more accessible and informative, and require less filtering through irrelevant posts. For example, posts from breast cancer patients typically discuss side effects of investigational 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 numbers of participants and observations is likely to be minimized 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 IN PATIENTS WITH MULTIFACETED RENAL CELL CARCINOMA 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 explore the 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 at the patient- and disease-characteristic registration level and for patients admitted to 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 on the indication, misuse of Instanyl®, 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 report), patients were adults (mean age ranging 46-55 years). Among patients who declared having cancer, 76% declared having cancer: 67% declared at least one indication/contraindication and 86% at least one posology misuse. Widening the definition of use for breathlessness to use for both breathlessness 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 progressed to mRCC. Average age at diagnosis was 62.9 years (range: 40-82) and 47.5% patients were male. Among patients with mRCC, reported an average EQ-5D utility score of 0.73 (95%CI: 0.66-0.84) (p<0.0319). Multiple linear regression showed that presence of comorbidities (>1), number of metastatic sites (>1), radiotherapy and presence of grade 3 or grade 4 toxicity were significantly associated with a lower EQ-5D quality score. Although presence of bone metastases significantly lowered the EQ-5D utility score, this factor was not significant after adjustment for other factors.

CONCLUSIONS: This is one of the first studies that provides insights into the HRQOL of patients with mRCC in daily practice. In contrast to previous studies, this study also identified patient- and disease characteristics that influence HRQOL. Presence of comorbidities, number of metastatic sites, radiotherapy and presence of severe toxicity related to targeted therapies were significantly associated with HRQOL. This study therefore contributes to correcting EQ-5D treatment for these characteristics and will be useful in future cost-effectiveness analyses.

PCN197

DEVELOPMENT OF A CONCEPTUAL MODEL FOR PEDIATRIC ONCOLOGY RESULTS FROM A REVIEW OF QUALITATIVE RESEARCH LITERATURE AND CLINICIAN INTERVIEWS

OBJECTIVES: Childhood cancer’s profound effects should be assessed appropriately, and this study aimed to develop an initial pediatric oncology conceptual model to elucidate and disseminate findings. The focus group participants provided further evidence to support the content validity of the post-trial questionnaire.

METHODS: A draft questionnaire assessing patients’ experiences of clinical trial participation 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 one (9 group members) were conducted to evaluate the questionnaires, further concepts for questionnaire inclusion. An updated questionnaire was developed based on combined insights from the focus groups and literature review.

RESULTS: Cognitive debriefing results are also presented. The focus groups provided evidence to support the content validity of the post-trial questionnaire.

CONCLUSIONS: Assessing the clinical trial experience from the patient perspective using a robust questionnaire may offer patients to improve trial design and ensure subjects stay engaged throughout the trial process.

PCN200

PATIENT-REPORTED OUTCOMES ASSESSMENT 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 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 Northern America (54%, 18/35). Studies that obtained a score from 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 significant PROs for other than BR. Among PROs scales, sexual well-being was consistently low (range: 30-84) and the scores of physical well-being and satisfaction with surgeons were consistently high (ranges: 68-49 and >70, respectively). Majority of the studies administered BQ as a single administration post-BR. Only 4 studies reported PROs at both pre- and post-BR (Range of change score – 19 to 36). From 3 of 4 studies, the scale with the largest Cohen’s d effect size (S) 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...