

Factors that Motivate Participation in Observational Genetic Cancer Research Studies

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How to cite this paper: Goodman, D., Johnson, C.O., Bowen, D., Wenzel, L. and Edwards, K. (2019) Factors that Motivate Participation in Observational Genetic Cancer Research Studies. *Open Journal of Epidemiology*, 9, 156-172.

<https://doi.org/10.4236/ojepi.2019.92014>

Received: March 21, 2019

Accepted: May 24, 2019

Published: May 27, 2019

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Abstract

Demographics, access to new treatment, altruistic motivations and continuity of care have been shown to influence motivation to participate in clinical trials. Less is known however, about factors that motivate research participants to agree to take part in observational studies and provide a biologic specimen. This study evaluates and quantitates factors that motivate participation in observational studies and provide a biospecimen among cancer patients, their family members, and controls. An online survey was completed by 450 participants from a cancer genetics registry, including cancer patients, their relatives, and controls. Overall, the benefit to society and the research institution reputation were the most important motivators for participation. Cancer cases were significantly more likely to endorse personal meaningfulness as a factor for participation compared to those without cancer and women were 50% more likely than men to believe that a family benefit is an important determinant of research participation. Researcher and institutional trustworthiness as well as security of stored data were most important when deciding whether to provide a biological sample, with differences seen by gender and history of cancer. This study demonstrated which factors are most important to participants when considering participation in an observational study and donating a biospecimen. Motivational factors significantly differed by gender as well as history and stage of cancer. The application of these study results may improve participation rates in cohort studies.

Keywords

Participation, Research, Motivation, Observational Studies

1. Introduction

The Precision Medicine Initiative (PMI) will enroll a million or more participants in a cohort program with the goal of learning about disease risk, discovering new disease biomarkers, expanding our knowledge of pharmacogenomics, and finding targeted and individualized treatment of diseases [1]. An understanding of research subject selection is critical. It is important to recruit from a broad population-representative sample to maximize generalizability of findings and minimize potential bias. An understanding of factors that influence participation in an observational longitudinal research study will enhance recruitment, improve study retention, and increase external validity.

It is well documented that participation in research studies is influenced by participant demographics including age, ethnicity, socioeconomic status, and gender [2] [3] [4] [5]. In addition to demographic predictors of participation, specific motivations like self-gain, or altruism, have been linked with participation [6]. Evaluating motivational factors that influence participation in clinical trials, several studies have shown that the most common reasons for participation include access to new treatment [7] [8], altruistic motivations [7] [8] [9] [10] [11] and continuity of care [11]. Unlike clinical trials, however, participation in observational studies does not usually offer the benefit of continuity of care or access to new treatment. In addition, population-based cohort studies include both healthy, unaffected participants and those with a spectrum of illnesses found in the general population. It is important to understand how motivators for study participation may differ for a cohort design compared to a clinical trial and for a healthy versus a diseased population. Few studies have examined factors that promote participation in observational studies [12] [13] [14] [15] [16], and the majority of this previous research has used qualitative methods to examine this issue [12] [13] [14] [15], making cross study comparisons difficult.

The PMI program will consist of an observational cohort of individuals and families with a spectrum of health conditions. Participation will consist of several distinct components, including completion of baseline survey information, access to patient electronic medical records, and providing a biospecimen for banking. It is possible that participants' motivators differ for each of these components and multiple approaches will be required to successfully recruit for this large project. It is also possible that level or reason for motivation may vary depending on what type of participant is being recruited (for example, case compared with relative or a control). At a time when participation in epidemiologic research studies has been declining [17], the PMI strives to create a cohort of historic size. However, the best ways to attract and motivate participation in the PMI are not known. The present timely study will fill this gap by evaluating and quantitating factors that influence participation and provision of a biological sample among cancer patients, their family members, and controls in an observational longitudinal research study.

2. Materials and Methods

2.1. Eligibility and Recruitment for the Participant Issues and Expectations Project (PIP)

The source population for the Participant Issues and Expectations Project (PIP) was the individuals ($n = 3553$) enrolled in the Northwest Cancer Genetics Registry (NWCGR), part of a national network designed to specialize in the study of inherited predisposition to cancer. The NWCGR was established in 2010 and has been described elsewhere [18]. This included people with cancer recruited from Western Washington ($n = 2027$), first-degree relatives of cases ($n = 451$), controls who were recruited from a random population sample from W. Washington ($n = 527$), and people who self-referred in response to community awareness efforts and included both people with and without cancer ($n = 904$ total; 340 with cancer). Self-referrals with cancer were grouped with cases and those without were grouped with the controls. There were no restrictions on the selection of controls or relatives. Letters, including informed consent, were sent by US mail in 2011 and 2012 inviting the enrolled individuals to take the online, confidential survey. Up to three invitations were sent to participants at approximately two-week intervals. Of the 450 participants that completed the online survey, 228 were from the case group, 155 were from the control group, and 67 were relatives.

2.2. Survey Methods

Development of the PIP Survey

The purpose of the survey was to document the range and frequency of occurrence of concerns and expectations regarding participating in human research studies, including genomic and family studies. Detailed methods for this study, including the survey instrument, have been published previously [19]. Briefly, the survey instrument had a total of 22 questions, divided into six general topic areas: decision to participate in research; relationship between researchers and participants; re-consent and broad consent; return of results; use and security of de-identified data; and family communication of health issues. The types of response categories included either yes/no/not sure options, Likert-scales (e.g., 5-point scales rating agreement, likelihood or importance of the statement with a sixth “don’t know” or “it depends” option) or categorical responses. Nine scenarios asked about the factors that would influence their decision to participate in research and 4 scenarios covered factors related to factors that would influence whether they would provide a biological sample for genetic analysis. We report here the results of these 13 items (see **Appendix 1**).

The survey was confidential, not anonymous, using a unique identification number for each participant, and participants were free to skip any questions that they did not wish to answer. Each participant was provided an individual URL to access the secure survey instrument. Links to each individual survey and the participant’s NWCGR data were retained to reduce the length of the survey

and to allow us to utilize existing demographic and other participant information.

All study procedures were approved by the University of Washington's Human Subjects Division, and also by the University of California, Irvine Institutional Review Board. All participants provided informed consent prior to participation.

2.3. Statistical Analysis

Responses to questions were first summarized using frequency distributions for the overall sample and by participant type (*i.e.*, cases, controls, relatives). Ordinal logistic regression was the primary tool to evaluate the association between participant characteristics and participation in research and providing a biological sample for genetic analysis. Differences examined included status (cases versus controls versus relatives), gender, diagnosis of cancer at baseline, diagnosis of cancer at follow-up, and stage of cancer for cases reported at either baseline or follow-up. The response categories for the 13 questions (dependent variable) were the same and were ordered and coded as follows: 1) very important as 1, somewhat important as 2, not very important as 3 and not at all important as 4. With ordinal logistic regression, several cumulative logits are modeled using all possible cut points of the dependent variable, but a single summary odds ratio (OR) and 95% confidence interval describing the relationship between the dependent and independent variable is obtained. Comparisons were adjusted for age, gender and education. R version 3.2.2 was used for all analyses; the `polr` function from the MASS package was used for ordinal logistic regression [20]. A p-value ≤ 0.05 was considered statistically significant for all tests. Sample sizes varied slightly by question since participants were allowed to skip any question they did not wish to answer.

3. Results

About half of this study population consisted of cases ($n = 228$), one-third were controls ($n = 155$), and the remainder of the population was relatives ($n = 67$) (Table 1). Overall, the average participant age was 63.6 years, and the majority were white (94.7%) and well educated, with over 60% of participants having a college degree. Compared to cases and relatives, controls were slightly more likely to be female. Among those participants with cancer at study enrollment, melanoma was the most frequent cancer type (29.5%), followed by thyroid cancer (18.3%), and breast cancer (15.5%). Thirty-five research participants without cancer at enrollment reported a cancer at the time of this (follow-up) survey.

As shown in Table 2, the knowledge that the research could benefit society and the reputation of the research institution were the most important reasons to study participants when making the choice to participate in a research study, with 99% and 97 of participants, respectively, stating these factors were either very important or somewhat important to their decision. Over 80% of participants

Table 1. Distribution of demographic characteristics of study population by participant type.

	Total (n = 450)	Cases (n = 228)	Controls (n = 155)	Relatives (n = 67)
Mean (SD) Age (yrs)	63.6 (11.8)	64.3 (11.4)	64.0 (11.5)	60.5 (13.6)
Women	292 (64.9%)	145 (63.6%)	110 (71.0%)	37 (55.2%)
Race				
Asian/Pacific Islander	7 (15.6%)	4 (1.8%)	2 (1.3%)	1 (1.5%)
Black	4 (0.9%)	2 (0.9%)	2 (1.3%)	0
Multi-Racial/Other	16 (3.6%)	8 (3.5%)	4 (2.6%)	4 (6.0%)
White	423 (94.7%)	214 (93.9%)	147 (94.8%)	62 (92.5%)
Education				
High School or less	40 (8.9%)	19 (8.3%)	13 (8.4%)	8 (11.9)
Some College	107 (23.8%)	57 (25.0%)	37 (23.9%)	13 (19.4%)
Bachelors Degree	276 (61.3%)	126 (55.3%)	105 (67.7%)	45 (67.2%)
Unknown	27 (6.0%)	26 (11.4%)	0	1 (1.5%)

Table 2. Frequency (%) of responses overall and by participant type to the question: "When making the decision to participate in a research study, how important are the following to you?"

	Total	Cases	Controls	Relatives
The reputation of the research institution or researcher				
Very important	346 (77.1)	176 (77.2)	121 (78.1)	49 (74.2)
Somewhat important	89 (19.8)	42 (18.4)	32 (20.6)	15 (22.7)
Not very important	8 (1.8)	5 (2.2)	1 (0.6)	2 (3.0)
Not at all important	6 (1.3)	5 (2.2)	1 (0.6)	0 (0)
The value of incentives (for example, gift cards or cash)				
Very important	16 (3.6)	6 (2.7)	7 (4.5)	3 (4.5)
Somewhat important	75 (16.8)	43 (19.0)	22 (14.3)	10 (15.2)
Not very important	179 (40.1)	89 (39.4)	67 (43.5)	23 (34.8)
Not at all important	176 (39.5)	88 (38.9)	58 (37.7)	30 (45.5)
The research must be meaningful to me personally				
Very important	204 (45.6)	109 (48)	64 (41.6)	31 (47)
Somewhat important	172 (38.5)	87 (38.3)	60 (39)	25 (37.9)
Not very important	44 (9.8)	18 (7.9)	18 (11.7)	8 (12.1)
Not at all important	27 (6.1)	13 (5.7)	12 (7.8)	2 (3.0)
The research will improve my health				
Very important	110 (24.7)	57 (25.2)	31 (20.1)	22 (33.3)

Continued

Somewhat important	190 (42.6)	98 (43.4)	69 (44.8)	23 (34.8)
Not very important	99 (22.2)	49 (21.7)	38 (24.7)	12 (18.2)
Not at all important	47 (10.5)	22 (9.7)	16 (10.4)	9 (13.6)
The research will provide information I can use to improve my health				
Very important	150 (33.6)	76 (33.8)	47 (30.3)	27 (40.9)
Somewhat important	186 (41.7)	101 (44.9)	68 (43.9)	17 (25.8)
Not very important	77 (17.3)	36 (16)	27 (17.4)	14 (21.2)
Not at all important	33 (7.4)	12 (5.3)	13 (8.4)	8 (12.1)
The research will provide information about me I didn't know				
Very important	129 (29.0)	67 (29.8)	42 (27.3)	20 (30.3)
Somewhat important	173 (38.9)	89 (39.6)	64 (41.6)	20 (30.3)
Not very important	98 (22.0)	48 (21.3)	31 (20.1)	19 (28.8)
Not at all important	45 (10.1)	21 (9.3)	17 (11.0)	7 (10.6)
The research could benefit my family				
Very important	262 (58.7)	134 (59)	85 (55.6)	43 (65.2)
Somewhat important	132 (29.6)	72 (31.7)	46 (30.1)	14 (21.2)
Not very important	34 (7.6)	11 (4.8)	17 (11.1)	6 (9.1)
Not at all important	18 (4.1)	10 (4.4)	5 (3.3)	3 (4.5)
The research could benefit people I know				
Very important	240 (53.9)	126 (55.5)	76 (49.7)	38 (58.5)
Somewhat important	147 (33.0)	75 (33.0)	52 (34)	20 (30.8)
Not very important	41 (9.2)	17 (7.5)	20 (13.1)	4 (6.2)
Not at all important	17 (3.9)	9 (4.0)	5 (3.3)	3 (4.6)
The research could benefit society				
Very important	360 (81.1)	183 (81)	124 (81.6)	53 (80.3)
Somewhat important	80 (18.0)	41 (18.1)	26 (17.1)	13 (19.7)
Not very important	3 (0.7)	1 (0.4)	2 (1.3)	0 (0)
Not at all important	1 (0.2)	1 (0.4)	0 (0)	0 (0)

felt that personal meaningfulness of the research and benefit to friends and family were important in their decision to participate, while 75% stated that it was important to participate if research provided information to improve their personal health. Two-thirds of the population related that it was important that the research improve their health or provide information they did not previously know. Only 20% of participant's felt that the value of incentives was an important factor in the decision to participate in research. These results did not materially differ between cases, controls, or relatives.

Participants with cancer at baseline or at the time of the survey completion

endorsed the personal meaningfulness of research as a factor for participation in research compared to participants without cancer (OR = 0.61, 0.42 - 0.89; OR = 0.62, 0.42 - 0.91) (**Table 3**). Those with a more advanced stage of cancer were significantly more likely to participate in research because they felt that the research could benefit their family (OR = 2.72, 0.99 - 7.50). While all cases were significantly more likely to feel that the research must be meaningful to them personally compared to controls (OR = 1.56, 1.05 - 2.34), women were 50% more likely than men to believe that a family benefit is an important determinant of research participation (OR = 1.73, 1.16 - 2.58).

As shown in **Table 4**, almost all of participants felt that the researcher trustworthiness, institutional trustworthiness, and security of stored data and samples are very important or somewhat important when determining whether to provide a biological sample. Receiving a personal report about individual genetic risks and/or benefits, as well as the security of the data and samples were cited by 86% and 87% of participants as important factors in providing a biological sample. Women were twice as likely as men to endorse researcher trustworthiness as an important factor in deciding whether to provide a biological sample (OR = 2.0, 1.03 - 3.90) (**Table 5**). Cases were significantly more likely than controls to feel that receiving individual genetic risks was important (OR = 1.92, 1.27 - 2.90), and a history of cancer at baseline or when the survey was administered increased the importance of receiving genetic risks and/or benefits as a factor for participation in biological sampling (OR = 0.54, 0.37 - 0.80; OR = 0.61, 0.41 - 0.90).

Table 3. Adjusted ordinal regression by participant characteristics.

		OR	95% CI	p-value
The reputation of the research institution or researcher	Subject Type			
	Control vs Case	0.92	0.55, 1.54	0.76
	Relative vs Case	0.87	0.43, 1.75	0.69
	Gender	1.51	0.92, 2.47	0.10
	Cancer at baseline	1.12	0.70, 1.81	0.64
	Cancer at survey	1.09	0.67, 1.78	0.72
	Stage of cancer	1.52	0.47, 4.90	0.48
The value of incentives (for example, gift cards or cash)	Subject Type			
	Control vs Case	0.98	0.66, 1.45	0.91
	Relative vs Case	1.47	0.84, 2.57	0.18
	Gender	0.83	0.56, 1.22	0.33
	Cancer at baseline	0.78	0.54, 1.12	0.18
	Cancer at survey	0.71	0.49, 1.04	0.08
	Stage of cancer	1.06	0.40, 2.82	0.90

Continued

The research must be meaningful to me personally	Subject Type			
	Control vs Case	1.56	1.05, 2.34	0.03
	Relative vs Case	1.15	0.67, 2.00	0.61
	Gender	1.15	0.78, 1.70	0.49
	Cancer at baseline	0.61	0.42, 0.89	0.01
	Cancer at survey	0.62	0.42, 0.91	0.02
	Stage of cancer	1.56	0.59, 4.14	0.37
The research will improve my health	Subject Type			
	Control vs Case	1.25	0.85, 1.83	0.27
	Relative vs Case	0.81	0.46, 1.42	0.47
	Gender	1.03	0.70, 1.50	0.89
	Cancer at baseline	0.77	0.54, 1.11	0.17
	Cancer at survey	0.79	0.54, 1.13	0.20
	Stage of cancer	1.54	0.59, 4.01	0.379
The research will provide information I can use to improve my health	Subject Type			
	Control vs Case	1.27	0.86, 1.88	0.223
	Relative vs Case	0.95	0.54, 1.68	0.858
	Gender	1.18	0.80, 1.74	0.39
	Cancer at baseline	0.77	0.54, 1.11	0.16
	Cancer at survey	0.74	0.51, 1.08	0.12
	Stage of cancer	1.53	0.58, 4.05	0.40
The research will provide information about me I didn't know	Subject Type			
	Control vs Case	1.05	0.71, 1.54	0.82
	Relative vs Case	1.04	0.60, 1.77	0.90
	Gender	1.01	0.69, 1.47	0.97
	Cancer at baseline	0.85	0.60, 1.22	0.38
	Cancer at survey	0.88	0.61, 1.26	0.48
	Stage of cancer	2.4	0.91, 6.34	0.08
The research could benefit my family	Subject Type			
	Control vs Case	1.32	0.87, 2.02	0.19
	Relative vs Case	0.85	0.46, 1.54	0.58
	Gender	1.51	1.00, 2.27	0.05
	Cancer at baseline	0.81	0.54, 1.19	0.28
	Cancer at survey	0.87	0.58, 1.31	0.51
	Stage of cancer	2.72	0.99, 7.50	0.05
The research could benefit people I know	Subject Type			
	Control vs Case	1.44	0.95, 2.18	0.08
	Relative vs Case	0.9	0.51, 1.61	0.73

Continued

	Gender	1.73	1.16, 2.58	0.01
	Cancer at baseline	0.74	0.51, 1.09	0.13
	Cancer at survey	0.78	0.53, 1.15	0.21
	Stage of cancer	2.56	0.95, 6.89	0.06
The research could benefit society	Subject Type			
	Control vs Case	1.42	0.17, 1.22	0.73
	Relative vs Case		N/A*	
	Gender	1.49	0.17, 1.32	0.70
	Cancer at baseline	2.24	0.27, 4.62	0.49
	Cancer at survey	1.53	0.18, 3.23	0.72
	Stage of cancer		N/A*	

Table 4. Frequency (%) of responses by participant type to the question: Imagine you were asked to provide health information about yourself and a biological sample (such as blood or saliva) for genetic analysis as part of your participation in a research study. Please indicate the importance of each of the following in determining whether or not you would participate.

	Total	Cases	Controls	Relatives
The researcher is trustworthy				
Very important	405 (90.3)	207 (91.6)	137 (88.4)	61 (91.0)
Somewhat important	39 (8.7)	17 (7.5)	17 (11.0)	5 (7.5)
Not very important	2 (0.5)	0 (0)	1 (0.6)	1 (1.5)
Not at all important	2 (0.5)	2 (0.9)	0 (0)	0 (0)
The institution where the research is being conducted is trustworthy				
Very important	409 (91.3)	205 (90.7)	142 (91.6)	62 (92.5)
Somewhat important	36 (8.0)	19 (8.4)	12 (7.7)	5 (7.5)
Not very important	1 (0.2)	0 (0)	1 (0.6)	0 (0)
Not at all important	2 (0.5)	2 (0.9)	0 (0)	0 (0)
I will receive a personal report about my individual genetic risks and/or benefits				
Very important	239 (53.9)	133 (59.1)	69 (45.4)	37 (56.1)
Somewhat important	142 (32.1)	73 (32.4)	53 (34.9)	16 (24.2)
Not very important	48 (10.8)	15 (6.7)	25 (16.4)	8 (12.1)
Not at all important	14 (3.2)	4 (1.8)	5 (3.3)	5 (7.6)
Data and samples are stored securely				
Very important	366 (82.3)	186 (82.7)	123 (79.9)	57 (86.4)
Somewhat important	66 (14.8)	33 (14.7)	27 (17.5)	6 (9.1)
Not very important	12 (2.7)	6 (2.7)	4 (2.6)	2 (3.0)
Not at all important	1 (0.2)	0 (0)	0 (0)	1 (1.5)

Table 5. Adjusted ordinal regression by participant characteristics.

	Model	OR	95% CI	p-value
	Subject Type			
The researcher is trustworthy	Control vs Case	1.46	0.72, 2.96	0.30
	Relative vs Case	0.97	0.35, 2.63	0.95
	Gender	2.00	1.03, 3.90	0.04
	Cancer at baseline	1.01	0.52, 1.95	0.99
	Cancer at survey	0.93	0.48, 1.83	0.84
	Stage of cancer	0.35	0.04, 3.08	0.34
The institution where the research is being conducted is trustworthy	Subject Type			
	Control vs Case	0.94	0.44, 1.99	0.86
	Relative vs Case	0.75	0.26, 2.17	0.60
	Gender	1.61	0.79, 3.27	0.19
	Cancer at baseline	1.39	0.69, 2.82	0.40
	Cancer at survey	1.37	0.66, 2.84	0.40
	Stage of cancer	0.31	0.04, 2.71	0.30
I will receive a personal report about my individual genetic risks and/or benefits	Subject Type			
	Control vs Case	1.92	1.27, 2.90	0.002
	Relative vs Case	1.25	0.69, 2.25	0.46
	Gender	1.15	0.77, 1.72	0.49
	Cancer at baseline	0.54	0.37, 0.80	0.002
	Cancer at survey	0.61	0.41, 0.90	0.01
	Stage of cancer	0.58	0.19, 1.74	0.33
Data and samples are stored securely	Subject Type			
	Control vs Case	1.24	0.72, 2.16	0.44
	Relative vs Case	0.78	0.33, 1.82	0.56
	Gender	1.60	0.94, 2.73	0.08
	Cancer at baseline	0.94	0.55, 1.58	0.80
	Cancer at survey	0.95	0.55, 1.62	0.85
	Stage of cancer		N/A*	

4. Discussions

The purpose of this study was to identify factors that motivate people to participate in a research study that has components required for participation similar to the PMI. We found that the two most important motivational factors for the decision to participate in an observational research study included a benefit to society and the reputation of the research institution. This is consistent with previous studies that have shown individual benefits, social value, and trust of

the physicians and/or research institution are motivators for study participants [12] [13] [14] [15] [16]. To our knowledge, only one previous study also used quantitative methods to evaluate these motivators to participation in an observational setting and, similar to our results, found that 87% of respondents cited future health benefits to society and oneself as important reasons to participate in health research [16].

It has been suggested that the altruistic component of motivation to participate in research may be related to a ratio of risks to benefits [13]. Compared to a cohort study, the benefits of participation in a clinical trial might be more concrete and observable to research participants. While this risk-benefit ratio is diminished in a cohort study, we found that a benefit to society is still the most important factor in determining participation.

Participants with a history of cancer were more likely to participate if the research was personally meaningful. In addition, stage of cancer was also associated with motivation to participate, and those with a higher stage were more likely to view the benefit to family members as an important motivator. It is possible that those with late stage cancer are more eager to obtain timely benefits from research studies. This study also found that women were significantly more likely than men to endorse a family benefit as an important motivator for research participation. To our knowledge, we are the first to identify this gender difference in motivation to participate in research. Surprisingly, only 20% of participants felt that incentives were an important factor in their decision to participate in research. The “leverage-saliency theory” describes the probability of participating in a survey as a combination of survey-specific factors (for example, study topic and who is doing the study), participant specific factors (for example, concerns about privacy), and the participant’s social and physical environment [21]. The impact of an incentive is weighed against the absence or presence of other factors impacting the motivation to participate [22]. It has been shown that monetary incentives have a greater impact when the study topic has little salience [21] [23] [24]. It is possible that in this study population, comprised largely of an older, white group of cancer cases and their relatives, strong participant and study factors outweighed the need for incentives [25] [26] [27] [28]. In addition, because education is a proxy for SES, people may value time more than money. In our highly educated study population, participants may weigh the time devoted to the research study with the benefits it provides to themselves, their families, and society.

Researcher and institution trustworthiness as well as data security were most important to participants when deciding whether to provide a biological sample. The finding of trustworthiness is consistent with others [29]. Gender differences related to trust have previously been shown; women show less distrust of medical researchers compared to men when asked to participate in a clinical trial [20]. This is consistent with our finding that women were significantly more likely to feel that trustworthiness is an important motivating factor in providing a biospecimen. Only one previous study evaluated gender differences related to

trust and the donation of a biological specimen and did not find a significant difference [29]. However, the study was conducted among twin pairs and therefore matched on both genetics and environment, potentially eliminating any differences in trust. In addition, it is possible that a difference in demographics accounts for the lack of association. Our population was older (mean age of 63.6 years compared to 37.5 years) and highly educated (85% with a greater than a high school education compared to only 50% having completed high school), with both age and education significantly associated with trust. Consistent with others [30], this study also demonstrated that among participants with a history of cancer, receiving genetic results is a strong motivator for donation of a biologic sample.

These results have implications for interventions designed to improve participation rates in cohort studies. One strategy for increasing or maintaining participation is always to make the altruistic motivations a salient part of promotional and instructional materials. If contributing to science or giving back to people with similar issues is an important motivation, then cohort studies should constantly find ways of showing participants how their contributions matter. This could take the form of printed words, like a newsletter or other correspondence, or could take the form of an image or logo that conveys assistance or scientific discovery. In every interaction with participants there is an opportunity to remind them of how their time and effort as participants will make a contribution that is both unique and valuable. These kinds of strategies can actually be tested and evaluated in the context of large-scale research projects [31] and, combined with other activities could form a battery of participation strategies for cohort studies as well as clinical trials.

Because this study population was limited to a highly educated and mostly white group of older adults, it is possible these results may not be generalizable to all populations. In addition, our study population was already willingly enrolled in a research study and it is possible that these motivators may differ from a general population. Although 35 participants in the control group reported cancer at baseline and 35 participants without cancer at baseline reported cancer at the time of the survey, we still found significant differences between cases and controls in several motivational factors. While some differences in motivational factors by stage of cancer were seen, these findings were based on small numbers and further conclusions are not possible. Finally, we were unable to evaluate motivational differences related to participation in research by cancer site because of small numbers for most cancer types. Given the gender differences seen in this study however, further research is needed to evaluate if a history of female-specific cancers impact research participation motivation.

Participant enrollment into the national population-based PMI cohort is quickly approaching. The major advantage of a population-based observational cohort design is external validity, it is therefore important to understand factors that motivate subjects to participate in this type of research study. Maximizing recruitment and limiting attrition will increase the representativeness of the

population and generalizability of study results.

Acknowledgements

The authors wish to thank the individuals enrolled in the NWCGR for their ongoing participation in and contribution to cancer research. They also acknowledge and thank Lesley Pfeiffer, Anne Renz, Joan Scott and David Kaufmann for their work contributing to the earlier stages of this project. This research was supported by NIH grant# R01CA149051 to Karen Edwards (PI), "Identification of Issues and Expectations of Subjects Participating in Genetic Studies of Cancer".

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix 1

When making the decision to participate in a research study, how important are the following to you?

- 1) The reputation of the research institution or researcher.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 2) The value of incentives (for example, gift cards or cash)
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 3) The research must be meaningful to me personally.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 4) The research will improve my health.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 5) The research will provide information I can use to improve my health.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 6) The research will provide information about me I didn't know.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 7) The research could benefit my family.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important
- 8) The research could benefit people I know.
 - a) Very important
 - b) Somewhat important
 - c) Not very important
 - d) Not at all important

9) The research could benefit society.

- a) Very important
- b) Somewhat important
- c) Not very important
- d) Not at all important

Imagine you were asked to provide health information about yourself and a biological sample (such as blood or saliva) for genetic analysis as part of your participation in a research study.

Please indicate the importance of each of the following in determining whether or not you would participate.

10) The researcher is trustworthy.

- a) Very important
- b) Somewhat important
- c) Not very important
- d) Not at all important

11) The institution where the research is being conducted is trustworthy.

- a) Very important
- b) Somewhat important
- c) Not very important
- d) Not at all important

12) I will receive a personal report about my individual genetic risks and/or benefits.

- a) Very important
- b) Somewhat important
- c) Not very important
- d) Not at all important

13) Data and samples are stored securely.

- a) Very important
- b) Somewhat important
- c) Not very important
- d) Not at all important