

# EXECUTIVE SUMMARY

Data from 610 clinical questionnaires, 264 sets of case notes and 158 organisational questionnaires were used to assess the quality of care provided to adult patients with a pre-existing epilepsy disorder or who were subsequently diagnosed with epilepsy and presented to hospital following a seizure, between 1<sup>st</sup> January and 31<sup>st</sup> December 2020.

## CONCLUSION

It was identified that action could be taken at all points of the patient pathway to improve the quality of care. Beginning with telling the patient's usual epilepsy team if they had been admitted, making sure anti-seizure medications were checked and ensuring the correct investigations were done. Continuing through to more input from the neurology team, as needed, particularly utilising the role of the epilepsy specialist nurse. Finally, planning and communication at discharge to make sure patients and their families/carers understand the risks associated with seizures and epilepsy so that they know what to do if they have a further seizure.

### 1. ALERT A PATIENT'S 'USUAL' EPILEPSY TEAM, WHEREVER BASED, WHEN A PATIENT PRESENTS WITH A SEIZURE



This provides an opportunity to discuss the patient's needs and undertake an inpatient review if appropriate.

133/315 (42.2%) patients with epilepsy did not have their admission discussed with their usual secondary care team.

45/143 (31.5%) hospitals reported that there was a policy for the emergency department to contact the epilepsy team when patients with known epilepsy were seen.

### 2. DOCUMENT ANTI-SEIZURE MEDICATIONS AND ACTION A CLEAR PLAN FOR ANY INVESTIGATIONS NEEDED



This ensures the information is clear in the notes, acted upon and flows through to discharge and follow-up.

47/180 (26.1%) patients did not have their anti-seizure medication (ASM) written in their notes.

119/158 (75.3%) hospitals had the facility to perform an ASM blood screen on-site.

58/252 (23.0%) patients should have had additional investigations in the emergency department.

### 3. MAKE NEUROLOGY ADVICE AVAILABLE WHEN NEEDED FOR PATIENTS PRESENTING WITH A SEIZURE



This supports the admitting team and therefore the patient, when seizures are hard to control.

175/503 (34.8%) patients were reviewed by a neurologist during their admission and a further 109/503 (21.7%) had their epilepsy management discussed with a neurologist, leaving 219/503 (43.5%) patients without input.

Neurology input was inadequate for 61/217 (28.1%) patients.

Only 36/494 (7.3%) patients were reviewed by an epilepsy specialist nurse.

### 4. EXPLAIN THE RISKS ASSOCIATED WITH SEIZURES AND EPILEPSY TO PATIENTS AND THEIR FAMILY/CARERS



Gently making people aware of risks associated with seizures will help keep them safe.

In 52/135 (38.5%) hospitals, specific information or education regarding epilepsy was not routinely provided to patients until their first clinic appointment, which may be many weeks after discharge.

Only 40/317 (12.6%) patients had any evidence in their notes that the risk of SUDEP had been considered and discussed with them.

### 5. COMMUNICATE DISCHARGE/FOLLOW-UP PLANS TO THE PATIENT, THEIR FAMILY/CARERS & HEALTHCARE TEAMS



This would help patients, their families/carers and healthcare team manage their epilepsy together.

Only 23/85 (27.1%) hospitals reported the waiting time for first seizure clinics to be within two-weeks following a first seizure.

42/212 (19.8%) discharge letters were poor.

Follow-up was less likely to be arranged prior to discharge if the ongoing epilepsy care was led solely by a GP (18/93; 19.4%) compared to secondary care teams (36/47; 76.6%).