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# Improving the Quality of Industry and Occupation Data at a Central Cancer Registry

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**Background** *Central cancer registries are required to collect industry and occupation (I/O) information when available, but the data reported are often incomplete.*
**Methods** *We audited the completeness of I/O data in the New Hampshire State Cancer Registry (NHSCR) database for diagnosis year 2005, and reviewed medical records for a convenience sample of 474 of these cases. We compared I/O data quality before and after a statewide registrar training session on occupationally related cancers.*
**Results** *The original 2005 data contained both I/O data in 11.5% of cases, and lacked any I/O data in 74.5%. Corresponding figures for cases selected for audit were 15.2% and 77.2%, which improved to 54.2% and 11.8% after medical record review. After registrar training, 47% of reports contained both I/O data, and only 14.4% of cases lacked any I/O data.*
**Conclusions** *Statewide training to highlight the importance of I/O data is an effective method to improve I/O data quality.* Am. J. Ind. Med. 53:995–1001, 2010.


***KEY WORDS: cancer registry; occupational cancer; medical record review; industry and occupation; data quality***

## INTRODUCTION

Although central cancer registries funded by the National Program of Cancer Registries (NPCR) are required to collect industry and occupation (I/O) information when available, it is recognized that I/O data in cancer registries have many limitations [NPCR Program Manual, 2008]. Obtaining reliable, standardized data may be affected by inconsistent recording of I/O in the medical record; lack of resources and trained personnel at the registry level; inconsistencies in documenting ''usual occupation;'' and complex coding schemes tied to vague narrative I/O (e.g., ''retired'' is listed in a very large percentage of cases) [Fulton et al., 2002].

In 2002, North American Association of Central Cancer Registries (NAACCR) researchers published a report on the collection and use of I/O data by NAACCR member registries [Fulton et al., 2002]. A survey of all member state registries found that three fourths of the 41 respondents required I/O data in case reports, but this requirement was mandated by state law in only half of these registries. Only 8% of central registry respondents routinely checked the completeness of I/O data in cancer case reports. One respondent had used I/O data in an annual report, but 27% had used their I/O data at least once in a special epidemiological study.

### Background and Preliminary Studies

There is evidence to suggest that a variety of cancers may result from occupation-related risk factors and exposures

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[Steenland et al., 2002]. Previously, New Hampshire epidemiologists examined patterns of occupational mortality in the state [Schwartz, 1988]. Occupation, industry, age, date and cause of death information was abstracted from the death records of all white male New Hampshire resident decedents (aged 20 years or older) for a 10-year period. Out of 37,500 death certificates abstracted and coded, useful occupational and industrial statements were found on more than 92% of death certificates. Another study using New Hampshire mortality data found an association between certain occupations and industries and the occurrence of prostate cancer [Krstev et al., 1988]. Several research studies relating to occupational cancers have already been carried out using registry data, illustrating that central registries can be a valuable source of data for such research [Commonwealth of Massachusetts, 2003; Bates, 2007; Kang et al., 2008].

A few studies have examined the usefulness of I/O data from the medical record or from a cancer registry [Swanson et al., 1984; Balarajan, 1985; Olsen et al., 1987; Brownson et al., 1989; McDiarmid et al., 1991]. In an audit by the Massachusetts Cancer Registry, a detailed medical record review improved either the presence or detail of I/O information for 32% of cancer case reports. When combining data from the audit and routine cancer reporting, I/O information could be found for 82% of the cases sampled [Levy et al., 2001]. To our knowledge, there have been no published studies evaluating improvements in I/O data quality after the provision of training to hospital registrars who report to central cancer registries.

We decided to examine the quality of I/O data in the NH State Cancer Registry and to quantify the potential improvement that could be gained by more focused medical record review and by training of cancer registrars.

## MATERIALS AND METHODS

### Cancer Registry Data

This study was based on cancer data from the New Hampshire State Cancer Registry (NHSCR), a statewide cancer surveillance program founded in 1986 that collects incidence information on in situ and invasive cancers diagnosed and/or treated at medical facilities in New Hampshire, including hospitals, physicians' offices, free-standing oncology clinics, and pathology laboratories. The New Hampshire State Cancer Registry received gold certification from the North American Association of Cancer Registries (NAACCR) for diagnosis year 2005 with an estimated case completeness of 107.4% (NAACCR Registry Certification on Quality, Completeness and Timeliness of 2005 Data, Summary of Certification Measures, May 2006). For every cancer case, hospitals report an initial, or *rapid*, case report within 45 days from the date of diagnosis, and a more complete, or *definitive*, case report is due within 180 days of diagnosis. As part of the definitive report, registrars are required to collect the patient's usual industry and occupation, which are defined as the kind of work performed during most of the patient's working life before a cancer diagnosis [Havener and Thornton, 2008].

We evaluated the presence of industry and occupation (I/O) data in reports for diagnosis year 2005 among New Hampshire residents with an incident cancer diagnosed or treated at a New Hampshire hospital ($n = 5{,}602$). We focused on data reported only by New Hampshire hospitals, which accounted for 79% of cancer case reports in 2005, to assess whether I/O data are generally available in hospital medical records. Cancer reports based only on death certificates or received from neighboring states were excluded from the audit because medical record review is not possible in those cases. We used the categories described below for the presence of all, some or no I/O data. From these cases, we randomly selected 20 cases for every cancer registrar in the 15 hospitals with in-house cancer registries (''registry hospitals''), and 20 cases for each of the 11 other reporting (''non-registry'') hospitals. The 20 cases consisted of 2 cases from each of the 5 major sites: female breast, prostate, lung, colon, and hematopoietic; and 10 cases from other sites. If enough records could not be accessed from the major sites, other sites were included to total 20. A total of 708 cases were eligible for review.

### Medical Record Review

During NHSCR's routine data quality audit, auditors were asked to collect all available data on past and current occupation and industry. Auditors reviewed records from the earliest available hospital encounter to the last provided in the hospital medical record. Auditors were not provided with the original reported I/O data. The following information was collected: date of source where I/O was found, source of I/O history, and exact text about I/O from medical record. We also collected duration of occupation, record of hazardous exposure, first and last dates of hospital encounter. The source within the medical record from which I/O was found was categorized into nine groups, including hospital face/admission sheets, dictated physician reports, and nurse/patient admission notes. Although 708 cases were potentially eligible for medical record review, some hospitals accessioned fewer than 20 cases/year, and not all cases were available at the time of review, resulting in a final sample of 474 cases actually reviewed.

### I/O Classification

A trained occupational coder from the National Institute for Occupational Safety and Health (NIOSH) classified I/O data according to the US Bureau of Census Industry and

Occupation Classification system [2000]. The Census 2000 Industry codes were grouped into 20 major sectors based on the 1997 North American Industry Classification System [NAICS, 1997], and occupation codes were grouped into 23 major occupation groups based on the 2000 Standard Occupational Classification [SOC, 2000] Manual [US Census, Standard Occupational Classification, 2000]. These classification systems are used by US government agencies for statistical reporting of industry and occupation responses. I/O codes were assigned to each case report in the study sample before and after medical record review. Both sets of codes were then categorized according to the availability of I/O information. Categories were developed for: Both I/O available; industry only; occupation only; both I/O coded to an unpaid workforce; occupation available, but industry coded to unpaid workforce; industry available, but occupation coded to unpaid workforce; industry coded to unpaid workforce, but occupation unknown; and I/O unknown. Unpaid workforce included homemakers (housewives), volunteers, students, ''retired,'' and ''did not work'' (never worked, child, infant, inmate, disabled, etc.). We then created a variable that used the best data that could be obtained by combining information from both the medical records review and the cancer registry database, or ''Best I/O.''

## Post-Training Data

New Hampshire cancer registrars and other hospital staff involved in cancer reporting were invited to participate in the NHSCR bi-annual training meeting in April 2008. This meeting included presentations on the rationale for improving I/O data, the results of our study on I/O data quality, and suggestions to improve the efficiency of collection of I/O text in cancer reports. We examined the presence of industry and occupation data in reports sent to NHSCR after this meeting, from May 2008 through February 2009 (n = 5,495), using the same categories described previously for the presence of all, some or no I/O data.

## Analysis

We calculated the proportions of records having all, some or no I/O data, as described above, in NHSCR data from diagnosis year 2005, from the sample of cases that we reviewed, and for data reported after the training meeting. Using the proportion of sampled NHSCR original reports (N = 474) containing some I/O data as the reference point, we used the two sample test of proportions (Stata 10.1, StataCorp, College Station, TX) to assess the quality of data (1) collected during our medical record review for these same 474 patients, and (2) reported to NHSCR during the 10 months after hospital registrar training.

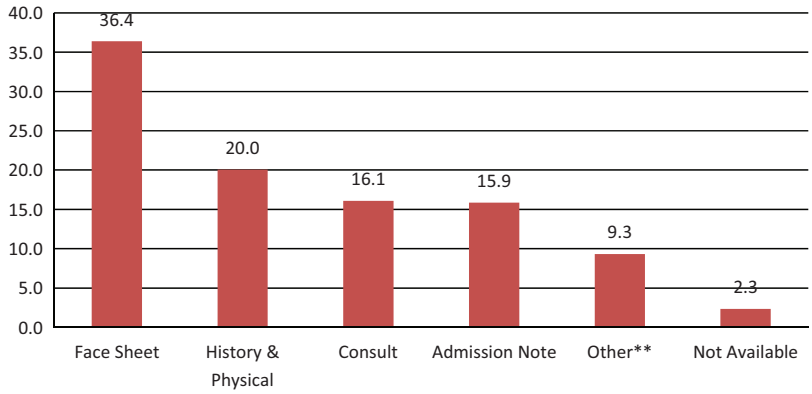
# RESULTS

There were 6,713 incident cancer reports in the NHSCR database for diagnosis year 2005 (Table I), of which the 5,602 used for analysis were those reported by New Hampshire hospitals. The 474 cases that we reviewed were reasonably representative of New Hampshire residents newly diagnosed

**TABLE I.** Characteristics of 6,713 Cancer Cases in the New Hampshire Cancer Registry and 474 Randomly Selected Cancer Cases Included in Study*

| | NHSCR | | Sample | |
|---|---|---|---|---|
| | No. | % | No. | % |
| Age | | | | |
| 0–49 | 1,142 | 17.0 | 65 | 13.7 |
| 50–59 | 1,454 | 21.7 | 106 | 22.4 |
| 60–64 | 832 | 12.4 | 64 | 13.5 |
| 65–69 | 861 | 12.8 | 43 | 9.1 |
| 70–74 | 963 | 14.3 | 60 | 12.7 |
| 75–79 | 569 | 8.5 | 58 | 12.2 |
| 80+ | 892 | 13.3 | 78 | 16.5 |
| Total | 6,713 | 100.0 | 474 | 100.0 |
| Race | | | | |
| White | 6,575 | 97.9 | 465 | 98.1 |
| Non-white | 68 | 1.0 | 4 | 0.8 |
| Unknown | 70 | 1.0 | 5 | 1.1 |
| Total | 6,713 | 100.0 | 474 | 100.0 |
| Sex | | | | |
| Male | 3,193 | 47.6 | 239 | 50.4 |
| Female | 3,520 | 52.4 | 235 | 49.6 |
| Total | 6,713 | 100.0 | 474 | 100.0 |
| Primary site | | | | |
| Female breast | 1,292 | 19.3 | 58 | 12.2 |
| Lung and bronchus | 937 | 14.0 | 47 | 9.9 |
| Prostate | 770 | 11.5 | 36 | 7.6 |
| Colo-rectal | 651 | 9.7 | 48 | 10.1 |
| Hematopoetic | 199 | 3.0 | 43 | 8.0 |
| Melanoma of skin | 432 | 6.4 | 30 | 6.3 |
| Female genital system | 335 | 5.0 | 24 | 5.1 |
| Bladder | 319 | 4.8 | 49 | 10.3 |
| Other digestive organs | 363 | 5.4 | 31 | 6.5 |
| Oral cavity and pharynx | 167 | 2.5 | 14 | 3.0 |
| Larynx | 60 | 0.9 | 3 | 0.6 |
| Testis | 31 | 0.5 | 1 | 0.2 |
| Other urinary organs | 143 | 2.1 | 11 | 2.3 |
| Brain and other nerv. syst. | 172 | 2.6 | 7 | 1.5 |
| Thyroid | 133 | 2.0 | 17 | 3.6 |
| Lymphoma | 288 | 4.3 | 27 | 5.7 |
| Unknown and other | 421 | 6.3 | 28 | 6.9 |
| Total | 6,713 | 100.0 | 474 | 100.0 |

*Diagnosis year 2005.




*Best I/O data obtained by combining original and reviewedcancer cases; excludes 45 cases with unknown I/O.
**Other includes reports from clinic/physician offices, obituary/death certificate, discharge summary and emergency room.

**FIGURE 1.** Source of industry/occupation (I/O) information in patient medical records of 429 cancer cases where I/O was available, diagnosis year 2005. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

with cancer in 2005: 98% Caucasians (NH incident cancer population 98%); 50% male (NH incident cancer population 48%); mean age was 65; sampled cases included a small excess of bladder cancer and hematopoetic (leukemia) cancers, and a lower number of prostate, breast and lung cancers (Table I). Of the 474 cases sampled for review, 15.2% contained complete I/O data (compared with 11.5% for NH cases overall), and 77.2% contained no I/O data [compared with 74.5% for NH cases overall (Table II)].

Careful review improved the proportion of registry reports with no industry or occupation data from 77% to 12%. Of the original I/O data reported to NHSCR, only 72 (15%) reports contained complete I/O data, 36 (8%) contained partial data and 366 (77%) reports lacked any information on industry and occupation. The detailed medical record review identified complete I/O data for 257 (54%) of cases; partial data for 161 (34%) and no I/O data for 56 (12%). The proportion of records containing partial or complete I/O data during our medical record review (418/474; 88%) was significantly higher than the equivalent proportion contained in the original reports to NHSCR (108/474; 23%; $P < 0.001$). Combining data from the original cancer registry case report and the study audit gave marginal additional improvements in data quality over the study audit data alone.

The location of I/O data within a medical record varied by facility, depending on the characteristics of their record system. Overall, I/O data could be easily identified 36% of the time on the face sheet. Physician-dictated reports, such as history and physicals and consults (36%), and admission notes completed by nurses or patients upon intake (16%) were also a valuable source of I/O data (Fig. 1). Patients were more likely to have some I/O data recorded in the medical records if they were males and if they were aged 50–59 (Table III). There was some variability in the I/O data

**TABLE II.** Comparison of Industry and Occupation (I/O) in Study Population, I/O Collected on Review, and Cancer Cases Reported After Training

| | | Study sample | | |
|---|---|---|---|---|
| | Diagnosis year 2005, total (n = 5,602) % | Original (n = 474) % | Review (n = 474) % | Post-training (n = 5,495) % |
| I/O available | 11.5 | 15.2 | 54.2 | 47.7 |
| Industry or occupation only | 7.7 | 3.2 | 13.1 | 14.6 |
| I/O unpaid workforce | 5.1 | 4.0 | 19.2 | 20.0 |
| Occupation available, industry unpaid workforce | 0.7 | 0.2 | 0.2 | 1.9 |
| Industry available, occupation unpaid workforce | 0.5 | 0.2 | 1.3 | 1.4 |
| Industry unpaid workforce, occupation unknown | 0.0 | 0.0 | 0.2 | 0.0 |
| I/O unknown | 74.5 | 77.2 | 11.8 | 14.4 |

obtained from records by cancer site, ranging from 85% for those with cancer of the lung and bronchus to 98% among patients with hematopoetic cancers.

Of the 5,495 cancer cases reported to NHSCR after the registrar training session, the proportion of records reported to NHSCR that contained any (partial or complete) I/O data (4,701/5,495; 85.6%) was significantly higher than the equivalent proportion contained in the reports submitted to NHSCR before training (108/474; 23%; $P < 0.001$). After training, only 14.4% of reports lacked any I/O data (compared with 75% of diagnosis year 2005 cases), and 47.7% of reports contained both industry and occupation data (compared with 12% of 2005 cases).

**TABLE III.** Percent of Cancer Cases With Industry/Occupation Data Recorded in Patient Medical Records, Diagnosis Year 2005

| | Total | | | | |
|---|---|---|---|---|---|
| | No. | % | Original % | Reabstract % | Best[a] % |
| Age | | | | | |
| 0–49 | 65 | 13.7 | 20.0 | 87.7 | 87.7 |
| 50–59 | 106 | 22.4 | 30.2 | 90.6 | 94.3 |
| 60–64 | 64 | 13.5 | 18.8 | 85.9 | 89.1 |
| 65–69 | 43 | 9.1 | 16.3 | 90.7 | 93.0 |
| 70–74 | 60 | 12.7 | 26.7 | 88.3 | 88.3 |
| 75–79 | 58 | 12.2 | 24.1 | 84.5 | 91.4 |
| 80+ | 78 | 16.5 | 17.9 | 88.5 | 88.5 |
| Total | 474 | 100.0 | 22.8 | 88.2 | 90.5 |
| Race | | | | | |
| White | 465 | 98.1 | 23.0 | 88.2 | 90.5 |
| Non-white | 4 | 0.8 | 0.0 | 100.0 | 100.0 |
| Unknown | 5 | 1.1 | 20.0 | 80.0 | 80.0 |
| Total | 474 | 100.0 | 22.8 | 88.2 | 90.5 |
| Sex | | | | | |
| Male | 239 | 50.4 | 26.8 | 89.1 | 92.9 |
| Female | 235 | 49.6 | 18.7 | 87.2 | 88.1 |
| Total | 474 | 100.0 | 22.8 | 88.2 | 90.5 |
| Primary site | | | | | |
| Female breast | 58 | 12.2 | 10.3 | 84.5 | 86.2 |
| Lung and bronchus | 47 | 9.9 | 17.0 | 80.9 | 85.1 |
| Prostate | 36 | 7.6 | 27.8 | 91.7 | 91.7 |
| Colo-rectal | 48 | 10.1 | 33.3 | 93.8 | 97.9 |
| Hematopoetic | 43 | 8.0 | 15.8 | 97.4 | 97.7 |
| Melanoma, skin | 30 | 6.3 | 23.3 | 83.3 | 90.0 |
| Female Gyn | 24 | 5.1 | 16.7 | 79.2 | 79.2 |
| Bladder | 49 | 10.3 | 30.6 | 89.8 | 91.8 |
| Oral cavity and pharynx | 14 | 3.0 | 42.9 | 78.6 | 85.7 |
| Other digve organs | 31 | 6.5 | 19.4 | 87.1 | 90.3 |
| Larynx | 3 | 0.6 | 0.0 | 100.0 | 100.0 |
| Testis | 1 | 0.2 | 0.0 | 100.0 | 100.0 |
| Other urinary organs | 11 | 2.3 | 45.5 | 90.9 | 100.0 |
| Brain and other nerv. syst. | 7 | 1.5 | 28.6 | 71.4 | 71.4 |
| Thyroid | 17 | 3.6 | 29.4 | 94.1 | 94.1 |
| Lymphoma | 27 | 5.7 | 18.5 | 88.9 | 88.9 |
| Unknown and other | 28 | 6.9 | 21.2 | 93.9 | 92.9 |
| Total | 474 | 100.0 | 22.8 | 88.2 | 90.5 |

[a]Best data obtained by combining original and reabstracted I/O data.

## DISCUSSION

Our study demonstrates for the first time that cancer registries can make substantial improvements in the quality of industry/occupation data through group training of cancer registrars. In New Hampshire, training meetings often include efforts to raise awareness of data needed for special studies and feedback on their results. Cancer registrars are frequently challenged by competing demands on their time, and justifiably focus their efforts on the provision of data directly related to the diagnosis and treatment of cancer. However, our study shows their willingness to respond when the central registry highlights its interest in the collection of high quality industry and occupation data in the cancer report.

While New Hampshire's cancer registrars have clearly shown their willingness to report high quality I/O data, they are constrained by the quality of data in medical records. Our analysis was limited to healthcare providers' documentation in hospital medical records, whose accuracy has not been assessed. Of the 474 medical records examined, 12% contained no I/O information, a proportion that most likely varies by provider, an inherent problem when there is no standard protocol for the collection of I/O during a provider-patient encounter.

In many cases, it takes additional effort for a cancer registrar to determine from medical records whether patients had changed occupations during their lifetime, and this often requires additional requests for old volumes of medical records that may not be readily available. There may also be a subjective element in deciding which occupation of several should be regarded as the ''usual'' occupation, although training documents are available [NCHS Guidelines, 1988]. In addition, the central registry database is not suited to the inclusion of a detailed occupational history. Other studies have shown that medical students' ability and willingness to collect occupational histories from all patients, including women and young persons, can be improved with training specific to occupational content [Sokas et al., 1991; McCurdy et al., 1998]. However, the importance that providers attach to this kind of activity is not clear.

An additional limitation of our study is its generalizability to other states. New Hampshire, with a population of 1.3 million, has only 27 reporting hospitals and approximately 32 cancer registrars. For many years, we have held biannual training meetings, and have developed strong relationships with reporters from the whole state: their ability to make an extra effort to improve I/O reporting when requested may not be as easily replicated elsewhere. In addition, we would need to repeat our assessment of I/O data quality in the future to determine whether the effect of training diminishes over time, and at what point that occurs. It would also be feasible to include the same topic in future training sessions in an effort to maintain the high quality data seen within the first year after training.

In conclusion, our study shows that central cancer registry data on industry and occupation among cancer patients can be substantially improved by means of minimal training provided to cancer registrars to highlight the importance of these data.

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