REMOTE Research Advising

Expanding Access Through Remote Research: Real-World Examples and Support from REMOTE Research Advising

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Agenda



Welcome & Purpose [5 min]



Dr. Alpana Waghmare [10 min]



Olivia Ohls [10 min]



The REMOTE Advisor Program Explained [10min]



Q&A [10 min]

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Introduction

Olivia Ohls	Clinical Research Coordinator at Seattle Children's Research Institute Dr. Tonya Palermo, Pediatric Pain and Sleep Innovations lab
Current Project	A remote de-centralized clinical trial testing an internet-delivered pain self-management program in individuals with chronic pancreatitis

Remote Recruitment and Consent

Utilize REDCap as a tracking database from recruitment through study completion

Recruitment

- Online community interest forms
  - Accessible through QR code on study flyer
  - Collect geo-location (latitude/longitude coordinates) to verify legitimacy
- Online provider referral forms from partnering referring sites
  - Collect basic eligibility criteria, confirm diagnosis
  - Track site engagement
- Verify information reported

Consent

REDCap e-consent framework to collect consent remotely

Remote Data Collection

1. **Patient-reported outcomes collected through scheduled surveys**
   Delivered by text or email, based on participant preference
2. **Scheduled daily diaries**
   With automated reminders, set data collection windows
3. **Control group online education modules**
   Track access and completion through date/time stamps
4. **Alerts and auto-survey invitations**
   Encourage retention and data completeness
5. **Data quality alerts & Customizable notifications**
   Flags for missing data, unusually short completion times, and new referral form received
6. **Multi-language Management**
   Expand inclusivity

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Actiwatch Deployment and Data Collection

Choose the right device

Match battery life and charge duration to how long the participant will wear it

Ship it and track it

- Store participant address and tracking numbers in REDCap
- Include a prepaid return label
- Package the device to protect it

Instruct

- Mail wear and return instructions with the device
- Call, text, email when wear starts and ends (depends on age)
- Send reminders as needed during wear

IRB Considerations

Human Subjects Research IRB determinations	Required from all referring sites
IRB Reliance	Sites that are determined “engaged” by their IRB need to establish IRB reliance
Training Sites	Train sites in referral procedures to ensure IRB protocol is followed
Partner Organizations	Consider how you may engage partner organizations
Community Sources	OpenClinica (formerly BuildClinical), ResearchMatch, PeachJar

Lessons Learned

COMMON CHALLENGE	WHAT WE DO
Open online interest/referral forms	Expect fraud and bad actors in community recruitment
Unverified contact methods	Screen thoroughly, verify with Whitepages, and ask specific questions
Unchecked details	Verify doctors, time zone, and similar details
Identity taken on faith	Use video conferencing to verify identity
Referring sites going quiet	Keep sites engaged, for example referral drives with prizes

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Exploring the **REMOTE** Advising Program:

Why It Matters

Why

- Enhance participant recruitment
- Reduce known barriers to participation
- Enhance participant retention

Exploring the **REMOTE** Advising Program:
How It Works



How

- Free consulting program aimed at leveraging remote technologies to expand reach of clinical and observational research
- Connecting investigators with existing and novel technologies
- Advise from a team of physician-researchers and research coordinators with experience in the use of decentralized research tools
- Online intake form to connect to the REMOTE Research Advising Team
- Proof-of-concept study – with short exit interview on your experience

Remote or Hybrid:

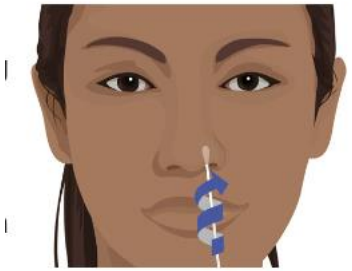
Bring the Study to the People

REMOTE

Learn from others who have experience:

- Electronic/telephone consent
- Courier or ship study supplies, blinded medications, to home or a PO box
- Data collection by symptom surveys sent to patients via email or text
  - telephone-based data collection for individuals without internet access
- Wearable and other biometric devices to track outcomes and safety
- Video-assisted walk-tests or neurocognitive evaluations
- Alarms on REDCap vital signs surveys prompt study staff to call participants with abnormal values
- Immediate referral to local ER or permission to liaise with primary care- saved lives for COVID-19 studies!









STOMP

Study of Tecovirimat for Human Monkeypox Virus

Q&A

REMOTE Advisor Contact:

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REMOTE Advisor Intake Survey

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