

Promoting Diverse Recruitment in Genomic Research: The Impact of Community Partnerships in the BabySeq Project

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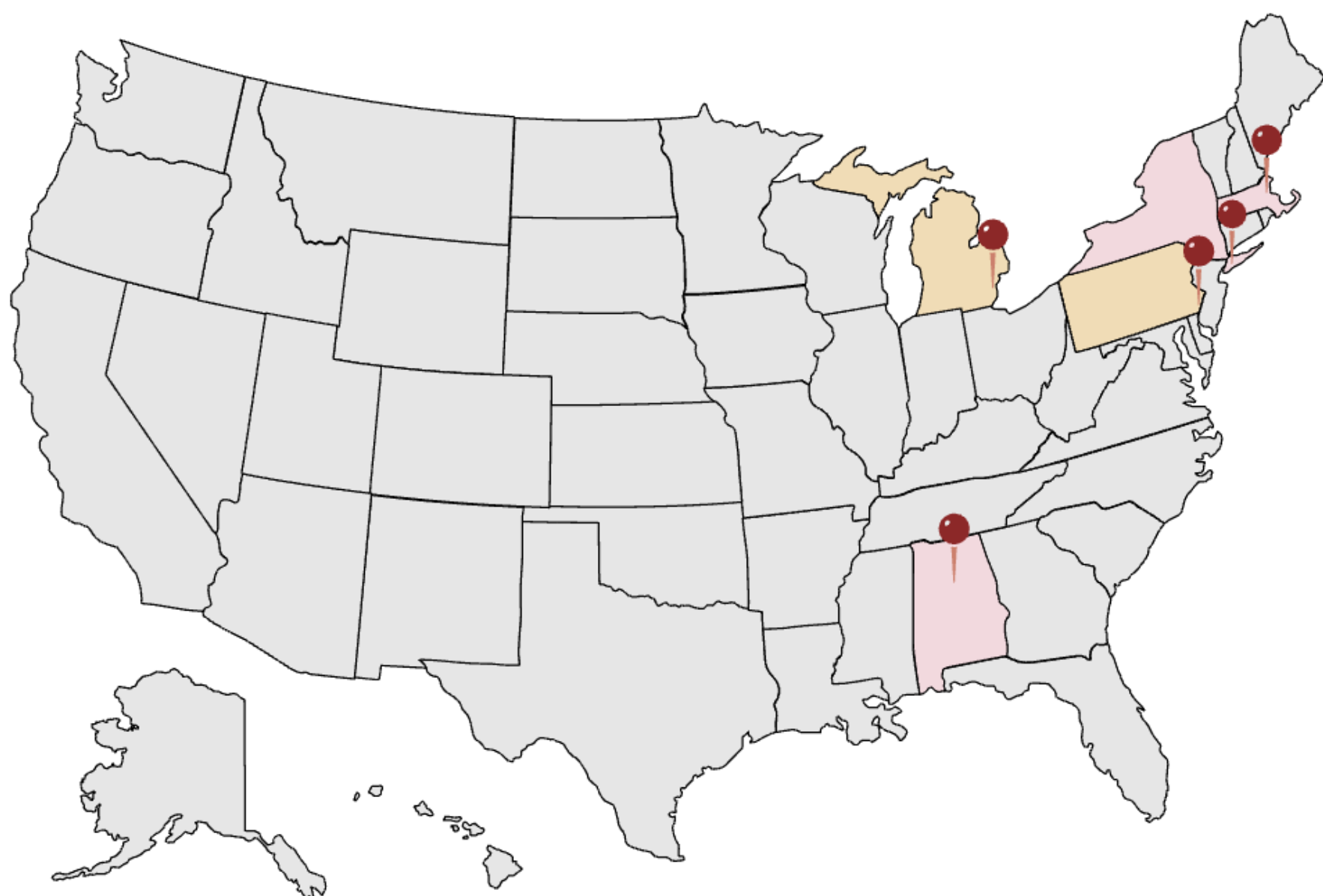
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INTRODUCTION

- Partnering with local community stakeholders in clinical research may help encourage participation among diverse populations.
- We studied whether these partnerships could increase diversity in the second iteration of the BabySeq Project: a randomized controlled trial of infant genome screening.

METHODS

- We convened a diverse Community Board from core enrollment cities (Boston, MA; New York, NY; Birmingham, AL) to provide input via virtual quarterly meetings with study staff.
- Collaborating with local pediatricians extending to two additional enrollment cities (Detroit, MI; Philadelphia, PA), we provided brief genomics education and hired local research assistants to recruit families in clinic.



Community Board Influence on Study Protocol

- Revised consent requirement to 1 parent/guardian (instead of 2)
- Simplified and clarified consent language
- Collaborated on formative research (interview guides & surveys)
- Implemented less invasive sample type (heel stick)
- Removed sample collection requirement from control group & parents

All graphics created with BioRender.com

DATA ANALYSIS

- The uptake rate and demographics (race; ethnicity; education; household income) of families recruited to date were compared to our first iteration of BabySeq using chi-square tests.

RESULTS

- Currently, there are 426 families enrolled in BabySeq, of which 140 (59 in sequencing group, 81 in control group) have had their results disclosed.

	BabySeq Phase 1	BabySeq Phase 2	p-value
Uptake Rate	6.9%	23.3%	p<0.001
Race			
Non-White	17.6%	86.7%	p<0.001
Ethnicity			
Hispanic	7.4%	39.9%	p<0.001
Education			
Below BA degree	8.3%	70.8%	p<0.001
Household Income			
Under \$140-150k	43.7%	92.5%	p<0.001

DISCUSSION

- In this second phase of the BabySeq Project, the uptake rate is significantly higher, and families are significantly more diverse and nationally representative.
- Early recruitment experiences suggest that engaging with local communities and clinicians and recruiting in diverse practices can help increase diversity in genomic research.

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