

eRAPID Systemic development work

Overview of eRAPID programme development grant (2011-2013)

The eRAPID systemic development work took place over 18 months during 2011-2013 funded by NIHR PDG scheme RP-DG-1209-1003. This section provides a brief overview of the developmental work completed during this phase and how this was subsequently built upon in the initial phases of the eRAPID programme grant.

Mapping professional and care pathways

Existing patient care pathways for the management of AE at St. James University Hospital were mapped in order to identify how eRAPID could be most effectively integrated. In order to map clinical pathways, patients (n=26), carers (n=6) and staff (n=15) at varying stages of the treatment trajectory were interviewed. An audit of the newly introduced local acute oncology service was undertaken, focusing on the telephone triage system. Patients who had unplanned admissions were asked to complete a survey about their experiences (n=40), and a sub-set (n=26) completed interviews to further explore their experiences. This audit is described in detail in a published paper.¹

In addition, methods of collecting patient information on contacts with healthcare outside of the hospital and health economics data on additional costs patients encountered as a result of their chemotherapy (e.g. non-prescription medications, travelling costs etc.) were piloted.

Development of the AE items

To identify the most common AE experienced by patients with breast, gynaecological, colorectal, lung and renal cancer which would be suitable for self-reporting, an extensive literature review was undertaken, in addition to analysis of a databank of 800 cancer patients' consultations. Sixteen common AE were identified and a further three item areas were added after consultation with clinical and patient representatives. Self-report items were developed for each AE, using criteria which mapped directly on the Common Terminology Criteria for Adverse Events (CTCAE). The CTCAE is commonly used by clinicians to grade patients' chemotherapy toxicities.

It was essential that patient self-reporting could map onto the CTCAE, in order for them to be clinically relevant to staff, and so that clear guidelines for necessary medical intervention could be established based on existing practice.

In order to evaluate the items for comprehensibility and relevance to patients, cognitive interviews were undertaken. Sixty patients purposively sampled by age, gender and tumour group (median age 61.5, range 35–84, 12 breast, 12 gynaecological, 13 colorectal, 12 lung and 11 renal) participated. Patients were asked to complete all items on a touch-screen computer prior to taking part in an audio-recorded cognitive interview to explore understanding of each item. Following interviews, 33 amendments were made. 29% of changes related to question comprehension, 68% to response options and 3% to order effects. These amendments to phrasing and language improved patient understanding but maintained CTCAE grading and key medical information. The cognitive interviews are described in detail in a published paper.²

Development of self-management advice

Self-management advice for each AE was collated from local and national guidelines and reputable websites. This advice was evolved into two forms – brief, immediate advice to be displayed at the end of the self-report questionnaire for reported symptoms, and more detailed advice (lifestyle advice etc.) for each symptom to be displayed on a separate website for patients to browse at their leisure. Self-management advice was iteratively reviewed by the local RAG (N=9), clinical staff (N=19) and patients actively receiving chemotherapy (N=13) to ensure comprehensibility and clinical relevance. Verbal and written feedback was collated and reviewed. The website was completed in September 2013 and only minor changes to content were made following this to keep content up to date with local guidelines.

Development of the IT systems

As described in Section 2 of this report, an existing web-based questionnaire tool (QTool³) was further developed to meet the needs of eRAPID⁴. The main development needed was the facility to provide automated, tailored advice based on scoring algorithms in response to patient symptom reports, in addition to general improvement of usability and functionality. The team worked closely with X-Lab (the software developers who built Qtool) to incorporate new functionality using scoring and dependencies to facilitate the use of scoring algorithms, which could then be used to display automated advice based on questionnaire responses.

Development of the algorithms

In addition to self-management advice where appropriate, guidelines were developed to identify thresholds for advising patients when to contact the hospital and when to self-manage. These were designed in keeping with local and national guidelines and were further developed into a set of algorithms to allow for automated tailored advice on the online system. The finalised algorithms are described in more detail below.

Additional refinement to the eRAPID systemic intervention prior commencing the RCT (2013- 2015)

During the initial stages of the eRAPID programme grant, the research team made further refinements to the intervention prior to commencement of the randomised controlled trial. An overview of activities conducted between 2013-2015 is described in Table 1.

Table 1 Overview of systemic intervention development prior to commencing RCT

	Activity
2013	Further IT development Creation of eRAPID login homepage and information website (completed September 2013- see Section 2 for more details) Refinement of QTool symptom reports-drop down options for additional symptoms reporting Refinement of QStore functionality and data display
	Consensus meetings conducted with colorectal/breast/gynae clinical teams to select items for symptom report and allocate severity grading
	Local R&D approval obtained for clinical usability of eRAPID intervention in breast clinic
2014	Clinical usability testing in breast clinic conducted (January-April)
	RCT protocol submitted for ethical REC approval
	REC approval obtained with minor amendments (August)
	Full REC approval received (September)
	Finalised QTool symptoms reports and scoring algorithms completed (October)
	Patient symptom report reminder system (via text/email) developed (completed December)
2015	eRAPID staff training begins
	RCT open to recruitment (January)

Further IT developments

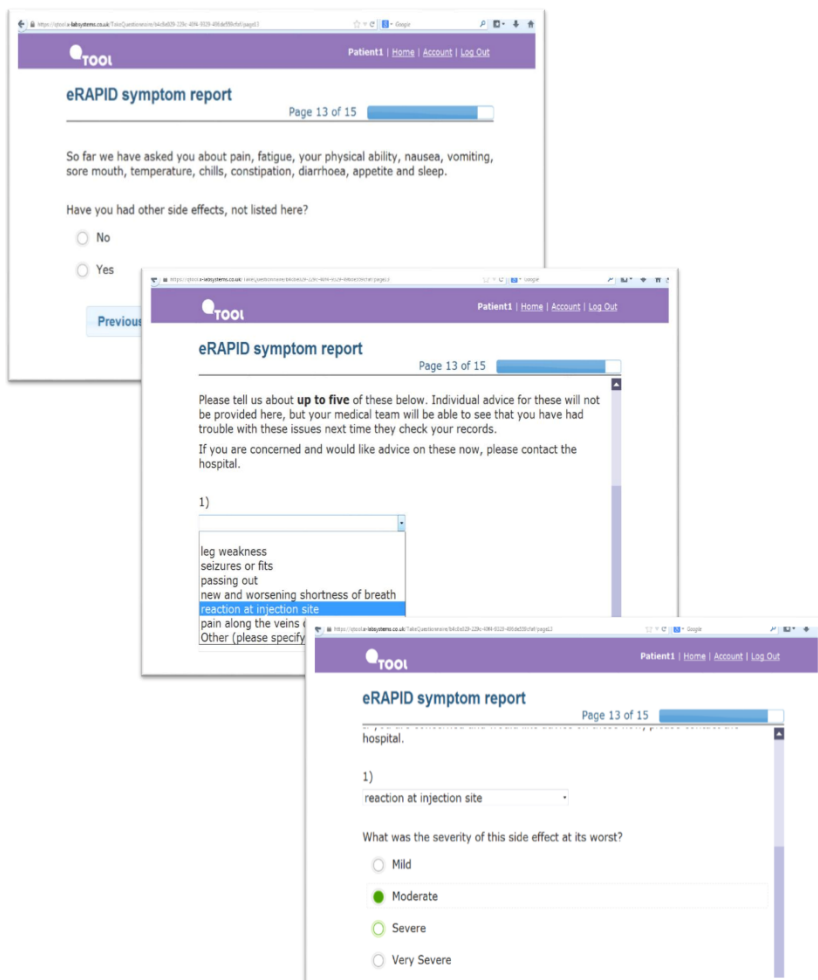
One of the challenges identified from the usability testing was the need for symptom reports to be capable of recording clinically significant and common AE and maintaining the ability to capture wider problems patients may experience- whilst trying to keep the questionnaires brief and limit completion burden.

Strategies to overcome this were investigated and a solution utilising optional dropdown menus was introduced. Dropdown menus could be included at the end of the main questionnaire and gave patients the option of reporting less common

toxicities. For example, if patients answered 'Yes' to the question 'Have you had any other symptoms', a series of dropdown menus would appear from which patients could select AE they had experienced not listed in the main questionnaire (see *Figure 1*)

Any symptoms which patients report via these dropdowns could then be treated in the same way as symptoms reported in the main questionnaire for the algorithms and advice provided. The addition of these questions required further development and testing of the algorithms which was undertaken by the eRAPID research team.

Figure 1 Dropdown questions option at end of main eRAPID systemic symptom reports



Refinement of QStore

The QStore interface was tested by members of the eRAPID research team (N=6) and changes were made to make this more user friendly for both researchers setting up studies, and for clinicians to access and interpret patient reported data.

These changes were mainly related to improving language (e.g. removing technical terms) and streamlining some of the more commonly used processes to make them more intuitive.

Finalising symptom report items and algorithms

An iterative approach was adopted to finalise items and algorithms, utilising consensus meetings with clinicians from each of the relevant disease groups (Colorectal consultant oncologists (N=2), Gynae consultant oncologists (N=2), Breast consultant oncologists (N=2). Clinicians were asked to review draft versions of the eRAPID questionnaires and provide feedback on the relevance of the items and to identify any additional AE that should be included. In addition, following the introduction of the dropdown menus, clinicians were asked to advice on which items would be better as part of the main questionnaire, and which would be suitable for inclusion in the dropdown menus.

A priority list of all items in each questionnaire was also generated to determine the order that advice should be shown in (see Table 5 for more detail)⁵.

In order to finalise the algorithms for symptom advice, clinicians were also asked to set 'levels' for each of the items included. These levels are then used to calculate algorithms to determine the advice displayed to patients.

Each question response is allocated a level of 1, 2 or 3, with three being the most severe:

- Level 1 - a number of mild and/or moderate problems, self-management is appropriate. Advice - self-management with shorter pre-amble
- Level 2 - potentially serious medical problem, need attention but not emergency admission. Advice – please contact the hospital when convenient to discuss your symptoms

- Level 3 - potential medical emergency. Advice – please contact the hospital now, you may need admission. The suggestion for admission generated a lot of comments, upset some patients. Discussed whether to keep the colour Red or Blue and whether to change the words. Decided to keep Red but to remove the words suggesting admission.

Following the clinical usability testing (described below) we introduced an additional branching questions to determine if clinically severe symptoms were currently being experienced or had been experienced (within the last seven days) but had now improved. If improved, the severity level is downgraded to Level 2.

Not all questions were allocated a Level 3 response. For example, although difficulty sleeping is a disruptive symptom for many patients, it is less clinically important in terms of safely delivering chemotherapy, and as such does not have a Level 3 response (see Table 2)

Table 2 Example of eRAPID symptom question and corresponding severity level

Question	Response wording	Severity level
Diarrhoea		
Have you had diarrhoea (loose or watery stools)?	No	0
	I have had diarrhoea and opened my bowels 2-3 times more in a 24 hour period than is normal for me	1
	I have had diarrhoea and opened my bowels 4-6 times more in a 24 hour period than is normal for me	2
	I have had diarrhoea and opened my bowels over 7 times more in a 24 hour period than is normal for me or I have been incontinent (unable to control my bowels)	3

Difficulty sleeping		
Have you had difficulty sleeping?	No	0
	I occasionally have difficulty falling asleep, staying asleep or I wake too early	1
	I often have difficulty falling asleep, staying asleep or I wake too early	1
	I always have difficulty falling asleep, staying asleep or I wake too early	2

A full list of the final symptom reports for each cancer group can be found below with the assigned severity grading for each response option. The following algorithm framework (Table 3) was then applied to the underlying scoring of the full symptom report to guide the level of patient advice immediately presented to patients.

Table 3 eRAPID systemic RCT symptom report algorithms⁵

Algorithm		Advice
A	One or more severe scores Level 3 item/ response followed by a branching question	<i>Comment - Reworded Red message appears after Level 3 is selected and at the end. Add link to eRAPID website for advice, but do not put specific advice as it may distract from the main message to call the medical team.</i>
A1	This is a current problem	Level 3 advice for current problems <i>Immediate feedback after the item</i> 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 Bleep Holder). Before you contact the hospital and if you feel able, please complete the remaining questions. <i>Feedback at the end</i>

		<p>You have indicated that you have experienced some serious symptoms with:</p> <p>A list is generated by QTool</p> <p>List all Level 3 and Level 2 in priority order</p> <p>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 Bleep Holder).</p> <p>You can also find information and advice about managing your symptoms here.</p> <p>[hyperlink to eRAPID website]</p>
A2	The issue has been improved	<p>Level 3 advice for resolved problems</p> <p>You have indicated that you have experienced some serious symptoms with:</p> <p>A list is generated by QTool</p> <p>List all Level 3 and Level 2 in priority order</p> <p>You have reported that you have been experiencing some serious problems which have now improved. If you have not already been in contact with your medical team, we recommend that you contact them to discuss your symptoms when convenient, or mention them at your next clinic appointment (if in the next 1-2 weeks). If you have already been in touch with your medical team regarding your symptoms, please follow the advice they have given you.</p> <p>You can find some advice on managing your symptoms below.</p> <p><i>List advice for all L3 (resolved) and L2 items.</i></p>

		<p>You can also find information and advice about managing your symptoms here [hyperlink to eRAPID website]</p>
B	<p>No Level 3 Level 2 - 3 or more <i>medically important</i> problems</p>	<p>Level 2 advice</p> <p>You have indicated that you have experienced some serious symptoms with:</p> <p>A list of all Level 2 items is generated by QTool, priority order as in word file 'Priority ratings...'. <i>The top highlighted items are medically important and are to be included in this algorithm. The rest, non-highlighted items are included in Algorithm C.</i></p> <p>If your symptoms are new or have changed recently, please either contact the hospital when convenient to discuss your symptoms with the medical team or mention them at your next clinic appointment (if in the next 1-2 weeks).</p> <p>You can find some advice on managing your symptoms below.</p> <p><i>List advice for all L2 items</i></p> <p>You can also find information and advice about managing your symptoms here. [hyperlink to eRAPID website]</p>
C	<p>No Level 3 scores AND less than three Level 2 scores OR both Level 2 and Level 1 scores</p>	<p>Level 1 advice – self-management</p> <p>You have indicated that you have experienced some mild symptoms with:</p> <p>A list all items is generated by QTool, priority order as in word file 'Priority ratings'</p> <p><i>Pre-amble:</i></p>

<p>OR</p> <p>Level 1 scores only</p>	<p>These symptoms do not require medical attention at present, but there are simple things you can do to help yourself.</p> <p>Please Note:</p> <p>The advice below has been prioritised to address the most important medical issues first.</p> <p>You may be directed to our website for more information.</p> <p>We cannot provide advice for any symptoms you have added yourself in the free-text boxes. If you are worried and would like advice now, please contact the hospital.</p> <p><i>Move to the end, after the specific advice</i></p> <p>Once you have finished reading the advice section, click 'Finish' at the bottom of the screen.</p> <p>You will then be able to:</p> <p>Print any of the advice or send it to an email address.</p> <p>Log out of the system.</p> <p><i>List advice for:</i></p> <p>If L2 item(s)- always add advice in priority order</p> <p>If L2 + L1 items – add advice for two L2 items, plus a maximum of two of L1 items. For L1 items only show a maximum of four L1 items.</p> <p>For the rest – refer to the website.</p>
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		You can also find information and advice about managing your symptoms here . [hyperlink to eRAPID website]
D	No problems at all	Thank you for completing the questionnaire. Please remember to report again in one weeks' time or at any other time you may experience problems.

Clinical usability testing (January – April 2014)

Following development of the eRAPID intervention, clinical usability testing was undertaken in a breast cancer clinic at St James Hospital. The overall purpose of the usability study was to have the end users (staff and patients) use eRAPID in a real life clinical setting. Extensive usability testing had already been undertaken and both patient and staff representatives were involved throughout the development process. A considerable amount of work had also been undertaken to map existing clinical pathways and identify where eRAPID might fit in. However, field usability testing can be a useful tool to troubleshoot practical issues that may not be identified by standard usability testing. This was an important step to streamline some of the complex processes of integrating eRAPID into clinical practice for both patients and staff, prior to the commencement of the RCT. The overall aims of the usability testing were to ensure that:

- 1) training provided to both patients and staff was sufficient and feasible
- 2) that procedures for patient completion and staff access of eRAPID symptom reports were feasible to both parties
- 3) that symptom advice was useful and relevant to patients
- 4) that the safeguards put in place for when severe symptoms were reported by patients were safe and reliable.

The reliability of the eRAPID system from an IT perspective was also assessed. A detailed report of the clinical usability testing is provided in our published paper ⁶.

The testing period ran from mid-January 2014 to mid-March 2014 involving 12 participating patients starting adjuvant or neo-adjuvant chemotherapy treatment for early breast cancer with an age range of 33-73 years (mean 47.5 years, SD=10.3).

Ten members of the breast care clinical team participated in the assessment including two adjuvant breast CNSs and eight doctors who accessed patient eRAPID symptom reports at routine clinic appointments (four senior oncologists (consultants), four oncology trainees).

Overall the clinical field testing indicated that the eRAPID intervention functioned as expected in practical terms and was deemed acceptable to patients. A number of important learning points were gained from this exercise that fine-tuned the intervention from the patient and staff perspective and a description of the main issues identified and the actions taken to resolve them are summarised in Table 4.

Table 4 Issues identified during clinical usability testing and actions taken (adapted from Warrington *et al* BMJ Open 2019)

	Issue identified	Actions taken
Patient adherence to weekly reporting	Adherence with weekly symptom reports was variable. Patients reported that they: Forgot/didn't see the point in completing when well/ sometimes did not feel well enough to complete/were unsure how often to complete	A text and email reminder system was implemented Patient training was adapted to emphasise the reasons for weekly completion, even when not experiencing symptoms
Alerts	Alerts were triggered for physical ability when neither patient nor clinician felt it was needed. Alerts could be generated for severe levels of AE that were experienced at any time during the last 7 days, including those issues which had already been resolved. This resulted in several 'false' alerts being triggered.	Thresholds for sending alerts for 'physical ability' were adapted Branching questions asking 'Is this a current problem?' were added as a further step before sending alerts to clinicians. See Figure 2 for illustration. Additional branching questions were added for physical ability and fatigue to determine whether the patient had

	Alerts triggered but then no evidence in PPM reports due to patient amending their response. Retracted alerts should still be documented in the reports.	sufficient support at home to manage Report was amended to show retracted alerts
Usability of patient interface	Graphs for symptom reported in the dropdown lists look a little out of place when not reported regularly Symptom names on graphs don't always correspond with those on the questionnaire Confusion with some wording – e.g. the 'Email your feedback' link. Patients expected to provide us with feedback, rather than emailing self-management advice to themselves.	After consultation with an expert on patient interpretation of graphical information (Dr. Yasmina Okan, University of Leeds), we removed graphs for symptoms reported in the dropdown lists as they didn't add much value and were confusing. Changes made to wording to ensure consistency and patient understanding
Usability of clinician interface	Feedback from clinicians indicated that: It would be useful to be able to annotate when alerts have been actioned on. It would be useful to incorporate patients' chemo cycles into the graphs Scores at 0 look like the patient hasn't completed.	The facility for clinicians to annotate when alerts were acted upon was added A triangle indicating each treatment chemo cycle was added to the graphs Changes made to graph display when patients report '0'
Acceptability of symptom report	Patients wanted to provide additional information about symptoms – e.g. when they	Two solutions implemented – Additional branching questions to specify the timing of symptoms

	<p>experienced them or the type of pain they had.</p> <p>Patients wanted to report individual symptoms without having to complete the full questionnaire</p>	<p>Addition of a free-text box to the pain question for more information</p>
<p>Acceptability of self-management advice</p>	<p>Query about what to do if you are following advice and symptoms are not resolving</p> <p>Query about adding additional links to other websites such as Macmillan</p> <p>Query about adding advice on achy veins and hot flushes</p>	<p>Advice added to let your clinical team know if symptoms are not resolving</p> <p>Decided against adding additional links to external websites as it would be too difficult to ensure links were always up to date</p> <p>Advice on achy veins and hot flushes added</p>
<p>Processes of recruitment and training</p>	<p>Patients were happy with the level of training given</p> <p>Patients felt pre-assessment/chemotherapy appointments might be a more suitable time to approach people as they were often quite anxious at the clinic appointment</p> <p>Patients were not always aware when staff were using results</p> <p>Staff reported that symptom report data was much more useful when completed regularly</p>	<p>Changed processes of recruitment for RCT so that patient information sheet was given at clinic appointment, and we would speak to them at pre-assessment.</p> <p>Staff training adapted to encourage staff to let patients know when they were using symptom report data and to encourage patients to complete regularly</p>

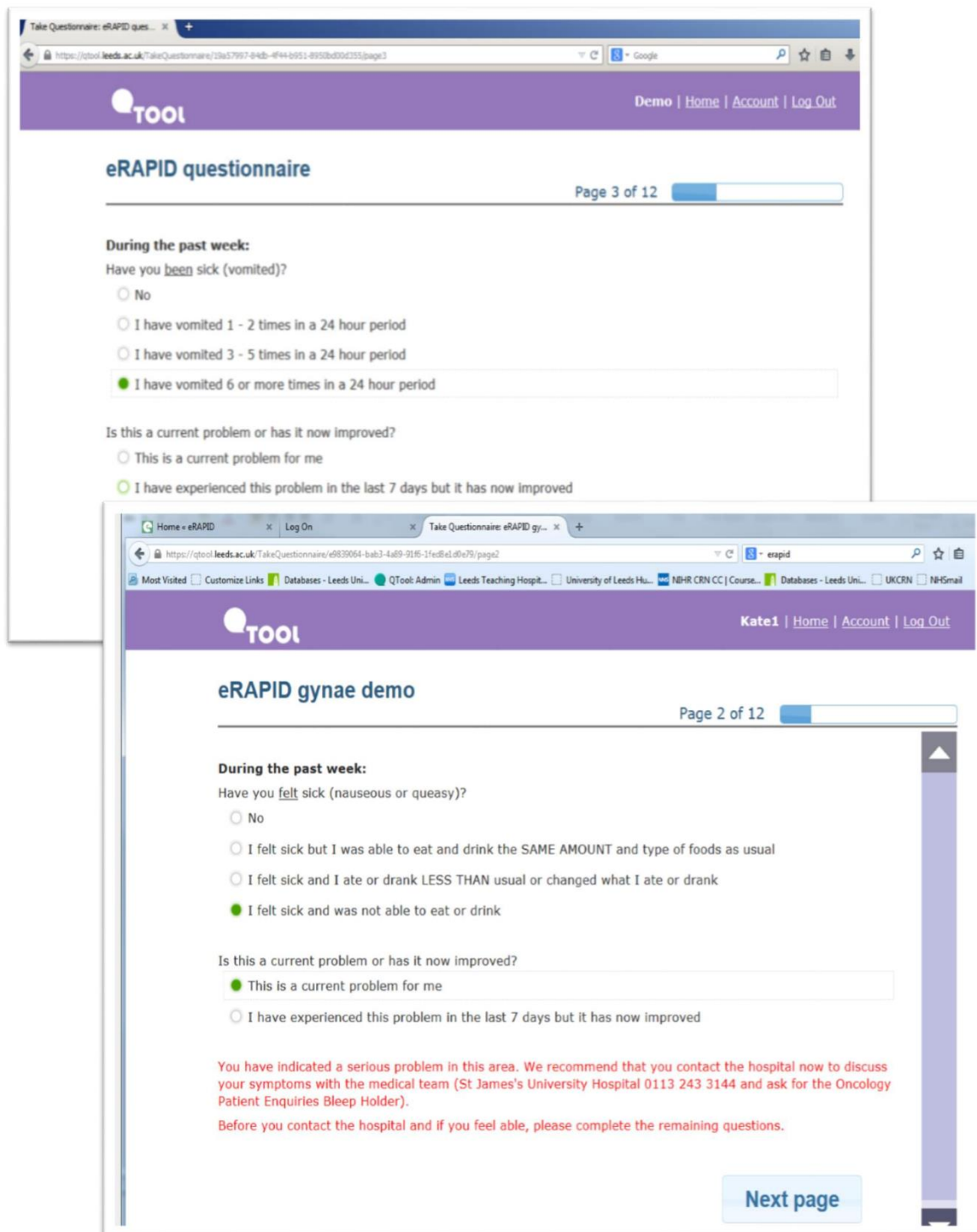


Figure 2 Example of branching questions added

Table 5 Master table of AE items used in symptom report by cancer group

Question	Item (Includes "During the last 7 days" for all standard items)	Dropdown menu wording	Responses	Breast Question type and level	Breast Metastatic Question type and level	Colorectal Question type and level	Gynae Question type and level
Pain	Have you had pain or discomfort anywhere on your body?	n/a	No	Standard	Standard	Standard	Standard
			I had mild pain or discomfort	1	1	1	1
			I had moderate pain or discomfort and I was not able to do some of the things I normally do (e.g. household chores, shopping)	2	2	2	2
			I had severe pain or discomfort and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)	3	3	3	3
Nausea		n/a	No	Standard	Standard	Standard	Standard

	Have you felt sick (nauseous or queasy)?		I felt sick but I was able to eat and drink the same amount and type of foods as usual	1	1	1	1
			I felt sick and I ate or drank less than usual or changed what I ate or drank	2	2	2	2
			I felt sick and was not able to eat or drink	3	3	3	3
Vomiting	Have you been sick (vomited)?	n/a	No	Standard	Standard	Standard	Standard
			I have vomited 1 - 2 times in a 24 hour period	1	1	1	1
			I have vomited 3 - 5 times in a 24 hour period	2	2	2	2
			I have vomited 6 or more times in a 24 hour period	3	3	3	3
Diarrhoea	Have you had diarrhoea (loose or watery stools)?	n/a	No	Standard	Standard	Standard	Standard
			I have had diarrhoea and opened my bowels 2-3 times	1	1	1	1

			more in a 24 hour period than is normal for me				
			I have had diarrhoea and opened my bowels 4-6 times more in a 24 hour period than is normal for me	2	2	3	2
			I have had diarrhoea and opened my bowels over 7 times more in a 24 hour period than is normal for me or I have been incontinent (unable to control my bowels)	3	3	3	3
Constipation	Have you been constipated?	n/a	No	Standard	Standard	Standard	Standard
			I have had occasional constipation which was relieved by changing my diet or taking laxatives	1	1	1	1
			I have had ongoing constipation with stomach discomfort. I was not able to	2	2	2	2

			do some of the things I normally do (e.g. household chores, shopping) and I have changed my diet or taken laxatives every day to relieve the constipation				
			I have had severe ongoing constipation with stomach pain, bloating or feeling sick. I was not able to care for myself (e.g. getting out of bed, bathing, dressing) and it was not relieved by regular laxatives	3	3	3	3
Temperature	Please take your temperature with a thermometer and choose the best answer below	n/a	My temperature is less than 37.0 °C	Standard	Standard	Standard	Standard
			My temperature is between 37.0 °C and 37.5 °C	1	1	1	1
			My temperature is above 37.5 °C but less than 38.0 °C	2	2	2	2

			My temperature is 38.0 °C or above	3	3	3	3
Chills	Have you had shivering, shaking and chattering of teeth?	n/a	No	Standard	Standard	Standard	Standard
			I have felt a little cold with shivering and chattering of teeth	1	1	1	1
			I have felt very cold, with shaking all over my body but this settled very quickly	2	2	2	2
			I have felt very cold, with shaking all over my body for 30 minutes or more	3	3	3	3
Physical Activity	Please select from the options below the statement that best describes your level of physical ability	n/a	I am up and about and can do everything that I could do before my illness without any difficulty	Standard	Standard	Standard	Standard
			I am up and about almost all of the time. I cannot do any heavy physical work but I can	1	1	1	1

	during the past week		do most other things (e.g. household chores, shopping)				
			I am up and about more than half the day; I can look after myself (e.g. getting out of bed, bathing, dressing) but I cannot do much else	2	2	2	2
			I am in bed or in a chair for more than half of the day and I need some help looking after myself	3	3	3	3
			I am in bed or in a chair all the time and I cannot look after myself	3	3	3	3
Appetite	Have you lacked appetite or lost interest in food?	n/a	No	Standard	Standard	Standard	Standard
			I have lacked appetite but I was able to eat and drink the same amount and type of food as usual	1	1	1	1

Stoma yes/no	Do you have a stoma (colostomy bag) or ileostomy?	n/a	Yes- Go to Q7	n/a	n/a	Standard	Standard
			No- Go to Q8	n/a	n/a	n/a	n/a
Stoma diarrhoea	Have you increased the number of times you have had to empty your stoma bag?	n/a	No	n/a	n/a	Standard	Standard
			I'm emptying my stoma bag 2 - 3 times more in a 24 hour period than is normal for me	n/a	n/a	1	1
			I'm emptying my stoma bag 4 - 6 times more in a 24 hour period than is normal for me	n/a	n/a	3	2
			I'm emptying my stoma bag over 7 times more in a 24 hour period than is normal for me	n/a	n/a	3	3
Sore mouth	Have you had a sore mouth or tongue? OR	Sore mouth or tongue	No	Standard	Standard	Standard	Dropdown
			My mouth was a bit sore	1	1	1	1
			My mouth was quite sore but I was still able to eat soft foods and drink fluids	2	2	2	2

	What was the severity of your sore mouth or tongue?		My mouth was very sore and I was not able to eat or drink	3	3	3	3
Sleep	Have you had difficulty sleeping? OR What was the severity of your difficulty sleeping?	Difficulty sleeping	No	Standard	Standard	Dropdown	Standard
			I occasionally have difficulty falling asleep, staying asleep or I wake too early	1	1	1	1
			I often have difficulty falling asleep, staying asleep or I wake too early	1	1	1	1
			I always have difficulty falling asleep, staying asleep or I wake too early	2	2	2	2
Neuropathy	Have you had tingling or numbness in your fingers or toes?	Tingling or numbness in your	No	Dropdown	Standard	Standard	Standard
			I had a bit of tingling or numbness (perhaps when handling cold or hot objects)	1	1	1	1

	OR What was the severity of the tingling or numbness in your fingers or toes?	fingers or toes	I had tingling or numbness and I was not able to do some of the things I normally do (e.g. buttoning up or using cutlery)	1	1	1	1
			I had tingling or numbness and I was not able to carry out daily activities (e.g. I had difficulty walking, dropped things or stepped on things by accident)	2	2	2	2
Taste	What was the severity of your problems with tasting food or drink?	Problems with tasting food or drink	None	Dropdown	Dropdown	Dropdown	Dropdown
			Mild	1	1	1	1
			Moderate	1	1	1	1
			Severe	2	2	2	2
			Very Severe	2	2	2	2
Ascites	What was the the severity of your swelling of the	Swelling of the tummy (abdomen)	None	n/a	n/a	n/a	Dropdown
			Mild	n/a	n/a	n/a	1
			Moderate	n/a	n/a	n/a	2
			Severe	n/a	n/a	n/a	3

	tummy (abdomen)?		Very Severe	n/a	n/a	n/a	3
Indigestion/ Heartburn	What was the severity of your indigestion or heartburn?	Indigestion or heartburn	None	Dropdown	Dropdown	Dropdown	Dropdown
			Mild	1	1	1	1
			Moderate	2	2	2	2
			Severe	3	3	3	3
			Very severe	3	3	3	3
SOB	What was the severity of your shortness of breath?	Shortness of breath	None	Dropdown	Dropdown	Dropdown	Dropdown
			I have been short of breath but only when exerting myself (e.g. climbing stairs)	1	1	1	1
			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 (e.g. household chores, shopping)	2	2	2	2
			I have been short of breath at rest and I was not able to care	3	3	3	3

			for myself (e.g. getting out of bed, bathing, dressing)				
Reaction at injection site	What was the severity of your pain, swelling or redness at injection site?	Pain, swelling or redness at injection site	None	Dropdown	Dropdown	n/a	n/a
			Mild	1	1	n/a	n/a
			Moderate	2	2	n/a	n/a
			Severe	3	3	n/a	n/a
			Very severe	3	3	n/a	n/a
Phlebitis	What was the severity of the pain along the veins of your arm?	Pain along the veins of your arm	None	Dropdown	Dropdown	n/a	n/a
			Mild	1	1	n/a	n/a
			Moderate	1	1	n/a	n/a
			Severe	2	2	n/a	n/a
			Very severe	2	2	n/a	n/a
Sore hands/feet	Have you had soreness or redness of your hands and feet OR	Soreness or redness of your hands or feet	None	Dropdown	Standard	Standard	Dropdown
			My skin was a bit red but was not painful	1	1	1	1
			My skin was painful, red, cracked or peeling and I was not able to do some of the	2	2	2	2

	What was the severity of soreness or redness of your hands or feet?		things I normally do (e.g. household chores, shopping)				
			My skin was very painful and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)	3	3	3	3
Nail changes	What was the severity of your nail changes (discolouration, ridges or bumps)?	Nail changes	None	Dropdown	Dropdown	n/a	Dropdown
			Mild	1	1	n/a	1
			Moderate	1	1	n/a	1
			Severe	2	2	n/a	2
			Very Severe	2	2	n/a	2
Anxiety	What was the severity of your feelings of anxiety (e.g. feelings of dread, restlessness, panic and tension)?	Feelings of anxiety	None	Dropdown	Dropdown	Dropdown	Dropdown
			I occasionally have experienced some of these feelings but they passed or I was able to calm myself down	1	1	1	1
			I have quite often experienced these feelings and they have interfered with my daily	1	1	1	1

			activities (e.g. household chores, shopping)				
			I have frequently experienced these feelings and I am finding it difficult to care for myself (e.g. getting out of bed, bathing, dressing)	2	2	2	2
Low mood	What was the severity of your feeling low in mood (e.g. hopeless, helpless, irritable, guilty or worthless)?	Feeling low in mood	None	Dropdown	Dropdown	Dropdown	Dropdown
			I occasionally felt low in mood but it passed or I could lift myself out of it	1	1	1	1
			I quite often feel low in mood and no longer enjoy things I used to and find it difficult to carry out daily activities (e.g. household chores, shopping)	1	1	1	1
			I have frequently experienced these feelings and I am finding it difficult to care for myself	2	2	2	2

			(e.g. getting out of bed, bathing, dressing)				
Skin rash	What was the severity of your skin rash?	Skin rash	None	n/a	Dropdown	n/a	Dropdown
			I had a small area of skin rash	n/a	1	n/a	1
			I had a skin rash over some of my body and I was not able to do some of the things I normally do (e.g. household chores, shopping)	n/a	2	n/a	2
			I had a skin rash affecting a large area of my body and I was not able to care for myself (getting out of bed, bathing, dressing)	n/a	3	n/a	3
Nosebleeds	Have you had any nosebleeds OR What was the	Nosebleeds	None	n/a	Standard	Dropdown	n/a
			I had a bit of blood from my nose (e.g. after blowing my nose)	n/a	1	1	n/a

	severity of your nosebleeds?		I had quite a bit of nose bleeding that took a while to stop	n/a	2	2	n/a
			My nose is bleeding and I cannot get it to stop	n/a	3	3	n/a
Other symptom	What was the severity of your symptom?	Other	None	Dropdown	Dropdown	Dropdown	Dropdown
			Mild	n/a	n/a	n/a	n/a
			Moderate	n/a	n/a	n/a	n/a
			Severe	n/a	n/a	n/a	n/a
			Very severe	n/a	n/a	n/a	n/a
Dependency questions							
Timing (all questions with level 3)	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					
Support at home (Physical ability and fatigue)	Is there someone with you who can help you take care of yourself?	No, there is no one with me who can help me					
		Yes, there is someone here who can help me					

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