



Celebrating 20 years of Patient Centred Outcomes Research (1996-2016)

Focus on the future

Galina Velikova



- **Mention ongoing studies**
- **Thoughts on implementation in patient care**
 - **eHealth opportunities and challenges**
- **NHS England- 2015 strategy “Achieving world-class cancer outcomes”**



Patient Reported Outcomes Group

REPORT UK



REPORT-UK

Real-time Electronic Patient Outcome ReportIng of adverse events in UK cancer trials

Feasibility pilot study

Fiona Kennedy, Beverly Clayton, Kate Absolom, Elaine O'Connell Francischetto,
Louise Flintoff, Kathryn Gordon, Will Crocombe, Faye Samy, Vicky Hiley, Julia
Brown, Jane M Blazeby & Galina Velikova



CANCER
RESEARCH
UK



University of
BRISTOL



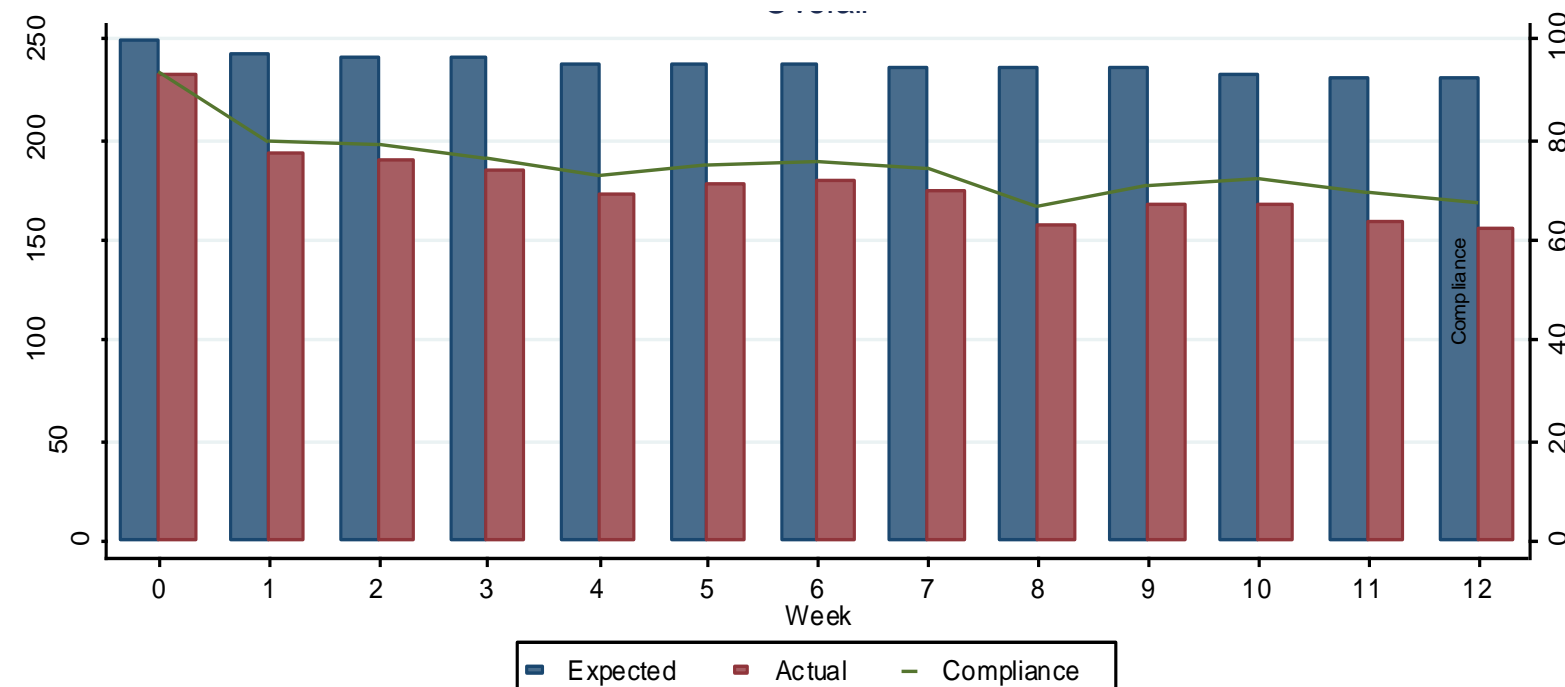
UNIVERSITY OF LEEDS

Key results (NCRI conference 2016)

249 patients (48% consent rate)

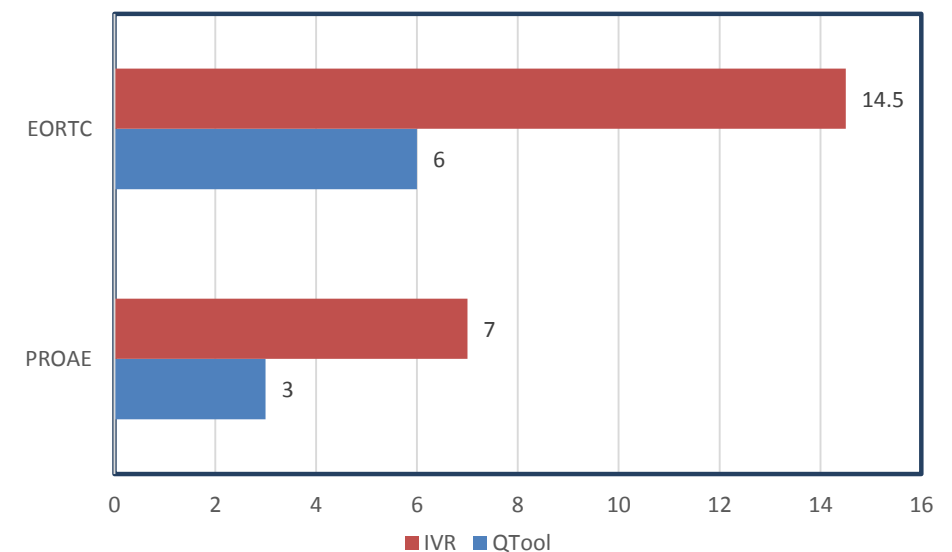
- 82% preferred Internet
- 17% IVR
- 1% no preference

Compliance – weekly PRO-CTCAE



Time for completion

Median time to complete



PLATO
Personalising Anal cancer radioTherapy dose – Incorporating ACT3, ACT4 and ACT5

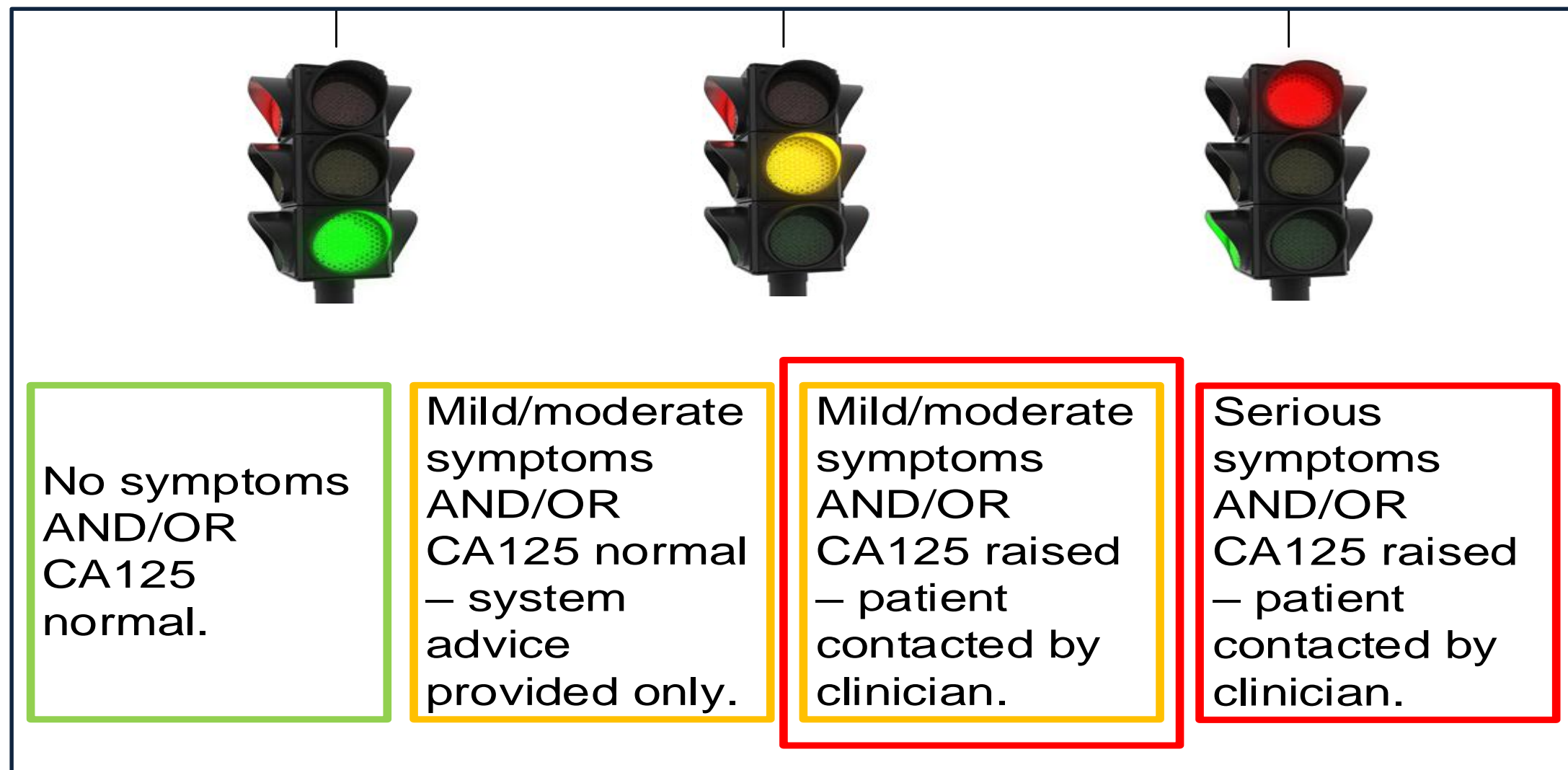
ACT3, ACT4 & ACT5
PLATO
Personalising Anal cancer radioTherapy dose


CANCER RESEARCH UK

STAND UP TO CANCER

PLATO is an integrated protocol, comprising 3 separate non-CTIMP trials (ACT3, ACT4 and ACT5) which aims to optimise radiotherapy dose (in combination with chemotherapy) (CRT) for low-, intermediate- and high-risk anal cancer.

- An innovative approach for remote monitoring and support of ovarian cancer patients using ePROMs and re-designed care pathways



 Phone call by the research team



PROs collection by QTool
(remote or in clinic-Kiosk)
system or paper

Leeds Lung MDT early stage NSCLC

150 PTS

150 PTS

Surgical Clinic

Oncology Clinic

Patient approach

LILAC discussed and information Sheet
provided

Pre-assessment

Planning-Scan

Patient Consents



QoL
Decision SE Scale

Surgery

SBRT

6 weeks

Surgical Clinic

Oncology Clinic

6 weeks

PS-Dyspnea score

Leeds patients

Leeds Outside patients

Survivorship Clinic

Oncology Clinic

3 months

FEV1-PS-Dyspnea score

PS-Dyspnea score

Survivorship Clinic

Oncology Clinic

6 months

FEV1-PS-Dyspnea score

PS-Dyspnea score

PFTs

Oncology Clinic

12 months

PFTs-PS-Dyspnea score



QoL
Pat Sat



QoL



QoL



QoL
End of Study questionnaire



Working with others linking PROMs data with population level data



Life after Prostate Cancer Diagnosis
(PIs: Adam Glaser and Anna Gavin)



Life And Bladder Cancer
(PIs: Jim Catto and Adam Glaser)



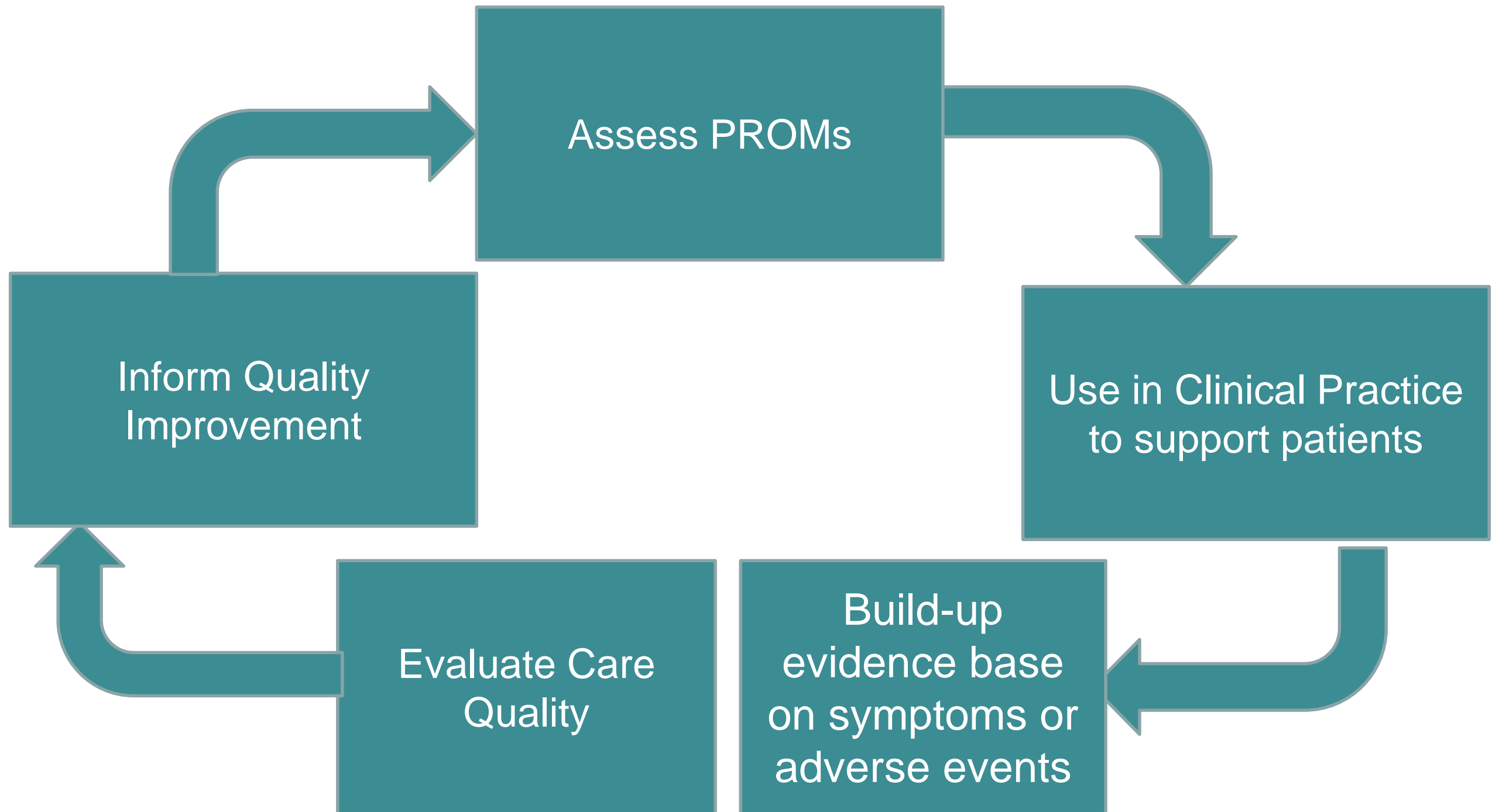
The Yorkshire Cancer Research bowel cancer improvement programme
(PI: Phil Quirke)



Comprehensive Patient records for cancer outcomes
(PIs: Geoff Hall and Adam Glaser)

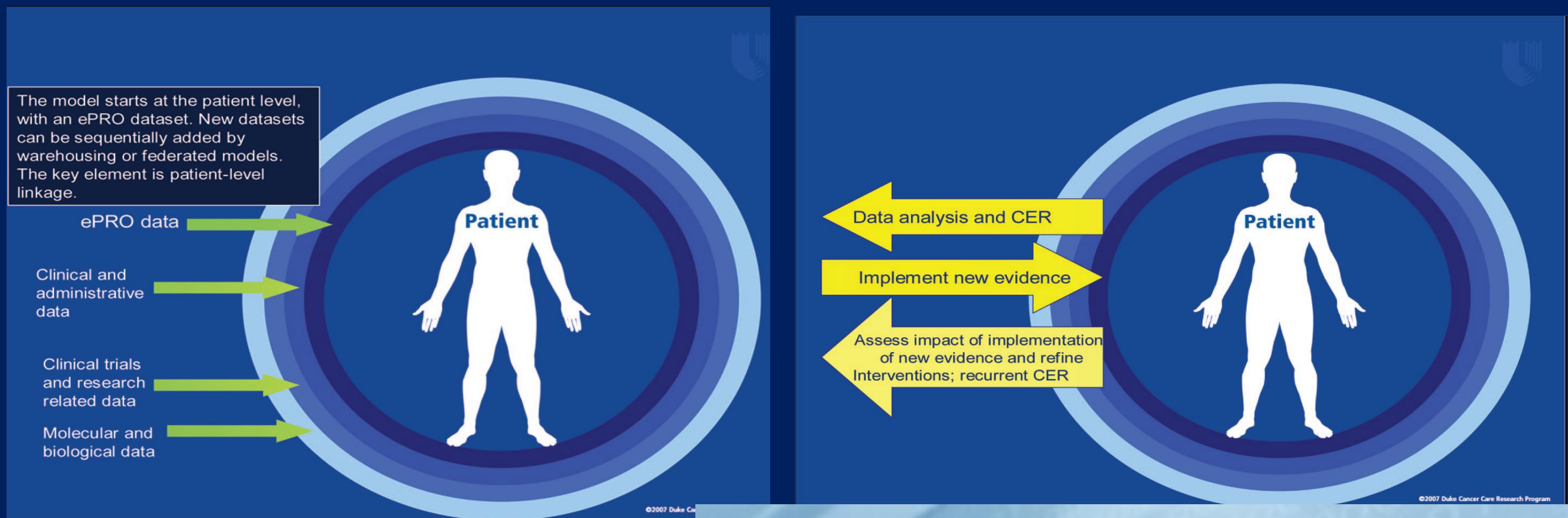
Multi-Purpose PROMs

(modified Claire Snyder)



Rapid learning healthcare model (Abernethy A, 2003)

- Integration of ePROMs into clinical care
- Patient-level linkage of PROs, clinical and administrative data



- PROMs to become a part of the Big Data



eHealth - Potential to transform cancer care

Original Contribution

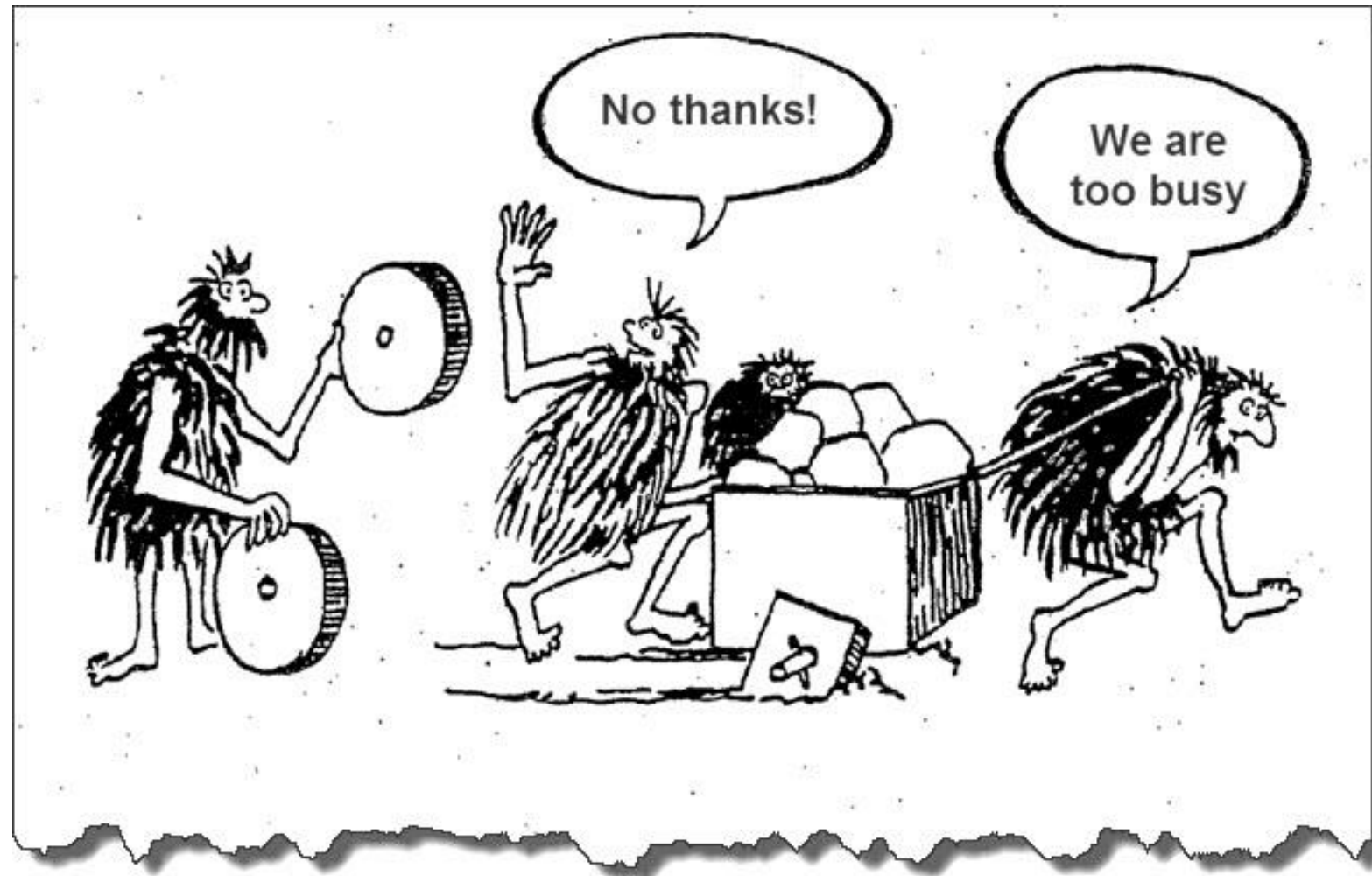
Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care

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
- Integration with Electronic Health Records
- Patient portals

Use of PROMs in clinical practice: change management



- Health care is hard to change
- Competing priorities for managers and staff
- Health economic perspective
- Upfront cost and staff training

PROMs implementation in Canada

Cancer Care Ontario
Action Cancer Ontario

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Prevention & Care

Cancer Care Overview

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)



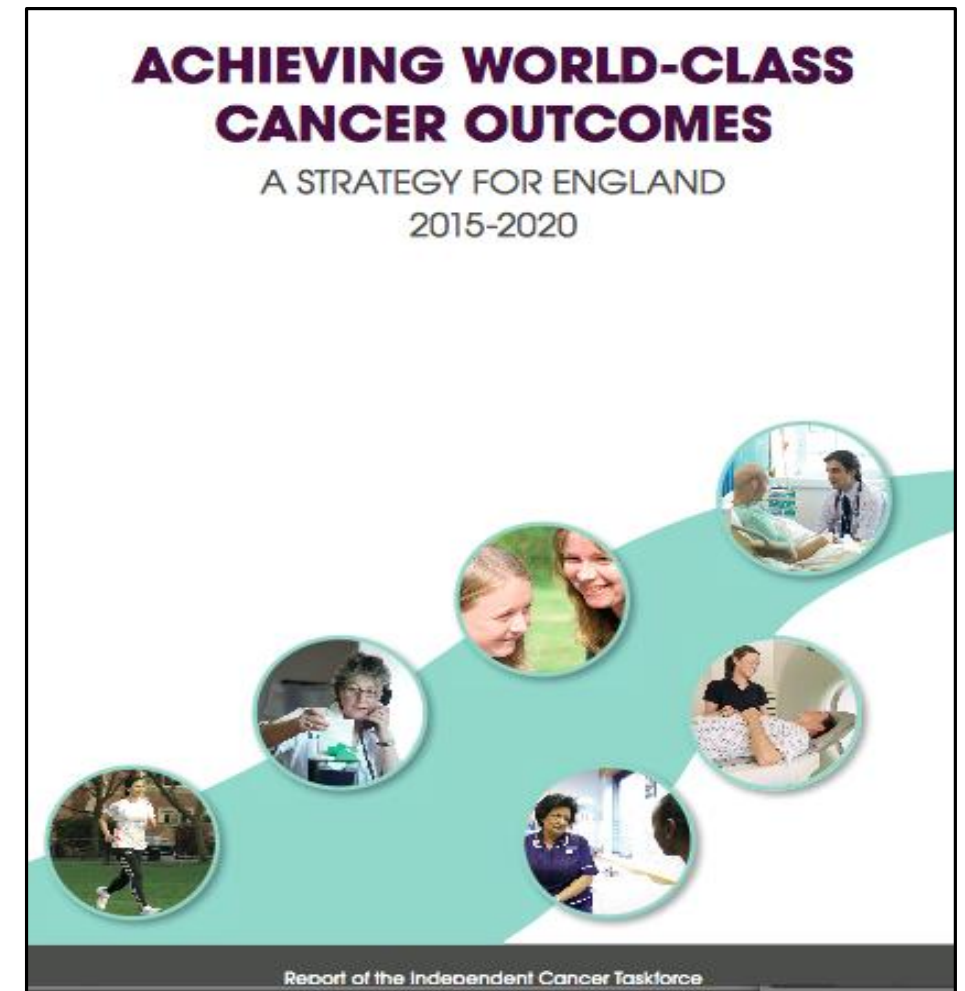
iPEHOC
Improving Patient Experience and
Health Outcomes Collaborative

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

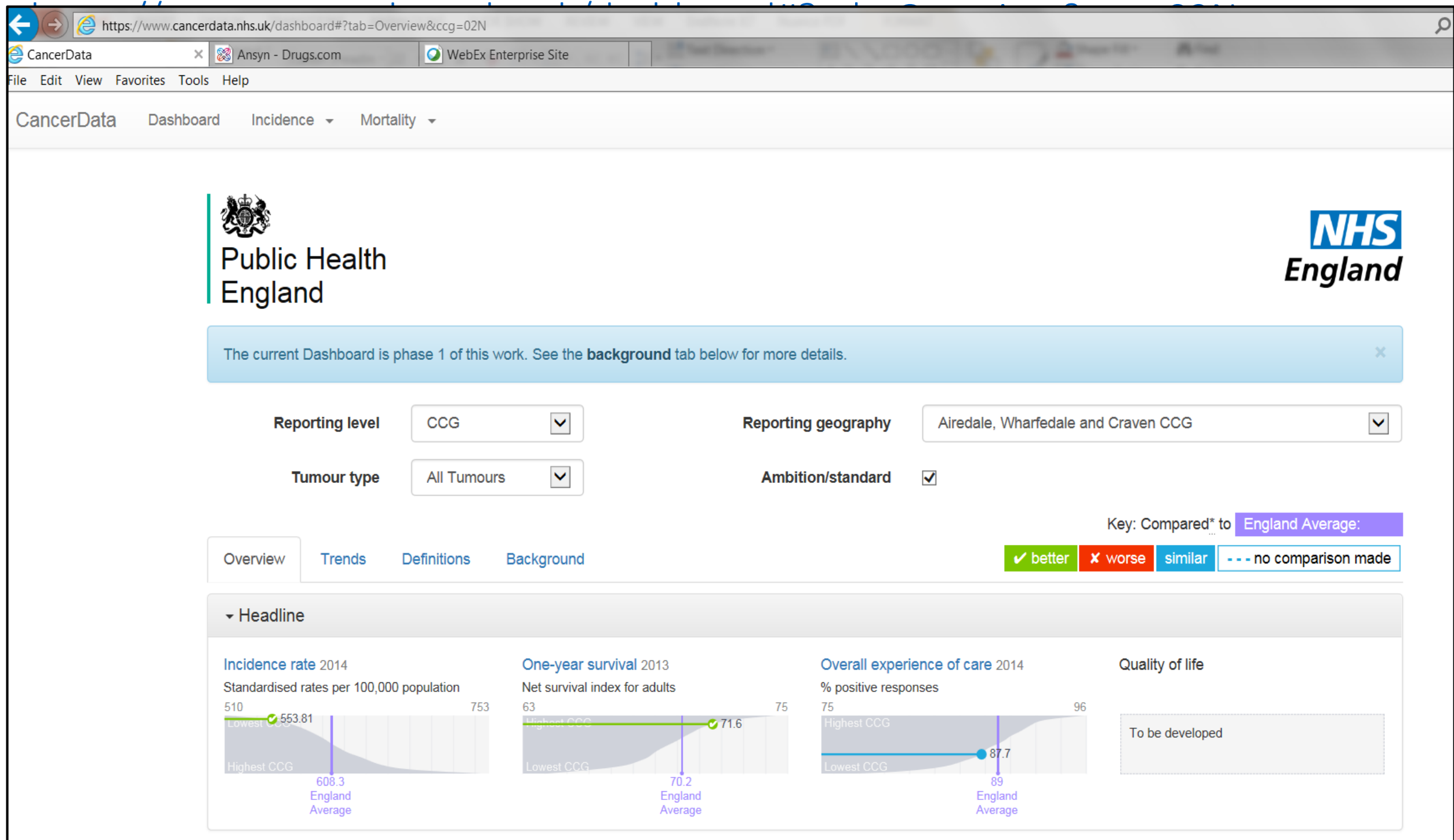
*2015 NHS England Independent
Cancer Taskforce report*

Achieving World-Class Cancer Outcomes

- **Recommendation 64**
- To develop a **national metric on quality of life by 2017** which would enable better **evaluation of long-term quality of life after treatment.**
- PROMs should be rolled out across breast, colorectal and prostate cancer by 2020, with evaluation and further rollout across other cancer types.



Quality of Life on the Cancer Dashboard



**“SCIENTIFIC RESEARCH IS ONE OF THE MOST
EXCITING AND REWARDING OF OCCUPATIONS.”**

FREDERICK SANGER

Thank you for coming!