# PROTOCOL

# Developing patient-centred, feasible alternative care for emergency department users with epilepsy: A model for service design.

## Version 1.6.1 (01/07/2020)

**Study Sponsor:**
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**Research Registry platform #:** researchregistry4723

**IRAS Project ID:** 253816

**Funder reference:** HS&DR 17/05/62

**Sponsor references:** 4258

**REC reference:** 19/WM/0012 (NHA HRA West Midlands – Solihull Research Ethics Committee ); 7766(Health and Life Sciences Research Ethics Committee – University of Liverpool)

**Funder:** This project is funding by the National Institute for Health Research's Health Services and Delivery Research Programme (HS&DR Programme) (project number 14/19/09). 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.

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## PROTOCOL TRACKING LOG

| *Description of Protocol or Amendment* (e.g. Version #/Date; Amendment details) | **Date of governance approval** | **Changes required to document (Y/N)** | **What changes are required?** |
|---|---|---|---|
| Version 1.0 (08/02/18) Submitted to funder as part of application | - | Yes | Board and reviewers required changes for approval |
| Version 1.1 (11/07/18) Incorporated changes recommended by board and reviewers | - | Yes | NHS ethics required minor changes |
| Version 1.2 (23/10/18) | 21/02/2019 | Yes | Upon NIHR's request, minor edit to include protocol tracking log and funder statement and disclaimer. |
| Version 1.3 (27/02/19) | -"- | No | |
| Version 1.4 (17/07/19) | 10/09/2019 | No | Change from using GPs to the ambulance service to invite participants to complete the DCE. |
| Version 1.5 (30/03/20) | 24/04/2020 | Yes | Inclusion of 4 questions relating to COVID-19 in background questions of DCE survey. |

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| Version 1.6 (15/05/20) | | Yes | Adding recruitment contingency plans (using Epilepsy Action) to the DCE phase. |
| Version 1.6.1 (01/07/20) | | Yes | As requested by our sponsor, an inclusion of a section relating to Knowledge Exchange workshops indicating that these may take place virtually rather than face-to-face depending on social distancing regulations and guidance. |
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# PROJECT PROTOCOL

## 1) FULL TITLE

Developing patient-centred, feasible alternative care for emergency department users with epilepsy. A model for service design.

## 2) SUMMARY OF INTENDED RESEARCH

The National Health Service (NHS) is being asked to make substantial efficiency savings, whilst working with stakeholders to improve care experience, outcomes and reduce inequalities (e.g.,[1,2]). Emergency department (ED) visits and admissions for epileptic seizures provide an opportunity where innovative ideas could help achieve such aims. These visits incur NHS costs, but typically have little patient benefit. Inequality in access to outpatient specialist services underlies many of these visits by adults. There is therefore a momentum to work with ambulance services to generate an alternative care pathway (ACP) that would, when appropriate, divert such adults with epilepsy away from ED and help them access specialist support, thereby improving the quality of care

Any such pathway should be informed by the care preferences of the target population. This will help ensure the ACP is acceptable to its intended recipients, thus increasing the feasibility, effectiveness and safety of care. This, “bottom-up” approach is not currently in use. Rather, a plethora of ACPs are being developed in a “top-down” fashion. There are strong indications, including from preparatory PPI work, that patients and carers will not accept them; with consequences of wasted resources and patients continuing to receive sub-optimal care.

Whilst it is beyond the scope of the current project, our *ultimate* aim is to work with the ambulance service to implement the most promising ACP for people with epilepsy (PWE), rapidly evaluate it and use the evidence to transform service organisation nationally. However, as patients and carers from the target population have yet to be consulted, it is not known what sort of ACP has the potential to be most effective.

Therefore, in partnership with Epilepsy Action (the British Epilepsy Association) and a study PPI group, we here describe a 28-month mixed-methods project that will first allow us to identify the preferred ACP to implement. It would involve us working in a novel way with adults with epilepsy, carers, health professionals and managers to identify what constitutes the most acceptable, but also NHS feasible ACP. To maximise the impact of the project and its ability to influence practice, all those considering ACPs for epilepsy would be informed of the project’s existence, updated on its progress and have an opportunity to contribute.

The project would first, via a survey, systematically identify the structure and objectives of ACPs currently being considered around England. In-depth qualitative interviews with ~30 patients/ carers from the target population will then be completed to explore reasons for seeking post-seizure emergency care, the characteristics of care that are important for them and their expectations and concerns regarding ACPs. Around ~15 representatives from English ambulance and neurology services would then, during a Knowledge Exchange event, consider the feasibility of incorporating into an ACP the features of care that patients and carers said were of importance to them. A representative sample of ~350 PWE/carers who have recently visited ED or are at risk of such visits will then be recruited via primary care to complete a Discrete Choice Experiment (DCE). The DCE will identify the relative importance of different service attributes under the common seizure scenarios that present to ED, and the trade-offs people are willing to make between these attributes. The likely uptake of different ACP configurations (under both current and potential future NHS states) will then be estimated for the sample and predefined subgroups.

Finally, two Knowledge Exchange workshops will be held at which key stakeholders (health professionals, managers, patient representatives) would form a consensus on which ACP best meets patients and carers needs – and is likely NHS feasible and appropriate for implementation/ evaluation.

This project, together with findings from a subsequent project to rapidly evaluate the identified ACP, could transform NHS practice within 5 years of the current project starting.

## 3) RESEARCH OBJECTIVES

The objectives are to:

a) Systematically identify alternative care pathways being considered by the NHS for epilepsy and describe extent to which service users have been involved in their design;
b) Understand patient and carers’ decision-making processes for seeking or not seeking ED care, and their concerns and expectations regarding alternative care pathways;
c) Identify the attributes of post-seizure emergency care that PWE and their carers consider important and to identify if this differs by the context in which the seizure occurs;
d) Determine patient and carer preferences for post-seizure emergency care using Discrete Choice Experiments and identify any subgroup differences;
e) Estimate uptake of different alternative care pathway configurations by patients (in both current and some potential future NHS states) and subgroup differences;

f) Hold a series of expert workshops to agree on what constitutes the optimal alternative care pathway following seizures and should be prioritised for implementation and evaluation (via a subsequent project).

The timing of these activities is shown on the Gantt chart on page 17.

As well as seeking to achieve the above, the project could provide a methodological template for service design generally within the NHS. The value of the project in this regard has been endorsed by NHS England. This is because, as the NHS seeks to deliver health care with better outcomes and lower cost, other changes to NHS practice are inevitable.[1,2] To increase likelihood of success, an efficient, transparent and scientifically defensible method is required to allow change to be informed, in a non-tokenistic way, by the voices of service users and other stakeholders.[3] The novel co-production approach we shall use could provide this (see section 7).

Please note, a glossary of abbreviations used in this document is provided in Appendix A.

## 4) BACKGROUND AND RATIONALE

### 4.1 Current NHS context and the need to manage demand on services

Like other health systems around the world, the NHS is operating within a context of rising demand, slow funding growth and increasing operating costs. This culminated in a 2015/16 aggregate funding deficit of £1.85 billion for NHS providers and commissioners.[4,5] The Five Year Forward View[1] and subsequent publications challenge the NHS to make substantial savings, whilst at the same time, work with patients and carers to improve care experience, outcomes, and reduce health inequalities.

### 4.2 Epilepsy identified as an area where opportunities exist to reduce demands

One way proposed to generate savings is by finding innovative ways to reduce clinically unnecessary use of expensive emergency health services. Epilepsy is identified as one condition that accounts for some of this use and where care inequalities appear to drive use.[6] Amongst chronic ambulatory care sensitive conditions, it is the second most common cause of unplanned hospital admissions (17%).[7]

### 4.3 Epidemiology of epilepsy

Epilepsy is the recurring tendency to have unprovoked seizures. This chronic relapsing condition is the United Kingdom's (UK) second most common serious neurological disorder, and affects people across the age spectrum. With a prevalence of ~1%,[8] it is twice as common as type 1 diabetes. Antiepileptic medication is the mainstay of treatment. PWE, particularly the ≤48% who continue to experience seizures,[9] are at increased risk of injury, psychological and social disadvantage, and premature death.[10,11]

### 4.4 Use of emergency hospital services for epilepsy and societal impact

In the UK, up to 20% of PWE visit hospital emergency departments (ED) each year.[12-14] In England alone, there are around 100,000 visits each year.[15] In 2015/16, this cost the NHS ~£70 million.[16,17]

One reason costs are so high is because half of the PWE visiting EDs are admitted to hospital;[7,14,15,18,19] 85% of admissions for epilepsy occur on such an unplanned basis.[20] Re-admissions further drive costs up;[21,22] ≤60% of PWE reattend ED within 12 months.[23] This rate of return is higher than for other chronic relapsing conditions, such as asthma and diabetes.[24,25]

### 4.5 Use of emergency hospital services for epilepsy is often clinically unnecessary

Seeking emergency care for epilepsy can be appropriate, and even life-saving. Reasons include a first seizure and status epilepticus.[26-28] Evidence now shows though that most PWE attending ED do not attend for such reasons. Our group completed the UK-wide National Audits of Seizure Management in Hospitals (NASH).[29,30] Data from >8,000 seizure-related ED attendances from 85% of UK acute hospitals was examined. It found most PWE attending ED have known, rather than new epilepsy and present with non-emergency states not requiring the full facilities of ED.

Available data [18,31] indicates the leading presentations for epilepsy are a person with established epilepsy who has: i) experienced an uncomplicated seizure that is in line with their usual presentation; ii) experienced a seizure in public and cannot be 'left at scene' (e.g., because they are alone, in a post-ictal state, been incontinent or had a minor injury); or iii) experienced a seizure that has self-terminated, but which is different to the person's 'normal' seizure/s.

Seizure presentations such as those above do not require the person to be cared for within an ED.[26-28] Not only are ED attendances in such instances disruptive to lives of patients and families and the operations of stretched hospital services, but there may also be iatrogenic harms for the patient due to unnecessary investigations and interventions (e.g., intravenous cannulations and head CTs).[32,33] Although a high proportion of epilepsy-related ED visits do result in admission, most appear unnecessary,[34] with factors beyond the patient's clinical need playing a role (e.g., lack of access to senior medical review, need to avoid breaches of 4-hour wait target in ED) [35]

### 4.6 Unmet need in those with epilepsy visiting ED

Whilst the acute episodes leading PWE to visit ED do not typically require care within an ED, many of the visits are due to failed ambulatory care.

NASH [15] found most (~65%) people visiting ED were not known to specialist epilepsy services, but that they often appeared to be in need of such support. Many were being treated using suboptimal, outdated drug treatment regimens. Thus, they were being placed at an increased risk of avoidable seizures, medication side-effects, psychosocial dysfunction, and avoidable death.[36] Epilepsy is the fifth highest amenable cause of years of life lost before the age of 75 for males, and eighth highest for females.[37] Those with ongoing seizures, those not adhering to antiepileptic medication and those with a recent injury are amongst those most at risk.[38]

Some PWE visiting ED may also need enhanced self-management support, such as that provided by epilepsy nurse specialists, so they and their family can learn more about their condition and how to manage seizures by themselves.[23, 39-41] In 7/10 cases, it is a relative, friend or carer who makes the '999' call.[42] Unlike for other chronic conditions, there is no routine course PWE can go on to learn about epilepsy once diagnosed. Consequently, knowledge and self-management confidence can be low, particularly in PWE who are older and those with low levels of formal education.[43,44]

### 4.7 Momentum to reduce ED visits for epilepsy by introducing alternative care pathway

The current policy agenda [1,2,45] and the publicity given to the NASH findings [16,46] has created a vigour to reduce visits for seizures and enhance patient outcomes. Systematic examinations of the literature[47] show there is no evidence on how to do this. An idea which is gaining traction though, is for the ambulance service to assume a greater role in the management of seizures[48]

The reason for this is that most (~90%) people who visit EDs for seizures have been transported there by an emergency ambulance.[19,29,30] At present, ambulances convey nearly every person they attend who has experienced a seizure to ED,[42,49,50] despite most patients not demonstrating a clinical need. Dickson et al.[42] reviewed the ambulance records for 178 seizure incidents presenting to a regional UK ambulance service and found medical emergencies were uncommon. For instance, seizures had already self-terminated before the emergency vehicle arrived in >90% of cases. Ambulance clinicians though still advised transport to ED in 89% of cases.

Qualitative work with paramedics has elucidated the reasons for this.[51-53] One is that paramedics currently lack access to alternatives to ED:

> *"We struggle for alternatives to ED. While we might be directed towards primary care, in practice they are lacking." (Paramedic, number 7)*
>
> *"There was a big investment in a new urgent care centre locally but they won't take people who've had a seizure. I've had patients…in a postictal state who need maybe half an hour until they come round…but [the centres] have this crazy idea that if somebody's had a seizure then they need to have a CT scan…Sometimes there is no alternative but to take them to ED." (Paramedic, number 8)*

Another reason reported for the high rate of conveyance was time pressure. Some paramedics described how under current funding arrangements they can feel able to only spend limited time 'on scene' to assess patients and permit them to recover. As such transporting the patient to ED could represent the most time-efficient management option*:

> *"As a practitioner, if I don't hit my times I'll be pulled in by my manager, so it does pile the pressure on, forcing crews to think, 'just put them on the truck and take them to hospital'". (Paramedic, number 8)*
>
> *"If someone has a seizure outside of the home, we wouldn't take them home… It's not necessarily the right option for that patient… But by taking them home, which is further away, we will be tied up for longer." (Paramedic, number 6)*

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* It is possible that the role of this factor is now more complicated due to recent increase in 'hand-over' times at EDs.

** Urgent and Emergency Care Review Team highlighted confusing mix of walk-in centres, minor injuries units and urgent care centres that exist in the UK. To establish commonality, most units are to be relabelled urgent treatment centres (UTC), open at least 12 hours a day, be GP-led, staffed by GPs, nurses and other clinicians and have access to simple diagnostics, e.g. urinalysis, ECG and in some cases X-ray.[146]

There is a vision therefore of what could help: ambulance service access to some form of ‘alternative care pathway’ (ACP) whereby those seeking help for seizures judged not to require ED are cared for within less costly, alternative environments.[54] Access to the ACP could be co-ordinated by those within dispatch control or on-board ambulances. The exact nature of the ACP is not entirely clear, and most efforts are in the early stages. However, what is apparent is different English regions and services are considering different formats, and development is occurring in an uncoordinated way. Via positions that members of our team hold (e.g., professional bodies, scientific advisory committees, and patient support organisations), we are aware of some of the packages envisioned. We are aware of at least 15 different versions. They include, the introduction of policies for ambulance crews to leave patients at scene with the offer of a telephone call from a general practitioner (GP), a pharmacist practitioner, or a nurse – within 24, 48, 72 or indeed 120 hours. Other regions are considering allowing ambulance crews to transport patients home after seizures rather than taking them to ED. Others are looking to work with urgent treatment centres** so those with seizures can be cared for within them.

### 4.8 ‘Alternative care pathways’ and the ambulance service in general

The Keough Urgent and Emergency Care Review [55-57] envisions that for the NHS to become sustainable, demand on acute services can be reduced by expediting the transformation of the ambulance service – from one where ambulances transport everyone to hospital, to one where they become mobile treatment centres, treating more patients at scene and where greater use is made of ACPs. Appendix B illustrates this.[58]

ACPs are not new and paramedics have not been obliged to transport everyone they see to ED since ~1997.[59,60] Snooks et al.[61] developed some of the first ACPs in 1999 and piloted them with the London Ambulance Service. These were so-called ‘See and Treat’ protocols. In brief, crews were provided with protocols for different presentations. They would select the applicable protocol and work through a series of questions to establish if the presentation satisfied certain criteria. If they did, they were guided towards alternatives to ED. This ranged from them contacting the patient’s primary care team, advising the patient to contact NHS Direct, asking the patient to arrange an appointment with their GP, or simply offering advice.

‘See and Treat’ ACPs are now common amongst regional ambulance services.[62-69] Other ACP response options have also become available, such as ‘Hear and Treat’ (where, rather than dispatching a vehicle, advice is given to patients over the telephone and they are signposted to other care providers) and the dispatching of alternative vehicles.[70,71]

Recently, there have also been attempts to widen the aims of ‘See and Treat’ ACP protocols so not only do they help avoid unnecessary ED conveyance, but also improve patient outcomes.[72-75] In Yorkshire, for example, an ACP for hypoglycaemia has been developed with diabetes specialist nurses.[72] Patients with acute hypoglycaemia for whom an ambulance has been called are assessed and treated on scene by paramedics, rather than being transported to ED. Patients are then referred directly by ambulance staff to the specialist nurses, who contact the patients via telephone.

As is often the case with behaviour change interventions,[76,77] the design and implementation of ACPs has been ‘theory-lite’. Most have not been informed by detailed modelling or with reference to a behaviour change theory. Instead, most have been designed according to the ISLAGIATT principle (‘it seemed like a good idea at the time’, a term coined by M. Eccles, Emeritus Professor of Clinical Effectiveness).[78]

The evidence on the utility of ACPs is nevertheless generally positive (albeit not definitive).[79-81] In their review of potential revisions to the urgent and emergency care system, the Nuffield Trust, for instance, identified greater ambulance/paramedic triage in the community as having the most the positive evidence.[48] Proponents of ACPs have highlighted headline data suggesting their introduction has helped ambulance services manage recent call increases. For example, whilst calls to the ambulance service have been increasing, the proportion of incidents resulting in conveyance to ED has reduced. In the period 1987-88 to 1992-93 there were 90 patient journeys in England for every 100 incidents.[82] In 2014-15 in England, there were only 60 journeys for every 100.[83]

There is also evidence that paramedics are willing to use ACPs and can do this safely. Turner et al.’s[80] NIHR funded review of seven systematic reviews and 12 primary studies on the management of patients with urgent care needs by the ambulance service in community settings concluded, based on a small number of high quality studies, that there is evidence to show paramedics can use ‘see and treat’ ACPs safely and reduce hospital transfers and admissions. O’Cathian et al.’s VAN study [169] which is looking at variation in ambulance transfer rates to the ED is also showing that there is substantial willingness by some paramedics and some services to engage with an agenda of non-conveyance.

There is also significant expert support for paramedics’ ability to manage patients without conveyance. Professor Willett, the National Director of Acute Episodes of Care, summarised the potential of the paramedic workforce to the House of Commons Health Committee. He said “they are probably the area of healthcare that has the greatest opportunity to manage demand for the rest of the health economy”.[170]

Finally, some studies have also indicated that ACPs can be associated with increased patient satisfaction and potential cost-savings.[79,80] For example, an initial evaluation of the aforementioned hypoglycaemia ACP found patients benefitted: 88% of patients reported their understanding of their condition had improved and 73% felt better able to self-manage future episodes.[72] In some cases, the uptake of ACPs has though been lower than anticipated [61] and, to date, epilepsy is a presentation that has received little attention .[84]

### 4.9 Potential of an alternative care pathway for epilepsy, including ability to reduce health inequalities

There are several reasons for the momentum to introduce an ACP for epilepsy.

Firstly, the rate of transportation for epilepsy and subsequent hospital admissions is high and has remained so, despite wider NHS initiatives.[7] It is probable therefore that this presentation will continue to be a challenge for the NHS.

Secondly, paramedics have indicated that they are keen (if they receive training and the necessary support) to take on more responsibility for managing seizures.[53] This is important as acceptability of an intervention to those expected to deliver it is important.[78]

Thirdly, recent changes to how ambulance services are funded may mean the use of ACPs becomes financially incentivised and paramedics might feel able to spend more time ‘on scene’.[85]

Finally, and most importantly, an ACP has the potential to work and improve patients outcomes. In the previous section we noted that ACPs within the ambulance have largely come about according the ‘ISLAGIATT’ principle. Having said this, qualitative research [51-53] and a systematic review [171] by our group is providing the beginnings of a theoretical basis for the use of an ACP in epilepsy. In the latter, facilitators and barriers to behaviour change were mapped onto Michie’s [73] Behaviour Change Wheel and Theoretical Domains Framework. On the basis of this work, possible mechanisms by which the intervention could reasonable make a difference are that it may: increase awareness and likelihood that paramedics will consider non-conveyance and referral pathways as an option in appropriate cases; increase paramedics’ clinical knowledge of how to make appropriate non-conveyance decisions; increase paramedics’ knowledge of alternative care providers that are acceptable to service users; and increase paramedics’ confidence about making a non-conveyance decision and reducing anxiety about risk.

By paramedics operating as part of an integrated healthcare team, some of the ACPs importantly have the potential to lead to reduce health inequalities and improve the support PWE receive. This is likely to come by the ACP introducing an efficient mechanism by which PWE ‘in need’ are brought to the attention of specialist services (e.g., neurology, nurse specialists, GPs with a Special Interest).

Despite indications that specialist input could help those attending ED,[86-88] and the National Institute for Health and Care Excellence recommending it,[89] most PWE (~80%) attending ED do not receive specialist input into their care at the time of their ED attendance and most (~60%) are not referred on.[15] PWE who are older, not known to the service and live in the most deprived areas are the least likely to be referred.[90]

Ensuring those PWE in need of specialist care receive it has been a longstanding challenge in the UK. Reasons why these patients are not always identified and supported are: i) primary care is not incentivised (as it is for other conditions) to identify PWE with uncontrolled seizures, where there is diagnostic uncertainty or treatment failure; ii) there are fewer neurologists per head than in other developed nations;[91] and iii) there are fewer nurse specialists than recommended.[92] An indication of the challenge is that only ~50% of PWE in the UK are currently seizure-free.[9] Trial evidence indicates this should be ~70%.[93] Importantly, it is those in socially deprived areas who fare worst. Ashworth et al.[165] found the difference in the proportion of PWE in the least and most deprived quintiles who were seizure free was 12%.

### 4.10 Acceptability of alternative care pathways to target population is unknown

Whilst we and our partner user organisation believe an ACP for epilepsy has much potential, it is unclear whether any of the ACPs being considered could deliver on it. This is because their acceptability to patients and carers is unknown since they are not being involved in ACP design. Acceptability of an intervention to its intended recipients and providers is a fundamental criterion an intervention needs to satisfy if it is to be well positioned to achieve its intended outcome (see ‘APEASE’ framework [78]).

ACPs for epilepsy (like some other recent service innovations [45,94]) are being developed in a largely ‘top-down’ fashion. This is despite evidence that decisions about whether or not to access health care services can be informed by how a patient or carer perceive their situation [95-97] and that there can be a mismatch between patients/carers and health professionals’ views, including about what constitutes an ‘emergency’ situation.[98-101] It is entirely possible therefore that the nature and content of these ACPs will not align with what patients and carers would consider to meet their needs.

A Patient and Public Involvement (PPI) event that we ran to discuss ACPs showed PWE recognised the potential of an ACP. However, service users were disappointed and concerned that the patient voice had not so far been factored into design (see Section 6 for more details).

To our knowledge, only one epilepsy ACP has been reported on to date. Piloted for 11-months by the Yorkshire Ambulance Service, the ACP allowed paramedics, when they felt it appropriate, to not convey adults with known epilepsy to ED but instead directly refer them to an epilepsy nurse specialist (who would telephone the patient within 5 days).[102] The ACP was launched with a training event for paramedics and they were provided with brief guidance document about which patients did not require conveyance to hospital. An evaluation of this ACP underscored the opportunities that existed to improve the management of those from the target population. Telephone consultations, for example, between the nurse specialist and patients lasted for only a median of 10 minutes. Despite this, independent review of the nurses' notes revealed positive action/ outcomes occurred in the majority of cases. Examples included: contacting the patient's pharmacist or GP to optimise AED therapy, arranging an appointment in the neurology clinic, referring the patient to a psychotherapy service and booking the patient an appointment in the epilepsy nurse clinic.

The problem though, was that over the 11-month evaluation period, less than 10% (87/891) of eligible PWE attended to by paramedics were put onto the ACP. The reasons for this low uptake rate were not explored. A possible explanation is the configuration of the ACP was not acceptable to PWE. To date, it has been assumed the target population *does not* want to be conveyed to ED and they will readily accept an alternative to ED. It may not be that straightforward.

Firstly, the characteristics of PWE who visit ED might mean they are less ready to accept *not* being transported to ED during the intense and worrying moments of a seizure and aftermath. Compared to the wider epilepsy population, they have lower epilepsy knowledge, demonstrate more clinical anxiety, report greater perceived epilepsy stigma and are more likely to live in a socially deprived area.[23,103-107] Up to 20% also have an intellectual disability.[29,30]

When interviewed about their visits to ED, PWE often express a need for immediate access to urgent care when they have a seizure. They explain how they and their family (to whom care decisions are often delegated when the patient is unconscious or lacks capacity) are often fearful of seizures, including the possibility of death and brain damage, and are unsure about how to manage them.[40, 41] This, they say, leads them to call for an ambulance when they are about to have, or have had, a seizure. For many, this is an established pattern of behaviour. One study found the median years diagnosed of PWE visiting ED was 11. Telling quotes from interviews [40, 41] with PWE include:

> *"Cancer, you're awake. I know you can die, but you're awake. I'd prefer something like that…Having epilepsy, you're going into a fit. You don't know if you're going to wake up or die. That's why I call [999]!" (Patient, number 23)*

> *"[I was] just worried because I don't know anything about epilepsy…I only know the bad things…I know you can die… I am so worried I decided just to ring an ambulance…better safe than sorry." (Carer, number 60)*

Another important piece of evidence comes from work with paramedics.[52] It highlights that although some PWE do not want to be conveyed to ED (due to inconvenience, noise), others *do*. One illustrative quote by a paramedic from a forthcoming article of ours is:

> *"when they talk to us about what their preference is it's mixed … many been taken to hospital before. They know that that's the pattern and they expect it... they feel nervous if you start talking about them staying at home ... Some feel very vulnerable and want to go through the motions of seeing the paramedic, the doctor, the nurse..." (Paramedic, number 1)*

Each of the ACPs being considered around the country would require financial expenditure by the NHS (e.g., fund the training of staff, to increase capacity). This is difficult to justify as the likelihood of any outlay translating into a service/s that patients and carers would use is low. There is also no indication that these approaches would be tested and refined by use of approaches such as 'Plan-Do-Study-Act'. If the current trajectory is pursued and various packages without evidence of patient acceptability implemented, then the approach would be akin to an expensive version of 'trial-and-error'. There are also implications beyond cost since if a pathway is implemented which is not acceptable to its intended recipients, PWE visiting ED will continue to be deprived of the benefits of improved care.

### 4.11 How to make the development of alternative pathway/s more rational and cost-efficient

To make the process rational and cost-efficient, it is necessary to engage with patients and carers and obtain information about their preferences and priorities for post-seizure care. This will establish to what extent they are open to the possibility of alternative management and permit an understanding of the target population's expectations and concerns. The information could then be used to co-design an ACP which encapsulates the features of importance to patients and carers, but which is also feasible within the NHS context.

We shall use use stated preference Discrete Choice Experiments (DCE). This is a particularly promising method by which preferences can be elicited to underpin service design.[108,109] DCEs are an attribute-based survey methodology, underpinned by the theory that any 'good' or service can be described by its constituent characteristics (attributes) and that the extent to which an individual prefers certain goods or services depends on the levels these attributes take.[110] In the case of a health care package, attributes would include process attributes (e.g., where you would be taken to by the ambulance; the health care professional that would be responsible for your care) and outcome attributes (e.g., likelihood of follow-up).

Within a DCE, a person's stated preferences and priorities are elicited by presenting them with a hypothetical scenario (e.g., having X health condition) and asking them to choose which of two (or more) care options described by a series of attributes they prefer. This process is then repeated with alternative care choices being presented each time. By varying attribute levels across choice tasks and observing how participants change their responses, DCEs allow one to infer the relative importance of different attributes and the extent to which they drive preference. One can also calculate the extent to which persons accept certain 'trade-offs' (e.g., amount of additional time willing to wait to see the preferred health care professional) and rank different care packages by their extent of likely uptake.

DCEs have increasingly been used to determine healthcare preferences, including for epilepsy.[111-113] This is because, when a DCE is designed well, the preferences expressed within them show strong congruence with real-world behaviour.[114-116] Ryan and Watson,[116] for example, had persons complete a DCE about different Chlamydia tests prior to seeing a doctor for unrelated reasons. A test was then offered during the subsequent consultation; 81% of patients' responses to the offer were consistent.

Testament to the importance that is now ascribed to evidence from DCEs is that findings from them is permissible in submissions for regulatory approval for new medical treatments.[117,118] Indeed, the European Medicine's Agency, as part of their first ever public hearing, considered DCE evidence on the risk-benefit ratio of sodium valproate as perceived by women with epilepsy (via submissions from A. Marson, D. Hughes).[119]

## 5) RESEARCH METHODS FOR CURRENT STUDY

We shall conduct a 28-month mixed-methods project that will comprise of three work packages (WP) (Figure 1 upload). In WP1, the ACPs being considered by NHS bodies around the country for epilepsy would be identified and patients and carers asked to give qualitative feedback on these, the reasons they attend ED and their priorities for care post-seizure. During WP2 a DCE would be designed and completed with PWE and their carers to determine their care preferences for the three most common seizure presentations to ED. For WP3, knowledge exchange events would be completed at which the findings would be relayed to key stakeholders within the NHS and workshops held to agree which ACP configuration best meet patients' and carers' preferences, is feasible within the NHS context and is a priority for testing/ implementation.

### 5.1 WORK PACKAGE 1

### 5.1.1 Pathways survey *(Project months 4-11)*

As noted, a range of ACPs for epilepsy are being considered across England. The type of organisation and indeed the profession of the person leading ACP initiatives appears to vary between areas. Some are being developed by ambulance services, some by EDs and others by neurology. To systematically determine what ACPs are being considered, a cross-sectional survey of NHS regional neuroscience centres, ambulance services and EDs in England will therefore be completed. In this way, the hypothetical ACPs presented to patients and carers within the DCE during WP2 will reflect the main ones being considered and allow us to model realistic possibilities.

#### *5.1.1.1 Design*

A survey including both open and closed questions will ask respondents whether their NHS service is considering (or has implemented) any policies, schemes or pathways that relate to the management of those with epilepsy, or indeed seizures generally, with a view to minimising ED visits. They will be asked what these are, to what extent service users have been involved in their development and whether they anticipate that the policy, scheme or pathway will address health care inequalities and, if so, how. If a policy or ACP has been developed, they will be asked to provide us a copy and inform us of what their experience with it has been.

The questionnaire will be designed with input from J. Dickson, A. Marson, E. Holmes and Epilepsy Action, all of whom have recently completed successful service surveys.[15,120-122] Depending on their preference, recipients will be able to complete the questionnaire online or on paper. The questionnaire will be piloted at 2 neurology sites, 2 ambulance services and 2 EDs, and the questions refined as necessary.

#### *5.1.1.2 Recruitment*

Previous surveys asking NHS services about their provisions for epilepsy or what ACPs they have for other presentations have achieved excellent rates of uptake (i.e.,~85%).[121,123,124] To maximise response, we shall exploit existing relationships which our team has with appropriate personnel at the institutions (e.g., clinical directors, clinical leads). Recipients will be asked, where necessary, to consult with managers of their service to ensure responses incorporate both current and planned redesign. The specifics are:

- *Epilepsy services*: Neurology for adults in England largely operates via a 'hub-and-spoke' model. Most (20/25) [125] of the Tier 3 tertiary neuroscience centres that are providers of Specialised Prescribed Services and act as 'hubs' – and whose staff operate clinics in 'spoke' hospitals - have been recruitment sites for the large SANAD (Standard and New Antiepileptic Drugs) trials [126,127] our group conducted. A. Marson, chief investigator for SANAD, will send a personalised invitation to complete the survey to the principal investigator or clinical lead at all sites. In responding to the survey, neuroscience centres will be asked about ACP considerations that their centre and their partner hospitals and community services are considering.

- *Emergency departments*: There are ~140 hospitals in England with a type 1 ED.[128] A random sample of 25% of these, stratified by geographic area and size, will be selected and invited to complete the survey. Over 90% of English EDs took part in NASH.[29,30] A. Marson, chief investigator for NASH, will therefore, together with S. Goodacre (Prof. Emergency Medicine), send a personalised invitation to the clinical lead of the selected EDs. To promote uptake, the chair of the research committee of the Royal College of Emergency Medicine (Prof. A Gray) has agreed to promote the survey.

- *Ambulance service*: There are 10 regional ambulance services in England. The 'National Ambulance Leads' group has representation from each. M. Jackson, chairs this group and will present the initiative to the group and members will each receive an invitation to participate. Our group has established research relations with most of the services.[42,51,52]

Reminder invitations will be sent to services not responding to the initial invites within 3 weeks. As a last resort, should a response not be forthcoming, then a freedom of information (FOI) request will be submitted to the institution's FOI unit to which they are obliged to respond within 20 days.

#### *5.1.1.3 Analysis*

Characteristics of the responding organisations will be examined using descriptive statistics and representativeness judged against publicly available information.

To determine the different types of care packages being considered and the proportion of responding institutions considering each, a subset of surveys will be selected to reflect the range of institutions responding. The responses given by these institutions will be read by a qualitative researcher to identify recurrent types of pathway. This will be used to develop an initial thematic coding framework capturing the main types. The framework will then be applied to the full data corpus to identify and code all responses. Responses that reflect care pathways insufficiently identified by the original coding framework will be used to modify the framework. Frequent discussions between the researcher and a multidisciplinary research team will help ensure interpretations and conceptualisations of the data are credible, valid and shared.

The final list of ACPs being considered will be used along with findings from other work streams, to inform the final list of attributes and levels for the DCE.

### 5.1.2 Interviews with service users and informal carers *(Project months 1-12)*

Interviews with persons from the target population will be conducted to identify attributes of post-seizure emergency care that PWE and their carers consider important; and to identify if this differs by whether the seizure occurs at home or in a public place. The qualitative study has been designed to ensure the DCE attribute development is rigorous, transparent, and adheres to good practice guidelines.[130,131] It will be conducted and reported according to COREQ guidelines [132] and be conducted at King's College London.

#### *5.1.2.1 Design*

A qualitative interview study will be conducted given the limited existing evidence of what care attributes PWE consider important. Face-to-face semi-structured interviews will be held with a purposive sample of PWE who have recently visited ED. Where feasible their significant other/ informal carer, will participate in a joint interview. Recording discussion in joint interviews and eliciting the concerns of both parties to the same event is regarded as particularly appropriate for studying complex shared practices and health decisions.[133,134]

#### *5.1.2.2 Recruitment*

Participants will be purposively selected based on: age ≥18 years, have epilepsy and have attended ED during the last 12 months or being are an informal carer to such a person.

Ostensibly eligible PWE will be identified by means of an existing research database our team holds of persons with poorly controlled epilepsy. These are persons who took part in our recent National Institute for Health Research (NIHR) funded SMILE (Self-Management education for adults with Epilepsy) trial in the South-East of England and who expressed interest in future projects.[135]

SMILE was a phase III trial comparing a 2-day education course to treatment as usual alone. Inclusion criteria were ≥2 seizures in the prior 12 months, having established epilepsy, being prescribed antiepileptic medication and an ability to independently complete questionnaires in English.

Ultimately, >400 PWE enrolled. Mean age was 42, 54% were female and 75% were white. At baseline, 70% experienced ≥10 seizures per year. Psychological symptoms were reported frequently; 54% reported anxiety symptoms and 28% reported depression symptoms at borderline or case-level. Of the sample, 46% reported a comorbid condition and 63% felt stigmatised by epilepsy. A higher than national proportion of the sample lived in the most socially deprived areas (61% [versus 40%] in areas with an Index of Multiple Deprivation score in quintile 4 or 5). The sample included some persons with mild intellectual disabilities and featured persons with different levels of self-management confidence. At 12-month follow-up 82% of patients were retained. No differences between trial arms on the primary (quality of life) or secondary outcome measures were found.[136]

Importantly, of the SMILE participants retained at 12 months, 140 (35%) had visited an ED in the prior 12 months. With ethics permission, we shall recruit a purposive sample via this list. Persons from the list will be randomly selected by a computer to fill the cells of a sampling matrix that will vary according to age and sex. The sample will also include those who have had a recent seizure at home and those who have had a seizure in a public place.

Anticipating an uptake of 25-50% and that some patients' eligibility may have changed, 4 patients for every slot will be selected. Invitation letters, signed by L. Ridsdale (chief investigator for SMILE) will be sent to these patients. To identify carer participants, patients will be asked to choose a significant other/informal carer to take part with them if they would like and will be interviewed together. Despite greater social isolation, up to 90% of PWE still identify a spouse, parent or friend who acts as an informal carer for them.[137]

It is our intention to capture a comprehensive range of perspectives and recruitment will continue until there is no new variation in observations (data saturation). Based on previous DCE design work,[112, 130] we anticipate obtaining interview data from ~30 PWE, with or without an informal carer and we shall ensure both those who have had recent seizures at home and in a public place are adequately represented.

Should recruitment be slower than anticipated, PWE from the target population will also be able to be recruited via those affiliated with our partner user organisation, Epilepsy Action. This would be done by research notifications and newsletters being circulated to its members and on its social media platforms. Epilepsy Action is the largest user organisation in the UK and has substantial reach. In 2016, it had >12,000 active members, 21,000 social media followers; and its website was visited >2 million times.[138] We would also consider broadening the recruitment criteria to allow people who have had ED or ambulance contact within the last 2 years, rather than just the last 12 months to participate.

#### *5.1.2.3 Interviews*

Semi-structured interviews will be held with the patient alone or if desired as joint interviews with both the patient and significant other/main informal carer.

The topic guide will be informed by current information regarding alternative care pathways together with input from a patient and carer advisory group and clinical experts. Interviews will be held in a location (e.g., home, university offices) and at a time of the persons choosing. Interviews are deemed preferable as stigma, lack of driving licence, and anxiety about travelling due to seizures, could limit alternative data collection approaches (e.g., focus groups).

Interviews will begin by asking participants for contextual information about their epilepsy (or the epilepsy of the person they care for) and recent seizures and episodes of ED care. The interviewer will then seek evaluative information, asking respondents to describe positive and negative perceptions concerning emergency care and any alternative methods of care they have experienced. The researcher will explore the decision-making processes that surrounded patients and carers seeking or not seeking ED care following recent seizures and the reasons for their choices.

Thirdly, we shall seek strategic data from respondents by describing some aspects of possible ACPs and asking them for their views of what they think may be positive aspects and their concerns if they had been offered them following a stated seizure of theirs. For example, they will be asked their views of where they should be taken once a seizure has finished (home, urgent care centre, ED) and views regarding follow-up options. This will help identify the key factors involved in their decision-making. As the qualitative WP will take place at the same time as the service survey, the ACPs discussed with the interviewees will include the ones already known about by the team (see Appendix C).

Finally, to help reduce the number of care attributes to a number manageable for a DCE and improve face validity, participants will, towards the end of the interview, be asked to reflect on what they have said rank what they personally consider to be the 5 most important aspects (attributes) of care following seizures. The interviewer will work with the participants to recall the attributes of ACPs they considered to be most important and write them onto show cards. The participant will select their top 5 and then place them in rank order.

#### *5.1.2.4 Analysis*

Data collection and analyses will proceed in an iterative manner. Interviews will be audio-recorded and transcribed verbatim. Transcripts, supplemented by interviewer notes and a data collection form for the ranking exercises, will form the data-set. The data will be analysed thematically [139] using NVivo 11 software. The goal will be to generate a list and description of the attributes of care (and levels) following a seizure that patients and carers identify as being most salient and which inform their choices and decision-making.

To do this, each transcript line will be read, and statements coded. Initial coding will be broad and refined as the analysis progresses. Analysis will pay attention to the similarity and differences in attributes of importance identified by patients and carer participants, according to where the seizure occurred (home v public place), who else may be with the patient, who made the 999 call (patient/informal carer v member of the public), whether the patients have seen a specialist in the prior 12 months, and whether they self-report an intellectual impairment. .

An experienced qualitative researcher will undertake this work, supported by L. Ridsdale, A. Noble, the wider project group and by M. Morgan who will advise on the topic guide, review interviews and input to analysis and interpretation. The attributes nominated during the ranking exercise will be categorised according to the thematic framework, then analysed quantitatively using standardised rank scores by E. Holmes.

### 5.1.3 Knowledge Exchange event with ambulance and neurology service representatives *(Project month 9)*

This event will seek to early in the life of the project determine what the potential barriers and facilitators are for the different ACP possibilities from the perspective of ambulance and neurology services. It will do this by assessing the feasibility of the attributes and associated levels that have been identified by WP1.1 and 1.2.

#### *5.1.3.1 Design*

A one-day event will be hosted within a room at one of the institutions of the investigative team. At the event, health care professional representatives will, as a group, be shown the draft attributes, levels, and choice sets and asked to deliberate each choice one question at a time.

#### *5.1.3.2 Recruitment*

Around n=15 ambulance staff and neurology service representatives will be sought for this knowledge exchange event, with persons being recruited from the sampling framework used for the WP1.1 pathways survey to ensure representatives come from geographically diverse areas. Should some persons be unable to attend the event, but be willing to share their feedback, then they will be sent a link to the workbook and invited to share their feedback with us in writing or by phone. RW1, supported by MJ and AM, will be responsible for recruiting representatives. Representatives will be reimbursed for travel.

#### *5.1.3.3 Analysis*

With attendees' consent, the session will be audio-recorded. The session itself will be facilitated by AN and by EH, with field notes also being recorded. The findings from the event will form part of the evidence base considered when the DCE questionnaire is composed during WP2. The approach described is one our team have successfully used before [112]. An advantage of the approach is that representatives feedback can be used to inform/enhance the attribute levels used within the DCE and allow it to generate evidence that better positions the project to be able to identify the ACP/s that is most acceptable to service users, but also NHS feasible and agreeable to service providers. Should concerns be raised about the viability or implementation of an ACP then this information could be used to ensure the DCE is based on realistic scenarios. For instance, should it emerge from the qualitative work that patients and carers consistently say they would prefer to be transported home by the ambulance service following an uncomplicated seizure, regardless of how far they were from home, then the health care representatives would be asked to consider what would constitute an acceptable distance that could be accommodated. This information could then be used to optimise the attribute levels used within the DCE.

## 5.2 WORK PACKAGE 2

### 5.2.1 Generating DCE questionnaire and piloting *(Project months 9-14)*

Using information generated by WP1, a multidisciplinary panel, chaired by D. Hughes (Prof. Health Economics), will compose the first draft of the DCE questionnaire, which will be refined following a pilot.

#### *5.2.1.1 Design*

The panel will include expertise in DCE design (E. Holmes), emergency medicine (S. Goodacre), neurology (A. Marson), paramedical science (M. Jackson), general practice (J. Dickson), and psychology (A. Noble), as well as having patient and carer representation.

The study will provide information on the care preferences of patients and carers for different seizure scenarios. To allow this, DCEs for the three most common seizure presentations to ED by PWE will be generated. These are a person with established epilepsy who has: i) experienced an uncomplicated seizure in line with their usual presentation; ii) experienced a seizure in public who cannot be 'left at scene'; and iii) experienced a seizure that has self-terminated, but which is different to the person's 'normal' seizure/s.

The specific design of the DCE will be informed by best practice [130,140] and be responsive to the findings of a pilot. It is anticipated though, that to reduce cognitive burden, participants will be asked to complete DCEs relating to only two of the three seizure presentations (with allocation being randomly determined and sample size being calculated accordingly).

Each DCE will likely involve the participant being presented with a vignette describing a specific seizure scenario and then being asked to complete a series of forced, pairwise comparisons to identify which care packages they would prefer. Like in most DCE studies in health care, respondents will be asked to choose between two unlabelled treatment pathways (i.e., option A, option B).

The vignettes for the DCE will be developed by the panel based on their clinical or lived-experience. They will use evidence from WP1 to form a consensus on which restricted number of care packages best represent the range being considered across the country and are to be valued using the DCE. Using the list of candidate attributes generated from the WP1 interviews, the panel will select 4-6 attributes by which to describe the care packages. They will favour attributes prioritised by patients and carers in WP1, which are potentially modifiable, are capable of being traded and best describe the ACPs under consideration.

Plausible levels for the attributes will be specified by the panel on the basis of findings from the survey, qualitative interviews, knowledge exchange event with ambulance and neurology representatives, evidence from the literature, and /or expert opinion. It is anticipated that categorical attribute variables will have at least 2 levels, and continuous attributes 3 levels. A strength of DCEs is that it is possible to vary attribute levels in such a way as to determine preference for different services within both the current context/'market place', but also within future ones. This is important as the ED environment may change over the next few years. One change that is possible are longer ED waiting times.[141] Using its expertise and knowledge of the NHS, the panel will look to assign levels to attributes within the DCE to account for such possible changes.

The number of attributes and levels selected will likely result in a large number of treatment options. Thus, as is common practice, a fractional factorial design will identify a purposeful subset of options for each DCE that will allow the study to estimate the main effect of each attribute independently and selected two-factor interactions, while minimizing the number of paired comparisons participants are asked to make. The profiles will be obtained from a published design catalogue.[142] Binary choices will then be created using the fold-over method which replaces each attribute level systematically.[143]

Should the design result in the number of choice questions participants are requested to respond to within each DCE still being high (i.e., >16), we will consider reducing the number of attributes and levels, or reducing participant burden by partitioning the questions into equally sized blocks and randomly assigning participants to a block rather than requiring them to answer the entire set. Two choice sets will be added to each DCE to test the internal consistency (rationality) of responses (e.g. Sen's expansion and contraction tests). Table 1 provides an example of a vignette and associated choice task. This is shown for illustrative purposes *only*. The presentation of quantitative levels will be informed by best practice guidelines.[140] In addition to completing the DCEs, participants will be asked brief questions relating to demographics (age, sex, work status, rural/urban home location), epilepsy profile (seizure type and frequency in prior 12 months, years diagnosed, treatments, medication adherence), knowledge and fear of seizures (by means of [144]) and service use (including number of ED visits in prior 12 months).

### *5.2.1.2 Pilot*

The finalised DCEs and wider questionnaire will undergo iterative, individual face-to-face pilot testing with ~15 PWE and carers from a Patient and Public Involvement group that will be established for this project.

The pilot will seek to check patients understanding of the task, interview duration, and ensure the participants understanding of the options being presented is accurate and sufficiently described by the DCE. This is because there is some evidence of limited public understanding of service beyond ED and GP. Should this be the case, it will be important to implement steps to ensure patients are sufficiently informed and orientated as what to the alternative care options are and mean.[145] For example, the term Urgent Treatment Centre is relatively new.[146]

To help achieve its intended goals, pilotees will be encouraged to 'think aloud' [147] when making their choices and asked to consider their preferred presentation of the attributes (e.g. use of text, pictograms). With participants' consent, interviews will be audio recorded, and notes made. The data will be used to determine whether the DCE is capturing issues of importance in a valid manner and identify revisions required.

After piloting, and given the COVID-19 pandemic and government requests to 'socially distance', 4 additional questions within the background section of the DCE were included. These questions will allow us to describe participants' experience of COVID-19, the level of concern within the recruited sample regarding COVID-19 and what implications they perceive this has for their or their 'loved-ones' service use preferences. This data will allow to describe the sample clearly, compare them and help us determine whether any of these indices are associated with care preferences when it comes to epilepsy that should be accounted for within the analysis. We also decided to explicitly instruct participants to answer the DCE questions about preferences during normal times, rather than during the current pandemic and have revised the instructions and animation which supports people how to complete the survey to this affect. This was done with the input of clinicians, experts in DCE and patient carer representatives.

### 5.2.2 Formal Discrete Choice Experiment *(Project months 14-23)*

A cross-sectional DCE survey will be completed with a representative sample of PWE aged ≥18 who have recently visited ED and their informal carers (i.e., family members, friends) and a sample of PWE (/carers) who are at risk of visiting ED in the future – namely, those have had a seizure in the prior 12 months, but not visited ED during that period. The following groups will be recruited:

#### *5.2.2.1 Study population:*

Group 1-

Patient inclusion criteria: 1) Clinically confirmed diagnosis of epilepsy (of any duration); 2) Any epilepsy syndrome and any types of focal or generalised seizures; 3) Currently being prescribed antiepileptic medication; 4) Age ≥18 (lower bound accords with Quality and Outcomes Framework register; no upper age

**Table 1** Illustration of a possible vignette and Discrete Choice Experiment choice that could be used

| **Question 1**<br>Imagine you have a seizure in a public place. It lasted no more than usual and stopped by itself. You are tired and need to sleep. Someone called an ambulance and the paramedic is with you. Which of the following options would you prefer to happen next? | | |
|---|---|---|
| | **Option A** | **Option B** |
| **Where**<br>*Where the ambulance takes you* | <br>***Accident and Emergency (A&E)*** | <br>***Urgent Treatment Centre*** |
| **Care provider**<br>*The health care professional responsible for your care when you get there* | <br>***Consultant doctor in emergency medicine*** | <br>***Emergency nurse practitioner*** |
| **Waiting time**<br>*How long you have to wait before you see the health care professional* | <br>***4 hours*** | <br>***1 hour*** |
| **Tests**<br>*The type of tests the health professional could carry out immediately if needed* | ***Advanced***<br>(examples...) | ***Basic***<br>(examples...) |

| | | |
|---|---|---|
| **Follow-up**<br>*The number of people referred to see a health professional with specialist training in epilepsy* | ●●●☐☐☐☐☐☐☐<br>***3 in 10 people***<br>***referred to specialist epilepsy services*** | ●●●●●☐☐☐☐☐<br>***5 in 10 people***<br>***referred to specialist epilepsy services*** |
| **Which service would you prefer?** | ☐ | ☐ |

limit); 5) Visited an ED on ≥1 occasion for epilepsy within the previous 12 months; 6) Able to provide informed consent and independently complete the questionnaire in English. 7) Lives in North-West England.

Patient exclusion criteria: 1) Severe current psychiatric disorders (e.g. acute psychosis); 2) Life-threatening medical illness; 3) Resides within a care or nursing home or has no fixed-abode.

Carer inclusion criteria: 1) A significant other to a person with epilepsy (e.g., family member, friend) who the patient identifies as providing informal support or self-identifies themselves following the patient receiving an invite; 2) The person with epilepsy that they know must have visited an ED on ≥1 occasion for epilepsy within the previous 12 months; 3) Age 16 years or older (no upper age limit); 4) Able to provide informed consent and independently complete the questionnaire in English; 5) Lives in North-West England.

Carer exclusion criteria: 1) Severe current psychiatric disorders; 2) Life-threatening medical illness.

Group 2

Patient inclusion criteria: 1) Clinically confirmed diagnosis of epilepsy (of any duration); 2) Any epilepsy syndrome and any type of focal or generalised seizures; 3) Currently being prescribed antiepileptic medication; 4) Age ≥18 (no upper age limit); 5) Been seen by the ambulance service for epilepsy within the prior 12 months, but was *not* conveyed to ED; 6) Able to provide informed consent and independently complete the questionnaire in English; 7) Lives in North-West England.

Patient exclusion criteria: 1) Severe current psychiatric disorders (e.g. acute psychosis); 2) Life-threatening medical illness; 3) Resides within a care or nursing home or has no fixed-abode.

Carer inclusion criteria: 1) A significant other to a person with epilepsy (e.g., family member, friend) who the patient identifies as providing informal support or self-identifies themselves upon the patient receiving an invite; 2) The person with epilepsy that they know must been seen by the ambulance service for epilepsy within the prior 12 months, but *not* being conveyed to ED; 3) Age 16 years or older (no upper age limit); 3) Able to provide informed consent and independently complete the questionnaire in English; 4) Lives in North-West England.

Carer exclusion criteria: 1) Severe current psychiatric disorders; 2) Life-threatening medical illness.

### *5.2.2.2 Sample size*

Lancsar and Louviere [148] highlight the complexities of performing sample size calculations for a DCE as information on many of the parameters – such as the number of choice tasks completed by respondents for a single DCE and the number of attributes and levels presented in each choice – is not known until development work has been completed. As this stage, however, we can estimate the likely DCE design and use Orme's [149] commonly used [150] rule of thumb formula. The formula is: $(n*t*a)/c$ must be ≥500, where $n$ is the number of respondents, $t$ the number of tasks, $a$ the number of alternatives per task, and $c$ the number of analysis cells (for main effects, the largest number of levels for any one attribute).

For the current project, if we anticipate using experimental design with two choice alternatives ($a$= 2), nine choice tasks ($t$= 9) and three as the maximum number of levels for any one attribute ($c$= 3), the required number of participants providing complete data for each of the DCEs needs to be n=84. We intend to obtain data for three separate DCEs (scenarios i, ii and iii). Participants will be randomised to complete a selection of two of the DCEs (i&ii, i&iii, or ii&iii). As such, a minimum sample of 126 participants would be required to satisfy Orme's guidance, based on this example. To allow for potential variation in the number of choice tasks and levels we approximate the required sample size to be in the region of 150. This is in line with the average sample size for DCEs.[151]

It is necessary however, to inflate this figure to accommodate for any missing data. In prior epilepsy DCEs, ~15% of returned questionnaires have been excluded.[112,152,153] For this reason, 174 patient/ carer participants would need to be recruited. Also, an objective of our study is to describe and compare the care preferences of two subgroups: those of patients (and associated carers) who have visited an ED in the prior 12 months and those of patients (and associated carers) who have had a seizure in the prior 12 months, but have not visited an ED. To do this in a robust way, at least 174 patients (and associated carers) who have visited ED in the prior 12 months and 174 patients (and associated carers) who have not, will be recruited.

#### *5.2.2.3 Recruitment via North West Ambulance Service*

Patients and carers will be recruited primarily with the support of the North West Ambulance Service (NWAS) NHS Trust in England who have agreed to act as patient identification sites. Their involvement would be supported by the NIHR Clinical Research Network North West Coast.

We intend to recruit via the ambulance service since PWE who visit ED are unknown to specialist services.[15] and because primary care are not necessarily informed of contact their patients have with the emergency services.

Emergency calls to NWAS are handled by an emergency operations centre. The Advanced Medical Priority Dispatch System (AMPDS) is used to code the reason for the call and prompts the call hander to ask standard questions. When a call is made regarding a suspected seizure then AMPDS Protocol 12 is used. A standard question asked under this protocol is whether the patient for whom the call is about has a diagnosis of epilepsy (i.e., "Is s/he an epileptic?"). As most (~70%) calls for a suspected seizure are made by a relative, friend or carer it is anticipated most callers will be able to answer the question in an accurate way. When a call is for suspected seizure is confirmed to relate to a person with a history of epilepsy the it is coded as “Protocol 12-suffix e”.

To identify potential participants, the NWAS will complete a search of the emergency calls it has received over the prior 12 months to identify those coded as “Protocol 12-suffix e”. For 2018, ~13,000 calls to NWAS were recorded under this code. Restrictions will be placed on this search to ensure only persons aged ≥18 are identified.

A member of NWAS staff (typically a paramedic) will then review the Patient Report Form for those on the list to exclude persons who are recorded as having life-threatening condition, a severe psychiatric disorder, and/or live in a nursing home or similar facility (where they will typically not be responsible for care decisions when a seizure occurs).

Those patients remaining on the list will, with the assistance of the secure “docmail” service, be posted a personalised invitation from the NWAS informing them about the study. Included in the pack will be a Participant Information Sheet and a FREEPOST response slip.

NWAS will record the number of persons identified by the search, the number excluded from invitation, the reasons and the number of sent invitations and any returns.

Based on a meta-analysis of responses to prior health DCEs [156] and work with the target population,[39,157] we anticipate 30-60% of the PWE invited will agree to participate.

Having submitted the current proposal for review to the CRN and having piloted the recruitment process, the network is confident that a sufficient number of PWE will be able to be recruited by this process. Allowing both PWE and informal carers to participate in the current study and that carers to PWE with intellectual impairment can participate in the study, even if the patient cannot, is a strength.[158]

Should close monitoring reveal that the recruitment process is not positioning the project to recruit its intended sample size then recruitment will be supplemented with GPs in the North-West being asked to asked to complete searches of their electronic epilepsy registers for PWE meeting the study inclusion criteria. Via the Quality and Outcomes Framework (QOF), 95% of general practices in England continue to have registers of PWE under their care.[154] Practices receive and record notifications they receive from EDs of visits by their patients.[29]

#### *5.2.2.4 Contingency recruitment via Epilepsy Action*

The recruitment phase for the formal DCE is March 2020 to the end of November 2020. The COVID-19 public health crisis has the potential to disrupt it in several ways. Of note, following NIHR guidance issued on 19 March 2020 NWAS requested a temporary pause to their involvement with recruitment for the project with a view to redirecting all their resources to research directly related to COVID19 and frontline service. The point at which this request was made was just as NWAS were about to mail invitations to persons they had identified as eligible. Given uncertainty as to when NWAS (or indeed other NHS services) might once again be able to assist with recruitment, a contingency plan was implemented to recruit an additional sample of participants from the target population using non-NHS resources – namely, via those affiliated with our user group partners, Epilepsy Action. Epilepsy Action is the working name of the British Epilepsy Association. They are the biggest user group in the UK and have substantial reach.

Potential participants will be identified via Epilepsy Action circulating recruitment adverts to their affiliates. The advert will specify the nature of the study and participation and eligibility criteria. Adverts will be placed within their newsletters, email circulars, magazines, on their social media platforms and distributed within their meetings (including potentially virtual ones). In 2016, Epilepsy Action >12,000 active members, 21,000 social media followers; and its website was visited >2 million times.

#### *5.2.2.5 Procedures – Ambulance Service*

How invited patients and carers take part in the study will depend on whether the patient is recorded as having visited an ED in the prior 12 months. Specifically, patients identified as having *not* visited an ED in the prior 12 months (and their carers) will be invited to visit a study webpage and, having confirmed their eligibility and provided informed consent, complete the DCE questionnaire online by themselves. In 2017, 90% of UK households had internet access.[159]

PWE identified by the NWAS as having been conveyed to ED in the prior 12 months will, in contrast, be told they can complete the questionnaire either online by themselves or during a face-to-face appointment with a researcher using a computer. The reason for this additional option is whilst we have found online recruitment and completion of a DCE to be viable in the epilepsy population,[112] cost remains a barrier to internet access. PWE who visit ED are more likely to reside in socially deprived areas and so might have less access.

Persons wanting to complete the questionnaire via a face-to-face appointment will be able to request this by contacting the research team (phone, email, or using the FREEPOST return slip). Appointments will occur at a time and place of the participant's choosing (home, university offices.). Qualtrics will host the survey and randomly determine which version of the DCE a participant completes.

The potential for interviewer bias during face-to-face appointments will be minimised by the use of scripts and researcher training. To ensure the research worker can offer appointments in a timely fashion to those requesting them, recruitment will proceed in a staged-fashion over 9 months.

To maximise recruitment, participants will be sent a £20 voucher upon completing the questionnaire.

Any invited patients/ carer not wishing to take part in the study will be encouraged to notify the team using the FREEPOST return slip and detail any reasons for this. After 2 weeks, we shall return to practices and ask them to send a final, repeat invitation to those who have not responded to our invite.

#### *5.2.2.6 Procedures – Epilepsy Action*

Persons seeing the advert who are interested in taking part will be directed to a study webpage where they will be able to view a (downloadable and printable) participant information sheet. Those wishing to proceed will be asked to confirm their eligibility, electronically sign a consent form and all complete the survey online. Interested participants will also be able to contact the research team by email or phone to discuss the study to have questions answered and ask for assistance to complete the survey online.

The study webpage to which people will be directed will be different to the one to which people recruited via the ambulance service are sent to. The content of survey itself will though be exactly the same and the survey hosted on Qualtrics. Participants will be randomised to complete a selection of two of the DCEs.

The eligibility criteria for patients and significant others recruited via Epilepsy Action is largely the same as for recruitment via the ambulance service. It will though all be based on self-report. Patients must be aged 18 years or over, have epilepsy and be prescribed antiepileptic medication, have been seen by an ambulance service for epilepsy in the last 12 months (the outcome of the incident, i.e., conveyance to ED or not, will not be not specified), and be able to complete the survey in English by themselves. Informal carers will also be able to take part if they are are aged over 16, able to complete a survey in English by themselves and are a family member or friend of a person with epilepsy who has been seen by an ambulance service for epilepsy in the prior 12 months (again, the outcome of the incident, i.e., conveyance to ED or not, will not be not specified).

The only meaningful difference in eligibility between this recruitment stream and the ambulance one is that participants will only be required to live in England, not specifically the North-West of England. The decision to relax this requirement was made because participant response to the advert at the time of a public health crisis remained unclear. It was decided to maximise the opportunity of the contingency plan to recruit a sufficient sized sample, especially as questions asked of participants by the survey would allow their locality to be described and factored into any analyses if required.

To maximise recruitment, all participants will be entered into a prize draw, where they will have a chance to win one of four £50 shopping vouchers.

#### *5.2.2.7 Analysis*

Any data that is generated from the two recruitment sources – namely the ambulance service and Epilepsy Action – will be treated as separate. There is no intention to merge the data for this project. In the event that recruitment via the ambulance service is able to provide a sufficient data set, then the data from those recruited via Epilepsy Action would be relegated and resources focused on the analysis of the data generated via the ambulance service. Should recruitment via the ambulance service not generate a sufficient sample, but recruitment via Epilepsy Action be able to do this then this data-set will form the basis for the primary analysis.

Once a data-set has been selected for primary analysis as per the logic above, the data for the different seizure vignettes will be analysed separately. Random effects logit regression models will be used for each to determine the importance of the different care attributes for preference and direction of effect (as indicated by the significance of the coefficients and their size). To test the validity of the resulting models, analyses will be completed with and without respondents failing the 'rationality' test included.

The influence of participants' characteristics on preference, including whether they had visited an ED in the prior 12 months and whether they were a patient or a carer, will be examined as a secondary analysis to allow us to determine what differences exist. We shall also conduct subgroup analyses to explore potential differences in preference based on: (1) social deprivation (with participants grouped according to how socially deprived the area is within which they live); (2) whether or not they have seen an epilepsy specialist within the prior 12 months (which they should have according to NICE guidelines [89] given they will all have uncontrolled epilepsy); and (3) whether they or the person they know in the case of carers, self-reports an intellectual disability.

Marginal rates of substitution (the rate at which respondents are willing to give up a unit change in one attribute in exchange for a unit change in another while maintaining the same level of utility) will be calculated using each quantitative attribute as the value attribute with bootstrapped confidence intervals (1000 reps). Comparison between vignettes will depend on attribute and level specification of each experiment.

'Utility scores' for different service configurations will be calculated and models ranked by their estimated level of uptake by patients and carers under the different seizure scenarios.

All analyses will be conducted in STATA 11 (StataCorp, College Station, TX, USA).

## 5.3 WORK PACKAGE 3

### *5.3.1 Knowledge Exchange workshops (Project months 24-26)*

These events will allow us to a) disseminate the qualitative, survey and DCE evidence to the health professionals, commissioners and managers involved in the development and/or funding of services, and b) then utilise their expertise, knowledge and experience to identify which of the ACPs favoured by patients and carers are likely to be most feasible and fundable in the NHS and warrant evaluation.

#### *5.3.1.1 Design*

Two one-day Knowledge Exchange workshops with key stakeholders will be run to consider the evidence collected during WPs 1 and 2. These will start with a series of presentations that will outline the purpose of the day and the project's key findings. We shall then utilise an adapted Nominal Group Technique to rank the ACPs by the extent to which the group considers them to strike the balance between patient/carer preference and feasibility within the NHS. In making their decision, stakeholders will be encouraged to consider potential barriers to change, supply constraints, acceptability of the service to staff, possible cost, the potential of the ACP to redress health care inequalities. The Knowledge Exchange workshops are currently scheduled to occur between January 2021 and March 2021. If restrictions are still in place due to COVID-19 and face-to-face meetings aren't compatible with government and University of Liverpool guidance at the time, we would intend to adapt the workshops and run them using video conferencing.

The Nominal Group Technique is a well-established and well-described approach to decision making. Our approach will closely follow that used and described by the James Lind Alliance during their priority setting workshops (www.jla.nihr.ac.uk/jla-guidebook/chapter-9/final-priority-setting.htm).

The technique permits decisions to be made relatively quickly by voting, but at the same time ensures everyone's opinion is considered. Each participant reviews the items for discussion (in this case ACP configurations) and gives their view. A shared voting or ranking exercise is undertaken with further structured small group discussions followed by ranking or voting. The ranked orders for each item from each contributor are then totalled, and the priority with the lowest (i.e. most favoured) total ranking is selected as the top priority. The technique is useful when: some group members may be more vocal than others; when group members do not know each other; and when the issue is potentially controversial.

As likely users of any evidence that would be derived from an ultimate evaluation of the ACP/s identified, a secondary objective will be for the 'breakout groups' to prioritise what they, as service providers or funders, would consider helpful outcome measures.

The workshops will be supported by the University of Liverpool's Knowledge Exchange team who will input, without additional cost, to ensure the design and facilitation for the day meets best practice guidelines. Each breakout group will be facilitated by a person who has no vested interests in the ranking of the ACPs.

With attendees' consent, the sessions will be audio-recorded. A qualitative researcher will also observe the main sessions and record field notes. Events will be held at the University of Liverpool's London and Liverpool campuses. No room hire costs will be charged.

*5.3.1.2 Recruitment*

A sampling matrix will be formed to help ensure broadly equal representation at the meeting by persons from health professional (ED doctors and nurses, neurologists, nurse specialists and GPs), commissioning and managerial roles. We aim to have 40-50 persons at each event. Persons will be recruited mainly from the institutions contacted as part of the service provider survey. Additional attendees will come from commissioning groups and the two main epilepsy patient groups in England (*Epilepsy Action*, British Epilepsy Association; *Epilepsy Society,* National Society for Epilepsy). The 15 patient and carer representatives from the project's Patient and Public Involvement group will also be invited to attend.

## 6. PATIENT AND PUBLIC INVOLVEMENT (PPI)

This project will permit the "voice" of PWE and carers to be factored into service design. This proposal has been developed in partnership with Epilepsy Action and in close conjunction with service users. Patients and carers have been key in the project's inception and will be active partners in its completion.

Specifically, our team was aware of moves towards the development and ultimate introduction of ACPs for epilepsy and that the views of PWE were not being considered. Epilepsy Action were also aware and concerned. In March 2017 we therefore held a PPI event with the help of Epilepsy Action and the 'Brain & Spine Foundation'. It allowed us to share our impressions regarding ACP development with patients and carers and hear their views. Ultimately, 23 PWE and carers participated in the process. Ten of the PWE had had seizures in the previous year, with 8 having visited an ED. The event provided a number of insights.

Firstly, service users confirmed findings from other studies that fear often motivates many people to seek emergency help. One patient, for example, who now has controlled seizures following surgery, said:

> *"Something like an ACP could be good. The NHS would save money and there would be less crowding in A&E. Before my surgery I used to go to A&E quite often. Looking back now I think that what I really wanted when I felt a seizure coming on and called 999 was just reassurance that I wasn't dying... I had no one around me who could do this..the only people I trusted were health professionals."* (PWE, Male 51)

Secondly, users said they were disappointed by the current trajectory with regards ACP development. Illustrative quotes are as follows:

> *"I'm annoyed. Epilepsy ain't my fault. It has stripped me of so much. Now the NHS is waking up to epilepsy, but we don't have a say."* (PWE, Female 33)

Service users did though recognise the potential of ACPs, if designed correctly. One for example said:

> *"I'm lucky. I saw a neurologist after years of 999 & A&E. But it was only cos' my friend phoned his office until they got sick of us. This shouldn't be how it is."* (PWE, Female 42)

At the PPI event, service users were presented with an outline of the current project. Using a structured questionnaire, service users were then asked a series of questions. The first was how important they felt it was on Likert scale from 1-10 (1="Not important at all", 10= "Extremely important"). The average rating given was 9.

Users were also asked for their thoughts on the project's potential design and we have factored their comments in. Services users were, for instance, keen that PWE be able to complete the DCE in various ways. Service users felt many from the target population might not have internet access due to lower income, but may be reluctant to travel due to not being allowed to drive and fears regarding their seizures.

Two carers said that they particularly valued that carers of PWE with intellectual disabilities were not automatically excluded from taking part which they said is often the case in other research projects.

If funded, not only will the voice of service users be accessed via the qualitative interviews and the DCE, but service users will also be members of the research team. They will be involved in two main ways. Firstly, with the help of Epilepsy Action, a PPI group will be established. It will work with the research team to design the recruitment materials, the DCE and attend the WP3 workshops. Members will feedback on recruitment materials, the interpretation of the findings from the qualitative interviews, be 'pilotees' for the DCE and take part in the workshops. Secondly, the study's steering committee will include 2 user representatives.

We shall also encourage users to advise on study findings and help with dissemination. This is something we have done for other projects. This includes users presenting project findings with us as part of our teaching to university students (medical and allied health) and at workshops for health professionals.

User representatives will be supported in their roles by Epilepsy Action. They have an active patient-participation scheme.[160,161] and will run 2 training days for representatives and host 'Q&A sessions' in advance of meetings. Representatives will be reimbursed for travel and time according 'INVOLVE' guidance. Via the North-West CLAHRC there is an established framework for high PPI involvement in research at the University of Liverpool.

## 7. DISSEMINATION

As a multi-disciplinary team of co-applicants and collaborators, we have an excellent track record of publishing high-quality research in peer-reviewed journals, in disseminating research findings to the wider NHS for implementation and for use by the academic community in further research studies. All applicants and user representatives shall contribute, and the media departments of involved institutions shall help ensure optimum coverage and delivery where appropriate.

The project will identify what, if any, ACP configuration/s is most likely to be acceptable to PWE and their informal carers and has the backing of those expected to deliver and support it. The project and its findings will be of significant interest to a range of stakeholders. A pro-active dissemination and knowledge mobilisation strategy will ensure that those who are considering developing, implementing, funding or supporting an epilepsy ACP are aware of the project from the outset, its progress and its findings.

Our dissemination plan will also seek to ensure that model of service design which we propose to use is brought to the attention of the wider field since it could provide a template for NHS service design generally. As the NHS seeks to deliver health care with better outcomes and lower cost, changes to NHS practice are inevitable.[1,2] To increase likelihood success, an efficient, transparent and scientifically defensible method is required to allow change to be informed, in a non-tokenistic way, by the voices of service users and other stakeholders. The approach we shall be using could be that method. It could be used to answer other questions relating to how teams deliver care in clinical microsystems (e.g., What features would ‘Community Respiratory Teams’ for Chronic obstructive pulmonary disease, or Crisis Resolution Teams for mental health need have to mean people experiencing exacerbations of these conditions access them rather than ED?), as well as larger-scale service reconfigurations (e.g., What reduction in travel time, wait or change in opening hours would patients need to see in order to find the replacement of A&Es with several minor injury units acceptable? Or, find seeing a clinical pharmacist or a physician associate, rather than their GP acceptable?).

Our dissemination plan will consist of the following elements:

i. 44 NHS Sustainability and Transformation Partnership (STP) regions have been formed to develop plans to show how they will achieve financial balance. The Secretary of State said [162] it was via reducing emergency hospital use that they will do this. To ensure those in positions of influence in ACP development/ funding are aware of this project, notification of its funding and progress will be sent to leads of STPs, the 8 Urgent and Emergency Care Vanguards and the National Clinical Director for Urgent Care for NHS England;

ii. As the project progresses, accessible briefings for funders, stakeholders, service user groups, policy makers, NHS audiences and research bodies will be produced. Recipients will include the King’s Fund, Nuffield Trust, NHS Confederation’s Urgent and Emergency Care Forum, NHS Improvement, National Institute for Health and Care Excellence (who identified how to support PWE attending ED as an area in need of research [163]), and the 'All-Party Parliamentary Group on Epilepsy’;

iii. Minimum of 4 papers in peer-reviewed journals across a range of disciplines which would appeal to clinical, organisational, sociological, general health and social policy audiences.

iv. Findings will be circulated via NHS network newsletters, in practitioner journals and the general press;

v. Oral and poster presentations at neurology and acute/ emergency care conferences and fora (International League Against Epilepsy and 999 EMS Research Forum);

vi. A summary of the projects findings will be distributed to participants in the different work packages.

vii. Updates on websites including Epilepsy Action, North-West Ambulance Service and the universities;

viii. Finally, we will look to use podcasts and other media to disseminate findings to service users.

## 8. PROJECT TIMETABLE AND MILESTONES

Our project is a 28-month study starting in ~February 2019. Table 2 illustrates the project’s milestones. The project’s length is realistic and informed by the lower bounds of participant uptake.

In the pre-funding stage, we will establish the study specific PPI group, compose the study steering committee and obtain the necessary ethical and research governance approvals.

**Table 2** Project milestones

| TASK | PROJECT TIMETABLE | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | YR 1 | | | | YR 2 | | | | YR 3 | |
| | Quarter | | | | Quarter | | | | Quarter | |
| | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 |

| | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Study set-up**<br>(e.g., finalise service survey, staff training). | ▨ | ▨ | | | | | | | | | | | | | | | | | | | | | | | | | | |
| **WP1 : Qualitative phase**<br>Recruit and interview ~n=30 PWE (with or without carers) and analyse data | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | | | | | | | | | | | | | | | | |
| **WP1: Survey of services**<br>Recruit and survey EDs, neurology and ambulance services and analyse data | | | | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | | | | | | | | | | | | | | | | | |
| **WP1 : Knowledge Exchange**<br>1 workshop event | | | | | | | | | ▨ | | | | | | | | | | | | | | | | | | | |
| **WP2 : DCE design**<br>Develop, pilot and finalise DCE | | | | | | | | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | | | | | | | | | | | | | | | |
| **WP2: Invitations sent out via GPs for DCE**<br>Site-set-up, then 9 monthly blocks of around 6 primary care practices sending out invites at a time. | | | | | | | | | | | | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | | | | | | | |
| **WP2: DCE completed**<br>N=348 PWE/ carers; ~50% via face to face home visits across NW England; ~50% online. | | | | | | | | | | | | | | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | | | | | | |
| **WP2: DCE analysis**<br>Headline analysis for WP3 and then separate outputs prepared | | | | | | | | | | | | | | | | | | | | | | | ▨ | ▨ | ▨ | | | |
| **WP3: Knowledge Exchange**<br>2 workshop events (1 in S.E. England; 1 in N.W.) | | | | | | | | | | | | | | | | | | | | | | | | ▨ | ▨ | ▨ | | |
| **Full report & Dissemination** | | | | | | | | | | | | | | | | | | | | | | | | | | | ▨ | ▨ |

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## **Appendix A** Glossary of abbreviations

| | |
|---|---|
| **A&E** | Accident & Emergency department |
| **ACP** | Alternative care pathway |
| **APEASE** | Affordability, Practicability, Effectiveness, Acceptability, Side-effects, Equity |
| **CT** | Computed tomography |
| **DCE** | Discrete Choice Experiment |
| **ED** | Emergency department |
| **FOI** | Freedom of information |
| **GP** | General practitioner |
| **GPwSI** | General practitioner with a Special Interest |
| **ISLAGIATT** | ‘it seemed like a good idea at the time’ principle |
| **NASH** | National Audits of Seizure Management in Hospitals |
| **NHS** | National Health Service |
| **NIHR** | National Institute for Health Research |
| **NW CRN** | Clinical Research Network North West Coast |
| **PWE** | People with epilepsy |
| **QOF** | Quality and Outcomes Framework |
| **SANAD** | Standard and New Antiepileptic Drugs |
| **SMILE** | Self-Management education for adults with Epilepsy |
| **STP** | Sustainability and Transformation Partnerships |
| **UK** | United Kingdom |
| **WP** | Work package |