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

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Morris Cancer Clinic

July 23, 2012

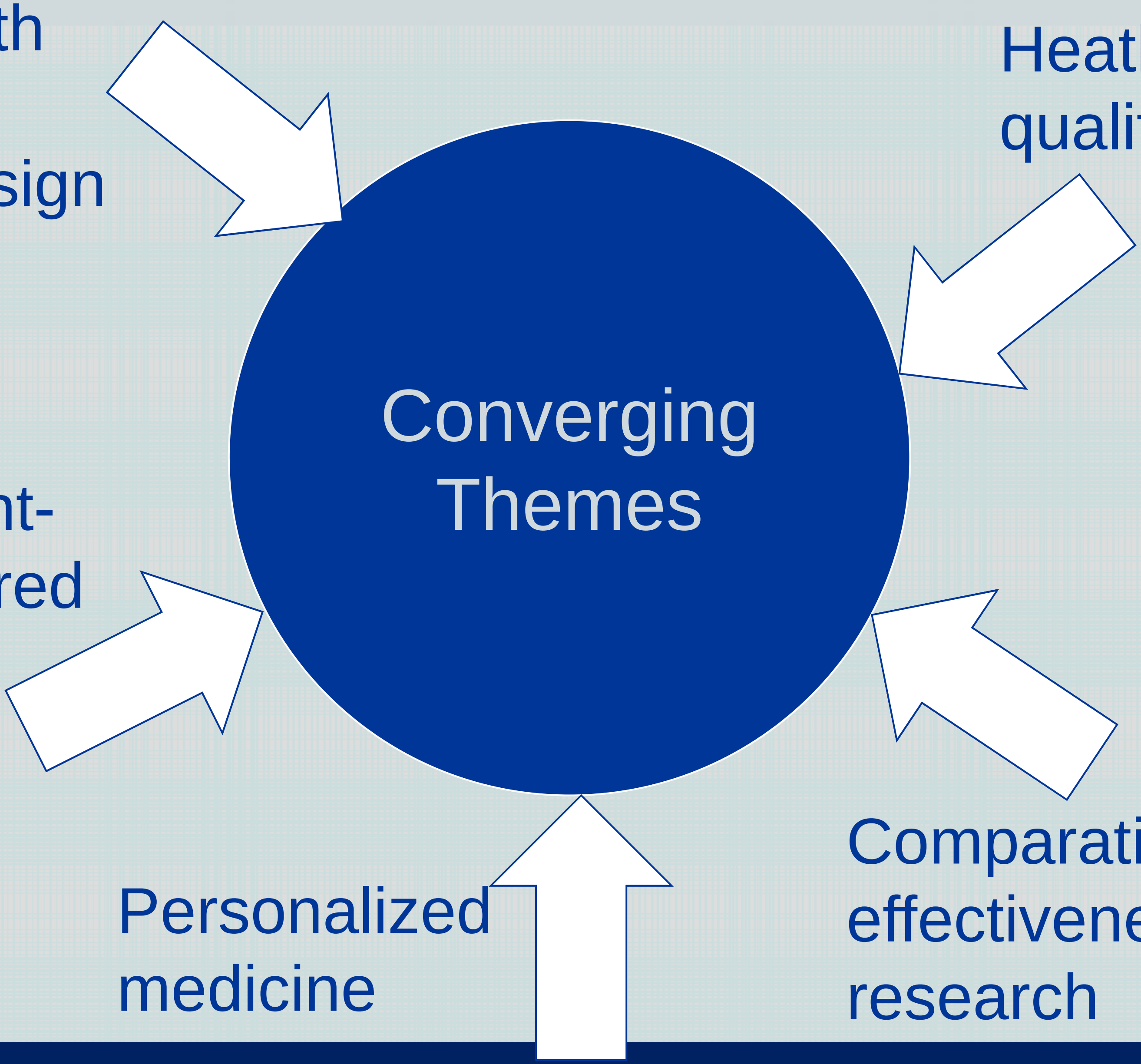
# Abernethy Funding & Disclosures

- 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
- Consultant <$5K annual in past 3 years – Helsinn (2010), Novartis (2011), Pfizer (2012)
- 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



Health care redesign

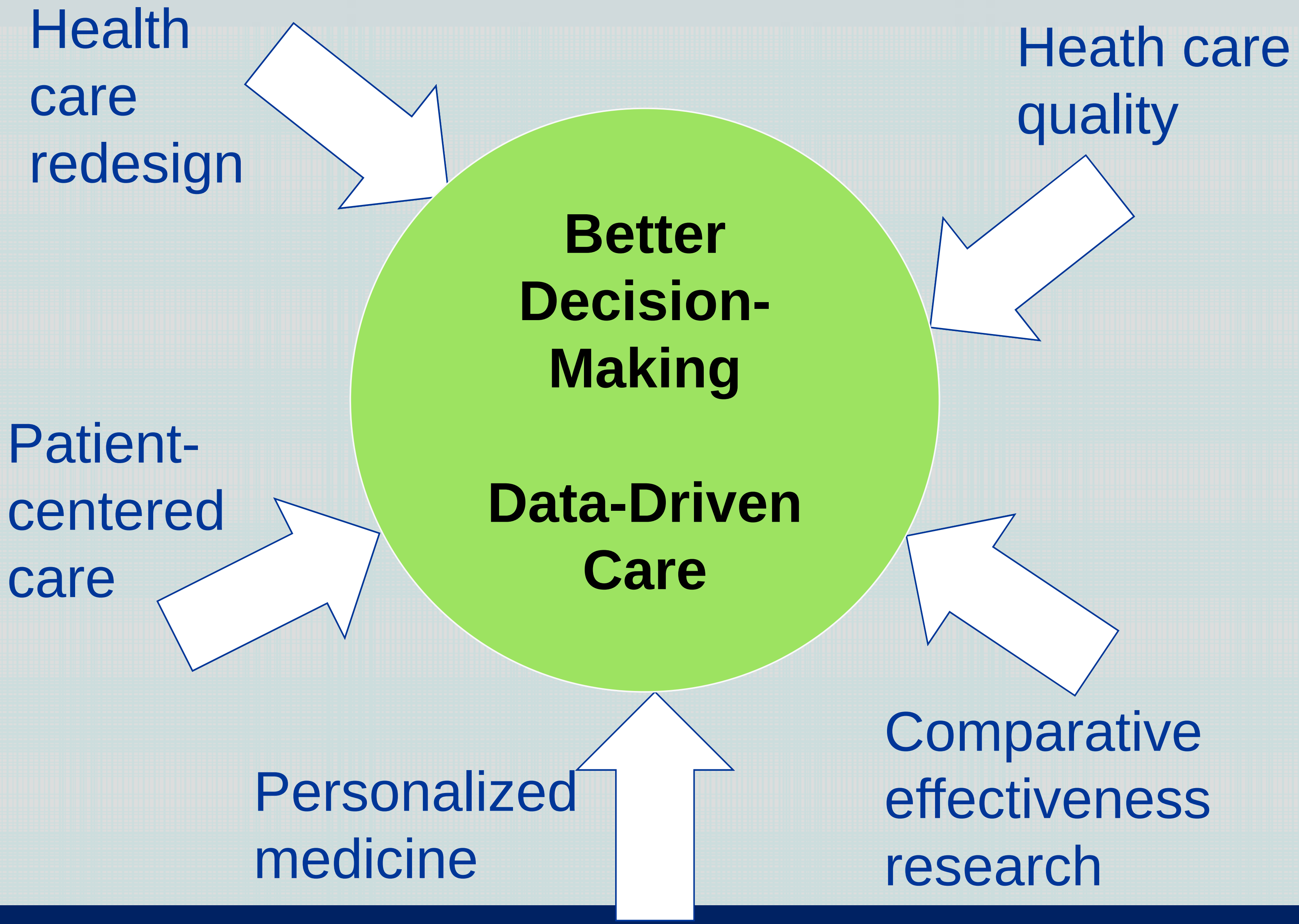
Heath care quality

Converging Themes

Patient-centered care

Comparative effectiveness research

Personalized medicine



Health care redesign

Heath care quality

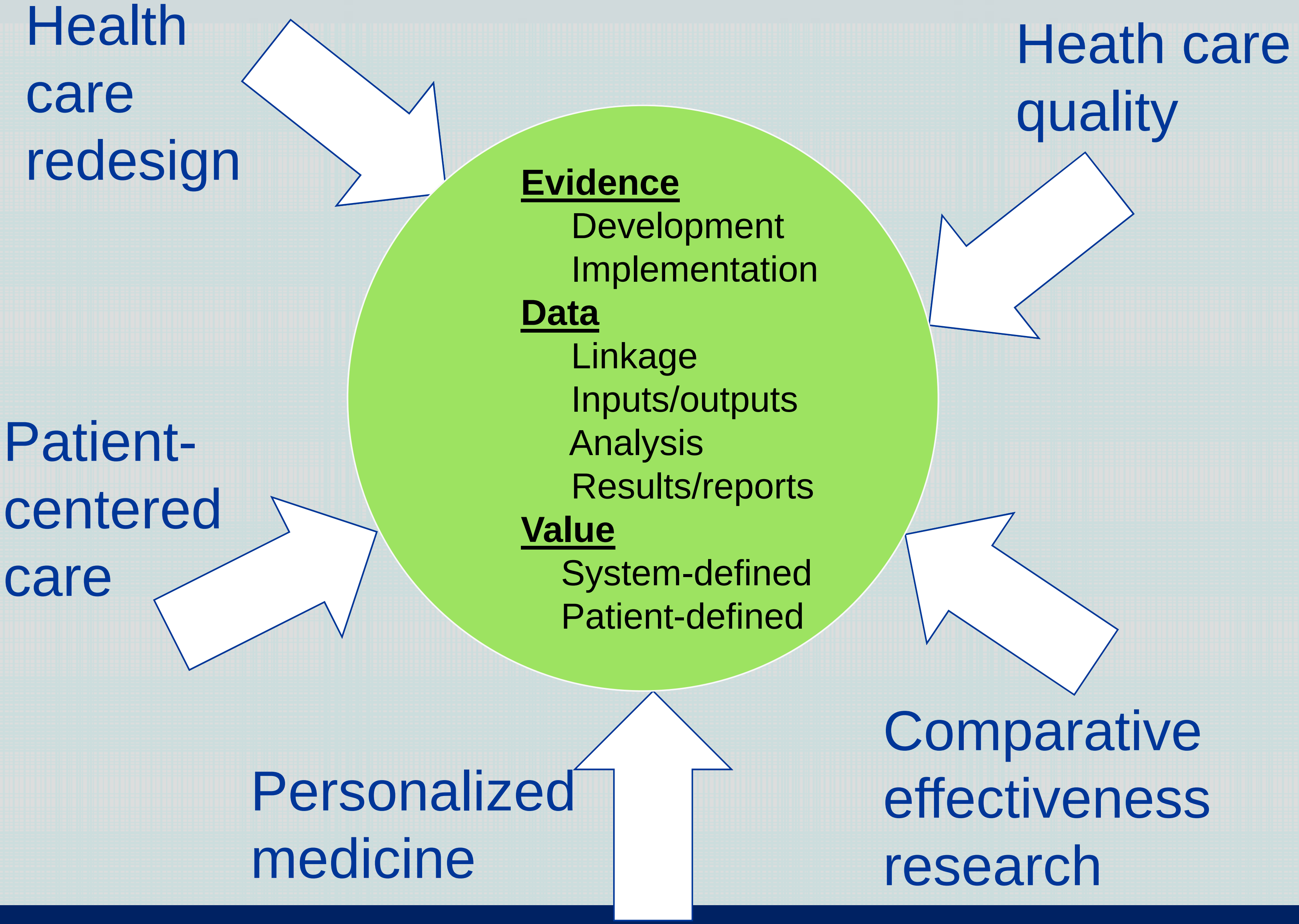
**Better Decision-Making**

**Data-Driven Care**

Patient-centered care

Comparative effectiveness research

Personalized medicine



Health care redesign

Heath care quality

Patient-centered care

Personalized medicine

Comparative effectiveness research

**Evidence**

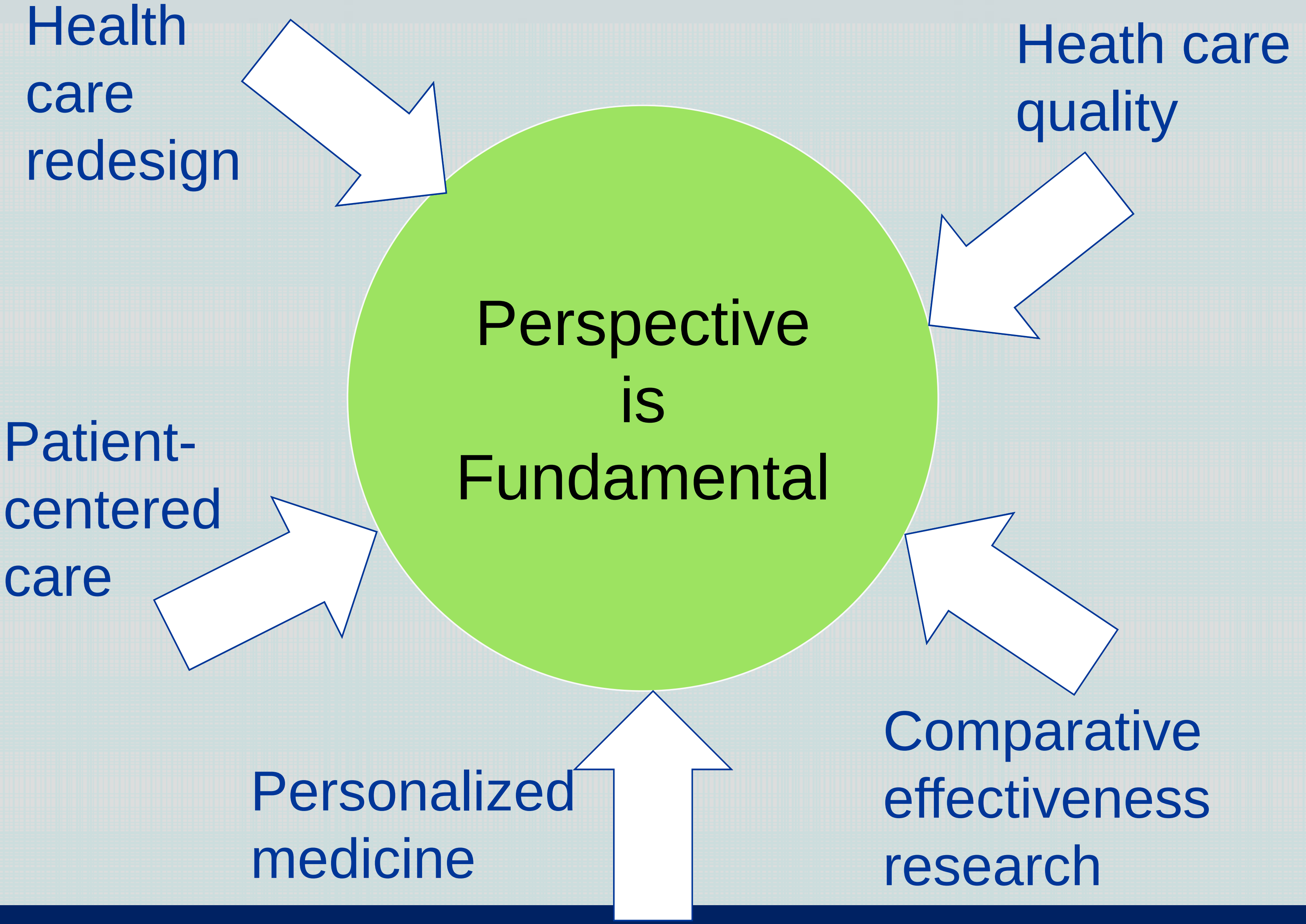
- Development
- Implementation

**Data**

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

**Value**

- System-defined
- Patient-defined



Perspective is Fundamental

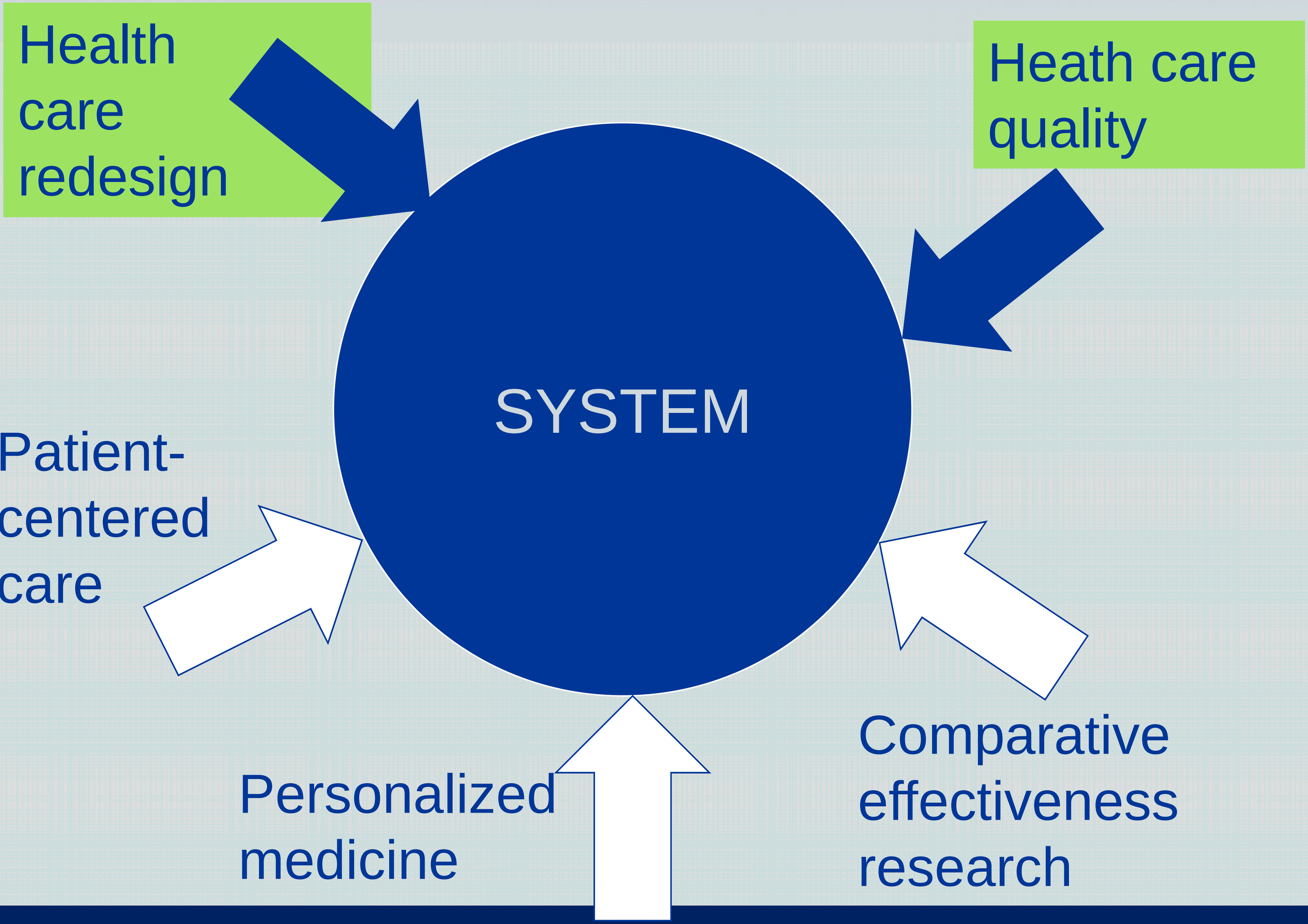
Health care redesign

Heath care quality

Patient-centered care

Personalized medicine

Comparative effectiveness research



Health care redesign

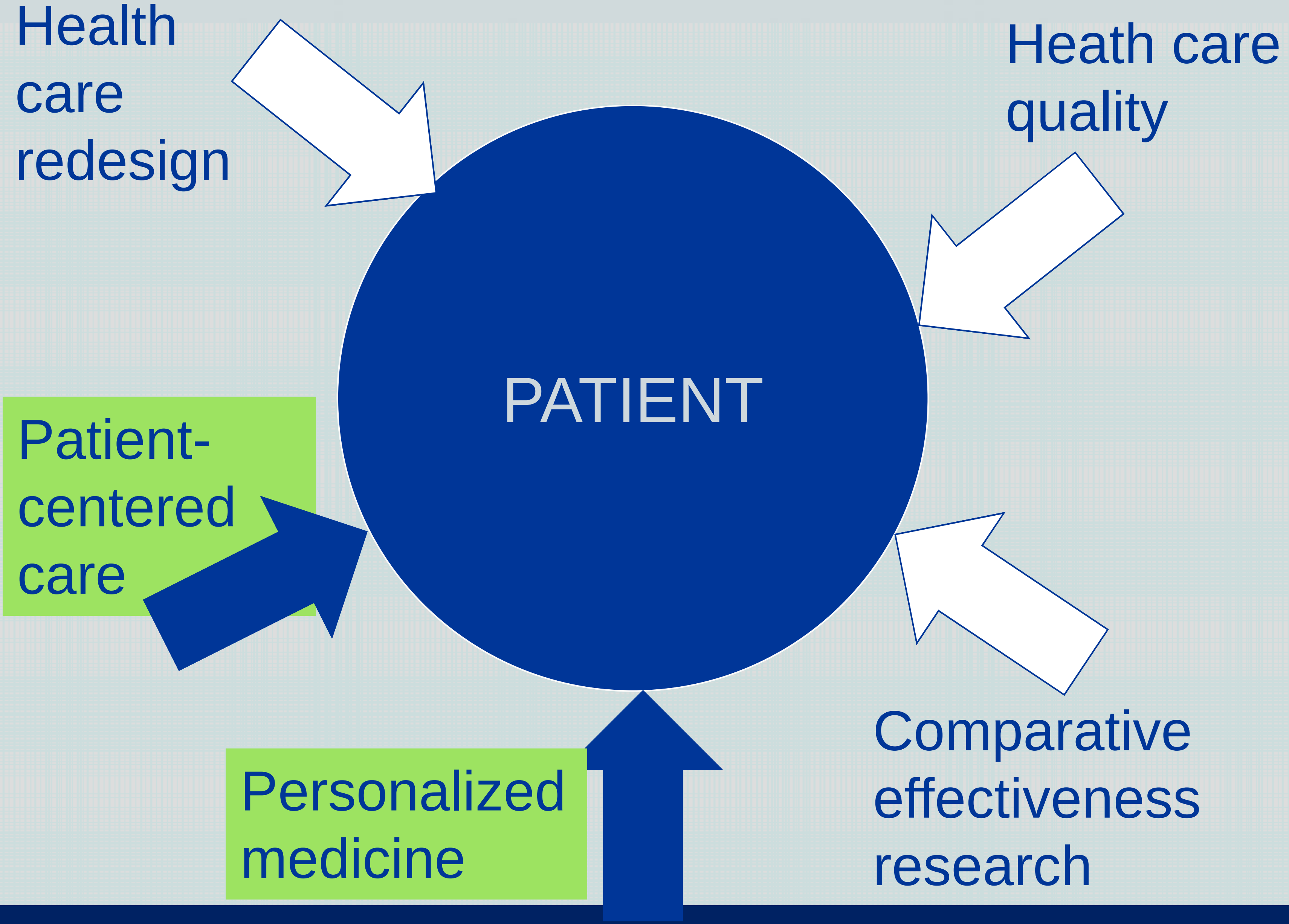
Heath care quality

SYSTEM

Patient-centered care

Personalized medicine

Comparative effectiveness research



PATIENT

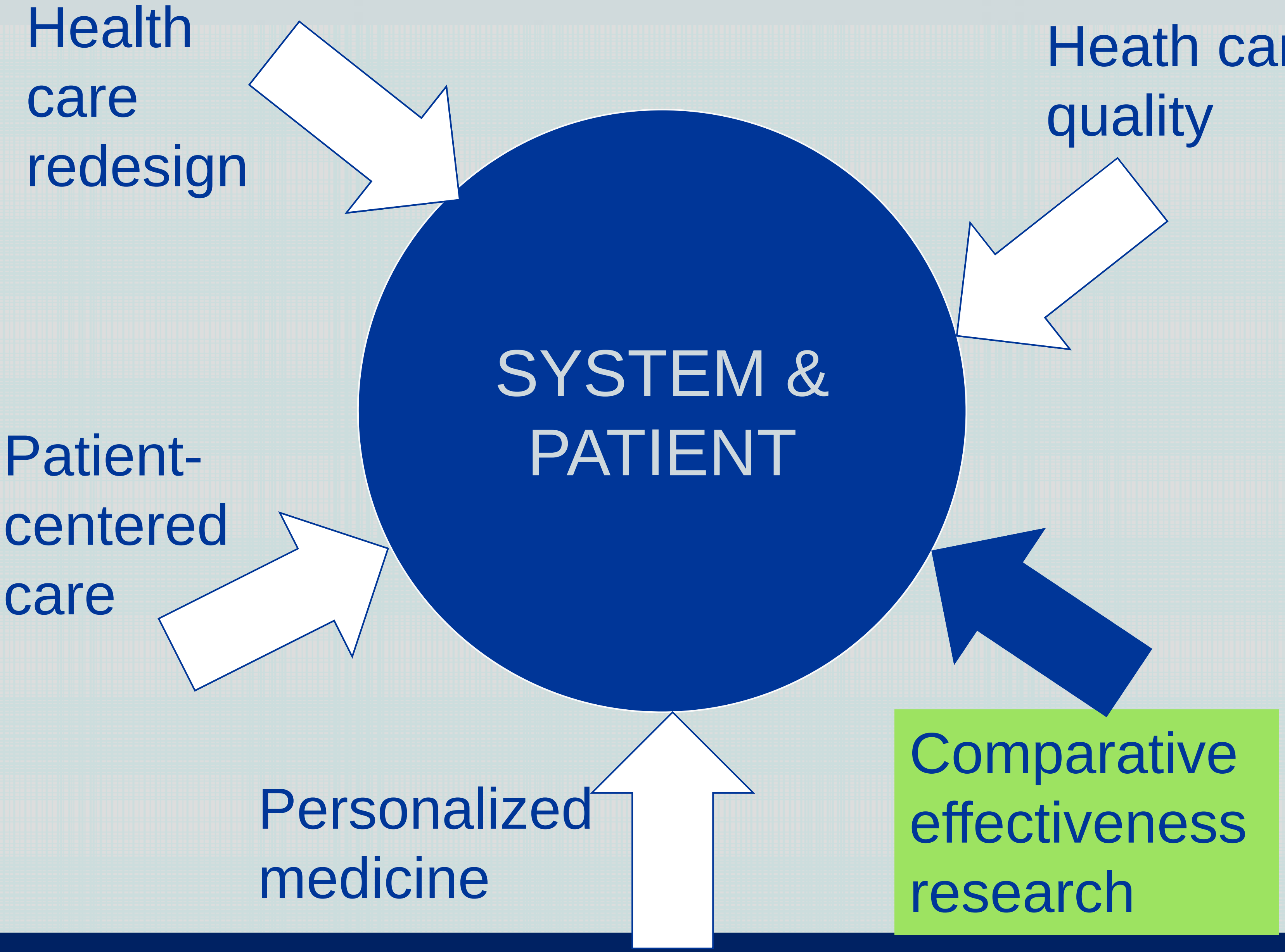
Health care redesign

Heath care quality

Patient-centered care

Personalized medicine

Comparative effectiveness research



SYSTEM & PATIENT

Health care redesign

Heath care quality

Patient-centered care

Personalized medicine

Comparative effectiveness research

My pain is 7 out of 10

| Inputs | Outputs |
|---|---|
| Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |
| Data element: Pain intensity measured on a 0-10 scale | Metric: # with pain scores / total # patients |
| Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |
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| | Inputs | Outputs |
|---|---|---|
| Health care redesign | Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |
| Health care quality | Data element: Pain intensity measured on a 0-10 scale | Metric: # with pain scores / total # patients |
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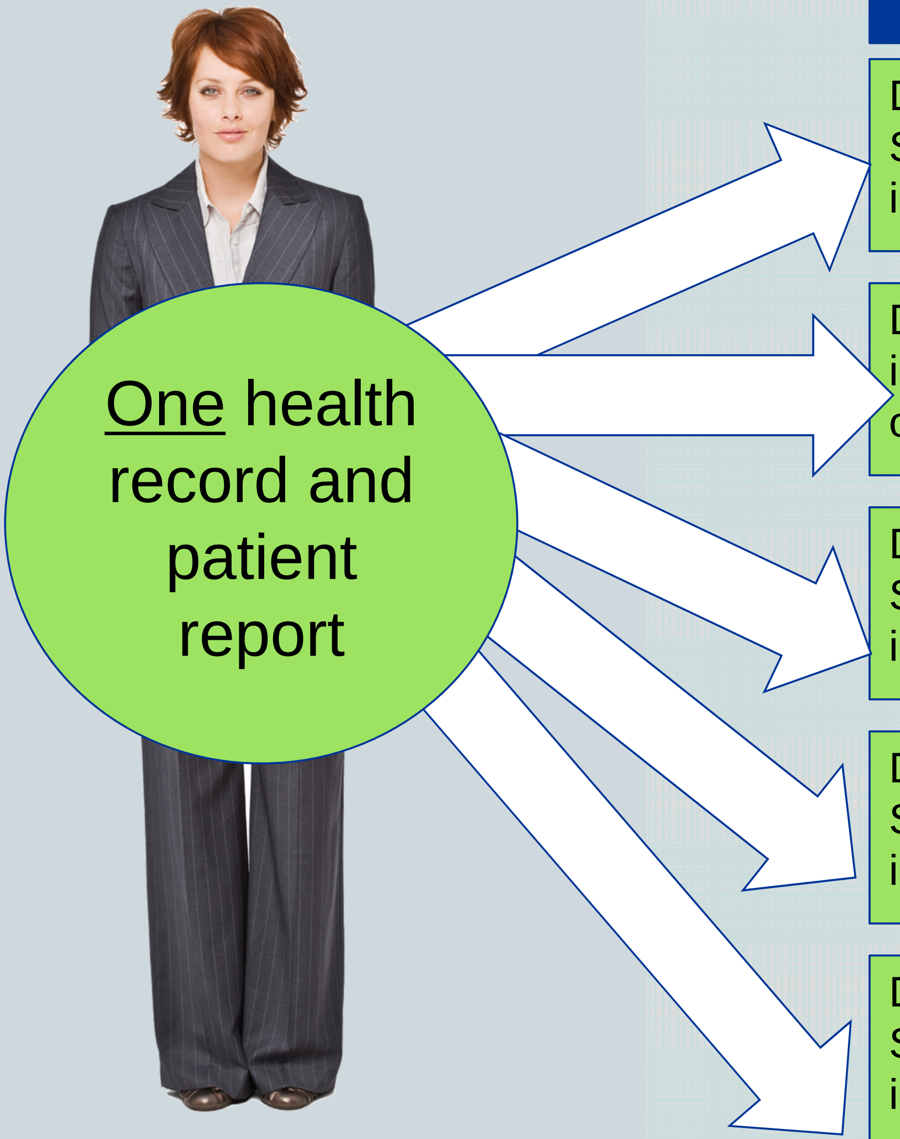
| Patient-centered care | Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |
| Personalized medicine | Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |



One health record and patient report

| Inputs | Outputs |
|---|---|
| Data elements: Standardized pain intervention info. | Data element: Pain intensity measured on a 0-10 scale |
| Data element: Pain intensity measured on a 0-10 scale | Metric: # with pain scores / total # patients |
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# What is a Learning Health System?

***A "learning health care system" (LHCS) leverages recent developments in health information technology and a growing health data infrastructure to access and apply evidence in real time, while simultaneously drawing knowledge from real-world care-delivery processes to promote innovation and health system change on the basis of rigorous research***. Ann Intern Med. 2012;157(3):207-210.

# What is a Learning Health System?

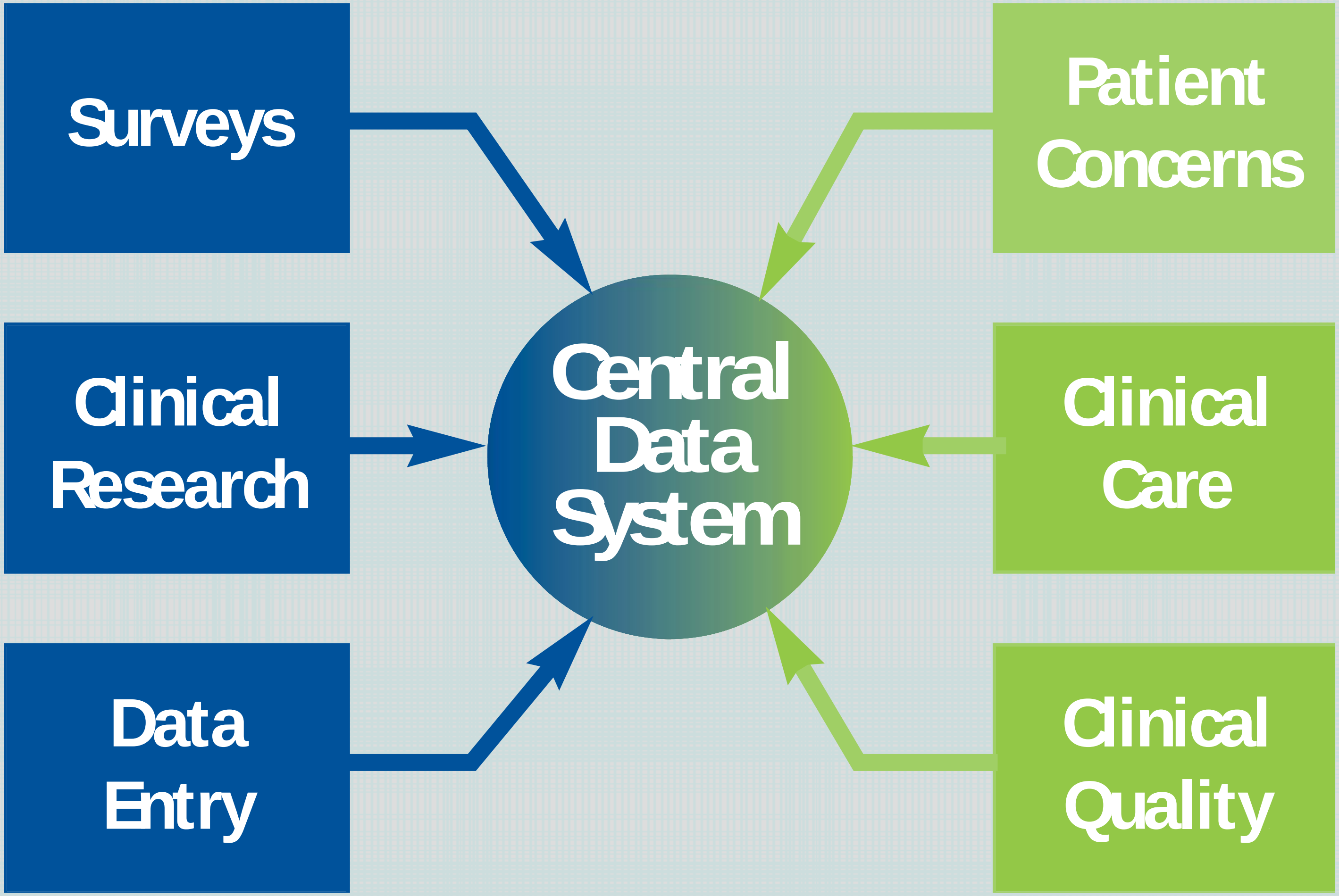
- Organization that learns (quality & PI view)
- Systematically linked process for evidence generation and implementation (Research / clinical trials)
- National system of linked data to generate novel insights and monitoring
- Continuously aggregating datasets to support point of care clinical decision 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

# Data generation, use and reuse

Data that are meaningful at the clinical interface

# PRO-BASED LEARNING
## HEALTH CARE

# The original story…



Surveys

Clinical Research

Data Entry

Central Data System

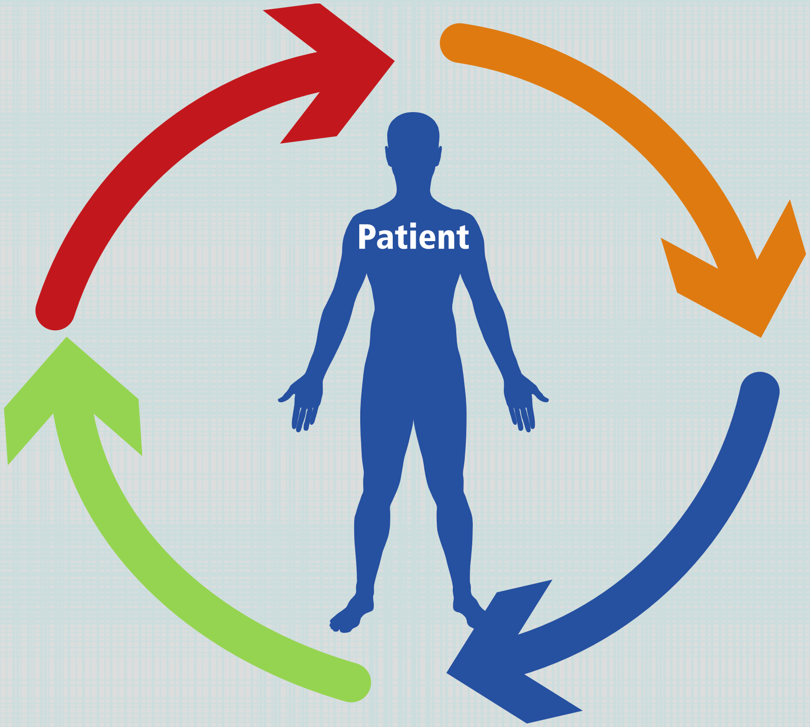
Patient Concerns

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)

PATIENT CARE MONITOR REPORT

Patient Name:

DOB/Age/Sex:

Doctor:

MR #:

Survey Date/Time: Apr 26 2006 (Wed) / 9:17AM

Version: English

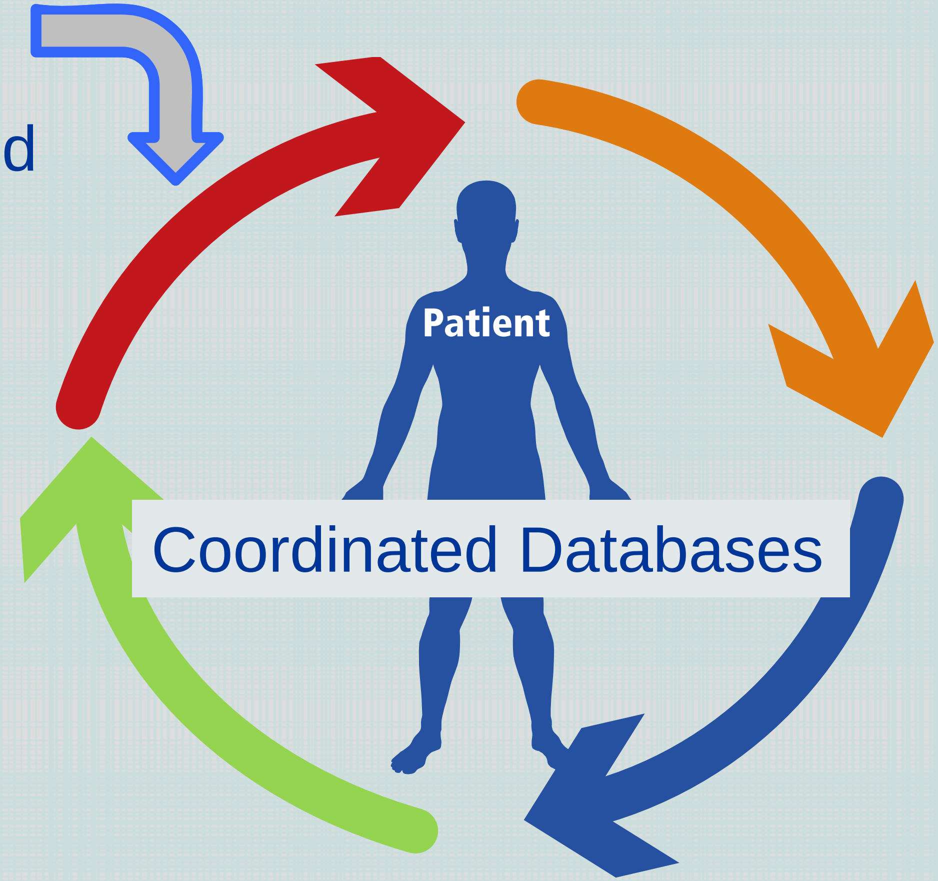
Dx/Dx Date:

Review of Systems

# BEWARE!!!

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

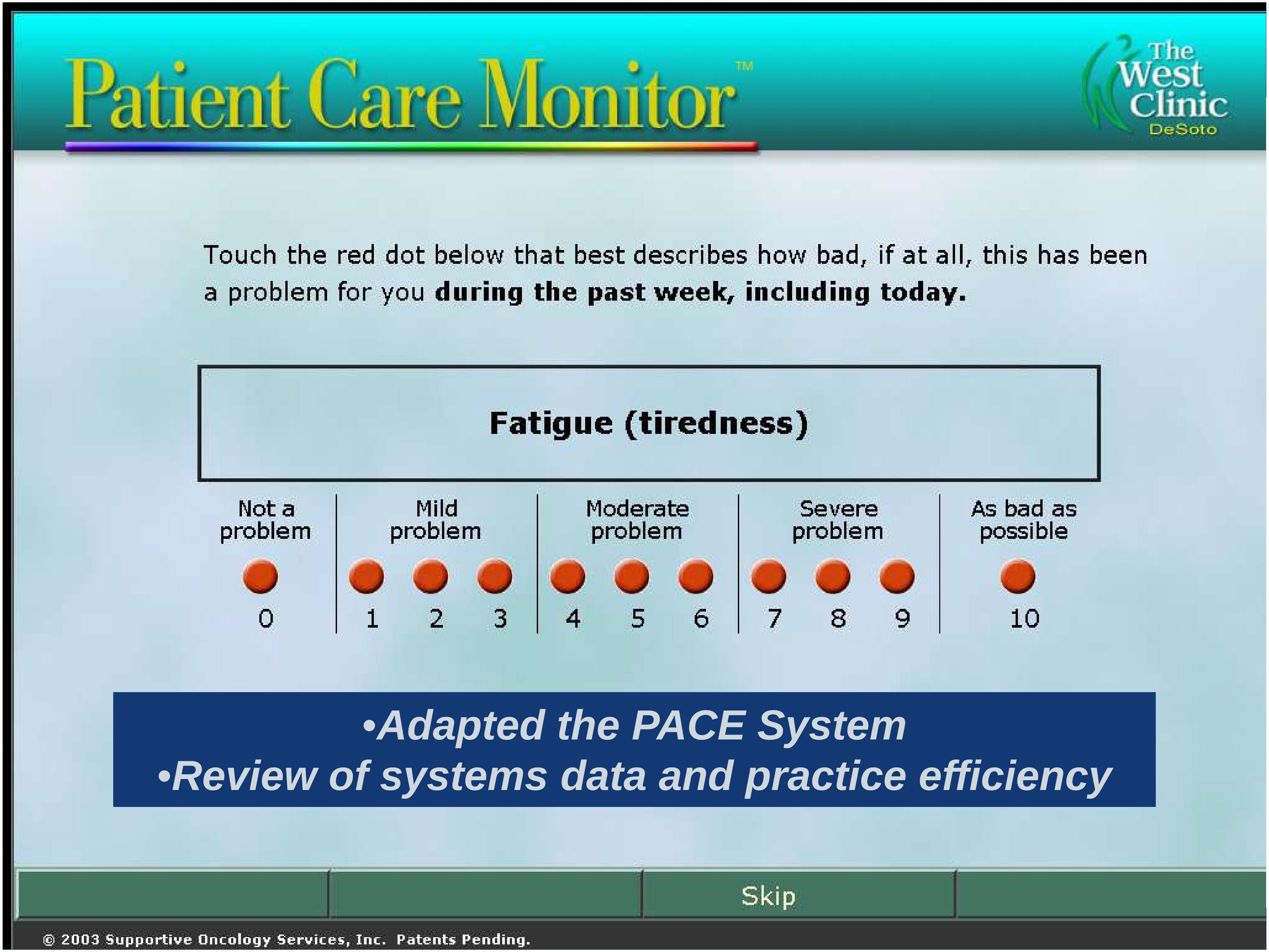
Patient
reports
standardized
data



Patient

Coordinated Databases

Location and platform agnostic



Patient Care Monitor™
The West Clinic DeSoto

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 |
|---|---|---|---|---|---|---|---|---|---|---|
| ● | ● | ● | ● | ● | ● | ● | ● | ● | ● | ● |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Skip

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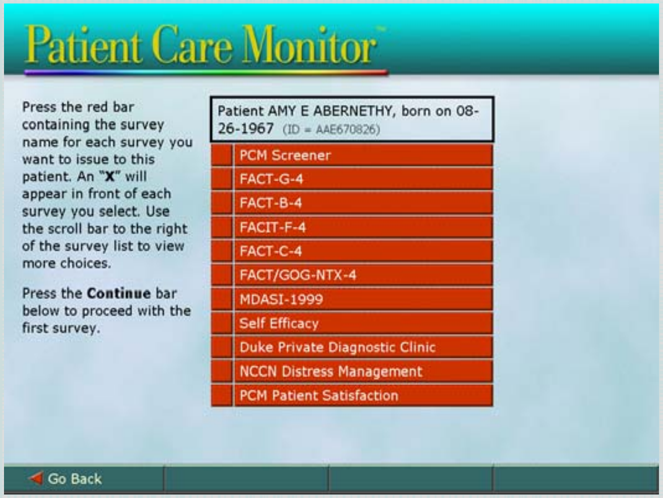
- ***Adapted the PACE System***
- ***Review of systems data and practice efficiency***

# 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

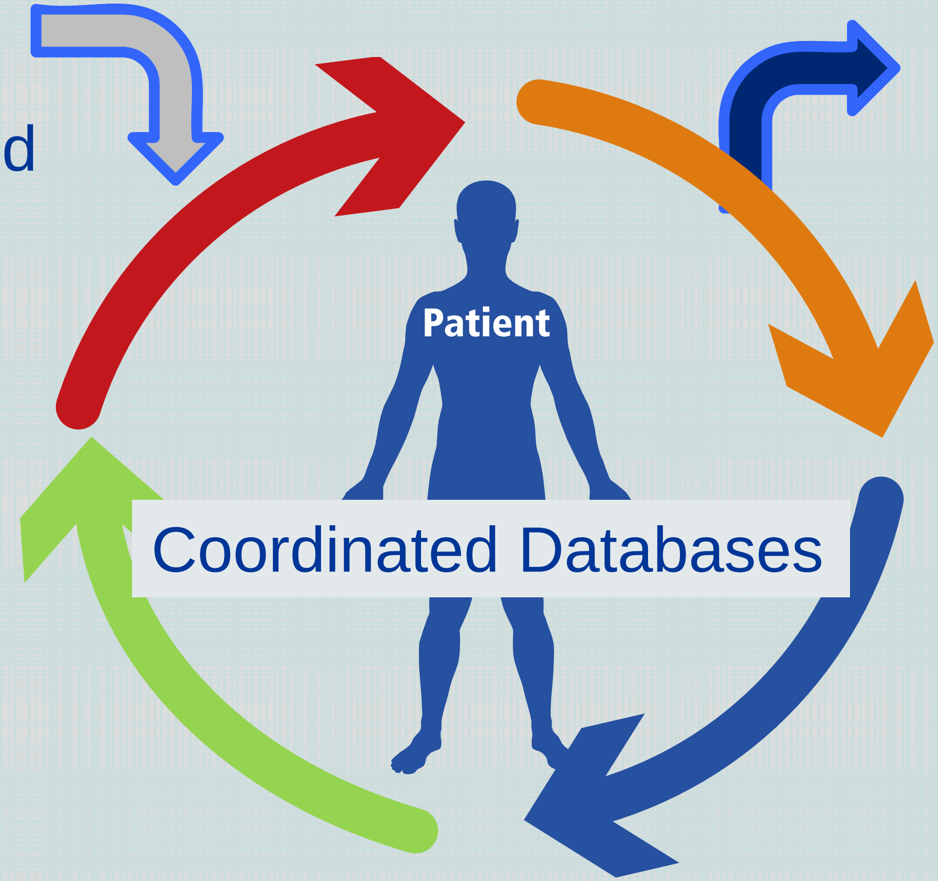

Patient Care Monitor™
PCM Screener
FACT-G-4
FACT-B-4
FACIT-F-4
FACT-C-4
FACT/GOG-NTX-4
MDASI-1999
Self Efficacy
Duke Private Diagnostic Clinic
NCCN Distress Management
PCM Patient Satisfaction
Go Back

Press the red bar containing the survey name for each survey you want to issue to this patient. An "**X**" will appear in front of each survey you select. Use the scroll bar to the right of the survey list to view more choices.

Press the **Continue** bar below to proceed with the first survey.

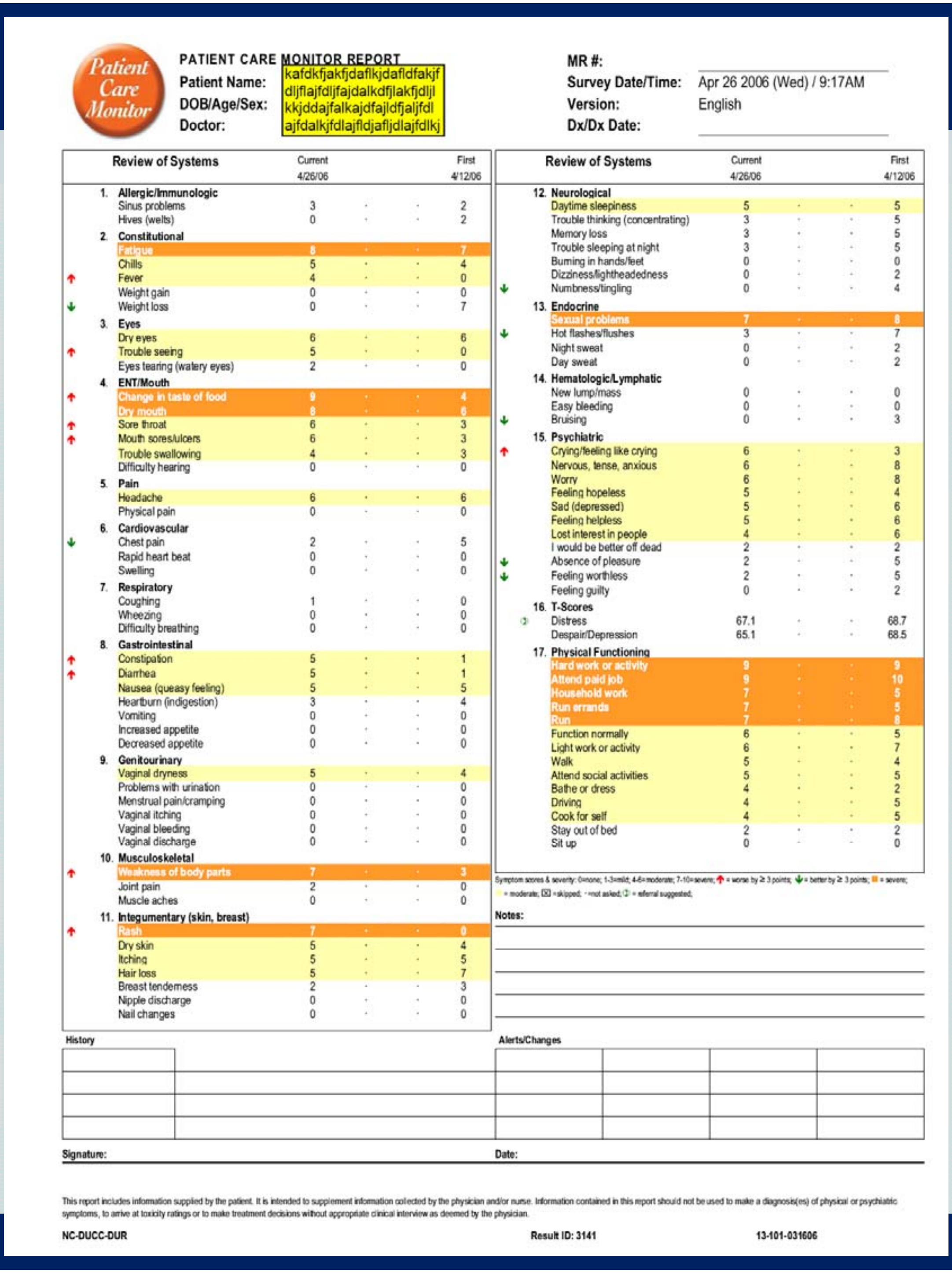
Patient AMY E ABERNETHY, born on 08-26-1967 (ID = AAE670826)

Patient reports standardized data


Patient
Coordinated Databases

## Clinical uses

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



**PATIENT CARE MONITOR REPORT**

**Patient Name:** kafdkfjakfjdaflkjdafldfakjf
**DOB/Age/Sex:** dljflajfdljfajdalkdfjlakfjdljl
kkjddajfalkajdfajldfjaljfdl
**Doctor:** ajfdalkjfdlajfldjafljdlajfdlkj

**MR #:**
**Survey Date/Time:** Apr 26 2006 (Wed) / 9:17AM
**Version:** English
**Dx/Dx Date:**

| | Review of Systems | Current 4/26/06 | | | First 4/12/06 |
|---|---|---|---|---|---|
| | **1. Allergic/Immunologic** | | | | |
| | Sinus problems | 3 | · | · | 2 |
| | Hives (welts) | 0 | · | · | 2 |
| | **2. Constitutional** | | | | |
| | Fatigue | 8 | · | · | 7 |
| | Chills | 5 | · | · | 4 |
| ↑ | Fever | 4 | · | · | 0 |
| | Weight gain | 0 | · | · | 0 |
| ↓ | Weight loss | 0 | · | · | 7 |
| | **3. Eyes** | | | | |
| | Dry eyes | 6 | · | · | 6 |
| ↑ | Trouble seeing | 5 | · | · | 0 |
| | Eyes tearing (watery eyes) | 2 | · | · | 0 |
| | **4. ENT/Mouth** | | | | |
| ↑ | Change in taste of food | 9 | · | · | 4 |
| | Dry mouth | 8 | · | · | 6 |
| ↑ | Sore throat | 6 | · | · | 3 |
| ↑ | Mouth sores/ulcers | 6 | · | · | 3 |
| | Trouble swallowing | 4 | · | · | 3 |
| | Difficulty hearing | 0 | · | · | 0 |
| | **5. Pain** | | | | |
| | Headache | 6 | · | · | 6 |
| | Physical pain | 0 | · | · | 0 |
| | **6. Cardiovascular** | | | | |
| ↓ | Chest pain | 2 | · | · | 5 |
| | Rapid heart beat | 0 | · | · | 0 |
| | Swelling | 0 | · | · | 0 |
| | **7. Respiratory** | | | | |
| | Coughing | 1 | · | · | 0 |
| | Wheezing | 0 | · | · | 0 |
| | Difficulty breathing | 0 | · | · | 0 |
| | **8. Gastrointestinal** | | | | |
| ↑ | Constipation | 5 | · | · | 1 |
| ↑ | Diarrhea | 5 | · | · | 1 |
| | Nausea (queasy feeling) | 5 | · | · | 5 |
| | Heartburn (indigestion) | 3 | · | · | 4 |
| | Vomiting | 0 | · | · | 0 |
| | Increased appetite | 0 | · | · | 0 |
| | Decreased appetite | 0 | · | · | 0 |
| | **9. Genitourinary** | | | | |
| | Vaginal dryness | 5 | · | · | 4 |
| | Problems with urination | 0 | · | · | 0 |
| | Menstrual pain/cramping | 0 | · | · | 0 |
| | Vaginal itching | 0 | · | · | 0 |
| | Vaginal bleeding | 0 | · | · | 0 |
| | Vaginal discharge | 0 | · | · | 0 |
| | **10. Musculoskeletal** | | | | |
| ↑ | Weakness of body parts | 7 | · | · | 3 |
| | Joint pain | 2 | · | · | 0 |
| | Muscle aches | 0 | · | · | 0 |
| | **11. Integumentary (skin, breast)** | | | | |
| ↑ | Rash | 7 | · | · | 0 |
| | Dry skin | 5 | · | · | 4 |
| | Itching | 5 | · | · | 5 |
| | Hair loss | 5 | · | · | 7 |
| | Breast tenderness | 2 | · | · | 3 |
| | Nipple discharge | 0 | · | · | 0 |
| | Nail changes | 0 | · | · | 0 |

| | Review of Systems | Current 4/26/06 | | | First 4/12/06 |
|---|---|---|---|---|---|
| | **12. Neurological** | | | | |
| | Daytime sleepiness | 5 | · | · | 5 |
| | Trouble thinking (concentrating) | 3 | · | · | 5 |
| | Memory loss | 3 | · | · | 5 |
| | Trouble sleeping at night | 3 | · | · | 5 |
| | Burning in hands/feet | 0 | · | · | 0 |
| | Dizziness/lightheadedness | 0 | · | · | 2 |
| ↓ | Numbness/tingling | 0 | · | · | 4 |
| | **13. Endocrine** | | | | |
| | Sexual problems | 7 | · | · | 8 |
| ↓ | Hot flashes/flushes | 3 | · | · | 7 |
| | Night sweat | 0 | · | · | 2 |
| | Day sweat | 0 | · | · | 2 |
| | **14. Hematologic/Lymphatic** | | | | |
| | New lump/mass | 0 | · | · | 0 |
| | Easy bleeding | 0 | · | · | 0 |
| ↓ | Bruising | 0 | · | · | 3 |
| | **15. Psychiatric** | | | | |
| ↑ | Crying/feeling like crying | 6 | · | · | 3 |
| | Nervous, tense, anxious | 6 | · | · | 8 |
| | Worry | 6 | · | · | 8 |
| | Feeling hopeless | 5 | · | · | 4 |
| | Sad (depressed) | 5 | · | · | 6 |
| | Feeling helpless | 5 | · | · | 6 |
| | Lost interest in people | 4 | · | · | 6 |
| | I would be better off dead | 2 | · | · | 2 |
| ↓ | Absence of pleasure | 2 | · | · | 5 |
| ↓ | Feeling worthless | 2 | · | · | 5 |
| | Feeling guilty | 0 | · | · | 2 |
| | **16. T-Scores** | | | | |
| ○ | Distress | 67.1 | · | · | 68.7 |
| | Despair/Depression | 65.1 | · | · | 68.5 |
| | **17. Physical Functioning** | | | | |
| | Hard work or activity | 9 | · | · | 9 |
| | Attend paid job | 9 | · | · | 10 |
| | Household work | 7 | · | · | 5 |
| | Run errands | 7 | · | · | 5 |
| | Run | 7 | · | · | 8 |
| | Function normally | 6 | · | · | 5 |
| | Light work or activity | 6 | · | · | 7 |
| | Walk | 5 | · | · | 4 |
| | Attend social activities | 5 | · | · | 5 |
| | Bathe or dress | 4 | · | · | 2 |
| | Driving | 4 | · | · | 5 |
| | Cook for self | 4 | · | · | 5 |
| | Stay out of bed | 2 | · | · | 2 |
| | Sit up | 0 | - | - | 0 |

Symptom scores & severity: 0=none; 1-3=mild; 4-6=moderate; 7-10=severe; ↑ = worse by ≥ 3 points; ↓ = better by ≥ 3 points; 🟧 = severe; 🟨 = moderate; ☒ =skipped; - =not asked; ○ = referral suggested;

**Notes:**

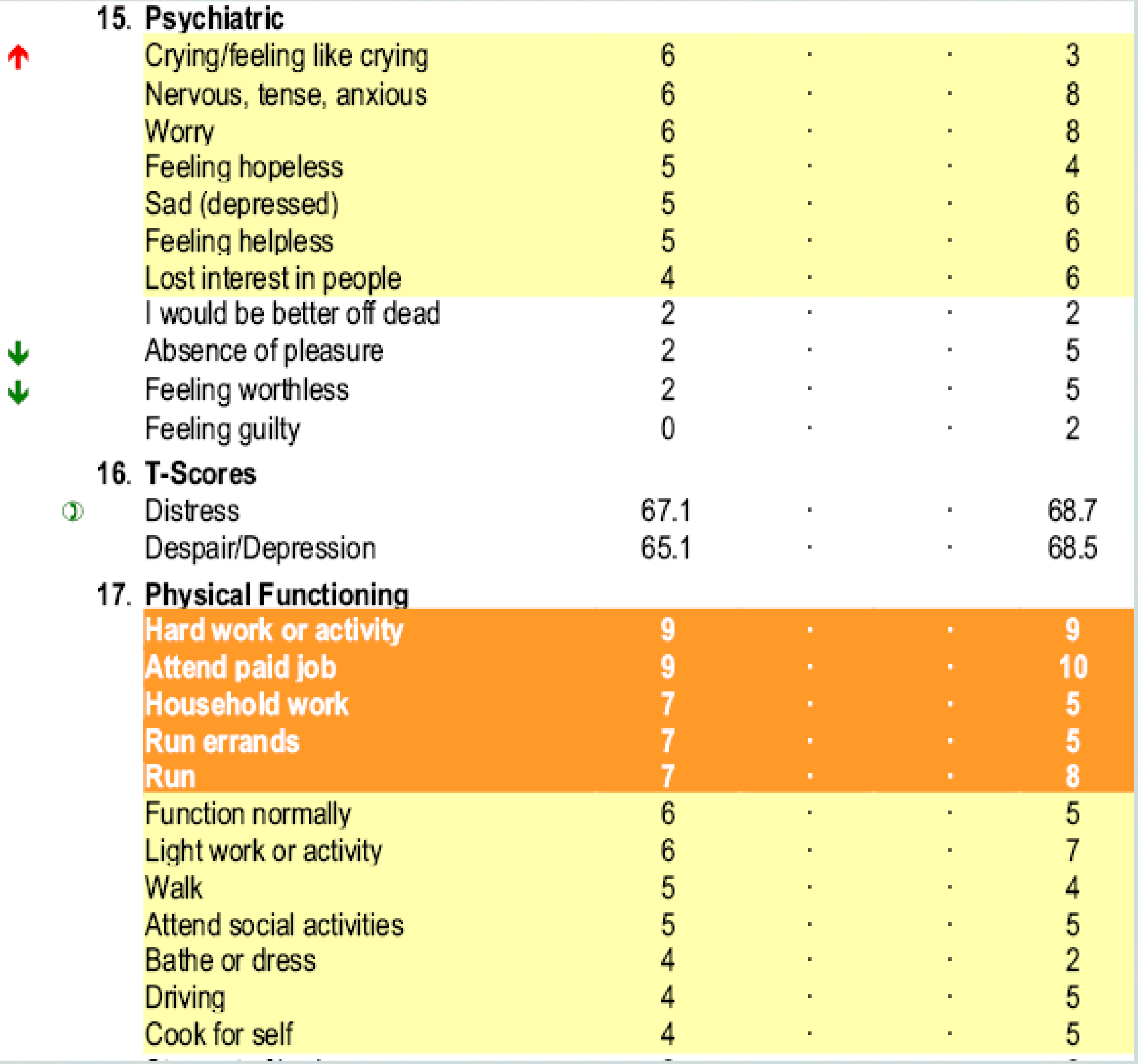
**History**

**Alerts/Changes**

**Signature:** **Date:**

This report includes information supplied by the patient. It is intended to supplement information collected by the physician and/or nurse. Information contained in this report should not be used to make a diagnosis(es) of physical or psychiatric symptoms, to arrive at toxicity ratings or to make treatment decisions without appropriate clinical interview as deemed by the physician.

NC-DUCC-DUR Result ID: 3141 13-101-031606



| | | | | | |
|---|---|---|---|---|---|
| | **15. Psychiatric** | | | | |
| ↑ | Crying/feeling like crying | 6 | · | · | 3 |
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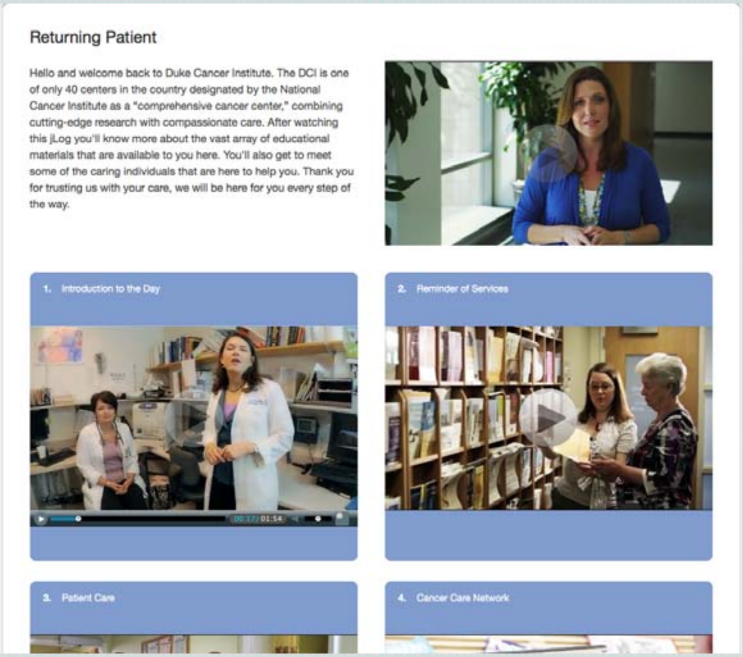
| | **16. T-Scores** | | | | |
| ◑ | Distress | 67.1 | · | · | 68.7 |
| | Despair/Depression | 65.1 | · | · | 68.5 |
| | **17. Physical Functioning** | | | | |
| | **Hard work or activity** | **9** | · | · | **9** |
| | **Attend paid job** | **9** | · | · | **10** |
| | **Household work** | **7** | · | · | **5** |
| | **Run errands** | **7** | · | · | **5** |
| | **Run** | **7** | · | · | **8** |
| | Function normally | 6 | · | · | 5 |
| | Light work or activity | 6 | · | · | 7 |
| | Walk | 5 | · | · | 4 |
| | Attend social activities | 5 | · | · | 5 |
| | Bathe or dress | 4 | · | · | 2 |
| | Driving | 4 | · | · | 5 |
| | Cook for self | 4 | · | · | 5 |

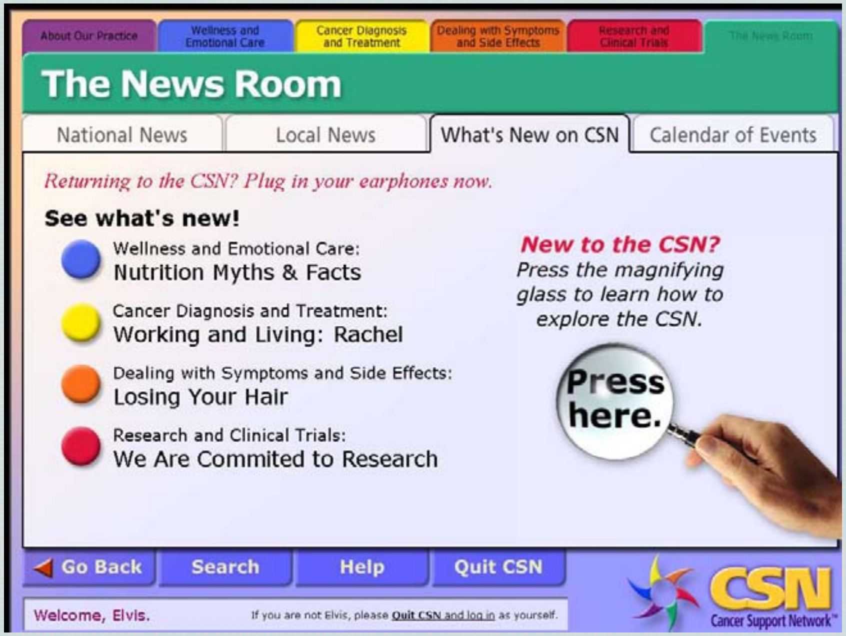
# Education matched to clinical needs and patient interest


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 jLog 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. Reminder of Services
3. Patient Care
4. Cancer Care Network

00:17 / 01:54


About Our Practice
Wellness and Emotional Care
Cancer Diagnosis and Treatment
Dealing with Symptoms and Side Effects
Research and Clinical Trials
The News Room
The News Room
National News
Local News
What's New on CSN
Calendar of Events
Press here.
Go Back
Search
Help
Quit CSN
CSN
Cancer Support Network™

*Returning to the CSN? Plug in your earphones now.*

**See what's new!**

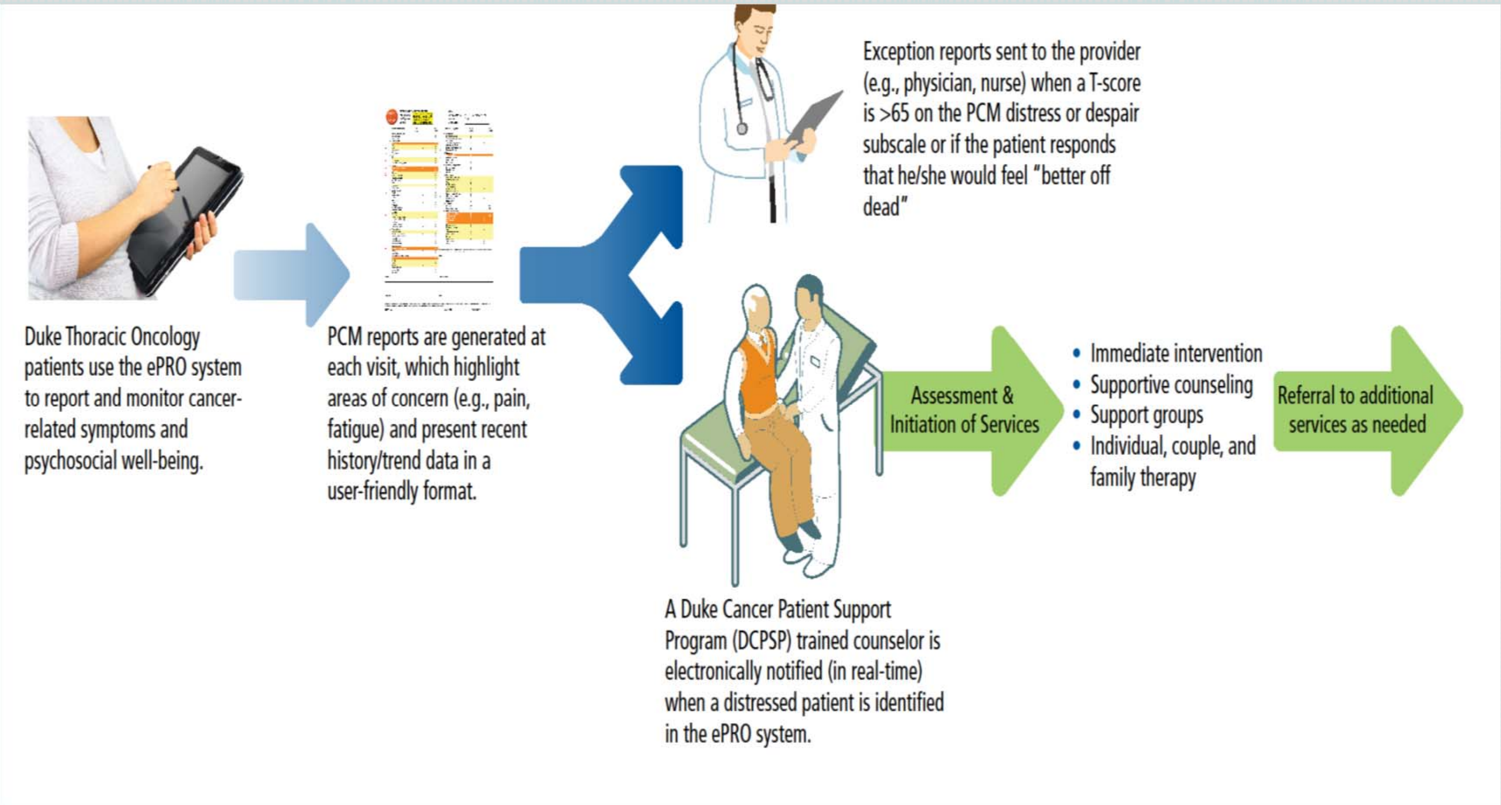
- Wellness and Emotional Care: Nutrition Myths & Facts
- Cancer Diagnosis and Treatment: Working and Living: Rachel
- Dealing with Symptoms and Side Effects: Losing Your Hair
- Research and Clinical Trials: We Are Commited to Research

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

Welcome, Elvis.

If you are not Elvis, please Quit CSN and log in as 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.

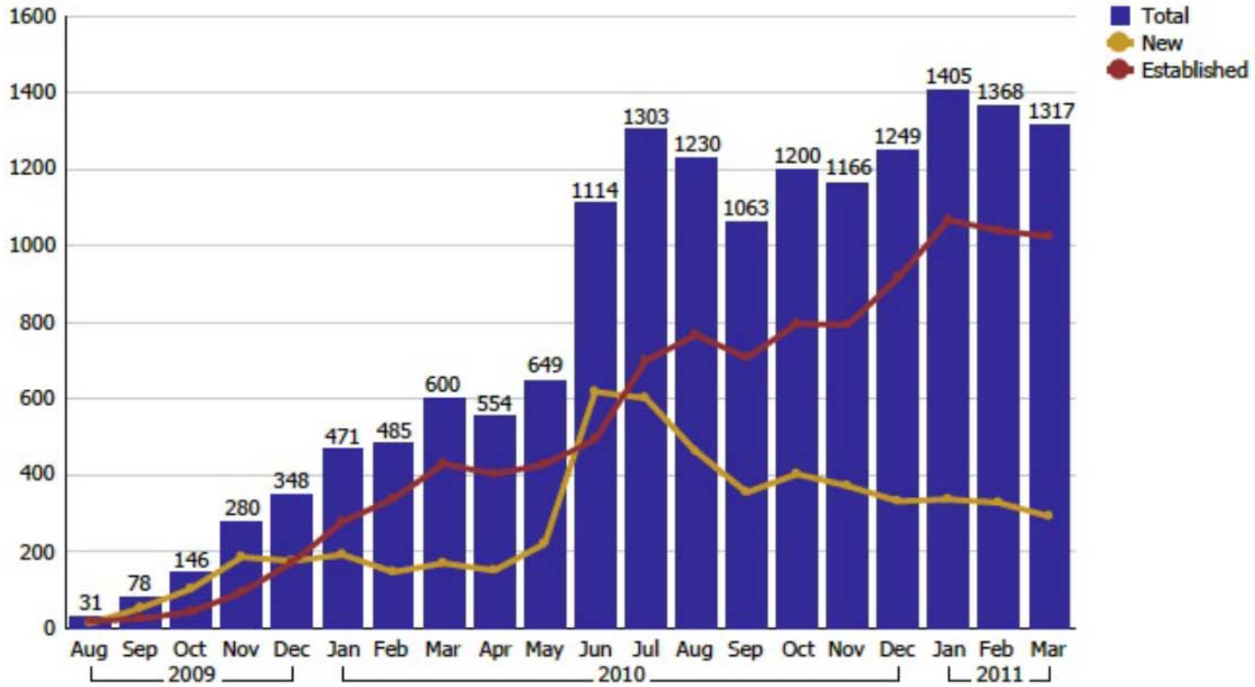
PCM reports are generated at each visit, which highlight areas of concern (e.g., pain, fatigue) and present recent history/trend data in a user-friendly format.

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"

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.

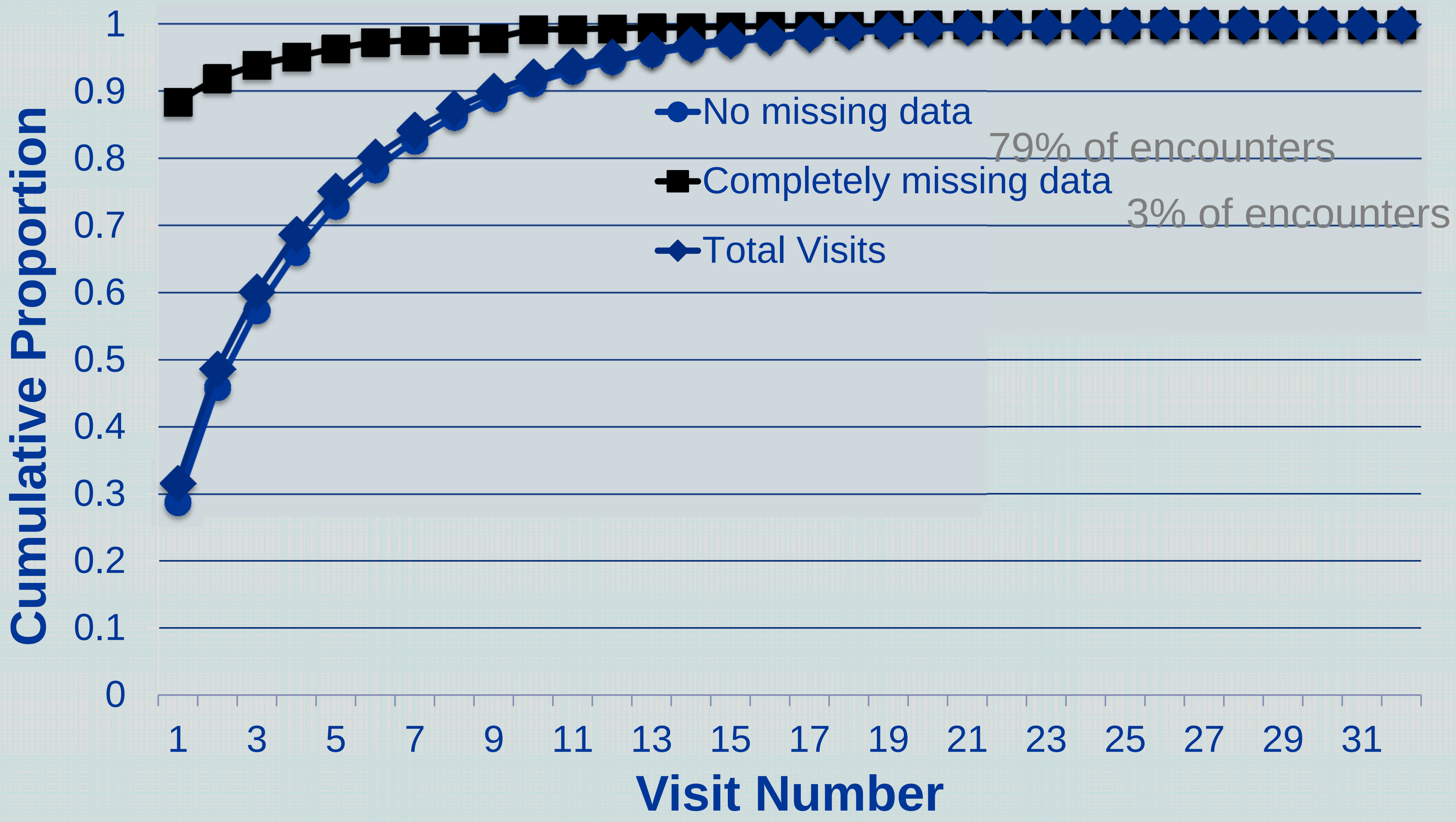
- Immediate intervention
- Supportive counseling
- Support groups
- Individual, couple, and family therapy

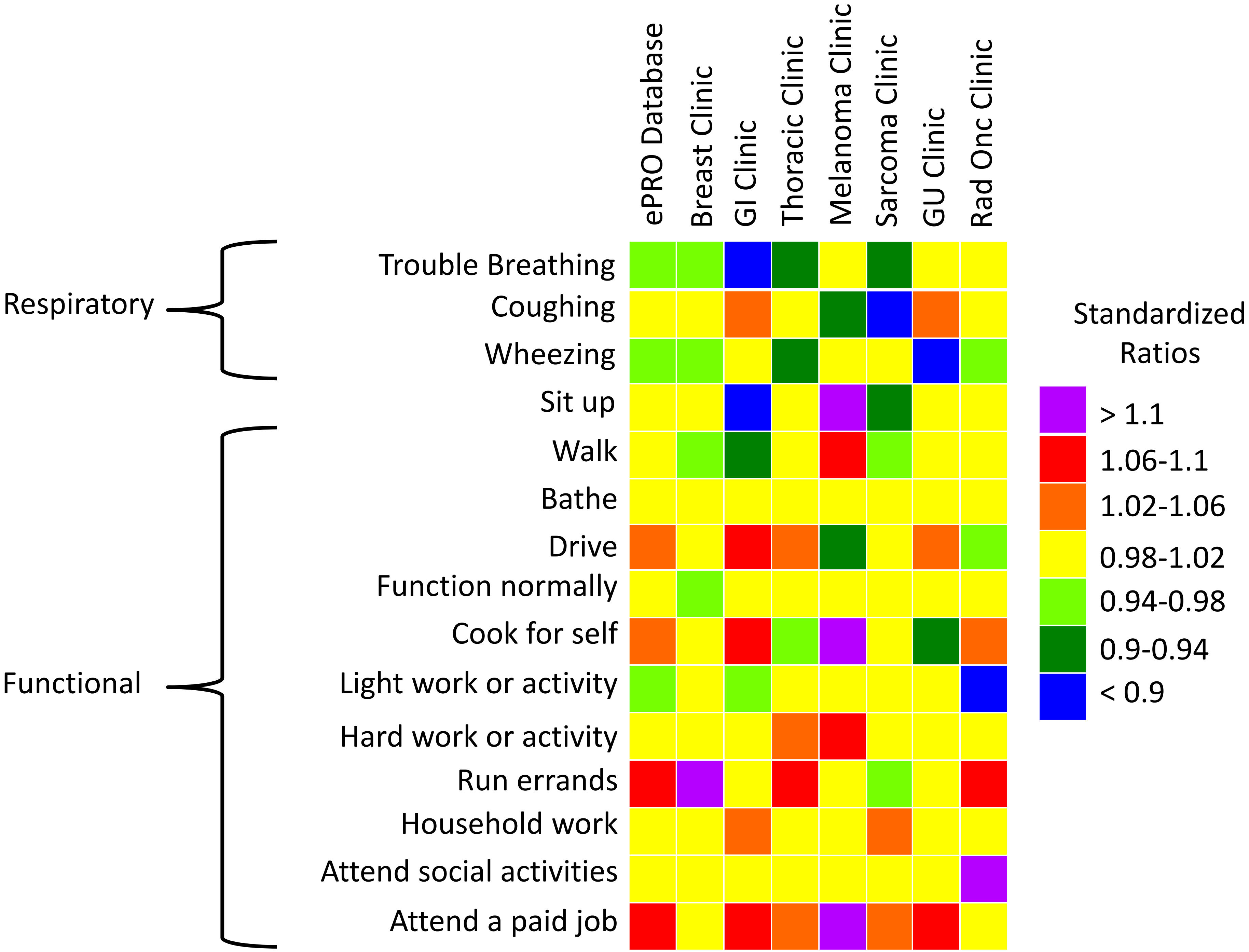
Number of (new and established) patients that have completed a PCM Survey



| | 2009 | | | | | 2010 | | | | | | | | | | | | 2011 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar |
| Total | 31 | 78 | 146 | 280 | 348 | 471 | 485 | 600 | 554 | 649 | 1114 | 1303 | 1230 | 1063 | 1200 | 1166 | 1249 | 1405 | 1368 | 1317 |
| New | 13 | 53 | 103 | 186 | 176 | 192 | 147 | 170 | 151 | 221 | 619 | 603 | 462 | 355 | 403 | 372 | 332 | 337 | 328 | 292 |
| Established | 18 | 25 | 43 | 94 | 172 | 279 | 338 | 430 | 403 | 428 | 495 | 700 | 768 | 708 | 797 | 794 | 917 | 1,068 | 1,040 | 1,025 |

# Missing Data: Encounter-level




ePRO Database
Breast Clinic
GI Clinic
Thoracic Clinic
Melanoma Clinic
Sarcoma Clinic
GU Clinic
Rad Onc Clinic
Respiratory
Trouble Breathing
Coughing
Wheezing
Sit up
Functional
Walk
Bathe
Drive
Function normally
Cook for self
Light work or activity
Hard work or activity
Run errands
Household work
Attend social activities
Attend a paid job
Standardized Ratios
> 1.1
1.06-1.1
1.02-1.06
0.98-1.02
0.94-0.98
0.9-0.94
< 0.9

# Research demonstrates…

*Vol. 37 No. 6 June 2009* *Journal of Pain and Symptom Management* 1027

***Original Article***

Feasibility and Acceptability to Patients of a Longitudinal System for Evaluating Cancer-Related Symptoms and Quality of Life: Pilot Study of an e/Tablet Data-Collection System in Academic Oncology

Amy P. Abernethy, MD, James E. Herndon, PhD, Jane L. Wheeler, MSPH, Jeannette M. Day, MS, Linda Hood, RN, MSN, Meenal Patwardhan, MD, Heather Shaw, MD, and Herbert Kim Lyerly, MD

*Division of Medical Oncology (A.P.A., J.L.W., L.H., H.S.) and Center for Clinical Health Policy Research (A.P.A., M.P.), Department of Medicine; Duke Comprehensive Cancer Center (A.P.A., H.S., H.K.L.); Department of Biostatistics (J.E.H., J.M.D.); and Department of Surgery (H.K.L.), Duke University Medical Center, Durham, North Carolina, USA*

❖ 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.

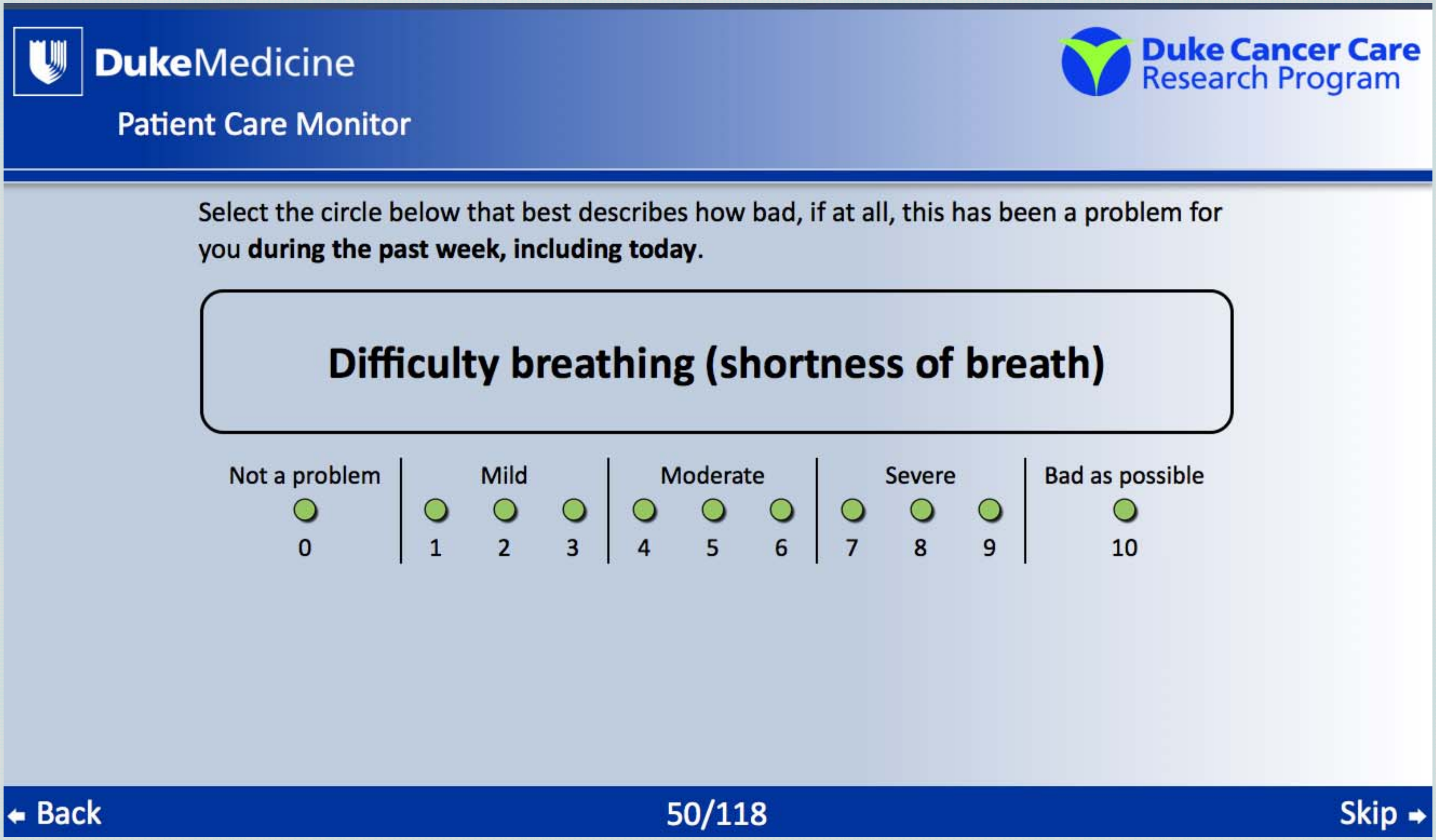
❖ ePRO system can be used to collect research-quality data using common, validated instruments (reliability & validity)

- Reliability, validity, and equivalence testing
- Appropriate for clinical trials

Improving Health Care Efficiency and Quality Using Tablet Personal Computers to Collect Research-Quality, Patient-Reported Data

*Amy P. Abernethy, James E. Herndon, Jane L. Wheeler, Meenal Patwardhan, Heather Shaw, H. Kim Lyerly, and Kevin Weinfurt*

# Understand the role of prototyping…



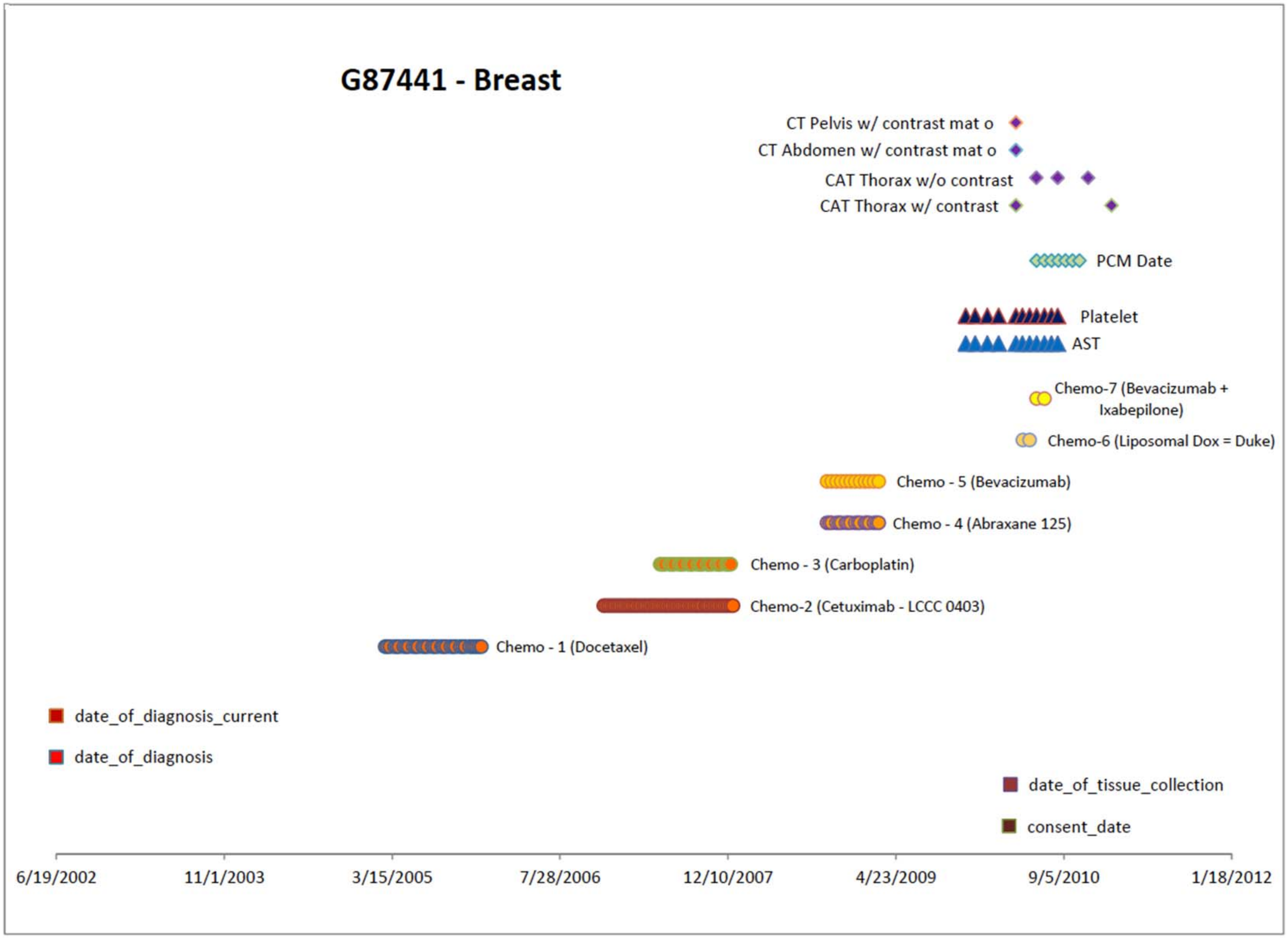
DukeMedicine
Patient Care Monitor
Duke Cancer Care
Research Program

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)**

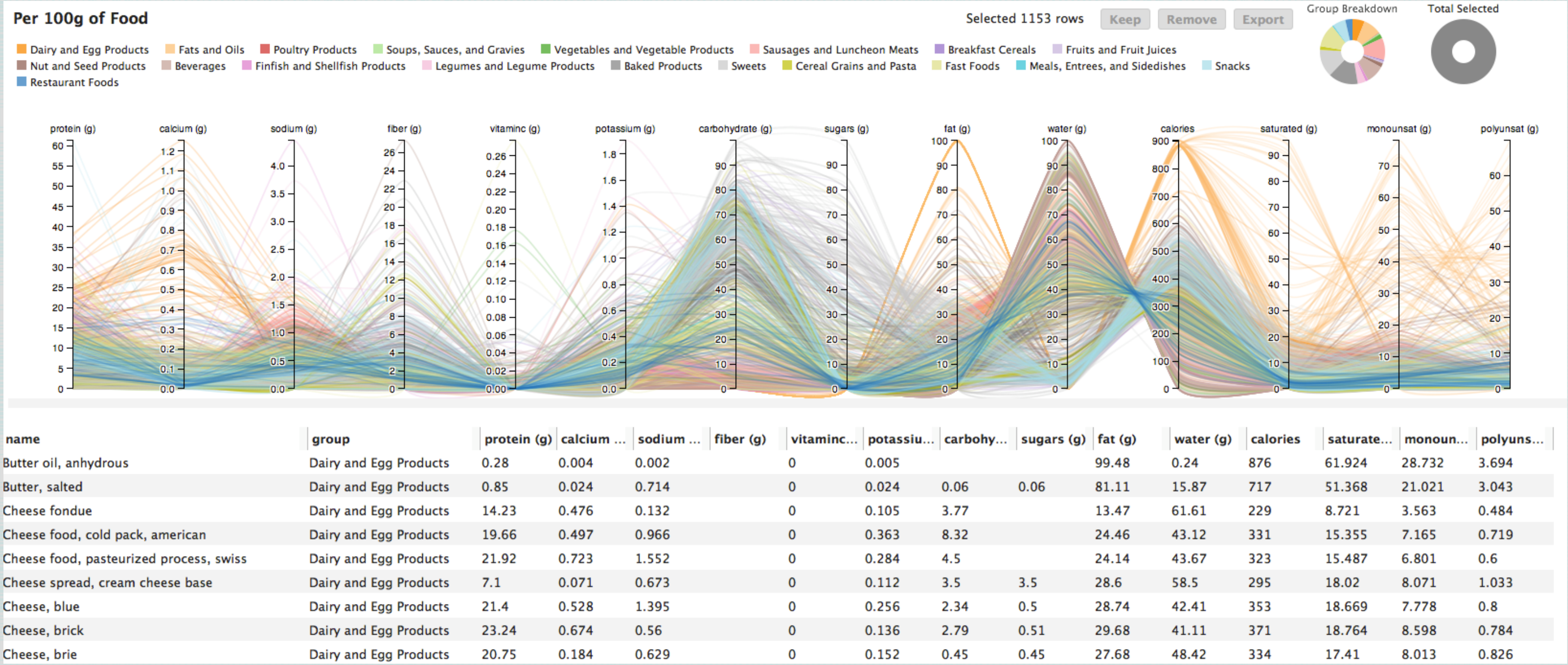
| Not a problem | Mild | | | Moderate | | | Severe | | | Bad as possible |
|---|---|---|---|---|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

← Back
50/118
Skip →



© 2009 Duke Cancer Care Research Program

# PRO Visualization

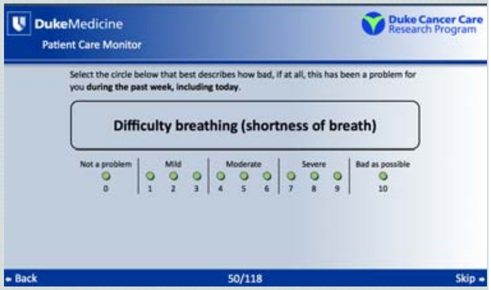

Per 100g of Food
Selected 1153 rows
Keep
Remove
Export
Group Breakdown
Total Selected
Dairy and Egg Products
Fats and Oils
Poultry Products
Soups, Sauces, and Gravies
Vegetables and Vegetable Products
Sausages and Luncheon Meats
Breakfast Cereals
Fruits and Fruit Juices
Nut and Seed Products
Beverages
Finfish and Shellfish Products
Legumes and Legume Products
Baked Products
Sweets
Cereal Grains and Pasta
Fast Foods
Meals, Entrees, and Sidedishes
Snacks
Restaurant Foods
protein (g)
calcium (g)
sodium (g)
fiber (g)
vitaminc (g)
potassium (g)
carbohydrate (g)
sugars (g)
fat (g)
water (g)
calories
saturated (g)
monounsat (g)
polyunsat (g)

| name | group | protein (g) | calcium ... | sodium ... | fiber (g) | vitaminc... | potassiu... | carbohy... | sugars (g) | fat (g) | water (g) | calories | saturate... | monoun... | polyuns... |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Butter oil, anhydrous | Dairy and Egg Products | 0.28 | 0.004 | 0.002 | | 0 | 0.005 | | | 99.48 | 0.24 | 876 | 61.924 | 28.732 | 3.694 |
| Butter, salted | Dairy and Egg Products | 0.85 | 0.024 | 0.714 | | 0 | 0.024 | 0.06 | 0.06 | 81.11 | 15.87 | 717 | 51.368 | 21.021 | 3.043 |
| Cheese fondue | Dairy and Egg Products | 14.23 | 0.476 | 0.132 | | 0 | 0.105 | 3.77 | | 13.47 | 61.61 | 229 | 8.721 | 3.563 | 0.484 |
| Cheese food, cold pack, american | Dairy and Egg Products | 19.66 | 0.497 | 0.966 | | 0 | 0.363 | 8.32 | | 24.46 | 43.12 | 331 | 15.355 | 7.165 | 0.719 |
| Cheese food, pasteurized process, swiss | Dairy and Egg Products | 21.92 | 0.723 | 1.552 | | 0 | 0.284 | 4.5 | | 24.14 | 43.67 | 323 | 15.487 | 6.801 | 0.6 |
| Cheese spread, cream cheese base | Dairy and Egg Products | 7.1 | 0.071 | 0.673 | | 0 | 0.112 | 3.5 | 3.5 | 28.6 | 58.5 | 295 | 18.02 | 8.071 | 1.033 |
| Cheese, blue | Dairy and Egg Products | 21.4 | 0.528 | 1.395 | | 0 | 0.256 | 2.34 | 0.5 | 28.74 | 42.41 | 353 | 18.669 | 7.778 | 0.8 |
| Cheese, brick | Dairy and Egg Products | 23.24 | 0.674 | 0.56 | | 0 | 0.136 | 2.79 | 0.51 | 29.68 | 41.11 | 371 | 18.764 | 8.598 | 0.784 |
| Cheese, brie | Dairy and Egg Products | 20.75 | 0.184 | 0.629 | | 0 | 0.152 | 0.45 | 0.45 | 27.68 | 48.42 | 334 | 17.41 | 8.013 | 0.826 |

© 2009 Duke Cancer Care Research Program

Software/Hardware

Instrument


DukeMedicine
Patient Care Monitor
Duke Cancer Care Research Program

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**.

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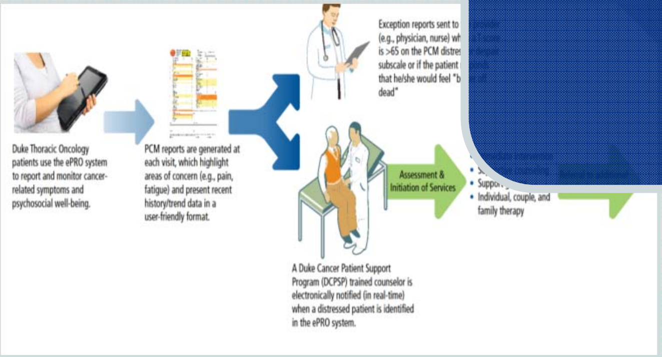
|---|---|---|---|---|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

◂ Back
50/118
Skip ▸

Process

Reporting/Analytics



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
(e.g., physician, nurse) wh
is >65 on the PCM distres
subscale or if the patient
that he/she would feel "b
dead"

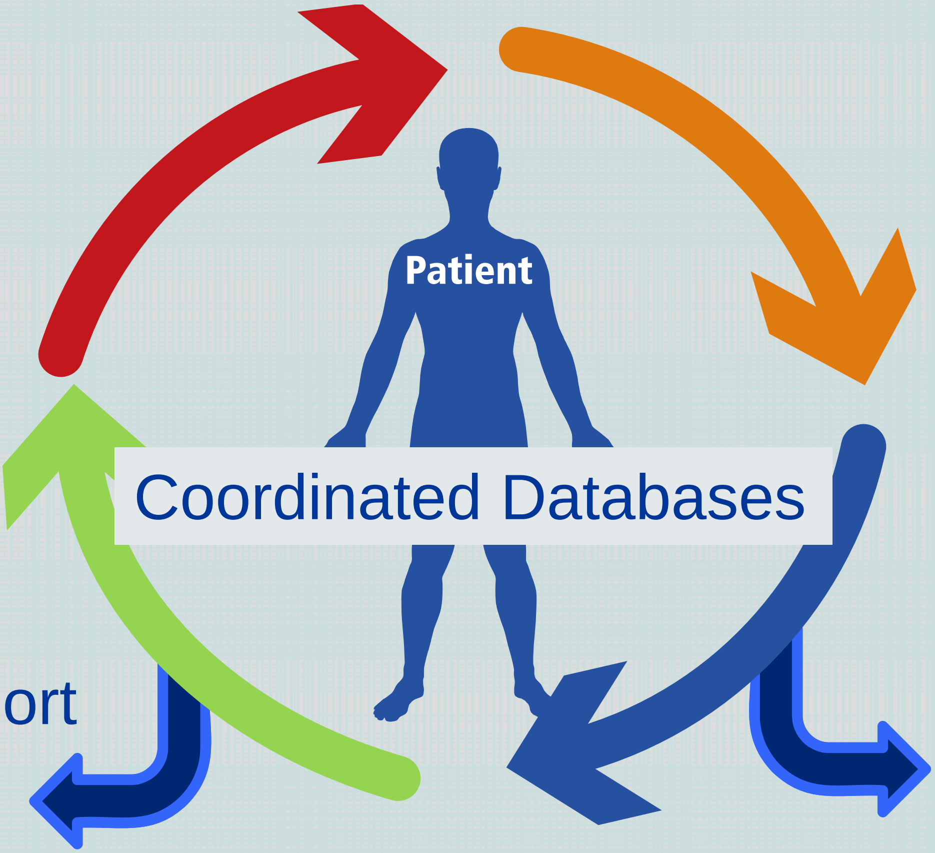
Assessment & Initiation of Services

- Suppo
- Individual, couple, and family therapy

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.

PATIENT CARE MONITOR REPORT

# Now that we have the data, there are a lot of ways we can use it…



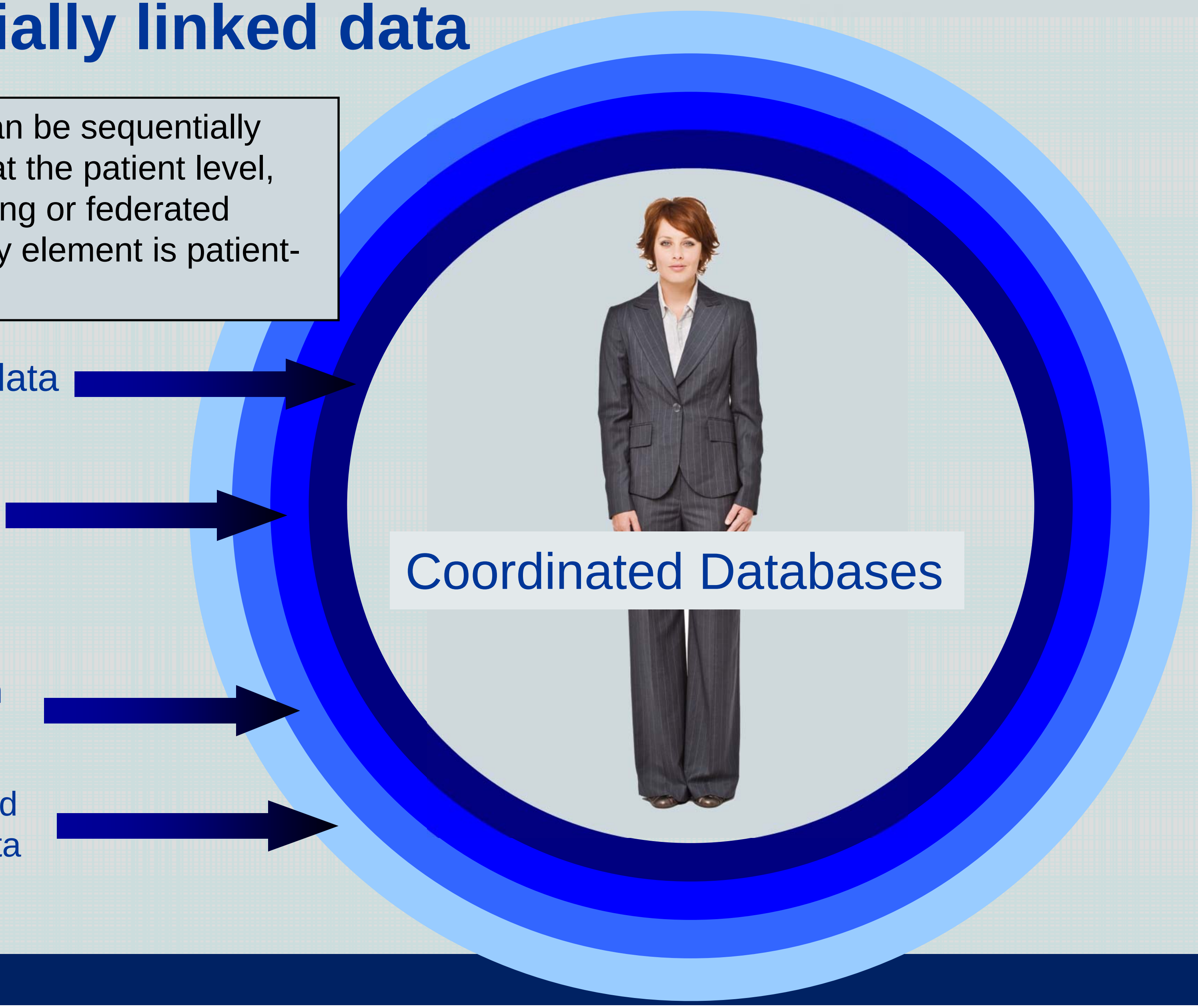
Coordinated Databases

Clinical
Decision Support
& Guidelines

Research Uses
- Quality reporting
- CER
- Hypothesis generation

# Sequentially linked data

New datasets can be sequentially added, starting at the patient level, using warehousing or federated models.  The key element is patient-level linkage.



ePRO data

Clinical and administrative data

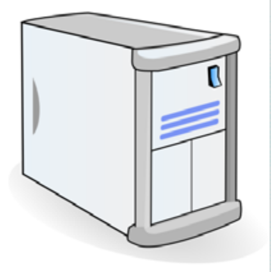
Clinical trials and research related data

Molecular and biological data

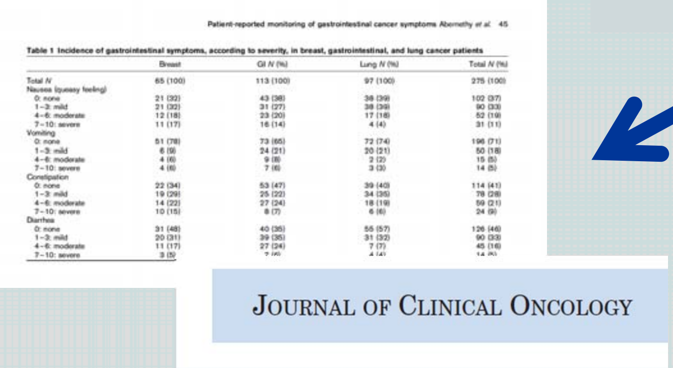
Coordinated Databases

# Describing the patient experience

Individual patient



Research reports



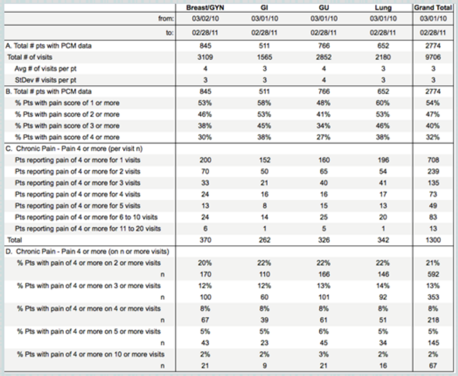
Patient-reported monitoring of gastrointestinal cancer symptoms Abernethy *et al.* 45

**Table 1** Incidence of gastrointestinal symptoms, according to severity, in breast, gastrointestinal, and lung cancer patients

| | Breast | GI *N* (%) | Lung *N* (%) | Total *N* (%) |
|---|---|---|---|---|
| Total *N* | 65 (100) | 113 (100) | 97 (100) | 275 (100) |
| Nausea (queasy feeling) | | | | |
| 0: none | 21 (32) | 43 (38) | 38 (39) | 102 (37) |
| 1–3: mild | 21 (32) | 31 (27) | 38 (39) | 90 (33) |
| 4–6: moderate | 12 (18) | 23 (20) | 17 (18) | 52 (19) |
| 7–10: severe | 11 (17) | 16 (14) | 4 (4) | 31 (11) |
| Vomiting | | | | |
| 0: none | 51 (78) | 73 (65) | 72 (74) | 196 (71) |
| 1–3: mild | 6 (9) | 24 (21) | 20 (21) | 50 (18) |
| 4–6: moderate | 4 (6) | 9 (8) | 2 (2) | 15 (5) |
| 7–10: severe | 4 (6) | 7 (6) | 3 (3) | 14 (5) |
| Constipation | | | | |
| 0: none | 22 (34) | 53 (47) | 39 (40) | 114 (41) |
| 1–3: mild | 19 (29) | 25 (22) | 34 (35) | 78 (28) |
| 4–6: moderate | 14 (22) | 27 (24) | 18 (19) | 59 (21) |
| 7–10: severe | 10 (15) | 8 (7) | 6 (6) | 24 (9) |
| Diarrhea | | | | |
| 0: none | 31 (48) | 40 (35) | 55 (57) | 126 (46) |
| 1–3: mild | 20 (31) | 39 (35) | 31 (32) | 90 (33) |
| 4–6: moderate | 11 (17) | 27 (24) | 7 (7) | 45 (16) |
| 7–10: severe | 3 (5) | 7 (6) | 4 (4) | 14 (5) |

JOURNAL OF CLINICAL ONCOLOGY

Clinical operations

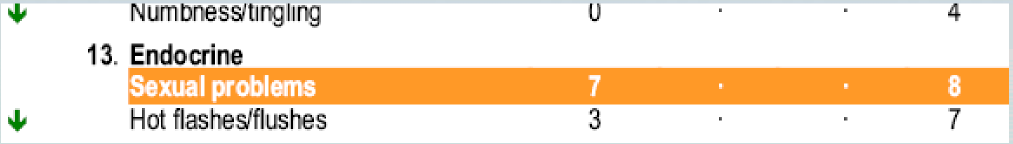


| | Breast/GYN | GI | GU | Lung | Grand Total |
|---|---|---|---|---|---|
| from: | 03/02/10 | 03/01/10 | 03/01/10 | 03/01/10 | 03/01/10 |
| to: | 02/28/11 | 02/28/11 | 02/28/11 | 02/28/11 | 02/28/11 |
| A. Total # pts with PCM data | 845 | 511 | 766 | 652 | 2774 |
| Total # of visits | 3109 | 1565 | 2852 | 2180 | 9706 |
| Avg # of visits per pt | 4 | 3 | 4 | 3 | 3 |
| StDev # visits per pt | 3 | 3 | 4 | 3 | 3 |
| B. Total # pts with PCM data | 845 | 511 | 766 | 652 | 2774 |
| % Pts with pain score of 1 or more | 53% | 58% | 48% | 60% | 54% |
| % Pts with pain score of 2 or more | 46% | 53% | 41% | 53% | 47% |
| % Pts with pain score of 3 or more | 38% | 45% | 34% | 46% | 40% |
| % Pts with pain score of 4 or more | 30% | 38% | 27% | 38% | 32% |
| C. Chronic Pain - Pain 4 or more (per visit n) | | | | | |
| Pts reporting pain of 4 or more for 1 visits | 200 | 152 | 160 | 196 | 708 |
| Pts reporting pain of 4 or more for 2 visits | 70 | 50 | 65 | 54 | 239 |
| Pts reporting pain of 4 or more for 3 visits | 33 | 21 | 40 | 41 | 135 |
| Pts reporting pain of 4 or more for 4 visits | 24 | 16 | 16 | 17 | 73 |
| Pts reporting pain of 4 or more for 5 visits | 13 | 8 | 15 | 13 | 49 |
| Pts reporting pain of 4 or more for 6 to 10 visits | 24 | 14 | 25 | 20 | 83 |
| Pts reporting pain of 4 or more for 11 to 20 visits | 6 | 1 | 5 | 1 | 13 |
| Total | 370 | 262 | 326 | 342 | 1300 |
| D. Chronic Pain - Pain 4 or more (on n or more visits) | | | | | |
| % Pts with pain of 4 or more on 2 or more visits | 20% | 22% | 22% | 22% | 21% |
| n | 170 | 110 | 166 | 146 | 592 |
| % Pts with pain of 4 or more on 3 or more visits | 12% | 12% | 13% | 14% | 13% |
| n | 100 | 60 | 101 | 92 | 353 |
| % Pts with pain of 4 or more on 4 or more visits | 8% | 8% | 8% | 8% | 8% |
| n | 67 | 39 | 61 | 51 | 218 |
| % Pts with pain of 4 or more on 5 or more visits | 5% | 5% | 6% | 5% | 5% |
| n | 43 | 23 | 45 | 34 | 145 |
| % Pts with pain of 4 or more on 10 or more visits | 2% | 2% | 3% | 2% | 2% |
| n | 21 | 9 | 21 | 16 | 67 |

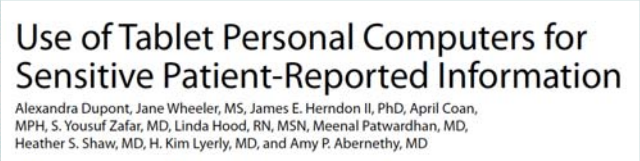
21% with pain $\geq$4/10 on $\geq$2 visits

# 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

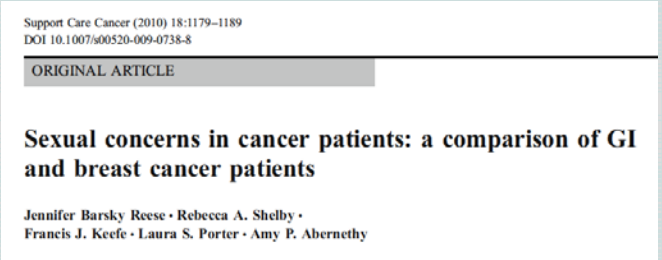


| | | | | | | |
|---|---|---|---|---|---|---|
| ↓ | | Numbness/tingling | 0 | · | · | 4 |
| | 13. | Endocrine | | | | |
| | | Sexual problems | 7 | · | · | 8 |
| ↓ | | Hot flashes/flushes | 3 | · | · | 7 |



**Use of Tablet Personal Computers for Sensitive Patient-Reported Information**

Alexandra Dupont, Jane Wheeler, MS, James E. Herndon II, PhD, April Coan, MPH, S. Yousuf Zafar, MD, Linda Hood, RN, MSN, Meenal Patwardhan, MD, Heather S. Shaw, MD, H. Kim Lyerly, MD, and Amy P. Abernethy, MD

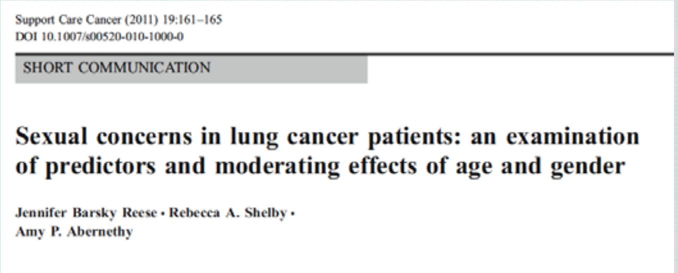


Support Care Cancer (2010) 18:1179–1189
DOI 10.1007/s00520-009-0738-8

ORIGINAL ARTICLE

**Sexual concerns in cancer patients: a comparison of GI and breast cancer patients**

Jennifer Barsky Reese · Rebecca A. Shelby · Francis J. Keefe · Laura S. Porter · Amy P. Abernethy

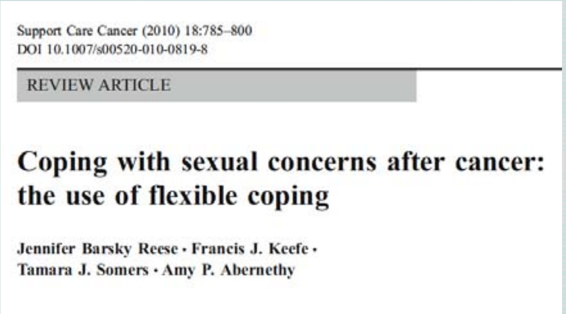


Support Care Cancer (2011) 19:161–165
DOI 10.1007/s00520-010-1000-0

SHORT COMMUNICATION

**Sexual concerns in lung cancer patients: an examination of predictors and moderating effects of age and gender**

Jennifer Barsky Reese · Rebecca A. Shelby · Amy P. Abernethy



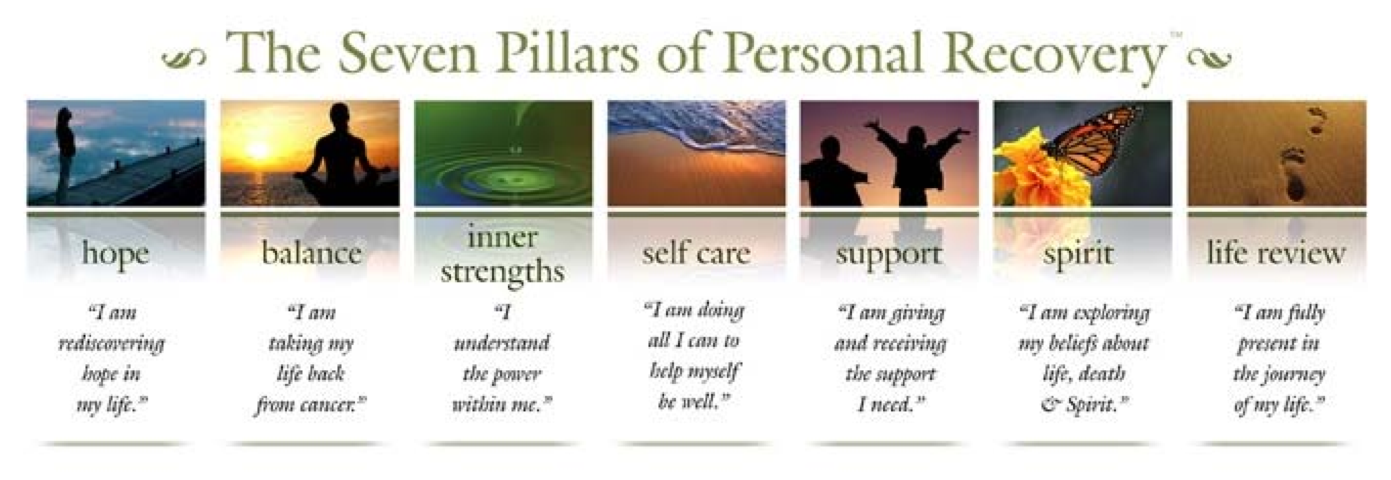
Support Care Cancer (2010) 18:785–800
DOI 10.1007/s00520-010-0819-8

REVIEW ARTICLE

**Coping with sexual concerns after cancer: the use of flexible coping**

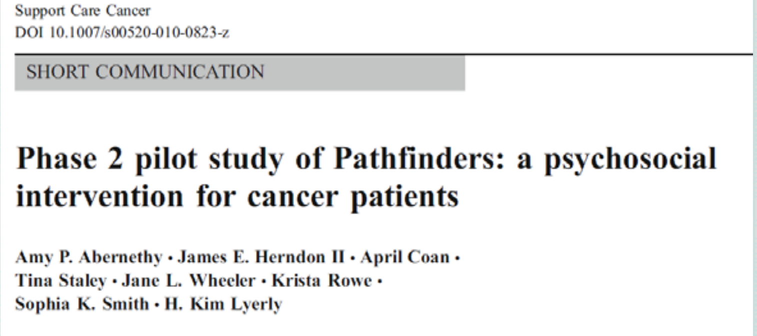
Jennifer Barsky Reese · Francis J. Keefe · Tamara J. Somers · Amy P. Abernethy

# Studying new interventions: Pathfinders



The Seven Pillars of Personal Recovery™

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

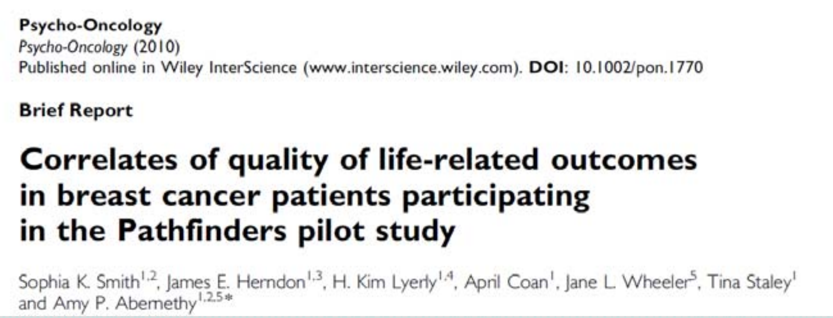


Support Care Cancer
DOI 10.1007/s00520-010-0823-z

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



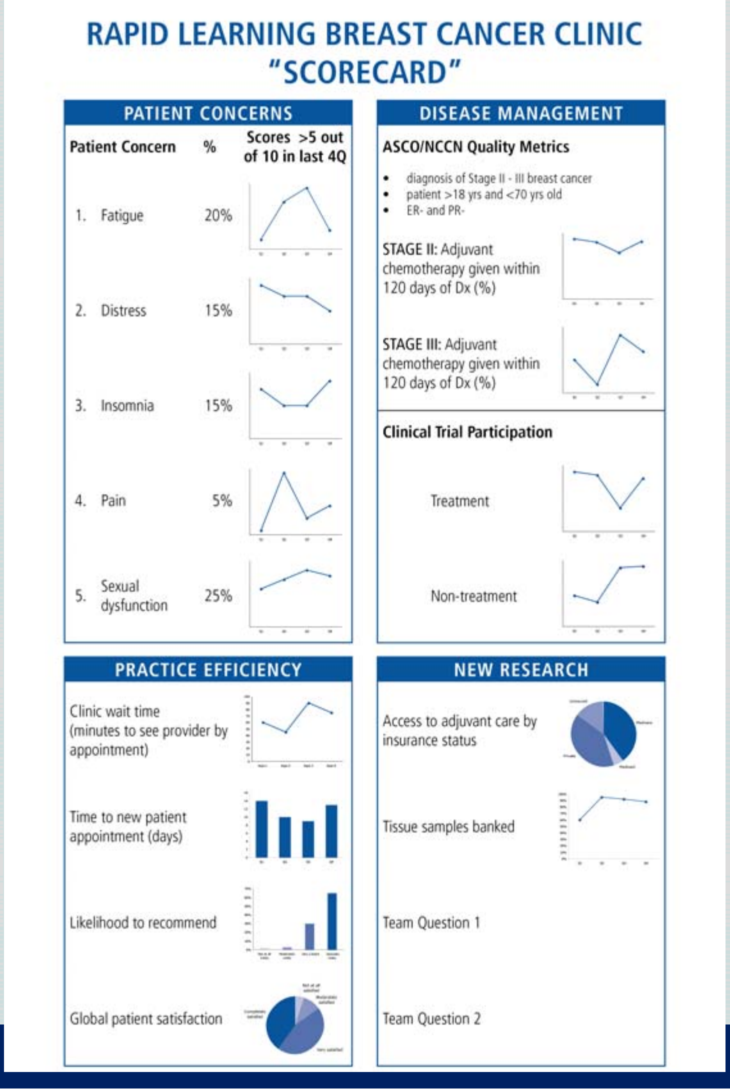
**Psycho-Oncology**
*Psycho-Oncology* (2010)
Published online in Wiley InterScience (www.interscience.wiley.com). **DOI**: 10.1002/pon.1770

**Brief Report**

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

Sophia K. Smith[1,2], James E. Herndon[1,3], H. Kim Lyerly[1,4], April Coan[1], Jane L. Wheeler[5], Tina Staley[1]
and Amy P. Abernethy[1,2,5*]

# Quality Monitoring: “Scorecards”



## RAPID LEARNING BREAST CANCER CLINIC “SCORECARD”

### PATIENT CONCERNS

| Patient Concern | % | Scores >5 out of 10 in last 4Q |
|---|---|---|
| 1. Fatigue | 20% | |
| 2. Distress | 15% | |
| 3. Insomnia | 15% | |
| 4. Pain | 5% | |
| 5. Sexual dysfunction | 25% | |

### DISEASE MANAGEMENT

**ASCO/NCCN Quality Metrics**

- diagnosis of Stage II - III breast cancer
- patient >18 yrs and <70 yrs old
- ER- and PR-

**STAGE II:** Adjuvant chemotherapy given within 120 days of Dx (%)

**STAGE III:** Adjuvant chemotherapy given within 120 days of Dx (%)

**Clinical Trial Participation**

Treatment

Non-treatment

### PRACTICE EFFICIENCY

Clinic wait time (minutes to see provider by appointment)

Time to new patient appointment (days)

Likelihood to recommend

Global patient satisfaction

### NEW RESEARCH

Access to adjuvant care by insurance status

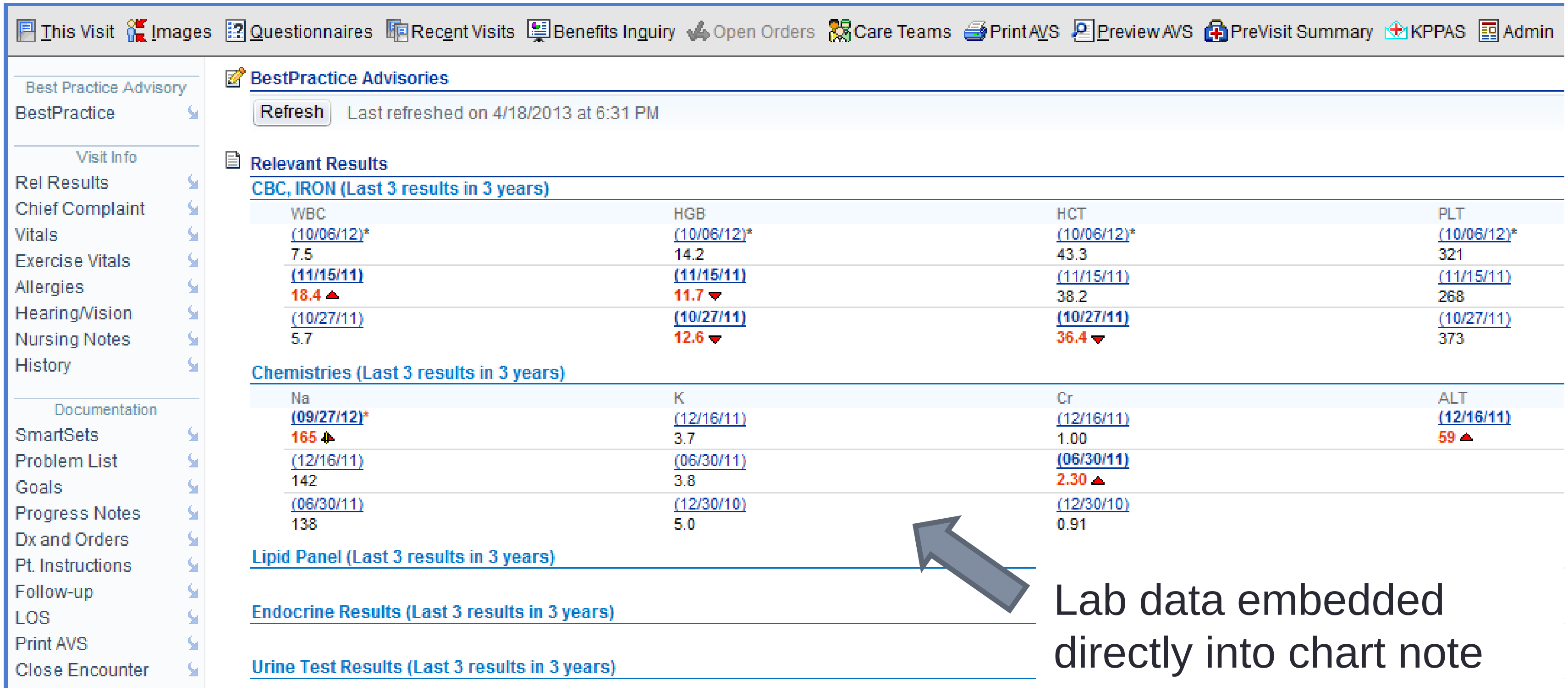
Tissue samples banked

Team Question 1

Team Question 2

# NOW – WHAT ABOUT EHR’S

PRO data entered in
separate charting area


This Visit
Images
Questionnaires
Recent Visits
Benefits Inquiry
Open Orders
Care Teams
Print AVS
Preview AVS
PreVisit Summary
KPPAS
Admin
Best Practice Advisory
BestPractice
Visit Info
Rel Results
Chief Complaint
Vitals
Exercise Vitals
Allergies
Hearing/Vision
Nursing Notes
History
Documentation
SmartSets
Problem List
Goals
Progress Notes
Dx and Orders
Pt. Instructions
Follow-up
LOS
Print AVS
Close Encounter
Refresh

**BestPractice Advisories**

Last refreshed on 4/18/2013 at 6:31 PM

**Relevant Results**

**CBC, IRON (Last 3 results in 3 years)**

| WBC | HGB | HCT | PLT |
|---|---|---|---|
| (10/06/12)*<br>7.5 | (10/06/12)*<br>14.2 | (10/06/12)*<br>43.3 | (10/06/12)*<br>321 |
| **(11/15/11)**<br>18.4 ▲ | **(11/15/11)**<br>11.7 ▼ | (11/15/11)<br>38.2 | (11/15/11)<br>268 |
| (10/27/11)<br>5.7 | **(10/27/11)**<br>12.6 ▼ | **(10/27/11)**<br>36.4 ▼ | (10/27/11)<br>373 |

**Chemistries (Last 3 results in 3 years)**

| Na | K | Cr | ALT |
|---|---|---|---|
| **(09/27/12)***<br>165 ▲ | (12/16/11)<br>3.7 | (12/16/11)<br>1.00 | **(12/16/11)**<br>59 ▲ |
| (12/16/11)<br>142 | (06/30/11)<br>3.8 | **(06/30/11)**<br>2.30 ▲ | |
| (06/30/11)<br>138 | (12/30/10)<br>5.0 | (12/30/10)<br>0.91 | |

**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)**

Lab data embedded
directly into chart note

Center for
Health
Research

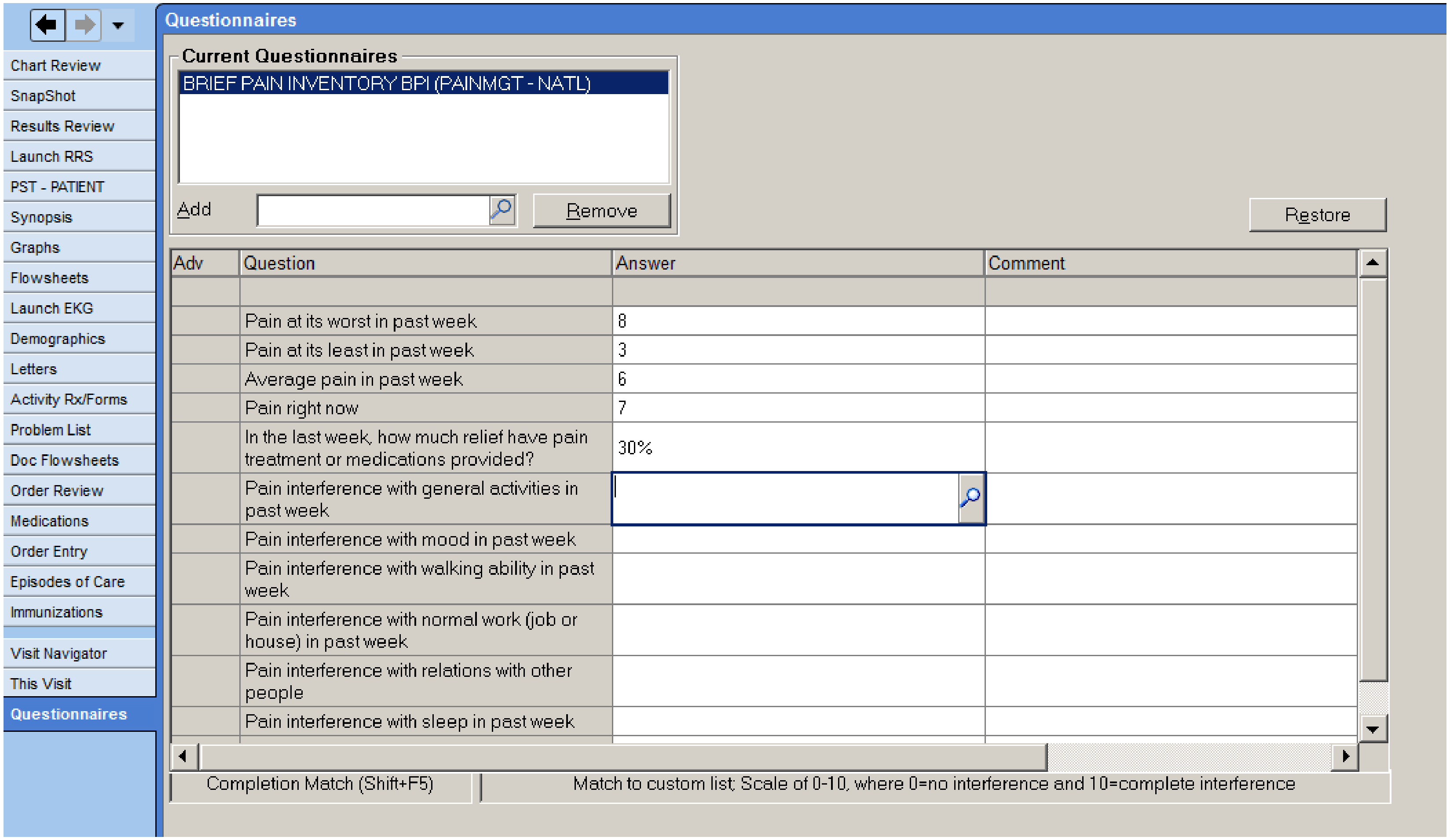


Chart Review
SnapShot
Results Review
Launch RRS
PST - PATIENT
Synopsis
Graphs
Flowsheets
Launch EKG
Demographics
Letters
Activity Rx/Forms
Problem List
Doc Flowsheets
Order Review
Medications
Order Entry
Episodes of Care
Immunizations
Visit Navigator
This Visit
Questionnaires
Questionnaires
Current Questionnaires
Add
Remove
Restore

BRIEF PAIN INVENTORY BPI (PAINMGT - NATL)

| Adv | Question | Answer | Comment |
|---|---|---|---|
| | | | |
| | Pain at its worst in past week | 8 | |
| | Pain at its least in past week | 3 | |
| | Average pain in past week | 6 | |
| | Pain right now | 7 | |
| | In the last week, how much relief have pain treatment or medications provided? | 30% | |
| | Pain interference with general activities in past week | | |
| | Pain interference with mood in past week | | |
| | Pain interference with walking ability in past week | | |
| | Pain interference with normal work (job or house) in past week | | |
| | Pain interference with relations with other people | | |
| | Pain interference with sleep in past week | | |

Completion Match (Shift+F5)

Match to custom list; Scale of 0-10, where 0=no interference and 10=complete interference

- Less than ideal interface and data entry

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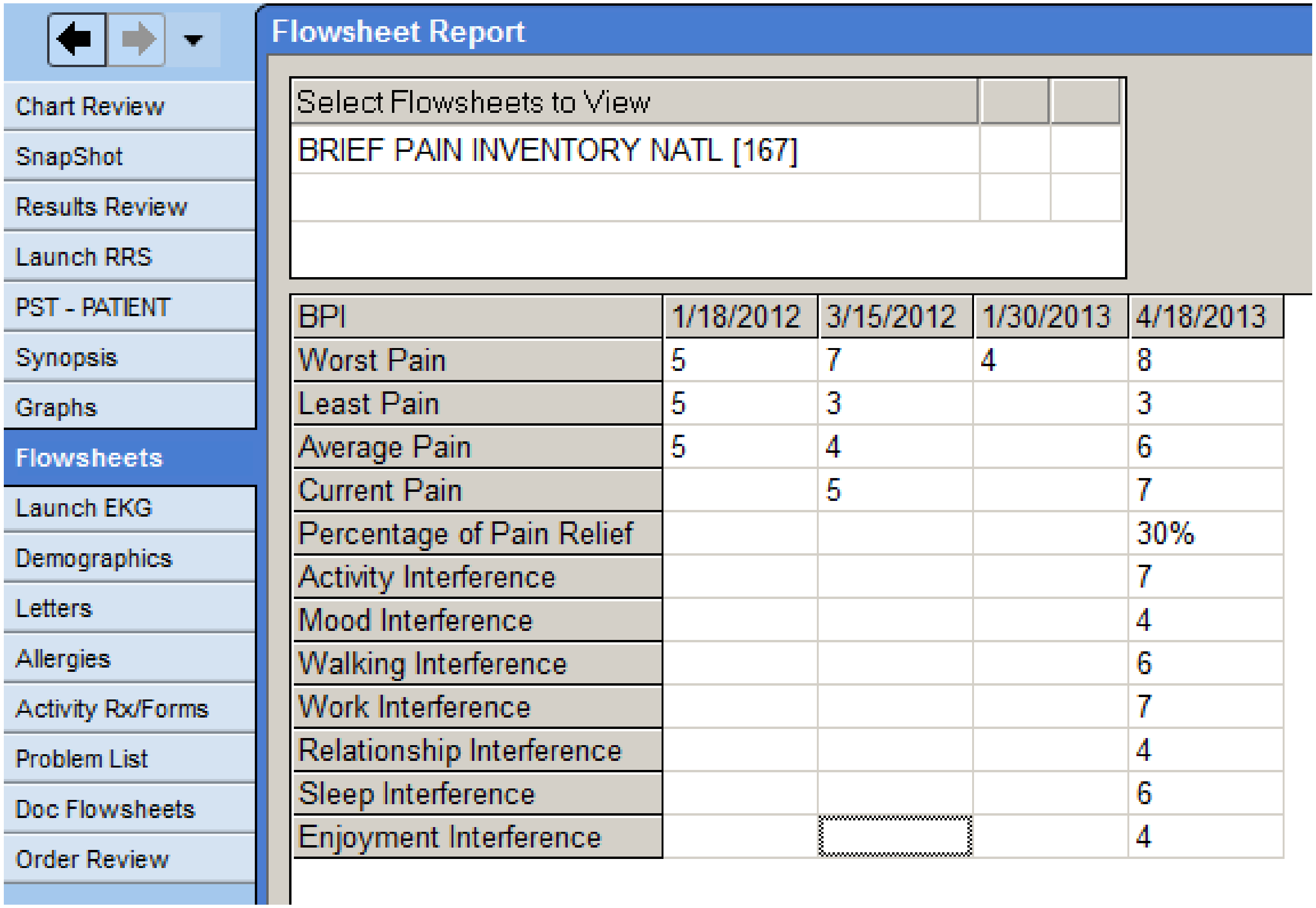
Chart Review
SnapShot
Results Review
Launch RRS
PST - PATIENT
Synopsis
Graphs
Flowsheets
Launch EKG
Demographics
Letters
Allergies
Activity Rx/Forms
Problem List
Doc Flowsheets
Order Review
Flowsheet Report
Select Flowsheets to View

BRIEF PAIN INVENTORY NATL [167]

| BPI | 1/18/2012 | 3/15/2012 | 1/30/2013 | 4/18/2013 |
|---|---|---|---|---|
| Worst Pain | 5 | 7 | 4 | 8 |
| Least Pain | 5 | 3 | | 3 |
| Average Pain | 5 | 4 | | 6 |
| Current Pain | | 5 | | 7 |
| Percentage of Pain Relief | | | | 30% |
| Activity Interference | | | | 7 |
| Mood Interference | | | | 4 |
| Walking Interference | | | | 6 |
| Work Interference | | | | 7 |
| Relationship Interference | | | | 4 |
| Sleep Interference | | | | 6 |
| Enjoyment Interference | | | | 4 |

- Variable collection of PROs

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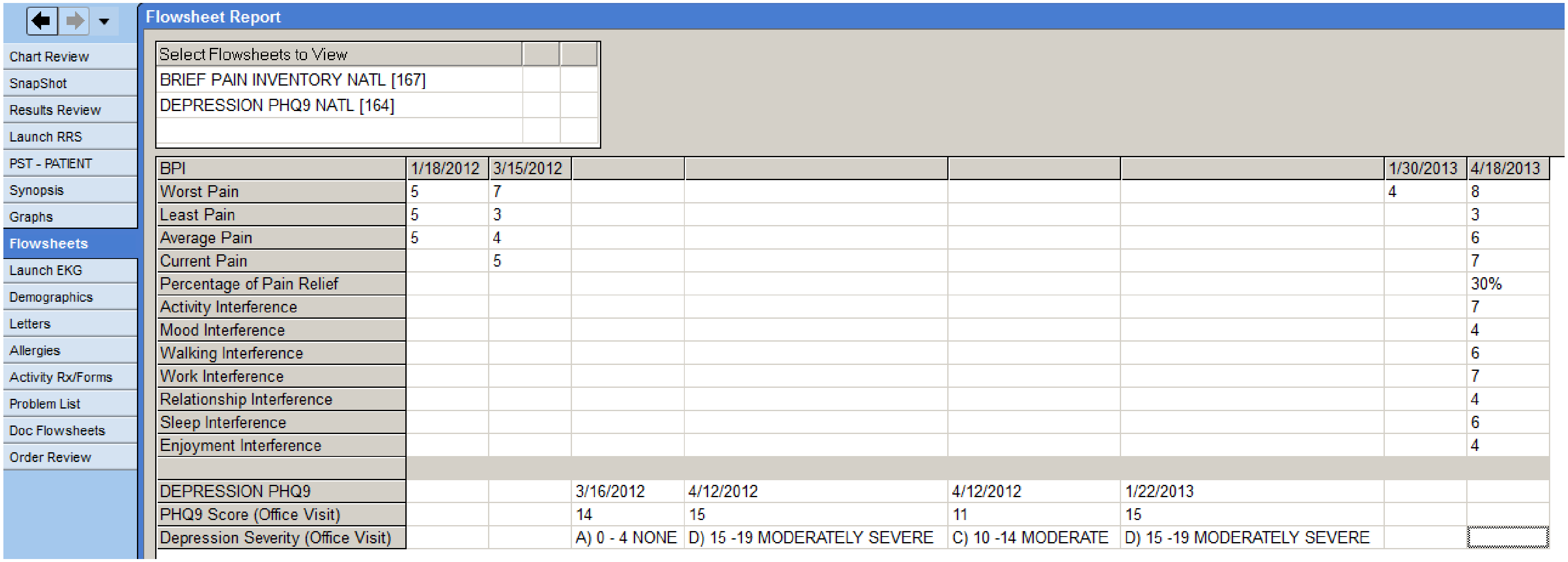
Flowsheet Report
Chart Review
SnapShot
Results Review
Launch RRS
PST - PATIENT
Synopsis
Graphs
Flowsheets
Launch EKG
Demographics
Letters
Allergies
Activity Rx/Forms
Problem List
Doc Flowsheets
Order Review

| Select Flowsheets to View |
|---|
| BRIEF PAIN INVENTORY NATL [167] |
| DEPRESSION PHQ9 NATL [164] |

| BPI | 1/18/2012 | 3/15/2012 | | | | | 1/30/2013 | 4/18/2013 |
|---|---|---|---|---|---|---|---|---|
| Worst Pain | 5 | 7 | | | | | 4 | 8 |
| Least Pain | 5 | 3 | | | | | | 3 |
| Average Pain | 5 | 4 | | | | | | 6 |
| Current Pain | | 5 | | | | | | 7 |
| Percentage of Pain Relief | | | | | | | | 30% |
| Activity Interference | | | | | | | | 7 |
| Mood Interference | | | | | | | | 4 |
| Walking Interference | | | | | | | | 6 |
| Work Interference | | | | | | | | 7 |
| Relationship Interference | | | | | | | | 4 |
| Sleep Interference | | | | | | | | 6 |
| Enjoyment Interference | | | | | | | | 4 |
| | | | | | | | | |
| DEPRESSION PHQ9 | | | 3/16/2012 | 4/12/2012 | 4/12/2012 | 1/22/2013 | | |
| PHQ9 Score (Office Visit) | | | 14 | 15 | 11 | 15 | | |
| Depression Severity (Office Visit) | | | A) 0 - 4 NONE | D) 15 -19 MODERATELY SEVERE | C) 10 -14 MODERATE | D) 15 -19 MODERATELY SEVERE | | |

- Less than ideal display when viewing multiple PROs

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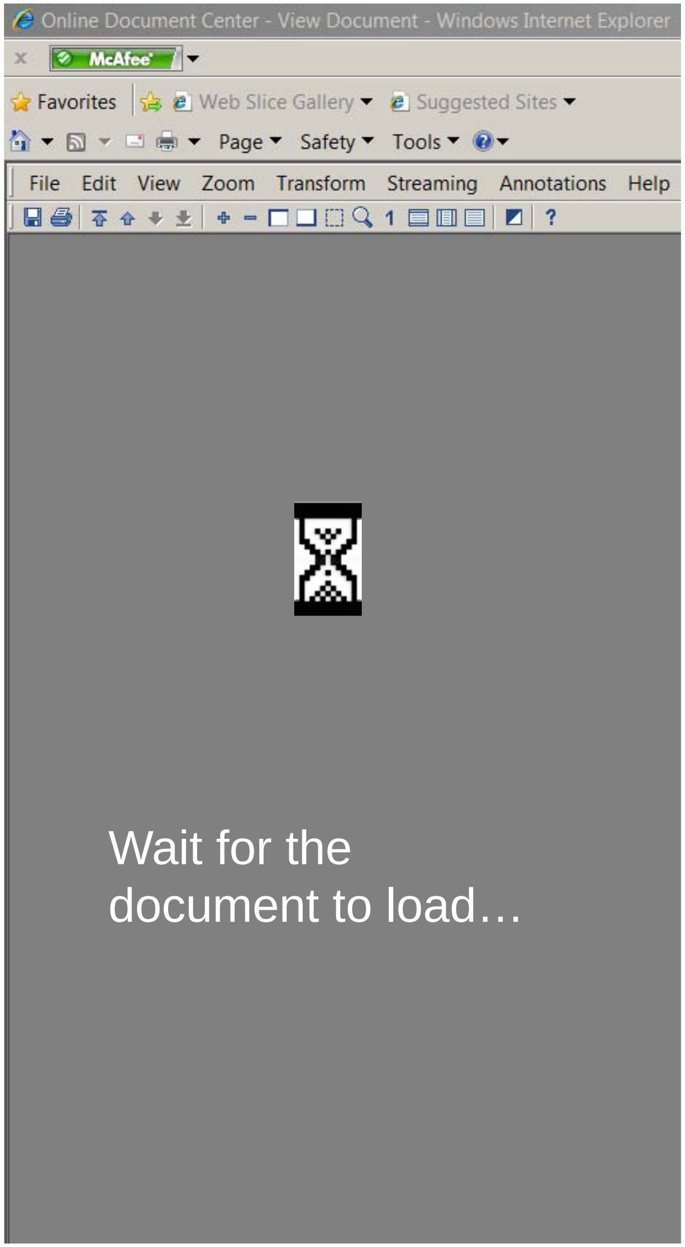
Online Document Center - View Document - Windows Internet Explorer
McAfee
Favorites
Web Slice Gallery
Suggested Sites
Page
Safety
Tools
File
Edit
View
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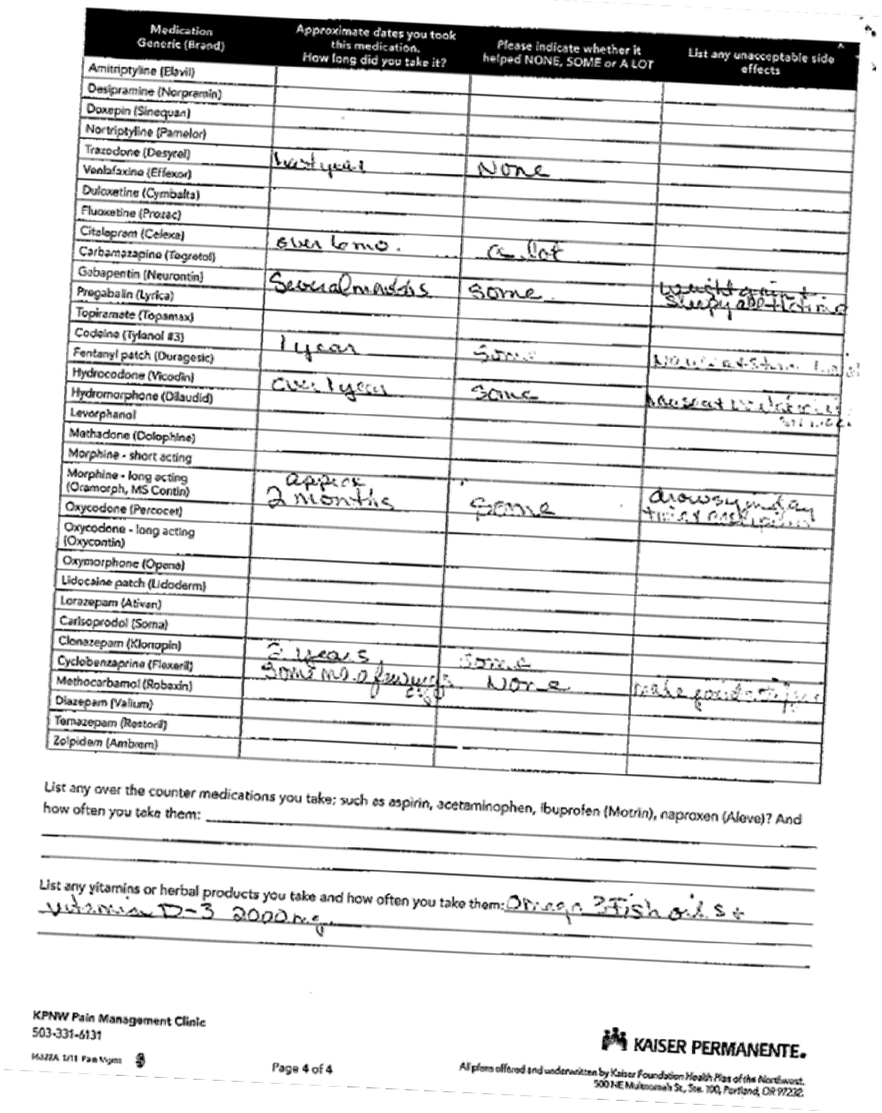
Transform
Streaming
Annotations
Help

Wait for the document to load…

Select each page individually…



| Medication Generic (Brand) | Approximate dates you took this medication. How long did you take it? | Please indicate whether it helped NONE, SOME or A LOT | List any unacceptable side effects |
|---|---|---|---|
| Amitriptyline (Elavil) | | | |
| Desipramine (Norpramin) | | | |
| Doxepin (Sinequan) | | | |
| Nortriptyline (Pamelor) | | | |
| Trazodone (Desyrel) | last year | None | |
| Venlafaxine (Effexor) | | | |
| Duloxetine (Cymbalta) | | | |
| Fluoxetine (Prozac) | | | |
| Citalopram (Celexa) | over 6 mo. | a lot | |
| Carbamazepine (Tegretol) | | | |
| Gabapentin (Neurontin) | Several months | some | weight gain + sleepy all the time |
| Pregabalin (Lyrica) | | | |
| Topiramate (Topamax) | | | |
| Codeine (Tylenol #3) | 1 year | Some | [illegible] |
| Fentanyl patch (Duragesic) | | | |
| Hydrocodone (Vicodin) | over 1 year | Some | nausea [illegible] |
| Hydromorphone (Dilaudid) | | | |
| Levorphanol | | | |
| Methadone (Dolophine) | | | |
| Morphine - short acting | | | |
| Morphine - long acting (Oramorph, MS Contin) | approx 2 months | Some | drowsy [illegible] |
| Oxycodone (Percocet) | | | |
| Oxycodone - long acting (Oxycontin) | | | |
| Oxymorphone (Opana) | | | |
| Lidocaine patch (Lidoderm) | | | |
| Lorazepam (Ativan) | | | |
| Carisoprodol (Soma) | | | |
| Clonazepam (Klonopin) | | | |
| Cyclobenzaprine (Flexeril) | 2 years | Some | |
| Methocarbamol (Robaxin) | Some mo. a few wks ago | None | [illegible] |
| Diazepam (Valium) | | | |
| Temazepam (Restoril) | | | |
| Zolpidem (Ambien) | | | |

List any over the counter medications you take; such as aspirin, acetaminophen, ibuprofen (Motrin), naproxen (Aleve)? And how often you take them: ____

List any vitamins or herbal products you take and how often you take them: Omega 3 Fish oils + vitamin D-3 2000mg

KPNW Pain Management Clinic
503-331-6131

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KAISER PERMANENTE.

All plans offered and underwritten by Kaiser Foundation Health Plan of the Northwest. 500 NE Multnomah St., Ste. 100, Portland, OR 97232.

Highly variable quality…

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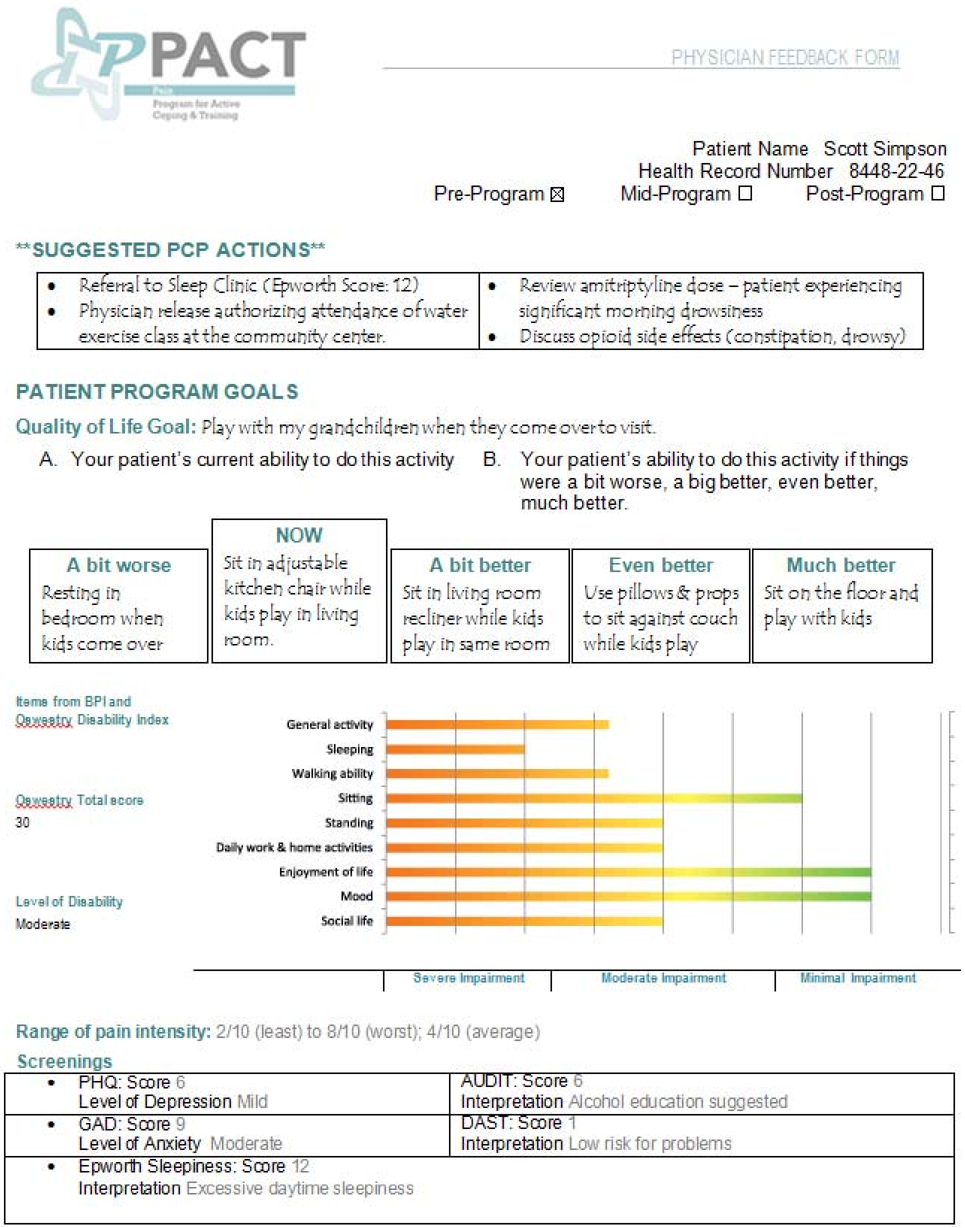
# EHR Attached PPACT Provider Feedback Form



PPACT
Pain
Program for Active Coping & Training

PHYSICIAN FEEDBACK FORM

Patient Name Scott Simpson
Health Record Number 8448-22-46
Pre-Program ☒ Mid-Program ☐ Post-Program ☐

**SUGGESTED PCP ACTIONS**

| | |
|---|---|
| • Referral to Sleep Clinic (Epworth Score: 12)<br>• Physician release authorizing attendance of water exercise class at the community center. | • Review amitriptyline dose – patient experiencing significant morning drowsiness<br>• Discuss opioid side effects (constipation, drowsy) |

**PATIENT PROGRAM GOALS**

**Quality of Life Goal:** Play with my grandchildren when they come over to visit.

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 big better, even better, much better.

| A bit worse | NOW | A bit better | Even better | Much better |
|---|---|---|---|---|
| Resting in bedroom when kids come over | Sit in adjustable kitchen chair while kids play in living room. | Sit in living room recliner while kids play in same room | Use pillows & props to sit against couch while kids play | Sit on the floor and play with kids |

Items from BPI and Oswestry Disability Index

Oswestry Total score
30

Level of Disability
Moderate

General activity
Sleeping
Walking ability
Sitting
Standing
Daily work & home activities
Enjoyment of life
Mood
Social life
Severe Impairment
Moderate Impairment
Minimal Impairment

**Range of pain intensity:** 2/10 (least) to 8/10 (worst); 4/10 (average)

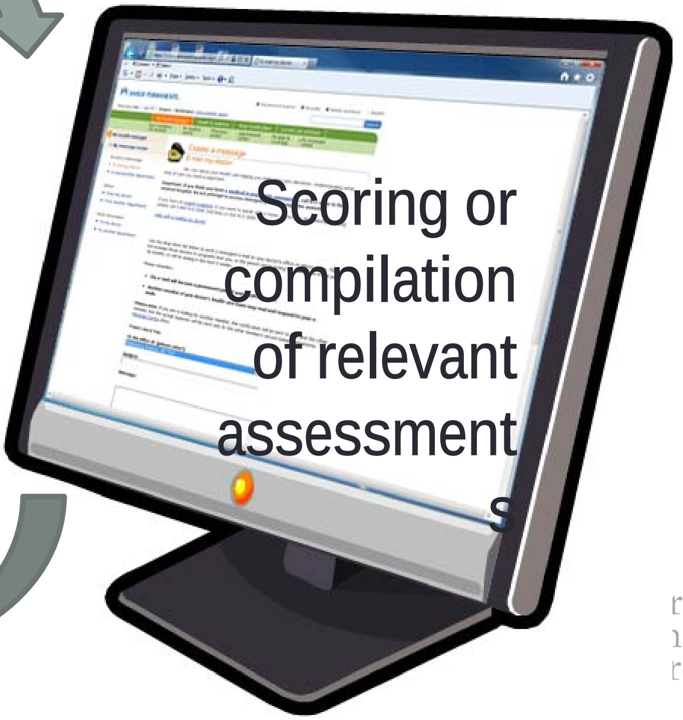
**Screenings**

| | |
|---|---|
| • PHQ: Score 6<br>Level of Depression Mild | AUDIT: Score 6<br>Interpretation Alcohol education suggested |
| • GAD: Score 9<br>Level of Anxiety Moderate | DAST: Score 1<br>Interpretation Low risk for problems |
| • Epworth Sleepiness: Score 12<br>Interpretation Excessive daytime sleepiness | |

Kaiser Permanente

Online or paper collection

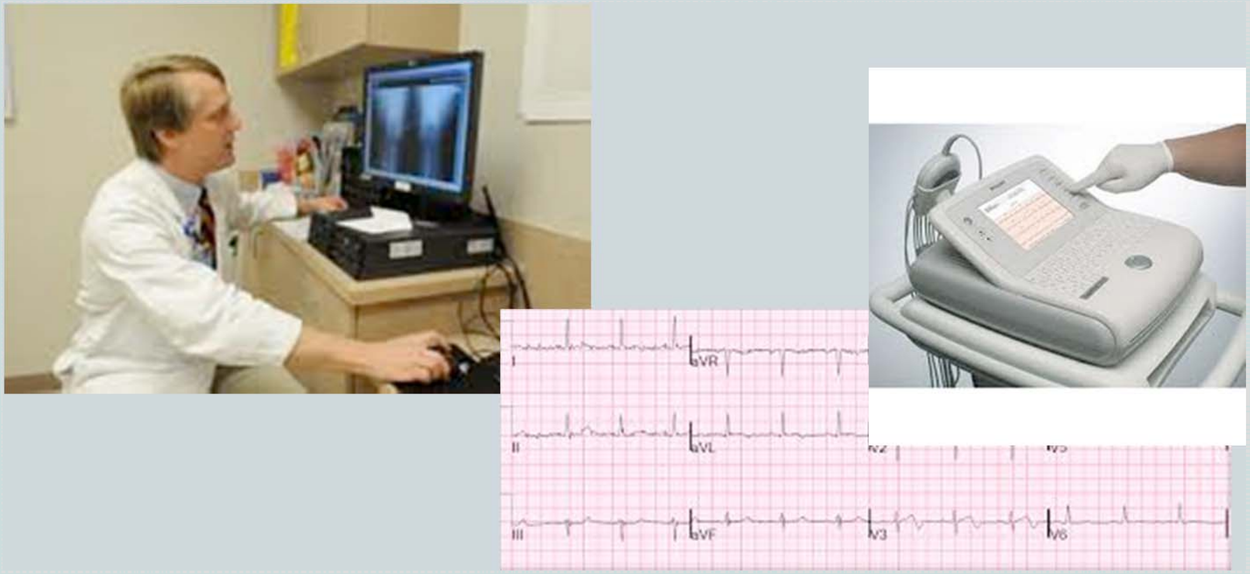
Outside vendor

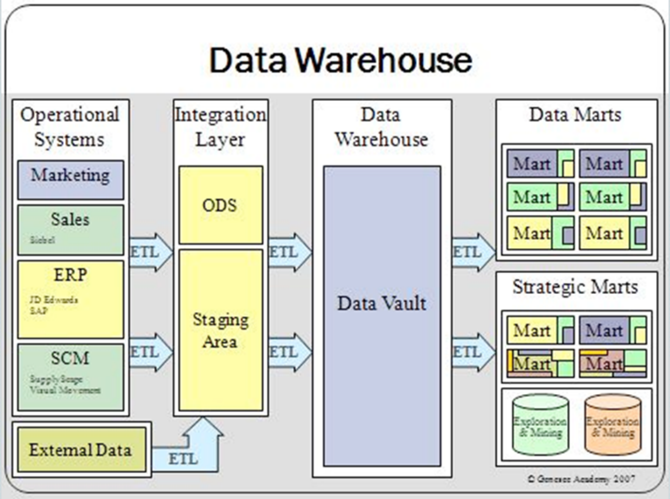


Scoring or compilation of relevant assessments

EMR Provider Summary Report

PATIENT PROGRAM GOALS


I
aVR
II
aVL
V2
V5
III
aVF
V3
V6


Data Warehouse
Operational Systems
Marketing
Sales
Siebel
ERP
JD Edwards
SAP
SCM
SupplyScape
Visual Movement
External Data
ETL
Integration Layer
ODS
Staging Area
ETL
Data Warehouse
Data Vault
ETL
Data Marts
Mart
Strategic Marts
Mart
Exploration & Mining
Exploration & Mining
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# 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

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# 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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Director, Duke Cancer Care Research Program
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Morris Cancer Clinic