Public Perception of Clinical Trials

July 2017

National public opinion survey commissioned by Research!America
This nationwide online survey was conducted by Zogby Analytics on behalf of Research!America in July 2017, among 1,000 adults. This survey has a theoretical sampling error of +/- 3.1 percentage points.*

*Due to rounding, the total may not add up to 100 on some slides
Support for this survey was provided, in part, by:

ACRO
ASSOCIATION OF CLINICAL RESEARCH ORGANIZATIONS
Majority Agree Discussion of Clinical Trials Should be Part of Standard Care

Do you agree or disagree that health care professionals should discuss clinical trials with patients diagnosed with a disease as part of their standard of care?

- **Strongly agree**: 47%
- **Somewhat agree**: 39%
- **Somewhat disagree**: 5%
- **Strongly disagree**: 0.4%
- **Not sure**: 9%

Clinical Trial Participation is as Valuable as Giving Blood

Please tell me if you agree with the following statement — Taking part in clinical trials is as valuable to our health care system as giving blood.

Opinions Split on Importance of Taking Part in a Clinical Trial

Please tell me if you agree with the following statement — It is important for everyone to take part in a clinical trial if they are asked.

Majority Would Participate if Asked by Someone They Trust

Please tell me if you agree or disagree with the following statement — I would take part in a clinical trial if I was asked by someone I trust.

- Strongly agree: 37%
- Somewhat agree: 37%
- Somewhat disagree: 14%
- Strongly disagree: 4%
- Not sure: 8%

Four in Five Americans Have Heard of Clinical Trials

One kind of medical research is often referred to as a clinical trial. In this, volunteers choose to participate to test the safety and effectiveness of certain treatments, drugs or devices. Have you ever heard of a clinical trial?

Most Americans Have Not Participated in Clinical Trials

Have you or anyone in your family ever participated in clinical trials?

- 73% No
- 18% Yes
- 9% Not sure

Fewer than 10% of Americans participate in clinical trials. Which of the following do you think is a reason that individuals don’t participate in clinical trials? (Check all that apply)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not aware/lack of information</td>
<td>55%</td>
</tr>
<tr>
<td>Too risky</td>
<td>43%</td>
</tr>
<tr>
<td>Lack of information about clinical trials process</td>
<td>41%</td>
</tr>
<tr>
<td>Lack of trust</td>
<td>38%</td>
</tr>
<tr>
<td>Adverse health outcomes</td>
<td>34%</td>
</tr>
<tr>
<td>Little or no monetary compensation</td>
<td>34%</td>
</tr>
<tr>
<td>No health conditions to treat</td>
<td>24%</td>
</tr>
<tr>
<td>Lack of access</td>
<td>22%</td>
</tr>
<tr>
<td>Too much time</td>
<td>18%</td>
</tr>
<tr>
<td>Privacy issues</td>
<td>15%</td>
</tr>
<tr>
<td>Lack of monetary compensation for physicians to discuss clinical trials with patients</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
<tr>
<td>Not sure</td>
<td>7%</td>
</tr>
</tbody>
</table>

Physicians, Clinical Trial Registry are Reliable Sources

Which of the following do you think is a reliable source for clinical trial information? (Check all that apply)

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor/health care provider</td>
<td>64%</td>
</tr>
<tr>
<td>Clinical trial registry (clinicaltrials.gov)</td>
<td>46%</td>
</tr>
<tr>
<td>National Institutes of Health</td>
<td>31%</td>
</tr>
<tr>
<td>Online/Internet</td>
<td>30%</td>
</tr>
<tr>
<td>Food and Drug Administration</td>
<td>25%</td>
</tr>
<tr>
<td>Universities</td>
<td>21%</td>
</tr>
<tr>
<td>Patient organizations</td>
<td>19%</td>
</tr>
<tr>
<td>Media (TV, radio, online and print publications)</td>
<td>15%</td>
</tr>
<tr>
<td>Industry (pharmaceutical companies, medical device companies)</td>
<td>14%</td>
</tr>
<tr>
<td>Advertisements</td>
<td>10%</td>
</tr>
<tr>
<td>Friends or family</td>
<td>10%</td>
</tr>
<tr>
<td>Foundations/charities</td>
<td>12%</td>
</tr>
<tr>
<td>Military (i.e. Walter Reed Army Institute of Research)</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
<tr>
<td>Not sure</td>
<td>12%</td>
</tr>
</tbody>
</table>

Which organizations listed below would you say have the greatest responsibility in educating the public about clinical trials? (Choose ONLY one)

- Doctors and other health care providers: 44%
- Government, for example the National Institutes of Health (NIH): 23%
- Pharmaceutical companies: 10%
- Patient organizations: 5%
- Insurance companies: 3%
- Military: 1%
- Other: 1%
- Not sure: 13%

Nearly Three-Quarters Say Doctors Don’t Talk About Medical Research

Has your doctor or other health care professional ever talked to you about medical research?

- 19% Yes
- 74% No
- 7% Not sure

Plurality Agree Clinical Trials Should be Routine Health Behavior

Do you agree or disagree clinical trial participation should be a routine health behavior, whether you are healthy or ill, similar to getting an annual check up with your health care provider?

- Strongly agree: 17%
- Somewhat agree: 27%
- Somewhat disagree: 23%
- Strongly disagree: 16%
- Not sure: 18%

More Men than Women Agree Clinical Trial Participation Should Be Routine Behavior

Do you agree or disagree clinical trial participation should be a routine health behavior, whether you are healthy or ill, similar to getting an annual checkup with your health care provider?

Young Adults More Likely to Agree Clinical Trial Participation Should Be Routine Behavior

Do you agree or disagree clinical trial participation should be a routine health behavior, whether you are healthy or ill, similar to getting an annual checkup with your health care provider?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-29</td>
<td>27%</td>
<td>26%</td>
<td>28%</td>
<td>8%</td>
<td>11%</td>
</tr>
<tr>
<td>30-49</td>
<td>20%</td>
<td>28%</td>
<td>16%</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>50-64</td>
<td>12%</td>
<td>26%</td>
<td>23%</td>
<td>19%</td>
<td>19%</td>
</tr>
<tr>
<td>65+</td>
<td>7%</td>
<td>27%</td>
<td>28%</td>
<td>18%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Majority Likely to Participate in Clinical Trials Recommended by Doctor

If your doctor found a clinical trial for you and recommended you join, how likely would you be to participate in a clinical trial?

11% increase in percentage that selected ‘Very likely’ from 2013

If your doctor found a clinical trial for you and recommended you join, how likely would you be to participate in a clinical trial?

### May 2013
- Very likely: 26%
- Somewhat likely: 46%
- Not likely: 12%
- Would not participate: 13%
- Not sure: 9%

### July 2017
- Very likely: 37%
- Somewhat likely: 44%
- Not likely: 7%
- Would not participate: 9%
- Not sure: 7%

Source: Research!America surveys of U.S. adults conducted in partnership with Zogby Analytics in July 2017 and May 2013.
Please indicate your willingness to share your personal health information, assuming that appropriate privacy protections are in place.

10% increase in percentage that selected ‘So researchers can better understand diseases and develop new ways to prevent, treat and cure them’ from 2013

9% increase in percentage that selected ‘To advance medical research’ from 2013

Increase in Percentage Willing to Share Personal Health Information to Fight Disease

Please indicate your willingness to share your personal health information, assuming that appropriate privacy protections are in place – so researchers can better understand diseases and develop new ways to prevent, treat and cure them.

Source: Research!America surveys of U.S. adults conducted in partnership with Zogby Analytics in July 2017 and May 2013.
Increase in Percentage Willing to Share Personal Health Information to Advance Research

Please indicate your willingness to share your personal health information, assuming that appropriate privacy protections are in place – to advance medical research

<table>
<thead>
<tr>
<th>Year</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2017</td>
<td>82%</td>
<td>8%</td>
<td>11%</td>
</tr>
<tr>
<td>May 2013</td>
<td>73%</td>
<td>11%</td>
<td>16%</td>
</tr>
</tbody>
</table>

Source: Research!America surveys of U.S. adults conducted in partnership with Zogby Analytics in July 2017 and May 2013.
Americans Admire Organ Donors, Those Who Give Blood

Please rate how much you admire each of the following groups of people on a scale of 1 to 4, where 1 means you do not admire them at all, and where 4 means you admire them a great deal.

9% increase in percentage that selected ‘a great deal’ for ‘People who volunteer for clinical trials’ from 2013

<table>
<thead>
<tr>
<th>People</th>
<th>4 (a great deal)</th>
<th>3</th>
<th>2</th>
<th>1 (not at all)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People who donate an organ</td>
<td>74%</td>
<td>14%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>People who give blood</td>
<td>62%</td>
<td>25%</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>People who volunteer for clinical trials</td>
<td>46%</td>
<td>34%</td>
<td>7%</td>
<td>9%</td>
</tr>
</tbody>
</table>

More Americans Admire People Who Volunteer for Clinical Trials

Please rate how much you admire each of the following groups — People who volunteer for clinical trials.

<table>
<thead>
<tr>
<th></th>
<th>4 A great deal</th>
<th>3</th>
<th>2</th>
<th>1 Not at all</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2017</td>
<td>46%</td>
<td>34%</td>
<td>7%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>May 2013</td>
<td>37%</td>
<td>38%</td>
<td>9%</td>
<td>13%</td>
<td></td>
</tr>
</tbody>
</table>

Source: Research!America surveys of U.S. adults conducted in partnership with Zogby Analytics in July 2017 and May 2013.
Majority Likely to Use Technology to Share Health Data

How likely are you to use technology such as apps, phones and monitoring devices to share your personal health data for clinical research?

- Very likely: 37%
- Somewhat likely: 35%
- Not likely: 10%
- Would not participate: 6%
- Not sure: 12%

Nearly Half Open to Receiving Data Through Phone

If you participated in a clinical trial, would you prefer to have clinical trial information/data/results delivered through your phone?

- Yes: 47%
- No: 34%
- Not sure: 19%

Majority Say Participants Should Have Access to Clinical Trial Results

Please tell me if you agree or disagree with the following statement — Participants should have access to results of clinical trials.

- **65%** Strongly agree
- **23%** Somewhat agree
- **4%** Somewhat disagree
- **1%** Strongly disagree
- **7%** Not sure

Risks and Benefits, Competence and Reputation Key Factors for Participation

How important would each of the following factors be in your decision to participate as a volunteer in a clinical trial?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Not very important</th>
<th>Not at all important</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding potential risks and benefits</td>
<td>75%</td>
<td>15%</td>
<td>6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competence and reputation of people or the institution conducting the research</td>
<td>74%</td>
<td>17%</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whether you would have medical bills covered if you had an injury from the study</td>
<td>71%</td>
<td>18%</td>
<td>6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunity to possibly improve your own health</td>
<td>63%</td>
<td>27%</td>
<td>6%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Risks and Benefits, Competence and Reputation Key Factors for Participation

How important would each of the following factors be in your decision to participate as a volunteer in a clinical trial?

- Having an expert guide you through the clinical trials process: 59% Very important, 27% Somewhat important, 5% Not very important, 7% Not at all important, 0% Not sure
- The location of the clinical trial is easily accessible: 59% Very important, 27% Somewhat important, 6% Not very important, 6% Not at all important, 0% Not sure
- Privacy and confidentiality issues: 54% Very important, 26% Somewhat important, 10% Not very important, 7% Not at all important, 0% Not sure
- Opportunity to improve the health of others: 52% Very important, 35% Somewhat important, 5% Not very important, 6% Not at all important, 0% Not sure
- Opportunity to advance scientific research: 51% Very important, 35% Somewhat important, 6% Not very important, 7% Not at all important, 0% Not sure

How important would each of the following factors be in your decision to participate as a volunteer in a clinical trial?

- Receiving psychological support and counseling for your illness and as a clinical trial participant: 49% very important, 28% somewhat important, 12% not very important, 3% not at all important, 8% not sure.
- Whether you would be paid to participate: 44% very important, 35% somewhat important, 12% not very important, 3% not at all important, 8% not sure.
- Your physician's recommendation: 40% very important, 38% somewhat important, 11% not very important, 4% not at all important, 8% not sure.
- Hearing from clinical trial participants: 40% very important, 33% somewhat important, 15% not very important, 4% not at all important, 8% not sure.
- Use of wearable health devices, mobile apps and digital technology to record your data: 31% very important, 35% somewhat important, 19% not very important, 6% not at all important, 9% not sure.

Strong Majority Agree Clinical Trials are Important to Advancing Science

Do you agree or disagree that clinical trials are important to advancing science?

Strong Majority Agree Clinical Trials are Important to Nation’s Health

Do you agree or disagree that clinical trials are important to improving our nation’s health?

- Strongly agree: 53%
- Somewhat agree: 34%
- Somewhat disagree: 7%
- Strongly disagree: 5%
- Not sure: 2%

More than Half Support Tax Incentives to Conduct Trials in the U.S.

Should the federal government provide tax incentives to companies to encourage them to conduct clinical trials in the U.S. rather than in other countries?

- Yes: 53%
- No: 19%
- Not sure: 28%

Differing Views on Medications Tested in Other Countries

How concerned are you that most medications approved by the FDA for use in America are tested in patients in other countries as well as in the U.S.?

- 38% Very concerned
- 30% Somewhat concerned
- 16% Not concerned at all
- 16% Not sure