much more accessible and informative, and require less filtering through irrelevant posts. It is hoped that posts from breast cancer patients typically discuss side effects of treatments and how to manage them, as well as offering emotional support. The limitations of using this type of information include the lack of a mechanism to confirm that contributors really do have the relevant disease, although the multitude of contributions makes this likely to be outweighed by "true" patients and caregivers. CONCLUSIONS: This study showed that more valuable information can be found in patient-to-patient correspondence in forum threads than in general social media. Breast cancer patients appear to be more vocal in patient forums than schizophrenia patients, possibly due to the stigma attached to mental health problems. Little was found on what matters to breast cancer caregivers, since patients tend to present their own personal experience.

PCN196
PATIENT AND DISEASE CHARACTERISTICS ARE IMPORTANT DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE (HRQOL) IN PATIENTS WITH METASTATIC RENAL CELL CARCINOMA (mRCC): RESULTS FROM A POPULATION-BASED REGISTRY

OBJECTIVES: Limited data are available on the health-related quality of life (HRQOL) of patients with metastatic renal cell carcinoma (mRCC) in daily practice. The aim of this study was to estimate HRQOL of patients with mRCC in daily practice, and to assess the influence of patient- and disease characteristics, such as comorbidities and adverse events on HRQOL.

METHODS: Patients with mRCC were selected from a Dutch population-based registry (PERCEPT). In this RCC registry, data were collected in clinical trials and registries, and from patients treated in general practice. To measure HRQOL, a generic questionnaire (EQ-5D) was used. Multiple linear regression was used to determine which patient- and disease characteristics were associated with HRQOL. RESULTS: In this study, 100 (65%) patients presented with or progressed to mRCC. Average age at diagnosis was 62.9 years (range: 40-82) and 77% was male. Patients with mRCC reported an average EQ-5D utility score of 0.73 (95% CI: 0.66-0.84) vs. 0.75 (95% CI: 0.69-0.84) for patients with a non-hospital pharmacy. An anonymous self-administered questionnaire was distributed to patients at the time of drug dispensation between 27 July 2011 and 12 November 2011. The questionnaire contained questions about comedication, side effects, Instanyl® use, and previous completion of the questionnaire. RESULTS: Among the 272 eligible questionnaires (at least one item completed in addition to age, gender, time since first prescription, and absence of previous completion of the questionnaire), patients were adults aged 18-87 years. Characteristics of patients who declared having cancer, 94% declared cancer: 76% declared at least one indication/contraindication and 86% at least one posology misuse. Widening the definition of use for breakthrough pain to use for both breakthrough and chronic pain in cancer patients, reduced the indication/contraindication misuse (63%), but when posology misuse was also considered this did not markedly change overall misuse (93%). Abuse of Instanyl® (using the drug for emotional reasons, relaxation, or sleep disorders) concerned 21 patients (15 with cancer and 6 without); diversion (passing the drug to another person) concerned 2 patients (1 with cancer and 1 without). CONCLUSIONS: Misuse of Instanyl® was widespread. Nearly half reported not to have cancer, and among those who did, only a few used this drug correctly, and its proper use when prescribed.

PCN197
DEVELOPMENT OF A PATIENT-LED END OF STUDY QUESTIONNAIRE TO EVALUATE THE EXPERIENCE OF CLINICAL TRIAL PARTICIPATION

OBJECTIVES: A literature review informed these draft concepts. Three interviewer-led focus groups involving clinical trial participants (on-going or completed within the last 12 months), and 272 patients with cancer (94%) were presented to evaluate the draft questionnaire. Results: A literature review confirmed the relevance of the draft questionnaire to clinical trial participation. METHODS: A draft questionnaire assessing patients’ experiences before, during and after the trial was developed in collaboration with oncology patient advocates before being qualitatively reviewed by individuals who have participated in a clinical trial or who have provided support to trial participants. A literature review informed these draft concepts. Three interviewer-led focus groups involving clinical trial participants (on-going or completed within the last 12 months) and 272 patients (94%) were presented to evaluate the draft questionnaire. CONCLUSIONS: The results provide evidence to support the content validity of the post-trial questionnaire. Assessing the clinical trial experience from the patient perspective using a robust questionnaire may offer potential to improve trial design and ensure subjects stay engaged throughout the trial process.

PCN200
PATIENT-REPORTED OUTCOMES ASSESSED USING THE BREAST-Q INSTRUMENT IN WOMEN UNDERGOING BREAST RECONSTRUCTION POST-MASTECTOMY: A SYSTEMATIC LITERATURE REVIEW

OBJECTIVES: Assessing the effects of breast reconstruction (BR) on patient-reported outcomes (PRO) is important as BR becomes increasingly common after mastectomy. A systematic literature review was conducted to assess the clinical use of a well-validated PRO instrument, the BREAST-Q (BQ) in women undergoing BR. METHODS: Searches using PubMed, ScienceDirect, Cochrane Library, and references in plastic surgery journals were conducted from when BQ was developed in 2008 to May 2014 using the term, ‘breast-q OR breastq’. Non-English, reviews, letters, protocols and single-patient case reports were excluded. BQ modules unrelated to reconstruction (e.g., Augmentation or Reduction) were also excluded. Each BQ scale range varied from 0-100 with a higher score representing better PRO. RESULTS: After applying exclusion criteria, 35 studies were retrieved. Majority of studies were conducted in North America (54%, 18/35) and Europe (34%, N=14 to 7,110 with mean age ranging 46-55 years. When compared to mastectomy alone, BR was associated with higher PROs (p<0.05) however, adjuvant radiotherapy was associated with lower PROs (p<0.005). For the BQ scales, sexual well-being was consistently low (range: 30-64) and the scores of physical well-being and satisfaction with surgery were consistently high (ranges: 68-89 and 70%, respectively). Majority of the studies administered BQ as a single administration post-BR. Only 4 studies reported repeat administration post-BR (range of change score – 19 to 36). From 3 of 4 studies, the scale with the largest Cohen’s d effect size (ES) was psychosocial well-being (ES range: 1.52-3.63). CONCLUSIONS: Our findings suggest that while BQ is widely used, study type and method of administration are disparate. Further assessment of the BQ...