

In or Out?

Acute-phase aphasia education can
increase interest in future research
participation

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Penn Medicine



LCNS LABORATORY FOR
COGNITION AND
NEURAL STIMULATION



Penn LDI
LEONARD DAVIS INSTITUTE *of* HEALTH ECONOMICS

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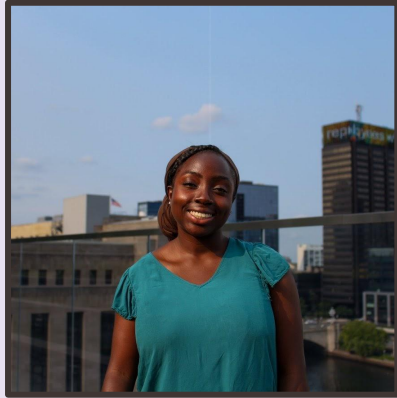
Overview of Project

Ongoing study that investigates whether an opt-out strategy enhances enrollment among patients with post-stroke aphasia

02

Lessons Learned

Introductions



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What is Aphasia?

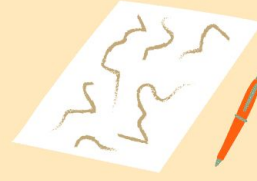
Symptoms of Aphasia



Trouble speaking clearly



Trouble understanding speech



Trouble writing clearly



Trouble understanding written words



Trouble remembering words

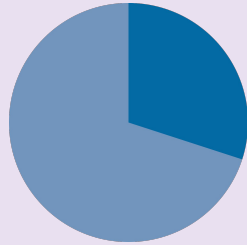


Trouble remembering object names

verywell

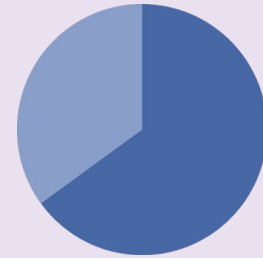
15%-42%
Incidence Rate of
post-stroke aphasia in
acute-care settings

Aphasia Education in Numbers



1/3

Of census represented population have never heard of aphasia



40%

Of people can identify aphasia as a language disorder

Significance of Aphasia Education

After stroke onset,
patients should
receive prompt
aphasia education

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Patient education: Aphasia (The Basics)

Written by the doctors and editors at UpToDate

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What is aphasia?

Aphasia is the medical term for when a person stops being able to use or understand language. It happens when the brain is damaged in some way, usually because of a stroke.

There are different types of aphasia. Some types affect a person's ability to understand speech or to read. Other types affect a person's ability to form speech or to write. There are many different types of aphasia. Just a few examples are listed below.

- **Broca's aphasia** (also called "non-fluent aphasia" or "expressive aphasia") – People with this type of aphasia can understand a lot of what is said but they have trouble speaking and writing.
- **Wernicke's aphasia** (also called "fluent aphasia") – People with this type of aphasia can form speech but have trouble understanding it. They often produce a lot of speech that doesn't make sense and sometimes use made-up words. Doctors sometimes call this "word salad."
- **Global aphasia** – People with global aphasia cannot speak or understand written or spoken language.
- **Anomic aphasia** – People with this type of aphasia have trouble naming specific objects. They might still be able to speak and use verbs, but they cannot recall what different things are called.
- **Alexia** – People with this type of aphasia lose the ability to read. They cannot understand written words. Most people who have this problem have other problems understanding language, too. Alexia does not usually happen on its own.

The Problem: Sample

LCNS has **10+ years** of experience with recruiting **chronic aphasia patients** for Transcranial Magnetic Stimulation (**TMS**) studies.

Yet, LCNS only treats **small fraction of 450 patients** who are treated for stroke and aphasia at Penn Medicine hospitals.



Current trial for chronic aphasia and TMS **requires larger sample size** which means increasing patient yield.

The Problem: Standard Recruitment Efforts for Chronic Aphasia

1. Reach out to patients referred by Penn Stroke Team during their **acute recovery phase**
2. Inform patients about LCNS studies and secure their permission to contact them **6 months later**
3. **Re-establish** contact 6 months later.

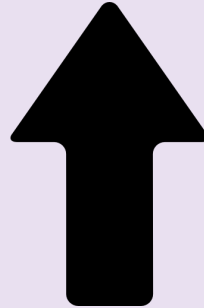
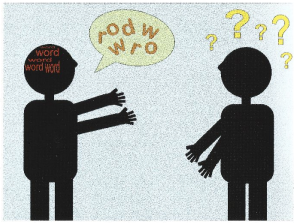


Research Question:

Does combining early aphasia education with a default option increase participation in research?

WHAT IS APHASIA?

Aphasia results from damage to the brain from a stroke, brain injury, or other neurological disease. It causes difficulty with communication skills (speaking, writing, listening/understanding, reading).



Opt-in or Opt-Out?

Behavioral Economics: combines the economics of incentives with insights from psychology about how people actually behave under real-world circumstances.

Nudges: subtle changes to choice or the framing of information that can **significantly** influence behavior without **restricting choice**

State public health records show you completed your primary COVID vaccine series at least 6 months ago and if so are due for a booster. For more info, visit <https://covid19.colorado.gov/vaccine/where-you-can-get-vaccinated>



Opt-in or Opt-out

Opt in:

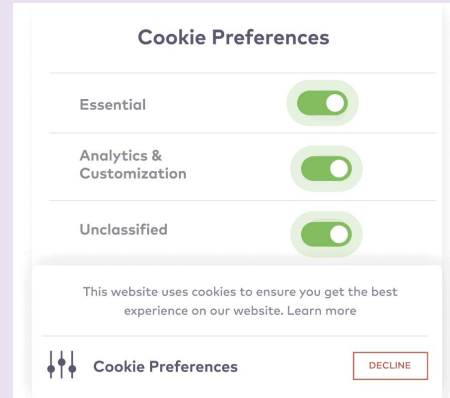
- default is **not** to participate
 - ❖ Typical standard recruitment procedure
 - ❖ Yields positive response rate of ~30%

A screenshot of a notification box with an orange border. It contains a small icon of a document and the text: "Share my registration data with Spotify's content providers for marketing purposes. Note that your data may be transferred to a country outside of the EEA as described in our privacy policy."

Share my registration data with Spotify's content providers for marketing purposes. Note that your data may be transferred to a country outside of the EEA as described in our privacy policy.

Opt out:

- **default** is to participate
 - ❖ Hypothesized to add an additional 30% positive response rate



Study Design

Participants

1. Individuals with left-hemisphere stroke
2. All prospective participants received aphasia education pamphlet



HOW YOU CAN HELP A PERSON WITH APHASIA COMMUNICATE:

- Be patient
- Let the person know you did not understand their message
- Accept any type of communication i.e. spoken, written, gestural, or assistive technology
- Maintain good eye contact
- Minimize distractions
- Speak at a normal volume and emphasize key words
- Stay on one topic at a time
- Confirm the person understands with “yes/no” questions
- Repeat or rephrase a message if not understood

WHAT CAN IMPROVE APHASIA?

- Individualized speech language therapy with a SLP in the hospital, home or outpatient clinic. Therapy may include impairment-based therapies and/or communication based therapies.
- Attending aphasia support groups
- Using assistive technology such as apps developed for persons with aphasia on a smart phone or tablet

Procedure

1. Provide aphasia education
2. Randomize to opt-in/opt-out enrollment
3. Inquire about interest in research through survey

Resources


- <https://www.asha.org>
- <https://www.aphasia.org>
- <https://www.stroke.org>

Research Opportunities at Penn Medicine

Contact the LCNS

The Laboratory for Cognition and Neural Stimulation (LCNS) is a team of clinicians and researchers dedicated to finding new therapies that enhance aphasia recovery

(215) 573-4336
braintms@penncmedicine.upenn.edu



In vs Out: Acute Script (initial)

At Penn Medicine, there is currently a trial for persons who are at least six months out from their stroke. This trial uses a safe, noninvasive therapy that modifies brain activity in an effort to enhance language recovery.



Opt-in (Control)

I wanted to inform you that you **have the option** of being a part of this trial/study. Amongst the resources we've given you today, there is a letter that explains that **if you would like to be contacted in the future** regarding our treatment trial, you have the option to do so.

Opt-out

Engagement in trials that may enhance speech recovery **is part of the standard of care** that we offer to patients with language problems due to stroke. In about 6 months, one of my colleagues or I **will reach out to you to schedule a visit**, in which we will discuss the details of the study, consider your eligibility, and if appropriate, enroll you.

Initial Interest in Research Scale

Instructions: Please circle the number that best describes your initial reaction to hearing about our clinical trial. Please answer honestly and follow your gut reaction!

Statement A	A Describes Me Much Better	A Describes Me Somewhat Better	I Am Neutral About Statements A and B	B Describes Me Somewhat Better	B Describes Me Much Better	Statement B
I am not interested in this clinical trial	1	2	3	4	5	I am very interested in this clinical trial

0
Not at all interested



5
Very interested

In vs Out: Chronic Script (6 months post Stroke)

When you were discharged you received an informational packet, which explained that the University of Pennsylvania is currently enrolling in treatment trials for patients who have had strokes.

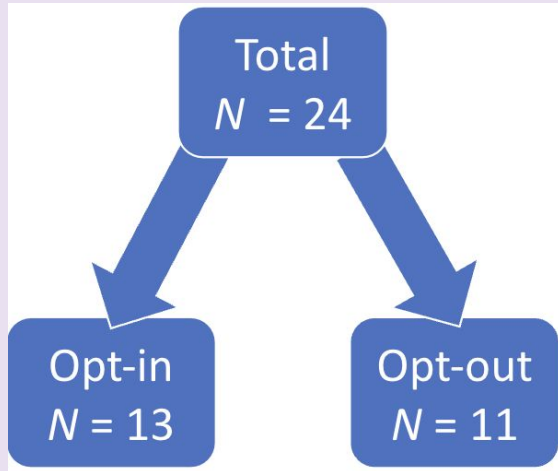
Opt-in (Control)

Opt-out

We informed you at that time that we would reach out to you about six months after your stroke in order to go over the details of our study with you and **ask if you are interested in scheduling a screening visit.** Is now a good time to talk more about this?

We informed you at that time that we would reach out to you about six months after your stroke in order to go over the details of our study with you, and **to schedule a screening visit.** Is now a good time to talk more about this?

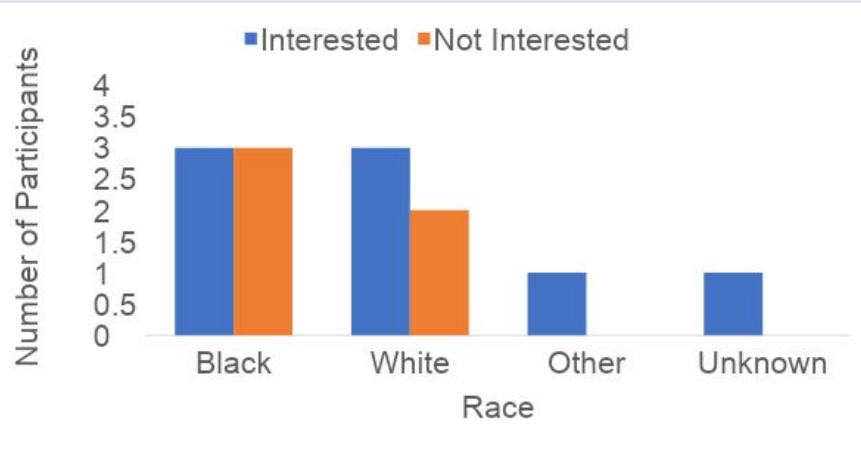
Participant Breakdown



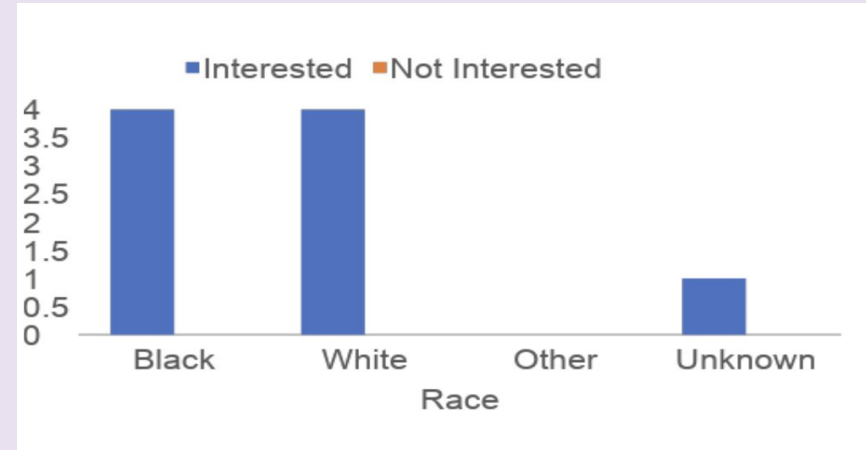
Demographics	Opt-In (Control)	Opt-Out	Total
Mean Age (SD)	55 (18.6)	62 (18.3)	58.1 (18.3)
Sex	F = 5; M = 8	F = 7; M = 4	F = 12; M = 12
Race	Black = 6 White = 5 Other = 1 Unknown = 1	Black = 6 White = 4 Other = 0 Unknown = 1	Black = 12 White = 9 Other = 1 Unknown = 2
Ethnicity	Non Hispanic or Latino = 13 Unknown (not listed) = 0	Non Hispanic or Latino = 9 Unknown (not listed) = 2	Non Hispanic or Latino = 22 Unknown (not listed) = 2

Preliminary Results: Racial Breakdown

Opt-in Group



Opt-out Group

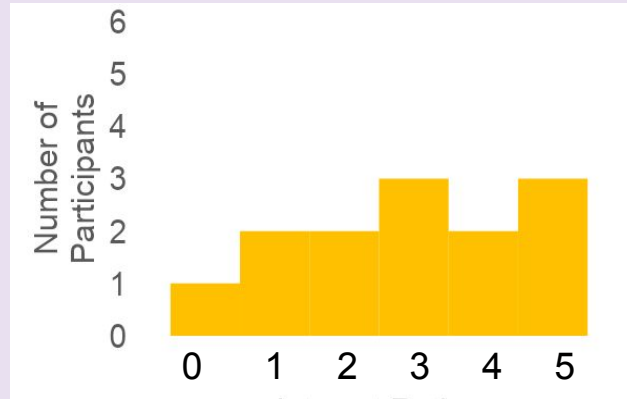


Race not significant

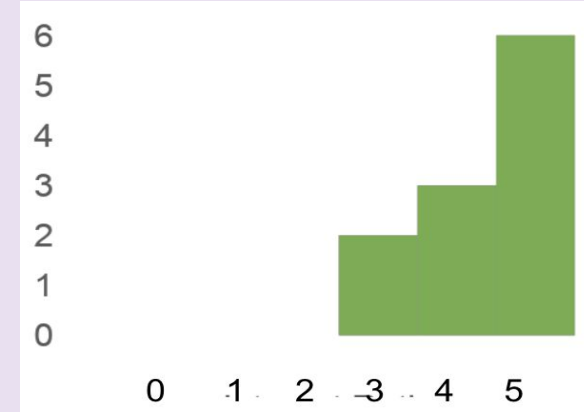
Preliminary Results: Ratings of Initial Interest

Ratings of interest in research participation were higher in the opt-out vs. opt-in group, $t(18) = -2.77, p = .013$.

Opt-in Group



Opt-out Group



Limitations and Next Steps

Limitations

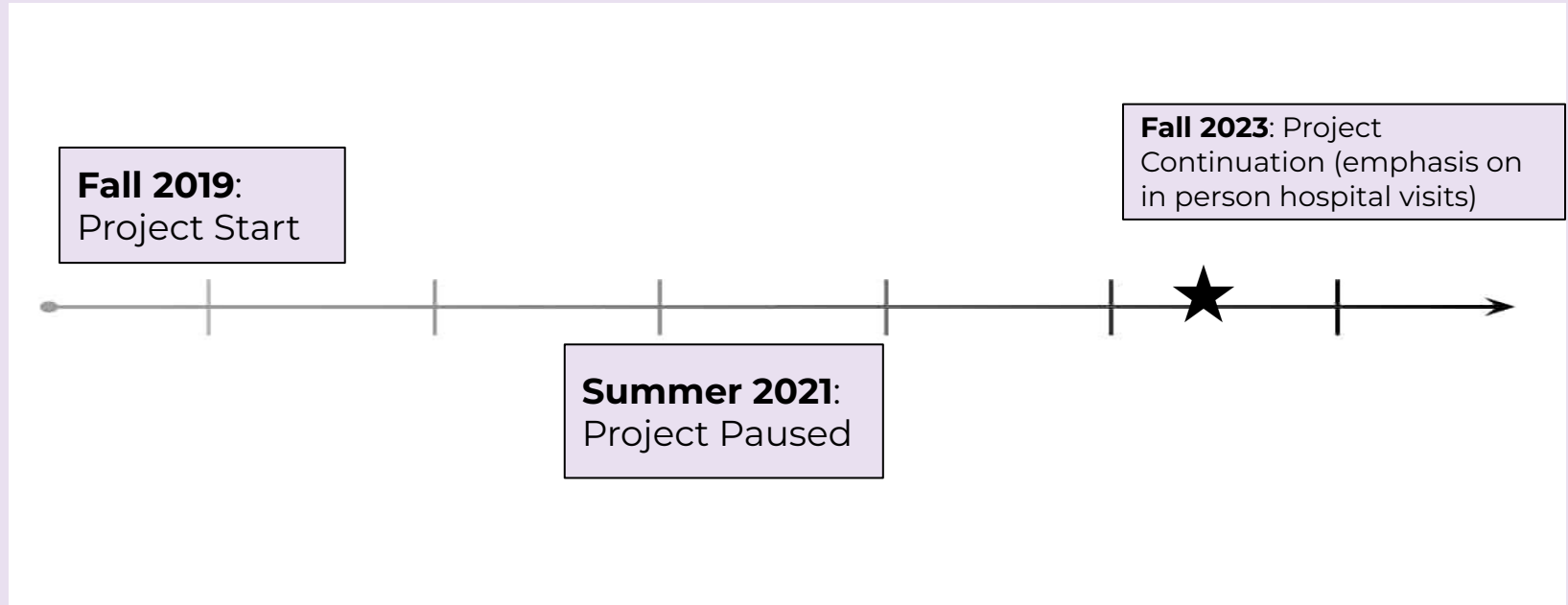
1. Small sample size
2. COVID-19 interrupted study progress and implementation of full study procedures

Next Steps

1. Gauge actual participation in larger sample size
2. Explore potential drawbacks of opt-out strategy, ie. perceived risk, coercion, commitment



Project Timeline



Outreach

Aphasia and healthy aging out
in the Philadelphia Community

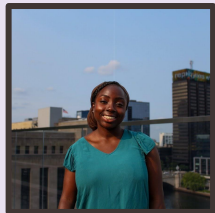


Penn Medicine
CAREs

Health Talk Tuesdays

Outreach Work at LCNS

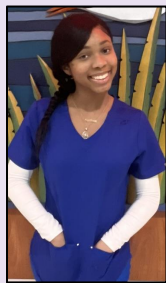
People



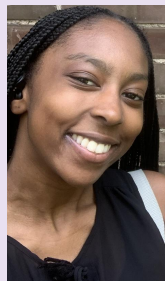
Christine Duah



Taylor Phillips,
BA



Dezhane
Sealy



Aisha Johnson



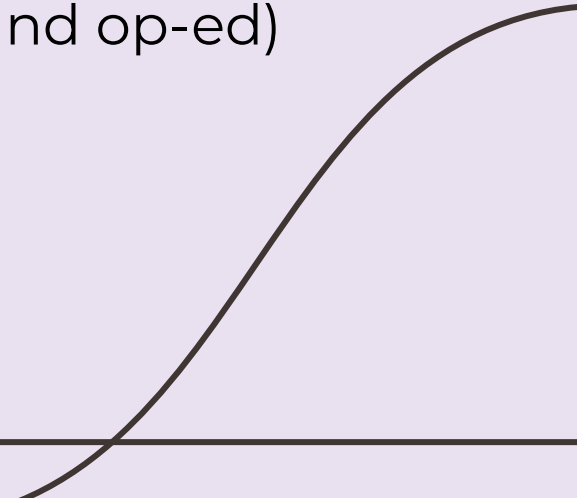
Best Practices for Educating Primary
Care Clinicians on Less Common
Conditions

Christine Duah

Clinician Outreach Plan for PPA or Stroke Aphasia

1. Identify target population for each condition
2. Identify primary care centers that serve target populations
3. Build a meaningful relationships with the clinicians
4. Build a learning plan that reflects the needs of the clinicians

Lessons Learned

1. Effective Communication with and listen to community members
 2. Analysis and organization of big data sets *
 3. Growth in writing skills (manuscript and op-ed)
 4. Time Management Skills
 5. Networking
 6. Independence
- 

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Dr. Roy Hamilton

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Taylor Phillips

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Dr. Denise Harvey

SUMR'23 Cohort



References

1. Hamilton, R. H., Sanders, L., Benson, J., Faseyitan, O., Norise, C., Naeser, M., ... & Coslett, H. B. (2010). Stimulating conversation: enhancement of elicited propositional speech in a patient with chronic non-fluent aphasia following transcranial magnetic stimulation. *Brain and language*, *113*(1), 45-50.
2. Kadojić, D., Rostohar Bijelić, B., Radanović, R., Porobić, M., Rimac, J., & Dikanović, M. (2012). Aphasia in patients with ischemic stroke. *Acta Clinica Croatica*, *51*(2.), 221-224.
3. Rice, T. (2013). The behavioral economics of health and health care. *Annual review of public health*, *34*, 431-447.
4. Ryglewicz, D., Hier, D. B., Wiszniewska, M., Cichy, S., Lechowicz, W., & Czlonkowska, A. (2000). Ischemic strokes are more severe in Poland than in the United States. *Neurology*, *54*(2), 513-513.
5. Tsao, C. W., Aday, A. W., Almarzooq, Z. I., Anderson, C. A. M., Arora, P., Avery, C. L., Baker-Smith, C. M., Beaton, A. Z., Boehme, A. K., Buxton, A. E., Commodore-Mensah, Y., Elkind, M. S. V., Evenson, K. R., Eze-Nliam, C., Fugar, S., Generoso, G., Heard, D. G., Hiremath, S., Ho, J. E., Kalani, R., ... American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee (2023). Heart Disease and Stroke Statistics-2023 Update: A Report From the American Heart Association. *Circulation*, *147*(8), e93–e621.
<https://doi.org/10.1161/CIR.0000000000001123>