


CURIE/ INDIGO

Timeline and questionnaires



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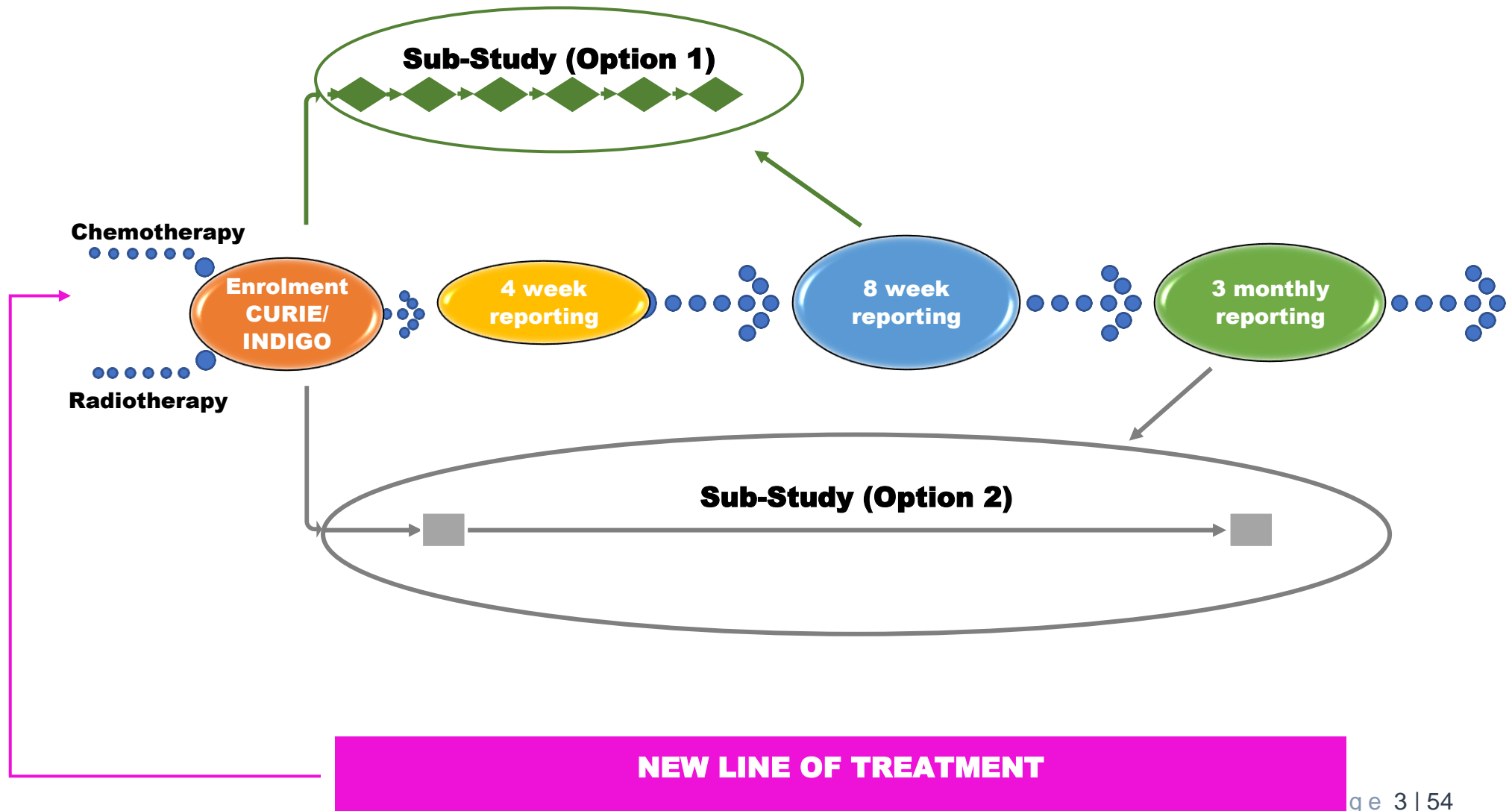
IMPORTANT:

This is an early draft of the questions we will ask and is meant for illustration only. In particular, the wording and response options for some of the questions are meant as placeholders only.

However, it does provide an outline of the process, the online consent form, and the questions that we will be using. Please remember that ALL of CURIE/INDIGO is online – we have provided paper versions to make it easier to visualise and discuss.

Also note that the patient-information sheet and consent process in INDIGO-specific; the process for CURIE is much easier.

Timeline



EXPLANATION OF THE TIMELINE

Schematic diagram of patient pathway for CURIE/ INDIGO. Example case: Patient receives cancer diagnosis and has consented for treatment (chemotherapy). Patient informed of CURIE/ INDIGO by chemotherapy nurse and decides to self-enroll using the online platform available at Trust. The enrolment process goes through some patient details, diagnosis and a set of core questions. The patient has entered that they have been diagnosed with breast cancer therefore the Sub-Study (Option 2 – Breast cancer specific Quality of Life Questionnaire) has been triggered. This optional sub-study requires the patient to complete two additional questionnaires – once at baseline and then again at 3 months. Furthermore, the patient has scored particularly high on their Pain Score and therefore triggered optional enrolment into a Sub-study (Option 1 – 6 weeks of questions specific to pain management). If patient is happy to complete this online consent is required to be completed. Although the patient is now in Sub-study (Option 1) and Sub-study (option 2) they continue the standard CURIE/INDIGO pathway and will receive the core questions again at 4 weeks, 8 weeks and then every 3 months.

In this scenario, the patient can be offered Sub-Study (Option 1) multiple times throughout time in CURIE/ INDIGO as this will be triggered every time the patient scores highly (above a set threshold) on the pain score. If the patient is needed to change onto a new line of treatment, they will come off the current reporting time point and will be taken back to the start of the pathway.

Patient information sheet

INDIGO: Integrating Digital assessments of Global Health Outcomes in cancer patients

PATIENT INFORMATION SHEET

Dr Matt Williams

CONTACT: matt.williams3@nhs.net

You are being invited to take part in a research study. Before you decide if you would like to join, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish.

You are free to ask us if there is anything that remains unclear or if you would like more information.

SUMMARY

Why?

The aim of this study is to explore the use of secure electronic health platforms to carry out digital health research, by assessing our ability to collect patient-reported outcome measures (PROMS) and patient-reported experience measures (PREMS).

What?

PROMS are standardised questionnaires that collect information on symptoms or side-effects of treatment from patients. PREMS collect information on patient experience on their treatment and care. More recently, the growth in digital health technology has allowed us to potentially capture data such as activity and sleep data from patients. In this project, we will use the catch-all term "Patient Reported Data" (PRD) to capture PROMS, PREMS and data from wearable and near-patient sensing devices (e.g. smartwatches).

Who?

You are being invited to take part as you are over the age of 16 and are undergoing treatment for cancer.

Where?

Our intention is to conduct this study alongside your regular clinic visits using the online platform used at your local treating centre therefore there should be no need to make extra trips.

What is the purpose of the study?

We recognise that cancer treatment has the potential to affect your day-to-day life. However, there is a lack of evidence as to which Patient Reported Data (PRD) to collect, how to do so, how to feed those results back to clinical teams. More generally, there is a significant lack of evidence around digital health. INDIGO aims to offer a platform to explore those issues, and evaluate them in a logical fashion, obtaining evidence as robustly as possible. In the future, we hope that this will help us to develop a firm, applicable, pragmatic evidence base on how to collect PRD for adult cancer patients within the UK and therefore enable us to develop our services appropriately.

Why have I been chosen?

You have been invited to take part in this study because you are over the age of 16 and are having treatment for your cancer at a hospital that is taking part in the study.

Do I have to take part?

No, it is entirely your choice whether or not you take part. If you do decide to take part, you will be asked to sign a consent form. You are still free to withdraw at any time without giving a reason. **Not participating, or later withdrawing, from this study will not affect your current or future clinical care.**

What do I have to do?

Once you have agreed to take part in this study and have signed the online consent form using "Simple Electronic Signature" (guidance <https://www.hra.nhs.uk/documents/1588/hra-mhra-econsent-statement-sept-18.pdf>) for initial enrolment, you will be asked to enter some details about yourself (name, date of birth) and some information about your illness and your treatment. We will then ask you some standard questions about your quality of life and symptoms. Some patients may also be offered the opportunity to complete more detailed questionnaires, and we may vary the questionnaires that we offer to people to work out which one is best. We ask everyone to complete questionnaires before treatment, and at 4 and 8 weeks after treatment. We would encourage you to complete questionnaires throughout the rest of your treatment, and afterwards if you would like to do so. The portal will not stop offering questionnaires after a set number of time points.

What are the potential benefits and disadvantages/risks of taking part?

There will be no direct benefit for you but ultimately, we hope that we will be able to understand how to collect and use data on outcomes and experiences to be able to improve services. We anticipate that the process completing questionnaires may highlight some areas of concern which may not have been discussed in your normal clinic visits. We would anticipate that this process would itself be beneficial; however, if required, we will be able (with your permission) to discuss these areas of concern with your wider treating team and access other support services if necessary.

What will happen if I decide I do not want to carry on with the study?

Taking part in this study is entirely voluntary and you can change your mind at any time. Any decision you take to withdraw from the study will not affect the care you receive, now or in the future. If you do withdraw from the study, information already collected may still be used.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during this study then you should immediately inform the Investigator (Dr Mathew Williams matt.williams3@nhs.net). The normal National Health Service complaints mechanisms are also available to you such as contacting the local Patient Advice Liaison Services (PALS; pals@imperial.nhs.uk, 020 3313 0088). A member of the team will be able to give you their

contact information upon request. If you are still not satisfied with the response, you may contact the Imperial College Healthcare NHS Trust, Joint Research Compliance Office

Will my taking part in this study be kept confidential?

Participants will be assigned study ID number to keep their identifiable data pseudo-anonymised. The electronic data will also store in the NHS sites and only pseudo-anonymised data from the NHS sites will be forwarded to the radiotherapy department at Charing Cross Hospital. With consent, your GP will be informed of your participation in the study. Imperial College Healthcare NHS Trust is the sponsor for this study, which is based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep pseudo-anonymised information from the study for ten (10) years after the study has finished in relation to data subject consent forms and primary research data. This will be held at Imperial College archives and Corporate Records Units (ACRU). Pseudo-anonymised data be transmitted to the Sponsor at completion of the study. Further information on Imperial College London's retention periods may be found at <https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf>.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting the principal investigator (*Dr Mathew Williams*; matt.williams3@nhs.net)

Legal Basis

As a university, we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

International Transfers

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

Contact Us

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact via Imperial College London's Data Protection Officer email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the

regulator.

Collaborating NHS sites will keep your name, NHS number and contact details confidential and will not pass this information to Imperial College Healthcare NHS Trust. The collaborating NHS sites will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Imperial College Healthcare NHS Trust and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Imperial College Healthcare NHS Trust will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details. The study site NHS will keep identifiable information about you from this study for 10 years after the study has finished. For Imperial College Healthcare NHS Trust patients this will be held at Imperial College Archives and Corporate Record Unit (ACRU). When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. Your information could be used for research in any aspect of health or care and could be combined with information about you from other sources held by researchers, the NHS or government. Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

What will happen to the results of the research study?

The results of the research will be analysed and published in scientific journals. No individual participants will be identifiable from any report or publication. We will happily provide you with a copy of the results after publication.

Who is organising and funding the research?

This study is sponsored by Imperial College Healthcare NHS Trust. The research is funded by NIHR Imperial BRC.

Who has reviewed the study?

This study has been reviewed and approved by the Research Ethics Committee (XXX).

Contact for Further Information

Dr Mathew Williams can be contacted for further information and support: Radiotherapy Department, Charing Cross Hospital, Fulham Palace Road, London, W6 8RF or for independent advice please contact: Patient Advice and Liaison Service (PALS), Ground floor, Main Hospital Entrance, Charing Cross Hospital, Fulham Palace Road, London, W6 8RF Email: IMPERIAL.PALS@NHS.NET; Contact Number: 020 3313 0088 Monday to Friday, 09.00-17.00. *An answer phone system operates at busy times and out of hours. Please leave a message with your name and phone number and a member of staff will call you back within 24 hours.*

Thank you for reading this information and for considering taking part in this research.

General adult consent forms

INDIGO CONSENT FORM

Name of Principal Investigator:

Summary

By providing consent to the items below, you confirm that you have read and understood the [patient information sheet \(v0.2 02/09/2020\)](#) (*hyperlink to PDF of PIS*) and have had the opportunity to ask questions.

In order to participate in INDIGO questions 1 to 5 are required. Questions 6 to 10 are optional. If you choose not to consent to any of the optional items at this time, you can return to this page at a later date to change your response and give your consent. If you have any questions or would like to withdraw your consent for any items, please call our team on (*phone number of the patient's treating team*)

Consent items for the INDIGO

1. I confirm that I have read and understand the information sheet version 0.2 dated 02/09/2020 for the INDIGO project. I have had the opportunity to consider the information and to ask questions.
☒ Yes ☐ No
2. I understand that my participation in this project is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
☒ Yes ☐ No
3. I agree to take part in INDIGO at the (name of the centre where INDIGO takes place)
☒ Yes ☐ No
4. I agree to provide questionnaire data, including information about my demographics (e.g., age, gender, and employment situation), health, lifestyle, emotional wellbeing, personality, and experiences of cancer.
☒ Yes ☐ No
5. I agree to be contacted by the INDIGO project and the (*other staff member*) to ask me to complete additional questionnaires or to invite me to participate in other studies (which may be cancer related but may also not be related to those conditions).
☒ Yes ☐ No

Optional:

6. I give permission for the INDIGO project and the (*other staff member*) to send me newsletters/updates about the research and website. If you change your mind later and wish to opt in or out of receiving these, please contact the INDIGO team on imperial.official_email_address@nhs.net.

☒ Yes ☐ No

7. I agree to long-term, pseudo-anonymised storage of my data for research, with storage to continue in the event of my incapacity or death. I understand that this data is a gift, and that my data may be used in future research in a secure and pseudo-anonymised fashion without my further permission.

☒ Yes ☐ No

8. I give permission for authorised individuals from the INDIGO and (*other teams susceptible to contact the patients*) teams to access my medical and health-related records, and to analyse and store this information long-term.

Please enter your NHS ID (e.g., 123-456-7890) details below. NOTE: You can find your ID numbers on a letter from your GP, or on any letter or document you have received from the NHS. If you do not have them right now, you can return to this page later to add them.

NHS ID

☒ Yes ☐ No

9. I agree that data produced by studying my samples may be included in publications and/or placed in electronic archives with no connection to my name or other personal information which identifies me.

☒ Yes ☐ No

10. I agree that my personal details (e.g., name, date of birth and NHS number) and contact details (e.g., address, email, phone number etc.) can be stored on a secure database so that I can be contacted by the INDIGO project team and the (*other teams susceptible to contact the patients*).

☒ Yes ☐ No

CURIE CONSENT FORM

1. Do you consent to share information with the NHS? (This information will be available to the hospital where you are receiving treatment and the team treating you, Imperial College Healthcare NHS Trust as they are managing the surveys, and the national cancer registries. Your personal details will not be shared with third parties. Anonymised information might be shared with non-commercial third parties.). If you want to opt-out, please contact us on imperial.curie.project@nhs.net.

☒ Yes ☐ No

Information to know

TIMELINE AND DISPLAY OF THE QUESTIONNAIRES

We do not know when patients will complete their questionnaires, so we wish to have a smooth flow for them.

AT REGISTRATION

Patients must consent by using the first form (page 10). The completion should be mandatory, and they should only be able to access the first assessment if they consent.

Patients will need to complete the questionnaire at the start of new drug/ hormone therapy or radiotherapy (page 18) then the questionnaire at enrolment (page 13). When available, they may be offered the choice to answer questionnaires of the sub studies (from page 38 onwards). When patients start a new line of treatment but are already registered on the platform, they will not need to complete the questionnaire at enrolment. They will be asked to review and confirm the data are still correct.

4-WEEK REPORTING

Patients will need to complete the questionnaires available at their 4-week reporting (page 23). When available, they may be offered the choice to answer questionnaires of the sub studies (from page 38 onwards).

8-WEEK REPORTING

Patients will need to complete the questionnaires available at their 8-week reporting (page 28). When available, they may be offered the choice to answer questionnaires of the sub studies (from page 38 onwards).

3-MONTH REPORTING

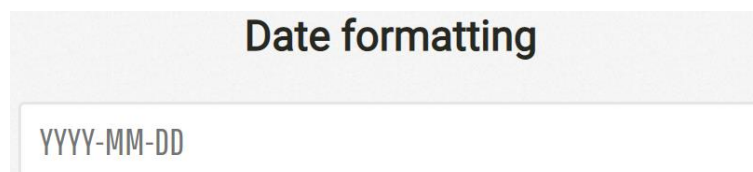
Patients will need to complete the questionnaires available at their 3-month reporting (page 33). When available, they may be offered the choice to answer questionnaires of the sub studies (from page 38 onwards).

TECHNICALITIES

The questionnaires can have multiple types of answers (i.e., single, multiple choices, free text), there are rules that we wish to be applied across all the questionnaires.

INPUT MASKING

Ideally, we would like to have text masking on free text boxes or when we expect something in a particular format (e.g., dates in the format dd/mm/yyyy), such as below:



Date formatting

YYYY-MM-DD

Figure 1: From [here](#)

DATE OF BIRTH

While the platform used by the Trust is directly connected to the Trust's systems, there is no need to ask patients to enter their date of birth. In the case of an independent platform, the date of birth must be asked.

FREE TEXT BOXES

The remaining characters should be displayed under the boxes, such as below.

<p>Describe yourself</p> <p>I am Groot. I am Groot. I am </p>	<p>Describe yourself</p> <p>I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. </p>
28/100	110/100

Figure 2: From [here](#)

<p>Describe yourself</p> <p>I am Groot. I am Groot. I am </p> <p>72 characters left</p>	<p>Describe yourself</p> <p>I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. I am Groot. </p> <p>10 characters over</p>
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Figure 3: From *here*

CONTROLS

When applicable, some questions should be asked only based upon the previous answer. Usually, when patients answer “Other”, then a free text box should appear.

In the section “Information about your past hospital visits”, the questions “If yes, where, and when?” should be displayed only when the previous answer is “yes”.

When possible, controls should be in place when patients must enter information such as numbers and dates. When numbers are asked, patients should enter a digit and not type the numbers. Also, there should be minimum and maximum limits on the numbers: we do not expect patients to enter values outside the number frames, for the health sliders.

Questionnaires offered to patients over time

ABOUT YOU

These answers should be editable at any time by the patient on their profile page.

These answers are editable at any time by going on your profile page. Please note questions d, e, f, g, k, and l are optional and do not stop you from continuing on CURIE/ INDIGO.

Questions		Justification	Choices offered to the patients	Justification
A	What is your preferred title?	We wish to compare the patient's response to what the Trust has recorded.	Miss	Common use
			Mrs	Common use
			Ms	Common use
			Mr	Common use
			Mx	For non-binary person
			Dr	Common use
			Prof	Common use
			Lady	Common use
			Sir	Common use
			Other + <i>free text box</i>	In case patients cannot find their title
B	What is your preferred forename and surname?	Patients may go by their first name and surname, but others may use a nickname or even their middle name instead of their first. This is what we want to capture and compare to the records in the Trust.	<i>Free text box</i>	
C	What is your date of birth (please submit with the following format: DD/MM/YYYY)? ¹	We wish to compare the patient's response to what the Trust has recorded.	<i>Free text box / date</i>	Control to make sure the patient has entered a valid date (dd/mm/yyyy) and patient being > 16 years old.
D	What was your sex assigned at birth?		Male	Common use

¹ Depends on the platform – with PKB, we shall already have this information, so no need to have this question implemented.

		Although it seems irrelevant to cis-gender persons, we want to capture this information to understand how LGBT+ patients experience their treatment.	Female	Common use
			Intersex	It might be considered as a disease (Disorder of Sex Development - DSD) by some but people are born intersex (the number comes out to about 1 in 1500 to 1 in 2000 births) and we want to reflect this in this questionnaire (sources: here and here)
			Other + <i>free text box</i>	In case we may not have considered something important to patients.
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
E	Is the gender you now identify with the same as your sex assigned at birth?	Although it may seem irrelevant to cis-gender persons, we want to capture this information to understand how LGBT+ patients experience their treatment. The data will be specifically useful for equality monitoring.	Yes	Common use
			No	Common use
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
F	Which of these options best describes how you think of yourself?	We want to capture this information to understand how LGBT+ patients experience their treatment. The data will be specifically useful for equality monitoring.	Straight / heterosexual	Common use
			Gay or lesbian	Common use
			Bisexual	Common use
			Queer	To reflect people who do not know how to describe their sexual orientation precisely and prefer this term.
			Pansexual	To represent people who declare being attracted to personality and not gender.
			Asexual	To represent people who do not experience sexual attraction.
			Unsure	In case patients are not sure of their own sexual orientation.
			Other + <i>free text box</i>	We could not define all the sexual orientation that patients may be

				attracted to, so they can complete this field.
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
G What is your ethnicity?		We want to know how patients see themselves versus how their ethnicity has been recorded. The data will be specifically useful for equality monitoring.	Official and extended list (1. List of ethnic groups)	Common use Use the recommended ethnics groups and subgroups.
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
H Which of the following apply?		We want to know if having a partner during treatment has an impact on outcomes and experience.	Never been married or in a registered civil partnership	Common use
			Married to a man	Common use
			Married to a woman	Common use
			In a registered civil partnership with a man	Common use
			In a registered civil partnership with a woman	Common use
			Separated but still legally married	Common use
			Separated but still in a registered civil partnership	Common use
			Formerly married now divorced	Common use
			Formerly in a registered civil partnership now dissolved	Common use
			Widowed	Common use
			Surviving partner of a registered civil partnership	Common use

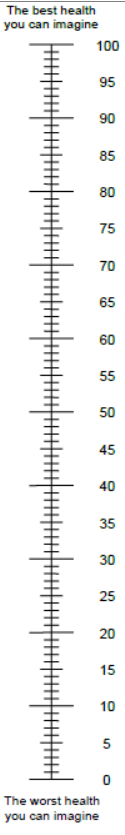
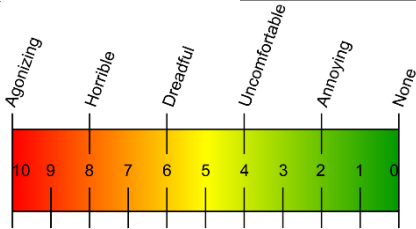
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
I	Which best describes your current occupation?	Trusts do not explicitly capture this information on their systems (or maybe in clinical letters). We want to know the patients' demographic when we analyse their experience to understand their answers. The patients should be able to choose multiple possible answers.	Employer, employee or self-employed (full time)	Common use
			Employer, employee or self-employed (part-time)	Common use
			Retired	Common use
			Student	Common use
			Looking after home or family	Common use
			Long-term sick or disabled	Common use
			Unemployed	Common use
			Other + <i>free text box</i>	Common use
J	Do you consider yourself to have a disability? (i.e. having a physical or mental condition that limits movements, senses and/or activities)	We want to know how the patients see themselves and understand if their cancer had a significant impact on their daily and physical life.	No	Common use
			Yes – due to cancer or cancer treatment (please let us know your disability or disabilities if multiple) + <i>free text box</i>	Disability due to cancer
			Yes – predates cancer diagnosis (please let us know your disability or disabilities if multiple) + <i>free text box</i>	Disability already presents at the time of diagnosis
			Yes – disability post-diagnosis, but not related to	We are trying to capture when and how the disability started

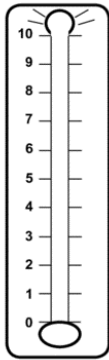
			cancer (please let us know your disability or disabilities if multiple) + <i>free text box</i>	
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
K	What is your current religion/ belief, if any?	The data will be specifically useful for equality monitoring.	Atheist	Common use
			Buddhism	Common use
			Christian	Common use
			Hinduism	Common use
			Islam	Common use
			Judaism	Common use
			Sikhism	Common use
			Not sure	Common use
			Other + <i>free text box</i>	Common use
			Prefer not to say	Since this question is a protected characteristic in the UK, we must include this option in the answers.
L	What three things would you like the team to know about you? (e.g., "I am an IT manager with kids who likes to be outdoor", "Father of two, I run the youth football team and I like growing my own vegetables", "I am an exercise sport lover, loves to bake and read")	We aim to understand if simple free text box could be used in order to gather all of the information above, which may save patients some time - or if you could gather more information on patients that we may not think would be relevant in this context (i.e. first language).	<i>Free text box</i>	Have a mask in the free text box with an example.

AT THE START OF NEW DRUG/ HORMONE THERAPY OR RADIOTHERAPY

Can we review the answers for the questionnaire at enrolment and ask the patient if they wish to update their information?

Questions		Choices offered to the patients	Comments
INFORMATION ABOUT YOUR DIAGNOSIS			
A	What is your primary cancer diagnosis?	<i>Free text box</i>	Limit of 200 characters.
INFORMATION ABOUT YOUR QUALITY OF LIFE			
B C D E F	<p>Under each heading, please tick the ONE box that best describes your health TODAY .</p> <p>MOBILITY</p> <p>I have no problems in walking about <input type="checkbox"/></p> <p>I have slight problems in walking about <input type="checkbox"/></p> <p>I have moderate problems in walking about <input type="checkbox"/></p> <p>I have severe problems in walking about <input type="checkbox"/></p> <p>I am unable to walk about <input type="checkbox"/></p> <p>SELF-CARE</p> <p>I have no problems washing or dressing myself <input type="checkbox"/></p> <p>I have slight problems washing or dressing myself <input type="checkbox"/></p> <p>I have moderate problems washing or dressing myself <input type="checkbox"/></p> <p>I have severe problems washing or dressing myself <input type="checkbox"/></p> <p>I am unable to wash or dress myself <input type="checkbox"/></p> <p>USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)</p> <p>I have no problems doing my usual activities <input type="checkbox"/></p> <p>I have slight problems doing my usual activities <input type="checkbox"/></p> <p>I have moderate problems doing my usual activities <input type="checkbox"/></p> <p>I have severe problems doing my usual activities <input type="checkbox"/></p> <p>I am unable to do my usual activities <input type="checkbox"/></p> <p>PAIN / DISCOMFORT</p> <p>I have no pain or discomfort <input type="checkbox"/></p> <p>I have slight pain or discomfort <input type="checkbox"/></p> <p>I have moderate pain or discomfort <input type="checkbox"/></p> <p>I have severe pain or discomfort <input type="checkbox"/></p> <p>I have extreme pain or discomfort <input type="checkbox"/></p> <p>ANXIETY / DEPRESSION</p> <p>I am not anxious or depressed <input type="checkbox"/></p> <p>I am slightly anxious or depressed <input type="checkbox"/></p> <p>I am moderately anxious or depressed <input type="checkbox"/></p> <p>I am severely anxious or depressed <input type="checkbox"/></p> <p>I am extremely anxious or depressed <input type="checkbox"/></p>		Measured with EQ-5D-5L. Could the layout be conserved on the platform?

G		<ul style="list-style-type: none"> We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine. Please mark an X on the scale to indicate how your health is TODAY. Now, write the number you marked on the scale in the box below. <p>YOUR HEALTH TODAY = <input type="text"/></p> 	<p>A slider would be ideal. If widget not available on the platform, then ask patients to choose a number between 0 and 100.</p>
H	<p>How would you rate your pain felt in the past week, including today?</p>	 <p>Figure 4: VAS</p>	<p>A horizontal slider would be ideal. If not, a drop-down list that starts by “0 – None” and finishes by “10 – Agonizing”.</p>

I	How much distress have you been experiencing in the past week, including today?	 <p>Figure 5: Distress thermometer</p>	A vertical slider would be ideal. If not, a drop-down list that starts by “0 - No distress” and finish by “10 – Extreme distress”.
J	What is the greatest cause of your distress?	Free text box	Limit 100 characters
INFORMATION ABOUT YOUR TREATMENTS			
K	If you've just finished treatment for your cancer, what was it? You can select more than one.	Surgery Radiotherapy Chemotherapy (including immunotherapy and hormone therapy) None	Multiple choices
L	What part of the body do you think your treatment is focused on?	Bone Brain Breast Head or neck Hips Legs Lung Pelvis Shoulder or arm Skin Spine Tummy or abdomen	Multiple choices

		All	
		Other + <i>free text box</i>	
M	What treatment are you about to have?	Surgery	
		Radiotherapy	
		Chemotherapy (including immunotherapy and hormone therapy)	
		None	
N	What do you hope to get out of your treatment? (e.g., "cure disease", "manage pain", "make me more comfortable", "improve my quality of life", "help my breathing")	<i>Free text box</i>	Limit 100 characters
INFORMATION ABOUT YOUR EXPERIENCES			
O	Do you know who to contact at the hospital if you have questions about your treatment or illness?	Yes	
		No	
		Not sure	
P	Do you know the next step after this treatment?	Yes	
		No	
		Not sure	
Q	How do you think your experience could be improved?	<i>Free text box</i>	Limit of 1000 characters.
INFORMATION ABOUT YOUR FUTURE CLINIC APPOINTMENTS			
R	Do you know when your next follow-up appointment is?	Within the next 6 weeks	
		6 to 12 weeks	
		3 to 6 months	
		More than 6 months	
		Follow-up in the community or treated elsewhere	
		Not sure	
		Other + <i>free text box</i>	
S	Would you be happy to share your answers above with your clinical team?	Yes	
		No	

Optional extension sub studies

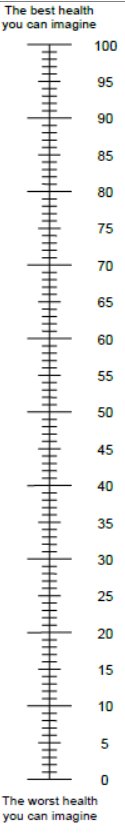
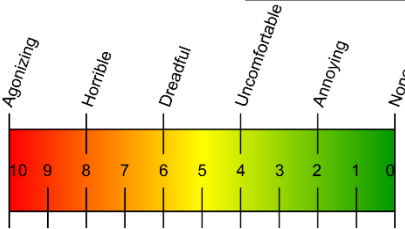
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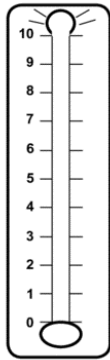
Appendix A

AT 4 WEEKS

Can we review the answers for the questionnaire at enrolment and ask the patient if they wish to update their information?

Questions		Choices offered to the patients	Comments
INFORMATION ABOUT YOUR QUALITY OF LIFE			
A B C D E	Under each heading, please tick the ONE box that best describes your health TODAY .		Measured with EQ-5D-5L. Could the layout be conserved on the platform?
	MOBILITY		
	I have no problems in walking about	<input type="checkbox"/>	
	I have slight problems in walking about	<input type="checkbox"/>	
	I have moderate problems in walking about	<input type="checkbox"/>	
	I have severe problems in walking about	<input type="checkbox"/>	
	I am unable to walk about	<input type="checkbox"/>	
	SELF-CARE		
	I have no problems washing or dressing myself	<input type="checkbox"/>	
	I have slight problems washing or dressing myself	<input type="checkbox"/>	
	I have moderate problems washing or dressing myself	<input type="checkbox"/>	
	I have severe problems washing or dressing myself	<input type="checkbox"/>	
	I am unable to wash or dress myself	<input type="checkbox"/>	
	USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)		
	I have no problems doing my usual activities	<input type="checkbox"/>	
	I have slight problems doing my usual activities	<input type="checkbox"/>	
	I have moderate problems doing my usual activities	<input type="checkbox"/>	
	I have severe problems doing my usual activities	<input type="checkbox"/>	
	I am unable to do my usual activities	<input type="checkbox"/>	
	PAIN / DISCOMFORT		
	I have no pain or discomfort	<input type="checkbox"/>	
	I have slight pain or discomfort	<input type="checkbox"/>	
	I have moderate pain or discomfort	<input type="checkbox"/>	
	I have severe pain or discomfort	<input type="checkbox"/>	
	I have extreme pain or discomfort	<input type="checkbox"/>	
	ANXIETY / DEPRESSION		
	I am not anxious or depressed	<input type="checkbox"/>	
	I am slightly anxious or depressed	<input type="checkbox"/>	
	I am moderately anxious or depressed	<input type="checkbox"/>	
	I am severely anxious or depressed	<input type="checkbox"/>	
	I am extremely anxious or depressed	<input type="checkbox"/>	

F		<ul style="list-style-type: none"> We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine. Please mark an X on the scale to indicate how your health is TODAY. Now, write the number you marked on the scale in the box below. <p>YOUR HEALTH TODAY = <input type="text"/></p> 	<p>A slider would be ideal. If widget not available on the platform, then ask patients to choose a number between 0 and 100.</p>
G	<p>How would you rate your pain felt in the past week, including today?</p>	 <p>Figure 6: VAS</p>	<p>A horizontal slider would be ideal. If not, a drop-down list that starts by “0” and finishes by “10”.</p>

H	How much distress have you been experiencing in the past week, including today?	 <p>Figure 7: Distress thermometer</p>	A vertical slider would be ideal. If not, a drop-down list that starts by “0 - No distress” and finish by “10 – Extreme distress”.
I	What is the greatest cause of your distress?	Free text box	Limit 100 characters
INFORMATION ABOUT YOUR TREATMENTS			
J	Have any changes been made to your treatment?	No – Ongoing	
		Yes – Stopped	
		Yes – Changed	
INFORMATION ABOUT YOUR EXPERIENCES			
K	Do you know who to contact at the hospital if you have questions about your treatment or illness?	Yes	
		No	
		Not sure	
L	Did you wait longer than you would have liked from deciding to have this treatment to starting this treatment?	Yes – far too long	
		Yes – within a reasonable time	
		No	
		Not sure	
M	Did you wait longer than you liked from arriving at hospital to having treatment on the day?	Yes – far too long	
		Yes – within a reasonable time	
		No	
		Not sure	
N	Were you given enough information on side-effects of the treatment you had?	Yes	
		No	

		Not sure	
O	Did the information on side-effects match the side-effects you experienced?	Yes	
		No – fewer side effects	
		No – more side effects	
		Not sure	
P	Were you treated with dignity and respect?	Yes	
		No	
		Not sure	
Q	Did you get to spend as long as you would like with the staff?	Yes	
		No	
		Not sure	
R	Do you know the next step after this treatment?	Yes	
		No	
		Not sure	
S	How do you think your experience over the last 4 weeks could be improved?	<i>Free text box</i>	Limit of 1000 characters.
INFORMATION ABOUT YOUR PAST HOSPITAL VISITS			
T	Have you had an unplanned (“emergency”) hospital visit since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
U	Have you had an unplanned (“emergency”) hospital admission (overnight stay) since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
INFORMATION ABOUT YOUR FUTURE CLINIC APPOINTMENTS			
V		Within the next 6 weeks	

	Do you know when your next follow-up appointment is?	6 to 12 weeks	
		3 to 6 months	
		More than 6 months	
		Follow-up in the community or treated elsewhere	
		Not sure	
		Other + <i>free text box</i>	
W	Would you be happy to share your answers above with your clinical team?	Yes	
		No	

Optional extension sub studies

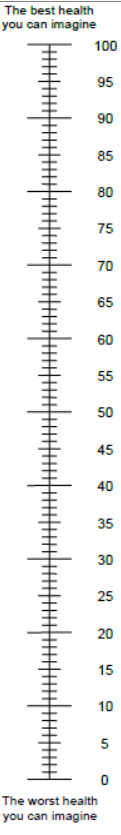
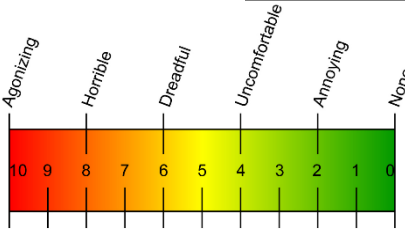
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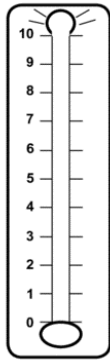
Appendix A

AT 8 WEEKS

Can we review the answers for the questionnaire at enrolment and ask the patient if they wish to update their information?

Questions		Choices offered to the patients	Comments
INFORMATION ABOUT YOUR QUALITY OF LIFE			
A B C D E	Under each heading, please tick the ONE box that best describes your health TODAY .		Measured with EQ-5D-5L. Could the layout be conserved on the platform?
	MOBILITY		
	I have no problems in walking about	<input type="checkbox"/>	
	I have slight problems in walking about	<input type="checkbox"/>	
	I have moderate problems in walking about	<input type="checkbox"/>	
	I have severe problems in walking about	<input type="checkbox"/>	
	I am unable to walk about	<input type="checkbox"/>	
	SELF-CARE		
	I have no problems washing or dressing myself	<input type="checkbox"/>	
	I have slight problems washing or dressing myself	<input type="checkbox"/>	
	I have moderate problems washing or dressing myself	<input type="checkbox"/>	
	I have severe problems washing or dressing myself	<input type="checkbox"/>	
	I am unable to wash or dress myself	<input type="checkbox"/>	
	USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)		
	I have no problems doing my usual activities	<input type="checkbox"/>	
	I have slight problems doing my usual activities	<input type="checkbox"/>	
	I have moderate problems doing my usual activities	<input type="checkbox"/>	
	I have severe problems doing my usual activities	<input type="checkbox"/>	
	I am unable to do my usual activities	<input type="checkbox"/>	
	PAIN / DISCOMFORT		
	I have no pain or discomfort	<input type="checkbox"/>	
	I have slight pain or discomfort	<input type="checkbox"/>	
	I have moderate pain or discomfort	<input type="checkbox"/>	
	I have severe pain or discomfort	<input type="checkbox"/>	
	I have extreme pain or discomfort	<input type="checkbox"/>	
	ANXIETY / DEPRESSION		
	I am not anxious or depressed	<input type="checkbox"/>	
	I am slightly anxious or depressed	<input type="checkbox"/>	
	I am moderately anxious or depressed	<input type="checkbox"/>	
	I am severely anxious or depressed	<input type="checkbox"/>	
	I am extremely anxious or depressed	<input type="checkbox"/>	

F		<ul style="list-style-type: none"> We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine. Please mark an X on the scale to indicate how your health is TODAY. Now, write the number you marked on the scale in the box below. <p>YOUR HEALTH TODAY = <input type="text"/></p> 	<p>A slider would be ideal. If widget not available on the platform, then ask patients to choose a number between 0 and 100.</p>
G	<p>How would you rate your pain felt in the past week, including today?</p>	 <p>Figure 8: VAS</p>	<p>A horizontal slider would be ideal. If not, a drop-down list that starts by “0 – None” and finishes by “10 – Agonizing”.</p>

H	How much distress have you been experiencing in the past week, including today?	 <p>Figure 9: Distress thermometer</p>	A vertical slider would be ideal. If not, a drop-down list that starts by “0 - No distress” and finish by “10 – Extreme distress”.
I	What is the greatest cause of your distress?	Free text box	Limit 100 characters
INFORMATION ABOUT YOUR TREATMENTS			
J	Have any changes been made to your treatment?	No – Ongoing	
		Yes – Stopped	
		Yes – Changed	
INFORMATION ABOUT YOUR EXPERIENCES			
K	Do you know who to contact at the hospital if you have questions about your treatment or illness?	Yes	
		No	
		Not sure	
L	Did you wait longer than you would have liked from deciding to have treatment to starting treatment?	Yes – far too long	
		Yes – within a reasonable time	
		No	
		Not sure	
M	Did you wait longer than you liked from arriving at hospital to having treatment on the day?	Yes – far too long	
		Yes – within a reasonable time	
		No	
		Not sure	
N	Were you given enough information on side-effects of the treatment you had?	Yes	
		No	

		Not sure	
O	Did the information on side-effects match the side-effects you experienced?	Yes	
		No – fewer side effects	
		No – more side effects	
		Not sure	
P	Were you treated with dignity and respect?	Yes	
		No	
		Not sure	
Q	Did you get to spend as long as you would like with the staff?	Yes	
		No	
		Not sure	
R	Do you know the next step after this treatment?	Yes	
		No	
		Not sure	
S	How do you think your experience could be improved?	<i>Free text box</i>	Limit of 1000 characters.
INFORMATION ABOUT YOUR PAST HOSPITAL VISITS			
T	Have you had an unplanned (“emergency”) hospital visit since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
U	Have you had an unplanned (“emergency”) hospital admission (overnight stay) since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
INFORMATION ABOUT YOUR FUTURE CLINIC APPOINTMENTS			
V		Within the next 6 weeks	Control to make sure patient has entered a date.

	Do you know when your next follow-up appointment is?	6 to 12 weeks	
		3 to 6 months	
		More than 6 months	
		Follow-up in the community or treated elsewhere	
		Not sure	
		Other + <i>free text box</i>	
W	Would you be happy to share your answers above with your clinical team?	Yes	
		No	

Optional extension sub studies

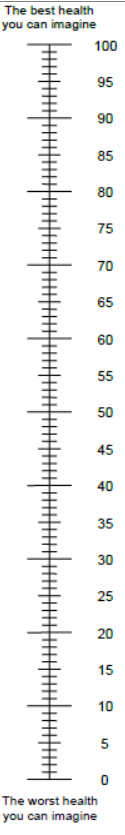
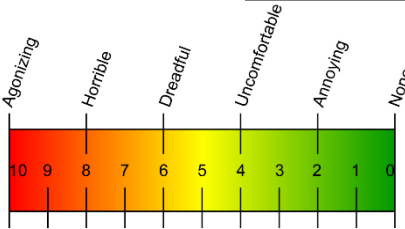
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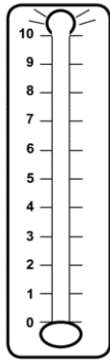
Appendix A

EVERY 3 MONTHS

Can we review the answers for the questionnaire at enrolment and ask the patient if they wish to update their information?

Questions		Choices offered to the patients	Comments
INFORMATION ABOUT YOUR QUALITY OF LIFE			
A B C D E	Under each heading, please tick the ONE box that best describes your health TODAY .		Measured with EQ-5D-5L. Could the layout be conserved on the platform?
	MOBILITY		
	I have no problems in walking about	<input type="checkbox"/>	
	I have slight problems in walking about	<input type="checkbox"/>	
	I have moderate problems in walking about	<input type="checkbox"/>	
	I have severe problems in walking about	<input type="checkbox"/>	
	I am unable to walk about	<input type="checkbox"/>	
	SELF-CARE		
	I have no problems washing or dressing myself	<input type="checkbox"/>	
	I have slight problems washing or dressing myself	<input type="checkbox"/>	
	I have moderate problems washing or dressing myself	<input type="checkbox"/>	
	I have severe problems washing or dressing myself	<input type="checkbox"/>	
	I am unable to wash or dress myself	<input type="checkbox"/>	
	USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)		
	I have no problems doing my usual activities	<input type="checkbox"/>	
	I have slight problems doing my usual activities	<input type="checkbox"/>	
	I have moderate problems doing my usual activities	<input type="checkbox"/>	
	I have severe problems doing my usual activities	<input type="checkbox"/>	
	I am unable to do my usual activities	<input type="checkbox"/>	
	PAIN / DISCOMFORT		
	I have no pain or discomfort	<input type="checkbox"/>	
	I have slight pain or discomfort	<input type="checkbox"/>	
	I have moderate pain or discomfort	<input type="checkbox"/>	
	I have severe pain or discomfort	<input type="checkbox"/>	
	I have extreme pain or discomfort	<input type="checkbox"/>	
	ANXIETY / DEPRESSION		
	I am not anxious or depressed	<input type="checkbox"/>	
	I am slightly anxious or depressed	<input type="checkbox"/>	
	I am moderately anxious or depressed	<input type="checkbox"/>	
	I am severely anxious or depressed	<input type="checkbox"/>	
	I am extremely anxious or depressed	<input type="checkbox"/>	

F		<ul style="list-style-type: none"> We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine. Please mark an X on the scale to indicate how your health is TODAY. Now, write the number you marked on the scale in the box below. <p>YOUR HEALTH TODAY = <input type="text"/></p> 	<p>A slider would be ideal. If widget not available on the platform, then ask patients to choose a number between 0 and 100.</p>
G	<p>How would you rate your pain felt in the past week, including today?</p>	 <p>Figure 10: VAS</p>	<p>A horizontal slider would be ideal. If not, a drop-down list that starts by “0 – None” and finishes by “10 – Agonizing”.</p>

H	How much distress have you been experiencing in the past week, including today?	 <p>Figure 11: Distress thermometer</p>	A vertical slider would be ideal. If not, a drop-down list that starts by “0 - No distress” and finish by “10 – Extreme distress”.
I	What is the greatest cause of your distress?	Free text box	Limit of 100 characters.
INFORMATION ABOUT YOUR TREATMENTS			
J	Has any changes been made to your treatment?	No – Ongoing Yes – Stopped Yes – Changed	
INFORMATION ABOUT YOUR EXPERIENCES			
K	Do you know who to contact at the hospital if you have questions about your treatment or illness?	Yes No Not sure	
L	Did you wait longer than you would have liked from deciding to have treatment to starting treatment?	Yes – far too long Yes – within a reasonable time No Not sure	
M	Did you wait longer than you liked from arriving at hospital to having treatment on the day?	Yes – far too long Yes – within a reasonable time No Not sure	
N	Were you given enough information on side-effects of the treatment you had?	Yes No	

		Not sure	
O	Did the information on side-effects match the side-effects you experienced?	Yes	
		No – fewer side effects	
		No – more side effects	
		Not sure	
P	Were you treated with dignity and respect?	Yes	
		No	
		Not sure	
Q	Did you get to spend as long as you would like with the staff?	Yes	
		No	
		Not sure	
R	Do you know the next step after this treatment?	Yes	
		No	
		Not sure	
S	How do you think your experience could be improved?	<i>Free text box</i>	Limit of 1000 characters.
INFORMATION ABOUT YOUR PAST HOSPITAL VISITS			
T	Have you had an unplanned (“emergency”) hospital visit since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
U	Have you had an unplanned (“emergency”) hospital admission (overnight stay) since the last questionnaire?	Yes	
		No	
		Not sure	
	If yes, where, and when?	<i>Free text box</i>	Should be displayed only if patient answered yes to the previous question. Limit of 100 characters.
INFORMATION ABOUT YOUR FUTURE CLINIC APPOINTMENTS			
V		Within the next 6 weeks	Control to make sure patient has entered a date.

	Do you know when your next follow-up appointment is?	6 to 12 weeks	
		3 to 6 months	
		More than 6 months	
		Follow-up in the community or treated elsewhere	
		Not sure	
		Other + <i>free text box</i>	
W	Would you be happy to share your answers above with your clinical team?	Yes	
		No	

Optional extension sub studies

See in

Appendix A

Appendix A

OPTIONAL EXTENSION SUB STUDIES

1. E1. Expanded set of disease and treatment specific questions:

E1 CORE: QLQ-C30



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

3	1								

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

E1 PALL: QLQ-C15-Pall



EORTC QLQ-C15-PAL (version 1)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

3	1								

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
2. Do you need to stay in bed or a chair during the day?	1	2	3	4
3. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following question please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

E1 CHEMO: Chemo Toxicity (*based on [this](#)*)

Assessment	Grade				
	0	1	2	3	4
Appetite loss					
Constipation					
Cough					
Diarrhoea/ loose bowels					
Dyspnoea/ shortness of breath					
Dysuria/ painful urination					
Fatigue					
Hot flashes					
Nausea					
Pain					
Neuropathy					
Vomiting					

E1 BREAST: QLQ-C30 + QLQ-BR23




EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

31 

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

During the past week:		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4

During the past week:

During the past week:		Not at All	A Little	Quite a Bit	Very Much
17.	Have you had diarrhea?	1	2	3	4
18.	Were you tired?	1	2	3	4
19.	Did pain interfere with your daily activities?	1	2	3	4
20.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21.	Did you feel tense?	1	2	3	4
22.	Did you worry?	1	2	3	4
23.	Did you feel irritable?	1	2	3	4
24.	Did you feel depressed?	1	2	3	4
25.	Have you had difficulty remembering things?	1	2	3	4
26.	Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27.	Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28.	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

Figure 12: QLQ-C30

+



EORTC QLQ - BR23

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week.

During the past week:		Not at All	A Little	Quite a Bit	Very Much
31.	Did you have a dry mouth?	1	2	3	4
32.	Did food and drink taste different than usual?	1	2	3	4
33.	Were your eyes painful, irritated or watery?	1	2	3	4
34.	Have you lost any hair?	1	2	3	4
35.	Answer this question only if you had any hair loss: Were you upset by the loss of your hair?	1	2	3	4
36.	Did you feel ill or unwell?	1	2	3	4
37.	Did you have hot flashes?	1	2	3	4
38.	Did you have headaches?	1	2	3	4
39.	Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
40.	Have you been feeling less feminine as a result of your disease or treatment?	1	2	3	4
41.	Did you find it difficult to look at yourself naked?	1	2	3	4
42.	Have you been dissatisfied with your body?	1	2	3	4
43.	Were you worried about your health in the future?	1	2	3	4
During the past <u>four</u> weeks:		Not at All	A Little	Quite a Bit	Very Much
44.	To what extent were you interested in sex?	1	2	3	4
45.	To what extent were you sexually active? (with or without intercourse)	1	2	3	4
46.	Answer this question only if you have been sexually active: To what extent was sex enjoyable for you?	1	2	3	4

During the past week:

During the past week:		Not at All	A Little	Quite a Bit	Very Much
47.	Did you have any pain in your arm or shoulder?	1	2	3	4
48.	Did you have a swollen arm or hand?	1	2	3	4
49.	Was it difficult to raise your arm or to move it sideways?	1	2	3	4
50.	Have you had any pain in the area of your affected breast?	1	2	3	4
51.	Was the area of your affected breast swollen?	1	2	3	4
52.	Was the area of your affected breast oversensitive?	1	2	3	4
53.	Have you had skin problems on or in the area of your affected breast (e.g., itchy, dry, flaky)?	1	2	3	4

Figure 13: QLQ-BR23

E1 LUNG: QLQ-C30 + QLQ-LC13



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

31

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

Figure 14: QLQ-C30

+



EORTC QLQ - LC13

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at All	A Little	Quite a Bit	Very Much
31. How much did you cough?	1	2	3	4
32. Did you cough up blood?	1	2	3	4
33. Were you short of breath when you rested?	1	2	3	4
34. Were you short of breath when you walked?	1	2	3	4
35. Were you short of breath when you climbed stairs?	1	2	3	4
36. Have you had a sore mouth or tongue?	1	2	3	4
37. Have you had trouble swallowing?	1	2	3	4
38. Have you had tingling hands or feet?	1	2	3	4
39. Have you had hair loss?	1	2	3	4
40. Have you had pain in your chest?	1	2	3	4
41. Have you had pain in your arm or shoulder?	1	2	3	4
42. Have you had pain in other parts of your body?	1	2	3	4
If yes, where _____				
43. Did you take any medicine for pain?				
1 No 2 Yes				
If yes, how much did it help?	1	2	3	4

Figure 15QLQ-LC13

E1 PELVIC: ALERT-B

Assessment of Late Effects of RadioTherapy-Bowel			
ALERT-B Screening Tool			
Date:			
Your specialist has asked you to complete this screening tool to pick up any bowel or tummy problems you may have developed following radiotherapy treatment.			
Please answer Yes or No to the following questions:			
1. Do you have difficulty in controlling your bowels (having a poo), such as:			
- Having to get up at night to poo	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
- Having accidents, such as soiling or a sensation of wetness ("wet wind")	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
2. Have you noticed any blood from your bottom recently? (any amount or frequency)	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
3. Do you have any bowel or tummy problems that affect your mood, social life, relationships or any other aspect of your daily life? (e.g., do you avoid any activities or situations- travel, work, social life or hobbies? Do you take continence supplies or spare clothing with you when you go out? Have you made any dietary changes? Do you need to allow for frequency or urgency of needing the toilet?)	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
If you have any other problems your doctor will be happy to discuss this with you.			

Figure 16: ALERT-B

E1 BRAIN: QLQ-C30 + QLQ-BN20



EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

31

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall <u>health</u> during the past week?	1	2	3	4	5	6	7
Very poor							Excellent
30. How would you rate your overall <u>quality of life</u> during the past week?	1	2	3	4	5	6	7
Very poor							Excellent

Figure 17: QLQ-C30

+



EORTC QLQ - BN20

Patients sometimes report that they have the following symptoms. Please indicate the extent to which you have experienced these symptoms or problems during the past week.

	Not at All	A Little	Quite a Bit	Very Much
31. Did you feel uncertain about the future?	1	2	3	4
32. Did you feel you had setbacks in your condition?	1	2	3	4
33. Were you concerned about disruption of family life?	1	2	3	4
34. Did you have headaches?	1	2	3	4
35. Did your outlook on the future worsen?	1	2	3	4
36. Did you have double vision?	1	2	3	4
37. Was your vision blurred?	1	2	3	4
38. Did you have difficulty reading because of your vision?	1	2	3	4
39. Did you have seizures?	1	2	3	4
40. Did you have weakness on one side of your body?	1	2	3	4
41. Did you have trouble finding the right words to express yourself?	1	2	3	4
42. Did you have difficulty speaking?	1	2	3	4
43. Did you have trouble communicating your thoughts?	1	2	3	4
44. Did you feel drowsy during the daytime?	1	2	3	4
45. Did you have trouble with your coordination?	1	2	3	4
46. Did hair loss bother you?	1	2	3	4
47. Did itching of your skin bother you?	1	2	3	4
48. Did you have weakness of both legs?	1	2	3	4
49. Did you feel unsteady on your feet?	1	2	3	4
50. Did you have trouble controlling your bladder?	1	2	3	4

Figure 18: QLQ-BN20

E2 MEASURES OF DIGITAL LITERACY: PERQ (Offered once only) (here)

Using the Internet for health care in the PL postcode area
We want to hear from **everybody**, not just those who have used the Internet or are interested in using it.

If this questionnaire is being completed by another member of the household on behalf of the adult with the next birthday, please tick this box []

A. ABOUT YOU AND HEALTH INFORMATION AND SUPPORT

A1. Are you: Male [] Female [] A2. How old are you?.....

A3. In the last three months have you tick ✓ all that apply:
Seen a doctor, nurse, or other health professional about your health []
Asked a family member or friend something about your health []
Phoned a helpline (e.g. NHS Direct, Samaritans, Diabetes UK) about your health []
Read a book, or magazine to find something out about your health []
Used the Internet for something to do with your health []
None of the above []

B. INTERNET USE FOR ANY PURPOSE
This section is about whether you have used the Internet, how often and where you use it.

B1. Have you personally used the Internet for any purpose in the last 3 months?
Yes [] No [] If yes, continue with question B2 below.
If no, go to question C1 on the next page

B2. Typically how often do you use the Internet (for any purpose)?
Many times a day []
At least once a day []
At least once a week []
Less than once a week - every now and then []

B3. What have you used the Internet for? Tick boxes in the first column for all the ways you have used the Internet for any purpose, and tick boxes in the second column for all the ways you have used the Internet for something related to your health.

	Have used the Internet for.....	
	Any purpose	For something health related
To find information (e.g. using Google)		
Email		
Internet telephony (e.g. Skype)		
Discussion forum		
Twitter		
Social network site (e.g. Facebook, Linked in)		
Watching videos (e.g. YouTube)		
Virtual World (e.g. Second Life)		

B4. Where and how have you accessed the Internet in the last 3 months? Tick all that apply.
Desktop / laptop computer at home []
Desktop / laptop computer at work []
Smart phone or mobile device (e.g. iPhone, iPad) []
Desktop computer in a library or community centre []
Paid for computer in an Internet café, shop, airport []
Elsewhere [] (Where?.....)

NOW PLEASE GO TO SECTION D

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C. FOR PEOPLE WHO HAVE NOT USED THE INTERNET IN THE LAST THREE MONTHS
This section asks about if you have EVER used it, whether you would like to use the Internet, if maybe you would like to use it for health related things, given help.
If you HAVE used the Internet in the last three months, go to section D.

C1. Have you EVER used the Internet (for any purpose)? (Tick one of the following)
I used to use it fairly often but not recently []
I have only ever used it a few times and not recently []
I have never used it []

C2. Do you have a long term disability that would make using a computer difficult?
No []
Yes - it would make using a computer very difficult []
Yes - it would make using a computer somewhat difficult []
If Yes, please give details.....

C3. Does your home have an Internet connected computer? Yes [] No []

C4. As far as you know do any of your neighbours have Internet access? Yes [] No [] Don't know []

C5. Has anyone ever used the Internet for you (e.g. to find out something for you, or to buy something for you, or to contact someone on your behalf by email)? Yes [] No []

C6. If someone was able to help you, would you 'have a go' at using the Internet?
No, it's really not for me [] Possibly [] Probably [] Yes []

C7. If you would 'have a go' using the Internet, do you have someone (e.g. family, friend, neighbour) who could help you?
No []
Yes, there is someone I can ask easily []
Yes, but they are not, or would not be very easy to ask [] Why is that?.....

C8. If someone was able to help you, and it was easy, and it was cheap, would you use a home Internet connection? No [] Possibly [] Probably [] Yes []

C9. If there were Internet connected computers available at some place (such as those listed below) that you go to, and they were free to use, easy to use, and there was help there to use them for any purpose, would you consider using them? No [] Possibly [] Probably [] Yes []

C10. If you answered possibly, probably, or yes, to question C9, in this list tick those places where you might be prepared to use the Internet for health. If none of these please tick last row.

A place of work	
A public library	
A community centre, or Age UK centre	
A place of worship	
Your doctor's practice	
Your local hospital	
The house of a family member	
A friend's house	
Other? (say where).....	
NONE of these	

If you have not used the Internet in the last three months, Please go to sections G and H on the last page.

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D. ACCESS TO INTERNET SERVICES
Only answer this section if you have used the Internet for any purpose in the last three months. If you have not used the Internet turn over to the last page section G.

D1. Does your home (tick ✓ one).....
Have an Internet connection that is fast enough for what you need [] (Go to D3)
Have an Internet connection that is slow for what you need []
Have no Internet connection []
Don't know []

D2. If you do not have an Internet connection, or slow for what you need, why is that? (tick ✓ one)
I would need to pay more []
I live in a rural area and there is no good connection to my home []
My local server is congested and unreliable []
My Internet provider does not offer a faster connection []
Don't know []

D3. Does your General Practitioner (family doctor) have a website (e.g. that you might find by Google)?
Yes I have looked at it []
Yes I think so but I have not seen it [] (Go to D6)
No []
Don't know []

If your General Practitioner (GP) has a website AND you have looked at it:
D4. If you wanted, can you order a repeat prescription by email, or on your GP's website?
Yes [] No [] Don't know []

D5. If you wanted, can you see your own medical record online via your GP's website?
Yes [] No [] Don't know []

D6. In the last three months, have you used the Internet trying to find information about health topics, services, treatments, advice etc.?
Never tried []
Tried, and found what I wanted most of the time []
Tried, but not been able to find what I wanted []
Can you say what topic?.....

D7. In the last three months, have you used the Internet trying to contact an organisation online, or discussion forum, or other people, for some reasons connected with your health and been able to get what you wanted?
Never tried []
Tried, and found what I wanted most of the time []
Tried, but not been able to contact who I wanted []
Can you say what/what organisation you were trying to contact?.....

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E. PERSONAL SKILLS AND CONFIDENCE IN USING THE INTERNET FOR HEALTH
This section is about whether you have or could have if you wanted it support from somebody in using the Internet for health. Only answer this section if you have used the Internet for any purpose in the last three months. If you have not used the Internet turn over to the last page section G.

E1. Do you have a long term disability that makes using the Internet difficult?
No []
Yes - makes use of the Internet very difficult []
Yes - makes use of the Internet somewhat difficult []
If Yes, please give details.....

E2. This question is a self-assessment of your general Internet skills, not necessarily concerned with health. In the following table, please read the 'task' and then tick one box to show if you think you could do that task.

I think I could.....	No	Maybe	Yes
Book tickets for a film online and save a copy of the booking into a folder on your computer			
Search on Google with keyword 'Asthma', and open the first three sites found, to compare what they say			
Use Google to find out what type of documents you need to apply for a new passport if yours was lost			
Compare the cost and convenience of a holiday using a 'package holiday' company to booking travel & accommodation separately			

E3. In general how confident are you in using the Internet for health, for example, knowing where and how to find helpful health resources, telling good quality from poor quality resources, or using the Internet to join a forum, or some other source of advice?

Circle a number between 1 (not at all confident) and 10 (totally confident).

Not confident										Totally confident	
1	2	3	4	5	6	7	8	9	10		

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F. SUPPORT FROM ANOTHER PERSON IN USING THE INTERNET FOR HEALTH

Only answer this section if you have used the Internet for any purpose in the last three months. If you have not used the Internet turn over to the last page section G. This section is about whether you have, or could have if you wanted it, support from somebody in using the Internet for health.

F1. Has a doctor, nurse, or other health professional ever given you information (e.g. a web address) to help you use the Internet for your health? Yes [] No []

F2. If you, or someone in your household, wanted help using the Internet, could you find it near where you live, or by phone or email? (e.g. from local library, Age UK, local authority, NHS, or University).

- [] Don't know
 [] Not that I am aware of
 [] Yes, from

If yes, have you ever made use of such help? Yes [] No []

F3. Have there ever been times when help from somebody in using the Internet for health was or might have been useful for you? Yes [] No []

If NO to F3, go to section G

F4. Do you have a family member or friend who could help you to use the Internet (for any purpose)?

- No []
 Yes, there is someone I can ask quite easily []
 Yes, but they are not, or would not be very easy to ask [] Why is that?

F5. If yes to question F4, would you feel OK about asking them to help you use the Internet for health purposes (to find information or to communicate with someone)?

- Yes []
 No [] If no, why is that?

F6. If you were to get support from an unknown person online or by phone in using the Internet for health, and you were anonymous to them, would you have any concerns about disclosing information about your health?

- [] No, not really
 [] Don't know
 [] Yes, please give details

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G. ECONOMIC CONSIDERATIONS IN USING THE INTERNET FOR HEALTH

This last section asks about the cost to you of using the Internet for health. Please answer even if you have never used the Internet.

G1. Please read each of the statements and tick one box for each to show whether you agree or disagree, as they relate to you at the moment.

For me.....	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
The monthly cost of home Internet is a major concern					
Mobile Internet access on smart phones and IPADS is expensive					
Getting to a public library to use the Internet does not cost much					
It costs me nothing, or very little, to get to see my GP					
It costs me nothing, or very little, to visit my nearest hospital					

H. OVERALL VIEWS ABOUT USING THE INTERNET FOR HEALTH

This last section asks about the factors most likely to reduce your use of the Internet for health, and for your views. Please answer even if you have never used the Internet.

H1. Which one statement best sums up how you feel about using the Internet for health? None of them may be exactly right, but try to choose one and then you can qualify your answer in the space in H2.

- [] I have no need for health information
 [] I have no interest in using the Internet
 [] I would use the Internet more for health if I could get a good Internet connection
 [] I don't understand the Internet that much
 [] I would use the Internet more for health if I could get someone to help me
 [] I would use the Internet more for health if money were no object
 [] I have or would use the Internet for health and have no real barriers to that use

H2. Lastly an open question. Do you have any thoughts about using the Internet for health? What could be done to help those who want access to the Internet for health? (Also use this space if you want to qualify your answer to H1).

.....

Thank you very much for your help in completing the questionnaire. The following six guides are all available on the Internet if you have access, but if you would like us to send you one free printed copy, please tick the appropriate box. Please tick one box only.

From Age UK www.ageuk.org.uk/Internet-and-learning/technology-and-internet/ [] Making the most of the Internet [] Internet security – staying safe online [] Buying a computer [] Ten hints for silver surfers	From the BBC http://downloads.bbc.co.uk/connect/colours_handbook.pdf [] First click – beginners guide to the Internet [] Give an hour and help someone take their first click online
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E3 RADIOTHERAPY EXPERIENCE: National Cancer Action Team (NCAT)

1. On which part of your body are you currently receiving radiotherapy treatment?

- | | |
|---|-----------------------------------|
| <input type="radio"/> Brain | <input type="radio"/> Lung |
| <input type="radio"/> Breast | <input type="radio"/> Oesophageal |
| <input type="radio"/> Colorectal | <input type="radio"/> Prostate |
| <input type="radio"/> Gynaecological | <input type="radio"/> Skin |
| <input type="radio"/> Head and neck | <input type="radio"/> Urology |
| <input type="radio"/> Other (please specify) + <i>free text box</i> | |

2. Were you given a clear explanation of where to go for your planning session and what to expect?

- ☐ Yes ☐ No ☐ Cannot remember

3. How easy was it to find the radiotherapy department using the hospital signs?

- | | |
|--|---------------------------------------|
| <input type="radio"/> Very easy | <input type="radio"/> Difficult |
| <input type="radio"/> Easy | <input type="radio"/> Very difficult |
| <input type="radio"/> Neither easy nor difficult | <input type="radio"/> Cannot remember |

Please comment + *free text box*

4. Did you receive a copy of your consent form?

- | | | | |
|---------------------------|--|---|---------------------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No – I did not want a copy | <input type="radio"/> No – I was not offered a copy | <input type="radio"/> Cannot remember |
|---------------------------|--|---|---------------------------------------|

5. When you gave your consent, to what extent did you understand what the benefits and side effects of radiotherapy were?

- | | |
|---|---|
| <input type="radio"/> I understood completely | <input type="radio"/> I did not understand at all |
| <input type="radio"/> I understood to some extent | <input type="radio"/> Cannot remember |

6. Please answer the following questions about the information you received.

	Yes	No	Cannot remember
Were you given any written information/advice about your radiotherapy treatment and its side effects?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was the information useful and easy to read?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. Were you told how long in total (i.e., days or weeks) your course of radiotherapy treatment would last?

- ☐ Yes ☐ No ☐ Cannot remember

8. If you attend radiotherapy as an outpatient, how do you travel to our hospital?

- ☐ I come by hospital transport ☐ I use the train and then walked
☐ I walk to the hospital ☐ I use the bus
☐ I come by car ☐ N/A
☐ Other (please specify) + *free text box*

9. Does your journey take longer than 45 minutes?

- ☐ Yes ☐ No

If yes – was this a problem for you (please comment below)? Do you have any other comments about your journey?

10. On arrival at the radiotherapy department, are you made to feel welcome by the reception staff?

- ☐ Always ☐ Never
☐ Usually ☐ Cannot remember
☐ Sometimes

11. How soon after your given appointment time do you usually have to wait for your treatment?
(Please note this is your actual treatment time not the time that you arrived to begin any preparation e.g., drinking or bowel preparation)

- ☐ On time or up to 20 mins ☐ It varied from visit to visit
☐ Between 20 minutes and 1 hour ☐ Cannot remember
☐ More than 1 hour

12. If you have waited longer than 20 minutes beyond your appointment time, were you told the reason for the delay?

- ☐ Always ☐ Never
☐ Usually ☐ Cannot remember

☐ Sometimes

13. To what extent do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Cannot remember	N/A
When visiting the radiotherapy department, I am treated as an individual.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am treated with courtesy and respect by all staff.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find the staff in the radiotherapy department professional and friendly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
On each visit the radiographer s confirmed my identity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All staff members present in the treatment room introduce themselves to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that enough time is always taken to deal with any problems or queries I may have.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am given enough privacy to ask questions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My questions are answered to my satisfaction.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Did you feel the changing facilities / arrangements allowed you to maintain your dignity?

☐ Yes ☐ Partially ☐ No ☐ N/A

15. Do you know the name of the Radiotherapy specialist, consultant, or doctor in charge of your care?

☐ Yes ☐ No ☐ Cannot remember

16. Were you given a clear explanation of where to go for your planning session and what to expect?

☐ Yes ☐ No ☐ Cannot remember

If 'yes', at what point were you first seen (week 1, week 2 etc.)? + free text box

17. To what extent do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Cannot remember	N/A
I find the doctor / nurse / radiographer treating me approachable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A doctor / nurse / radiographer always is available when I need one.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Do you know who your designated key worker is (e.g., Clinical Nurse Specialist, Specialist Social Worker, Dietitian, Physio)?

☐ Yes ☐ No ☐ Cannot remember

19. Did you feel well informed after the radiographer explained possible side effects prior to treatment?

☐ Yes ☐ No ☐ Cannot remember ☐ N/A

20. Do you feel supported by the radiotherapy staff in managing any side-effects you may be experiencing or have experienced due to your radiotherapy treatment?

☐ Yes ☐ No ☐ Cannot remember

21. Please rate the care you received from the radiotherapy department staff

Excellent Good Satisfactory Poor Unacceptable N/A

Receptionist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiographer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Review Specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. Please rate the cleanliness of the radiotherapy department

	Excellent	Good	Satisfactory	Poor	Unacceptable	N/A
Toilets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment room	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consultation room	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corridors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. Overall, how would you rate the care and support you received from the radiotherapy department?

Excellent	Good	Satisfactory	Poor	Unacceptable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Following your experience of our service, would you like to make any comments about the radiotherapy department or the treatment you received? *free text box*

25. Were you given an opportunity to ask for a different treatment time?

☐ Yes ☐ No ☐ Cannot remember

26. Did you receive your preferred treatment time?

☐ Always ☐ Never
☐ Usually ☐ Cannot remember
☐ Sometimes ☐ N/A