#### **Description of changes from 2012 survey**

Plain text indicates original text from the 2012 survey that will be retained for the 2019 survey.

Highlighting indicates new text for the 2019 survey that was not included in the 2012 survey.

Strikethrough indicates text from the 2012 survey that will not be included in the 2019 survey.

**For telephone surveys**, response options are preceded with "Would you say..." For web surveys, response options are listed below the question.

**Response options** of "don't know (DK)," "refused," and "N/A" are not read aloud by the interviewer but may be volunteered by the respondent. These implicit response options are in parentheses. Web survey respondents may indicate these types of answers by not responding to the question.

#### Introduction

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. [Phone: If there is any question you do not wish to answer, just tell me.] [Web: If you do not know the answer to a question, or do not want to answer, you may leave that question blank.] 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  $\frac{15}{20}$  minutes of your time.

Q1 In the past year, have you heard, read, or seen any information at all about organ donation or transplantation? [Response Choice: Yes, No, Don't Know, Refused]

(INTERVIEWER NOTE: If necessary, read:) By ORGAN-AND TISSUE 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. Donate Life America (DLA) believes that tissue and cornea should be included throughout – either explicitly or by definition upfront of "organ donation", though not bone marrow

Q2 (If Q1 = Yes) In the past year, please tell me whether each of the following has been an important source of information for you about organ donation and transplantation. Where how have you seen or heard about organ donation or transplantation?

Note: items in parentheses will be read as "such as..." in the phone survey, and appear in parentheses in the web survey. [Response Choice: Yes, No, (DK, Refused, N/A)]

How about (read and rotate A-T below)?

- **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, and or tissue or cornea 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 or DMV)
- **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 and or tissue donation organization
- **P.** A senior center or other older adult setting
- Q. Social media such as Facebook, <u>Instagram</u>, YouTube, or Twitter <u>HILARY TO INSERT COMMENTS</u>
- **R.** Search engines, such as Google, Yahoo, or Bing
- T. On a signed donor card
- S. Health related or Other websites
- **T.** Some other source
- Q2A (If Q2T = Yes) What is that other source? [open-ended response]
- Q2B (If Q2Q = Yes) Which social media websites? [open-ended response]
- Q2C (If Q2R = Yes) Which search engine websites? [open-ended response]

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Q2D	(If Q2S = Yes) Which other websites? [open-ended response]
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? [Response option: computer, mobile device, or both (DK, Refused, N/A)]
Q3	Which sources of information would be most likely to influence how you think or act about organ donation and
	transplants transplantation? [Open-ended response]
Q4	In general, do you strongly support, support, oppose, or strongly oppose the donation of organs for transplant
	transplantation? [Response Choice: Strongly support, support, oppose, strongly oppose, (DK, Refused, N/A)]
Q13	Have you granted permission for signed up-registered your decision (through a DMV/MVAD transaction or online in a
	state or national donor registry) to be an organ donor donation? [Response Choice: Yes, No, (DK, Refused, N/A)]
Q13A	(If Q13 = Yes) (rotate Q13A A-C) Where How did you sign upregister? [Response choices: Yes, No, (DK, Refused,
	N/A)
	A. On your driver's license Through a DMV/MVD transaction
	B. AAtT a donor drive
	<u>C. Online</u>
	D. iPhone Health App
	B. On a signed donor card
	B. Through a website
	C. By joining your state or the national donor registry
	D. Some other way
Q13B	(If Q13AD = Yes) What other way did you sign up to be an organ donor? [open-ended response]
Q13C	(If Q13 = Yes) Did you sign up using a hand-held mobile device such as a smart phone or tablet? [Response Choice: Yes,
	No, (DK, Refused, N/A)]
Q5	(If Q13 NOT = Yes) Regardless of whether you have formally granted permission, Would you want your organs to be
	donated for transplant after your death? Would you say definitely yes, probably yes, probably no, or definitely no?
Q14B	(If $Q5 = definitely yes or probably yes)$
	Would you be willing to grant permission for organ donation by joining your state's organ donor registry?
	sign up to be an organ donor? [Response Choices: Yes, No, (DK, Refused, N/A)]
Q14C	(If Q14B <u>NOT</u> = Yes) Why aren't you willing to sign upregister to be an organ donor? a donor in your state donor
	registry? [Open-ended response]
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Q14C1 (If Q14C = "don't know" or "no reason") Would you say it is for one of these reasons? Response Choices: Yes, No, (DK, Refused, N/A)] A. Haven't thought about it B. I would need more information C. I believe I am unable to donate for medical reasons C. I am not in good health 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 F. Other Consider adding A, C, D and E from O6A1 (If Q14B NOT = No) Why haven't you registered to be an organ donor? a donor in your state donor registry? [Open-Q14D ended response] (If Q5 = definitely yes or probably yes) Would you be willing to sign up to be an organ donor through a hand-held mobile Q14E device such as a smart phone or tablet? [Response Choices: Yes, No, (DK, Refused, N/A)] (If Q5 NOT = definitely yes or probably yes) Is there a particular reason why you do not want your organs donated upon Q6A your death? If Yes, what might that reason be? [Open-ended response] (If Q6A = "don't know" or "no reason") Would you say it is for one of these reasons? [Response Choices: Yes, No. (DK, Q6A1 Refused, N/A)] A. I believe It's against my religion B. I believe I am unable to can't donate for medical reasons C. I don't want fear that my body will be cut up or disfigured D. Lam concerned that dDonation costs might be passed to my family E. They might take my organs before death E. I am concerned that my organs may be taken before my death F. I don't believe I will receive the best medical treatment if I'm a donor

(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? [Response Choices: Yes, No, (DK, Refused, N/A)]

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**O6B** 

G. I feel I am too old to donate

(If Q5 NOT = definitely yes or probably yes) Is there one thing that could change your mind to want to be a donor? (If
Yes): What would that be? [Open-ended response]
(If Q13 = Yes) If you had to identify the single-biggest reason or reasons why you want to be an organ donor, what would
those be? [Open-ended response]
(If Q6BC= "don't know" or "no reason") "Would you say it is for one of these reasons?" [Response Choices: Yes, No,
(DK, Refused, N/A)]
A. To save a life
B. I won't need them any longer
C. It's the right thing to do
(If Q13 = Yes) Have you discussed your wish decision (determine whether or not you are trying to determine if there has
been a conversation vs. that the person has registered and adjust language to suit – willingness to dDiscuss donation vs.
willingness to discuss their wishes vs. willingness to convey/discuss their decision to donate by having registered)_to be
an organ donor with a member of your family? [Response Choices: Yes, No, (DK, Refused, N/A)]
(If Q6C NOT Yes) How willing are you to discuss your wishes (see comment above) about organ donation with your
family? Would you say very willing, somewhat willing, not very willing, or not at all willing?
(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?
(If Q8 = Yes) What is that reason? [Open-ended response]
(If Q8A = "don't know" or "no reason") Would you say it is for one of these reasons?
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 status registration is not my family's business
G. Whether or not I become a donor My donor status 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? [Response Choices: Yes, No, (DK, Refused, N/A)]
- 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?
- Q11 (If Q6B NOT N/A or No Family Members or Q6C NOT N/A or No Family Members) If a family member had told you of their wish 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?
- 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.
  - **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 life-lives Most people who receive transplants gain additional years of healthy life.
  - **E.** Organ donation allows something positive to come out of a person's death.
  - F. DLA believes this should be omitted. If it is kept, we suggest that if you keep it, you clarify if you asking about overriding a wish or a registration (which is legal authorization) or reword to say "Do you think a person's donation decision/registration should be upheld?" instead of "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.
- Q14E Some organs, such as kidneys or parts of lungs or livers, can be donated while you are alive. DLA believes you should leave the preceding statement in -Have you ever donated an organ or a part of an organ? [Response Choices: Yes, No, DK, Refused, N/A]

**Commented [HC1]:** See note above for 6C, consistency of decision vs wish language depending on intent of question and sub-question.

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**Commented [HC2]:** Same note as above re decision vs wish language

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- Q15 (If 14E = No, DK, Refused) Assuming you are medically able, how likely would you be to agree to donate an organ while you are living to [insert response text rotate]? Would you say very likely, somewhat likely, not very likely, or not at all likely?
  - 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) Why would you not agree to donate an organ while you are living? [Openended response]

We request that you add additional questions regarding living donation – one about dialysis vs. transplantation as best treatment option and one asking for perception of risk to the living donor before and after donation surgery

**Commented [HC3]:** Consider specifying "kidney" instead of "organ" for more specific, comparable and actionable data collection.

- 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]
  - A. Discrimination prevents minority patients from receiving the organ transplants they need.
  - A. Minority patients are less likely to receive organ transplants. Needs to be qualified too many variables less likely to be listed on the national transplant waiting list (awareness/education/access) or -less likely to receive an organ/be transplanted once on the list... or both questions
    - (If Q16A=Strongly Agree or Somewhat Agree) "Why do you think minority patients are less likely to receive organ transplants?" [open ended response]
  - **B.** You are worried that a loved one's body would be disfigured appear differently in a casket/that a regular viewing and funeral would not be possible 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 <u>(clarify if you mean wish or registration)</u> to donate his or her organs should be honored under all circumstances, even over the objections of surviving family members <u>(consider use of "next of kin" instead of "surviving family members")</u>.
  - **I.** Transplants often go to undeserving people.
  - **J.** You would agree to receive an organ transplant if it would save your life.
  - **K.** People over 50 can donate their organs.
  - L. People over 50 can receive a transplant.
  - **K.** The U.S. transplant system uses a fair approach to distribute organs to patients.
- Q16N (If Q13A = No, DK, Refused, N/A) Please choose the statement that comes closest to your view (Rotate) [Response Choices: 1, 2, (DK, Refused, N/A)]
  - 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 a patient in my local area even if they are not the more medically urgent patients waiting for an organ.

Q17	Due to the complexities and general misperceptions about an Opt Out system (see Opt Out points on slides), we ask that this question – as well as Q17A and Q17C - be omitted so that respondents don't answer in the affirmative thinking that is
	what would alleviate the current shortage of donated organs in the US. This could result in potentially damaging
	unintended consequences. Some countries assume that people wish to donate their organs at death be organ donors upon
	their death. This is called presumed consent (more accurately termed Presumed Intent or an Opt Out system. Their organs
	may be used for transplanting unless they signed a document indicating that they don't wish to donate their organs. In
	these countries, unless a person opts out of being an organ donor their organs are automatically donated after they die (as
	noted in slide presentation, this is false <del>not accurate</del> and inclusion of the language is misleading to the public). Would you
	strongly support, support, oppose, or strongly oppose using this presumed consent approach in the United States?
Q17A	(If Q17 = oppose or strongly oppose) Is there a particular reason why you oppose presumed consent? [Open-ended
Q1/11	response]
<del>Q17B</del>	Do you think a system of presumed consent would increase or decrease the number of available organs for transplants?
<b>(</b>	[Response Choices: Increase, Stay the same, Decrease, DK, Refuse]
Q17C	If a system of presumed consent were adopted in the United States, would you opt out to ensure you are not a donor?
	If the United States had a presumed consent system, where people were assumed to be organ donors unless they opted
	out, would you choose to opt out? We ask that this question be omitted - see above. [Response Choices: Yes, No, (DK,
	Refused, N/A)]
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. [Response Choices: More Likely, Less Likely, No Effect, (DK, Refused, N/A)]
	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?
Q19A	(If Q19= Yes) What reason? [Open-ended response]
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?
Q20A	(If Q20= Yes) What reason? [Open-ended response]

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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.
  - **A.** Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant <u>once they are on</u> the national transplant waiting list.
  - **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 and tissue donation is against my religion.
  - E. People my age can donate organs.
  - F. It is impossible to have a regular funeral service following organ-and tissue donation.
  - G. People my age can have organ transplants.
  - **H.** Many people on the national <u>transplant</u> waiting list <u>for organs</u> die because <u>an the</u> organ <u>they need isn't donated doesn't become available</u> 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 response text rotate)? Would you say you are very willing, somewhat willing, not very willing, or not at all willing?
  - **A.** Upon your death to donate your hands
  - **B.** Upon your death to donate your face
- Q15E1 If your family member signed upregistered to be an organ donor, upon their death will would you also be willing to (Insert response text rotate)? Would you be very willing, somewhat willing, not very willing, or not at all willing?
  - A. Donate your family members' member's hands (not covered byincluded in donor registration)
  - **B.** Donate your family member's face (not <del>covered by</del>included in donor registration)
- Q23 Have you, or has anyone close to you, ever been an organ, eye or tissue donor or ever received a transplant?
- Q23A Have you, or has anyone close to you, ever been an organ, eye, or tissue donor? [Response Choices: Yes, No, (DK, Refused, N/A)]
- Q23B Have you, or has anyone close to you, ever received an organ transplant? [Response Choices: Yes, No, (DK, Refused, N/A)]
- Q23C Are you, or is anyone close to you, currently waiting for an organ? [Response Choices: Yes, No, (DK, Refused, N/A)]

Q23D	Do you believe these statements about organ donation are true? [Response Choices: Yes, No, (DK, Refused, N/A)]
	A. Kidneys can be donated from a living donor.
	<b>B.</b> Parts of livers can be donated from a living donor.
	C. Parts of lungs can be donated from a living donor.
Q26A	Do you believe there is an age when someone is too old to donate an organ upon their death?
Q26A2	(If Q26A = Yes) What is that age? [open ended number]
Q26B	Do you believe there is an age when someone is too old to receive an organ? [Response Choices: Yes, No, (DK, Refused
	N/A)]
Q26B2	(If Q26B = Yes) What is that age? [open ended number]
Q28	In general, how would you rate your overall health? Would you say excellent, very good, good, fair, poor?
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?
Q30	How important is religion to you? [Response Choices: very important, somewhat important, not very important, not at all
	important (DK, Refused, N/A)]
D1	What is your sex? [Response Choices: Male, Female, Other, (DK, Refused, N/A)]
D2	What is your age? [Open-ended response]
D3	What is the highest level of education you have completed? [Response Choices: less than high school graduate, high
	school graduate, some college, trade/technical/vocational training, college graduate, post-graduate work/degree, (DK,
	refused, N/A)]
D4A	What is your current marital status? [Response Choices: single/never been married, married, separated, divorced,
	widowed, domestic partnership/living with partner (not legally married), (DK, Refused, N/A)]
<del>D5</del>	Including the phone line I just called you on, how many different residential phone NUMBERS do you have coming into
	your household, not including lines dedicated to a fax machine, modem, or used strictly for business purposes? Do not
	include cellular phones.
<del>D6</del>	How many adults age 18 or older live in your household?
<del>D6A</del>	Do you have a cellphone that you use to make and receive personal calls? [Response Choices: Yes, No, (DK, Refused,
	$\frac{N(A)}{A}$
D6B	Do you have a regular, landline telephone in your home that you use to make and receive personal calls? [Response
	Choices: Yes, No, (DK, Refused, N/A)]

<del>D6C</del>	Of all the telephone calls your household receives [Response Choices: All or almost all calls are received on cellphones, Some are received on cellphones and some on regular phones, Very few or none are received on cellphones]
<del>D7</del>	Do you work in the healthcare profession? [Response Choices: Yes, No, (DK, Refused, N/A)] DLA asks that this
	question remain included in order to see what beliefs, myths and misconceptions are held by those in the healthcare
	profession so we can address them through partnerships with healthcare organizations, etc.
D8	What is your zip code?
D11	What best describes your race (can select more than one option)? Would you say White, Black or African American,
	Asian, American Indian or Alaskan Native, Native Hawaiian or Other Pacific Islander, or something else?
D12	Would you describe yourself as Hispanic or Latino? [Response Choices: Yes, No, (DK, Refused, N/A)]
D13	What best describes your current employment status? [Response Choices: Employed full-time, Employed part-time,
	Taking care of home or family but not working for pay, Not employed but looking for work, Student, Retired, Unable to
	work, Other, (DK, Refused, N/A)]
D14	Do you currently have any type of health insurance plan or health coverage? [Response Choices: Yes, No, (DK, Refused,
	N/A)]
D15	(If D14 = Yes) What best describes the source of your health plan. If you have more than one, please select your primary
	plan. [Response Choices: Private plan, such as through an employer, the federal insurance exchange at healthcare.gov, or
	a state insurance plan; Medicaid; Medicare; Veterans' Affairs; TRICARE/Military Health System; Other government or
	state plan; Other; (DK, Refused, N/A)]

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D9 What is your total MONTHLY household income, before taxes? Please include income from wages and salaries, remittances from family members living elsewhere, farming, and all other sources. [Response choices: Under \$60, \$60 to \$499, \$500 to \$999, \$1,000 to \$1,999, \$2,000 to \$2,999, \$3,000 to \$3,999, \$4,000 to \$4,999, \$5,000 to \$7,499, \$7,500 to \$9,999, \$10,000 to \$14,999, \$15,000 to \$19,999, \$20,000 and over, DK, Refused]

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.

[Response choices:

Less than \$20,000,

\$20,000 or more, but less than \$30,000

\$30,000 or more, but less than \$40,000

\$50,000 or more but less than \$60,000

\$60,000 or more, but less than \$75,000

\$75,000 or more but less than \$100,000

\$100,000 or more, but less than \$150,000

\$150,000 or more

(DK, Refused, N/A)]

D10 (If D9 = DK or refused) Is your total MONTHLY household income before taxes \$4,000 or more, or is it less than \$4,000?

(If under, ask:) Is it over or under \$3,000?

(If under, ask:) Is it over or under \$2,000?

(If under, ask:) Is it over or under \$1,000?

(If under, ask:) Is it over or under \$500?

(If under, ask:) Is it over or under \$60?)

(If over, ask:) Is it over or under \$5,000?

(If over, ask:) Is it over or under \$7,500?

(If over, ask:) Is it over or under \$10,000?

(If over, ask:) Is it over or under \$15,000?

(If over, ask:) Is it over or under \$20,000?