# *Utilization and Effectiveness of Using a Patient Portal for Health Research Recruitment*

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The presenter has documented that they have no financial relationships to disclose or Conflicts of Interest to resolve.

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# Recruitment: Translational Science Barrier

- For decades trials have failed to recruit and retain participants
    - 50% of trials

- Not treated as a science
    - Plans should be informed by literature and previous experience
    - Data should be collected and tracked in real-time

- CTSA Recruitment Innovation Center (trialinnovationnetwork.org)

Austin, C.P. (2021), Opportunities and challenges in translational science. Clin Transl Sci, 14: 1629-1647. https://doi.org/10.1111/cts.13055
Beskow LM, Brelsford KM, Hammack CM. Patient perspectives on use of electronic health records for research recruitment. BMC Med Res Methodol. 2019 Feb 26;19(1):42. doi: 10.1186/s12874-019-0686-z. PMID: 30808279; PMCID: PMC6390331.

# Use of EHR for Recruitment

- Patients support direct contact by researcher

- How can this be achieved?
    - Point of Care notices
    - Research registries and clinic registration
    - Patient Portal messages (MyChart)
        - >12 CTSA institutions

- TIN Webinar, Johns Hopkins University
    - https://trialinnovationnetwork.org/elements/network-events/?key-element=18344&category=archives

Beskow LM, Brelsford KM, Hammack CM. Patient perspectives on use of electronic health records for research recruitment. BMC Med Res Methodol. 2019 Feb 26;19(1):42. doi: 10.1186/s12874-019-0686-z. PMID: 30808279; PMCID: PMC6390331.

Embi PJ, Jain A, Clark J, Harris CM. Development of an electronic health record-based Clinical Trial Alert system to enhance recruitment at the point of care. AMIA Annu Symp Proc. 2005;2005:231-5. PMID: 16779036; PMCID: PMC1560758.

Kluding PM, Denton J, Jamison TR, Brooks W, Blackwell K, Lantos JD, Waitman LR, McMahon TM, Choudhary A, Bott MJ, Greiner A, Klaus S, O'Brien-Ladner A, Aaronson LS, Burns J, Barohn R. Frontiers: Integration of a Research Participant Registry with Medical Clinic Registration and Electronic Health Records. Clin Transl Sci. 2015 Oct;8(5):405-11. doi: 10.1111/cts.12309. Epub 2015 Aug 3. PMID: 26243261; PMCID: PMC4673893.

# Recruitment Unit Team



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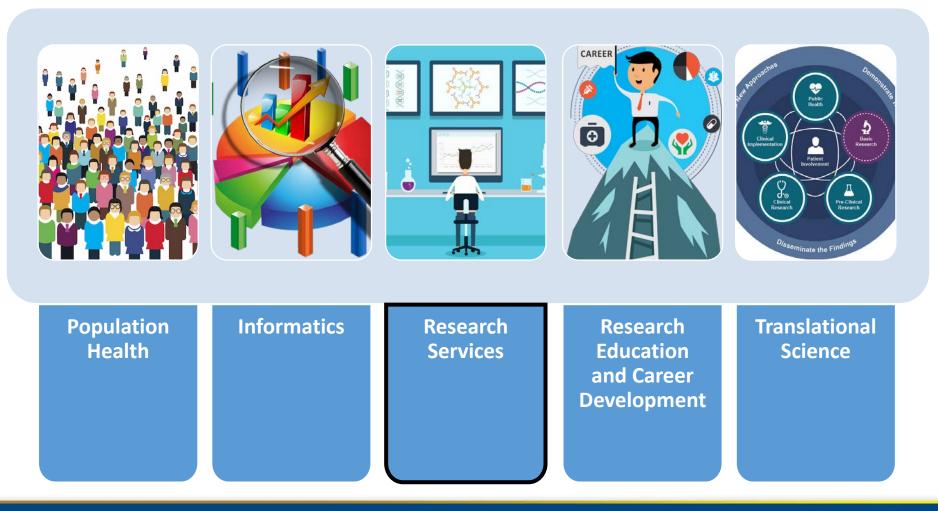Health Project Coordinator

# Mission

*To provide efficient and high-quality research services to UR faculty, staff, trainees, UR Medicine patients and community members.*
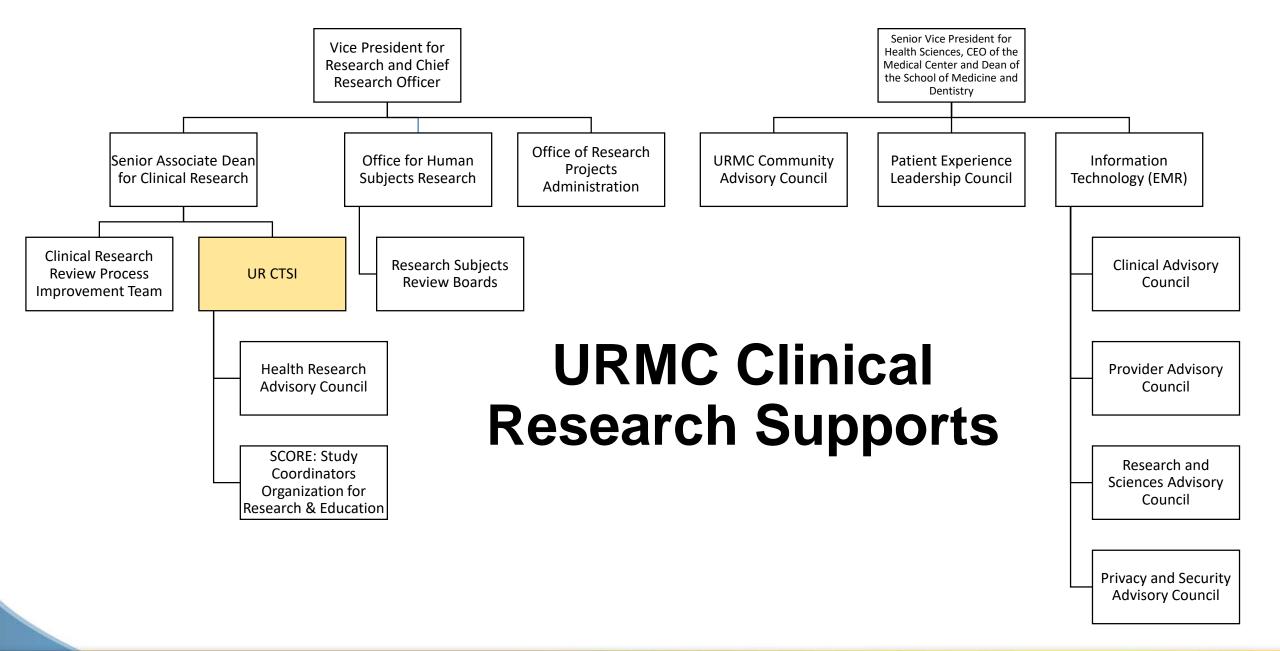
# CTSI Structure and Supports



| Population Health | Informatics | Research Services | Research Education and Career Development | Translational Science |

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**URMC Clinical Research Supports**

Vice President for Research and Chief Research Officer
- Senior Associate Dean for Clinical Research
  - Clinical Research Review Process Improvement Team
  - UR CTSI
    - Health Research Advisory Council
    - SCORE: Study Coordinators Organization for Research & Education
- Office for Human Subjects Research
  - Research Subjects Review Boards
- Office of Research Projects Administration

Senior Vice President for Health Sciences, CEO of the Medical Center and Dean of the School of Medicine and Dentistry
- URMC Comunity Advisory Council
- Patient Experience Leadership Council
- Information Technology (EMR)
  - Clinical Advisory Council
  - Provider Advisory Council
  - Research and Sciences Advisory Council
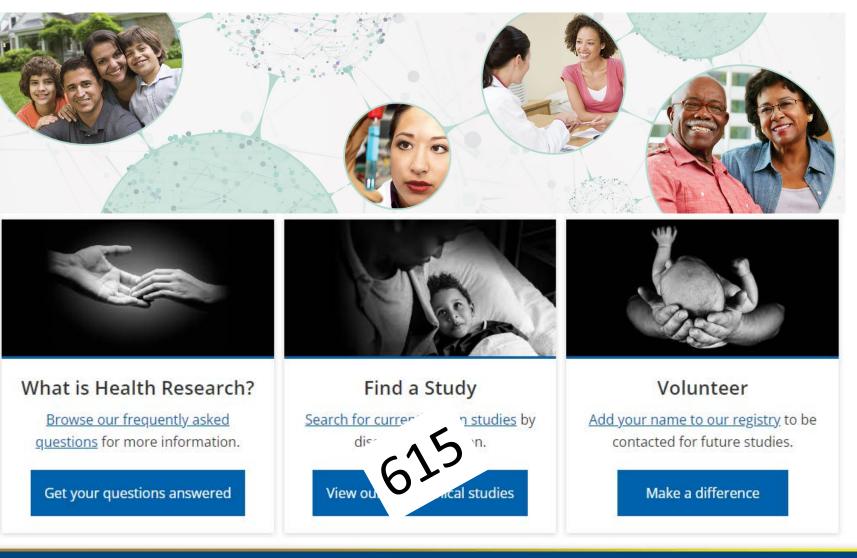  - Privacy and Security Advisory Council

# Participant Recruitment Services

- Consultations

- Education
  - Recruitment and Retention Course- offered through PHS

- Surveys
  - Empowering the Participant Voice
  - Community Survey on Research

- Tools and Resources
  - Health research study listing page
  - Facebook advertising
  - Participant registries
  - Greater-Rochester Practice-Based Research Network
  - MyChart for Recruitment

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# UR Health Research

# Social Media

- UR Health Research Facebook Page
- Meta ads
  - 91 campaigns for 71 projects from 2019 to 2023
  - Manuscripts
    - Hispanic young adult smokers
    - People with previous COVID infection
    - Country of Palau during COVID

# Registries

- ResearchMatch.org
- UR CTSI Research Participant Registry

# ResearchMatch.org



ResearchMatch.org is a national recruitment registry that brings together two groups of people who are looking for one another:
(1) people who are trying to find research studies
(2) researchers who are looking for people to participate in their studies via a secure website.

>157,000 registrants
>1300 studies
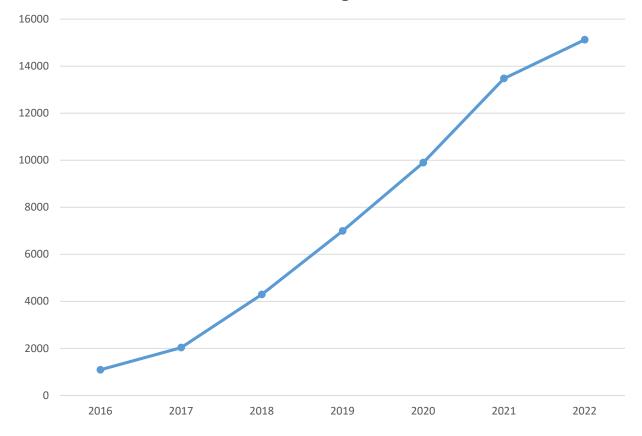230 institution
>14,000 researchers

# UR CTSI Local Registry

- Built a local registry of >15,000 participants
  - ~10,000 have email

| | Registry | County Census |
|---|---|---|
| Children | 6% | 21% |
| Black registrants | 20% | 16% |
| Hispanic or Latino registrants | 9% | 10% |

# of active registrants

Weekly emails of recruiting studies. 40% open rate

- NCATS-funded collaborative grant
  - Rockefeller, Vanderbilt, Johns Hopkins, Wake Forest, Duke
- Collect feedback from research subjects using a validated survey
- Collects information about
  - Satisfaction with the research experience
  - Informed consent, coercion
  - Ability to reach research team
  - Respect, courtesy, value
- Developing interventions to improve scores

# Community Research Survey

Survey done every other year

Community-not our patients

80% of participants think health research is important

Less willing to participate in studies with drugs, devices, injections

Black and Hispanic/Latino people think they are more likely to be asked to participate in riskier studies

Use to get feedback from subpopulations- complex care, rural, etc.

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# Recruitment Services



Consultation | Education
Surveys | Tools

# MyChart for Recruitment Implementation

# Why MyChart?

- Point of Care alerts were a no-go with the clinicians
- We already had a process for our registries
- We have a no cold-calling policy
- Researchers could not get access to patients

# Timeline

**05** Results
May 2021-Jan 2023

**04** Opened Service

**03** 5 month pilot
May-Sept

**02** EPIC upgrade
Patient communication

**01** ISD Notification
EPIC upgrade

Q1 Q2 Q3 Q4 | Q1 Q2 Q3 Q4 | Q1 Q2 Q3 Q4 | Q1 Q2 Q3 Q4

2020 | 2021 | 2022 | 2023

# Stakeholders- Approval and Feedback

# Patient Communication 7 ways

## How to learn more and how to opt out

# Online MyChart Terms and Conditions

**RESEARCH**

Within MyChart you may receive notifications or messages from researchers about studies you may be eligible for. To learn more, log in and go to your Research Studies page. *If you do not want to receive these messages, you must log in and indicate that you do not want to be contacted about research studies through MyChart.* If you do want to be contacted, you can create a profile to select areas of research you are interested in, see what new opportunities you may be eligible for and what studies you are enrolled in. *If you do not make a selection, we will assume that you are willing to be contacted.*

Research Connections

UR Medicine now offers health research studies right in MyChart. Patients will be offered research studies tailored to their health status. Visit the **Research Studies page in your MyChart** to learn more (you will need to login first), and to opt out if you do not want to receive research messages via MyChart. **Click to learn more!**

Prior to your UR Medicine upcoming appointment if you are experiencing a cough, fever, difficulty breathing that is new, body aches and/or a sore throat please call your doctor's office before you come to your appointment to be assessed. Please be aware that visitor restrictions are in place. If you have questions, please contact your care team.

## MyChart Login

MyChart Username

Password

**SIGN IN**

Using Internet Explorer? **Login Here**

## Sign Up

Become more engaged with your health, message your providers, view test results, appointments, pay your bills, and more!

**I Have An Activation Code**

## Need Help?

Did you forget your username, password, or have general questions? Use the tools below to get started.

**I Forgot My Username**

# Bottom of Login Screen

**Additional Resources**

- Nominate an ICARE Star - Recognize a UR Medicine employee who takes that extra step to deliver *Medicine of the Highest Order*

- MedlinePlus® - Disease, treatment, drug, healthy living information from the National Library of Medicine's MedlinePlus®

- Cost Estimates - Get a free cost estimate for an upcoming procedure.

- Ask A Medical Librarian - Can't find what you're looking for in MedlinePlus®? Ask a medical librarian.

- Research Connections - UR Medicine offers health research studies right in MyChart. You will be offered research studies tailored to your health status; you can also opt-out.

**Site Links**

Home

Sign Up (I Have An Activation Code)

**Additional Resources**
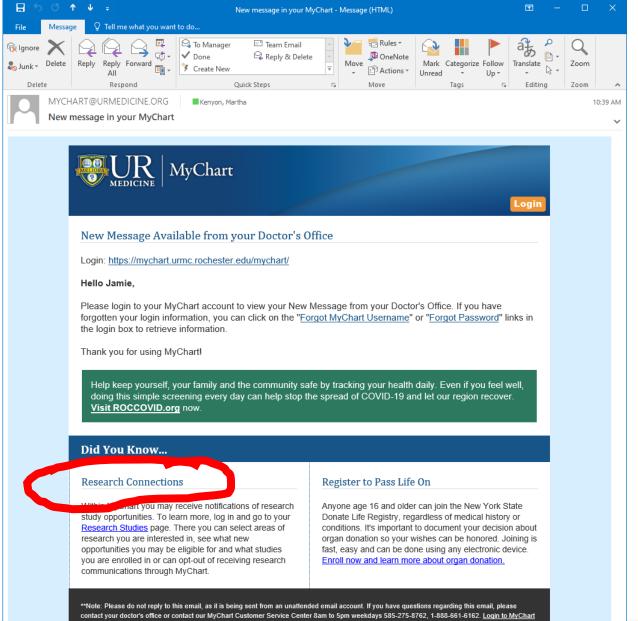
UR Medicine Labs Locations

UR Medicine Imaging Locations
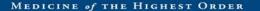
**Contact Information**

📞 Phone Number

» 1-888-661-6162, Opt. 1

File    Message    Tell me what you want to do...

Ignore    Delete    Reply    Reply All    Forward    To Manager    Done    Create New    Team Email    Reply & Delete    Rules    OneNote    Actions    Move    Mark Unread    Categorize    Follow Up    Translate    Zoom

Junk

Delete    Respond    Quick Steps    Move    Tags    Editing    Zoom

MYCHART@URMEDICINE.ORG    Kenyon, Martha    10:39 AM

New message in your MyChart

## UR MEDICINE | MyChart

**Login**

### New Message Available from your Doctor's Office

Login: https://mychart.urmc.rochester.edu/mychart/

**Hello Jamie,**

Please login to your MyChart account to view your New Message from your Doctor's Office. If you have forgotten your login information, you can click on the "Forgot MyChart Username" or "Forgot Password" links in the login box to retrieve information.

Thank you for using MyChart!

Help keep yourself, your family and the community safe by tracking your health daily. Even if you feel well, doing this simple screening every day can help stop the spread of COVID-19 and let our region recover. **Visit ROCCOVID.org** now.

### Did You Know...

#### Research Connections

Within MyChart you may receive notifications of research study opportunities. To learn more, log in and go to your Research Studies page. There you can select areas of research you are interested in, see what new opportunities you may be eligible for and what studies you are enrolled in or can opt-out of receiving research communications through MyChart.

#### Register to Pass Life On

Anyone age 16 and older can join the New York State Donate Life Registry, regardless of medical history or conditions. It's important to document your decision about organ donation so your wishes can be honored. Joining is fast, easy and can be done using any electronic device. Enroll now and learn more about organ donation.

**Note: Please do not reply to this email, as it is being sent from an unattended email account. If you have questions regarding this email, please contact your doctor's office or contact our MyChart Customer Service Center 8am to 5pm weekdays 585-275-8762, 1-888-661-6162. Login to MyChart to learn more about your notification settings on the Profile > Communications page.

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Your Menu    📅 Appointments and Visits    ✉ Messages    🧪 Test Results    💊 Medications

J  **Jamie**
Switch ▼

## Research Studies

🖨

Health research (which refers to clinical studies) is the way we learn about new and better ways to help people be healthier. Every study is a partnership between members of the community (you), doctors, and researchers. Participation from volunteers like you ensures there are ongoing advances in the healthcare. Your involvement plays a crucial role in improving the health of current and future generations.

MyChart will now offer health research studies to URMedicine patients of all ages, unless you indicate that you do not want to be contacted about research via MyChart. Your choice will not affect your use of MyChart for your clinical care.

If you are interested in learning more about research at the University of Rochester, visit URHealthResearch.urmc.edu. You can search a list of currently enrolling studies or sign up to contacted for research outside of MyChart by either email, phone or letters.

Participation Preferences ⌃

May we contact you about opportunities to participate in research studies? **If no choice is made**, we will assume that you are willing to be contacted for research studies through MyChart. You can always change your contact preference in the future.

| OK to Contact | Do Not Contact |

Create a profile to let us know the types of research you may be interested in.

**CREATE PROFILE**

### Your Studies

You are not enrolled in any research studies or your research studies are not visible in MyChart.

- **Available Studies** - New study opportunities
- **Active Studies** - Studies in which you are currently enrolled. Note, this list may not include all research studies you participate in, but only those offered to you through MyChart. You may also be enrolled in research studies which were offered to you through other modes of communication such as email, phone or letters.

### Participation Preferences

Your preferences will help us let you know about research opportunities that might interest you.

- **OK to Contact** - You are willing to be notified through MyChart about a research study that might be a fit for you.
- **Do Not Contact** - You are not willing to be notified through MyChart about a research study. You may still be contacted directly through your provider about a study either through MyChart or through other types of communication such as letters and phone calls.

**If no choice is made:** We will assume that you are willing to be contacted for research studies through MyChart. You can always change your contact preference in the future. Visit the Research Studies page.

# Study Opportunity Description

## Available Studies

Based on your medical record, you have been identified as potentially eligible for these studies. Click "I'm Interested" to notify the research team that you may want to participate in the study.

### RSRB00070003 IMLT 17105 A Phase 1/2, Open-Label, Dose-Escalation, Safety and Tolerability Study of INCAGN01949 in Subjects With Advanced or Metastatic Solid Tumors

**Principal Investigator**

MARCUS NOEL, MD

**Description**

This study is testing the effectiveness of using MyChart functionality for recruiting patients. Specifically we are looking for patients with Rheumatoid Arthritis.

If you do not wish to be contacted via MyChart for research recruitment opportunities, please update your preference by clicking on the Participation Preferences section above.

I'M INTERESTED          NO, THANK YOU

# Patient View

85% Ok to Contact
15% Do not Contact

# "Rules"

**CTSI Consultation**

**Research Team**

Children 0-11
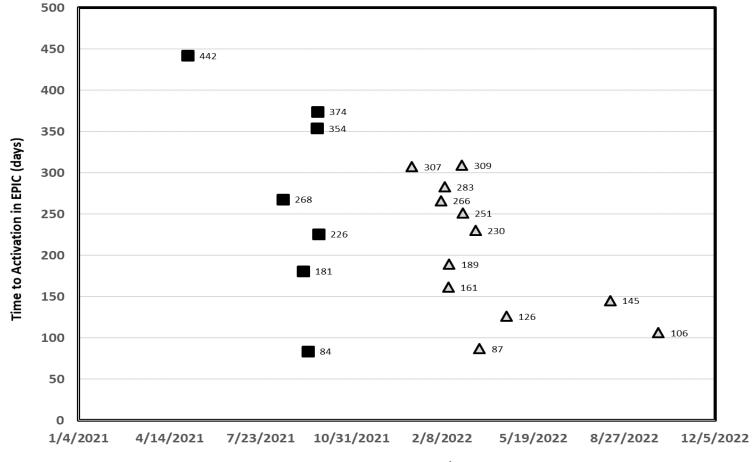
# University of Rochester MyChart for Recruitment Process

# Results

- Data collected from Jan 2021 to Jan 2023

- 59 requests

- 51 consults
  - 8 withdrew before consulting

- Average time from consult to study activation was 231 days (84-442)

- 19 studies sent messages

- 8,240 messages to 8,168 patients
  - 1-3 messages per patient

# Time to Activation

# Wide Range of Departments Participated

| Department | # of Studies |
|---|---|
| Dermatology | 1 |
| Dentistry | 1 |
| Family Medicine | 1 |
| Gastroenterology and Hepatology | 1 |
| Neurology | 2 |
| Neurosurgery | 1 |
| Obstetrics and Gynecology | 1 |
| Oncology | 2 |
| Otolaryngology | 1 |
| Public Health Sciences | 2 |
| Psychiatry | 4 |
| Pulmonology | 1 |
| Surgery | 1 |

Response rate varied by study

# Demographics of patients receiving MyChart messages and Response Rates

| | | # of Patients (%) | Response Rate (%) |
|---|---|---|---|
| **All Patients** | | 8,168 (100) | 23 |
| **Sex** | Female | 4,713 (57) | 24 |
| | Male | 3,526 (43) | 20 |
| **Age** | 0-10 | 16 (0.2) | 0 |
| | 18-34 | 1,067 (12.9) | 19 |
| | 35-54 | 2,610 (31.7) | 22 |
| | 55-64 | 2,253 (27.3) | 24 |
| | 65-95 | 2,292 (27.8) | 25 |
| **Ethnicity** | Hispanic | 361 (5) | 14 |
| | Non-Hispanic | 7,360 (95) | 24 |
| **Race** | American Indian or Alaska Native | 28 (0.3%) | 11 |
| | Asian | 604 (7.3) | 9 |
| | Black or African American | 717 (8.7) | 14 |
| | White | 6,564 (79.7) | 26 |
| | Unknown/Not Reported | 327 (4.0) | 12 |

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# Response Rates



8240 messages (8168 patients*)

1878 responses (23% response rate)

636 interested (8% interested rate)

156 screened/enrolled

*5% opt out of future contact

# Study status of interested patients (N=636)

| Study Status | # of patients (%) |
|---|---|
| Interested | 480 (75) |
| Eligible | 7 (1) |
| Not Eligible | 16 (3) |
| Waiting for consent | 14 (2) |
| On Study | 67 (11) |
| On Treatment | 5 (0.8) |
| Off Study | 47 (7) |

- Inability of research teams to reach patient
- Teams need reminders to update CTMS

# Comments from Study Teams

*Very helpful to talk through MyChart for recruitment as well as recruitment materials, graphics possibilities, and suggestions for future growth of our research program.*

*Using MyChart for enrollment made things so much easier and faster than having to go into clinics and wait to speak to potential participants.*

*We used CTSI for MyChart recruitment- it turned out helpful, but time consuming.*

*The CTSI's assistance with recruitment through MyChart has been a game changer, immensely helpful in our ever-increasing technology-heavy age.*

*My feedback would be to improve the tracking of subjects in the eRecord interface.*

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# Lessons Learned

All types of studies can benefit

Study teams needed support identifying populations in EMR

Study teams needed support writing in plain language

Confusion about policy of using MyChart for Research

Created great visibility of other recruitment tools

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# We would like to acknowledge the members of the MyChart for Recruitment working group:

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Lauren Bruckner, Associate Professor of Pediatrics

Kellie Snider, Information Systems Division (ISD)

Martha Kenyon, ISD

Rachel Aleese, ISD

Carrie Irvine, Assistant Professor of Obstetrics and Gynecology

Ann Dozier, Chair and Professor of Public Health Sciences

Steven Wormsley, former Director of Research and Academic IT

Nicole Mason, former Director of the Office of Clinical Research

Kelley O'Donoghue, Associate VP for Human Subject Protection

Kathleen Tranelli, URMC Privacy Officer

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# Funding

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# Abbreviations

CTMS; clinical trial management system

CTSA; Clinical and Translational Science Awards

EMR; electronic medical record

ISD; Information Systems Division

IT; Information Technology

NCATS; National Center for Advancing Translational Science

UR CTSI; University of Rochester Clinical and Translational Science Institute

URMC; University of Rochester Medical Center

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