



Original research paper

# A review of people who did not attend an epilepsy clinic and their clinical outcomes

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## ABSTRACT

**Purpose:** To review the clinical outcomes of people who failed to attend or failed subsequent follow up in a Primary Care based specialist epilepsy service.

**Method:** The case notes of 200 people who had failed to initially attend the service or subsequent follow up from 2005 to 2013 were reviewed.

**Results:** Clinical outcomes were determined for 152 people, with the remaining 48 having left the area. For those not attending at all, 64% had no further recorded events, a further 22% came under alternative specialist care and were managed appropriately, 6% were already in remission at the time of referral or at follow up and stayed seizure free. For people attending, but were subsequently lost to follow up, 78% were in remission, had improved seizure frequency, and normal pregnancies. In total 6% of those with poor control came under subsequent Neurological care.

**Conclusion:** This study suggests that for the majority of people who fail to attend or are lost to follow up in a primary care specialist epilepsy clinic, the primary reasons appear to be that they had no further events, improved seizure control or that seizure remission has been achieved. The majority with persistent poor control came under Neurological care.

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## 1. Introduction

On the strength of several audits which demonstrated variable standards of care for People with Epilepsy (PWE) in primary care, the Western Cheshire Primary Care Trust (PCT) agreed to fund the training and creation of a primary care-based Epilepsy clinic managed by a General Practitioner (GP) with Special Interest in epilepsy (GPwSle) [1,2]. This clinic commenced in July 2005, with an Epilepsy Specialist Nurse allocated to the service for the initial first 12 months but not thereafter. Referrals were accepted from GPs, Practice Nurses, Consultant Neurologists and Paediatricians by direct letter or via the Choose and Book system (National Health Service (NHS) computerised appointment service) with appointments booked directly with the clinic. Follow up review appointments were given, where appropriate, upon leaving the clinic. Clinical telephone support is available on a weekly basis from a Consultant Neurologist, in addition to routine Consultant review of

all clinical letters generated in response to all new referrals to the service.

The aim of this case notes review was to evaluate the clinical outcomes of people who were referred but did not attend or were initially reviewed but subsequently lost to follow up in the clinic.

## 2. Methods

The GP notes of the 200 people, newly referred to the service, who had failed to attend or who had attended an initial appointment but were subsequently lost to follow up from July 2005 to December 2013 were reviewed in all the 37 practices in West Cheshire Clinical Commissioning Group (with the exception of IM's practice). In 31 of these practices, patient record review was achieved remotely using the EMIS (Egton Medical Information System) operating system on which GP consultations are recorded and consultant correspondence filed. Three practices expressed confidentially concerns so were reviewed on site, as were 3 who did not use the EMIS system.

Clinical outcomes concerning newly diagnosed or established epilepsy and other diagnoses were evaluated from GP consultations or letters received from secondary care, including any

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personal reasons documented for not attending. The review took place from June 2014 to allow at least six months to have elapsed since the last follow up.

### 3. Results

In total 555 people had been referred to the service (Fig. 1).

Excluding the 16 patients who moved out of area, the non-attendance rate for the clinic was 9% (50/529). Sixty six (12%) never attended, of whom 16 had left the area, 2 had no further records and 3 had died. Of the remaining 45, 29 (64%) who saw no clinician had no further reported clinical events, 3 (6%) were already in remission and remained so, 6 (13%) were seen by a Neurologist and diagnosed with epilepsy and 4 (9%) were diagnosed with syncope or Non Epileptic Attack Disorder (NEAD) (Table 1). All people not attending who subsequently came under secondary care did so from further referral by their GP or following an Accident and Emergency department attendance.

One hundred and thirty four people were initially reviewed in the service but were then subsequently lost to follow up, representing 35% of all those offered follow-up (253 of the 355 followed up to discharge were seen more than once). Of these 32 had left the area and therefore no further clinical information was available. Of the remaining 102 people who initially attended and who were subsequently lost to follow up, 79 (78%) had positive outcomes, 56 (55%) appear to have stopped having seizures or episodes either as a direct consequence of an intervention initiated by the service or otherwise. Another 16 people appear to have had improved seizure control as a result of an initiation or AED change initiated by the service. One person was subsequently given an alternative diagnosis. Four women were referred for pre-conceptual/pregnancy advice, one of whom was subsequently seen by local neurology services (Table 2).

Of the remaining 23 people who failed to attend follow up, all of whom had documented poorly controlled epilepsy or ongoing episodes, just over half (13) were seen by the local neurology service with no documented improvement in seizure control (Table 3). Overall three patients (one to Neurology and two to Cardiology) were referred onwards from the service.

### 4. Discussion

The primary aim of this notes review, in so far as was possible, was to try to determine the clinical outcomes of people newly referred to a primary care specialist epilepsy clinic who did not attend, or who initially attended but were then subsequently lost to follow up. The principal findings were of those who never attended on whom we were able to obtain further clinical information, the majority (80%) were not seen by other specialities, all but two of whom appear not to have had any further episodes. These two patients had poorly controlled epilepsy but declined further referral to a specialist service. The remaining 10 patients were seen in the Neurology or Cardiology services.

To our knowledge this is the first study to look at outcomes of people with epilepsy (or suspected epilepsy) lost to follow up from a specialist epilepsy clinic. Given the fact that this clinic was primary care based (and run by a GP with a special interest in epilepsy) it could be hypothesised that the majority of those failing to attend did so to attend services in secondary or tertiary care centres in preference yet this does not appear to be the case, particularly for those who failed to engage entirely with the service. Previous work suggests that there is little difference in PWE's satisfaction with primary and secondary care [3,4]. It is however true that the CSAG [4] data relates to PWE's opinions in the UK in the late 1990s and attitudes and expectations may have changed in the intervening years. Moreover, it is unknown whether

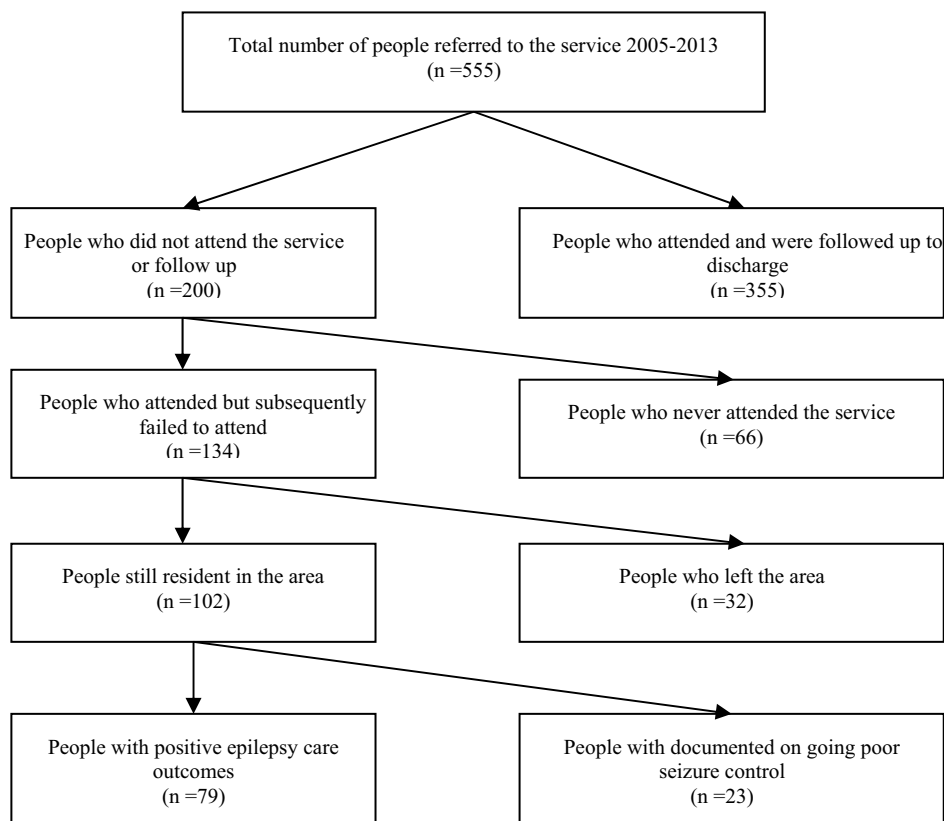


Fig. 1. Flow chart of people referred to the Service and subsequent attendance or non-attendance.

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