Patient reported outcome measures

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What are PROMs?

- Patient's direct reports of health

- Obtained by:
  - Self-report (postal) questionnaire
  - Interview
  - Computer terminal, Internet, App

Typical content of PROMs

- Physical function
- Symptoms
- Global judgments of health
- Psychological well-being
- Social well-being
- Cognitive function
- Role activities
- Personal constructs (eg stigma, satisfaction with bodily appearance)
- Satisfaction with care

Methods for establishing a PROM

- Generate questionnaire items from extensive interviews/focus groups with patients and public
- Select most important items
- Formatting and testing with patients /invariably iterative
- Series of studies to examine how it performs

Types of PROM

- Generic
    eg SF-36, EQ-5D
- Condition-specific, but broad
-     eg EORTC QLQ C30
- Very specific:
    eg Oxford Hip Score

Patient reported outcome measures (PROMs)

- PROMs are patients' self reports of health status at a point in time

- Usually used before and after a treatment /intervention

- Change/difference t1 – t2= outcome

PROMs –key properties

- Reliability
- Validity
- Sensitivity to change
- Acceptable to patient -low burden
- Feasible to process
- Interpretability

Evolution of PROMs

- Initially research tools eg secondary, or less often, primary endpoints in clinical trials

- NHS National PROMs programme (mandated from 2009: especially joint replacement)

- A resource to improve healthcare

Role in routine patient care

- Improved symptom assessment and control
- Improved professional – patient communication
- Improved patient satisfaction with care
- Efficiency of use of clinical time
- Improve shared decision-making
- Linked data to improve research

Impact of PROMs: individual patient care: general

- Initial reviews of trials largely negative
- More recent reviews more mixed
- Significant trial results Valderas et al., (2008):
  - 7/14 impact on diagnosis and problem recognition
  - 3/6 impact on patient functional status
  - 5/12 impact on patient satisfaction

Memorial Sloan Kettering cancer study

- 766 patients randomised
- Initiating chemotherapy for metastatic solid tumours
- Web-based PROM monitoring of symptoms vs usual care
- Median follow-up 6.9 years
- 31.2 months vs 26.0 months survival (p=0.03)

Basch et al., 2017 (JAMA)

Memorial Sloan Kettering cancer study

■ Postulated mechanisms:

– Earlier response to reported symptoms

– Improved tolerance of continued chemotherapy

Basch et al., 2017 (JAMA)

Danish hospital study (Ambuflex)

- E-PRO, decision-algorithm, graphic (colour coded) system of decision-support
- Across 9 different clinical areas
- Some dramatic proportions of patients did not need follow-up clinic appointments
- Epilepsy (48%), sleep apnoea 57%, prostate cancer (26%)

Schougard et al., 2016)

Implementation issues

- Choosing measures
- IT platform and degree of integration with other medical records
- Defining and agreeing actionable scores
- Developing staff and organisation commitment / patient engagement