Use of technology for research aimed at improving patient care
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

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

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

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

- Prostate
- Rectum
- Breast
- Kidney
- Melanoma
- Colon
- Ovary
- Leukaemia
- NHL
- Testis
- Uterus
- Multiple myeloma
- Stomach
- Oesophagus
- Lung
- Cervix
- Bladder
- Brain
- Larynx
- Pancreas

2010
- >2 million people
- Rise of 3% per year
- 1 in 8 adults over 65

© Cancer Research UK

solid bars show statistically significant change at 95%
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?

- **Patient completes self-report questionnaire**
- **Data transferred to National Cancer Data Repository**
- **Questionnaire data fed back to clinical team for use in consultation**

- **Answer**: Questionnaire data fed back to clinical team for use in consultation.
The POCPRG technological pathway

- **1996**: Adopted touch screens
- **1999**: Rejected scanners
- **2003**: Improvements in information, sign-posting and referral pathways
- **2004**: Demonstrated feasibility, acceptability and compliance
- **2005**: Showed benefits to patient well-being

**Q-Tool**: ePOCS, eRAPID, ALLINEX, eCAS, HCA

**Questionnaires**
- Developed in 2009
- Demonstrated acceptability of using web-based assessment
- Developed flexible web-based data collection system (Q-Tool)

**Information, sign-posting and referral pathways**

**Staff roles/responsibilities & training**

**Links Clinical & Epidemiological**
Touch screens
• Easy for patients
• Acceptable
• Scores equivalent
• Reliable & valid
• Print-out with historical

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

the whole system informing self management engagement (WISE) model

Simple and compatible
Ease of implementation
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**
  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

- **Clinical Utility**
  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

Changes in SD and subscales over time

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

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

Professional: change professional response

- 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

Support Services Information Pack for Patients

On-line

Welcome to the study zone!

Thank you very much for agreeing to take part in our study.

The purpose of the study is to find out from you what you think of this website. This website provides:

1. Information for you on local and national support services
2. The study questionnaires

We want you to complete the study questionnaires and look at the website, trying out the links to information and support websites and making notes of what you think works well and what is not so good.

What to do next?

Please take your time to go through your way around the website, click on the link pages, look at the information on support services, as we want your feedback.

Then, when you are ready, please go to the questionnaires section by clicking here or on the Study Questionnaires menu bar at the top of the page, to complete the questionnaires.

Further information

The study is being funded by the National Institute for Health Research. If you would like to know more about the research team, please click on the Research Team menu bar at the top of the page.

Although you should already have been provided with a copy of the study information sheet, please feel free to browse the copy of the information sheet, easily available here, for your convenience, by clicking on the following information statements:

Continue with questionnaires?
Structure: continuity of care

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

Make sure the people who need this information have it
Change professional response

- Nurses
- Score interpretation
- Context
- Intervention
- Recording

ASSESSMENT
Within clinical context
- Basic exploration
- Nurses may take a lead
- Recording of action taken important

INTERVENTION
Level One: General discussion
Acknowledgement, Monitoring, General advice, Clinical explanation

Level Two: Encourage mobilization of commonly available resources
- Personal: Family
- General: i.e. Bank manager, Occupational health, Lawyer

Level Three: Provision of information
- Provide leaflets: i.e. benefits, Macmillan return to work
- Local: i.e. Cancer support centres, Careers advice, Citizens Advice Bureau
- National: i.e. Macmillan Cancer Support, Cancer Research UK

Level Four: Supportive intervention
- Filling in forms: i.e. Insurance forms, Welfare benefit forms
- Writing letters: i.e. Insurance companies
- Acting as an advocate: i.e. Employer

Level Five: Referral for specialist help
Secondary/tertiary care: Social work,
Primary care: GP, District Nurse, Palliative care
Community social services

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

Changes in SD and subscales over time

SD
Everyday living
Money matters
Self and others
radiotherapy
surgery

SD
0
5
10
15
20
25
30
base
6 months
12 months
24 months

score
Time
Changes in SD and subscales over time

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

Patient input into website
• On steering group
• In website design
• Website feedback

• Information
• Monitoring
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)

Acceptability
From the telephone interviews

<table>
<thead>
<tr>
<th>How easy was it to work your way through the questionnaires?</th>
<th>Easy</th>
<th>Satisfactory</th>
<th>Difficult</th>
<th>Missing</th>
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<td>1</td>
<td>4</td>
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<table>
<thead>
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<th>How easy was it to use the links to other websites?</th>
<th>Easy</th>
<th>Satisfactory</th>
<th>Difficult</th>
<th>Missing</th>
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<td>10</td>
<td>2</td>
<td>11</td>
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<table>
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<th>Overall was the website useful for providing links to information and support?</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
<th>Missing</th>
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<td>1</td>
<td>3</td>
<td>8</td>
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<table>
<thead>
<tr>
<th>Is the website a good way of providing healthcare professionals with information?</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>96</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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 (ePOCS)

Merged English Cancer Registry Data
Hospital Episode Statistics
National Cancer Data Repository (NCDR)

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

ALLINEX

Q-Tool

eCAS

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