electronic Patient-reported Outcomes from Cancer Survivors

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Aims

ePOCS is a study in progress, currently open to recruitment

- Explain the background and rationale to the study
- Describe progress up to date
- Present some preliminary results

What is the ePOCS study?

- Macmillan funded, NIHR CRN Portfolio study, sponsored by University of Leeds
- Run by the Applied Informatics and Cancer Care (AICC) research team
  - Based at St James's Institute of Oncology, Leeds
  - Managed by Dr Penny Wright (ePOCS Chief Investigator)
- Allied with Psychosocial Oncology and Clinical Practice Research Group
  - Prof Galina Velikova (co-investigator)
- **AIM: To develop a UK-scalable electronic system for regularly collecting patient-reported outcomes (PROs) from cancer patients and linking these with clinical cancer registry data**

Why do we need the ePOCS system?

To improve understanding of the psychosocial challenges of survivorship

- Cancer registries produce comprehensive incidence and survival statistics
- Number of cancer survivors is increasing (2million and ↑ 3% per year)
- But comprehensive understanding of the survivorship ***experience*** is limited
  - We know some survivors experience difficulties, but also that many don't
- Research is based on small, short-term, non-UK studies, with limited PROs
- It is vital to know who experiences what problems and when
  - To inform development of services and interventions
  - To facilitate targeted provision
- A key NCSI priority is to improve and increase measurement of cancer PROs

Why do we need the ePOCS system?

To overcome the difficulties of PRO data collection and clinical data linkage

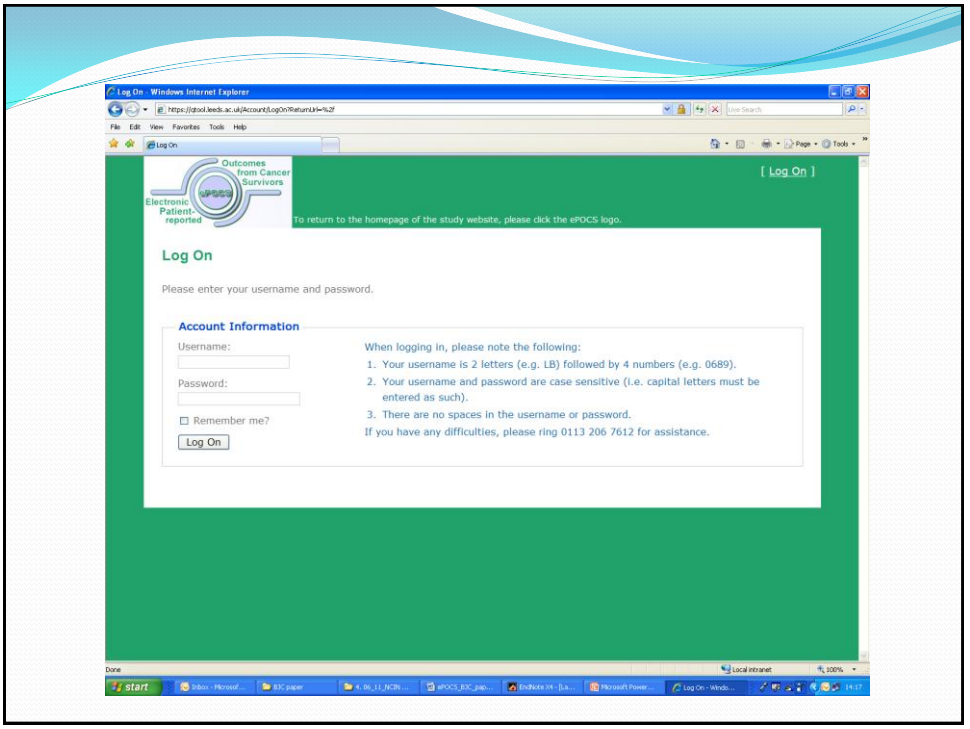
- Questionnaire data collection is traditionally very expensive
- Poor accrual and high attrition are common research problems
  - There is potential to reduce cost and improve patient convenience with an electronic internet-based data collection system
- To be maximally useful, PROs must be linked and analysed with clinical data
  - There is potential to achieve PRO and clinical data linkage efficiently, securely, economically via the registries
- Can we develop an electronic system in which PROs are regularly completed via the Internet and are linked and stored with clinical data in the registries?

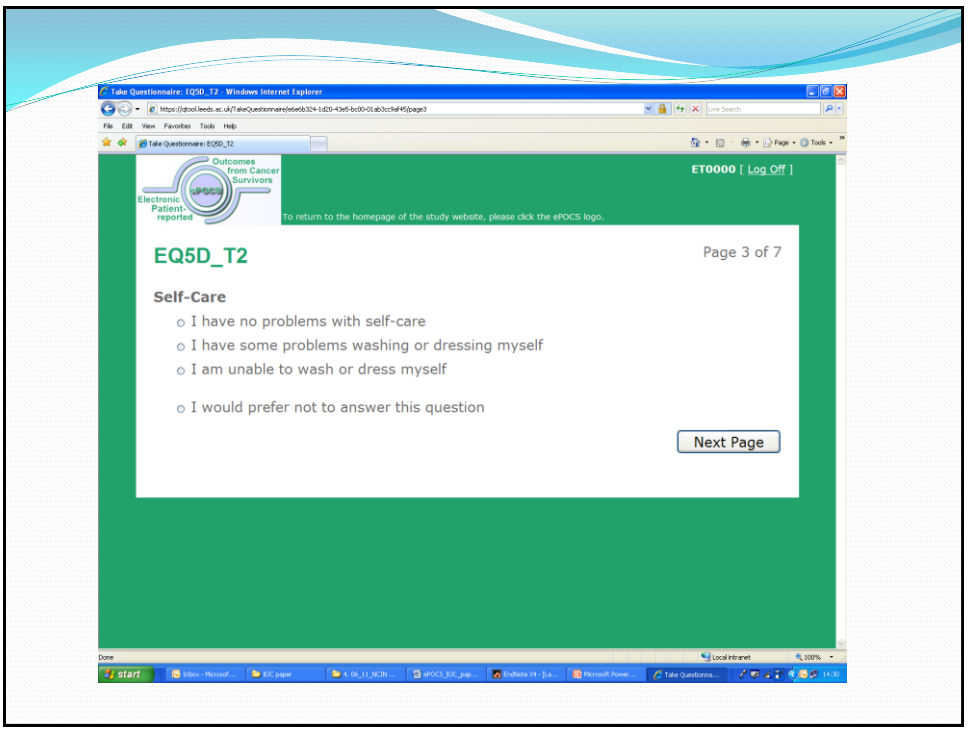
Development of the ePOCS system

- The ePOCS study is two-part:
  - Stage 1 (Oct 2009 – Sept 2010): System design and building
  - Stage 2 (Oct 2010 – Dec 2012): System testing
- Stage 1 entailed:
  - Process mapping the system using MS Visio™ 2007
  - Interviewing patients and clinicians to obtain their input into system design
  - Designing and constructing a study website
  - Designing and building a web-based questionnaire administration tool (QTool)
  - Building an electronic patient-tracking database (Tracker)
  - Establishing new data flows (e.g. QTool ↔ Tracker, Tracker ↔ Registry)
  - Modifying existing data flows (e.g. Registry ↔ EPR)

What does the ePOCS system look like?

- PROs are completed on the internet
  - Using a bespoke questionnaire administration tool (QTool)
  - Accessed via a public-facing internet website
  - With a unique, secure username and password
    - Qs can be completed from any internet-accessible location / mobile device
    - Qs can be accessed any time of day/night, and any day of the week
    - Completion can be split-up / spread out


Log On - Windows Internet Explorer
Outcomes from Cancer Survivors
Electronic Patient-reported
[Log On]
To return to the homepage of the study website, please click the ePOCS logo.
Log On
Please enter your username and password.
Account Information
Username:
Password:
Remember me?
Log On
When logging in, please note the following:
1. Your username is 2 letters (e.g. LB) followed by 4 numbers (e.g. 0689).
2. Your username and password are case sensitive (i.e. capital letters must be entered as such).
3. There are no spaces in the username or password.
If you have any difficulties, please ring 0113 206 7612 for assistance.

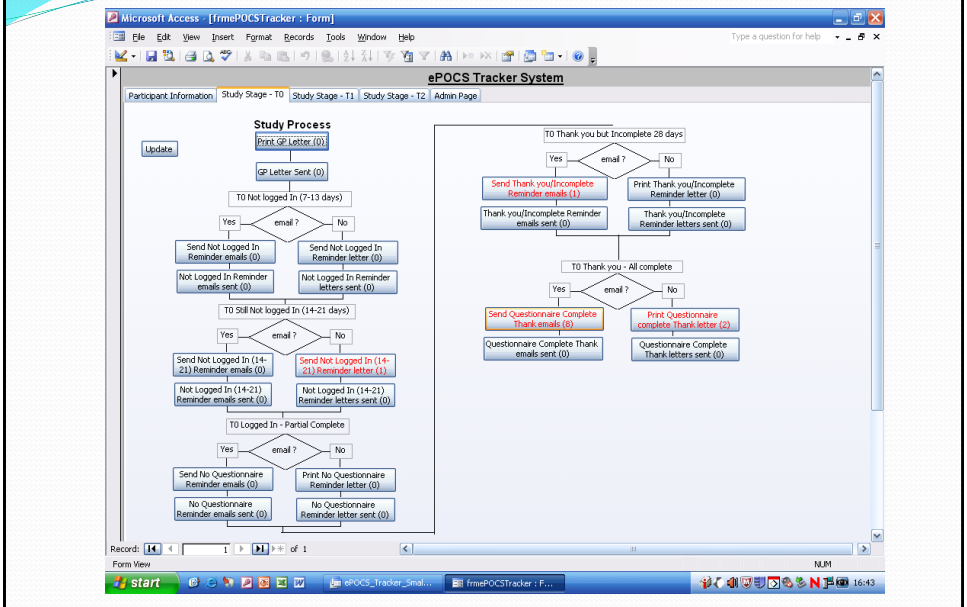

Take Questionnaire: EQ5D_T2 - Windows Internet Explorer
Outcomes from Cancer Survivors
Electronic Patient-reported
ET0000 [Log Off]
To return to the homepage of the study website, please click the ePOCS logo.
EQ5D_T2
Page 3 of 7
Self-Care
I have no problems with self-care
I have some problems washing or dressing myself
I am unable to wash or dress myself
I would prefer not to answer this question
Next Page

What does the ePOCS system look like?

- The PRO data are stored in the local cancer registry (/NCDR)
  - With patients' clinical data
  - Potentially linkable with HES data etc.

NHS
Northern and Yorkshire
Cancer Registry and Information Service

- Patient management is semi-automated via a tracking database application
  - Invitations to complete PROs, Reminders, Thank Yous
  - Automatic notifications
  - Automatic generation of appropriate communications ready to send
- Patient communication is primarily email-based



Testing the feasibility of the system

- We are currently in Stage 2 (Oct 2010 – Dec 2012): System testing
- In 2 Yorkshire NHS Trusts and using the NYCRIS registry
  - Leeds (PI, Dr Penny Wright)
  - Calderdale & Huddersfield (PI, Dr Johnathan Joffe)
- Breast, colorectal and prostate cancer patients
  - Adult, English literate, treated with curative intent
- Patients consented ≤6 mo of diagnosis by secondary care clinical teams
  - Supported by dedicated Network research nurses (5 nurses = 4 WTE)
- Patients are managed thereon by the ePOCS team
  - GP notification, PRO reminders, PRO queries

Testing the feasibility of the system

- In the study, patients complete a range of health and QOL Qs
  - E.g. EQ-5D, SDI-21, EORTC-QLQ-BR23, CES-D
    - Pain
    - Fatigue
    - Physical symptoms
    - Depression and anxiety
    - Social functioning
    - Concentration and memory
    - Relationships and sexual functioning
    - Finance and work
    - Body / image concerns
    - Views about cancer (illness perceptions)

- At 3 time-points
  - When they join (T1), 9 months (T2) and 15 months (T3) post-diagnosis
- Patients sent invitations to log-on and ≤2 reminders at each time-point

Feasibility Outcomes

- The proportion of patients recruited into the system
- The representativeness of consented patients (relative to all invited)
- The proportion of patients retained in the system
- The representativeness of retained patients (relative to all consented)
- Completeness, quality and timeliness of PRO data
- Success and reliability of informatics infrastructure (e.g. data feeds)
- Running costs

Preliminary results: Recruitment

- Recruitment opened 26/11/10, and is ongoing until 30/09/11
- In the last 6.5 months:
  - 682 patients have been approached about participation
    - 376 have consented and joined the study
      - 6 have left the trial
      - 5 were recruited in error
    - 214 have declined
    - 92 are still deciding

Preliminary results: Recruitment

- 365 patients have joined (and remain in) the system
  - 63% consent rate (CR)
    - excluding pending
  - Leeds: 300 (67% CR)
  - Huddersfield: 65 (52% CR)
  - Breast: 165 (61% CR)
  - Colorectal: 111 (68% CR)
  - Prostate: 89 (62% CR)

Leeds Breast	n = 132
Leeds Colorectal	n = 99
Leeds Prostate	n = 69
Huddersfield Breast	n = 33
Huddersfield Colorectal	n = 12
Huddersfield Prostate	n = 20

Preliminary results: Recruitment

- 214 patients have actively declined to join the system
  - Most common reasons: lack of access to/interest in the internet (≈ 80%)
- Are those who decline different from those who consent?
  - Decliners are significantly older (69 years v 62 years)
  - Decliners have a significantly higher IMD score (living in more deprived areas)
  - Gender is not associated with consent
- 6 patients have left the study
  - 1 patient died
  - 1 cited lack of time
  - 1 experienced difficulties accessing the website
  - 3 unknown

  = 98% retention rate

Preliminary results: Questionnaires

- 275 patients have fully completed their first Qs (80qs)
  - 75% completion rate (of 365 in study)

Breast	n = 127	77%
Colorectal	n = 78	70%
Prostate	n = 70	79%

- To date, 75 patients have reached T2 (9 mo. post-diagnosis)
  - Of these, 46 have so far completed their second Qs (61%)
- No patients have yet reached T3 (15 mo. post-diagnosis)

Preliminary results: Questionnaires

- Most patients have provided an email address for communication
  - < 20% receive postal letter reminders etc.
- The average completion time for T1 Qs is 20 minutes (80q)
  - Range 6 – 90 min, median 17 min
- The proportion of missing responses is < 1%
  - Patients selected '*I would prefer not to reply*' to a question
- T1 reminders have been sent to 52% of patients
  - 63% of whom have responded
- Few patients have reported difficulties with the system (< 10%)
  - Vast majority same issue – misreading of username/password

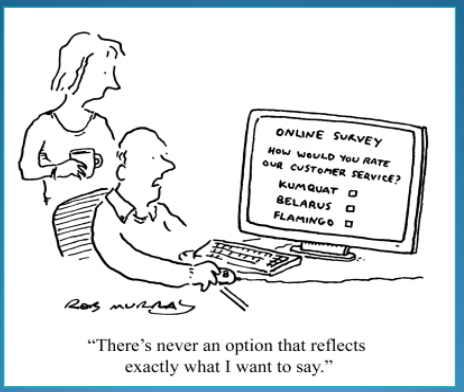
Preliminary results: Informatics

- Informatics are working and reasonably reliable
- From the patient perspective, essentially no problems with QTool
- From the management p-o-v, the Tracker is a work-in-progress :
  - Patients without up-to-date EPR = not in the Tracker
  - Overnight data feeds fail = Information not up-to-date in Tracker
- There are limits to automating data collection
  - Need a way to feed unique, individual information into the system

Concluding comments

- Preliminary feasibility results are promising
  - Typically ≈ 70% consent rate for paper questionnaire studies
  - Main reason for decline is a lack of internet access
  - The no. of internet-enabled households is ↑ yr on yr (ONS)
- The ePOCS system has potential to provide an inexpensive UK-scalable means of sustainably adding PROs to registries' datasets
- Which has potential to increase understanding of survivorship and thereby improve supportive services and interventions

Thank you for listening



"There's never an option that reflects exactly what I want to say."

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