

Developing feasible person-centred care alternatives to emergency department responses for adults with epilepsy: a discrete choice analysis mixed-methods study

Adam J Noble,^{1*} Pete Dixon,¹ Amy Mathieson,^{1,2}
Leone Ridsdale,³ Myfanwy Morgan,⁴ Alison McKinlay,^{4,5}
Jon Dickson,⁶ Steve Goodacre,⁷ Mike Jackson,⁸
Beth Morris,¹ Dyfrig Hughes,⁹ Anthony Marson¹⁰
and Emily Holmes⁹

¹Department of Public Health, Policy and Systems, University of Liverpool, Liverpool, UK

²Centre for Primary Care and Health Services Research, University of Manchester, Manchester, UK

³Department of Basic and Clinical Neuroscience, King's College London, London, UK

⁴Institute of Pharmaceutical Science, King's College London, London, UK

⁵Research Department of Behavioural Science and Health, University College London, London, UK

⁶Academic Unit of Primary Medical Care, University of Sheffield, Sheffield, UK

⁷School of Health and Related Research, University of Sheffield, Sheffield, UK

⁸North West Ambulance Service NHS Trust, Bolton, UK

⁹Centre for Health Economics and Medicines Evaluation, Bangor University, Bangor, UK

¹⁰Department of Pharmacology and Therapeutics, University of Liverpool, Liverpool, UK

*Corresponding author adam.noble@liv.ac.uk

Published August 2024

DOI: 10.3310/HKQW4129

Scientific summary

Developing feasible person-centred care alternatives to emergency department responses for adults with epilepsy: a discrete choice analysis mixed-methods study

Health and Social Care Delivery Research 2024; Vol. 12: No. 24

DOI: 10.3310/HKQW4129

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Emergency department (ED) visits for epilepsy are common, costly, often clinically unnecessary and typically lead to little benefit for epilepsy management. An alternative care pathway (CP), which diverts people with epilepsy (PWE) away from ED when '999' is called and leads to care elsewhere, could potentially generate savings and instigate improvements in the person's ambulatory care. This project sought to identify the optimal configuration, ensuring the CP is both acceptable to service users and NHS-feasible.

A key method used was discrete choice experiments (DCEs). They involved users being presented with hypothetical seizure scenarios and making a number of choices to say which CP configuration, described according to a fixed set of characteristics (attributes), they would prefer.

The project's aims were as follows.

Aims and objectives

Work Package 1

- Systematically identify alternative CPs being considered by NHS services and describe extent to which service users have been involved in their design.
- Understand decision-making processes of PWE and their significant others (SOs) for seeking ED care and their concerns and expectations regarding alternative CPs.
- Identify attributes of postseizure care that PWE and their SOs (close family and friends) consider important.

Work Package 2

- Determine users' and SOs' preferences for postseizure care using DCEs and identify subgroup differences.
- Estimate utility of different CP configurations to service users and subgroup differences.

Work Package 3

- Hold expert workshops at which stakeholders, informed of the DCE evidence, would identify the optimal alternative CP/s for seizures that could be recommended for implementation and evaluation.

Methods

Work Package 1

Work Package 1a. Survey of service providers

England's ambulance services, epilepsy services and a random sample of its EDs were surveyed (April–June 2019). They were asked what alternative CPs they were considering and the extent to which they had consulted users.

Work Package 1b. Interviews with service users

Semistructured interviews were conducted in Southeast England with a purposive sample of PWE (April–September 2019). They also completed a ranking exercise to identify the characteristics (attributes) of postseizure care they considered most important.

Participants were recruited from third-sector user groups and via a research newsletter. To be eligible, the person needed to be (1) aged ≥ 18 , (2) have been diagnosed with epilepsy for ≥ 1 year, (3) had contacted the emergency services in the previous 12 months and (4) be able to provide informed consent and complete an interview in English. People with epilepsy were invited to be interviewed along with a SO.

Work Package 1c. Knowledge exchange event

Work Package (WP) 1b and 1c findings were used to select a set of candidate attributes that could be used to describe CPs within the DCE. To ensure attributes were features of alternative CPs and the levels likely NHS-feasible, a 1-day 'knowledge exchange' event was run (October 2019). Participants were representatives from ambulance and epilepsy services. They were identified for participation via WP1a.

Work Package 2**Work Package 2a. Discrete choice experiment design panel and pilot**

A DCE design panel used evidence from WPs 1a–c to generate the DCE survey, using a D-efficient experimental design (Ngene 1.2.1, ChoiceMetrics, Sydney, Australia). The survey's purpose was to obtain data of users' care preferences for three separate scenarios, namely, a 'typical seizure at home', a 'typical seizure in public' and an 'atypical seizure'. It, and vignettes describing the different seizure scenarios, was iteratively refined and finalised based on piloting.

Work Package 2b. Formal discrete choice experiment

A sample of $n = 348$ adults with epilepsy (and their SOs) from the target population was sought to complete the DCE. They filled in the DCE via an online platform.

Participants were recruited via two routes between July and November 2020: (1) from the Merseyside area via the North West Ambulance Service and (2) nationally via public advert.

PWE needed to (1) be aged ≥ 18 years, have a diagnosis of epilepsy, (2) have been seen by the ambulance service in prior 12 months and (3) be able to provide informed consent and independently complete the survey in English. Significant others needed to be aged ≥ 16 .

Data were analysed using a random-effects logit model. Preference weights were estimated for each attribute. Data from PWE and SOs were analysed separately, thus creating six seizure contexts for which preferences were modelled (three seizure scenarios \times two participant types).

Work Package 3

To identify which CP configuration(s) represented the optimal balance between user preference and NHS feasibility, three online 'knowledge exchange' workshops were run.

Attendees were representatives from the ambulance service, from epilepsy services and commissioning. Service user representatives were also present. Commissioning and managerial representation was secured via national professional bodies.

The DCE findings from WP2 were disseminated, and attendees were introduced to Michie *et al.*'s affordability, practicability, effectiveness, acceptability, side-effects and equity (APEASE) feasibility criteria. Nominal group techniques were then utilised, with stakeholders sharing views on the extent to

which they considered the attribute levels favoured by users to be NHS-feasible. The groups then specified the levels for each attribute they believed represented the optimal balance.

Results

Work Package 1

Work Package 1a. Survey of service providers

Clinical leads and managers from 72 (82.8%) of the invited services responded. Sixty per cent were considering or using an alternative CP change; only 21.2% had consulted service users on it.

A range of CP configurations were reported. Some involved caring for PWE at home, 'on scene' or in some instances conveying them to an urgent treatment centre. The potential of configurations to improve ambulatory care varied.

Work Package 1b. Semistructured interviews with service users

Thirty service users (25 PWE and 5 SOs) were interviewed. The average age of PWE was 37 years; mean years was diagnosed 21.

Participants provided insights into the challenges service users experience and disruptions they experience due to inadequate information transfer and co-ordination between ambulatory and urgent and emergency care services. Interviews highlighted some initial concerns users had with some possible CP configurations.

The ranking exercise provided an approximation of the factors contributing to the 'decision calculus' users use when considering postseizure care options. Six attributes appeared most important: (1) whether the ambulance crew would have access to their medical records or care plan, (2) where the CP would take them, (3) how long it would take for them to be assessed, monitored and treated during the emergency episode, (4) extent to which the emergency care provider could request advice from an epilepsy specialist (e.g. epilepsy nurse, neurologist), (5) whether the CP would mean their usual care provider/s would be informed of the incident and, finally, (6) whether any follow-up from the epilepsy specialist would be instigated.

Work Package 1c. Knowledge exchange event

Thirteen representatives attended the workshop ($n = 6$ paramedics, $n = 4$ neurologists, $n = 2$ epilepsy nurse specialists and $n = 1$ user group representative).

Participants agreed the six attributes identified by WP1b were all characteristics of an alternative CP, plausible and could be 'traded'. Much of the event focused on identifying attribute levels that were considered feasible.

Work Package 2

Work Package 2a. Discrete choice experiment design panel and pilot

The panel decided that the six attributes identified in the formative work should be used to describe the CP options within the DCEs. Accordingly, DCEs for the three seizure scenarios were developed with the intention that participants would be randomised to each complete DCEs for two of three seizure scenarios, achieving a 1 : 1 : 1 allocation ratio.

The six attributes and their associated levels (between 2 and 4) had the potential to generate 288 possible CP configurations. Use of an efficient experimental design meant that for each of the seizure scenarios a person would consider 24 CPs that were paired into 12 binary choices.

The presentation of the DCE was finalised following pilot interviews. The final labels used for the attributes were as follows: (1) 'The paramedic has access to medical records or a care plan'; (2) 'What happens next'; (3) 'Time'; (4) 'Epilepsy specialists today'; (5) 'GP told'; (6) 'Additional contact with an epilepsy specialist'.

Work Package 2b. Formal discrete choice experiment

Useable submissions to the DCE survey were secured from $n = 594$ participants ($n = 427$ PWE; $n = 167$ SOs). Most (81.1%) were recruited via the public advertisement route.

When participants from the two recruitment routes were merged to form a single sample, it was broadly representative of the target population. Two exceptions were its younger age and higher proportion reporting recent contact with an epilepsy specialist.

The main ways that the SO participants knew someone with epilepsy was that they were the patient's parents. The characteristics of the PWE known by SOs differed from those of the PWE taking part themselves (e.g. more learning disability).

Across the three seizure scenarios, both PWE and SOs preferred CP configurations that differed from the way care is currently provided. Using coefficients from the random-effects logit models, the expected utility to service users for all possible CP configurations was calculated for the six seizure contexts. Care pathways were then ranked: rank 1 = most preferred; 288 = least preferred. The highest rank that the CP configuration approximating current care achieved was 220/288.

There was similarity across the seizure contexts in terms of which attribute levels featured in the top-ranked configurations. In fact, three of the six contexts shared the same top-ranked configuration.

For all six contexts, the highest-ranked CP configurations included (1) the paramedic having access to medical records or a care plan, (2) an epilepsy specialist (e.g. epilepsy nurse, neurologist) being available to advise the attending paramedic, (3) the patient's GP being notified of the incident and (4) an appointment with an epilepsy specialist within 2–3 weeks being booked for the patient.

The only attributes that varied within the top-ranked configurations were 'What happens next' and 'Time'. For five of them, the top configuration involved the patient staying 'where they were'. For the remaining ones – namely, for an 'atypical seizure' when considered by a SO – it involved the patient being conveyed to an urgent treatment centre.

Different attributes had different levels of effect on preference. Providing crews with access to the medical records or care plan of the patient being attended to and having a specialist able to advise the paramedics had the strongest and consistent positive effect.

Not all intended subgroup analyses could be completed due to insufficient cases. Those which could, showed social deprivation, recruitment route, presence of an intellectual impairment, contact with an epilepsy specialist in the prior 12 months, familiarity with the seizure scenario and whether the person with epilepsy had a care plan were not significantly related to preference.

Work Package 3

Twenty-seven stakeholders attended a workshop. They included 10 ambulance clinicians, 8 epilepsy specialists, 5 commissioners and 4 patient and public involvement (PPI) representatives.

Stakeholders believed the attribute levels preferred by service users were broadly feasible in the next 5–10 years. They identified those where most investment/work was required for them to be deliverable.

Stakeholders were of the view that there was sufficient commonality in users' preferences across the six seizure contexts for a single CP to be deployed.

The groups were of the same position as to which configurations represented the optimum. They comprised of the following: (1) ambulance clinicians having access to medical records, (2) the person typically staying where they were, (3) the time taken being < 6 hours (be it 1, 2 or 3 hours), (4) crews being able to be advised by a specialist (an epilepsy nurse or neurologist) on the day, (5) for the person's GP to be notified and, finally, for the incident to result in an appointment being made for the patient to have a follow-up appointment with an epilepsy specialist (be it within 1 week or 2–3 weeks).

When attribute levels were restricted to these, the number of CP configurations for consideration reduced from 288 to 18. Evidence from WP2b showed these 18 included the configurations most preferred by service users for each scenario. Moreover, the evidence indicated that all 18 would be expected to hold more utility to users than the configuration representing current care.

Conclusions

By working collaboratively with service users from the target population, clinicians and commissioners, this project has provided clear answers to a pressing service delivery question. It provides evidence indicating that for common seizure scenarios, users appear open to paramedics not conveying them to ED and how poorly current care aligns with their preferences. Our project has also shown what postseizure care service users appear to want and that limited differences exist for different seizure scenarios. This appears to support the deployment of a single CP configuration. The study also provided evidence on the estimated improvement in utility that would result from individual attribute changes. This could be used to prioritise CP changes.

Importantly, service providers and commissioners were found to be of the view that the CP configuration favoured by users could be NHS-feasible within 5–10 years, and they identified which attribute levels require the most work.

It is important to now take the evidence this project has captured on people's stated preferences and views and seek to implement one of the possible 18 CP configurations and evaluate it to determine its actual feasibility and efficacy in practice.

Implications for NHS service commissioning, policy and practice

- The project identified a refined set of CP configurations that are considered optimal and the most promising candidates for formal evaluation.
- Pressures on acute services have intensified since our project was completed. This may incentivise ambulance services to use our findings and implement some form of alternative CP before an evaluation has occurred.
- Not all ambulance services would have the infrastructure and/or relationships with partner organisations to immediately implement the entire CP configuration considered optimal. Commissioners, policy-makers and service providers could support the development of the systems – such as shared record initiatives – to permit it to be offered.
- Identifying eligible people for the DCE survey via the NHS ambulance service was time-consuming compared to using public adverts. This could be made for efficient by embedding processes within NHS records systems to temporarily 'strip' them, including free-text fields, of confidential data. This would enable trained individuals not involved in a person's care to screen anonymised records.

Recommendations for research

- Using the attribute levels specified by stakeholders as representing the optimum, one of the possible 18 CP configurations should be evaluated for its efficacy.
- Any evaluation should consider short- (e.g. rates of recontact, death) and long-term outcomes (e.g. proportion of PWE 'unknown' to specialists brought to their attention).
- A cluster-randomised controlled trial would likely provide the most rigorous evidence. However, an alternative, faster evaluation approach may be needed to ensure evidence is generated in an acceptable time frame.
- Other ways to reduce unnecessary ED attendance warrant research attention. One is how to address ambulance crews' requests for support in identifying persons suitable for non-conveyance. Attention is also needed on users' seizure first aid confidence and knowledge.

Study registration

This study is registered as [researchregistry4723](https://www.researchregistry.com/record/researchregistry4723).

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: 17/05/62) and is published in full in *Health and Social Care Delivery Research*; Vol. 12, No. 24. See the NIHR Funding and Awards website for further award information.

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the [NIHR Journals Library website](#)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA), NCBI Bookshelf, Scopus and MEDLINE.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

Criteria for inclusion in the *Health and Social Care Delivery Research* journal

Manuscripts are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at <https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm>

This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number 17/05/62. The contractual start date was in February 2019. The draft manuscript began editorial review in March 2022 and was accepted for publication in May 2023. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

This article presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

This article was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Copyright © 2024 Noble *et al.* This work was produced by Noble *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaptation in any medium and for any purpose provided that it is properly attributed. See: <https://creativecommons.org/licenses/by/4.0/>. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).

