TRIP Translating Research Into Practice

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

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REDCap
Research Electronic Data Capture

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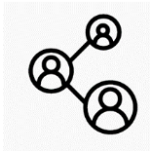
Translating Research Into Practice (TRIP)

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

Intervention: Standardized patient navigation protocol across 6 academic medical centers

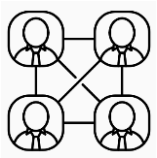
Problem: How to Create a Real-time Registry?



Track patients in real-time

Identify patients most vulnerable for delays

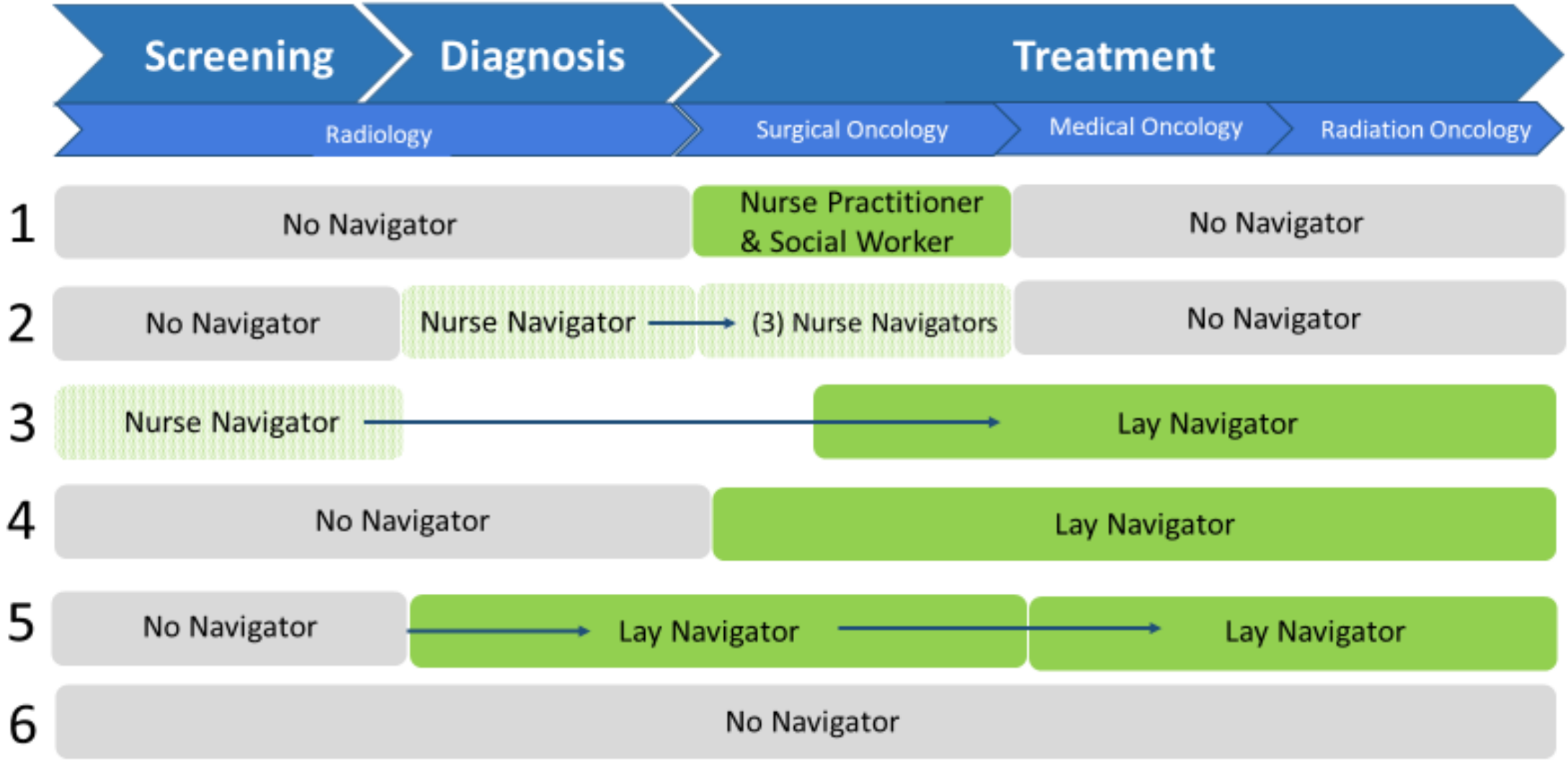
Allow navigators to see which patients need attention



Facilitate Inter-System Communication

Monitor Navigators' Activities

Patient Navigation Workflow Across 6 Sites



Solution: REDCap

Research Electronic Data Capture

Benefits

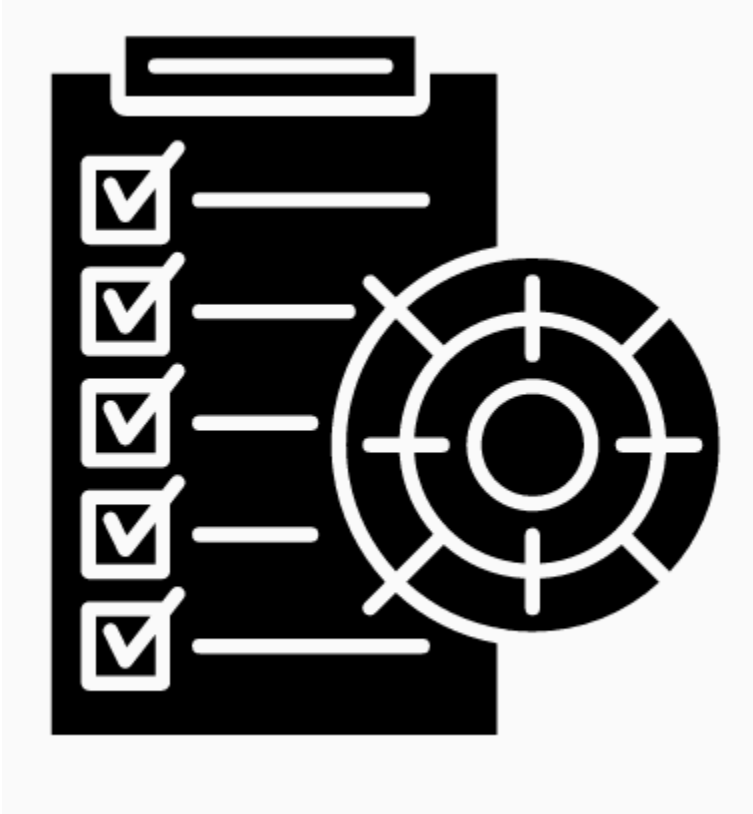
- HIPAA compliant
- Free for researchers - embedded within CTSA hubs
- Facilitates dissemination

Challenges

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

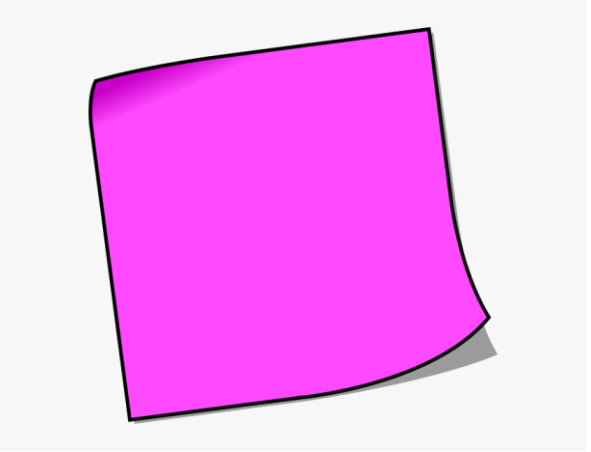
Challenges for the Registry

- 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

Patient Navigators: Massachusetts General Hospital

PN ID	301 To rename the record, see the record action drop-down at top of the Record Home Page.
PN First Name	Amiable
PN Last Name	Aardvark
Hospital Affiliation	MGH reset Massachusetts General Hospital
PN Phone	(617)111-1111
Languages spoken (in addition to English)	Spanish

Patient Navigator Aardvark, Amiable (MGH) (617)111-1111
* must provide value *required

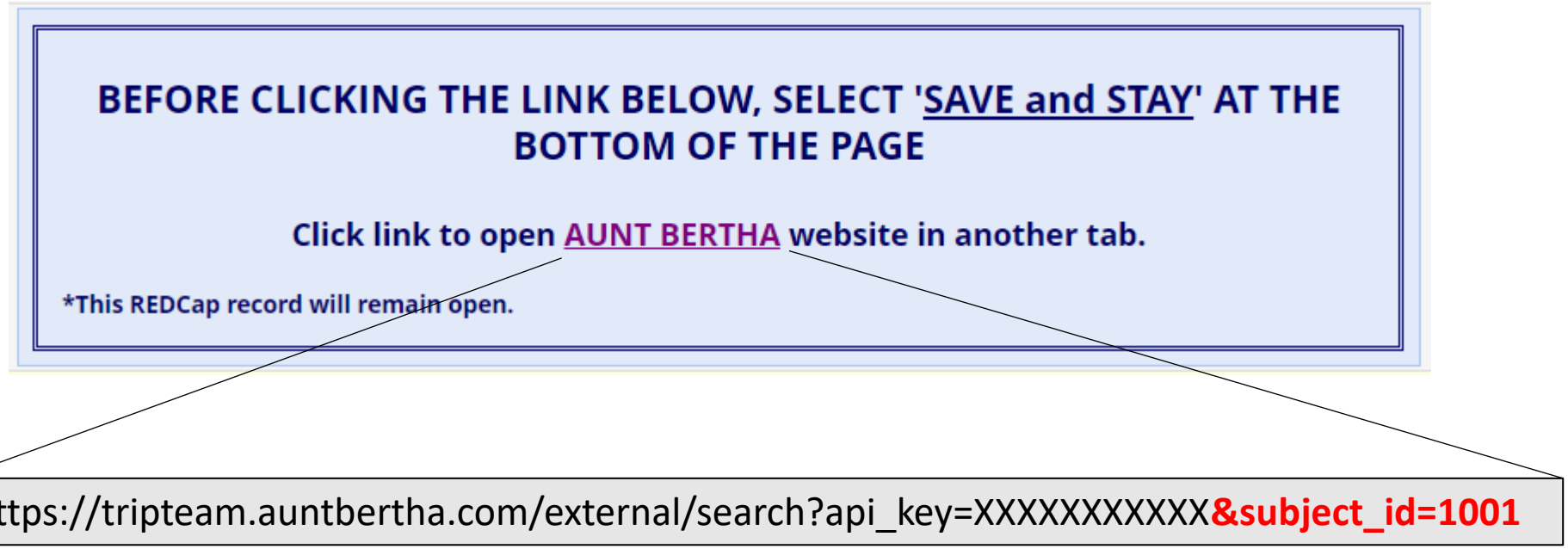
Patient Navigator
pn_by_site_t

Aardvark, Amiable MGH (617)111-1111 Spanish (301)

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

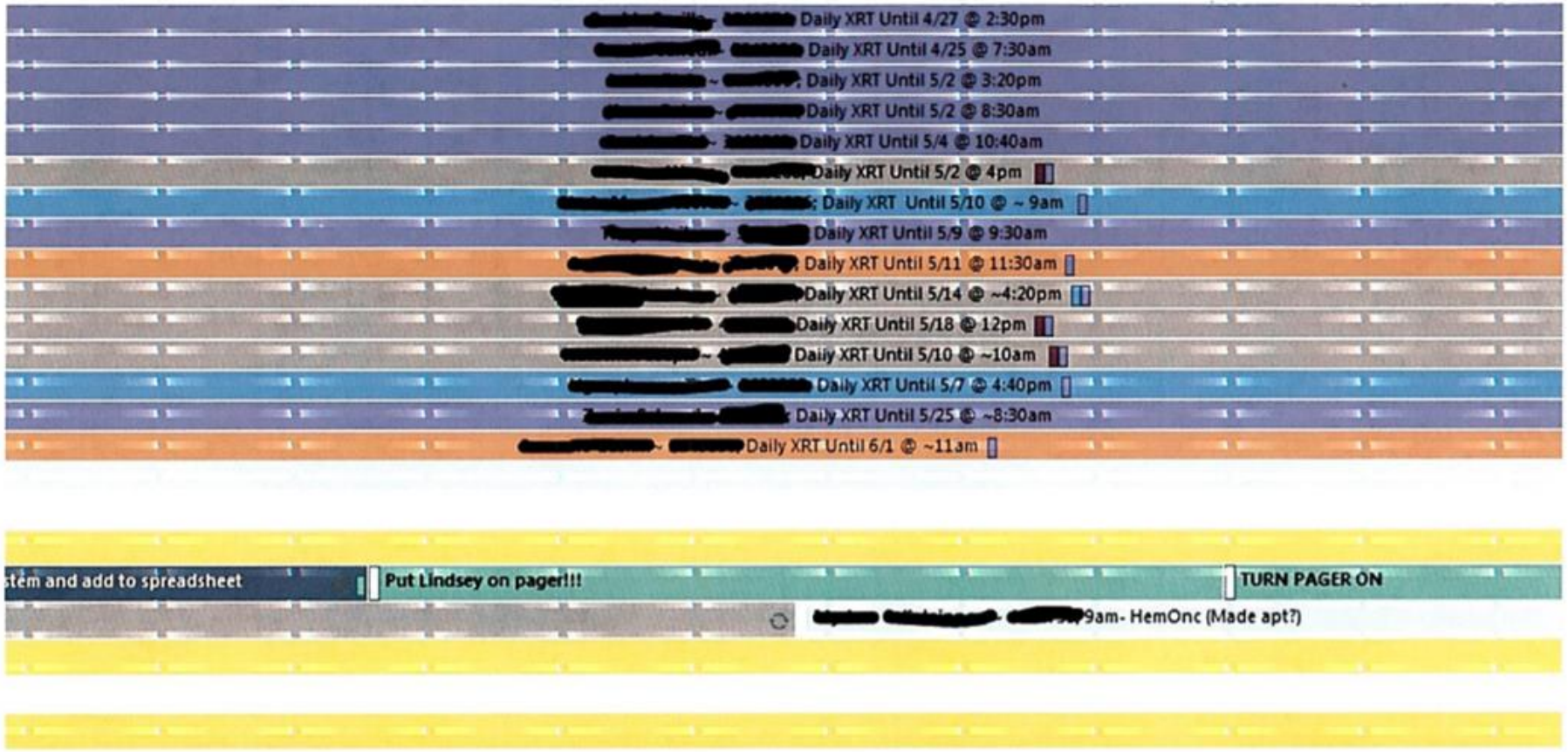
Using Referring URLs

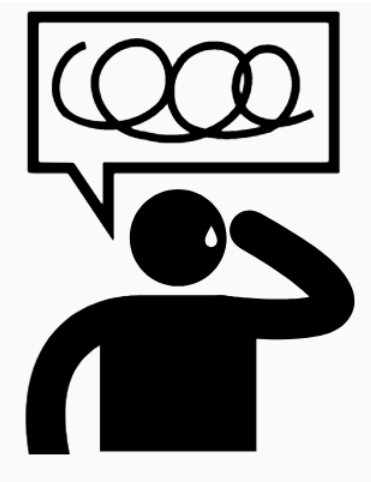
Within the participant-specific data entry page in REDCap, there's a descriptive field with a clickable URL that incorporates TRIP Registry ID into the constructed URL:



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

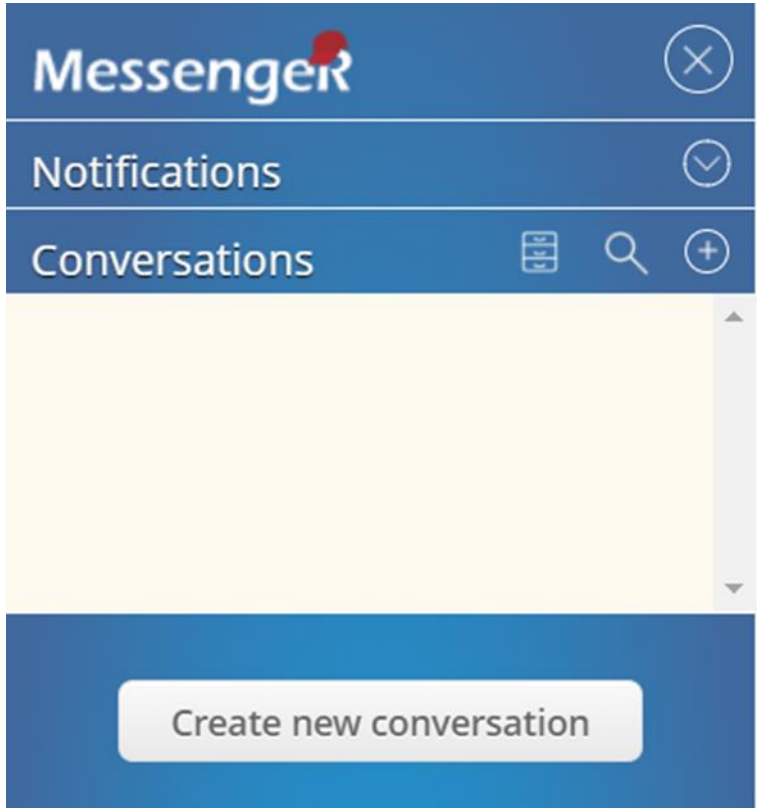
Patient Registry ID pid	**Event Name** redcap_event_name	**Repeat Instrument** redcap_repeat_instrument	**Repeat Instance** redcap_repeat_instance	**Days since diagnosis** days_since_dx	**Intake Completed** intake_required	**Initial SDOH screen complete** sdoh_initial	**Number of days since last SDOH** days_last_sdoh	**Active** active	**PN Transfer** transfer_pn	**Current PN** pn_current	**Current Site** site_current	**TRIP Eligibility** eligibility	**System last updated:** date_today
1001 Patient, Marguerite (03-28-1990)	Intake												
1002 Patient, Suzanne (11-29-1957)	Intake			716	Yes (1)	Missing (2)			No (0)	Navigator B 617-100-1000 BIDMC (201)	BIDMC (2)	Ineligible (0)	08-21-2020
1003 Patient, Deborah (03-02-1966)	Intake			689	Yes (1)	Yes (1)		Active (1)	No (0)	Navigator A 617-111-1111 BIDMC (202)	BIDMC (2)	Eligible (1)	08-21-2020
1004 Patient, test (12-26-1967)	Intake			696	Yes (1)	Yes (1)		Active (1)	Yes (1)	Navigator C 508-100-1111 MGH (301)	MGH (3)	Eligible (1)	08-21-2020

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/

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