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Rare Diseases and the ORPHAN Cures Act

Polling by **Morning Consult** on behalf of **BIO**

**NOVEMBER 2023**

KEY FINDINGS

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1. A strong majority of U.S. voters (72%) find research on rare disease treatments *very important*, and more than four-in-five view the expansion of **incentives** for developing drugs to treat rare conditions as a critical priority for policymakers.

2. Americans agree the federal government should prioritize passing laws and regulations that encourage experimentation related to rare disease treatments - specifically when those medicines may have **multiple applications**.

3. Two-thirds of Americans (67%) support their congressional representative voting in favor of the **ORPHAN Cures Act**. Support is even stronger among those 'absolutely certain' to vote in the 2024 general election.

4. Support for government action on rare disease research is **bipartisan**. The impact of incumbent representatives voicing support for the ORPHAN Cures Act is net-positive for Republican, independent, and Democrat voters alike.

METHODOLOGY

This poll was conducted between November 23- 25, 2023, among a sample of 1,990 Registered Voters. The interviews were conducted online, and the data were weighted to approximate a target sample of Registered Voters based on gender by age, educational attainment, race, marital status, home ownership, race by educational attainment, 2020 presidential vote, and region. Results from the full survey have a margin of error of plus or minus 2 percentage points.
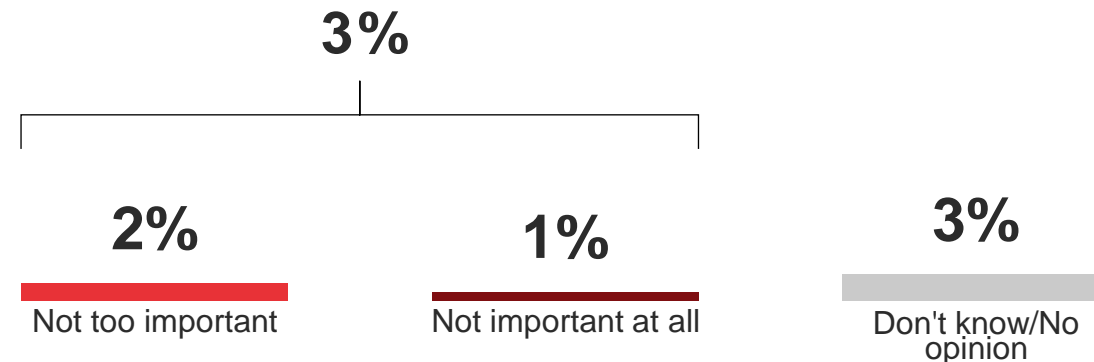
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Americans are **nearly unanimous** in their belief that research on how to treat rare diseases <u>is important</u>. Nearly three-fourths characterize it as *very important.*

How important, if at all, do YOU believe it is for scientists to conduct research into treatments for rare diseases?
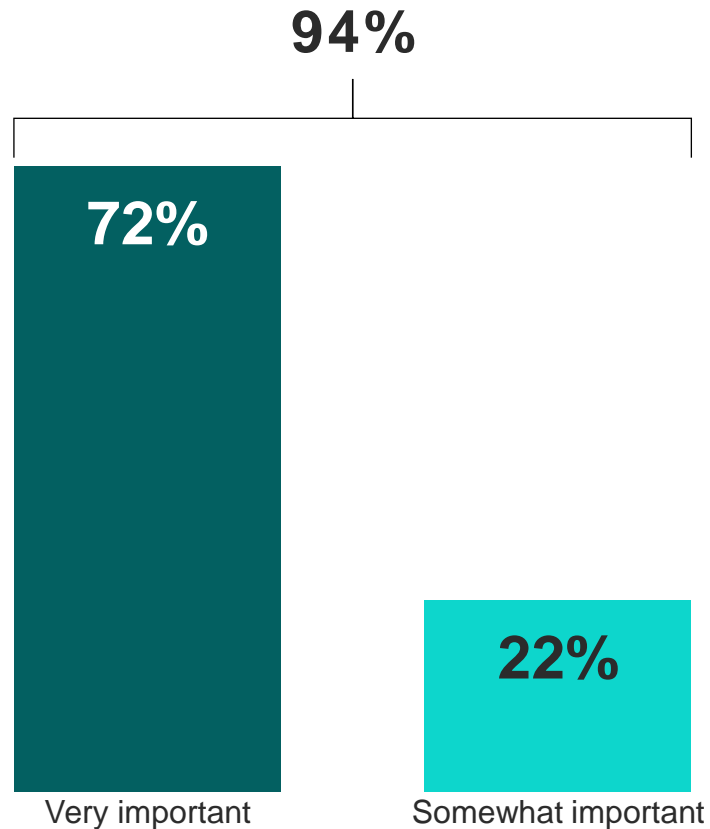
Context Provided to Respondents

As you may know, the U.S. government defines a **rare disease** as any illness that affects fewer than 200,000 Americans. Examples of rare diseases include ALS, cystic fibrosis, sickle cell anemia, and many types of cancer. There are at least 7,000 known rare diseases, with scientists continuing to discover more. Children make up two-thirds of the rare disease population globally.

94%

72%

22%

3%

2%

1%

3%

Very important

Somewhat important

Not too important

Not important at all

Don't know/No opinion

4

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Research on how to treat rare diseases is viewed as *important* across age and party groups, with senior (65+) voters and Democrats holding particularly strong views.

How important, if at all, do YOU believe it is for scientists to conduct research into treatments for rare diseases?

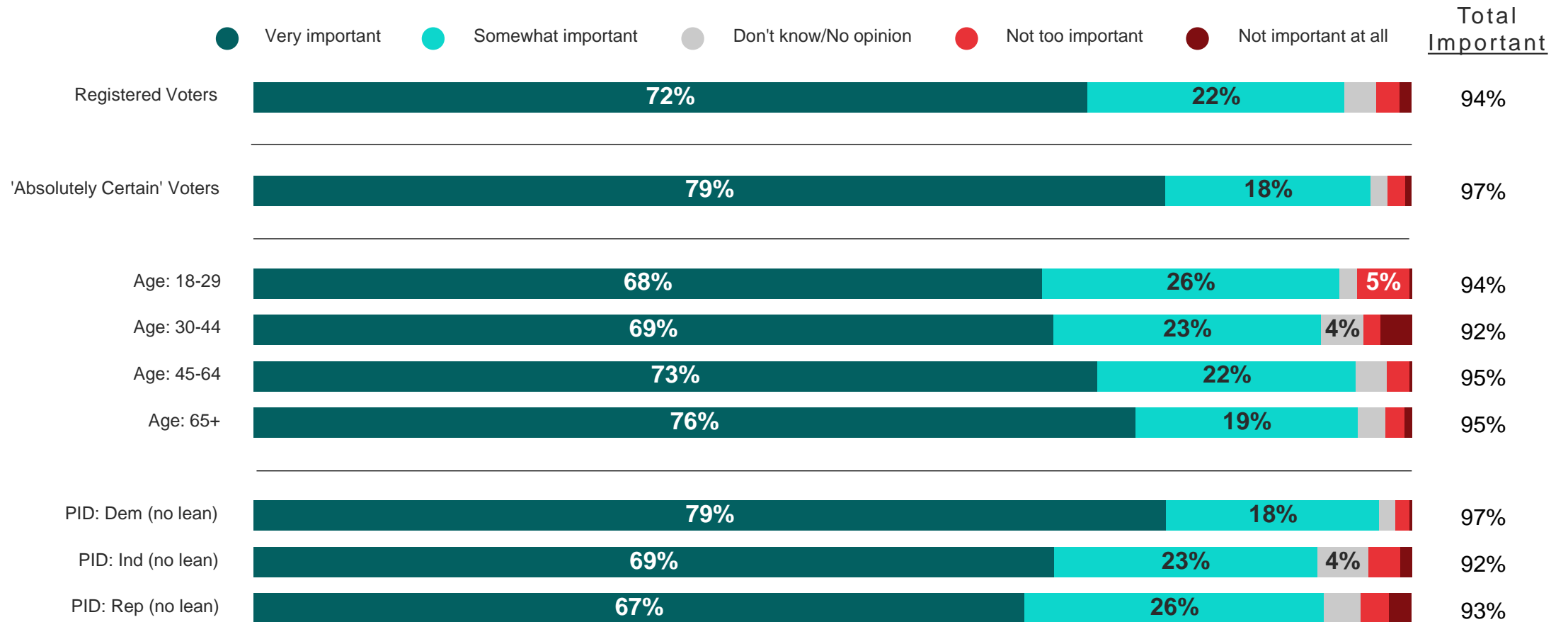● Very important   ● Somewhat important   ● Don't know/No opinion   ● Not too important   ● Not important at all

	Very important	Somewhat important		Total Important
Registered Voters	72%	22%		94%
'Absolutely Certain' Voters	79%	18%		97%
Age: 18-29	68%	26%	5%	94%
Age: 30-44	69%	23%	4%	92%
Age: 45-64	73%	22%		95%
Age: 65+	76%	19%		95%
PID: Dem (no lean)	79%	18%		97%
PID: Ind (no lean)	69%	23%	4%	92%
PID: Rep (no lean)	67%	26%		93%

Total Important = % *Very important* + % *Somewhat important*

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Half of registered voters *strongly agree* on the critical nature of the government expanding incentives for rare disease drug development. Only 8% disagree.

Do you agree or disagree with the following statement? *It is critical for the government to expand incentives for rare disease drug development.*
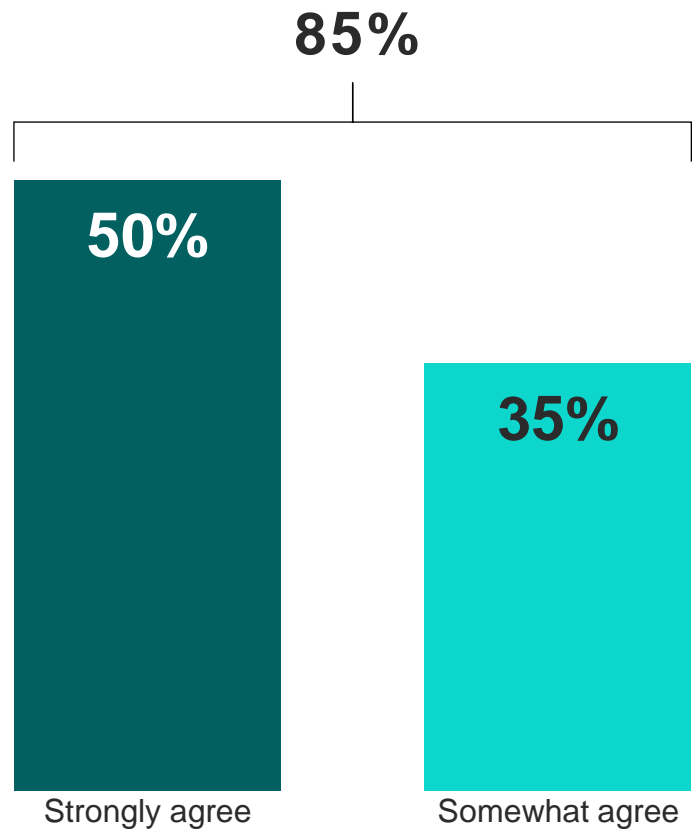
Context Provided to Respondents

Since the 1980s, scientists have invented over 770 FDA-approved drugs to treat **rare diseases**, thanks in part to tax credits, research grants, and other government incentives. Despite this progress, 95% of the rare diseases still have <u>no approved treatment.</u>

85%

50%
Strongly agree

35%
Somewhat agree

8%

5%
Somewhat disagree

3%
Strongly disagree

6%
Don't know/No opinion

6
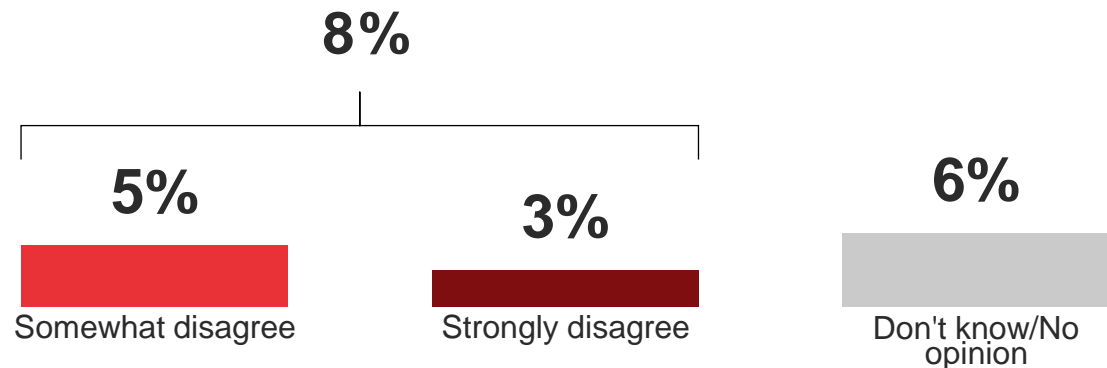
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Strong majorities of Republicans, Democrats, and independents surveyed agree on the need for government incentivization of rare disease research.

Do you agree or disagree with the following statement? *It is critical for the government to expand incentives for rare disease drug development.*
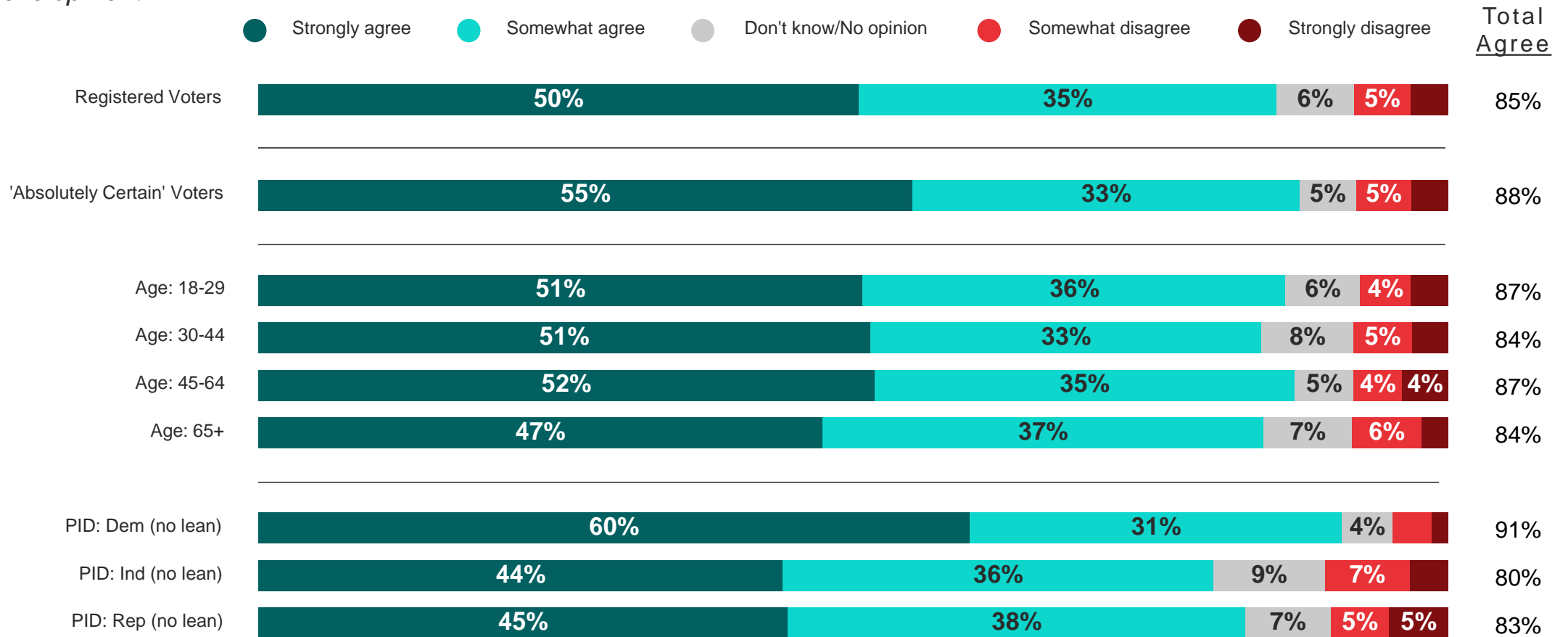
● Strongly agree   ● Somewhat agree   ● Don't know/No opinion   ● Somewhat disagree   ● Strongly disagree

	Strongly agree	Somewhat agree	Don't know/No opinion	Somewhat disagree	Strongly disagree	Total Agree
Registered Voters	50%	35%	6%	5%		85%
'Absolutely Certain' Voters	55%	33%	5%	5%		88%
Age: 18-29	51%	36%	6%	4%		87%
Age: 30-44	51%	33%	8%	5%		84%
Age: 45-64	52%	35%	5%	4%	4%	87%
Age: 65+	47%	37%	7%	6%		84%
PID: Dem (no lean)	60%	31%	4%			91%
PID: Ind (no lean)	44%	36%	9%	7%		80%
PID: Rep (no lean)	45%	38%	7%	5%	5%	83%

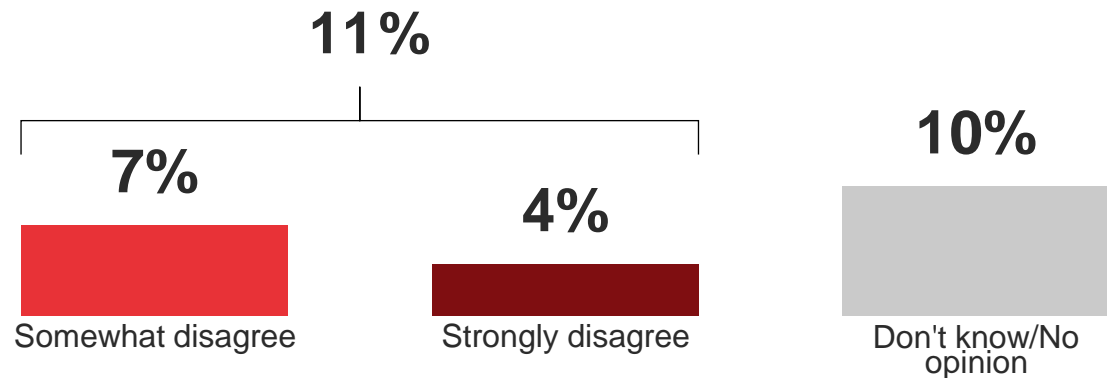Total Agree = % *Strongly agree* + % *Somewhat agree*

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Nearly four-in-five U.S. voters express agreement that federal laws and regulations should be constructed in ways that avoid discouraging experimentation re: whether existing treatments for rare diseases may have multiple applications.

Do you agree or disagree with the following statement? *It is important for federal lawmakers to avoid discouraging biotech companies from studying whether existing rare disease drugs can treat multiple illnesses.*
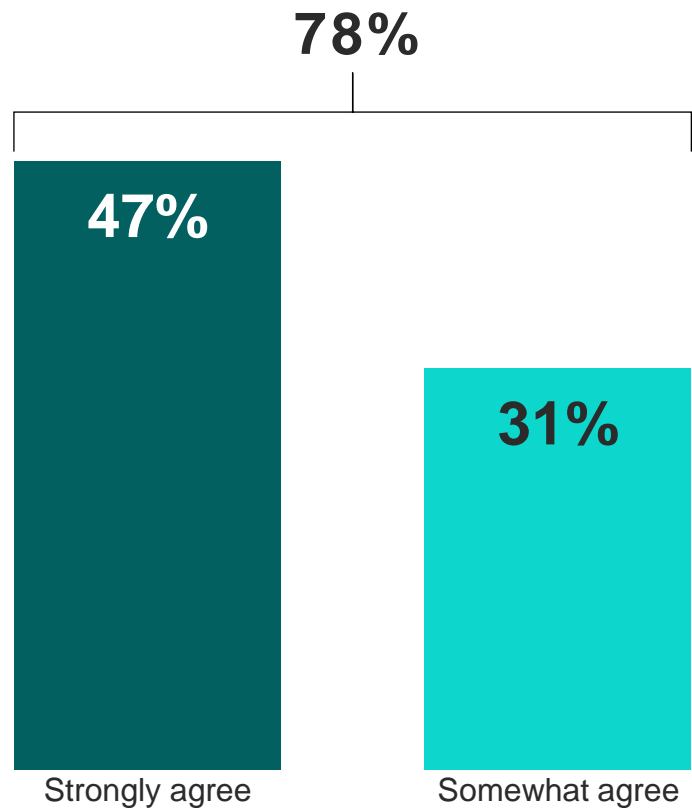
Context Provided to Respondents

Many medicines developed to treat rare diseases are capable of treating <u>more than one</u> rare disease. However, some experts have warned that legislation passed last year will discourage biotech companies from studying whether their *existing* rare disease drugs can treat other conditions.

78%

47%
Strongly agree

31%
Somewhat agree

11%

7%
Somewhat disagree

4%
Strongly disagree

10%
Don't know/No opinion

8

More than half of voters who are *absolutely certain* to vote in the 2024 general election *strongly agree* on the importance of avoiding such discouragement.

Do you agree or disagree with the following statement? *It is important for federal lawmakers to avoid discouraging biotech companies from studying whether existing rare disease drugs can treat multiple illnesses.*

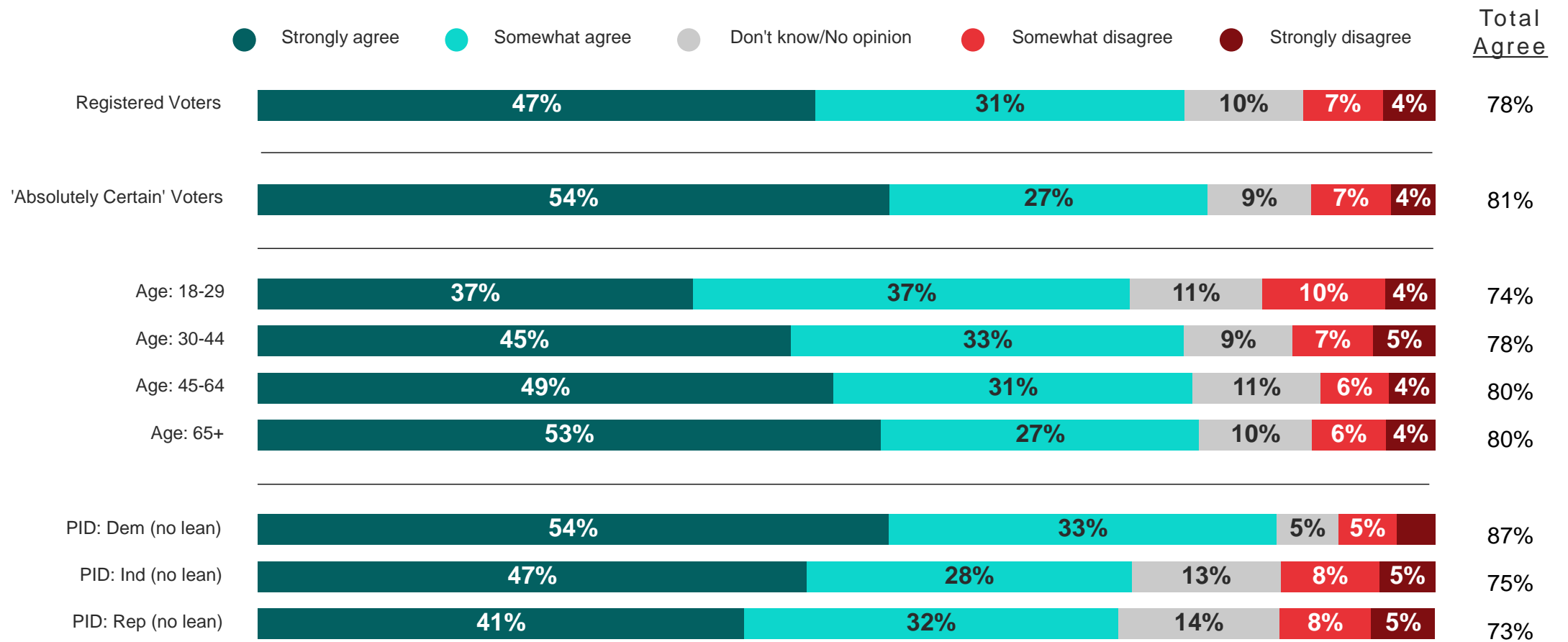● Strongly agree   ● Somewhat agree   ● Don't know/No opinion   ● Somewhat disagree   ● Strongly disagree

	Strongly agree	Somewhat agree	Don't know/No opinion	Somewhat disagree	Strongly disagree	Total Agree
Registered Voters	47%	31%	10%	7%	4%	78%
'Absolutely Certain' Voters	54%	27%	9%	7%	4%	81%
Age: 18-29	37%	37%	11%	10%	4%	74%
Age: 30-44	45%	33%	9%	7%	5%	78%
Age: 45-64	49%	31%	11%	6%	4%	80%
Age: 65+	53%	27%	10%	6%	4%	80%
PID: Dem (no lean)	54%	33%	5%	5%		87%
PID: Ind (no lean)	47%	28%	13%	8%	5%	75%
PID: Rep (no lean)	41%	32%	14%	8%	5%	73%

Total Agree = % *Strongly agree* + % *Somewhat agree*

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Responses indicate widespread support for the ORPHAN Cures Act, with two-thirds of voters favoring their own congressional representatives backing the bill.

Members of Congress from both parties recently introduced a bill, known as the ORPHAN Cures Act, that would reduce barriers to researching whether existing rare disease drugs can be effective in treating other conditions.

Do you support or oppose your representative in the U.S. Congress voting in favor of the ORPHAN Cures Act?

67%

39%

28%

5%

14%

3%

2%

14%

Strongly
support

Somewhat
support

Neither support
nor oppose

Somewhat oppose

Strongly oppose

Don't know/No
opinion
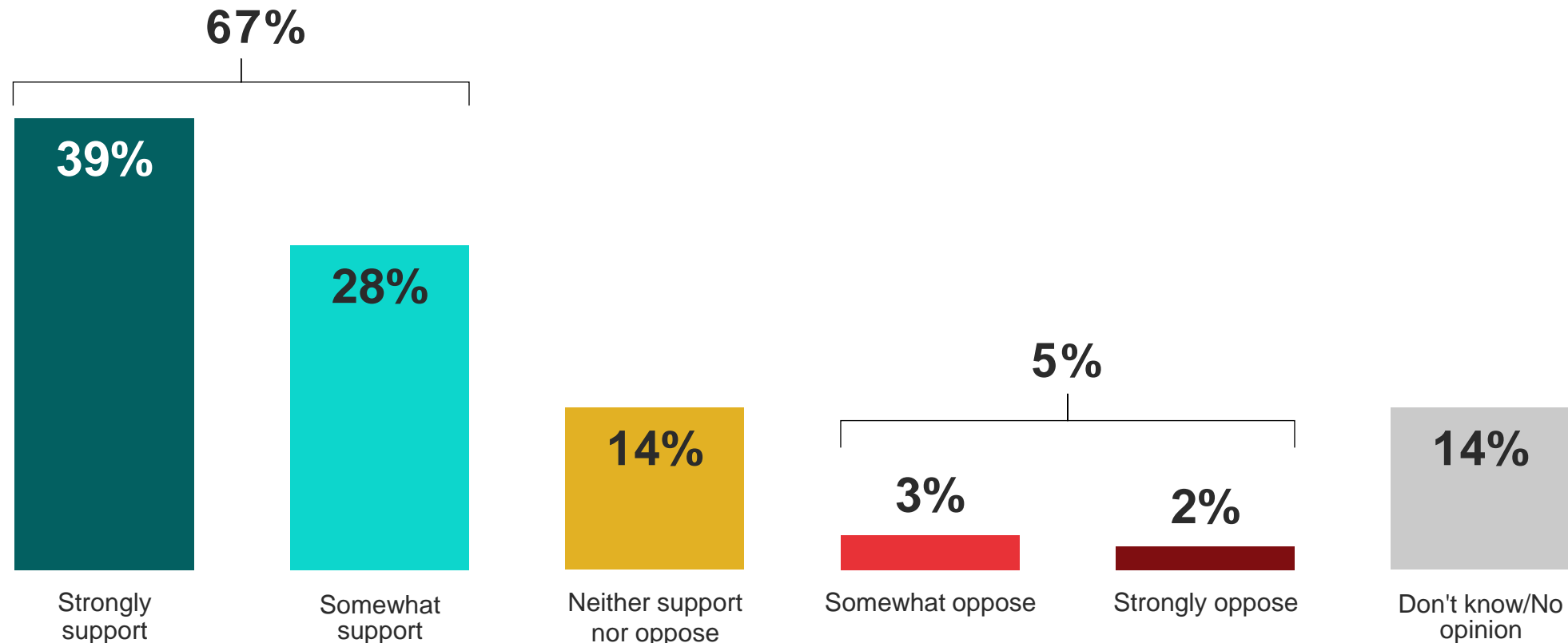
Voters across the political spectrum support their representatives voting in favor of the ORPHAN Cures Act.

Members of Congress from both parties recently introduced a bill, known as the ORPHAN Cures Act, that would reduce barriers to researching whether existing rare disease drugs can be effective in treating other conditions.

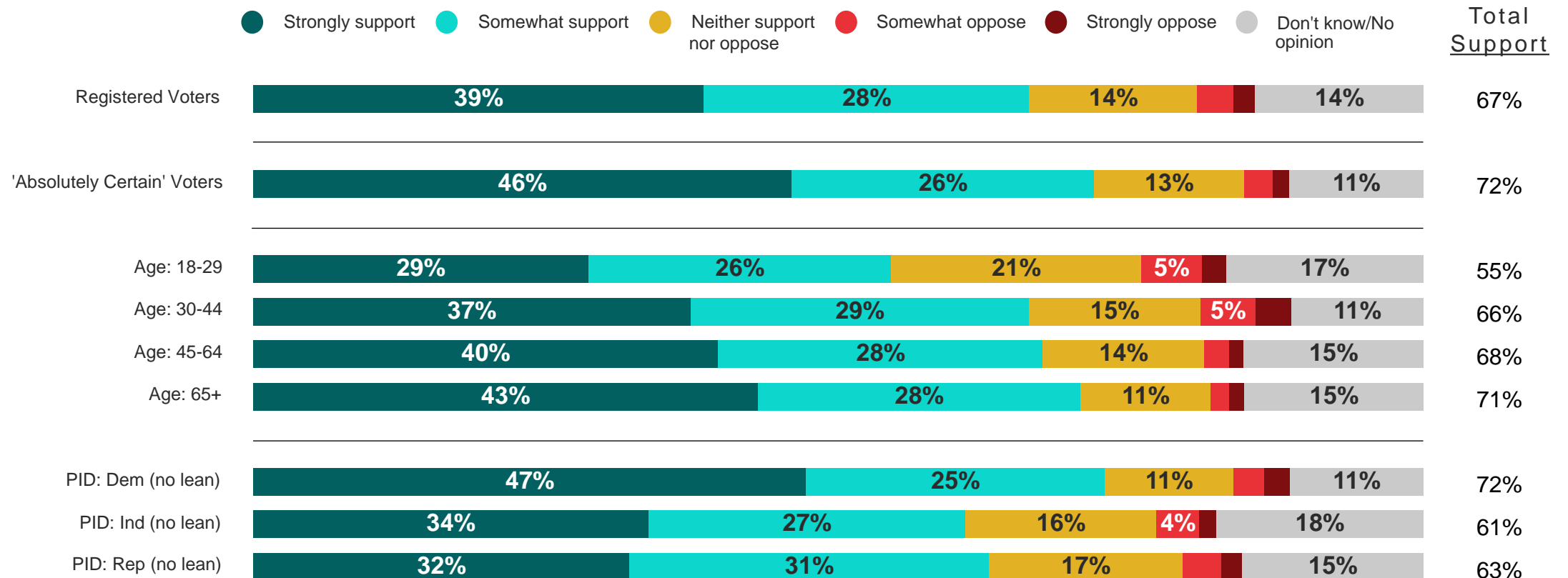Do you support or oppose your representative in the U.S. Congress voting in favor of the ORPHAN Cures Act?

● Strongly support ● Somewhat support ● Neither support nor oppose ● Somewhat oppose ● Strongly oppose ● Don't know/No opinion

	Strongly support	Somewhat support	Neither support nor oppose	Somewhat oppose	Strongly oppose	Don't know/No opinion	Total Support
Registered Voters	39%	28%	14%			14%	67%
'Absolutely Certain' Voters	46%	26%	13%			11%	72%
Age: 18-29	29%	26%	21%	5%		17%	55%
Age: 30-44	37%	29%	15%	5%		11%	66%
Age: 45-64	40%	28%	14%			15%	68%
Age: 65+	43%	28%	11%			15%	71%
PID: Dem (no lean)	47%	25%	11%			11%	72%
PID: Ind (no lean)	34%	27%	16%	4%		18%	61%
PID: Rep (no lean)	32%	31%	17%			15%	63%

Total Support = % *Strongly support* + % *Somewhat support*

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Congressional representatives stand to **gain considerable support** from voters by speaking out in favor of the ORPHAN Cures Act.

If your current representative in the U.S. Congress voiced support for the ORPHAN Cures Act, how (if at all) might that affect your likelihood of voting for them in the next election?

50%

43%

28%

22%

7%

4%

3%

Much more likely to vote for them

Slightly more likely to vote for them

Would not affect likelihood

Slightly less likely to vote for them
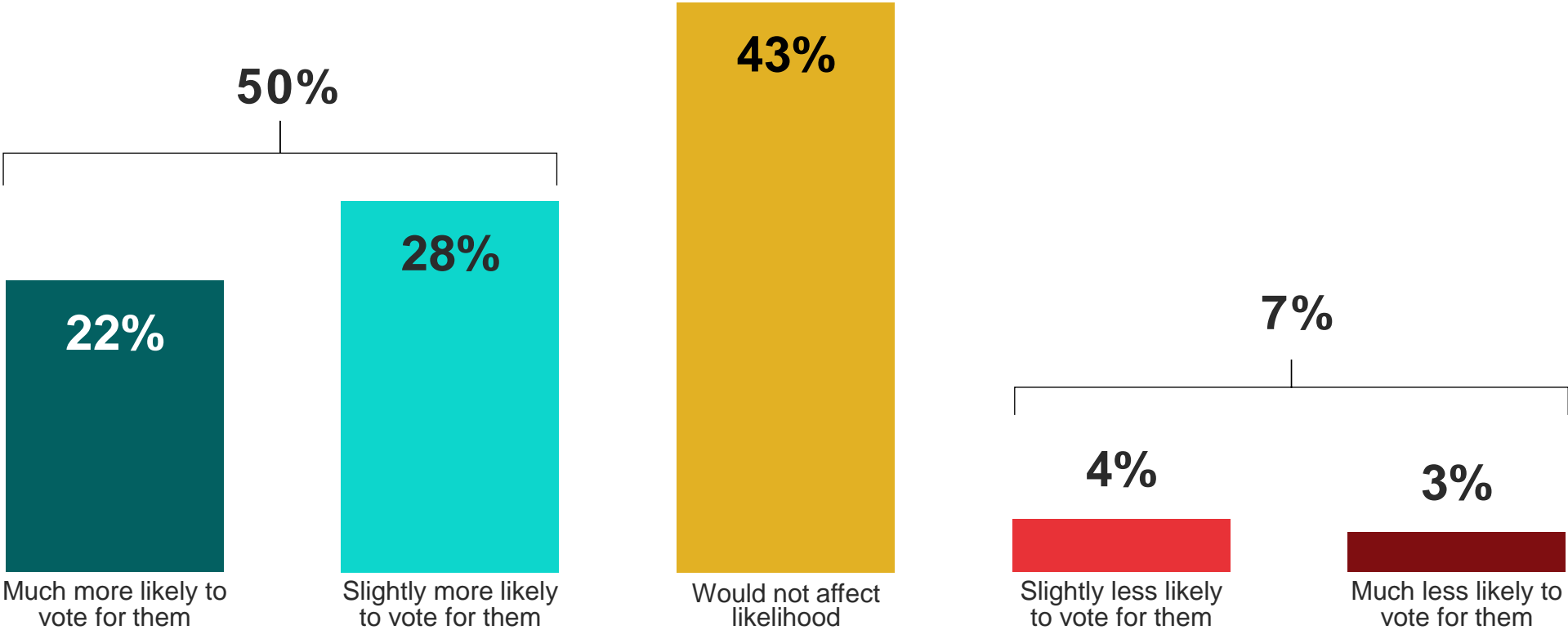
Much less likely to vote for them

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Impact on candidate support is very positive regardless of voters' age or party affiliation. One-fourth of certain 2024 voters are *much more likely* to vote for an incumbent who voices support for the ORPHAN Cures Act.
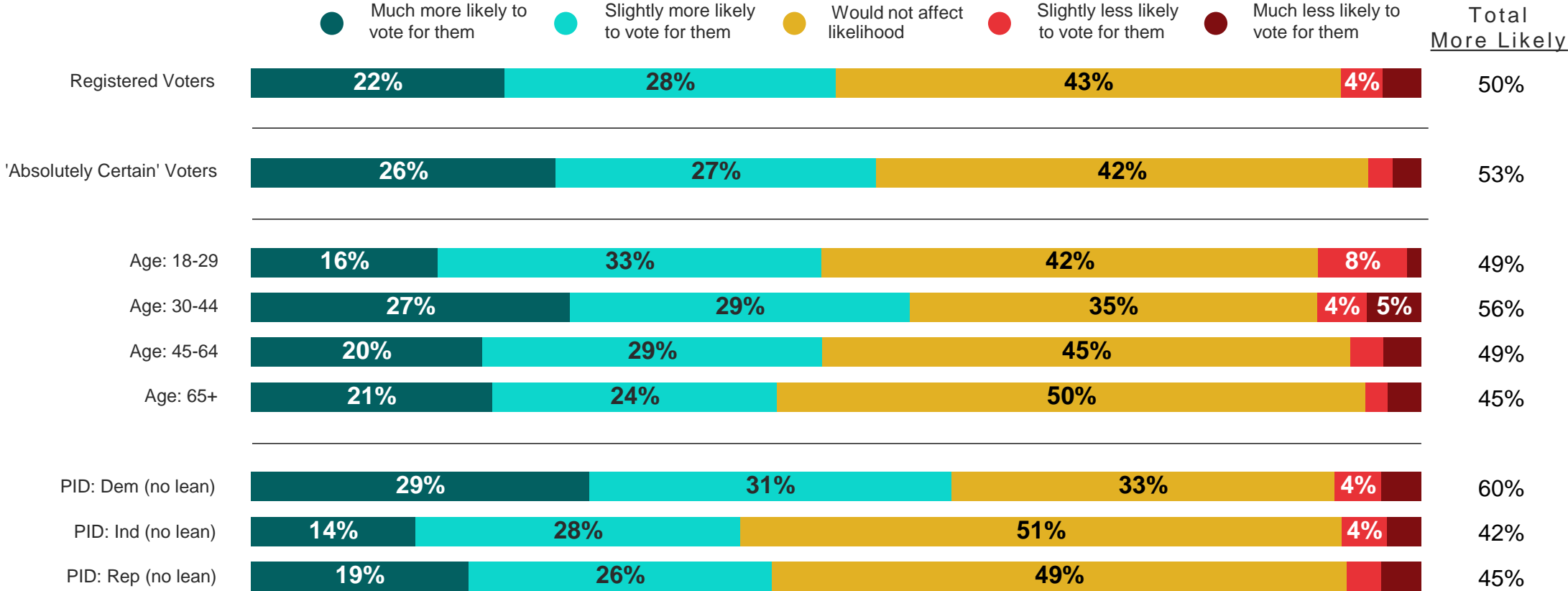
If your current representative in the U.S. Congress voiced support for the ORPHAN Cures Act, how (if at all) might that affect your likelihood of voting for them in the next election?

- ● Much more likely to vote for them
- ● Slightly more likely to vote for them
- ● Would not affect likelihood
- ● Slightly less likely to vote for them
- ● Much less likely to vote for them

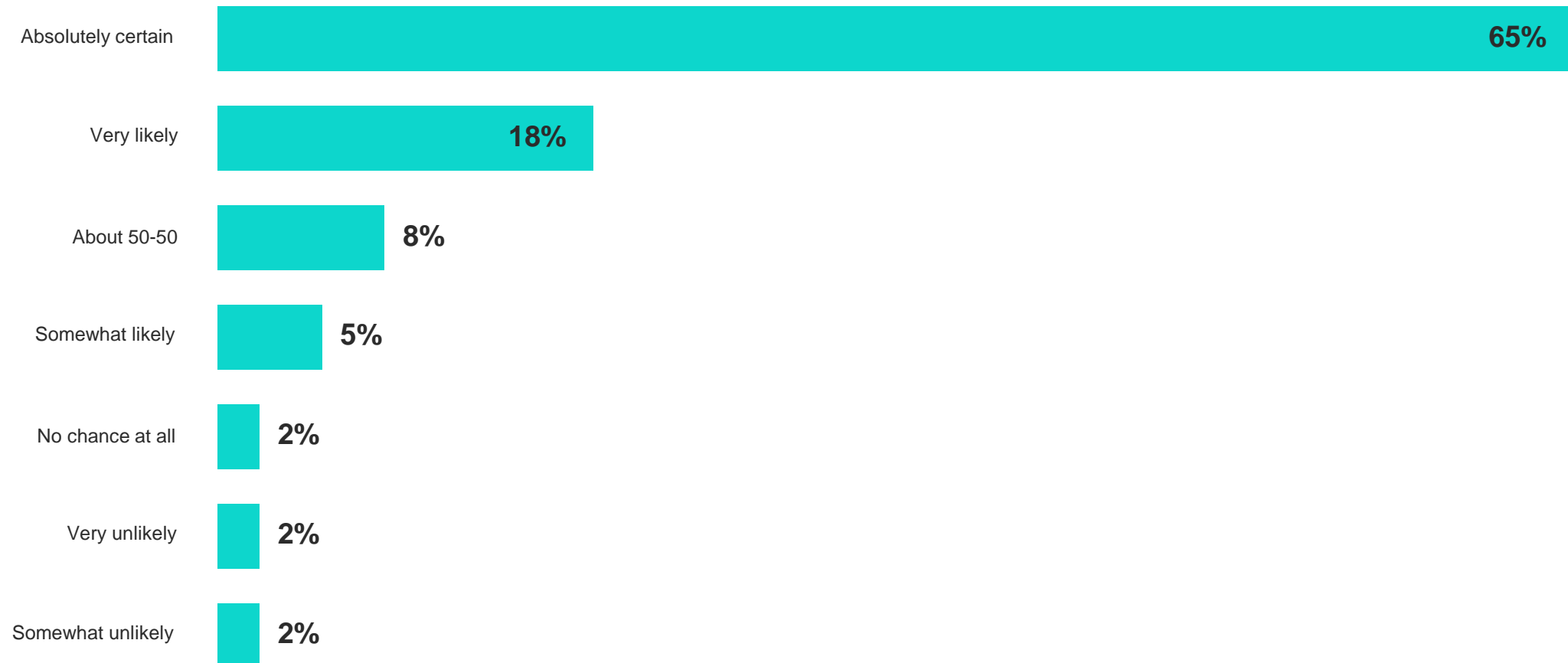|	Much more likely	Slightly more likely	Would not affect	Slightly less likely	Much less likely	Total More Likely
Registered Voters	22%	28%	43%	4%		50%
'Absolutely Certain' Voters	26%	27%	42%			53%
Age: 18-29	16%	33%	42%	8%		49%
Age: 30-44	27%	29%	35%	4%	5%	56%
Age: 45-64	20%	29%	45%			49%
Age: 65+	21%	24%	50%			45%
PID: Dem (no lean)	29%	31%	33%	4%		60%
PID: Ind (no lean)	14%	28%	51%	4%		42%
PID: Rep (no lean)	19%	26%	49%			45%

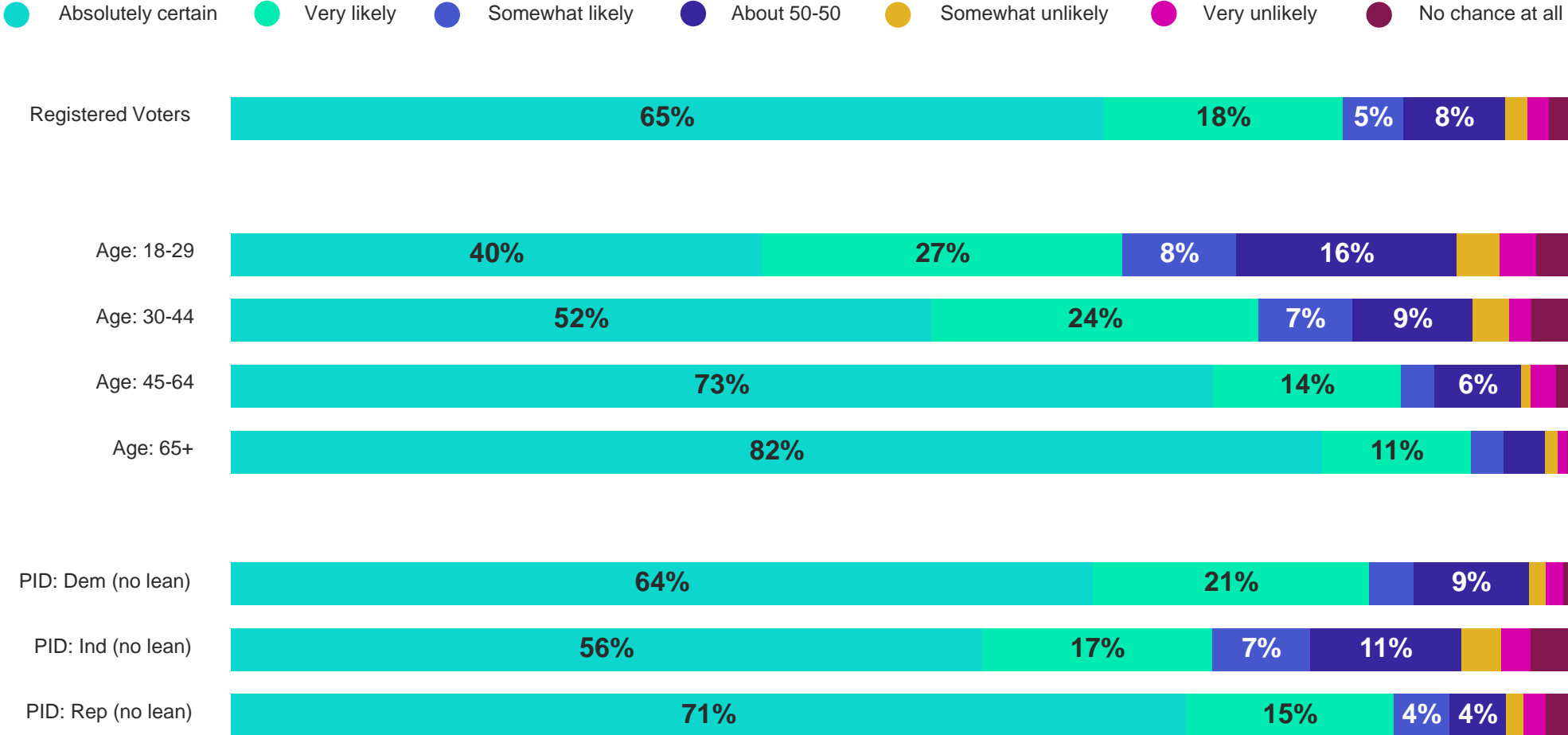Total More Likely = % *Much more likely* + % *Slightly more likely*

APPENDIX: 2024 VOTE LIKELIHOOD

How likely, if at all, are YOU to vote in the November 2024 general election? *This is when new leaders will be elected to federal and state government positions next year, including the Presidency.*

Absolutely certain	65%
Very likely	18%
About 50-50	8%
Somewhat likely	5%
No chance at all	2%
Very unlikely	2%
Somewhat unlikely	2%

15

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How likely, if at all, are YOU to vote in the November 2024 general election? *This is when new leaders will be elected to federal and state government positions next year, including the Presidency.*

● Absolutely certain   ● Very likely   ● Somewhat likely   ● About 50-50   ● Somewhat unlikely   ● Very unlikely   ● No chance at all

Registered Voters — 65% | 18% | 5% | 8%

Age: 18-29 — 40% | 27% | 8% | 16%

Age: 30-44 — 52% | 24% | 7% | 9%

Age: 45-64 — 73% | 14% | 6%

Age: 65+ — 82% | 11%

PID: Dem (no lean) — 64% | 21% | 9%

PID: Ind (no lean) — 56% | 17% | 7% | 11%

PID: Rep (no lean) — 71% | 15% | 4% | 4%

16

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