What we have learned about integrating PROs with EMRs for learning systems?

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Abernethy Funding & Disclosures

- AHRQ (CMS), NCI, NIH/NINR, RWJ
- Clinical research: Biovex, DARA, Helsinn, MiCo and Pfizer
- Clinical research now complete: Alexion, Amgen, Eli Lilly, and Kanglaite
- Pending: BMS, Genentech
- Corporate Board of Directors – Advoset (education company, including contracts from Novartis), Orange Leaf Associates LLC (IT development company)
- Pending consultancy – BMS (amount unknown, Co-Chair of Scientific Advisory Committee)
- Paid leadership roles – American Academy of Hospice & Palliative Medicine (starting March 2013, President)
Getting on the same page… PROs

- Symptoms
- Health-related quality of life
- Health state (e.g., towards utilities/QALYs)
- Medication use/compliance
- Satisfaction
- “Value” of treatment
LEARNING HEALTH SYSTEMS
Converging Themes

Health care redesign

Patient-centered care

Personalized medicine

Comparative effectiveness research

Health care quality
Better Decision-Making

Data-Driven Care

- Health care redesign
- Patient-centered care
- Personalized medicine
- Comparative effectiveness research
- Heath care quality
Health care redesign

Patient-centered care

Personalized medicine

Comparative effectiveness research

Health care quality

**Evidence**
- Development
- Implementation

**Data**
- Linkage
- Inputs/outputs
- Analysis
- Results/reports

**Value**
- System-defined
- Patient-defined
Perspective is Fundamental

- Health care redesign
- Patient-centered care
- Personalized medicine
- Comparative effectiveness research
- Health care quality
Health care redesign

Patient-centered care

Personalized medicine

Comparative effectiveness research

Health care quality

SYSTEM
Health care redesign

Patient-centered care

Personalized medicine

Health care quality

Comparative effectiveness research
### Inputs

- Data elements: Standardized pain intervention info.
- Data element: Pain intensity measured on a 0-10 scale
- Data elements: Standardized pain intervention info.
- Data element: Pain intensity measured on a 0-10 scale
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- Data elements: Standardized pain intervention info.
- Data element: Pain intensity measured on a 0-10 scale
- Data elements: Standardized pain intervention info.
- Data element: Pain intensity measured on a 0-10 scale

### Outputs

- Data element: Pain intensity measured on a 0-10 scale
- Metric: # with pain scores / total # patients
- Data element: Pain intensity measured on a 0-10 scale
- Data element: Pain intensity measured on a 0-10 scale
- Data element: Pain intensity measured on a 0-10 scale
- Data element: Pain intensity measured on a 0-10 scale
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- Data element: Pain intensity measured on a 0-10 scale
- Data element: Pain intensity measured on a 0-10 scale
- Data element: Pain intensity measured on a 0-10 scale

---

**My pain is 7 out of 10**
<table>
<thead>
<tr>
<th>Health care redesign</th>
<th>Inputs</th>
<th>Outputs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Data elements: Standardized pain intervention info.</td>
<td>Data element: Pain intensity measured on a 0-10 scale</td>
</tr>
<tr>
<td>Health care quality</td>
<td>Data element: Pain intensity measured on a 0-10 scale</td>
<td>Metric: # with pain scores / total # patients</td>
</tr>
<tr>
<td>Comparative effectiveness research</td>
<td>Data elements: Standardized pain intervention info.</td>
<td>Data element: Pain intensity measured on a 0-10 scale</td>
</tr>
<tr>
<td>Patient-centered care</td>
<td>Data elements: Standardized pain intervention info.</td>
<td>Data element: Pain intensity measured on a 0-10 scale</td>
</tr>
<tr>
<td>Personalized medicine</td>
<td>Data elements: Standardized pain intervention info.</td>
<td>Data element: Pain intensity measured on a 0-10 scale</td>
</tr>
</tbody>
</table>
One health record and patient report

**Inputs**
- Data elements: Standardized pain intervention info.
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- Data element: Pain intensity measured on a 0-10 scale

**Outputs**
- Data element: Pain intensity measured on a 0-10 scale
- Metric: # with pain scores / total # patients
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- Data element: Pain intensity measured on a 0-10 scale
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What is a Learning Health System?

What is a Learning Health System?

- Organization that learns (quality & PI view)
- Systematically linked process for evidence generation and implementation (Research / clinical trials)
- National system of linked data to generate novel insights and monitoring
- Continuously aggregating datasets to support point of care clinical decision making, personalized medicine, and research
- Closer approximation of research and practice so that each informs the other
- Learning laboratories of healthcare to optimize and prioritize innovations and solutions
Achievable?

Data generation, use and reuse
Data that are meaningful at the clinical interface
PRO-BASED LEARNING
HEALTH CARE
The original story…

Central Data System

Surveys
Clinical Research
Data Entry
Patient Concerns
Clinical Care
Clinical Quality
Rapid Learning Cancer Clinic

Start off with electronic patient-reported outcomes (ePRO) data, and then build in additional linked datasets over time.

Endeavor to obtain “research-quality” clinical data

- Equal quality of a clinical trial
- Reliable data can be parsed out for clinical trials, clinical care, quality monitoring, and CER simultaneously

(Abernethy et al, Health Services Research, 2008)
What a great opportunity – why weren’t they already doing it?

- PRO data are historically difficult to collect
  - Missing data are frequent
  - Confidence in the patient report
  - Reliability, validity, accuracy, data quality
  - Standards are needed

- Who is driving the process?
  - Practical implementation of standardization PRO data collection in research and clinical care can be difficult
  - Research or clinical care?
  - Which researcher or which clinician?
  - Alignment of incentives
BEWARE!!!

Patient reported outcomes (PROs)
BEWARE!!!

Data liquidity
Real-time data use
Data reuse
Standards
Culture & Incentives
Learning
Patient reports standardized data

Coordinated Databases
Location and platform agnostic
Touch the red dot below that best describes how bad, if at all, this has been a problem for you during the past week, including today.

Fatigue (tiredness)

- Not a problem
- Mild problem
- Moderate problem
- Severe problem
- As bad as possible

• Adapted the PACE System
• Review of systems data and practice efficiency
Choice of other survey instruments

- Portfolio of validated instruments
  - Permission
  - Paper – electronic equivalence testing
- Portfolio of surveys
  - Quality monitoring and improvement
  - Satisfaction
  - Can be changed ad hoc
- Can electronically designate what questions a person receives at the patient – day/hour (or encounter) level
Patient reports standardized data

Clinical uses
- Longitudinal reporting at POC
- ROS & Decision making
- Patient education
- Triggered interventions

Coordinated Databases
### Review of Systems

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Allergy/Immuneologic</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>2. Constitutional</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Respiratory</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>3. Dyspnea</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>4. Edema</td>
<td>9</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>5. Fatigue</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6. Gastrointestinal</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>7. Genitourinary</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>8. Hematologic</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>9. Musculoskeletal</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>10. Neurological</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>11. Psychiatric</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>12. Rheumatological</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

**Notes:**
- This report contains information supplied by the patient. It is intended only for the use of the physician and the patient. Information contained in this report should be considered as confidential and protected by rights of the patient. No information contained in this report may be used by the patient without the express written consent of the physician.
- The patient should not be allowed to discuss or interpret this report with others.
- The patient should be instructed to notify the physician immediately if any of the information contained in this report is inaccurate or if the patient experiences any of the symptoms listed.

**Signature:**

**Date:**
<table>
<thead>
<tr>
<th>15. Psychiatric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crying/feeling like crying</td>
</tr>
<tr>
<td>Nervous, tense, anxious</td>
</tr>
<tr>
<td>Worry</td>
</tr>
<tr>
<td>Feeling hopeless</td>
</tr>
<tr>
<td>Sad (depressed)</td>
</tr>
<tr>
<td>Feeling helpless</td>
</tr>
<tr>
<td>Lost interest in people</td>
</tr>
<tr>
<td>I would be better off dead</td>
</tr>
<tr>
<td>Absence of pleasure</td>
</tr>
<tr>
<td>Feeling worthless</td>
</tr>
<tr>
<td>Feeling guilty</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>16. T-Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
</tr>
<tr>
<td>Despair/Depression</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>17. Physical Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hard work or activity</td>
</tr>
<tr>
<td>Attend paid job</td>
</tr>
<tr>
<td>Household work</td>
</tr>
<tr>
<td>Run errands</td>
</tr>
<tr>
<td>Run</td>
</tr>
<tr>
<td>Function normally</td>
</tr>
<tr>
<td>Light work or activity</td>
</tr>
<tr>
<td>Walk</td>
</tr>
<tr>
<td>Attend social activities</td>
</tr>
<tr>
<td>Bathe or dress</td>
</tr>
<tr>
<td>Driving</td>
</tr>
<tr>
<td>Cook for self</td>
</tr>
</tbody>
</table>
Education matched to clinical needs and patient interest

Returning Patient

Hello and welcome back to Duke Cancer Institute. The DCI is one of only 40 centers in the country designated by the National Cancer Institute as a “comprehensive cancer center,” combining cutting-edge research with compassionate care. After watching this clip, you’ll know more about the vast array of educational materials that are available to you here. You’ll also get to meet some of the caring individuals that are here to help you. Thank you for trusting us with your care, we will be here for you every step of the way.

1. Introduction to the Day
2. Tour of Services
3. Patient Care
4. Cancer Care Network

The News Room

About Our Practice Wellness and Emotional Cancer Diagnosis and Treatment Dealing with Symptoms and Side Effects Research and Clinical Trials

National News Local News What’s New on CSN Calendar of Events

Returning to the CSN? Plug in your earphones now.

See what’s new!
- Wellness and Emotional Care: Nutrition Myths & Facts
- Cancer Diagnosis and Treatment: Working and Living: Rachael
- Dealing with Symptoms and Side Effects: Losing Your Hair
- Research and Clinical Trials: We Are Committed to Research

New to the CSN? Press the magnifying glass to learn how to explore the CSN.

Welcome, Elvis. If you are not there, please visit new patient registration yourself.
Integrating into Process: Distress Triage

Duke Thoracic Oncology patients use the ePRO system to report and monitor cancer-related symptoms and psychosocial well-being.

PCM reports are generated at each visit, which highlight areas of concern (e.g., pain, fatigue) and present recent history/trend data in a user-friendly format.

Exception reports sent to the provider (e.g., physician, nurse) when a T-score is >65 on the PCM distress or despair subscale or if the patient responds that he/she would feel "better off dead".

Assessment & Initiation of Services
- Immediate intervention
- Supportive counseling
- Support groups
- Individual, couple, and family therapy

Referral to additional services as needed.

A Duke Cancer Patient Support Program (DCPSP) trained counselor is electronically notified (in real-time) when a distressed patient is identified in the ePRO system.
Missing Data: Encounter-level

- **No missing data**: 79% of encounters
- **Completely missing data**: 3% of encounters
- **Total Visits**: Numbers from 1 to 31

Cumulative Proportion vs. Visit Number graph.
<table>
<thead>
<tr>
<th>Activity</th>
<th>ePRO Database</th>
<th>Breast Clinic</th>
<th>GI Clinic</th>
<th>Thoracic Clinic</th>
<th>Melanoma Clinic</th>
<th>Sarcoma Clinic</th>
<th>GU Clinic</th>
<th>Rad Onc Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trouble Breathing</td>
<td>Green</td>
<td>Yellow</td>
<td>Green</td>
<td>Blue</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Yellow</td>
</tr>
<tr>
<td>Coughing</td>
<td>Red</td>
<td>Red</td>
<td>Red</td>
<td>Red</td>
<td>Yellow</td>
<td>Yellow</td>
<td>Yellow</td>
<td>Yellow</td>
</tr>
<tr>
<td>Wheezing</td>
<td>Green</td>
<td>Yellow</td>
<td>Green</td>
<td>Blue</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Yellow</td>
</tr>
<tr>
<td>Sit up</td>
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<td>Green</td>
<td>Green</td>
<td>Green</td>
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<td>Green</td>
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</tr>
<tr>
<td>Walk</td>
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<td>Green</td>
<td>Green</td>
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<td>Green</td>
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</tr>
<tr>
<td>Bathe</td>
<td>Green</td>
<td>Green</td>
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<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Drive</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Function normally</td>
<td>Green</td>
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<td>Green</td>
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<td>Light work or activity</td>
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<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
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<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Run errands</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Household work</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Attend social activities</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
<tr>
<td>Attend a paid job</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
<td>Green</td>
</tr>
</tbody>
</table>

Standardized Ratios:
- > 1.1: purple
- 1.06-1.1: red
- 1.02-1.06: orange
- 0.98-1.02: yellow
- 0.94-0.98: green
- 0.9-0.94: dark green
- < 0.9: blue
Research demonstrates…

- Easy to use, navigate, and read (usability & feasibility)
  - Patients satisfied with e/Tablets, and would recommend them to other patients.
  - Help patients recall symptoms to report.

- ePRO system can be used to collect research-quality data using common, validated instruments (reliability & validity)
  - Reliability, validity, and equivalence testing
  - Appropriate for clinical trials
Understand the role of prototyping…

Select the circle below that best describes how bad, if at all, this has been a problem for you during the past week, including today.

**Difficulty breathing (shortness of breath)**

- Not a problem: 0
- Mild: 1
- Moderate: 2
- Severe: 3
- Bad as possible: 4

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Patient Care Monitor
Now that we have the data, there are a lot of ways we can use it...

Coordinated Databases

Clinical Decision Support & Guidelines

Research Uses
- Quality reporting
- CER
- Hypothesis generation
New datasets can be sequentially added, starting at the patient level, using warehousing or federated models. The key element is patient-level linkage.
Describing the patient experience

Individual patient

Research reports

Clinical operations

21% with pain ≥4/10 on ≥2 visits
Intervening:
Sexual distress

- >30% breast, GI, and lung cancer patients with moderate to severe
- Correlated with QOL, functional status, symptoms
- Clinicians sidestep the issue
- Reorganized education and patient care
- Developed flexible coping model
- ACS funded study
- Reinvestment of lessons learned
Studying new interventions: Pathfinders

The Seven Pillars of Personal Recovery

- **hope**: “I am rediscovering hope in my life.”
- **balance**: “I am taking my life back from cancer.”
- **inner strengths**: “I understand the power within me.”
- **self care**: “I am doing all I can to help myself be well.”
- **support**: “I am giving and receiving the support I need.”
- **spirit**: “I am exploring my beliefs about life, death & Spirit.”
- **life review**: “I am fully present in the journey of my life.”

Support Care Cancer
DOI 10.1007/s10780-010-9823-1

**SHORT COMMUNICATION**

Phase 2 pilot study of Pathfinders: a psychosocial intervention for cancer patients

Amy P. Abernethy • James E. Herndon II • April Coan • Tina Staley • Jane L. Wheeler • Krista Rowe • Sophia K. Smith • H. Kim Lyerly

**Psycho-Oncology**
Psycho-Oncology (2010)
Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/po.1770

**Brief Report**

Correlates of quality of life-related outcomes in breast cancer patients participating in the Pathfinders pilot study

Sophia K. Smith1,2, James E. Herndon1,2, H. Kim Lyerly1,2, April Coan1, Jane L. Wheeler2, Tina Staley1 and Amy P. Abernethy1,2,3,4,
Quality Monitoring: “Scorecards”
NOW – WHAT ABOUT EHR’S
**PRO data entered in separate charting area**

**Lab data embedded directly into chart note**

<table>
<thead>
<tr>
<th>CBC, IRON (Last 3 results in 3 years)</th>
<th>HGB, HCT (Last 3 results in 3 years)</th>
<th>PLT (Last 3 results in 3 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC (10/08/12)*</td>
<td>HGB (10/08/12)*</td>
<td>PLT (10/08/12)*</td>
</tr>
<tr>
<td>7.5</td>
<td>14.2</td>
<td>43.3</td>
</tr>
<tr>
<td>(11/15/11)</td>
<td>(11/15/11)</td>
<td>(11/15/11)</td>
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<td>8.6</td>
<td>11.7</td>
<td>38.2</td>
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<td>(10/27/11)</td>
<td>(10/27/11)</td>
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</tr>
<tr>
<td>5.7</td>
<td>12.6</td>
<td>56.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chemistries (Last 3 results in 3 years)</th>
<th>K (Last 3 results in 3 years)</th>
<th>Cr (Last 3 results in 3 years)</th>
<th>ALT (Last 3 results in 3 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No (09/27/12)*</td>
<td>(12/16/11)</td>
<td>(12/16/11)</td>
<td>(12/16/11)</td>
</tr>
<tr>
<td>165 ▲</td>
<td>3.7</td>
<td>1.00</td>
<td>59 ▲</td>
</tr>
<tr>
<td>(12/18/11)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>142</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(09/28/11)</td>
<td>2.30 ▲</td>
<td></td>
<td></td>
</tr>
<tr>
<td>130</td>
<td>(12/29/10)</td>
<td>(12/29/10)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5.0</td>
<td>0.91</td>
<td></td>
</tr>
</tbody>
</table>

**Lipid Panel (Last 3 results in 3 years)**

**Endocrine Results (Last 3 results in 3 years)**

**Urine Test Results (Last 3 results in 3 years)**

---

*Center for Health Research*
• Less than ideal interface and data entry
• **Variable collection of PROs**
• Less than ideal display when viewing multiple PROs
### Medication

<table>
<thead>
<tr>
<th>Medication (Generic/Brand)</th>
<th>Approximate dose you took this medication</th>
<th>How long did you take it</th>
<th>Please indicate whether it helped before, now, or not at all</th>
<th>List any unacceptable side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amitriptyline (Elavil)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Desylazine (Neurontin)</td>
<td>300mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Methadone (Heroin)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Hydromorphone (Hidale)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Loperamide (Imodium)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Oxycodone (Percocet)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Darvon (Darvocet)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Tramadol (Ultram)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Vicodin (Priam)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Lyrica (Pregabalin)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Elavil (Amitriptyline)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Zoloft (Sertraline)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Effexor (Venlafaxine)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Prozac (Fluoxetine)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Cymbalta (Duloxetine)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Serzone (Ziprasidone)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Abilify (Aripiprazole)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Quetiapine (Seroquel)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Ritalin (Methylphenidate)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
<tr>
<td>Adderall (Amphetamine)</td>
<td>100mg / day</td>
<td>1 year</td>
<td>Some</td>
<td>None</td>
</tr>
</tbody>
</table>

### List any over the counter medications

- Advil, Pain Reliever
- Tylenol, Pain Reliever
- Inflamex, Pain Reliever

### Other comments

- “I feel better with medication.”
- “I feel worse with medication.”
- “I don’t feel any different.”

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**KPMN Pain Management Clinic**
503-533-4431

**Kaiser Permanente**

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**Center for Health Research**
EHR Attached PPACT Provider Feedback Form

**SUGGESTED PCP ACTIONS**
- Referral to Sleep Clinic (Epworth Score 12)
- Physician review authorizing attendance of water exercise class at the community center.
- Review amitriptyline dose - patient experiencing significant morning drowsiness
- Discuss opioid side effects (constipation, dry eyes)

**PATIENT PROGRAM GOALS**
Quality of Life Goal: Play with my grandchildren when they come over.
A. Your patient’s current ability to do this activity
B. Your patient’s ability to do this activity if things were a bit worse, a bit better, even better, much better.

<table>
<thead>
<tr>
<th>A bit worse</th>
<th>A bit better</th>
<th>Even better</th>
<th>Much better</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NOW</strong> Sit in a comfortable kitchen chair while kids play in living room</td>
<td>Sit in living room recliner while kids play in same room</td>
<td>Use pillows &amp; props to sit against couch while kids play</td>
<td>Sit on the floor and play with kids</td>
</tr>
</tbody>
</table>

**Screenings**
- PHQ. Score 6: Level of Depression Mild
- AUDIT. Score 6: Interpretation Alcohol education suggested
- GAD-7: Score 6: Interpretation Low risk for problems
- Epworth Sleepiness Score: 12: Interpretation Excessive daytime sleepiness

Range of pain intensity: 2/10 (least) to 8/10 (worst); 4/10 (average)
Online or paper collection

EMR Provider Summary Report

Scoring or compilation of relevant assessment scores
The Goals

- Patient portals, home interfaces, interfaces in the clinics
- Apps, web-based solutions, etc with APIs to transfer data
- Information to support care in real-time
- PROs that drive a number of solutions
  - Education, quality monitoring, triage
- Alignment with process
  - One size doesn’t fit all
- Risk management
What do we need?

- **Tools that make sense**
  - How is my patient doing?
  - Data that are valuable for multiple purposes
  - Just because I can change the questions around, should I?

- **Patient participation in serial assessment**

- **Integration into clinical process**
  - Alignment of incentives
  - Engage providers
  - Improve clinical productivity

- **Data governance**
  - Data interoperability
LESSONS LEARNED
ePRO environment for Learning Health Care: Lessons learned

- Four interchangeable components
- Importance of user interface and reporting
- Must meet patient and clinical needs first
  - Research with service
- Efficient and high quality approach for data collection
  - Missingness is a critical signal
  - Data visualization
Data generation, use and reuse
Contact

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amy.abernethy@duke.edu