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European Association of Urology



Letter to the Editor

Re: Agustina Bessa, Steven Maclellan, Deborah Enting, et al. Consensus in Bladder Cancer Research Priorities Between Patients and Healthcare Professionals Using a Four-stage Modified Delphi Method. *Eur Urol* 2019;76:260–1

We read with great interest the recent research letter by Bessa et al. [1]. They applied a four-stage modified Delphi method to identify and prioritize bladder cancer (BC) research questions. They subsequently summarized the top 10 unanswered questions in BC research. This study highlighted a very strong link between the needs and research priorities of patients and healthcare professionals (70% concordance). However, BC still has less public awareness than other urological malignancies [1]. In 2014, Borgmann et al. [2] published an article on the activity of and content for urological oncology on Twitter; they analyzed the most representative hashtags from the urology oncology list on Symplur (Twitter web-based analytic platform focused exclusively on healthcare, <http://symplur.com>). They found that Twitter discussion on urological oncology was global; healthcare organizations were the top influencers for all urological cancers, and #prostatecancer discussion outnumbered all other cancers (mean monthly Tweet activities were 6603 for #prostatecancer, 866 for #testicularcancer, 457 for #bladdercancer, and 401 for #kidneycancer). Leveridge [3] confirmed this trend in his literature review of resources and publications on BC and social media (SoMe), showing that overall #bladdercancer Tweets had the lowest-volume activity among all urological cancers [3]. SoMe has become an established communication tool in our society and has widespread outreach with increasingly broad discussion between physicians, patients, researchers, healthcare professionals, associations, and support groups on a multitude of aspects. In this context, a member of our working group (Jeremy Y.C. Teoh @jteoh_hk) created, in December 2018, a Twitter #UroSoMe community by inviting and encouraging people to use a common hashtag for a broad urological discussion [4]. Later, we were asked to start a Twitter discussion on BC to draw more attention toward BC and to analyze what are the major concerns of BC.

The first #UroSoMe #LiveJournalClub was conducted on February 17, 2019 [5], and the topic was Bessa et al.'s [1] research letter. Five sets of questions were posted in a sequential manner:

1. What is the methodology for reaching a consensus? How are patients and healthcare professionals recruited? Do you think they are representative of this consensus? (https://twitter.com/jteoh_hk/status/1097148700424515586)
2. What are the top 10 unanswered research questions for bladder cancer? Do you agree that these questions are important? (https://twitter.com/jteoh_hk/status/1097153513090572288)
3. Are there any other questions that you think are important but not mentioned in the consensus? (https://twitter.com/jteoh_hk/status/1097158526177136640)
4. What are the implications of the consensus meeting? Do you think bladder cancer deserves more attention and funding for research work? How about patient education and public awareness? (https://twitter.com/jteoh_hk/status/1097163500550381574)
5. How can we further increase attention to and awareness of bladder cancer? What should be the next step forward? (https://twitter.com/jteoh_hk/status/1097167591150215168)

On February 28, we conducted a detailed data analysis in Symplur; we performed a search in this platform for the date of February 17. We used the official hashtag that we had been using from December 2018 (#UroSoMe) as the keyword and limited the Twitter analysis to a period of 12 h. It was found that 1200 Tweets had been written during that period. These Twitter engagements by 180 users accounted for an astonishing 1.9 million impressions. Of these 180 users, 86 were physicians, nine were international organizations including the British Association of Urological Nurses, and 85 were not identified to have particular Twitter user accounts.

This activity raised awareness regarding BC and different topics were mentioned.

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Top five topics of discussion in this #LiveJournalClub were the following:

1. Bacillus Calmette–Guérin (BCG) worldwide shortage and the need for a substitute treatment
2. Exhausting cystoscopy for follow-up
3. Risk stratification for non-muscle-invasive BC
4. Need to raise more awareness and specific curricula of BC for general practitioners and family doctors
5. Funding for research and education on BC

We think that collaborative data should be shared through SoMe, especially Twitter, as it is a platform that enables broader outreach. Through Twitter, we can raise awareness, involve healthcare professionals globally, and most importantly ascertain what patients and advocacy groups think about any particular topic.

We, at #UroSoMe working group, consider the work of Bessa et al. [1] to have great value. We think that BC is one of the most expensive urological cancers to treat, thus requiring a more extensive public awareness level, and involvement of government and pharmaceutical companies to fund and promote more research toward it. We also believe that Twitter is a great platform to raise awareness, with great potential to initiate meaningful discussion with a multitude of individuals and groups.

Conflicts of interest: The authors have nothing to disclose.

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Linden-Castro, M. Pelayo-Nieto, V. Gauhar, R. Donalasio, L. Tortolero, H. Trujillo, M. Wroclawski, M. Bellote, Z. Adwin, N. Gadzhiev, K. Gudar, and A. Mesbah.

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