UNIVERSITY OF CALGARY
O'Brien Institute for Public Health

W21C

CAMPUS ALBERTA
HEALTH OUTCOMES & PUBLIC HEALTH (HOPH)

The Role of Patient-Reported Outcome Measures in Clinical Practice

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Outline

1. Definitions of PROMs
2. Rationale for Measuring Patient-reported Outcomes
3. Implementation

Key Definitions

Patient-reported outcome (PRO)	Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else. (U.S. FOOD AND DRUG ADMINISTRATION. Guidance for Industry.Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. Federal Register 2009;74(35):65132-133.)
PRO patient-level measure	Tools to assess health condition (e.g., health status and status of physical, mental, and functioning) as perceived by the patient obtained by directly asking the patient to self-report (e.g., PHQ-9)
Performance measure	Numeric quantification of healthcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, clinician, etc.
PRO-based performance measure	A performance measure that is based on patient-reported outcome data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved)

https://www.qualityforum.org/Projects/n-r/Patient-Reported_Outcomes/Patient-Reported_Outcomes

Why Measure PROs?

"You can't manage what you don't measure."

Source: Old management adage.

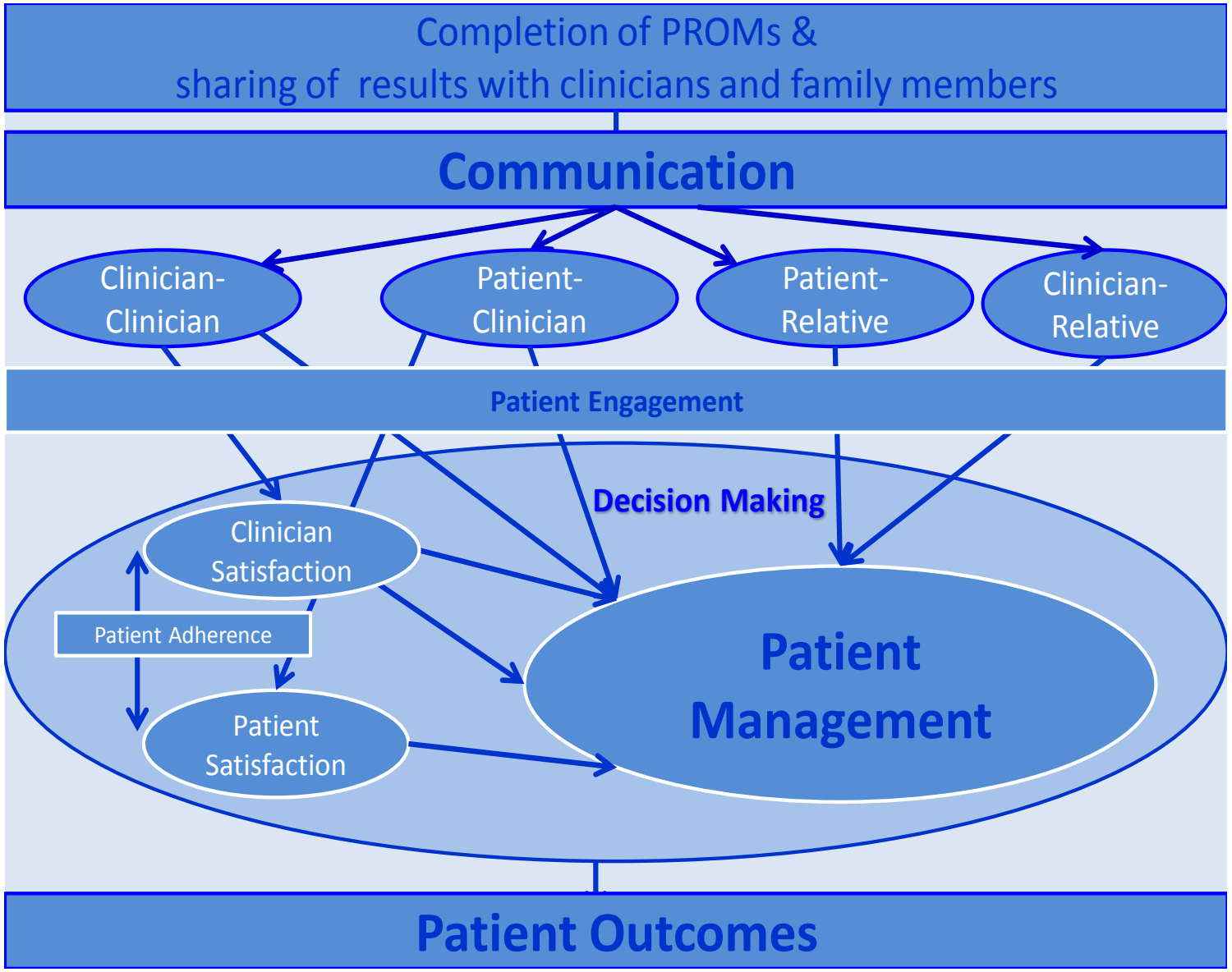
"The underlying reason for using PRO measures in clinical practice is to ensure that treatment plans and evaluations focus on the patient rather than the disease."

Source: Higginson and Carr, 2001, p. 1297.

How to Use PROMs?

- Clinical practice
- Program evaluation
- Quality improvement

Conceptual Model Uses/Effects of PROMs in Daily Clinical Practice



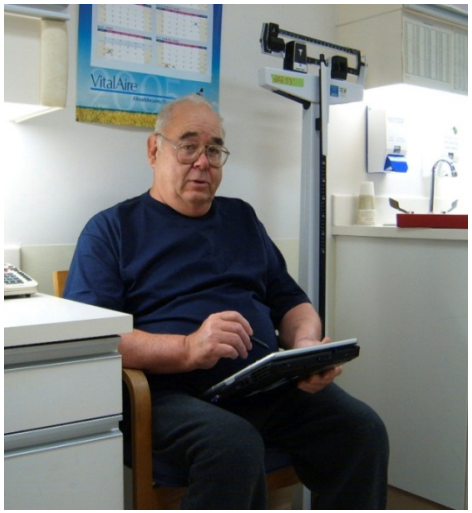
Santana MJ, Feeny D. Framework to assess the effects of using patient-reported outcome measures in chronic care management. Qual Life Res. 2013 Dec 7.

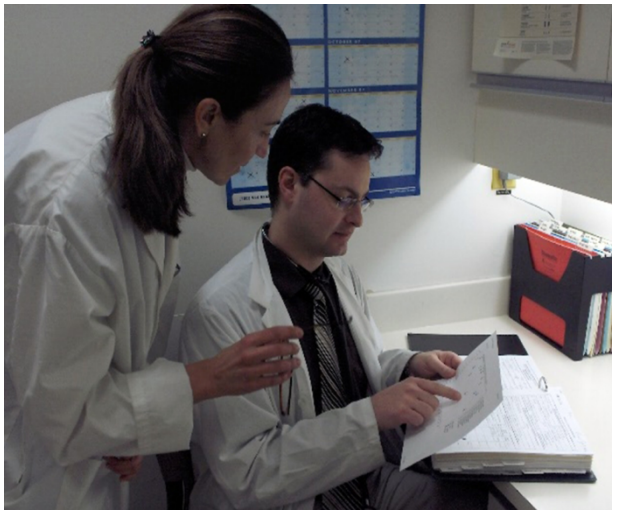
What Has Been Done in Diverse Healthcare Settings?

- Lung Transplant program, University of Alberta Hospital, Edmonton, Alberta, Canada; Cancer Care Ontario, Toronto
- European experience
- USA experience
- New Zealand

Lung Transplantation Outpatient Clinic

University of Alberta Hospital



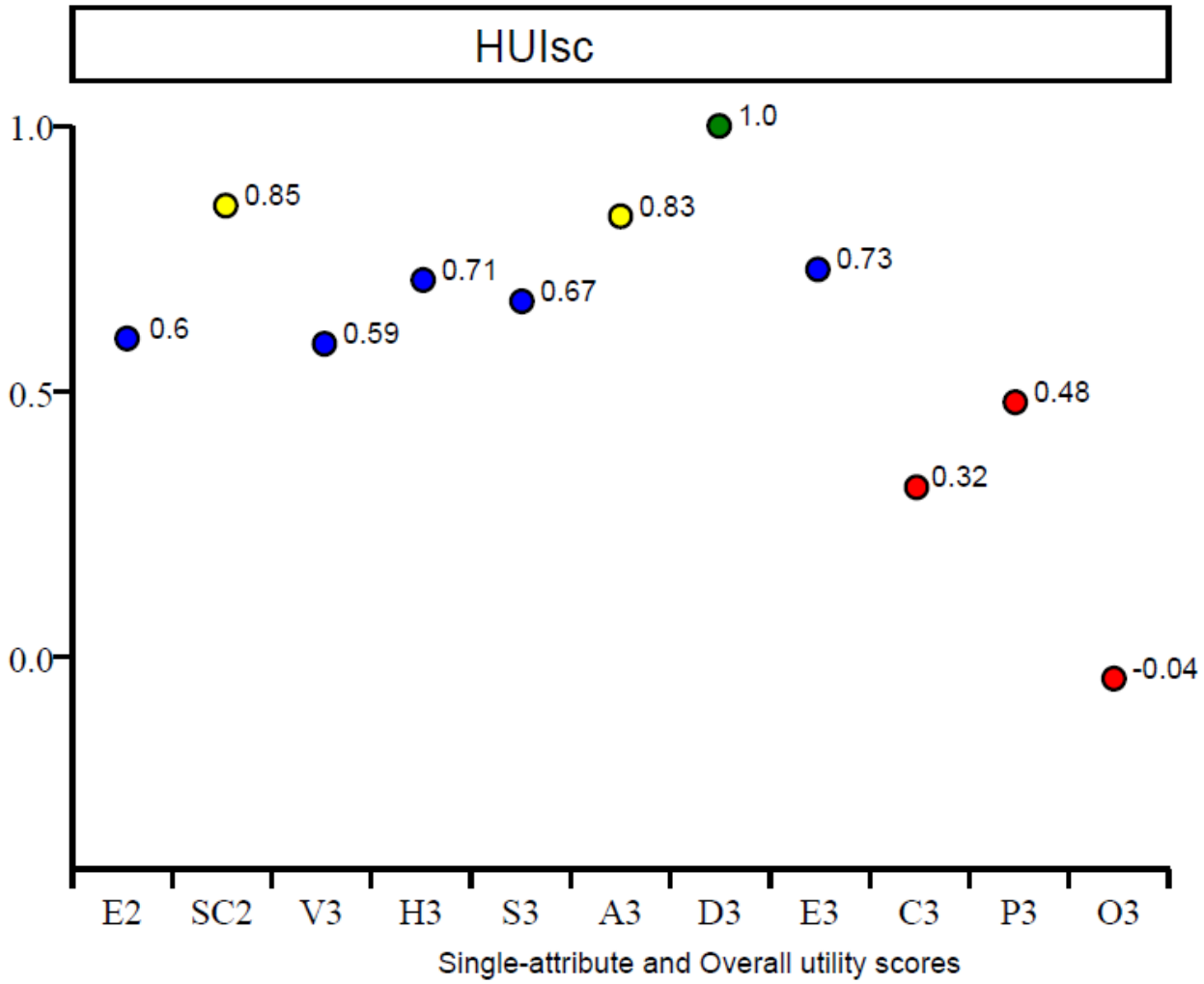


Sources: Santana, Maria J., and David Feeny, "Using the Health Utilities Index in Routine Clinical Care: Process, Feasibility, and acceptability. A Randomized Controlled Trial" *The Patient: Patient-Centered Outcomes Research*, Vol. 2, No. 3, September 1, 2009, pp 159-167

Santana, Maria-Jose, David Feeny, Jeffrey A. Johnson, Finlay A. McAlister, Daniel Kim, Justin Weinkauf, and Dale C. Lien, "Assessing the Use of Health-Related Quality-of-Life Measures in the Routine Care of Lung-Transplant Patients." *Quality of Life Research*, Vol. 19, No. 3, April, 2010, pp 371-379.

HRQL Results

Clinical Interpretation of Results



HUI

Single-attribute utility scores: differences of >=0.05 are important.

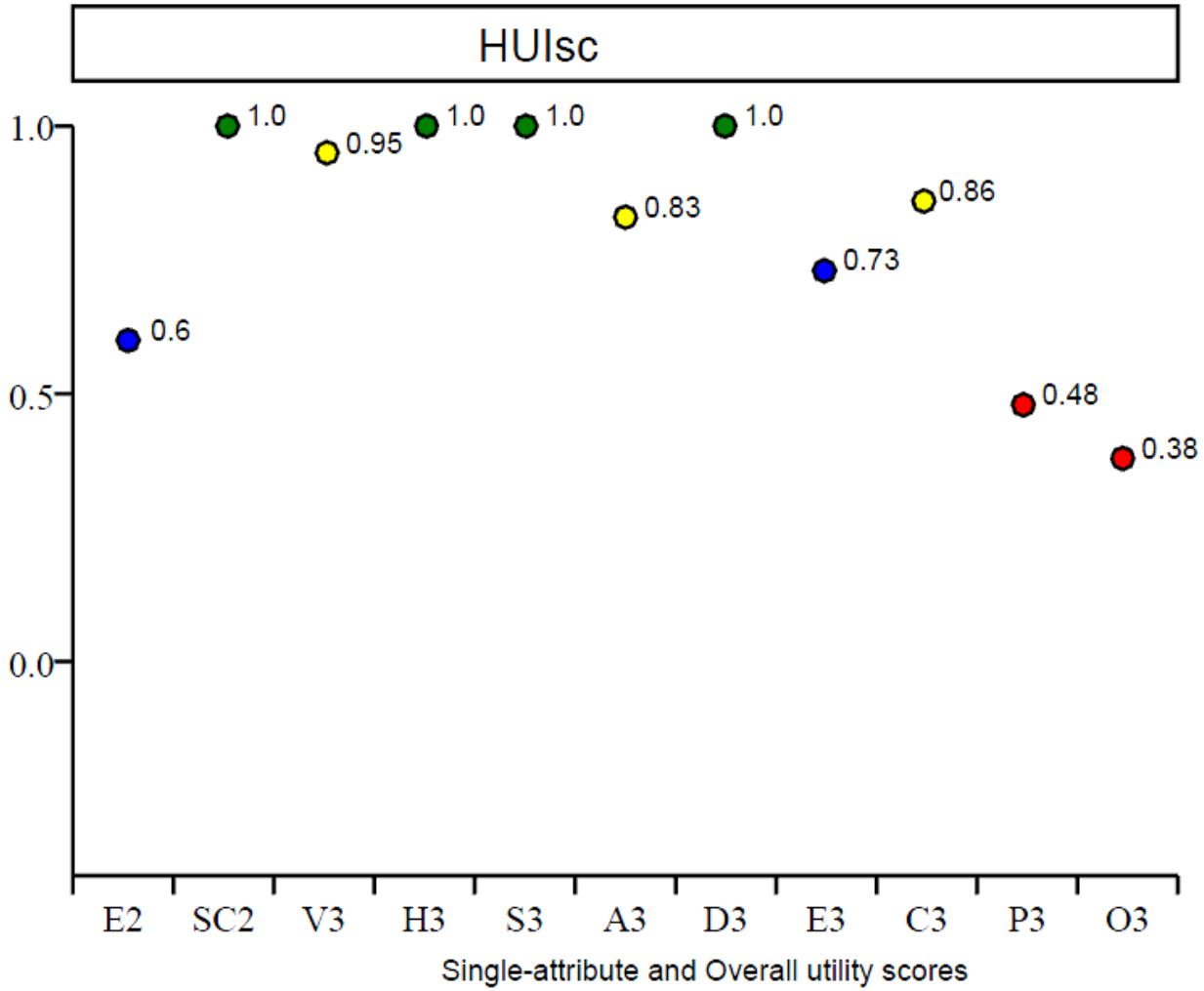
Overall utility score: differences of >=0.03 are important.

PH = Perfect Health
E2 = HUI2 Emotion
SC2 HUI2 Self-care
V3 = HUI3 Vision
H3 = HUI3 Hearing
S3 = HUI3 Speech
A3 = HUI3 Ambulation
D3 = HUI3 Dexterity
E3 = HUI3 Emotion
C3 = HUI3 Cognition
P3 = HUI3 Pain
O3 = HUI3 Overall

Legend:
- = Normal
- = Mild
- = Moderate
- = Severe

HRQL Results

Clinical Interpretation of Results



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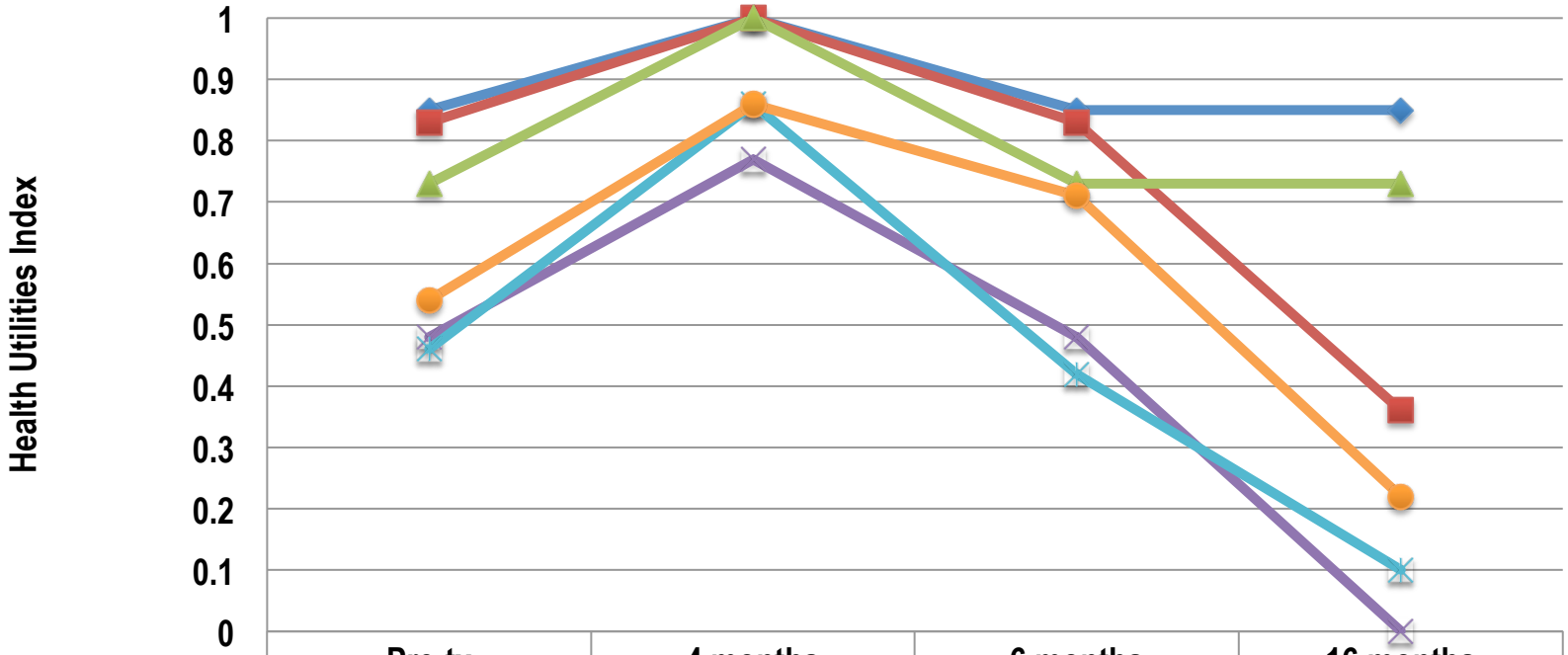
HRQL scores and FEV1% pred *vs.* transplant time



	Pre-tx	4 months	6 months	16 months
Self-care	0.85	1	0.85	0.85
Ambulation	0.83	1	0.83	0.36
Emotion	0.73	1	0.73	0.73
Pain	0.48	0.77	0.48	0
Overall	0.46	0.86	0.42	0.1
FEV1% pred	0.54	0.86	0.71	0.22

Emma Children Hospital, Amsterdam, Netherlands

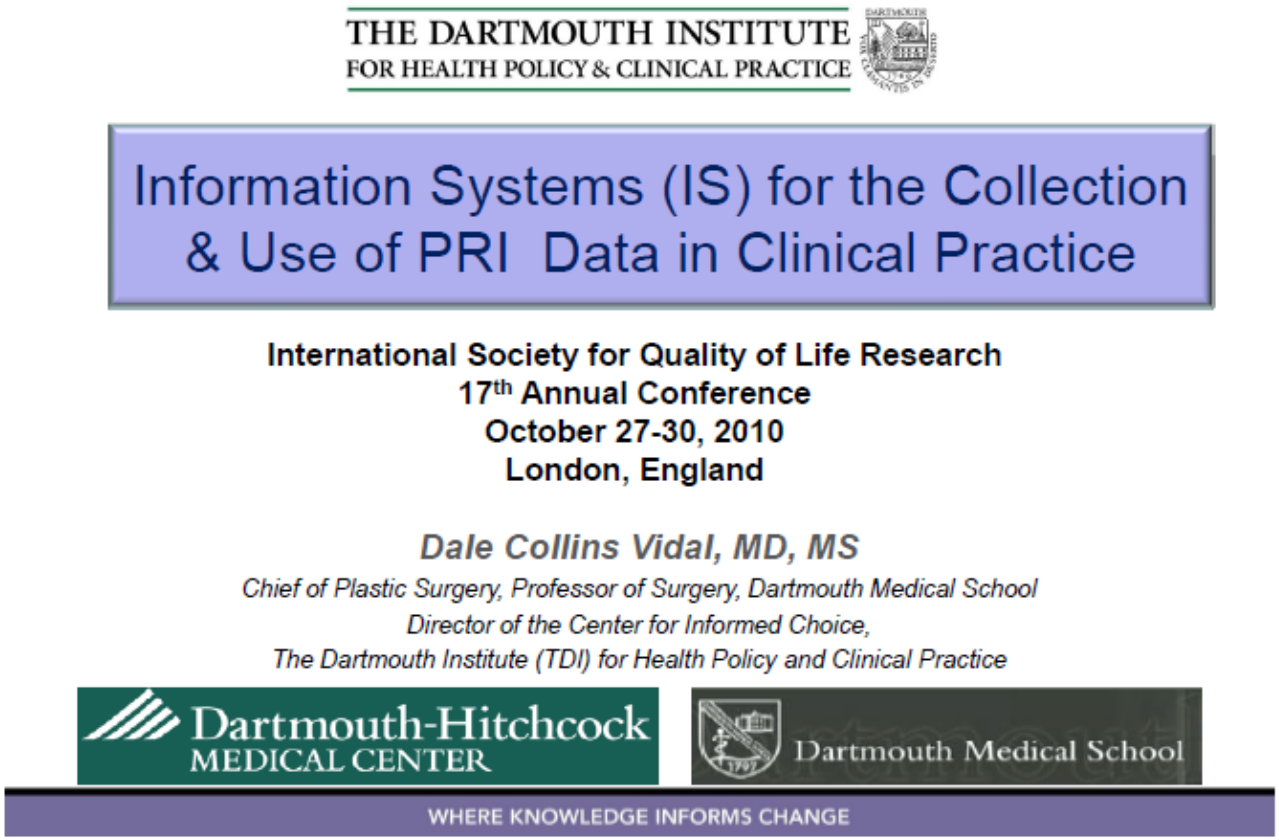
https://www.hetklikt.nu/how.php

Effectiveness of a Web-Based Application to Monitor Health-Related Quality of Life
Lotte Haverman, Marion A.J. van Rossum, Mira van Veenendaal, J. Merlijn van den Berg, Koert M. Dolman, Joost Swart, Taco W. Kuijpers and Martha A. Grootenhuis
Pediatrics; January 6, 2013 ***https://www.hetklikt.nu***

USA Experience

1. Epic Systems Corporation (MyChart, EpicCare)
2. Cleveland Clinic (Knowledge Program)
3. Dartmouth Spine Center
4. Group Health Cooperative (Health Profile e-HRA)
5. Cincinnati Children's Hospital
6. Kaiser Permanente Colorado (PATHWAAY)
7. Essentia Health (MN Community Measurement)
8. University of Pittsburgh Medical Center
9. Duke University (Patient Care Monitor)
10. UCLA/Michigan (My GI-Health)
11. University of Washington/ Centers for AIDS Research Networks of Clinical Systems

USA Experience



Dana Faber Cancer Institute, Boston *http://www.youtube.com/watch?v=6rWtA66Q7OY*

Dartmouth Medical Centre

Improve Quality and Efficiency of the clinical encounter by incorporating

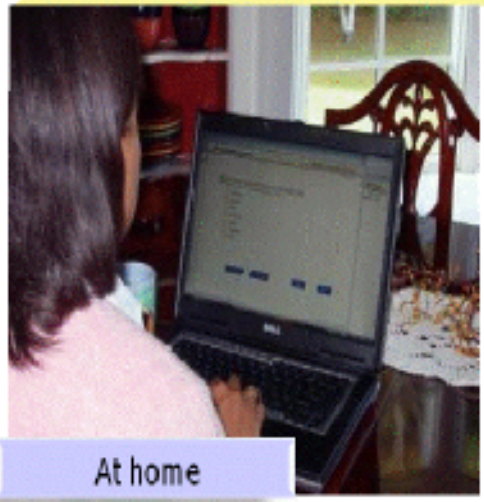
- Patient-reported information systems

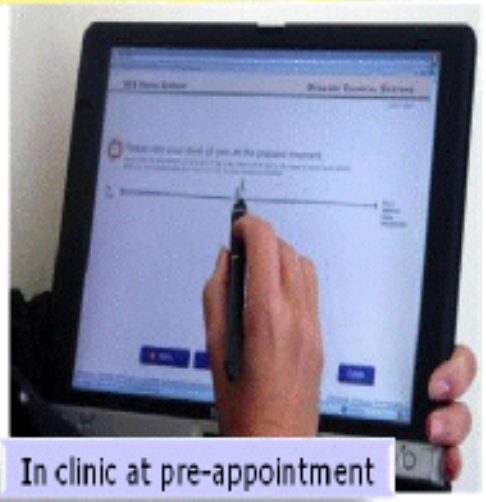
Reports:

- Web accessible at home or clinics
- Incorporated to the EMRs

Integrating ISS into Breast Care

Auto-queue survey → Patient completes survey → Clinician reviews summary report → Social Worker processes referral → Auto-trigger follow-up surveys → Monitor patients at home





1. Auto-email sent with survey instructions
2. Patient signs onto Web to complete survey from home OR
3. Patient sent reminder to come for appointment to complete survey

Breast History

Left breast cancer dx	2004
Right breast cancer dx	2003
Palpable lump?	Left
1st degree relatives with breast cancer:	2
2nd degree relatives with breast cancer:	1
Bra Size:	44DD

Gyn History

History of ovarian cancer?	Yes
Last menstrual period:	w/in last month
Post Menopausal?	No
Hx of HRT?	Yes
Current HRT?	No
1st degree relatives with ovarian ca:	1

ROS and Comorbidities per Charlson index* (Score 3/23)

Current smoker: 2 packs/day x 30 yrs

Drinks: 15/week CAGE Score: 1/4

Positive For

Incr BP	Asthma/meds*
Breast cancer*	PUD*
Admission for mental health	

Surgical History

Positive For

Appendectomy	C-section
Knee Surgery	Tonsillectomy
Tubal Ligation	

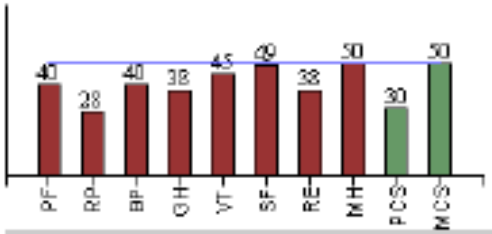
Breast Symptom Questionnaire PSC = 1/7

All or Most of the Time

Physical	Psychosocial
Lower back pain	Difficulty finding clothes
Painful strap grooves	Difficulty with sports
	Difficulty running
	Unwanted attention

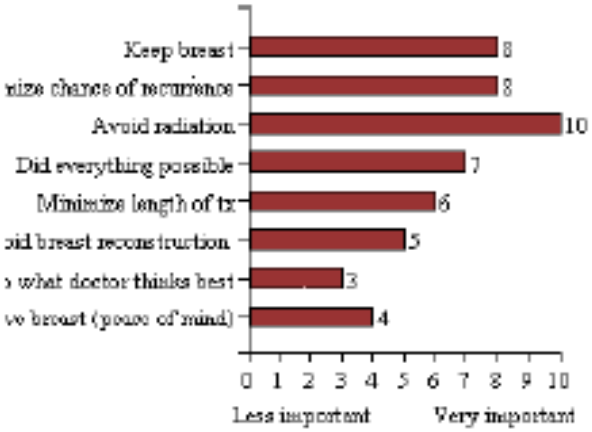
Surgeon:
Smith, William / 2/17/2005
Jones, Kim / / appt date N/A
Height: 5'5" **Weight (lbs):** 205
BMI: 34.1 **BSA:** 2.00

nean=50, standard dev=10



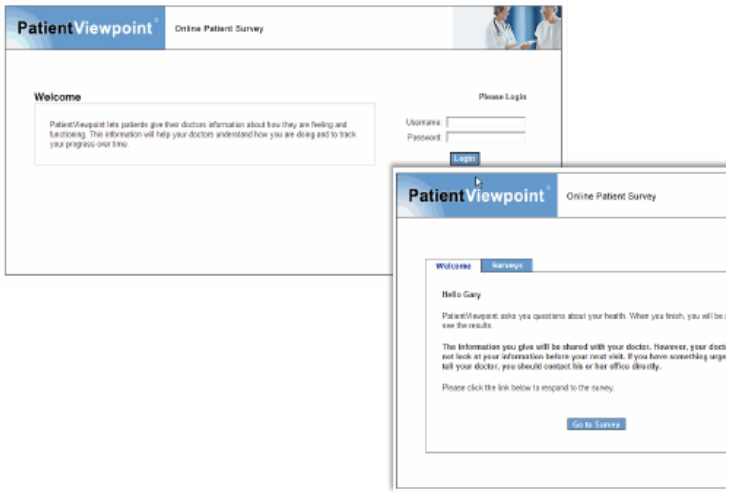
ss Level :
ate : 7.0 / 10
ral to a breast care coordinator has been made. A
l for familial counseling has been made

s : Decision Making
ng toward : Mastectomy
about choice : No
ledge :
rstands :
urvival rates
ecurrence rates



PatientView

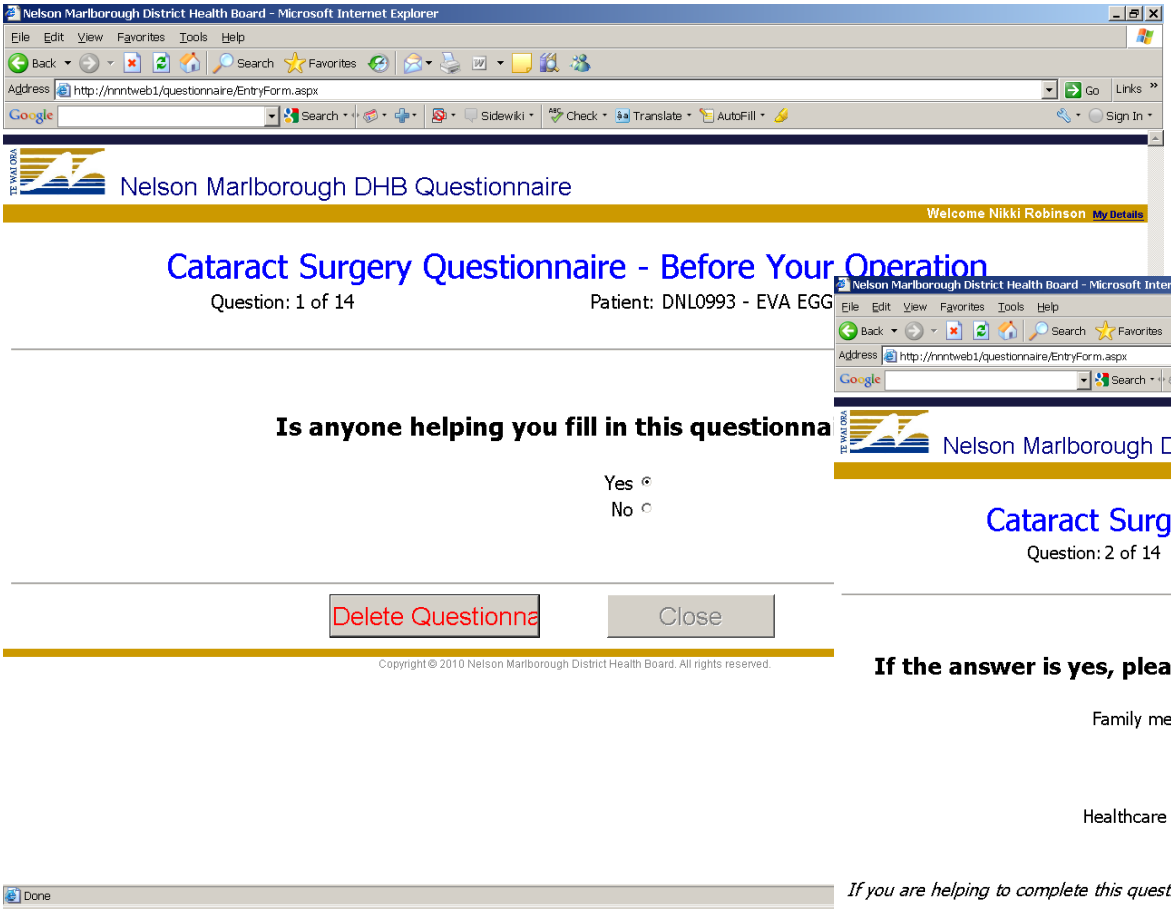
Patient Logs In

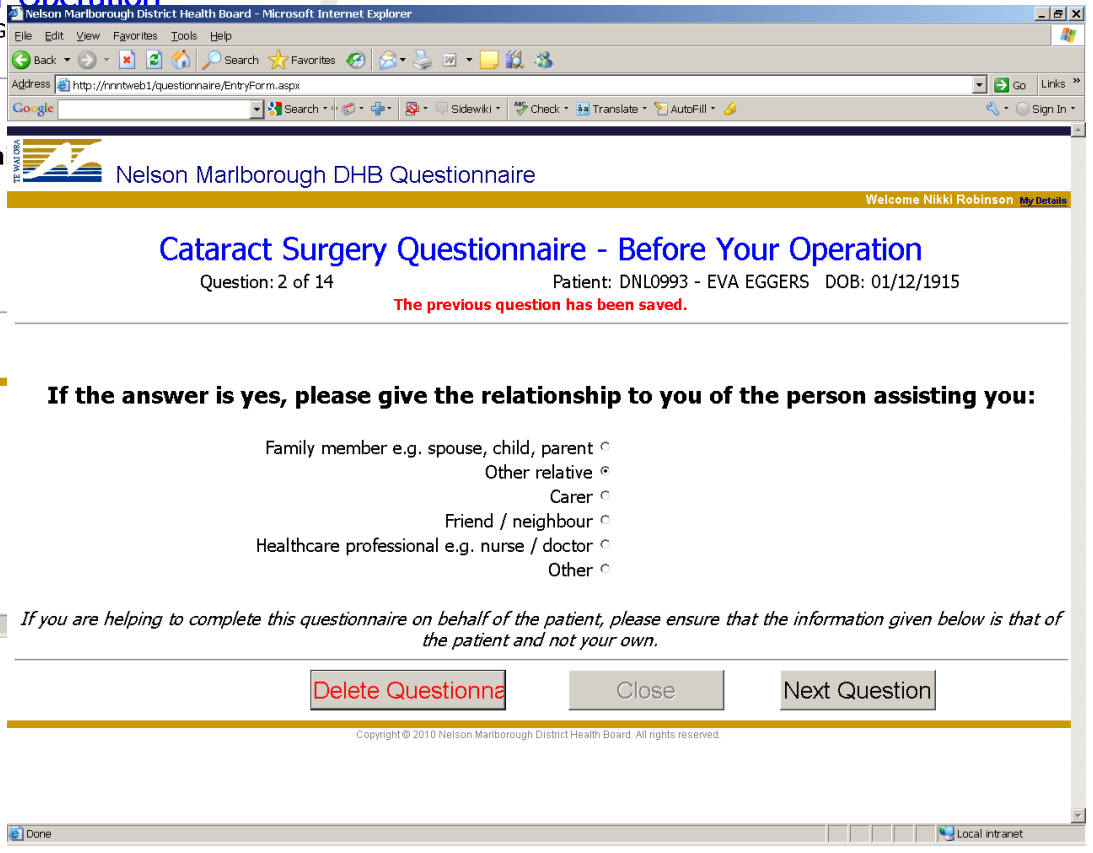


Patient Selects and Begins Survey

[Johns Hopkins Hospital](http://www.youtube.com/watch?v=S-r4ykaUhfU)
http://www.youtube.com/watch?v=S-r4ykaUhfU

New Zealand National IT/IS Strategy

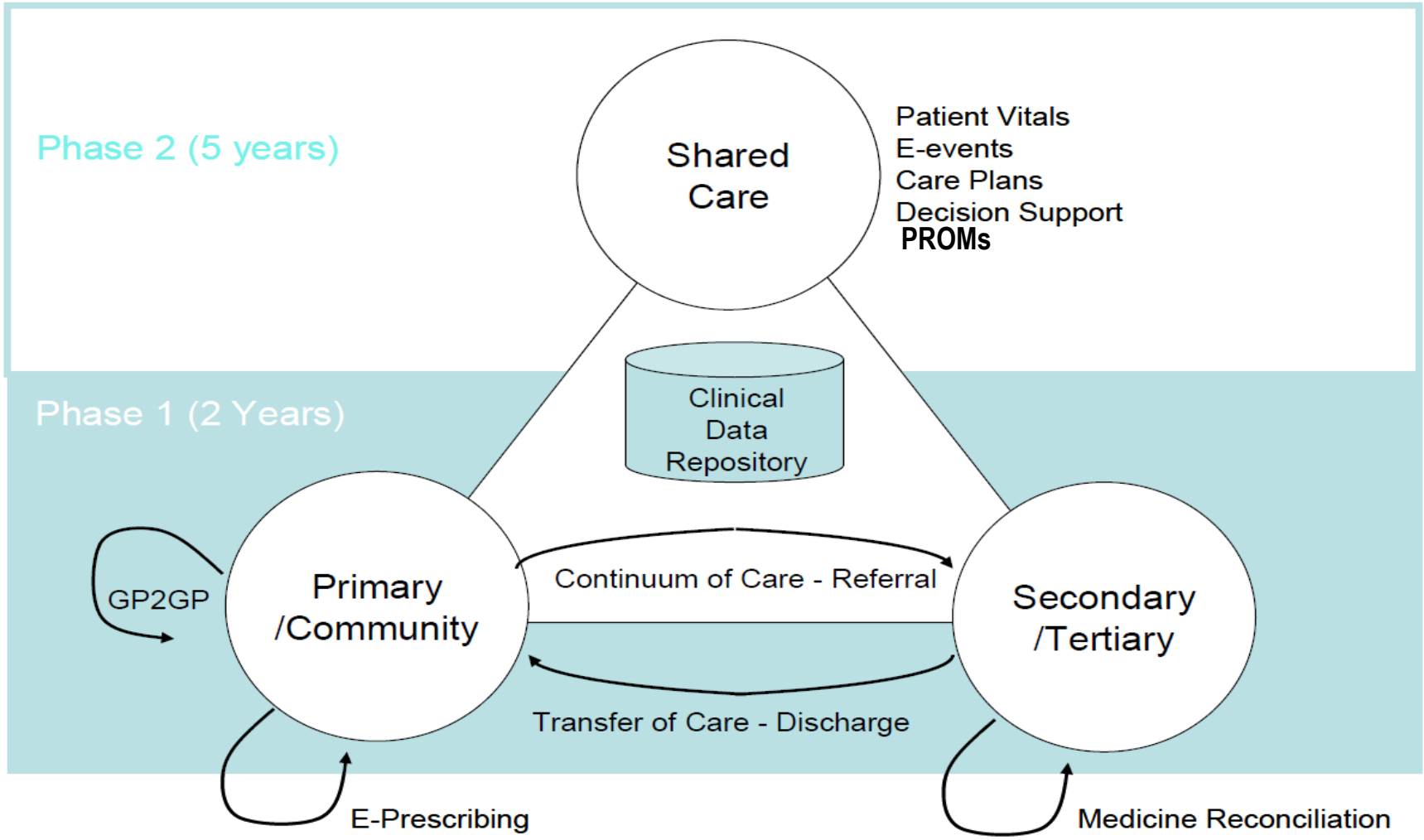




Dr Sharon L Kletchko

New Zealand National IT/IS Strategy

"Enabling an integrated healthcare model"



Individual-PROMs in Daily Clinical Practice

Qual Life Res
DOI 10.1007/s11136-011-0054-x

REVIEW

Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations

Claire F. Snyder · Neil K. Aaronson · Ali K. Choucair · Thomas E. Elliott · Joanne Greenhalgh · Michele Y. Halyard · Rachel Hess · Deborah M. Miller · Bryce B. Reeve · Maria Santana

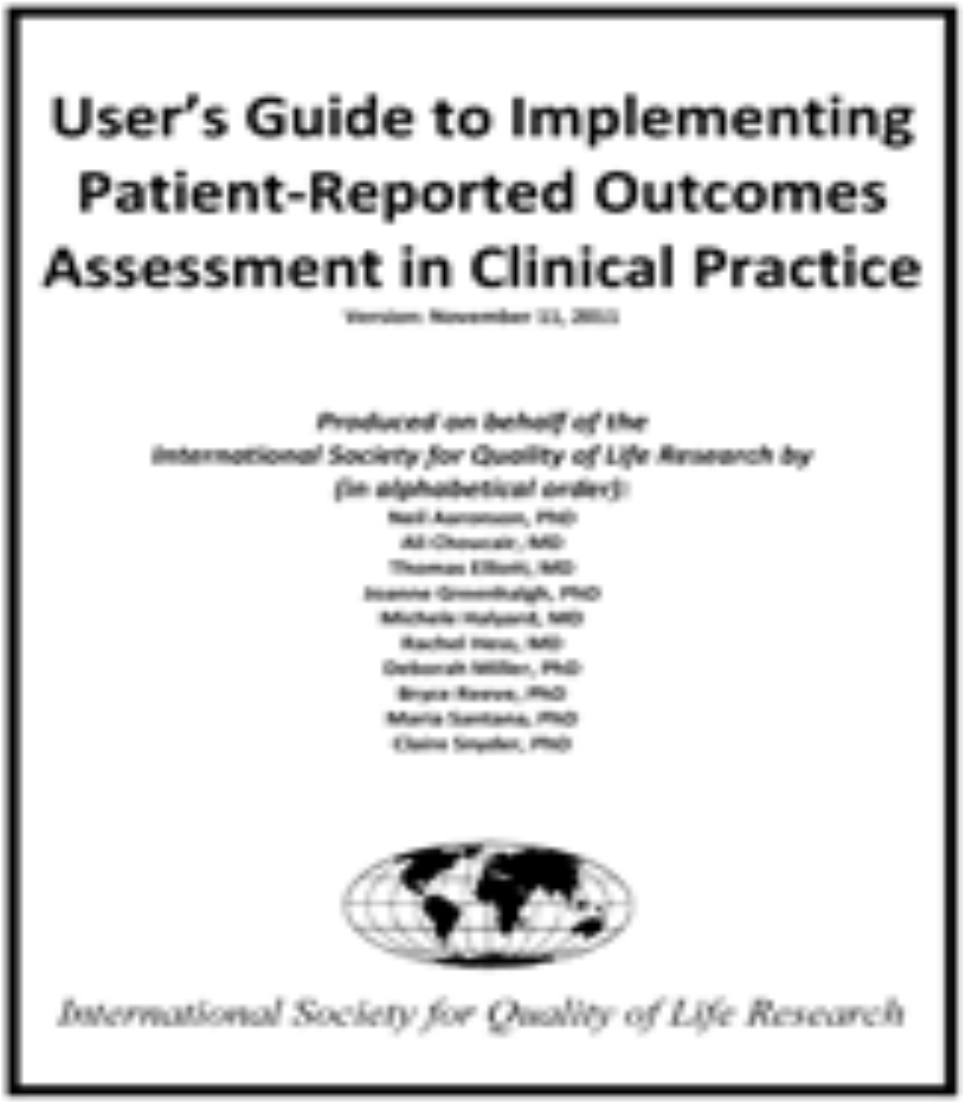
Accepted: 18 October 2011

Implementation: A Review of the Options and Considerations

- Identifying the goals for collecting PROs in clinical practice
- Selecting the patients, setting, and timing of assessments
- Determining which measure(s) to use
- Choosing a mode for administering and scoring the questionnaire

Implementation: A Review of the Options and Considerations

- Designing processes for reporting results
- Developing strategies for responding to issues identified by the questionnaires
- Evaluating the impact of the PRO intervention on the practice



Available at: http://www.isoqol.org/

Need I Say More?

"…we have the instruments and we have the technologies to collect, store, and transmit the data.

What is needed now is the will to measure output

(outcomes) and not just inputs."

D. Feeny / Journal of Clinical Epidemiology 66 (2013) 706-709)

Summary

- PROMs are health measurements elicited from the patients
- PROs can be used in clinical practice
- PROMs are here to stay