



Public Health Surveillance and Research: Evolution of the Cancer Registry Dataset



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Background: Cancer registries have a long-standing history in data collection and contain a wealth of information that is not used to its full potential. Cancer registry data needs to be more visible and more readily available for use to increase cancer registries' importance, use and role in public health and research. Cancer registries have a minimum core dataset that started with 25 required data elements and now consists of more than 200 required data elements.

Methods: A literature review and review of cancer registry requirements were conducted to analyze and show the evolution of the cancer registry dataset over time. We searched Ovid Medline, Pub Med and Compendex with the Medical Subject headings public health, cancer registry, clinical dataset, standards and we included Cancer program manuals, standards, and coding systems.

Results and Conclusions: The cancer registry dataset as is now does not meet requestors' needs; data are not available in the time needed to conduct studies and may not include what the requestor needs. In addition, cancer registry data may not be easily accessed. As a result, cancer registry data is not used to its full potential. This is a lost opportunity since most cancer registries by now have more than 10 years of quality data available that could better serve public health and significantly contribute to current research.

CANCER REGISTRY DATASET

TIMELINE

SEER Extent of Disease 1993

ACoS - CoC Cancer Registry Manual 1974
SEER Summary Staging 1977
ACoS - CoC Data Acquisition Manual 1986

1976 ICD-O
1989 CD-O-1 trial ed.

ACoS - CoC ROADS Volume I 1996
SEER Extent of Disease 1998
ACoS - CoC ROADS Volume II 1998

1992 ICD-O-2
2001 ICD-O-3

ACoS - CoC FORDS 2003

SEER Summary Staging 2001

ACoS - CoC FORDS Rev. 2004

Collaborative Staging 2004

Collaborative Staging 2007

Collaborative Staging 2005

Collaborative Staging 2010

2007 CD-O-3 including multiple primaries

Purpose: To identify the development of cancer registry datasets over time from 1985 to 2010 and assess quality and utility of data elements.

Discussion: Even though the cancer registry dataset has evolved to more than 200 required data fields, , soft data requestors seek elements or a level of detail not collected. Do we need that many data elements to fulfill the requirements for public health, surveillance and research? Furthermore, are registries collecting the data elements needed to conduct effective public health surveillance and research?

MCR-ARC barriers to fulfilling requests for registry data include:

- Information not available
- Information not collected
- Information not complete
- Information not timely

Standard setters: WHO, ACS, AJCC, CoC, SEER, NPCR, NAACCR

Recommendations:

- Evaluate the relevance, completeness and quality of current data elements;
- Identify elements that may need to be collected for surveillance and research;
- Develop a smaller, relevant required list of elements; and
- Identify mechanisms to enable increased research capabilities through standardized best practice for cancer registries.