

Introduction to the Community Research Advisory Council (C-RAC): A Consult Service of ICTR

ICTR's Third Thursday Series:
October 21, 2021, 2:00 pm

Presenters: Roger Clark, MBA; Pamela Ouyang MBBS; Crystal Evans, MS; Suzanne Grieb, PhD, MPH; Cyd Lacanienta, MSW

Objectives



- To introduce the work 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.

C-RAC Leadership

Roger Clark, Pamela Ouyang

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

C-RAC Membership

- As of November 2020, C-RAC had 22 members: 61% were 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

Strategies to strengthen community engagement

1

- LISTEN

2


- BE UNDER-
STANDABLE

3

- BE A TRUSTED
PARTNER

4

- GIVE BACK



C-RAC: How we
engage research
teams and the
community?



10-Step Framework For Continuous Engagement

PLANNING

- 1: Topic Solicitation
- 2: Prioritization
- 3: Framing the question
- 4: Selection of outcomes

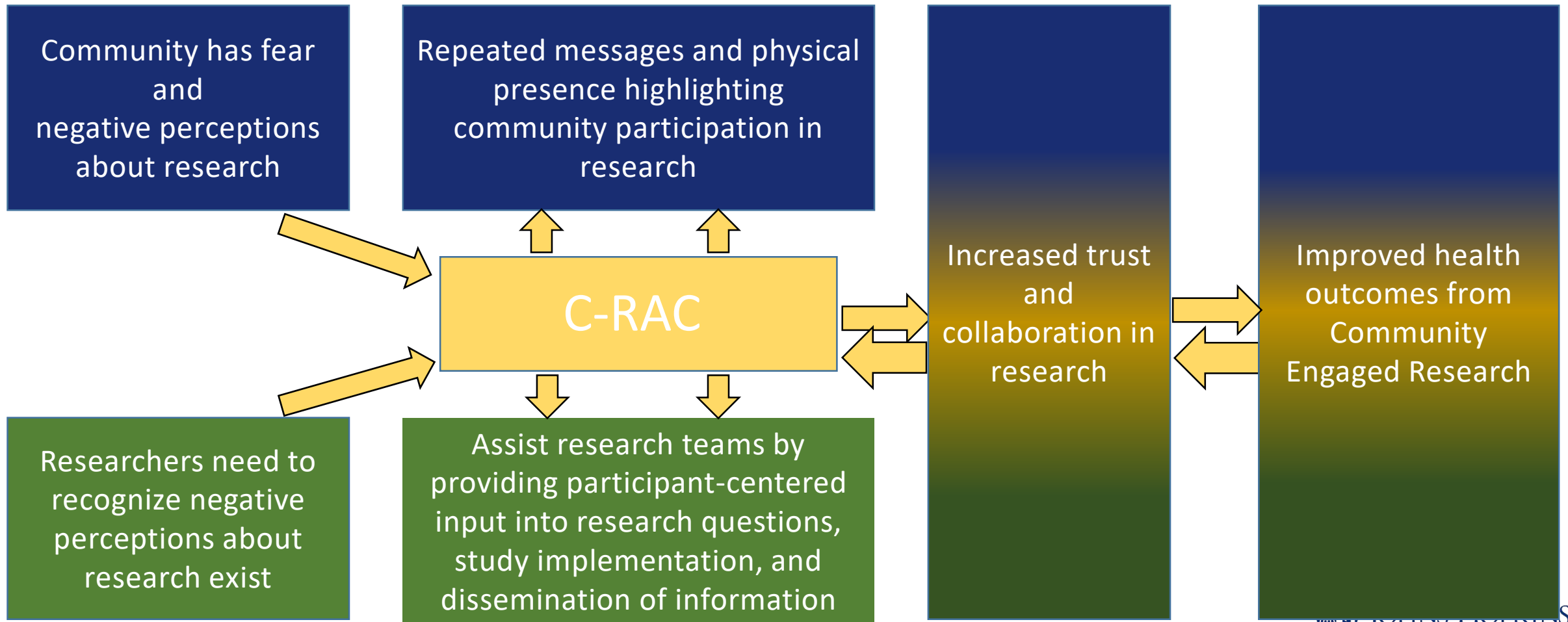
IMPLEMENTATION

- 5: Create the framework
- 6: Develop analysis plan
- 7: Data collection (recruitment and retention)

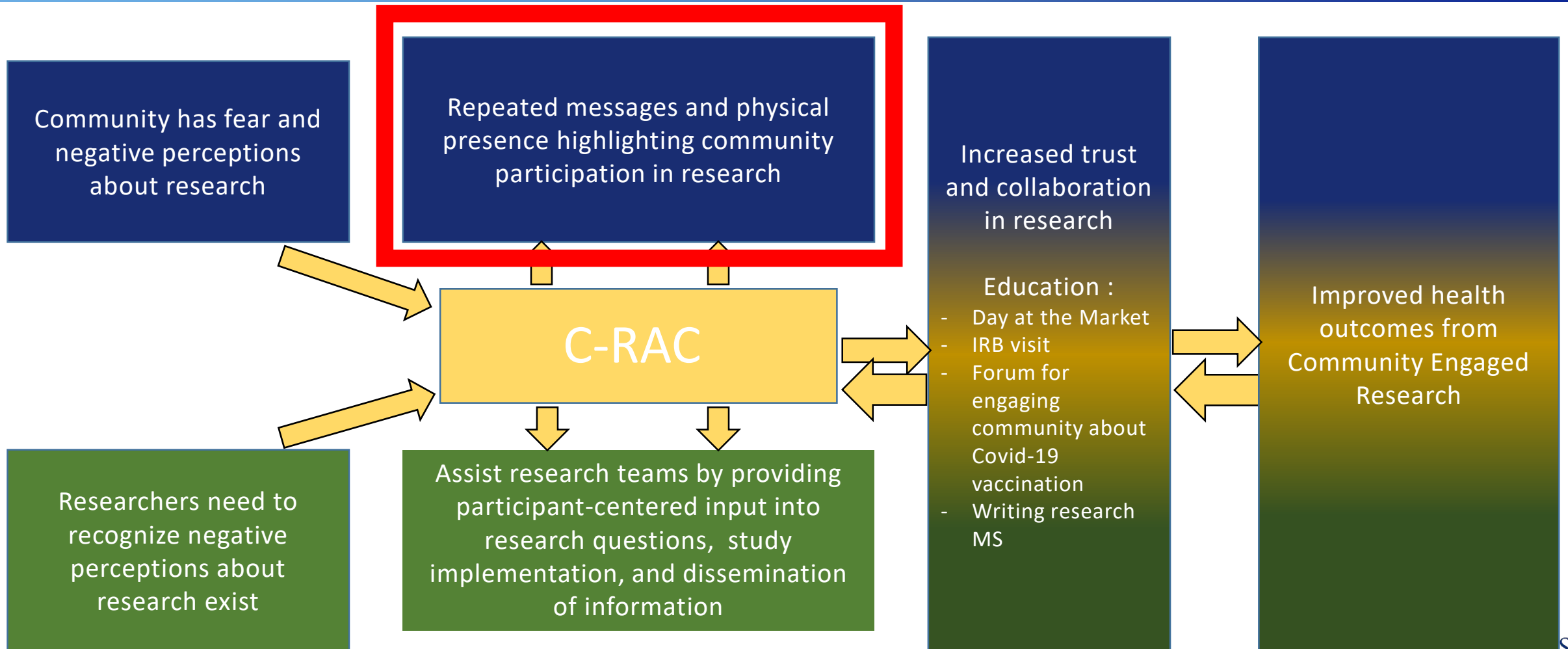
ANALYSIS & DISSEMINATION

- 8: Reviewing and interpreting results
- 9: Translation
- 10: Dissemination

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



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

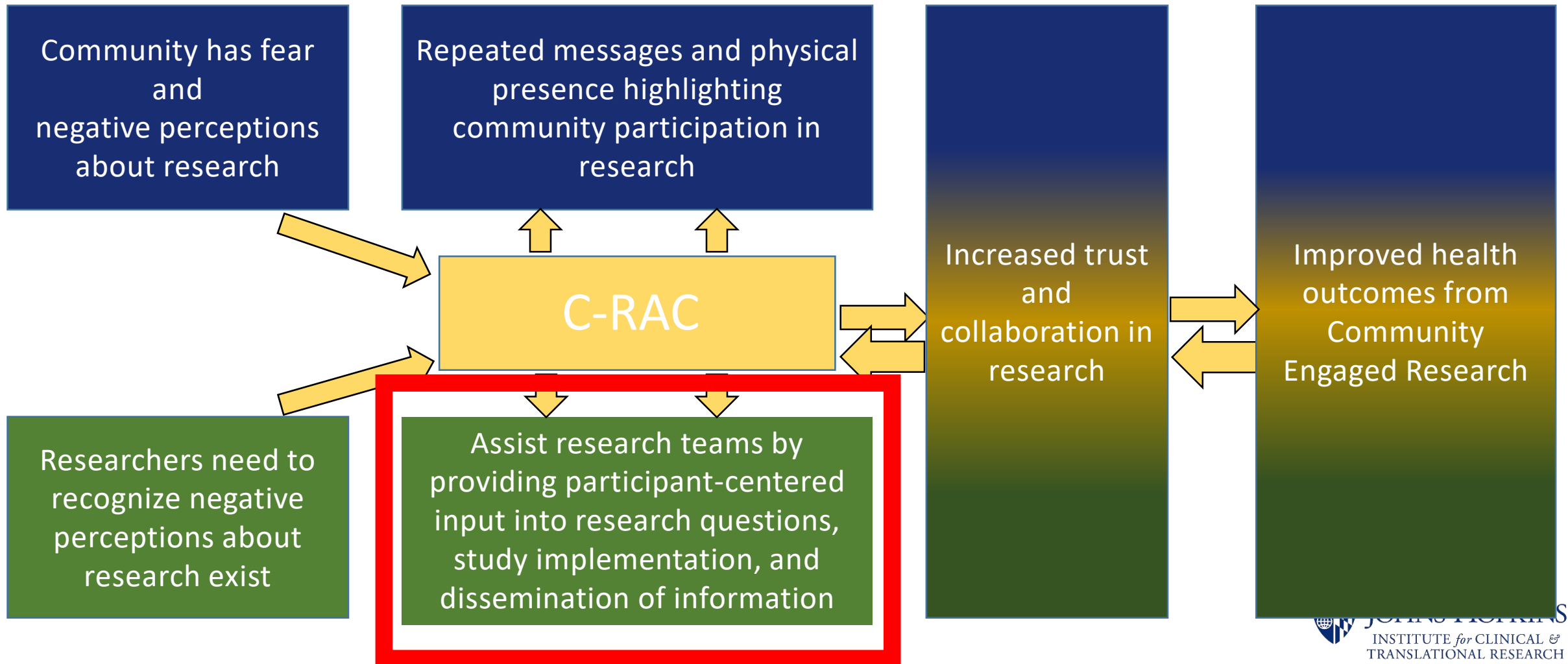


C-RAC: Examples of responding to community needs/interests

Examples of Opportunities:

- Day at the Market (Northeast Market and Lexington Market)
- Healthy Aging Community Forum
- Visit to 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.”
- Virtual Henrietta Lacks Symposium
- Educate our C-RAC members about the research process.
 - Writing research manuscript. C-RAC members are invited to write/collaborate on manuscripts
 - ⑩ Research ethics and the IRB

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

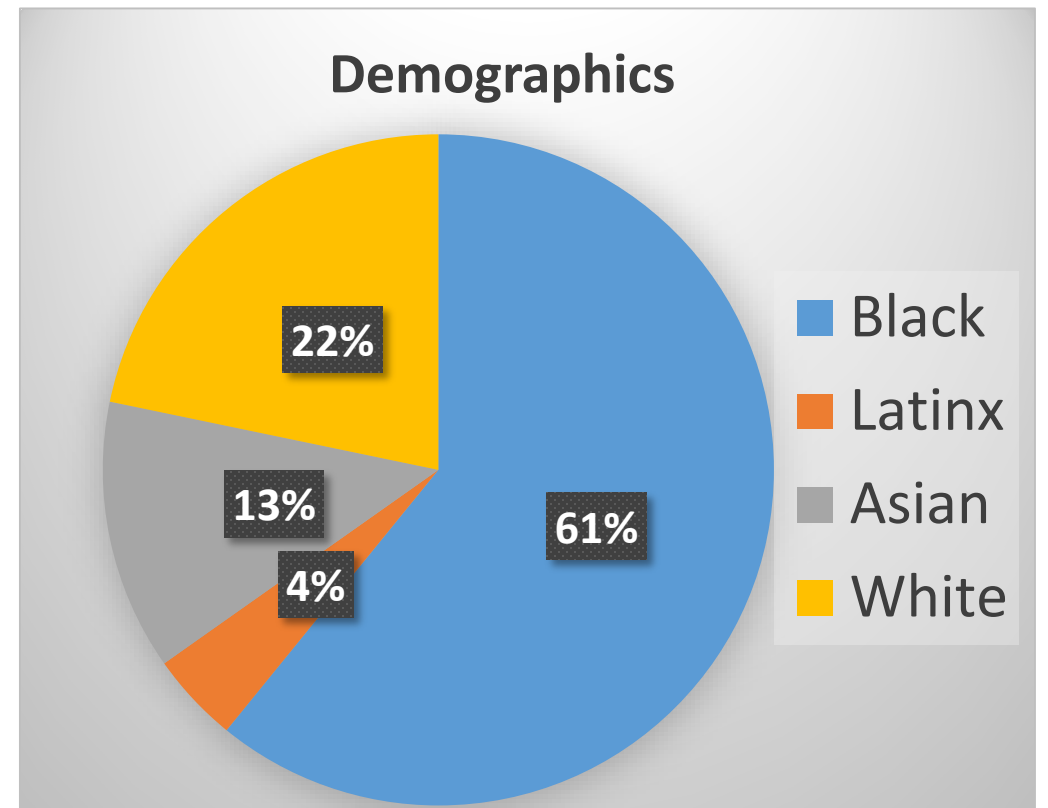


C-RAC: assistance to researchers during COVID

- 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
 - Increased meetings from quarterly to weekly to meet the needs of research team providing solutions during the pandemic
 - Maintained a high level of engagement from our community stakeholders that remains consistent 18 months into the pandemic
 - The frequency of meetings forged a highly integrated, high performance team comprised of community and academic partners

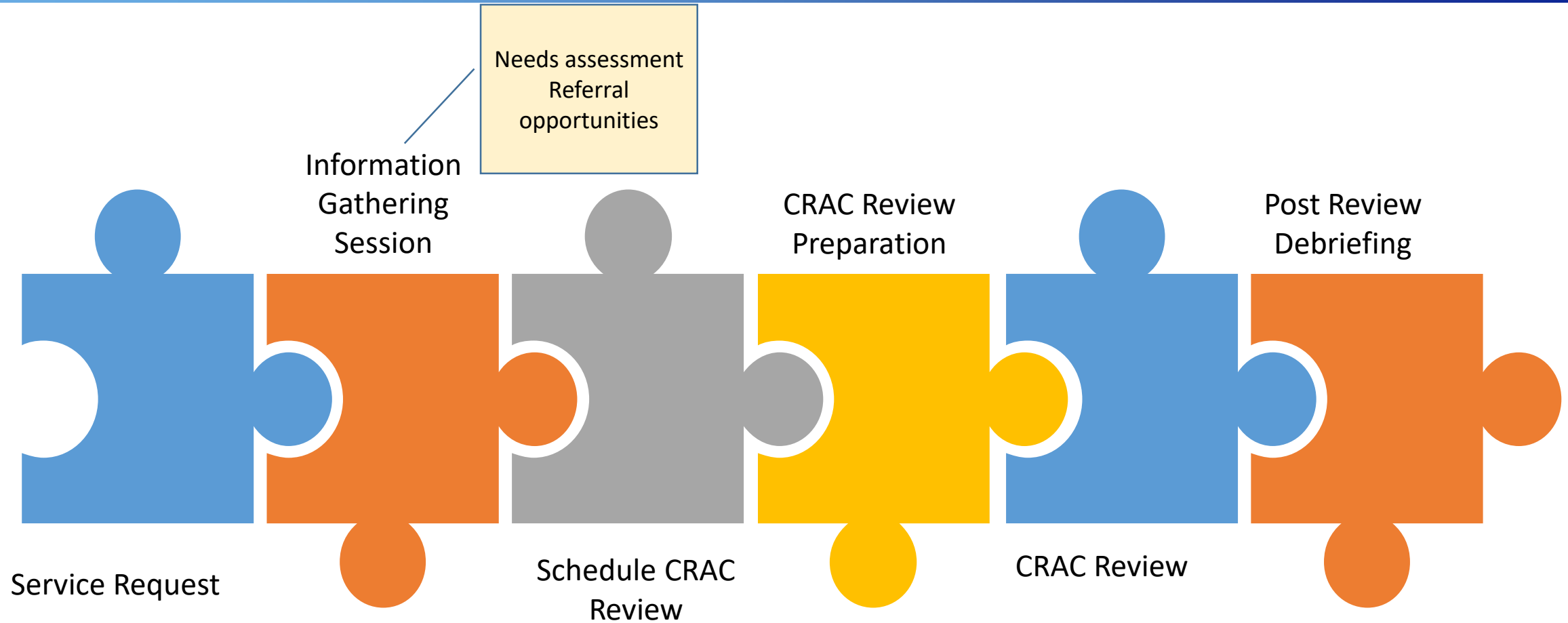
C-RAC: Review of 2020

2020	
Total reviews	34
Total COVID-19 related reviews	14
Total reviews for TL1 scholars	15
# of projects with ≥ 2 reviews over study life cycle	3
Projects reviewed seeking feedback based on re-designing their studies due to COVID restrictions	5
% of community members on the board	61%






C-RAC Consult 6-Step Process: CE Technical Assistance



Community-Engaged Research Consultations with C-RAC

- 45-minute virtual meeting
- Consultants provide community-centered review of study design, including:
 - Recruitment
 - Communications
 - Implementation
 - Dissemination
- Mondays, from 5 -6 pm



**COVID-19 Expedited
Community-Engaged Research
Consultation**

A service for researchers investigating the impact of the COVID-19 pandemic.

Format

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

Day/Time
Mondays, 5 PM – 6 PM


For more information, contact:
ICTR-CRAC@jhmi.edu

**COMMUNITY RESEARCH
ADVISORY COUNCIL (C-RAC)**

For over 10 years, the Community Research Advisory Council of the Johns Hopkins Institute for Clinical and Translational Research (ICTR) has provided research reviews and *Community-Engaged Research Consultations* to the Institutional Review Board, departments, and research teams throughout all phases of the research process. Our aim is to provide the 'real world' perspectives of patients, community members and diverse stakeholders to Johns Hopkins research teams at any stage of the study design process. Our council includes patients, local residents, healthcare providers, scientists, students, and representatives from state and local organizations.

The C-RAC is part of Johns Hopkins ICTR's community collaboration efforts to provide technical assistance and build the capacity of researchers to rapidly respond and discover solutions to address the COVID-19 pandemic and other health concerns that impact our patients, our neighborhoods, and our communities.

Because
we are all
in this together.

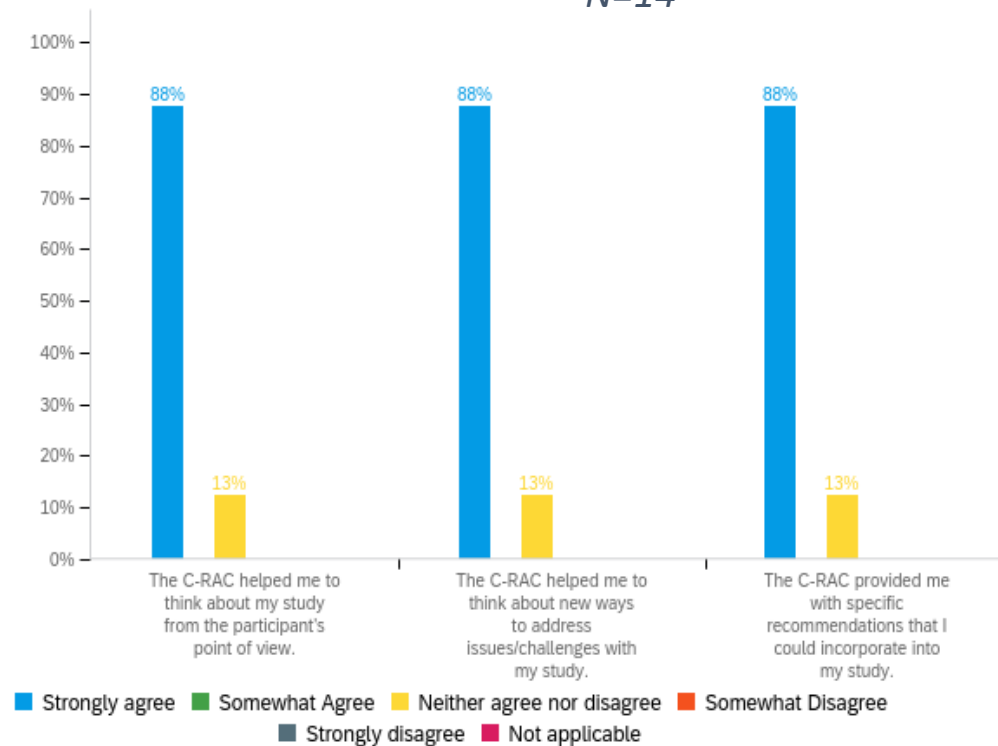
 **JOHNS HOPKINS**
INSTITUTE for CLINICAL &
TRANSLATIONAL RESEARCH

Release: 5/11/2020 DRAFT

Results – Research teams' feedback

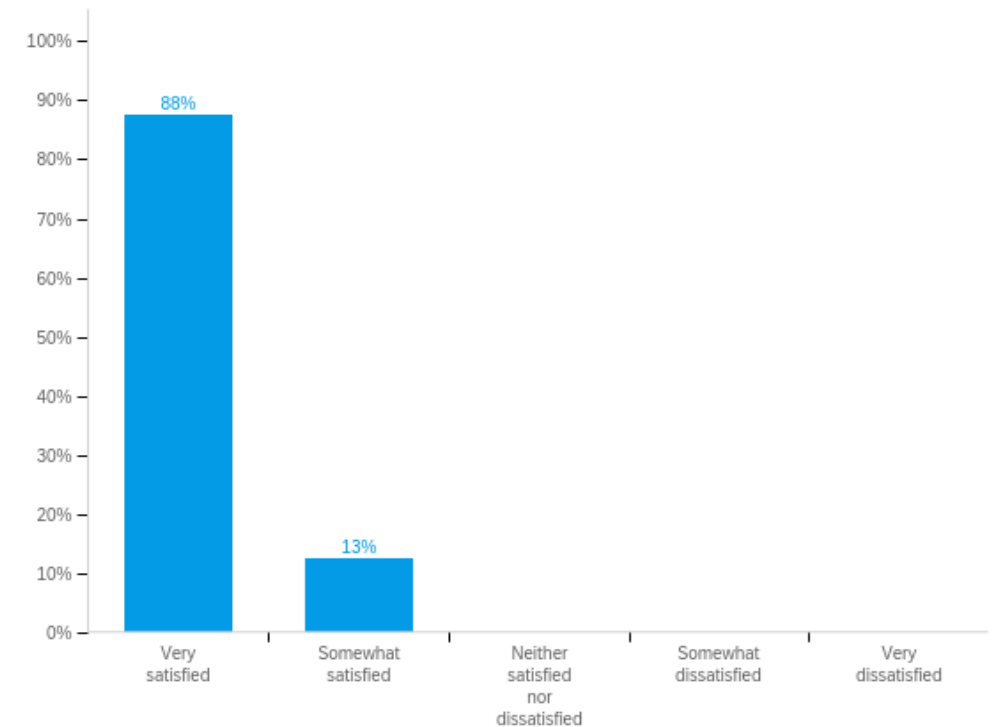
Please select how much you agree with the following statements

N=14



How satisfied were you with the C-RAC research review?

N=14



Case Experience: C-Forward Research Team

Community Collaboration to Combat COVID-19 (C-FORWARD)



Suzanne M. Grieb, PhD, MSPH
Assistant Professor
Johns Hopkins School of Medicine
Dept. of Pediatrics



Principal Investigators



Shruti Mehta, PhD
Professor
BSPH



Jason Farley, PhD
Professor
SON



Jacky Jennings, MPH, PhD
Associate Professor
SOM, BSPH

Project Aims

- To determine barriers and facilitators to COVID-19 testing
- To identify the optimal modality of testing and maximize testing acceptance, uptake, and timeliness
- To evaluate the impact of testing modality and receipt of positive results on subsequent behavioral, economic, and clinical outcomes

C-RAC Engagement: Pre-Study Implementation

4/7/20

- Discuss ways to message/
inform about project
- Feedback on reaching
potential participants

5/18/20

- Feedback on project
messaging and
advertising/ recruitment
materials

Marketing Materials

JOHNS HOPKINS MEDICINE
Approved November 17, 2020

JOIN US

FOR A COVID-19 SURVEY TO IMPROVE TESTING.

If eligible, you may receive \$50 for participation.

JOHNS HOPKINS MEDICINE
C-FORWARD

JOHNS HOPKINS MEDICINE
Approved November 17, 2020

JOIN US

TO HELP BALTIMORE FIGHT COVID-19.

Your household was chosen to participate in a research study with the goal of improving COVID-19 testing and testing access for Baltimore City community members.

TO PARTICIPATE YOU MUST:

- Live in Baltimore City
- Have at least one member of your home who is 18 years old or older

ENROLL TODAY:

VISIT www.cforward.info

CALL 1-855-6C4-WARD

EMAIL CFORWARD@jhu.edu

Protocol Title: Community Collaboration to Combat Coronavirus (C-FORWARD) IRB Application #: 880022006 Principle Investigator: Jason E. Hilty PhD, MPH, AND

Community Dissemination

	Recommended	Implemented
Social media	✓	✓
Radio (WERQ-FM/92Q James, WLIF-FM/Praise 106.1)	✓	✓
Bayview's COVID-19 Community Partners Call (Dr. G)	✓	✓
Urban Health Institute Newsletter	✓	✓
BCHD listserv (Sheridan Johnson)		✓
Sent materials to various organizations to share (e.g., SPARC Center, Chase Brexton, Esperanza Center, various large churches)	✓	✓
Food distribution sites	✓	
C-RAC member networks	✓	✓
Door hangers	✓	✓ **

C-RAC Engagement: Study Implementation

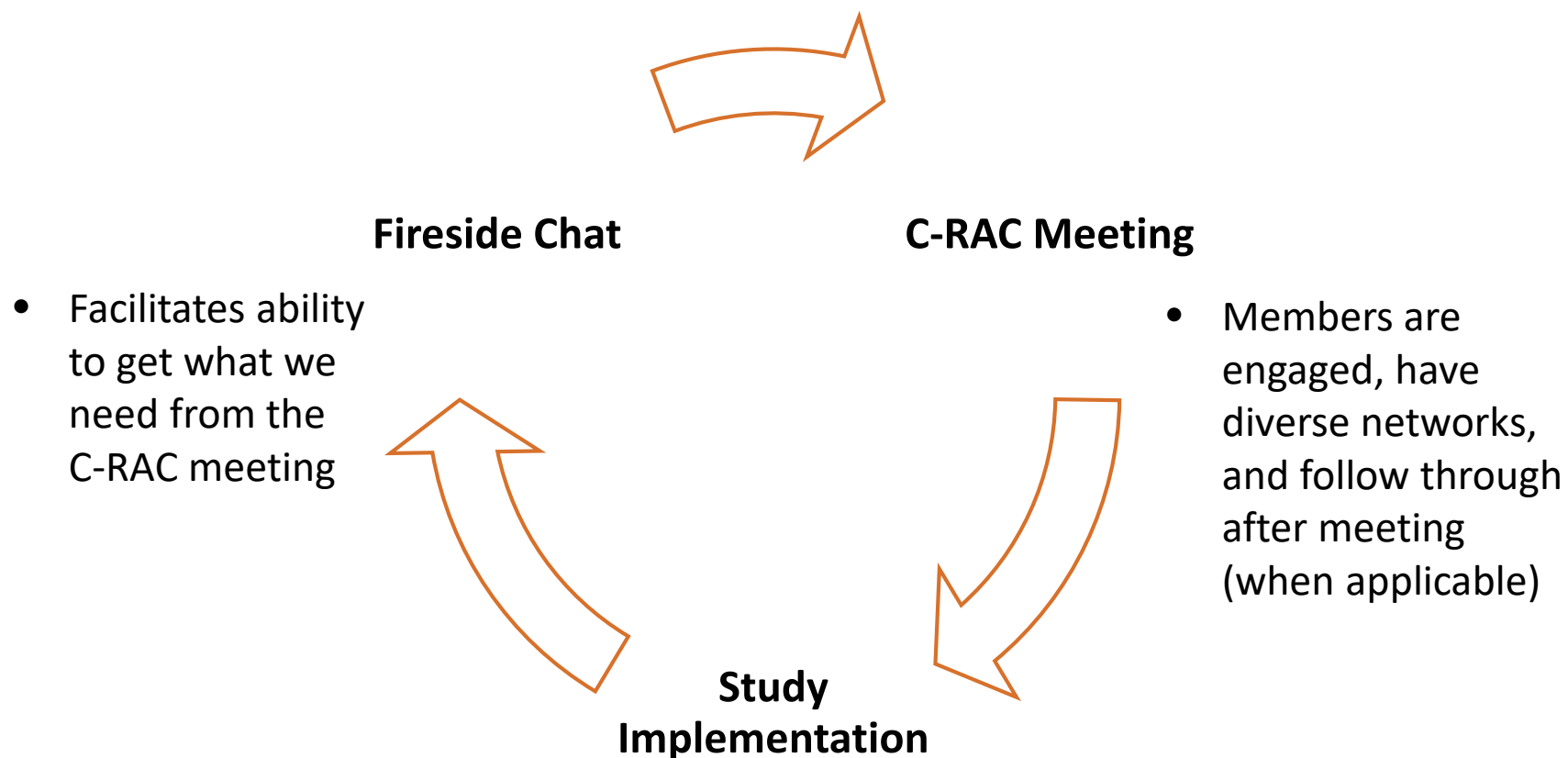
2/22/21

- Updates
- Review recruitment-focused dissemination
- Introduce Community and Scientific Advisory Board

6/7/21

- Updates
- Discuss in-depth interviews for development of interview questions

Engagement Experience



THANK YOU!

sgrieb1@jhmi.edu



How does community engagement help your research?

- Research will be helped by engaging the Community and understanding their priorities throughout the entire trajectory of research from the point of developing the research goals, design, implementation, and dissemination.
- Meaningful and sustained connections with the Community will help research teams successfully complete studies.
- C-RAC is committed to:
 - Strengthening bi-directional trust between research teams and community.
 - Helping researchers gain the communities' trust.

Questions?

For more information, please visit the ICTR website:
<https://ictr.johnshopkins.edu/community/community-involvement/>

Or contact our Community and Collaboration Core staff, Crystal Evans, at cevens20@jhmi.edu.

Thank you.