

PROMs data visualization in the clinical setting: what, how and when

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Outline

- Background to PCOR team in Leeds
 - Work using PROMs in cancer setting
 - Experiences of presenting PROMs data in clinical practice
- What's the growing evidence around visualising PROMs data telling us?
 - Reviews
 - Resources
 - Examples
- What is the future direction of this work? Why is this important?

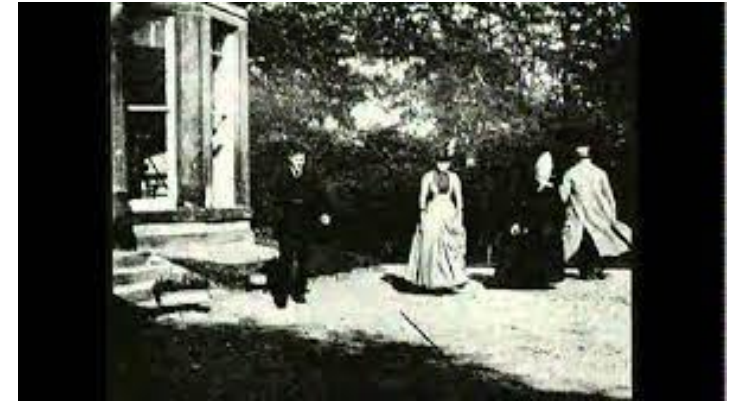
VISITOR CONFERENCE TRADE

VISIT LEEDS



Leeds- fun facts

- Location of the first known film/motion picture footage filmed in the city
- Fizzy drinks invented in Leeds
- Origin of Marks & Spencer (retailer/department store)



SPICE UP YOUR LIFE

SPICE

GIRLS





Patient Centred Outcomes Research Leeds Cancer Centre (Est. 1999)



Prof Galina Velikova



Strong focus on the collection and utilisation of patient reported data- patient reported outcome measures (PROMs)

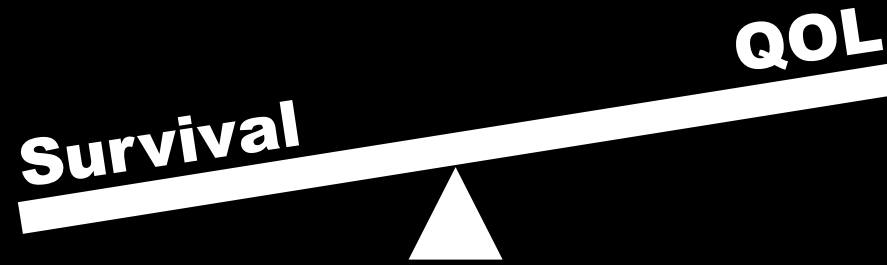


Why collect PROMs?

Clinical trials

Population studies

Everyday clinical
practice



Why collect PROMs?

Clinical trials

Survival

QOL

Population studies



Everyday clinical
practice



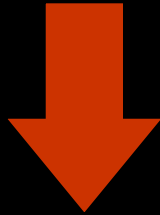


Clinical method - Medical interview

- Gathering subjective information
- Diagnostic aim
- Not designed to monitor change/assess outcomes

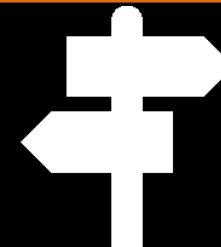
PROMs

- Patient centred
- Quantitative information on symptoms and functioning
- Track changes over time



Benefits

- Detect and monitor physical problems, wider social and psychological issues
 - Enhance patient-health professional communication
 - Facilitate patient involvement in decision making



Patient self-reporting of symptoms using PROMs in cancer care

- Evidence patient benefit:
- Potential benefits for
 - Clinician awareness of patient symptoms
 - Symptom control and quality of life
 - Use of emergency services
 - **Survival (advanced cancers)**

Trials:

- *Basch JCO 2016;34:557*
- ***Basch JAMA 2017;318:107***
- ***Denis JNCI 2017; 109:9***
- *Berry D JCO 2014;32:199*
- *Velikova JCO 2004;22:714*
- *Maguire BMJ Open; 2021;374:n1647*
- *Basch JAMA 2022; 327(24);2413*
- *Absolom et al, 2021J Clin Oncol. 1;39(7):734-747.*

Reviews:

- *Kotronoulas: JCO 2014;32:1480;*
- *Moradian Supp Care cancer 2018;26:361*
- *Penedo Lancet Onc 2020;21:e240*
- *Howell Supp Care cancer 2017;25:1323*

1996

Technology to capture patient reported outcomes in clinical practice: PCOR timeline

- Paper chase
- Error prone
- Time consuming

- Too small
- Too easy to lose



- Great for 'in-house'
- No good if too far away from clinical areas

- Delay in data transfer
- Cumbersome
- Bar code reader would 'read' any barcode



- Great for 'in-house'
- Portable but less vulnerable

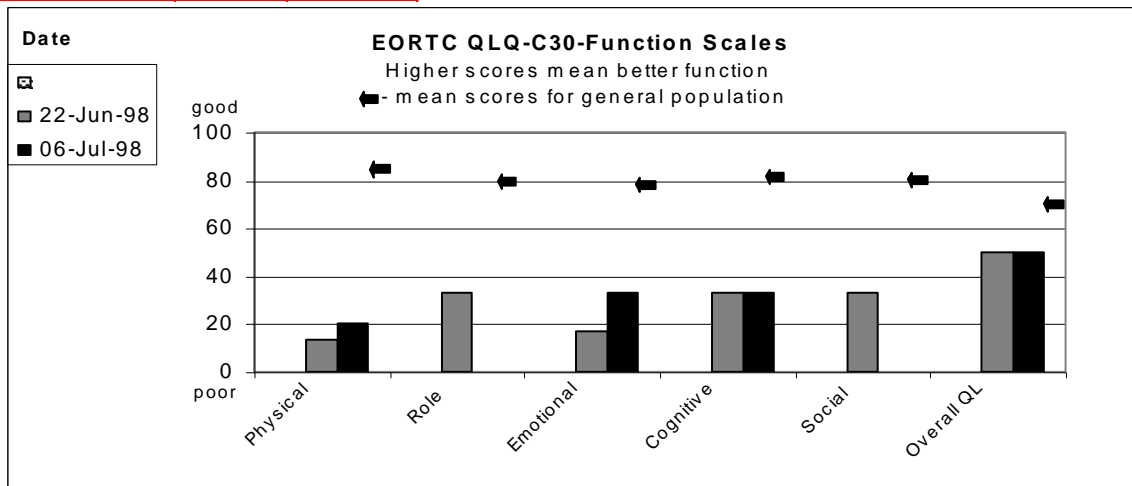
Today

- Online
- Linked to electronic patient records
- With alerts

Technology research

1. Velikova, G. et al. J Clin Onc, 1999. **17**(3): p. 998-1007
2. Cull, A. et al., Br J Cancer, 2001. **85**(12): p. 1842-1849
3. Wright, P. et al., J Clin Onc, 2003. **21**(2): p. 374-382
4. Ashley, L. et al., Br J Cancer, 2011. **105**(S1): p. S74-Sp81
5. Ashley, L. et al., J Med Internet Res, 2013. **15**(10): E230
6. Holch et al., Ann Oncol, 2017 Sep **28**(9):2305-2311

Examples of how PROMs scores
presented/visualised across our studies...



- Patient completed on touchscreen and results printed out and given to clinician

- PROMs

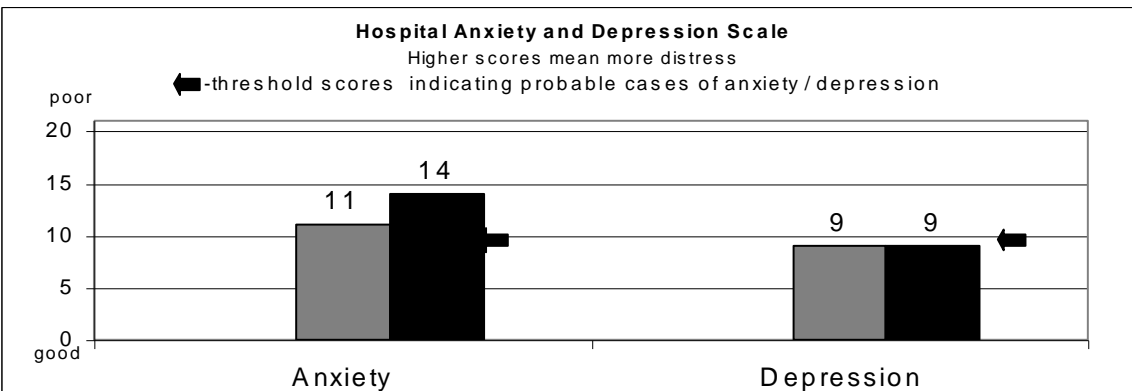
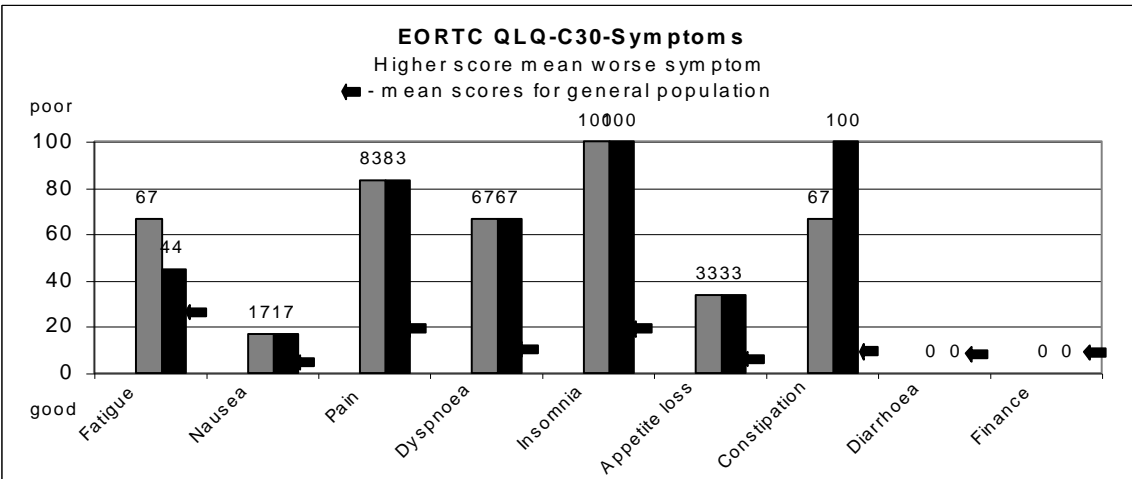
- European Organization for Research and Treatment of Cancer–Core Quality of Life Questionnaire, version 3.0

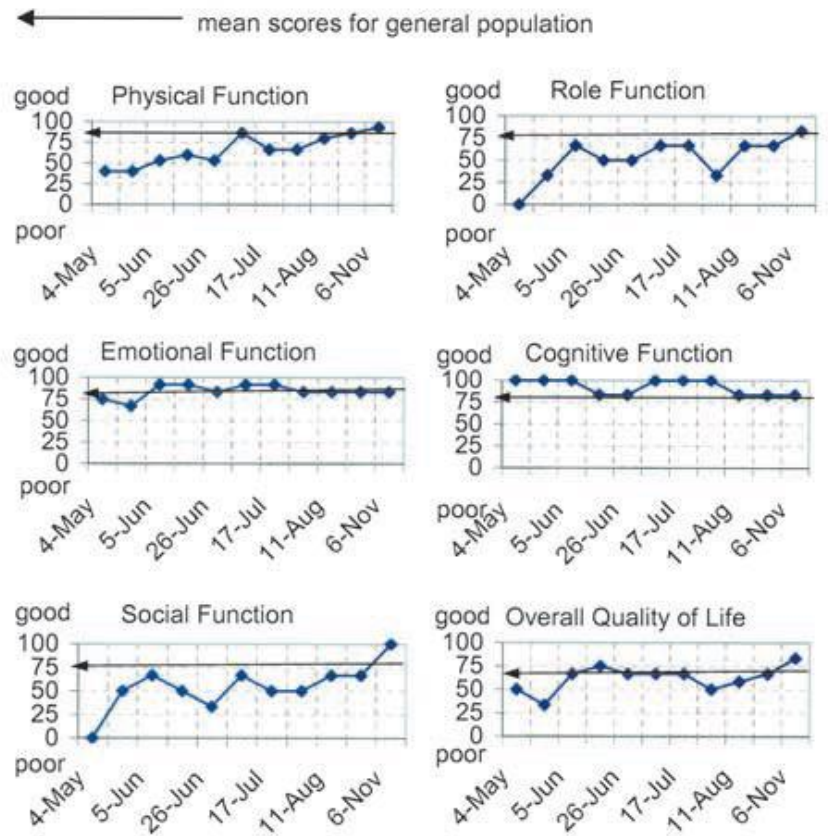
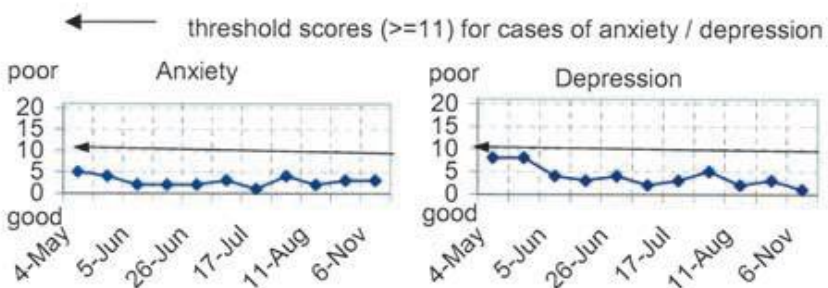
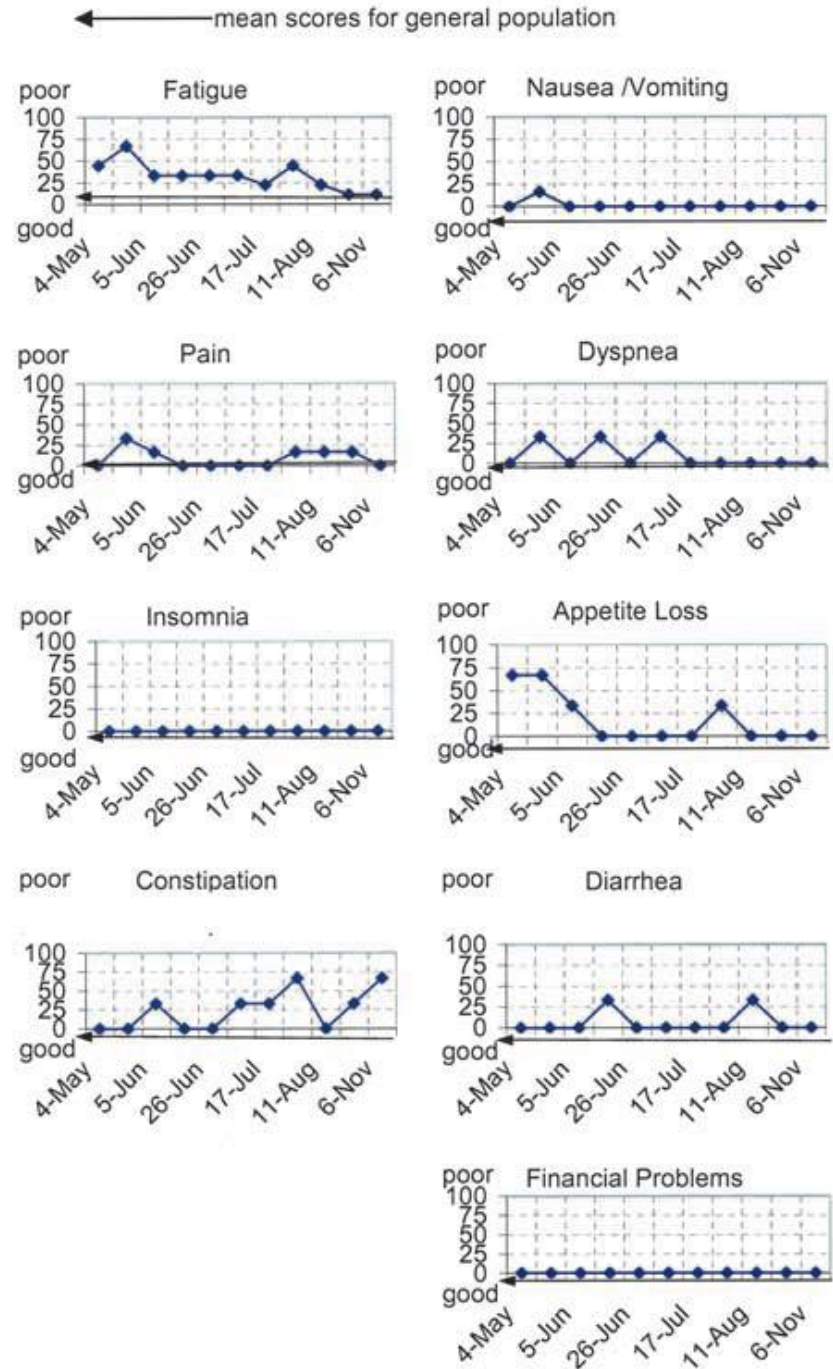
- Hospital anxiety and depression scale. Higher scores mean more distress.

- Lines to indicate mean general population scores

- And labels to high scoring direction for good or poor/worse

- Line graph to highlight trajectory/trends in scores



A**B****C**

QuEST programme: Refining PROMs for cancer groups and staff training

(Harley et al., Quality of Life Research, 2012, N = 458)

- Questionnaire developed from symptom/functioning items from previously validated quality of life measures
 - 3 questionnaires created (colorectal, gynae and breast), 51-56 items covering:
 - Everyday tasks, Pain, Fatigue, Impact on Activities, Body image, Sex life
 - Relevant individual symptoms- taste, appetite, hot flushes, nausea, bowel functioning etc
 - Emotional Distress measured with Mental Health Inventory (MHI-5)
- Also included a checklist for issues patients wanted to discuss with staff

- Questionnaire designed for completion on touchscreen computer-scores calculated and graphically presented to doctor
- Traffic light system
 - Red = severe
 - Yellow = moderate
 - Green = no/mild problems

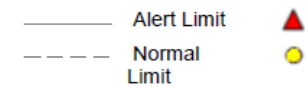
Questionnaire Summated Scales - Longitudinal Charts

[Display Subscales](#)

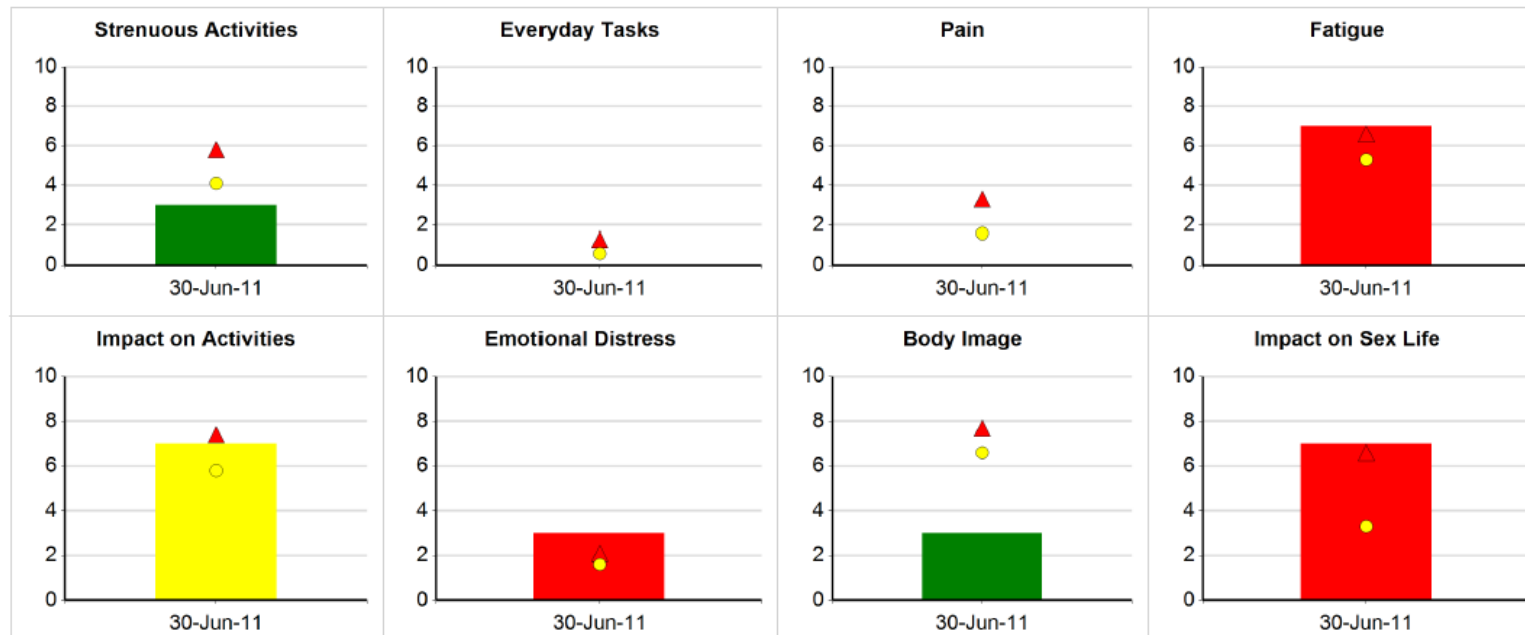
[Display Alerts Only](#)

Subject Name	Subject Number	Unit Number	BirthDate	Gender
Anonymous Subject	4	Not Given	Not Given	N

Key:

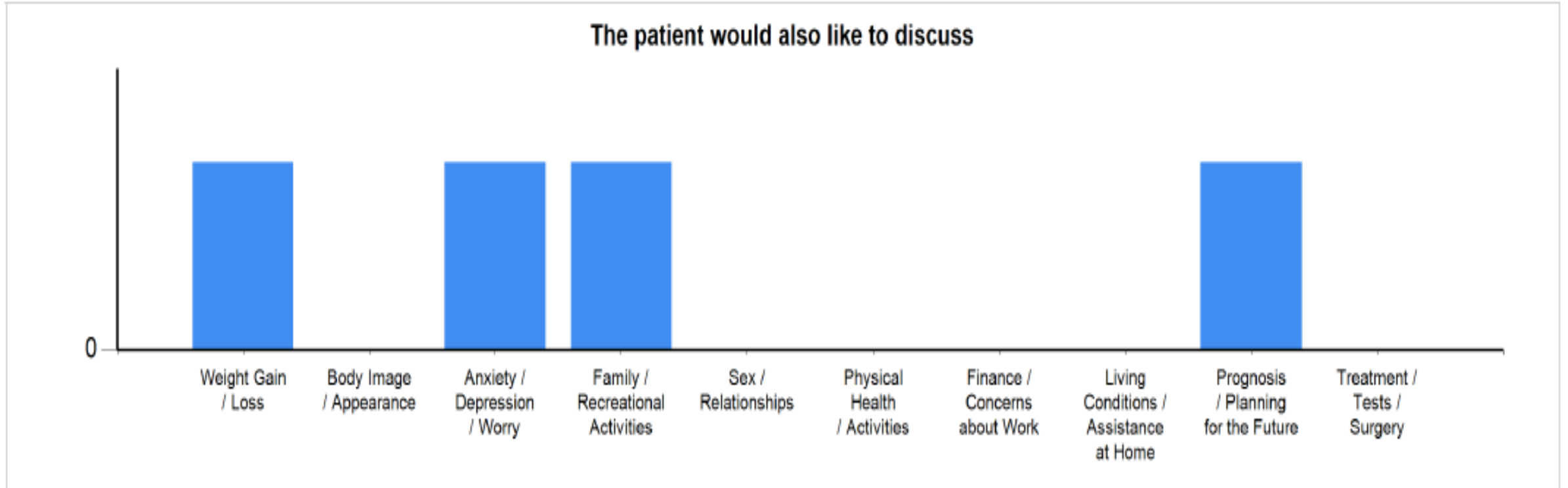


QuEST- Br



The topics to discuss checklist

QuESTQ Validation Checklist



Pilot work to explore how disease specific PROMs were on issues raised in consultation.

Still being printed out to give to clinician.....next step integrate PROMs into the electronic patient records.....

National Institute for Health and Care Research Programme

Grant <https://doi.org/10.3310/FDDE8516> 2013-2019

Electronic self-reporting of adverse events for patients undergoing cancer treatment: the eRAPID research programme including two RCTs

Galina Velikova^{1 2}, Kate Absolom^{1 3}, Jenny Hewison³, Patricia Holch^{1 4}, Lorraine Warrington¹, Kerry Avery⁵, Hollie Richards⁵, Jane Blazeby⁵, Bryony Dawkins³, Claire Hulme⁶, Robert Carter¹, Liz Glidewell⁷, Ann Henry^{1 2}, Kevin Franks^{1 2}, Geoff Hall^{1 2}, Susan Davidson⁸, Karen Henry², Carolyn Morris⁹, Mark Conner¹⁰, Lucy McParland¹¹, Katrina Walker¹¹, Eleanor Hudson¹¹, Julia Brown¹¹

Southampton (UK): NIHR Journals Library; 2022 Feb.
Programme Grants for Applied Research.



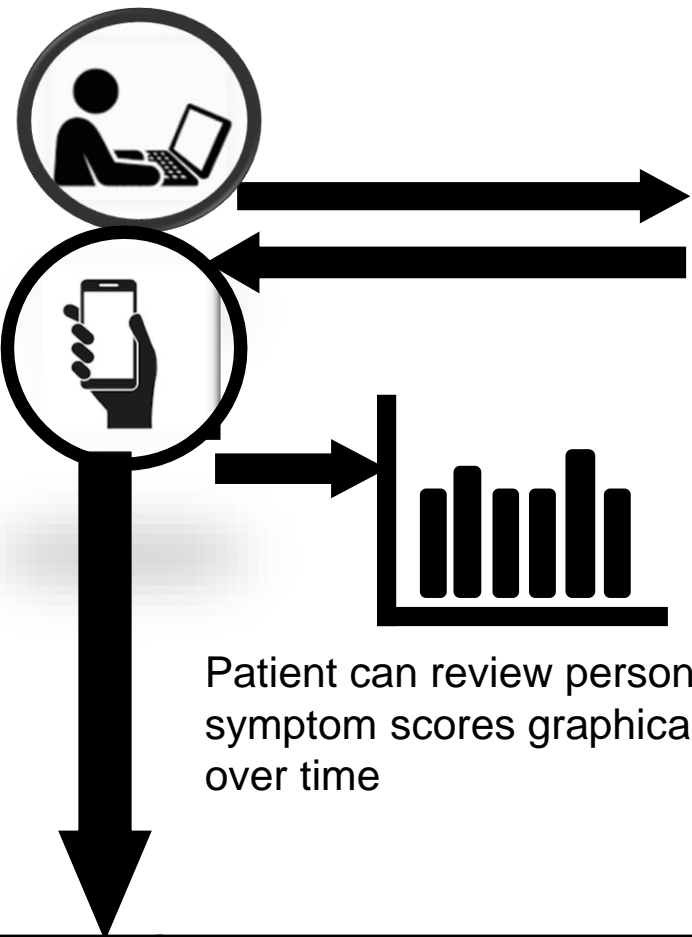
SUPPORTED BY

NIHR | National Institute for
Health and Care Research

Supported by the National Institute for Health & Care Research (NIHR), Research Program Grant for Applied Research (RP-PG-0611-20008). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.


eRAPID Online symptom monitoring: Adverse events

- Asked to complete symptom report weekly (or as needed)
- Reminder sent by SMS/email.



Patient receives immediate severity tailored advice

Symptom scoring algorithm	
No symptoms	No advice
Mild/moderate symptoms	Self-management advice
Severe improving symptoms/combination of moderate symptoms	Advised to contact hospital /discuss at treatment review
Medically severe symptom	Advised to contact hospital immediately

 Severe symptom email notification sent to allocated medical staff



Symptom data made available real time to staff in individual electronic patient records

PROMs in clinical practice: Complex intervention



Patients- Symptom items
Self-reporting of side effects with severity grading

Electronic platform
- Functional in Real-time
- Confidential
- Well-supported

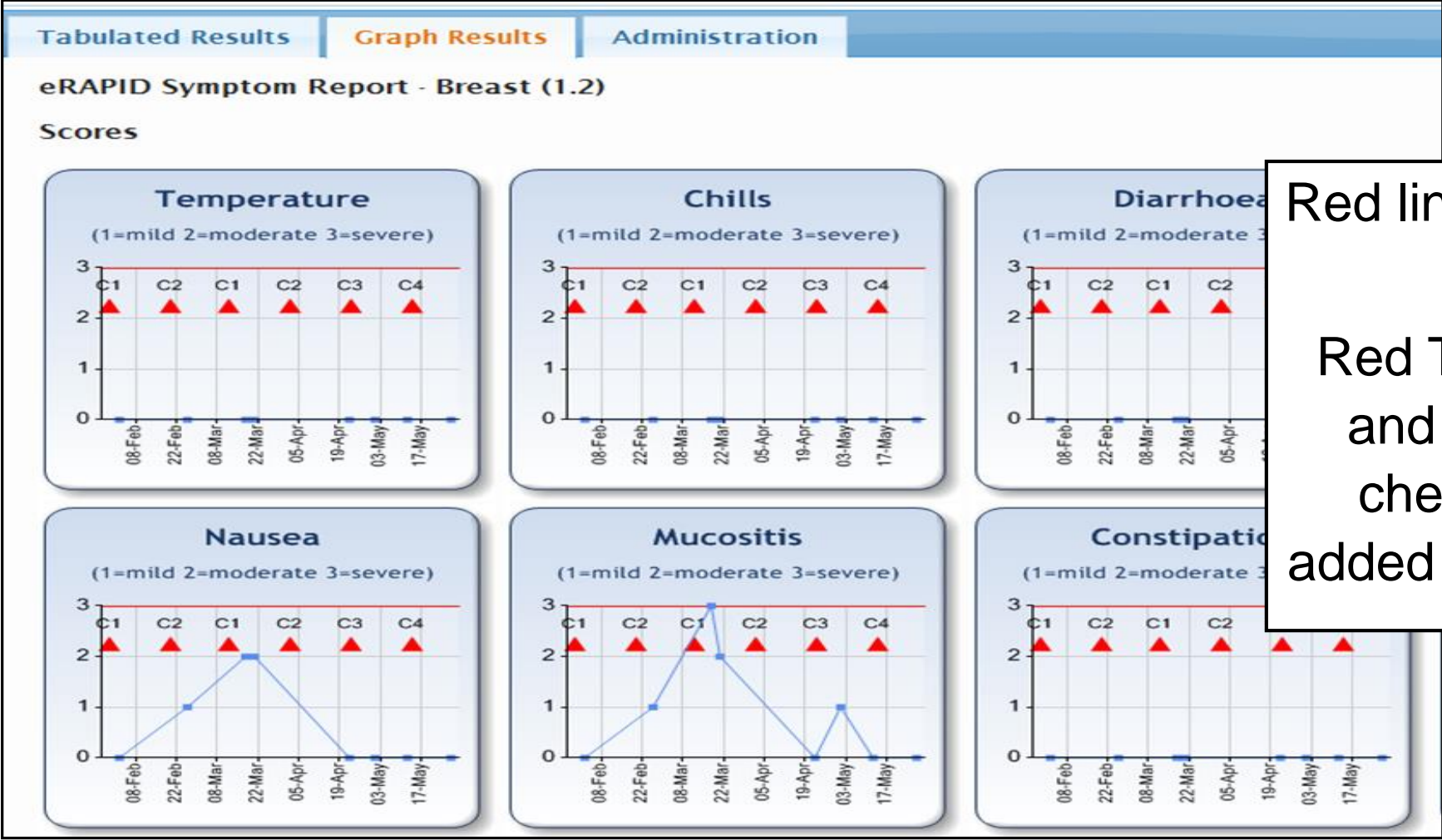
**eRAPID
Intervention**

Patients - Advice and alerts
-Mild self-management advice
-Serious Alerts to patients and clinicians

Integration in patient care pathways
- Staff training
- Patient training

Visualisation of patient reported data
essential component- for clinical staff and patients

Patient reported data in electronic records: Graphs



Red line indicates threshold for severe problem

Red Triangles indicate when and what number cycle of chemotherapy delivered-added based on staff feedback

Patient reported data in electronic records: Tables

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)

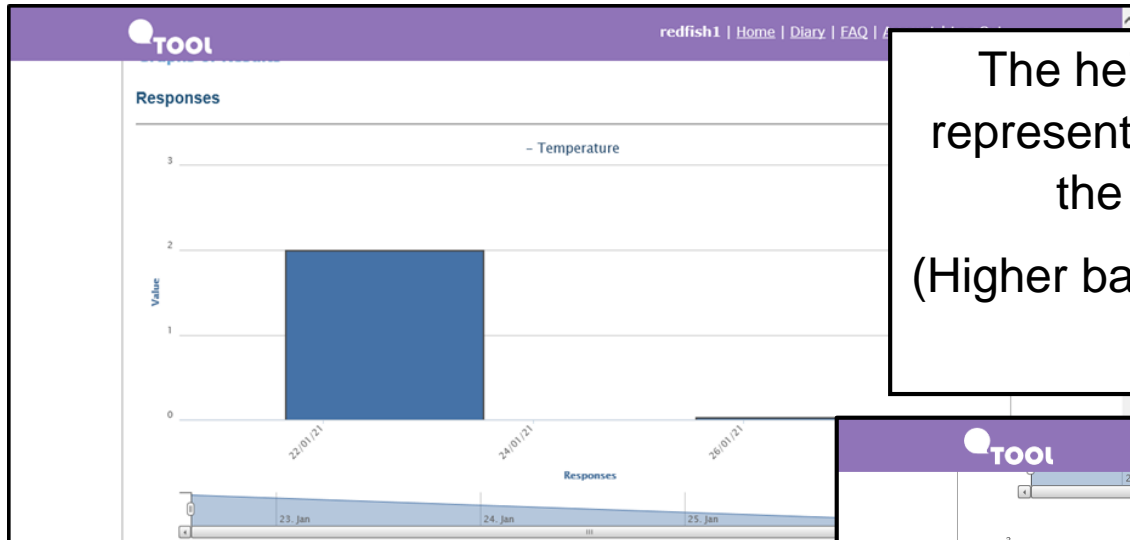
eRAPID Toxicity (4.5)

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
Difficulty 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				

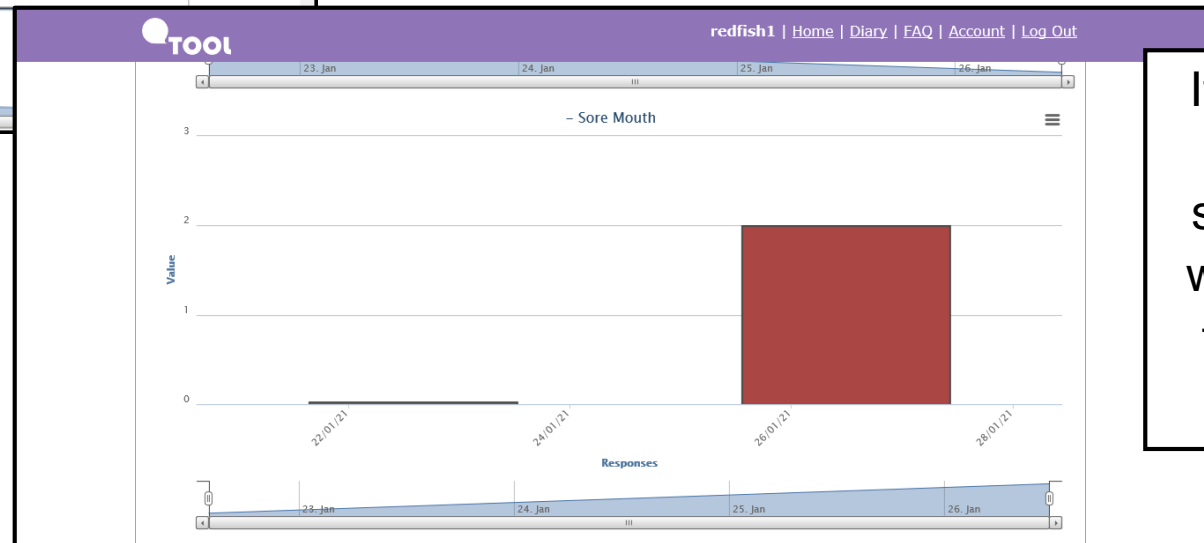
Record Status
 Trial Stage - Overdue Trial Entry (>1 month).

Scores appear in red when severe and any notifications for clinically severe problems highlighted at top of page with the date

Patients could view own data- via patient facing web based interface- Bar charts and Graphs



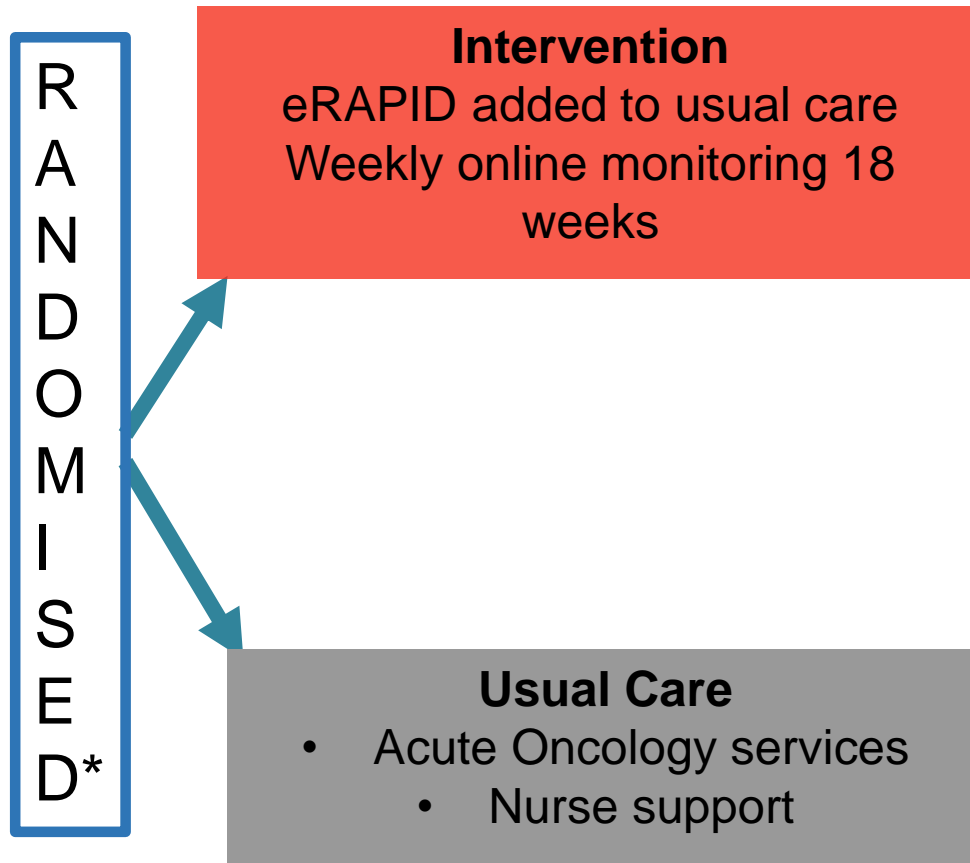
The height of the bar represents the severity of the symptom.
(Higher bar = more severe)



If your symptoms increase in severity, the bars will be higher and the line beneath will increase.

eRAPID RCT design (systematic/chemotherapy setting)

Patients starting chemotherapy for breast, gynaecological and colorectal cancer



Outcomes

Baseline, 6,12 and 18 weeks

- **Symptom control** – FACT-PWB
- **Clinical process measures**-
 - hospital contacts
 - admissions
 - chemotherapy changes
- **Self-efficacy** –Lorig 6-item SES
- **Quality of life**- FACT-G, EQ-VAS; EORTC QLQ-C30
- **Cost-effectiveness**- EQ-5D-5L

* 1:1 Randomisation stratified by cancer site, gender, previous chemotherapy

Journal of Clinical Oncology.
<http://dx.doi.org/10.1200/jco.2015.02>

Kate Absolom, PhD^{1,2}; Lorraine Warrington, PhD¹; Eleanor Hudson, MSc³; Jenny Hewison, PhD, MSc²; Carolyn Morris, BA⁴; Patricia Holch, PhD^{1,5}; Robert Carter, HND, OND¹; Andrea Gibson, RGN^{1,6}; Marie Holmes, MSc¹; Beverly Clayton, RGN¹; Zoe Rogers, MSc¹; Lucy McParland, MSc³; Mark Conner, PhD⁷; Liz Glidewell, MA, PhD, MSc²; Barbara Woroncow, MA⁸; Bryony Dawkins, MSc²; Sarah Dickinson, BSc¹; Claire Hulme, MA, PhD^{2,9}; Julia Brown, MSc³; and Galina Velikova, MD, PhD^{1,6}

Key findings
n=508

SYMPTOM CONTROL

- Benefit at 6 and 12 weeks (early cancers)
- No significant difference at 18 week

SELF-EFFICACY

- Improved self-efficacy scores at 18 weeks

QUALITY OF LIFE

- EQ 5D VAS 0-100 scale- significantly better at 12 and 18 weeks

HOSPITAL CONTACTS

- No impact on calls to hospital, admissions
- No increase in workload

COST-EFFECTIVE

- Better QALYs and small differences in costs in favour of eRAPID



original reports

Phase III Randomized Controlled Trial of eRAPID eHealth Intervention During Chemotherapy



Kate Absolom, PhD^{1,2}; Lorraine Warrington, PhD¹; Eleanor Hudson, MSc³; Jenny Hewison, PhD, MSc²; Carolyn Morris, BA⁴; Patricia Holch, PhD^{1,5}; Robert Carter, HND, OND¹; Andrea Gibson, RGN^{1,6}; Marie Holmes, MSc¹; Beverly Clayton, RGN¹; Zoe Rogers, MSc¹; Lucy McParland, MSc³; Mark Conner, PhD⁷; Liz Glidewell, MA, PhD, MSc²; Barbara Woroncow, MA⁸; Bryony Dawkins, MSc²; Sarah Dickinson, BSc¹; Claire Hulme, MA, PhD^{2,9}; Julia Brown, MSc³; and Galina Velikova, MD, PhD^{1,6}

What did patients and clinical staff feed back about eRAPID and how they used and interpreted the patient reported data?

- Interviews
- Feedback forms



Patient feedback: eRAPID overall

Connection with hospital

*'....it's like keeping in touch...
without making an
appointment to see anyone.'*



Reassurance

*'Gave me 'permission'
to contact the hospital
if I was worried by side
effects.'*



Patient reports not always used

*'No feedback from anyone..... so
stopped using it.'*



Personally useful

*'felt like I was
taking an active role
in my treatment.'*



Patient feedback: Seeing their data

*Easy to complete and use.
Data saved and good to
compare information from
week to week.'*



**Found the graphs difficult to
understand.**



**I could see a pattern to my
symptoms (using the
graphs) so I could
anticipate symptoms for
each cycle. It gave me tips
on how to deal with
symptoms. It provided
reassurance: symptoms
were normal/to be
expected.**



**Enabled me to see
what was
happening to me
over the period of
my treatment**



Staff feedback: eRAPID overall

'There is an instant rapport because [patient] thinks okay this one knows about me and I think that's been very helpful for me



I think it will be even more useful when, if it's used in routine practice because you wouldn't forget to look at it.



'stops you having to ask the patient 300 questions every time they come,

'....it just didn't kind of resonate with me I'm afraid



Staff feedback: eRAPID visualisation of data

'I quite liked the graphs, simply because it was very quick and easy to be able to see if something had particularly changed, it was, so, the graph, for me, the graphs were preferable, just because it's so easy to look at and see if there'd been a particular change or anything like that...'



'I like the tables, I'm not a big fan of the graphs. I think, I'm not sure why, I think probably because it's easier to see quite a lot of information quickly on the tables.... Personally I didn't see the extra value to the graphs'

'...very easy to use, it's on the system we use in clinic, you just have to click a button, all the information is there, so it was easy to use, readily available'

Current work



<https://pcor.org.uk/>

Increased interest in collecting and using PROMs in clinical practice

- Growing evidence base around value of PROMs
- Awareness of use of PROMs to change care pathways- remote follow-up of patients
 - Impact of covid-19
- **Real-world insight-** observational, pharmaceutical and health information technology industry, **how do we share with patients?**
- Ongoing IT challenges



Current approach to Clinician View of PROMs data: PROMPT

- Local Electronic Patient Record (EPR) system updated
- Change to software provider supporting our web based platform

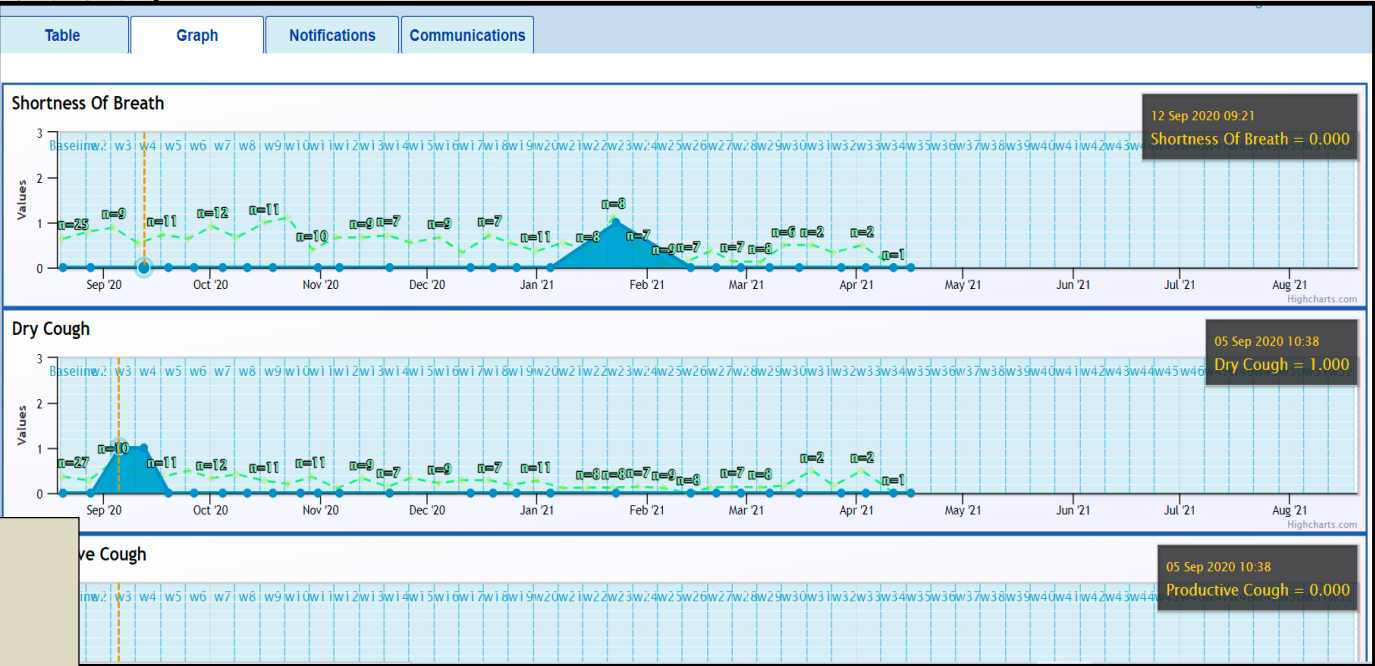
The screenshot displays the PPM+ (Patient Portal Management) interface for a clinician. The patient is identified as TESTTEAM, Six (Mrs). The interface is divided into several sections:

- Header:** PPM+ logo, a notification bell, and a patient dropdown menu.
- Navigation:** Home button and a breadcrumb trail for TESTTEAM, Six (Mrs).
- Patient Information:** Address (St. James's University, Beckett Street, Leeds) and Phone (0113 3333 3333). GP: DUMPHY, N (Dr).
- Left Sidebar (Actions):** A list of clinical actions including Clinical Documents (24+), Encounters/Events (52), Medications, Observations (1), Orders, Plans, Procedures, Results (0+), Scheduling, Tasks, and Trials/Studies. The PROMPT system is highlighted under Trials/Studies.
- Central Summary Table:** A table titled 'Summary' showing events for 2020. The table has columns for Date, Event Type, and Description. Events include Ward Stay, Summary, Outpatient Medication, Admission, and Alerts.
- Right Panel:** Contains 'Patient Clinical Alerts' with a table of alerts (Date, Name, Description) categorized into High Priority Alerts, Clinical Alerts, and Administrative Alerts. Below this is the 'Patient history' section, which currently shows 'No summary text entered.'



Current PCOR approach to Clinician View of PROMs data: PROMPT

	Table	Graph	Notifications	Communications																
Measure	Follow-up	w35	w34	w33	w32	w30	w29	w28	w27	w26	w23	w20	w19	w18	w17	w14				
		16/04/2021 11:37	11/04/2021 14:11	03/04/2021 14:43	27/03/2021 16:41	15/03/2021 20:46	07/03/2021 16:27	27/02/2021 11:09	20/02/2021 12:56	13/02/2021 10:16	23/01/2021 11:00	04/01/2021 20:02	26/12/2020 11:09	19/12/2020 14:07	13/12/2020 10:37	20/11/2020 11:59	06/11/2020 11:11			
Shortness Of Breath		0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0			
Dry Cough		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Productive Cough		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Pain		1	1	0	1	2	0	2	0	1	1	1	1	1	1	1	1			
Fatigue		1	0	0	0	1	1	1	1	1	1	1	1	1	1	1	1			
Physical Activity		1	0	0	0	1	1	1	1	1	1	1	1	1	1	1	1			
Temperature		0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0			
SkinRash		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
SkinRash Severity		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
SkinRash Fade		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
SkinRash Size		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Nausea		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Vomiting		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Appetite		0	0	0	0	1	0	2	1	1	1	1	1	1	1	1	1			
Diarrhoea		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
Neuropathy		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			



Graphs show patients symptom reported values over time with overlaid scheduled time windows.

Trend symptom data- averaged reported values for all patients on similar treatment pathway (shown in green) the numbers by each data point represent the number of patients (N) reporting at that time point.

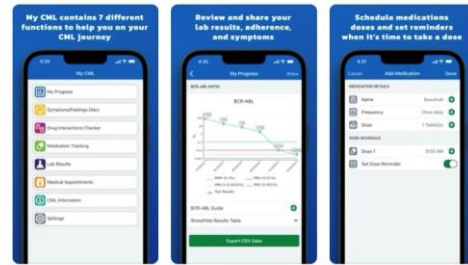
PROMs in clinical practice: Information Technology busy space



DNV Imatis



vinehealth



DrDoctor



Your secure online health connection



MY CLINICAL OUTCOMES

Amplitude
clinical outcomes

What's the growing evidence around visualising PROMs data telling us?

- Reviews
- Resources
- Examples

Evidence from reviews....

Bantug et al., 2016 Patient education and counseling, 99(4), 483–490.

Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words?

Review of graphical displays PRO data- what makes them effective?

Only 9 studies included in review

Evidence from reviews....

Bantug et al., 2016 *Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words?*

Findings/conclusions

- Patients and clinicians can accurately comprehend graphs (but not always)
- Patients prefer simple graphs, clinicians want more detail
- Variation in how PRO measures are scored/scale creates challenges for presentation



Evidence from reviews.....

Albers et al. 2022 J Patient Rep Outcomes 6, 18 Visualization formats of patient-reported outcome measures in clinical practice: a systematic review about preferences and interpretation accuracy

Evaluated evidence for graphic visualization formats of PROMs data in clinical practice for patients and clinicians, for both individual and group level PROMs data

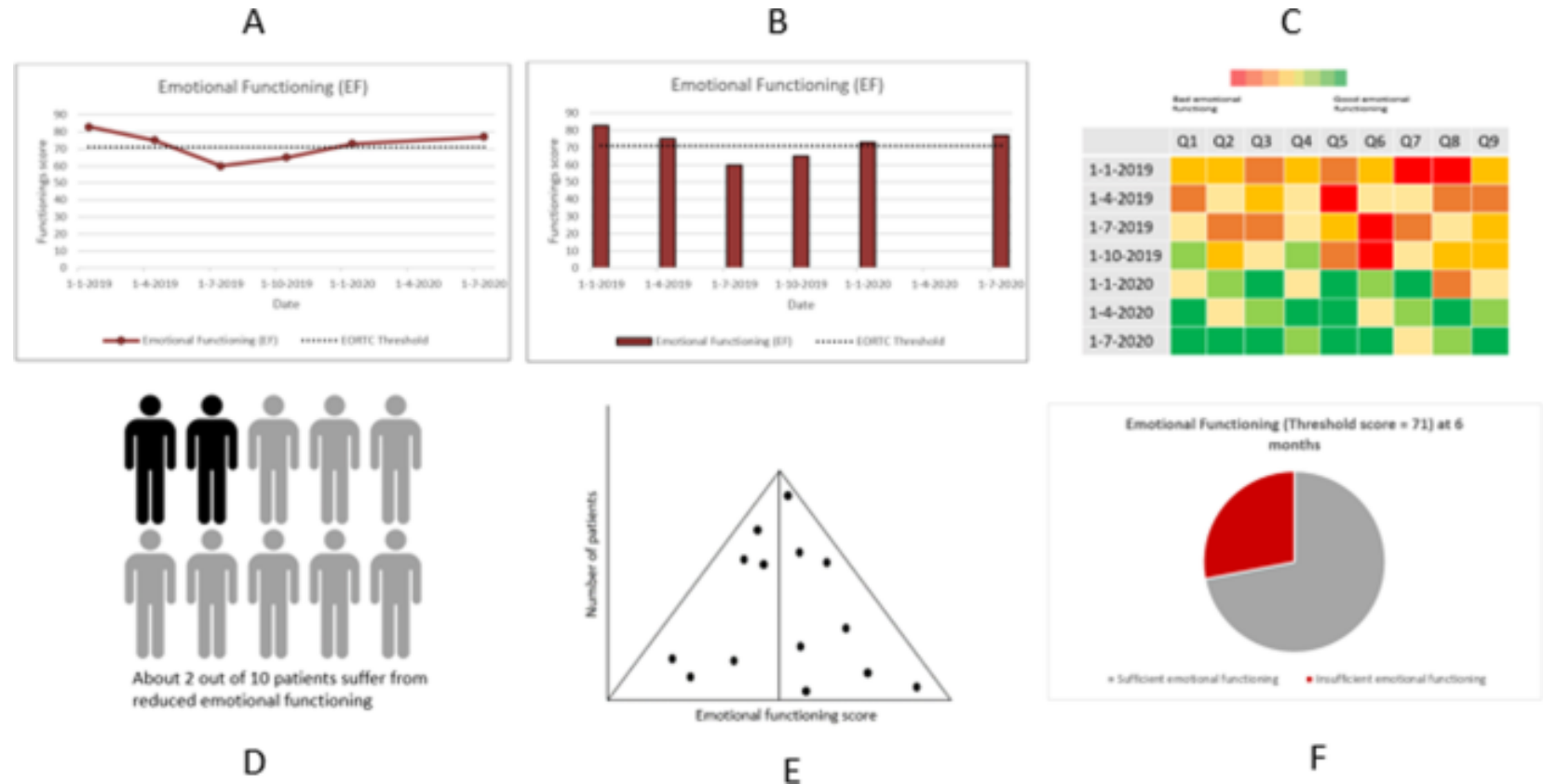
Included 25 papers

Evidence from reviews....

Albers et al. 2022 J Patient Rep Outcomes 6, 18 Visualization formats of patient-reported outcome measures in clinical practice: a systematic review about preferences and interpretation accuracy

Longitudinal:

- A. line graph, including threshold line
- B. bar chart, including threshold line
- C. heat map
- D. icon array
- E. funnel plot
- F. pie chart



Evidence from reviews.....

Albers et al. 2022 *Visualization formats of patient-reported outcome measures in clinical practice: a systematic review about preferences and interpretation accuracy*

Findings/conclusions

- No predominant graphical visualization format approach in terms of preferences or interpretation accuracy for both patients and clinicians.
- Patients preferred bar charts and line graphs – for ease
- Participant literacy information missing from studies

A very helpful resource.....

<https://epros.becertain.org/>

- ePROs in clinical care Funded by the Agency for Healthcare Research and Quality (AHRQ) as part of Digital Healthcare Research Program.
- University of Washington- Co-PIs Danielle Lavalley & Cynthia LeRouge
- Real-world experience to advise on ePROS in clinical settings
 - Governance
 - Integration
 - Reporting
 - Tools and resources

<https://epros.becertain.org/> Reporting

Drill Up/Down

Filter Data

Integrate Clinical Data

Accomodate Platforms

Presentation
Guidelines



Key Concepts



Data & Information



System Function &
Interaction



Presentation



Using Reports

- Advice Statistical presentation
- Longitudinal information
- Comparative information
- Contextual

<https://epros.becertain.org/> Visualisation library

Longitudinal

used to
trend single patient

Comparison

used for
clinical care

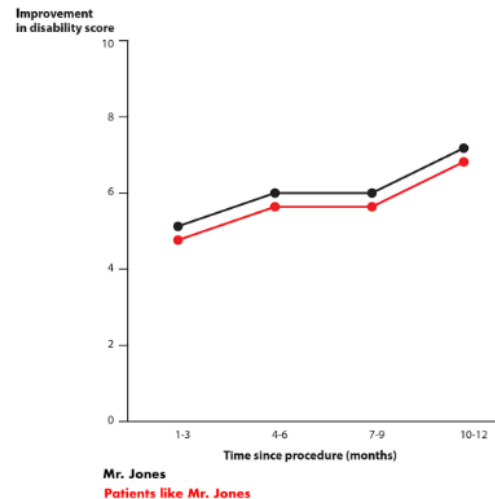
Aggregated Group

used for
performance assessment

Single Score

used for
single patient, set time

Post-procedure improvement in PRO disability scores comparing Mr. Jones to patients like Mr. Jones



Graph — Line graph

Graph Type

Longitudinal, Comparison

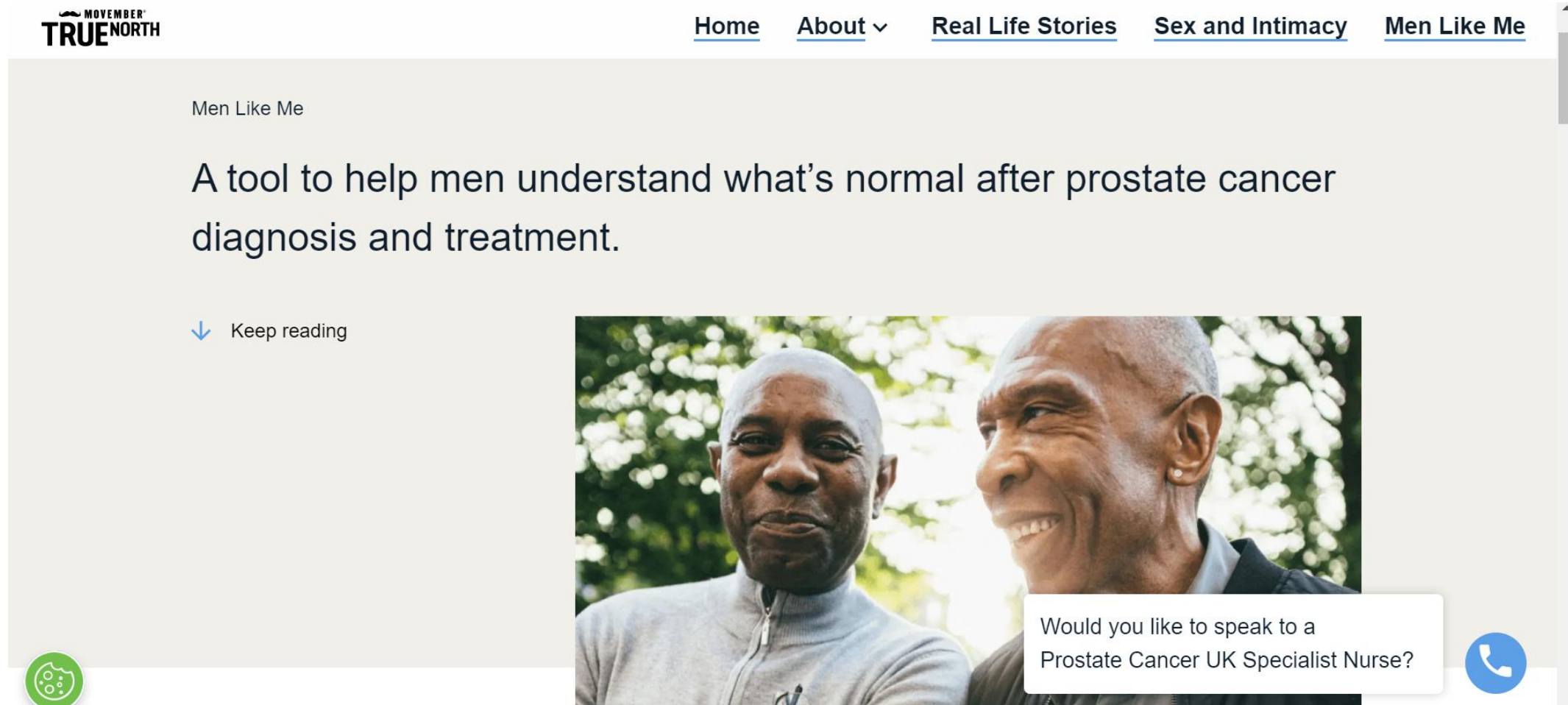
Description

Post-intervention improvement in PRO disability scores for Mr. Jones and patients like Mr. Jones.

Examples of PROMs visualisation outputs and projects

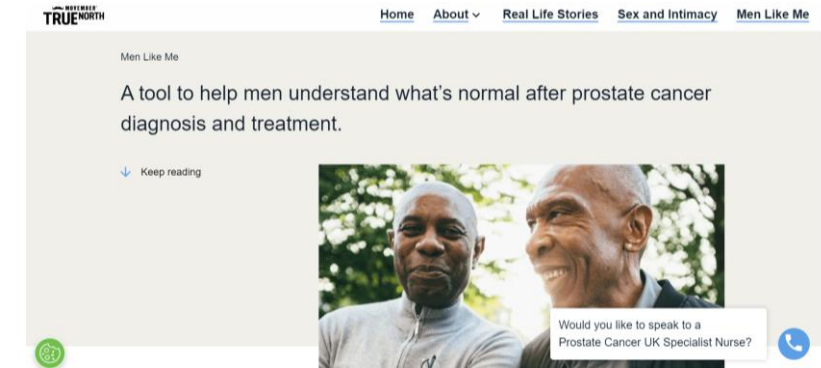
Examples of PROMs visualisation outputs and projects: Men like Me

<https://truenorth.movember.com/en-gb/men-like-me>



The screenshot shows the 'Men Like Me' page on the True North Movember website. The navigation bar includes links for Home, About, Real Life Stories, Sex and Intimacy, and Men Like Me. The main content area features the title 'Men Like Me' and a description: 'A tool to help men understand what's normal after prostate cancer diagnosis and treatment.' Below this is a 'Keep reading' link with a downward arrow. A large photograph of two men is displayed, with a white chat bubble overlaid on the bottom right corner of the image. The chat bubble contains the text: 'Would you like to speak to a Prostate Cancer UK Specialist Nurse?'. A blue telephone icon is positioned to the right of the chat bubble. In the bottom left corner of the page, there is a green circular icon with a white outline of a person's head and shoulders. In the bottom right corner, the University of Leeds logo is visible.

Men like Me



- Patient facing resources for PROMs data collected as part of a large national Life After Prostate Cancer Diagnosis study
- Data from 35,000 men who completed Quality of life surveys after prostate cancer
- Interactive tool allow people to tailor the information they see about quality of life and health outcomes for men similar to them
 - Age, cancer stage, treatment received, other comorbidities

Men like Me

Men Like Me

A tool to help men understand what's normal after prostate cancer diagnosis and treatment.

↓ Keep reading



Learn from Men Like You.

[Edit selections](#)

We've pulled together dozens of insights from men with prostate cancer. Explore each section below to get the real deal.

About these results

These insights are powered by data from the [LAPCD study](#). Over 35,000 men participated in the study, 18 to 42 months after prostate cancer diagnosis.

Impact on Daily life

60% of men like you said prostate cancer had a significant impact on daily life.

URINARY ISSUES

Urinary Incontinence



Urinary Irritation



Explore insights

Men like Me

Bowel Function



SEXUAL ISSUES

Sexual Function



Sexual Activity



HORMONAL ISSUES

Hormonal Issues



Men Like Me

A tool to help men understand what's normal after prostate cancer diagnosis and treatment.

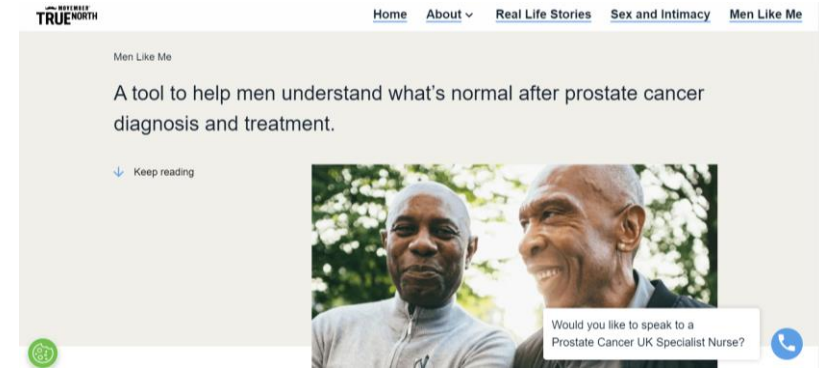
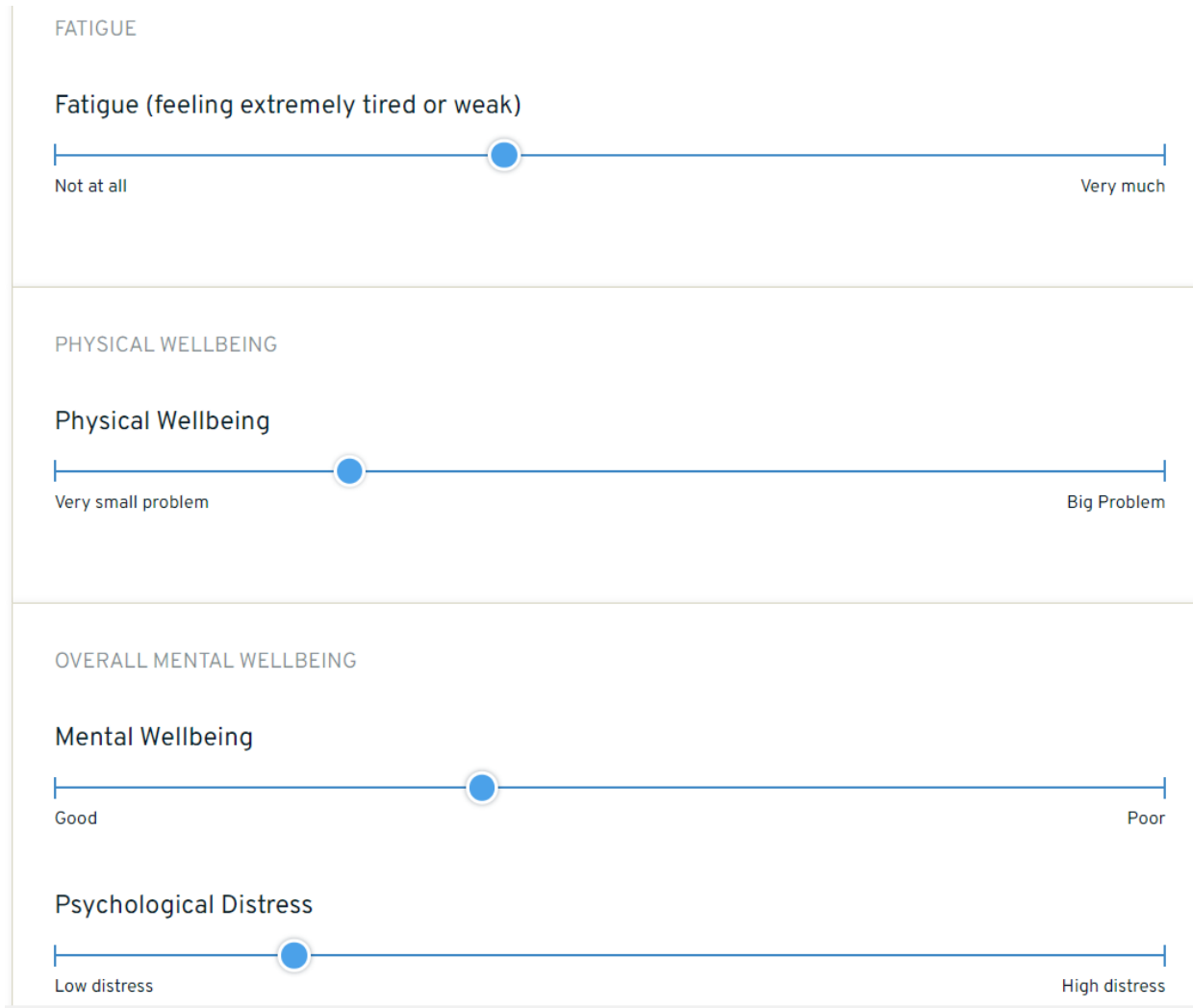
↓ Keep reading



Would you like to speak to a Prostate Cancer UK Specialist Nurse?



Men like Me



Not clear how far the site is still be advertised to patients or how/if patients are using the information

Or how lack of representation from some participant groups is conveyed/understood

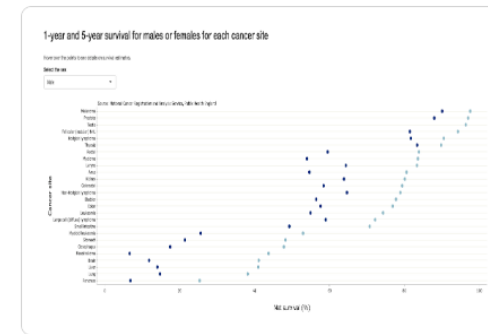
National Cancer Registration and Analysis Service (NCRAS): Cancer Dashboards (data from England)

- Incidence
- Survival, mortality
- Route to diagnosis
- Treatment
- Now includes Quality of Life



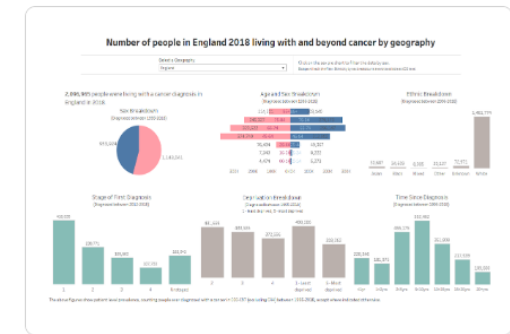
Incidence and Mortality

Numbers of cancer diagnoses and cancer deaths (with crude and age adjusted rates).



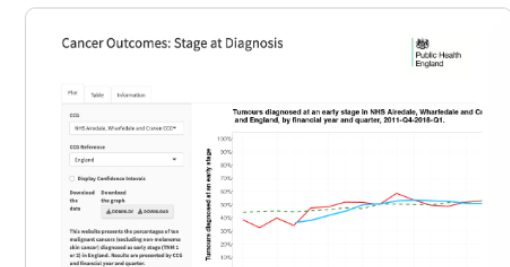
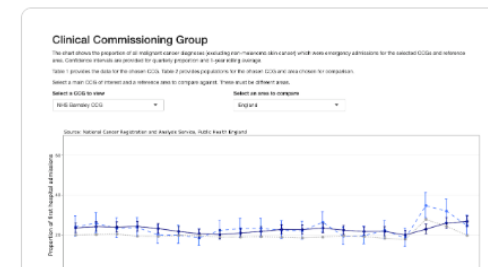
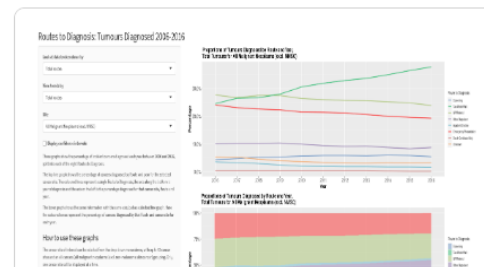
Survival

Net survival for cancer



Prevalence

Numbers of people living with a cancer diagnosis



National Cancer Registration and Analysis Service (NCRAS) <https://www.cancerdata.nhs.uk/cancerqol>

- EQ5D
- EORTC QLQ C30
- 111,470 completions
- View comparisons with general population, by region, cancer type etc

Comparisons by patient factors Who has taken part so far? More information Download data

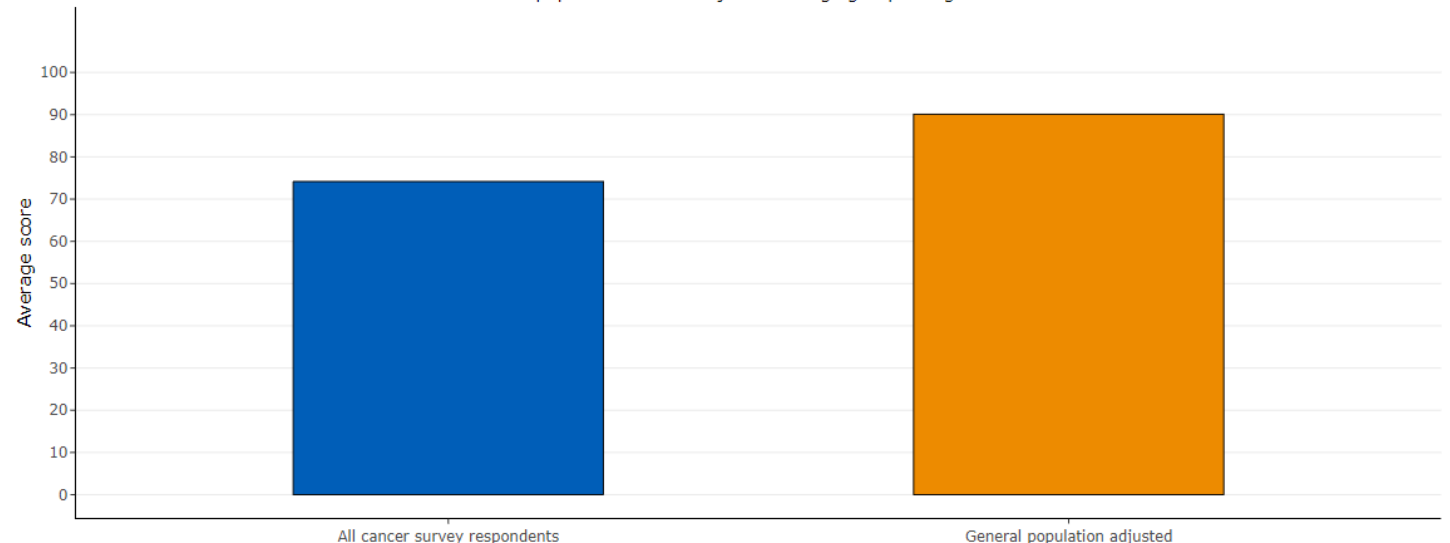
Summary scores (EQ-5D)

Overall health (EQ-5D)

The charts on this page show summary scores from the EQ-5D questionnaire. These scores give an overview of overall health. The charts show the national picture for all cancer types included in the survey and compare the cancer survey respondents to the general population. The maximum score is 100; higher scores suggest better quality of life.

Overall health summary score (EQ-5D Index)

General population values adjusted for age group and gender.



The chart above shows the average summary score from the questionnaire measuring overall health (EQ-5D). It is based on how the person answers each of the five individual questions that make up the questionnaire.



SISAQOL: Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints



- Aim: to develop international consensus recommendations for the design, analysis, interpretation, and presentation of PRO data in cancer clinical trials (CCTs).
- Work package 4 – Communication tools for PROs- graphical representation of findings
 - Reviews and stakeholder work
 - Watch out for outputs <https://www.sisaqol-imi.org/>

What is the future direction of visualising PROMs data?

Review of features and functionality of electronic PROMs systems

JOURNAL OF MEDICAL INTERNET RESEARCH

Warrington et al

Review

Electronic Systems for Patients to Report and Manage Side Effects of Cancer Treatment: Systematic Review

Lorraine Warrington¹, BSc, MSc, PhD; Kate Absolom¹, BSc, PhD; Mark Conner², BSc, PhD; Ian Kellar², BA, D Phil; Beverly Clayton¹, RGN, RSCN, BHSc; Michael Ayres³, MBBS, MSc; Galina Velikova¹, BMBS, PhD

¹Section of Patient Centred Outcomes Research, Leeds Institute of Cancer and Pathology, University of Leeds, Leeds, United Kingdom

²School of Psychology, University of Leeds, Leeds, United Kingdom

³Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom



Lorraine Warrington

Recently updated for new EU funded project: MyPath



Key findings: 69 individual systems

- 10 (14%) integrated results into electronic records
- 26 (38%) gave patients access to visualise their own reports



Future work: Addressing challenges in routine PROMs collection

Journal of Medical Radiation Sciences

Open Access

REVIEW ARTICLE

A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care

Hanh Nguyen, B Rad Therapy,¹  Phyllis Butow, BA (Hons), M Clin Psych, MPH, PhD,²
Haryana Dhillon, BSc, MA, PhD,² & Puma Sundaresan, BSc (Hons), MBBS, FRANZCR, PhD^{1,3} 

¹Western Sydney Local Health District, Radiation Oncology Network, Sydney, Australia

²Centre for Medical Psychology & Evidence-based Decision-making, The University of Sydney, Sydney, Australia

³Sydney Medical School, The University of Sydney, Sydney, Australia

- Patient level
- Health professional level
- System level

eRAPID INSIGHTS

FUNDED BY

NIHR | National Institute for
Health and Care Research

- Awarded additional funding to:
 - Conduct further analysis of PROMs data- patient profiles, predictions of outcomes
 - Explore case studies where, how the intervention worked
 - Understand more about how to share PROMs data with patients
 - Idea generated by patient representatives
 - Focus groups and interviews- discuss value and interpretations of different mock ups of visualisations of eRAPID symptom data
 - Hoping to also do some very early work with non-English speakers- South Asian communities



INSIGHTS Data Visualisation advisor- Andy Kirk <https://visualisingdata.com/>

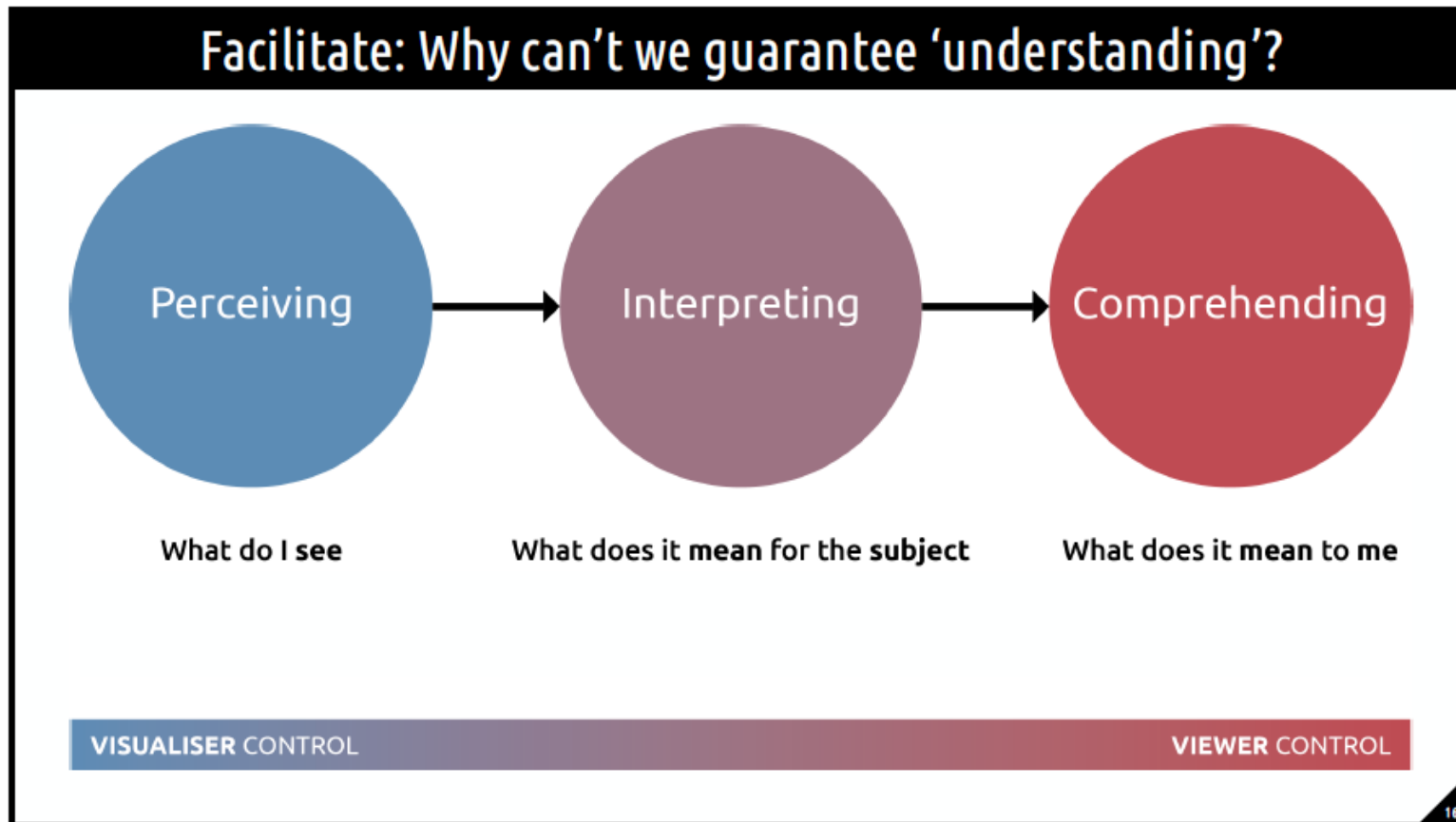
Visualisation: The visual **representation** and **presentation** of **data** to facilitate **understanding**

- Data (raw material)
- Representation ('seeing' data, attributes -)
- Presentation (interactive elements, annotation, colour, composition)
- Understanding....

Data visualisation- Andy Kirk

<https://visualisingdata.com/>

- How individuals 'understand' is not straightforward:



What does it mean for me?

Patient views of when, what sort of visualisations/depictions of PROMs data do they want to see at different points of their cancer trajectory

Kirk, A. (2019). Data visualisation: A handbook for data driven design. Second Edition (Revised Edition) edition, Sage.

Summary: PROMs data visualization in the clinical setting

- Not definitive answers on...
 - What
 - How
 - When
 - (And Why...)
- But useful resources becoming increasingly available and scope for further knowledge exchange
- More commitment to sharing PROMs data with patients

Summary

- Visualising patient reported data is fundamental to maximising it's use in clinical practice- both for clinical teams and patients
 - Not done in isolation
- Mixed evidence on optimal presentation/visualisation formats
 - Individual differences and preferences
- Scope for
 - More research on how improving PROMs data sharing can lead to better knowledge/outcomes for patients
 - Exploring how literacy or sociodemographic differences may influence

ACKNOWLEDGEMENTS

- All current and past members of Patient Centred Outcomes Research group www.pcor.org.uk
- Clinical collaborators and patient advisors (Research Advisory Group)
- Patients and participants
- Funders



Funded by
the European Union



Innovate
UK

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