Editorial

# Clinical registries in upper tract urothelial carcinoma: commitment to collaboration

**Jiping Zeng, Juan Chipollini^**

Department of Urology, University of Arizona College of Medicine, Tucson, AZ, USA

*Correspondence to:* Juan Chipollini, MD, FACS. Department of Urology, The University of Arizona, 1501 N. Campbell Ave., Tucson, AZ 85724, USA. Email: jchipollini@arizona.edu.

*Comment on:* Kealey J, Snider R, Hayne D, *et al.* The utility of clinical registries for guiding clinical practice in upper tract urothelial cancer: a narrative review. Transl Androl Urol 2023;12:497-507.

**Keywords:** Registry; commentary; Upper Tract Urothelial Carcinoma

Submitted Apr 15, 2023. Accepted for publication May 30, 2023. Published online Jun 19, 2023.
doi: 10.21037/tau-23-232
**View this article at:** https://dx.doi.org/10.21037/tau-23-232

In this article, Kealey *et al.* conducted a narrative review of clinical registries in upper tract urothelial carcinoma (UTUC) (1). Their analysis highlighted a rise in UTUC-specific registries over the past five years, resulting in more detailed and comprehensive data analyses. These registries are the result of collaborative efforts within the urologic oncology community to bolster research efforts in rare diseases such as UTUC. This comprehensive narrative review succinctly discusses strengths, limitations, and future directions of registries in UTUC.

Clinical registries are databases that collect and store standardized data on patients with specific medical conditions. These registries are designed to provide a comprehensive and ongoing view of patient outcomes and can be used to improve clinical care, facilitate research, and inform policy decisions. UTUC is a relatively rare disease, accounting for only about 5% to 10% of all urothelial cancers (2). This means that there are fewer patients available for clinical studies making it difficult to conduct large-scale trials.

Clinical registries will play an important role in advancing our understanding of UTUC by providing a comprehensive view of the disease and its management. They will help identify gaps in knowledge and areas for further research, ultimately leading to standardization of care and improve patient outcomes. For example, international registry collaboration such as the Global Society of Rare Genitourinary Tumors (GSRGT) (3) allow for discussion about treatment controversies while increasing clinical research in rare genitourinary malignancies.

When interpreting research from clinical registries, it should be noted that registries have several limitations. First, there is an inherent selection bias. Patients included in registries may not be representative of the general UTUC population. This will limit the generalizability of the study findings. Second, it is not uncommon to have missing data on certain variables in these registries. This may result in suboptimal analyses. Third, registries may not have standardization of how data are collected across different sites. This could make it less consistent and challenging to interpret data.

Nevertheless, clinical registries have gained recognition and yielded promising research indicating they will continue to play a crucial role in enhancing our comprehension of rare diseases (4). By promoting international collaboration, registry data will become more representative and assist in developing appropriate management for patients worldwide. We strongly advocate for further International cooperation to help homogenize data and treatment across different parts of the world with goals of improving care for patients with rare tumors such as UTUC.

^ ORCID: 0000-0003-2603-0382.

 

## Acknowledgments

*Funding:* None.

## Footnote

*Provenance and Peer Review:* This article was commissioned by the editorial office, *Translational Andrology and Urology*. The article did not undergo external peer review.

*Conflicts of Interest:* Both authors have completed the ICMJE uniform disclosure form (available at https://tau.amegroups.com/article/view/10.21037/tau-23-232/coif). The authors have no conflicts of interest to declare.

*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.



**Cite this article as:** Zeng J, Chipollini J. Clinical registries in upper tract urothelial carcinoma: commitment to collaboration. Transl Androl Urol 2023;12(7):1043-1044. doi: 10.21037/tau-23-232

## References

1. Kealey J, Snider R, Hayne D, et al. The utility of clinical registries for guiding clinical practice in upper tract urothelial cancer: a narrative review. Transl Androl Urol 2023;12:497-507.
2. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2012. CA Cancer J Clin 2012;62:10-29.
3. Necchi A, Pederzoli F, Bandini M, et al. Revolutionizing care for rare genitourinary tumours. Nat Rev Urol 2021;18:69-70.
4. Lwin AA, Hsu CH, Chipollini J. Urothelial Carcinoma of the Renal Pelvis and Ureter: Does Location Make a Difference? Clin Genitourin Cancer 2020;18:45-9.e1.

 