National Audit of Seizure management in Hospitals round 3: NASH 3

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BACKGROUND

The National Audit of Seizure management in Hospitals (NASH) has twice been run successfully across the UK, with over 80% of trusts taking part[1,2,3]. The results showed huge divergence in processes of care delivery that are likely to feed through into patient outcomes and efficiency of use of NHS resources. While the best trusts showed that a high standard care that meets NICE guidelines and quality standards is possible, there are many trusts in whom basic items of care are apparently un-recorded and thus probably 'not done', and by inference from other national audits are markers of poor quality care.

Cases were included in NASH because they presented to a hospital emergency department (ED) with seizure i.e. a failure of current care for those with known epilepsy, or a new incident case. In either of these cases, one might expect a referral to neurology (the only specialists interested in epilepsy) to try and prevent further seizures and to make a confident diagnosis. However, over 60% of patients with known epilepsy were not under regular neurology follow up, and the rate of referral to neurology following the ED attendance was well under 50% for almost all trusts. NASH also showed that half of the cases with known epilepsy were on a single antiepileptic drug, most commonly lamotrigine, valproate and carbamazepine, indicating a clear opportunity for more proactive drug management including use of newer antiepileptic drugs and drug combinations.

In a supporting piece of work funded by the Cheshire & Merseyside Strategic Clinical Network, admissions with seizure to trusts within Cheshire and Merseyside are being identified and tracked within the anonymised Hospital Episode Statistics (HES) data[4]. This mirrors the findings of NASH, in that only 10-15% of those not under existing neurology care are referred for neurology assessment, yet this group have on average 2-3 other ED attendances in the next year. It is most unlikely that any other physician group, or GPs, will take on the management of epilepsy so there is the presumption that these patients are simply left to 'cope'. Seizures make up 1.4% of all acute medical admissions to hospital with a mean bed stay of 2 days, i.e. this has significant cost to the health service and for the patients experiencing seizures.

Data from Ireland[5] – linked to a referral project there – has shown that readmission rates can be reduced by 80% (45% to 9%) over the next 12 months, and on that basis a NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North West Coast funded project has installed a nurse in selected EDs to actively case find and stimulate referral. This project continues, but early results suggest that changing customary practice in a significant way is proving challenging.

Epileptic seizures are not high on the list of priorities as Clinical Commissioning Groups (CCGs) focus on heart disease, diabetes and cancers. However, all CCGs share concerns about rising numbers of acute admissions that requires attention to all the contributing chronic medical conditions. Seizure numbers are probably more amenable to intervention than most.

Impacts of NASH 1 and 2

NASH 1 and 2 have had the following impacts:

NASH informed the NICE quality standards for epilepsy in adults and in children, and Prof Marson was invited onto the group that developed the standards.

The Cheshire & Merseyside Strategic Clinical Network used the results of NASH to make the case for developing and implementing a seizure care pathway for adults presenting to emergency services.

This was developed in collaboration with stakeholders including emergency physicians, general physicians, alcohol services, neurologists, general practice, patient and public representation and commissioners.

As a consequence of NASH, implementing the seizure pathway is one of the main work streams of the Walton Centre Vanguard project (Neuro Network) which is funded by NHS England. This includes implementing the pathway as well as education to teams in emergency departments and medical admission units.

A NIHR North West Coast project was funded to assess the impact of dedicated nurses to ensure the local seizure care pathway is being utilised.

The results of NASH were used to inform analysis of routinely collected HES data to assess the outpatient appointment rates following emergency seizure admissions for hospitals in Cheshire and Merseyside. This work resulted in a paper published in BMJ Open, and now forms the basis of quarterly reports sent out to the local hospitals to aid their performance management.

The NASH team were invited to sit on the Epilepsy Commissioning Working Group.

NASH results were presented to the All Party Parliamentary Working Group on epilepsy.

The results of NASH were requested for briefing the Northern Ireland Minister of Health, for a debate on epilepsy services in the Northern Ireland Assembly.

Members of the NASH team have given presentations at a number of conferences and regional meetings.

“We are putting an epilepsy nurse into A&E for a year on a part time basis in the hope of improving management of seizures and it has been really helpful to have these data to demonstrate the need for change.” - Consultant neurologist at a hospital in the north east

“With regard to my specific hospital, NASH has served the useful function of highlighting the limitations of the service offered in the emergency department and showing further evidence for the need for the first seizure clinic. So far this has led to a new pathway in the ED.” - Consultant neurologist at a hospital in the south west

AIMS

The aims of NASH3:

1. Ascertain adult cases attending EDs with an unprovoked epileptic seizure, from a range of UK hospitals, who therefore require assessment by a neurologist or seizure expert.
2. Audit the care provided to those adult patients. This will include audit of:
    a. Care during attendance or hospital admission
    b. Prior care from epilepsy or neurology services; and onward care to epilepsy or neurology services

OBJECTIVES

The objectives of NASH3 are to:

1. Identify all hospitals with ED departments in the UK.
2. Identify 30 adult (aged 16 or older) ED attendances with a suspected seizure in each of those hospitals.
3. Collect anonymous data on each ED attendance about their acute care, and about their prior and onward care.
4. Provide reports for each hospital showing how their results compare with both their national average.
5. Enable recommendations to be made for best practice
6. Raise profile of seizure management at CCG and national levels

Coordination and oversight

NASH3 will be coordinated at the University of Liverpool, led by Professor Tony Marson. Whilst this project is not a clinical trial, the audit will be run via the University's Clinical Trials Research Centre (CTRC) (https://www.liverpool.ac.uk/translational-medicine/research/ctrc/about/), for which epilepsy projects are a major strand. The epilepsy and CTRC teams have extensive experience of running multicentre projects, developing database and IT support, and providing quality assurance.

NASH3 will be overseen by a steering committee, chaired by Professor Marson, with representatives from UCB (the funder), neurologists, emergency physicians, patient representatives (Epilepsy action and the Epilepsy Society), and the Walton Centre Vanguard

Permissions

NASH3 is an audit that collects anonymous data in order to assess the process of care in a number of European countries. This should not require individual patient consent, nor HRA and ethical approval.

Timelines

Data will be collected retrospectively from cases presenting to the Emergency Department (ED) from 1st June 2018.

NASH3 will be open to data collection from 1st November 2018 until the end of June 2019.

Selection of hospitals to participate

NASH3 is will open to any UK hospital with an Emergency Department that wishes to participate.

Number of cases per hospital (sample size)

NASH3 is an audit and our plan is to provide summary statistics and to investigate potential reasons for any important variability found among sites. For most items we will estimate averages (mean or median) and proportions. Previous experience shows that collecting data on 30 ED attendances at each hospital will provide sufficient data to make a comparison as to how an individual hospital compares with a national average.

Case ascertainment

Each hospital will be asked to identify 30 consecutive ED attendances, with the date of the first attender per hospital being 1st June 2018 It is important to highlight that all data will need to be collected retrospectively in order to allow time to assess patients onward care pathways.

The exact mechanism by which cases will be ascertained will vary by site according to local systems. We anticipate that, at many sites, the reason for ED attendance will be computer coded on a database for administrative and reimbursement purposes. These databases will be searched to identify cases. At other sites, records may be paper-based and ascertainment may require searching through paper records.

Cases to be included

The aim is to assess the care provided to patients attending the ED where the attending physician considered that an unprovoked epileptic seizure was the most likely diagnosis, regardless of whether the patient has an established epilepsy diagnosis.

The following inclusion and exclusion criteria should be used to identify cases.

Inclusion Criteria

Patients will be included if:

1. They were considered an adult on the day of ED attendance.

2. They attended the ED due to a definite or suspected unprovoked epileptic seizure. We expect that patients will fall into one of the following three groups:

- A first unprovoked seizure
- A history of previous blackouts or seizures, but no diagnosis of epilepsy prior to ED attendance
- An established diagnosis of epilepsy prior to ED attendance

Exclusion criteria

Patients will be excluded if:

1. The patient is aged between 16 and 18 and was admitted under the care of a pediatrician.

2. Their primary reason for attending the ED was for an event with a diagnosis other than seizure (e.g. syncope)

3. Their ED attendance was due to a provoked/acute symptomatic seizure, including

    a. Seizure purely due to alcohol misuse

    b. Seizure due to other substance abuse

    c. Seizure due to acute head injury

    d. Seizures due to acute stroke or subarachnoid haemorrhage; and

    e. Seizure due to acute metabolic disturbance such as hypoglycaemia, renal or hepatic failure.

Data collation and analysis

Anonymous data collection

Data will be collected by staff holding an appropriate contract or permissions at participating hospitals. This will most likely be medical or nursing staff from neurology or ED

Each site will keep a list, with patient identifiers, of included patients so that they can respond to any data queries. It is important to note that these data will **not** be shared with anyone outside of the hospital, and **no** personal identifying data will be collected on the audit data collection tool.

Development of the audit tool questions

The NASH3 audit data collection tool is based on the tool developed for the previous rounds of NASH. This tool was developed in collaboration with the Association of British Neurologists, the UK Chapter of the International league Against Epilepsy, The College of Emergency Medicine, and the patient organisations Epilepsy Action and the Epilepsy Society. The questions have been adapted slightly by the steering committee to ensure they are still appropriated for use in the UK.

The audit collection tool is password protected, and the study coordinator will only grant access once all necessary approvals are in place at each hospital.

The tool includes demographics and items relating to epilepsy/seizure history, and items on the acute care of patents in the ED, their prior care, and their onward care:

Demographics and epilepsy/seizure history

- Age and gender
- The patient's Lower Super Output Area of residence
- Whether the patient is known to have epilepsy
- Whether the patient has a history of provoked seizures (e.g. alcohol, head injury)
- Whether the patient attended with a seizure in the previous 12 months
- Whether the patient has an intellectual disability

Acute care

- Whether the patient was seen within 4 hours of attendance
- The grade of the most senior doctor assessing patient during attendance/admission
- Whether drug treatment was given for acute seizure management
- Whether observations and clinical examinations were recorded
- Investigations (e.g. blood levels of antiepileptic drugs, brain imaging, EEG)
- If the patient as admitted, and where to (e.g. medical or neurology ward, ITU), and under the care of which specialty.
- Neurology assessment during admission
- Duration of admission
- Whether advice was provided about driving and management of future seizures
- Diagnosis (first seizure, epilepsy, other)
- Antiepileptic medication on discharge

Prior care

- Antiepileptic medication prescribed prior to attendance
- Whether the patient was seen by an epilepsy specialist in the previous 12 months

Onward care

- Whether the patient was referred to neurology or epilepsy services
- Investigations ordered as outpatient (e.g. EEG or MRI)
- If the patient was referred to a neurology, first seizure or epilepsy clinic, how long was the wait and did they attend?

Development of the software

Anonymous data will be collected using a bespoke Good Clinical Practice (GCP) compliant web audit system written in C#.Net, and JQuery by a developer at the Clinical Trials Research Centre at the University of Liverpool, with the data being stored in a mysql database. This will be hosted on a server at the CTRC at Liverpool University.

The web audit system is password protected. Access to the system will be granted by the study coordinator once necessary approvals are in place at each hospital.

Sites will enter their data over the internet using a web browser of their choice. Each site and patient will be allocated a unique identifier within the system. No identifiable information will be recorded in the system, or asked for by the e-forms. Online help is available for the majority of questions.

Individual sites **only** have access to the data entered by their site, while study administrators at the University of Liverpool are able to view the data from all sites.

Data collection

Sites will be asked to identify the most appropriate personnel to complete the audit locally. In the previous audits, consultants or trainees in neurology or emergency medicine, or by specialist nurses most commonly completed this. Once the team are familiar with the data entry web site, we estimate that it will take between 10 and 30 minutes to enter data for each case.

Analysis

A number of consistency checks will be built into the electronic software to help reduce typographical errors in data inputting and maximise the quality of the data. Frequent data checks will be made at the study office and an email highlighting missing data and/or data queries will be sent to the participating staff at each hospital.

Analyses will be descriptive, and no formal statistical analyses with significance testing are planned. For each hospital we will provide a report showing how they compare on each data item with their national average. We will also prepare an overall report assessing variability in care across the UK.

National Engagement/Public Profile

A PR campaign will be required to get results actioned once the audit is completed. Key relationships for this will be with the patient charities (Epilepsy Action and Epilepsy Society) and the audit funders

(UCB). Work with these groups will continue through data collection so that when results are available they are able to have maximum effect.

Once NASH 3 is completed, meetings will be held to discuss findings, implications, and to plan service change.

We currently anticipate 8 regional meetings taking place across the UK to disseminate the audit results. These would be chaired by Prof. Marson. The proposed attendees for these meetings include:

- Neurologists
- Medical Director - Neurology
- A&E
- STP lead
- Regional Director Commissioning Operations
- GP planned care lead
- GP urgent and emergency care lead
- GP long term condition lead

- The meetings would comprise:
- Virtual Reality Experience
- NASH 1 and 2 outputs and positive initiatives (e.g. the CAPS nurses, ESN business case, improved measures etc. as outlined above)
- NASH 3 data presentation
- Q&A or flipchart session, highlighting key issues/areas for improvement and suggestions for change
- Examples of areas with excellent service
- Build networks for sharing best practice

A webcast would be available for individuals unable to attend any of the regional meetings. This could be a recording of one of the regional meetings addresses or could utilise the UCB Healthcare Partner Network to present via a Webcast (Adobe Connect).

References:

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2. Ziso B, Dixon PA, Marson AG, Epilepsy management in older people: Lessons from National Audit of Seizure management in Hospitals (NASH). *Seizure*. 2017 Aug; 50:33-37. doi: 10.1016/j.seizure.2017.05.002
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4. Grainger R, Pearson M, Dixon P, *et al* Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data. BMJ Open 2016;6:e010100. doi: 10.1136/bmjopen-2015-010100
5. Iyer PM, McNamara PH, Fitzgerald M, et al. A seizure care pathway in the emergency department: preliminary quality and safety improvements. Epilepsy Res Treat 2012;2012:273175