

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

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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

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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

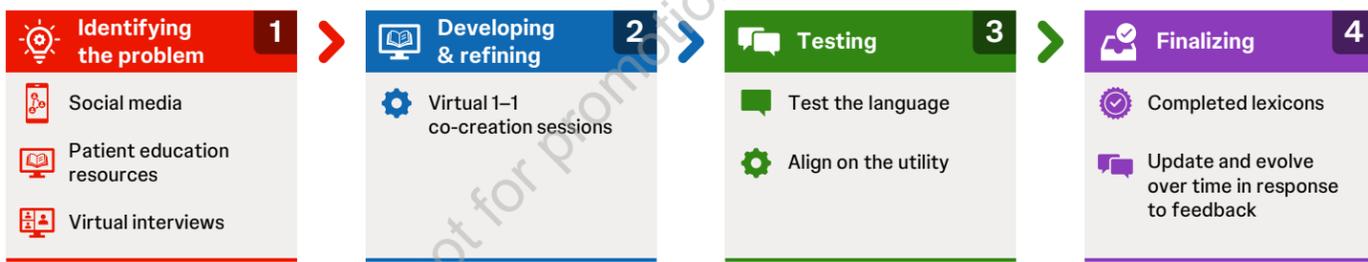
- A four-step co-creation⁵ process was undertaken with people living with GU cancer, advocates, and company stakeholders (Figure 1)

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

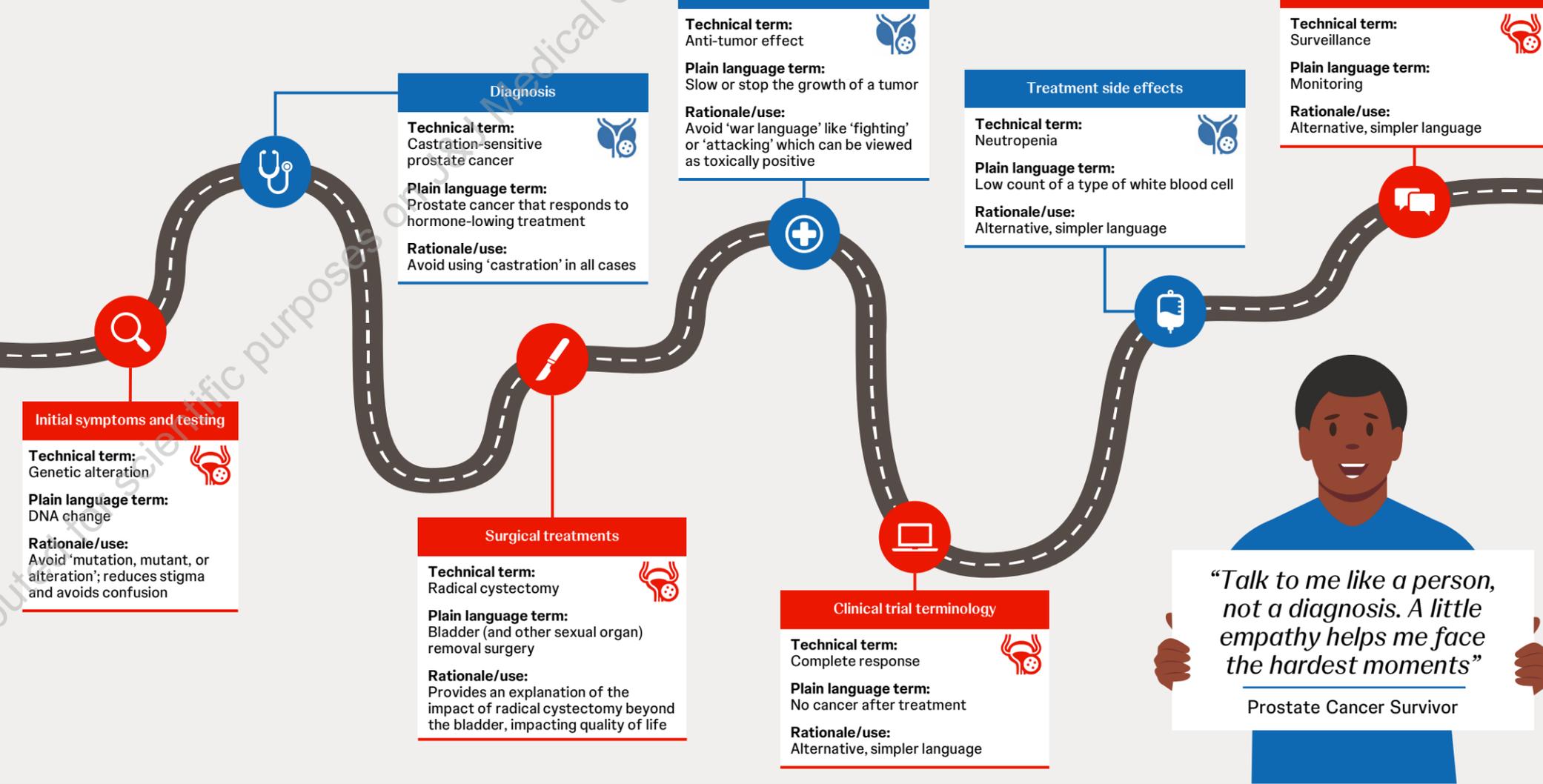
62 terms

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



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