

Supplementary material 3

Current epidemiology of cerebrospinal fluid shunt surgery in UK & Ireland (2004-2013)

Report on missing data

Until 2013, data input in the UK shunt registry (UKSR) consisted of a multi-step method, where information was handwritten by local teams, posted to the registry and, after relevant data quality checks, entered into an electronic database (Dendrite UK Ltd). Submitted paper forms were not always complete, and the reasons for this could be that the information was unknown or the data field was missed. Possible trends in missing data were explored using descriptive statistics and are presented below.

Summary

There were 2476 (11.8%) patients with missing region of residence, 110 (0.4%) patients with missing sex, 486 (1.8%) patients with missing age, and 2774 (10.5%) patients with missing diagnosis. There were 528 (1.3%) procedures with missing centre of operation; 8523 (42.4%) revision procedures with missing reason for revision (including the first and subsequent revisions); and 2923 (57.9%) primary procedures with their first revision reason missing (amongst those who needed a revision within the study period).

The percentage of patients or procedures with the patient residence or the centre of operation missing was similar in all three age groups. The percentage of children and adults with their diagnosis missing was similar, and about 1.4 times higher than in infants. The percentage of children and adults with the reason for first revision missing was similar, and slightly (about 1.1 times) higher than in infants.

There seemed to be a time trend with an increase over time in the percentage of missing data on patients' address (from 9.9-10.3% in the first years to 16.6% in the last year), and reason for first revision (from 53.0-54.8% to 66.3%); but not on the first diagnosis. Nonetheless, the first year of the study period (2004) had the highest percentage of patients with missing age (8.6%, while the remaining years had less than 1.5% missing), and centre for shunt operation (2.4%, while the remaining centres had less than 1.7%).

All key variables differed by centre in their percentage of missing data. Age and sex were rarely missing in most centres (less than 2.0% of the patients), except for two centres, which had 6.8% and 7.0% of patients with their age missing. Patients' region of residence was missing in less

than 15.0% of the procedures in most centres, with this percentage ranging from 0.5% (Centre-62 and Centre-69) to 30.9% (Centre-67) procedures per centre, except for three centres where this was considerably higher (Figure S3-3). The percentage of patients with missing primary diagnosis was generally lower than 15% in most centres, ranging from 0% (Centre-33) to 18.8% (Centre-67) of patients, except for three centres where this was higher (Figure S3-5). In half of the centres, the reason for first shunt revision was missing in less than 50.0% of the patients (24.3-50.0%); and in the remaining half of the centres this was missing in 50.0% to 70.5% of the patients (and in 5 of the 6 patients of one of the centres).

The percentage of patients with the reason for first revision missing varied by primary diagnosis, ranging from 47.0% (among patients with IHH) to 64.2% (in patients with acquired other conditions).

Age and sex

There was one value per patient for age (at the first available shunt) and for sex, as included in the first available procedure (at primary shunt if inserted in 2004-2013, or at first available revision of primary shunts inserted before 2004). Patient age and sex on the first available procedure was missing in 486 (1.8%) and 110 (0.4%) of the patients respectively. As a consequence, those 486 and 110 patients are dropped in calculations stratified by age group or sex respectively.

By year, the percentage of patients with missing age on the first available shunt intervention ranged from 0.5% (years 2005 and 2006) to 1.3% (years 2010 and 2011), except for year 2004 when there were 8.7% patients with missing age. By centre, most centres had less than 2.0% and all centres had 4.0% or less of the patients with their age missing, except for three centres which had 7.0% (Centre-46) to 8.0% (Centre-8 and Centre-24) of patients with their age missing.

The percentage of patients with sex missing by year ranged from 0.1% (years 2011 and 2012) to 0.7% (years 2008 and 2009). In most centres patients' sex was not missing or missing in less than 1% of the patients. In five centres, patients' sex was missing in 1.7% to 2.6% of patients.

Centre of operation at any procedure (primary or revision)

The centre of operation had one value per procedure, and included both primary and revision procedures. The three age groups had similar percentages of procedures with missing centre.

The centre was missing in 528 (1.3%) procedures, with percentages of procedures with missing centre per year ranging from 0.8% to 2.4% (year 2004).

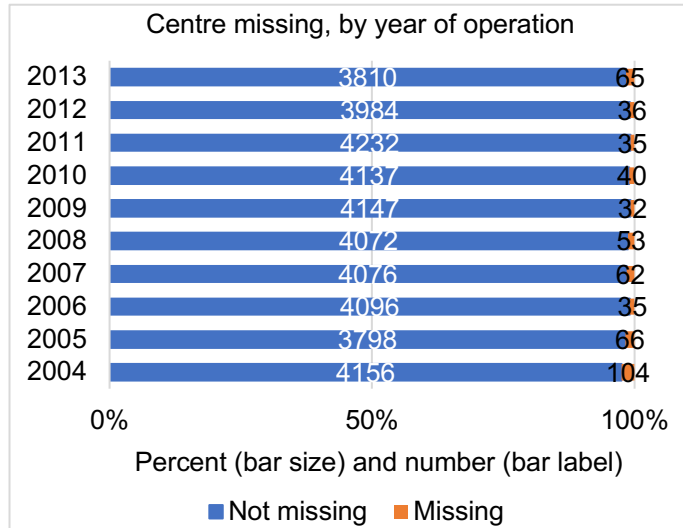


Figure S3-1 – Number (bar label) and percentage (bar size) of primary and revision procedures with the centre of operation missing, by year

Patient region of residence on primary shunt

The geographical region of patients' residence, at the date of their primary shunt, was used to stratify primary shunts incidence rates by region. It was calculated only among those whose primary shunt was inserted in 2004-2013, and it had one value per patient. The three age groups had similar percentages of procedures with missing patient residence.

Patients' residence on their primary shunt was missing in 2476 (11.8%) patients, with percentages per year increasing with time, from about 10% (years 2005-2007) to about 17% (year 2013).

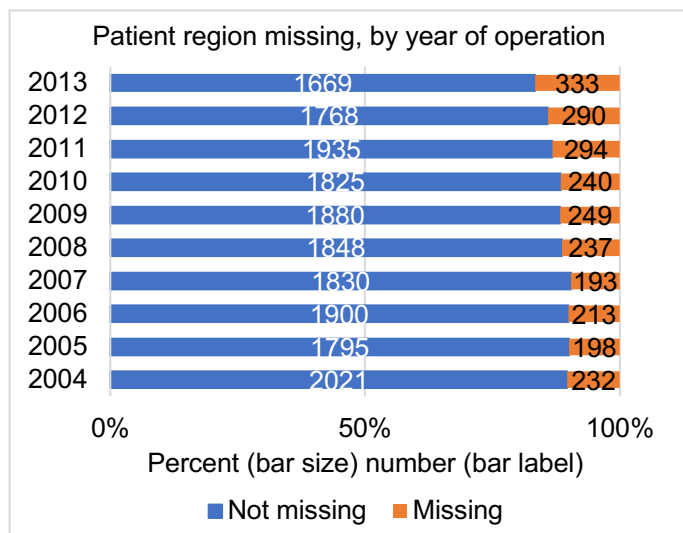


Figure S3-2 – Number (bar label) and percentage (bar size) of patients with their region missing on primary shunt, among patients whose primary shunt was inserted in 2004-2013, by year

Diagnostic group, as diagnosed on primary shunt

There was one value for diagnostic group per patient, as diagnosed on primary shunt, based on the first available procedure (at primary shunt if inserted in 2004-2013, or at first available revision of shunts inserted before 2004).

Infants had the lowest percentage of patients with their diagnosis missing (7.6%), while in children and adults this percentage was about 1.4 times higher (11.1% and 10.6% respectively).

Diagnostic group was missing in 2774 (10.5%) patients, with percentages by year ranging from 8.7% (in 2004) to 12.5% (in 2013).

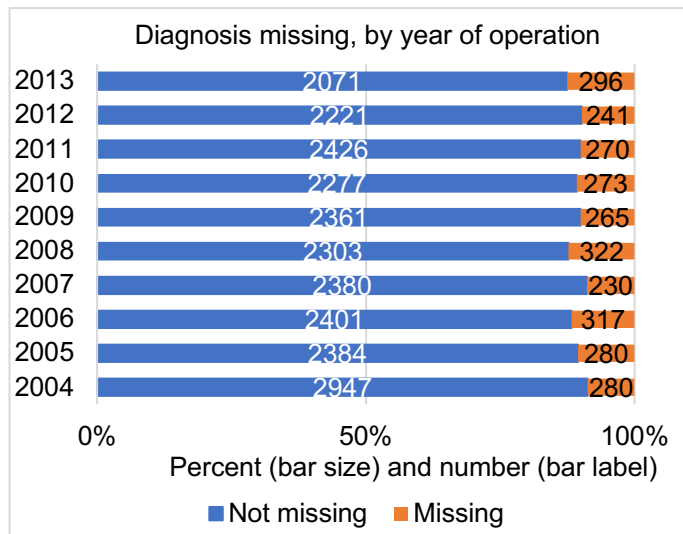


Figure S3-4 – Number (bar label) and percentage (bar size) of patients with their diagnosis (as in primary shunt) missing, by year

By centre, about half of the centres (21 out of 41) had less than 10% patients with their primary diagnosis missing, the remaining having 10.0% (Centre-39) to 32.7% (Centre-11) of the patients with their primary diagnosis missing.

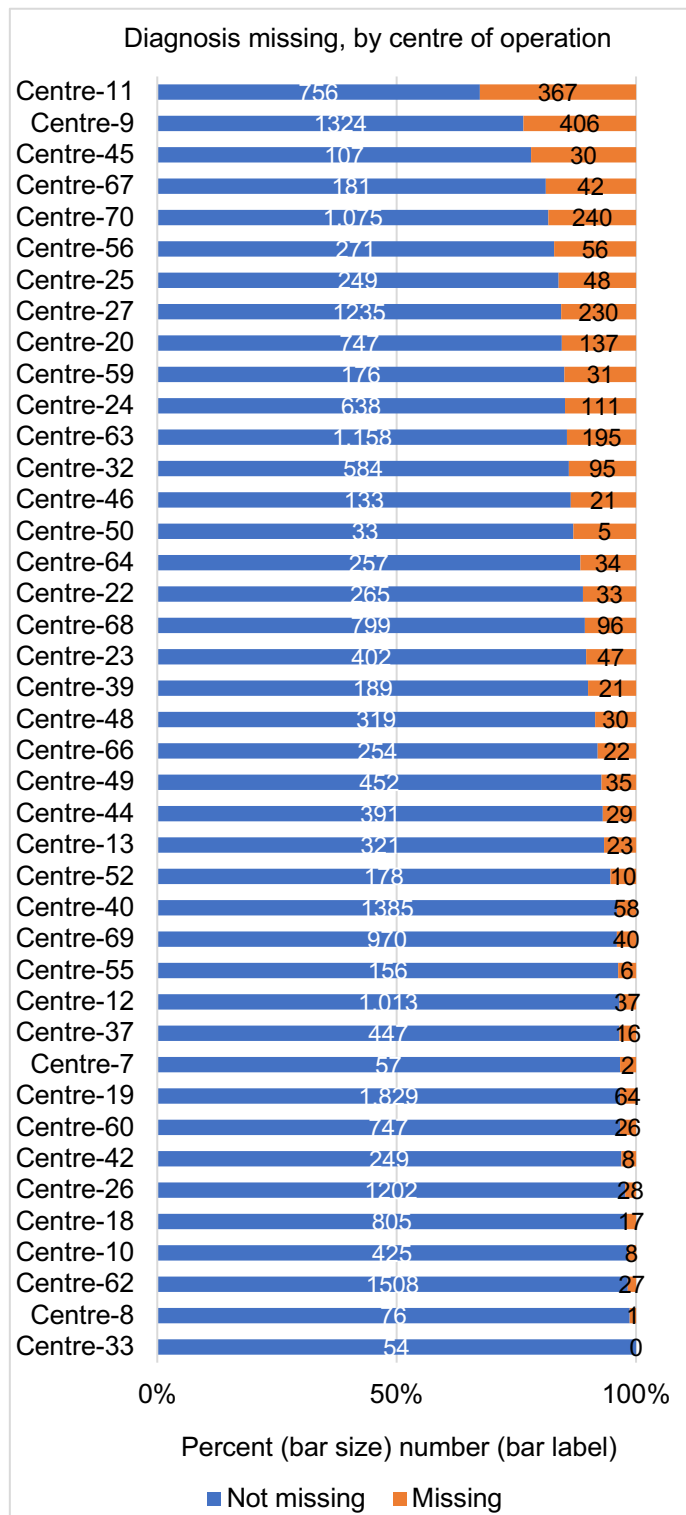


Figure S3-5 – Number (bar label) and percentage (bar size) of patients with their diagnosis (as in primary shunt) missing, by centre

Reason for first revision of primary shunt, and reasons for revision of any shunt

There was one reason for revision of the first primary shunt revision per patient, and one reason for revision for each revision procedure.

Infants had the lowest percentage of patients with their first reason for revision missing (53.6%), while in children and adults this percentage was about 1.1 times higher (62.5% and 58.2% respectively).

The first reason for revision of primary shunts that were inserted in 2004-2013 was missing in 2923 (57.9%) patients, and these percentages increased with time, ranging from 53.0% (in 2005) to 66.3% (in 2013).

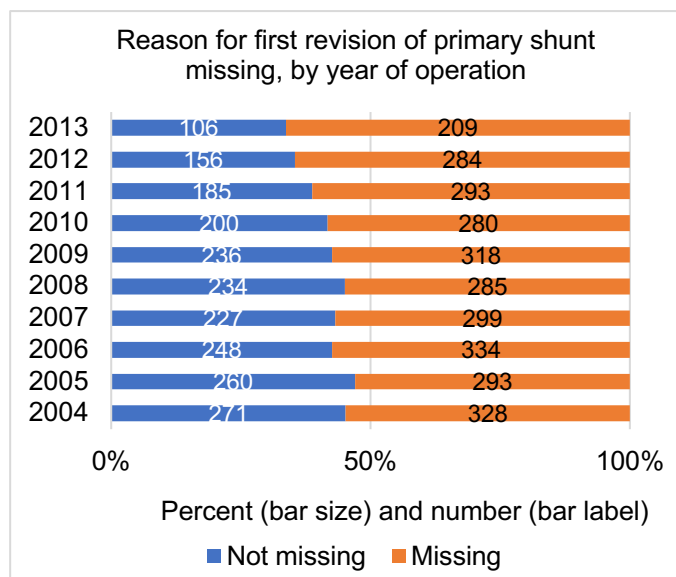


Figure S3-6 – Number (bar label) and percentage (bar size) of patients with the reason for first revision of the primary shunt missing among patients whose first shunt was inserted in 2004-2013, by year

The reason for revision of any shunt was missing in 8523 (42.4%) revision procedures, with these percentages showing a slight increase with time, ranging from 38.1% (in 2005) to 48.8% (in 2012).

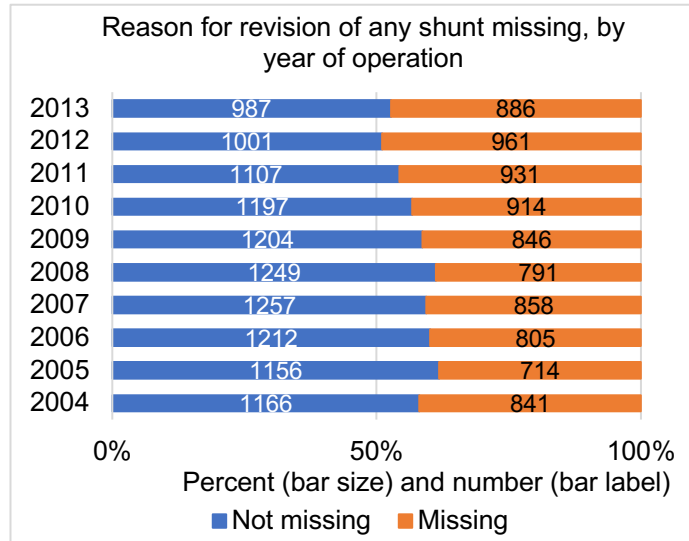


Figure S3-7 – Number (bar label) and percentage (bar size) of revisions with missing reason, by year

By diagnostic group, patients with some diagnostic groups seemed to be more likely to have the reason for their first and subsequent revisions missing.

Patients with unknown diagnosis (68.6%), Acquired other conditions (64.2%), cysts (63.6%) and tumours (63.7%) had the highest percentages of missing reason for first revision of the primary shunt. Patients with idiopathic intracranial hypertension (47.5%) had the lowest percentage of missing reason for first revision of primary shunt.

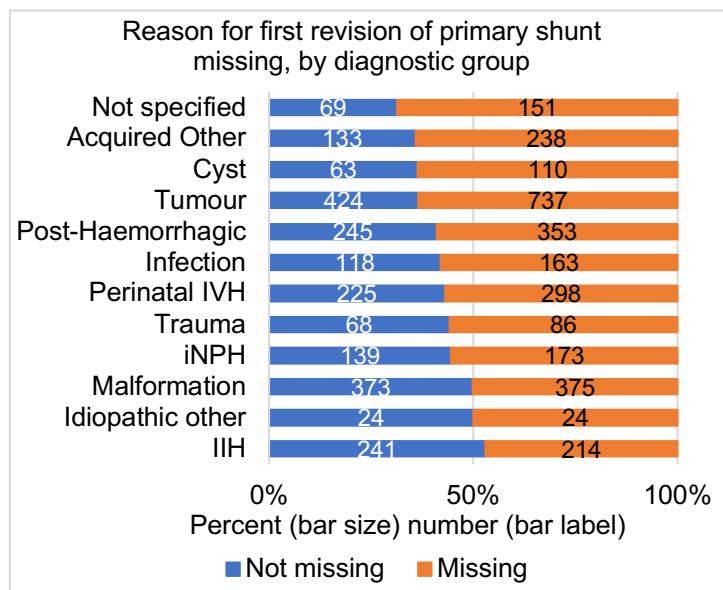


Figure S3-8 – Number (bar label) and percentage (bar size) of patients with the reason for first revision of the primary shunt missing among patients whose first shunt was inserted in 2004-2013, by diagnostic group

When looking at all revisions, those for post-haemorrhagic hydrocephalus (52.9%) had the highest percentages of revisions with missing reason. The remaining diagnostic groups had less than 50% of the revisions with no reason stated, the group with the lowest percentage being perinatal IVH (34.3%).

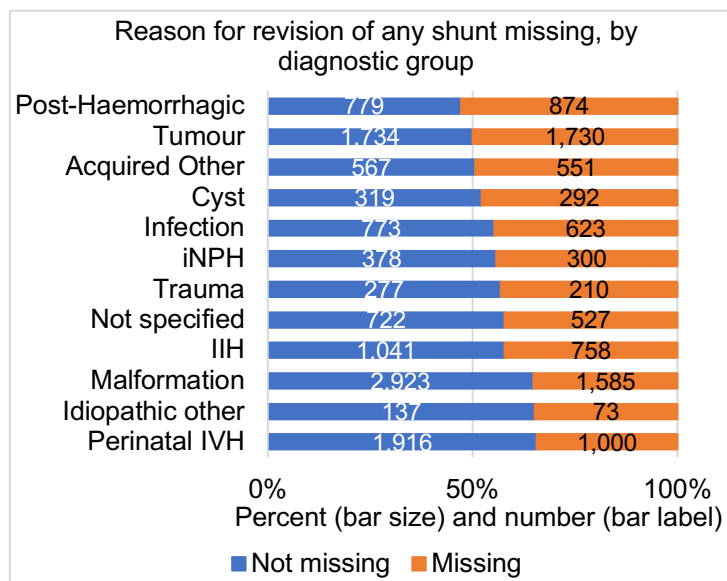


Figure S3-9 – Number (bar label) and percentage (bar size) of revisions with missing reason, by diagnostic group

By centre, about half of the centres (21 of 41) had more than 50% of the patients with the first reason for revision of primary shunt missing. The remaining centres had 24.3% (Centre-55) to 50.0% (Centre-33, Centre-59 and Centre-64) of the patients with the reason for first revision of primary shunt missing.

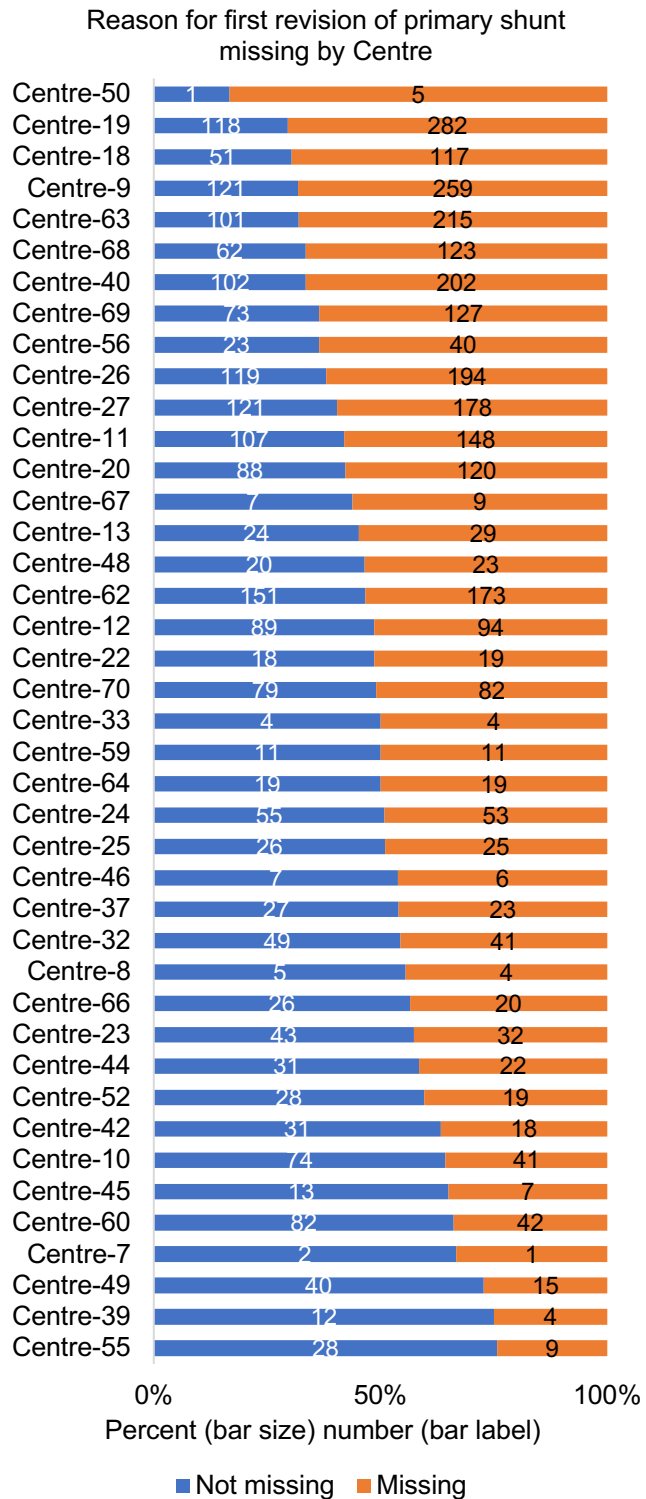


Figure S3-10 – Number (bar label) and percentage (bar size) of patients with the reason for first revision of the primary shunt missing among patients whose first shunt was inserted in 2004-2013, by centre

When looking at all revision procedures, only eight of 41 centres had more than 50% of the revision procedures with their reason missing. The remaining centres had 16.1% (Centre-45) to 47.2% (Centre-59) of the revision procedures with the reason missing.

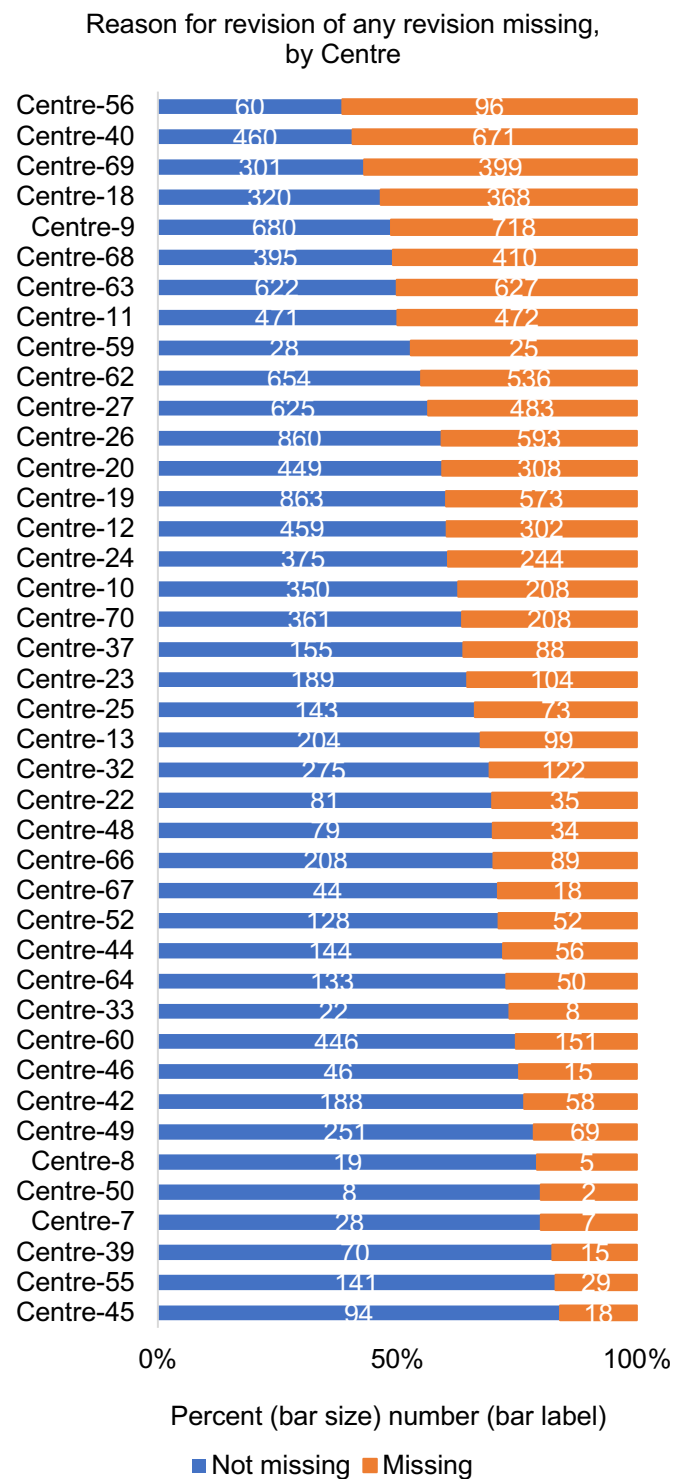


Figure S3-11 – Number (bar label) and percentage (bar size) of revisions with missing reason, by centre