

Patient Reported Outcomes for Care and Research: Move into the 21st Century Practice of Neurology

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Rational for PRO Collection Value-based Care

$$\text{Value} = \frac{\text{Outcome}}{\text{Cost}}$$

- “Measuring, reporting, and comparing outcomes are perhaps the most important steps toward rapidly improving outcomes and making good choices about reducing costs”

Michael Porter, NEJM, 2010

Rationale for PRO Collection

Patient-centered care

Patient-centered care has become central to vision of future health care delivery system

The question patients ultimately care about is:

“Do I feel better?”

- Institute of Medicine - “Crossing the Quality Chasm” (2001) listed patient-centered care as one of its six aims
- Patient-centered medical societies have started - such as *Society for Participatory Medicine*, and the *Institute for Patient and Family-Centered Care*.

Rationale for PRO Collection

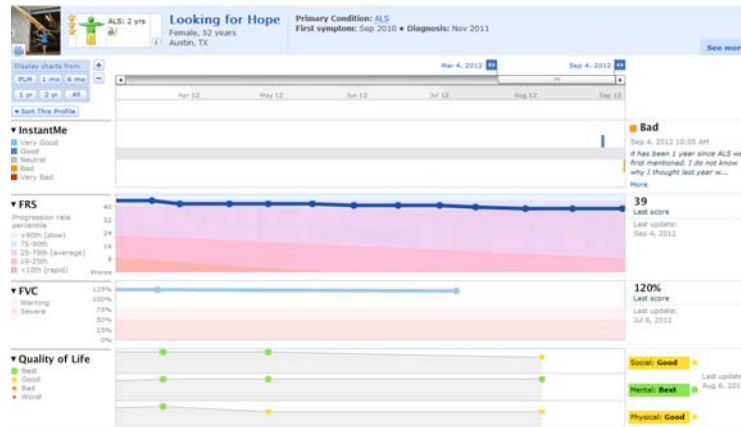
Patient-centered care

- Affordable Care Act:
 - Patient medical homes
 - Patient-Centered Outcomes Research Institute (PCORI)
 - National Quality Strategy – patient engagement is a priority to help achieve better care, better health, and lower costs

Rationale for PRO Collection Patient demand

- Patients clamoring for data on how they are doing

Patientslikeme.com



PRO Collection

Increasing Regulatory Requirements
for Assessment of Health Status reported by the Patient

1. Cancer Program Accreditation
 - American College of Surgeons
 - *Psychosocial assessment*
2. Reimbursement for PT/OT/ST
 - CMS
 - *Functional status at initial, 10th, and discharge visits*
3. Cardiac Rehabilitation Program Certification
 - Amer. Association of Cardiovascular and Pulmonary Rehab.
 - *Health-related quality of life assessment*
4. Comprehensive Stroke Center Certification
 - American Stroke Association
 - *Depression assessment*

**Clinical Quality Measures for 2014 CMS EHR Incentive Programs
for Eligible Professionals that involve PRO Measures**

CMS eMeasure ID	NQF #	Measure Title/ Description
CMS161v1	0104	Major Depressive Disorder: Suicide Risk Assessment (each visit)
CMS169v1	0110	Bipolar Disorder and Major Depression: Appraisal for alcohol or chemical substance use (new diagnosis)
CMS157v1	0384	Oncology: Medical and Radiation – Pain Intensity Quantified (% of visits)
CMS2v2	0418	Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan
CMS159v1	0710	Depression Remission at 12 Months (% with PHQ9>9 with follow-up PHQ9 < 5)
CMS160v1	0712	Depression Utilization of the PHQ9 tool (pts with diagnosis of depression/dysthymia)
CMS177v1	1365	Child & Adolescent Major Depressive Disorder: Suicide Risk Assessment (qvisit)
CMS82v1	1401	Maternal depression screening (% children 6 mo whose mother had depression screening)
CMS66v1	TBD	Functional status assessment for knee replacement (baseline and 60-180d post)
CMS56v1	TBD	Functional status assessment for hip replacement (baseline and 60-180d post)
CMS90v2	TBD	Functional status assessment for complex chronic conditions

**Is PRO collection feasible.. and
possibly helpful
in clinical practice?**

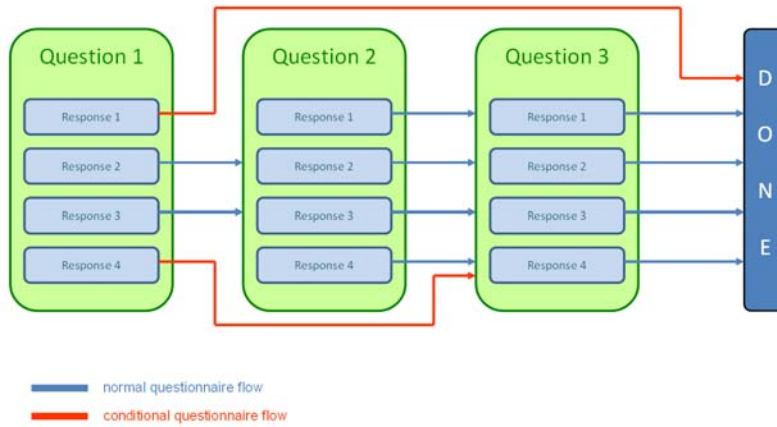


An Example of Systematic PRO Collection Cleveland Clinic Knowledge Program

- Began in 2007 as a collaboration between the Neurological Institute, Imaging Institute, & Information Technology Division
- Strategic Goals
 - Incorporate the collection and tracking of patient reported outcomes into existing clinical work flows
 - To use PROs and health information technology to help optimize healthcare management and delivery



Knowledge Program Questionnaires Question Dependencies



11

Standard Question Types

Describe your pain frequency:

Some of the following statements:

Some days
A few times a day
Several times a day
Most of the day
Constantly

How much pain do you have in your problem areas?

Click on the line around in the number between 1 and 10 that best represents your response.

Describe your pain conditions:

Some of the following responses that apply:

At night	In the morning
At rest	With daily activities
When exercising	When walking
None of the above	

Questionnaires Custom

Please rate the level of your abdominal pain

Please select the number below that best represents your Quality of Life.

0 1 2 3 **4** 5 6 7 8 9 10

No Pain Worst Pain Imaginable

How is your asthma today?

Very Bad Bad Good Very Good

The first four columns please click on as how much emotional upset you have including today. In the final column help for these concerns.

Knowledge Program Integration within the EHR

KP Patient Data

Your current login context, NEUR.MELLEN CENTER MN, relates to the following primary center:

Primary: Mellen Center Flowsheet

Available:

- ADRC
- Access Clinic
- Adult Epilepsy
- Adult Neurology
- Adult Psychiatry
- Adult Psychology
- Brain Health
- Brain Health Research
- Brain Tumor
- Cerebrovascular
- Child Psychiatry
- Florida Neurology
- Headache
- NeuroRestoration
- Neuromuscular
- Neuropsychology
- Neurosurgery
- OT
- PT
- PT Liver Transplant
- Pain Medicine
- Pediatric Epilepsy
- Pediatric Neurology
- Pediatric Sleep
- Peds-Congenital N/S
- Regional
- Rehab
- ST
- Sleep
- Spine
- Vestibular

Access to KP Data through tab on navigation panel

Questionnaire given to multiple sclerosis patient

Questionnaire sets available within the Neurological Institute. Can be completed during visit.

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Knowledge Program Provider Review

European Quality of Life (EQ-5D), interviewer reported: **Index = 0.566** (range: -0.109 to 1.0, a higher score indicates a better quality of life)

- Mobility: (1) I have no problems in walking about.
- Self-Care: (1) I have no problems with self-care.
- Usual Activities: (3) I am unable to perform my usual activities.
- Pain / Discomfort: (2) I have moderate pain or discomfort.
- Anxiety / Depression: (2) I am moderately anxious or depressed.

- Health state: 60 (0 - 100, a higher score indicates a better perceived health state)

Immediate calculation of scores

Can review or update information

Have You Seen a Specialist in the Past: (Not Necessary)

Patient Health Questionnaire (PHQ-9), interviewer reported, Score: 11
- Individual responses: 1-1-1-2-1-1-2-1-1

Score interpretation:

Score	Depression severity
0-4	Minimal
5-9	Mild
10-14	Moderate
15 -19	Moderate-severe
20 -27	Severe

Knowledge Program Provider Review

******* ALERT *******

PHQ-9 screening suggests moderate-to-severe depression

Recommended actions: (Final decision depends on your clinical judgment)

1. Provide depression literature to patient (family)
2. Encourage patient (family) to seek further assessment from PCP or behavioral healthcare specialist
3. Consider initiating antidepressant medication and following patient

PHQ-9 Score: 27 of 27, Individual responses: 3-3-3-3-3-3-3-3

Patient: Zz Test Mouse, Minnie MRN: 56872876

[Links ==> bottom of page | provider section](#)

European Quality of Life (EQ-5D), interviewer reported: Index = 0.514 (range: -0.109 to 1.0, a higher score indicates a better quality of life)

- Mobility: (1) I have no problems in walking about.
- Self-Care: (2) I have some problems washing or dressing myself.
- Usual Activities: (1) I have no problems with performing my usual activities.
- Pain / Discomfort: (1) I have no pain or discomfort.
- Anxiety / Depression: (3) I am extremely anxious or depressed.

- Health state: 78 (0 - 100, a higher score indicates a better perceived health state)

Have You Seen a Specialist in the Past: (Not Necessary)

Knowledge Program Provider Entry

Clinical Course
Select one

- Clinically Isolated Syndrome (including CIS / RIS)
- Relapsing remitting
- Secondary Progressive with relapses
- Secondary progressive without relapses
- Primary Progressive
- Progressive Relapsing
- Other

Explain:

Other disease characteristics
Select all that apply

- Yes
 - Devics Neuromyelitis Optica with NMO-IG positive
 - Devics Neuromyelitis Optica with NMO-IG negative
 - Devics Neuromyelitis Optica with NMO-IG not tested
 - Fulminant MS
 - Acute Disseminated Encephalomyelitis
 - Tumefactive MS
 - Other unusual manifestations
- Explain:
- None

Timed 25-foot walk

- Not Completed
- Time to complete

(between 3 and 180 seconds, within 0.1 second)

- Unable to complete

Reason:

show instructions >>

Knowledge Program Provider Entry

Not Applicable: All of the patient responses have been reviewed; the healthcare provider questions below are not applicable to today's visit
 Not Applicable

Reason Patient Did Not Start Health Assessment

- Patient refused
- Patient arrived late
- Patient unable to complete
- Unknown
- Other

Describe:

Reassigned from active care list due to

- Patient using other providers
- Patient not seen for > 1 year
- At least two "no shows", cancelled appts or failure to follow up
- Other diseases

Keep Patient Questionnaire Open

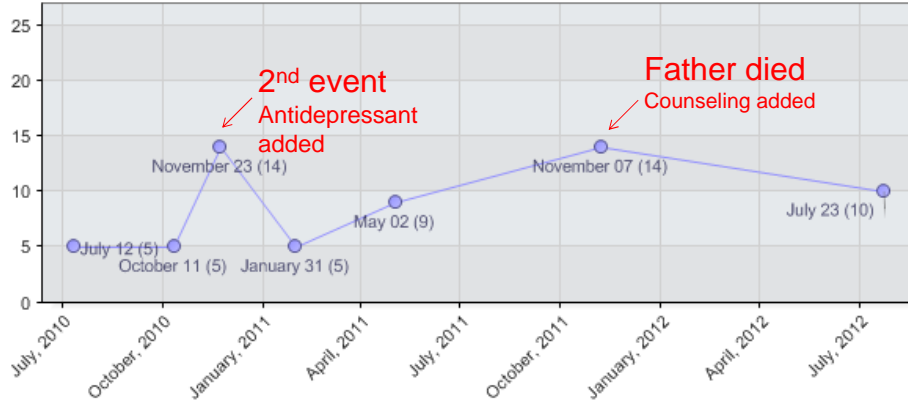
Neurological Institute (Headache Center)

Provider Approval

Knowledge Program Flowsheets

Flowsheets track status over time

- Depression Screen (PHQ9) of patient:

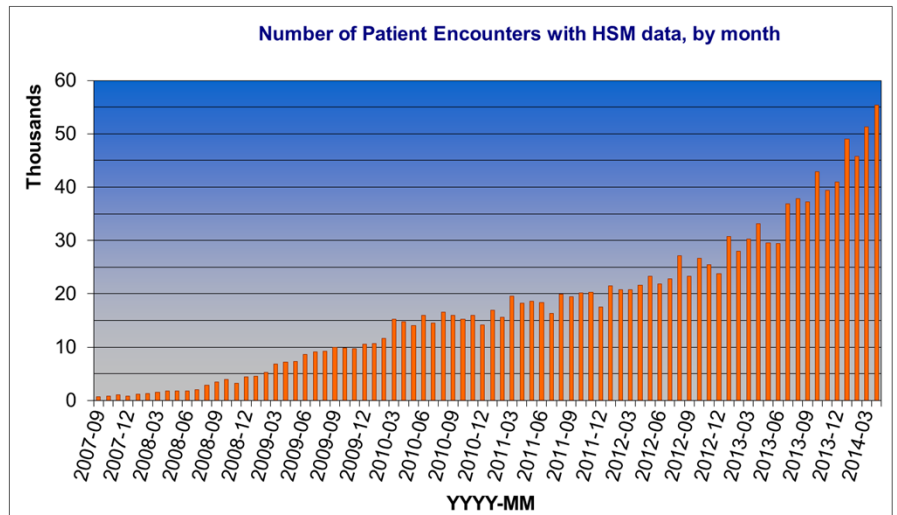


Example of Neurology Measures

- | | | |
|--|--|--|
| <p>Outcome/Analysis ↔</p> <ul style="list-style-type: none"> • European Quality of Life • Epilepsy Quality of Life • PROMIS tools • Stroke Impact Scale 16 • Pain Disability Index • Headache Impact Test 6 • Modified Rankin scale • Friedrich Ataxia Scale (Ataxia) • Fisher grade (ICH) • Toronto Western Spasmodic Torticollis Rating Scale | <p>Clinical Care/Analysis ↔</p> <ul style="list-style-type: none"> • Patient Health Questionnaires 9 (depression screen) • Epilepsy Neurotoxicity Scale • Generalized Anxiety Disorder 7 • STOP (OSA screen) • Epworth Sleepiness Scale • Early Autism Screening Tool • Columbia Suicide Severity Rating Scale • Impulse-Compulsive Disorder in Parkinson's | <p>Clinical Care</p> <ul style="list-style-type: none"> • # seizures in last 4 weeks • CAGE Alcohol Screen • # falls in the past month • Flu vaccine • Epilepsy-related ER visits within the past 3 months • Days missed from usual activity within past month • driving |
|--|--|--|

Best Practice Alerts
 Relevant Education information print with After Visit Summary
 Preselected orders

Knowledge Program Data Collection*



*HSM includes PRO and provider-completed measures

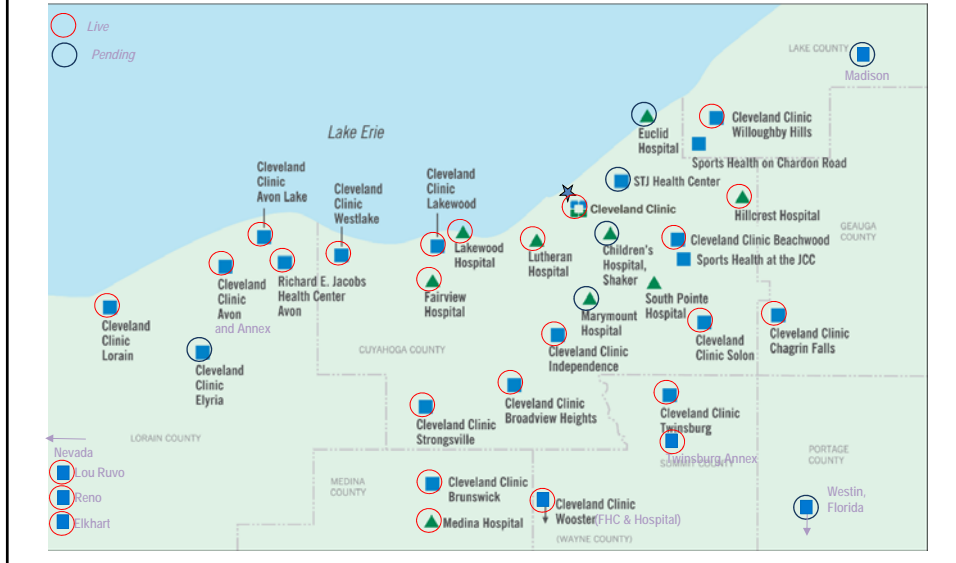
Knowledge Program Health Status Data

KP Database Statistics

- >1,000 providers actively contributing to data collection
- 173 patient or provider validated questionnaires
(additional 354 individual questions)
- Over 1.34 million patient visits contain PRO data
- Over 18 M responses
- >330,000 individual patients with PRO data
- Over 500,000 completions of the Patient Health Questionnaire 9 (depression screen)

Data as of 5/7/2014

Knowledge Program Enterprise Coverage



Can PROs be useful for research?



Comparative Effectiveness Research – then and now

	Traditional	Near Future
Research	“Comparative Effectiveness Research”	“Patient-centered” outcomes Research
Clinical documentation	Paper medical records	Electronic health records
Outcomes	Non-standardized mention of health status in documentation: “patient doing well”	<div style="text-align: center;">+</div> Systematic collection of patient-reported outcomes

Ability to leverage patient-reported outcome measures with clinically-derived electronic data will offer tremendous research opportunities

Examples of research questions that can be explored using PRO Data combined with EHR Data

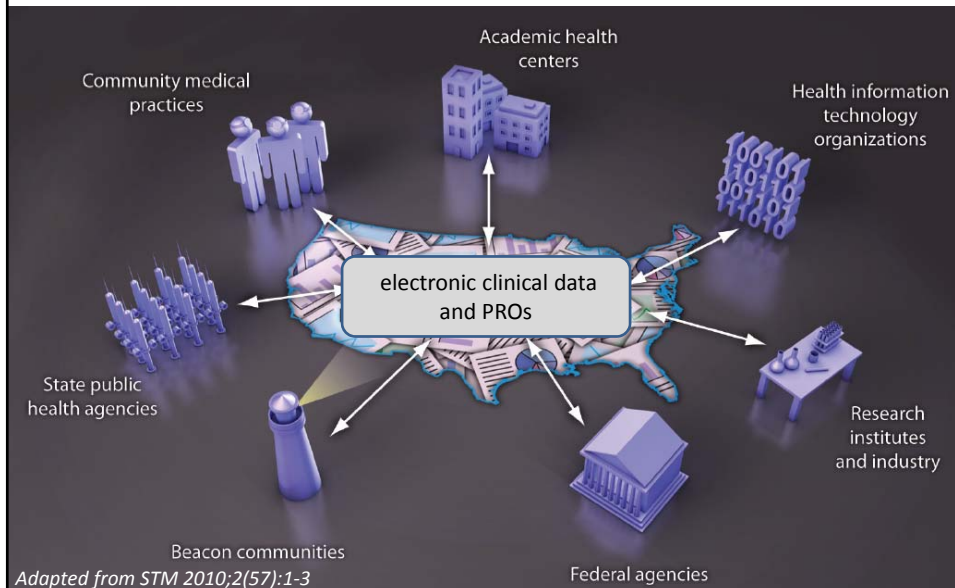
- Evaluation of factors associated with patient-centered outcomes
- Evaluation of Relationships between Different Outcomes
- Prediction Modeling
- Comparative effectiveness of interventions
- Cost-effectiveness of interventions

The Research Value of Data on Large Cohorts of Patients

‘The most successful researchers of the 21st century will be those who have the largest and best-defined cohorts of patients’.

Elias Zerhouni, MD, Director
National Institutes of Health
Cleveland, Ohio
July, 2004

Ability to generate new knowledge will grow exponentially with improved health information connectivity



The Future of PROs for Care and Research

- PROs will likely become an integral part of healthcare in the near future
- PRO data can be used real-time to help understand patient's health status and identify most appropriate interventions
- They will enable clinicians to identify strengths and weaknesses in the care provided, and to benchmark their outcomes against those of peers
- PRO data will help usher in a new era of clinical research and discovery.



Cleveland Clinic

Every life deserves world class care.