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Short communication

Clinically unnecessary and avoidable emergency health service use for epilepsy: A survey of what English services are doing to reduce it

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ABSTRACT

Purpose: Epilepsy is associated with costly unplanned health service use. The UK's National Audits of Seizure Management in Hospital found use was often clinically unnecessary, avoidable and typically led to little benefit for epilepsy management. We systematically identified how services have responded to reduce such use.
Methods: We invited England's ambulance services, neuroscience and neurology centres and a random sample of Emergency Departments (EDs) to complete a survey. It asked what innovations they (or services they worked with) had made in the past 5 years or were making, the priority afforded to them, user involvement, what comprised usual practice, and barriers to change.
Results: 72/87 of invited (82.8 %) services responded. EDs ascribed less priority to reducing emergency hospital use for epilepsy and convulsions, than other service types. Overall, 60 % of services reported a change(s) and/or were planning one. Neurology/neuroscience sites (93.8 %) were most likely to report change; EDs (15.4 %) least likely. Eleven types of change were identified; 5 sought to promote proactive epilepsy care and avert the need for emergency care; 3 focused on the care received from emergency services; and 3 focused on follow-up care ED attendees received. Most were for those with established, rather than new epilepsy and targeted known limitations to current care provision.
Conclusion: Reducing emergency hospital use by PWE is a high priority for most health services in England and a number of new services have been developed. However, they have not been consistently implemented and innovation is lacking in some areas of care.

1. Introduction

Of chronic ambulatory care sensitive conditions (ASC), epilepsy is the UK's second most common reason for unplanned hospital use; 20 % of people with epilepsy (PWE) attend a hospital emergency department (ED) each year; half are admitted [1]. This use is important as whilst expensive, much is clinically unnecessary.

The 2011 and 2013 National Audits of Seizure Management in Hospitals (NASH) [2] indicated most attendees did not require the full facilities of ED; ~61 % had known, rather than new epilepsy, and most had experienced uncomplicated seizures. Others (e.g.,(3)) report similar findings.

Some visits by PWE were also associated with suboptimal ambulatory care, with indications that some patients were on outdated treatment regimens. Attending ED did not though typically instigate care improvements; most (80 %) were not seen by a specialist at the time, and 60 % were not referred to one. Unsurprisingly, ~60 % of PWE therefore re-attend within 12 months [4]. In the UK, once diagnosed and prescribed treatment by a specialist, adults with epilepsy tend to be referred back to their general practitioner. They are though, meant to be referred back to specialist services as need arises (e.g., inadequate seizure control) [5].

In view of NASH's findings, calls for health organisations to innovate to improve care quality arose. However, it is unknown whether they have translated into action and what the nature of any change was. This information is needed to interpret any care improvements that may

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Table 1
Survey questions.

Purpose		Questions	Answer
Priority		How much of a priority would you say reducing unplanned hospitalisation for chronic ambulatory care sensitive conditions is for your service? [a]	1 = Not a priority, 2 = Low priority, 3 = Moderate priority, 4 = High priority, 5 = Very high priority
		Order these conditions in terms of how much priority the urgent and emergency care system should be giving each of them, so as to reduce associated emergency admissions [b]	(Position 1 = most important; position 8 = least important) ● Iron deficiency anaemia ● Congestive heart failure ● Convulsions and epilepsy ● Asthma ● Diabetes complications ● Chronic obstructive pulmonary disease ● Hypertension ● Angina
Changes	***Past***	Has your service (or any local service you may work with) made changes (within the last 5 years) to how people with suspected seizures/epilepsy are cared for that could reduce clinically unnecessary and/or avoidable unplanned health service use? [c]	Yes/ No/ Don't know If Yes… ● Provide details: (Free-text response; can append any relevant documentation, such as treatment protocols, to support answers). ● Describe how it was anticipated the change(s) might reduce clinically unnecessary and/or avoidable unplanned health service use?
	Future	Is your service (or any local service you may work with) considering or planning to implement any changes (within the next 12 months) to how people with suspected seizures/epilepsy are cared for?	Yes/ No/ Don't know If Yes… ● Provide details (Free-text response): ● Describe how it is anticipated that the change(s) might reduce clinically unnecessary and/or avoidable unplanned health service use? (Free-text response)
	Service user involvement[d]	Were service users involved in any way in informing this service change? By "service users" we mean representatives from the target population, e.g. patients, carers, persons from relevant user groups	Yes/ No/ Don't know If Yes, how: ● Survey? ● Focus group? ● Attending service redesign workshops? ● Discussions with local support group members? ● Other, please specify
Barriers [e]		If your service has not recently made, nor is planning to make, any service changes to reduce clinically unnecessary and/or avoidable visits for suspected seizures/epilepsy, why might this be?	Free-text response.
Usual practice questions[f]		What some services have recently introduced to reduce clinically unnecessary and/or avoidable visits for suspected seizures/epilepsy might already be part of usual practice in your service. Please indicate whether any of these are usual practice within your service or local area.	● Introduced a pathway or protocol that means patients with established epilepsy who present with an uncomplicated seizure are always redirected away from ED (e.g. to an Urgent Treatment Centre, taken home, left at scene) ● Specialist epilepsy services are automatically informed of patients accessing urgent and emergency care services for suspected seizures, including 'first seizures'. ● Medical records (potentially including 'care plans') for people with epilepsy have been made accessible to ambulance service staff on-scene, to help them interpret normality of presentation and care needs.

Notes:[a] The following definition was provided: “Chronic ambulatory care sensitive conditions are defined as conditions for which effective management and outpatient or community care treatment could prevent admission to hospital”; [b] These are the 8 most common chronic ACSs see Bardsley M, Blunt I, Davies S, et al. BMJ Open 2013;e002007. In descending order they were associated with the following number of unplanned admissions in the year 2010/11: Chronic obstructive pulmonary disease 1,117,248, Convulsions and epilepsy 77,165, Asthma 61,151, Angina 61,125, Congestive heart failure 54,728, Diabetes complications 53,693, Iron deficiency anaemia 11,425, Hypertension 6320; [c] The period of 5 years was considered suitable as NASH I was conducted in March-July 2011, NASH II in June-September 2013 and sites received reports on their sites performance in December 2011 and January 2014 respectively. The overall findings appeared within the peer-reviewed literature in 2015; [d] "Service users" were defined as representatives from the target population, e.g. patients, carers, persons from relevant user groups; [e]Findings relating to barriers to change are presented in Supplementary File 3; [f] Question asked of services not reporting any recent or planned changes. Options presented based on the team’s knowledge.

or may not be identified by subsequent NASH rounds and to ensure innovations are shared. The findings will be of interest to those in the UK, as well as other European countries given EuroNASH is now occurring [6].

We completed a cross-sectional survey to systematically determine what changes services made.

2. Materials and methods

2.1. Design

A piloted online survey ran from 1st April to 30th June 2019 (Table 1).

Respondents rated the priority their service assigned to reducing unplanned hospitalizations for chronic ACSs and ranked different ACSs for the priority each should be given. They reported changes their organization (or local services they worked with) had made and/or were planning to make to how PWE are cared for to reduce clinically unnecessary and/or avoidable unplanned health service use. They were asked for anticipated benefits and how service users were involved in informing the change/s.

Services not reporting or planning changes were asked why and shown three known care innovations, and asked if they comprised usual practice within their organization.

Ethical approval was not required for this service evaluation [7].

2.2. Recruitment

We sent invitations to clinical leads/directors of England’s ambulance trusts (n = 11), regional neuroscience (n = 25) and neurology centres (n = 16), and a random sample of 25 % (n = 35) of its ‘Type 1’ EDs (stratified by area and size). Type 1 EDs are those which offer a consultant-led 24 h service with full resuscitation facilities and designated accommodation for the reception of accident and emergency patients.

2.3. Analysis

The first 50 % of responses were imported into QSR International's NVivo 10. A qualitative researcher (AM) identified recurrent service change types and, with wider team support, collated them into a thematic coding framework. This was applied to the full dataset and modified to ensure all types were captured.

3. Results

3.1. Sample

Seventy-two (82.8 %) services responded – 36 (85.7 %) neurology and neuroscience centres, 26 (74.3 %) EDs, and 10 (90.9 %) ambulance services. Responding services' characteristics were similar to those of non-participating sites (SF.1). Responding individuals were doctors (72.2 %), paramedics (13.9 %) and nurses (13.9 %). Analyses relating to service changes are based on responses from 68 (94.4 %) services without missing data.

3.2. Priority

The pooled response indicated reducing unplanned hospitalizations associated with chronic ACSs was a "high priority" (median 4; interquartile range [IQR] 3–5). In ranking the 8 ACSs, 'epilepsy and convulsions' was given a pooled median rank of 3 (IQR = 2–4). Neurology/neuroscience centres gave it a median rank of 2 [1–3], ambulances services 3.5 (2.75–5) and EDs 4 (IQR = 3–5).

3.3. Service changes

Forty-one (60.3 %) services said they or service(s) they worked with had made and/or were planning a service change(s) (SF. 2). Thirty-four (50.0 %) reported a change(s) had occurred. Neurology/neuroscience sites (n = 30, 93.8 %) were most likely to report changes, EDs (n = 4, 15.4 %) least likely.

3.4. Types of change

Eleven change types were identified. Table 2 describes them. Most addressed the care of those with established, rather than new epilepsy. They fell into three categories according to the part of the patient's care journey they focused:

3.4.1. Before emergency help is sought

Seventeen (25 %) services reported such changes. These related to care planning; attempting to prevent a person's condition from requiring emergency help. The most widely made change was the introduction of Rapid Access clinics, providing specialist epilepsy support to patients between routine appointments as needs arose. Less common changes included implementing education for PWE on seizure first aid, and – to enable more proactive and risk-stratified care – access by specialist services between appointments to data on a person's seizure control and medication.

3.4.2. When person is being cared for by emergency services

Nineteen (27.9 %) services reported these changes. The most common was the introduction or expansion of an acute neurology service, whereby an epilepsy nurse specialist (ENS) or neurologist was available to review ED attendees, either face-to-face or virtually. The aim being to facilitate discharge and identify support needs. Another change was the introduction by ambulance services of protocols to support non-conveyance to ED and alternative care arrangements for PWE with uncomplicated seizure presentations. Some included these persons having a telephone review by an epilepsy service within 1–5 days.

3.4.3. Follow-up care

Twenty three (33.8 %) services reported these changes, with most expanding neurology services for those with established epilepsy. These sought to reduce waiting times for ED referrals (aim 1–4 weeks). Some services offered telephonic clinics, others face-to-face appointments but within primary care locations to increase accessibility. To further minimise referral times, one neurology service allowed EDs to directly book patients into their service's appointment slots, whilst two other services had implemented processes to automatically notify them of seizure-related ED attendances.

3.5. Usual practice

Nine (33.3 %) of the 27 services that had not made and did not plan any changes, reported usual practice comprised at least one of the three presented service innovations (Table 2). Five (18.5 %) said epilepsy services were automatically informed of patients attending ED, three (11.1 %) used protocols to divert people presenting with an uncomplicated seizure away from ED, and 2 (7.4 %) reported medical records for PWE were accessible to ambulance staff.

3.6. Service user involvement

Of the 34 services that had implemented a change, only 7 (21.2 %) had consulted service users.

4. Discussion

Our survey shows to what extent calls for change to the care of people presenting with seizures have been heard and acted on. Neurological and ambulance services appear to be making efforts to bring about change; ~90 % of neurological services and 70 % of ambulance services reported a made and/ or planned change.

EDs, in contrast, appear less engaged – only 15 % reported a change. The number did improve when EDs' descriptions of usual practice were considered. Most though continued to not report innovative practice in relation to convulsions and epilepsy. This might be because a change by a service they work with had not been sufficiently communicated to them. It might also reflect a lower perceived priority. Of chronic ACSs, convulsions and epilepsy is the second leading cause of unplanned hospital use. EDs though placed it fourth in terms of the priority it should receive.

With respect to the changes made by services, eleven types were reported. These varied in complexity and the part of the patient's care journey they targeted. Most focused on established epilepsy, corresponding with its burden on ED. The changes typically targeted known limitations to current service provision from which ED use might arise – including inequality in referrals from acute to specialist epilepsy services [8]; variable seizure first aid training provision [9]; limited information sharing between specialist, acute and primary care services [10]; and the challenge of a comparatively small specialist workforce being able to promptly learn of and respond to exacerbations in a patients conditions [1].

In describing the changes and their benefits, most respondents did not report that the service change had been evaluated. Thus, it remains to be seen whether they will deliver anticipated benefits. For some changes to have an effect, others might need to first occur. Access to medical records, for instance, might enable paramedics be able to confidently identify those suitable for non-conveyance to ED [10].

Despite being a statutory obligation, few services consulted service users on changes. It is unclear therefore whether they will be acceptable to the target population. For instance, available alternative care packages may not encapsulate the things PWE want [11].

Our survey received an excellent response rate. For services not reporting changes, we also captured the reasons (SF. 3). We asked respondents to report on changes their service or one they work with had

Table 2
Implemented and planned changes reported by the services.

Change focus	Type of service change	Description of change	Services reporting the change (n, %)			
			Ambulance N = 10	*ED N = 26*	*Neuro N = 32*	*Total N = 68*
Before emergency help is sought	1. Rapid Access clinics	To help manage changes in severity or presentation, including an ability to address concerns between any scheduled appointments with specialist (wait time aim: ~1-2 weeks). Mode of delivery included telephone hotline, email, and face-to-face appointments or combinations thereof. Personnel delivering them was typically ENS.	0	0	10 (31.3)	10 (14.7)
	2. Educating patients and carers	Introduction of programmes to educate patients and carers on seizure first aid to increase confidence and skills and ameliorate unnecessary emergency calls for uncomplicated seizures. In some instances, this included ensuring patients (or care home if patient within one) carried a seizure care plan to aid those helping them, including ambulance crews.	0	0	6 (18.8)	6 (8.8)
	3. Educating frontline staff	For paramedics it was on seizure types, alternatives to ED and red flags; to support decision-making and improve staff confidence. For ED staff, focus was on differentiating non-epileptic attack disorder and on criteria for referral to onward services.	0	1 (3.8)	4 (12.5)	5 (7.4)
	4. Collaborative working	Increased working between epilepsy specialists and other services caring for persons at an increased risk of seizures/epilepsy (e.g. neuro-oncology, stroke, learning disabilities) to proactively identify patients that may need support from or referral to the epilepsy service. Changes included more straightforward referrals pathways, promoting awareness of the specialist service and participation in multidisciplinary team meetings by epilepsy specialists.	0	0	4 (12.5)	4 (5.9)
	5. Sharing of seizure and medication data	Epilepsy services described efforts to access data on their patient's condition between scheduled appointments to identify need for review. Changes included provision of a portal where patients could upload seizure data themselves, the use of wearable seizure detection devices, and accessing data held within primary care medical records on patients' antiepileptic prescription and collection to identify issues with non-adherence and errors.	0	0	2 (6.3)	2 (2.9)
	*Individual services reporting at least one of these = 17 (*25.0 %*)*					
When being cared for by emergency services	6. Acute epilepsy service	ENS and/or consultant available to review attendees face-to-face or virtually during the emergency episode admissions. Eligibility criteria varied. For some services focus was on those with intractable epilepsy and/ or those with intellectual disabilities.	0	0	9 (28.1)	9 (13.2)
	7. Protocols to redirect away from ED	Use of protocols, with flow-charts to support decision making when managing seizures, with recommendation of non-conveyance to ED of persons with certain presentations. For those not conveyed to ED, protocols recommended leaving patients at home, 'on scene' or in some instances urgent treatment centres. A few protocols included mechanisms by which patients could be referred on to other services. In some instances this was in the form of ambulance crews having access to a directory of local services and their contact details. In one instance, an e-referral system allowed crews to electronically notify GPs of the attendance and its details. In two areas, patients could be referred to the epilepsy service, with an ENS contacting the patient within 1-5 days by telephone. Eligibility criteria differed. In one area, it was open to anyone with established epilepsy. In another, it was only for patients already under the epilepsy service and in certain geographical locations.	5 (50.0)	0	2 (6.3)	7 (10.3)
	8. Medical record accessible to front-line staff	Paramedic access to information on patients' medical history from their medical record. The extent of coverage, comprehensives and ease of access varied. In some instances, it was in the form of access to a generic 'Summary Care Record' which as a standard includes demographics, current medication and allergies. In other instances, access was to a seizure care plan, that described the patient's usual seizure presentation/s and next of kin to help the ambulance crew interpret the normality of the presentation and facilitate non-conveyance where appropriate. In some cases, paramedics had direct access to the information whilst on scene via internet enabled mobile devices. In other instances, they needed to communicate with colleagues at a 'clinic hub' who communicated the information to them over the phone. ED staff access to information on patients' medical history from their medical record. This came in the form of access to a seizure care plan, with the aim being that care decision could be expedited, and unnecessary investigations and admissions avoided.	3 (30.0)	0	2 (6.3)	5 (7.4)
	Individual services reporting at least one of these = 19 (27.9 %)					

(*continued on next page*)

Table 2 (*continued*)

Change focus	Type of service change	Description of change	Services reporting the change (n, %)			
			Ambulance N = 10	*ED N = 26*	*Neuro N = 32*	*Total N = 68*
Follow-up care	9. Expansion of established epilepsy service	Increased capacity to allow for shorter waiting times (aim ranged 1–8 weeks) for those with established epilepsy who were referred following an ED attendance and/ or to allow more regular patient reviews. Services noted offering additional telephone appointments, several had introduced face-to-face clinics within primary care settings to increase ease of patient access. One service also allowed EDs to directly book patients into follow-up slots to reduce time associated with booking process. Several other services had implemented a process whereby the epilepsy service was automatically notified of ED attendances for seizures. In some instances they were notified of visits only by patients under their care. In other, it was all patients. These patients' ED attendance record would be reviewed and the person contacted by the epilepsy service if needed.	0	1 (3.8)	13 (40.6)	14 (20.6)
	10. 'First seizure' clinics	Established or expanded (be it locations and/or clinic slot spaces) first seizure clinic to which acute and community services could refer. This typically included introduction of (or clarification) of referral criteria, mechanisms and proposed management of patients to promote consistency of care and avoid unnecessary tests and earlier discharge from ED if appropriate. Expansion was seen as allowing shorter-wait times and thus facilitated discharge. Aimed wait time 2–4 weeks.	0	3 (11.5)	7 (21.9)	10 (14.7)
	11. 'NEAD' clinic	Introduction of specialist non-epileptic attack disorder clinic which accepted referrals from ED.	0	0	1 (3.1)	1 (1.5)
	Individual services reporting at least one of these = 23 (33.8%)					

Notes:ED, emergency department; Neuro, regional neuroscience centre or neurology centre.

or were planning to make. A limitation of this is that our finding on the number of services making a change might be an exaggeration since we cannot rule out 'double-counting'.

5. Conclusion

Reducing emergency hospital use by PWE is a high priority for health services in England and a number of new services have been developed. However, they have not been consistently implemented and innovation has been lacking in some areas of care.

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Declaration of Competing Interest

We declare there are no conflict of interests.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.seizure.2020.02.012.

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