

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

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Presented by A Filicevas at the 2026 American Society of Clinical Oncology Genitourinary Cancers Symposium (ASCO-GU); February 27, 2026; San Francisco, CA, USA



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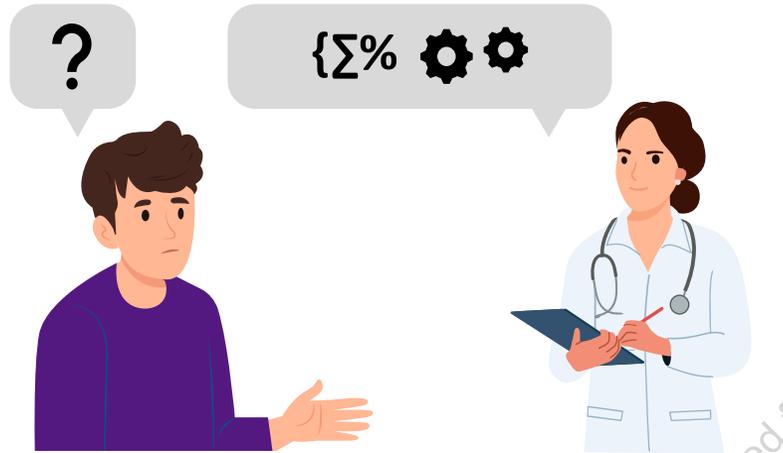


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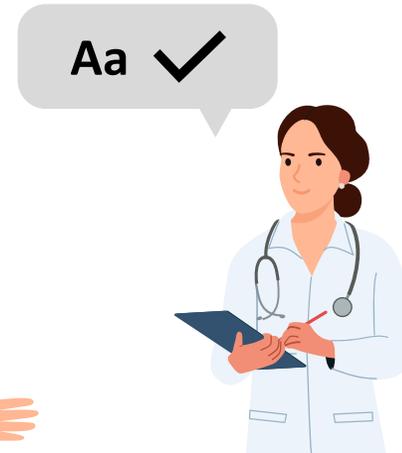
KEY TAKEAWAY

Before (*too complex*)



Exclusion

After (*plain language*)



Inclusion

GU, genitourinary.



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CONCLUSIONS

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

GU, genitourinary.



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INTRODUCTION

- Inclusive cancer research and care requires involving people across a range of **literacy levels and life experiences**¹
- 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}

OBJECTIVE

To make genitourinary (GU) cancer research more accessible by using non-technical language that is more readily understood by the public

GU, genitourinary.

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.

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Urothelial Cancer



Prostate Cancer



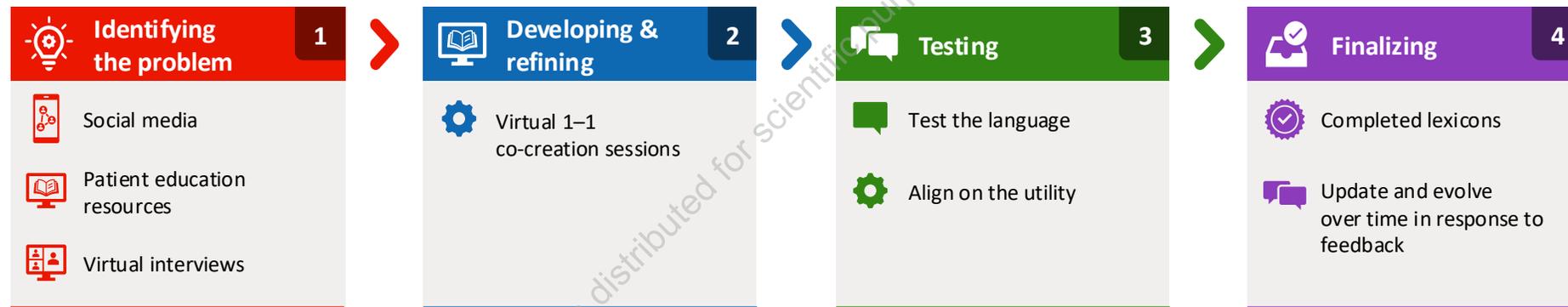
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METHODS

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



GU, genitourinary.

5. Greenhalgh T, et al. *Milbank Q* 2016;94(2):392-429.

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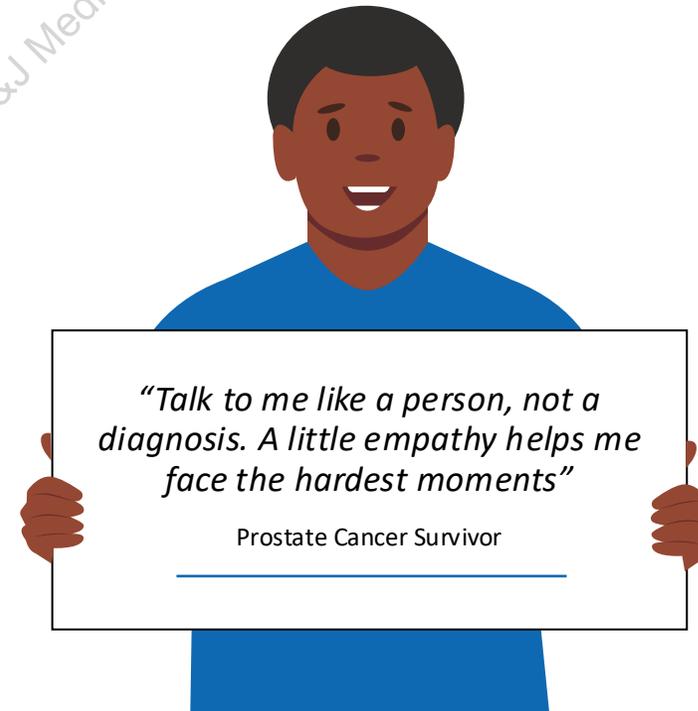
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RESULTS

- A total of **146 terms** were included in the lexicons
- 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



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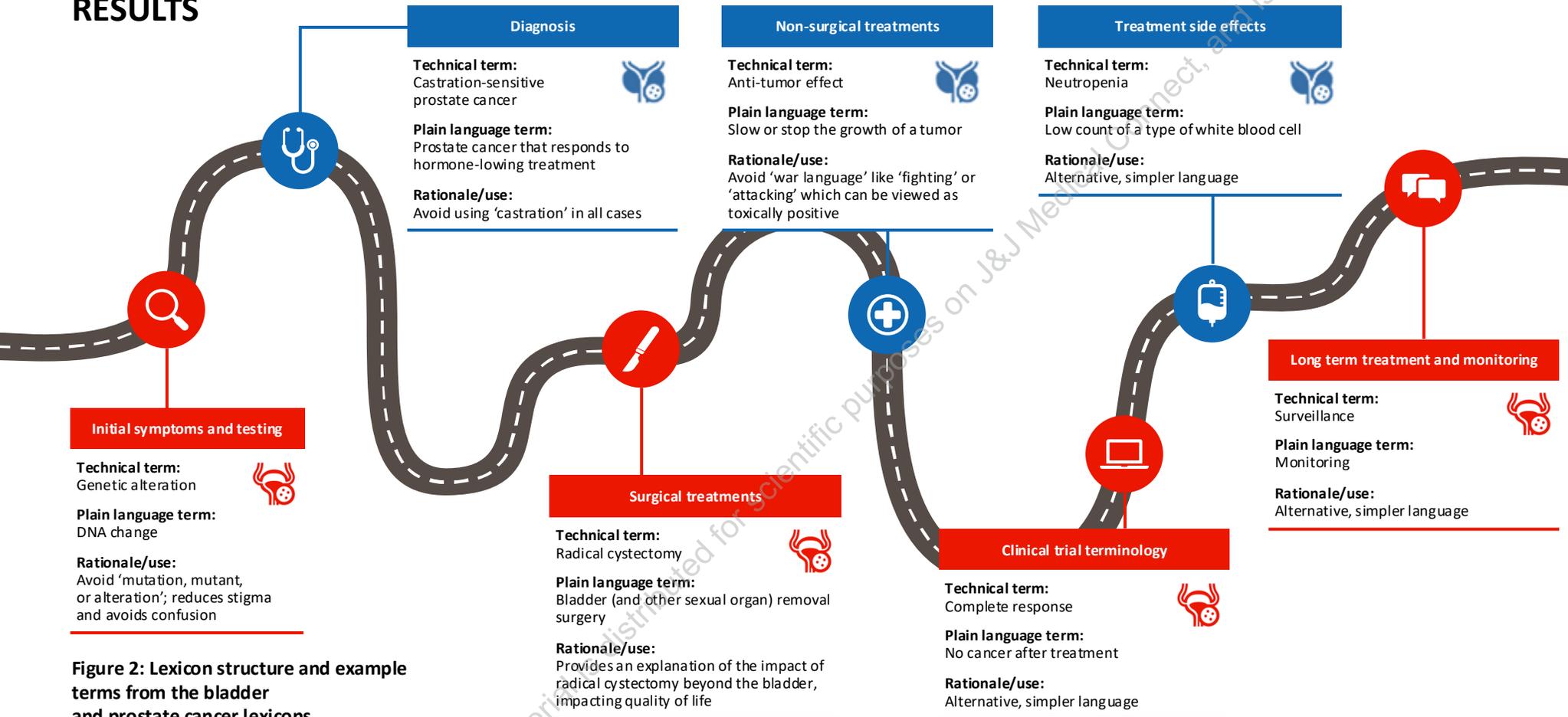


Figure 2: Lexicon structure and example terms from the bladder and prostate cancer lexicons

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5. Greenhalgh T, et al. *Milbank Q* 2016;94(2):392-429.

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.

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.

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