A Real-time Registry to Track Breast Cancer Patients Across Boston

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Goal: address racial and socioeconomic disparities in receipt of timely breast cancer treatment

Intervention: Standardized patient navigation protocol across 6 academic medical centers
Problem: How to Create a Real-time Registry?

- Track patients in real-time
- Identify patients most vulnerable for delays
- Allow navigators to see which patients need attention
- Facilitate Inter-System Communication
- Monitor Navigators’ Activities
Patient Navigation Workflow Across 6 Sites

1. Screening
   - Radiology: No Navigator
   - Diagnosis: Nurse Practitioner & Social Worker
   - Treatment: No Navigator

2. Screening
   - Radiology: No Navigator
   - Diagnosis: Nurse Navigator (3) Nurse Navigators
   - Treatment: No Navigator

3. Screening
   - Radiology: Nurse Navigator
   - Diagnosis: Lay Navigator
   - Treatment: No Navigator

4. Screening
   - Radiology: No Navigator
   - Diagnosis: Lay Navigator
   - Treatment: Lay Navigator

5. Screening
   - Radiology: No Navigator
   - Diagnosis: Lay Navigator
   - Treatment: Lay Navigator

6. Screening
   - Radiology: No Navigator
Solution: **REDCap**

**Benefits**
- HIPAA compliant
- Free for researchers - embedded within CTSA hubs
- Facilitates dissemination

**Challenges**
- Designed for data capture, not clinical use
- Minimize entering same content in multiple software platforms
- User resistance
Challenges for the Registry

• Streamline data entry for Patient Navigators

• Visual tracking at-a-glance

• Facilitate communication between sites
Clinical Challenge #1 - Streamlining data entry

• Six sites, each with own existing methods of tracking
  • Electronic medical record, MSExcel, Outlook, sticky notes

• Patient Navigators’ biggest challenge is a lack of time
  • Reduce the burden of entering the same information into multiple software platforms
Technical Solutions – Streamlining data entry

• Multiple projects combined using dynamic SQL joins
• Site-specific dropdowns and piped fields
• Use of embedded links and referring URL to reduce keying on external partners’ websites
Using Dynamic SQL Joins

Site-specific Patient Navigator information is piped into dropdown menus and reports
Using Referring URLs

Within the participant-specific data entry page in REDCap, there’s a descriptive field with a clickable URL that incorporates TRIP Registry ID into the constructed URL:


This TRIP Registry ID is automatically inserted into the external partner’s website when it is opened.
Clinical Challenge #2 – Visual Tracking At-a-Glance
Technical Solutions –
Visual Tracking At-a-Glance

• Technical solutions
  • More customized dashboards and reports
  • Encouraged use of search function within REDCap
## Visual Tracking At-a-Glance: Patient Tracking Report

<table>
<thead>
<tr>
<th>Patient Registry ID</th>
<th>Event Name</th>
<th>Repeat Instrument</th>
<th>Repeat Instance</th>
<th>Days since diagnosis</th>
<th>Intake completed</th>
<th>Intake required</th>
<th>Initial SDOH screen complete</th>
<th>Number of days since last SDOH</th>
<th>Active</th>
<th>PN Transfer</th>
<th>Current PN</th>
<th>Current Site</th>
<th>TRIP Eligibility</th>
<th>System last updated: date today</th>
</tr>
</thead>
<tbody>
<tr>
<td>1001 Patient, Marquelette (03-28-1990)</td>
<td>Intake</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1002 Patient, Suzanne (11-29-1957)</td>
<td>Intake</td>
<td></td>
<td></td>
<td>716</td>
<td>Yes (1)</td>
<td>Missing (2)</td>
<td></td>
<td></td>
<td>No (0)</td>
<td>Navigator B 617-100-1000</td>
<td>BIDMC (2)</td>
<td>Ineligible (0)</td>
<td>08-21-2020</td>
<td></td>
</tr>
<tr>
<td>1003 Patient, Deborah (03-02-1956)</td>
<td>Intake</td>
<td></td>
<td></td>
<td>689</td>
<td>Yes (1)</td>
<td>Yes (1)</td>
<td></td>
<td></td>
<td>Active (1)</td>
<td>Navigator A 617-111-1111</td>
<td>BIDMC (2)</td>
<td>Eligible (1)</td>
<td>08-21-2020</td>
<td></td>
</tr>
<tr>
<td>1004 Patient, test (12-26-1967)</td>
<td>Intake</td>
<td></td>
<td></td>
<td>696</td>
<td>Yes (1)</td>
<td>Yes (1)</td>
<td></td>
<td></td>
<td>Active (1)</td>
<td>Navigator C 508-100-1111</td>
<td>MGH (3)</td>
<td>Eligible (1)</td>
<td>08-21-2020</td>
<td></td>
</tr>
</tbody>
</table>
Clinical Challenge #3 – Facilitate Communication Across Sites

- No easy way to document communications between hospitals
- Each site had their own electronic medical record (EMR) and notes
Technical Solutions – Facilitate Communication Across Sites

• Technical solutions

  • Data entry forms providing more detail around transitions between navigators and between sites

  • REDCap Messenger
User Feedback – What works

The messenger service is definitely, in terms of what is useful for me, the number one thing that's helpful is being able to have every navigator involved on the same kind of messaging database. So, instead of exchanging emails or even phone numbers, it's all just right there and I know that if I'm sending a message that they're getting an email notification that that is happening.
User Feedback – What works

Generally, if there was a patient who was lost to follow up, and if I had known let's say they were going to [TRIP Site], I may be able to call over to their oncology department and introduce myself and try to see if that patient was being taken care of. **But the REDCap service allowed me a shortcut** in a way that I am able to directly reach out to somebody who I know is back there and just immediately give them ...the name and date of birth, and then see if that patient is being followed.
User Feedback – Ongoing Challenges

And I still find that it [REDCap] is a little bit cumbersome to work with and maybe because I'm not working with it every day that it feels that way to me. But every time I go into to find things, I'm always, "All right, now where is that again?" And even though I take out my [training manual], and I do try to look and, but, and maybe it's just me and others don't really have that trouble with it.

We document in our medical record and then REDCap just becomes another site to document. So again, it just feels like an additional task to take on top of other things I'm already doing, which can be a time consuming.
Acknowledgements

TRIP Registry Team
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For more information

http://sites.bu.edu/coeinwomenshealth/research/trip-redcap-registry/