Meaningful Value Added by Standardized, Internationally Validated, and Evidence-Based Pathology Data Sets for Cancer Reporting of Head and Neck Sites Coordinated by the International Collaboration on Cancer Reporting

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"**Y**ou have cancer."

With the utterance of these words, the patient's life is forever changed. It usually has an emotionally charged and devastating effect on the patient's mindset and launches a cascade of additional tests, discussions, options, alternatives, treatments, side effects, complications, and cure, stabilization, or progression to an unavoidable known final disposition—of course, dependent on the tumor type, the tumor grade, the tumor stage, the margin status, and a whole host of similar details that medical practitioners use to provide more meaningful prognostication than the usual lay person realizes is part of his/her management.

It is the pathology report that sets in motion the cancer patient's treatment journey, providing the initial diagnosis, staging, and essential predictive and prognostic information required for accurate and quality management. Any one pathology cancer report may contain more than 50 unique and significant data elements. How this information is conveyed and, more importantly, understood by the treating physicians is of the utmost importance to inform patient care. When rendered by using universally standardized nomenclature, computer-readable information, and accurate and essential prognostic and predictive data metrics, the pathology report represents a rich data source for not only individual personalized patient care, but also system-wide monitoring of cancer control and quality management and research in cancer and tumor diagnostics.

The International Collaboration on Cancer Reporting (ICCR) was established in 2011 through a collaboration between the College of American Pathologists (CAP), the Canadian Association of Pathologists–Association Canadi-enne des Pathologistes (CAP-ACP) in association with the Canadian Partnership Against Cancer (CPAC), the Royal Colleges of Pathologists of Australasia and the United Kingdom, joined in 2013 by the European Society of Pathologists, and followed by the American Society of Clinical Pathology (ASCP) and the Royal College of Physicians of Ireland, Faculty of Pathology as sustaining members. Importantly, the founding member organizations cover a population of more than 1 billion people. The ICCR aims to develop globally standardized, internationally agreed-upon, evidence-based reporting data sets for pathology reporting of cancers and tumors of various organ systems by harnessing international experience and expertise. It is through global standardization of pathology information on tumor classification, staging, prognostic and predictive information that best practices in patient care can be developed, the natural prerequisite for epidemiologic research and benchmarking in cancer monitoring and management both nationally and internationally. These synoptic, structured, and checklist-styled reports provide information that is complete, clear, concise, consistent, and that conforms to accepted standards. Importantly, structured data elements allow for a more meaningful encoding of the data so that it can be used in data aggregation across populations and by people using different platforms. Thereby, data processing can be automated, linked, and analyzed more quickly and accurately to provide significant and actionable reports from very complex databases.

The ICCR is affiliated with the World Health Organization/International Agency for Research on Cancer (WHO/IARC), where the nomenclature agreed upon in the WHO Tumour Classification book series is included in data set development by recognized pathology and epidemiology experts, produced in synchrony with new editions' publication schedules. Further, working together with SNOMED CT International, ICCR data sets are being linked to internationally standardized terminology to enable computer readability and in conjunction with the ASCP, ICCR data sets are being translated to International Organization for Standardization (ISO) standard in Spanish, French, and Portuguese.

ICCR data sets are freely available for use royalty-free worldwide and, by adopting the ICCR standards at the core of their own data sets, all participating institutions will help

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to shift alignment and normalization of pathology cancer data worldwide. In the rapidly developing field of targeted therapies, tumor biomarkers, and personalized medicine, the development and maintenance of more than 85 different, evidence-based cancer reporting data sets represents a significant burden that is better shared within the broader international pathology community.

Specifically, for the head and neck organs data set suite covering all of the head and neck anatomic region, the members of the data set authoring committees were drawn from the additional sponsoring organizations: North American Society of Head and Neck Pathology; American Academy of Oral and Maxillofacial Pathology; the British Society for Oral and Maxillofacial Pathology; and the International Association of Oral and Maxillofacial Pathologists. More than 90 authors, representing nearly all of the major geographic regions of the globe, were participants in creating these data sets. The world's leading and best domain experts were intimately involved in the development process, providing for a single, authoritative, and evidence-based overview of reporting elements that can be used globally, including in countries that may lack the resources for local development, thereby reducing unnecessary duplication efforts. With these standardized reporting data sets, software development can be more easily performed to achieve terminology binding and electronic implementation and comparison.

Head and neck organ neoplasms are uncommon, frequently misinterpreted, and often lacking in meaningful data aggregation owing to the rare nature of the tumors. The head and neck data set is 1 domain of more than 85 individual cancer data sets that have been or are being developed by the ICCR. The most common cancers worldwide, accounting for about 90% of all reported cancers, will be covered by these data sets at the time of completion. With implementation of these reporting data sets, it is hoped that using a single international reporting standard will (1) enable global interoperability and flow of core cancer data; (2) allow for collaboration; (3) provide a single authoritative and evidence-based overview for worldwide education; (4) assure key pathologic data are conveyed to clinicians, cancer registries, and other end users of the data without any ambiguity; (5) result in improved cancer data assessment globally, while still providing insights into locoregional geographic differences; and (6) harmonize the information to be used as a benchmark and ladder for diagnostic advancement and meaningful progress in cancer diagnosis and treatment. Importantly, while this is the first edition of the head and neck reporting data sets, the goal is to revise the existing data sets on a planned cycle to coincide with new WHO Tumour Classification books and updates to the staging manuals. The authors endorse use of these data sets as meaningful tools to ultimately achieve better tumor diagnosis, management, and outcomes.

A total of 9 articles covering the head and neck reporting data sets will be published in 2 parts: 5 included in Part I of this special section, with the remaining 4 in Part II, covered in the next issue.

Lester D. R. Thompson, MD

Lester D. R. Thompson, MD, graduated from Loma Linda University School of Medicine (Loma Linda, California) and completed anatomic and clinical pathology residencies at University of California, Los Angeles, with additional training in cytopathology. As a member of the United States Navy (CAPT, MC, USNR, retired), he worked for a decade at the Armed Forces Institute of Pathology (Washington, District of Columbia), serving as the chief of the Otorhinolaryngic-Head and Neck Pathology Division, chief of the Immunohistochemistry Division, and as assistant chairman of the Scientific Laboratories. He continued as a consultant and research pathologist in the ensuing years with the Southern California Permanente Medical Group in Woodland Hills, California, which provides health care to more than 4 million patients. With more than 25 years of experience in head and neck and endocrine organ pathology, he thoroughly enjoys research (more than 265 papers), particularly focused on "orphan" tumor types; serves on the editorial boards of many peer-reviewed scientific journals; teaches at national and international conferences; serves as an active member of a number of national and international societies (including past president of the North American Society of Head and Neck Pathology); is an active member of the College of American Pathologists Protocol Committee (among others); is a former member of the CheckPath program of the American Society of Clinical Pathology; and collaborated on the 2 most recent editions (2003; 2017) of the World Health Organization's (WHO) *Classification of Head and Neck Tumours* and *WHO Classification of Tumours of Endocrine Organs* and is presently serving as a standing member of the WHO Blue Books Editorial Board. He is the coeditor of the *Head and Neck Pathology* journal, a publication devoted exclusively to topics in head and neck pathology. He has published 8 books in the fields of head and neck and endocrine organ pathology. He has a keen interest in standardized terminology and structured reporting, especially as head and neck and endocrine organ tumors are much less common, with a relatively low prevalence and incidence, making these anatomic sites uniquely positioned to benefit from this type of aggregated data collection and reporting. Additional interests include travel, cooking, weightlifting, and stained-glass creation.