The acceptability and feasibility of eRAPID (electronic patient self-reporting of adverse-events: patient information and advice) in pelvic radiotherapy for cancer: views of patients relatives and staff

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Overview

• Overview of eRAPID
• Components of the complex intervention
• Pre-implementation qualitative interviews
• Usability study of the whole complex intervention in prostate pts at Leeds
eRAPID (electronic patient self-Reporting of Adverse-events: Patient Information and aDvice) is a NIHR-funded web-based electronic patient reporting system including severity linked alerts/self-management advice.

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

Secure Internet-based Patient self-reports

Suitable for patients receiving chemotherapy, surgery and radiotherapy

Integrated real-time in Electronic Patient Records

Supporting Patient care
Patient advice
Alerts

The Leeds Teaching Hospitals NHS Trust

The Christie NHS Foundation Trust

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

National Institute for Health Research
The eRapid system

**eRapid Radiotherapy System Overview**

**Patient portal**
- **Patient**
  - Issued unique login
  - Completes eRapid questionnaire from home/hospital via QTool

**Self-management**
- Generated via QTool and accessed via eRapid website for low-level symptom management advice
- Alert to contact hospital for severe symptoms

**Data**
- Responses stored under patients unique username

**Clinician portals**
- **Clinician**
  - Notified of severe alerts during treatment
  - View results in graphical and tabular format at review

**Data**
- QTool responses identified via username and integrated into the EPR

**Hospital firewall**
- Data pulled behind firewall to be stored securely in QStore database

**QTool database**

**QStore database**

**EPR database**
eRAPID websites

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 Grant (RP-PG-0611-20008).

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 Q2D) 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.

If you have any queries regarding the content of this website, please contact the researchers.

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eRAPID is a complex intervention following MRC and WISE models.

**Patients - AE Items**
Self-reporting of side effects with severity grading

**Electronically platform**
- Functional in Real-time
- Secure
- Well-supported

**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

**eRAPID Intervention**
eRAPID is a complex intervention

Patients - AE Items
Self-reporting of side effects with severity grading

Electronic platform
- Functional in Real-time
- Confidential
- Well-supported

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

Integration in patient care pathways
- Staff and patient training
- Timing, acceptability

eRAPID Intervention
Key questions

• Would eRAPID be acceptable?
• To patients; staff and relatives
• Would radiotherapy patients/relatives see the potential in online AE reporting?
• Would staff find it useful?
• When would be the best time to introduce it?
• Can we integrate eRAPID successfully into the treatment pathways?
Method

We conducted audio-recorded semi structured interviews with 72 participants.

Patients (N=37) undergoing radiotherapy / concurrent chemotherapy for prostate, colorectal and gynaecological cancer (age range 42-81 mean 62) 16 in the Christie Manchester; 21 in Leeds. During, on completion and 6 weeks post treatment

Additionally we interviewed patient relatives (N=9) (6 : Leeds; 3 Manchester) and staff (nurses, oncologists and radiographers) involved in their care (N=26) (Leeds 16 : Manchester 10).
Interview schedule

**Patients /relatives:**
- Benefits of eRAPID
- Feasibility of reporting online
- Timing of eRAPID
- Types of symptoms
- Viewing results over time
- Self-management advice

**Staff:**
- Benefits of eRAPID
- Staff patient communication
- How it could improve AE reporting
- How could eRAPID fit into the patient trajectory
- Timing of the questionnaires
# Patient demographics

<table>
<thead>
<tr>
<th>Patients</th>
<th>Age both groups Mean 62 (42-81)</th>
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<tbody>
<tr>
<td><strong>Manchester (N=16)</strong></td>
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<tr>
<td>Months since diagnosis</td>
<td>n</td>
</tr>
<tr>
<td>Mean 4; Range 1-10</td>
<td>16</td>
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<tr>
<td>Tumour group</td>
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<tr>
<td>Prostate</td>
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<tr>
<td>Gynaecological</td>
<td>7</td>
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<tr>
<td>Anorectal</td>
<td>4</td>
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<tr>
<td><strong>Leeds (N=21)</strong></td>
<td></td>
</tr>
<tr>
<td>Months since diagnosis</td>
<td>n</td>
</tr>
<tr>
<td>Mean 6.19; Range 4-14</td>
<td>21</td>
</tr>
<tr>
<td>Tumour group</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
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</tr>
<tr>
<td>Gynaecological</td>
<td>3</td>
</tr>
<tr>
<td>Anorectal</td>
<td>5</td>
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<tr>
<td></td>
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</tbody>
</table>
# Staff Demographics

## Health professionals

### Manchester (N=10)

<table>
<thead>
<tr>
<th>Role</th>
<th>n</th>
<th>Years in role</th>
<th>Age</th>
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</thead>
<tbody>
<tr>
<td>Specialist radiographer</td>
<td>3</td>
<td>Mean 8.5</td>
<td>Mean 41</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range 1-23</td>
<td>Range 26-54</td>
</tr>
<tr>
<td>Consultant Clinical Oncologist</td>
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<td></td>
<td></td>
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<tr>
<td>Clinical nurse specialist</td>
<td>3</td>
<td>Prostate</td>
<td>Male 1</td>
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<tr>
<td>Nurse clinician</td>
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<td>Gynaecological</td>
<td>Female 9</td>
</tr>
<tr>
<td>Anorectal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Leeds (N=17)

<table>
<thead>
<tr>
<th>Role</th>
<th>n</th>
<th>Years in role</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist radiographer</td>
<td>3</td>
<td>Mean 8.5</td>
<td>Mean 44.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range 1-26</td>
<td>Range 35-59</td>
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<tr>
<td>Consultant Clinical Oncologist</td>
<td>5</td>
<td></td>
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<tr>
<td>Clinical nurse specialist</td>
<td>4</td>
<td>Prostate</td>
<td>Male 3</td>
</tr>
<tr>
<td>Radiography manager</td>
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<td>Gynaecological</td>
<td>Female 14</td>
</tr>
<tr>
<td>Radiographer</td>
<td>2</td>
<td>Anorectal</td>
<td></td>
</tr>
<tr>
<td>Staff nurse</td>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interviews were transcribed, coded utilising thematic analysis and managed in NViVo.

Patient coping

“I think we’ve always lacked providing support in that 6 weeks post-treatment. I think we probably don’t fully understand the side effect profile of patients and how they cope….patients have a miserable time, often the first month following radiotherapy”
(Nurse clinician, female Christie)

“rather than dragging them up to outpatients and sit there and get worried, they report their own symptoms so you could either pick up symptoms that were worrying in terms of say recurrence”
Consultant Clinical Oncology (Gynae), Leeds

“I think you could seek out advice about your symptoms a lot quicker……you’ve finished your radiotherapy and you’re waiting your six weeks for your appointment, if you’ve got any symptoms,……. You don’t have to hassle the doctors or, you know, I think it’s a really good idea”
(PTC3_StartingRT_Cervical)

“…… that’s where I’d quite like to introduce it as a tool for grading so that I could then stratify those patients that I want to follow them up a bit more closely”
Consultant Clinical oncologist, Christie

“... when I left and finished treatment I was left to my own devices…. a bit scared”
(PTA2 Starting RT Anal)
Communication

“we never touch sexual function”
(Radiographer, Leeds)

“I think an online tool would be much better...because its..less personal”.
Prostate (female relative)

“...first of all you know the your sex drive goes your manhood goes basically erm and err you know there’s always going to be a..............bit of a psychological bath there isn’t there...you know it’s difficult for people to take that whole thing on board”
(PT11_CompletingRT_Prostate)

“It is a good idea, cos not everybody can express their emotions....I think especially men, cos they think they are brave not to show their emotions, don’t they?”
Rectal (female relative)

“...we were going to ask them about sexual dysfunction as well, because there might be things like that they may report online, ..............I think they might do because to me, they don’t want to talk about, about what they’re doing really.”
(Radiographer, Leeds)

“yeah, I think that would be a good idea, cos not everybody can express their emotions....I think especially men, cos they think they are brave not to show their emotions, don’t they?”
Rectal (female relative)

Communication

Reporting of difficult or challenging symptoms

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eRapid

National Institute for Health Research
“It sounds like a good idea to me, to be able to access something at home that might give you peace of mind or something like that...Yes, that erm, you know everyone is so busy in the hospital itself, and you never can think of the things to ask until you get home, or anything. So yes it sounded, y’know, it sounded a good idea.”

(PT03_CompletingRT_Prostate)

“That’s right, because it is the time after 5pm that’s it’s not easy is it? You are a little bit in no man’s land”

(PT01_CompletingRT_Prostate)

“Very useful for when you are discharged or in the night when you need to report something”

(PT09_CompletingRT_Prostate)

“Even though they are being seen every day by the radiographers they don’t necessarily tell them if there’s anything wrong, they’re just coming for the treatment, having it and going.”

(Gynae Nurse specialist, female Leeds)
“Yes I have had enough to read I was given it all at diagnosis and I was so shocked that I didn’t take it out of the carrier bag all the way though my treatment- I was given this by XXXX the CNS. You don’t read information you shut down when you have cancer”  
(PT09_CompletingRT_Prostate)

“see it’s awkward because everything moves quite quickly and then you’re in treatment and it really doesn’t work and it’s like you forget half of what’s been said to you”  
(PTC2_CompletingRT_Cervical)

“I don’t know whether this could fit in to eRAPID when it’s developed, is for treatment in that they have an enema and a full bladder for treatment and we find that a lot of patients don’t drink very much generally...they are quite often not prepared .or aren’t expecting that whole process .......... it comes as quite a shock”  
Radiotherapy manager (Leeds)

“...............would be useful to access the self-management advice. I also think the Doctor should introduce it to the patient”  
Prostate (female relative)

“well yeah, it gives you more information as well doesn’t it?”  
Cervical  
(Male relative)
Summary

Useful for reporting difficult or challenging symptoms

Enable support during follow up prior to 6 week appt

A source of out-of-hours information & support - on treatment

Source of staged information provision

Understand side-effect profile

Screening – targeted resources
Usability study

- N=10 prostate cancer patients completed weekly online symptom reports (or when unwell) via eRAPID during radical radiotherapy.
- To assess usability and engagement with eRAPID, patients completed the System Usability Scale and took part in an end-of-study audio recorded interview which was transcribed and analysed thematically.
- Patients were recruited over 6 week period
- (Mean age 70 range 63-84) and compliance for weekly completion was 100%.
100% of patients ‘strongly agreed’ that the system was easy to use.

90% patients ‘agreed or strongly agreed’ they had confidence in using the system.

90% strongly agreed that people would learn to use the system quickly.

50% said they would like to use the system frequently (40% neutral).

Patient feedback usability in prostate N=10

Supporting patient help seeking

Increasing knowledge and self confidence

Monitoring symptoms over time

“instead of you wondering if you should ring a doctor or other health professional and ask for advice, then feel a fool for bothering them”

“Found this site gave me peace of mind on a raft of questions at the click of a mouse”

“I was reluctant to speak to radiographer regarding a symptom before treatment as I have a full bladder so don’t want to delay their own treatment or others who are waiting (thus system is beneficial)”

“Found eRAPID to be a reassuring tool to see if any side effects were usual and treatable”

“I wish I had done a reply every day to make the graphs more comprehensive and show the movements more precisely”
Conclusions

- Patients found the system easy to use and a beneficial adjunct to usual care despite daily visits to the RT department. A multi-site randomised pilot study is underway with 168 prostate, gynaecological, anal and rectal patients in Leeds and Manchester.

- In this feasibility pilot study we plan to test the complete eRAPID radiotherapy (RT) platform including patient and clinician interface.
- We aim to examine feasibility, acceptability, and adherence to the intervention from the perspective of cancer patients and health professionals and explore the impact on patient care and quality of life.
- In addition we aim to determine the effect sizes for study outcomes to inform the design and recruitment targets for a future RCT.
Trial diagram pilot study

Patients consented to study

Randomised to usual care or eRAPID intervention

eRAPID intervention
Receive eRAPID training

Usual Care

Longitudinal completion of eRAPID symptom/AE questionnaire from home
- Prostate 4 weeks
- Chemo-rad (anal/cervix, endometrial and rectal 5 weeks, vulval, 6 weeks).

End of study interviews/questionnaires with participants, decliners, carers and staff.

Key
eRAPID AE symptom questionnaire completed weekly/when experiencing symptoms (up to week 6) and weekly for 6 weeks post treatment [12 weeks total] and at 18 & 24 weeks

Completion of QOL, Use of resource forms, on paper at baseline (BL) then 6, 12 and 24 weeks after dependent on timings of radiotherapy and chemotherapy schedules and follow up

Endpoints and analysis
- Patient recruitment rates, attrition over time; proportion of missing data
- Use of resources: providing patient reports of hospital contacts, community health care contacts, medication and additional expenses incurred
- Patient reported outcomes: QOL: FACT-G, EORTC QLQ-C30 (Role and Social function scales), EQ-5D, patient activation measure (PAM), Lorig self-efficacy scale, system usability scale (SUS)
- Clinical process measures: hospital contacts, alerts and hospital admissions, re-admissions (with reasons), changes to supportive medications and radiotherapy/chemotherapy dose changes, contacts with GP/district nurse community services will be extracted from hospital records

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Conclusion

• Despite attending the hospital daily patients undergoing treatment for pelvic cancers and their relatives stated eRAPID would be a useful adjunct during treatment and beyond.

• Staff agree that eRAPID would be a valuable enhancement to current service provision.

• Randomised feasibility study in RT is running at Leeds and The Christie NHS Trusts.

• Important to do this sort of mapping prior to implementation -consultation process to enable successful integration.
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Any Questions?