

APOA SURVEY ON CANCER COMMUNICATION - Informed Consent

My name is Dr. David Lounsbury. I am from the Albert Einstein College of Medicine, New York, USA. I am working with Dr. Melissa Henry from McGill University's Faculty of Medicine (Co-Principal Investigator) and with other investigators to conduct a survey to learn about current programs, practices and policies regarding breaking bad news including delivery of a cancer diagnosis. This study is conducted in collaboration with the African Organization for Research and Training in Cancer (AORTIC) and the Association for Psycho-Oncology in Africa (APOA).

As a physician or nurse who delivers care to cancer patients in an African hospital or clinic, you are being invited to participate in this brief on-line (digital) survey. The survey takes approximately 15 minutes to complete. Your participation may help inform the development of guidance guidelines to oncology providers on how to improve upon current methods of delivering a cancer diagnosis and other bad news to patients and family members in your institution.

Your participation is voluntary. You do not have to participate; it is your choice. Completing the survey will indicate your consent to participate. You may be uncomfortable answering some questions. You do not have to answer all the questions and you may stop at any time.

A risk of taking part in this study is the possibility of a loss of confidentiality or privacy. Loss of privacy means having your personal information shared with someone who is not on the study team and was not supposed to see or know about your information. The study team plans to protect your privacy, and no risks or discomforts are anticipated from taking part in this study. If you feel uncomfortable with a question, you can skip that question or stop taking the survey altogether. If you decide to quit at any time before you have finished the survey, your answers will not be retained. We will not pay you to join this study.

Information from this study may be used in future research studies by our study team. Data from this study may also be shared with other researchers (without links to your identity) for future research studies.

If you have any questions or problems with this study, or if you change your mind and don't want your information used for the study anymore, you can call or e-mail me, the person in charge of this study: Dr. David Lounsbury (phone: +1.718.839.7452; e-mail David.Lounsbury@einstein.yu.edu), Co-Principal Investigator for this study. Or, you can call Einstein Institutional Review Board at +1.718.430.2253. They will let you know how to write to the Principal Investigator to let him know you want to stop participating. Just remember, if we have already used your information for the study, the use of that information cannot be cancelled.

Thank you for your valuable time in participating in this very important study.

I agree to participate

☐ Yes
☐ No

APOA SURVEY ON CANCER COMMUNICATION - PART A

PART A - Sociodemographic and Work-Related Questions

What is your licensure status?

- ☐ Physician
- ☐ Nurse
- ☐ Trainee - Medicine
- ☐ Trainee - Nursing
- ☐ Other

Please specify other

What is your specialty?

- ☐ Oncology
- ☐ Radiology
- ☐ Surgery
- ☐ Primary Care
- ☐ Other

Please specify other

What is your gender?

- ☐ Male
- ☐ Female

What year did you complete your highest level of medical training (e.g., MD or RN)?

(yyyy)

What is your age?

In which African nation do you currently practice?

- ☐ Nigeria
- ☐ Egypt
- ☐ South Africa
- ☐ Algeria
- ☐ Morocco
- ☐ Angola
- ☐ Sudan
- ☐ Ethiopia
- ☐ Tanzania
- ☐ Kenya
- ☐ Tunisia
- ☐ Ghana
- ☐ Libya
- ☐ Uganda
- ☐ Ivory Coast
- ☐ Cameroon
- ☐ Zambia
- ☐ Democratic Republic of the Congo
- ☐ Botswana
- ☐ Senegal
- ☐ Madagascar
- ☐ Gabon
- ☐ Chad
- ☐ Mozambique
- ☐ Burkina Faso
- ☐ Mali
- ☐ Zimbabwe
- ☐ Republic of the Congo
- ☐ Equatorial Guinea
- ☐ Mauritius
- ☐ Namibia
- ☐ Benin
- ☐ Malawi
- ☐ Rwanda
- ☐ Niger
- ☐ Mauritania
- ☐ Guinea
- ☐ Swaziland
- ☐ Togo
- ☐ Eritrea
- ☐ Burundi
- ☐ Somalia
- ☐ Lesotho
- ☐ Gambia
- ☐ Liberia
- ☐ Cape Verde
- ☐ Djibouti
- ☐ Seychelles
- ☐ Guinea-Bissau
- ☐ Central African Republic
- ☐ Comoros
- ☐ São Tomé and Príncipe
- ☐ Not applicable

Does this African nation have a National Cancer Plan?

- ☐ Yes
- ☐ No
- ☐ I don't know

In what kind of community setting or environment do you primarily provide cancer care?

- ☐ Urban
- ☐ Semi-urban (e.g. suburban)
- ☐ Rural

Is your current place of practice affiliated with a university or medical school?

- ☐ University affiliated
- ☐ Non-university affiliated

When did you start practicing at this institution
(month/year)?

(mm/yyyy)

Typically, how many hours per week do you provide
clinical care at this institution?

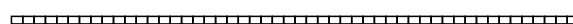
Do you treat ADULT cancer patients (i.e., patients
over the age of 21)?

☐ Yes

☐ No

Approximately what percentage of your clinical care
hours do you spend treating late stage (metastatic)
BREAST CANCER patients in a typical month? (0% to
100%)

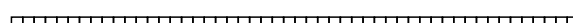
0 50 100



(Place a mark on the scale above)

Approximately what percentage of your clinical care
hours do you spend treating late stage (metastatic)
PROSTATE CANCER patients in a typical month? (0% to
100%)

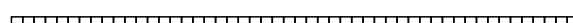
0 50 100



(Place a mark on the scale above)

Approximately what percentage of your clinical care
hours do you spend treating late stage (metastatic)
CERVICAL CANCER patients in a typical month? (0% to
100%)

0 50 100



(Place a mark on the scale above)

Approximately what percentage of your clinical care
hours do you spend treating late stage (metastatic)
COLORECTAL CANCER patients in a typical month? (0%
to 100%)

0 50 100



(Place a mark on the scale above)

Do you typically disclose a cancer diagnosis to your
adult patients?

☐ Yes, all or most of the time

☐ No, never or rarely

☐ No, disclosure of diagnosis is not my
responsibility

Which of the following reasons explain why YOU WOULD NOT DISCLOSE a cancer diagnosis to an ADULT PATIENT (check all that apply):

- ☐ The family/spouse doesn't want patients to know about their cancer diagnosis
- ☐ The family/spouse want to inform the patient themselves
- ☐ There are no treatment options
- ☐ Fear demoralizing the patient
- ☐ Financial worries (about the cost of cancer care)
- ☐ Threat of separation or divorce from the husband/wife
- ☐ Rejection of the patient by family, friends, and/or society
- ☐ Beliefs around fear that cancer is contagious
- ☐ Cancer being seen by the patient as a punishment
- ☐ Cancer being seen by the family as a punishment
- ☐ Lack of time
- ☐ Lack of access to specialists
- ☐ Challenges in care coordination
- ☐ The patient's socio-economic status
- ☐ Not enough training on communicating a cancer diagnosis to patients and their families
- ☐ Other reason(s) not listed above

Please specify other

Do you treat PEDIATRIC cancer patients (i.e., patients age 21 or younger)?

- ☐ Yes
- ☐ No

Do you typically disclose a cancer diagnosis to pediatric patients?

- ☐ Yes, all or most of the time
- ☐ No, never or rarely
- ☐ No, disclosure of diagnosis is not my responsibility

Which of the following reasons explain why YOU WOULD NOT DISCLOSE a cancer diagnosis to an PEDIATRIC PATIENT (check all that apply):

- ☐ The family/spouse doesn't want patients to know about their cancer diagnosis
- ☐ The family/spouse want to inform the patient themselves
- ☐ There are no treatment options
- ☐ Fear demoralizing the patient
- ☐ Financial worries (about the cost of cancer care)
- ☐ Capacity of the pediatric patient to understand the diagnosis
- ☐ Rejection of the patient by family, friends, and/or society
- ☐ Beliefs around fear that cancer is contagious
- ☐ Cancer being seen by the patient as a punishment
- ☐ Cancer being seen by the family as a punishment
- ☐ Lack of time
- ☐ Lack of access to specialists
- ☐ Challenges in care coordination
- ☐ The patient's socio-economic status
- ☐ Not enough training on communicating a cancer diagnosis to patients and their families
- ☐ Other reason(s) not listed above

Please specify other

Briefly, tell us about your current role(s) at this institution?

Which of the following best describes your current institution? (Check all that apply)

- ☐ Cancer Centre
- ☐ Cancer Advocacy Agency
- ☐ General Hospital
- ☐ Private Practice (free-standing clinic)
- ☐ Non-Governmental Organization
- ☐ Faith-based Organization
- ☐ Other

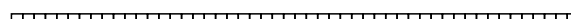
Please specify

Is this institution public (government), private, or non-profit?

-
- ☐ Public
 - ☐ Private
 - ☐ Charitable (Non-profit)
 - ☐ Mixed (Public/Private)

Approximately what percentage of TOTAL patient visits to your institution involve cancer-related treatments or support services in a typical month? (0% to 100%)

0 50 100



(Place a mark on the scale above)

Does your institution offer psychological counseling to cancer patients and their families?

- ☐ Yes
- ☐ No
- ☐ Don't know / Not sure

APOA SURVEY ON CANCER COMMUNICATION - Part B

PART B - SPIKES Model Questionnaire and Communication-Specific Questions

In an average month, how often do you have to break bad news to a cancer patient (e.g., diagnosis, recurrence, progressive disease, etc.)?

- ☐ 0 times - I never break bad news to patients
- ☐ Less than 5 times
- ☐ 5 to 10 times
- ☐ 10 to 20 times
- ☐ More than 20 times

Which do you find the most difficult task?

- ☐ Discussing diagnosis
- ☐ Telling patient about recurrence
- ☐ Talking about end of active treatment and beginning palliative treatment
- ☐ Discussing end-of-life issues (e.g., do not resuscitate)
- ☐ Involving family/friends of patient
- ☐ Other

Please specify other

Have you had any specific teaching or training for breaking bad news?

- ☐ Formal teaching (e.g., course work, seminar, and/or supervision)
- ☐ Observation (e.g., sat in with clinicians in breaking bad news interviews)
- ☐ Both
- ☐ Neither

How confident do you feel about your own ability to break bad news?

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not at all confident

What do you feel is the most difficult part of discussing bad news?

- ☐ Being honest but not taking away hope
- ☐ Dealing with the patient's emotions (e.g., crying, anger)
- ☐ Spending the right amount of time
- ☐ Involving friends and family of the patient
- ☐ Involving patient or family in decision-making
- ☐ Other

Please specify other

How would you rate your own comfort in dealing with patient's emotions (e.g., crying, anger, denial, etc.)?

- ☐ Quite comfortable
- ☐ Somewhat comfortable
- ☐ Uncomfortable

When you break bad news to your patients, do you have a consistent, preferred plan or strategy in mind?

- ☐ Have a consistent plan or strategy
- ☐ Several techniques/tactics but no overall plan
- ☐ No consistent approach to task

Describe how you typically communicate a cancer diagnosis to your cancer patients.

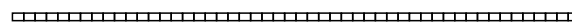
When you break bad news to your patients, how often do you include the patient's family?

- ☐ Always
- ☐ Very often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

Describe how you typically communicate a cancer diagnosis to a patient's family members.

To the best of your knowledge, what percentage of oncology clinicians in your institution support disclosing a cancer diagnosis to adult patients? (0% to 100%; SKIP if you prefer not to answer)

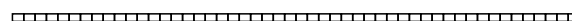
0 50 100



(Place a mark on the scale above)

To the best of your knowledge, what percentage of oncology clinicians in your institution support disclosing a cancer diagnosis to pediatric patients? (0% to 100%; SKIP if you prefer not to answer)

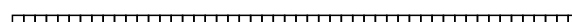
0 50 100



(Place a mark on the scale above)

Approximately what percentage of your ADULT cancer patients know about their cancer diagnosis?(0% to 100%; SKIP if you prefer not to answer)

0 50 100



(Place a mark on the scale above)

Among ADULT patients you care for, approximately what percentage of THEIR FAMILY CAREGIVERS know about their family member's cancer diagnosis?(0% to 100%; SKIP if you prefer not to answer)

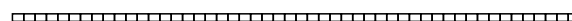
0 50 100



(Place a mark on the scale above)

Approximately what percentage of your PEDIATRIC cancer patients know about their cancer diagnosis?(0% to 100%; SKIP if you prefer not to answer)

0 50 100



(Place a mark on the scale above)

Among PEDIATRIC patients you care for, approximately what percentage of THEIR FAMILY CAREGIVERS know about their family member's cancer diagnosis? (0% to 100%; SKIP if you prefer not to answer)

0 50 100



(Place a mark on the scale above)

Does your institution have a formal policy about the disclosure of cancer diagnosis to patients in adult and pediatric settings?

- ☐ Yes
☐ No
☐ Don't know / Not sure

Please describe your institution's formal policy about disclosure of cancer diagnosis to patients here

How useful would having a written policy or guideline to breaking bad news be helpful to you in your oncology practice?

- ☐ Very helpful
☐ Somewhat helpful
☐ Neither helpful nor unhelpful
☐ Somewhat unhelpful
☐ Very unhelpful

When breaking bad news:

	Never	Rarely	Sometimes	Very Often	Always
I use a private space with uninterrupted time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am seated with the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make sure to have tissues available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I consider who should be there	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I check the understanding of the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I determine information gaps and expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I correct misunderstandings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I define my current role and goal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I determine what type of information the patient wants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I acknowledge that information needs change over time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I forecast to the patient what will come (e.g., say something like "I'm afraid I have some bad news for you")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I share the information in small pieces	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoid using jargon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I draw diagrams and/or write down details	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I explore the patient's emotions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I acknowledge the patient's emotions empathetically	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I validate the patient's emotions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I promote a sense of support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I discuss future treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I check the patient's current and future needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I review the next steps with the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

LAST QUESTION! In your professional opinion, what are the most pressing needs of Africa-based oncology clinicians for training around communication of the diagnosis with patients and family members in adult and pediatric settings?

We thank you for your time in completing this survey. Please click on the submit button below:

APOA SURVEY ON CANCER COMMUNICATION - Optional Contact Information

Thank you! Your responses have been registered and sent. If you would like to be contacted by the principal investigator about future studies that explore and apply the current results of this survey, or if you would simply would like to be kept informed of upcoming activities by the study team, please provide your contact information below:

Name

(First and Last Name)

E-mail

Title

Current country of practice
