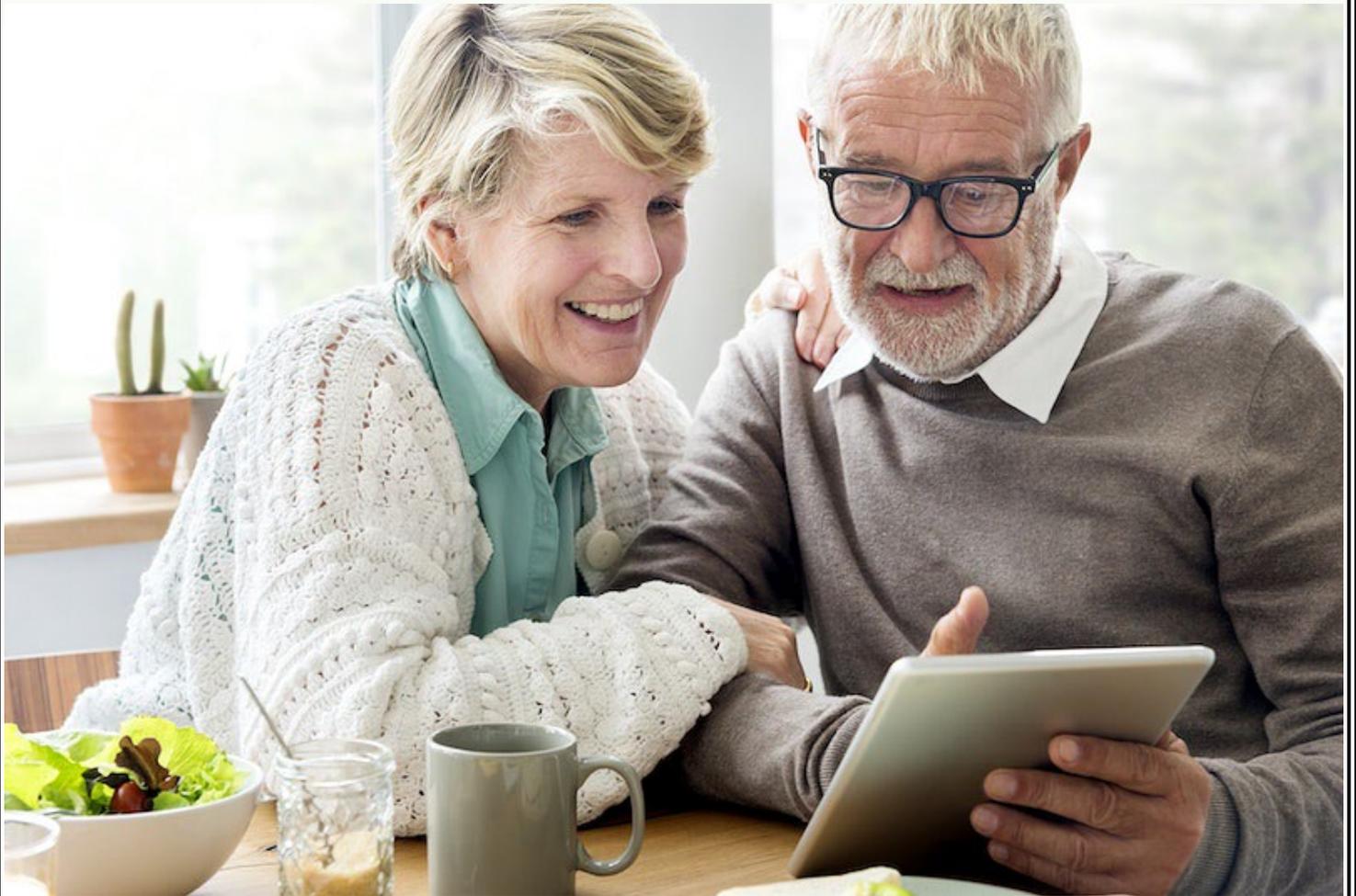


# Getting Health Information Directly From Adults with Intellectual Disability (ID)



Adults with ID can provide information  
about their own health and feelings  
when surveys are clear and easy-to-use.

**ORIGINAL ARTICLE:**

Walton, K., Krahn, G. L., Buck, A., Andridge, R., Lecavalier, L., Hollway, J. A., Davies, D. K., Arnold, L. E., Havercamp, S. M. & the Nisonger RRTC on Health and Function. (2022). Putting "ME" into measurement: Adapting self-report health measures for use with individuals with intellectual disability. *Research in Developmental Disabilities*, 128(2022), 1-14. <https://doi.org/10.1016/j.ridd.2022.104298>

## THE PROBLEM

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**Doctors and researchers do not always get health information directly from adults with intellectual disability (ID).**

**They may only ask a support person how the adult with ID is doing or feeling.**

- A support person (parent, staff) may be needed to help with communication
- It is important to listen to adults with ID before asking someone else for help



**Many health surveys are not easy to use.**

**Many questions about health are not easy to understand.**

This can make it hard to:

- ask adults with ID how they are doing or feeling
- get answers to health questions directly from adults with ID

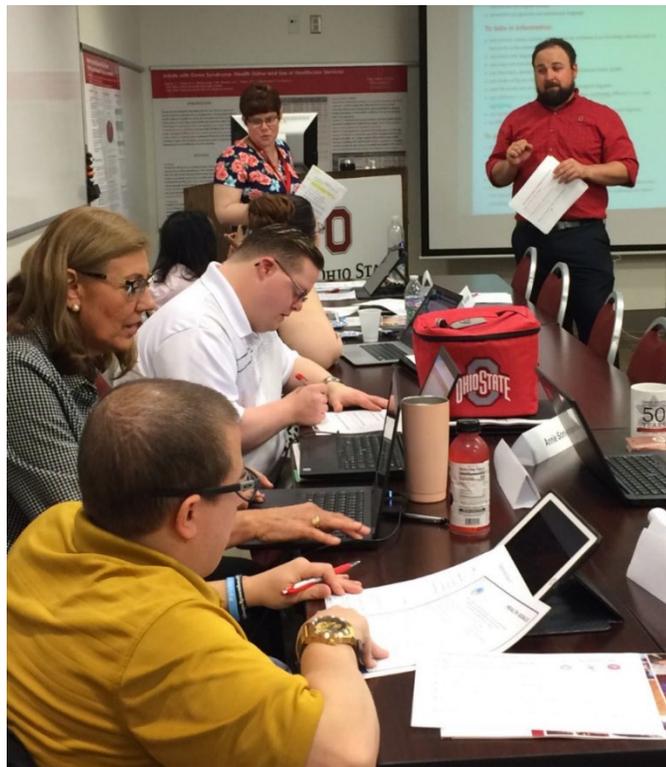
## OUR RESEARCH STUDY

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**Our research team wanted to know if they could make health surveys better for adults with intellectual disability (ID) to use and understand.**

### **How our research team made the new health surveys:**

- They chose 3 health surveys that they wanted to make better for adults with ID
- They worked with a group of research partners with disabilities to make the questions & answer choices clear



- They worked with a technology team to put the new survey online and in an app, so people could use text-to-speech and hear the words out loud
- Then, they asked the research partners to test the new survey on devices, such as laptops & tablets
- They used ideas from the research partners to make final changes to the words and pictures in the new health survey

## How our research partners helped the research team:

- They told our research team what words were hard-to-understand and how to ask questions clearly
- They told our research team to begin each question with a time period (for example, *"In the last two weeks, how often did you feel sad?"*)



- They told our research team to only use 3 answer choices: (a) almost always; (b) sometimes; and (c) almost never
- They told our research team to use pictures of a two-week calendar with different days checked off to make answer choices easier to understand
- They told our research team to use real-life photographs instead of icons, symbols, or cartoon faces to show different feelings

**The research team also made a training part to start the new health survey.**

They added the training part to teach people how to:

- use technology options in the app and on the website, like:
  - clicking text to hear the words out loud
  - clicking buttons to answer questions, move on, go back, or skip
- understand the answer choices (almost always, sometimes, almost never)



**Then, the research team tested the new health surveys with a group of adults with intellectual disability (ID).**

- First, they asked 6 adults with ID to answer the questions and tell them what was hard-to-understand
- Next, they took out the questions that were not clear
- Then, they asked 41 other adults with ID to answer the questions using a tablet or computer on their own or with support

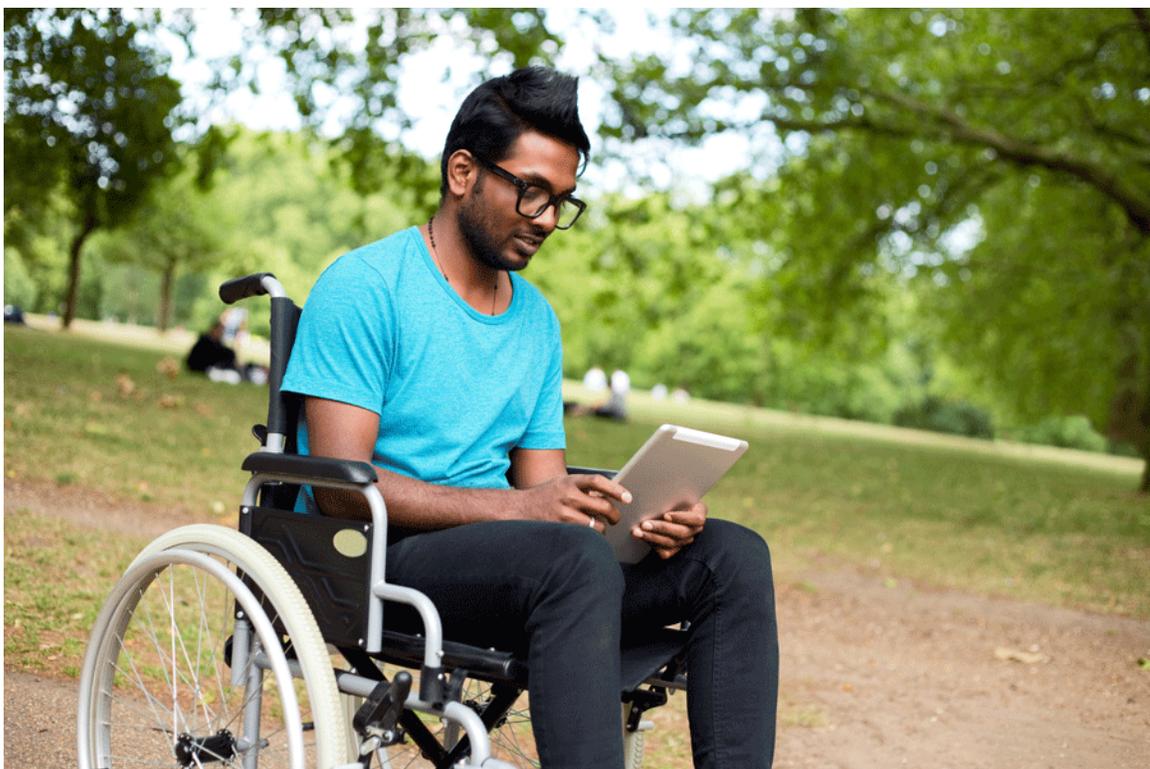
## KEY FINDINGS

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**Adults with intellectual disability (ID) can provide information about their own health and feelings when surveys are clear and easy-to-use.**

### **What the study did and learned:**

- 41 adults with ID took the new health survey on a tablet or computer
- Some did the survey in-person, and some did the survey in a Zoom meeting
- 24 of the adults took the survey twice to test if their answers changed or stayed the same
- Most of the answers were the same after 2-weeks, which was a good way to tell that they understood the questions



- Everyone finished the survey and answered the questions on their own
- The survey was easier to use independently on a touch-screen tablet

## Why Is This Important?

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**Learning how adults with intellectual disability (ID) think and feel about their own physical and mental health is key to:**

- **Respecting** their ability and independence
- **Understanding** their health and healthcare needs
- **Improving** their healthcare services and supports



**Two key things helped the research team make health surveys better for adults with ID:**

- 1. Asking a team of research partners with disabilities to help make choices:**
  - a. Which questions to ask
  - b. What words and pictures to use
  - c. How many answer choices to use
- 2. Putting the survey on an app and website with supports:**
  - a. Text-to-speech to read text out loud
  - b. Touch-screen controls
  - c. Real-life photos and visual support icons

**More work is needed to test the new health survey and make other health surveys better for adults with intellectual disability.**



**THE OHIO STATE  
UNIVERSITY**  

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**NISONGER CENTER**

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