**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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[UKCC Baseline Questionnaire Page 1 of 2]

**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.**

[UKCC Baseline Questionnaire Page 1 of 2]

**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:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Organisation 2:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Organisation 3:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_ hours per week \_\_\_ hours per week \_\_\_ 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***

[UKCC Follow-up questionnaire Page 1]

**Follow up Questionnaire**

**Date of Completion: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Patient Initials: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Participant Trial Number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Time-point:**  Midpoint Assessment (month 3) 

Endpoint Assessment (month 6) 

**Completion Instructions**

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

**Thank you very much for your time and effort.**

[UKCC Follow-up questionnaire Page 2]

**Employment and Support**

When you are answering these questions **please consider your situation over the last 3 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:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Organisation 2:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Organisation 3:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_ hours per week \_\_\_ hours per week \_\_\_ hours per week  |
| **4. Do you receive any state benefits (excluding pension) or other financial support?** | Yes  No  |
| If yes, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  |

[UKCC Follow-up questionnaire Page 3]

**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 | [ ]  |  |  |
|  Oncologist | [ ]  |  |  |
|  Breast Care Nurse | [ ]  |  |  |
|  Other (please specify) |  |  |  |
|  1.  | [ ]  |  |  |
|  2. | [ ]  |  |  |
|  3. | [ ]  |  |  |
|  4. | [ ]  |  |  |

I have not used any inpatient hospital services [ ]

|  |  |  |
| --- | --- | --- |
| **Hospital tests** (over the last 3 months) | **Had test? (Y/N)** | **Number of tests** |
|  X-Ray | [ ]  |  |
|  Mammogram | [ ]  |  |
|  Heart scan | [ ]  |  |
|  Other (please specify) |  |  |
|  1.  | [ ]  |  |
|  2. | [ ]  |  |
|  3. | [ ]  |  |

I have not had any hospital tests [ ]

[UKCC Follow-up questionnaire Page 4]

**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?** *(tick if yes)* | **Total number of clinic visits** | **Total number of home visits** | **Total number of contacts by telephone** |
| GP surgery, doctor |  |  |  |  |
| GP surgery, nurse |  |  |  |  |
| NHS 24 |  |  |  |  |
| Out of hours GP |  |  |  |  |
| District Nurse |  |  |  |  |
| Nurse, other |  |  |  |  |
| Psychologist |  |  |  |  |
| Physiotherapist |  |  |  |  |
| Dietitian |  |  |  |  |
| Occupational therapist |  |  |  |  |
|  Other (please specify)1. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
 | [ ] [ ] [ ] [ ]  | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_ |

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

[UKCC Follow-up questionnaire Page 5]

**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**

|  |  |
| --- | --- |
| 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.? | £ \_\_\_\_\_\_\_\_\_\_ |

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.**

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

[UKCC Follow-up questionnaire Page 6]

**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***