Developing a patient reported experience measure (PREM) in secondary breast cancer (SBC)

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**Background:** Metastatic breast cancer (SBC) is now seen as a chronic disease, however the number of patients currently living with SBC is unknown. Despite widespread recognition of the importance of understanding and evaluating patients’ experiences, little research has been undertaken within SBC. Generally, there has been significant expansion in the development and application of patient reported questionnaires that measure care experiences (PREM), which is a major indicator of healthcare quality, however there is no specific PREM for people with SBC.

**Methods:** This study aims to develop and pilot test a unidimensional PREM in SBC for clinical application using a mixed methods sequential exploratory design. Semi-structured interviews were conducted with 25 people with SBC to explore their experiences,
priorities and needs diagnosis of metastatic disease and during palliative treatment. Potential items for PREM-SBC were extracted from interview data focusing on patients’ experiences and priorities for care. Cognitive interviews were undertaken with patients to ensure all items listed were clear and easily understood.

Results: Following cognitive interviews a draft PREM questionnaire was created for patients with SBC. The structured questionnaire contains 48 items (statements) based on patients’ experiences, treatment / care, priorities and needs. A five point scale is used to rate each item from strongly agree to strongly disagree. Patients report the PREM is easy to complete, taking less than 5 minutes. Further pilot testing is currently being undertaken (n = 130) to assess the validity, reliability and repeatability of PREM-SBC, drawing comparisons with other quality of life measures.

Conclusions: There is currently a lack of research focusing on patients with SBC. A draft PREM-SBC questionnaire was developed and pilot tested for clinical use. This will increase understanding of patients’ experiences, needs and priorities to enhance patient care.

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