

# COVID-19 and Access to Cancer Care in Kenya: Patient Perspective

Supplementary Material

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## Supplementary Material. Survey Instrument for In-Person Administration

### Screening the participant for eligibility

**Script:** I will now ask you several questions to ensure that we are asking the right person.

**2.1. Have you completed this survey online or with someone's assistance in the past month?**

- No {proceed to the next question}
- Yes {say "We can only collect your response once, and you have already shared them with us. Thank you for completing this survey! End here."}

**2.2. What is your current age?**

{Select one. DO NOT read the list below. Let the participant answer and then you choose the age range that matches their answer.}

- ① Less than 18 {STOP the survey as the participant is not eligible to take it}
- ② 18 to 29                      ③ 30 to 39                      ④ 40 to 49                      ⑤ 50 to 59
- ⑥ 60 to 64                      ⑦ 65 to 69                      ⑧ 70 to 79                      ⑨ 80 or older

**2.3. Have you ever been told by a doctor or other health provider that you have a cancer or a suspected cancer diagnosis?**

- No {close the survey since the participant is not eligible to respond}
- Yes {proceed to the next question}

{Please note that we are NOT asking the participant to sign the consent form since we are not collecting any evidence of their participation in order to protect their PII. But the data collector must leave a printed copy (unsigned) of the consent form with the participant for their reference for in-person data collection or must explain where the consent form is available for pick up if the data is collected by phone.}

### Survey Demographic Questions

{At this stage, after each question, if the participant seeks clarification, please provide an explanation}.

**Script:** Now I will ask you some basic information about yourself, the county you are from, your income, and your cancer diagnosis.

**3.1. What is your gender?**

- ① Male                              ② Female                              ③ Other (please explain): \_\_\_\_\_

**3.2. I am going to read a list of statements to understand where you are in your cancer journey. Please listen to the statements and tell me which of them best describes your situation?**

{Select one. Read the list below and record the answer.}

- ① I am in the process of getting or confirming a diagnosis (e.g., doing investigations)
- ② I am in treatment planning (but treatment has not yet started)
- ③ I am currently receiving treatment (e.g., actively going to health facility for chemo- or radiotherapy)
- ④ I have completed treatment (e.g., visiting health facility for periodic follow-up visits)

- ⑤ I am receiving palliative care/hospice care
- ⑥ None of the above **{STOP the survey as the participant is not a current patient or someone seeking a cancer diagnosis, and thus is ineligible to respond.}**

**3.3. In the course of your cancer diagnosis and/or treatment, which health facility (or facilities) have you visited?**

**{Select all that apply. If the participant has difficulty recalling, you may read the list below}**

- |   |  |
|---|--|
| <input type="checkbox"/> Kenyatta National Hospital (KNH)                   | <input type="checkbox"/> Bomet Hospital                    |
| <input type="checkbox"/> Agha Khan Hospital                                 | <input type="checkbox"/> Garissa Hospital                  |
| <input type="checkbox"/> AIC Kijabe Hospital                                | <input type="checkbox"/> Embu Hospital                     |
| <input type="checkbox"/> Kenyatta University Teaching and Referral Hospital | <input type="checkbox"/> Kakamega Hospital                 |
| <input type="checkbox"/> Texas Cancer Centre                                | <input type="checkbox"/> Kisumu Hospital                   |
| <input type="checkbox"/> MP Shah Hospital (HCG CCK)                         | <input type="checkbox"/> Machakos Hospital                 |
| <input type="checkbox"/> Nairobi Hospital                                   | <input type="checkbox"/> Meru Hospital                     |
| <input type="checkbox"/> Nairobi West Hospital                              | <input type="checkbox"/> Mombasa Hospital                  |
| <input type="checkbox"/> Mater Misericordiae Hospital                       | <input type="checkbox"/> Nakuru Hospital                   |
| <input type="checkbox"/> Moi Teaching and Referral Hospital                 | <input type="checkbox"/> Nyeri Provincial General Hospital |
| <input type="checkbox"/> Other  | <input type="checkbox"/> Othaya Hospital                   |
|   | <input type="checkbox"/> Tenwek Hospital                   |

Other - Please explain:

**3.4. In an average month, how much do all members of your household earn in total?**

**{Please explain what is meant by “all members of your household.” Read the statements below so that the participant understand that we are asking them about the combined income of these various types of people who may be a part of the respondent’s household.}**

- *all persons who live in the same house at least 5 days a week, share a kitchen, and*
- *someone living elsewhere but providing the household with financial support (e.g. someone who may be working in a city far away but who sends money to the family), and*
- *someone living elsewhere but receiving financial support from members of your household (e.g. a student living in a city but who is supported financially by members of your household)}*

Total average amount in Shillings, per month:

- |                 |                 |                 |                  |
|-----------------|-----------------|-----------------|------------------|
| ① 0 (no income) | ② 1-5,000       | ③ 5,001-10,000  | ④ 10,001-15,000  |
| ⑤ 15,001-20,000 | ⑥ 20,001-25,000 | ⑦ 25,001-30,000 | ⑧ 30,001 or more |

**3.5. What county do you live in? {Select one, only read the list if the participant has trouble recalling}**

- |                                       |                                 |                                |                                     |
|---------------------------------------|---------------------------------|--------------------------------|-------------------------------------|
| <input type="radio"/> Nairobi         | <input type="radio"/> Kericho   | <input type="radio"/> Mandera  | <input type="radio"/> Samburu       |
| <input type="radio"/> Baringo         | <input type="radio"/> Kiambu    | <input type="radio"/> Marsabit | <input type="radio"/> Siaya         |
| <input type="radio"/> Bomet           | <input type="radio"/> Kilifi    | <input type="radio"/> Meru     | <input type="radio"/> Taita/Taveta  |
| <input type="radio"/> Bungoma         | <input type="radio"/> Kirinyaga | <input type="radio"/> Migori   | <input type="radio"/> Tana River    |
| <input type="radio"/> Busia           | <input type="radio"/> Kisii     | <input type="radio"/> Mombasa  | <input type="radio"/> Tharaka-Nithi |
| <input type="radio"/> Elgeyo/Marakwet | <input type="radio"/> Kisumu    | <input type="radio"/> Murang'a | <input type="radio"/> Trans Nzoia   |
| <input type="radio"/> Embu            | <input type="radio"/> Kitui     | <input type="radio"/> Nakuru   | <input type="radio"/> Turkana       |

- |                                |                                |                                 |                                   |
|--------------------------------|--------------------------------|---------------------------------|-----------------------------------|
| <input type="radio"/> Garissa  | <input type="radio"/> Kwale    | <input type="radio"/> Nandi     | <input type="radio"/> Uasin Gishu |
| <input type="radio"/> Homa Bay | <input type="radio"/> Laikipia | <input type="radio"/> Narok     | <input type="radio"/> Vihiga      |
| <input type="radio"/> Isiolo   | <input type="radio"/> Lamu     | <input type="radio"/> Nyamira   | <input type="radio"/> Wajir       |
| <input type="radio"/> Kajiado  | <input type="radio"/> Machakos | <input type="radio"/> Nyandarua | <input type="radio"/> West Pokot  |
| <input type="radio"/> Kakamega | <input type="radio"/> Makueni  | <input type="radio"/> Nyeri     |                                   |

**3.6. What is your highest level of education? {if the participant cannot identify, read them the list of**

**options. Select one option only}**

- |  |  |
|--|--|
| <input type="radio"/> ① Never went to school       | <input type="radio"/> ⑥ Some college                               |
| <input type="radio"/> ② Some primary school        | <input type="radio"/> ⑦ Completed college (diploma or certificate) |
| <input type="radio"/> ③ Completed primary school   | <input type="radio"/> ⑧ Some university                            |
| <input type="radio"/> ④ Some secondary school      | <input type="radio"/> ⑨ Completed university or higher             |
| <input type="radio"/> ⑤ Completed secondary school |  |
| <input type="radio"/> ⑩ Other                      |  |

Please explain:

**3.7. What type of cancer do you/did you have? If you have been diagnosed with more than one cancer, please let me know your most recent cancer diagnosis. If you have not yet received a confirmation of cancer, please let me know that you do not yet have a confirmed diagnosis. {Select ONE, most recent cancer}**

- |   |   |   |   |
|---|---|---|---|
| <input type="radio"/> Anal cancer                               | <input type="radio"/> Head and neck cancer (e.g. oral cavity, pharyngeal, larynx, parotid, maxilla, palate, sinuses, tonsil, or ear cancer) | <input type="radio"/> Melanoma          | <input type="radio"/> Kaposi sarcoma                          |
| <input type="radio"/> Bladder cancer                            | <input type="radio"/> Leukemia/blood cancer   | <input type="radio"/> Multiple Myeloma  | <input type="radio"/> Kidney cancer                           |
| <input type="radio"/> Bone cancer                               | <input type="radio"/> Liver cancer  | <input type="radio"/> Ovarian cancer    | <input type="radio"/> Skin/scalp cancer (other than melanoma) |
| <input type="radio"/> Breast cancer                             | <input type="radio"/> Lung cancer   | <input type="radio"/> Pancreatic cancer | <input type="radio"/> Stomach cancer                          |
| <input type="radio"/> Cervical cancer (cancer of the cervix)    | <input type="radio"/> Lymphoma (Hodgkin)  | <input type="radio"/> Prostate cancer   | <input type="radio"/> Vaginal cancer                          |
| <input type="radio"/> Colon cancer                              | <input type="radio"/> Lymphoma (Non-Hodgkin's)  | <input type="radio"/> Rectal cancer     | <input type="radio"/> Vulvar cancer                           |
| <input type="radio"/> Endometrial cancer (cancer of the uterus) |   | <input type="radio"/> Thyroid cancer    | <input type="radio"/> <b>No confirmed diagnosis</b>           |
| <input type="radio"/> Esophageal cancer                         |   |   |   |
| <input type="radio"/> Eye cancer                                |   |   |   |
| <input type="radio"/> Other                                     |   |   |   |

Please explain:

**3.8. Since the COVID-19 (coronavirus) pandemic, have you ever been tested for coronavirus? {Select one}**

- ① No, I have never been tested for coronavirus
- ② Yes, I tested *positive* for coronavirus (I have coronavirus) **{Please move to Question 3.8.a.}**

- ③ Yes, I tested *negative* for coronavirus (I do not have coronavirus)
- ④ Yes, I tested for coronavirus, but I am waiting for my results.

***{If the participant selected option ②, ask them the following question. Otherwise, move to question 3.9.}***

**Script:** In the previous question, you indicated that you tested positive for coronavirus.

**3.8.a. What actions, if any, were taken after your positive test result came in?**

- ① I was taken to an isolation centre
- ② I remained at home
- ③ I was hospitalized into an intensive care unit
- ④ I was admitted to hospital but not an intensive care unit
- ⑤ Other

Please explain:

**3.9. What is your current activity level because of the COVID-19 outbreak?**

- ① I have not made any changes to my usual routines
- ② I am still leaving my house to go to work, but am trying to limit my trips to places other than work
- ③ I am sheltering in place, with trips out only as needed
- ④ I am not leaving my home at all

## Impacts of COVID-19

**Script:** Thank you! We are now about halfway through the survey. Let's now move into the next section. I will ask you questions about where you usually get your cancer treatment. This may be a local, regional or national health facility.

**4.1. Based on where you are in your cancer journey (e.g. diagnosis, treatment, etc.), have you experienced any delays since the start of COVID-19? If yes, can you describe the amount of time of your delay?**

**{Do not read the options but solicit the information and based on that, select the appropriate response}**

- ① I have not experienced any delays
- ② I have experienced a delay of less than a month
- ③ I have experienced a delay of a month to two months
- ④ I have experienced a delay of more than two months

***{Review the participant's response to question 3.2. If the participant selected option ③, ask them question 4.2. Otherwise, move to question 4.3.}***

**4.2. You indicated that you are on treatment. Has your doctor changed your treatment plan since the start of COVID-19?**

- ① Yes {go to Question 4.2.a}
- ② No {skip to Question 4.3}

**4.2.a. {Only for those who responded ① to question 4.2}**

**Script:** I will read out the names of different treatments for cancer. I would like to know if any of the treatments you are receiving have changed for you since the start of COVID-19. And by changed, I mean if the treatment has been delayed, stopped or reduced, or you were switched to another mode of treatment.

If you have not received a specific treatment that I name, we will skip it. If you are receiving more than one treatment, please tell me about all of the treatments you are undergoing. When I read the treatment name, please tell me if it has changed OR not changed.

TREATMENT {Interviewer ask all and mark every row}:	Changed	Remained Unchanged	Not Applicable
Chemotherapy	①	②	③
Radiotherapy	①	②	③
Surgery	①	②	③
Other (please specify)	①	②	③
Please specify:			

**{Question 4.2.b is only for those who were in the middle of investigating their cancer diagnosis}**

**4.2.b. Earlier, you said that you were in the middle of a diagnosis investigation. Have your diagnostic tests been delayed due to COVID-19 pandemic?**

- ① My cancer diagnostic tests were delayed
- ② My cancer diagnostic tests were not delayed
- ③ Not applicable

**{The next question is for everyone}**

**4.3. Script:** I will read you several statements at once. Please let me know which ones, if any, correctly describe your situation. If none of them describes your situation, please let me know.

**How, in your opinion, has Covid-19 impacted your cancer treatment and care journey? {Mark all that apply}**

- I have limited access to hospitals (e.g. hospitals are seeing less patients, changing appointments)
- I am scared to contract Covid-19 while seeking cancer treatment
- My household has less income income, and I cannot afford cancer treatment at this time
- My ability to travel for treatment has been limited by curfews or county lockdowns
- COVID-19 has not impacted me in any way
- I do not know how if or how COVID-19 has impacted me
- Other (please specify)

Please Specify:

**4.4. Script:** To assess if your access to various services and therapies related to your treatment/condition {enumerator: select based on the diagnosis} has changed due to COVID-19, we would like to ask you some questions about your situation before and after the start of COVID-19. If a certain service or therapy doesn't apply to you, please let me know and I will skip the question.

{For this question, read each row one by one. If someone says they didn't need the service or therapy, please select "did not need."}

**4.4a: prior to COVID-19, did you have access to the following:**

Did you have access to:	Pre-COVID-19		
	Did not need	Yes	No
Pain relief medicines	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Other prescription medicines (not pain relief) like refills, treatment for other symptoms (e.g. nausea, vomiting)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Spiritual support	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
General counselling (e.g. in nutrition, psychosocial support)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

**4.4.b. Since the start of COVID-19 pandemic, have you had access to:**

Do you have access to:	Since COVID-19 started		
	Do not need	Yes	No
Pain relief medicines	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Other prescription medicines (not pain relief) like refills, treatment for other symptoms (e.g. nausea, vomiting)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Spiritual support	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
General counselling (e.g. in nutrition, psychosocial support)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

**Script:** For this next question, please think about the income of all members of your household.

**4.5. In what ways, if any, has the COVID-19 pandemic impacted the income of your household?**

- ① Decreased significantly
- ② Somewhat decreased
- ③ Remained unaffected
- ④ Somewhat increased
- ⑤ Increased significantly

**Script:** Going through the cancer diagnosis and treatment process can result in additional costs that a patient must pay on their own even if they have access to care (such as health insurance). We would like to understand if COVID-19 has had any effect on these types of costs for you. I will read the statement and the options. Please tell me which option applies to your situation and why.

**4.6. Since COVID-19 started, have your out-of-pocket costs related to your cancer care:**

{Please select one response and also record the explanation in the box}:

- ① Decreased significantly
- ② Somewhat decreased
- ③ Remained unaffected
- ④ Somewhat increased
- ⑤ Increased significantly

**4.6.a Based on your responses to the two previous questions, how have the changes in your income (if any) and the costs of treatment (if any) impacted your ability to afford the care you need?**

Please use as much space as you need:

**Script:** Now, please think about your health coverage. I mean health insurance, financial assistance you receive from your community or family, or any other financial support you may be receiving for your treatment other than your own money. I am going to read the question first and then the types of coverage. For any coverage applicable to you, please tell me if it has decreased, stayed the same or increased. We will skip any coverage that doesn't apply to you.

**4.7. Have any of the following types of coverage changed since the start of COVID-19?**

{Please select one response in every row, select N/A if the respondent does/did not have access to this type of coverage}

Your access to:	N/A	<u>D</u> ecreased	<u>U</u> nchanged	<u>I</u> ncreased
National health insurance (NHIF)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Universal Health Coverage (UHC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Private health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support from an NGO or trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Script:** You may remember that earlier today, I asked you about the medical facilities you have visited in your cancer journey. Now, please think about the medical facility (such as a clinic) you **usually** visit (most often) for cancer services. It will be one of the facilities you indicated earlier. {Enumerator: at this point, please review with the patient their response to question 3.3. Once reviewed, proceed to the next question}

**4.8. Thinking about the medical facility where you usually receive your cancer care, since the start of COVID-19, are your transportation options to reach that facility still available? Please listen to the options and then select the one that most closely matches your situation.**



**{Read all options and select one options that match the respondent’s situation}**

- ① My options for transportation have *expanded* since the start of COVID-19 **{skip to Q 4.9}**
- ② My options for transportation have *remained the same* since the start of COVID-19
- ③ My options for transportation have become *more limited* since the start of COVID-19
- ④ My options for transportation have *disappeared completely* since the start of COVID-19

**4.9. What can you say about the *cost* of transportation? Please listen to the options and then select the one that most closely matches your situation.**

- ① My options for transportation have become *more expensive* since the start of COVID-19
- ② My options for transportation have become *less expensive* since the start of COVID-19
- ③ The cost of my options for transportation *has remained the same* since the start of COVID-19 **{Skip to Q4.10}**

**{Question 4.9a should only be asked if the participant has selected response option3 or 4 to question 4.8 or 1 or 2 to question 4.9}**

**4.9.a. How stressful have the changes in transportation and/or cost of getting treatment been for you? (select one)**

- ① Extremely stressful
- ② Very stressful
- ③ Somewhat stressful
- ④ Not so stressful
- ⑤ Not at all stressful

**4.9.b Based on your responses to the two previous questions, how have the changes in the transportation availability and/or costs may have impacted your ability to access the care you need?**

Please use as much space as you need:

**Script:** *Now, please think about the last time you needed to go to a health facility to receive a service related to your cancer diagnosis or treatment prior to the start of COVID-19.*

**4.10. Where did you stay the *last time* you visited the health facility *before the pandemic*? I will read you a number of options, and you may choose more than one option.**

**{Please select all that apply but keep in mind – we are asking you about the *last visit* pre-COVID-19}.**

- 1 I returned home once I finished at the clinic and stayed at my house
- 2 I was admitted to the health facility / hospital ward
- 3 I stayed at a friend or relative’s place
- 4 I stayed at a hotel or another rented place
- 5 I stayed on the hospital grounds
- 6 I stayed outside in the street/park, etc.
- 7 I stayed in an accommodation facility for cancer patients (e.g., patient hostel, dormitory, home)
- 9 Other (please specify)

Please Specify:

**4.11. Since COVID-19 started, which option(-s) have you used, are you using now, or are you most likely to use for your visit to a health facility for cancer care? You may choose more than one option, but keep in mind – I am asking about your *first visit since the start of COVID-19* (which may have been before your current visit).**

**{Please select all that apply}.**

- 1 I returned (or most likely to return) home once I finished at the clinic and stayed at my house
- 2 I was (or am most likely to be) admitted to the health facility / hospital ward
- 3 I stayed (or am most likely to stay) at a friend's or relative's place
- 4 I stayed (or am most likely to stay) at a hotel or another rented place
- 5 I stayed (or am most likely to stay) on the hospital grounds
- 6 I stayed (or am most likely to stay) outside in the street/park, etc.
- 7 I stayed (or am most likely to stay) in an accommodation facility for cancer patients (e.g., patient hostel, dormitory, home)
- 9 Other (please specify)

Please Specify:

**4.12. We would like to know if you have received any personal communication or specific information as someone facing cancer about certain topics since the start of COVID-19? I will name the topics one by one and please tell me if you have received any information about any of them.**

**{Data collector, read each option and select those options that apply}**

- 1 The vulnerability of cancer patients related to the transmission of COVID-19
- 2 How COVID-19 is affecting the functioning of health facilities providing diagnostic services and/or cancer treatment
- 3 How COVID-19 is affecting the functioning of patient services outside of health facilities (e.g., patient hostels, support groups, palliative care services, etc.)
- 4 How to receive pain relief and palliative care services (e.g. pain medicines, treatment for wounds, end-of-life support, etc.)
- 5 How to take care of yourself to stay healthy (e.g., nutrition advice, importance of social distancing, effective hygiene practices, mask-wearing)
- 6 Other topics related to dealing with cancer during the COVID-19 outbreak (please describe)
- 7 I have not received any information described above **{Skip to question 4.13}**

**4.12.a. For any of the information that you received, please tell me who provided it to you. I will read you the options now and tell me which ones gave you information.**

**{please select all that apply}**

- 1 Health facility staff (e.g. doctors, nurses, patient navigators)
- 2 Family member
- 3 Friend or neighbor
- 4 Cancer organization (e.g. NGO, support group, palliative care or hospice)
- 5 Media (radio, television, social media)
- 6 Other (please explain)

Please explain:
-----------------

**Script (for Q.4.13):** *We have made so much progress! I only have three questions left for you. Now, I am going to read a series of statements to you. You will tell me how well you agree or disagree. After I read the statement, please tell me if you: strongly disagree, disagree, neither agree nor disagree, agree, strongly agree. If you don't remember these options, I will be happy to repeat them after I read the statement.*

**4.13. {Please read each statement and mark the participant's response}**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am worried that the financial impact of COVID-19 has made it hard for me to afford the care I need as a cancer patient or someone facing a possible diagnosis	①	②	③	④	⑤
The COVID-19 outbreak has made it harder for me to contact health care providers with questions about my needs as a cancer patient or someone facing a possible diagnosis	①	②	③	④	⑤
I am worried that my cancer could be growing or returning because of the delays or disruptions in my care due to the COVID-19 outbreak	①	②	③	④	⑤
I am worried about going to health care facilities where I might have a higher chance of exposure to COVID-19	①	②	③	④	⑤

**4.14. I am going to read a series of statements to you about how you feel different people may be treating you prior to COVID-19 and since the start of the pandemic. As I mention the person(-s) that may be around you, please tell me if you think they are treating you worse, about the same, or better than before COVID-19 started. If you don't remember these options, I will be happy to repeat them after I read the statement.**

**To what extent, if at all, are you being treated differently since the start of COVID-19 as a cancer patient or someone facing cancer by various groups of people in your life?**

**{Select one response for every statement}**

<b>I have been treated by...</b>	<b>Worse than before COVID-19</b>	<b>About the same as before COVID-19</b>	<b>Better than before COVID-19</b>	<b>Not Applicable</b>
... my family members (e.g. siblings, spouse, children, parents, extended family)	①	②	③	④
... my friends	①	②	③	④
... my wider community	①	②	③	④
... my health care providers	①	②	③	④
... other group of people (please identify)	①	②	③	④

{please turn the page}

**4.15. In your own words, how has COVID-19 and the restrictions put in place to limit its spread affected you? I will capture the story that you tell me, but please know that your story will not be shared in any way that would expose your identity.**


**4.16. This is the last question. What would you recommend should be done to improve this situation?**


**{END OF SURVEY. Thank the participant for their response and close the survey}**

**Input the responses into the electronic tool as soon as possible (if you did not input those during the survey). Once the data has been entered, destroy (burn) this form.**