

Implementation of Genomic Medicine in Diverse Healthcare Settings and Populations

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Diversity in Genomic Medicine Research: Overview



- IGNITE priority: understand/address barriers to dissemination in diverse practices, and patient /provider populations
 - Those with fewest resources, greatest challenges & disparities
 - Underrepresented populations should benefit equally from genomic discoveries
- IGNITE mix of populations, clinicians, practice settings =’s rich opportunity to test, institutionalize, disseminate programs to translate genomic medicine into routine practice.
- As IGNITE Network matures
 - Share and build upon successes, lessons
 - Further diversify
 - Expand knowledge, tools, strategies to benefit diverse stakeholders



IGNITE's Diverse Composition

Patients (N~30,000)	% (est)
Female	48
African Ancestry/Black	25
Latino	2
Asian	1
Children/adolescents	<1%

Practices Settings (N=148)	%
Academic	45%
Urban	47%
Rural	4%
Safety net/Low-Income	25%

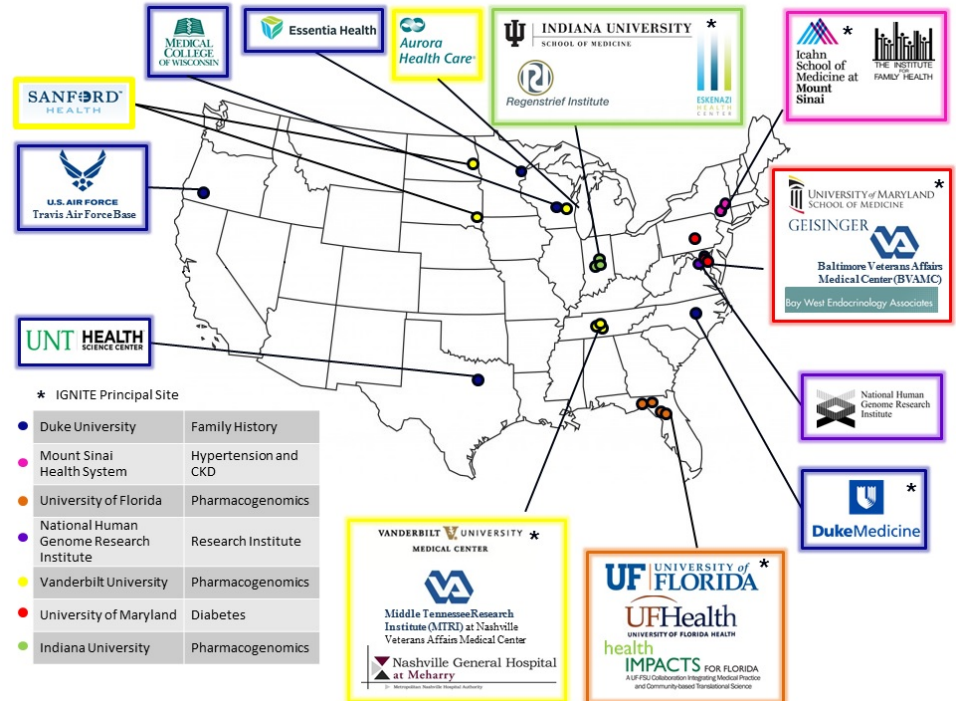
Translational Researchers

Genomic, clinical, health systems, team science, engagement, mHealth, impl/dissem, clinical trials, 2ndary data.

Providers* (N~2000)	% (est)
Female	58%
African Ancestry/Black	8%
Latino	8%

* Include nurses, pharmacists, genetic counselors, internists (general & specialty) pediatricians, family physicians, surgeons psychiatrists, residents, fellows, attendings

Geographic Diversity



The Good News

- Diverse patients- high interest in race, ancestry, genomics, taking part in genomics research
 - Outsiders more worried than insiders
- Diverse clinicians- little understanding of genomics, but willing to incorporate testing/ROR into patient care if have information and if it will impact management/outcomes.
- Diverse stakeholders- high interest in getting involved
 - As participants and as research collaborators

Implementation



Challenges and Responses

1. ID implementation challenges
 - Mixed methods research, build out CFIR implementation framework
2. Recruiting diverse **patients**
 - Actively involve patients/clinicians (e.g. boards)
 - Develop/evaluate innovative strategies
3. Limited **clinician** knowledge (many research/genomics naïve)
 - Educational meetings, materials
4. Lack genomic implementation systems in **practices**
 - New strategies tailored to current practice environments (e.g., EHR integration)
5. Lack comparative effectiveness **research** to compare impact across geographies, practice/clinician types, pt. groups
 - Early agreement on shared elements to collect across network and commitment to collecting them.

Future Opportunities: Center, Programs



- Create **genomic medicine diversity resource center**
 - Hub of activities, experiences, expertise and repository for tools tailored for diverse pt/clin populations and practice environments
 - Formalized, centralized genomic translational services for diverse stakeholders
 - e.g. genetic counselors, surveys, EHR platforms, educational materials, low literacy and multilingual tools
- Establish **genomic medicine mentorship program** for investigators underrepresented in genomics research
 - Wide net - disparities, minority health researchers
 - Encourage fellows and junior faculty participation as mentees

Future Opportunities: Expand Research



- Expand **translational genomics research for diverse populations**
 - Tools: e.g. educational tools for providers and patients tailored to their genomic literacy
 - Topics: e.g. genetic-epigenetic connections; social-environmental-cultural interactions, cultural competence, literacy, numeracy.
 - Methods and instruments to study diversity: e.g. geomapping, personal utility, mixed method (qualitative-quantitative)
- **Expand implementation science research tools for genomics**
 - To identify and build evidence for effective ways to engage and inform diverse stakeholders.
 - Comparative effectiveness research to identify best strategies

Future Opportunities: Network Expansion



- **Expand IGNITE Network**
 - Stakeholders with focus on diverse populations
 - Patients, clinicians, payers, advocates, industry
 - As co-investigators, co-authors, co-presenters.
 - Further increase diversity of practices
 - Practice types- small groups; EHR + and EHR -
 - Other health professionals
 - Patients (e.g. Asian, South Asian, Native Am., linguistic diversity).
 - Pediatric populations
 - Engage affiliates in diversification of the network
- **Target genomic medicine opportunities in diverse populations**
 - “Sweet spots” for implementation aligned with population-specific diseases (similar to *APOL1* and Blacks with hypertension)