Beyond the digital divide: Lessons from behavioral interventions on equitable participation of minorities and health disparity populations

Sherine El-Toukhy, PhD, MA

Earl Stadtman Investigator & NIH Distinguished Scholar
National Institute on Minority Health and Health Disparities
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Virtual Clinical Trials: Challenges & Opportunities
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REALITY VS. PROMISE

Health information technologies

- Safety
- Effectiveness
- Patient-centeredness
- Efficiency
- Timeliness
- Equity
User attachment & utility

It’s always on, unless it dies on me

I got Siri. Whenever I have a question, I ask Siri ... Siri will go get the information or lead me to it

I have an app where it tracks my steps

Email your doctors, and email you back

If I want to see any of my medical results that I took previously, I can go online and go that

I use reminders ... like if I got an appointment ... blood work or this or that

They always let me know when [my prescription is] ready to be filled. And it says, well text back ‘yes’ if you want me to go ahead and fill it

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Recruitment

Point prevalence abstinence rates among program initiators

Point prevalence abstinence rates among program completers

Recruitment plan: Who, how, where

I think you have to be sensitive to the community that you're dealing with and not be prejudge - not be judgmental, but reach them where they are and educate them, and try to bring them to where you want them to be.

Uh uh, I don’t trust that, that’s the government.

I have like four gigs or something.

Just make it simpler.

I had a limited plan then I wouldn’t...

I guess it’s only in English and I live in Columbia Heights and there are a lot of Hispanics.

We don’t want like a global, we want personal [messages].

I had a limited plan then I wouldn’t...

Opt-out numbers per day

- **Opt-outs**
- **Whites**
- **Blacks**
- **Hispanics**

Engagement

PROMIS®
Self-reported and parent-reported measures of global, physical, mental, and social health for adults and children in the general population and those living with a chronic condition.

Neuro-QoL
Self-reported and proxy-reported measures of physical, mental, and social health for adults and children living with a neurological condition.

ASCQ-Me®
Self-reported measures of physical, mental, and social health for adults living with sickle cell disease.

NIH Toolbox®
Performance tests of cognitive, motor, and sensory function and self-reported measures of emotional function for adults and children in the general population and those living with a chronic condition.

Engagement

http://www.healthmeasures.net/index.php

Sanders, E. & Stappers, P. Co-creation and the new landscapes of design. https://doi.org/10.1080/15710880701875068

Research participation

Top five reasons to participate in mhealth study

Interest in topic
Positive impact on life
Helping minority groups
Contributing to greater good
Encouraged by family/friends

Top five reasons to not participate in mhealth study

No interest in topic
Privacy concerns
Too busy
Mistrust researchers
Research has no value

“There were only like 25 African Americans in this study, so when they put all the stuff together, it really doesn't benefit African Americans if we do not participate. We have to participate.”

“And also, continuing to get input from participants to make certain that you're on point in terms of what the needs are, what the interests and the needs are for a program of this nature. I think it's important to get the input of the participants. And not just get the input but take their input into account so as to improve on the program itself.”

"As we see here, is African Americans, and we look at these studies but they don't benefit [us], they don't have enough of us in it for it to benefit me."
Take away points

- Digital health technologies represent an opportunity for equitable participation in clinical trials

- Disparities exist in access, recruitment, and engagement

- Engaging communities, using new methodologies and measures can alleviate disparities
Thank you
sherine.el-toukhy@nih.gov