

Service Development: Clinician training and eLearning module

Staff training:

Key clinical staff members were identified and their specific training needs explored to tailor the more appropriate method of training.

Table 1: Staff who received formal training prior to the start of study

Breast team	Gynae Team	Colorectal team	Other
6 Oncologists 4 Research nurses 4 Nurse specialists 2 Admin staff	4 Nurse specialists 3 Research nurses 3 Oncologists	6 Research nurses 5 Oncologists 3 pre-assessment nurses Chemo lead nurse	26 Nurses Outpatients and Chemo suite 10 Nurse practitioners 6 Pharmacists 5 Oncologists 3 Research staff LCRF

Prior to training written materials were produced in the form of a trainer prompt sheet, staff training manual and one page staff prompt sheets which were distributed to all relevant clinical areas as a guide in how to access the patient reported results within the EHR.



eRAPID Staff training prompt sheet

Introduction of staff facilitating training

- Introductions
- Ask staff to complete training log
- Overview of objectives of training session
 - Aim to describe the eRAPID research programme and RCT in systemic cancer treatment
 - Provide practical demonstration of the eRAPID system on the computer (internet and PPM)
- Show certificates
- Discuss request for eRAPID champion (communication link) with opportunity to attend eRAPID update meetings.

BACKGROUND

What is eRAPID?

- eRAPID stands for Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice. This is a 5 year programme grant funded by the NIHR (£1.9 million). This is being conducted by POCPRG led by Prof Galina Velikova
- eRAPID is an online system for patients to report information about their symptoms and side effects during cancer treatment. Patients can complete questions about their symptoms from home or in the hospital via a website. We will be asking patients to complete this at least weekly and when unwell for 18 weeks of their chemotherapy treatment. The questionnaire asks questions specific to the patients cancer diagnosis to reflect different symptoms (Gynae, Breast or G.I) The system:



- Provides patients with immediate advice on how to self-manage mild/low level problems
- Informs patients when to contact the hospital for severe symptoms
- Is linked to PPM to allow for patient reported data to be included in medical records for staff to use to monitor patients throughout treatment
- Can send email alerts to staff to notify them of severe symptoms. (This will be sent to nurse specialists)

• IMPORTANT

- **eRAPID IS NOT A REPLACEMENT FOR USUAL CARE**

eRAPID is a project we have been working on and developing for the last 4 years with funding for NIHR. During this time we

- developed the patient symptom questionnaires- (based on the CTCAE criteria for assessing chemotherapy toxicity)
- devised the eRAPID website, collated self-management advice for low level symptoms
- set up the IT infrastructure to allow for patient questionnaire data to be transferred into PPM from an online questionnaire website
- conducted testing in the breast cancer clinic with 14 patients receiving chemotherapy
- Patients and oncology staff were involved in all steps of the development of eRAPID taking part in interviews, choosing symptom questions, advising on the website and participating in usability testing.

eRAPID RCT in systemic cancer treatment January 2015- December 2017

- Does eRAPID work in clinical practice?
- The study is randomised with half of the patients using the online system.
- The disease groups covered will be (Adj Breast, Adj G.I. and Gynae)



- We are hoping to recruit 84 patients to the pilot stage of the study and 484 in the main study.

- The overall aims of the eRAPID system are to improve the safe delivery of cancer treatments, enhance patient care and standardise documentation of adverse events (AE) within the clinical datasets.

Potential benefits of eRAPID:

- Benefits for patients
 - Earlier symptom detection and improved self-management, timely admissions
 - Improved supportive medication use
 - Appropriate hospital/GP/community contacts
 - Better outcomes (improved symptom control, functioning and quality of life)
- Benefits for staff
 - Reduce the number of hospital/GP/community contacts
 - Save time spent on enquiring and recording AEs
 - Focus attention during clinical contacts on most important/sever AEs
 - Support decision making in routine care
- Benefits to the NHS
 - eRAPID provides a cost-effective approach to supporting patient self-management and reducing hospital/GP contacts

PRACTICAL DEMONSTRATION

How does eRAPID work?

[QTool and eRAPID website](#)

Practical demonstration of patient symptom questionnaire and how staff access results. (Also how to access alert report for those responding to alerts)



- Logging onto website and QTool.-
<https://qtool.leeds.ac.uk/Account/ParticipantLogOn/LTHT>
Username: Demo Password: demo
- 1st demo complete mild/moderate symptom responses to activate self-management advice
- 2nd demo complete severe symptom responses to show alert message for contacting hospital
- Show website advice

PPM

Using patients (007 and 023) from breast usability study as example eRAPID QTool data demonstrate:

- Accessing results on PPM (graphs and tabulated results)
- Show cycle graphs on Usability patients and go through refining results. (patient 007)
- Show how to access alert report for those staff receiving e-mail alerts.
- How to respond to an alert (specifically for Breast CNS, Gynae CNS). Still go through this process with other teams highlighting they have the option to respond if they have had contact with a patient.
- Request staff document in PPM their annotation if patient contact them as a result of completing the eRAPID questionnaire.

How to use PPM results

- Encourage clinicians to report back to patients that they have seen the eRAPID toxicity. Show the patients the graphs or the table. Go through it
- *Thank you for reporting your symptoms. I can see you had xxxxx, tell me more about this, when, how did you deal with it?*
- *Have you got any other problems/symptoms?*

Figure 1: Trainer prompt sheet



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

eRAPID RCT in systemic cancer treatment
Staff training guide

Version 1.0 January 2014

eRAPID Staff Training Guide

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Thank you for your help with the eRAPID research study. This guide provides an overview of eRAPID, the RCT in systemic treatment, information on accessing patient reported symptoms in PPM

The guide is divided into the following sections:

- 1. What is eRAPID?**
- 2. Why and how was eRAPID developed?**
- 3. How does eRAPID work?**
- 4. Accessing patients symptom report information in PPM**
- 5. Using patient reported information- An example from the eRAPID usability testing**
- 6. The eRAPID RCT in systemic cancer treatment: What is expected of me?**
- 7. Frequently asked questions**

To contact the eRAPID research team please:

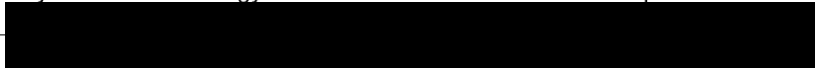
Email:



Telephone:



Psychosocial Oncology & Clinical Practice Research Group



1. What is eRAPID?

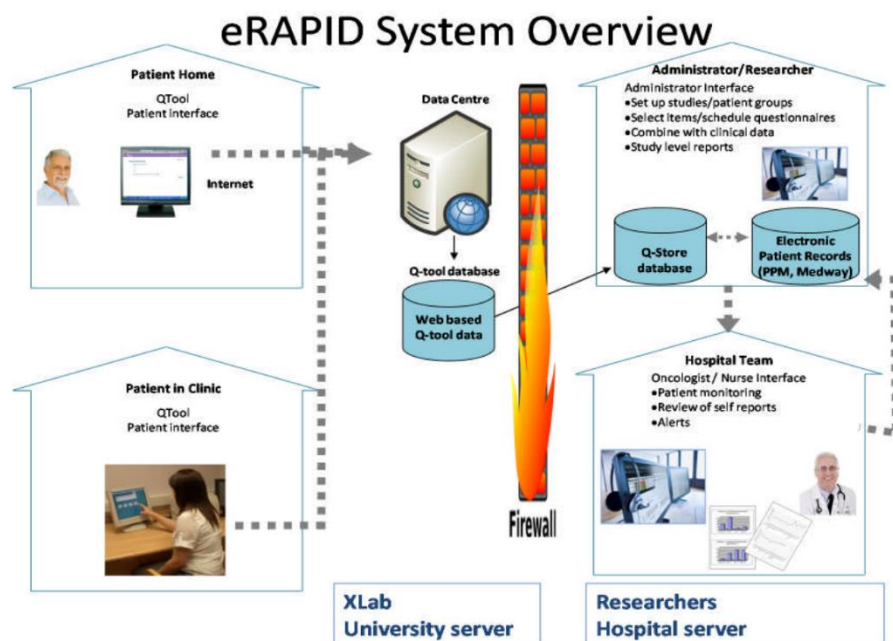
- eRAPID stands for Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice
- eRAPID is a 5 year programme grant of £1.9million funded by the National Institute for Health Research (NIHR). The research is being conducted by the Psychosocial Oncology and Clinical Practice Research Group (Level 3 Bexley Wing), led by Professor Galina Velikova.
- eRAPID is an online system (see Figure 1) for patients to report information about their symptoms and side effects during cancer treatment. Patients can complete questions about their symptoms from home or in the hospital via a website. The system:
 - Provides patients with immediate advice on how to self-manage mild/low level problems
 - Informs patients when to contact the hospital for severe symptoms
 - Is linked to PPM to allow for patient reported data to be included in medical records for staff to use to monitor patients throughout treatment
 - Can send email alerts to staff to notify them of severe symptoms
- The overall aims of the eRAPID system are to improve the safe delivery of cancer treatments, enhance patient care and standardise documentation of adverse events (AE) within the clinical datasets.
- In the 5 year research programme we aim to assess the value of eRAPID in clinical practice.

We hypothesise that eRAPID has the potential to bring benefit to patients, staff and the NHS in the following ways:

- Benefits for patients
 - Earlier symptom detection and improved self-management, timely admissions
 - Improved supportive medication use
 - Appropriate hospital/GP/community contacts
 - Better outcomes (improved symptom control, functioning and quality of life)
- Benefits for staff
 - Reduce the number of hospital/GP/community contacts

- Save time spent on enquiring and recording AEs
- Focus attention during clinical contacts on most important/sever AEs
- Support decision making in routine care
- Benefits to the NHS
 - eRAPID provides a cost-effective approach to supporting patient self-management and reducing hospital/GP contacts

Figure 1. Overview of the eRAPID system



2. Why and how was eRAPID developed?

Why?

- Systemic drug treatments for cancer are often associated with acute and long term adverse events (AE).
- Severe AEs can escalate to hospitalisation for potentially life-threatening toxicities: 18% of cancer patients present to emergency services within 14 days of a scheduled hospital visit for symptom management (infection, fever, nausea/vomiting, pain, breathlessness)
- Many patients however, delay seeking emergency care especially out of hours
- AE are documented consistently by physicians in clinical trials however in routine care recording of AE by clinicians and reporting by patients is variable and often omitted and this may be a factor in preventable fatalities
- The need for monitoring of cancer treatment AE is at odds with a health care system relying increasingly on patient self-management and home based care. In order to bridge the gap in service provision to detect, identify and manage AE in cancer patients we have developed the eRAPID system
- In our previous research in Leeds the Psychosocial Oncology and Clinical Practice research group have shown that electronic reporting of patient-reported outcome measures (PROMs) has proven extremely acceptable to patients in the clinic setting

How?

- Between 2010-2013 the eRAPID developmental work was conducted (funded by an NIHR programme development grant), which focused on
 - Building the online system for patient reporting of AE and linking this information into the electronic patient records (PPM)
 - Exploring the cancer teams and care pathways to establish where eRAPID would best fit within these.

- Selecting and adapting the symptom questions that could be understood by patients and clinicians and mapped onto the Common Terminology Criteria for Adverse Events (CTCAE) severity grades already used by clinical teams.
- Collating patient information and advice for managing the common symptoms and side effects of systemic cancer treatment and putting this information on the eRAPID website.

Staff and patients have played a vital role in the development of the eRAPID system throughout the past 4 years by taking part in interviews, choosing symptom questions, advising on the website and participating in usability testing

- In 2013 the NIHR awarded Professor Galina Velikova the 5 year programme grant to assess the value of eRAPID in clinical practice.

- Early in 2014 we conducted a testing exercise of the full eRAPID system
 - 14 breast cancer patients receiving adjuvant chemotherapy agreed to assist with the testing. Patients were given access to the eRAPID symptom reporting questionnaire and eRAPID website at the start of treatment.
 - The clinical nurse specialists and oncologists involved in patient care were trained to access the patient reports in PPM.
 - Feedback from both staff and patients and patients was predominately very positive and the comments and advice received helped to refine the intervention further.
 - Patients have felt the system is easy to use and provides valuable information about managing the symptoms and side effects of treatment.


Figure 2. Comments from breast cancer patients involved in the eRAPID testing phase

Feedback from patients

I found this website to be very useful and puts your mind at ease as you can have a lot of questions or problems regarding your illness and with one click they can be answered and absorbed within minutes. No waiting till your next appointment.

Just to let you know that I found questionnaire extremely quick and easy to access and complete and from my first use I can't see that it requires any improvements. Well done to you and your team!

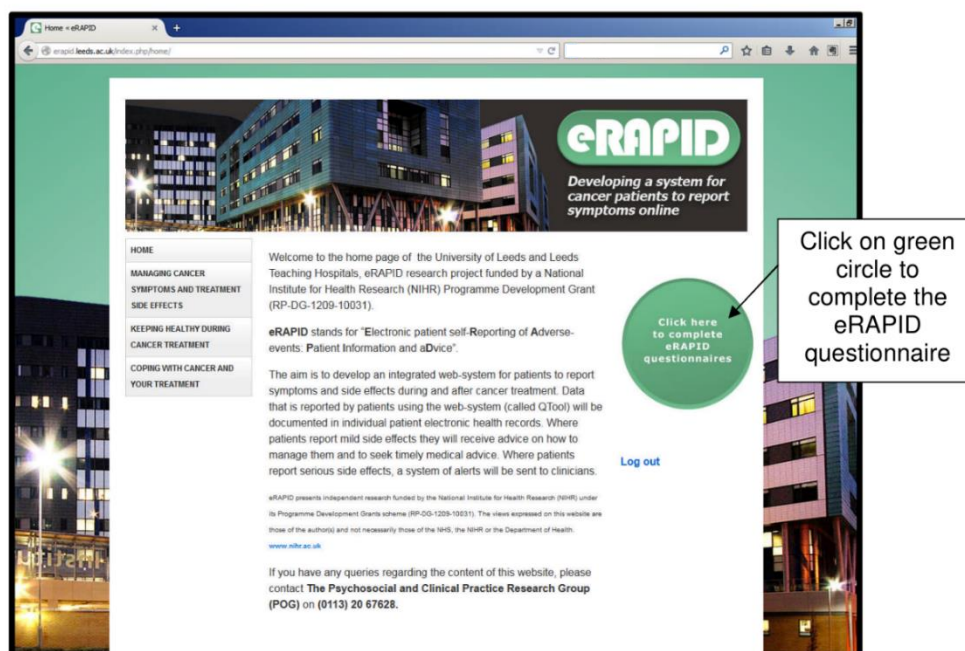
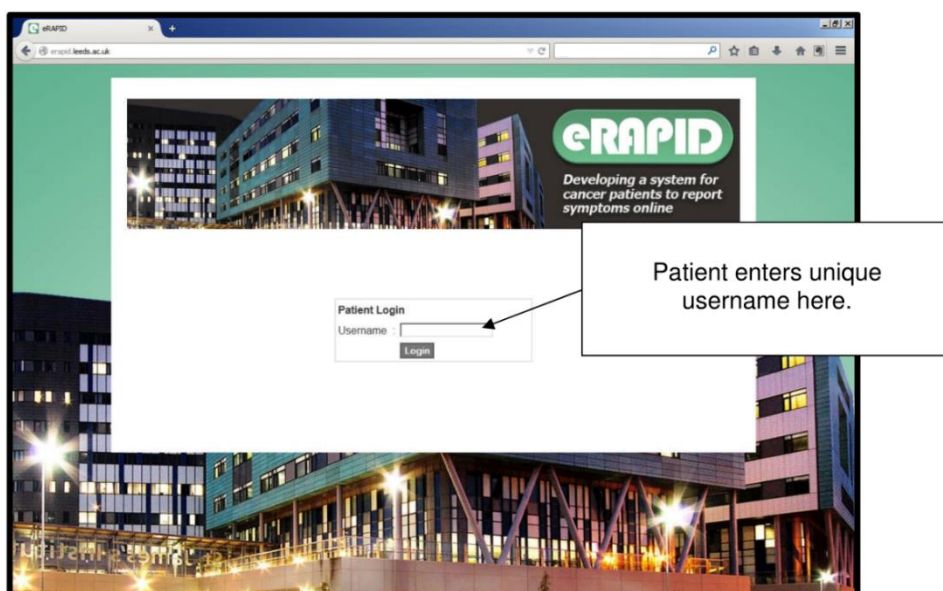
Its like a life line when you feel isolated when you're at home and feeling poorly or just for more information on certain aspects of your illness.



If I can use it, anyone can!

3. How does eRAPID work?

- In this section we describe how eRAPID works from the patients' perspective.
- Patient participants consenting to the eRAPID study will be asked to complete the symptom questionnaires by logging in via the eRAPID website <http://erapid.leeds.ac.uk/>



Log On

https://zpool.leeds.ac.uk/Account/Participant/LogOn.THT

Login

Username:

Password:

[Forgotten your Username or Password?](#)

Access QTool (the online questionnaire builder where the eRAPID symptom questionnaires are available)

Questions will appear on the page one at a time.

File Questionnaire: eRAPID ques... x

https://zpool.leeds.ac.uk/TakeQuestionnaire/19a57997-84db-4f64-b051-895b0d0351/page2

Demo | Home | Account | Log Out

eRAPID questionnaire

Page 2 of 12

During the past week:
Have you **felt** sick (nauseous or queasy)?

No

I felt sick but I was able to eat and drink the SAME AMOUNT and type of foods as usual

I felt sick and I ate or drank LESS THAN usual or changed what I ate or drank

I felt sick and was not able to eat or drink

Take Questionnaire: eRAPID ques... x

https://jphd.leeds.ac.uk/7/ahn/questionnaire/19457997-646-4944-6951-9959b000355?page3

Demo | Home | Account | Log Out

eRAPID questionnaire

Page 3 of 12

During the past week:
Have you been sick (vomited)?

- No
- I have vomited 1 - 2 times in a 24 hour period
- I have vomited 3 - 5 times in a 24 hour period
- I have vomited 6 or more times in a 24 hour period

Is this a current problem or has it now improved?

- This is a current problem for me
- I have experienced this problem in the last 7 days but it has now improved

[Previous page](#) [Next page](#)

When patients report having had a severe symptom, in the last week we ask whether this is a current problem or if it has now improved.

Take Questionnaire: eRAPID ques... x

https://jphd.leeds.ac.uk/7/ahn/questionnaire/19457997-646-4944-6951-9959b000355?page3

Demo | Home | Account | Log Out

eRAPID questionnaire

Page 3 of 12

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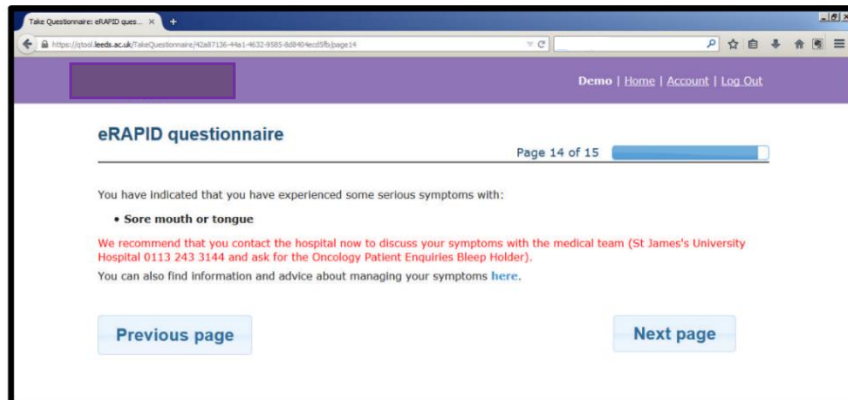
- This is a current problem for me
- I have experienced this problem in the last 7 days but it has now improved

You have indicated a serious problem in this area. We recommend that you contact the hospital now to discuss your symptoms with the medical team (St James's University Hospital 0113 243 3144 and ask for the Oncology Patient Enquiries Bleed Holder). Before you contact the hospital and if you feel able, please complete the remaining questions.

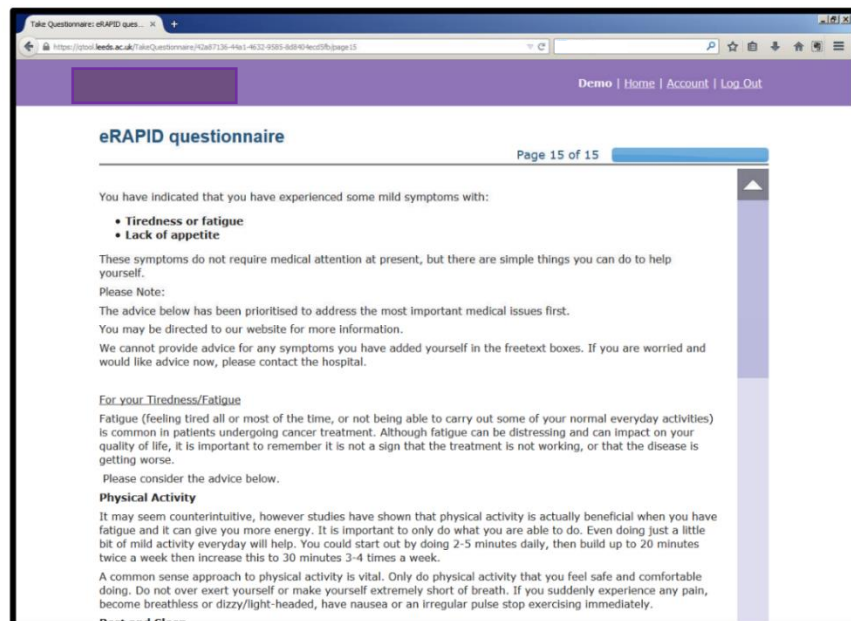
[Previous page](#) [Next page](#)

If the patient reports a symptom that needs immediate medical attention, they are advised to contact the oncology bleed holder.

- When all the eRAPID questions are completed the system will provide advice for the symptoms that have been reported to be a problem. For serious symptoms, patients will be advised to immediately call the medical team at the hospital to speak to someone about the problem.



- For less serious symptoms the system will provide some advice for helping patients self-manage these issues. Information on all symptoms and side effects is available on the eRAPID website.



In addition the eRAPID website <http://erapid.leeds.ac.uk/>, includes advice on managing general and specific issues patients may experience during cancer treatment

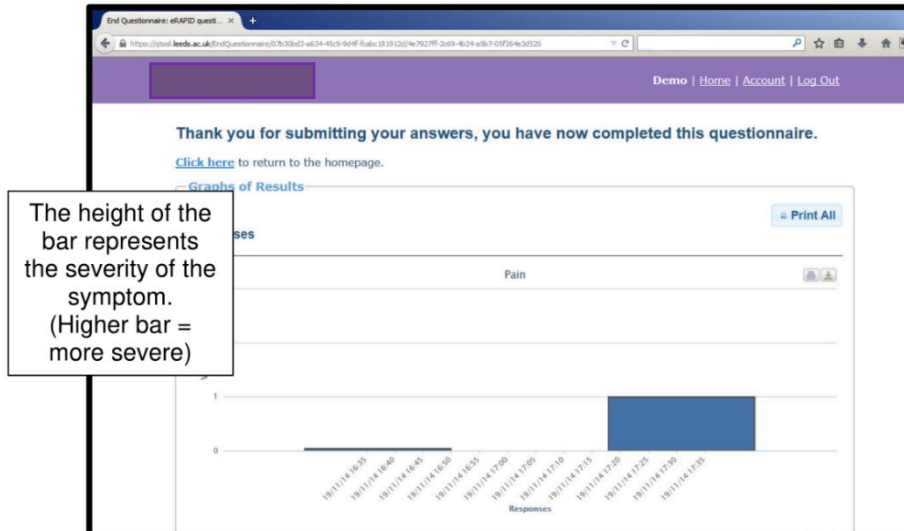
The screenshot shows the eRAPID website interface. The browser address bar displays 'erapid.leeds.ac.uk/index.php/home/'. The main header features a large image of a modern building at night with the eRAPID logo and the tagline 'Developing a system for cancer patients to report symptoms online'. A navigation menu on the left lists categories: HOME, MANAGING CANCER, SYMPTOMS AND TREATMENT, SIDE EFFECTS, KEEPING HEALTHY DURING CANCER TREATMENT, and COPING WITH CANCER AND YOUR TREATMENT. The main content area includes a welcome message, the acronym definition 'eRAPID stands for "Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice"', and a description of the system's aim. A green circular button labeled 'Click here to complete eRAPID questionnaires' is prominent. A 'Log out' link is also visible. At the bottom, there is a disclaimer and contact information for the Psychosocial and Clinical Practice Research Group (POG).

Symptom advice.

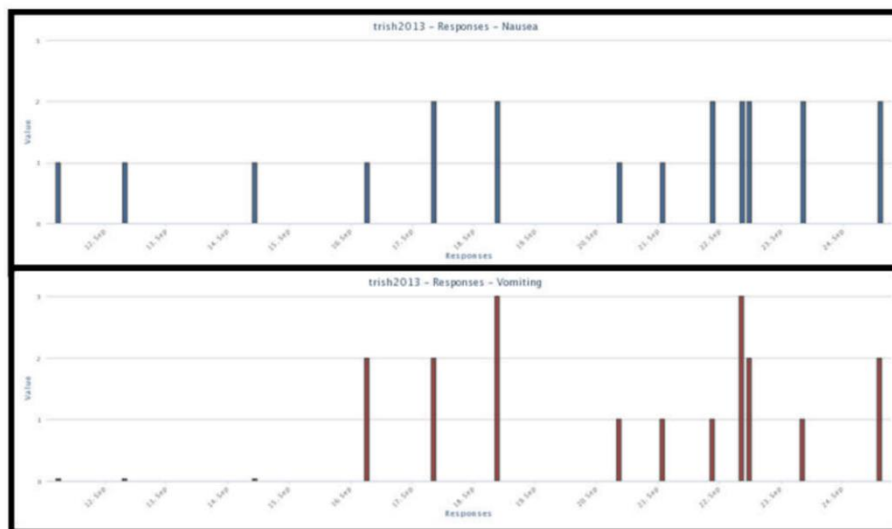
General advice on physical wellbeing

General advice on emotional wellbeing

After completing the questionnaires patients can see their results presented as graphs so they can monitor their results over time.



When you have completed the questionnaire more than once, your results are displayed as



The patient reported symptom information is immediately passed into their electronic medical record in PPM

4. Accessing patients' symptom report information in PPM

In the patient browser:

- 1) Find the patient.
- 2) The "QTool" tab will appear in the right-hand panel. Click on this to bring up the questionnaire responses.
- 3) Ensure the correct trial "eRAPID RCT in systemic therapy" is selected.
- 4) You can view results in graph or tabulated form by clicking on the tabs.

You can then:

- 1) View patient's responses in graph form.
- 2) View the results in tabulated form.
- 3) Print results by scrolling to the bottom of the page and clicking "Download current results".
- 4) Click "Open" to show a PDF document of the results.

	11 Dec 2014	04 Dec 2014	04 Dec 2014
Pain (1= Mild 2= moderate 3= severe)	0	3	1
Vomiting (1= Mild 2= moderate 3= severe)	3	0	2
Nausea (1= Mild 2= moderate 3= severe)	0	0	1
Diarrhoea (1= Mild 2= moderate 3= severe)	0	0	0
Constipation (1= Mild 2= moderate 3= severe)	0	0	0
Mucocitis (1= Mild 2= moderate 3= severe)	0	0	1
Temperature (1= Mild 2= moderate 3= severe)	0	0	0
Chills (1= Mild 2= moderate 3= severe)	0	0	0
Difficulty with physical ability (1= Mild 2= moderate 3= severe)	0	0	2
Lack of appetite (1= Mild 2= moderate 3= severe)	0	0	0
Fatigue (1= Mild 2= moderate 3= severe)	0	0	1
Difficulty sleeping (1= Mild 2= moderate 3= severe)	0	0	0

You can change the number of questionnaire results you can see by using the refine the results functions...

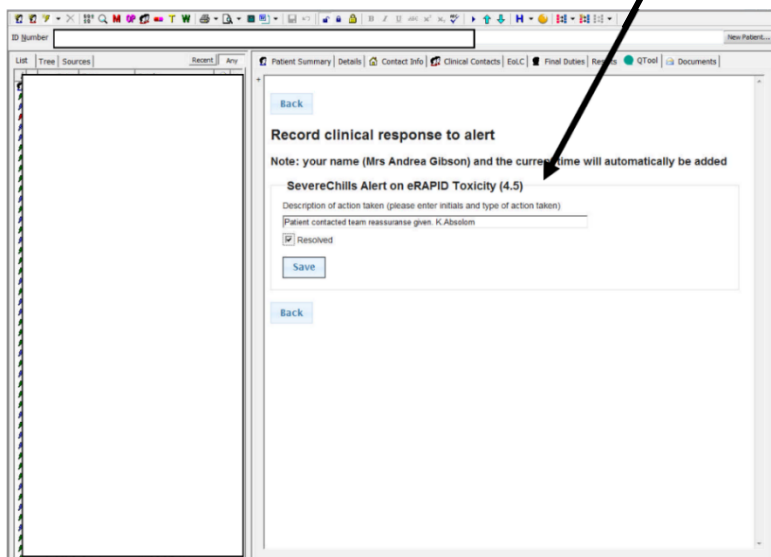
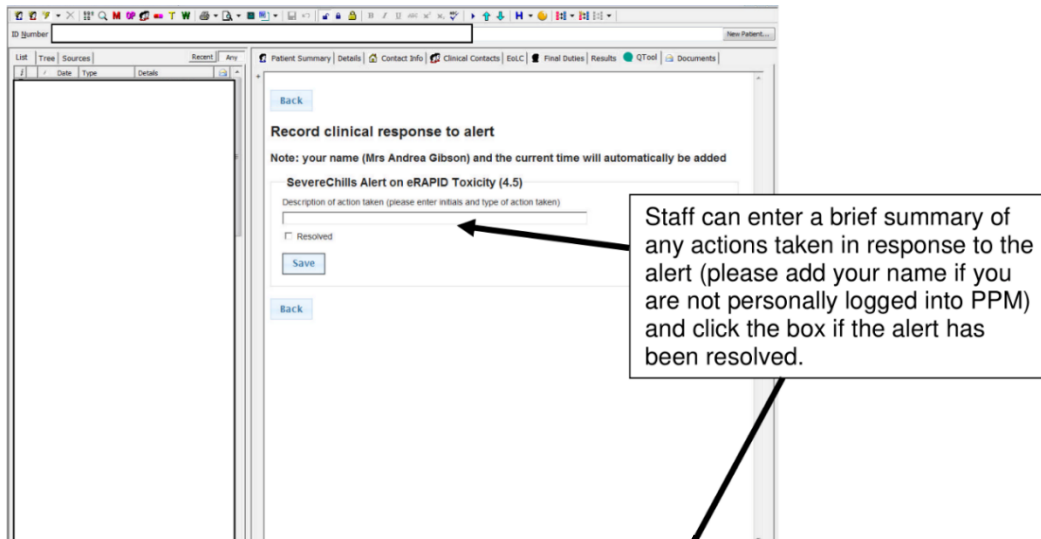
Use these drop down boxes to change the date range for the questionnaire results you want to view, or just view result from one questionnaire completion.

When a patient has reported a severe symptom that has generated an alert this will appear at the top of their QTool page:

Symptom alerts will appear in red at the top of the patients QTool page along with the date it was reported.

Staff can report responding to an alert by clicking on the 'Record response to alert' button.

Clicking on the 'Record response to alert' button will lead to the following page...



An additional alert response can be added or previous information can be edited or removed if required...

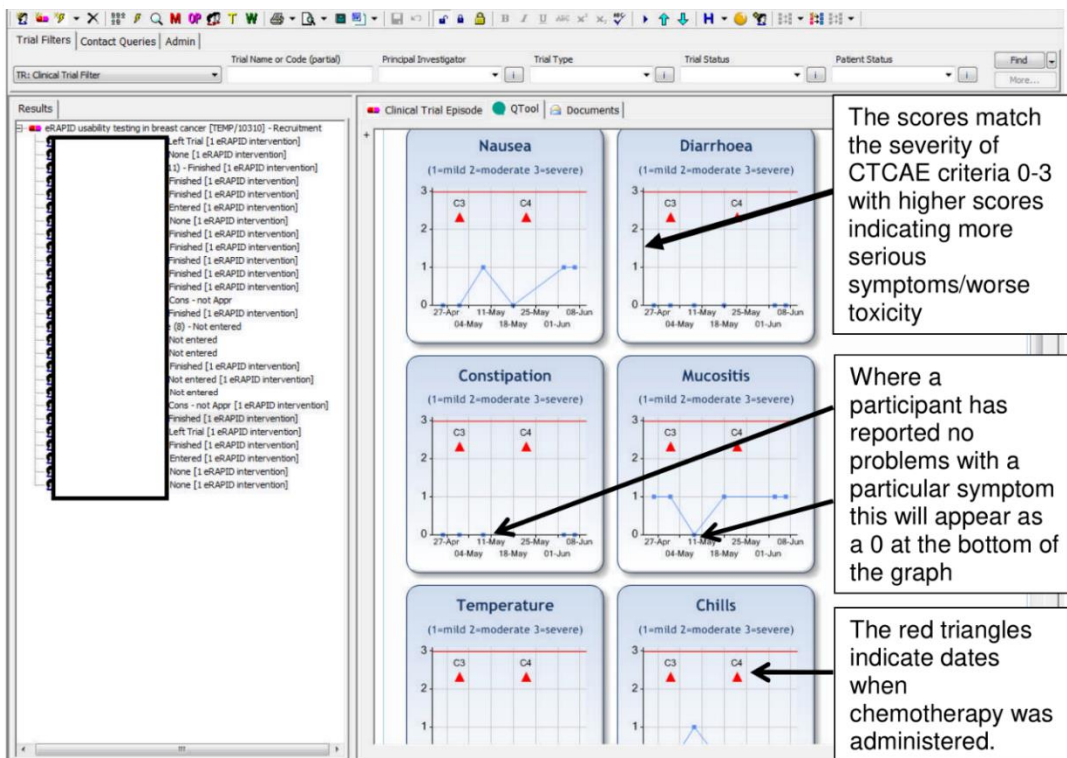
The screenshot shows a web application interface for managing patient alerts. On the left, there is a sidebar with a search bar and a list of alerts. The main area displays a detailed view of an alert. The alert is titled "eRAPID Toxicity (4.5) Alerts" and lists two alerts: "25-Feb-2014, Name: SevereChills - eRAPID Toxicity (4.5)" and "25-Feb-2014, Name: SevereTemperatureChills - eRAPID Toxicity (4.5)". For each alert, there are buttons for "Add new response", "Edit response", and "Remove alert response". A callout box with arrows pointing to these buttons contains the text: "Click on the relevant box to add a further alert response, or edit/remove a previous response."

Resolved alerts will then appear in green text...

The screenshot shows the same web application interface, but now displaying resolved alerts in green text. The alert list on the left shows "RESOLVED: 12-Jan-2015 Patient contacted team reassurance given. K.Absolom Entered by Mrs Andrea Gibson" in green. The detailed view on the right shows the "Record Response to alert" section with tabs for "Tabulated Results", "Graph Results", and "Administration". The "Graph Results" tab is selected, showing two line graphs for "Pain" and "Vomiting". The scores for Pain and Vomiting are shown as red triangles on the graphs. The text "Updated clinical alert response" and "eRAPID usability testing in breast cancer (trial)" is also visible at the top of the detailed view.

5. Using patient reported information- An example from the eRAPID usability testing

- Routinely collecting patient reports of their symptoms throughout treatment can help staff see how symptoms and side effects change over time and may help to identify key problems for discussion during chemotherapy review consultations. We hope eRAPID data will be a valuable tool in consultations in conjunction with a discussion with the patient
- Below are some screenshots from PPM showing QTool data for a patient who helped with testing eRAPID in 2014 whilst receiving chemotherapy.
- The symptom questionnaire scores match the severity of the CTCAE- higher scores = worse toxicity
- Patients can report additional symptoms that are not routinely asked about in the standard questionnaire but this information will only appear in the tables not the graphs



The patient reported information can also be viewed in a table:

eRAPID usability testing in breast cancer (trial) Administration

Displaying 6 out of 14 questionnaire responses

Note: displayed questionnaires can be refined at the bottom of this screen

Alerts for: eRAPID Toxicity (4.50)
 ALERT: 25-Feb-2014 SevereChills
 ALERT: 25-Feb-2014 SevereTemperatureChills

Record Response to alert

Tabulated Results | Administration

eRAPID Toxicity (4.5)

Scores

Pain (1=mild 2=moderate 3=severe)
 3
2
1
0
06-Mar 06-Apr 20-Apr 04-May

Vomiting (1=mild 2=moderate 3=severe)
 3
2
1
0
06-Mar 06-Apr 20-Apr 04-May

Nausea (1=mild 2=moderate 3=severe)
 3
2
1
0

Diarrhoea (1=mild 2=moderate 3=severe)
 3
2
1
0

Click on 'Tabulated results' to view data in a table.

Results

Scores	06-Jun-2014	02-Jun-2014	17-May-2014	08-May-2014	30-Apr-2014	25-Apr-2014
Pain (1=mild 2=moderate 3=severe)	1	1	1	0	0	0
Vomiting (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Nausea (1=mild 2=moderate 3=severe)	1	1	0	1	0	0
Diarrhoea (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Constipation (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Mucositis (1=mild 2=moderate 3=severe)	1	1	1	0	1	1
Temperature (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Chills (1=mild 2=moderate 3=severe)	0	0	0	1	0	0
Difficulty with physical ability (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Lack of appetite (1=mild 2=moderate 3=severe)	0	0	0	0	0	0
Fatigue (1=mild 2=moderate 3=severe)	1	1	0	1	1	1
Difficulty sleeping (1=mild 2=moderate 3=severe)	0	1	1	1	1	1
Shortness of breath (1=mild 2=moderate 3=severe)						
Sore hands/feet (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)						
Leg weakness (1=mild 2=moderate 3=severe)						
Seizures (1=mild 2=moderate 3=severe)						
Passing out						

The screenshot shows the eRAPID clinical trial interface. On the left, a list of symptoms is displayed, including 'Injection', 'Phlebitis', and various 'Other symptom - check tabulated results' entries. On the right, a table shows the results for these symptoms over time, with columns for dates from 06 Jun 2014 to 25 Apr 2014. A callout box points to the 'Other symptom' entries in the table, stating: 'Other' symptoms that patients report are listed in the table. E.g. dizziness and sore throat were reported by this patient.

Question	06 Jun 2014	02 Jun 2014	17 May 2014	08 May 2014	30 Apr 2014	25 Apr 2014
Injection (1=mild 2=moderate 3=severe)			1	1		
Phlebitis (1=mild 2=moderate 3=severe)						
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		Muscle aches		Sore throat	Sore throat	Painful throat
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		2		1	1	3
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		Sore throat	Painful throat			Sore back if toungue
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		1	2			2
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		Dizzy head		Dizzy		
Other symptom - check tabulated results (1=mild 2=moderate 3=severe 4=very severe)		1		1		

Note

- Results displayed were correct as of 12-Dec-2014 15:32
- All results shown are patient reported unless indicated otherwise
- QTool is checked for new completed questionnaires every 5 minutes
- A cross is displayed on a graph to denote an unanswered question

Some advice on using the information during consultations and discussions with patients:

- Please remember to tell the patient you are using or have looked at the symptom reports they have provided
- The patient information is most useful if it has been completed regularly (we are asking eRAPID study participants to complete the questionnaire on a weekly basis). Patients are more likely to complete the symptom questionnaire if they see it is being used by staff.
- The information should be used to guide conversations with patients- feel free to ask patients to clarify their answers and check whether your interpretation of the results matches that of the patient.

6. The eRAPID RCT in systemic cancer treatment

Timeframe

Recruitment will take place from January 2015- December 2017.

Eligible patients

Adult patients attending St James' University Hospital Bexley Wing with

- early breast or colorectal cancer requiring adjuvant systemic treatment or
- gynaecological cancer requiring chemotherapy

Sample and study design

- We aim to recruit a maximum of 568 patients to the study.
- This will be a prospective randomised parallel group design study with repeated measures and mixed methods and will include an internal pilot phase.
- Participants will be randomised (following a 1:1 randomisation strategy) to receive the eRAPID intervention or usual care.

Participants in the intervention arm will receive training in using the eRAPID system to report their symptoms and side effects (at least on a weekly basis) from home via the internet whilst they are receiving treatment. Hospital staff will be able to review eRAPID reports and use the information in the decision-making process when seeing patients in clinic or answering phone calls. Alerts will also be sent to the relevant clinical team when severe symptoms are reported by patients.

Study outcome measures

This study will use several outcomes to compare the eRAPID intervention with usual care:

Clinical outcomes and process of care measures (e.g. number of hospital contacts including admissions, clinic appointments, phone calls with hospital staff and changes to supportive medications and chemotherapy dose change).

Patient-reported outcomes

We will assess overall quality of life using validated questionnaires and appropriate subscales

We will also assess participants' views of their ability to manage and control their treatment related side effects with a number of measures assessing self-efficacy and patient activation.

Costs to patients and the NHS

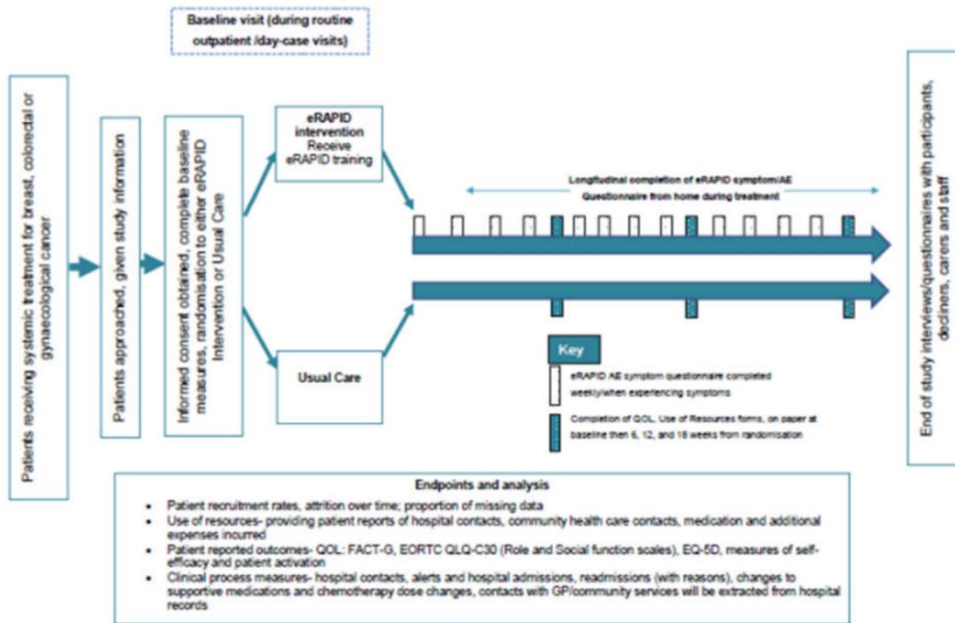
Resource use will be assessed using patient questionnaires detailing contacts with GPs/community services, hospital visits and patient incurred costs.

Patient and staff interviews

Semi-structured staff, patients and carer interviews will be conducted to explore experiences of using the eRAPID intervention and any recommendations for improvement.

All participants will be asked to complete study measures at baseline, 6, 12 and 18 weeks.

Figure 3. eRAPID RCT diagram



7. Frequently asked questions

Below are some commonly asked questions about eRAPID.

What is expected of me during the eRAPID study?

Members of staff will be using the eRAPID patient information in different ways during the study. We will be encouraging doctors and nurses who have consultations and chemotherapy review assessments with eRAPID participants to use the patient reported information during their discussions with patients.

A small number of staff will be sent email alerts when study participants report severe symptoms. These staff members will receive specific training from the study team and will be asked to record their response to alerts in PPM.

We hope other members of staff (such as nurse practitioners who take phone calls from patients) may also use the patient reported symptom information and we would like staff to record in PPM if they used the eRAPID information or if the patient mentions being on the study. This will help us identify if eRAPID is helping patients make decisions about managing their symptoms and contacting the hospital.

eRAPID is a research study and it is important that we gather feedback from both patient participants and staff on their views of this new system for collecting and using patient reported information. Therefore we will be asking staff for their views of eRAPID during the study, either by a brief questionnaire or interview to determine how eRAPID is being used and suggestions for improvements.

Will eRAPID replace routine consultations and contacts with hospital staff?

eRAPID is not a replacement for usual care. The aim is for eRAPID to become an additional tool to assist with clinical decision making and patient symptom monitoring over time.

Will having to access results and discussing them with patients add to the consultation time?

Our previous research using patient reported data was in oncology clinics demonstrated that consultations times were not significantly increased in length. We hope that the patient reported

data collected in eRAPID will help make consultations efficient as the information can be used to assist with identify key problems and aid communication about symptoms and adverse events.

Will research staff be available if I have issues with accessing patient information in PPM?

During the study the research team will be recruiting and following up study participants in outpatients and day case wards. Please feel free to ask any of the team for help or advice if you are experiencing any issues. Alternatively you can contact the team using the number or email address below and we will aim to respond to your query as soon as possible (during normal working hours).

What do I do if a patient asks for help using eRAPID?

It is the responsibility of the research team to train participants in logging in and using the eRAPID online system. If a study participant is having problems accessing or using eRAPID then please ask them to contact the research team using the phone number or email address provided in the participant user guide and login postcard.

Is the information patients provide on the internet secure?

The answers patients provide to the symptom questionnaire during the eRAPID study will be linked to their electronic health record in PPM and the clinical staff will be able to access these. The answers provided will also be stored on secure databases within the University of Leeds, but they will be anonymous and confidential.

The research team:

Professor Galina Velikova, Chief Investigator

Kate Absolom, Senior Research Fellow

Andrea Gibson, Research Sister

Marie Holmes, Research Assistant

Beverly Horne, Senior Research Nurse

Zoe Rogers, Research Assistant

Lorraine Warrington, Research Assistant

To contact us please:

Email: [REDACTED]

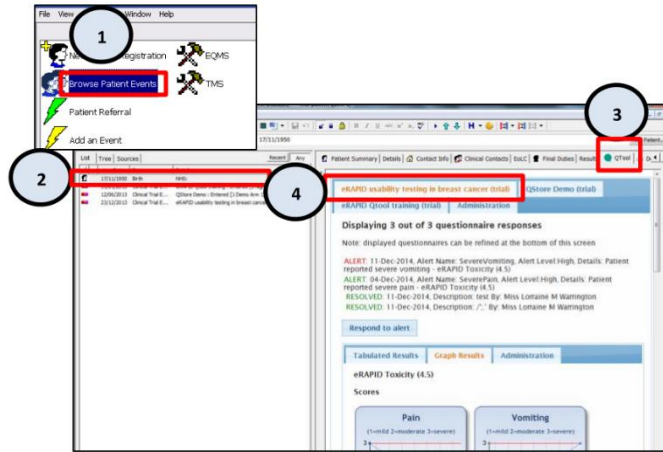
Telephone: [REDACTED]

[REDACTED]

Figure 2: Staff training manual

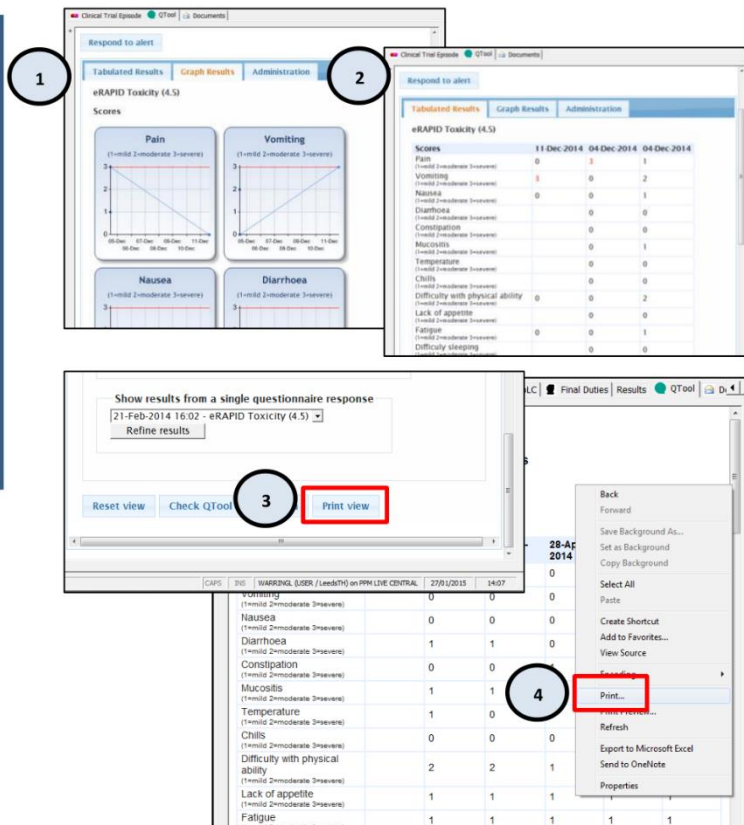
In the patient browser:

- 1) Find the patient.
- 2) Ensure the "Birth" event is selected in the left-hand events screen
- 3) The "QTool" tab will appear in the right-hand panel. Click on this to bring up the questionnaire responses.
- 4) Ensure the correct trial "eRAPID RCT in systemic therapy" is selected.



You can then:

- 1) View patient's responses in graph form.
- 2) View the results in tabulated form.
- 3) Print results by scrolling to the bottom of the page and clicking "Print view".
- 4) You can then use the right click on the mouse and select "Print".



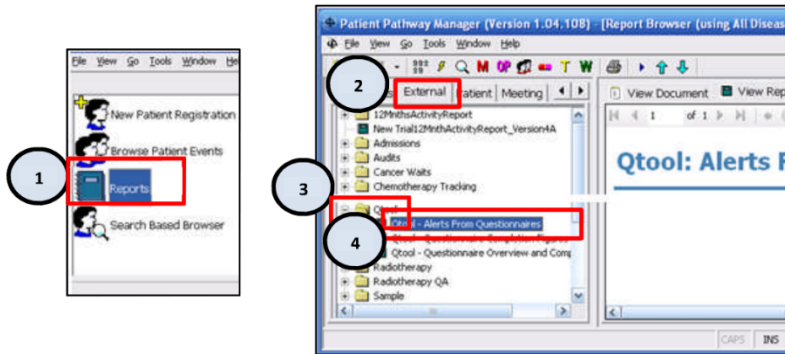


Accessing the eRAPID patient alerts report in PPM

At PPM

Switchboard (first time)

- 1) Select 'Reports'
- 2) Select 'External' tab
- 3) Expand 'QTool' folder
- 4) Select 'QTool – Alerts from Questionnaires'

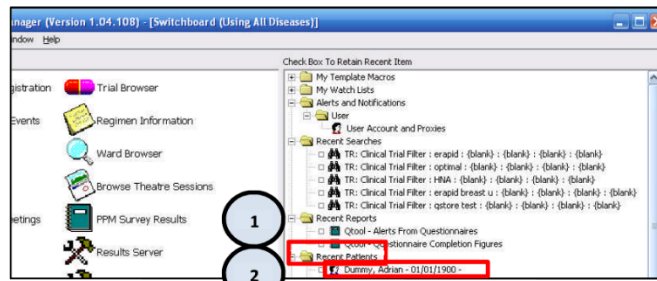


After you have accessed the reports once, you can follow these steps thereafter which will be quicker.

At PPM

Switchboard

- 1) Locate 'Recent Reports'
- 2) Select 'QTool – Alerts from Questionnaires'



Accessing eRAPID patient symptom reports and alert details

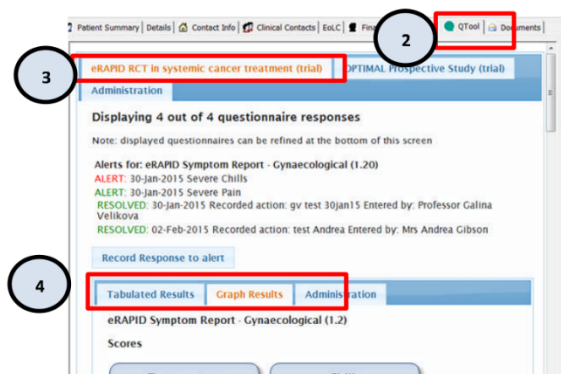
From alert report

- 1) Click on patients name to link to patients record and QTool results.
- 2) The "QTool" tab will appear in the right-hand panel. Click on this to bring up the questionnaire responses.
- 3) Ensure the correct trial "eRAPID RCT in systemic cancer treatment" is selected.
- 4) You can view results in graph or tabulated form by clicking on the tabs.

Qtool: Alerts From Questionnaires

N.B. (1) Items in blue are clickable hyperlinks to the relevant PPM record (the PatientID links the subject to their relevant trial episode - click on PPM QTool tab to see QTool record). (2) The QTool Participant Name lookup list is filtered by the 'Specify a trial' value. The default value is 'All'.

Has the alert	Patient name	QTool user name	Questionnaire	Date of questionnaire completion	Patient reported symptom	Has the alert been cancelled by the patient
	Dummy, Albert	sedyng	eRAPID Symptom Report - Breast	23/01/2015	Severe Extravasation	No
				26/01/2015	Severe Lack of appetite	No
				26/01/2015	Severe Lack of appetite	No
Unresolved	quest 1, trial patient	ivoref	eRAPID Symptom Report - Colorectal	19/01/2015	Severe Vomiting	No
				20/01/2015	Severe Pain	No





To document that you have responded to an alert

To respond to an alert

- 1) Click "Record response to alert"
- 2) Click "Add response" below the alert you wish to respond to.
- 3) Tick the "Resolved" box ONLY if you are
- 4) Notate the text box with the action taken and your name if you are not the person logged into PPM, and then click save.
- 5) The alert will now show as resolved and will be colour coded green.
- 6) You can add another note to the alert if needed by repeating the process.

The figure consists of three screenshots from the eRAPID web application, illustrating the steps to respond to an alert. The first screenshot shows the 'Administration' tab of an 'eRAPID Symptom Report - Gynaecological (1.2)' with a list of alerts. A red box highlights the 'Record Response to alert' button, which is also circled with a '1'. The second screenshot shows the 'Setup responses to patient alerts' section with a list of alerts. A red box highlights the 'Add response' button, which is also circled with a '2'. The third screenshot shows the 'Record clinical response to alert' form. A red box highlights the 'Resolved' checkbox and the 'Save' button, which are also circled with a '3 & 4'. The form includes a text box for the description of action taken and a 'Back' button at the bottom.

V1.1 04/02/2015

Figure 3: One page staff prompt sheets

Formal training consisted of one on one sessions and group sessions including power point presentations and practical demonstrations in accessing the results within the EHR.

Informal training involved the research team attending clinic sessions offering ad hoc refresher sessions and introductions for new clinical staff members.

All clinical staff who received formal training completed an evaluation form which was evaluated by the research staff to inform changes to training. This ensured the training remained relevant and easily accessible.



Staff Training Evaluation Form

I am a: CNS Staff Nurse Other Please specify

Please indicate your impressions of the items listed below.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The training met my expectations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I will be able to apply the knowledge learned.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The training objectives were identified and followed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The content was organised and easy to follow.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The materials distributed were pertinent and useful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. The trainer was knowledgeable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. The quality of instruction was good.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. The trainer met the training objectives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Class participation and interaction were encouraged.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Adequate time was provided for questions and discussion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. How do you rate the training overall?					
Excellent Good Average Poor Very poor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. What aspects of the training could be improved?					
11. Other comments?					

THANK YOU FOR YOUR PARTICIPATION

Figure 4: Staff training evaluation form

Attendance certificates signed by the P.I. were provided for staff to add to their training portfolio.

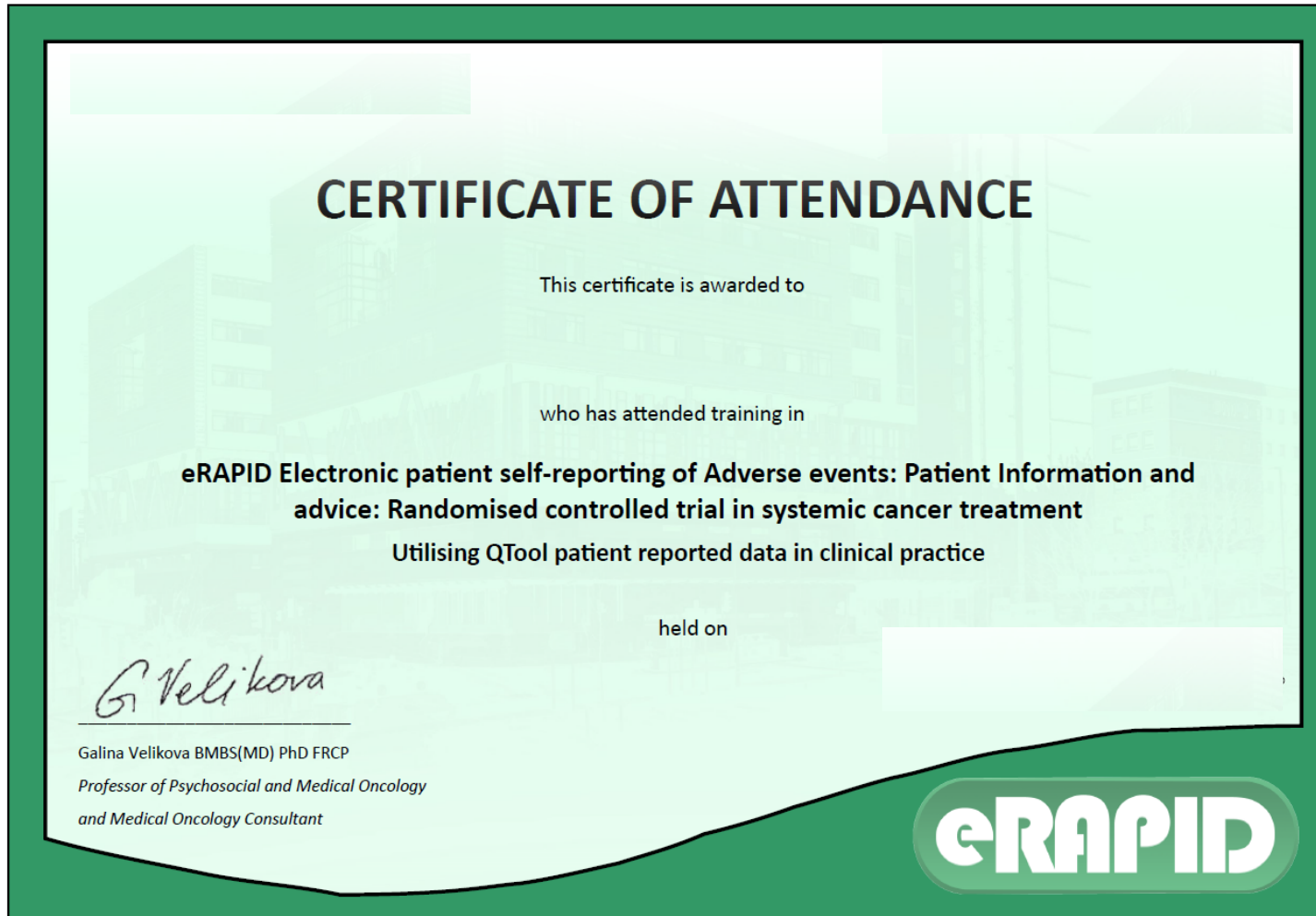


Figure 5: Attendance certificate

Key personnel within the clinical teams were identified as 'eRAPID Champions'. Regular communication with these staff members contributed to continued staff engagement and fostered an environment of collaboration.

Development of eRAPID staff eLearning module

Based on feedback from staff interviews following the pilot study an eLearning package was developed in 2016 which was available online in December 2017. The resource was made available via a hyperlink from within the QTool symptom report section of the EHR at Leeds.

https://onlinecourses.leeds.ac.uk/eRAPID_training/index.html

Articulate software was used as the platform for the module (following a suggestion from co-applicant Dr Liz Glidewell). Key members of the research team worked in collaboration with Liz Glidewell to develop an overview/story board outline for the content of the training; though this was shaped by what was technically feasible to create and display within the software package.

The content and its presentations was guided by fundamental theories of adult learning¹ and built on a previous interactive staff training course we had piloted in Leeds². Clinical and research staff reviewed the content prior to online publication and amendments made accordingly.

The eLearning package consists of seven individual sections which the user can access in any order depending on time constraints and specific learning needs:

- Introduction to eRAPID
- How do I access and use the eRAPID symptoms report?
- eRAPID patient data in practice (clinical vignettes of a breast, colorectal and gynae cancer patient along with complementary QTool symptoms reports based on real-life patient case studies)
- Co-development of eRAPID with staff and patients
- How are we evaluating eRAPID?
- What is the value of Patient Reported Outcomes Measures (PROMs)
- eRAPID quiz.



The main didactic elements of the eLearning covers the purpose of eRAPID, practical steps for accessing results in the EHR and basic information on PROMs

and evidence supporting their use in cancer care. In addition the interactive case studies give the user an opportunity to reflect on the interpretation of example symptom reports and about how this might add to understanding the patient experience and guide the focus on a clinical consultation.

The eLearning allows flexibility in how the training can be delivered including an opportunity for blended learning (to supplement face-to-face training) or used as a standalone resource as needed (supporting self-directed learning).

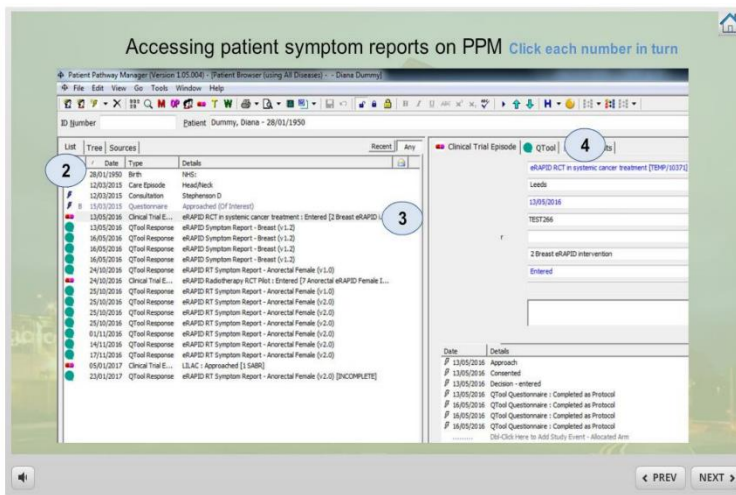
The eRAPID (Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice) online learning course.

Thank you for choosing to visit the eRAPID online learning course.

- ❖ You can navigate the 8 modules in any order.
- ❖ Click on the home icon button  to return to the module menu.
- ❖ Click on the next button  to enter the modules.

A) Front main menu

Accessing patient symptom reports on PPM [Click each number in turn](#)



Date	Type	Details
28/01/1990	Birth	Male
12/03/2015	Care Episode	Head/Neck
12/03/2015	Consultation	Stephenson O
13/03/2015	Questionnaire	Approached (27 Intervent)
13/05/2016	Clinical Trial E...	eRAPID RCT in systemic cancer treatment : Entered (2 Breast eRAPID
13/05/2016	QTool Response	eRAPID Symptom Report - Breast (v1.2)
16/05/2016	QTool Response	eRAPID Symptom Report - Breast (v1.2)
16/05/2016	QTool Response	eRAPID Symptom Report - Breast (v1.2)
16/05/2016	QTool Response	eRAPID Symptom Report - Breast (v1.2)
24/10/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
24/10/2016	Clinical Trial E...	eRAPID Radiotherapy RCT P04 : Entered (7 Anorectal eRAPID Female L...
25/10/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
25/10/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
25/10/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
25/10/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
01/11/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
14/11/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
17/11/2016	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2)
05/01/2017	Clinical Trial E...	LSAC : Approached (1 eRAPID)
23/01/2017	QTool Response	eRAPID RT Symptom Report - Anorectal Female (v1.2) [INCOMPLETE]

B) How to access patient results in EHR



C) Clinical nurse specialist discussing eRAPID with PI

Patients comments on using the eRAPID system

My chemotherapy doctor would talk me through my results and any concerns that he had. This reincentivised me to use the system.

It gives you permission and that's what I liked about it, you think, am I making a fuss? It actually gives you permission to contact the hospital.

Reassurance when you can't sleep on steroids, sometimes you don't want to disturb everybody else. Almost like a chemo buddy in the night.

I think it creates an empathy between patient and hospital. I did feel a bit guilty phoning but both the doctor and nurse said I did the right thing.


It just felt like part of my routine, to know that it was there for me all this information and that it would guide me. It would give you that confidence.

I liked being able to see the graphs and I think the descriptions were good.

< PREV NEXT >

D) Patient comments on using eRAPID

Colorectal case study data in QTool



Tony Stark is a 43 year old man who is online symptom reporting as part of the eRAPID study.

Diagnosis: Adenocarcinoma distal sigmoid colon, anterior resection, pT3 (6mm), N1 (1/27), V0, R0 (CRM 2mm), M0.

PMH: Taking selective serotonin reuptake inhibitors for depression.

Treatment Plan: Adjuvant chemotherapy . For at least 6 and up to 9 fortnightly cycles of adjuvant OxMdG (Oxaliplatin plus 5FU) chemotherapy.

Click on Tony

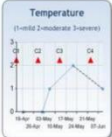
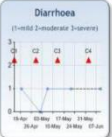
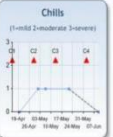
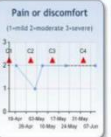
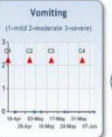
The following slides show his online symptom reporting through 4 cycles of chemotherapy.

< PREV NEXT >

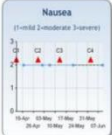

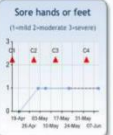
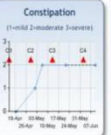
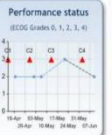
E) Example of a case study

Colorectal case study data in QTool [Click each number in turn](#)

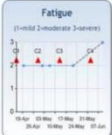
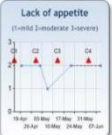
1

2

3

4

< PREV NEXT >

F) Example of patient results in EHR

Colorectal case study data in QTool

Question	09-Jun-2015 (Latest)	21-May-2015	21-May-2015	06-May-2015	01-May-2015	19-Apr-2015
Site of pain	Stomach		Stomach, joints	Stomach	Tummy	Legs, stomach, bowel
Other symptom (1=mild 2=moderate 3=severe 4=very severe)				Spasms in hands	Spasms in eye, throat and hands	
Severity (1=mild 2= moderate 3=severe 4=very severe)				2	2	

Things to consider when using the symptom report data:

- ❖ Patient reported data is presented in graphical, tabulated and freetext form.
- ❖ It is important to thank patients for completing the symptoms and that you are using or have looked at the symptom reports they have provided.
- ❖ The information should be used to guide conversations with patients - feel free to ask patients to clarify their answers and check whether your interpretation of the results matches that of the patient.

G) Example of patient free text comments in EHR

What is the aim of eRAPID?

- To remotely monitor symptoms of cancer patients in remission
- To improve the monitoring and management of symptoms and side effects related to cancer treatment
- To publish information cancer patients normally receive about symptoms online rather than paper





H) eRAPID Quiz

Figure 6: Screenshots from eRAPID eLearning module

References

1. Kaufman DM. ABC of learning and teaching in medicine - Applying educational theory in practice. *Bmj-Brit Med J* 2003;**326**:213-6. <https://doi.org/DOI> 10.1136/bmj.326.7382.213
2. Santana MJ, Haverman L, Absolom K, Takeuchi E, Feeny D, Grootenhuis M, *et al.* Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Quality of Life Research* 2015;**24**:1707-18. <https://doi.org/10.1007/s11136-014-0903-5>