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.
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)

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

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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
URMC Clinical Research Supports
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
What is Health Research?

Browse our frequently asked questions for more information.

Get your questions answered

Find a Study

Search for current studies by discipline.

View our clinical studies

Volunteer

Add your name to our registry to be contacted for future studies.

Make a difference
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

<table>
<thead>
<tr>
<th></th>
<th>Registry</th>
<th>County Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>6%</td>
<td>21%</td>
</tr>
<tr>
<td>Black registrants</td>
<td>20%</td>
<td>16%</td>
</tr>
<tr>
<td>Hispanic or Latino registrants</td>
<td>9%</td>
<td>10%</td>
</tr>
</tbody>
</table>

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.
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
Stakeholders- Approval and Feedback
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.
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.
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

MyChart may send you 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 enrolling 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 MyChart Customer Service Center at 855-325-6672 or 1-844-661-962. Login to MyChart to learn more about your notification settings on the MyChart + Communications page.
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 UR Medicine 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](http://URHealthResearch.urmc.edu). You can search a list of currently enrolling studies or sign up to be 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.

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.
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

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Description</th>
</tr>
</thead>
</table>
| MARCUS NOEL, MD              | 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

Children 0-11

Research Team
University of Rochester MyChart for Recruitment Process

1. Submit REDCap intake form “Request to Use MyChart for Recruitment”

2. Recruitment Consultation with the UR CTSI

3. Get IRB approval: Submit updated protocol & MyChart Request Form (e-signed by UR CTSI)

4. Send IRB approval letter and materials to UR CTSI

5. Get list of eligible patients: Submit Service Request to UR CTSI Informatics

6. Work with Office of Clinical Research to create OnCore study record and set up study in EPIC

7. Notify UR CTSI of study in eRecord. UR CTSI Informatics will arrange for activation of MyChart for Recruitment with eRecord team.

8. Research coordinator receives workflow instructions and can begin sending MyChart messages

9. Patient responds to message

10. Coordinator screens/enrolls patient and updates status in OnCore

11. UR CTSI collects enrollment data

12. Coordinator retracts messages when enrollment is complete
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

<table>
<thead>
<tr>
<th>Department</th>
<th># of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatology</td>
<td>1</td>
</tr>
<tr>
<td>Dentistry</td>
<td>1</td>
</tr>
<tr>
<td>Family Medicine</td>
<td>1</td>
</tr>
<tr>
<td>Gastroenterology and Hepatology</td>
<td>1</td>
</tr>
<tr>
<td>Neurology</td>
<td>2</td>
</tr>
<tr>
<td>Neurosurgery</td>
<td>1</td>
</tr>
<tr>
<td>Obstetrics and Gynecology</td>
<td>1</td>
</tr>
<tr>
<td>Oncology</td>
<td>2</td>
</tr>
<tr>
<td>Otolaryngology</td>
<td>1</td>
</tr>
<tr>
<td>Public Health Sciences</td>
<td>2</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>4</td>
</tr>
<tr>
<td>Pulmonology</td>
<td>1</td>
</tr>
<tr>
<td>Surgery</td>
<td>1</td>
</tr>
</tbody>
</table>

Response rate varied by study
Demographics of patients receiving MyChart messages and Response Rates

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

<table>
<thead>
<tr>
<th>Study Status</th>
<th># of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interested</td>
<td>480 (75)</td>
</tr>
<tr>
<td>Eligible</td>
<td>7 (1)</td>
</tr>
<tr>
<td>Not Eligible</td>
<td>16 (3)</td>
</tr>
<tr>
<td>Waiting for consent</td>
<td>14 (2)</td>
</tr>
<tr>
<td>On Study</td>
<td>67 (11)</td>
</tr>
<tr>
<td>On Treatment</td>
<td>5 (0.8)</td>
</tr>
<tr>
<td>Off Study</td>
<td>47 (7)</td>
</tr>
</tbody>
</table>

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

Jeanne Holden-Wiltse, CTSI Director of Informatics
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
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Kathleen Tranelli, URMC Privacy Officer
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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