Academic researcher decision making processes for research participant compensation

Kathleen Marie Beck

University of Iowa

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ACADEMIC RESEARCHER DECISION MAKING PROCESSES FOR RESEARCH PARTICIPANT COMPENSATION

by

Kathleen Marie Beck

A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Interdisciplinary Studies in the Graduate College of The University of Iowa

May 2019

Thesis Supervisor: Associate Professor John Wadsworth
This is to certify that the Ph.D. thesis of

Kathleen Marie Beck

has been approved by the Examining Committee for
the thesis requirement for the Doctor of Philosophy degree
in Interdisciplinary Studies at the May 2019 graduation.

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Michael Lovaglia

____________________________________________

David Moser
To my daughters, for their unwavering support.
ACKNOWLEDGEMENTS

Many people have guided and supported my academic journey that I would like to acknowledge. Their support and guidance were an integral part of my personal and professional growth as a scholar and researcher.

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The support of family and friends throughout my academic journey has helped me throughout the successes and challenges I faced. I am appreciative for the constant encouragement and support from my daughters when I made the decision to return to graduate school.

Thank you to all who have supported me during this journey.
ABSTRACT

The purpose of this study was to explore the academic researcher decision-making processes related to participant compensation. Three interlocking questions guided this exploratory study:

RQ₁: When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

RQ₂: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

RQ₃: How, from the perspective of academic researchers, can compensation practices be improved?

Both slippery slope theory and complexity theory grounded this research study. The researcher applied slippery slope to specific interactions and relationships between researchers and the IRB. The researcher also applied complexity theory to analyze the broader, systems approach, essentially to the human subjects research program at one R01 institution, the research setting.

Compensation for research participants is a complex issue nested within human subjects research, involving potential ethical pitfalls like undue influence and coercion. Regulations require researchers possess sufficient understanding of their subject population to make informed decisions with respect to compensation issues. Despite the key role compensation practices play in the research process, few researchers have considered these practices from the perspective of the academic researcher.

The researcher used a purposive selection method to recruit diverse participants. The study participants spanned multiple disciplines, conducting both biomedical and
behavioral-social science-based research. The final N for this study was 16. This qualitative study had a small N, but nevertheless attempted to recruit participants that would provide a variation in research experiences. The participant perspectives exhibited elements both of uniqueness and shared meaning, and for this reason a semi-structured, one-to-one interview approach was a particularly elucidatory method.

The researcher identified the following eight major themes during the data analysis. The six themes related to compensation are: (1) compensation defined, (2) rationale for compensating, (3) compensation factors considered, (4) a combination of compensation and reimbursement discussion and decisions, (5) collaborative effort in research participant-compensation decision making, and (6) ethical concerns related to compensation. Two additional themes were identified, but fell outside of the scope of the study: (7) participant motivation to volunteer for studies, and (8) non-compensation issues related to human subjects research.

Compensation is an integral part of human subjects research, but it involves ethical considerations due to its potential impact on the participant’s voluntarism. Researcher decision making about compensation is complex and is influenced by myriad factors, including budgetary constraints, the type of study, perceptions of participant burden, institutional and departmental factors, and more. This study expanded the understanding of participant compensation by exploring the researcher decision-making processes and analyzing the data from complexity and slippery slope theories.
PUBLIC ABSTRACT

The purpose of this study was to explore the academic researcher decision-making processes related to participant compensation. Compensation for research participants is a complex issue nested within human subjects research, involving potential ethical pitfalls, such as undue influence and coercion. Regulations require researchers possess sufficient understanding of their subject population to make informed decisions with respect to compensation issues. Despite the key role compensation practices play in the research process, few researchers have considered these practices from the perspective of the academic researcher.

The researcher collected data via semi-structured interviews to understand factors academic researcher consider when electing to compensate or not compensate research participants, the ethical challenges faced by academic researchers when determining research compensation for their studies, and, from the perspective of academic researchers, how compensation practices be improved.

Compensation is an integral part of human subjects research, but it involves ethical considerations due to its potential impact on the participant’s voluntarism. Researcher decision making about compensation is complex and is influenced by myriad factors, including budgetary constraints, the type of study, perceptions of participant burden, institutional and departmental factors, and more. This study expanded the understanding of participant compensation by exploring the researcher decision-making processes.
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CHAPTER 1

INTRODUCTION

Ethical concerns abound in human subjects research, and regulations and guidance are essential to protect research participants from exploitation. Compensation for research participants is a complex issue nested within human subjects research, involving potential ethical pitfalls, such as undue influence and coercion. Regulations require researchers possess sufficient understanding of their subject population to make informed decisions with respect to compensation issues. Despite the key role compensation practices play in the research process, few researchers have considered these practices from the perspective of the academic researcher. This research study explored the decision processes academic researchers use to determine compensation and the ethical issues addressed.

Relevant human subjects regulations and ethical issues involving participant compensation were reviewed first, as this study interfaces regulations and is grounded on a set of ethical principles. The lack of clearly defined regulations continues to challenge researchers when determining compensation strategies. For example, undue influence and coercion are not used in the evaluation of compensation but are defined in the human subjects research regulations, thus requiring researchers and institutional review boards (IRBs) to make subjective interpretations and decisions about these important ethical issues. Specifically, the federal regulations and guidelines that guide human subjects research and address compensation, 45 C.F.R. 46 state:

1. Compensation should be just and fair.
2. Compensation should not affect the potential participant’s choice to participate or their evaluation of the study risks.

3. There are no predetermined standards to evaluate the appropriateness of the proposed compensation. (Office for Human Research Protections [OHRP], 2016)

This lack of narrowly defined regulations and guidance has benefits and drawbacks. The ambiguity means that researchers and IRBs can flexibly apply the regulations and guidance and can take into consideration study-level specifics, such as subject population, study location/environment, and institutional requirements. However, this inherent vagueness also creates issues with inconsistency in interpretations and decisions.

Further complicating decision making about compensation, human subjects research regulations are undergoing significant changes. On January 18, 2017, the final rule for the revised human subjects protections regulations was released by the Office for Human Research Protections; however, its implementation was delayed until July 19, 2018 (Federal Register, 2017). The transitioning to the new regulations have been amended, limiting implementation of elements from July 19, 2018 through January 20, 2019 (OHRP, 2018b). The anticipated revisions will significantly alter many aspects of human subjects research regulations and guidance; however, the ethical considerations, such as how to make decisions regarding research participant compensation, will remain.

The current literature reviewed in Chapter 2 explores the ethical issues involved in offering compensation to research subjects and methods for avoiding compensation structures that erode voluntariness. A common thread in the literature is compliance with human subjects protections regulations that assist researchers in avoiding issues with
coercion and undue influence. Notably, there is a lack of information about the compensation determination process investigators use when establishing the compensation strategy for each study. A study was conducted due to the ambiguous compensation regulations and limited literature available examining the implications of research participant compensation from the academic researcher perspective.

In October 2016, a pilot study was conducted utilizing an electronic survey featuring questions about participant compensation at the University of Iowa. The pilot study indicated that there are complex ethical concerns involved in compensation, as well as a dearth of precise guidelines to assist researchers in navigating those decisions. The survey indicated that 70% of respondents faced some degree of ethical challenge in determining compensation amounts in their field of research. Pilot study participants shared their perspectives, including, “There needs to be a guideline on best practices for research compensation across populations and disciplines” and “Sometimes it can be hard [to determine compensation].” At least one person indicated they had “conflicted feelings” about compensation. The pilot findings revealed inconsistencies in IRB decisions, variations in compensation amounts for similar procedures, and pressing ethical concerns that compensation may impair the voluntariness of participants. These ethical issues span research designs and locations.

This dissertation explores these topics further, examining the academic researcher perspective regarding compensation, including the ethical challenges and considerations researchers face when making decisions about participant compensation. The dissertation is a traditional five-chapter document. The first chapter introduces the research study. It includes the purpose and background of the research, an overview of the study design, the
research questions, the theoretical framework, a discussion of potential impact, and
definitions of key terms. Next, the literature review examines the current compensation
practices for research participants. The methodology chapter discusses the methodology
used in this dissertation. It reviews the aims and guiding questions for the research, gives
a rationale and explanation of the methodological approach selected, and presents
potential limitations. The fourth chapter will present the study findings. The final chapter
presents the synthesis of the data, discusses the implications of the findings, and offers
recommendations for future research and human subjects protections education.

Purpose of Study

Academic researchers are key actors involved in human subjects research
protections, yet little is known about their views regarding compensation practices and
concerns. This qualitative research study explored academic researcher decision-making
process related to compensation by addressing the following three interlocking
questions:

1. When electing to compensate or not compensate research participants for a
   study, what factors do academic researchers consider?

2. What are the ethical challenges faced by academic researchers when
determining research compensation for their studies?

3. How, from the perspective of academic researchers, can compensation
   practices be improved?

To ensure that research perspectives were appropriately connected to the wider
context of research ethics and governance, these questions had to be placed within a
larger theoretical framework. Both slippery slope theory and complexity theory
frameworks are suited to a study of researcher perspectives on compensation. Slippery slope theory is also noted as slippery slope framework in literature. This theory is applied to specific interactions and relationships between researchers and the IRB. Complexity theory was applied in a much broader, systems approach, essentially to the human subjects research program at one R01 institution.

Researchers have explored elements of research participant compensation within different contexts, illuminating multiple perspectives. The field of biomedical studies in particular has offered some insight into the decisions researchers make regarding types of compensation. Researchers have found, for example, that exploration of compensation can be included as part of a post-participation survey of a randomized clinical trial for a specific disease. Researchers have also designed studies to explore what clinical trial participants expect as payment for different types of procedures. In addition, investigators have examined the ethical and social justice issues presented by research studies that offer compensation (Beecher 1966; Denny & Grady 2007; Emanuel 2005; Jones, Grady, & Lederer 2016; Seidenfeld, Horstmann, Emmanuel, & Grady 2008; Tishler & Bartholomae 2003; Wong & Bernstein 2011).

Exploration of compensation involves multiple angles, and the perspectives can be categorized into the key actors involved in human subjects research: researchers, participants, institutions, IRBs, regulatory entities, and society at large. Some individuals may simultaneously take on multiple roles while participating in human subjects research. For example, academic researchers can be involved in both the IRB and accreditation teams. The researchers may be participants and investigators. This further
complicates the question of how these multiple experiences might inform a researcher’s decisions.

Human subjects protections regulations are based on ethics, which evolve as they embrace shifting societal expectations and address novel research ideas and technologies. The Belmont Report (1978) presents ethical principles that provide the foundation for human subjects regulations in the United States, with “respect for person” and “justice” applicable to research compensation. Respect for person includes ensuring the voluntariness of the person’s participation in the research study. For this reason, compensation must not cause undue influence. The principle of justice can be addressed by analyzing who bears the burden of the research versus who receives the benefits of the findings. Underrepresentation of individuals from various ethnic and cultural backgrounds, or the soliciting of vulnerable populations for high-risk studies, are two additional justice issues found in the literature on compensation (Denny & Grady 2007; Dickert & Grady 1999; Elliott & Abadie 2008).

It is important to note that regulations and guidance do not always prevent breaches in ethical research conduct. Indeed, breaches in ethical conduct are not isolated events or a thing of the past; they occur even with the ongoing revisions to the regulations. The protection of human subjects will always remain an integral part of the research process.

Compensation strategies are not static, and the types and amount of compensation vary both between different research sites and even within a given institution. Exploring the academic researcher perspective on compensation provides valuable insight into human subjects research protections for researchers and the IRBs reviewing proposed
research studies and can also enable a more systematic and informed decision-making process regarding communication with potential participants.

In considering the complex nature of researcher decision making regarding participant compensation—and the many factors at play within it—this study provided rich qualitative data on researcher perspectives and attitudes toward compensation for research subjects. Disseminating results and conducting further research can help shape scientific understanding of compensation practices from the researcher perspective.

Statement of the Problem

Human subjects research is a dynamic system that is influenced by society’s ethical and moral underpinnings. The lack of information published on research compensation and researchers’ suggestions for additional research, guidelines, documentation in publicly published works support the need for continued research related to the ethical issues surrounding compensation of research participants. (Trung et al. 2017). Also, Bernstein and Feldman (2015) conducted a literature review of 76 studies, reporting only seven articles presented compensation data. The authors found that when a study required follow-up visits, the compensation amount for follow-up visits was greater than the initial compensation offered as an incentive to enroll in the study. There was no information provided in the publication regarding the process by which the amounts were determined. The present research study explored this little-described process in order to expand available compensation knowledge, which, will assist both researchers in developing compensation and IRB members in reviewing compensation strategies for compliance with regulations.
Additionally, published compensation literature is generally presented by biomedical researchers. The limited compensation information published and its biomedical research focus supports the need for continued study. Ongoing compensation issues identified from the literature review are grounded in a social justice perspective. Determining when compensation may cause undue influence is not concrete.

Exploring the decision making processes by researchers in different settings can expand the understanding of factors considered and the weights of the factors in different settings. Undue influence also intersects with coercion issues as compensation can be a part of the recruitment process. Compensation is one of many factors considered by the researcher and IRB when evaluating the research design for undue influence and coercion. Importantly, exploring the decision making processes of researchers will help to identify potential bias that compensation may have on the analysis of the study findings.

Attaining a more robust empirical understanding of the ethical and social justice issues associated with the compensation of research participants will be beneficial to researchers, institutions, and research participants. Determining the amount of compensation that can incentivize a person to participate and continue participation, but not unduly influence them involves multiple considerations and varies by study design. Compensation is a component with other concerns, such as protecting participants voluntarism intertwined in the decision processes.

As research designs continue to evolve to address emerging needs, compensation’s influence will continue to be assessed. This need intersects with the social justice aspect of compensation as part of participant recruitment. Recruiting
individuals who may be vulnerable due to short-term or long-term financial need continues to be evaluated for the undue influence of compensation and the recruitment process for coercion. Ethical discussions continue on recruitment processes compared to the population expecting to receive the benefits. Alternatively, research exploring methods to increase an ethnic or cultural group’s participation in research includes an exploration of compensation’s degree of influence within different settings. Increased understanding of the dynamic and evolving decision making processes by researchers can lead to new best practices in human subjects protections education and promote ethical research practices generally. Human subjects research protections regulations reflect societal and cultural shifts in addition to addressing recent technological advances.

The University of Iowa, where I work, is a research-intensive university and one of the nation's top public research universities (University of Iowa [UI], 2016a). University of Iowa researchers conduct both biomedical and social-behavioral research in many settings. According to the Human Subjects Office website, there were 3,511 active study protocols at the University of Iowa in 2015 (UI, 2016b). It is notable that approximately 39–48% of the new studies reviewed in 2015 by one of the University of Iowa IRBs did not have funding. Researchers submitted the highest proportion of unfunded studies to the Behavioral IRB-02, while 40% of the studies researchers submitted to the Biomedical IRB-01 were funded. At the University of Iowa, IRB-03 reviews all studies researchers affiliated with the Iowa City VA Health Care System carry out, with 39% of these new submissions being funded in 2015 (UI, 2016b). Thus, the majority of human subjects research conducted in 2015 at the University of Iowa lacked formal funding with which to compensate research participants, an important
factor to consider when approaching the issue of research compensation. However, this lack of funding does not necessarily mean that research participants are not being compensated, nor does formal funding necessarily mean that research participants are automatically compensated by the researchers.

Research compensation can be monetary or nonmonetary (e.g., extra course credit) and may be drawn from resources other than formal funding. Additionally, even in the case of a funded study, researchers may opt not to provide monetary compensation to its participants for any number of reasons. For this dissertation study, a mix of funded and unfunded biomedical and behavioral studies at the University of Iowa provided an appropriately diverse sample for a qualitative methods study designed to explore the academic researcher’s perspective of the compensation processes.

Pilot Study

For this dissertation, a pilot study exploring compensation practices at the University of Iowa was conducted October 2016. The aim of the study was to obtain a basic idea of how researchers approached compensation at the University of Iowa and whether researchers had any ethical concerns related to compensation. I collected data via an online survey by recruiting subjects via a mass email that was sent to all University of Iowa faculty, staff, and students. Of the 576 individuals that responded, 406 met the inclusion criteria. To be eligible for the survey, researchers needed to: (a) be affiliated with the University of Iowa, as indicated by an active University of Iowa email, and (b) have offered any form of compensation to research participants in the past two years. Researchers in nine of the eleven colleges indicated that they had offered compensation to their study participants in this timeframe. The participants were able to check all the
compensation methods that applied to the research they were associated with. The overall percentages of monetary and nonmonetary compensation were similar. Table 1 summarizes the respondents’ recent research compensation practices by general research type. The results of the pilot study indicate that research participant compensation is occurring at the University of Iowa.

Table 1

<table>
<thead>
<tr>
<th>Compensation Type</th>
<th>Biomedical</th>
<th>Behavioral-Social Science</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Money</td>
<td>68%</td>
<td>41%</td>
<td>8%</td>
</tr>
<tr>
<td>Gift Cards or Other Cash Equivalents</td>
<td>53%</td>
<td>52%</td>
<td>6%</td>
</tr>
<tr>
<td>Nonmonetary</td>
<td>64%</td>
<td>46%</td>
<td>4%</td>
</tr>
</tbody>
</table>

However, I did not explore how the compensation strategy was determined and how it may be altered for different study designs in the pilot study. The present dissertation study addresses how compensation is conceptualized by experienced researchers.

Theoretical Frameworks

Researchers have used tenets of slippery slope in their analysis of taxpayer compliance and given that human subjects research and taxpayer compliance both occur within bureaucratic systems. These tenets are applicable to compliance with human subjects research regulations. Both systems involve regulations at multiple levels, such as federal, state, and local, and in both cases, elements of the regulations undergo revisions. Kirchler, Hoelzl, and Wahl (2008) presented taxpayer compliance similarly, noting “the slippery slope approach supposes two routes to tax compliance: deterrence of tax evasion by audits and fines on one hand, and building a trusting relationship with taxpayers by services and support on the other hand” (p. 20). Prinz, Muehlbacher, and Kirchler (2014)
expanded the dichotomy of the antagonistic and synergistic perspective to include
dynamic interactions. Similar to the taxpayer–tax-authority environment, researchers and
IRBs are a part of a regulated community.

Analyzing participant compensation through the slippery slope lens included: (a)
the trust in authorities, (b) the power of authorities, and (c) their dynamic interaction.
Similar to taxpayers’ approach to compliance (voluntary or avoiding penalty),
compliance with human subjects regulations can be voluntary or forced to avoid penalty.
Compliance with the regulations can thus be approached by researchers and regulators
from a synergistic stance, in which a researcher cooperates with the IRB to achieve
compliance, or from an antagonistic stance, where a researcher believes the IRB and
bureaucracy are hampering their research. In this way, the framework shed light on all
three research questions, which involved academic researchers’ relationships to various
authorities that regulate human subjects research.

Researchers have used complexity theory to analyze complex, dynamic systems
in many disciplines, including the physical sciences, economics, mathematics, education,
healthcare, and epidemiology (Elton, 2010; English, 2008; Eppel, 2012; Horn, 2008; Jess,
Atencio, & Thorburn, 2011; Mason, 2008, 2009; Rickles, Hawe, & Shiell, 2007; Sanger
& Giddings, 2012). Complexity theory, a broader theoretical framework, was the
framework used to analyze, as human subjects research is complex and occurs in a
dynamic environment. Rickles et al. (2007) described human subjects research as a
“highly composite [system], built up from very large numbers of mutually interacting
subunits (that are often composites themselves) whose repeated interactions result in rich,
collective behaviour that feeds back into the behaviour of the individual parts” (pp. 933-934).

Qualitative investigators often use a conceptual framework as a theoretical lens or perspective to guide research and raise questions related to a phenomenon (Creswell, 2003). However, researchers generally frame compensation in relation to compliance with the Belmont Principles, not a specific theoretical framework. Avoiding undue influence caused by the compensation offered is an essential component of preserving participant voluntarism. This general concept is used by researchers and regulators as the benchmark when discussing research participant compensation. Researchers have employed theoretical frameworks in studies exploring motivation; Dhalla and Poole (2013), for example, used the health belief model framework to explore motivation in medical trials. Swanson and Betensky (2015) used statistical inference to explore research participant compensation, but generally theoretical underpinnings for compensation analysis are not presented in research literature.

Exploring compensation after the decision is made, coupled with the variability of study designs, limits compensation analysis. Robinson et al. (2015) conducted a literature review focused on retention strategies, finding 47 (57%) of the descriptive studies had financial incentives. Participant motivation and researchers’ rationales to compensate their participants present a piece of the picture. The lack of data on how researchers determine compensation on a study-by study basis, including their consideration of the impact of local context and sponsor-driven compensation guidelines, inhibits the development of best practices and the evaluation of undue influence at the study level.
Slippery slope theory provides a framework to explore the rationale for the decisions; complexity theory provides a framework to explore compensation within a highly dynamic environment, with evolving regulations and scientific advances. The literature review chapter presents a more detailed explanation and applicability of these theories to this study.

Potential Impact

Compensation of research participants will remain relevant even with the anticipated changes coming in human subjects research and regulations. Largent (2016) observed that human subjects research “has grown in scale while becoming more diverse” (p. 207). Evaluation of compensation will continue as part of human subjects protections, as compensation amount or type must not be unduly influential or coercive for individuals contemplating volunteering for a study. Ethical issues surrounding participant compensation continue to be researchers, including research conducted by Resnik (2015).

This study provides rich qualitative data on researcher perspectives and attitudes toward compensation that will help researchers, regulators, and institutions better understand this decision-making process. Given that such data are not widely available in the current literature, insights from the study may help shape scientific understanding of compensation practices from the researcher perspective. Without accounting for this perspective, policies toward compensation may not find the right traction among members of the scientific community.

This dissertation also provides information that may be leveraged for educational purposes, such as to enhance how IRBs work with researchers on the matter of
compensation. Exploring the academic researcher’s perceptions and compensation-related activities will increase understanding of how these decisions are made and can ultimately inform actors’ research-related decisions.

Defining Terms

Researchers frequently reference the concepts of undue influence and coercion when discussing compensation. Additionally, researchers use terms such as compensation and reimbursement as well as coercion and undue influence interchangeably or as separate concepts. Likewise, some study participants used the term coercion when sharing experiences and concerns about undue influence and compensation to reference both incentives and reimbursement.

This chapter concludes with defining key terms used in this research study and provides a list of commonly used abbreviations in the literature. Table 2 provides the definitions. Table 3 provides the key abbreviations used in the applicable long forms that are used frequently in literature and discussions related to human subjects research. The next chapter reviews relevant literature.
Table 2

**Definition of Key Terms**

<table>
<thead>
<tr>
<th>Key Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coercion</td>
<td>Amdur and Bankert (2011) defined this as “A person is to some degree forced, or at least strongly pushed, to do something that is not good for him [or her] to do” (p. 22).</td>
</tr>
<tr>
<td>Compensation</td>
<td>Monetary amount or nonmonetary items offered to individuals to participate in the study. Monetary refers to cash and cash equivalents. Nonmonetary compensation includes all other items, such as extra credit for a course.</td>
</tr>
<tr>
<td>Healthy volunteer</td>
<td>“A person with no known significant health problems who participates in clinical research to test a new drug, device, or intervention” (NIH, 2016).</td>
</tr>
</tbody>
</table>
| Human subject | “A living individual about whom an investigator (whether professional or student) conducting research obtains:
1. Data through intervention or interaction with the individual, or
2. Identifiable private information” (45 CFR 46.102, 2010). |
| Incentive | Something that incites or has a tendency to incite determination or action. (Incentive [Def. 1], 2014). |
| Local context | “Local standards, knowledge of institutional policies and capacity, investigator and study staff qualifications and community and subject considerations” (SACHRP, 2016). |
| Participant | Individual who volunteers as a human subject for a research study. |
| Patient volunteer | Individual who “Has a known health problem and participates in research to better understand, diagnose, treat, or cure that disease or condition” (NIH, 2016). |
| Reimburse | To pay someone an amount of money equal to an amount that person has spent (Reimburse, 2016). |
| Research | “A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge” (45 CFR 46.26.102). |
| Undue influence | “An offer of an excessive or inappropriate reward or other overture in order to obtain compliance” (HHS, n.d.). |
### Table 3

**Long Form of Key Terms with Abbreviation**

<table>
<thead>
<tr>
<th>Long Form</th>
<th>Abbreviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code of Federal Regulations</td>
<td>45 CFR 46</td>
</tr>
<tr>
<td>Title 45</td>
<td></td>
</tr>
<tr>
<td>Public Welfare</td>
<td></td>
</tr>
<tr>
<td>Department of Health and Human Services</td>
<td></td>
</tr>
<tr>
<td>Part 46</td>
<td></td>
</tr>
<tr>
<td>Protection of Human Subject</td>
<td></td>
</tr>
<tr>
<td>Code of Federal Regulations</td>
<td>21 CFR 50</td>
</tr>
<tr>
<td>Title 21</td>
<td></td>
</tr>
<tr>
<td>Part 50</td>
<td></td>
</tr>
<tr>
<td>Association for the Accreditation of Human Research Protection Programs, Inc.</td>
<td>AAHRPP</td>
</tr>
<tr>
<td>45 CFR 46</td>
<td>Common Rule</td>
</tr>
<tr>
<td>Food and Drug Administration</td>
<td>FDA</td>
</tr>
<tr>
<td>International Conference on Harmonisation of Technical Requirements for</td>
<td>ICH</td>
</tr>
<tr>
<td>Registration of Pharmaceuticals for Human Use</td>
<td></td>
</tr>
<tr>
<td>Department of Health and Human Services</td>
<td>HHS</td>
</tr>
<tr>
<td>Human Subjects Office</td>
<td>HSO</td>
</tr>
<tr>
<td>Office for Human Research Protections</td>
<td>OHRP</td>
</tr>
<tr>
<td>Principal Investigator</td>
<td>PI</td>
</tr>
<tr>
<td>Notice of Proposed Rulemaking</td>
<td>NPRM</td>
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<tr>
<td>Research Project Grant (<em>R01</em>) by National Institutes of Health</td>
<td>R01</td>
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CHAPTER 2
LITERATURE REVIEW

Compensation is a complex ethical issue that researchers have explored within multiple study designs and populations. Regulation is integral to research participant compensation considerations and affects many aspects of the participant compensation process. In this literature review, I begin with a summary of key regulatory elements and ethical concepts that often come up in discussions of compensation. This foundational information helps to contextualize the ethical issues surrounding research participant compensation. As noted in the previous chapter, there is a scarcity of literature addressing the decision-making processes of researchers related to compensation. Available compensation literature is organized into five perspectives:

1. Participant decision making
2. Researcher decision making
3. Phase I clinical trials ethical issues
4. Biomedical focus
5. Compensation literature and theoretical frameworks

Overview of Human Subjects Research Protections Relevant to Compensation

The regulations and guidelines referenced in literature about participant compensation include federal, international, and local regulations and requirements. For the most part, there is congruence in the various regulations regarding protecting participants from undue influence created by the compensation strategy.

The Declaration of Helsinki and The International Conference on Harmonization Guidelines for Good Clinical Practice (ICH-GCP) are examples of regulations and
guidelines applied to international human subjects research protections. The Declaration of Helsinki provides a set of “ethical guidelines for physicians and other participants in medical research” (Carlson, Boyd, & Webb, 2004, p. 695). The Council for International Organizations of Medical Sciences provided more detailed guidance, stating participant compensation can include payment for inconvenience and time spent, reimbursement for research study-related experiences, and free medical care; however, payments to participants should not cause undue influence (Grady, Dickert, Jawetz, Gensler, & Emanuel, 2005).

Researchers can be held accountable to multiple standards, such as ICH-GCP and federal regulations. The U.S. Department of HHS regulations for human subjects research are documented in the Code of Federal Regulations at 45 CFR 46. These regulations are also known as the Common Rule because many federal agencies, in addition to the Department of Health and Human Services (HHS), have adopted these rules. The Food and Drug Administration (FDA), on the other hand, has its own regulations, which are found at 21 CFD 50. Neither the regulations provided by the HHS (45 CFR 46) nor the regulations provided by the FDA (21 CFD 50) offer specific limitations for the payment of research subjects.

In compensation literature, researchers and authors refer the regulations described at 45 CFR 46 as “federal regulations” interchangeably. The Common Rule regulations and guidance apply to researchers who receive funding support or conduct HHS research and for institutions meeting these same requirements. The regulations are based on the Belmont Report, which is in sync with the federal guidelines. The Belmont Report was a crucial development in the history of human research protections.
Human subjects research protections are grounded in social justice with the aim to conduct ethical studies and protect participants from exploitation. Henry Beecher’s (1966) seminal article highlighted ethical issues occurring in human subjects research, noting “An experiment is ethical or not at its inception; it does not become ethical post hoc – ends do not justify the means. There is no ethical distinction between ends and means” (p. 1360). However, despite the potential ethical complexities, the role human subjects research continues to play in spurring medical advancements is, and long has been, well-acknowledged. As Lederer noted, “experimentation on human beings has played, and continues to play, a vital role in advancing medical treatments and biomedical knowledge” (2005, p. 22). The ethical underpinnings of a given historical period of research reflect the moral culture of that time, with the regulations and guidance evolving alongside the culture and the available empirical data.

In the United States, the Belmont Report was a major development in this evolutionary process. The National Research Act of 1974 established the National Commission for Protection of Human Subjects of Biomedical and Behavioral Research. Four years later, the commission members presented the Belmont Report. The three ethical principles providing the foundation for the report are: (a) respect for persons, (b) beneficence, and (c) justice (Belmont Report, 1978). The Belmont Report does not specifically address compensation. Rather, the ethical principles in the dicta—respect for persons and justice—underlay the justification for evaluating proposed research participant compensation for undue influence and coercion (OHRP, 2016). The Belmont Report does not provide specific outlines, nor is there a seminal event that spurred the initiation of compensation review processes; rather, these processes evolved from a
gradual awareness of the ethical complexities inherent in participant compensation. Now, the same ethical principles applied to ethical research are typically used as benchmarks by IRBs and researchers when reviewing proposed research participant compensation.

There is not complete consensus among researchers that compensation should be offered to research participants. Nevertheless, it is explicitly permitted per the federal regulations (OHRP, 2016). Researchers have, for the most part, dispelled the concern that compensation itself causes undue influence and coercion. Grady (2013) noted that, by 2012, the National Institutes of Health, the OHRP, and the FDA all supported the idea—based on empirical evidence—that participant “payments did not compromise informed consent and was not coercive or unduly influential” (p. 3).

Researchers and IRBs are tasked with understanding the local subject population and cultural attitudes towards research. This understanding is referred to as “local context review” and includes reviewing studies for compliance with federal, state, and local requirements. For example, the study population can be vulnerable based on a financial need or their health condition (Lemmens & Elliott, 1999). This vulnerability might influence the person considering volunteering’s perception of a particular compensation structure or amount—something that must be taken into account when reviewing for coercion or undue influence.

The lack of specific federal guidelines or rules means that local IRBs have flexibility in determining acceptable compensation strategies for each study and can take into account the local context in offering recommendations to researchers. Selected regulations and guidance provided by OHRP related to compensation include the following:
1. Compensation to research participants is acceptable,
2. Compensation can be monetary or nonmonetary,
3. Compensation for research participants should be just and fair,
4. Compensation should not affect the potential participant’s choice to participate or their evaluation of the study risks,
5. There are no predetermined standards to evaluate the appropriateness of the proposed compensation,
6. Selected groups of individuals have been identified as vulnerable populations, with additional regulations to be followed when they are involved in the research,
7. IRB tasked with evaluating compensation for undue influence, and
8. Risks should not be considered when determining compensation (45 CFR 46, 2010; OHRP, 2016).

Notably, the acceptability of the proposed compensation is determined at the study level by IRB evaluating the compensation strategy calculation within the context of each study. Institutional Review Boards are tasked with applying regulations and guidelines to research studies under their purview. As described in the OHRP (2017a), “IRBs should know who the subject population will be, what incentives are being offered, and the conditions under which the offer will be made” (n.d.). Bernstein and Feldman (2015) observed that, according to federal regulations, compensation “should not be considered a benefit to be weighed against study risks” (p. 1199).

To contextualize some of the topics and themes presented in the literature, it is also important to note some common terminology used throughout that intersects both
with regulatory aspects and ethical issues within human subjects research. In the literature, studies involving experimental drugs are referred to as drug trials, clinical trials, or intervention trials. Researchers have placed particular attention on the Phase I participants and will be presented in its own section. Phase I studies are designed to evaluate the safety of a new drug or treatment in a small number of humans (NIH, 2017). The literature also offers ample discussion of the ethical discussions about compensation in human subjects research, especially exploring individuals’ various motivations for participating in different types of clinical trials.

There is no definitive method to determine if the compensation would cause an undue influence or have a coercive bearing on the potential research participant. Institutional Review Boards and researchers need to consider many study-specific factors and subject characteristics to reduce undue influence. As noted in U.S. federal regulations:

Because of their relative nature and lack of clear-cut standards on the boundaries of inappropriate and appropriate forms of influence, investigators and IRBs must be vigilant about minimizing the possibility for coercion and undue influence. Reasonable assessments can be made to minimize the likelihood of undue influence or coercion occurring. For example, IRBs may restrict levels of financial or nonfinancial incentives for participation and should carefully review the information to be disclosed to potential subjects to ensure that the incentives and how they will be provided are clearly described (OHRP, 2017b).

Many R01 institutions post IRB standard operating procedures online, which address research participant compensation. These procedures typically state that research
participants can be compensated for their time as well as for reasonable expenses such as transportation, parking, and lodging. The IRB standard operation procedures also note that participant compensation should be prorated throughout the study to avoid the perception of coercion on the part of the investigator. The local guidelines do not indicate a specific amount nor a defined method for calculation of appropriate compensation amounts or for calculating prorated compensation. This specific institutional example illustrates how, regardless of the research design or theoretical approach of researchers, there is a universal component to decision making regarding compensation, which is the regulations governing human subjects research.

Regulations and guidelines are interpreted and applied at the institutional level and then at the study level by multiple individuals—the researcher(s), the IRB, the sponsor, and the institutional and regulatory entities—and these interpretations are manifested in the study-level decision making carried out by researchers as they perform their academic duties. The next section explores recent participant compensation literature, including researchers’ references to regulations and ethical issues.

Literature Search Strategy

The initial literature review began with searches of databases that University of Iowa librarians previously identified for other human subjects protections-related projects. Search terms included the following: compensation, payment, reimbursement, incentives, participant, volunteer, patient, human subjects research, and clinical trials. Several themes were identified in the compensation literature, including participant motivation, researcher’s motivation for offering compensation, ethical concerns such as unfair burden, human subjects projects regulations, Phase I volunteers, and clinical trials.
A significant gap in literature addressing the faculty/academic researcher perspective on decisions about participant compensation was identified. This became the focus of my dissertation research. Due to additional human subjects protections regulations, studies related to prisoners and research involving federal government locations and employees were excluded. The findings from this study can be used to develop future research studies to explore these populations.

The initial literature search yielded many findings that were not applicable to the study. Working with multiple librarians to revise the search criteria, additional database searches were conducted. However, the searches continued to yield many articles that were not applicable. For example, in some cases, despite the fact that compensation was listed as a key term, information regarding compensation was not detailed in the publication. In other instances, researchers indicated whether participants were compensated without providing further details on the compensation strategy. Additional relevant articles were identified by examining each article’s reference list and reviewing similar articles that were suggested by InfoLink and the journals. The literature search was repeated throughout April and May of 2018 with a small number of additional references identified. These additional searches indicated that although there continues to be a lack of literature exploring the researcher’s point of view on participant compensation, researchers continue to explore participant compensation issues.

Reporting of compensation information is not a universal requirement for publishing in medical journals (Trung et al., 2017). Klitzman, Albala, Siragusa, Nelson, and Appelbaum (2007) found that 13.5% of publications the authors reviewed documented compensation. The lack of compensation details in the literature is an
ongoing issue. Trung et al. (2017), conducted a systematic review with 927 of the 2,000 studies most recently published in the top 50th ranked medical journals meeting their criteria. The researchers revealed 21 publications (2.26%) of the publications reported participant incentive information. Fifteen of the 21 studies reported monetary incentives, while six reported nonmonetary incentives. Bernstein and Feldman (2015) conducted a literature review with 76 studies meeting inclusion criteria. They found seven studies presented compensation data.

The dearth of published compensation information data challenges researchers and regulatory bodies to establish best practices. The limited amount of compensation data published may not present an accurate description of compensation practices and considerations made by researchers and IRBs.

Published scholarship that addresses research participant compensation generally presents compensation in relation to the motivational influence compensation has on the research participant, the researchers’ rationale to offer compensation, methods to calculate compensation, and ethical issues. However, the decision making processes and determination factors are generally not found in literature. This missing information exacerbates the challenges in exploring the complex ethical issues associated with participant compensation and in developing best practices that span study designs.

While many researchers have explored compensation, most have kept their focus within a specific study design. Common themes researchers have reported in studies of compensation amounts include:
• Compensation can be the primary or secondary motivation factor, or not a motivation factor at all, when individuals consider enrolling in a research study.

• Researchers compensate to facilitate meeting recruitment and retention/avoiding attrition.

• The importance of the timing of compensation payments, as well as the type and amount of compensation, vary by study population.

• Researchers must ensure they comply with human subjects research regulations by ensuring their compensation structure does not lead to undue influence.

Preservation of voluntarism of the participants while meeting research objectives is an ongoing issue. Researchers continue to explore compensation issues within different context and changing regulations. This chapter presents compensation literature published during the past three years, referencing previously published literature as needed to provide clarity in findings. Studies published prior to 2015 are presented in the Appendices E–G.

Participant Decision Making

Researchers have explored compensation from the participant’s perspective. Recent research publications present research focused on participant motivation and participant preferences related to the timing and type of compensation. Researchers generally frame explorations the influence of compensation as a motivational factor within the context of a specific study design and, at times, specific study populations with narrowly defined inclusion criteria. The timing of compensation payment and type of
compensation offered will be explored latter will be explored further when literature
presenting the researcher perspective is explored.

Researchers continue to assert that the degree to which compensation incentivizes
participants ranges on a spectrum from no influence to the primary motivational factor.
The degree of influence compensation may have on an individual is dynamic, as different
cultural and societal values affect what is considered appropriate in a particular context.
Arevalo et al. (2016) found that money could positively influence the recruitment of their
targeted population—Mexican-American individuals—but that participants also took into
consideration various nonmonetary factors, such as access to medication, reimbursement,
and medical information. Irani and Richmand (2015) conducted a secondary analysis
data collected from a longitudinal study consisting of 275 adults that sought care from an
emergency department for minor injuries. Likewise, they found the participants were
motivated by multiple factors, including being asked, desire to help others and help
advance science, personal benefit potential, financial reasons, curiosity, and their
personal value placed on research participation. Chin, Berenson, and Klitzman (2016)
showed that 5% of their participants, 20 men participating in an interview study regarding
motivation to participant in high risk study, identified compensation as the primary
motivation and 45% identified that compensation had no influence. The findings in their
study aligned with Nelson and Merz (2002), who reviewed literature and found the
influence of monetary compensation multifaceted, with different factors weighing
differently depending on the study design and study participant characteristics.
Conversely, researchers have not reported how the researcher uses this information when
determining compensation strategies and if certain factors are weighted differently.
Researchers continue to explore compensation as an incentive within narrowly defined parameters. Chin et al. (2016) studied a narrowly defined participant pool with a small sample size (N=20). At times, the published findings do not articulate details on the influence of compensation. For example, Garza et al. (2017) explored the willingness of African Americans and Latinos to participate in research and the factors that influenced their decision. However, the details related to the importance of the identified motivation factors were not included in the publication.

Generally, compensation has a positive impact on individuals’ willingness to enroll in a study (Bentley & Thacker 2004), but the reverse may also be true. Rikin, Shea, LaRussa, and Stockwell (2017) noted that incentives for a hypothetical vaccine trial decreased the willingness of the elderly Hispanic study population to be recruited to participate.

Researchers have found that compensation generally is a primary motivation factor for healthy individuals, while participants with the disease or condition of interest tend to identify non-compensation motivation factors (Aby, Pheley, & Steinberg 1996; Almeida, Benedita, Nunes, Vaz-daSilva, & Soare-da-Silva, 2007; Bigorra & Baños, 1990; Carroll et. al. 2012; Edelblute & Fisher, 2015; Tishler & Bartholomae 2002; Wiener, Viola, Wilfond, Wendler, & Grady, 2015). Researchers have conducted additional studies to explore the influence compensation has on participants who are minors and their parents. Wiener, et al., (2015) investigated research risk and the influence monetary compensation had on willingness of adolescents and their parents to agree to participate in studies that involved various research procedures. Compared to the parents, adolescent participants were more willing to participate in procedures that did
not provide personal benefit without being compensated. Additional research has been conducted to explore how changes in the compensation influences the participants. Acharya, Norton, and Lumeng (2017) conducted a randomized controlled trial study to estimate the degree of elasticity compensation amounts had on the parents’ decisions to permit their child to undergo various study procedures. Similarly, they found that their healthy adolescent participants and their parents were more motivated by compensation than adolescent participants with the disease or condition of interest.

Researchers continue to explore the influence of compensation strategies within different study designs. Researchers have demonstrated compensation can incentivize individuals to participant in research and encourage them to follow through during longitudinal studies (Brueton 2013; Croft, Festinger, Dugosh, Marlowe, & Rosenwasser 2007; Grant & Sugarman 2004). Researchers, in turn, have conducted studies designed to explore compensation’s impact on recruitment and retention strategies. Avoiding attrition is comparable to retention as both address a participant’s continuation in longitudinal studies. However, as the majority of compensation literature is associated with biomedical research and the researchers use term ‘retention’, this dissertation will also use retention to discuss ongoing participant participation.

Researcher Perspective

Compensation reporting from the researcher perspective generally focuses on compensation as it relates to recruitment and retention strategies. Researchers have explored the timing of compensation payments in an effort to identify timely recruitment goals, as well as retaining participants in order to keep a representative sample in a cost-efficient manner. Chin, Choi, and Lam (2015) found that the timing of compensation did
not alter recruitment efforts or influence the cost to conduct the study. Other researchers have noted increased administrative costs related to delayed and graduated payment schedules (Cole, Doan, Ballinger, & Brown 2009). Tailoring the compensation process to meet specific study participants’ needs, and balancing this with the need to minimize study costs, involves researcher decision making related to compensation. However, researchers have not articulated their decision-making process. Devine et al. (2015) suggested that exploring the participant payment expectations for different types of study procedures “may inform researchers’ decision-making when setting payment levels” (p. 6).

Marathe et al. (2018) examined participant payment from the regulatory perspective in relation to decisions made by three IRB committees. The authors’ findings demonstrated that studies funded by pharmaceutical companies had higher monetary compensation amounts and that 60% of the studies reviewed indicated they had provided reimbursement for travel expenses. The indication that studies funded by pharmaceutical companies had higher compensation amounts leads to a need to explore the reasons. The reasons for higher compensation and methods to determine the compensation strategy, and individuals involved in developing the compensation are not provided, but potentially play a role in how researchers make decisions about compensation. Future exploration of these details and the decision-making processes researchers used will provide a clearer understanding of compensation practices in general, and the rationales for compensation used by researchers will provide insight into the ways in which researchers ensure their practices comply with regulations. This understanding can lead to developing best
practices for researchers and IRBs, as well as informing human subjects research regulations.

**Phase I Clinical Trials Ethical Issues**

Phase I trials are a broad category, comprising a significant breadth of pharmaceutical drug types, study locations, and targeted study populations. Phase I clinical trials have their own particular issues related to compensation. As with other types of studies regarding compensation, there is a lack of published detail on how researchers determined the compensation amount and how amounts are revised based on local context, IRB directives, and study design.

Depending on the type of biomedical study, researchers recruit either healthy individuals or individuals with the disease or condition of interest. Researchers generally discuss compensation in Phase I trials as it relates to healthy volunteers. A number of researchers have reported that healthy volunteers are generally motivated by money (Almeida, et.al, 2007; Bigorra & Baños, 1990; Edelblute & Fisher, 2015; Wiener et al., 2015). The influence of compensation on the healthy Phase I volunteer has been identified as an ethical issue, especially in the case of individuals who routinely participate in Phase I studies (Almeida et al. 2007; Elliott, & Abadie 2008). Healthy volunteers who repeatedly enroll in Phase I studies are known as *professional* research participants and as *guinea pigs* (Motluk 2009).

Additional ethical issues have arisen related to these professional volunteers. Deception or concealment of facts by some participants during the recruitment process have been observed by researchers (Motluk 2009; Resnik & Koski 2011; Zanini & Marone 2005). Czarny et al. (2010) reported that monetary compensation may “prompt
subjects to lie, deceive, or conceal information that, if known, would disqualify them as participants in a research project” (pp. 1-2). One example of this type of behavior is not revealing participation in a different clinical trial within the past 30 days (Motluk, 2009; Resnik & Koski, 2011). Motluk (2009) provided an example of the deception and the self-reported rationale by the participant, “Career volunteer Brandon, who is living in his car between trials, says that he regularly flouts the 30-day rules. He claims he cannot afford to take a month out when a trial comes to an end” (p. 42). Indeed, there are cases where professional volunteers regularly misrepresent themselves to make a living from study participation.

When the individual employs deception to qualify for study participation, they can expose themselves to greater risk and may skew the findings of the study. For example, if an individual participates in a drug trial and does not wait the required time for the drug to be out of their system before participating in a study for a second drug, this may result in a side effect they experience being reported as an effect of the new drug, when it is actually an effect of the previous study’s drug or a combination of the two drugs together (Dickert, 2013; Resnik & Koski 2011). Ripley (2006) reported instances in which research staff recognized a participant from a different trial that required the person to have a specific health issue. The same participant subsequently denied having that same condition to be eligible to enroll in another study (Ripley, 2006). The safety of the participant and the integrity of the research findings are both potentially compromised in instances of participant deception (Dickert, 2013). Deceptive practices by some participants intersects with compensation and other ethical issues. For example, Edelblute and Fisher (2015) proposed a tracking option to address deceptive practices.
some Phase I participants use to meet eligibility criteria. Literature does not detail the influence potential deception has the compensation determination processes by researchers.

Researchers have expanded the compensation issue to explore the importance of risk evaluation compared to compensation. Grady, Bedarida, Sinaii, Gregoria, and Emanuel (2017) revealed a shift from previous Phase I studies reported in the literature. The authors’ noted while monetary compensation continued to be the primary motivator for participants, the consideration of study risks was more important for the individual participating in this study than the compensation offered. Similarly, researchers have examined other issues that intersect with research participant compensation. The regulatory aspects, such as Grady (2015) discussed regulatory aspects regarding IRBs and efforts to develop models related to IRB oversight and review. Potential and actual ethical misconduct continues to be a concern of human subjects stakeholders including researchers, participants, and regulating bodies. Jones, et al. (2016) revisited Beecher’s 1966 seminal article about questionable or unethical human subjects research. The continued research on compensation practices reflects efforts for compensation to achieve what is intended, whether to show appreciation or to encourage participation and continued participation, without negatively impacting a person’s voluntarism.

Biomedical Focus

Researchers have conducted qualitative studies that explored compensation in biomedical studies. Researchers have explored successful recruitment and retention strategies, in which findings include compensation as a strategy (Brueton, et al. 2013; Permuth-Wey & Borenstein 2009). Other researchers explore participant motivation with
compensation identified as a motivation factor. Luchtenberg, Maeckelberghe, Locock, Powell, and Verhagen (2015), who explored the motivations of individuals aged 10-23 who participated in clinical trials. Two of the 25 participants considered financial compensation a personal benefit and a primary motivational factor. Compensation literature continues to be weighted towards biomedical researchers providing information compared to behavioral-social sciences.

Compensation Literature and Theoretical Frameworks

Generally, a theoretical framework has not been applied to the compensation information reported in the literature. Slippery slope and complexity theories provide a framework for exploring the dynamic environment and evolving issues associated with human subjects research. They also allow for an examination of compliance issues arising within a bureaucratic system that relies on voluntary compliance with regulations. While complexity theory provides a nuanced framework for analyzing the varied systems in which human subjects researchers must carry out their work, slippery slope provides a foundation from which to examine researchers’ varying approaches to regulation, from antagonistic to collaborative.

The slippery slope framework has been used to analyze tax compliance. This framework applies economic and psychological considerations in the analysis of compliance. The basic framework assumes individuals comply with tax regulations from either a voluntary or enforced compliance perspective. The voluntary perspective is based on the willingness of individuals to pay their taxes due to an obligation. Alternatively, enforced compliances is when individuals pay taxes to avoid penalties.
Individuals comply with tax obligations based on their trust of the tax authorities or due to the power the tax authority has to levy penalties. Researchers have explored tax compliance using the slippery slope framework to explore tax compliance within multiple settings. Exploring compliance from the intersection of trust and power in the bureaucratic tax authority systems provides insights on the tax culture and strategies to facilitate compliance based on rationale taxpayers have towards compliance. An example is why the individual will report all taxable income. The individual can report the income because they trust the tax authority is fair in its tax assessment. Alternatively, they can report the income because they fear they will be caught and penalized if they do not. Both of the individuals are compliant, yet their approach to compliance is dissimilar.

Similarly, this framework was used to analyze specific interactions and relationships between researchers and the IRB. Similar to the tax system, human subjects research operates within a bureaucratic system. Table 4 highlights the slippery slope theory elements that will be used to analyze the study findings.

Regulatory bodies employ both synergistic and antagonistic approaches in human subjects research regulations. Muehlbacher and colleagues (2011) described a synergistic approach, with the tax regulatory personnel aiding taxpayers in satisfying their tax obligations. The IRB is the regulatory body at the operational level. Synergistic interactions between the IRB and researchers include the IRB assisting researchers by answering questions raised prior to and throughout the review process of a research application. This contrasts with the authoritative power associated with the antagonistic approach.
### Table 4

*Slippery Slope Framework Elements Applied to Study Design*

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<tr>
<th>Slippery Slope Elements</th>
<th>Application to This Study</th>
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<tr>
<td>Taxpayers’ relationships to regulatory personnel: synergistic or antagonistic</td>
<td>Researchers’ relationships to IRB: synergistic or antagonistic.</td>
</tr>
<tr>
<td>Synergistic relationship: voluntary compliance</td>
<td>Researchers and IRB proactively discuss issues and concerns during the application process; IRB offer presentations addressing human subjects research issues, which are open to researchers and staff involved in research processes.</td>
</tr>
<tr>
<td>Antagonistic relationship: forced compliance</td>
<td>Researchers comply with the requests of the IRB for study approval; researchers speak negatively about IRB in other settings, such as in classrooms and among other researchers.</td>
</tr>
<tr>
<td>Power and trust interactions contribute to slippery slope dynamics</td>
<td>Researchers, IRB, and administrative staff establish effective communications, minimizing drift down the slippery slope. However, if relationship is primarily antagonistic and hierarchical and transgressions are not identified, drift down slippery slope may occur.</td>
</tr>
<tr>
<td>Strategies to increase trust and commitment motivation: education, correction of unintentional errors, and providing service</td>
<td>Findings indicate that IRB could mitigate drift down slippery slope by providing education and assistance applying human subjects research regulations to its research committee.</td>
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(Kirchler et al., 2008)

Trust in authorities is a part of the synergistic relationship and encourages voluntarism of the researchers towards compliance. According to Muehlbacher, Kirchler, and Schwarzenberger (2011), a synergistic approach involves “a respectful and trusting relationship between authorities and citizens” (p. 90). Kirchler et al. (2008), proposed that for tax compliance, there is a positive relation between knowledge and compliance: “taxpayers will act on the basis of the perceived fairness of the system and comply
voluntarily” (p. 220). Applying this concept to the researcher–IRB relationship, it is imperative that the IRB offer education and guidance to the researcher.

Assessing study activities for compliance with IRB requirements and regulation aligns with the antagonistic perspective. The Office for Human Research Protections (OHRP) is the federal agency tasked with the “leadership in the protection of the rights, welfare, and well-being of subjects involved in research conducted or supported by the U.S. Department of Health and Human Services” (OHRP, 2018a). Institutional Review Boards apply federal, state, local, and international regulations to the study under review. Within tax compliance, the antagonistic approach is framed by the power of the tax bureaucracy to enforce taxpayer compliance. Failure of the taxpayer to comply with the tax laws results in penalties for the taxpayer. Similarly, sanctions can be applied to researchers who do not comply with IRB requirements and regulations, such as loss of ability to conduct research and inability to obtain funding for research.

The researcher’s approach to regulatory compliance may be fluid. At times, a researcher may work collaboratively with the IRB in finalizing a compensation strategy. At other times, the same researcher might comply with the IRB mandates but simultaneously feel the IRB is constraining research and the advancements the researcher is working towards. In the findings chapter, Tables 21 and 22 expand Table 4 to highlight the application of the slippery slope elements to the findings and in the analysis of the data. The slippery slope theory also guides the implications and provides suggestions for further research, which are discussed in the final chapter.

Complexity theory is the second theoretical framework applied to this study. As suggested by Nielsen, Nicol, and Owuor (2008), “Complexity science attempts to explore
how components or agents within a system self-organize and evolve into complex and coherent unities” (p. 38). The dynamic environment in which human subjects research occurs becomes particularly relevant in the analysis of participant compensation decision-making processes. Complexity theory provided the flexibility required to discover academic researcher perspectives, including the myriad factors involved in determining the compensation.

According to complexity theory, individual-level actions may have a nonlinear impact on the overall system. Rickles et al. (2007) described complexity as involving the “generation of rich, collective dynamical behaviour from simple interactions between large numbers of subunits” (p. 934). Due to geography alone, the present study is nested within three different regulatory systems: federal, state, and institutional.

Table 5 highlights the complexity theory elements that will be used to analyze the study findings. The complexity theory enables the exploration of research compensation occurring within an entity by researchers representing many disciplines, theoretical perspectives, and research designs, whose decisions may not be constant, even though the events appear to be similar.

What may appear at first glance to be a minor or inconsequential event within a subsystem can have a significant, nonlinear influence on the overall system (Doll, 2008; Mason, 2008, 2009). From the perspective of complexity theory, Morrison (2008) proposed relationships or the interactions affected by an event are more relevant than the actual event or situation itself. In addition, Beswick, Watson, and DeGeest (2010) observed the intrinsic unpredictability in human systems. For example, one might ask if the compensation practices of biomedical researchers influence IRBs or the institutional
culture differently than those of the behavioral-social scientist. The answer to this question can be further explored through complexity theory to discover the how and why of a given event’s effects on both the systems and the actors within those systems.

Table 5  
*Complexity Theory Applied to Study Findings*

<table>
<thead>
<tr>
<th>Complexity Theory Element</th>
<th>Element Applied to This Study</th>
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<tr>
<td>The system “whole”</td>
<td>Human subjects research is a complex system.</td>
</tr>
<tr>
<td>Nested, interacting, and interdependent systems</td>
<td>Key actors or systems: regulations and guidance, researchers, IRBs, participants, society, research design.</td>
</tr>
<tr>
<td>Multiple interactive systems, creating feedback mechanisms within and between systems</td>
<td>Regulations and interpretation of regulations are ongoing; communications occur within and between systems.</td>
</tr>
<tr>
<td>Change through self-organization and emergence</td>
<td>Researchers can work independently and/or within collaborative groups; issues within a system or subsystem can impact one or many systems/subsystems.</td>
</tr>
<tr>
<td>Open systems and socially constructed boundaries</td>
<td>Researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts.</td>
</tr>
<tr>
<td>The history of the system influences its starting point for change</td>
<td>Addressing ethical misconduct provides foundation for some of the guidelines and regulations, and revisions are ongoing, reflecting cultural norms.</td>
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(Eppel, 2012)

While slippery slope theory provides a framework for analyzing this study’s data and its implications, applying complexity theory to human subjects protections provides a foundation to explore the research questions in a dynamic environment. The dynamism and complexity inherent in these multiple systems becomes clear when looking at the ethical issues implicit in human subjects research. The influence of compensation is
study-specific and must be viewed on a continuum. Acceptable compensation in one context might cause undue influence in another scenario. This study explored how this flexibility in the regulations informs researchers’ compensation decision processes. Using both slippery slope and complexity theories allowed this study to fill a gap in the literature by addressing the complex, dynamic nature of the decision-making processes of academic researchers regarding research participant compensation in their studies.

Summary

This chapter presented key human subjects regulations related to participant compensation and findings of current compensation literature. Participant compensation is a complex issue that involves decisions regarding the rationale to compensation and the developing compensation strategies on a per-study basis. This study was designed to collect empiric data to further understand participant compensation by exploring the researcher decision-making processes and analyzing the data from complexity and slippery slope theories. Exploring how the compensation strategy is determined and how these different strategies are used together or in isolation, will provide insight and a basis to develop best practices. The next change will describe the data collect methods and how the data will be analyzed.
CHAPTER 3

METHODOLOGY

The purpose of this study was to explore the academic researcher decision-making processes related to participant compensation. As noted in the literature review, researchers have previously explored participant compensation in various contexts, yet the literature is for the most part silent on the compensation determination processes prior to the proposed compensation strategy review by the IRB. This chapter reviews (1) the three interlocking research questions that guided this research, (2) provides the rationale for the methodological approach, (3) provides the details of the study design, (4) explains the qualitative method used in the data analysis, and (5) addresses concerns raised regarding qualitative research.

Research Questions

To explore the academic researcher perspectives regarding research participant compensation, the researcher gathered primary data from researchers and study coordinators involved in the decision-making process related to participant compensation. The following three research questions are addressed:

RQ\(^1\): When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

RQ\(^2\): What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

RQ\(^3\): How, from the perspective of academic researchers, can compensation practices be improved?
Research Design

Due to the subject matter, and its focus on mental processes and contextualized decision making, a qualitative approach was the most appropriate for this study. The paucity of data in the current literature regarding researcher decision making as it relates to compensation—and my own experience working with researchers as they make these complex decisions—further encouraged the PI to pursue this line of inquiry. Research compensation literature focuses on ethical issues and explores general guidelines but does not provide a universal method to determine applicable compensation (Dominguez et al., 2012). The considerations researchers make, and decision-making processes they follow, are not presented by these researchers in the literature, which is something this study seeks to begin to address.

Purpose of Qualitative Methods Approach

Qualitative approaches allow the researcher to scrutinize the context of an event, activity, or process to gain valuable insights into the meanings and attributes embedded in those actions. However, as Creswell (2007) maintained, “there is no agreed upon structure for how to design a qualitative study” (p. 41). The qualitative format offers academic researchers participating in the study an opportunity to share their perspectives on compensation in a flexible manner and to present their perspectives, concerns, and understanding in a meaningful way (Drew, Hardman, & Hosp, 2008).

For this study, the researcher sought empirical data on the lived experiences of researchers and delegates tasked with research participant compensation, specifically biomedical and behavioral-social science researchers in Iowa. The basic qualitative approach provided the opportunity to explore essential elements of the researchers’
experiences and the manner in which these factors influenced their decision making regarding participant compensation. Vishnevsky and Beanlands (2004) proposed that qualitative methods “are concerned with providing a rich, holistic description of a particular phenomenon or human experience” (p. 237).

The researcher collected the primary data via semi-structured interviews, enabling academic researchers to detail their perspectives. Semi-structured interviews can be particularly apt “for examining the complex moral issues that bioethics confront” (Sankar & Jones, 2007, p. 12). A thorough and rich description was created by exploring the how, what, and why of that decision-making process (Glesne, 2010; Merriam, 2009). Participants in this qualitative study shared their stories, which offer a glimpse into their personal experiences, values, and concerns regarding compensation of research participants.

**Study Design Summary**

A qualitative design facilitates a deeper and more holistic understanding of the academic researcher’s perspective and experiences related to compensation for research participant practices. Semi-structured interview questions provided the opportunity to delve into what research participant compensation means to academic researchers at the University of Iowa and enabled the participants to provide empirical data in their own words, highlighting personal experiences and outcomes. This approach is well-recognized in social science research as a means “to get at the essence or basic underlying structure of the meaning of an experience, [for which] the phenomenological interview is the primary method of data collection” (Merriam, 2009, p. 25). The researcher used a scripted semi-structured interview (see Appendix C) to facilitate the
overall consistency of topics presented to each research participant. The participant responses frequently led to new topics, some unique to the participant, and others touching on commonly-identified themes. This often resulted in unscripted follow-up questions. This expansion of the discussion elicited a thicker description of issues, giving the participants the opportunity to provide supporting examples. The probing questions encouraged discussion, which added further depth and clarity to the responses—one of the benefits of this interview style (Merriam, 2009).

The researcher’s conversational approach with the participants, as well as previous, non-research interactions between some of the participants, facilitated a more well-rounded view of the complexities and nuances of researchers’ decision making. In some cases, this included anecdotes that shed light on the researchers’ specific experiences and offered insight into their unique perspectives on the issue of compensation. Some of these insights point toward larger questions regarding compensation and ethics than can be further explored.

This exploratory study provides a foundation of information to expand the research compensation issues occurring in an academic research institution to other venues. My study design with the human subjects protections was developed based on the literature, the pilot study findings, the expertise of my dissertation committee, and the guidance of the Human Subjects Office/IRB staff.

Institutional Review Board

This research project met the definition of human subjects research. The University of Iowa IRB reviewed the research study and granted approval of this study prior to the initiation of any study activity.
Research Setting and Sample

The researcher selected the University of Iowa as the study setting for several reasons. First, the university is a research-intensive institution that is involved in both biomedical and behavioral-social science research. Second, the researcher has the unique perspective of having conducted research at the university as a graduate research assistant, as well as working as a PI with a faculty advisor. Third, the researcher is also familiar with the regulatory perspective within the university, assisting researchers in their human subjects research applications for regulation compliance.

According to the Research and Economic Development department at the University of Iowa, there were over 2,000 faculty and 13,000 staff, and the Graduate Admissions Office states that 9,300 individuals are enrolled in graduate or professional degree programs (University of Iowa, 2016a). This equates to 24,300 individuals who met the fourth criteria. Given the potential subject pool and the findings of the pilot study, the researcher anticipated recruiting individuals representing different research interests and experiences with participant compensation.

The researcher employed a purposive selection method to recruit participants from biomedical and behavioral social sciences disciplines. Purposive selection is a deliberate selection method (Shadish, Cook, & Campbell, 2002). As Merriam (2009) explained,

Purposeful sampling is based on the assumption that the investigator wants to discover, understand, and gain insight and therefore must select a sample for which the most can be learned. (p. 77)
Purposeful sampling provided an opportunity to consciously recruit individuals representing a variation in research perspectives to attain an information-rich group (Merriam & Tisdell, 2016). This method enabled the selection of a diverse group of participants who represented the various types of human subjects research being conducted by biomedical and behavioral-social science researchers at the University of Iowa.

The number of participants in a qualitative study is typically considered adequate when saturation of information is achieved. Saturation occurs when information collected is redundant rather than new (Burns & Grove, 2009). The researcher, in consultation with an experienced qualitative researcher, estimated that data saturation would occur with 30 participants. The initial goal was to recruit a 50:50 mix of biomedical (N = 15) and behavioral (N = 15) researchers.

Additionally, within these two distinct groups, the goal was to recruit for variation of researchers. This meant recruiting a strong mix of participants so that qualitative, quantitative, and mixed-methods researchers were included. The intent was also to recruit participants from multiple college and professional disciplines, as well as researchers with a variety of job titles, such as differently ranked faculty and professional researchers. To achieve this goal, the researcher implemented a two-phase recruitment strategy.

The researcher recruited the study group from the total population of University of Iowa researchers who met the following four inclusion criteria. The PI needed to: (a) have conducted or be conducting human subjects research in the past five years, (b) be affiliated with the University of Iowa, (c) have offered monetary and/or nonmonetary
compensation to research participants within the past two years, and (d) have an active University of Iowa email account.

The initial recruitment phase involved snowball sampling recruitment. The researcher sent targeted emails to (1) individuals who had previously expressed interest in my research topic and (2) dissertation committee members. The recruitment emails outlined the specifics of the study’s inclusion criteria and an elements of consent attachment. The elements of consent included: an invitation to participate, the purpose of the study, an overview of the study procedures, and clarification that participation was voluntary, as well as contact information for the Human Subjects Office and the PI. Snowball sampling permitted the individuals to identify potential researchers from their personal networks (see Appendices A, A2, and A3 for recruitment emails).

The first recruitment phase did not elicit any participants, so the PI initiated the second phase of the recruitment strategy. In this phase, the PI sent a mass email via the University of Iowa’s Qualtrics platform, soliciting researchers meeting the criteria. The PI had developed additional recruitment emails targeting specific types of researchers, such as biomedical or behavioral-social sciences. Yet, the PI did not send these IRB-approved mass emails as the recruitment goal was met. By clicking the link included in the recruitment emails the Qualtrics survey, the person was directed to a Qualtrics survey that opened with inclusion criteria. If the person answered affirmatively, the survey then opened the elements of consent. The next screen asked for the respondent’s contact information. The Qualtrics survey was designed to halt enrollment after N was achieved.

The PI anticipated that study participants would be recruited from nine of the 11 colleges that comprise the University of Iowa: the Colleges of Medicine, Dentistry,
Education, Engineering, Liberal Arts & Sciences, Nursing, Pharmacy, Public Health, and Business. Researchers from the College of Law and the Graduate College generally do not conduct research under the purview of the human subjects research regulations. The current metrics posted by the HSO were for 2016 and indicate no submissions from the College of Law. There were submissions from the graduate college, although the metrics for the number of submissions by department did not list the graduate college in either the top 11 biomedical departments or top ten behavioral-social science department submissions. As anticipated, there were no respondents from the College of Law or the Graduate College.

The N was reached in Qualtrics within hours. However, after reviewing the names with the University of Iowa online directory, the PI noted multiple respondents did not have a faculty status. The researcher decided with the advice of the dissertation chair, that (1) based the email feedback indicating that PIs sometimes delegate compensation decision-making tasks, we felt it was important to expand the inclusion criteria and (2) that the responsibility of answering the inclusion criteria rested with the individual completing the survey. A modification was submitted and approved by the IRB to increase the N to 52 and expand the participant pool to include academic researchers and their delegates tasked with compensation decision-making. The PI sent a mass email to faculty and staff, recruiting the additional participants. The revised N was reached within hours. (See the findings chapter for analysis of the recruitment process)

The PI sent the potential participants an email thanking them for agreeing to be contacted and for considering participating in my study. I provided a range of dates and asked for a preferred time and a few alternative options. I asked the potential participants
for their office location and indicated I would reply to confirm the time and location. To minimize the possibility of coercion or undue influence during the consent process, I also provided participants with a second copy of the exempt information sheet (elements of consent) that had been attached with the initial email.

The PI and potential participant negotiated and finalized the date, time, and location for the interview. If there was no response to the email, the PI sent a second email three to five days after the initial email. The PI sent the third and final email to the potential participant seven days after the second email if no response was received. If there was still no response, the contact was considered lost to follow-up. When the potential participant entered an invalid email, the person was also categorized as lost to follow-up.

The PI developed Excel spreadsheets to assist in the data management and analysis of ordinal and nominal data. The PI tracked participant information from recruitment to verification of the transcription. The pre-interview information contained in this spreadsheet included the participant contact information, the date, time, and location of interview.

Study Visit

The PI conducted face-to-face interviews in a meeting room or in an academic researcher’s office space located on the University of Iowa campuses. Depending on the location, the potential participant met the PI at a location near the office suites and then escorted the PI to the meeting space. The PI brought a copy of the elements of consent to each interview and offered it to the participant. Each interview began with a review of the elements of consent and the participant’s verbal authorization to audio record the
interview. The PI asked participants if they had questions regarding the elements of consent document or the study procedure, including the request to audio tape. Participants were also given an opportunity to ask questions before the interview began. The participants agreed to the audio recordings and, reconfirmed once the recorder started. All participants verbalized understanding that they could stop the audio recordings at any time.

The PI conducted interviews in a conversational manner, with few field notes taken. It is important to note that many of the participants began sharing their research stories while we were getting set-up or walking to the designated room. After the study interview was completed and the audio recorder stopped, many of the participants continued to talk about research in general or initiated discussions specific to my professional role. The PI collected only data related to the study and the minimum private information needed to answer the research questions. The semi-structured interview questions were based on the results of the pilot study, the relevant literature, and discussions with the dissertation committee.

The semi-structured interviews included three broad questions, with additional probing or supplemental questions that varied with the circumstances and nuances of the individual interview (see Appendix C). The interviews lasted 30–60 minutes, depending on the length of the participant’s responses and availability.

The first research question was:

**RQ\(^1\):** When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?
This question explored the factors considered by the academic researcher when making participant compensation decisions and helped to illuminate the lived experiences of the researchers and point toward common concerns and challenges the researchers faced. It explored how participant compensation is determined, including formal and informal processes, revisions after the study has been initiated, and participant response. For example, Devine et al. (2015) asked research participants to provide dollar values for the minimum amount they expected to be paid for different procedures.

The second research question was:

RQ₂: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

This question explored what, if any, ethical concerns an academic researcher may have when developing and implementing studies for the academic researchers from various disciplines and multiple research designs at the University of Iowa.

The third question was:

RQ₃: How, from the perspective of academic researchers, can compensation practices be improved?

This explored ethical and IRB issues identified by the researchers. Many of the issues identified by the participants had been mentioned in previous literature and in the pilot study, while others were unique to the local context. Many researchers mentioned that participant safety and study integrity related to fabrication and concealment of information were of particular concern to them, especially for the professional Phase I participant. This question offered academic researchers an opportunity to provide examples of practice revisions and problems they had experienced firsthand.
Probing questions focused on the six elements of complexity theory highlighted by Eppel (2012); their application to this study was presented earlier in this chapter.

Table 6 illustrates the connection between the elements of complexity theory and the semi-structured interview.

Table 6

*Application of Complexity Theory to Research Questions*

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Semi-Structured Interview Tool</th>
<th>Complexity Element (Eppel, 2012)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RQ¹: When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?</td>
<td>• Please tell me how you explain or define “compensation for research participants.”&lt;br&gt;• Please tell me about your experiences with compensating research participants.&lt;br&gt;• How do you decide if compensation should be offered?&lt;br&gt;• How do you decide on the type of nonfinancial incentives to offer?</td>
<td>2, 3, 4, 5</td>
</tr>
<tr>
<td>RQ²: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?</td>
<td>• Please tell me about your experiences with compensating research participants.&lt;br&gt;• How do you feel your experience with compensating subjects is going?&lt;br&gt;• Please tell me about your experiences in revising the compensation strategy after the study was initiated.&lt;br&gt;• How do you decide how much to offer, if you offer financial compensation?</td>
<td>1, 3, 4, 6</td>
</tr>
<tr>
<td>RQ³: How, from the perspective of academic researchers, can compensation practices be improved?</td>
<td>• When human subjects research guidelines and regulations are revised, this can result in changes to institutional policies.&lt;br&gt;• What do you think IRBs should know about the research participant compensation process from the researcher perspective?&lt;br&gt;• What complaints do you have regarding the functioning of the University of Iowa IRB related to participant compensation?&lt;br&gt;• Is there anything else you would like to share about research participant compensation?</td>
<td>1, 2, 3, 4, 5, 6</td>
</tr>
</tbody>
</table>

(Eppel, 2012)
The elements are referenced by the numbers listed below:

1. The system “whole”
2. Nested, interacting, and interdependent systems
3. Multiple interactive systems, creating feedback mechanisms within and between systems
4. Change through self-organization and emergence
5. Open systems and socially constructed boundaries
6. The history of the system influences its starting point for change

Because the PI previously worked with some of the participants outside the realm of this study, rapport did develop more quickly with some participants than with others. In a few instances, the conversation also became more free-flowing, with participant responses addressing multiple questions and drawing relationships between various relevant experiences.

Data Collection and Processing

From the 52 individuals that enrolled in this study, the PI conducted and audio-taped 17 semi-structured interviews, resulting in 16 successfully audio-taped interviews. The final N for data analysis was 16. Additional details regarding enrollment and lost to follow up is presented in the next chapter.

The PI used a USB digital recorder obtained from the University of Iowa College of Education to audio record the interviews. After each interview, the PI uploaded the audio recordings to UIOWA OneDrive and then electronically transmitted the records to a professional transcription service. The PI created a password-protected account with the transcription service that only the PI had access to. The IRB reviewed and approved the certificate of confidentiality as part of the initial approval.
After the transcribed interviews were received, the PI verified the transcripts by the audio recording and deleted the audio recording after verification process. Next, the PI sent an electronic copy of the transcript to participants that requested to review it. This form of member checking or respondent validation is a method that promotes data veracity (Merriam, 2009). In this case, two participants requested to review the transcribed audio recordings. Both participants returned edited transcripts, with the edits being grammatical in nature.

To protect the participant’s privacy and confidentiality, the PI destroyed the link between the participant and the transcript after the member checking process. If the participant indicated that they did not want to review the transcript, the link was destroyed once the transcript was verified. There was no further study-related contact between the PI and the participants. The data management spreadsheet included fields to document the post-interview tasks, from transcript verification to destroying audio recording, assisting in tracking progress and ensuring all steps were completed.

Data collected by the audio recordings were supplemented with field notes. As suggested by qualitative research best practices, field notes included descriptions of the interview environment, subject demeanor, and nonverbal cues, as well as the investigator’s comments and perceptions (Merriam, 2009). The PI documented nonverbal and environmental factors which included the participants’ body positioning and movement, meeting space, seating arrangements, and the degree of formality in the introduction.

To facilitate data collection, the PI was concurrently cognizant of the verbal and nonverbal communications of both the participants and herself. The PI attempted to note
in the field journal when the participants mouthed specific information, or used very quiet tone of voice, and pointed to branded items from sponsors located in the room, so they could be factored into, and used to enrich, the qualitative analysis of the interview data. When the professional transcriber indicated “inaudible” on the transcript, the participants were generally referencing specifics names that they did not want on the tape or were pointing to branded items from the sponsor of the study.

The additional description, at times, referenced specific situations in which the participant and PI had interacted on a professional basis. Proper names were either given pseudonyms or a specific department name was redacted. These communications added a thicker description to the study data, while maintaining the person’s desire to keep these data anonymous.

Data Analysis Process

This section details the data analysis process and rationale. Data analysis began when the initial interviews began. The initial interview and data analysis guided the development of the coding methods. The first cycle involved choosing a coding method and establishing broad codes that captured the meaning of the data as well as coding of the PI’s initial reflections. The interview questions and coding strategy were dictated by the analysis, as Charmaz (2014) advocated, “let your research problem shape the methods you choose” (p. 27). These revisions facilitated rich data collection. The participant interviews and coding procedures established the underlying meaning of the data.

As Sankar and Jones (2007) emphasized, coding is a crucial part of this data organization. The authors described coding as “the process of mapping interview transcripts so that patterns in the data can be identified, retrieved, and analyzed” (Sankar
Saldaña (2009) detailed a cyclical coding process, with the initial round being “fairly simple and direct” (p. 45) and advised considering alternative coding strategies that may facilitate validity and reliability.

The PI coded the data in an iterative manner. In the initial cycle, the PI chose the coding method and established broad codes that captured the meaning of the empiric data. Attribute coding classified demographic data, putting into context the information provided by the participants and initiating data organization. After the attribute coding, the PI continued with the cyclical coding process as the data was analyzed and synthesized. Descriptive code summarized the data by topics. According to Burns and Grove (2009), “descriptive statistics allow the researcher to organize the data in ways that give meaning and insight and to examine a phenomenon from a variety of angles” (p. 470). The PI documented the participants’ and PI’s emotions during the interview and analysis of the data. Table 7 summarizes the coding method used, its purpose, and its application to this study.

Emotion coding was iterative, with real-time notations made during the interview, during the review of audio recordings, and during the transcript analysis. The PI created provisional codes based on topics and issues raised from previous research. When participants presented a personal perspective on an issue the PI applied the value coding.

Coding the data from multiple perspectives facilitated a deeper understanding of how the data addressed the research questions. The next round of coding shifted to identifying themes and reflecting on the participants’ meanings, requiring both analysis and synthesis of the data and codes. The PI conducted further analysis and recoded the data into themes. The focus coding method resulted in discovering the major themes and
frequencies of identified topics and issues, providing insight into decision-making processes.

Table 7

Coding Method and Application

<table>
<thead>
<tr>
<th>Coding Method*</th>
<th>Primary Purpose</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute</td>
<td>Document information for future reference</td>
<td>Demographic for type of research, participant’s role, types of compensation offered</td>
</tr>
<tr>
<td>Descriptive</td>
<td>Use words to describe data, such as topic</td>
<td>Emotions noted during interviews and researcher’s emotions</td>
</tr>
<tr>
<td>Emotion</td>
<td>Document emotions</td>
<td>Emotions noted during interviews and researcher’s emotions</td>
</tr>
<tr>
<td>Focus</td>
<td>Identify major themes</td>
<td>Identify compensation strategy development decisions and issues identified by participants</td>
</tr>
<tr>
<td>Provisional</td>
<td>Topics identified from previous research</td>
<td>Undue influence, voluntarism, type of compensation</td>
</tr>
<tr>
<td>Values</td>
<td>Personal perspective</td>
<td>Example, when participants shared their personal belief regarding being required to pay taxes on research compensation</td>
</tr>
</tbody>
</table>

(Saldaña, 2009)

Theme and Category Development

Before beginning the study, I had anticipated that some themes would emerge, such as concerns with undue influence and use of compensation for recruitment and retention. These provisional codes provided guidance in organizing the data; however, these codes were not predetermined. Instead, the PI identified the main themes after analyzing the data.
Thematic analysis provides a framework for the previously explained focus coding method. Specifically, the PI followed the thematic analysis phases presented by Nowell, Norris, White, and Moules (2017) to demonstrate the reliability and trustworthiness of the research methodology and analysis. The PI identified the major themes and subcategories using the coding and theme analysis strategies.

Some of the anticipated themes, such as concerns with undue influence and use of compensation for recruitment and retention, were indeed evident from the beginning of the interviews. Unique themes emerged, including some specific to the local context. The degree to which each participant discussed elements of the major themes varied, but a common thread of a desire to carry out ethical research is woven throughout the interviews. Table 8 summarizes the thematic analysis, with Appendix D providing additional details.

Interpreting qualitative data involves organizing data into themes and categories. To develop the themes and their corresponding codes, the PI read each transcript a minimum of three times, with partial sections reexamined multiple times as the different coding methods were used to analyze the data. The method of coding was influenced by knowledge and experience working on the regulatory side of human subjects protections, the experiences as a researcher, and guidance from faculty. The coding manuals evolved throughout the data collection and analysis process.

The PI inputted the basic codes and major themes into an Excel spreadsheet and then organized the codes into categories and subcategories. Themes and categories with nominal and ordinal data were also evaluated using descriptive analysis. Prior to entering the transcripts into NVivo, the random numbers were replaced with gender-neutral names.
from an online website (Babycenter, 2018). The gender-neutral names selected were not the names of any of the participants. The pseudonyms were replaced with “Participant A,” “Participant B,” etc. for the written dissertation.

Table 8

*Application of Thematic Analysis Phases*

<table>
<thead>
<tr>
<th>Phase</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Searching for themes</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers</td>
</tr>
<tr>
<td></td>
<td>Used NVivo and Excel to document themes and connections</td>
</tr>
<tr>
<td></td>
<td>Audit trail included electronic coding documentation, with documentation of code revisions</td>
</tr>
<tr>
<td>Reviewing themes</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers</td>
</tr>
<tr>
<td></td>
<td>Dissertation committee conducts their (peer) review</td>
</tr>
<tr>
<td></td>
<td>Raw data is stored electronically for future analysis and comparison to future studies</td>
</tr>
<tr>
<td>Defining and naming</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers</td>
</tr>
<tr>
<td>themes</td>
<td>Oral defense includes review with discussion committee members</td>
</tr>
<tr>
<td></td>
<td>Audit trail included electronic coding documentation, with documentation of code revisions</td>
</tr>
<tr>
<td>Producing the report</td>
<td>Participants review the transcripts for accuracy summarized participants’ stories to check for understanding during and at end of interview</td>
</tr>
<tr>
<td></td>
<td>Oral defense includes review with discussion committee members</td>
</tr>
<tr>
<td></td>
<td>Detailed in Coding Method and Application section</td>
</tr>
<tr>
<td></td>
<td>Semi-structured interview provided participants an opportunity to provide supporting examples</td>
</tr>
<tr>
<td></td>
<td>Detailed in Establishing Validity and Reliability section</td>
</tr>
<tr>
<td></td>
<td>Detailed throughout dissertation</td>
</tr>
</tbody>
</table>

(Nowell et al., 2017)
Descriptive Analysis

The quantitative data for the one-to-one interviews consisted primarily of ordinal and nominal interview-response data that were analyzed using descriptive statistics. Descriptive data factors were also gathered from the online institution directory, such as employment status and department affiliation. Given the study’s small N, the findings are presented in aggregate; for example, University of Iowa Hospitals and Clinics represents multiple disciplines and departments.

Data on researcher gender—required by the IRB—as well as data on research design, type of compensation, and other numerical data points were all treated using descriptive statistics. As required by the IRB, the gender of participants was documented using dichotomous gender categories, but not associated with the participant characteristics. The count of male/female participants was completed and documented after the interviews were completed. Means, percentages, and frequencies were used to tentatively describe trends in the quantitative data.

Establishing Validity and Reliability

Strategies employed to promote validity and reliability in this qualitative research study include the following: triangulation, member checking, adequate engagement in data collection, researcher reflexivity, peer review, audit trail, rich and thick descriptions (Merriam & Tisdell, 2016, p. 259). Before detailing how these strategies were implemented, it should be noted that other researchers frame this discussion in terms of trustworthiness. Researchers continue to reference the four elements to establish trustworthiness in qualitative research that were proposed by Lincoln and Guba (1986): credibility, transferability, dependability, and conformability, which continue to be used
to address trustworthiness. These four elements are applied to this study in the following manner:

- **Credibility**: The issues and concerns identified in this study are similar to results presented in literature.

- **Transferability**: The variability in study design and researchers’ discipline/research topics enable the findings to be applied to other research settings, such as other research-intensive universities.

- **Dependability**: The study findings, such as rationale for offering compensation, are consistent with literature. The novel data elicited by the semi-structured interviews can be repeated in other settings and compared to the findings of this study.

- **Conformability**: The semi-structured interviews generated responses that were included in the analysis, supporting the findings.

The first strategy to establish validity and reliability is triangulation of qualitative data. Triangulation involves capturing the data from a variety of methods (Glesne, 2010; Merriam, 2009). Conducting the literature review and pilot study strengthens the validity of the outcomes, albeit, analysis of the literature is different than the pilot study and dissertation.

A member-checking strategy permitted participants to review the transcripts for accuracy. Only two participants requested to review the printed transcripts. However, throughout the interview process, the PI summarized their stories to check for understanding. Providing the opportunity for the participant to review the transcript and
verbally verify during the interview facilitated trust in the research procedures and increased accuracy of meaning-making of the participants’ contributions.

The next strategy, adequate engagement in data collection, includes the methodical coding analysis of the data collection, described earlier. The reflexivity strategy was implemented when I presented my reasons for conducting this research, my qualifications to conduct the research, and my research biases. Sharing motivations to conduct research in a transparent method helps to eliminate concern of a hidden agenda.

The peer review strategy is an integral part of the dissertation research process; my dissertation committee conducted their (peer) review of my dissertation. Merriam and Tisdell (2016) described the peer review process as a “discussion with colleagues regarding the process of study, the congruency of emerging findings with the raw data, and tentative interpretations” (p. 259). The audit trail strategy is the coding documentation, which was completed in an electronic format. Details of the development and revision of codes and the synthesis into themes were included in an audit trail (Merriam & Tisdell, 2016).

Developing a rich or thick description involved data gathering from semi-structured interview, field notes, and self-reflection and analytical memos. Saldaña (2009) explained that analytic memos are used to describe the “coding process and code choices; how the process of inquiry is taking shape; and the emergent patterns, categories and subcategories, themes, and concepts in your data” (p. 32). The thick description is demonstrated in the quotes and stories shared by the participants, and self-reflective analyses are included in the discussion of the findings.
The last strategy employed is detailed in the research setting and sample section. Seeking a diversified participant pool enabled the exploration of the issues by individuals representing multiple perspectives.

Qualifications to Conduct This Research

My professional and academic experiences assisted in my conducting of a qualitative research study. As a certified professional involved in a human subjects protections program, I review human subjects research applications and work with researchers, IRB members, research participants, and other stakeholders. In this role, I review studies related to compliance with the applicable regulations and guidance. I have also conducted human subjects research as a graduate student, as a PI of a pilot study, and as a research team member.

Throughout the process, I was conscious of how my own experiences impacted this study. According to Locke, Spirduso, and Silverman (2007), qualitative researchers must be aware of the perspective they bring to a study. My academic coursework has included qualitative, quantitative, and mixed-methods training. Involvement in qualitative and mixed-methods graduate research has operationalized the theoretical training I have received in academic courses and from faculty and academic researchers. My experiences conducting face-to-face interviews and assisting in focus groups has shown me the benefits and constraints of these data collection methods.

I began this study aware not only of the theoretical considerations necessary when carrying out this kind of research, but also the pragmatic realities qualitative researchers often face. The face-to-face interviews I have conducted previously included a semi-structured interview with the use of field notes, but not audio recordings. The decision to
use audio recordings for this study was influenced by my experience with this field
notes—only study and my desire to capture additional details of the participants’ stories.
Quotes and the frequency with which the participant discussed certain concerns, for
example, would not have been captured as extensively with field notes as the primary
method of interview documentation. Transcribing focus groups and integrating field
notes are skills that translate well to a semi-structured interview process. This firsthand
experience strengthened my practical knowledge of the ins and outs of performing the
interviews required by this study.

Researcher Bias

As I explored the ethics-related aspects of compensation, it was crucial to
understand what I valued and how my values could evolve and come into question
throughout the study. As Creswell (1994) argued, in qualitative research, it is essential for
researchers—themselves being the primary data collection instrument—to assess their
own personal values, assumptions, and biases at the outset of a study (p. 163).

I am a researcher and a certified IRB professional who works with researchers in
applying the rules and explaining the rationale for requests. Being responsible for
applying human subjects protections regulations to specific studies, I am aware of the
multiple perspectives and interpretations of regulations and understand that, frequently,
these regulations are not narrowly defined. As I was exposed to researchers with varied
experiences, ideas, and preferences related to compensation, it was possible that my
perspective on using compensation for recruitment versus appreciation could shift.

I am aware that my regulatory position inherently has a degree of power as it
relates to compliance with regulatory compliance. This power places my positionality to
an outsider perspective, which in turn, may influence the participants’ willingness to share scenarios that had a potential or actual lack of compliance.

I previously interacted with four of the sixteen individuals who participated in my study in my role as a professional in human subjects research protections at the University of Iowa. I worked to establish the boundaries of my role as a researcher before the interviews began; however, previous interactions I had with interviewees inevitably had some impact on our discussion. For example, some participants referenced previous conversations and regulations to support their stories.

When study participants used words out of context, I asked clarifying questions, rather than framing my question from a regulatory perspective. For example, when the participant mentioned “coercion,” I asked questions that helped me decipher if they were talking about “coercion” or “undue influence.”

It is possible my previous interactions—from the administrative side of human subjects protections— inhibited some participant responses, especially when participants referenced aspects of their research that could have relayed a failure to comply with institutional policy or human subjects regulations. Alternatively, some of the participants who had worked with me in my professional role may have answered questions differently than they would have with a stranger, referencing issues that we had addressed in previous conversations that are outside the scope of this research. When the participants shared examples that may conflict with regulations, I focused on the issue being raised, not the regulation. This information provided a potential educational opportunity.
Validity of Qualitative Methodology

Even though the use of the trustworthiness model is commonly referenced in the literature, researchers have expressed concerns about the validity of qualitative research methods that include the lack of a representative sample of the population, no experimental controls, small number of participants, and intrinsically subjective. These concerns ultimately lead to a lack of trust in the study results. This section reviews how qualitative researchers have explored and addressed these issues.

The concept of trustworthiness is established by meeting the following criteria: dependability, credibility, and transferability instead of reliability, validity, and generalizability used to establish rigor in quantitative research (Morse, 2015). Cope (2014) proposed that if transferability criterion has been met the readers can associate the results and have meaning to them.

Researchers continue address achieving trustworthiness. Proactive strategizing to achieve trustworthiness begins with the study design. Amankwaa (2016) developed a trustworthiness protocol to assist qualitative researchers creating studies. The protocol template includes creating timelines for planned tasks, as well as specific examples of the ongoing documentation of various activities. It is important to note that strategies to achieve trustworthiness are employed throughout the research process is crucial (Cope, 2014; Cypress, 2017). Table 9 presents strategies that are used by qualitative researchers to achieve trustworthiness.
Table 9  
*Strategies to Achieve Trustworthiness*

<table>
<thead>
<tr>
<th>Trustworthiness Criterion</th>
<th>Strategy to Achieve Criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Research methods appropriate for research question; triangulation; member checking; reflectivity; researcher's qualifications detailed; thick description; findings compared to literature; peer review</td>
</tr>
<tr>
<td>Transferability</td>
<td>Detailed description of: research topic, study design, implementation, analysis, application to other scenarios</td>
</tr>
<tr>
<td>Dependability</td>
<td>Detailed description of methods; data collection from multiple sources</td>
</tr>
<tr>
<td>Confirmability</td>
<td>Triangulation; documentation of researcher's assumptions and personal beliefs; study limitations, study methods, and audit trail</td>
</tr>
</tbody>
</table>

Detailed documentation is one of the strategies employed to achieve trustworthiness. According to Cope (2014), “To support credibility when reporting a qualitative study, the researcher should demonstrate engagement, methods of observation, and audit trails” (p. 89). Shenton (2004) observed that, in addition to triangulation, a “detailed methodological description enables the reader to determine how far the data and constructs emerging from it may be accepted.” (p. 72). Researchers reporting and discussing all data, including conflicting findings, support the authenticity of the study. Detailed descriptions support reader trust as they can determine the merits of the study design, analysis, and applicability to other situations. According to Koch (2006), “the original context must be described adequately so that a judgement of transferability can be made by readers” (p. 92). Detailed documentation of processes occurring throughout the research study is vital.

Peer review is another strategy that occurs to various degrees throughout the research process, including communication of the findings and interpretation. Peer review
for publications is a layer of review in which evaluator guidelines assist in consistency of peer reviews, which address trustworthiness and rigor. For example, Clark (2003) developed a guide for conducting peer reviews of qualitative research submissions known as RATS, which stands for relevance of study question, appropriateness of qualitative method, transparency of procedures, and soundness of interpretative approach. Tong, Sainsbury, and Craig (2007) created the Consolidated Criteria for Reporting Qualitative Research (COREQ), which is a 32-item checklist designed to assist researcher reporting interviews and focus groups. This checklist is organized into three areas: (a) research team and reflexivity; (b) study design; and (c) data analysis and reporting critical elements. The use of checklists by researchers and publishers assist in reporting critical elements of research for readers. Additionally, these guidelines support elements of the criteria used to establish trustworthiness such as providing rationale for study design and detailed documentation of study procedures and data analysis.

Regarding small-scale concern, Shenton (2004) observed that even though additional studies using similar method in different research settings are generally not completed, “the accumulation of findings from studies staged in different settings might enable a more inclusive, overall picture to be gained” (p. 70-71). For example, published compensation literature illustrates how researchers explore relevant issues within multiple study designs and perspectives without duplicating specific studies.

The use of traditional quantitative terms versus use of qualitative terms depends on the researcher and research study design. According to Leung (2015), “the three gold criteria of validity, reliability and generalizability apply in principle to assess quality for both quantitative and qualitative research,” (p. 327). Likewise, Cypress (2017) states
“Researchers assert that rigor of qualitative research equates to the concepts reliability and validity and all are necessary components of quality.” (para 2). Table 10 likens the trustworthiness of credibility, transferability, dependability, and confirmability to comparative quantitative concepts.

Table 10
Comparative Approach Demonstrating Trustworthiness and Rigor

<table>
<thead>
<tr>
<th>Qualitative: Trustworthiness</th>
<th>Quantitative: Rigor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Internal Validity</td>
</tr>
<tr>
<td>Confirmability</td>
<td>Objectivity</td>
</tr>
<tr>
<td>Dependability</td>
<td>Reliability</td>
</tr>
<tr>
<td>Transferability</td>
<td>Generalizability; External Validity</td>
</tr>
</tbody>
</table>

Even though the trustworthiness criteria are commonly used by qualitative researcher, other perspectives have been presented. Davies and Dodd (2002) suggested by what means qualitative researchers can address rigor in terms of “attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, context” (p. 288). According to Collingridge and Gantt (2008), researchers can use assertational logic to support their interpretation and generalizations. This type of analysis involves denoting the similarities and differences of the scenarios and interpretation based on a theoretical perspective.

Qualitative researchers have responded to critiques of qualitative research methods, addressing concerns and demonstrating strategies to support the trustworthiness of this methodology. I reviewed several recent publications related to human subjects research to identify the strategies the researchers used to document trustworthiness. Appendix H details the strategies by criterion while Table 11 highlights the findings by strategy. The degree of details provided varied as did the study design.
Table 11

*Review of Trustworthiness Strategies in Selected Publications*

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Strategy Used to Achieve Criterion</th>
<th>Publication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Research methods appropriate for research question; findings compared to literature; peer review</td>
<td>Garza et al., (2017); Grady et al., (2017); Simon et al., (2011); Perez, Ohrt, &amp; Bruening, (2016); Chin, et al., (2015); Devine et al., (2015); Edelblute &amp; Fisher, (2015)</td>
</tr>
<tr>
<td>Transferability</td>
<td>Detailed description of: research topic, study design, implementation, analysis</td>
<td>Garza et al., (2017); Grady et al., (2017); Simon et al., (2011); Perez et al., (2016); Chin et al., (2015); Devine et al., (2015); Edelblute &amp; Fisher, (2015)</td>
</tr>
<tr>
<td></td>
<td>Application to other scenarios</td>
<td>Grady, et al., (2017); Simon et al., (2011); Perez et al., (2016); Devine et al., (2015)</td>
</tr>
<tr>
<td></td>
<td>Data collection from multiple sources</td>
<td>Edelblute &amp; Fisher, (2015)</td>
</tr>
<tr>
<td>Confirmability</td>
<td>Documentation of study limitations, study methods</td>
<td>Garza et al., (2017); Grady et al., (2017); Simon et al., (2011); Perez et al., (2016); Chin et al., (2015); Devine et al., (2015); Edelblute &amp; Fisher, (2015)</td>
</tr>
<tr>
<td></td>
<td>Audit trail</td>
<td>Simon et al., (2011)</td>
</tr>
<tr>
<td></td>
<td>Suggestions for additional research settings and rationale for additional research</td>
<td>Devine et al., (2015)</td>
</tr>
</tbody>
</table>

The studies reviewed demonstrated compliance with the strategies to achieve the criterion established to establish trustworthiness. Thick description was evident in the studies that utilized open-ended survey questions and focus groups. Triangulation expands understanding as data is collected from multiple sources. Negative case analysis for studies utilizing unstructured and semi-structured interviews should be a part of the analysis and reported. Prolonged engagement reduces observer bias but is not necessary for study designs using interviews and focus groups.
Ultimately, the reader of the research will determine the merits of the study design, analysis, and applicability to other scenarios. This study follows the criteria for trustworthiness.

**Summary**

Chapter 3 detailed the qualitative research approach, including the participant recruitment, data collection, and analysis procedures. The study design was grounded on the trustworthy criteria and established strategies to achieve trustworthiness. The chapter concludes with a discussion on issues related the validity of qualitative research, followed by a summary of the strategies researchers used in recent human subjects research studies. Chapter 4 presents the data analysis, including detailing the data collection procedure, analysis, and key findings.
CHAPTER 4

FINDINGS

This chapter presents the study findings. To review, three research questions framed this exploration of the academic researcher perspective regarding research participant compensation:

RQ\(^1\): When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

RQ\(^2\): What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

RQ\(^3\): How, from the perspective of academic researchers, can compensation practices be improved?

These research questions address different issues surrounding research participant compensation practices at the University of Iowa, a research-intensive academic institution. PIs and their delegates were the primary sources of information for this study. The motivation to conduct this research study was to identify researcher practices and concerns to determine how this information may affect the application of human subjects regulations at the study level and inform how human subjects research regulation is communicated to researchers, IRB members, and regulators.

Both complexity theory and slippery slope theory framed this analysis, with complexity theory addressing the overall issues related to participant compensation and the layered and intersecting systems in which researchers must make these decisions, while slippery slope theory aided in articulating the various synergistic and antagonistic facets of researchers’ relationships with the IRB. The findings are presented by the three
research questions. The first research question is framed by complexity theory, while complexity theory and slippery slope theory inform the second and third research questions.

This chapter contains is organized to present the findings in the following manner: circumvention of the enrollment eligibility question, coding process, descriptive analysis of ordinal and nominal data, and participant interview data, organized by research question.

Circumvention of the Enrollment Eligibility Criteria

Circumvention of the enrollment eligibility criteria was an unanticipated finding. The rapid rate of recruitment goal achievement for this study resulted in multiple individuals without a faculty appointment enrolling in the study. Even though 73% of the persons enrolling in this study answered the prescreening question affirming they had a faculty status, the university directory revealed that 8 of 30 (27%) respondents had the requisite faculty appointment. The high percentage of individuals enrolling in the study without a faculty appointment raised the question of why they chose to enroll.

The inclusion criteria stated that participants should be presently conducting human subjects research or have done so within the past five years. This allowed for the possibility that a respondent could have switched employment categories. Yet despite this possibility, the respondents revealed a non-employment reason for enrolling in the study. Indeed, some of the respondents emailed me to share their rationale for enrolling, while others were known to me in as study coordinators.

In addition to the responses received in Qualtrics, multiple individuals sent queries to my University of Iowa email address, which was listed in recruitment
solicitation. The inquiries ranged from expressing a willingness to participate in the research study to providing examples of how compensation was determined and suggesting expansion of the participant pool to include other researchers that are involved in compensation decision making. These responses yielded valuable information, including: (a) PIs, at times, delegate compensation development responsibility to other research members; (b) examples of how researchers determine compensation; (c) some volunteers would agree to participate if compensation provided; (d) some volunteers indicated interest in participating but were not able to enroll; and (e) some volunteers had enrolled in the study because they had been delegated compensation tasks by the PI. Additional data collected from emails researchers sent in response to my recruitment emails aligned with data collected during the semi-structured interviews and the pilot study. Based on this feedback, my research advisor and I determined it was appropriate to expand the inclusion criteria, based on their role these individuals had in deciding compensation.

Additional Notes on Enrollment and Lost to Follow Up

Of the 52 individuals that enrolled in this study, I conducted 17 semi-structured audio-taped interviews, resulting in 16 unique audio transcriptions. The audio recorder failed in one interview. Three males and 14 females were interviewed. The participants who did not complete the semi-structured interview were considered “lost to follow up.”

Per the IRB, when the potential participant clicked to proceed to the next screen and provide their information, the person was considered “enrolled”. The Qualtrics study was designed to prevent enrollment after the N was reached. The Qualtrics survey did not include a text field for potential participants to provide rationale for not participating.
Because of this, for some of the potential participants, the reasons they eventually chose not to participate are unknown. However, email communication with a few of the potential participants provided some insight. Factors they cited included scheduling conflicts, having misread the recruitment documents, or deciding to decline due to the lack of compensation.

Table 12 summarizes the lost to follow up by recruitment email. Twenty individuals had listed an invalid email, did not list an email, or did not reply to the requests to schedule an interview. Eight did not qualify to participate, while 5 did not come to the interview, canceled, or were not available to complete the interview. Two declined to continue to participate and seven individuals initiated, but did not complete the Qualtrics survey during the enrollment period.

Table 12

<table>
<thead>
<tr>
<th>Email</th>
<th>Rationale</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Mass Email</td>
<td>Invalid email</td>
<td>10%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Did not reply</td>
<td>23%</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Did not qualify</td>
<td>17%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>No show, canceled, not available</td>
<td>13%</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Declined</td>
<td>3%</td>
<td>1</td>
</tr>
<tr>
<td>2nd Mass Email</td>
<td>Invalid or no email</td>
<td>13%</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Did not reply</td>
<td>7%</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Did not qualify</td>
<td>20%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>No show, canceled, not available</td>
<td>7%</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Declined</td>
<td>7%</td>
<td>1</td>
</tr>
<tr>
<td>Incomplete Qualtrics Survey</td>
<td></td>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>

Generally, the participants that enrolled revealed their decision to respond to the call for volunteers was the term compensation. Some of the participants indicated that they enrolled when saw the term compensation in the email. Others indicated that they had scanned the written recruitment text and enrolled because they were interested in
compensation, which meant either the topic itself, in some cases, or potentially receiving compensation for their participation in the study.

Approximately 44% of the participants who completed the study interview had a faculty appointment. There was a 50:50 split between respondents with a University of Iowa Hospitals and Clinics and the University of Iowa (UIOWA) appointment. To facilitate the de-identification of results, the researcher did not conduct analyses of department level and appointment type data due to this small N. The non-transcribed participant interview field notes indicate that the participant represented biomedical research and used monetary compensation. There were no significant issues or comments documented.

Coding Analysis

The coding analysis included using multiple coding methods. The focus coding process included redefining and labeling both broad concepts and basic-level elements. The initial seven codes were definition of compensation, rationale researchers choose to compensate, type of compensation offered, compensation strategy factors, ethical issues related to participant compensation relationship with IRB, and other. Monetary and nonmonetary sub codes further defined the type of compensation offered code. Tertiary code further defined the major codes, as applicable. For example, when the participant discussed using gift cards to compensate, the passage would be coded as “monetary,” “gift card,” “type of gift card,” such as local store, Visa-type. The passage would include additional codes based on the context, such as rationale for compensation and factors in determining the amount and type of gift card.
Each participant summarized their research experience. Two of the three provisional codes for type of research were used: biomedical and behavioral-social science to categorize the participants’ research background. Due to the small N, no additional coding was completed for department-level information. These two provisional codes were also attribute and descriptive codes. In addition to describing the type of research they conducted, some participants referenced the type of research during their responses related to the compensation strategies they employ. Table 13 presents key findings by participant. Some participants focused on their definition of compensation and how that is integrated into the compensation strategies, while others focused on participant motivation and other ethical issues that interface with compensation.

Table 13

<table>
<thead>
<tr>
<th>Participant</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Compensation is a token of appreciation, “an honorarium almost.” Participating in research is an opportunity that is offered; compensation is a “thank you” and a chance to “make it a little bit easier for you to participate.” Compensation offered when visit to institution is for research – to reimburse transportation costs.</td>
</tr>
<tr>
<td>B</td>
<td>When offering compensation via gift card, chose specific store gift cards because “everybody needs groceries…or gas station.” “Compensation can be as personalized as possible based on your research participants.”</td>
</tr>
<tr>
<td>C</td>
<td>Individuals involved in decision making, “I think it starts as one person.” “I think it’s a team effort, kind of a longitudinal team where multiple people look at it.” When discussing voluntarism, “[I] think it’s the balance of what you’ve got coming down from a budget, where you feel like you can justify to a scientific community as well as an ethical community, and then trying to be realistic with what is fair to the participant.”</td>
</tr>
<tr>
<td>D</td>
<td>Expressed concern regarding the consent process, “It takes more time to read the information sheet than it does to run the entire experiment,” and applying the medical model to behavioral research.</td>
</tr>
<tr>
<td>Participant</td>
<td>Key Findings</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------</td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>Provided rationale for increasing compensation after study initiated. “[W]e looked at the effort and thought, ‘They’re putting a lot of effort forward; let’s give them more money.’” Shared that participants may not want to provide SSN for reimbursement.</td>
</tr>
</tbody>
</table>

**F**

Compensation acknowledges the participants’ contributions and that “a lot of people would participate in research even if it was uncompensated.” When providing information on how compensation is determined: “I don’t usually have a formula…I have an idea in my head how much the subjects need to be compensated, and I usually try to make sure we have enough money to do with what I had in my head.” Acknowledged that the compensation may personally “sway” to participate in a study: “I think that it’s important. It’s not coercive, but I’m just thinking, ‘Oh, a little extra money in my pocket for doing what I think I should be doing anyway,’ so that’s a nice incentive.”

**G**

“I think any primary data collection when you’re asking people for their time, I usually try and compensate if I have the funds to do it.”

**H**

“When you got to cut your budget, that’s one [compensation] of the first things to go.”

**I**

“If we really want to incentivize a study then we’ll do a monetary payment that might be a bit higher.” Participation in a research study as part of the class, such as one method of extra credit, increased retention/avoided attrition. Compensation should be provided when you “disrupt someone’s life to do research.” Compensation strategy factors were developed: “over time and negotiation with the IRB we’ve come up with these monies, amounts.” Determine purpose of compensation: “You have to think about how compensation is actually part of the study itself and how it’s tied to independent variables.”

**J**

Defining compensation: “I think of compensation for research as what you’re going to provide to the subject for taking the time and effort to do the research study. It can take lots of different forms.” Regarding amount determination, “I do a lot of comparison of what we’ve paid before for studies like that and what, maybe going forward, we should pay for that, for compensation.” When individuals are primarily motivated by money: “you do get the occasional person that you know looks for studies for money. I think you have to be really careful with that.” “You do have people that sometimes tell you they’re not in a specific study and then you find out when you go in that they in fact are.” “Compensation is a huge part of studies.”
Multiple codes were applied to compensation. Some participants provided a concrete definition, yet the definition of compensation appeared more fluid as participants discussed compensation from multiple perspectives, such as type of compensation offered, describing the type of compensation. The emotion and values were frequently intertwined when the participant presented a passionate perspective that compensation shows appreciation and when compensation is used to achieve recruitment goals.

Participants comingled the concepts of compensation and reimbursement, but in a way that led to a layered and thorough response to all three research questions. Contrarily, the noncompensation human subjects issues related more strongly to the ethical challenges academic researchers faced and also led to discussion of strategies for
improving compensation practices. The eight major themes identified covered the three study research questions and are presented in Table 14.

Table 14

\textit{Major Themes and Subcategories}

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compensation defined</td>
<td>(a) Payment to participant</td>
</tr>
<tr>
<td></td>
<td>(b) Appreciation/recognition</td>
</tr>
<tr>
<td>Rationale for compensating</td>
<td>(a) Recruitment and retention/avoiding attrition</td>
</tr>
<tr>
<td></td>
<td>(b) Appreciation of participants’ contributions</td>
</tr>
<tr>
<td>Compensation factors considered</td>
<td>(a) The burden to the person participating in the research</td>
</tr>
<tr>
<td></td>
<td>(b) Constraints to conduct the study</td>
</tr>
<tr>
<td>A combination of compensation and reimbursement discussion and decisions</td>
<td></td>
</tr>
<tr>
<td>Collaborative effort in research participant-compensation decision making</td>
<td></td>
</tr>
<tr>
<td>Ethical concerns related to compensation</td>
<td></td>
</tr>
<tr>
<td>Participant motivation to volunteer for studies</td>
<td></td>
</tr>
<tr>
<td>Non-compensation issues related to human subjects research</td>
<td></td>
</tr>
</tbody>
</table>

The interview structure provided participants the opportunity to share their thoughts, which frequently incorporated noncompensation issues in addition to those directly addressed by this study. All participants discussed ethical practices and concerns. For example, one story—related to parking reimbursement—touched on aspects of all three research questions: defining compensation, issues of voluntarism, and suggestions for the IRB. In this way, the interview format elicited rich descriptions of participants’
experiences and observations concerning compensation and the related ethical considerations.

Field notes were another source of empirical data that added additional context and nuance to the findings of the study interviews. For example, notes about my own level of *uncomfortableness* showed that my discomfort tended to rise when (a) I perceived the participants addressed the question posed but then shifted their response to complain about their interactions with the IRB; (b) when the participants (with whom I had worked with professionally) requested specific guidance related to IRB rules and regulations during the interview; (c) when the participants requested I provide specific feedback to my dissertation chair in his capacity as IRB chair; and (d) when the participant wanted to illustrate their answer with an IRB decision related to a specific study decision by demonstrating how the study design worked.

Descriptive Analysis of Ordinal and Nominal Data

Descriptive data analysis for the one-to-one interviews consisted primarily of ordinal and nominal interview-response data. This analysis captured the fundamental characteristics of the participants and research designs represented by these participants and established the setting for the findings. Descriptive statistics were conducted on research design and type of compensation data, as well as other numerical data points.

Biomedical and behavioral-social science researchers use the intervention study design. As 11 of the 16 participants were affiliated with biomedical research studies, it is not surprising that 12 participants discussed studies that involved more than one study visit (see Table 15 for details). Multiple study visits frequently occur in clinical trials involving both experimental drugs and devices. Eleven of the 16 participants discussed
studies with an intervention, while seven participants discussed non-intervention studies. The majority of the participants referenced both types of study designs. When asked if they had experience with requiring participants to attend one study visit or multiple study visits, twelve participants replied yes, while six had only carried out studies involving one-time visits.

Table 15

<table>
<thead>
<tr>
<th>Visit and Intervention</th>
<th>Drug/Device/Other Intervention</th>
<th>Non-Intervention</th>
<th>One-time Visit</th>
<th>More Than One Visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>11</td>
<td>7</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

The rationales provided by participants aligned with the rationales discussed in the literature. Overwhelmingly, participants explained that they offered monetary compensation to encourage recruitment, foster retention, and avoid attrition, echoing the reasons noted in literature. Participant I offered one example of this, stating that if a researcher needed to increase enrollment in a study, one option would be to “do a monetary payment that might be a little bit higher” to incentivize participation. Participant G explained that for funded studies, “I try and think what is the most I could give that people would think would be reasonable. Because I just think it’s so—it is so hard to get people to respond.” This participant anticipated greater recruitment response rates in response to higher amounts of compensation offered.

However, not all participants offered compensation as a method of improving recruitment and retention and avoiding attrition. In fact, some of the participants were quite emphatic in expressing their view that compensation was a way to show appreciation and acknowledge the contributions of research volunteers, rather than a tool for boosting recruitment. Similar to the rationales researchers have published, Findings
from this study parallel rationale reported by other researches, generally supporting the idea that researchers offer compensation for two primary reasons: (a) an enticement for recruitment and to foster retention/avoid attrition, and (b) appreciation for their participants.

Eleven of the sixteen participants cited recruitment and enticement as rationale to offer compensation. Retention and avoiding attrition was the next highest rationale provided, followed by appreciation and recognition. Five participants indicated they consider the amount of burden to their participants when determining the compensation amount. Table 16 summarizes the participants rationale for offering compensation.

Table 16

<table>
<thead>
<tr>
<th>Rationale for Compensating</th>
<th>Appreciation/ Recognition</th>
<th>Recruitment/Enticement</th>
<th>Retention/Avoiding Attrition</th>
<th>Depends on Type of Study/Participant Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>4</td>
<td>11</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

When discussing the key factors they took into consideration when choosing a compensation strategy, the participants generally mentioned time, participant effort, risk, invasiveness, pain, embarrassment, financial burden to the participants, and budget constraints. These tended to be the main factors participants considered when developing their compensation strategy, regardless of whether or not they used compensation for recruitment and retention or for appreciation.

One of the participants explained that in their experience, the term retention is generally used for biomedical studies, while avoiding attrition is used in behavioral-social science literature. While this might be just a difference in terminology between the two areas, it was intriguing to note the tendency of biomedical researchers to focus on
encouraging participants to stay in the studies, while behavioral-social science
researchers focus on keeping participants from leaving the studies. Generally, the priority
or weight of the factors considered when designing a compensation strategy was
dependent on study design and financial restraints as well as study pool characteristics.

Table 17 presents the type of compensation referenced during the semi-structured
interviews. The primary monetary compensation method was by cash and check, while
nonmonetary compensation exceeded gift card payments. The descriptive analysis of the
type of compensation and rationale to offer compensation was similar to findings already
reported in literature. However, it is important to remember that the N for this study was
16, and the percentages reflect these 16 participants.

Table 17

<table>
<thead>
<tr>
<th>Compensation Method</th>
<th>Percentage</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash/Check</td>
<td>75%</td>
<td>12</td>
</tr>
<tr>
<td>Gift Card</td>
<td>44%</td>
<td>7</td>
</tr>
<tr>
<td>Nonmonetary</td>
<td>63%</td>
<td>10</td>
</tr>
<tr>
<td>No Compensation Due to Benefit of Treatment</td>
<td>19%</td>
<td>3</td>
</tr>
</tbody>
</table>

Cash, including checks, was the most common monetary payment method for
compensation. At least half of the participants considered the participants’ time and effort
when deciding if and how much to compensate, including considerations of the
invasiveness, potential pain, and risk involved with the study procedures; travel-related
expenses; occupational issues, such as if the participant would miss work; and the
researchers’ constraints, namely the budget.

Overall, the numbers of studies discussed in the interviews providing monetary
and nonmonetary compensation were essentially equal. A few researchers said that they
opted not to compensate when there was an anticipated benefit to the participant for participating in the study. Some researchers offered nonmonetary compensation in addition to monetary compensation. These nonmonetary items included a bag to carry study supplies or cookies after the study procedure was completed. Other examples of nonmonetary compensation offered, either alongside monetary compensation or in lieu of it, included extra credit in a particular course, as well as the provision of items that were related to the study but not directly part of it, such as nonessential protective equipment.

Participant Interview Data Analysis Organized by Research Question

The findings of this research are presented by research question, with data gathered from participants’ answers to those questions. The themes that emerged from the data will be framed by the elements of complexity theory and/or slippery slope theory. The findings, unless otherwise noted, are from the transcribed interviews. The first question addresses factors researchers who represent multiple disciplines and research designs have considered. The analysis explores the data from a broader, systems approach, so complexity theory provides the foundation for the first research question.

Research Question 1

RQ1: When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

Complexity theory helps frame the findings about factors academic researchers consider and the different systems they must navigate as they make those decisions. Four of the eight themes address the first research question, which were analyzed within the context of complexity theory. The themes are organized into their corresponding
complexity theory elements. One theme, *compensation factors considered*, is explored within the context of more than one element.

The participants’ experiences included working with multiple PIs; carrying out varied study designs; leading studies that had received funding from federal, non-profit, and commercial sources; and carrying out non-funded studies. The collaboration between individuals tasked with compensation included working with individuals within their department as well as individuals from other disciplines. The participants who had worked in a variety of research settings involving multiple disciplines noted that compensation decision strategies varied by department and by individual investigator within departments. Table 18 highlights the application of complexity theory to the study findings and the themes related to this research question.

Human subjects research is a complex system. The first of four complexity theory elements applied to this research question is *human subjects research is a complex system*. Each of the study participants was part of human subjects research as a system, and one of the fundamental factors affecting their interaction with that system was their own view of compensation, beginning with how they defined the term. The term compensation, as defined in the first chapter, appears unambiguous, but the researchers who participated in this study provided multiple definitions for this ostensibly simple term. The compensation definitions, in general, illuminated one of two common themes: (a) payment to participant, or (b) appreciation and recognition. Variations of the definitions within each category occurred within disciplines and study designs.
Table 18

*Data Analysis by Complexity Theoretical Elements—RQ*¹

<table>
<thead>
<tr>
<th>Complexity Theory Element</th>
<th>Overall Findings</th>
<th>Major Qualitative Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Human subjects research is a complex system</td>
<td>Participants shared experiences that encompassed multiple study designs and disciplines</td>
<td>Compensation defined; Rationale for compensating</td>
</tr>
<tr>
<td>Key actors or systems: regulations and guidance, researchers, IRBs, participants, society, research design</td>
<td>Researchers, IRBs, regulations, participant, and conventions within disciplines were identified as key contributors in compensation decision making</td>
<td>Compensation factors considered</td>
</tr>
<tr>
<td>Regulations and interpretation of regulations are ongoing; communications occur within and between systems</td>
<td>Participants shared inconsistent IRB decisions and application of regulations to biomedical and behavioral-social science-based research, and researcher experiences with the IRB; some participants had multiple years of experience that spanned multiple disciplines and study designs</td>
<td>Compensation factors considered</td>
</tr>
<tr>
<td>Researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts</td>
<td>Participants initiated topics: variation of IRB determinations for language used in recruitment materials regarding compensation and the reversal of a previous IRB decision about what is considered compensation</td>
<td>Combination of compensation and reimbursement discussion and decisions</td>
</tr>
</tbody>
</table>

The basic premise of compensation as something provided to the participant was apparent in both biomedical and behavioral-social science research. The participants who defined compensation as money paid to participants or as something given to the participants, referenced multiple study designs and research being conducted by professionals representing various disciplines. Some definitions were more theoretical, while other researchers provided study-level examples that illustrated their definitions. The dynamic environment in which human subjects research is conducted means that
researchers must apply their definition of compensation to specific study scenarios involving real participants.

Some participants shared succinct definitions in which compensation was essentially defined as a payment to participate. For example, Participant P defined compensation as “monetary.” Participant N defined compensation in a more general fashion: “I think about something that I give you because you stopped and did this.” Similarly, Participant J considered research compensation to be "what you’re going to provide to the subject for taking the time and effort to do the research study.”

When the participants defined compensation as a type of payment to research participants, the payment included both monetary and nonmonetary compensation. Monetary compensation encompassed various payment options, including gift cards, e-vouchers and checks, parking vouchers, and drawings for monetary prizes such as gift cards. Nonmonetary compensation mentioned by the researchers included extra credit for courses, bags, pens, and other token items.

The majority of studies participants discussed involved monetary compensation as the primary compensatory method, although some researchers did indicate the use of occasional supplemental nonmonetary items. One common example was a sponsor-provided bag to help participants carry the research study supplies. Some of the study participants shared they provided their study participants food items, such as cookies and gum. For example, in some interventional studies, researchers provided participants with another type of protective device that was considered nonessential to the study but may have been appreciated by the participants. These interventional studies, conducted in several different departments, featured a variety of study designs. In the majority of
cases, the researchers who participated in this study did not consider supplemental nonmonetary items to fall under the definition of compensation.

Studies that primarily used nonmonetary compensation were behavioral-social science studies. Extra credit was a common nonmonetary compensation option noted in behavioral-social science disciplines. Researchers who did not participate in this study have shared that they used food, such as candy bars, and toys to compensate participants.

Another definition several interviewees offered for compensation was appreciation, which included recognition of study participants. When researchers defined compensation in this manner, they tended to include both monetary and nonmonetary compensation methods in their definition. Some of the participants indicated that they preferred not to use the term compensation at all, instead preferring the term appreciation. For these researchers, appreciation captured their intent, which was to show participants in their study that they were thankful for their contributions, using monetary or nonmonetary means. Participant K, for example, perceived compensation as appreciation: “I look at it as appreciation; that they're doing me a huge favor to be in my project.” Participant A supported this definition of compensation as appreciation, explaining it was “more of a thank you, a token of appreciation for somebody's time, an honorarium almost.” Participant P explained, “If I were going to compensate someone, that means it's equivalent to what they put into it. I don't think we're close. It's really just a token of appreciation.”

Participant P also suggested that carrying out the study in an efficient way could be one way to show appreciation, thereby expanding the definition of what might be considered compensation: “I also think it’s really, really important to think of
compensation to the patient as being able to do the study in an efficient way that isn’t [going to] cost the patient any more time than need be.” Beginning the study visit at the scheduled time and not making the participant wait were strategies participants indicated they used to show how researchers might demonstrate appreciation in a nonmonetary fashion.

These researchers’ reasons for compensating or not compensating volunteers in their study tended to intersect, and interact, with how they defined and thought about compensation. Frequently, the reasons for compensating mirrored the researchers’ definitions of compensation: (a) to achieve recruitment goals, foster retention, and avoid attrition; or (b) to demonstrate appreciation of participants’ contributions. These motivations align with compensation motivations presented in the literature.

For some researchers, their study design influenced their thinking about whether or not to compensate. Some indicated that they believed that compensating participants was especially important in studies that included the collection of primary data. Participant P, for example, stated, “If it is face-to-face, you should have compensation.” Likewise, Participant G indicated, “any primary data collection when you’re asking people for their time, I usually tend to try and compensate if I have the funds to do it.” Participant I shared a similar consideration, framing it within the idea of respecting the time that participants invested: “compensation for any time you disrupt someone’s life to do research should be given.”

Even within these finite rationales for offering, or choosing not to offer, compensation to study participants, there were many factors influencing how the researchers made their decisions. The diversity of study designs also affected the
rationale to offer compensation, including the variety of study procedures, study locations, study population characteristics, and time commitment. This further underscored the complexity of human subjects research as a system, and the ways in which that complexity affected how researchers thought about compensation and the decisions they made regarding it.

Key actors or systems. The second of four complexity theory elements applied to this research question is key actors or systems: regulations and guidance, researchers, IRBs, participants, society, research design. The key actors for this study were the participants, while, in the context of this study, the primary systems in which the participants took part included the University of Iowa and the participants’ various academic departments. Some of the participants were novice researchers, while others had decades of experience. Likewise, some participants had only been involved in one area of research, while others had conducted within multiple disciplines, with each discipline considered a system.

The participants’ definitions of compensation, and their rationales for compensating or not compensating participants in their studies established a foundation from which to explore their compensation decision-making practices and how those practices were affected by the systems in which they were carried out. Many of the participants defined compensation and provided multiple examples of how their definition was applied within the context of the studies and their interactions with their participants. These examples involved other concepts, such as recruitment, participant motivation to volunteer for studies, budget, and interactions with the IRB. Sometimes, the participants’ definitions were further underscored by the examples they offered, and their
idea of compensation stayed consistent throughout the interviews. In other instances, the participants’ definitions stretched and broadened as they discussed their compensation strategy in an operationalized context. In all cases, the participants’ decision making about compensation was multifaceted, with many systemic factors being taken into account. These factors included the researchers’ interactions with other human subjects research systems—namely, the IRB and the sponsors of the research project.

When participants developed the study compensation structure for a study, the factors they considered varied but fell into two broad categories: (a) the burden to the person participating in the research, and (b) constraints to conduct the study. The key categories for participant burden included: the study procedures, such as the level of risk; degree of participant embarrassment and pain; amount of time required; costs to participate; and timing of payments. The constraints to conduct the study were primarily budget-related but also included other issues, such as IRB decisions and the administrative process for participant payments. The degree of influence these elements had on the compensation determination included various ethical considerations, explored in more depth in RQ²: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

Many participants discussed participant burden in broader terms than what is outlined in the regulations, highlighting one way that researchers’ decision making about compensation and the various systems that influence it may be more nuanced and layered than current regulations suggest. For example, some interviewees discussed compensation from the perspective of the time participants must invest in the study. Participant N shared, “what I learned is when you’re giving compensation, you need to
consider what’s an adequate compensation for somebody’s time taken.” Similarly, Participant M reported that the compensation strategy for one study was based on whether the study participant was taking a day off work to volunteer.

Some participants described a more systematic method for determining compensation, though generally the standards still left room for variability in study design and purpose of the compensation—that is, whether the researcher used compensation as a form of enticement to participate or a way of showing appreciation for volunteers. For example, one PI considered if their participant would miss work and tried to compensate for missed income; however, a consistent, quantifiable wage-rate was not the ultimate factor to determine the amount. The findings of this study revealed that compensation determination strategies encompassed various elements of the four methods Grady (2005) presented, and that there was a divergence between Grady and the findings of this study. It is relevant to note that Grady found that the reimbursement method may ultimately have little impact on recruitment—though the data from this study are contrary, as research-related reimbursements such as food, travel, and parking were shown to influence recruitment and retention in some instances. Table 19 compares key compensation determination models with the findings from this study (Grady, 2005).
### Table 19

*Comparison of Compensation Determination Models with Study Findings*

<table>
<thead>
<tr>
<th>Model (Purpose)</th>
<th>Advantages/Disadvantages</th>
<th>Grady (2005)</th>
<th>Study Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market Model (Incentive)</td>
<td>Advantage</td>
<td>Rapid recruitment, encourages retention</td>
<td>Timing of payments and increased payments after initial study visit encourages retention</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Some participants volunteer to earn money; limited funding for many of the studies discussed</td>
</tr>
<tr>
<td></td>
<td>Disadvantage</td>
<td>Undue inducement, better-funded studies more likely to meet recruitment goals, different payments for multi-site studies based on locale</td>
<td>Some participants volunteer to earn money; limited funding for many of the studies discussed</td>
</tr>
<tr>
<td>Wage-Payment (Compensation)</td>
<td>Advantage</td>
<td>Less risk of undue inducement, uniform payment, recognizes participant compensation</td>
<td>Formula to calculate can be provided by sponsor, discipline convention, and modeled by previous studies; given to all participants of a study</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Motivation to participate includes both altruistic motivations and enticement of compensation offered</td>
</tr>
<tr>
<td></td>
<td>Disadvantage</td>
<td>May have little impact on recruitment; amount may under-compensate some and attract others</td>
<td>May have little impact on recruitment; amount may under-compensate some and attract others</td>
</tr>
<tr>
<td>Reimbursement (Reimbursement)</td>
<td>Advantage</td>
<td>Little risk of undue inducement</td>
<td>Important to many participants, influencing recruitment and retention</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limited funding influences if reimbursement and/or compensation can be offered</td>
</tr>
<tr>
<td></td>
<td>Disadvantage</td>
<td>May have little impact on recruitment; uneven reimbursements between subjects; financial lost if wages not reimbursed; reimburse wage costs may lead to targeting low-income populations</td>
<td>May have little impact on recruitment; uneven reimbursements between subjects; financial lost if wages not reimbursed; reimburse wage costs may lead to targeting low-income populations</td>
</tr>
</tbody>
</table>
Some of the compensation determination strategies discussed by participants in this study involved a formula based on the type or circumstances of the study procedure. Similarly, Participant J described studies that featured a compensation amount typically based on a standard of $15 per hour, but did also consider the compensation amounts for similar studies when making the calculation. Some participants also highlighted that these values could change based on various contextual factors. For example, the formulas could look different when the researchers were factoring in differences in target study.
populations. One interviewee, Participant G, shared that the determination strategy was “not set in stone” and cited a survey or interview that took approximately half an hour to complete, for which participants were paid $20; however, if recruiting subjects who were in a higher socioeconomic bracket, it was possible to offer $50.

Throughout the interviews for this study, it also appeared that researchers recruiting from a target population with a lower socioeconomic status considered reimbursement of expenses to be the greater priority, rather than the overall compensation amount. In this way, even when the researchers did have a formula available for helping them make decisions about compensation, the various systems in which they operated and factors within those systems—including departmental conventions, their awareness of similar research, their relationships with their study population, and their understanding of the study population’s characteristics—often changed the way they ultimately used or chose not to use those formulas.

Many researchers also described compensation strategies that were less formulaic. For Participant C, the compensation decision-making process began with one person but then expanded to a team effort, with multiple people examining the proposed budget. Participant F did not have a formula but stated, “I have an idea in my head how much the subjects need to be compensated.” Many participants echoed this sentiment, saying they often began their compensation determination processes with a general idea of the amount they would offer. Participant J indicated that considering past studies, similar procedures, and study procedures helped determine an appropriate compensation amount.

The constraints to conduct the study were primarily budget related but also included other issues, such as IRB decisions and the administrative process for
participant payments. Many of the participants in this study considered the risks to their participants when determining compensation; however, this consideration was tempered by budgetary concerns, often cited as a key constraint. The majority of the researchers who participated in this study identified study constraints, including the limited funds available for compensation after the basic costs were covered, as well as the difficulty of determining how much to compensate versus the amount of funds to designate for covering research expenses.

Regulations and interpretation of regulations are ongoing. The second of four complexity theory elements applied to this research question is regulations and interpretation of regulations are ongoing; communications occur within and between systems. The contextual application of the participants’ definitions of compensation demonstrated the complex nature of the at times intersecting, at times nested systems in which human subjects researchers must act. Decisions about compensation tended to become more complex in practice than in theory, regardless of the simplicity or ease with which the researchers were able to define the term. Despite the underlying consistency in how the participants defined compensation, there was significant variability in how compensation decisions were integrated into other aspects of the research study design (something discussed in more depth in RQ2: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

Overall, the participants tended to integrate their department culture and study participant characteristics into their definition of compensation and their compensation practices. However, this was complicated by the fact that some of the participants had worked with a variety of researchers in different departments.
Researchers design studies, yet the IRB can require changes. The fourth complexity element applied to this research question is researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts. This complexity element addresses the IRB’s influence determining what is considered compensation for a particular study. Participant I highlighted the importance of considering whether compensation type affects the dependent study variable: “You have to think about how compensation is actually part of the study itself and how it’s tied to independent variables.”

For some behavioral-social science studies, compensation is a part of the study design and can also be used as an enticement, which adds another layer to the compensation strategy development. The IRB determination of what amount is considered compensation may be different than the PI proposed. The interactions between the PI and IRB highlight the interdependent nature the human subjects research systems. The discussions and negotiations between the PI and the IRB expands beyond what is to be considered compensation to include how to present the monies used within the context of the research study. The nuances involved in this scenario are explored further in RQ²: What are the ethical challenges faced by academic researchers when determining research compensation for their studies? Compensation as part of the study design was not an issue raised by the participants in this study who conduct biomedical research.

Research Question 2

RQ²: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?
Elements of complexity theory and slippery slope theories frame the four major themes identified during the data analysis. Complexity theory frames the analysis to examine the broader research environment the participant engages in, which exposes similarities and differences between disciplines, departments, and research designs. Slippery slope theory facilitates analysis of the choices and the rationale offered by the participants to support their decisions. This dynamism and the complexity inherent in these challenging decisions became apparent as my participants shared study-level experiences.

The participants in this study raised ethical issues surrounding compensating individuals who participate in research and additional issues that intersect compensation. These issues are examined briefly from three complexity elements: (a) regulations and interpretation of regulations are ongoing; communications occur within and between systems, (b) researchers can work independently and/or within collaborative groups; issues within a system or subsystem can impact one or many systems/subsystems, (c) researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts. This broad examination by complexity theory aids in framing the perspectives shared while positing their antagonistic and collaborative approaches to operationalizing compensation activities compliantly. Table 20 highlights the study findings and major themes as analyzed from complexity theory.
Table 20

*Data Analysis by Complexity Theoretical Elements— RQ²*

<table>
<thead>
<tr>
<th>Complexity Theory Element</th>
<th>Overall Findings</th>
<th>Major Qualitative Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regulations and interpretation of regulations are ongoing; communications occur within and between systems</td>
<td>Participants shared inconsistent IRB decisions and application of regulations to biomedical and behavioral-social science-based research and researcher experiences with the IRB; some participants had multiple years of experience that spanned multiple disciplines and study designs</td>
<td>Ethical concerns related to compensation Non-compensation issues related to human subjects research</td>
</tr>
<tr>
<td>Researchers can work independently and/or within collaborative groups; issues within a system or subsystem can impact one or many systems/subsystems</td>
<td>Experiences of the participants included working with multiple PIs, varied study designs with both unfunded studies and studies funded by federal agencies and/or for-profit entities. The collaborations between individuals tasked with compensation at times were conducted within the discipline and other times included individuals from other disciplines</td>
<td>A combination of compensation and reimbursement discussion and decisions Collaborative effort in research participant-compensation decision making</td>
</tr>
<tr>
<td>Researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts</td>
<td>Participants raised various topics, including the range of IRB determinations for language used in recruitment materials regarding compensation and the reversal of a previous IRB decisions about what is considered compensation</td>
<td>Ethical concerns related to compensation Non-compensation issues related to human subjects research</td>
</tr>
</tbody>
</table>
Regulations and interpretations of regulations are ongoing. The first of three complexity theory elements applied to this research question is *regulations and interpretation of regulations are ongoing; communications occur within and between systems*. Participants who self-reported minimal research experience or limited experience with compensating participants expressed concern with establishing compensation amounts generally discussed compensation as an incentive and concern with undue influence.

The participants shared examples of their budget negotiations with sponsors. A study’s budget might include a specific amount of funding available for compensation on a per-participant basis or an overall amount provided to the study team for all costs. Researchers made decisions about their compensation strategies based on the funding available for participant compensation and reimbursement. Multiple participants voiced concerns over rising overhead costs, such as IRB fees without detailing impact by study design. Throughout the interviews, it often appeared that both the conventions of the participant’s particular discipline, as well as the guidelines of study sponsors, impacted a study’s compensation strategy. In one example, Participant D noted that, over time, the conventions within the discipline had shifted the compensation for a particular study design, from $3 to $5. Participants also shared their observations of the shifting of compensation type from cash to other monetary payment methods, but not generally did not specify the actual change in value. Some of the participants expressed concern with payment processing time by the institution. The participants shared their communications they had with potential study participants about the type of compensation and the timing of payments and concerns raised by potential participants.
Researchers can work independently or within collaborative groups. The second of three complexity theory elements applied to this research question is *researchers can work independently and/or within collaborative groups; issues within a system or subsystem can impact one or many systems/subsystems*. Participants shared examples of their collaborative efforts with other researchers as they sought input and advice when structuring compensation. These collaborations occurred within specific departments and with biomedical researchers in other disciplines and departments. In some instances, they collaborated with one another, sharing tips and past experiences for navigating parts of the process, such as budget negotiations with the study sponsor. In other cases, they independently addressed these steps, without any peer-to-peer collaboration.

Most of the participants combined compensation and reimbursement at some point during the interview. Participants also shared indirect examples, noting they did not have the personal experience but shared highlights from other researchers’ experiences. The context varied some, but generally assigning the amount of monies for compensation and reimbursement was a common thread that branched out into discussions on the ethical consequences.

Researchers design studies, yet the IRB can require changes. The third of three complexity theory elements applied to this research question is *researchers design studies, yet the IRB can require changes to the study design, such as compensation methods and amounts*. The participants shared that guidelines from their study sponsor or department norm, at times, constrain participant compensation options. The participants considered the type and degree of participant burden as the budget permitted. The participants in this study did not share if study sponsors considered participant burden
when determining the budget for participant compensations. The compensation agreed to by the researcher and the sponsor is reviewed by the IRB. The participants shared stories of the IRB requiring additional information and rationale for the compensation proposed and revising compensation based on suggestions from the IRB.

As noted earlier, human subjects research is dynamic, with multiple interactions occurring within a specific system and between many systems. Exploring the participants’ navigation of compensation issues from the slippery slope theoretical lens, provided additional insights into their decision making. Figure 1 (modified from Kirchler, et al., 2008) presents a two-dimensional graphic of slippery slope elements related to the level of researcher participation based on their relationship with the IRB. The greater the cooperation, the greater the compliance with the IRB.

Figure 1. Level of compliance.

According to slippery slope theory, taxpayers have either a synergistic or antagonist relationship with the Internal Revenue Service. Similarly, the participants’ relationships with the IRB exhibited this dichotomous relationship. The participants used the term collaboration when describing a synergistic working relationship with the IRB, so this synonym will be used during the discussion and analysis instead of synergistic.
The findings of this study revealed both types of compliance, with a high level of cooperation with the IRB. This relationship informs the general approach to working with the IRB and compliance with regulations.

By sharing specific examples of their interactions with the IRB, the participants’ approach to the IRB was apparent. For example, when participants spoke of inconsistencies of IRB decisions, they tended to describe the scenario in a negative context and frequently included noncompensation issues. Other participants shared their proactive approach, which involved seeking IRB input during the study design phase. Table 21 highlights the study findings and major themes as analyzed from slippery slope theory.

Even though participants had a propensity towards either a collaborative or antagonistic relationship with the IRB, their interactions varied ranged between the two spectrums. Similarly, the rationale for compliance varied dependent on the issue. In spite of the type of relationship, participants also shared experiences and concerns in a neutral manner. Neutrality was observed, for example, when some participants discussed complying with local context requirements when conducting multi-site biomedical trials. The participants identified different local requirements for compensation as an issue. The issues included the different local requirements regarding amount of compensation and type of payment, such as cash, check, and gift card. Local context issues require negotiating compensation, reimbursement, recruitment strategy, and consent language with the sponsor and the IRB. Due to variability in the participant-IRB relationship, the findings will be presented by ethical issues raised by the participants.
<table>
<thead>
<tr>
<th>Slippery Slope</th>
<th>Overall Findings</th>
<th>Major Qualitative Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher’s antagonistic relationship to IRB</td>
<td>Tended to be related to compensation determinations, such as how it was defined; regulations for reporting compensation as income; consent and recruitment language issues; and required documentation</td>
<td>Ethical concerns related to compensation Non-compensation issues related to human</td>
</tr>
<tr>
<td>Researcher’s synergistic relationship to IRB</td>
<td>Included proactive, collaborative compensation strategy development</td>
<td>Ethical concerns related to compensation Non-compensation issues related to human</td>
</tr>
<tr>
<td>Researchers comply with the requests of the IRB for study approval; researchers speak negatively about IRB in other settings, such as in classrooms and among other researchers</td>
<td>Participants, at times, verbalized compliance with regulations while voicing dissatisfaction with the required actions; the experiences shared were personal stories, without much information provided about how other researchers the participant works with views IRB directives</td>
<td>Ethical concerns related to compensation Non-compensation issues related to human</td>
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Ethical Issues Identified. Interestingly, the participants expressed antagonistic, collaborative, and neutral positions when discussing ethical issues. Regardless of the position, the following ethical issues and concerns that influenced, constrained, and otherwise affected their decision making about participant compensation:

- voluntarism,
- timeliness of payments,
- changing strategies after the study initiated,
- the researcher–participant relationship,
• the administrative issues, and
• compensation as a part of the research process.

These concerns revealed the tensions that arose as the researchers operationalized their ideas about participant compensation and moved from developing their compensation methods to putting them into practice within the systems in which they carried out their research. In some cases, these concerns also demonstrated the various, often dynamic, ways researchers interacted with the IRB and the collaborative or antagonistic relationships that developed as they worked with this regulatory body.

Voluntarism. The amount of compensation and reimbursement for studies is determined by numerous factors, all tempered by the goal of not compromising voluntarism. Participants in this study frequently used the term coercion when they were actually discussing undue influence. However, some acknowledged both issues using the corresponding terminology. For the purposes of this discussion, issues related to participant voluntarism include both undue influence and coercion.

For the majority of the researchers interviewed for this study, the primary method of compensation was monetary, and concerns about avoiding coercion and undue influence tended to arise while discussing monetary compensation. Although one participant, Participant E, did identify voluntarism as an issue when research participation was part of a particular course’s curriculum.

Participant L shared the struggles that arose when trying to find a balance between the amount of compensation and its influence on the individual’s choice to participate: “The balance, of course is, trying to make sure that it isn’t the compensation that’s causing them to participate.” Another researcher, Participant J, indicated a
particular concern about finding the right compensation amount to encourage participation and retain volunteers, while still avoiding undue influence:

It’s hard to get a subject to come back for a very small amount of money, $10.00 or $15.00. Sometimes I put $20.00 just to ensure that they’ll come back. That sounds like coercion but it’s—really, they have to be paid for their time. The University of Iowa Hospital is a pain to get in and out of. It’s really hard.

(Participant J)

The participants articulated concerns about the balance between the budget and ethical fairness, which includes being able to justify their approach to both the scientific and ethical stakeholders. Participant A noted that advances in medicine are gained from research, highlighting the importance of being able to successfully carry out research, including recruiting and retaining participants. Offering compensation is an opportunity to assist those participants or help them be able to participate. Together, these quotes begin to highlight the researchers’ awareness of conducting ethical research within the confines of the study constraints and not compromising the participant’s voluntary decision to participate, while also considering issues such as recruitment, retention, and participant burden.

Other researchers tended to think of compensation less in terms of enticement to volunteer and more as a way of expressing appreciation, but they did also discuss the motivations of their participants volunteering for the study. Participant F, for example, saw participant motivation in the context of researchers’ efforts to recognize their participants’ contributions:
I think a lot of people would participate in research even if it was uncompensated, but I think that we need to acknowledge the contributions that they are making to science and not just say, “Well, you’re getting treated at a teaching and research hospital, so we deserve to have this information about you.” I think it’s a way of recognizing their contribution. (Participant F)

Participant P, meanwhile, explained that, in their view, participants were generally not motivated by compensation, though compensation was still a way to thank them:

These patients originally do the study because they feel like they want to help—to improve their treatment and that’s the reason that I want them to go into it. But I feel like I need to compensate them because I’m asking an awful lot of them.

( Participant P)

Some of the participants in this study voiced the opinion that being a part of academia was in itself a rationale to participate in studies without compensation. However, this was not a shared belief among all faculty. In fact, as mentioned earlier, the lack of compensation was one reason a faculty member gave when declining to participate in this study. Even faculty who might otherwise participate in studies without compensation could find themselves motivated by compensation, when it is provided. Participant F shared a personal example of the enticement factor of compensation in recruitment:

I have to say that sometimes when I’m eyeing the ads in the noon news or whatever, if it says compensation provided, then sometimes that will sway me to participate or not participate. I think that’s important. It’s not coercive, but I’m
just thinking, “Oh, a little extra money in my pocket for doing what I think I should be doing anyway,” so that’s a nice incentive. (Participant F)

Some participants shared personal decision making for studies they considered enrolling in. Compensation was an enticement factor, but did not unduly influence them.

Timeliness of payments. The timeliness of payments involves two distinct considerations: timing of the payments based on completion of research study tasks and the processing of the payments to the participants. Determining the timing of the payments involved consideration of study constraints and participant needs. The timeliness of payment processing is generally presented from the participant burden perspective and its influence on both the participant and the researcher.

   The type of participant burden, and how researchers perceive that burden and factor it into their decision making about compensation, varied by study design. Participant O noted, “It all depends upon the type of study it is, the needs of the patient, and basically the condition that we’re studying.” Participant F considered time and “hassle factor” when designing a compensation strategy, noting,

   If you’ve got a group of patients and maybe they—you know that this group of patients has a tendency to not follow up…That would be, I think, a population of patients where some kind of compensation would be fair, but it would also be an inducement because it might be group of patients that don’t follow up.

   (Participant F)

   Similarly, Participant O noted that the implicit benefit to the participants, or lack thereof, influenced the consideration of how to compensate, explaining, “I’m [going to] pay more money to patients that are not getting any benefit out of doing the research.”
Participant O went on to describe an instance in which compensation was partially decided based on the specific study population and burden to the participant due to the nature of the study procedures. Understanding the general needs of their participants, and the burdens associated with their research study, provided a foundation for communicating compensation strategy proposals with the IRB.

Several participants referenced Phase I studies as presenting particular issues in regard to decision making about compensation. As defined in the literature review, Phase I clinical trials are the first testing of a new drug or treatment on humans. In the context of Phase I trials, according to Participant P, the amount of compensation is frequently increased when there is “absolutely no benefit” to the person volunteering to participate.

Other participants discussed clinical trials, without further specifying the phase. Also, in the context of clinical trials, Participant A proposed the idea that participant compensation should reflect the nature of the trial and the drug or treatment being tested, indicating, “We should offer more reimbursement if it's more noxious.” The specifics of the study design, coupled with the discipline and department convention, increased the complexity of the situation. However, participants voiced compliance with the regulations as directed by the IRB and in conjunction with the IRB.

In some cases, researchers used payment timing to encourage retention or discourage attrition. Participant E, for example, explained that one study was designed to pay participants part of their compensation before the study, while saving the final payment for after study completion: “Before they come, we will send them a portion of their compensation and then afterward, we send them the rest, so post-effort and pre-effort.” Similarly, Participant F shared an example of the prorating of visit payments.
based on retention, in which compensation for the two-year follow-up visit was twice the amount compared to compensation for visits occurring within the first year. As Participant F explained, “It’s a little added incentive at the end of it to follow this whole thing through.” The way Participant H saw it, the compensation itself served to recognize participants for their time, while the timing of that compensation served to encouraged retention: “They get paid after every questionnaire they return. They mail them back to me, so it also is a positive reinforcement to keep mailing the data back to me, so I get something. They get something.” Other participants described a graduated compensation structure for longitudinal studies, with an increased amount further into the study to promote retention. The type of study procedure, the length of the study, and study population characteristics are elements of “participant burden.” No consistency was found in participants’ rationales for considering these elements. Many participants discussed issues surrounding compensation, appreciation, and incentives in tandem with one another. Participant G, for example, considered incentives such as reimbursement when developing a compensation strategy that would encourage participation.

Some participants considered attaining recruitment and study completion goals when developing a compensation strategy, while others highlighted their considerations of participant burden and showing appreciation. When discussing participant burden, several researchers mentioned the impact delays in compensation payments to participants could have on study participants, thereby also affecting retention and participants’ potential decisions to volunteer for other studies. Participant L explained, “we’ve had people who were ready to quit our trials, because the turnaround time in our university was too slow.” In other instances, the participants’ expectations became an
issue because they anticipated payment the day of the study visit, something researchers could not provide. Participant A mentioned having heard participants ask, “Is there any way I can get it right away?” This tension between participant expectations and administrative realities could become complicated as researchers work to carry out their studies.

The expansion of issues, such as the time it takes for processing of the checks via the university system, illustrates how non-research processes intersect with compensation, impacting both the researchers and participants. Some of the researchers participating in this study provided gift cards to their participants after the study visit was completed. They noted that many of their participants preferred to receive payment immediately instead of waiting for a check to be mailed to them. For example, Participant B noted that for one study, the participants could opt for a Hy-Vee Grocery or Walmart gift card. Groceries and gas could be purchased at either of the businesses. Other participants were unable to utilize gift cards due to administrative constraints.

Participants shared a variety of concerns and issues related to compensation payment processes. The impact of the institution’s payment processing, compensation tax regulations, participant characteristics and preferences, administrative constraints, and transparent communications to potential study participants regarding the amount and timing of compensation and reimbursement during the recruitment and consent process were identified as issues researchers contend with regardless of study design and discipline.

Changing strategies after the study was initiated. Some participants shared ethical concern when compensation or reimbursement strategies were changed during the course
of a study. Participant G provided one example of this, in which an institution changed its policy regarding payment methods for study participants while a study was already underway. In other instances, research teams instituted changes in compensation or reimbursement mid-study. These changes were sometimes initiated due to participant feedback, such as requests for parking; in other instances, they were spurred by researcher observations. Participant E provided an example of a change related to the participant burden: “One study, in particular, we did increase the compensation just because we looked at effort and thought, ‘They’re putting a lot of effort forward; let’s give them more money.’”

Some participants verbalized ethical concerns related to the fairness of such changes. Participant M articulated one ethical dilemma that might arise in such a scenario, questioning how a research team member may feel when considering that some of their participants were not paid, while participants who joined later in the study did receive payment. Other researchers who participated in this study focused more on the impact of compensation changes on recruitment goal achievement, without raising the issue of fairness or other ethical concerns.

Researcher–participant relationship. Many factors can influence the researcher–participant relationship in a given study, including the researcher’s understanding of the study’s participant pool or the researcher’s ability to foster a working relationship with participants in a way that promotes retention and future participation. One participant in this study, Participant J, shared the importance of clear communication with participants about what the compensation or reimbursement amount would cover (such as clarifying
whether parking was included) and at which point in the consenting process they would receive compensation.

Participant K also focused on communication between researchers and participants, particularly during the consent process. According to Participant K, the consent process was a crucial step in building a relationship between researchers and participants, thus supporting the successful retention of those participants. Participant K used the consent process as an opportunity to address participants’ questions and concerns:

I try very carefully to lay out exactly what the study involves because I think the more a person knows what you're doing and why you're doing it, the more cooperative they are. I need people to lay still for an hour and a half. They have to be motivated. They're motivated because they understand that it's important, little things. I also, part of the consent project—process, I try to address things that aren't necessarily in the consent form but are real… I nurture them very carefully throughout the whole process. That's not compensation, but it's part of appreciation. (Participant K)

Understanding the needs and characteristics of their study populations and accommodating them were key areas the researchers discussed in relation to compensation and the larger framework of the researcher–patient relationship. When considering the targeted participant pool characteristics, Participant J wondered, “would you think that patient population would rather have the full amount, reimbursement cash or a check? Or would they rather have reimbursement in form of a check and then parking compensation for that day?” Participant B discussed personalization of
compensation in similar terms: “I think the big thing for me is that the compensation can be as personalized as possible based on your research participants.” Further exploring the idea that different participant pools may have different characteristics, Participant J noted that the pool of participants in Iowa tended to be loyal, something that could have impacted retention positively.

One of the participants in this study shared that the PI with whom they worked would not consider the money paid for reimbursement compensation, noting their participants were “an unusual population” that would be difficult to recruit and retain without reimbursement of their expenses related to participation. This illustrates how a researcher’s understanding of the participant pool might affect their thinking about compensation and reimbursement. For several researchers in the study, their understanding of the particular characteristics of their participant pool also had an influence on the type and timing of compensation payments. Participant O, for example, described a compensation strategy in which participants were generally compensated for most of their clinical trials, unless it was anticipated that the participant would benefit from the study, in which case no compensation was offered. This understanding of their participants’ preferences and needs framed their discussion of fine tuning a compensation and reimbursement strategy that can meet both the researcher’s and participants’ needs while maintaining the voluntarism of the individuals choosing to participate in the study.

Compensation as a part of the research process. The participants in this study frequently combined observations about both compensation and reimbursement into their discussion of their decision making about compensation. For this reason, researchers’
considerations of compensation and reimbursement, and how they intersected and interacted, form part of the findings for all three research questions.

Several factors led to many of the participants conflating compensation and reimbursement during their discussion of compensation methods, including the ethical issues surrounding the strategies to allocate funds for participant compensation and reimbursement, as well as the need to make satisfactory decisions with limited funding. On the topic of reimbursement, researchers participating in this study frequently shared the importance of parking reimbursement, noting this was highly valued by many of their study participants. This may be partially attributable to the challenges of parking and navigating the University of Iowa and University of Iowa Health Care and Clinics campuses, thus highlighting the importance of researchers’ understanding of the needs and expectations of their subject population. Parking may not be a concern in other locales—for example, urban areas where participants are more likely to arrive via public transit or on foot—but it is a primary consideration for researchers conducting studies at the University of Iowa. Some researchers, like Participant J, discussed parking reimbursement as a specific concern, while others integrated this topic into the broader issues of participant burden. Participant J explained:

Sometimes, because you need people to come back for repeat visits, if you don’t give them parking vouchers then there may be a time when they maybe can’t afford to park and so you have to make sure that they have parking compensation in there. Let’s say that the company is going to give you $60.00 a visit for those subjects. Sometimes we’ll do $55.00 for a check and $5.00 worth of parking vouchers. We wanted to make it as easy for these subjects to come back for repeat
visits as possible. The harder it is for them to come back, the less likely they’re going to come back. (Participant J)

Many of the participants discussed compensation and reimbursement in when the issues focused on the participant burden, especially delays in paying participants. Again, all of these considerations were affected by the context in which the researchers were making these decisions, including the specific characteristics of the research institution—in this case, the University of Iowa—and its geographical location, as well as the population of potential subject participants living nearby. Participant M revealed these multifaceted considerations when describing researchers’ access to study populations and its implications for compensation and reimbursement:

I think compensation is a good thing if it’s appropriate. Then, again, it’s not the end-all for people participating. We happen to live in a place that we aren’t highly populated and, for certain diseases, we may bring people into our academic center from all over the world. By providing some reimbursement for travel, if the finances are there, I feel it’s very viable for what we’re doing, in particular, because the population may be such that they’re already tapping all sources and support systems to be able to live. How do you differentiate that from someone who might live across the country and wants to come participate in a trial here? Does that create an issue? (Participant M)

Budget. Throughout the interviews, almost all of the participants mentioned budget as a key constraint to compensation. When discussing budgetary influence, some participants shared that once overhead costs and reimbursement for expenses, such as parking, were integrated into the study design, there was not much left over for
compensation. Participant M explained, “By the time you get done with that, sometimes, there isn’t anything to provide, other than, maybe, a parking pass.” Likewise, Participant H pointed out that compensation was not a top budgetary priority: “When you got to cut your budget, that’s [compensation’s] one of the first things to go.” In one instance, a researcher mentioned diverting study funding to compensate participants instead of completely supporting their own salary. Researchers also mentioned that a study’s sponsor could influence how much money was available for compensation and reimbursement. Participant J, for example, shared that sometimes, the funding source had a set dollar amount they would pay for reimbursement of travel expenses, but in other instances, reimbursement could be decided on a case-by-case basis.

Generally, researchers talked about ethical challenges related to participant burden to the participant as they discussed both compensation determinations and other aspects of study design. Often, these researchers described searching for a way to balance the compensation amount with recruitment and retention goals, budgetary concerns, regulatory considerations, and their desire to acknowledge the contributions of the individuals who volunteer to participate and offset any costs those participants must incur.

Administrative issues. A common administrative issue related to participant compensation participants raised was related to the collection of Social Security numbers (SSNs) for participant payment processing. The issues with collecting SSNs generally fell into two categories: (a) study participants’ hesitancy or refusal to provide the numbers; and (b) the administrative tasks required for SSN collection and submission for payment processing.
Per federal tax mandate, researchers are required to collect participants’ SSNs when the payment amount exceeds certain compensation thresholds. However, not all participants want to provide this information. Several of the participants talked about having worked with participants who did not want to provide their SSN, or even particular study populations who tended to be averse to sharing this information. In these instances, researchers described taking this into consideration when developing their compensation strategies, with the goal of ensuring that they kept the compensation to a level that did not require collecting SSNs. Participant E, for example, worked to ensure the compensation strategy would not exceed the reportable level, regardless of the effort level on the part of the participants—based on the understanding that participants valued not providing SSN information more than they would value additional compensation. Participant K shared the process of documenting and protecting the participant’s SSN, noting the importance of explaining this carefully during the consent process, so the person enrolling in the study understands that, to receive payment, they will need to provide their SSN.

In addition to the willingness of participants to provide their SSN, researchers must follow the processes detailed in the research application that the IRB reviewed and approved. Researchers are responsible for maintaining the confidentiality of the personal information collected on their subjects, which includes the SSN. For some researchers, collecting SSNs also led to complications for their studies, as the collection of SSNs began after the study was initiated. Participant M experienced issues that arose when it became necessary to collect SSNs later in the research study process:
One thing that I ran into is you can have everything planned out with your project and then, you find out that the income of the participant—as a coordinator and as a PI, you’re focusing on the research and then, it’s, like, oh, well, gee whiz now, you’re over the income level, and we have to pursue a W-9 form for tax purposes … Then, the participants hmm, hawh, I don't know if I [want to] sign this. If they don’t, then we can’t compensate them, and you’re in the middle of a trial.

(Participant M)

The majority of participants who discussed the collection of SSNs identified both the participants’ hesitancy to provide this information and the additional administrative burdens placed on the research team in the collection and protection of this information. Many of my participants discussed their processes for adhering to required reporting elements but tended to complain about what they considered an “IRB mandate.”

Collaboration between researchers as a strategy encompasses more than compensation questions. The participants in this study tended to have a starting point from which they began the compensation determination. This included who was involved in who began the compensation strategy development. For many participants in this study, the first steps of developing a study compensation strategy began with one individual, though a few participants described collaborative processes that featured discussion among multiple individuals from the start. Despite the fact that, in many cases, the initial compensation development had begun as a solo effort, it frequently expanded to include other individuals, such as study coordinators and other research team members with compensation determination experience.
Sponsors, at times, provide the initial starting point for compensation strategy development; in others, it was a convention of the discipline or was based on previous studies with a similar study design. At times, unit leadership influenced compensation strategies. In one example, Participant N noted that the department encouraged researchers to provide nonmonetary items both as “giveaways” and as “research incentives,” citing the department’s outreach focus and federal funding. Sometimes, participants considered the ethical implications of “giveaways.” Participant M noted that if a branded pen was provided by a study sponsor, it might be offered to participants for use in completing a questionnaire but was not given as a “gift for their time.”

The majority of the participants discussed compensation for a specific study with other researchers who had experience in developing compensation amounts for studies. Participants shared the highlights of these collaborative discussions, focusing on how the conversations assisted in their process of developing their compensation strategies. However, they did not provide any substantive insight into how these researchers viewed or interacted with the IRB. Researchers’ relationships with the IRB and the collaborations in designing elements of a study provide a foundation to explore the final research question.

Research Question 3

RQ3: How, from the perspective of academic researchers, can compensation practices be improved?

The third question was meant to encourage participants to provide ideas to improve compensation practices, especially ideas directed toward the IRB. Slippery slope
theory framed the perspective for data analysis because the focus was on the individual, not how the system was influenced by the decisions.

This question did not yield many data when compared with the first two questions. Generally, interviewees were unaware of the types of changes that would likely be associated with the approaching revisions to the federal regulations or researcher education initiatives the IRB might be able to implement. A few of the participants chose not to offer suggestions related to the IRB, while other participants offered general recommendations. Table 22 summarizes elements of slippery slope theory and the findings derived from RQ³: How, from the perspective of academic researchers, can compensation practices be improved?

Table 22

*Data Analysis by Slippery Slope Theoretical Elements— RQ³*

<table>
<thead>
<tr>
<th>Slippery Slope Element</th>
<th>Overall Findings</th>
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<tbody>
<tr>
<td>Researcher’s synergistic relationship to IRB</td>
<td>Included proactive, collaborative compensation strategy development</td>
</tr>
<tr>
<td>Researcher’s antagonistic relationship to IRB</td>
<td>Tended to be related to compensation determinations, such as how compensation was defined, regulations for reporting compensation as income, consent and recruitment language issues, and required documentation</td>
</tr>
<tr>
<td>Researchers and IRB proactively discuss issues and concerns during the application process; IRB offers presentations addressing human subjects research issues, which are open to researchers and staff involved in research processes</td>
<td>Requests for consistent definition and use of key concepts, such as whether IRB included reimbursement in their wider definition of compensation; requests for best practice guidelines, such as suggested types and amounts of compensation for different types of research designs</td>
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The slippery slope tenet related to proactive communications and IRB educational opportunities included participants representing antagonistic and collaborative
relationships with the IRB. The type of relationship the participants had with the IRB was most evident when the participant presented suggestions by providing examples of interactions they had had with the IRB related to (a) reporting of compensation and (b) auxiliary issues, such as consent and recruitment language.

Trust in authorities is a part of the synergistic relationship between the individuals representing the bureaucratic perspective and the end user. As noted earlier, my participants used the term collaboration instead of synergistic. Participant C indicated a collaborative aspect to the researcher–IRB relationship, saying the IRB’s input was generally valuable to researchers:

I always say their input is always welcome. I don’t think I’ve ever had an IRB comment, “Oh, that’s too much,” or “That’s too little.” It’s more that they ask a procedural, “Do you need their Social Security Number?” … I would not mind the IRB saying, “How’d you come up with that compensation? Do you think that’s too much? Have you thought about compensation?” (Participant C)

Participant J addressed the need for more general guidance on the types and amount of compensation that take into consideration our local culture and expectations. Participant A echoed this sentiment: “I think that their [IRB’s] role can be helping to determine whether that’s an appropriate—an appropriate degree of compensation has been chosen or an appropriate method that has been given is chosen.” Participant A also noted that they hoped that the IRB understood the importance of continuing with compensation generally, in order to recognize “the sacrifices that people make to participate in research.”
Though participants in this study generally shared experiences related to specific studies, some mentioned that they had sought IRB advice to establish a compensation strategy that would be applied to studies with a common, underlying design. Participant I, for example, shared that collaborative interactions with the IRB helped to establish a compensation strategy that could be applied to multiple studies of a similar design. This collaborative effort involved multiple interactions.

Generally, researchers expressed varying levels of guidance they would like to see from the IRB when making decisions about participant compensation, reflecting the varying and dynamic ways they viewed the researcher–IRB relationship. Participant B shared the importance of flexible compensation guidelines: “I think trying to keep it as personal to the study and to the budget and to the participants as possible I think is really important—not setting these really strict guidelines.” Participant J discussed general guidelines but did not mention any strictly defined rules to assist in the determination of compensation amounts. Participant B, on the other hand, suggested, “Anything that could aid researchers in the future knowing—and the IRB—knowing what’s an appropriate amount of compensation. It’s not just not coercing people, but we also [want to] reimburse people for their time.”

The stories shared by researchers who had a collaborative relationship with the IRB tended to highlight the guidance they had received, pointing toward ideas for additional researcher direction and education the IRB might consider. Participant J suggested the IRB could provide more guidance and offer more opportunities for open, clear conversations with researchers:
It’s just better guidance … When I talk to you about reimbursement or compensation, we’re talking the same language and we have a definition. Even if we’re not talking the same language, you can say to me, “Are you saying this? This is what I call reimbursement. Is this what you’re talking about?” I could say, “Oh, no. I’m talking about this.” If I know what your—if I know what the definition is or you know, then we can have a better conversation.

[Compensation] is a small part of working with the IRB. (Participant J)

As Participant J suggested, a common language is key for this education and communication to work. Another participant touched on the issue of language, and a need for common terminology in communication with and education provided by the IRB as well. This participant expressed their desire for a common understanding between researchers and the IRB regarding terms and compensation language required in the consents.

The lack of consistent language challenges effective communications between researchers and IRBs. To work collaboratively, the IRB and researchers must understand each other. Some hurdles to developing this common language became apparent in the interviewees’ use of particular terminology. Similar to use of terms in published literature, some of the participants used compensation and reimbursement as synonyms, and others use coercion and *undue influence* to describe the same issue.

Many of my participants expressed a desire for more information from the IRB, either about the reasoning behind specific application of regulations or ways the researchers might improve their decision-making processes around compensation and other issues. For example, one participant shared an example when the IRB requested
the PI to add specific language to the participant consent form without providing the rationale for the request or a reference to the applicable regulation.

An extension to common language is the transparency of IRB requests for changes. Some of the participants acknowledged educational opportunities, such as IRB presentations addressing various regulatory and ethical issues. However, participants also requested transparency by the IRB, that requests for revisions should include the rationale for the requests. Participant F suggested the IRB should do what they could to “make sure that people know why these rules are in place.”

Likewise, several participants shared their concerns regarding voluntarism, at times identifying the need for additional guidelines and information from the IRB in order to make good decisions and maintain participant voluntarism. Participant N noted that the lack of information from the IRB about how to ensure compensation offered would not unduly influence the potential volunteer:

I think there’s not a whole lot of information or training given on that; on where is that balance. Where do you draw the line? What’s too much? How do you know what’s enough? I don’t feel like we were ever really given that training.

(Participant N)

Participants indicated an opportunity imparting information that could be useful to researchers while making these decisions regarding appropriate and ethical compensation.

Researcher’s antagonistic relationship to IRB. Researchers design studies, but the IRB can require revisions based on human subjects research regulations, such as wording of recruitment materials and consents. Depending on the relationship the participants had
with the IRB, their perception varied from helpful or hindrance. For participants who had more antagonist for the IRB to foster this collaborative relationship with researchers by transparently relationships with the IRB, they tended to voice the additional burden placed on the research team, rather than learning the rationale for the request.

Some of my participants expressed concerns that the IRB and institutional bureaucracy present barriers to conducting research, referencing participant compensation, reimbursement, and other issues. When queried on what they thought the IRB should know regarding participant compensation, interviewees’ suggestions ranged from stating concerns to sharing the importance of compensation and IRB member experiences. Participant G, for example, stated, “Well, obviously, hopefully they know how important it is. I don't think … it’s hard enough to get a response rate these days even with adequate compensation.” Participant A shared that the IRB needs to understand that the rationale to offer compensation varies between research studies and that the IRB’s role should be to assist the researcher in determining the appropriateness of the type and amount of compensation.

While discussing reimbursement of study participants, one researcher, Participant L, summarized an overall antagonistic view of the IRB: “mostly we’re fighting the bureaucracy to try to accomplish what we think is the best for our patients.” Participant B shared a similar sentiment: “It’s sort of like the IRB is preventing that path from crossing sometimes in a way that I don’t think is getting those participants to us and us to them, if that makes sense.” Participant B saw the importance of keeping compensation from having a coercive effect but also shared concern about the nature of IRB decisions regarding this ethical issue:
I feel like people are for the most part, unless they’re a special population, are able to make these choices about whether to participate or not or refuse. I feel like the IRB sometimes gets in the way of that free—it’s a little bit paternalistic, I guess, of the research participant in a way that I don’t think helps research.

(Participant B)

Participants shared compensation is not an isolated event, but rather a part of the research process that includes many additional ethical concerns. Some of the issues may intersect with compensation, others influenced other aspects of human subjects research.

Non-compensation issues. When asked what they wished the IRB knew or understood, multiple participants discussed concerns when IRB required the collection of SSN when compensation amounts exceeded a defined threshold. The requirement to provide SSNs for taxable income is a federal tax code requirement. The IRB’s role in requiring consent language to meet local context requirements is likely the source of confusion. Despite having its origin elsewhere, this bureaucratic regulation did seem to have an impact on the researchers’ relationships to, and interactions with, the IRB. Some participants also expressed their personal opinions that research participants should not have to claim research compensation on their taxes, arguing that taxes on compensation was a form of penalizing volunteers for participating in research. These participants did not elaborate further.

Another concern raised by many participants was the consent language requirements. Participant D presented an example expressing the concern that the consent process took longer than the study procedure itself: “the consent information sheet is longer than the experimental instructions and takes more time to explain.” A few
participants shared their concern about the appropriateness of applying a medical model to behavioral research, referencing issues the consent; however, they did not provide suggestions for a behavioral model that might offer an appropriate substitute.

Additionally, participants raised concerns and reported frustration that all consent changes to consent language must undergo IRB review prior to implementation, especially when they considered the changes insignificant—for example, changing the word triple to three times. Their perspective was that the IRB’s focus is on protecting the institution and protecting the participants from undue influence at the expense of focusing on supporting researchers and issues specific to community-based research. These concerns were not a common finding in this study but do highlight additional issues that may intersect with compensation decision making.

Some participants expressed concerns when they believed that their study participants could be motivated by monetary compensation. Participant J explained that there might be a volunteer for a study “that you know looks for studies for money. I think you have to be really careful with that.” Participant J also shared an experience of a participant not disclosing participation in other research studies, something cited in the literature as a behavior of professional study participants who may break study rules in order to participate in more studies:

You do have people that sometimes tell you they’re not in a specific study and then you find out when you go in that they in fact are. That can really either skew results, even if it’s an observational study there’s some—other observational studies that don’t want anybody in something else. (Participant J)
These participants did not share additional thoughts and actions implemented when an individual appears to be engaging in deception during the recruitment process. The participants who conducted behavioral-social science research did not reveal issues with professional study volunteers in their studies.

The majority of participants they shared experiences from their researcher roles. However, some participants in this study shared their personal experiences when considering enrolling in a study. They shared their interpretation and noted that compensation did not unduly influence. They reviewed compensation amount with their interpretation of risk and noted they would enroll in a study regardless if compensation was offered. For example, Participant E shared a personal experience with volunteering for a research study that included compensation: “I was compensated on an hourly rate, which is great, because people who take the full hours, then they’re getting a little bit more for the work.”

These personal examples of motivation are outside the scope of this study. However, the degree personal beliefs in compensation may influence compensation strategy decisions, even though not self-revealed by the participants.

Summary

This study explored designed compensation decision making by academic researcher. However, the participants expanded the discussion to include additional issues within human subjects research, which included the working relationship with the IRB. The type of relationship researchers had with the IRB (collaborative or antagonistic) not only influenced compensation decision-making processes but also had an impact on other areas of their human subjects research practices.
Throughout the interviews, the participants voiced the underlying desire to conduct ethical research and protect the voluntarism of study participants. The participants offered thoughts about their learning needs and suggestions as to how to improve compensation practices at the University of Iowa. The participants also revealed further questions and gaps in knowledge about compensation decision making, supporting the need for continued research. The next and final chapter discusses the study findings as it relates to current literature and the applicability to current and future research.
CHAPTER 5
DISCUSSION AND IMPLICATIONS

The purpose of this qualitative research study was to explore compensation from the perspectives of academic researchers. A total of 17 academic researchers participated in this study and the data analysis included 16 semi-structured interviews. The participants represented biomedical and behavioral-social science disciplines and were either the PI or had been designated with the task of making compensation-related decisions for a research study. Three research questions formed the basis for the interviews:

RQ\(^1\): When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

RQ\(^2\): What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

RQ\(^3\): How, from the perspective of academic researchers, can compensation practices be improved?

The semi-structured interview format facilitated the collection of thick, rich data. In the previous chapter, findings were presented research question and organized by the two theoretical frameworks. This chapter presents the theoretical contribution of those findings, along with the findings’ implications, the limitations of this study, recommendations for further research, and a conclusion.

Exploration of Findings

Compensation is an integral part of human subjects research, but it involves ethical considerations due to its potential impact on the participant’s voluntarism. The
following eight major themes during the data analysis: (1) compensation defined, (2) rationale for compensating, (3) compensation factors considered, (4) a combination of compensation and reimbursement discussion and decisions, (5) collaborative effort in research participant-compensation decision making, (6) ethical concerns related to compensation, (7) participant motivation to volunteer for studies, and (8) non-compensation issues related to human subjects research.

Compensation defined. Despite the lack of a common participants clearly defined compensation as (a) a type of payment to their research participant, and (b) a way to show appreciation for and recognize the individuals who participate in their studies. Compensation defined as a way to show appreciation for research participants’ contributions was not found in the literature. Though the participants generally expressed these definitions with clarity, when asked to operationalize their definition in the context of their compensation decision-making decisions, the distinctions tended to become more muddled.

Despite the lack of a common definitions, in general, the participants tended to describe the idea of compensation as a payment offered to individuals agreeing to participate in a research study. The majority of study participants noted that monetary compensation was the primary payment method of compensation. However, participants generally used the term payment for both monetary and nonmonetary items, even when appreciation was a part of their definition or rationale to offer compensation.

Similar to the participants who defined compensation as payment, the participants who defined compensation as appreciation, shared how they determined the amounts, ethical considerations, and external constraints. They simply preferred to frame the
discussion as appreciation rather than payment. Compensation defined as appreciation was not found in the literature.

The simplicity of the researchers’ definitions of compensation was in sharp contrast to the complexity and multifaceted nature of their compensation decision making. This diverseness, along with the feedback loop between the participants’ definitions and their rationales for compensating or not compensating, was one of the more interesting patterns to emerge from the interviews.

From the analysis of the compensation definitions, I have concluded that the definition of compensation is not fixed in time and place. Thus, the circumscribed definitions provided by the participants became convoluted as they shared operationalization of their definitions.

Rationale for compensating. In the current literature, researchers’ rationale for compensating research participants are presented from a dichotomous perspective, fulfilling either (a) researcher needs or (b) participant needs. Rationales for compensation that address researcher needs include compensation as an enticement to promptly achieve recruitment goals and as a method for encouraging retention (Aitken, Gallagher, & Madronio, 2003; Brody, Dalen, Annett, Scherer, & Turner, 2011; Cryder, Cryder, London, Volpp, & Loewenstein, 2010; Grady, 2005). The present study participants reported similar rationales. However, based on these categorizations and the findings of this study, the rationales were grouped slightly differently: (a) fostering recruitment and retention/avoiding attrition and (b) expressing appreciation of the participants’ contributions. Similar to other researchers’ descriptions, participants who offered
payment generally referenced the payment as either compensation or reimbursement, even when appreciation was a part of their definition or rationale to offer compensation.

Participant appreciation discussion included recognizing the burdens faced by individuals to participate and methods the researchers employ to lessen this burden. The burdens the participants identified included the time commitment, type of study procedures, and challenges related to attending the visits, including travel and food. When studies involved minors, the participants included both the minors and the sacrifices parents or guardians made so the minor could participate. Similar to previous research, in some cases, only the minors were compensated, while others also included either compensation or reimbursement of travel-related expenses to the parent or guardian (Acharya et al., 2017).

When participants defined compensation as appreciation, the rationale for compensating was inextricably tied to their definition of compensation. Essentially, the rationale and the definition were the same, which encompassed offering tangible items, such as monetary compensation. It is unclear whether this finding was specific to this study or simply something that previous researchers have not explored. Nevertheless, these participants’ comments, and the rationale behind their compensation decision making, tended to be similar to that of researchers who defined compensation as payment.

Participants frequently intermingled burdens from both the participant and researcher perspectives. Participant burdens were the costs to the individuals for participating, with the degree of inconvenience dependent on the study design and participant pool characteristics. Researcher burden was generally framed meeting
recruitment goals within a specific timeline. Similarly, researcher have reported multiple rationales when compensating participants in a particular study.

In the analysis of rationale to compensate, I found the reasons reported by the participants similar to the basic themes that have been reported in the literature by other researchers, with one significant caveat. Some participants defined compensation as appreciation and then reported appreciation as the rationale to compensate. This added dimension provides a better understanding of appreciation as a rationale to compensate.

Compensation factors considered. As noted throughout this dissertation, there is a general dearth of information about how researchers make decisions about patient compensation. Despite this lack of information, previous researchers have suggested models for determining compensation amount (Grady, 2005; Dominguez et al., 2012). As anticipated, the participants used elements of these models as part of the compensation determination decision-making processes.

The participants considered many factors when deciding their compensation amounts, including study population characteristics, type of study procedures, participant motivations to volunteer, and cost to the participant to partake in the study. The participants also considered the potential embarrassment the study participant would feel due to the nature of the study procedure, as well as the amount of pain they would feel, the time commitment, and the risks the volunteer would assume. In general, this list reflects what other researchers have reported in the literature.

Many of the participants indicated they would attempt to compensate larger amounts when their study participants were exposed to greater risk, with some indicating appreciation as the rationale to support increased compensation. From the regulatory
perspective, IRB determinations should not include payment to offset the risks participants are exposed to in studies (OHRP, 2018b). The methods the participants employed to determine compensation amounts demonstrates that there is still a gulf between the theoretical understanding of compensation and the pragmatic considerations researchers face as they operationalize those theories.

Additionally, researchers who did not participate in this study provided information via email regarding their approach to compensation decision-making strategies, which tended to align with elements of Grady’s (2005) models. These researchers indicated that sponsors had provided a formula for determining compensation based on study intervention type, such as a blood draw, survey, or medical procedure. The researchers all noted that the formula was the starting point for the negotiations, rather than the only consideration. Similar to the participants, these researchers did not provide specific details regarding the weight each factor had when determining compensation within different study contexts.

The analysis of the findings yielded what was anticipated and were similar to the findings reported by researchers in the published literature. Additional information was gained as researchers shared how they developed compensation strategies within the context of similar study designs and degrees of compensation structure provided by sponsors and discipline convention.

Combination of compensation and reimbursement discussion and decisions. Often, interviewees discussed compensation and reimbursement in tandem when talking about study recruitment and retention efforts. Echoing a pattern found in the literature, some participants either used the terms compensation and reimbursement
Participants shared that their decision-making included a determination of how the allotted monies should be distributed between compensation and reimbursement. However, there were some shades of difference in the participants’ use of the two terms. The participants tended to delve deeper into the potential participant burden when addressing reimbursement, discussing issues rooted in the local and institutional context as well as the study design. These issues included the length of time between the completion of the study visit and when the participant received the reimbursement.

Parking reimbursement was of particular concern identified by the participants, as it. It tended to be an important factor for alleviating participant burden and encouraging retention in their studies. This may have something to do with the institutional context, given that when the participants conduct their research at the University of Iowa, many study participants arrive at the campus in their own vehicles. Yet this specific consideration also fits a larger trend in how researchers make decisions about compensation and reimbursement, frequently taking specific characteristics of their participants into account. The reimbursement model presented by Grady (2005), the costs a participant must take on to volunteer for a study, including expenses like parking fees, are factored into compensation strategies.

Comparable the researchers that have included compensation and reimbursement information for their studies in the literature, the participants framed data about compensation within the context of a specific study design and the unique characteristics of its participant pool. This suggests that any guidelines developed for calculating
compensation should leave room for researchers to make adjustments based on their understanding of their participant pool’s specific needs and burdens.

The analysis of this section was consistent with the literature findings, that compensation and reimbursement can be discussed separately or comingled. The most important take away from the analysis of this section was that the participants frequently needed to develop compensation and reimbursement concurrently based on available budget and participant pool’s preferences. The important of local context was evident as the participants discussed institutional processes, IRB requirements, and the preferences of their participants pool, if known.

Collaborative effort in research participant-compensation decision making. Generally, information about study-level decision-making processes is not presented by the researchers in the literature. Researchers have focused on the mechanics of researcher decision making about participant compensation, this research tends to omit any discussion of the study-level communications occurring as a part of the compensation determination decision-making process. One of this study’s findings was that compensation decision making was often a collaborative, iterative process. As noted in the previous chapter, the participants generally elicited advice from others at some point during the compensation decision-making process. However, the extent of this collaboration and the phase of the process in which it took place, was different for each of the participants. Some of the participants initiated the compensation strategy process individually, while others collaborated with fellow researchers from the start.

From, the analysis of this section, I concluded that there is a gap in the literature on the collaborative efforts involved in determining compensation. Additional research
can explore the nature of the collaborations, which in turn, can yield information to develop guidance for researchers.

Ethical concerns related to compensation. The participants also extensively discussed their need to balance the requirements of their study with the protection of voluntarism of human subjects. When sharing anecdotes about their own decision making, many of the participants framed their stories from this perspective. This discussion included the importance of conducting ethical research that protects the voluntarism of the individuals participating in their studies while still meeting recruitment and scheduling goals. As reviewed in the literature review chapter, both IRBs and researchers review compensation for potential undue influence on their study populations. The findings are congruent with this understanding. Participants referenced their study participants’ needs and motivations, as well as the influence compensation and reimbursement had on their participants and ultimately meeting their study’s recruitment and retention/avoid attrition goals. The degree in which the participants sought advice from the IRB during the development of the compensation strategy varied.

Breaches in ethical research conduct continue to be a problem, and revisions to human subjects research regulations reflect society’s continual reassessment of what constitutes ethical research practices. Echoing these concerns, participants in this study voiced the desire to conduct ethical research and, when compensating participants in their studies, to do so in a manner that does not compromise participant voluntarism. Often, these broader ethical considerations manifested themselves in issues specific to a particular study. For example, one researcher expressed concern about maintaining
fairness when changing compensation structure after their study had already been initiated.

The main takeaway from the analysis of this section are that the findings were similar to the published literature. Ethical considerations related to participant voluntarism continue to be explored from multiple perspectives, including compensation. Publishing compensation research findings informs regulators, IRBs and researcher current compensation issues and considerations.

Participant motivation to volunteer for studies. Even though participant motivation was not the focus of this study, participants frequently raised this issue. The researchers often talked about motivation when they discussed participant burden and tended to commingle their perception of their participants’ motivations to volunteer their concerns about the burdens their participants needed to take on in order to participate in their study. Along with other considerations about participant population characteristics, participant motivation was an important part of determining compensation for many of the researchers. However, due to privacy concerns, the participants discussed the issue broadly without providing detailed information. Frequently, the participants would not share the specifics of their study population characteristics, only stating they believed their study population should be compensated.

Generally, researchers have presented participant motivation information for biomedical, clinical studies. This study provides unique insight into, if not participants’ motivations specifically, the researcher perceptions of their participants’ motivations to volunteer in the context of various types of studies. Participants shared their perception of
motivation for individuals participating in biomedical and behavioral–social science studies.

Some participants offered insight into their personal motivations to participate in research and their thoughts about compensation from the participant point of view. Some participants discussed their reactions to research recruitment solicitations, including their thoughts on various amounts and types of compensation offered. It is possible that these experiences and reactions also influenced, or were influenced by, their professional approach when developing participant compensation strategies. However, this consideration was beyond the scope of this study and remains unexplored. Nevertheless, the researcher-as-participant dynamic certainly adds complexity to compensation decision making and underscores the multifaceted compensation decision-making by researchers.

In conclusion, this section identified issues outside of the scope of this research study and therefore, analysis was not conducted.

Non-compensation issues related to human subjects research. Throughout the interviews, participants also referenced issues that were part of human subjects research but that were not directly related to compensation decision-making processes. The participants relayed many issues related to conducting research, such as inconsistencies in IRB decisions, consent language requirements, and mandatory reporting of participant compensation. These issues impacted the study-level operations and, in some cases, had an indirect impact on compensation as well. There is a need for further research into the various auxiliary issues raised by the participants and their implications for developing
best practices within human subjects research. However, these issues were beyond the scope of this study.

Similar to the previous section, the identified issues were outside of the scope of this research study and therefore, analysis was not conducted.

Theoretical Contributions

The theoretical frameworks that undergird this study provide a useful tool for exploring potential explanations for my findings. Researchers have used complexity theory to analyze complex, dynamic systems that span bio, medical and behavioral–social science disciplines (Elton, 2010; English, 2008; Eppel, 2012; Horn, 2008; Jess et al., 2011; Mason, 2008, 2009; Rickles et al., 2007; Sanger & Giddings, 2012). Rickles et al. (2007) observed that complexity involves the “generation of rich, collective dynamical behaviour from simple interactions between large numbers of subunits” (p. 934), which certainly fits the nature of the decision-making processes participants in this study described. Representing multiple disciplines, study designs, and professional and personal belief systems, researchers in this study all made their decisions in dynamic and complex environments featuring multiple stakeholders and interacting systems. The actions and influences of sponsors, regulatory entities, and IRBs all had a bearing on the participants’ work, and their participants and colleagues also impacted the systems in which they conducted this research.

Complexity theory offers a framework for examining the dynamic environment and the variability of researchers’ decisions and perspectives as they navigate within an evolving system that includes multiple constraints and opportunities, which includes the changes in the academic researchers’ decisions as they interacted within and between
systems. This framework helps to elucidate and explore the researchers’ difficulty operationalizing their initially quite simple definitions of the term compensation. The contrast between the simplicity of their definitions and the complexity of the discussion that followed as participants tried to operationalize the term was intriguing, and the dynamic, multifaceted nature of the system in which they conduct their research is one likely explanation. It may be that the complexity of the context in which researchers must carry out their compensation decision-making processes contributed to the difficulty of putting their clear-cut definitions into practice.

Complexity theory was also especially relevant when exploring participants’ answers to the first research question:

RQ1: When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

While many of the participants noted similar factors, the departments and types of research conducted and the years of experience of my participants varied, reflecting departmental and other influences on the researchers’ decision making. Exploring compensation factors through the lens of complexity theory provided the flexibility required to discover academic researcher perspectives within the multiple interacting systems present in their environment.

Due to the current culture and conventions within their new environment, when study coordinators change positions and work within another discipline or even researcher, they may share their experiences as well as revise their approach to compensation strategies. Such experiences may be more impactful if the PI is a novice researcher and new to the university. It seems reasonable to assume that the experiences
the coordinator brings to their new work environment can contribute to best practices. The coordinator can share what has worked well or failed and the underlying study context. This probably holds true for researchers. One participant self-identified as a novice researcher and shared her reliance on more experienced research staff to provide guidance. The dynamism of decisions can evolve, as considerations are weighted differently within the context of the situation. It is reasonable to assume that the complexity of the issue and the experiences of the individuals involved inform processes as study-level decisions are determined.

The other theoretical framework used for this study, slippery slope theory, was especially useful in analyzing the data elicited by the second research question:

RQ2: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

When answering this question, many researchers relayed ethical concerns they had confronted throughout the course of their research. These concerns both directly and indirectly illuminated the researchers’ relationships with the IRB. From the perspective of the academic researcher, this relationship was either antagonistic or collaborative, yet involved a dynamism based on the context of the situation. The type of relationship the researcher had with the IRB guided their general approach to compliance with the IRB’s decisions and interpretations of the regulations. Similar to tax payer compliance driven by deterrence or by the trusting relationship presented by Kirchler, et al. (2008), participants approach compliance with IRB in a similar fashion.

Parallel to the taxpayer–tax-authority environment, researchers and IRBs are a part of a regulated community with the dynamic interactions occurring (Prinz, et al.,
2014). Generally, the researchers that described working with the IRB collaboratively encouraged the IRB to provide guidelines for best compensation practices, especially related to different study designs. Conversely, researchers who presented an adversarial approach to the IRB generally suggested that they hoped the IRB knew the importance compensation played in the success of their studies. Similar to previous research findings, in this study, slippery slope theory helps explain how the researchers’ relationships to the regulatory body, such as the IRB, influence their attitude toward compliance. This relationship also influenced the researchers’ ideas regarding how the IRB might better assist them as they confront challenges, ethical or otherwise, in the course of conducting their research.

Researchers with a collaborative approach toward the IRB offered suggestions for how the IRB might improve human subjects research guidelines and expressed appreciation for the research being conducted. These participants acknowledged that it might be useful for regulators to better understand how researchers make decisions about participant compensation. In contrast, researchers with an antagonistic relationship to the IRB tended to frame their responses as suggestions that the IRB needed to better understand the researcher’s constraints and the importance of compensation. These researchers also tended to share experiences they had with IRB processing issues. It may be that participants with knowledge of the IRB’s role tempered their comments related to questionable compliance, which masked a potential downward slide on the slippery slope. Despite the lack of identifiable noncompliance or questionable compliance examples provided by the participants, it is assumed that their location on the slippery
slope is not static. None of my participants suggested that the consequences of noncompliance motivated them to comply with IRB directives.

All participants voiced an underlying desire to conduct ethical research and protect the voluntarism of study participants, a goal shared by the IRB. Yet the interviewees’ individual approaches to cooperating with the IRB differed. It is possible that their relationship with the regulatory body influenced this approach, as slippery slope theory suggests. Muehlbacher et al. (2011) proposed that a collaborative approach requires both parties to be respectful and trusting. This suggests that the manner in which the IRB presents guidance, posts guidelines, and interacts with the researchers could play an integral part in influencing the researcher-IRB relationship, which subsequently influences the researcher’s attitude toward compliance. This is something that IRBs could take into account as they seek to foster a more collaborative relationship with researchers. There are likely additional factors that influence the development of a collaborative or antagonistic relationship. However, these additional factors were not explored in this study; the topic was outside of the scope of this research. Given the importance of this regulator-researcher dynamic in preventing a downward slide toward noncompliance with compensation regulations, and other requirements related to human subjects protections, this is a crucial area for future investigation.

The findings were rich with potential takeaways for regulatory bodies, researchers, and other stakeholders in human subjects research. Based on comments from interviewees, the IRB can search for ways to support researchers by providing general guidance on compensation strategies for different study designs. This approach could help prevent drift down the slippery slopes and, ultimately, risk of noncompliance.
Multiple participants requested greater guidelines and guidance from the IRB. However, participants also indicated that they would like the IRB to allow for flexibility within those guidelines, enabling researchers to take their individual study designs and study populations into account. Additionally, the IRB can seek feedback from study coordinators about how to better support ethical research. This would be especially informative, given that study coordinators provide a voice not generally found in literature about human subjects research. The IRB can use the results of that feedback to inform compensation guidelines. This knowledge can help institutions and regulatory bodies develop improved models, guidelines, and guidance about participant compensation, thereby better supporting researchers as they conduct their studies.

The findings of this study also strongly suggest that increased availability of information about participant compensation, in general, will help researchers, regulatory bodies, and institutions make better, and better-informed, decisions about this important aspect of human subjects research. Though some compensation disclosure practices are already in place, particularly for clinical trials, similar practices are needed in the behavior and social science research. With more knowledge about compensation amounts in their fields, researchers can make data-informed decisions about compensation in their own trials, and departments and institutions can develop norms.

Finally, suggested models for calculating compensation could be strengthened with more knowledge about how researchers are already making these decisions. Methods and benchmarks like Grady’s (2005) and those provided by the National Institutes of Health (NIH) already help guide researchers in determining compensation amounts. However, they could be strengthened and improved with increased knowledge
about how researchers make these decisions and which factors such as institutional, budgetary, contextual, and patient-related, researchers currently take into account.

To conclude this section, contrary to the findings published in the literature, the data was analyzed within specific theoretical frameworks. The theoretical frameworks provided an opportunity to explore issues occurring in dynamic settings and explore underlying motivations to comply with bureaucratic-based regulations. Theoretical analysis provided a more expansive understanding of the issues raised by the participants and their actions.

Limitations and Recommendations

Although in-person interviews provided some benefits, there were limits in interpretation, as presented by limitation:

1. The findings are limited by the accuracy of the participants’ responses. When one considers that the group of individuals participating in this study was self-selected, the findings may underrepresent the aggregate. The participants shared many examples to support their concerns and perspectives yet may not have provided examples of more extreme experiences. For example, they may not have revealed stories that demonstrated a lack of compliance with the study procedures approved by the IRB. The face-to-face interview format may have limited the participants’ willingness to report potential or actual compliance breaches. Individuals with outlier experiences, such as those not concerned with compensation to the other extreme of potential compliance breaches, may not have enrolled in this study. All individuals that enrolled shared opinions compensation. Yet, it is unknown the extent of potential or
actual compliance breaches the participants have experienced. The analysis was limited to the experiences shared.

2. The breadth of the questions and the semi-structured formatted provided an opportunity to gather rich, thick data from key decision makers whose perspectives are not found in research. However, the sample study group did not include all research disciplines and research designs. Analysis of the findings was limited to the study contexts and operational definitions provided by the participants.

3. This study was the first attempt to explore how the academic researcher approaches compensation strategy decision making. Participants provided information on decision making and ethical issues. However, participants provided limited data on the research question regarding improving compensation practices, which restricted analysis.

The analysis of the findings include my outsider perspective. In addition to the participants that had previously interacted with me in my professional IRB role, other participants may have known of my professional role based on the university’s directory and Human Subjects Office website. Furthermore, this study did not offer compensation as offering compensation could have introduced a bias towards compensating participants and analysis from my decision making processes. Yet, participants shared their decision making processes that included both offering compensation and not offering compensation.

Compensation decision making processes also expanded to include other aspects of protecting participant voluntarism. Based on this study’s limitations, as well as some
ideas gleaned from the participant interviews, three recommendations for further research into the topic of researcher decision making about patient compensation are offered:

1. The range of operational definitions of compensation support additional research on a mutual definition of compensation between the researchers and the IRB. A shared definition would facilitate compensation strategy discussions, including the interpretation and application of regulations. Conducting a future research study based on the Delphi method to explore a working definition of compensation for all study designs reviewed by the local IRB is warranted. Subsequent studies can be conducted in other R01 institutions, using an electronic platform. The increase in knowledge of compensation practices from the academic researcher perspective will continue to fill the gap in literature and provide a foundation to develop best practices.

2. Several individuals expressed interest in sharing their story as a compensated participant. Future research exploring compensation perspectives should be expanded to collect original data from the participants. The findings can help guide best practices by researchers when developing compensation strategies and IRBs who evaluate the study for ethical procedures and protection of participants rights.

3. When the participants were asked how compensation practices could be improved, minimal detailed data was collected. Generally, the participants expressed wanting more guidance from the IRB with flexibility to apply to varied study designs. For example, some participants discussed providing
maximum amount of compensation based on budget and IRB approval for particular studies. Others expressed a need to know what would be an acceptable compensation for different types of studies. Designing studies to review past and current compensation strategies would provide an opportunity to explore compensation by disciplines that conduct research in different settings. With recent mandates requiring the establishment of a single IRB of record for multi-site studies, exploring how the different local compensation requirements are addressed in multi-site research studies could provide valuable data to inform best practices.

Conclusion

Compensation is an integral part of human subjects research, but it presents ethical considerations due to its potential impact on the participant’s voluntarism. The purpose of this qualitative study was to investigate participant compensation decision making by researchers by exploring the following three questions:

RQ¹: When electing to compensate or not compensate research participants for a study, what factors do academic researchers consider?

RQ²: What are the ethical challenges faced by academic researchers when determining research compensation for their studies?

RQ³: How, from the perspective of academic researchers, can compensation practices be improved?

This study expanded the understanding of participant compensation by exploring the researcher decision-making processes and analyzing the data from complexity and
slippery slope theories. All the participants voiced an underlying desire to conduct ethical research and protect the voluntarism of study participants, a goal shared by the IRB.

Researcher decision making about compensation is complex and is influenced by myriad factors, including budgetary constraints, study design, and perceptions of participant burden, as well as institutional and departmental factors. The major theme that arose from the analysis is that researchers want the IRB to provide more guidance on participant compensation while maintaining flexibility for adapting to individual studies.

Perhaps the most important lesson is that by expanding our knowledge of how researchers make compensation strategy decisions, this information can be incorporated into best practices in order to protect participants, support researchers, and maintain the integrity of human subjects research as a whole. With more knowledge about compensation amounts in their fields, researchers can make data-informed decisions about compensation in their own trials, and departments and institutions can develop norms. Finally, suggested models for calculating compensation could be strengthened with more knowledge about how researchers are already making these decisions.

Given the importance of this regulator-researcher dynamic in preventing a downward slide toward noncompliance with compensation regulations, academic researcher decision making process is a crucial area for future investigation. The absence of precise guidelines complicates the compensation strategy decision-making process as personal beliefs and study constraints intersect with IRB guidelines and requests. In order to protect participants, support researchers, and maintain the integrity of human subjects research as a whole, it is crucial to continue to build our knowledge of how researchers make these important decisions. Especially in light of proposed changes to human
subjects research regulations, research questions and designs will continue to evolve, which will likely elicit shifts in compensation decision making strategies.

This study added to the empirical understanding of compensation by exploring a gap in literature, the academic researcher decision making process, and using theoretical frameworks to conduct the analyses. Novel findings included some researchers define compensation as appreciation and circumscribed compensation definitions can become convoluted when operationalized.
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APPENDIX A: RECRUITMENT MASS EMAIL 1

Subject Header: Research Study Recruitment- Participant Compensation Practices

Email Content: I am an Interdisciplinary Studies PhD candidate who is exploring the academic principal investigator decision-making processes related to participant compensation. I am seeking faculty researchers representing (biomedical or behavioral-social science) disciplines who conduct (quantitative, qualitative, or mixed methods) research to participate in a study involving face-to-face interviews, which will take about 40-60 minutes. If you have been a PI on a research project that has compensated research participants during the past 5 years and are interested, you are eligible to participate.

Please review the attached document. Please contact me if you have questions or if you are interested in participating at kathleen-beck@uiowa.edu. Please respond by DATE (The date listed will be 3 weeks from the date the targeted emails are sent to the dissertation committee members and the date the PI sends the targeted email).

You may forward this email other University of Iowa researchers that may be interested in participating.

Thanks,

Kathy

gmail address
APPENDIX A2: RECRUITMENT MASS EMAIL 2

Subject Header: Study Recruitment- Participant Compensation Practices

Email Content: You are have been invited to participate in a research study on research compensation. If you agree to participate, I would like to conduct a 60-minute interview with you to discuss compensation issues. Faculty representing (biomedical or behavioral-social science) disciplines who have been a PI on a project that has compensated research participants during the past 5 years are eligible to participate in a research study. To participate or learn more about this study, please click this link:

Sincerely,

Kathy Beck
Interdisciplinary Studies PhD Candidate

email address
Subject Header: Study Recruitment- Participant Compensation Practices

Email Content: You are have been invited to participate in a research study on research compensation. If you agree to participate, I would like to conduct a 60-minute interview with you to discuss compensation issues. Non-Faculty Researchers who have been a PI on a project that has compensated research participants during the past 5 years and Individuals delegated this responsibility by the PI are eligible to participate in a research study. To participate or learn more about this study, please click this link:

Sincerely,
Kathy Beck
Interdisciplinary Studies PhD Candidate

e-mail

After clicking link:

Are you a non-faculty researcher that has been a PI on a research project that has compensated research participants during the past 5 years OR have been delegated this responsibility by the PI?

If answered yes: taken to the Elements of Consent

If answered no: Thank you for considering the research message was shown
APPENDIX B: QUALTRICS SURVEY

We invite you to participate in a research study being conducted by investigators from The University of Iowa. The purpose of the study is to understand the academic principal investigator decision-making processes related to participant compensation.

We are inviting you to be in this study because you are a University of Iowa Principal Investigator (or delegate) that has offered compensation to your study participants within the past 5 years. If you agree to participate, we would like you to contact the PI of this study via email to schedule a time to complete the interview. The interview will consist of some broad questions, such as “Please tell me about your experiences with compensating research participants” and “Please tell me how you explain or define “compensation for research participants.” You are free to skip any questions that you prefer not to answer. You will be given time to share any additional thoughts and comments you have. The interview will be audio recorded to assist me in capturing your thoughts and ideas. The audio-recording is preferred, but not mandatory, to participate in the interview. It will take approximately 60 minutes to complete study procedures. Approximately 45 people will take part in this study at the University of Iowa.

We will keep the information you provided confidential. The audio recordings will be transcribed and verified for accuracy. Participants will have the option to review the transcribed interview. After the review of the transcribed interview, a random number will be assigned and the link between you and the data will be destroyed. Pseudonyms (fictitious names) will replace proper names of the individuals. It will not be possible to
link you to your responses in the interview. If we write a report about this study we will do so in such a way that you cannot be identified.

Taking part in this research study is completely voluntary. If you do not wish to participate in this study, do not contact in investigator. You can decide to stop participating at any time during the interview.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319)335-6564, or email irb@uiowa.edu.

Thank you very much for your consideration of this research study.

Name, Principle Investigator

Research Faculty Advisor and Contact information

☐ I wish to provide my UIOWA email information
☐ No, I do not wish to provide my UIOWA email information

>>
• If selected “I wish to provide my UIOWA email information”: “Please enter your University of Iowa email address to be contacted for this study.
  o If you provide email, next screen: “Thank you for considering participating in this research study. Your response has been recorded.”
  o If you do not wish to provide your University of Iowa email information, close the survey.”
• If selected “No, I do not wish to provide my UIOWA email information”: “Thank you for considering participating in this research study. Your response has been recorded.”
APPENDIX C: SEMI-STRUCTURED INTERVIEW GUIDE

I am gathering information from University of Iowa researchers about their experiences related to research participant compensation. I plan to ask some broad questions and give you time to share any additional thoughts and comments you have. I would like to tape this interview to assist me in capturing your thoughts and ideas. May I record this interview?

If yes, turn on the recorder. I am going to repeat the question, may I record this interview?

(Warm up question): To get started, would you tell me about your (your PI’s) research interests?

Probing:

a. Clarify type of research methods: qualitative, quantitative, mixed methods, other
b. Years conducting HSR (0-5, 6-10, >10) (how many years worked with the PI)
c. Years offered compensation (0-5, 6-10, >10) (that delegate is aware of/assisted with)

1. Please tell me how you (the PI) explain or define “compensation for research participants”

2. Please tell me about your experiences with compensating research participants.

Probing:

a. How do you feel your experience with compensating subjects is going?
b. How do you decide if compensation should be offered?
c. How do you decide how much to offer, if you offer financial?
d. How do you decide on the type of non-financial incentives to offer?

e. Please tell me about your experiences in revising the compensation strategy after the study was initiated.

f. How is the PI updated on compensation strategy for the study?

3. When human subjects research guidelines and regulations are revised, this can result in changes in institutional policies.

   a. What do you think Institutional Review Boards (IRBs) should know about the research participant compensation process from the researcher perspective?

      i. What do you think the University of Iowa IRB does well when process changes are implemented?

      ii. What complaints do you have regarding the functioning of the University of Iowa IRB related to participant compensation?

4. Is there anything else you would like to share about research participant compensation?

General probing questions:

- Tell me more about xxx

- Could you elaborate more on xxx

- What do you mean by xxx
## APPENDIX D: APPLICATION OF THEMATIC ANALYSIS PHASES

<table>
<thead>
<tr>
<th>Thematic Analysis Phase</th>
<th>How Facilitates Trustworthiness</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Searching for Themes</strong></td>
<td>Researcher triangulation.</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers.</td>
</tr>
<tr>
<td></td>
<td>Diagramming theme connections.</td>
<td>Used NVivo and Excel to document theme and subtheme connections to facilitate discovery and understanding.</td>
</tr>
<tr>
<td></td>
<td>Keep detailed notes about</td>
<td>Audit trail included electronic coding documentation, with documentation of code revisions.</td>
</tr>
<tr>
<td></td>
<td>development, hierarchies of</td>
<td>concepts and themes.</td>
</tr>
<tr>
<td></td>
<td>themes.</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Reviewing themes</strong></td>
<td>Researcher triangulation.</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers.</td>
</tr>
<tr>
<td></td>
<td>Themes and subthemes vetted by</td>
<td>Dissertation committee conducts their (peer) review with discussion during oral defense.</td>
</tr>
<tr>
<td></td>
<td>team members.</td>
<td>-------------</td>
</tr>
<tr>
<td></td>
<td>Test for referential adequacy by</td>
<td>Raw data is stored electronically for future analysis and comparison to future studies.</td>
</tr>
<tr>
<td></td>
<td>returning to raw data.</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Defining and naming themes</strong></td>
<td>Researcher triangulation.</td>
<td>Data collected from semi-structured interviews, pilot study, literature, and additional interactions with researchers.</td>
</tr>
<tr>
<td></td>
<td>Peer debriefing.</td>
<td>Oral defense includes review with discussion committee members.</td>
</tr>
<tr>
<td></td>
<td>Documentation of theme naming.</td>
<td>Audit trail included electronic coding documentation, with documentation of code revisions.</td>
</tr>
<tr>
<td><strong>Producing the report</strong></td>
<td>Member checking.</td>
<td>Participant review of their transcripts, PI summarized participants’ stories to check for understanding during and at end of interview.</td>
</tr>
<tr>
<td></td>
<td>Peer debriefing.</td>
<td>Oral dissertation defense with committee members.</td>
</tr>
<tr>
<td></td>
<td>Describing process of coding and</td>
<td>Detailed in Coding Method and Application section.</td>
</tr>
<tr>
<td></td>
<td>analysis in sufficient details.</td>
<td>-------------</td>
</tr>
<tr>
<td></td>
<td>Thick descriptions of context.</td>
<td>Semi-structured interview provided participants an opportunity to provide supporting examples.</td>
</tr>
<tr>
<td></td>
<td>Description of the audit trail.</td>
<td>Detailed in Establishing Validity and Reliability section.</td>
</tr>
<tr>
<td></td>
<td>Report on reasons for theoretical,</td>
<td>Detailed throughout dissertation.</td>
</tr>
<tr>
<td></td>
<td>methodological, and analytical</td>
<td>choices throughout the entire study.</td>
</tr>
</tbody>
</table>

(Nowell et al., 2017)
## APPENDIX E: PHASE I CLINICAL TRIALS

<table>
<thead>
<tr>
<th>Reference</th>
<th>Objective</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almeida et al. (2007)</td>
<td>Characterize motivations and attitudes of healthy subjects in Phase I studies and perception of the informed consent procedure and participation.</td>
<td>Financial reward was main motivational factor; compensation less important for participants with higher income and education; Study population: N = 136, 48.5% male.</td>
</tr>
<tr>
<td>Burgess, Sulzer, &amp; Emanuel (2008)</td>
<td>Document participant opinions regarding remuneration in clinical trials and clarify the monetary amount that represents undue influence.</td>
<td>Findings: 74% indicated should compensate; 93.6% indicated would participate without payment; 94% indicated would not conceal medical history to meet inclusion criteria. Rationale to compensate: 72.9%: travel expenses, 13.9%: incentive, 13.1%: time spent; Study population: N = 250 (118 males, 132 females); Clinical trial patients, South Africa.</td>
</tr>
<tr>
<td>Elliott, &amp; Abadie (2008)</td>
<td>Discussion on exploitation.</td>
<td>Term compensation viewed as reimbursing for expenses and inconvenience; many participants volunteer to help &quot;make ends meet&quot;; compensation allowed, yet not required to provide other benefits afforded employees.</td>
</tr>
<tr>
<td>Ilits (2009)</td>
<td>Discussion: alternatives to low-value compensation.</td>
<td>If low compensation amounts &quot;de facto target the less well-off for phase 1 studies&quot;, proposes priority of avoiding undue influence over the obligation of justice or alternative recruitment strategies.</td>
</tr>
<tr>
<td>Lynch (2014)</td>
<td>Discussion: regulations and classification of participants.</td>
<td>Uses analogical and legal reasoning to support perspective human subjects regulations should be at least as protective as labor and employment laws; research participants should be considered human research workers.</td>
</tr>
<tr>
<td>Pasqualetti, Gori, Blandizzi, &amp; Del Tacca (2010)</td>
<td>Discussion: issues concerning first-in-man trials health</td>
<td>Ongoing issues: lack of international and national guidelines, including definition of healthy status, offered suggestions for research in Italy.</td>
</tr>
<tr>
<td>Resnik &amp; Koski (2011)</td>
<td>Discussion: implementing national registry.</td>
<td>National registry to address concealment by participants to: (1) help protect them from risks and (2) promote data integrity.</td>
</tr>
<tr>
<td>Tishler &amp; Bartholomae (2003)</td>
<td>Discussion: ethical issues with &quot;repeat volunteers&quot; and guidelines.</td>
<td>Recommends: registry for tracking, centralized recruitment program, and providing participants written description of study, drug and dose, frequency, length given.</td>
</tr>
<tr>
<td>Zanini &amp; Marone (2005)</td>
<td>Shared experiences of healthy research volunteer registry.</td>
<td>Detected fraud, provided data for epidemiological analysis; location – Switzerland.</td>
</tr>
</tbody>
</table>
# APPENDIX F: PARTICIPANT DECISION MAKING

<table>
<thead>
<tr>
<th>Reference</th>
<th>Objective</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aby, Pheley, &amp; Steinberg (1996)</td>
<td>Assess altruism, healthcare receipt, and financial gain as motivation of Phase III participants.</td>
<td>Motivation: Most important: improved symptom control, education regarding illness and medications; financial motives were less important. Study population: Individuals with specific medical condition, N = 296.</td>
</tr>
<tr>
<td>Bentley &amp; Thacker (2004)</td>
<td>Survey: Hypothetical scenario to evaluate (1) effects of risk and payment on participation (2) payment’s influence on behavior and risk evaluation.</td>
<td>Money positively influences willingness to participate; higher amounts did not appear to influence risk assessment or reporting of side effects, but had some influence on concealment. Study population: N = 326, pharmacy students attending specific US institution.</td>
</tr>
<tr>
<td>Bevan, Chee, McGhee, &amp; McInnes (1993)</td>
<td>Investigate factors influencing decision to participate and assess opinion of information provided.</td>
<td>Altruistic and improve own treatment listed as motivating factors; compensation not reported; Participants: patients under the care of the investigators or participant in clinical trial. Study population: N = 197. Location: UK.</td>
</tr>
<tr>
<td>Breitkopf et al. (2011)</td>
<td>Semi-structured interviews of healthy participants at conclusion of a clinical trial.</td>
<td>Generally, reimbursement viewed as a benefit; amount should reflect time, inconvenience, and the potential and degree of risk, with experimental products offering greater amount. Monetary reimbursement unlikely to coerce. Study population: N = 30; demographics presented.</td>
</tr>
<tr>
<td>Byrne, Croft, French, Dugosh, &amp; Festinger (2012)</td>
<td>Discuss preliminary evaluation of a coercion assessment questionnaire.</td>
<td>Money primary motivation for 30%, &lt;5% felt financial incentives coercive; additional analysis of tool anticipated. Study population: N = 266.</td>
</tr>
<tr>
<td>Carroll et al. (2012)</td>
<td>Understand motivations of patients with PAH for participating in RCTs to facilitate future recruitment.</td>
<td>Compensation not included in the options explored; approximately one-fourth reported compensation important. Participants randomized to review hypothetical clinical trials. Motivated primarily by personal benefits and altruism. Study population: N = 26 from one academic center.</td>
</tr>
<tr>
<td>Croft, Festinger, Dugosh, Marlowe, &amp; Rosenwasser, (2007)</td>
<td>Examine compensation detail recall.</td>
<td>Higher-magnitude cash incentives increased recall over a six-month period; greater recall reduced required staff actions for follow-up appointments. Cash had greater recall compared to gift certificates. Study population: N = 220, substance abuse patients; demographics presented.</td>
</tr>
<tr>
<td>Cryder et al. (2010)</td>
<td>Measure interest in potentially risky research studies and perception of the risk by amount of compensation.</td>
<td>Reported results on 3 experiments conducted 2007-2008. Higher amounts increased willingness to participate and increased perceived risk and time potential participants review study risks. Study population: N=1,884 online nationwide or from a northeastern U.S. city.</td>
</tr>
<tr>
<td>Dainesi &amp; Goldbaum (2014)</td>
<td>Literature review examining participant decision making in biomedical research.</td>
<td>Motivation factors: disease being treated, study phase, prognosis and socioeconomic and cultural environment and at times access to better health care, personal benefits, financial rewards, altruism. Degree money motivated varied.</td>
</tr>
<tr>
<td>Reference</td>
<td>Objective</td>
<td>Summary</td>
</tr>
<tr>
<td>-----------------------------------</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Denny &amp; Grady (2007)</td>
<td>Ethical discussion enrolling and excluding economically disadvantages.</td>
<td>Presents ethical concerns and propose “careful attention to information disclosure techniques, ensure fair benefits for study participants and reduce unnecessary barriers to participation” (p. 385).</td>
</tr>
<tr>
<td>Doshi, Kulkarni, Ghia, Gogtay, &amp; Thatte (2013)</td>
<td>Explore motivation.</td>
<td>65% motivated by financial reward; other factors: altruism, free medical check-up, curiosity and personal health benefit. Study population: N=102 healthy, 16 patient volunteers.</td>
</tr>
<tr>
<td>Eassign (2006)</td>
<td>Describe experiences and perspectives of young, homeless participants.</td>
<td>Findings related to compensation: All reported incentives important, small monetary or prepaid phone cards were appropriate; concern expressed that large incentives could be coercive and harmful for some. Study population: N=43.</td>
</tr>
<tr>
<td>Fry et al. (2005)</td>
<td>Examine participant motivations.</td>
<td>Motivational themes: economic gain = 46%, expression of citizenship = 38%, altruism = 19%, personal satisfaction = 17%, drug user activism = 16%, seeking information or assistance = 5%. Study population: N=154, drug users, Melbourne area; additional demographics presented.</td>
</tr>
<tr>
<td>Grady (2005)</td>
<td>Discussion.</td>
<td>Review ethical issues related to compensation, including rationale to compensate, models to determine payment amount, including advantages and disadvantages of model.</td>
</tr>
<tr>
<td>Halpern, Karlawish, Casarett, Berlin, &amp; Asch. (2004)</td>
<td>Evaluate undue or unjust inducement using hypothetical trials.</td>
<td>Findings: payment motivated to participants; commonly used payment amounts did not present undue or unjust inducement. Study population: N=126, patients eligible to participate in Phase II and Phase III hypertension trials.</td>
</tr>
<tr>
<td>Hassar et al. (1977)</td>
<td>Explore motivation and study impression by participants.</td>
<td>Pharmacologic study with financial reward primary motivational factor. Study population: N = 79; 33 from a specific university, 46 from a pharmaceutical company.</td>
</tr>
<tr>
<td>Kost et al. (2011)</td>
<td>Conduct focus groups as the initial step in developing a validated instrument assessing the perceptions of research participants.</td>
<td>Motivation Findings: Altruism and personal relevance of the research common; less common financial compensation. Study population: N = 114; multiple focus groups; participants (1) with medical condition participating in interventions, (2) in natural history studies, (3) healthy volunteers, (4) institutional review board members, ethicists, and research subject advocates, (5) research nurses/Coordinator, and (6) investigators</td>
</tr>
<tr>
<td>Newburg, Holland, &amp; Pearce (1992)</td>
<td>Examine motivation and possible relationship to participant’s background.</td>
<td>Nonmonetary motivators; compensation not listed. Study population: N = 139, currently enrolled in clinical trial; additional demographics presented.</td>
</tr>
<tr>
<td>Reference</td>
<td>Objective</td>
<td>Summary</td>
</tr>
<tr>
<td>------------------------------------------------</td>
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</tr>
<tr>
<td>Novak, Seckman, &amp; Stewart (1977)</td>
<td>Compare prospective volunteer rates of 4 subpopulations and examine rationale to volunteer for a hypothetical clinical study.</td>
<td>Participants compensated after questionnaire completed. Study population: N = 480; college students, industrial employees, previous and new incarcerated individuals. Specific results to compensation: financial remuneration was motivation factor identified by many; not needing money and payment not worth the risk identified as reason not to volunteer.</td>
</tr>
<tr>
<td>Permuth-Wey &amp; Borenstein (2009)</td>
<td>Literature review; Summarize ethical and practical considerations and to make recommendations for researchers.</td>
<td>Financial remuneration is (1) considered ethical by many researchers and participants and (2) can be helpful in the recruitment process. Recommends consider the following factors: nature of the study, potential benefits and risks to participants, institutional or organizational guidelines, and cultural and societal norms specific to study population.</td>
</tr>
<tr>
<td>Russell, Moralejo, &amp; Burgess (2000)</td>
<td>Explore opinions on participant payment.</td>
<td>43.3% agree with compensation. Reasons to compensate: improve problematic recruitment, reimburse costs, recognize participants – especially their time. Recognition could be monetary or nonmonetary. Study population: N = 72, Unpaid healthy volunteers for randomized vaccine trial in Canada.</td>
</tr>
<tr>
<td>Wilcox, Bogenschutz, Nakazawa, &amp; Woody (2012)</td>
<td>Secondary analysis to determine effect of compensation amounts on rates of missing data and observed rates of drug use.</td>
<td>Findings: variations in the compensation amounts can affect outcome measurements, depending on treatment group assignment. Study population: N = 152, treatment-seeking opioid-dependent.</td>
</tr>
</tbody>
</table>
## APPENDIX G: RESEARCHER PERSPECTIVE

<table>
<thead>
<tr>
<th>Reference</th>
<th>Objective</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dickert, (2009)</td>
<td>Ethical discussion related to economically disadvantaged.</td>
<td>Proposes standardized compensation strategy using the prevalent wage for similar jobs which will from undue inducement and generally avoid exploitation.</td>
</tr>
<tr>
<td>Dickert &amp; Grady (1999)</td>
<td>Ethical discussion.</td>
<td>Presented ethical issues related to enrolling economically disadvantaged; compensation is generally an issue.</td>
</tr>
<tr>
<td>Dickert, Emanuel, &amp; Grady (2002)</td>
<td>Analyze existing compensation guidance and identify common characteristics.</td>
<td>Findings: 37.5% had written guidelines; 31 had “rules of thumb” Rationale for payment: time, inconvenience, travel, incentive, incurring risk. Study population: N = 32 organizations.</td>
</tr>
<tr>
<td>Emanuel (2004)</td>
<td>Ethical discussion.</td>
<td>Explores undue influence; references non-research inducements; recommends IRBs focus on other ethical concerns and not compensation in clinical research.</td>
</tr>
<tr>
<td>Emanuel (2005)</td>
<td>Ethical discussion.</td>
<td>Explores undue influence; suggests focus shift to favorable risk-benefit ratios, participants provide informed consent, and equitable recruitment of “poor” and “rich”.</td>
</tr>
<tr>
<td>Festinger, Marlowe, Dugosh, Croft, &amp; Arabia, (2008)</td>
<td>Questionnaire.</td>
<td>Findings related to compensation: higher amount and cash payments increased response rate and decrease researcher efforts to encourage follow up; Cash did not increase perceived coercion or new drug use rate. Study population: drug dependent individuals.</td>
</tr>
<tr>
<td>Reference</td>
<td>Objective</td>
<td>Summary</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-----------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Fisher (2013)</td>
<td>Ethical discussion.</td>
<td>Explores coercion from social, economic, and political contexts.</td>
</tr>
<tr>
<td>Grady (2001)</td>
<td>Ethical discussion.</td>
<td>Ethical discussion related to compensating research participants.</td>
</tr>
<tr>
<td>Ilitis, Matsuo, &amp; DeVader (2008)</td>
<td>Additional review of previous study.</td>
<td>Variations in payments and policies; identified multiple issues to be considered when determining compensation, noting new information may necessitate protocol revisions. Study population: previous pediatric research.</td>
</tr>
<tr>
<td>Klitzman (2013)</td>
<td>Telephone interview.</td>
<td>Modified grounded theory approach; issues and processes identified; IRBs did use coercion and undue influence interchangeably and decide “how much is too much”; study population: IRB leadership. Study population: IRB leaders, administrators, and members.</td>
</tr>
<tr>
<td>Largent, Grady, Miller, &amp; Wertheimer (2013)</td>
<td>Discussion on previous survey.</td>
<td>Findings: many IRB members views related to payment; coercion, undue influence “indefensible”; influence on their reviews not evaluated nor compensation strategies not submitted by researchers assuming IRB would not approve. Study population: IRB members.</td>
</tr>
<tr>
<td>Mduluza, Midzi, Duruza, &amp; Ndebele (2013)</td>
<td>Surveys and discussion during workshop.</td>
<td>Participants and guardians expected “reasonable value” compensation and that incentives and compensation need to be detailed. Study population: local and international stakeholders. Study location: Zimbabwe.</td>
</tr>
<tr>
<td>Phillips (2011a)</td>
<td>Ethical discussion.</td>
<td>Explores issue of a lower limit for compensation: proposes compromise: unconditional lower limit so compensation offered at least fair wage and if cannot offer then no compensation should be offered.</td>
</tr>
<tr>
<td>Phillips (2011b)</td>
<td>Ethical review of compensation determination.</td>
<td>Findings: proposed a base wage that prevents undue inducement, crowding out, and monetary exploitation.</td>
</tr>
<tr>
<td>Resnik (2008)</td>
<td>Ethical discussion.</td>
<td>Addresses ethical concerns and operational considerations when changing compensation strategy during study and rationale for offering compensation (participant costs, appreciation, or fair share of research benefit).</td>
</tr>
<tr>
<td>Reference</td>
<td>Objective</td>
<td>Summary</td>
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<td>-----------</td>
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</tr>
<tr>
<td>Ripley, Macrina, Markowitz, &amp; Gennings, (2010a)</td>
<td>Hypothetical cases to explore participant reimbursement issues.</td>
<td>Findings: lack actual expense information. Study population: IRB Chairs and researchers.</td>
</tr>
<tr>
<td>Ripley, Macrina, Markowitz, &amp; Gennings (2010b)</td>
<td>Survey, included hypothetical scenarios.</td>
<td>Primary rationale for payment: compensation, guided by incentive – recruitment, inconvenience, and risk; variability in payment strategies; study population: developed predictive model per scenario. Study population: IRB Chairs and investigators.</td>
</tr>
<tr>
<td>Roche, King, Mohan, Gavin, &amp; McNicholas (2013)</td>
<td>Postal survey to explore participant payment policies and issues.</td>
<td>Findings: 80% did not have policy related to participant payments; 20% had studies not approved noting proposed participant payments. Potential for inducement and concern with voluntarism were most common concerns of participants. Study population: Ireland Research Ethics Committees.</td>
</tr>
<tr>
<td>Seidenfeld, Horstmann, Emmanuel, &amp; Grady (2008)</td>
<td>Secondary review.</td>
<td>Identified participant characteristics, which are not generally considered vulnerable, but need to assess on individual basis.</td>
</tr>
<tr>
<td>Shields &amp; Pearn (2007)</td>
<td>Ethical discussion of nurse responsibilities.</td>
<td>Suggests: nurses need to be aware of research inducement issues and clinician and researcher roles.</td>
</tr>
<tr>
<td>Singer &amp; Couper (2008)</td>
<td>Web survey, hypothetical scenarios focus on undue influence of compensation.</td>
<td>Findings: statistically significant interaction between risk and incentive for undue influence; determine undue influence on empirical evidence; need to understand benefits and risks of participating. Study population: Survey Sampling International’s Internet panel.</td>
</tr>
<tr>
<td>VanderWalde (2005)</td>
<td>Response to intrinsic consequence publication.</td>
<td>Proposes there are intrinsic consequences due to unfair payment.</td>
</tr>
<tr>
<td>Wong &amp; Bernstein (2011)</td>
<td>Ethical discussion.</td>
<td>Using morality, logic and pragmatism, propose participant compensation is ethically unacceptable when research is determined greater than minimal risk.</td>
</tr>
</tbody>
</table>
### APPENDIX H: REVIEW OF TRUSTWORTHINESS STRATEGIES

<table>
<thead>
<tr>
<th>Publication</th>
<th>Criterion</th>
<th>Strategy Used to Achieve Criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garza et al. (2017)</td>
<td>Credibility</td>
<td>Research methods appropriate for research question; findings compared to literature; peer review.</td>
</tr>
<tr>
<td></td>
<td>Transferability</td>
<td>Detailed description of: research topic, study design, implementation, analysis.</td>
</tr>
<tr>
<td></td>
<td>Dependability</td>
<td>Detailed description of methods.</td>
</tr>
<tr>
<td></td>
<td>Confirmability</td>
<td>Documentation of study limitations, study methods.</td>
</tr>
<tr>
<td>Grady et al. (2017)</td>
<td>Credibility</td>
<td>Research methods appropriate for research question; findings compared to literature; peer review.</td>
</tr>
<tr>
<td></td>
<td>Transferability</td>
<td>Detailed description of: research topic, study design, implementation, analysis, application to other scenarios.</td>
</tr>
<tr>
<td></td>
<td>Dependability</td>
<td>Detailed description of methods.</td>
</tr>
<tr>
<td></td>
<td>Confirmability</td>
<td>Documentation of study limitations, study methods.</td>
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<td>Simon et al. (2011)</td>
<td>Credibility</td>
<td>Research methods appropriate for research question; thick description; findings compared to literature; peer review.</td>
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<td>Transferability</td>
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<td>Study limitations, study methods, and audit trail.</td>
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<td>Perez, Ohrt, &amp; Bruening (2016)</td>
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<td>Chin, Choi, &amp; Lam (2015)</td>
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