

Systematic reviews and guidance on implementing PROs in clinical practice

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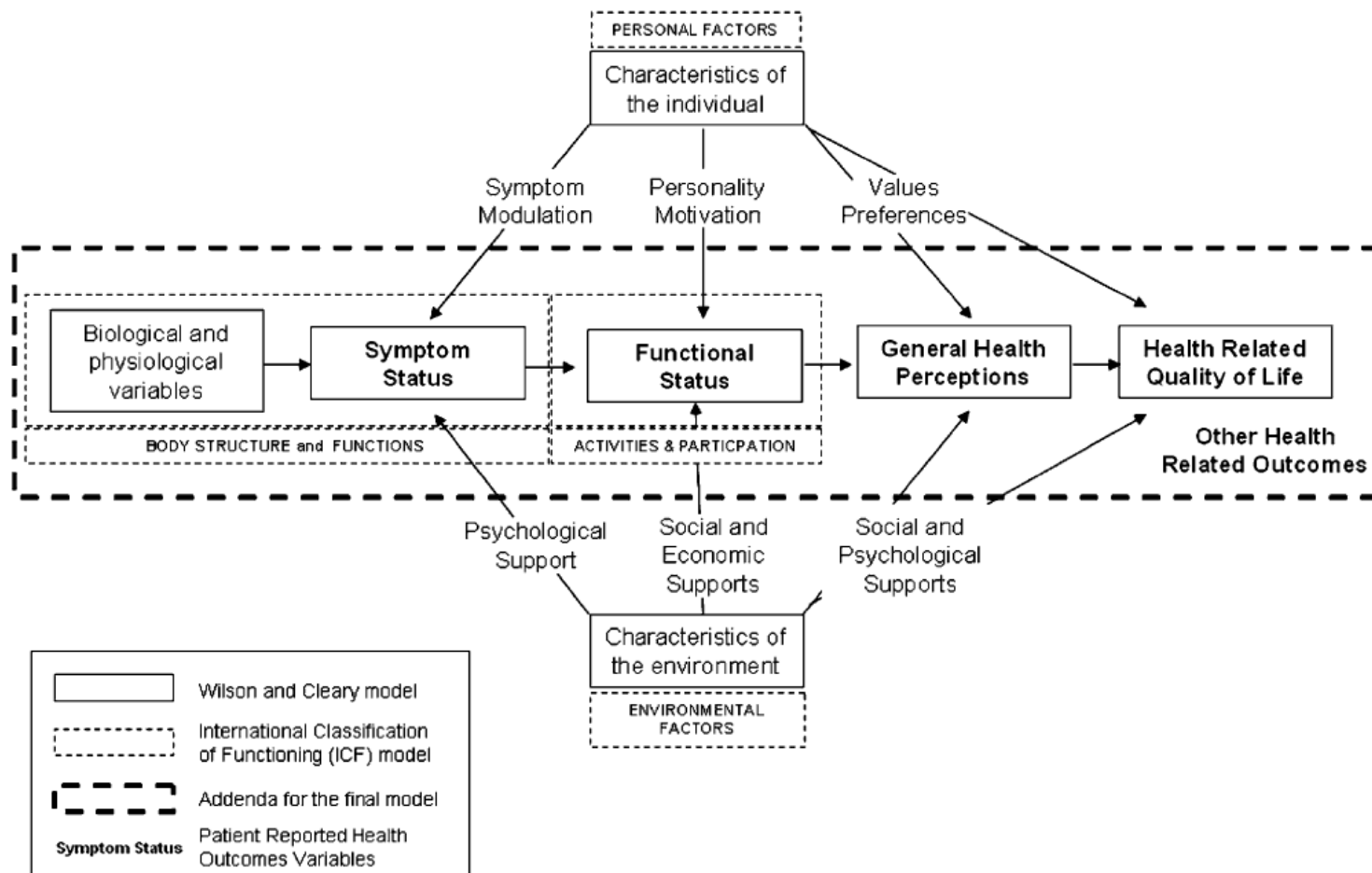
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Celebrating 20 years of Patient Centred Outcomes Research (1996-2016)

Thursday 3rd November 2016

University House, University of Leeds



Clinical use of PROMs

		Level of aggregation of PRO data	
		Individual	Group
Used at the clinician–patient interface	Yes	Screening	Decision aids
		Monitoring	
		Promoting patient-centred care	
	No	Facilitating communication within multidisciplinary teams	Population monitoring and assessing quality of care

Greenhalgh J. *Qual Life Res* 2009

Box 1. Potential clinical applications of patient-reported outcomes.

- Supporting decision-making in the diagnostic process:
 - Screening
 - Diagnosis
- Informing risk stratification and prognosis (identification of vulnerable patients and patients 'at risk')
- Supporting prioritization and goal setting
- Supporting decision-making in indication for treatment (medical/surgical)
- Facilitating monitoring of:
 - General health status
 - Response to treatment/management
- Facilitating communication:
 - Between patients and health professionals
 - Within teams and between professionals: consistent use along the care pathway

Condition	PRO measures	Type of recommendation	Relevant guidance [source]
Asthma	<ul style="list-style-type: none"> Royal College of Physicians (RCP) 3 questions Asthma Control Questionnaire (ACQ) Asthma Control Test (ACT) Children's Asthma Control Test Mini Asthma Quality of Life Questionnaire (Mini-AQLQ) Paediatric Asthma Quality of Life Questionnaire (PAQLQ) 	<ul style="list-style-type: none"> Use of PRO measures recommended (assessment) Identification of interventions that can improve PROs 	<ul style="list-style-type: none"> "An assessment of asthma control should use a recognised tool. The tool used should be appropriate for the age of the person with asthma. The available tools include the Royal College of Physicians (RCP) 3 questions, the Asthma Control Questionnaire, the asthma control test or children's asthma control test and the Mini Asthma Quality of Life Questionnaire or Paediatric Asthma Quality of Life Questionnaire." [NICE quality standard 25] "<u>Direct or passive exposure to cigarette smoke adversely affects quality of life</u>, lung function, the need for rescue medications for acute episodes of asthma, and long term control with inhaled steroid. <u>Assessment of anxiety may help identify individuals who are at risk for poorer asthma specific quality of life</u>. <u>Breathing exercise programmes (including physiotherapist-taught methods)</u> can be offered to people with asthma as an adjuvant to pharmacological treatment <u>to improve quality of life and reduce symptoms</u>." [BTS, 2011]
COPD	<ul style="list-style-type: none"> Clinical COPD questionnaire (CCQ) The Medical Research Council (MRC) dyspnoea scale COPD assessment tool (CAT) St George's respiratory questionnaire (SGRQ) 	<ul style="list-style-type: none"> Use of PROs measures recommended (assessment) Identification of interventions for improving PROs PRO scores linked to clinical management options 	<ul style="list-style-type: none"> "<u>A tool such as the Clinical COPD Questionnaire (CCQ) could be used to assess current health status</u>. Additionally there is evidence that <u>inhaled therapies can improve the quality of life</u> in some patients with COPD." [Quality and Outcomes Framework 2014/2015, COPD-003] "<u>A comprehensive clinical and psychosocial assessment should include</u>, but is not limited to, the following: <u>health status measures</u> (using for example, the COPD assessment tool [CAT] or St George's respiratory questionnaire [SGRQ])." [NICE quality standard 10] "<u>Pulmonary rehabilitation should be offered to all patients who consider themselves functionally disabled by COPD (usually MRC grade 3 and above)</u>. Pulmonary rehabilitation is not suitable for patients who are unable to walk, have unstable angina or who have had a recent myocardial infarction." [NICE CPG CG101].
Depression	<ul style="list-style-type: none"> Patient Health Questionnaire (PHQ-9) Hospital Anxiety and Depression Scale [HADS] Beck Depression Inventory [BDI] 	<ul style="list-style-type: none"> Use of PROs measures recommended (assessment, informing and evaluating treatment) 	<ul style="list-style-type: none"> "When <u>assessing a person with suspected depression</u>, consider using a <u>validated measure (for example, for symptoms, functions and/or disability) to inform and evaluate treatment</u>." [NICE CPG CG90] "Clinicians may wish to use <u>formal assessment questionnaires</u> such as PHQ9, HADS and BDI-II <u>to monitor response to treatment</u>." [Quality and Outcomes Framework 2014/2015, DEP-003]
Diabetes	<ul style="list-style-type: none"> None identified 	<ul style="list-style-type: none"> Generic recommendations 	<ul style="list-style-type: none"> "A specific focus when <u>assessing the patient's quality of life</u> should be placed on the impact of diet, self-monitoring of plasma glucose and other efforts to maintain the individual target for HbA1C (including hypoglycaemia and frequency of injections)." [NICE CPG CG66]
Heart Failure	<ul style="list-style-type: none"> None identified 	<ul style="list-style-type: none"> Identification of interventions for improving PROs 	<ul style="list-style-type: none"> "<u>Diuretics should be routinely used for the relief of congestive symptoms</u> and fluid retention in patients with heart failure, <u>and titrated (up and down) according to need</u> following the initiation of subsequent heart failure therapies." [NICE CPG CG108] "<u>Specialist referral for transplantation should be considered in patients with severe refractory symptoms</u> or refractory cardiogenic shock." [NICE CPG CG108]
Osteoarthritis (hip/knee)	<ul style="list-style-type: none"> Oxford Hip Score (OHS) Oxford Knee Score (OKS) New Zealand Score for Hip and Knee Surgery 	<ul style="list-style-type: none"> Use of PROs measures recommended (assessment, informing and evaluating treatment) Identification of interventions for improving PROs 	<ul style="list-style-type: none"> "The effect of osteoarthritis on the person's <u>function, quality of life, occupation, mood, relationships and leisure activities</u> should be assessed. Regular reviews should be offered to all people with symptomatic osteoarthritis. Reviews should include <u>monitoring the person's symptoms</u> and the <u>ongoing impact of the condition on their everyday activities and quality of life</u>. Referral for joint surgery should be considered for <u>people with osteoarthritis who experience joint symptoms (pain, stiffness and reduced function) that have a substantial impact on their quality of life</u> and are refractory to non-surgical treatment." [NICE CPG CG177] "The <u>use of orthopaedic scores and questionnaire-based assessments</u> to identify people who are eligible for referral for consideration of joint surgery has become widespread. These usually <u>assess pain, functional impairment</u> and sometimes radiographic damage. The commonest are the New Zealand score and the Oxford Hip or Knee score. Many (such as the Oxford tools) were designed to measure population-based changes after surgery, and none have been validated for assessing appropriateness of referral." [NICE quality standard 87]

Evidence for using PROMs in clinical practice

- Greenhalgh, J., & Meadows, K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: A literature review. *Journal of Evaluation in Clinical Practice* 1999;5: 401–416.
- Espallargues M, Valderas JM, Alonso J. Provision of feedback on perceived health status to health care professionals: A systematic review of its impact. *Medical Care* 2000; 38, 175–186.
- Gilbody S, House A, Sheldon T. Screening and case finding instruments for depression. *Cochrane Database of Systematic Reviews* 2005, Issue 4. Art. No.: CD002792.
- Marshall, S., Haywood, K., & Fitzpatrick, R. Impact of patient reported outcome measures on routine practice: a structured review. *Journal of Evaluation in Clinical Practice* 2006;12(5), 559–568.
- Valderas JM, Kotzeva A, Espallargues M, et al. The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Qual Life Res* 2008;17:179-93.
- Knap C, Koesters M, Schoefer D, et al: Effect of feedback of treatment outcome in specialist mental healthcare: meta-analysis. *British Journal of Psychiatry* 2008;195:15–22.
- Valderas JM, Espallargues M, Kotzeva A, Alonso J. Assessing the impact of routinely measuring patient-reported outcomes in clinical practice: critical appraisal of 34 randomized clinical trials. *International Society of Quality of Life Research*. London, UK. November 2010. Published in: *Qual Life Res* 17(Suppl 1), 2010.
- Alsaleh, Khalid. "Routine administration of standardized questionnaires that assess aspects of patients' quality of life in medical oncology clinics: A systematic review." *Journal of the Egyptian National Cancer Institute* 2013;25(2): 63-70.
- Etkind, et al. Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review." *J Pain Sympt Manag* 2014;49(3):611-24
- Kendrick T, El-Gohary M, Stuart B, Gilbody S, Churchill R, Aiken L, Bhattacharya A, Gimson A, Brütt AL, de Jong K, Moore M. Routine use of patient reported outcome measures (PROMs) for improving treatment of common mental health disorders in adults. *The Cochrane Library*. 2016 Jul 13.

Systematic Review of RCTs

- Systematic review of RCT (2008): 28 studies
- Intervention: feedback of PROMs to health professionals (+/- additional interventions) compared to no feedback
- USA (21), UK (5), Canada (1), The Netherlands (1)
- Mental health (50%), generic health status, other
- 65% studies showed some impact on processes (diagnosis, advice/education/counselling)
- 47% studies showed some impact on outcomes (PROMs)
- Most clear benefit for screening/diagnosis of depression
- More recent additional studies are showing increased impact on outcomes

Valderas JM et al. Qual Life Res, 2008

**Routine provision of information on patient-reported
outcome measures to healthcare providers and patients in
clinical practice (Protocol)**

Gonçalves Bradley DC, Gibbons C, Ricci-Cabello I, Bobrovitz NJH, Gibbons EJ, Kotzeva A,
Alonso J, Fitzpatrick R, Bower P, van der Wees PJ, Rajmil L, Roberts NW, Taylor RS,
Greenhalgh J, Porter I, Valderas JM



**THE COCHRANE
COLLABORATION®**

Framework for implementing PROMs in clinical practice

- PRO instrument: valid, responsive, interpretable (actionable: explicit link to clinical activity/task), simple, tailored to the particular setting and purpose
- Feedback system: integrated in clinical information systems, structured, health care professionals and patients, frequent and timely
- Training on the interpretation of scores and outputs

Realist synthesis of individual use of PROMs

Function

- Information exchange, supporting decision-making AND relationship-building
- Supporting patients in raising issues with clinicians rather than changing clinicians' communication practices with patients.
- Shift in clinicians' perceptions of their remit for PROMs feedback to shift clinicians' communication practices or focus discussion on psychosocial issues.

Type of measures

- Patients value both standardised and individualised PROMs (selective approach)
- Standardized:
 - Useful for patients who find it difficult to raise sensitive issues verbally for sharing information with clinicians.
- Individualised PROMs
 - Time consuming, feasibility in primary care or outpatient appointments?
 - Clinicians feel not useful for measuring change over time
 - 'conversation opener' rather than as an 'outcome measure'

Realist synthesis of individual use of PROMs

- Administration

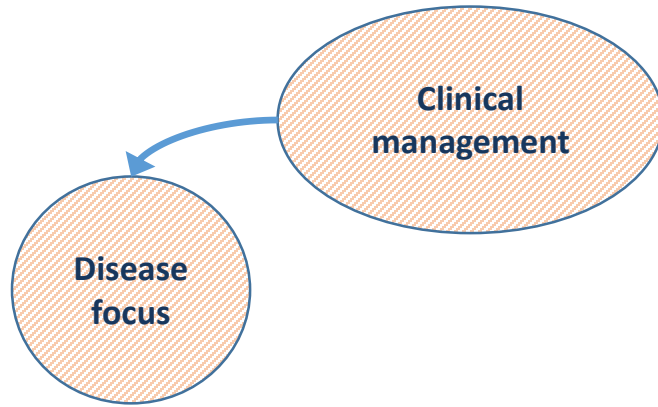
- Nurses!
- PROMs completion may be an emotional experience for some patients (terminally ill), would require support

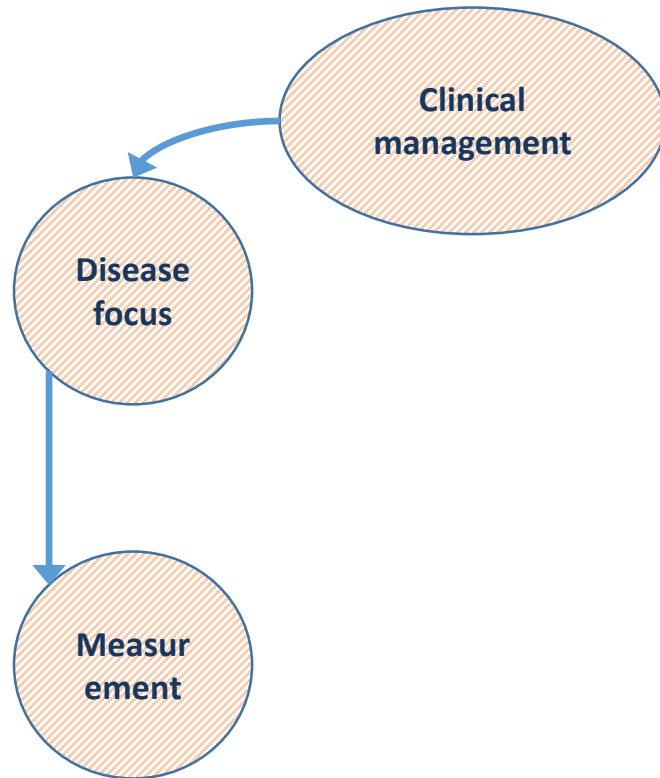
- Recipients

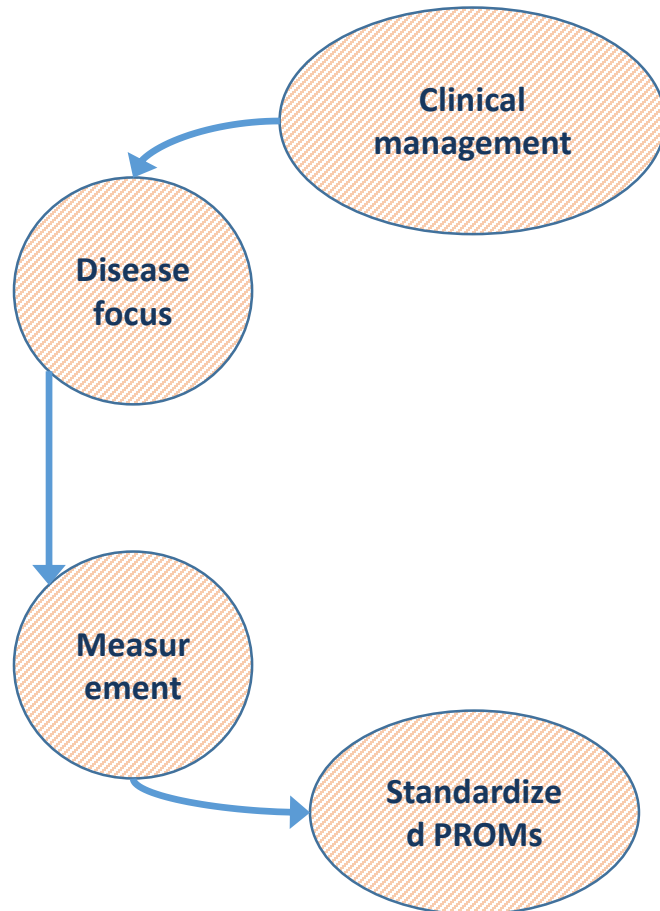
- Accessible to multiple clinicians so that issues can be addressed by those with the appropriate remit (integration into the patients' electronic record).
- Clear division of labour/responsibility among professional groups

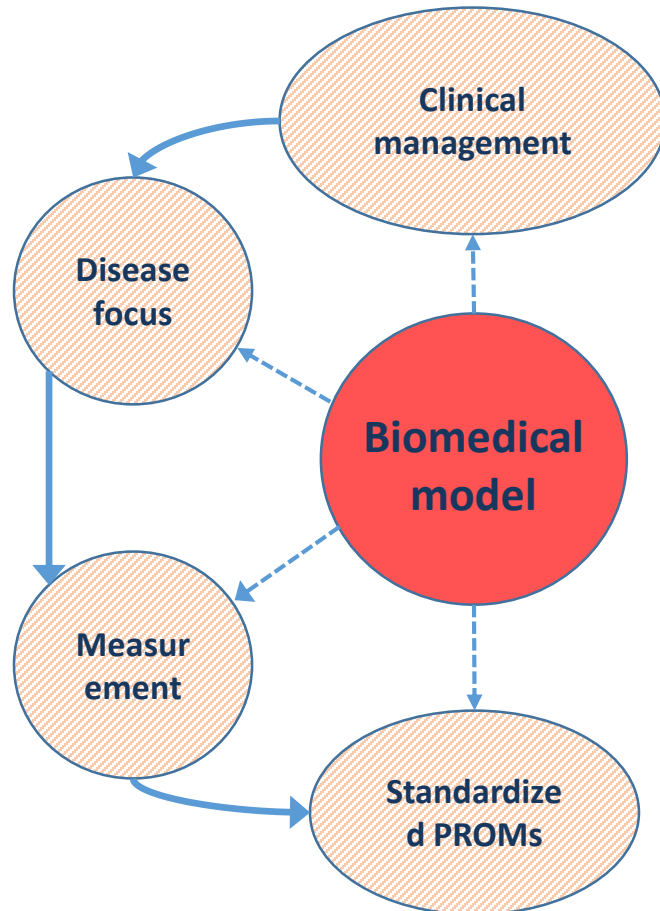
Greenhalgh J, et al. NHR ES&DR 2016 (in press)



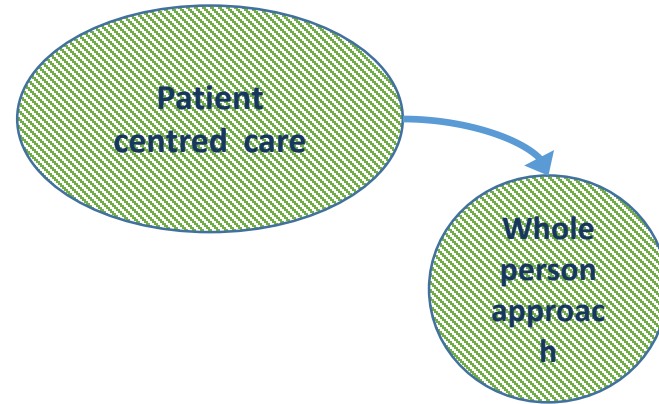


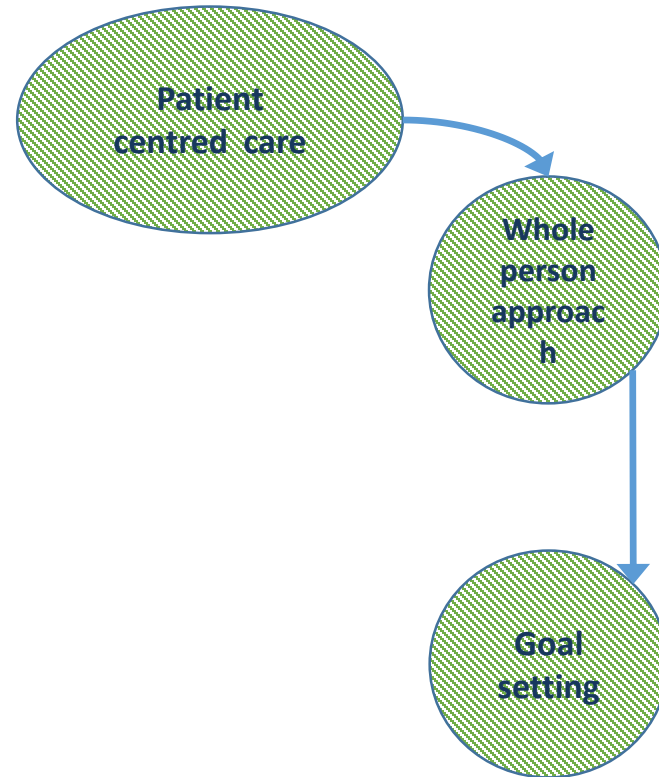


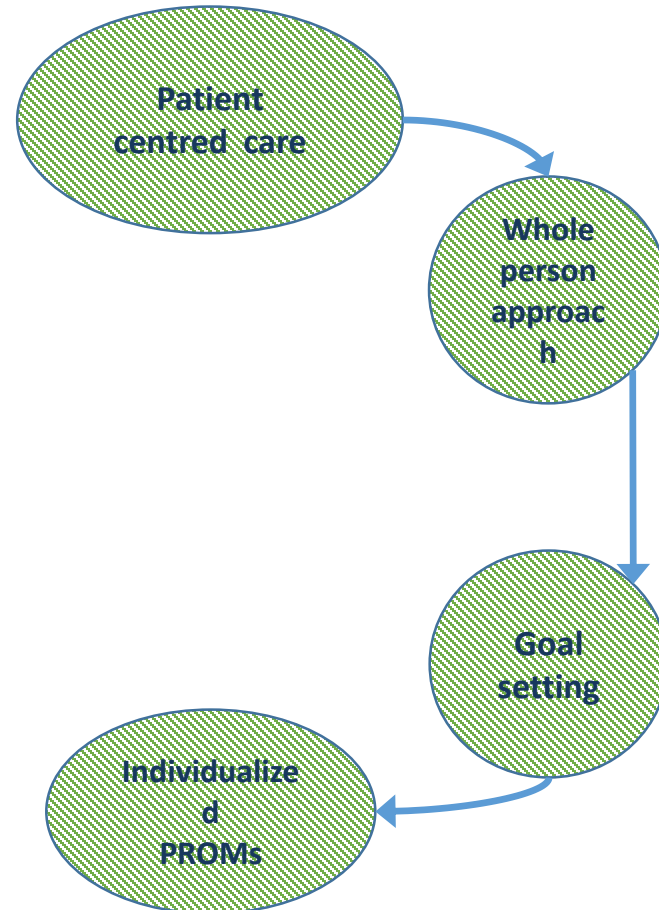


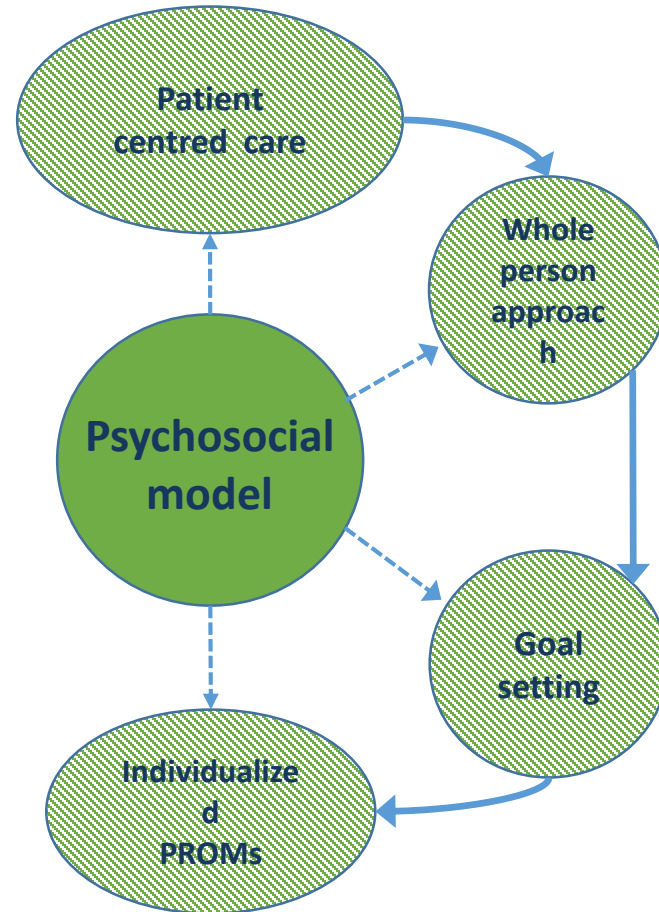


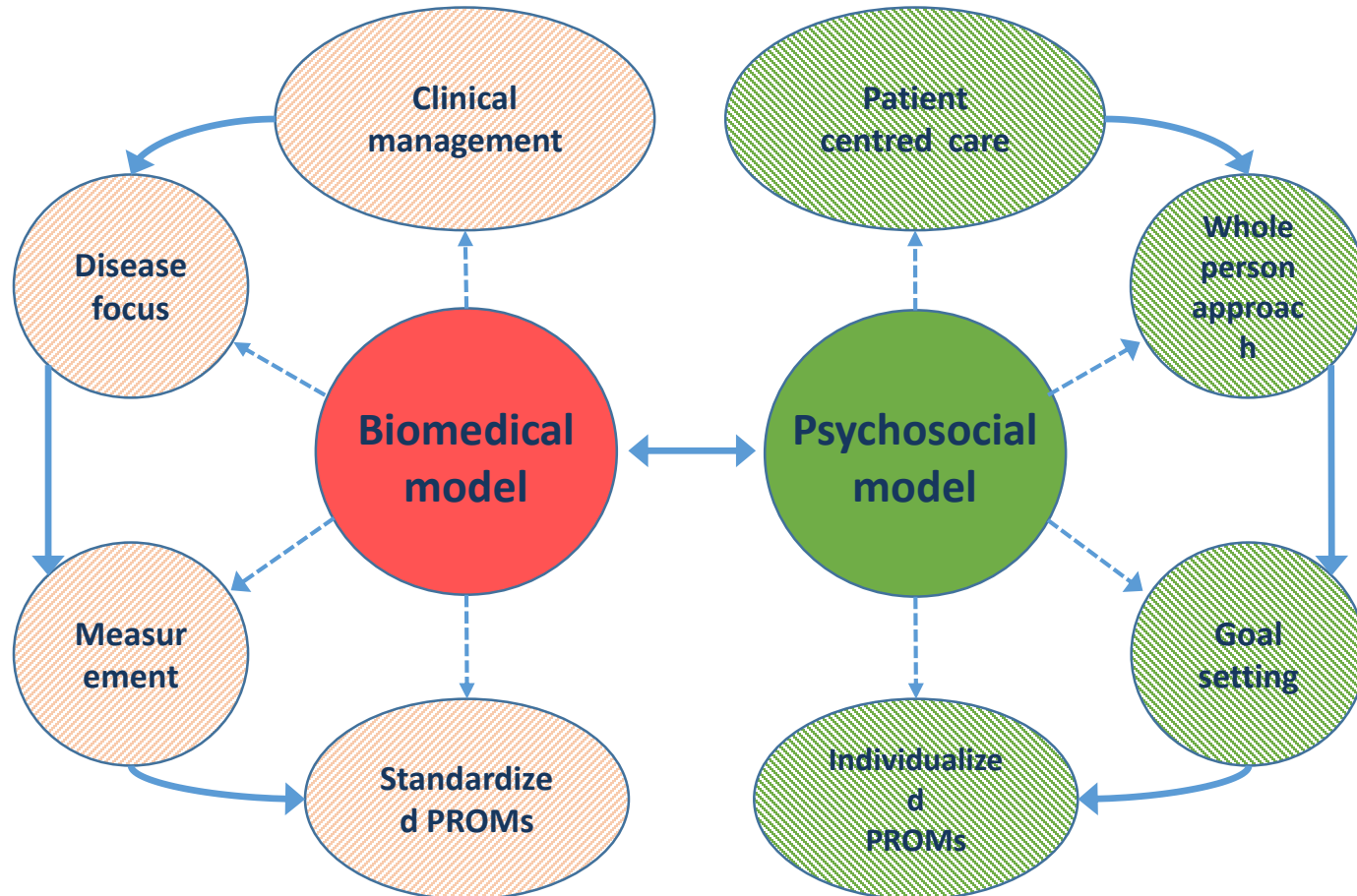


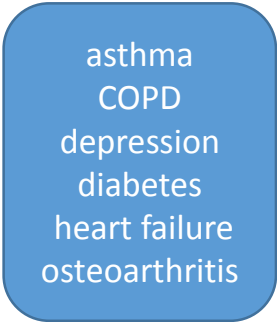




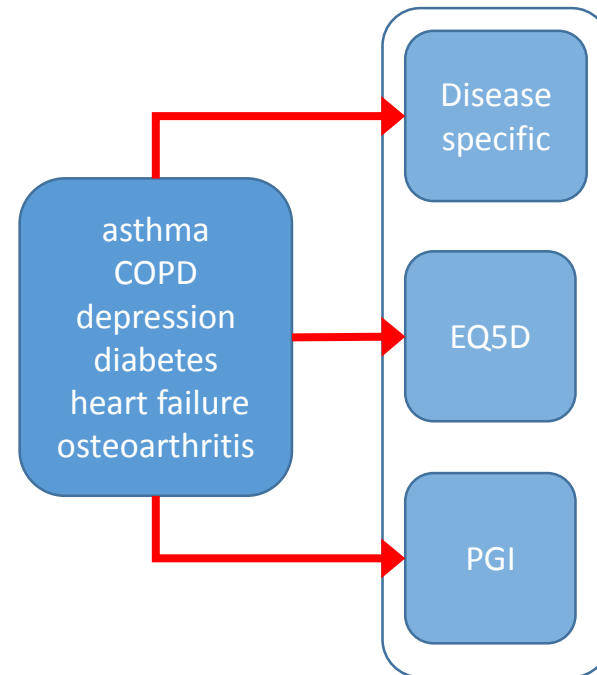


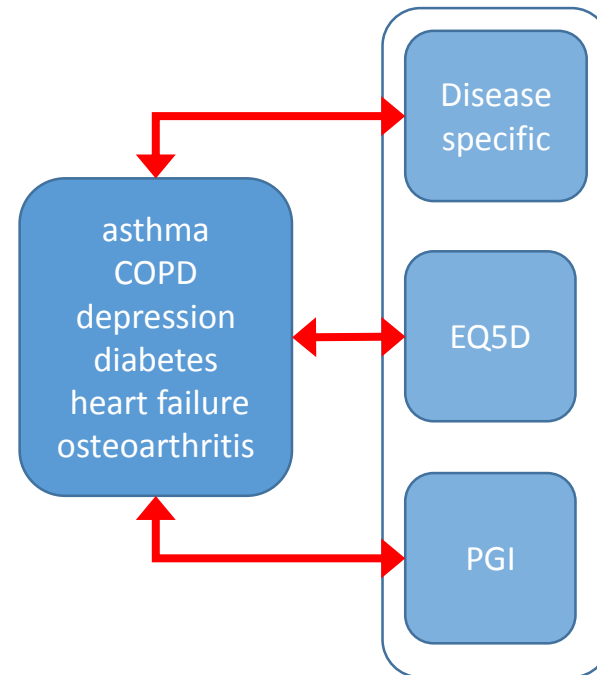


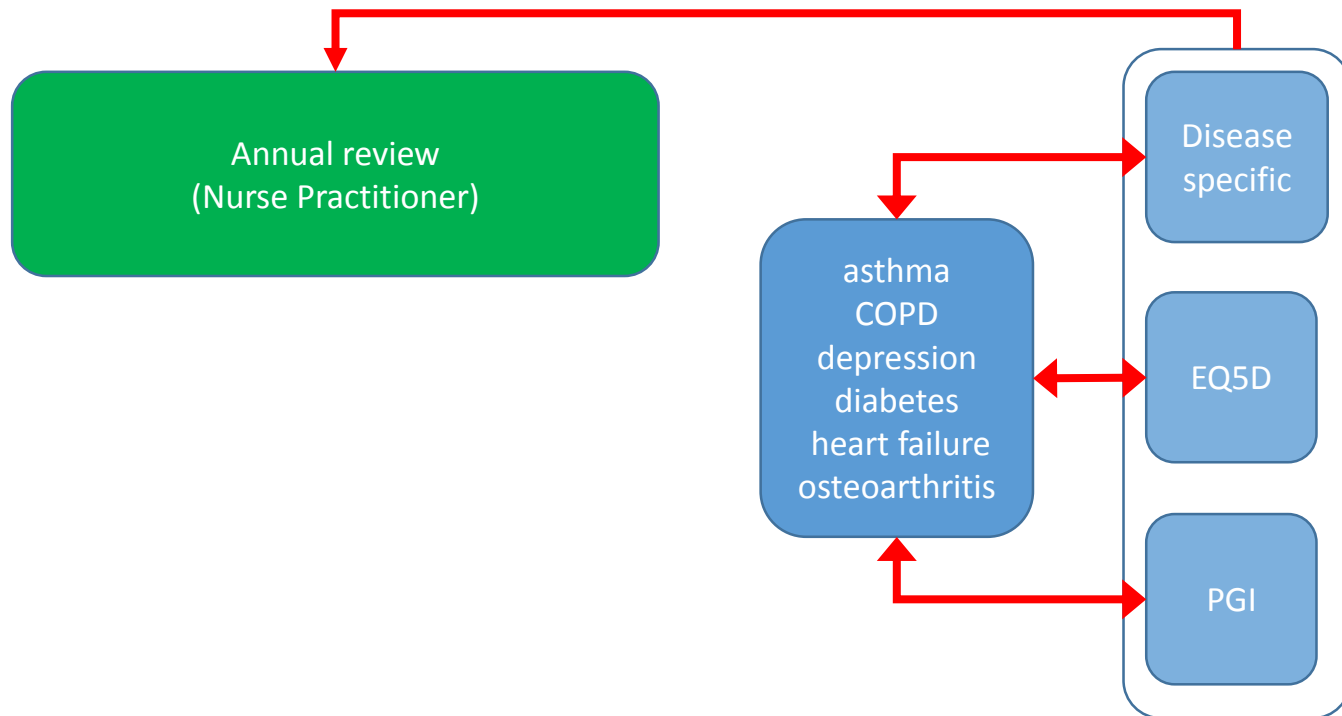


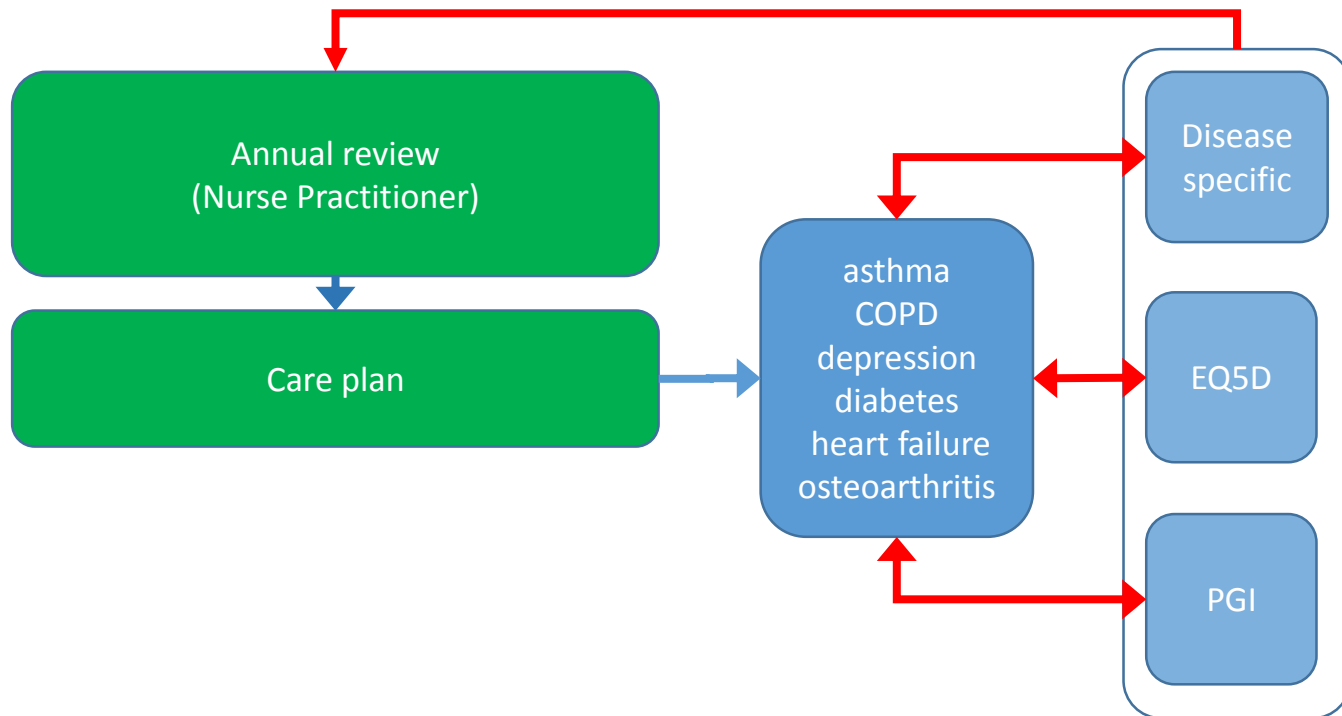


asthma
COPD
depression
diabetes
heart failure
osteoarthritis









ISOQOL User's Guide to Implementing PROs Assessment in Clinical Practice

- What are your goals for collecting PROs in your clinical practice and what resources are available?
- Which key barriers require attention?
- Which groups of patients will you assess?
- How do you select which questionnaire to use?
- How often should patients complete questionnaires?
 - Should it be tied to visits or a way to follow patients between visits?
- How will the PROs be administered and scored?

ISOQOL User's Guide to Implementing PROs Assessment in Clinical Practice

- What tools are available to aid in score interpretation and how will scores requiring follow-up be determined?
- When will results be presented?
- Where will results be presented?
- How will results be presented?
- Who will receive score reports?
- What will be done to respond to issues identified through the PROs?
- How will the value of using PROs be evaluated?

Summary

- Mostly *black box* approach to evaluation in RCTs, progressive improvement in methods
- Increasingly solid evidence on the use of PROMs in clinical practice using a range of methodologies (systematic review, meta-ethnography, realist synthesis)
- PROMs use can improve processes AND outcomes of care
- Research is needed on effectiveness for specific clinical applications and more generally on interpretation, training of health professionals, role of individualized PROMs