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

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MEDICINE of the HIGHEST ORDER

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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
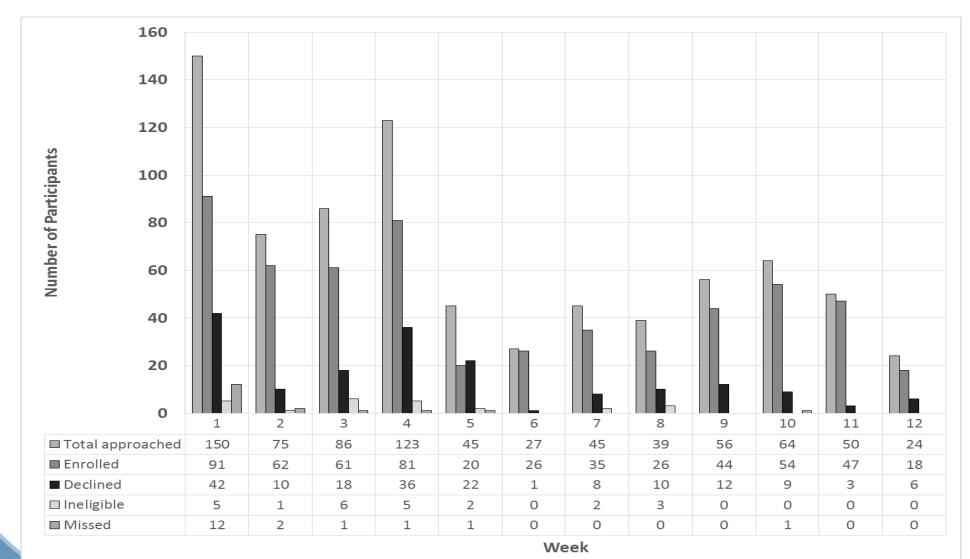   - Inability to give informed consent

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

			REDCap Survey ID Number	____

Date :	09 / 16 / 18	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

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

Name (Last, First)	MRN	Rm	Sex/Age	Race	Ethnicity	Notes (Chief Complaint, Reason Ineligible/Refused/Missed, Provider)	ST
		4R	F/26	black/AA	not hispanic	abd. cramping	①
		24R	F/36	White	not hispanic	seizures	①
		42L	F/38	white	not hispanic	abd. cramping, local registry down	①
		9L	M/23	black/AA	not hispanic	aggresive behavior, pt. only wanted to do local one	①

Enrollments Per Week

Week	1	2	3	4	5	6	7	8	9	10	11	12
Total approached	150	75	86	123	45	27	45	39	56	64	50	24
Enrolled	91	62	61	81	20	26	35	26	44	54	47	18
Declined	42	10	18	36	22	1	8	10	12	9	3	6
Ineligible	5	1	6	5	2	0	2	3	0	0	0	0
Missed	12	2	1	1	1	0	0	0	0	1	0	0

Demographic Characteristics of Enrolled and Declined Participants compared to registrants prior to the pilot

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

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

Beau Abar, PhD

Ann Dozier, PhD

Joseph Glick

EDRAs

Patients and family members