Poster P109

Improving the quality of death data in the UK CHIC Study

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Background

Data on deaths in the UK CHIC Study may be underreported due to:
- patient loss to follow-up
- lack of documentation in HIV clinical databases

What are the consequences of under-reporting deaths?
- Overestimation of the denominator in data analyses
- Overestimation of follow-up
- Underestimation of death as an endpoint

More complete and correct death data would allow more accurate determination of clinical progression rates in data analyses

We explored a number of processes to supplement and improve the existing death data submitted by clinical centres to the UK CHIC Study

Methods

Processes to supplement existing UK CHIC death data
- UK CHIC data: eleven clinical centres submitted data on a total of 36,809 individual patients seen for care since 01/01/1996, and data covered the period up to the end of 2006. Of these, 2,623 (7.1%) records had a date of death included

Process 1 : Matching UK CHIC records with Office of National Statistics (ONS) death registry data
- ONS data for 2000–2006 were obtained for deaths of individuals aged 55 years of age or less
- UK CHIC records were matched to ONS death data by
  - Date of birth
  - Soundex (non-unique code of one letter + 3 numbers derived from surname)
  - First initial
  - Sex
- Where there was a match, centres were asked to confirm whether the individual had died or was still alive. If no information was available or patient notes were difficult to obtain, and there was no UK CHIC data after the ONS date of death, the ONS death date was entered into UK CHIC data

Process 2 : Matching UK CHIC records with UK HIV surveillance data provided by the Health Protection Agency (HPA)
- Sources of HIV surveillance data
  - SOPHID (Survey of Prevalent HIV Infections Diagnosed)
  - New diagnoses database (new HIV and AIDS diagnoses and deaths)
  - matching of these 2 data sources to ONS data (1996-2006, age ≤60 years)
- The HIV surveillance data sources (covering 9/11 UK CHIC centres) provided records of a total of 2,599 deaths

- UK CHIC records were matched to HIV surveillance data by
  - Date of birth
  - Soundex
  - Sex

Process 3 : Completion by centres of Coding of Death in HIV (CoDe) forms
- As part of the Coding of Death in HIV Project, centres were asked to complete forms for individuals who had died since 2006. As well as date of death, these forms include information on:
  - the circumstances leading up to an individual's death
  - further details on the cause of death
  - the patient's last CD4 count and viral load

De-duplication of records in UK CHIC data
We identified records from multiple UK CHIC centres that were assessed by a computer algorithm and by additional manual checking to belong to the same individual.

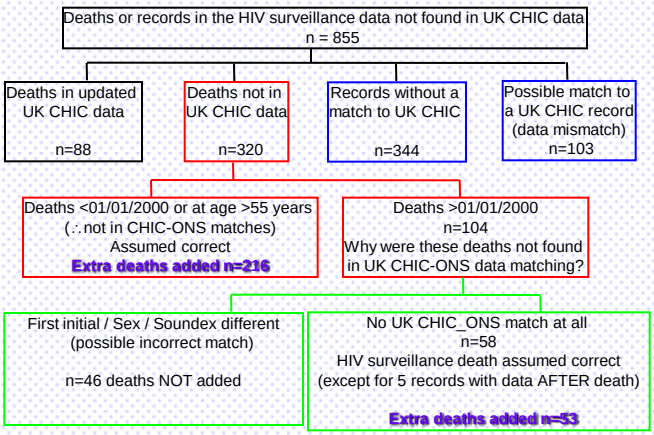
The data from these records were then merged to a single record, making a total of 29,055 records in the UK CHIC dataset.

Results

Process 1: n = 875 ONS deaths matched to a UK CHIC record that did not have a date of death or where the date was different to the ONS date. Of these:
- n = 181 UK CHIC dates of death were within 3 months of ONS date
  - UK CHIC dates were retained
- n = 117 where there were UK CHIC data AFTER the ONS death
  - the ONS deaths were NOT added into the UK CHIC data
- n = 577 where there was no death in the UK CHIC data and no data to suggest the patient had been seen after the ONS death date
  - the ONS dates of death were added into the UK CHIC data

Extra deaths added n = 577

Process 2



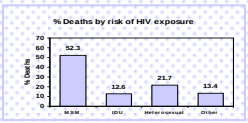
Process 3
Out of the 74 CoDe forms returned:
- n = 52 matched to a UK CHIC record with a date of death
- n = 8 matched to a UK CHIC record without a date of death
- n = 14 were for individuals that were not found in the UK CHIC data

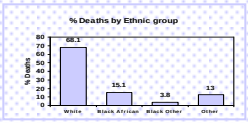
Extra deaths added n = 8

Why were there HIV surveillance data / ONS / CoDe records that did not match to a UK CHIC record?
We recognize that the matching processes used may not be not 100% accurate and that there may be differences in the identifiers used within the HIV surveillance and UK CHIC data. However, we investigated 54 records relating to individuals in HIV surveillance data seen at one particular centre, and found the following possible reasons why their records might not have been found in the UK CHIC data:
- the patient did not attend for care and did not have a record on the clinic database, therefore would not have been included in the data submitted to UK CHIC
- the patient was younger than 16 years, so was ineligible for the UK CHIC Study
- the patient had haemophilia and care was provided separately from the HIV centre
- the patient was admitted as an in-patient then died in hospital, so did not attend the HIV clinic for care
- there were differences in the time periods covered by the UK CHIC data and the other sources of death data
- delays between the patient's death and it being recorded on the clinic database

Some of these reasons are likely to apply to data from other centres, and we will need to determine whether or not to include these patients in UK CHIC data in future

Death data summary
Of the records in the UK CHIC dataset for patients now assumed to have died:
- ~ 90% have some information on the cause of death
- ~ 70% have taken 1 or more antiretroviral drugs at any time
- ~ 57% have a recorded AIDS diagnosis at any time
- ~ 80% have ≥ 1CD4 count: last recorded CD4 median (95% CI) of 100 (90, 108)
- ~ 70% have ≥ 1 viral load: last recorded viral load median (95% CI) of 4404 (2630, 7399)





Discussion

A total of 854 extra deaths were added into the UK CHIC data, bringing the number of deaths in the de-duplicated UK CHIC data to 3,308 (9.9%), a 26% increase on the original number.

The data matching exercise has also been a two-way process, and the HPA also identified deaths known to UK CHIC but not reported to the surveillance databases. Thus, the process has helped to improve the quality of death data in two studies.

The methods implemented have provided valuable additional data on deaths, but have highlighted limitations in the process of matching between datasets, in the timeliness and flow of information relating to deaths from hospital sources to clinic databases, and in the reasons for possible exclusion of patient records in data submitted to UK CHIC.

Improvement to the quality of death data is essential to increase the accuracy of data analyses in the UK CHIC Study. We suggest that regular audits and linking exercises between databases would help to achieve this aim.

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