

Welcome!

Webinar 6: Making an impact
Thursday, February 16 2017, 12:30 – 1:30 pm

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How to participate in this webinar

The screenshot shows the Blackboard Collaborate interface. On the left, the 'AUDIO & VIDEO' section has 'Talk' and 'Video' buttons. Below it, the 'PARTICIPANTS' section shows 'Marieke Guy' with a 'MAIN ROOM' button circled in red. A list of participants follows, including 'mgramstadt', 'mhahnel', 'Michael Davis', 'Nicola Cockarill', 'Paul Hatton', 'paul laidler (Durham University)', 'Phil Vaughan', and 'Rachel Beaton'. The 'CHAT' section is also circled in red, showing a list of messages. The main window displays 'Blackboard Collaborate Orientation for Participants' with the 'JISCnetskills' logo. A 'Participant Interactions' window is open, showing 'Alice Brown (College of Knowledge)' as the selected participant. This window includes buttons for 'Emoticons', 'Step Away', 'Your details', 'Raise Hand', and 'Voting'. A 'Moderators' list is also visible, including 'Lisa Vincent' and 'Gail Higgins'. A notification at the bottom right states 'Andrew Treloar 1 #2 joined session.' at 12:00.

Participant Interactions

Blackboard Collaborate Orientation for Participants

JISCnetskills

Step Away

Your details

Raise Hand

Emoticons

Voting

Moderators

All Participants (listed alphabetically)

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3 notifications Dismiss All Dismiss

Introduction

Moderator:

(Lidewij) Eva Vat, Training and Capacity lead – NL
SUPPORT

Guest speaker:

Clinical Psychologist and Assistant Professor of
Psychology and Oncology at Memorial University



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Webinar #6

Making an impact!



Learning Objectives

- What are PROMS and what are they used for?
- How do you decide what PROM to choose?
- Generic and specific PROMS – strengths and weaknesses
- How do I evaluate a PROM?
- Where can I find a PROM?

Introduction

Outcomes that matter to patients



What is a PROM?

- Patient reported outcomes (PROs) are outcomes known only to the patient
- Patient reported outcome measures (PROMS) are tools we use to measure patient outcomes
- All are based on self-assessment
- Measures any aspect of the patients health status that come directly from the patient
 - Without interpretation of the patients responses by a physician or anyone else

What is a PREM?

- Patient reported experience measures (PREMS) assess various domains of patient-centered care
 - e.g. access to care, coordination of care, emotional support, information
- Provide information from the patients' perspective without interpretation by the 'middle man'

How to decide what PROM to choose?

- Need to identify the outcomes that are important to individuals in the population of interest (e.g., survival, symptoms, health-related quality of life).
 - Input from patients is necessary for accurately identifying these outcomes of interest.
- Evidence should support the selection of outcomes as meeting the criteria of ‘clinically meaningful,’ ‘patient-centered,’ and ‘relevant to decision-makers,’ such as patient and decision-maker input from meetings or surveys or published literature relevant to the question of interest.

Generic PROMs

Generic instruments are designed to measure very broad aspects of health and are therefore potentially suitable for a wide range of patient groups and the general population. Example: SF-36

- *Advantages:*

- they are suitable for use across a broad range of health problems.
- They can be used for comparisons between treatments for different patient groups to assess comparative effectiveness.
- They can also be used with healthy populations to generate normative data that can be used to compare different patient groups.
- They have potential to capture the influence of co-morbidity on health, as well as unexpected positive or negative effects of an intervention.

- *Disadvantages:*

- Broad applicability means that some level of detail has to be sacrificed which may limit the relevance of generic instruments when applied to a specific patient population.
- They are potentially less responsive to clinically important changes in health.

For each of the following questions, please mark an in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

Disease Specific PROMs

Disease-specific PROMs are designed to identify specific symptoms and their impact on the function of those specific conditions. Example: FACT-G

- *Advantages:*

- Clinically relevant.
- Should be responsive to clinically important changes in health that result from interventions.
- Do not contain any items or health dimensions that are not relevant to the disease.
- Because the instrument has clear relevance to patients with the presenting problem, acceptability is likely to be high.

- *Disadvantages:*

- Health status scores cannot be compared with those for the general population.
- It is not possible to make comparisons across treatments for different diseases, which limits the application of disease-specific instruments in economic evaluation.
- The restricted focus of disease-specific instruments may prevent them from detecting side effects or unforeseen effects of treatment.

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

PHYSICAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea.....	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
GP4	I have pain.....	0	1	2	3	4
GP5	I am bothered by side effects of treatment.....	0	1	2	3	4
GP6	I feel ill.....	0	1	2	3	4
GP7	I am forced to spend time in bed.....	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends.....	0	1	2	3	4

Population Specific PROMs

Population-specific instruments are designed to be appropriate to particular demographic groups, such as children or elderly people. Example: CHIP-CE

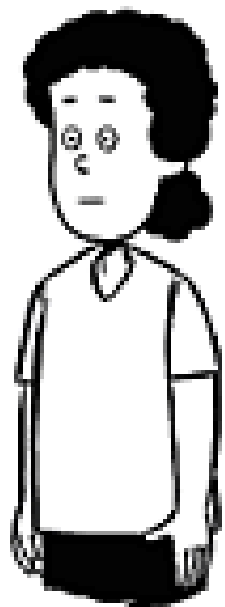
- *Advantages:*

- The content may be more relevant to the group in question - e.g. school performance in young children.
- A specifically tailored format, e.g. cartoon illustrations to convey instructions rather than text, can make these measures more accessible
- May also be sensitive to systematic differences between population groups.

- *Disadvantages:*

- Similar to those of disease-specific measures
 - Can't make comparisons with the general population
 - Difficult to compare the efficacy of particular treatments across population groups.

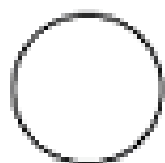
In the past 4 weeks, how often did you feel really worried?



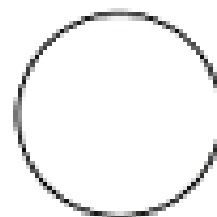
Never



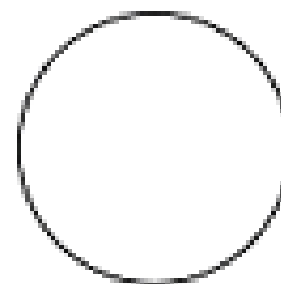
Almost
Never



Sometimes



Almost
Always



Always

Dimension Specific PROMs

Dimension-specific instruments assess one particular aspect of health status. Aspects most commonly identified as relevant to patient reported outcomes

- *Physical Function*
 - e.g. mobility, dexterity, range of motion, physical activity, activities of daily living
- *Symptoms*
 - e.g. pain, nausea, appetite, energy/vitality/fatigue, sleep
- *Psychological well-being*
 - e.g. anxiety, depression, coping, sense of control
- *Personal constructs*
 - e.g. satisfaction with body appearance, stigma, spirituality
- *Social well-being*
 - e.g. family and intimate relationships, social contact/integration, leisure activities
- *Cognitive Functioning*
 - e.g. concentration, memory, confusion, ability to communicate
- *Role activities*
 - e.g. employment, household management, financial concerns
- *Satisfaction with care*

Dimension Specific PROMs

- *Advantages:*
 - provide a more detailed assessment than is often than that provided by disease-specific or generic instruments
 - Many of the instruments, which include measures of physical functioning as well as psychological well-being, have been widely used, so that there is a wide range of data available for comparing and interpreting results.
- *Disadvantages:*
 - Measures of psychological well-being in particular were often developed with the primary objective of diagnosis or needs assessment. Before such instruments are used in evaluative applications their appropriateness as outcome measures should be examined carefully.

Hospital Anxiety and Depression Scale (HADS)

**Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.**

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

ADDITIONAL CONCERNS

		Not at all	A little bit	Some- what	Quite a bit	Very much
C2	I am losing weight.....	0	1	2	3	4
Ga1	I have a loss of appetite.....	0	1	2	3	4
Ga2	I am bothered by reflux or heartburn	0	1	2	3	4
HN1	I am able to eat the foods that I like.....	0	1	2	3	4
Ga6	I have discomfort or pain when I eat	0	1	2	3	4
Ga5	I have a feeling of fullness or heaviness in my stomach area.....	0	1	2	3	4
C1	I have swelling or cramps in my stomach area.....	0	1	2	3	4
Ga 12	I have trouble swallowing food	0	1	2	3	4
Ga4	I am bothered by a change in my eating habits.....	0	1	2	3	4
E6	I am able to enjoy meals with family or friends	0	1	2	3	4
Ga 10	My digestive problems interfere with my usual activities	0	1	2	3	4
Ga9	I avoid going out to eat because of my illness	0	1	2	3	4

Individualized PROMs

Individualised instruments allow respondents to select the content of items and/or rate the importance of individual items. Example: PGI

- *Advantages:*

- Can address the concerns of the individual patient rather than impose an external standard that may be less relevant.
- Can have high content validity.

- *Disadvantages:*

- May to be administered by interview in order to produce response rates similar to those for standardised instruments.
- This has implications for the feasibility of individualised instruments when compared to standardised instruments that can be self-administered.

Patient Generated Index

STEP 1: Identifying areas

We would like you to think of the most important areas of your life. Please write up to FIVE areas in the boxes below.

Here are some areas other patients have mentioned that might help you to think how your life has been affected:

Social life, work, housework, hobbies, interests, mood, loss of independence, can't go shopping, walking, climbing stairs, sitting, sleep, tiredness

STEP 2: Scoring each area

In this part we would like you to score the areas you mentioned in step 1. This score should show how badly affected you were over the past MONTH. Please score each area out of 10 using this scale:

- 10 Exactly as you would like to be
- 9 Close to how you would like to be
- 8 Very good but not how you would like to be
- 7 Good, but not how you would like to be
- 6 Between good and fair
- 5 Fair
- 4 Between poor and fair
- 3 Poor but not the worst you could imagine
- 2 Very poor but not the worst you could imagine
- 1 Close to the worst you could imagine
- 0 The worst you could imagine

STEP 3: Spending points

We want you to imagine that any or all the areas of your life could be improved. You have 14 imaginary points to spend to show which areas you would most like to see improve. Spend more points on areas you would most like to see improve and less on areas that are not so important.

You don't have to spend points in every area. You can't spend more than 14 points in total.

<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>
<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>
<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>
<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>
<input type="text"/>	→	<input type="text"/>	→	<input type="text"/>

Please use the last two boxes to score all areas affected by other health problems and all other non-health areas of life

AREAS AFFECTED BY OTHER HEALTH PROBLEMS

ALL OTHER NON-HEALTH AREAS OF LIFE

<input type="text"/>	→	<input type="text"/>
<input type="text"/>	→	<input type="text"/>

Remember total must add up to 14

Real Life Examples

The CHOICE Study: Choosing Options for
Insomnia in Cancer Effectively

<http://www.pcori.org/research-results/2014/choosing-options-insomnia-cancer-effectively-choice-comparative-effectiveness>

And

The PRIME Study: Priorities for Improving
Experience in Young Adult Cancer Survivors

How do I evaluate a PROM?

- When considering your PROM options, you should understand:
 - the concept(s) underlying each PRO measure (e.g., symptom or impairment) and how it is meaningful to, and noticed by, patients in the population of interest;
 - how the concept relates to the health decisions the study is designed to inform;
 - how the PRO measure was developed, including how patients were involved in the development

Patient engagement

- Review study: total of 189 studies describing development of 193 PROMs
- Patients were mostly involved in:
 - Item development (58.5%)
 - Testing comprehensibility (50.8%)
 - Determining outcomes (10.9%)
- In 25.9% of the PROM development studies, no patients were involved

Reference: Wiering et al. (2016) Patient involvement in development of patient-reported outcome measures: a scoping review [[link](#)]

How do I evaluate a PROM?

- A good PROM should also have evidence of solid measurement properties including:
 - content validity
 - construct validity
 - reliability
 - responsiveness to change over time
 - score interpretability (including meaningfulness of score changes in the population of interest with consideration of important subgroups)

Content Validity

- Does the instrument measure what it is supposed to?
 - The representativeness and the relevance of the assessment instrument to the construct being measured.
 - A tool is typically created by experts and then reviewed by users to ensure face validity

Construct Validity

- It is defined as evidence that relationships among concepts, domains and items conform to *a priori* hypotheses concerning logical relationships that should exist with other measures or characteristics of patients and patient groups.
 - It includes convergent, divergent, and known groups' validity.
- In convergent validity, measures of constructs theoretically should be related to each other, e.g. hopelessness and depression.
- In divergent validity, one should be able to discriminate between dissimilar constructs, e.g. depression and life satisfaction.
- In known groups' validity, evidence for the thing that the instrument can differentiate between clinically distinct groups is checked, e.g. depressed and non-depressed people.

Reliability

- It is the ability of a PRO instrument to yield reproducible and consistent estimates of true treatment effect.
- It is a necessary (but not adequate) component of validity.
- Reliability can be predicted by three ways as
 - 1) test-retest reliability- it is a measure of the ability of an instrument to yield the same result for a single Patient at 2 different test periods, which are closely spaced so that any variation detected reflects reliability of the instrument rather than changes in the Patient's status. This type of reliability is checked by intra-class correlation coefficient (ICC). Time period between test and retest is an important factor here.
 - 2) Internal consistency-The consistency of the results delivered in a test, ensuring that the various items measuring the different constructs deliver consistent scores. Internal consistency is determined with Cronbach's alpha.
 - 3) Inter-interviewer reliability – It determines the changes in the results when the instrument is administered by two or more interviewers. It is generally measured by Pearson's 'r' value.

Responsiveness to Change

- The instrument should be able to detect the changes in the expected outcomes.
- Statistical significance \neq clinically meaningful difference
 - E.g. insomnia severity index

Where can I find a PROM?

- PROMIS – Patient Reported Outcomes Measurement Information System
 - <http://www.healthmeasures.net/explore-measurement-systems/promis>
 - Search & view measures example
 - <http://www.healthmeasures.net/search-view-measures>

Where can I find a PROM?

- Patient Reported Outcomes Measurement Group - <http://phi.uhce.ox.ac.uk/>
- Reports and publications
 - <http://phi.uhce.ox.ac.uk/selectpubs.php>

Where can I find a PROM?

- Pubmed
 - Systematic reviews
 - Examples:
 - Fatigue in patients with chronic illness
 - Nordin Å, Taft C, Lundgren-Nilsson Å, Dencker A. (2016). Minimal important differences for fatigue patient reported outcome measures-a systematic review. BMC Med Res Methodol, 16:62. doi: 10.1186/s12874-016-0167-6.
 - Quality of life of individuals with Lupus
 - Ogunsanya ME, Kalb SJ, Kabaria A, Chen S. (2017). A systematic review of patient-reported outcomes in patients with cutaneous lupus erythematosus. Br J Dermatol. 176(1):52-61. doi: 10.1111/bjd.14868.

Upcoming sessions

Save the date:

- Clinician-led research grant, March.2 12:30-1:30PM
- Big Data, Big Stories, Mar.23 12:30-1:30PM
- Reach People, Apr. 13 12:30-1:30PM

Go to <http://nlsupport.eventbrite.ca> to register

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to complete the evaluation of this session.

End of session

