Supplementary File 5 Further details relating to NWAS and the management of calls relating to seizures

The North-West Ambulance Service NHS Trust (NWAS) has responsibility for ~7 million people and covers a geographic region of ~14000 square miles that includes a mix of urban and rural areas. It employs ~2800 full-time equivalent qualified ambulance staff and has demonstrated a non-conveyance rate comparable to the average. At the time of the project, when crews were 'on scene' they did not use an electronic recording system, rather they completed standardised 'Patient Report Forms' (PRFs) by hand and these were subsequently 'scanned in'.

Emergency calls to NWAS are handled by an emergency operations centre. Like most English ambulance services, it uses the Advanced Medical Priority Dispatch System (AMPDS) to code the reason for the call based on the presentation that is described.

When a call is received regarding what is described as a suspected seizure then AMPDS Protocol 12 is activated. In 2018/19, NWAS received 12,935 calls for persons aged ≥18 years that were coded as AMPDS Protocol 12. They conveyed ~65% of these to Type 1 EDs (S Bell, North West Ambulance Service, 29/7/2019).

The AMPDS system prompts trained, but non-clinical call handlers to ask standard questions. The callers' responses to questions yields 'determinant descriptors' (such as 'continuous or multiple fitting' or 'effective breathing not verified') which are used to assign a specific subcode to the call, priority, target response times and the type of response.

One of the standard questions that caller handlers are prompted to endeavour to ask when managing a call via AMPDS Protocol 12 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 can 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 then the specific subcode is given an 'e' suffix.

The information that is received by the caller handler results in the AMPDS Protocol 12 incident receiving one of 16 possible subcodes. Persons with 8 of them were eligible for identification (see Table below). The restriction on subcodes was necessary due to ethical concerns about the possibility of inadvertently sending an invitation letter to someone who had died. It was also an attempt to screen out incidents unrelated to epilepsy (e.g., acute symptomatic seizures, preeclampsia, hypoglycaemia). The eligible codes were selected by a consultant neurologist (AM) and consultant paramedic (SB) and captured 79% of the suspected seizure incidents managed by NWAS in 2017/18 that were assigned suffix 'e' (S Bell, North West Ambulance Service, 29/7/2019).

Table. Eligible Advanced Medical Priority Dispatch System Protocol 12 subcodes

AMPDS Protocol 12	Determinant descriptor
subcode	
12-A-01-E	Not fitting now. Effective breathing verified (Epileptic or Previous
	diagnosis of fitting)
12-A-04-E	Focal fit (Alert)- Epileptic or Previous diagnosis of fitting
12-A-05-E	Impending Fit (Aura)- Epileptic or Previous diagnosis of fitting
12-B-00-E	Convulsion/Fitting Bravo Override Epileptic or Previous diagnosis of fitting
12-C-00-E	Convulsion/Fitting Charlie Override Epileptic or Previous diagnosis of
	fitting
12-C-01-E	Focal Fit (not Alert) – Epileptic or Previous diagnosis of fitting
12-C-07-E	Atypical Fit – Epileptic or Previous diagnosis of fitting
12-D-02-E	Continuous or Multiple Fits – Epileptic or Previous diagnosis of fitting

Notes: AMPDS, Advanced Medical Priority Dispatch System. The use of the term 'epileptic' within the table represents the exact language used within the AMPDS system. So-called 'person first language' is largely preferred over approaches like this that label a person by their diagnosis. ^[2]

References

- 1. Noble, A., et al., *Qualitative study of paramedics' experiences of managing seizures: a national perspective from England.* BMJ Open, 2016. **6**: p. e014022.
- 2. Noble, A.J., et al., 'Epileptic', 'epileptic person' or 'person with epilepsy'?

 Bringing quantitative and qualitative evidence on the views of UK patients and carers to the terminology debate. Epilepsy & Behavior, 2017. **67**: p. 20–27.