

Use of technology for research aimed at improving patient care



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**WE ARE
MACMILLAN.
CANCER SUPPORT**





**Use of
technology for
research
aimed at
improving
patient care**

- **Some cancer information**
- **How we use technology**
 - touch screens
- **Implementation to adoption**
- **How we use technology**
 - use of the internet

People living with and beyond cancer



CT screening cuts lung cancer death better than X-ray: study
Saturday, 6 November 2010
The Independent



Not managing these consequences of treatment can cause real problems to people in terms of disabling their lives at the other end

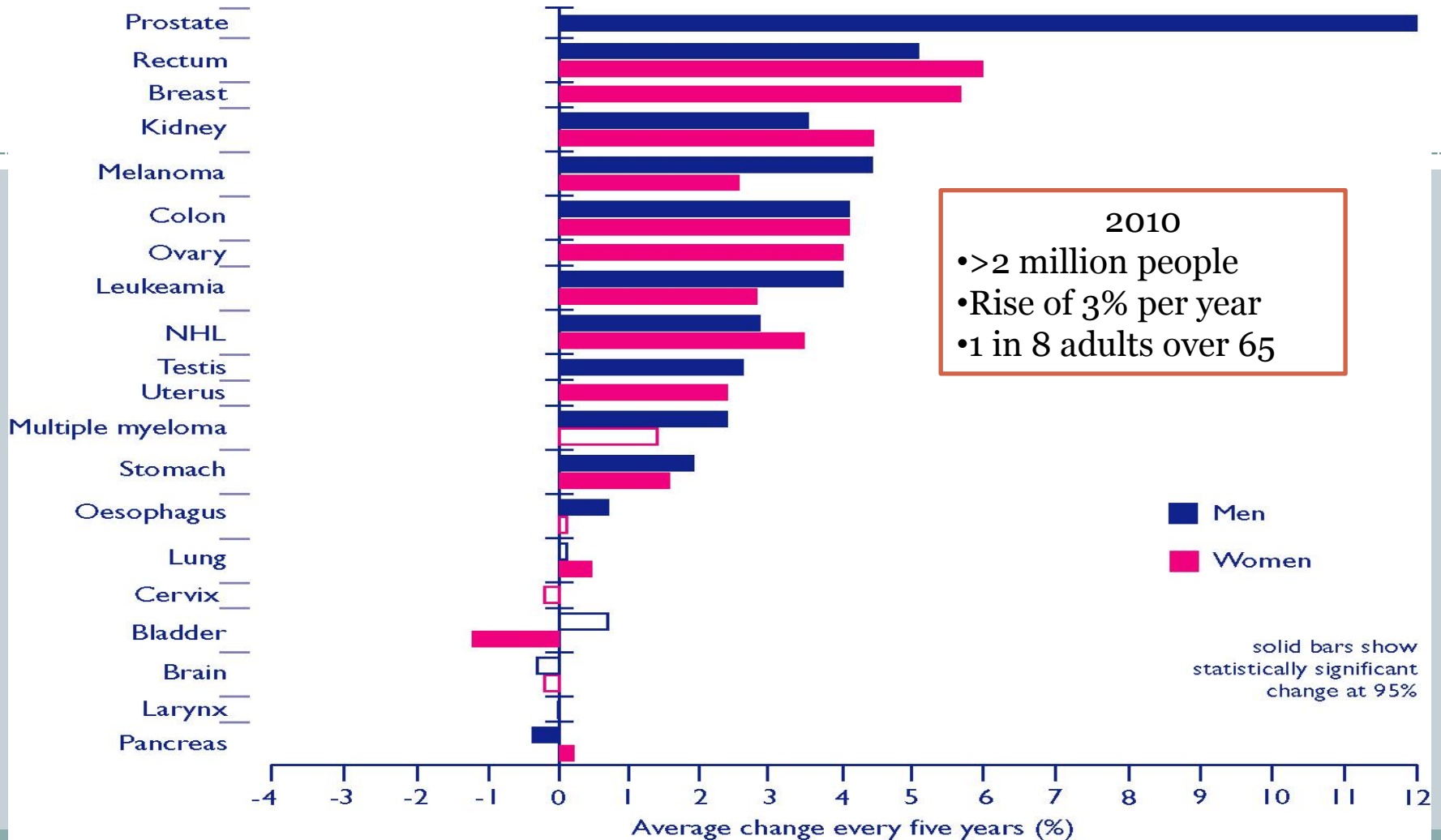
Professor Jane Maher
Macmillan Cancer Support

BBC 6 January 2010

4% increase in new cancer cases
By Neil Lancefield, PA
Thursday, 21 October 2010 *The Independent*



Average change (%) every five years in five-year relative survival, by site and sex, adults diagnosed in England and Wales during 1986-1999



What does this mean for cancer services?

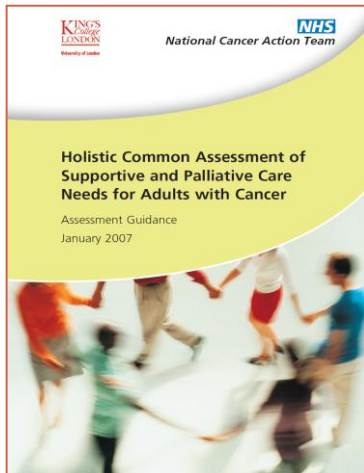


- More people attending cancer clinics
- Side & late effects of treatment may be complex
- ‘Chronic cancer’ patients
- Many follow up appointments for those treated with curative intent may be ‘empty episodes’
- Clinics run late
- Patients have long waits, staff get stressed
- Money may be better spent

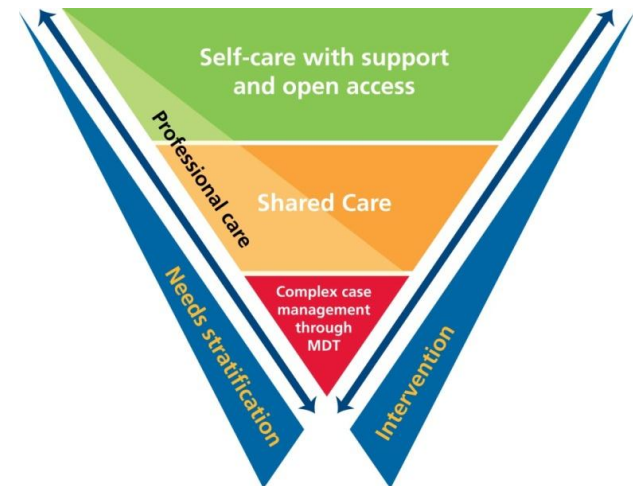
Individual assessment

Holistic Common Assessment (2007)

- Background information
- Physical needs
- Social and Occupational needs
- Psychological well-being
- Spiritual well-being



National Cancer Survivorship Initiative Update 2010



Risk Stratified Model of Care

- A personalised assessment and care plan
- Support to self-manage their condition
- Information on the long-term effects of living with and beyond cancer
- Access to specialist medical care for complications that occur after cancer

Cancer Information

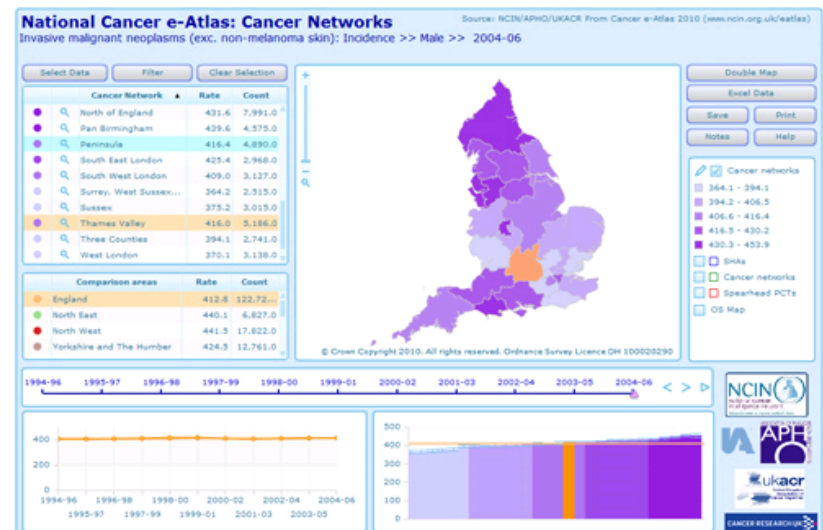


About the National Cancer Intelligence Network

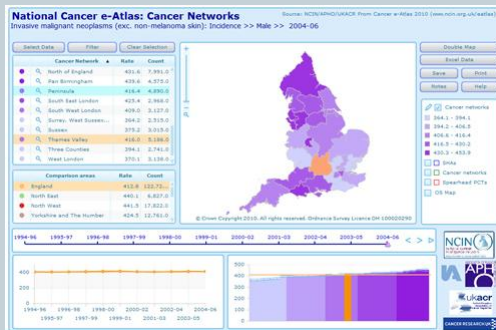
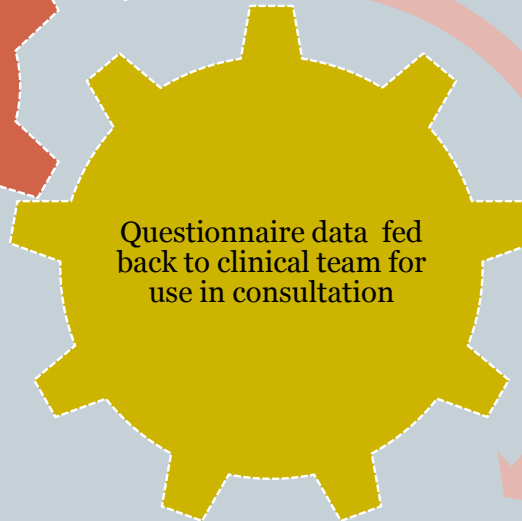
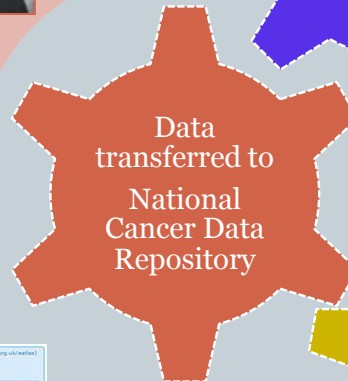
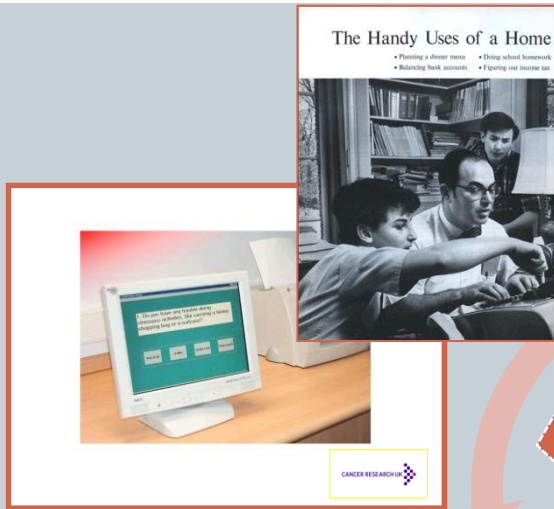
The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

“Quite simply, we want to have the best cancer information service in the world by 2012”

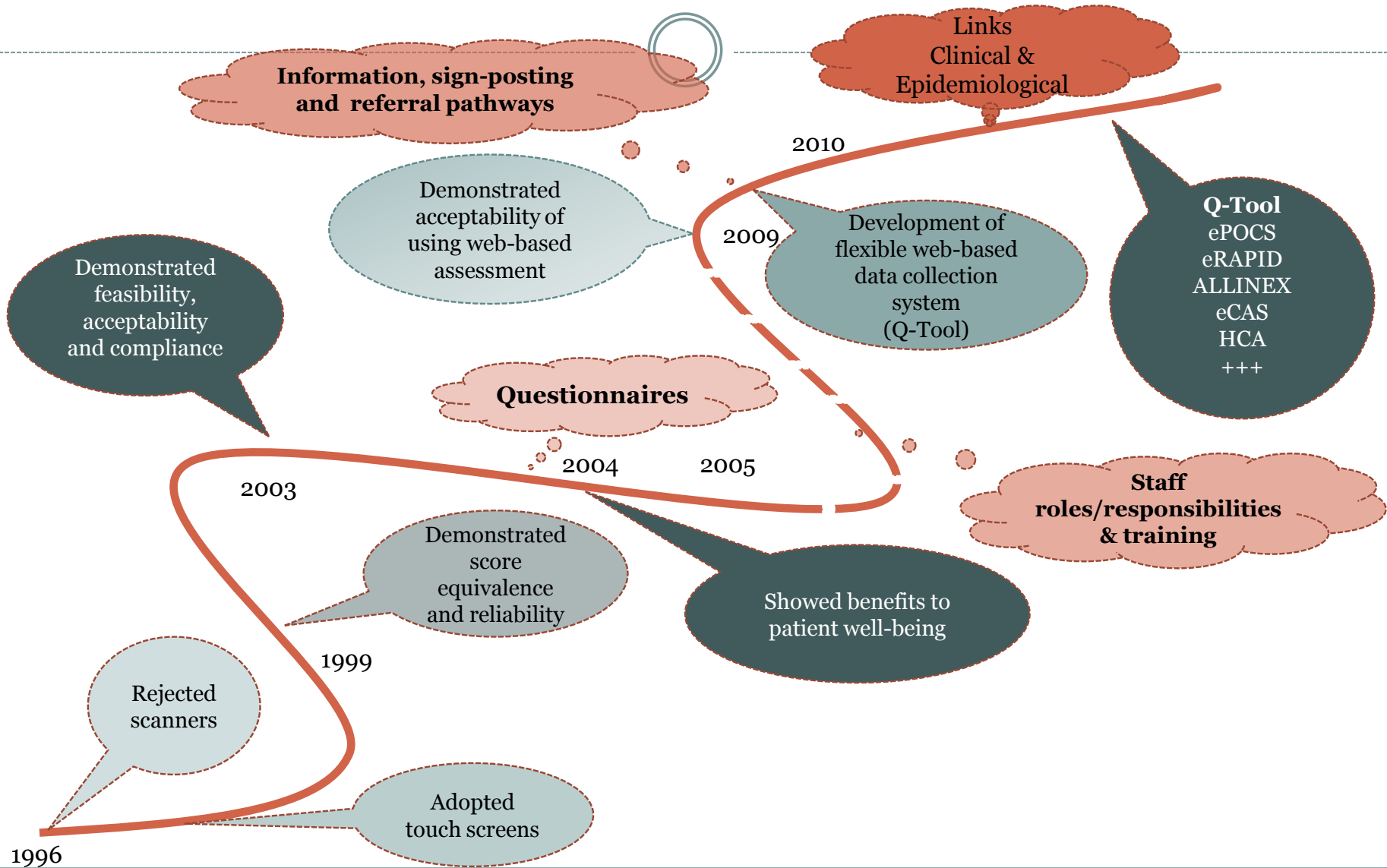
Professor Sir Mike Richards, National Cancer Director, December 2007



How can technology help?

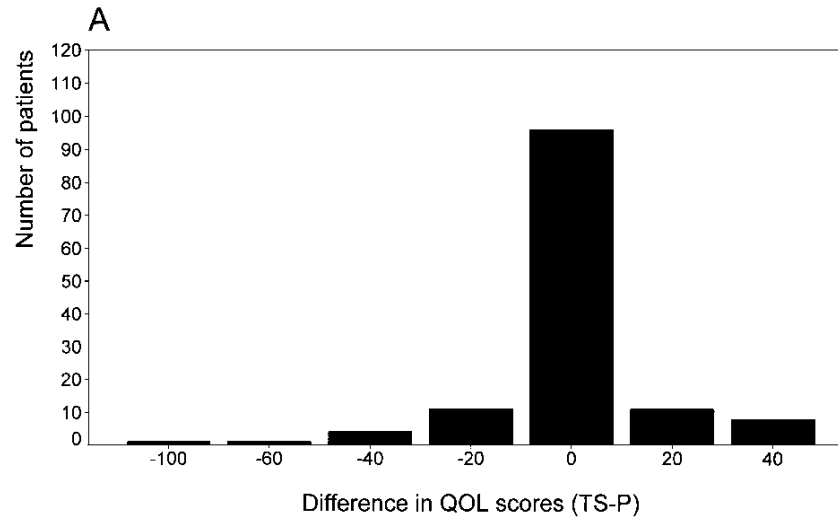


The POCPRG technological pathway



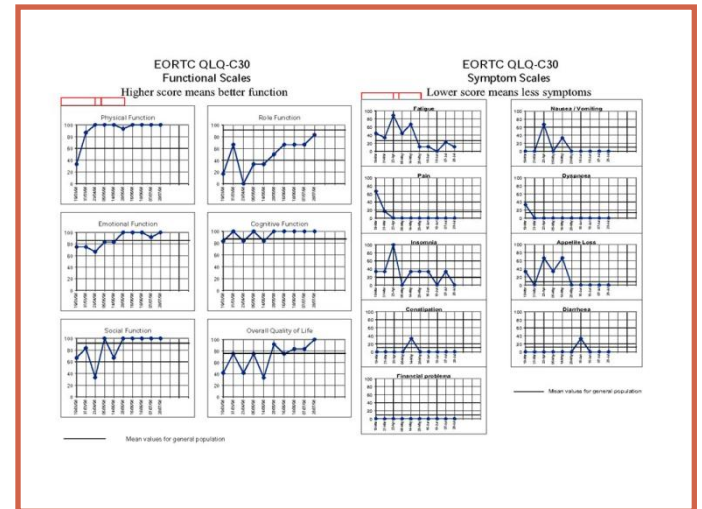
Touch screens

- Easy for patients
- Acceptable
- Scores equivalent
- Reliable & valid
- Print-out with historical



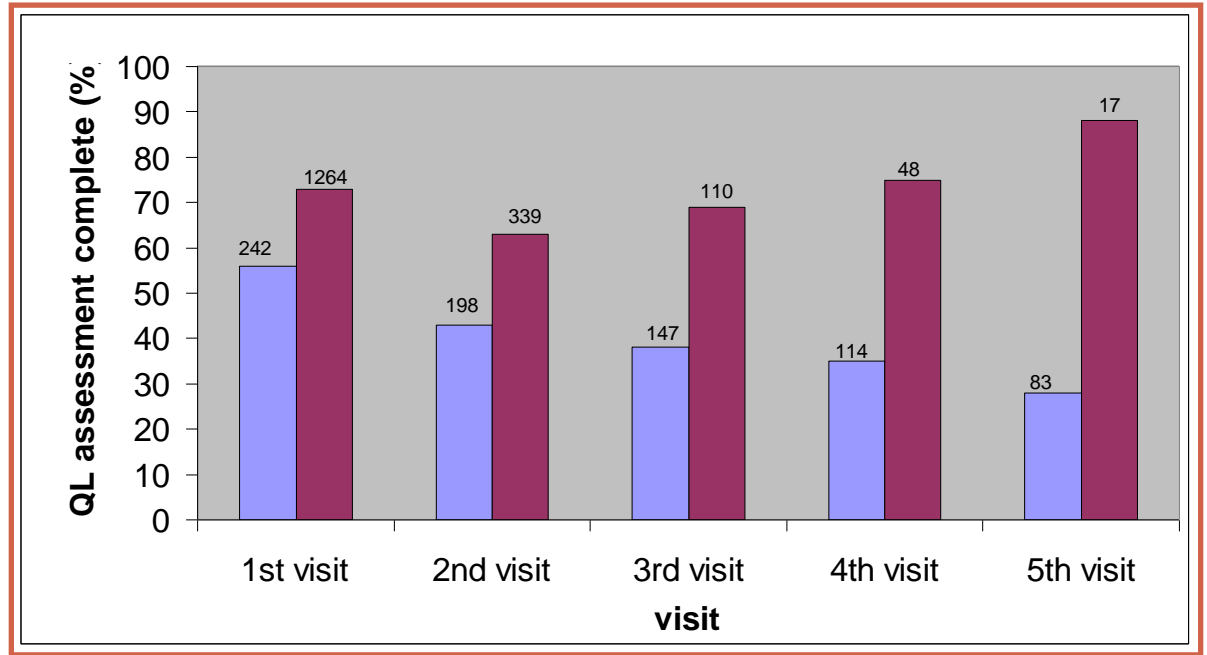
Emotional functioning

Comparison TS vs paper (Velikova et al, J Clin Oncol 1999)



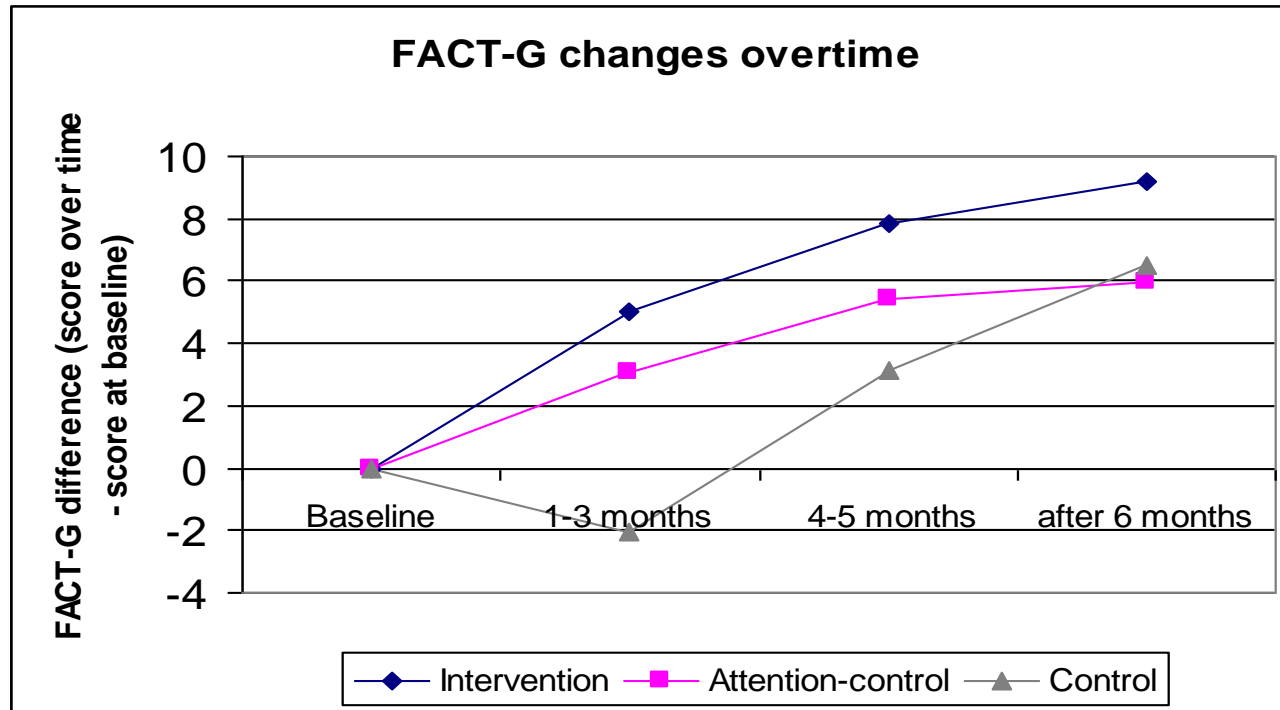
Touch screens

- Patient compliance good when integrated into everyday practice



(Wright et al, J Clin Oncol 2003)

Benefits for patients



- Patients had improved well-being in the intervention arm
- Consultation times not increased
- No greater referral for specialist help
- More discussion of non specific symptoms

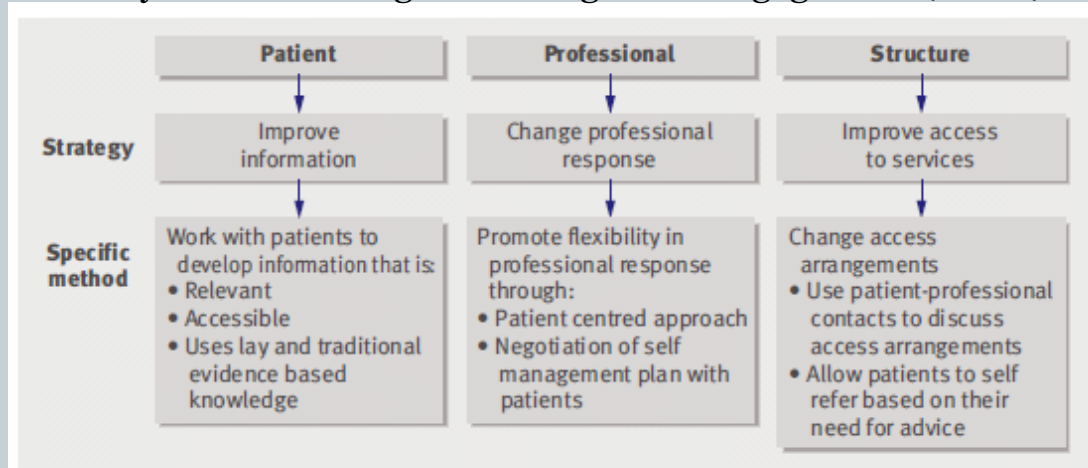
(Velikova et al, J Clin Oncol 2004)

Implementation to adoption

Simple and compatible

Ease of implementation

the whole system informing self management engagement (WISE) model)



Example of an intervention based on a whole systems perspective⁹

Kennedy A et al. British Medical Journal. 2007; 3 35 :9 68-70.

Pros and cons

Advantageous with their current roles and beliefs

Relevance and patient centred: Questionnaires



- **Content**
 - Purpose
 - Relevance
 - Content validity
 - Burden
- **Psychometrics**
 - Frequency of endorsement
 - Reliability
 - Validity
 - Factor structure
- **Item Response Theory**
 - Rasch analysis
 - DIF
 - Scoring
 - Stability
- **Clinical Utility**
 - Cut points
 - Changes in scores over time
 - Known group differences
 - Normative data

Questionnaires: Social Difficulties Inventory (SDI-21)



Content

Wright EP et al. 2002 British Journal of Cancer



Psychometrics

During the past month	No difficulty	A little	Quite a bit	Very much
1. Have you had any difficulty in controlling your independence?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Have you had any difficulty in coping in your domestic life? (e.g. shopping, parking, cooking, shopping?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you had any difficulty with carrying out your personal care? (e.g. bathing, dressing, washing?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Have you had any difficulty with health? (e.g. getting on and off, attending appointments, difficulty being observed?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Have you had any financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Have you had any difficulty with general control? (e.g. being recognized, privacy, harassment?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Have you had any difficulty concerning your work? (or education if you are a student?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Have you had any difficulty with planning for your own or your family future? (e.g. use of deposits, legal issues, business affairs, post-grad partner, children, parents?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Have you had any difficulty with communicating with those close to you (e.g. partner, children, parents)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, team?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Have you had any difficulty concerning social matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Have you had any difficulty concerning plans to have a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Have you had any difficulty concerning your appearance or body image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Have you life isolated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Have you had any difficulty with getting around? (e.g. transport, not getting your mobility?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Have you had any difficulty with whom you live? (e.g. spouse, partner, being, having neighbours, rooming?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Have you had any difficulty in coping with your emotional control? (e.g. feelings, partner, social pressure?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Have you had any difficulty with your plans to travel or take a holiday?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Have you had any difficulty with any other areas of your everyday life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your help

Wright EP et al. 2005 Quality of Life Research

Item Response Theory

Smith et al 2007 Quality of Life Research
Smith et al Quality of Life Research in press

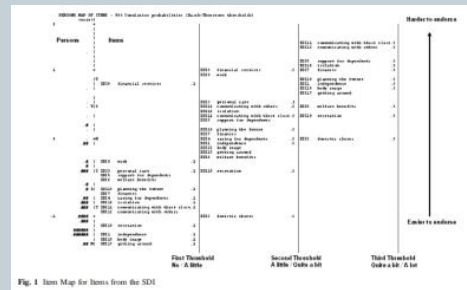


Fig. 1. Item Map for Items from the SDI.

Clinical Utility

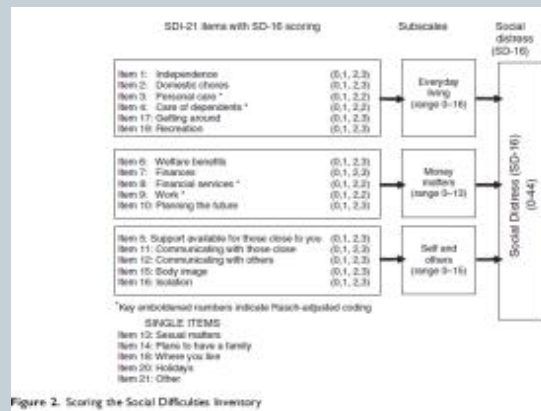
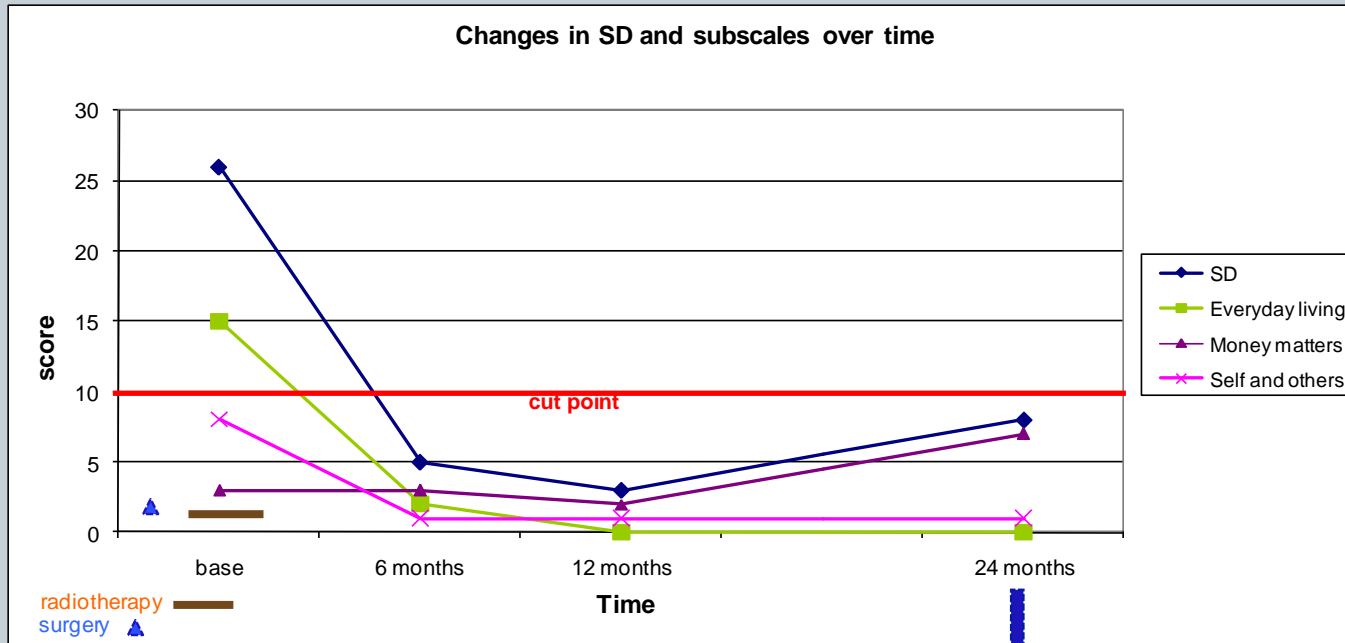


Figure 2. Scoring the Social Difficulties Inventory

Wright et al 2007 British Journal of Cancer.
Wright et al 2008 European Journal of Cancer.
Wright P et al Psycho-oncology. Published online.

SDI-21: Clinical Utility



- 35 year old man with testicular cancer

- Treatment: surgery and radiotherapy at baseline

- Disease free, on routine review

- Married, living with wife

- Became unemployed between 12-24 months

Individual items

- Plans to have a family (quite a bit)

SD-16 items

(Money Matters)

- Work (very much)
- Planning the future (quite a bit)

Roles and responsibilities: everyday living

Patients: improve information



Professional: change professional response

- Acknowledgement
- Reassurance
- Manage on their own
- Simple advice
- Practical solutions
- Access to services

- Confident in this area
- Within their remit
- Doctors – clinical approach
 - i.e. blood transfusion
- Nurses- holistic approach
 - i.e. asking partner to take on new role
- Item - ‘Caring for dependents’
 - less confident
 - lacked expertise

Roles and responsibilities: money matters

Patients: improve information



- Information early
- Leaflets for basic information
- Help with form filling
- Someone available to speak to for specific advice

Professional: change professional response

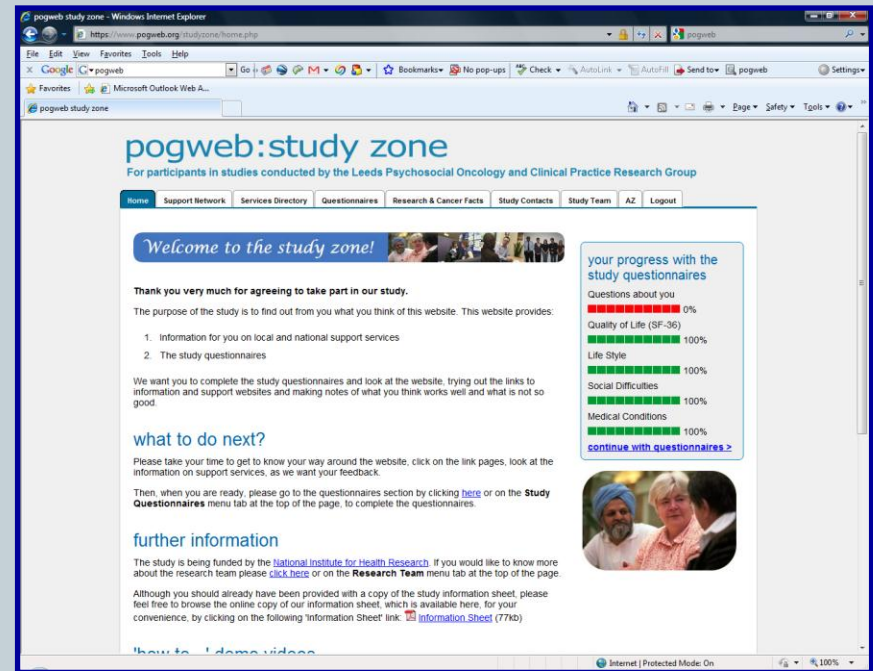
- Limited knowledge
- Doctors -marginal activity
- Interventions doctors
 - completion of medical forms
 - writing letters for insurance or employment
- Interventions nurses
 - linking
 - referral

Structure: improve access to services

Paper format



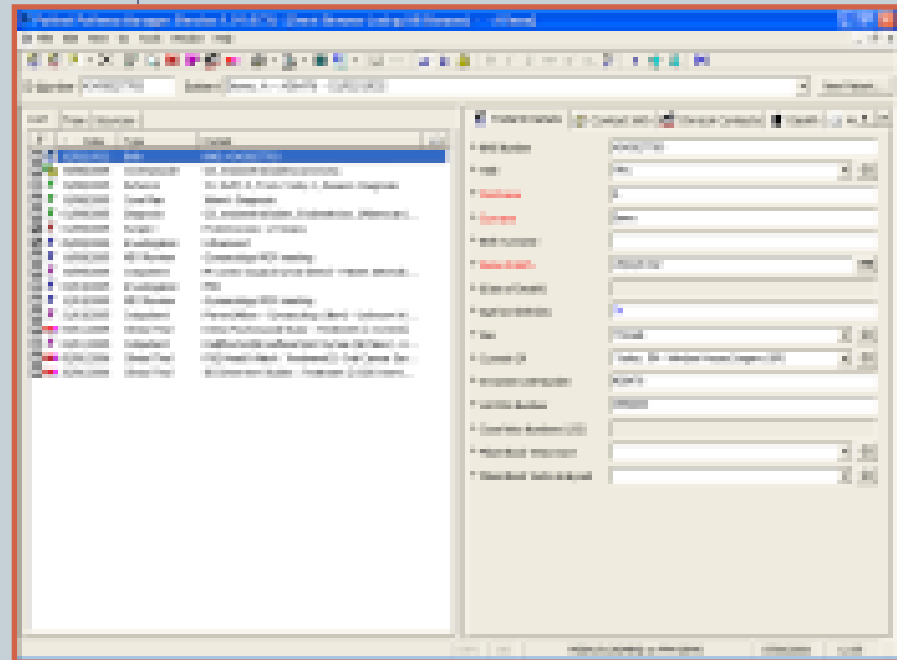
On-line



Structure: continuity of care

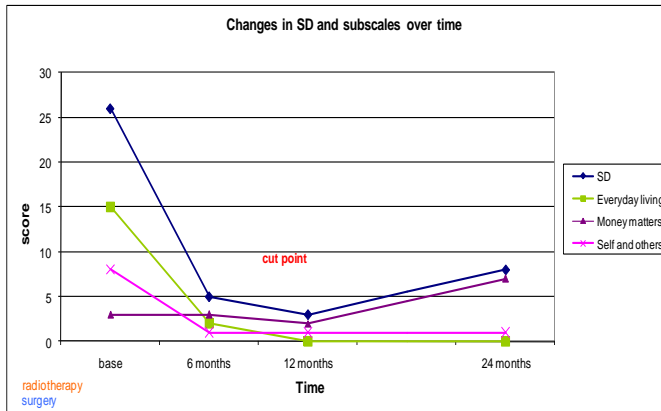


- When the assessment took place
- Who did it
- What the scores were
- What was discussed
- What decisions made
- What information give
- What referrals made



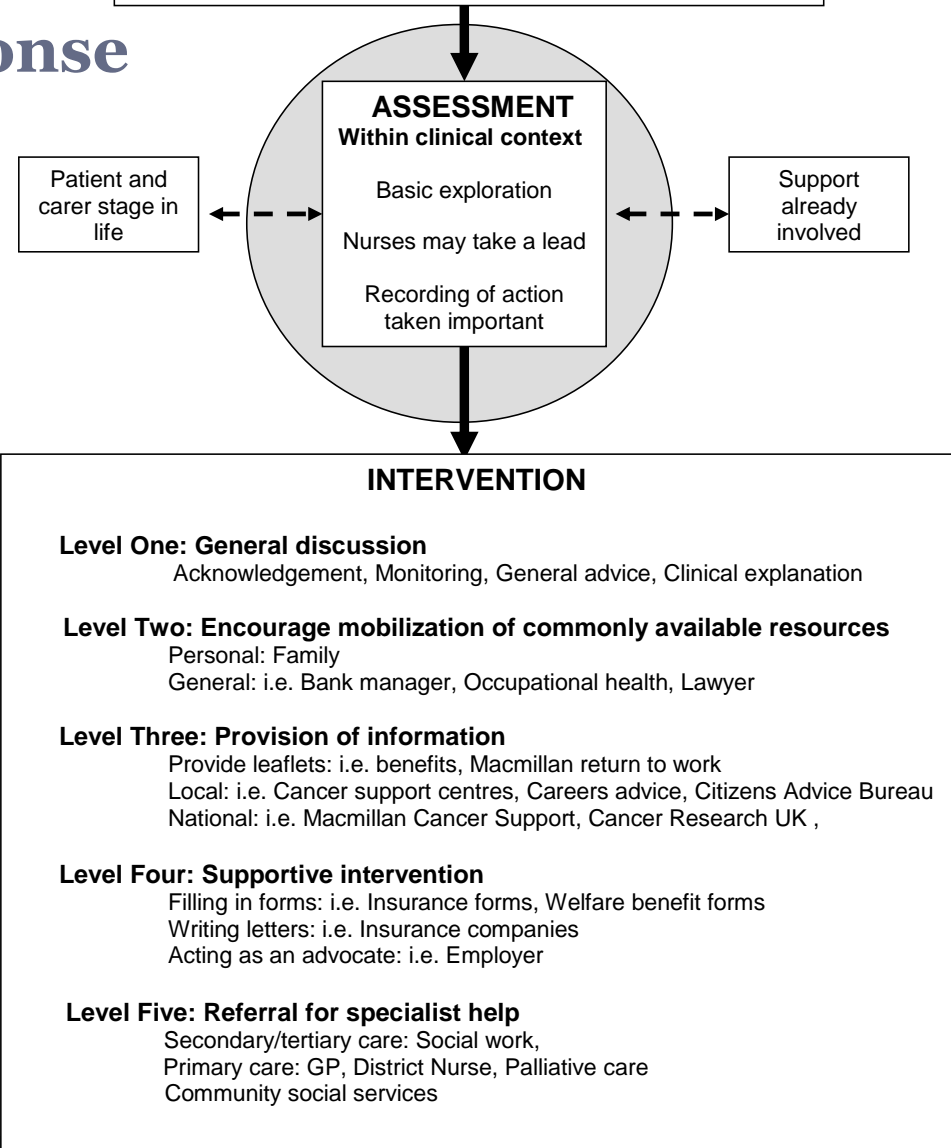
Make sure the people who need this information have it

Change professional response



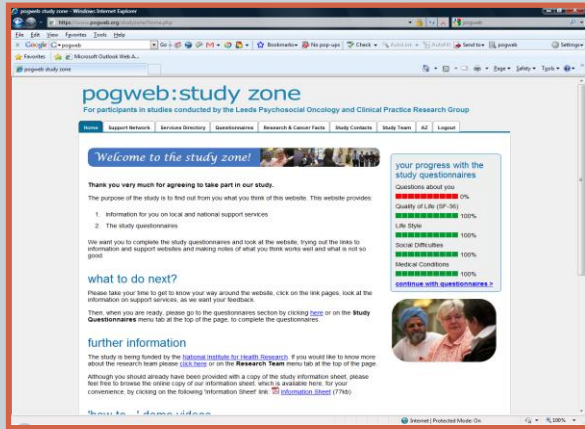
- Nurses
- Score interpretation
- Context
- Intervention
- Recording

SD-16 ≥ 10 WITH Money matters subscale contributing significantly to this score
OR
Change in Money matters ≥ 2



The Internet

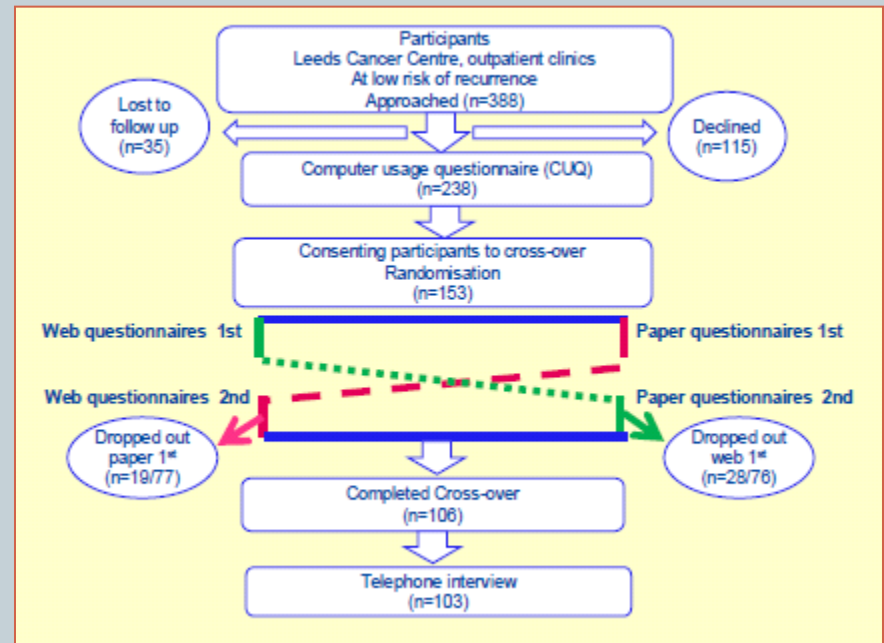
Using the internet for information exchange



- Information
- Monitoring

Patient input into website

- On steering group
- In website design
- Website feedback

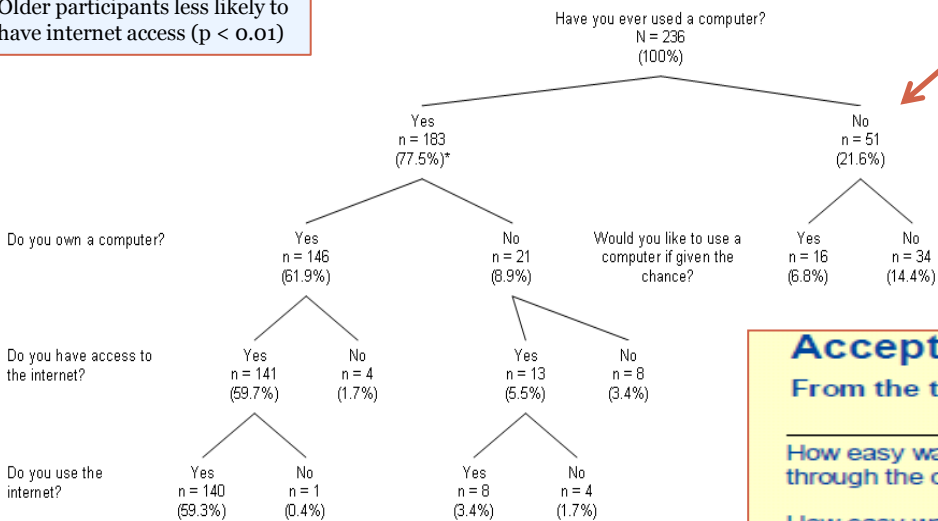


The internet

Using the internet for information exchange

Access to computers and the internet

Older participants less likely to have internet access ($p < 0.01$)



Were more likely to be older ($p < 0.001$) and of lower socioeconomic status ($p < 0.01$)

* Answers missing where percentages do not add up to tier above

Acceptability

From the telephone interviews

	Easy	Satisfactory	Difficult	Missing
How easy was it to work your way through the questionnaires?	87	11	1	4
How easy was it to use the links to other websites?	80	10	2	11
	Yes	No	Unsure	Missing
Overall was the website useful for providing links to information and support?	91	1	3	8
Is the website a good way of providing healthcare professionals with information?	96	2	2	3

Wanted on the website:

- the means to contact their own clinical team
- cancer site specific and after-care information
- access to appointment information
- capacity to write comments in addition to questionnaire responses

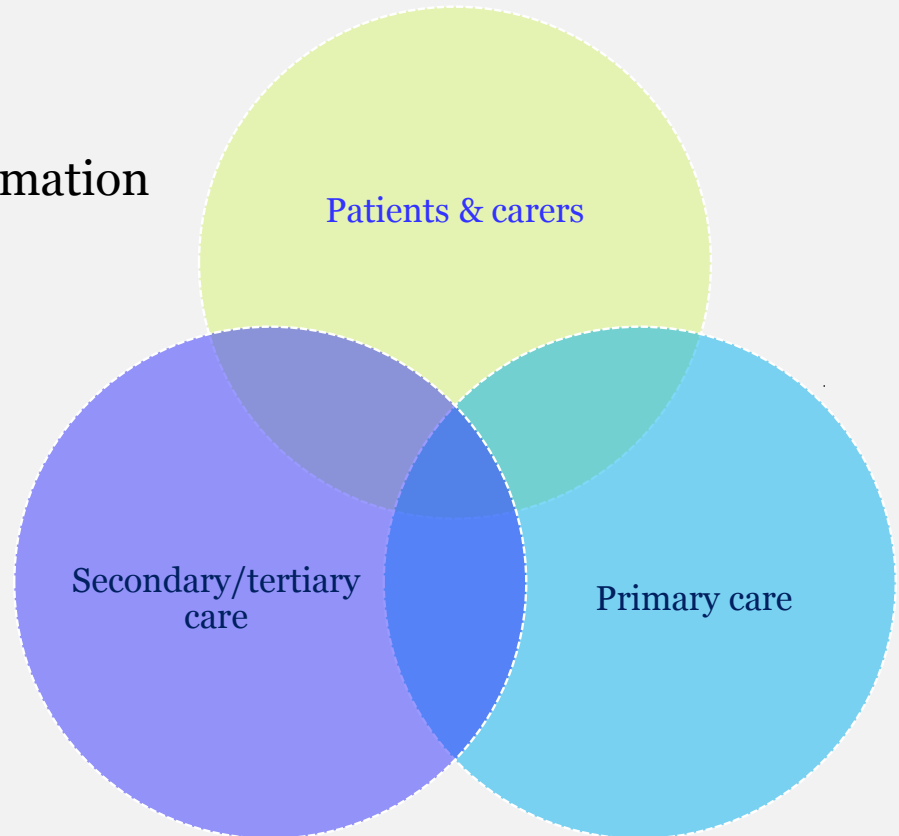
The internet

ALLograft Information Exchange (ALLINEX)



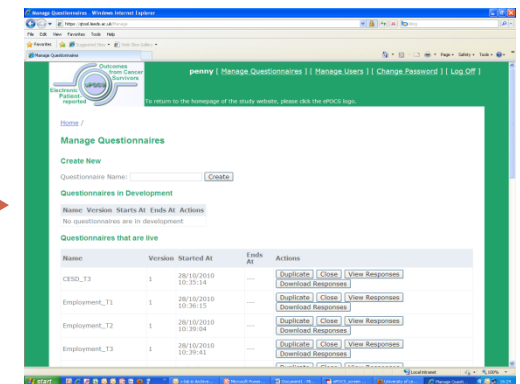
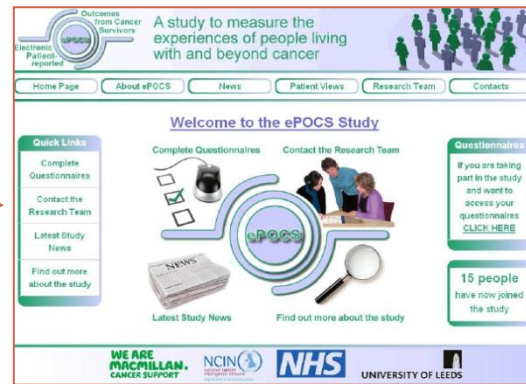
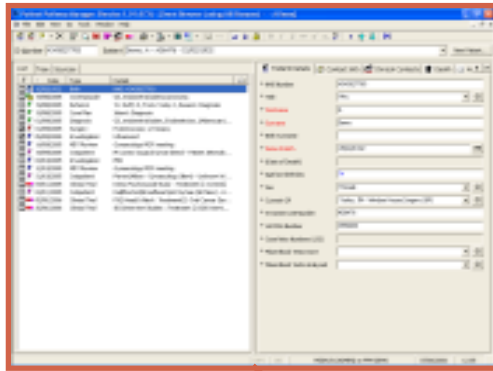
WEBSITE

- Psychosocial supportive care information
 - In house
 - Local
 - National
- HSCT information
- Monitoring
- Means of contacting HSCT team
- Other????

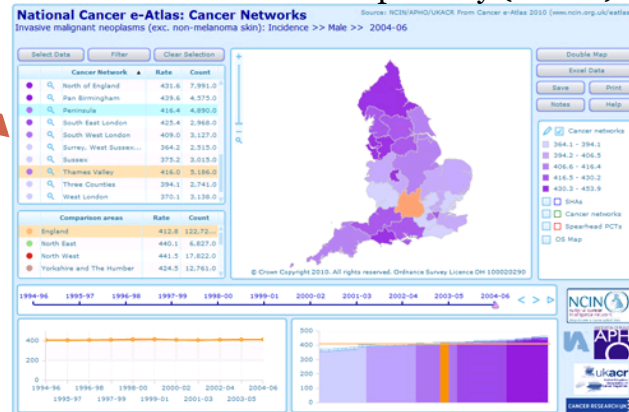


The internet

electronic Patient Reported Outcomes from Cancer Survivors



National Cancer Data Repository (NCDR)



Merged English
Cancer Registry
Data

Hospital
Episode
Statistics

National
Clinical
Audit Data

ONS minimal
dataset



The internet Q-Tool

Developed by X-Lab
Systems

IP University of Leeds

Funded by:

Macmillan Cancer
Support

+ in the future

Macmillan Cancer
Support

Cancer Research UK

NCIN

Other

- Q-Tool is an on-line questionnaire system with capacity for:
 - different types of study
 - users
 - time points
 - questionnaires
 - reporting
- Q-Tool is being further developed for:
 - ✦ use in clinical practice
 - ✦ studies out with Cancer Services

Future work: Touch screens and the internet



eCAS

Q-Tool

ALLINEX

eRAPID

Thanks to



The patients and staff who have
participated this work

Psychosocial Oncology and Clinical Practice
Research Group

Cancer Research UK, Macmillan Cancer Support,
NIHR & Leeds Teaching Hospitals NHS Trust

