

Experiences with web-based electronic system for collecting patient-reported data in oncology practice

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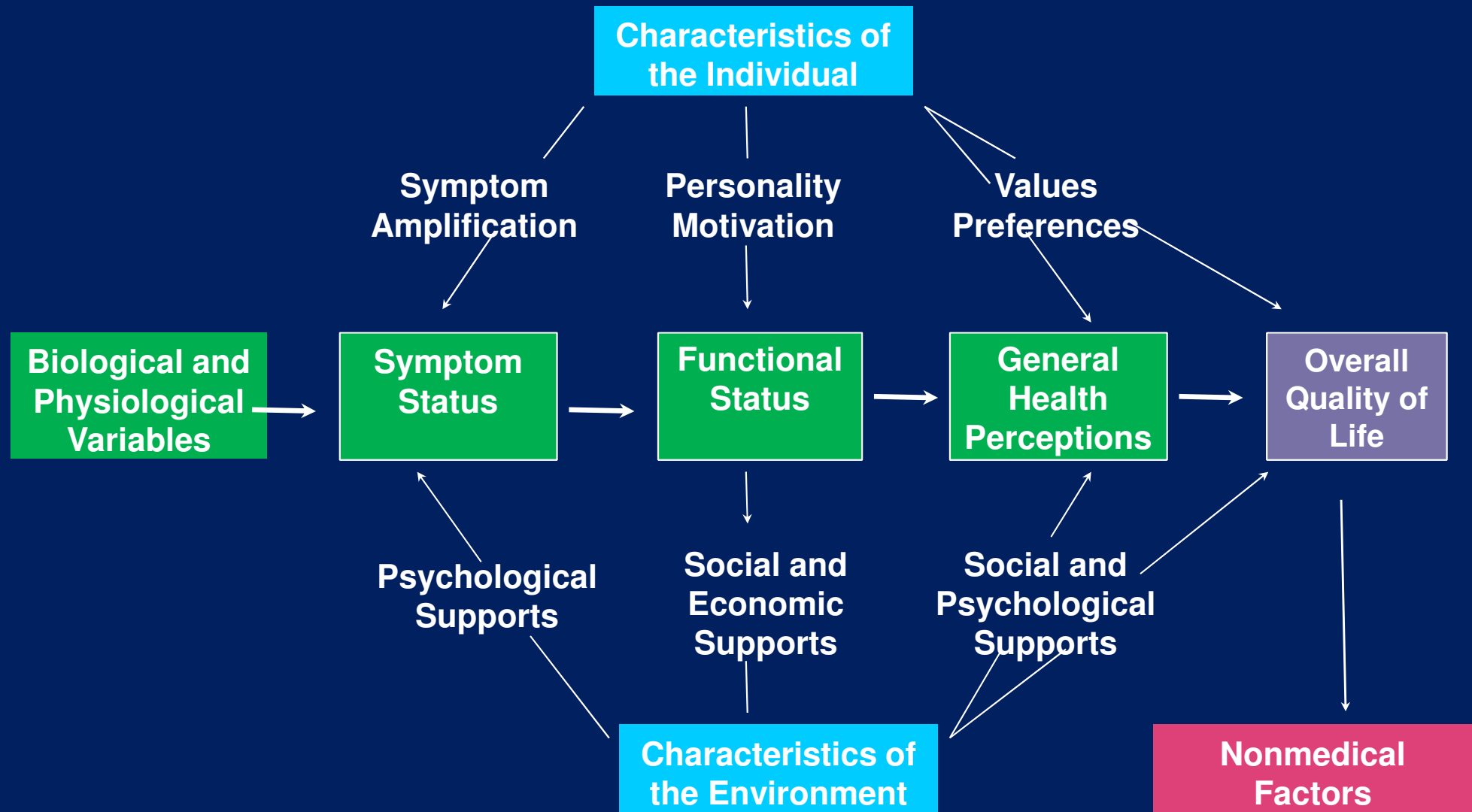


Outline

- Definitions and theoretical models of Patient-Reported Outcomes (PROs) in patient care
- The evidence - Systematic reviews
- Experience in Leeds, UK
 - RCT of HRQOL in oncology practice
 - Engaging and motivating clinicians
 - Monitoring of side-effects
 - Holistic needs assessment
- Implementation

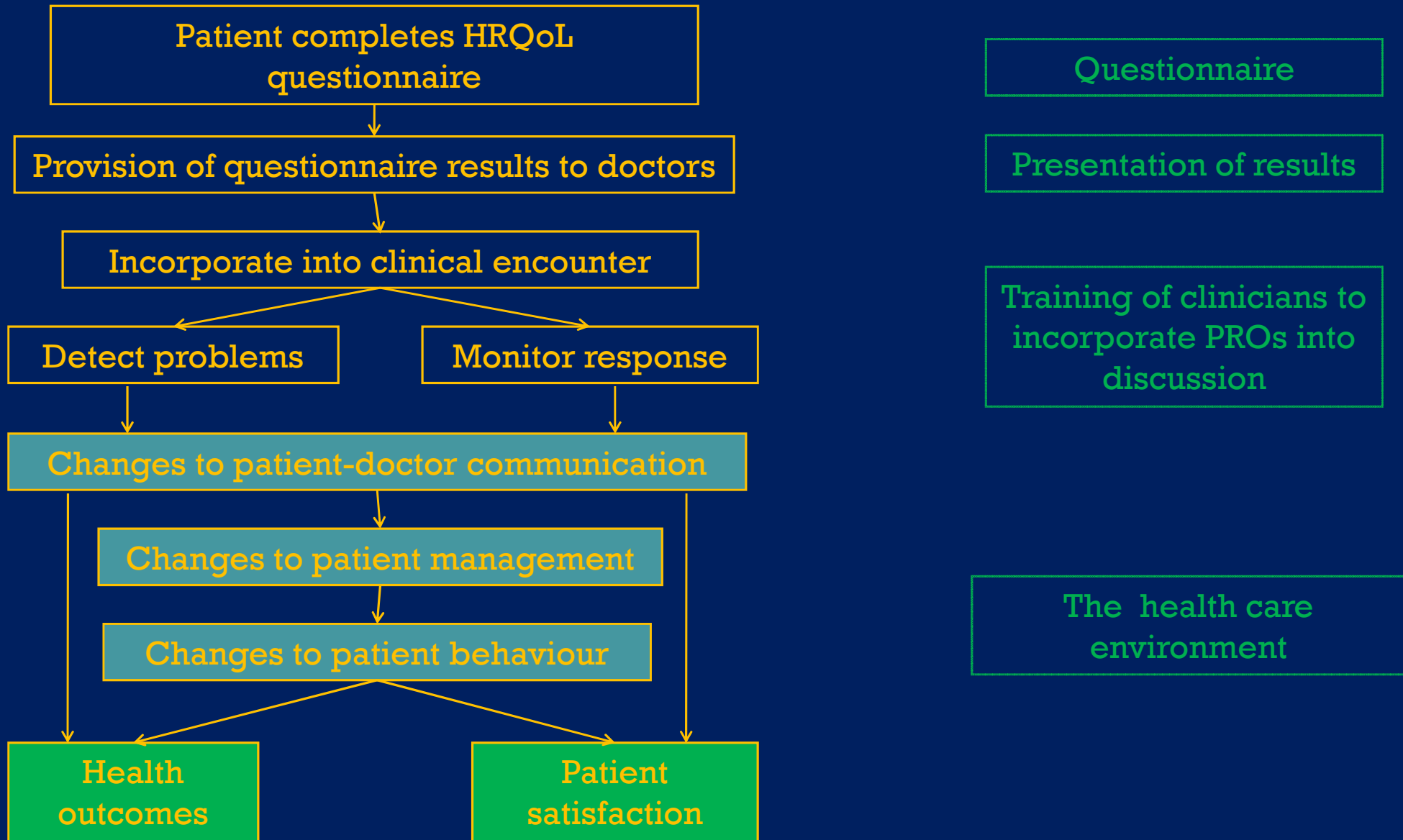
HRQOL conceptual model and Patient-Reported Outcomes

(Wilson and Cleary, JAMA 1995; 273(1): 59-65)



Assessment of symptoms/functioning in clinical practice
Patient-centred models of care

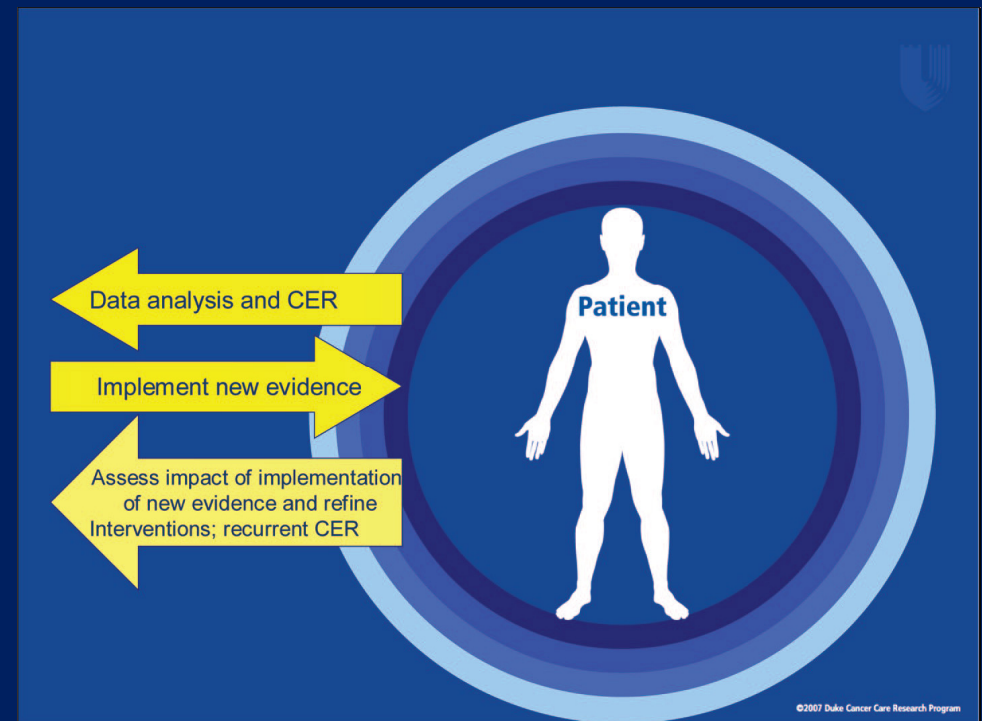
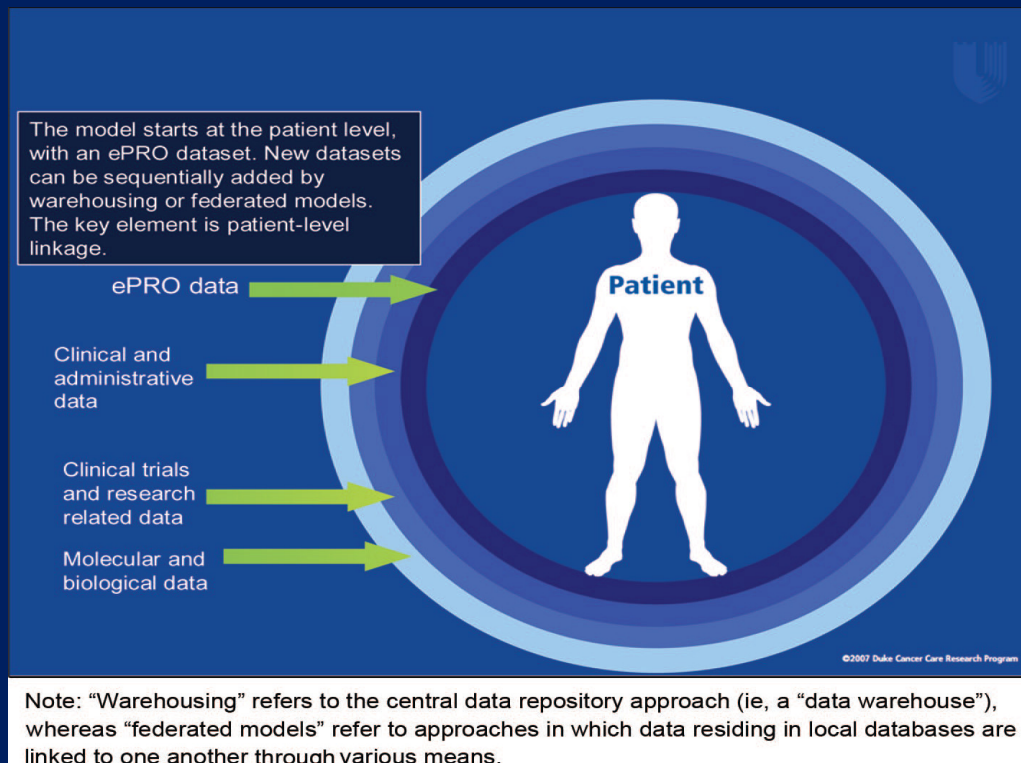
Theoretical model of impact of HRQOL measurement in daily practice (Greenhalgh 2005 modified)



Rapid learning healthcare model

(Abernethy A, 2003)

- Integration of ePROs into clinical care
- By patient-level linkage of clinical and administrative databases



Outline

- Definitions and theoretical models of Patient-Reported Outcomes (PROs) in patient care
- **The evidence - Systematic reviews**
- Experience in Leeds, UK
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The Evidence - Systematic reviews

Authors	Number of trials	Setting	Process of care communication	Patient outcomes	Satisfaction with care
Greenhalgh 1999	13	Primary care	+ 8/11 (73%)	+ 2/7 (29%)	+ 0/3 (0%)
Espallargues 2000	21	Primary care	+ 11/20 (55%)	+ 4/11 (36%)	+ 3/7 (43%)
Gilbody 2002	9**	Primary care	+ 2/8** (25%)	+ 2/5** (40%)	NA
Marshall 2006	38*	PC/cancer/ chronic d.	+17/30 (57%)	+ 5/18 (28%)	+ 3/12 (25%)
Valderas 2008	28	Primary care	+ 15/23 (65%)	+ 8/17 (47%)	+ 5/12 (42%)

Studies in oncology – RCT only

Authors	Patient No	Process of care-communication	Decision-making	Patient well-being	Satisfaction with care
McLachlan 2001	N=450	NA	--	-- (+ psychol)	--
Detmar 2002	N=214	+	--	-- (+ psychol)	--
Velikova 2004	N=286	+	--	+	--
Rosenbloom 2007	N=213 nurses	-/+	--	--	--
Berry 2011	N=660	+	NA	NA	NA
Calrson 2010	N=585 N=549	+		+ Distress	NA
Basch 2015	N=766	NA	Less ER visits	+ (+ survival)	NA

Outline

- Definitions and theoretical models of Patient-Reported Outcomes (PROs) in patient care
- The evidence - Systematic reviews
- **Experience in Leeds, UK -20 years**
 - **RCT of HRQOL in oncology practice**
 - Engaging and motivating clinicians
 - Monitoring of side-effects
 - Holistic needs assessment
- Implementation



Measuring Quality of Life in Routine Oncology Practice Improves Communication and Patient Well-Being: A Randomized Controlled Trial

Galina Velikova, Laura Booth, Adam B. Smith, Paul M. Brown, Pamela Lynch, Julia M. Brown, and Peter J. Selby

From the Cancer Research UK Clinical Centre—Leeds, Cancer Medicine Research Unit, St James's University Hospital; and Northern and Yorkshire Clinical Trials and Research Unit, Leeds, United Kingdom.

Submitted June 18, 2003; accepted December 5, 2003.

Supported by grants from Cancer Research UK (formerly Imperial Cancer

A B S T R A C T

Purpose

To examine the effects on process of care and patient well-being, of the regular collection and use of health-related quality-of-life (HRQL) data in oncology practice.

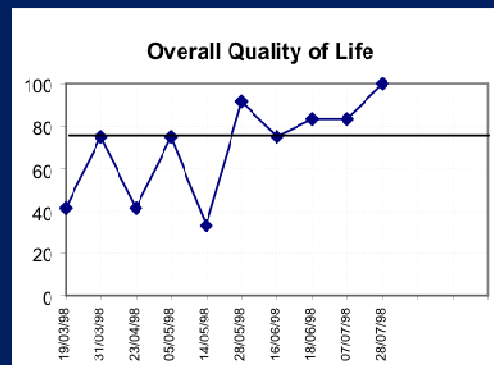
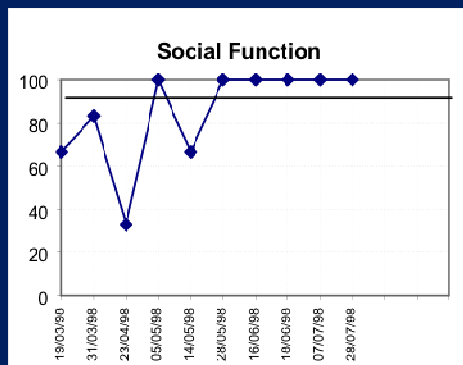
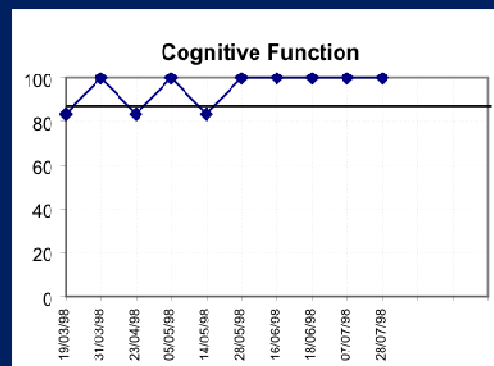
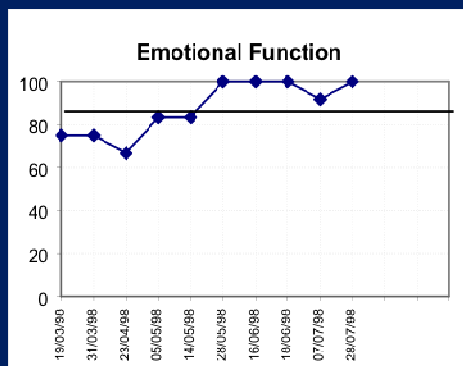
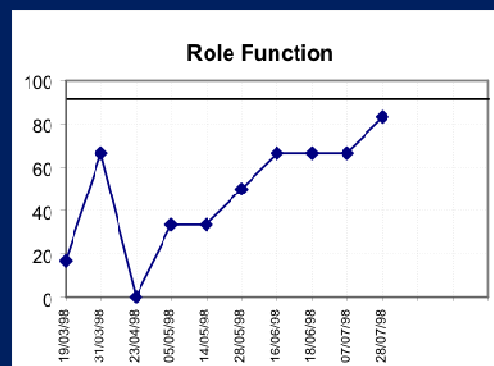
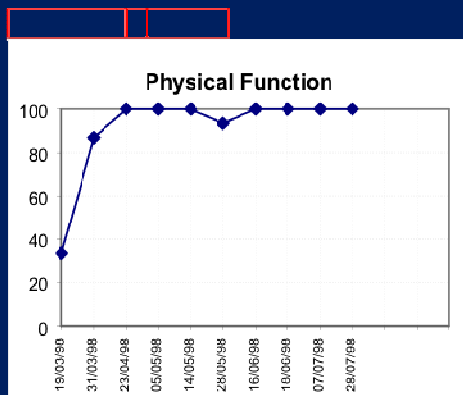
Patients and Methods

In a prospective study with repeated measures involving 28 oncologists, 286 cancer patients were randomly assigned to either the intervention group (regular completion of European Organization for Research and Treatment of Cancer—Core Quality of Life Questionnaire version 3.0, and Hospital Anxiety

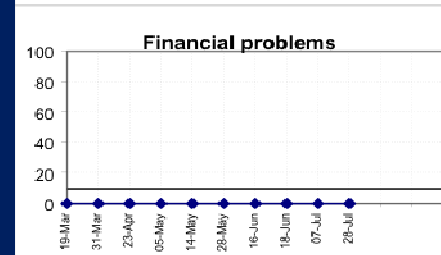
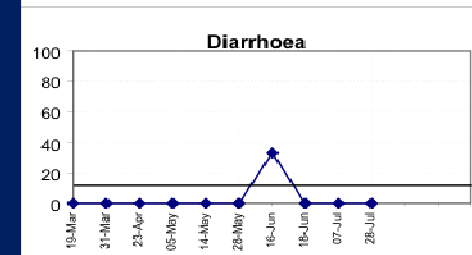
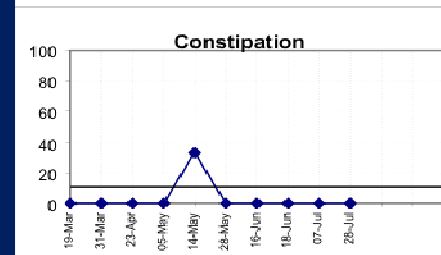
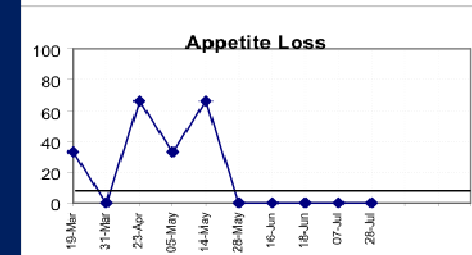
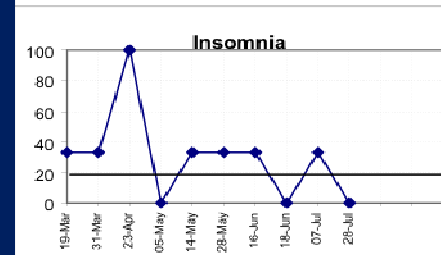
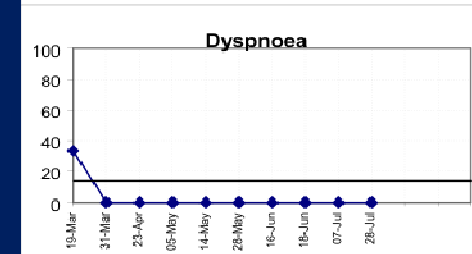
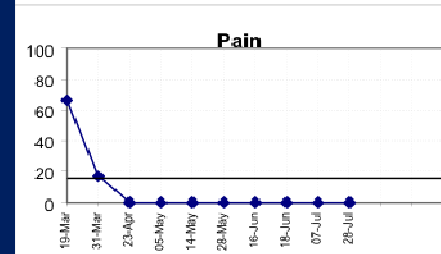
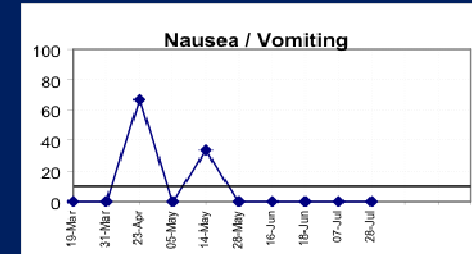
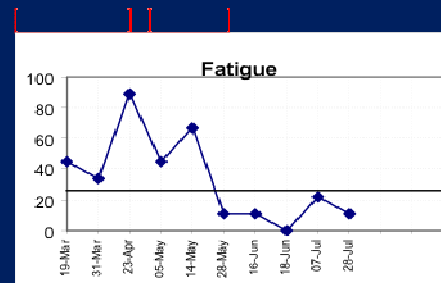
Velikova et al. J Clin Oncol 2004; 22, 714-724

EORTC QLQ-C30 Functional Scales

Higher score means better function
Lower score means less symptoms



EORTC QLQ-C30 Symptom Scales

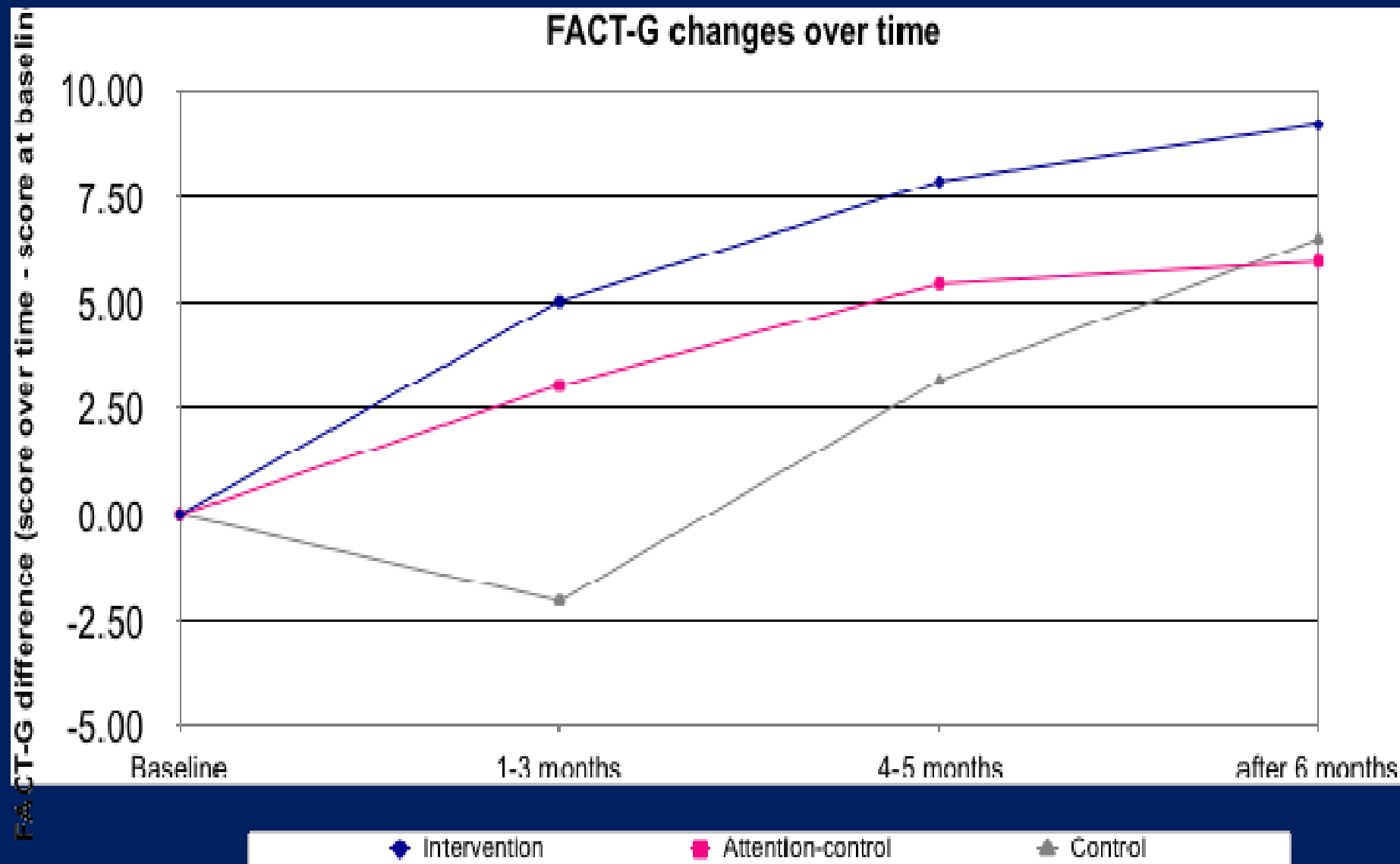


Mean values for general population

Mean values for general population

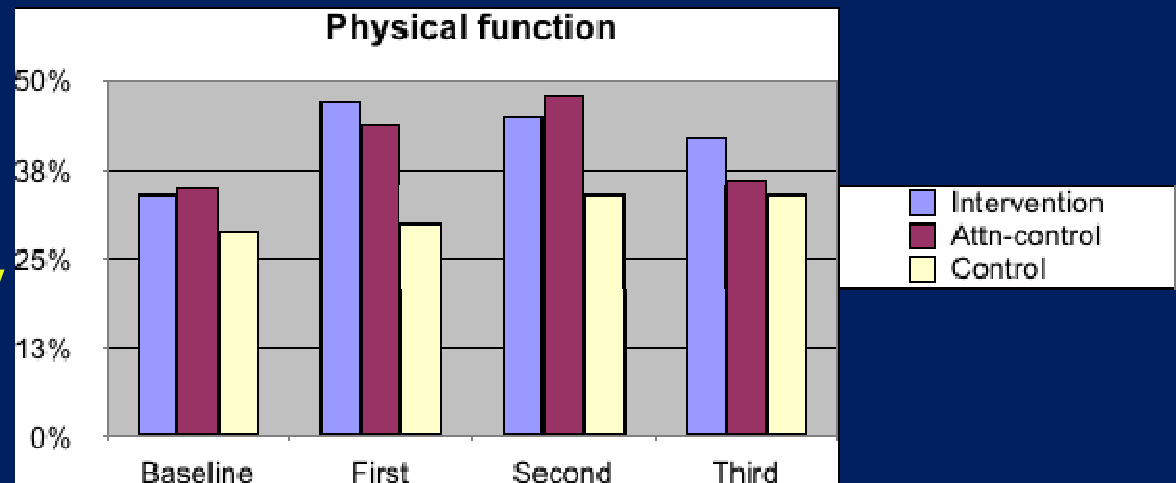
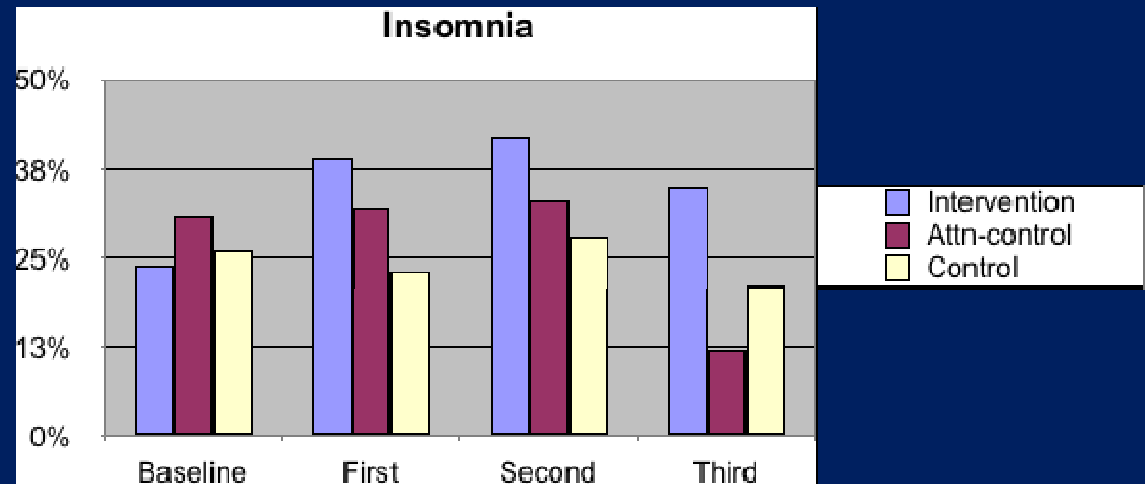
Results - Patient well-being

Changes in FACT-G scores over time



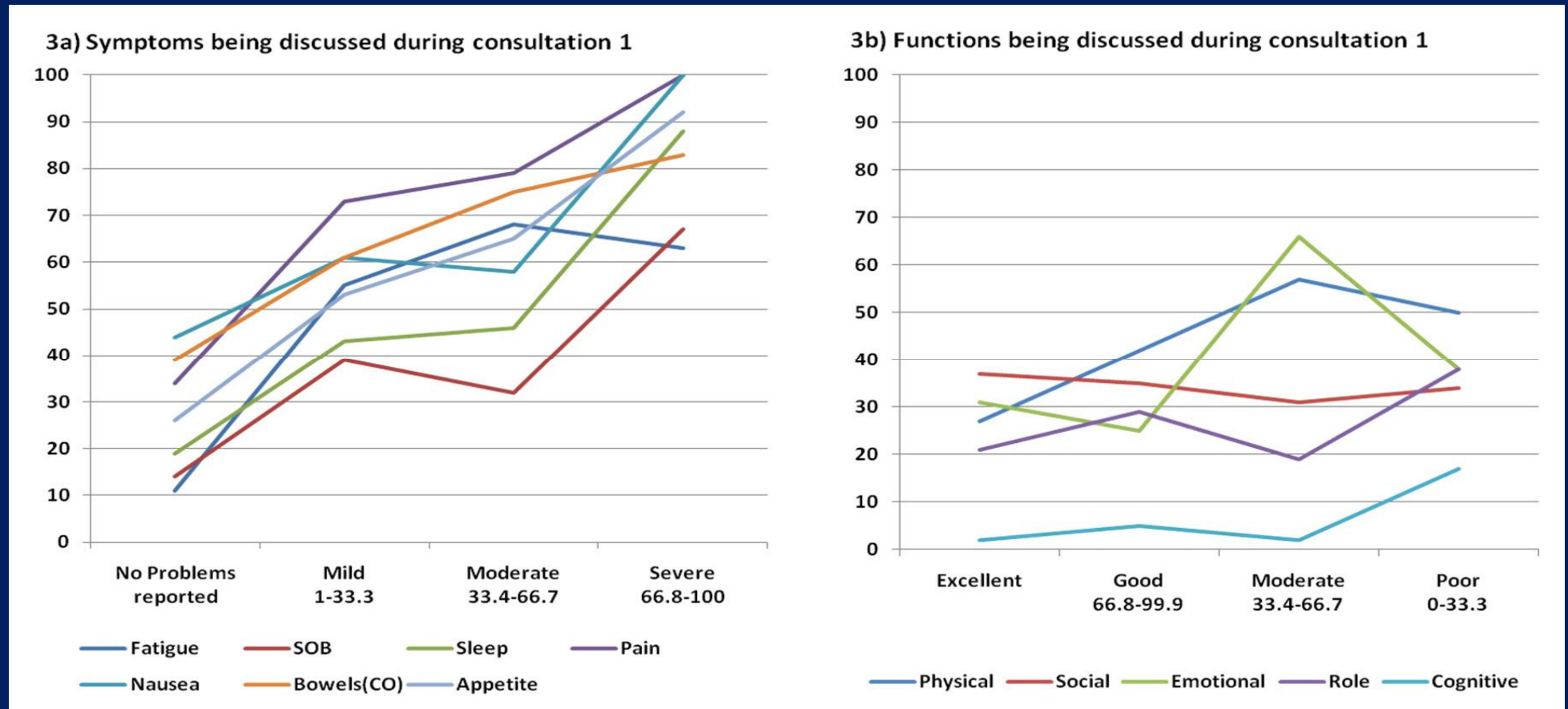
Results- Process of care measures- Communication

- Content analysis of **n=860** consultations
- Providing QOL data lead to more consistent discussion of
 - Insomnia ($p=0.003$)
 - Dyspnoea ($p=0.03$)
 - Physical function ($p=0.006$)
 - Emotional function ($p=0.03$)
- Symptoms were usually raised by the doctor
- Functions by patients



Oncologists discuss physical symptoms, but often do not address even serious functional problems (content analysis of 860 consultations)

(Takeuchi et al., 2011, JCO)



How to increase the impact?

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Training clinicians in how to use patient-reported outcome measures in routine clinical practice

Maria J. Santana · Lotte Haverman ·
Kate Absolom · Elena Takeuchi · David Feeny ·
Martha Grootenhuis · Galina Velikova

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Abstract

Introduction Patient-reported outcome measures (PROs) were originally developed for comparing groups of people in clinical trials and population studies, and the results

daily practice to identify/monitor symptoms, evaluate treatment outcomes and support shared decision-making. A key issue limiting successful implementation is clinicians' lack of knowledge on how to effectively utilize PROs data

Theoretical framework for implementing changes in medical practice

(R. Grol 1997 BMJ)

- A combination of approaches
- Education – adult learning
- Evidence base
- Marketing (needs of target audience)
- Behavioral (feedback and performance)
- Social interactions (opinion leaders)
- Organizational change

Training session

- The structure and content of the training session was based on:
 - Feedback received from oncologists during previous PROs studies
 - National communication skills program for oncologists- experiential learning
 - Role play
 - “Trigger tapes”

Qualitative studies

- Conversation analysis of consultations (with J Greenhalgh)
- Explicit referral to PROs results is important
- Interviews with oncology staff
- Requested more
 - Training in interpretation and use of PROs data
 - Tumour specific questions

Qual Life Res (2013) 22:939–950
DOI 10.1007/s11136-012-0218-3

How do doctors refer to patient-reported outcome measures (PROMS) in oncology consultations?

Joanne Greenhalgh · Purva Abhyankar ·
Serena McCluskey · Elena Takeuchi ·
Galina Velikova

Accepted: 23 May 2012 / Published online: 16 June 2012
© Springer Science+Business Media B.V. 2012

Abstract

Purpose We conducted a secondary qualitative analysis of consultations between oncologists and their patients to explore how patient-reported outcome measures (PROMs) data were referred to in the process of (1) eliciting and exploring patients' concerns; (2) making decisions about supportive treatment and (3) making decisions about chemotherapy and other systemic treatments.

Methods We purposively sampled audio recordings of 18 consultations from the intervention arm and 4 from the

Findings Explicit reference to the PROMs data provided an opportunity for the patient to clarify and further elaborate on the side effects of chemotherapy. High scores on the PROMs data were not explored further if the patient indicated they were not a problem or were not related to the cancer or chemotherapy. Symptomatic treatment was more often offered for problems like nausea, constipation, pain and depression but much less so for fatigue. Doctors discussed fatigue by providing a cause for the fatigue (e.g. the chemotherapy), presenting this as 'something to be

Psycho-Oncology

Psycho-Oncology 17: 690–698 (2008)

Published online 21 November 2007 in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/pon.1295

The clinical value of quality of life assessment in oncology practice—a qualitative study of patient and physician views[†]

Galina Velikova^{1,*†}, Noha Awad¹, Rebecca Coles-Gale¹, E. Penny Wright¹, Julia M. Brown^{2§} and Peter J. Selby^{1§}

¹ Cancer Research UK Clinical Centre—Leeds, Cancer Medicine Research Unit, St James's University Hospital, Leeds, UK

² Clinical Trials and Research Unit, University of Leeds, Leeds, UK

* Correspondence to: Cancer Research UK Clinical Centre—Leeds, St James's University Hospital, Beckett Street, Leeds LS9 7TF, UK.
E-mail: gvelikova@leeds.ac.uk
[†] Presented in part as a poster at the 7th World Congress of Psycho-Oncology, 25th–28th August 2004, Copenhagen, Denmark.
[§] Cancer Research UK Clinician Scientist.
[§] Joint senior authors.

Abstract

Background: Patients' self-reported questionnaires measuring symptoms, functioning and quality of life (QOL) can help physicians to screen and monitor patient problems in oncology practice. Although many self-reported questionnaires have been developed, their role in clinical practice remains unclear. This study explores what oncologists and patients need from QOL questionnaires, what their clinical value is and generates recommendations how to improve the questionnaires for use in oncology practice.

Methods: Focus groups were conducted in the Leeds Cancer Centre (St James's and Cookridge hospitals, UK), with 31 patients (9 groups) and 16 oncologists (4 groups). Twenty patients completed a questionnaire. Framework analysis was employed for the analysis.

Results: Patients and physicians wanted the questionnaires to cover: common symptoms and problems (e.g. pain, fatigue), disease and treatment-specific issues (common for patients with similar diagnosis and/or treatment), individual patient-specific issues (usually non-physical, e.g.

Development of “trigger tapes”

Common and typical clinical scenarios

- Patient with multiple physical symptoms and emotional distress
 - Help prioritise and structure the consultation
- Patient with depression
 - Management of depression
- Patient with physical symptoms limiting work and family
 - Detect functional problems
- Patient responding to treatment doing well
 - Make consultation more efficient



Content and supporting material

- Training session – 3 hours
- Didactic overview (evidence base – 15 mins)
- Review and discussion of PROs graphs
- Interactive session
 - Review of specific “trigger tapes”
 - Clinical information presented
 - PRO data presented - what does this add?
 - View DVD clips
 - How PRO data was used by doctor
 - Feedback from the patient actor on value of PRO data

Box 1. Example training scenario: Patient with multiple problems

Patient

- Pauline Barker- 70 year old woman with stage 3C ovarian cancer (papillary serous histology)

Clinical summary

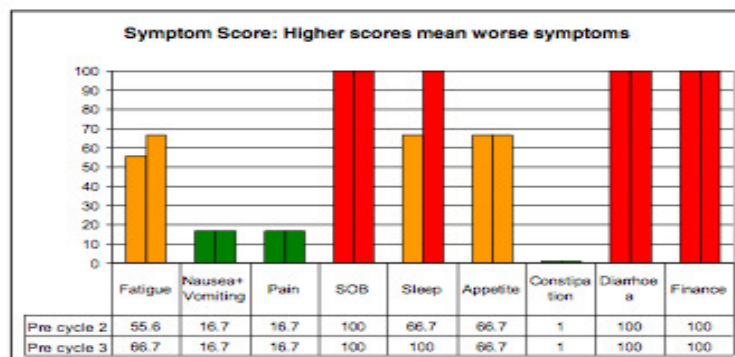
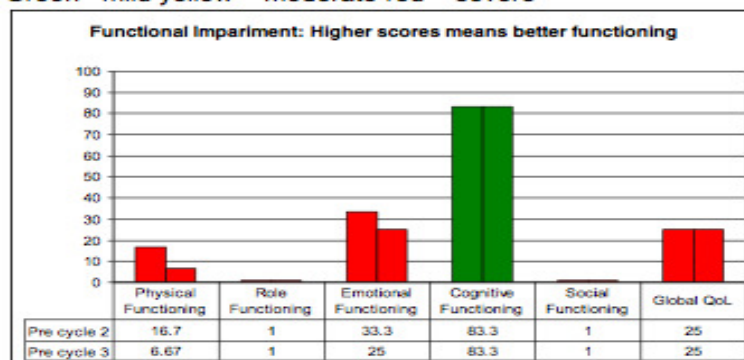
- Presented with subacute bowel obstruction
- Underwent defunctioning ileostomy formation and multiple biopsies, which confirmed histological type. The patient has experienced post-operative problems with high output stoma
- Commenced on palliative chemotherapy with single agent carboplatin
- CA125 which was initially >3000 is improving. The last result was 2640 after cycle 1
- No problems with neutropenia or thrombocytopenia so far but she is becoming anaemic
- Attending clinic today for review prior to 3rd cycle of chemotherapy

Social summary

- Married. Lives with elderly husband who is 77 years of age, who is recovering from abdominal surgery
- Has a district nurse that visit regularly
- 3 adult children, none live locally

Patient reported data

Green= mild yellow = moderate red = severe



Key learning points from simulated consultation

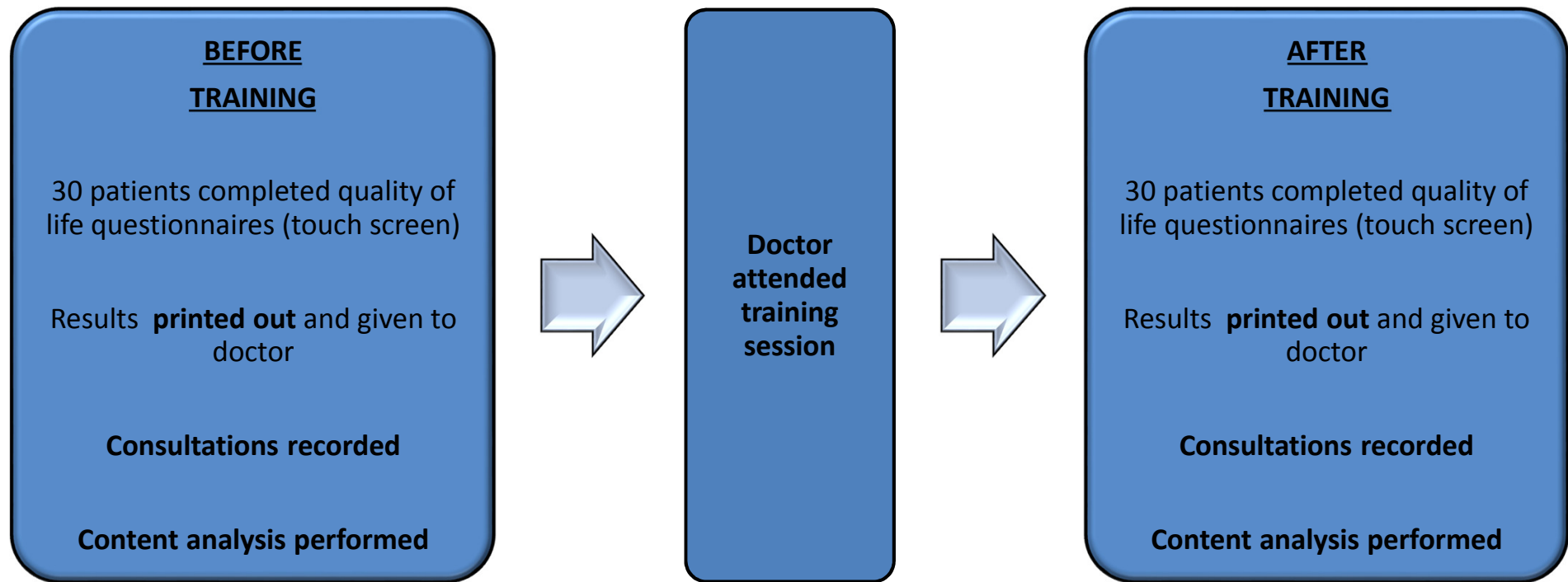
The patient reported data:

- helped to give structure and focus to the consultation
- provided the doctor with a quick route to key issues
- lead to a more holistic approach to patient care
- allowed the doctor to acknowledge that the patient was experiencing a lot of problems but that everything could not be 'fixed' in one consultation

Discussion of the case

- Interpretation of PRO scores
 - DVD clip
 - How HRQOL was included
 - How did it contribute?
-
- https://youtu.be/1SorGQev_Hs clip 2

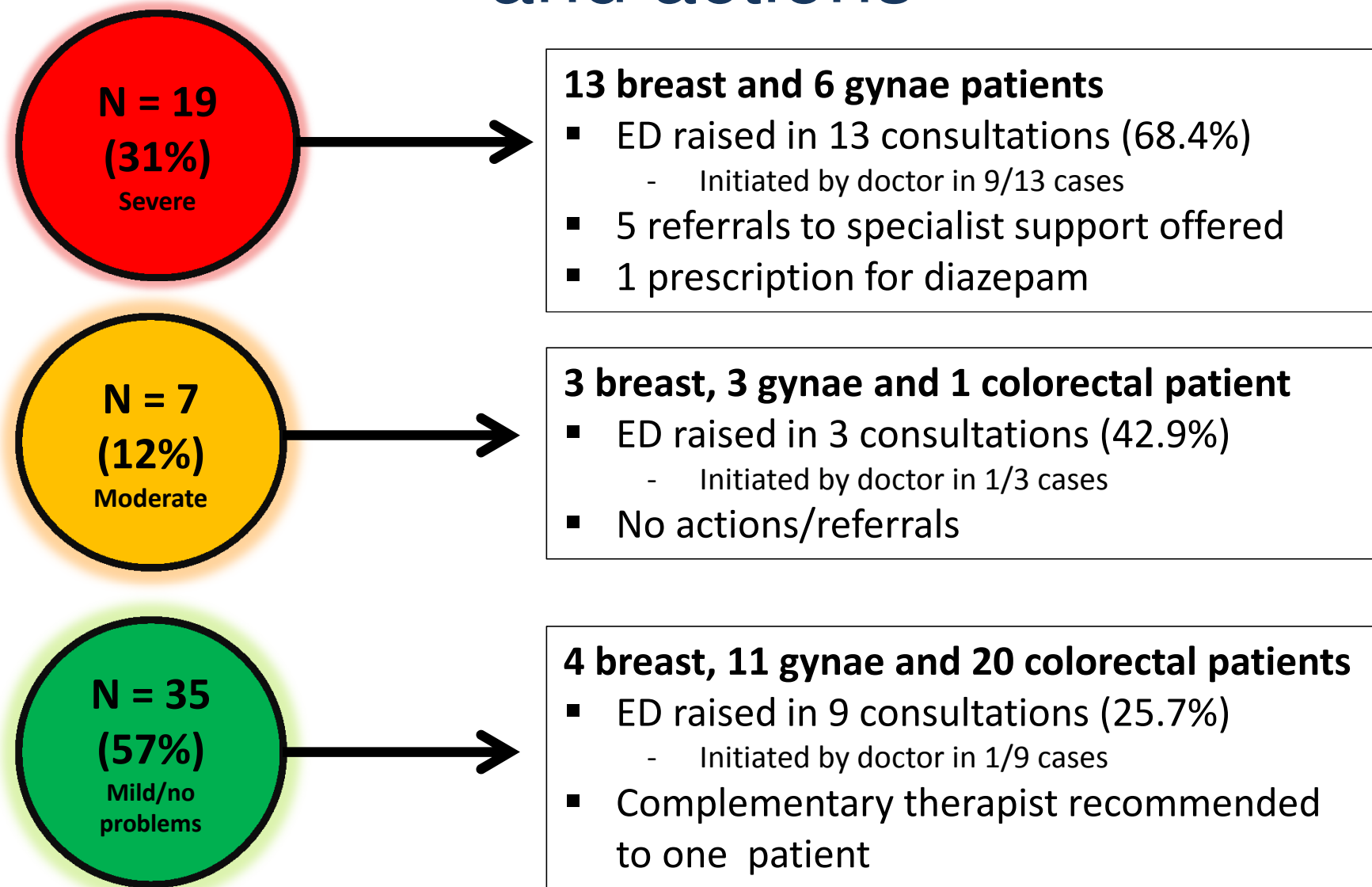
Small pilot study using Before- After design



Results - Content Analysis

- The questionnaire was explicitly referred to in more consultations in the post-training phase (48% vs 77%, $p < 0.05$).
- The mean number of discussed cancer symptoms did not differ (3.81 vs 4.27, $p = 0.24$)
- The mean number of functions discussed did differ (2.23 vs 2.90, $p < 0.05$).
- Specifically
 - Physical functioning (61% vs 87%, $p < 0.05$)
 - Pain (52% vs 87%, $p < 0.05$).

Results - Levels of emotional distress and actions



What have we learned?

- Worked examples and scenarios are great but time consuming
- Brief but focused training and support
 - How to access the data (Written instructions/pocket cards)
 - How to interpret the graphs
 - **Refer explicitly to PROs**
 - **Invite patient to explain**
 - **Discuss and act**
 - Guidelines and referral pathways

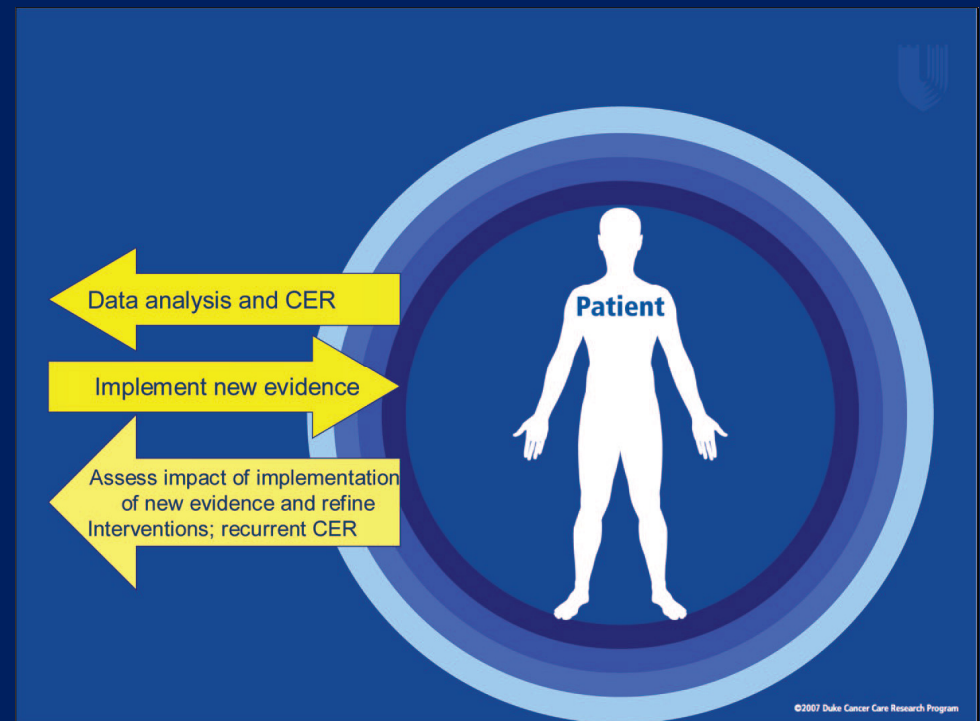
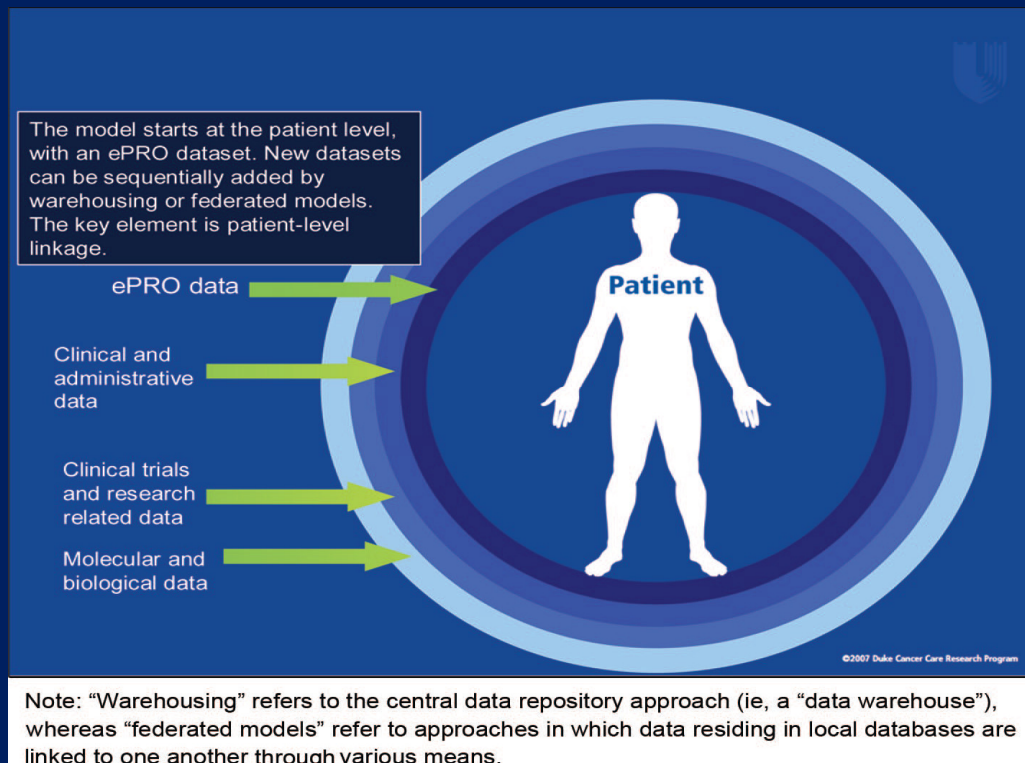
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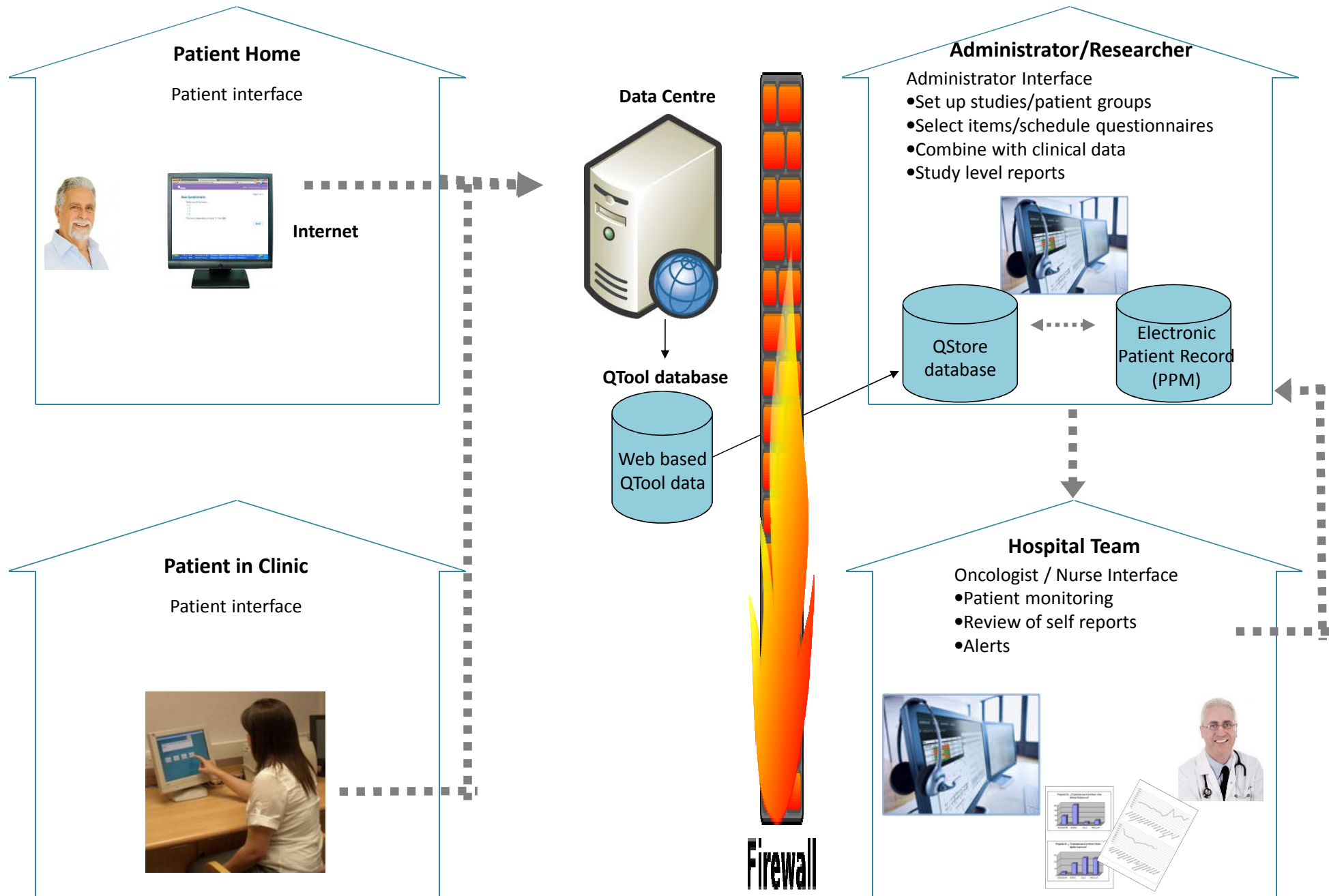
Rapid learning healthcare model

(Abernethy A, 2003)

- Integration of ePROs into clinical care
- By patient-level linkage of clinical and administrative databases



eRAPID System Overview



Current projects

- eRAPID – Adverse events/Toxicity monitoring during cancer treatment
 - NIHR funded research development programme
- Holistic Needs Assessment by nurses
 - Service development
 - Distress Thermometer



eRAPID

*Developing a system for
cancer patients to report
symptoms online*

HOME

MANAGING CANCER
SYMPTOMS AND TREATMENT
SIDE EFFECTS

KEEPING HEALTHY DURING
CANCER TREATMENT

COPING WITH CANCER AND
YOUR TREATMENT

Welcome to the home page of the University of Leeds and Leeds Teaching Hospitals, eRAPID research project funded by a National Institute for Health Research (NIHR) Programme Development Grant (RP-DG-1209-10031).

eRAPID stands for “**E**lectronic patient self-**R**eporting of **A**dverse-events: **P**atient **I**nformation and **aD**vice”.

The aim is to develop an integrated web-system for patients to report symptoms and side effects during and after cancer treatment. Data that is reported by patients using the web-system (called QTool) will be documented in individual patient electronic health records. Where patients report mild side effects they will receive advice on how to manage them and to seek timely medical advice. Where patients report serious side effects, a system of alerts will be sent to clinicians.

eRAPID presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Development Grants scheme (RP-DG-1209-10031). The views expressed on this website are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

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If you have any queries regarding the content of this website, please contact **The Psychosocial and Clinical Practice Research Group (POG)** on (0113) 20 67628.



Psychosocial
Oncology and Clinical
Practice Research Group

Click here
to complete
eRAPID
questionnaires



eRAPID demo questionnaire

Page 1 of 6



Have you had pain or discomfort anywhere on your body?

☐

No

☒

I had mild pain or discomfort

☐

I had moderate pain and discomfort and was not able to do some of the things I normally do (for example, household chores/ shopping)

☐

I had severe pain and discomfort and was not able to care for myself (for example getting out of bed, bathing, dressing)

[Next page](#)

Generating Alerts for Severe Symptoms

eRAPID demo questionnaire

Page 1 of 6

Have you had pain or discomfort anywhere on your body?

- ☐ No
- ☐ I had mild pain or discomfort
- ☐ I had moderate pain and discomfort and was not able to do some of the things I normally do (for example, household chores/ shopping)
- ☒ I had severe pain and discomfort and was not able to care for myself (for example getting out of bed, bathing, dressing)

You have indicated serious problems in this area. Please contact the hospital **immediately** to discuss your symptoms with the medical team, you may need a hospital admission.

Before you contact the hospital and if you feel able, please still complete the remaining questions.

[Next page](#)

Automated Advice for Mild Symptoms



https://qtool.leeds.ac.uk/TakeQuestionnaire/a55f1b79-81b3-4cf9-9e5a-89805f2a446d/page6



Google



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eRAPID demo questionnaire

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For your Pain:

If you have been prescribed painkillers (also known as analgesics) by your doctor, take the maximum dose that you have been recommended as soon as you first feel you have pain. Make sure that you take your painkillers regularly, even if you have mild pain, which you think you can cope with. It is easier to prevent the pain than to treat existing pain. Do not exceed the maximum dose that you have been prescribed.

If you haven't been prescribed any painkillers by your doctor and you have mild pain, there are certain painkillers that you can take which can be bought without a prescription. Painkillers suitable for mild pain include:

✚ Paracetamol

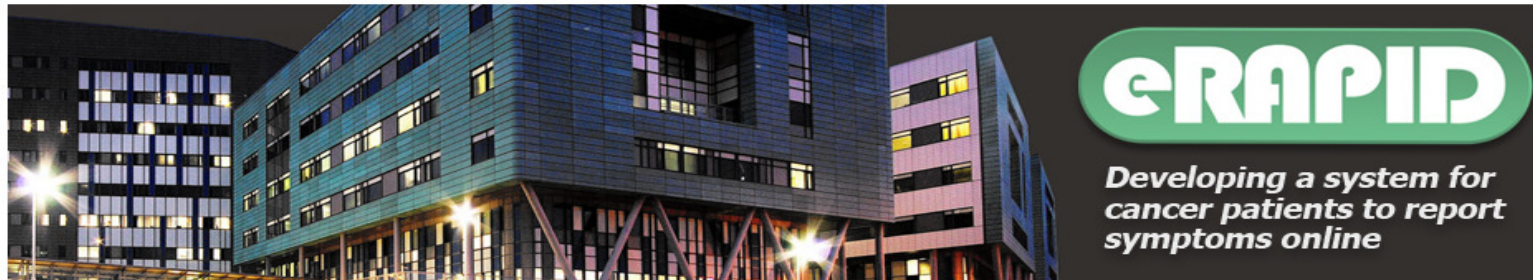
✚ Ibuprofen

Take the dose that is advised by the pharmacist or indicated on the drug information as soon as you feel that you first have pain. Make sure that you take your painkillers regularly, even if you have mild pain, which you think you can

Link to the eRAPID Website for

erapid.leeds.ac.uk/index.php/advice-for-patients-during-cancer-treatment/symptoms-and-side-effects/pain/

Google



HOME

MANAGING CANCER

SYMPTOMS AND TREATMENT SIDE EFFECTS

Feeling Or Being Sick

Pain, Aches And Discomfort

Diarrhoea

Constipation

Sore Mouth

Lack Of Appetite

Temperature / Chills

Shortness Of Breath

Fatigue

Difficulty Sleeping

Numbness In Hands And Feet

Low Mood

Anxiety

KEEPING HEALTHY DURING CANCER TREATMENT

COPING WITH CANCER AND YOUR TREATMENT

Pain, Aches and Discomfort

Pain is a very personal experience and nobody else can understand exactly how you feel when you have pain. This means you are actually the most important person in making sure your pain is kept under control as you are the one who can tell your medical team how it feels, what makes it worse, when it gets better and what it prevents you from doing. Even if you have only mild pain or discomfort which you think you can cope with, if it isn't managed quickly sometimes it can become very difficult to control. Having pain can make things harder for you, both emotionally and physically. If your pain is well controlled you should enjoy a better overall quality of life.

Medication

If you have been prescribed painkillers (also known as analgesics) by your doctor, take the dose that you have been recommended as soon as you first feel you have pain. Even if you have only mild pain or discomfort which you think you can cope with, make sure that you take painkillers as it is easier to prevent pain than to treat existing pain. Do not exceed the maximum daily dose that you have been prescribed.

If you have pain but haven't been prescribed any painkillers, there are certain painkillers that you can take which can be bought without a prescription. Painkillers suitable for mild pain include:

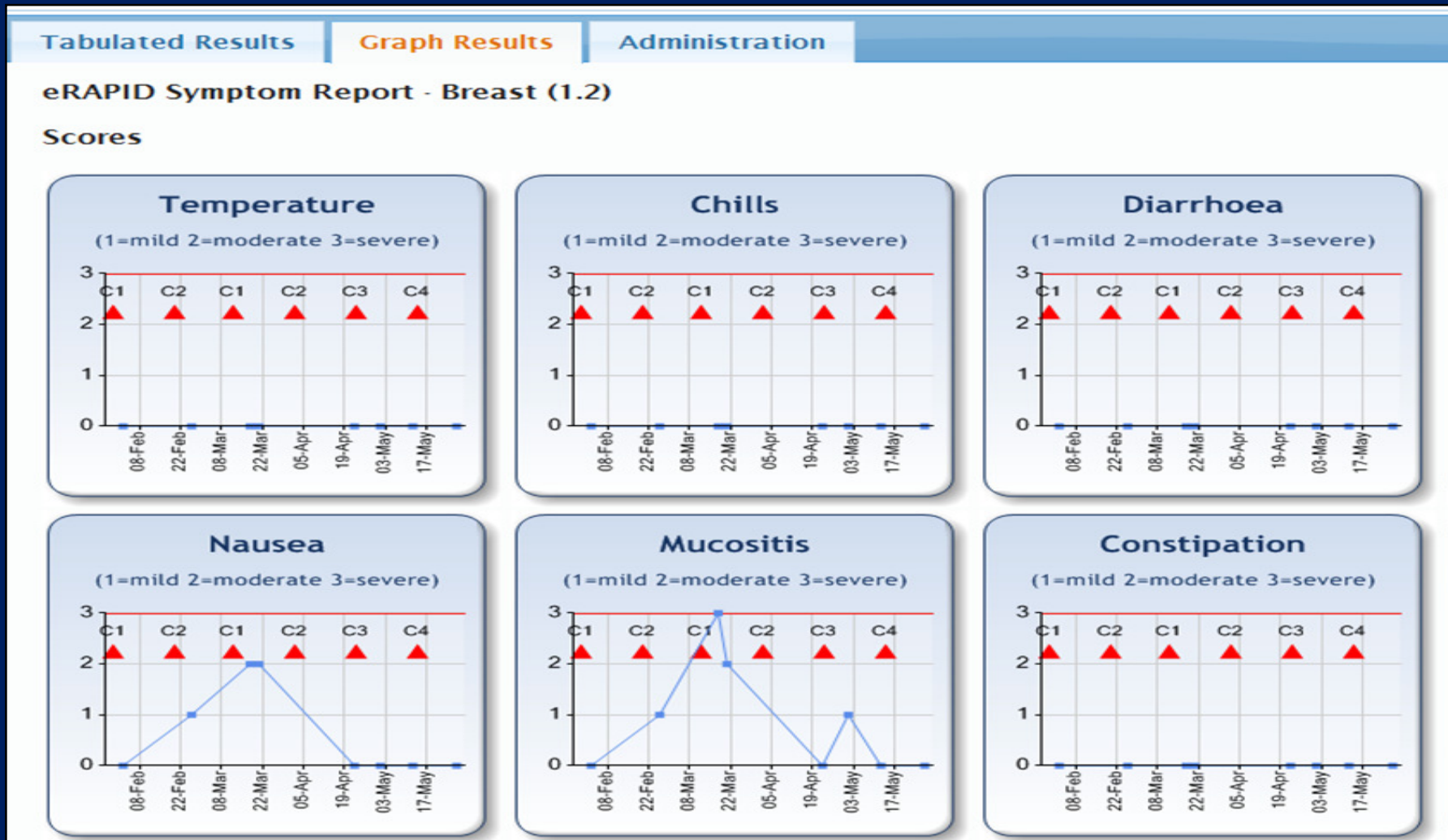
Paracetamol

pog Psychosocial
Oncology and Clinical
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Click here
to complete
eRAPID
questionnaires

Clinician view EHR- graphs

- Integration with Electronic Patient records in real time



Clinician View in EHR - Table

Patient Pathway Manager (Version 1.04.108) - [Trial Browser (using All Diseases)]

File Edit View Go Tools Window Help

Trial Filters Contact Queries Admin

TR: Clinical Trial Filter Trial Name or Code (partial) Principal Investigator Trial Type Trial Status Patient Status Find More...

Results Clinical Trial Episode QTool Documents

Tabulated Results Graph Results Administration

ALERT: 11-Mar-2014, Alert Name: SevereNausea, Alert Level:High, Details: Patient reported severe nausea - eRAPID Toxicity (4.5)
 ALERT: 11-Mar-2014, Alert Name: SeverePain, Alert Level:High, Details: Patient reported severe pain - eRAPID Toxicity (4.5)
 ALERT: 11-Mar-2014, Alert Name: SeverePhysicalAbility, Alert Level:High, Details: Patient reported severe physical difficulty - eRAPID Toxicity (4.5)

eRAPID Toxicity (4.5)

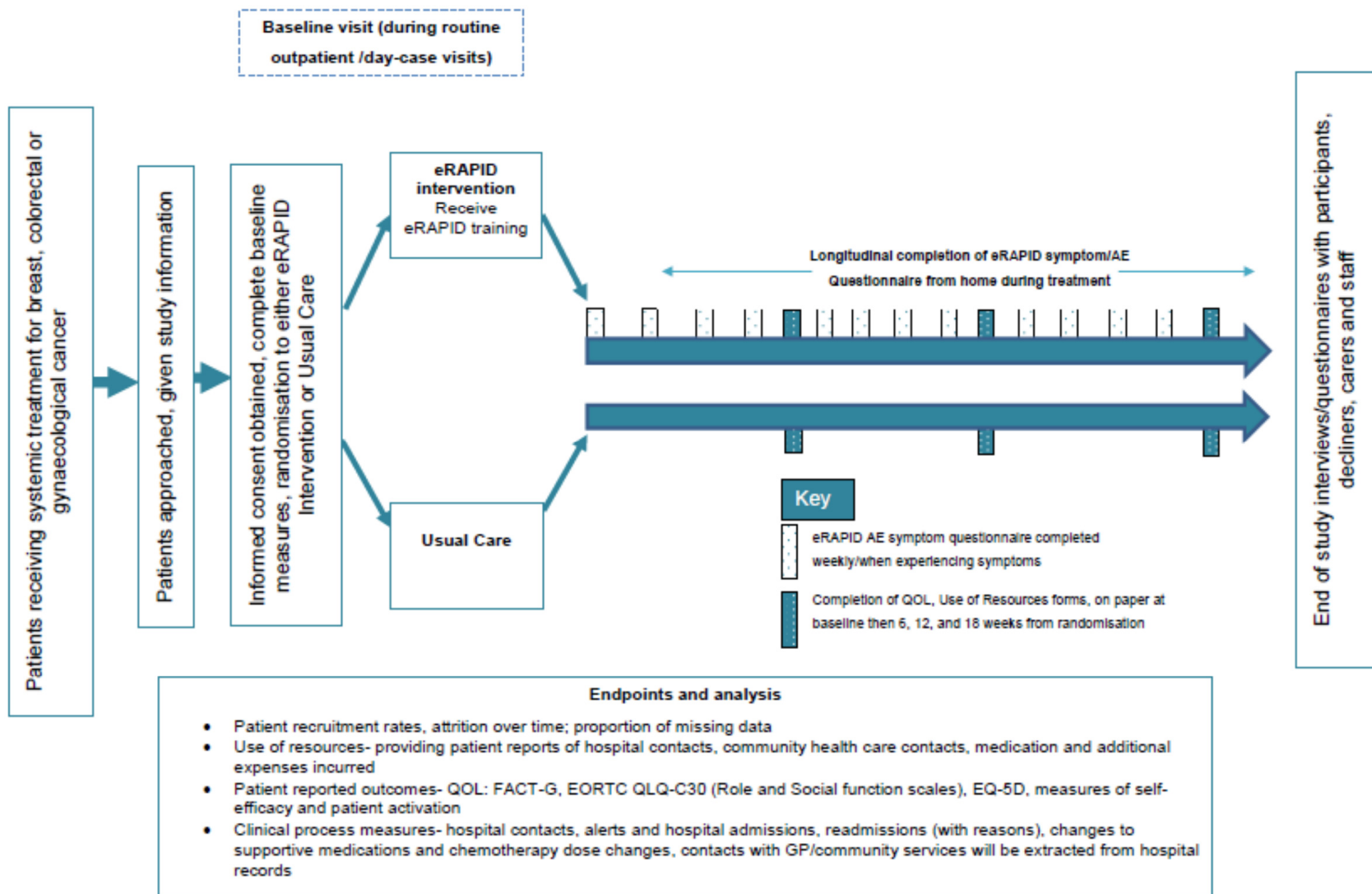
Scores	12-May-	28-Apr-	14-Apr-	07-Apr-	24-Mar-	11-Mar-
Pain (1=mild 2=moderate 3=severe)	2	1	1	0	1	3
Vomiting (1=mild 2=moderate 3=severe)	0	0	2	0	0	0
Nausea (1=mild 2=moderate 3=severe)	1	0	2	0	2	3
Diarrhoea (1=mild 2=moderate 3=severe)	1	0	0	0	0	0
Constipation (1=mild 2=moderate 3=severe)	0	1	1	1	1	1
Mucositis (1=mild 2=moderate 3=severe)	1	1	1	0	1	2
Temperature (1=mild 2=moderate 3=severe)	0	0	0	0	0	2
Chills (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Difficulty with physical abil (1=mild 2=moderate 3=severe)	2	1	1	0	2	3
Lack of appetite (1=mild 2=moderate 3=severe)	0	0	1	0	1	1
Fatigue (1=mild 2=moderate 3=severe)	1	1	1	1	1	2
Difficuly sleeping (1=mild 2=moderate 3=severe)	1	1	0	1	1	1
Shortness of breath (1=mild 2=moderate 3=severe)						
Sore hands/feet (1=mild 2=moderate 3=severe)						
Neuropathy (1=mild 2=moderate 3=severe)					1	1
Anxiety (1=mild 2=moderate 3=severe)	1					
Depression (1=mild 2=moderate 3=severe)					1	
Leg weakness (1=mild 2=moderate 3=severe)						
Seizures (1=mild 2=moderate 3=severe)						
Passing out (1=mild 2=moderate 3=severe)						
Reaction at the site of injec >		1				

Record Status

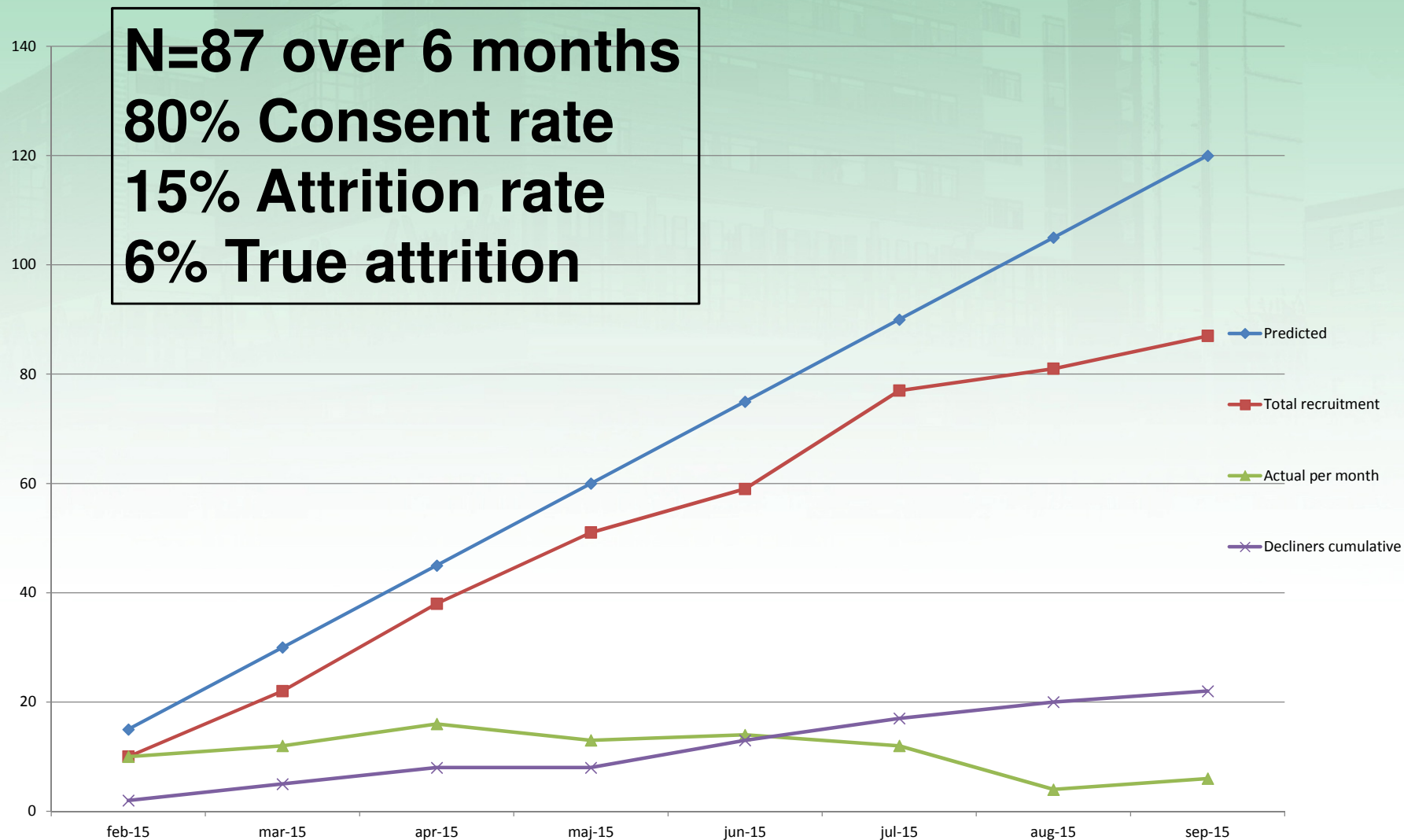
Trial Stage - Overdue Trial Entry (>1 month).

CAPS INS VELIKOVG (USER / LeedsTH) on PPM LIVE CENTRAL 23/06/2014 16:28

start Patient Pathway Man... Results Server V2.5 ~... Positions for Qtool Ta... Document1 - Microsof...



Recruitment to the Internal Pilot



Service Development with Nurses

Holistic Needs Assessment

Distress Thermometer

Take Questionnaire: Holistic Needs Assessment - General - Windows Internet Explorer provided by Trust Computer Services

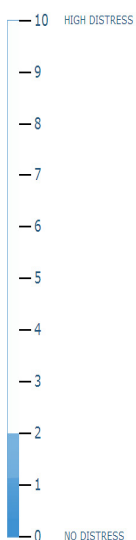
http://ttest.x-hisystems.co.uk/TakeQuestionnaire(2654b0c2-997f-4f52-95d1-60f99e103e5d)/page1

TOOL yoraway | Change Password | Log Out

Page 1 of 3

Holistic Needs Assessment - General

First please select the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today, by clicking on the scale below. Then click 'Next' at the bottom of the screen.



10 HIGH DISTRESS

9

8

7

6

5

4

3

2

1

0 NO DISTRESS

Next

Take Questionnaire: Holistic Needs Assessment - General - Windows Internet Explorer provided by Trust Computer Services

http://ttest.x-hisystems.co.uk/TakeQuestionnaire(2654b0c2-997f-4f52-95d1-60f99e103e5d)/page2

TOOL yoraway | Change Password | Log Out

Page 2 of 3

Holistic Needs Assessment - General

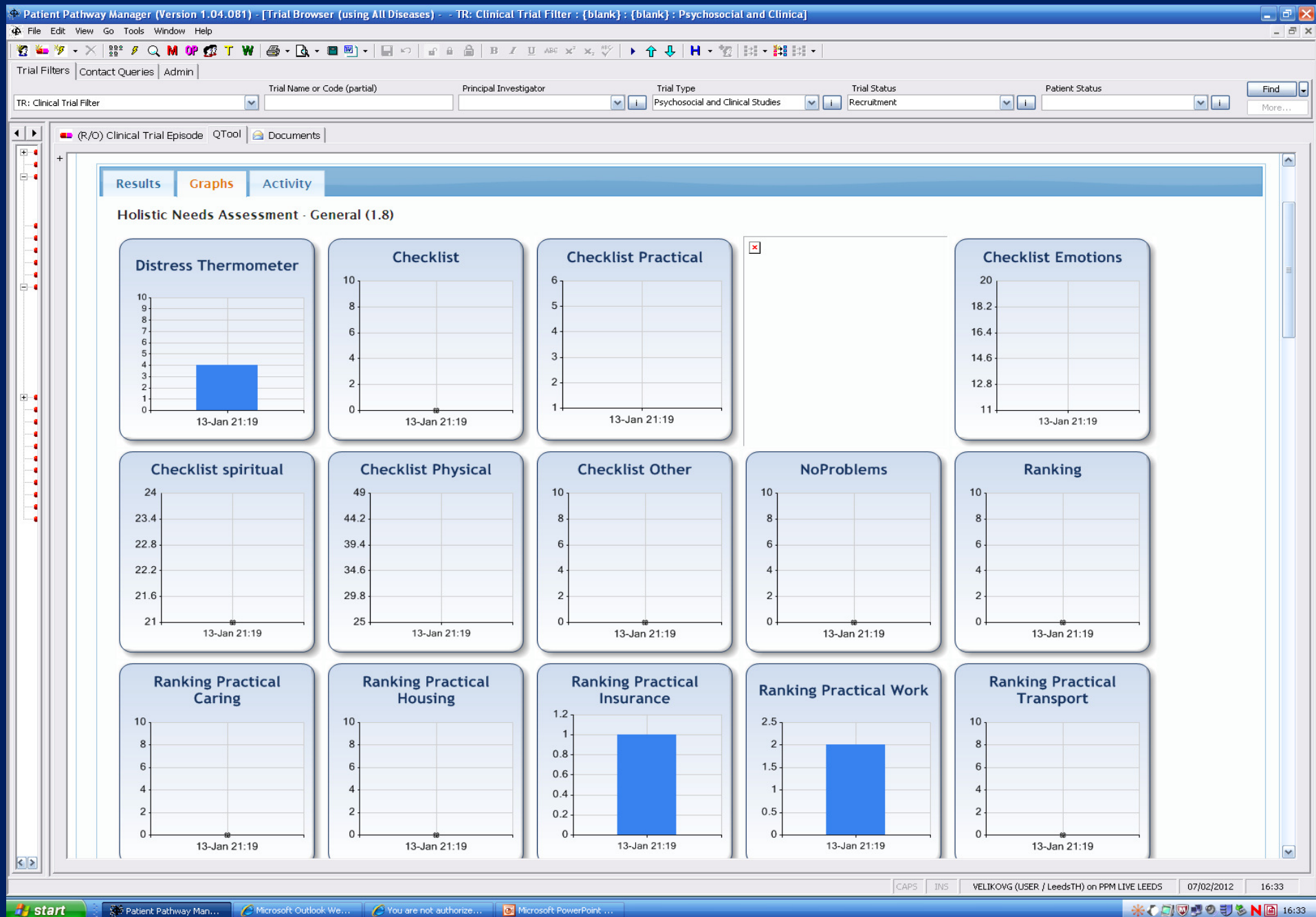
If any items below have been a cause of distress for you over the last week, including today, please tick the box next to it or leave it blank if it does not apply to you. Then click 'Next' at the bottom of the screen.

Practical Problems

- ☐ Caring responsibilities
- ☐ Housing
- ☐ Insurance / finance
- ☐ Work / school
- ☒ Transport or parking
- ☐ Questions about my illness/treatment

Family Problems

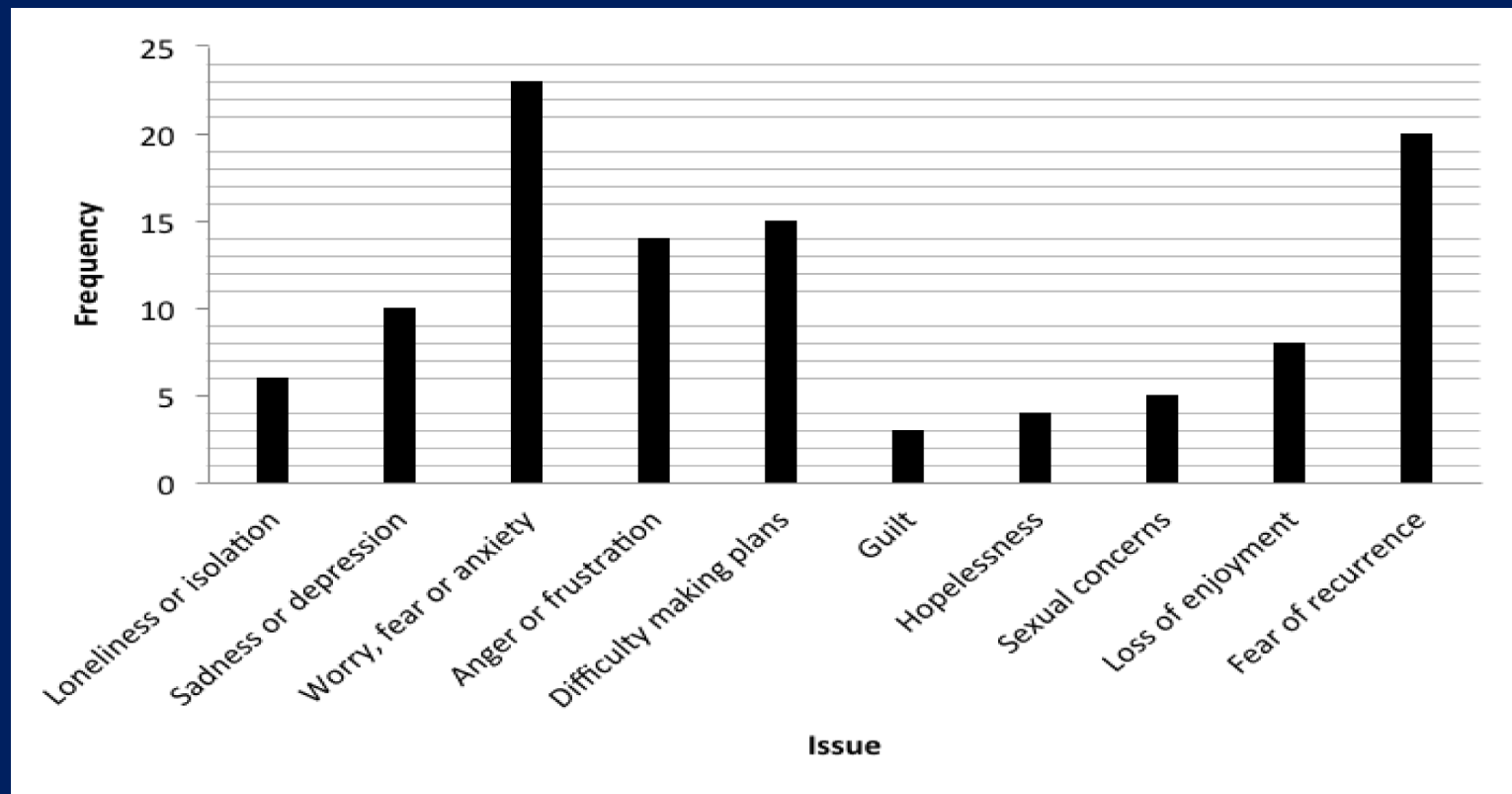
- ☒ Relationship with partner
- ☐ Relationship with children
- ☐ Relationship with other relatives/friends



Nurse-led Prostate cancer clinic over 8 months

88/136 patients (65%)

Reporting of Emotional Problems



Implementation

Original Contribution

Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care

By Roxanne E. Jensen, PhD, Claire F. Snyder, PhD, Amy P. Abernethy, MD, Ethan Basch, MD, Arnold L. Potosky, PhD, Aaron C. Roberts, Deena R. Loeffler, MA, and Bryce B. Reeve, PhD

Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, Washington, DC; The Johns Hopkins University School of Medicine and the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD; Duke

- 33 unique systems used in cancer practice
- Treatment-Centered n=8
- Patient –Centered n=19
- No consensus on administration, integration, results reporting
- Integration with EHRs

Implementation - Denmark

Qual Life Res (2016) 25:525–534
DOI 10.1007/s11136-015-1207-0



SPECIAL SECTION: PROS IN NON-STANDARD SETTINGS (BY INVITATION ONLY)

AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases

Liv Marit Valen Schougaard¹ · Louise Pape Larsen¹ · Anne Jessen¹ ·
Per Sidenius² · Liv Dorflinger³ · Annette de Thurah^{4,5} · Niels Henrik Hjollund^{1,6}

- PRO data collection, decision algorithm, graphical overview
- 9 diagnostic groups
- >13,000 completions

Implementation- Canada

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Action Cancer Ontario

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Disease Pathway Management

Ontario Cancer Symptom Management Collaborative

Interactive Symptom Assessment and Collection (ISAAC) Tool

Interactive Symptom Assessment and Collection (ISAAC) Tool

Commonly referred to as ISAAC, our Interactive Symptom Assessment and Collection tool allows patients to assess and monitor their symptoms through an online computer program.

ISAAC is available at kiosks in 14 regional cancer centres and 28 partner hospitals across Ontario. More than 27,000 patients are screened every month through the ISAAC system.



Key Features and Functions of ISAAC

- An accessible, touch-screen-based platform allowing for the completion of patient-reported symptom measurement tools
- A reporting tool for both patients and clinicians facilitating improved communication by enabling patients to track and report their physical and emotional pain caused by cancer symptoms, across the cancer journey




Related Resources

ISAAC Frequently Asked Privacy Questions for Patients

Symptom Assessment and Management Tools





Share








Implementation- Canada

Cancer Care Ontario
Action Cancer Ontario



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[Types of Cancer](#)
[Primary Care Program](#)
[Person-Centred Care](#)
[Patient and Family Engagement](#)
[Patient and Family Advisor Volunteer Opportunities](#)
[Person-Centred Care Report](#)
[Person-Centred Care Guideline](#)
[iPEHOC Toolkit](#)

iPEHOC Toolkit

This toolkit was developed to support the six pilot sites across Ontario and Quebec that are implementing the Improving Patient Experience and Health Outcomes Collaborative (iPEHOC) project. The ultimate goal of the project is to develop a common and sustainable patient-reported outcome (PRO) and patient experience measurement system that is applicable to all jurisdictions in Canada. The primary aim of this project is to reduce symptom burden and improve patient experience of care by engaging clinicians in the meaningful use of Patient-Reported Outcome data in routine clinical care.

iPEHOC Project Documents

Asset	Description	Download
iPEHOC Project Summary	Overview of the iPEHOC project	iPEHOC Project Summary (PDF)



iPEHOC

Improving Patient Experience and Health Outcomes Collaborative

Exceptional Care, Personalized Experience
Des soins exceptionnels, une expérience personnalisée

How to increase the impact

- Online/ Mobile reporting by patients
- Integration of PROs data with Electronic Health Records
- Training professionals how to respond to PROs data (physicians and nurses)
- Evaluation and Health economics
- Whole system perspective - Integrated care pathways
 - Referral pathways based on patient self-reports
- Organizational changes
- Online Toolkits

Acknowledgements

- We wish to thank the patients, oncologists and clinic staff who made this work possible
- Cancer Research UK
- NHS Research & Development
- National Institute for Health Research of England



- **Section of Patient-Centred Outcomes Research**

Peter Selby

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Ada Keding

Kate Absolom

Leon Bamfort

Emma Ingleson

Trish Holch

Sally

- **Clinical Trials and Research Unit**

Julia Brown

Kim Cocks

Example of training scenario

Scenario 3 – Ms Jane Roberts

Jane Roberts: 45 year old woman with metastatic breast cancer

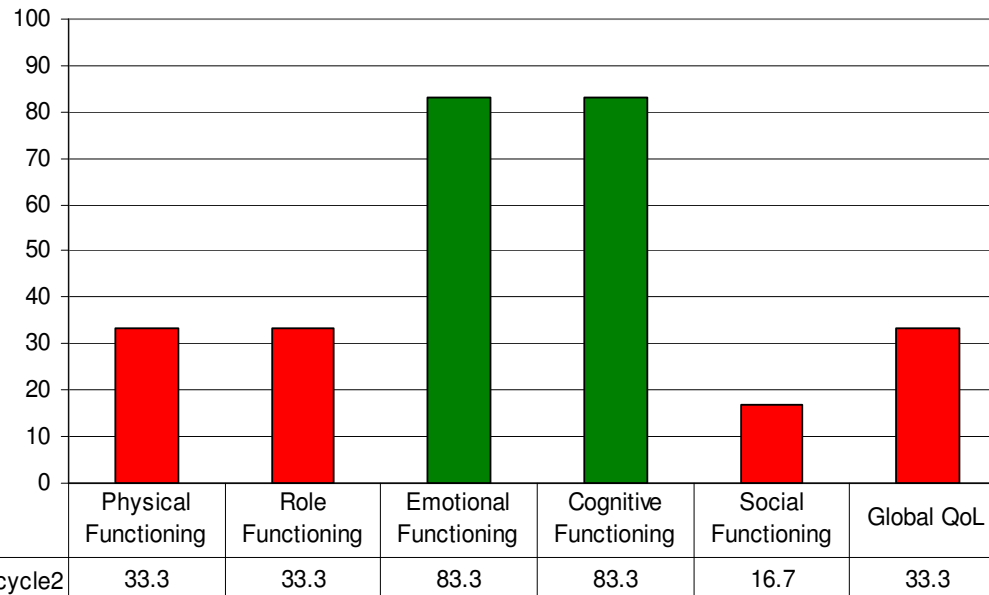
Breast cancer history

1. Diagnosed with metastatic breast cancer 2 years ago. Triple receptor negative disease.
2. Has received 2 lines of palliative chemotherapy
3. Presented with discomfort in right hip. Restaging with a CT scan and bone scan revealed progressive bone disease. Started on further palliative chemotherapy with ECF
4. Attends for review prior to second cycle of chemotherapy

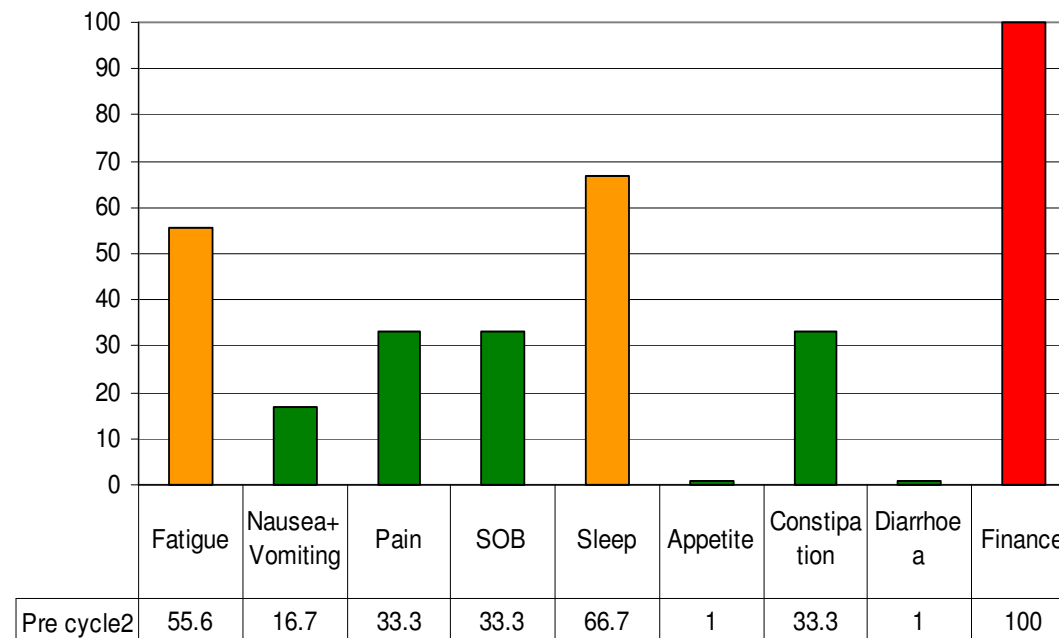
Social Background

- Single parent. Has a daughter currently studying for A-levels
- Had been working as a part time dinner lady in a primary school
- On sick leave since starting ECF chemotherapy

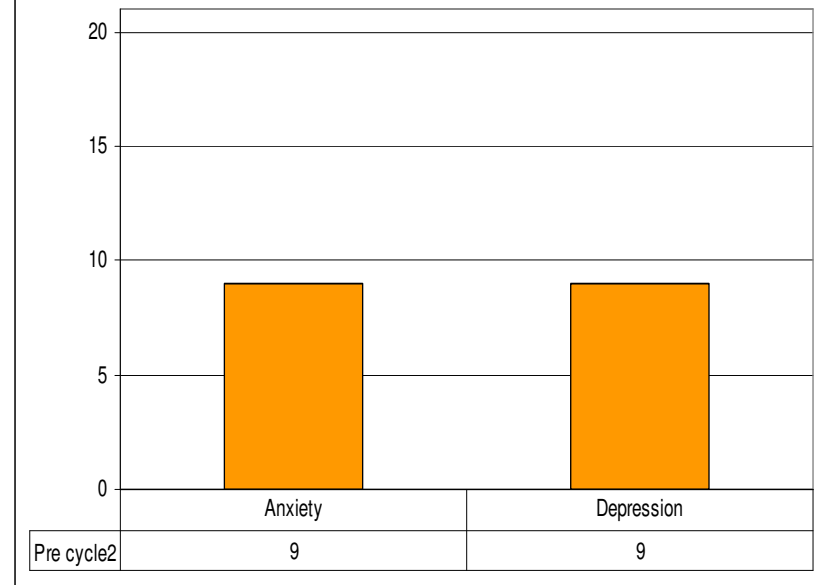
Functional Impairment: Higher scores means better functioning



Symptom scores: Higher scores mean worse symptoms



HADS



Discussion of the case

- Interpretation of HRQOL scores
 - DVD clip
 - How HRQOL was included
 - How did it contribute?
-
- https://youtu.be/1SorGQev_Hs clip 2