The ePOCS study: electronic Patient-reported Outcomes from Cancer Survivors

Understanding the experiences of people living with and beyond cancer

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Improving understanding of cancer survivorship

- There are 2 million people living with and beyond cancer in the UK
- It is known cancer survivors may experience late effects of treatment and psychosocial problems, but comprehensive understanding of survivorship is limited
- Research studies have examined a narrow range of patient outcomes, in the immediate years post-diagnosis and treatment, and have been mostly conducted in the US and Europe
- There is a pressing need for patient-reported outcome (PRO) data from UK cancer survivors, across a range of health and quality of life domains, for many years after treatment ends
- Large-scale, long-term data collection requires a solid, scalable and sustainable system
- In the UK there is no system in place for routinely and regularly collecting PRO data from cancer survivors in the years after diagnosis and treatment

Via a patient-reported data collection system

- The ePOCS study aims to develop a PRO data collection system
- To have UK-wide scalability and sustainability potential, we envisage:

- **An electronic system**
PRO measures (PROMs) are completed cheaply and conveniently via the internet

- **Integrated into routine secondary-care**
Clinical care teams identify eligible patients and consent them into the system

- **Linked-up with the National Cancer Data Repository (NCDR)**
PRO data is stored in the NCDR and is linkable with clinical and registry data

ePOCS Stage 1: System Design (Oct 2009 – Sept 2010)

Designing the ePRO data collection system involves:

- Process mapping the system using MS Visio™ 2007
- Securing the support and cooperation of clinical care teams
- Obtaining clinicians' and patients' input into system design
- Writing and user testing patient information materials
- Determining the timing of patient consent into the system
- Selecting the battery of PROMs
- Building a website and questionnaire administration system
- Enabling the NCDR for ePOCS patient-tracking and data storage

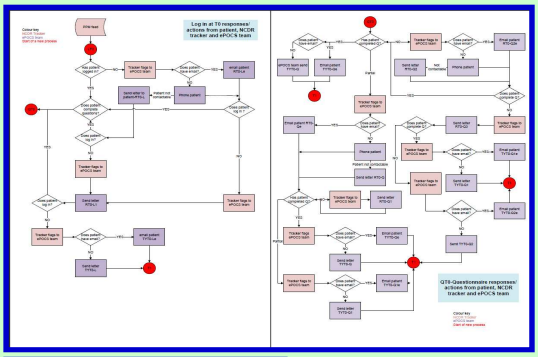

Figure 1: An excerpt from the system process map

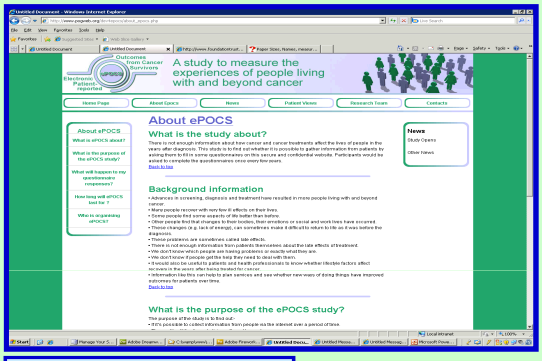

Figure 2: A screenshot of the ePOCS study website

ePOCS Stage 2: System Testing (Oct 2010 – Sept 2012)

Testing the resulting system involves:

Running the system:

- For 18 months in 2 local NHS Trusts
- Recruiting a cohort of breast, prostate and colorectal cancer patients
- Completing ePROMS at 3 time-points

Evaluating feasibility outcomes:

- Efficiency and practicality of recruitment standard operating procedures
- Patient recruitment and retention rates
- PRO data completeness, quality and timeliness

System development: Progress to date

We are part-way through system design and have currently:

- Mapped the system and determined its many steps and their interrelationships (Figure 1)
- Secured clinical teams' role in patient consent, and funding from WYCLRN to support this
- Consulted over 30 clinicians , and run 3 patient focus groups, to obtain user input into system design
- Written, designed and user tested patient information materials
- Selected PROMS assessing quality of life, social difficulties, depression and illness perceptions
- Built a web-based questionnaire administration system and ePOCS study website (Figure 2)
- Begun work with the NCIN to develop the NCDR informatics infrastructure

The future: Benefits of system success

- Clinician and patient feedback indicates the planned ePOCS system is necessary and important, and likely to provide worthwhile information with clinical utility
- A wide-scale, long-term PRO data collection system is the route to generating a dataset sufficiently large and longitudinal to indicate **which** survivors experience **what** problems and **when**
- This in-depth understanding of survivorship will allow:
  - Cancer patients to receive detailed, individualised information about the symptoms and challenges they may face ahead – based on the self-reported experiences of other patients
  - Effective, tailored and timely interventions to be developed, for the physical, emotional and social difficulties experienced by many UK-based cancer survivors

The Leeds Teaching Hospitals NHS Trust

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