

After the Expert: Involving People with Aphasia in Research & Care

Wednesday, Jan 14, 2026

12-1 pm EST



Elevator Speech

The National Aphasia Association is leading a new project funded by PCORI to find out how aphasia really affects people's lives.

We're working with people who have aphasia, families, health care professionals and researchers to make a list of the most important ways aphasia impacts everyday life.

This list will help improve research, care, and support—so it's focused on what matters most to people with aphasia.

Listening to What Matters Most



What Involving People with Aphasia in Research looks like...

Leadership Team

- Meets monthly
- Provides input on all aspects of project

Advisory Board

- Recruitment of participants in project
- Communication support for participants
- Roadmap Development

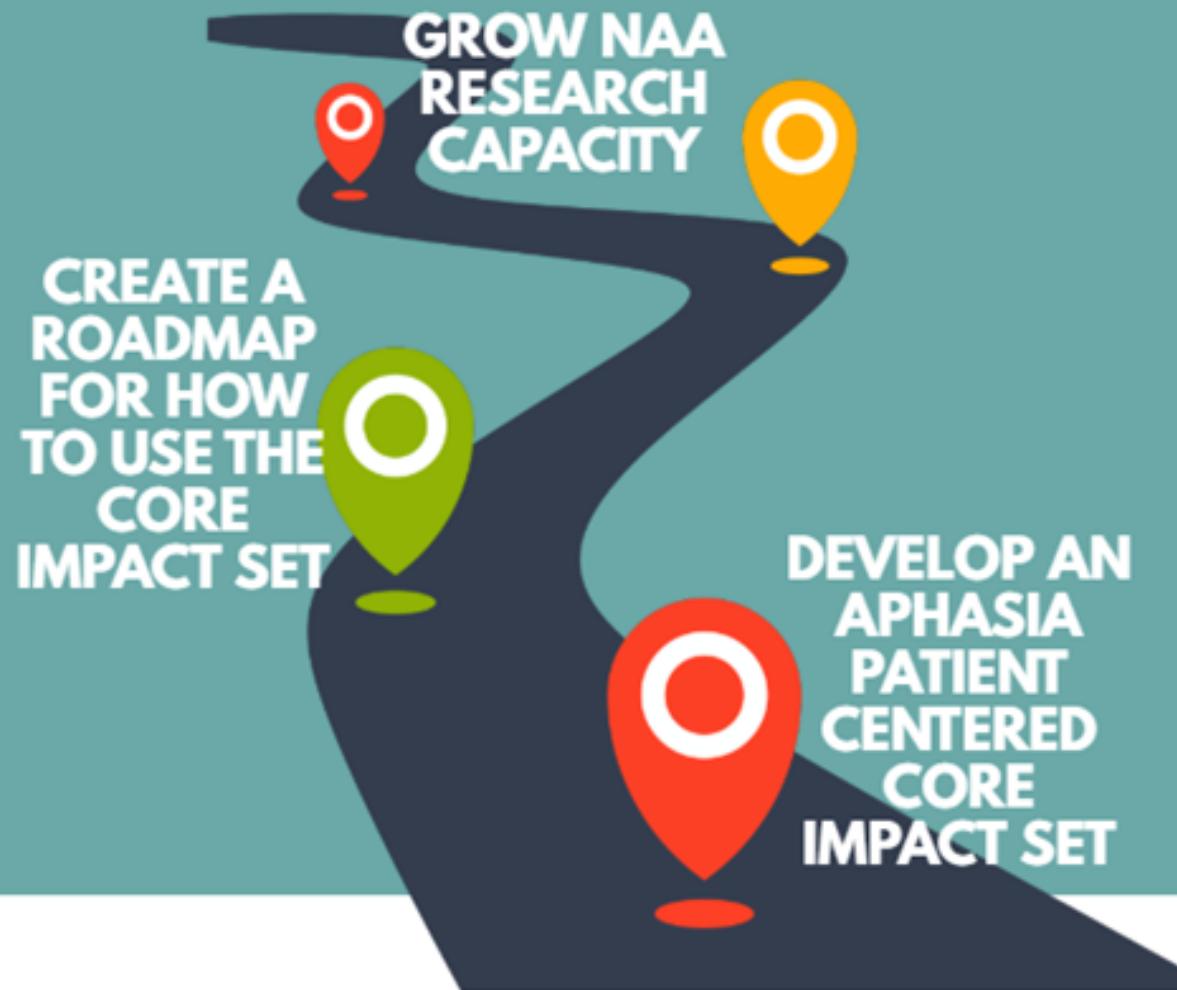
Feedback

- Graphics
- Videos
- Presentation
- Roadmap
- Dissemination

Project Participation

- Convening participants
- Prioritization of impacts

WHAT WILL THIS PROJECT DO?



What will this project do?

- **Develop a patient centered – core impact set**
- Create a roadmap for how to use this patient centered – core impact set to guide research
- Grow NAA research capacity



What are Patient-Centered Core Impact Sets?

- List of **impacts** as reported by **those living with a condition**
- Disease or **condition-specific**
- **Goal** is to align research and policy efforts with the priorities of **those who are living with the condition**
- **Validated procedures for creating Core Impact Sets** are available through the National Health Council



Aphasia Patient -Centered Core Impact Set

A 2-year project that involves all stakeholders.
The Core Impact Set will help drive research priorities.



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Identify impacts of aphasia we already know about



ਅੱਖਾਫਾਫਾਨਕਾਚਕਾਲਾਵਾਨਾ

Identify and prioritize which impacts are most important



ਛਹਾਵਾਖਾਨਾ, ਜਾਵਾਂਧਾਨਾ ਬਾਖਾਖਾਨਾ

Add & build on impacts already developed by persons with aphasia



ਅੱਖਾਫਾਫਾਨਾ ਜਾਕਾਚਕਾਲਾਵਾਨਾ

Finalize a prioritized list of impacts of living with aphasia.



3 Convenings: Working Together

1st Meeting

- People living with aphasia
- Hearing about what matters most
- What are the biggest impacts of living with aphasia
- Prioritizing impacts of living with aphasia

2nd Meeting

- Clinicians & Researchers
- What they think are the biggest impacts of living with aphasia
- Prioritizing impacts of living with aphasia
- Patient priorities remain first

3rd Meeting

- Everyone together: persons living with aphasia, clinicians & researchers
- Prioritizing impacts of living with aphasia
- Patient priorities remain first



What will this project do?

- Develop a patient centered – core impact set
- **Create a roadmap for how to use this patient centered – core impact set to guide research and programming**
- Grow the NAA



Aphasia Patient Centered Core Impact Set Road Map



new website



top challenges



research priorities

What will this project do?

- Develop a patient centered – core impact set
- Create a roadmap for how to use this patient centered – core impact set to guide research
- **Grow the NAA**



How this Project Helps the NAA

Establish NAA as the leading organization for identifying the needs of people with aphasia

Build the national aphasia community

Provide patient-centered content for discussing what is important to people with aphasia

Help many people with aphasia to feel represented

Put the NAA at the leading edge of recognizing the patient's voice in policy and advocacy

Build NAA research capacity

Questions



Questions

If you have any questions:

Email: coreimpact@aphasia.org

QR Code:



Website: <https://tinyurl.com/NAAImpact>

THANK
you