

ENGAGING THE LATINO COMMUNITY FOR RECRUITMENT INTO A LARGE POPULATION REGISTRY AND BIOREPOSITORY


Contributors: Perla B. Nunes, Maria C. Plez, Leah B. Bouk, Melissa A. Cornish, Ashley A. Dunham, Kimberly Ellis, Rowena Dolor, Victoria Christian, Robert M. Califf, L. Kristin Newby

Background: The MURDOCK Study Community Registry and Biorepository (“MURDOCK Registry”) is working to enroll 50,000 adult residents (~11,000 already enrolled) whose annotated biological samples and data can be accessed for –omic, population, and epidemiological studies. A variety of methods are used to recruit and enroll participants to ensure representativeness of the study within the local Cabarrus County, North Carolina region and surrounding areas.

One of the many goals of the MURDOCK Registry is to increase Latino representation and provide this ethnic community with opportunities to participate in clinical trials, intervention studies, patient-centered research, and work intended to reduce health disparities.

Methods undertaken to enhance Latino enrollment in the MURDOCK Registry:

- Staffing: Five bilingual clinical research coordinators/clinical trials assistants (of the 14 dedicated clinical research staff) and two bilingual data technicians
- Deeply embedded in the local community with an understanding of cultural and community perspectives
- Study and marketing materials translated into Spanish
- Flexible appointment times, home visits and study enrollments at workplaces, healthcare sites, churches and schools
- Tailored approach to recruiting and retaining Latinos, including door-to-door visits for annual follow-up if no working phone number is available for reminders
- Education of community organizations with a high prevalence of Latino representation/involvement
- Engagement of a diverse network of enrollment locations with a high Latino patient population such as the health department, Federally Qualified Health Centers, and free clinics

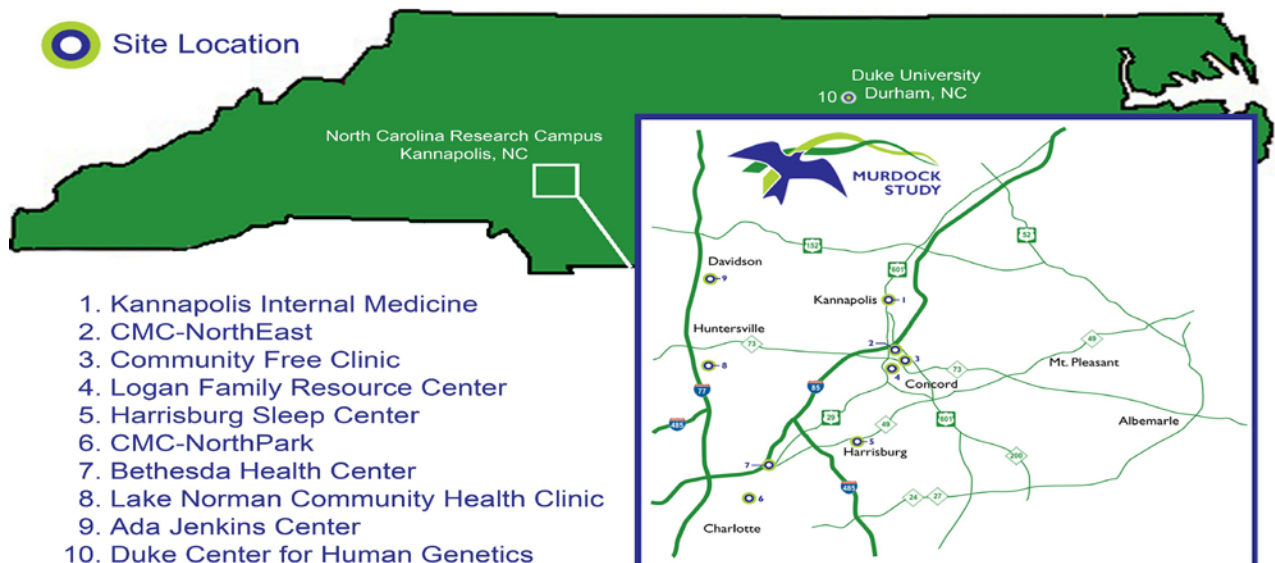


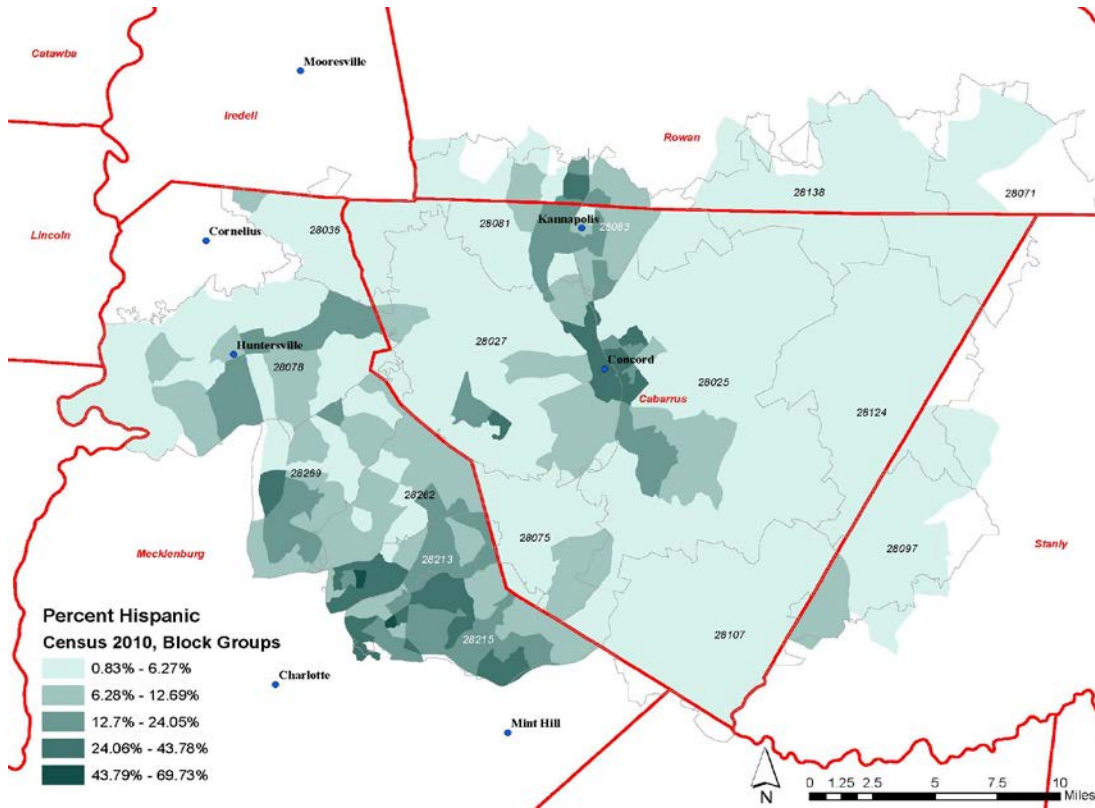
Sólo para uso de la oficina
Id. del participante: _____
Iniciales del integrante del personal de revisión: ____
Id. del sitio donde se revisó: _____
Fecha de la revisión: ___/___/____
mm dd aaaa

Formulario del participante del registro del estudio MURDOCK
Escriba sólo con tinta negra

Demografía general **Fecha en que se completo el formulario:** _____

1. Nombre: _____ Inicial 2º nombre: ___ Apellido: _____





Map 1: Distribution of Hispanic population in MURDOCK Study catchment region.

Table 1 provides an overview of the demographics of the Hispanic participants represented in the MURDOCK Study Community Registry and Biorepository.

Conclusion: Prior to these efforts, only 2% of the MURDOCK Registry was Latino. While these grassroots efforts have been highly successful in engaging and recruiting from within the Latino communities of the region, the remaining challenge is to retain this Latino population in long-term follow-up so their valuable contribution to science can be fully realized (**Table 2**).

Table 1: Characteristics of Hispanic Study Participants

| | |
|---|--|
| N, Hispanic | 1368 (12.5% of total) |
| % female | 75.4% |
| Age distribution | |
| <30 | 14.6% |
| 30-64 | 79.5% |
| ≥ 65 | 5.8% |
| Top (3) self-reported disease conditions | High cholesterol High blood pressure Obesity |
| Total N of MURDOCK Cohort: 10,925 | |

Table 2: Hispanic Follow-up Rates, October 2014

| Sex | Completed Latest Follow Up | Total | Row Fraction | Mean Age |
|-----|----------------------------|-------|--------------|----------|
| F | 360 | 911 | 39.5% | 42 |
| M | 104 | 303 | 34.3% | 45 |

Perla B. Nunes
 Project Leader, Community Engagement & Outreach
 Phone: (704) 250-5858
 Email: perla.nunes@duke.edu
 Website: www.murdock-study.org

