National database of urological malignancies: The vision and road ahead

“Data is the new oil. It’s valuable but, if unrefined, it cannot really be used.” This quote by Clive Humby (2006) illustrates both the importance of data collection and the necessity of processing such data to yield meaningful and actionable inferences. Although randomized trials occupy the highest level of evidence in science, prospective cohort studies that can determine the natural history of disease have unparalleled importance in medicine. Cancer, with its finite lifecycle, allows stringent documentation which in turn enables the identification of subtle differences in outcomes that may be influenced by patient, disease, and treatment factors. Such data, if shared and collaborated between many centers, increases the robustness of inferences which can be drawn and the recommendations which can be made.

The Surveillance, Epidemiology, and End Results Program database is one such example that collects cancer data from cancer registries and covers 34.6% of the United States (US) population. The Cancer Moonshot initiative in the US was started in 2016 and one of the key goals was to improve cancer data capture and sharing across institutes and enhance collaboration. In the United Kingdom (UK), the National Cancer Registration and Analysis Service (NCRAS) captures cancer data. It collects data from the National Health Service where most of the UK population (>98%) is registered. The strength of the NCRAS database is the national coverage with quality data, standardized disease coding, data completeness, and de-duplication of data across registries. However, it has limited data on cancer recurrence, progression, quality of life, and other lifestyle factors.

While there is no lack of technical expertise and resource availability in India, we do not have robust data-keeping or collaborative efforts in maintaining a national database. The National Cancer Registry Program–National Centre for Disease Informatics and Research of Indian Council of Medical Research collects Indian cancer data from various population or hospital-based cancer registries since 1985. However, the population-based cancer registries in India have a poor coverage, lack of follow-up data and no data exchange between the registries, limiting their use in generating for population inferences. The Government of India started the National Digital Health Mission recently, acknowledging the need for a digital health database. The National Database of Urological Malignancies (NDUM) is a realization of the goal to have a collaborative database of selected urological cancers, populated by data from multiple centers across India.

THE INITIAL STEPS

In 2016, the Urological Society of India initiated a consultative process to determine the structure, management, and operating procedures for a pan-India database of urological cancers. These consultations focused on identifying the important cancers, aspects of disease that could be uniformly captured at institutions of varying expertise, methods of securing data, and of providing academic credit to individuals who contribute to this exercise. This was followed by drafting of data sheets, creation of standard operating procedures (SOPs), and securing ethics approvals from the institutional review boards of the participating institutions. Each of these steps required multiple attempts, meetings, and modifications before the creation of a dedicated website for data recording (www.usi-ndum.org). NDUM is currently designed to capture the basic demographic and standard disease parameters. However, it could be the starting point for collaboration and is an evolutionary process that allows more complex disease data capture in the future.

OPERATIONAL DETAILS

NDUM at present has databases for five urological cancers (Prostate, Bladder, Kidney, Testis, and Penile cancer). Five institutions have been identified as nodal centers, each with a designated nodal coordinator, to monitor data for each of these cancers. Any urologist in the country can register to feed data. The structure and SOPs (https://usi-ndum.org) aims to address common concerns about such databases such as homogenization to allow search functions, validation of data, anonymization, security with logging all access, and most importantly, a well-defined algorithm for allowing academic credit to the contributors.

THE JOURNEY SO FAR

In the last 1 year, the data of 329 urological cancer patients have been collected. While it is still too soon to analyze the data, a few interesting findings were that urine cytology is obtained in only about 15% of patients with bladder
cancer and 20% of bladder cancers were diagnosed at an advanced stage. Prostate cancer was suspected on digital rectal examination in 58% of cases while prostate-specific antigen screening-based detection alone occurred in only 6%. About 46% of kidney tumors presented with a mass and hematuria and was not detected on screening. Up to 30% of patients with penile cancer had unilateral or bilateral palpable groin nodes, showing pick up of disease at an advanced stage. While these data may be skewed because of the small numbers, they are an important pointer of what the real-life data in the country may be and would profoundly affect our detection and treatment focus.

**CHALLENGES**

There are many challenges for a multi-institutional collaborative database. In India, health record keeping is still either on paper or on a hybrid system having both paper and electronic databases.[8] The data from various centers need to be of a standard quality and at an interoperable interface. The routinely collected data in a hospital is not meant for research and may be incomplete, heterogeneous or very large.[8] In India, access to healthcare is variable, leading to a fragmented data. Urological cancer care is provided by general surgeons and oncologists apart from urologists. NDUM will clearly not be able to provide a complete picture at the moment.

One of the important aspects of a database is its privacy and security which is regulated by the Health Insurance Portability and Accountability Act in the US.[9] In India, the Information Technology Act 2000 and the personal protection bill 2019 govern this aspect.[10]

While many of these may be overcome in a prospective database, one of the most important aspects is the need to generate faith and trust among the contributors. Why should busy clinicians spend time and effort to populate the database? If data is oil, why should they give theirs away? Why should they not publish their own papers and get the accompanying glory? And, finally, what if their results are poorer than their contemporaries and this gets disclosed? Addressing these concerns may be the bedrock of success and the SOPs of NDUM aim to mitigate this fear. This, the first publication from the database, showcases some of the safeguards that have been put in place. It gives credit to all who contributed but also places a responsibility on them for their authorship.

**THE FUTURE**

Considering the volume of patients treated in India, we sit on a goldmine of data. Generating interest and faith in NDUM will be the most important task before the USI. While providing logistic support will be useful, the most important hurdle is of intent rather than ability. NDUM is the first of its kind collaborative database in urology in India. Data accrued in NDUM shall enable Indian urologists to frame India specific treatment guidelines, benefit our patients, and our members. The future goals of NDUM include expanding its scope in terms of diseases and contributors, generating testable hypotheses regarding disease causation in India, and helping devise novel diagnostic and treatment strategies applicable to our population. NDUM will also act as a surgical audit providing benchmarks that practitioners may aim to achieve.

The launch of NDUM is clearly a progressive step toward bridging a gap which we all know exists. Prioritizing the progress of NDUM would certainly translate into better patient care and in making our global presence even more prominent.

Girdhar S. Bora, Gautam Ram Choudhary¹, Vijay Kumar Sarma Madduri¹, Brusabhanu Nayak², Uday Pratap Singh³, Gagan Prakash⁴, Rajeev Kumar⁵*

Department of Urology, PGIMER, Chandigarh, ¹Department of Urology, All India Institute of Medical Sciences, Jodhpur, Rajasthan, ²Department of Urology, All India Institute of Medical Sciences, New Delhi, ³Department of Urology and Renal Transplantation, SGPGIMS, Lucknow, Uttar Pradesh, ⁴Department of Surgical Oncology, Tata Memorial Centre, Homi Bhabha National Institute, Mumbai, Maharashtra, India
⁵E-mail: rajeev.urology@aiims.edu

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