

UTAH

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Added Value in Cancer Registry Data: Birth Certificates for Race, Ethnicity, and Place of Birth

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: The Utah Cancer Registry and the Utah Department of Health (UDOH) collaborated to share data to improve completeness of several key demographic variables in registry data.

Monitoring cancer trends by race, ethnicity, and place of birth is important for understanding and bridging cancer disparities. Race and ethnicity information are available to registries through cancer case reports from hospitals, but these variables may be incomplete or of unknown quality. As a new participant in the National Program of Cancer Registries, Utah Cancer Registry had not previously treated place of birth as a required reportable variable and therefore the registry had a large proportion of missing data for place of birth. Whereas linkage with death certificates is a longstanding practice for central cancer registries, birth certificate data is not typically accessed for cancer surveillance. The Utah Cancer Registry partnered with the UDOH Office of Vital Statistics to supplement cancer registry patient data with the race, ethnicity, and birth place information available from matching to birth certificates. Place of birth was obtained for 47,883 cases born in Utah and 50,819 cases who matched as a parent on a Utah birth certificate and for whom place of birth was previously unknown. The registry was also able to fill race and Spanish/Hispanic ethnicity from self-reported data for a number of cases.

CHALLENGE: To improve completeness of cancer registry data on place of birth, race, and ethnicity.

SOLUTION: Utah Cancer Registry entered into a data sharing agreement with the Utah Department of Health Office of Vital Statistics for this novel use of birth certificate data. Utah Cancer Registry case identifiers are matched to other health data through a unique research resource, the Utah Population Database. The registry took advantage of the linkages built within this database to assure quality matches. Matching of a cancer case as a child on a Utah birth certificate was used to determine that Utah was state of birth and United States was country of birth. Self-reported race, Spanish/Hispanic ethnicity, and country of birth was obtained for cases matched as a parent on a birth certificate.

RESULTS: Of the 364,054 patients with one or more cancer case records in Utah Cancer Registry from 1973 to 2016, we found 197,198 high-quality matches to Utah birth certificates and 8,081 potential links. From this linkage, the registry determined that 47,883 cases with previously unknown birth state were born in Utah. An additional 50,819 cases with previously unknown country of birth matched as a parent on a birth certificate and self-reported country of birth was obtained. The registry also obtained race and Spanish/Hispanic origin for 278 and 786 cases, respectively, who matched as a parent and for whom we were missing this information.

SUSTAINING SUCCESS: Under the agreement with the Office of Vital Statistics, Utah Cancer Registry will continue to improve its data quality through annual linkages of new reported cancer cases to Utah birth certificates. We use birth certificate information to fill unknown race, ethnicity, and place of birth. We will develop approaches to resolve conflicting information between birth certificate and other sources.

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