



GUIDANCE MANUAL FOR THE 2014 ACCIDENT AND EMERGENCY DEPARTMENT (A&E) SURVEY

THE CO-ORDINATION CENTRE FOR THE
NHS PATIENT SURVEY PROGRAMME

Contacts

The Co-ordination Centre for the Patient Survey Programme
Buxton Court
3 West Way
Oxford
OX2 0JB

Tel: 01865 208127
Fax: 01865 208101
E-mail: emergency.data@pickereurope.ac.uk
Website: www.nhssurveys.org

Key personnel

Esther Ainley
Hannah Atherton
Maria Bogdanovskaya
Kelsey Flott
Chris Graham
Caroline Killpack
Jenny King
Mark Waters

Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the national survey. More guidance on how to reach ethnic minority groups can be found in Section 8. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised, and such results may not be acceptable for computation of the relevant measures within the Care Quality Commission assessments for that trust. If trusts want to make any adjustments to the method or materials set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability or impact on Research Ethics Committee or Section 251 approvals (see sections 6 and 7).

Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will e-mail all trust contacts and contractors directly to inform them of the change.

This document is available from the Co-ordination Centre website at:
www.nhssurveys.org

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1 Introduction: The importance of patient feedback

1.1 The Care Quality Commission

The national patient survey programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission took over from its predecessor, the Healthcare Commission, in April 2009 and is responsible for administering the programme. The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England and is responsible for administering the survey programme with the Survey Co-ordination Centre. CQC regulates care provided by the NHS, private companies and voluntary organisations and aims to ensure better care is provided for everyone – in hospitals, care homes and people's own homes.

CQC is committed to involving people who use health and care services in all its work, as well as ensuring that the providers of care services also involve and respond to people's views. The experiences of patients, people who use services, carers and families are at the heart of CQC's work.

By ensuring that organisations carry out these surveys in a consistent and systematic way it is possible to build up a national picture of people's experience and, *with care*, to compare the performance of different organisations, monitor change over time, and identify variations between different patient groups. The surveys are expected to inform local improvement activity; they are seen as an important source of information for people to help them choose between providers and for informing commissioners of services. As well as supplying NHS England and the Department of Health with data to assess performance against national targets on patient experience, the survey programme provides an important source of data for CQC's assessments.

1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the Patient Survey Programme is based at the Picker Institute and works under contract to the Care Quality Commission to design, test, and co-ordinate the patient survey programme.

1.3 Why we need patient feedback

Quality in health and medical care has two distinct dimensions. One has to do with the quality of care from the perspective of professional, technical standards; and the other dimension concerns the quality of care from the perspective of patients. Understanding the way patients experience the care they receive is essential to a complete assessment of the quality of healthcare, and this can only be obtained by asking the patients themselves.

It is important to adopt systematic, appropriate and effective ways to ask patients about their experiences, and use this information to shape and improve the way healthcare is delivered. This manual is designed to help staff in NHS hospital trusts to obtain patient feedback through the national patient survey. It also provides guidance on how you may use the information you gather in quality improvement programmes and for monitoring performance. By following this guidance, you will also help to ensure that the survey results from your trust are comparable with other trusts, and with national benchmarks.

1.4 Patient feedback and the NHS Constitution

Improving the experience of each individual patient is at the centre of the NHS Constitution. Obtaining feedback from patients and taking account of their views and priorities are vital for the delivery of high quality services and for driving real service improvements.

The NHS Constitution requires that NHS services reflect the needs and preferences of patients, their families and their carers. It is therefore important that all NHS trusts carry out local surveys asking patients their views on the services they have received. The national patient survey programme is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this by:

- providing information to support local quality improvement initiatives
- tracking changes in patient experience locally over time
- providing information for active performance management
- providing information to support public and parliamentary accountability
- providing information for the Care Quality Commission to inspect and regulate services

1.5 Care Quality Commission assessments

Information drawn from the questions in the A&E survey will be used by the Care Quality Commission (CQC) in its assessment of trusts in England, both as part of intelligent monitoring of services and to support hospital inspections. A consultation regarding our new approach to regulation closed on 12th August 2013. On 18th July CQC's new Chief Inspector of Hospitals, Professor Sir Mike Richards, announced radical changes to the way CQC inspects hospitals. The announcement included details of the new methods to be used, which are based on the proposals in the consultation.

More information about CQC's consultation can be found here

<http://www.cqc.org.uk/public/sharing-your-experience/consultations/consultation-changes-way-weinspect-regulate-and-monito>

More information on Sir Mike's announcement and CQC's new way of inspecting hospitals can be found here <http://www.cqc.org.uk/public/news/prof-sir-mike-richards-chief-inspector-hospitalsannounces-our-inspection-plans>

1.6 Measuring performance over time

In addition to performance assessment, the Care Quality Commission will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data, while providing a detailed picture of patients' experiences. Information collected nationally in a consistent way is also essential to support public and Parliamentary accountability. The results are also used by NHS England and the Department of Health (DH) for performance assessment, improvement and regulatory purposes. These include the NHS Outcomes Framework (domain 4: Ensuring patients have a positive experience) and the Patient Experience Overall Measure. Results can also be used for NICE Quality Standards.

The Care Quality Commission intends to archive the survey data with the UK Data Archive after the analysis is completed and published. This will be done with appropriate safeguards that ensure patient confidentiality.

1.7 Basic requirements for the A&E Survey

For comparisons between and within trusts to be accurate, fair and effective, it is essential that the surveys are carried out using a standard procedure in all NHS trusts. Furthermore, this is essential in order to comply with the procedures and standards covered by the Research Ethics Committee and Section 251 approvals. Those standards are set out in detail later in this document. In summary, they are as follows:

- You should already have contacted the Co-ordination Centre to tell them who is carrying out your survey (i.e. whether it will be carried out by an approved contractor or in-house). Please do this by e-mail: emergency.data@pickereurope.ac.uk).
- The survey must be carried out using a postal questionnaire.
- The sample of patients must INCLUDE DETAILS as outlined in Section 10 - Compiling a list of patients.
- You must also submit a [sampling checklist declaration](#) when your sample is submitted to the Co-ordination Centre. This confirms all patient names and addresses have been removed from the sample file.
- Sample data must be submitted to the Co-ordination Centre for final checks before mailing as outlined in Section 11 - Final sampling inspection by the Co-ordination Centre. You should aim to submit these sample files to us between **21st April and 16th May 2014**. Submitting at the start of this period will allow sufficient fieldwork period to maximise your response rates.
- You should aim to obtain the highest response rate possible. For this survey, the target response rate is 50%, (that is, you should get 425 returned questionnaires from the 850 mailed out). Three mailings will be necessary for most trusts to achieve this target. However, trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible and by publicising the survey to staff, patients and the community
- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **8th May 2014**. A spreadsheet has been created for this purpose. For further details see Section 12 – Weekly monitoring
- The questionnaire must include the 51 questions. See Section 14 - The questionnaire
- The standard covering letters and reminder letters (which can be found at <http://www.nhssurveys.org/surveys/755>) must be used as outlined in Section 15 – Materials
- Two reminders must be sent to non-responders, even if a 50% response rate is already achieved. These procedures are outlined in Section 16.7 – Sending out reminders
- The data must be checked carefully for errors before submitting it to the Co-ordination Centre. Specific advice on how to carry this out is included in Section 17.4 – Checking for data errors
- Two paper copies of the questionnaire you used and the covering letters for each mailing must be submitted to the Co-ordination Centre in the form outlined in Section 17.4 – *Submitting data to the Co-ordination Centre* - by **30th May 2014**
- The data from the core questions, and the required information about the patient sample, must be submitted to the Co-ordination Centre in the form outlined in Section 17.4 – *Submitting data to the Co-ordination Centre* - by **5th September 2014**
- The free text comments must also be submitted to the Co-ordination Centre. These should be included as part of the main data file and submitted at the same time as the survey response data.

- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until **5th December 2014** but please do not send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre.
- You must not delete the sample file from your records until 5th December 2014 in case there are any queries from the Co-ordination Centre.

1.8 Why you need this guide

Trusts have the option of conducting the survey in-house or using an approved contractor (see Section 4). Whichever route you take, you will need to address the guidance in sections 1 to 13 and 18 to 20 of this guide. Sections 15, 16 and 17 cover the practicalities of mailing out the survey, following-up responses and processing data, and submitting it to the Co-ordination Centre. These sections will be most relevant to approved contractors, or trusts undertaking the surveys themselves. Section 14 contains details of the questions in the core and bank questionnaires.

2 Setting up a project team

Whether you choose to do the survey in-house, or to use an approved contractor, we recommend you set up a project team to assist you. The best way to ensure that your survey is a success is to work hard *in the beginning* to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey.

We suggest:

- **Establishing a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
 - Board members
 - Doctors, nurses and other health care staff
 - Managers
 - Medical records personnel or Patient Administration System (PAS) staff
 - Patients and carers
 - Members of patient groups with a special interest in the trust
 - Caldicott Guardian
 - Staff or directors responsible for:
 - Clinical governance
 - Patient advice and liaison service (PALS)
 - Quality improvement
 - Strategic planning
- **Involving the person responsible for drawing the patient sample in planning meetings.** It is essential that this person, and their line manager, understand the purpose of the survey and the importance of drawing the sample correctly.
- **Keeping everyone informed.** Notify as many people as possible about ideas and activities. All Departments in the trust should be made aware when a survey is being conducted, in case patients contact the trust (eg the Emergency Department or PALS) asking questions about the survey they have received.
- **Not overlooking front-line staff.** These people have the most direct impact on patients' experiences.

3 What's new for 2014?

The 2014 A&E questionnaire has been kept as similar as possible to the 2012 version to allow comparisons to be made between survey years. There are now 51 core questions, a net loss of one question since the 2012 survey. The changes made to the questionnaire are listed below:

2 new questions have been added to the questionnaire:

If you were feeling distressed while you were in the A&E Department, did a member of staff help to reassure you?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I was not distressed
- 5 Not sure/ can't remember

Who was the main person or people that filled in this questionnaire?

- 1 The **patient** (named on the front of the envelope)
- 2 A **friend or relative** of the patient
- 3 **Both** patient and friend/relative together
- 4 The patient with the help of a health professional

2 questions have been taken from the 2012 question bank and added to the 2014 questionnaire:

Did you request pain relief medication?

- 1 Yes **→ Go to 29**
- 2 No **→ Go to 30**
- 3 I was offered or given pain relief medication without asking **→ Go to 30**

How many minutes after you requested pain relief medication did it take before you got it?

- 1 0 minutes / right away
- 2 1 – 5 minutes
- 3 6 – 10 minutes
- 4 11 – 15 minutes
- 5 16 – 30 minutes
- 6 More than 30 minutes
- 7 I asked for pain relief medication but wasn't given any

2 questions have had the response options modified:

Who advised you to go to the A&E Department? **(Cross ONE only – if more than one option applies, cross the MAIN source of advice)**

- 1 The ambulance service
- 2 A doctor or nurse at a walk-in centre or minor injuries unit
- 3 A GP out of hours service
- 4 A GP from my local surgery
- 5 An NHS telephone advisor (e.g. NHS 111 or NHS Direct)
- 6 Some other health professional (e.g. pharmacist)
- 7 Somebody else (e.g. friend, relative, colleague)
- 8 No-one, I decided that I needed to go
- 9 Don't know / can't remember

Do you have any of the following long-standing conditions? (CROSS ALL THAT APPLY)

- 1 Deafness or severe hearing impairment **→ Go to Error!**
Reference source not found.
- 2 Blindness or partially sighted **→ Go to Error!**
Reference source not found.
- 3 A long-standing physical condition **→ Go to Error!**
Reference source not found.
- 4 A learning disability **→ Go to Error!**
Reference source not found.
- 5 A mental health condition **→ Go to Error!**
Reference source not found.
- 6 Dementia **→ Go to Error!**
Reference source not found.
- 7 A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy **→ Go to Error!**
Reference source not found.
- 8 No, I do not have a long-standing condition **→ Go to 51**

1 question has had minor changes to question wording:

Before your most recent visit to A&E, had you previously been to this A&E about **the same condition** or something related to it?

- 1 Yes, within the previous week
- 2 Yes, between one week and one month earlier
- 3 Yes, more than a month earlier
- 4 No
- 5 Don't know / can't remember

Did doctors or nurses talk to each other about you as if you weren't there?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

4 questions have been removed from the questionnaire:

How well do you think the ambulance service and A&E staff worked together?

- 1 Very well

- 2 Fairly well
- 3 Not very well
- 4 Not at all well
- 5 Don't know / can't remember

How clean were the toilets in the A&E Department?

- 1 Very clean
- 2 Fairly clean
- 3 Not very clean
- 4 Not at all clean
- 5 I did not use a toilet

While in the A&E Department, did you ever see any posters or leaflets explaining how to complain about the care you received?

- 1 Yes
- 2 No
- 3 Don't know/ can't remember

How many times (including this one) have you visited an A&E department **as a patient** in the last 12 months?

- 1 This was the only time
- 2 2 – 3 times
- 3 4 – 5 times
- 4 6 or more times
- 5 Don't know / can't remember

Question bank

For the 2014 survey, no question bank will be available. Only the core version of the questionnaire should be used to assist trusts with maximising their response rates.

Sampling month for 2014

Trusts can choose to sample from January or February or March 2014. Trusts should select the month most reflective of their normal performance, and we recommend you select the same month as in 2012 for comparability purposes. Please note for the A&E Survey, trusts need to take a

systematic sample of 850 patients from a list sorted by year of birth, gender and GP Practice Code (GPPC).

GP Practice Code (GPPC)

Formerly known as the General Medical Practice Code (GMPC). We will require this piece of information to do additional analyses so it must be in both the sample and final data.

Sampling checklist declaration

For this year we have introduced an additional checklist- this is a document that needs to be completed at the time of sampling and will be submitted to the Co-ordination Centre alongside your sample when transferred for checking. This form must be completed by the person who drew the sample at your trust and asks you to be 100% certain that all patient identifiable data (patient names and addresses) have been removed from the sample file. If this data is transferred to the Co-ordination Centre as part of the sample file, this is considered a breach of the survey's Section 251 Approval and CQC will be required to take action.

Letters

Since 2012, the first mailing letter and second reminder mailing allow for the inclusion of patient name. We strongly recommend this approach as there is evidence that this increases response rates. If you decide to include patient name, we recommend using patient title followed by surname. The salutation will also be a mail merge field allowing you to either use 'Yours sincerely' or 'Yours faithfully' depending on whether you decide to use patient names.

For 2014, we have also added a section in the letter where you can include a short paragraph highlighting how the 2012 survey results have resulted in action taken by your trust to improve particular aspects of patient experience and quality of care. Providing evidence of how patient's feedback has led to direct change at a trust will demonstrate the value and importance of the survey and encourage participation from patients.

CQC flyer

CQC have produced a flyer that should accompany the first mailing and second reminder to all respondents. This highlights the value of the data to CQC. All contractors and trusts undertaking their own mailings will be given sufficient copies of this flyer to insert in mailing envelopes.

Instructions for completing the questionnaire

Following changes on other surveys with the national programme, respondents to the 2014 A&E survey will be asked to cross, rather than tick boxes (e.g. instead of) in the instructions for completing the questionnaire contained on the front page of the questionnaire.

Patient record number

The format of the patient record number was revised as of the 2012 survey. Again, for the 2014 survey, the number should be in the format AE14XXXNNNN where XXX is your 3-digit trust code and NNNN is the 4-digit number relating to your sampled patients, e.g.

AE14	ABC	0001
↑	↑	↑

Free Text Comments

For 2014, patients' written comments ('free text') should be submitted to the Co-ordination Centre in an **anonymised format** along with the final data file. Please note that we require free text comments to be submitted at the same time as the main data file on **5th September 2014**. This is discussed further in Section 17.

Hard copy of questionnaire and cover letters

Please could you send a hard copy of your questionnaire and cover letters by 30th May 2014 to:

A&E Survey 2014
The Patient Survey Co-ordination Centre
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

3.1 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to patients does not show any indication of the NHS Trust. Some patients may not have told family or friends that they have gone to hospital and, under data protection regulations, it is important that this information remains confidential to the patient.

PO Box

For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently, in-house Trusts are advised to set up a PO Box so that mail which is undelivered can be returned (please see section 16.2 for further detail).

Patients who have requested that their details are not used for secondary purposes such as research

If your trust has a mechanism in place to flag patients that do not wish their data to be used for secondary purposes, we advise that you refer to this when drawing your sample. You will need to indicate on the sampling checklist declaration that patients who have indicated dissent have been removed from your sample, and the total number of patients removed for this reason. Please see Section 6.2 - *Section 251 Approval* - for further detail.

3.2 Important information to remember

Questionnaire: This year only a core version of the questionnaire is available, which should be used consistently in all trusts. Please do not add any additional questions. We recommend font size 12 for all questions and response options. **Please also ensure the questionnaire is an**

exact copy of the template if you are transcribing the questionnaire as any errors in wording or filters can make the data unusable.

Ethnic category: Ethnic category will be requested in the standard 16 + 1 alphabetical format. However, in the past there was some confusion over what data should be coded as “Z” (“not stated”). This code should be used **only** when a person had been asked for their ethnic category and had declined either because of refusal or genuine inability to choose. A blank or full-stop should still be used to indicate where ethnic category is “not known” i.e. where the patient had not been asked or the patient was not in a condition to be asked, e.g. unconscious. For most trusts, ethnic category will contain both “Z” codes **and** “blanks”. Further information can be found in section 10.6 – *Create the sample file*.

Embargo on results: Trust-level findings for the A&E Survey 2014 should **not** be released outside of the hospital/trust until the national results are published by the Care Quality Commission. Please continue to use the results from your in-house survey teams or approved contractor to improve services, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. **This is because any benchmarking data you are provided with by your contractor will not include all trusts who participate in the survey across England.** For this reason there may be some difference in your performance compared to others when CQC results are released. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

4 Deciding whether to use an approved contractor or carry out the survey in-house

Trusts may choose to carry out their surveys in-house or to commission an approved contractor to carry out the work for them. We do not recommend you carry out large-scale surveys such as these in-house if you do not already have experience in carrying out surveys. Tracking large surveys with appropriate follow-up is an administratively complex task requiring dedicated resources for several months. Getting systematic feedback from patients requires money, resources and staff time. Considering the following questions can help you decide whether it makes sense for your trust to conduct the survey in-house or to commission an approved contractor:

- Costs
- Internal resources/Expertise
- Timing
- Quality and confidence in the findings

Please remember that if the survey is not undertaken in accordance with the guidance manual, the results for your trust might not be eligible for inclusion in any CQC publications, or assessments. In turn, it would not be available for use by others, such as NHS England and the Department of Health, for performance assessment, improvement and regulatory purposes.

4.1 Costs

The financial resources needed to carry out a survey in-house are often underestimated. The following is a list of the main items of expenditure for a postal survey, including the two reminders that must be sent out for all NHS trust surveys.

Staff time

This is one of the largest expenditures but it is sometimes overlooked. Be sure to include the cost of staff time, including salary and fringe benefits, and time spent away from other work. Please note that weekly submissions will be required for each trust taking part in the A&E Survey 2014, involving increased staff time for both trusts and contractors compared with previous surveys.

Stationery and postage

You will need to cover the cost of stationery and postage for three mailings. The first mailing will go out to 850 patients and the second and third mailings will be sent only to non-responders (see Section 15 – *Materials* for more details). You will need to cover the cost of second class postage for three mailings, two of which will include the questionnaire.

FREEPOST licence

There is a charge for obtaining a freepost license which enables you to print a freepost address on return envelopes so that respondents can send back completed questionnaires at no cost to themselves. You will also be charged for each returned questionnaire. (For details, see 16.1 – *Setting up a FREEPOST address*).

PO Box

For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently, in-house Trusts are advised to set up a PO Box so that mail which is undelivered can be returned to sender. There is a fee for setting up a PO Box. (For details, see 15.3– *Mail out envelopes*).

FREEPHONE service

This service gives patients easy access to advice and staff who can reassure them on any concerns they have about the survey. The cost of setting up such a service and of staff time in responding needs to be included. (For details, see 16.3 – *Setting up a FREEPHONE line*).

Data entry

If the data are entered manually, you will need to allow enough staff time for this, and for checking the accuracy of the data file. Alternatively, a data processing or scanning company may be contracted to process the data for which there would be a charge. We recommend you allow enough time for agreeing the details of a contract with a company and discussing their specific requirements (such as the size of the response boxes). If you use in-house scanning equipment, allow time for setting it up to read the data correctly from questionnaires and for checking this is accurate.

Design and production of reports

This requires a considerable amount of skilled staff time.

4.2 Internal resources

To carry out a survey effectively, the following areas of experience and skills are needed:

- Administration of postal surveys
- Communication with and co-ordination of multi-disciplinary teams
- Data entry, validation and cleaning
- Data analysis and interpretation, and familiarity with a statistical computing package
- Report writing.

4.3 Timing

It is often possible to carry out small, localised surveys quickly in-house. However, even in the best of situations, other demands on staff can side-track them into other work. If you commission an approved contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set. **The deadlines set by the Coordination Centre must be met in order for data to be submitted in time to the Care Quality Commission.**

4.4 Quality and confidence in the findings

It is important to remember that the results of the survey will be used not only within the trust to identify areas for improvement but also by the Care Quality Commission and NHS England to contribute to performance assessment and possibly for other uses, such as the NHS Choices

website. It is therefore essential that the data are as accurate and reliable as possible and that the information is gathered in the same way for all trusts. Using the expertise of an approved contractor may add credibility to the survey findings in the eyes of staff, patients and the general public.

When you have decided who will carry out your survey, ie an in-house team or an approved contractor, you must inform the Co-ordination Centre by 4th April 2014.

5 Commissioning a survey from an approved contractor

The framework agreement set up by the Care Quality Commission covers the core survey process. Approved contractors are expected to provide the following services:

- Advising on sampling, providing support to trusts for sampling
- Printing questionnaires, covering letters, reminders and providing consumables
- Handling receipt of questionnaires, liaising with trusts re non-responses and reminders
- Support to ensure good response rates, eg. FREEPHONE line
- Data entry, cleaning data and providing data to Co-ordination Centre by the deadline
- Preparing standard reports for trusts.

Four organisations have been approved by the Care Quality Commission to carry out surveys for the NHS patient survey programme and have been approved to work on the A&E survey. Trusts may commission any one of these contractors without further tendering the survey work. Before committing to a contractor, you are advised to **check exactly what is covered** within the cost.

Information about each of these organisations can be found on the NHS Surveys website.

5.1 List of approved contractors

If a Trust chooses to use a contractor, it is a requirement of the survey that one of the following approved contractors is used:

Capita Surveys and Research

Contacts: Cheryl Kershaw and Aimi Blueman

Spa House
Hookstone Park
Harrogate
HG2 7DB

Tel: 01423 818700

E-mail: Cheryl.kershaw@capita.co.uk; Aimi.blueman@capita.co.uk

Website: www.capitasurveys.co.uk

Patient Perspective

Contacts: Stephen Bruster and Chris Henderson

Standingford House
26 Cave Street
Oxford
OX4 1BA

Tel: 01865 205100

Fax: 01865 205111

E-mail: stephen.bruster@PatientPerspective.org, chris.henderson@PatientPerspective.org

Website: www.PatientPerspective.org

Picker Institute Europe

Contacts: Tim Markham, Matt Cadby, Lucas Daly and Vincent Coole

Buxton Court
3 West Way
Oxford
OX2 0JB

Tel: 01865 208100
Fax: 01865 208101
E-mail: surveys@pickereurope.ac.uk
Website: www.pickereurope.org

Quality Health

Contacts: Dr Reg Race, Kerry Hibberd, Daniel Ratchford, Lucinda Phillips and Mandy Moore

Unit 1 Holmewood Business Park
Chesterfield Road
Holmewood
Chesterfield
Derbyshire
S42 5US
Tel: 01246 856263 Fax: 01246 855897

Email: reg.race@quality-health.co.uk; kerry.hibberd@quality-health.co.uk;
daniel.ratchford@quality-health.co.uk; lucinda.phillips@quality-health.co.uk;
mandy.moore@quality-health.co.uk
Website: www.quality-health.co.uk

5.2 Contracts with survey contractors

The Care Quality Commission has produced a document that we shall refer to as the 'service contract', for NHS trusts to use as a template agreement when providing sampling details to their approved contractor. Further details are available in *Section 6– Data protection and confidentiality*. The CQC strongly recommend that the contract template is reviewed by your trust and legal advice is obtained to ensure each clause is relevant and accepted by the trust. Further details are available in *Section 6 – Data protection and confidentiality*

We suggest that the service contract is used as either an arrangement separate to the financial agreement made between a trust and an approved contractor when commissioning that contractor, or combined with the financial agreement to minimise the administrative burden. In either case, trusts should specify the following when confirming the requirements of the contractor:

- The groups, and numbers, of patients to be surveyed
- The survey methodology (i.e. postal questionnaire with two reminders to non-responders)
- Exactly what the survey provider and the trust are responsible for in carrying out the survey project (division of responsibilities)
- The main contact at the survey provider and the individual at the trust responsible for managing the project
- A timetable showing the dates when each task is to be carried out and by whom

- The outputs of the project. That is, types of and numbers of reports to be delivered and details of any presentations to be carried out by approved contractors
- The costs and a payment schedule.

6 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. **If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects.** You will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles. You should take particular care to ensure that your use of patient data in carrying out the survey complies with these six principles. In particular, you should be aware of the flows of patient data, and the issues which these present.

The Caldicott Principles

Each NHS trust has a Caldicott Guardian who is responsible for overseeing proper use of patient data. They have to ensure that any use of patient data conforms to the following principles:

- **Principle 1:** Individuals, departments and organisations must justify the purpose(s) for which information is required
- **Principle 2:** Don't use patient-identifiable information unless it is absolutely necessary
- **Principle 3:** Use the minimum necessary patient-identifiable information
- **Principle 4:** Access to patient-identifiable information should be on a strict need-to-know basis
- **Principle 5:** Everyone should be aware of their responsibilities
- **Principle 6:** Understand and comply with the law

It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors (see section 5.2). Your trust's Caldicott Guardian and legal advisors should be able to advise you on these matters.

Guidelines on the use and security of the data collected have been agreed by the Care Quality Commission and the Patient Survey Co-ordination Centre. These guidelines will help to ensure that data are handled in a manner most in keeping with the spirit of the Data Protection Act 1998 and the Market Research Society's *Guidelines for social research* (2005). They have implications for approved contractors and for NHS trusts conducting surveys in-house.

Their website below has further information:

<http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/fs/en>

Information about the Data Protection Act 1998 can be found at the [ICO – Information Commissioner's Office](http://www.ico.gov.uk) (<http://www.ico.gov.uk>)

Further guidance can be found in the Market Research Society document at http://www.mrs.org.uk/standards/downloads/revise/legal/data_protection_social.pdf

6.1 Statements of compliance with data protection

In-house surveys

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of patient data. If you are conducting the survey in-house then, before mailing out the sample, you must submit a formal declaration (see Appendix 1), signed by the Caldicott Guardian and survey lead(s) for the trust, to the Co-ordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines. Templates for these declarations are available on the website containing the survey guidance (<http://www.nhssurveys.org/surveys/757>).

You must wait for confirmation of receipt from the Co-ordination centre before you mail out your sample.

If the Caldicott Guardian is unable to make such a declaration, then the trust must use an approved contractor to ensure that appropriate standards of confidentiality data protection are maintained.

Approved contractors

The framework agreement between the approved contractors and the Care Quality Commission contains clauses stating that the approved contractor will comply with the Data Protection Act so no declaration is required if a trust appoints a contractor. The contractors' procedures and policies have also been reviewed as part of the recommendation for support under section 251 of the NHS Act 2006, granted by the Health Research Authority Confidentiality Advisory Group have each completed the relevant sections of the Information Governance Toolkit¹.

6.2 Section 251 Approval

Approval for the NHS A&E Survey 2014 was sought this year, as it was in 2012, under section 251 of the NHS Act 2006. This approval allows the common law duty of confidentiality to be put aside in order to enable the processing of patient identifiable information without consent. The survey methodology was reviewed by the Health Research Authority (HRA), covering trusts using an approved survey contractor (those listed in Section 5). Their Confidentiality Advisory Group (CAG) of the Health Research Authority (previously NIGB) granted a recommendation of support on 4th March 2014. **Please note that any deviation from the methodology outlined in this guidance manual may render the approval invalid.**

The recommendation of support does not cover the transfer of patient identifiable information where a patient has indicated dissent - by this we mean instances where a patient has indicated that they do not want their information to be shared for purposes such as patient surveys, or specifically stated that they do not want their details shared outside of the trust.

Consequently, if any patients have indicated that they do not want their records used for secondary purposes (e.g. they have asked to be excluded from all surveys or they do not want their address details shared for any reason other than clinical care), please ensure that these patients are excluded from your mailing list. This should be done using your local records.

¹ <https://www.igt.connectingforhealth.nhs.uk/>

There is, however, evidence available from research to suggest that a considerable degree of bias is likely to be introduced depending on the stage at which 'dissent' is recorded, the severity of patients' conditions, and their understanding of the aim and purpose of the research or evaluation. Such bias would negatively impact on the results for a trust.

In order to keep the potential for bias to a minimum, we request that trusts ensure that where any opportunity is provided for patients to opt out, patients are made aware of the purpose of this specific use of the data, including the aim of the NHS Patient Survey Programme and how data will be used by the Care Quality Commission (and others) to assess and improve the care that is provided in the future. Information on the NHS Patient Survey Programme is available on the CQC website here: www.cqc.org.uk/public/reports-surveys-and-reviews/surveys

Please discuss this issue with your Caldicott Guardian to ensure that any patients who have indicated that they do not wish to have their details shared for purposes such as this survey, yet may have sufficient address details visible in PAS, are not included in the sample that is submitted to contractors/Co-ordination Centre.

For more information on the fair processing of data, please see the Q&A on the NHS surveys website at:

http://www.nhssurveys.org/Filestore/documents/20120704_FAQs_on_fair_data_processing_draft4.pdf

6.3 Keeping patient mailing data and sample data separate

For patient confidentiality reasons, patient responses must never be matched to the patients that made them. The best way to ensure this is to store patient names and address details separately from sample information or survey response data. **For this reason, we strongly recommend that once the sample has been returned from DBS and the 850 patients are finalised, patient names, addresses and postcodes are removed from the sample file to a 'mailing file'.**

Before this is done, it is essential each patient is provided with a unique number (a patient record number (PRN)) and that this number is available and correctly matched on both the 'mailing file' and the sample information file (the 'sample file') (see Sections 10.5 and 10.9). Note the PRN must be in the format: AE14XXXNNNN where XXX is your trust's 3 digit trust code and NNNN is the 4 digit number relating to your sampled patients, e.g., 0001-0850.

It is fundamentally important to remove all patient identifiable data (patient names and addresses) from the sample file- any patient identifiable data that is transferred as part of the sample file is considered a breach of our Section 251 Approval for this survey. If this happens, we have to inform the Confidentiality Advisory Group about the breach including details of what happened.

6.4 Mailing questionnaires to patients

When working with approved contractors, trusts must be aware of any implications for data protection when deciding who should mail out the questionnaires. There are two common methods practised by trusts, and advised by the Care Quality Commission, when working with approved contractors:

1. **The contractor mails out the questionnaires.** If a contractor is going to be mailing out questionnaires on behalf of a trust, this will require the trust to share patient name and address details with their approved contractor. This method is only possible if the contractor is carrying out the work under a service contract, which can be set up with the agreement of the trust's Caldicott Guardian. The Care Quality Commission has provided the template service contract for trusts and approved contractors carrying out the survey, to avoid the need for each trust to develop its own arrangements. It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required. When personal data is shared with contractors, trusts must adhere to the principles outlined in Sections 6.5 and 6.6 below.
2. **The trust mails out the questionnaires.** If a Trust has not signed a service contract with a contractor then they will have no recourse if any breach of the contract were to occur. In this case the Trust must conduct the survey mailing in-house. The contractor will deliver pre-packed envelopes (clearly marked with the patient record number) containing questionnaires, covering letters and FREEPOST envelopes to the trust. The trust must then attach number-matched address labels to the envelopes and send them out to patients. Completed questionnaires can then be returned to the contractor and, by checking the record numbers on returned questionnaires, they can inform the trust which patients need to be sent reminders. This process is described in more detail in Sections 16.5-16.7.

6.5 Sharing personal data (patients' names and addresses)

Please note that under the data protection guidelines for patient surveys, the following principles **must** be followed:

- Trusts/contractors must undertake to keep their products up to date to ensure that security is effective and must strictly observe the following guidance. The requirements that dictate the guidelines include the Data Protection Act 1998, the Health and Social Care Act (Community Health and Standards) Act 2003 and the NHS confidentiality code of practice 2003 (which incorporates the Caldicott principles), see: [https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality - NHS Code of Practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf)
- Personal data such as names and addresses must be sent by trusts to contractors securely (please see further details below).
- As the owners of the data, the method for transferring patient samples is ultimately the trust's decision because the trust remains legally responsible for the security and processing of the information it shares. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health see: <http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf>

6.6 Encryption of personal data

Any patient identifiable information sent between trusts and contractors should be in an encrypted format with password protection to help ensure good standards of information security. Many different encryption algorithms exist and not all of these are suitable, so both the Coordination

Centre and the Care Quality Commission very strongly recommend the use of the **256-bit AES** (Advanced Encryption Standard) algorithm. There are several software tools that can be used to encrypt data in this way, the most commonly available of these being WinZip® (v9 and above)².

6.7 Contractor responsibilities (service contract)

A service contract has been drafted by the Care Quality Commission. This is an agreement between the approved contractor and the trust contracting them. By signing it, the approved contractor is obliged to keep the information confidential at all times, and to comply with the Data Protection Act 1998. It provides the trust with some recourse if any breach of the Data Protection Act were to occur, as a result of the actions of the approved contractor. The document also ensures that approved contractor staff members sign and abide by the contract, as it is set up between the trust and the approved contractor who will have access to patients' information. The contract describes how patients' personal data will be sent to the approved contractor, and how the data can be used.

The service contract in Word format is available on the NHS Surveys website (<http://www.nhssurveys.org/surveys/762>).

The service contract is designed to be used as a template contract; trusts and approved contractors may agree on amendments to the wording and content when using them.

6.8 Patient anonymity

In-house surveys

It is important to ensure that any claims you make about patient anonymity are accurate; and you are obliged by law to honour any statements that you do make. In most cases where a survey is carried out in-house, it is not accurate to tell patients that their responses will be anonymous. The person who receives the completed questionnaires is usually able to match these responses to patient names and addresses.

Approved contractors

Patient anonymity can be achieved if there is a clear separation between the information seen by an approved contractor and the information held by the trust. Patients' names and addresses will be seen by trust staff when generating the sample, while contractor staff will usually possess both patient details and patient responses. As long as the response data supplied to trusts do not include patient record numbers or any other detail that allows individuals to be identified or linked, it can reasonably be claimed, with regard to the trust and trust staff, that patients' responses are anonymous.

6.9 Patient confidentiality

It is essential that any patient survey is conducted in such a way that patient confidentiality is respected and given a high priority. The covering letters that accompany the mailed questionnaires inform patients that their name and address will never be linked to their responses.

² <http://www.winzip.com/>

Furthermore, patients' responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a patient is known to have visited the A&E Department on a particular date, and his or her year of birth, sex and ethnic category are known from their survey responses, it might be possible to use this information to identify them. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

Trust level

- 1) The raw data set should not be provided to any member of staff at the trust who do not need to view it, i.e. those who are not directly working on the project
- 2) Additional data analysts may be added later by a second submission of the declaration of compliance to the Co-ordination Centre (see Appendix 2). Additional data analysts cannot view the raw data until approval has been received from the Co-ordination Centre.
- 3) If data are to be presented to other trust staff who have not signed the declaration using the declaration of compliance, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than **30 respondents** should be suppressed (replaced by a dash). The data should be presented as in the following example. In this case, responses for the 'Mixed' and 'Asian' ethnic categories are suppressed (though the subgroup totals are shown):

Ethnic category	Q12. Did the doctors and nurses listen to what you had to say?			
	Yes, definitely	Yes, to some extent	No	Total responses
	%	%	%	n
White	71	10	19	261
Mixed / multiple	-		-	18
Asian	-		-	28
Black / African / Caribbean	69	13	18	52
Other	81	15	4	36

- 4) Do not present response information (including comments) in a form that allows an individual patient to be identified by the group receiving the information. For example, if you are presenting the results of a small number of patients, make sure that it will not be possible for the reader/audience to identify individual patients from their responses, and pay particular attention to the patients' free text comments in this context.

The electronic file containing the patients' names and addresses should be stored securely (ie password protected). Access to the file should be given only to those individuals who have signed the declaration of compliance.

Approved contractor

- 1) Approved contractors must not provide raw data to the trust as a matter of course.

- 2) If the trust has a particular need for the raw data from the survey from the approved contractor, the contractor may provide an abridged version of this dataset to the trust upon request, providing that the steps below are undertaken first:
- The contractor must delete the two variables pertaining to ethnicity (both sample and response variables).
 - The contractor must delete the responses to questions Q47 and Q48 pertaining to the respondents' religion and sexual orientation.
 - The contractor must band year of birth into four age groups (16-35, 36-50, 51-65, 65+). This process should be repeated separately for both sample and response variables. The original year of birth variables (eg those specifying an exact year rather than age group) must then be deleted.
 - The date of attendance at the A&E Department must be removed.
 - The contractor must band the time of attendance at the A&E Department into time periods of *at least* four hours (e.g. 09:00-12:59, 13:00-16:59, 17:00-20:59, 21:00-00:59, 01:00-04:59, 05:00-08:59). The original time of attendance variable must then be deleted.
 - Any additional information specific to the survey that can be used to identify individual patients must also be removed e.g. GPPC.
 - Free text comments that could lead to any staff identifying respondents must be removed, eg those mentioning patient, staff, ward, or unit names³.
 - Receive confirmation from the trust that they have destroyed the names and addresses of the sampled patients, otherwise they will be able to identify individual patients by matching up the patient record number/serial numbers on the name and address list to those in the raw data file.

These steps **MUST** be followed before supplying raw data to trusts. This is to prevent the disclosure of a patients' identity by specific demographic factors. Different arrangements govern the supply of raw data to the co-ordination centre. The arrangements are described in full in Section 17. The response data will be anonymous when passed to the Co-ordination Centre and Care Quality Commission, and published and archived results will not identify patients.

If data are to be presented to trust staff, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than **30 respondents** should be suppressed. The data should be presented as in the following example. In this case responses for the 'Mixed / Multiple' and 'Asian' ethnic categories are suppressed (though sub-group totals are shown):

Ethnic category	Q12. Did the doctors and nurses listen to what you had to say?			
	Yes, definitely	Yes, to some extent	No	Total responses
	%	%	%	n
White	71	10	19	261
Mixed / Multiple	-		-	18
Asian	-		-	28
Black / African / Caribbean	69	13	18	52
Other	81	15	4	36

³ Please be aware that there are exemptions allowing disclosure, such as the prevention of crime exemption which **might** allow disclosure of free text describing criminal matters actual or threatened. Neither the Care Quality Commission nor the Co-ordination Centre can offer legal advice on these matters; the contractor or trust must seek its own independent legal advice before disclosing patients' comments to trusts.

Furthermore, do not present response information (including comments) in a form that allows an individual patient to be identified by the group receiving the information. For example, if you are presenting the results of a small number of patients, make sure that it will not be possible for the reader/audience to identify individual patients from their responses, and pay particular attention to the patients' free text comments in this context.

The electronic file containing the patients' names and addresses should be stored securely (ie password protected). Access to the file should be given only to those individuals who have signed the service contracts.

6.10 Sharing of survey data between contractors

If a trust will be using a different approved contractor than in the last survey year, contractors are permitted to transfer an unabridged version of the data set if there is a clear need to use the data from the previous year's surveys to allow year-on-year comparison.

6.11 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names, and the questionnaires kept until 5th December 2014. All mailing lists of patients' names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of patients' names and addresses should be destroyed when the mailing process is complete. The final sample should be kept until 5th December 2014 when it can be deleted.

7 Ethical issues, ethics committees and research governance

Research Ethics Committees provide independent advice to participants, researchers, care organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards. The purpose of Research Ethics Committees in reviewing a proposed study is to protect the dignity, rights, safety and well-being of all actual or potential research participants. They will also seek reassurances regarding issues such as data protection, confidentiality and patient anonymity, and they will want to check that proposed research projects will not cause physical or mental harm to patients.

7.1 Ethical approval for the A&E Department survey

Multi-Centre Research Ethics Committee (MREC) approval has been obtained for the A&E Department questionnaire and the covering and reminder letters, all of which can be downloaded from the NHS Surveys website (<http://www.nhssurveys.org/surveys>). In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.

Trusts do not, therefore, need to seek individual ethical approval for this survey. If you wish, you can send your Local Research Ethics Committee(s) (LREC) a copy of the MREC approval letter, but you are not required to do this and you do not need to wait for confirmation or approval from the LREC before starting your survey. Trusts should notify the relevant R&D office that ethical approval has been obtained for the 2014 A&E Survey. The MREC letter can be downloaded from the NHS Surveys website (<http://www.nhssurveys.org/surveys/758>).

Further information on the ethical approval process can be found at National Research Ethics Service (<http://www.nres.npsa.nhs.uk>) or by e-mailing queries@nres.npsa.nhs.uk

7.2 Research governance requirements

The *Research Governance Framework* (2002, 2003, 2005) aims to ensure that health and social care research is conducted to high scientific and ethical standards. It spells out standards and the responsibilities of various parties involved in the research. One of the main purposes of the framework is to reduce unacceptable variations in research practice.

The Care Quality Commission, as sponsor of this national survey, has taken steps to ensure that principles of research governance and ethics are followed thoroughly. A standard core questionnaire and guidance notes are an important step in ensuring that the survey is carried out by all trusts in the same way without any variations.

The Department of Health has confirmed to the Care Quality Commission that it would be inappropriate for individual trusts to follow the same local research governance processes as they would if the survey were a study the trust is sponsoring. As this national patient survey has multi-centre research ethics committee approval and the Care Quality Commission takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

The following table has been prepared by the Care Quality Commission and is taken from Section 3.10 of the *Research Governance Framework for health and social care (2005)*. The left-hand

column sets out the responsibilities of organisations providing care and the right-hand columns sets out the arrangements made by the Care Quality Commission for patient surveys. If you are required to seek approval from your research governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

7.3 Responsibilities of NHS organisations who are carrying out research

Research Governance Framework	Care Quality Commission sponsored patient surveys
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	<i>The survey is carried out on the experiences of patients after they have received the care so this does not apply.</i>
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	<i>All Chief Executives are informed of forthcoming surveys. Trusts should notify their Research and Development Managers of the survey.</i>
Ensure patients or users and carers are provided with information on research that may affect their care.	<i>The survey does not affect the care of the patients. Anonymised results are used by the Care Quality Commission and the Department of Health in assessments, and also results used for local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on patient care.</i>
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	<i>This requirement is not specific to this survey.</i>
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	<i>The Care Quality Commission as sponsors of the study have sought ethics approval from MREC. There is a designated lead for each survey who is appointed by the Chief Executive.</i>
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	<i>The Care Quality Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in Section 3.8 of the Research Governance Framework are followed thoroughly.</i>
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	<i>Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.</i>
Maintain the necessary links with clinical governance and/or best value processes.	<i>The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.</i>

Research Governance Framework	Care Quality Commission sponsored patient surveys
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities. ⁴	<i>In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an appropriate contract with the trust. These procedures are specifically detailed in the guidance notes.</i>
Put and keep in place systems to identify and learn from errors and failures.	<i>The Care Quality Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Care Quality Commission. The survey programme is constantly evaluated and reviewed in light of these.</i>
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	<i>This requirement is not specific to this survey.</i>
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	<i>The Care Quality Commission maintains a helpline facility, which can be used by patients or trusts to report any complaints. Similar arrangements are in place with the Co-ordination Centre who are commissioned by the Care Quality Commission to co-ordinate the patient surveys.</i>
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	<i>Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.</i>
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	<i>The results of the surveys are used for monitoring of trusts performance by the Care Quality Commission.</i>

⁴ When universities and hospitals employ staff on joint or dual contracts, they are expected to make joint arrangements for accountability and management. See *A Review of Appraisal, Disciplinary and Reporting Arrangements for Senior NHS and University Staff with Academic and Clinical Duties*, a report to the Secretary of State for Education and Skills by Professor Sir Brian Follett and Michael Paulson-Ellis, September 2001 (The Follett Report).

8 Collecting data from non-English-speaking populations

The patients who respond to your survey should be representative of all of the patients who use the trust, so it is important that groups with limited understanding of English are not excluded. The core questionnaire and the question bank have been written in as **plain language** as possible to facilitate optimum understanding by all respondents.

For this survey, translated questionnaires are not being used since it is not possible to identify non-English-speaking patients, or their specific language, from patient records before questionnaires are sent out because language spoken is not usually included on patient administrative systems. Therefore, the first contact with them will have to be in English.

There are a number of strategies you can adopt to facilitate the process of collecting the views of people with a limited understanding of English within this survey:

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of who offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter (Note that trusts may already have arrangements with such a service). If you are a trust that intends to conduct the survey using an in-house team, and you do not have access to such a service, please contact the Co-ordination Centre for further advice
- A multi-language leaflet template is available on our site, and this can be included with your first and third mailings. Trusts and approved contractors can use this leaflet by inserting their appropriate helpline number. This gives directions in the 20 most common non-English languages spoken in England and also in EasyRead (routed to a separate number run by Mencap to help those with learning disabilities)
- Many households include at least one **competent English speaker** who can help the patient to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a patient's family or friends translate questions or interpret their responses, and it does not allow the patient to answer the questions directly.

9 Timetable

The survey fieldwork period for 2014 is 18 weeks. We strongly recommend making full use of this time to maximise response from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond⁵. If your patient population has high proportions of either group, it is especially vital you allow enough fieldwork time to capture responses from these patients. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. and have this sent to the Co-ordination Centre for checking between 21st April- 16th May) and mail out your questionnaire packs promptly once permission has been received. Ensuring your survey results are representative of your patients will create more value for the survey.

If you commission an approved contractor, much of the work will be done by them, but you will still have to be involved in some of the stages of the process, marked in **bold** in the timetable below.

Week	Task	See Section
-	Inform Co-ordination Centre who is carrying out your survey by 7th March 2014 (in-house or using an approved contractor)	5
1-2	Draw sample of patients to be included in the survey	10
1-2	Check sample for deceased patients using hospital records	10
1-2	Submit sample list to DBS to check for deceased patients	10
1-2	If using an approved contractor, supply them with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the service contract is signed	15
2-6	Print questionnaires and covering letters.	15.1
2-6	Ensure you have enough envelopes, return envelopes and labels	15
2-6	Set up FREEPOST address and FREEPHONE line	16
2-6	Establish system for responding to telephone enquiries	16.3
2-6	Establish system for booking in questionnaires	16.6
2-6	Stick labels on pre-packed numbered questionnaires and reminders supplied by approved contractor (if NOT using a service contract)	16.5

⁵ For details of this research carried out by the Picker Institute Europe see

http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf

6 – 8	Send out first questionnaires	15.5
6	Send first weekly response rate and helpline monitoring form to Co-ordination Centre (8 th May 2014)	12
6 – 21	Continue to respond to telephone enquiries	16.3
9	Send two copies of the questionnaire used and all covering letters to the Co-ordination Centre (by 30 th May 2014)	17.6
6 – 21	Log and process returned questionnaires	16.6
6 – 21	Enter data	17
6-10	Check your own trust's records for any patient deaths	10
8- 12	Send out first reminders to non-responders	15.6
8- 12	Be prepared for a small peak in telephone calls as first reminders received	16.3
11-14	Check your own trust's records again for any patient deaths	10
12-16	Send out second reminders to non-responders	15.7
23	Complete data entry	17
23	Check data for errors	17.4
23	Send data to Co-ordination Centre (by 5th September 2014 at the latest)	17.4
27	Send patients' written comments to the Co-ordination Centre in an anonymised format (by 5th September 2014 at the latest)	17.2
24+	Begin analysing trust's results and writing report	18
	Disseminate results to staff, patients and the public	19, 20
	You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until 5 th December 2014	

Key dates

Inform Co-ordination Centre who is carrying out survey	By 7 th March 2014
Submission of sample data	21 st April – 16 th May 2014
Approval of sample data	From 25 th April 2014
Fieldwork starts	5 th May 2014
Weekly monitoring starts	8 th May 2014
Close of fieldwork	5 th September 2014

Please remember to leave no more than 2- 3 weeks between each mailing.

10 Compiling a list of patients

This section explains how to draw a sample of patients. This task will need to be carried out by a member of staff at the NHS Trust. In hospital trusts, the sample will normally be drawn from the Patient Administration System (PAS). Prior to sending out questionnaires, the list will also have to be checked by the Demographics Batch Service (DBS) to identify deceased patients.

Please follow the instructions below carefully and allocate sufficient work time to check the sample with DBS before the first mailing and within the trust prior to each mailing.

We strongly advise that you read all of this section BEFORE you start to compile your patient list. It is imperative that you use the provided templates for each stage of the process- this will make it easier for you to draw the sample, and the correct number of records.

10.1 Compile a full list of patient attendances in 1 month

- 1) Select the month of A&E Department attendances that your survey will cover. This should be January **OR** February **OR** March 2014.

Note:

If you decide to sample attendances in **March 2014**, we recommend that you wait until the week commencing 14th April **BEFORE** you draw your sample to avoid having to remove a large number of patients from your sample because they are current inpatients (i.e. patients who were admitted to hospital following their attendance at the A&E Department).

- 2) Compile a full list of **all patient attendances** at all Accident and Emergency Departments **at all sites** in your trust during one month.
- 3) This is a list of **attendances/visits**, rather than a list of patients, so some patients will appear in the list more than once, but that does not matter at this stage.

The information you obtain about each patient will be used both for administering the survey and for sending to the tracing service to check for deceased patients. It saves time and effort if all the information is gathered at the same time.

The list should **include**:

ALL eligible adult patients, who have attended a major Accident and Emergency Department(s) within the trust for the chosen 'sampling month' (i.e. January or February or March 2014)

Note: A major Accident and Emergency Department is defined as a major or consultant led 24 hour service with full resuscitation facilities and designated accommodation for the reception of accident and emergency patients

The list should **exclude**:

- **Deceased** patients;
- Children or young persons aged **under 16 years** at the date of their attendance at the A&E Department;
- Any attendances **at Minor Injuries Units or Walk-in Centres**;
- Any patients who were admitted to hospital via **Medical or Surgical Admissions Units** and therefore have not visited the A&E Department;
- Any patients who are known to be **current inpatients**;
- Planned attendances at **outpatient clinics which are run within the A&E Department** (such as fracture clinics);
- Patients attending primarily to obtain contraception (eg the morning after pill), patients who suffered a miscarriage or another form of abortive pregnancy outcome whilst at the hospital, and patients with a concealed pregnancy;

Note: Trusts should be confident that they have taken all reasonable efforts to exclude women attending A&E for the above reasons.

Whilst not an exhaustive list, ways to do this include:

Checking ICD-10 codes for any women admitted to hospital following their attendance at A&E, between the ages of 16 and 55, and removing any related to miscarriage and so on;

Checking any obstetric or gynaecology diagnosis codes on records for women, between the ages of 16 and 55, attending A&E;

Checking the notes on records for women, between the ages of 16 and 55, for any information relating to miscarriage, abortive, abortion, concealed pregnancy, pv bleed, pregnant, pregnancy.

- Patients **without a UK postal address** (but do not exclude if addresses are incomplete but useable e.g. no postcode);
- Any patient known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those patients from your sample list at this stage).

Data fields to include in the list of attendances

Please note: not all these fields are required by DBS but it will save time and effort if all the information is gathered at the same time.

You will need to keep the list in an electronic file in a programme such as Microsoft Excel or Access. The list should contain the following information:

- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields
- Postcode
- Year of birth
- Gender
- Ethnic category
- Day of attendance
- Month of attendance
- Year of attendance
- Time of attendance
- NHS site code
- GP Practice Code

10.2 Stage 1: Creating a sample of patients to send to the DBS

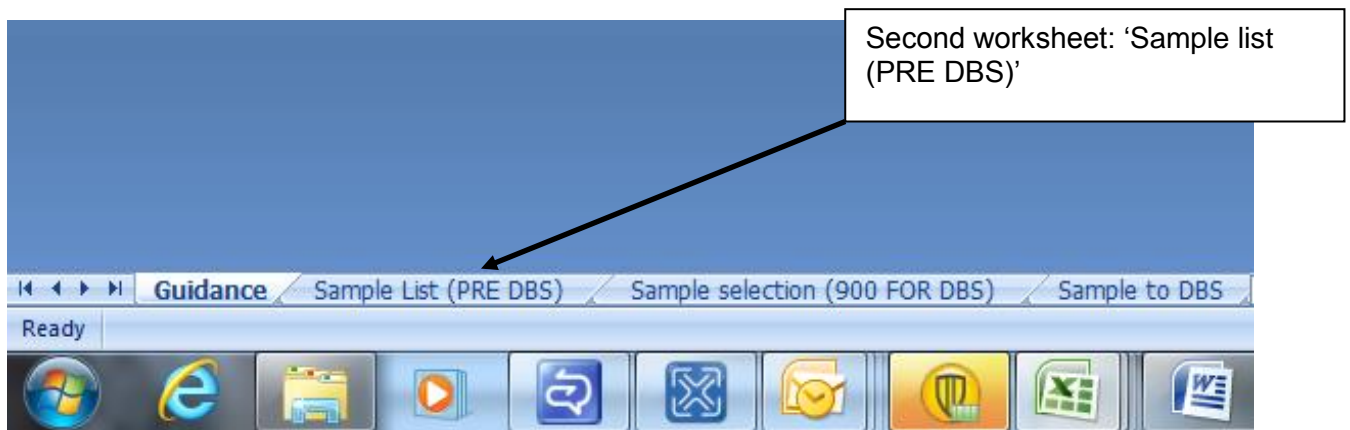
It is likely that your full list will include thousands of attendances, but you will need to send questionnaires to only 850 patients.

Note: You are aiming for a **response rate of at least 50%**, which means that you should have about 425 completed questionnaires if you send questionnaires to 850 patients. You will be able to maximise your response rate by following this guidance carefully. It is **not** acceptable to try to boost the number of responses you receive by sending out questionnaires to a larger number of patients. The Co-ordination Centre will only be able to accept responses from the 850 patients in your list that have been correctly sampled. (See Section 10.12 for the accepted options for increasing your sample size)

The first stage is to take a systematic sample of patients to send to the DBS (Demographic Batch Service). It is likely that some of your patients will have died, so it is advisable to select an initial sample of 900 patients, which will later be reduced to 850.

To select the 900 patients for sending to DBS, you should follow the procedure below:

1. Download the sample construction workbook for creating a DBS sample from the NHS surveys website (<http://www.nhssurveys.org/surveys/756>). **The workbook is called 'AE2014_Sampling construction workbook_900 FOR DBS_v1.0'.**
2. In the **second worksheet** called **'Sample list (PRE DBS)'** put the list of **all** eligible attendances in your chosen month (i.e. January, February OR March 2014) into the appropriate columns in the sheet (starting from column C which is called Trust code).



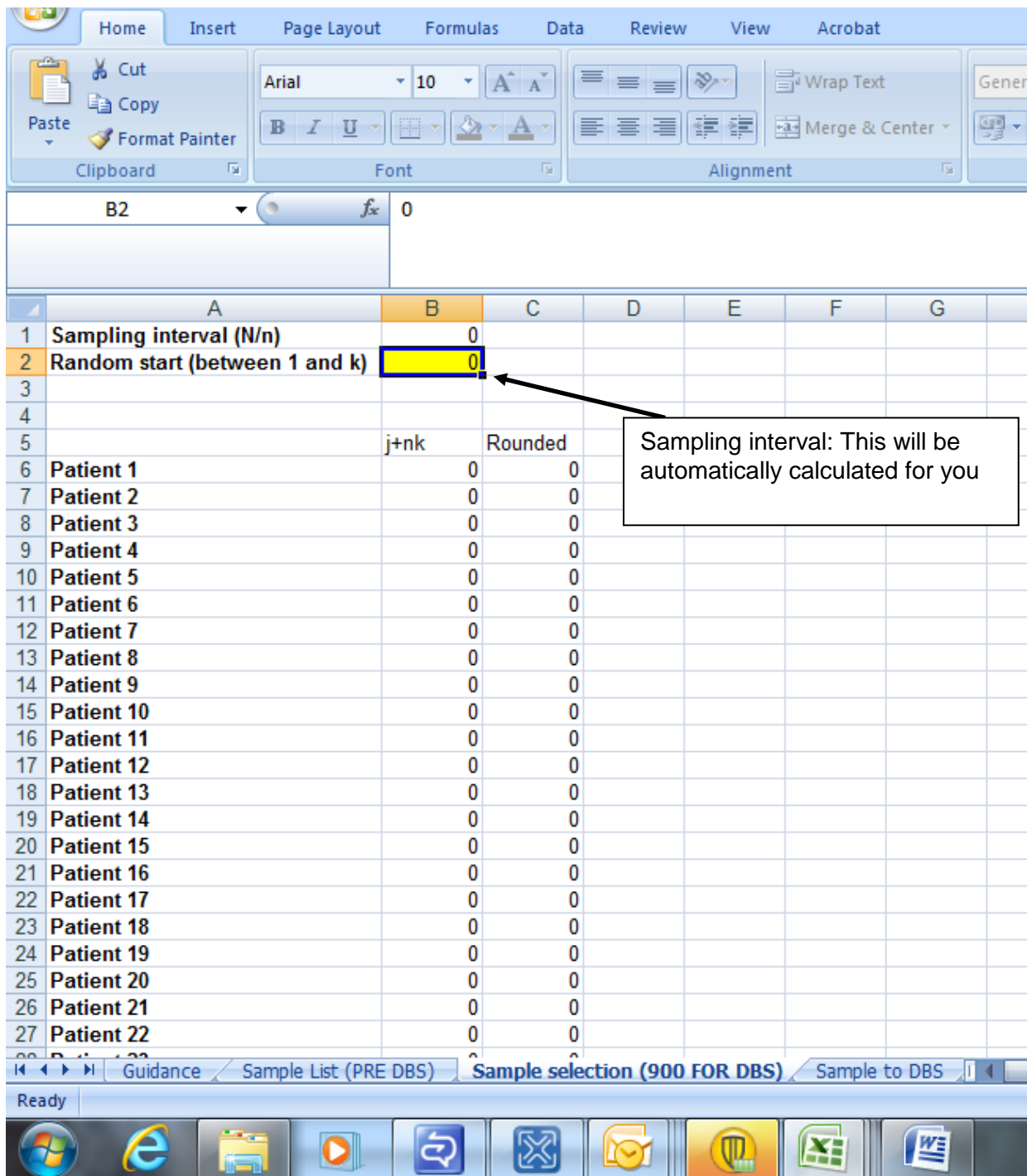
3. Sort the list by the patient's year of birth, gender and GP Practice Code (GPPC). (N.B. Ensure that you select all columns before sorting in Excel, otherwise the patient details will get mixed up). Sorting should ensure that all attendances by the same patients come next to each other in the list.
4. Count the total number of attendances in the chosen month, **and in column A** which is called **'Position in list' and is highlighted blue, number each attendance in the list in ascending order** (for example, if you had 2510 attendances, you would number from 1 through to 2510).

The screenshot shows an Excel spreadsheet with the following columns:

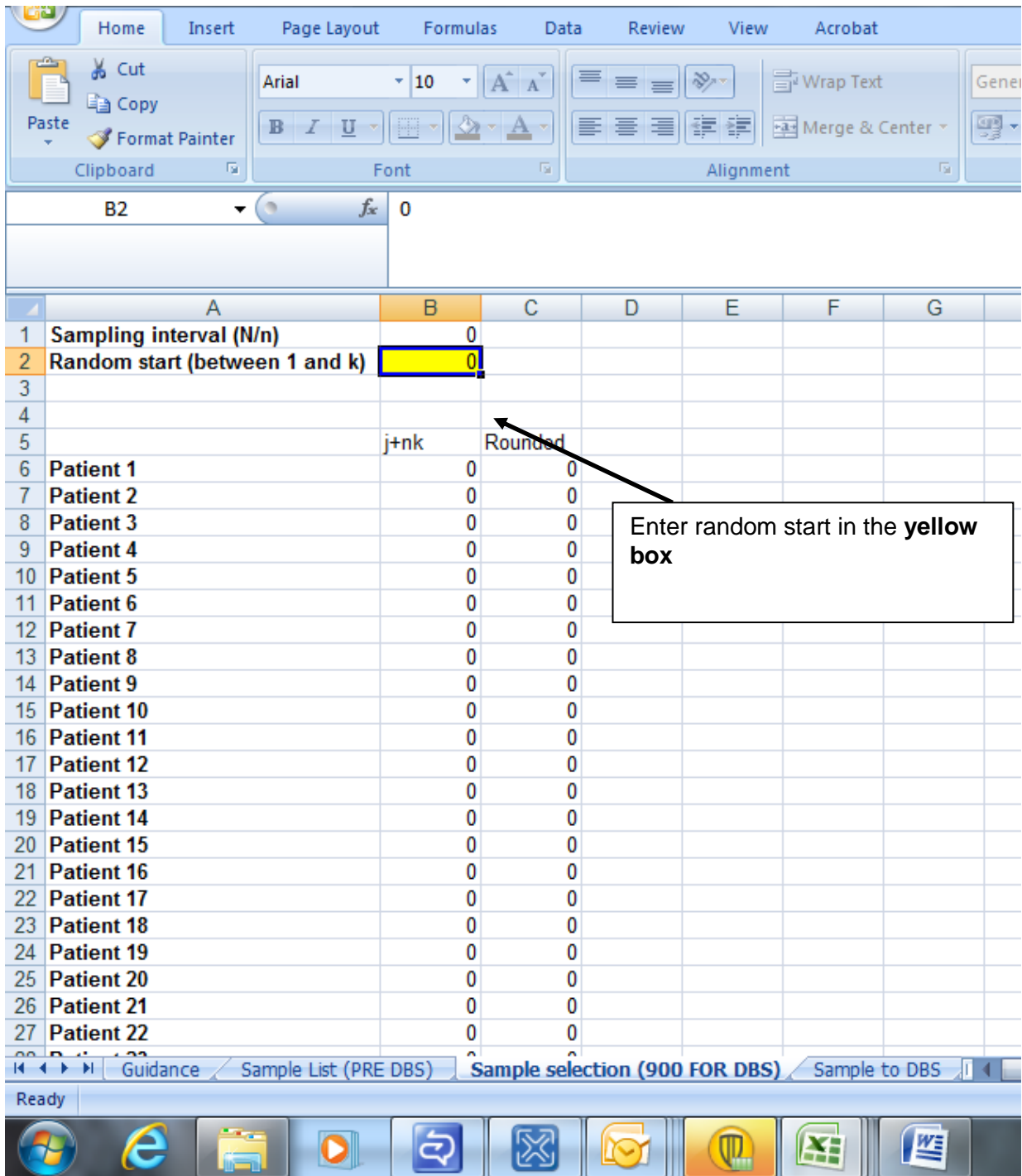
	A	B	C	D	E	F	G	H	I
1	Position in list	In sample?	Trust code	Title	Initials	Surname	Address 1	Address 2	Address 3
	Number your patients from 1-N (where N is the total number of patients in the list). They MUST be in ASCENDING order.	Is patient included in systematic sample? 0= NO, 1= YES	The three character code of your organisation (e.g. RNH), maintained by NHS Connecting for Health	Title of patient	Initials or first name of patient	Last name of patient	First line of patients' UK address	Second line of patients' UK address	Third line of patients' UK address
2									
3									
4									
5									
6									

A callout box points to the 'Position in list' column with the text: "Number every attendance in your list in ASCENDING ORDER and enter in this column".

- Once you have numbered **every** attendance, your sampling interval will have been automatically calculated for you (**this can be found in the third worksheet called 'Sample selection (900 for DBS)'**).



- You need to decide what your random start is going to be: this must be a whole number between 1 and the value of your sampling interval.
- Go to the **third** worksheet called '**Sample Selection (900 for DBS)**' and enter the random start into the **yellow box**. When you do this you may notice that some of the figures in this worksheet change- this is what is meant to happen and will be used to determine which records to select.



8. Go back to the **second** worksheet called '**Sample list (PRE DBS)**' and you will see that each record should have either a 0 or 1 in **column B** which is called '**In sample?**'. All records with a 1 in column B will be included in the DBS sample for your trust.

IT IS VITAL THAT YOU DO NOT CHANGE ANY OF THE VALUES IN COLUMN B- THIS MAY INTRODUCE SAMPLE BIAS WHICH MEANS THE SAMPLE WOULD NEED TO BE REDRAWN

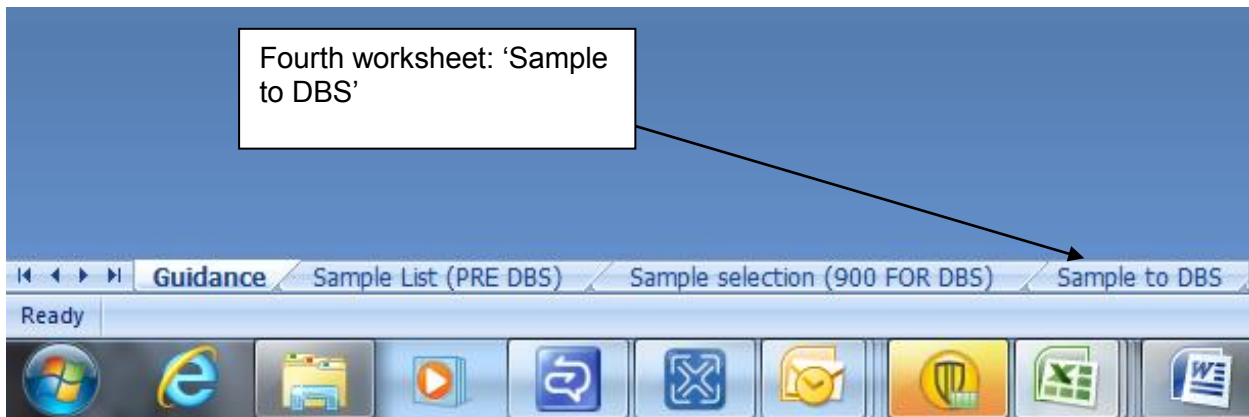
The screenshot shows an Excel spreadsheet with the following columns:

Position in list	In sample?	Trust code	Title	Initials	Surname	Address 1	Address 2	Address 3
1	Is patient included in systematic sample? 0= NO, 1= YES	The three character code of your organisation (e.g. RNH), maintained by NHS Connecting for Health	Title of patient	Initials or first name of patient	Last name of patient	First line of patients' UK address	Second line of patients' UK address	Third line of patients' UK address
2								
3	1							
4	2							
5	3							
6	4							

A callout box points to the 'In sample?' column with the following text:

This column will either have a 0 or 1 in it:
1= record IS included in sample
0= record IS NOT included in sample

9. Delete all records that DON'T have a value of 1 in column B.
10. Select **all the remaining** records (with any required information for DBS) and copy across into the **fourth worksheet** called 'Sample to DBS'. **THIS IS THE INFORMATION THAT WILL BE SENT TO THE DBS FOR CHECKS.**
11. Note that if patient's name appears more than once, remove any duplications so you **only have one attendance per patient**. COPY THIS WORKSHEET ACROSS INTO A SEPARATE WORKBOOK FOR SUBMISSION TO THE DBS (see below for creating a tracing file).



10.3 Checks carried out by the trust

Once you have compiled your list of 900 patients, you should carry out the following checks before you send the list to the DBS to carry out a further check for deceased patients.

- **Duplications.** You should check your list to make sure patients' names do not appear more than once, and you should remove any duplicated names.
- **Current inpatients.** Check that none of the patients are known to be current inpatients in your trust (or elsewhere, if possible)
- **Patient ages.** Check that all patients are aged 16 or over at the time of their attendance at the A&E Department
- **Postal addresses.** Exclude any addresses that are outside the UK
- **Incomplete information.** Check for any records with incomplete information on key fields (such as surname and address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias
- Check that you have not included any patients who attended primarily to obtain contraception (eg the morning after pill), patients who suffered a miscarriage or another form of abortive pregnancy outcome whilst at the hospital, and patients with a concealed pregnancy.
- Any patient known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those patients from your sample list at this stage).
- **Deceased patients.** Check hospital records do not have a record of a patient's death from a subsequent attendance or visit to hospital

Checks for deceased patients

One of the most reliable and up-to-date sources of information on patient deaths is your own trust's records. **It is essential that you check that your trust has no record of a patient selected for the survey having died at your trust.** Relatives are likely to be particularly upset if they receive a questionnaire or reminder from the trust where their relative died. Clearly, patients may also have died at home or while under the care of another trust, so you still need to check with the demographic batch service (DBS) as well.

The methodology for this survey requires three stages of checks for deceased patients before the first mailing is sent out. The checks are carried out sequentially by:

- 1) the trust
- 2) DBS
- 3) again by the trust (for patients who may have died in hospital after submission of the sample to DBS)

You are also advised to repeat this check before the second and third mailings, and to ensure that approved contractors are advised immediately if any patients in the sample die during the survey period.

10.4 Submit the patient list to the Demographics Batch Service (DBS)

Before sending out the questionnaires, the list of patients should be checked for any deaths by the Demographics Batch Service (DBS).

The DBS enables users to submit and receive a file containing relevant patient records electronically using dedicated client software. The patient records in the file are matched against the NHS Spine Personal Demographics Service (PDS).⁶

Create a trace request file

Using your list of patients, you need to create a correctly-formatted batch trace request file to send to DBS. You should take advice from your local Trust PAS team on the correct format to submit files. Technical details on the file format are available from:

<http://www.connectingforhealth.nhs.uk/industry/docs/files/dbs/index.html>

For each patient you will need to include as a minimum:

- NHS number and full date of birth (yyyymmdd) – this is the recommended approach *OR*
- Surname, first name, gender, date of birth and postcode (can be wildcarded eg LS1*)

Although residential postcode is not mandatory it is highly recommended to include it to avoid incorrect matches. Due to the way addresses are recorded throughout the NHS, it is very difficult to get an exact match on address lines. For this reason, **do not** include address lines in the trace request file.

Submitting the trace request file

⁶ The PDS is a national electronic database of NHS patient demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

Please note that the DBS does **not** accept the transfer of files by encrypted emails or on physical media. Instead, **request and response files must be transferred electronically using the dedicated DBS client software**. The DBS client software should have already been installed on a server within your trust. Please speak to a member of your IT department or PAS team if you do not know how to access and use the application. If your IT department cannot help, contact the DBS implementation team at: demographics@nhs.net and they should be able to advise you.

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client in-box. The DBS client will then send the file to the Spine and, if you are registered, you will receive an email to say that the file was received. The DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

The response file

The DBS will return a header row, response body and trailer row. The response row will be in two parts:

- The response containing all the data supplied in the request record, together with a trace outcome indicator. The main record is returned in all cases.
- An additional response column, which is returned only when there is a single unique match. It is on this additional response column that patients found to be deceased will be indicated.

Further information is available from www.cfh.nhs.uk/demographics/dbs

Note

Please be aware that tracing services are not foolproof and even after your patient list has been checked for deaths, some patients may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased patients remain in your sample. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives.

10.5 Stage 2: When the patient file is returned from DBS

The trace response file returned from DBS can be used to identify any patients that have died (indicated by a letter 'D') and therefore need to be deleted from the sample file. This will reduce the numbers in your sample list slightly.

You should not exclude patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.

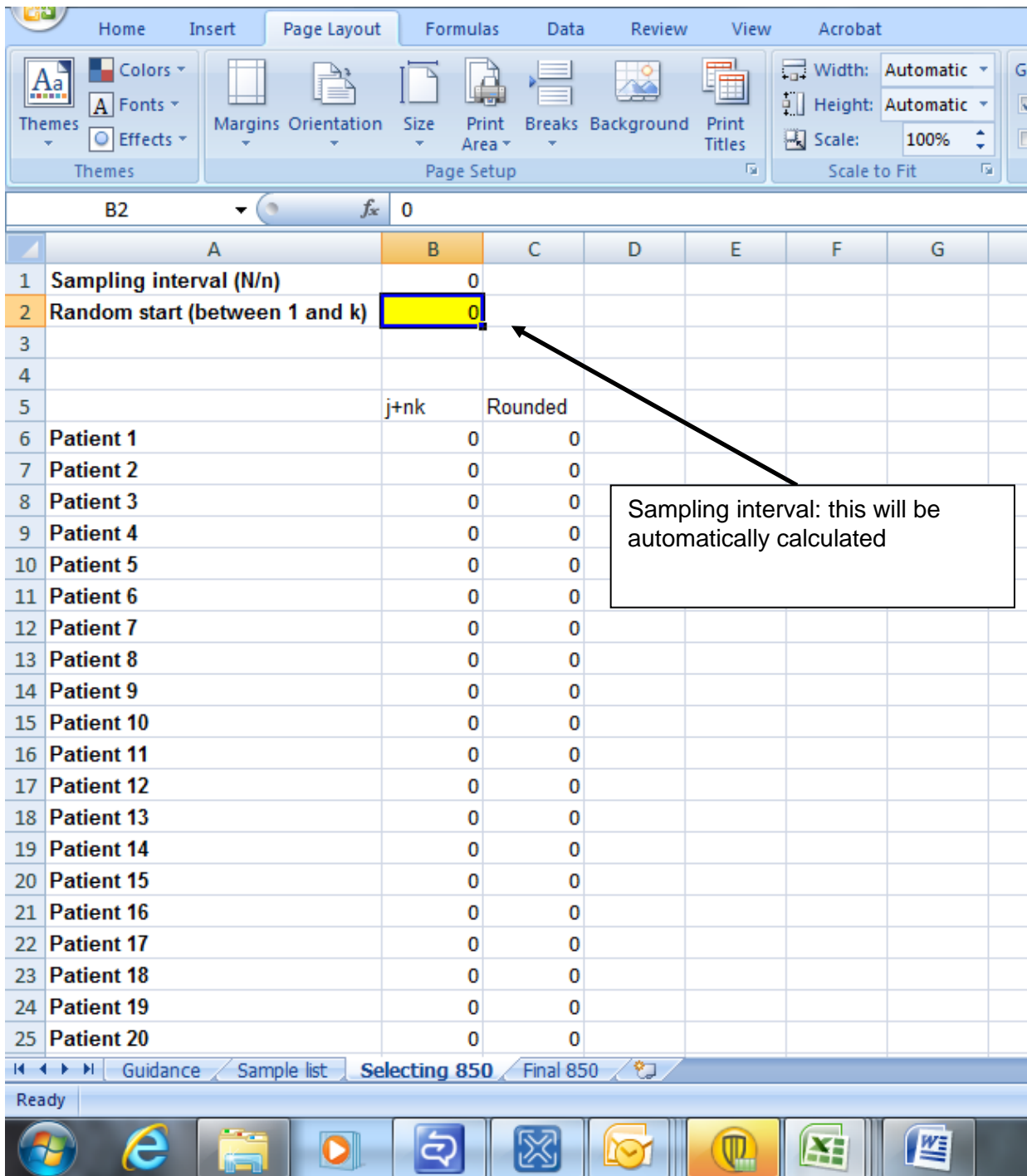
If you have more than 850 patients remaining on your list

When your patient list comes back from DBS and you have removed all deceased patients, there may still be more than 850 patients in the list. You will need to systematically sample again to reduce it to 850 records.

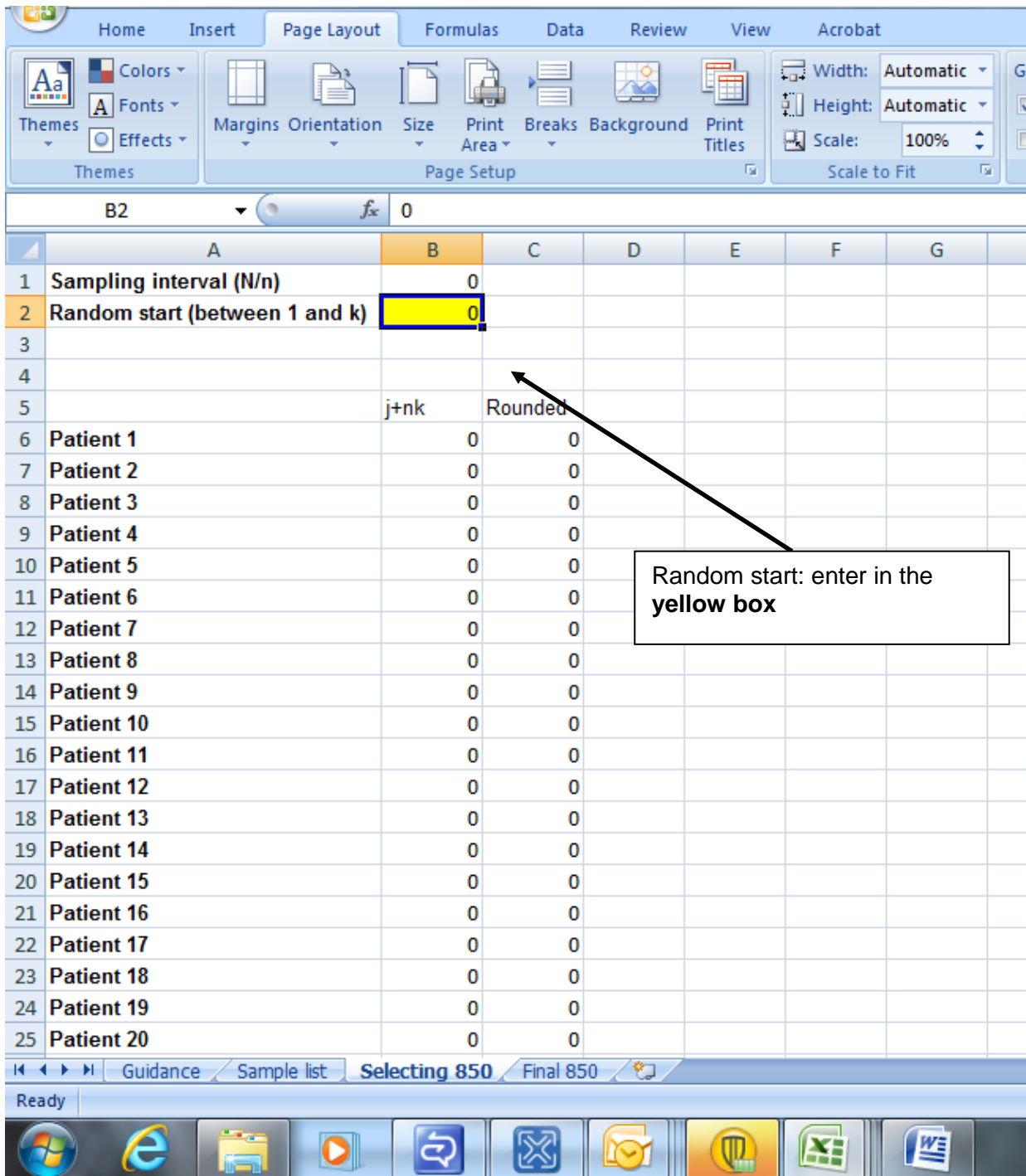
To do this please follow the procedure outlined below:

1. Download the sample construction workbook for creating your final sample from the NHS surveys website (<http://www.nhssurveys.org/surveys/756>). **The workbook is called 'AE2014_Sample construction workbook_FINAL 850 SAMPLE_v1.0'.**
2. In the **second worksheet** called '**Sample list**' put the list of **all eligible** cases from the DBS returned file.
3. Count the total number of records, **and in column A called 'Position in list' and highlighted blue, number each record in the list in ascending order** (for example: from 1 to 872 if you had 872 records).

Once you have numbered **every** record, your sampling interval will have been automatically calculated for you and will be shown in the **third worksheet called 'Selecting 850'.**



- You need to decide what your random start is going to be: this must be a whole number between 1 and the value of your sampling interval.
- Go to the **third worksheet** called '**Selecting 850**' and enter the random start into the **yellow box**- the other numbers on this worksheet will change, but this is meant to happen and should be left as is.



6. Once you have done this, go back to the **second worksheet** called '**Sample list**' and you will see that each record should have either a 0 or 1 in **column B** which is called '**In sample?**'. All records with a 1 in column B will be included in the final sample for your trust.

IT IS VITAL THAT YOU DO NOT CHANGE ANY OF THE VALUES IN COLUMN B- THIS MAY INTRODUCE SAMPLE BIAS WHICH MEANS THE SAMPLE WOULD NEED TO BE REDRAWN

The screenshot shows an Excel spreadsheet with the following columns and data:

	A	B	C	D	E	F	G	H
1	Position in list	In sample?	Trust code	Title	Initials	Surname	Address 1	Address 2
	Number your patients from 1-N (where N is the total number of patients in the list). They MUST be in ASCENDING order.	Is patient included in systematic sample? 0= NO, 1= YES	The three character code of your organisation (e.g. RNH), maintained by NHS Connecting for Health	Title of patient	Initials or first name of patient	Last name of patient	First line of patients' UK address	Second line of patients' UK address
2								
3	1	0						
4	2	1						

Callout box text: This column will either have a 0 or 1 in it:
1= record IS included in sample
0= record IS NOT included in sample

7. **Delete all records that DON'T have a value of 1 in column B.**
8. **Select all the remaining records (along with corresponding information) and copy across into the fourth worksheet called 'Final 850'. THIS IS THE INFORMATION THAT WILL BE SENT TO THE CO-ORDINATION CENTRE FOR CHECKING.**
9. **Before sending your final sample file to the Co-ordination Centre, make sure you remove the patient identifiable data and that every record in the file has a patient record number (format AE14NNNXXXX where NNN= your trustcode and XXXX=0001-0850)**

A	B	C	D	E	F	G
Trust code	Patient Record Number	Title	Initials	Surname	Address 1	Address 2
The three character code of your organisation (e.g. RNH), maintained by NHS Connecting for Health	Patient Record Number: format is AE14NNNXXXX, where NNN= your trustcode and XXXX= position of record in sample (001, 002, 003 etc)	Title of patient	Initials or first name of patient	Last name of patient	First line of patients' UK address	Second line of patients' UK address

Patient record number: unique number for each patient

PATIENT IDENTIFIABLE DATA: this **MUST** be removed before your sample is sent to the Co-ordination Centre for checking

READY

If you have fewer than 850 patients remaining on your list

If your patient list has fewer than 850 patients after deceased patients have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email emergency.data@pickereurope.ac.uk.

Important note

You are aiming for a **response rate of at least 50%**, which means that you should have about 425 completed questionnaires if you send questionnaires to 850 patients. You will be able to maximise your response rate by following this guidance carefully, drawing your sample and mailing out as soon as possible, and you will need to send out two reminders. It is **not** acceptable to try to boost the number of responses you receive by including more patients when compiling the sample of 850 for the survey as this would bias the survey. The Co-ordination Centre will only be able to accept responses from the patients in your list of 850 that have been correctly sampled and mailed. (See section 10.12 for the accepted options for increasing your sample size)

10.6 Create the sample file

An example of the final sample worksheet you should complete has been included below. **This worksheet is called 'Final 850' and is found in the 'AE2014_Sample construction workbook_FINAL 850 SAMPLE.xls' (see section 10.5).**

This worksheet has three purposes:

- 1) It will be used to keep a record of which patients have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from the 8th May 2014 until the closing date of the survey.
- 3) The anonymous data in this file (i.e. all the data **except** patient name and address information) will form part of the file that you will submit to the Co-ordination Centre when the survey is completed.

Table 1 – Sample Excel file of patient details

<i>NHS Trust Code</i>	<i>Patient record number</i>	<i>Title</i>	<i>Initials</i>	<i>Surname</i>	<i>Address1</i>	<i>Address5</i>	<i>Postcode</i>	<i>Year of birth</i>	<i>Gender</i>	<i>Ethnic category</i>	<i>Day of attendance</i>	<i>Month of attendance</i>	<i>Year of attendance</i>	<i>Time of attendance</i>	<i>NHS Site code</i>	<i>GPPC</i>	<i>Day of questionnaire being received</i>	<i>Month of questionnaire being received</i>	<i>Year of questionnaire being received</i>	<i>Outcome</i>	<i>Comments</i>
R1X	AE14 RX1 0001	Mr s	AM	Abbot			AB1 1YZ	1934	2	A	5	3	2014	10:30	RR11 5	A1234 5				3	Informed that patient had died
RQA	AE14 RQA 0002	Mr	EC	Ahmed			AB2 6XZ	1970	1	J	20	3	2014	13.45	RTE0 3	B1234 5	04	07	2014	1	
RZZ	AE14 RZZ 0849	Ms	K	Yoo			AB4 7MX	1950	2	R	17	3	2014	11.10	RR11 5	F5678 9					
RLF	AE14 RLF0 850	Ms	F	Young			AB9 5ZX	1946	2	A	14	3	2014	23.55	RR11 7	G5678 9	16	06	2014	1	

Important note about table 1

The headings of Table 1 are in three different colours:

Bold black headings: these columns contain information on patients' names, addresses and comments that may allow them to be identified. This information should be deleted from all files sent to the Co-ordination Centre

Red italic headings: these columns should be completed during the sampling phase and submitted to the Co-ordination Centre prior to mailing for final inspection (see Section 11) and at the conclusion of the survey

Green italic headings: these columns should be completed when the patient responds to the survey, either by returning a completed questionnaire, or the trust has been notified that the patient will not be participating (patient deceased, moved address, too ill, or called to opt out).

The following information is compiled using hospital records:

- NHS Trust Code
- **Patient record number.** Please use the following format: AE14NNNXXXX where NNN is your trusts 3 digit trust code and XXXX is the 4 digit number relating to your sampled patients, e.g., 0001-0850. The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the approved contractor) will be able to use these numbers to monitor which patients have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your patients.
- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields ⁷
- Postcode

Note

The **Patient Record Number, Title, Initials, Surname, Address** fields and **Postcode** are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose.

- The **Year of Birth** should be included in the form of NNNN.
- **Gender** should be coded as 1 = male and 2 = female.
- **Ethnic Category.** The ethnicity of a person is specified by that person, and should be coded using the 17 item alphabetical coding specified by NHS Connecting for Health⁸. The codes are as follows:

⁷ The address should be held as separate fields (eg. street, area, town and county), consistent with the address format required by the DBS.

⁸ These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/enh/ethnic_category_code_de.asp?shownav=1

National Codes:

White

A	British
B	Irish
C	Any other White background

Mixed

D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background

Asian or Asian British

H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background

Black or Black British

M	Caribbean
N	African
P	Any other Black background

Other Ethnic Groups

R	Chinese
S	Any other ethnic group
Z	Not stated ⁹

It is acknowledged that patient records might not always contain complete data on patients' ethnic category. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic categories. This is in keeping with the aims of the Care Quality Commission and NHS England to be more responsive to all ethnic groups and provide services that take account of their individual requirements.

- **Day** of the month of attendance (1 or 2 digits; eg 7 or 26)*
- **Month** of attendance (1 or 2 digits; eg 02 or 3) *
- **Year** of attendance (4 digits; eg 2014) *
- **Time** of attendance (4 digits in 24-hour format; HH:MM e.g. 09:25, 23:15)
- **Hospital Site Code:** As per the 2012 survey, please use this space to record the site at which the patient was seen using the five character NHS Trust Site Codes <http://systems.hscic.gov.uk/data/ods/datadownloads/index>
- **GP Practice Code (GPPC):** Please record the six character organisation code of the GP practice at which the patient is registered. <http://systems.hscic.gov.uk/data/ods/datadownloads/index>

Additional information should also be entered on this spreadsheet. The details of this information are discussed below:

⁹ The code "Z" should only be used if the patient was asked for their ethnic category but refused to provide it. If this code is missing for any other reason, ethnic category should be left blank in the sample information.

* Date fields must be supplied in separate columns (eg date, month, and year).

- 1) **Day of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a one or two digit numerical response **not** a date format, eg. N or NN not 12/06/14.
- 2) **Month of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a one or two digit numerical response, **not** a date format.
- 3) **Year of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a four digit numerical response, **not** a date format.
- 4) The **Outcome** field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which patients opt out of the survey, etc.
 - 1 = Returned useable questionnaire
 - 2 = Returned undelivered by the mail service or patient moved house
 - 3 = Patient died
 - 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire
 - 5 = Patient was not eligible to fill in questionnaire
 - 6 = Questionnaire not returned (reason not known).

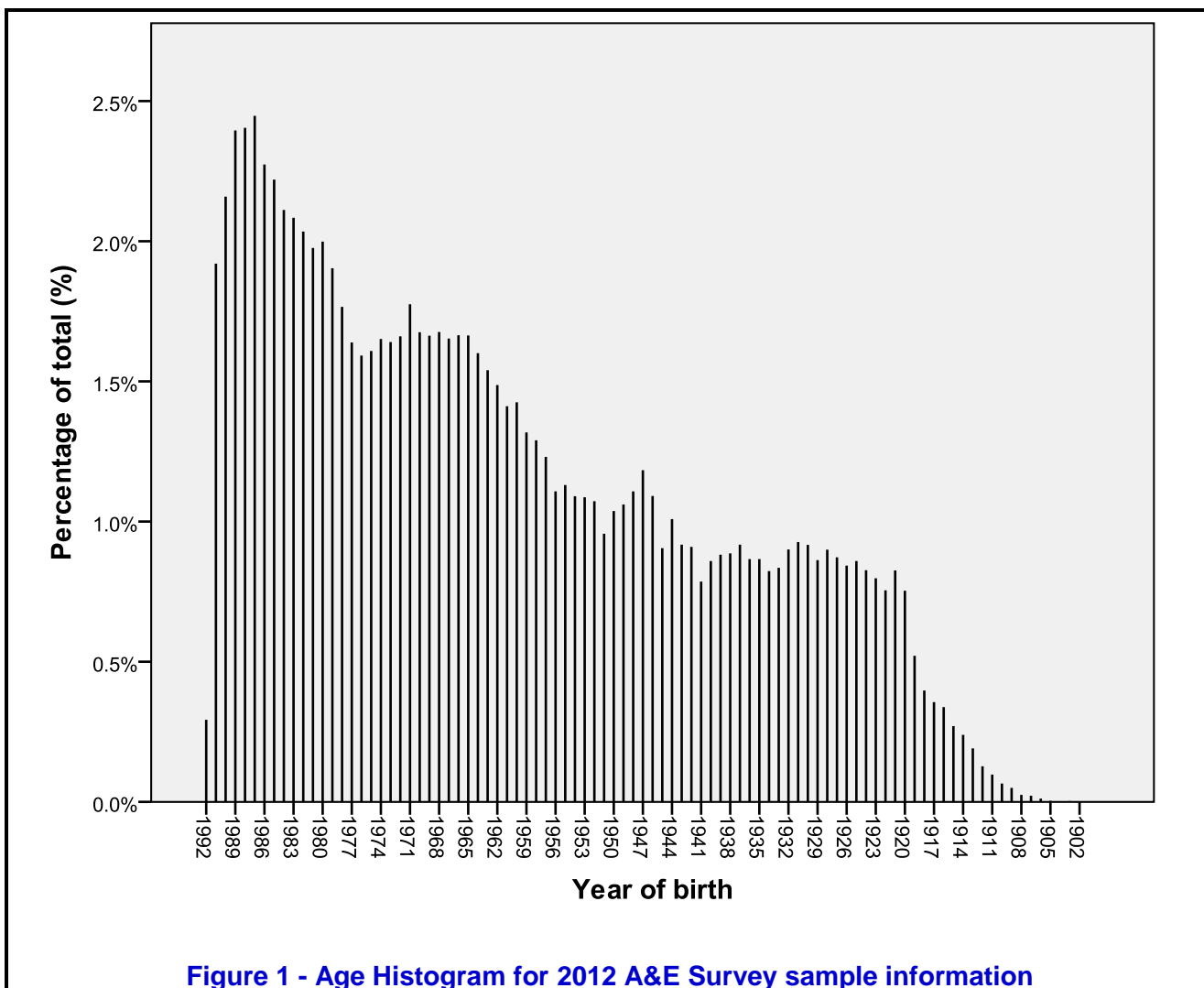
The outcome column is left blank at first if the survey has not been returned (on table 1 you can see that Ms Yoo has not yet returned her questionnaire).

- 5) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline – for example, to inform you that the respondent has died or is no longer living at this address.

10.7 Distribution of patient ages

You should check that patients of all ages are included in your sample, especially those aged 16, 17, 18 or over 75 years. We have found these age groups are the most likely to be excluded due to poor sampling. It is possible there may not be any young adults or very old adults in your sample, but this should be confirmed by checking your original sample (before exclusion criteria were applied) and your sampling techniques.

Check that your sampled patients' ages cover the full range of expected ages. Ideally, you should do this by checking the distribution of ages on a histogram (See Figure 1). For most trusts the histogram should generally decrease with age, (representing higher numbers of younger adults) then increase slightly for those aged around 60 years (baby-boomers), before entering a further decline to reflect fewer people at extreme old age.



10.8 Distribution of patient gender

Your sample will probably have similar proportions of men and women- unless your trust treats men or women only. You should check both of these genders are included and that you can explain if the sample is skewed toward male or female patients.

10.9 Check for other sample errors

The most common sampling errors made by trusts include:

- Including patients aged under 16
- Excluding patients aged 16
- Excluded patients born before a particular year (1930)
- Incorrect ethnicity coding
- Missing year of birth data
- Incorrect age distribution due to incorrect following of the guidance

Using the guidance correctly will prevent any errors and may reduce delays caused by mis-sampling.

10.10 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each patient in the sample to a new file. The patient record number (PRN) for each patient should be copied to the new file, so that the two datasets are connected using the unique PRN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as “A&E2014_mailing data”.

This file should be used for mailing purposes: it will be used to check for deceased service users prior to reminder mailings and will be cross-referenced with the sample file (“<NHStrustname>_A&E 2014”) to identify service users who will need to be sent reminders.¹⁰

As this “A&E2014_mailing data” file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing data file should be destroyed when the survey is complete. This should be done by both the trust and the approved contractor, along with all other files created for the survey (aside from the survey response file).

For patient confidentiality reasons, **it is essential that you do not keep patient name and address details in the same file as their survey response data.**

You should not have any patient identifiable data (patient names or addresses) in you sample file. It is imperative that you check this and DO NOT transfer your sample file to the Co-ordination Centre until this has been removed. Submitting patient identifiable data to the Co-ordination Centre is a serious breach of our Section 251 Approval.

Table 2 – Example mailing file

<i>NHS Trust Code</i>	<i>Patient record number</i>	<i>Title</i>	<i>Initials</i>	<i>Surname</i>	<i>Address1</i>	<i>Address2</i>	<i>Address3</i>	<i>Address4</i>	<i>Address5</i>	<i>Postcode</i>
R1 X	AE14R 1X000 1	M r s	A M	Abbot	14 Station Road	London				AB1 1YZ
RQ A	AE14R QA002	M r	E C	Ahme d	Flat 7	Short Street	Oxford			AB2 6XZ
						--				
RZ Z	AE14R ZZ084 9	M s	K	Yoo	The Maltings	Birch Road	Little Abington	Cambridg e	Camb s	AB4 7MX

¹⁰ As shown in table 1(section 10.6), the ‘outcome’ field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which patients opt out etc.

RL F	AE14R LF085 0	M s	F	Young	634 Tyne Road	Newcastle-Upon- Tyne	Tyne and Wear			AB9 5ZX
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10.11 Sharing the patient sample file with an approved contractor

If you are working with an approved contractor and have a contract in place relating to the transfer of patient identifiable information (i.e. names and addresses) both the sample file (“<NHStrustname>_A&E2014”) **and** the mailing file (“A&E2014_mailing data”) file should be sent to the contractor staff in encrypted format (see *Section 6.6 - Encryption of personal data*).

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, within the trust, you should supply them with just the sample file (this will resemble Table 1- Sample Excel file of patient details but with the patient names, addresses and postcodes removed). The contractor can use this list to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about patient deaths, etc.

10.12 Making more use of the survey locally

Up to this point, this section of the guidance has described in detail how sampling must be undertaken to provide the basic required sample of 850 patients for the national survey. In addition to this minimum requirement, though, your trust may wish to use the A&E survey as an opportunity to gather further data beyond that required by the Care Quality Commission. Increasing the sample size is a good way to do this.

Increasing the sample size for the survey may be helpful if, for example, you wish to:

- Analyse or compare results for specific subgroups (for example, patients treated at different sites or patients of different ethnicities) in more detail than would be possible from a sample of 850 patients. By increasing the sample size you can ensure that you have a large enough sample of patients from each group¹¹
- Alternatively, if your trust regularly treats very large numbers of patients, you may wish to draw an extra sample of patients to survey additionally to those included in the main survey. For example, you could select patients discharged in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out an A&E survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of patients which do not overlap. Guidance for carrying out a local survey is available at: <http://www.nhssurveys.org/localsurveys>

If you are using an approved contractor for the survey then they will be able to advise you on the best way to increase your sample size to achieve your specific goals. If you are not using an approved contractor, then the coordination centre will be able to advise on any queries you might

¹¹ See section 18 for more information on the reliability of data based on different numbers of respondents.

have via e-mail at Emergency.Data@PickerEurope.ac.uk or call 01865 208127. However, before you decide to do this, there are some important points to consider:

- Please note that the section 251 approval obtained for the 2014 A&E Survey only covers the transfer of patient information required for carrying out the Core survey. If you wish to collect any additional sample information you will need to seek advice from the National Information Governance Board as to whether further approval is needed. For further information please see: <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/>
- The core sample for the 2014 A&E survey **must** be drawn as specified in this guide; any deviation from the guidance may make it impossible for the Care Quality Commission to use the data that you collect. It is therefore essential that any additional sample drawn can be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.
- If you are planning to undertake surveys more frequently than the national programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking.

11 Final sampling inspection by the Co-ordination Centre

Trust data should be checked for errors and received back from DBS before being forwarded to the Co-ordination Centre. An anonymised sample file¹² **must** be submitted to the Co-ordination Centre **prior** to the first mailing. This is to allow us to make final quality control checks. All columns *in red italics* in Table 1 (sample Excel file of patient details – Section 10.6) must be submitted, but name, address and postcode details must be removed.

If you are using an **approved contractor**, the sample should be checked as normal by the trust and by DBS before being submitted to the contractor. We strongly recommend the contractor carries out the same high standard of checks as in previous years, before submitting the file to the Co-ordination Centre. The Co-ordination Centre will address any issues arising from these final checks to the approved contractor.

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files. Emails discussing any sample anomalies will be returned to the trust or approved contractor which provided them on the Friday of each week. [Please note: samples submitted on a Thursday must be sent to the Co-ordination Centre by 11am for the samples to be returned to the trust or approved contractor the following day.]

Making the most of the fieldwork period

Because certain demographic groups (specifically younger patients and those from black and minority ethnic categories) have been shown to take longer to respond to patient surveys, we strongly recommend that files are submitted within the four weeks specified for sample checking. The best way to ensure you can do this is to prepare before the start date of the survey (5th May 2014). You can do this by:

- 1) Allocating sufficient time to the individual who will generate your sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by your contractor or the Co-ordination Centre
- 2) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey
- 3) Ensure your trust is registered with DBS and that the person who submits your sample to them understands their requirements – problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered – please check this ahead of time.
- 4) Printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire.

You must have also completed the sampling checklist declaration when you submit your sample to the Co-ordination Centre (<http://www.nhssurveys.org/surveys/757>). This checklist

¹² Created by removing the patients' names, addresses and postcodes.

covers the main points of the sampling process before you submit your sample to the Co-ordination Centre.

Your first mailing should take place as soon as possible after your sample has been approved by the Co-ordination Centre but **must not be later than seven days** after this. A large time lag increases the likelihood of patients having died between the sample file being received back from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

For the 2014 A&E survey, the specified sample submission dates are:

Date sample received	Date sample returned
21/04/2014 – 24/04/2014	25/04/2014
28/04/2014 – 01/05/2014	02/05/2014
05/05/2014- 08/05/2014	09/05/2014
12/05/2014-15/05/2014	16/05/2014

Samples should be submitted to the Co-ordination Centre by the **16th May 2014 at the latest**. If they do not, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may then result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

Trusts which have not submitted their sample for checking by the **16th May 2014** will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **23rd May 2014**, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

12 Weekly monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the 2012 A&E survey. First submission of data must be made on **8th May 2014**¹³, and every Thursday thereafter until the final date of submission. An Excel spreadsheet for trusts conducting the survey in-house is available at <http://www.nhssurveys.org/surveys/764>, which **must** be used to return this information to the Co-ordination Centre. An excel spreadsheet for approved contractors to use is also available at <http://www.nhssurveys.org/surveys/764>. This information should be emailed to the Co-ordination Centre (emergency.data@pickereurope.ac.uk) by the end of the workday every Thursday throughout the survey.

Weekly submissions only apply to the core sample of patients

Important note

It is important that the structure of the Excel weekly monitoring spreadsheet is not altered and that the correct file name is used when submitting the data.

For trusts carrying out the survey in-house:

When the data is submitted, the file name **must** be in the following format:
AE14_<trust code>_<week of submission>.xls

e.g. AE14_RAC_1.xls (first submission of monitoring data on 8th May 2014)
AE14_RY2_4.xls (fourth submission of monitoring data on 29th May 2014)

For approved contractors:

When the data is submitted, the file name **must** be in the following format:
AE14_<contractor code>_<week of submission>.xls

e.g. AE14_ACP_1.xls (first submission of monitoring data on 8th May 2014)
AE14_ACL_4.xls (fourth submission of monitoring data on 29th May 2014)

Each approved survey contractor should use their unique 'contractor code'. If you do not know your contractor code, please contact the Co-ordination centre.

12.1 Response rate

The information submitted should contain the following data:

- The total number of patients in your sample, ie the total number of all those included in the first mailing,
- The number of patients in each outcome field

¹³ This submission must be made regardless of whether mailing has commenced.

This will allow the Co-ordination Centre to monitor progress at a trust level and to identify trusts that may need assistance. It will also allow us to provide the Care Quality Commission with regular updates on response rate at trust level.

12.2 Helpline monitoring

The information you submit should contain the following data for each trust:

- The overall total number of calls received by the helpline for this survey. This total should also include the calls listed below:
 - The total number of calls that led to completion of the questionnaire using the helpline (this should include completions via translation services)
 - The total number of calls seeking assistance with language and translation (this should include completions via translation services)
 - The total number of calls that led to completion of the questionnaire using translation services

Examples

If a caller rang the helpline and completed the questionnaire over the phone using translation services, then this call should be recorded in all four 'categories'.

If a caller rang the helpline to opt out of the survey (and did not require translation services), this call should just be recorded in the 'overall total' number of calls' (ie first category).

If a caller completed the questionnaire over the phone (and did not require translation services) this call should be recorded in the 'overall total' and the 'total number of calls that led to completion' (ie first and second categories).

This information allows the Co-ordination Centre to identify areas of concern to patients and to improve future surveys.

13 Publicising the survey

The following measures will help to increase response rates and reduce the number of questions and any complaints received about a survey:

13.1 Pre-survey communication with staff

The best way to ensure your survey is a success is to work hard in the beginning to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey. We suggest you put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:

- Caldicott Guardian
- Board members
- Doctors, nurses and other health care staff
- Members of patient groups with a special interest in the trust
- Patients and carers
- Medical records personnel or Patient Administration System (PAS) staff
- Managers
- Staff or directors responsible for:
 - Clinical governance
 - Patient advice and liaison service (PALS)
 - Quality improvement
 - Strategic planning

Keeping everyone informed

Notify as many staff members as possible about the survey, in case patients contact the trust asking questions about the questionnaire they have received. Patients can be expected to ask receptionists, doctors, nurses, patient liaison officers, or the Chief Executive's office about the survey, even when your covering letters give contact details for the survey manager(s) and the dedicated helpline. Notify front line staff and executive offices that a survey is being conducted, and give them the name and number of a contact person. Survey manager(s) should be prepared to respond to these calls quickly.

Staff could be notified of the survey through a variety of methods:

- Electronic (e.g. e-bulletins, website, intranet)
- Paper-based (e.g. staff briefings, newsletters, flyers, posters)
- Face-to-face (e.g. meetings, presentations and events)

13.2 Publicising the survey externally

To help promote involvement and maximise response rates, the survey can be publicised to patients and the public through a number of ways, for example:

- Send a press release to the local media to raise awareness of the survey and gain publicity just before the survey takes place. Talk to your hospital's press office for more ways in which you can gain publicity locally.
- Put up posters around the hospital which show the importance the trust places on gathering patient feedback. To be most effective at increasing your response rate, posters should be put up in the hospital during the sampling period (i.e. during the month from which your patient sample will be drawn). This poster will also give patients to opt-out of participating in the survey if they wish.

To encourage patients to respond, we recommend you illustrate how the trust has acted on the results of the previous A&E surveys carried out by the trust. Patients are likely to be more motivated to take part in the survey if they can see tangible outcomes from a previous survey.

Examples of pre-survey publicity materials can be found on the NHS surveys website at <http://www.nhssurveys.org/surveys/760>

14 The questionnaire

For the 2014 survey, there is a core questionnaire only. A question bank will not be available for this survey and trusts will not be able to amend the questionnaire to include additional questions. Each trust must use the questionnaire template provided by the Co-ordination Centre which contains the 51 questions that CQC require data on.

The questionnaire contains 51 questions over 8 pages. Most questions are directly comparable with questions patients were asked in the 2012 survey. The front page of the questionnaire explains the purpose of the survey and gives instructions on how to fill it in. In the pages that follow, the survey questions are divided into sections that broadly follow the patient's experience.

There is a pre-designed core questionnaire on the NHS Surveys website, which includes only these questions (<http://www.nhssurveys.org/surveys/761>).

15 Materials

15.1 Printing questionnaires

Questionnaire layout

The questionnaire is rigorously tested in the format of the core questionnaire. All questionnaires used by trusts must replicate this format as any differences can impact on the responses patients give. The format should be comprised of the following:

- Two columns of questions on each page
- Questions should be presented with a consecutive question number, followed by the exact question wording used in the core or question bank questionnaire, and then each of the response options presented on a separate line beneath the question, for example:

15. Did doctors or nurses talk to each other about you as if you weren't there?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

- Please do not arrange the response options horizontally across the page, rearrange the question options, or change the order of the questions in the questionnaire.
- Please ensure all routing instructions are accurate as any errors might impact on the use of ensuing data.

Number of pages

It is practical to ensure that the number of pages in a questionnaire is a multiple of four so that sheets can be printed double-sided on A3 paper and folded to make an A4 booklet, stapled in the middle. If pages are stapled at the corner, there is a greater chance that some pages will become detached and get lost. The questionnaire, available in PDF format on the NHS Surveys website, is designed to fit onto 8 sides of A4 paper (<http://www.nhssurveys.org/surveys/761>).

Number of questionnaires

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires with second reminders. Printing costs can be unnecessarily high if a second print-run is required, so it is worth ensuring that the first print-run is sufficiently large to allow for contingencies. As a rule of thumb, multiply the number of patients in the sample by 1.7 to obtain the total number of questionnaires required. So, if the number of first mailing questionnaires you intend to send out is 850, then you might want to print 1.7 x 850, or approximately 1,500 copies.

Other mailings and inclusion of other information in the mailing packs

Trusts should only use their sample information to mail out the three official survey mailings. The sample list should not be used for any other type of mailing ie Trusts should not mail their own letter to the sample list prior to the first mailing being despatched.

Furthermore, only the materials described below should be included in the mailings because of the unmeasurable impact upon response rates to the survey.

15.2 Trust headed paper

You will need headed paper from your trust for covering letters for the first and third mailing. A reminder letter is used for the second mailing. Therefore, depending on your response to the initial mailings, you will need approximately 1,200 to 1,600 sheets of trust headed notepaper. If an approved contractor is being used to carry out the survey work, it is preferable that the paper does not include a telephone number for the trust, as patients should call the contractor's FREEPHONE line, rather than the trust.

15.3 Survey Flyer

For the 2014 survey, a survey flyer has been produced by the CQC. This flyer explains who the CQC are, the importance of gathering patient feedback and what will be done with the data collected. The flyer will be included in both the first and third mailings. It is hoped that it will highlight the importance and purpose of the survey to patients and provide evidence of how their feedback contributes to monitoring the performance of the NHS.

For trusts using a contractor, sufficient numbers of flyers will be provided to each contractor. For in-house trusts, who are managing the mailing process themselves, these will be provided to you directly.

15.4 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to patients does not show any indication of the NHS Trust. Some patients may not have told family or friends that they have gone to hospital and, under data protection regulations, it is important that this information remains confidential to the patient. We would therefore recommend that the return address used on any mail out envelope(s) does not indicate Trust name or address. It is, however, important that we record questionnaires which are returned undelivered as this affects response rate. We would therefore advise that, where necessary (ie for Trusts conducting the survey in-house), a PO Box address is set up for envelopes which are returned undelivered.

Please note that the above does not apply to the address on the reply paid envelope (which can be a hospital address) as we assume that the patient is responsible for opening his or her own mail.

For further details on how to set up a PO Box please go to:
<http://www2.royalmail.com/delivery/inbound-mail/po-box>

15.5 First mailing

You will need 850 of each of the following items:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient

- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts)
- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead
- Multi-language helpline sheet (recommended)¹⁴.
- Survey flyer

15.6 Second mailing (first reminder)

First reminders are sent to all patients who do not respond to the first mailing (except, of course, those who withdraw). Usually you will need to send first reminders to around 55-75% of the original patient sample. The following items are needed:

- Reminder letters
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts)

15.7 Third mailing (second reminder)

The second reminder should replicate the first mailing, and you will need to send this to around 45-65% of the original sample, depending on the number of responses to the previous two mailings. The following items are needed:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts)
- FREEPOST envelopes for returning questionnaires
- Reminder letters
- Multi-language helpline sheet (if used in first mailing).
- Survey flyer

¹⁴ This document can be found on our website alongside the cover letters. The languages covered by this document are: Arabic, Bengali, Chinese (Cantonese), Farsi /Persian, Gujarati, Hindi, Kurdish, Chinese (Mandarin), Punjabi, Tamil, Thai, Turkish, Urdu, French, Italian, Polish, Portuguese, Russian, Somali, Spanish.

16 Implementing the survey - practicalities

16.1 Setting up a FREEPOST address

A FREEPOST address allows patients to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines. Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: <http://www.royalmail.com>

Alternatively, you can call your local Sales Centre on 0845 7950 950.

16.2 Setting up a PO Box

This is recommended for in-house Trusts to ensure that the mail out envelope(s) does not include any indication of the hospital address (please see Section 15.3 for further detail). Information on setting up a PO address can be found at:

<http://www2.royalmail.com/delivery/inbound-mail/po-box>

16.3 Setting up a FREEPHONE line

The covering letter to patients should include a telephone number for patients to call if they have any questions or complaints about the survey. All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive. If you run the survey in-house, you might want to set up a FREEPHONE line for this purpose. Alternatively, many approved contractors offer this service.

Where appropriate, ask the patients who calls to tell you their patient record number, which should be on the address label of the envelope they received, and on the questionnaire itself. You can then use this number to identify people who do not want to receive any further reminders.

Below are some questions and comments commonly asked by patients and some advice on how they can be managed:

I have had two or more attendances at the A&E Department - which one should I refer to?

Patients should be advised to refer to their **most recent** A&E Department attendance. Usually, this is the attendance covered by your sampling period but, for the few patients who have attended since you drew the sample; it is simpler to tell them to refer to their most recent visit. It will not make the results invalid if a few of the patients refer to a more recent episode than the others.

I have a specific comment, complaint or question about my care or treatment. Who can I contact at the trust?

Patients can be referred to the trust's PALS, the complaints manager or patient services manager. Approved contractors should be given the contact details of the PALS office or an appropriate member of trust staff so that they can refer callers to that person.

The person to whom the questionnaire is addressed is unable to understand the questionnaire.

Relatives or carers may call to pass on this information. In some cases, they may offer to complete the questionnaire for the patient, but this is only advisable if there is a good chance that the responses are a true reflection of the patients' views. There is a question in the questionnaire that allows you relatives or carers to say if they have completed the questionnaire on behalf of the patient.

The person to whom the questionnaire is addressed has died.

Even with the use of a deceased patients tracing service, it may not be possible to identify all deceased patients, particularly those who have died most recently. It is very important that staff who take the calls are aware of this possibility and are prepared to respond sensitively to such calls. These patients should be logged as outcome = three (patient deceased).

I would like to take part but English is not my first language.

If a patient's spoken English is better than their written English, they may be willing to have someone, such as a family member, fill in a form on their behalf. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet template in the twenty most commonly spoken languages in England is available on our website (<http://www.nhssurveys.org/surveys/755>), and trusts or contractors can make use of this by inserting the appropriate number for their helpline and/or translation service.

I do not wish to participate in this survey

A few patients might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the patient and reiterate the statement in the covering letter - that taking part in the survey is voluntary, and that the patient's care will not be affected in any way if they do not respond. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of the patient's responses. If the patient is willing to tell the staff member the identification number (patient record number) written on their survey, it might also be possible to prevent any further reminders being sent to that patient. It is also advisable to ask the patient to ignore any future reminders that they might receive. These patients should be logged as outcome = four (opt out).

Making a record of the calls

It is important to keep a record of the reasons patients called, as this can help to make improvements to future surveys and can provide useful additional information on patients' concerns. A standard form should be produced for completion by those taking the calls. The relevant details of each call can be recorded so that survey organisers can monitor any problems and remove patients who wish to be excluded from the mailing list.

We are also asking for weekly submissions of helpline use for each trust to the Co-ordination Centre. This is discussed in detail in Section 12.2.

16.4 Covering letters

The standard covering letter is available in Microsoft Word format on the A&E Survey section of the NHSSurveys website for you to download and add your own trust's details (<http://www.nhssurveys.org/surveys/755>). This letter has been given ethical approval for use in the 2014 A&E Survey and changes are not permissible. It should be printed on the trust's letterhead paper. Two paper copies of the letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

Please note, for the first mailing letter and second reminder mailing there is now the option to include patient name. We strongly recommend this approach as there is evidence to show that this increases response rate (we would recommend using patient title followed by surname). If patient name is used, please take great care that each letter is correctly matched to its corresponding questionnaire.

For the 2014 survey, we have also amended the first mailing letter and second reminder letter to allow trusts to insert a short paragraph on how feedback from the 2012 survey has been used to make changes or improvements in the quality of care provided at the local level. If you wish to include a paragraph of this nature, and are using an approved contractor, please provide your contractor with the text who will insert it into the letters for you.

16.5 Sending out questionnaires

Mailing labels

Three mailing labels are needed for each patient. One set of labels will be used for the first mailing, one for the first reminder and one for the second reminder.

We recommend using the mail merge feature in a word processing package to create the mailing labels from the database of patient names and addresses. **It is essential that the patient record number is on each address label**, as this has to be matched with the number on the front of the questionnaire. The label should not include any other information except the patients' name, address and postcode details, and the patient record number.

Note on the patient record number (PRN)

The patient record number is a unique number allocated to all patients at the start of the survey that allows their responses to be kept separate from their name and address, but allows matching up of the response data with the sample data. It also allows them to identify themselves if they contact the trust or contactor without needing to provide name and address information. This should be centrally placed and large enough to be visible to all patients. The Royal National Institute of the Blind recommends the number be printed in size 14 font and located inside the box on the lower half of the front page of the questionnaire.

If patients delete this number from the cover page and then return the questionnaire, please add their response information in an additional row to the bottom of the data file before submitting it to the Co-ordination Centre. Please do not attempt to match this data to a non-responder of similar demographics, but instead inform the Co-ordination Centre about this respondent and they will be treated as an additional patient to the sample.

Questionnaire packs

The envelope sent to each patient at the first mailing should include the following:

- 1) A questionnaire **numbered with the patient record number**. The number must match the number on the address label, and the number on the list of patient details.
- 2) A covering letter.
- 3) The multi-language helpline sheet (recommended)
- 4) A large envelope, labelled with the FREEPOST address on it
- 5) Survey flyer
- 6) These items should be packed into an envelope that has a return address on the outside. (PO Box recommended for in-house Trusts). This should be the contact at the NHS trust, or the approved contractor.

Postage

The postage may exceed the standard letter rate. It is essential that the appropriate postage rate is paid.

Approved contractors – mailing questionnaires

If an approved contractor is carrying out the work under a service contract, they will send out questionnaires directly to the patient, and the return address label will be the approved contractor's address.

Approved contractors – trusts mailing questionnaires

If an approved contractor is carrying out most of the work but not operating under a service contract, they should send pre-packed questionnaires to the trust for mailing out. The envelopes should be clearly marked with the patient record numbers so that trust staff can match these with their patient list and put on appropriate patient address labels.

16.6 Booking in questionnaires

When questionnaires are received, match up the patient record numbers against the list of patients, so that you can record (in the *outcome* column) which patients have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until 5th December 2014, but please **do not** send these to the Co-ordination Centre.

Approved contractors

If an approved contractor carries out the work, questionnaires will be returned directly to them, so they will be able to record these returns against the list of patient record numbers. Trusts should inform the contractor of any questionnaires that were returned to the trust undelivered, and of any patients who inform the trust that they do not wish to be included in the survey, or if any patient dies during the period of the survey. The contractor can then record these details in their own patient list, and ensure that reminders are not sent out to those patients.

16.7 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, you must send out two reminders to non-responders. **Remember, it is essential that you send out both reminders, even if you already have achieved a 50% response rate.**

Depending on the time that has elapsed since you first checked your patient list for deaths, it might be necessary to send your list back to the tracing service for a further check before you send out reminders.

Approved contractors

If a trust is using an approved contractor but is carrying out the survey mailing in-house, the approved contractors should send the pre-packed envelopes bearing the patient record numbers of the non-responders to the acute trust. Again, the envelopes should be clearly marked with the patient record number so that those carrying out the mailing can correctly label the address for each patient record number.

First reminders

The first reminder should be sent to patients who have not responded after **one to two weeks**. We recommend approximately **ten** days between the mailing day of the first questionnaire and the mailing day of the first reminder. The first reminder should reach the participant while they are still in possession of the first questionnaire, and the optimal time for this will vary between trusts.

The standard first reminder is available in Microsoft Word format on the NHS Surveys website for you to download (<http://www.nhssurveys.org/surveys/755>). It can be printed on A5. It has been given ethical approval so no changes are permitted. Two paper copies of the reminder letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

Second reminders

Second reminders should be sent out approximately two to three weeks after the first reminder to patients who have not yet responded. Again the optimal time will vary between trusts and experience is the best guide for choosing mailing dates.

The envelopes should include the following:

- 1) A questionnaire numbered with the patient record number. The number must match the number on the address label and the number on the list of patient details.
- 2) A covering letter.
- 3) A multi-language helpline sheet (if used in first mailing)
- 4) Survey flyer
- 5) A large envelope, labelled with the FREEPOST address on it.

The standard second reminder letter is available in Microsoft Word format on the NHS Surveys website for you to download and add your trust's details (<http://www.nhssurveys.org/surveys/755>). Two paper copies of the second reminder letter you use must be sent to the Co-ordination Centre by the 30th May 2014.

Remember that you should check your trust's own records for deaths before sending out reminders.

17 Entering data

The data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of **5th September 2014**. If an approved contractor is used, they will be responsible for all of the data entry and checking, and when the survey is completed they should submit the data to the Co-ordination Centre in the correct format and supply the trust with an anonymised data set (see Section 6 on data protection issues).

17.1 Entering and coding data from the core questionnaire

The data should be entered into the pre-designed Excel file, which can be found in the A&E Survey 2014 survey section of the NHS Surveys website (<http://www.nhssurveys.org/surveys/756>)

You will see that, at the bottom of the Excel screen, there are labelled tabs for each of the worksheets within the workbook. The first of these tabs is labelled "Data". Click on this tab to show the data entry window. Data should be entered using the following guidelines:

- Each row records one patient's responses to the survey
- For each question, the small number next to the box crossed by the patient should be entered as the response
- If a response is missing for any reason, it should be left blank, or coded as a full stop (.)¹⁵
- If two boxes are crossed (where only one should be crossed), the response should be left blank or coded as a full stop (.)
- For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions Q49 and Q50 that give the instruction "Cross all that apply", each response option is treated as a separate question.
- If the questionnaires are being scanned, it is important to check the visual image of Q43 against the data file. If there is a discrepancy between the visual image and the response reported in the data set, change the answer in the dataset to match the visual image.

¹⁵ If you want to use the data input file on the website to display frequencies on the other pages of the workbook, you will need to fill in the blank cells with a full stop (.)

Example

Q49. Do you have any of the following long-standing conditions? (Cross all that apply)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 A long-standing physical condition
- 4 A learning disability
- 5 A mental health condition
- 6 Dementia
- 7 I have a long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
- 8 No, I do not have a long-standing condition

Responses to each part of this question are coded: **1 if the box is crossed**
0 if the box is not crossed¹⁶

Q49 takes up seven columns in the data file, labelled as follows:

Column headings	Q49_1	Q49_2	Q49_3	Q49_4	Q49_5	Q49_6	Q49_7	Q49_8
Codings for this example	1	0	0	0	1	1		0

When saving this file to submit data to the Co-ordination Centre, please save only the first sheet as a worksheet, rather than saving the whole file as a workbook; the Co-ordination Centre does not need the additional formula pages.

Adapting the data file for sending data to the Co-ordination Centre

You will need to send the data from the A&E Survey to the Co-ordination Centre. To do this, you will need to transfer those columns of data that cover responses in the pre-designed Excel file available on the website (<http://www.nhssurveys.org/surveys/756>) . The columns of this standard Excel file are headed with the numbers corresponding to the question numbers in the A&E questionnaire. They also include the wordings of the 51 questions so that you can match them up. It is essential that you check carefully that the columns of data you select correspond to the Survey questions.

¹⁶ Please note: if a respondent does not answer any part of a multiple response question, (ie does not cross any of the response options) then it should be left blank or coded as a full stop (.)

17.2 Entering the patients' written comments

The Care Quality Commission has asked the Co-ordination Centre to request all free text comments provided by respondents to the 2014 A&E survey. Any analysis of these free text comments will be conducted in a way that would not allow individuals to be identified.

Please ensure that the comments have been **anonymised** (i.e. by replacing certain words with asterisks) and ensure comments are checked before sharing with NHS staff involved in patients' care. **It is very important that neither the patient, nor a particular staff member should be able to be identified from any comments.** Respondents are told that responses to the questionnaire will be kept confidential, so if data is shared without checking and removing identifiable details, this would be a breach of that confidentiality assurance.

Anonymising free text comments

When anonymising patient comments, please ensure you adhere to the following guidelines:

- 1) Any mention of patient/staff names, ethnicity, marital status and sexuality should be removed. For example: "The Scottish nurse was really friendly" should be amended to read: "The **** nurse was really friendly".
- 2) Mentions of ward names in general comments, such as "I was treated very well on Ward 7" are acceptable, but ward names should be removed from more specific comments, for instance if a specific group of staff is mentioned.
- 3) It is acceptable for hospital names to be left in.
- 4) Names of specific groups of staff are acceptable (e.g. anaesthetist, matron, ward sister). But, please take care when additional information is supplied (such as gender) that this does not lead to this person being identified.
- 5) In situations where a comment gives a lot of detail about dates, what the procedure/reason for being in was, some information should be removed so that the patient is not identifiable.
- 6) Please take care that the mentioning of a specific procedure/treatment/condition does not allow the patient to be identified.

As a rule of thumb, if there is something that you are not sure about, but you think it might identify the patient or a member of staff, please either remove it or contact the Co-ordination Centre for advice. For an example, please see Table 3.

Preferably, the anonymised patients' written comments should be entered in the main data file alongside the responses to the 51 questions and submitted to the Co-ordination Centre on or before 5th September 2014. Please see [Table 5 – Example of data file to be submitted to Co-ordination Centre](#) in section 17.4.

Alternatively, if you are unable to submit the free text comments by this deadline, then you may submit them to the Co-ordination Centre anytime before the 19th September 2012. If you do submit the free text comments to the Co-ordination Centre after the main data submission on 5th September, then please ensure you include the trust code and the same record number for that patient used in the final data set submitted by 5th September 2014. Also include the patients' gender, year of birth, ethnic group and outcome fields from the sample data. Include all patients in the sample for each trust, not just those who made comments (some text boxes will therefore be blank). For example:

Table 3 – example free text comments

Trust code	Patient Record Number	Gender	Year of Birth	Ethnic category	Outcome	If there is anything else you would like to tell us about your experiences in the A&E Department, please do so here
RUB	AE14 RUB 0001	2	1956	A	1	The care was generally excellent, especially from Dr *****
RUB	AE14 RUB 0002	1	1978	A	6	
RUB	AE14 RUB 0003	1	1942	G	1	
RUB	AE14 RUB 0004	2	1981	Z	1	I was seen really quickly and got good care – thank you

17.3 Checking the data for errors

For the 2014 A&E survey, trusts and contractors are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created by the following:

- 1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (eg where patients answer questions that they have been directed to skip past, these responses should still be entered).
- 2) Where a respondent has crossed more than one response category on a question, this should be set to missing in the data. The **exception** to this is for the 'multiple response' questions Q49 and Q50, where respondents may cross more than one response option.
- 3) Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead crossed a second response option, this second choice should be entered into the data.
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a patient has written their date of birth in the boxes for Q46, but written their year of birth in at the side of this, then the respondent's year of birth should be entered.
- 5) For the year of birth question, unrealistic responses should still be entered except following rule 4) above). For example, if a respondent enters '2014' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.

- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient’s intended response has not been captured. This includes ‘out-of-range’ responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent’s intended response.

A data cleaning document will be made available on our website (<http://www.nhssurveys.org/surveys/759>) , which documents all filtering and cleaning that will be carried out on the collated dataset by the Co-ordination Centre so that trusts and approved contractors can duplicate this process after submitting the raw data to the Co-ordination Centre.

17.4 Submitting data to the Co-ordination Centre

The data from the core questions of the 2014 A&E Survey must be supplied to the Co-ordination Centre as one anonymised Excel file that includes information about the patient sample and responses. To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre.

Required file format

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable.
- The file name must be in the form <NHStrustName>_A&E2014.xls
- Use one row of data for each patient in the sample.
- Use one column of data for each item of patient information or response.
- Patients who are missing their Patient Record Numbers should be added to the bottom of the list, and not matched to patients with similar demographics.
- Missing data should be left blank or coded as a full stop (.).¹⁷

Table 4 shows the information that must be provided for each of the 850 patients in the original sample.

Table 4 - Data fields to be included in file submitted to Co-ordination Centre

Field	Format	Data codes	Comments
Patient record number	AE14NN NXXXX		The unique serial number allocated to each patient by the trust or approved contractor administering the survey.

¹⁷ Data may be missing for a number of reasons. The patient may have skipped a question or a set of questions by following instructions; a patient may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

Field	Format	Data codes	Comments
Year of birth	NNNN		Format this simply as a number, not in date format.
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.)
Ethnic category	N	<p>National Codes:</p> <p>White A British B Irish C Any other White background</p> <p>Mixed D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background</p> <p>Asian or Asian British H Indian J Pakistani K Bangladeshi L Any other Asian background</p> <p>Black or Black British M Caribbean N African P Any other Black background</p> <p>Other Ethnic Groups R Chinese S Any other ethnic group</p> <p>Z Not stated</p>	Ethnic category should be included if the information is available.
Day of attendance	N or NN	Format this field as a number, not a date	For example, if the patient attended on 10 th March 2014, this column should read '10'.
Month of attendance	N or NN	Format this field as a number, not a date	For example, if the patient attended on 10 th March 2014, this column should read '03'.

Field	Format	Data codes	Comments
Year of attendance	NNNN	Format this field as a number, not a date	For example, if the patient attended on 10 th March 2014, this column should read '2014'.
Time of attendance	HH:MM	Format this field in 24 hour time: hours and minutes separated by a colon (HH:MM)	For example, if the patient attended at 3.45pm, this column should read '15:45'
NHS Site Code	NNNNN	Use the character codes provided by Connecting for Health to complete this field	Use the five characters of the NHS site code
GPPC	NNNNN N	Use the character codes provided by HSCIC to complete this field	Use the six characters of the GPPC
Day questionnaire received	N or NN	This is the day you receive a returned questionnaire from a respondent, or you are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 12 th June 2014, this column should read '12'.
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 12 th June 2014, this column should read '06' (as June is the 6 th month of the year).
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 12 th June 2014, this column should read '2014'.
Outcome of sending questionnaire	N	1 = Returned useable questionnaire 2 = Returned undelivered by the mail service or patient moved house 3 = Patient died 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire 5 = Patient was not eligible to fill in questionnaire	Remember to fill in all the blank cells with 6s when the survey is complete.

Field	Format	Data codes	Comments
		6 = questionnaire not returned (reason not known)	
Responses to each of the 51 cross-box questions	N or NN or NNNN		Each column must be clearly headed with the core questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys.
Patients' free text written comments: If there is anything else you would like to tell us about your experiences in the A&E Department, please do so here.	Text		Verbatim comments that could lead to any staff identifying respondents must be removed, eg those mentioning patient, staff, ward, or unit names

NB: To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre.

Table 5 is an example of the columns of data to be included in the file. Your file should have 850 rows (one for each patient included in your sample). You will notice that there are several blank cells in the response section of the file. This is because the file includes a row for every patient in the sample, but you will only have responses from about 50% of the patients (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code "1").

Table 5 – Example of data file to be submitted to Co-ordination Centre

Patient Sample Information								Patient Response Information											
Patient record number	Year of birth	Gender	Ethnic category	Day of attendance	Month of attendance	Year of attendance	Time of attendance	NHS Site Code	GPPC Code	Day of receiving questionnaire	Month of receiving questionnaire	Year of receiving questionnaire	Outcome	Q1	Q2	Q50_7	Q50_8	Q51	If there is anything else that you would like to tell us about your experiences in the A&E Department, please do so here
AE 14 XX X0	19 34	2	A	04	0	2014	14:2	R1					3						
AE 14 XX X0	19 70	1	C	16	0	2014	08:4	R1		17	06	2014	1	3	1	0	1	A	I was seen straight away ...
AE 14 VV	19 65	2	A	09	0	2014	11:2	R1					6						
AE 14 VV	19 35	2	A	12	0	2014	07:1	R1		03	06	2014	1	2	2	0	0	E	
AE 14 VV	19 29	2	C	23	0	2014	18:3	R1		29	06	2014	1	1	5			A	Excellent care and...
AE 14 XX VV	19 23	1	J	29	0	2014	23:5	R1		12	06	2014	2						
AE 14 XX X0	19 50	2	R	02	0	2014	04:3	R1					6						
AE 14 XX X0 00	19 46	2	A	19	0	2014	12:1	R1		18	07	2014	1	6	1	1	0	A	

Additional information required

The following information should also be included when submitting the data file to the Co-ordination Centre:

- **Contact details** (telephone numbers and e-mail addresses) of at least two members of trust staff (usually the main and secondary contacts) who will be available to answer any queries about the data
- **Two blank paper copies** of the questionnaires, the covering letters and the reminder letters you used
- A completed copy of the **checklist** (See Section 17.5 - Checklist).

Delivery

Data may be sent on encrypted CD-ROMs or by e-mail (see section 6.6 of this document for details on the recommended encryption and delivery methods to use).

Hard copy documents should be posted to the address below:

Postal address:

A&E Survey 2014
Co-ordination Centre for Patient Survey Programme
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

E-mail: emergency.data@pickereurope.ac.uk

Deadline for submission

The data must be supplied by **5th September 2014**

17.5 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below, and include this checklist when you submit paper copies of the questionnaire and covering letters.

It is essential that these checks are carried out thoroughly. The Co-ordination Centre is not obliged to make any corrections to data supplied by trusts or approved contractors.

If incorrect data are submitted, it is possible that the data will be considered unreliable and will not be used by the Care Quality Commission in its assessment for your trust. We cannot accept re-submissions of data after the deadline.

A printable version of the checklist can be found on our website at:

<http://www.nhssurveys.org/surveys/738>

Check	Done?
1) Check that your file name follows the naming convention: <NHStrustName>_A&E2014.xls)	
2) Check that you have saved the data sheet only as an Excel worksheet , rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the website are intended for your use only)	
3) Check that you have included data columns for all 51 questions and patient written comments	
4) Check that all data are correct , and that all values are in range	
5) Send data only for the 850 patients sampled from your trust in the chosen month.	
6) Check that all the data for the 51 questions are in numeric format only (including dates)	
7) Check that patients' written comments are in an anonymised format	
8) Check that you have completed the columns for the day, month and year you received the questionnaire back from patients	
9) To comply with Data Protection regulations, any patient name and address details must be removed before the file is sent to the Co-ordination Centre	
10) Notify the Co-ordination Centre of the password separately from the data file	
11) Include two paper copies of the covering letters you used for the first, the second and third mailing.	
12) Include telephone and e-mail contact details of two people who will be available to respond to any queries about the data	
13) Check again that all data are correct, and that all values are in range.	

18 Making sense of the data

The usefulness of your survey data will depend on how well you plan the survey process and on how effectively you analyse the data. Standard data analysis usually involves examination of the frequency of responses to each question and some cross-tabulation of responses against demographic and other information.

18.1 Using the NHS Surveys website to look at your results

Once you have entered the data from the core questions into the Excel file on the website (the Data Entry Spreadsheet), the counts and percentages of responses to each of the 51 questions are automatically computed and displayed on the other sheets of the Excel workbook, which correspond to sections of the A&E Department core questionnaire (excluding the "Other Comments" section). For each question, the numbers and percentages of respondents who gave each answer is shown. The number of missing responses will also be shown, as long as you have coded missing responses on the data sheet as a full stop (.)

18.2 Suggestions on data analysis

The following suggestions may help you make the data analysis more useful and focused.

Use the data to help pinpoint problems

It is often tempting to focus on organisational strengths. This may be important for public relations and employee morale. However, if you emphasise only the positive, you may miss a critical opportunity to use the data to spur improvement.

One way to focus attention on where improvements are needed is to analyse responses in terms of the proportion of answers that suggest a problem with care. Try to maintain high standards in determining what constitutes a problem. For example, if questions allow respondents moderate response categories (such as "to some extent" or "sometimes"), in addition to more extreme ones ("always" or "never"), your analysis will be more powerful if you identify these moderate responses, as also indicating a problem.

"Drill down" into the data

It is impossible to analyse absolutely every issue a patient survey raises. One reasonable way to control the number of analytical questions is to conduct a staged analysis.

The **first** level of analysis should be the most general - for example, summary measures or measures of overall performance. The next level should delve into particular issues that underlie the summary measures - performance along particular dimensions of care, for example, or of particular units or staff. The final level should entail statistical or cross-tab analysis to get at the causes of the particular issues.

Group similar questions together to provide summary analysis

Analysing questions and presenting findings in a way that is comprehensive, logical and not overwhelming is a significant challenge. To make the data more compelling for others, and to speed up the analysis, we suggest:

- Linking questions that cover similar topics or processes
- Combining several questions into a single composite measure (by averaging responses, for example)

Use statistical tests to make comparisons and subgroup analyses

Statistical tests can be used to examine relationships and associations between groups (for example age, sex or ethnic categories). These tests take into account the number of responses, the variation in responses, and values of the items you are comparing (such as average responses). If tests show that the differences between two groups are not statistically significant, you should view the patterns of responses as only suggestive.

Calculate confidence intervals to give an indication of the uncertainty surrounding your results

Although there are many methods of describing uncertainty, confidence intervals are used most often. By taking into account the number of responses, the variation in response, and the magnitude and direction of the estimate, the confidence interval describes the range of plausible values within which the "true" value for the population is likely to fall. Remember that the estimate itself is the most likely result, and this is therefore your best estimate, not the limits of the confidence interval.

Make use of the free text

Patients' comments on the back page of the questionnaire can provide valuable feedback on their experiences. Such data illustrate responses to closed questions, and allow respondents to identify new issues not captured elsewhere in the questionnaire. It can be effective to group comments made about similar topics to identify themes in patient's experience of maternity care.

Any information that could allow respondents to be identified, such as patient and staff names should be removed.

Use patient feedback data with other data

Patient feedback data provides one valuable source of information about how patients experience and feel about the health services they receive. Linking feedback data with clinical data, outcomes data, and routinely collected data, when done appropriately, can provide useful insights.

Perform analysis by sub-groups

You may want to compare the answer to a survey question between two different groups to see if the differences are significantly different (e.g. the answers for men versus women, or between patients treated under different specialties). However, comparing results *within* your trust considerably reduces the number of responses in each group. This will impact upon the level of confidence you have in the results and, therefore, your ability to accurately detect differences between these groups.

Table 6 (below) shows the level of confidence you would achieve for various numbers of respondents.

Table 6: Confidence intervals*

Number of respondents	Widest Confidence Interval (+/-) ¹⁸
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%

*at a 95% confidence level

If you are interested in looking at different sub-groups within your trust population (for example, patients treated at different sites in your trust), you will need to think about the number of respondents you need in each group, and how this will impact on the confidence you can have in the results. The Co-ordination Centre recommends a minimum of 100 respondents per group for comparison between sub-groups. Confidence intervals for analysis with groups of fewer than 100 respondents will be so large that there would be little certainty of detecting reliable statistical differences¹⁹

Example

For a trust, 400 patients responded in total. Taking a particular question, of which 50% of respondents answered 'Yes', from the table we can see that the widest confidence interval for 400 respondents would be +/- 4.9%. We would therefore be 95% confident that the true results would be between 45.1% and 54.9% - that is, if you had surveyed the entire population of A&E attendances at a trust.

However, if we are looking at the results for this particular question *by eight different groups of patients* (assuming an equal number of respondents in each region), there would only be 50 respondents in each group. If there are 50 respondents and 50% answered 'Yes', the confidence interval would be +/- 13.9%, so the true results could be between 36.1% and 63.9%.

If you are using a survey contractor to help you carry out your survey, they should be able to advise you on the minimum sample size for comparisons by particular sub-groups

¹⁸ This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

¹⁹ A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

19 Reporting results

19.1 Prioritising your findings

Patient surveys can raise many compelling and important issues. To help you decide which issues to focus on first, you may like to consider the following suggestions:

Rank results by their magnitude

The most straightforward method of prioritising is to rank issues in order of the size of the problem and to focus first on those that are the greatest.

Compare your results against outside norms or benchmarks

A common method of prioritising is to select issues that compare unfavourably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Compare your trust's results with the benchmarks on the NHS Surveys website (www.nhssurveys.org) to find out where your trust performs better or worse than other trusts.

Compare results within your organisation

Comparisons within organisations can facilitate networking among units or Departments and the sharing of information about effective practices. Internal 'competitiveness' may also fuel improvement efforts. You will need to ensure that you have collected this information in your sample frame.

Compare results over time

Investigating trends in survey results over time is another powerful analytical tool for prioritising areas for improvement. Analysis of trends allows you to focus on correcting aspects of performance that are slipping, although you should confirm any apparent changes between years are statistically significant. The nature of a trend in the data (does the trend go up, or down, or is there no trend) and the extent of any trends or changes (are they steady, sharp rises or falls, or erratic) are good starting points for making comparisons over time. It should also be possible to measure the impact of any initiatives that have been introduced.

However, the composition of both the samples and the respondents can vary significantly between surveys, even if the sampling criteria remain unchanged. Certain groups of patients respond more positively than others, such as older patients compared with younger; if your results improve significantly from one survey to the next but the proportion of older patients has increased, the improvement may be due to a change in those responding. One solution to this issue is to "standardise" your data, ie to control for these variations in population so that you can be more confident that any change reported is due to changes in service quality, not just those who are responding.

If comparing two or more sets of survey results, we suggest that you compare the key demographics of the respondents early in your analysis. If there are significant differences in the proportions of respondents by, ethnic group or parity, you may need to weight, or otherwise standardise, your data. Some analysis programmes can standardise your data for you but you

may need to seek the assistance of a statistical expert before you attempt to control for variations in respondent demographics.

Comparison with predefined goals

Another way to identify priorities is to set threshold or target goals prior to the survey. You would then focus on issues where performance does not meet these goals. This method is particularly effective when there is clear consensus on what those goals should be.

Correlation with overall measures

Correlating patient responses to specific questions with responses to the question about overall quality of care can help focus attention on issues that are important for patients.

Predictive value on overall measures (regression analysis)

Similar to correlation, regression analysis also gives a sense of the issues that most sharply affect patients' overall assessments of care. Regression analysis is superior to simple correlation, in that it can adjust for other things that have an impact on the overall measure, and it provides more precise estimates of how overall measures will change in response to improvement on individual items. Regression analysis is also more complex but in essence, it allows for a more level 'playing field'. There are limits to a univariate (crude) analysis and so regression analysis is an attractive option.

Ease of action

Many organisations focus initially on the issues that are easiest to improve. By demonstrating successful interventions, this prioritisation method can rally support for more difficult improvement efforts later on.

Areas of excellence

An organisation may also want to maintain excellence in areas where it is already perceived to be doing well. This approach can provide a clear and positive focus for clinical and administrative staff.

19.2 Writing the report

User-friendly reports that enable readers to understand and begin to take action on key issues are critical to the success of any survey project. The following suggestions will help you produce useful reports:

Tailor the document to the audience

- Use brief, succinct summaries for executive audiences
- Use comprehensive summaries for those who will implement improvements. They will help achieve buy-in and generate action
- A separate resource booklet or data disks/CD-ROMs with full details may be important if staff or researchers have questions

Use graphics

- Data that are displayed visually can be easier to interpret
- Display trends or comparisons in bar charts, pie charts, and line charts
- Remember that colours don't photocopy or fax very well

Keep the format succinct and consistent

- Graphics, bullets, tables, and other visuals help guide the reader
- Choose a few of these elements and use them consistently
- Too many types of visual elements can detract from the message
- Be consistent in the use and appearance of headers, fonts, graphic styles and placement of information

Emphasise priorities clearly

- Emphasise the highest priority items for action or commendation in executive summaries and major findings sections
- Highlight the most important items - for example, use bold type

20 Using results for quality improvement

Arguably the most important aspect of the survey process is making use of the results to bring about improvements. It is essential that this patient feedback is used to set priorities for quality improvement programmes and to create a more responsive, patient-centred service. It should then be possible to measure progress when the survey is repeated.

20.1 Prepare in advance

The most important way to ensure that the survey will result in improvement is to plan for improvement work before the survey is conducted.

- We recommend the survey lead / team take responsibility for developing a dissemination strategy to inform all of the relevant stakeholders about the survey findings
- Publicise the survey before it happens. Engaging staff from the start will help to ensure their support later on with any improvement initiatives. Involving the local media and informing the public may encourage a good response rate from patients

20.2 Dissemination of survey results

Engage key stakeholders

Raising awareness of the survey programme in your organisation is vital. Publication is an excellent way to inspire staff to take patient feedback seriously. By communicating your survey results to key stakeholders you will help to ensure they are used effectively and not forgotten.

Consider the following groups:

- Staff throughout the trust as they will be responsible for tackling any problems identified by patients
- Board members as they are involved in prioritising areas for improvement and shaping action plans. Their support is often crucial for the successful implementation of change
- Patients have taken time to report their experiences so they it is important they are informed of the results via local meetings, newsletters and articles in the local press
- Patient groups with special interest in the trust who may have a key role to play in initiating discussions with the board about priorities for improvement and be keen to monitor progress as it occurs
- When reporting the results it is a good idea to also invite people to contribute their ideas on how services could be improved and to suggest ways in which they can become involved if they wish to.

Spread the Word

Disseminating survey results entails far more than producing and photocopying a report. Consider how to share the survey results in training sessions, staff and public meetings, employee newsletters, executive communications, process improvement teams, patient care conferences, and other communications channels. You may wish to consider the following:

- Determine whether information should be shared initially with only senior-level people, or whether (and when) it should be spread further afield
- Make presentations to your trust board and to as many groups of staff as possible, each tailored appropriately for the audience
- Organise a high profile event to publicise the results and invite staff and patients to contribute to improvement plans
- Encourage staff at all levels in the organisation to contribute their ideas for improving patients' experience
- Publish the survey results on your website, including any intranet site and give readers the opportunity to feed back their ideas
- Email staff to tell them about the survey results and the action plan
- Share information with other NHS organisations in your area and other partner organisations including local authorities
- Give the results to community organisations and ask them for their views and suggestions
- Publicise results via local press, radio and community newsletters
- Publish results in your trust newsletter along with details of improvement plans

Promote understanding

To assist others in understanding the results, we recommend the following:

- Present results in user-friendly formats. Remember not everyone will be an expert in reading graphs and deciphering data
- Communicate information in a visual way, perhaps in the form of posters which can be displayed around your organisation
- Focus on key messages arising from the results and emphasise both the positive and negative themes
- Illustrate themes with relevant patient comments or other forms of patient feedback to put the results in context

20.3 Identify key "change agents"

The people who can motivate others to bring about change and who hold the 'keys' to improvement in the organisation are not necessarily the most senior people. Identify these individuals and involve them as "change agents" early in the survey process.

20.4 Prioritising areas for improvement

Compare with other trusts

Compare your trust's results with the benchmarks on the Care Quality Commission and NHS Surveys website to find out where your trust performs better or worse than other trusts.

Compare Departments within your trust

If your data allow it, further analysis of your results by sites or Departments will provide a more detailed breakdown of performance. You may be able to identify examples of good practice within your trust which can be applied to other areas requiring improvement.

Identify where patients report most room for improvement

Issues can be ranked according to the size of the problem. Look at questions where more patients indicate that their care was not perfect and could be improved. Select the questions where most problems are reported and focus on the issues that are a priority for your organisation.

Focus on areas where work is already underway and solutions can be easily identified

Focusing on issues that present solutions (e.g. improving information provided to patients about medications they are given when they leave hospital) and choosing topics currently being considered by existing groups in your Trust (e.g. the Clinical Governance Group) will help to gain the ownership and involvement of staff and patients and avoid duplication of effort.

Identify problems surrounding particular aspects of the patient experience

There may be particular aspects of care or elements of the patient experience where more problems are reported than others. For example:

- The time waiting to be examined by a doctor or nurse
- Being given enough privacy when being examined or treated
- Accessing suitable food and drinks
- Receiving enough information at the end of the visit to the A&E Department

20.5 Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and patients to prioritise and then identify the actions required. Decide on achievable timescales and on the individuals who will be responsible for taking this work forward. This will form the basis of an action plan which can be updated on a regular basis.

Wherever possible, link the information from the patient survey results with other activities in the trust. You can also use other sources of patient feedback from:

- Patient Advice and Liaison Service (PALS)
- Complaints
- Service Improvement/Modernisation Teams

Initially it is a good idea to focus on one or two key areas for improvement and not to attempt to tackle all of the issues at once. Publishing regular progress reports widely throughout your trust and the local area will help to enlist ongoing support. Repeat surveys can then be used to monitor any improvements.

20.6 Use small follow-up surveys or focus groups to delve deeper

Your initial survey can help you identify areas in need of improvement, but you might need more detailed information to focus your improvement effort. It can be time-consuming and expensive to gather this information on a large scale. Small follow-up surveys focusing on selected groups of patients can provide valuable information and faster feedback.

20.7 Use already existing resources

The Department of Health published the guide 'Understanding what matters: A guide to using patient feedback to transform care', which provides guidance on getting the most from your survey results.

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780.

21 Appendix 1: Declarations of data protection compliance

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
2014 NHS National A&E survey
FOR TRUSTS USING IN-HOUSE SURVEY TEAMS**

While carrying out the 2014 NHS National A&E survey, all trusts need to comply with:

- the Data Protection Act 1998,
- the NHS Code of Practice on Confidentiality, and
- the Caldicott principles.

Due to the large amount of patient information requested by the NHS patient survey programme, it has become necessary to regulate which individuals at a trust are able to view the raw data and some of the processed data. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise access to patient identifiable information, all declarations must be co-signed by the trust's Caldicott Guardian. If the trust's Caldicott Guardian does not authorise this, the trust must carry out the survey using an approved contractor.

For further information on the new guidelines, please see the "Data protection" section in the Guidance Manual for the 2014 NHS National A&E survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date:

I, **[insert name of first survey lead]** the first Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 NHS National A&E survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date:

I, **[insert name of second survey lead]** the second Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 NHS National A&E survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date:

22 Appendix 2: Declarations for additional data analysts

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
2014 NHS National A&E survey
Additional data analysts**

If the trust requires additional data analysts to have access to the raw data set, this form must be completed and sent to the Co-ordination Centre, and a response received before access to the data set is granted. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise this access, all declarations must be co-signed by the Caldicott Guardian. If the Caldicott Guardian does not authorise this, the raw data set and responses from subgroups numbering less than twenty can only be viewed by the authorised survey leads.

For further information on the new guidelines, please see the “Data protection” section in the Guidance Manual for the 2014 NHS National A&E survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section “Data protection” in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date:

I, **[first additional data analyst]** the first additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 NHS National A&E survey and will conform to these requirements and the guidelines set out under the section “Data protection” in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date:

I, **[second additional data analyst]** the second additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 NHS National A&E survey and will conform to these requirements and the guidelines set out under the section “Data protection” in the Guidance Manual for the 2014 NHS National A&E survey.

Signature: Date: