Integrated Care Pathways
For Cancer Survivors
A role for Patient-Reported Outcome Measures (PROMs) and Health Informatics

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Leeds Cancer Centre
Outline

- Background
- The need to redesign healthcare pathways for cancer survivors
- The potential role of PROMs and eHealth in survivorship care pathways
- Integration of PROMs into clinical practice during treatment - example from work in Leeds
  - Choosing PROM questionnaires
  - Evidence-based clinical algorithms
  - The electronic platform (infrastructure)
  - Training and engagement of patients
  - Training and engagement of clinicians
  - Evaluation of cost-effectiveness and implementation strategies
- Discussion – a vision for cancer survivorship care
Background - The Numbers

- Successful cancer treatments – 5 year survival rates of approx. 70%
- In UK, estimated 2 million people living with or beyond cancer, 3% annual increase (2008)
- In USA, over 13 million
- Worldwide – over 30 million
Background – the Challenges to Cancer Survivors

- Cancer survivors face numerous challenges
- Secondary problems as a result of cancer treatments
  - Physical – fatigue, pain, neurological
  - Late morbidity – Cardiovascular, Gastro-intestinal, second malignancies
  - Psychological and cognitive problems
- Difficulties of societal discrimination
  - Education, gaining employment, insurance, mortgage
Background – Traditional Follow-Up

- Hospital / secondary care based
- Detection of recurrence
- Provides medical support to manage some symptoms
- Usually no psycho-social care, dietary or life style support
- General practice role – variable, not defined
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Redesigned Care Pathways

• Routine planned telephone contact- nurse or Allied Health Professional led

• Patient-initiated contact
  ➢ Exit consultation, shared contact with HP
  ➢ Rapid access to advice
  ➢ Initial self-management education program
  ➢ Sometimes including initial symptom checklist or PROM

• Need for planned supported self-management, so that patients are confident, informed, and aware.
Sample Survivorship Care Plans

The sample Care Plans below were built using Journey Forward’s Survivorship Care Plan Builder.

<table>
<thead>
<tr>
<th>Attachment</th>
<th>Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer Care Plan (sample)</td>
<td>53.34 KB</td>
</tr>
<tr>
<td>Colon cancer Care Plan (sample)</td>
<td>45.07 KB</td>
</tr>
<tr>
<td>Lymphoma Care Plan (diffuse large B-cell) (sample)</td>
<td>75.51 KB</td>
</tr>
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</table>
Cancer Survivor Care Plan

What’s Next?
Life After Cancer Treatment
Individualized Cancer Care Plans UK

Developing communications to improve patient outcomes

Cancer Care Review

What is a General Practitioner (GP) Cancer Care Review?

The Quality and Outcomes Framework (QOF) requires all patients diagnosed with cancer to receive a Cancer Care Review by their GP within six months of the GP receiving confirmation of their diagnosis.

The QOF lacked clarity surrounding what the Cancer Care Review should consist of and what is helpful and necessary to include. As a result, the patient experience is variable.

Template available on EMIS and INPS GP systems
Vision of Integrated Care Pathways

Supportive care services:
- Counseling, psychology, physiotherapy, diet, financial advice

Voluntary sector, charities:
- Supported self-management - empowered survivor

General Practice

Cancer specialists

The Leeds Teaching Hospitals NHS Trust

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

UNIVERSITY OF LEEDS
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Patient Reported Outcome Measures (PROMs)

- Definition and potential role for cancer survivors care
  1. Screening for psychological or physical problems
     - ASCO recommendations
     - Added to tumour markers, imaging?
  2. Evaluation of rehabilitation interventions
     - Physical exercise
  3. Epidemiology - Part of Big Data sets
     - Merging PROMs with Cancer Registries Data; hospital statistics or GP data
The Role of Health Informatics

- The routine use of PROMs is made possible by the development of Health Informatics
- Electronic Patient Records (EPR)
- Remote monitoring (Telehealth, Telecare) in chronic disease management
- eHealth (mHealth) tools
- Health Informatics platform will support integrated solutions across the spectrum of care (self-management, supportive care, GP, hospital specialists)

- Data sharing problems are not resolved!
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eRAPID - electronic patient self-reporting of Adverse-events: Patient Information and a Device

Patients - AE Items
Self-reporting of symptoms with severity grading

Electronic platform
- Internet-based
- Real-time integration in EPR
- Confidential

Patients - Advice and alerts
-- Mild AE - Patient self-management advice
-- Serious AE - Alerts to patients and clinicians

Integration in patient care pathways
- Staff training
- Patient training

Will improve the safe delivery of cancer treatment
Enhance patient care and experiences
Standardise documentation of AE
Choosing PROMs Questionnaires

<table>
<thead>
<tr>
<th>CTCAE Item</th>
<th>Patient self-report item</th>
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<tr>
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Common Terminology Criteria for Adverse Events (CTCAE)

Version 4.0
Published: May 28, 2009 (v4.03: June 14, 2010)

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute
### Choosing PROMs Questionnaires

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Electronic platform - eRAPID System

**Data Centre**
- eRAPID System
- QTool database
- Web based QTool data

**Administrator/Researcher**
- Administrator Interface
  - Set up studies/patient groups
  - Select items/schedule questionnaires
  - Combine with clinical data
  - Study level reports

**Hospital Team**
- Oncologist / Nurse Interface
  - Patient monitoring
  - Review of self reports
  - Alerts

**Patient Interface**
- Patient at Home
  - Internet
  - Helpdesk for patients
- Patient in Clinic
  - Helpdesk for clinicians

**Software**
- QTool
- QTool database

**Hosting ISS servers**
- Electronic Patient Record (PPM)
Welcome to the home page of the University of Leeds and Leeds Teaching Hospitals, eRapid research project funded by a National Institute for Health Research (NIHR) Programme Development Grant (RP-DG-1209-10031).

eRapid stands for “Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice”.

The aim is to develop an integrated web-system for patients to report symptoms and side effects during and after cancer treatment. Data that is reported by patients using the web-system (called QTool) will be documented in individual patient electronic health records. Where patients report mild side effects they will receive advice on how to manage them and to seek timely medical advice. Where patients report serious side effects, a system of alerts will be sent to clinicians.

eRapid presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Development Grants scheme (RP-DG-1209-10031). The views expressed on this website are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health.

www.nihr.ac.uk

If you have any queries regarding the content of this website, please contact The Psychosocial and Clinical Practice Research Group (POG) on (0113) 20 67628.
Welcome to QTool

Your Questionnaires

Please complete the following questionnaires:

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Closing date</th>
</tr>
</thead>
<tbody>
<tr>
<td>eRAPIED demo questionnaire</td>
<td>No closing date</td>
</tr>
</tbody>
</table>

Start

Your Studies

eRAPIED Demo

Your Previous Responses

Click here to view detailed responses and feedback.
Have you had pain or discomfort anywhere on your body?

- [ ] No
- [x] I had mild pain or discomfort
- [ ] I had moderate pain and discomfort and was not able to do some of the things I normally do (for example, household chores/shopping)
- [ ] I had severe pain and discomfort and was not able to care for myself (for example getting out of bed, bathing, dressing)

Next page
Have you had pain or discomfort anywhere on your body?

- No
- I had mild pain or discomfort
- I had moderate pain and discomfort and was not able to do some of the things I normally do (for example, household chores/shopping)
- I had severe pain and discomfort and was not able to care for myself (for example getting out of bed, bathing, dressing)

You have indicated serious problems in this area. Please contact the hospital **immediately** to discuss your symptoms with the medical team, you may need a hospital admission.

Before you contact the hospital and if you feel able, please still complete the remaining questions.
So far we have asked you about pain, diarrhoea and appetite.

Have you had other side effects, not listed here?

- [ ] No
- [ ] Yes
eRAPID demo questionnaire

Please tell us about **up to three** of these below. Individual advice for these will not be provided here, but your medical team will be able to see that you have had trouble with these issues next time they check your records.

If you are concerned and would like advice on these now, please contact the hospital.

1)  
- new and worsening shortness of breath
- Sore hands/feet
- Tingling/numbness in fingers/toes
- Other (please specify)

3)
If you are concerned and would like advice on these now, please contact the hospital.

1)  
new and worsening shortness of breath  

What was the severity of your shortness of breath?

- [ ] I have been short of breath but only when exerting myself (for example, climbing stairs)
- [x] I have been short of breath when walking around the house and I was not able to do some of the things I normally do (for example, household chores/shopping)
- [ ] I have been short of breath at rest and I was not able to care for myself (getting out of bed, bathing, dressing)

2)  

Review and Change Responses

eRAPID demo questionnaire

Page 5 of 6

Your previous answers will be shown. In this case, you can just click 'Next' without re-reading the question.

Click 'Next' to view self management advice based on your answers.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Amend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you had pain or discomfort anywhere on your body?</td>
<td>I had mild pain or discomfort</td>
<td></td>
</tr>
<tr>
<td>Have you lacked appetite/lost interest in food?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Have you had diarrhoea (loose or watery stools)?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Have you had other side effects, not listed here?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>1) new and worsening shortness of breath</td>
<td></td>
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Previous page  

Next page
For your Pain:

If you have been prescribed painkillers (also known as analgesics) by your doctor, take the maximum dose that you have been recommended as soon as you first feel you have pain. Make sure that you take your painkillers regularly, even if you have mild pain, which you think you can cope with. It is easier to prevent the pain than to treat existing pain. Do not exceed the maximum dose that you have been prescribed.

If you haven’t been prescribed any painkillers by your doctor and you have mild pain, there are certain painkillers that you can take which can be bought without a prescription. Painkillers suitable for mild pain include:

- *Paracetamol*

- *Ibuprofen*

Take the dose that is advised by the pharmacist or indicated on the drug information as soon as you feel that you first have pain. Make sure that you take your painkillers regularly, even if you have mild pain, which you think you can cope with.
Pain, Aches and Discomfort

Pain is a very personal experience and nobody else can understand exactly how you feel when you have pain. This means you are actually the most important person in making sure your pain is kept under control as you are the one who can tell your medical team how it feels, what makes it worse, when it gets better and what it prevents you from doing. Even if you have only mild pain or discomfort which you think you can cope with, if it isn’t managed quickly sometimes it can become very difficult to control. Having pain can make things harder for you, both emotionally and physically. If your pain is well controlled you should enjoy a better overall quality of life.

Medication

If you have been prescribed painkillers (also known as analgesics) by your doctor, take the dose that you have been recommended as soon as you first feel you have pain. Even if you have only mild pain or discomfort which you think you can cope with, make sure that you take painkillers as it is easier to prevent pain than to treat existing pain. Do not exceed the maximum daily dose that you have been prescribed.

If you have pain but haven’t been prescribed any painkillers, there are certain painkillers that you can take which can be bought without a prescription. Painkillers suitable for mild pain include:

Paracetamol
The Clinician View in EPR - Graphs

eRAPID Toxicity (4.5)

Scores

- Pain
  - (1=mild, 2=moderate, 3=severe)
- Vomiting
  - (1=mild, 2=moderate, 3=severe)
- Nausea
  - (1=mild, 2=moderate, 3=severe)
- Diarrhoea
  - (1=mild, 2=moderate, 3=severe)
- Constipation
  - (1=mild, 2=moderate, 3=severe)
- Mucositis
  - (1=mild, 2=moderate, 3=severe)
- Temperature
  - (1=mild, 2=moderate, 3=severe)
- Chills
  - (1=mild, 2=moderate, 3=severe)
- Difficulty with physical ability
  - (1=mild, 2=moderate, 3=severe)
- Lack of appetite
  - (1=mild, 2=moderate, 3=severe)
- Fatigue
  - (1=mild, 2=moderate, 3=severe)
- Difficuly sleeping
  - (1=mild, 2=moderate, 3=severe)
- Neuropathy
  - (1=mild, 2=moderate, 3=severe)
- Anxiety
  - (1=mild, 2=moderate, 3=severe)
- Depression
  - (1=mild, 2=moderate, 3=severe)
## eRAPID Toxicity (4.5)

**Scores**
- Pain (mild to moderate = 1, severe = 3): 2, 1, 1, 0, 0, 3
- Vomiting (mild to moderate = 1, severe = 3): 0, 0, 2, 0, 0
- Nausea (mild to moderate = 1, severe = 3): 1, 0, 2, 0, 2, 3
- Diarrhoea (mild to moderate = 1, severe = 3): 1, 0, 0, 0
- Constipation (mild to moderate = 1, severe = 3): 0, 1, 1, 1, 1
- Mucositis (mild to moderate = 1, severe = 3): 1, 1, 1, 1, 2
- Temperature (mild to moderate = 1, severe = 3): 0, 0, 0, 0, 0
- Chills (mild to moderate = 1, severe = 3): 0, 0, 0, 0
- Difficulty with physical ability (mild to moderate = 1, severe = 3): 2, 1, 1, 0, 2, 3
- Lack of appetite (mild to moderate = 1, severe = 3): 0, 0, 1, 0, 1
- Fatigue (mild to moderate = 1, severe = 3): 1, 1, 1, 1, 2
- Difficulty sleeping (mild to moderate = 1, severe = 3): 1, 1, 0, 1, 1
- Shortness of breath (mild to moderate = 1, severe = 3): 0, 0, 0, 0
- Sore hands/feet (mild to moderate = 1, severe = 3): 0, 0, 0, 0
- Neuropathy (mild to moderate = 1, severe = 3): 1
- Anxiety (mild to moderate = 1, severe = 3): 1
- Depression (mild to moderate = 1, severe = 3): 1
- Leg weakness (mild to moderate = 1, severe = 3): 0, 0, 0, 0
- Seizures (mild to moderate = 1, severe = 3): 0
- Passing out (mild to moderate = 1, severe = 3): 0, 0, 0, 0, 0
- Reaction at the site of injection (mild to moderate = 1, severe = 3): 1
Training and Engagement of Patients

- Usability test n=12 breast cancer patients; 8 clinicians
- Face-to-face plus a manual
- Motivators
  - Self-management advice
  - Seeing scores in graphs over time
  - Seeing the clinicians using the reports
- Reasons for non-compliance
  - Forgetting
  - Unclear how often, how useful?

‘That really does help because it will say to you whether it’s mild or whatever, or you need to ring... rather than either sitting there worrying or constantly ringing somebody’
Changing medical practice is difficult
Barriers to innovation
Patient compliance depends on clinicians using the information
How to utilise PROMs data

• Interactive session using 5 DVD scenarios
• Discussion of different ways of integrating the information
• Strategies for managing issues raised (e.g. multiple problems, distress)
• Local guidelines for psychological distress and fatigue
Doctor Training Pilot Before/After study Design

BEFORE TRAINING

- 30 patients completed quality of life questionnaires (touch screen)
- Results printed out and given to doctor
- Consultations recorded
- Dr completed survey of how questionnaire data was used

AFTER TRAINING

- 30 patients completed quality of life questionnaires (touch screen)
- Results printed out and given to doctor
- Consultations recorded
- Dr completed survey of how questionnaire data was used

Doctor attended training session
Doctor Training Pilot - Early Results

• In post training consultations

• Doctors explicitly referred to the PROMs data more often

➢ 48% vs 77%

• More frequent discussion of physical function and pain
Key Points for Clinician Training

• Brief training and ongoing support
• How to access the data
  ➢ written instructions / pocket cards
• Worked examples
  ➢ Refer explicitly to PROMs
  ➢ Explore and invite patient to explain
  ➢ Discuss and act
  ➢ Guidelines and referral pathways
Cost-Effectiveness and Implementation Strategies

- Evaluation of cost-effectiveness is essential
  - RCT- eRAPID
  - Quality improvement programs
- Wider implementation ???
- Organizational changes to support the new practice
  - Pilot study in early prostate cancer
- Sustainable electronic platform (updates, helpdesk)
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Vision of Integrated Care Pathways

Supportive care services
- Counseling, psychology, physiotherapy, diet, financial advice

Voluntary sector, charities

Supported self-management - empowered survivor

General Practice

Cancer specialists

Electronic platform for PROMs
- Integrated with Electronic Patient Records (GP/hospital)
- Patient portals
- Secure data sharing
We wish to thank the patients, oncologists and clinic staff who made this work possible

National Institute for Health Research of England
Cancer Research UK

• **Psychosocial Oncology and Clinical Practice Research Group**
  Leon Bamforth
  Trish Holch
  Ceri Hector
  Andrea Gibson
  Beverley Horne
  Elena Takeuchi
  Peter Selby

• **Clinical Trials and Research Unit**
  Julia Brown
Patient logs on to system using a unique username and password, which gives them access to the eRAPID questionnaire.

Patient's questionnaire results are immediately available for clinicians to view in graphical or tabular format.

NHS Firewall

Electronic Patient Record

The patient’s QTool responses are identified by their unique username and integrated with their clinical data in the EPR interface.

Data is pulled behind the NHS firewall into the QStore database. All patient data is kept securely behind the NHS firewall.

QTool software can generate automated self-management advice triggered by reported problems.

Questionnaire responses are stored in the QTool database under the patient’s unique username.

EPR database

QTool database