

Supplementary material

Supplementary material 1

Informed Consent

Introduction and Purpose of Study

The purpose of this study is to learn more about how people feel about of organ donation.

Description of the Research

You are being asked to complete a survey that will take about [30] minutes of your time. The survey will ask about your thoughts and feelings towards organ donation. You will also be asked to watch a short video that will talk about organ donation from different people's views. We will ask you about how the video made you feel.

Eligibility

You must live in the state of New York to complete this survey. If you do not currently live in New York, you are not eligible to complete the survey.

Your participation can also be rejected for any of the following reasons:

- You did not agree to participate
- You reside outside of the US
- You failed to answer a question(s) that checked to see if you read and understood the instructions

This follows Amazon Mechanical Turk policy, which states that "a Requester may reject your work if the HIT is not completed correctly or the instructions were not followed."

Potential Risks and Discomforts

There are no known risks associated with completing this survey.

Potential Benefits

There are no direct benefits to participating. The results of this survey will be used to inform the researchers to make an intervention program that specifically address New York residents' concerns about becoming an organ donor.

Confidentiality

Your specific responses to the survey will be confidential. The information that we collect from you will be stored on a secure server. We will only report "group" data- meaning that it will be based on information from many people.

Compensation

You will be paid \$5 upon completion of the survey. If you do not complete the survey all the way through, you will not receive payment.

Voluntary Participation Your participation in this survey is voluntary. You do not have to participate, may refuse to participate, or can withdraw from the survey at any time, simply by exiting out of the survey window. When you are finished with the survey, please do not close the survey window. Copy and paste the survey code into the appropriate Mturk box. If you have questions or concerns, please feel free to contact Kayla Finuf, M.S. (KFinuf@northwell.edu).

You may print a copy of this consent document for your records.

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IRB # 19-0009



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Consent and Authorization

If you are interested in participating in this study, click the CONSENT button. If you are NOT interested in participating in the study, click the NO CONSENT button.

- CONSENT
- NO CONSENT

Authorization Statement (if consent given)

By consenting to participate in this survey, you are aware that:

- You will be asked about your thought and feelings towards organ donation
- You must be a resident of New York State to continue
- You must answer the questions that checked to see if you read and understood the instructions correctly to be compensated
- There are no known risks or benefits to participating
- Your responses are kept confidential

Do you wish to continue?

- YES, I WISH TO PARTICIPATE
- NO, I DO NOT WISH TO PARTICIPATE

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Supplementary material 2

Impressions

In New York state, an individual can consent to give their organs, eyes, and tissue after their death. This is called donation after death. Recipients are registered on a national

waiting list. Once you decide to be an organ donor, your organs will be given to a person in need.

11. Are you registered as an organ donor?

Living donors are those who voluntarily donate an organ while they are still alive and continue with a normal life following donation. Living organ donation may be directed by the donor where the recipient is known by the donor. Living organ donation may also be non-directed where the recipient is unknown by the donor.

12. What kind of organ donor are you? You may check all that apply.

- i. Living organ donor
- ii. Donor after death

13. What made you become a living organ donor?

14. What made you become a donor after death?

15. What does organ donation mean to you?

16. What are your overall impressions of organ donation?

Body integrity

17. Did your religious beliefs influence your decision to be or not to be an organ donor after death?

- i. Yes
 - 1. How so?

- ii. No

18. Do you think all organs should still be inside the body for burial?

- i. Yes
 - 1. Why do you think that?

- ii. No

19. Do you think organ donation after death will impact funeral proceedings?

- i. Yes
 - 1. Why do you think so?

- ii. No

Medical mistrust

20. Do you think doctors will treat you differently if you are an organ donor after death?
- i. Yes
 1. How so?
 - ii. No
21. If you are a donor after death, would it matter to you who received the organs?
- i. Yes
 1. Why?
 - ii. No
- b. Who do you think will receive the organs?

ICK

22. Does the thought of organ donation after death bother you?
- i. Yes
 1. How so?
 - ii. No
23. Does the thought of your organs being put into someone else's body bother you?
- i. Yes
 1. How so?
 - ii. No
24. (ATTN) We are interested in learning a little bit more about how you feel about putting your organs into someone else's body. Please type "I disagree" in the text box.
- i. How does this make you feel?

Jinx

25. Do you have any concerns about signing up to be an organ donor after death?

- i. Yes
 - 1. What are those concerns?
- ii. No

Age/Health

26. Do you think there is an age limit to organ donation?
- i. Yes
 - ii. No
27. At what age do you think you can no longer be an organ donor after death?
28. Why do you think you can no longer donate after that age? Please be as specific as possible.
29. Do you think your current health affects your ability to be a donor after death?
- i. Yes
 - 1. How so?
 - ii. No

Other

30. Do you think you will be treated differently by doctors based on your race if you are an organ donor after death?
- i. Yes
 - 1. How might you be treated differently?
 - ii. No
31. Do you think that organ donation after death is associated with physical pain?
- i. Yes
 - ii. No
32. Do you think it is legally possible to buy an organ?
- i. Yes
 - ii. No

Signing up

33. Do you know where to go to sign up to be an organ donor after death?
 - i. Yes
 - ii. No
34. Do you know the process, or how, to register as an organ donor after death?
 - i. Yes
 - ii. No
35. Are you aware that you can sign up to be an organ donor after death at the DMV?
 - i. Yes
 - ii. No

DMV

36. For the following, please recall your last visit to the DMV. What was your experience like?
 - i. Please be as specific as possible.
37. Did you have to wait?
 - i. Yes
 - ii. No
38. Approximately how long did you have to wait?
 - i. Less than 1 hour Should we include less than 30 minutes as well
 - ii. 1 to 2 hours
 - iii. 2 to 3 hours
 - iv. 3 to 4 hours
 - v. More than 4 hours
 - vi. Don't know.
39. What kind of emotions did you experience?
40. Did the clerk speak with you about organ donation?
 - i. Yes
 - ii. No

iii. Don't recall.

41. Were there materials in the DMV on organ donation after death?

i. Yes

ii. No

iii. Don't recall.

42. Did the wait time you experienced prevent you from registering as an organ donor after death?

i. Yes

1. How so?

ii. No

43. Did the emotions you experienced prevent you from registering as an organ donor after death?

i. Yes

1. How so?

ii. No

44. Did the clerk not speaking to you about organ donation prevent you from registering as an organ donor after death?

i. Yes

ii. No

45. Did the clerk speaking to you about organ donation prompt you to registering as an organ donor after death?

i. Yes

ii. No

46. Did the material in the DMV on organ donation prompt you to registering as an organ donation after death?

i. Yes

1. How so?

ii. No

47. Did the lack of material in the DMV on organ donation prevent you from registering as an organ donation after death?

i. Yes

1. How so?

ii. No

48. Do you think it is appropriate to be asked about organ donation after death at the DMV?

i. Yes

ii. No

49. Where do you think it would be appropriate to ask about donation after death?

Motivation to donate.

50. What would motivate you to participate in an organ donation after death program?

i. Please be as specific as possible.

51. Do you think it is important that the message is from someone like you?

i. Yes

ii. No

52. Is it important they are the same gender as you?

i. Yes

ii. No

iii. Doesn't matter.

53. Is it important they are the same race as you?

i. Yes

ii. No

iii. Doesn't matter.

54. Is it important they are from your community?

i. Yes

ii. No

iii. Doesn't matter.

55. Is it important they are the same economic status as you?
- i. Yes
 - ii. No
 - iii. Doesn't matter.
56. (ATTN CHK) select Doesn't matter. This may be confusing for some people.
could we include it
as a question in between topics
57. Would hearing individual stories of those whose lives were accepted by organ donation after death as either a donor or a recipient motivate you?
- i. Yes
 - ii. No
58. Would hearing about how organ donation after death increases the welfare of those in need motivate you?
- i. Yes
 - ii. No
59. Would a message from a public figure (singer, actor, etc.) motivate you?
- i. Yes
 - ii. No
60. Who would motivate you?
61. Do you think it is important that the message is from someone of your own ethnic background?
- i. Yes
 - ii. No

Compensation

62. Would compensation prompt you to sign up to be an organ donor after death?
- i. Yes
 - ii. No
63. What would you consider to be a fair amount?

64. In general, how much would be fair amount to sign up as an organ donor after death at the DMV?
65. In general, how much would be a fair amount to sign up as an organ donor after death through a website not associated with the DMV?
66. In general, when an individual is an organ donor after death, should compensation be made in order to pay for funeral arrangements of the donor?
- i. Yes
 - ii. No
67. In general, do you think organ donors should be paid for an organ prior to donation?
- i. Yes
 - 1. How much money do you think would be appropriate?
 - ii. No
68. Do you think people should be paid while alive and well to donate their organs after death?
- i. Yes
 - 1. How much money do you think would be appropriate?
 - ii. No
69. Do you think the relatives of the donor should be paid when they agree to donate the organs of a deceased family member in cases where the deceased had not decided in life whether to donate?
- i. Yes
 - 1. How much money do you think would be appropriate?
 - ii. No

70. (ATTN CHK)

Why might relatives have a say in the organ donation process, even though the deceased did not share their wishes? Respond to this with the last food you ate (e.g., banana, pizza, cake) in generic terms. Please be as specific as possible. This is confusing and takes away credibility

71. Do you think live organ donors should be paid to donate an

? Note: Although at the present time hospital o

i. Yes

ii. No

72. Do you see/have any moral, social, or ethical issues about being paid to donate an organ?

i. Yes

1. Please explain these concerns in as much detail as possible.

ii. No

Taxes

Currently, when you fill out a 1040 Tax Form, you are asked if you would like to donate to the Presidential Election Campaign (see below).

73. Do you think it would be appropriate to include the option to become an organ donor after death on tax forms, such as below?

i. Yes

ii. No

74. Would including the option to become an organ donor after death on your tax forms (as above) prompt you to become a donor?

i. Yes

1. How so?

ii. No

Video

Please watch the following video. The password (case-sensitive) is: Northwell_DMV

75. How did the video make you feel about organ donation after death? Please be as specific as possible.

76. After watching the video, would you be willing to become an organ donor after death?

i. Yes

1. Why?

ii. No

iii. Not sure

77. Which scenario moved you more to want to become an organ donor after death?

- i. Hearing from the relatives of the organ donor
- ii. Hearing from the recipient of an organ donation (with or without their family members)
- iii. Hearing from the family members whose loved one died waiting for an organ
- iv.

Supplementary material 3

Link to intervention video: <https://vimeo.com/306432691>