Third Thursdays at ICTR: Community Engagement Services

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CCC Stakeholder Engagement

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Co-chairs, Community Research Advisory Council
Objectives

• To introduce the work of the CCC and Community Engaged Research services.
• To introduce the work of the Community Research Advisory Council to the Johns Hopkins research community.
• To share how C-RAC’s work supports community-engaged research for the Johns Hopkins system.
• To encourage bi-directional communications between communities JH serves and the research teams.
Introduction to community engagement services at ICTR

Community and Collaboration Core

C-RAC
Research
Governance
Outreach

CEnR
Training Research

Team Science
Training Research

Community engagement platforms
Day at the Market
Symposia, events
CEAL
Why was the Community Research Advisory Council formed?

- Leadership at Johns Hopkins University wanted to become more informed about the health and research priorities of patients and local residents.

- The Johns Hopkins University Institute for Clinical and Translational Research wanted to create a forum for ongoing community input in the research process.

- Patients and local residents wanted to become more involved in the research process.

- From 2010-2018 there were chapters on the Johns Hopkins East Baltimore Medical Campus and Johns Hopkins Bayview. In 2019, these chapters merged to form the Combined C-RAC Board.
ICTR Community Research Advisory Council (C-RAC)
A volunteer board formed in 2009 to connect researchers and community members

Mission
The Community Research Advisory Council (C-RAC) aims to promote trust, understanding, and involvement of the Greater Baltimore-Washington region in research, education, and service activities to enhance overall health, reduce health disparities, and promote social justice.

Goals include:
- Promoting equitable access to health care in research and address health disparities and social justice in study design
- Improving community awareness, trust, knowledge, understanding and participation to all phases of the research continuum
- Improving researchers' commitment to a fully engaged community within the entire research process
C-RAC Membership & Responsibilities

C-RAC Membership

- As of November 2023, C-RAC had 25 members, 61% not JH affiliated (Bylaws require at least 51% non-JH affiliates)
- Membership is open for all people working or living in Greater Baltimore- Washington region, interested in community engagement in Research.
- Individuals with various ages, professions, background, and expertise are encouraged to reflect the diversity in the Greater Baltimore- Washington region

Members’ responsibilities

- Attend the 1 ½ hour monthly meetings by at least 75% each year of service
- Serve at least 2 years
- Serve on at least one sub-committee by actively attending its meetings and activities
C-RAC: How we engage research teams and the community?
C-RAC provides an opportunity for bi-directional interchange between community and researchers

- Community has fear and negative perceptions about research
- Repeated messages and physical presence highlighting community participation in research
- Researchers need to recognize negative perceptions about research exist
- Assist research teams by providing participant-centered input into research questions, study implementation, and dissemination of information
- Increased trust and collaboration in research
- Improved health outcomes from Community Engaged Research

C-RAC provides an opportunity for bi-directional interchange between community and researchers

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Researchers need to recognize negative perceptions about research exist

C-RAC

Assist research teams by providing participant-centered input into research questions, study implementation, and dissemination of information
Strategies to strengthen community engagement

1. LISTEN
2. BE UNDERSTANDABLE
3. BE A TRUSTED PARTNER
4. GIVE BACK
In April 2020, C-RAC re-aligned its processes to support efforts of COVID-19 research teams

- Promoted community capacity for remote engagement
- Developed expedited review consultation for research teams
- Acknowledged the elephant in the room: We acknowledged that the words “research” and “clinical trials” still evoke negative reactions from community stakeholders

**Expedited Review Consultation**

- 45-minute virtual meeting
- Consultants provide participant-centered review of study design in preparation for COVID-19 IRB submissions, including:
  - Recruitment
  - Communications
  - Implementation
  - Dissemination
WHO WE ARE

The Community Research Advisory Council (C-RAC) is a group of community stakeholders and Johns Hopkins University faculty and staff that provides consultations for study teams on community engagement throughout the research life cycle, from planning to dissemination of findings. By working together with research teams and faculty, C-RAC informs research and educational programs and promotes community health and knowledge.

PATIENTS
HEALTHCARE PROVIDERS
LOCAL RESIDENTS  CITIZEN SCIENTISTS
RESEARCHERS  STUDENTS  TEACHERS
REPRESENTATIVES FROM LOCAL & STATE ORGANIZATIONS

57%
of C-RAC members are from the community

77%
of members identify as belonging to communities of color

2022 in review

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<tr>
<td>Total reviews 2020-2022</td>
<td>114</td>
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<tr>
<td># of research teams served</td>
<td>74</td>
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<tr>
<td>Total COVID-19 related reviews from 2020-2022</td>
<td>18</td>
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<tr>
<td>Total reviews for TL1 scholars (research trainees)</td>
<td>48</td>
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<tr>
<td># of projects with &gt; 2 reviews over study life cycle</td>
<td>53</td>
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<td>% of community members on the board</td>
<td>61%</td>
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C-RAC Consult 6-Step Process: CE Technical Assistance

Service Request

- Schedule CRAC Review
- CRAC Review

Fireside Chat: Information Gathering Session

CRAC Review Preparation

Post Review Debriefing

Needs assessment & referral opportunities
C-RAC and TL 1 Scholars partnership – born virtual

• In 2020, the CCC/C-RAC, and TL 1 program formed an innovative partnership that helped support the TL 1 Program’s multi-institution partnership to train students pursuing careers in clinical and translational research.

• Provided the C-RAC with the opportunity to provide community input and support to trainees early in their research career _and_ an opportunity to learn more about research design.

• From **September to November**, the C-RAC met with 15 TL 1 Scholars and provided input on study design, dissemination, and provided linkages to community groups.
MEET THE TL1 TRAINEES OF COHORT 2023
C-RAC provides an opportunity for bi-directional interchange between community and researchers

Community has fear and negative perceptions about research

Repeated messages and physical presence highlighting community participation in research

Increased trust and collaboration in research

- Education:
  - Day at the Market
  - Community Forum on Healthy Aging
  - Clinical Trials Day
  - Henrietta Lacks Memorial Lecture
  - Writing research MS

Assist research teams by providing participant-centered input into research questions, study implementation, and dissemination of information

Researchers need to recognize negative perceptions about research exist

Improved health outcomes from Community Engaged Research
Examples of Opportunities:

• Day at the Market (Northeast Market and Lexington Market)
• Healthy Aging Community Forum
• Henrietta Lacks Symposium
• Clinical Trials Day
• Educate our C-RAC members about the research process.
  • Writing research manuscript. C-RAC members are invited to write/collaborate on manuscripts
  • Research ethics and the IRB
• Community Conversation: We asked community stakeholders what they wanted to know about research and COVID-19.
  • “I want to know that there are people like me working with researchers about those issues that matter to me and my community.”
Healthy Aging Forum: An Example of responding to community needs/interests

7th Virtual Community Forum on Healthy Aging

Part 1 • Monday Nov. 13th • 5-7 PM

Brain Health, Mental Wellness, & Long Covid

Crystal Evans & Dr. Panagis Galiatsatos
Monday’s Co-Hosts

Dr. Pamela Ouyang & Jennifer Ayanna Harrison
on Exercises for the Mind & Body

for more information visit tinyurl.com/Healthy-Aging-Forum

C-RAC Fun Fact
The Healthy Aging Forums have reached audiences as far away as Australia and Jordan.
Help Us Make a Difference!
Join our organization.

The Community Research Advisory Council (C-RAC) is a group of Baltimore community stakeholders and Johns Hopkins University faculty and staff that provides consultations for study teams on community engagement throughout the research life cycle, from planning to dissemination of findings.

Help us promote community engagement in research.

What We Do

Conduct Research Reviews
Support Community Engagement Events
Host Community Forums
Sponsor Trainings on Community Engagement

Membership
Our membership is broad and diverse and includes:
Patients • Local Residents • Healthcare Providers
Researchers • Citizen Scientists • Students & Teachers
Representatives from State & Local Organizations

Apply To Be a Member
Who can join? Anyone who is interested in health research and wants to serve the community!

For more information, please contact us at:
(443) 370-7928 | C-RAC@jhmi.edu
Or Visit BIT.LY/JHUICTR
Requesting a Service

Go to https://ictr.johnshopkins.edu/

Select “Request a Service” and “View List” from the dropdown

Select “Submit a Request” on the next page and fill out our request form!
Strategies to strengthen community engagement

1. LISTEN
2. BE UNDERSTANDABLE
3. BE A TRUSTED PARTNER
4. GIVE BACK
Questions?
How to contact Community and Collaboration Core services and the Community Research Advisory Council (C-RAC)
Crystal Evans, MS
cevans20@jhmi.edu

Thank you.