

THE IMPACTS OF APHASIA DEFINED BY STAKEHOLDERS: DEVELOPING A PATIENT-CENTERED CORE IMPACT SET FOR APHASIA IN THE US

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BACKGROUND/MOTIVATION

Unfortunately, people with aphasia and their families are often left out of the research process as collaborators or as determiners of research priorities. The National Aphasia Association (NAA) is committed to closing these gaps by providing better and more accessible resources, involving people with aphasia in research, and making sure that all their voices are heard.

WHAT ARE CORE IMPACT SETS?

- Lists of impacts as reported by patients and 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

Impacts vs. Outcomes

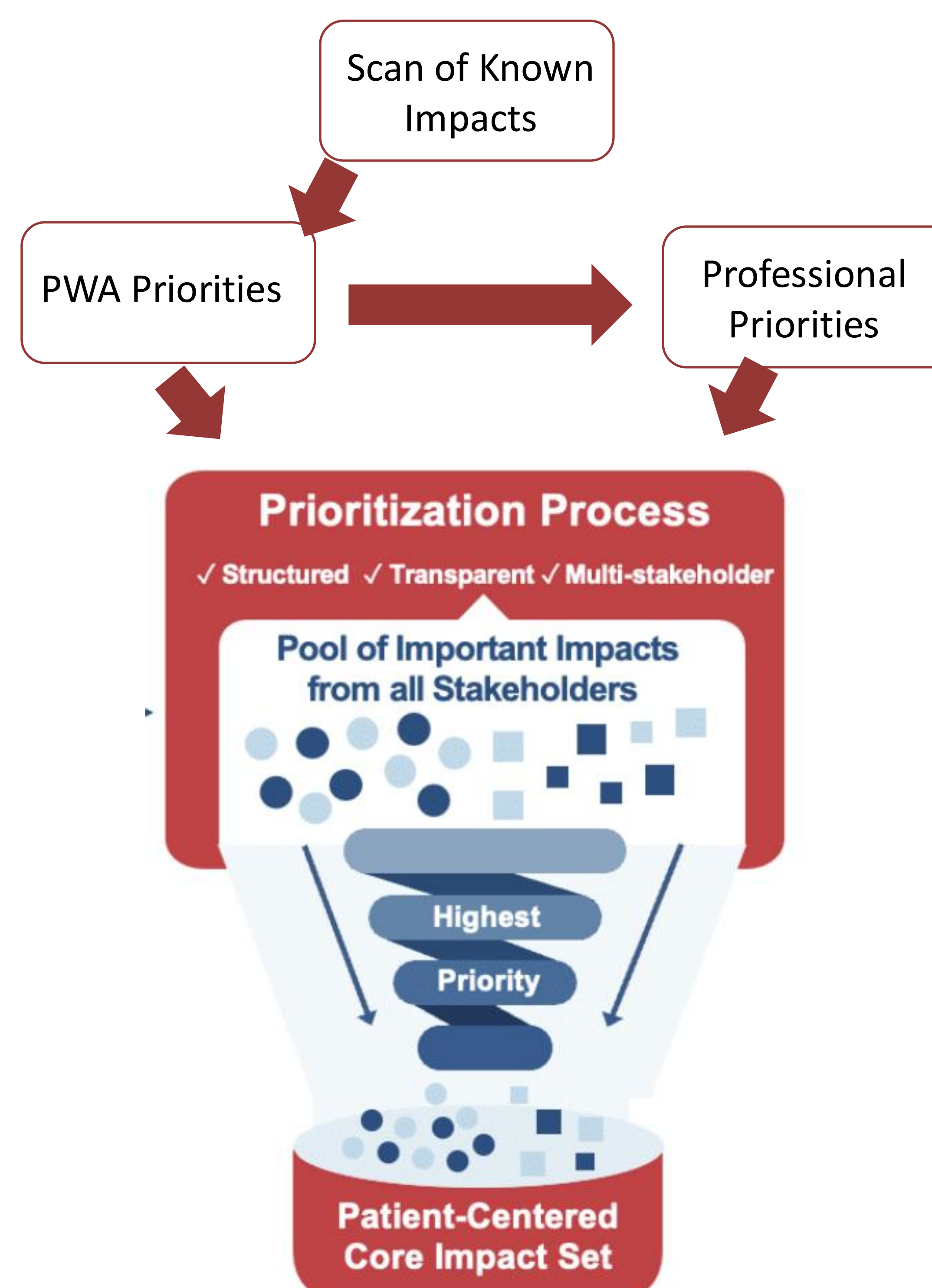
Core Impact Sets	Core Outcome Sets
<ul style="list-style-type: none"> • Developed by people living with condition and represents the patient's voice • List of experiences that have the greatest impact on a person's life • Examples: caregiver stresses, social isolation/loss of friendships, economic burdens 	<ul style="list-style-type: none"> • Developed by researchers and clinicians • List of tests/assessment measures that help researchers to compare across studies • Examples: Western Aphasia Battery, General Health Questionnaire, Stroke and Aphasia Quality of Life Scale

OBJECTIVE

Our goal is to include people with aphasia and their families into a systematic process for developing research priorities that address the consequences of aphasia in the US context.

METHODOLOGY

The National Health Council's Blueprint for Patient-Centered Core Impact Sets is an established and validated approach to ensure that the priorities of patient stakeholders are preserved within the process (Perfetto et al, 2022, 2023).



KEY POINTS

- Project Title: APHASIA IS (APHASIA Impacts defined by Stakeholders)
- Anticipated Start: June 2025
- Project Duration: June 2025 – June 2027
- Supporting Partner: Aphasia Access
- Funding: Proposal under review

OPPORTUNITIES TO PARTICIPATE

There will soon be opportunities for people with aphasia, care partners, and professionals from all disciplines to join:

- Advisory Board
- Volunteer to participate in convenings

Watch the NAA website for details (www.aphasia.org)

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