Helpful Terms

Collaborator: A person who works together with others on a project

Participant: A person who takes part in a study.

Rightsholder: A person who has a right to be included and help make decisions.

Ethics: Rules about what is fair and respectful to people.

IRB: A group that checks if a study is far and safe for people.

Consent: Saying “yes” to take part in something after getting clear information.

Capacity: The ability to understand and make decisions.

Inclusion: Making sure everyone can take part.

Exclusion: Leaving someone out.

BrainNYC
Building Resources for Aphasia
in New York City

Our Mission

At Brain NYC, our mission is to enhance the lives of those impacted by aphasia by creating a more inclusive, informed, and accessible New York City.

We aim to empower the aphasia community through education, research, advocacy, and collaboration.

Our goal is to connect people with aphasia to resources, support, and social opportunities to engage in ways that are meaningful to them.

Scan for our webpage

✉ BrainNYCAphasia@gmail.com

AphasiaAccess
Until Every Voice is Understood

Aphasia in the research journey

Thinking about ethics and how to work together

E. Susan Duncan

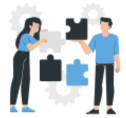
Bernadine Gagnon

Amy Vogel-Eyny

on behalf of

BrainNYC
Building Resources for Aphasia
in New York City

What you will learn



- Why include people with aphasia in research
- How to do it in a helpful way
- How to solve problems that may come up

01. People with Aphasia as Team Members

- People with aphasia can help with research-not just be in it.
- This makes research more helpful and fair.

Helpful tips:

- Give information ahead of time.
- Use plain language and pictures.
- Let people help in ways that match their strengths.
- Check if everyone understands.

02. People with Aphasia as Research Participants

- People with aphasia are often left out of research.
- This is not fair and breaks important rules.
- Aphasia does not mean someone cannot decide.

To include people:

- Give more time to talk.
- Use pictures and clear words.
- Let people write, speak, or point.
- Ask speech therapists to help

03. People with Aphasia as Research Readers

People with aphasia are not just in research — they are affected by it.

They deserve to know what research says and how it might help them.

We need to share research in ways that match what people need in different way.

For people with aphasia, that might mean:

- **Plain language summaries**
  - short versions using simple words.
- **Video summaries**
  - someone explains the research out loud, sometimes with images

DISCUSSION SUMMARY

Aphasia throughout the Research Lifecycle:
Ethical and Institutional Considerations in Partnership and Participation

E. Susan Duncan, Bernadine Gagnon, Amy Vogel-Eyny
on behalf of ***BrainNYC*** *(Building Resources for Aphasia in NYC)*
2025 Aphasia Access Leadership Summit

Thank you for attending our 2025 Aphasia Access Roundtable and participating in a discussion we found highly enjoyable, informative, and provocative! Below we highlight some key points from the discussion and share some additional resources. Let's keep the conversation going!

Involving People with Aphasia in Research

- Arnstein's Ladder (1969): model for hierarchical engagement from participation to true co-design
- Project BRIDGE (Building Research Initiatives by Developing Group Effort) as model for multi-"stakeholder" research teams
    - Project BRIDGE resource page; noting some links are broken such as UNC aphasia-friendly print material and Aphasia Institute templates
    - Provided webinars in advance, differing for researchers/clinicians and people with aphasia/family members (playlist of videos on YouTube)
- Many strategies are just good practice for any research team, especially one with community partners
    - Advance training; clarifying expectations for all parties; providing relevant materials prior to meetings; assigning roles based on strengths/expertise; avoiding jargon; regular meetings/check-ins; summary follow-ups soon after meetings
- Additionally, create aphasia-friendly materials and communication supports, more ground-level training
    - Some individuals may also require a communication facilitator and/or AAC device

IRB and Informed Consent: Challenges

- Difficult to navigate and institution-specific, whether for engaging people with aphasia as research participants (i.e., accessibility of consent forms) or as members of the research team
- For co-design processes including people with aphasia (and co-survivors), "official" IRB status may be:
    - As participants (easier for compensation but can be role-limiting)
    - As co-investigators (requires CITI training, which highly inaccessible for people with aphasia)
    - As advisors or consultants (unclear IRB requirements)

IRB and Informed Consent: Possible Strategies

- For program development without data collection, IRB may not be needed
    - Formal application to IRB for exempt status can offer IRB # and official approval
- Community advisory boards may be handled differently than research participants or co-investigators (if not viewing data)
    - This may include alternative mechanisms for paying as consultants (vs. participants)
- Some institutions accept alternative training for community partners, or it may be possible to establish a non-CITI IRB-approved training for laypersons
    - University of Pittsburgh has a Community Partners Research Ethics Training
    - University of Illinois-Chicago has developed a CIRTification training
    - University of Pennsylvania adapted this for its Community Partner Training
    - Noting these are developed for community partners *without* aphasia
- For co-design processes, all participants could be co-authors
    - Check with your IRB, but typically approval is not required if all human participants are authors

Informed Consent Adaptations

- Nearly all institutions require standard complex consent forms to be signed
  - With specific “legalese” passages intended to protect the participant? The institution?
- Consent process needs to be adapted for people with aphasia to permit true informed consent
  - Some researchers create aphasia-friendly versions to be presented alongside official forms
    - May be submitted to the IRB as "support material"
  - May be considered "information sheets" since they're not part of the official consent document
    - IRB may want to review and approve these also
  - Since signature is required on the less accessible form, side-by-side review of both documents during consent process may be more comfortable for both researcher and participant
- Pre-consent discussions are important regardless (may require > 1 hour to explain the project)
  - Noting that consent is an ongoing process for the duration of the study
- Some participants have requested video explanations with captions
  - Sending these and other aphasia-friendly materials in advance may help reduce time requirements for initial in-person consent process

Disseminating Research to People with Aphasia

- Creating aphasia-friendly abstracts of published articles in plain language
  - Noting Article Friend tool introduced during Aphasia Access Brag & Steal
- Including graphical or video abstracts when publishing in journals that support these
  - Project Bridge Journal Guide (2021) lists journals accepting aphasia-friendly formats
- Sharing research with aphasia groups and discussing it together (e.g., ARCH offers “Science of Aphasia for People with Aphasia” virtual community meetings)
- Converting research into conversational podcasts discussing key points via Google’s Illuminate or Language Model Notebook
- Developing infographics to communicate research findings via social media and other avenues
- Making aphasia-friendly materials available on our research and community websites for wider access
- Noting that these approaches are also useful for member checking to help validate qualitative results when working with individuals with aphasia and co-survivors in a participatory or design capacity

Future Directions & Needs

- Standardized guidelines for community engagement in research
  - Including specific, shared terminology for level of engagement (e.g., per Arnstein’s Ladder)
- Developing better CITI training alternatives for people with aphasia
  - Could benefit from creating and sharing resources across institutions, such as examples above
- Presenting at conferences like PRIM&R (Public Responsibility in Medicine and Research) could help advance understanding among IRB members and administrators, leading to widespread adoption of more accessible practices for consent forms and community partner engagement

Contact Information:

- E. Susan Duncan (The Graduate Center, CUNY): esduncan@gc.cuny.edu

- Bernadine Gagnon (Teachers College, Columbia University): bgagnon@exchange.tc.columbia.edu

- Amy Vogel-Eyne (Hunter College, CUNY): avoge@hunter.cuny.edu

- BrainNYC (Building Resources for Aphasia in New York City): brainnycaphasia@gmail.com

Aphasia throughout the Research Lifecycle: Ethical and Institutional Considerations in Partnership and Participation

E. Susan Duncan, Bernadine Gagnon, Amy Vogel-Eyny
*on behalf of **BrainNYC** (Building Resources for Aphasia in NYC)*

2025 Aphasia Access Leadership Summit

Participants will be able to:

1. Describe the advantages of including aphasia “rightsholders” in a collaborative research role
2. Discuss strategies for effectively engaging people with aphasia in research, whether as collaborators or participants
3. Formulate solutions in response to potential ethical and institutional challenges that may be encountered when conducting research with aphasia “rightsholders”

Part 1: People with aphasia as research collaborators

There are many strong, evidence-based reasons to involve people with aphasia in research not only as participants but also as collaborators. Engaging those directly affected by aphasia leads to research that better reflects lived experiences, produces more applicable findings, and helps bridge the gap between research and clinical practice. Beyond these practical benefits, ethical principles such as **respect for persons** emphasize the importance of including those impacted by research in its design and execution. The disability movement’s phrase, **"nothing about us without us,"** highlights the need for full and direct participation of marginalized groups in decisions that affect them. While the term "stakeholder" has traditionally been used, concerns raised by Indigenous communities have led to the adoption of **"rightsholder"** as a more inclusive alternative. In aphasia research, rightsholders may include people with aphasia, co-survivors, and speech-language pathologists working in clinical settings. Many of the strategies that are useful for including people with aphasia as members of the research team are best practices for effective collaboration. These include offering training, clarifying expectations, providing relevant materials in advance of meetings, assigning roles according to strengths/interests, avoiding jargon, actively ensuring understanding, recognizing contributions, and providing summaries as follow-up. Additional support in the form of aphasia-friendly materials, assistive devices, and communication facilitators may also be required.

Part 2: People with aphasia as research participants

People with aphasia are often excluded from stroke research, sometimes because consent procedures are not adapted to their communication needs. This exclusion not only undermines the external validity and ethical integrity of studies, it also violates essential principles such as **respect for persons** (from the Belmont Report) and the **right to information** (from the United Nations Declaration of Human Rights). It further demonstrates the “Inverse Care Law,” by which those with the greatest need—people who have poorer outcomes, higher healthcare costs, and more social isolation—are left out of research. Researchers may mistakenly presume that aphasia means an inability to consent, confusing the ability to make an informed decision (capacity) with legal competence. As a result, Institutional Review Boards (IRBs) sometimes err on the side of exclusion rather than providing the necessary accommodations. This leads to **scientific bias and healthcare inequities**. By allowing extra time for consent, involving trusted support persons, using clear language with visual aids, offering multiple ways for participants to communicate, and verifying understanding at each step, researchers can make their studies accessible. Speech-language pathologists can also support these efforts by helping design and carry out communication strategies. Ultimately, **inclusion should be the default**: IRBs, funders, and journals can insist on accessible protocols, ensuring that stroke research genuinely serves everyone.

Part 3: People with aphasia as research consumers

Beyond participation and co-creation, people with aphasia are consumers of research who **deserve access** to information that affects their lives. However, many lay people face challenges understanding research due to complex language and formatting. To improve access, researchers should use **plain language, visual supports, and multimodal formats** like videos and infographics. Short sentences, clear layout, and simple vocabulary support comprehension. Involving people with aphasia in co-creating and reviewing research summaries ensures materials are truly accessible. These strategies promote **engagement, inclusion, and empowerment**, allowing people with aphasia to be active participants in research that affects them.

Select Resources/References

Part 1: People with aphasia as research collaborators

Brice, A., & Hinckley, J. (2022). Building Research Initiatives by Developing Group Effort (BRIDGE): Patient-partners in aphasia research. *Seminars in Speech and Language, 43*(5), 426-444.

Charalambous, M., Kountouri, A., Schwyter, J. R., Annoni, J. M., & Kambanaros, M. (2023). The development of the People with Aphasia and Other Layperson Involvement (PAOLI) framework for guiding patient and public involvement (PPI) in aphasia research. *Research Involvement and Engagement*, *9*(1), 74.

Hersh, D., Israel, M., & Shiggins, C. (2022). The ethics of patient and public involvement across the research process: Towards partnership with people with aphasia. *Aphasiology*, 1-26.

Part 2: People with aphasia as research participants

Hinckley, J., & Jayes, M. (2023). Person-centered care for people with aphasia: Tools for shared decision-making. *Frontiers in Rehabilitation Sciences*, *4*, 1236534.

Penn, C., Frankel, T., Watermeyer, J., & Müller, M. (2009). Informed consent and aphasia: Evidence of pitfalls in the process. *Aphasiology*, *23*(1), 3–32.

Russell, A. M., Shepherd, V., Woolfall, K., Young, B., Gillies, K., Volkmer, A., Jayes, M., Huxtable, R., Perkins, A., Noor, N. M., Nickolls, B., & Wade, J. (2023). Complex and alternate consent pathways in clinical trials: Methodological and ethical challenges encountered by underserved groups and a call to action. *Trials*, *24*(1), 151.

Shiggins, C., Ryan, B., O'Halloran, R., Power, E., Bernhardt, J., Lindley, R. I., McGurk, G., Hankey, G. J., & Rose, M. L. (2022). Towards the consistent inclusion of people with aphasia in stroke research irrespective of discipline. *Archives of Physical Medicine and Rehabilitation*, *103*(11), 2256–2263.

Part 3: People with aphasia as research consumers

Dormer, L., Schindler, T., Williams, L. A., et al. (2022). A practical 'How-To' guide to plain language summaries (PLS) of peer-reviewed scientific publications: Results of a multi-stakeholder initiative utilizing co-creation methodology. *Research Involvement and Engagement, 8*(23).

Finch, E., Pierce, J. E., Pais, A. M., Dow-Richards, C., Reed, A., Charalambous, M., ... & Breitenstein, C. (2024). Preferences of people with post-stroke aphasia for aphasia research videos: An international project. *Aphasiology*, *38*(4), 758-769.

Hinckley, J., & El-Khouri, C. (2023). Why and how to publish aphasia-friendly research summaries. *Journal of Communication Disorders*, 104, 106338.

Notes: