

Brain Donation Efforts Among Minoritized Groups

Neuropathology Core Survey Results

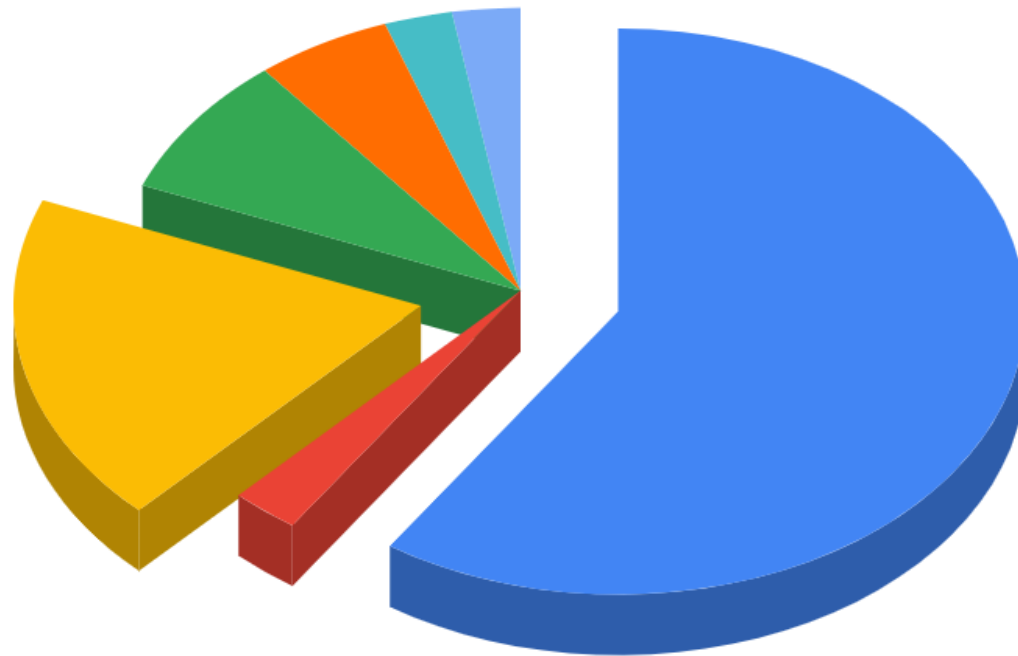
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Goal of the Survey

- Promote collaboration and synergy between Neuropath cores and ORE and/or other cores.
- Understand effective strategies for research participation or agreement to brain donation, with a focus on minoritized groups.
- Identify what neuropathology core activities are conducted within and outside of the center to promote education of brain donation.
- 100% RESPONSE RATE - BIG THANKYOU TO YOU ALL!!!

How do you identify yourself in relation to the ADRC?



- 60% Neuropathology Core Leader
- 19% Neuropathology Core Co-Lead
- 21% Other ADRC positions

● Neuropathology Core Leader ● Coordinator ● Neuropathology Core Co-Leader
● Administrator ● Other ● Research Specialist ● Director

Brain donation among minoritized/underrepresented groups across the ADRC's

Does your ADRC have outreach programs for brain donation?

76% Yes

16% No

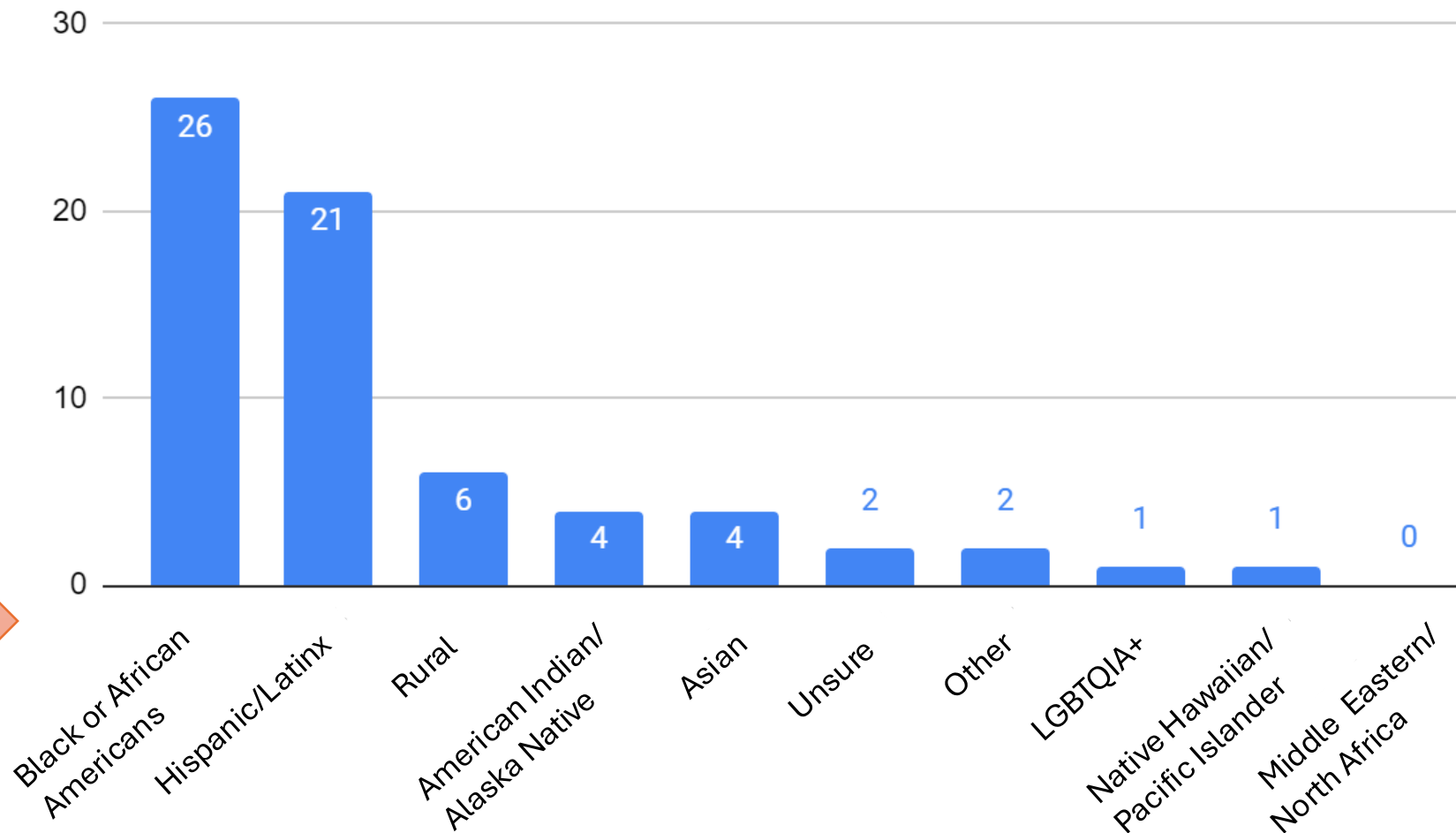
8% Unsure

Written languages for brain donation materials

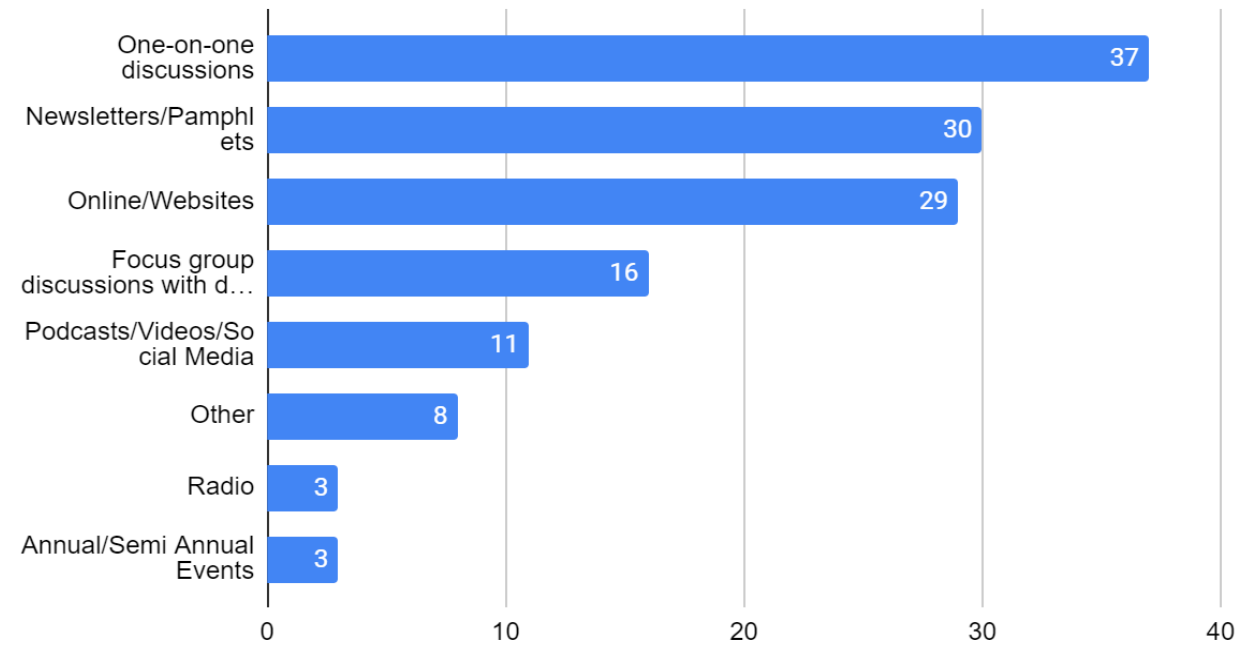
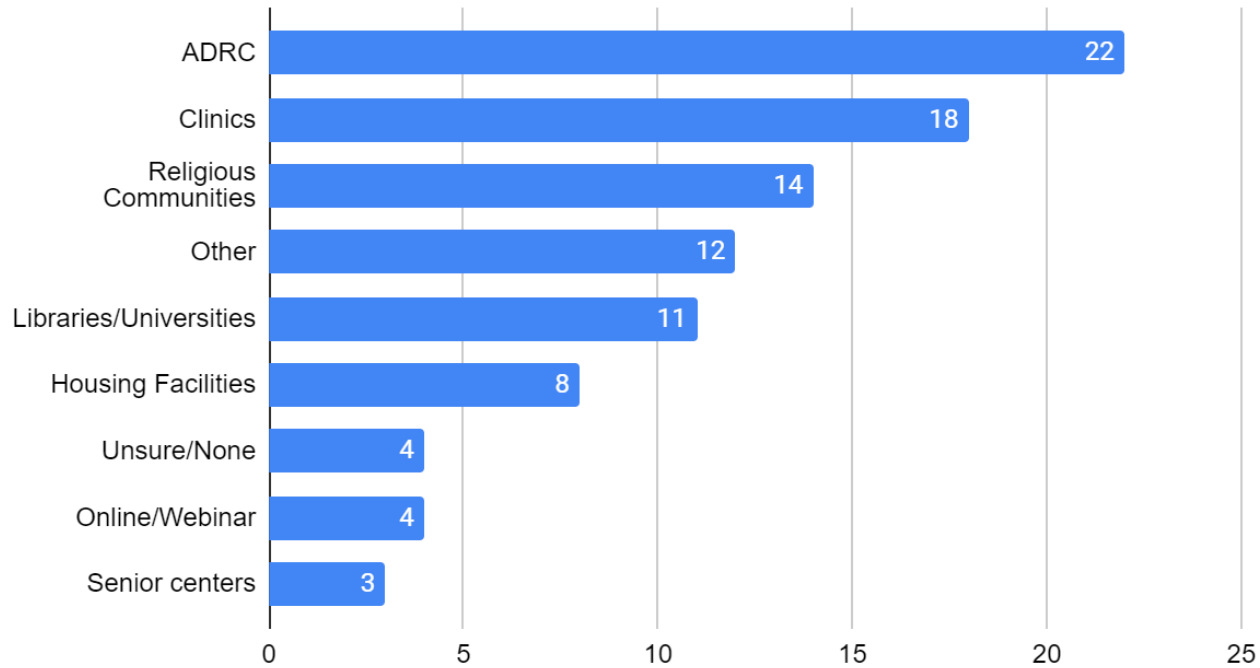
English – 36 ADRC'S

Spanish – 17 ADRC'S

Chinese/Mandarin - 1 ADRC



Where and how is information on brain donation disseminated at your ADRC?



Most effective strategies for outreach and recruitment for research participation

- **Being present in the community!!!**
- Retention events and trust-building activities
- Advice from community advisory board
- Advertisements: bus, train, public libraries, mailing campaigns
- Social media: Facebook, websites, podcasts
- Collaborations with local foundations and/or organizations
- Through clinics/clinical teams
- Educational events or health & wellness fairs
- Recruitment for community engagement positions and having bilingual and bicultural staff.
- Having current participants serve as 'research champions' for others
- Recurrent ADRC tours

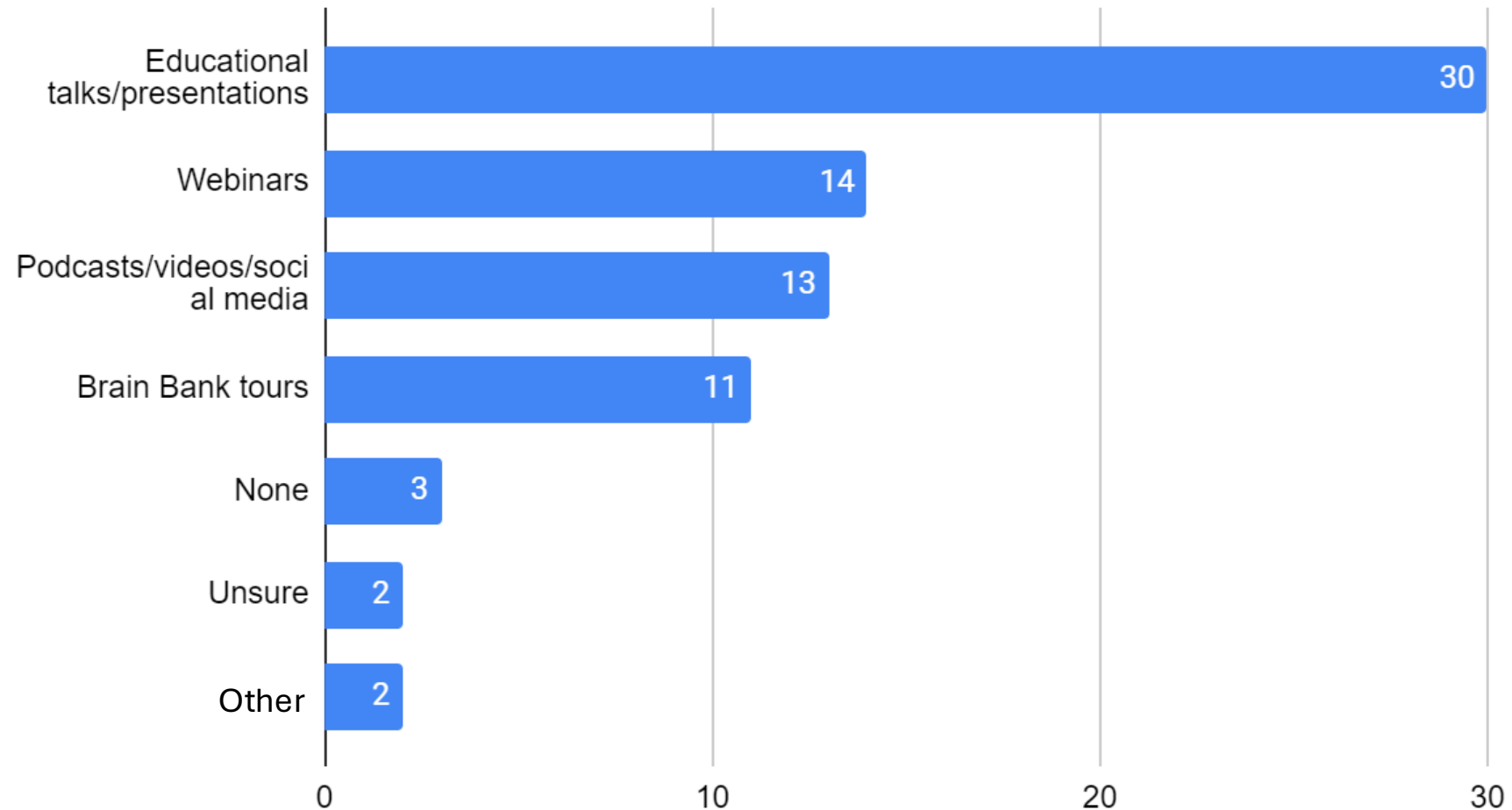
Neuropathology Core involvement in outreach activities on brain donation?

Neuropathology Core involved in outreach?

62% Yes
27% No
11% Unsure

Frequency?

49% As Needed
22% Monthly
19% Annually
5% Never
5% Unsure



To what extent does the Neuropathology Core actively consent individuals for brain donation ?

- 17 ADRC's: No involvement
- 12 ADRC's : High involvement (most participants)
- 5 ADRC's: Limited Involvement (few participants)
- 2 ADRC's: Other – NP Core consent for unexpected brain donors
- 1 ADRC: unsure

What additional educational activities does your Neuropathology Core perform, beyond the CPC?

- **Brain cutting conferences**
- **Microscopy case consults/conferences**
- **Training of NP and neurology fellows, REC investigators, graduate and post-grad students**
- Neuropathology didactic lectures
- Thesis committee participation
- Invited talks, symposiums, grand rounds, journal clubs
- Diversity seminars
- Elementary and high school site/lab visits
- Development of web-based pre- and post-test materials
- Summer educational programs
- Lab tours

Established affiliated programs/grants that conduct brain donation with a focus on racial/ethnic communities

- Collaboration between Duke/UNC ADRC and OCME in Baltimore to collect postmortem brains of individuals 30 to 65 years of age with 20% - 30% of decedents being African-Americans.
- KHANDLE study: Lifecourse health, cerebral pathology and ethnic disparities in dementia
- Life after 90: Brain Pathology in a Multiethnic Cohort of Oldest-Old
- The Minority Aging Research Study (MARS): Brain donation among African Americans without dementia
- R01AG082278: Obstructive Sleep Apnea with higher Alzheimer's disease risk in older Blacks/African-Americans with brain donation component

Other established brain donation programs/grants

- Manhattan HIV brain bank
- Neurobiobank
- VA Parkinson's neuropath project (CANPARK)
- Late effects of TBI (LETBI)
- California NeuroAIDS Tissue Network (CNTN)
- Autism Tissue Program / Autism BrainNet
- The Last Gift Study: Tissue Donation for HIV Research
- ALLFTD
- AG062418: Center On Alpha-synuclein Strains in ADRD
- AG066597 : Heterogeneity of FTLT-DTP and aging

**YOU'RE
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Thank you!!!

Hannah Rosentreter

Neuropathology Core Steering Committee Members

ORE Core Steering Committee Members

Dr. Nina Silverberg and all at NACC