GENERAL DATA

The data presented in this report relate to deaths occurring between 1 April 1999 and 31 March 2000. The period through which questionnaires were dispatched ran through until 31 August 2000 with the final deadline for return being 31 December 2000. It is unfortunate that the number of questionnaires returned late continues to increase despite a minimum of four months for completion. The protocol for data collection is detailed in Appendix E.

INTRODUCTION

Key points

- There are significant differences between the number of NCEPOD reported cases and Hospital Episde Statistics.
- The return rates for both surgeons and anaesthetists continue to improve at 87% and 90% respectively.
- Several Trusts are now involving clinical governance departments to assist clinicians in their participation of NCEPOD.
- All deaths are not reported and questionnaires on deaths remain unanswered.
- There is still no simple way of collecting details of deaths that occur in the community.
- In over 5% of the sampled cases it was not possible to identify the anaesthetist involved.
- A small minority of clinicians continue to question the policy of NCEPOD in terms of the relevance of the final procedure performed before death.

As NCEPOD reported last year[13], participation is now compulsory within NHS trusts. It is not yet mandatory for the independent sector although it is expected that this anomaly will be addressed as part of the proposed Care Standards Act due to be implemented in April 2002. Despite the guidance given in 'Clinical Governance: Quality in the new NHS'[31] which stated that *"NHS Trusts have a responsibility for ensuring that all hospital doctors take part in national clinical audits and confidential enquiries"*, there are Trusts where the data looks incomplete. We also have evidence from a variety of sources that some high profile cases have not been reported. This can only lead to the conclusion that reporting is not complete across the NHS and that doctors have not learned the lessons of Bristol.

Whilst NCEPOD has put into place some mechanisms to improve this situation, such as quarterly reporting to Medical Directors, information systems within Trusts still need refinement to ensure that the correct base data is reported in order that NCEPOD can follow up individual cases.

The sample reviewed in detail during this period was, once again a random 10% of the total deaths reported. The selection of this group has enabled NCEPOD to make direct comparisons with data collected in 1990 and 1998/99 and reported in 2000[13] when a similarly randomised group was reviewed.

This year NCEPOD has asked additional questions about those patients in the sample who had a diagnosis of can-cer at the time of death regardless of the cause of death.

DATA COLLECTION

Data was requested from all hospitals in England, Wales, Northern Ireland, Guernsey, Jersey, Isle of Man and the Defence Secondary Care Agency. In addition, the majority of hospitals in the independent sector contributed data. Data was not collected from Scotland where the Scottish Audit of Surgical Mortality (SASM) performs a similar function.

Deaths occurring in hospital, between 1 April 1999 and 31 March 2000, and within 30 days of a surgical procedure were reported to NCEPOD by the designated Local Reporter for each hospital (Appendix F). A few reports of deaths occurring at home were also received. NCEPOD continues to pursue the possibility of collecting a more complete picture of this latter group of deaths but data collection remains extremely difficult. The simplest way of collecting this data would be to record on the death certificate if a surgical procedure had been performed in the preceding 30 days. NCEPOD will continue to pursue this issue.

GENERAL DATA ANALYSIS

Figure 5.1 shows that a total of 21 654 reports were received. Of these 1093 were excluded from further analysis: 858 were deemed inappropriate according to the NCEPOD protocol (Table 5.1 and Appendices E and I), 192 were received after the deadline of 31 August 2000 and 43 remained incomplete despite all efforts to identify missing information. It is interesting to note that although the total number of deaths reported in this period showed an increase of 401 over the previous year, the number of cases that could be included rose from 93.3% to 94.9% showing a small improvement in the quality and timeliness of the reports.

Fig 5.1 Total deaths reported

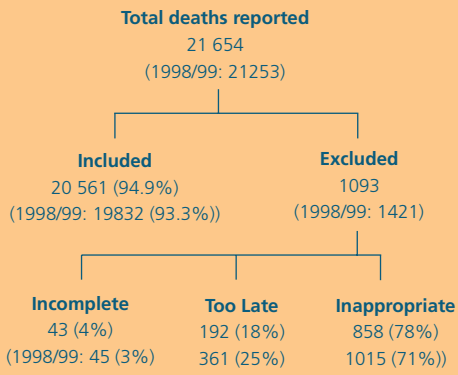


Table 5.1 shows that there have been further increases in the numbers of reported procedures performed by a non-surgeon from 221 in 1997/98 to 319 in 1999/00. The two special reports published by NCEPOD in 2000, Percutaneous Transluminal Coronary Angioplasty[32] and Interventional Vascular and Neurovascular Radiology[33], reviewed many of these procedures but by far the largest group of procedures performed which are not currently reviewed are endoscopies undertaken by physicians. These will form part of a future study by NCEPOD.

An area of improvement in the quality of data received from Trusts manifested itself in a reduction of duplicate reports received. One hundred and sixty one were received in 1999/00, a reduction from 485 in 1998/99. Whilst it is pleasing to report that reporting systems appear to be stabilising, NCEPOD still has considerable concerns that deaths are under reported, an issue discussed later in this section, and generally that information systems are not robust

Table 5.1 Inappropriate reports received and excluded

Reason for exclusion	1999/00	1998/99	1997/98
Death occured more than 30 days after operation	265	230	220
Procedure not performed by a surgeon	319	235	221
Duplicate report	161	485	271
No surgical procedure performed or procedure excluded by NCEPOD criteria	110	59	106
Procedure performed in non-participating independent hospital	1	4	14
Procedure performed overseas	1	1	0
Patient still alive	1	0	2
Total	**858**	**1014**	**834**

A breakdown of the remaining 20 561 deaths, by region is shown in Table 5.2. Comparison with the figures for previous years is not possible due to the major regional boundary changes that occurred in April 1999. However, a comparison with the number of Finished Consultant Episodes (FCEs) from Hospital Episode Statistics (HES) has been given. The region with the highest difference is a good reporter of deaths to NCEPOD and this may act against them in this comparison. Appendix A gives more detail by reporting deaths by Trust.

Table 5.2 Deaths reported to NCEPOD by region

Region	1999/00	% of total deaths (for England NHS)	% of FCE's (for England NHS)*
Eastern	1809	9.7	9.5
London	2558	13.7	12.3
North Western	2754	14.6	15.7
Northern & Yorkshire	3183	17.1	13.5
South Eastern	2531	13.6	14.6
South & West	1834	9.8	10.4
Trent	2104	11.3	11
West Midlands	1895	10.2	10.4
Wales	1217	-	-
Northern Ireland	360	-	-
Guernsey	14	-	-
Jersey	31	-	-
Isle of Man	22	-	-
Defence Secondary Care Agency	7	-	-
Independent Sector	242	-	-
Total	**20 561**		

*Over 250 000 FCE's could not be attributed to a region as place of residence was not recorded

Whilst NCEPOD has for several years suspected that not all deaths (within our criteria) are reported by hospitals, it now has actual evidence that this is the case. The following quote comes from a Medical Director following up on the non-return of questionnaires:

"My colleagues have been in difficulties with this particular case because as a result of the death of a patient a consultant.... in this Trust was suspended...., and an independent inquiry panel has been set up. I need hardly say that the case has been well and truly reviewed. I am not sure whether this information is of use to you. There are significant medical legal sensitivities around the death of this patient and this lies behind the reluctance of my colleagues to respond to your request for information."

Further high profile cases that have been reported in the national press are also missing from our database. It is a pity that all Trusts cannot benefit from the lessons to be learned from these cases.

Further support to our belief that numbers of deaths reported to NCEPOD are not accurate comes from the audit undertaken by Poloniecki and Roxburgh [34].

They found that less than 80% of deaths after cardiac surgery were recorded on either the departmental database or the hospital administration system.

Last year NCEPOD commented on the discrepancies that existed between the data submitted as HES to the Department of Health (DoH) and our data. The HES data is used by the DoH for a number of purposes including the calculation of NHS Performance Indicators. The DoH has provided a breakdown of deaths within Trusts that meet NCEPOD's criteria and the results are shown in Appendix A.

Both NCEPOD and the DoH are concerned at the results for some Trusts where there is a significant difference between the two figures. One might expect slightly fewer deaths to be reported to us as some Trusts rely on manual data collection for the data but what is difficult to explain is where NCEPOD reported deaths are higher than the HES data. As can be seen there are also Trusts that reported no deaths in 1999/00 despite a quarterly report to the Medical Director detailing the returns that had been made. We have already been notified by one Trust that they will not be returning details of deaths for 2000/01 because their newly acquired hospital information system cannot provide a report of this information. The specification for such a system should surely be examined. NCEPOD will be strengthening its links with the Commission for Health Improvement (CHI) to ensure that such problems are investigated during the four yearly clinical governance reviews.

Fig 5.2 Calendar days from operation to death

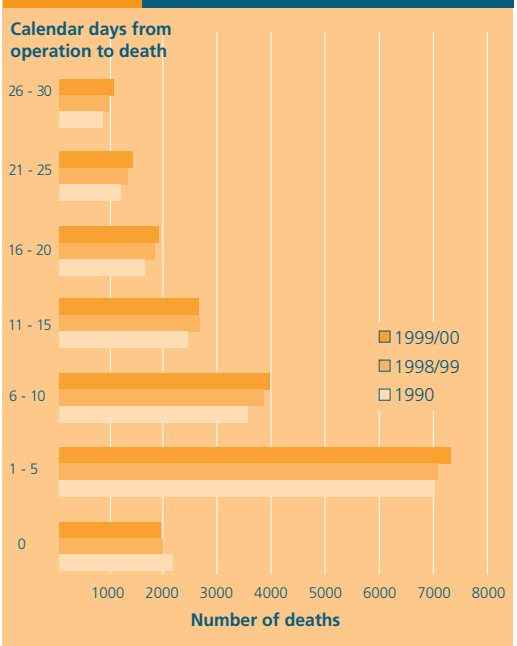
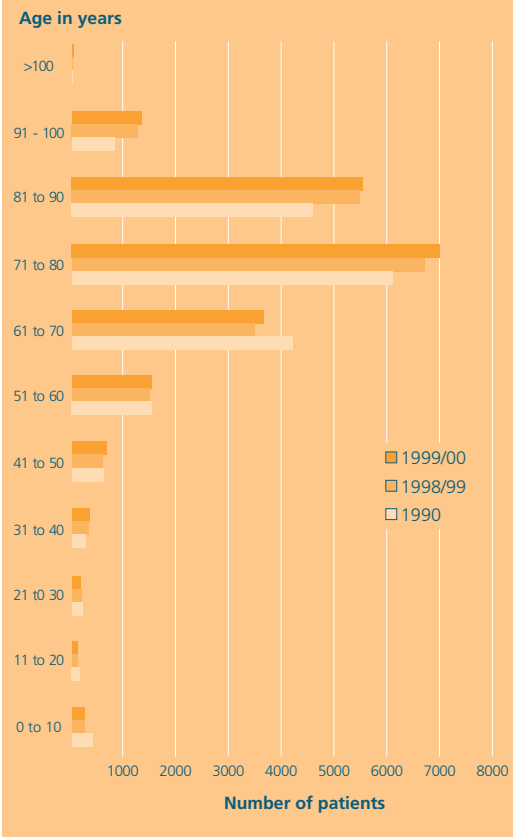


Figure 5.2 shows the distribution of the number of calendar days between operation (day 0) and death, with 44% (9132/20 561) of deaths occurring in the first six days compared to 48% in 1998/99 and 49% in 1990.

Fig 5.3 Age at time of death

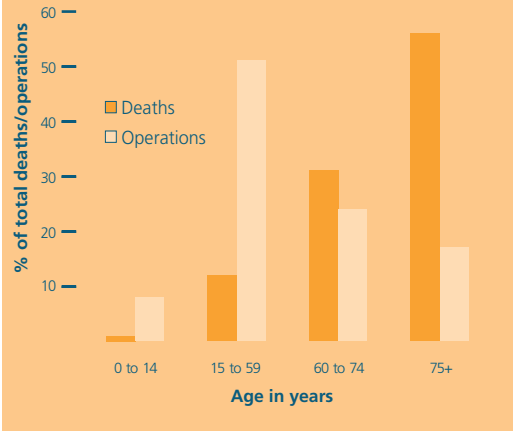


There is a trend towards an increase in the age of patients that die after their operation (Figure 5.3). In 1999/00 68% of the patients were over 70 years, and this compares with 61% in 1990.

Using the HES data, the age of all patients who were operated on in 1999/00 (excluding certain non-NCEPOD operations - see Appendix I) were reviewed. This was compared with the age profile of deaths reported to NCEPOD and is shown graphically in Figure 5.4.

A recent study on assessment of operative risk, the Revised Cardiac Risk Index[35] failed to detect age as an operative risk factor. However, Figure 5.4 clearly demonstrates that it is. Most operations are on patients of between 15-59 years and most deaths are patients of 75 or older. The conclusions from the assessment of operative risk and the findings of this report differ because the profile of patients studied differed. Those in the risk assessment groups underwent non-emergency operations whilst most deaths reported to NCEPOD are after urgent or emergency operations. It would appear then that age is a risk factor for death after an urgent or emergency operation.

Fig 5.4 Effect of age on mortality after surgery



The distribution between the sexes is almost unchanged; in 1998/99 52% (10 277/19 832) were male compared to 51.4% in 1999/00 (10 572/20 561).

The number of days taken for Local Reporters to inform NCEPOD of deaths is shown in Table 5.3. Local Reporters are nominated by their Trust/hospital to collate this data and use a variety of different collection methods. Clinical audit and clinical governance departments are increasingly taking on this responsibility. It is of concern that the percentage of deaths being reported in less than 60 days has fallen slightly whilst those taking in excess of four months has risen. However Figure 5.1 shows that overall the number of notifications received too late is falling.

Table 5.3 Calendar days between deaths and receipt of report by NCEPOD

Calendar days (i.e. not 24hr periods)	Number of deaths reported					
	1999/00		1998/99		1991/92	
1-29	4330	21%	4137	21%	9084	50%
30-59	4213	20%	4398	22%	3526	19%
60-89	3277	16%	3033	15%	1960	11%
90-119	2089	10%	2134	11%	1153	6%
120-149	1581	8%	1724	7%	747	4%
150-179	1179	6%	1099	6%	528	3%
180+	3892	19%	3307	17%	1134	6%
Total	**20 561**		**19 832**		**18 132**	

If there is a six-month delay before NCEPOD becomes aware of a death, then there is, of necessity, a considerable time lapse between death and receipt of a questionnaire

by a clinician. This is particularly problematic for anaesthetists, since Local Reporters are often unable to provide the name of the relevant consultant. This then needs to be ascertained from correspondence with the local Anaesthetic College Tutor. The earlier questionnaires can be dispatched to clinicians, the more likely it is that the medical records will be available, the case clearly remembered and the relevant clinicians (especially junior staff) still working at the same hospital. In addition, it allows more time for questionnaires to be completed and returned by the annual deadline of 31 December.

In 1991/92 - the first year the data was analysed in this way over 50% of deaths were reported to NCEPOD within 29 days of death. As can be seen, this figure now stands at 21%. The investment in computerised information systems within the NHS over the last decade seems to have had a detrimental impact in this area of data collection. NCEPOD is reliant upon the efforts of Local Reporters to obtain this most basic of information on patients who have died and such information should be valuable throughout Trusts for local clinical governance and audit activities. It is unacceptable that Local Reporters are required to fulfil this now obligatory requirement without adequate resources in terms of time and information systems.

SAMPLE DATA ANALYSIS

The sample selected for review in 1999/00 was again a randomised 10% of the total deaths reported, with cases for inclusion being identified by the NCEPOD computer system on entering basic case details onto the main database. A randomised sample has the advantage of ensuring that no clinicians feel that they, or their speciality, are being unfairly burdened.

Questionnaires were sent to a total of 1359 different consultant surgeons and 1182 different consultant anaesthetists. Table 5.4 shows that the majority (70% of surgeons and 69% of anaesthetists) received only one questionnaire in the year.

It is important to stress that forms are sent to consultants, but relate to cases conducted not only by themselves but also by a range of non-consultant or locum staff. This is particularly the case for anaesthetists, where it is common for all forms relating to cases conducted by non-consultants to be sent to a single designated consultant who has taken the responsibility for the completion of NCEPOD returns. These figures do not, therefore, reflect poor practice.

Table 5.4 Number of questionnaires received by clinicians

No of questionnaires received	Anaesthetists	Surgeons
1	820 (69%)	956 (70%)
2	265 (22%)	268 (20%)
3-5	92 (8%)	130 (9%)
6-8	4 (<1%)	5 (1%)
Over 9	1*	

* Local arrangement whereby one anaesthetist acts as receiving point in cases of non-identification of consultant

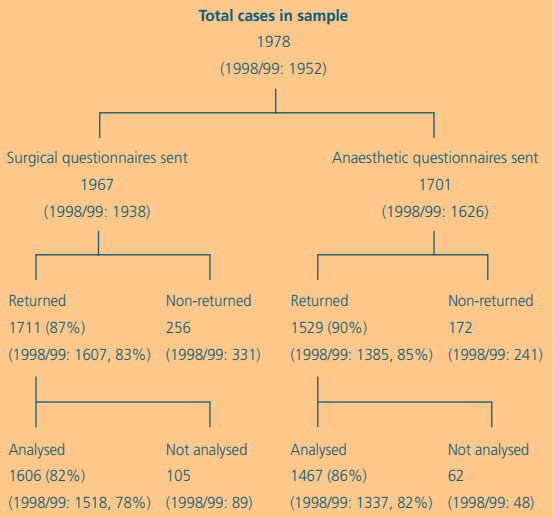
In relation to the 1999/00 sample, 11 surgical questionnaires were not sent as NCEPOD had already been notified that the consultant had left the Trust/hospital.

In the 277 (14%) cases where no anaesthetic questionnaire was sent, this was either because the procedure was performed without an anaesthetist present (142, 7%), the name of the appropriate consultant was unobtainable (109, 5%), the case was notified too late (21, 1%), or because NCEPOD had been notified that the appropriate consultant had left the Trust/hospital (5). The clinical governance implications of not knowing who the anaesthetist

was are important but the legal ramifications are frightening. NCEPOD urges Trusts to review this situation to ensure that the names of all health professionals who have cared for a patient are recorded in the medical case notes.

One thousand seven hundred and eleven surgical questionnaires (1711/1967, 87%) and 1529 anaesthetic questionnaires (1529/1701, 90%) were returned (Figure 5.5). Clinicians should be commended for ensuring that the return rates continue to improve.

Fig 5.5 **Distribution, return and analysis of questionnaires**



One hundred and five surgical questionnaires were excluded from analysis for the reasons given in Table 5.5. Similar exclusions occurred for 62 anaesthetic questionnaires (Table 5.6). For the first time, 2 questionnaires were completed for the wrong patient.

It remains a concern of NCEPOD that these questionnaires are unusable since they represent a significant investment of valuable time. It has been estimated that it can take a clinician up to a session to complete each questionnaire. This wasted time could therefore aggregate to over fifteen weeks work assuming 11 sessions a week (167 cases/11 sessions).

There continues to be a small number of clinicians who continually question NCEPOD's method because they seem to believe that NCEPOD is interested primarily in the cause of death. They therefore either refuse to complete a questionnaire for some patients where they do not believe that NCEPOD should be interested in a life-saving procedure or palliative procedure such as a tube oesophagostomy (as in the case below), or they insist on completing the

Table 5.5 **Reasons for exclusion of surgical questionnaires from analysis**

Reasons for exclusion	1999/00	1998/99
Questionnaire completed for an earlier operation	57	54
Questionnaire received too late	40	32
Questionnaire incomplete	6	3
Questionnaire related to excluded procedure	2	0
Total	**105**	**89**

Table 5.6 **Reasons for exclusion of anaesthetic questionnaires from analysis**

Reasons for exclusion	1999/00	1998/99
Questionnaire completed for an earlier operation	25	18
Questionnaire received too late	34	26
Questionnaire incomplete	0	4
Questionnaire related to excluded procedure	1	0
Questionnaire completed for wrong patient	2	0
Total	**62**	**48**

questionnaire for the more major procedure preceding death. The arrogance of a small minority of clinicians in regard to this issue is of great concern.

"I say to you without fear of contradiction that if I had to fill in one of these forms on every occasion that I performed a humanitarian procedure of this kind, my inclination to carry out the procedure would be greatly reduced to say the least. I have now reached the end of my surgical career and I feel that I should not leave without telling you that in this instance the form is totally inappropriate and you should in future take care to be a little bit more humane."

Fig 5.6 Response rates for questionnaires

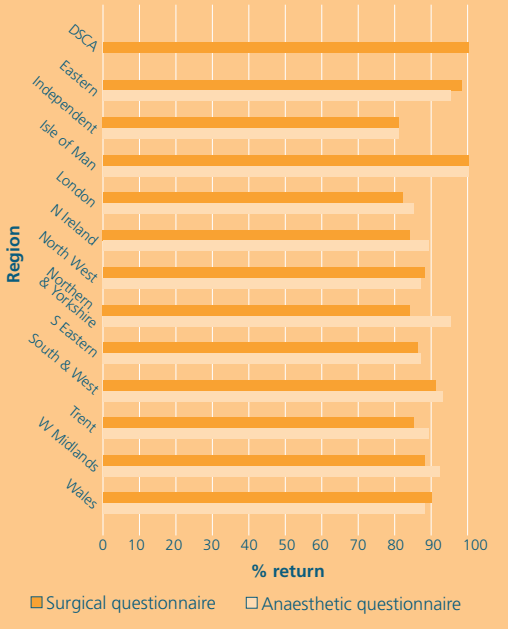


Table 5.7 Regional return rates

Region	Surgical questionnaire	Anaesthetic questionnaire
Eastern	156/160	141/148
London	234/284	207/243
North Western	224/256	193/223
Northern & Yorkshire	244/292	241/255
South Eastern	195/227	155/178
South & West	168/185	143/153
Trent	166/195	160/179
West Midlands	154/176	151/164
Wales	115/128	90/102
Northern Ireland	26/31	25/28
Guernsey	No cases sampled	No cases sampled
Jersey	5/5	Anaesthetist unidentifiable
Isle of Man	6/6	6/6
Defence Secondary Care Agency	1/1	0/1
Independent Sector	17/21	17/21

Figure 5.6 and Table 5.7 show the return rate by region. It is not possible to show comparisons with the 1998/99 return rates as the regions changed in April 1999. A breakdown by Trust/independent group is shown in Appendix A.

Individual Trusts/hospitals are kept informed of their return rates on a quarterly basis so there is an opportunity to improve return rates where there are difficulties. NCEPOD is encouraged by the letters received throughout the year describing revised procedures to assist clinicians in completing their questionnaires.

"It is requested that all future requests for detailed reviews be directed to the Clinical Governance Support Centre (CGSC). The CGSC will take responsibility for validating the information provided, including the consultant in charge of the case at the time of death, and will arrange for the audit form and case notes to be made available to the relevant consultant. We anticipate that this new procedure will reduce the burden upon clinical staff and therefore improve our compliance with this important national review."

It is unfortunate that this is not the situation in all Trusts as this next letter from a surgeon illustrates.

"I recently received a second reminder from you about a CEPOD form I had not completed. I do not think it is at all appropriate for individual consultants to be named to their hospitals on clinical governance grounds as you suggest. To my knowledge, CEPOD has not provided any form of support whatsoever for the fairly arduous work involved in completing these forms, and the ever increasing pressure on consultants to complete reports for various bodies means that this type of activity is rapidly becoming unmanageable. Rather than taking your current approach, CEPOD should be supporting consultants by addressing their comments to the Chief Executives of hospitals, and demanding better support for consultants in their onerous administrative workload. You will gather that you have not persuaded me to give your request any priority. It will have to wait, like the other non-clinical duties that take up an increasing proportion of my time, until more urgent matters have been attended to."

The completed questionnaire was received three weeks after the closing date (27 weeks after it was sent).

Reasons for non-return of questionnaires

The figures for the last two years (Figures 5.7a, 5.7b, 5.8a and 5.8b) show little or no change in the high percentage of cases where no reason is offered for non-return of a questionnaire. Regular feedback to Trusts and hospitals indicating any valid reasons for non-return will, of course, highlight those cases where no contact has been made with NCEPOD to explain the inability to complete the questionnaire.

Fig 5.7a Reasons for non-return of surgical questionnaires

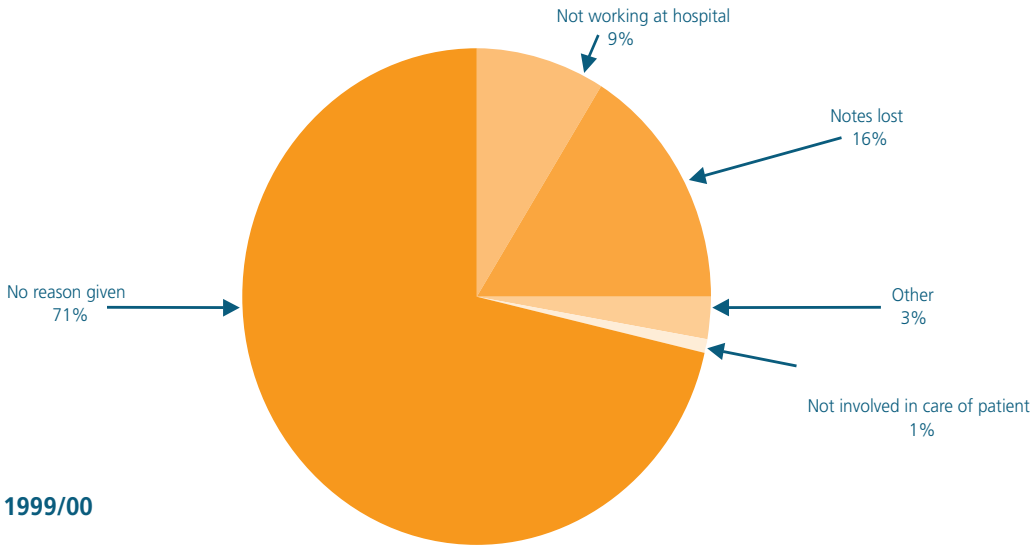


Fig 5.7b Reasons for non-return of surgical questionnaires

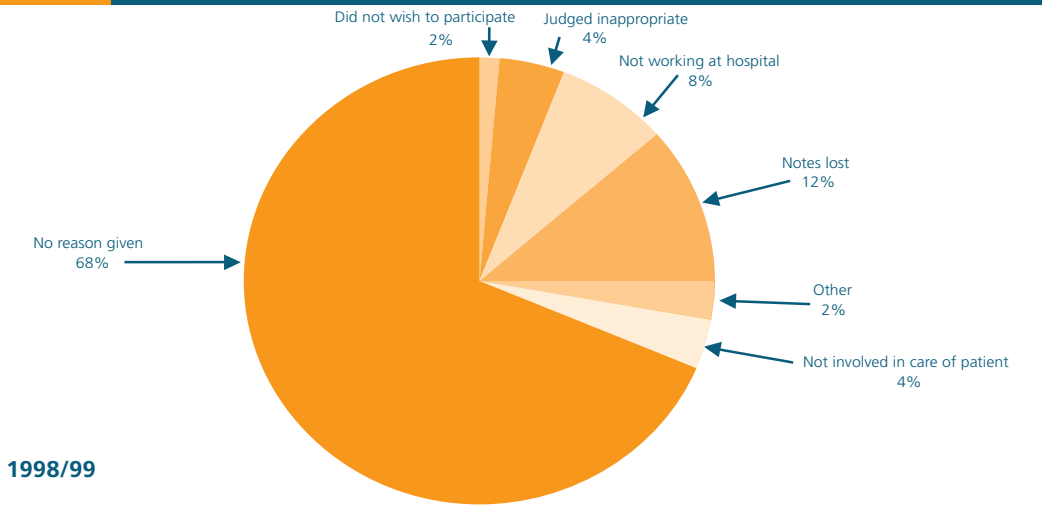


Fig 5.8a Reasons for non-return of anaesthetic questionnaires

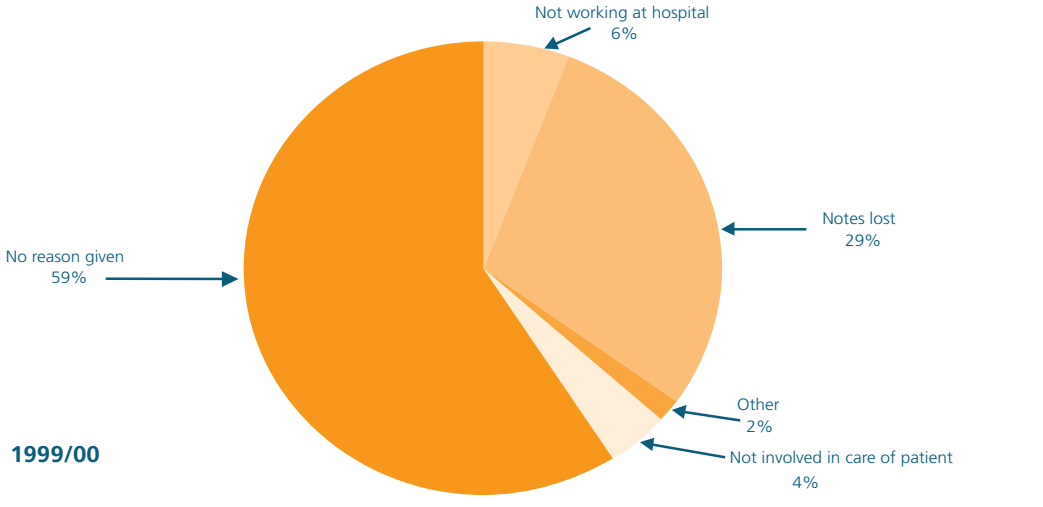
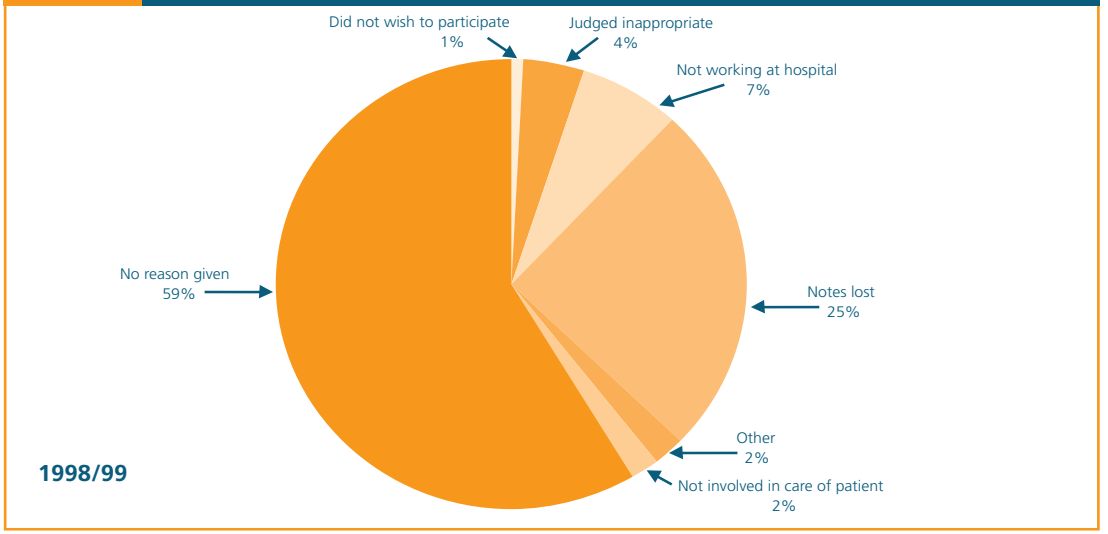


Fig 5.8b **Reasons for non-return of anaesthetic questionnaires**



There are mainly small percentage changes shown in these figures, which should disappear if hospitals take their clinical governance responsibilities seriously.

We would have hoped to see this group diminish as Medical Directors act on the feedback given and it is disappointing that this decrease is not yet in evidence.

Lost medical records

The final group needing particular attention is that where clinicians stated that they were unable to complete the questionnaire as the notes were incomplete, lost, or otherwise unobtainable. One of the Local Reporters has written a series of letters to the Medical Director, Chief Executive and Chairman of their Trust to bring their attention to the appalling way in which the notes of dead patients are stored.

"It is very disappointing for me to be writing to you on the above topic as yet again we are failing in our ability to complete NCEPOD forms due to a lack of clinical notes. This mandatory clinical governance issue should be of major concern to the Trust and should have resulted in some initiatives to correct the problems that I have highlighted during 1999, 2000 and now have to do again in 2001. I have a considerable file of correspondence with [the Medical Director] who assures me that "large initiatives" and "much effort" is being put into improvements in Medical Records. Initial impressions indicate this is not effective."

Another incident which indicated the difficulties of retrieving notes for deceased patients came to light during the data quality audit (see section 4), which was undertaken this year. The Chief Executive of the Trust had given permission for the audit to take place and asked NCEPOD to give seven days notice in order that the notes could be pulled. In fact two months notice of the date the notes were needed was given. A week before the audit was due to take place, NCEPOD were advised that it would not be possible to retrieve the notes for at least another three weeks. The reason given was that the notes had been given to a document archiving company, they were possibly in Bristol (several hundred miles away from the hospital) but no details were kept of which notes had gone or their exact location.

"Further to your request for a CEPOD questionnaire to be filled in by myself on this gentleman, I write to inform you that the hospital have not been able to provide me with relevant notes to allow the said questionnaire to be completed. In fact in the notes provided to date, the only sign to indicate that he ever was under my care was a front sheet showing his date of admission and a sticker showing a Thompson's prosthesis. In the absence of appropriate notes you will understand that I cannot complete the questionnaire and I will request the hospital records department to find the notes for me, but in the meantime, I expect you to demonstrate patience and I hope that you will not harass me in the manner you have previously harassed me and my colleagues when we have had difficulty in filling in these questionnaires for you."

The harassment that NCEPOD was accused of comprised of a reminder 2 months after the questionnaire had been sent followed by another reminder 4 weeks later.

There has been an increase in the number of lost notes for both surgeons (1999/00:16%; 1998/99: 12%) and anaesthetists (1999/00: 29%; 1998/99 25%) which is

disappointing given the improvement seen in the previous year. As commented on in 'Then and Now' [13] it would appear that in the majority of cases where anaesthetists state that notes are 'lost', they had in fact been retrieved by the operating surgeon.

Recommendations in last year's report[13] should have helped improve this situation. They cannot be improved on this year and so are repeated verbatim:

- *"Trusts/hospitals should establish systems to ensure that all 'NCEPOD case notes' are retrieved and passed from surgeon to anaesthetist."*
- *"If clinicians are informed by medical records departments that the notes are lost/missing, they should first enquire of their surgical/anaesthetic colleagues who may well have the records (this applies particularly to anaesthetists)."*
- *"Medical records departments should ensure that adequate tracer systems are in place in relation to the medical records of deceased patients."*

Health Service Circular 1999/053 'For the Record', gives guidance on the management of records including the best practice on the storage and retrieval of such records. NCEPOD would commend this to hospitals as the starting point in improving this 'Cinderella service'.

Recommendations

- There should be a standard way of collecting data on deaths occurring within 30 days of surgery but happening outside hospital.
- Trusts should ensure that all deaths (falling within the NCEPOD protocol) should be reported in a timely manner. Local Reporters should be given the necessary resources to ensure that this is possible.
- Trusts should review the discrepancies between HES data and NCEPOD data and ensure accurate data returns for both purposes.
- The names of anaesthetic personnel should be clearly recorded in the patient's casenotes.
- Medical Directors should ensure that all questionnaires are returned.