

The National Association of Health Data Organizations (NAHDO) and the North American Association of Central Cancer Registries (NAACCR) share concerns regarding the collection of uniform standard patient demographic data.

Public health agencies maintain a rich source of health care data and have considerable experience in data management. However, our major public health data sets collect patient fields in a slightly different format that may vary across states and jurisdictions. Variation in collection practices have resulted in a fragmented patchwork of data bases. We must continue to find innovative solutions to these barriers to promote the integration of clinical and administrative data which have the potential to support robust measurement and surveillance.

Public health data bases will benefit from harmonization/standardization of the patient fields that are captured. When data elements are in different formats (or are lacking), linkages of two data sets are less accurate and more difficult to complete.

- Harmonization of patient fields across data bases and data systems will improve the quality and validity of data linkage and reduce provider reporting burden
- Collecting patient demographic fields in a standardized format across data systems will improve linkages across data bases.
- Working together, public health entities can implement national standards to meet public health practice needs.

Public Health/Health Care Data agencies should collect data using endorsed national standards in an effort to promote uniformity in how patient fields are captured and stored across data sets.

Health care data agencies and cancer registries should review their data collection policies in light of the use cases for data linkage across data sources, sites of care, and over time. A common definition or definitions of Personal Health Information (PHI) needs to be articulated.

Public Health data systems must be safe and secure while being available for use to protect and promote the health of the populations they serve.

Working together NAHDO and NAACCR members should explore/endorse national standards and engage with other public health data systems to continue to promote the standard collection of data to enable further downstream analysis.



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