

# Frontline Workers in Cancer Data Management: Workforce Analysis Study of the Cancer Registry Field

**Executive Summary** • June 2006



Susan A. Chapman, PhD, RN  
Vanessa Lindler, MA  
Vasey McClory, MPH  
Christine Nielsen, BA  
Wendy Dyer, MA

Prepared by staff at the UCSF Center for the Health Professions  
and Department of Social and Behavioral Science, School of Nursing

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# Executive Summary

## Background

The National Cancer Registrars Association (NCRA) is interested in gaining a better understanding of the cancer registry workforce; size, composition, educational preparation, recruitment, job satisfaction and retention, and issues related to supply and demand. To address these issues, the NCRA formed a Recruitment and Retention task force and Advisory Committee. The task force contracted with the University of California, San Francisco (UCSF), Center for the Health Professions and School of Nursing in 2003 to conduct a workforce study. The objective of this 15-month study was to inform the cancer registry profession, national organizations responsible for cancer data collection, the health professions educational community, policymakers, and the public about issues related to the Cancer Registrar workforce. The primary goal was to develop a baseline understanding of the current workforce, including a demographic profile of the field, the number of current Cancer Registrars, supply and demand trends, vacancy and turnover rates within the field, perspectives of registrars, and workforce projections for the future. Another objective was to assess training and pathways into the field, career satisfaction, and career commitment, in order to provide a foundation for the development of strategies to address recruitment to and retention within the field.

## Study Methods

The study included a number of qualitative and quantitative approaches that were designed to build a cumulative body of knowledge. Data collection occurred within a 12-month period. An extensive review of the pertinent literature and an analysis of secondary data were conducted throughout the study. Because Cancer Registrars do not have unique identifiers in common labor and population databases, we were unable to conduct any comparative analyses with other healthcare workforce occupational groups.

### *Focus Groups*

We conducted six focus groups, two in-person and four telephone focus groups, from May-June 2004. The purpose of the focus groups was to gain an in-depth understanding of the issues important to cancer registry workers and to inform the key informant interview and survey processes. There were between 7–10 participants in each group. Recruitment was conducted by professional recruiters using screening guides that ascertained Certified Tumor Registrar (CTR) status, employment status, and years employed in the field. A total of 53 individuals participated in the six focus groups.

### *Key Informant Interviews*

We conducted 30 in-person and telephone interviews with key informants who are experts in the cancer surveillance community. Key informants were drawn from the leadership of professional organizations, employers, educators from formal educational programs and health information technology programs, and relevant credentialing and

accreditation bodies. Interview questions were tailored to the type of agency, organization, or institution that the informant represented. The key informant interviews preceded the online survey and further informed the items included in the survey.

### *Online Survey*

An online survey was developed and administered by the research team. A random sample of 990 respondents was selected from three sources including the NCRA membership database, the North American Association of Central Cancer Registries (NAACCR) directory, and an additional list of CTRs who were not members of the NCRA. The survey consisted of 143 items including demographics, type of worksite, primary job functions, wages, benefits, career commitment, and satisfaction with compensation and other aspects of the job. There were 532 usable responses, a response rate of 55%.

## **Summary of Major Findings and Recommendations**

The general types of findings are grouped around several major issues including awareness, recognition, and reward; educational pathways and certification; job satisfaction and career commitment; and current workforce size, shortages, and projections for the future.

### *Awareness, Recognition and Reward*

Focus group participants, key informants, and survey respondents all agreed that a lack of awareness of the profession from the public and health care community is a pervasive problem. There was widespread agreement that Cancer Registrars are not recognized by their supervisors, administrators, or the cancer community for the importance of the work they do. The greatest source of dissatisfaction among Cancer Registrars is in monetary compensation. Focus group participants nearly all agreed that pay is insufficient for the type of work performed by Cancer Registrars. Less than half of survey respondents were satisfied with their chances for salary increases. Career growth opportunities for Cancer Registrars are perceived as being limited.

### *Recommendations*

- Develop tool kits for registrars to use to advocate for their position and compensation, containing such information as:
  - comparative salary information
  - sample job descriptions
- Outreach campaigns to hospital administrators, physicians, registry managers, and the public regarding:
  - the value of the registry in cancer prevention, education, tracking, and treatment, and
  - the economic and educational value of cancer data to generate grants and develop new cancer programs.

### *Educational Pathways and Certification*

There is no clear educational pathway to the profession of cancer registration and, unlike most other health professions, there is no minimal college degree required for entry into the profession. Of those currently working in the profession, 55% stated that an Associate's Degree would best prepare students for working as a Cancer Registrar. The lack of a degree requirement impacts both public awareness and the ability to recruit to the profession. Achieving certification in the field of cancer registry is also not adequately valued or compensated according to focus group participants, key informants, and survey respondents. While more study is needed on data quality comparing certified and non-certified workers, there is some data and a great deal of consensus that professional certification leads to a higher quality of cancer data reporting.

### *Recommendations*

- Consider implementing a minimum Associate's Degree requirement for entry into the field
- Enable more students to access formal degree-granting educational programs
  - expand the number of degree-granting programs if needed
  - expand opportunities for students to complete clinical internship requirements
- Encourage requirement of CTR credential as the professional standard
  - adopt state regulations such as in New York and New Jersey
  - adopt organizational requirement for certification: employer-based or through accrediting bodies such as the Commission on Cancer

### *Job Satisfaction and Career Commitment*

Cancer Registrars are generally very dedicated to their work, believe in the importance of their contribution to the field of cancer, and many intend to stay in the field until their retirement. There is a strong sense of obligation in the cancer registry workforce; 50% of survey respondents stated that they felt an obligation to stay in the cancer registry profession. It is not clear whether a new and younger cohort of workers will feel the same level of dedication and commitment. More than half of the survey respondents who stated an intent to leave the field within the next 1-3 years were age 40 or less. The average age of the current registrar workforce is 48 and the retirement of a great many current Cancer Registrars is a looming issue.

### *Recommendations*

- Develop and implement a recruitment strategy for the field
- Develop toolkits for managers of Cancer Registrars to focus on issues important to retention
- National cancer organizations should partner to develop a comprehensive recruitment and retention plan addressing identified workforce issues

### *Current Workforce Size, Shortages and Projections for the Future*

It is difficult to know precisely the number of Cancer Registrars currently working in the field. The Department of Labor and U.S. Census surveys that track the number of other health professionals do not collect data unique to Cancer Registrars. Using data from the Commission on Cancer (CoC), the American Hospital Association (AHA), and NAACCR, we estimate about 7,280 registrars currently in the workforce. Projecting just 15 years in the future, we estimate the need for at least 800 new registrars to meet the needs of a larger and older population with the expected increased incidence of cancer. In addition, the pending retirement of older registrars will require many more replacement workers. Key informants and survey respondents indicated that there are current shortages in the workforce, defined as jobs unfilled and difficult to fill, but the difficult to fill positions vary by geographic region and type of position. Certain types of jobs are more difficult to fill and certain regions of the country have a harder time filling positions.

### *Recommendations*

- Advocate to the Department of Labor and/or Census Bureau to obtain a code for Cancer Registrars
- Cancer organizations including CoC and NAACCR should collect more systematic and detailed employment data on an annual or every other year basis
- Need to develop a recruitment strategy and implement a program in order to prepare for expected increase in demand.

### **Conclusion**

The cancer registry profession is critical to the field of cancer and to the nation's public health. National cancer data and statistics all begin from the same source, the Cancer Registrar. The quality and accuracy of the data are only as good as the training and dedication of the Cancer Registrar abstracting and reporting the data. This profession has changed cancer research remarkably from the days when the only source of data was from physician notes in medical records. Cancer Registrars are dedicated, hard-working, and generally satisfied with their work except that they would like to feel more recognition and be better compensated. The field of cancer registry is a unique yet important component of the growing field of health information technology. We can expect to see an increased need for Cancer Registrars in the future. The major cancer surveillance organizations need to collaborate to create and implement a strategy to meet the workforce challenges ahead.

## Introduction

A cancer registry is an information system designed for the collection, management, and analysis of data on individuals with the diagnosis of cancer. There are three types of cancer registries:

1. Healthcare facility registries; These facilities report to the central or state cancer registry as required by law.
2. Central registries; Population-based registries that maintain data on all patients within a certain geographical area.
3. Special purpose registries; Maintain data on a particular type of cancer. <sup>1</sup>

Healthcare facility registries represent the majority of Cancer Registries. Typically these registries are located within the Health Information Management Department (Medical Record Department) or under another department specifically related to Oncology at a hospital or medical facility. Central registries are government agencies typically located at state or regional health departments. Special purpose registries are typically located within specialized treatment areas of hospitals.

Cancer registry data is unique in that the information is not only collected from medical records, but from clinics, physician's offices, other healthcare facilities, and Internet resources for the lifetime of every patient.<sup>2</sup> Patients are tracked over their lifetimes both to remind patients and physicians of the need for regular clinical examinations, and to maintain accurate survival data for epidemiological purposes.<sup>3</sup> Cancer registry data is used for a variety of purposes including the tracking and understanding of cancer incidence as it relates to race, gender, age, and geographic location. For example, the CDC used cancer registry data covering 92% of the U.S. population for their major 2001 cancer report: *U.S. Cancer Statistics: 2001 Incidence and Mortality*.<sup>4</sup>

The staff professional of a cancer registry is the Cancer Registrar. Cancer Registrars collect accurate and timely cancer data and report this data to state and federal registries. Specifically, they collect data on the occurrence of cancer, the type and site of cancer, the extent of the cancer at the time of diagnosis, and the treatment that the patient receives.<sup>5</sup> Core duties of a Cancer Registrar include case finding, abstracting, and follow-up.<sup>6</sup> Key qualifications include experience in medical terminology, skill in computer operations, a strong knowledge base in anatomy and physiology, and an understanding of statistics and database management.<sup>7</sup>

It is difficult to estimate the number of Cancer Registrars because national occupational and census databases do not collect specific information on this workforce. The closest workforce with unique national and census tracking information is health information technology, a group of which Cancer Registrars could be considered a subset. In 2002 the total number of people working in medical records and health information, a group which includes Cancer Registrars, was approximately 147,000.<sup>8</sup>

Much of what we do know about Cancer Registrars is collected from the National Cancer Registrars Association (NCRA) or from other national organizations including the

American College of Surgeons' Commission on Cancer (CoC) and the North American Association of Central Cancer Registries (NAACCR). The NCRA is a non-profit professional organization, representing nearly 4,000 cancer registry professionals and Certified Tumor Registrars (CTRs). In 2003, the NCRA reported that there were 3,314 CTR certificants.<sup>9</sup> The research team updated the estimate of the current number of Cancer Registrars using two different methods and sources of data. The methods and findings are described in more detail later in the report. Based on those updated estimates, it is likely that the current size of the workforce is significantly larger than previously estimated and is closer to about 7,200 individuals.

In 2003, the NCRA estimated that there were about 4,000 Cancer Registries in the U.S.<sup>10</sup> These estimates were based on the numbers of approved and non-approved American College of Surgeons (ACoS) cancer programs, as well as the number of central registries.<sup>11</sup>

## Purpose of Study

The NCRA became interested in gaining a better understanding of the cancer registry workforce; size, composition, educational preparation, recruitment, job satisfaction and retention, and issues related to supply and demand. The NCRA formed a Recruitment and Retention Task Force and an Advisory Committee. The Task Force contracted with UCSF, Center for the Health Professions and School of Nursing to conduct a workforce study. The objective of this 15-month study was to inform the health professions educational community, policymakers, industry, and the public about issues related to the Cancer Registrar workforce. The primary goal was to develop a baseline understanding of the current workforce, including: size of the current Cancer Registrar workforce, supply and demand trends, vacancy and turnover rates within the field, workforce projections, and a demographic profile of the field. Another objective was to assess training and pathways into the field, career satisfaction, and career commitment, in order to provide a foundation for the development of strategies to address recruitment to and retention within the field.

## Methods

The study utilized both quantitative and qualitative approaches to address the research questions. Methods included literature review, a survey of Cancer Registrars, structured interview, focus group, and collection and review of secondary data. The project was designed to address the following major research goals and questions:

1. What is the current number of individuals working as Cancer Registrars and at what position level?
2. What are the numbers of individuals entering and exiting the field per year by position level?
3. What is the number of desired positions now and in the future for the Cancer Registrar by position?
4. What is the supply vs. demand gap currently and in the future?
5. What strategies can be identified to close the gap?

Additionally, the study addresses the utilization of registry workers, job and career satisfaction, and critical policy issues that will aid the NCRA in addressing strategic issues over a longer period.

### *Focus Groups*

We conducted six focus groups, including two in-person focus groups with Cancer Registrars across the country. Two in-person groups were conducted during NCRA's annual conference in Portland, Oregon in March of 2004 and four telephone focus groups were held in May and June 2004. The purpose of the focus groups was to gain an in-depth understanding of the issues important to cancer registry workers and to inform the key informant interview and survey processes. Detailed focus group questions were developed in consultation with the NCRA. The focus groups were moderated and summarized by Arthur Associates, a health care consulting firm specializing in health care and health care workforce research.

A total of 9-12 individuals were recruited for each focus group, with a goal of 7–10 respondents for each group. Recruitment was conducted by professional recruiters using screening guides that ascertained CTR status, employment status, and years employed in the field. Groups lasted 1.5 hours each.

A total of 53 individuals participated in the six focus groups. Of these, 23 participated in the in-person groups and 30 in the telephone focus groups.

### *Key Informant Interviews*

We conducted 30 in-person and telephone interviews over four months with key informants. Key informants were defined as individuals who are expert in some capacity within the cancer surveillance community. Our key informants were drawn from the leadership of professional organizations, employers, educators from the NCRA-approved formal educational programs and health information technology programs, and relevant credentialing and accreditation bodies. Interview questions were tailored to the type of agency, organization, or institution that the informant represented<sup>i</sup>, and each interview included questions that addressed the project's core research issues.

### *Online Survey*

The online survey was developed and administered on a secure server at the Center for the Health Professions. A random sample of 990 respondents was selected from three sources including the NCRA membership database, the NAACCR directory, and a list of CTRs who were not members of the NCRA. A 143-item survey was developed to collect information on a number of factors including demographics, type of worksite, primary job functions, wages, benefits, career commitment, and satisfaction.

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<sup>i</sup> Informants were not regarded as representing the official viewpoint of their agency, organization, or institution.

A letter introducing the survey, signed by the Chair of the NCRA Recruitment and Retention Task Force, was e-mailed to the sample, along with a live link to the online survey. Following a somewhat disappointing initial response rate of 38%, reminder e-mails and phone calls were made to each non-responder. This effort resulted in a final response rate of 55%. These results were adequate for the summary analyses included in this report. They were not sufficient to allow statistical comparisons between subgroups of respondents.

This report includes the following chapters. Chapter 1 includes background information on Cancer Registries and Registrars, and a review of pertinent literature and previous studies. Chapter 2 includes information on educational pathways and certification of Cancer Registrars. Chapter 3 includes a summary of the focus group process and discussion. Chapter 4 summarizes the perspectives of key informants interviewed. Chapter 5 presents data and analysis from the online survey. Chapter 6 includes a discussion of factors impacting the supply of and demand for Cancer Registrars and projections for the future workforce. Chapter 7 includes a summary of major findings and recommendations for further study, as well as strategic direction for the workforce.





1340 Braddock Place Suite 203  
Alexandria, VA 22314  
[www.ncra-usa.org](http://www.ncra-usa.org)