The Role of the ICAB Member

Goals of the Presentation

- ICAB Members will understand their important role in representing the perspective of the community in IMPAACT research.
- ICAB members will know the expectations for site CAB and ICAB representation.
- ICAB Members will gain skills and feel empowered to fulfill their role in representing the community.

"With great power comes great responsibility..."



Do you feel powerful? ©

- You are! Your role is critical.
- "The role of the IMPAACT Community Advisory Board Resource Committee (ICAB) is to provide HIV/AIDS life-experience based expertise that will positively impact the formulation and implementation of research by community integration throughout the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) Leadership Committee, Scientific Committees, Resource Committees and Protocol Teams."

The mission of the ICAB

To improve the value of clinical research for pregnant women, children, adolescents and families infected with or affected by HIV/AIDS by being a resource to researchers and the global community.

ICAB partners with researchers to focus on:

- the nature of the research process
- the **relationships** within the research process
- the **real life problems** of pregnant women, children, adolescents and families infected with or affected by HIV/AIDS.

Being a Representative

noun

- 1. a person or thing that represents another or others.
- 2. an agent or deputy: a legal representative.
- 3. a person who represents a constituency or community in a legislative body, especially a member of the U.S. House of Representatives or a lower house in certain state legislatures.
- 4. a typical example or specimen of a group, quality, or kind.

dictionary.com

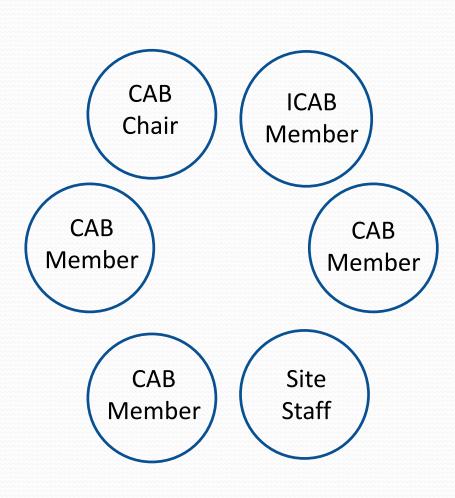
Being a Representative



Well, not just about me... ©

Being a Representative - Site CAB

- Conducting and attending CAB meetings at your site
- Listening to and obtaining input from CAB members from your community
- Representing the perspective of your CAB and community
- Representing the community perspective on site-level protocols



Being a Representative - Site CAB

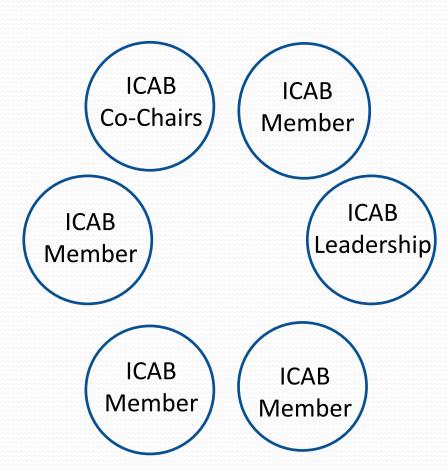
- Develop and submit Community Research Priorities as requested by the ICAB.
- Provide input into protocol development (IMPAACT protocols and site-specific protocols)
- Interact with site staff about the research being conducted locally or planned for the specific site.
- Inform the site on issues of importance and relevance to the community members' lives.

Being a Representative - Site CAB

- Learn about and inform research staff about access to research population, barriers, community concerns or other issues.
- Learn about research ethics and the informed consent process.
- Maintain confidentiality about people and research before, during and after meetings.

Being a Representative - ICAB

- Represent your site's/ community's perspective to IMPAACT when attending IMPAACT/ ICAB meetings and calls
- Provide input on research, including Community Research Priorities
- Facilitate information flow between the sites and network, including new and emerging research and study results when available
 - Report back to the site about ICAB and IMPAACT developments
 - Report back to ICAB about site developments and perspectives



Being a Representative - ICAB

- Train and mentor CAB members with assistance from site staff, ICAB, and IMPAACT Operations Center.
- Share challenges and solutions, best practices, experiences, and lessons learned with each other.
- Learn about research ethics and the informed consent process.
- Maintain confidentiality about people and research before, during and after meetings.

Great Responsibility

- Attending ICAB Retreat, IMPAACT, and Scientific Committee sessions (Attendance logs)
- Listen, learn, and ask questions
- Provide input from your site CAB
- Take notes and complete Report Back forms to share updates from the ICAB Retreat and IMPAACT Annual Meeting

Tools: Community Reporting Templates

- Committee Report-back Form
- IMPAACT Meeting/Retreat Report-back Form
- External Meeting Report-back Form

Samples of these documents may be found in your handouts

What Makes a Good Report?

- Short but complete (concise)
- Simple and written in good language
- Having no repetition/redundancy
- Including no lecturing
- Containing interesting/relevant information
- Well structured and organized
- Neat and tidy

Community is Powerful - Represent!

