NHS Abdominal Aortic Aneurysm Screening Programme
Protocol for reporting deaths

Updated August 2016

Public Health England leads the NHS Screening Programmes
About Public Health England

Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Executive Summary

This document outlines the process for reporting deaths within the NHS Abdominal Aortic Aneurysm Screening Programme (NAAASP).

Mortality rates in patients with abdominal aortic aneurysms (AAA) will be monitored as part of the quality assurance process within NAAASP. In addition, NAAASP may be able to learn from deaths of screened individuals, to the benefit of future patients. The National Programme Team has developed a revised on-line survey of reporting deaths to enable healthcare professionals to report in a confidential manner in order to identify issues which may influence outcomes.

Death data

Data on the number of deaths of patients, identified through the screening programme, will be recorded via existing processes. However, this data does not currently provide detailed information on the cause of death. The national programme therefore requires the support of local programmes to supply information on men who have died, including the registered cause of death.

It is a mandatory requirement that any patients who die in the screening programme, in either of the following circumstances, should be reported to NAAASP:

1. During surveillance with AAA <5.5cm
2. AAA ≥ 5.5cm waiting for treatment after referral

Local programmes should also report to NAAASP the deaths of any men, who have been part of the screening programme, in any of the following circumstances:

3. Following treatment for AAA up to 1 year
4. AAA ≥ 5.5cm but a decision made not to intervene
5. Men with a negative scan thought not to have an AAA who subsequently die of ruptured AAA
Survey

An online survey (https://surveys.phe.org.uk/TakeSurvey.aspx?SurveyID=p21L9981) has been developed to collect death data in each of the five different circumstances outlined above. Information for each of the groups will need to come from a variety of sources. The following guidance outlines the processes for obtaining this information:

1. **The patient died during surveillance of an AAA <5.5cm**

When a patient under active surveillance dies, the on-line survey should be completed by the local programme manager/co-ordinator using the option ‘The patient died during surveillance of an AAA <5.5cm’. It is the programme manager/co-ordinator’s responsibility to ascertain when the patient died together with details of the cause of death. The survey is required to be completed within six weeks (see flowchart below).

2. **The patient died with an AAA ≥5.5cm while waiting for treatment**

These patients have been referred to a vascular unit. The survey option ‘The patient died with an AAA ≥ 5.5cm while waiting for treatment’ should be completed by the local programme manager/co-ordinator and submitted on-line within six weeks (see flowchart below).

3. **The patient died following treatment for an AAA**

These men may have died in hospital, at home or in another institution after treatment or they may have died in the same hospital after readmission. The survey option ‘The patient died following treatment for an AAA’ should be completed by the programme manager/co-ordinator, in liaison with the Consultant Surgeon under whose care treatment was undertaken, if the death was within three months of the date of treatment. If the death occurred after three months, the programme manager/co-ordinator should liaise with the most appropriate member of staff and complete the on-line survey within six weeks (see flowchart below).

4. **The patient died with an AAA ≥5.5cm when a decision had been made not to operate**

This includes patients who are not fit for, or decline intervention and who subsequently die. The programme manager/co-ordinator should liaise with an identified person to assist in completion of the on-line survey under option ‘The patient died with an AAA ≥ 5.5cm when a decision had been made not to operate’. This will usually be the consultant to whom the patient was originally referred although information may be required from the patient’s GP or other medical professionals. The on-line survey should be completed within six weeks (see flowchart below).
5. The patient was initially identified as not having an AAA but subsequently died of a ruptured AAA

These patients will have been screened and are likely to have had an aortic diameter between 2.0cm and 2.9cm at initial screening. When NAAASP is notified that such a patient has died, the on-line survey should be completed using the option ‘The patient was initially identified as not having an AAA but subsequently died of a ruptured AAA’. It will be the responsibility of the programme manager/co-ordinator to ascertain when the patient died and details of the cause, where possible. These patients should also be reported if they survive a rupture. The on-line survey should be completed within six weeks (see flowchart below).

Timescales

Details of any potential avoidable deaths (including inappropriate delay) must be completed within 48 hours via the survey. Potential avoidable deaths should also be reported to the regional Screening QA Service and the local screening and immunisation team in accordance with Managing Safety Incidents in NHS Screening Programmes (PHE 2015).

Post mortems

It is very important that information from post mortems is provided on the forms and local programmes should endeavour to find this information. It is acknowledged that there will be a delay in response when post mortems are required. It is the responsibility of the local Programme Director to inform Tim Lees and Jonothan Earnshaw.

Reporting

A quarterly report will be made available to the QA Steering Group.

The QA Steering Group (or suggested representative) will feed back to the local programmes on a six monthly basis to show that NAAASP and QA are trying to improve care by learning from past events.
Flowchart for reporting deaths within the NHS AAA Screening Programme

1. Patient with AAA known to programme dies. Was the death avoidable? (including inappropriate delay)
   - **No**
     - Programme manager/co-ordinator completes the on-line AAA Patient Death Questionnaire within 6 weeks
     - Research Lead
     - Projects circulate quarterly report to QA Steering Group
     - QA Steering Group feedback to local programmes six-monthly
   - **Yes**
     - Programme manager/co-ordinator completes the on-line AAA Patient Death Questionnaire, screening incident assessment form and sends to QA & SIT* within 48 hours
     - Regional QA teams generic mailbox
     - Data entered onto Trackwise if appropriate (potential incident) and actioned
     - Follow incident report management guidelines where necessary.
     - Query with Research Lead/NAAASP in event of uncertainty

* Managing Safety Incidents in NHS Screening Programmes (PHE 2015) guidance to be followed in addition to use of online survey