

NATIONAL SURVEY OF ORGAN DONATION ATTITUDES AND PRACTICES Computer-Assisted-Telephone-Interviewing (CATI) Script (English Version)

Public Burden Statement: The overall purpose of this study is to conduct an independent multi-mode (web and telephone) survey of public opinion regarding various issues related to organ donation. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0915-0290 and expires xx/xx/2024. Public reporting burden for this collection of information is estimated to average 0.27 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 14N136B, Rockville, Maryland, 20857.

PROJECT – HRS R658

INTRO1

Hello, my name is _____, and I am calling from American Directions Research Group. I am calling on behalf of the U.S. Department of Health and Human Services. We're conducting a national survey about organ donation. Am I speaking to someone 18 or older? (*Skip: If "Yes", continue; if "No", ask to speak to Respondent available or (Continue)*)

1. No one 18 or older in household – (Thank and Terminate)
2. Respondent not available/Not a good time -(Set time to call back)
3. (Soft Refusal)
4. (Hard Refusal) -(Thank and Terminate)

(Skip this question if cell/landline data present in sample file)

S1B Have I reached you on a cellphone or landline phone?

1. Landline
2. Cell
3. (DK)
4. (Refused)

(If S1B = Landline)

S1 First, I would like to identify the adult living in your household, 18 or older, who had the most recent birthday. Who would that be?

1. Respondent -(Skip to S1B)
2. Someone else in household -(Ask to speak to that person, then reset to Introduction)
3. No adults 18 or over in household – (Thank, Terminate, and Tally)
4. Respondent not available – (Record First name and set time to call back)
5. (Refusal) – (Thank and Terminate)

(If S1B = Cell)

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S1C For your safety, are you currently driving?

1. Yes [SET CALLBACK IF DRIVING, ELSE CONTINUE]
2. No
3. (DK)
4. (Refused)

INTRO 2

This is an important study of people's opinions about organ donation. Your assistance in this study is voluntary, but your opinions are needed to provide an accurate understanding of the public's views. If there is any question you do not wish to answer, just tell me. Your answers are confidential and will be combined with those of others. You, as an individual, will never be identified. The questions will require about 20 minutes of your time.

Q1 In the past year, have you heard, read, or seen any information at all about organ donation or transplantation?

1. Yes
2. No
3. Don't Know
4. Refused

[IF NECESSARY READ] By ORGAN DONATION, I mean the donation of organs, such as hearts or kidneys from a person who has died, or the donation of organs, such as kidneys or parts of a liver or lung, from a person who is alive. Transplantation is the surgical transfer of an organ from one person to another. Organ donation does not include donation of bone marrow or tissue, such as skin or corneas.

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Q2 (If Q1 = Yes) In the past year, how have you seen or heard about organ donation or transplantation?

[RESPONSE CODES]

1. Yes
2. No
3. DK
4. Refused

How about [READ AND ROTATE]:

- A. A discussion with a family member
- B. A discussion with a friend
- C. Information provided by a medical professional, clinic, or doctor's office
- D. Information provided by a member of the clergy of your religious organization
- E. Information provided by an attorney
- F. Personal experience or involvement with organ, eye or tissue donation
- G. A billboard or a poster in a public place
- H. News coverage (TV, radio, newspaper, or internet)
- I. Your work or school
- J. A Motor Vehicles Office (MVA, DMV, or SOS)
- K. An advertisement on TV
- L. An advertisement on the radio
- M. A movie and/or a TV show
- N. A community activity, such as a health fair
- O. An organ or tissue donation organization
- P. A senior center or other older adult setting
- Q. Social media such as Facebook, Instagram, YouTube, or Twitter
- R. Search engines, such as Google, Yahoo, or Bing
- S. Other websites
- T. Some other source

Q2A (If Q2T = Yes)

What is that other source? [open-ended response RECORD VERBATIM]

Q2B (If Q2Q = Yes)

Which social media websites? [open-ended response RECORD VERBATIM]

Q2C (If Q2R = Yes)

Which search engine websites? [open-ended response RECORD VERBATIM]

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Q2D (If Q2S = Yes)

Which other websites? [open-ended response RECORD VERBATIM]

Q2E (If Q2Q or Q2R or Q2S = Yes)

When you are online, do you typically use a computer, a hand-held mobile device, such as a smart phone or tablet, or do you use both?

1. Computer
2. Mobile device
3. Both
4. DK
5. Refused

Q3 Which sources of information would be most likely to influence how you think or act about organ donation and transplantation? [open-ended response RECORD VERBATIM]

Q4 In general, do you strongly support, support, oppose, or strongly oppose the donation of organs for transplantation?

1. Strongly support
2. Support
3. Oppose
4. Strongly oppose
5. DK
6. Refused

Q13 Have you signed up to be an organ donor?

1. Yes
2. No
3. DK
4. Refused

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Q13A (If Q13 = Yes) (rotate Q13A A-D) How did you sign up?

1. Yes
2. No
3. DK
4. Refused

A. Your State's Department of Motor Vehicles, Motor Vehicle Department, or Secretary of State Office

B. At a donor registration drive or event

C. Through a mobile phone app

D. Through a website

E. Some other way

Q13B (If Q13A=E 'Some other way')

What other way did you sign up to be an organ donor? [open-ended response RECORD VERBATIM]

Q13C (If Q13A = D (website))

Did you sign up using a hand-held mobile device such as a smart phone or tablet?

1. Yes
2. No
3. DK
4. Refused

Q5 (If Q13 NOT = Yes)

Would you want your organs to be donated after your death? Would you say definitely yes, probably yes, probably no, or definitely no?

1. Definitely Yes
2. Probably Yes
3. Probably No
4. Definitely No
5. DK
6. Refused

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Q14B (If Q5 = definitely yes or probably yes)

Would you be willing to sign up to be an organ donor?

1. Yes [SKIP TO Q14D]
2. No [SKIP TO Q14C]
3. DK
4. Refused

Q14C (If Q14B = NO)

Is there a particular reason why you do not want to sign up to be an organ donor? [open-ended response RECORD VERBATIM]

Q14C1 (If Q14C = “don’t know” or “no reason”)

Would you say it is for one of these reasons?

1. Yes
 2. No
 3. DK
 4. Refused
-
- A. Haven’t thought about it
 - B. I would need more information
 - C. Because of medical reasons
 - D. I feel I am too old to donate
 - E. I don’t believe I will receive the best medical treatment if I’m a donor

Q14D (If Q14B = YES)

Is there a particular reason why you have not signed up to be an organ donor? [open-ended response RECORD VERBATIM]

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Q14E (If Q5 = definitely yes or probably yes)

Would you be willing to sign up to be an organ donor through a hand-held mobile device such as a smart phone or tablet?

1. Yes
2. No
3. DK
4. Refused

Q6A (If Q5 NOT = definitely yes or probably yes)

Is there a particular reason why you do not want your organs donated upon your death? If Yes, what might that reason be?

1. [open-ended response RECORD VERBATIM]
2. DK
3. Some Other Reason

Q6A1 (If Q6A = “don’t know” or “no reason”)

Would you say it is for one of these reasons?

1. Yes
2. No
3. DK
4. Refused

- A.** It’s against my religion
- B.** For medical reasons
- C.** I don’t want my body cut up or disfigured
- D.** Donation costs might be passed to my family
- E.** They might take my organs before death
- F.** I don’t believe I will receive the best medical treatment if I’m a donor
- G.** I feel I am too old to donate

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Q6B (If Q5 NOT = definitely yes or probably yes)

Have you discussed with a member of your family your wish not to donate your organs after your death?

1. Yes
2. No
3. DK
4. Refused
5. N/A or No Family Members

Q6BB (If Q5 NOT = definitely yes or probably yes)

Is there one thing that could change your mind to want to be a donor?

1. Yes [SPECIFY AND RECORD VERBATIM]
2. No
3. DK
4. Refused

Q6BC (If Q13 = Yes)

If you had to identify the biggest reason or reasons why you want to be an organ donor, what would those be? [Open-ended response RECORD VERBATIM]

Q6BD (If Q6BC= “don’t know” or “no reason”)

Would you say it is for one of these reasons?

1. Yes
2. No
3. DK
4. Refused

- A. To save a life
- B. I won’t need them any longer
- C. It’s the right thing to do

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Q6C (If Q13 = Yes)

Have you discussed your wish to be an organ donor with a member of your family?

1. Yes
2. No
3. DK
4. Refused
5. N/A or No Family Members

Q7 (If Q6C NOT Yes)

How willing are you to discuss your wishes about organ donation with your family? Would you say very willing, somewhat willing, not very willing, or not at all willing?

1. Very willing
2. Somewhat willing
3. Not very willing
4. Not at all willing
5. DK
6. Refused

Q8 (If Q6C = not very willing or not at all willing or DK)

Is there a particular reason why you are unwilling to discuss donation with your family?

1. Yes
2. No
3. DK
4. Refused

Q8A (If Q8 = Yes)

What is that reason?

1. [SPECIFY AND RECORD VERBATIM]
2. DK
3. No Reason

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Q8B (If Q8A = “don’t know” or “no reason”)

Would you say it is for one of these reasons? [MULTIPUNCH SELECT ALL THAT APPLY]

- A. I don’t want to discuss death with my family
- B. My family wouldn’t understand
- C. My family believes the body should be buried whole
- D. My family is too young to discuss this
- E. I am not in good health
- F. My donor registration is not my family’s business
- G. Whether or not I become a donor is my family’s decision to make
- H. Talking about death may increase the chance of dying
- I. Someone in my family may need my organs

Q9 (If Q6B NOT N/A or No Family Members or Q6C NOT N/A or No Family Members)

Has any member or your family told you about his or her wish to donate or not to donate his or her organs after death?

- 1. Yes
- 2. No
- 3. DK
- 4. Refused

Q10 (If Q6B NOT N/A or No Family Members or Q6C NOT N/A or No Family Members)

If you didn’t know your family member’s wishes, how likely would you be to donate his or her organs upon his or her death, if it were up to you? Would you be very likely, somewhat likely, not very likely, or not at all likely?

- 1. Very likely
- 2. Somewhat likely
- 3. Not very likely
- 4. Not at all likely
- 5. DK
- 6. Refused

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Q11 (If Q6B NOT N/A or No Family Members or Q6C NOT N/A or No Family Members)

If a family member had requested that his or her organs be donated upon death how likely would you be to donate his or her organs, if it were up to you? Would you be very likely, somewhat likely, not very likely, or not at all likely?

1. Very likely
2. Somewhat likely
3. Not very likely
4. Not at all likely
5. DK
6. Refused

Q12 Now, I am going to read you a number of statements. For each one, please tell me if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

1. Strongly Agree
2. Somewhat Agree
3. Somewhat Disagree
4. Strongly Disagree
5. DK
6. Refused

- A.** It is important for a person's body to have all of its parts when it is buried.
- B.** It is important for people to tell their families whether or not they would want their organs to be donated upon death.
- C.** Most members of my family would support the idea of organ donation.
- D.** Receiving organ transplants improve people's lives.
- E.** Organ donation allows something positive to come out of a person's death.
- F.** A deceased person's next of kin should be able to override the deceased person's wish to donate his or her organs.
- G.** Organs should be distributed so that the expected life of the organ is similar to the expected life of the recipient. For example, older people should generally get older organs and younger people should get younger organs.
- H.** All people who need an organ transplant should be able to receive a transplant.

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Q14F Do you believe these statements about organ donation are true?

1. Yes
2. No
3. DK
4. Refused

- A. Kidneys can be donated from a living donor.
- B. Parts of livers can be donated from a living donor.
- C. Parts of lungs can be donated from a living donor.

Q14E Have you ever donated an organ or a part of an organ?

1. Yes
2. No
3. DK
4. Refused

Q15 Assuming you are medically able, how likely would you be to agree to donate an organ while you are living to [INSERT ROTATED CHOICES]? Would you say very likely, somewhat likely, not very likely, or not at all likely?

1. Very likely
2. Somewhat likely
3. Not very likely
4. Not at all likely
5. DK
6. Refused

- A. A close friend
- B. A family member
- C. An acquaintance
- D. Someone you don't know

Q15A (If Q15 = not very likely or not at all likely)

What are your reasons for not agreeing to donate an organ while you are living? [Open-ended response RECORD VERBATIM]

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Q16 Now I am going to read you several statements. For each one, please tell me whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree. [ROTATE STATEMENTS]

1. Strongly Agree
2. Somewhat Agree
3. Somewhat Disagree
4. Strongly Disagree
5. DK
6. Refused

- A. Minority patients are less likely to receive organ transplants.
- B. You are worried that a loved one's body would be disfigured if his or her organs were donated.
- C. It is possible for a brain-dead person to recover from his or her injuries.
- D. People who choose to donate a family member's organs end up paying extra medical bills.
- E. Organ donation helps families cope with their grief.
- F. Every year, thousands of people die due to a lack of donated organs for transplantation.
- G. If you indicate you intend to be a donor, doctors will be less likely to try to save your life.
- H. A person's wish to donate his or her organs should be honored under all circumstances, even over the objections of surviving family members.
- I. Transplants often go to undeserving people.
- J. You would agree to receive an organ transplant if it would save your life.
- K. The U.S. transplant system uses a fair approach to distribute organs to patients.

Q16AA

[IF Q16A=1,2 ASK Q16AA, ALL OTHERS GOTO Q16N]

Why do you think minority patients are less likely to receive organ transplants? [open ended response RECORD VERBATIM]

Q16N Please choose the statement that comes closest to your view (Rotate)

1. If I were a donor, I would like my organs to go to the more medically urgent patients regardless of where they live in the U.S., OR
2. If I were a donor, I would like my organs to go to patients in my local area even if they are not the more medically urgent patients waiting for an organ.
3. DK
4. Refused

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Q17 Some countries assume that people will be organ donors upon their death, unless there are strong objections from the family. This is sometimes called presumed consent. Would you strongly support, support, oppose, or strongly oppose using this presumed consent approach in the United States?

1. Strongly support
2. Support
3. Oppose
4. Strongly oppose
5. DK
6. Refused

Q17A (If Q17 = oppose or strongly oppose)

Is there a particular reason why you oppose presumed consent? [Open-ended response RECORD VERBATIM]

Q17C If the United States changed to a presumed consent system, where people will be organ donors unless they opted out, would you choose to opt out?

1. Yes
2. No
3. DK
4. Refused

Q18 It has been suggested that more organs would be donated if families who donate the organs of a deceased loved one received assistance in paying funeral expenses, a cash award to the donor's estate, or a cash award to a charity of the family's choice. Would payments like these make you more likely or less likely to donate (read and rotate), or would it have no effect.

1. More Likely
2. Less Likely
3. No Effect
4. DK
5. Refused

A. Your own organs

B. A family member's organs at their time of death

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Q19 (If Q18A or Q18B = more likely)

Is there a particular reason why a payment would make you more likely to donate your organs or a family member's organs?

1. Yes
2. No
3. DK
4. Refused

Q19A (If Q19= Yes)

What reason? [Open-ended response RECORD VERBATIM]

Q20 (If Q18A or Q18B = less likely)

Is there a particular reason why a payment would make you less likely to donate your organs or a family member's organs?

1. Yes
2. No
3. DK
4. Refused

Q20A (If Q20= Yes)

What reason? [Open-ended response RECORD VERBATIM]

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Q22 Now I am going to read you several statements. For each one, please tell me whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

1. Strongly Agree
2. Somewhat Agree
3. Somewhat Disagree
4. Strongly Disagree
5. DK
6. Refused

[ROTATE FOLLOWING CHOICES]

- A. Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant.
- B. Doctors do everything they can to save a person's life before organ donation is even considered.
- C. Organ transplantation is an experimental medical procedure.
- D. Organ donation is against my religion.
- E. It is impossible to have a regular funeral service following organ donation.
- F. Many people on the national transplant waiting list die because the organ they need isn't donated in time.

Q15E Recent medical breakthroughs have resulted in successful face and hand transplants for people who have suffered the loss of limbs or facial disfigurement from traumatic injuries, such as accidents and war. How willing would you be [INSERT ROTATED CHOICES]? Would you say you are very willing, somewhat willing, not very willing, or not at all willing?

1. Very Willing
2. Somewhat Willing
3. Not Very Willing
4. Not at all Willing
5. DK
6. Refused

- A. Upon your death to donate your hands
- B. Upon your death to donate your face

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Q15E1 If your family member signed up to be an organ donor, upon his or her death will you also be willing to [INSERT ROTATED CHOICES]? Would you be very willing, somewhat willing, not very willing, or not at all willing?

1. Very Willing
2. Somewhat Willing
3. Not Very Willing
4. Not at all Willing
5. DK
6. Refused

- A.** Donate your family member's hands
B. Donate your family member's face

Q23A Have you, or has anyone close to you, ever been an organ donor?

1. Yes
2. No
3. DK
4. Refused

Q23B Have you, or has anyone close to you, ever received an organ transplant?

1. Yes
2. No
3. DK
4. Refused

Q23C Are you, or is anyone close to you, currently waiting for an organ?

1. Yes
2. No
3. DK
4. Refused

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Q26A Do you believe there is an age when someone is too old to donate an organ upon his or her death?

1. Yes
2. No
3. DK
4. Refused

Q26A2 (If Q26A = Yes)

What is that age? [RECORD NUMERIC]

Q26B Do you believe there is an age when someone is too old to receive an organ?

1. Yes
2. No
3. DK
4. Refused

Q26B2 (If Q26B = Yes)

What is that age? [RECORD NUMERIC]

Q28 In general, how would you rate your overall health? Would you say excellent, very good, good, fair, poor?

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor
6. DK
7. Refused

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Q29 What best describes your religion, if any? Would you say Protestant, Evangelical, Roman Catholic, Orthodox, Mormon, Jewish, Muslim, Buddhist, atheist, agnostic, or something else?

1. Protestant
2. Evangelical
3. Roman Catholic
4. Orthodox
5. Mormon
6. Jewish
7. Muslim
8. Buddhist
9. atheist
10. agnostic
11. something else
12. DK
13. Refused

Q30 How important are your religious beliefs?

1. Very Important
2. Somewhat Important
3. Not Very Important
4. Not at all important
5. DK
6. Refused

D1 What is your sex?

1. Male
2. Female
3. Other
4. DK
5. Refused

D2 What is your age? [RECORD NUMERIC]

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D3 What is the highest level of education you have completed? [READ CHOICES]

1. less than high school graduate
2. high school graduate
3. some college
4. trade/technical/vocational training
5. college graduate
6. post-graduate work/degree
7. DK
8. Refused

D4A What is your current marital status?

1. single/never been married
2. married
3. separated
4. divorced
5. widowed
6. domestic partnership/living with partner (not legally married)
7. DK
8. Refused

D7 Do you work in the healthcare profession?

1. Yes
2. No
3. DK
4. Refused

D8 What is your zip code?

1. [RECORD 5 DIGIT NUMERIC]
2. DK
3. Refused

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D12 Would you describe yourself as Hispanic or Latino Origin?

1. No, not of Hispanic, Latino, or Spanish origin
2. Yes, Mexican, Mexican American, Chicano
3. Yes, Puerto Rican
4. Yes, Cuban
5. Yes, another Hispanic, Latino, or Spanish origin, please specify_____

D11 What best describes your race (can select more than one option)? Would you say [READ CHOICES]

1. White
2. Black or African American
3. American Indian or Alaska Native please specify_____
4. Asian Indian
5. Chinese
6. Filipino
7. Japanese
8. Korean
9. Vietnamese
10. Other Asian, please specify _____
11. Native Hawaiian
12. Guamanian or Chamorro
13. Samoan
6. Other Pacific Islander, please specify_____

D13 What best describes your current employment status? [READ CHOICES]

1. Employed full-time
2. Employed part-time
3. Taking care of home or family but not working for pay
4. Not employed but looking for work
5. Student
6. Retired
7. Unable to work
8. Other
9. DK
10. Refused

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D14 Do you currently have any type of health insurance plan or health coverage?

1. Yes
2. No
3. DK
4. Refused

D15 (If D14 = Yes)

What best describes the source of your health plan. If you have more than one, please select your primary plan. [READ CHOICES]

1. Private plan, such as through an employer
2. The federal insurance exchange at healthcare.gov, or a state insurance plan
3. Medicaid
4. Medicare
5. Veterans' Affairs
6. TRICARE/Military Health System
7. Other government or state plan
8. Other
9. DK
10. Refused

D9 What is your total ANNUAL household income, before taxes? Please include income from wages and salaries, remittances from family members living elsewhere, farming, and all other sources. Please say "yes" when we reach your annual household income.

[READ CHOICES]

1. Less than \$20,000,
2. \$20,000 or more, but less than \$30,000
3. \$30,000 or more, but less than \$40,000
4. \$50,000 or more but less than \$60,000
5. \$60,000 or more, but less than \$75,000
6. \$75,000 or more but less than \$100,000
7. \$100,000 or more, but less than \$150,000
8. \$150,000 or more
9. DK
10. Refused

Thank you for your participation. Results of the survey will be available in about six months on a government web site at www.organdonor.gov.