

ILAE-UK Audit Group

Adult First Seizure Assessment Audit – Guidance Notes

v1.0 - July 2011

The database tool/proforma (a choice of a Microsoft Access database or a single page .pdf proforma) is available to download on the ILAE-UK website, as are these guidance notes.

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Scope of the Audit

The diagnosis and management of blackouts and epilepsy in adults varies in quality throughout the UK; many patients with epilepsy may never be assessed by an epilepsy specialist. Through the ILAE-UK chapter's audit group we have an opportunity to audit epilepsy diagnosis and management across several centres and combine and compare results. We have well-established clinical standards (NICE and SIGN) and large numbers of epilepsy patients seen by clinicians from various disciplines. We aim to assess three key areas of practice; service provision (including access to services), assessment quality and investigations, and counselling/patient information.

Audit Population and Inclusion / Exclusion Criteria

This audit is intended to measure performance of:

- **Adult out-patient services in assessing the patient who is a new referral (from any source) to secondary care services with a presumed seizure or seizure disorder (epilepsy).**
- Patients may be collected for inclusion from any relevant clinic, including but not limited to; epilepsy, neurology, learning disabilities psychiatry, general/acute medicine and elderly care clinics. Methods of patient ascertainment will necessarily differ between hospitals.
- Importantly, it measures **only the outcomes resulting from this first 'new patient' appointment**, and does not include follow up.

This **includes** patients who:

- Have already had a number of seizures (i.e. not just 'first' seizure patients)
- Following assessment are not thought to be having seizures (i.e. syncope, migraine etc.)
- Are referred for a second opinion or were assessed previously, but no diagnosis was reached.

The audit should **not include**:

- Patients with an established diagnosis of epilepsy (or any other diagnosis), including those on treatment, being seen for optimization of their condition.
- Patients being referred with a suspected diagnosis other than seizures or epilepsy.

The most reliable results will come from prospective patient collection, however retrospective audits can also be carried out.

Audit Standards

The audit standards (based on the NICE and SIGN guidelines) to be measured are as follows (targets in brackets). Users may audit as many or as few of the standards as they wish for their population:

1. Percentage of **all referrals** with evidence of input by a **specialist in epilepsies*** within 2 weeks of referral (100%)
2. Percentage of **patients diagnosed with epilepsy** with evidence of an **offer of contact** with an Epilepsy Specialist Nurse **within 30 days** of first assessment (i.e. diagnosis) (100%)
3. Percentage of **patients with alteration in awareness** with evidence of a **witness account** of the paroxysmal events in question being **sought and/or recorded** at the first assessment (100%)
4. Percentage of **patients diagnosed with epilepsy** with **evidence of an attempt at seizure classification** at the first assessment (i.e. diagnosis) (100%)
5. Percentage of **patients diagnosed with epilepsy** with evidence of **an attempt at epilepsy syndrome or syndrome category classification** at the first assessment (i.e. diagnosis) (100%)
6. Percentage of **all referrals** being referred **inappropriately for an EEG*** (0%)
7. Percentage of **patients meeting indications for epilepsy neuroimaging*** having appropriate neuroimaging **within 4 weeks of being requested** (100%)
8. Percentage of **patients with loss of consciousness (i.e. collapse) or generalised convulsions** having had a **current 12 lead ECG at or prior to the first assessment** (100%)
9. Percentage of **patients with loss of consciousness (i.e. collapse) or generalised convulsions** having a **current 12 lead ECG** filed within their medical notes (100%)
10. Percentage of **all patients who drive** having appropriate **driving advice given and documented**, by the nurse or the doctor at their first assessment (100%)
11. Percentage of **patients with epilepsy** with evidence of a discussion on the potential risks of future seizures, and related safety issues (100%)
12. Percentage of **all patients** with evidence of the clinic letter being **copied to the patient** (100%)

***Further details** on definitions of the terms used in these standards, and requirements needed to meet each standard are included later in this document. Guidance for each audit standard is also included electronically within the database proforma, see figure 3 below.

Paper Proforma

A 'pdf' proforma is available for users who do not wish to use the electronic database proforma. This is more straightforward, but data analysis may be much more time consuming.

Using the Electronic Database Proforma - Opening the Database

All instructions refer to use with Microsoft Office 2003; in use in most trusts. When opening the database you will likely get a security prompt, just press 'open'.

Using the Electronic Database Proforma – Password Protection

The database should be stored on a trust computer and password protected. To do this, before starting to enter data, open the database file as above then close it again by closing the small database window (click the red cross in the top right of the small window, not the main screen). Then select the 'File' menu bar, then 'Open...'. In the dialog box that appears, locate the database file, single click it and then click the small arrow in the right hand side of the 'open' button, and select 'Open Exclusive'. Click 'Open' on the security warning, then select the 'Tools' menu bar, then 'Security', then 'Set Database Password...'. You can then create a password.

Beginning to Enter Data

Once a password is created you can begin entering patient data. First open the database as normal, then select 'Forms' in the small database window and double click 'ILAE-UK Adult First Seizure Audit Tool Proforma'. This is shown in Figure 1 below.

Entering data is simple, some boxes are typed in to, but most have drop down menus (as in figure 2 below) with standardized answers. Dates must be entered in the format DD-MM-YYYY. It is useful to enter some basic notes on each case in the 'notes' box at the end, particularly if there is something unusual about the case that you may need to recall when analyzing your results. Examples may include unusual routes of referral, or patients previously thought to have had epilepsy who are representing etc. **It is VITAL to record reasons for not meeting standards (if known) for each patient, in order to make sense of your results afterwards.** In particular, it is important when there is a reasonable explanation as to why a standard was not met in a patient (e.g. the patient had learning disabilities such that they couldn't have a scan).

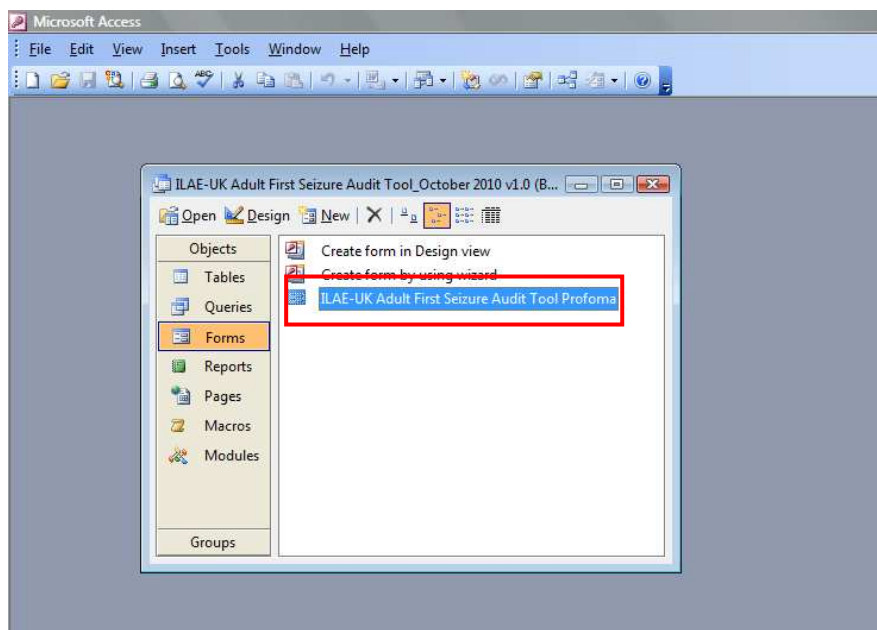


Figure 1. Opening the Audit Proforma

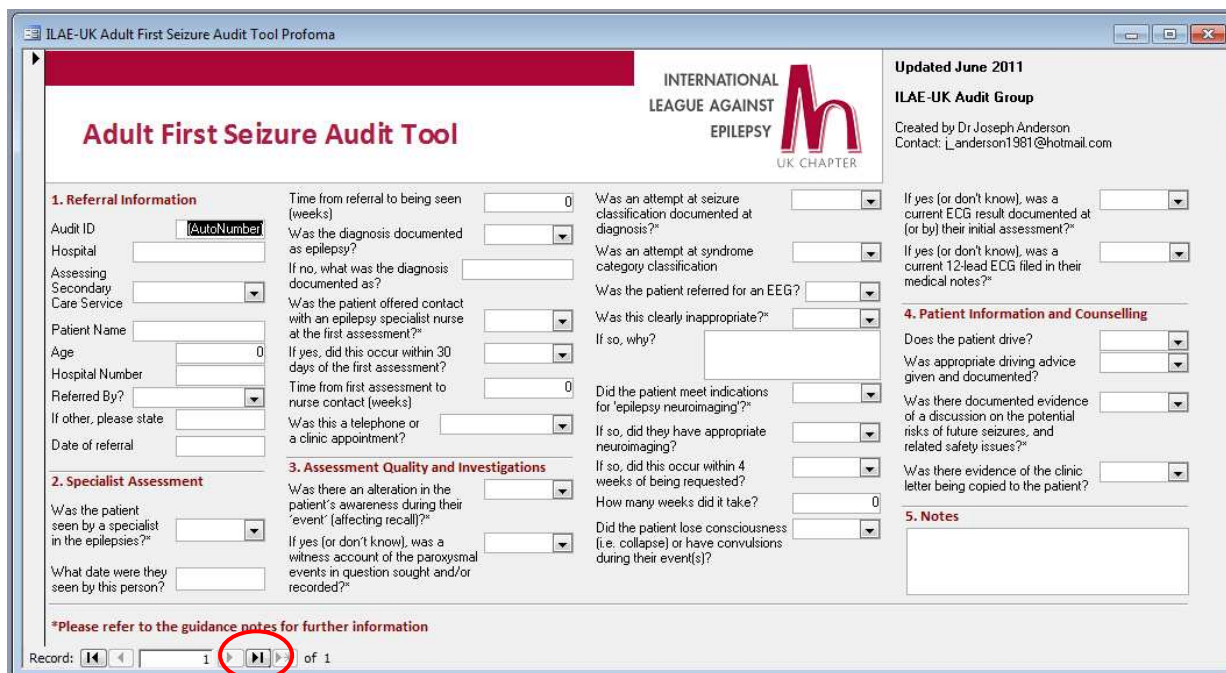


Figure 2. User interface of the audit proforma

When you have finished entering the data for a patient, you can move on to a new record by clicking the button shown with a red circle in figure 2. These buttons also allow you to browse back and forth through previous records.

When entering data, there are brief explanatory notes in the bottom of the screen that appear when some of the boxes are selected, as shown in figure 3.

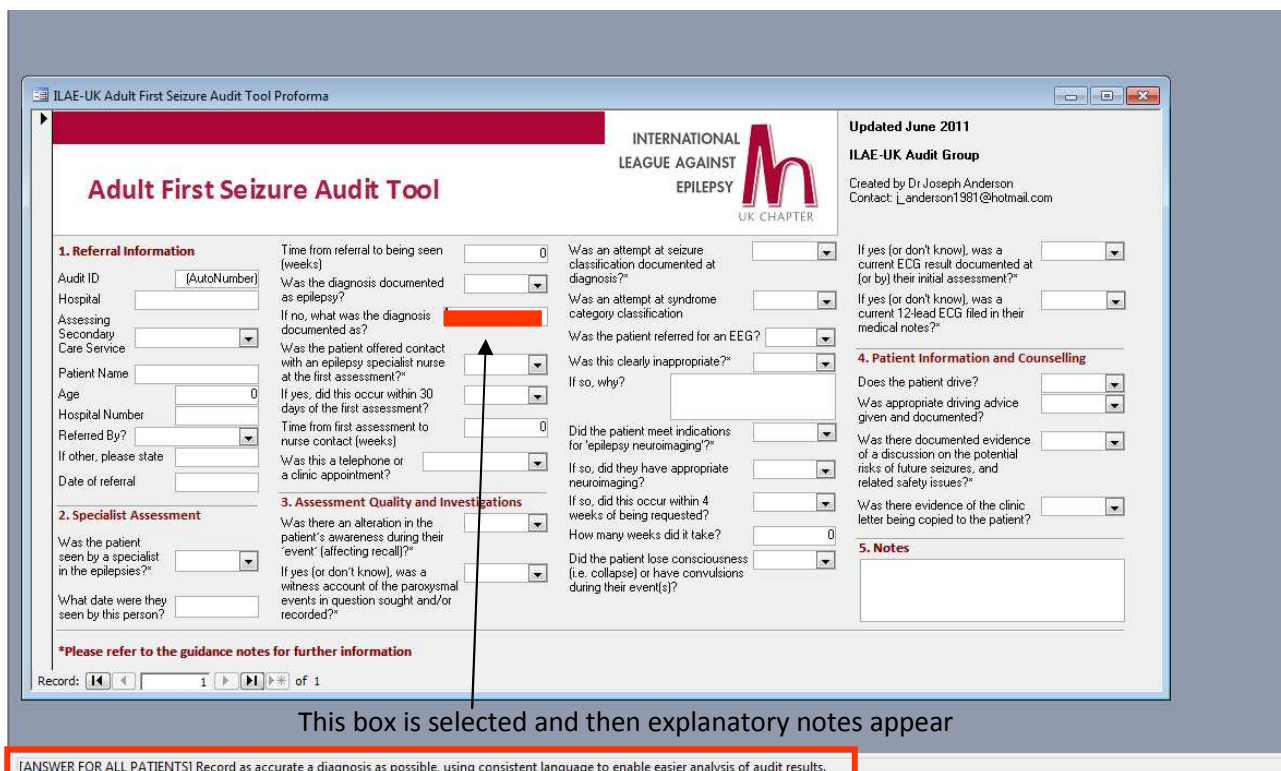


Figure 3. Guidance notes appear at the bottom of the screen

Specific Audit Standards – Guidance Notes

For all standards the user should ideally inspect the clinic letter and the hand written clinic entry in the hospital notes to determine whether the standard was met.

1. Assessment by a Specialist in the Epilepsies

This standard **applies to ALL patients**, i.e. waiting time to be seen for all patients, not just those eventually diagnosed with epilepsy. The original referral letter is required for this standard, to provide the date of referral, and as such patient's hospital notes should be requested for the audit.

For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy. This includes SpRs and Consultants in Neurology, Learning Disabilities Psychiatry and in some cases Elderly Care/General Medicine, or a GP with specialist interest. Where services are set up such that Epilepsy Nurses perform diagnostic assessments of 'first seizure' patients, they are also included as a 'specialist in epilepsies'. A degree of 'local knowledge' will be required to decide in some instances whether the clinician is a 'specialist in the epilepsies'.

2. Offer of Contact with an Epilepsy Specialist Nurse

This standard only **applies to PATIENTS DIAGNOSED WITH EPILEPSY at the first assessment**. If the patient has any other diagnosis, please select 'N/A'.

For adults, an epilepsy specialist nurse is defined throughout as a nurse practitioner with training and expertise in epilepsy. This includes nursing staff working in conjunction with a Neurology department as well as those working with Learning Disability Psychiatrists. To meet this standard there should be some evidence that the clinician offered the patient the opportunity to speak to an epilepsy specialist nurse, at least by telephone, preferably in an out-patient clinic setting. Some patients may decline this, but all should be offered it. The time limit of 30 days comes from patient survey results that suggest any longer than this is viewed as unacceptable to patients.

3. History Taking – Witness Account

This standard **applies to all patients who suffered an alteration in awareness during their event**, such that their ability to recall events was impaired. Unless the notes clearly indicate that the patient recalled everything (e.g. in the case of simple partial seizures), this standard should apply. As such, when analyzing results those cases where you 'don't know' if awareness was altered should be included in the analysis.

To meet this standard the user requires evidence from the clinic letter or the written entry in the hospital notes that the clinician at least sought (preferably documented) a witness account of the patient's events in question. This may include a witness being present in clinic, a written witness description brought with the patient, or a telephone call to a witness. If a witness is called but does not respond, answer 'yes' (i.e. 'sought'). **If there was no witness, answer N/A.**

4. Evidence of seizure classification

This standard only **applies to PATIENTS DIAGNOSED WITH EPILEPSY at the first assessment**. If the patient has some other diagnosis, then please leave the question 'was an attempt at seizure classification documented?' blank, or record 'N/A'.

Seizures should usually be classified as generalised-onset, partial-onset, focal-onset, or unclassified (or anatomically; 'frontal lobe', 'temporal lobe' etc.), but any reasonable attempt at classification is acceptable. A comment to the effect that it is not possible to classify ('unclassifiable') the seizure **does count as an 'attempt'** to classify, and as such passes this standard. Simply stating '[epileptic] seizure' does not pass this standard.

5. Evidence of epilepsy syndrome or syndrome category classification

This standard only **applies to PATIENTS DIAGNOSED WITH EPILEPSY at the first assessment**. If the patient has some other diagnosis, then please leave the question 'was an attempt at syndrome category classification documented?' blank, or record 'N/A'.

Epilepsy syndrome should be classified either as a specific syndrome (e.g. JME); one of generalised or focal (partial), plus one of idiopathic, symptomatic or cryptogenic; or as unclassified. A comment to the effect that it is not possible to classify ('unclassifiable') the syndrome **does count as an 'attempt'** to classify, and as such passes this standard. Simply stating 'epilepsy' does not pass this standard.

6. Indications and Appropriateness of Use of Electroencephalography (EEG)

This standard **applies to ALL patients**. Inter-ictal EEG is not necessarily mandatory but may still be helpful in adults with new onset of spontaneous seizures. EEG may be helpful in patients with frequent psychogenic non-epileptic attacks as a typical event may be captured. However, EEG is definitely **not indicated** if the likely diagnosis is syncope.

In summary, **EEG should be used:**

1. To **support a diagnosis of epilepsy** (or first unprovoked epileptic seizure) where the clinical history suggests that the seizure is likely to be epileptic in origin. i.e. not before the detailed history and not unless epilepsy / unprovoked seizure is the most likely diagnosis.
2. To further characterise a syndromic epilepsy diagnosis where one is suspected clinically, e.g. in confirming a diagnosis of an idiopathic generalized epilepsy.
3. In a person where the clinical presentation supports a diagnosis of a non-epileptic event **only** where there is a high likelihood of capturing a typical event on a routine recording (including hyperventilation and photic testing).
4. **Not** for a case of probable syncope.
5. EEG should **not be used to** exclude a diagnosis of epilepsy.

To pass this standard the patient will either not have had an EEG, or will have had an appropriate EEG, in line with the guidelines above (based on NICE). Patients who will not pass this standard are those referred for EEG despite the clinical impression being that of syncope or migraine etc. Use of EEG as a diagnostic test where the clinical impression is very much uncertain (e.g. minimal clinical history available) is not appropriate.

7. Indications for use of Neuroimaging

IMPORTANT: This standard only **applies to patients with epilepsy or those who have had an unprovoked seizure**. It is recognized that some patients need neuroimaging for other reasons but we are not assessing these patients in this audit. **As such, there is a question in the audit tool asking 'did the patient meet indications for epilepsy neuroimaging?'. This should be answered**

for each patient by referring to the list in grey below. This is important for reporting the results afterwards.

Where a patient **did** meet indications for ‘epilepsy neuroimaging’ but in fact they had already had the imaging performed by the time of out-patient assessment (perhaps for another reason, or it was arranged by the referring acute medical team for example), please record ‘yes’ for ‘if so, did they have appropriate neuroimaging?’ and record ‘0’ for ‘how many weeks did it take?’.

Where neuroimaging is performed this should be an MRI scan in most cases. Cases where CT would be appropriate instead include patients where MRI is contraindicated, where MRI would require sedation or general anaesthetic (and this is deemed too great a risk), or where detailed information on MRI is unlikely to alter management (e.g. in an elderly patient with multiple comorbidities where it would not be appropriate to offer surgical resection of a lesion if one was found with MRI. However CT (preferably with contrast) could still be used in such cases to identify any gross pathology that may need medical treatment, e.g. a tumour or vascular pathology).

Further still, it is anticipated that some patients will meet the indications for ‘epilepsy neuroimaging’ but for some reason (e.g. severe learning disabilities, claustrophobia, dementia etc.) it is not possible or practicable to arrange any form of scan, and the risk of general anaesthetic is deemed to outweigh the potential benefits (e.g. long standing seizures, low risk of a tumour etc.). **Please record this information in the free text ‘notes’ section, to explain why they failed to meet this standard.**

The idea with neuroimaging is that most adult patients with new onset first seizures or epilepsy require it, in effect the only exception being patients with a clear diagnosis of an idiopathic generalized epilepsy, whose seizures started in adolescence. Therefore, **indications for epilepsy neuroimaging** (as per the 2004 NICE guidelines) are:

1. Onset of epilepsy (or onset of first unprovoked epileptic seizure) in an adult.
2. Epilepsy (or first unprovoked epileptic seizure) with any suggestion of a focal onset on history, examination or EEG (unless clear evidence of benign focal epilepsy).
3. Epilepsy where seizures continue in spite of first-line antiepileptic medication.

8. Use of 12-Lead Electrocardiogram (ECG)

This standard **applies to all patients with loss of consciousness (i.e. collapse) or generalised convulsions (whether it was deemed to be a seizure or not)**, as there is a potential that these patients have suffered a cardiac syncope. 12-Lead ECG is cheap, safe and easy to perform and can help identify those patients at risk of sudden cardiac death. It is therefore mandatory in all patients presenting with unexplained transient loss of consciousness. This is now also enshrined in the related NICE guidelines on transient loss of consciousness. If it is not known (‘don’t know’) whether the patient lost consciousness (collapsed) or had a generalized convulsion, an ECG should still be performed and these patients included in the analysis of results.

To pass this standard a ‘current’ ECG is defined as one recorded since the onset of the patient’s attacks (so that congenital (e.g. long-QT) and acquired (e.g. pathological q waves) abnormalities can be detected). Therefore the user should seek evidence that the patient has had an ECG performed **and reported** by either the referring or the assessing clinicians. An ECG taken prior to

the events is not valid. This would usually be a comment on the ECG in the either the referral letter or the clinic letter.

9. Recording of 12-Lead Electrocardiogram (ECG)

This standard **applies to all patients with loss of consciousness (i.e. collapse) or generalised convulsions (whether it was deemed to be a seizure or not)**. 12-lead ECG is so important in these patients that a copy should be kept (as is the case for MRI and EEG) for others to view. This minimises the risk of abnormalities being missed by individual clinicians.

To pass this standard a 'current' ECG is defined as one recorded since the onset of the patient's attacks (so that congenital (e.g. long-QT) and acquired (e.g. pathological q waves) abnormalities can be detected). This current ECG should be filed and easily visible in the patient's clinical notes.

10. Documentation of driving advice

This standard **applies to all those patients who hold a UK driving license (and therefore who currently drive or may drive)**.

To pass this standard a comment to the effect that driving advice was given, documented in the clinic letter or the hand written notes, is sufficient. Where detailed advice is documented this should be commensurate with the clinical presentation (including patients who have conditions other than epilepsy or seizures, for example, TIA or syncope). It may be given by the clinician at the first assessment or by the epilepsy specialist nurse (where such a contact is made).

It is recognized that some patients have driving advice documented even though their driving status is not documented. It is therefore advised to report audit results in two groups; those who are documented as drivers who had driving advice documented, and those whose status is not documented but advice was documented anyway. Filling in both driving questions on the audit tool allows this. Clearly those patients who do not and will not drive (and are documented as so) do not require advice and need not be included in the analysis.

11. Counseling on Seizure Risk and Safety Issues

This standard **applies to PATIENTS DIAGNOSED WITH EPILEPSY at the first assessment**.

Patients at risk of further seizures need to have this explained to them, and they need to be aware of safety issues related to this risk, and what they can do to avoid harm to themselves or others. The degree of information required for each individual will vary markedly, and moreover, the detail included in clinic letters may be substantially less than that which is discussed with the patient at their appointment. As such, this is a difficult standard to measure, however its importance is unquestionable and so **to pass this standard the user should seek written evidence that at least some discussion on the risk or further seizures and/or safety issues (bathing alone, occupation etc.) was made. This might be documented in the clinic letter or the clinical notes.**

12. Patient information and Clinic Letters

This standard **applies to all patients**.

To pass this standard there should be evidence that the clinic letter was copied to the patient for their information (e.g. a 'CC' at the end of the letter). Whilst not included formally in guidelines,

this is encouraged in most areas and acts as a marker of patient empowerment. Some patients are asked and do not want a copy of their clinic letter and it will not be possible to capture this information. As such, no target exists for this standard but its completion is encouraged as it may be useful to compare the outcome with the other standards in this audit.

Notes

There is a free text 'notes' section at the end of the proforma. It is advisable to use this to enter unusual features of the case, reasons for failure on any of the 12 standards, or reasons they may be exempt from some of the standards for example.

Analysing Results

The aim of the electronic database audit tool is that when potentially hundreds of patients are included in a collection of databases across sites they can be collated and the results of the 12 audit standards made available at the click of a few buttons. This is only possible if care is taken to answer all the relevant questions accurately for each patient at the point of data entry.

If sending the database to somebody else to analyze the results, it is necessary to make a copy with all patient identifiable information removed. If needed you can contact me and I can explain how to do this.

To analyze results we use the 'query' function of Microsoft Access. An example is given for standard 3; percentage of **patients with alteration in awareness** with evidence of a **witness account** of the paroxysmal events in question being **sought and/or recorded** at the first assessment. To calculate this figure we need to ask Access to show us only patients who **had an alteration in awareness**, and then whether or not they had evidence of a witness account being sought and/or obtained. We will also want to see their unique ID number (so we know which patient it is).

So, first create a query in design view as shown in figure 4, by double-clicking the highlighted area.

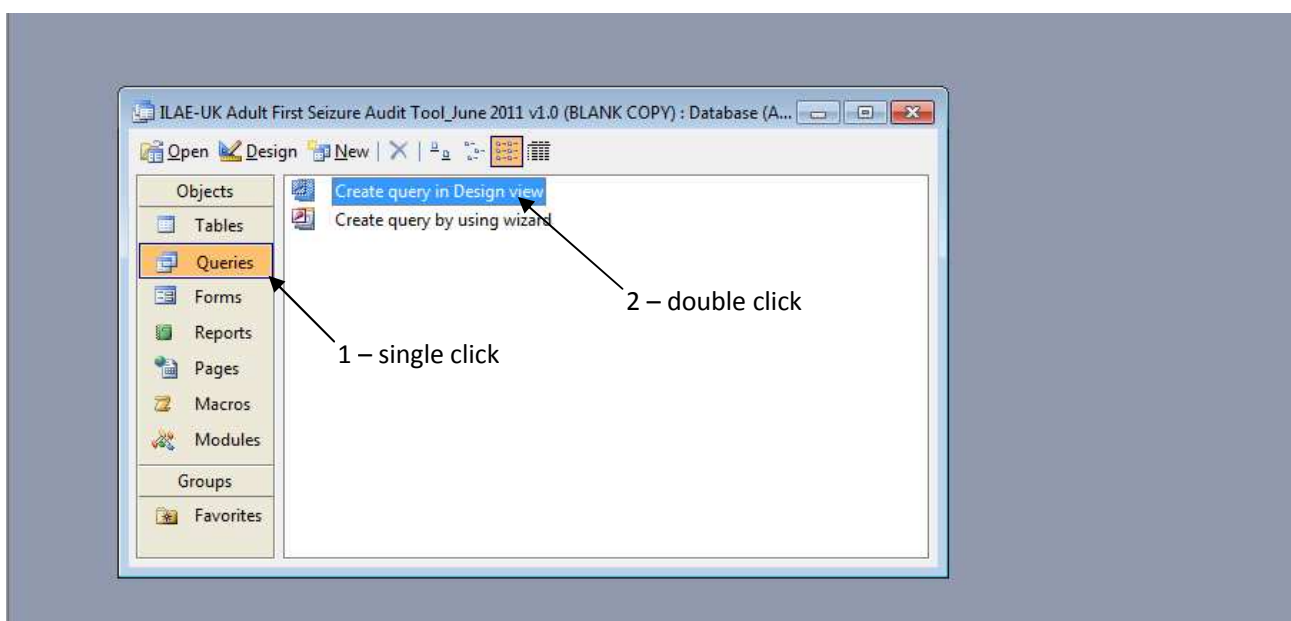


Figure 4. Opening a query in design view

A 'show table' box appears; double click 'ILAE-UK Adult First Seizure Audit Tool Data', then click close. By resizing the resulting windows to be more manageable you should have a screen like this.

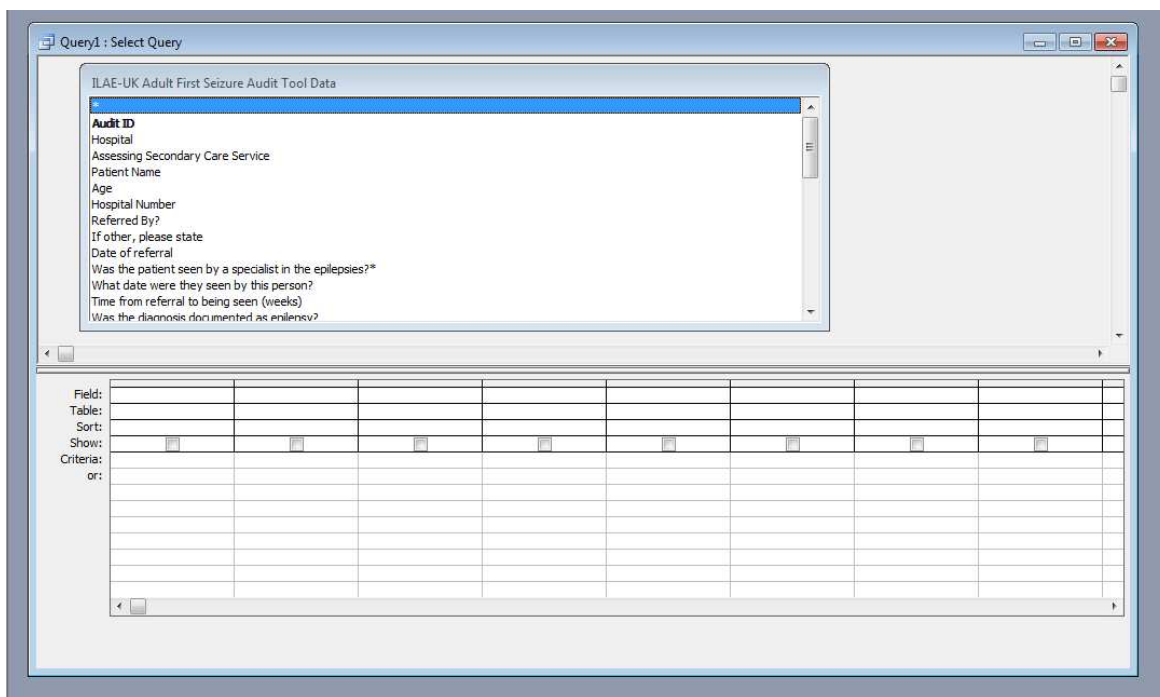


Figure 5. The query interface

Now we simply click each of the audit questions we wish to include in the query. Proceed by scrolling through all the questions and double clicking 'Audit ID', 'was there an alteration in the patient's awareness?', 'if yes (or don't know), was a witness account sought?' and 'notes'. Then type "Yes" in the 'criteria' box of the 'was there an alteration in the patient's awareness?' column, and "Yes" in the 'if yes (or don't know), was a witness account sought?' column. The screen should appear like this:

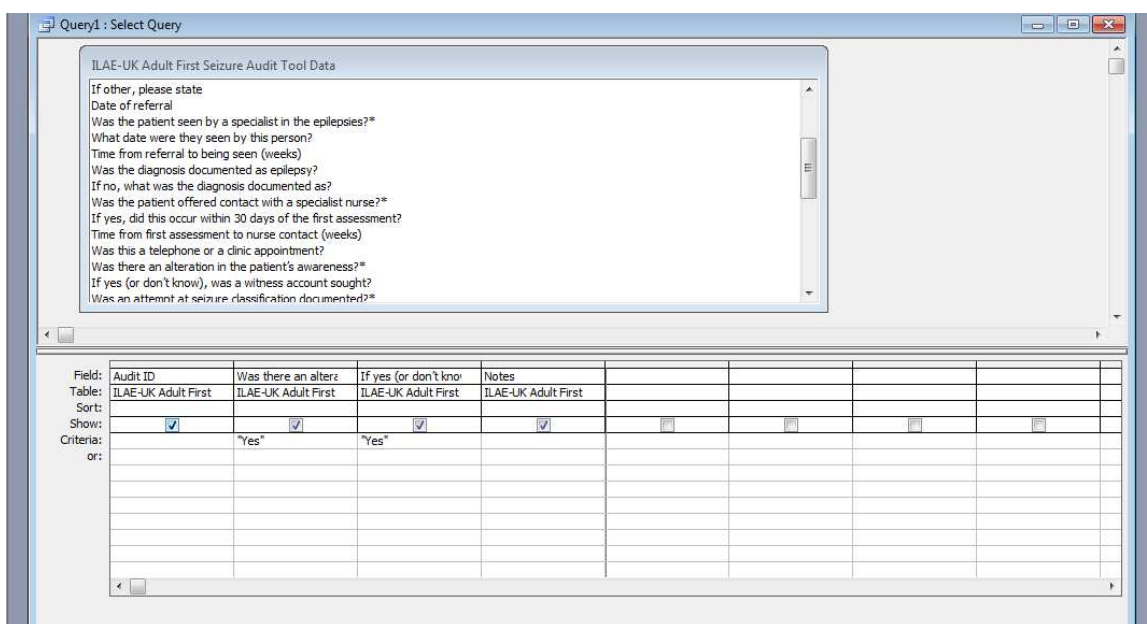


Figure 6. The final query setup's appearance

Now simply click the button in the top-left of the screen to be able to view your results.

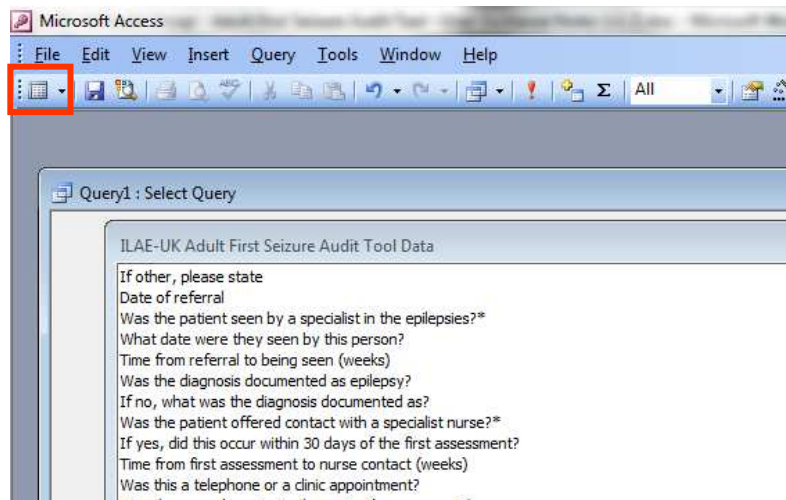


Figure 7. Click here to see your query results

When viewing your results you can click this button to switch back to the query design view in order to change the setup, for example to view those who did not have a witness account sought (by changing “Yes” to “No”) in order to be able to get all the figures needed to calculate the result for standard 3.

It should be possible to run a number of these queries using different combinations of included fields to generate results quickly for all audit standards, being careful to include only the correct patients for each standard (see bold type in audit standards, grey table, top of document).

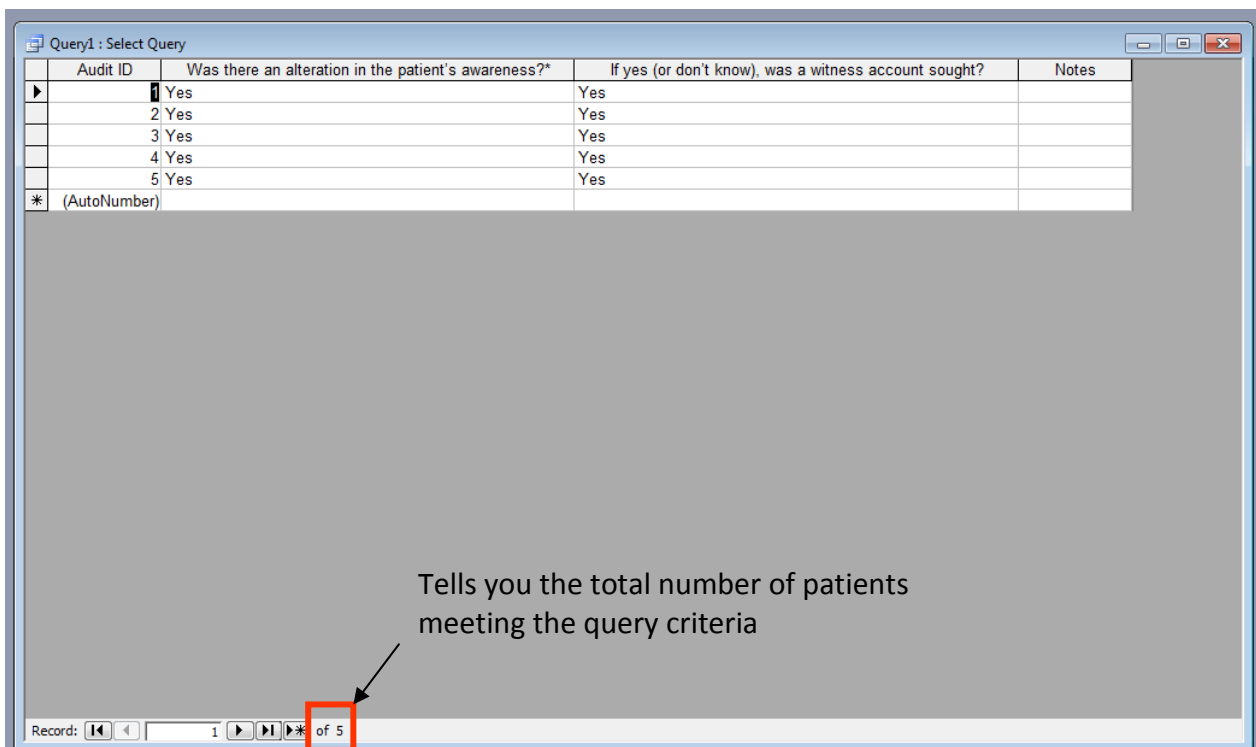


Figure 8. Appearance of audit results

Hopefully this should all help to complete a full audit. Again, any questions or comments on the audit tool, standards, or proforma, please e-mail me.

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