

Fostering Inclusive Language for Genitourinary Cancer Research: A Multi-Stakeholder Co-Creation Effort

Alex Filicevas^{1,2}, Keith Crawford^{1,3}, Jola Ignaciuk⁴, and Michelle Hull⁴

¹Patient Author; ²World Bladder Cancer Patient Coalition, Brussels, Belgium; ³Prostate Health Education Network, Quincy, MA, USA; ⁴Johnson & Johnson, Raritan, NJ, USA

Key Takeaway

Before (too complex)

Exclusion

After (plain language)

Inclusion

Conclusions

- i Co-created plain language lexicons can broaden access to GU cancer research
- i Plain language lexicons can support better communication by encouraging healthcare professionals to use language that enables informed, shared decision-making
- i Ongoing evaluation will assess how well these lexicons support understanding and continued engagement in research among people living with GU cancer

https://www.congresshub.com/Oncology/GU2026/GeneralGU/Filicevas

Please scan QR code

Copies of this presentation obtained through Quick Response (QR) Code are for personal use only and may not be reproduced without permission from ASCO® or the author of this presentation.

Contact: alex.filicevas@worldbladdercancer.org / kcrawford@prostatehealth.org

Acknowledgments

We thank the people living with GU cancer, advocates, caregivers, clinicians, and researchers who provided valuable insights toward the development of these plain language lexicons. This work was sponsored by Johnson & Johnson. Medical writing support was provided by Simon R. Stones, PhD, ISMPP CMPP™, of Amica Scientific, and funded by Johnson & Johnson.

Disclosures

Alex Filicevas: Employment: World Bladder Cancer Patient Coalition, which receives funding from Astellas, AstraZeneca, Bristol Myers Squibb, EMD Serono, Johnson & Johnson, Merck & Co., Pfizer, Roche, and Seagen; Volunteer Board Membership: All Can International (up until May 2025), which receives funding from Amgen, Bristol Myers Squibb, Johnson & Johnson, Illumina, and Roche; Keith Crawford, MD, PhD: Employment: Prostate Health Education Network; Consultancy: American Cancer Society, Novartis, Pfizer; Jola Ignaciuk and Michelle Hull: Employment: Johnson & Johnson.

Introductions

- Inclusive cancer research and care requires involving people across a range of literacy levels and life experiences¹
- Technical terminology can unintentionally limit the full participation of people with lived experience of cancer in research and care²
- Plain language lexicons provide commonly understood terms and definitions that support understanding and engagement^{3,4}
- We aimed to make genitourinary (GU) cancer research more accessible by using non-technical language that is more readily understood by the public

Methods

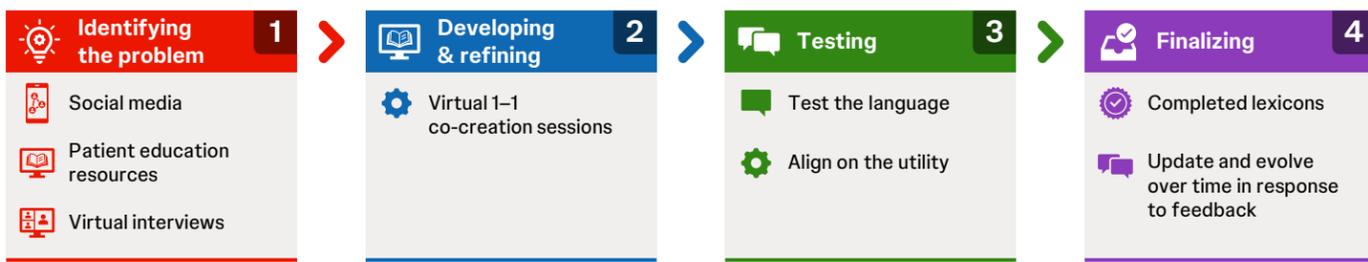
- A four-step co-creation⁵ process was undertaken with people living with GU cancer, advocates, and company stakeholders (Figure 1)

Methods (continued)

- Lexicons were developed for bladder and prostate cancer

- Johnson & Johnson facilitated the process to help make research easier to access and understand for people living with GU cancer

Figure 1: Lexicon development process



Results

- A total of 146 terms were included in the lexicons

Bladder cancer

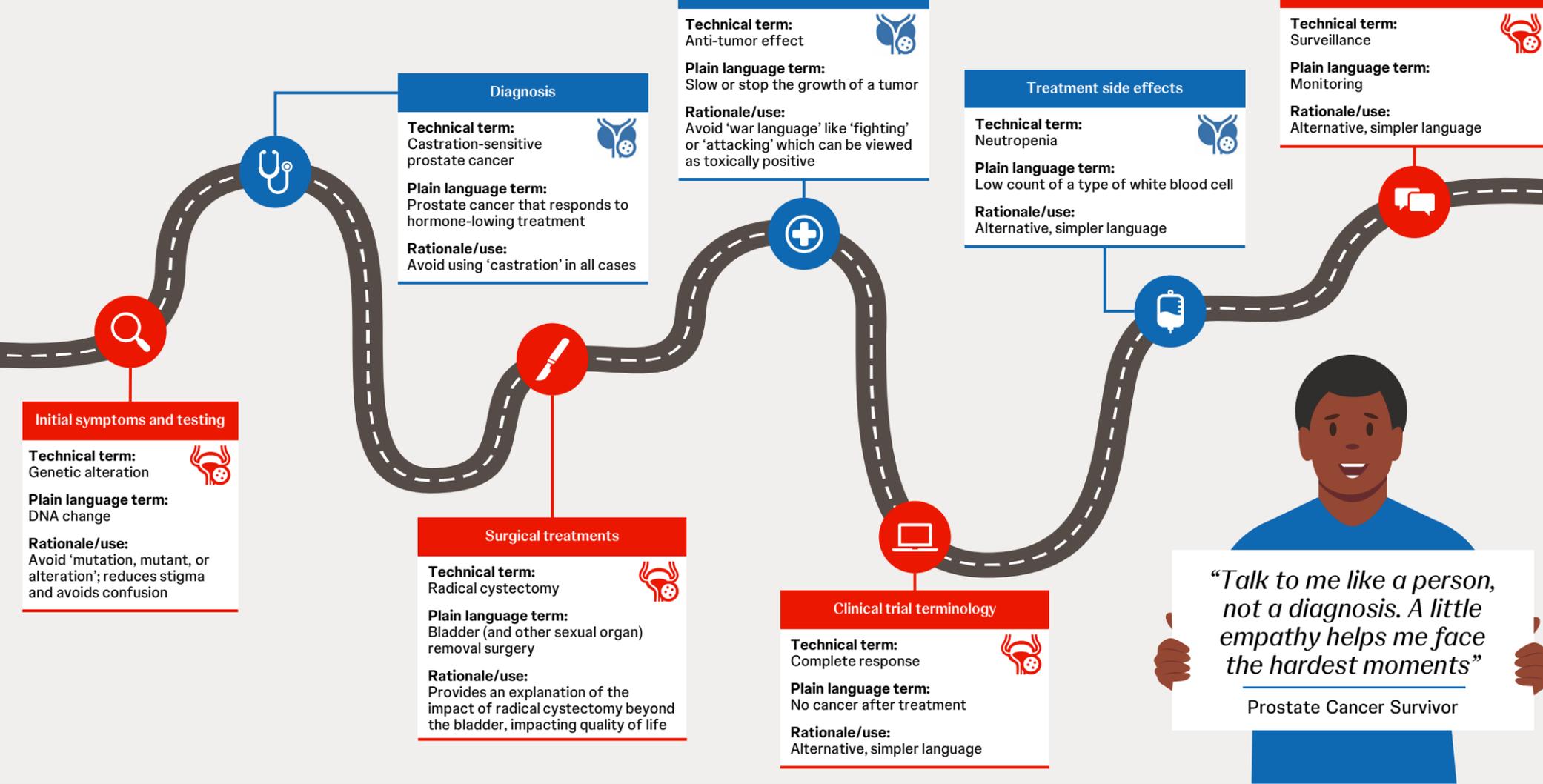
62 terms

Prostate cancer

84 terms

- The lexicons were designed to mirror the experience of living with GU cancer; example terms aligned with the journey are shown in Figure 2
- Following rollout in 2025, the lexicons have supported researchers in using terms designed to be more inclusive of lived experience perspectives and improve accessibility of research data
- The lexicons have been used by cross-functional teams on projects including advisory boards, surveys, and publications
- The lexicons also serve as a reminder of the importance of using appropriate language to promote informed shared decision-making

Figure 2: Lexicon structure and example terms from the bladder and prostate cancer lexicons



References

1. Holden CE, et al. *PLoS ONE* 2021;16(11):e029815. 2. Dews SA, et al. *Curr Med Res Opin* 2024;40(2):279-291. 3. Ježek E. The lexicon: An introduction. Oxford University Press; 2016. 4. Warde F, et al. *Can Med Educ J* 2018; 9(2):e52-e59. 5. Greenhalgh T, et al. *Milbank Q* 2016;94(2):392-429.

Urothelial Cancer

Prostate Cancer