

**Clean Air Coalition of Western New York
Academic Research Policy
May 20, 2010**

Manifesto

Research by the Clean Air Coalition of Western New York is about the true sense of empowering individuals to understand their reality in the path of environmental pollution. Given science and its limits surrounding conclusive evidence between exposure and illness, it makes sense to focus on the basic needs that provide individuals with a high quality of life. The issues are about human rights and justice: human beings have the right to exist in a space that provides an environment free from toxic pollution. It is an injustice to exist in a space where another body, state or corporate, knowingly pollutes the environment and one's body is negatively impacted by this pollution.

The Clean Air Coalition's research will fill a gap in existing literature and practice that focuses on the connection between exposure and illness, but rarely touches on the quality of life issues that are inherent to each community. If a community's quality of life is impacted, but the exposures do not fall within the deemed statistical significance necessary for the state to act, consideration should still be given to the community's right to pursue life in a clean, healthy environment.

In the model of participatory action, we seek to:

- Serve to improve social practice by changing it
- Empower individuals by having them tell their stories of environmental justice
- Encourage authentic participation
- Establish a pathway of knowledge from the individual level to the institutional level
- Help participants objectify their own experiences
- Make critical analyses of the social context of the problem
- Help participants theorize about solutions to the community problem

Purpose of Research for the Coalition

To develop the information and evidence base necessary to support effective advocacy on behalf of the community, including:

- Community education
- Community building
- Change in public policy via legislation and regulatory activity

Fundamental Principles

1. Communities have the right to know, to understand, and to participate in decisions that affect health and equity. The purpose of community-based research projects is to enhance understanding of issues affecting communities and to develop, implement and evaluate

plans of action that will address those issues in ways that benefit the community. Therefore, research should be driven by the needs of the community and of the Coalition acting on behalf of the community.

2. Research, community education, and community building are intertwined and promote the objectives of increasing the community's trust, increasing community engagement in environmental issues that affect it, and developing the "critical consciousness" necessary for community members to act in their own interest and organize for change.
3. Community-based research projects are designed in ways that enhance the capacity of residents to participate in the process.
4. Community-based research projects produce, interpret and disseminate the findings to community members in clear language respectful to the community and in ways that will be useful for developing plans that will benefit the community.
5. Specific policies relating to research conducted at the request of the Coalition for purposes identified by the Coalition:
 - a. The Coalition controls the information collected through community studies conducted on the Coalition's behalf. The Board must approve the study before it is conducted, as well as resulting presentations and publications before they are submitted outside of the Coalition.
 - b. Academics wishing to use data collected through Coalition studies must submit a proposal to the Coalition's Board of Directors who will vote to approve or deny access to the data.
 - c. A majority vote of the Board is required for approval with regard to both Section 5.a. and Section 5.b.
 - d. Studies conducted on behalf of the Coalition will adhere to best practices for protecting the rights, welfare, and privacy of human subjects. Proposals will be submitted to the institutional review boards of participating academic researchers for approval (See Section 8).
6. Specific policies relating to funded research collaborations between the Clean Air Coalition and academic researchers:
 - a. The Coalition may partner with academic researchers to conduct studies designed to contribute to the body of knowledge as well as support community action. Specific policies regarding the study and control and use of the data will be negotiated between the Coalition and academic researchers.

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 - b. Collaborations with academic researchers will be conducted in conformance to Sections 1 through 4 and protect the rights, welfare, and privacy of human subjects as stated in Section 5.d. and Section 8.
 - c. A majority vote of the Board is required for approval of the Coalition's participation in a collaborative research project.
7. Any publications resulting from research will acknowledge the contribution of community affiliates, who will be invited, as appropriate, to collaborate as co-authors.
8. Data should be collected and maintained according to current best ethical practices, including respecting the rights of all participants, doing no harm, and maintaining confidentiality of information.
 - a. Measures for accomplishing this include:
 - 1) Obtaining from study participants informed consent that conforms to current standards, including the right to refuse to answer any question and to terminate participation at any time without consequence to the participant.
 - 2) Removing personal identifying information from the data as soon as is practical.
 - 3) Storing the data in a secure location: under lock and key in the offices of the academic researchers who collect and analyze the data.
 - 4) Restricting access to the data only to the individuals who collect and analyze it.
 - b. Each study will be submitted for review and approval by the appropriate institutional review boards of the academic researchers conducting the study. A copy of the IRB application and IRB approval and comments will be available to the community.
9. Although members of the Coalition Board of Directors will not have access raw data, information involving specific community members is sometimes discussed at Board meetings and in other conversations among Board members. Therefore, it is necessary that Board members sign and abide by a confidentiality of information agreement that adheres to best practices for such agreements. Conversations pertaining to individuals in the study will take during an executive session of the board and the notes will not be recorded in the minutes.