

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

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Plain language summary

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Ambulances often attend to people with epilepsy. Most of them are taken to the hospital's accident and emergency department. This typically has little benefit since most patients are already diagnosed and visit the accident and emergency department with non-emergency states.

To change things, National Health Service organisations want an 'alternative care pathway' for paramedics to use. It could mean the person is not taken to the accident and emergency department but cared for elsewhere. Our project brought stakeholders together to develop an alternative care pathway that includes things important to patients and carers but is also National Health Service-feasible.

Seventy National Health Service organisations first told us via a survey and a workshop which pathways they were considering and which might be feasible.

Thirty people with epilepsy and their family members and friends were then interviewed. They explained what is wanted after a seizure and problems with current care. One problem was that going to the accident and emergency department does not lead to them getting a follow-up appointment with an epilepsy specialist to check their treatment is right.

Using 'discrete choice experiments', around 430 people with epilepsy who recently contacted the ambulance service and 170 of their family and friends were asked to make a choice between alternative packages of care, to say which pathway they would prefer in different seizure situations.

The results were clear. People wanted care different from what National Health Service organisations told us was available. The choice experiment showed everyone prefers pathways where paramedics have access to their medical records, an epilepsy specialist is available to advise the paramedic, the general practitioner gets a report and they get an appointment with an epilepsy specialist in the future. Everyone wants to avoid long episodes of care (6 hours) and after a typical seizure people with epilepsy want to stay at home.

Three workshops were run with paramedics, epilepsy specialists and managers. They said the alternative care pathway wanted by users could be National Health Service-feasible. There is a need to implement and evaluate it now.

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