

Patient Reported Outcomes Data in Action – *real time information for clinical care and research*

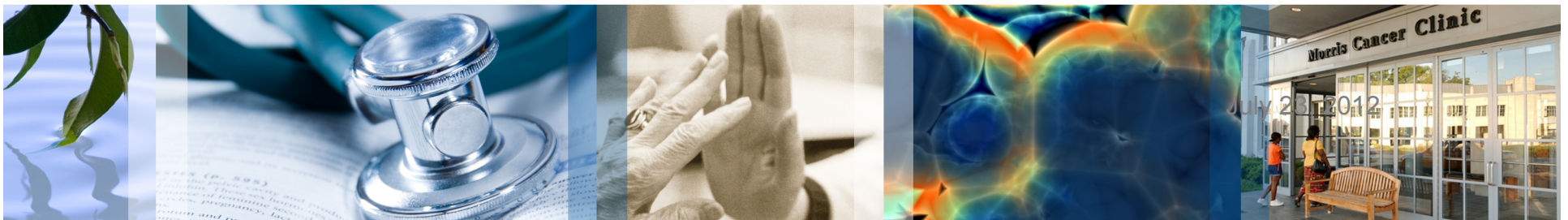
Amy Abernethy, MD

Director, Center for Learning Health Care, Duke Clinical Research Institute

Director, Duke Cancer Care Research Program, Duke Cancer Institute

Duke University Medical Center, Durham, North Carolina, USA

March 2013



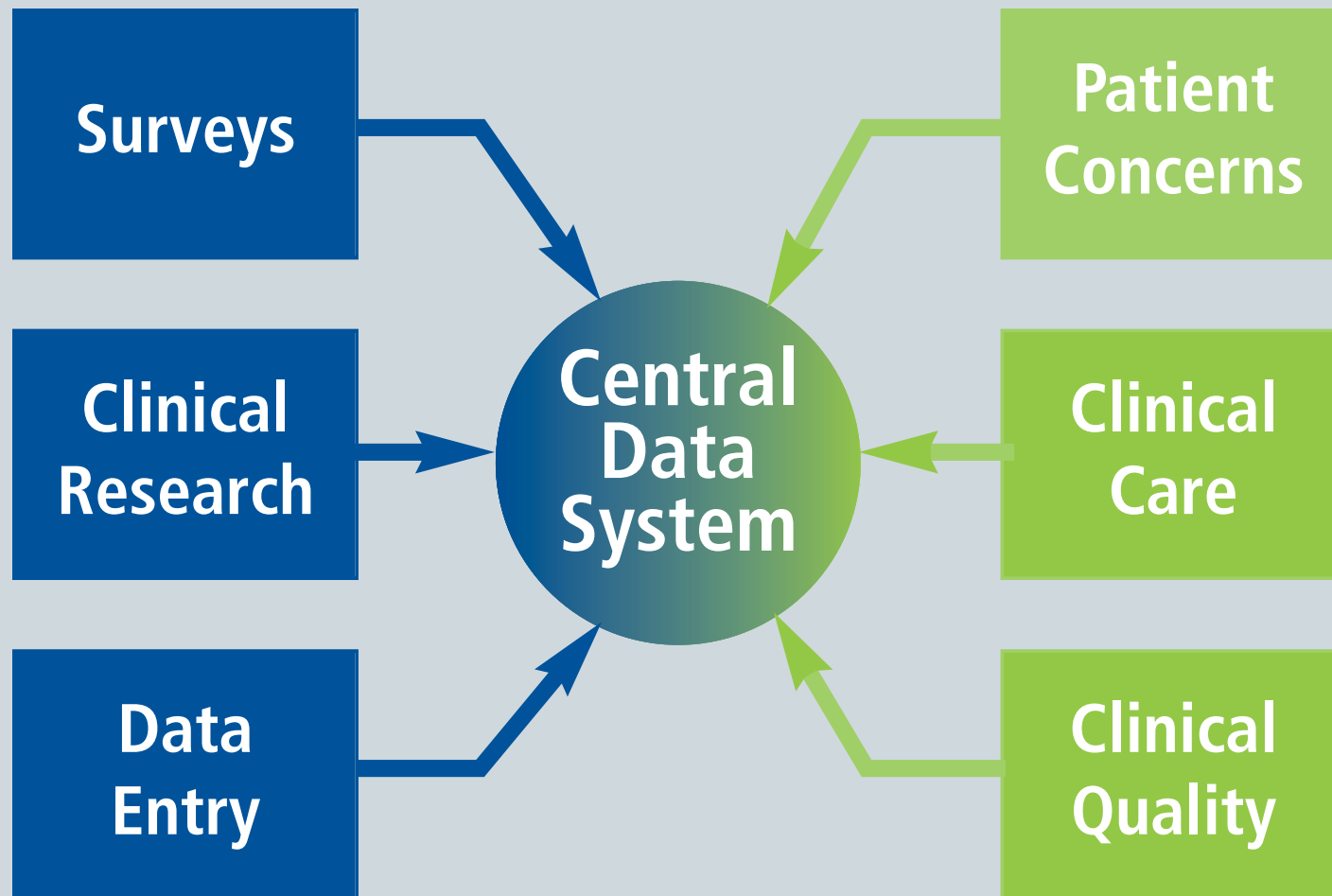
Abernethy Funding & Disclosures

- ❖ 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
- ❖ HRQL
- ❖ Health state (e.g., towards utilities/ QALYs)
- ❖ Medication use/compliance
- ❖ Satisfaction
- ❖ “Value” of treatment

The original story...



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 bus?

- 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 Results

Patient Name: [Redacted]
DOB/Age Sex: [Redacted]
Survey Date/Time: Apr 28 2008 (Wed) 9:17AM
Version: English
Device Date:

Review of Systems	Current	Previous	Final
1. Allergic/Immunologic	0	0	0
2. Cardiovascular	0	0	0
3. Endocrine/Metabolic	0	0	0
4. Eye	0	0	0
5. Gastrointestinal	0	0	0
6. Hematologic	0	0	0
7. Infectious	0	0	0
8. Integumentary	0	0	0
9. Musculoskeletal	0	0	0
10. Neurologic	0	0	0
11. Psychiatric	0	0	0
12. Respiratory	0	0	0
13. Skin	0	0	0
14. Urinary	0	0	0
15. Vascular	0	0	0
16. Other	0	0	0
17. Total	0	0	0

History

Signature: _____ Date: _____

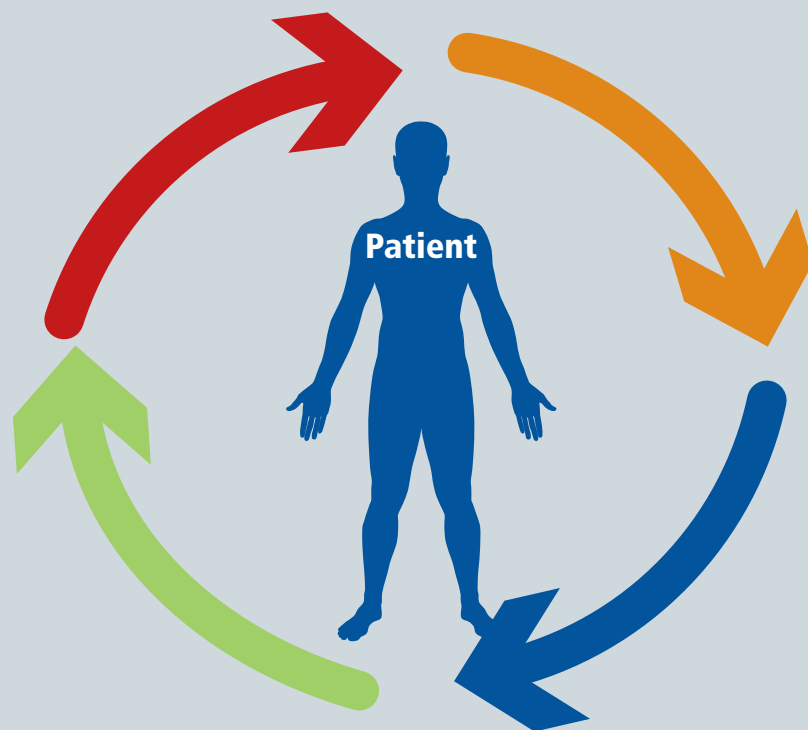
A large, bright yellow starburst graphic with many sharp points, centered on the slide. It has a slight drop shadow, giving it a 3D appearance.

BEWARE!!!

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

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)

mHealth approach to efficient PRO collection



VISION

Patient
reports
standardized
data

Clinical uses

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

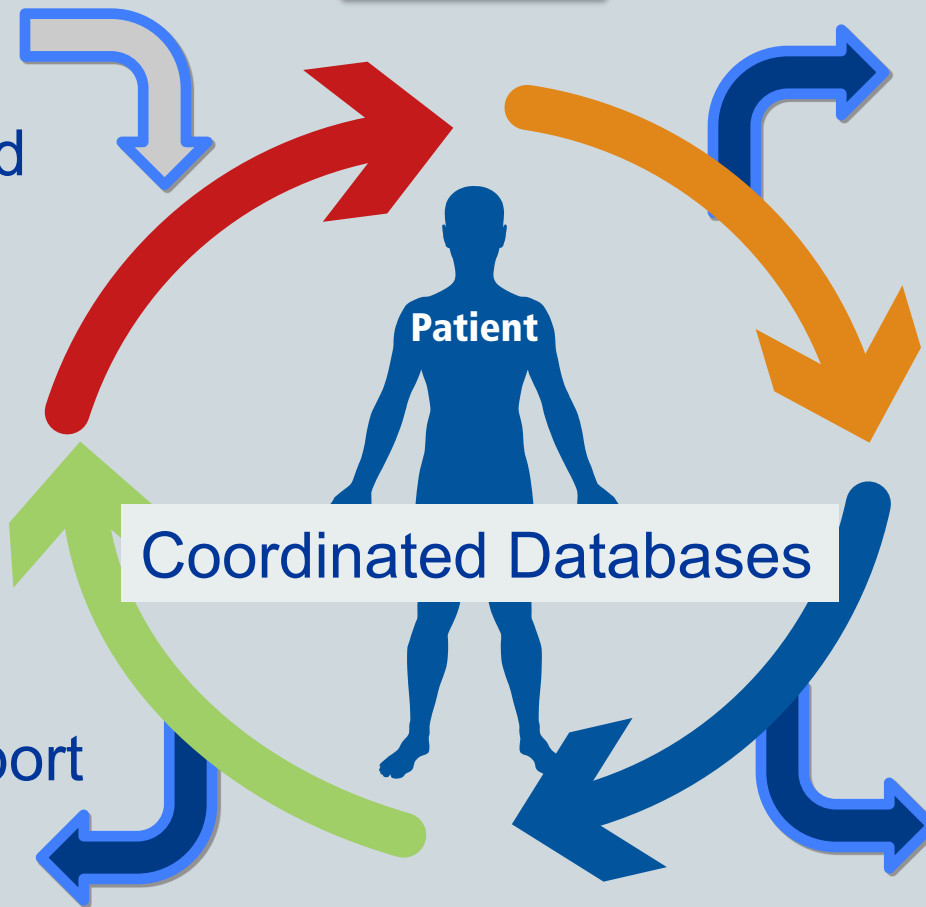
Patient

Coordinated Databases

Clinical
Decision Support
& Guidelines

Research Uses

- Quality reporting
- CER
- Hypothesis generation



Patient
reports
standardized
data

Clinical uses

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

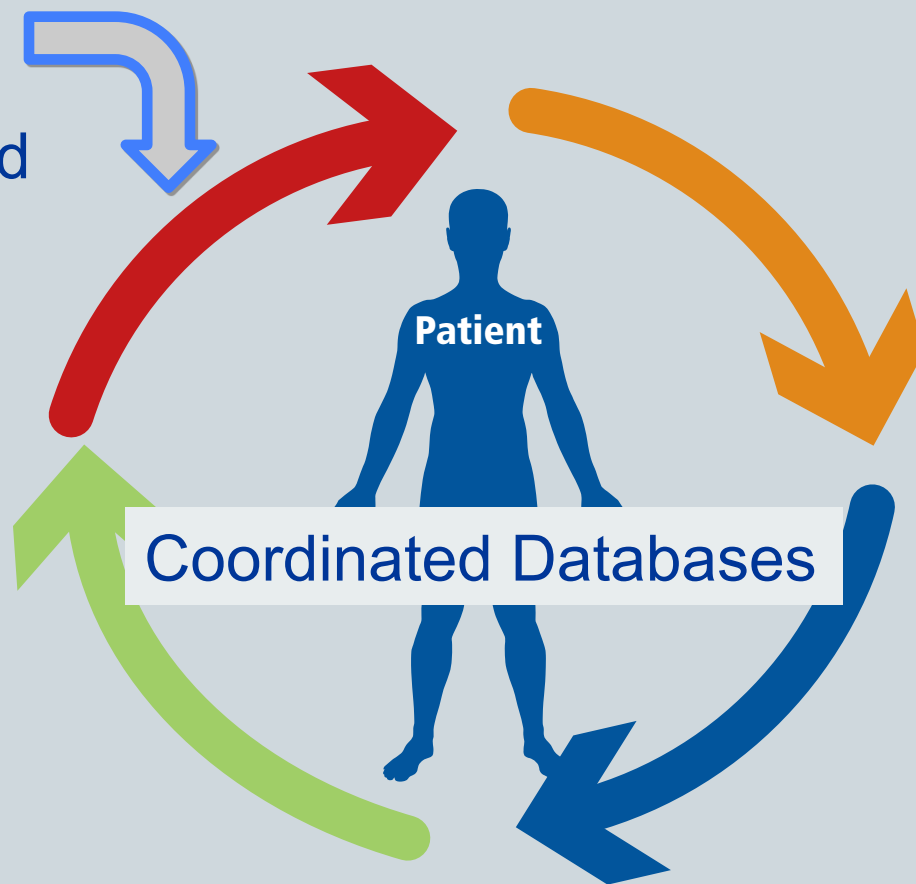
Iterative learning cycles
Continuously aggregating data

Clinical
Decision Support
& Guidelines

Research Uses

- Quality reporting
- CER
- Hypothesis generation

Patient
reports
standardized
data





Location and
platform agnostic



Patient Care Monitor™



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



0

Mild
problem



1



2



3

Moderate
problem



4



5



6

Severe
problem



7



8



9

As bad as
possible



10

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

Skip

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™

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.

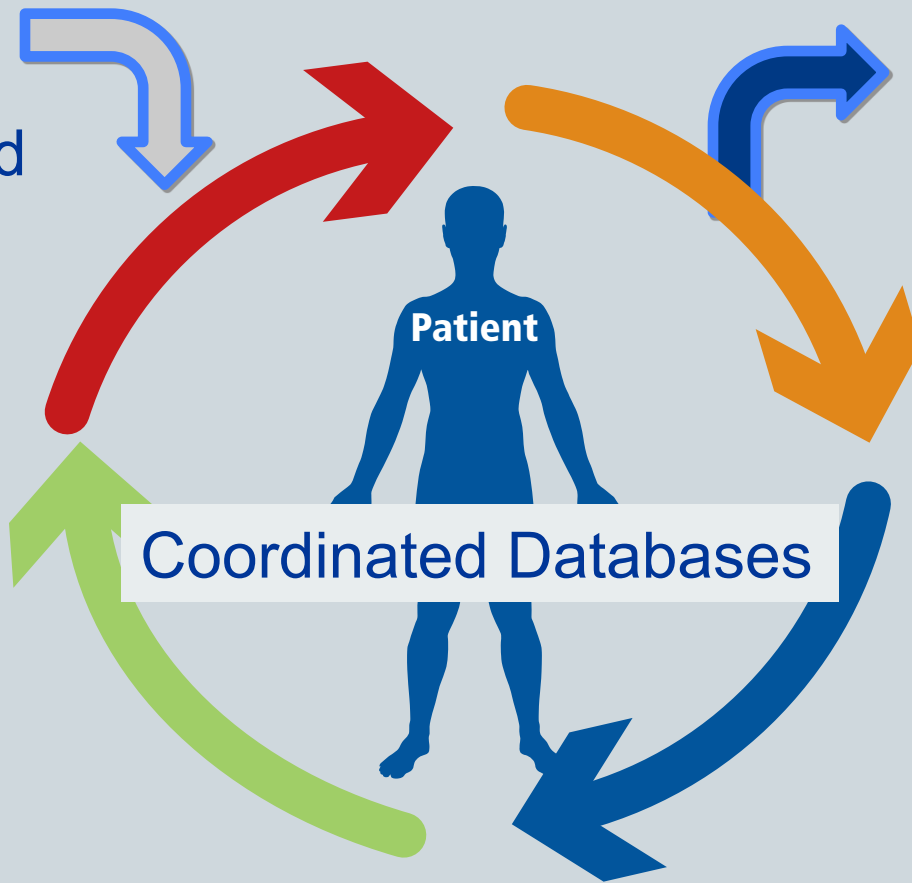
Press the **Continue** bar below to proceed with the first survey.

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

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

Patient
reports
standardized
data



Clinical uses

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

**PATIENT CARE MONITOR REPORT**

Patient Name: kafdkfjakfjdafkjdafldfakjf
DOB/Age/Sex: djfjafjdjfafjdalkdfjakfjdj
Doctor: kkjddajfalkajdfajldfjaljfdl
ajfdalkjfdlafjdjafjldajfdlkj

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

History

Signature:

Alerts/Changes

Date:

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/light-headedness	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; = moderate; = severe; = skipped; = not asked; = referral suggested.

Notes:

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
	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				
①	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 iLog 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.



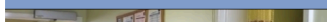
1. Introduction to the Day



2. Reminder of Services



3. Patient Care



4. Cancer Care Network



[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](#)

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 Committed to Research

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

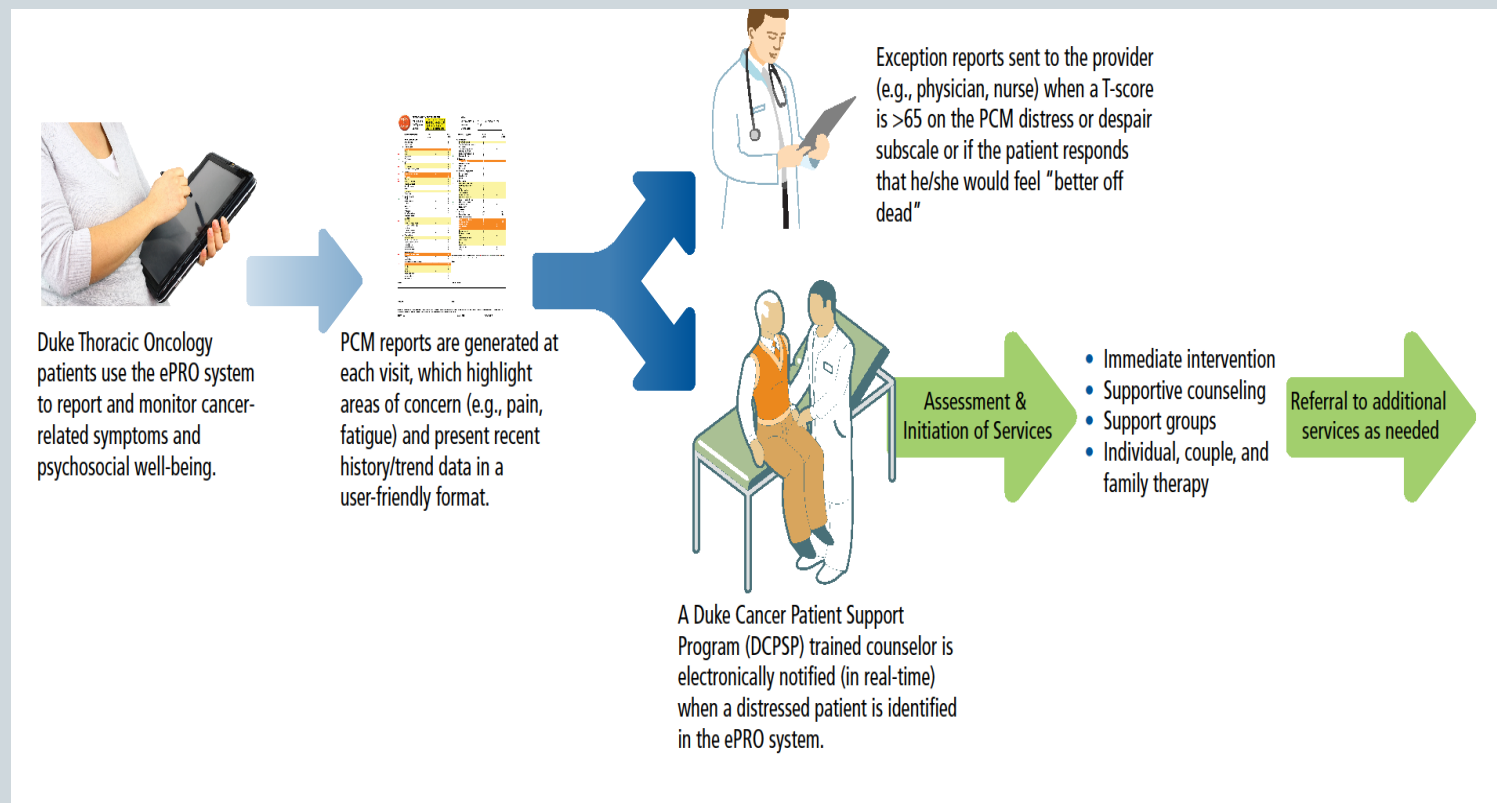
Press here.

[Go Back](#) [Search](#) [Help](#) [Quit CSN](#)

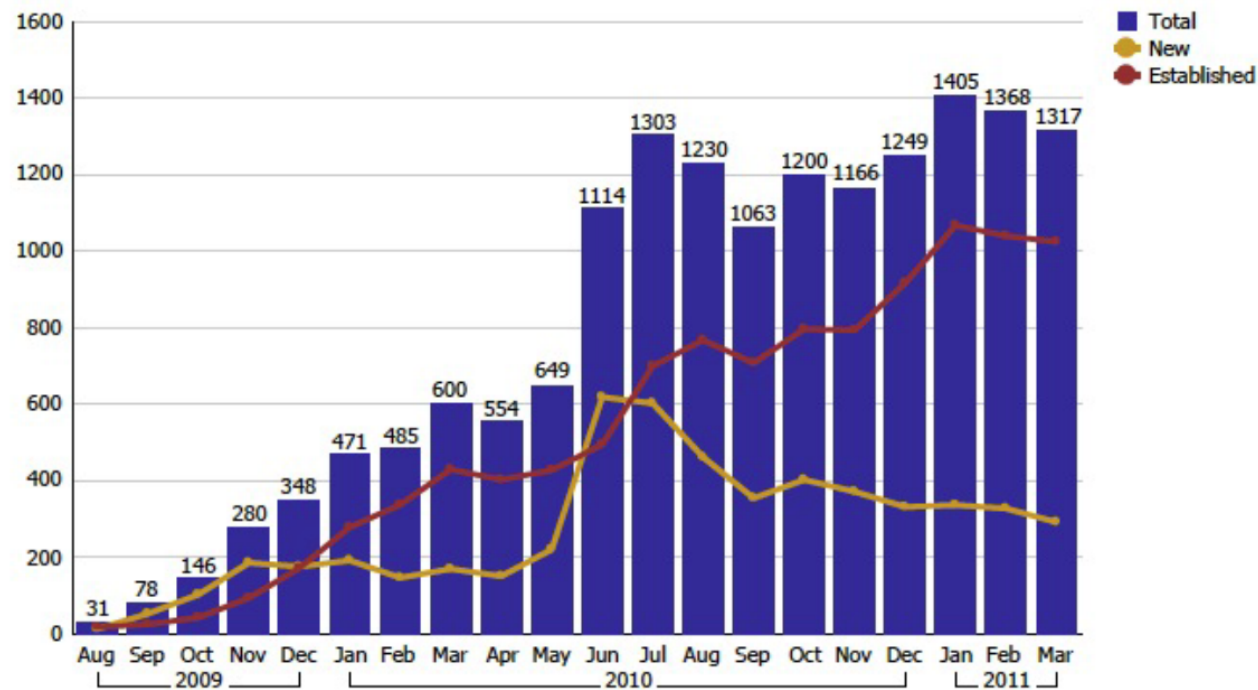
Welcome, Elvis. If you are not Elvis, please [Quit CSN](#) and [log in](#) as yourself.



Integrating into Process: Distress Triage

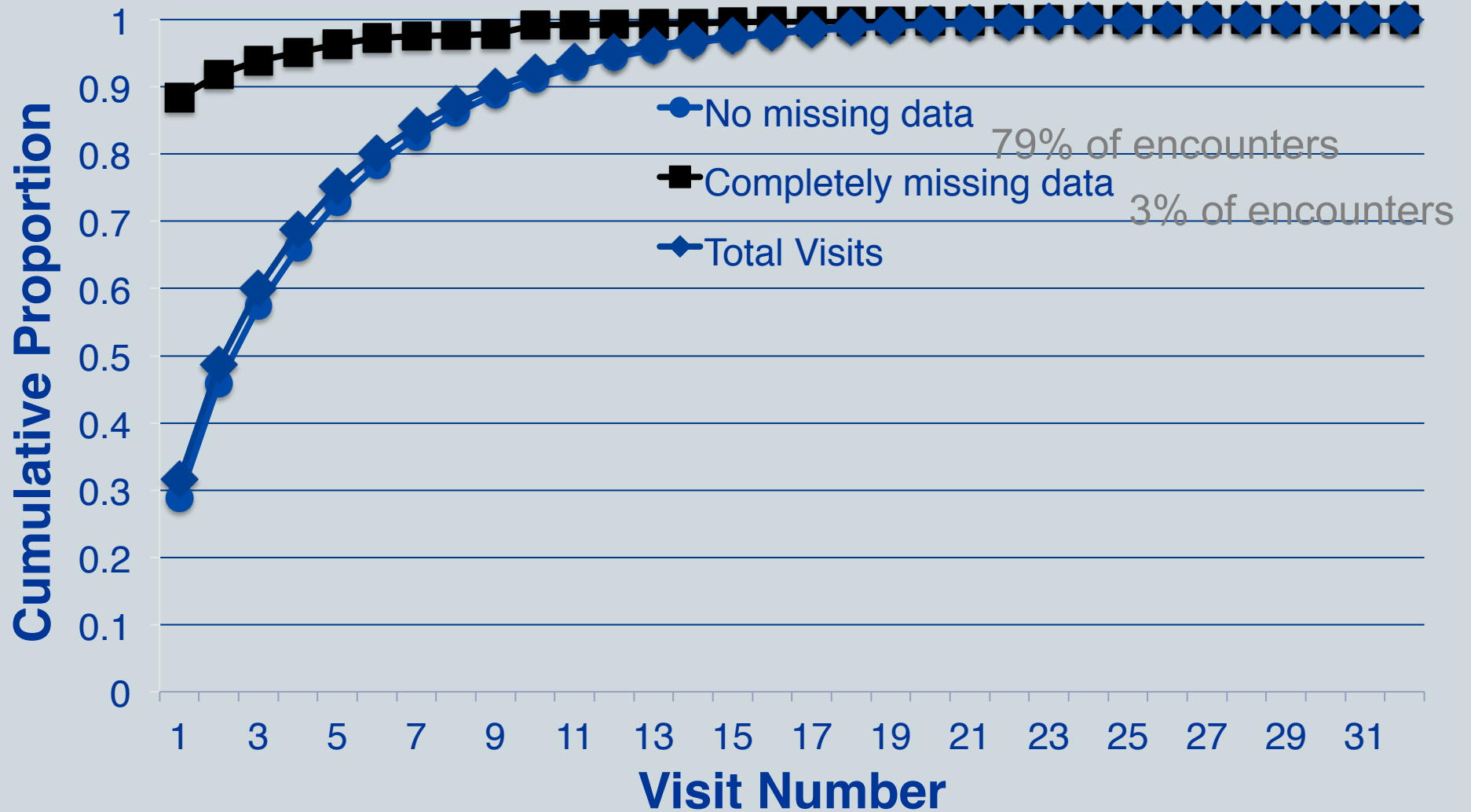


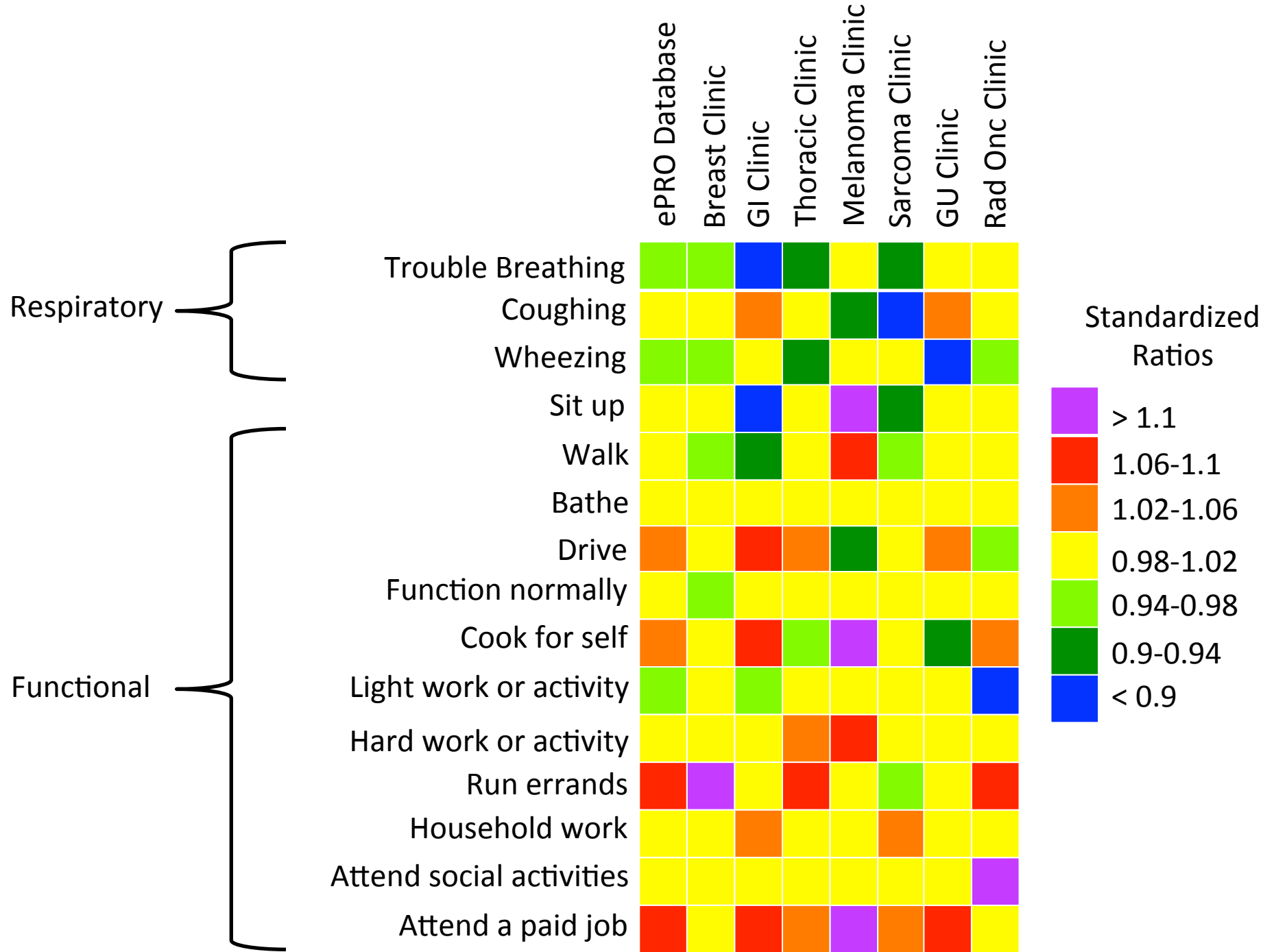
Number of (new and established) patients that have completed a PCM Survey



	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





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

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

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



0

Mild



1



2



3

Moderate



4



5



6

Severe



7



8



9

Bad as possible



10

← Back

50/118

Skip →

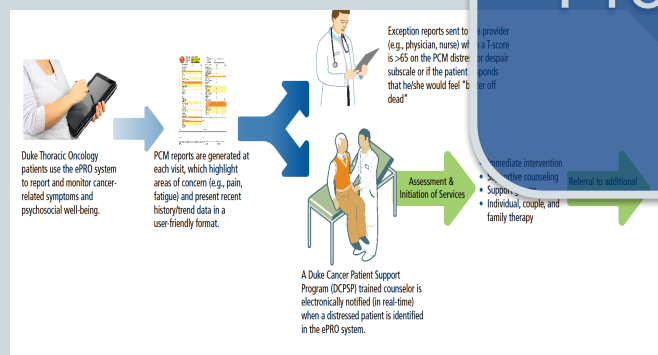


Software/ Hardware

Instrument

Process

Reporting/ Analytics



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 0 Mild 1 2 3 Moderate 4 5 6 Severe 7 8 9 Bad as possible 10

Back 50/118 Skip

PATIENT CARE MONITOR RESULTS

Patient Name: [Name] MR #: [MR#]
DOB/Age/Sex: [DOB/AGE/SEX] Survey Date/Time: Apr 20 2008 (Thu) 1:11 PM
Version: English Date/Time: [DATE/TIME]

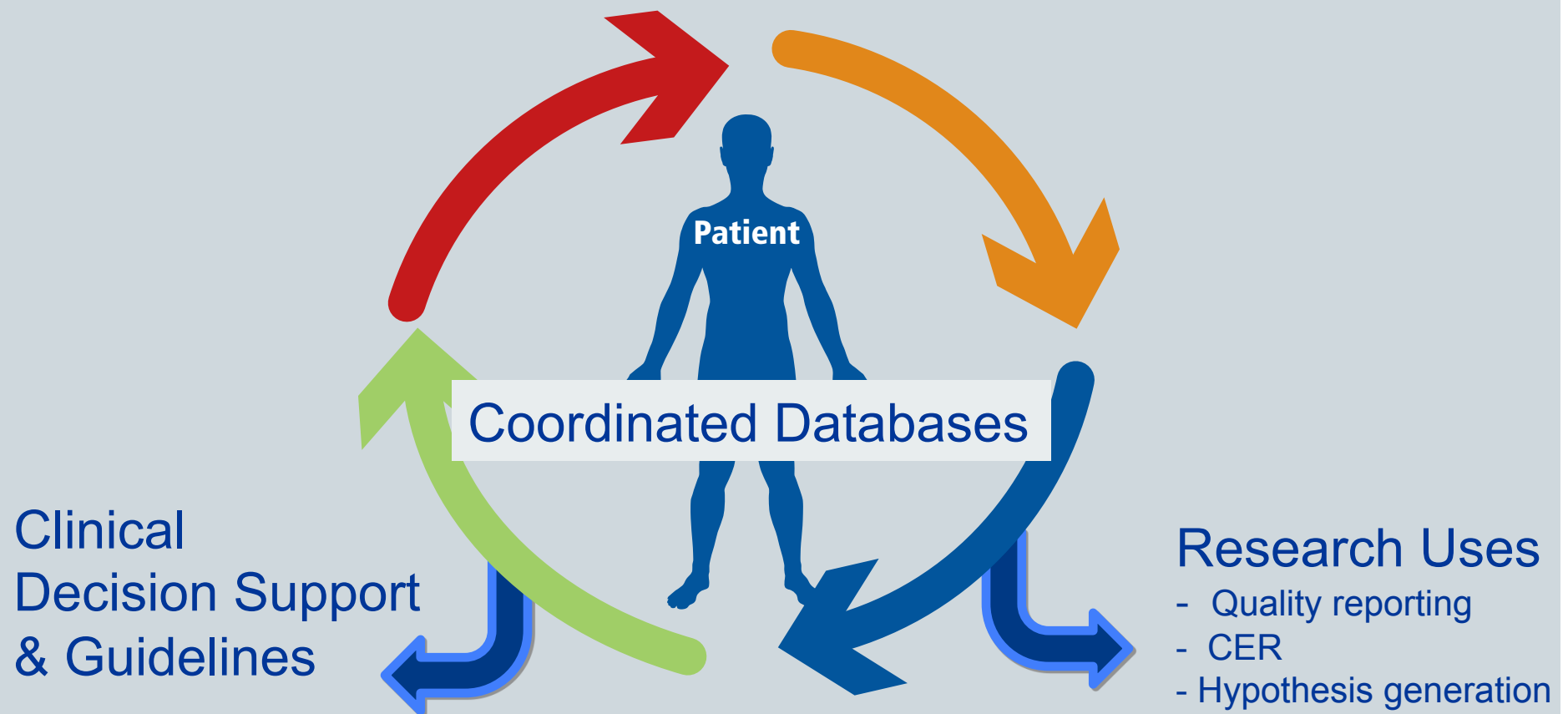
Review of Systems	Current Score	First Score	Review of Systems	Current Score	First Score
1. Alleviation/Improvement	0	0	12. Neurological	0	0
2. Constipation	0	0	13. Pain	0	0
3. Cough	0	0	14. Psychological/Emotional	0	0
4. Fatigue	0	0	15. Sleep	0	0
5. Hair Loss	0	0	16. Social/Relationship	0	0
6. Headache	0	0	17. Spiritual/Religious	0	0
7. Heart	0	0	18. Total Score	0	0
8. Indigestion	0	0			
9. Infection	0	0			
10. Joint Pain	0	0			
11. Loss of Appetite	0	0			
12. Nausea	0	0			
13. Pain	0	0			
14. Psychological/Emotional	0	0			
15. Sleep	0	0			
16. Social/Relationship	0	0			
17. Spiritual/Religious	0	0			
18. Total Score	0	0			

Notes: []

Signature: [] Date: []

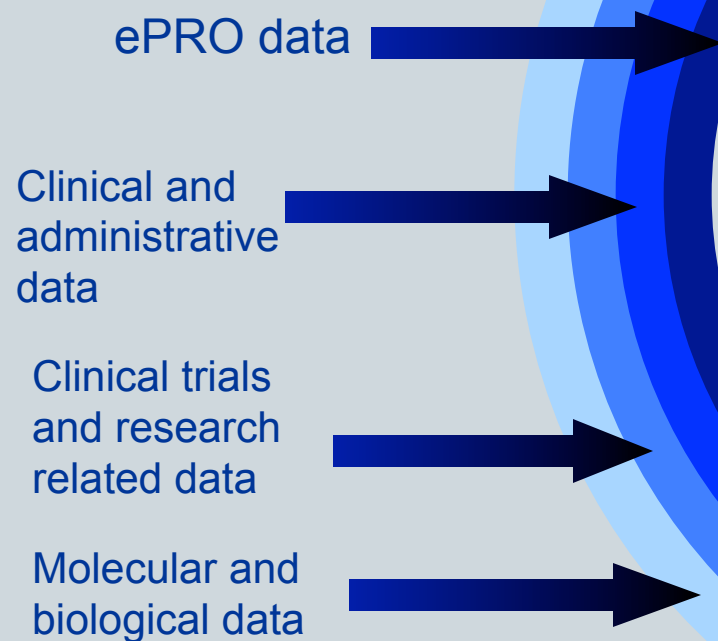
WDCPC-001 Rev 01-2007

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



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.



Coordinated Databases

Describing the patient experience

Individual patient



Research reports

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

	Breast	GI (%)	Lung (%)	Total (%)
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	61 (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)	28 (25)	34 (35)	79 (29)
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	GI	GI	Lung	Grand Total
	02/02/10	03/01/10	03/01/10	03/01/10	03/01/10
A. Total # pts with PCM data	845	511	766	652	2774
Total # of visits	3109	1965	2852	2180	9706
Avg # of visits per pt	4	3	4	3	3
SDV # 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	52%	58%	48%	60%	54%
% Pts with pain score of 2 or more	46%	50%	41%	53%	47%
% Pts with pain score of 3 or more	38%	45%	34%	48%	40%
% Pts with pain score of 4 or more	30%	38%	27%	38%	32%
C. Chronic Pain - Pain 4 or more (per visit)					
Pts reporting pain of 4 or more for 1 visit	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	19	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	325	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%
% Pts with pain of 4 or more on 3 or more visits	12%	12%	13%	14%	13%
% Pts with pain of 4 or more on 4 or more visits	5%	5%	5%	5%	5%
% Pts with pain of 4 or more on 5 or more visits	3%	3%	3%	3%	3%
% Pts with pain of 4 or more on 6 or more visits	1%	1%	1%	1%	1%
% Pts with pain of 4 or more on 7 or more visits	0%	0%	0%	0%	0%
% Pts with pain of 4 or more on 8 or more visits	0%	0%	0%	0%	0%
% Pts with pain of 4 or more on 9 or more visits	0%	0%	0%	0%	0%
% Pts with pain of 4 or more on 10 or more visits	0%	0%	0%	0%	0%

21% with pain $\geq 4/10$ 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

↓	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



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

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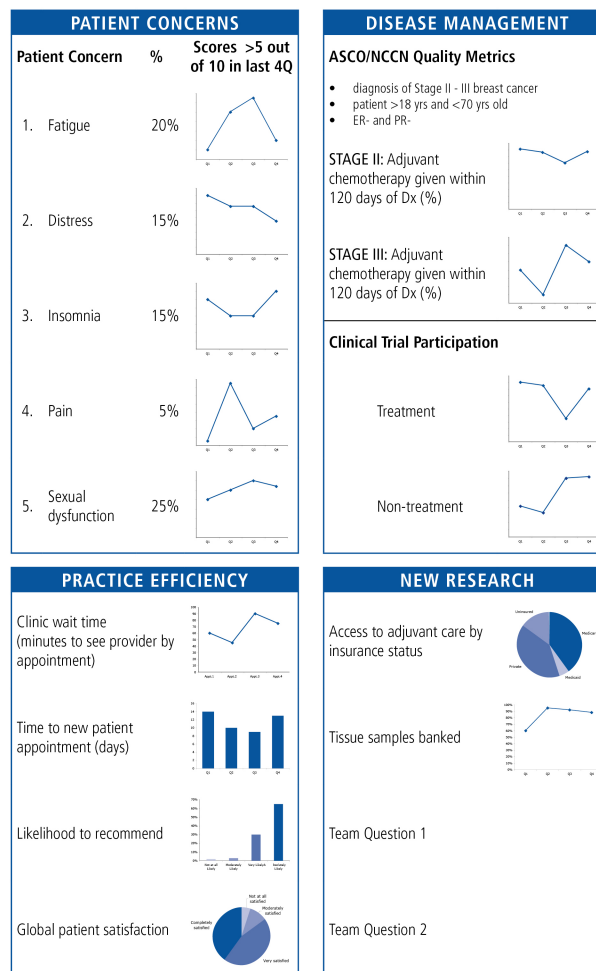
Brief Report

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 Coan¹, Jane L. Wheeler⁵, Tina Staley¹ and Amy P. Abernethy^{1,2,5*}

Quality Monitoring: "Scorecards"

RAPID LEARNING BREAST CANCER CLINIC "SCORECARD"



**TAKING THE TECHNOLOGY
TO THE NEXT LEVEL**

A large, bright yellow starburst graphic with many sharp points, centered on the slide. It has a slight drop shadow, giving it a 3D appearance.

BEWARE!!!

Don't be enamored with
the technology – this is
really the story of process

**TAKING THE TECHNOLOGY
TO THE NEXT LEVEL**

Developing the needed technology solution - QDACT



The screenshot shows the QDACT website in a Firefox browser window. The browser's address bar displays "www.qdact.org/home". The website's header includes a navigation menu with links: Home, Background, Carolinas Consortium Members, Development Team, Training Videos, FAQs, Contact Us, and Sign In. A search bar is located in the top right corner.

The main content area features the QDACT logo, which consists of a stylized 'Q' made of blue and green squares, followed by the text "DACT" and "QUALITY DATA COLLECTION TOOL". Below the logo is a navigation bar with the same links as the header.

The text "The Quality Data Collection Tool (QDACT) is:" is followed by a list of three points:

1. a prospective, standardized, quality-based monitoring system for real-time data collection applicable to a spectrum of palliative care organizations, medical specialties, and initiatives
2. able to provide a useful and informative data reporting structure to be clinically useful and drive quality improvement
3. translatable to other large data registries and various information technologies

A blue "SIGN IN" button is positioned to the right of this list.

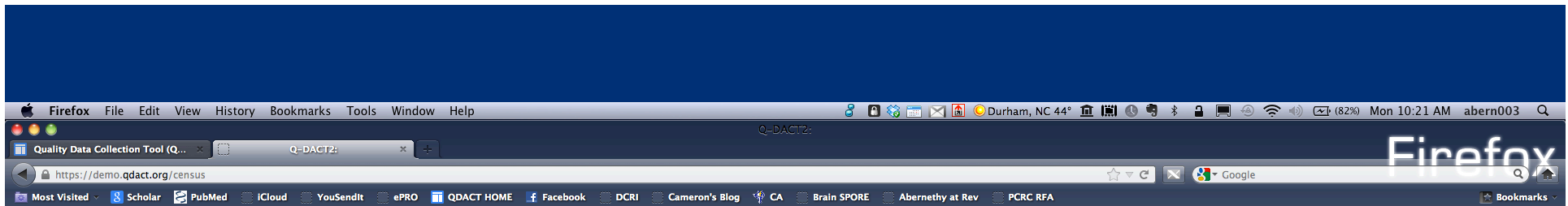
The section "Why is this important to you and your practice?" is followed by a diagram of a triangle. The triangle is divided into four sections: "Clinical Care" (top), "Robust Valid Data" (left), "Quality Assessment" (bottom-left), and "Outcomes Improvement" (bottom-right). Arrows indicate a clockwise flow between these sections.

To the right of the triangle is a list of bullet points:

- There are ever-increasing expectations for quality monitoring and reporting in patient care
- Data-driven quality assessment is needed to meet these expectations
- These data-driven processes require information technology (IT) support throughout the process, from collection to analysis and reporting
- In addition to quality improvement, data captured can also inform clinical care and research, which are inherently linked (see figure)
- In the past, program-specific, low-tech data collection efforts were the only solution to meeting these requirements
- To develop and test an implementable system, we created a community-based palliative care Consortium in North Carolina, which is nationally scalable

Below the triangle and bullet points is a video player. The video is titled "Welcome to QDACT from Arif Kamal, MD" and shows a man in a white lab coat speaking. The video player includes a play button, a progress bar, and a "vimeo" logo.

The footer of the website states: "The tool, which is continually being iteratively refined, can be used by providers to collect data for reporting on >60% of published quality measures applicable to palliative care."



Search: ☒ Census list ☐ All patients
Show 10 entries

Date of Last Encounter	Patient Name	MRN	DOB	Location	Encounter	Patient
None	amy, amy	GGGGGAA			New History Edit Remove	
2012-12-22	Flinstone, Fred	G45321	1911-01-01	Hospital - general floor (includes step-down, ER, pre-op)	New History Edit Remove	

Showing 1 to 2 of 2 entries

Previous Next

- Clinical interface
- Interacts with local EHR / administrative database

Add New Patient to Q-DaCT





Name: Flinstone, Fred MRN: G45321 Diagnosis: Cardiovascular - Heart failure Code Status: Full Code Barriers: No

* Pain

Source: Patient

* Presence of Current Pain (Status changed during visit) (Answered / Saved)

None	Mild	Moderate	Severe	As bad as possible
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
0	1 2 3	4 5 6	7 8 9	10

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

* Frequency of Recent Pain (Answered / Saved)

Never / Rarely	Occasionally	Frequently	Almost Constantly
<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

* Severity of Recent Pain (Unanswered)

Slight	Moderate	Severe	Very Severe
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

* Distress of Recent Pain (Unanswered)

Not at all	A little bit	Somewhat	Quite a bit	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

* Interventions for Pain (Status changed during visit) (Answered / Saved)

☐ Unknown

☐ No

☐ No - patient declines

☒ Yes

☐ NSAID's or acetaminophen ☒ Weak opioids (e.g. tramadol, codeine, propoxyphene) ☐ Moderate / strong opioids (e.g. morphine, oxycodone, hydrocodone)

☐ Adjuvant medications (e.g. gabapentin, pregabalin, duloxetine, steroids) ☐ Other (write in)

* Short-acting opioid available when long-acting opioid prescribed (Unanswered)

☐ Not applicable/patient not on long-acting opioid ☐ Yes ☐ No

* Intervention for Opioid-induced Constipation Prevention (Unanswered)

☐ Not applicable / patient not on an opioid ☐ Yes ☐ No - not indicated ☐ No - patient declines ☐ No ☐ Other (write in)

- Colors change in real time
- Navigation interface designed by clinicians





Name: Flinstone, Fred MRN: G45321 Diagnosis: Cardiovascular - Heart failure Code Status: Full Code Barriers: No

* Pain

*** Presence of Current Pain** (Status changed during visit) (Answered / Saved)

None	Mild	Moderate	Severe	As bad as possible
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
0	1 2 3	4 5 6	7 8 9	10

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

*** Frequency of Recent Pain** (Answered / Saved)

Never / Rarely	Occasionally	Frequently	Almost Constantly
<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

*** Severity of Recent Pain** (Unanswered)

Slight	Moderate	Severe	Very Severe
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

*** Distress of Recent Pain** (Unanswered)

Not at all	A little bit	Somewhat	Quite a bit	Very much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

☐ Unknown ☐ Patient unable to respond ☐ Other (write in)

*** Interventions for Pain** (Status changed during visit) (Answered / Saved)

☐ Unknown
☐ No
☐ No - patient declines
☒ Yes

☐ NSAID's or acetaminophen ☒ Weak opioids (e.g. tramadol, codeine, propoxyphene)
☐ Adjuvant medications (e.g. gabapentin, pregabalin, duloxetine, steroids) ☐ Other (

*** Short-acting opioid available when long-acting opioid prescribed** (Unanswered)

☐ Not applicable/patient not on long-acting opioid ☐ Yes ☐ No

*** Intervention for Opioid-induced Constipation Prevention** (Unanswered)

☐ Not applicable / patient not on an opioid ☐ Yes ☐ No - not indicated

* Consult Characteristics

* Advance Care Planning

Symptom Assessment

- * Pain
- * Dyspnea
- Nausea
- Anxiety
- Insomnia
- Dysphagia
- Fatigue
- Anorexia
- Depression
- * Constipation

* Psychosocial

* Independence/Functionality

Spirituality

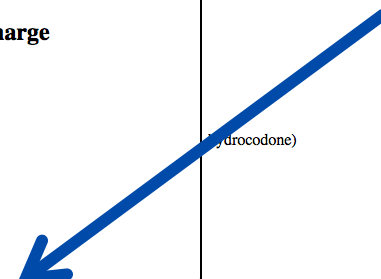
Prognosis

Transitions/Discharge

Source: Patient



Navigation interface
designed by clinicians




Care Setting by Site (encounters)					
	Duke	Forsyth	FourSeasons	Wake	Total
Hospital floor location, demonstrates capacity	10	21	3	1	35
Hospital floor location, does not demonstrate capacity	6	16	3	2	27
ICU location, demonstrates capacity	0	4	2	0	6
ICU location, does not demonstrate capacity	0	15	1	0	16
Non-hospitalization location, does not demonstrate capacity	0	0	10	0	10
Non-hospitalized location, demonstrates capacity	0	0	15	3	18
Total	16	56	34	6	112


Care Setting by Site (unique patients)					
	Duke	Forsyth	FourSeasons	Wake	Total
Hospital floor location, demonstrates capacity	7	13	3	1	24
Hospital floor location, does not demonstrate capacity	4	15	3	2	24
ICU location, demonstrates capacity	0	4	2	0	6
ICU location, does not demonstrate capacity	0	9	1	0	10
Non-hospitalization location, does not demonstrate capacity	0	0	10	0	10
Non-hospitalized location, demonstrates capacity	0	0	15	3	18
Total	11	36	33	6	86


Question category	Question	Wake	FourSeasons	Duke	Forsyth	Total
* Advance Care Planning	Surrogate Decision Maker	18 100%	62 93.9%	54 70.1%	192 84.2%	326
	Preference for CPR	18 100%	64 97%	63 81.8%	189 82.9%	334
	Documented Advanced Directives	18 100%	55 83.3%	30 39%	191 83.8%	294
* Constipation	Presence of Current Constipation	18 100%	64 97%	71 92.2%	198 86.8%	351
	Distress of Recent Constipation	7 38.9%	24 36.4%	19 24.7%	90 39.5%	140
	Frequency of Recent Constipation	18 100%	34 51.5%	71 92.2%	193 84.6%	316
	Severity of Recent Constipation	7 38.9%	26 39.4%	19 24.7%	90 39.5%	142
	Interventions for Constipation**	17 94.4%	49 74.2%	110 142.9%	248 108.8%	424
* Dyspnea	Presence of Current Dyspnea	18 100%	61 92.4%	70 90.9%	209 91.7%	358
	Distress of Recent Dyspnea	8 44.4%	32 48.5%	20 26%	130 57%	190
	Severity of Recent Dyspnea	8 44.4%	32 48.5%	20 26%	131 57.5%	191
	Interventions for Dyspnea**	19 105.6%	61 92.4%	82 106.5%	356 156.1%	518
	Frequency of Recent Dyspnea	16 88.9%	42 63.6%	70 90.9%	199 87.3%	327
* Independence/Functionality	PPS	18 100%	64 97%	61 79.2%	203 89%	346
	AKPS	16 88.9%	10 15.2%	2 2.6%	2 9%	30
* Pain	Presence of Current Pain	18 100%	65 98.5%	72 93.5%	209 91.7%	364
	Distress of Recent Pain	9 50%	50 75.8%	50 64.9%	134 58.8%	243
	Severity of Recent Pain	9 50%	50 75.8%	51 66.2%	139 61%	249
	Frequency of Recent Pain	17 94.4%	55 83.3%	72 93.5%	205 89.9%	349
	Interventions for Pain**	17 94.4%	84 127.3%	108 140.3%	233 102.2%	442
	Rx long-acting opioid with short-acting available	8 44.4%	19 28.8%	61 79.2%	108 47.4%	196
	Intervention Opioid-induced Constipation**	8 44.4%	31 47%	61 79.2%	111 48.7%	211
* Psychosocial	Level of Social Activity	18 100%	47 71.2%	5 6.5%	182 79.8%	252
	Overall Quality of Life	18 100%	57 86.4%	33 42.9%	193 84.6%	301
	Emotional Wellbeing	18 100%	48 72.7%	4 5.2%	179 78.5%	249
	Burden to Family	18 100%	48 72.7%	6 7.8%	179 78.5%	251


Cc: <joe.kelly@duke.edu>
Subject: QDACT Weekly Quality Report


Arif Kamal

Nov-05 to Date
Timely Management of Dyspnea ⁴  60%
(3/5)

Nov-05 to Date
Timely Management of Constipation ⁵  100%
(4/4)

 0% to 32%

 33% to 49%

 50% to 100%
1

1 - Consortium's goal is greater than 50%.
2 - Denominator = Recorded encounters that received a symptom
3 - Numerator = Denominator entries receiving a recorded interve reported encounter.
4 - National Quality Forum measure #1638: Hospice and Palliative (paired with measure 1639).
5 - Hospice PEACE Measure Set, Hanson et al.

- Real-time reports
- Push and pull
- Overlay of data visualization layer

• Human factors research

• Usability & feasibility testing

• IRB approved protocols

Developing new solutions and interventions: eBIP as a case example

- ❖ Tammy Somers, PhD
- ❖ Point of service patient reported outcome
 - Clinical information driving implementation of the intervention
 - Continuous data collection to refine intervention and evaluate it
- ❖ Behavioral therapy for cancer pain
 - Demonstrated benefit but poor uptake
 - Efficiency and access
 - Persistent Cancer Pain Identified at Clinic Appointment
 - Electronic medical records
 - Past pain score of ≥ 3
 - Today's clinical pain score ≥ 3

Patient consents to the eBIP study



CRC initiates conversation with patient after they meet the pain criteria

Three distinct interfaces

❖ Patient

- takes surveys before and after therapy sessions with their provider.

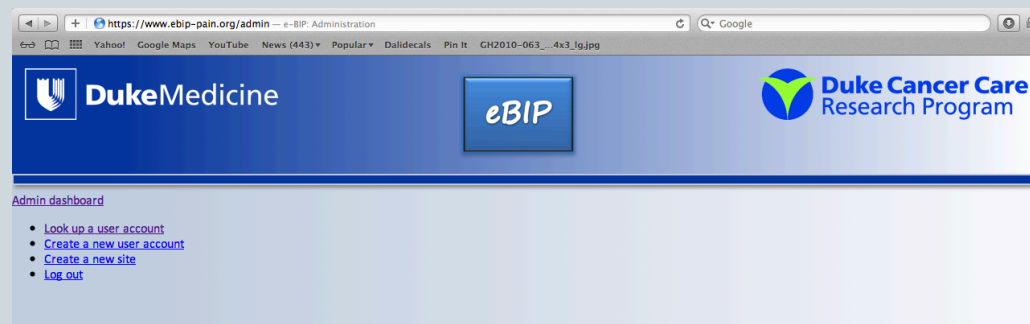
❖ Admin

- Sets the schedule for the surveys based on the session dates determined by the provider
- Admin can see which surveys have been completed and when
- Unique scheduling feature – patient cannot complete next set of surveys until the pre-scheduled time

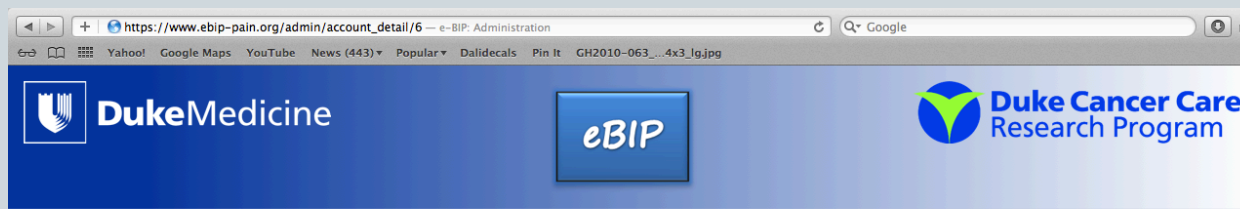
❖ Provider

- completes questionnaires about the patient therapy sessions as well

eBIP software allows background administrative functions – getting the study set up for a new patient...



eBIP software allows coordination of pain behavioral intervention and data collection timepoints ...



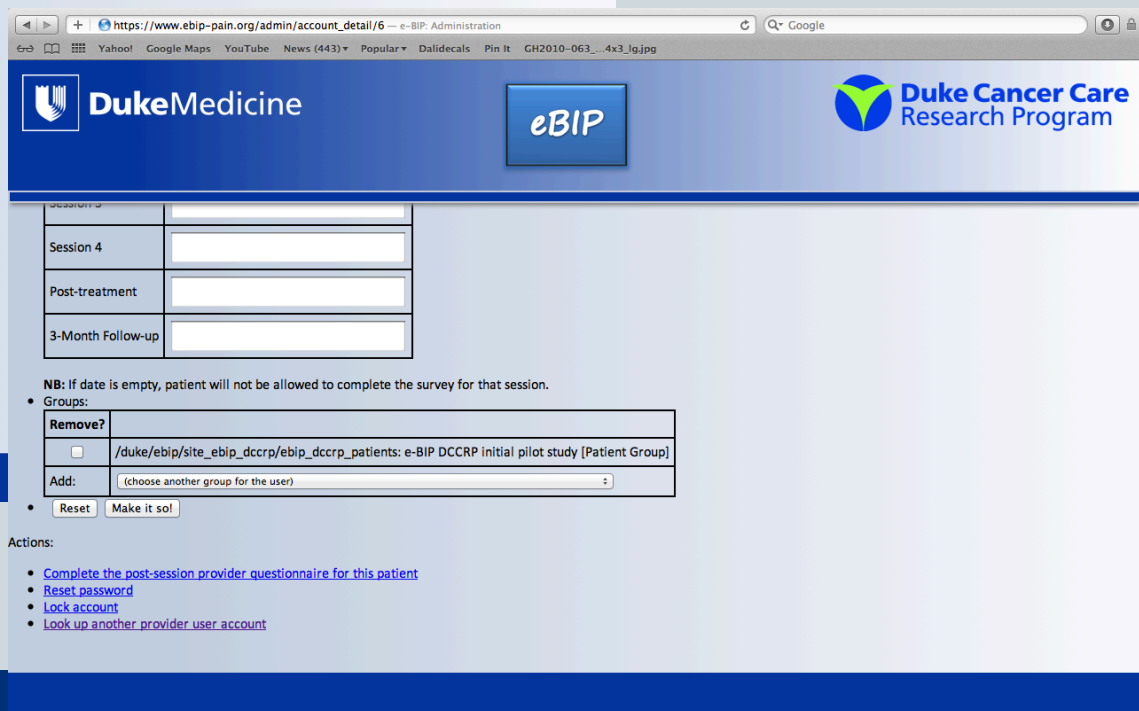
• Session history:

Number	Type	Date	Type
Pre-treatment	N/A	2012-06-12	completed questionnaire
Session 1	Pre-session	2012-08-23	completed questionnaire
N/A	Provider Assessment	2012-08-23	completed questionnaire
Session 1	Post-session	2012-08-23	completed questionnaire

• Next step in patient workflow: Session 2 Pre-session

• Scheduled appointments:

Session	Date (MM/DD/YYYY)
Pre-treatment	
Session 1	08/23/2012
Session 2	08/29/2012
Session 3	
Session 4	
Post-treatment	





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.**

Pain

Not a problem



0

Mild



1



2



3

Moderate



4



5



6

Severe



7



8



9

Bad as possible



10

← Back

50/118

Skip →

Verizon 3G 1:54 PM 99 %



Newsstand



Entertainment



Music



e-BIP: Login



Skype

Do you have a history of:

- | | | |
|---|--------------------------|---------------------------|
| Hypertension | <input type="radio"/> No | <input type="radio"/> Yes |
| Heart Disease | <input type="radio"/> No | <input type="radio"/> Yes |
| Rheumatoid Arthritis | <input type="radio"/> No | <input type="radio"/> Yes |
| Osteoarthritis | <input type="radio"/> No | <input type="radio"/> Yes |
| Diabetes | <input type="radio"/> No | <input type="radio"/> Yes |
| Sciatica | <input type="radio"/> No | <input type="radio"/> Yes |
| Emphysema, asthma, or COPD | <input type="radio"/> No | <input type="radio"/> Yes |
| Crohn's disease or irritable bowel syndrome | <input type="radio"/> No | <input type="radio"/> Yes |

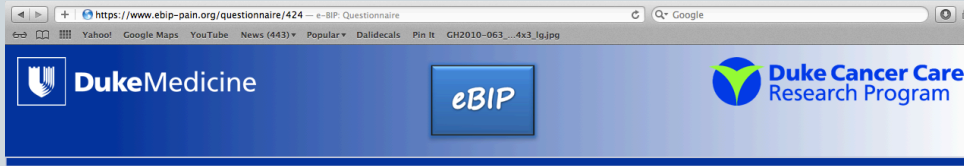
← Back

Please rate your pain by marking the one number that best describes your **average** pain in the last week.

No pain										Pain as bad as you can imagine
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
0	1	2	3	4	5	6	7	8	9	10

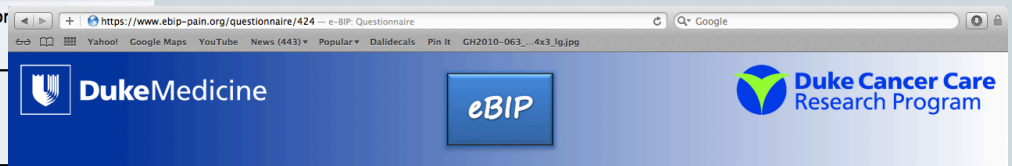
← Back

Skip →



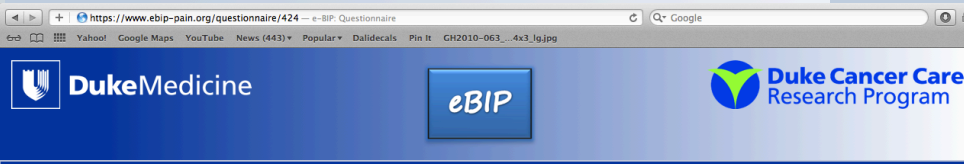
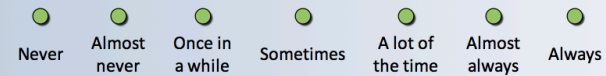
Select the dot below that best describes how bad, if at all, this has been a problem for you during the past week, including today:

I am worried



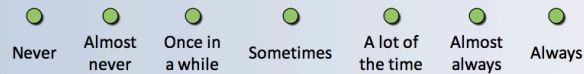
Individuals who experience pain often have a number of ways to cope or deal with their pain. This item refers to ways people have felt when coping with pain. Please touch the dot that represents the answer that best applies to you.

When I feel pain it is terrible and I feel it's never going to get any better.



Individuals who experience pain often have a number of ways to cope or deal with their pain. This item refers to ways people have felt when coping with pain. Please touch the dot that represents the answer that best applies to you.

When I feel pain I worry all the time about whether it will end.



[← Back](#)

[Skip →](#)

[Skip →](#)

Patient receives a Skype-based skills training session with her eBIP therapist...



Patient works with the therapist



Patient works with the therapist



Example Patient Handouts...

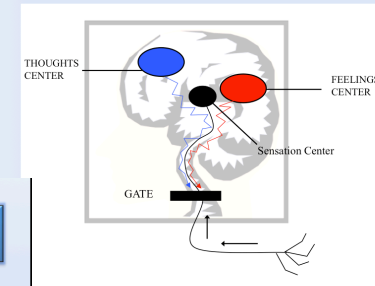
eBIP

Pain Coping Skills for Cancer Pain

Welcome to this program.

Electronic Behavioral Intervention for Pain

eBIP



Behavioral Intervention for Pain

Skills for Coping with Pain

eBIP

Menu

Coping Skills

1. Progressive muscle relaxation
2. Activity Rest Cycle
3. Pleasant activity planning
4. Positive thinking
5. Imagery for relaxation

Pain & Tension Thermometer



Your pain rating.
Before:
After:

Your tension rating.
Before:
After:

Electronic Behavioral Intervention for Pain

Electronic Behavioral Intervention for Pain

eBIP

What to do this week...


- Look for times that your automatic thoughts influence how you are feeling
 - Work to write it in the ABC model
- Place your calming self-statement card somewhere that you will see it
- Keep using progressive muscle relaxation at least daily
- Schedule pleasant activities


Electronic Behavioral Intervention for Pain


Follow up data collection from patients...

Browser address bar: <https://www.ebip-pain.org/questionnaire/424> — e-BIP: Questionnaire

Navigation links: Yahoo! Google Maps YouTube News (443) Popular Dalidecals Pin It GH2010-063_...4x3_lg.jpg

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 **Duke Cancer Care**
Research Program

Please rate your pain by marking the one number that best describes your **average** pain in the last week.

No pain

Pain as bad as you can imagine

0 1 2 3 4 5 6 7 8 9 10

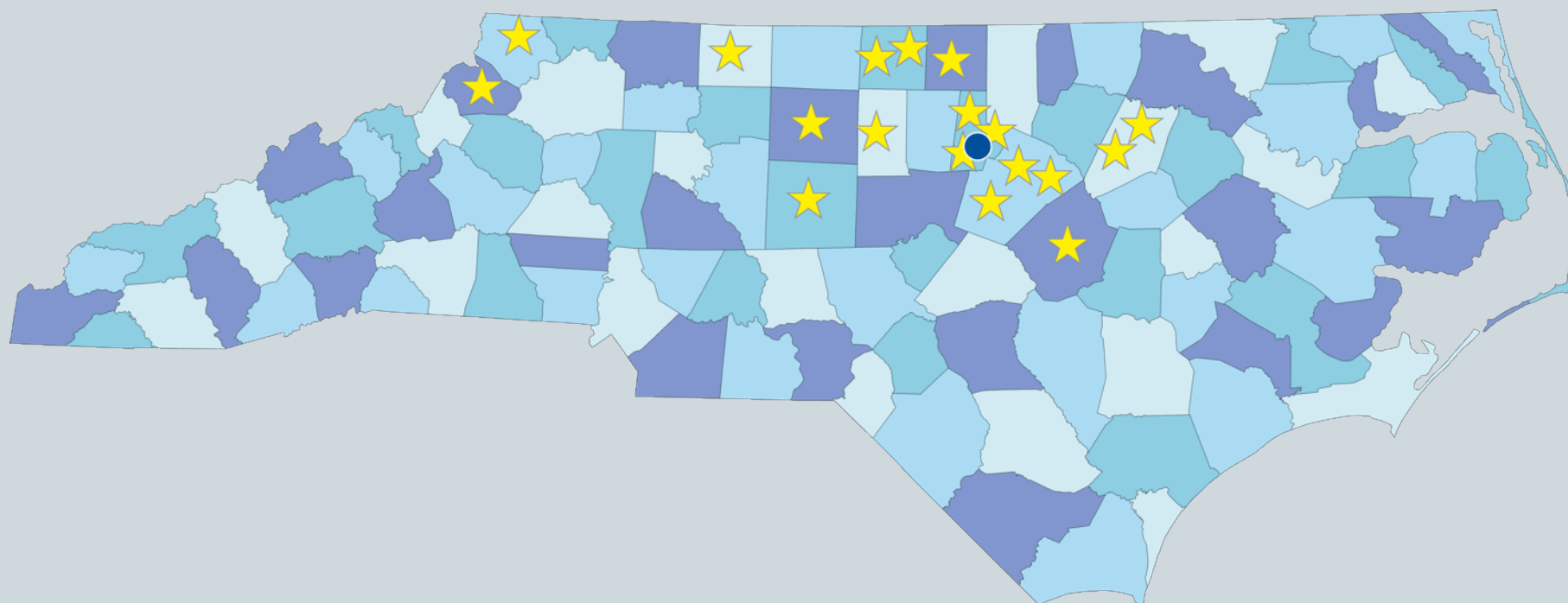
← Back Skip →

eBIP study data ready to be analyzed...

IM_YYYY	grouper_id	chart_num	QID	p.	v.	s.	entry_by	domain_id	site	question	response	value2	score
May-12	1	99	6	1	2	4	4	7	e-BIP DCCRP initial pilot study	session_number	Pre-treatment	0	0
May-12	2	30	8	3	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkChemo	No	0	0
May-12	2	30	9	4	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkRad	No	0	0
May-12	2	30	10	5	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkSurgery	No	0	0
May-12	2	30	11	6	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkHormone	No	0	0
May-12	2	30	12	7	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkVaccine	No	0	0
May-12	2	30	13	8	2	4	4	7	e-BIP DCCRP initial pilot study	CantxwkPill	No	0	0
May-12	3	10	29	2	2	4	4	7	e-BIP DCCRP initial pilot study	PtDayspainmed	0	0	0
May-12	2	30	30	2	2	4	4	7	e-BIP DCCRP initial pilot study	Ptyeardiagnosis	2011	2011	[Null]
May-12	2	30	31	2	2	4	4	7	e-BIP DCCRP initial pilot study	Ptmonthdiagnosis	November	11	11
May-12	2	30	32	2	2	4	4	7	e-BIP DCCRP initial pilot study	Currentcanc	First/initial cancer	1	1
May-12	3	20	36	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtheightFt	5	5	5
May-12	3	20	37	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtheightIn	9	9	9
May-12	4	50	38	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtHypertension	No	0	0
May-12	4	50	39	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtHeartDisease	No	0	0
May-12	4	50	40	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtRheumA	Yes	1	1
May-12	4	50	41	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtOsteoA	No	0	0
May-12	4	50	42	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtDiabetes	No	0	0
May-12	4	50	43	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtSciatica	No	0	0
May-12	4	50	44	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtEmAsCOPD	No	0	0
May-12	4	50	45	3	2	4	4	7	e-BIP DCCRP initial pilot study	PtCDIBS	No	0	0
May-12	4	10	46	4	2	4	4	7	e-BIP DCCRP initial pilot study	BPI1	7	7	7
May-12	4	10	47	4	2	4	4	7	e-BIP DCCRP initial pilot study	BPI2	7	7	7
May-12	4	10	48	4	2	4	4	7	e-BIP DCCRP initial pilot study	BPI3	7	7	7
May-12	4	10	49	4	2	4	4	7	e-BIP DCCRP initial pilot study	BPI4	6	6	6

Observations to date

- ❖ Usability testing completed and system updated in response
 - Even older patients with few computer skills have been comfortable and efficient using the system
 - Rapport is positive with the video-chat
- ❖ Availability of a mHealth-based behavioral health strategy improves access to care
 - People from far western and eastern North Carolina who would normally have been excluded from in person behavioral interventions due to proximity are able to participate
 - Electronic identification of potential study participants has streamlined recruitment
- ❖ Continuous refinement



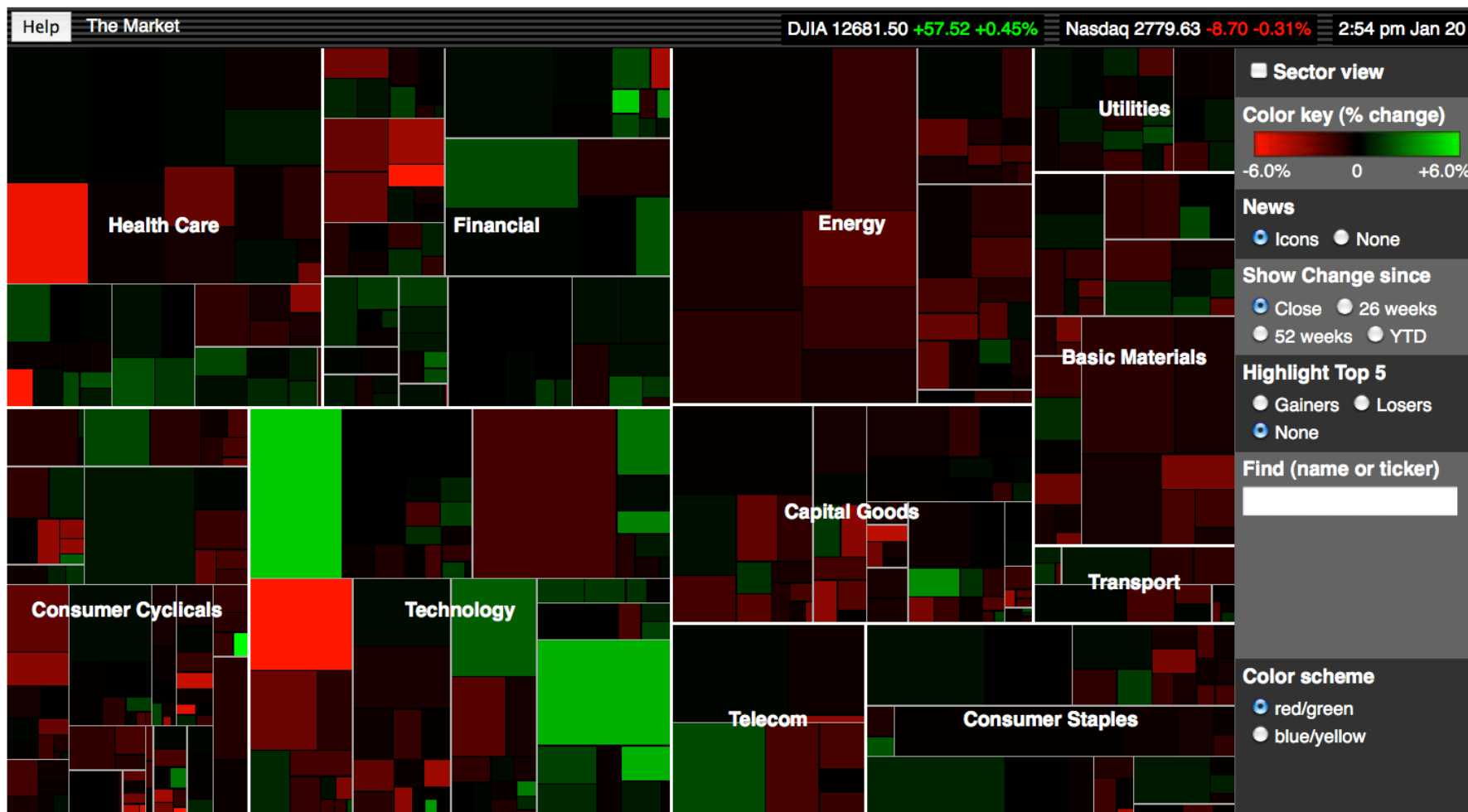
ADDING SOPHISTICATION



Map of the Market

SmartMoneySelect

Upgrade [here](#) to access the **Market Map 1000** and search 1,000 companies with enhanced capabilities.

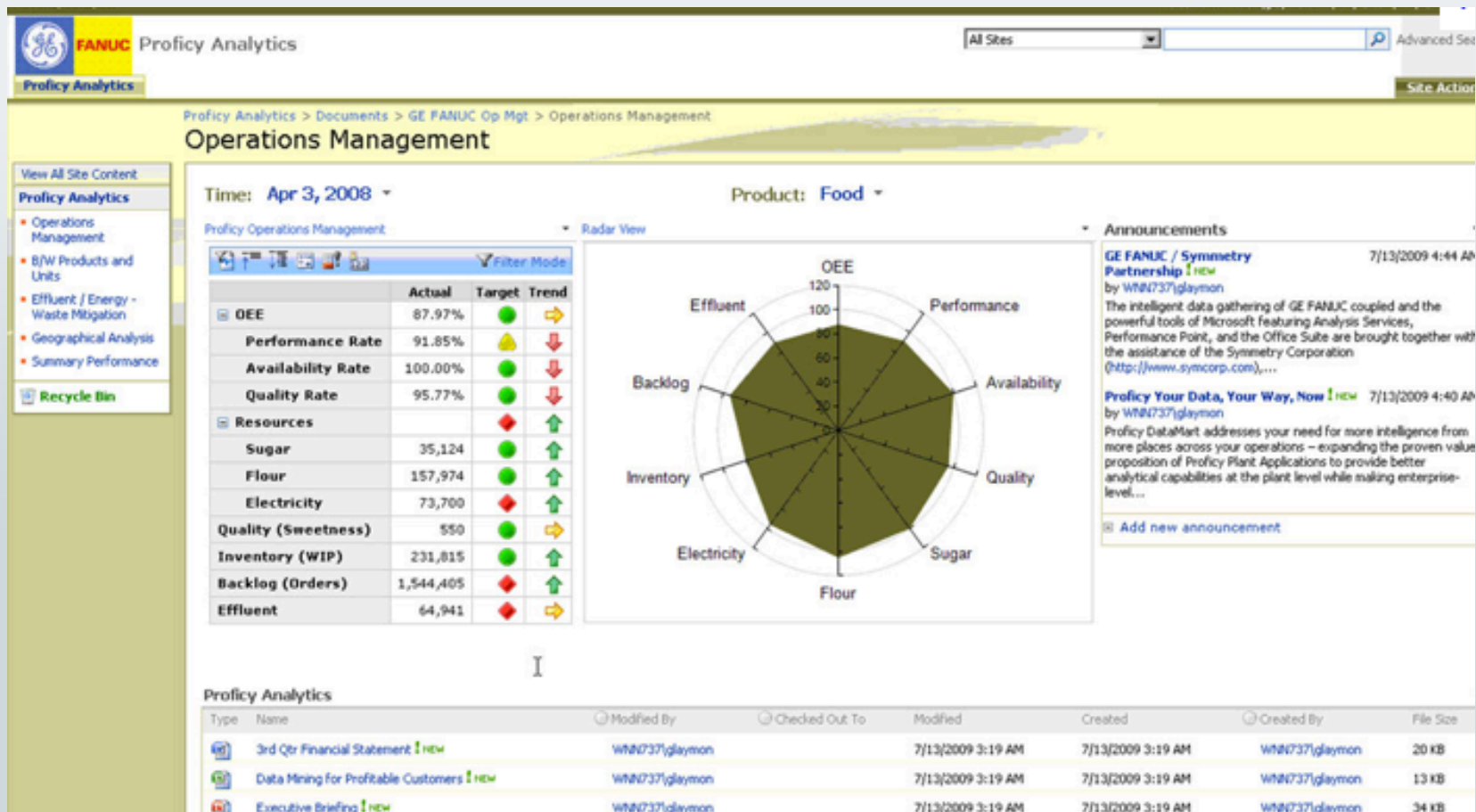


Patent No.: US 6,583,794 B1

[Click Here to License the Map Applet](#)



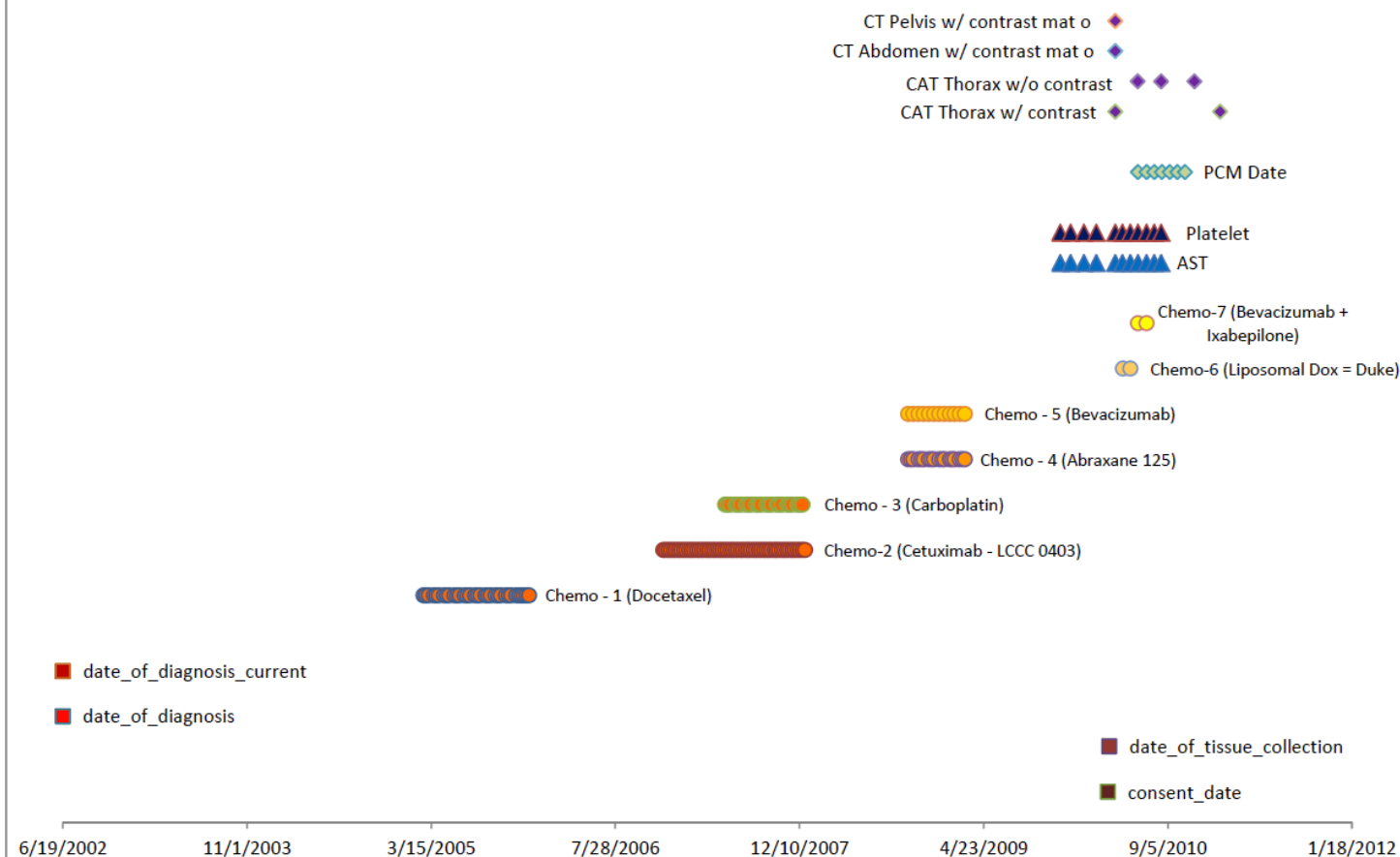
Customizable Reports



DukeMedicine

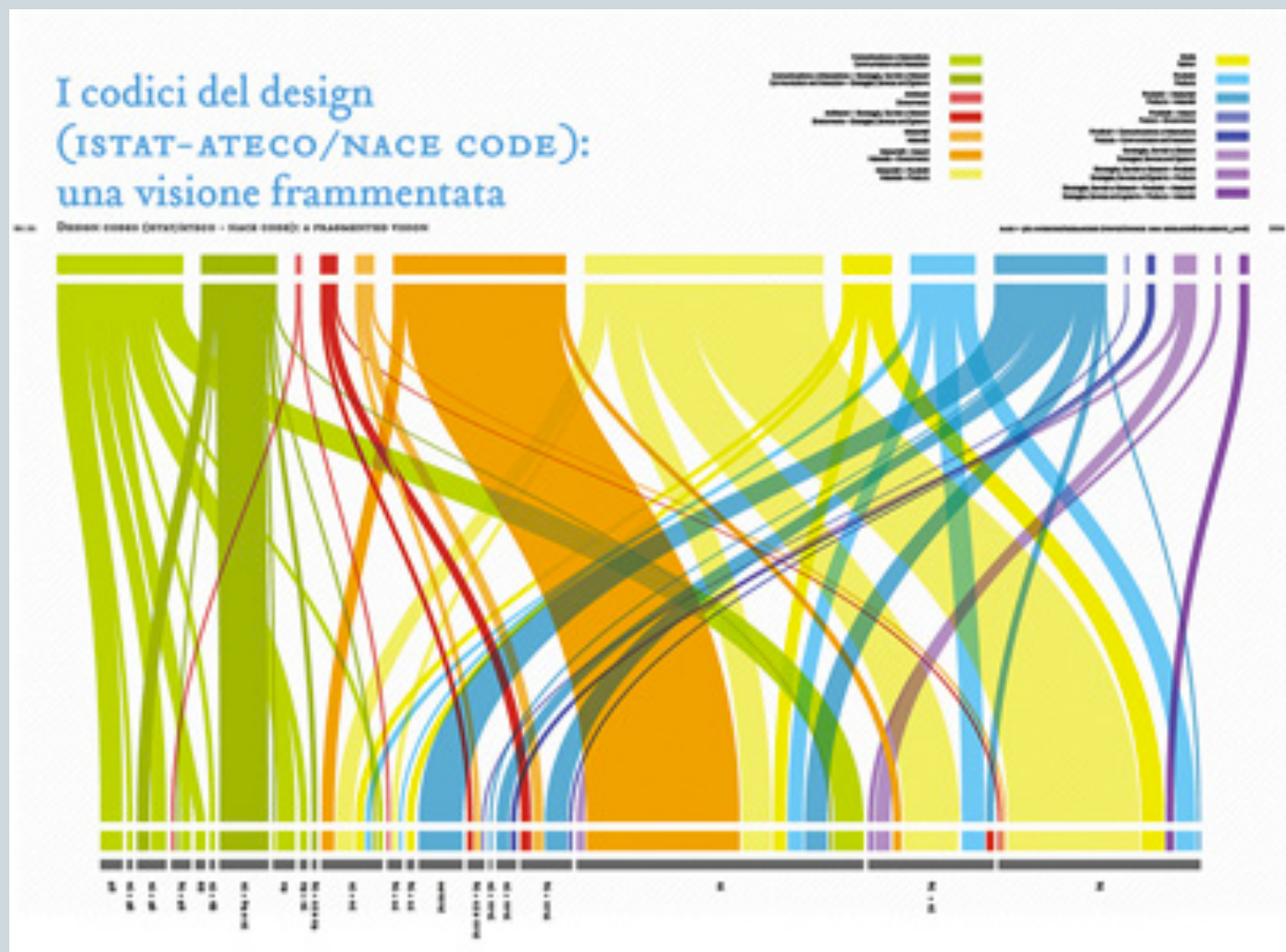


G87441 - Breast





Treatment sequence/Sankey



Reingold–Tilford Tree

The diagram is a radial tree structure representing the 'lib' library. The root node is 'lib', which branches into several main categories: 'core', 'math', 'physics', 'display', 'data', 'events', 'ui', 'util', 'network', 'animation', 'render', 'input', 'output', 'storage', 'audio', 'video', and 'game'. Each of these main categories further branches into numerous sub-nodes, representing a comprehensive list of library features and components. For example, the 'core' branch includes 'array', 'string', 'object', 'function', 'promise', 'async', 'error', 'event', 'timer', 'interval', 'requestAnimationFrame', 'setInterval', 'clearInterval', 'setTimeout', 'clearTimeout', 'setImmediate', 'clearImmediate', 'setInterval', 'clearInterval', 'setTimeout', 'clearTimeout', 'setImmediate', 'clearImmediate'. The 'math' branch includes 'math', 'vector', 'matrix', 'quaternion', 'color', 'angle', 'distance', 'area', 'volume', 'mass', 'moment', 'inertia', 'torque', 'force', 'torque', 'force', 'torque', 'force', 'torque'. The 'physics' branch includes 'physics', 'rigidbody', 'spring', 'damping', 'friction', 'collision', 'collision', 'collision', 'collision'. The 'display' branch includes 'display', 'text', 'text', 'text', 'text'. The 'data' branch includes 'data', 'table', 'table', 'table', 'table'. The 'events' branch includes 'events', 'event', 'event', 'event'. The 'ui' branch includes 'ui', 'button', 'button', 'button', 'button'. The 'util' branch includes 'util', 'util', 'util', 'util'. The 'network' branch includes 'network', 'network', 'network', 'network'. The 'animation' branch includes 'animation', 'animation', 'animation, 'animation'. The 'render' branch includes 'render', 'render', 'render', 'render'. The 'input' branch includes 'input', 'input', 'input', 'input'. The 'output' branch includes 'output', 'output', 'output', 'output'. The 'storage' branch includes 'storage', 'storage', 'storage', 'storage'. The 'audio' branch includes 'audio', 'audio', 'audio', 'audio'. The 'video' branch includes 'video', 'video', 'video', 'video'. The 'game' branch includes 'game', 'game', 'game', 'game'.



PRO Visualization

Per 100g of Food

Selected 1153 rows

Keep

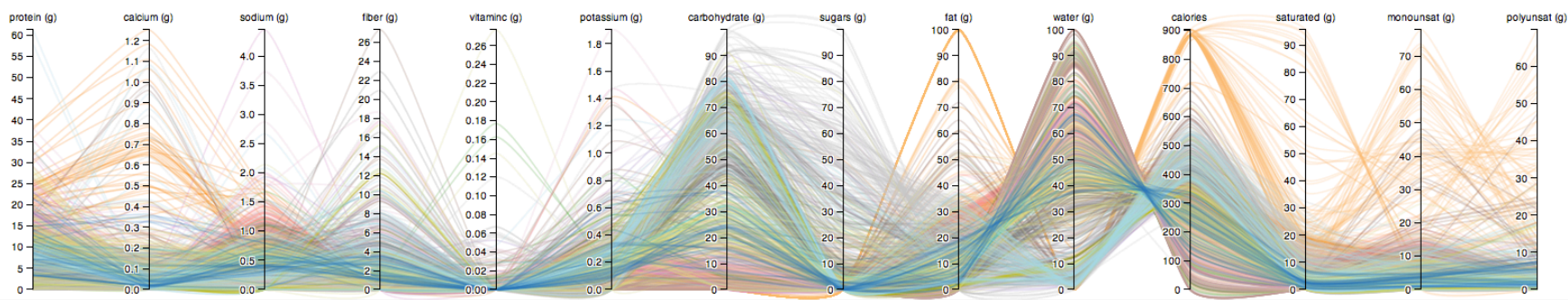
Remove

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



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



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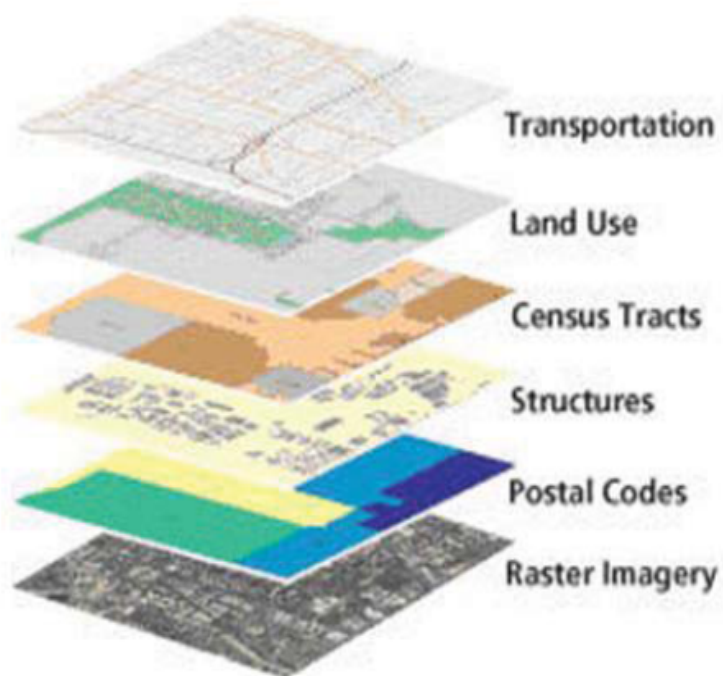


Duke Cancer Care
Research Program

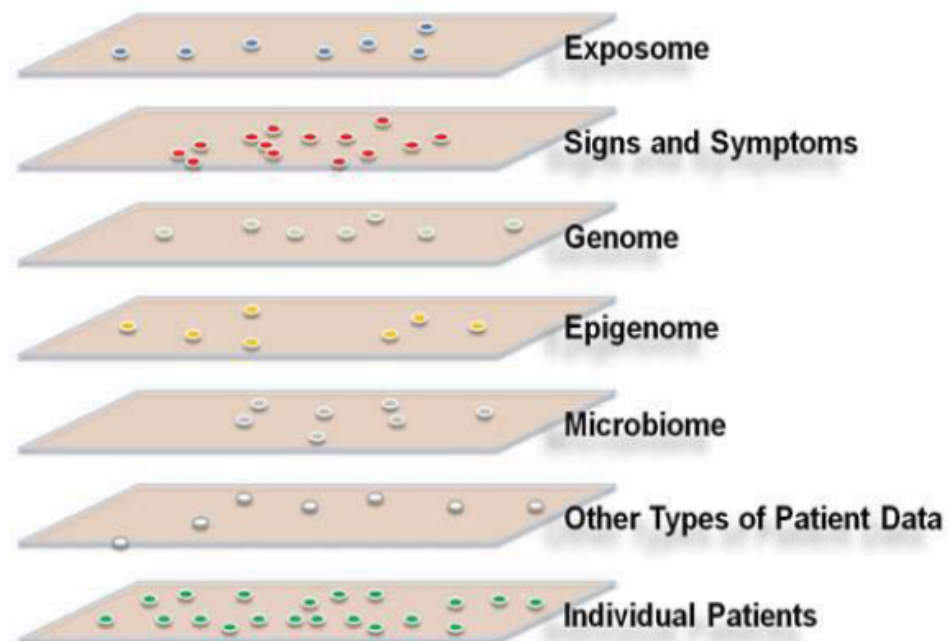
INTEGRATING SCIENCE TO ACHIEVE PRECISION



Google Maps: GIS layers Organized by Geographical Positioning



Information Commons Organized Around Individual Patients





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





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Duke Cancer Care
Research Program

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

Who needs to be at the table?

- ❖ Data architects
- ❖ Data analysts
- ❖ Software engineers
- ❖ Graphics design
- ❖ (Infographics and visualization)
- ❖ Statisticians and clinicians working with the IT team
- ❖ Behavioral medicine
- ❖ Clinical trials



**Data
generation,
use and
reuse**

Contact

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