NATIONAL AUDIT PROJECT 5
Accidental Awareness during General Anaesthesia

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LOCAL CO-ORDINATOR GUIDE

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First and foremost we wish to thank you for agreeing to take on the role of Local Co-ordinator (LC) for NAP5: a role crucial to the success of NAP5. Many LCs who have volunteered for this role also served as local reporters for the NAP4 project, so are familiar with many activities such as uploading of information onto a secure website, and this will also be the case with NAP5. There are some differences, and this document is a guide to the role, so that LCs can understand and plan what will be needed to perform it successfully.

For each activity or 'workstream' listed below, there may be further information sent, as not all the protocols are finalised. For general information, there will be articles in the Royal College of Anaesthetists' *Bulletin* and Anaesthesia News, and also at the National Institute of Academic Anaesthesia (NIAA)/ Health Services Research Centre (HSRC) website (http://www.niaa.org.uk/HSRC_home under 'Projects').

Baseline Survey

LCs will soon receive a one-page questionnaire which we will be asking them to circulate to each of their Consultant and Career Grade Anaesthetist colleagues. LCs will then be asked to collate the responses and populate the information onto a second form, and then return this second form to NAP5. We are aiming for a 100% response rate.

This survey will provide us with an indication of the experience of accidental awareness, from the perspective of anaesthetists. It will also give us some idea as to which methods are used to monitor the depth of anaesthesia. Some of the data may inform the core project (see below). The deadline for completed survey returns will be **30 April 2012**.

Core Project

The Core Project will begin on 1 June 2012 and last for one year. From 30 June 2012 and on a monthly basis until 31 May 2013, LCs will be asked to check if there have been any formal reports of accidental awareness during general anaesthesia (AAGA) in the hospital for which they are reporting.

NAP5 regards a 'report' as a complaint or statement made by (or on behalf of) a patient to the healthcare services.

This may take the form of a formal complaint, or threat of or actual legal action, or it may be a more informal comment made to any member of staff (ie, one which the patient does not necessarily wish to pursue). LCs will be asked formally to check with the following sites for any such reports:

- The anaesthetic department (eg, by monthly email shot, or formally raising the question at any monthly departmental or staff meetings)
- The Trust/Board legal department
- The Trust/Board complaints department
- The Trust/Board Clinical Governance department
- The Patient Advice and Liaison Service (PALS)
- The department of psychiatry and/or clinical psychology (asking if there have been any new patients complaining of accidental awareness during anaesthesia, or who have been diagnosed as such, or who in their professional opinions have symptoms indicative of such)

It is possible that some patients initially present to their GPs, but the NAP5 Steering Panel could not readily find a way of LCs checking with each and every GP practice. However, we anticipate that GPs would in turn refer such cases to either the anaesthetic department (for clarification) or the psychiatric department (if

for example, the presentation was one of post-traumatic stress disorder, PTSD).

Each month the LC will be asked to report the number of cases of awareness reported to their Trust, including when this is zero. If the LC discovers a case of accidental awareness, then we would anticipate the following steps would be necessary:

Inclusion: which cases should be reported to NAP5?

*Definition of a '**Patient report of anaesthetic awareness'***

The broad working definition of a patient report of awareness required to file a Report to NAP5 is that **the patient (or someone acting on their behalf) makes a report or complaint that they have experienced wakefulness when they believed they should be unconscious**

In applying this, we wish you to err on the side of filing a report to NAP5 rather than not filing a report. This is an audit of patient-reported awareness, so the patient defines what they consider awareness to be; a secondary judgment may later be made by local clinicians, and others if necessary. By collecting a wide range of reports, there is the opportunity to get an idea of what patients believe are valid cases of awareness (regardless of the anaesthetist's opinion). For example a patient waking up in recovery in agony may be construed as awareness by the patient even though anaesthesia at this time was not intended by the anaesthetist. If such events lead to psychological sequelae (at least enough for the patient to report 'awareness') then that may be useful information to NAP5, so a case such as this should be reported to NAP5. However, a patient simply complaining of uncontrolled pain (without mention of the possibility of 'awareness') does not need to be reported.

Therefore NAP5 will intend to receive notification of any patient report of awareness, accepting that a proportion of these will not be AAGA: clarification of the type of event will be made when reporting in detail to NAP5.

What is NAP5 definition of AAGA? –

*Definition of an '**AAGA event**'*
Notwithstanding these issues, NAP5 does have a working definition of the various types of awareness experiences. When you report the case to NAP5's secure website you will be asked to classify the event based on all the information you have. By having a large number of such reports we will be able to glean useful information on how many reports of awareness by patients are AAGA and how many arise outside this definition.

Definition of AAGA: a complaint or statement made by (or on behalf of) a patient to the healthcare services of accidental awareness during general anaesthesia. By accidental awareness we mean any instance of recall of events during general anaesthesia (ie after induction, during surgery or before full emergence) whether with or without pain or distress. This includes:

- Awareness of events after induction of anaesthesia before surgery started (e.g. airway management)
- Awareness of intraoperative events
- Awareness of events after surgery but before full emergence (e.g. airway management)

The complaint/statement could range from a patient mentioning they have been aware to a member of a medical team (but not being perturbed by it) to a formal written complaint to the Trust made by a patient extremely unhappy with their experiences.

We therefore do include events such as awareness of intubation due to difficult intubation, syringe swaps or wrong drug order errors.

Timing in relation to data collection period: we wish to capture all new *reports* of AAGA within a calendar year (1 June 2012 to 31 May 2013 inclusive) rather than all *cases* of AAGA occurring in one year. Therefore, a patient may make a first report/complaint in July 2012 about awareness during an anaesthetic that was administered in Jan 2012 (or before); this report is eligible for submission to NAP5. However, the NAP5 data collection period is strictly for one year, so a report of a patient who experiences awareness before 1 June 2012 but does not report it until later is not eligible, as in this case the report occurred after the data collection period. A patient who first made a report/complaint before 1 June 2012, and whose case is still being handled during the data collection period is also not eligible for inclusion.

Summary of steps to take after a case of awareness is reported to you, to the anaesthetic department, or discovered by you reported to another site (see above):

1. Retrieve anaesthetic case notes

2. Extract the key information (we will provide this later, but will include data such as: age range, weight, surgery type, induction agents and doses, maintenance drugs, monitoring used, etc).

   A relevant piece of information is the time interval between the report/complaint being made and the date of anaesthesia. It is possible that some patients wait months or even years before making a report. NAP5 hopes to collect data from all reports made in the year 1 June 2012 – 31 May 2013.

3. Once relevant information is extracted from casenotes, contact NAP5 where (after ensuring the case meets NAP5 inclusion criteria) we will issue you with secure logon information.

4. Use these details to access the secure site and upload the information. No patient identifier information is requested, and if it is entered, will result in the form being returned. Later, the NAP5 Lead (Professor Jaideep Pandit) will separately analyse this anonymised information.

Workstreams additional to the Core Project

In addition to the Core Project outlined above, NAP5 will have several other potential workstreams. These are far from finalised, but we want to let you see an outline of the plans, to provide an indication of the workload involved.

Psychological Workstream

Because patients who report awareness during anaesthesia form a relatively rare cohort, it is important that as much can be learned from their experiences as possible. We are especially interested in how psychological symptoms evolve over time, and the expert psychologists on the panel will design a questionnaire to be sent to affected patients.

Ethics committees require information on how patients are identified and recruited for any study. Because we at NAP5 will not know where or which patients have been affected, the only means of co-ordinating such a study is via service evaluation information held by the LCs. It is deemed suitable, for clinical governance purposes, for LCs to hold a register locally of those patients who have experienced awareness. It is important beforehand to establish who of that cohort is willing to be contacted to assist with other aspects of NAP5. We will therefore ask LCs to write a simple letter to the patients who make a report, as soon as is judged practical, asking their permission to be contacted at some unspecified time in the future for more information. Further specific consent will be needed at the time of any study, so this initial letter is simply a means of enabling the patients to be contacted in order to obtain the informed consent. The form of the letter might be:

> *"We understand that you have reported experiencing awareness during a general anaesthetic. This letter simply asks if you are prepared to be contacted in the future with a view to answering anonymous questions by a postal questionnaire. If you say yes, we will need to ask your permission again before we send out any questionnaire, so you will be able to change your mind even if you say yes now. Any questionnaire we send to you in the future will have been checked by the ethics committee.*
> *If you do not wish to be contacted, then we will not write to you again.*
> *In either case, we assure you none of your contact details will be shared with anybody outside of this hospital and all questionnaires you answer will be anonymous."*

Whether the LC is able to write such a letter will depend upon the exact circumstances of the case, and the exact wording may change from patient to between Trusts.

If the patient responds to the above letter (eg, by signing a suitably-designed tear-off slip) in the affirmative, LCs may keep a register of patient contact details for the Psychological Workstream. If the patient responds in the negative, then any patient details should be kept in a separate register and the patient should not be contacted further.

A 'Brice Day'

The Brice questionnaire is short, consisting of 5-questions (see Appendix). In studies of AAGA it is normally administered to a patient after anaesthesia as a screening test to assess if they may have been aware. It is normally administered immediately in recovery, 24-48 hours postop and then after 2-3 weeks. If we adopt a workstream employing a Brice protocol, we will only seek to ask you to administer it in recovery on waking. It may be possible, with LC support and co-operation, to select a single day in which every case of general anaesthetic in your hospital (and hence the UK) is administered a Brice questionnaire. We may ask you briefly to indicate to us if you think this is feasible.

The day could also be an opportunity to obtain key information on components of general anaesthesia (eg, drugs, monitors, airway devices used, etc). Such a 'Brice Day' would be challenging and require ethical permission, so we will update you with the possibility of our being able to undertake this.

SPAs and support for LCs

It is our view that all activity related to the NAP5 Local Co-ordinator role is valid for inclusion in SPA activity, and should be used to help support the SPA allocation in consultant and career grade job plans (noting that 2.5 SPAs are regarded as 'typical' in the 2003 Consultant Contract Terms and Conditions). Where doctors who wish to act as Local Co-ordinators are prevented from doing so by inappropriate allocation of SPAs, or where Trust/ Boards fail to recognise this activity as appropriate for SPAs, both the Association and the

College will provide evidence in support of relevant activity. In recognition of the role played by the NAP local Co-ordinators if you agree to be a Local Co-ordinator for NAP5 we will send you a certificate confirming the role which you may include in your personal portfolio.

Yours sincerely,

Professor Jaideep J Pandit
Oxford & NAP5 Lead

Dr Tim Cook
Consultant Anaesthetist, Bath & NAP5 Advisor

Appendix: the Brice questionnaire

The Brice interview is used by anaesthetists to detect awareness. The interview comprises five questions addressed to the patient after surgery. The questions are based on the study by Brice at al in 1970 (Brice D, Hetherington RR, Utting JE. A simple study of awareness and dreaming during anaesthesia. Br. J. Anaesth. 1970: 42; 535-42) and are:

- What was the last thing you remember before going to sleep?
- What is the first thing you remember on waking up?
- Can you remember anything in between?
- Did you dream during the procedure?
- What was the worst thing about your operation?

FAQS

Q: Baseline survey: With this Guide, you have sent me 2 questionnaires - why?
A: One is for you to copy and distribute to your consultant and SAS colleagues. Please then collate their responses and populate the 2nd questionnaire (form 2). Send us only the 2nd (form 2) (departmental) questionnaire.

Q: Will NAP5 include cases of paediatric awareness?
A: Yes, all age ranges will be included

Q: If there are no cases of awareness at the end of the month, do I still need to upload 'zero' information?
A: Yes. We need to know that cases have been actively sought in the areas we have suggested.

Q: Do we need to ask each patient if they have been aware or administer a questionnaire?
A: No, the 'trigger' for a case is that the patient makes a report or a complaint to the healthcare (or legal) services

Q: Some colleagues are very enthusiastic and it is their normal practice to conduct a formal questionnaire to ascertain possibility of awareness after each and every anaesthetic. Do we include cases these colleagues report as 'awareness' in our return to NAP5?
A: Yes, but when you upload the information on the secure website, you will be asked to record in the details that this was a case detected by direct questioning and not a patient-triggered report.

Q: A patient complains they have been aware only at intubation – do we report this to NAP5?
A: Yes, and you will be asked the details so that we can record it as such.

Q: A patient complains they have been aware only at extubation – do we report this to NAP5?
A: Yes, and you will be asked the details so that we can record it as such.

Q: A patient who has been ventilated on the ITU for several days complains of having been aware – do we report this to NAP5?
A: No, and there should be a prompt on the secure website to remind that this is likely a different issue of 'awareness'

Q: An ITU patient undergoes a surgical procedure, and later complains of unpleasant recall of that procedure, but not of their time when ventilated on ITU – do we report this to NAP5?
A: Yes, and you will be asked the details so that we can record it as such.

Q: A patient has complained of awareness, but on our perusal of the casenotes we do not believe this to be genuine. What shall we do?
Report it but the questions on the secure website will ask your opinion of the merits of the claim, and there is free text for you to provide us with additional (non-identifiable) information.

Q: A patient makes a report/complaint of awareness during the data collection year 1 June 2012 – 31 May 2013, but the anaesthetic took place very many years previously and the casenotes are lost. What shall we do?
A: Please report the case in the normal way to NAP5, providing these anonymised details – you will be asked to state if casenotes are available or not. Please also try ensure you have sent the patient the letter asking if they are willing to be contacted again.

Q: We have sent initial letters to patients, so developed 2 local databases – one of patients willing to be contacted and one for patients not willing to be contacted. Do we send these databases to NAP5?
A: No. These are your own local databases, necessary for local service evaluation. The data must not leave the Trust/ Board. Any further approach to send questionnaires to patients willing to be contacted will only be through you, as intermediaries, so that the patient details remain anonymous to anyone outside the immediate anaesthetic provider team.

If you have any further queries relating to your role as LC, please do not hesitate to contact Professor Jaideep J Pandit, NAP5 Lead, via mcenan@nap5.org