

# Innovative Clinical Trials Education & Outreach to African Americans

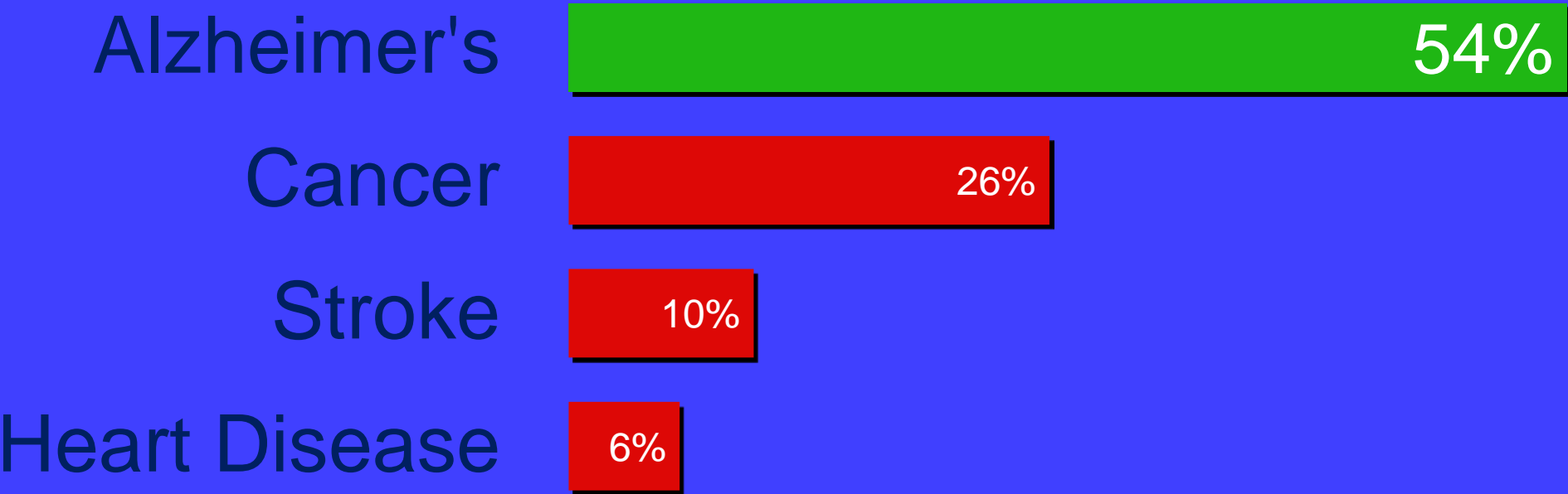
Stephanie J. Monroe, JD  
Executive Director,  
AfricanAmericans**Against**Alzheimer  
's



AfricanAmericanNetwork**Against**Alzheimer's

Stand up. Speak out. Overcome.

# Most Feared Diseases



# Forget Me Not Event Format

- Light reception
- 2 hour dramatic presentation
- Expert panel discussion with doctors, researchers, former AA research participants and Q&A
- Information tables with local research information, community resources and advocacy information

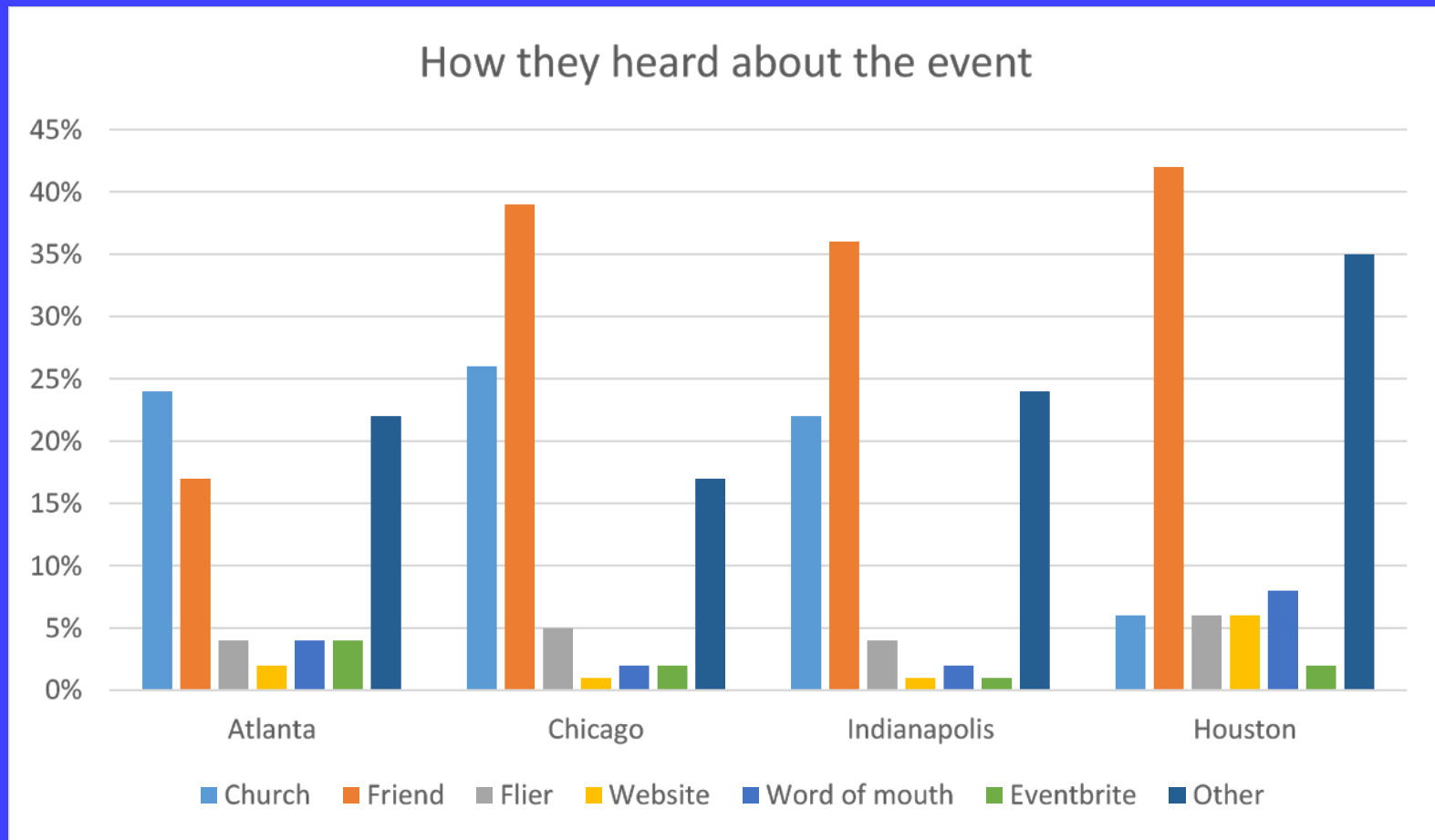


# 2015 Forget Me Not Attendees

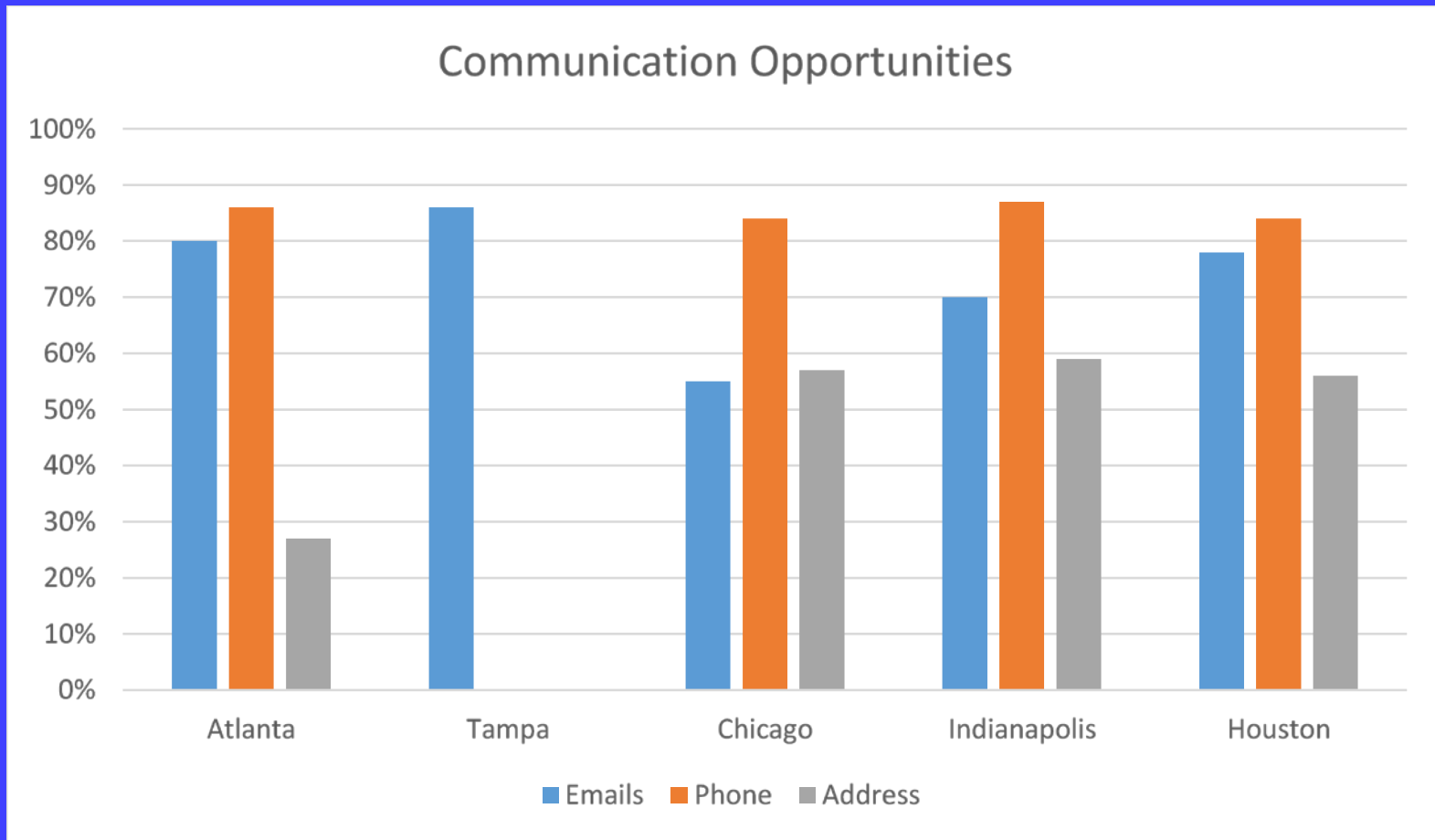
- Primarily 65 and older
- 86% women
- Primarily African American (over 80%)
- 5 Cities (Atlanta, Tampa, Chicago, Indianapolis, and Houston) 3699 Registrants



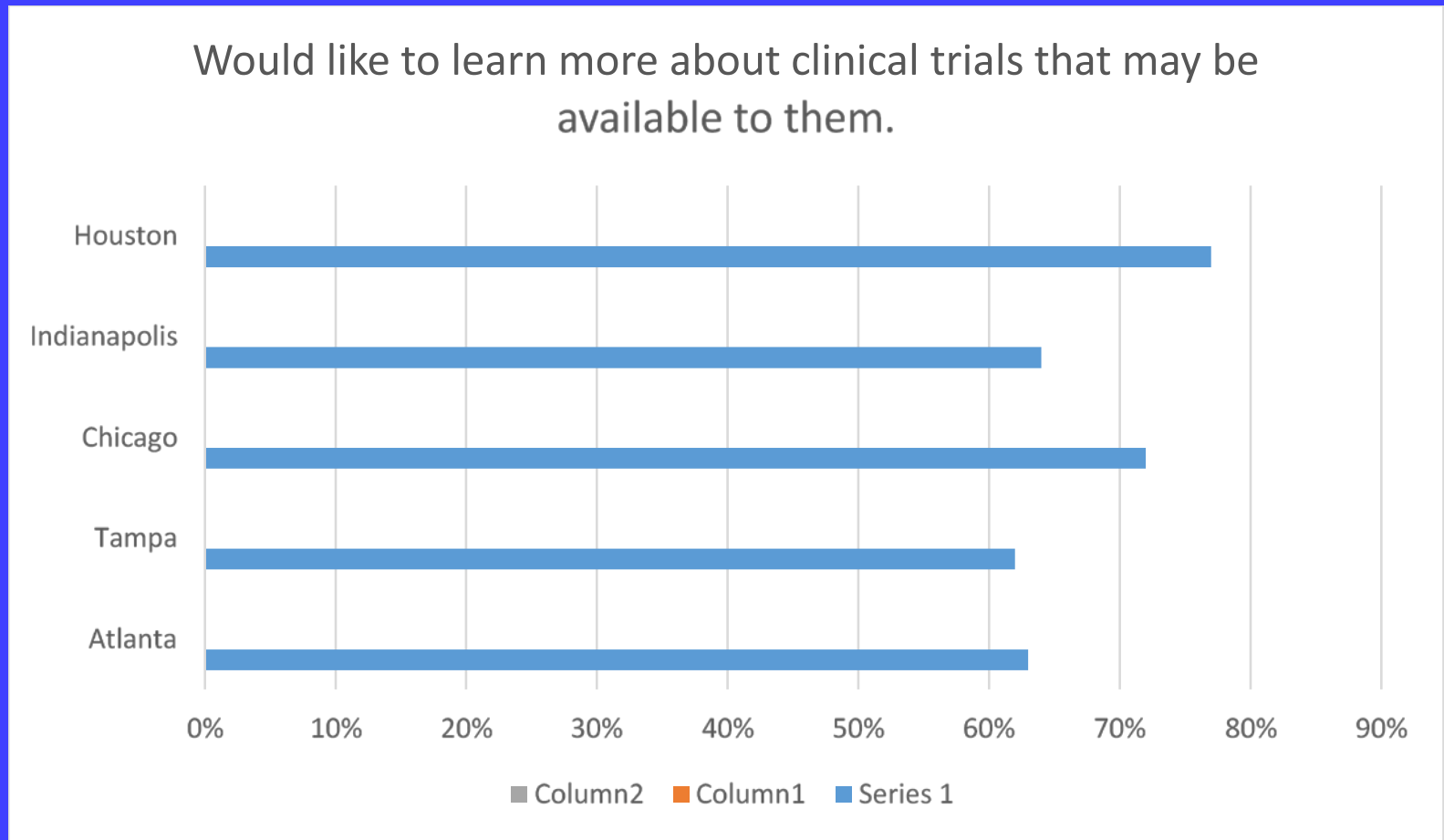
# Communication Channels: How We Reached Them



# Communications Methods

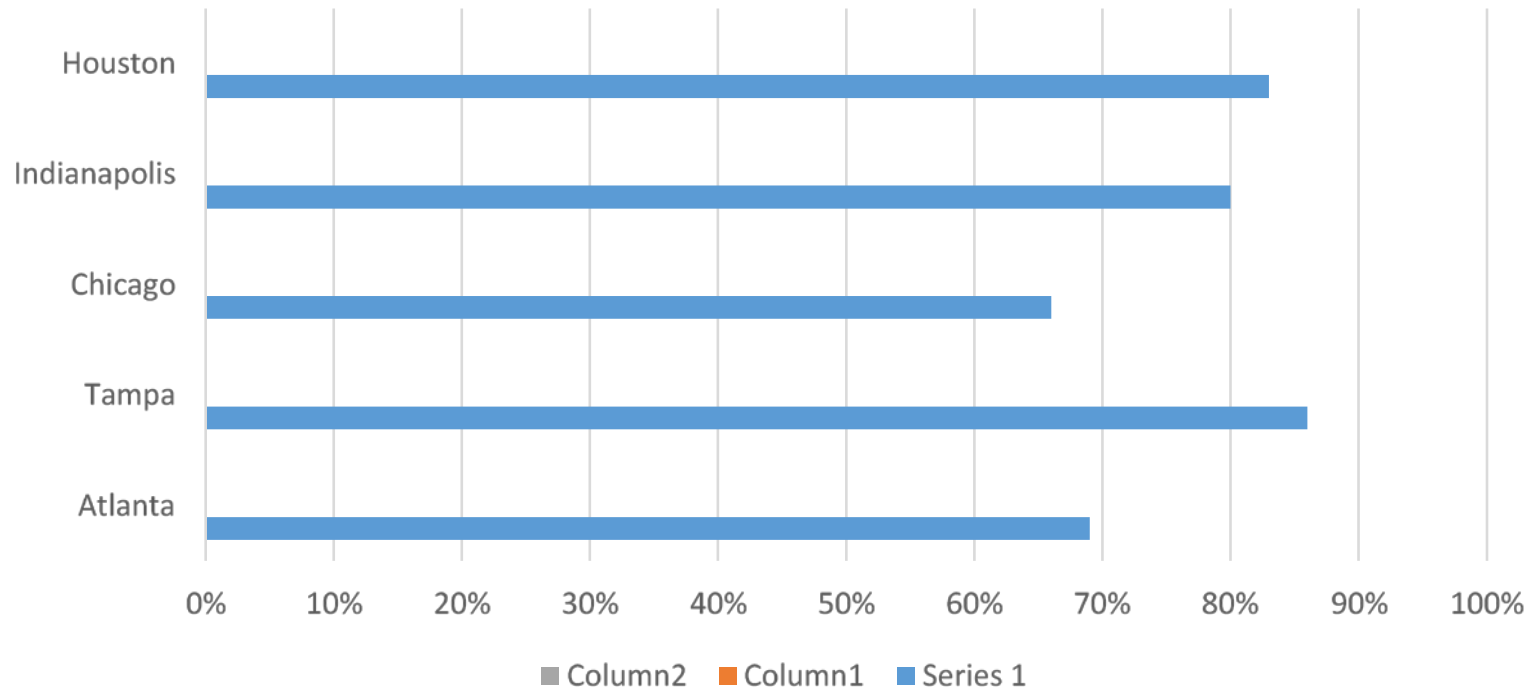


# High Interest in Receiving Clinical Trials Information



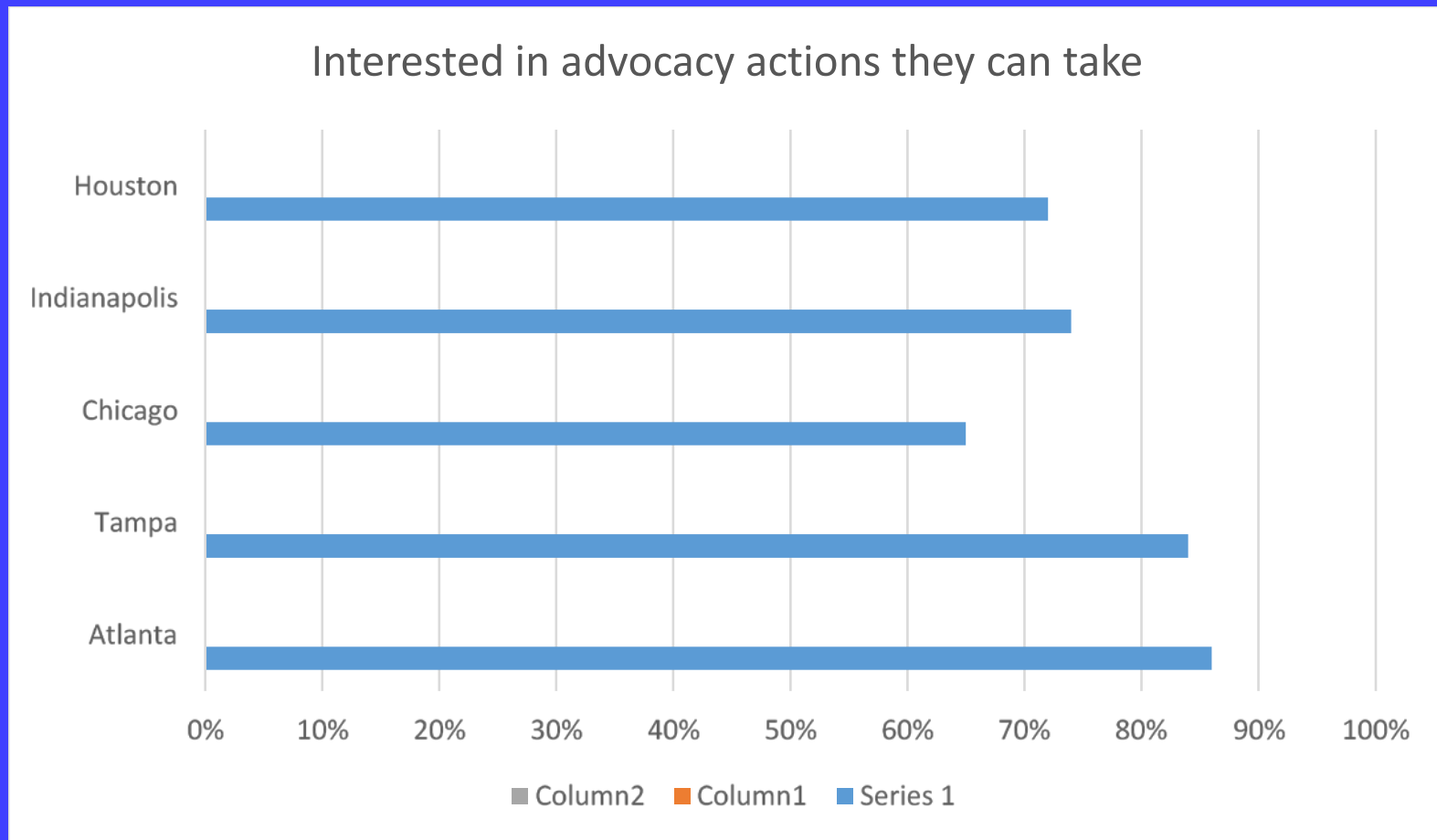
# Willing to Join Online Brain Health Registry (BHR)

Willing to go to the Brain Health Registry (BHR) website,  
play games and provide health and other information





# Willing to Advocate for Additional Alzheimer's Research



# What We Learned

- If we are creative they will come
- They are interested in participating in research if asked
- They are interested in their brain health and will do online work if they have access
- They are hungry for information and answers from trusted, engaged, and 'present' institutions.



# A New Opportunity

Minority Recruitment

Patient Engagement

Patient Voice in to Development of  
Trials

# The National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network (AD PCPRN)



**US**AgainstAlzheimer's  
we can stop it by 2020.

**UF** UNIVERSITY of  
FLORIDA

AfricanAmericanNetwork**Against**Alzheimer's  
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# National AD PCPRN

**Governed by:** patients, caregivers, leaders of patient groups, directors of existing patient registries, CDRN/PPRN collaborators, and clinical studies representatives

## **Goals of PCPRN:**

- 1) enroll an increasingly large number of subjects into this patient-centered network with a minority recruitment focus,
- 2) obtain self-reported information and measures of cognition at baseline and longitudinally,
- 3) screen & refer subjects for clinical trials, and
- 4) test a computable patient phenotype



# B. SMITH SHARES HER STORY

Renowned model, actress and restaurateur B. Smith is partnering with the Brain Health Registry to help find cures faster for all people.

[Learn More »](#)



It's safe, easy and free.

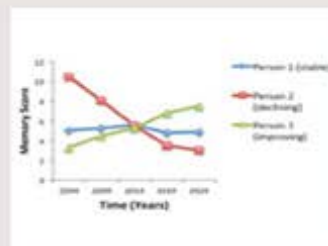
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**New Approach for  
Speeding Recruitment for  
Clinical Trials -...**



**Brain Health Registry  
Starts Return Visits for  
1500 Members**



**Draymond Green of the  
Golden State Warriors  
Records Video PSA on...**

# Thank You

[www.AfricanAmericansAgainstAlzheimers.org](http://www.AfricanAmericansAgainstAlzheimers.org)

**AfricanAmericanNetworkAgainstAlzheimer's**

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