

RESEARCH ARTICLE

Maintaining Professionalism, Appropriate Distance, and Consistency in Relationships with Participants in Longitudinal Research: Guidelines for Investigators and Research Staff

Robin G. Lanzi

University of Alabama at Birmingham

Sharon L. Ramey

Virginia Tech Carilion Research Institute

When conducting longitudinal studies, particularly those that measure personal and sensitive issues and depend upon establishing a relationship with study participants that is respectful, trustworthy, and consistent to ensure study participants are comfortable, clear about the purpose of the research, and likely to remain engaged over time, natural relationships are formed between those collecting data and study participants. A paramount concern for longitudinal research is that these relationships do not exert differential effects on the data collected, participants' retention in the study, or the well-being of either the study participants or research staff. We propose specific strategies to minimize differential effects of these relationships on the study's scientific and ethical integrity. The guidelines are ones we have developed and refined over the past 3 decades in multiple large-scale longitudinal studies, primarily with low-income and minority families whose children have higher than average levels of biological and social risk factors. These guidelines focus on specifying explicit boundaries for the relationships and consequences of deviating from these and the challenging issue of how to be warm and supportive without crossing boundaries of professionalism, altering the data collection process, or treating study participants differently and perhaps confusing them about the established research contract.

Among those of us who have conducted community-based studies that involve repeated contact with study participants, we have encountered a wide array of issues that focus on the relationships we establish with study participants. Informally, we share stories (while protecting anonymity and confidentiality of study participants) with other investigators and often develop our own ideas about how to support the professionalism and consistency of our research staff in terms of their interactions with study participants. These relationship-based concerns can be particularly challenging in studies that have a large and sometimes multi-site community data collection component, such as visiting study participants in their homes, community clinics, schools, and other natural settings. In this article, we propose that most of the problems that

arise can be anticipated and prevented by implementing explicit procedures that all research staff know about and agree to fulfill as part of the condition for employment (or volunteering) on the study. In Table 1, we share our template that summarizes major principles of scientific integrity in a document that we have all research team members sign for all projects. (Note: this is in addition to participating in mandated training and certification related to protection of human subjects). The overall purpose of creating these procedures as an integral part of every study is to maximize fulfilling high standards of scientific conduct. These standards include active efforts to minimize any potential bias in data collection, analysis, and interpretation; to promote consistency in the data collection process across all study participants and over time (when collecting repeated measures); to honor the fundamental contract established through the informed consent process that ensures protection of privacy, confidentiality, and participant safety; and to avoid any actions that could either misrepresent or confuse study participants about the scope and purpose of the research.

TABLE 1
A Research Pledge to Support Major Principles of Scientific Integrity

to uphold the highest standards of scientific conduct and of ethical behavior during data collection, which includes but is not limited to:

- adhering to multiple levels of safeguards regarding the standardization of data collection, in ways that are comparable for all study participants;
 - minimizing and documenting any potential biases that might arise over the course of the study;
 - fully honoring the research contract to protect the privacy, anonymity, and safety of the study participants at all times during and after the conduct of a study;
 - demonstrating consistently high standards of professional conduct, both within and outside the research context;
 - avoiding all situations that may compromise the research endeavor through actual or perceived conflict(s); and
 - considering and conveying appropriate respect for cultural, community, and cohort norms and practices throughout the conduct of the study, while also complying with legal requirements related to reporting adverse events or situations.
- to adhere to all study protocols exactly as reviewed during training and thereafter;
 - to never falsify any information;
 - to never provide or sign statements in a way that misrepresents what has occurred;
 - to be sure all data are maintained in appropriate locked and secure files;
 - to identify and report any apparent deviations or contradictions between the actual study procedures and methods being used and the original informed consent and IRB protocols;
 - to immediately report any possible deviations from the study protocol or possible wrongdoing that I know of *firsthand*. Depending on the matter, this will be reviewed and corrective action(s) taken in a timely matter;
 - to immediately report any possible derivations from the study protocol or possible wrongdoing that I have heard about from others, or suspect may have occurred. (these include actions by other research staff as well as those that directly involve me.) I will have an opportunity to report this privately and confidentially so that my supervisor may take appropriate follow-up actions to investigate as appropriate; and

- to seek assistance and advice about any matter that I think might affect the validity, reliability, and integrity of the research and the well-being of the participants and any collaborators in the community.

By signing this, I understand that I must actively uphold these principles for scientific and ethical behavior for this project. I understand that I can talk to my supervisor about any issues in a private and confidential manner. I also understand that corrective actions will be taken and reported if any of these standards are violated.

Staff Member's Name

Signature

Date

Principal Investigator's Name

Signature

Date

Note: This is the template we developed and now use in all of our research projects. Research team members sign this after we provide training sessions and extended opportunities for discussion related to a specific research protocol. We return to this document throughout the course of the project as a way of reminding all research team members about the importance of conducting research that adheres to these principles of scientific integrity to maximize the potential that the research will lead to new, accurate, and sensitive findings that will help promote understanding of the factors that contribute to positive human development and well-being.

When engaging with study participants, there are multiple natural threats to the scientific and ethical integrity of a project. Not all research staff members have formal education related to or a clear understanding about scientific integrity and why it is so important. Accordingly, systematically addressing some of the factors that could impact scientific integrity is a powerful strategy to prevent problems. There are four major relationship threats we have identified. The *first* is that research staff and study participants may see opportunities to have contact that extends beyond that necessary for conducting the study, based on their own personal histories and interests. These opportunities often become apparent when research staff and study participants interact frequently and when the data collection involves information about personal matters. If acted upon, these contacts outside the research study comprise a potentially serious threat to scientific integrity. A *second* concern is that research staff members may reveal personal information and/or personal opinions when they interact with the study participants. This self-revealing can sometimes occur without awareness, while other times the research staff may do so intentionally because they think it will be helpful. Regardless of whether this occurs consciously or not, and regardless of whether this appears to be “just natural and socially appropriate,” when research staff introduce personal information, it can lead to shifts in how study participants view the research project and may influence participants’ future level of engagement and the types of information they provide. A *third* threat occurs when research staff develop negative perceptions about one or more study participants, based on the research staff

member's personal life views (e.g., life philosophy, religious beliefs, personal and political values). When this occurs, such negative feelings can lead to dislike, disrespect, distrust, or other interpersonal difficulties with study participants. In turn, these negative perceptions could impact the data collection process (that is, alter its neutrality, objectivity, and consistency across study participants) and contribute to study participants experiencing distress and withdrawing from the project. *Fourth* and finally, unplanned connections and events can occur over the course of a study that involve unexpected contact or sharing of information between the research staff person and study participants. These could occur in a wide variety of community situations or during a sudden-onset event (such as a natural disaster, urgent health condition, or intrusion by another person). Each of these potential types of threats is discussed in greater detail below, along with suggested strategies for how to prevent them, as well as how to minimize and handle effectively if they are not successfully avoided.

The strategies we propose to maintain scientific integrity and professionalism are grounded in the following fundamental premise about the process of scientific inquiry: that the science of human development depends upon the conscientious application of standards that simultaneously ensure that (a) the data collected will be accurate and valid and analyzed in ways consistent with the intent of the research and (b) participants will be fully protected, consistent with approved Institutional Review Board (IRB) protocol. Thus, the scientific integrity of longitudinal research is critically linked to: (1) establishing and fully implementing multiple levels of safeguards that explicitly detail the standardization of data collection and analysis for all study participants (note: individualization of procedures can be designated as part of this standardization); (2) actively observing and fully documenting and reporting any potential sources of bias that might arise over the course of the study; (3) fully honoring the research contract to protect the privacy, anonymity, and safety of the study participants at all times during and after the conduct of a study; (4) demonstrating consistently high standards of professional conduct, both within and outside the research context; (5) avoiding all situations that may compromise the research endeavor through actual or perceived conflict(s) of interest; and (6) considering and conveying appropriate respect for cultural, community, and cohort norms and practices throughout the conduct of the study, while also complying with any local legal requirements related to reporting adverse events or situations (note: these must be described and discussed in advance with all study participants).

This commitment to conducting research in ways that fulfill this scientific premise serves to support both current and future research by the scientific investigators and their staff, the supporting institution, and beyond. This premise further recognizes that the scientific advances in a given field depend upon more than the discoveries of individual research groups. Stated otherwise, future scientific inquiry often represents a collective decision to invest in certain types of research regarding certain topics, based on the probability that this scientific work can be conducted in ways that will yield trustworthy, accurate, and useful new knowledge about a topic. Accordingly, the public's trust in the scientific process and willingness to invest public, private, and philanthropic resources in research, particularly about complex human issues, is essential to maintain. When research projects fail to visibly and consistently uphold the standards of scientific integrity, they potentially can destroy public trust. Remarkably, despite the fact that protection of human subjects training is required in all studies and covered in many ways (see for example: DHHS, 2009; NIH, 2012; OHRP, 2008; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) and that most research projects include many checks about the overall processes of collecting, entering, analyzing, and

reporting data, the topic of interactions between research staff and study participants is frequently overlooked and typically not monitored actively over the course of a project. We strongly advocate that for all projects this topic needs to be elevated to a central position, supported by written procedures, formal training, and ongoing monitoring, so that the standards of scientific integrity are fully supported.

What is undeniable is that over the course of conducting a longitudinal study that involves personal contact with study participants, the investigators and research staff may develop their own feelings and form their own impressions of study participants, as individuals or as representatives of a group or subgroups. Just as frequently, the research team may want to help study participants in ways that extend beyond the research project. Accordingly, it is essential that each study establish clear guidelines, in advance, to help all members of the research team have an explicit understanding of what is expected, appropriate, and acceptable. For us, the research team includes the study's leaders (principal investigators, project directors, project coordinators), collaborators (co-investigators), and advisers as well as the research staff (hired employees, students, volunteers) and any study partners (such as community clinics, agencies, and schools). Further, we use the term research to encompass all basic and applied research and evaluation projects, whether initiated by those who identify as scientists or by the community or program initiatives. We consider any systematic effort to gather and analyze information about the lives and well-being of individuals for the purposes of increasing knowledge about human development to be a form of research. Accordingly, we believe that the situations that pose threats to a research study apply just as strongly to required program evaluations (increasingly included in publicly supported service delivery projects and educational initiatives) as they do to projects funded solely as a research study. In this paper, we provide examples of these situations that may pose threats to research and guidelines and recommendations to handle them; but first, we provide an overview of our major multi-site research studies to help contextualize our guidelines and recommendations. We provide details such as frequency and timing of data collection because we think these aspects of the study contribute to the likely formation of relationships between the research staff and study participants; further, knowing about the general purpose of each study helps to specify the types of information that is revealed over the course of conducting the longitudinal study, and indicates sources of potential, but often unrecognized challenges, to the integrity and consistency of the project.

BRIEF OVERVIEW OF RESEARCH

The guidelines are ones we have developed and refined over the past two decades in multiple, often multi-site and large-scale longitudinal studies, primarily with low-income and minority families whose children are eligible for Early Head Start and Head Start services. These studies include the National Head Start-Public School Early Childhood Transition Demonstration Study, a congressionally legislated study in 30 sites throughout the United States, with more than 7,500 former Head Start children and families in 450+ schools, designed to test the efficacy of a program to help low-income children and their families make successful transitions from Head Start programs to kindergarten through third grade (Ramey et al., 2000; Lanzi, Pascoe, Keltner, & Ramey, 1999; Lanzi, Ramey, & Ramey, 2007; Ramey, Ramey, & Lanzi, 2001, 2006; Ramey, Ramey, & Lanzi, 2004, 2007). More recently, we completed three NIH-funded multisite

longitudinal studies, two of which are home-based parenting studies, one focused on first-time adolescent mothers compared to adult mothers with and without resources (Lanzi, Ramey, & Bert, 2012; Lanzi, Bert, Keltner, & the Centers for the Prevention of Child Neglect, 2009; Lanzi et al, 2007; Lefever et al., 2008) and the other a RCT testing a multi-component home visiting intervention (“My Baby and Me”) designed to increase parenting responsiveness, home health and safety, maternal decision-making, and early literacy exposure (Guttentag et al, In Press; Lanzi, Guttentag, Baggett, Willard-Noria, & the Centers for the Prevention of Child Neglect, 2008). In both studies, mothers enrolled early in pregnancy and children were assessed at multiple time points through age three. The third NIH study is a 5-site, prospective community-based participatory research study with more than 2,500 mothers recruited when their baby was born and followed through the first 2 years of life. This Community Child Health Network research focuses on stress and resilience in parents and how these influence maternal allostatic load – a composite index of the wear-and-tear on multiple body systems associated with stress exposure – as well as pregnancy outcomes and child health and development (Dunkel Schetter, Schafer, Lanzi, et al, In Press; Lanzi, Ramey, et al, 2012; Patchen, Ramey, & Lanzi, 2009).

Collectively, these studies provided many natural opportunities to detect and address issues associated with the relationships that developed between the investigative teams and those who volunteer to be study participants. Our study samples include a majority of very low-income (<200 percent federal poverty level) parents and children, with more than half of the samples comprised of Black/African-American and Hispanic/Latino families. Each study also included higher income families as well as White/non-Hispanic families. None of these studies focused on individuals selected because of their need for or participation in treatment related to severe physical or mental health conditions. As such, we judge that our experiences with these multi-year, multi-site studies – a combination of observational and experimental studies – provide a broad base for identifying the types of problems that frequently arise, many of which can be averted and/or quickly detected and thereby minimized if investigative teams are well prepared for these relationship-based problems.

SPECIFIC SOURCES OF CHALLENGES AND THREATS TO THE SCIENTIFIC INTEGRITY AND ETHICAL CONDUCT OF A RESEARCH EFFORT

In this section, we describe types of behavior and attitudes that represent a threat to maintaining high scientific standards. We make recommendations for how to address these and identify alternative and divergent ways of thinking about these issues.

1. Having contact that extends beyond that required for conduct of the study

Research staff often want some additional contact with study participants - a quite natural situation when they have concern for individuals and families in need and when they share interests and have positive feelings about study participants. This occurs most frequently in studies of low resource families that face multiple life challenges. All research projects should have procedures in place to make referrals and discuss problems that are identified in the course of collecting data. However, contact that extends beyond the project protocol for offering

assistance and for socializing can seriously alter how study participants view the research, and often this can influence the data that are being collected.

How might this look in the field? Often research staff will discover that they share some common interests, life histories, and local knowledge with some of the study participants. These areas of mutual interests tend to lead to further conversation and considering possible further contact outside the research context. Other times, study participants extend a direct and warm invitation to research staff to join them in other activities, such as inviting an interviewer or observer to stay for a meal or refreshment, to attend a church service with them, or to respond to an invitation to the research team to join a family celebration, such as a baby shower, a marriage, or a child's graduation. Even stronger potential for relationships can occur when research staff and study participants feel a personal attraction or want to introduce someone to another person for the possibility of a close friendship or romantic relationship. The opportunities and desire for some additional contact thus can range from minimal (e.g., accepting a refreshment or staying to watch a television program) to moderate (e.g., having long discussions about certain topics or agreeing to meet in a way that involves some social support) to high (e.g., wanting to date someone or to establish a sustained friendship). In fact, all of these situations have arisen, on multiple occasions, over the course of our experiences.

The minimal extended contact situations appear to be the least problematic and the most natural and frequently occurring. Nonetheless, they pose a risk for the following reasons: First, if a research staff member accepts or extends offers for minimal contact, there is the likelihood that the study participant may come to expect this. For example, for projects that involve home visiting, accepting an invitation to dinner may then lead to the expectation that this will recur. If this invitation is accepted once, but not again, this may be perceived as a rejection and may alter the relationship. Another example is that of a research staff member giving a small present to a family (not part of the study's pre-planned remuneration), such as homemade cookies, a baby rattle, or a book to a mother. The problem with this is that study participants may not accurately understand the source of the present, may come to expect more presents on a regular basis, or may tell other study participants (who did not receive the same gift) about this act of kindness. For any of these situations, even minimal additional contact is highly likely to be associated with additional conversation and sharing in a warm, positive manner. At first, this may appear to be good for the research. In fact, however, the variation in how study participants are treated and the additional potential exchange of personal information can lead to the perceptions that there will be continued contact beyond the scope of the research project. Although this contact is inherently not harmful to anyone, it is a non-regular and potentially harmful behavior in terms of the research project's consistency across participants and in terms of possible misunderstanding, hurt feelings, and inappropriate expectations by study participants.

How to handle this? First, most research projects plan to develop some amount of casual, informal, and positive rapport with participants. The nature and extent of this positive relationship should be carefully described as part of the research team's plan. This plan should be shared with all research staff and study participants. This affirms the value of feeling comfortable with and showing positive appreciation for the manner in which the research study is conducted. The plan also should identify activities that are not allowed. This can help research staff explain why they have to decline some of the warm invitations they might receive.

Examples of acceptable social exchanges might include “get-togethers” for certain research projects, small tokens of appreciation as well as more substantive remuneration given to all study participants, and a permissible amount of chit-chat and even professional discussion (appropriate to the professional background, skill level, and specialized training of the research staff and consistent with the purpose of the study). To allow research staff members to make their own judgments about responding to initiations from study participants for additional contact or advice places a decision-making burden on them; in turn, this could be very difficult to monitor and could alter the way that the research protocol is implemented.

What to say when rejecting an overture that is warm and well-intentioned, and that appears to be quite minimal in the actual threat to the study? All research staff team members should adopt a standard practice of responding with a clear statement about the study limits imposed on everyone, such as “Thank you, but I am not allowed to. The research project does not allow any extra contact between researchers and people participating in the study.” If needed, the research staff member can explain that this is part of the responsibility for conducting the research in exactly the same way at all times, and that in other projects, unexpected problems have arisen from contact that have become serious. This rejection of a positive social advance can feel awkward and even arbitrary for some research staff. This makes it essential that this topic is addressed in detail during initial training and re-visited during on-going training and supervision.

For moderate and high contact situations, there usually is a stronger connection or potential perceived by the research staff and/or the study participant. Under these conditions, the same prohibition applies, but further actions may be warranted. These may include re-assignment for future data collection, and sometimes may necessitate terminating employment. These actions should be decided through individual discussion with the principal investigator and/or project coordinator. One possible solution, for certain types of relationships, may involve discussing the possibility of having contact when the entire research project is completed. This should, however, be discussed openly in advance with the research leadership and possible difficulties be considered thoroughly (e.g., if this involves conferring personal or professional benefits that could influence the remainder of the data collection process, the participation level of the study participant, or the integrity of the overall study).

Serious issues that are obviously prohibited involve direct offers related to employment or professional services (in either direction), intimate contact, or knowledge about or participation in any illegal activities. Finally, it warrants stating that maintaining this highly consistent pattern of “no extra contact” throughout the course of the study serves to protect the research staff from possible criticism and personal harm, and also will serve to educate study participants about the integrity of the research process itself.

2. Exchanging personal and/or professional information and opinions that are not part of the planned research protocol

When research projects are gathering information that is personal in nature, it is likely that questions will arise that lead to the study participant wanting to know more about a topic, perhaps concerning a direct question raised during an interview or a test protocol or related to an intervention that is being tested as part of the study. There will be a wide array of topics on which the research and/or intervention staff will be competent to provide additional information

related to the study itself. Extensive training and preparation for these likely queries should be an explicit part of the initial and ongoing training and supervision process of the study. The threat to scientific integrity concerns research staff providing information that goes beyond the formal part of the research protocol or explaining the research procedures clearly. In our experience, we find that research staff with a background in the helping professions (e.g., social work, nursing, psychology, early childhood education, nutrition) often slip into giving advice that links to their professional background and experience. For some, they may feel uncomfortable adhering to the research protocol if they think they could do something that would immediately “help” a study participant.

How might this look in the field? Examples include study participants asking the research staff what they know or think about certain treatments or practices (e.g., medical or therapeutic intervention, how best to parent their child), what their impressions or judgments are about the study participant (e.g., “How do you think I am doing compared to others in the study?” or “Is it normal that I am doing this or feeling this way?”), or discussions about general life topics (e.g., political views, religious preferences and practices, where to shop for something). As in the category above, the opportunities for additional information exchange can range from quite minor (e.g., “Do you think I should keep my child inside if it rains?”) to far more personal and substantial (e.g., “What do you advise me to do about my family situation?”).

How to handle this? For very minor factual or superficial information exchanges, there is unlikely to be a risk to the integrity of the project or the maintenance of a highly professional, appropriately distant yet warm and supportive relationship. Topics that should be off limits include discussion of personal possessions and their cost or procurement, politics, religion, sexual orientation and behavior, personal problems or lifestyles, and individual health concerns. It is quite understandable that minor comments about politics, for instance, could be expressed by a study participant (e.g., concern about an act of Congress, the Supreme Court, or the President) and it would feel minor that the research staff express a concordant, supportive concern. The problem with this is that the repercussions and interpretation from a casual remark may be greater than anticipated. The study participant might live or work with others who do not agree, and may seek to use your supportive comment as adding weight to the correctness of his or her views. In a complex and potentially volatile family situation, for example, this could lead to increased probability of domestic violence. Alternatively, a study participant may suspect that the project holds a certain “bias” already in its orientation (e.g., its views related to controversial health-related and personal decision-making topics such as abortion, homosexuality, the legalization of marijuana, whether parental rights should be terminated in child abuse cases) and may be setting a “trap” by stating a view and then seeking agreement or disagreement from the research staff. Once again, the members of the research team all need to be prepared for and, ideally, practiced in ways of being polite and clear in refusing to express personal opinions or give advice or information beyond the scope of the project. This is simple when written policies prohibit this, and the research staff person can honestly say “The guidelines for my work and my employment prevent me from telling you my own personal views. This is because sometimes these may interfere with my ability to conduct the research in the way I have been trained. Everyone on the project is required to follow the study procedures in exactly the same manner.” Once again, the initial engagement in “small talk” seems quite natural and sometimes even

necessary. Yet even small comments and conversations can lead to unanticipated consequences, great care must be taken that the content of the exchanges are appropriate.

Obvious legal and ethical issues present themselves if information or opinion exchange occurs that leads to subsequent decisions and actions of uncertain outcomes. Frequently, research staff have outside interests, small businesses, or private practices that they or their relatives are engaged in that might be of direct practical benefit or interest to study participants. Despite the potential helpfulness, such offers are beyond the scope of the research project and may interfere substantially with the long-term participation of the study participant(s). In the event that there is an urgent matter that arises, such as a serious health threat or a need for immediate assistance in a crisis-like situation, the study should have formal procedures in place that include timely review and explicit approval for providing information or advice. Obvious exceptions involve life-threatening assistance, such as calling 911 in the event of an emergency in which the study participant or others cannot call for help. Similarly, if research staff are formally trained in and certified to provide emergency procedures such as CPR and emergency first aid, these could be provided if there were not another alternative available and if a delayed response could result in likely harm. Each research study should explicitly address these matters. Often the research staff can respond to reasonable queries for information (e.g., “How I can find out more about enrolling in your university?” or “What other types of research like yours are going on in the country?”) by stating that the question will be referred to the Project Director or Principal Investigator who will then follow through and provide a response. This procedure is especially strong because it ensures uniform and documented exchange; it also allows for the possibility of studying whether certain study participants have particular informational needs, which may relate directly or indirectly to the study’s purpose, the interpretation of findings, and/or future planning to provide clearer instructions and information at the time of enrollment in similar types of research projects.

3. The emergence of negative perceptions about study participant(s)

For many types of longitudinal research projects, there is a risk that as more is learned about certain individuals and/or settings, non-optimal factors may be revealed. It is practically impossible for those collecting data not to have their own set of feelings when they are told about or directly observe negative things occurring. For research that enrolls “at risk” or vulnerable populations, these feelings are likely to be even stronger and more problematic than in projects focused on stable, healthy, middle class samples – although personality clashes and lifestyle difference can trigger negative perceptions that span across all socioeconomic and ethnic/racial groups.

How to handle this? For all projects engaged in longitudinal research, and particularly so for those that enroll identified high-risk populations, it is imperative that specific procedures be in place for making referrals for suspected and/or documented problems that may indicate need for further evaluation, treatment, or intervention consistent with professional, legal, and ethical standards. For example, our multi-site parenting studies have standard written procedures that have been reviewed with all research staff, in ways that are consistent across all sites but further are locally adapted to be consistent with local statutes and procedures, for reporting suspected child neglect or abuse. At the time of enrollment, all participants are informed about

this legal and ethical requirement for reporting suspected abuse and neglect. Similarly, when young children are evaluated as part of the standardized assessment protocol and we detect significant delays, irregularities, or possible disabilities that are not already recognized and being treated, we have a standard method of informing the responsible adults about the results of the assessment and offering to provide information related to follow-up and evaluation by the appropriate professionals who are not connected with the research project. These are not considered to be “negative perceptions,” but rather reflect a conscientious concern for the well-being of participants and the use of information obtained in the course of conducting the research.

The negative perceptions of concern fall into two major categories: (1) negative perceptions about the validity of the information being provided by the study participant or the appropriate levels of engagement and compliance in the study protocol; and (2) personal negative feelings about a study participant or participants, such that being in their presence elicits strong emotions and negative judgments that possibly could influence the data collection and/or data analysis process. The negative concerns about the validity and reliability of information or levels of cooperation should always be recorded and then reported and discussed with the research group leadership so that decisions about corrective actions can be made and documented. For example, if a study participant provides contradictory information that is likely to be of some consequence for the study, appears disturbed or confused by aspects of the research process, is openly hostile or uncooperative, tries to influence other study participants to be less cooperative, or appears to be concealing information about being in another research project, these instances warrant action, to be decided on an individual basis.

In the more frequent situation when research staff members are exposed to situations and receive information about non-optimal life circumstances, it is valuable to seek to maintain the appropriate distance and perspective on this. On many of our long-term projects, we have been concerned about both the physical safety and mental health (well-being) of our research staff members, because they are engaged in highly demanding research activities and exposed to high levels of human distress, neglect, or suffering that is beyond the scope of the study to correct (after fulfilling all appropriate referrals and interventions consistent with the study intent and ethical professional behavior). We regularly have individual and group sessions designed to encourage research staff to share and alleviate these negative perceptions. Through peer support and project leadership, we seek to offer affirming and practically useful perspectives for coping to all research team members. However, at the point a particular conflict or situation arises that cannot be resolved readily through discussion and review, the research staff member needs to be considered for re-assignment and the data gathered to date needs to be reviewed carefully to ensure there have not been any irregularities in collecting or recording data thus far. If a research staff member has frequent negative encounters, these will warrant decision-making by the research leadership about the suitability of continuing this staff person in similar research activities.

At no time should the research staff member pass open and observable negative judgments on study participants, in any manner whatsoever that would identify the study participant or go beyond the research team established lines of communication. If a session or activity needs to end, this should be done as early as possible and the reason for ending described in neutral terms, such as “I am sorry, but I am having a problem that requires me to end this session. I or someone else will contact you as soon as possible to schedule another session. I am very sorry for any trouble or inconvenience I have caused by this need to stop now.” The details

of why a session or protocol is not being completed should not be told directly to the individual. If feasible, a supervisor or another research staff member should step in, although this cannot always occur. When challenged by a study participant as to why a session is being ended, the research staff member may say something like “I am not sure I am able to complete the rest of the session the way I am supposed to, so I am going to seek help from the Project Director.” Although these statements are not fully revealing, they are defensible in terms of protecting the study participant’s privacy and sense of worth, and the integrity of the overall research project.

4. Informal or unplanned contact.

Over the course of a longitudinal study, especially if study participants live in the same locale as the research staff, informal contact in the community is likely to occur.

How to handle this? It is imperative that there be no open discussion of the study participant’s engagement in the project, or how the individuals know one another, as revealed by the research staff. Brief friendly acknowledgements, such as a wave or smile or hello, are appropriate. Ideally, it is best to wait until a study participant initiates this brief contact. Extended contact is not appropriate. If the situation is beyond the control of the research staff member, such as two individuals finding themselves in a small secluded retreat for which they signed up and are committed, corrective action will be needed later so that adjustments in the data collection and data analysis process are made to prevent potential bias. In a social setting, such as a party or reception, the contact can remain superficial and distant, with the research staff member explaining, if necessary, in a brief, clear, and professional manner why he or she is maintaining a distance. In the commercial world, transactions should be kept to a minimum, but sometimes are unavoidable, such as meeting when one of the two individuals is in a retail or service setting and receiving compensation to do another job. The same guidelines for minimal contact and no discussion about the research project are in order. These informal and unplanned contacts should be documented and reported to the research leadership.

In summary, researchers are often faced with many challenges to maintain professionalism and appropriate distance when conducting research. These challenges may include: (1) contact that extends beyond that required for conduct of the study; (2) the exchange of personal and/or professional information and opinions that are not part of the planned research protocol; (3) negative perceptions by the research staff person regarding the study participant; or (4) informal or unplanned connections that involve contact between the research staff person and study participants. The strategies proposed are intended to serve as general guidelines for handling the situations. These strategies include each longitudinal research project establishing the importance of identifying and adhering to standard policies and procedures related to professionalism, appropriate inter-personal distance, and consistency in relationships with all study participants. We recommend that Institutional Review Boards seek evidence from investigators about how each study will monitor the behavior of research staff regarding interactions with study participants during the initial review process. We recognize every situation is different and it is ultimately the decision of the specific Principal Investigator, in accordance with the ethical guidelines of the IRB, to direct the research staff. We hope that these scenarios provide a useful tool for discussion and training research field staff.

Finally, we propose that longitudinal research is one of the most powerful strategies available to increase our understanding about the factors that serve to promote (versus diminish) the health, educational attainment, and personal well-being of individuals and families. Being sure that the findings generated by a longitudinal study are accurate, unbiased, and truly address the sensitive and complex issues in the study is a shared responsibility by all research team members. Research leaders have an opportunity to be sure that all research staff understand and value longitudinal research. As we have increased our training and monitoring of the issues addressed in this article, we have discovered that research staff are openly appreciative of the consideration we show to them and to study participants. We also have frequently heard that our research staff becomes more committed to the rigor and consistency in the data collection process because of their increased understanding of the potential impact of the findings. A policy we have adopted involves all research staff signing an agreement (pledge) about upholding the core principles of scientific integrity (which go beyond just those addressed in this article), as summarized in Table 1 above. Contrary to our initial fears that research staff might view signing this agreement as onerous and indicating that we distrust them, we have learned that this serves to create a strong and shared unity of purpose in our research projects. In fact, many research staff members have shared the “research pledge” and the training approach we describe in this article when they have moved on to other studies. Science is inherently a social endeavor; recognizing how our social contract and interactions with study participants can influence the scientific process – in positive versus threatening ways – needs to become an integral feature of all longitudinal research that directly engages study participants.

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Baltimore: Baltimore City Healthy Start and Johns Hopkins University

Community PI: M. Vance
Academic PI: C. S. Minkovitz
Co-Invs: P. O'Campo, P. Schafer
Project Coordinators: N. Sankofa, K. Walton

Lake County, Illinois: Lake County Health Department and Community Health Center and the NorthShore University Health System

Community PI: K. Wagenaar
Academic PI: M. Shalowitz
Co-Invs: E. Adam, G. Duncan*, A. Schoua-Glusberg, C. McKinney, T. McDade, C. Simon
Project Coordinator: E. Clark-Kauffman

Los Angeles: Healthy African American Families, Cedars-Sinai Medical Center, University of California, Los Angeles

Community PI: L. Jones,
Academic PI: C. Hobel,
Co-PIs: C. Dunkel Schetter, M. C. Lu,
Co-I: B. Chung
Project Coordinators: F. Jones, D. Serafin, D. Young

North Carolina: East Carolina University, NC Division of Public Health, NC Eastern Baby Love Plus Consortium, and University of North Carolina, Chapel Hill

Community PIs: S. Evans, J. Ruffin, R. Woolard
Academic PI: J. Thorp
Co-Is J. DeClerque, C. Dolbier, C. Lorenz
Project Coordinators L. S. Sahadeo, K. Salisbury

Washington, DC: Virginia Tech Carilion Research Institute, Virginia Tech, and Washington Hospital Center, and Developing Families Center

Community PI: L. Patchen,
Academic PI: S. L. Ramey
Academic Co-PI: R. G. Lanzi
Co-Invs: L. V. Klerman, M. Miodovnik, C. T. Ramey, L. Randolph
Project Coordinator: N. Timraz
Community Coordinator: R. German

Data Coordination and Analysis Center (Pennsylvania State University)

PI: V. M. Chinchilli
Project Coordinator: G. Snyder
Co-Invs: R. Belue, G. Brown Faulkner*, M. Hillemeier, I. Paul, M. L. Shaffer
Biostatisticians: E. Lehman, C. Stetter
Data Managers: J. Schmidt, K. Cerullo, S. Whisler
Programmers: J. Fisher, J. Boyer, M. Payton

NIH Program Scientists: V. J. Evans and T. Raju, Eunice Kennedy Shriver National Institute of Child Health and Human Development; Linda Weglicki, National Institute of Nursing Research,
Program Officers: Michael Spittel,* and, Marian Willinger, NICHD; and Yvonne Bryan*, NINR.

Steering Committee Chairs: M. Phillippe (University of Vermont) and E. Fuentes-Afflick* (University of California - San Francisco School of Medicine)

*Indicates those who participated in the planning phase of the CCHN.

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