

Remote Retention and Engagement Strategies Across ADRCs

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Clinical Research Practices & General Engagement



The pandemic made us reimagine standard operating procedures that we had all relied on to engage with our participants.

- clinical research visits to telehealth
- Mailed newsletters to digital
- In-person events to virtual
- Appreciation dinners to drive-thru lines

We learned many lessons and created sustainable engagement that will continue on “post-pandemic”

Mayo Clinic: Office for Human Research Protection
Telephone Script

COVID Courtesy Calls

Protocol Title: Alzheimer's Disease Research Center
IRB #: 712-98
Principal Investigator: Ronald Petersen, MD, PhD

Introduction:

Hello, this is _____ calling from the Mayo Clinic in Rochester, Minnesota OR Jacksonville, Florida (if out of state). May I please speak to _____?

***If the participant is there continue with the script.

***If the participant is not there, ask when it would be a good time to speak with _____?

Describe the Reason for the Call:

We are calling you today because you are an active participant in the Alzheimer's Disease Research Center study. First of all, we hope that you and your family are well. Our first priority at Mayo is the health and safety of our patients, participants in research studies and our staff. We greatly appreciate your willingness to help us out with the study.

Our Alzheimer's Disease Research Center Executive Team met recently to discuss the current COVID-19 situation. In order to best protect the health and safety of our participants and our staff, we have decided to suspend on-site research activities until it is deemed safe to resume. This will include in-person visits and testing, MRIs, PET scans, blood draws and lumbar puncture procedures.

Again, we hope that you are well and we will reach out again to schedule your next appointment when this suspension has been lifted.

Closing

Thank you for participating in our research study and please feel free to contact us if you have questions about the study. [Give them some follow-up contact information (name and telephone number) in case they think of any more questions afterwards.]

Educational Programming

- Launched the Community Connection program which provides information on community resources to study participants. – Wake Forest
- “Ask the Doc” events via Facebook Live (various topics related to ADRD) – Indiana University
- Conducted virtual caregiver workshop and caregiver bootcamp sessions to support ADRC community – UC Davis
- Dementia Matters Podcast on website, Spotify, iTunes, Google Play Music, etc. – Wisconsin



Community Engagement

- Forget Me Not play converted to weekly segments and discussion over 4-week period reaching 500 viewers - Pittsburgh
- Virtual Museum Tours and Docent Training – UC San Diego
- Cognitive Comedy – a free improv comedy workshop for people with cognitive impairment and their loved ones; now meets virtually on a weekly basis – Pennsylvania
- Activity book for People with Memory Loss – Rush
- Birthday card game with puzzles and answers on the website to drive traffic – Knight
- Participant Appreciation: Drive-thru coffee and donuts - Kansas



UC San Diego
SCHOOL OF MEDICINE
Shiley-Marcos Alzheimer's Disease
Research Center

Quality of Life Programs

Providing emotional support, education,
meaningful engagement, and coping strategies

Virtual Memories at the Museum



Engagement of Individuals from Under-Represented Groups

- Virtual diversity workshop: Racism and Its Implication for Clinical Research: A Workshop to Promote Understanding and Action with national speakers and discussions - Pittsburgh
- Monthly Minority men's programs - Average attendance 50+ to highlight resources and research – Emory
- Black History Month Dementia Education Programs – Columbia



Recruitment & Retention

- Launched quarterly Wellness Calls program that served as a personal check-in with participants. – Wake Forest
- Annual Honor Program – Emory
- MBTA advertisement, more than 1 million people ride the T every week – Boston



 MASSACHUSETTS
Alzheimer's Disease
Research Center

Meet Mike & Helene, our amazing research participants, at MADRC's "Let's Talk Research Participation" events! They will share what it's like to be in a research study.

Learn more & register online at:
<http://bit.ly/RsrchTalk>



Thank You!



University of Washington ADRC's New Years "Thank you" video