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## I. PURPOSE

The purpose of this SOP is enumerate the additional considerations and resources needed for planning and executing community-based participatory research (CBPR).

## II. POLICY STATEMENT

When the CHOP IRB reviews CBPR, they will consider, in addition to the criteria for IRB approval as outlined in the federal regulations, any appropriate factors related to the community setting. These will include but are not limited to the following additional protections as relevant:

1. Creating and using advisory panels which are comprised of in whole or in part prospective participants or parents of prospective participants representing the population that will be the subject of research (e.g., a rare disease, HIV/AIDS, disenfranchised communities, etc.)
2. Involving members of a definable group (same examples as above) as members of the research team in order to assist in the identification and recruitment of potential participants.
3. Utilizing Centers of Excellence or Institutes within CHOP that focus on understanding and improving health issues facing defined populations or conditions in which the research will take place (e.g. reducing teen pregnancy, educating children on proper diet, etc.).


## III. SCOPE

This policy applies to research conducted in community-based settings.

## IV. DEFINITIONS

Community-Based Participatory Research (CBPR): CBPR is research that is conducted as an equal partnership between traditionally trained "experts" and members of a community. In CBPR projects, the community participates in the research process. CBPR projects start with the community. CBPR encourages collaboration of "formally trained research" partners from any area of expertise, provided that the researcher provide expertise that is seen as useful to the investigation by the community, and be fully committed to a partnership of equals and producing outcomes usable to the community.

Community: is often self-defined, but general categories of community include geographic community, community of individuals with a common problem, disease, condition or issue, or a community of individuals with a common interest or goal.

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## V. PROCEDURES

### A. Additional Steps when the CHOP IRB Reviews CBPR

#### 1. Assessment of Planning Process

The IRB will assess the additional protections proposed by the investigator when community-based research is proposed. The IRB will take into account whether or not the investigator has implemented one or more of the following:

- (a) Advisory Boards developed to assist in project development and execution. Membership on the Board may vary but should be appropriate to the proposed research.
- (b) Representatives from involved communities which can include individuals or parents of individuals who are representative of the community.
- (c) Consultation or partnership with one or more Centers of Excellence or Institutes at CHOP should be considered. In particular the Community Pediatrics Advocacy Program (CPAP), may be used as a model. An outline of the process used by CPAP is in the Appendix.

#### 2. Community-Based Investigative Team Members

When the CHOP Principal Investigator includes a study team member who is based in the community, the IRB will receive a copy of this individual's CV or relevant information to help the IRB ascertain the community team member's expertise in the area. Additionally, this individual will be required to demonstrate appropriate training such as CITI or other similar training.

#### 3. Community-Based IRB Approval

The CHOP IRB will consider whether or not there is a community-based IRB that can oversee the research and may ask for a copy of the community-based IRB's approval.

### B. Risks Assessment


When reviewing community-based research, the IRB will consider potential risks to the entire community and not just to the individual participants.

## VI. APPLICABLE REGULATIONS AND GUIDELINES



## VII. REFERENCES TO OTHER APPLICABLE SOPS

SOP 402: Criteria for Initial IRB Approval	
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## VIII. RESPONSIBILITIES

Title	Responsibility
Director, HSR	The Director will provide consultative services to investigators to review resources available within CHOP related to CBPR.

## IX. ATTACHMENTS

Introduction to the Community Pediatrics & Advocacy Program (CPAP)  
<https://at.chop.edu/pediatrics/cpap/intranet-pages/welcome>.

## X. REVISIONS:

9/25/2018 Revised for minor administrative edits.

## XI. APPROVAL

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Director, Human Subjects Research

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Date

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Chair, Committees for the Protection of Human Subjects

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Date

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## **XII. APPENDIX**

### **A. Community Pediatrics and Advocacy Program at CHOP**

The Community Pediatrics and Advocacy Program (CPAP) at CHOP is a program that promotes community interaction and support for children. The goal of CPAP is to broaden the focus of pediatric resident education to include an understanding of and responsibility for the health of all children in their community. CPAP has developed a curriculum and outlined core skills that will enable residents to effectively advocate for children, adolescents and their families by working in partnership with community-based agencies. CPAP aims to create a framework for professional development by providing opportunities to understand, experience and practice core advocacy skills.


The CPAP website is available on the CHOP Internet Site at it contains valuable links to CHOP and outside resources:

<https://at.chop.edu/pediatrics/cpap/intranet-pages/welcome>

### **B. Core Advocacy Skills**

The CPAP promotes core advocacy skills:

1. Needs Assessment
  - (a) Defining the problem in context and as clearly as possible
  - (b) Identifying key stakeholders and other sources of information
  - (c) Exploring previous and ongoing efforts to address the problem
  - (d) Interpreting critical information to create a meaningful and obtainable plan of action
2. Networking
  - (a) Initiating contact with key stakeholders from various communities
  - (b) Fostering professional interactions with multiple disciplines
  - (c) Maintaining collaborative relationships
  - (d) Coordinating collaborative efforts to attain mutually identified goals
3. Program Development
  - (a) Creating a plan of action that responds to a specific community need
  - (b) Developing an infrastructure to meet specific goals
  - (c) Acquiring necessary funds for implementation
  - (d) Implementing programs, focusing on sustainability

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- (e) Evaluating feedback and incorporating recommendations
- 4. Cultural Effectiveness
  - (a) Building trust with individuals and communities
  - (b) Speaking effectively to community groups, families, and media personnel in public settings
  - (c) Preparing data to educate, affect attitudes, or obtain funding from the target audience
- 5. Policy Development
  - (a) Identifying areas of public policy amenable to change
  - (b) Researching history of specific policy areas and established guidelines on related health outcomes
  - (c) Designing a plan of action that builds on incremental policy change to achieve a broader goal
- 6. Educating Elected Representatives
  - (a) Building a reputation as child/adolescent policy expert on interest area through effective networking and public presentation
  - (b) Identifying key representatives and staff members
  - (c) Initiating contact and maintaining dialogue with key representatives and staff members
  - (d) Lobbying effectively to key representatives and staff members, concisely communicating information pertaining to a specific health outcome
  - (e) Listening non-judgmentally and questioning appropriately
  - (f) Recognizing different perspectives of health and illness