Lessons Learned:

Recruiting and Retaining a Diverse Population in Research

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Objectives

• Describe the value of diversity in genomic research.

• State two actions which may improve recruitment of multicultural study participants.

• State two actions which may improve retention of multicultural study participants.
• Diversity of study participants is critical to the quality of genomic research.
• Race and ethnicity are rarely consistent with genomic variations.
• Health outcomes/disparities are related to allele frequency, epigenetic exposures and ancestry/migratory patterns.
• Understanding interactions among genetic variation, race, ethnicity, and disease one of the most challenging issues facing genomic researchers.

• Specific efforts are required to recruit participants of diverse race, ethnicity and socioeconomic status.
First 1000 Days of Life...and Beyond

- WGS + ‘omics + clinical data
- Longitudinal study (≥18 yrs)
- Consent participants during pregnancy in five obstetric practices
- Blood, saliva, urine, cord blood, placenta
- DNA, RNA, protein, epigenetic + clinical data
• Recruitment of participants in a racially diverse safety net clinic – over 85% Spanish speaking.

• Collaboration with clinical staff, leadership and providers – physicians, nurse midwives, nurse practitioners.

• Workforce diversity – correct staff placement in key recruitment areas.
• Bilingual research staff present daily in clinic
• Access to patient appointment schedules
• Culturally competent recruitment materials
• All materials in English are also in Spanish.
• Expect to see potential participant 2-3 times before consenting.
Participation requires:
- Mom, baby and dad lab specimens;
- Questionnaires from mom and dad;
- Surveys every 6 months.

Surveys require frequent phone calls and follow up.
- Electronic Data Capture
- GYN and Pediatric Clinic Schedules

Hope families will agree to continuation of consent after age 2.
Diversity in ITMI Research

- **White**: 70%
- **Asian/Pacific Islander**: 16%
- **Black**: 4%
- **American Indian/Alaska Native**: 0%

*Hispanic Ethnicity*
- **ITMI**: 32.40%
- **Fairfax County**: 16.10%
- **National**: 16.30%
Outcomes - Recruitment
Outcomes – Retention

<table>
<thead>
<tr>
<th>Year/Quarter</th>
<th>Percentage</th>
<th>Goal</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>81%</td>
<td>90%</td>
<td>435/534</td>
</tr>
<tr>
<td>Q1 2014</td>
<td>89%</td>
<td>90%</td>
<td>317/355</td>
</tr>
<tr>
<td>Q2 2014</td>
<td>90%</td>
<td>90%</td>
<td>424/472</td>
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<tr>
<td>Q3 2014</td>
<td>92%</td>
<td>90%</td>
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<tr>
<td>Q4 2014</td>
<td>85%</td>
<td>90%</td>
<td>560/658</td>
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<tr>
<td>National Average*</td>
<td>61.20%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: National Average is not directly comparable due to different calculation methods.
Challenges

• Verifying participant literacy
• Dads!
• Correct demographic information
• Affordable Care Act and Community Rumors
• Dialect /correct terminology, e.g. foods
What We Have Learned

• Embedding staff in recruitment site increases chances that site will be successful.

• Workforce diversity essential for participant diversity.

• Recruitment materials should be culturally relevant.

• Consistency in study staff builds trust and promotes long term success for retention.

• Future Plans
Research Outcomes

Research Staff

Families

Physicians and Office Staff
THANK YOU

• To the Inova Translational Medicine Team who work tirelessly every day to recruit and retain study participants;
• To the staff and physicians in the practices that allow us to recruit in their offices; and
• To the gracious participating families who allow us into their lives at such a critical point of their lives – welcoming a new baby!