

Operations and Preliminary Results of a Linkage of Cancer Registry Data and HIV Data

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BACKGROUND

HIV/AIDS patients are at an increased risk of developing certain types of cancers due to weakened immune systems and high exposures to some viral infections. Concurrent HIV and cancer also present special challenges in the clinic for simultaneous treatment of cancer and HIV. Our linkage of the population-based Louisiana Tumor Registry (LTR) data with the statewide STD/HIV Program (SHP) data is prompted by the pressing need of cancer-HIV research and patient care. Both the LTR and the SHP are authorized by law to collect data from the other program. The purpose of this presentation is to share our experience in linking registry data with the state HIV data.

Table 1: Program History

Program	History of Data Collection
Louisiana Tumor Registry	Collection of cancer data began in New Orleans in 1947, but did not expand to the entire state until 1988.
STD/HIV Program	AIDS diagnosis collection began in 1984; HIV diagnosis collection began in 1993.

OBJECTIVES

1. Develop a procedure for an annual linkage with the SHP.
2. Establish prevalence of HIV infection within Louisiana's cancer population.
3. Facilitate research within the HIV/AIDS and cancer community.

METHODS

A data-sharing agreement was developed and approved by the authorities from both parties (LTR and SHP) for annual linkage activities. Specific procedures were designed and implemented including the selection of variables for the linkage and crosswalk file to ensure full protection of confidential patient information. Data release policies that will govern all data releases were established which included approval requirements by both parties. The first linkage included cancers diagnosed from 1995 to 2013.

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METHODS (cont.)

Confidentiality Procedures

1. The LTR extracted individual patient IDs and patient identifiers from the registry database and divided the data into small data files enabling completion of linkage, review, and complete erasure of all LTR data from the SHP computers prior to LTR staff leaving the SHP office. The linkage was completed in three sessions.
2. During each linkage session at the SHP office, the LTR personnel downloaded the file from the LTR's secure website (WebPlus) onto the SHP computer.
3. The linkage was conducted utilizing Link Plus software. Both the LTR and the SHP personnel reviewed and decided on the matches together based on the available data including name, date of birth, social security number, and address.
4. After finalizing the matches in each session, a file with the registry's patient ID, the SHP patient ID, and the date of HIV diagnosis was created. This file was then uploaded to the LTR's secure website.
5. The SHP personnel wiped the cancer registry file from the computer using PGP Encryption Software in the presence of the LTR personnel after each session.
6. After completion of the three linkage sessions, the crosswalk files from each session were downloaded at the registry's office and combined into one file. The cancer type and date of cancer diagnosis for each match were appended to the file. This crosswalk file was then uploaded to the LTR's secure website where it was retrieved by the SHP staff.
7. The LTR appended the date of HIV diagnosis to the matched records within the registry's database; the SHP appended cancer type and date of cancer diagnosis to the matched records within the HIV database.

RESULTS

Overall, 0.6% (n=2,640) of the LTR cancer cases (invasive and in situ) matched with SHP data. This represented 6.2% of the persons ever living with HIV in Louisiana. Approximately 72% (n=1,904) of those matches were among those with HIV-related cancers. In an analysis of the data from 1995 to 2013, 77.2% of those that were HIV positive were males and 60.5% were black.

Table 2: Descriptive Statistics

Characteristic	No. (%)	HIV-Related Cancers (%)	All Other Cancers (%)
Matched Cases	2,640	1,904 (72.1)	736 (27.9)
Sex			
Male	2,037 (77.2)	1,499 (73.6)	538 (26.4)
Female	603 (22.8)	405 (67.2)	198 (32.8)
Race			
White	1,026 (38.9)	767 (74.8)	259 (25.2)
Black	1,597 (60.5)	1,121 (70.2)	476 (29.8)
Other	17 (0.6)	16 (94.1)	1 (5.9)

Table 3: HIV-Related Cancers

Cancers Associated with HIV/AIDS	
Kaposi Sarcoma	Oral Squamous Cell Carcinoma
Non-Hodgkin Lymphoma	Colon Cancer
Hodgkin Lymphoma	Leukemia
Hepatocellular Carcinoma	Vaginal Cancer
Anorectal Carcinoma	Vulvar Cancer
Cervical Cancer	Penile Cancer
Testicular Cancer	Brain Cancer

CONCLUSIONS

- Monitoring cancer and HIV co-morbidity is critical to assessing disease trends and may reveal prevention opportunities.
- With an appropriate data-sharing agreement and specific procedures to protect confidential patient information through the linkage process, a successful linkage is feasible and legal.
- An annual linkage of this nature is planned so that the prevalence of HIV/AIDS within Louisiana's cancer population can remain up-to-date and provide an excellent starting point for cancer research in the HIV/AIDS community.
- Data release policies must be developed to govern the use of linked HIV-cancer data.
- The data has already been incorporated into the LTR's database and is being used by local researchers.

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