

## Patient-and-Carer Cancer Cost (PaCCcT) survey

### Details of interview and Disease

(using patient's medical record/health passport where necessary)

	Question	Answer categories (check all that apply or fill answer on the answer line)	<i>Instructions and actions for interviewer</i>												
	WHO performance score of patient at time of interview	0 1 2 3 4	<p>Interviewer needs to assess WHO performance score at time of interview, if patient is anything other than WHO Grade 0 then conduct a WHO danger signs assessment (below)</p> <table border="1" data-bbox="1218 807 1883 1155"> <thead> <tr> <th data-bbox="1218 807 1267 858">Grade</th> <th data-bbox="1267 807 1883 858">Explanation of activity</th> </tr> </thead> <tbody> <tr> <td data-bbox="1218 858 1267 909">0</td> <td data-bbox="1267 858 1883 909">Fully active, able to carry on all pre-disease performance without restriction</td> </tr> <tr> <td data-bbox="1218 909 1267 979">1</td> <td data-bbox="1267 909 1883 979">Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td> </tr> <tr> <td data-bbox="1218 979 1267 1050">2</td> <td data-bbox="1267 979 1883 1050">Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours</td> </tr> <tr> <td data-bbox="1218 1050 1267 1120">3</td> <td data-bbox="1267 1050 1883 1120">Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours</td> </tr> <tr> <td data-bbox="1218 1120 1267 1155">4</td> <td data-bbox="1267 1120 1883 1155">Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair</td> </tr> </tbody> </table>	Grade	Explanation of activity	0	Fully active, able to carry on all pre-disease performance without restriction	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work	2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours	4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
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	Type of cancer	Kaposi's Sarcoma  Cervical cancer	<p><i>this should be verified by documentation as indicated in the health passport/medical records,</i></p> <p><i>choice of cancer diagnoses as directed by local/study setting</i></p>												

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		Oesophageal cancer Hepatocellular carcinoma	
	HIV status (as indicated on treatment card)	1. positive 2. negative 3. not available	<i>this should be verified by documentation as indicated in the health passport/medical records</i>

### Section 1. Baseline costs

#### Part 1a. details of household vulnerability factors and social position

to be completed once per household by asking either the patient or the carer

	Question	Answer categories (circle appropriate number or fill answer on the answer line)	Action for interviewer
	Who is answering the questions today?	1. Patient 2. Carer	
		The following questions are used as a proxy means test for poverty based on national data from the Integrated Household Survey. They can be used to determine poor/non poor status for those dwelling in urban and/or rural setting. To select asset variables for prediction of household annual income based on asset ownership/dwelling characteristics visit surveys available through World Bank microdata library ( <a href="http://microdata.worldbank.org/index.php/home">http://microdata.worldbank.org/index.php/home</a> ).	
	What education level did the head of the household/primary income earner in the household complete?	1. Never attended school 2. primary school 3. secondary school 4. non-university diploma 5. University diploma/degree 6. postgraduate degree	
	What does the head of your household sleep on	1. Bed and mattress 2. Bed and mat (grass) 3. Bed alone 4. Mattress on floor 5. Matt (grass) on floor 6. Cloth/sack on floor 7. Floor (nothing else) 8. other	
	How many people live in your household? Please count all the people who normally live with you and eat meals together include yourself when counting	(number)	

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	In the past 7 days, did you worry that your household would not have enough food?		
	Concerning your household's clothing, which of the following is true?		
	Is the household head able to read and write in English?	1. Yes 0. no	
	Do you have working electricity in your dwelling?	1. Yes 0. no	
	Do you, either by yourself or together with another household member or someone outside your household, currently have an account at a bank, credit union, micro finance institution, village savings organisation or another financial institution?	1. yes 0. no	
	Imagine six steps, where on the bottom, the first step, stand the poorest people, and on the highest step, the sixth, stand the rich. (SHOW THE PICTURE OF THE STEPS). On which step are you today?	1. Step 1 2. Step 2 3. Step 3 4. Step 4 5. Step 5 6. Step 6	
	Concerning your housing which of the following is true?	1. It was less than adequate for household needs 2. It was just adequate for household needs 3. It was more than adequate for household needs	
	Concerning your household's clothing which of the following is true?	4. It was less than adequate for household needs 5. It was just adequate for household needs 6. It was more than adequate for household needs	
	Does your household have:?	<i>design these questions using validated asset scores from the latest socio-economic or demographic and health survey in the country. The appropriate choice of questions is essential.</i>	

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		<i>Answers from the asset questions will be used to estimate income for each household.</i>		
		A bed	0=no 1=yes	
		A table	0=no 1=yes	
		A tape or CD/DVD player, HiFi	0=no 1=yes	
		An upholstered chair, sofa set?	0=no 1=yes	
		Iron for pressing clothes	0=no 1=yes	
	Do you have any of the following health insurance types?	<ol style="list-style-type: none"> <li>1. medical aid scheme (MASM etc.)</li> <li>2. donor</li> <li>3. family</li> <li>4. savings</li> <li>5. community fund</li> <li>6. churches</li> <li>7. Other (specify)</li> </ol>	<i>Circle any support that the patient/carer have</i>	
	Which is your main source of funds for medical costs at the moment?	<ol style="list-style-type: none"> <li>1. medical aid scheme (MASM etc.)</li> <li>2. donor</li> <li>3. family</li> <li>4. savings</li> <li>5. community fund</li> <li>6. churches</li> <li>7. Other (specify)</li> </ol>		

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**1b – Costs and healthcare utilisation before the time of diagnosis of cancer**

to be completed once per household by asking either the patient or the carer

<b>Out-of-pocket expenditure, reimbursements and time loss before cancer diagnosis</b>			
	<b>Question</b>	<b>Answer categories (check all that apply or fill answer on the answer line)</b>	<b>Instructions and actions for interviewer</b>
	Relating to this cancer problem, when did you first realise that you/your patient was unwell?	Years before diagnosis _____  Months before diagnosis _____  Weeks before diagnosis: _____  Days before diagnosis _____	<i>First construct a timeline of events, either starting with the first symptom, or start with time of diagnosis and work backwards. Use the locally adapted calendar with main seasonal events that the carer can relate to and use as a reference point for timing. To help the carer remember when the illness started, you can ask which symptom was first experienced. If there is a problem defining the difference between cancer symptoms and other health problems, ask which symptom led the carer to seek care, and then ask when that symptom first occurred or became worse and started to worry the carer.</i>
	<p><b>Looking at the time before you/your patient found out about the diagnosis of cancer</b> (including the visit when you/your patient actually received the diagnosis)</p> <p>Regarding your visits to health providers</p> <p>1.How many times did you visit each provider below?</p> <p>2.How much money did you spend in total at each provider?</p>	<ul style="list-style-type: none"> <li>• See table below, and ask for each item</li> <li>• Fill one line per visit</li> <li>• Use the health passport to check and confirm use of services (note : documentation typically minimal/incomplete)</li> <li>• For all that don't apply, mark/select NA (= not applicable)</li> <li>• If there were payments for an item, but the respondent cannot remember the amount, mark NR (=not remembered)</li> </ul> <p>Explanation of table headings:</p> <p>Travel time: Hours or days spent to travel to and from facility</p> <p>Time spent for visit: Fill in hours for outcarer visits and days for hospitalizations</p> <p>Day charge: Fees for hospital days. Only for hospitalizations, and <u>only to be filled if not covered by the cost items below (consultation fee, radiography etc.)</u></p> <p>Consultation fee: Other charges, not covered under day charge, including direct payment to health care staff</p>	

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	3. How much time did you spend in total at each provider?	<p>Radiography and other imaging: out-of-pocket payments for imaging investigation (x-rays, CT-scan, ultrasound), cancer-specific and other</p> <p>Lab test fees: out-of-pocket payments for all tests, cancer specific and others</p> <p>Other procedures: out-of-pocket payments for biopsy, bronchial lavage etc. but not surgery unrelated to cancer</p> <p>Medicine fees: Any medicine prescribed before cancer was diagnosed</p> <p>Other, including nutritional supplements: any other treatments, such as nutritional supplements medically indicated</p> <p>Other payments for non-medical remedies : prayers, traditional healer</p> <p>Travel: out-of-pocket payments for travel to the facility (does not include income loss), for both carer and any household member.</p> <p>Food: out-of-pocket payments for additional food bought in relation to travelling the health care visit, and during visit or hospitalization, for both carer and any household member</p> <p>Other, including accommodation: includes out-of-pocket payments related to renting a room/bed during health care visits, and any other non-medical payments related to health care visit, for both carer and any household member (firewood, sobo, snacks, laundry, soap, communication,</p> <p><b>Health insurance reimbursement:</b> amount reimbursed to carer through medical insurance (private or social security) so far, does not include expected future reimbursement</p> <p><b>Out-of-pocket payments (gross):</b> Direct payment made to health-care providers by individuals at the time of service use, i.e. excluding prepayment for health services – for example in the form of taxes or specific insurance premiums or contributions. It is calculated as the sum of direct medical (A) and direct non-medical (B) costs. If carer cannot remember the details of costs above, ask for the total out-of-pocket payments of the visit, hospitalization.</p>
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**OR 4b – Follow up : Costs and healthcare utilisation**

*to be completed once per household by asking either the patient or the carer*

**Out-of-pocket expenditure, reimbursements and time loss**

	Question	Answer categories (circle the most appropriate or fill answer on the answer line)	Notes/action for interviewer
	Has you/your patient attended any booked visits to any kind of health provider since we last saw you?	0=no 1=yes	<p><i>Definition of booked visit = any planned visit arranged by health providers</i></p> <p><i>If yes proceed to next question then complete section 5a</i></p> <p><i>If no proceed to next question</i></p>

	Has you/your patient attended any unscheduled/emergency visits to any kind of health provider since we last saw you?	0=no 1=yes	<i>Definition of Unscheduled visit= all other visits</i>  <i>If yes complete section 5b</i>  <i>If no proceed to section 6</i>
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	<b>Question</b>	<b>Answer categories</b> (circle the most appropriate or fill answer on the answer line)	<b>Notes/action for interviewer</b>
	Has you/your patient attended any booked visits to any kind of health provider since we last saw you?	0=no 1=yes	<i>Definition of booked visit = any planned visit arranged by health providers</i>  <i>If yes proceed to next question then complete section 5a</i>  <i>If no proceed to next question</i>
	Has you/your patient attended any unscheduled/emergency visits to any kind of health provider since we last saw you?	0=no 1=yes	<i>Definition of Unscheduled visit= all other visits</i>  <i>If yes complete section 5b</i>  <i>If no proceed to section 6</i>



**1b Before diagnosis / 4b planned visits/4b Emergency visits**

				Medical out-of-pocket payments, (Total per Provider) (A)						Non-medical out-of-pocket payments, (Total per provider) (B)				Out-of-pocket payments (A+B) (Gross)	(C)
				Day charges (for hospitalizations only) A1	Consultation fee A2	Radio-graphy and other imaging A3	Lab tests A4	Medi-cines A6	Medical payments, total ΣA1-7	Travel B1	Food during health care visit or hospital stay B2	Other, including accommo-dation B3	Non-medical out-of-pocket payments (Total) ΣB1-3	Total out-of-pocket payments (ΣA1-7) + (ΣB1-3)	Health insurance reimburse-ment
Provider	No of visits	Travel time (hours on average per visit)	Time spent for visit (hours on average per visit)												
Government Health centre															
CHAM health centre															
Government hospital															
CHAM hospital															
Private hospital															
Private clinic															
Pharmacy / drugstore															
Facility based palliative care															
Home based palliative care															
Community health worker/HSA															
Traditional healer															
Other facility_____															

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**Part 1c : reported income, Income changes, social consequences and coping strategies before diagnosis (patient and carer will be asked separately)**

**OR Form 4c : reported income, income changes, social consequences and coping strategies following diagnosis**

	How much do you estimate your total net household revenue was per month (income after tax) before you became unwell?		
	Is there anyone else living in your household who needs long term care?	1=yes 0=no	<i>If Yes : continue with next question If No: skip next questions</i>
	How many?	(number)	
	Are there any other adults (people over age of 18) who miss work in order to care for you/your patient?	1=yes 0=no	<i>If yes go to the next question, if no skip to question</i>
	total no of adults (people over age of 18) caring for you/your patient	0 1 2 3 4 More than 4	
	How many females	(number)	
	Are there any children (people under the age of 18) who miss school in order to take care of you/your patient?	0=no 1=yes	<i>If yes go to the next question, if no skip to question</i>
	How many of the children miss school in order to provide care for you/your patient at home	0 1 2	

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		3 4 More than 4	
	How many females?		
	On average, how many days in a week does the child/these children miss school because of your illness?	Half day one day two days three days four days withdrawn from school	<i>If more than one child has been affected, the Interviewer should determine how much time is lost FOR EACH CHILD, e.g. if 3 children affected, and child 1 misses 0.5 days/week, child 2 misses 2 days per week and child 3 has dropped out then list the number of children affected accordingly after each option (in the example above this would be half day 1, two days 1, dropped out 1)</i>  <i>Note should be as a result of illness</i>
	What is your primary employment, or normal work, or normal other main activity now?	0. Unemployed 1. Formal paid work 2. Informal paid work 4. Retired 5. Student 6. Housework 7. Other (specify): _____	
	Do you have any extra sources of income support which have been assisting you and you?	1=yes 0=no	<i>If yes proceed to next question, if no skip next question</i>
	What extra income sources do you have	1. Extended family in country 2. Extended family overseas 3. Church support 4. NGO support 5. Support other _____(specify)	
	Please specify total cash value of support received per month	(amount _____/month)	<i>Don't include loans (or other money which is expected to be repaid) here</i>
	Did you borrow or receive any money to cover costs due to the illness?	1=yes 0=no	<i>If yes: go to next question</i>  <i>If no: skip next four questions</i>
	From whom did you borrow/receive? What was the amount of the loan?	1. Family 2. Neighbours/friends	

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		<ol style="list-style-type: none"> <li>3. Commercial bank</li> <li>4. Cooperative/village bank</li> <li>5. Employer</li> <li>6. Unofficial lender</li> </ol>	
	In total, how much did you borrow/receive?	(number)	
	Are you expected to pay the loan(s) back?	1=yes 0=no	<i>If yes please provide details in next question</i>
	In total, how much are you expected to pay back?	(number)	
	Have you sold any of your property (land, livestock, household appliances, cars, phone etc.) to finance the cost of the illness before diagnosis?	1=yes 0=no	<i>If yes: go to next question</i> <i>If no: skip next two questions</i>
	If yes, what did you sell?	<ol style="list-style-type: none"> <li>1. Land</li> <li>2. Livestock</li> <li>3. Transport/vehicle</li> <li>4. phone</li> <li>4. other Household item</li> <li>5. Farm produce</li> <li>6. Gold/jewelry</li> <li>7. Other (specify):</li> </ol>	<i>Multiple responses allowed. Circle all that are mentioned.</i>
	How much money did you receive from the sale of all items of your property?	(number)	
	Have you made plans or provision for yourself, your family or your belongings in the event of your illness becoming worse? (this is sometimes called a will)	1=yes 0=no	

**Section 2 and 3: Wellbeing patient/carer**

**Part 2a. Details of interview and Disease**

*(using patient's medical record/health passport where necessary)*

	Question	Answer categories (check all that apply or fill answer on the answer line)	<b>Instructions and actions for interviewer</b>
	Has the patient had chemotherapy in the last 7 days	1 yes 0 no	<i>If patient answers yes, then wellbeing questions should be delayed</i>

**Part 2b : wellbeing**

*(questions should be asked separately of both patient and carer at each visit to assess household wellbeing)*

	<p><b>Complete IPOS</b></p> <p><b>Complete EQ5D (paper based)</b></p>
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		<i>The following questions relate to the time <b>before the patient became unwell</b> (are should be asked only once)</i>	
	What was your primary employment, or normal work, or normal other main activity before you became unwell?	<ol style="list-style-type: none"> <li>1. Unemployed</li> <li>2. Formal paid work</li> <li>3. Informal paid work</li> <li>4. Retired</li> <li>5. Student</li> <li>6. Housework</li> </ol> <p>Other (specify): _____</p>	
	Before you became unwell were you the main breadwinner in the household?	1 yes 0 no	
	Were you the spouse of the breadwinner?	1 yes 0 no	
	When you were well how many days a week were you working?	(number)	. This refers to the time before symptoms developed. If patient has answered that they are unemployed or not in paid work this question and the next can be skipped
	If you were in paid work when you were well, how much do you estimate your net income was per month from labour related activities (after tax)?	(number)	.

		<i>The following questions relate to <b>NOW</b></i>	
	As of now are you the main breadwinner in the household?	1 yes 0 no	
	What is your primary employment or normal other main activity NOW?	<ol style="list-style-type: none"> <li>1 Unemployed</li> <li>2 Formal paid work</li> <li>3 Informal paid work</li> <li>4 Retired</li> <li>5 Student</li> <li>6 Housework</li> </ol>	

		7 . Other (specify): _____	
	How many days a week are you working now (time of diagnosis)?	(number)	
	If you are in paid work, how much do you estimate your net income is per month (after tax) now?	(number)	

	which of these phrases would most accurately describe your current situation ?	<ol style="list-style-type: none"> <li>1. I have no problems with income generating activities</li> <li>2. I have slight problems with income generating activities</li> <li>3. I have moderate problems with income generating activities</li> <li>4. I have severe problems with income generating activities</li> <li>5. I am unable to take part in income generating activities</li> </ol>	
	which of these phrases would most accurately describe your current situation?	<ol style="list-style-type: none"> <li>1. I have no problems with discrimination</li> <li>2. I have slight problems with discrimination</li> <li>3. I have moderate problems with discrimination</li> <li>4. I have severe problems with discrimination</li> <li>5. I am unable to take part in society because of discrimination</li> </ol>	

	which of these phrases would most accurately describe your current situation?	<ol style="list-style-type: none"> <li>1. I have no problems getting food</li> <li>2. I have slight problems getting food</li> <li>3. I have moderate problems getting food</li> <li>4. I have severe problems getting food</li> <li>5. I am unable to get food</li> </ol>	
	How much do you estimate your total net household revenue is per month (income after tax) now?	(number)	Refers to all persons in the household, including the carer.
	has the illness affected your social or private life through divorce or separation from spouse/partner	1=yes 0=no	
	What – in your own words – is your main concern relating to your illness/ your patient's illness today?		



### Section 5 : Funeral costs

There must be extra sensitivity around this topic as family members may still be actively grieving.

None of these questions should be asked **until at least 2 weeks** after the date of death.

<i>On visiting home and finding the patient has died this section can be completed, either at the time or if the offer of a separate visit later is acceptable</i>			
	Question	Answer categories (circle the most appropriate or fill answer on the answer line)	Action for interviewer
	How much did you and your household spend on the funeral in total	(number)	<i>If yes: go to next question If no: skip next question</i>
	Did you borrow any money to cover funeral costs?	0=no 1=yes	
	In total, how much did you borrow to cover funeral costs?	(number)	
	For the money / goods borrowed how much will you be expected to pay back?	(amount/number)	
	Did you receive (i.e. support that does not have to be paid back) money to cover funeral costs?	0=no 1=yes	<i>If yes , go to question 5 If no, interview is finished</i>
	<p><i>Please rank the following in order according to who gave the largest amount:</i></p> <p>1. Family</p> <p>2. Neighbors/friends</p>		

	3. <i>Private bank</i> 4. <i>Cooperative</i> 5. <i>Employer</i> 6. <i>“Unofficial lender” (Black market)</i> 7. <i>church</i>		
	In total , how much did you receive to cover funeral costs?	(number)	