**A Practical Framework for Navigating Ethical Challenges in Collaborative Community Research**

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## A Practical Framework for Navigating Ethical Challenges in Collaborative Community Research

Joyce Hunter, David Lounsbury, Bruce Rapkin, and Robert Remien

### Abstract

To effectively mobilize community-based organizations (CBOs) and international non-governmental organizations (NGOs) in research, important ethical issues must be addressed. A memorandum of understanding (MOU) approach, providing a framework and a tool to be used for establishing effective community-research partnerships, was developed by the Community Collaboration Core (CCC) of the HIV Center for Clinical and Behavioral Studies. Aims of the CCC include: (1) Initiating and sustaining successful partnerships in HIV prevention research in areas of sexuality, gender, mental health, and of mutual benefit to communities; (2) Advancing the science of collaboration among researchers, practitioners, and government in HIV prevention. Developed and assessed over a two-year period by researchers, CBO/NGO and public health representatives, this MOU can be used by potential research and community partners to address the most important issues early in a collaborative research project. Clarifying essential roles, responsibilities, and relationships, establishing trust and transparency in that process, can guide collaborators in planning the important steps for beginning and sustaining an ethical and successful research project.

### Introduction

In order to effectively mobilize communities and settings such as public hospitals, clinics, churches, civic groups, and other community-based organizations and non-governmental organizations (CBOs/NGOs) for full participation in scientific projects, a mutual understanding of the purpose and aims of the research and an explicit agreement to work collaboratively is essential. Failure to do so threatens the delicate balance between the need to achieve beneficial outcomes in research and the need to preserve valued social norms and characteristics of local communities (Berger & Neuhaus, 1996; Rapkin et al., 2006; Ribisl & Humphreys, 1998). Achieving and maintaining such a balance is extremely challenging, as evidenced by the experiences of a growing number of investigators who have attempted to apply community-focused, collaborative methods in their epidemiological, clinical, behavioral, and health services research (Chung & Lounsbury, 2006; Green, 2001; Israel, Schulz, Parker, & Becker, 1998; Lasker & Weiss, 2003; Schensul, 1999; N. Wallerstein, 1999).

This challenge is clearly evidenced in the global AIDS crisis, where strategies in the fight against AIDS must be continually reexamined and improved. Many assert that further progress in reducing the burden of HIV can only be achieved through collaborative, community-based interventions (Trickett, 2005). Methods that use participatory and action-oriented research designs are a promising way to address the social, economic, cultural, and religious factors often associated with disparities in HIV prevention, treatment and care (Minkler & Wallerstein, 2003; Wallerstein et al., 2003). Many well-conceived community-based HIV studies and interventions have fallen short of their aims (Foster-Fishman, Berkowitz, Lounsbury, Jacobson, & Allen, 2001).

Researchers and community partners alike have noted many ethical challenges in creating and sustaining productive relationships, pointing to inherently divergent professional mandates and an inequitable distribution of power and control over the research process as the main culprits to achieving stated project outcomes (Berger & Neuhaus, 1996; Bond & Keys, 1993; Fawcett et al., 1995; Kahn, 1982; Riger, 2002; Sarason, 1978; Zimmerman, 1995). One problem concerns the lack of understanding on the part of the researcher of the composition of the "community." Likewise, social and political realities brought to the partnership, including the constraints faced by community partners, can all lead to diminished effectiveness in collaboratively developed and implemented research processes, beginning with the development of the research questions (Green & Mercer, 2001; Stoecker, 2005; Trickett & Pequegnat, 2005). Unresolved problems serve to compromise the project's potential to create new knowledge and foster sustainable community change, an outcome that many have declared to be ethically unacceptable (Boser, 2006; Currie et al., 2005; Khanlou & Peter, 2005). To the degree that collaborative approaches are needed to

effectively combat HIV, our failure to work together unjustly compromises the health and well-being of entire communities.

As new partnerships are being formed to address the AIDS crisis, there is an urgent need to forge a working understanding of roles, responsibilities, and relationships among collaborators in projects (Davis, Olson, Jason, Alvarez, & Ferrari, 2006; McKay, 2001; Rapkin et al., 2006). For example:

- Community-based service providers have reported that they still play too limited a role in helping to conduct basic science projects, such as studies of HIV and immunity, vaccine development, new medical treatments (Koniak-Griffin, Nyamathi, Tallen, Gonzalez-Figueroa, & Dominick, 2007; Trussler, Perchal, & Barker, 2000).

- Public health authorities have been criticized as being unable or unwilling to implement data-sharing agreements with health service providers and their research partners, who need such information for programming planning and research proposal development (Grazier, Hegedus, Carli, Neal, & Reynolds, 2003).

- Community concerns regarding research ethics are often neither adequately documented by researchers nor properly investigated by Institutional Review Boards (McClure, Delorio, Schmidt, Chiodo, & Gorman, 2007; Schuppli & Fraser, 2007); and

- A research bias for funding treatment and supportive care services relative to much needed primary prevention has exacerbated the impact of HIV in many high prevalence communities (Holtgrave & Kates, 2007).

A deep understanding and appreciation of the inherent conflicts of agenda and perspective between researchers and their community partners, and the broader community affected by the project, must be emphasized (El Ansari, Phillips, & Hammick, 2001; Foster-Fishman et al., 2001; Weiss, Anderson, & Lasker, 2002). The process of developing successful collaborative community research projects takes time, but building trust and respect and fostering transparency are essential (Davis et al., 2006; El Ansari, Phillips, & Zwi (2002); Public Health, 2002). Joint decision making, including a continuous process of review and reassessment, and if need be, modification of the project, must be instituted (Boser, 2006). Within this process, there must be a provision for dealing with change, whether it be from changes

in funding levels, staff turnover, or other unforeseen problems that are bound to occur (Stoecker, 2005).

An important ethical concern is the effect of the researcher and the research project on the community. Public health professionals addressing an epidemic such as HIV/AIDS have faced challenges in bringing about changes in sexual behaviors and reproductive health. Sometimes the interventions initiated are in conflict with a group's values and norms and, as a result, will not be sustained (Schensul, 2005). Further, positive changes brought about today may lead to unintended consequences in the future. For example, unintended consequences may involve reallocation of resources that negatively affect one community group relative to another (Kelly, Azelton, Burzette, & Mock, 1994).

While communities are more often thought of as in need of education and assistance to enable them to participate as partners in research, academic researchers are at least as much in need of education and support in identifying community partners and establishing successful and equitable collaborations (Shoultz et al., 2006). With this need in mind, the Community Collaboration Core (CCC) of the HIV Center for Clinical and Behavioral Studies was established in 2003. Its primary purpose was to study and promote effective community-research partnerships. The CCC, of which the authors were active members, included representatives from several academic/research agencies, community-based organizations, and government agencies from the New York City metropolitan area. The specific aims of the CCC included: (1) To initiate and sustain successful partnerships to conduct HIV prevention and treatment research and program activities that are related to key priorities of the HIV Center, such as sexuality, gender, and mental health and that are of mutual interest and benefit to communities; and, (2) To advance the science of collaborative process in the field of HIV prevention and treatment by developing and disseminating theoretical models and methods that may then be applied to other areas of health research behavior.

One of the products of the CCC was a tool, a memorandum of understanding, for developing effective community research partnerships. This framework was informed by CCC members' professional experiences, including insights gained from a series of community outreach initiatives organized and facilitated by core members over a two-year period (2004-2005). This tool serves as a tool for initiating an open dialogue among prospective research and community partners about

the purpose, context, methods, and outcomes of a proposed community-based research project. It is intended to facilitate open communication and thoughtful planning among all potential project partners, helping to affirm each partner's readiness to begin and shaping the project's activities toward starting and sustaining a successful project.

**Developing the Framework for Establishing Community Research Partnerships**

Over the course of two years, the CCC facilitated a series of activities at various events that served to foster the development and assessment of the framework. These activities are briefly described in chronological order, below:

**Exploratory Focus Groups.** In order to begin to identify the content of the framework, two focus groups were conducted. These groups were organized as part of CCC's first Annual Community Partnership Conference, held in October 2004. The one-day conference entitled "Building Partnerships for HIV Research and Evaluation with the Community" attracted approximately 80 participants (34% from AIDS service organizations; 17% from state and local public health agencies; and 49% researchers from the HIV Center and other academic institutions in New York City).

Participants of the first focus group included representatives of six well-established community-based HIV service organizations in New York City. Participants of the second group included eight senior social and behavioral scientists, the majority of whom had appointments at the HIV Center. A 'fishbowl' design for the groups was used, so that each group had a turn participating while the other group observed.

The following questions were posed to the focus group of community representatives: What are the benefits to community-based organizations of participating in research? What challenges do community-based organizations face when they participate in research? What do researchers need to bring to the table? What kind of guarantee would you want before signing on to a collaborative research project? What would need to be established in order to allow your staff to work directly with researchers? Similarly, to work directly with your clients? What tensions does the prospect of collaborating in research conjure among your organization's leadership, staff, and clients? What are your impressions of researchers? What are their values and beliefs regarding participatory projects? What is your definition of a 'culturally competent' researcher? Do

researchers share your concept of time? What are possible negative outcomes that could happen to an agency that becomes involved in a research project? and, finally; If you were to draft a written agreement, or memorandum of understanding, with a research partner, what would be your single most important point to include?

A similar set of questions was posed to the group of researchers: Why involve the community in your research? From your perspective as a researcher, what is appealing about community-research partnerships? How does working with the community serve your research? (i.e., does it improve the quality of your data? Can the community help validate results?) For what parts of the research project do you actually involve a community partner in your research? How do you adopt a research project to unanticipated or changing situations within the CBO? (e.g., Staff changes? CBO priorities?); How do you manage the fidelity of the design or implementation of the intervention? How can researchers adjust to work within the shorter timeframe accustomed to community-based service organizations? Do you believe that community agencies have the perception that researchers are powerful? How do you communicate all the financial constraints that researchers face? How do you define 'community'? When you see a problem within a partner organization, when and how do you intervene? When wouldn't you intervene? How do you anticipate, or plan for, the end of the research partnership or relationship at the beginning? If you were to draft a written agreement, or memorandum of understanding, with a community partner, what would be your single most important point to include?

The responses offered by participants of both groups in turn and the general discussion held with all conference attendees that followed served to identify important issues in managing the quality of collaborative social and behavioral research in HIV/AIDS. It also prompted a discussion of alternative models for gauging the capacity of community settings for undertaking various research and service collaborations. Conference participants also recommended that the HIV Center and the CCC articulate the scientific issues that affect standards for planning, implementing, and evaluating research projects done in partnership with communities. Post-conference, CCC members coded and summarized the material generated by the focus group participants. Results were used to draft an outline of what would become the memorandum of understanding, a framework for establishing

community research partnerships, as presented in
Table 1. This tool is most useful when implemented
as early as possible in the collaborative research
process, prior to formulation of the research design.

**Table 1 – Framework for Establishing Effective Community Research Partnerships**

| | |
|---|---|
| **Entré** | Review and define the social, economic, language, and cultural characteristics of the community involved in the research. Identify key stakeholders (i.e., researchers, community leaders, CBOs/NGOs, government agencies) who need to be involved in the research to effectively define the problem (e.g., health care, education, employment, etc.). Develop strategies that foster the involvement of stakeholders. Ensure ways of appreciating the context of the community that will shape problem definition. Make use of pre-existing relationships or networks among stakeholders that can facilitate entrée. |
| **Goals & expectations** | Identify the goals and expectations of each potential partner. Discuss the pros and cons of working together, giving special attention to completed or on-going joint projects. Define principles that promote transparency and mutual exchange of information. |
| **Logistics** | Foster a critical understanding of each partner's limitations to contributing to the research, with particular attention paid to competing priorities. Work to elicit concerns about the collaborative process, giving careful attention to issues of partners' readiness to participate. Assess potential partners' capacity to engage in the research project including their time demands, available work space and staffing. Identify important administrative functions and activities to facilitate the research project. Negotiate timelines that meet specific aims of the research. |
| **Risks, benefits, and privacy rights** | Researchers and their partners must discuss the matter of privacy rights and ensure confidentiality of participants' data. Benefits and risks to participating partners and their clients must be communicated in a culturally sensitive manner and clearly understood in the language of targeted communities. In addition, researchers must work with representatives of participating CBOs/NGOs and other stakeholders to protect from 'pathologizing' members of targeted groups or communities, or from damaging the reputation of participating organizations. |
| **Ownership** | As thoroughly as possible, researchers and community partners must agree about who will own specific products, including data, instruments, manuals, and intervention materials. In addition, policies regarding authorship on manuscripts and other presentations must also be addressed. Discuss the potential for dissemination of research products, including research findings, program curricula, or other materials among new as well as current partners. |
| **Deliverables** | Researchers and community partners should clarify their respective roles and responsibilities within the context of the research project. Specific work plans and contracts should be established during project startup. |
| **Flexibility/ adaptation** | A mechanism must be created to allow for modification when unanticipated events impact the research project. To the extent possible, researchers and community partners should have alternates to key positions in the project team (i.e., establish co-chairs). |
| **Remedies for problems** | Feedback mechanisms for monitoring of project activities to ensure quality and address problems as they arise should be devised. Contingency plans, with consequences for non-delivery or delays, should be established. |
| **"Escape" clause** | A provision should be available to end the collaboration, when and if needed. |

**Confirmatory Workshops.** At an international HIV/AIDS research conference in April 2005, the authors conducted workshops for researchers and community representatives interested in community research partnerships. These workshops began with a general presentation of the framework as a tool for establishing effective community research partnerships. Next, multiple break-out groups of from 6-12 persons were organized, each with a mix of participants from research/academia, community-based organizations or non-governmental organizations (CBO/NGO), and government/policy-

makers. One member of each group was selected to facilitate discussion about the framework and its relevance to their own work in their own country. Another group member was chosen to take notes and report about the full group at the end of the break-out session. A series of questions were to be discussed by each group, as follows: Is the partnership framework adaptable to your needs? How would you apply this framework to the project(s) you are involved with in your region or community? What perceptions do you have of each other? (i.e., as researchers, community members, government agents, people living with HIV); What values guide your work? What is a 'culturally competent' research partnership? What do you think could be the most troublesome outcomes of a research partnership? If you were to use our framework to draft a written agreement with a partner to develop a research project, what would be your single most important point to include?

A general discussion (25 minutes) followed the break-out group discussions, during which a number of observations and comments were offered by workshop participants about research partnerships and about the utility of the framework. Observations provided by participants about the challenges of participating in a community research partnership, based on their own professional experiences in the field, were diverse. The most daunting challenges reported were issues raised by CBO/NGO representatives, the most frequent issue relating to the difficulties they have had in finding the time and resources necessary to develop the relationships and the trust needed for a successful collaboration. Many CBO/NGO participants also voiced frustrations about unequal distribution of power and control over the research process in previous partnership experiences. (In one project, for example, researchers ran out of funds and left without completing the work and without plans or resources to continue the program.) Several individuals stated that if a framework of this type had been used to develop the project collaboratively, their experience might have been better. The *escape clause* at the end of the document was seen as an important tool allowing agencies to disengage from the research project if need be. There was agreement among the CBO/NGO participants that this model would be a valuable tool to help develop research partnerships.

Recognizing that researchers do bring knowledge and experience to the community, they are usually valued and welcomed. However, researchers have not always been open or sharing with their community partners. CBO/NGO representatives also noted that researchers need to inform themselves better about

the communities they plan to work in. They should be aware of and deal with broader issues of concern to a community, not just their research questions. It was also noted that although researchers are skilled at data analysis, they do not always take care to give meaningful or timely feedback to their community partners. Many participants also questioned the utility of the high volume of research being carried out in some locations but not in others. Also, it was strongly felt that community partners need tangible compensation, either monetary or in-kind, and opportunities to develop skills that will help them as frontline providers develop, grow, and succeed.

What it means to be part of a research partnership network was discussed at length. Before reaching consensus, the group, both the researchers and the CBO/NGO representatives, engaged in a long discussion about what is community and who are the new community members affected by HIV/AIDS. The group discussed ways to share power and resources, including ways to bring in needed funding and in-kind resources for research. In addition, CBOs/NGOs expressed a need for researchers to be in partnership with them as they plan and implement new services and programs. Researchers present, affirming CBO/NGO representatives' concerns, agreed that they need to become more culturally competent about new communities and must spend time building relationships with its stakeholders before initiating a research project. Building trusting relationships requires spending the time needed to develop the working relationship, including time to discuss and plan the research agenda fully. They also agreed that communities are complex, and such a partnership should include issues of concern to the community as well as those of the researcher, including power issues that must be addressed.

Both CBO/NGO representatives and researchers noted that research outcomes could reveal a message that no one wants to hear and that could stigmatize a community. For example, one researcher in the group pointed to how the U.S. Congress used results of some early behavioral studies in HIV to curtail funding for prevention. However, group members noted that the pros outweigh the cons in conducting such studies. These studies were important for the development of tailored prevention programs for diverse communities, such as men who have sex with men in communities of color. Problems can arise based on how results are presented to politicians, who have their own priorities and agendas, some of which may contradict the purposes and values of the researchers and their community partners.

The question for many CBO/NGO participants was: Are these studies necessary? Also of concern to them was the practice of implementing models developed in the west by western researchers in different cultural contexts. Both CBOs/NGOs and researchers have been experiencing frequent cuts in funding, resulting in diminished research efforts and prevention of the dissemination of interventions that have been developed, and, in many cases, resulted in termination of a project and the partnership. In summary, the workshop helped valid the usefulness of this collaborative framework for international as well as U.S.-based research partnerships.

**Field Testing: Memorandum of Understanding.**
Based on the information and validation gathered at the international workshops, this framework was further assesses in its utility as a tool for promoting collaborative research projects. In July 2005, the CCC held its second annual conference, "Working Together: Partnerships to Address the Impact of HIV on Families," in New York City. This conference was held in conjunction with the National Institute of Mental Health's (NIMH) International Research Conference on the Role of Families in Preventing and Adapting to HIV/AIDS. Working with representatives of the New York Community Trust, the NY State Department of Health's AIDS Institute, the NY City Department of Health and Mental Hygiene, the Health Resources and Services Administration (HRSA), the NY City CHAMP Program in the Bronx, and other community agencies, a day of speakers and working groups focused on the challenges and rewards of joint research, community, and government collaborations. A total of 113 people from 63 different organizations in the New York City metropolitan area participated. More than half represented community-based organizations (42%) or hospital/clinic (12%), followed by HIV/AIDS researchers (32%) and public health practitioners, policy-makers, or other government representatives (14%).

After a morning of presentations and discussions about the current challenges in the fight against HIV and the need for community-focused interventions in prevention and treatment, the remainder of the day was dedicated to building on information collected in a pre-conference survey of participants, an assessment of previous experience with and interest in a wide range of HIV-related topics. Eight separate workgroups were each organized around a chosen HIV-related topic of interest and were given the task of planning a community research project in their common areas of interest, using the MOU. As in the workshops, each group included a mix of participants

with ties to community, research, government, and clinical settings (average group size of 15). Co-facilitators, responsible for guiding the group's activities, were Post-Graduate Fellows from the HIV Center, CCC Core Members, and volunteers from NYC CHAMP. Facilitators were trained by Drs. Hunter and Lounsbury.

Data from a pre-conference survey indicated that participants had most experience with programs that helped reduce risky sexual behaviors and that assisted PLWHA with medication management. However, participants had highest interest in developing new programs to address HIV-related stigma and discrimination, promote mental health issues in treatment and care, as well as programs that help persons reduce risky sexual behavior. Survey data also indicated that participants' had substantive experience conducting HIV research. They reported most experience in research about HIV prevention, followed by studies of stigma and discrimination among people living with HIV and AIDS (PLWHA), and about assessing HIV-related knowledge, attitudes and beliefs. Participants had highest interest in designing new studies to address matters of disclosure, promote medication management, and teach communication skills. These data determined the final topic areas addressed by the workgroups (see Table 2).

**Table 2 – Workgroup research topics**

| Group 1 | Primary and Secondary Prevention/Intervention with Adolescents |
|---------|----------------------------------------------------------------|
| Group 2 | Primary and Secondary Prevention with Adults |
| Group 3 | Mental Health Issues in Prevention and Care, Including Stigma and Dealing with Disclosure |
| Group 4 | Women's HIV Health Issues: Prevention and Treatment |
| Group 5 | Women over 50: Prevention and Treatment |
| Group 6 | HIV Vaccines and HIV Testing Issues |
| Group 7 | Family Issues in Treatment and Care, Including Special Needs of Youth and Adolescents |
| Group 8 | Living Long-term: Mental Health and Treatment Issues, Including adherence, harm reduction/substance use |

Each workgroup was instructed to envision itself as a 'real world' collaborative research partnership. Workgroups were directed to identify priority issues regarding their topic areas; identify a researchable issue or project that could be undertaken by a community-partnership; begin to develop a work plan that included research aims, critical partners, organizational tasks, and capacity-building and funding needs. In addition, workgroups members were asked to assess foreseeable challenges and rewards to implementing their envisioned partnership. To guide this effort, the framework for community research partnership was applied.

While the workgroups identified many, specific pressing issues in HIV prevention and care, the process of developing a research question of interest to all group members proved to be most challenging. Each workgroup engaged in intense discussion (sharing concerns, ideas, and visions) before identifying one or more researchable questions. Feedback from conference participants indicated that research about developmental changes and HIV, prevention among persons over 50, as well as mental health of long-term survivors were among the most compelling topics for future investigation, as indicated by a sample of the research questions that were shaped by the workgroups: "Among adolescents who are living with HIV, what is the role of the caretaker over time?" [Group 1]; "How can mental health practitioners engage adolescents and their caretakers in care?" [Group 1]; "How effective is a peer education testing promotion among women over 50?" [Group 5]; "How are health providers meeting the long-term mental health needs of HIV positive individuals and their families?" [Group 8]). Important challenges and rewards to partnerships, as identified by the workgroups, were also identified (see Table 3). In general, an evaluation of the afternoon workgroup sessions indicated that this framework was very useful to participants in these hypothetical research teams.

**Table 3 – Important challenges and rewards to research partnerships**

| Challenges to Partnerships: | Rewards to Partnerships: |
|---|---|
| 1. Lack of meaningful feedback | 1. Generating new knowledge/Learning new things |
| 2. Lack of time | |
| 3. Power issues (ego; ownership of data and other products; cultural dynamics) | 2. Improving outcomes for the community |
| | 3. Gaining access to new resources |
| 4. Unclear goals / | 4. Sharing |
| unclear priorities | resources/Sharing the burden |
| 5. Bureaucracy (IRBs and state and local governments) | 5. Building new alliances/Helping each other |
| 6. Commitment and follow through | 6. Improving resources and programs for communities |
| 7. Building relationship with large groups | 7. Improving our understanding of the community |
| 8. Community buy-in | 8. Making new friends |
| 9. Lack of funding | |
| 10. Lack of support/ resources for participation | |

## Summary

We believe the process behind the development of this framework for establishing effective community research partnerships demonstrates its utility. Using this framework, potential research partners can identify and address the most important matters concerning their collective capacity to collaborate on a given research project. After carefully reviewing all the points in our framework, the partnership should be able to ask the following questions, and answer them to its satisfaction:

1. Does each partner affirm a feeling of mutual trust and transparency, or shared values and open communication among members, in moving forward with the research project?

2. Are each partner's roles, responsibilities, and expectations sufficiently complementary and compatible for the research project? Are they agreed to and do they reflect individual and shared interests of members.

3. Collectively, do we (partners) have the skills and resources to meet the aims of the research project?

4. Have we (partners) identified a means for managing contingencies that may impact the success of the partnership?

5. Have we (partners) identified and agreed upon strategies for quality assurance of the research design and its potential for positive contributions to the community?

The importance of careful reflection on these questions is supported by Boser (2006), who notes that community partnerships for research must explicitly seek to establish a working group that understands both the science and the social context of

the project to be conducted. We concur with Boser that questions such as those included in this framework should be raised periodically over the course of the research partnership. Revisiting is a strategy to anticipate, to the greatest extent possible, the ways in which partners and other stakeholders may be impacted, either adversely or beneficially. The objective is to ensure that a process for ethical review is integrated into each stage of the research partnership, beginning at start-up and continuing through its completed implementation.

## Conclusion

Both researchers and community members must be involved in all aspects of forming a community-research partnership. Government and private funders must also be made aware of the importance of and the time and resources involved in laying the groundwork for ethical community research practices. The MOU approach presented here is a strategy to address new rules of engagement between researchers and community partners that incorporates the principle that all partners are partially accountable and responsible for the integrity of the research project. This framework for community research partnership development, through ethical principles and practical discussion points, can promote effective collaboration, allowing collaborating stakeholders to anticipate, to the greatest extent possible, the ways in which individuals, groups, and communities could participate in and be affected by a research process, both in terms of potential benefits, and, necessarily, adverse consequences as well.

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