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Merging Australia's national HIV and AIDS registries: improving quality and completeness of data

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Records of notification of new AIDS and HIV diagnoses have been maintained separately in Australia. The National AIDS Registry (NAR) was established in 1982, following the diagnosis of the first prospectively identified AIDS case in Australia, to provide information on the pattern of advanced HIV infection.[1] The National HIV Registry (NHR) was established in 1990 and incorporated state and territory health department records of HIV diagnoses from 1985, when HIV antibody testing first became available in Australia.[2] The NAR and the NHR have been independently maintained, partly because of incomplete information – particularly prior to 1991 – on the four-letter name codes and dates of birth used to uniquely identify each case of newly diagnosed HIV infection.[3,4]

Here, we report merging of these two registries to establish a single registry containing all notifications of HIV infection and AIDS in Australia. The merged registry will be used as the single national HIV registry and will contain AIDS diagnosis data matched to the corresponding HIV diagnosis.

A deterministic record linkage process was used to match and link cases, following the steps: (i) development of a decision algorithm and data-preprocessing (such as uniform coding and formatting of the variables that were common in both registries); (ii) matching (included identification of matched and unmatched records); and (iii) merging (included linkage of matched cases and creation of new records for unmatched cases). A step-wise two-tier linkage algorithm was designed. Each record from the NAR was compared with records in the NHR using the pre-developed decision tree. Cases were compared using key identifiers ('Date of birth', 'Family Name code', 'Given Name code', 'Sex') and checked for consistencies in key dates ('Date of HIV diagnosis', 'Date of AIDS diagnosis', 'Date of last contact', 'Date of death', 'Date of last negative test', 'Date of primary HIV infection' and 'Date of indeterminate Western Blot test').

For AIDS cases that were either an 'Exact match' or 'Close match' (such as AIDS cases that were accurately matched with an HIV record by key identifiers with minor inconsistencies in date variables), fields associated with the NAR (National AIDS Number, date of AIDS diagnosis and AIDS defining illnesses) were added to the corresponding records in the NHR. Record inconsistencies were corrected for linked pairs where necessary. A new HIV entry was created in the merged registry for each 'Unmatched' AIDS record. Finally, major characteristics of HIV notifications in Australia were compared before and after the merging of the NAR and the NHR. SAS software, version 9.2, was used for both pre-processing and linkage of the data.

As of 22 August 2011, there were 10,525 AIDS and 30,506 HIV records in the NAR and NHR, respectively. Overall, 9,338 AIDS records from the NAR were determined as matched cases and subsequently linked to a corresponding HIV record in the NHR. Among them, 5,439 were exact matches and did not require any further change before automated linkage was done. A total of 3,899 AIDS records were close matches and were also linked to the NHR. Almost three-quarters of the closely matched records (2,791 cases) needed clerical review. Four AIDS records were found to be duplicates and were deleted. No matches could be established for 1,183 AIDS records (11.2%) and therefore a new HIV record was created in the NHR for these cases. Almost 90% of these unmatched cases were diagnosed prior to 1995, and more than 95% were diagnosed earlier than 2000. The proportion of unmatched AIDS records declined from 49.1% (95% CI 35.4%-62%) in 1984–1988 to 13.2% (95% CI 5.5%-25.3%) in 2010–2011. After the merging was complete, there was a 4% (95% CI 3.7%-4.1%) increase in total number of HIV notifications in Australia. The trend over time in HIV notifications did not change following inclusion of the newly identified cases (Figure 1).

The merged registry contained a total of 31,689 records including all HIV and AIDS notifications in Australia. The most notable change following the merging was the proportion of HIV

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notifications in which the case is now confirmed to have died. Before the linkage was conducted, 11.3% (95% CI 10.9%-11.7%) of all HIV notifications in the NHR were recorded as dead. This proportion rose substantially to 24.9% (95% CI 24.4%-25.4%) after merging. Other key characteristics of newly diagnosed HIV notifications in Australia (State/Territory and year of HIV diagnosis, sex, age at diagnosis, and exposure category) remained similar after merging the registries.

The single national HIV registry will facilitate matching of death records from the National Death Registry more regularly which will help to better measure the burden of the disease. It will provide comprehensive information in a single source, enabling more efficient conduct of studies. With completeness of records and improved quality of data, better understanding of past and current trends in HIV notifications is also anticipated.

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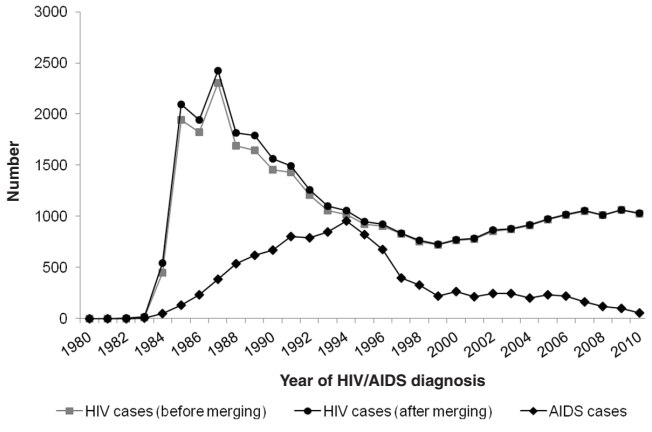
Figure 1: Number of notifications of newly diagnosed HIV before and after merging of the National AIDS and HIV registries and AIDS diagnoses in Australia, 1980-2010.



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