

# Patient and Clinician Engagement statements as a tool to explore patient preferences for metastatic breast cancer treatments in Scotland

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## Background

- Effective patient-centred care requires sufficient understanding of patient preferences
- Qualitative research is effective in the area of metastatic breast cancer, where an incurable diagnosis and high uncertainty leads to complicated and emotionally charged reasoning
- In 2014, Scotland’s advisory body for medicines, the Scottish Medicines Consortium (SMC), introduced the Patient and Clinician Engagement (PACE) process, giving a stronger voice to the clinician and patient perspectives on new medicines. PACE statements are useful for the area of patient preference because;
  - they provide patient and clinical perspectives for societal decisions rather than the personal and highly emotional context of a consultation
  - secondary data forgoes the need for potentially lengthy and costly data collection
  - they provide qualitative data from an independent source

## Aims

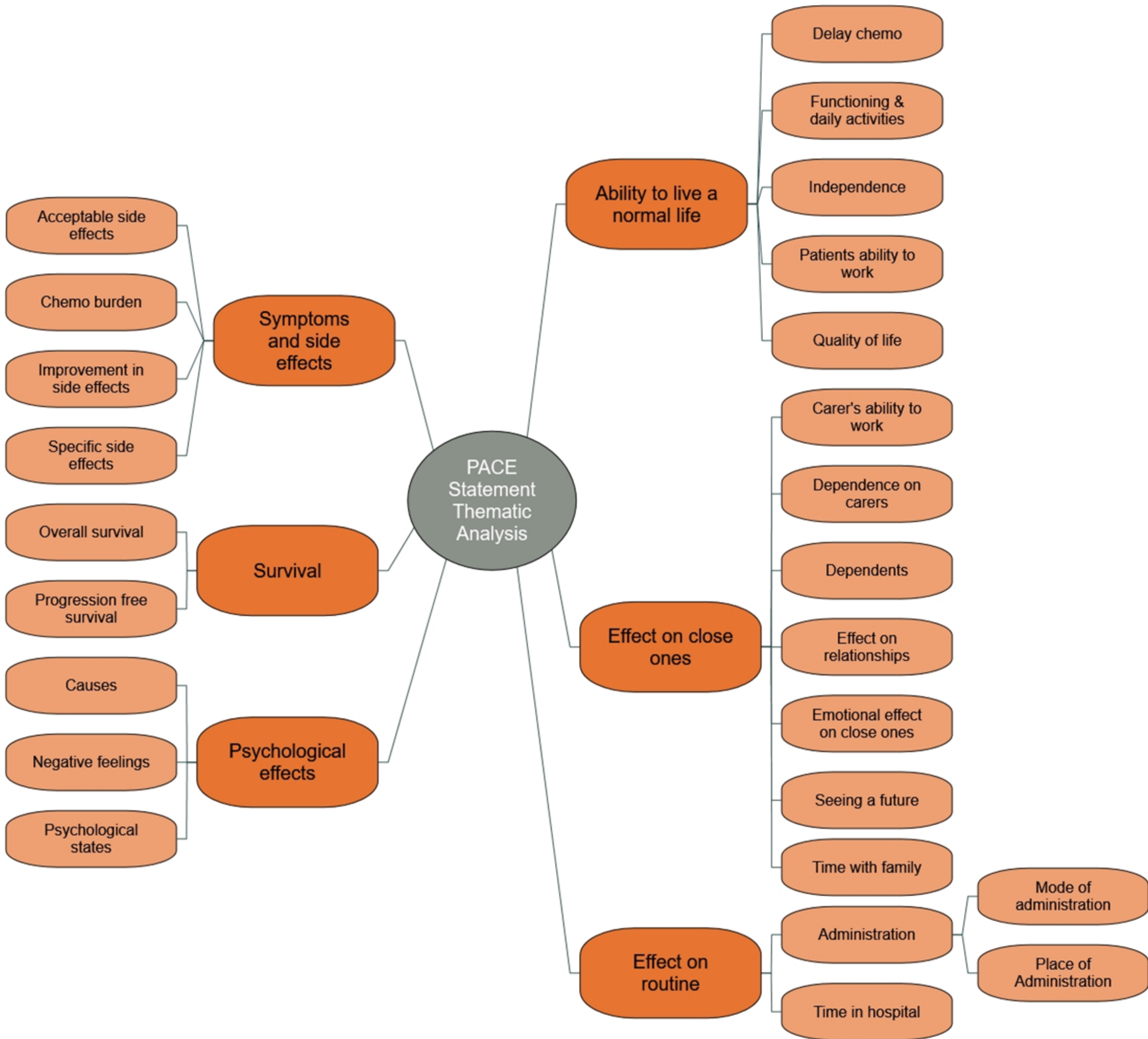
To identify the themes relevant to patient preferences and patient experience from PACE statements for drugs seeking approval for treatment of metastatic breast cancer

## Methods

- Between Oct 2014 and Oct 2018, eight PACE meetings had been convened for medicines seeking reimbursement for the treatment of metastatic breast cancer.
  - Fulvestrant (Faslodex)
  - Eribulin (Halaven)
  - Everolimus (Afinitor)
  - Trastuzumab (Kadcycla)
  - Pablociclib (Ibrance)
  - Ribociclib (Kisqali)
  - Pertuzumab (Perjeta)
  - Abemaciclib (Verzenios)
- In this study, we conducted a formal thematic analysis using the PACE statements from those meetings to systematically identify the dominant issues that patients consider important regarding new medicines.
- NVIVO software was used to facilitate analysis conducted by consensus of two researchers.

## Results

- Themes are not mutually exclusive and there is often overlap between them
- Core themes are comprised of additional sub-themes
- We identified six core themes:
  - Symptoms and side effects** - Mentions of the symptoms and side effects which impact the lived experience of the patient. Often treatments were praised for alleviating symptoms and side effects. The side effects of drugs such as eribulin, everolimus and pablociclib were acknowledged, but it was argued that the side effects were acceptable relative to the benefits.
  - Survival** - This theme was comprised of overall survival (OS) and progression-free survival (PFS). We chose to interpret mentions of disease progression and periods with relatively few symptoms and side effects as relevant to the PFS sub-theme. OS was a core goal of treatment but with the caveat that quality of life was at an acceptable level
  - Psychological effects** - The psychological distress of the cancer experience was mentioned frequently enough to justify its own theme. Feelings such as hope, uncertainty, and isolation were mentioned in addition to clinical diagnoses such as stress, anxiety and depression.
  - Ability to live a normal life** - This theme is rich with examples. Treatments’ ability to affect the patient’s ability to live normally was central to all PACE statements. The central importance of the issue is a symptom of the structure of PACE statements necessitating discussion in this area.
  - Effect on family and close ones** - This theme is also the result of the structure of PACE statements. The effect on others is traditionally overlooked in traditional economic evaluations, part of the purpose of PACE is to present evidence of this nature.
  - Effect on daily routine** - This theme is unique from ‘Ability to live a normal life’ in the sense that is specifically focussed on administration of treatments and the necessity of hospital visits. Treatments which required fewer hospital visits were argued to be beneficial to both the patients and the healthcare system.



## Discussion

- PACE statements are a useful secondary data resource. The results of our analysis offer a summary of the issues that are considered important by patients and clinicians.
- In particular, they highlight how the goals of treatment for metastatic breast cancer extend beyond simply prolonging life. Our analysis of PACE statements has highlighted the lived experience of the patient and also the effects of their family and carers.

## Lay Summary

PACE statements are summaries from meetings where patients and health professionals discuss the benefits of medicines. 8 PACE statements existed for medicines seeking to treat patients with cancer which has progressed to the advanced stage. We analysed the statements and identified 6 core themes which summarised the key features of the statements. The core themes were symptoms and side effects, survival, psychological effects, ability to live a normal life, effects on close ones, and effect on routine.