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

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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

Site Location

1. Kannapolis Internal Medicine
2. CMC-NorthEast
3. Community Free Clinic
4. Logan Family Resource Center
5. Harrisburg Sleep Center
6. CMC-NorthPark
7. Bethesda Health Center
8. Lake Norman Community Health Clinic
9. Ada Jenkins Center
10. Duke Center for Human Genetics
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

<table>
<thead>
<tr>
<th>N, Hispanic</th>
<th>1368 (12.5% of total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% female</td>
<td>75.4%</td>
</tr>
<tr>
<td>Age distribution</td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>14.6%</td>
</tr>
<tr>
<td>30-64</td>
<td>79.5%</td>
</tr>
<tr>
<td>&gt;65</td>
<td>5.8%</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Sex</th>
<th>Completed Latest Follow Up</th>
<th>Total</th>
<th>Row Fraction</th>
<th>Mean Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>360</td>
<td>911</td>
<td>39.5%</td>
<td>42</td>
</tr>
<tr>
<td>M</td>
<td>104</td>
<td>303</td>
<td>34.3%</td>
<td>45</td>
</tr>
</tbody>
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