RPN Workshop: November 21, 2019

Putting Participants First: Creating a recruitment plan FOR your participants, not just for your research

Ashley Smith, Boston Medical Center | Deaven Hough, University of Florida

Here's what we got going on today...

- Why is it so hard to recruit participants?

- The solution: Consider the participant

- Case studies

Most recruitment presentations...

We're here to help you think differently.

# Think of us as the "Fab Duo" of recruitment

Ashley Smith

Deaven Hough

We're going to get started with an activity.

- Divide into groups of 2-4 members

- Take the next 10 minutes to consider the questions from Activity #1 on your worksheet

- Select one person to be your "spokesperson" to share what you discussed as a group

- We will select 1-2 teams per site to share

Why is it so hard to recruit?

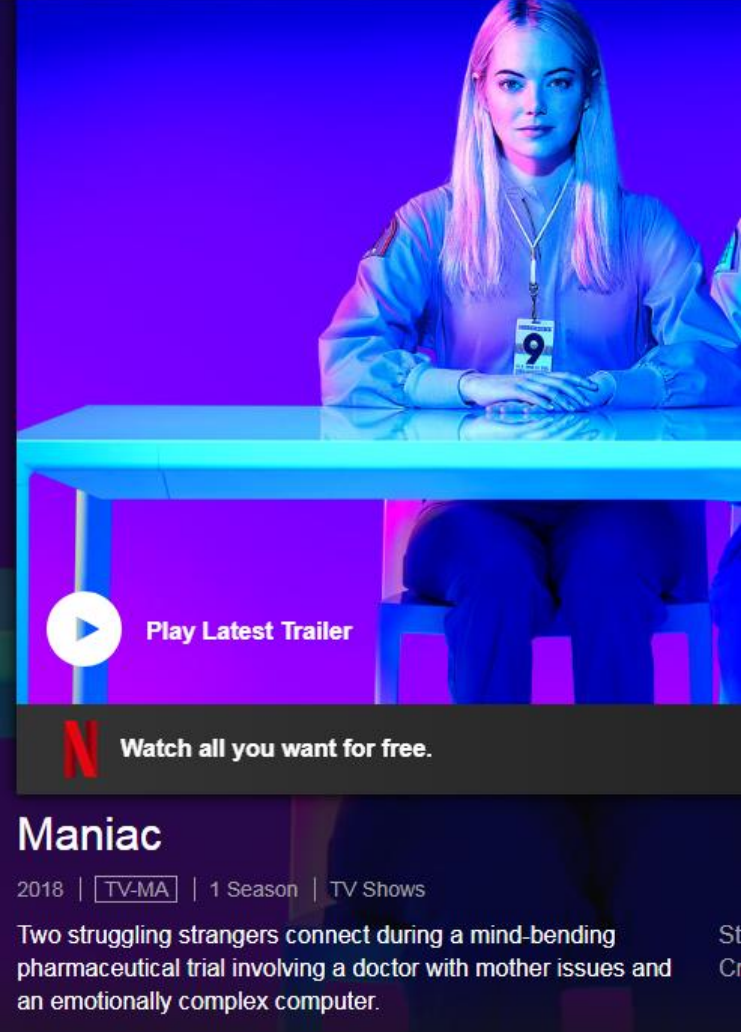THIS IS FINE.
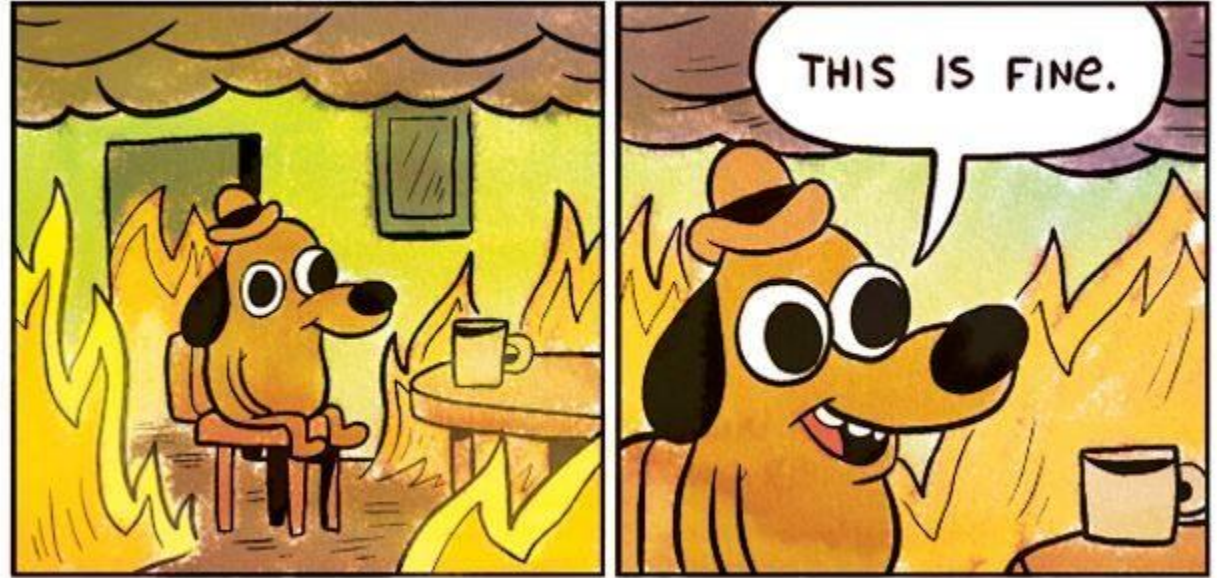
The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Could Amazon Revolutionize The Patient Experience In Clinical Trials?

Play Latest Trailer

N Watch all you want for free.

Maniac

2018 | TV-MA | 1 Season | TV Shows

Two struggling strangers connect during a mind-bending pharmaceutical trial involving a doctor with mother issues and an emotionally complex computer.

We need more emphasis on the participant themselves, think about their experience and how they can sustain being involved in the study.

Understand their condition

- What kind of treatment does someone with this condition typically receive?

- What is their doctor appointment schedule like?

- Get an idea of what living with this health condition is like so you can better design your study and recruitment methods.

Understand their emotions

- Are they newly diagnosed with a condition?

- Do they consider this research study their last chance?

- Understanding their emotions associated with their conditions is an essential step as well.

Understand their barriers

- Transportation

- Language

- Mistrust of medical research

- Research studies hold "bankers hours"

Understand their barriers

- Transportation

- Language

- Mistrust of medical research

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Understand their value

- It is a challenge for them to say "yes" to participating in a clinical trial

Understand that they want to know

- Share results! Thank them!

- Show that they made a difference

- Knowing they get their data back or the results of the study increases retention

- Make this full circle, by sharing results you are building trust

No time for user testing? Try these online tools.

Online tools

Claritas

- Learn about demographics and lifestyles of audience segments in your zip code

2019 Statistics

US Households: 1,737,973
Median Household Income: $42,698

Demographics Traits

- Urbanicity : Rural
- Income : Low Income
- Income Producing Assets : Low
- Household Technology : Below Average
- Age Ranges : Age <55
- Presence of Kids : Family Mix
- Homeownership : Mix
- Employment Levels : Mix
- Education Levels : High School

Lifestyle & Media Traits

- Owns a Dodge
- Eats at Hardee's
- Shops at Wal-Mart
- Follows pro wrestling
- Stays at Days Inn
- Watches MTV
- Listens to Country

55 - Red, White & Blue

Low Income Middle Age Family Mix
The residents of Red, White & Blue typically live in rural areas. Middle-aged, with high school educations and lower incomes, many of these folks are transitioning from blue-collar jobs to the service industry. In their spare time, they are active members of their local community organizations.

Research	Behaviors	Demographics	Multicultural
• Financial	• Lifestage	>120,000,000 HH	• Ethnic & Cultural Data
• Tech	• Location	>10,000 lifestyle	• Hispanic & Asian
• Retail	• Financial	behaviors	Acculturation
• Energy	• Media consumption	>8,000 demo	• Language spoken
• Insurance	• Insurance	variables	at home
• Small Business	• Lifestyle		• LGBT& Religion

Audiences	Proprietary Segmentation		Identity Characteristics

• 2,300+ across Retail, Lifestyle, Auto, Technology, Travel	• PRIZM® Premier
	  – Lifestyle
	  – Behavioral
		• P$YCLE® Premier
		  – Financial
		  – Insurance
			• Emails
			• IP Addresses
			• Device IDs

• Consumer economic indicators	– Media
	  – Buying
		• ConneXions®
		  – Technology
			• Device Statistics

• Custom audiences	• Custom Segmentation	– Telecom	

Online tools

Facebook Audience Insights

- Learn about interests like page likes and devices they are using

Create "profiles"

32-40 years old

Married to partner (could be second marriage)

Third pregnancy, previous were normal

Uses blogs and online forums

Knowledgeable and shares tips often

Aware of preeclampsia and risks

Keeps record of pregnancy through apps

Experienced Mom

26-30 years old

Living with or married to partner

Unexpectedly pregnant, but excited

Told she has a **high-risk pregnancy**

Uses Instagram to search and share info

Downloaded apps to track pregnancy

Nervous that she has a lot to learn

First-Time Mom

Tailor your communication

Upload your materials or informed consent to a readability website like WebFX or Readability Formulas

Flesch Reading Ease score: 34.4 (text scale)
Flesch Reading Ease scored your text: difficult to read.
[f] | [a] | [r]

Gunning Fog: 19.1 (text scale)
Gunning Fog scored your text: difficult to read.
[f] | [a] | [r]

Flesch-Kincaid Grade Level: 16
Grade level: College Graduate and above.
[f] | [a] | [r]

The Coleman-Liau Index: 12
Grade level: Twelfth Grade
[f] | [a] | [r]

The SMOG Index: 13.5
Grade level: college
[f] | [a] | [r]

Automated Readability Index: 17.9
Grade level: College graduate
[f] | [a] | [r]

Linsear Write Formula : 20.8
Grade level: College Graduate and above.
[f] | [a] | [r]

Use methods that will work

- Did you know that older adults are an increasing demographic on Facebook?

- Or that study names are ineffective?

- Flyers with tear-offs perform better than flyers that do not have them

- Want a bus ad? TV ad? Radio?

  - $$$$ but what is the return?

RTS Service Area Demographics:
Median Age and Average Household Income by Census Block Group

Note: Each dot represents 50 people

Prepared by RTS: January 2011
Source: 2000 Census

Bus Routes
1 Dot = 50
AGE_5_17
AGE_18_21
AGE_22_29
AGE_30_39
AGE_40_49
AGE_65_UP
Average Household Income
AVG_HH_INC
Less than $10K
$10K to $20K
$20K to $40K
$40K to $60K
$60K to $75K
$75K +

NORTH
1 in = 1.5 miles

23
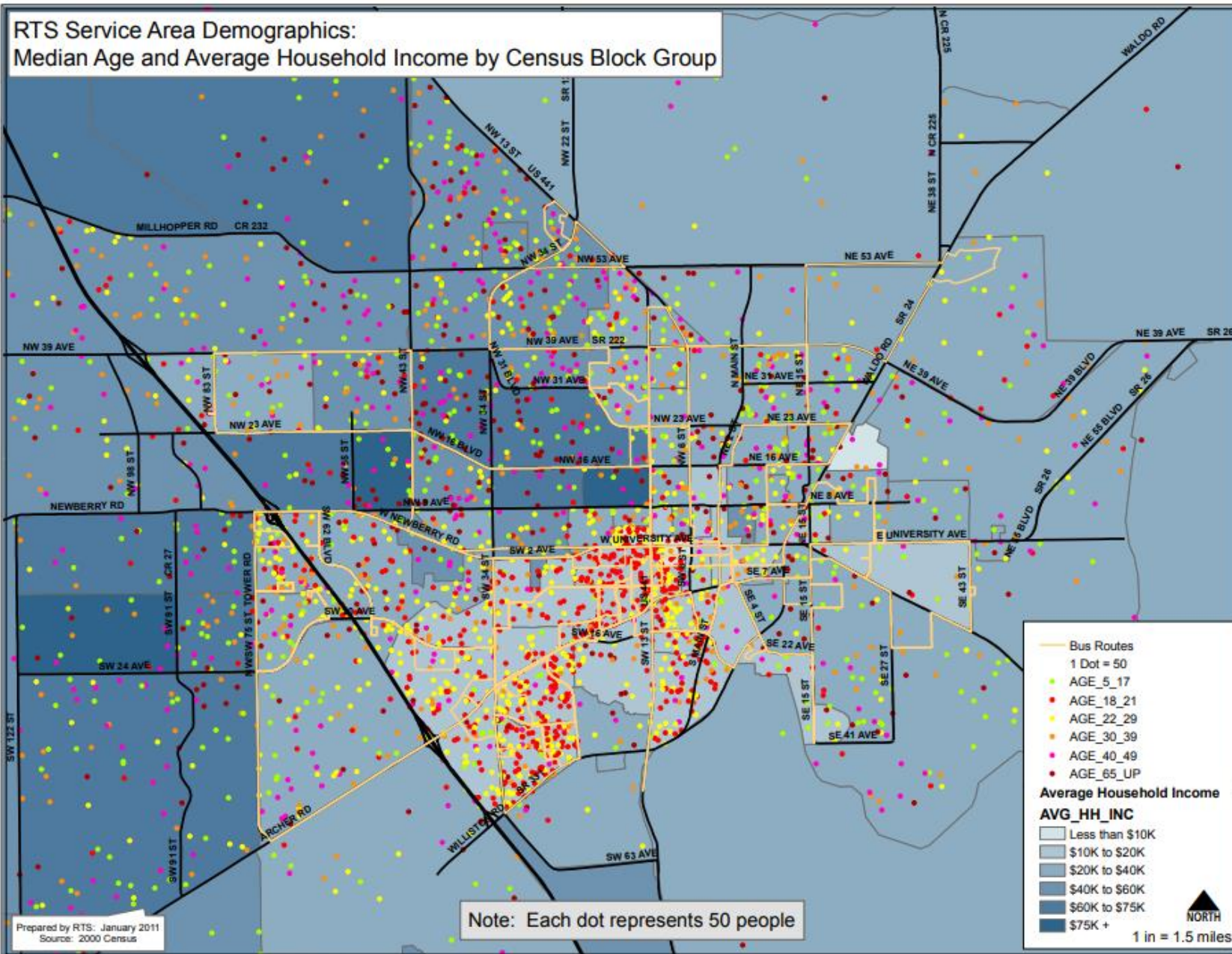
Audience Definition
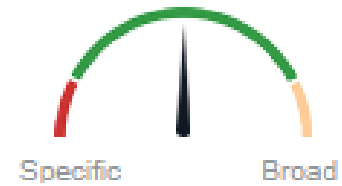
Your audience is defined.

Specific — Broad

Potential Reach: 3,500,000 people ⓘ

Estimated Daily Results

Reach ⓘ

269 - 777
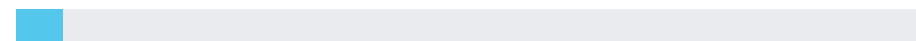
Link Clicks ⓘ

7 - 30
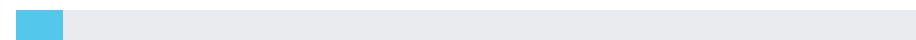
Activity #2

Get back into your groups!

- Take the next 10 minutes to consider the questions from Activity #2 on your worksheet

- Select one person to be your "spokesperson" to share what you discussed as a group

- We will select 1-2 teams per site to share

Let's look at some case studies to put it all together...

Case study #1: Recruiting marginalized populations

Examples

Populations struggling with low SES, disability, chronic physical/mental health problems, homelessness, Racial/ethnic minority, immigrant/refugee communities

The past matters

Emphasize the benefits to the community, the researchers' intention to 'heal' past injustices

Additional barriers

Unpredictable work schedules, many appointments, transportation, higher priority issues (food, shelter, job, family, medical)

Case study #1: Recruiting marginalized populations

Case study
Task-sharing in Recovery Learning Communities: Implementation of STAIR-PC for PTSD

Consider barriers
Transportation, housing instability, disabilities, literacy

Eligibility
Most pre-screened to the study, but only a fraction were eligible based on study visit 1 ($$$)

Effort
Recruitment/attrition took a lot of effort – for every 3 people we connected with, only 1 stayed in study (consenting v. committing)

Pre-screened: $n = 63$

Did not complete baseline assessment (n = 25):
Screen fail (n = 11)
Lost contact ($n = 11$)
Did not schedule study visit (n = 2)
Decided not to participate (n = 1)

Baseline: $n = 38$

Excluded (n = 12):
Did not meet PCL-5 criteria (n = 7)
Not appropriate for outpatient care (n = 4)
Did not meet LEC-5 criteria (n = 1)

Eligible: $n = 26$

Did not complete Session 1 of STAIR-PC (n = 7):
Lost contact after no-show / cancellation (n = 5)
Moved away (n = 1)
Withdrew from the study (n = 1)

ITT sample: $n = 19$

Removed from analysis due to concerns with validity of data [capacity concern] (n = 1)

Analytic sample: $n = 18$

Case study #1: Recruiting marginalized populations

Built-in recruitment facilitators:

- Understanding peer model
- Community-based Participatory Research methods
- Participants already in the study enjoyed it and talked it up to others

Strategies to improve engagement:

- Pre-screening specificity – don't forget your IRB: Brief Screening Agreement
- Expanding inclusion criteria to general patient population
- Attending community events and talking to peers about the study
- Sending flyers to providers in Psychiatry
- Utilizing PROVEn Registry

Case study #2: Recruiting "hidden" populations

| **Definition** | No sampling frame exists / Random sampling response rates would be low & public acknowledgement of membership is potentially threatening. Examples? |

| **Strategies** | Snowball sampling, other chain referral methods |

| **Be mindful** | Individuals who show or disclose their "hidden" identities face real consequences – must be careful in terms of privacy/confidentiality – appreciate the risk your participants are taking |

Heckathorn DD. Respondent-driven sampling: A new approach to the study of hidden populations. Social Problems. 1997; 44(2): 174-199. http://www.respondentdrivensampling.org/reports/RDS1.pdf

Case study #2: Recruiting "hidden" populations

Case study

Influence of discrimination on adaptation following trauma among diverse transgender and gender nonconforming (TGNC) persons

Contribution

Despite historical pathologization/mistreatment, TGNC folks are often open and excited to participant in studies

How to find

CTMS at BMC (biased sample), First Event (not local, many folks interested but few followed up)

Availability

Visits are 3 hours and must occur during work hours – most can't take the time off

COLOR

Outlining eligibility requirements and study procedures

Clear contact information

Positive language

PAYMENT = Huge appeal

TGNC Trauma & Resilience Study

Do you identify as…

transgender, gender nonconforming, non-binary, genderqueer, or gender fluid?

The **TGNC Trauma & Resilience Study** is looking for people like you to help us understand **resilience** among transgender or gender nonconforming people who have experienced **trauma** or **discrimination**.

Eligibility:

- Must be between 18 and 65 years old
- Must speak English
- Identify as any gender identity other than cisgender

What will I be asked to do?

- Schedule a time to meet for a 3 hour study visit
- Study Visits will take place at Boston Medical Center
- Complete surveys and interviews asking about your past experiences, current coping, and current mental health symptoms
- Provide up to 3 saliva samples during the study visit

Payment:

- You will be paid $60 for your time

Interested in participating?

Contact Ashley Smith, the primary research assistant for this study, at **(617) 414-1904** or Ashley.Smith4@bmc.org OR email Sarah Valentine, PhD, the Principal Investigator for this study, at Sarah.Valentine@bmc.org

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Case study #2: Recruiting "hidden" populations

Strategies to improve engagement:

- Using contacts within the Taskforce, actually meeting face-to-face to tell them about our study

- Compiling a list of clinics that see a significant number of TGNC-identifying patients – AND reposting flyers regularly

- Follow up emails to providers – reminding them we're here!

- Reaching out to other local LGBTQ+-affiliated organizations

- Spend effort online to research contacts

- Emphasizing that we're researching trauma and discrimination in TGNC folks to inform treatment development to address these things specific to the TGNC community

Case study #3: Multi-site, Clinical Drug Trials

Case study	Medication augmentation to improve cognition in patients with schizophrenia
Consider condition	Participants experiencing psychotics symptoms have many barriers to engagement
Eligibility	Trial is not designed with population in mind, and site-specific population characteristics compound difficulties
Additional barriers	High compensation rate may attract 'professional subjects

Case study #3: Multi-site, Clinical Drug Trials

Strategies to improve engagement:

- Meet patients in clinic

- Engage providers

- Engage patients' families

- Provide reminder calls – day before and day of

- Collaborate with other sites – see what they are doing

- Utilize resources – clinical drug trials provide sites with funds for recruitment, consider buying ad space on public transportation or newspapers

- Limit the impact strict exclusion criteria has on participants / Offer future opportunities to participate in research (PROVEn Registry)

- *Advocate for change when possible!*

Case study #4: Recruiting key informants

Definition	Key informant recruitment is a chain referral sampling method, involves utilizing persons who know your population of interest very well, i.e., providers or stakeholders
Benefits	May be more objective, understand systems-level better, easier to engage/retain, can inform study development prior to recruiting population of interest (CBPR)
Drawbacks	May be biased, perceive differently than population of interest – not a direct capture of community experiences

Heckathorn DD. Respondent-driven sampling: A new approach to the study of hidden populations. Social Problems. 1997; 44(2): 174-199. http://www.respondentdrivensampling.org/reports/RDS1.pdf

Case study #4: Recruiting key informants

Case study
An implementation science approach to optimizing PTSD treatments for non-specialty settings

Need
In order to successfully implement in primary care, we needed systems-level info that patients wouldn't have

Identify
Ops managers, admin staff, physicians, clinicians, specialists, stakeholders/leadership

Challenges
Lack of protected time, burnout, may not understand importance of their perspective or of research compared to clinical demands

Case study #4: Recruiting key informants

Strategies to improve engagement:

- Focus on the importance of their role and insights, emphasize their unique perspective and hard work

- Talk to leadership / management first – buy-in at higher levels trickles down

- Make it as easy as possible for professionals to participate – offer tele-procedures or meet them where they are located

- Be cognizant of time limitations

Let's get together one last time!

- Take the next 10 minutes to consider the questions from Activity #3 on your worksheet

- Select one person to be your "spokesperson" to share what you discussed as a group

- We will select 1-2 teams per site to share

Wrapping it all up...

Activity #1

1. Think of a current study you're working on or a potential study you want to design or are in the process of designing. Pick one to work on as a group. This will be the basis of all 3 activities in this workshop – so choose carefully! Write the name below:

2. Who is your study / sample population? How many participants are you aiming to recruit?

3. List 3 (current/planned/proposed) recruitment methods / strategies and think about why you chose them. We will be workshopping these methods today, so don't worry if they aren't perfect!

1.	
2.	
3.	

Activity #2

1. Think of the same study population from Activity #1. What do you need to consider about their…

a. Condition?	
b. Emotions?	
c. Barriers?	
d. Values?	
g. Other factors?	

(Activity #2 continued on next page)

Activity #2 continued

Now that you've worked in those considerations, think back on your recruitment methods and protocol as a whole. What will you keep and what will you change now that you've thought more about the participant?

What to keep in recruitment methods and protocol	What to change in recruitment methods and protocol

Activity #3

1. Are there similarities between the study you have been workshopping and any of the case studies presented today?

2. Can you think of anything that could go wrong during your recruitment period, or any factors that could impact the effectiveness of your chosen recruitment methods/strategies?

1.	
2.	
3.	

3. Imagine you are 3 months into your study and are having trouble recruiting participants. What steps would you take to increase recruitment or improve your recruitment methods/strategies?