



Creating Inclusive Research Through a Culturally Aware Data Collection Site

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Background

Barriers to URG participation in research

- Historical trauma
- Lack of cultural safety
- Transportation
- Financial
- Racism
- Mistrust
- Research design

- Black individuals in the United States are at high risk for health disparities which increases risk for cognitive decline and Alzheimer's Disease and Related Dementias (ADRD).
- Black and Latino communities are 1.5-3 times more likely to suffer from Alzheimer's Disease than white individuals.

The goal of this study was to establish a community site for ADRD research. We address two major barriers to clinical research participation for under-represented groups:

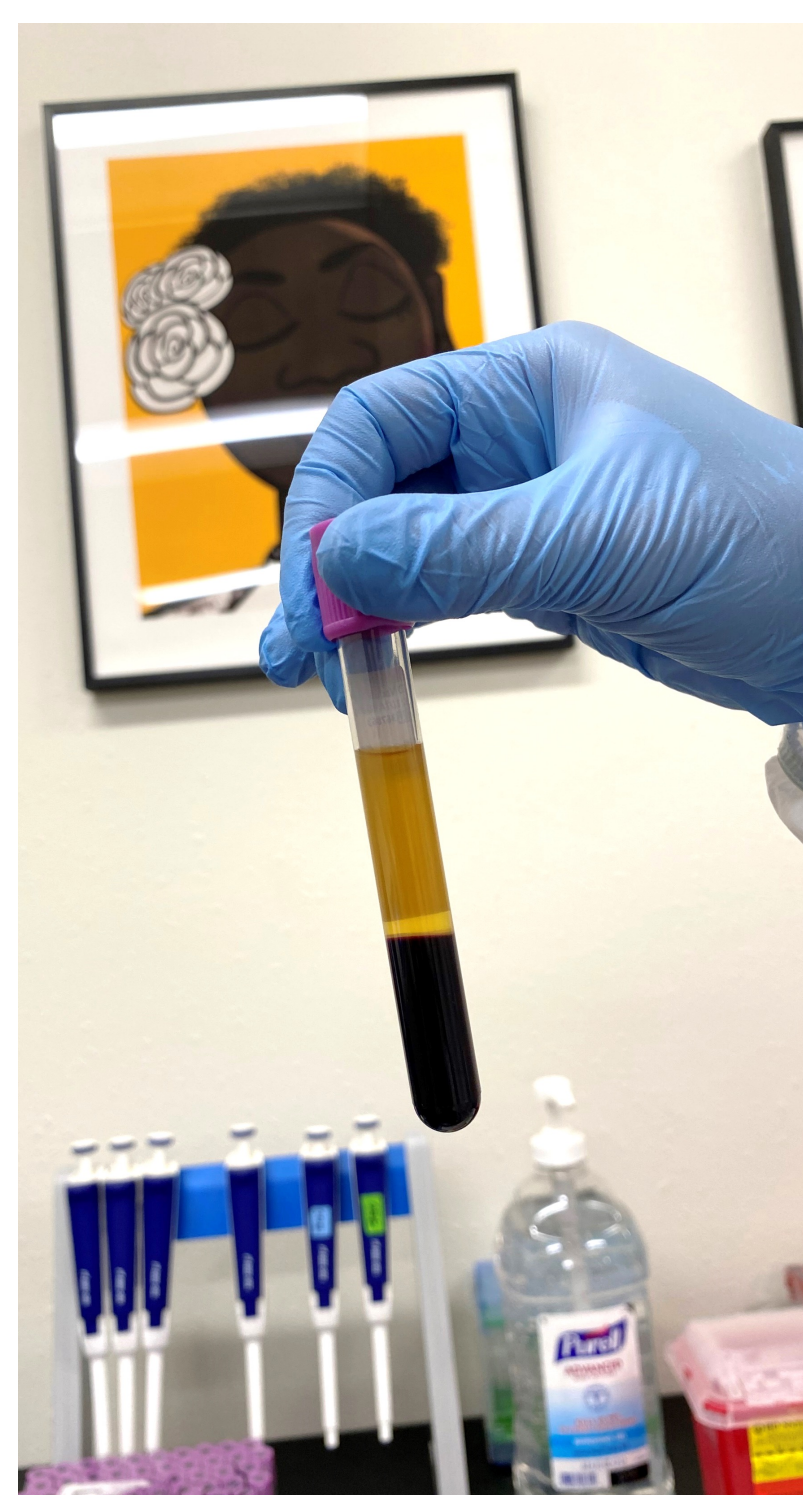
1. Lack of cultural safety
2. Inaccessible research sites

Our model aligns with community partners' values and advances goals for organizational and systemic change directed toward improving health equity.

Citation:

- Zahodne, L. B., Morris, E. P., Sharifian, N., Zaheed, A. B., Kraal, A. Z., & Sol, K. (2020, August 3). Everyday discrimination and subsequent cognitive abilities across five domains. *Neuropsychology*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8006470/>
- Barnes, L. L., & Bennett, D. A. (2014, April). *Alzheimer's disease in African Americans: Risk factors and challenges for the future*. Health affairs (Project Hope). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4084964/>
- Hispanic Americans and Alzheimer's Disease*. Alzheimer's Disease and Dementia. (n.d.). <https://www.alz.org/help-support/resources/hispanics-and-alzheimers>

Site visit protocol

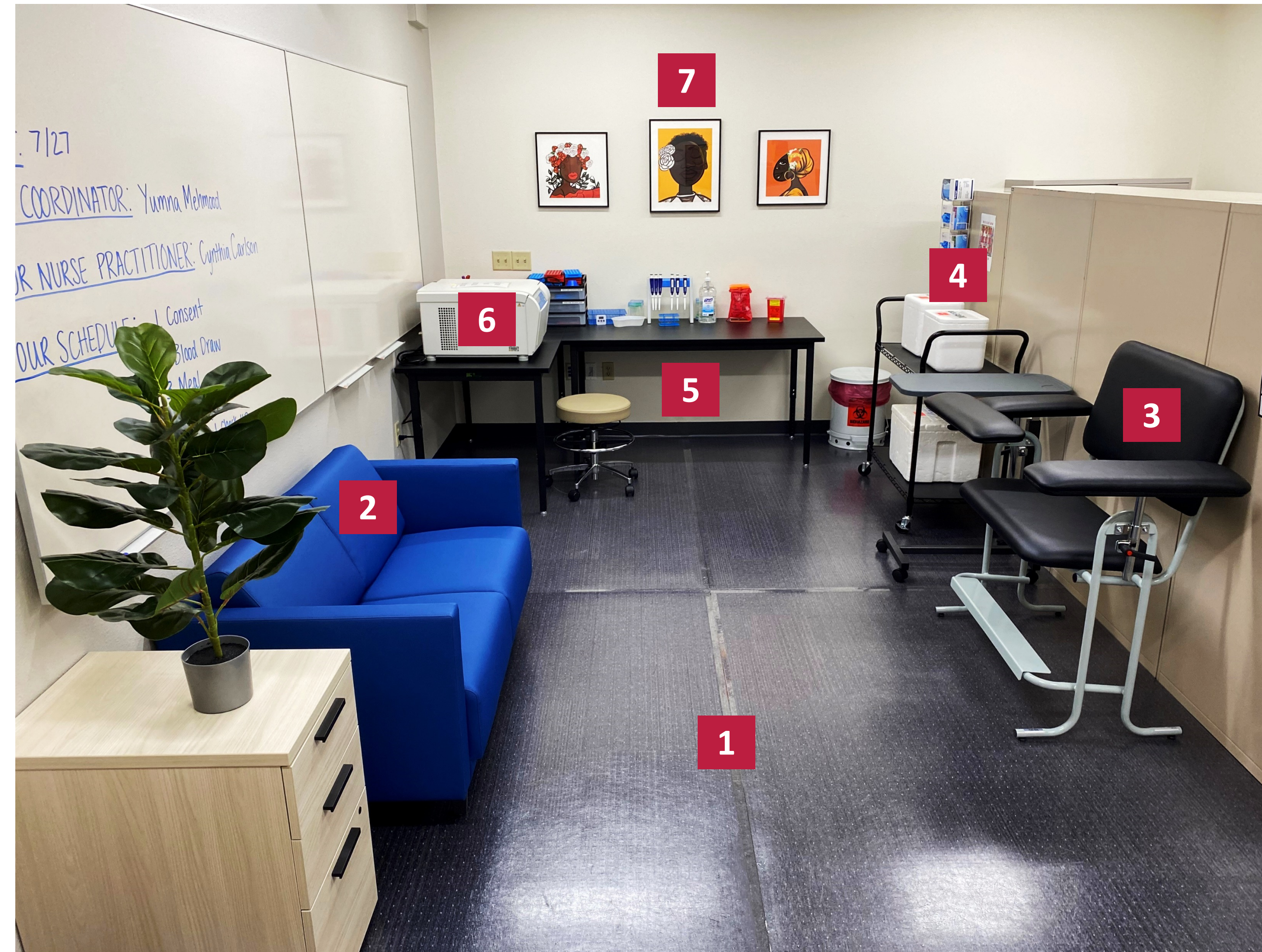


Full research visits, including biometrics, blood draws, and neuropsych testing, are all performed on site at the South Madison Partnership Office. A typical participant visit goes as follows:

1. Consent
2. Blood draw and biometrics
3. Meal
4. Memory check
5. Physical and neurological exam with nurse practitioner

Blood sample are centrifuged on-site, then divided into two samples. One sample is frozen for long-term storage, and the other is stored on ice and transported to our processing labs (UW Clinical Labs) for analysis.

Community location



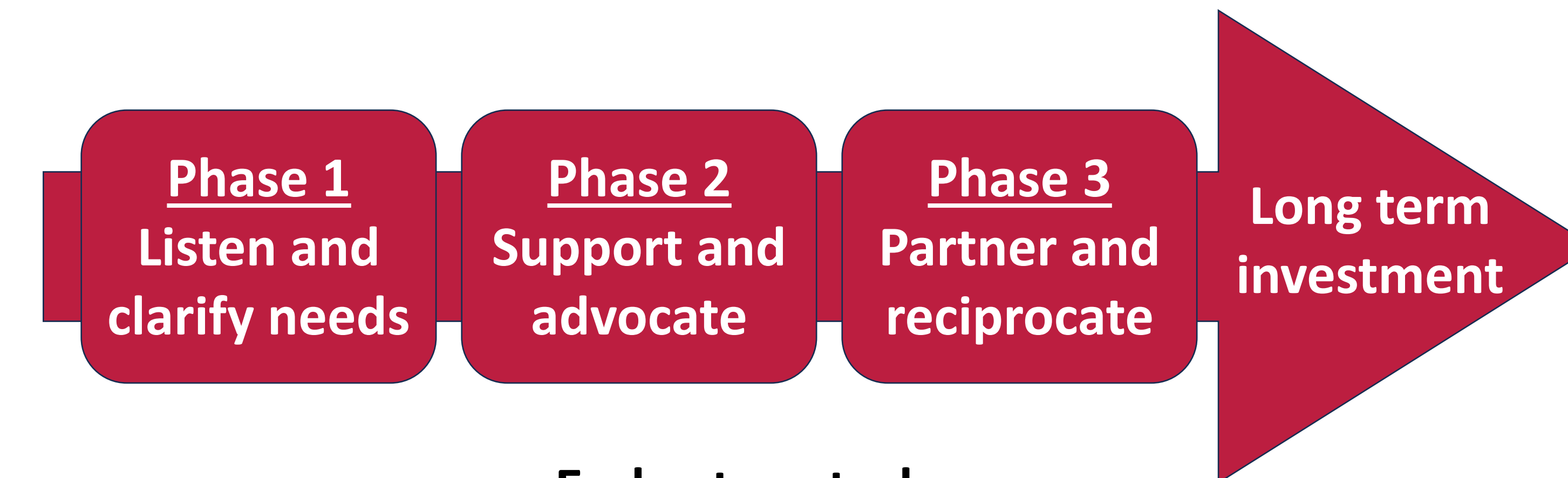
1. **Floor mats** covering carpet, custom fit to research area
2. **Couch** for lounging and comfort, made of chemical- and water-resistant fabric
3. **Phlebotomy chair** for blood draws and biometrics, large size and holds 700lbs
4. **Dry ice** for transporting blood samples
5. **Lab bench** for processing blood samples. All relevant equipment (pipettes, gloves, biowaste, etc.) is at hand.
6. **Centrifuge** with refrigeration
7. **Culturally appropriate art** purchased from local Black artist, to promote inclusivity

Values

Community-engaged research requires:

- Research leaders and their teams come to the community
- Share power with stakeholders
- Invest in emerging leaders from the communities
- Advocate for policy changes to dismantle institutional racism and exclusionary practices
- Ensure that the community benefits from the research
- Invest in the long-term health of communities

Steps to build a community site



Early-stage tasks:

- Identify your target community
- Connect with stakeholders and local leaders
- Choose a location
- Get funding
- Determine staff for site visits, emphasizing diversity and representation in personnel
- Complete IRB and biosafety protocols

Middle-stage tasks:

- Acquire technical equipment for space
- Acquire furniture that adheres to biosafety guidelines
- Purchase diverse art and decor
- Establish food contracts for post-blood draw meal
- Create welcome package for participants
- Create call scripts for recruiting to site visit
- Design scheduling scheme

Late-stage tasks:

- Run mock visits with staff
- Final walkthrough with biosafety specialists and staff
- Acquire participant payment
- Reminder calls for participants

Future directions

- Invite studies to use this community site for their research
- Open additional community sites
- Formalize participant exit survey after participant visits to collect empirical data on functionality and quality of visit

Funding

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