

Additional Explanatory Notes for the Bristol Royal Infirmary Inquiry: Clarification of UKCSR and HES/ONS Data Quality Issues

Background:

Additional tables and comments have been provided to clarify some of the issues relating to the UKCSR data and HES/ONS data linkage, which have been raised by the Inquiry Panel in response to the draft reports on these matters.

1. ONS/HES agreement with UKCSR by 4 definitions of 30 day mortality

Summary: Figures obtained from HES/ONS data for each of the four definitions of 30 day mortality^a applied at the 12 units, when compared against the UKCSR figures, do not add to the understanding of the data. In theory, we would have hoped to see a pattern emerging, which reflects the definition a unit is known to have used, but for various reasons, this does not happen.

Table 1

Table of reported deaths. UKCSR and linked HES/ONS data (applying 4 definitions of 30 day mortality)^a

Inquiry No.	Name	UKCSR total 1992-1994	HES / ONS Data			
			(i) 30 day	(ii) All in-hosp only	(iii) 30 day+ all in-hosp.	(iv) 30 day in-hosp only
1	Bristol	49	53	53	54	51
2	Leicester	36	30	28	30	28
3	Leeds	?	47	41	51	37
4	Oxford	20	33	34	37	29
5	Guy's	42	22	27	29	20
6	Liverpool	69	70	73	76	67
7	South'ton	33	23	25	26	22
8	GOSH	?	73	72	76	61
9	Newcastle	29	36	35	39	32
10	Harefield	62	49	49	54	44
11	Birm'ham	82	74	74	81	67
12	Brompton	47	50	43	52	40

Investigation of figures for individual years (table 12 of Murray's report¹) shows that only 4 of the 12 centres consistently under or over-report numbers of deaths for the 3 years reported.

Oxford and Newcastle UKCSR figures consistently under-report (although the numbers are small), Guy's and Southampton consistently over-report.

^a Definitions of 30-day mortality applied:

- (i) 30 days post-operation, whether in hospital or discharged elsewhere;
- (ii) all in-hospital deaths (including > 30 days) with no systematic follow-up post-discharge;
- (iii) all in-hospital deaths (including > 30 days), up to 30 days post-operation for patients discharged within 30 days
- (iv) 30 days post-operation, in-hospital only;

Table 2*Table comparing linked HES/ONS deaths with UKCSR deaths*

Centre	1992		1993		1994	
	HES/ONS	CSR	HES/ONS	CSR	HES/ONS	CSR
Oxford	13	12	12	8	8	0
Guy's	12	18	5	9	5	15
South'ton	11	18	6	7	6	8
Newcastle	10	8	9	6	17	15

The information obtained from the UKCSR Survey led us to believe that the quality of the data collection at both Oxford and Guy's was poor. Even allowing for this, the magnitude of the discrepancies between HES/ONS and CSR figures for Guy's is substantial. During the interview, the consultant at Guy's said that some children were discharged to other hospitals, where they subsequently died. These deaths may therefore be associated with a different HES hospital code. The discrepancy could also be due to the number of children over 15, but we do not know.

The figures for Southampton are consistent with collecting deaths up to 30 days, and some in-hospital deaths beyond 30 days.

The impression gained from the interview at Newcastle was that deaths occurring post-discharge were not entered in their local departmental database, from which UKCSR figures were obtained. This would be consistent with the apparent under-reporting.

Limitations of the data

- The data available for comparison only cover a brief period, and there are missing UKCSR data.
- Units may have not have been consistent in the definition of 30 day mortality used over the years.

Possible reasons for differences between UKCSR and HES/ONS figures

- UKCSR figures include patients over 15 years, HES figures do not. (The separate recording of over 15s on the UKCSR form was not introduced until 1994.)
- Patients who die overseas may be reported for the UKCSR (due to post-discharge follow-up) but would have no equivalent ONS death record. We do not know whether HES records are routinely completed for such cases.
- Reporting of operative rather than patient mortality (UKCSR) will result in an under-reported mortality rate but should not affect the number of deaths reported.
- Complex diagnoses resulting in a death may have been coded for the UKCSR as multiple, fatal diagnoses.
- HES data may have missed relevant cases. Records may not have been included in the analysis dataset due to errors in coding of diagnosis, age or hospital code^a.

Stark comments on this in detail in his report to the Inquiry², suggesting that there are not insubstantial errors in dates of birth, and quoting a figure of 30% of one department's diagnoses being miscoded in the hospital system. Whether this miscoding would have resulted in these records being omitted from our analyses is not known.

The UKCSR survey³ also found that consultants at the 12 centres were unanimous in their mistrust of HES data, particularly relating to the recording of procedures.

Varying combinations of these factors will have contributed to the UKCSR and HES figures at different units and, probably, at different times. It is therefore possible for different factors to cancel each other out, resulting in the UKCSR figures appearing to provide a reasonable approximation to the HES/ONS figures, but to actually be representing quite different patients. The magnitude of such discrepancies could only be ascertained by a detailed audit.

^a Hospital code data: there were 818 patients whose HES record included a hospital code which does not represent any of the 12 named units. These may be genuine codes, or they may be errors. 78 of these cases were confirmed dead by the linkage exercise.

Limitations of the record linkage exercise

The number of HES/ONS deaths represent lower estimates, based on the linkage algorithm used by ISD. This used post code, sex and date of birth from the HES and ONS files to identify matched patients. There will undoubtedly be additional, missed links due to errors in these files occurring at coding, data entry or transcription. For example, transposition of digits, or of day and month of birth would result in a non-match. Given the lack of quality control and data validation associated with the recording of the HES data (Willmer ⁴), such errors could be substantial, but there does not appear to be any adequate information on this subject. Most studies of HES data have looked at diagnostic coding discrepancies and data coverage and completeness, and in a limited way, rather than at overall data accuracy.

Moreover, the issue of post codes associated with overseas patients has resulted in a substantial number of cases at three of the centres being impossible to match. (See (2) below)

2. Overseas and private patients

Summary: Further information has been obtained about the numbers of overseas patients per centre. As expected, Harefield, GOSH and the Brompton have treated considerably more of these patients than other centres, with as many as 24% of patients at a centre coming from overseas. It has not been possible to check these cases against the ONS records and so the relevant numbers of deaths occurring at these centres remains unknown.

- In theory, the UKCSR is intended to reflect NHS practice, and consultants interviewed during the UKCSR survey generally said that all patients treated in their units were recorded for the register. Consultants were not asked how many patients they treated at private hospitals.
- HES records do not include private patients.
- ONS records only deaths occurring in the UK. Deaths of patients from overseas have been recorded as either a 'ZZ..' code (not compatible with the HES 'ZZ' codes) or a blank post code (personal communication with Allan Baker, ONS).

There are 735 HES records with post code of the format 'ZZ...', which we assume represent overseas countries of origin. These are distributed between the named centres as follows:

Table 3

Inquiry No.	Name	% of cases 'ZZ..'	No. of cases	Of which HES Outcome 'Dead'
10	Harefield	24%	123	22
8	GOSH	22%	365	29
12	Brompton	10%	80	8
7	South'ton	6%	33	3
11	Birm'ham	4%	61	6
5	Guy's	3%	14	2

Remaining 6 units : 1% or less, maximum of 13 cases.

References

1. Murray GD, Lawrence AE and Boyd J. Linkage of Hospital Episode Statistics (HES) Data to Office for National Statistics (ONS) Mortality Records. *Bristol Royal Infirmary Inquiry. Crown Copyright 2000.*
2. Lawrence AE and Murray GD. The UK Cardiac Surgical Register : Assessment of Data Quality Issues for the Bristol Royal Infirmary Inquiry. *Bristol Royal Infirmary Inquiry. Crown Copyright 2000.*
3. Stark J. Comments on statistical analysis and review of outcomes of paediatric cardiac surgical services at Bristol and other specialist centres. *Bristol Royal Infirmary Inquiry, April 2000.*
4. Statement of Mr Richard Willmer 24th June 1999. Bristol Royal Infirmary Inquiry.

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