



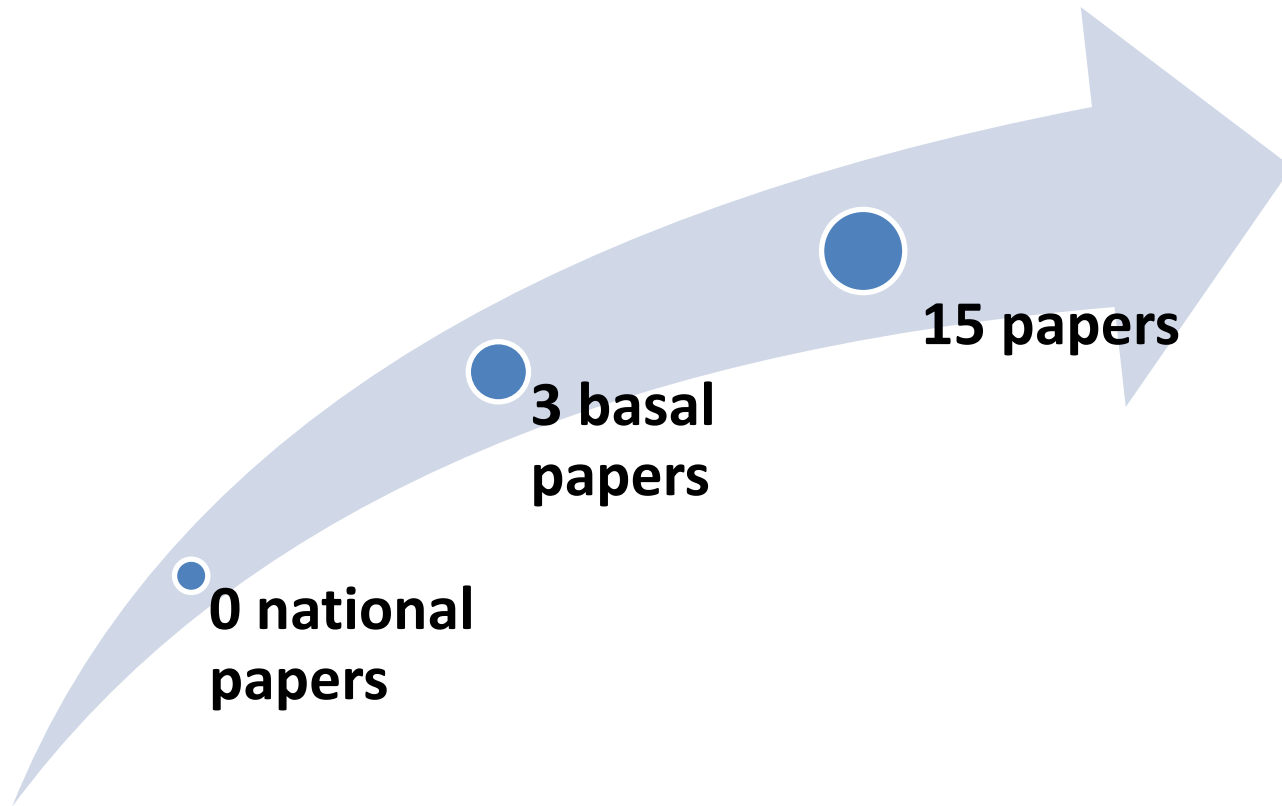
# Report Patient Symptoms by Using Digital Technology and Its Integration Into Clinical Trials and Medical Care

Andrés Cortés R

Tutora: Dra. Bettina Muller

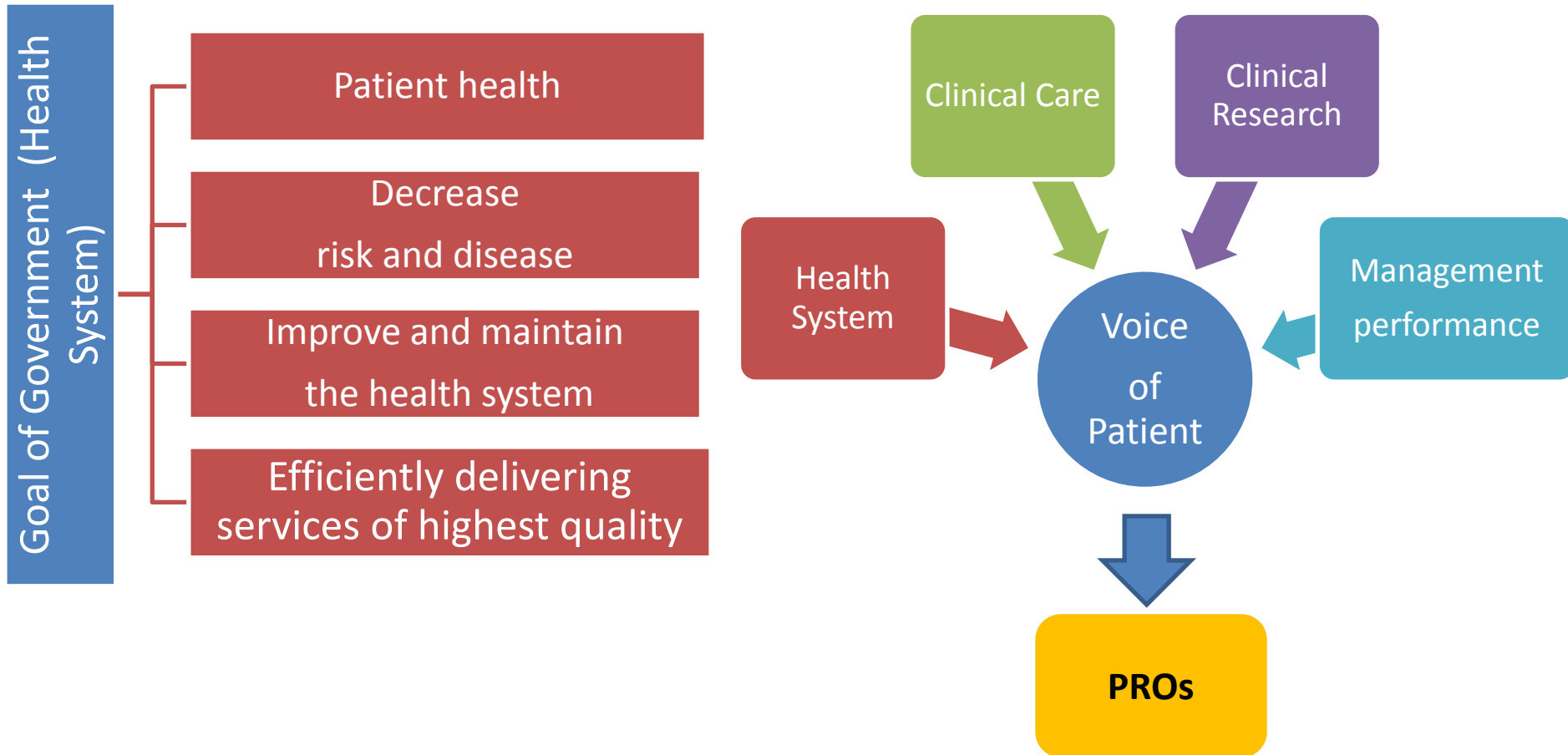
GOCCHI

# How was this done?



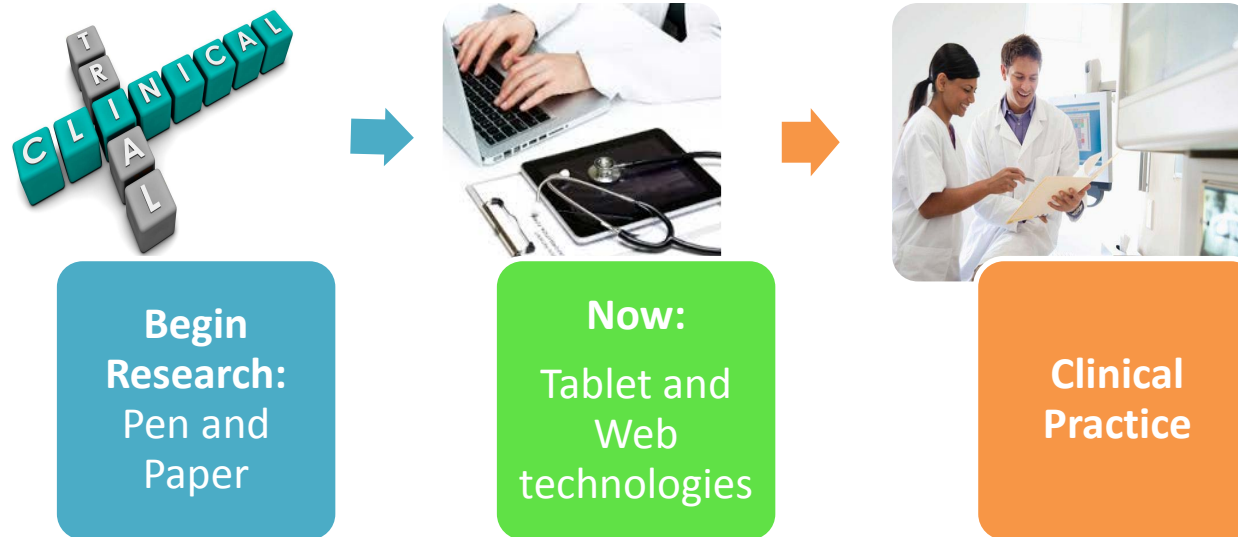
- Search Engine: Pubmed, plosOne, Google Scholar y Scielo,

# Overview



# Overview

- PROs are defined as any report coming directly from patients about their health condition and treatment (FDA 2009) and include a range of **outcomes** such as symptoms, functional status, and **health-related quality-of-life** (Acquadro 2003).





Trial Design



In trial  
processes



Reporting

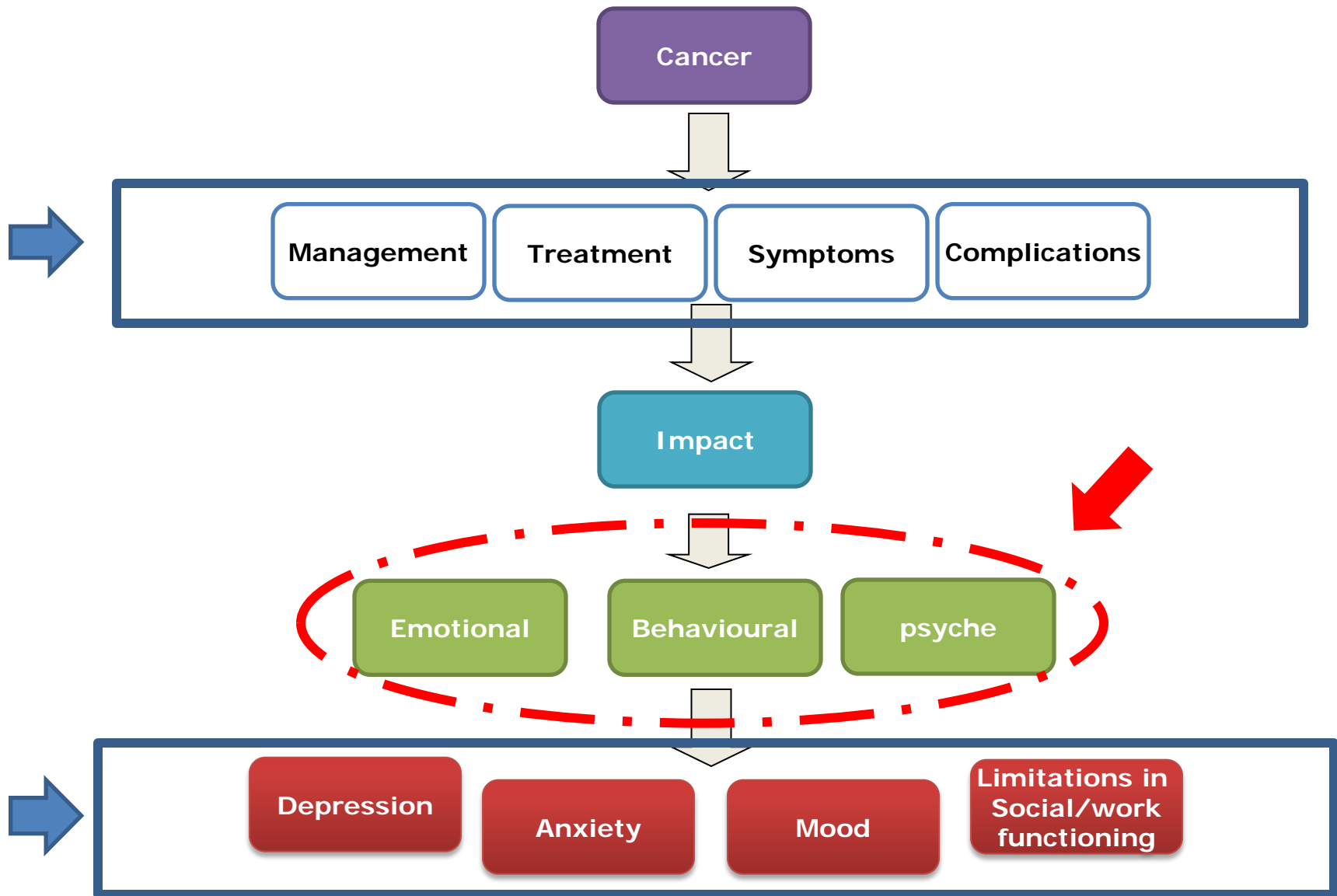


Implementation  
in Clinical  
practice

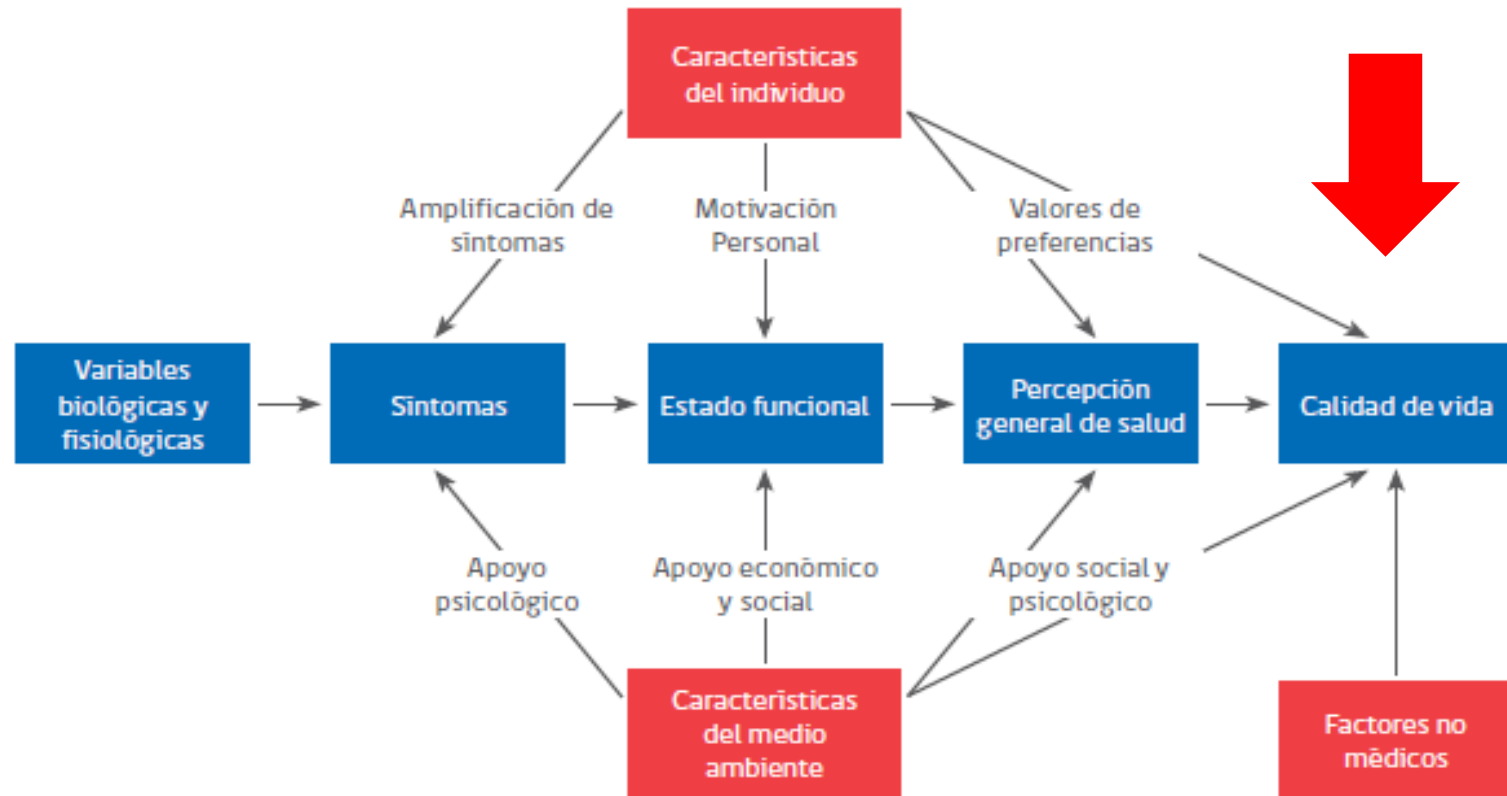


**Ethics / Education / Training / Knowledge Translation**

# Why is it necessary to include them?



# General Frame



Fuente: Traducido de Wilson y Cleary (1995)

# What's PRO?

## PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

### •Characteristics

- Reliability, Validity and Ability to Detect Change
- Must be demonstrated empirically (for example, by confirmatory factor analysis)



# Development of a PRO Instrument: **An Iterative Process**

## i. Hypothesize Conceptual Framework

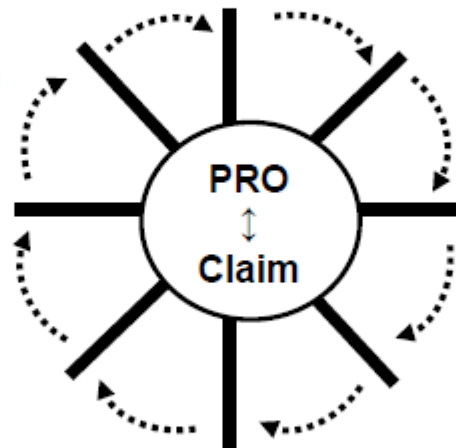
- Outline hypothesized concepts and potential claims
- Determine intended population
- Determine intended application/characteristics (type of scores, mode and frequency of administration)
- Perform literature/expert review
- Develop hypothesized conceptual framework
- Place PROs within preliminary endpoint model
- Document preliminary instrument development

## v. Modify Instrument

- Change wording of items, populations, response options, recall period, or mode/method of administration/data collection
- Translate and culturally adapt to other languages
- Evaluate modifications as appropriate
- Document all changes

## iv. Collect, Analyze, and Interpret Data

- Prepare protocol and statistical analysis plan (final endpoint model and responder definition)
- Collect and analyze data
- Evaluate treatment response using cumulative distribution and responder definition
- Document interpretation of treatment benefit in relation to claim



## ii. Adjust Conceptual Framework and Draft Instrument

- Obtain patient input
- Generate new items
- Select recall period, response options and format
- Select mode/method of administration/data collection
- Conduct patient cognitive interviewing
- Pilot test draft instrument
- Document content validity

## iii. Confirm Conceptual Framework and Assess Other Measurement Properties

- Confirm conceptual framework with scoring rule
- Assess score reliability, construct validity, and ability to detect change
- Finalize instrument content, formats, scoring, procedures and training materials
- Document measurement development

# Tools Usually Used

## Response Option Types

Type	Description
Visual analog scale (VAS)	A line of fixed length (usually 100 mm) with words that anchor the scale at the extreme ends and no words describing intermediate positions. Patients are instructed to indicate the place on the line corresponding to their perceived state. The mark's position is measured as the score.
Likert scale	An ordered set of discrete terms or statements from which patients are asked to choose the response that best describes their state or experience.
Rating scale	A set of numerical categories from which patients are asked to choose the category that best describes their state or experience. The ends of rating scales are anchored with words but the categories are numbered rather than labeled with words.
Recording of events as they occur	Specific events are recorded as they occur using an event log that can be included in a patient diary or other reporting system (e.g., interactive voice response system).
Pictorial scale	A set of pictures applied to any of the other response option types. Pictorial scales are often used in pediatric questionnaires but also have been used for patients with cognitive impairments and for patients who are otherwise unable to speak or write.
Checklist	Checklists provide a simple choice between a limited set of options, such as <i>Yes</i> , <i>No</i> , and <i>Don't know</i> . Some checklists ask patients to place a mark in a space if the statement in the item is true. Checklists are reviewed for completeness and nonredundancy.

## Core set of PROQOL questions.



Please check the number that describes your feelings **over the past month** from as bad as it can be to as good as it can be



Your overall quality of life:

as bad as it can be  0  1  2  3  4  5  6  7  8  9  10 as good as it can be

Your overall physical well being:

as bad as it can be  0  1  2  3  4  5  6  7  8  9  10 as good as it can be

Your overall emotional well being:

as bad as it can be  0  1  2  3  4  5  6  7  8  9  10 as good as it can be

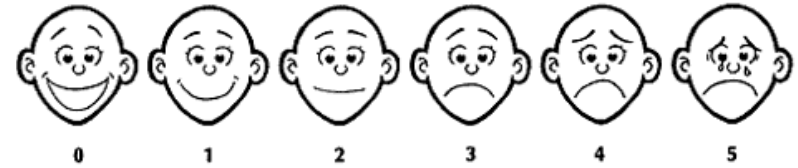
Your social interaction with other people (family, friends, or others):

as bad as it can be  0  1  2  3  4  5  6  7  8  9  10 as good as it can be

### VISUAL ANALOG SCALE



### HAPPY FACE - SAD FACE SCALE



Ridgeway JL, Beebe TJ, Chute CG, Eton DT, et al. (2013) A Brief Patient-Reported Outcomes Quality of Life (PROQOL) Instrument to Improve Patient Care. PLoS Med 10(11): e1001548. doi:10.1371/journal.pmed.1001548  
<http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1001548>

# The Patients point of view and Voice: Very Important to consider

*“If quality is to be at the heart of everything we do, it must be understood from the perspective of the patient”*



*“**Just as important** (as clinical measures) is the effectiveness of care from the patient’s own perspective which will be measured through **patient-reported outcome** measures”*

# Benefits of PRO (QoL) in clinical practice

## Treatment

Physicians take more actions regarding the patient-report

- The experimental group physicians diagnosed more symptoms of stress or anxiety than did the control group physicians (**p < 0.001**) and took more actions recommended by the feedback form (**p < 0.02**) (**Rubenstein et al. 1995**). 73 % in the experimental group vs 69 % control group (**p < 0.005**) (**Magruder-Habib et al. 1990**)

## Referral

Physicians reported more referral rates to other professionals

- The referral is bigger in the experimental group (Psychiatric referral (14.1% vs 7.7%) and received psychosocial referral (36.1% vs 5.7%)(**P < than .0001**))(**Gold and Baraff . 1989**)

## Communication

Improves communication between physicians and patients .

- (**Wagner et al 1997**) moderate percentage (67%) of patients reported positive attitudes about completion of the assessment as well as sharing their feelings and physical abilities with their physician.

NIH  
&  
NCI



conclude that QoL measures should be incorporated into research studies when possible.



# QoL on Medical Practice

## Health-Related Quality-of-Life Assessments and Patient-Physician Communication

A Randomized Controlled Trial

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Symone B. Detmar, PhD

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Martin J. Muller, MSc

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Jan H. Schornagel, MD, PhD

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Lidwina D. V. Wever

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Neil K. Aaronson, PhD

**Context** There has been increasing interest in the use of health-related quality-of-life (HRQL) assessments in daily clinical practice, yet few empirical studies have been conducted to evaluate the usefulness of such assessments.

**Objective** To evaluate the efficacy of standardized HRQL assessments in facilitating patient-physician communication and increasing physicians' awareness of their patients' HRQL-related problems.

Of the patients stated that the QoL profile provided an accurate summary of their functioning and well-being

57% Reported their physicians used the profile explicitly during their visits.

79% Believed the profile enhanced physician awareness of their health problems

87% Thought it would be useful to introduce a QoL assessment as a standard part of the outpatient clinical experience.

However, the **control group visits took longer** than the intervention group (20.4 minutes vs. 19.8 minutes, respectively)

# Problems with PRO (QoL) measure

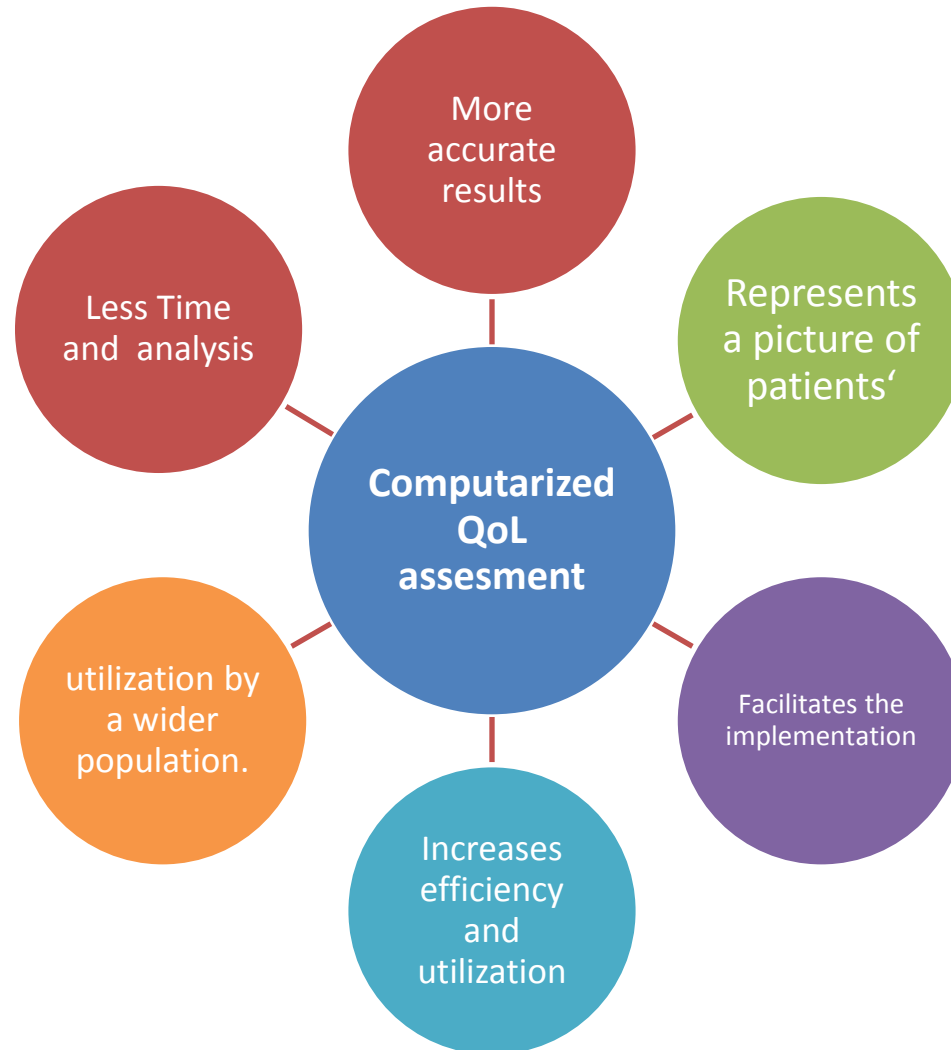
## Characteristics of QoL assessments

- Physicians often view it as providing "**soft data**" that does not permit "hard" measurement such as that obtained in the laboratory.
- Questions that are **too personal**, sensitive, or irrelevant are more likely to be omitted by patients.

## Implementation

- **Morris et al. 1998** 80% of healthcare professionals believed that information obtained from QOL assessments is valuable, fewer than **50% of them implemented QOL assessments in their practice.**
- Problems related due to logistical and resource constraints

# What Happens if we introduce IT to Medical Practice?





# Example

J Clin Oncol. 1999 Mar;17(3):998-1007.

## **Automated collection of quality-of-life data: a comparison of paper and computer touch-screen questionnaires.**

Velikova G<sup>1</sup>, Wright EP, Smith AB, Cull A, Gould A, Forman D, Perren T, Stead M, Brown J, Selby PJ.

Comparing the touch-screen versions and paper versions of the EORTC QLQ-C30 and the HADS, the quality of the data extracted from a touchscreen version was found to be **excellent**, with no **missing** or problematic responses, mainly because the patient could not progress through the questionnaire **without answering each question**.

Less time to complete the touch-screen version (**8.3 minutes**) as opposed to the paper version (**9.6 minutes**).

The same study found that **52%** of the patients surveyed preferred the touch-screen computer, compared to 24% preferring the paper version.

**Computer touch-screen QOL questionnaires were well accepted by cancer patients, with good data quality and reliability**

# A Randomized Study of Electronic Diary versus Paper and Pencil Collection of Patient-Reported Outcomes in Patients with Non-Small Cell Lung Cancer

*Alistair E. Ring,<sup>1</sup> Kerry A. Cheong,<sup>1</sup> Claire L. Watkins,<sup>2</sup> David Meddis,<sup>2</sup> David Cella<sup>3</sup> and Peter G. Harper<sup>1</sup>*

1 Medical Oncology, Guy's Hospital, London, UK

2 AstraZeneca, Macclesfield, Cheshire, UK

3 Evanston Northwestern Healthcare, Evanston, Illinois, USA

The mean completion time was shorter for the paper and pencil method than the e-PRO method ( $p < 0.0001$ ). However, most patients stated that they **preferred the e-PRO method over paper and pencil (60% vs 12%)**.

Therefore, the group results obtained using the e-PRO should be similar to the originally validated paper method, **with the advantages of improved patient acceptability and ease of reliable interfacing with trial databases.**

Ring AE1, Cheong KA, Watkins CL, Meddis D, et al. (2008) **A Randomized Study of Electronic Diary versus Paper and Pencil Collection of Patient-Reported Outcomes in Patients with Non-Small Cell Lung Cancer.** Patient, Apr 1;1(2):105-13.

# Issues with computerized assessment

## Problems

Technical  
difficulties

Some patients had difficulty with the handheld computers because of the small screens as well as the software design

Difficult touch due to the wearing down of equipment towards the end of the study

Funding

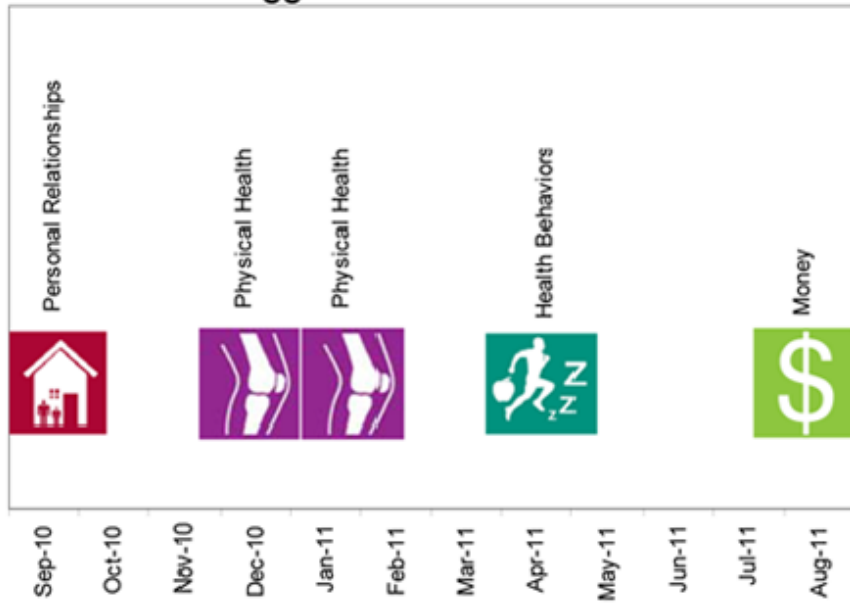
which of the following, if any, represents your  
**single biggest concern**  
right now...



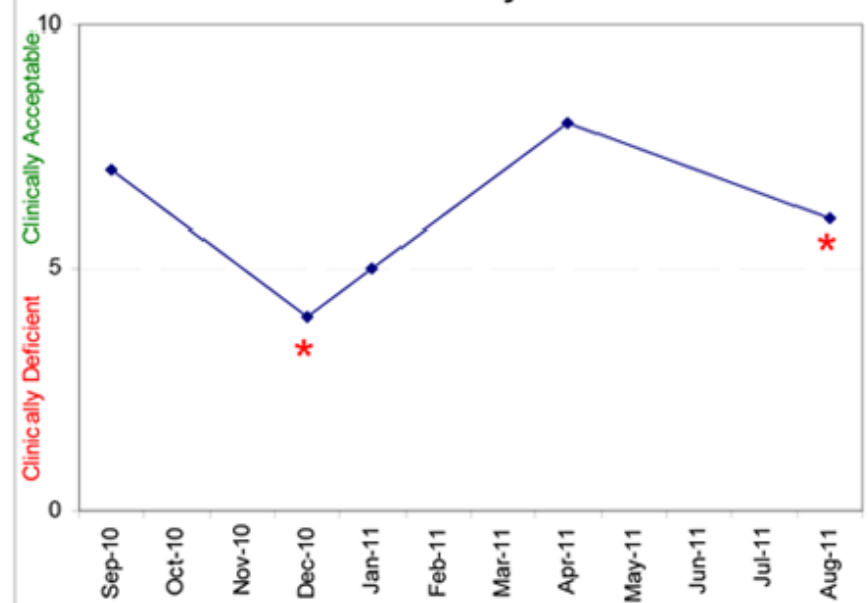
## Trends over time

\* = **ALERT**: Clinically meaningful decline or clinically deficient score

### Biggest Concern Domain



### Overall Quality of Life



Ridgeway JL, Beebe TJ, Chute CG, Eton DT, et al. (2013) A Brief Patient-Reported Outcomes Quality of Life (PROQOL) Instrument to Improve Patient Care. PLoS Med 10(11): e1001548. doi:10.1371/journal.pmed.1001548  
<http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1001548>

## Single Biggest Concern Domain Today



## Specific Concerns Identified Today

- Problems paying your medical bills
- Cut pills in half or skipped doses of medicine
- Skipped dental, vision or mental health care costs because of cost

### Problems paying your medical bills

- Direct patient to your clinic's patient account services for information on payment options.
- Connect patient with financial aid services

[http://www.dlife.com/diabetes\\_resources/saving\\_money/financial\\_help/index.page1](http://www.dlife.com/diabetes_resources/saving_money/financial_help/index.page1)

### Cut pills in half or skipped doses of medicine

- Review medication list for opportunities to substitute generic or less expensive options.
- Consider printing and reviewing with the patient the "Financial Help for Diabetes Care" information from the NIDDK website.

<http://diabetes.niddk.nih.gov/dm/pubs/financialhelp/financialhelp.pdf>

- Direct patient to programs for free or discounted prescription medicine.

<http://www.state.mn.us/portal/mn/jsp/home.do?agency=Rx>

<http://www.health.state.mn.us/clearinghouse/prescription.pdf>

<http://www.minnesotahelp.info/QA/default.aspx?se=senior>

### Skipped dental, vision or mental health care costs because of cost

- Direct patient to resources for free or discounted eye exams (if eligible).

<http://www.aoa.org/visionusa.xml>

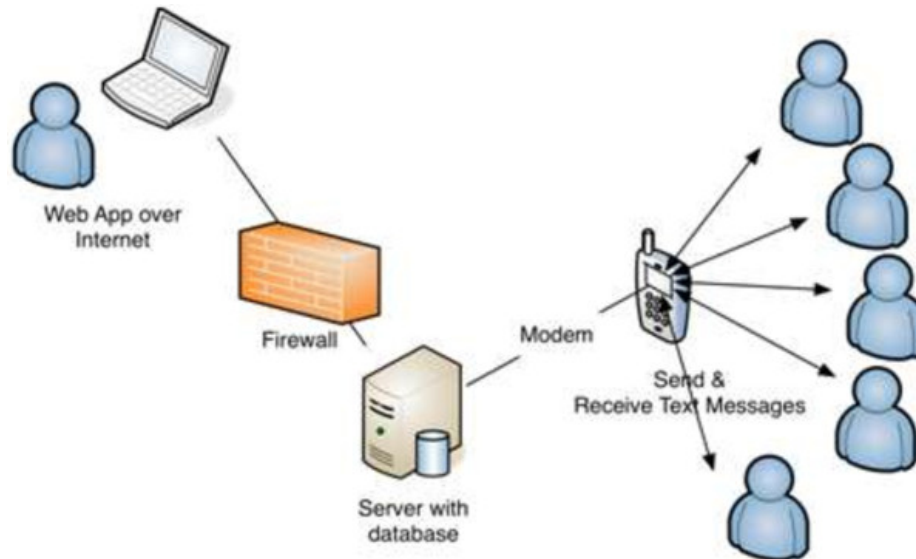
<http://www.eyecareamerica.org/>

- Provide NIDDK brochure on dental self-care

Ridgeway JL, Beebe TJ, Chute CG, Eton DT, et al. (2013) A Brief Patient-Reported Outcomes Quality of Life (PROQOL) Instrument to Improve Patient Care. PLoS Med 10(11): e1001548. doi:10.1371/journal.pmed.1001548

<http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1001548>

# ePRO adaptative change!



## Evolution of ePRO

Traditional ePRO	ePRO using Classical Test Theory	ePRO using Modern Test Theory
Single Item/Collection of Items	Classically Developed Assessment	IRT-based Assessment

1. <https://adapttest.vpgcentral.com/>

2. Christie, A., Dagfinrud, H., Dale, Ø., Schulz, T., & Hagen, K. B. (2014). Collection of patient-reported outcomes; - text messages on mobile phones provide valid scores and high response rates. *BMC Medical Research Methodology*, 14, 52. doi:10.1186/1471-2288-14-52

# Ideas for the Future

- What could be the impact in the medical practice and Trial investigations in Chile?

Studies About That = 0

- Economic indicators
- Resource allocation
- Hour consultation
- Prevention
- etc

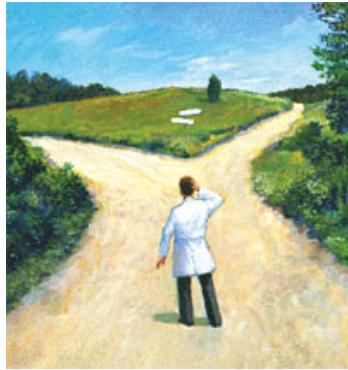




# Conclusion



Patient takes QoL



## Analysis

AmbuFlex 2.0		Name	CPR number	Tel.	Phone	Age
	HISTORY	SETTINGS	DEMOGRAPHICS	SHOW PRO		
	WE 17 OCT 2012	TH 10 JAN 2013	SU 21 APR 2013	TH 08 AUG 2013		
<b>Seizures</b>	Overall 12 months Absences 3 months Seizures 3 months	Number of days: 0 Number of days: 0 Number of days: 0	Number of days: 0 Number of days: 0 Number of days: 0	Number of days: 0 Number of days: 0 Number of days: 0	Number of days: 0 Number of days: 0 Number of days: 0	Number of days: 0 Number of days: 0 Number of days: 0
<b>Symptoms</b>	Headache Dizziness Shaking / tremor Double vision Loss of appetite Memory Concentration Aggressiveness Lethargy Sadness Anxiety / attack Presence of side effects Eating too much	2   3   4   1   3   2   4   2   4   1   1   1   1	1   4   1   1   1   3   4   2   2   1   1   1   1	1   3   1   1   1   1   3   3   3   4   1   1   1	2   3   1   2   1   3   4   2   2   4   4   1   3	
<b>Compliance</b>	Forget medicine General health	4   2	4   2	4   2	4   2	4   2
<b>SF-36</b>	Wellbeing index State of mind/mood	52   2	60   1	56   2	60   2	56   2
<b>WHO-5</b>	Energy Interest Pleasant Relaxed	2   2   3   5	1   2   3   5	2   2   4   5	2   2   6   5	
<b>Self-measurement</b>	Weight	No answer	Kg 100	Kg 105	Kg 95	Kg 85



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- Ring AE1, Cheong KA, Watkins CL, Meddis D, et al. (2008) A Randomized Study of Electronic Diary versus Paper and Pencil Collection of Patient-Reported Outcomes in Patients with Non-Small Cell Lung Cancer. *Patient*, Apr 1;1(2):105-13.



**ARE THERE ANY  
QUESTIONS?**

**I HOPE NOT**

# Additional

- <https://www.youtube.com/watch?v=gcWpGSFHL2s>
- <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001548>

Essentia Health: After answering questions, patient can review and edit answers

The screenshot shows a patient's review of their PHQ-9 questionnaire. The interface includes a navigation sidebar on the left, a patient profile header, and a table of questions with their answers. At the bottom, there are buttons for navigation and submission.

**Opti (Me)** GG Jacqueline Kimberly Vs Patient

**PHQ-9** ©2013 Epic Systems Corporation. Used with permission

Please review your responses. To finish, click **Submit Questionnaire**. Or, click any question to modify an answer.

Question	Answer	
Over the last two weeks, how often have you been bothered by having little interest or pleasure in doing things?	Several days	
Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless.	Not at all	
Over the last 2 weeks, how often have you had trouble falling or staying asleep, or sleeping too much?	Several days	
Over the last 2 weeks, how often have you been bothered by feeling tired or having little energy?	Not at all	
Over the last 2 weeks, how often have you been bothered by poor appetite or overeating?	Several days	
Over the last 2 weeks, how often have you been feeling bad about yourself - or feeling that you are a failure or have let yourself or your family down?	Not at all	
Over the last 2 weeks, how often have you had trouble concentrating on things, such as reading the newspaper or watching television?	Several days	
Over the last 2 weeks, how often have you been bothered by moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	Not at all	
Over the last 2 weeks, how often have you had thoughts that you would be better off dead, or of hurting yourself in some way?	Several days	
You checked off one or more problems. How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	

< Back Submit to Clinic Save for Later Cancel

## Electronic Patient-Reported Outcome Consortium

Overview

Members

Critical Path Institute has established the Electronic Patient-Reported Outcome (ePRO) Consortium, in cooperation with firms that provide electronic data collection technologies/services to the medical products industry for

ePRO Consortium

- <http://c-path.org/programs/epro/#wrapper>

Your demo session has ended, thank you.



## Adapttest™ - Smart ePRO™ System

[Features](#)    [Examples](#)    [Smart ePRO™](#)    [Contact Us](#)



Adapttest™ from VPG allows study sponsors to use a range of PRO measures from single-item responses to the most advanced adaptive testing technology using item response theory (IRT).

- Make better decisions based on better data
- Reduce patient burden
- Assessments based on science
- Protect your market position
- Flexible, customizable, secure
- 21 CFR Part 11 compliant, 128-bit AES encryption
- Data is securely stored in the private Vector cloud system

- <https://adapttest.vpgcentral.com/>

## Patient-Reported Outcomes

**Chair:** Kevin Weinfurt

**NIH Representatives:** Susan Czajkowski, William Riley

**Members:** Amy Abernethy, Gloria Coronado, Richard Deyo, Kathryn Flynn, Janna Friedly, Francis Keefe, Linda Khan, Dana Miskulin, Bret Moran, Ashli Owen-Smith, Doug Zatzick

**Project Manager:** Tracie Locklear

Patient-reported outcome (PRO) data are defined by the FDA as "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." These data are increasingly used to inform and guide patient-centered care, clinical decision-making, and health policy decisions and are an important component of many of the Collaboratory's Demonstration Projects.

The PRO Core works closely with the Collaboratory to create guidelines and define best practices with respect to



## Products and Publications

[Strategies for Overcoming Barriers to Patient Reported Outcomes Measures](#)

[Patient-Reported Outcomes Living Textbook Chapter](#)

## Presentations

[8/19/2014: Patient-Reported Outcomes Core Presentation at Steering Committee Meeting](#)

[2/25/2014: Patient-Reported Outcomes Core Presentation at Steering Committee Meeting](#)

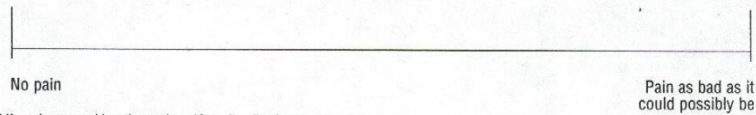
[1/10/2014: Grand Rounds Presentation: Incorporating Research Driven Changes into Health Care Systems' IT Operations: A Multi](#)



# Meta-Analysis

- The results summarized here show that computer and paper measures produce equivalent scores. Mean differences were very small and neither statistically nor clinically significant. Correlations were very high, and were similar to correlations between repeated administration of the same paper-and-pencil measure

c. Visual Analog Scale (VAS)<sup>2</sup>



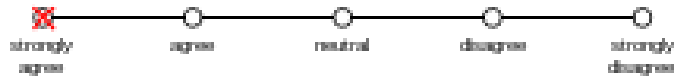
<sup>1</sup> If used as a graphic rating scale, a 10 cm baseline is recommended.  
<sup>2</sup> A 10 cm baseline is recommended for VAS scales.

## Example Likert Scale

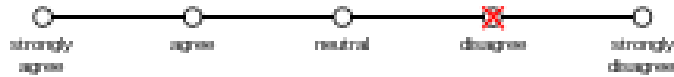
1. Wikipedia has a user friendly interface.



2. Wikipedia is usually my first resource for research.



3. Wikipedia pages generally have good images.



4. Wikipedia allows users to upload pictures easily.



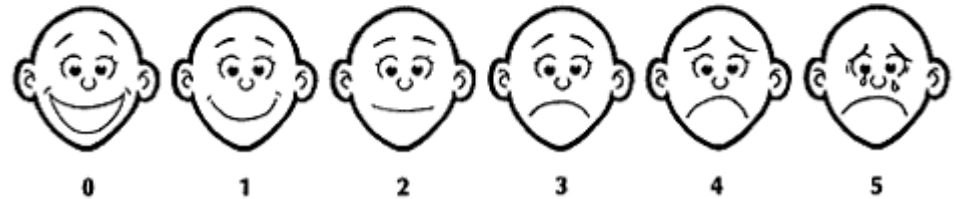
5. Wikipedia has a pleasing color scheme.



## VISUAL ANALOG SCALE



## HAPPY FACE - SAD FACE SCALE








## Severity Rating Scale

Rating	Description	Definition (Severity of Effect)
10	Dangerously high	Failure could injure the customer or an employee.
9	Extremely high	Failure would create noncompliance with federal regulations.
8	Very high	Failure renders the unit inoperable or unfit for use.
7	High	Failure causes a high degree of customer dissatisfaction.
6	Moderate	Failure results in a subsystem or partial malfunction of the product.
5	Low	Failure creates enough of a performance loss to cause the customer to complain.
4	Very Low	Failure can be overcome with modifications to the customer's process or product, but there is minor performance loss.
3	Minor	Failure would create a minor nuisance to the customer, but the customer can overcome it without performance loss.
2	Very Minor	Failure may not be readily apparent to the customer, but would have minor effects on the customer's process or product.
1	None	Failure would not be noticeable to the customer and would not affect the customer's process or product.

# Suggestions to resolve some issues

Table 1: Suggested solutions to overcome the challenges of implementing QOL assessments into clinical practice

Challenges	Solutions
 <b>Instrument characteristics</b> QOL assessments provide "soft data."  The types of questions asked can be too sensitive, personal, or irrelevant.	Support the implementation of QOL assessments, as the soft data provides additional insights into a patient's health, as it provides qualitative data in addition to the quantitative data provided by "hard" measurement.  It is recommended that, when developing questionnaires, potential questions be tested by a population of elderly patients to gauge respondents' sensitivity and how effectively the questions measure a patient's QOL.
 <b>Patient population</b> Questionnaires do not assess long-term survivors (over 5 years) – only 1 year survivors. Among the elderly, there is illiteracy, worse compliance with questionnaires, and cognitive disorders.	Long-term survivors of more than 5 years should be included in the original development and testing of instruments.  The option of questionnaires administered in an interview format should be available to elderly patients. This solution would address compliance. In addition, it would address illiteracy and cognitive disorders, because the questionnaires could be read to the respondents, explained, and discussed with them.
 <b>Healthcare professionals</b> Physicians are less familiar with how to utilize QOL assessments and how to interpret or respond to results.  Physicians do not have the proper tools needed to make QOL assessments part of their practice.	Training classes about the importance, potential benefits, proper utilization of QOL assessments, interpretation of results, and appropriate action to be taken are recommended to be offered at medical schools and through Continuing Medical Education courses. To help better understand their utilization, healthcare providers could be taught whom the appropriate specialists to refer their patients would be based on the results of the QOL assessments.  QOL assessments could be made accessible through online availability, allowing physicians to have a centralized location to download efficiently instruments as needed.
 <b>Logistics and resources</b> Time limitations exist.  Measures are usually reported manually, which leads to inaccurate results and a long turnaround time.	Questionnaires could be administered while the patient is waiting to be seen by the physician.  The utilization of computerized assessments would improve the accuracy of QOL assessments and increase the efficiency of their use.
 <b>Computerized assessment</b> Respondents may be unfamiliar with how to use computers or touchpad personal computers (PCs).  The programming of some questionnaires makes it difficult for patients to change their answers.	Brief training sessions of 10–15 minutes could be held while patients are in waiting rooms, where respondents would learn by the administrator how to manipulate the mouse, keyboard, and touchpad.  Efforts could be made to modify computer programming and software to facilitate computerized administration of questionnaires.

# Examples of Electronic Systems

formhub

**State your height**

What is your profession? \*

1 selected -

What is your gender? (This field is not mandatory)

none selected -

Do you want to record your height in centimetres or in feet & inches? \* Required

Centimetres

Feet and inches

**Provide your height (imperial):**

**Feet \***  
allows only integer values

6

**Inches \***  
allows only integer values < 12

6

Conversion into metric system: 198.12 cm

Write an optional comment (will be attached to the height value).

as M)

Save as Draft

Powered by ENKETO

<http://tschuler.github.io/prosaiq/tech>

Body Pain Index

Touch on the diagram to indicate the areas you are feeling pain or discomfort.

You may also indicate that you are experiencing no pain.

You may decline to answer this question.

No Pain Experienced

Choose Not To Answer Question

← →

10:58

Touch screen EQ5D health scale

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
<u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Lifting or carrying groceries	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Climbing <u>several</u> flights of stairs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

← →

03:16

Arrows allow patient to easily review previous questions

assisTek : <http://www.assistek.com/about/overview>

Figure 1. PROQOL domains and item checklist.

which of the following, if any, represents your  
**single biggest concern**  
right now...

 <b>personal relationships</b> <ul style="list-style-type: none"><li>• Family</li><li>• Friends</li></ul>	 <b>monitoring health</b> <ul style="list-style-type: none"><li>• Testing blood sugars</li><li>• Checking feet</li></ul>	 <b>emotional health</b> <ul style="list-style-type: none"><li>• Sad</li><li>• Anxious</li><li>• Other emotional concerns</li></ul>	 <b>money</b> <ul style="list-style-type: none"><li>• Cost of medicine or supplies</li><li>• Paying for care</li></ul>	 <b>health behaviors</b> <ul style="list-style-type: none"><li>• Diet</li><li>• Exercise</li><li>• Sleep</li></ul>
 <b>medicine</b> <ul style="list-style-type: none"><li>• Taking medication</li><li>• Managing side effects</li></ul>	 <b>getting health care</b> <ul style="list-style-type: none"><li>• Finding a provider to talk to</li><li>• Scheduling appointments</li></ul>	 <b>work</b> <ul style="list-style-type: none"><li>• Schedule</li><li>• Environment</li><li>• Managing your health condition at work</li></ul>	 <b>physical health</b> <ul style="list-style-type: none"><li>• Pain</li><li>• Fatigue</li><li>• Physical difficulties</li></ul>	 <b>something else</b>

 **money**

Have you recently had any of the following problems or concerns?  
(Check all that apply)

<input type="checkbox"/>	Problems paying your medical bills
<input type="checkbox"/>	Problems paying for all the care you needed
<input checked="" type="checkbox"/>	Problems paying for all the medicines or supplies that you needed
<input type="checkbox"/>	Not maintaining health insurance coverage
<input type="checkbox"/>	Skipped a recommended test or medical treatment
<input checked="" type="checkbox"/>	Not filled a prescription for a medicine
<input type="checkbox"/>	Cut pills in half or skipped doses of medicine
<input type="checkbox"/>	Skipped dental, vision or mental health care visit because of cost
<input type="checkbox"/>	Put off or postponed getting health care you needed
<input type="checkbox"/>	Something else






 back  next

Ridgeway JL, Beebe TJ, Chute CG, Eton DT, et al. (2013) A Brief Patient-Reported Outcomes Quality of Life (PROQOL) Instrument to Improve Patient Care. PLoS Med 10(11): e1001548. doi:10.1371/journal.pmed.1001548  
<http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1001548>

# Some Survey PRO (QoL)

	<b>Measure</b>	<b>Purpose</b>
➔	1 Beck Depression Inventory (BDI) [1]	Designed to measure depression
➔	2 Breast Cancer Chemotherapy Questionnaire (BCQ) [3]	Developed to measure outcomes of women with stage II breast cancer receiving adjuvant chemotherapy
	3 Breast Cancer Prevention Trial Symptom Checklist (BCPT [4,5])	Designed to examine the physical and psychological symptoms associated with menopause and Tamoxifen usage
➔	4 Cancer Needs Questionnaire – Short Form (CNQ-SF) [6]	Developed to assess cancer patients' needs
	5 Cancer Rehabilitation Evaluation System (CARES-SF) [8]	Developed to assess patients' cancer-related problems
	6 Center for Epidemiologic Studies Depression Scale-10 (CES-D)	Designed to measure depression
➔	7 European Organization for Research and Treatment of Cancer QOL Breast Cancer Specific Version (EORTC QLQ-BR23) [12]	Designed to measure QOL in the breast cancer population at various stages and with patients with differing modalities
➔	8 European Organization for Research and Treatment of Cancer QOL Cancer Specific Version (EORTC QLQ-C30) [13]	Cancer specific questionnaire designed to measure QOL in the cancer population
	9 Edmonton Symptom Assessment System (ESAS)	Designed to measure a variety of symptoms

# Some Survey QoL

	Measure	Purpose
	10 Functional Assessment of Cancer Therapy – Endocrine System (FACT-ES) [20]	Focus on endocrine concerns experienced during breast cancer treatment
	11 Functional Living Index – Cancer ((FLIC) [21])	Designed to assess the effect that cancer treatment and symptoms have on functional ability in all areas of life
	12 Geriatric Depression Scale – Short Form ((GDS-SF) [23])	Designed to assess depression in the elderly
	13 Hospital Anxiety and Depression Scale ((HADS) [26])	Developed to measure anxiety and depression
	14 Life Satisfaction Questionnaire (LSQ) [14]	Developed to measure one’s general sense of satisfaction with life as it relates to school, relationships, leisure time, religious practices, and overall health, specifically for women with breast cancer
	15 Medical Outcome Short Form Health Survey (SF-36) [29]	Developed to assess health-related QOL
	16 Quality of Life Index ((QL-Index) [32]	Designed to assess health outcomes of those with cancer and other chronic diseases
	17 Rotterdam Symptoms Checklist – Modified [33]	Developed to assess symptom-related distress among cancer patients
	18 Satisfaction with Life Domains Scale for Breast Cancer (SLDS-BC) [34]	Developed to measure satisfaction with life among breast cancer patients