



Institutional Review Board

University of Missouri-Columbia

Standard Operating Procedure

Community Outreach

## Community Outreach

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#### 1.0 Purpose

To provide information to the community regarding the rights of a research participant as a volunteer and provide guidance when the research involves the community.

#### 2.0 Scope

The SOP applies to all human subject research falling under the purview of the University of Missouri Institutional Review Board.

#### 3.0 Policy/Procedure

##### A. Research Participant as a Volunteer

- I. The IRB will provide a contact number to each participant consented to participate in research in which the IRB has jurisdiction. The number should appear on every informed consent document following a statement about whom the participant may contact regarding questions (i.e., need for additional information), concerns, or complaints

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regarding his/her rights as a research participant.

- II. The IRB has a participants section on the website to provide potential and current research participants additional information regarding participation in a research study. The website is located at: <http://research.missouri.edu/irb/participants>
  - III. A participant brochure is available entitled, “Becoming a Research Volunteer” developed by OHRP and includes the following:
    - A. A lay definition of research;
    - B. Why research is important;
    - C. Points to consider;
    - D. Questions to ask about participation in a research study;
    - E. Who to contact for questions concerning participation in a research study.
  - IV. A Veteran Participant brochure entitled, “I’m a Veteran: Should I Participate in Research?” has been developed by the Department of Veterans Affairs and includes the following:
    - A. A lay definition of a research study;
    - B. List of questions to ask before agreeing to participate in a research study;
    - C. Lay description of the informed consent process;
    - D. Information in the informed consent document;
    - E. Who will see my medical records and/or research records if I participate in a research study;
    - F. A description of the IRB and its role; and
    - G. A description of the VA R&D committee and its role.
  - V. UMC faculty who are also (VA) investigators can participate in VA Research Day, held each spring nationwide to educate both the veteran population and the campus community regarding research protocols and programs occurring within the VA.
  - VI. UMC faculty and the HS IRB have the opportunity to participate in the UMC School of Medicine “Research Day” held each fall.
  - VII. Representatives from the IRB and Human Research Protections Program participate in community outreach activities such as speaking engagements to patient support groups or other community organizations.
  - VIII. The IRB along with the Human Research Protections Program will annually evaluate the quality and effectiveness of community outreach activities. Improvements will be made as needed based on this evaluation to promote continual improvement of community outreach activities.
- B. Research Involving the Community
- I. The IRB needs to have an awareness of the unique challenges that may present themselves when research seeks to engage the community in the process.

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- A. There is increasing community (lay) involvement in research.
  - B. There needs to be greater awareness of the potential for community or collective risks in research.
  - C. There is rising demand for and occurrence of disclosure of individual results to research participants.
- II. Additional considerations for the IRB:
- A. Community participation:
    - a. Who is the community
    - b. Who represents the community
    - c. Who speaks for the community
  - B. Identify Roles
    - a. Researcher/IRB/Community
    - b. Educate the IRB
    - c. Encourage community participation on the IRB's- Currently all panels have community participants
  - C. Dissemination of Research Results
    - a. How do research results get re-presented
    - b. Are findings presented in a meaningful way for community members

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