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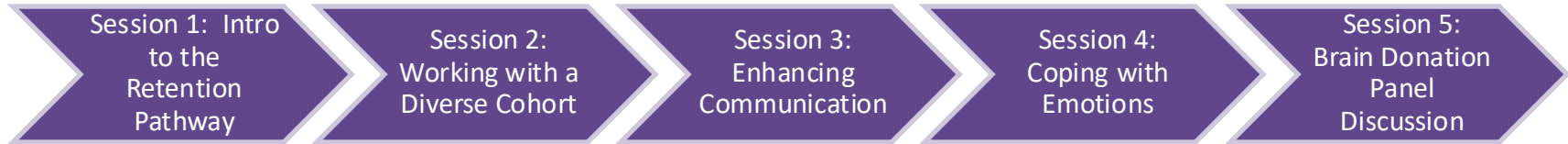
# Retention Pathway: Addressing Challenges to Longitudinal Study Participation

ORE Core Directors' Meeting  
October 16, 2024

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Northwestern ADRC



# Retention Pathway Seminar Series Training

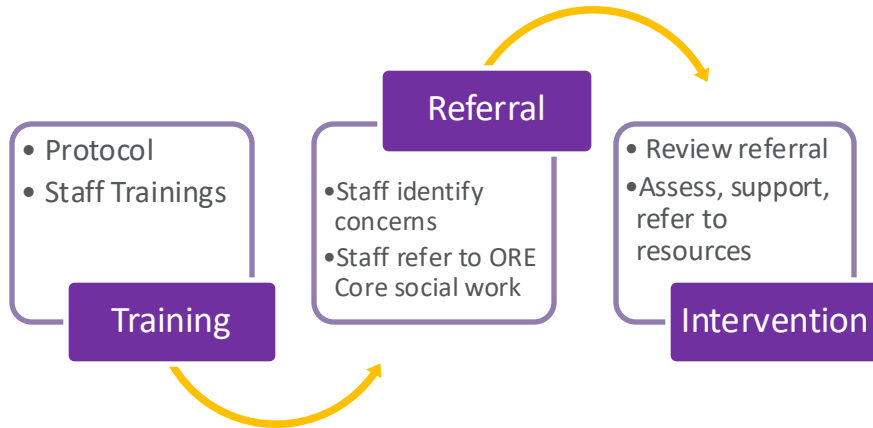


I'm excited to learn how to better advocate for participants by using the psychosocial pathway as a resource, how to better handle emotionally distressing conversations with participants, and to be equipped with knowledge and skills to be prepared for the different situations I might encounter in my daily work with research participants and their families.

# Retention Pathway

## Testing a Method for Research Retention

- Since 2019 received 113 referrals (31% URGs)
- Retained 84% of Retention Pathway referrals.



- Referral type

- Retention 39%

- Reduced availability (i.e., transportation or life stressor)
- Reduced interest in research participation generally (i.e., perceived benefit of research, time commitment)
- Reduced interest in study activity (i.e., testing, imaging)

- Depression, anxiety, caregiver burden 37%

- Access to resources 11%

- Brain donation 11%

- Other 2%

# Retention Pathway Examples

93 year-old: enrolled 15 years ago as not cognitively impaired who became cognitively impaired over time

68 year-old: enrolled 7 years ago with FTD

62 year-old: care partner of person living with PPA with high depression scores

# Other Retention Practices

- Glen & Wendy Miller Family Buddy Program
  - 28<sup>th</sup> program year. Total N=356
  - 2024: 19 pairs
- Monthly Care Partner Support Groups
  - PPA – 30 per month
  - FTD – 9 per month
  - Younger-Onset – 7 per month

- **Phone Call Onlys**
  - **Approximately 30 per year**
  - **Secure confirmation of brain donation and address psychosocial concerns, advance care planning, palliative care and hospice**
  - **Reinforce ongoing availability**

# Conclusion



Research participant retention in longitudinal trials is challenging



Retention Pathway is a method of providing individualized attention to participants and their families and reinforces reciprocity

# Acknowledgements

## ORE Core

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## Clinical Core

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## Data Core

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