In or Out?

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

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Table of contents

01 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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Cognitive Neuroscientist
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

15%-42%

Incidence Rate of post-stroke aphasia in acute-care settings

Kadojic et al. 2012
Ryglewicz et al. 2000
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

NAA “Aphasia Statistics” 2022
Significance of Aphasia Education

After stroke onset, patients should receive prompt aphasia education.
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.

Hamilton, R.H. et al. (2010).
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?
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

Rice (2013)
Opt-in or Opt-out

**Opt in:**

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

**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

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

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.

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!

<table>
<thead>
<tr>
<th>Statement A</th>
<th>A Describes Me Much Better</th>
<th>A Describes Me Somewhat Better</th>
<th>I Am Neutral About Statements A and B</th>
<th>B Describes Me Somewhat Better</th>
<th>B Describes Me Much Better</th>
<th>Statement B</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am not interested in this clinical trial</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>I am very interested in this clinical trial</td>
</tr>
</tbody>
</table>

0  Not at all interested

5  Very interested
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.

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

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Opt-In (Control)</th>
<th>Opt-Out</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (SD)</td>
<td>55 (18.6)</td>
<td>62 (18.3)</td>
<td>58.1 (18.3)</td>
</tr>
<tr>
<td>Sex</td>
<td>F = 5; M = 8</td>
<td>F = 7; M = 4</td>
<td>F = 12; M = 12</td>
</tr>
<tr>
<td>Race</td>
<td>Black = 6</td>
<td>Black = 6</td>
<td>Black = 12</td>
</tr>
<tr>
<td></td>
<td>White = 5</td>
<td>White = 4</td>
<td>White = 9</td>
</tr>
<tr>
<td></td>
<td>Other = 1</td>
<td>Other = 0</td>
<td>Other = 1</td>
</tr>
<tr>
<td></td>
<td>Unknown = 1</td>
<td>Unknown = 1</td>
<td>Unknown = 2</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Non Hispanic or Latino = 13</td>
<td>Non Hispanic or Latino = 9</td>
<td>Non Hispanic or Latino = 22</td>
</tr>
<tr>
<td></td>
<td>Unknown (not listed) = 0</td>
<td>Unknown (not listed) = 2</td>
<td>Unknown (not listed) = 2</td>
</tr>
</tbody>
</table>
Preliminary Results: Racial Breakdown

**Opt-in Group**

- Black: 4 Interested, 2 Not Interested
- White: 3 Interested, 4 Not Interested
- Other: 1 Interested, 2 Not Interested
- Unknown: 0 Interested, 1 Not Interested

**Opt-out Group**

- Black: 4 Interested
- White: 3 Interested
- Other: 1 Interested
- Unknown: 0 Interested

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, $t(18) = -2.77, p = .013$. 

![Histograms showing number of participants in Opt-in and Opt-out groups](chart.png)
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

- **Fall 2019:** Project Start
- **Summer 2021:** Project Paused
- **Fall 2023:** Project Continuation (emphasis on in person hospital visits)
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

Clinic 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

Best Practices for Educating Primary Care Clinicians on Less Common Conditions
Christine Duah
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
Acknowledgements

Dr. Roy Hamilton
Joanne Levy
ChiChi Nwadiogbu
Taylor Phillips
Dr. Tifani Biro
Dr. Denise Harvey
SUMR’23 Cohort
References


