Effectiveness and Cost of Recruiting Participants to a Research Registry Using an Emergency Department Research Associate (EDRA) Program

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Registries

- Disease specific or disease agnostic
  - ResearchMatch.org
  - Parkinson’s Disease Registry (updr.org)
- Prohibition on "cold-calling"
  - our registry helps patients gain access to studies
- Ways to build registries
  - Outpatient clinic registration
  - Direct approach in the clinic
  - Employee wellness data
  - Patient portals
  - Online websites and advertising
UR Health Research

• Created in 2013 as part of a NCATS supplement
• Created registry and Open Studies Page and dedicated email
• Later a Facebook page was added
Methods

• EDRA program was hired for 3 months
  • 12/01/2017-02/28/2018

• Instructed to approach everyone in the ER with a minimum of 6 enrollments per day

• iPads were used for enrolling

• ER covered 24/7

• 2 months after the pilot 6 EDRAs were interviewed to discuss the challenges and successful techniques to recruitment

• Uni-variant and bi-variant frequencies were calculated
Inclusion/Exclusion Criteria

• **Inclusion criteria**
  - Patient or family member at ER
  - UR Registry- Mailing address, email or phone number
  - RM- valid email address

• **Exclusion Criteria**
  - Non-English speaking unless a translator was present
  - Not already registered
  - Inability to give informed consent
Data Collection

- There are typically 2 EDRAs on each shift.
- Each person keeps a shift chart.
- They collect
  - Name
  - MRN
  - Room
  - Sex
  - Age
  - Race
  - Ethnicity
  - Family member?
  - Notes
# Emergency Department Research Associate Shift Chart

**Date:** 09/11/16

**Research Associate:** Olivia Brumfield

**Shift:** A B C D (circle)

**EDRA Codes:**
- 1 = Enrolled
- 2 = Ineligible (explanation required)
- 3a/3b = Refused (explanation required)
- 4 = Missed (explanation required)
- Blank = Left for next EDRA

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**CTSI Research Registry (All Ages) – PI: Ann Dozier, Ph.D., R.N., Coordinator: Carrie Dykes, Ph.D.**

<table>
<thead>
<tr>
<th>Name (Last, First)</th>
<th>MRN</th>
<th>Rm</th>
<th>Sex/Age</th>
<th>Race</th>
<th>Ethnicity</th>
<th>Notes (Chief Complaint, Reason Ineligible/Refused/Missed, Provider)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4R</td>
<td>F126</td>
<td>4R</td>
<td>F</td>
<td>black/AA</td>
<td>not hispanic</td>
<td>abd. cramping</td>
</tr>
<tr>
<td>24R</td>
<td>F136</td>
<td>24R</td>
<td>F</td>
<td>White</td>
<td>not hispanic</td>
<td>seizures</td>
</tr>
<tr>
<td>42L</td>
<td>F138</td>
<td>42L</td>
<td>F</td>
<td>white</td>
<td>not hispanic</td>
<td>abd. cramping, local registry down</td>
</tr>
<tr>
<td>9L</td>
<td>M/23</td>
<td>9L</td>
<td>M</td>
<td>black/AA</td>
<td>not hispanic</td>
<td>aggressive behavior, pt. only wanted to do local one</td>
</tr>
</tbody>
</table>

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**Notes:**

ST (Status)
Enrollments Per Week

Week

Number of Participants

<table>
<thead>
<tr>
<th>Week</th>
<th>Total approached</th>
<th>Enrolled</th>
<th>Declined</th>
<th>Ineligible</th>
<th>Missed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>150</td>
<td>91</td>
<td>42</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>75</td>
<td>62</td>
<td>10</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>86</td>
<td>61</td>
<td>18</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>123</td>
<td>81</td>
<td>36</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>45</td>
<td>20</td>
<td>22</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>27</td>
<td>26</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>45</td>
<td>35</td>
<td>8</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>39</td>
<td>26</td>
<td>10</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>56</td>
<td>44</td>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>64</td>
<td>54</td>
<td>9</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>50</td>
<td>47</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>12</td>
<td>24</td>
<td>18</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
## Demographic Characteristics of Enrolled and Declined Participants compared to registrants prior to the pilot

<table>
<thead>
<tr>
<th></th>
<th>No. of volunteers</th>
<th>Percent White</th>
<th>Percent Hispanic or Latino</th>
<th>Percent Male</th>
<th>Mean Age ± Stdev</th>
<th>Median Age (Range)</th>
<th>Percent of participants 0-17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enrolled</strong></td>
<td>565</td>
<td>65%</td>
<td>9%</td>
<td>40%</td>
<td>37±16</td>
<td>33 (3-92)</td>
<td>1.9%</td>
</tr>
<tr>
<td><strong>Declined</strong></td>
<td>177</td>
<td>64%</td>
<td>1.7%</td>
<td>38%</td>
<td>40±16</td>
<td>37 (14-85)</td>
<td>0.6%</td>
</tr>
<tr>
<td><strong>Registrants prior to pilot</strong></td>
<td>1911</td>
<td>83%</td>
<td>4.6%</td>
<td>28%</td>
<td>42±18</td>
<td>40 (&lt;1-90)</td>
<td>5.2%</td>
</tr>
</tbody>
</table>
Cost

- Total cost of the three month pilot was $3,348
- $5.93 per registrant
- Cost includes:
  - Administrative set up
  - Protocol specific training (30 minutes per EDRA)
  - Volunteer registration into researchmatch.org and local registry
  - Supervisor oversight
Informal Interviews

- Likelihood of registering
  - younger individuals were more likely to register and had an easier time using the iPADs.
  - older adults liked to talk about their medical issues, create a rapport with the EDRAs and were likely to register when given help with the iPADs.
  - they were able to enroll people in less pain and with lower acuity more easily
  - parents were less likely to enroll themselves or their children because they were too concerned about the health of their child
  - they observed that patients waiting for a bed in the hospital and patients in the observation unit were more likely to register
Informal Interviews

• Process observations
  • helpful to tell them they could do it while they waited and that anyone with any condition or even healthy people could participate
  • keep the “pitch” of the registries short and told them it would only take 10 minutes people were more likely to agree
  • acknowledging everyone in the room upon entering
  • being more confident and sure of yourself when approaching patients helped
Informal Interviews

• Local and ResearchMatch.org
  • hard to get people to complete the ResearchMatch.org registration after doing the local registration.
  • there was confusion on the part of the registrants about what the difference was between the local and national registries
  • things they did like about ResearchMatch.org included survey based research and being able to specify different categories of disease (i.e. ALS or Huntington’s)
  • for the local registry, changing the way the date is entered would be helpful.
  • for ResearchMatch.org is was time consuming to click through the different pages to complete the enrollment
  • showing the map on ResearchMatch.org with all the different states
Conclusions

• More registrants then when passive methods were used
• Higher proportion of male and minority registrants
• Not effective for children
• Competition with other studies did decrease registration
• Lower burden forms work better
• Cost was higher than passive approach
• Acute illness was a barrier to registration
Acknowledgments

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