

**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 survey of public opinion regarding various issues related to organ donation. This Data is essential for planning, targeting, and implementing outreach efforts to increase public donation commitment as well as for tracking the results of such efforts over time. 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 it is valid until XX/XX/202X. This information collection is voluntary. Data will be private to the extent permitted by the law. Public reporting burden for this collection of information is estimated to average 17 minutes (0.29 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 Information Collection Clearance Officer, 5600 Fishers Lane, Room 14N39, Rockville, Maryland, 20857 or paperwork@hrsa.gov.

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 someone who is 18 or older*)

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

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

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

1. Landline
2. Cell
3. (Don't Know)
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)

S1C For your safety, are you currently driving?

1. Yes [SET CALLBACK IF DRIVING, ELSE CONTINUE]
2. No
3. (Don't Know)
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.

[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 the donation of bone marrow or tissue, such as skin or corneas.

Q1A Thinking about the last 6 months, do you remember hearing or seeing anything about organ donation and transplantation?

1. Yes
2. No
3. (Don't know)
4. (Refused)

Q1B (If Q1A = Yes) How would you describe what you heard or saw about organ donation in the past 6 months?

1. Mostly positive
2. Mostly negative
3. Both positive and negative
4. (Don't know)
5. (Refused)

Q2F Thinking about the last 6 months, do you remember hearing or seeing anything about how to sign up to be an organ donor?

1. Yes
2. No
3. (Don't know)
4. (Refused)

Q2G (If Q2A = Yes) Where did you see information about how to sign up to be an organ donor?
[RESPONSE CODES]

1. Yes
2. No
3. (Don't know)
4. (Refused)

How about [READ AND ROTATE]:

- A. A discussion with a friend or family member
- B. Information provided by a medical professional, clinic, or doctor's office
- C. A billboard or a poster in a public place
- D. News coverage (TV, radio, newspaper, or internet)
- E. A Motor Vehicles Office (MVA, DMV, or SOS)
- F. An advertisement on TV
- G. An advertisement on the radio
- H. An advertisement on the web
- I. A community activity, such as a health fair
- J. An organ or tissue donation organization
- K. Social media such as Facebook, Instagram, YouTube, or Twitter
- L. On a website other than social media
- M. Some other source

Q3 Which sources of information would be most likely to influence how you think or act about organ donation? [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. (Don't Know)
6. (Refused)

Q13 Are you signed up to be an organ donor?

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

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

1. Yes
2. No

3. (Don't Know)
4. (Refused)

- A. During a transaction at your motor vehicle office or website
- B. At a donor registration drive or event
- C. Through a mobile phone app
- D. Through a website other than during a motor vehicle transaction
- E. Through the Department of Defense as a member of the US military
- F. 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]

Q13D (If Q13 = No)

Have you ever signed up as an organ donor?

1. Yes
2. No
3. (Don't Know)
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. (Don't Know)
6. (Refused)

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. (Don't Know)
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. (Don't Know)
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
- E. I don't believe I will receive the best medical treatment if I'm a donor
- F. I prefer to leave the choice to my family
- G. I don't trust putting my name on a registry

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]

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. (Don't Know)
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. (Don't Know)
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
- H. I don't believe an autopsy could be performed if organs are donated
- I. My family does not support donation

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. (Don't Know)
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. (Don't Know)
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. (Don't Know)
4. (Refused)

A. To save a life

B. I won't need them any longer

C. It's the right thing to do

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. (Don't Know)
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. (Don't Know)
6. (Refused)

Q8 (If Q6C = not very willing or not at all willing or (Don't Know))

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

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

Q8A (If Q8 = Yes)

What is that reason?

1. [SPECIFY AND RECORD VERBATIM]
2. (Don't Know)
3. No Reason

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 of your family told you about their wish to donate or not to donate their organs after death?

1. Yes
2. No
3. (Don't Know)
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 their organs upon their 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. (Don't Know)
6. (Refused)

Q11 (If Q6B NOT N/A or No Family Members or Q6C NOT N/A or No Family Members)
a family member had told you they wanted to be an organ donor but were not signed up on the donor registry, how likely would you be to donate their 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. (Don't Know)
6. (Refused)

Q24 What percentage of adults in the US do you think are signed up as organ donors?
[0% to 100%]

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. (Don't Know)
6. (Refused)

[ROTATE FOLLOWING CHOICES]

12A. It is important for a person's body to have all of its parts when it is buried.

12B. It is important for people to tell their families whether or not they would want their organs to be donated upon death.

12C. Most members of my family would support the idea of organ donation.

12D. Receiving organ transplants improve people's lives.

12E. Organ donation allows something positive to come out of a person's death.

12F. A deceased person's next of kin should be able to override the deceased person's registration status to donate their organs.

12H. All people who need an organ transplant should be able to receive a transplant.

- 16A.** Racial and ethnic minority patients are less likely to receive organ transplants.
- 16B.** You are worried that a loved one's body would be disfigured if their organs were donated.
- 16D.** People who choose to donate a family member's organs end up paying extra medical bills.
- 16G.** If you indicate you intend to be a donor, doctors will be less likely to try to save your life.
- 16J.** You would agree to receive an organ transplant if it would save your life.
- 16K.** The U.S. transplant system uses a fair approach to distribute organs to patients.
- 22A.** Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant.
- 22B.** Doctors do everything they can to save a person's life before organ donation is even considered.
- 22D.** Organ donation is against my religion.
- 22E.** It is impossible to have a regular funeral service following organ donation.
- 22F.** Many people on the national transplant waiting list die because the organ they need isn't donated in time.
- 22G.** Too many donated organs are not transplanted.

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

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

- A.** Kidneys can be donated from a living donor.
- B.** Parts of livers can be donated from a living donor.
- C.** The uterus can be donated from a living donor.
- D.** Intestines can be donated from a living donor.

Q14G Have you ever donated an organ or a part of an organ?

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

Q15 Assuming you are medically able, how likely would you be 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. (Don't Know)
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]

Q25 It has been suggested that more people would consider living donation of organs like a kidney if they received some incentive to do so. This might include something like a cash payment, free health insurance, or a cash donation to a charity of their choice. Would you support using incentives like this to increase living organ donation?

- 1. Strongly support
- 2. Support
- 3. Oppose
- 4. Strongly oppose
- 5. (Don't Know)
- 6. (Refused)

Q27 Would incentives make you more likely or less likely to be a living organ donor? What about...

- A. A cash payment
- B. Free health insurance
- C. A donation to a charity of your choice

- 1. Much more likely
- 2. A little more likely
- 3. No more or less likely
- 4. A little less likely
- 5. Much less likely

Q27D. Are there other types of incentives that would make you more likely to be a living organ donor?
[Free text]

Q16AA [IF Q16A= "Strongly Agree" or "Somewhat Agree" ASK Q16AA, ALL OTHERS GOTO Q16N] Why do you think racial and ethnic 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. (Don't Know)
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. (Don't Know)
5. (Refused)

A. Your own organs

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

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. (Don't Know)
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. (Don't Know)
4. (Refused)

Q20A (If Q20= Yes)

What reason? [Open-ended response RECORD VERBATIM]

D16. What best describes your gender identity?

1. Male
2. Female
3. Non-binary
4. Something else
5. (Don't Know)
6. (Refused)

D1 What is the sex on your original birth certificate?

1. Male
2. Female
3. (Don't Know)
4. (Refused)

Q15E Medical breakthroughs have resulted in new types of transplants, such as hands, face, larynx, and uterus, for those who may have lost theirs through traumatic injury or illness. 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. (Don't Know)
6. (Refused)

Upon your death to donate your...

- A. Hands
- B. Face
- C. Larynx, or voicebox
- D. (If female) Uterus

Q15E1 If your family member signed up to be an organ donor, upon their 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. (Don't Know)
6. (Refused)

Donate your family member's...

- A. Hands
- B. Face
- C. Larynx, or voicebox
- D. (If female) Uterus

Q23A Has anyone close to you ever donated an organ or tissues, either while living or after death?

5. Yes
6. No
7. (Don't Know)
8. (Refused)

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

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

Q23C Have you, or has anyone close to you, ever been on a transplant waiting list?

5. Yes
6. No
7. (Don't Know)
8. (Refused)

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

1. Yes
2. No
3. (Don't Know)
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. (Don't Know)
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. (Don't Know)
7. (Refused)

Q36 Have you ever been vaccinated for COVID-19, even just once?

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

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. Hindu
10. atheist
11. agnostic
12. something else
13. (Don't Know)
14. (Refused)

Q30 How important are your religious beliefs?

1. Very Important
2. Somewhat Important
3. Not Very Important
4. Not at all important
5. (Don't Know)
6. (Refused)

Q32. How much of the time do you think you can trust the health care system to do what is right for you?

1. Almost all of the time
2. Most of the time
3. Some of the time
4. Almost none of the time
5. (Don't Know)
6. (Refused)

Q33. In general, would you say the organ transplant system in the US is headed in the right direction, or is it on the wrong track?

1. Right direction
2. Wrong track
3. Somewhere in between
4. Don't have an opinion or don't have enough information
5. (Don't Know)
6. (Refused)

Q33A

Why do you feel that way? [Open-ended response RECORD VERBATIM]

D2 What is your age? [RECORD NUMERIC]

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. (Don't Know)
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. (Don't Know)

D8 What is your zip code?

1. [RECORD 5 DIGIT NUMERIC]
2. (Don't Know)
3. (Refused)

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

1. White
2. Black or African American
3. Hispanic or Latino
4. American Indian or Alaska Native, please specify_____
5. Asian
6. Indian
7. Chinese
8. Filipino
9. Japanese
10. Korean
11. Vietnamese
12. Other Asian, please specify _____
13. Middle Eastern or North African
14. Native Hawaiian or Pacific Islander
15. Guamanian or Chamorro
16. Samoan
17. 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. (Don't Know)
10. (Refused)

D18 Have you ever served in the US Uniformed Services?

[If clarification needed: This includes the Army, Navy, Marine Corps, Air Force, Space Force, Coast Guard, Public Health Service Commissioned Corps, and Commissioned Corps of the National Oceanic and Atmospheric Administration.]

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

D19 For how many years of your life have you lived in the United States?

1. My whole life
2. _____ years
3. (Don't Know)
4. (Refused)

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

1. Yes
2. No
3. (Don't Know)
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. (Don't Know)
10. (Refused)

D21 How many people, including yourself, live in your household?
[RECORD NUMERIC]

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. (Don't Know)
10. (Refused)

D22 When it comes to social and political issues, how would you describe yourself?

1. Conservative
2. Moderate, conservative-leaning
3. Moderate but varies depending on the issues
4. Moderate, liberal-leaning
5. Liberal
6. Other
7. (Don't Know)
8. (Refused)

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