



# A Roadmap for Precision Medicine Research Recruitment: Empirical Assessment of Opinions and Willingness to Participate



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## Background & Purpose

**Background:** Precision medicine incorporates an individual's genetic, environment and lifestyle information in order to determine strategies to help prevent and treat disease.<sup>1,2</sup> Many precision medicine research studies are currently underway across the world to compile evidence and make this objective a reality in healthcare.<sup>3</sup> To accomplish this goal, precision medicine research requires large cohorts and significant recruitment efforts.<sup>4</sup> Novel strategies are necessary to capture data representative of society as a whole.

**Hypothesis:** Tailoring studies to match the needs and desires of potential participants will help to increase recruitment, engagement and further precision medicine research studies.<sup>5</sup>

**Study Aim:** To gain knowledge about factors impacting recruitment, this study assessed the public's opinions of and familiarity with precision medicine research and hypothetical willingness to participate in such research.

## Methods

Adult attendees at the 2017 Minnesota State Fair completed a 75-question electronic survey to characterize participants' opinions. Linear and logistic regression analyses identified significant predictors of overall willingness to participate in precision medicine research and willingness for five specific medical conditions.

## Sample Demographics

Table 1: Demographics (N=942)		
	n	%
<b>Gender</b>		
Female	562	60.6
Male	366	39.4
<b>Age</b>		
< 50	357	32.5
≥ 50	547	60.5
<b>Education</b>		
< Bachelor's degree	315	33.5
≥ Bachelor's degree	606	64.3
Prefer not to answer	7	0.7
<b>Income</b>		
< \$50,000	167	17.7
≥ \$50,000	624	66.4
Prefer not to answer	149	15.9
<b>Race</b>		
White	819	87.2
Asian	44	4.7
Multiracial	33	3.5
Black or African American	12	1.3
Hawaiian or Other Pacific Islander	4	0.4
American Indian or Alaska Native	3	0.3
Other	9	1.0
Prefer not to answer	15	1.6
<b>Ethnicity</b>		
Not Hispanic, Latino or Spanish	786	89.7
Hispanic, Latino or Spanish	17	1.9
Prefer not to answer	73	8.3

Note. n's vary as not every participant answered every question; \*Some percentages do not total to 100 due to rounding

## Selected References

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## Acknowledgements

- Survey participants
- State Fair volunteers
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## Results

**Attitudes and Perceptions:** Factor analyses of responses to items assessing attitudes and perceptions of precision medicine yielded three attitude factors (Conditional Research; Unconditional Research; and Own Participation but not One's Family), and four perception factors (Precision Medicine Research is Beneficial, Trustworthy, and Confidential; Precision Medicine has Negative Social Repercussions; Precision Medicine Research has Negative Personal Repercussions; and Precision Medicine may have Additional Impacts). These factors were then assessed as possible predictors of willingness.

**Familiarity, Awareness and Willingness:** Results of participants' familiarity, awareness and willingness to participate in precision medicine research are displayed below.

## Familiarity

Figure 1: Precision Medicine Familiarity (n= 940, n=167)

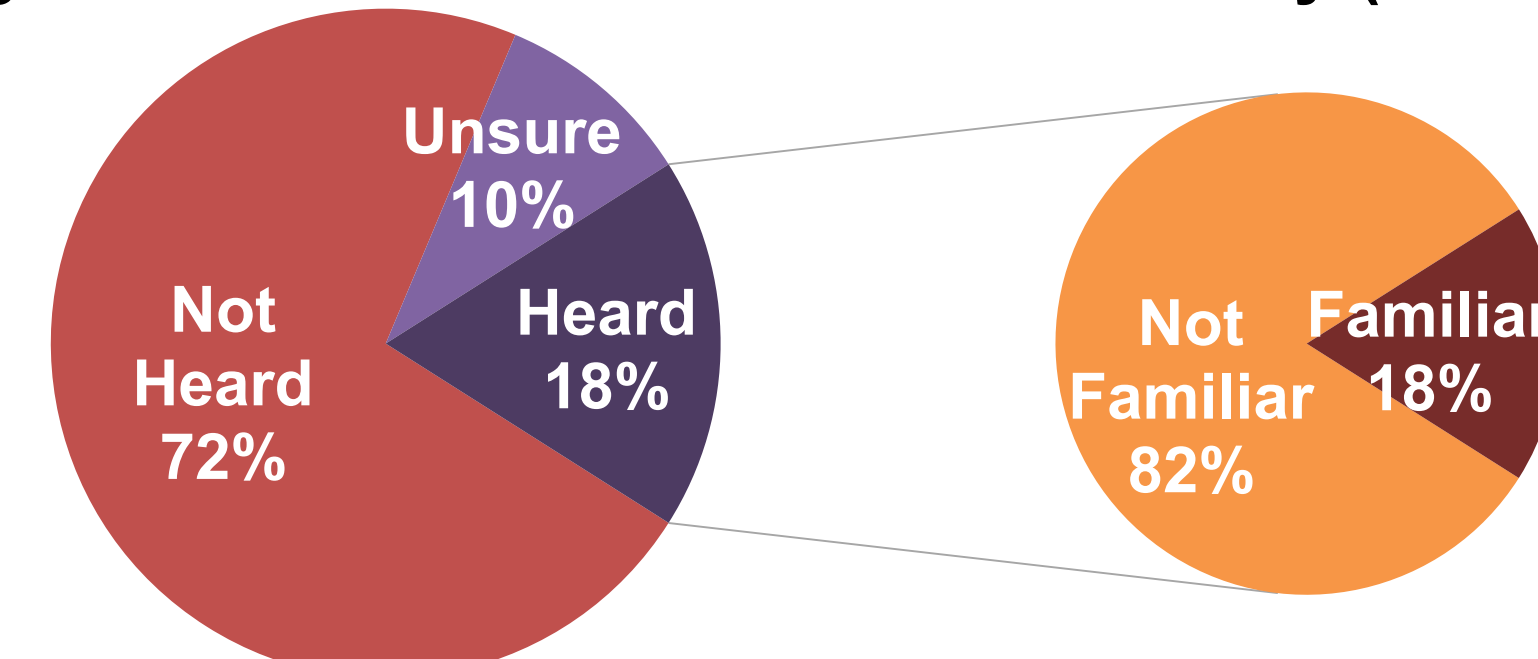
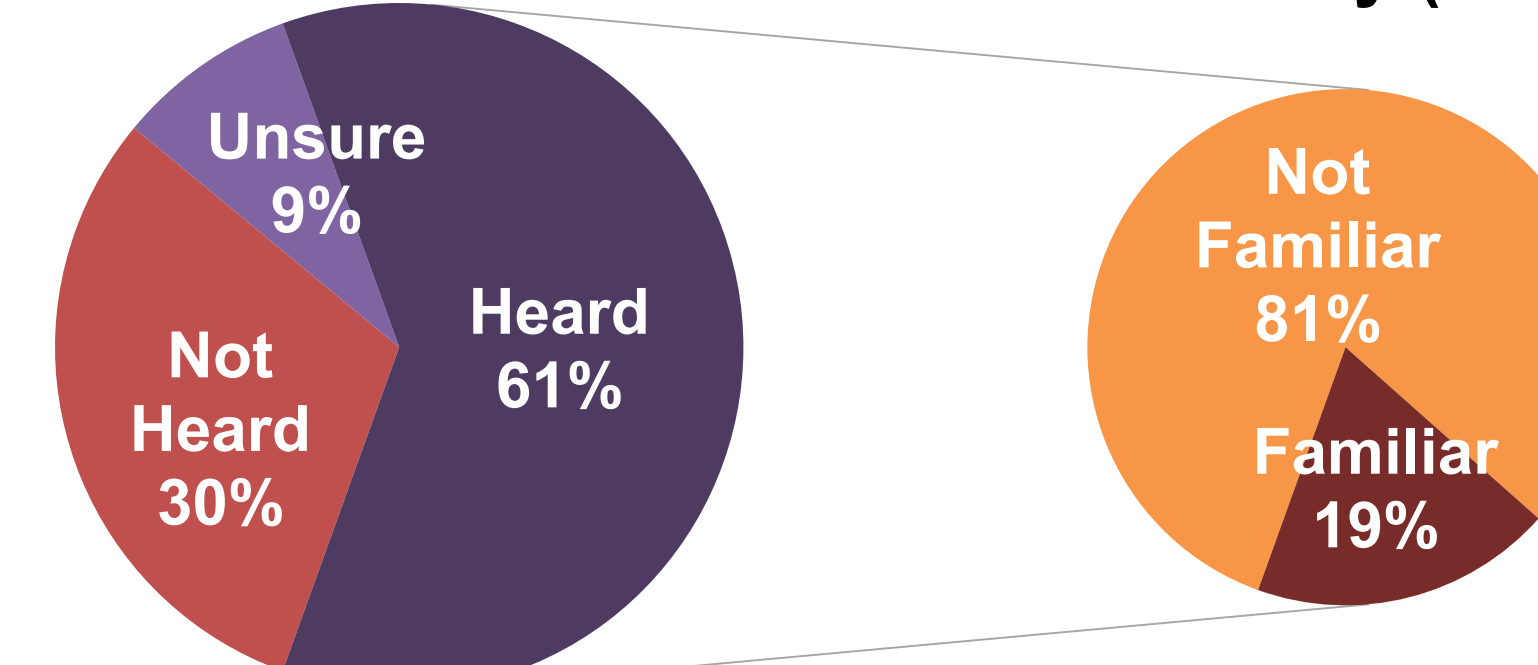


Figure 2. Personalized Medicine Familiarity (n=918, n=554)



## Awareness

Fig. 3: Source of Awareness of Precision Medicine

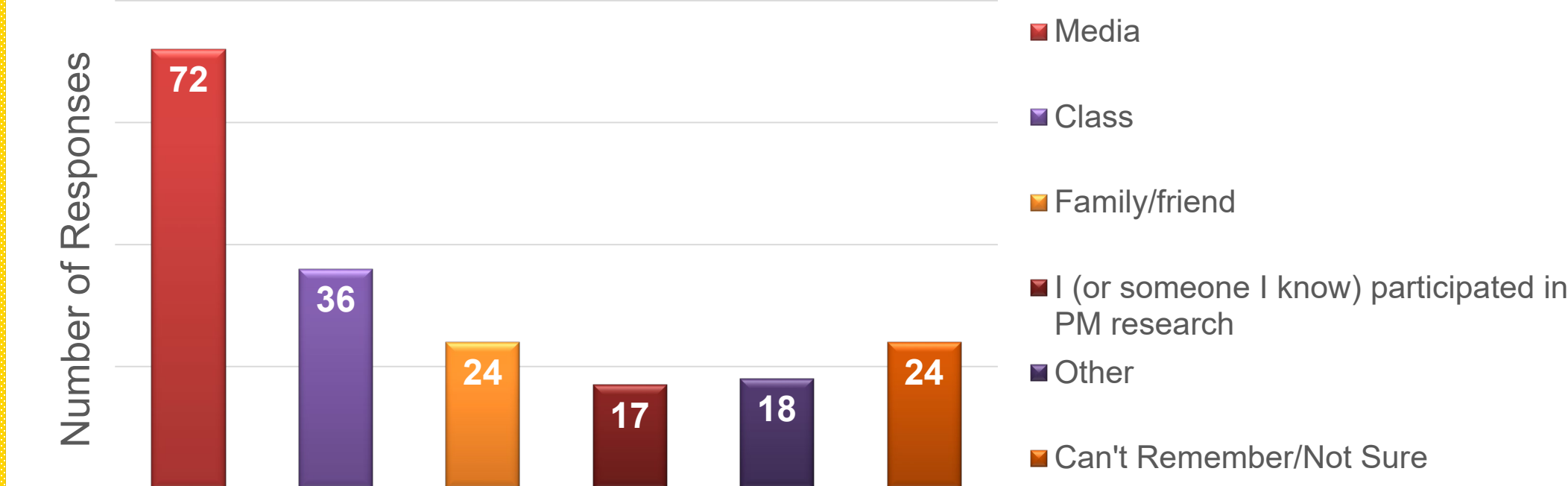
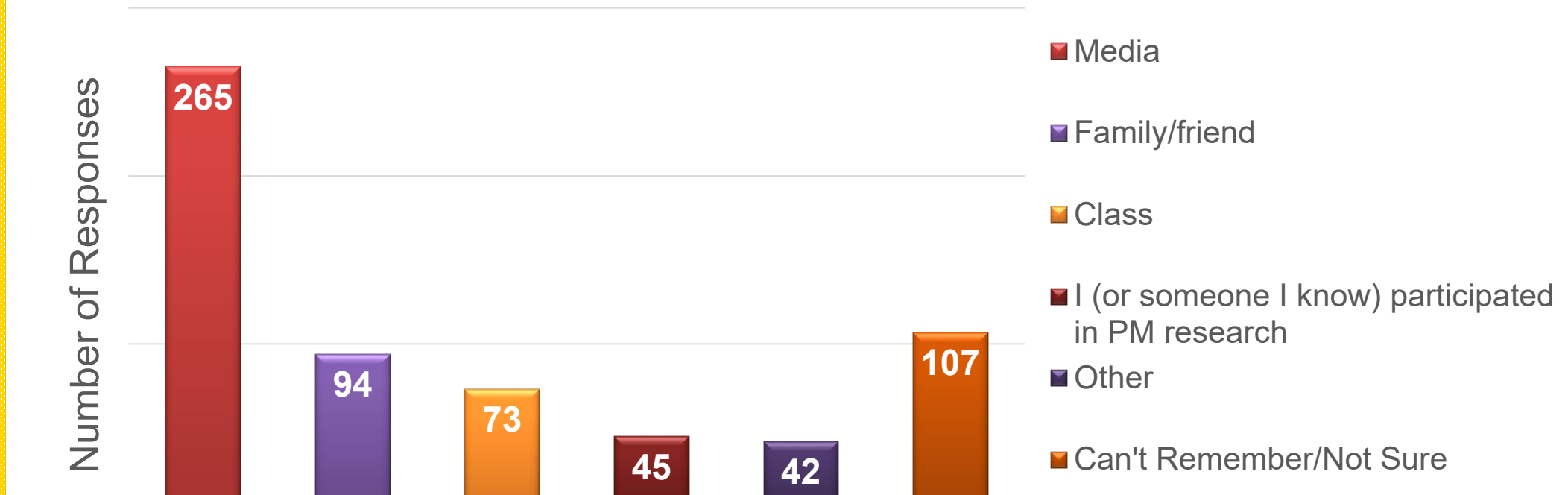


Fig. 4: Source of Awareness of Personalized Medicine



## Condition-Specific Willingness

Table 2: Willingness to Participate in Precision Medicine for Specific Medical Conditions

	Very Willing	Willing	Somewhat Willing	Little or Not Willing
Heart Disease (n= 934)	52.1%	32.9%	11.6%	3.4%
Cancer (n= 936)	51.8%	34.0%	10.3%	4.0%
Dementia (n= 936)	50.0%	31.3%	14.1%	4.6%
Bad Reaction to a Prescription Medication (n= 936)	45.5%	34.4%	14.1%	6.0%
Depression (n= 932)	45.3%	32.7%	16.1%	5.9%

Note. \*Some percentages do not total to 100 due to rounding

## Predictors of Condition-Specific Willingness

Figure 5: Attitude factors that are significant predictors of hypothetical willingness to participate in condition-based research scenarios

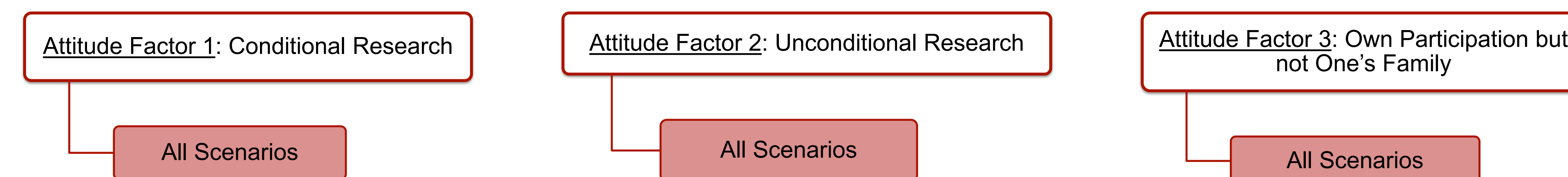


Figure 6: Perception factors that are significant predictors of hypothetical willingness to participate in condition-based research scenarios

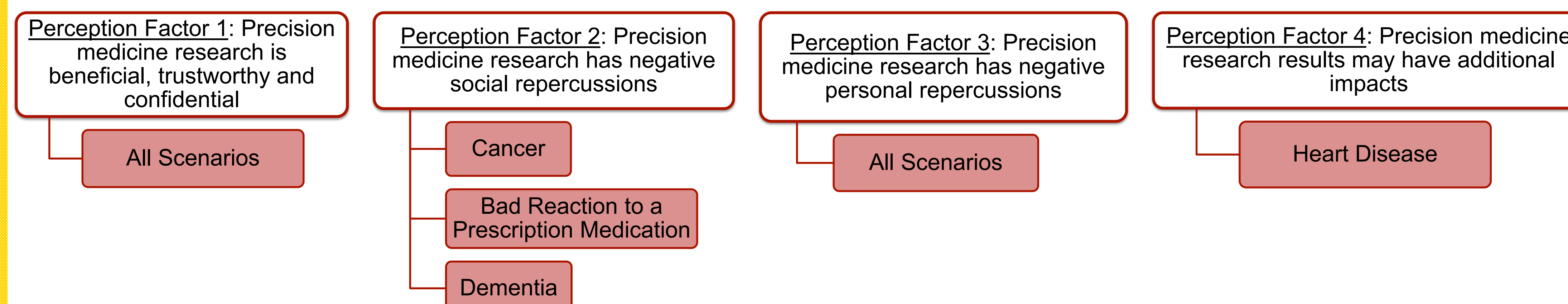
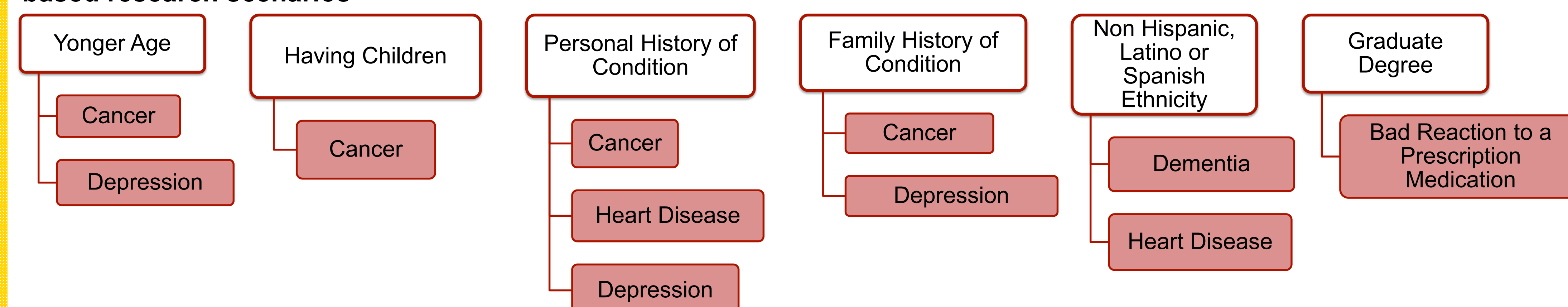
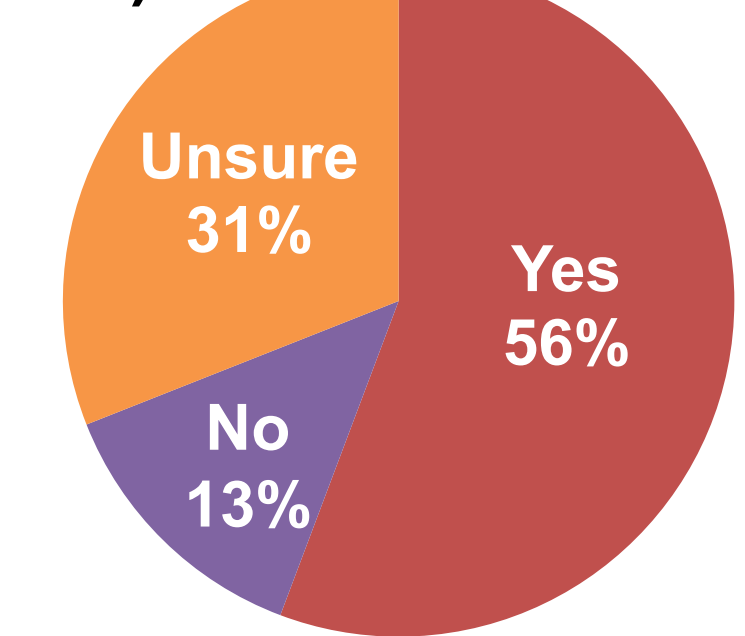


Figure 7: Demographic factors that are significant predictors of hypothetical willingness to participate in condition-based research scenarios



## Overall Willingness

Fig. 8: Willingness to participate in a precision medicine research study (n=942)



## Predictors of Overall Willingness

Table 3: Results of Logistic Regression Analysis Modeling of Overall Hypothetical Willingness to Participate (n = 942)

Variable	R <sup>2</sup>	AIC	p	OR [95% CI]
<b>Final Model</b>	0.445	932.58		
Intercept			0.46246	
Familiarity			2.78e-06 ***	1.21 [1.12-1.31]
Urban			0.15204	0.71 [0.44-1.14]
Bachelor's Degree			0.94761	1.01 [0.69-1.49]
Graduate Degree			0.03490*	1.57 [1.03-2.38]
Married			0.07415	0.74 [0.53-1.03]
Unconditional Research			3.95e-15 ***	2.15 [1.77-2.60]
Own Participation but not One's Family			8.13e-06 ***	1.52 [1.26-1.83]
Precision Medicine Research is Beneficial, Trustworthy and Confidential			1.13e-09 ***	1.84 [1.51-2.24]
Precision medicine research has negative personal repercussions			0.00125 **	0.75 [0.63-0.89]

Note. For Logistic Regression Analysis: R<sup>2</sup> is Nagelkerke's R<sup>2</sup>; Reference group for education is those with less than a Bachelor's degree; Significant at : \*.05 ; \*\*.01 ; \*\*\*0.001

## Conclusion and Discussion

**Familiarity & Awareness:** Participants were more familiar with "personalized medicine" vs. "precision medicine." Therefore, increased knowledge of terminology used to describe precision medicine research is an important first step to improve recruitment. The media was the most commonly reported source of hearing the terms precision/ personalized medicine. While media may help increase awareness, recruitment efforts may depend on type of media and need to involve other additional sources.

**Opinions & Willingness:** The current study identified significant predictors of hypothetical willingness to participate in precision medicine research through a large sample, obtained outside the healthcare setting, to engage those who may be potential participants in future precision medicine research. Willingness to participate was much higher for the condition specific scenarios than for participation in research without a specific focus, suggesting that incorporating condition-based scenarios may increase individuals' willingness and possibly enhance recruitment.

## Implications for Recruitment

