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The Limits of Disclosure: What Research Subjects Want to Know about Investigator Financial Interests

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Concerns about the influence of financial interests on research have increased, along with research dollars from pharmaceutical and other for-profit companies.[1] Researchers' financial ties to industry sponsors of research have also increased.[2] Financial interests in biomedical research could influence research design, conduct, or reporting,[3] and could compromise data integrity, participant safety, or both. Investigators' financial ties with for-profit companies may influence reported scientific results,[4] and may have compromised research participant safety.[5]

Disclosure is one commonly accepted method of managing financial relationships in order to minimize possible threats to scientific objectivity, the safety of research participants, or public trust in the integrity of clinical research.[6] Disclosure is presumed useful to the extent that "it gives those who would be affected, or who are otherwise in a good position to assess the risks, information they need to make their own decision."[7] Existing policies reflect wide support for disclosure to journal editors, readers, the federal government, institutional administrators, and institutional review boards (IRBs).[8] Although support is increasing for disclosure of financial interests to research participants – the very persons whose interests may be most affected – only some policies explicitly require it.[9]

Disclosure to research participants raises many unsettled issues. Do research participants have the background to evaluate the information disclosed? Are they well-positioned to use such information to evaluate risks and make choices? Would having such information influence the amount of trust they have in investigators or research? Although most people want to know about financial interests, exactly what they want to know and how they will use the information in decision making is less clear.[10] More than half of individuals with coronary artery disease, breast cancer, or depression responding to an internet survey said investigators should be required to disclose financial information to potential research participants, yet the majority said it would not change their inclination to participate.[11] The views of actual *research participants* are largely unknown.

Given the varied circumstances and complex motivations of research participants, it is important to know 1) their views about investigator financial information, 2) whether they would find such information useful, confusing, or burdensome and 3) the extent to which they can or will use it to make research decisions. This study explored these questions.

Methods

Design

This qualitative study of individuals actively participating in biomedical research utilized face-to-face semi-structured interviews conducted by the authors. Because knowledge of conflicts of interest could possibly influence confidence in researcher judgment and research, respondents were first asked to describe their experiences in research, including their relationships with investigators and research staff. They were then presented with four hypothetical scenarios in which the principal investigator of the proposed trials 1) held a patent on the intervention being tested in the clinical trial, 2) held stock in the company that made the investigational intervention, 3) received consulting fees from the company that made the investigational intervention, or 4) received funding from the sponsoring company over and above per participant costs of the study (Table 1). Respondents were asked to describe in an open ended manner: 1) their thoughts about each hypothetical situation, 2) whether and what they would want to know, and why, and 3) how it might affect their decisions about participation in such a study. The number of research participants interviewed was increased until the point of informational redundancy, that is, until we were no longer hearing distinctly new perspectives on the questions we were investigating.

Sample

Participants in HIV, Hepatitis, Arthritis, and Surgical Oncology clinical protocols at the National Institutes of Health Clinical Center were invited to participate. Fliers were distributed in these clinics, and interested individuals contacted the researchers. Research participants at least eighteen years old who spoke English were eligible. Interviews took approximately forty-five minutes (range twenty-five to ninety minutes) and were conducted in a private office. Each respondent was offered twenty dollars for his or her time.

Analytic Methods

Interviews were audio-taped and transcribed. The accuracy of the transcripts was checked against taped interviews and interview notes. Transcripts were reviewed and coded by a pair of investigators to identify major concepts and themes. Mismatches in coding were reconciled by the two coders. Codes were revised in an iterative fashion as new perspectives were uncovered in subsequent interviews. Coding and analysis were facilitated by the use of QSR-N6, a software package for qualitative data. Patterns among themes were identified and qualitative differences in responses to the scenarios explored. Direct quotations were selected for their clarity and representativeness within a category of responses. Trends between responses to the scenarios and demographic characteristics were explored.

Human Subjects Issues

The study was approved by the Institutional Review Board of the National Institute of Allergy and Infectious Diseases. All respondents gave written informed consent.

Results

Sample Characteristics

Thirty-three research participants, twenty male and thirteen female, were interviewed (Table 2). Twenty-three were Caucasian, eight African American, and one each Hispanic and Asian. Respondents reported post graduate education (eleven), college degrees (eight), some college (ten), and high school or less (four). Most were long-term participants in clinical studies (median seven years – range eight months to twenty-two years). Participants described their illness as serious, life-threatening or chronic; all were outpatients with an ECOG performance status of at least two.[12] Almost all said they enrolled because the NIH study offered what looked like the best treatment option for them.

> Well, for me there really wasn't any other choice… I mean everywhere I went, nobody could help me… They really didn't know how it was going to work, I mean, if it was going to work…But at that point, I really didn't have any other choice but to try it.

Respondents often described feeling chosen to participate by investigators because they met eligibility criteria or were just lucky or "blessed." Many also described being motivated by the knowledge that their research participation would help others.

Level of Trust in Researchers

Respondents described significant trust in researchers and the research team, found research participation a positive experience, and overwhelmingly said they would recommend it to others. Almost all denied ever feeling that the research team put research interests ahead of their medical interests.

Overall, most respondents said that investigators were not motivated to do research because of money, and some acknowledged that although money played a role it was not the primary motivation; only one respondent said definitively that researchers were motivated by money. Many remarked that researchers deserved to be compensated.

Familiarity with the Issues

Although ten respondents reported familiarity with controversies or recalled media accounts about researcher financial conflicts of interest, most were unsure how common these types of financial interests are. Some respondents spontaneously used the term "conflict of interest," and a few mentioned Martha Stewart, as interviews coincided time-wise with her trial. Three respondents seemed to not understand the scenario details, were not interested in engaging in the issues, or were inconsistent in their responses despite extensive probing by interviewers, while for others the scenarios elicited descriptions of related personal or professional experiences in the federal government, law, or health care.

Reactions to Financial Interest Scenarios

No typical positive or negative response emerged to any of the four investigator financial interest scenarios. Responses ranged from explicit concern about data integrity and "conflicts of interest" in some or all four scenarios, to acceptance of financial rewards for investigator expertise and hard work, to indifference (Table 3). Some expressed ambivalence, recognizing the legitimacy of financial reward but worrying about money's potential corrupting influence, and a few recognized a potential positive influence in that an investigator so invested might be more motivated to conduct a rigorous and careful study. No scenario stood out as the most concerning.

Those worried about the hypothetical financial interests tended to be more educated, and most commonly expressed concern about the potential for "manipulating" or "fudging" data; some expressed concern about participant safety. A few explicitly mentioned concern about the impact of investigator financial interests on the price of the drug.

Disclosure of Financial Information

Most favored transparency about financial relationships in the hypothetical scenarios and thought that prospective research participants should be informed about such relationships. "I think it makes everybody feel better if all the cards are on the table.…" Yet, none of the four scenarios elicited uniform interest in disclosure, and a majority said they would not want to know about consulting (scenario number three). (Table 4).

Most who said they did *not* want financial information explained, that they did not really care, or that it would not matter to them, or that respect for investigator privacy should take priority. Others said such information could be burdensome or increase their anxiety.

> No, I'm sorry…just the thought of having to…It just seems like how much can you know about your doctor before – you're trying to learn all these things about the condition, about the alternatives, about the thing. Then in the midst of that you have to sit down and do, like a whole profile of your doctor to see what his, you know, affiliations, what his investments…it's like after a while, it's like, oh, my God.

A small number voiced a preference not to be informed because they did *not* want to be deterred from what they wanted.

> It is just too much. Because my main objective, I already know what I want. And I don't want to read anything or hear anything that's going to deter me from getting what I came to NIH for.

> …suddenly you are putting the patient in the role of adjudicators – people who are making decisions. I am here because I am sick. I'm not here because I *want* to come to NIH.…

Others suggested that financial information be given to the institution rather than to participants.

> It would make me comfortable to know that the organization is looking out for people…a statement that the organization does its best to ensure that there are no conflicts of interest with our researchers…and if you have any questions ask us.

What Research Participants Want to Know

Of those interested in disclosure, most wanted to know that the relationship exists and that there are institutional safeguards to monitor financial interests and protect data integrity. Only a few wanted full disclosure, including such details as the amount of money an investigator might receive.

> I think they need to be transparent about what type of stake the main researcher has in the potential profits. How many shares…who is going to determine safety and efficacy?

In contrast, several said although they wanted general information about financial interests, receiving details was none of a patient's business.

> I don't think any doctor should have to discuss with a patient what he would make off of it…I don't think that is a patient's right…

Influence on Decisions about Research Participation

Approximately two-thirds of respondents said that receiving information about financial relationships similar to that presented in the four scenarios would have no impact on their decisions or willingness to participate in research (Table 5). Yet for each scenario, there were some who explicitly would choose not to participate in a study where the investigator had the described financial relationships and a couple more said it would make them suspicious. "…It gets tricky because the more you highlight, the more the patient starts saying- why am I being told this? Is there something else going on that I don't know about? If I wasn't told about this, I wouldn't be that upset."

In contrast, a few said it would make them more likely to participate.

> …that [consulting] would make me think, oh, he's really on board with this…it would be a positive…make me a little more [interested in participating].

Those who said financial relationship information would have no effect on their research decisions explained that: 1) other things were more important, 2) they trusted institutional safeguards that oversee investigator financial interests, or 3) it just did not matter to them. Those who found financial information less important than other factors said the most crucial factors in study participation decisions were the track record of an investigational intervention, predicted risks and benefits, available alternatives, and participant trust in the investigators or institution.

> I was more concerned with what the drug does, the safety of that drug, and how we can tolerate that drug…I wasn't worried about the financial aspects of it. My primary reason that I participate is because of the drug. It has nothing to do with the patent…I'm not worried about how much money the doctor makes…

Several acknowledged that concern about investigator financial interests depends on the severity of their clinical condition, options for treatment, and expectations or hope in the possibility of benefit from a trial. Serious illness, limited options, and/or a determination to participate in a particular study were associated with less interest in or concern about investigator financial interests.

> It depends on the drug. It depends on how sick I am, and it depends on how much I want the drug, I guess. I guess those are the ultimate guidelines…if you are desperate enough, you don't really care about all this stuff, you just want the treatment.
>
> If I am ill and he's got a drug that could help me, I don't care about that…How sick they are, and how desperate they are, and how badly they want help I guess is more important than how much money the doctor might be making.

Ideas about Oversight

Many respondents assumed that financial interests are routinely reported to institutions, that some financial interests are prohibited, and that institutional safeguards and guidelines, such as quality assurance, management controls, and data quality mechanisms, among others, prevent permitted interests from interfering with research. Knowing about or trusting institutional mechanisms or regulations was described as taking some burden off the research participant:

> So, it shouldn't really be the patient's problem to have to worry about this. The patient should feel comfortable that the institution has monitored all these things.

Discussion

This is the first published study reporting research participants' views about financial interests of investigators. This qualitative description of the attitudes and beliefs of research participants points to important issues that should be considered in the development of appropriate policies and language for disclosure of financial interests to research participants. Several important themes emerged.

First, the majority, but clearly not all of those interviewed, wanted to receive information about investigator financial interests. Yet, while recognizing the value of transparency and having "all the cards on the table," only a minority thought such financial information would influence their decisions about research participation in any way. Importantly, our study provides some insight as to *why* research participants might not want or would not find information about investigator financial interests useful. Respondents often did not want financial information because it did not matter to them or was perceived as a burden that they did not want to have to deal with. In contrast to the widely accepted view that such information can help people to assess risks and make decisions, these research participants said it would have no effect on their research participation decisions. This was true even with interviewer probing and explanation, something participants would likely not have if provided with written disclosures about financial information in consent documents. Information about the investigational intervention, risks and track record, potential benefits, and alternatives, as well as trust in the institution and its investigators was described as more important to research decisions than information about financial relationships.

Second, these research participants described health circumstances as an important influence on their interest in financial information. Because they identified themselves as chronically or seriously ill and perceived participation in NIH studies to be a good, and sometimes the only or last, treatment option, they described other considerations as more salient to their decision than financial information would be. Under these circumstances information about investigator financial interests was described as low priority, not relevant, or even troublesome; and was envisioned as dissuasive by very few. In fact, several said that in the midst of dealing with illness and difficult decisions, such information could be frustrating, confusing, or more than they could handle. Thompson recognized that a “deficiency of disclosure is that those who receive the information may not…have reasonable courses of action in the circumstances.”[13] Many research participants have limited “reasonable courses of action” because of few treatment options and a fervent need or desire to participate or be “chosen” to participate in a particular study.

Third, those who did want financial interest information most often wanted to know that financial relationships exist and that the institution employs safeguards to monitor them and protect against any possible harms. Generally, respondents took for granted that institutional oversight mechanisms are operative, including mechanisms to monitor data quality and patient safety, and mechanisms to monitor or limit investigator financial interests and manage financial relationships perceived as possible conflicts. Several respondents suggested that disclosure language include information about oversight systems and where interested research participants could get more information.

Finally and surprisingly, respondents had very mixed reactions to the scenarios presented. Even when probed by the interviewer, some did not see any problems with investigators having consulting relationships with pharmaceutical companies, holding patents on certain drugs, or holding stocks in the company. A minority, usually those with more education, expressed explicit concerns about conflicts of interest and possible negative influences on the study for each of the scenarios presented. Fewer still consistently expressed concern across all four scenarios. Not only did some people find certain relationships acceptable for investigators, a few perceived financial interests as a positive sign that the investigator would be invested in ensuring a study was done well.

The findings of this study might not be generalizable to all research subjects, as the respondents were primarily white, educated individuals with long term experience in research at the NIH, which may have a unique population of research participants. Second, individuals responded to hypothetical scenarios, which may not reflect what they would do if presented with actual information about investigators’ interests. Nonetheless, their descriptions of experiences with research, the multiple considerations that went into research decisions, and the limited relevance for them of investigator financial information in light of seeking investigational treatment for various illnesses were compelling. Finally, despite prompting and suggestions by interviewers, a few responses reflected lack of engagement or understanding of the issues.

Conclusion

In the interests of transparency and openness and maintaining public and research participant trust, disclosure of investigator financial relationships to institutions and IRBs, and also to research participants may be extremely important. However, the value of disclosure to research participants is limited. Although research participants may be most affected by investigator financial interests, this cohort predicted that they would rarely use such information in making decisions about research participation. In fact, because of their disease, a need or desire for investigational treatment, and other priorities, research participants may arguably be the least likely to be in a position to use such information to assess risks associated with financial interests and make decisions accordingly. Respondents told us they rely on institutional mechanisms to monitor investigator financial relationships, study integrity, data safety, and participant welfare so that investigator financial relationships do not jeopardize them or the studies they participate in. Future research should evaluate these institutional mechanisms, research subjects' reactions to receiving information about such mechanisms and the effect such information has, if any, on research decisions. Careful attention is needed to assure that other mechanisms for managing and oversight of investigator financial interests provide adequate safeguards for subjects with limited choices for whom disclosure is not enough.

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Table 1

Hypothetical Financial Scenarios

Patent	Suppose a researcher, Dr. Smith, owns a patent for a drug developed with the hope of treating Disease K.This means that Dr. Smith is recognized as the inventor of the drug and that other people cannot make or use the drug without Dr.Smith’s permission. Dr. Smith is studying the drug in a clinical trial to see if it is safe and effective in treating Disease K. If the drug is safe and effective, Dr. Smith will receive money from sales of the drug.
Stock	Suppose Dr. Jones owns stock in a company that makes a drug Dr. Jones is studying in a clinical trial. The trial is to determine if the drug is a safe and effective treatment of Disease G. If the results of the trial show that the drug is safe and effective for treating Disease G, then the stock of the company might go up in price and anyone who owns stock in the company, including Dr. Jones, would earn money from owning the stock. If the drug is not found to be safe and effective, the company’s stock might go down, and Dr. Jones might lose money.
Consulting	Suppose Dr. Johnson is conducting a study of a drug made by Company B. The study is to find out if the drug is a safe and effective treatment of Disease M. Company B asks Dr. Johnson to lecture at company events, which sometimes involve traveling to vacation spots, or to do some consulting based on Dr. Johnson’s scientific expertise. Dr. Johnson is paid in exchange for speaking at the company events and doing the consulting.
Above *per capita* payments	Suppose Company E makes a drug that they want Dr. Jackson to study in a clinical trial to see if the drug is a safe and effective treatment for Disease Z. Company E pays Dr. Jackson a certain amount of money for each patient with Disease Z that Dr. Jackson enrolls in the research study. The money covers more than just the costs of the study. Dr. Jackson can then use the extra money for things like other research projects, or to travel to scientific meetings.

Table 2

Respondent Characteristics

CLINIC	# (%) Female	# Caucasian	Mean age	Median time in research (months)
Hepatitis n=8	2	7	58	48
HIV n=13	4	7	45	108
Arthritis n=3	2	3	59	96
Surgical Oncology n=9	5	6	55	48
Total n=33	**13 (39%)**	**23 (70%)**	**52**	**84**

Table 3

Range of Reactions to Financial Interests

	Concern	Indifference	Acceptance	Ambivalence	Encouragement
Patent	"…Dr. Smith has a monetary interest in it, you know, it's likely to be biased toward the drug being approved…in a best case scenario, there should be some arm's length between the primary researchers and whoever stands to benefit." "…there's too much potential for conflict of interest."	"That's life. That's the way it works" "Isn't that the way it all happens?"	"I don't have a problem with Dr. Smith receiving money if he discovered it…" "You know – he's created it – he has a right to it…"	"I think it's an inevitable part of our economic system. But, there's definitely room for abuse in a situation like that." "…that's kind of a double edged sword."	"But also, if you could make a lot of money, let's face it, at times that could encourage a person to try to make it better." "…it could also be an incentive to make him make it better."
Stock	"I do not believe that a doctor owning stock, owning a patent or who might receive great financial compensation for the sales of a particular drug…should be participating…it sounds like a conflict of interest…he shouldn't own stock in the company and be an investigator."		"…I mean, we live in America… and people can invest where they want to invest…I don't see ethical problems in it…"	"I understand that if they've worked hard on something… why can't they gain financially…but maybe it could be after the fact, not from a direct result of this failing or succeeding during the study."	"So he's in it for the money, and he's afraid he's going to lose, then I think he will put his best foot forward to make this a good drug…to make sure you have the right data on it…"
Consulting	"…you have a case here where he is conducting the study, he's doing the research…But then the company itself, is, you know paying for his additional consulting work, teaching, going to resort locations…I mean it's almost as if they are trying to influence the results of the study." "You have true conflict of interest and you have appearance of conflict of interest…"	"…getting paid to lecture?…these people are not doing it *pro bono*…So, to me, it's just the way things are and it's not really that big of a deal." "…Just because he has lectured or he's had some fun on that company's expense on occasion, I don't see that as a problem."	"I have no problem at all… Dr. J's time is-money. It is worth some-thing… That is the way our economy works." "I think that is a doctor's job, especially in research…" "She or he should get some compensation."	"…it's a bit of a gray area. I mean, you don't want to hog-tie the doctors as far as what they can and can't do, as far as consulting or sharing their knowledge…or scientific expertise…whether or not it should be disclosed-it's a gray area- not very cut and dry."	"Because of his expertise in this specific area that the drug is supposed to treat…this expertise gives him the right to consult…in my opinion, that would be a good thing." "It would be a positive, sure."
Above *Per Capita*	"I would never participate in a study …I've never participated to my knowledge… where the doctor is being compensated for recruitment and enrollment…" "…that would bother me (because) his incentive is getting patients into the study… …there's more of a tendency for the physician to lie to get me into the study as opposed to (when) his incentive is to have a successful study…that would bother me more than if he makes $10 billion because the drug works. That doesn't bother me at all because I want it to work."	"It's fine. Use the extra money for research projects or travel. That's OK." "All that's none of my business…doesn't bother me at all."	"I think this is a true case… these things could happen any day. It really doesn't have any affect on me. I would still participate in it." "It says the money covers more than the cost of the study. Well, the cost of the study is very broad…there's a lot that goes into what a doctor has to do."	"I just hope all the research, the drug itself in all of these scenarios, that it turns out to be safe and effective treatment for the disease to help mankind. What does that got to do with their money is between them and their conscience. And I think the fact that they're doctors, hopefully good doctors and drug companies that their main objective is to help."	

Table 4

Participants’ Interest in Knowing about Investigator Financial Interests

	Yes, want to know	No, don’t want to know	If no, Why not?
Patent	20[a]	14	• Not a concern • None of my business • It wouldn’t matter
Stock	19	14	• Makes no difference • I don’t care • Only to invest myself • Investigator’s privacy • Burdensome – “I have other things to worry about”
Consulting	10[b]	20	• Privacy, it is none of my business, • I don’t care • He/she should be paid • It doesn’t matter, can’t control it anyway
Above *per capita*	17[c]	9	• Not a concern

[a] Total adds up to 34 because one person said he did not want to know and when re-asked said, “Oh, why not?”

[b] Total does not equal 33 because 3 people did not directly answer the question. However, 2 of the 3 said it wouldn’t matter at all to them.

[c] Total does not equal 33 because 5 people were not asked the question; I said she did not know and I said it should not be allowed.

Table 5

Effect of Disclosure on Willingness to Participate in a Study

	Yes, would affect my decision	**Depends**[c]	**No, would not affect my decision**
Patent	8[a]	3	21
Stock	6	4	22
Consulting	3[b]	3	25
Above *per capita*	8	3	18

[a] 3 of the 8 said it should not be allowed.

[b] One respondent said it would affect her decision in a positive way.

[c] Most of these said it depended on the safeguards that were in place or on their illness. Totals do not add up to 33 because not everyone was asked the question for each scenario.