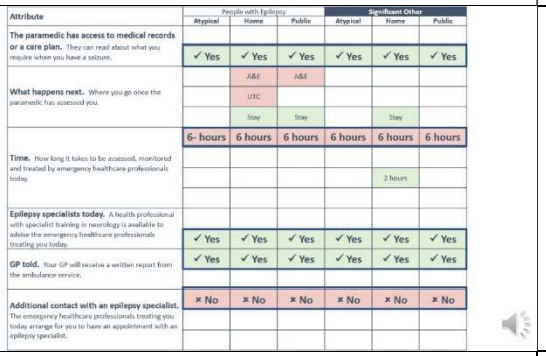
"Again, we see a consistent preference for access to the care plan or medical record, a duration of less than six hours, specialist input today, GP notification and a future appointment to be arranged with epilepsy specialist."

"There is a significant preference to stay at home after a typical seizure."

"There is also a significant preference for the 'time' it takes to be assessed monitored and treated at home to be at least two hours."

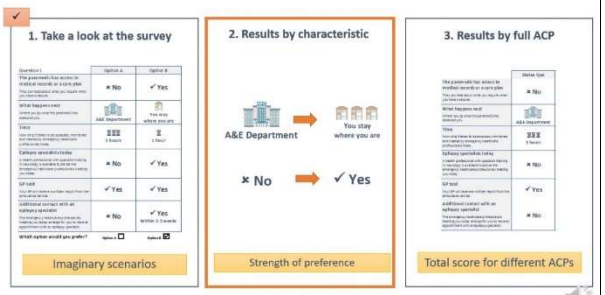


"And so across both sets of respondents - people with epilepsy and their friends and family – we can see this consistent pattern emerging in terms of…"
."

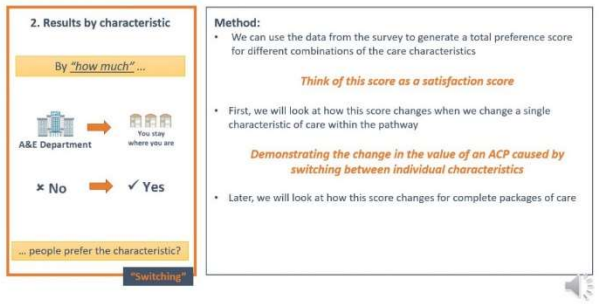
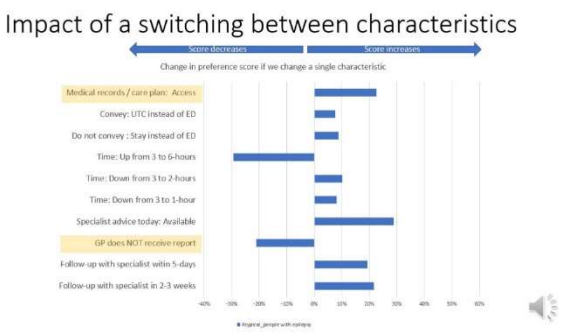
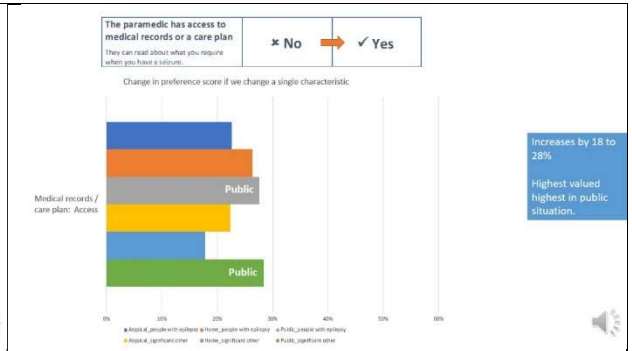
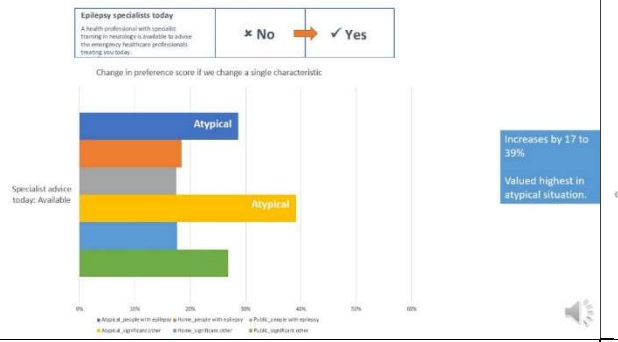
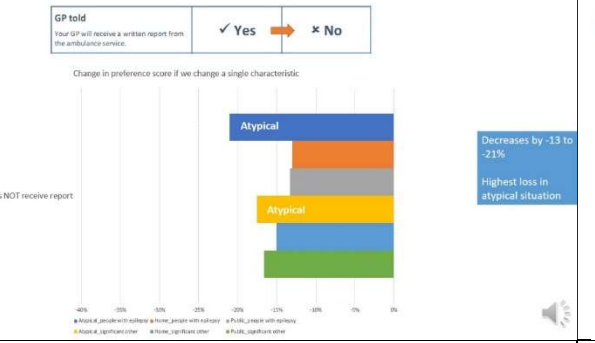
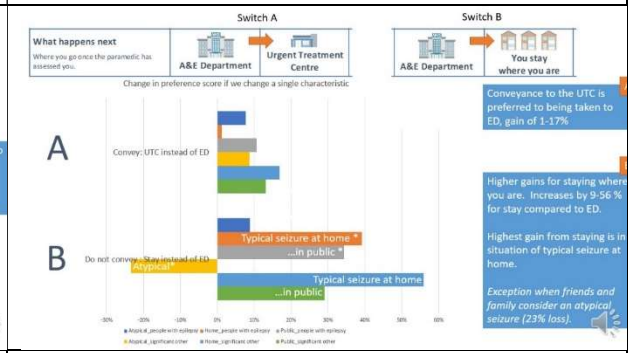


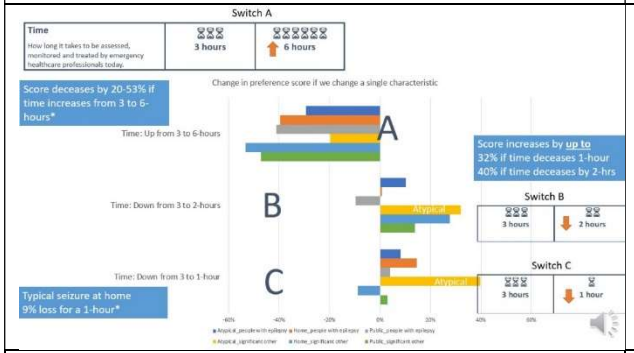
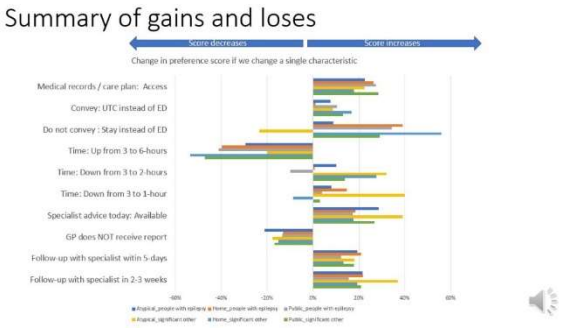
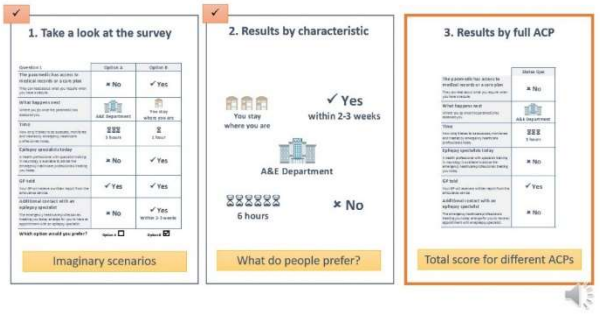
"What they'd prefer and what they'd like to avoid."

"And variation in terms of 'what happens next' and the duration of 'time'."

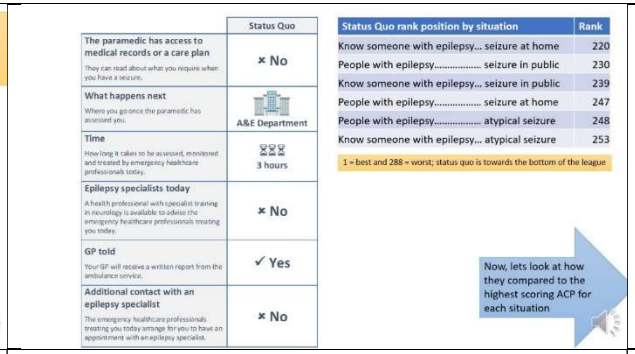


"Staying with the results by characteristics but we are now going on to look at the strength of preference for each of the characteristics."

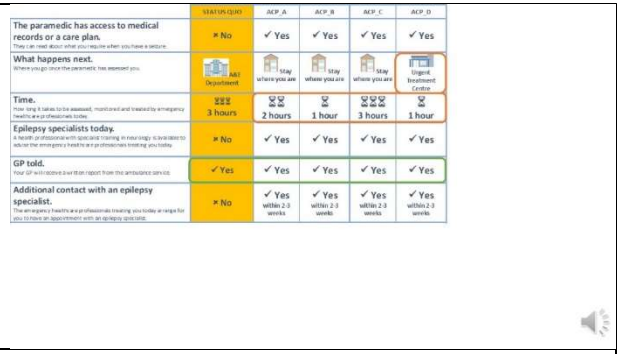
		
"We did this by using the survey data to generate a total preference score for different combinations of care characteristics. Think of this as a 'satisfaction sco'e'. We're going to look at how this score changes when we change a single characteristic of care within pathway. So essentially we are demonstrating the change in value of an alternative care pathway that's caused by switching between individual characteristics."	*"So, to explain how we present this fi'ding I'm starting with an example of people with epilepsy in the atypical scenari' and I'm going to show you the impact of switching between characteristics. So if we look here on the right hand side, the score increases and if we look on the left hand side we can see where the score decreases.* *Take the top row. This is when there is access to medical records or the care plan. You can see the overall preference would increase by 22% if we were to provide this. However, if the GP did not receive a report and we look at the bottom of the chart we can see the overall preference decreases by around 22%. And,'now we're going to look at this in detail across all of our six situations for each level change."*	*"So, looking at the value of the paramedic having access to medical records or a care plan we can see this increases the score by 18 to 28% and the highest value is in the scenario of a seizure in public."*
		
"Next to look at the epilepsy specialist being available today and we see that increases the value between 17	*"In terms of GP notifi–ation - that is routinely pr–vided - so we look at what would happen if that was taken*	*"Now, let's look at the value of 'what happens next'. So, if a patient is conveyed to an urgent treatment centre*

and 39% and it has the highest value in an atypical situation."	*away. We can see that decreases the score by between 13 and 21% and the highest loss is in the atypical situation."*	*rather than the emergency department we can see gains of between 1 and 17%. However, if they are able to stay where they are rather than being conveyed to the A&E there are higher gains with increases between 9 and 56%. The highest gains from staying where you are in a situation of a typical seizure at home or in public, with the exception of when friends and family consider an atypical seizure when there is a 23% loss if they are able to stay where they are."*
		
"Finally, we consider the impact of changes in 'time'. So, if the time increases from three to six hours then the preference score will decrease between 20 to 53%. However, if the time decreases we see an increase in the preference score of up to 32% for a decrease of one hour or up to 40% for a decrease of two hours. There are some exceptions, however. If we consider the views of family and friends for example considering a typical seizure at home we can see that there's a 9% loss for a reduction from 3 hours to one hour."	*"So we can see their gains and losses associated with switching levels within an alternative care pathway and that these vary according to the situation."*	*"So fin'lly we're going to look at the total score for different alternative care pathways."*

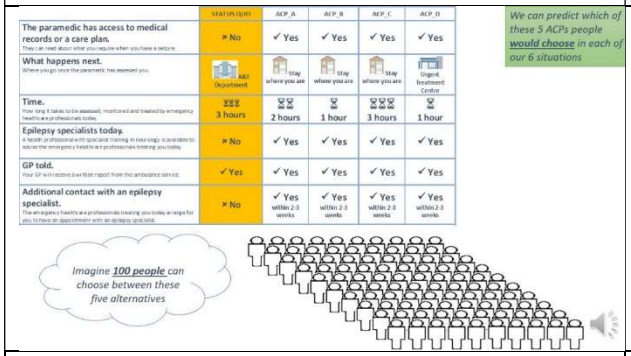
"Considering our six categories and their descriptions in different combinations there are up to 288 alternative care pathways."



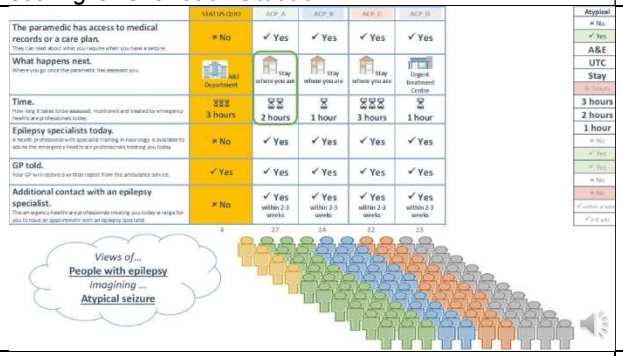
"We selected one of the CPs to represent current practise so the status quo. We said that the paramedic has no access to medical records or care plan, the patient is conveyed to the A&E department, time is 3 hours, no specialist input today, the GP is notified, but there is no additional contact via a specialist.
If we consider the highest scoring CP to be number 1 the best and the lowest to be ranked 288 this status quo is towards the bottom of the league. So we can see it ranks between 220 to 253 across our six scenarios. And,'now we're going to look at how this compares to the highest scoring CPs for each situation."



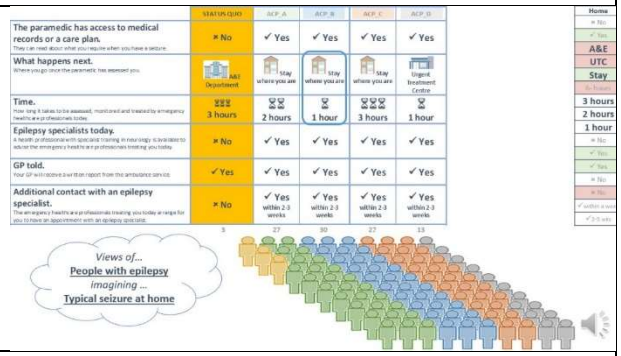
"OK, so here are the highest scoring a CPs. Four of them labelled CP A across CP D. You'll see that the only characteristic that was consistent with current practise is that people want the GP to be notified. The variation within the alternatives is in terms of 'time' and 'what happens next'.



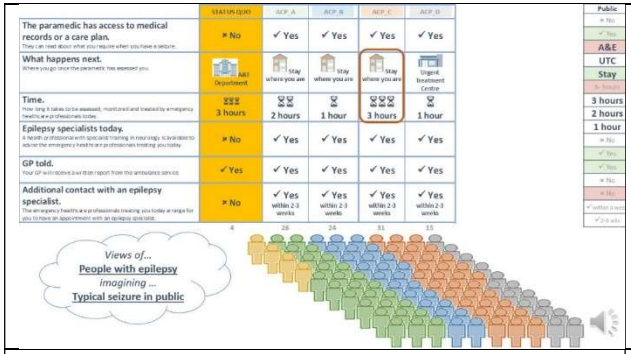
"And we can predict which of these five CPs people would choose in each of our six situations. So imagine a 100 people can choose between these five alternatives."



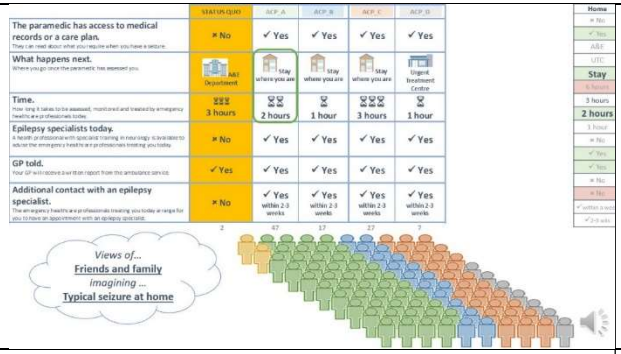
"Starting with the views of people epilepsy imagining an atypical scenario we can see that 27 out of the 100 would choose CP A. 'What happens next' and 'time' were not important characteristics for this group so we can see quite an even distribution of people between the four alternatives."



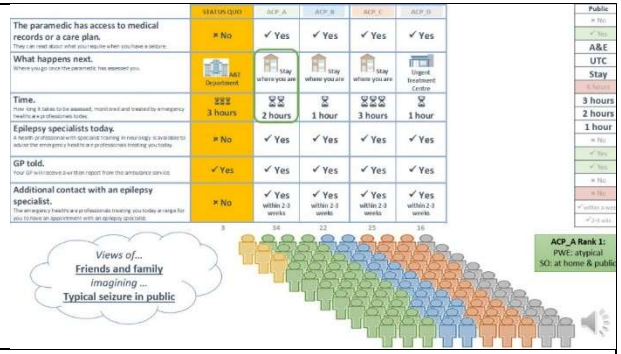
"Next, considering the views of people with epilepsy imagining a typical seizure at home' There's a significant preference to 'stay where you are' within this group and to avoid the urgent treatment centre, so the majority chose CP A to C, CP B being the most preferred with 30 out of the 100."



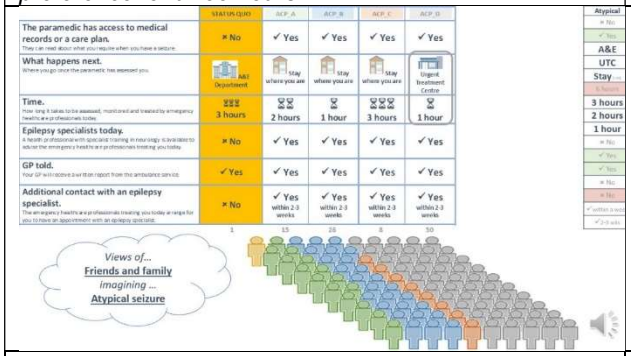
"And where the seizure occurs in public, again there is a significant preference to 'stay where you are' but in this case CP C is the most preferred due to a higher preference for three hours."



"Moving on to the views of friends and family imagining a typical feature at home. You'll recall this group had a preference to 'stay where they are' and for a 'time' of two hours. So we see 47 out of the 100 prefer CP A."

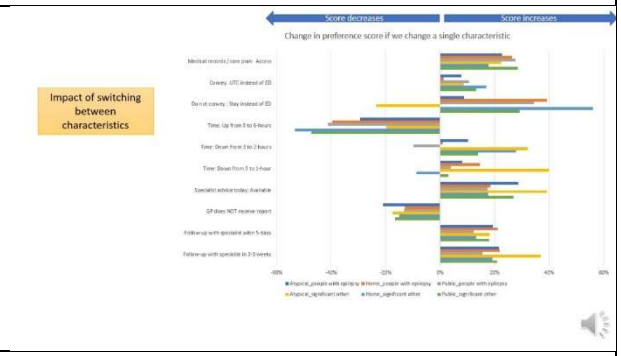


"When imagining a seizure in public they also prefer CP A."

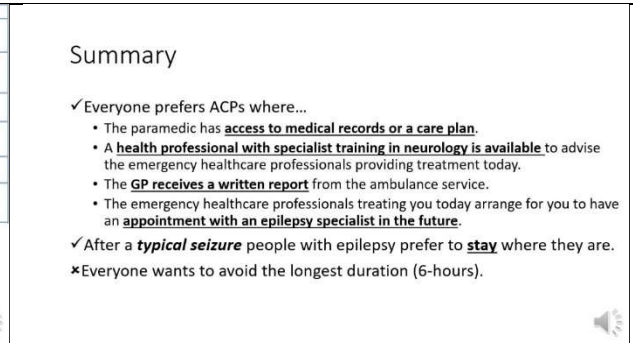
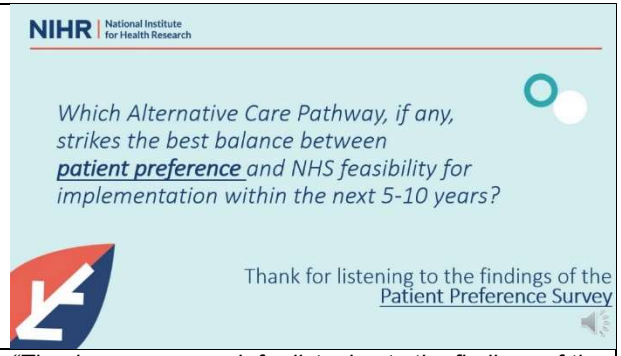


"But if we consider the views of family and friends imagining an atypical seizure we can see that 50 out of the 100 prefer CP D. Here we saw so stronger preferences for shorter times and pathways to convey to the urgent treatment centre or the emergency department rather than 'staying where you are' although these preferences did not reach statistical significanc' so it's likely that there is variation in the preferences in this group."

"To recap, we've looked at the most important characteristic'."



"We've looked at how preference changes when we swap these characteristics."

		
"And we've compared current practise to four alternatives."	*"In summary, everyone prefers a CP where the paramedic has access to medical records or a care plan, they want specialist input today, the GP to be notified and a future appointment with an epilepsy specialist. After a typical seizure people with epilepsy prefer to stay where they are. And everyone wants the episode to be less than six hours."*	*"Thank you very much for listening to the findings of the patient preference survey."*

Notes: This presentation was pre-recorded and was preceded by another pre-recorded presentation which introduced the project and purpose of the workshop. The presentations were pre-recorded to reduce opportunity for technical difficulties and to standardise the evidence the different groups received. Both presenters attended each workshop to address questions delegates had.

Supplementary File 3 Topic guide for Knowledge Exchange workshops

1. Which configuration would you back and why?
    - What positive impacts would this configuration have on service users?
    - What affects may this have on specialist clinics?
    - What affects may this have on the ambulance service? e.g. time – increased time at patient home

2. What factors attract you to any of the configurations?
    - Is there one characteristic of particular interest to you?
    - Does any factor seem essential for the overall success of implementing an alternative CP?

3. What factors dissuade you from any of the configurations?
    - Does any factor seem superfluous?
    - Which characteristic would be your lowest priority to include in an alternative CP ?

4. As a person with epilepsy, what are your thoughts?
    - Would you be satisfied if your care followed one of the alternative CP configurations?
    - Do you think the CP configurations presented would increase satisfaction with care amongst the epilepsy population?
    - What difference would following one of the favoured alternative CP configurations have on your day
    - Imagining that one of the favoured CPs has been implemented, does it change the way you feel about potential seizures in the future? Do they seem more/less daunting?

5. How confident would you feel using one of the CP configurations?
    - As a paramedic, would you have any reservations about following one of the CPs
    - As a Neurologist, would you be satisfied that people with epilepsy are still receiving safe and appropriate care if one of the CP configurations was implemented?
    - Do you anticipate that alternative care pathways would be acceptable to your ambulance service?/NHS Trust?
    - What may increase confidence in following a CP? (safeguarding measures?)

6. What barriers may the most favoured CP configuration incur?
    - Does the NHS currently have the resources/facilities to implement the most favoured CP? If not, how big is the gulf between current and required resources/facilities?

- Would you anticipate reluctance or hesitation from HCPs to follow an alternative CP?

7. Do any configurations seem unattainable?
    - Are there logistical issues which could prevent a CP working together as a whole?

8. Is one alternative CP configuration suitable for all six seizure scenarios?
    - Do different scenarios warrant different CPs? I.e., One for typical, another for atypical, etc.?

9. Are the characteristics of care important to service users as you expected?
    - Do any of the characteristics surprise you?

10. Would implementing any of the favoured CP configurations serve all people with epilepsy equally?
    - Health inequalities

Supplementary File 4 Summary of DCE evidence on service user preferences presented during Part 3 of Knowledge Exchange workshops

Characteristics of ACP	Atypical Seizure		Typical Seizure at Home		Typical Seizure in Public	
	PWE	SO	PWE	SO	PWE	SO
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
	✓ 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
	UTC	UTC	UTC	UTC	UTC	UTC
	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
	3 hours	3 hours	3 hours	3 hours	3 hours	3 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
Epilepsy specialists today. A health professional with specialist training in neurology is available to advise the emergency healthcare professionals treating you today.	× No	× No	× No	× No	× No	× No
	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
GP told. Your GP will receive a written report from the ambulance service.	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes	✓ Yes
	× 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
	✓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

Notes: A&E, accident and emergency department; ACP, alternative care pathway; DCE, Discrete Choice Experiment; GP, general practitioner; PWE, people with epilepsy; SO, significant others; Stay, “Stay where you/they are”; UTC, urgent treatment centre; wks, weeks. The term “Accident and Emergency” was used during workshop as it is often the term used to describe EDs in the UK. A ‘green; cell indicates an attribute level the respondents significantly preferred

the CP to have in that scenario; a red cell means an attribute level that respondents significantly preferred to not have in the CP for the scenario; white cells indicate those that did not reach statistical significance.

Supplementary File 5 Additional quotes from Knowledge Exchange workshops groups further illustrating some of themes

Theme	**Sub-theme**	**Illustrative quotes**
General impressions and reactions to DCE survey findings		"…I wasn't overly surprised… having worked on an ambulance a few years myself… this is broadly probably what they want and, and what you would like to see as well as a paramedic…" (Paramedic, Male 1) "…the ideal care pathway which avoids emergency admission to hospital really has a lot of er, communication between the emergency services, the specialist services and primary care which currently just do not exist." (Neuroscience representative, Male 2)
The ambulance clinician has access to medical records or a care plan	Potential benefits	"…it's your medical records, the paramedics should definitely know because it's just pointless going to hospital, wasting hospital time and taking up space in ED when you don't need to be there…" (Person with epilepsy, Female 1) "…what you'll find is erm, paramedics on the road pretty much know the right answer but they want…that bit of reassurance…if you've got a well-documented care clear plan that supports their already decision…that would give them the confidence to stick with that…" (Paramedic, Male 3)

Theme	Sub-theme	Illustrative quotes
	Necessary content and presentation	"Some of our levels of clinicians can struggle to interpret some of the information that's in there. Er, it's not always very consistent and clear," (Paramedic, Female 3).
		"We cover over 30 CCG [clinical commissioning group] footprints, so we've got er over 30 variations in documentation that we may see on scene." (Paramedic, Male 6)
	Infrastructure for sharing is or will soon be place	"…it's great that erm, that that people want us to have access to…care records…from an ambulance point of view…we've got a lot of structures that are already there for that." (Paramedic, Female 1)
		"the whole digital agenda for ambulance trusts will continue over the next few years, so I think that's a, a definite that should be possible" (Commissioner 3, Female)
		"we've got access to Summary Care Records, and we've got access to a system called 'Co-ordinate my Care' … a purpose-built platform for er sharing care plans. [So implementing a medical record or care plan access is] Very doable. You could do it tomorrow." (Paramedic, Female 1)

Theme	Sub-theme	Illustrative quotes
What happens next – are patients conveyed and, if so, where to?	Potential benefits of non-conveyance	"[recalling instance of seizure presentation]…I was like no I don't want to go to ED but then they made me go… I didn't really need that. I just, er, yeah because I knew there was nothing different or wrong at all… if it's totally different then yes, call and go to ED. But the rest of it, all you need is your GP and your neurologist to know about the situation." (Person with epilepsy, Female 1)
	There are some restrictions on which crew grades are permitted to not convey	"…we're limited in the actions that we can take depending on the skill perhaps of the clinician that goes there." (Paramedic, Female 3) "… we might start to change dispatch behaviour…to use different responses in terms of, erm, cars or specialist…to go out to…that patient cohort. So there may be elements that create some more positive operational benefits…" (Paramedic, Male 2)
	Not conveying a person with an atypical seizure would be a significant change in practice	"anything different in the seizure presentation has typically been a red flag for us to warrant more urgent investigation to check there's no underlying illness or something…we certainly wouldn't be looking normally to leave people…," (Paramedic, Female 2)

Theme	Sub-theme	Illustrative quotes
		"[I have]…slight concerns about atypical. But definitely possible with typical seizures and I think it would be brilliant," (Paramedic, Female 3).
	Not all atypical seizures will be suitable for non-conveyance	"we need to be careful not to drive that message [keeping patients at home] so hard that paramedics are not looking at red flags." (ENS, Male 1)
	Label 'atypical' seizure can mean lots of things #	"The difficulty with referring to 'atypical' is it's a wide term. If a patient's seizure lasted 30 seconds longer than normal that may be construed as atypical, but they are probably still safe to stay at home…" (Paramedic, Male 4) : "…a euphemism for an atypical seizure is often a non-epileptic seizure erm, and I just wondered – one, one wonders if there's a big pitfall there which must create a huge headache for our paramedic colleagues…"(ENS, Male 1)
	Might need to restrict staff grades that can use CP	"[For pathways for some other presentations] certain skill groups are not allowed to just discharge people on the scene without a signoff from a senior clinician…" (Paramedic, Female 2).

Theme	Sub-theme	Illustrative quotes
		"…there aren't just paramedics throughout ambulance trusts, there are non-registrants that go out to patients on their own as well…" (Paramedic, Female 3)
Time taken to be assessed monitored and treated by an emergency health care professional	Preferred duration is achievable (assuming travel to person is not included) Potential conflict between service user preference and performance measures	"if we're looking at discharge from the scene, I think the two hours is absolutely achievable." (Commissioner, Male 1) "…if the pathway's complex, if there's some issues around transporting patients home if they're in a public place and things like that…those won't deliver performance to the trust – they won't reduce ambulance cycle times… come almost directly into conflict with I guess our commissioning and, and how we work operationally" (Paramedic, Male 1) "…my operational management colleagues will… be worried about the next patient that they want to send the ambulance to…" (Paramedic, Female 1)
Epilepsy specialist accessed for advice on the day of seizure presentation	Advice service needs to be responsive	"…we know that our clinicians if they speak to a clinician at the end of the phone, immediately that will give them far more confidence. Erm, the

Theme	Sub-theme	Illustrative quotes
		minute you put in delay…they'll call you back in an hour or they'll call the patient back in an hour – that creates…uncertainty" (Paramedic, Male 2)
	Potential variability in skill and availability of who will be able to advise	"…there's no one size fits all epilepsy nurse services around the country is there…in some areas they don't even have epilepsy nurse specialists so…for the crews it's going to be really difficult to think oh we know we can follow this alternate care pathway…where are these specialists and specialist nurses?" (ENS, Female 2) "I think the epilepsy specialist access er, you'd have to plan for the future and recruit and train a lot of people if you want 24 hour, seven days a week access." (ENS, Female 3) "Often it's [going to be] 'out of hours' and then …that involves talking to the 'on-call' erm neurology registrar which, you know may be quite junior and, you know I think there's would be a tendency for them to air of the side of caution…" (Neuroscience doctor, Male 1)
	Potential advantages of specialist being familiar with the patient/ or having records	"what do you mean by a specialist? I mean there's the on-call neurologist but they're not going to know the actual patients … and being rung up in the middle you know without warning and saying Mister So-and-so is

Theme	Sub-theme	Illustrative quotes
		here, what can you advise? You're, you know – do I know them well enough to be able to ad-hoc off the cuff give you advice."(ENS, Female 3) "…if it's not someone who knows them or who really understands their epilepsy and their background then actually the value of that specialist advice I think is massively diminished." (Neuroscience doctor, F1) "the actual advice that you, that you'll get would more useful and perhaps accurate from the care plan than actually speaking to the specialist" (Neuroscience doctor, Male 1).
	Circumstance in which specialist advice might be particularly helpful	"…when you're working in the ambulance setting… you can't just kind of pop out to like the, the cubicle and catch your colleague…" (Paramedic, Female 1) "Sometimes we may well have a crew that are registered newly qualified … that's where this specialist referral I think is really, really handy. For myself [as an experienced paramedic], the complex presentation, I'd probably want to speak to a specialist if it was an atypical seizure … that's where I'd think actually, I need to speak to someone who knows a lot more about this than I do." (Paramedic, Male 6)

Theme	Sub-theme	Illustrative quotes
	How specialist advice for crews could be accessed	"…the way we offer that is we have what's called [propriety name for a service information search tool]. It can be used by health care professionals to find service information …someone else mentioned a directory of service, where if there is specialist phone numbers, specialist advice then that will all be there for the locality that they're in at the time." (Commissioner, Female 3)
	System would need to be responsive:	"…there's got to be a reaction, there's got to be someone picking up that phone… otherwise…very quickly that can…lead to lack of confidence… crews…saying…it's never working and we just end up conveying anyway…" (Commissioner; Male 1)
GP informed of seizure presentation via report provided by attending ambulance clinicians	Infrastructure for sharing in place	"…we're a little bit behind the curve on erm, electronic er report forms, but I, I don't think that would hold us back in the, the timescales that we're talking about." (Paramedic, Female 1) "there should be no reason on electronic records that that, you know the GPs shouldn't be notified. Erm, but I think it's, the question to the GP is what they then do with that."(ENS, Female 2)

Theme	Sub-theme	Illustrative quotes
Additional contact with an epilepsy specialist arranged by attending ambulance clinicians	Other types of service can already refer	"…fast track epilepsy clinics are in, in existence now and that's, that's the usual…So, I think that, I think that should be achievable yeah" (Neuroscience doctor, Male 1)
	Potentially little burden to crews	"…If you just have an automated process where these PRFs [patient report forms] go into a caseload and then somebody follows them back into referrals and arranges an appointment…[then]….there's no add on then to the paramedic workloads…"(Paramedic, Male 1)
		"Yeah, it's absolutely doable and we do it for other areas and er other clinical conditions." (Paramedic, Male 3)
	Potential benefits	"[I] speak from experience here…it's a really good laudable erm ambition for crews to book on scene or book into something and really sort of tie that patient off as they leave, because that will give them the confidence that they can." (Commissioner, Male 1)
	Capacity to provide the additional follow-up	"Where there isn't a larger group of epilepsy nurses or epilepsy specialists, then they would have to look at investing and training and setting up services. But I think that would be possible…" (ENS, Female 3).

Notes: DCE, Discrete choice experiment, ENS, epilepsy nurse specialist; GP, general practitioner. When presenting quotes from neuroscience representatives, those from ENSs are presented separately to those of neuroscience doctors (i.e., neurologists and neuropsychiatrist). This is to preserve potentially different views. The merging of comments from neurology and neuropsychiatry was required to help maintain anonymity.