



Medicines & Healthcare products
Regulatory Agency



National Cancer Patient Experience Survey (CPES) Data Dictionary

Version 3.0

Date: 29 April 2019



Documentation Control Sheet

Over time, it may be necessary to issue amendments or clarifications to parts of this document. This form must be updated whenever changes are made.

Version	Affected Areas Summary of Change	Prepared By	Reviewed By
1.0	First CPRD-NCRAS-CPES data release for set 14. No changes for set 15.	Helen Strongman	Rachael Williams
2.0	Updated for Set 16	Rachael Williams	Eleanor Yelland
3.0	Updated for Set 17	Eleanor Yelland	Tarita Murray-Thomas

Version 1.0

- First version (20 June 2017)

Version 2.0

- Updated for Set 16

Version 3.0

- Updated for Set 17



National Cancer Patient Experience Survey Data Dictionary

Data coverage

The Cancer Patient Experience Survey (CPES) has been conducted in 4 waves; the period of data coverage for each wave is outlined below.

Wave 1 - 2010: Patients discharged between 01/01/2010 – 31/03/2010

Wave 2 - 2011/12: Patients discharged between 01/09/2011 – 30/11/2011

Wave 3 - 2013: Patients discharged between 01/09/2012 – 30/11/2012

Wave 4 - 2014: Patients discharged between 01/09/2013 – 30/11/2013

Wave 5 – 2015: Patients discharged between 01/09/2014- 30/11/2014



Wave 1 2010 Data Dictionary - Questions and Values

Column Description	Column Name	Field Type	Valid Content
CR patient Identifier	e_cr_patid	Number	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Q1	NUMBER	1-None I did not see my GP before going to hospital 2-I saw my GP once 3-I saw my GP twice 4-I saw my GP 3 or 4 times 5-I saw my GP 5 or more times 6-Don't know / Can't say
After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor?	Q2	NUMBER	1-I was seen the same day or next day 2-I was seen after 2-14 days 3-I was seen in 3 to 4 weeks 4-Waited 1 to 4 months 5-Waited more than 4 months 6-I did not see my GP before going into hospital 7-I chose to have a later appointment than the one I was offered 8-Don't know / Can't remember
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Q3	NUMBER	1-I was seen as soon as I thought was necessary 2-I should have been seen a bit sooner 3-I should have been seen a lot sooner
How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?	Q4	NUMBER	1-Less than 3 months 2-3-6 months 3-6-12 months 4-More than 12 months 5-Don't know / Can't remember
Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?	Q5	NUMBER	1-My health got worse 2-My health got better 3-My health stayed about the same
In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Q6	NUMBER	1-Yes 2-No
Beforehand, did a member of staff explain the purpose of the test(s)?	Q7	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember



Beforehand, did a member of staff explain what would be done during the test procedure(s)?	Q8	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember
Beforehand, were you given written information about your test(s)?	Q9	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No but I would have liked written information about the test(s) 4-I did not need written information 5-Don't know / Can't remember
Were the results of the test(s) explained in a way you could understand?	Q10	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember
Who first told you that you had cancer?	Q11	NUMBER	1-A hospital doctor 2-A hospital nurse 3-A GP (family doctor) 4-Another health professional 5-A friend or relative 6-Nobody – I worked it out for myself
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Q12	NUMBER	1-Yes 2-No 3-It was not necessary 4-I was told by phone or letter 5-Don't know / Can't remember
How do you feel about the way you were told you had cancer?	Q13	NUMBER	1-It was done sensitively 2-It should have been done a bit more sensitively 3-It should have been done a lot more sensitively
Did you understand the explanation of what was wrong with you?	Q14	NUMBER	1-Yes, I completely understood it 2-Yes I understood some of it 3-No I did not understand it 4-Can't remember
When you were told you had cancer, were you given written information about the type of cancer you had?	Q15	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about the type of cancer I had 4-I did not need written information 5-Don't know / Can't remember
Before your cancer treatment started, were you given a choice of different types of treatment?	Q16	NUMBER	1-Yes 2-No but I would have liked a choice 3-I was not given a choice because only one type of treatment was suitable for me 4-Not sure / Can't remember
Were the possible side effects of treatment(s) explained in a way you could understand?	Q17	NUMBER	1-Yes definitely 2-Yes to some extent 3-No side effects were not explained 4-I did not need an explanation 5-Not sure / Can't remember
Before you started your treatment, were you given written information about the side effects of treatment(s)?	Q18	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about side effects 4-Don't know / Can't remember
Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?	Q19	NUMBER	1-Yes definitely 2-Yes to some extent 3-No but I would like to have been more involved 4-Only one type of treatment was suitable for me



Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?	Q20	NUMBER	1-Yes 2-No 3-Don't know / Not sure
How easy is it for you to contact your Clinical Nurse Specialist?	Q21	NUMBER	1-Easy 2-Sometimes easy sometimes difficult 3-Difficult 4-I have not tried to contact her/him
The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?	Q22	NUMBER	1-Yes definitely 2-Yes to some extent 3-No
When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	Q23	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I do not ask any questions
The last time you saw or spoke to your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?	Q24	NUMBER	1-Too short 2-About right 3-Too long
Did hospital staff give you information about support or self-help groups for people with cancer?	Q25	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
Did hospital staff give you information about how to get financial help or benefits?	Q26	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
Did hospital staff tell you that you could get free prescriptions?	Q27	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	Q28	NUMBER	1-Yes 2-No
The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?	Q29	NUMBER	1-No 2-Yes it was changed once 3-Yes it was changed 2 or 3 times 4-Yes it was changed 4 times or more
Before you had your operation, did a member of staff explain what would be done during the operation?	Q30	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember



Beforehand, were you given written information about your operation?	Q31	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about my operation 4-Don't know / Can't remember
After the operation, did a member of staff explain how it had gone in a way you could understand?	Q32	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation`
During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?	Q33	NUMBER	1-Yes 2-No
When you had important questions to ask a doctor, how often did you get answers that you could understand?	Q34	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the doctors treating you?	Q35	NUMBER	1-In all of them 2-In some of them 3-In none of them
Do you think the doctors treating you knew enough about how to treat your cancer?	Q36	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-Don't know / Not sure
Did doctors talk in front of you as if you weren't there?	Q37	NUMBER	1-Yes often 2-Yes sometimes 3-No
If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	Q38	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-No family or friends were involved 5-My family did not want or need information 6-I did not want my family or friends to talk to a doctor
When you had important questions to ask a ward nurse, how often did you get answers you could understand?	Q39	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the ward nurses treating you?	Q40	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did ward nurses talk in front of you as if you weren't there?	Q41	NUMBER	1-Yes often 2-Yes sometimes 3-No
In your opinion, were there enough nurses on duty to care for you in hospital?	Q42	NUMBER	1-There were always or nearly always enough on duty 2-There were sometimes enough on duty 3-There were rarely or never enough on duty



While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?	Q43	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?	Q44	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
Were you given enough privacy when discussing your condition or treatment?	Q45	NUMBER	1-Yes always 2-Yes sometimes 3-No
Were you given enough privacy when being examined or treated?	Q46	NUMBER	1-Yes always 2-Yes sometimes 3-No
Do you think the hospital staff did everything they could to help control your pain?	Q47	NUMBER	1-All of the time 2-Some of the time 3-Not at all 4-I did not have any pain
Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Q48	NUMBER	1-Always 2-Most of the time 3-Some of the time 4-Never
Were you given clear written information about what you should or should not do after leaving hospital?	Q49	NUMBER	1-Yes 2-No 3-Can't remember
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Q50	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Q51	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-No family or friends were involved 5-My family or friends did not want or need information 6-I did not want my family or friends to be given information
After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?	Q52	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-I did not need help from health or social services 5-Don't know / Can't remember



During the last 12 months, have you had radiotherapy at one of the hospitals named in the covering letter?	Q53	NUMBER	1-Yes 2-No
Did hospital staff do everything possible to control the side effects of radiotherapy?	Q54	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I have not had any side effects from radiotherapy
During the last 12 months, have you had chemotherapy at one of the hospitals named in the covering letter?	Q55	NUMBER	1-Yes 2-No
Did hospital staff do everything possible to control the side effects of chemotherapy?	Q56	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I have not had side effects from chemotherapy
While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	Q57	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I did not have any pain
While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	Q58	NUMBER	1-Yes definitely 2-Yes to some extent 3-No I would have liked more support 4-I did not need emotional support from staff
In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?	Q59	NUMBER	1-Yes 2-No
The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?	Q60	NUMBER	1-Seen on time or early 2-Waited up to 5 minutes 3-Waited 6 - 15 minutes 4-Waited 16 - 30 minutes 5-Waited 31 - 60 minutes 6-Waited 1 to 2 hours 7-Waited more than 2 hours 8-Don't know / Can't remember
The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or, about right?	Q61	NUMBER	1-Too short 2-About right 3-Too long



The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Q62	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Q63	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Q64	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-My general practice was not involved
Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Q65	NUMBER	1-Yes always 2-Yes most of the time 3-Yes some of the time 4-No never 5-Don't know
How much information were you given about your condition and treatment?	Q66	NUMBER	1-Not enough 2-The right amount 3-Too much
Sometimes people with cancer feel they are treated as "a set of cancer symptoms", rather than a whole person. In your NHS care over the last year, did you feel like that?	Q67	NUMBER	1-Yes often 2-Yes sometimes 3-No
In what year were you born?	Q68	NUMBER	Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Are you male or female?	Q69	NUMBER	1-Male 2-Female. Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Do you have any of the following longstanding conditions?...Deafness or severe hearing impairment	Q70a	NUMBER	1-Deafness or severe hearing impairment



Do you have any of the following longstanding conditions?...Blindness or partially sighted	Q70b	NUMBER	2-Blindness or partially sighted
Do you have any of the following longstanding conditions?...A long-standing physical condition	Q70c	NUMBER	3-A long-standing physical condition
Do you have any of the following longstanding conditions?...A learning disability	Q70d	NUMBER	4-A learning disability
Do you have any of the following longstanding conditions?...A mental health condition	Q70e	NUMBER	5-A mental health condition
Do you have any of the following longstanding conditions?...A long-standing illness, such as HIV diabetes, chronic heart disease, or epilepsy	Q70f	NUMBER	6-A long-standing illness such as HIV diabetes chronic heart disease or epilepsy
Do you have any of the following longstanding conditions?...No I do not have a longstanding condition	Q70g	NUMBER	7-No I do not have a longstanding condition
How long is it since you were first treated for this cancer?	Q71	NUMBER	1-Less than 1 year 2-1 to 5 years 3-More than 5 years 4-Don't know / Can't remember
Which of the following best describes your sexual orientation?	Q72	NUMBER	1-Heterosexual / straight (opposite sex) 2-Bisexual (both sexes) 3-Gay or Lesbian (same sex) 4-Other 5-Prefer not to answer. Please note that due to the sensitivity of this variable, explicit justification must be provided in your protocol as to why it is required.
Could we send you a survey in the future to ask about your health and healthcare?	Q73	NUMBER	1-Yes and I understand that this does not mean that I would have to take part in the future survey 2-No I would prefer you not to contact me again



To which of these ethnic groups would you say you belong?	Q74	NUMBER	<p>1-British 2-Irish 3-Any other White background 4-White and Black Caribbean 5-White and Black African 6-White and Asian 7-Any other mixed background 8-Indian 9-Pakistani 10-Bangladeshi 11-Any other Asian background 12-Caribbean 13-African 14-Any other Black background 15-Chinese 16-Any other ethnic group.</p> <p>Please note that you should request this variable grouped to the highest level of aggregation appropriate for your study, with explicit justification provided in your protocol as to why this variable is required and at what level.</p>
---	-----	--------	--



Wave 2 2012 Data Dictionary - Questions and Values

Column Description	Column Name	Field Type	Valid Content
CR patient Identifier	e_cr_patid	Number	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Q1	NUMBER	1-None I did not see my GP before going to hospital 2-I saw my GP once 3-I saw my GP twice 4-I saw my GP 3 or 4 times 5-I saw my GP 5 or more times 6-Don't know / Can't say
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Q2	NUMBER	1-I was seen as soon as I thought was necessary 2-I should have been seen a bit sooner 3-I should have been seen a lot sooner
How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?	Q3	NUMBER	1-Less than 3 months 2-3-6 months 3-6-12 months 4-More than 12 months 5-Don't know / Can't remember
Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?	Q4	NUMBER	1-My health got worse 2-My health got better 3-My health stayed about the same
In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Q5	NUMBER	1-Yes 2-No
Beforehand, did a member of staff explain the purpose of the test(s)?	Q6	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember
Beforehand, did a member of staff explain what would be done during the test procedure(s)?	Q7	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember



Beforehand, were you given written information about your test(s)?	Q8	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No but I would have liked written information about the test(s) 4-I did not need written information 5-Don't know / Can't remember
Were the results of the test(s) explained in a way you could understand?	Q9	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember
Who first told you that you had cancer?	Q10	NUMBER	1-A hospital doctor 2-A hospital nurse 3-A GP (family doctor) 4-Another health professional 5-A friend or relative 6-Nobody – I worked it out for myself
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Q11	NUMBER	1-Yes 2-No 3-It was not necessary 4-I was told by phone or letter 5-Don't know / Can't remember
How do you feel about the way you were told you had cancer?	Q12	NUMBER	1-It was done sensitively 2-It should have been done a bit more sensitively 3-It should have been done a lot more sensitively
Did you understand the explanation of what was wrong with you?	Q13	NUMBER	1-Yes, I completely understood it 2-Yes I understood some of it 3-No I did not understand it 4-Can't remember
When you were told you had cancer, were you given written information about the type of cancer you had?	Q14	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about the type of cancer I had 4-I did not need written information 5-Don't know / Can't remember
Before your cancer treatment started, were you given a choice of different types of treatment?	Q15	NUMBER	1-Yes 2-No but I would have liked a choice 3-I was not given a choice because only one type of treatment was suitable for me 4-Not sure / Can't remember
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	Q16	NUMBER	1-Yes definitely 2-Yes to some extent 3-No my views were not taken into account 4-I didn't know my treatment was being discussed by a team of doctors / nurses 5-Not sure / Can't remember
Were the possible side effects of treatment(s) explained in a way you could understand?	Q17	NUMBER	1-Yes definitely 2-Yes to some extent 3-No side effects were not explained 4-I did not need an explanation 5-Not sure / Can't remember
Before you started your treatment, were you given written information about the side effects of treatment(s)?	Q18	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about side effects 4-Don't know / Can't remember



Were you involved as much as you wanted to be in decisions about your care and treatment?	Q19	NUMBER	1-Yes definitely 2-Yes to some extent 3-No but I would like to have been more involved 4-Not sure / Can't remember
Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?	Q20	NUMBER	1-Yes 2-No 3-Don't know / Not sure
How easy is it for you to contact your Clinical Nurse Specialist?	Q21	NUMBER	1-Easy 2-Sometimes easy sometimes difficult 3-Difficult 4-I have not tried to contact her/him
The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?	Q22	NUMBER	1-Yes definitely 2-Yes to some extent 3-No
When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	Q23	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I do not ask any questions
Did hospital staff give you information about support or self-help groups for people with cancer?	Q24	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Q25	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
Did hospital staff tell you that you could get free prescriptions?	Q26	NUMBER	1-Yes 2-No but I would have liked information 3-It was not necessary 4-Don't know / Can't remember
Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Q27	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
If yes, were you glad to have been asked?	Q28	NUMBER	1-Yes 2-No
If no, would you have liked to have been asked?	Q29	NUMBER	1-Yes 2-No
During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	Q30	NUMBER	1-Yes 2-No



The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?	Q31	NUMBER	1-No 2-Yes it was changed once 3-Yes it was changed 2 or 3 times 4-Yes it was changed 4 times or more
Before you had your operation, did a member of staff explain what would be done during the operation?	Q32	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation 5-Don't know / Can't remember
Beforehand, were you given written information about your operation?	Q33	NUMBER	1-Yes and it was easy to understand 2-Yes but it was difficult to understand 3-No I was not given written information about my operation 4-Don't know / Can't remember
After the operation, did a member of staff explain how it had gone in a way you could understand?	Q34	NUMBER	1-Yes completely 2-Yes to some extent 3-No but I would have liked an explanation 4-I did not need an explanation`
During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?	Q35	NUMBER	1-Yes 2-No
When you had important questions to ask a doctor, how often did you get answers that you could understand?	Q36	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the doctors treating you?	Q37	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did doctors talk in front of you as if you weren't there?	Q38	NUMBER	1-Yes often 2-Yes sometimes 3-No
If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	Q39	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-No family or friends were involved 5-My family did not want or need information 6-I did not want my family or friends to talk to a doctor
When you had important questions to ask a ward nurse, how often did you get answers you could understand?	Q40	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the ward nurses treating you?	Q41	NUMBER	1-In all of them 2-In some of them 3-In none of them



Did ward nurses talk in front of you as if you weren't there?	Q42	NUMBER	1-Yes often 2-Yes sometimes 3-No
In your opinion, were there enough nurses on duty to care for you in hospital?	Q43	NUMBER	1-There were always or nearly always enough on duty 2-There were sometimes enough on duty 3-There were rarely or never enough on duty
While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?	Q44	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?	Q45	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Q46	NUMBER	1-Yes all of them did 2-Only some of them did 3-None of them did
Were you given enough privacy when discussing your condition or treatment?	Q47	NUMBER	1-Yes always 2-Yes sometimes 3-No
Were you given enough privacy when being examined or treated?	Q48	NUMBER	1-Yes always 2-Yes sometimes 3-No
Were you able to discuss any worries or fears with staff during your hospital visit?	Q49	NUMBER	1-As much as I wanted 2-Most of the time 3-Some of the time 4-Not at all but would have liked to 5-I did not have any worries or fears
Do you think the hospital staff did everything they could to help control your pain?	Q50	NUMBER	1-All of the time 2-Some of the time 3-Not at all 4-I did not have any pain
Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Q51	NUMBER	1-Always 2-Most of the time 3-Some of the time 4-Never
Were you given clear written information about what you should or should not do after leaving hospital?	Q52	NUMBER	1-Yes 2-No 3-Can't remember



Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Q53	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Q54	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-No family or friends were involved 5-My family or friends did not want or need information 6-I did not want my family or friends to be given information
After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?	Q55	NUMBER	1-Yes definitely 2-Yes to some extent 3-No 4-I did not need help from health or social services 5-Don't know / Can't remember
Did hospital staff do everything possible to control the side effects of radiotherapy?	Q56	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I have not had any side effects from radiotherapy 5-I have not had radiotherapy
Did hospital staff do everything possible to control the side effects of chemotherapy?	Q57	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I have not had any side effects from chemotherapy 5-I have not had chemotherapy
While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	Q58	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-I did not have any pain
While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	Q59	NUMBER	1-Yes definitely 2-Yes to some extent 3-No I would have liked more support 4-I did not need emotional support from staff
In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?	Q60	NUMBER	1-Yes 2-No
The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?	Q61	NUMBER	1-Seen on time or early 2-Waited up to 5 minutes 3-Waited 6 - 15 minutes 4-Waited 16 - 30 minutes 5-Waited 31 - 60 minutes 6-Waited 1 to 2 hours 7-Waited more than 2 hours 8-Don't know / Can't remember



The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or about right?	Q62	NUMBER	1-Too short 2-About right 3-Too long
The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Q63	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Q64	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Q65	NUMBER	1-Yes definitely 2-Yes to some extent 3-No they could have done more 4-My general practice was not involved
Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Q66	NUMBER	1-Yes always 2-Yes most of the time 3-Yes some of the time 4-No never 5-Don't know
How much information were you given about your condition and treatment?	Q67	NUMBER	1-Not enough 2-The right amount 3-Too much
Have you been offered a written assessment and care plan?	Q68	NUMBER	1-Yes 2-No 3-Don't know / Can't remember
Sometimes people with cancer feel they are treated as "a set of cancer symptoms", rather than a whole person. In your NHS care over the last year, did you feel like that?	Q69	NUMBER	1-Yes often 2-Yes sometimes 3-No
Overall, how would you rate your care?	Q70	NUMBER	1-Excellent 2-Very good 3-Good 4-Fair 5-Poor



In what year were you born?	Q71	NUMBER	Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Are you male or female?	Q72	NUMBER	1-Male 2-Female. Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Which of the following best describes your sexual orientation?	Q73	NUMBER	1-Heterosexual / straight (opposite sex) 2-Bisexual (both sexes) 3-Gay or Lesbian (same sex) 4-Other 5-Prefer not to answer. Please note that due to the sensitivity of this variable, explicit justification must be provided in your protocol as to why it is required.
Do you have any of the following longstanding conditions?...Deafness or severe hearing impairment	Q74a	NUMBER	1-Deafness or severe hearing impairment
Do you have any of the following longstanding conditions?...Blindness or partially sighted	Q74b	NUMBER	2-Blindness or partially sighted
Do you have any of the following longstanding conditions?...A long-standing physical condition	Q74c	NUMBER	3-A long-standing physical condition
Do you have any of the following longstanding conditions?...A learning disability	Q74d	NUMBER	4-A learning disability
Do you have any of the following longstanding conditions?...A mental health condition	Q74e	NUMBER	5-A mental health condition
Do you have any of the following longstanding conditions?...A long-standing illness, such as HIV diabetes, chronic heart disease, or epilepsy	Q74f	NUMBER	6-A long-standing illness such as HIV diabetes chronic heart disease or epilepsy
Do you have any of the following longstanding conditions?...No I do not have a longstanding condition	Q74g	NUMBER	7-No I do not have a longstanding condition



How long is it since you were first treated for this cancer?	Q75	NUMBER	1-Less than 1 year 2-1 to 5 years 3-More than 5 years 4-Don't know / Can't remember
Could we send you a survey in the future to ask about your health and healthcare?	Q76	NUMBER	1-Yes and I understand that this does not mean that I would have to take part in the future survey 2-No I would prefer you not to contact me again
To which of these ethnic groups would you say you belong?	Q77	NUMBER	1-British 2-Irish 3-Any other White background 4-White and Black Caribbean 5-White and Black African 6-White and Asian 7-Any other mixed background 8-Indian 9-Pakistani 10-Bangladeshi 11-Any other Asian background 12-Caribbean 13-African 14-Any other Black background 15-Chinese 16-Any other ethnic group. Please note that you should request this variable grouped to the highest level of aggregation appropriate for your study, with explicit justification provided in your protocol as to why this variable is required and at what level.



Wave 3 2013 Data Dictionary - Questions and Values

Column Description	Column Name	Field Type	Valid Content
CR patient Identifier	e_cr_patid	Number	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Q1	NUMBER	1-None - I did not see my GP before going to hospital 2-I saw my GP once 3-I saw my GP twice 4-I saw my GP 3 or 4 times 5-I saw my GP 5 or more times 6-Don't know / can't say
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Q2	NUMBER	1-I was seen as soon as I thought was necessary 2-I should have been seen a bit sooner 3-I should have been seen a lot sooner
How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?	Q3	NUMBER	1-Less than 3 months 2-3-6 months 3-6-12 months 4-More than 12 months 5-Don't know / can't remember
Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?	Q4	NUMBER	1-My health got worse 2-My health got better 3-My health stayed about the same
In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Q5	NUMBER	1-Yes 2-No
Beforehand, did a member of staff explain the purpose of the test(s)?	Q6	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Beforehand, did a member of staff explain what would be done during the test procedure(s)?	Q7	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember



Beforehand, were you given written information about your test(s)?	Q8	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, but I would have liked written information about the test(s) 4-I did not need written information 5-Don't know / can't remember
Were the results of the test(s) explained in a way you could understand?	Q9	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Who first told you that you had cancer?	Q10	NUMBER	1-A hospital doctor 2-A hospital nurse 3-A GP (family doctor) 4-Another health professional 5-A friend or relative 6-Nobody - I worked it out for myself
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Q11	NUMBER	1-Yes 2-No 3-It was not necessary 4-I was told by phone or letter 5-Don't know / can't remember
How do you feel about the way you were told you had cancer?	Q12	NUMBER	1-It was done sensitively 2-It should have been done a bit more sensitively 3-It should have been done a lot more sensitively
Did you understand the explanation of what was wrong with you?	Q13	NUMBER	1-Yes, I completely understood it 2-Yes, I understood some of it 3-No, I did not understand it 4-Can't remember
When you were told you had cancer, were you given written information about the type of cancer you had?	Q14	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about the type of cancer I had 4-I did not need written information 5-Don't know / can't remember
Before your cancer treatment started, were you given a choice of different types of treatment?	Q15	NUMBER	1-Yes 2-No, but I would have liked a choice 3-I was given a choice because only one type of treatment was suitable for me 4-Not sure / can't remember
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	Q16	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, my views were not taken into account 4-I didn't know my treatment was being discussed by a team of doctors / nurses 5-Not sure / can't remember
Were the possible side effects of treatment(s) explained in a way you could understand?	Q17	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, side effects were not explained 4-I did not need an explanation 5-Not sure / can't remember
Before you started your treatment, were you given written information about the side effects of treatment(s)?	Q18	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about side effects 4-Don't know / can't remember



Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	Q19	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, future side effects were not explained 4-I did not need an explanation 5-Not sure / can't remember
Were you involved as much as you wanted to be in decisions about your care and treatment?	Q20	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, but I would like to have been more involved 4-Not sure / can't remember
Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?	Q21	NUMBER	1-Yes 2-No 3-Don't know / not sure
How easy is it for you to contact your Clinical Nurse Specialist?	Q22	NUMBER	1-Easy 2-Sometimes easy, sometimes difficult 3-Difficult 4-I have not tried to contact her/him
The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?	Q23	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No
When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	Q24	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I do not ask any questions
Did hospital staff give you information about support or self-help groups for people with cancer?	Q25	NUMBER	1-Yes 2-No, but I would have liked information 3-It was necessary 4-Don't know / can't remember
Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?	Q26	NUMBER	1-Yes 2-No, but I would have liked a discussion or information 3-It was not necessary / relevant to me 4-Don't know / can't remember
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Q27	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
Did hospital staff tell you that you could get free prescriptions?	Q28	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
Have you seen information (such as leaflets, posters, information screens etc.) about cancer research in your hospital?	Q29	NUMBER	1-Yes 2-No



Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Q30	NUMBER	1-Yes 2-No 3-Don't know / can't remember
If yes, did you then go on to take part in cancer research?	Q31	NUMBER	1-Yes 2-No
During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	Q32	NUMBER	1-Yes 2-No
Before you had your operation, did a member of staff explain what would be done during the operation?	Q33	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Beforehand, were you given written information about your operation?	Q34	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about my operation 4-Don't know / can't remember
After the operation, did a member of staff explain how it had gone in a way you could understand?	Q35	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation
During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?	Q36	NUMBER	1-Yes 2-No
When you had important questions to ask a doctor, how often did you get answers that you could understand?	Q37	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the doctors treating you?	Q38	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did doctors talk in front of you as if you weren't there?	Q39	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	Q40	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family did not want or need information 6-I did not want my family or friends to talk to a doctor



When you had important questions to ask a ward nurse, how often did you get answers you could understand?	Q41	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the ward nurses treating you?	Q42	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did ward nurses talk in front of you as if you weren't there?	Q43	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
In your opinion, were there enough nurses on duty on care for you in hospital?	Q44	NUMBER	1-There were always or nearly always enough on duty 2-There were sometimes enough on duty 3-There were rarely or never enough on duty
While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?	Q45	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something completely different?	Q46	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Q47	NUMBER	1-Yes, all of them did 2-Only some of them did 3-None of them did
Were you given enough privacy when discussing your condition or treatment?	Q48	NUMBER	1-Yes, always 2-Yes, sometimes 3-No
Were you given enough privacy when being examined or treated?	Q49	NUMBER	1-Yes, sometimes 2-Yes, sometimes 3-No
Were you able to discuss any worries or fears with staff during your hospital visit?	Q50	NUMBER	1-As much as I wanted 2-Most of the time 3-Some of the time 4-Not at all, but would have liked to 5-I did not have any worries or fears
Do you think the hospital staff did everything they could to help control your pain?	Q51	NUMBER	1-All of the time 2-Some of the time 3-Not at all 4-I did not have any pain



Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Q52	NUMBER	1-Always 2-Most of the time 3-Some of the time 4-Never
Were you given clear written information about what you should or should not do after leaving hospital?	Q53	NUMBER	1-Yes 2-No 3-Can't remember
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Q54	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Q55	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family or friends did not want or need information 6-I did not want my family or friends to be given information
After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?	Q56	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-I did not need help from health or social services 5-Don't know / can't remember
Did hospital staff do everything possible to control the side effects of radiotherapy?	Q57	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I have not had any side effects from radiotherapy 5-I have not had radiotherapy
Did hospital staff do everything possible to control the side effects of chemotherapy?	Q58	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I have not had any side effects from chemotherapy 5-I have not had chemotherapy
While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	Q59	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I did not have any pain
While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	Q60	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, I would have liked more support 4-I did not need emotional support from staff
In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?	Q61	NUMBER	1-Yes 2-No



The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Q62	NUMBER	1-Yes 2-No 3-Don't know / can't remember
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Q63	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Q64	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-My general practice was not involved
Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Q65	NUMBER	1-Yes, always 2-Yes, most of the time 3-Yes, some of the time 4-No, never 5-Don't know
Have you had any treatment from any of the following for your cancer? Physiotherapist	Q66a	NUMBER	1-Physiotherapist
Have you had any treatment from any of the following for your cancer? Occupational therapist (OT)	Q66b	NUMBER	2-Occupational therapist (OT)
Have you had any treatment from any of the following for your cancer? Dietician	Q66c	NUMBER	3-Dietician
Have you had any treatment from any of the following for your cancer? Speech and language therapist	Q66d	NUMBER	4-Speech and language therapist
Have you had any treatment from any of the following for your cancer? Lymphoedema specialist	Q66e	NUMBER	5-Lymphoedema specialist
How much information were you given about your condition and treatment?	Q67	NUMBER	1-Not enough 2-The right amount 3-Too much



Have you been offered a written assessment and care plan?	Q68	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Sometimes people with cancer feel they are treated as "a set of cancer symptoms", rather than a whole person. In your NHS care over the last year did you feel like that?	Q69	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
Overall, how would you rate your care?	Q70	NUMBER	1-Excellent 2-Very good 3-Good 4-Fair 5-Poor
What year were you born?	Q71	NUMBER	Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Are you male or female?	Q72	NUMBER	1-Male 2-Female. Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Which of the following best describes your sexual orientation?	Q73	NUMBER	1-Heterosexual / straight (opposite sex) 2-Bisexual (both sexes) 3-Gay or Lesbian (same sex) 4-Other 5-Prefer not to answer. Please note that due to the sensitivity of this variable, explicit justification must be provided in your protocol as to why it is required.
What is your main employment status?	Q74	NUMBER	1-Full time employment 2-Part time employment 3-Homemaker 4-Student (in education) 5-Retired 6-Unemployed - and seeking work 7-Unemployed - unable to work for health reasons 8-Other
Do you have any of the following longstanding conditions? Deafness or severe hearing impairment	Q75a	NUMBER	1-Deafness or severe hearing impairment
Do you have any of the following longstanding conditions? Blindness or partially sighted	Q75b	NUMBER	2-Blindness or partially sighted
Do you have any of the following longstanding conditions? A long-standing physical condition	Q75c	NUMBER	3-A long-standing physical condition



Do you have any of the following longstanding conditions? A learning disability	Q75d	NUMBER	4-A learning disability
Do you have any of the following longstanding conditions? A mental health condition	Q75e	NUMBER	5-A mental health condition
Do you have any of the following longstanding conditions? A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy	Q75f	NUMBER	6-A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
Do you have any of the following longstanding conditions? No, I do not have a long-standing condition	Q75g	NUMBER	7-No, I do not have a long-standing condition
How long is it since you were first treated for this cancer?	Q76	NUMBER	1-Less than 1 year 2-1 to 5 years 3-More than 5 years 4-Don't know / can't remember
How has your cancer responded to treatment?	Q77	NUMBER	1-My cancer has responded fully to treatment (I have no signs or symptoms of cancer) 2-My cancer has been treated but is still present 3-My cancer has not been treated at all 4-My cancer has come back after it was originally treated 5-My original cancer responded but I now have a new cancer 6-I am not certain what is happening with my cancer
Could we send you a survey in the future to ask about your health and healthcare?	Q78	NUMBER	1-Yes, and I understand that this does not mean that I would have to take part in the future survey 2-No, I would prefer you not to contact me again
What is your ethnic background?	Q79	NUMBER	1-British 2-Irish 3-Any other White background 4-White and Black Caribbean 5-White and Black African 6-White and Asian 7-Any other mixed background 8-Indian 9-Pakistani 10-Bangladeshi 11-Any other Asian background 12-Caribbean 13-African 14-Any other Black background 15-Chinese 16-Any other ethnic background. Please note that you should request this variable grouped to the highest level of aggregation appropriate for your study, with explicit justification provided in your protocol as to why this variable is required and at what level.



Wave 4 2014 Data Dictionary - Questions and Values

Column Description	Column Name	Field Type	Valid Content
CR patient Identifier	e_cr_patid	Number	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Q1	NUMBER	1-None - I did not see my GP before going to hospital 2-I saw my GP once 3-I saw my GP twice 4-I saw my GP 3 or 4 times 5-I saw my GP 5 or more times 6-Don't know / can't say
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Q2	NUMBER	1-I was seen as soon as I thought was necessary 2-I should have been seen a bit sooner 3-I should have been seen a lot sooner
How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?	Q3	NUMBER	1-Less than 3 months 2-3-6 months 3-6-12 months 4-More than 12 months 5-Don't know / can't remember
Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?	Q4	NUMBER	1-My health got worse 2-My health got better 3-My health stayed about the same
In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Q5	NUMBER	1-Yes 2-No
Beforehand, did a member of staff explain the purpose of the test(s)?	Q6	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Beforehand, did a member of staff explain what would be done during the test procedure(s)?	Q7	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember



Beforehand, were you given written information about your test(s)?	Q8	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, but I would have liked written information about the test(s) 4-I did not need written information 5-Don't know / can't remember
Were the results of the test(s) explained in a way you could understand?	Q9	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Who first told you that you had cancer?	Q10	NUMBER	1-A hospital doctor 2-A hospital nurse 3-A GP (family doctor) 4-Another health professional 5-A friend or relative 6-Nobody – I worked it out for myself
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Q11	NUMBER	1-Yes 2-No 3-It was not necessary 4-I was told by phone or letter 5-Don't know / can't remember
How do you feel about the way you were told you had cancer?	Q12	NUMBER	1-It was done sensitively 2-It should have been done a bit more sensitively 3-It should have been done a lot more sensitively
Did you understand the explanation of what was wrong with you?	Q13	NUMBER	1-Yes, I completely understood it 2-Yes, I understood some of it 3-No, I did not understand it 4-Can't remember
When you were told you had cancer, were you given written information about the type of cancer you had?	Q14	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about the type of cancer I had 4-I did not need written information 5-Don't know / can't remember
Before your cancer treatment started, were you given a choice of different types of treatment?	Q15	NUMBER	1-Yes 2-No, but I would have liked a choice 3-I was given a choice because only one type of treatment was suitable for me 4-Not sure / can't remember
Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?	Q16	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, my views were not taken into account 4-I didn't know my treatment was being discussed by a team of doctors / nurses 5-Not sure / can't remember
Were the possible side effects of treatment(s) explained in a way you could understand?	Q17	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, side effects were not explained 4-I did not need an explanation 5-Not sure / can't remember
Before you started your treatment, were you given written information about the side effects of treatment(s)?	Q18	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about side effects 4-Don't know / can't remember



Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	Q19	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, future side effects were not explained 4-I did not need an explanation 5-Not sure / can't remember
Were you involved as much as you wanted to be in decisions about your care and treatment?	Q20	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, but I would like to have been more involved 4-Not sure / can't remember
Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?	Q21	NUMBER	1-Yes 2-No 3-Don't know / not sure
How easy is it for you to contact your Clinical Nurse Specialist?	Q22	NUMBER	1-Easy 2-Sometimes easy, sometimes difficult 3-Difficult 4-I have not tried to contact her/him
The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?	Q23	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No
When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	Q24	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I do not ask any questions
Did hospital staff give you information about support or self-help groups for people with cancer?	Q25	NUMBER	1-Yes 2-No, but I would have liked information 3-It was necessary 4-Don't know / can't remember
Did hospital staff discuss with you or give you information about the impact cancer could have on your work life or education?	Q26	NUMBER	1-Yes 2-No, but I would have liked a discussion or information 3-It was not necessary / relevant to me 4-Don't know / can't remember
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Q27	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
Did hospital staff tell you that you could get free prescriptions?	Q28	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
Have you seen information (such as leaflets, posters, information screens etc.) about cancer research in your hospital?	Q29	NUMBER	1-Yes 2-No



Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Q30	NUMBER	1-Yes 2-No 3-Don't know / can't remember
If yes, did you then go on to take part in cancer research?	Q31	NUMBER	1-Yes 2-No
During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	Q32	NUMBER	1-Yes 2-No
Before you had your operation, did a member of staff explain what would be done during the operation?	Q33	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation 5-Don't know / can't remember
Beforehand, were you given written information about your operation?	Q34	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about my operation 4-Don't know / can't remember
After the operation, did a member of staff explain how it had gone in a way you could understand?	Q35	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation
During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?	Q36	NUMBER	1-Yes 2-No
When you had important questions to ask a doctor, how often did you get answers that you could understand?	Q37	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the doctors treating you?	Q38	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did doctors talk in front of you as if you weren't there?	Q39	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	Q40	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family did not want or need information 6-I did not want my family or friends to talk to a doctor



When you had important questions to ask a ward nurse, how often did you get answers you could understand?	Q41	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I did not ask any questions
Did you have confidence and trust in the ward nurses treating you?	Q42	NUMBER	1-In all of them 2-In some of them 3-In none of them
Did ward nurses talk in front of you as if you weren't there?	Q43	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
In your opinion, were there enough nurses on duty on care for you in hospital?	Q44	NUMBER	1-There were always or nearly always enough on duty 2-There were sometimes enough on duty 3-There were rarely or never enough on duty
While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?	Q45	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something completely different?	Q46	NUMBER	1-Often 2-Sometimes 3-Only once 4-Never
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Q47	NUMBER	1-Yes, all of them did 2-Only some of them did 3-None of them did
Were you given enough privacy when discussing your condition or treatment?	Q48	NUMBER	1-Yes, always 2-Yes, sometimes 3-No
Were you given enough privacy when being examined or treated?	Q49	NUMBER	1-Yes, sometimes 2-Yes, sometimes 3-No
Were you able to discuss any worries or fears with staff during your hospital visit?	Q50	NUMBER	1-As much as I wanted 2-Most of the time 3-Some of the time 4-Not at all, but would have liked to 5-I did not have any worries or fears
Do you think the hospital staff did everything they could to help control your pain?	Q51	NUMBER	1-All of the time 2-Some of the time 3-Not at all 4-I did not have any pain



Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Q52	NUMBER	1-Always 2-Most of the time 3-Some of the time 4-Never
Were you given clear written information about what you should or should not do after leaving hospital?	Q53	NUMBER	1-Yes 2-No 3-Can't remember
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Q54	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Q55	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family or friends did not want or need information 6-I did not want my family or friends to be given information
After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?	Q56	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-I did not need help from health or social services 5-Don't know / can't remember
Did hospital staff do everything possible to control the side effects of radiotherapy?	Q57	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I have not had any side effects from radiotherapy 5-I have not had radiotherapy
Did hospital staff do everything possible to control the side effects of chemotherapy?	Q58	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I have not had any side effects from chemotherapy 5-I have not had chemotherapy
While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	Q59	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-I did not have any pain
While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	Q60	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, I would have liked more support 4-I did not need emotional support from staff
In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?	Q61	NUMBER	1-Yes 2-No



The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Q62	NUMBER	1-Yes 2-No 3-Don't know / can't remember
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Q63	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Q64	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-My general practice was not involved
Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Q65	NUMBER	1-Yes, always 2-Yes, most of the time 3-Yes, some of the time 4-No, never 5-Don't know
Have you had any treatment from any of the following for your cancer? Physiotherapist	Q66a	NUMBER	1-Physiotherapist
Have you had any treatment from any of the following for your cancer? Occupational therapist (OT)	Q66b	NUMBER	2-Occupational therapist (OT)
Have you had any treatment from any of the following for your cancer? Dietician	Q66c	NUMBER	3-Dietician
Have you had any treatment from any of the following for your cancer? Speech and language therapist	Q66d	NUMBER	4-Speech and language therapist
Have you had any treatment from any of the following for your cancer? Lymphoedema specialist	Q66e	NUMBER	5-Lymphoedema specialist
How much information were you given about your condition and treatment?	Q67	NUMBER	1-Not enough 2-The right amount 3-Too much



Have you been offered a written assessment and care plan?	Q68	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Sometimes people with cancer feel they are treated as "a set of cancer symptoms", rather than a whole person. In your NHS care over the last year did you feel like that?	Q69	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
Overall, how would you rate your care?	Q70	NUMBER	1-Excellent 2-Very good 3-Good 4-Fair 5-Poor
What year were you born?	Q71	NUMBER	Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Are you male or female?	Q72	NUMBER	1-Male 2-Female. Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Which of the following best describes your sexual orientation?	Q73	NUMBER	1-Heterosexual / straight (opposite sex) 2-Bisexual (both sexes) 3-Gay or Lesbian (same sex) 4-Other 5-Prefer not to answer. Please note that due to the sensitivity of this variable, explicit justification must be provided in your protocol as to why it is required.
What is your main employment status?	Q74	NUMBER	1-Full time employment 2-Part time employment 3-Homemaker 4-Student (in education) 5-Retired 6-Unemployed - and seeking work 7-Unemployed - unable to work for health reasons 8-Other
Do you have any of the following longstanding conditions? Deafness or severe hearing impairment	Q75a	NUMBER	1-Deafness or severe hearing impairment
Do you have any of the following longstanding conditions? Blindness or partially sighted	Q75b	NUMBER	2-Blindness or partially sighted
Do you have any of the following longstanding conditions? A long-standing physical condition	Q75c	NUMBER	3-A long-standing physical condition



Do you have any of the following longstanding conditions? A learning disability	Q75d	NUMBER	4-A learning disability
Do you have any of the following longstanding conditions? A mental health condition	Q75e	NUMBER	5-A mental health condition
Do you have any of the following longstanding conditions? A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy	Q75f	NUMBER	6-A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
Do you have any of the following longstanding conditions? No, I do not have a long-standing condition	Q75g	NUMBER	7-No, I do not have a long-standing condition
How long is it since you were first treated for this cancer?	Q76	NUMBER	1-Less than 1 year 2-1 to 5 years 3-More than 5 years 4-Don't know / can't remember
Is this the first time you have been treated for cancer?	Q77	NUMBER	1-Yes, this is the first time I have been treated for cancer 2-No, I have been treated for the same type of cancer before but it has now come back 3-No, I have been treated for a different type of cancer before
How has your current cancer responded to treatment?	Q78	NUMBER	1-Treatment has not yet started for this cancer 2-I am in the course of treatment and I can't tell yet how my cancer has responded 3-The treatment has been effective and I have no signs or symptoms of cancer 4-I have finished the course of treatment but my cancer is still present 5-My cancer is being treated again because it has not responded fully to treatment 6-I am not in active treatment but I am on "Watch and Wait" 7-My cancer has not been treated at all
Could we send you a survey in the future to ask about your health and healthcare?	Q79	NUMBER	1-Yes, and I understand that this does not mean that I would have to take part in the future survey 2-No, I would prefer you not to contact me again



What is your ethnic group?	Q80	NUMBER	<p>1-English / Welsh / Scottish / Northern Irish / British 2-Irish 3-Gypsy or Irish Traveller 4-Any other White background 5-White and Black Caribbean 6-White and Black African 7-White and Asian 8-Any other Mixed / multiple ethnic background 9-Indian 10-Pakistani 11-Bangladeshi 12-Chinese 13-Any other Asian background 14-African 15-Caribbean 16-Any other Black / African / Caribbean background 17-Arab 18-Any other ethnic group.</p> <p>Please note that you should request this variable grouped to the highest level of aggregation appropriate for your study, with explicit justification provided in your protocol as to why this variable is required and at what level.</p>
----------------------------	-----	--------	--



Wave 5 2015 Data Dictionary - Questions and Values

Column Description	Column Name	Field Type	Valid Content
CR patient Identifier	e_cr_patid	Number	Unique patient identifier based on ENCORE data. In some cases, the same person may have multiple patient IDs. Patient IDs will be retained even after two patient records are found to be the same person.
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	Q1	NUMBER	1-None - I went straight to hospital 2-None – I went to hospital following a cancer screening appointment 3-I saw my GP once 4-I saw my GP twice 5-I saw my GP 3 or 4 times 6-I saw my GP 5 or more times 7-Don't know / can't remember
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Q2	NUMBER	1-I was seen as soon as I thought was necessary 2-I should have been seen a bit sooner 3-I should have been seen a lot sooner
How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?	Q3	NUMBER	1-Less than 3 months 2- 3-6 months 3- 6-12 months 4- More than 12 months 5-Don't know / can't remember
In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Q4	NUMBER	1-Yes 2-No
Beforehand, did you have all the information you needed about your test? (Yes)	Q5a	NUMBER	1 - Yes



Beforehand, did you have all the information you needed about your test? (No, I would have liked more written information)	Q5b	NUMBER	2- No, I would have liked more written information
Beforehand, did you have all the information you needed about your test? (No, I would have liked more verbal information)	Q5c	NUMBER	3- No, I would have liked more verbal information
Beforehand, did you have all the information you needed about your test? (I did not need/want any information)	Q5d	NUMBER	4 - I did not need/want any information
Beforehand, did you have all the information you needed about your test? (Don't know/ Can't remember)	Q5e	NUMBER	5- Don't know/ Can't remember
Overall, how did you feel about the length of time you had to wait for your test to be done?	Q6	NUMBER	1-It was about right 2-It was a little too long 3-It was much too long 4-Don't know \ Can't remember
Were the results of the test explained in a way you could understand?	Q7	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, I did not understand the explanation 4- I did not have an explanation but would have liked one 5-I did not need an explanation 6- Don't know / can't remember
When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Q8	NUMBER	1-Yes 2-No 3-It was not necessary 4-I was told by phone or letter 5-Don't know / can't remember



How do you feel about the way you were told you had cancer?	Q9	NUMBER	1-It was done sensitively 2-It should have been done a bit more sensitively 3-It should have been done a lot more sensitively
Did you understand the explanation of what was wrong with you?	Q10	NUMBER	1-Yes, I completely understood it 2-Yes, I understood some of it 3-No, I did not understand it 4- Don't know/ Can't remember
When you were told you had cancer, were you given written information about the type of cancer you had?	Q11	NUMBER	1-Yes, and it was easy to understand 2-Yes, but it was difficult to understand 3-No, I was not given written information about the type of cancer I had 4-I did not need written information 5-Don't know / can't remember
Before your cancer treatment started, were your treatment options explained to you?	Q12	NUMBER	1- Yes, completely 2- Yes, to some extent 3 – No 4 – There was only one type of treatment that was suitable for me 5- Don't know\ Can't remember
Were the possible side effects of treatment(s) explained in a way you could understand?	Q13	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, side effects were not explained 4-I did not need an explanation 5- Don't know / can't remember
Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	Q14	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, I was not offered any practical advice or support 4- Don't know / can't remember
Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	Q15	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, future side effects were not explained 4-I did not need an explanation 5- Don't know / can't remember
Were you involved as much as you wanted to be in decisions about your care and treatment?	Q16	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, but I would like to have been more involved 4- Don't know / can't remember
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	Q17	NUMBER	1-Yes 2-No 3-Don't know / not sure



How easy is it for you to contact your Clinical Nurse Specialist?	Q18	NUMBER	1- Very easy 2- Quite easy 3 – Neither easy nor difficult 4- Quite difficult 5- Very difficult 6-I have not tried to contact my Clinical Nurse Specialist
When you have important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	Q19	NUMBER	1-All or most of the time 2-Some of the time 3-Rarely or never 4-I have not asked any questions
Did hospital staff give you information about support of self-help groups for people with cancer?	Q20	NUMBER	1- Yes 2- No, but I would have liked information 3- It was not necessary 4 – Don't know / Can't remember
Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	Q21	NUMBER	1-Yes 2-No, but I would have liked a discussion or information 3-It was not necessary / relevant to me 4-Don't know / can't remember
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Q22	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
Did hospital staff tell you that you could get free prescriptions?	Q23	NUMBER	1-Yes 2-No, but I would have liked information 3-It was not necessary 4-Don't know / can't remember
During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	Q24	NUMBER	1-Yes 2-No
Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Q25a	NUMBER	1- Yes



Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Q25b	NUMBER	2- No, I would have liked more written information
Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Q25c	NUMBER	3- No, I would have liked more verbal information
Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Q25d	NUMBER	4- I did not need/want information
Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Q25e	NUMBER	5- Don't know/ Can't remember
After the operation, did a member of staff explain how it had gone in a way you could understand?	Q26	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No, but I would have liked an explanation 4-I did not need an explanation
During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?	Q27	NUMBER	1-Yes 2-No
Did groups of doctors and nurses talk in front of you as if you weren't there?	Q28	NUMBER	1-Yes, often 2-Yes, sometimes 3-No
Did you have confidence and trust in the doctors treating you?	Q29	NUMBER	1- Yes, in all of them 2- Yes, in some of them 3- No, in none of them
If your family or someone else close to you wanted to talk to a doctor, were they able to?	Q30	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family did not want or need information 6-I did not want my family or friends to talk to a doctor



Did you have confidence and trust in the ward nurses treating you?	Q31	NUMBER	1-Yes, in all of them 2- Yes, in some of them 3- No, in none of them
In your opinion, were there enough nurses on duty on care for you in hospital?	Q32	NUMBER	1-There were always or nearly always enough on duty 2- There were sometimes enough on duty 3-There were rarely or never enough on duty
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Q33	NUMBER	1-Yes, all of them did 2-Only some of them did 3-None of them did
Were you given enough privacy when discussing your condition or treatment?	Q34	NUMBER	1-Yes, always 2-Yes, sometimes 3-No
During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	Q35	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-I had no worries or fears
Do you think the hospital staff did everything they could to help control your pain?	Q36	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-I did not have any pain
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Q37	NUMBER	1-Yes, always 2- Yes, sometimes 3- No
Were you given clear written information about what you should or should not do after leaving hospital?	Q38	NUMBER	1-Yes 2-No 3- Don't know/ can't remember
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Q39	NUMBER	1-Yes 2-No 3-Don't know / can't remember
During the last 12 months, have you been treated as an outpatient or day case for cancer care at one of the hospitals named in the covering letter?	Q40	NUMBER	1-Yes 2-No



While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	Q41	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-I had no worries or fears
The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Q42	NUMBER	1-Yes 2-No 3- I didn't have an appointment with a cancer doctor 4- Don't know / can't remember
During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?	Q43	NUMBER	1-Yes 2-No
Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Q44	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No 4-I did not need any information
Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	Q45	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No 4- It is too early to know if my radiotherapy is 5-I did not need any information
During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?	Q46	NUMBER	1-Yes 2-No
Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Q47	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No 4-I did not need any information



Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	Q48	NUMBER	1-Yes, completely 2-Yes, to some extent 3-No 4-It is too early to know if my chemotherapy is working 5-I did not need any information
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Q49	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4-No family or friends were involved 5-My family or friends did not want or need information 6-I did not want my family or friends to be given information
During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Q50	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4- I did not need help from health or social services 5- Don't know / Can't remember
Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Q51	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No 4- I did not need help from health or social services 5- I am still having treatment 6- Don't know / Can't remember
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Q52	NUMBER	1-Yes 2-No 3-Don't know / can't remember
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Q53	NUMBER	1-Yes, definitely 2-Yes, to some extent 3-No, they could have done more 4-My general practice was not involved
Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Q54	NUMBER	1-Yes, always 2-Yes, most of the time 3-Yes, some of the time 4-No, never 5-Don't know/ can't remember



Have you been given a care plan?	Q55	NUMBER	1-Yes 2-No 3- I Do not know / understand what a care plan is 4- Don't know / can't remember
Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?	Q56	NUMBER	1--Very good 2-Good 3- Neither good nor bad 4- Quite bad 5 – Very bad 6- Don't know / can't remember
Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	Q57	NUMBER	1- It was much too long 2- It was a little too long 3- It was about right - Don't know /can't remember
Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Q58	NUMBER	1-Yes 2-No 3-No, but I would have liked them to 4-Don't know / can't remember
Overall, how would you rate your care?	Q59	NUMBER	Scale: 0-10
How long is it since you were first treated for this cancer?	Q60	NUMBER	1-Less than 1 year 2-1 to 5 years 3-More than 5 years 4- Don't know / can't remember
Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?	Q61	NUMBER	1-Yes 2-No 3-Don't know 4- Does not apply to my type of cancer
Which of the following applies?	Q62	NUMBER	1-My cancer has been taken out / treated, without any sign of further problem 2- My cancer was taken out / treated without any sign of further problem, but has since come back / spread to other parts of my body 3- None of the above options apply to my type of cancer 4- I would prefer not to say 5 – I don't know
What year were you born?	Q63	NUMBER	Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient



Are you male or female?	Q64	NUMBER	1-Male 2-Female. Explicit justification must be provided in your protocol as to why this variable is required and the year of birth recorded in primary care / cancer registration data are not sufficient
Which of the following options best describes how you think of yourself?	Q65	NUMBER	1-Heterosexual / straight (opposite sex) 2-Bisexual (both sexes) 3-Gay or Lesbian (same sex) 4-Other 5-Prefer not to answer. Please note that due to the sensitivity of this variable, explicit justification must be provided in your protocol as to why it is required.
Do you have any of the following longstanding conditions? Deafness or severe hearing impairment	Q66a	NUMBER	1-Deafness or severe hearing impairment
Do you have any of the following longstanding conditions? Blindness or partially sighted	Q66b	NUMBER	2-Blindness or partially sighted
Do you have any of the following longstanding conditions? A long-standing physical condition	Q66c	NUMBER	3-A long-standing physical condition
Do you have any of the following longstanding conditions? A learning disability	Q66d	NUMBER	4-A learning disability
Do you have any of the following longstanding conditions? A mental health condition	Q66e	NUMBER	5-A mental health condition
Do you have any of the following longstanding conditions? A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy	Q66f	NUMBER	6-A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
Could we send you a survey in the future to ask about your health and healthcare?	Q67	NUMBER	1-Yes, and I understand that this does not mean that I would have to take part in the future survey 2-No, I would prefer you not to contact me again



Is English your first language?	Q68	NUMBER	1 – Yes 2- No
What is your ethnic group?	Q69	NUMBER	1-English / Welsh / Scottish / Northern Irish / British 2-Irish 3-Gypsy or Irish Traveller 4-Any other White background 5- White and Black Caribbean 6-White and Black African 7- White and Asian 8-Any other Mixed / multiple ethnic background 9-Indian 10-Pakistani 11-Bangladeshi 12- Chinese 13-Any other Asian background 14-African 15- Caribbean 16-Any other Black / African / Caribbean background 17-Arab 18-Any other ethnic group. Please note that you should request this variable grouped to the highest level of aggregation appropriate for your study, with explicit justification provided in your protocol as to why this variable is required and at what level.