

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

From brainwave to impact

Penny Wright



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1994: Britain braced for first lottery draw

An estimated jackpot of £7m may be won tonight in Britain's first ever lottery draw.

A £1 ticket gives you a one-in-14-million chance of striking lucky and guessing correctly the winning six out of 49 numbers.

The lottery operator Camelot says around 15 million players have



Noel Edmonds launches the first national lottery draw show

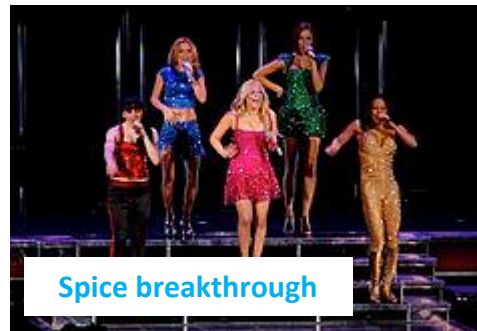


Automated Screening and
Recording of Quality of Life Data in
Clinical Practice

NHS R&D grant £324,150
(Selby, Cull, Gould, Forman)



1995



1996



As European veterinary experts met yesterday to discuss easing the ban on British beef, the Consumers' Association issued a report claiming the Government had failed to put consumers first in the BSE crisis. Have people been misled? Today, CHRIS ELLIOTT reports on how a Mid-Arglian scientist is attempting to put the crisis in perspective — by launching a crusade to banish misinformation about it.

Public just want truth about BSE says expert



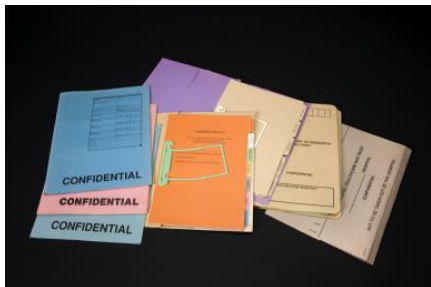
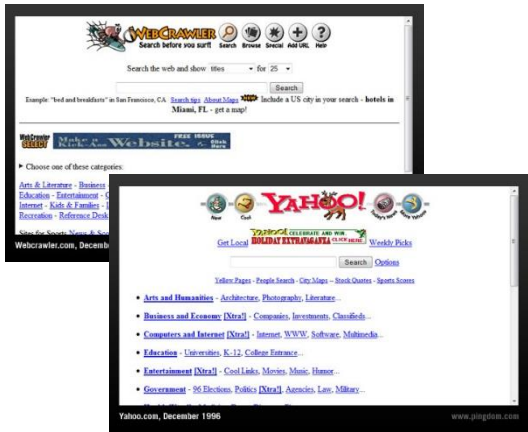
January 1996:100,000

websites

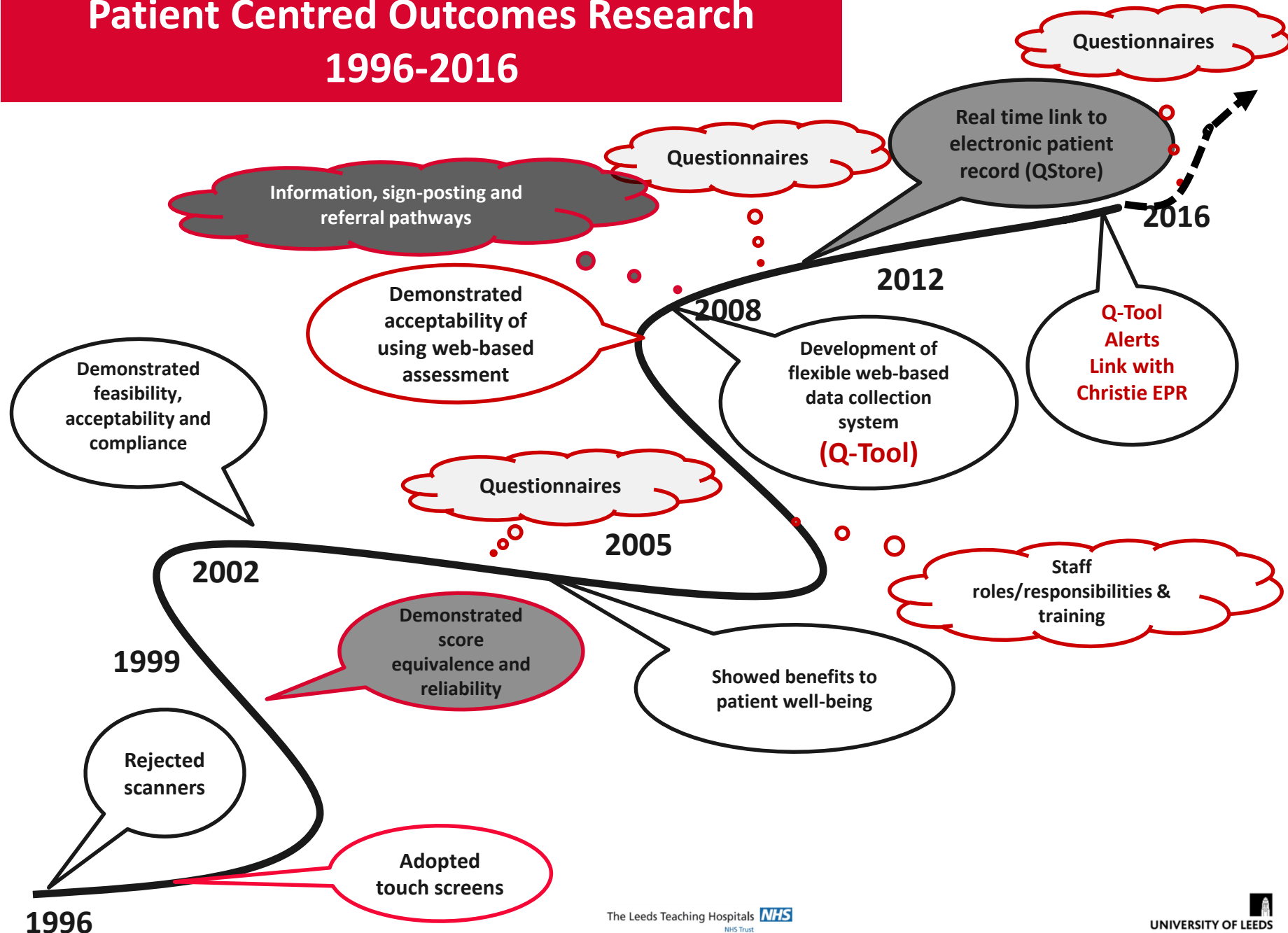
Mainly dial-up Internet
connections



The 10-digit
NHS number
introduced

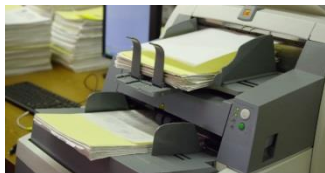


Patient Centred Outcomes Research 1996-2016



Research and Impact

- Technological approach
- Use of Patient Reported Outcome Measures (PROMs) in clinical practice
- Development and use of the Social Difficulties Inventory (SDI-21)



- Paper chase
- Error prone
- Time consuming

Staff and patients have got to find the technology useful and really easy to use or they will get frustrated and abandon it.



- Too small
- Too easy to steal



- Need a delay between screens
- Too heavy
- Bar code reader would 'read' any barcode



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

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, E.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-S81.
5. Ashley, L., et al., J Med Internet Res, 2013. **15**(10): p. e230.



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



- QTool: Online
- **Now linked to EPR**
- **With alerts**

Technological approach

Is it feasible and acceptable?

- People answer questions in the same way
- Less error than paper versions
- Costs less money to administer
- Most staff and patients like the approach
 - But.....

- Older people
- Those who can't speak English
- Those living in areas of greater deprivation

may be at a disadvantage

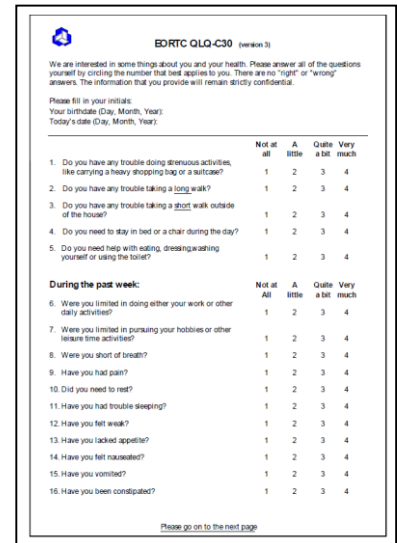
"Very easy to do. You don't have to worry about finding a pen or posting the information back and maybe getting lost in the post"



"I liked it because it was very flexible and I could fit it round anything that had been planned in the day then done in my own time"

Patient Reported Outcome Measures (PROMs) in clinical practice

- PROMs developed for use in clinical trials
- Designed to pick up differences between groups
- Could they be used meaningfully in individual patient care for:
 - Monitoring
 - Enhancing communication
 - Helping inform decision making?
- Would they make a difference to patient well-being?
- Apart from the technology being ok you need:
 - the right questionnaires
 - understandable/ interpretable results
 - trained staff



The image shows a screenshot of the BORTC QLQ-C30 (version 3) questionnaire. It includes instructions for patients to fill in their initials, birthdate, and today's date. The questionnaire consists of 16 items, each with a rating scale from 1 to 4. The scale is defined as: 1 = Not at all, 2 = A little, 3 = Quite a bit, 4 = Very much. The items cover various aspects of physical, functional, and social well-being, as well as symptoms and quality of life.

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page



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.

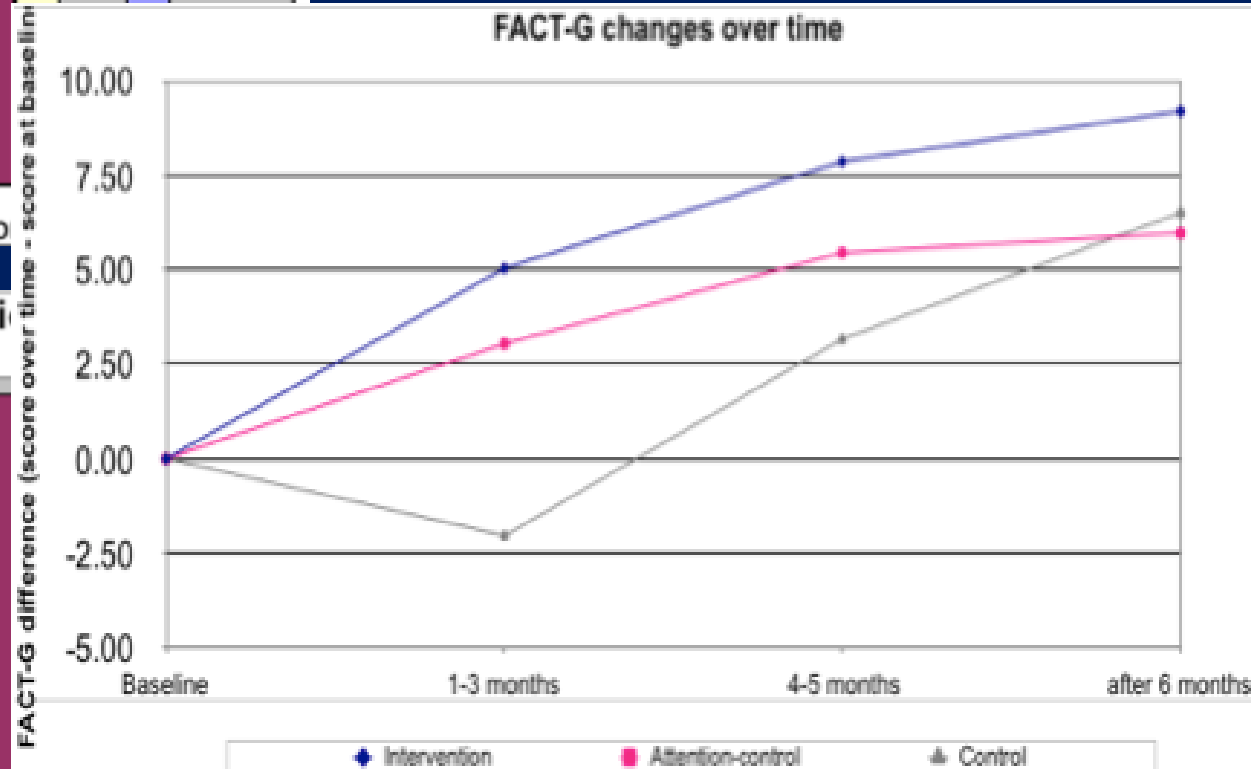
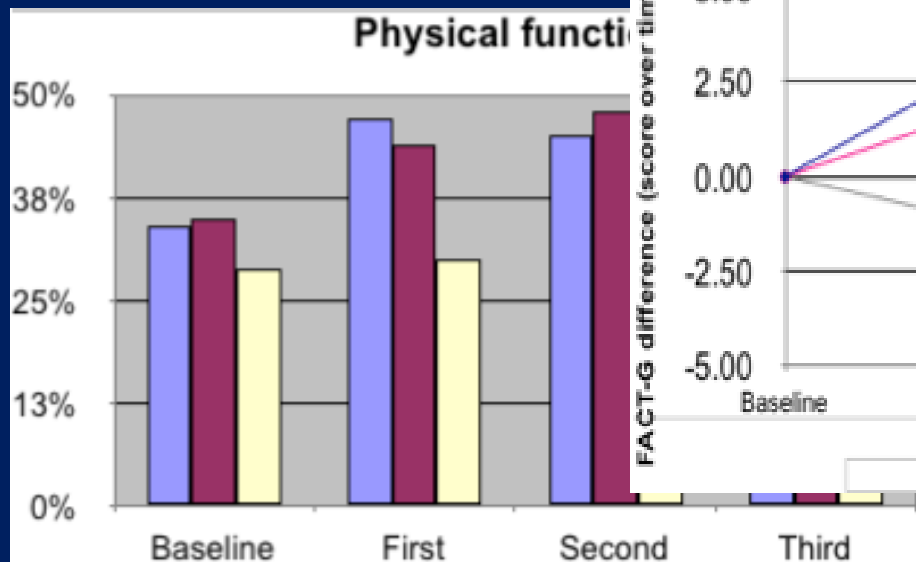
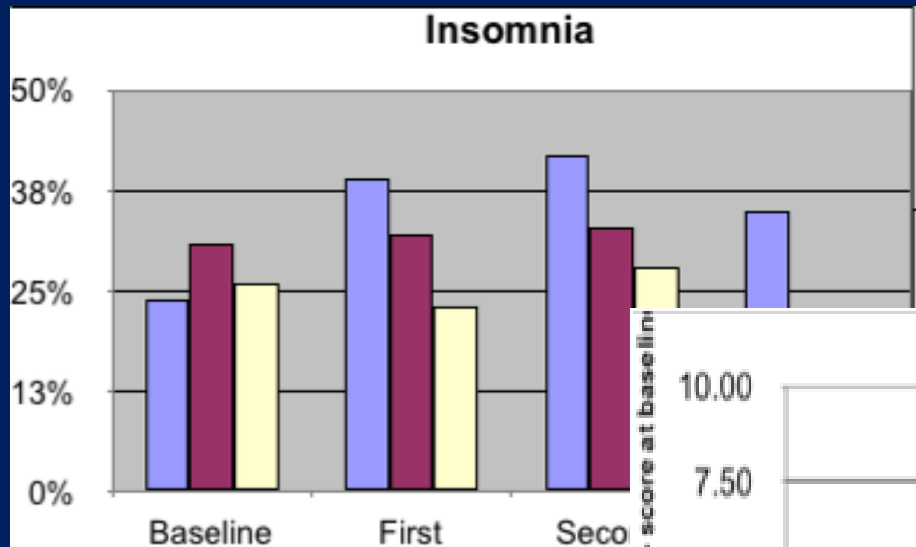
Patients and Methods

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

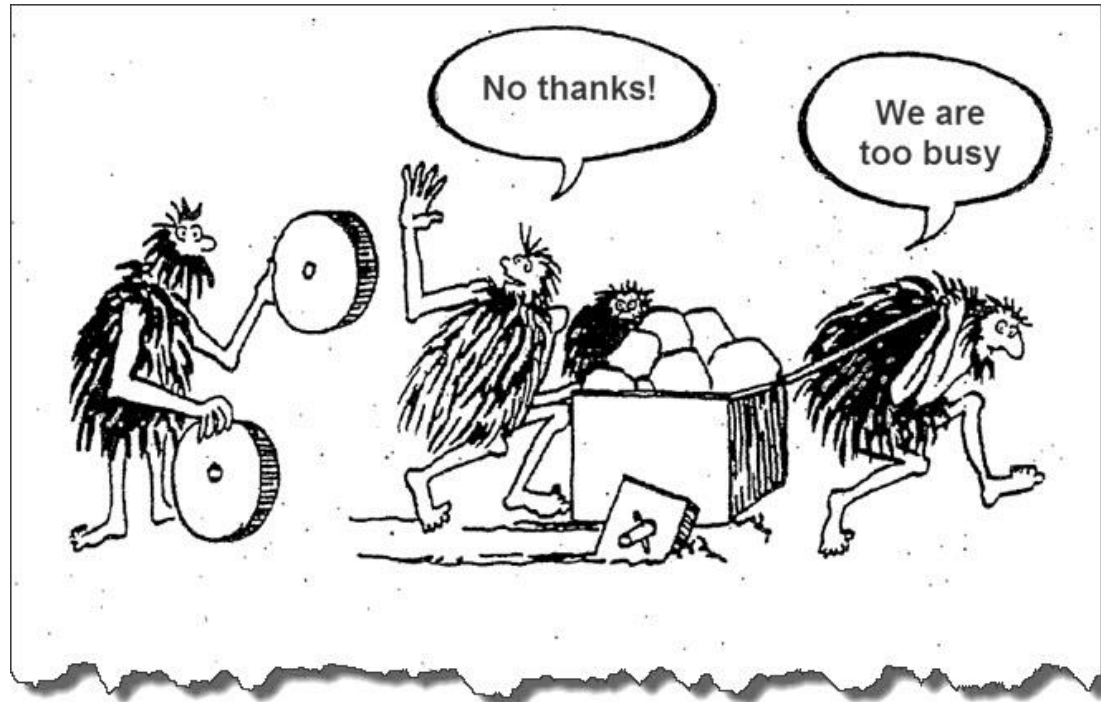
Velikova et al. J Clin Oncol 2004; 22, 714-724

Changes communication

Improves Patient well-being



Use of PROMs in clinical practice: staff training



- Different staff needs
- Other associated training
(e.g. PPM, Holistic Needs Assessment)
- Project specific training
- Training style/type
- Training manual
- Timing
- Scheduling/priority
- Staff changes
- Critical mass

Training clinicians to use PRO data

“Trigger tapes” Common clinical scenarios and key learning points

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



PhD Dr Elena Takeuchi

International collaboration

Qual Life Res (2015) 24:1707–1718
DOI 10.1007/s11136-014-0903-5



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

Accepted: 17 December 2014 / Published online: 15 January 2015
© Springer International Publishing Switzerland 2015

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

Use of PROMs in clinical practice: eRAPID

Electronic patient self-Reporting of Adverse-events: Patient
Information and aDvice (NIHR programme grant)

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



eRAPID Multi-centre programme in systemic therapy, radiotherapy and surgery

The Leeds Teaching Hospitals **NHS**
NHS Trust



Prof Jane Blazeby
Elaine O'Connell
Steve Gray

Dr Alexandra Gilbert
NIHR Clinical PhD student

Dr Susan Davidson
Jacki Routledge
Matthew Barker-Hewitt

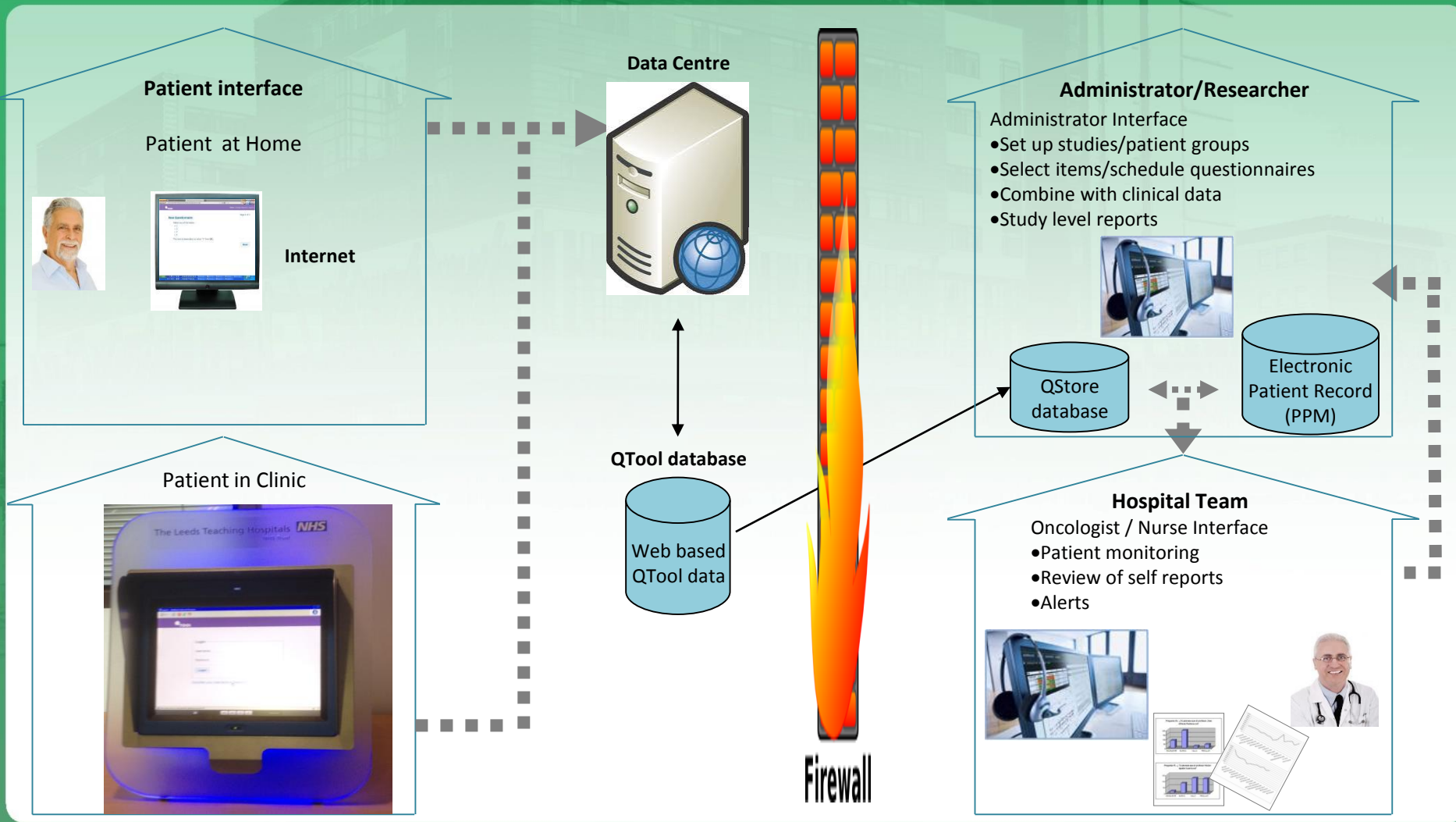


University Hospitals Bristol **NHS**
NHS Foundation Trust



The Christie **NHS**
NHS Foundation Trust

eRAPID System Overview



UNIVERSITY OF LEEDS

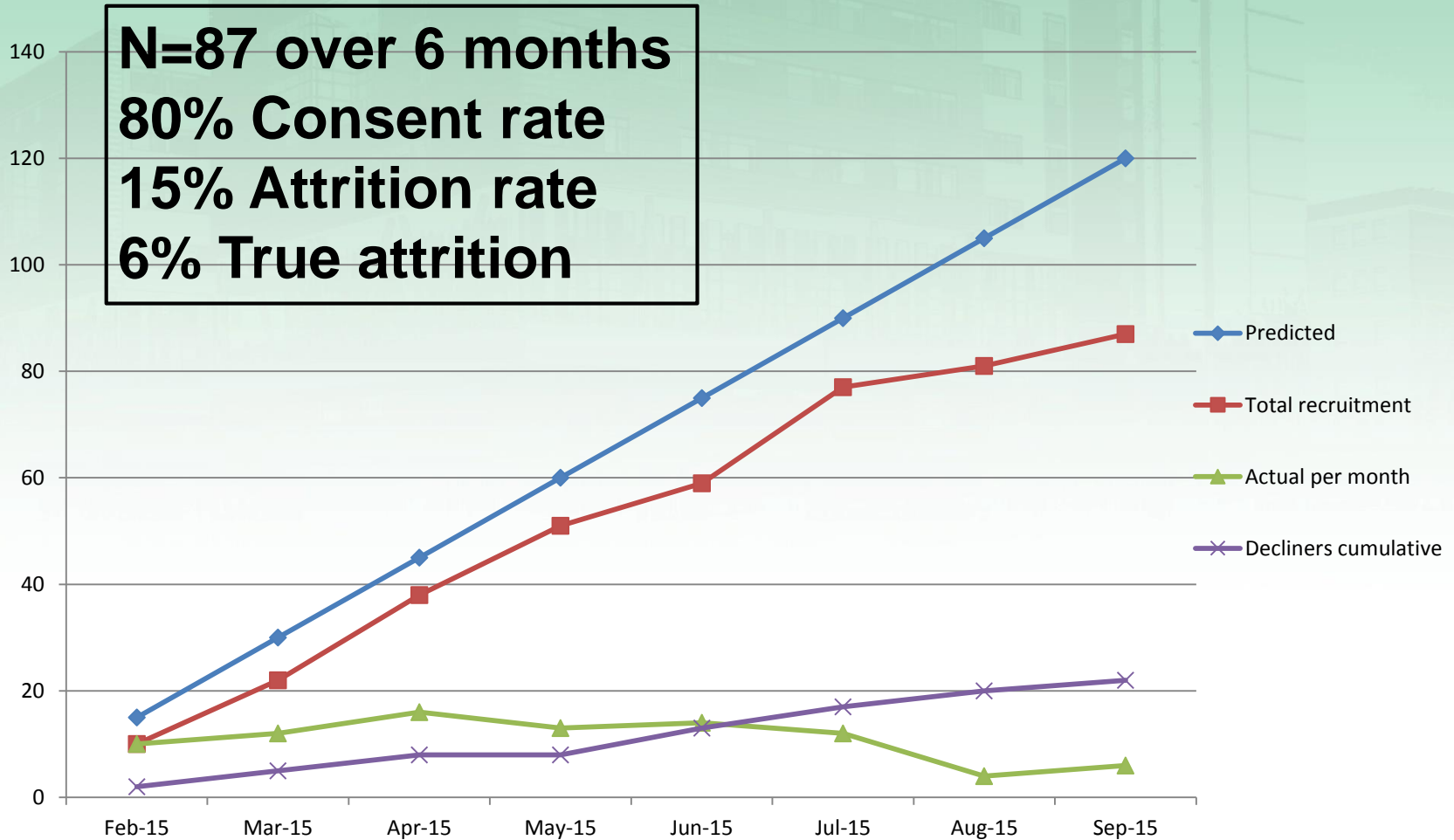
eRAPID

Electronic patient self-Reporting of
Adverse-events: Patient Information
and aDvice

NHS

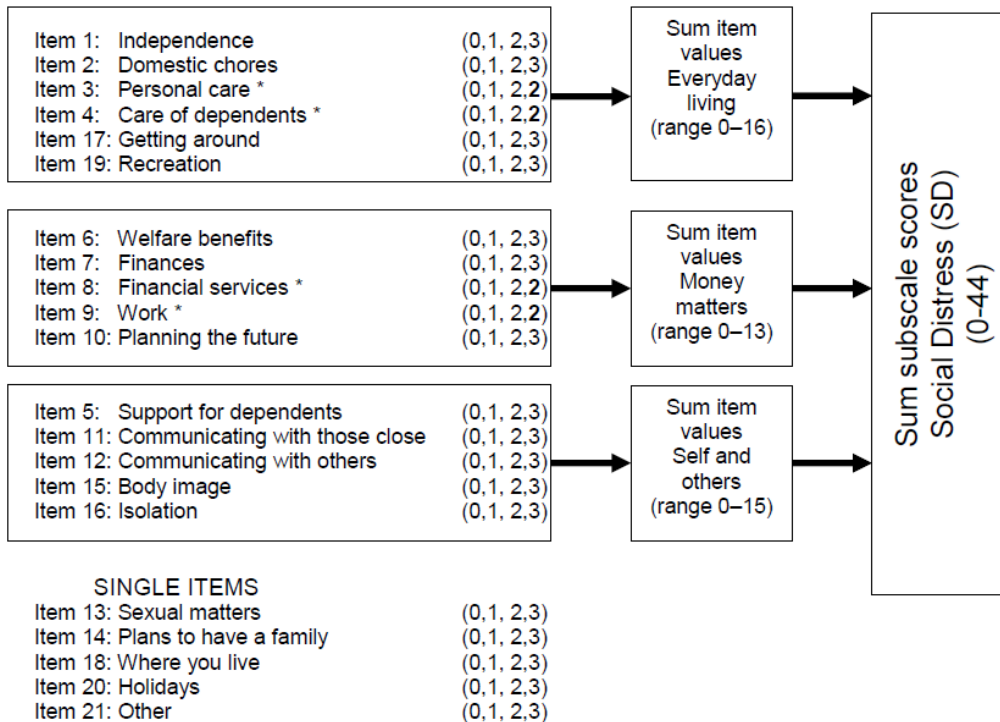
National Institute for
Health Research

RCT - Internal Pilot



The Social Difficulties Inventory (SDI-21)

- Gap in questionnaires to measure **social/everyday** impact of cancer
- Developed for use in clinical practice
- RASCH analysis allowed for individuals **AND** for group comparisons
- Three subscales, one summary scale (SD-16) and five single items
- Clinical meaning and utility established



9 SDI-21 methodology papers



NHS
National Institute for
Health Research



Continuing with
measurement of **social**
impacts of illness



So what are the impacts?

Use of technology in clinical practice

- UK (DoH/Macmillan eHNA)



- USA Patient Outcomes Program at Cancer Treatment Centres of America



- Canada (lung-heart transplant)



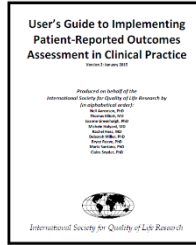
- Canada Electronic Distress Assessment and Response Tool (DART)



So what are the impacts?

Contributing to guidelines

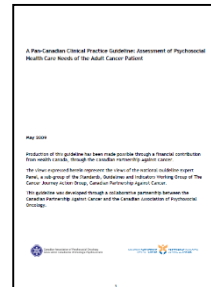
- 2011 & 2015 ISOQoL



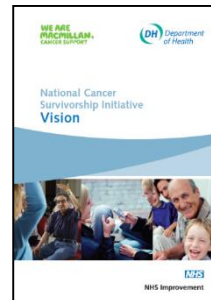
- Manual for use of the EORTC measures in daily clinical practice



- Pan Canadian Clinical Practice Guidelines



- National Cancer Survivorship Vision Document



So what are the impacts?

Change in policy

- NHS policy and the Health and Social Care Act 2012

Sir Mike Richards, National Cancer Director (1999-2013)

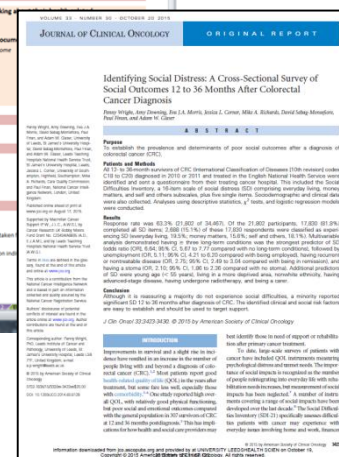
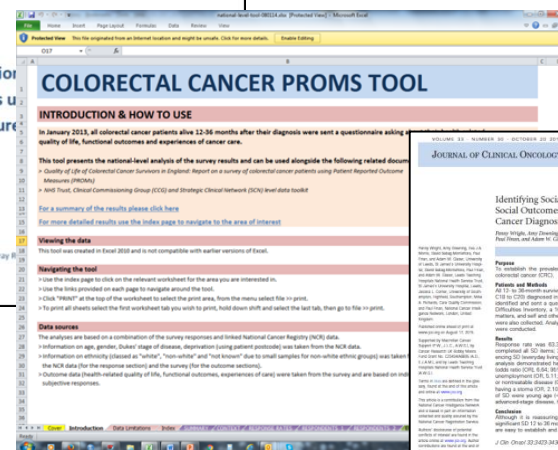
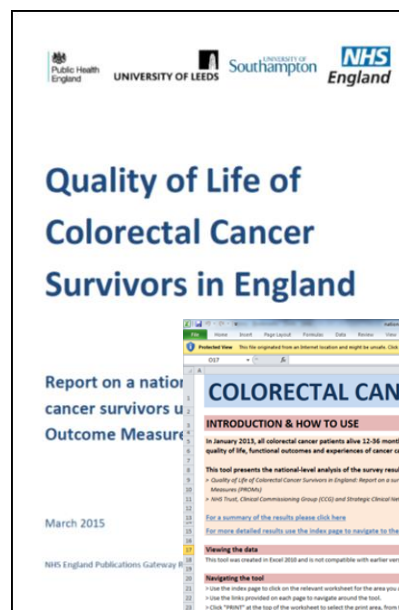
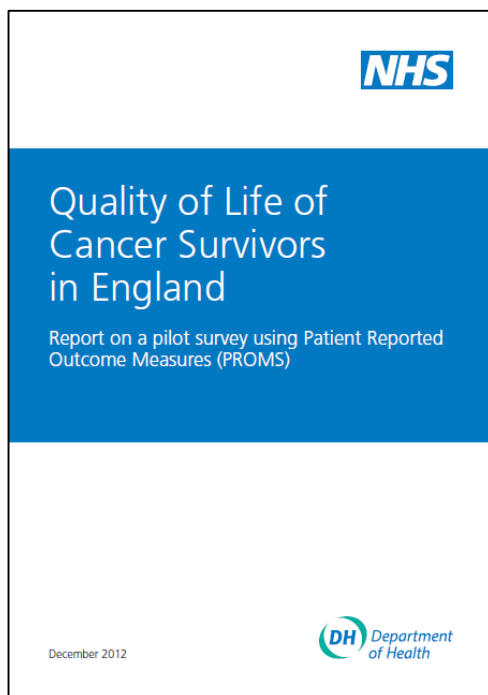
*“Health services must become more patient-centred. We urgently require methods to measure this aspect of care. **Leeds researchers** have provided us, not only with technologies for this purpose but also evaluated their measurements in a positive randomised controlled trial. **This was very influential in development of policy and the incorporation of Patient Reported Outcome Measures as a central theme within the NHS**”*

So what are the impacts?

National PROMs Initiatives

- National PROMs Surveys (NHS England)

<https://www.england.nhs.uk/ourwork/cancer/cancer-resources/>



Other impacts

What about the patients?

- Participants (>7,000)
 - Direct benefits for some
 - Referrals
 - Information
 - Indirect benefits for others
 - RAG members

"Makes me feel that I haven't been forgotten. When everything goes quiet following treatment it can be difficult to come to terms - the questionnaire keeps me in touch"



Other impacts

What about the research team?

- Over 70 people
 - Research assistants
 - Research nurses
 - Research fellows
 - Doctors
 - One Dentist
 - One user researcher
 - Administrators
 - Data/IT/ Statisticians
- Where are they now?
 - PhDs – academic career
 - DClin – clinical psychology
 - Academic research/teaching
 - Clinical trials
 - Nursing
 - Academic Medicine
 - Complete change
 - Retired
 - A few still hanging around



10 PhDs and 1 ongoing

What about the research team?



Proud to support RCN 1045077



Section of Patient Outcomes Research (Section head: Galina Velikova)

Psychosocial
Research Group
Penny Wright

Patient Reported
Outcomes Group
Galina Velikova

Teenage and
Young Adults
Research Group
Dan Stark



Programme grants: £5,155,000

Project grants: £3,610,000

Fellowships: £1,323,000





[A blood count in a case of hidatid disease of the liver](#)

Loncridge, CJN

LANCET Volume: 2 Pages: 44-45 Published: 1902

[The blood count. Improvements in method.](#)

Alport, AC

LANCET Volume: 2 Pages: 756-758 Published: 1922

[The interpretation of the blood count.](#)

By: Dyke, SC

LANCET Volume: 2 Pages: 936-937 Published: 1928

[Determining the stability of complete blood count parameters in stored blood samples using the SYSMEX XE-5000 automated haematology analyser](#)

Joshi, A.; Mcvicker, W.; Segalla, R.; et al.

INTERNATIONAL JOURNAL OF LABORATORY HEMATOLOGY Volume:

37 Issue: 5 Pages: 705-714 Published: OCT 2015



- Takes time
- What is true of blood counts may be true for Patient Reported Outcomes
- You have to have belief it is worthwhile
- Then reflect on impact and take stock

Many thanks to all who have helped over the years