The validation and use of patient-reported outcome and experience measures in older adult populations

Rick Sawatzky, PhD, RN
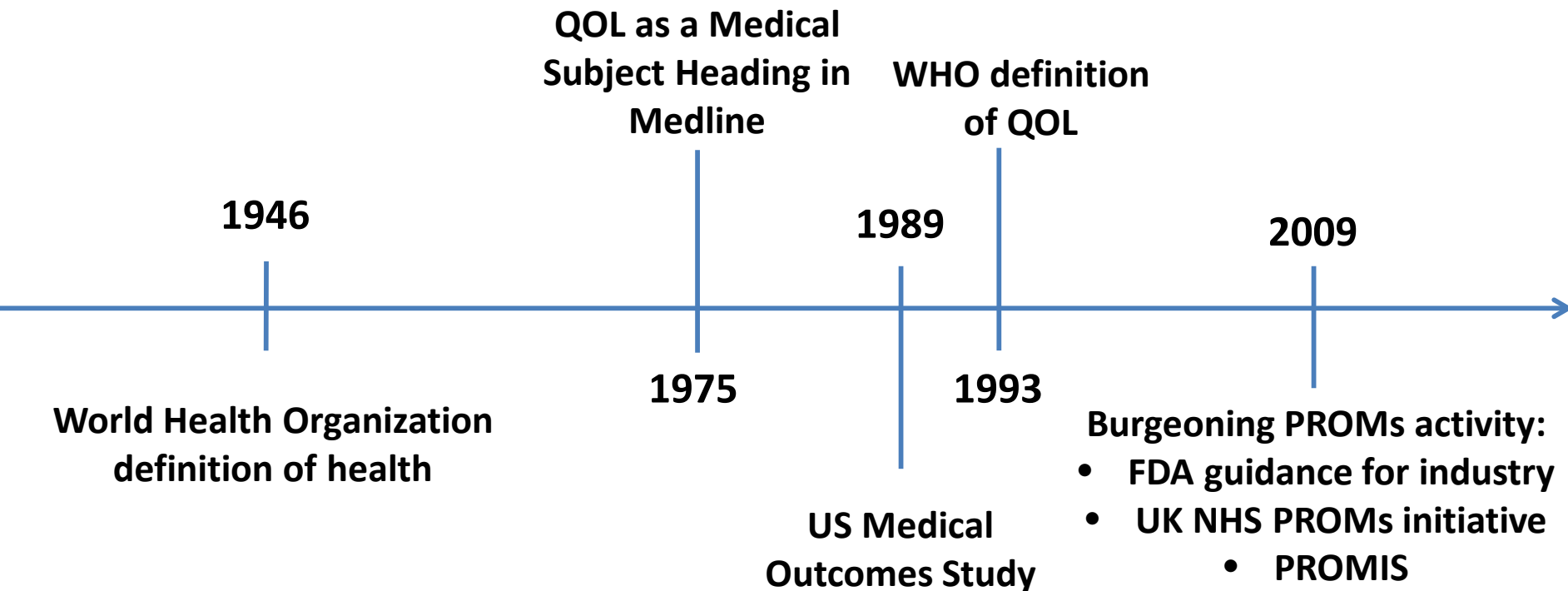
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Objectives

- Introduction to PROMs and PREMs: Report on the results of a knowledge synthesis of PROM and PREM instruments for older adults in acute care

- Contextualize the use of PROM and PREM instruments in relation to modern perspectives of measurement validation

- Clinician and patient perspectives regarding the use of an electronic (tablet-based) quality of life assessment and practice support system (QPSS) in palliative home
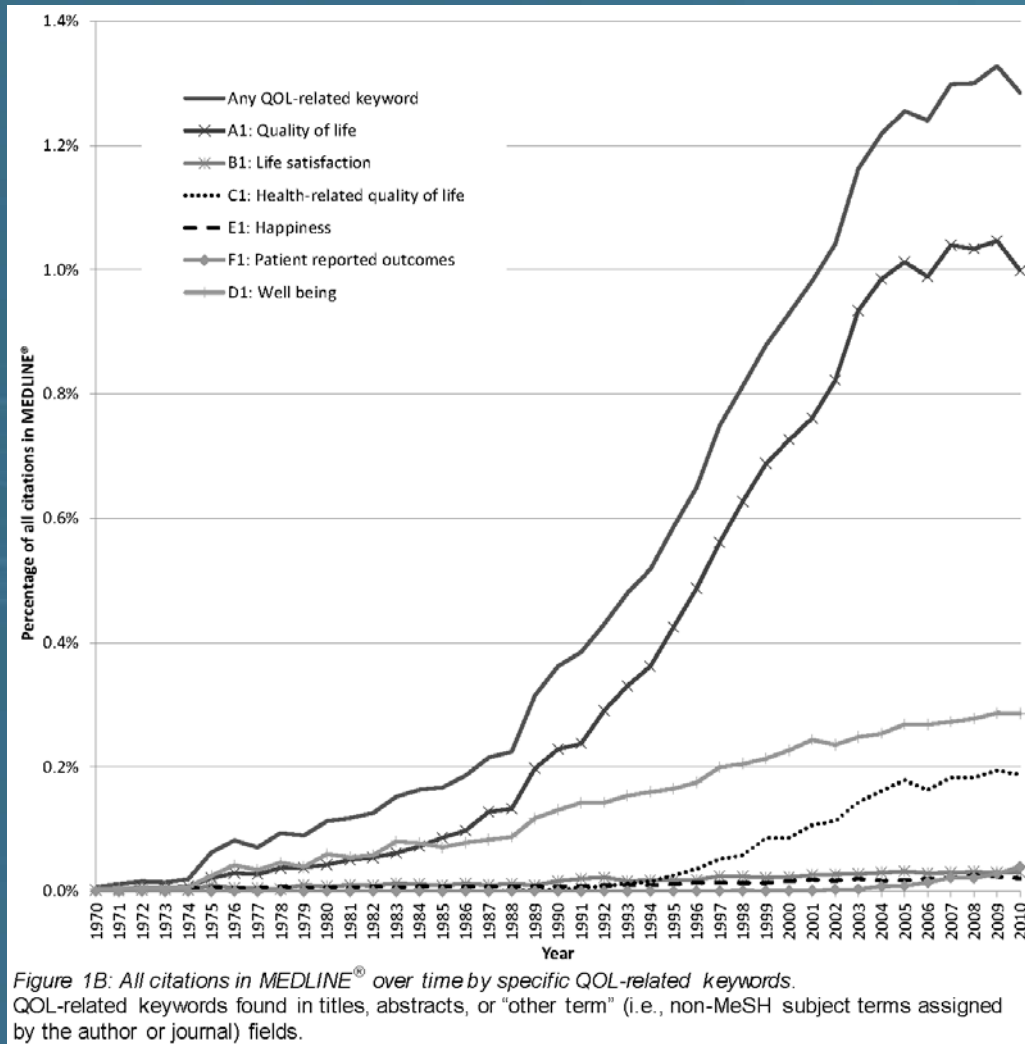
Background on PROMs and PREMs

Quality of Life and Patient-Reported Outcomes in health services and research

QOL as a Medical Subject Heading in Medline

WHO definition of QOL

1946

1989

2009

1975

1993

World Health Organization definition of health

Burgeoning PROMs activity:
- **FDA guidance for industry**
- **UK NHS PROMs initiative**
- **PROMIS**

US Medical Outcomes Study

- Increasing emphasis on understanding the impact of illness and healthcare services on people's daily lives

- This includes individuals' perspectives of their symptoms, functional status, and physical, social, and emotional wellbeing

Increasing emphasis in health research

Figure 1B: All citations in MEDLINE® over time by specific QOL-related keywords.
QOL-related keywords found in titles, abstracts, or "other term" (i.e., non-MeSH subject terms assigned by the author or journal) fields.

March 2014 update

- **233,754 PubMed citations** use QOL-related terms in the article title or abstract (2% of all PubMed citations in 2013)

- **3,637 PubMed citations** use the term "patient-reported outcomes" (1,067 in 2013)

Sawatzky, R., & Ratner, P. A. (2014). Medline.
In A. Michalos (ed.).
Encyclopedia of well-being quality of life.
New York: Springer

Person-centered outcomes and experiences

Essential building blocks for person-centered care

"Our aim should be to find out what each patient wants, needs, and experiences in our health care system" M. Gerteis et al. (1993)
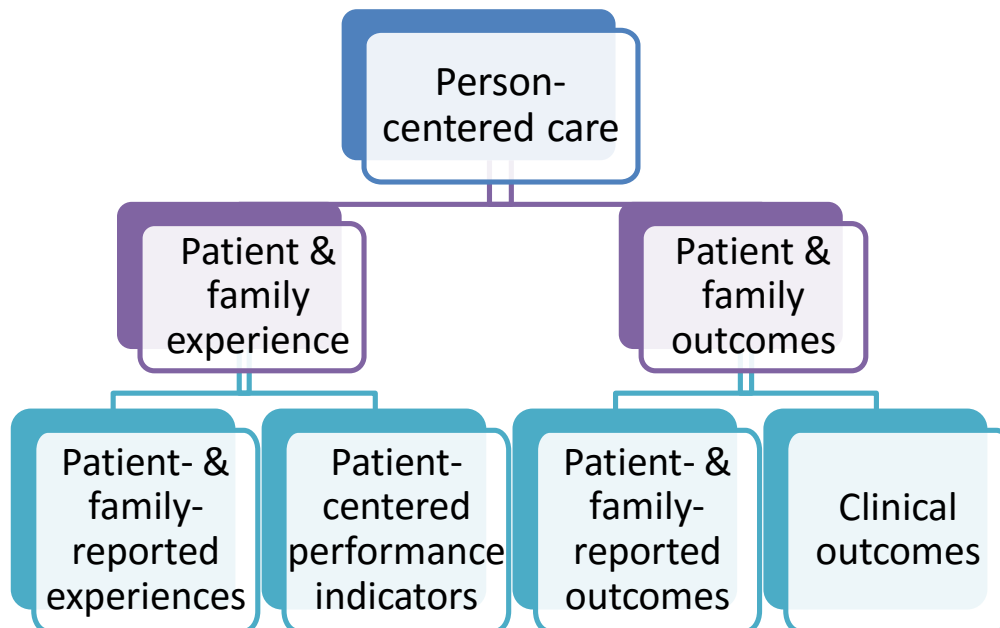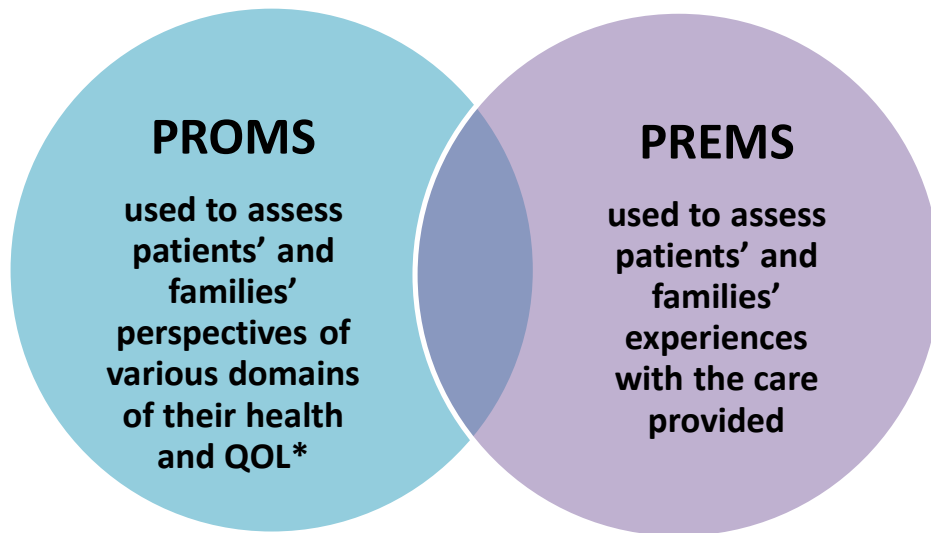

The imperative for person-centered care requires that the full range of healthcare needs relevant to the quality of life of palliative home care clients, and of their family caregivers, is routinely assessed.

Patient- and family-centred outcomes and experiences

Essential building blocks for patient- and family-centered care

Patient-Reported Outcome Measures (PROMs) and **Patient-Reported Experience Measures (PREMs),** provide information about patients' perspectives of their quality of life (QOL) and healthcare experiences without prior interpretation by a clinician or any other person.

Self-report instruments that facilitate measurement of quality of life, including the health outcomes and healthcare experiences of patients and their family caregivers.

PROMS
used to assess patients' and families' perspectives of various domains of their health and QOL*

PREMS
used to assess patients' and families' experiences with the care provided

* includes overall health, physical symptoms, mental health, social health and existential wellbeing
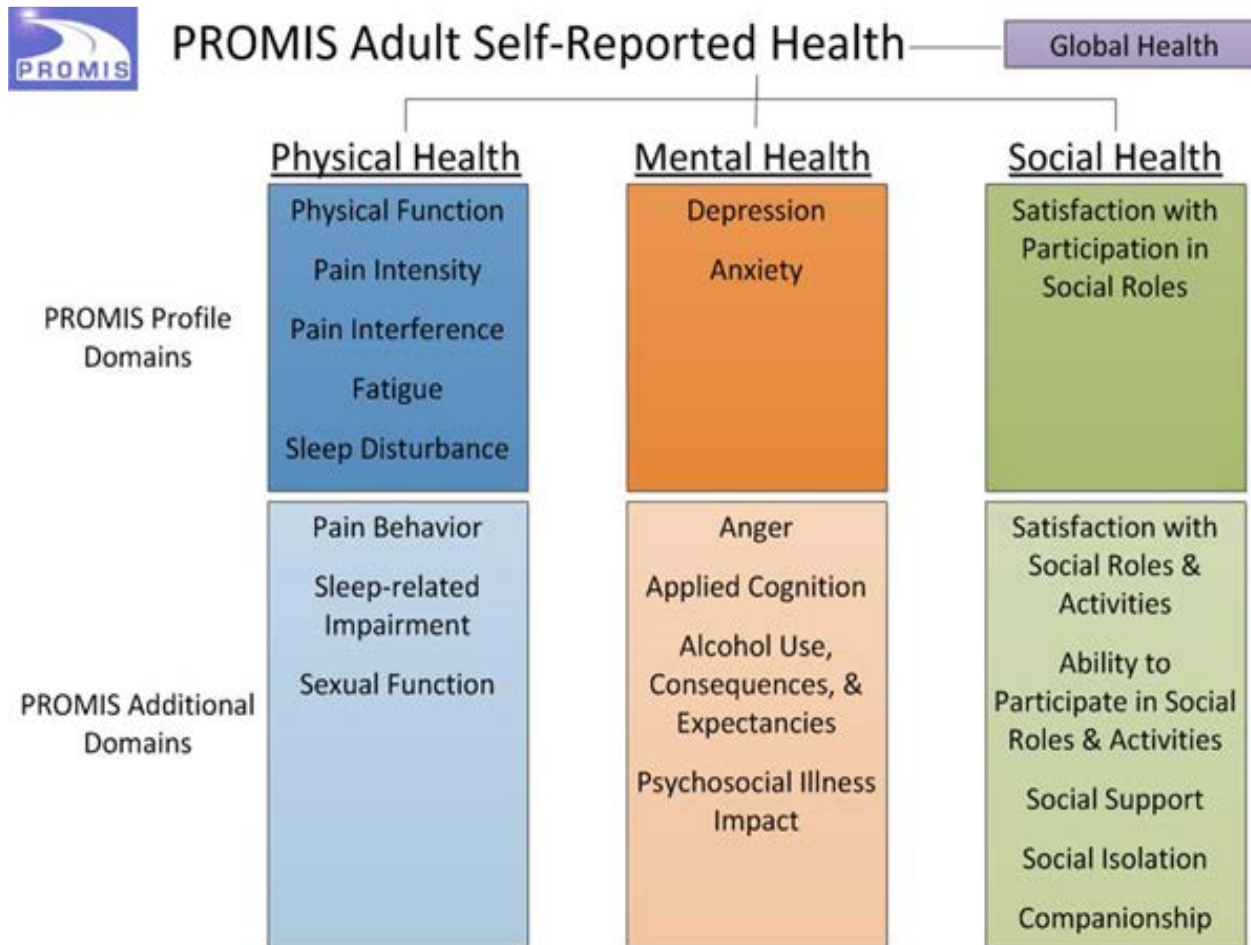
Patient-reported outcome measures (PROMs)

- **Self-report instruments** used to obtain healthcare recipients' appraisals of their health status.

- Most PROMs are **multidimensional** in that they address various domains of human experience, including symptoms, functional status, and psychological and social and spiritual wellbeing.

- PROMs provide information about **patients' perspectives of their health and quality of life** without interpretation by a clinician or any other person.
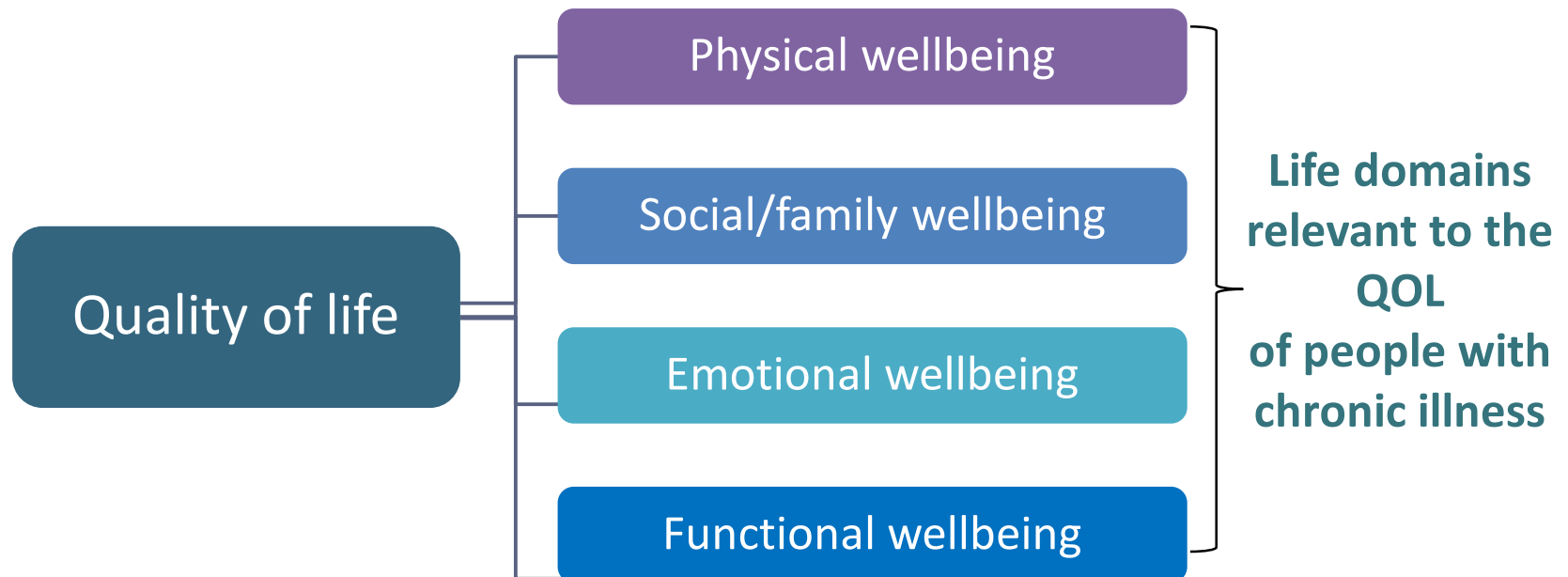
What do PROMs measure?

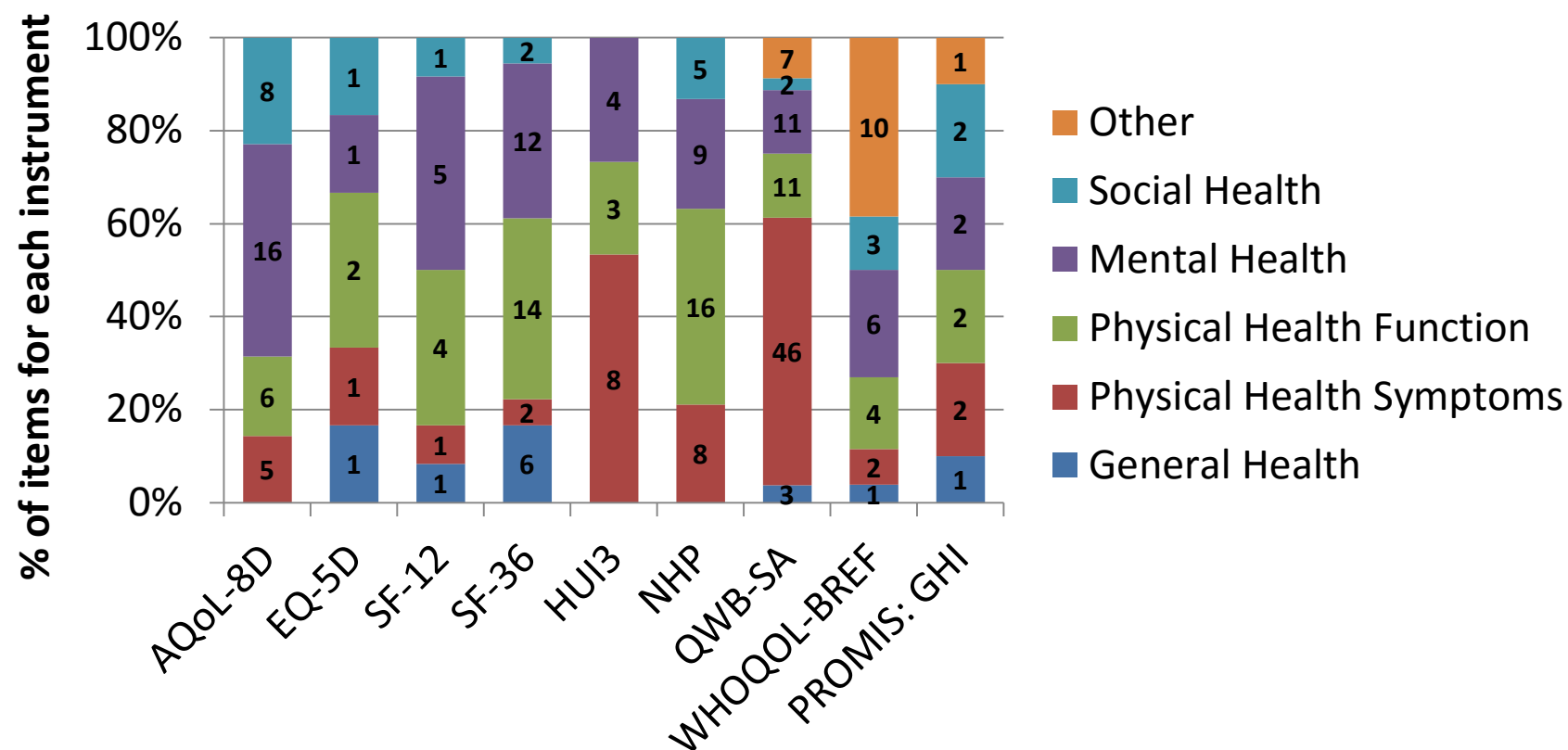## Explaining Patient-Reported Outcomes Measures

What do PROMs measure?

Explaining Patient-Reported Outcomes Measures

Functional Assessment of Chronic Illness Therapy Measurement system

Quality of life

- Physical wellbeing
- Social/family wellbeing
- Emotional wellbeing
- Functional wellbeing

Life domains relevant to the QOL of people with chronic illness
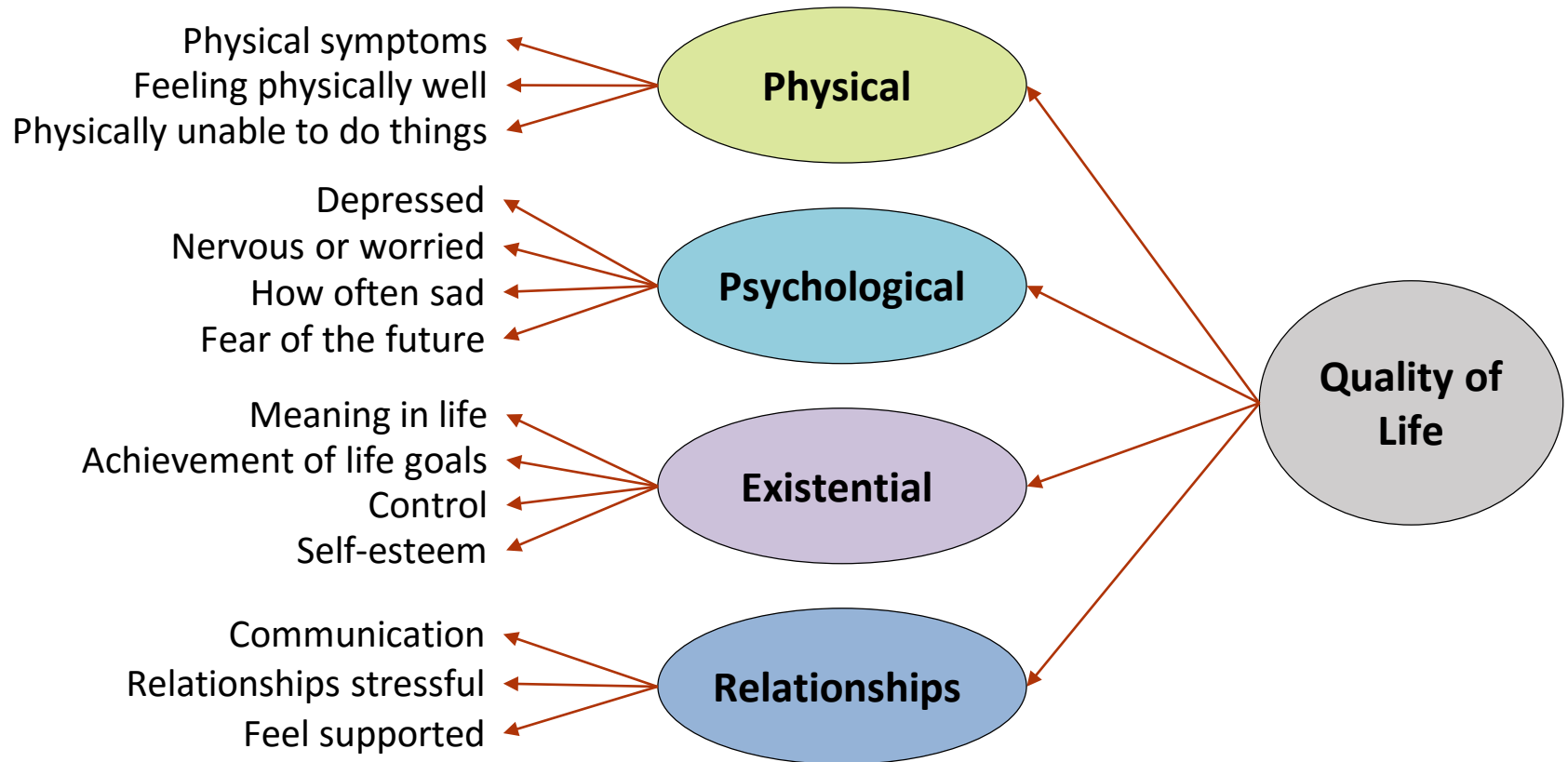
Domain coverage of generic PROMs*

*Refers to the representation of domains in the pool of items.

Example PROM for palliative care
The McGill Quality of Life Questionnaire (MQOL) Revised

Physical symptoms
Feeling physically well
Physically unable to do things
→ **Physical**

Depressed
Nervous or worried
How often sad
Fear of the future
→ **Psychological**

Meaning in life
Achievement of life goals
Control
Self-esteem
→ **Existential**

Communication
Relationships stressful
Feel supported
→ **Relationships**

Quality of Life

Cohen, S. R., Sawatzky, R., Shahidi, J., Heyland, D., Jiang, X., Day, A., Gadermann, A. M. (2014). McGill Quality of Life Questionnaire (MQOL) – Revised. *Journal of palliative care, 30*(3), 248.

Patient-reported experience measures (PREMs)

- Assess various domains of patient-centred care (e.g., access to care, coordination of care, emotional support, information.)

- Provide information from patients' perspectives without interpretation by a 'middle man'.

Common dimensions of patient experience

Through the Patients' Eyes (Picker Institute, 1986)	Model for Patient & Family Centred Care (IPFCC, 1992)	Achieving an Exceptional Care Experience (IHI, 2012)
Respect for patient values & preferences	Respect and Dignity	Respectful Partnerships
Information, Communication & Education	Information Sharing	Evidence Based Care
Coordination of Care	Collaboration	Leadership
Involvement of Family	Participation	
Emotional Support		Hearts & Minds
Physical Comfort		
Preparation for Discharge / Continuity & Transitions in Care		Reliable Care
Access		

Example PREM for palliative care
Canadian Health Care Evaluation Project (CANHELP)

Domain	# questions
Relationship with doctor	3
Illness management	9
Communication	3
Decision making	4
Feeling at peace	1

Each question is rated on (1) Importance, (2) Satisfaction

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., et al. (2010). The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: The Canadian Health Care Evaluation Project (CANHELP) Questionnaire. *Palliative Medicine, 24(7), 682-695.*

Example questions:

You were treated by doctors, nurses, and other members of the health care team in a manner that preserved your sense of dignity.

Your emotional problems (for example: depression, anxiety) were adequately assessed and controlled.

Reasons for using PROMs and PREMs

Health professionals

- At point of care, to inform treatment decisions, monitor patients' conditions, promote patient-clinician communication, reveal health and quality of life concerns that may otherwise have not been noticed

Health researchers

- Examine the effectiveness of treatments and the impact of healthcare interventions
- Better understand the impacts of treatments and services on people's health from their point of view

Health service decision makers

- Evaluate the efficacy, effectiveness and cost-effectiveness of healthcare services and programs

Health care recipients

- Monitor symptoms and concerns and communicate with health care professionals

Patient- and family-reported outcome and experience measures for elderly acute care patients

Knowledge synthesis

Knowledge Synthesis Team

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Knowledge synthesis

Patient- and family-reported outcome and experience measures for elderly acute care patients

Motivation for the synthesis

- Although there are many PREM and PROM instruments, information about their reliability and validity, applicability, and administration in acute care settings for seriously ill older adults, and their families, has not been systematically reviewed and synthesized.

- Healthcare professionals, administrators, and decision makers require up-to-date information to direct the selection and utilization of appropriate PREM and PROM instruments.

AIM

The overarching aim of this knowledge synthesis project was to provide a comparative review of available PROMs and PREMs that would facilitate the selection and utilization appropriate measures for seriously ill elderly patients and their families in acute care settings.

Knowledge synthesis objectives and methods

|	Objective	Method	Selection criteria
STAGE 1	To identify a comprehensive list of generically applicable PROM's and PREM's.	• Extensive searches of library databases, PROQOLID©, review articles, books, and websites. • Bibliometric analysis of instrument publications. • Data extraction of instrument characteristics.	• The instrument is applicable to elderly patients or their family caregivers. • There is evidence of use in a hospital setting. • The instrument has at least one publication during the past 5 years or has been developed during the past 5 years.
STAGE 2	To describe and compare characteristics of *generic* PROMs and PREMs.	• Systematic database searches of selected PROMs and PREMs. • Data extraction of information regarding their reliability, validity, applicability and use within the target population, as well as information regarding their administration.	• Exclude disease- or condition-specific instruments • PROMs must measure physical health and mental health domains • PREMs must measure more than one domain.
STAGE 3	To review the psychometric properties of the generic PROMs and PREMs.	• The COSMIN search strategy was used to identify psychometric validation studies. • The EMPRO criteria were used to evaluate the psychometric properties of the PROMs and PREMs.	• We only included PROM and PREM instruments with validation studies pertaining to elderly patients in acute care.

Stage 1 | Identification of relevant PROMs and PREMs

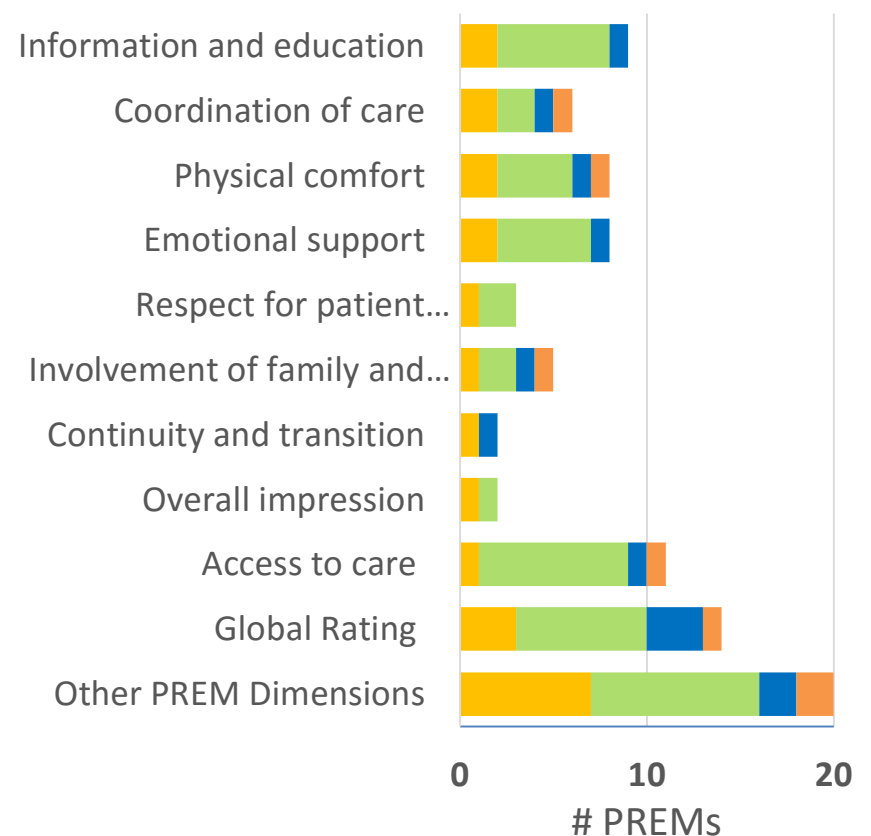|	PROMs		PREMs		PROMs/PREMs	
	Patient	FCG	Patient	FCG	Patient	FCG
# of Instruments	136	13	9	4	20	4
Disease-/ Condition-specific	67	9	3	4	14	4
Generic	50	4	4	0	5	0
Population-specific	19	0	2	0	1	0

NOTE: Short forms, revisions, and adaptations of original instruments are counted separately.

STAGE 1 | # of PROMs & PREMs per dimension
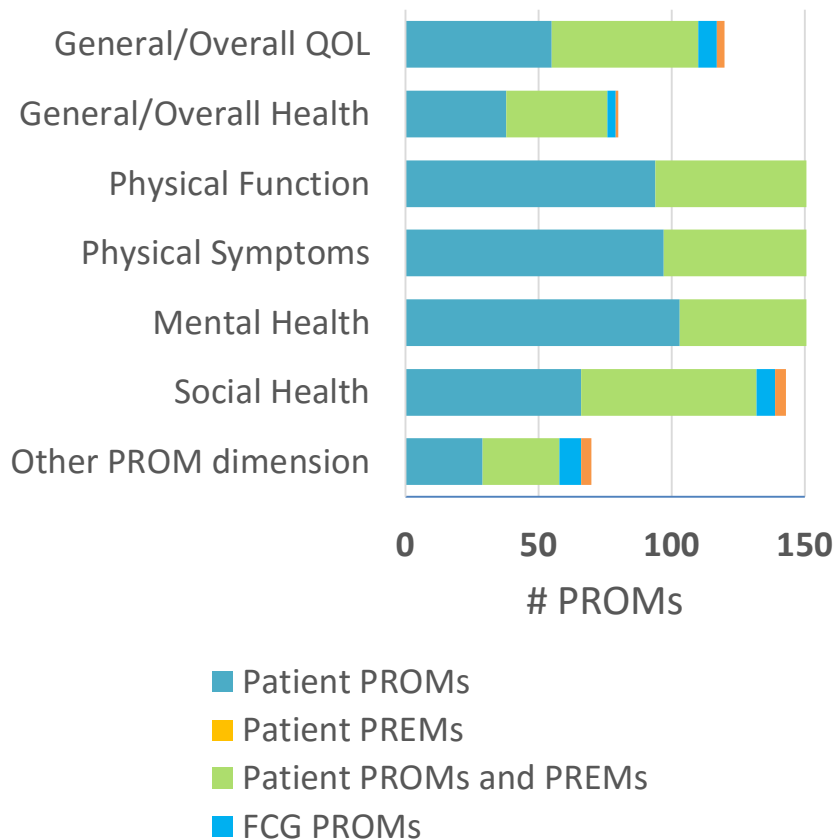
STAGE 2

Selection criteria

Selection criteria for PROMS

1. Exclude disease and condition specific instruments
2. Include multidimensional instruments that measure both physical health and mental health domains
3. Include all family caregiver PROMs
4. Include all instruments developed for palliative or end-of-life care
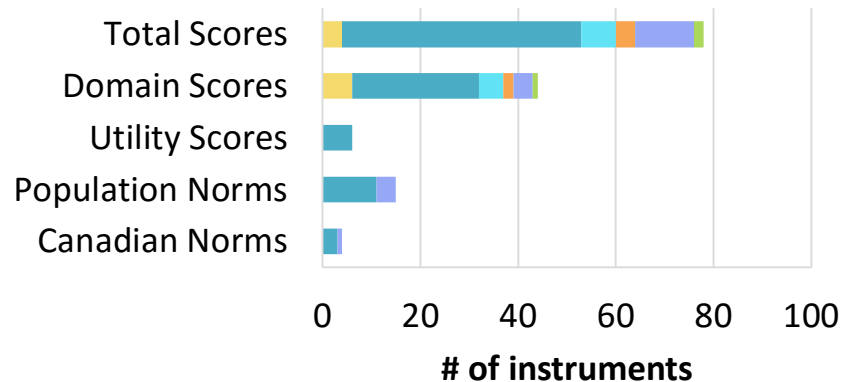
Selection criteria for PREMs:

1. Include only instruments that measure more than one domain (i.e., multidimensional)
2. Include all family caregiver PREMs
3. Include all instruments developed for palliative or end-of-life care
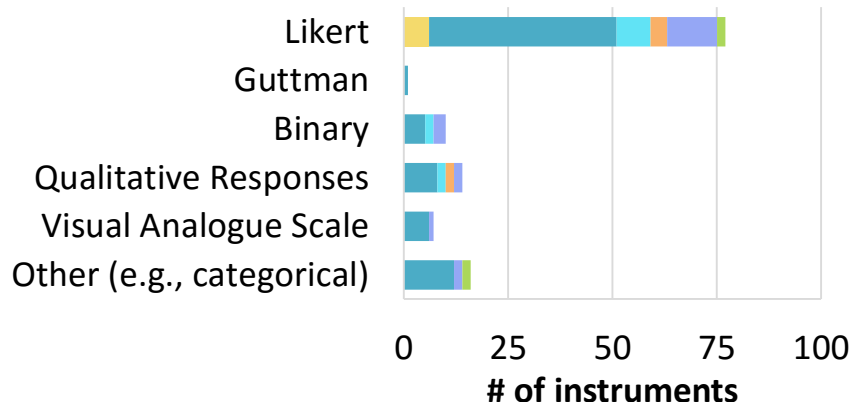
Data collected

- Scoring
- Scaling
- Mode of Administration
- Response Burden
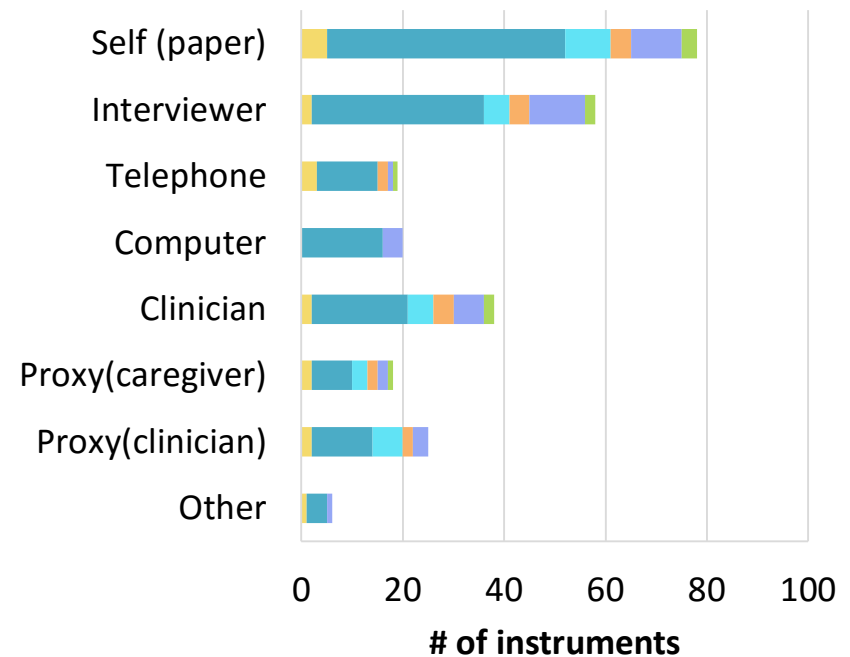- Translations

Measurement characteristics

Scoring — # of instruments

Scaling — # of instruments

Mode of administration — # of instruments

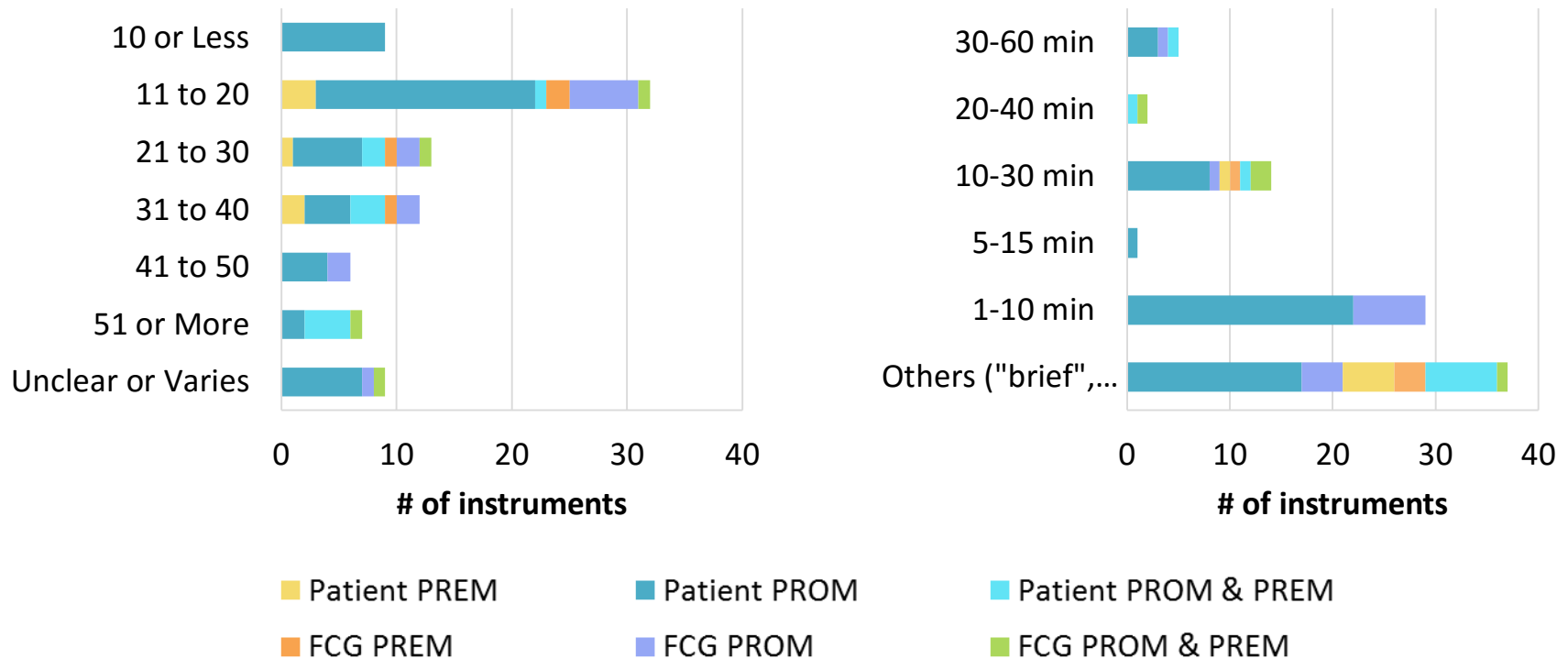Legend: Patient PREM, Patient PROM, Patient PROM & PREM, FCG PREM, FCG PROM, FCG PROM & PREM
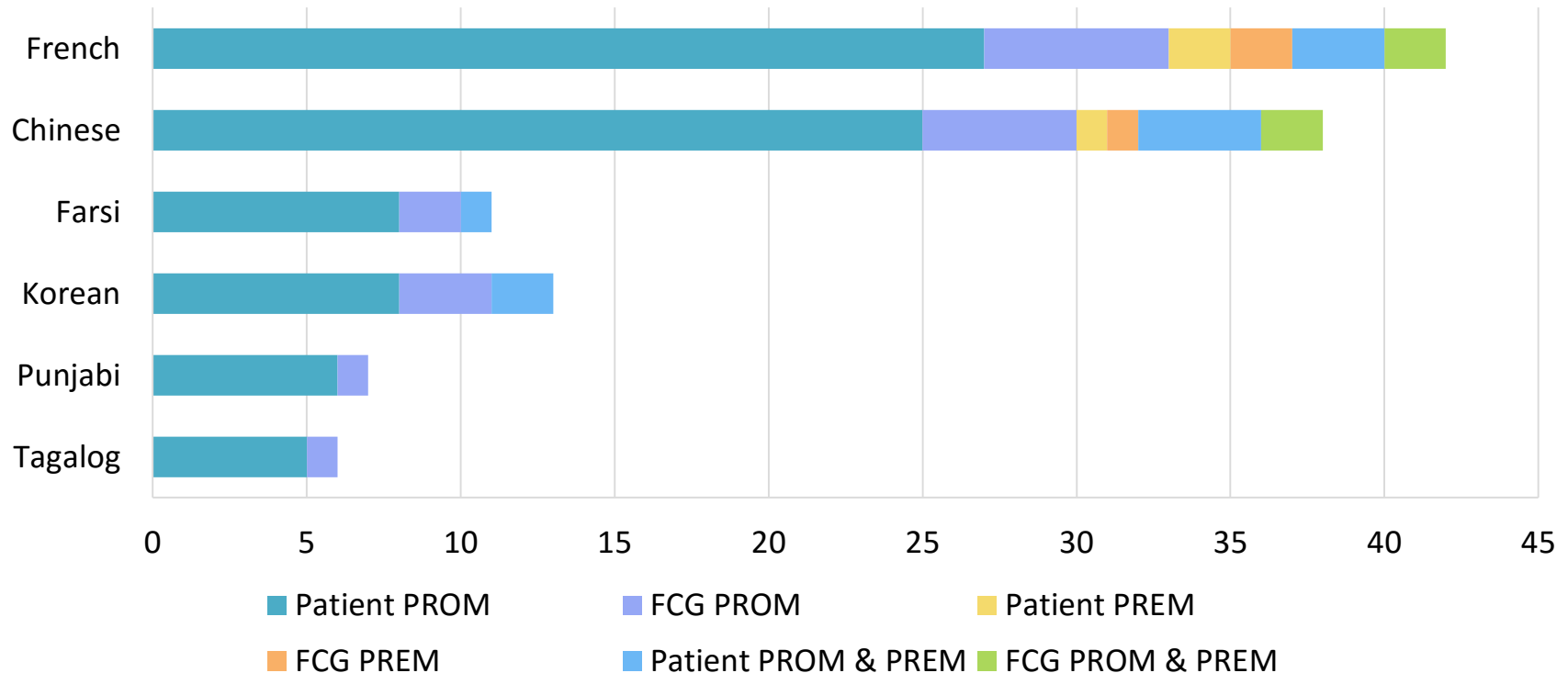
Response burden

- Most instruments consist of less than 20 items and take less than 10 minutes to complete

Language

- All 88 instruments are available in English
- Although instruments have been translated into different languages, validity evidence of the translated versions is limited

STAGE 3 | Results

Instruments with a validation study pertaining to elderly patients in acute care:

Canadian Health Care Evaluation Project Questionnaire
(CANHELP and CANHELP LITE)

- Designed to measure satisfaction with care for older patients with life threatening illnesses, and their family members.

- CANHELP:

    38 items (Patient version)

    40 items (Family version)

- CANHELP LITE:

    21 items (Patient version)

    23 items (Family version)

Heyland, D. K. et al. (2010). The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: The Canadian Health Care Evaluation Project (CANHELP) Questionnaire. *Palliative Medicine, 24(7),* 682-695.

Quality of Dying and Death Questionnaire
(QODD)

- Designed to measure the quality of dying and death using the perspective of family members

- 31 items

Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. (2002). A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *Journal of Pain Symptom Management,,24,* 17-31.

STAGE 3 | Results

	QODD	CANHELP	CANHELP Lite
Conceptual and Measurement Model	28.57	90.48	90.48
Reliability	0	75	75
Validity	26.67	100	100
Responsiveness	0	-	-
Interpretability	0	88.89	88.89
Respondent Burden	11.11	100	100
Administrative Burden	0	91.67	91.67
Alternative Modes of Administration	N/A	N/A	N/A
Language Adaptations	-	-	-
Overall	11.05	70.87	70.87

Table 6: EMPRO Domain and Overall Scores
*NOTE: Dash denotes no information available; N/A denotes not applicable.
Higher scores indicate better "quality"

Summary of knowledge synthesis results

- There are many PROMs and PREMs that have been used in acute care settings for elderly patients. Several instruments were specifically developed for use in older adults, whereas others, such as the SF-36, were developed for general populations but are widely-used in older adults.

- Many of the identified PROMs and PREMs have not been validated for this population (i.e., elderly patients in acute care).
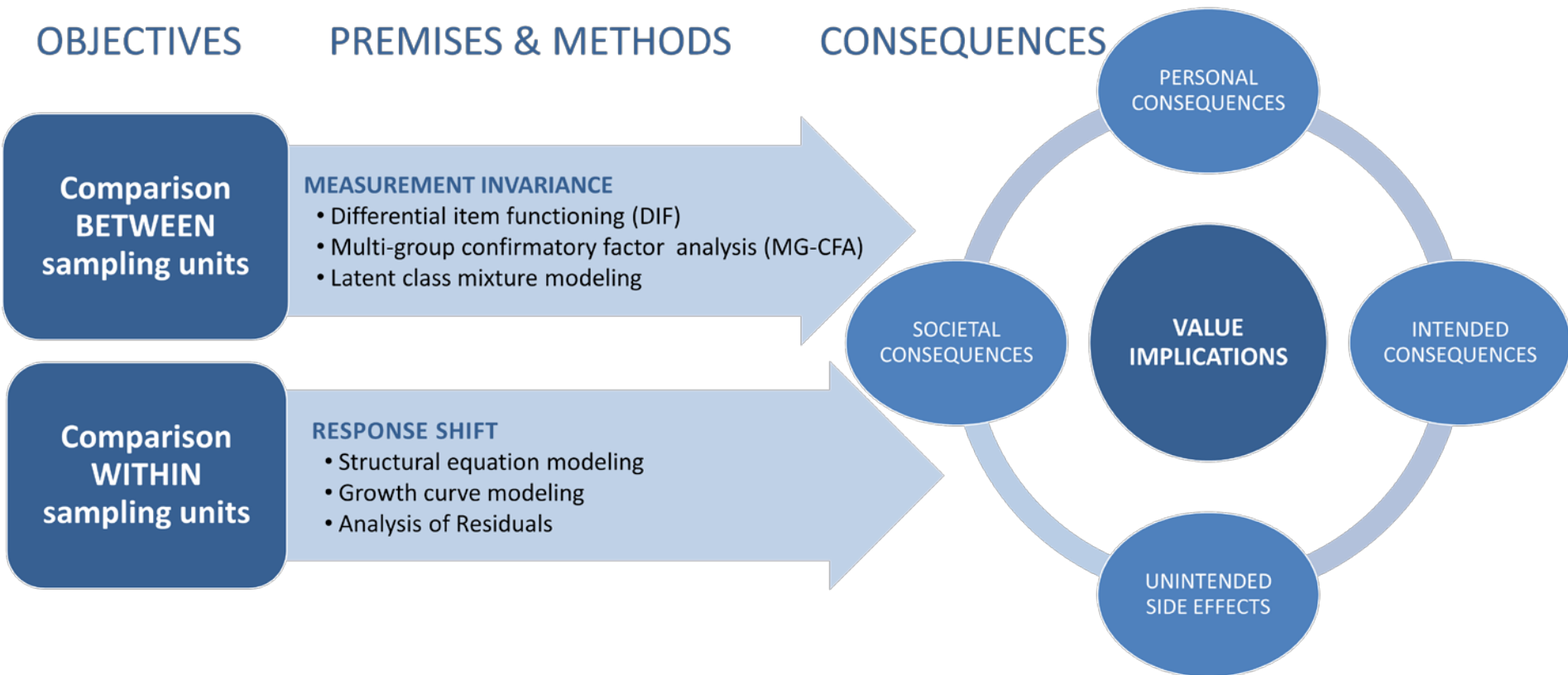
The Validation and Utilization of PROMs and PREMs for Health Services and Clinical Practice

An "explanatory" perspective of measurement validation

"an integrated evaluative judgment of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of interpretations and actions based on test scores or other modes of assessment"

Messick, S. (1995). Validity of psychological assessment: Validation of inferences from persons' responses and performances as scientific inquiry into score meaning. *American Psychologist, 50*(9), 741-749.

An "explanatory" perspective of measurement validation

OBJECTIVES · PREMISES & METHODS · CONSEQUENCES

Comparison BETWEEN sampling units

MEASUREMENT INVARIANCE
- Differential item functioning (DIF)
- Multi-group confirmatory factor analysis (MG-CFA)
- Latent class mixture modeling

Comparison WITHIN sampling units

RESPONSE SHIFT
- Structural equation modeling
- Growth curve modeling
- Analysis of Residuals

PERSONAL CONSEQUENCES

SOCIETAL CONSEQUENCES

VALUE IMPLICATIONS

INTENDED CONSEQUENCES

UNINTENDED SIDE EFFECTS

Sawatzky, R., Chan, ECK., Zumbo, B.D., Bingham, C., Juttai, J., Lix, L., Kuspinar, A., Sajobi, T. (2015) Challenges and opportunities in patient-reported outcomes validation.

Hubley, A.M., & Zumbo, B.D. (2011). Validity and the consequences of test interpretation and use. *Social Indicators Research, 103,* 219-230.

Three foundational considerations

Comparisons of different people
- **What evidence is needed to warrant comparisons between groups and individuals?**
  - Comparisons between groups
  - Comparisons at the individual level

Comparisons over time
- **What evidence is needed to warrant comparisons over time?**
  - Comparisons before and after a treatment
  - Evaluation of trajectories over time

Consequences
- **What are the value implications, including personal and societal consequences, of using PRO scores?**

Sawatzky, R., Chan, ECK., Zumbo, B.D., Bingham, C., Juttai, J., Lix, L., Kuspinar, A., Sajobi, T. (In review) Challenges and opportunities in patient-reported outcomes validation.

Validation of PROMs

Population heterogeneity

- Differences in how people interpret and respond to questions
- **Threatens the comparability of scores across individuals or groups**

Response shift

- An individual's frame of reference may change in response to a health event or intervention
- **Threatens the comparability of scores over time**

Heterogeneity in the population

A conventional assumption underlying PROMs is that individuals interpret and respond to questions about their health in the same way, such that scores are equivalently applicable to all people in the population.

The challenge of heterogeneity

Is it reasonable to believe that people from different backgrounds and with different life experiences interpret and respond to questions about their health and quality of life in the same way?

People may respond to QOL and PROM questions in systematically unique ways because of:

- Cultural, developmental, or personality differences
- Contextual factors or life circumstances
- Different health experiences or events

In this situation, the PROMs will produce biased scores that are not comparable across different individuals or groups

Examining the implications of heterogeneity

Sawatzky, R., Ratner, P. A., Kopec, J. A., & Zumbo, B. D. (2011).
Latent variable mixture models: A promising approach for the validation of patient reported outcomes.
Quality of Life Research. doi: 10.1007/s11136-011-9976-6

The Draper-Lindley-de Finetti (DLD) framework of measurement validation

Adapted from: Zumbo, B. D. (2007). Validity: Foundational issues and statistical methodology. In C. R. Rao & S. Sinharay (Eds.), *Handbook of statistics* (Vol. 26: Psychometrics, pp. 45-79). Amsterdam: Elsevier Science.

Two conditions for general measurement inference

1) Item homogeneity / unidimensionality:

- The items must be exchangeable so that the scores of different questions are comparable on the same scale.

2) Population homogeneity / parameter invariance:

- The sampling units must be exchangeable (the items' parameters must be invariant) so that the scores are comparable irrespective of any differences among individuals other than the characteristic being measured.

The validation of PROMs in heterogeneous populations

Factor loadings (λ) for items y_i, $i = 1, ..., I$ conditioned on latent class variable C_k, $k = 1, ..., K$.

Thresholds (τ) for $j - 1$ response categories per item conditioned on latent class variable C_k, $k = 1, ..., K$.

Variance of the latent factor (θ) conditioned on latent class variable C_k, $k = 1, ..., K$.

▶ The cumulative probability of an item response at or above category j within a latent class can be computed as follows:

$$P_{ijk}\left(Y \geq j \mid \theta, C = k\right) = \frac{\exp(-\tau_{ijk} + \lambda_{ik}\theta)}{1 + \exp(-\tau_{ijk} + \lambda_{ik}\theta)}.$$

▶ Each class has a unique set of parameters that are estimated simultaneously in the latent variable mixture model:

$$f(x) = \sum_{k=1}^{K} \pi_k f_k(x)$$

, where f is the mixture of the class-specific distributions, and π_k is the mixing proportion.

▶ The cumulative probability of an item response at or above category j within a latent class can be computed as follows:

$$P_{ijk}\left(Y \geq j \mid \theta, C = k\right) = \frac{\exp(-\tau_{ijk} + \lambda_{ik}\theta)}{1 + \exp(-\tau_{ijk} + \lambda_{ik}\theta)}.$$

▶ The cumulative probability of an item response at or above category j within a heterogeneous population is obtained by:

$$P_{ij}(Y \geq j \mid \theta) = \sum_{k=1}^{K} (X_k * P_{ijk}(Y \geq j \mid \theta))$$

, where X_k is the posterior probability of an individual being in class k.

Examining the implications of heterogeneity

Model specification and estimation

For example: an IRT graded response model

Model fit and class enumeration

Compare predicted and observed item responses and evaluate relative model fit

Implications of sample heterogeneity

Compare predicted score of the LVMM to those of the one-class model

Explaining latent class membership

Regression of latent classes on explanatory variables

Generic latent variable measurement model

Does your health limit you in any of the following activities:

- Walking one block

- Moderate activities, such as ....

- Vigorous activities, such as ....

item

item

Physical function
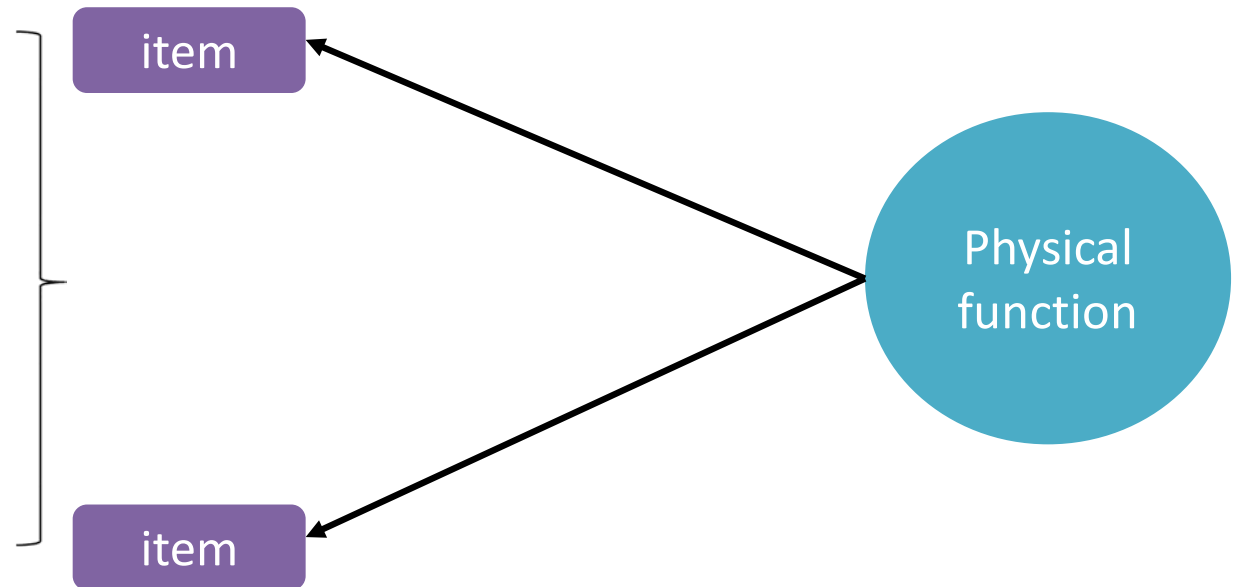
Measurement model that accommodates heterogeneity

Does your health limit you in any of the following activities:

- Walking one block

- Moderate activities, such as ....

- Vigorous activities, such as ....

item

item

Physical function

Diversity
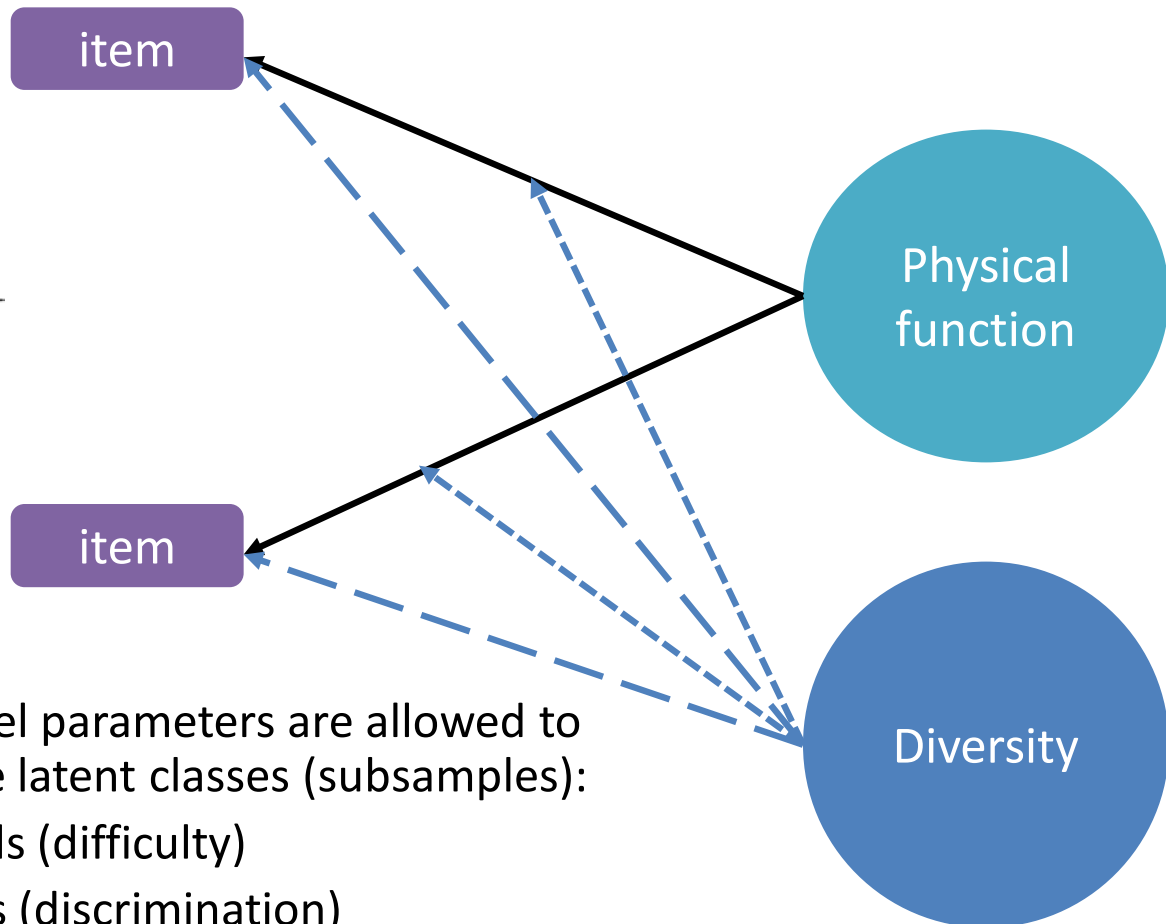
The measurement model parameters are allowed to vary across two or more latent classes (subsamples):

- – – – → item thresholds (difficulty)
- – – – – → factor loadings (discrimination)

SF-36 physical function

Physical function items	
SFRC_03	Vigorous activities
SFRC_04	Moderate activities
SFRC_05	Lifting or carrying groceries
SFRC_06	Climbing several flights of stairs
SFRC_07	Climbing one flight of stairs
SFRC_08	Bending, kneeling, or stooping
SFRC_09	Walking more than one kilometer
SFRC_10	Walking several blocks
SFRC_11R	Walking one block
SFRC_12R	Bathing and dressing

Response options
0. No limitations
1. Limited a little
2. Limited a lot

Conventional scoring method*
1. Add all items
2. - 20 (reverses the scale)
3. x 5 (scaled from 0 – 100)

Implications of ignoring heterogeneity on item response theory predicted scores
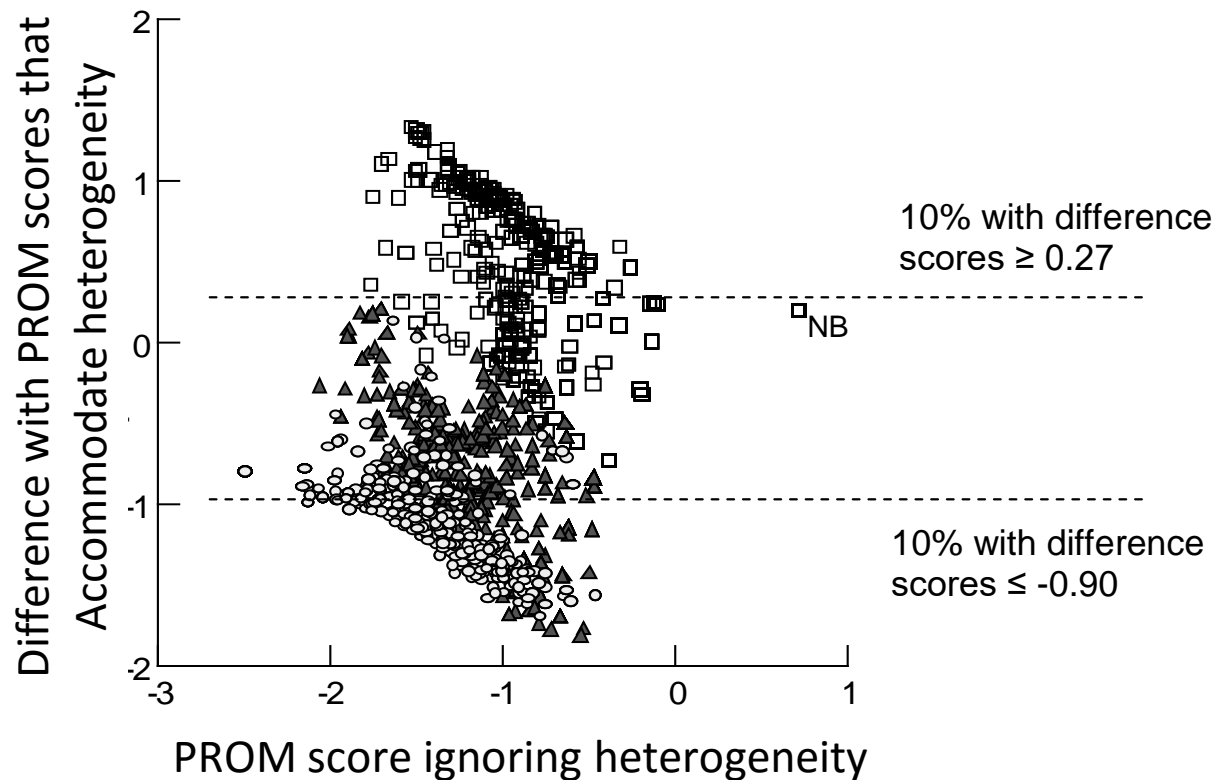
DO PEOPLE INTERPRET AND RESPOND TO QUESTIONS ABOUT THEIR PAIN IN A COMPARABLE MANNER?

Richard Sawatzky

Jacek A. Kopec

Eric C. Sayre

Pamela A. Ratner

Bruno D. Zumbo

Research objectives

> We examined the fundamental assumption of sample homogeneity (exchangeable sampling units) by:

1. Identifying whether a sample is homogeneous with respect to a unidimensional IRT structure for the measurement of pain.

2. Evaluating the implications of sample heterogeneity with respect to:

   A. The invariance of measurement model parameters of the items measuring pain

   B. The IRT-predicted pain scores

3. Exploring potential sources of sample heterogeneity with respect to a unidimensional IRT model for the measurement of pain

Latent variable mixture model

Pain item bank of 36 items measuring severity, frequency, and impact of pain

- ▸ The thresholds and loadings are allowed to vary across two or more latent classes (subsamples).
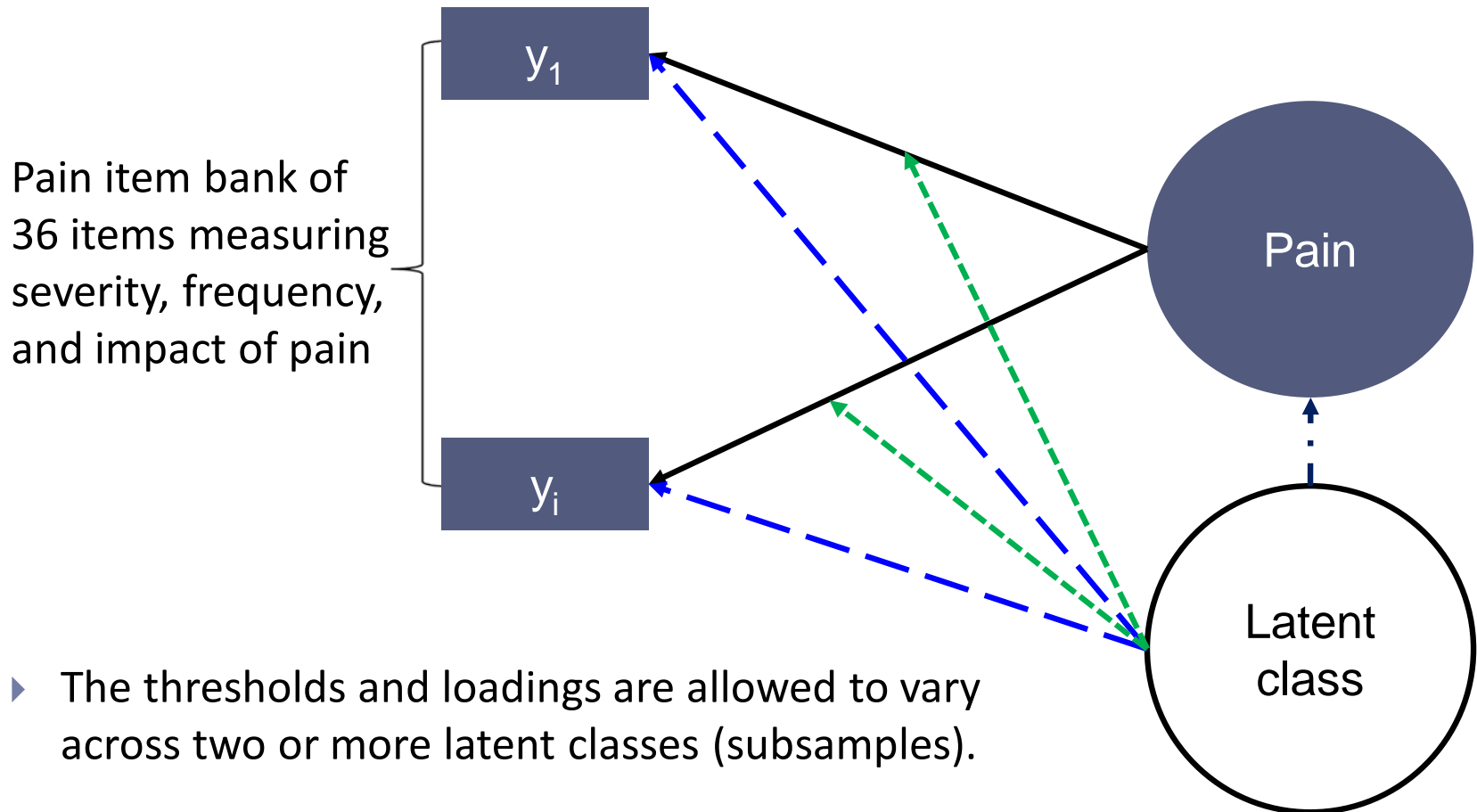
The pain item bank

▶ Part of a previously developed Computerized Adaptive Test, the CAT-5D-QOL (Kopec et al., 2006).

▶ 36 items measuring the severity and frequency of pain or discomfort and the impact of pain on daily activities and leisure activities.

▶ Various ordinal formats:
  ▶ not at all (1) ⟷ extremely (5) (17 items)
  ▶ never (1) ⟷ always (5) (12 items)
  ▶ none of the time (1) ⟷ all of the time (5) (2 items)
  ▶ Various item-specific response formats (5 items)

Kopec, J. A., Sayre, E. C., Davis, A. M., Badley, E. M., Abrahamowicz, M., Sherlock, L., et al. (2006). Assessment of health-related quality of life in arthritis: Conceptualization and development of five item banks using item response theory. *Health and Quality of Life Outcomes, 4, 33.*

Sampling methods

Total sample: N = 1,666

Adults from two rheumatology clinics in Vancouver (BC):

N = 340

Adults on a joint replacement surgery waiting list in BC:

N = 331

Stratified random community sample of adults in BC:

N = 995
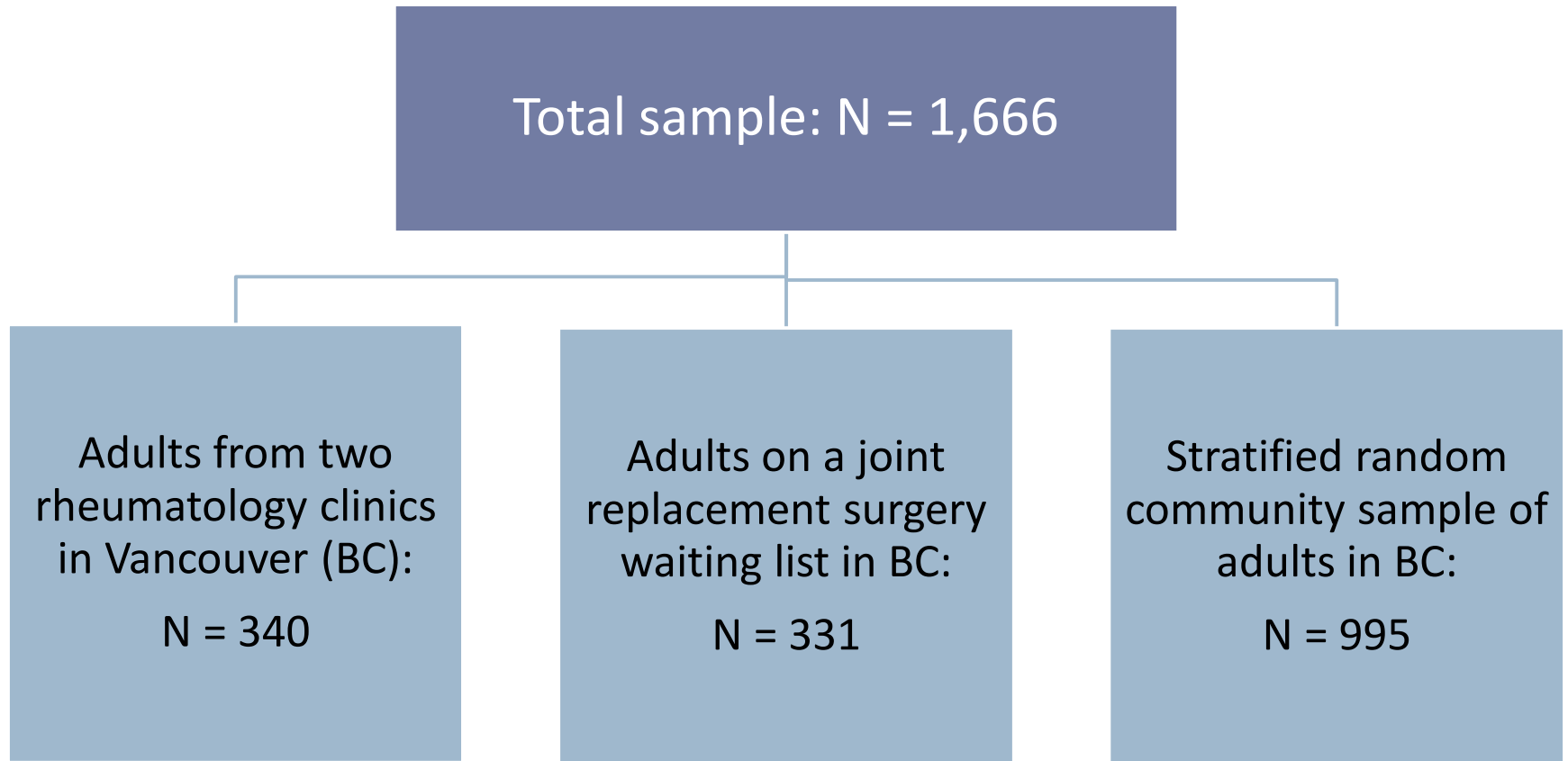
Sample description

Variables	Percent / mean(sd)
Gender = female	60.7%
Age (mean (SD))	56.7(15.9)
Has a medical problem	84.5%
Has osteoarthritis	36.6%
Has rheumatoid arthritis	28.0%
Uses one medication	23.5%
Uses two or more medications	54.2%
Has been hospitalized during the past year	20.5%

Fit of the IRT mixture model

Global model fit

Model	P	BIC	LL ratio[*]	Entropy	Class proportions[**]		
					Class 1	Class 2	Class 3
1 class	177	87884	n/a	1.00	1.00		
2 classes	354	86056	3141	0.86	0.59	0.41	
3 classes	531	85654	1713	0.83	0.25	0.30	0.45

N = 1,660. P = number of model parameters. BIC = Bayesian Information Criterion. LL = log likelihood. [*]Likelihood ratio of K and K-1 class models. Statistical significance was confirmed using a bootstrapped likelihood ratio test with simulated data. [**]Based on posterior probabilities.

Conclusions

▸ The sample is not homogeneous with respect to a unidimensional structure for the pain items.

▸ A relative improvement in model fit was obtained when 3 classes were specified.

Implications with respect to the IRT-predicted scores

Comparison of one-class and three-class model predicted scores
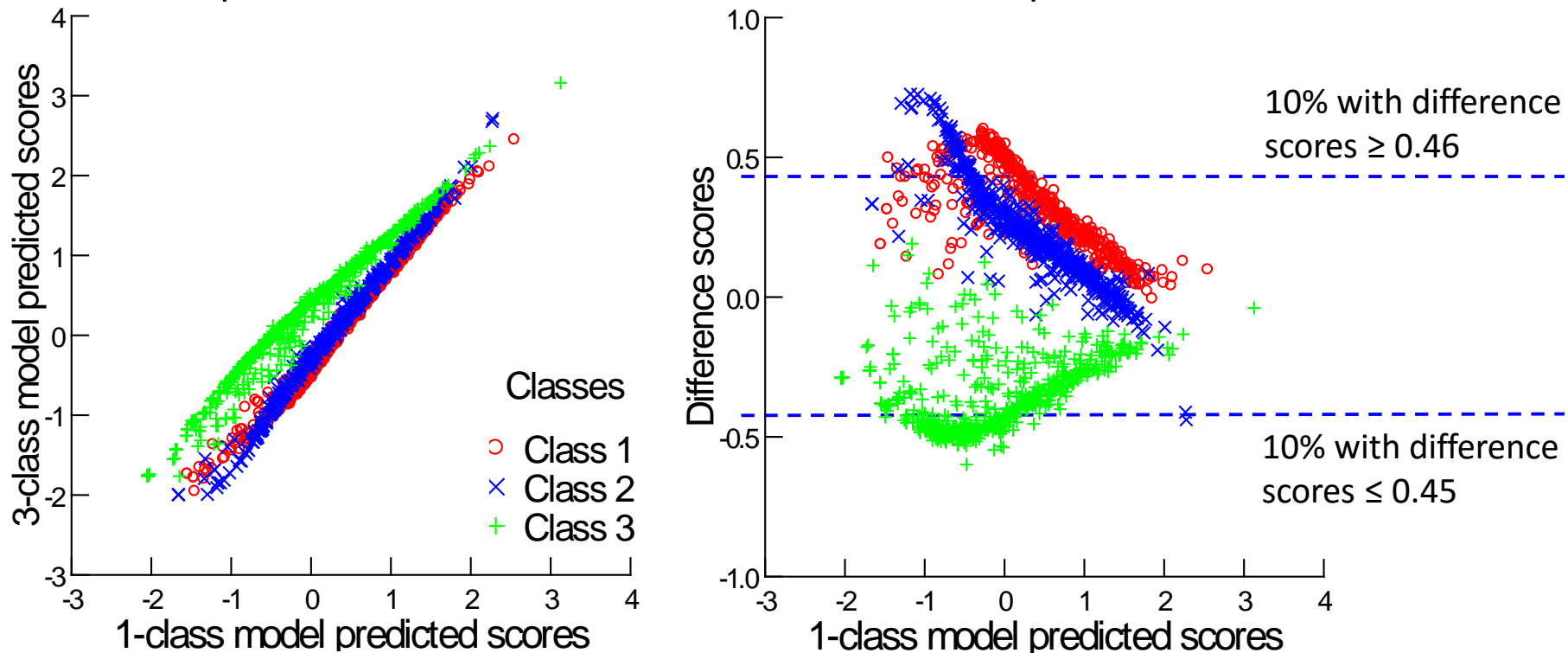
- ▸ There were considerable differences in the standardized IRT scores of the one-class model (ignoring sample heterogeneity) and the three-class model (adjusted for sample heterogeneity)

▸

Potential sources of sample heterogeneity

Bivariate associations with latent class membership

Variables	Class 1	Class 2	Class 3
Gender (% male)	36.6	36.8	42.1
Age (means)	58.3	57.0	55.3
% has a medical problem (other than RA/OA)*	82.1	83.7	70.1
% has osteoarthritis (OA)*	40.1	45.6	27.7
% has rheumatoid arthritis (RA)*	37.6	27.9	21.9
% hospitalized during the past year*	27.2	16.3	17.2
% taking one or more medications*	85.9	84.3	67.8
Self-reported health status* (1 = excellent; 5 = very poor) (mean)	3.3	3.1	2.6

Greatest   Smallest

Notes: Based on pseudoclass draws. *Statistically significant bivariate association ($p < 0.05$)

What we have learned to date

The challenge of heterogeneity in the population

People may not interpret and respond to questions about their health and quality of life in the same way.

Differences among people that may explain such inconsistencies include:

- Differences in health experiences
- Differences in age
- Cultural differences
- Gender differences

Application to PRO measurement

These and other sources of heterogeneity, if ignored, could result in substantial error (bias) in health and quality of life scores (PROMs).

The challenge of response shift

Is it reasonable to believe that people will be consistent over time in how they interpret and respond to questions about their health and quality of life?

Schwartz and Sprangers defined response shift as ''a change in the meaning of one's self-evaluation of a target construct as a result of change in'':

recalibration	• internal standards of measurement
reprioritization	• values (i.e. the importance of component domains constituting the target construct)
reconceptualization	• definition of the target construct

Theoretical model of response shift
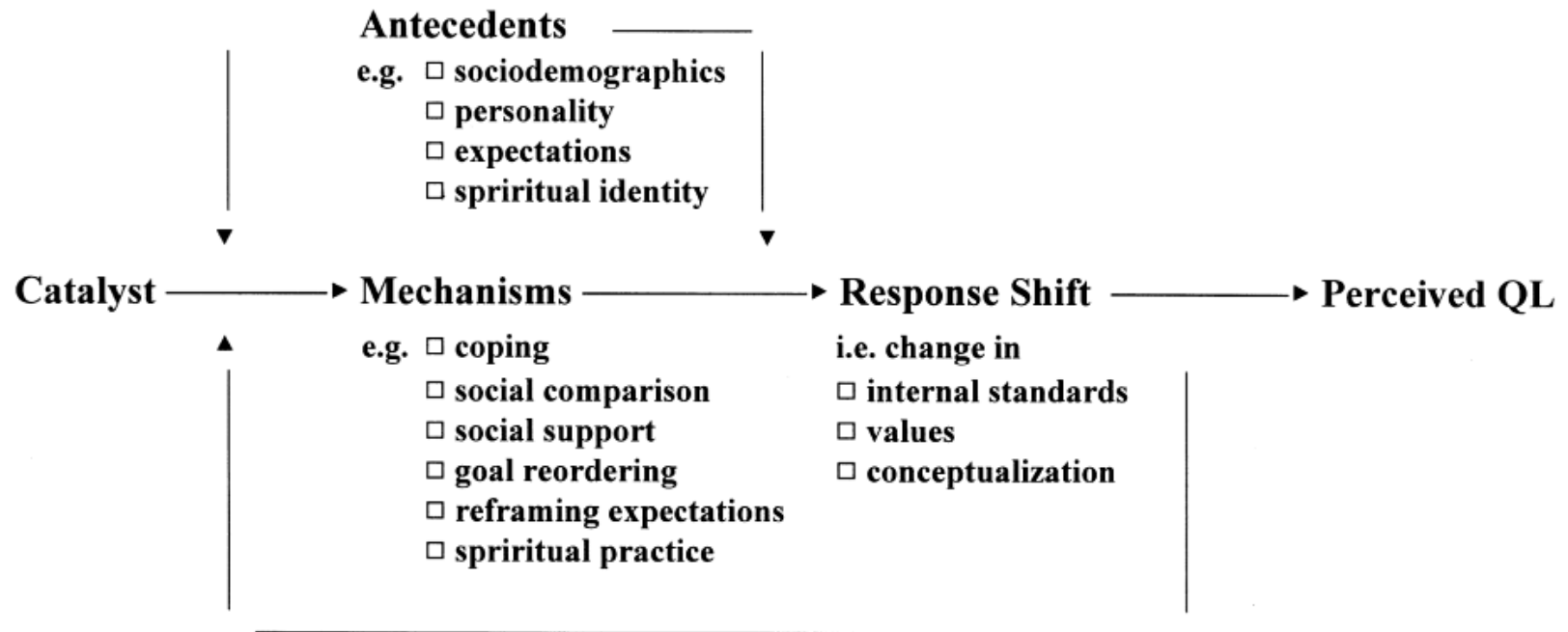
Fig. 1. A theoretical model of response shift and quality of life (QOL).

Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine, 48(11), 1507-1515.*

Why care about response shift?

- From a validation point of view, it is important to distinguish "true change" from RS change
  - Ignoring RS could lead to measurement bias:
    - Decreased sensitivity to detect change over time
    - Detecting change over time that does not exist

- Contributes to understanding regarding the meaning of scores
  - Unexpected health outcomes

- May want to promote response shift
  - Palliative care
  - Rehabilitation
  - Self-management
  - Other non-curative interventions

Integrating a quality of life assessment and practice support system in palliative home care

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Objectives

Do right by our patients

This presentation reports on a collaborative in-progress research initiative about the implementation and integration of an electronic innovation, the **Q**uality of life Assessment and **P**ractice **S**upport **S**ystem (QPSS), into routine palliative home care for older adults who have and advancing life-limiting condition and their family caregivers.

Background

Research project

Emerging results

Research team

Principal Investigators

- Rick Sawatzky, Trinity Western University
- Robin Cohen, McGill University
- Kelli Stajduhar, University of Victoria

Co-Investigators

- Researchers from Trinity Western University, University of British Columbia, University of Victoria, McGill University, Ersta University College (Sweden), Manchester University (UK), Cambridge University (UK)

Fraser Health Knowledge Users

- Carolyn Tayler, Director of End of Life Care
- Barbara McLeod, Clinical Nurse Specialist Hospice Palliative Care
- Jean Warneboldt, Tri-Cities Palliative Physician

Highly Qualified Personnel

- Jennifer Haskins, Fraser Health Palliative-Focused Nurse
- Melissa Kundert, Fraser Health Palliative-Focused Nurse
- Kathleen Lounsbury, graduate student, Trinity Western University
- Esther Mercedes, doctoral student, McGill
- Sharon Wang, graduate student, Trinity Western University

Quality of life assessments

Routine use of PROMs and PREMs at point of care

Routine use of PROMs and PREMs can:

- Make patients' and family caregivers' concerns more visible

- Raise awareness of problems that would otherwise be unidentified

- Lead to improved clinician-patient communication

- Result in improved care plans

- Improve collaboration among healthcare professionals

Despite the benefits of QOL assessments and the availability of many PROM and PREM instruments, their routine use at point of care has been limited

Benefits of e-QOL Assessment Instruments

1. *Reduce patient burden*
2. *Reduced clinician burden*
3. *Enhanced visualization and monitoring of patient concerns through ongoing and immediate feedback*
4. *PROM & PREM information become part of administrative data for program evaluation and cost-effectiveness analysis*

Practice innovation

The Quality of Life Assessment and Practice Support System – QPSS

An innovative, integrated health care information system for patient- and family-centered care that facilitates:

- use of QOL assessment instruments (including PROMs and PREMs) at point of care

- instantaneous feedback with information about scores, score interpretation, change over time, and targets for improvement

- documentation of interventions planned to address areas of unmet need

- tracking and assessing whether an implemented intervention has achieved the desired result

- capacity to integrate with other health information systems
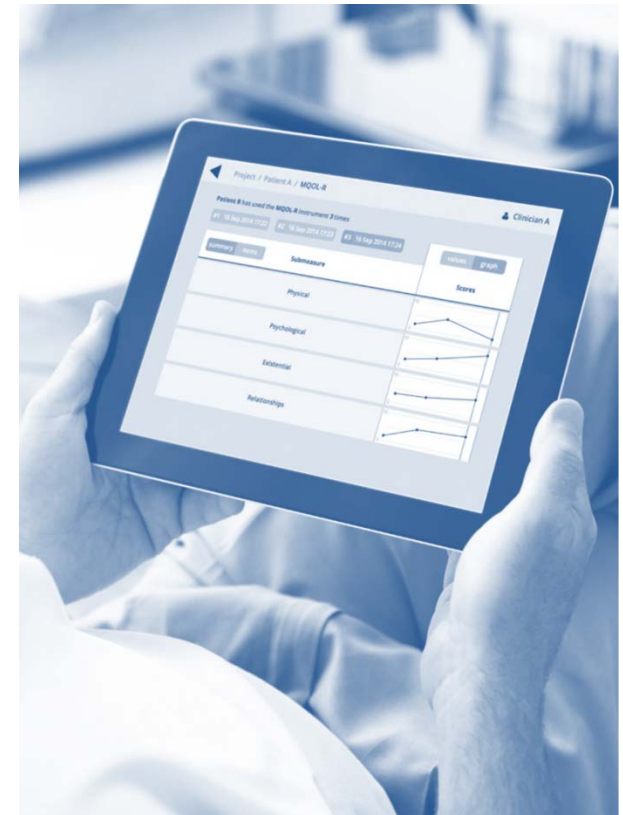
Examples

QOL Assessment & Practice Support Tools for Palliative Care

Examples of QOL Assessment Instruments:

- Edmonton Symptom Assessment System – Revised (ESAS-R)

- McGill Quality of Life Questionnaire -Revised (MQOL-R)

- Quality of Life in Life-Threatening Illness-Family caregiver version 2 (QOLLTI-F v2)

- Canadian Health Care Evaluation Project Lite Questionnaire (CANHELP Lite)

Research project

Integrating a quality of life assessment and practice support system in palliative homecare

The project involves working with clinicians, clients and family caregivers to answer the following <u>research questions</u>

1) How can we best facilitate the integration and routine use of electronically-administered quality of life (QOL) and healthcare experience assessment instruments as practice support tools in palliative homecare nursing for older adults who have chronic life-limiting illnesses and for their family care givers?

2) Does the routine use of these instruments improve quality of care, as indicated by patients' and family caregivers' reports of enhanced QOL and experiences with the care provided?

Research Design

The project involves working with clinicians, clients and family caregivers to answer the following research questions

Mixed-methods integrated knowledge translation study that involves 2 stages:

1. Local adaptation

- Focus groups and interviews with clinicians', patients', and family caregivers to understand how to best adapt and integrate a QPSS into palliative homecare nursing
- Collection of pre-intervention outcomes evaluation data

2. Evaluation

- Qualitative evaluation of the process of QPSS integration
- Quantitative evaluation of impact on the QOL and health care experiences of clients and FCGs
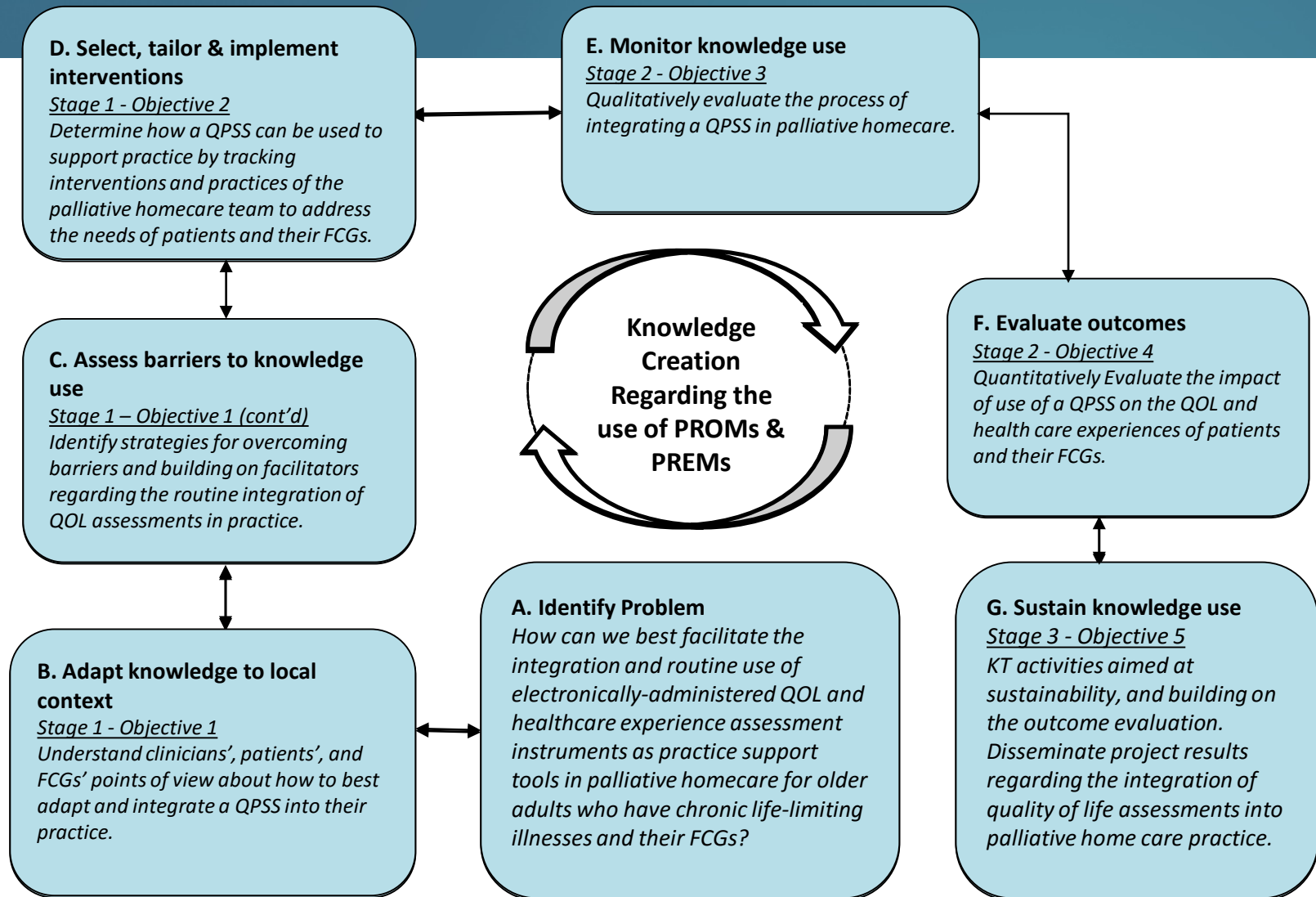
Samples

Qualitative data

- Entire homecare nursing team
- 10 clients who are registered with the palliative support program
- 10 family caregivers who are most involved in the client's care

Quantitative data

- Comparator group: 40 clients and 40 family caregivers in stage 1
- Intervention group: 40 clients and 40 family caregivers in stage 2

QPSS design and implementation
An integrated knowledge translation approach*

D. Select, tailor & implement interventions
Stage 1 - Objective 2
Determine how a QPSS can be used to support practice by tracking interventions and practices of the palliative homecare team to address the needs of patients and their FCGs.

E. Monitor knowledge use
Stage 2 - Objective 3
Qualitatively evaluate the process of integrating a QPSS in palliative homecare.

C. Assess barriers to knowledge use
Stage 1 – Objective 1 (cont'd)
Identify strategies for overcoming barriers and building on facilitators regarding the routine integration of QOL assessments in practice.

F. Evaluate outcomes
Stage 2 - Objective 4
Quantitatively Evaluate the impact of use of a QPSS on the QOL and health care experiences of patients and their FCGs.

Knowledge Creation Regarding the use of PROMs & PREMs

B. Adapt knowledge to local context
Stage 1 - Objective 1
Understand clinicians', patients', and FCGs' points of view about how to best adapt and integrate a QPSS into their practice.

A. Identify Problem
How can we best facilitate the integration and routine use of electronically-administered QOL and healthcare experience assessment instruments as practice support tools in palliative homecare for older adults who have chronic life-limiting illnesses and their FCGs?

G. Sustain knowledge use
Stage 3 - Objective 5
KT activities aimed at sustainability, and building on the outcome evaluation. Disseminate project results regarding the integration of quality of life assessments into palliative home care practice.

Research design

Outcome evaluation

Before- and after-design:

- Comparator group
- Intervention group

Time period for each group

- From enrollment until the end of each phase (6 months)

Frequency of outcome measures

- Every two weeks

Analysis

- Area under the curve
- Comparison of trajectories

Outcomes

Quality of life of patients and family caregivers

Satisfaction with care of patients and family caregivers

Emerging findings

Qualitative data from clients and family caregivers

Advantages of using the tablet modality: Simplicity and ease of use, increased speed of access to information, increased completion of tools at multiple time points, ability to see trends in items over time, and potential decrease in the amount of paper charting.

"*I found the questions were very easy to understand. And it was easy for me to just read them on the tablet. And when I got used to not pressing too hard and using the light touch, I found it very easy to use. I'm very surprised… How did you feel?*" (family caregiver)

Participants	Clients	Family caregivers
Gender		
Male	1	2
Female	4	4
Highest Education		
High School	2	2
College/U niversity	3	3
Country of birth		
Canada	4	3
Other	1	2

Emerging findings

Focus groups with palliative home care clinicians

Use of QOL assessment instruments in routine care: Providing structure for holistic assessment, improvement in communication, opportunities for reflection, as well as the risk of assessment burden.

"As nurses we don't use these tools enough, we will use them once, the pain scale, and then it won't always be redone a second time, I think that if we have a tablet it will be easier, done more quickly, it's analysed, we have all the results, it's not just our words, there is something there to describe the situation. I think it's super useful." (Clinician)

"…as a nurse, I tend to focus quite a bit on physical symptoms. But it's a really, really nice tool to find out what the other symptoms are that we're not able to pick up on – psychological, emotional, existential. So I felt that's a great tool to use for patients. Then we get to focus on those." (Clinician)

Emerging findings

Focus groups with palliative home care clinicians

Contradictory opinions about the tablet modality: Potential interferences with communication and relationship building, patients' physiological barriers to use, anxiety using technological mediums, damage and loss of the tablets.

"I find it's so impersonal; it's difficult for me to get a client to tell me, you know, do you feel your relationship with your doctor is very important and are you satisfied? In a way it's a lot of juice to extract from a client, from the situation, so I go easy, but I see that it could be good for my practice to use it more."

I have a client in his 90s – him and … his wife said to me yesterday that she's finding it really helpful because it's … like, reflecting on his care and his situation and that he's coming up with things that he hasn't made her aware of. So it's kind of enriching the level of care that he's going to get, from his feedback.

Next steps

Scaling up

Concurrent QPSS study at the tertiary palliative care unit in Abbotsford regional hospital

Funding applications in review for multi-site complex intervention studies:

- Home care
- Hospital-based care

Partnership with Intogrey and Cambian to operationalize integration with health information systems

Research on computerized adaptive testing to further increase efficiency and reduce response burden

Concluding comments

The importance of measurement validation

Modern view of measurement validation

Our ultimate goal is to arrive at justifiable or "valid" inferences, judgements, and decisions based on the measurement of patient-reported outcomes and experiences, where measurement validation is defined as:

"an integrated evaluative judgment of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of interpretations and actions based on scores …"

Messick, S. (1995). Validity of psychological assessment: Validation of inferences from persons' responses and performances as scientific inquiry into score meaning. *American Psychologist, 50*(9), 741-749.

Framework for the selection and utilization of PROMs and PREMs
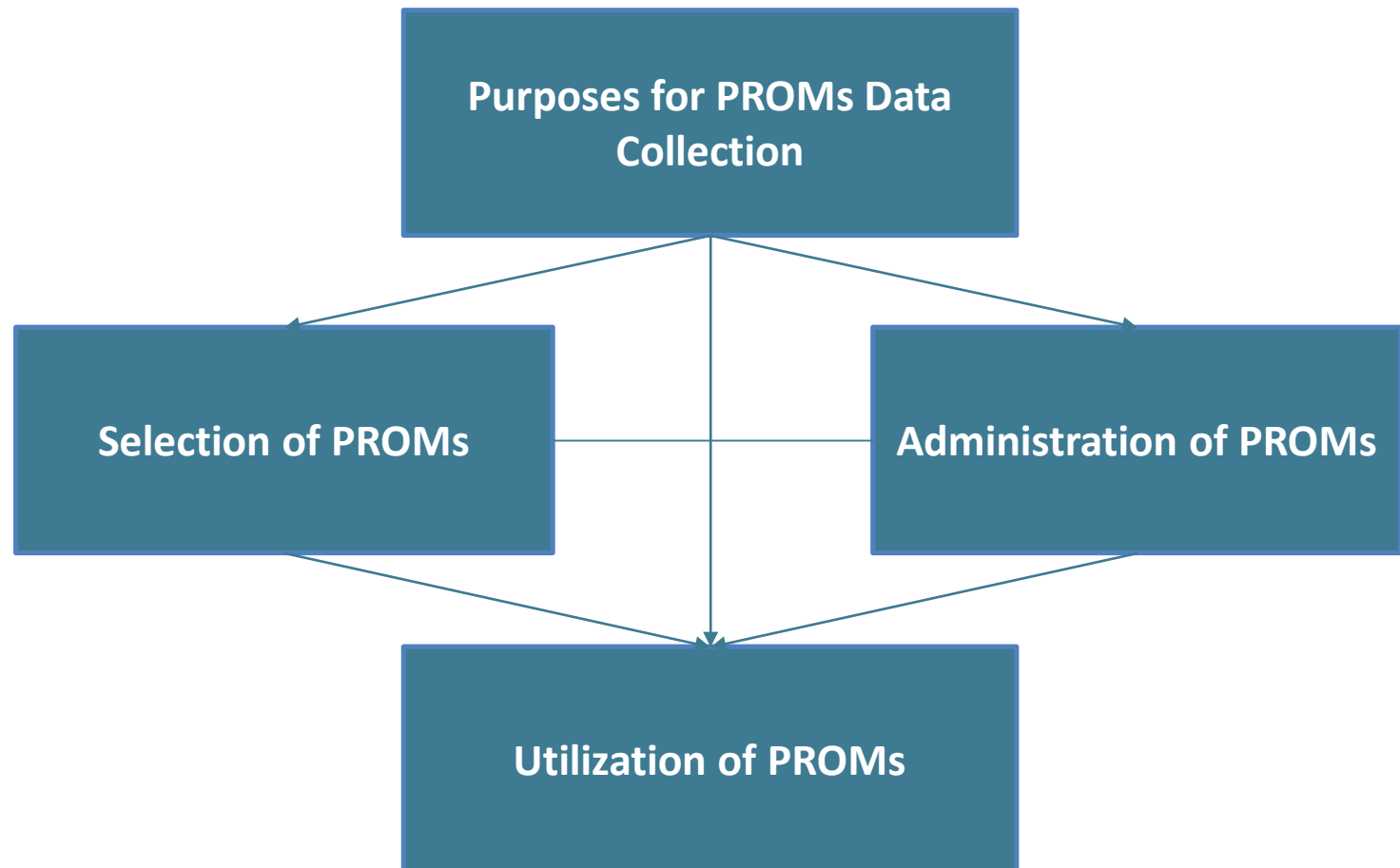
"Our aim should be to find out what each patient wants, needs, and experiences in our health care system."

M. Gerteis et al. (1993)

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