



NUCATS

RECRUITMENT AND CONSULTATION SERVICES

Northwestern University
NUCATS
Clinical and Translational Sciences Institute



Our consult TEAM



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ALVARADO AVILA, MPH



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KATHRYN
MACAPAGAL PhD

- Extensive R&R experience in studies across translational research spectrum with adolescents and adults
- Expertise in online and community - based recruitment and retention in Chicagoland and across USA

Poll: What percentage of survey responses do you think get excluded due to fraud in online studies?

- Less than 5% (no big deal)
- 5-20% (manageable problem)
- 20-50% (yikes, that's concerning)
- Over 50% (we have a **SERIOUS** problem)
- Up to 94% (show me the receipts)

ABOUT NUCATS

The Northwestern University Clinical and Translational Sciences (NUCATS) Institute provides scientists with consultative resources and expertise to accelerate how quickly transformative scientific discoveries make their way from the lab to patients and communities.



The Recruitment and Retention Consultation service strives to guide researchers towards **equitable** and efficient recruitment practices by leveraging our own expertise and centralizing recruitment and retention resources via our SharePoint.

Our history

- Launched as a pilot in 2020 within Medical Social Sciences/Impact; now a formally funded NUCATS service
- We employ innovative approaches that are adaptable across diverse populations and study contexts
- Designed to reach minoritized populations and address stigmatized conditions through innovative, community - engaged methods
- Published process model and delivered award winning, invited presentations nationally and internationally
- Your content/population expertise 🤝 Our R&R methods expertise

Current HIV/AIDS Reports (2020) 17:190–202
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EHEALTH AND HIV (J SIMONI AND B GUTHRIE, SECTION EDITORS)



The CAN-DO-IT Model: a Process for Developing and Refining Online Recruitment in HIV/AIDS and Sexual Health Research

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Abstract

Purpose of Review HIV/AIDS and sexual health research has increasingly relied on online recruitment in recent years. However, as potential online recruitment avenues (e.g., dating and sexual networking applications, websites, social media) have proliferated, navigating this process has become increasingly complex. This paper presents a practical model to guide researchers through online recruitment irrespective of platform.

Recent Findings The CAN-DO-IT model reflects 7 iterative steps based on work by the authors and other investigators: conceptualize scope of recruitment campaign, acquire necessary expertise, navigate online platforms, develop advertisements, optimize recruitment, respond accordingly, and refine. **Summary** Online recruitment is a complex process across platforms and enrollment barriers. This paper facilitates this process and reduces barriers.



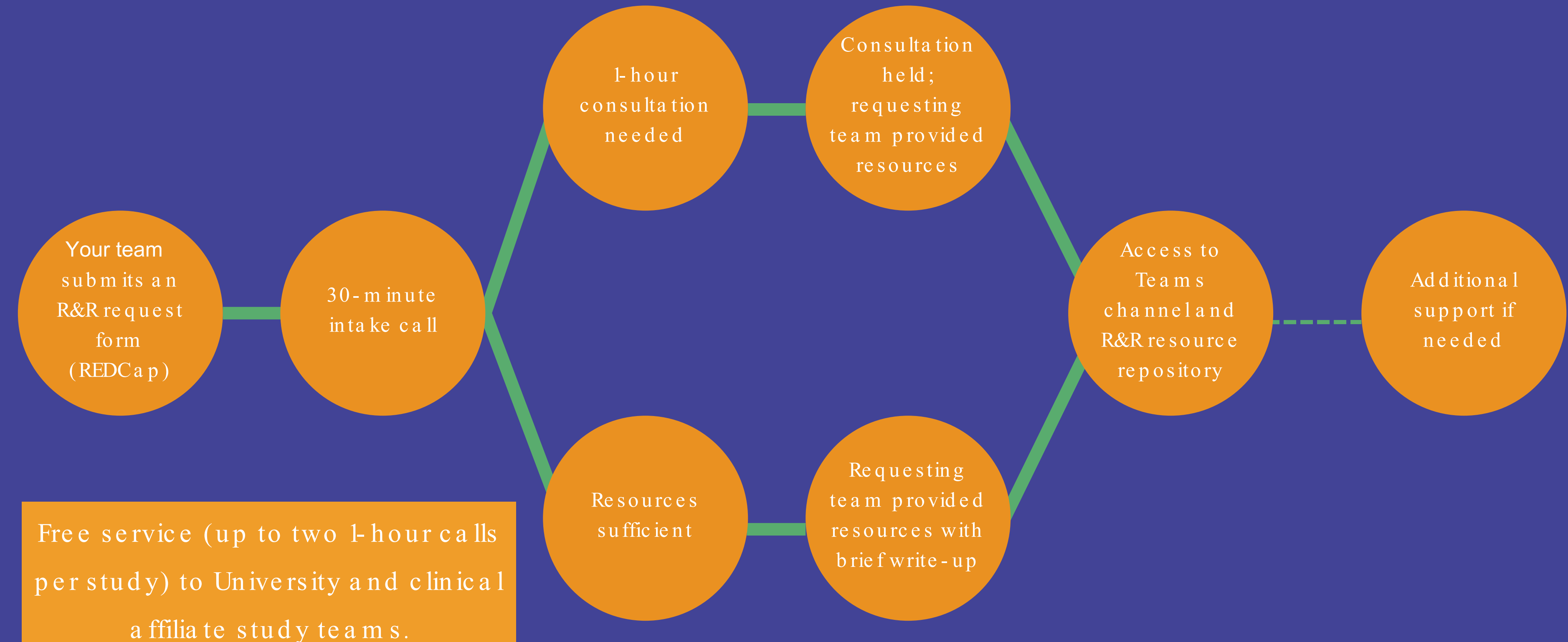
WE OFFER SCIENTIFIC GUIDANCE & TECHNICAL ASSISTANCE ON RECRUITMENT & RETENTION ACROSS THE LIFECYCLE OF YOUR STUDY



ADDITIONAL SUPPORT

- Navigation to relevant NUCATS/FSM services (e.g., ethics consultations, community engagement, digital tools for tracking and communication)
- SharePoint resources and Teams - based R&R online community (**new!**)
- % effort available for sustained or in - depth recruitment and retention support

Consultation PROCESS



Our areas of expertise

RECRUITMENT

- IRB guidance and templates
- Ad creative & copy
- Social media, dating apps, other online
- Detecting fraudulent participants
- Participant registries
- Community - informed recruitment practices
- ...and more

RETENTION

- IRB guidance and templates
- Optimizing outreach patterns & scripts
- Remote retention strategies
- Newsletter guidelines & templates
- Digital approaches to retention (e.g., texting, websites)
- Gamification techniques
- ...and more

What Study Teams get

Following a consultation call, the study team will receive a summary of strategies discussed with links to resources to help the team implement the strategies

Example
summary
document



1. Tighten Eligibility Communication & Establish legitimacy

- **Plain-language reframing** – Lead with the benefit (“free, one-on-one intensive therapy that may improve arm function”) before the narrow criteria; list *all* deal-breakers in one place so candidates can self-screen quickly.
- **Visual aid** – A one-page infographic showing the study flow (study schedule, travel stipend, parking info) helps potential participants and caregivers see the commitment at a glance.
- **Caregiver call-outs** – Add a line such as “Family members/caregivers welcome on visits—ask us how we can help with logistics.” Caregivers often drive the decision for severely impaired survivors.
- **Video** – create a video that introduces that study and is shared via study website or private YouTube video.
- **Establish study online legitimacy** – Create study specific social media accounts and population with some content. Ensure the affiliation to Northwestern University is clear and provide contact information that has the NU domain.

2. Expand Zero-Cost Recruitment Channels

Channel	How to activate this week	Tips
Stroke support groups	Request 5-min speaking slots & share flyers/interest form QR code at:- Shirley Ryan AbilityLab monthly group (3rd Thurs., 5:30 pm)	Offer to bring a short demo to spark interest and consider

IRB Language for recruitment

Aim 1 Beta-testing and Youth Advisory Council: We will recruit participants via a combination of free venues and paid social media advertising. Free venues include 1) free online ads posted across the research team’s social media channels (e.g., TikTok; Instagram; Snapchat); 2) forum websites (e.g., Craigslist, Reddit); and 3) three existing participant registries (Third Coast Center for AIDS Research – CHAMP participant registry STU00202589; Impact Institute participant registry STU00066112; HIV prevention for adolescent MSM SMART STU00201997). Paid national social media ads (e.g., Facebook; Instagram) allow us to target potential participants by various characteristics, such as gender and race/ethnicity.

Aim 2 Randomized controlled trial: Recruitment strategies will be similar to those described in the “beta-testing” section (see above). Additionally, we will also recruit participants via paid advertisements on dating/sex partner applications (e.g., Grindr; Jack’d). Although these applications’ terms of service require being age 18+, the PI’s research indicates that many SGM adolescents under 18 utilize these applications⁶⁴. Not recruiting from apps like these means that we may miss some of the highest risk adolescents that are in most need of services. Another avenue of recruitment will be BuildClinical, a HIPAA compliant company specializing in recruitment for clinical trial studies. Similarly, we will collaborate with Chipper Digital, an advertising firm specializing

Case example of our expertise in action



The benefits and pitfalls of remote recruitment & digital research studies

Online research and recruitment is becoming increasingly popular, but it is not without risks

Opportunities

- Expands access to geographically diverse, hard to reach populations
- Cost-effective
- Streamlines enrollment

Costs / risks

- “Illusion of ease”, desire for bigger Ns
- Potential for fraudulent participation, bad actors, poor quality data
 - Excluded responses due to fraud range from 3% to 94% (Comachio et al., 2024)

Why It Matters:

- Drains research resources (\$ and time)
- Poses risks to participant safety in some studies
- Undermines data quality and study validity
- Biases findings



Dealing with fraud, data quality, bad actors in research isn't new, and it has gotten more complex over time

From “careless responding” and “mischievous responders” to bots and imposters

Educational Researcher
Volume 43, Issue 4, May 2014, Pages 171-185
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<https://doi.org/10.3102/0013189X14534297>

Feature Article

Inaccurate Estimation of Disparities Due to Mischievous Responders: Several Suggestions to Assess Conclusions

Joseph P. Robinson-Cimpian





Annual Review of Psychology

Dealing with Careless Responding in Survey Data: Prevention, Identification, and Recommended Best Practices

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**Beyond Bot Detection:
Combating Fraudulent Online Survey Takers***

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Sharma et al. *BMC Health Services Research* (2024) 24:724
<https://doi.org/10.1186/s12913-024-11166-x>

BMC Health Services Research

RESEARCH

Open Access



Navigating the challenges of imposter participants in online qualitative research: lessons learned from a paediatric health services study

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2024 IEEE Symposium on Visual Languages and Human-Centric Computing (VL/HCC)

**Challenges and Opportunities for Survey Research in the Age of Generative AI:
An Experience Report**

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Our Experience Doing Online Recruitment

10+ years in online recruitment and translational online research in sexual health, HIV, relationships, substance use, mental health, and COVID



Study	Design	Enrolled	Underrepresented (%)	Retention (%)
2gether*	RCT	636	44%	90%
Fab400	4-yr cohort	488	72%	85%
Keep it Up!*	RCT	901	63%	86%
RADAR	>10-yr cohort	1,200	75%	80%
SMART*	Adaptive RCT	1,289	50%	83%
SCAN	Observational cross-sectional	7,935	52%	n/a

Current studies:

Cross-sectional

SCRIPT: Understanding biomedical HIV prevention perspectives in adolescents (two surveys, N = 700 and N=200)

PrEP4Teens: Adolescents’ perspectives on HIV prevention campaigns (one survey, target N = 1000, \$5 incentive)

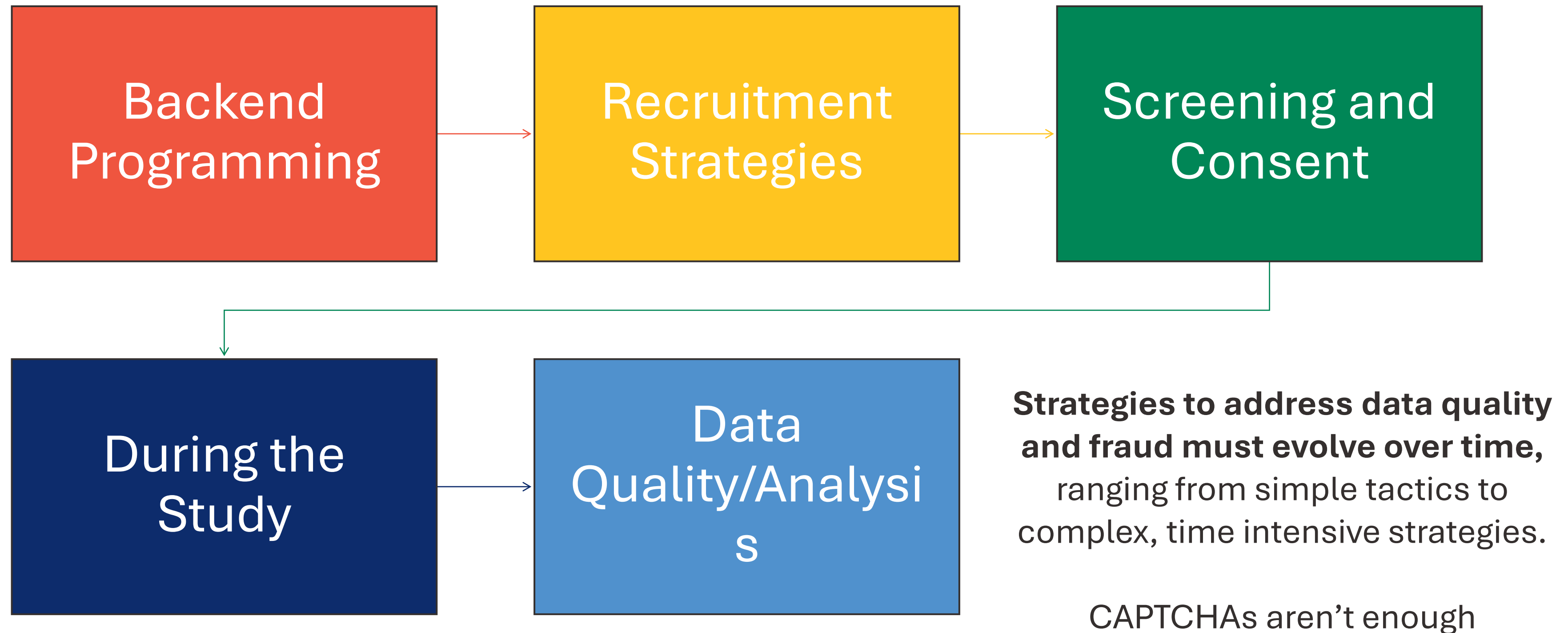
Interventional/Implementation

SHER: A nationwide RCT to increase HIV testing in LGBTQ+ adolescents via a text messaging intervention (N = 360; \$250 total for completing seven surveys)



A Multilayered Approach to Preventing and Addressing Fraud

Using “end to end” approaches across the research lifecycle can mitigate concerns about data quality and fraud



Poll: How would you feel if a researcher came to you saying, “I think half my participants might be fake”?

- “Internal scream”
- “Tell me everything about your methods...”
- “Why didn’t you plan for this?!”
- “Great learning opportunity!”
- “I need more coffee for this conversation”

Screening and Consent Fraud Prevention Strategies

Balance need to protect data integrity while considering participant burden

Strategy	Purpose	Participant Burden Level	Staff Burden Level
MinFraud	Uses IP address to deliver a “IP Risk score”.	None	Minimal
Qualitative questions pre-consent	Analyze responses to determine use of AI.	Minimal	Moderate-High (depending on sample size)
Video recording	Determine it is a real participant and can be combine with other strategies like asking participant to hold up X fingers or show their ID.	Minimal-Moderate (depending on age)	Minimal
Photo Identification Upload	Determines it is a real participant and can determine place of residence.	Moderate-High (depending on age and immigration status)	Minimal
Video chats	Determines it is a real participant and can determine place of residence.	Moderate-High (depending on age)	Minimal-Moderate

Recruitment Strategies

Where you place your advertisements matters

Be intentional and strategic about where you place your advertisements

- Consider what platforms your population is using BUT assess risk of placing advertisements on certain platforms
 - Placing advertisements on Facebook has resulted in higher rate of fraudulent participants but Facebook may be an appropriate placement if you are recruiting older individuals
- Collaborate with trusted organizations or labs to promote your study
 - Ask organizations to email their registry or post on social media
- Clearly state participants who are found to provide fraudulent information will not be compensated

Hi there

SHER is a text messaging program that will provide LGBTQ+ teens and young adults with sexual and mental health education that meets their needs in a way that is quick and interactive. Our team at Northwestern University is looking to improve **SHER** and **we need your help to do it.**

With **SHER**, you can earn up to **\$150** for completing surveys. Start by answering the questions on the next page to see if SHER is right for you. **It takes just a couple minutes!** We will reach out if you are eligible. Your information, including contact details, will remain secure. You can request we delete your information at any time by reaching out to teenhealth@northwestern.edu. **Cases determined to have fake information will not be paid for study participation.**

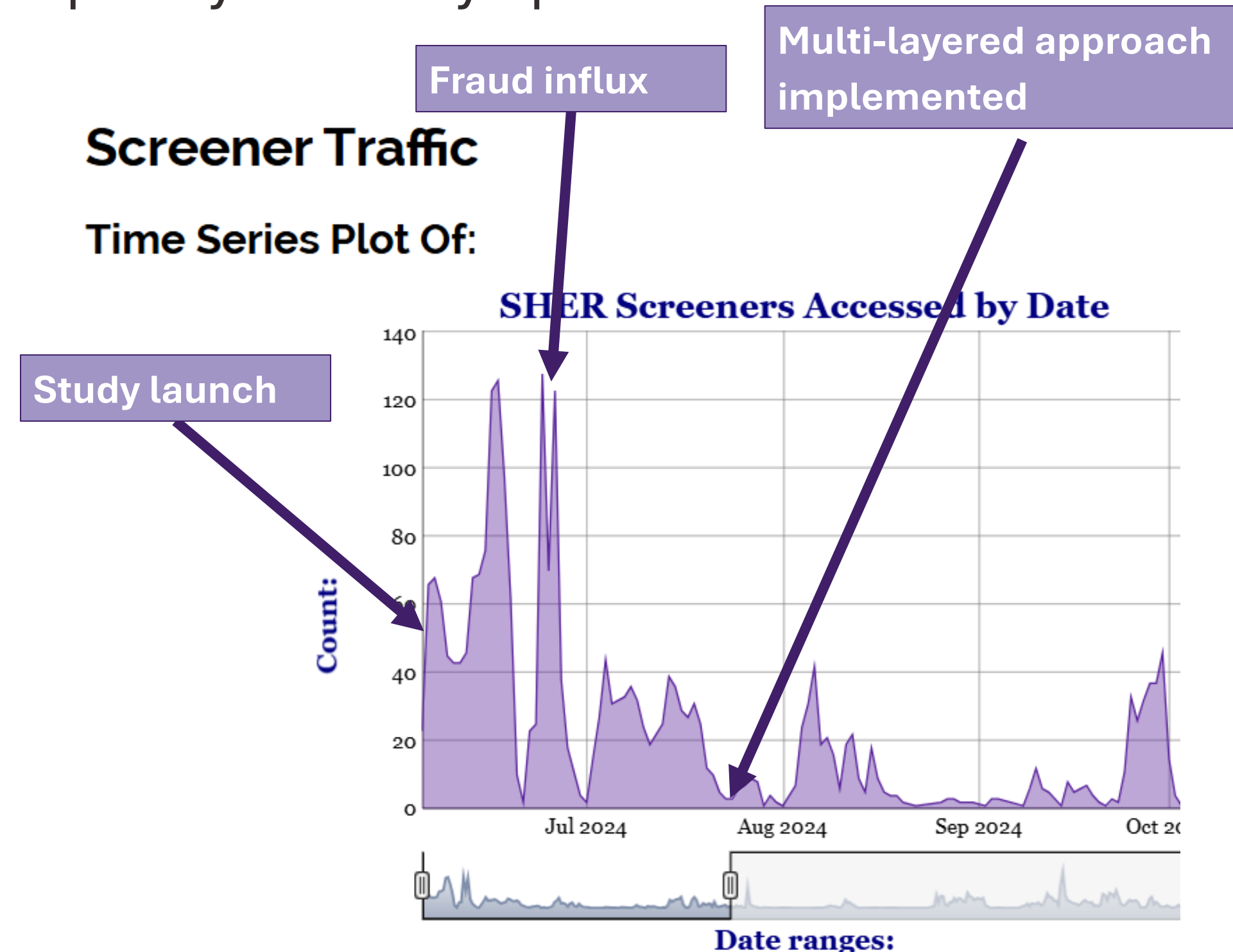
Sign up here!

Backend Programming

An opportunity to optimize resources that help set your study up for success

Set yourself up for success by automating fraud detection

- Program ability to use unique source links
 - Switch out links routinely
 - Use unique links for each recruitment source
 - Program reports to help you visualize the problem
- Use data capture software to automatically detect suspicious activity
 - Collect at least two identifiers that help detect duplicate entries (e.g., email and phone number)
 - Set up timestamps
 - Use a data capturing software that allows collection of IP address



Qualitative Questions

A tool with minimal participant burden

Open ended questions allow you to look for patterns typical with AI answering questions created for research participants.

- Design the questions to “trick AI”
- Use simple questions that focus on lived experience
- Use this as an opportunity to collect additional data while adding an extra layer of fraud prevention

Question	Typical Participant Response	AI response
How many "r"s are there in "strawberry?"	3	The word "strawberry" contains two "r"s.
How many words are in your answer to this question?	One	There are six words in my answer to this question.
Prompt E: LGBTQ+ people are regularly forced to come out of the closet. How does this pattern of coming out impact you?	I don't tell my parents that I'm gay, and I tell my friends to not tell them that I'm gay.	As a queer person, I've experienced both the liberating and exhausting sides of coming out.... (answer was multiple paragraphs)

Videochats

Videochats can serve as an additional data point to determine fraud, while also serving as an onboarding or consent tool

Use the videochat to ask participant conversational questions that help build rapport while helping determine eligibility

- Example questions include:
 - What is your high school mascot?
 - What is your favorite local restaurant?
 - What is the weather like where you are at?
- Create a detailed protocol to help staff conduct these videochats.
- Use this as an opportunity to provide additional information about the study and answer participant questions.



During the Study and Data Analysis

Ongoing monitoring during the study and at the data analysis phase.

Monitor your data to detect unusual patterns in activity

- Monitor enrollment trends to detect spikes in activity
 - Increased enrollment rate without modifications to study may signal fraudulent cases
- Implement data quality checks to identify fraudulent cases that may have passed initial checks

Know your population

- How is your target population likely to answer questions?
 - For example, are they likely to use American English syntax/grammar or have knowledge of specific cultural references?
- Community Advisory Boards can help!



Final Recommendations

A review of some of the lessons learned and implications

It takes a village to address the issue of fraudulent participation in online studies

- Account for this issue in your study timeline, staff effort, and budget
- Implement multiple strategies along the research study pipeline while aiming to reduce participant burden
- Disclose strategies used in publications and presentations
- Reviewers: Assess if methods used in empirical papers are sufficient to protect integrity of data/results

No method is perfect and this issue will require solutions that evolve over time.

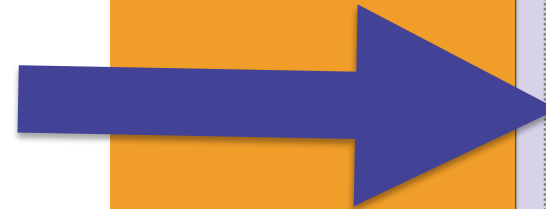
Caveats: money, staffing are rate limiting factors. Ask whether you really need to recruit online and whether you need a very large N



Poll: After seeing all these fraud prevention strategies, what's your reaction?

- Mind = blow, I had no idea this was so complex
 - This sounds exhausting (but necessary)
- I'm definitely asking about this in my next protocol review
- Can NUCATS just handle all of this for everyone?
 - New fear unlocked: AI generated fake data/participants

REQUEST A CONSULT OR PRESENTATION



reset	
CLINICAL RESEARCH ETHICS CONSULTATION	
Request Clinical Research Ethics Consult	Clinical Research Ethical Consultation (CREC) service offers support to address challenging ethical and equity-related issues * Service is currently limited to NU FSM and our clinical affiliates only.
reset	
RECRUITMENT AND RETENTION CONSULTATION	
Request Recruitment and Retention Consultation	- Pre-award research participant recruitment and retention support (e.g., recruitment budget, recruitment and retention plans) - Research participant recruitment support (e.g., social media advertisements, community outreach, budget optimization, recruitment advertisement performance analysis/optimization, recruitment advertisement designs) - Research participant retention support (e.g., retention plans) - Service is currently only available to FSM and clinical affiliates
reset	
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Request a free consultation:
bit.ly/nucatsrnr
Or email
nucatsrandr@northwestern.edu

Thank you

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Feinberg School of Medicine

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