Patient-Reported Outcomes (PRO) in the Swedish National Quality Registers

Evalill Nilsson, MD, PhD

QRC Stockholm,
PROMcenter/RCSO, and County Council of Östergötland

evalill.nilsson@lio.se
Individualized health care data in the National Quality Registers

Administrative
Laboratory & technical/surgical
Person-reported
  – Patient
  – Professional/Clinician
Patient-Reported Outcomes (PRO)

Symptoms
Functional ability
Health/quality of life
Satisfaction/experiences
PROM – patient-reported outcome measures

The result of the treatment described by the patient -

*Does the patient feel and function better after the treatment?*

Generic or disease-specific
PREM – patient-reported experience measures

Patient satisfaction, value
- Patient information
- Communication/clinical encounters
- Treatment satisfaction
- Access and convenience, etc

Depends on personality, preferences, and earlier health care experiences

Often most patients report high overall satisfaction

Therefore, ask instead for experiences?

Suitable for individualized registers?
Structure

Process

Outcome

PREM
- Patient satisfaction
- Patient experiences

PROM
- Health related quality of life
- Symptom/functional ability
To be certified at level 2 a National Quality Register is required to include PRO

108 annual applications for 2015
93 registers report including PRO

- ≈ 45% includes generic PROMs (≈35 registers use EQ-5D and ≈10 the SF-36/RAND-36)
- ≈ 60% includes disease/symptom-specific PROMs
- ≈ 30% includes PREM
- < 10% include other patient-reported measures, like lifestyle factors
Do the national quality registers use the PRO data to improve health care?

20 registers give examples of how PRO data are used to improve health care.
Registers reports of how they use PRO data to improve health care

- Shared decision-making in clinical encounters
- Basis for care plans and decision-aids
- Revisions of treatment guidelines
- Tighten up indications for treatment
- Monitor complications also after the patient has left the hospital
- Improve patient information and postoperative support
Why should the use of PROMs improve health care?

Researchers have been more interested in creating new questionnaires than in the theory behind why PROM should be suitable for the improvement of health care.

Feedback Intervention Theory (FIT)

- Health care professionals become more focused on the target (better health for their patients) when given new, earlier unknown data about their patients.
Does the use of PROMs improve health care?

The communication and relation between patients and health care professionals are improved and patients become more satisfied.

Increased monitoring of treatment effects, including adverse effects, and detection of unrecognized problems.

Beneficial changes in patient management.

Earlier detection of health problems.
**Disease-specific**

Specific self-rated symptoms and signs for a certain disease, ill-health, or functional impairment

Often more responsive than generic measures

**Generic**

General aspects of self-rated health and health related quality of life

Unnoticed health problems

Psychosocial needs

Effects of comorbidities

Adverse effects from treatments (including treatment sequelae)

One intervention, but mixed patient group

Health economic evaluations

Comparisons across patient groups/populations
Generic or disease-specific – combinations superior?

Be in the frontline, involve the patients!

Detecting all important changes in health-related quality of life and avoid missing unexpected effects

Substantial generic impact beyond the disease-specific impact

Need to describe also the relative burden of the specific disease in a general population

Always interpret in the context of each other?
RAND-36

Free, original version of the SF-36, which is the most common generic measure globally today

Differs slightly in the algorithm for the Bodily Pain and General Health scales, and the composites PCS and MCS

A Swedish version is now available from http://www.promcenter.se/

Validation study will be published in 2015 (two publications), data analyses are ongoing