

Patient Centered Methods to
Collect Sexual Orientation and
Gender Identity Status in the ED

ID: 2015P002475

Date: March 14, 2018

Protocol Title: Patient Centered Approaches to Collect Sexual Orientation and Gender Identity Information in the Emergency Department – Phase 3 Trial

Principal Investigator: Adil Haider, MD, MPH

Sponsor: Patient-Centered Outcomes Research Institute (PCORI)

We are asking every patient who comes to the emergency department at Brigham and Women’s Hospital and Brigham and Women’s Faulkner Hospital to fill out this form. There are 10 questions and it will take less than 5 minutes to complete.

This tool is being used as part of a research study. The purpose of this research is to test a new way to collect sexual orientation and gender identity information from patients in the emergency department. This information is normally verbally collected by nurses as a part of standard care; we are testing this new tool to identify if patients prefer non-verbal collection of the information. The information will be entered into the medical record in the appropriate fields by the registrar. Form completion will be actively monitored by the research staff that will observe standard hospital policies and guidelines for patient safety and confidentiality.

Your participation is voluntary, and you can stop participating at any time. Deciding not to participate will not affect medical care you receive at Partners now or in the future, or any benefits you receive now or have a right to receive.

Some participants may be invited to participate in a follow-up satisfaction survey prior to discharge from the emergency department.

We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement (see [Partners Privacy Notice](#)). During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy.

If you have any questions about this project and your participation, please contact Adil Haider, MD, MPH at [617-525-7300](tel:617-525-7300) or ahhaider@partners.org.

If you’d like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Partners Human Research Committee at 617-424-4100.

Do you agree to participate in this survey? Yes/No

Signature: _____ **Date:** _____

1. Legal Name: _____
2. Date of Birth: _____
3. Preferred name: _____
4. Race
 - a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Declined
 - e. Native Hawaiian or Other Pacific Islander
 - f. Other
 - g. Unavailable
 - h. White or Caucasian
5. Hispanic
 - a. Hispanic or Latino/Latina
 - b. Not Hispanic
 - c. Declined
 - d. Unavailable
6. Marital status
 - a. Declined
 - b. Divorced
 - c. Legally Separated
 - d. Life Partner
 - e. Married/Civil Union
 - f. Single
 - g. Unavailable
 - h. Widowed
7. Sexual orientation
 - a. Straight/Heterosexual
 - b. Gay/Lesbian/Homosexual
 - c. Bisexual
 - d. Queer
 - e. Questioning/Unsure
 - f. Pansexual
 - g. Prefer to speak with nurse
 - h. Declined to state
 - i. Other
8. Assigned sex at birth
 - a. Female
 - b. Male
 - c. Prefer to speak with nurse
 - d. Declined to state
 - e. Other
9. Gender identity now
 - a. Female
 - b. Male
 - c. Transgender Female-to-Male
 - d. Transgender Male-to-Female

- e. Queer/Genderqueer
 - f. Questioning/Unsure
 - g. Prefer to speak with nurse
 - h. Declined to state
 - i. Other
10. Preferred pronoun
- a. She/Her/Hers
 - b. He/Him/His
 - c. They/Them/Theirs
 - d. Ze/Hir/Hirs
11. Religion
- a. Advent Christ
 - b. Agnostic
 - c. Anglican
 - d. Atheist
 - e. Bahai
 - f. Baptist
 - g. Buddhist
 - h. Christian
 - i. Christian Scientist
 - j. Congregational
 - k. Declined
 - l. Disciples of Christ
 - m. Episcopalian
 - n. Evangelical Church
 - o. Greek Orthodox
 - p. Hindu
 - q. Jehovah's Witness
 - r. Jewish
 - s. Lutheran
 - t. Methodist
 - u. Mormon
 - v. Muslim
 - w. No Preference
 - x. Not Affiliated
 - y. Orthodox
 - z. Other
 - aa. Pentecostal
 - bb. Presbyterian
 - cc. Protestant
 - dd. Quaker
 - ee. Roman Catholic
 - ff. Russian Orthodox
 - gg. Scientologist
 - hh. Seventh Day Adventist

- ii. Sikh Southern Baptist
- jj. Spiritualist
- kk. Unavailable
- ll. Unitarian Universalist
- mm. Wiccan

12. Education

- a. 8th Grade or Less
- b. Declined
- c. Did not attend school
- d. Graduated – College
- e. Graduated – Grad School
- f. Graduated – High School
- g. Graduated – Post Graduate
- h. Obtained GED
- i. Other
- j. Some College
- k. Some High School
- l. Some Technical Program
- m. Some Vocational Program
- n. Unavailable

[Display]

Consent Form for EQUALITY STUDY

We are conducting a research study to learn more about patient preferred ways of collecting sexual orientation and gender identity (SO/GI) in the emergency department. We are asking all emergency department staff involved in the collection of SO/GI to consider participation in this study. This is a research study being conducted by researchers at Partners Healthcare (Brigham and Women's Hospital and Brigham and Women's Faulkner Hospital) and Johns Hopkins Hospital.

There are no right or wrong answers to the questions and you may stop participation at any time. Your response to this survey, or any individual question on the survey, is completely voluntary. Deciding not to participate won't affect your employment status at Partners now or in the future, or any benefits you receive now or have a right to receive.

We will be collecting potentially identifiable information; however your responses will be kept completely private and secure. Data will be secured on an encrypted storage drive that is only accessible by research team members.

There are no physical risks to you by participating in this interview and no direct benefits. However, the information you give us may help us with data gathering and ultimately patient care in the future. There is no cost to you but you will receive a \$10 gift card for your time.

If you have questions about this survey, you may contact the Principal Investigator, Dr. Adil Haider, at 617-525-7300. If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Partners Human Research Committee at 617-424-4100.

In this survey, we will ask you about sexual orientation and gender identity in healthcare. Your responses to this survey are private and will be kept confidential. This data will be used for research purposes only. It will take approximately 10 minutes to complete. Thank you for your time and participation.

Your completion of this survey will serve as your consent to be in this research study.

[I AGREE TO PARTICIPATE IN THIS RESEARCH]

(THIS IS A BUTTON THAT TAKES RESPONDENT TO SURVEY)

**EQUALITY PHASE III
EMERGENCY DEPARTMENT STAFF-REPORTED
OUTCOME MEASURES INSTRUMENT**

Format:

- Online survey using Qualtrics, REDcap or other available online survey platform
- Administered through email
- Distributed to eligible staff once per mode (to compare responses between Mode 1 and Mode 2)

Eligibility:

- Currently work as a nurse at a study site (Mode 1)
- Currently work as a nurse or registrar at a study site (Mode 2)
- Involved in collection and/or use of SO/GI data during study period
- Willing and able to provide informed consent (by completing survey)

Target Population:

- Nurses involved in collection of SO and GI data (Mode 1)
- Registrars and nurses involved in collection of SO and GI data (Mode 2)

SURVEY INSTRUMENT:

Part I. Basic Demographic Information

1. What is your role in the emergency department?
 - a. Registered Nurse
 - b. Nurse Practitioner
 - c. Licensed Practical Nurse
 - d. Registrar
 - e. Other (please explain) _____
 - f. Decline to answer (please explain) _____

2. What is your age?
 - a. < 20 years
 - b. 20 – 30 years
 - c. 31 – 40 years
 - d. 41 – 50 years
 - e. 51 – 60 years
 - f. >60 years
 - g. Other (please explain) _____
 - h. Decline to answer (please explain) _____

3. How would you identify your race?
 - a. Black or African-American
 - b. White or Caucasian

- c. Asian
 - Asian- Chinese
 - Asian-Japanese
 - Asian-Indian
 - Asian-Korean
 - Asian-Filipino
 - Asian-Vietnamese
 - Asian-Others
 - d. American Indian or Alaska Native
 - e. Pacific Islander
 - Native Hawaiian
 - Guamanian or Chamoro
 - Samoan
 - Other Pacific Islander
 - f. Other race (please explain) _____
 - g. Decline to answer (please explain) _____
4. Are you of Hispanic and/or Latino(a) origin?
- a. Yes
 - b. No
 - c. Other (please explain) _____
 - d. Decline to answer (please explain) _____
5. Do you identify as:
- a. Straight/Heterosexual
 - b. Lesbian/Gay/Homosexual/Same gender-loving
 - c. Bisexual
 - d. Queer
 - e. Questioning
 - f. Not Listed (please describe) _____
 - g. Not sure
 - h. Decline to Answer (please explain) _____
6. What is your gender identity?
- a. Male
 - b. Female
 - c. Female-to-Male/Transgender Male/Trans Man
 - d. Male-to-Female/Transgender Female/Trans Woman
 - e. Genderqueer/Outside the gender binary
 - f. Agender/Neutrois
 - g. Intersex
 - h. Not Listed (please describe) _____
 - i. Decline to Answer (please explain) _____
7. What sex were you assigned at birth?
- a. Male

- b. Female
- c. Not listed (please describe) _____
- d. Decline to Answer (please explain) _____

Part II. The EQUALITY Study – General Questions

8. I attended the EQUALITY study education session.
- a. Yes
 - b. No
 - c. Other (please explain) _____
 - d. Decline to answer (please explain) _____
9. I have directly participated in **verbally** collecting sexual orientation and gender identity data as part of the EQUALITY study for this proportion of all patients.
- a. Never
 - b. 1-25% of patients
 - c. 25-49% of patients
 - d. 50-74% of patients
 - e. 75-99% of patients
 - f. 100% of patients
 - g. Other (please explain) _____
 - h. Decline to answer (please explain) _____
10. I have directly participated in **administering a form** to collect sexual orientation and gender identity data as part of the EQUALITY study for this proportion of all patients.
- a. Never
 - b. 1-25% of patients
 - c. 25-49% of patients
 - d. 50-74% of patients
 - e. 75-99% of patients
 - f. 100% of patients
 - g. Other (please explain) _____
 - h. Decline to answer (please explain) _____
11. I feel prepared to collect **sexual orientation** data.
- a. Not at all prepared
 - b. A little prepared
 - c. Somewhat prepared
 - d. Mostly prepared
 - e. Well prepared
 - f. Other (please explain) _____
 - g. Decline to answer (please explain) _____
12. I feel prepared to collect **gender identity** data.
- a. Not at all prepared
 - b. A little prepared

- c. Somewhat prepared
- d. Mostly prepared
- e. Well prepared
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

Part III. Feasibility/Acceptability of Sexual Orientation/Gender Identity Data Collection

13. Did you experience difficulty collecting **sexual orientation** data from patients?

- a. Never
- b. Rarely
- c. Sometimes
- d. Usually
- e. Always
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

14. Did you experience difficulty collecting **gender identity** data from patients?

- a. Never
- b. Rarely
- c. Sometimes
- d. Usually
- e. Always
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

15. How did collecting **sexual orientation** data impact your workflow?

- a. Improved workflow considerably
- b. Improved workflow somewhat
- c. Neither improved nor slowed workflow
- d. Slowed workflow somewhat
- e. Slowed workflow considerably
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

16. How did collecting **gender identity** data impact your workflow?

- a. Improved workflow considerably
- b. Improved workflow somewhat
- c. Neither improved nor slowed workflow
- d. Slowed workflow somewhat
- e. Slowed workflow considerably
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

Part IV. Utility of Sexual Orientation/Gender Identity Data

17. I found it helpful to know the patient's **sexual orientation** to provide patient-centered care.

- a. Never
- b. Rarely
- c. Sometimes
- d. Usually
- e. Always
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

18. I found it helpful to know the patient's **gender identity** to provide patient-centered care.

- a. Never
- b. Rarely
- c. Sometimes
- d. Usually
- e. Always
- f. Other (please explain) _____
- g. Decline to answer (please explain) _____

19. What else would you like to tell us about your experience with sexual orientation and gender identity information collection?

[Display]

Consent Form for EQUALITY STUDY

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Your responses will only be seen by our research team and will be kept completely private and secure.

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Your completion of this survey will serve as your consent to be in this research study.

[I AGREE TO PARTICIPATE IN THIS RESEARCH]

(THIS IS A BUTTON THAT TAKES RESPONDENT TO SURVEY)

In this survey, we will ask you about sexual orientation and gender identity in healthcare. This survey is anonymous and will be used for research purposes only. It will take approximately 10 minutes to complete. Thank you for your time and participation.

EQUALITY Phase III Patient–Reported Outcomes – Patient Form

FOR PATIENTS DECLINING ALL PARTICIPATION ONLY

Can you please share your **main** reason for not speaking with us today?

This is not a private space

I am concerned my information won't be confidential

I do not have time to sit here today to answer questions

There is not enough payment for my time

These questions are none of your business

SECTION A – LEADERSHIP COMMITMENT SUBSCALE (C-CAT)

Dear patient: Please help us find out how well we communicate with patients. This survey will take less than 10 minutes. Please do not write your name on the survey. **Your answers to these questions will be matched with your medical record at this visit, for research purposes only. This will not become part of your record in any way.** Your answers to these questions will not change how you are treated.

Instructions:

1. Please, fill out this survey.
2. Please answer all questions about only your healthcare visit today.

Your answers to these questions are very important. But, you do not have to fill out this survey if you do not want to.

Thank you for your help.

1.) Was it easy to ask questions at the hospital?



2.) Was information in the waiting areas helpful?



3.) Was it easy to reach someone on the phone if you had a question?



4.) Do you feel welcome at the hospital?



5.) Are you happy with the care you get at the hospital?



6.) Does the hospital communicate well with patients?

7.) Would you bring a family member to this hospital?



SECTION B – PROCESS SATISFACTION AND SUGGESTIONS

READ: Thank you for agreeing to answer these questions. We are interested in your experience in reporting information during your visit today. Each question has a set of answer choices for you to select from. There are no right or wrong answers, and all of your information will be kept confidential.

Section B.1 Overall comfort with providing information

1.) How comfortable did the ED staff (doctors, nurses, front desk) seem to be when interacting with you today?

- 1 – Very uncomfortable
- 2 – Uncomfortable
- 3 – Neither comfortable nor uncomfortable
- 4 – Comfortable
- 5 – Very comfortable
- 99 – Refuse to answer

2.) How respectfully have you been treated by the ED staff today?

- 1 – Very disrespectfully
- 2 – Disrespectfully
- 3 – Neutrally
- 4 – Respectfully
- 5 – Very respectfully
- 99 – Refuse to answer

2a.) What made you feel this way about how you were treated today?

3.) How often were you ignored by the ED staff during your visit?

- 1 – Never

- 2 – Rarely
- 3 – Sometimes
- 4 – Often
- 5 – Constantly
- 99 – Refuse to answer

3a.) What made you feel this way during your visit today?

4.) Was there anything you were not able to share during your visit today?

- 1 – No
- 2 – Yes
- 99 – Refuse to answer

4a.) What did you wish to share today?

5.) How concerned were you about your privacy while answering questions today?

- 1 – Not at all concerned
- 2 – A little concerned
- 3 – Somewhat concerned
- 4 – Concerned
- 5 – Very concerned
- 99 – Refuse to answer

6.) Which of the following personal information were you least comfortable with providing today? Please choose only one.

- My race/ethnicity _____
- My income _____
- My sexual orientation _____
- My gender identity _____
- My religion _____ Not applicable/I
- was not asked _____
- Other _____

7.) How easy was it to understand the questions you were asked today?

1 – Very difficult

2 – A little difficult

3 – Acceptable

4 – Easy

5 – Very easy

99 – Refuse to answer

8.) How can we make improve our registration process? Please check all that apply.

Ask the questions in a more private space _____

Make the wording simpler _____

Shorten the number of questions _____

Have someone read me the questions _____

Make the text larger _____

Other _____

[Display]

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[I AGREE TO PARTICIPATE IN THIS RESEARCH]

(THIS IS A BUTTON THAT TAKES RESPONDENT TO SURVEY)

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EQUALITY Phase III Patient–Reported Outcomes – Patient Form

FOR PATIENTS DECLINING ALL PARTICIPATION ONLY

Can you please share your main reason for not speaking with us today?

This is not a private space

I am concerned my information won't be confidential

I do not have time to sit here today to answer questions

There is not enough payment for my time

These questions are none of your business

SECTION A – LEADERSHIP COMMITMENT SUBSCALE (C-CAT)

Dear patient: Please help us find out how well we communicate with patients at [ORG NAME]. This survey will take less than 10 minutes. Please do not write your name on the survey. **Your answers to these questions will be matched with your medical record at this visit, for research purposes only. This will not become part of your record in any way.** Your answers to these questions will not change how you are treated.

Instructions:

1. Please, fill out this survey.
2. Please answer all questions about only your healthcare visit today.

Your answers to these questions are very important. But, you do not have to fill out this survey if you do not want to.

Thank you for your help.

1.) Was it easy to ask questions at the hospital?



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2.) How respectfully have you been treated by the ED staff today?

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- 5 – Very respectfully
- 99 – Refuse to answer

2a.) What made you feel this way about how you were treated today?

3.) How often were you ignored by the ED staff during your visit?

- 1 – Never

- 2 – Rarely
- 3 – Sometimes
- 4 – Often
- 5 – Constantly
- 99 – Refuse to answer

3a.) What made you feel this way during your visit today?

4.) Was there anything you were not able to share during your visit today?

- 1 – No
- 2 – Yes
- 99 – Refuse to answer

4a.) What did you wish to share today?

5.) How concerned were you about your privacy while answering questions today?

- 1 – Not at all concerned
- 2 – A little concerned
- 3 – Somewhat concerned
- 4 – Concerned
- 5 – Very concerned
- 99 – Refuse to answer

6.) Which of the following personal information were you least comfortable with providing today? Please choose only one.

- My race/ethnicity _____
- My income _____
- My sexual orientation _____
- My gender identity _____
- My religion _____
- Not applicable/I was not asked _____
- Other _____

7.) How easy was it to understand the questions you were asked today?

- 1 – Very difficult
- 2 – A little difficult
- 3 – Acceptable
- 4 – Easy
- 5 – Very easy
- 99 – Refuse to answer

Section B.2 Comfort level with providing SO/GI information

8.) How comfortable were you reporting your sexual orientation at your healthcare visit today?

- 1 – Not at all comfortable
- 2 – A little comfortable
- 3 – Somewhat comfortable
- 4 – Comfortable
- 5 – Very comfortable
- 99 – Refuse to answer
- 00 – I was not asked about sexual orientation today

9.) How comfortable were you reporting your gender identity at your healthcare visit today?

- 1 – Not at all comfortable
- 2 – A little comfortable
- 3 – Somewhat comfortable
- 4 – Comfortable
- 5 – Very comfortable
- 99 – Refuse to answer
- 00 – I was not asked about gender identity today

10.) Do you consider sharing your sexual orientation related to your visit today?

- 1 – Not at all related
- 2 – A little related
- 3 – Somewhat related
- 4 – Related
- 5 – Very related
- 99 – Refuse to answer

10a.) Why or why wasn't this information related to your visit?

11.) Do you consider sharing your gender identity related to your visit today?

- 1 – Not at all related
- 2 – A little related
- 3 – Somewhat related
- 4 – Related
- 5 – Very related
- 99 – Refuse to answer

11a.) Why or why wasn't this information related to your visit?

12.) How important is it for all patients to provide their sexual orientation in healthcare visits?

- 1 – Not at all important
- 2 – A little important
- 3 – Somewhat important
- 4 – Important
- 5 – Very important
- 99 – Refuse to answer

12a.) Why or why isn't this information important for healthcare visits?

13.) How important is it for all patients to provide their gender identity in healthcare visits?

- 1 – Not at all important
- 2 – A little important
- 3 – Somewhat important
- 4 – Important
- 5 – Very important
- 99 – Refuse to answer

13a.) Why or why isn't this information important for healthcare visits?

14.) How can we make improve our registration process? Please check all that apply.

Ask the questions in a more private space _____

Make the wording simpler _____

Shorten the number of questions _____

Have someone read me the questions _____

Make the text larger _____

Other _____

[Display]

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Your responses will only be seen by our research team and will be kept completely private and secure.

If you have questions about this survey, you may contact the Principle Investigator, Brandyn Lau, at 443-287-3031. If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Johns Hopkins Institutional Review Board at 410-955-4367.

Your completion of this survey will serve as your consent to be in this research study.

[I AGREE TO PARTICIPATE IN THIS RESEARCH]

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SECTION A – LEADERSHIP COMMITMENT SUBSCALE (C-CAT)

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Thank you for your help.

- | | | | | |
|---------------------------------------------------------------|---------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|----------|
| 1.) Was it easy to ask questions at the hospital? |  |  |  | ? |
| 2.) Was information in the waiting areas helpful? |  |  |  | ? |
| 3.) Was it easy to reach someone on the phone had a question? |  |  |  | ? if you |
| 4.) Do you feel welcome at the hospital? |  |  |  | ? |
| 5.) Are you happy with the care you get at the hospital? |  |  |  | ? |
| 6.) Does the hospital communicate well with patients? |  |  |  | ? |
| 7.) Would you bring a family member to this hospital? |  |  |  | ? |

SECTION B – PROCESS SATISFACTION AND SUGGESTIONS

READ: Thank you for agreeing to answer these questions. We are interested in your experience in reporting information during your visit today. Each question has a set of answer choices for you to select from. There are no right or wrong answers, and all of your information will be kept confidential.

Section B.1 Overall comfort with providing information

1.) How comfortable did the ED staff (doctors, nurses, front desk) seem to be when interacting with you today?

- 1 – Very uncomfortable
- 2 – Uncomfortable
- 3 – Neither comfortable nor uncomfortable
- 4 – Comfortable
- 5 – Very comfortable
- 99 – Refuse to answer

2.) How respectfully have you been treated by the ED staff today?

- 1 – Very disrespectfully
- 2 – Disrespectfully
- 3 – Neutrally
- 4 – Respectfully
- 5 – Very respectfully
- 99 – Refuse to answer

2a.) What made you feel this way about how you were treated today?

3.) How often were you ignored by the ED staff during your visit?

- 1 – Never
- 2 – Rarely
- 3 – Sometimes
- 4 – Often
- 5 – Constantly
- 99 – Refuse to answer

3a.) What made you feel this way during your visit today?

4.) Was there anything you were not able to share during your visit today?

- 1 – No

- 2 – Yes
- 99 – Refuse to answer

4a.) What did you wish to share today?

5.) How concerned were you about your privacy while answering questions today?

- 1 – Not at all concerned
- 2 – A little concerned
- 3 – Somewhat concerned
- 4 – Concerned
- 5 – Very concerned
- 99 – Refuse to answer

6.) How easy was it to understand the questions you were asked today?

- 1 – Very difficult
- 2 – A little difficult
- 3 – Acceptable
- 4 – Easy
- 5 – Very easy
- 99 – Refuse to answer

7.) How can we make improve our registration process? Please check all that apply.

- Ask the questions in a more private space _____
- Make the wording simpler _____
- Shorten the number of questions _____
- Have someone read me the questions _____
- Make the text larger _____
- Other _____