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The DS-AD Connection: Clinical Trial Awareness and Participation

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perspective
shifting
insights

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PART **1**

Method

Current clinical trials to prevent DS-AD represent a critically relevant opportunity for the Down syndrome community; however, participation in these studies has been limited, leading trials to be discontinued.

To better understand what is driving low participation—and **how engagement can be strengthened before this opportunity window closes**—the National Down Syndrome Society partnered with Conifer Research to conduct a mixed-method study.

Project Goals

Learn about **decision-makers' roles in healthcare decisions** for their loved ones with Down syndrome, including how they balance their loved one's autonomy with safety and navigate shared decision-making.

Understand awareness of and attitudes toward **clinical trial participation**, including prior experiences, decision-making processes, sources of influence, and factors that build or erode trust in clinical research.

Explore baseline **awareness of the DS-AD connection**, how families approach future planning, communication around DS-AD, and emotional and practical considerations shaping their responses to the DS-AD risk.

Identify specific **barriers preventing participation** in DS-AD clinical trials. In addition, identify **opportunities to improve clinical trial participation**, and how trial design elements facilitate or impede engagement.

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Research Methodology

QUALITATIVE METHODS

In-depth Remote Interviews

- **15-20-minute introductory meet-and-greet calls** to establish rapport and gain a better understanding the relationship between the decision-makers' and their loved ones
- **90-minute remote video interviews** exploring decision-maker roles, DS-AD awareness and planning approaches, research participation attitudes and experiences, review of example clinical trial fliers, and barriers and motivations to DS-AD clinical trial participation
- **N = 18**
  - 9 respondents from NDSS network outreach
  - 9 respondents from specialized recruiting panel
  - **Recruitment criteria:** Primary or shared decision-makers of a person with Down syndrome who is at least 20 years old; sample included participants with varying levels of clinical trial experience, **including four who had declined to participate or had withdrawn from trials**
  - *Note: For ethical reasons, only decision-makers who already had awareness of DS-AD were invited to participate in interviews.*

QUANTITATIVE METHODS

NDSS DS-AD Survey 2025

- **15-minute online survey** covering awareness of the connection between Down syndrome and Alzheimer's disease, awareness and access to resources relating to the connection between Down syndrome and Alzheimer's disease, and the barriers to participation in clinical trials
- **N = 200***
  - 51 respondents from online survey panels
  - 33 respondents from social media outreach on Facebook groups (including DS-AD support groups)
  - 116 respondents from NDSS Email outreach campaign
  - **Recruitment criteria:** Primary or shared decision-makers of a person with Down syndrome who is at least 20 years old

*n=26 of the respondents' loved ones **currently have DS-AD diagnoses** —they were excluded from analyses about awareness where appropriate.

Quantitative

Designed to assess awareness, attitudes, and barriers at scale

How participants were recruited

For our **quantitative survey sample**, we specifically wanted to **not only reach decision-makers connected to NDSS and other advocacy organizations**, but also reach the **general population**, as we hypothesized that those connected to NDSS would likely be **more informed and engaged** than those who are not.

Intentional, Multi-Source Recruitment

To do this, we used three recruiting streams in tandem:

- **NDSS network outreach** via the general newsletter
- **Independent survey panels** that specialize in recruiting participants across a broad range of medical conditions
- **Facebook support groups** for parents of people with Down syndrome and Alzheimer's disease (e.g., "Aging with Down Syndrome" group)

Designed to Avoid Advocacy Bias

By intentionally recruiting across these sources the quantitative sample was designed to:

- Capture **variation in awareness, trust, and information access**
- Surface **patterns and contrasts** across different types of decision-makers
- Better understand the **challenges and barriers families face** when it comes to clinical trial participation
- **Avoid over-representing** the most informed or advocacy-engaged voices

Quantitative Survey

KEY DEMOGRAPHICS

200 Respondents

Respondent

Age	33% are less than 60 YO 40% are 60-69 YO 28% are 70+ YO	**Relationship**	75% Parents (biological, adoptive, foster, or step) 21% Sibling or Sibling in-law 4% Other relative or friend 1% Self — I am the person with Down syndrome
Gender	**88%** women **12%** men	**Decision-making Role**	**63%** primary decision-maker **37%** shared decision-maker
Employment Status	29% Full-time employee 17% Part time employee 3% Self-employed 9% Stay at home parent 44% Retired 7% Unemployed/Not working/Disabled		
HH Income	49% Less than $100,000 26% $100,000 - $199,999 14% $200,000+ 12% Preferred not to answer		

Person with Down syndrome

Age	44% are 20-35 YO 37% are 36-50 YO 20% are 51+YO	**Region**	27% Northeast 25% Midwest 24% South 23% West
Gender	49% Male 50% Female 1% Non-binary	**Urbanicity**	17% Urban 62% Suburban 22% Rural
Race/Ethnicity	90% White or Caucasian 6% Hispanic or Latino 4% Asian 4% Black or African-American 2% American Indian 2% Other 2% Prefer not to say	**DS-AD Status**	13% Diagnosed with DS-AD 87% Not Diagnosed with DS-AD
Living Situation	65% Lives with one or both parents 14% Lives in group home, supported apartment, or long-term care facility 8% Lives with adult sibling 6% Lives alone or with a roommate 3% Lives with other family 1% Lives with spouse or partner 4% Other		

Qualitative

Designed to understand how decisions about DS-AD clinical trials are made

How participants were recruited

Participants were intentionally selected to help us understand how decision-makers think through DS-AD risk and clinical trial participation—including concerns, trade-offs, and decision-making dynamics. **This qualitative sample was designed for detail, depth, and perspective, not statistical representation**.

Intentional, Information-Rich Recruitment

Pre-interview calls ensured participants were comfortable sharing nuanced experiences and perspectives. **The sample was designed to capture maximum variation within:**

- Decision-maker **roles** (parents, siblings, paid caregivers)
- Research and clinical trial **experience** (none → prior participation)
- **Family and environmental contexts** (Family structures, caregiving demands, and geographic contexts)
- **Demographic** diversity (age, race/ethnicity, and household income)
- **Levels of awareness** of the DS-AD connection

Comparative Insights

By intentionally including **both NDSS-connected families and independently recruited participants**—based on the hypothesis that these groups might differ in awareness and engagement—this study surfaced **patterns and contrasts** in how awareness, trust, and engagement with research develop over time.

Note: For ethical reasons, only decision-makers who already had an awareness of DS-AD were invited to participate in interviews.

In addition, all participant names in this report have been changed to protect their privacy.

Qualitative

KEY DEMOGRAPHICS

18 Decision-makers

Decision-maker

Age	**1** Under 34 years old **5** 45-59 years old **12** Over 60 years old	**Relationship**	12 Parent (biological, adoptive, or step) 5 Sibling or sibling in-law 1 Paid caregiver 1 Self — I am the person with Down syndrome*
Gender	**17** Female **1** Male	**Decision-making Role**	**15** primary **3** shared
Education	1 High school graduate or GED 1 Some college, no degree 1 Associate's degree 7 Bachelor's degree 8 Graduate or professional degree	**Familiarity of Alzheimer's disease and Down syndrome connection**	**0** Unaware of connection **2** Not very familiar **9** Somewhat familiar **7** Very familiar
HH Income	4 $25,000 - $49,000 5 $50,000 - $74,000 1 $75,000 - $99,000 4 $100,000 - $149,000 2 Over $150,000 2 Preferred not to answer	**Likelihood to participate in a future study focused on DS-AD**	**8** Very likely **5** Somewhat likely **2** Somewhat unlikely **0** Very **3** Not sure/would need more information

Person with Down syndrome

Age	7 20-34 years old **6** 35-55 years old **5** Over 55 years old	**Region**	27% Northeast 25% Midwest 24% South 23% West
Gender	7 Female 11 Male	**Urbanicity**	3 Urban 13 Suburban 2 Rural
Race/Ethnicity	10 White or Caucasian 3 Hispanic or Latino 2 Asian 2 Black or African-American 1 Middle Eastern or North African	**Prior experience with research participation**	8 Yes 10 No
Living Situation	7 Live with one or both parents 4 Live with adult sibling 2 Live in a supported apartment 3 Live in a group home 2 Live independently without any support (either alone or with a roommate or spouse)		

*The self-represented decision-maker did a joint interview with their parent

PART **2**

Key Findings

Most of the **decision-makers in this sample are familiar with the connection** between Alzheimer's disease and Down syndrome.

80%

are "Somewhat" or "Very Familiar" with the connection

20%

are "Not Very" or "Not at all Familiar" with the connection

**Source: Survey Question "How familiar are you with the connection between Down syndrome and Alzheimer's disease?" (n=200)*

When we exclude the n=26 decision-makers in the sample with loved ones who have a diagnosis of DS-AD, the familiarity drops slightly from 80% to 76% being "somewhat" or "very familiar."

**Source: Survey Question "How familiar are you with the connection between Down syndrome and Alzheimer's disease?" (n=174), excluding DMs for loved ones with DS-AD diagnosis*

Decision-makers familiar with the DS-AD connection are:

- **More likely to be from the NDSS email campaign than survey panels**

  84% Very/Somewhat Familiar from NDSS email campaign

  Compared to

  57% Very/Somewhat Familiar from survey panels

- **More likely to subscribe to newsletters**

  81% who are Somewhat / Very Familiar with the connection subscribe to at least 1 newsletter about Down Syndrome

  Compared to

  41% who are Not Very / Not At All Familiar with the connection subscribe to at least 1 newsletter about Down Syndrome

- **More knowledgeable about the connection of Down syndrome to the other conditions such as celiac, congenital heart disease, leukemia, sleep apnea, and thyroid disorders.**

  98% of those who are Somewhat/Very Aware correctly identified at least one other condition with a connection to Down syndrome

  Compared to

  78% Who are Not Very/ Not At All Familiar

Even when decision makers are aware of the DS-AD connection, most feel that **they lack understanding and support related to the topic.**

	"Somewhat" or "Very Familiar" with the connection N=133	"Not Very" or "Not at all Familiar" with the connection N=41
DON'T HAVE a good understanding of how to care for someone with Alzheimer's disease.	54%	73%
DON'T HAVE adequate support for understanding and addressing the risk of their loved one developing DS-AD.	56%	78%

**Source: Various Survey Questions (n=174, excluding those who have a DS-AD diagnosis)*
All differences in this chart have p-values < .1

LACK OF FUTURE PLANS

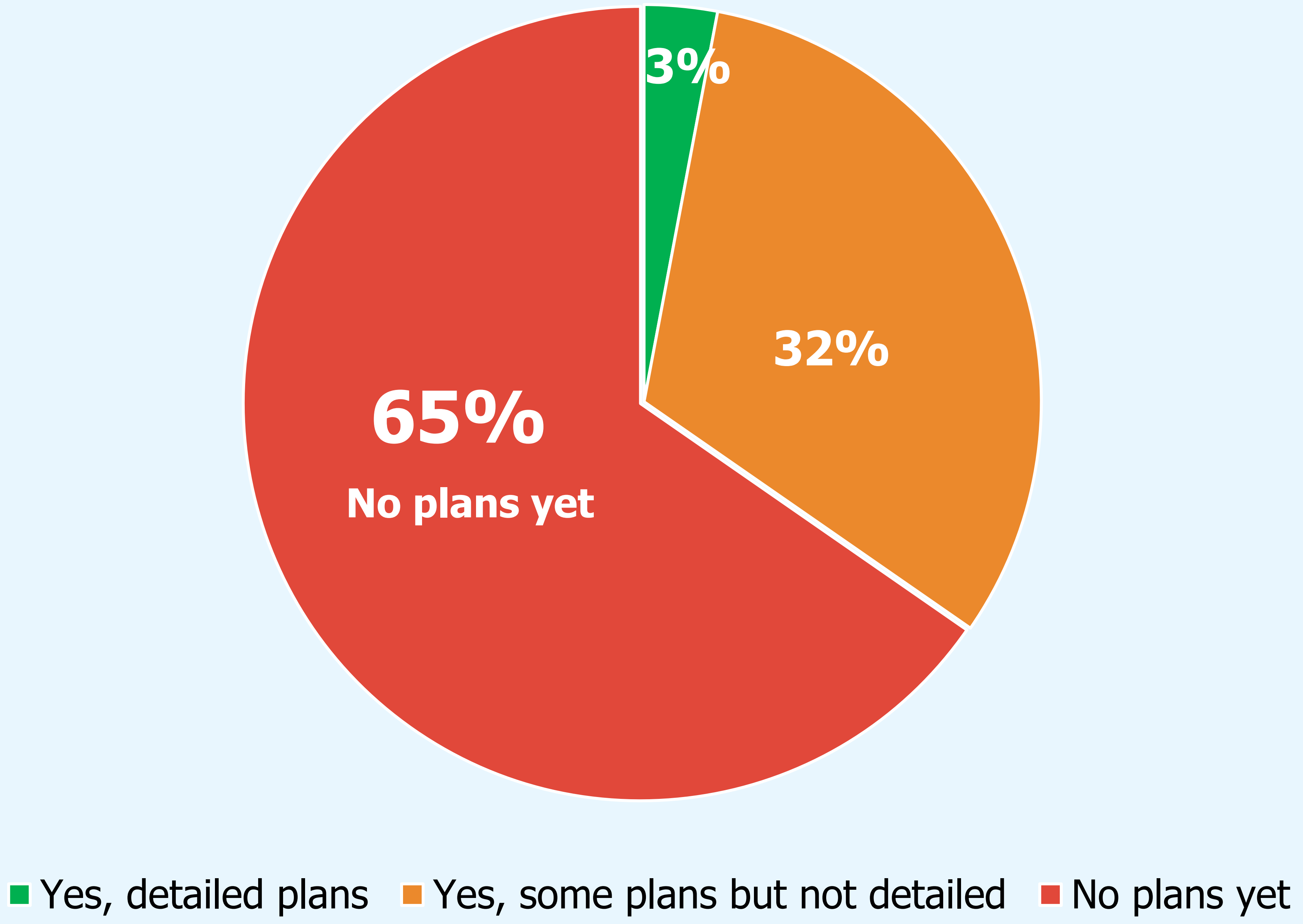
Most decision-makers do NOT have plans in place if their loved one develops DS-AD. This is especially true for loved ones who are younger adults.

78%

**of decision-makers whose loved one is between
20 to 34 years old, do NOT currently have a plan in place to manage care if their loved one were to develop Alzheimer's disease. (compared 65% in the full sample)**

Source: Survey question "Do you have plans in place for how you would manage care for this person with Down syndrome if they were to develop Alzheimer's disease?" (n=87)

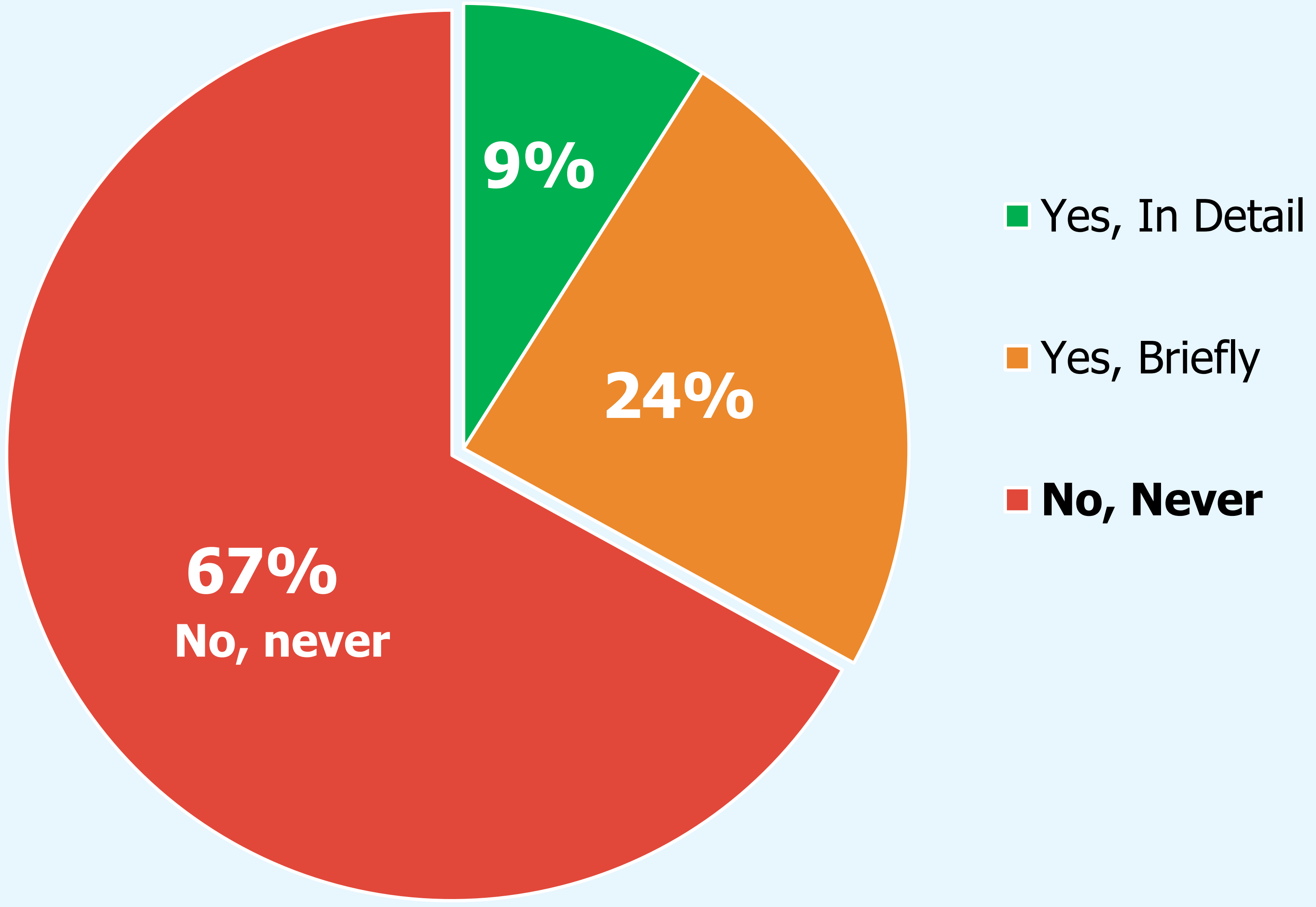
**Nearly two-thirds of all decision-makers said they
do NOT have any plans in place if their loved one develops Alzheimer's disease.**



**Source: Survey Question "Do you have plans in place for how you would manage care for this person with Down syndrome if they were to develop Alzheimer's disease?" Among those who's loved one has not already been diagnosed with Alzheimer's disease (n=174)*

Most decision-makers have **never discussed the DS-AD risk with a medical professional.**

"Has a healthcare provider ever discussed the risks of Alzheimer's disease with you in relation to the person you care for?"



**Source: Survey Question "Has a healthcare provider ever discussed the risks of Alzheimer's disease with you in relation to the person you care for?" (n=174, excluding those who have a DS-AD diagnosis)*

The most common ways that decision-makers learn about the connection are:

- **65%** Personal research online
- **53%** Advocacy organizations
- **36%** Conference, workshop, or educational event
- **32%** Doctor or other healthcare

**Source: Survey Question* "How did you learn about the connection between Down syndrome and Alzheimer's disease*? Select all that apply." (n=144)*

Decision-makers who have discussed DS-AD with healthcare providers **report feeling higher confidence, support, and have made some plans for the future.**

	Have discussed DS-AD with a healthcare professional **N=57**	**Have NOT discussed** DS-AD with a healthcare professional **N=117**
Confident in **distinguishing normal aging vs early signs** of Alzheimer's disease	**74%**	**54%**
Have a good **understanding of treatment and support services**	**40%**	**21%**
Feel **adequately supported** to address DS-AD risk	**53%**	**39%**
Have at least **some plans in place** for how they would manage care for their loved one	**46%**	**29%**

**Source: Various Survey Questions (n=174, excluding those who have a DS-AD diagnosis)*
All differences in this chart have p-values < .1

While decision-makers are generally familiar with the concept of clinical trials, **most are unaware of trials taking place for people with Down syndrome.**

94%

of decision-makers feel they at least have a general idea of what a clinical trial is.

*Source: Survey Question "Do you feel like you have a good Q42: Are you familiar with the term "clinical trial?" *(n=174, excluding those who have a DS-AD diagnosis)*

"Have you heard about clinical trials specifically for people with Down syndrome?"

16% Yes, and I know about specific trials

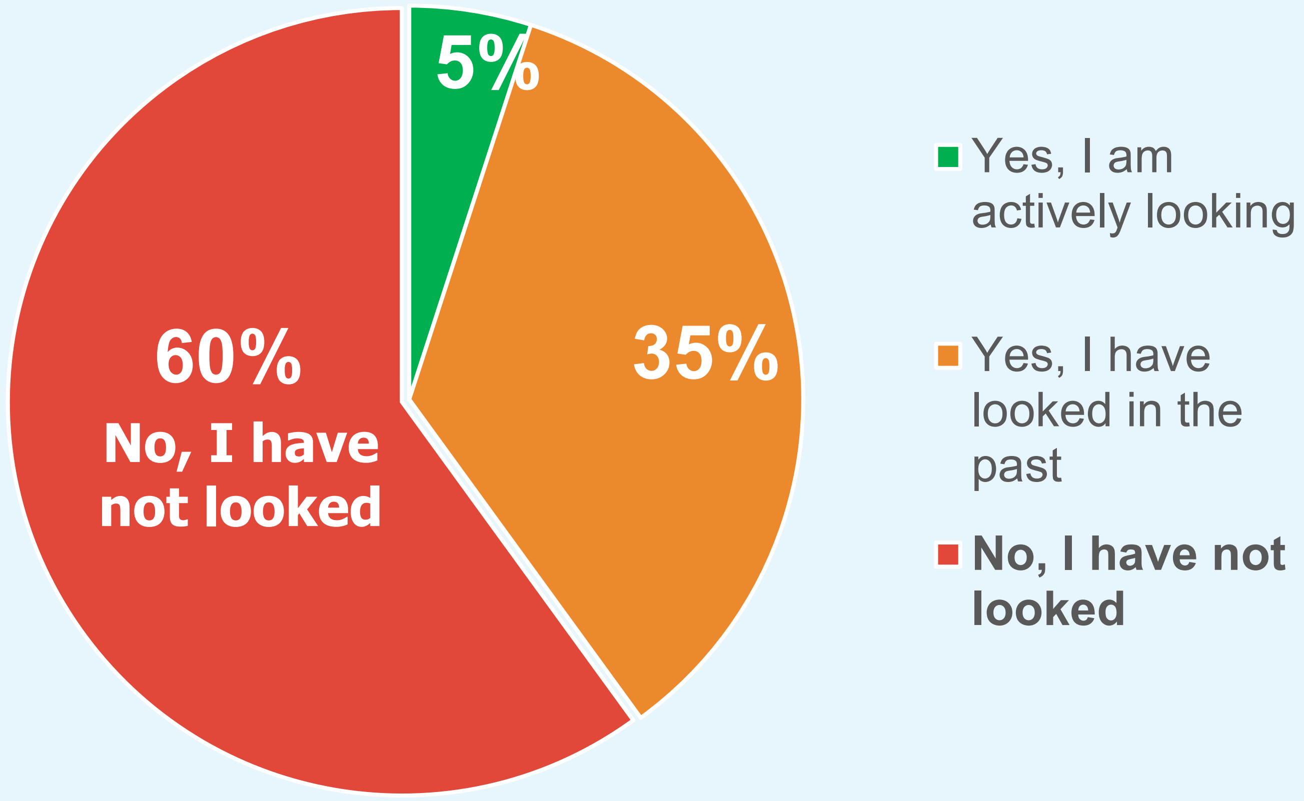
41% Yes, I am aware that trials exist, but don't know details

43% No, I haven't heard about this

1 % I don't know what clinical trials are

**Source: Survey Question "Have you heard about clinical trials specifically for people with Down syndrome?" NOTE: Participants were given a definition for the term "clinical trial" prior to answering this question. (n=174, excluding those who have a DS-AD diagnosis)*

"Have you ever looked for information about clinical trials for people with Down syndrome?"



**Source: Survey Question "Have you ever looked for information about clinical trials for people with Down syndrome?" (n=174, excluding those who have a DS-AD diagnosis)*

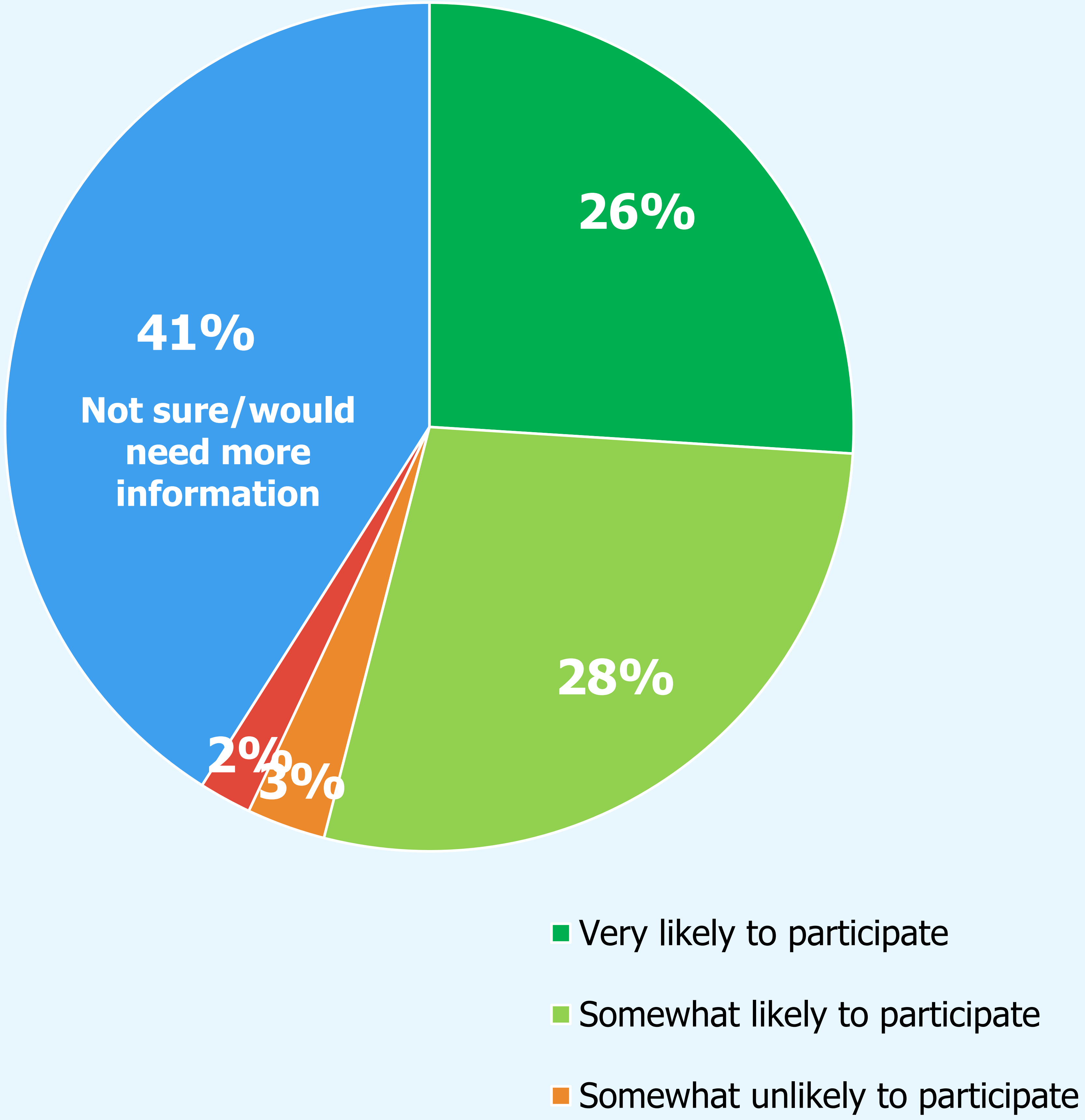
While most decision-makers feel positively about clinical trials involving people with Down syndrome, **nearly half would need more information before they would enroll their loved one in a clinical trial.**

60%

of decision-makers feel positively about clinical trials involving people with Down syndrome.

*Source: Survey Question "How do you feel about clinical trials involving people with Down syndrome? by BANNER 11" *(n=174, excluding those who have a DS-AD diagnosis)*

If your loved one with Down syndrome was eligible to participate in a clinical trial aimed at improving the lives of people with Down syndrome, you would be…?



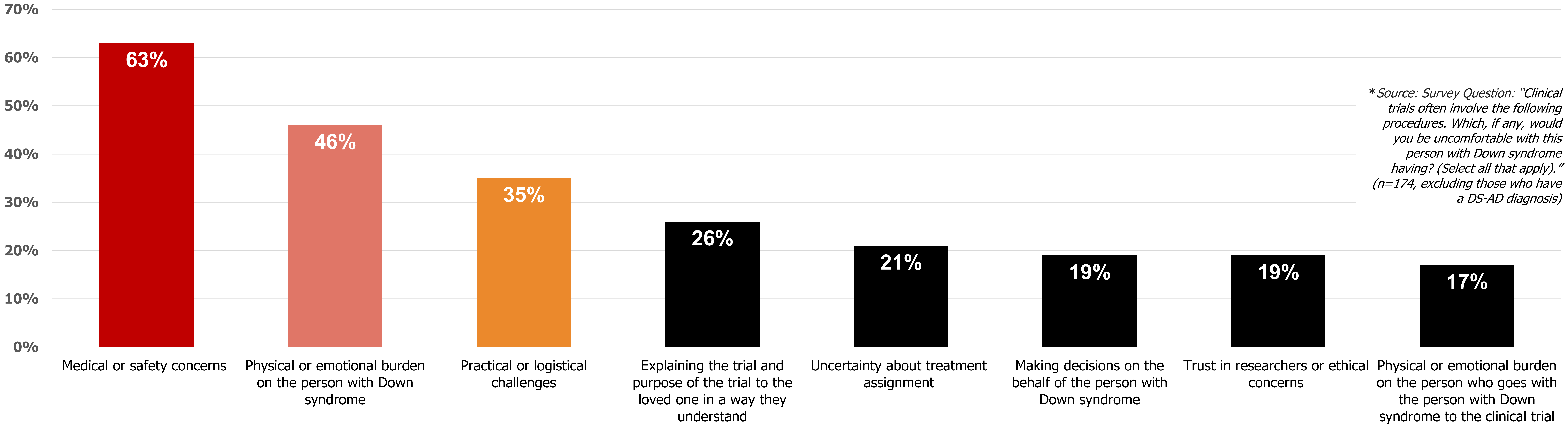
(n=174, excluding those who have a DS-AD diagnosis)

To increase engagement in clinical trial participation, **the top three barriers and concerns of decision-makers need to be understood and addressed**

63%
of decision-makers selected **medical or safety concerns** (defined in the question as side effects, complications, pain, discomfort, unknown long-term effects)

46%
of decision-makers selected **physical or emotional burden** on the person with Down syndrome (defined as stress, fear, anxiety, disruption to their routine)

35%
of decision-makers selected **practical or logistical challenges** (e.g., transportation, scheduling, time off work, costs, distance)



**Source: Survey Question: "Clinical trials often involve the following procedures. Which, if any, would you be uncomfortable with this person with Down syndrome having? (Select all that apply)." (n=174, excluding those who have a DS-AD diagnosis)*

Which, if any, of the following are your **biggest concerns or barriers** to this person with Down syndrome participating in a clinical trial?

One standout concern for medical or safety risks among decision-makers is the lumbar puncture. Unclear information about the procedure and its risks fuel anxiety.

Only

22%

of decision-makers feel comfortable with their loved one having a lumbar puncture as part of a clinical trial.

*Source: Survey Question "How would you feel about this person with Down syndrome undergoing a lumbar puncture as part of a clinical trial studying Down syndrome and Alzheimer's disease?" (n=174, excluding those who have a DS-AD diagnosis)

Overall familiarity with lumbar punctures is quite high. However, familiarity is not the same as having an accurate understanding of the procedure.

> *"My dad…had a [lumbar puncture] done [when I was a kid]…*
> *I have never seen my dad cry before, ever. And he came back from that thing just so distraught."*
>
> — Qual participant Keith (32), paid caregiver for Patrick (55), FL

Familiarity with lumbar punctures:

68% I know what a lumbar puncture is

26% I have heard of a lumbar puncture but don't know anything about the procedure

6% I have never heard of a lumbar puncture

**Source: Survey Question "How familiar are you with a procedure called a lumbar puncture, otherwise known as a spinal tap?" (n=174, excluding those who have a DS-AD diagnosis)*

82%

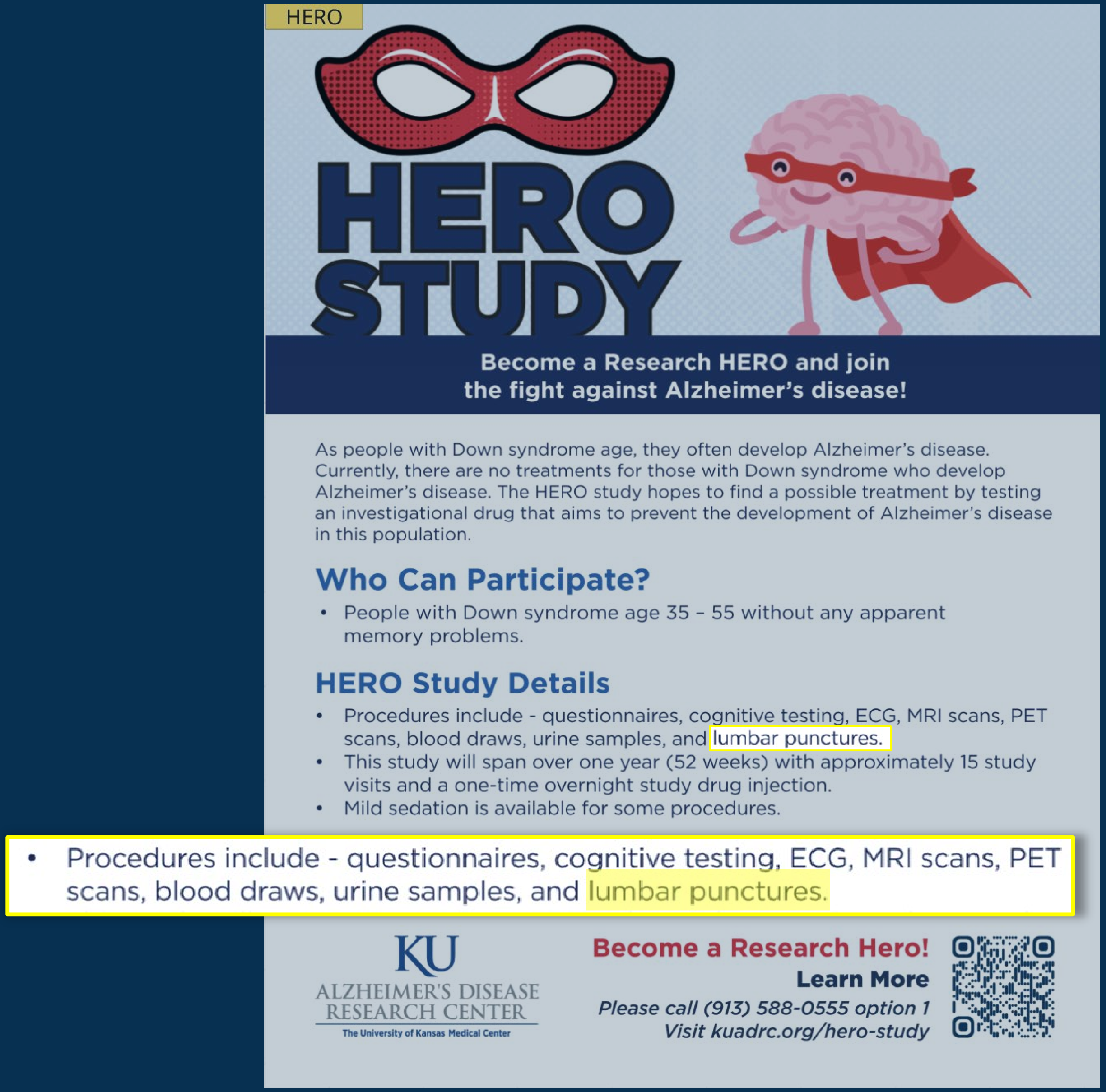
Of decision-makers, whose loved one has not been diagnosed with Alzheimer's disease, are unaware that lumbar punctures may be part of the diagnostic process to detect Alzheimer's disease and/or is used to provide a drug treatment.

*Source: Survey Question "Before now, were you aware that a lumbar puncture may be used as part of the diagnostic process to detect Alzheimer's disease biomarkers and/or to provide an investigational drug treatment?" (n=174, excluding those who have a DS-AD diagnosis)

When reviewing this DS-AD clinical study flyer, nearly every decision-maker had a visceral reaction to the lumbar puncture.

*"After I saw '**lumbar punctures,**' and then I read the second line [of the HERO study flyer] where it said drug injection, I will be honest with you, I didn't read that last line because at that point, those two, study drug injection and lumbar punctures, scare me."*

— Qual participant Daria (60), mother of Justin (29), CA



HERO STUDY

Become a Research HERO and join the fight against Alzheimer's disease!

As people with Down syndrome age, they often develop Alzheimer's disease. Currently, there are no treatments for those with Down syndrome who develop Alzheimer's disease. The HERO study hopes to find a possible treatment by testing an investigational drug that aims to prevent the development of Alzheimer's disease in this population.

Who Can Participate?

- People with Down syndrome age 35 – 55 without any apparent memory problems.

HERO Study Details

- Procedures include - questionnaires, cognitive testing, ECG, MRI scans, PET scans, blood draws, urine samples, and lumbar punctures.
- This study will span over one year (52 weeks) with approximately 15 study visits and a one-time overnight study drug injection.
- Mild sedation is available for some procedures.

- Procedures include - questionnaires, cognitive testing, ECG, MRI scans, PET scans, blood draws, urine samples, and lumbar punctures.

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HERO trial* flyer reviewed during qualitative interview.

**HERO trial was cancelled due to lack of participation*

The second major barrier—physical and emotional burden on the person with Down syndrome—centers on perceived **gaps between trial requirements and the lived realities of people with Down syndrome**.

The responsibility of making the right decisions
for their loved ones about clinical trials weighs on decision-makers.

51% I'm not sure they understand what's happening

45% I worry about making the wrong decision for them

**Source: Top 2 answers to Survey Question: "What concerns do you have about making decisions regarding clinical trials on behalf of this person with Down syndrome? Please select up to three." (n=174, excluding those who have a DS-AD diagnosis)*

Routines & Environment

- **Unfamiliar medical settings** can feel unpredictable or overwhelming.
- **Changes to routine** can affect emotional regulation and behavior.
- **Sensory demands** (noise, pacing, rotating staff) can add strain before procedures begin.

Structure & Expectations

- Trials may require staying still for long periods or completing activities in highly regimented ways, with **limited flexibility in timing or pacing**.
- **Expectations can be misaligned** with how individuals with Down syndrome process or engage.

Communication & Comprehension

- Pain or discomfort may be **difficult to describe clearly** or consistently.
- **High pain tolerance** can delay recognition of adverse effects.
- **Distress may not present in ways clinicians expect** or immediately notice.

The third major barrier—practical and logistical challenges—centers on **competing demands for families' limited time, money, and support.**

Financial Barriers: Participation can feel financially risky for families, particularly when costs are uncertain.

- Even when reimbursement is available, **families may still need to absorb indirect costs** such as lost wages or additional caregiving costs.

47%

of decision-makers were "Not at all aware" that clinical trials typically reimburse expenses

*Source: Survey Question *(n=174, excluding those who have a DS-AD diagnosis)*

Study Partner Requirements: It can be difficult to determine whether participating would be feasible.

- Working caregivers often worry about coordinating visits around **existing work and caregiving schedules**.
- Without clear expectations about time demands or flexibility, families **struggle to assess** whether participation is feasible.

Competing Responsibilities: Adding new commitments can feel like a risk to already fragile routines and support systems.

- Many decision-makers are already balancing work, caregiving for aging parents or children, **in addition to supporting their loved one with Down syndrome.**
- Over a third of decision-makers in the qualitative interviews **cite impact on work or other responsibilities as a barrier to participation.**

PART **3**

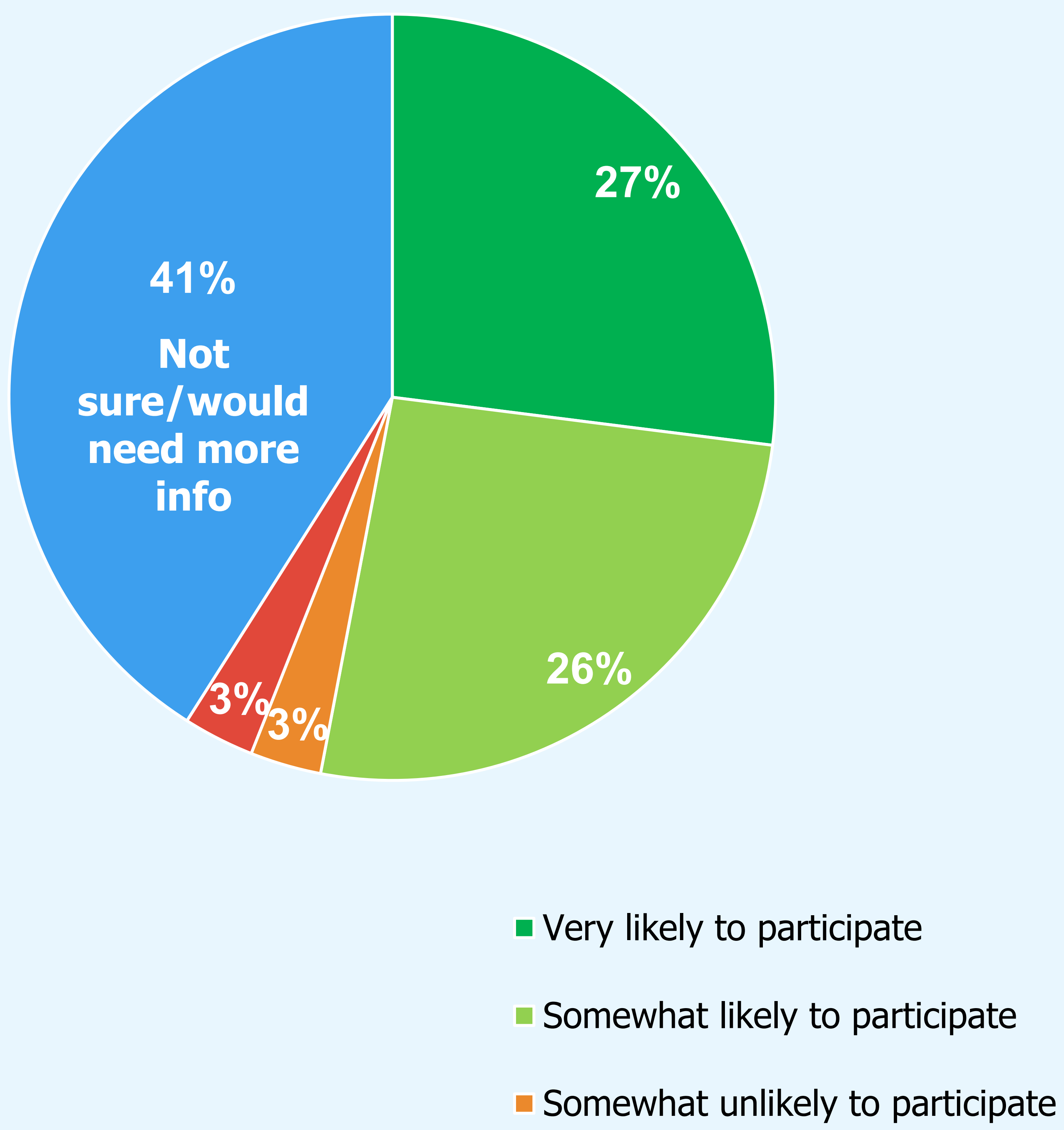
Opportunities

When evaluating trial participation, decision-makers face **multiple, compounding challenges** that are **hard to imagine in the abstract.**

- **Lack of foundational** DS-AD understanding (probability, signs and symptoms, disease trajectory)
- **Absence of education**, guidance, and validation from medical professionals regarding clinical trials
- **Emotional burden** of confronting and accepting DS-AD potential/decline
- **Ethics of balancing loved one’s autonomy**, personal comfort, and safety vs. altruistic service to the Down syndrome community
- **Trial requirements** that introduce new, practical burdens for decision-makers—on top of their existing responsibilities

The complex, interwoven nature of these challenges makes it difficult for decision-makers to confidently assess if trial participation would be a good fit for their loved one and themselves.

If your loved one with Down syndrome was eligible to participate in a clinical trial aimed at improving the lives of people with Down syndrome, you would be…?



*Source: Survey Question (n=200)

Unified Messaging around Awareness & Prevention

GAP

Awareness doesn't translate into action.

- Information comes from fragmented sources (or from independent research) and lacks a clear, actionable message.
- When providers don't talk about DS-AD, families assume it's not urgent.
- The concept of treatment without overt symptoms is unclear.
- Action often happens only after crisis, when trial eligibility has passed.

OPPORTUNITY

Integrate DS-AD conversations into standard care best practices.

- Starting conversations and focusing on "proactive brain health," rather than "planning for decline," gives families the time and context to act.
- Providing caregivers with talking points and prompts for conversations with doctors empowers them to act.
- Trusted voices are needed to explain disease trajectory and the "window of opportunity" when treatments can impact disease progression.
- Connecting families to Down syndrome experts, in person or virtually, brings new levels of information and understanding.

> One mom's take on trial participation: Tanya's explained her primary barrier to enrolling her daughter in clinical trials was that she won't put Marta through invasive procedures when Marta "may never get that (Alzheimer's disease)." However, Tanya said she would be "way more likely" to participate in research if Marta showed symptoms, because Tanya does feel DS-AD research offers "hope" and "there aren't really any treatments" available.

Qual participant Keith (32), paid caregiver for Patrick (55), FL, advocated for years that Patrick needed to move from independent living to a care facility as his cognitive decline worsened. Patrick's mother resisted until a crisis forced the decision.

> *"[When it comes to talking about DS-AD, it's about] approaching it gently… You got to have some firmness to be like, 'I know you might not want to hear this. I know that this is hard information to take in…' Make it a discussion with someone… look at it through the lens of hope and possibility instead of fear. Because that word: Alzheimer's, dementia—it instantly makes people afraid… But instead, looking at it like, 'We know the potential that they could have it, so let's see what we can do."*

73%

Of all survey decision-makers want to hear about trials from their doctor

BUT:

67%

have never discussed DS-AD with a healthcare professional.

**Source: Survey Question (n=174, excluding those who have a DS-AD diagnosis)*

Accessible Explanations of Drugs & Procedures

GAP

Unclear explanations and lack of reasoning fuel fear and mistrust.

- Decision-makers often don’t understand how investigational drugs work or why certain procedures are necessary, especially in the context of complex health needs.
- When cognitive challenges are discussed, some expect therapy-based or non-invasive approaches, not drugs or injections.

OPPORTUNITY

Translate clinical information into context families can understand.

- Ground explanations in families’ real concerns about safety, side effects, and existing conditions.
- Create space for follow-up questions so families can clarify concerns before disengaging.
- Break down individual procedures by steps, and include explanations as to why each procedure is necessary, and how it contributes to the overall study.

> *I don't mind blood work and studies and that kind of thing, but I am a little torn by the lumbar puncture. You need a really good reason. That is not a comfortable thing even if he was numbed up, and I don't want him to have a bad experience. I might be a little more apt to roll with it if he had signs of Alzheimer’s or something... as opposed to taking somebody perfectly healthy [with] no signs of it.*
>
> **Qual participant Sherry (66), sister of Greg (62), NC**

> **Qual participant Peggy (67), mother of Shawna (40), OH**
>
> *”What mechanism are you approaching here? What part of the Alzheimer's are you trying to deal with? Are you dealing with the plaques? …I would be interested in knowing more about it — the mechanics and side effects — before I would ever want to know to say yes for sure.”*

56% **of decision-makers identified “taking investigational medicines.”**

80% **decision-makers identified “Lumbar puncture (or spinal tap)”**

As something they would be uncomfortable with their loved one doing as part of a clinical trial.

*Source: Survey Question *(n=174, excluding those who have a DS-AD diagnosis)*

56% **of decision-makers said a dedicated contact person available to answer their questions would make them feel more confident about understanding a clinical trial for their loved one.**

*Source: Survey Question *(n=174, excluding those who have a DS-AD diagnosis)*

De-mystifying the Logistical and Practical Burdens of Trial Participation

GAP

Unclear logistics prevent families from determining whether participation is feasible.

- Information about time, travel, costs, and study partner responsibilities is often unclear upfront.
- Families assume participation will be too burdensome to manage alongside existing responsibilities.
- Without clear information, many opt out before asking questions or exploring available supports.

OPPORTUNITY

Make logistical expectations and available support explicit early.

- Clearly outline what participation requires, what support is and is not provided, and what flexibility exists to help families realistically assess whether participation is possible.
- Establish trust with clear information, and authentic relationships with caregivers and participants so they feel valued.
- Build in a system for potential participants to ask follow-up and clarifying questions could help maintain engagement.

Qual participant Jenna (72), mother of Jude (46), MA

> *"I've never been given an outline [of what a clinical study will entail], which is another flaw... You're asking someone to apply for a job which you haven't given them a job description… This stage of recruitment needs to have a lot more transparency than I have seen so far."*

35%

Of decision-makers identified "practical or logistical challenges" as a top 3 barrier to participation in clinical trials

HOWEVER:

47%

of decision-makers were "Not at all aware" that clinical trials usually fully reimburse expenses incurred

**Source: Survey Question (n=174, excluding those who have a DS-AD diagnosis)*

Most decision-makers say that travel-related financial support would make participation in a clinical trial more possible for their family.

72% Free lodging

43% Meal vouchers for long appointments

43% Reimbursement for gas/mileage

**Source: Survey Question "What types of support would make participation in a clinical trial more possible for you? Please select up to three." (n=174, excluding those who have a DS-AD diagnosis)*

Preparing Clinical Teams to Welcome People with Down syndrome & their Families

GAP

Families aren't confident clinical trial teams are prepared to accommodate the needs of people with Down syndrome.

- Tests and exams can feel poorly suited to people with Down syndrome, putting their loved ones at a disadvantage from the start.
- Decision-makers are skeptical clinical teams will have the specialized knowledge, patience, or flexibility needed to make their loved one feel comfortable and to have the procedure be successful.

OPPORTUNITY

Design clinical trials that are clearly suited for people with Down syndrome.

- Account for the wide range of ways individuals with Down syndrome respond, process, and engage.
- Plan testing and visits with sensory needs, activity pacing, communication differences, and emotional regulation in mind.
- Allow study teams the latitude to slow down, adjust, or adapt procedures based on individual comfort and behavior.
- Employ team members who have real experience working with people with Down syndrome— and communicate that to potential participants.

Recognizing the role of decision-makers in successful clinical trials

- Leverage decision-makers' expertise of what their loved one needs to complete procedures (e.g., triggers, behavioral challenges, and supports that help).

Qual participant Jenny (49), mother of Abigail (23), TX

" They're going to have to be cognizant of the fact that this is not general population. They are going to have to know not everybody is going to be the same and how they react... My daughter will be like, 'Here, take my blood, this is cool. Where's my lollipop? Whatever.' Another may have to be hogtied practically in order to get that blood test… And they need to be able to listen to the parent... because we've been there, we've seen it, we know exactly how our kid's going to react if you don't do xyz."

60%

of decision-makers said "Researchers who have personal or professional experience working with people with Down syndrome" would increase their trust in a clinical trial.

**Source: Survey Question (n=174, excluding those who have a DS-AD diagnosis)*

THANK YOU!

Conifer Research in partnership with NDSS

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