



Observer-Reported Communication Ability Measure

## Frequently Asked Questions Version 2.3 (April 28, 2021)

### What is the ORCA measure?

The Observer-Reported Communication Ability (ORCA) measure is designed to assess the communication ability of an individual from the perspective of their caregiver. The measure is designed to be used for individuals with a neurodevelopmental disorder associated with a significant impact on communication ability.

### What content is included in the ORCA measure?

The ORCA captures overall **communication ability** observed by the caregiver over the past 30 days. Items cover important communication behaviors in numerous areas within expressive, receptive, and pragmatic communication.

The measure consists of **84 total questions** with 70 behavioral items within 22 concepts/functions (Table 1) that cover expressive, receptive and pragmatic areas of communication, alongside a set of 14 descriptive items that capture important information about the individual's unique ways of communicating (e.g. modalities the individual uses, their current vocabulary, and language complexity). The descriptive items follow skip logic, so it is possible not every caregiver will complete every question.

**Table 1: Communication concepts included in the ORCA measure, as informed by concept elicitation interviews, cognitive testing interviews, and psychometric testing with caregivers**

Expressive Communication	Receptive Communication	Pragmatic Communication
Seek Attention	Respond to Name	Greeting
Direct Attention	Understand Mood	Comfort Others
Refuse Object	Understand Isolated Words	Play Games
Request Object	Turns in Conversation	Use Names
Request Object Out of View	Make Choices	
Request "More"	Respond to Familiar Directions	
Communicate Understanding	Respond to New Directions	
Asking Questions	Answer Questions	
Communicate with Others		
Telling About the Past*		

\*The concept "telling about the past" is currently included in the ORCA measure but not a part of the scoring metric at this time.

## What populations were recruited to design and evaluate the ORCA measure?

The ORCA measure was originally designed to assess communication ability of an individual with Angelman syndrome (AS) from the perspective of their caregiver. The target population was any individual with AS (of any genotype) aged 2 years old or older (including adults with AS). The content included in the ORCA measure was informed by interviews with parents of individuals with AS and by communication specialists (e.g., speech-language pathologists). Specialists treated both individuals with AS and individuals with other developmental communication disorders.

The investigators are open to further evaluation of the ORCA measure in individuals with AS and in new populations that have similar communication issues. (Please see additional information below).

## I work with individuals who have neurodevelopmental disorders that impact communication ability, but not Angelman syndrome (AS). Can I use the ORCA measure with my population?

Although the ORCA measure has not been currently validated in populations other than AS, the investigators are excited about the possibility of applying it to other similar disease groups. The investigators purposely designed the ORCA measure to be modality agnostic – meaning that a child could score high or low on the ORCA regardless of whether they use gestures/signs, vocalizations, sounds, and/or assistive technology to communicate.

The investigators believe the ORCA measure is likely most appropriate for neurodevelopmental disorders that have similar communication barriers to AS: most individuals are non-verbal or communicate primarily through modalities other than spoken words, they often have stronger pragmatic and receptive communication skills compared to expressive skills, communication develops heterogeneously, and 'mastery' of communication behaviors is shown when they are observed frequently and consistently.

If you are interested in using the ORCA measure in a population other than AS, please [click here](#) for more information and recommendations. If you'd like to discuss a potential partnership with Duke University to collect additional validity evidence, please contact Nicole Lucas ([nicole.lucas@duke.edu](mailto:nicole.lucas@duke.edu)).

## Who should complete the ORCA measure?

It is recommended that the individual's **primary caregiver** complete the ORCA measure, as this person will have the most experience with the individual's typical communication across a number of different situations.

If you are measuring changes in communication ability over time, it is recommended that the same caregiver complete the ORCA measure at all time points. Caregivers can complete this in their home or in a clinic setting.

### **How should I use the ORCA measure?**

The ORCA measure can be used cross-sectionally (at one time point) or at multiple time points (e.g., before intervention and post-intervention) to assess change in communication ability. Note the reference period is the past 30 days.

### **Do I need to pay for the ORCA measure?**

The ORCA Measure is copyright Duke University. Pattern Health is the exclusive authorized distributor of the ORCA Measure. If you are interested in obtaining a license to use the ORCA measure, please fill out a [license request form](#). There is no cost for noncommercial use. There are fees associated with commercial use. **You may not alter, modify, or otherwise create derivative works (including translations) without permission.** The investigators ask that in any publication or presentation, you cite the original manuscripts.

### **How was the ORCA measure developed?**

The ORCA measure was developed using best practice guidelines provided by the FDA, ISPOR, ISOQOL, PROMIS and other organizations. The process centered on input and guidance from caregivers of individuals with AS at all stages and communication experts, including speech-language pathologists. Although validation studies are always ongoing, the following steps have been taken and provide support for the validity and reliability of the measure within the AS population:

1. Concept elicitation interviews
2. Item generation
3. Cognitive testing
4. Translatability review
5. Psychometric testing

### **How long does it take someone to complete the ORCA?**

During the psychometric study, it took caregivers between 10-15 minutes to complete the ORCA measure electronically.

### **Do I need to train anyone to administer the ORCA measure to caregivers?**

No. The ORCA measure was designed for caregivers of individuals with Angelman syndrome to complete the measure independently (electronically or on paper), without the need for a trained expert administrator. In other words, caregivers should be encouraged to read the instructions independently and complete the ORCA measure on their own. Assistance should only be given if the caregiver can't read or has difficulty using an electronic survey system.

### **In what settings can I use the ORCA?**

The ORCA measure was specifically designed for clinical trial and research settings to identify differences between two or more groups or evaluate changes in communication ability over time within the same group(s). Although clinicians may be interested in the ORCA measure to direct therapy, its validity for use in clinical settings has not yet been examined.

### **Do I need to print out paper copies of the ORCA measure to administer it?**

The ORCA measure was designed to be administered either electronically (through a web-based survey platform) or via paper & pencil. Note that the original psychometric validation study used only electronic versions of the ORCA measure. At this time, equivalence has not been established between paper-and-pencil and electronic assessment of the ORCA measure. However, there has been numerous studies that have shown negligible differences between paper and electronic clinical outcome assessments (Gwaltney, Shields, & Shiffman, 2008)<sup>1</sup>.

### **What do scores on the ORCA measure mean?**

Total scores on the ORCA measure reflect the individuals **total communication ability** based on their caregiver's assessment of the individual's ability to "master" each of the concepts representing expressive, receptive, and pragmatic forms of communication. Mastery means that the individual could (and did) perform the behavior frequently and consistently over the past 30 days, and was indicated by caregivers choosing the 'Yes, *almost all the time*' response option.

### **How do I score the ORCA measure?**

If administering the ORCA measure with Pattern Health, scores are computed automatically. Otherwise, you may use the SAS macro file provided with the measure to obtain total scores. Scoring the ORCA measure is complex due to the double hierarchy (items are leveled within communication concepts, and concepts are leveled within the larger concept of "communication ability").

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<sup>1</sup> Gwaltney, C.J., Shields, A.L., & Shiffman, S. (2008). Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: A meta-analytic review. *Value in Health*; 11(2), 322-333. DOI: 10.1111/j.1524-4733.2007.00231.x

The macro file will score response patterns using an IRT-based model to reflect the caregiver’s observations of an individual’s communication ability over the past 30 days via reported mastery of specific behaviors within 21 concepts reflecting expressive, receptive, and pragmatic types of communication. The IRT scores are then converted to a T-score metric with a mean of 50 and standard deviation of 10 in the original calibration sample of individuals with AS.

**Is the ORCA measure available in other languages?**

Currently, the ORCA measure is available in American English, French Canadian, English UK, Dutch Netherlands, Spanish Spain, Spanish USA and Italian. The investigators are open to collaborating with other interested parties to culturally validate and translate the ORCA measure into other languages.

If you are interested in translating the ORCA measure, please contact the investigators (see contact information below). If you would like to obtain a copy of one of the translations of the ORCA measure, please fill out a [license request form](#).

**Who funded the development of the ORCA measure?**

The development of the ORCA measure was financially supported by the Foundation for Angelman Syndrome Therapeutics (FAST).

**Who was responsible for developing the ORCA measure?**

The ORCA measure was developed by a multi-disciplinary research team from Duke University in close collaboration with FAST. Team members and their affiliations are listed below.

Allyson Berent (FAST)	Nicole Lucas (Duke)
Paula Evans (FAST)	Molly McFatrach (Duke)
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Kelly Gordon (Duke)	Christy Zigler (Duke)
Harrison Jones (Duke)	

**Who should I contact if I have more questions?**

For licensing questions please fill out a [license request form](#). **To discuss validating the ORCA measure in a new population** reach out to Nicole Lucas ([nicole.lucas@duke.edu](mailto:nicole.lucas@duke.edu)) or Allyson Berent ([allyson.berent@gmail.com](mailto:allyson.berent@gmail.com)).