

An Exploration of Patient Involvement in NICE and SMC Appraisals of Breast and Ovarian Cancer Therapies

Arieta Azariadi, Jovita Brantley, Adam Gordois; Labcorp Clinical Development Ltd, London, UK

Introduction

- Patient engagement in health technology assessment (HTA) appraisals is important to identify unmet needs, ensure the authorisation of safe and effective treatments and enhance the implementation of patient-centred care leading to better health outcomes.
- England’s National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) have formal processes to collect input from patient groups during their appraisals of new technologies. Specifically, NICE reports the experiences of patient experts/representatives, while SMC can convene a Patient and Clinician Engagement (PACE) meeting if requested by sponsors. These processes potentially give patients a stronger voice in HTA decision-making.
- Concerns have been raised by patient groups about how their perspectives and priorities are recorded, leading to uncertainties about their impact on recommendations.
- The aim of this study was to investigate how patient engagement is incorporated in NICE and SMC decision-making with respect to its value, impact, changes over time and any associations with positive/negative recommendations.

Methods

- NICE guidance and SMC advice for breast and ovarian cancer therapies published between 2018 – 2022 were reviewed to determine how patient input was incorporated in final recommendations.
- Key points made by patient groups/experts/representatives were identified and entered manually into an Excel data extraction tool covering seven areas: prognosis, unmet clinical need, overall and/or progression-free survival, generalisability, quality-of-life (QoL), impact of the technology on family/caregivers and impact of side effects.

Results

Patient Feedback

- Of the 13 NICE appraisals for breast cancer therapies, patient feedback related to survival and side effects was most frequently reported (12/13) and the least frequently reported type of feedback related to prognosis (5/13) (Figure 1).
- Of the 16 SMC appraisals for breast cancer therapies, patient feedback on survival was most frequently reported (13/16) and the least frequently reported was on prognosis (4/16) (Figure 1).
- Feedback on generalisability was not reported in any SMC appraisals of breast cancer therapies.
- Of the six NICE appraisals for ovarian cancer therapies, patient feedback on prognosis, survival and QoL was most frequently reported (5/6) and feedback related to generalisability was reported least (2/6) (Figure 2).
- Of the six SMC appraisals for ovarian cancer therapies, the most frequently reported feedback related to prognosis, impact on family/caregivers and QoL (5/6) and the least frequently reported feedback was on unmet need (2/6) (Figure 2).

Appraisal Recommendations

- In the 13 breast cancer therapy appraisals by NICE, patients were considerably engaged in the process – their views were considered in the final recommendations and 11 received positive recommendations.
- All 16 breast cancer therapy appraisals by the SMC received positive recommendations, including ten incorporating feedback from a PACE meeting and four incorporating feedback from a patient group (e.g., Breast Cancer Now) (Figure 3a).
- All six ovarian cancer therapy appraisals by NICE received a positive recommendation - patients were engaged in the process and their views were assessed in the final recommendations.
- All six ovarian cancer therapy appraisals by the SMC received a positive recommendation of which there were four incorporating feedback from a PACE meeting, one which did not request a PACE meeting and one abbreviated submission including no patient feedback (Figure 3b).

Conclusions

- The appraisals reviewed for this research showed that the main priority of NICE and SMC was to assess the cost-effectiveness of these interventions against agreed thresholds.
- Information reported in the final appraisals by NICE and SMC do not clearly demonstrate how the statements and submissions made by patient groups affected the agencies’ recommendations, despite the efforts to incorporate them into their HTA processes.
- It is noted that NICE and SMC systematically capture patient feedback in their appraisals across a range of areas; however, the uncertain impact of this patient engagement on final decision-making does not fully demonstrate its added value.
- The most efficient ways of incorporating and reporting feedback in agency appraisals and the extent to which patient input is evaluated in the decision-making, requires further investigation.

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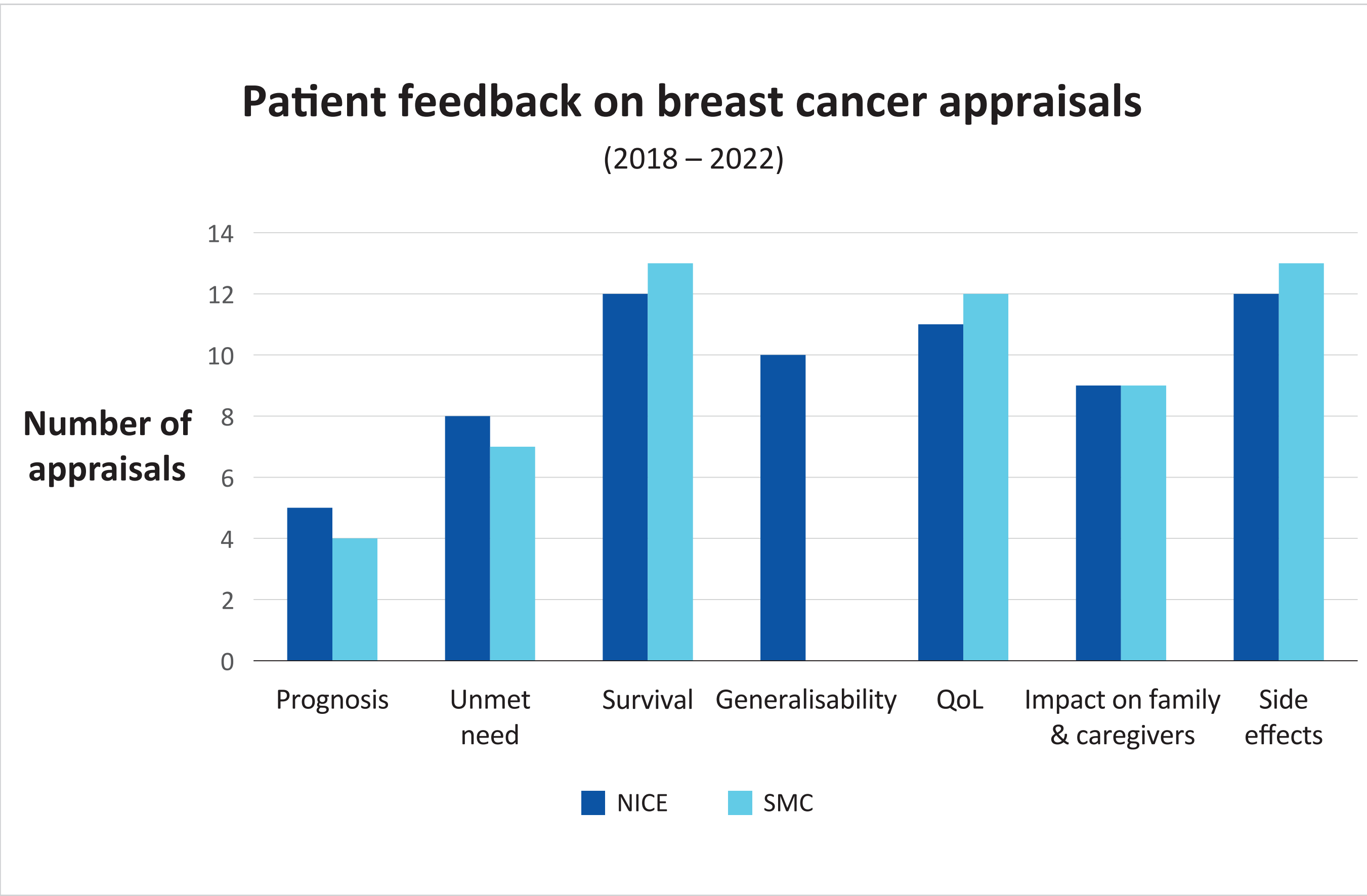


Figure 1. Patient feedback on breast cancer appraisals.

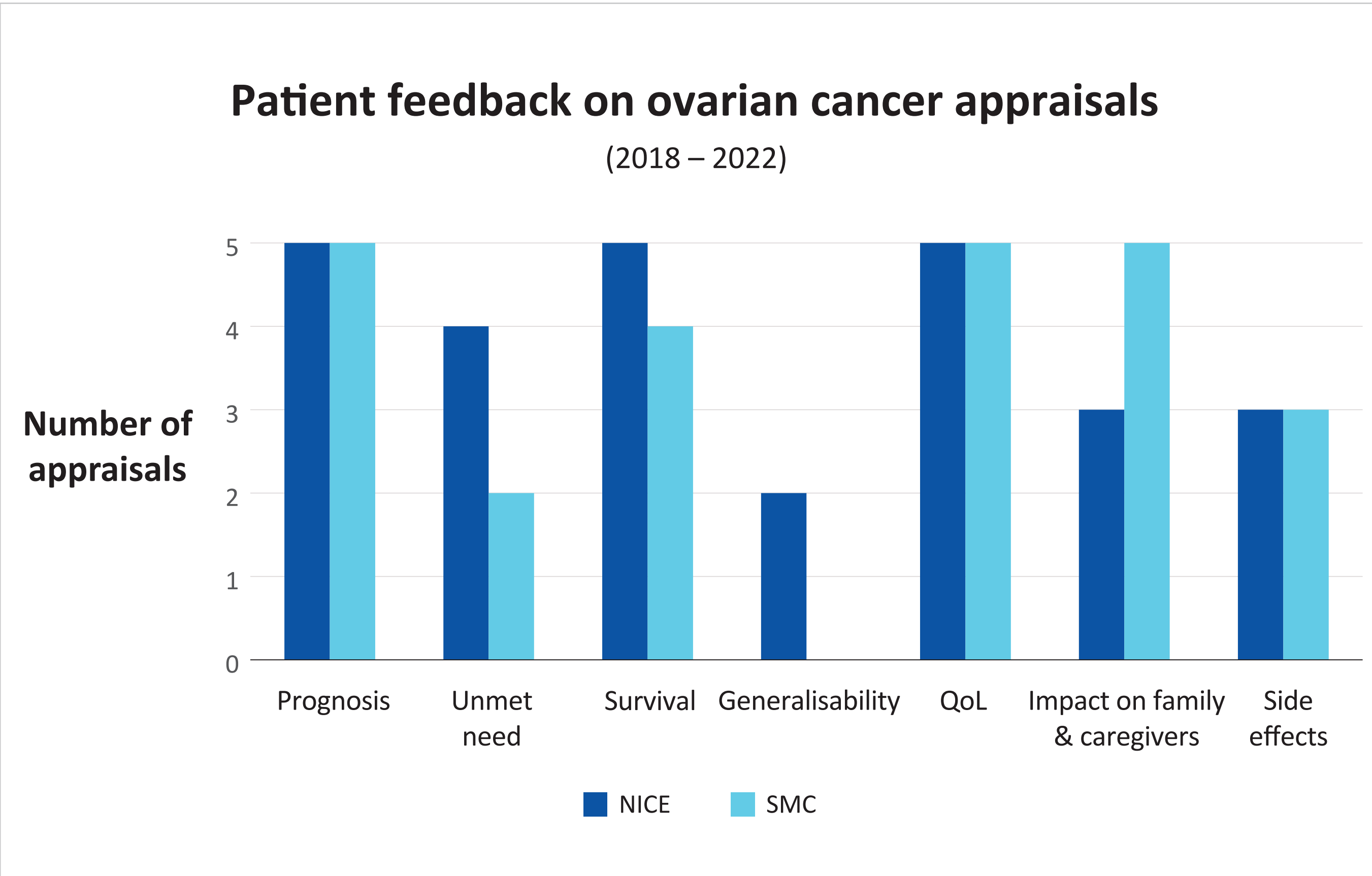


Figure 2. Patient feedback on ovarian cancer appraisals.

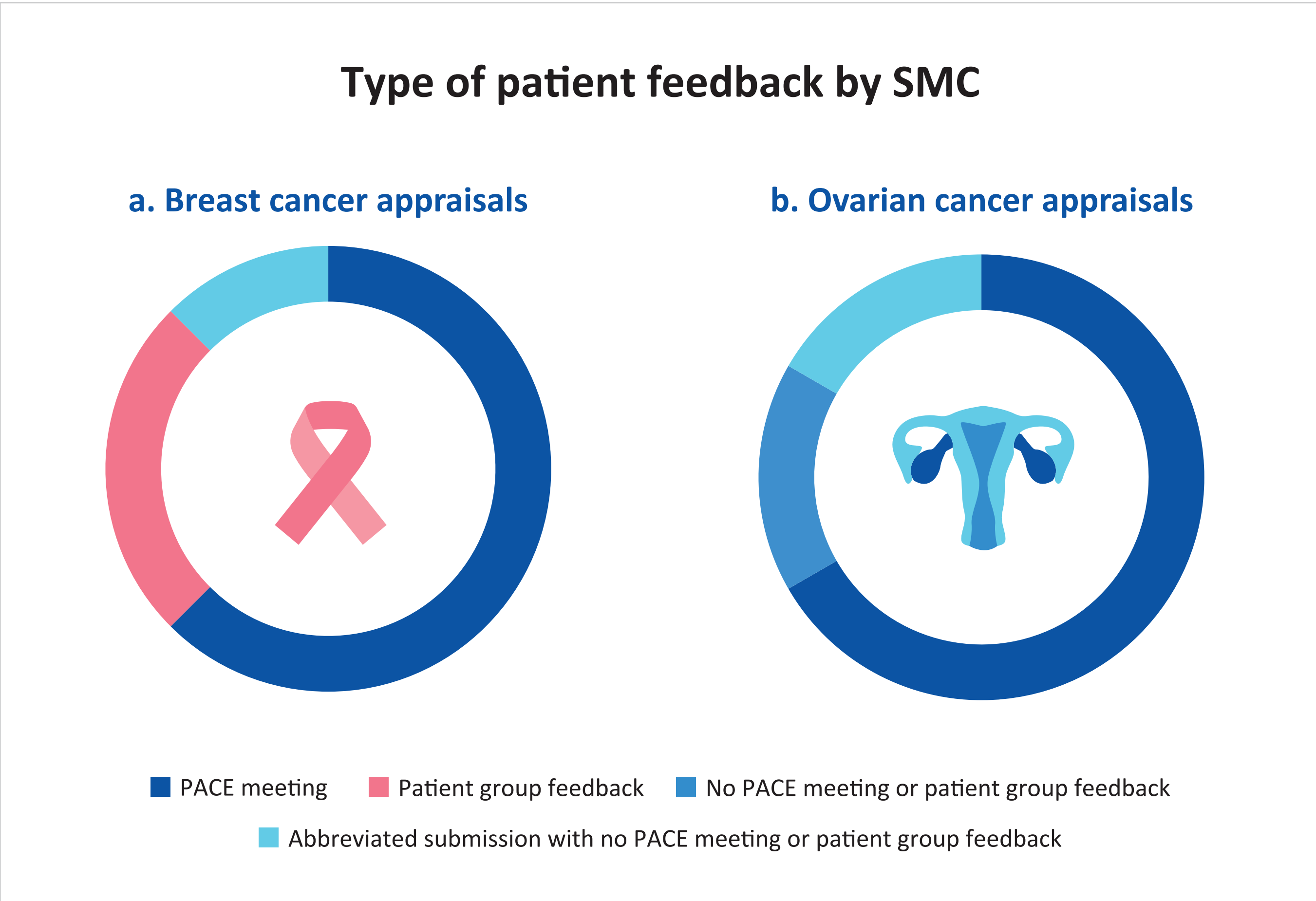


Figure 3. Type of patient feedback by SMC.

NICE= National Institute for Health and Care Excellence; PACE= Patient and Clinician Engagement; QoL= Quality of life; SMC= Scottish Medicines Consortium