The Role of the Certified Tumor Registrar in Cancer Data Abstraction
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1 BACKGROUND

Collecting cancer data to study the causes and impact of malignant diseases can be traced back to the origins of epidemiology. Cancer data abstracting has been a valued profession since the early twentieth century gaining further recognition and standing through the efforts of American College of Surgeon’s (ACoS) Commission on Cancer (CoC) to include it as a required part of all accredited program’s responsibilities. The process for abstracting cancer data remained essentially unchanged in modern times until the introduction of relational computer databases. With their routine use in the Cancer Registry, the functional department responsible for data abstraction, the power of collected data increased exponentially. The Certified Tumor Registrar (CTR) is the designated professional who has earned certification through the National Cancer Registrars Association (NCRA) and is responsible for abstracting patient information into the database and transmitting it to the CoC’s National Cancer Database (NCDB), the States’ Central Registries, the CDC’s National Program of Cancer Registries, and/or The National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Program. In the 21st century the role of the CTR has become more complex by adding the challenge of finding patient information from multiple paper sources and various electronic health records (EHRs) where it is stored. With that accomplished, the modern CTR provides conceptual analysis and then concisely transfers the required information from various sources into the highly controlled fields in the cancer abstract to provide a data-driven narrative of patient’s cancer story.

As in most professions, technology has simplified some tasks and added layers to others. In response, Cancer Registries and CTRs have adopted continuous process improvements building on a historical reputation for accuracy and quality. The National Cancer Registrars Association (NCRA) has established continuing education requirements that underpin the CTRs continuing certification.

Recently a shift in the relationship of the profession to technology has occurred. This has been precipitated by an emerging capability of EHR software. EHR vendors can now offer the possibility to map from the EHR’s data fields to the cancer abstract’s data fields in a simulation of the Cancer Registrar’s abstraction process. The challenge in front of facility administrators is to maximize care and minimize cost. The operational motivation for chief executives in considering these vendor products is to conserve resources in the highly competitive and rapidly changing medical oncology service line.
The critical question that must be analyzed before a decision can be made on a financial modeling basis only is whether the new technology offers an elegant and robust alternative to the proven value a CTR brings to the abstraction process.

2 THE VALUE OF ABSTRACTION THROUGH HUMAN INTELLIGENCE

A quality abstract fundamentally relies on the dual principles of fidelity and predictability. Neither of these principles takes priority and in fact must be in balance for the abstract to have value and yield quality data.

- **Fidelity**

Fidelity can broadly be defined as the degree to which the abstract resembles the actual patient history. Since the abstracts are used to gather data on cancer diagnosis methods, staging, treatment patterns, recurrence, survival, mortality, along with other more refined outcomes queries-- absolute fidelity is the goal. The derived data are then used by researchers to establish treatment guidelines across oncological specialties.

During the abstraction process the abstractor makes hundreds of decisions based on subject knowledge, type of source material, ability to extract information based on the organization of the materials, while functioning under the guidance of the abstraction process rules established by national standard setters.

To enable a high degree of fidelity, it is necessary that the abstractor have subject knowledge in all facets of oncology. CTRs receive primary and continuing oncology education to accurately describe the statements and concepts represented in the patient’s medical record.

In determining the usefulness of information, a cancer registrar relies on a hierarchy of source documents to establish which information may be used in preference over any other. This is balanced by a thorough understanding of where to locate details to enable completion of the abstracts required fields. This comes from a deep understanding of how information is organized within a patient’s medical record which may have input from a team of clinicians at various sites.

- **Predictability**

Quantified predictability is the equivalent of accuracy. Without argument it can be stated that an abstract must be near 100% accuracy for the data realized from it to have integrity. The cancer data abstraction process, when data is entered by a CTR, is highly controlled as to content through the use of a data dictionary, success criterion with field-level edits, completion reports, real-time clinical quality assessments and practice program benchmark reports. The CTR must adhere to the standards set by national bodies for completion of the abstract. Attention to these standards builds-in the ability to compare elements within the abstract and also elements between abstracts.
For predictability to be achieved in abstracting, the abstractor must have the ability to work equally well with both structured and natural language while moving back and forth between the patient’s medical record and the developing work product of the abstract itself. The core to creating an accurate abstract is in understanding and managing the dynamic of this translation process in relationship to the tools provided by the national standard setters. The current generation of software that is being offered by EHR vendors to aid in the abstraction process cannot equally and simultaneously interpret both types of language. This is a core skill leading to predictability. A software vendor offering a product it self-describes as “disruptive” may logically be asked to demonstrate both predictability and fidelity if and when it enters into cancer abstracting.

3 Conclusion

The potential to use a software product to transfer some data elements from an EHR to a cancer abstract holds promise for resource savings, in particular those expended by a CTR on the abstraction process. Meaningful Use Standards will position the EHR strongly to accomplish this. Mapping of elements from the patient’s medical record to the abstract has been accomplished from demographic fields without loss of fidelity or predictability. Some vendors have proposed that the entire abstract can be completed via mapping enhanced with other programming refinements. The time may come when it is possible, but the current technology cannot execute at a level necessary to achieve fidelity or predictability. As discussed above, the necessary cognitive skills cannot simply be duplicated through current technology.

As further evidence, in 2016 the Standard Setters once again confirmed the importance of directly coded TNM staging done by CTRs over staging derived via an algorithm. The TNM staging results in assigning the overall stage of cancer disease (I-IV) which researchers, for example, may use as a descriptor in defining the parameters of the files they request and use in an investigation. TNM staging is a skill requiring the highest level of information synthesis. The use of an algorithm increased the number of fields required within the abstract and became burdensome for the abstractor to complete and the data warehouses to manage. CTRs are educated and proficient at assigning TNM.

The CoC, in particular, recognizes the many levels of skills a CTR imprints on the abstract. The CoC requires abstracts be completed by a CTR then transmitted for final warehousing where the information collected is ultimately used by researchers.

Beyond the inability for the current technology to offer a solution to the abstracting process, little is known about its Recall Rate benchmarks. Recall Rate is the fraction of the cases that are relevant to the query which are successfully retrieved. The recall rate directly impacts the researcher who is the end user of the data. On the research side, there remains much work to be done to assess how the data “in” impacts the data “out” when accomplished through developing technology.
On both sides of the cancer data optimization, abstracting and research use, there is much to lose by putting in place a process relying on developing an unproven technology. Where there may be room for discussion on when new or disruptive technology can be deployed to save resources using a business model, the stakes in cancer research are much too high to put in place an unproven technology. Going forward efforts should be made by NCRA along with Standard Setters on behalf of professional CTRs to establish metrics that must be reached before endorsing abstracting technology that originates with the EHR and which offers little input from the subject expert CTR.