



JOHNS HOPKINS  
INSTITUTE *for* CLINICAL &  
TRANSLATIONAL RESEARCH

MyChart Recruitment Service and Community Research Advisory Council

Presented by: Cassie Lewis-Land, MS, CCRP

May 21, 2020

# RIU Aims

The RIU aims are to:

- Establish a comprehensive suite of customizable services, tools, and training to promote efficient and effective local recruitment and retention;
- Develop innovative and scalable informatics approaches, including computational phenotyping, that more accurately identifies and engages potential study participants and helps research teams manage tradeoffs between sensitivity and specificity to better target those who are eligible; and
- Advance recruitment science by rigorously engaging our CTSA community and testing innovative recruitment strategies that can be implemented locally and shared nationally.

# Services and Tools

- Needs Assessment
- Study Design Assessment
- Pre-screening / Cohort Discovery
- Recruitment Feasibility Survey / Focus Group
- Outreach to Stakeholder Partners
- Customized Recruitment and Retention Plans
- Recruitment and Retention Troubleshooting
- Community Research Advisory Council (C-RAC)



# Patient Recruitment into Clinical Trials

- One of the most common challenges of clinical trials is related to problems with recruitment
  - Validity of study requires adequate sample size
  - Insufficient recruitment results in trials being extended, which increases resource use and cost
  - Delays the potential benefits of treatments to the public
  - The trial closes due to lack of sufficient enrollment

# The MyChart Recruitment Service

- MyChart Recruitment Service uses computable phenotyping with Epic to identify study specific eligible patients and patient portal messaging to recruit eligible participants
- Developed out of the need to create and implement standards for protecting patient information in the use of EMR for research
  - Successfully piloted with two studies in early April 2017 and PaTH study cohorts in Fall 2015
- Meet as a MyChart Recruitment Council once a month to review and refine the process
  - Team includes leading ICTR administrators, CCDA analysts, Epic Research Team members, and researchers
  - Patient advocates meet with us on a quarterly basis
  - To date the service has been utilized by 17 research teams studying various populations and topics of interest

# MyChart User Representativeness

Characteristic	Johns Hopkins Health System**	Active MyChart Users
<b>Total N (%)</b>	1,308,820 (100)	519,800 (40)
<b>Sex</b>		
Female	746,027 (57)	313,888 (60)
Male	562,792 (43)	205,890 (40)
<b>Race</b>		
Black	327,205 (25)	97,100 (19)
White	772,204 (59)	355,134 (68)
Asian	65,441 (5)	33,414 (6)
Other	143,970 (11)	41,714 (8)
<b>Ethnicity</b>		
Not Hispanic or Latino	1,164,850 (89)	475,779 (92)
Hispanic or Latino	78,529 (6)	22,094 (4)
Unknown/Patient refused	65,441 (5)	20,975 (4)
<b>Age in Years</b>		
0-17	217,590 (17)	37,182 (7)
18-39	327,600 (25)	134,972 (26)
40-59	343,160 (26)	156,917 (30)
60-79	333,590 (25)	144,021 (28)
80+	86,900 (7)	26,880 (5)

## MyChart User Representativeness:

- 40% of JHHS patients were active MyChart users.
- Similar to JHHS population in terms of age and sex.
- More likely to be white and non-Hispanic.

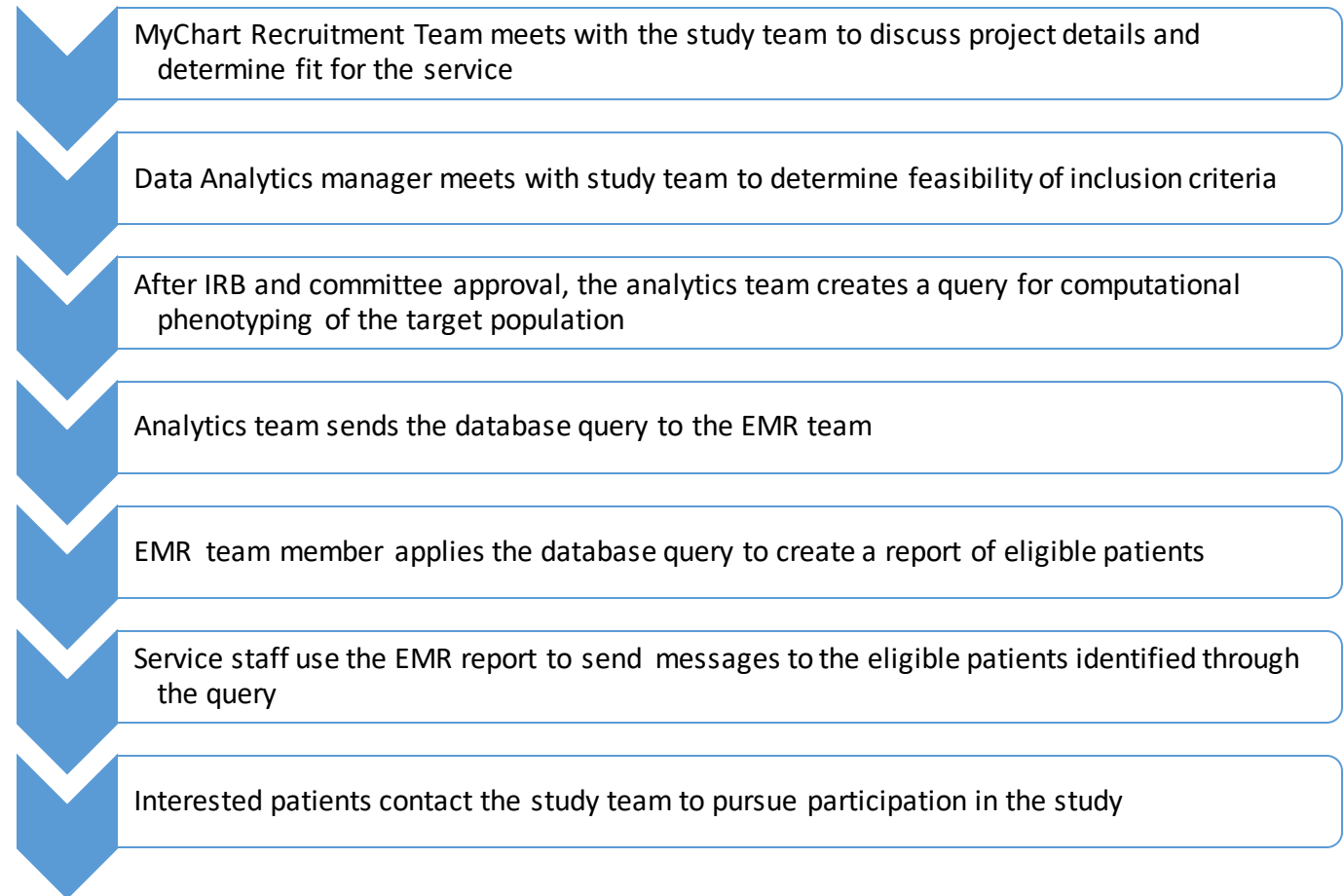
\*Includes individuals that have had at least one diagnosis, medication order, laboratory result, OR procedure since 9/1/2016.

\*\*Data in JHHS column do not include individuals greater than 90.

# Overview

MyChart Recruitment Service is a multi-stage process with collaborations between:

- Core for Clinical Research Data Acquisition (CCDA)
- Program to Accelerate Clinical Research using Epic (PACE)
- Recruitment Innovation Unit (RIU)



# MyChart Recruitment Messaging and Study Characteristics

Study Characteristics		Messaging Characteristics				Recruitment Efficacy N (%)		
Population Age	Health Concern	Report Size	Message Batch Size	Frequency	Duration (in mos.) *	Response Rate*	Eligibility Rate*	Enrollment Rate*
<i>Completed Recruitment</i>								
70+	Vitamin D and Falling	6896	250-1000	Bimonthly	5	116 (1.7)	49 (0.7)	12 (0.2)
<1	Peanut Allergies	409	Variable	Monthly	3	16 (4.3)	11 (3.0)	10 (2.7)
>18	Atrial Fibrillation	1303	303-1000	Monthly	2	127 (9.7)	127 (9.7)	127 (9.7)
50-90	Type II Diabetes	1382	250	Monthly	6	34 (2.5)	1 (0.07)	0
18-45	Asthma	1599	200	Monthly	7	44 (3.1)	9 (0.6)	9 (0.6)
>18	Diet and Gout	1229	250-500	Bimonthly	3	53 (4.1)	20 (1.6)	9 (0.7)
<i>Suspended Recruitment</i>								
>40	COPD	14336	250-1000	Variable	16	84 (1.5)	2 (0.03)	2 (0.03)
3-13	Brain and Appetite	3719	250-500	Bimonthly	4	48 (1.8)	16 (0.6)	12 (0.4)
18-80	COPD	1171	200	Monthly	5	43 (4.1)	-	0
<i>Active Recruitment</i>								
<1	Peanut Allergies	2083	200	Variable	11	7 (0.3)	4 (0.2)	3 (0.1)
13-22	Weight Loss	9978	150-1000	Monthly	17	135 (0.9)	44 (0.3)	44 (0.3)
>18	Mood Disorders in Pregnancy	1868	350	Monthly	9	116 (5.0)	56 (2.4)	21 (1.0)
4-17	Mood Disorders	15709	250-1000	Bimonthly	10	66 (0.5)	-	0
>18	Anemia	9096	500	Bimonthly	8	166 (2.4)	1 (0.00)	1 (0.00)

Note: \*Data is current as of 05/10/2019. Please see extra slides to find definitions of report size, batch size, response rate, eligibility rate, and enrollment rate

## Messaging Characteristics:

- Frequency of messaging ranged from weekly to monthly
- The average active messaging period was 6 months

## Efficacy Rates:

- The average response rate was 3%
- The average eligibility rate was 1.6%
- The average enrollment rate was 1.13%



# Research Messaging Opt In

**MyChart**

Your health. Your knowledge. Your connection.



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MEDICINE

## Terms and Conditions

To proceed, you must agree to the following conditions governing the use of this Web site.

Information maintained on Johns Hopkins Medicine MyChart presents unique security and privacy issues as addressed below. Therefore, certain necessary measures for protecting the security and privacy of such information are the responsibility of the user as detailed below.

The information from your medical record available through Johns Hopkins Medicine MyChart may not constitute your entire medical record. The scope of medical record information accessible through Johns Hopkins Medicine MyChart is determined at the discretion of Johns Hopkins. You will continue to have access to your complete medical record by contacting the office of your health care providers directly. THEREFORE, YOU ACKNOWLEDGE THAT JOHNS HOPKINS MEDICINE MYCHART SHALL NOT BE USED TO MAKE HEALTHCARE DECISIONS OR DIAGNOSIS AND JOHNS HOPKINS SHALL NOT BE LIABLE FOR ANY PERSONAL INJURY, INCLUDING DEATH, ARISING FROM YOUR USE OR MISUSE OF JOHNS HOPKINS MEDICINE MYCHART OR ANY INFORMATION OR CONTENT THEREIN. Remedies under these Terms of Service are sole and exclusive and are limited to those expressly provided for in these Terms of Service.

Johns Hopkins MyChart may be used to send invitations for studies you may be eligible to participate in. For more details on this feature and how to opt out, please [click here](#).

You are not required to utilize Johns Hopkins Medicine MyChart and may discontinue usage at anytime. You acknowledge that Johns Hopkins Medicine MyChart is being provided to you without charge. Therefore, Johns Hopkins reserves the right to terminate your access to Johns Hopkins Medicine MyChart at any time, with or without cause.

Please do not show this page next time

ACCEPT

DECLINE

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# MyChart Messaging Template

Hello,

In addition to providing high-quality medical care, Johns Hopkins facilitates distinguished research with the ultimate goal of improving health.

I am reaching out today regarding a research study that may be of interest to you. This research study aims to: *This is where you can include title, purpose of the study/why it is necessary, etc.* A computer search of information in Johns Hopkins medical records found you might be eligible for this study. Specifically we are looking to identify people who XXXX and were seen at Johns Hopkins facility in the past year.

Other factors that might make you qualify to participate in this study include:

Participation in this study is voluntary. If you decide not to be part of this study, it will not change the medical care you receive.

-

If you are interested in participating, please contact our study team at **email** or **phone** and one of our team members would be glad to speak with you and answer any questions you may have. You may also complete this short survey and a member of our research team will contact you [here will be inserted a unique REDCap study specific link for tracking of participant interest and follow-up]

Sincerely,

PI Name

IRB Number

*Mandatory signature of Dr. Ford*

Daniel E. Ford, MD, MPH  
Vice Dean for Clinical Investigation  
Director, Institute for Clinical and Translational  
Research ICTR Research Recruitment Office

*Mandatory language required*

Participation in this study is voluntary. If you decide not to be part of the study, it will not change the medical care you receive. For more information and frequently asked questions (FAQs) related to research recruitment through MyChart, visit



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# Report Display in Epic

The screenshot displays the Epic 'My Reports' interface. At the top, a navigation bar includes 'Epic', 'Chart', 'Patient Lists', 'Apts', 'View Sched', 'Pt Research Studies', 'Study Maintenance - View Only', 'My Reports', and 'SlicerDicer'. The user is logged in as 'cogito CASSIA L.' with a search bar. The main area is titled 'My Reports' and contains a 'My Favorite Reports' tab. A 'Folders' pane is on the left, and a '+ Create a new folder' link is at the bottom left. An 'Open results immediately' checkbox is at the top right. The central area shows a grid of 20 report cards, each with an IRB number, report title, and 'Ready to view' status with a result count.

Appel IRB00063914 Patient Recruitment Outreach Ready to view - 45081 results	Payne IRB00027369 Patient Recruitment Outreach Ready to view - 1789 results	Hansel IRB00069904 Patient Recruitment Outreach Ready to view - 14788 results	TBrady IRB00065277 Patient Recruitment Outreach Ready to view - 13531 results
Rosenberg IRB00104679 Patient Recruitment Outreach Ready to view - 30183 results	CKeet IRB00095833 Patient Recruitment Outreach Ready to view - 2149 results	Findling IRB00110020 Patient Recruitment Outreach Ready to view - 16997 results	CassAppel_ReportZip Ready to view - 45081 results
Liu IRB00060778 Patient Recruitment Outreach Ready to view - 1170 results	Miller IRB00153409 Patient Recruitment Outreach Ready to view - 1328 results	Rosenberg IRB00062802 Patient Recruitment Outreach Ready to view - 1374 results	Carnell NA_00092328 Patient Recruitment Outreach Ready to view - 3910 results
Overby Taylor IRB00107475 RWB Survey Report Ready to view - 1504 results	Earley IRB00103955 Patient Recruitment Outreach Ready to view - 18952 results	Eakin IRB00091482 Patient Recruitment Outreach Ready to view - 2297 results	Heller NA_00070373 Patient Recruitment Outreach Ready to view - 1918 results
Bennett IRB00174516 Patient Recruitment Outreach Ready to view - 10749 results	Magge IRB00178127 Patient Recruitment Outreach Ready to view - 455 results		

# Selecting Eligible Patents

**Eakin IRB00091482 Patient Recruitment Outreach 6/25/19 2:01 AM [29078281] as of Tue 6/25/2019 2:01 AM**

MRN	Patient First Name	Patient Last Name	DOB	Patient Age Cal	Patient Gender	Race	Ethnicity	Status	Pt. Portal Status	Opt Out Flag?	Pt Comm Pref	Last Research Pt Outreach	Last Research Pt Outreach Actions
			10/10/1953	66 years	F	White or Caucasian	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart		
			05/24/1935	84 years	F	Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart	04/01/2019	Patient Portal Message
			12/16/1938	80 years	F	White or Caucasian	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart	08/06/2018	Patient Portal Message
			07/04/1943	77 years	F	Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart	06/06/2019	Patient Portal Message
			08/22/1944	75 years	F	Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart	06/10/2019	Patient Portal Message
			09/09/1942	79 years	M	White or Caucasian	Not Hispanic or Latino [1]	Alive	Activated	(None)	Mail,MyChart	08/14/2018	Patient Portal Message
			01/25/1949	71 years	M	Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	Mail,MyChart	09/24/2018	Patient Portal Message
			04/13/1919	99 years	F	White or Caucasian	Not Hispanic or Latino [1]	Alive	Activated	(None)	Mail,MyChart	08/14/2018	Patient Portal Message
			12/01/1942	77 years	M	Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	Email,MyChart	06/06/2019	Patient Portal Message
						Black or African American	Not Hispanic or Latino [1]	Alive	Activated	(None)	MyChart	08/30/2018	Patient Portal Message

# Message Center in Patient Portal

The screenshot shows a web browser window with the URL <https://mychart.hopkinsmedicine.org/MyChart/Messaging/Review?mailbox=1>. The page header includes the Johns Hopkins Medicine logo, a user profile for Cassia, and navigation icons for Health, Visits, Messaging, Billing, Resources, and Profile. A "Ver en Español" link is also present. The main content area is titled "Message Center" and features a "SEND A MESSAGE" button and a search bar. Below the search bar, there is a list of messages:

From	Subject	Date
Johns Hopkins Recruitment Office	Research Opportunity	03/07/2019 04:42 PM
Johns Hopkins Recruitment Office	You're Invited to Join the Daily24 Team!	02/14/2019 12:41 PM
Johns Hopkins Medicine	Appointment Reminder	01/14/2019 02:35 PM

Below the message list, a message states: "There are no more messages available." A "BACK TO THE HOME PAGE" button is located at the bottom of the message list area. The footer contains links for Site Map, Terms & Conditions, Contact Us, High Contrast Theme, and MyChart® licensed from Epic Systems Corporation © 1999 - 2018.

# Example of MyChart Message

The screenshot shows a web browser window with the MyChart Message Center interface. The message is from the Johns Hopkins Recruitment Office, dated 03/07/2019 04:42 PM. The subject is "Research Opportunity". The message text is as follows:

**Johns Hopkins Recruitment Office**  
03/07/2019 04:42 PM

**Research Opportunity**

In addition to providing medical care, physicians at Johns Hopkins conduct research with the ultimate goal of improving health.

One study that may be relevant to you is the STURDY study. STURDY is a research program conducted by the Johns Hopkins University and the National Institutes of Health (NIH) that tests the effects of 4 doses of vitamin D supplements on the risk of falling.

Every year, 1 in 3 seniors fall, and falls can have devastating effects. Some researchers think that vitamin D may help prevent falls, but we don't know for sure.

I wanted to personally invite you to consider joining STURDY as a volunteer participant. This is an opportunity to advance our scientific understanding of vitamin D and falls. You are receiving this email because you might qualify for this study based on your age and geographic location. Participation in this study is voluntary. If you decide not to be part of this study, it will not change the medical care you receive.

If you are age 70 or older, afraid of falling or have had a fall in the past year, and are willing to take vitamin D pills, you may be eligible for STURDY.

For more information or to contact us to see if you qualify visit [www.sturdystudy.org](http://www.sturdystudy.org)

Sincerely,  
Daniel E. Ford, MD, MPH  
Vice Dean for Clinical Investigation  
Director, Institute for Clinical and Translational Research  
ICTR Research Recruitment Office

Lawrence J. Appel, MD, MPH  
Principal Investigator of STURDY  
Protocol #: IRB00063914

Please do not respond to this MyChart message. For any questions about STURDY, please use the contact information above or on our website. For more information and frequently asked questions (FAQs) related to research recruitment through MyChart click here: [ictr.johnshopkins.edu/community/community-involvement/mychart-recruitment-messages/](http://ictr.johnshopkins.edu/community/community-involvement/mychart-recruitment-messages/)

# Precautions Taken for Patient Experience

- Only one invitation every 30 days
- Patients can opt out and are given a “flag” on their Epic account right after opting out
- Messages are targeted to specific characteristics so patients are not overwhelmed with messages
- Including notification that MyChart may be used for study invitations in Terms and Conditions

# What happens when a patient responds?

- We have created a REDCap link that can be personalized to each study
- These links are embedded into the message for interested patients to complete
- After completion, the study coordinator is notified
- An affiliated link is sent to the research coordinator to follow up on patient eligibility and enrollment status
- These surveys track basic demographics, including race, age, ethnicity and gender

# Barriers and Strategies for Improvement

Identified Barriers	Strategies for Improvement
Study team's intake capacity	<ol style="list-style-type: none"><li>1. Customized scheduling</li><li>2. Controlled batch sizes</li><li>3. REDCap survey link</li></ol>
Saturation of frequently targeted populations	<ol style="list-style-type: none"><li>1. Controlled batch sizes</li><li>2. Strategic messaging schedule</li><li>3. Adding eligibility criteria</li></ol>
Low response rates for general populations	<ol style="list-style-type: none"><li>1. Adding eligibility criteria to create more specific phenotypes</li></ol>
Limited representativeness for specific populations within MyChart	<ol style="list-style-type: none"><li>1. Research consults</li><li>2. TriNetX exploration</li><li>3. Multiple recruitment methods</li></ol>



# Is MyChart Right for your Team/Project ?

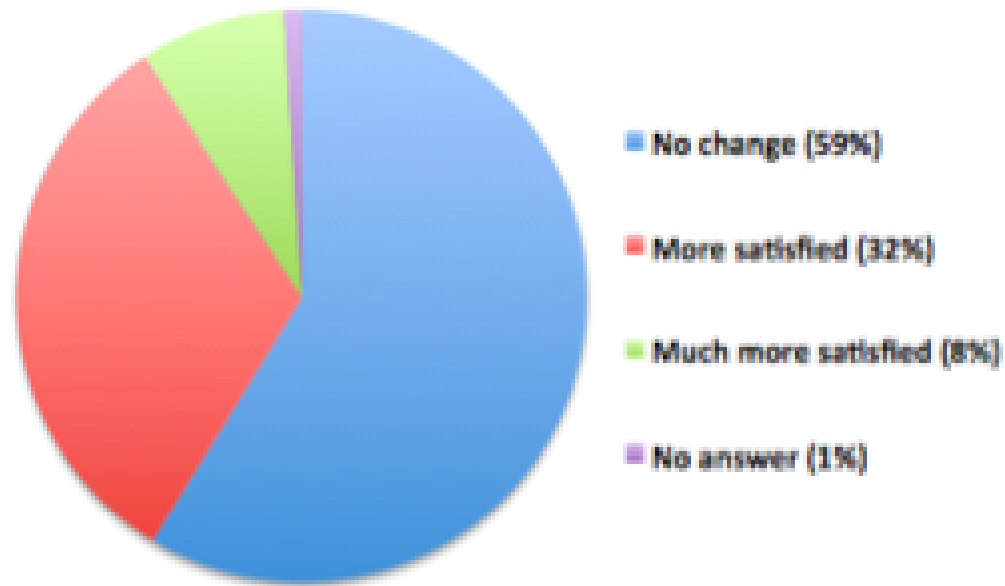
Some things to think about are:

1. Your target population
  - Are they in Epic? → Run a report on TriNetX
2. Are they represented among MyChart Users?
  - Review the demographics of MyChart users
3. Can your eligibility criteria be identified within the EMR?
  - Keep in mind that certain data elements are more difficult/costly to query due to time requirements, such as:
    - flowsheet values (devices, lines/drains, vitals),
    - imaging results and pathology reports contained in semi-structured notes, and
    - socioeconomic indicators such as education level, median household income, homelessness, and whether or not the patients speak English fluently
  - Keep in mind that reports with fewer eligible patients will have a high cost per person
4. Are you using other recruitment methods in tandem to MyChart?
5. Do you have the staff members available to be attentive to inquiries following messages being sent?

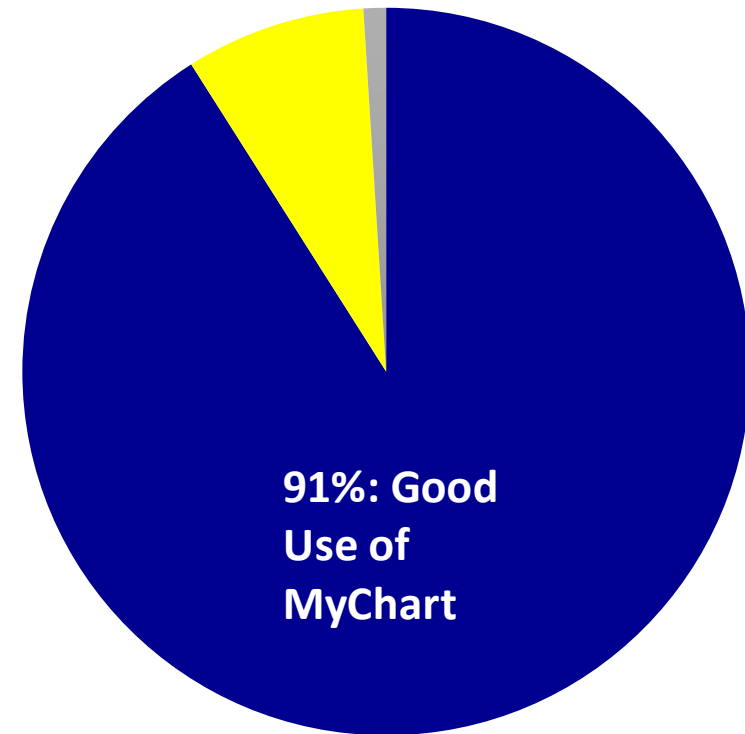


# Feedback from the Patients

To what extent did getting this information in MyChart change your satisfaction with being a patient at Johns Hopkins?



Patients' Opinion on MyChartStudy Invitations



# Key Definitions

Report Size: total number of patients that were identified through the computable phenotype criteria as eligible for a given report

Batch Size: total number of patients that are messaged each time messages are distributed

Response Rate: total number of interested patients who inquired with the respective study team following receiving a message divided by the total number patients who received a message for that respective study

Eligibility Rate: total number of patients who qualified as eligible for the respective study after responding to a message divided by the total number of patients who received a message for that respective study

Enrollment Rate: total number of patients that enrolled in the respective study after receiving a message divided by the total number of patients who received a message for that respective study



# Questions and Contacts

ICTR MyChart Recruitment Service

410-361-6467

[Research\\_recruitment@jhmi.edu](mailto:Research_recruitment@jhmi.edu)

Cassie Lewis-Land: [clewis4@jhmi.edu](mailto:clewis4@jhmi.edu)

[https://ictr.johnshopkins.edu/programs\\_resources/programs-resources/research-participant-recruitment-and-retention/my-chart-pic-based-recruitment/](https://ictr.johnshopkins.edu/programs_resources/programs-resources/research-participant-recruitment-and-retention/my-chart-pic-based-recruitment/)

# RIU Team

- Casey Overby, PhD
- Daniel Mullin, PhD
- Kelly Gleason, PhD, RN
- Jeanne Charleston, RN, BSN
- Liz Martinez RN,BSN,CCRC
- Hailey Miller, RN, BSN
- Monica Guerrero Vazquez, MS
- Marianne Gildea, RN, MS, CCRC
- Yvonne Higgins, MAS, MS
- *Community Partners*
- **Administrative Coordinator:** Mary Thomas
- **Program Manager:** Cassia Lewis-Land, MS
- **Deputy Director:** Cheryl Dennison Himmelfarb, PhD, RN



# Community Research Advisory Council

5/21/20

# ICTR Community Research Advisory Council (C-RAC)

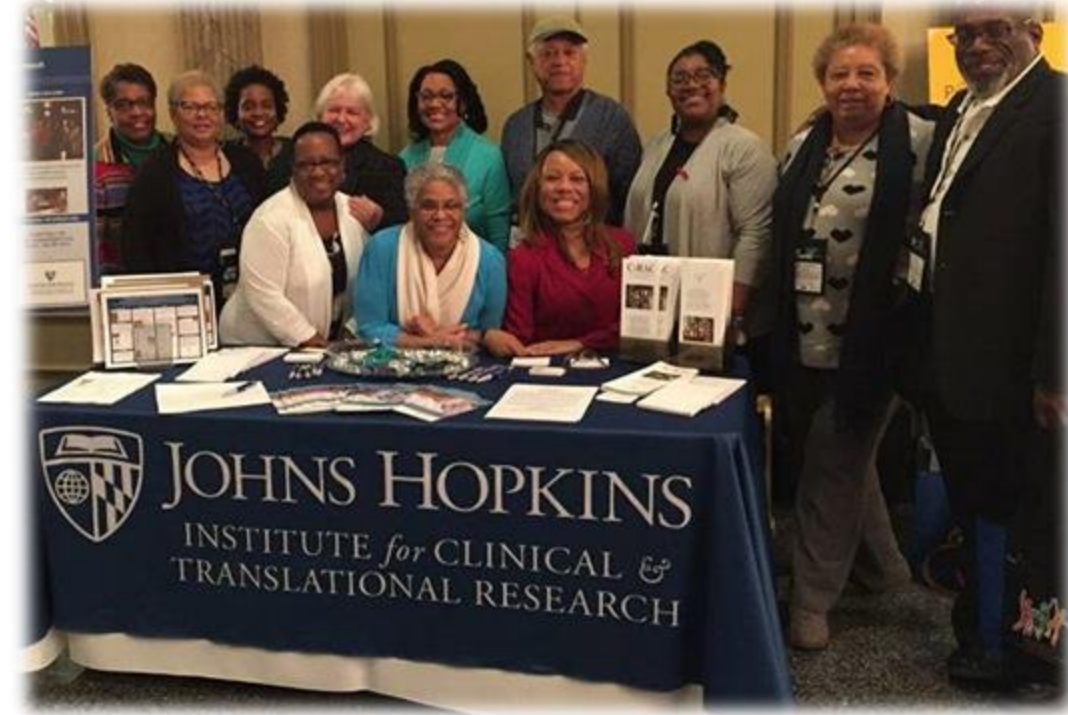
A volunteer board formed in 2009 to connect researchers and community members to:

## Improve community health and knowledge

- Ensure the integrity and safety of research
- Ensure that research is mutually beneficial
- Increase community access to resources & research
- Promote patient-centered research

## What We Do

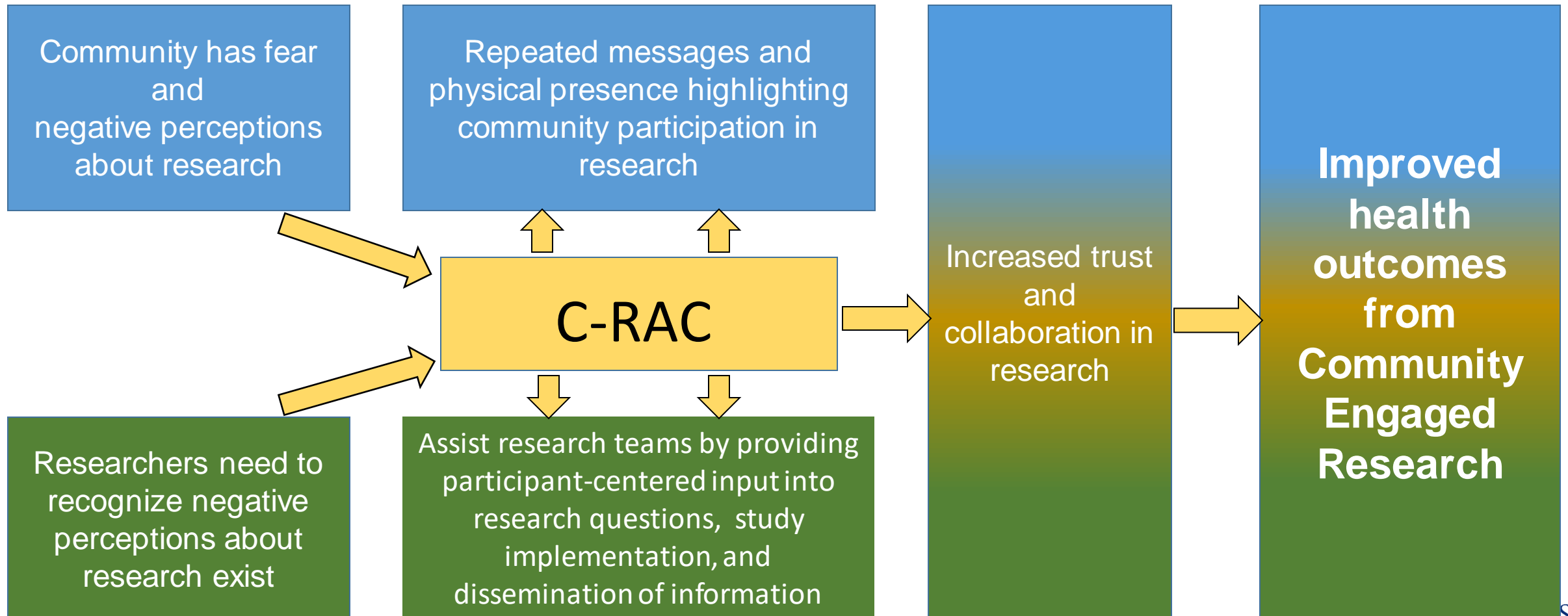
- Evaluate and review health research
- Inform researchers about community interests and preferences
- Share health and research information
- Support community and faith-based projects



# C-RAC and COVID Response


- In April, C-RAC re-aligned its processes to support efforts of COVID-19 research teams
  - Promoting 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
- 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.”

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



# COVID-19 Expedited Community-Engaged Research 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
- Mondays, from 5 -6 pm
- In April, C-RAC assisted three research teams in the areas of communication and implementation. Early feedback from those team indicate incorporation of C-RAC recommendations into their submissions to the IRB.
- C-RAC in the next several weeks will refine its process to better track its services and impacts.



**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:
  - Recruitment
  - Communications
  - Implementation
  - 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.

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Release: 5/11/2020 DRAFT

# Strategies to strengthen community engagement

1

- LISTEN

2

- BE UNDER-  
STANDABLE

3

- BE A TRUSTED  
PARTNER

4

- GIVE BACK



For more information on C-RAC and other Community Collaboration Core initiatives at Johns Hopkins ICTR, please visit us at:

E-mail: [ICTR-C-RAC@jhmi.edu](mailto:ICTR-C-RAC@jhmi.edu)

Website: <https://ictr.johnshopkins.edu/community/community-involvement/community-research-advisory-council/>

Facebook: [@JohnsHopkinsICTR](https://www.facebook.com/JohnsHopkinsICTR)

Twitter: [@ictrjhu](https://twitter.com/ictrjhu)

Cyd Lacanienta, MSW

Asst. Director, Stakeholder Engagement, Community and Collaboration Core

Johns Hopkins Institute of Clinical and Translational Research

E-mail: [clacani1@jh.edu](mailto:clacani1@jh.edu)