

LGBTQ+ attitudes to sexual PROMs

Insights from LGBTQ+ cancer patients
and implementation recommendations
for healthcare professionals



OUTpatients

The UK's LGBTIQ+ Cancer Charity



We are OUTpatients, the UK's LGBTIQ+ cancer charity. We are a proudly patient-led organisation that understands what it is like to be an LGBTIQ+ person with cancer. We have made it our mission to transform cancer care into a more inclusive environment for all.

LGBTIQ+ people can face barriers to accessing care across all areas of the cancer pathway. We tackle these with a multi-layered approach, including peer support, education, policy influencing, and creating new resources for our community. Our vision is a world in which no LGBTIQ+ person with cancer has to go through it alone or receive poorer care because of who they are.

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Content notice

This report includes the discussion of sexual wellbeing and contains language and terms drawn directly from patient contributions. Such language has been retained where necessary to ensure accurate and authentic representation of patient views.

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Introduction

Patient Reported Outcome Measures (PROMs) are questionnaires that are given to patients to assess their experiences of care or their perception of their outcomes.

PROMs can provide both patients and clinicians with an example of available or appropriate language about a health condition or presentation. They can also suggest a structure for discussions around health and wellbeing that may facilitate the patient-professional rapport. This may be particularly true for PROMs that discuss sexual wellbeing and function.

However, the administration of these PROMs is not without issue. Existing psychosexual PROMs are founded upon heteronormative and cisnormative assumptions of the patient. Therefore, when a patient identifies as LGBTIQ+, their sexual function, interest, and performance may not align with the PROMs commonly used in clinical practice. This scenario was explored through patient insight sessions held by OUTpatients in late 2025. This short report summarises the learnings from these sessions.

A total of eight LGBTIQ+ cancer patients spoke with the charity about their reaction to common psychosexual PROMs. The insight group members were allocated to one of three subgroups based on their demographics, these were: cisgender men who have sex with men (cis MSM), cisgender women who have sex with women (cis WSW), and transgender and gender diverse people (TGD). Attendees were shown the following PROMs:

cis MSM	cis WSW	TGD	
●		●	Expanded Prostate Cancer Index Composite (EPIC)
●		●	International Index of Erectile Function (IIEF)
●		●	Sexual Health Inventory for Men (SHIM)
	●	●	Female Sexual Function Index (FSFI)
	●	●	6-item Female Sexual Function Index (FSFI-6)
●	●	●	EORTC Sexual Health Questionnaire (SHQ-C22)

Sessions were facilitated online by OUTpatients. Transcripts were auto-generated by Microsoft Teams software. Notes from the facilitator and the transcript were analysed for common themes which form the structure and content of this report.

Language

Clinical terms

When the language we use to describe sexual wellbeing is seen as clinical or outdated by patients (e.g. sexual intercourse), this can be seen as off-putting. Some terms like 'libido' were also thought to be vague and not universally understood by patients. When these terms and phrasings were present in psychosexual PROMs, the insight group showed a dislike or disinterest towards completing the PROM. This issue happened whether these terms were in the PROM or its title. They also showed a broader scepticism to the concept of sexual wellbeing being measured.

"Outdated language makes me feel embarrassed [...] you're not getting what you need from me." - cis MSM participant

Similarly, words like 'satisfy' and 'ability' were thought to be too performance-oriented and lacked emotional and relational importance. Our insight group also felt that the PROMs failed to measure positive aspects, such as enjoyment related to sex and intimacy.

**"For me, satisfaction is that both partners have fun. Does it matter whether or not you both were able to orgasm?"
- cis MSM participant**

Our insight group felt that describing their sexual activity was much more natural to them than trying to use clinical labels. They recommended that the PROMs should try to include more modern language, or that the clinical staff should help the patients to understand the clinical terms in a supportive way. In particular, it was recommended that language choices should focus on sexual and gender diversity, and inter-generational differences in what terms might be most acceptable.

Recommendation 1: Discuss clinical terms related to sexual function and wellbeing with patients to gauge their comfort, understanding, and acceptance of the language.

Communicating the purpose of the PROM

Nearly all members of our insight group were focused on understanding the purpose of the PROMs. Rather than just answering the items, they were trying to understand the overarching themes or intended use of the PROM in relation to their care and management. When this was thought to be unclear or not well communicated to them, they described higher levels of doubt and distrust related to the PROM, which reduced their likelihood to complete it. This tendency to try to understand the purpose of the PROM applied to the whole survey and its individual questions. This was considered more of an issue when the language of the PROM was thought to be too vague, outdated, technical, or unrepresentative of their own experiences.

Recommendation 2: Tell patients what the PROM is designed to measure, how it can support their care, and why you are giving it to them.

Gendered language

For cisgender MSM, the language of the male-oriented PROMs can help patients to build awareness of the potential issues from treatment they undergo. One man described seeing these PROMs as "quite radical" in the way they helped him to reflect on, process, and articulate his experience. He also said it was "liberating and reassuring" to review the questions on the PROMs as they helped normalise his experience.

However, one of the cisgender men described how the language related to menopausal symptoms, such as "hot flashes", did not feel like it was representative of his own hormonal changes as a result of his treatment. He found that during his treatment, no one was able to talk to him about his "sweaty balls", which was how he experienced and understood his hot flashes. Similarly, the language about "breast tenderness/enlargement" felt unusual to the cisgender men, who did not consider the breast tissue on their chests to be breasts. They felt that describing it as such may emasculate men who are already having complex feelings about their masculinity as a result of their treatment.

Cisgender women from the insight group felt that the PROMs they reviewed made assumptions about their body and how they experienced their gender. This caused one woman to have an "existential" reaction to these questions. The women described their experience of surgery as a point of distress during

both their treatment and recovery. To help them navigate this, they preferred when their care teams asked about their bodies in a non-gendered way. Similarly, they preferred when lay terms were used for anatomy wherever possible.

Both the cisgender men and women also showed concern for TGD people and how the gendering of the PROMs may negatively affect them. One of the cisgender women shared that her partner is a transgender man and felt that “He would have a breakdown if he was given the FSFI.”

The TGD insight group members felt that none of the PROMs they were given accurately described their experiences. Questions specific to physiology were felt to be presented with gendered assumptions and were a trigger for gender dysphoria. It was also felt that these PROMs actually presented barriers for them to express their sexual wellbeing in sufficient detail. This was because the PROMs were found to be unable to reflect the broad diversity of trans bodies, sexual activity, and sexual responses.

“As a non binary person I kind of feel like none of them really worked for me. I was so kind of put off by [the PROM] saying female at the top of the one for my own symptoms, and then when I tried looking at the male one, it seemed very focused around erections.” - TGD participant

The TGD insight group members were very invested in the concept of holistic assessments. They questioned whether the PROMs’ focus on the ‘mechanics of sex’ was a fair representation of sexual wellbeing. Due to so many of the questions on the PROMs being related to anatomy or an assumption of sexual activity (most often ‘penis in vagina’ intercourse), the TGD insight group members understood this to mean that the PROM was not appropriate for them.

**“I just get the immediate impression, OK, here's another form designed by a heterosexual person about heterosexual sex, and therefore I'm not going to really be able to relate to this.”
- TGD participant**

Recommendation 3: Check PROMs for gendered language or assumptions and address these with the patient directly to capture any of their questions or concerns about completing the PROM.

Masculinity and femininity

PROMs questions that specifically asked about masculinity and femininity were not received well. One cisgender man shared that “This was the one question that slightly triggered me.” It was felt that drawing a distinct line between erection potency and a person's masculinity was unhelpful and also not representative of the queer experience. This was especially the case for one cisgender man who had previously worked through his feelings of emasculation related to his erectile function. He felt that being asked about his masculinity in this way had reopened an old issue and potentially reintroduced a sense of pathology or shame that he had worked to move past.

**“Have I lost my masculinity because I can't get an erection?”
- cis MSM participant**

Similarly, the cisgender women found the questions about femininity alienating. Though they recognised that other women might feel differently, they shared that their cancer treatments had resulted in side effects that they felt “exclude you from womanhood” (i.e. primary ovarian insufficiency), and so they felt pushed out from the idea of femininity. The women also questioned whether feeling less feminine was inherently negative, as inferred by the PROMs. Instead, they recognised that the queer female experience may be less tied to traditional concepts of femininity, and for people who are treated for cancer, the relationship may be even further removed.

For trans patients, the measurement of masculinity and femininity within the PROMs “felt really jarring” and less relevant to their sexual wellbeing. A non-binary participant also took issue with the framing of a change in a person's masculinity or femininity as being inherently negative. They shared that this did not reflect their own experience, where their surgical treatment for cancer was instead felt to be gender affirming.

Recommendation 4: Avoid leading with concepts of masculinity and femininity when discussing sexual wellbeing with LGBTQ+ cancer patients.

Sexual activity

Sexual response

A 'sexual response' is the body's mental and physiological response to a sexual stimulus or stimuli. Participants felt that the PROMs described and prioritised sexual responses differently for men and women.

The insight group felt that the male-oriented PROMs assumed arousal more often than the female-oriented PROMs. Similarly, they noted that there was a high degree of focus on erections and their potency for men, but physiological responses in the female-oriented PROMs felt under-explored.

In the FSFI there is a sexual response domain of 'lubrication', also described as 'wetness'. The cisgender women found this domain to be limited in its representation of vaginal sexual response. They questioned why the physiological markers of arousal were in relation to receiving penetration, and further queried why other markers of genital arousal were absent, such as clitoral engorgement. They felt that the focus on the potential to be penetrated inferred passivity in the sexual activity of women, which did not align with their own experiences. Further, it was felt that a dry vagina was in fact a relatively common sexual response difference, and easily mediated through the use of over-the-counter vaginal lubricants.

The TGD group members noted how the male PROMs appeared to be solely focused on erection potency and failed to take a holistic view of sexual response. They also reinforced the cisgender women's concerns about the PROMs' preoccupation with lubrication. They felt that this cisheteronormative lens ignored the wider sexual activity and priorities that a person may have. The transmasculine patients in particular noted that vaginal dryness is a regular occurrence when receiving testosterone therapy, and as such they felt that this was not an accurate marker of sexual response for them. Across the PROMs, the TGD group noted that none of the physiological questions mapped well onto their experiences of their bodies and sexual response. They also felt that there was no way to express this problem within the PROMs.

Recommendation 5: Recognise the diversity in human sexual response with the patient and describe how scores on PROMs may indicate a sexual difference rather than a dysfunction.

Widening the definition of sexual activity

When asked if the PROMs were missing any sexual activities that were important to the participants, the resounding answer was "most of it". It was unanimously felt that the PROMs described heterosexual sex and did not describe or measure the variety of sexual activities that were common and important to the insight group members.

The cisgender men questioned why their PROMs appeared to only ask about erections and a person's ability to penetrate another person. This did not align with their own sexual activity or their concept of sexual intimacy.

"Why is it especially focusing just on the erection as opposed to the sexual engagement or sexual experience?"
- cis MSM participant

One of the cisgender men shared how, after prostatectomy, he felt that his consultant "wrote off" his ability to continue to have a sexual life. He shared how this dramatically affected his confidence. This was particularly important to him as he had come out as gay later in life and did not want to believe that his sexual exploration had been cut short at such an important time. He also reported being taken aback by the phrasing of the PROMs as they failed to account for, and at worst invalidated, the sense of sexual wellbeing he had been able to achieve post-prostatectomy. He felt that, although his score may be limited by his physiological response, the PROMs failed to recognise that he had done extensive work to no longer feel distressed by the change to his erections.

"I can answer the questions, but they don't apply to me as I enjoy sex. [...] Once I've penetrated [someone], that's the end of my erection - but I'm still enjoying it." *- cis MSM participant*

Aspects like sexual roles felt underrepresented in the PROMs for the cisgender men. Concepts such as being a 'top' (penetrative partner) and 'bottom' (receptive partner) in anal sex can be important and were not well mapped in the existing PROMs. This is particularly salient as some men change their sexual role as a result of their treatment in an effort to adjust to their sexual side effects, such as erectile dysfunction. In this vein, one of the men disliked the question "Have you been sexually active?" as it was felt that the heteronormative view of penetrative sex excluded him from sharing his own

sexual activity. In particular, the cisgender men noted that there was a lack of questions relating to anal sex, being the receptive partner in anal sex, and the use of hands or sex toys as supportive strategies or alternatives when they were the insertive partner. The cisgender men also agreed that the PROMs made assumptions of monogamy and failed to account for people who may have multiple partners or engage in group sex.

The cisgender women discussed how the PROMs failed to adequately explore the differences between interest, desire, and arousal. They also noted how treatment-induced menopause had left their desire to be more of a “slow burn”. They felt that this had changed their desire to be more responsive, and that this could be adapted to if a person was prepared for this change with information and potential adaptive strategies. It was also felt that orgasm being presented as a goal of the sexual experience was not helpful. Whilst orgasm can be a marker of a positive sexual experience, they felt that it should not be seen as the definitive endpoint.

The cisgender women discussed the assumption and prioritisation of ‘penis in vagina’ sex in the PROMs, and shared that this left them with questions that were not easy to raise and often went unanswered. They reported good standard information given to patients in relation to atrophy, stenosis, and menopause, but found a lack of information or support about their specific needs.

“I had to call my CNS and ask if I could masturbate.”
- cis WSW participant

This lack of information or support compounded their sexual dysfunction and created additional aversion, often persisting for multiple years until they found their own answers. One woman shared how she did not get any support with managing penetration after her treatment. No one had explained to her that narrower sex toys are available until her friend mentioned this years later. At the time of our discussion, she was similarly not aware of depth management sex toys.

“Nobody talked about sex toys and no-one knew if I could use them safely.” - cis WSW participant

The cisgender women described how their sexual activity often felt disregarded. They reported feeling that there was a “hierarchy of sex” in society, in which ‘penis in vagina’ sex was at the peak. This theme felt present

to them in the PROMs and made the women less comfortable about engaging with them. Instead, they would prefer to report their sexual wellbeing in a way that decentres the penis and broadens the view of sexual activity beyond penetrative sex. In particular, oral and anal sex were noted as being missing.

Myths regarding the safety of returning to sex after cancer treatment were also raised. One cisgender woman reported that she was scared to use a vibrator in case it would make her cancer grow faster. She was unable to find reliable information about this myth, and due to a lack of professional support and potential shame and embarrassment about sex toys, it went unchallenged. The women also felt that the more complex their health became, the less likely they were to challenge or seek support with addressing these norms and myths.

TGD people had similar concerns which went unanswered, including questions about the safety of oral sex during chemotherapy. They shared the view that their sexual scripts were much wider than the PROMs could capture. They also noted that the PROMs did not ask whether the person was having the sex they wanted to have, and found it surprising that solo sex (masturbation) was missing. One respondent shared that the retrospective window set out by a PROM for sexual activity (four weeks) was too short as they were not that regularly sexually active but did not consider this to be an issue.

“I feel like none of these forms are really a good fit, and that's before I kind of even got on to like how queer sex is sometimes different to more heterosexual normative sex. So it's weird because normally I can kind of tune out language that's not trans inclusive, but I think because this is such a sensitive topic it really kind of jolted me and kind of stopped me being able to move forward with the form.”
- TGD participant

Recommendation 6: Recognise that the PROMs only ask about a small portion of potential sexual activity and provide other opportunities for patients to share details about their sexual activity.

Implementation

Accessibility

PROMs that were reduced item versions were preferred. Longer PROMs were thought to be overwhelming and poorly laid out. Dyslexic group members reported difficulty independently completing the PROMs, with one person sharing how they had printed and folded a paper version of the PROM in a way that allowed them to only view a single question at a time. Dyslexic group members also reported difficulty with reading serif fonts (e.g. Times New Roman) and advocated for the use of sans serif fonts (e.g. Arial). One person revealed that they had previously gone so far as to edit the files they were sent to their preferred font type so that they could read and respond to them.

There was a broad level of support for digital versions of the PROMs (ePROMs). Participants were clear that ePROMs should go beyond replicating the paper version online. Instead, ePROMs should be improved from a user experience point of view, such as segmenting the PROM by its sections or questions to make it easier for the patient to respond.

"You want to be handed an iPad showing one question at a time." - cis MSM participant

Multiple participants felt that a glossary may help for some of the terms that were uncommon to them or felt particularly technical. However, it was recommended that this should be as unobtrusive as possible and not over-complicate navigation or completion of the PROM.

Recommendation 7: Screen for and address any accessibility adjustments a patient might need to complete the PROM.

Supported administration

Many participants in the insight group felt restricted or confused by the language in the PROMs. A key issue appeared to be the difference between a person's interpretation of a question versus how it was phrased in the PROM. The insight group said this reduced their confidence and ability to complete the PROMs they were given. To remedy this issue, they said that they would like to have a professional available if they needed help understanding or answering any of the questions. Despite this request, many of the participants in the insight group questioned if this would be possible due to the workload of clinical staff.

Recommendation 8: Let the patient know that they can ask you questions about the PROM as they complete it.

Importance of rapport

Many participants of the insight group reported that they had never been presented with any of the PROMs given to them as part of this exercise. They also shared that they had not had conversations with healthcare professionals that reflected the concepts measured by the PROMs. When they were asked to review the PROMs for this report, it made them reflect and consider how much an effective PROM or discussion about sexual wellbeing could have improved their experience and outcomes.

A few insight group members shared that they did prepare or ask questions to their clinical teams, but these went unanswered. They felt that if there had been enough of a rapport built between the patient and the clinician administering the PROM, they would have had much more comfort and confidence in advocating for themselves and asking clarifying questions where necessary.

"If I trust somebody, I'm a pretty open guy and I'm happy in the right context to talk about it." - cis MSM participant

It is important to recognise that many LGBTIQ+ people have a history of poor healthcare experiences that affects the way they engage with ongoing care. For example, one of the cisgender women detailed how she had tried to speak to a GP about her sexual wellbeing. However, the GP repeatedly asked about her condom use despite her describing sex with her wife. This caused her to

eventually give up seeking support. The insight group was understanding that professionals have limited information and tools at their disposal. However, they also made it clear that they are looking for an acknowledgement of their concerns and a sense of responsibility from their clinicians.

Though some in the LGBTIQ+ community take on the role of educating their healthcare providers to improve their care, many others find this exhausting and can at times resent this being their responsibility. In one example, a TGD participant shared how they felt humiliated by a professional's conduct and questions, and made a complaint. Sadly, this complaint was not dealt with well, further eroding the patient's trust in their care team.

**"I often look for micro-cues to know if things are safe."
- cis MSM participant**

TGD patients shared this frustration with self-advocating or solution-making. They described how they would have to manage their dysphoria, try to deduce what the form wanted to know, contrast this with what they wanted to share, and somehow do this all without support.

Recommendation 9: Build a strong rapport with patients that allows you to understand and take ownership of their concerns to improve their patient experience.





Summary

- 1.** Discuss clinical terms related to sexual function and wellbeing with patients to gauge their comfort, understanding, and acceptance of the language.
- 2.** Tell patients what the PROM is designed to measure, how it can support their care, and why you are giving it to them.
- 3.** Check PROMs for gendered language or assumptions and address these with the patient directly to capture any of their questions or concerns about completing the PROM.
- 4.** Avoid leading with concepts of masculinity and femininity when discussing sexual wellbeing with LGBTQ+ cancer patients.
- 5.** Recognise the diversity in human sexual response with the patient and describe how scores on PROMs may indicate a sexual difference rather than a dysfunction.
- 6.** Recognise that the PROMs only ask about a small portion of potential sexual activity and provide other opportunities for patients to share details about their sexual activity.
- 7.** Screen for and address any accessibility adjustments a patient might need to complete the PROM.
- 8.** Let the patient know that they can ask you questions about the PROM as they complete it.
- 9.** Build a strong rapport with patients that allows you to understand and take ownership of their concerns to improve their patient experience.

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