

# Do you Agree to Participate? Evaluating Informed Consent Materials for the National Longitudinal Survey of Youth

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Bureau of Labor Statistics

FCSM Conference

October 22, 2024

# National Longitudinal Survey of Youth (NLSY)

- The NLSY is a longitudinal study that follows American youth over time to collect data on employment, education, health, family life, and other topics
- Interviewer-administered, in respondent's home
- Respondents are interviewed every 1-2 years
  - ▶ NLSY79: Born between 1957-1964
  - ▶ NLSY97: Born between 1980-1984
  - ▶ NLSY27: Born between 2011-2016
    - **New Cohort**
    - **Opportunity to redesign materials, including informed consent documents**

# Informed Consent in NLSY

1. Parent/Guardian consent form for youth to participate

2. Youth assent form

3. Consent for Separate Parent/Caregiver Survey



# Components of Informed Consent with Youth Respondents

Study purpose and procedures

Study duration and length

Risks/benefits

Protection of children's privacy and confidentiality

Compensation/incentives

Statement that participation is voluntary

Who to contact with questions

From: Health and Human Services 45 CFR 46:116 General requirements of informed consent  
(<https://www.hhs.gov/ohrp/regulations-and-policy/guidance/checklists/>).

# Research on Informed Consent

- Potential respondents tend NOT to:
  - ▶ Closely read informed consent documents
  - ▶ Lack comprehension of the content of the forms
  - ▶ Do not retain the content of the forms well
  
- These issues can be even more pronounced with youth respondents



O'Lonergan et al. (2011)



# Research on Informed Consent

- Lack of comprehension for consent materials with youth can:
  - ▶ Result in noncompliance with study
  - ▶ Decrease future participation
  - ▶ Result in regret of study respondent
- Crucial to ensure these materials are clear and easy to understand for both parents/guardians and youth

Antal et al. (2017)



# Research Questions

- **Goal: Obtain feedback on draft informed consent materials for the NLSY27 new cohort**
- **Mental models: ideas, beliefs, and expectations for how a process works**
  - ▶ What do parents/guardians expect to see in a consent form asking their children to participate in a federal survey?
- **Comprehension: Do youth and parents/guardians understand the information in the assent and consent forms?**
  - ▶ Do younger youth (11-14) understand the assent form differently than older youth (15-17)?
- **Willingness to participate: Do youth and parents/guardians think they would be willing to participate in the NLSY?**



# Study Overview

| Round | Data collection type | Sample size | Participant group                               |
|-------|----------------------|-------------|---|
| 1     | Web survey           | 395         | Parents/guardians of children aged 11-17        |
| 2     | Moderated interviews | 10 families | Parents/guardians and their children aged 11-17 |



# Web Survey Design ~15 min.

## Mental Models- Before reading consent form:

- Top 3 things you'd want to know about the survey
- How would you expect the consent process to be administered

Read Consent  
Form  
(~3 pages)

## After reading consent form:

- Comprehension
- Willingness to participate
- Differences based on age group

# Parental Consent Form Sections

- What is the NLSY27?
- Why is my child in the NLSY27?
- What will happen in the NLSY27?
- Does my child have to be in the NLSY27?
- Will my child be paid for participating in the NLSY27?
- Who will see the information my child provides?
- How will my child's information be used?
- What if I have questions?



# Round 1 Participants

- N=395 recruited from a non-probability web panel
- Had to live in the U.S. and have children aged 11-17
- Mean age of parent/guardian = 42.5 years old



# Demographics (N=395)

| Gender  | Percentage |
|---|------------|
| Female  | 65.1%      |
| Male  | 34.7%      |
| Transgender, non-binary, or another gender identity | 0.3%       |

| Education                        | Percentage |
|----------------------------------|------------|
| Less than a high school diploma  | 0.5%       |
| High school graduate, no college | 14.4%      |
| Some college or associate degree | 36.5%      |
| Bachelor's degree or higher      | 48.6%      |



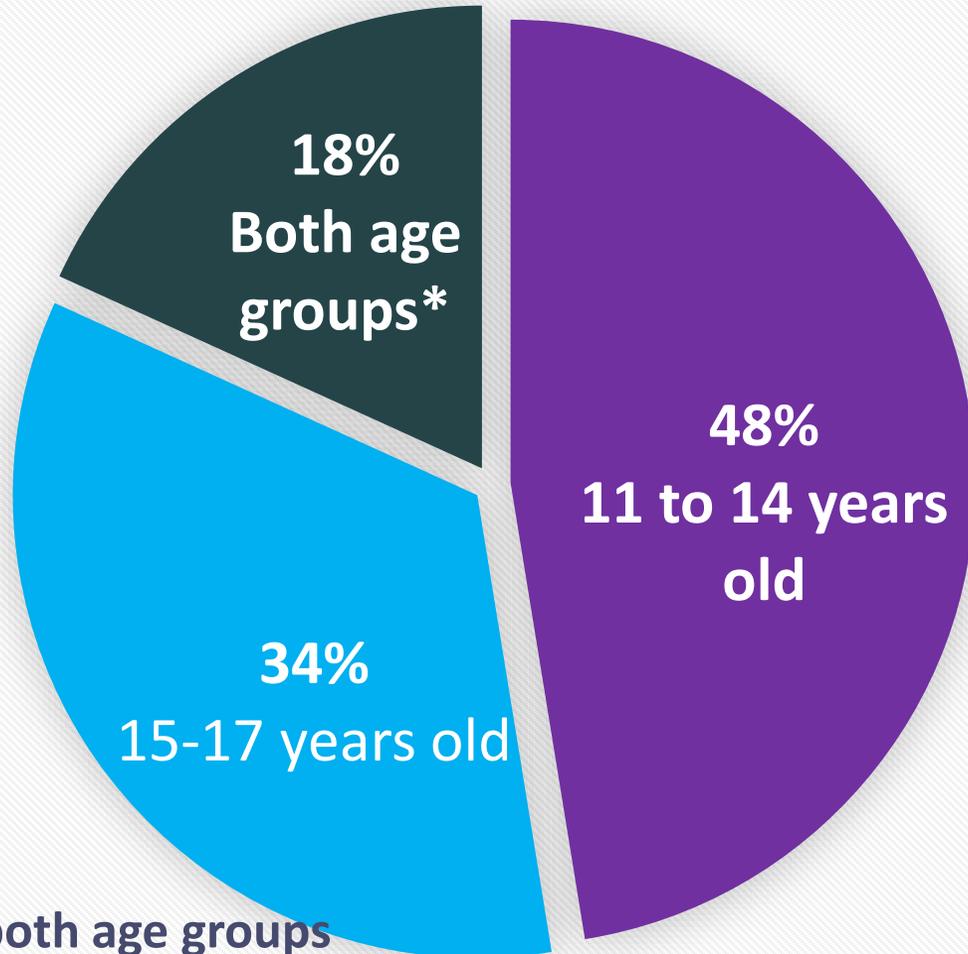
# U.S. Region (N=395)

| Region    | Percentage |
|-----------|------------|
| Midwest   | 23.2%      |
| Northeast | 26.0%      |
| South     | 24.4%      |
| West      | 26.5%      |
| Total     | 100%       |



# Age of Youth

Percent of participants (N=395) who reported having children in each age group



\*Asked questions about both age groups

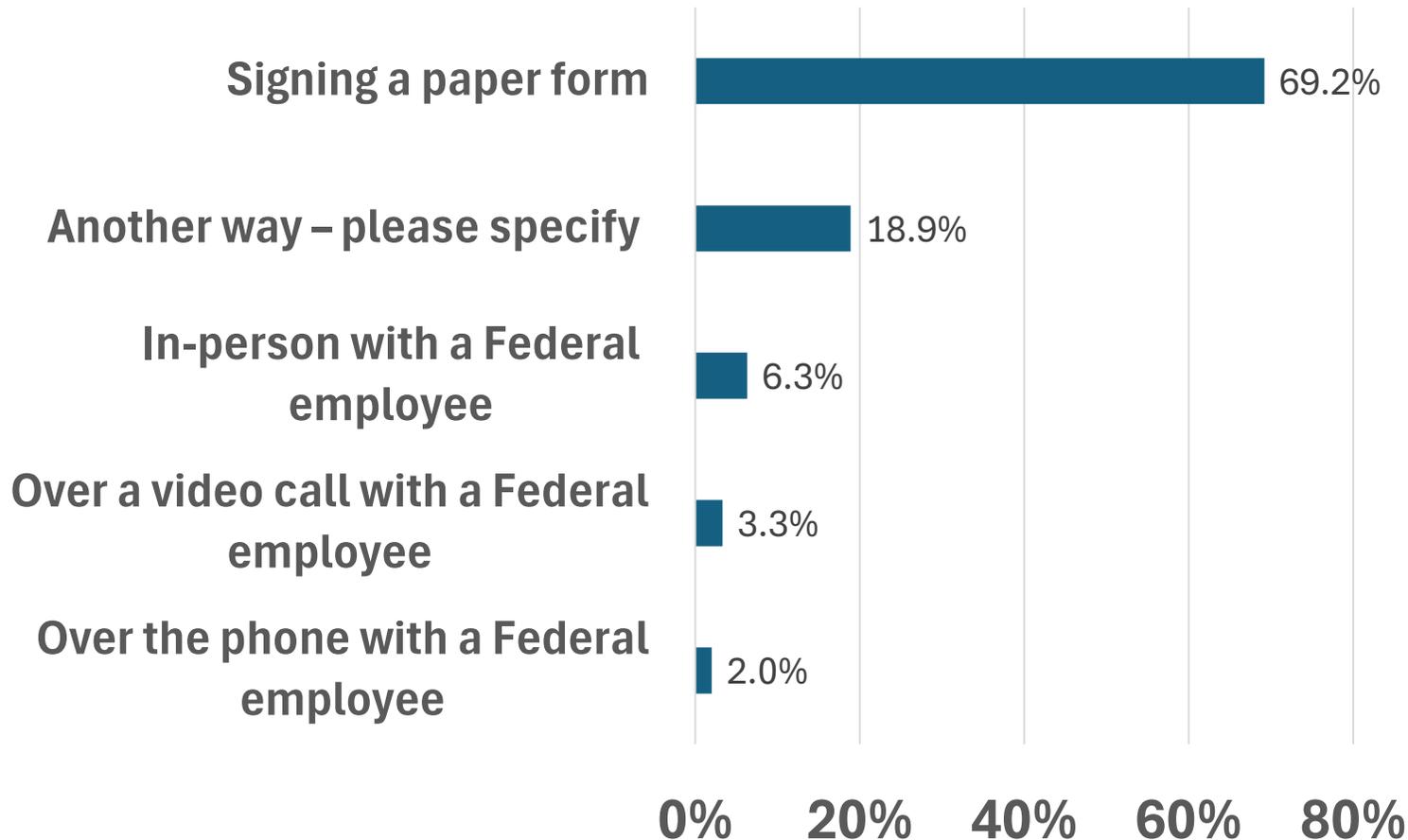
# Results: Mental Models

## What are the top THREE topics you would want to see addressed in the consent process?\*

| Top 3 Consent Topics   | Count       | Percentage  |
|--|-------------|-------------|
| Confidentiality of the survey data                           | 233         | 19.7%       |
| How the survey data will be used                             | 191         | 16.2%       |
| The content of the survey                                    | 160         | 13.6%       |
| Purpose of the survey  | 145         | 12.3%       |
| What your child will receive for participating in the survey | 101         | 8.6%        |
| The possible risks or discomforts of the survey              | 84          | 7.1%        |
| Whether your child can withdraw from the survey              | 78          | 6.6%        |
| Who to contact if you have questions about the survey        | 57          | 4.8%        |
| Why your child was asked to participate                      | 55          | 4.7%        |
| Length of the survey   | 30          | 2.5%        |
| Whether or not the survey is voluntary                       | 26          | 2.2%        |
| Whether your child can skip any survey questions             | 20          | 1.7%        |
| <b>Total</b>   | <b>1180</b> | <b>100%</b> |

# Results – Consent Mode

How would you expect to receive the information on the consent form? (N=395)



## Other Responses:

- Email
- Docusign
- E-sign
- Online form
- PDF file form
- Through a secure online platform (verified government)

# Results – Comprehension

- Median time spent reading form = **90.1 seconds**
  
- How many minutes does the NLSY27 survey take to complete?
  - ▶ **60 to 90 minutes = 72.9%**
    - Other responses ranged from 1 to 120 minutes
  
- Would the survey be one time or multiple times?
  - ▶ **Multiple times = 53.2%**
  - ▶ One time = 40.5%
  - ▶ Not sure = 6.3%
  
- Would your child be able to withdraw from the NLSY27 survey anytime?
  - ▶ **Yes = 97.2%**
  - ▶ No = 0.0%
  - ▶ Not sure = 2.8%

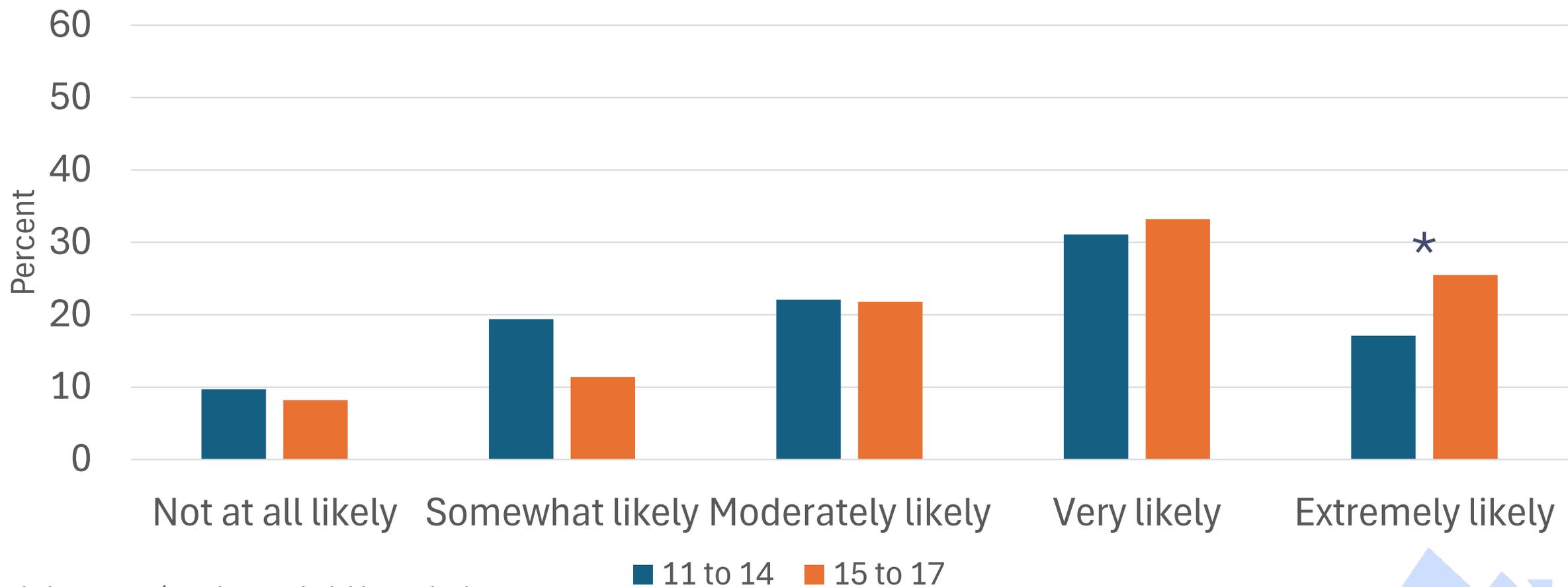


# Results – Comprehension

- Would your child be able to skip any questions they do not want to answer?
  - ▶ Yes = **83.0%**
  - ▶ No = 3.8%
  - ▶ Not sure = 12.7%
  
- Would your child be paid for participating in the NLSY27 survey?
  - ▶ Yes = **96.2%**
  - ▶ No = 1.0%
  - ▶ Not sure = 2.8%

# Results - Participation

How likely would you be to allow your child (or children) to participate in the NLSY27 survey? (N=395)

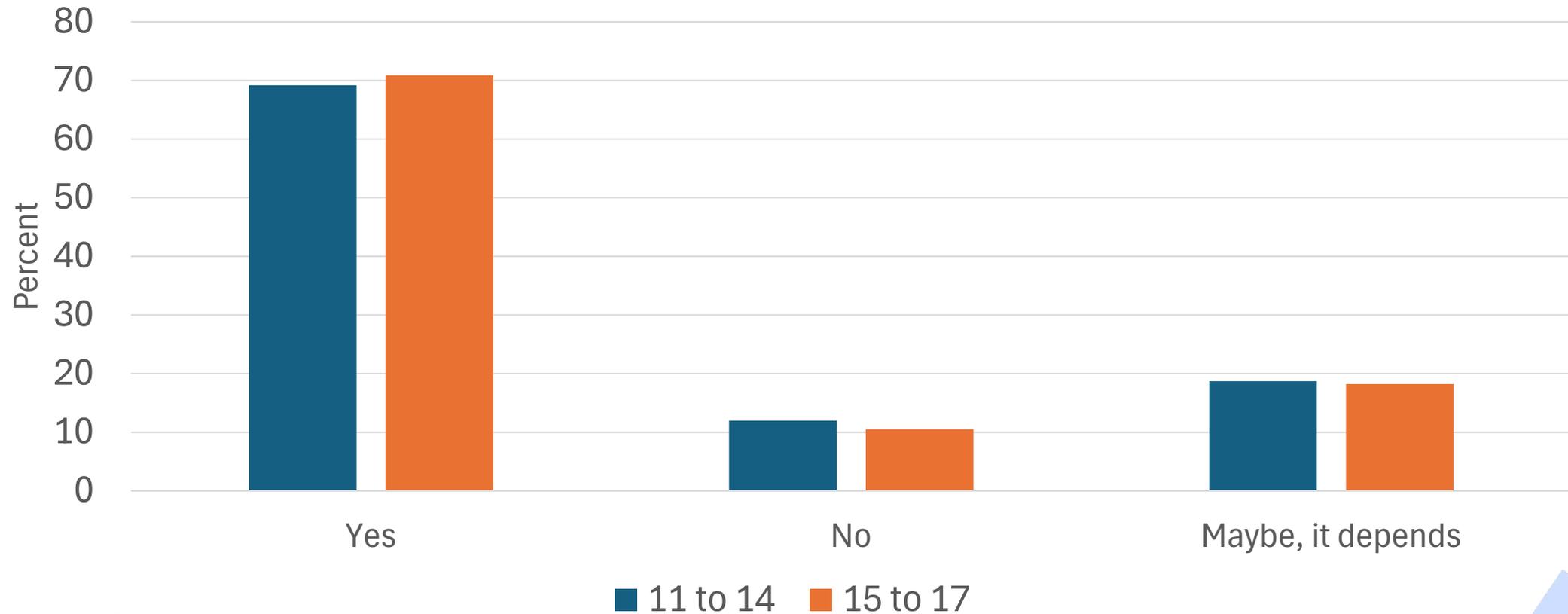


\*Includes parents/guardians with children in both age groups



# Results - Participation

Do you think your child (or children) would participate in the NLSY27 survey? (N=395)



\*Includes parents/guardians with children in both age groups



# Round 2: Moderated interviews

- **Methods:**

- Recruited parents or guardians/child participants (N=10) of younger (11-14) and older (15-17) children
- Participated in 60-minute remote cognitive interviews to get feedback on the parental consent form and youth assent form
  - 30 minutes with parent/guardian
  - 20 minutes with child
- Participants read the form(s) and answered debriefing questions:
  - Highlighted in **blue** what was helpful or important
  - Highlighted in **orange** what was confusing or unclear



# Youth – Helpful/Important

## ■ Purpose of the survey

- ▶ How technology or social media affect their lives
- ▶ How kids or teenagers see the world
- ▶ How different views are shared

## ■ Youth permission

- ▶ “Asking us if we want to participate. I think that was very important.”
- ▶ “It stands out for me trying to make it optional and not trying to force it on you.”

## ■ Skipping questions and stopping the interview

- ▶ “You have the right to answer or not answer. You have the right to give out your personal information or not.”
- ▶ “It really made me a little bit relieved because sometimes I can get a little emotional.”

## ■ Helps researchers and lawmakers understand youth

## ■ We saw similar findings regardless of younger vs. older youth

# Youth – Unclear/Confusing

## ■ Location and modality of interview/survey

- ▶ Where is the survey taking place?
- ▶ Is it going to be in person or online?
- ▶ Is it like an online quiz?
- ▶ “So this is like done virtually, right? Because it asks like puzzles and tasks, and I was like how would you do that virtually?”
- ▶ “I prefer online.”

## ■ How long the survey would be

- ▶ “How long will we be doing the survey? Forever?”

## ■ We saw similar findings regardless of younger vs. older youth

# Conclusions and Takeaways

- Parent/guardian consent forms should emphasize:
  1. Confidentiality
  2. How the survey data will be used
  3. The content of the survey
- Alternative methods of consent (e.g., electronic modes, videos) should be explored
- Parents/guardians had more concerns about their 11-14 year olds participating than 15-17 year olds, but they rated both groups as equally likely to participate
- Forms should clearly outline the duration, length, and mode of the survey



# Next Steps – Iterative Testing

| Round | Data collection type | Sample size | Participant group                      |
|-------|----------------------|-------------|--|
| 3     | Intercept testing    | 40          | Children 11-14 (n=20) and 15-17 (n=20) |
| 4     | Web survey           | 400         | Parents/guardians of children 11-17    |



# Contact Information

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## ***What is the NLSY27?***

The NLSY27 is a federal survey to learn how youth aged 11-17 experience work and the labor market throughout their lives. BLS has been conducting surveys like the NLSY for over 50 years. The last time a NLSY survey was started was 1997, and the teens that started in that survey are now in their 40s. The NLSY27 helps many people, including researchers and lawmakers, understand how your child's experiences at home, school, and work impact their life as they age.

Your child's involvement is vital to advancing our understanding of the labor market experiences of youth as they transition from school to work. The NLSY27 will provide valuable information about the educational, economic, and social progress of people in the United States from your child's generation over time.

## ***Why is my child in the NLSY27?***

Your child was randomly selected along with 17,000 young people across the country. Your child's participation is very important and will help ensure the study results represent the experiences of all youth in the United States.



# Web Results – 11-14 years (Open-ends)

## Reasons unlikely to allow child to participate

- Unsure how data would be used or the survey topics
- Not worth the time/burden
- Protective over children
- Privacy/confidentiality concerns
- Child might feel uncomfortable
- Do not want to do in-person survey, don't want interviewer in home

## Reasons child would or would not want to participate

- Want to participate:
  - Incentive (money)
- Would not want to participate:
  - Privacy concerns
  - What mood they're in that day, shy, anxious, etc.
  - Would depend on how easy or difficult the questions are, or how long it takes to complete the survey

# Web Results – 15-17 years (Open-ends)

## Reasons unlikely to allow child to participate

- Want more information on survey, topics, and sensitivity of questions
- Time/burden
- Don't see purpose of collecting data from children in general
- Would let child decide, prefer to wait until they're 18 and can decide
- Privacy/confidentiality concerns

## Reasons child would or would not want to participate

- Would not want to participate:
  - Mood, anxiety issues
  - Privacy concerns
  - Would have to ask the child

# Time spent reading consent form on web survey – Median Split

- Participants who spent above the median time reading the consent form differed from those who spent less than the median time reading the form on the following:

|                                 | <b>Below median (n=198)</b> | <b>Above median (n=197)</b> |
|---------------------------------|-----------------------------|-----------------------------|
| Minutes to complete NLSY27      | M=59.3, range 1-120         | M=76.3, range 0-120         |
| Child receive payment           | Y=185, N=2; Not sure = 11   | Y=195; N=2, Not sure = 0    |
| How much \$ child would receive | M=49.9                      | M=55.9                      |
| Parent receive payment          | Y=58; N= 93; Not sure = 47  | Y=96; N=63; Not sure = 36   |

# Participants in Moderated Interviews

- Parents (N = 10) – 8 females, 2 males
- Youth (N = 13)
  - ▶ 11-14 years (n = 6) – 3 females, 3 males
  - ▶ 15-17 years (n = 7) – 3 females, 4 males
- 3 families had more than one youth who participated in interviews

# Parents/Guardian – Helpful/Important

- How data are kept confidential
- Voluntary survey
- Long-running survey conducted for more than 50 years
  - ▶ Has a long history, not being done for the first time
- Importance of participation
  - ▶ “They are saying your involvement is important.”
  - ▶ “Knowing I’m being heard, knowing my child is being heard, is important to me.”
  - ▶ “Your child’s involvement is vital. I think that was the main point.”

# Parents/Guardians – Unclear/Confusing

## ■ Duration and Longevity

- ▶ Is this an ongoing study? Is it just one time?
- ▶ How many surveys will there be?
- ▶ Do they have to take this survey throughout their life?
- ▶ How long is the commitment? How much time will it take?

## ■ Location and modality of interview/survey

- ▶ Does the survey take place at their home?
- ▶ Can the survey be done somewhere other than their home (e.g., a library)?
- ▶ Is it virtual or in person?
- ▶ Is it on paper or online?
- ▶ Is it an interview or a survey? Is it both?