

ORIGINAL ARTICLE

A cross-sectional survey on patient perception of subject payment for research

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ABSTRACT

Background: Research subjects may receive payment for their participation. Multiple models for payment have been proposed, however, the most ethical model is not completely clear.

Objective: The purpose of the present study is to evaluate and quantify the public's perception and to identify demographic determinants influencing said perceptions.

Methods: Patients from a New York City medical clinic were queried using an adapted survey on medical research compensation consisting of 6 opinion-style questions pertaining to the payment of subjects enrolling in clinical trials and 9 demographic questions. Pearson's chi-squared tests of independence with two-tailed alpha of 0.05 and correction for multiple testing were performed to determine statistical significance.

Results: 440 respondents were recruited for participation, with broad distribution across age, race, and socioeconomic levels. For research payment, surveyed respondents preferred the market model (n = 265, 62%) compared to the reimbursement model (n = 72, 16.8%) or wage payment model (n = 64, 15%) and no payment (n = 27, 6.3%). Patients under the age of 60 were more likely to choose the market model ($p = .01$) compared to those over 60 selecting the reimbursement model ($p = .001$). 88.7% (n = 377) of respondents indicated they did not perceive clinical trial payment to be a bribe, with non-white patients being more likely to identify payment as a bribe ($p = .025$). 73.2% of respondents (n = 344) believed that poorer individuals were more likely to enroll. Patients without high school education and patients 60 years of age or older were more likely to believe that payment ($p = .006$ and $p < .001$, respectively) would have no influence on enrollment than those with high school education.

Conclusions: Differences in mind-set towards clinical trials demonstrate older patients and individuals without a high school education may have differing opinions with regards to financial incentives in clinical trials. Sensitivity towards these attitudes may require alternative models of payment for future clinical trials.

Key Words: Research compensation, Reimbursement, Market model, Institutional Review Board, Wage payment model, Reimbursement model

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1. INTRODUCTION

Payment of research subjects is an accepted aspect of medical research; however, care should be taken to ensure that the amount of compensation does exert undue influence on the potential subjects. The purpose(s) of payment may therefore include recognition, reward, and/or compensation for time spent by study participants.^[1] Monetary or other inducements carry an associated problem, namely the possible negative effect on informed consent.^[2] As a result, multiple models for payment of research subjects have been proposed and compared by ethics committees; however, there is scant data regarding the lay public's perceptions of the practice of subject compensation in medical research.^[3-5] The purpose of the present study is to evaluate and quantify the public's perception and to identify demographic determinants influencing said perceptions.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1979 released the Belmont Report, which warned against the possibility that compensating research subjects may impair the voluntary element of informed consent by exerting "undue influence" on the potential study participant.^[6] Several years prior, the establishment of Institutional Review Boards (IRB) through the United States Department of Health and Human Services via the National Research Act stated that "IRBs must consider whether paid participants in research are recruited fairly, informed adequately, and paid appropriately. . . the IRB must determine whether the rewards offered for participation in research constitute undue inducement."^[7] Conversely, IRBs should not consider payment as a benefit to offset research risks when deciding whether or not to approve a study, but rather discuss the issue of payment only after the risks and benefits of a study are assessed and found to be ethically acceptable.^[8]

Ultimately, there is no general agreement on how exactly how to accomplish the task of ethical payment.^[9] Recent studies have proposed three models of payment: the market model, the wage-payment model, and the reimbursement model.^[1, 10, 11] The market model utilizes the principle of supply and demand, in which researchers compete for subjects by offering higher payments, with greater payments correlating to greater risk. The wage-payment model suggests patients be paid an hourly wage commensurate with the unskilled labor market, and ideally this wage would be standardized among research protocols. In the reimbursement model, payments are designed to cover participants' expenses such as parking, travel, meals, and potentially time away from work, however they can neither make a net profit nor claim reimbursement for pain or risk. Additional research has demonstrated that up to 90% research participants cite

financial reward as their main participation incentive.^[12-14]

This study further investigates this subject by addressing the layman's perceptions of payment for medical research in a broader population. Questions were designed to investigate this population's opinions regarding the optimal model for paying research subjects, as well as the role financial reward should play in the decision to enter a research study.

2. METHODS

2.1 Participants

Participants were informed verbally that participation was voluntary and responses required no identifiers to protect their anonymity. Those who were unable to give informed verbal consent, did not demonstrate complete understanding of the survey, minors, and refusal to complete were omitted from this study. Subjects who were over 18 and answered at least one question were included in the study. This study was approved by the Beth Israel Medical Center Institutional Review Board (IRB #235-10).

2.2 Measures

The survey consisted of 6 opinion questions and 9 demographic questions in English (see Appendix) and took approximately 10 mins to complete. Demographic information was also collected, both to determine the characteristics of the study population and to investigate the influence of the demographic factors on their perceptions; however, no specific identifying information was recorded.

2.3 Data collection

Multilevel research team comprised of graduate medical students and support personnel recruited subjects from a consecutive series of all patients found in the waiting areas in outpatient medical offices at a multidisciplinary facility (which include primary care and the specialties of allergy, cardiology, dermatology, gastroenterology, hematology/oncology, infectious disease, nephrology, otolaryngology, pulmonology, and rheumatology). This outpatient facility is affiliated with a large metropolitan hospital, with physicians being part of this system. All patients that met inclusion criteria were given a survey to complete and oral consent was given prior to administration. No other specific recruitment methodologies were utilized. No financial compensation or other incentive was provided to participants who voluntarily took the survey and noted that their healthcare or relationship with their provider would not be compromised in any way for refusal to participate. Collection occurred during standard business hours from June 2018 to December 2018.

2.4 Data analysis

Complete case analysis was performed and missing values were excluded from analysis. Missing responses included cases where no answer was provided, more than one answer was provided or the response was illegible. Survey data were scanned and a data spreadsheet was electronically created using a licensed version of Microsoft Excel, version 2003 (Microsoft Corporation, Redmond, WA, USA). The data

was subsequently coded for statistical analysis with comparison of demographics used to identify characteristics of the study population. Group comparisons, percentages, and differences were tested using Pearson’s chi-squared tests of independence with two-tailed alpha of 0.05 and correction for multiple testing. Statistical analysis was performed using the release version R-2.15.3.tar.gz of R: A Language and Environment for Statistical Computing.^[15]

Table 1. Demographics of research participants

Characteristic*	Response*	Absolute Number (%)
Age (n = 432)	18-39	191 (44.2%)
	40-59	173 (40.0%)
	> 59	68 (15.7%)
Gender (n = 425)	Male	146 (34.4%)
	Female	279 (65.6%)
Education (n = 429)	Did not graduate high school	56 (13.1%)
	Graduated high school, No college	83 (19.3%)
	College but did not graduate	102 (23.8%)
	College Graduate	188 (43.8%)
Income (n = 415)	< \$20,000/yr	122 (29.4%)
	\$20,000/yr-\$40,000/yr	101 (24.3%)
	\$40,000/yr-\$60,000/ yr	85 (20.5%)
	\$60,000/yr-\$80,000/ yr	42 (10.1%)
	> \$80,000/yr	65 (15.7%)
Race (n = 422)	Asian	30 (7.1%)
	Black or African American	78 (18.5%)
	Hispanic or Latino	153 (36.3%)
	White	151 (35.8%)
	Other	10 (2.4%)
Healthcare Worker (n = 428)	Yes	73 (17.1%)
	No	355 (82.9%)
Experienced Subject (n = 424)	Yes	56 (13.2%)
	No	368 (86.8%)
Would Consider Being A Subject in the Future (n = 417)	Yes	208 (49.9%)
	No	209 (50.1%)
Self-rated Health (n = 432)	Excellent	62 (14.4%)
	Good	246 (56.9%)
	Fair	105 (24.3%)
	Poor	19 (4.4%)

Note. * p < .05

3. RESULTS

Participant Demographics 440 subjects were recruited over the time period of June 2018 to December 2018, with 88 patients ultimately declining (see Table 1). All subjects were adults, two thirds were female, the majority had graduated

high school, and had a median income of \$20,000-\$40,000 per year. All participants had some form of health insurance and none utilized self-payment. Racial demographics were of subjects were approximately one-third White Non-Hispanic, one-third Hispanic, and one-third Asian, Black or

“other”. A small minority (17%) stated they had worked in the healthcare field while an even smaller minority (13%) had previously participated in a research study. There was an even split between those who said they would consider being a subject in a future study (49.9%) and those who stated they would not (50.1%). The subjects were generally healthy; nearly three-fourths rated their health as excellent or good and only very few (4%) as poor.

3.1 Survey responses

Complete aggregate responses are detailed in Table 2. In the first question, participants were asked about the three

models of research compensation using lay definitions and as followed: People who participate in medical research where there is a risk of harm or injury should:

- (*No reimbursement*): not be paid
- (*Reimbursement model*): be paid only enough money to cover expenses (travel, missed work, etc.)
- (*Wage payment model*): be paid an hourly wage similar to what people make for “regular jobs” (\$10-\$15/hour)
- (*Market model*): be paid a much larger amount (to make up for the risk to their health)”

Table 2. Aggregate responses of the study population

Question (summarized)*	Answer Choice (summarized)*	Absolute Number (%)
Optimal payment model (n = 428)	No payment	27 (6.3%)
	Reimbursement model	72 (16.8%)
	Wage payment model	64 (15.0%)
	Market model	265 (61.9%)
Acceptable level of influence of financial incentives (n = 425)	No influence	97 (22.8%)
	Some influence	257 (60.5%)
	Primary influence	71 (16.7%)
Payment is “a bribe” (n = 427)	Yes	50 (11.7%)
	No	377 (88.3%)
Poorer people are more likely to be subjects (n = 429)	Yes	314 (73.2%)
	No	115 (26.8%)

Note. *p < .05

A majority (62%) chose the market model while only 6% felt that subjects should not be paid at all. The reimbursement and wage payment models were each chosen by a similar number of the remaining one-third (16.8% and 15.0% respectively). In question 2, majority (61%) thought compensation could be a secondary factor but only 17% felt it was acceptable for compensation to be the main reason to participate. The remaining 23% believed money should play no role at all in a potential subject’s decision whether to participate in a study.

Question 3 asked, “When someone accepts money to be in a research study, is this a bribe?” while question 4 examined the motivations and perceptions of research participation with “When medical researchers offer money for people to be in a study, are poor people more likely to enter the study than rich people?”. In response to questions 3 and 4, most of our study participants considered payment of research subjects not to be “a bribe” (88%) while agreeing that poorer subjects were more likely to enter a study with financial compensation (73%).

3.2 Bivariate analysis

Responses to each of the questions were stratified by demographic characteristics for further analysis. Four of nine demographic factors (age, education, income, and race) impacted the responses to more than one of the questions. When a demographic was found to affect the responses to a specific question, that factor was simplified to a binary variable to facilitate the analysis (see Table 3). Gender and self-rated health only impacted the responses to one question each. Work in the healthcare field, whether the subject had previously been a subject in a research study or whether they would consider being a subject in a future study had no impact on the responses to any of the questions (data not shown). Those who rated their own health as fair or poor were more likely to choose “no role” than those in good or excellent health [30% vs. 20%, p = .034 (Question 13)].

Those over 60 years stated that money should play no role in a decision whether to enter a research study twice as often (40% vs. 20%, p < .001) in comparison younger subjects. The over 60 age group were also less likely to allow money to

be a primary or secondary factor, although these differences were not statistically significant. This age range also selected the reimbursement model nearly three times as frequently (34% vs. 13%, $p < .001$) in comparison to the market model (44% vs. 65%, $p = .001$) for their younger counterparts. Research payment was considered “a bribe” more often than

those under 60, and those who had not graduated from high school more frequently agreed than high school graduates, although these differences were not statistically significant. There was a trend towards those over 60 feeling that the poor people were more likely to be swayed which was not statistically significant ($p = .41$).

Table 3. Stratification of responses by selected demographic characteristics

Demographics	1. Optimal Payment Model				2. Influence of Incentives			3. Payment is a “bribe”		4. More likely to be poor	
	No Payment	Reimburse	Wage Payment	Market Model	Primary	Secondary	None	Yes	No	Yes	No
Age											
< 60 years	6.2%	13.4%	15.1%	65.3%	18.4%	62.1%	19.5%	11.5%	88.5%	73.7%	26.3%
> 60 years	7.8%	34.4%	14.1%	43.8%	9.2%	50.8%	40.0%	12.3%	87.7%	68.8%	31.2%
<i>p</i> -value	.62	.001*	.83	.001*	.07	.08	< .001*	.85		.41	
Income (\$/year)											
< \$40,000	6.5%	15.8%	14.4%	63.3%	12.5%	61.1%	26.5%	13.9%	86.1%	72.0%	28.0%
> \$40,000	3.7%	19.0%	15.9%	61.4%	22.5%	62.0%	15.5%	7.4%	92.6%	73.8%	26.2%
<i>p</i> -value	.20	.39	.68	.70	.008*	.84	.008*	.038*		.69	
Education Level											
No HS Grad	17.3%	21.2%	7.7%	53.8%	7.5%	47.2%	45.3%	16.4%	83.6%	58.2%	41.8%
HS Grad	4.9%	16.2%	15.9%	63.0%	18.5%	62.4%	19.1%	10.8%	89.2%	75.6%	24.4%
<i>p</i> -value	.001*	.37	.12	.20	.048*	.034*	< .001*	.23		.006*	
Race											
White	6.1%	18.2%	15.5%	60.1%	26.5%	54.5%	19.0%	14.0%	86.0%	69.1%	30.9%
Other	6.8%	16.3%	14.4%	62.5%	11.8%	63.9%	24.3%	6.8%	93.2%	78.2%	21.8%
<i>p</i> -value	.77	.61	.75	.64	.001*	.06	.22	.025*		.046*	

Note. * $p < .05$

Those who did not graduate from high school selected “no payment” at more than triple the rate (17% vs. 5%, $p = .001$) of high school graduates. Those who never graduated from high school were more than twice as likely to oppose money as an incentive (45% vs. 19%, $p < .001$), less likely to agree that money could be a secondary incentive (47% vs. 62%, $p = .034$), and less than half as likely to agree that money could be a primary incentive (8% vs. 19%, $p = .048$) than those who had graduated from high school. High school graduates agreed that poorer people were more likely to be swayed by money more frequently (76% vs. 58%, $p = .006$) than those who did not graduate from high school. Those making less than \$40,000 were more likely to pick “no role” (26% vs. 16%, $p = .008$) and less likely to take “primary role” (13% vs. 23%, $p = .008$) than those making more than \$40,000 for the influence of financial incentives. Those who earned less than \$40,000 per year were twice as likely to agree that payment was “a bribe” as those who earned more than \$40,000 per year (14% vs. 7%, $p = .038$). Whites were more than twice as likely to choose “primary factor” (27% vs. 12%, $p < .001$)

compared the other ethnicities for the influence of research payment. Whites versus other races (78% vs. 69%, $p = .046$), men more than women (79% vs. 70%, $p = .036$) were more likely to agree than all the other ethnicities that poor people were swayed by money (Question 4 and 9).

4. DISCUSSION

Advantages and disadvantages exist for each model of paid medical research, with ethical and economical arguments present for all three models as seen in Figure 1. Under the market model, payment could theoretically reach a level that all other factors become irrelevant to the participant’s original decision to participate or leave a study through the economic influence of reward. In doing so, patients may choose to conceal or withhold vital information due to their perception that this could jeopardize their ability to remain in the study and receive payment, which could negatively affect the subject as well as future participants by biasing study results.^[16] A favorite of medical ethicists, the wage-payment model in theory eliminates money as an incentive as it matches

compensation to other low-skilled labor, however has also faced criticism as an elaborate front-loading strategy to offset qualitatively significant, but statistically rare risks in terms of payment for recruitment.^[17] The reimbursement model is difficult to employ because it is cumbersome to calculate each individual subject’s expenses and usually requires the

subjects to make some financial sacrifice. Depending on the unique circumstances and social makeup of every patient, each model may be reasonable to some, but anathematic to others.^[18] As demonstrated in this study, public opinion may support any one of these models when factors such as age, sex, race, and income are put into play.

	No Payment	Reimbursement Model	Wage-Payment Model	Market Model
Summary	No financial compensation; subjects participate for altruistic, personal or other reasons.	Compensation only for expenses (e.g. food, travel), which may or may not include lost wages. Subjects do not lose or gain money by participating.	A working wage is paid commensurate with the unskilled labor market; subjects participate because it is preferable to other available jobs.	Money is used as an incentive to recruit subjects. Researchers compete for potential subjects with larger payments.
Determinants of Payment	None	Subject’s expenses (+/- lost wages)	Community’s standard wage for unskilled labor	Market forces (supply and demand)
Relative Compensation	-	+ (wages not included) ??? (wages included)	++	++++
Potential Profit for Subjects	No	No	No	Yes
Risk for Undue Influence	No	Minimal	Minimal	Yes
Standardization of Payments	Yes	No	Yes	No
Compensation for pain or risk	No	No	No	Yes

Figure 1. Comparison of various research compensation models and their advantages/disadvantages

The current discourse and three model view of paid medical research have not been without challenges and criticism. Other studies have argued that rights are given to wage earners and therefore research subjects as workers should be entitled to the same rights of those employed, ranging from the ability to collectively organize to overtime compensation and a standardized schedule.^[19-21] Other models of payment have also been suggested such as the blended model, in which patients could be paid an hourly “wage” offered to all patients regardless of employment status and wage with additional reimbursement of travel costs.^[22, 23] To combat premature withdrawal or termination, a modest completion bonus could be employed in the form of money or similar material item could be given, which coincides with an appreciation model. Therefore, a blended model would thus capture the actual amount of time spent for study visits and procedures since the payment is through an hourly wage with small bonuses.^[24] Payment of research subjects has previously also been subcategorized based on their health status, which further complicates efforts to understand lay perceptions of compensation.^[25] While it is widely accepted that healthy subjects receive payment, it may not be necessary for patient-subjects, especially if the study provides treatment that renders a therapeutic benefit.^[26]

Several small studies on participation in medical research have consistently found that financial incentives as an important motivator for participants.^[27, 28] In these studies, young and healthy participants frequently cited money and financial reward vis a vis limited commitment as a main reason for participation.^[29, 30] In many survey-based studies, the single most cited self-reported reason for participating in research was economic gain, although few were solely motivated by money alone.^[31] Educational status can also play a role as those who have identified with higher levels of education, typically college equivalent or higher, tended to eschew the need for financial compensation for participation.^[32] With this in mind, while financial compensation is an important motivating factor that drives medical research participation, it is equally apparent that care must be taken to ensure that payments do not constitute undue influence or duress for participants.^[1, 9] Medical ethics has predominantly focused on the moral and legal obligations of financial compensation from a scientific point of view, there is a paucity of data on the beliefs of non-ethicists/the lay population regarding payment of research subjects.^[33]

Focusing on the framework of the three-model system of research payment, the questionnaire provided a foundational base to determine perceptions of compensation in the lay

community. Utilizing colloquial definitions of the three models in the first question, the majority of participants chose the market model, in which patients would “be paid a much larger amount (to make up for the risk to their health)”. The wage payment model—the optimal scheme for medical ethicists—received minimal support amongst participants, second only to those stating that no compensation should be given. This contrasts sharply with numerous reports and guidelines developed by medical ethicists that generally discourage the market model in research compensation. On the role of money as a form of influence, in response to the second question, only 22% of participants felt that subjects should not be influenced at all by money while 16% even indicated that it was acceptable to participate in a study “mainly because of the money”. This ambivalence failed to carry over to question 3, where an overwhelming majority of 86% disagreed that the pejorative term “bribe” could be used to describe research compensation, thus calling to question whether participants recognized the implications of “undue influence”. That said, when queried in question 4 on whether economic status influences paid research participation, the majority (71%) stated that poorer people were more likely to enroll. All participants had some variant of health insurance which could be an influential factor compared to those who have the means to privately pay versus those who are unable to obtain health insurance for various reasons. It is unclear whether participants of this study still did not feel this was exploitation or if they simply believed strongly in libertarian-like values.

Four of nine demographic characteristics were found to impact more than one question in a statistically significant manner: age, education, income, and race. In an overarching view, many of the subjects were under the age of 60, earned more than \$40,000 a year, graduated from high school, and identified as Caucasian, which in turn had similar answer patterns. As such, this group favored the market model, agreed that money could play a role in study participation, and did not believe this money as a bribe. In contrast, participants not part of this select grouping were more likely to agree that money should not be an influencing factor in participation and oppose payment of research subjects while less likely to favor the wage payment model or agree that money could be the primary deciding factor (see Table 3). They were also

more likely to refer to payment as “a bribe” and less likely to believe that poorer people would be more inclined to enter a study with financial compensation.

The lessons to be gleaned by those conducting medical research are complicated. Professional ethicists and the lay public generally agree that it is acceptable to pay subjects.^[4,34] Ethicists have espoused the view that money should not be used as an incentive, and that when money is offered, great care should be taken to ensure that it does not exert “undue influence”.^[1] Meanwhile, this study population favored the market model for payment and indicated their view that poorer people would be more likely to be subjects when money was involved. Nevertheless, the subjects of this study felt that money was an acceptable incentive for potential subjects and overwhelmingly asserted that payment was not “a bribe.” This is in accordance with several studies of research subjects that have shown financial compensation was an important motivating factor in their decision to participate in a project.

5. CONCLUSIONS

Age over 60, earned income less than \$40,000 per year, those who have not graduated high schools, and non-Caucasian race demonstrated an enhanced sensitivity to the potential role monetary compensation can play in undue influence. Future directions include an analogous survey of healthcare workers (other than the previously detailed “professional ethicists”) for the purpose of addressing healthcare worker motivation in research and the view of the medical professional on the topic. Ultimately, there is a fine balance in the responsibility to improve medical care and science and the responsibility to treat research subjects as autonomous individuals; incentives, when used in an ethically appropriate manner are central to this process and remain an integral, but tricky, part of scientific research.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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