

Community Attitudes about Research: 2019 Survey Results

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Recruitment Locations

2019 Survey

Community-Based Agencies

Rochester Area Task Force on AIDS
CTSI Community Advisory Council

Races/Walks for a Cause

Strollin' for the Colon 5k
Tour De Cure bicycle and foot race

Farmers Markets

Pittsford Farmers Market
Westside Farmers Market
Rochester Public Market*

Festivals

Clarissa St Reunion
Summer Soul Fest*
Puerto Rican Festival*
Black Pride
Clothesline Festival at MAG

Community Events

Speak Life! Health Equity Conference
Men's Health Day at Locust Hill Country Club
Parsells Ave Health Fair*
"March for Science" at Lyell Ave Library

Street Outreach

Susan B. Anthony Neighborhood
Ontario Beach Park

Social Media

Shared across CTSI social media channels
Paid Facebook/Instagram Advertising**

* *High Yield Location (>30 surveys completed)*

** *31% of all surveys completed via this method*

Demographics (N=637)

Demographic		Number (%)	Demographic		Number (%)
Gender	Woman	352 (55)	Ethnicity	Not Hispanic	417 (65)
	Man	179 (28)		Hispanic/Latino	57 (9)
	Other	9 (1)	Language	English	505 (79)
Age	18-34	191 (30)		Spanish	15 (2)
	35-64	256 (40)		Other (ASL, Arabic, French, USA)	16 (3)
	65+	91 (14)	Education	Graduate School	149 (23)
Sexual Orientation	Heterosexual	435 (68)		University Graduate or 4-yr degree	148 (23)
	Gay or Lesbian	43 (7)		Some College or 2-yr degree	148 (23)
	Bisexual	35 (5)		High School or GED	76 (12)
	Other	16 (3)		Some High School	15 (2)
Race	White	337 (53)		8 th grade or less	3 (<1)
	Black or AA	126 (20)	Zip Code	NYS	297 (47)
	Asian	34 (5)		City of Rochester	173 (27)
	Not Listed	28 (4)		Outside NYS	67 (11)
	A. Indian or A. Native	12 (2)			
	N. Hawaiian or other P. Is.	2 (<1)			

Research Experience

2019 Survey

- 47% of respondents have never been asked to participate in a research study
- 38% said they did participate
 - 15% were unsure or left the question blank
- 26% declined participation in a research study
- 74% said they had seen a research advertisement in the past

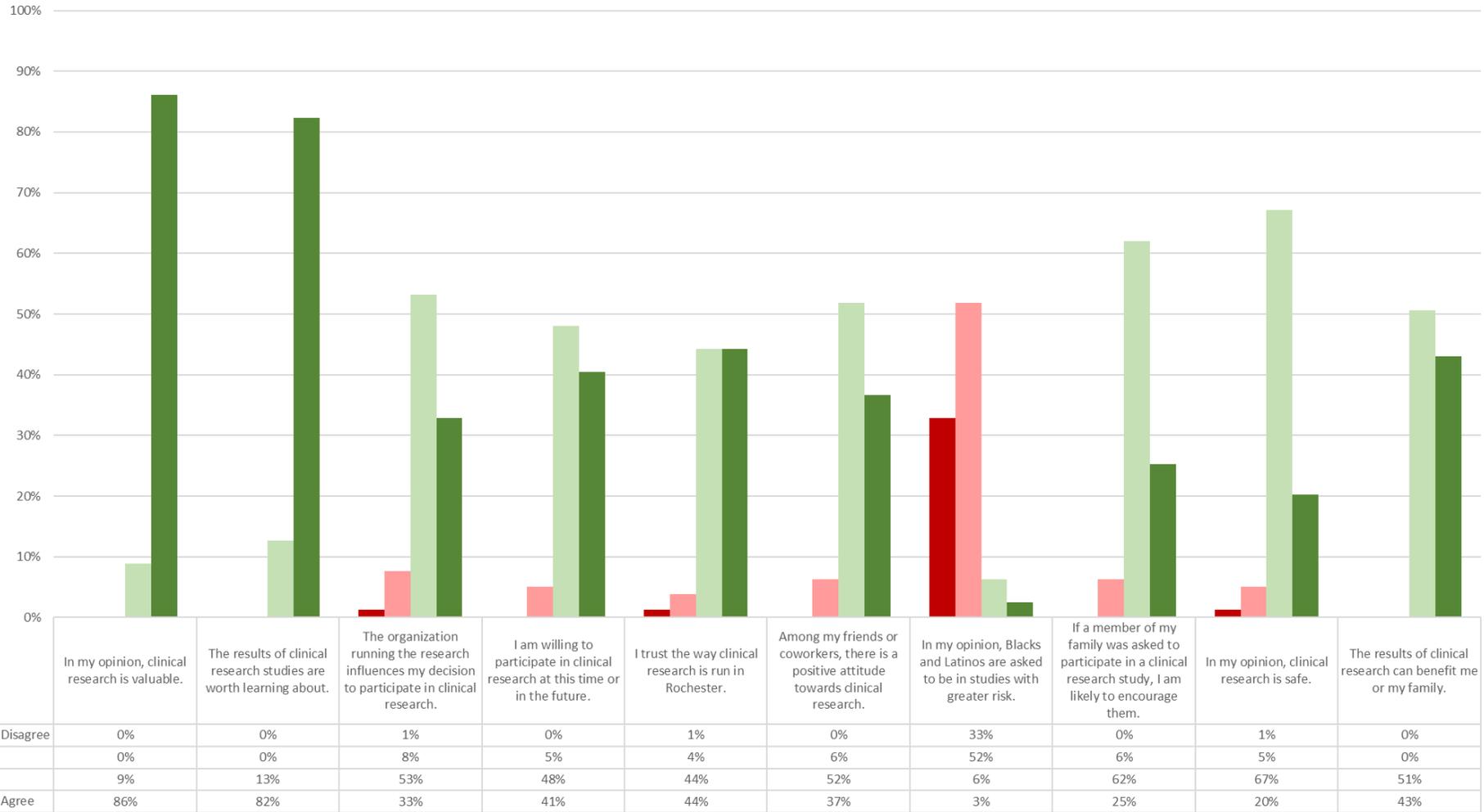
26% said they declined to participate in a research study

Reason	% (N=163)
Too many risks	32
Did not qualify	28
Not enough time	28
Not interested	17
Other	13
Not enough money	12
Too afraid	12
No Benefit	10
Lack of Transportation	9

Opinions about Clinical Research

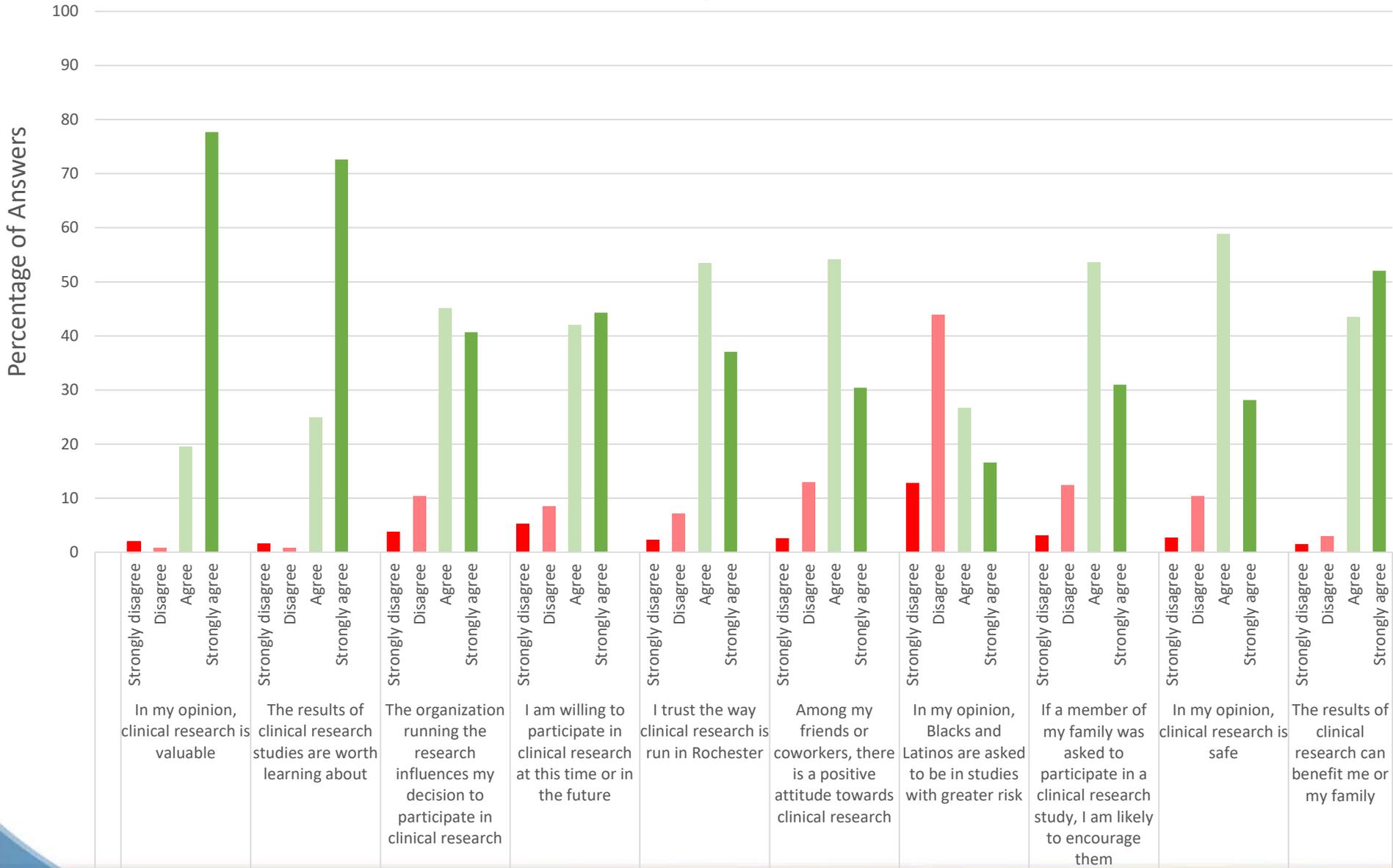
Below are 10 statements. Mark the box that best describes <u>YOUR OPINION</u> .	Strongly Disagree	Disagree	Agree	Strongly Agree
In my opinion, clinical research is valuable.				
The results of clinical research studies are worth learning about.				
The organization running the research influences my decision to participate in clinical research.				
I am willing to participate in clinical research at this time or in the future.				
I trust the way clinical research is run in Rochester.				
Among my friends or coworkers, there is a positive attitude towards clinical research.				
In my opinion, Blacks and Latinos are asked to be in studies with greater risk.				
If a member of my family was asked to participate in a clinical research study, I am likely to encourage them.				
In my opinion, clinical research is safe.				
The results of clinical research can benefit me or my family.				

Mark the box that best describes YOUR OPINION
SCORE Responses (n=79)



Mark the box that best describes YOUR OPINION

2019 Survey (n=637)



Opinions

2019 Survey

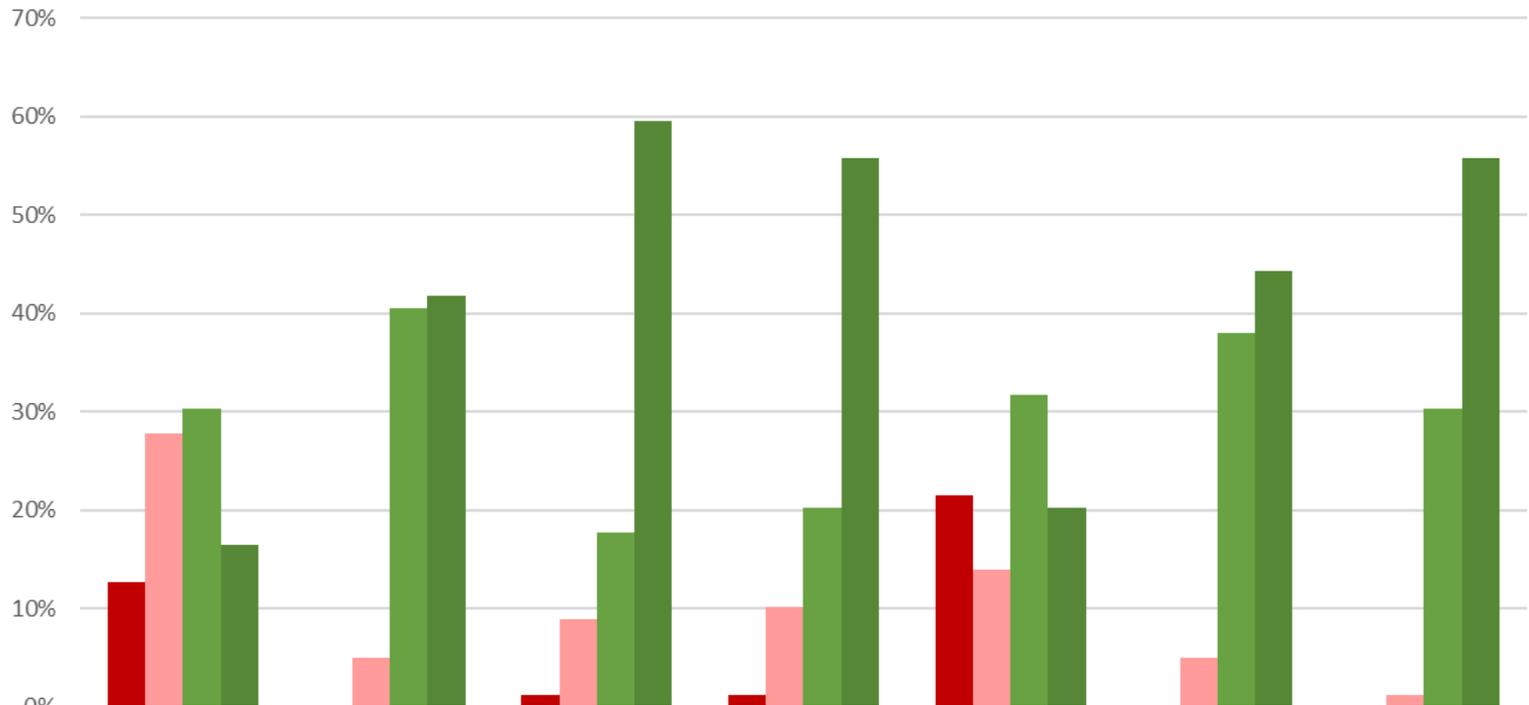
- 84-97% gave positive responses (Agree or Strongly Agree)
 - In my opinion, clinical research is valuable.
 - The results of clinical research studies are worth learning about.
 - The organization running the research influences my decision to participate in clinical research.
 - I am willing to participate in clinical research at this time or in the future.
 - I trust the way clinical research is run in Rochester.
 - Among my friends or coworkers, there is a positive attitude towards clinical research.
 - If a member of my family was asked to participate in a clinical research study, I am likely to encourage them.
 - In my opinion, clinical research is safe.
 - The results of clinical research can benefit me or my family.
- 43% gave positive responses (Agree or Strongly Agree)
 - In my opinion, Blacks and Latinos are asked to be in studies with greater risk.

Motivators

There are many reasons people participate in clinical research studies. In thinking about whether to join a clinical research study, how important are the following considerations to you?	Not at all important	Slightly important	Moderately important	Very important
You would get paid				
You are curious about the research study				
You or someone you care about had or has the disease being studied				
It might improve your own health				
You would receive some medical care at no cost				
It might benefit my community				
It might help improve medical care for future generations				

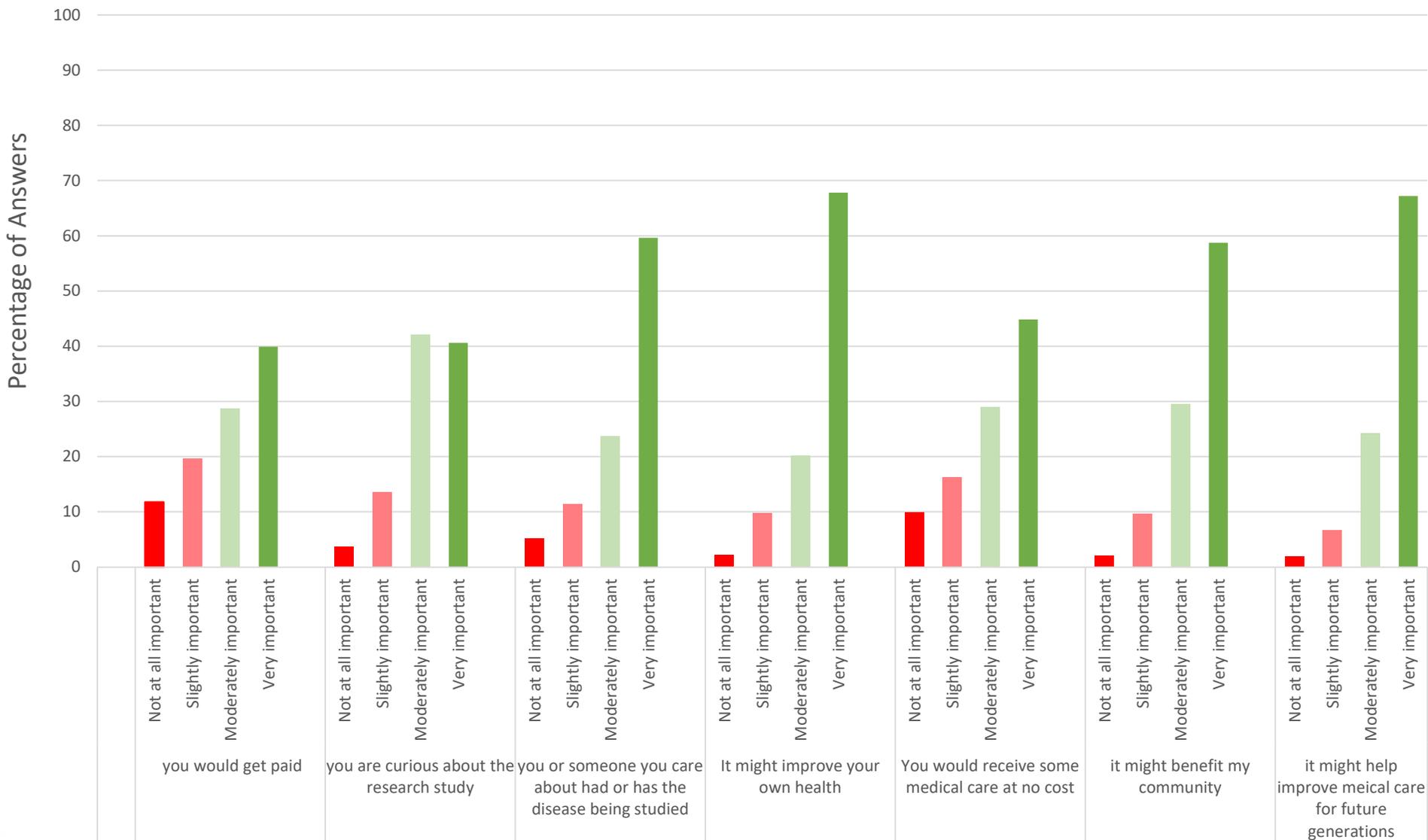
How important are the following considerations to you?

SCORE Response (n=79)



	You would get paid	You are curious about the research study	You or someone you care about had or has the disease being studied	It might improve your own health	You would receive some medical care at no cost	It might benefit my community	It might help improve medical care for future generations
■ Not at all important	13%	0%	1%	1%	22%	0%	0%
■ Slightly important	28%	5%	9%	10%	14%	5%	1%
■ Moderately important	30%	41%	18%	20%	32%	38%	30%
■ Very important	16%	42%	59%	56%	20%	44%	56%

How important are the following considerations to you?



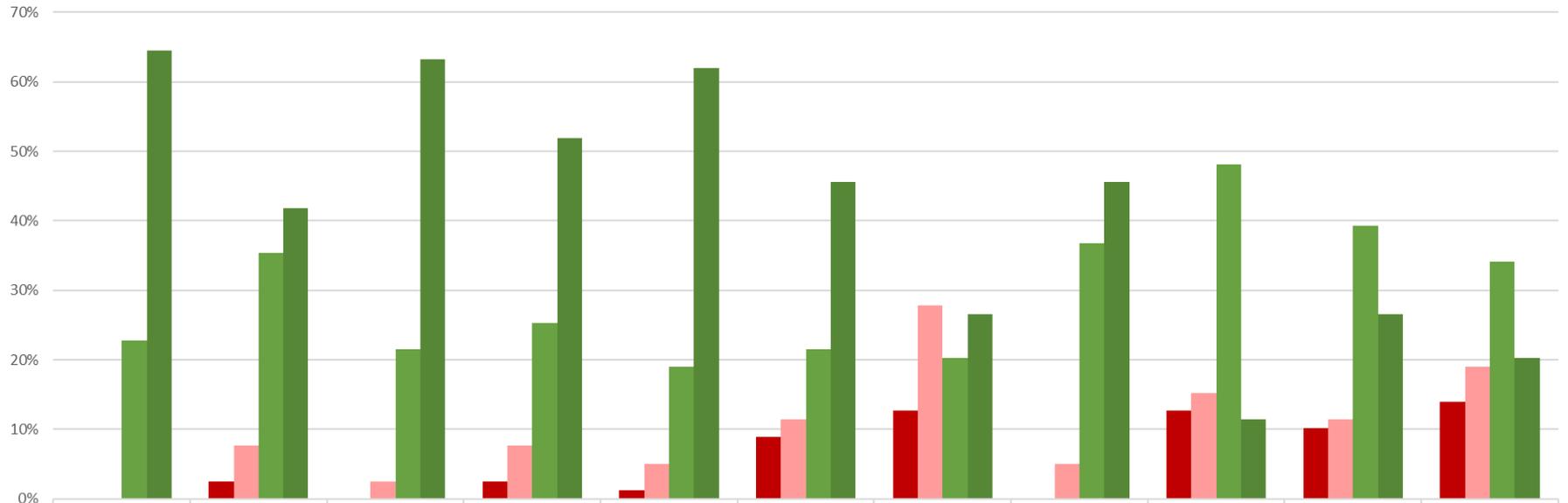
Motivators

	% that selected Moderately Important or Very Important
It might help improve medical care for future generations	91
It might benefit my community	88
It might improve your own health	88
You or someone you care about had or has the disease being studied	83
You are curious about the research study	82
You would receive some medical care at no cost	73
You would get paid	69

Type of Research Activity

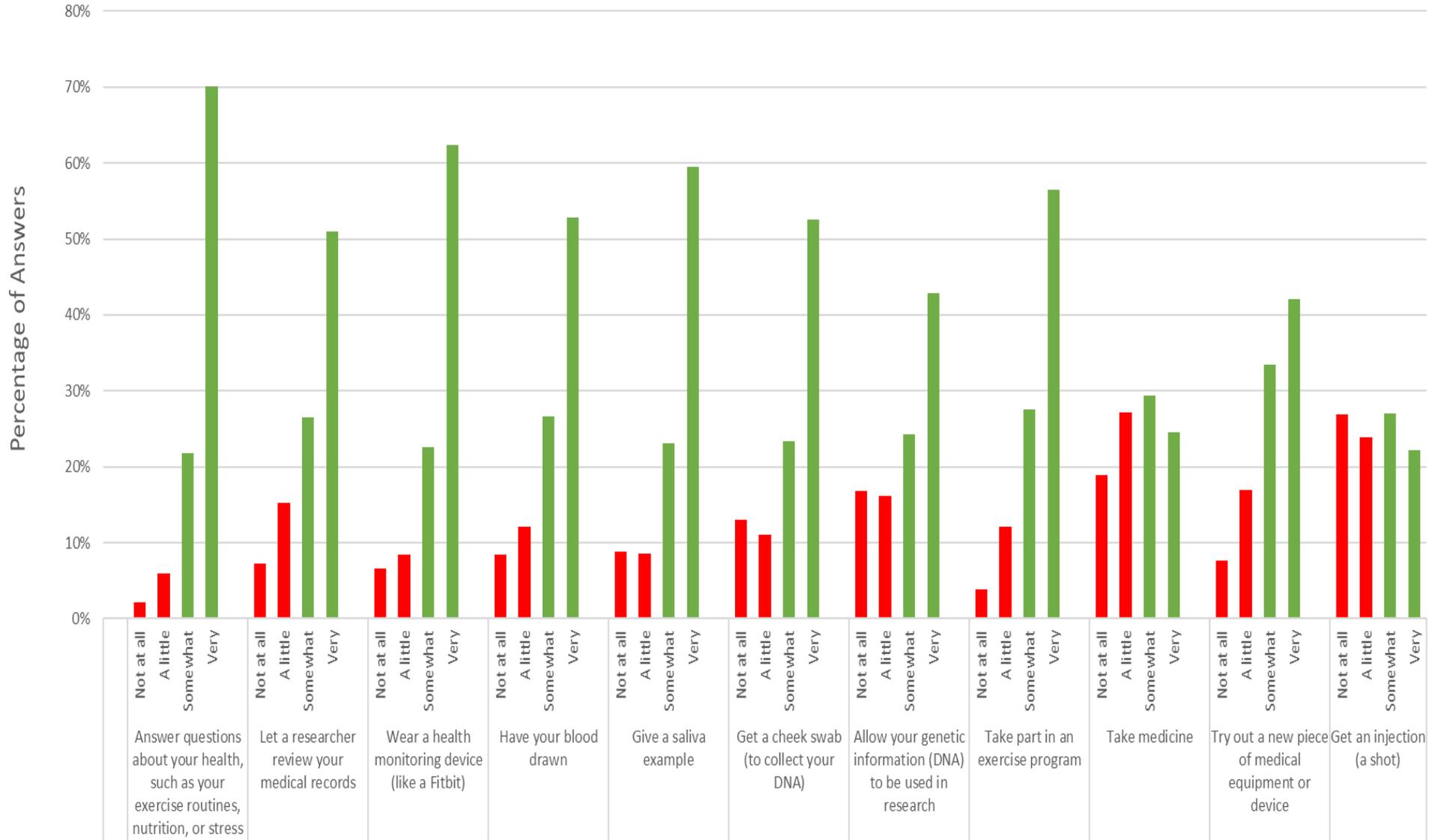
How likely are you to participate in clinical research if you had to:	Not at all	A little	Somewhat	Very
Answer questions about your health, such as about your exercise routines, nutrition, or stress				
Let a researcher review your medical records				
Wear a health monitoring device (like a Fitbit)				
Have your blood drawn				
Give a saliva sample				
Get a cheek swab (to collect your DNA)				
Allow your genetic information (DNA) to be used for research				
Take part in an exercise program				
Take medicine				
Try out a new piece of medical equipment or device				
Get an injection (a shot)				

How likely are you to participate in clinical research if you had to...
SCORE Response (n=79)



	Answer questions about your health, such as about your exercise routines, nutrition, or stress	Let a researcher review your medical records	Wear a health monitoring device (like a Fitbit)	Have your blood drawn	Give a saliva sample	Get a cheek swab (to collect your DNA)	Allow your genetic information (DNA) to be used for research	Take part in an exercise program	Take medicine	Try out a new piece of medical equipment or device	Get an injection (a shot)
■ Not at all	0%	3%	0%	3%	1%	9%	13%	0%	13%	10%	14%
■ A little	0%	8%	3%	8%	5%	11%	28%	5%	15%	11%	19%
■ Somewhat	23%	35%	22%	25%	19%	22%	20%	37%	48%	39%	34%
■ Very	65%	42%	63%	52%	62%	46%	27%	46%	11%	27%	20%

How likely are you to participate in clinical research if you had to:



Demographic Comparisons

- Men vs Women
- Age
 - 18-34, 35-64, 65+
- Education
- Zip code
 - City vs Non-city
- Ethnicity
- Race
- Chi-square analysis was used to calculate p values

Men vs Women

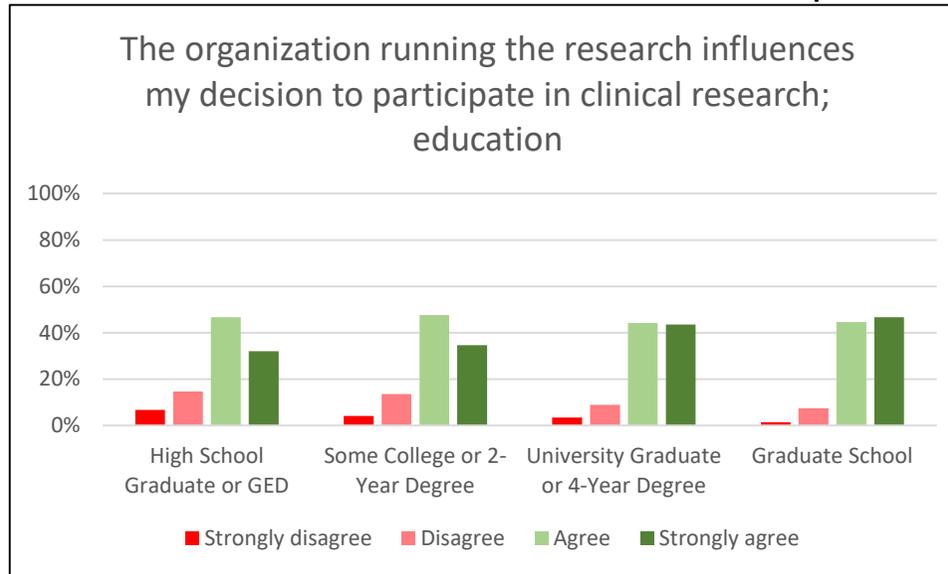
% of Respondents	Women	Men	P value
	answering moderately important or very important		
Motivator-receive medical care at no cost	76	69	0.0048
	answering somewhat or very		
Research activity- review medical record	75	84	0.0252
Research activity- blood drawn	76	87	0.0127
Research activity- saliva	79	88	0.0183
Research activity- check swab	74	82	0.0447
Research activity- genetic info	67	70	0.0185
Research activity- take medication	49	60	0.0289
Research activity- medical device	70	85	0.0008
Research activity- injection	44	60	<0.0001

Age

% of Respondents	18-34	35-64	65+	P value
	answering agree or strongly agree			
Opinion-Black asked to participate in riskier studies	50	41	33	0.0414
	answering somewhat or very			
Research activity- blood sample	73	81	90	0.0003
Research activity- genetic info	57	70	78	0.0005
Research activity- take medication	43	55	71	0.0004
Research activity- get injection	38	53	62	0.0004
	answering moderately important or very important			
Motivator- get paid	83	65	51	<0.0001

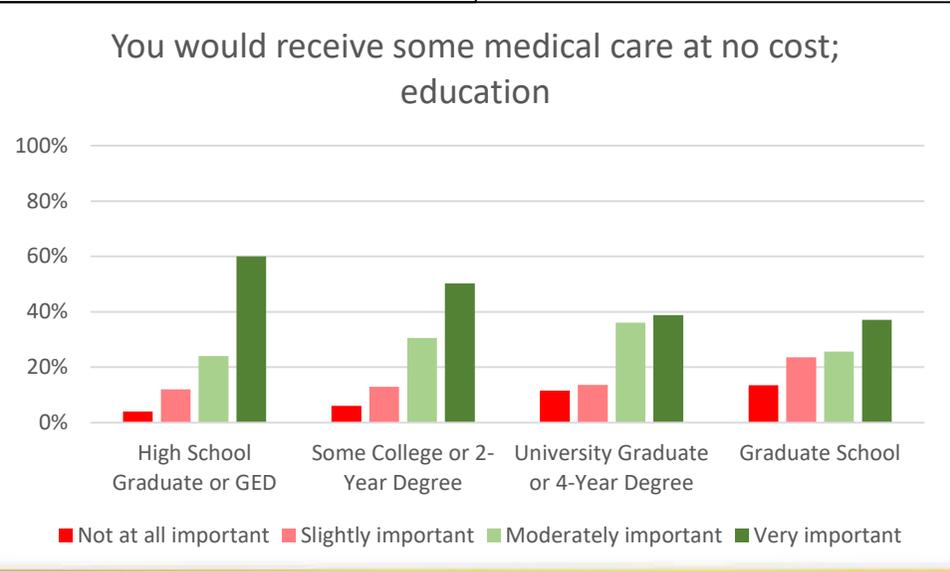
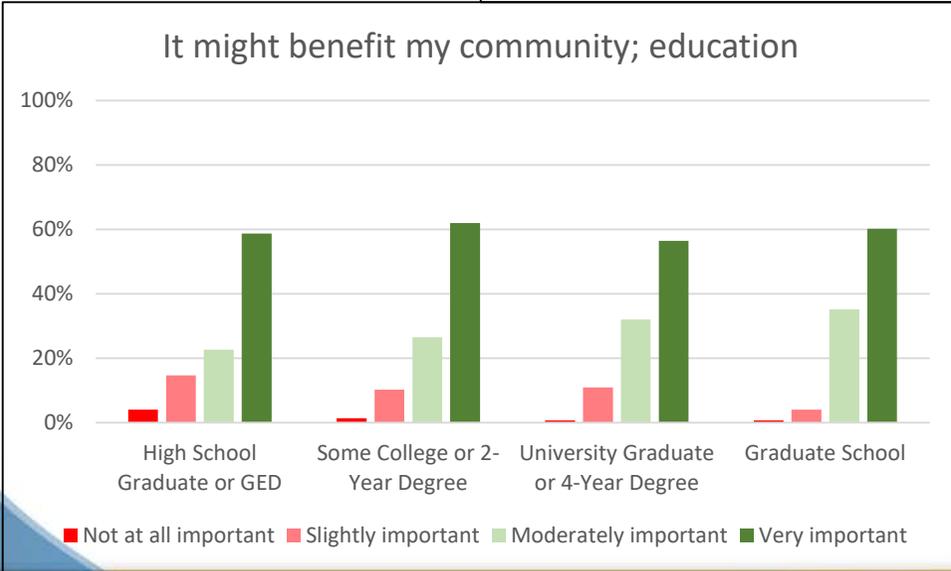
Level of Education

p=0.034



p=0.0001

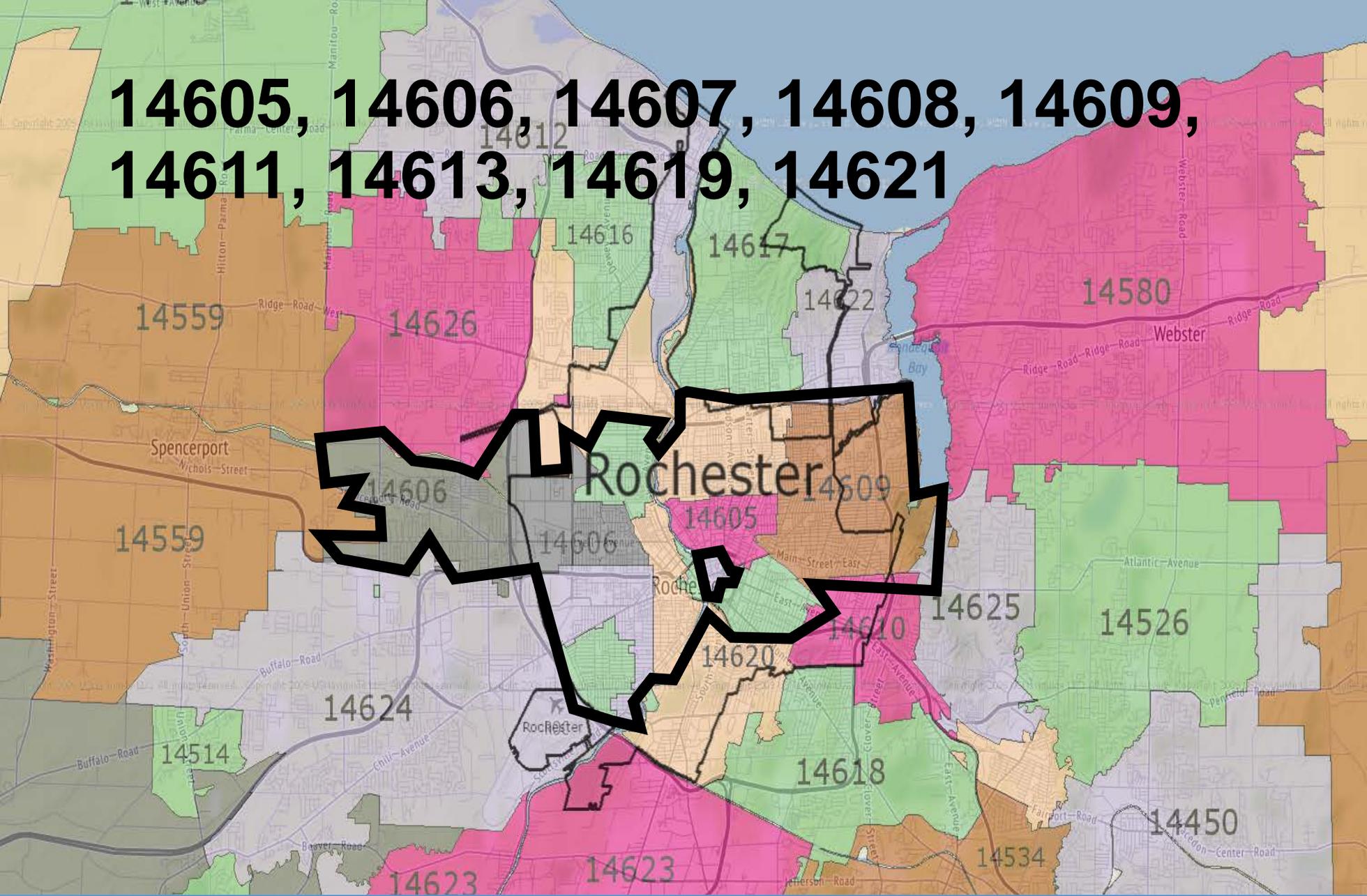
p=0.0227



Zip Code

People in the city were more often motivated to participate in a research study if they received medical care at no costs (82% of city vs. 72% of non-city; $p=0.0364$).

**14605, 14606, 14607, 14608, 14609,
14611, 14613, 14619, 14621**



Ethnicity

% of Respondents answering Agree or Strongly Agree	Hispanic	Non-Hispanic	P value
Opinion- Research is valuable	89	99	0.0025
Opinion- trust	84	93	0.0050
Opinion- Encourage family member	82	87	0.0272
Opinion- Likely to participate	77	88	0.0486
Opinion- safe	86	88	0.0270
Opinion- benefit me or my family	90	97	0.0435

No significant differences in motivators or research activities.

Race- Opinions

% of Respondents answering Agree or Strongly Agree	People of Color	White	P value
Trust	85	96	<0.0001
Blacks greater risk studies	53	36	<0.0001
Encourage family member	78	91	<0.0001
Benefit them or family	92	98	<0.0001

Other significant differences where people of color responded less positively were research is valuable, results of research are worth learning about, organization running research, among friends and coworkers there is a positive attitude about research, research is safe.

Race- Motivators

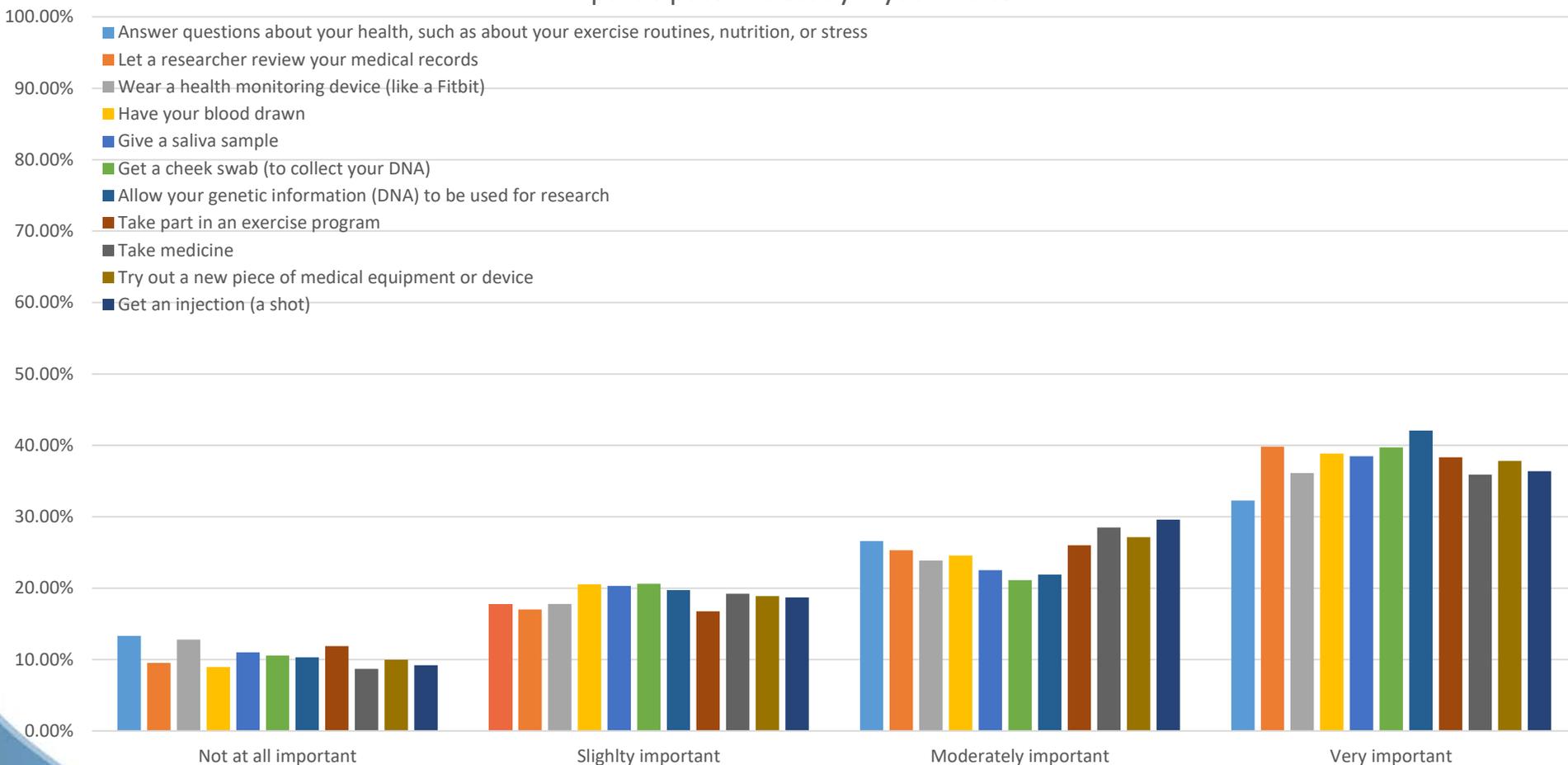
% of respondents answering moderately important or very important	People of Color	White	P value
Being paid	75	66	<0.0001
Might benefit my community	78	71	<0.0001
Improving care for future generations	85	96	<0.0001
Receive medical care at no cost	84	93	0.0027
You or someone has the disease	79	88	0.0159

Race- research activities

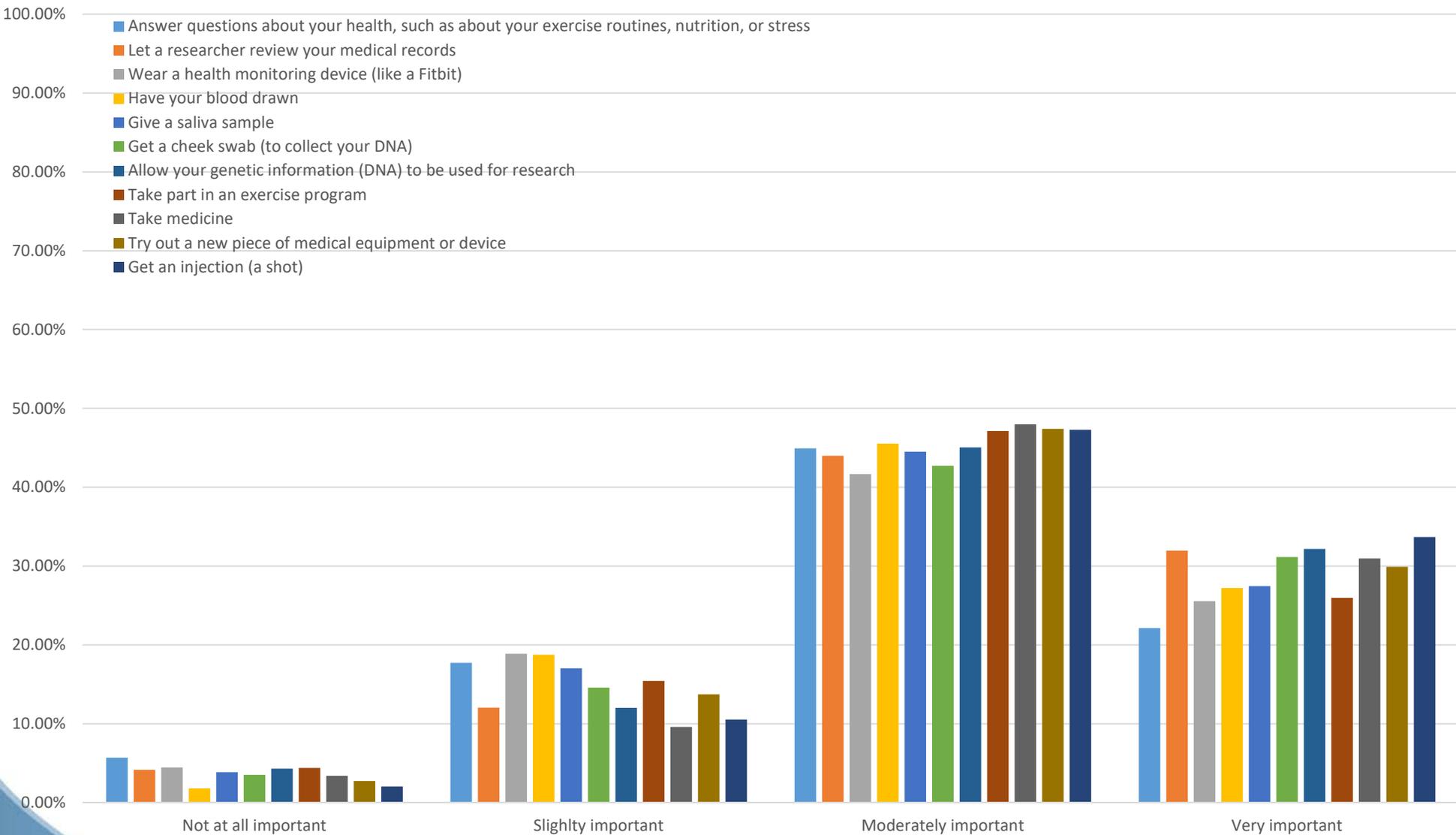
People of color were less likely to participate regardless of the type of research activity except for taking part in an exercise program.

Does motivator affect research activity?

How important is "You would get paid" if you participate in a study vs. How likely are you to participate in a study if you had to...



How important is "You are curious about the research study" if you participate in a study vs. How likely are you to participate in a study if you had to...



Conclusions

Research viewed positively in general.

People of color still have concerns about riskier studies.

Younger adults and people of color are less likely to participate.

Altruism is a strong motivator.

Compensation should be considered for younger people and people of color.

People are less likely to participate in studies with riskier methods.

Future work

Multivariate analyses

Compare 2019 data to 2008 and 2010



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