



# 2019 National Survey of Organ Donation Attitudes and Practices (NSODAP) Webinar

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**Vision: Healthy Communities, Healthy People**



# Agenda

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- Welcome and Introduction
- HRSA, Healthcare Systems Bureau, and Division of Transplantation Overviews
- Survey Overview
- Main Findings
- Summary of Findings
- Questions and Answers



# Introduction

## HRSA Overview

A graphic consisting of a teal rounded rectangle behind a white rounded rectangle with a teal border. The letters "HRSA" are centered in the white rectangle in a bold, black, sans-serif font.

HRSA

- Health Resources and Services Administration (HRSA)
  - Is an agency of the U.S. Department of Health and Human Services (HHS)
  - Supports more than 90 programs that provide health care to the geographically isolated and economically or medically challenged
  - Serves tens of millions of people annually, including people living with HIV/AIDS, pregnant women, mothers and their families, and those otherwise unable to access quality health care
  - Provides grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities

# Introduction

## HSB Overview



- HRSA's Healthcare Systems Bureau (HSB)
  - Protects the public health and improves the health of individuals through programs that provide national leadership and direction in targeted areas
    - Organ, bone marrow, and cord blood transplantation (Division of Transplantation, DoT)
    - Vaccine and Countermeasures Injury Compensation
    - Poison Control
    - Drug Pricing
    - Hansen's Disease (leprosy)

# Introduction

## DoT Overview



- HSB's Division of Transplantation (DoT)
  - DoT is the primary federal entity responsible for oversight of the organ and blood stem cell transplant systems in the U.S. and for initiatives to increase organ donor registration and donation in this country.
  - HRSA oversight is exercised according to:
    - Statutory Requirements
    - Federal Regulations
    - Federal Contracts

# Introduction

## Division of Transplantation (DoT) Overview

### DoT Programs

#### Organ Donation Public Awareness Program

- Educates the public and encourages more people to register as organ, eye, and tissue donors

#### Organ Procurement and Transplantation Network (OPTN)

- Links professionals involved in the organ transplantation system and collects input to inform policy to distribute organs to individuals waiting for an organ transplant

#### Scientific Registry of Transplant Recipients (SRTR)

- Provides statistical and analytic support to help evaluate OPTN policies surrounding organ distribution

#### C.W. Bill Young Cell Transplantation Program (CWBYCTP) and National Cord Blood Inventory (NCBI)

- CWBYCTP: Facilitates bone marrow and cord blood transplants from unrelated donors
- NCBI: Builds a public inventory of at least 150,000 new, genetically diverse cord blood units



# Survey Overview



# National Survey of Organ Donation Attitudes and Practices (NSODAP) Overview

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## NSODAP Purpose

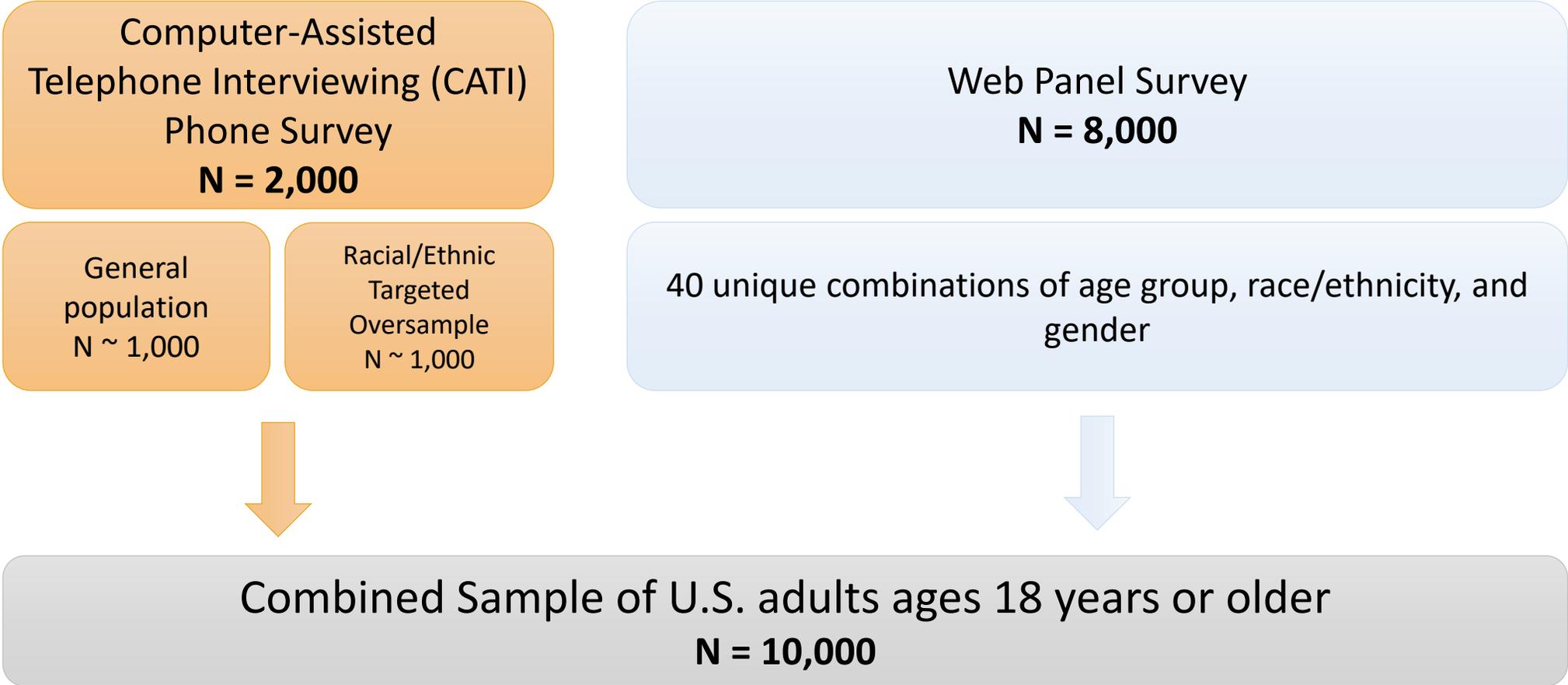
- To understand public opinion about organ donation in the United States, and changes in opinion over time
- To provide the donation community with current and reliable information about the public's opinions and attitudes about organ donation

## 2019 NSODAP

- 4<sup>th</sup> iteration of the survey
  - 2019 survey was conducted under contract with American Directions Research Group
  - 2005 and 2012 surveys conducted under contract with Gallup, Inc.
  - 1993 survey was conducted by a private organization
- Many questions retained to allow trend comparisons over time



# NSODAP Sampling Overview



# Multi-Mode Data Collection

## Telephone Segment

- Address-based sampling
- Landlines and cell phones
- Average interview time = 23 minutes
- Response rate = 7.4%
- November 2018 – March 2019

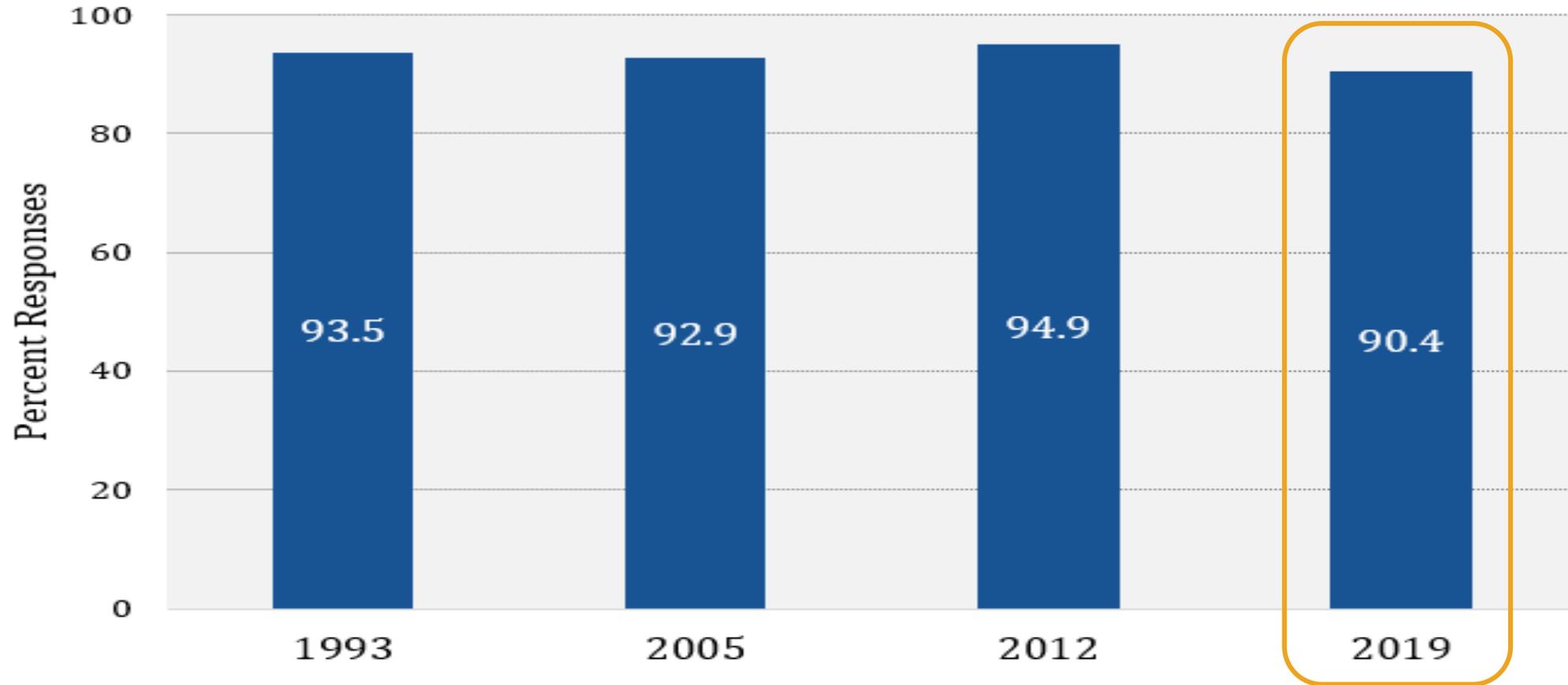
## Web Segment

- Web panel
- Average response time = 13 minutes
- Completion rate = 72.2%
- March 2019 – April 2019

# Main Findings



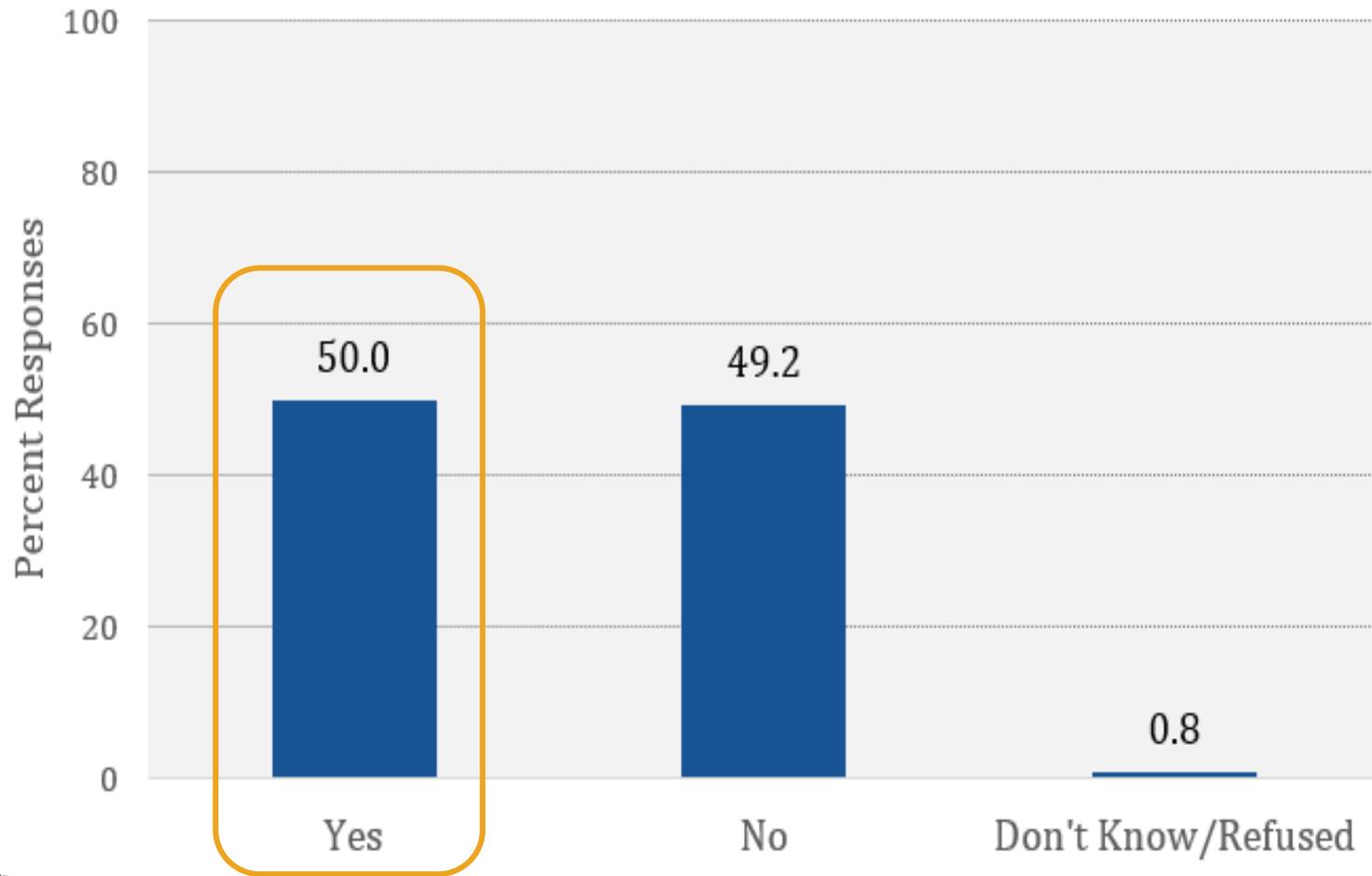
# Overall Support for Organ Donation Remains High



- More support: Age 50 and over, White or Native American, College graduates or higher



# Half of U.S. Adults Signed Up as Organ Donors

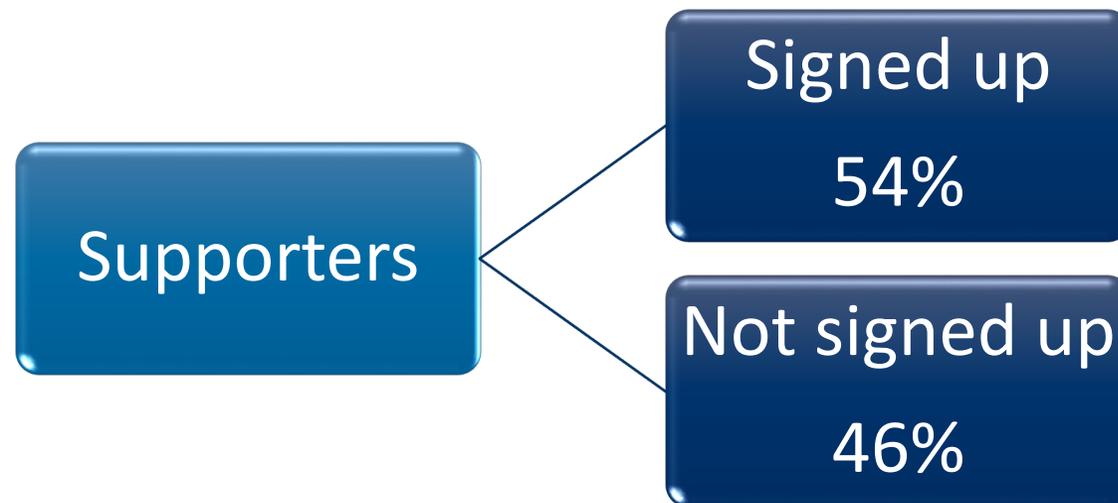


- More likely to have signed up if
  - Under 50
  - White or Native American
  - Non-Hispanic
  - More than high school education
- 93% signed up at DMV

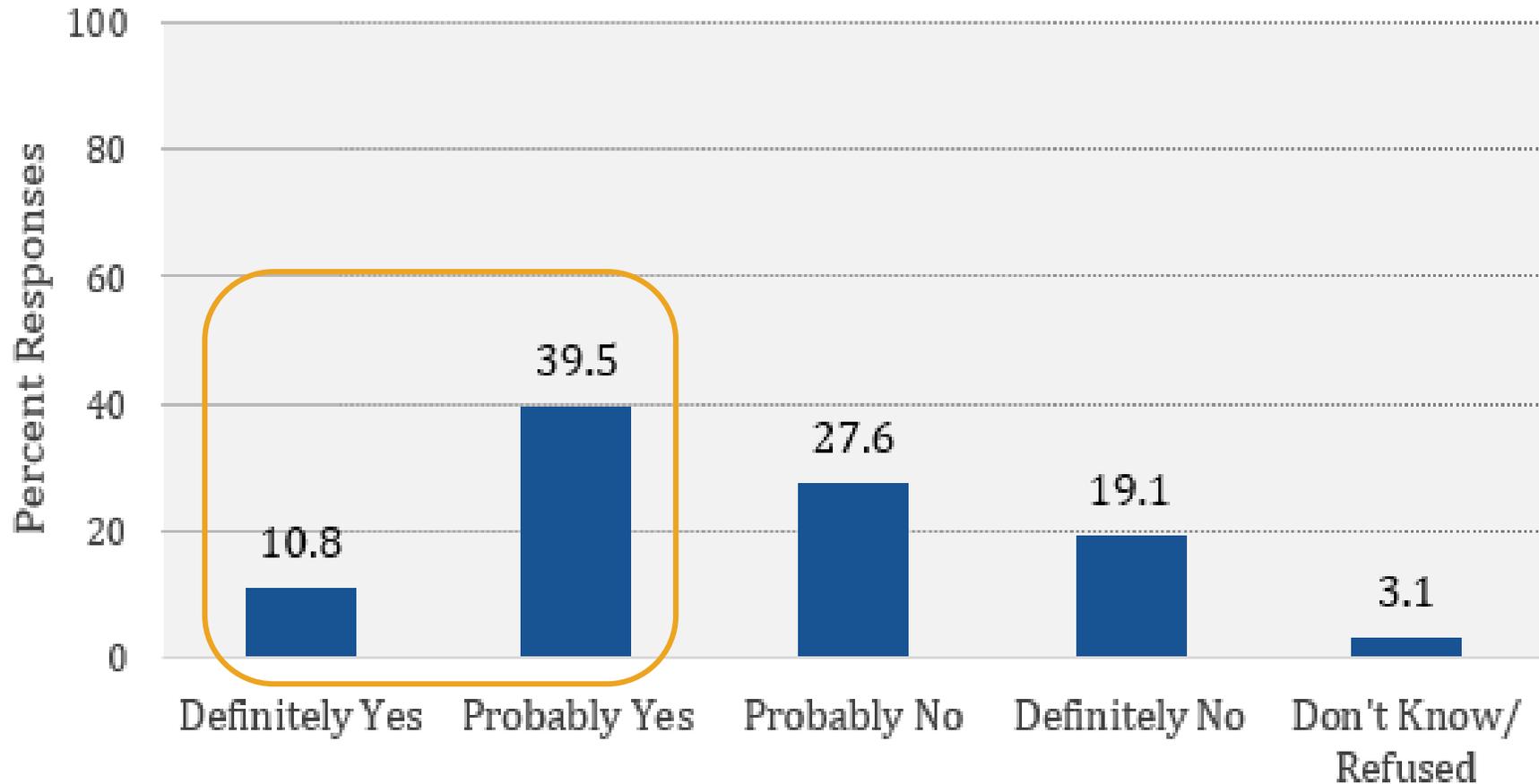


# Nearly Half are Unregistered Supporters

- Unregistered supporters more likely to be
  - 50 and above
  - Black or Asian
  - High school education or less
- No difference by gender and Hispanic ethnicity



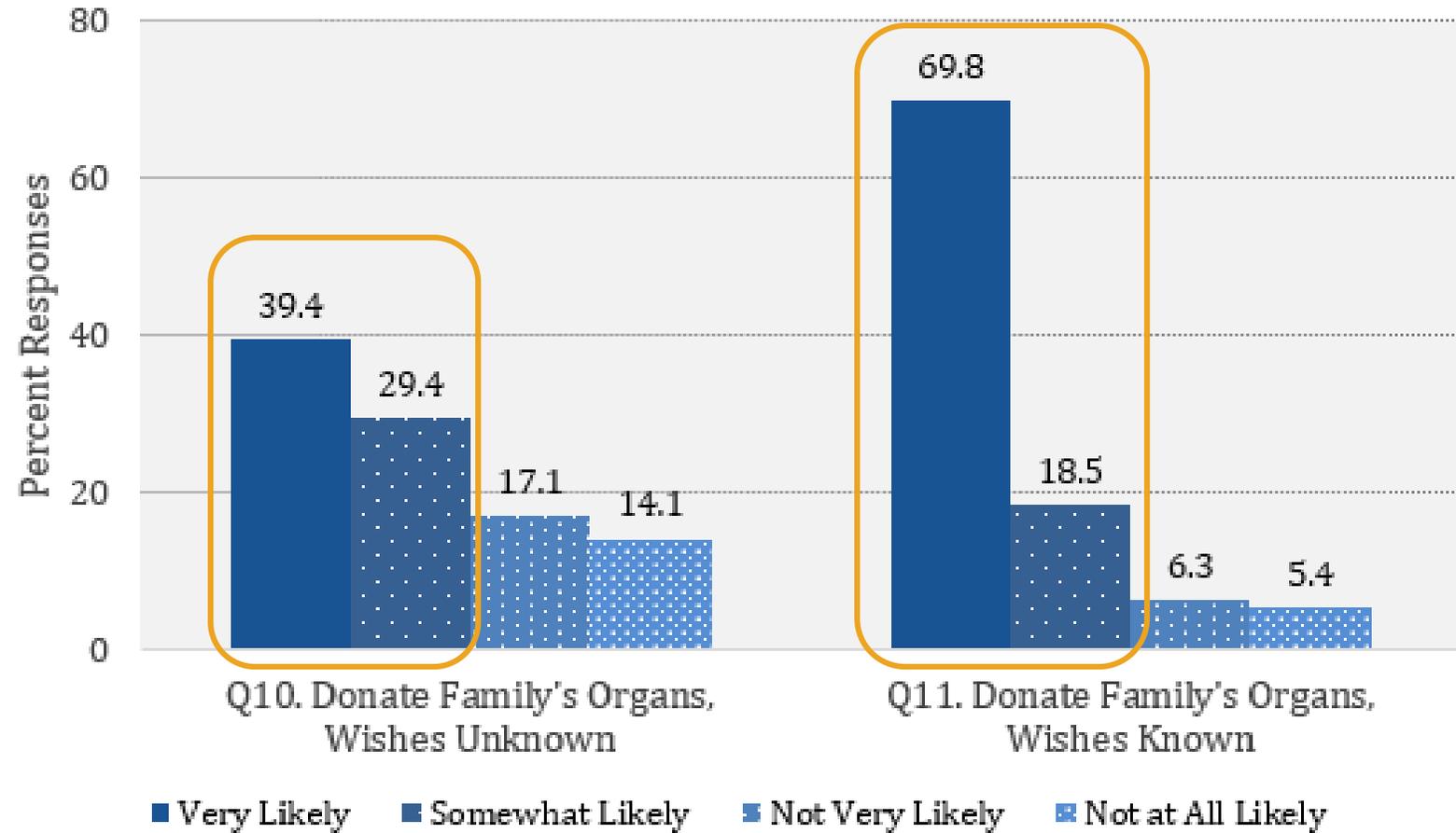
# Half of Unregistered Adults Wish to Donate Organs after Death



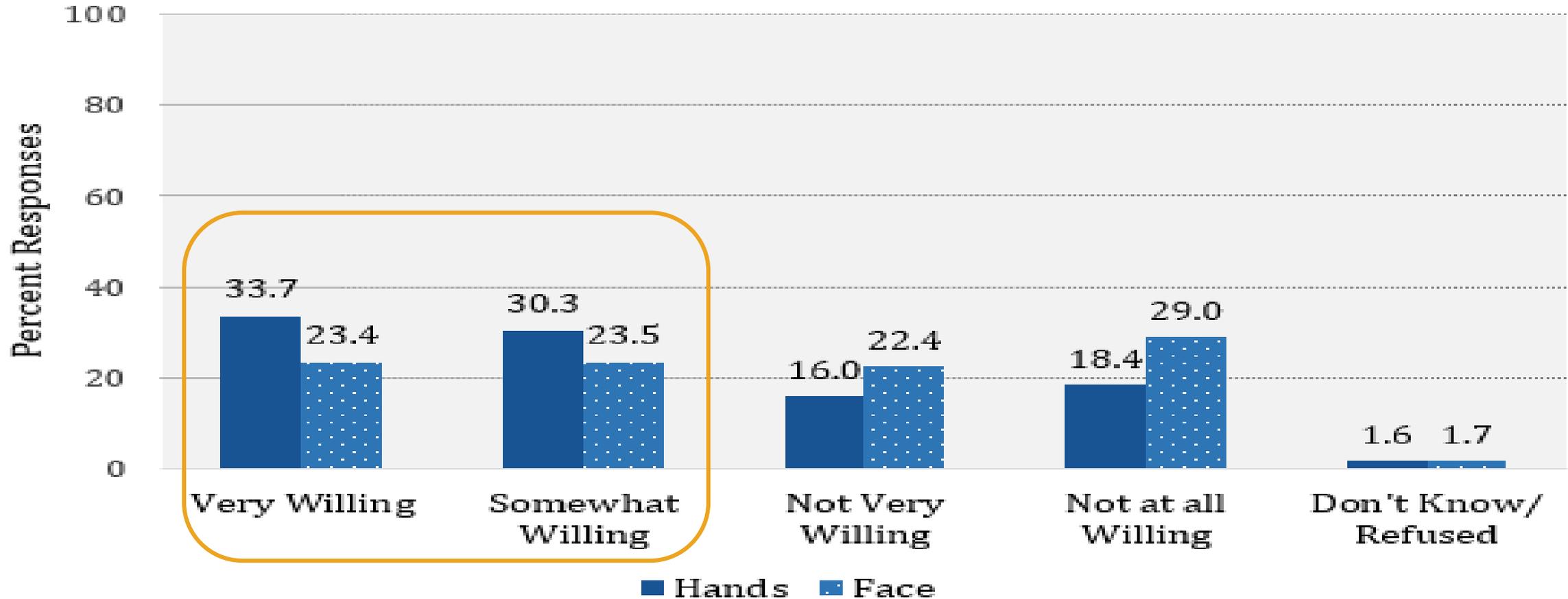
- About 70% of these adults willing to sign up
- Many who did *not* want to sign up said they were too old or too sick
- 1/3 willing to sign up on mobile device and varied by age

# Willingness to Donate Family Member's Organs Varies by Whether Wishes are Known

- When wishes to donate are **unknown**, 69% would donate
- When wishes to donate are **known**, 88% would donate
- More likely to donate family member's organs if
  - Female
  - Under 50
  - White or Native American
  - Have college degree



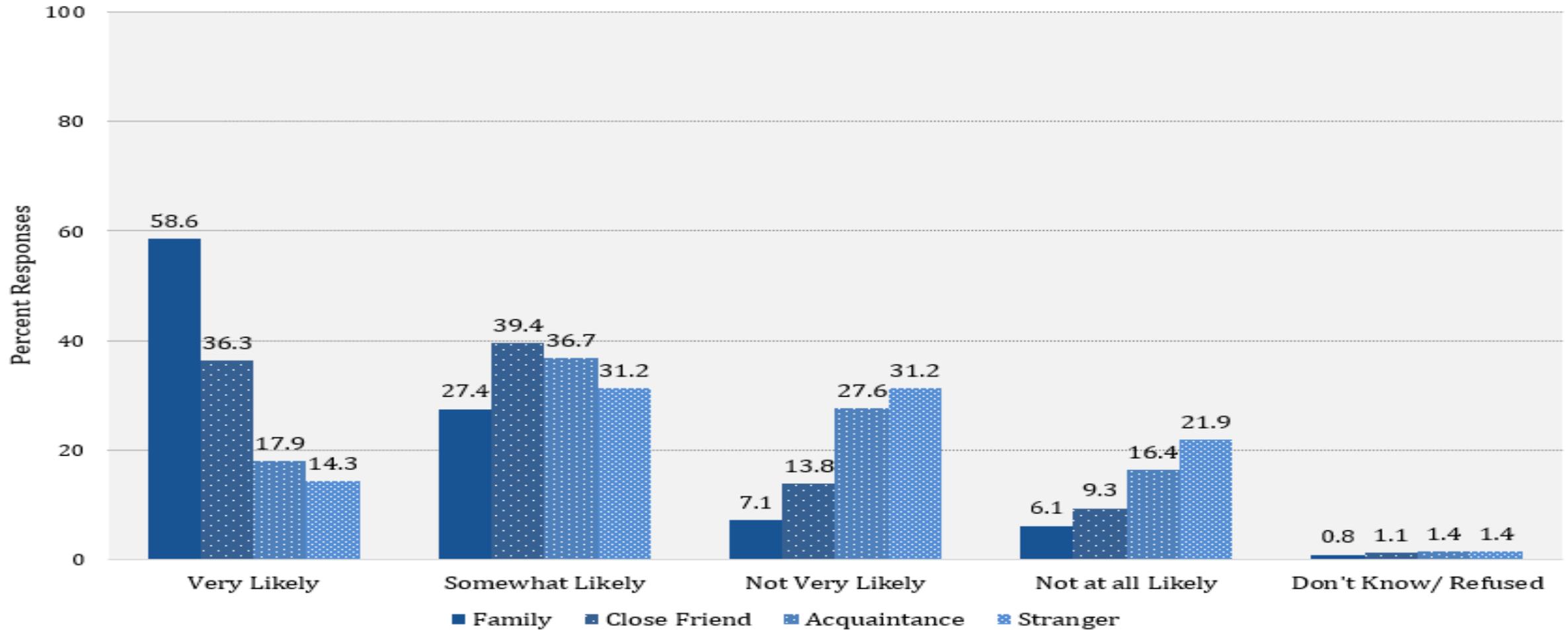
# 64% Willing to Donate their Hands and 47% Willing to Donate their Face



More likely if White and higher education

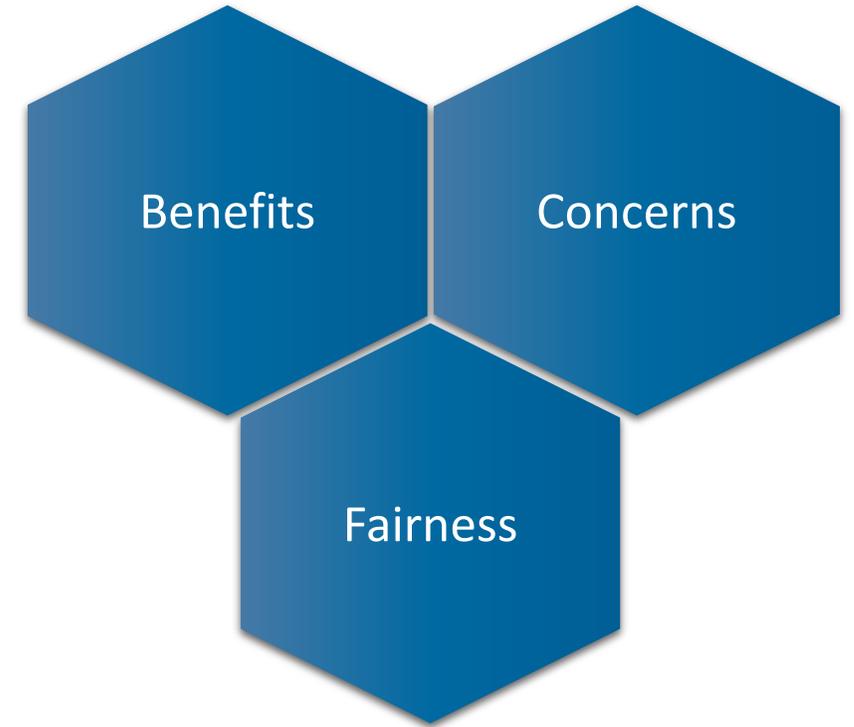


# Willingness to Donate While Living Depends on Intended Recipient



# Organ Donation Beliefs

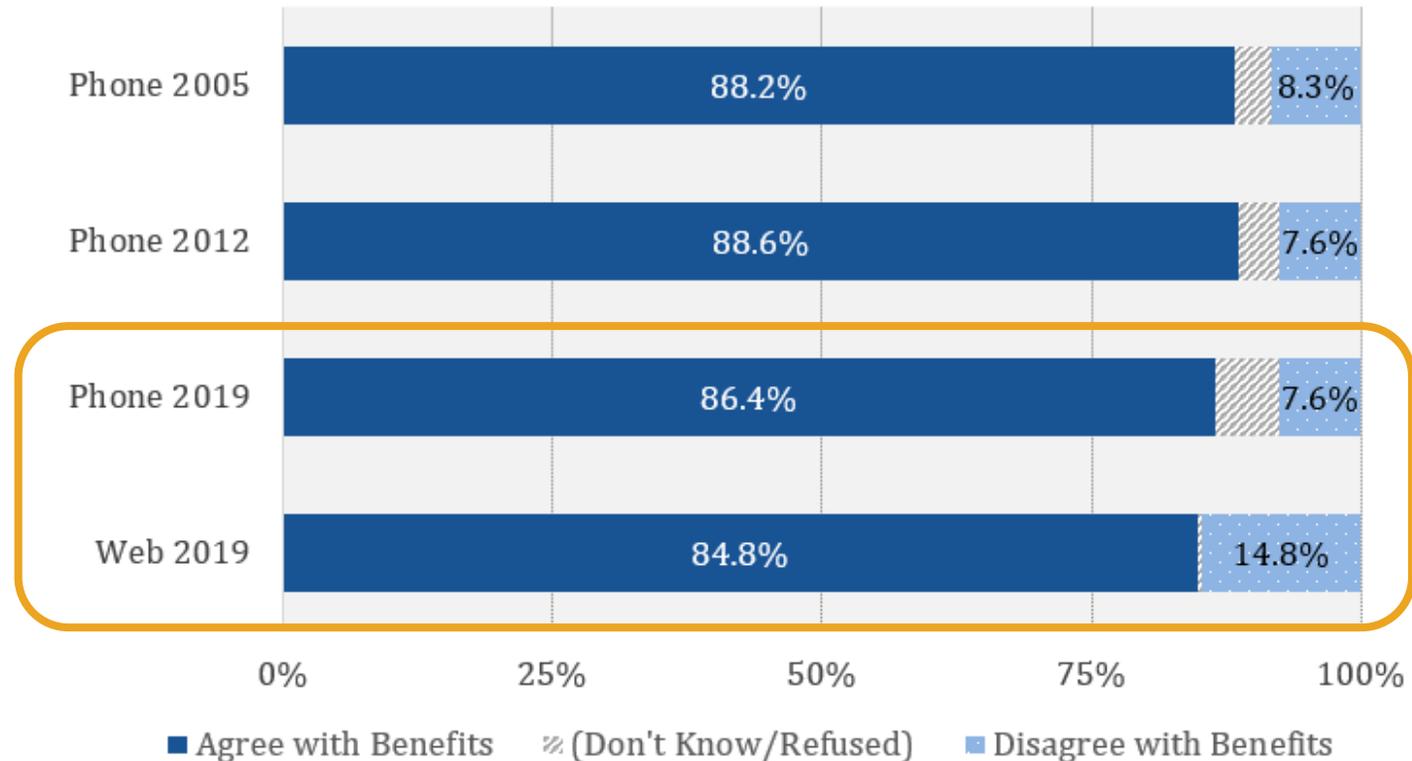
- Over 20 organ donation belief questions asked
- Clustered together into three “latent beliefs”
- Beliefs about benefits and concerns largely unrelated
- People can believe strongly in the benefits of organ donation, but *also* have concerns about it at the same time



# Belief in Benefits of Organ Donation Remains High

- 11 'benefit' beliefs
- Benefit beliefs related to signing up as donor
  - Most Family Supports Organ Donation
  - Organ Donation Allows Positive to Come Out of a Person's Death
  - Organ Donation Improves Lives
- More likely to agree to benefits if
  - Female
  - 50+
  - White or Native American
  - More educated

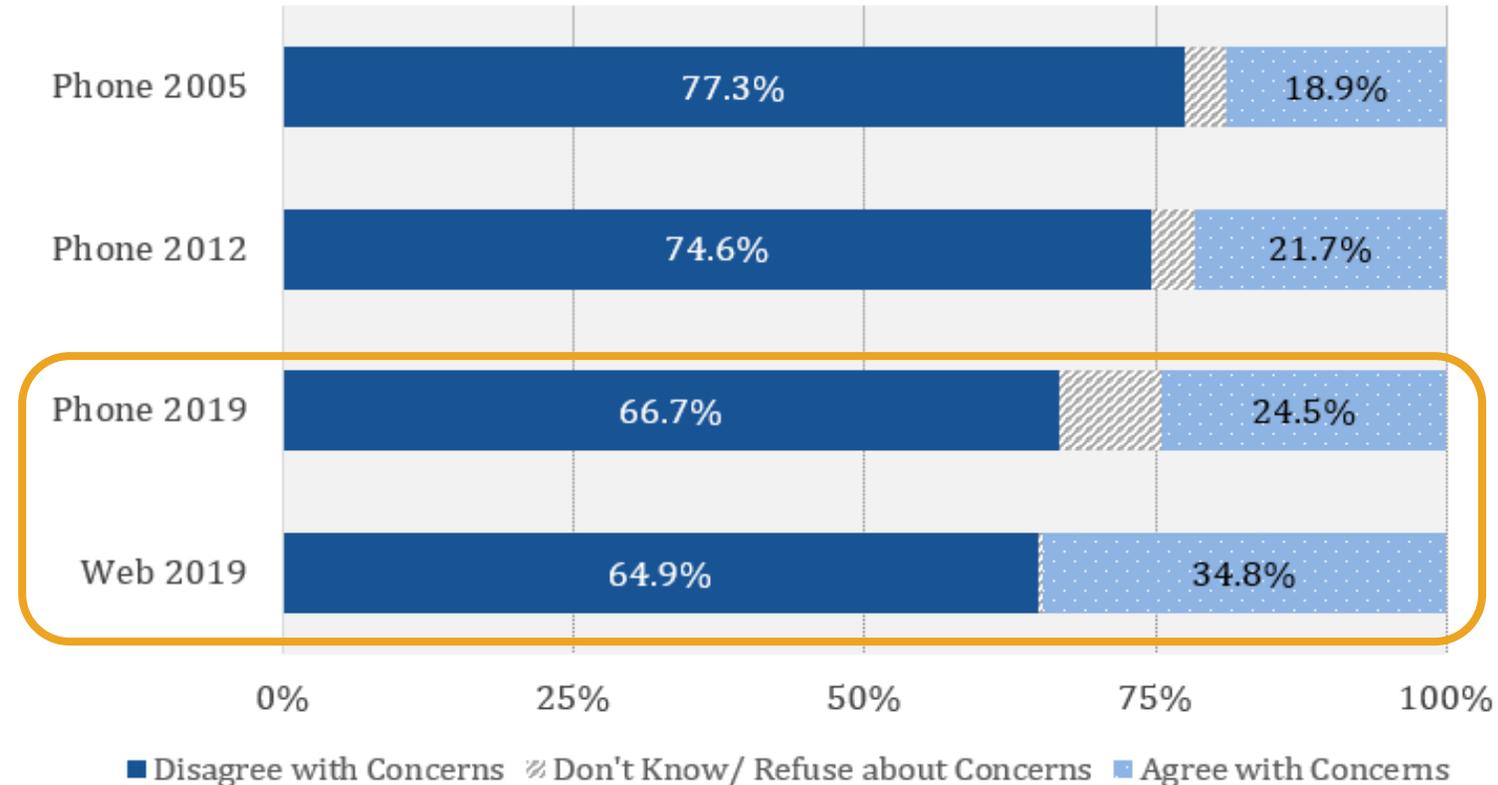
Beliefs in Benefits of Organ Donation, 2005-2019



# Belief in Concerns about Organ Donation Increased since 2012

- 11 'concern' beliefs
- Concerns related to signing up as donor
  - Body Should Have Its Parts at Burial
- Most concerns had no relationship to support or signing up
- More likely to agree to concerns if
  - Male,
  - Under 50
  - Black, Asian, or Other Race
  - Less educated

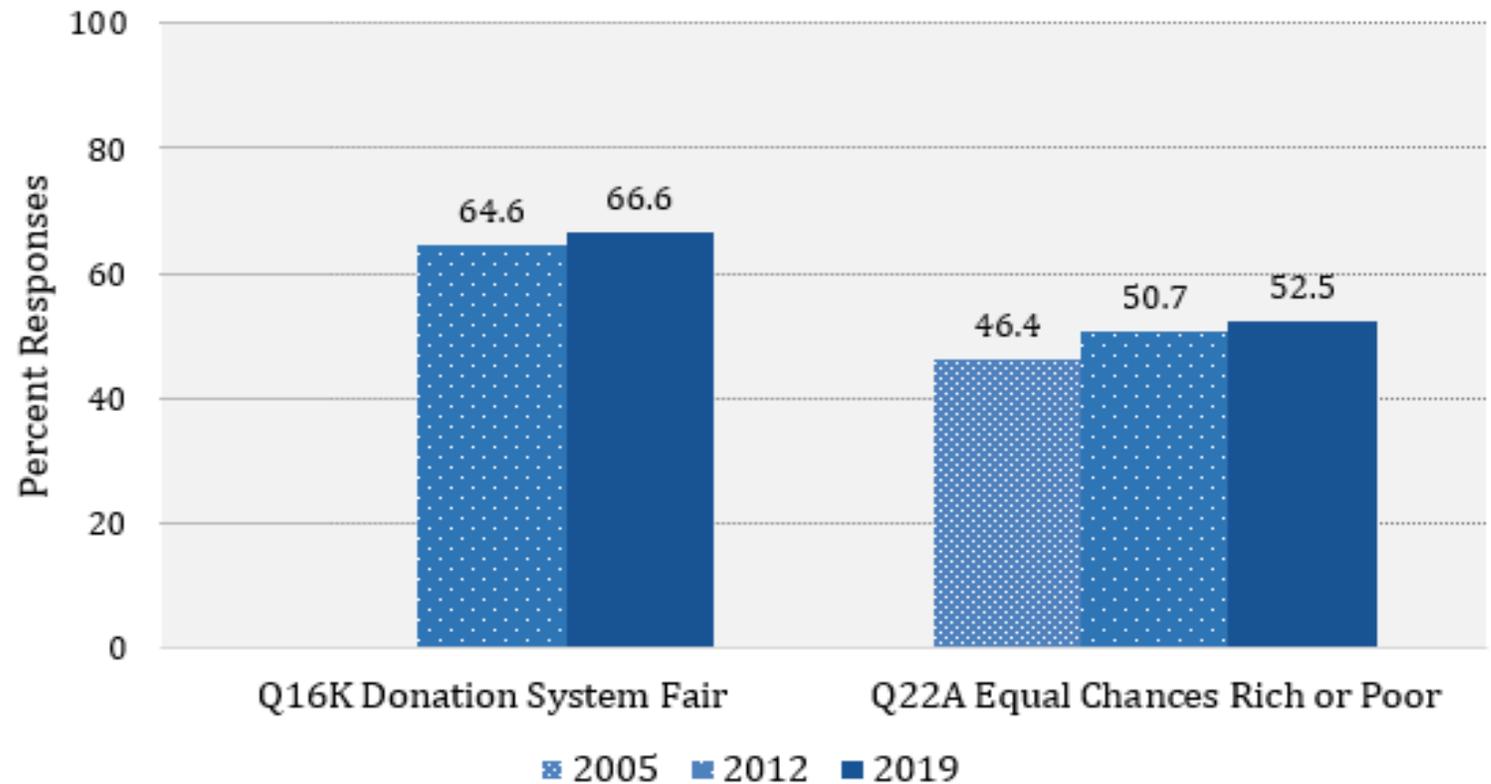
Belief in Concerns about Organ Donation, 2005-2019



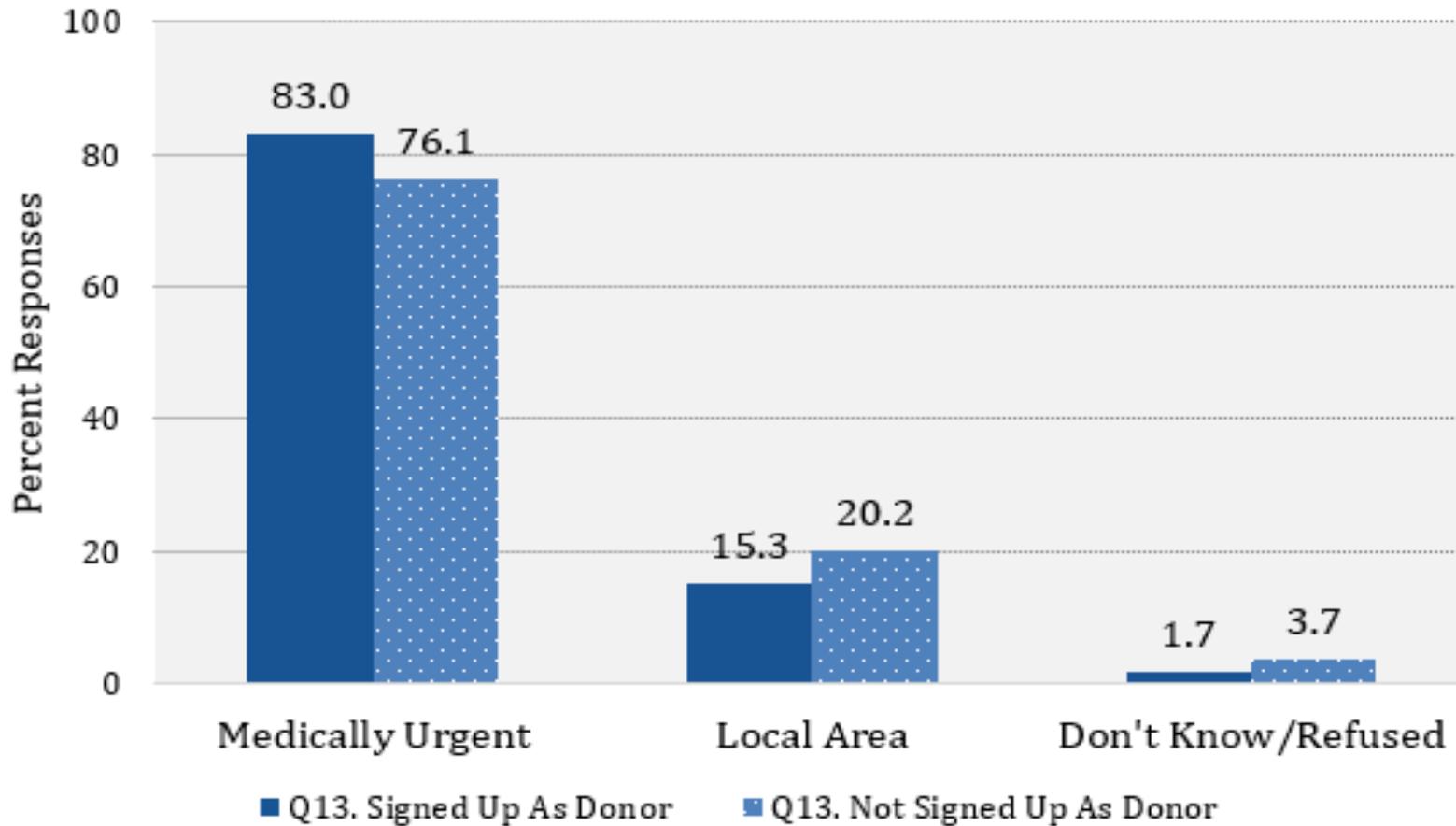
# Belief in Fairness of Organ Donation

- 2 fairness questions
- No relationship to support or signing up

Figure 17. Percent Agreeing with Organ Donation Fairness (Q16K, Q22A), 2005–2019



# 4 of 5 Adults Prefer Organs Allocated Based on Medical Urgency

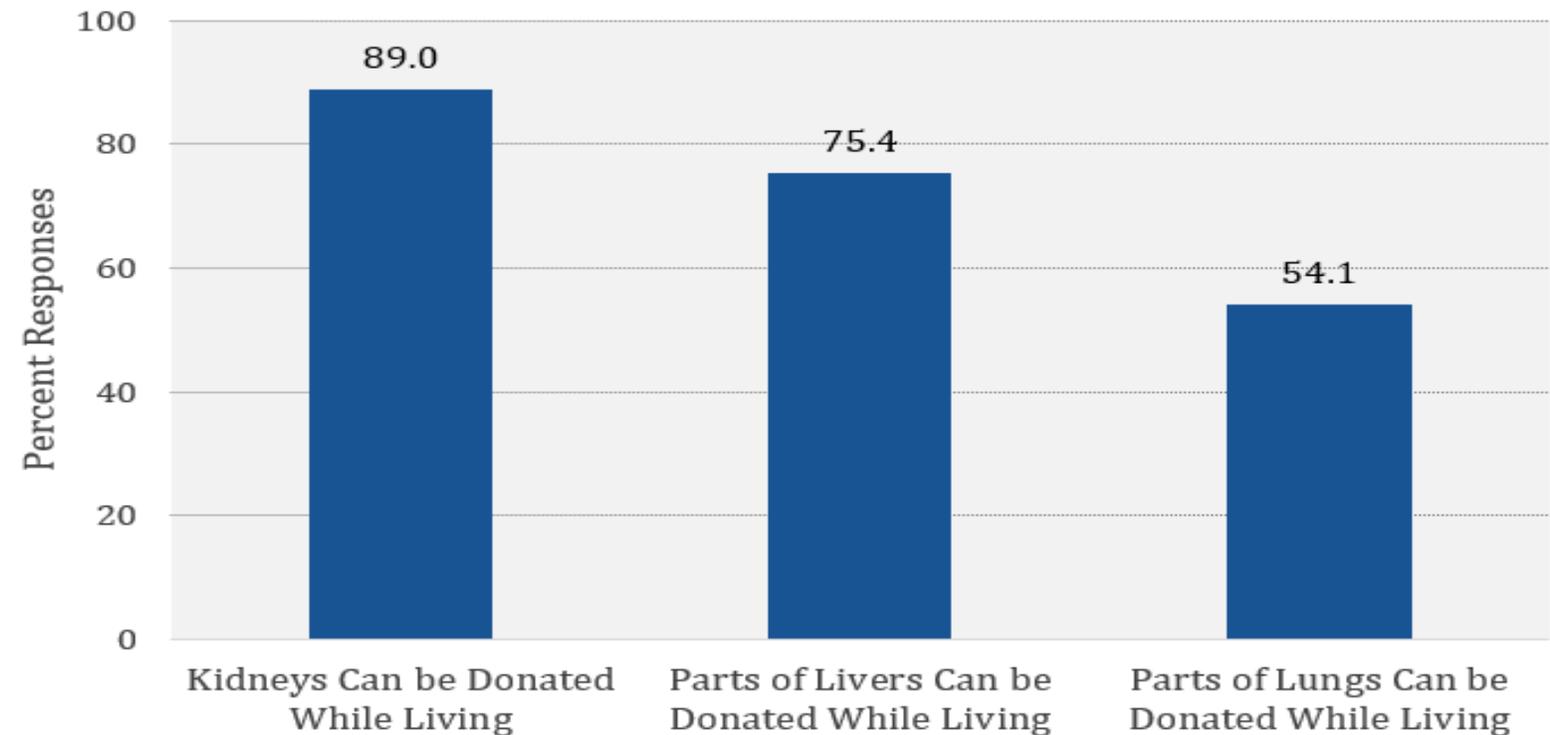


- Medical urgency more likely to be preferred by
  - Over 50
  - Female
  - White, Native American, or Non-Hispanic
  - More than high school education
- Not significantly different from 2012

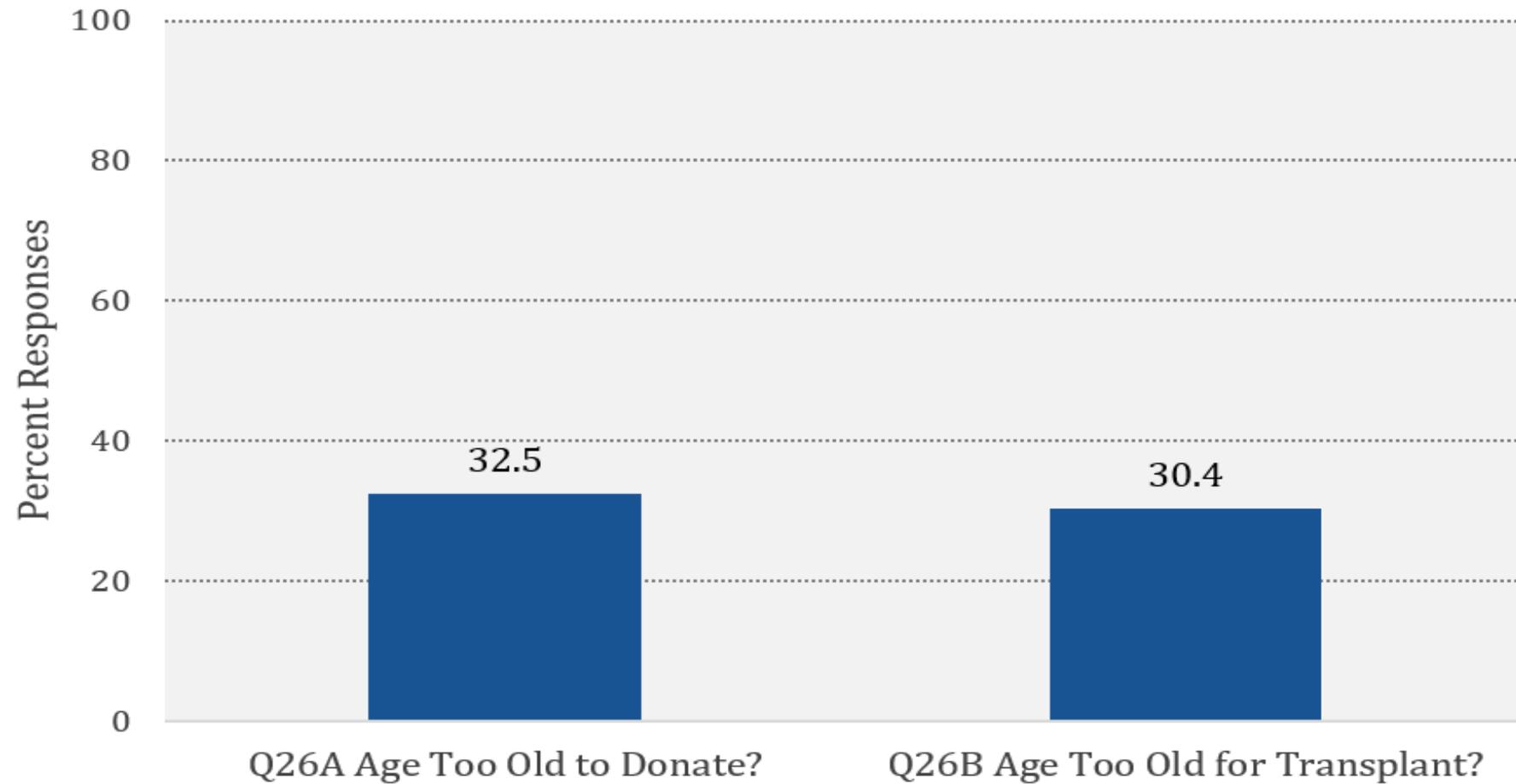
# Knowledge of Living Donation High for Kidney

- New question in 2019
- Correct living donation knowledge
  - 50+
  - White, Native American
  - Non-Hispanic

Percent Correctly Agreeing Organs can be Donated from Living Donor (Q14F), 2019



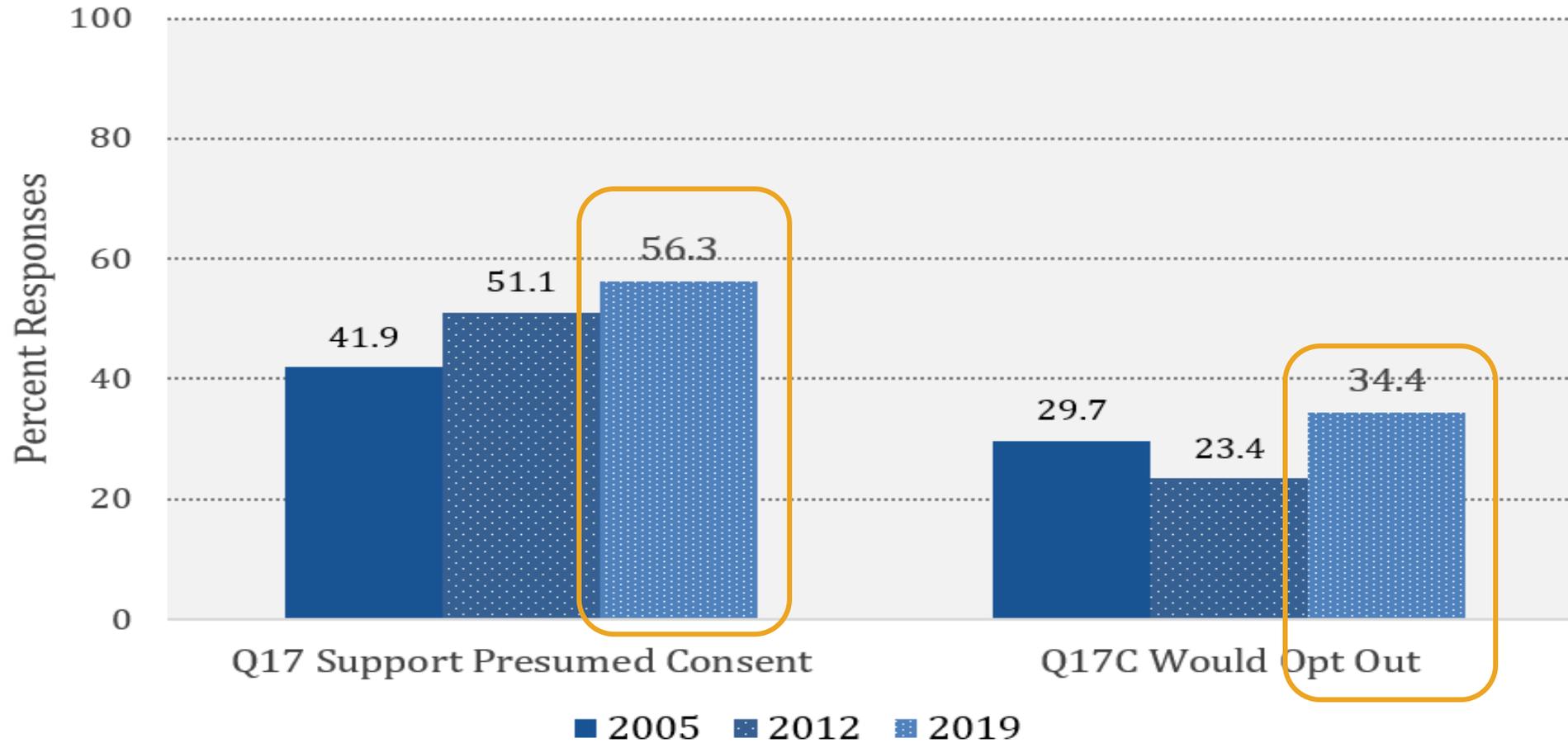
# Nearly One-Third Indicated Age Limitation to Organ Donation and Transplantation



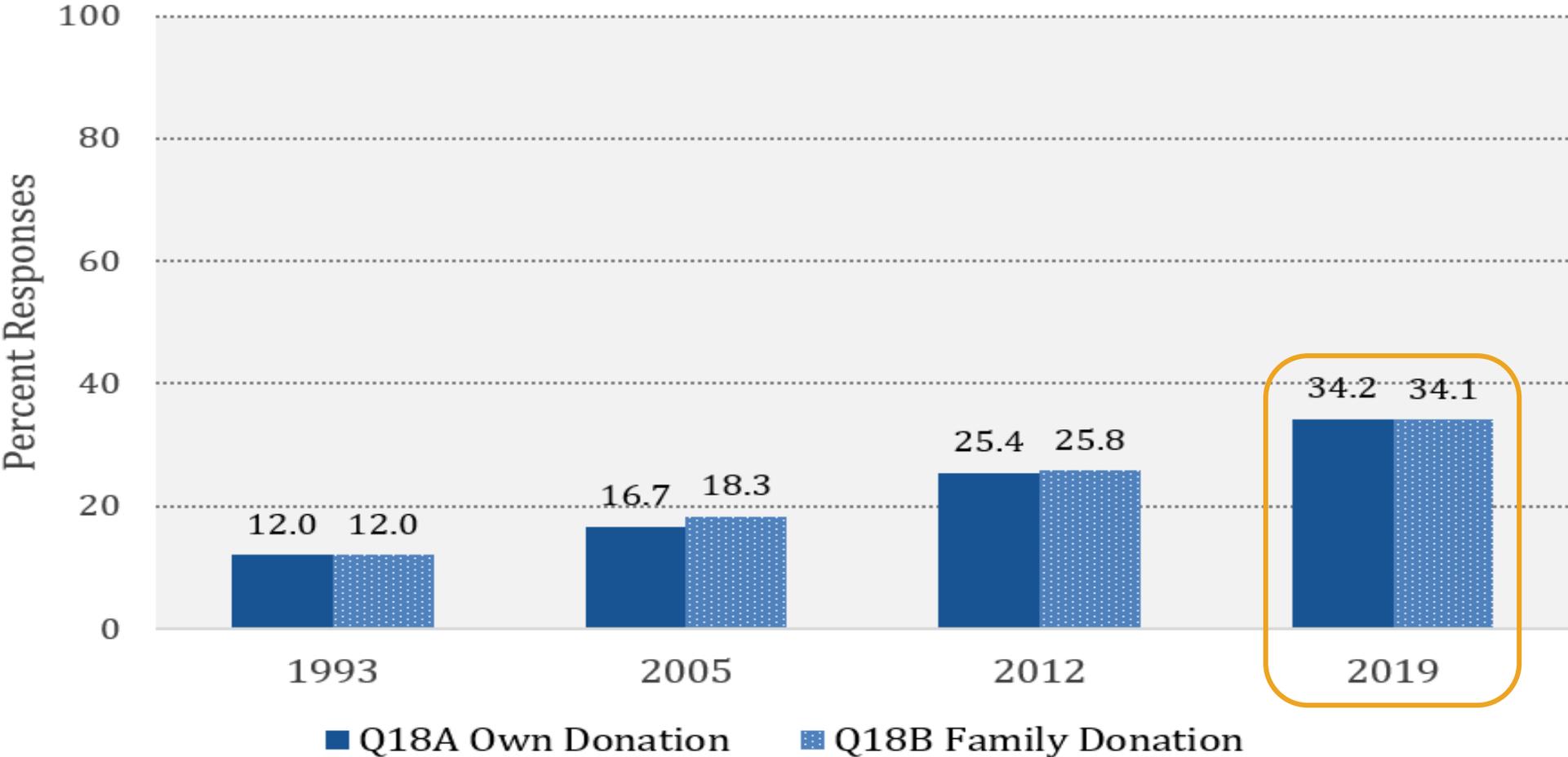
- Average age was 67 for donation and 73 for transplantation



# Over Half Support Presumed Consent



# More Adults in 2019 Willing to Donate if Payment Assistance Received

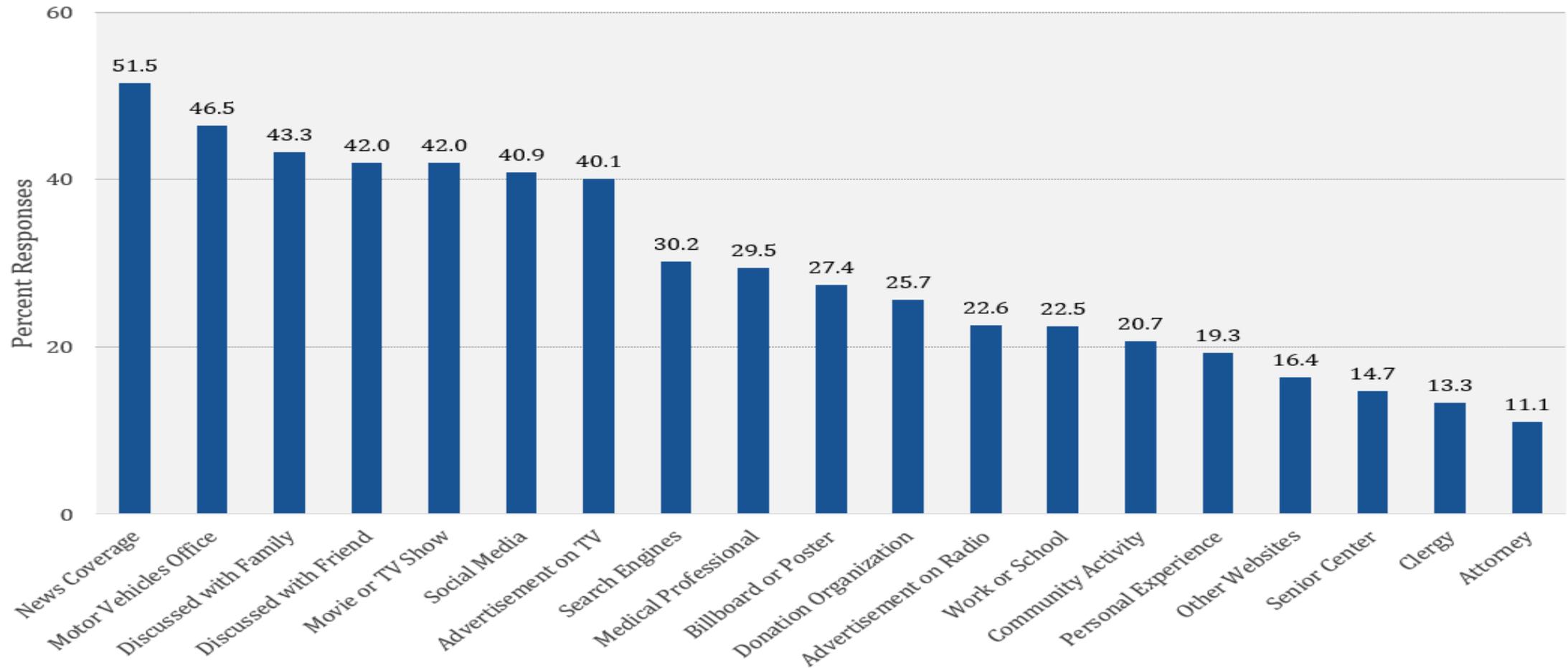


# Half Heard About Organ Donation in Past Year

- Top info sources: News coverage, DMV, discussions, TV/movies, social media
- Source varied heavily by demographics
  - Under 50 had more info sources overall, including discussions, work/school, and especially online sources
  - 50+ more likely to get their information from news coverage
- Three sources showed no age difference: DMV, TV/movies, and TV advertisements
- Hispanic respondents were much more likely to say “yes” to uncommon info sources (e.g., info from an attorney)



# Sources of Information for Organ Donation



# Predictors of Organ Donation

- Demographics, personal experiences, and belief predictors for the following:
  - Support for organ donation
  - Signed up as organ donor
  - Signing up among supporters
  - Willingness to donate a family member's organs
- All four models were highly predictive
- Top predictors included
  - Disagreeing with “It is important for a body to have all of its parts”
  - Agreeing with “Most of my family members support the idea of organ donation”
  - (For signing up) Personal experience for organ donation and transplantation



# Profiles of Support for Organ Donation

- Expanded sample size (N=10,000) allows for more detailed demographic combinations
- Compared 40 unique demographic combinations of race, age, and education and their support for organ donation
- Overall support was lowest for Black respondents with less education, especially those under 50 with a high school education or less
- Unregistered supporters were more likely to be over 50, with mixed race and education backgrounds

# Summary of Results

## Support and Signing Up

- Overall support for organ donation remains high at 90%
- Half of the U.S. adults have signed up to be organ donors
  - Majority signed up at the Department of Motor Vehicles
  - Of those who have not signed up, half desired to donate organs after death

## Donating Family Member's Organs

- Nearly half of respondents' family members discussed their wishes to donate with their family
- If family member's wishes to donate are
  - Known, 88% would donate family member's organs
  - Unknown, 69% would donate family member's organs



# Summary of Results (cont.)

## Hands and Face Donation

- Nearly two-thirds (64%) willing to donate their hands, nearly half (47%) were willing to donate their face
- Less support for donating a family member's hands (58.7%) or face (43.6%)

## Living Donation

- Willingness for living donation varies by intended recipient

## Organ Donation beliefs

- Belief in benefits of organ donation remains high
- Belief in benefits and concerns are independent
- Primary concern driving opposition is belief the body should be buried whole
- Many other concerns have no bearing on support for donation



# Summary of Results (cont.)

- Support for allocating by medical urgency than by locality remains high at 80%
- Majority knew kidney could be donated while alive, 50% knew parts of lung could be donated
- About one-third of U.S. adults said there is an age limitation for donation and transplant
  - Average age 67 for donation and 73 for transplantation
- More than half support presumed consent
- More people are willing to donate if payment assistance received



# Summary of Results (cont.)

## Sources of Information

- 47% of U.S. adults heard about organ donation in the past year
- Top information sources: news coverage, the Department of Motor Vehicles, talks with friends or family, movies or TV shows, social media, and TV advertising

## Predictors of Support and Signing Up

- Two of the three strongest predictors
  - Belief that a body needed its parts when buried
  - Belief that most family members support organ donation

## Demographic Profiles of organ donation

- Racial/ethnic minorities and several groups over age 50 more likely to be unregistered supporters



# Questions & Answers



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# National Context for Results

- Several national trends provide context for these results:
  - Trust in health care has declined tremendously  
[Trust in doctors has plummeted by 75%. What can be done?](#), Advisory Board, 2018
  - As out of pocket costs increase, overall health care utilization has decreased  
[Lower utilization dampened health spending growth in 2017](#), Modern Healthcare, 2018
  - Health care costs are the top financial concern among Americans  
[Healthcare Costs Top Financial Problem for U.S. Families](#), Gallup, 2019
  - Perceived divisions between Americans is at an all time high.  
[Record-High 77% of Americans Perceive Nation as Divided](#), Gallup, 2016

