Research with hard-to-survey populations: Lessons learned recruiting and tracking an urban, adolescent sample

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U N I V E R S I T Y

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PROJECT POWER

Purpose

▶ Outline successes and lessons learned recruiting, tracking, and assessing "hard-to-survey" study participants

▶ Identify correlates related survey participation

"Hard-to-survey" Populations

- ► Sampling concerns
  - ► Rarity
  - ► High mobility

- ► Identification problems
  - ► Stigmas

- ► Difficulties locating and contacting
  - ► Frequent moves
  - ► Gatekeepers

- ► Recruitment issues
  - ► Mistrust of researchers

- ► Interview challenges
  - ► Language barriers

Tourangeau, 2014

Literature Review: Survey Nonresponse

► Nonresponse has increased over time for both face-to-face and telephone surveys

► Telephone surveys have suffered from more dramatic increases in nonresponse than face-to-face surveys

► Ratio of contact attempts per completed survey has increased

► Scarce literature on methods for surveys of urban youth

Figure 3. Response Rate Trends from 2000 through 2014.

Williams and Brick, 2018
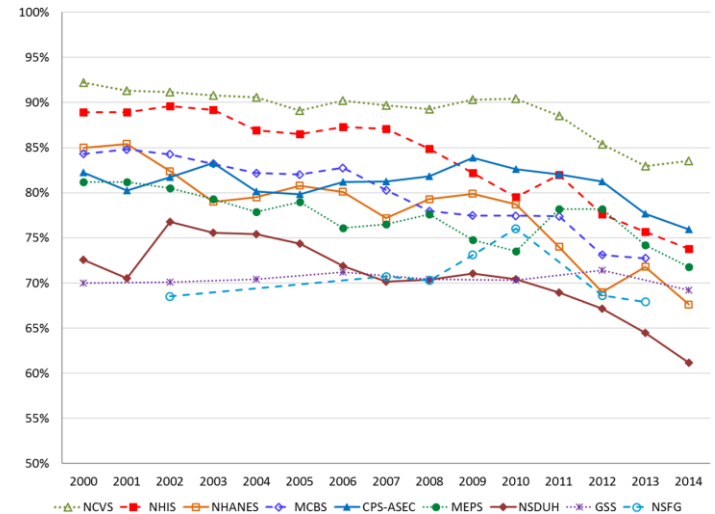
Literature Review: Improving Response Rates

► Tailored methods to contact members of different groups

► Customized outreach plans

► Using local informants to assist with planning

► Providing helplines and questionnaires in multiple languages

► Increase the effort level of data collection

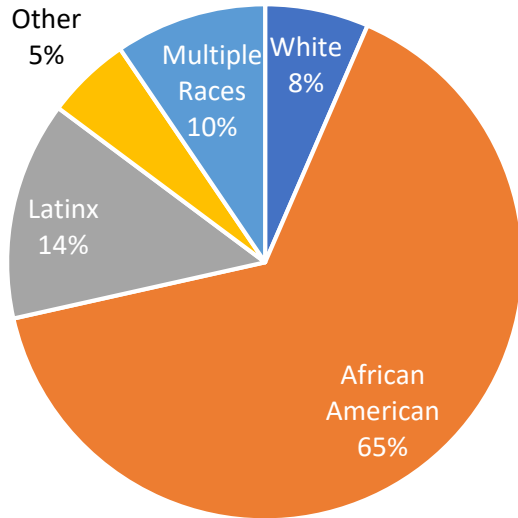**Figure 7.** Ratio of Total Study Contact Attempts per Completed Interview.

Williams and Brick, 2018; Tourangeau, 2019
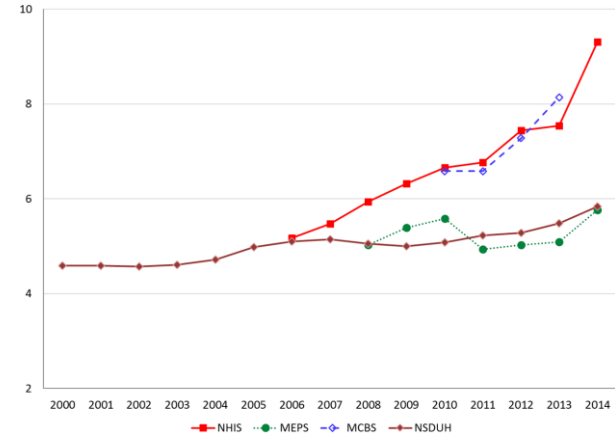
Project POWER

► IES- and NICHD-funded Randomized Control Trial

► Conducted over a 4-year period with 8th grade students in Baltimore City Public Schools

► Participants were assigned to one of two groups
  ► Mindfulness and emotion regulation (RAP Club; intervention)
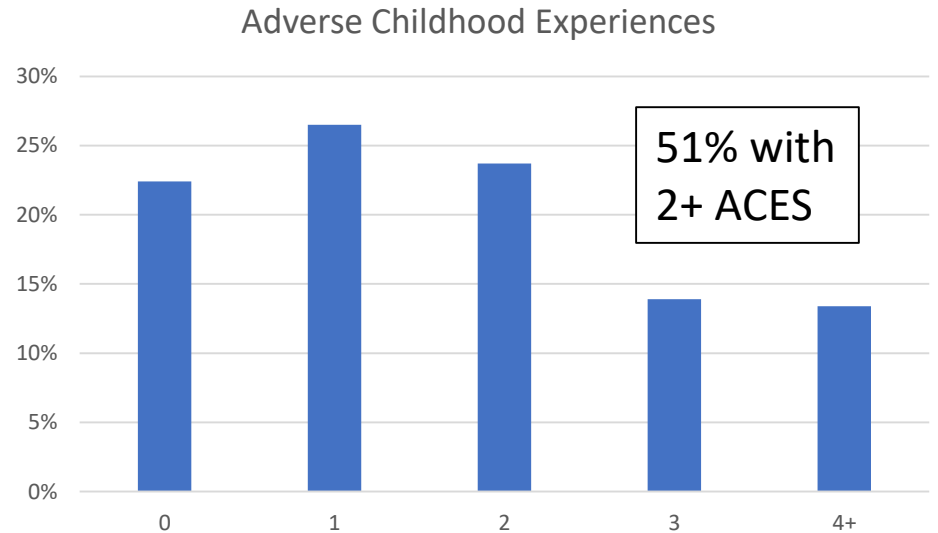 ► Health education (Healthy Topics; active control)

Participants
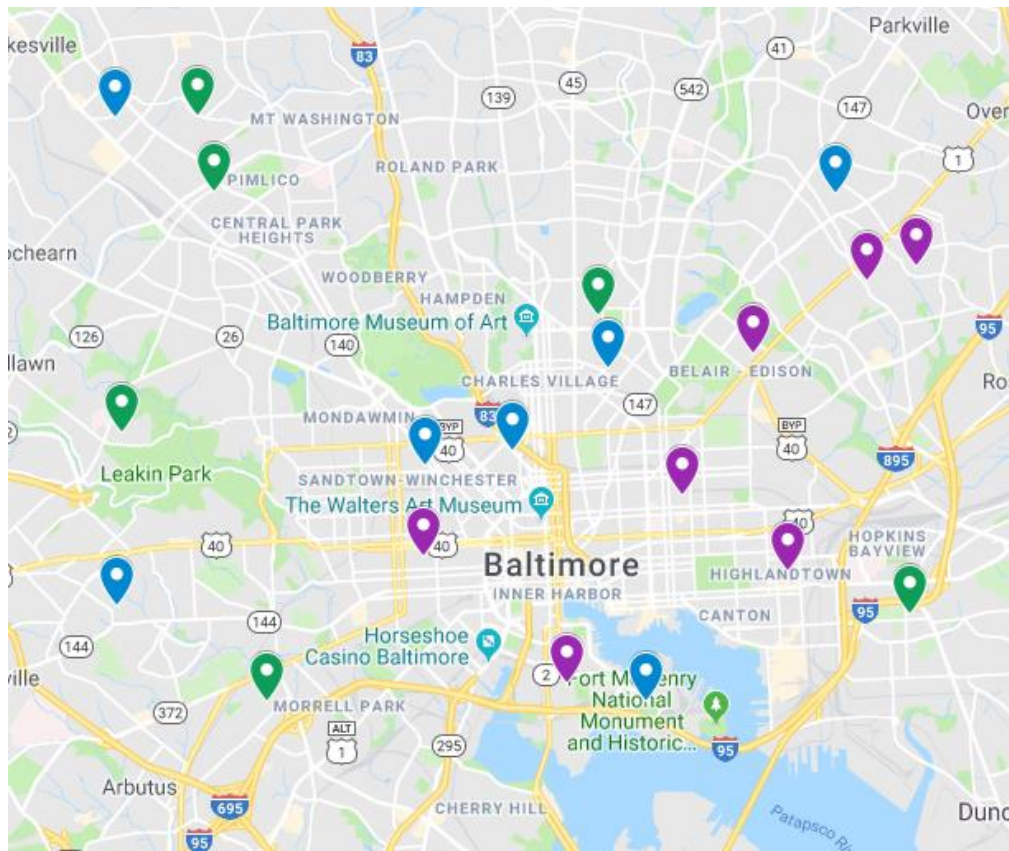
► 8th graders in Baltimore City Public Schools

► Primarily minority youth

► Urban, low-income communities where poverty-related adversities are common

Adverse Childhood Experiences

51% with 2+ ACES

Pie chart:
- African American 65%
- Latinx 14%
- Multiple Races 10%
- White 8%
- Other 5%

Partner Schools

Key

- Cohort 1
- Cohort 2
- Cohort 3

Cohorts 1-3	
Average School Size	463
FARMS eligible students	62%

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Recruitment and Assessment

	Participant Enrollment	Baseline survey	Post-Test Survey	4-Month Follow Up Survey	12-Month Follow Up Survey
Cohort 1	124	122 (98%)	113 (91%)	107 (86%)	44 (35%)
Cohort 2	149	148 (99%)	127 (85%)	141 (95%)	90 (60%)
Cohort 3	163	162 (99%)	157 (96%)	147 (90%)	*In Progress*
TOTAL	**436**	**432 (99%)**	**397 (91%)**	**395 (91%)**	**134 (50%)***

*Cohort 1 and 2 data only

12-Month Follow-Up Survey

► NICHD grant funding received to conduct a 12-month follow-up survey after the end of the first year of the study

► Goal of assessing student mental health and behavior a year after participating in the intervention

Survey Administration Challenges

► Outreach
  ► Housing instability
  ► Disconnected phones
  ► Dangerous neighborhoods

► Recruitment
  ► Groups affected by structural racism
  ► Justified concerns about exploitation as research participant
  ► Research institution with reputation for harming the community

► Assessment
  ► Time-consuming (45mins – 1hr)
  ► Lack of email/internet access
  ► Distractions and other ways to spend time

Cohort 1 Challenges	Cohort 2 Adjustments
Limited Contact Information - Phone numbers and addresses over a year old - Many home visits	**New Contact Information Sheets** - Collected at 4-month follow-up - Instagram - Emails - Alternate contacts

Additional Consent Required
- Parents needed to provide consent
- Extra contact needed and an opportunity to refuse
- Time consuming
	More Systematic Approach
	- Participant
	    - Email – online questionnaire
	    - Phone
	    - Instagram
	- Parent/Guardian - Alternate Contact

Results
- 44/118
- 37% response rate
    - 29 in-person, 1 mail-in, 14 online
	Results
	- 90/146
	- 62% response rate
	    - 90 online

Contact Methods

▶ Contact Information
  ▶ Phone numbers
    ● Calls
    ● Voicemails
  ▶ Addresses
    ● Home visits
    ● Mailings

▶ Follow-up Information
  ▶ Emails
    ● Questionnaire distribution
  ▶ Social Media
    ● Instagram
  ▶ Search Databases
    ● LexisNexis
  ▶ Alternate Contacts
    ● Relatives
    ● Friends

Participant Engagement

► Community Partnerships
  ► Groups held in schools with endorsement of principals and teachers
  ► Local community members acted as "mentors" for participants to increase comfort and confidence in program
  ► Helped overcome mistrust of Johns Hopkins and research in general

► Incentives
  ► Participants were given snacks and other incentives throughout the program
  ► Could earn gift cards for reaching attendance goals
  ► Developed trust and goodwill with research team
  ► $25 e-gift card upon completion of 12-month follow-up survey

Study Sample Demographics

Table 1. Student Demographics by Cohort

Variable	Cohort 1 (n=118)		Cohort 2 (n=146)		
	n (mean)	%	n (mean)	%	p
Completed Questionnaire					<0.001
Yes	44	37.3	90	62.1	
No	74	62.7	54	37.9	
Age	13.27		13.21		0.671
Race					0.434
African American	76	64.4	94	64.4	
White	6	5.1	11	7.5	
Latinx	17	14.4	19	13.0	
Other	6	5.1	8	5.5	
Multiple	13	11.0	12	8.2	
Sex					0.371
Male	47	39.8	66	45.2	
Female	71	60.2	78	53.4	

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Demographics by Survey Participation

Table 2. Student Demographics by Questionnaire Completion

Variable	Yes (n=134)		No (n=130)		
	n (mean)	%	n (mean)	%	p
Age	13.21		13.27		0.458
Race					0.295
African American	86	64.2	84	65.6	
White	11	8.2	6	4.7	
Latinx	16	11.9	20	15.6	
Other	5	3.7	9	7.0	
Multiple	16	11.9	9	7.0	
Sex					0.130
Male	52	38.8	61	47.7	
Female	82	61.2	67	52.3	

Nonresponse

Most cohort 1 refusals were parents refusing to provide consent

Nonresponse by Cohort

	Noncontact	Refusal	Other	Total
Cohort 1	38 (51.4%)	14 (18.9%)	22 (29.7%)	74
Cohort 2	44 (78.6%)	3 (5.4%)	9 (16.1%)	56

p **0.005**

Nonresponse by Race/Ethnicity

|	Noncontact	Refusal	Other	Total
African American	53 (62.4%)	9 (10.6%)	23 (27.1%)	85
Latinx	13 (61.9%)	4 (19.0%)	4 (19.0%)	21
White	5 (83.3%)	1 (16.7%)	0 (0.0%)	6
Other	6 (66.7%)	1 (11.1%)	2 (22.2%)	9
Multiple	5 (55.6%)	2 (22.2%)	2 (22.2%)	9

p 0.843

No difference in nonresponse patterns by race

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When were surveys completed?
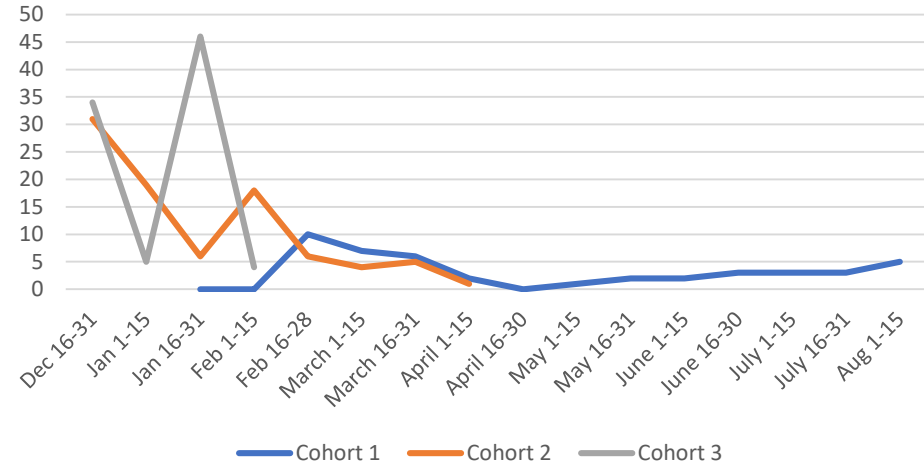

Contact Attempts

C2 and C3 Emailed survey links

C1 First round of consent calls

C1 Final push

Questionnaires Completed
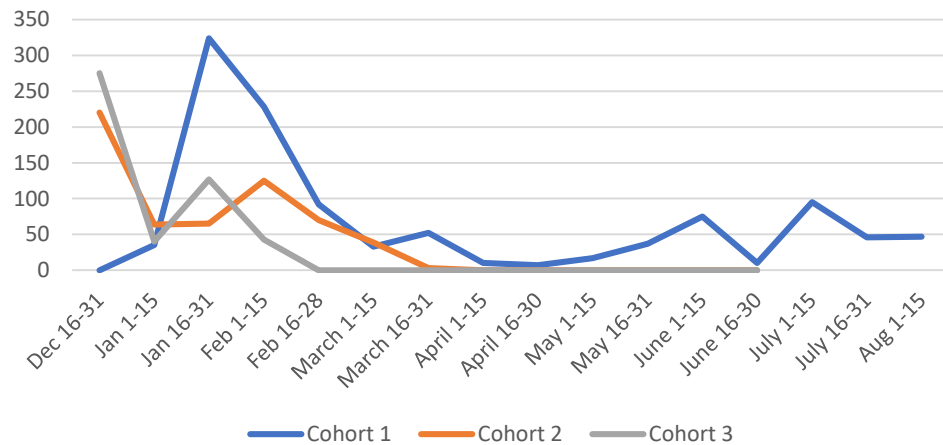
C2 and C3 Winter break

C2 and C3 RA Transition

Survey Administration Productivity

Survey Administration Data

Both Cohorts

Participated	Attempts	Contacted	Surveys
Yes	4.36	57%	2.89
No	6.28	40%	2.76
p	**<0.001**	**0.006**	**0.015**

Cohort 1

Participated	Attempts	Contacted	Surveys
Yes	5.98	93%	2.91
No	7.43	53%	2.76
p	**0.009**	**<0.001**	**0.039**

Cohort 2

Participated	Attempts	Contacted	Surveys
Yes	3.57	40%	2.88
No	4.70	20%	2.76
p	**0.036**	**0.013**	0.125

Cohorts 1 and 2
Contact Attempts by Participation Status

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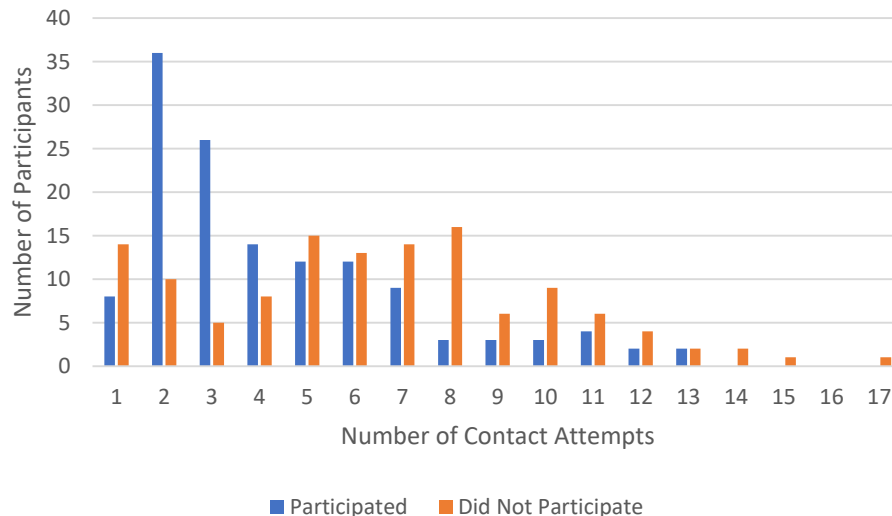
Baseline Self-Reported Mental Health Correlates with 12-Month Follow-Up Survey Participation

Mean Participant Self-Reported Mental Health Correlates by Survey Participation

Participated	PTSD Severity	PTSD Reexperiencing	PTSD Avoidance	CDI	YOQSR	Peer Relations	ACEs
Yes	14.07	4.36	5.07	2.43	50.91	15.95	1.64
No	18.07	5.16	7.08	3.81	61.88	14.87	2.03
p	**0.011**	0.129	**0.002**	**0.005**	**0.038**	**0.016**	0.058
Range	0-47	0-15	0-21	0-20	-16 - 220	4-20	0-8
Cohort 1							
Yes	19.20	6.10	6.41	2.92	63.57	15.78	1.88
No	18.65	5.20	7.16	3.91	63.50	14.49	1.91
p	0.821	0.285	0.464	0.163	0.993	0.063	0.916
Cohort 2							
Yes	11.47	3.49	4.42	2.24	43.02	16.04	1.32
No	17.32	5.10	6.96	3.67	59.39	15.45	2.07
p	**0.005**	**0.031**	**0.004**	**0.019**	**0.014**	0.346	**0.046**
Compare Cohorts							
Cohort 1	18.86	5.54	6.88	3.54	63.52	14.97	1.90
Cohort 2	13.62	4.08	5.37	2.77	49.30	15.83	1.76
p	**0.001**	**0.005**	**0.022**	0.107	**0.007**	0.057	0.504

Baseline Teacher-Reported Mental Health Correlates with 12-Month Follow-Up Survey Participation

Average Teacher-Reported Scores for the Strengths and Difficulties Questionnaire

Participated	Total SDQ Score	Externalizing Score	Internalizing Score	Emotional Symptoms	Conduct Problems	Hyperactivity	Peer Problems	Prosocial Behavior
Yes	14.76	3.67	2.98	1.44	1.16	2.60	1.53	7.36
No	16.37	5.11	3.78	1.82	1.85	3.24	2.00	6.89
Range	0-40	0-20	0-20	0-10	0-10	0-10	0-10	0-10
p	**0.002**	**0.002**	**0.021**	0.065	**0.003**	**0.018**	**0.010**	0.075
Cohort 1								
Yes	15.91	4.50	3.67	1.47	1.64	2.97	2.23	7.16
No	17.30	5.66	4.24	1.93	2.22	3.41	2.33	6.7
p	0.094	0.137	0.304	0.145	0.123	0.300	0.738	0.248
Cohort 2								
Yes	14.19	3.25	2.64	1.42	0.927	2.42	1.18	7.45
No	15.17	4.39	3.19	1.67	1.38	3.02	1.58	7.14
p	0.128	0.071	0.226	0.388	0.116	0.102	0.093	0.419
Compare Cohorts								
Cohort 1	16.76	5.21	4.02	1.75	2.00	3.24	2.29	6.88
Cohort 2	15.56	3.68	2.85	1.51	1.10	2.64	1.33	7.34
p	**<0.001**	**0.001**	**0.001**	0.257	**<0.001**	**0.029**	**<0.001**	0.081

Average Teacher Self-Report Scores

Participated	OHI	School Problems
Yes	3.03	2.66
No	2.86	2.8
Range	1-4	1-4
p	**0.005**	**0.007**

How did location impact participation?

- Interpolation map predicting 12-month survey participation based on location
- Yellow/green areas indicating increased likelihood of participation
- Downtown, northwest (far from office), and southeast (Spanish-speaking population) have notable areas of low response rates
- Need more data points for a more accurate interpolation

Both cohorts
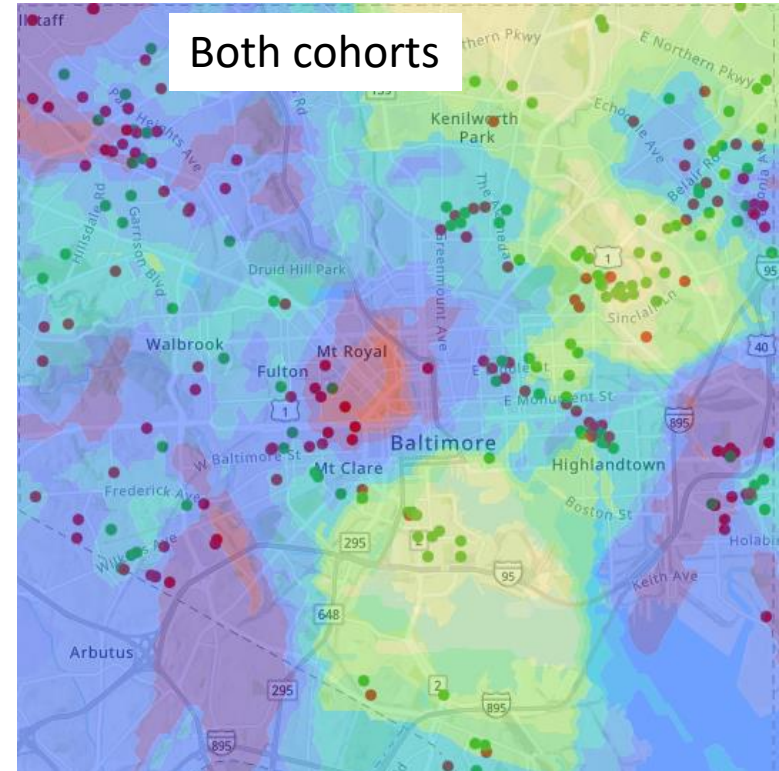
Discussion

▶ Tailored approaches to recruitment, tracking, and interviewing are critical for best results
  ▶ Contact methods
  ▶ Timing
  ▶ Culturally appropriate

▶ A mixture of traditional and nontraditional contact methods helped maximize our ability to contact participants

▶ It appears that some mental health correlates are associated with 12-month follow-up survey participation, but further data and analysis are needed to confirm

Acknowledgements

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