

UK Cancer Costs Questionnaire (UKCC) Version 2.0

The UKCC is a modular questionnaire designed to capture the resources used by people with a current or previous diagnosis of cancer. The design 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 primary 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 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 and comments and contributions are welcome via AUHE@leeds.ac.uk for the attention of Peter Hall or Claire Hulme.

Baseline Questions

Please tick one box for the category that describes your employment status prior to your diagnosis of cancer.

- In full time employment (30 hours or more a week)
- In part time employment (less than 30 hours a week)
- Employed but on sick leave
- Retired
- Not in paid employment

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

If you normally work a fixed number of hours per week, please specify

hours

Do you have dependent children at home?

Yes
No

Do you provide support for someone else with health problems?

Yes
No

Follow-up Questions

Recommended maximum follow-up interval 3 months (this can be shortened)

This set of questions is aimed at finding out the financial cost to you and your family and the health services over the last 3 months. Please think back over the past 3 months. If you are unsure about any answer please write in your best guess.

Please tick one box for the category that describes your current employment

In full time employment (30 hours or more a week)

In part time employment (less than 30 hours a week)

Employed but on sick leave

Retired

Not in paid employment

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

If you are employed, approximately how much time have you taken off work **in total** during the last 3 months due to your health?

<input type="text"/>	days
<input type="text"/>	hours

Have you **provided** support for someone else with health problems?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

Have you **received** help or support from family or friends due to your own health problems?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

If yes, approximately how much time have they set aside to help you in a **typical week**?

<input type="text"/>	hours
<input type="text"/>	days

If yes, and if they work, approximately how much time have they taken off work in order to help you in a **typical week**?

<input type="text"/>	hours
<input type="text"/>	days

Healthcare log

In the past 3 months, did you see any health or care professionals in the community? (this refers to all health care and social care that is not based in the hospital.

This includes for example your GP, practice or community nurse, social worker, home help or physiotherapist who is not based in the hospital.

Please indicate the person you saw, how many times you saw them. If the type of professional is not listed then please write this in. Please record all contact whether or not this was related to your cancer.

<u>Number:</u>	<u>Home visit</u>	<u>Clinic/ practice</u>	<u>By phone</u>
Contact with doctor (GP)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Contact with nurse	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other Health Professional (.....)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other Health Professional (.....)	<input type="text"/>	<input type="text"/>	<input type="text"/>

In the past 3 months, have you spend any time in any of the following institutions. (Please indicate the number of days).

Residential home	<input type="text"/>	days
Nursing home	<input type="text"/>	days
Hospice	<input type="text"/>	days
Respite care	<input type="text"/>	days
Other (please specify.....)	<input type="text"/>	days
Other (please specify.....)	<input type="text"/>	days

Travel

Over the past 3 months:

How many miles in total have you travelled to attend hospital or other health or social care appointments including any unplanned visits? Please record all travel whether or not it was related to your cancer

miles

How much have your spent on healthcare-related parking?

£

Medications

What medications are you currently taking on a regular basis including over-the-counter and non-prescription medications? Please record the name of all medications whether or not they are related to your cancer.

Medication name	On prescription? (tick if yes)

Do you pay for your prescriptions? *(please tick)*

Yes
No

Other Expenses

Please record any other expenses you have had to meet over the last 3 months because of your health or treatment. Please record all expenses, whether or not they were related to your cancer.

Brief description	Cost