

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

REDCapCon, September 22, 2020

Amy LeClair, PhD, Tufts Medical Center, Boston, MA

Clara Chen, MHS, Boston University, Boston, MA







Funding & Disclosures

NAtional Center for Advancing Translational Sciences

1U01TR002070-01

Views expressed are our own, do not represent NIH/NCATS.

No financial interests to declare.



Principal Investigators

Tracy Battaglia, MD MPH Boston Medical Center



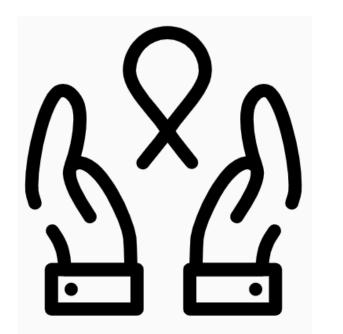
Jennifer Haas, MD Mass General Hospital

Karen M. Freund, MD MPH Tufts Medical Center

Stephenie Lemon, PhD UMass Medical Center

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



Track patients in real-time

Problem: How to Create a Real-



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

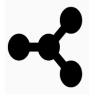
	Screening Diagnosis	Treatment							
	Radiology	Surgical Oncology Medical Oncology Radiation Oncology							
1	No Navigator	Nurse PractitionerNo Navigator& Social WorkerNo Navigator							
2	No Navigator Nurse Navigator —								
3	Nurse Navigator	Lay Navigator							
4	No Navigator	Lay Navigator							
5	No Navigator Lay N	Navigator Lay Navigator							
6		No Navigator							



Benefits



HIPAA HIPAA compliant



Free for researchers embedded within **CTSA** hubs



Facilitates dissemination

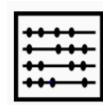
Challenges



Designed for data capture, not clinical use



Minimize entering same content in multiple software platforms

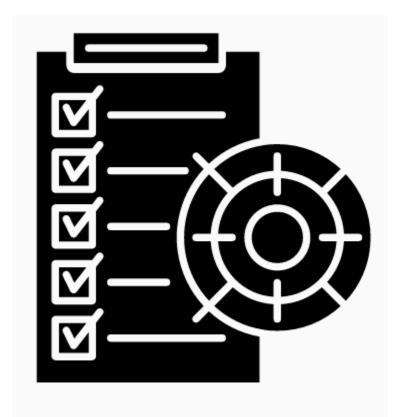


User resistance



Challenges for the Registry

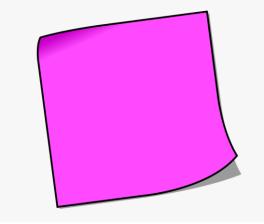
- Streamline data entry for Patient Navigators
- Visual tracking at-a-glance
- Facilitate communication between sites



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 PN First Name PN Last Name Hospital Affiliation	301 To rename the record, see the record action drop-down at top of the <u>Record Home Page</u> .			
PN First Name	B Amiable	-	Patient Navigator * must provide value	ardvark, Amiable (MGH) (617)111-1111 🔹
PN Last Name	Aardvark			
Hospital Affiliation	 MGH Massachusetts General Hospital 			Patient
PN Phone	⊖ (617)111-1111			Navigator pn_by_site_t
Languages spoken (in addition to English)	⊖ Spanish			Aardvark, Amiable MGH
Sita spacific Patient Navig	ator information is			(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:

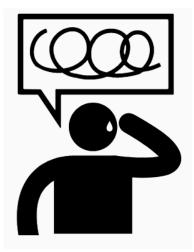


This TRIP Registry ID is automatically inserted into the external partner's website when it is opened.

Clinical Challenge #2 – Visual Tracking At-a-Glance

and the second second	AND DECK OWNERS AND	And in case of the local division of the	No. of Concession, Name				Contraction of the local division of the loc	and the second se	And in case of the local division of the loc	A STATISTICS
	and the second second					Daily XRT Until 4/27 @ 2:30pm	-	-	and the second second	and the second
Service La				-		Daily XRT Until 4/25 @ 7:30am				and the second
	CAN SHARE		Te In the second	-	-	Daily XRT Until 5/2 @ 3:20pm		and the second s	and a second second	TANEN DITT
Contraction of the local division of the loc		A STREET, STRE	States of the local division of the	-		Daily XRT Until 5/2 @ 8:30am		and the second s	The strates of	and the second second
	-11	and the second	A DECK OF THE OWNER	-	-	Daily XRT Until 5/4 @ 10:40am			4.1	
The second second	AL MORE MANAGER	State of the second	Contraction of the second			Daily XRT Until 5/2 @ 4pm	10 Mar 94		and the second se	and the second second
	-		Contraction of the			Daily XRT Until 5/10 @ ~ 9am	0			States and Belleville
				1	-	Daily XRT Until 5/9 @ 9:30am				
N	and the second s	No. of Concession, Name	Street Bernard	-		Daily XRT Until 5/11 @ 11:30am	1		A.	1 million 1
A CONTRACTOR	State State State	Stores Press	Concernant of the		and the second second	Daily XRT Until 5/14 @ ~4:20pm	•	Same mark		Contraction of the
The second second	Street Providence	Contraction of the local division of	and the second s			Daily XRT Until 5/18 @ 12pm		Contraction of the local division of the loc	Contraction of the second second	
and the second second	State State State	Surger Real for the Local	the second second			Daiiy XRT Until 5/10 @ ~10am		No. of Concession	Sector Street of	1000
a anti-	ALCON DESCRIPTION	Street, Barriston	LINE BRANCH			Daily XRT Until 5/7 @ 4:40pm	IN BRANCH			LINER BROOM
S SECON	and a second		Contraction Name	a s dente	data and a different state	Daily XRT Until 5/25 @ ~8:30am	-	and Reality		
				-	Da	ily XRT Until 6/1 @ ~11am 📋				







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
<u>1001</u> Patient, Marguerite (03-28-1990)	Intake												
<u>1002</u> 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
<u>1003</u> 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
<u>1004</u> 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



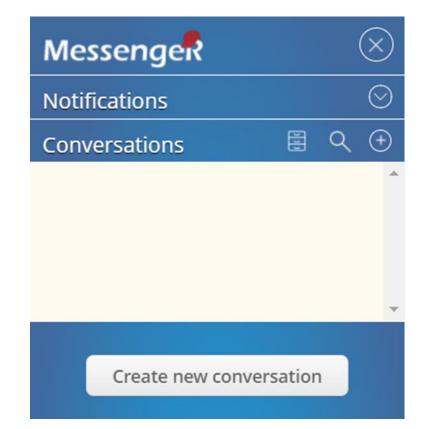
Technical Solutions – Facilitate Communication Across Sites

- 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

Tracy Battaglia, Boston Medical Center Christopher Shanahan, Boston Medical Center Sharon Bak, Boston Medical Center Bill Adams, Boston Medical Center Victoria Xiao, Boston Medical Center Katelyn Mullikin, Boston Medical Center Carolyn Finney, Boston University Chris Lloyd-Travaglini, Boston University Marisa Massaro, Boston University Karen Freund, Tufts Medical Center Stephenie Lemon, UMass Medical Center Jennifer Haas, Mass General Hospital Caylin Marotta, Mass General Hospital

<u>REDCap Team</u> Mark McEver, Vanderbilt University

oston Breast Cancer Equity Coalitie



CTSI Tufts Clinical and Translational Science Institute



THE HARVARD CLINICAL AND TRANSLATIONAL SCIENCE CENTER



Clinical & Translational Science Institute



CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE



For more information

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

