

UK Cancer Costs Questionnaire (UKCC) Version 3.0

The UKCC is a modular questionnaire designed to capture the resources used by people with a current or previous diagnosis of cancer.

The design of this questionnaire prioritises brevity in an attempt to minimise the burden of data collection on participants and research personnel. The tool is designed to be used alongside a clinical trial or trial-standard data collection within an observational study, without duplicating standard data collection on case report forms. Each question can be used in isolation. Captured activity includes NHS care, NHS community care, medications and personal social services. Societal costs are also captured including patient out-of-pocket costs, costs incurred by carers and time taken off work. The tool has been developed in the context of a series of UK clinical trials including OPTIMA, Mammo-50, Persephone, PETNECK, SABRTOOTH, STAR, ACUFOCIN, EMT-2, ENeRgy, MABEL. ABC Survivourship, CardiacCARE and others in various cancer populations including breast, lung, bowel and kidney cancers. This document contains wording only; formatting may vary. The questions can be administered on paper, over the web or over the phone.

The UKCC is undergoing further development as part of a collaboration between with Health Economics departments at the Universities of Edinburgh, Exeter and Leeds. Comments and contributions are welcome via p.s.hall@ed.ac.uk.

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THE UNIVERSITY
of **EDINBURGH**



UNIVERSITY OF LEEDS

UNIVERSITY OF
EXETER

To be completed at baseline

Date of Completion:	_____
Patient Initials:	_____
Participant Trial Number:	_____

Completion Instructions

When you entered the trial you kindly agreed to complete this questionnaire. This is an important part of the trial and we would very much appreciate your efforts in completing and returning it. A research nurse can assist you if required.

The following pages contain questions that relate to you, your present health and how any treatment is affecting you.

Once you have completed the questionnaire please just hand it to a research nurse.

Thank you very much for your time and effort.

Employment and Support

When you are answering these questions **please consider your situation over the last three months.**

1. Were you in employment before you started treatment?

Yes No

If yes, how much time have you taken off work due to your health

_____ days per week

If yes, how much income have you lost due to your health and its treatment?

£ _____

2. Have you received help or support from family or friends?

Yes No

If yes, how much time have they typically spent helping you?

_____ hours per week

If you answered yes to receiving support from family or friends:

Did they take any time off work to help or support you?

Yes No

If yes, how much time did they typically take off?

_____ days per week

3. Are you receiving help, care or support from any other person or organisation (e.g. governmental, charities, church)?

Yes No

If yes, please name the organisation(s):

Organisation 1: _____

_____ hours per week

Organisation 2: _____

_____ hours per week

Organisation 3: _____

_____ hours per week

4. Do you receive any state benefits (excluding pension) or other financial support?

Yes No

If yes, please specify: _____

End of questionnaire ***Thank you for your time and effort***

Follow up Questionnaire

Date of Completion:	_____
Patient Initials:	_____
Participant Trial Number:	_____
Time-point:	Midpoint Assessment (month 3) <input type="checkbox"/>
	Endpoint Assessment (month 6) <input type="checkbox"/>

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If yes, please name the organisation(s):

Organisation 1: _____

_____ hours per week

Organisation 2: _____

_____ hours per week

Organisation 3: _____

_____ hours per week

4. Do you receive any state benefits (excluding pension) or other financial support?

Yes No

If yes, please specify: _____

Healthcare log

Please record the **number** of services you have used **over the last 3 months**.

NHS Hospital services

This refers to any contacts you make with the hospital. This includes overnight stays in hospital, day-case attendances and telephone calls to/from **hospital-based** health professionals.

In-patient hospital services (over the last 3 months)	Total number
Hospital inpatient stay (>24 hours, or with an overnight stay)	_____ nights
Other unscheduled hospital attendance (<24hrs without an overnight stay)	_____ attendances

I have not used any inpatient hospital services

Out-patient hospital service	Contact (Y/N)	Number of contacts by phone	Number of contacts in clinic
Breast surgeon	<input type="checkbox"/>		
Oncologist	<input type="checkbox"/>		
Breast Care Nurse	<input type="checkbox"/>		
Other (please specify)			
1.	<input type="checkbox"/>		
2.	<input type="checkbox"/>		
3.	<input type="checkbox"/>		
4.	<input type="checkbox"/>		

I have not used any inpatient hospital services

Hospital tests (over the last 3 months)	Had test? (Y/N)	Number of tests
X-Ray	<input type="checkbox"/>	
Mammogram	<input type="checkbox"/>	
Heart scan	<input type="checkbox"/>	
Other (please specify)		
1.	<input type="checkbox"/>	
2.	<input type="checkbox"/>	
3.	<input type="checkbox"/>	

I have not had any hospital tests

Community and primary care services

This refers to all health care and social care that is **not** based in the hospital. This includes your GP, practice or community nurse, dietitian, home help, physiotherapist etc.

Type of service	Have you used the service in the last 3 months? <i>(tick if yes)</i>	Total number of clinic visits	Total number of home visits	Total number of contacts by telephone
GP surgery, doctor	<input type="checkbox"/>			
GP surgery, nurse	<input type="checkbox"/>			
NHS 24	<input type="checkbox"/>			
Out of hours GP	<input type="checkbox"/>			
District Nurse	<input type="checkbox"/>			
Nurse, other	<input type="checkbox"/>			
Psychologist	<input type="checkbox"/>			
Physiotherapist	<input type="checkbox"/>			
Dietitian	<input type="checkbox"/>			
Occupational therapist	<input type="checkbox"/>			
Other (please specify)				
1. _____	<input type="checkbox"/>	—	—	—
2. _____	<input type="checkbox"/>	—	—	—
3. _____	<input type="checkbox"/>	—	—	—
4. _____	<input type="checkbox"/>	—	—	—

I have not used any community, GP or primary care services in the last 3 months

Charity or non-NHS organisation (e.g. MacMillan, Maggie's, Breast Cancer Care, Church, Citizen's advice, HMRC... others please specify)

Type/name of Charity	Reason/Treatment	Number of visits

I have not used any other services in the last 3 months

Travel

This section refers to how much you spent on travel to attend hospital, GP or other health and social care appointments, including any unplanned visits. When you are answering these questions, **please consider the last 3 months.**

Approximately how many miles have you travelled by car? _____ miles

Approximately how much have you spent on health-care related parking? £ _____

Approximately how much have you spent on public transport, taxis, etc.? £ _____

I have not travelled to healthcare appointments or hospital in the last 3 months

Other services and personal expenses

Have you personally incurred any other services and possible expenses due to your health or treatment? (e.g. home adaptations, extra laundry, cleaning services, anything else)

Please fill in **all services used, by whom they were provided and if you had to pay for them, how much they cost you.**

Description	Provided by	Cost to you (£)

End of questionnaire ***Thank you for your time and effort***