Patient Reported Outcomes
Oncology

Peter Paul Yu, M.D.
Palo Alto Medical Foundation
President-Elect
American Society of Clinical Oncology
Defining Value in Oncology

• Clinically meaningful survival gain
  – Distinguish from statistically significant
  – Risk of losing a weak signal

• Value Based Framework: patients and populations
  – Beneficial Outcomes
  – Toxicity
  – Cost
Patient Reported Outcomes

- Beneficial Outcomes: Disease symptom improvement
- Patient Experiential Outcomes
  - Obtaining personal goals
  - Tracking over the cancer journey
- Toxicities of Therapy: Epic-26, PROMIS
- Cost: deductible, co-pay
Cancer PROs

• Disease Management: ASCO Quality of Care Committee & PROs Workgroup
  – Nausea post chemotherapy: NCI PRO CTCAE
  – Pain advanced cancer: MD Anderson Brief Pain Inventory

• Long Term Survival: ASCO Survivorship & Guidelines Committees
  – Anxiety & Depression
  – Neuropathy
  – Fatigue
The primary goal of the QOPI® Certification Program is practice improvement.

ASCO/ONS Safety Standards & On-Site Review

QOPI Participation and Demonstrated Performance on Quality Measures

Putting Guidelines and Policy Into Practice
What We Measure

QOPI®

Core Measures
- Care Documentation
- Chemo Administration
- Pain Management
- Smoking Cessation
- Psychological Support

Disease-Specific Modules
- Breast Cancer
- Colorectal Cancer
- Non-Hodgkin’s Lymphoma
- Non-small cell Lung Cancer
- Ovarian, fallopian tube, primary peritoneal (gynonc)

Domain-Specific Modules
- End of Life Care
- Symptom/Toxicity Management
QOPI Measures Amenable to PROs

- Pain assessment and control plan
- Constipation related to narcotics
- Performance status
- Emotional well being
- Dyspnea
Cancer LinQ: ASCO

• Rapid Learning Health System
• More than Registry
• Accepts health data from diverse sources including patients
• Central premise: motivation for sharing
• eQOPI
Cancer LinQ Users

• See their own data over time
• Overlay intervention over symptoms
• See comparison group
• See provider quality performance
Data Liquidity Documents

- EHRs CPOE
- CAP eCC LIS
- Radiation Software
- Surgery Software
- Chemotherapy data
- Pathology data
- Radiation Therapy data
- Surgery data

Patient Generated Data
Patient Preferences and PROs
ASCO HL7 Breast Cancer Document

• Approved as HL7 draft standard October 2013
• Based on HL7 cCDA architecture, it is modular and extendable
• ONC Project Inspire: UC System and CADPH
Palo Alto Medical Foundation

- Integrated Multidisciplinary Medical Group
- 900,000 patients, 1,000 physicians
- PAMF Research Institute: Shared Decision
- Epic EHRs 1999
- 75% of patients active users of MyChart
- Initially used non integrated software for diabetes management
What is PRO?

The Workflow:

- Define the questions you want to ask – standardized questionnaires e.g. Epic-26
- Select inclusion criteria for patients:
  - Bulk assignment by running a report (e.g. all cancers with prostate cancer)
  - If a patient is not enrolled, provide point of care alerts to enroll patients
- Invite the patient to complete the questionnaire via My Health Online (MyChart)
  - Remind them automatically if they don’t reply
- Compare questionnaire responses over time and vs. other clinical parameters like drug treatments
- Use the Epic database for analysis across cohorts of patients
Expanded Prostate Cancer Index Composite

Please answer the following questions and click the Continue button.

How big a problem, if any, has each of the following been for you during the last 4 weeks?

- Dripping or leaking urine
  - No Problem
  - Very Small Problem
  - Small Problem
  - Moderate Problem
  - Big Problem

- Pain or burning on urination
  - No Problem
  - Very Small Problem
  - Small Problem
  - Moderate Problem
  - Big Problem

- Bleeding with urination
  - No Problem
  - Very Small Problem
  - Small Problem
  - Moderate Problem
  - Big Problem

- Weak urine stream or incomplete emptying
  - No Problem
  - Very Small Problem
  - Small Problem
  - Moderate Problem
  - Big Problem
If a patient was accidentally not enrolled in PRO, point of care BPA to enroll.
Synopsis – Compare PRO vs. other clinical parameters (e.g. drug regimen)

See Epic-26 "response" vs. Lupron treatment
Future – Mobile Questionnaires – answer on the phone
Future – PRO Across Organizations
What’s Value of Using PROs in EHRs: A Triple Play or a Grand Slam?

Eugene C. Nelson, DSc, MPH
Carolyn Kerrigan, MD, MSc

Director Population Health & Measurement
Dartmouth-Hitchcock
Professor, Community and Family Medicine
The Dartmouth Institute

“I can’t be a good doctor without this.”  J. Weinstein, President D-H

• Feed forward PROs data in flow of care & in EHR
  1. Better care for this person matched to needs & preferences
  2. Comparative data to improve clinical programs based on outcomes
  3. Outcomes data for collaborative CE research
Using PROs with Individuals: Dartmouth Spine Center

Feed Forward

Referral or Visit Request → Orientation & PROMs → Initial Work Up Plan of Care → Acute Care Management

Orientation & PROMs → Chronic Care Management

Initial Work Up Plan of Care → Functional Restoration

Acute Care Management → Palliative Care

Feed Back

✓ Improvement registry
✓ Public reports website
✓ SPORT NIH research

People with healthcare needs

Functional & Risk Status

Expectations For Good Care

Disease Status

Sunk Costs

Experience Against Need

Incremental Costs

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The summary report generated from patient-reported data is critical to a physician's ability to care for a patient: same page care.
Herniated Disk Outcomes @ 2 Years

**Surgery**
- 44 Ave Age
- 43% Female

**Non-Surgery**
- 30 Ave Age
- 45% Female

**Reduced Oswestry Symptoms**
- -37
- -25

**Cost Per Quality Adjusted Life Year Added By Surgery $34,355**

**Total Direct & Indirect Costs**
- $13,108
- $27,341

**Costs**
- $34,355

**Functional Satisfaction**
- 1.64 QALY
- 1.44 QALY

**Physical SF-36 Improvement**
- 44
- 30

**SPORT NIH CER TRIAL**
- 13 sites
- 6 years of follow up
- 3 spine conditions
- PROs primary outcomes
Herniated Disk Outcomes @ 2 Years

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<thead>
<tr>
<th>Surgery</th>
<th>Non-Surgery</th>
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<tr>
<td>44 Ave Age</td>
<td>30 Ave Age</td>
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<tr>
<td>43% Female</td>
<td>45% Female</td>
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Reduced Oswestry Symptoms

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Cost Per Quality Adjusted Life Year Added By Surgery $34,355

Personalized risk assessment based on people like me ...
From research back to patient care
Swedish Rheumatology Quality Register

Today

- Feed forward PROs data in flow of care
  - 44 of 61 centers adopted feed forward
  - 90% of RA patients covered
- Practice improvement & new care models
- National outcomes transparency
- Integrated with EHRs in some settings
- Better outcomes faster for RA patients in Sweden
**EHR + PHR:**

Same page care for people living with RA

PROs entered by patient (HAQ)

Clinical data entered by physician (DAS-28 & labs)

Together review “next” care plan based on new outcomes (co-production)

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<td>05-Jan</td>
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<td>05-Sep</td>
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| Månads-Kontroll | | | | | | |
| MK-grupp | 1 | 3 | 3 | 6 | 9 | 12 |
| | | | | | | |

| Arbetsförmåga | / | / | / | / | / | / |
| Allmän hälsa | 75 | 75 | 71 | 35 | 35 | 36 |
| SR | 54 | 63 | 48 | 25 | 15 | 5 |
| Läkarbedömning | Hög | Hög | Hög | Måttlig | Låg | Låg |
| EQ5D | -0.045 | -0.045 | -0.045 | 0.808 | 0.931 |
| CRP | 35 | 35 | 20 | 8 | 2 | 1 |
| Spond. artrit, Ank. spond. BASFI | | | | | | |
| Svullna leder (66) | | | | | | |
| Ömma leder (68) | | | | | | |
| Daktylit | | | | | | |
| Entesit | | | | | | |
| Funktionsneds. - HAQ | 1.75 | 1.75 | 1.63 | 0.88 | 0.88 | 0 |
| Smärt | 81 | 80 | 75 | 40 | 30 | 27 |
| Svullna leder (28) | 12 | 12 | 11 | 2 | 0 | 1 |
| Ömma leder (28) | 12 | 12 | 11 | 3 | 1 | 2 |
| Emf | 6.75 | 6.86 | 6.49 | 4.11 | 2.95 | 2.7 |
| AI | | | | | | |
| B2CRP | 6.21 | 6.21 | 5.84 | 3.61 | 2.41 | 2.79 |
| BD 1 | COX1 | COX1 | COX1 | COX1 | COX1 | COX1 |
| 1 dos | PRE | PRE | PRE | PRE | PRE | PRE |
| BD 2 | MTX | MTX | MTX | MTX | MTX | MTX |
| 1 dos | SAL | SAL | SAL | SAL | SAL | SAL |
| BD 2 dos | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v |
| BD 3 | COX1 | COX1 | COX1 | COX1 | COX1 | COX1 |
| 1 dos | PRE | PRE | PRE | PRE | PRE | PRE |
| BD 3 dos | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v |
| BD 4 | MTX | MTX | MTX | MTX | MTX | MTX |
| 1 dos | MTX | MTX | MTX | MTX | MTX | MTX |
| BD 4 dos | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v | 20/1v |
| Antagl. månad | | | | | | |
| Uppslj utländska läkemedel | | | | | | |
| Läkemedelsdös | | | | | | |
Key point: Patients served by Swedish health system are doing better

All Patients in the SRQ, from 1994 – 2006*

*Black line shows DAS at initial visit and blue after 6 months and turquoise after 12 months.
Triple Play

3rd

2nd

1st
Feed forward PROs & EHRs: Triple Play or Grand Slam?

1. Better care for individuals based on needs and preferences
   – Co-production of care
2. Better data on outcomes for clinical practice improvement
   – Improvement collaboratives
3. Better research data on outcomes for patient centered research
   – Research collaboratories
4. Link patient value networks (& PHRs) with clinical population registries (& EHRs)
   – Integrate world of the patient with world of the practitioners caring for the patients
How to Make PROs for Individuals Fit for the Future?

**Aim**: Patient-centered decision support for co-production of good care, better health & more confidence in self-management.

**Key Mechanism**: Integrating patient’s voice into flow of care & EHR to co-produce care plans that reflect needs & values.

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**Patients Pull**

1. **Patient Value Networks**
   - **Patient & Family System**
   - **PHR**
   - **Patient Value Network Features**
     - Curated & facilitated**
     - Patients with shared problem**
     - Subject matter expertise**
     - Peer support**
     - Information I need for self-care**
     - My personal health plan
     - E.g., PatientsLikeMe, HowsYourHealth

2. **Clinical Microsystem**
   - **Co-production**
   - **Key Patient Outcomes**
     - Experience
     - Disease
     - Function
     - Risks
     - Costs
     - Confidence (Competence)

3. **Feed-forward Patient Generated Health Data (PGHD)**

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**Providers Pull**

1. **Clinical Registries**
   - **Provider & Care Team System**
   - **EHR**
   - **Clinical Registry Features**
     - Feed forward PGHD at point of care for care planning & outcomes tracking**
     - Comparative data for practice improvement**
     - Research Database as by-product**
     - Maintenance of Certification
     - PQRS (Physician Quality Reporting System) data feeds
     - Data Flows Designed into Work Flows
     - E.G. SRQ, ACR, NPF Registries

**Key Stakeholders**: Patients, Providers, “C” Suite Leaders

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References


Leslie Kelly Hall
Senior Vice President, Policy
Healthwise

HHS: Appointee: Office of the National Coordinator
Health Information Technology Standards Committee
    Chair: Patient/Consumer Technology
Health Information Technology Policy Committees
    Patient/Consumer Empowerment
    Meaningful Use
    Patient Generated Health Data
National E-Health Collaborative: Board Member & Chair Consumer Consortium
DirectTrust.org: Board Member & Chair Patient Engagement
2015—Improved Outcomes

2013—Advanced Clinical Processes & Interoperability

2011—Data Capture & Sharing

The Activated Patient

Stage 3

Stage 2

Stage 1

Meaningful Use

Meaningful Use Will Help Activate Patients
4019 Hospitals

299,402 Providers

$ 15,884,674,565

http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/DataAndReports.html
Nothing About Me Without Me...

I am a Contributing Care Team Member...

How Do I Compare?...

PFS should not be encumbered by EHR...

EHR Action: PFS Reaction
Nothing About Me
Without Me...
Understandable to Me: Plain language and my language...
Communication based upon my preference...
CC: Me...
Some or all of my records
My preferences inform care, safety and decisions…
Nothing About Me Without Me

My access should be based upon my preference...
I am a Contributing Care Team Member...
I am a credible source of information...
The data I generate is material to care...
My goals may be episodic, chronic, or quality of life...
I can contribute to quality outcomes...
I am a Contributing Care Team Member

I am part of a care team reflected in the EHR...
I am a contributing care team member.

I am an important safety checkpoint...
I am a health data exchange of one...
I am a Contributing Care Team Member

I am an important participant in shared decision making...
The messages we share are material to my health and care
EHR Systems Action: Patient System Reaction
Structured data advances all systems...
Current workflow can adapt to support patient engagement…
EHR Systems Action: Patient System Reaction

Expand and harmonize standards …
Create once use often...
View, download and transfers may be directed by me.
Orders can be directed to me...
I am the only source of adherence information...
Data reconciliation and curating should include the *me*
Metadata helps my system too...
Patient Facing Systems should not be encumbered by legacy technology...
Innovation should be encouraged not limited…
Consumer standards for EHR data out, Provider standards for EHR data in …
When I view, download or transmit I should have opportunities to be educated...
Data I generate should be interoperable with all...
Accelerate standards where patient generated data likely…
Consumer and health vocabularies should be standardized and harmonized...
New design should be with the patient in mind...
How Do I Compare?...
How Do I Compare?

Patient specific dashboards; me compared to others...
How Do I Compare?

My trajectory of health can be impacted by my actions...
How Do I Compare?

I know what research is available to me...
I know what research has been effective for people like me…
How Do I Compare?

I want to know the care I should be getting...
Six Healthcare Consumer Segments

- **Out & About**: 4% - independent; prefers alternatives; wants to customize services.
- **Shop & Save**: 9% - active; seeks options and switches for value; saves for future health costs.
- **Sick & Savvy**: 14% - consumes considerable health care services & products; partners with physicians to make treatment decisions.
- **Casual & Cautious**: 34% - not engaged; no current need; cost conscious.
- **Online & Onboard**: 22% - online learner; happy with care but interested in alternatives & technologies.
- **Content & Compliant**: 17% - happy with physician, hospital and health plan; trusting and follows care plans.

Deloitte’s 2012 Survey of U.S. Health Care Consumers
DRAFT: My Medical Records Experience Map (within Patient Engagement Framework)

Key Assumptions We’re Making

--------Most patients will seek their records out of necessity, not curiosity......... others

Patient Journey (first person perspective – in patient’s words/language)

PEF Stage: Inform Me Engage Me Empower Me Partner with Me Support My e-Community

How I’m Using My Record

Things I’m Doing

Things I’m Feeling

Things I’m Thinking

My Records Experience is About...
Key Assumptions We’re Making (need validation)
Most patients will seek their records out of necessity, not curiosity. Others

Patient Journey (first person perspective – in patient’s words/language)

PEF Stage: Inform Me | Engage Me | Empower Me | Partner with Me | Support My e-Community

How I’m Using My Record
- Changing Docs
- Travel
- Meds

Things I’m Doing
- What my doc tells me.
- Get shot records.
- Get the info for school or work.
- I’ll dig up my history if needed.
- A lot of my health is in my own hands.
- I like comparing my options.
- I’ll get my info when somebody needs it.
- Difficult to dig up my records.
- About asking questions of my doc.
- About sharing stuff with my doc.
- I like comparing my options.
- Choosing the best value or easiest is smartest when possible.
- Moving care around.
- Getting 2nd opinions.
- Using my doc as a back up plan – the place up the street is often easier.
- That I have choices.
- Confident and able to be part of my own health.
- I can partner with my doc.
- I want my doctor to know about the stuff I put in my record.
- I want some control in my care.

Things I’m Feeling
- Like my doc will let me know.
- I’ll let my doc handle that.
- My doc will fill me in.
- I’ll get my info when somebody needs it.
- Difficult to dig up my records.
- About asking questions of my doc.
- About sharing stuff with my doc.
- I like comparing my options.
- Choosing the best value or easiest is smartest when possible.
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- I want my doctor to know about the stuff I put in my record.
- I want some control in my care.

Things I’m Thinking
- I’m advised to by my doc or someone else.
- Occasional need based on someone else requesting it of me.
- I like having it to consult, but don’t want to touch it much.
- I hang on to the records I’m given – my info is all over the place.
- Seeing & having my info
- Adding to my info – making it a real snapshot of me.
- My expectations are that I should have full control and things should be easier.

My Records Experience is About...
- Occasional need based on someone else requesting it of me.
- I like having it to consult, but don’t want to touch it much.
- I hang on to the records I’m given – my info is all over the place.
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Content & Compliant
- Mary

Casual & Cautious
- Jesse

Sick and Savvy
- Bill

Shop and Save
- Nancy

Online & Onboard
- Peggy Jo

Out & About
- Janice
Thank you!
Lkellyhall@healthwise.org