**Background**

- Comparison and amalgamation of patient-reported outcome (PRO) data from trials is hindered partly because of the wide range of scales and items measured by generic and disease-specific questionnaires.
- The identification of a core set of PRO domains for particular treatments or conditions would facilitate this process, because mandatory predetermined domains would be measured and reported in all trials.
- We aim to develop a core outcome set for RCTs of curative treatment for oesophageal cancer.

**Objective**

- This study examined existing patient-reported outcomes for curative treatments for oesophageal cancer, and grouped PROs into domains to inform the development of a core outcome set.

**Methods**

- Systematic literature searches identified studies measuring PROs.
  
  **Search strategy:**
  - MEDLINE, Embase, PsycINFO and CINAHL databases
  - Oesophageal cancer studies with curative intent
  - Surgical / chemotherapy / radiotherapy interventions
  - At least 1 multi-dimensional PRO measure
  - Jan 2006 – May 2011

- All validated questionnaires used in the studies were examined, including additional oesophageal-specific questionnaires known to authors.

- A complete list of PROs was compiled from verbatim names of questionnaire scales, single items and ad-hoc questions measured in each study.

- Terminology was examined, and scales with identical and similar names were compared.

- Components of questionnaires (individual items) were categorised into generic or symptom specific health domains.

**Results**

- Search results:
  1351 identified records
  111 full-text articles assessed for eligibility
  55 papers included (reporting 4 RCTs & 52 non-randomised studies)

  **19 questionnaires identified from studies**
  **2 questionnaires from authors’ knowledge**

  **116 scales**
  **32 single items**
  **74 ad-hoc questions**

  **132 verbatim terms for PROs**

  - Inconsistent / unclear terminology
  - Identically named scales but heterogeneity in content

  **Categorised into 32 health domains:**
  - Appetite/Eating/Taste
  - Sexual function
  - Belching/Bloating/Gas
  - Weight
  - Body Image
  - Cognition
  - Breathing
  - Emotional function
  - Choking
  - Fatigue
  - Communication/Speech difficulties
  - Financial issues
  - Constipation
  - Generic health
  - Cough
  - Global QOL
  - Diarrhoea/Frequent bowel movements
  - Hair loss
  - Dry mouth
  - Financial issues
  - Hoarseness
  - Emotional function
  - Choking
  - Fatigue
  - Communication/Speech difficulties
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  - Choking
  - Fatigue
  - Communication/Speech difficulties
  - Financial issues
  - Constipation
  - Generic health
  - Cough
  - Global QOL
  - Diarrhoea/Frequent bowel movements
  - Hair loss
  - Dry mouth
  - Hoarseness

- Emotional function, pain/odynophagia, physical activity/activities of daily life and appetite/eating/taste were most commonly assessed across questionnaires.
- Ad-hoc questions most typically related to appetite/eating/taste.

**Conclusions**

- A myriad of tools are available to assess PROs after treatment for oesophageal cancer. Heterogeneity between instruments prevents comparison across studies and meta-analysis of results.
- A Delphi consensus study is underway to prioritise which PRO domains are important for a core outcome set.