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

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National Institutes of Health

Virtual Clinical Trials: Challenges & Opportunities

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National Institute on Minority Health and Health Disparities

Disclaimer

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- No conflicts of interest to report

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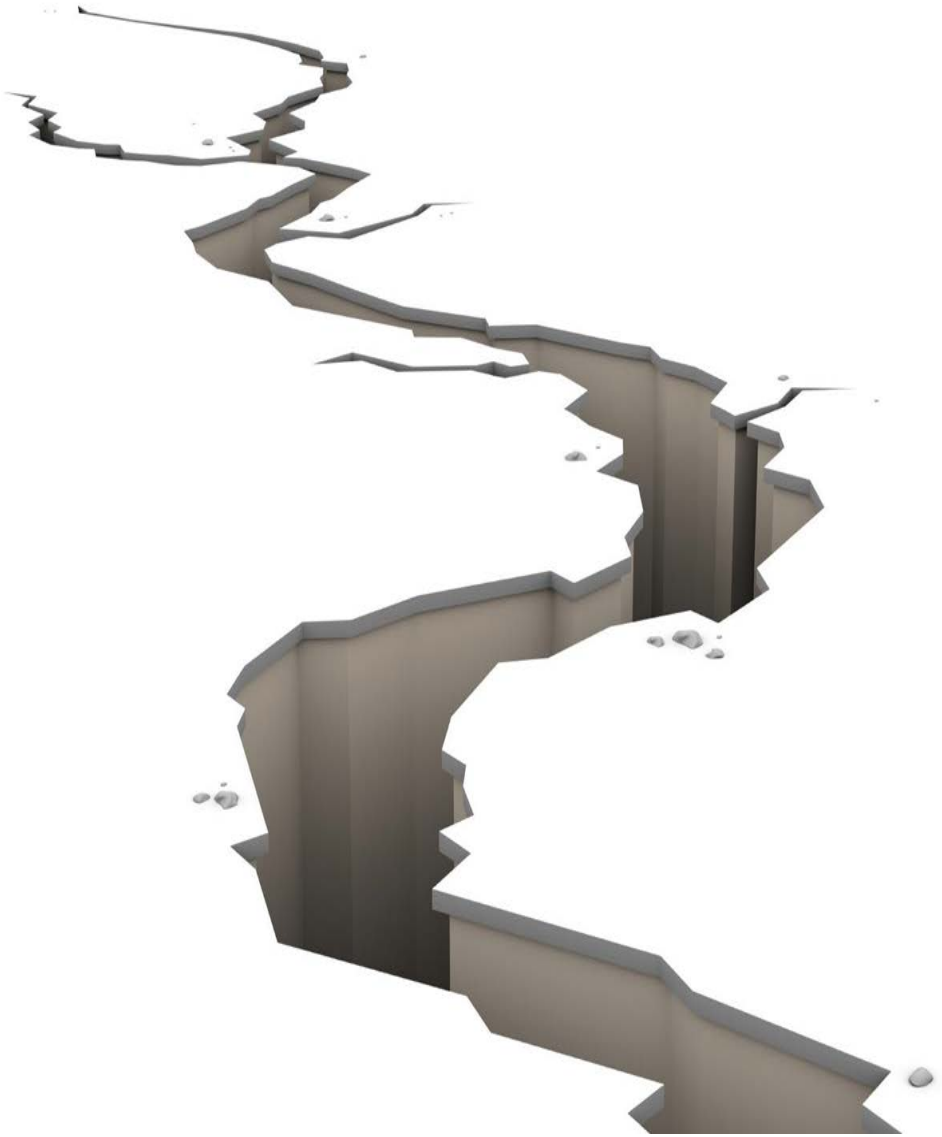
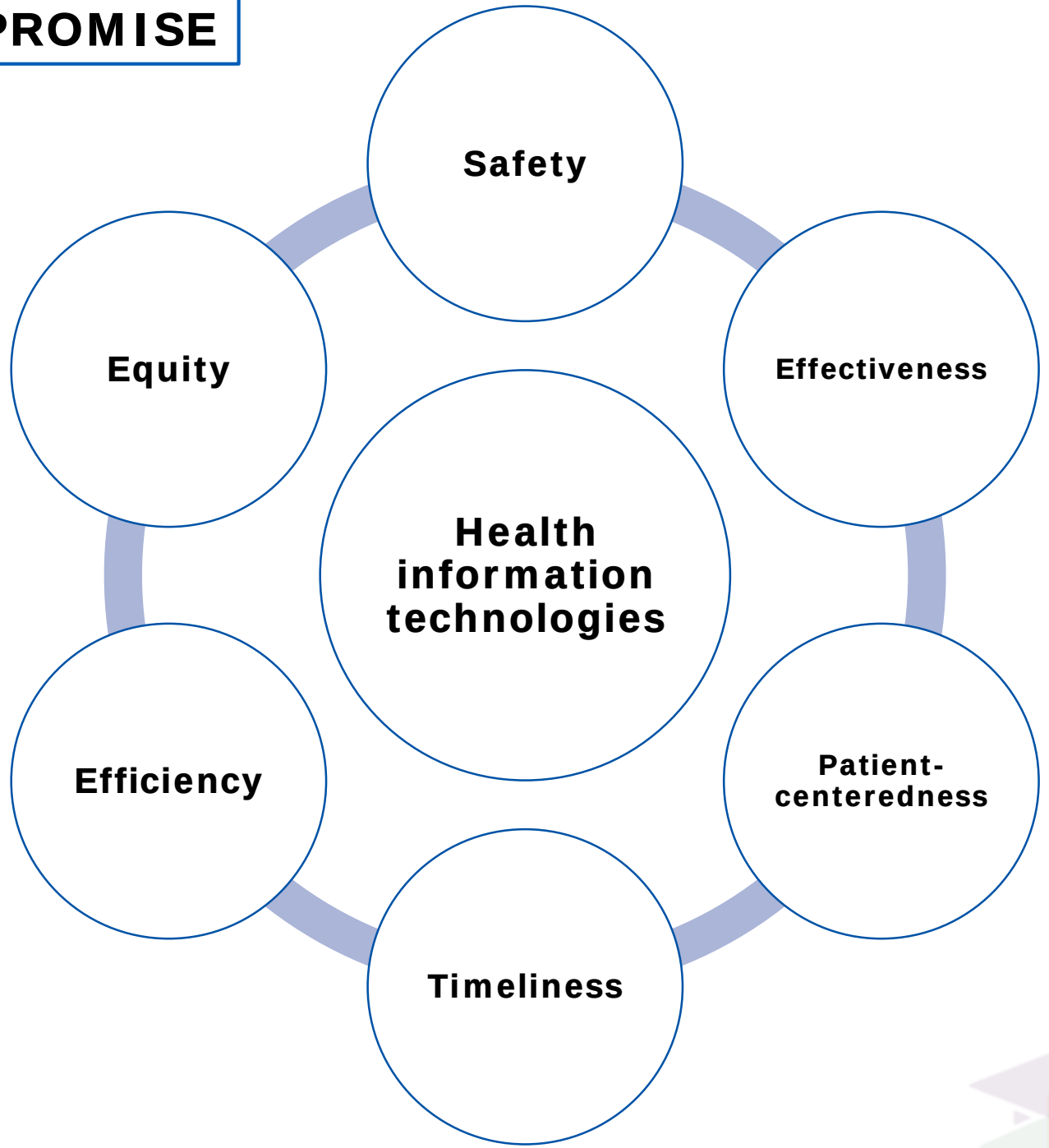
REALITY VS. PROMISE





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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

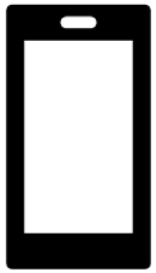
I have an app where it tracks my steps

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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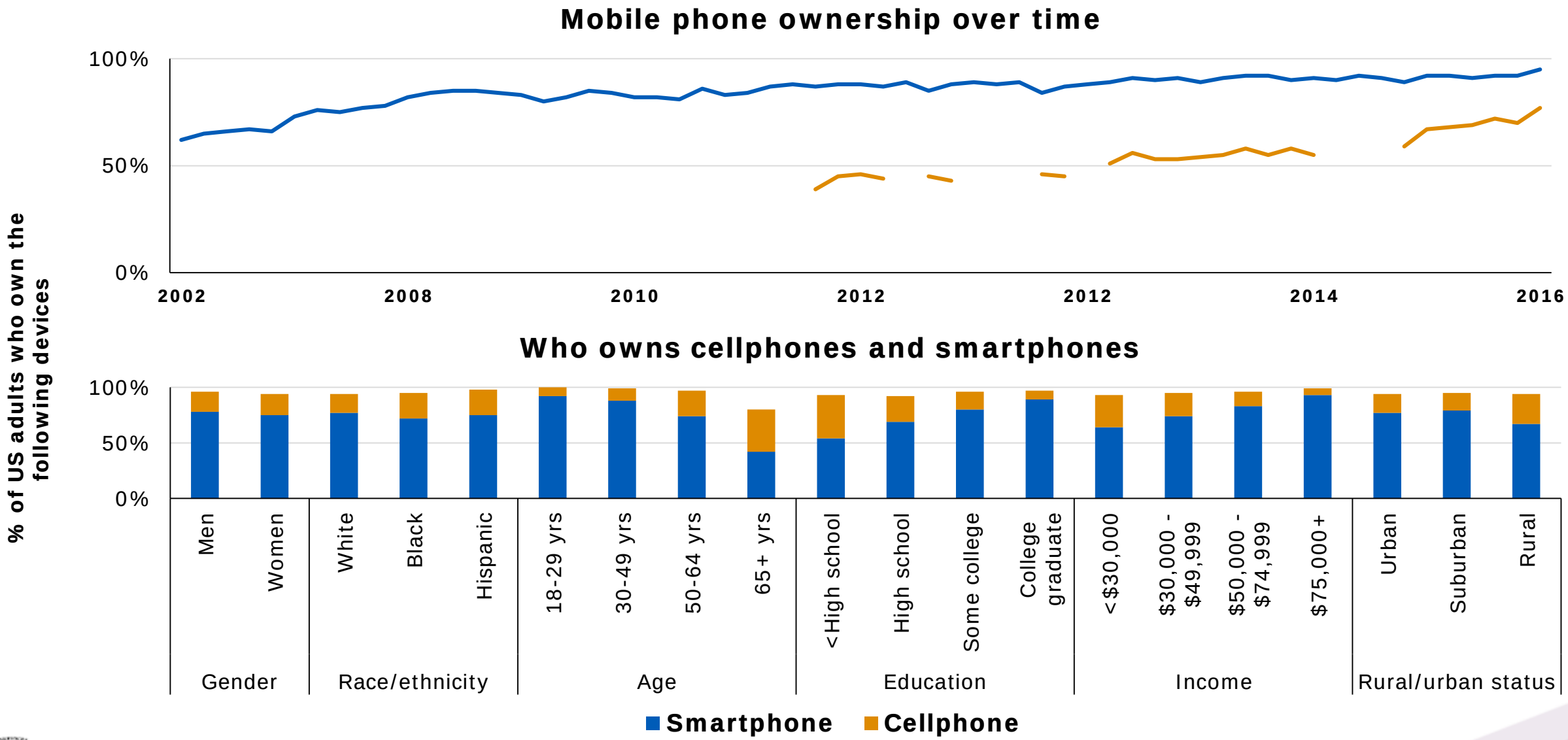
Ceasar, J., Time to listen: Community-based views of mhealth scope, benefits, and barriers. In preparation.

Access



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Pew Research Center Internet & Technology, 2017

Access

	Internet	Means to access Internet		
		Broadband	Cellular data	Wifi
40-59 yrs old	↓			
≥60 yrs old	↓		↓	
Latino				↑
<49K income	↓	↓		↓
≤High school grad	↓			
Separated, widowed	↓			
Speak English not well	↓			

56%

66%

82%

***N* = 3285**

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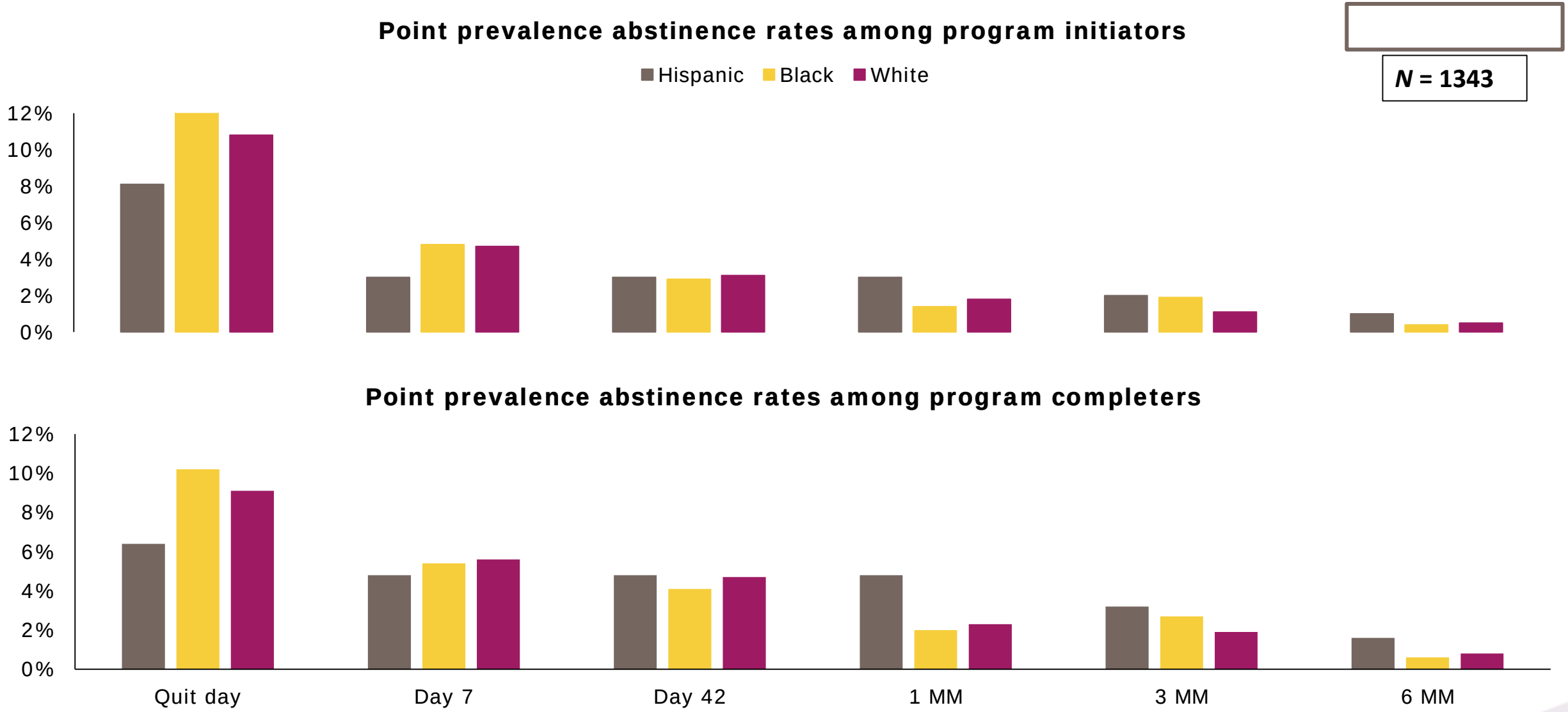
El-Toukhy, S. et al. Disparities in electronic health records access and use. In preparation.

Recruitment



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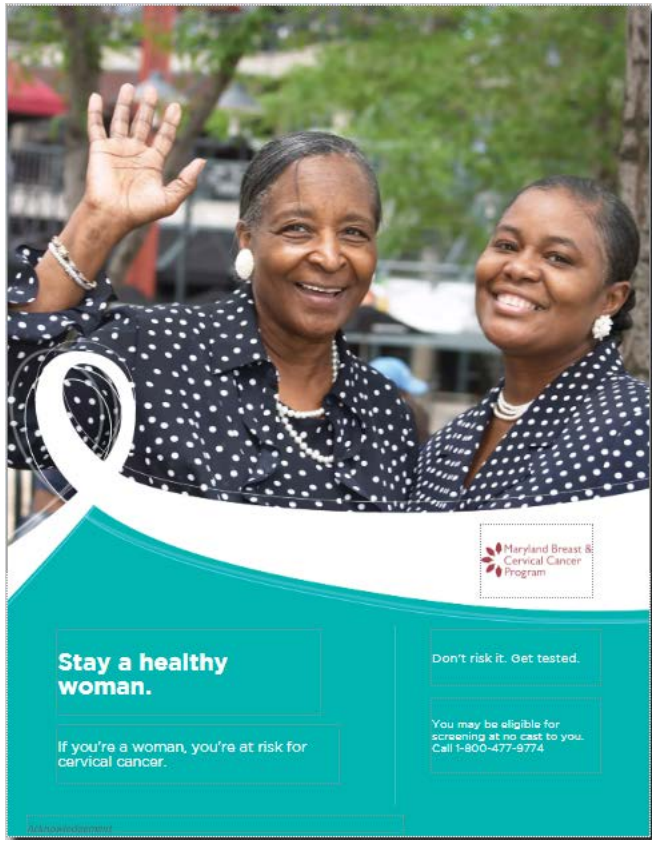
El-Toukhy, S., et al. Disparities in dropout and cessation outcomes of SmokeFreeMOM: A national text message intervention for pregnant women. In preparation.

Recruitment

Recruitment plan: Who, how, where



http://www.miyoworks.org/

I have like four gigs or something

I had a limited plan then I wouldn't…

Uh uh, I don't trust that, that's the government

Just make it simpler

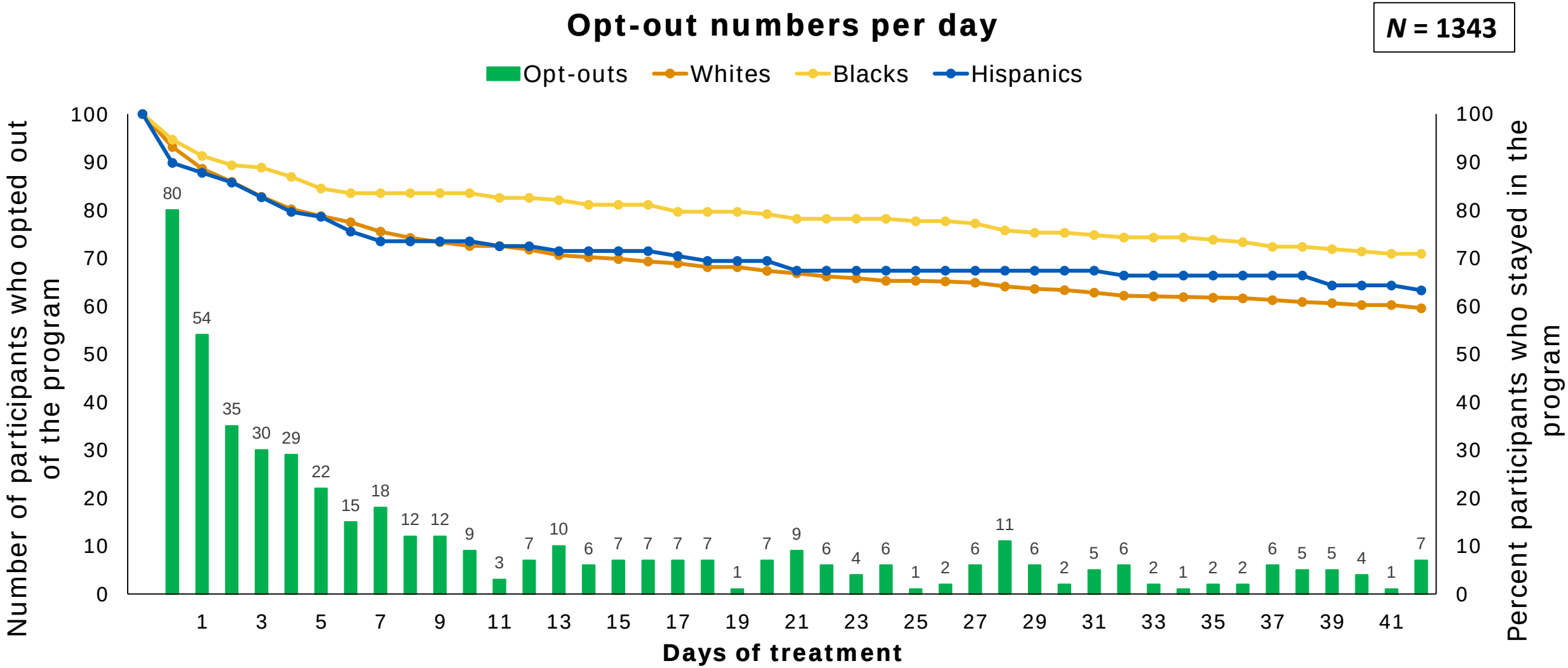
I guess it's only in English and I live in Columbia Heights and there are a lot of Hispanics

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

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

Ceasar, J., Time to listen: Community-based views of mhealth scope, benefits, and barriers. JMIR Formative Research. In press.

Engagement



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El-Toukhy, S., et al. Disparities in xxx.

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

READ MORE

Neuro-QoL

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

READ MORE

ASCQ-Me®

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

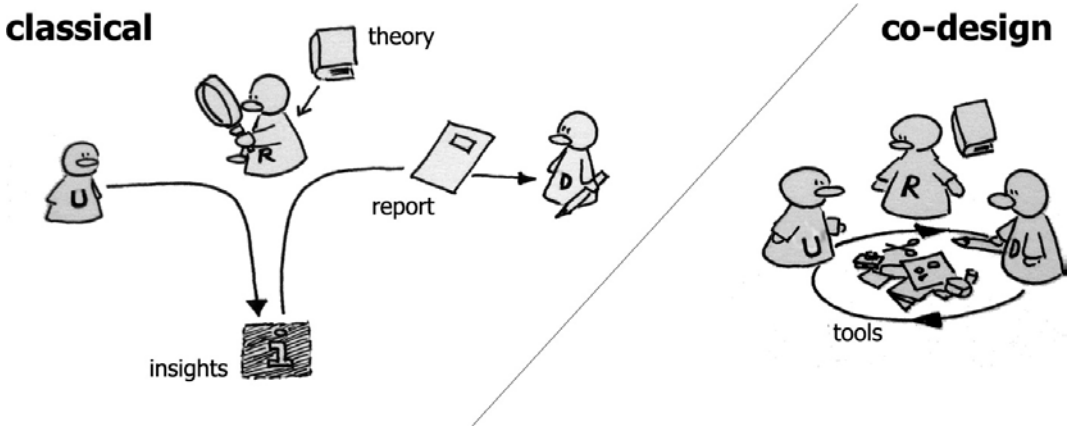
READ MORE

NIH Toolbox®

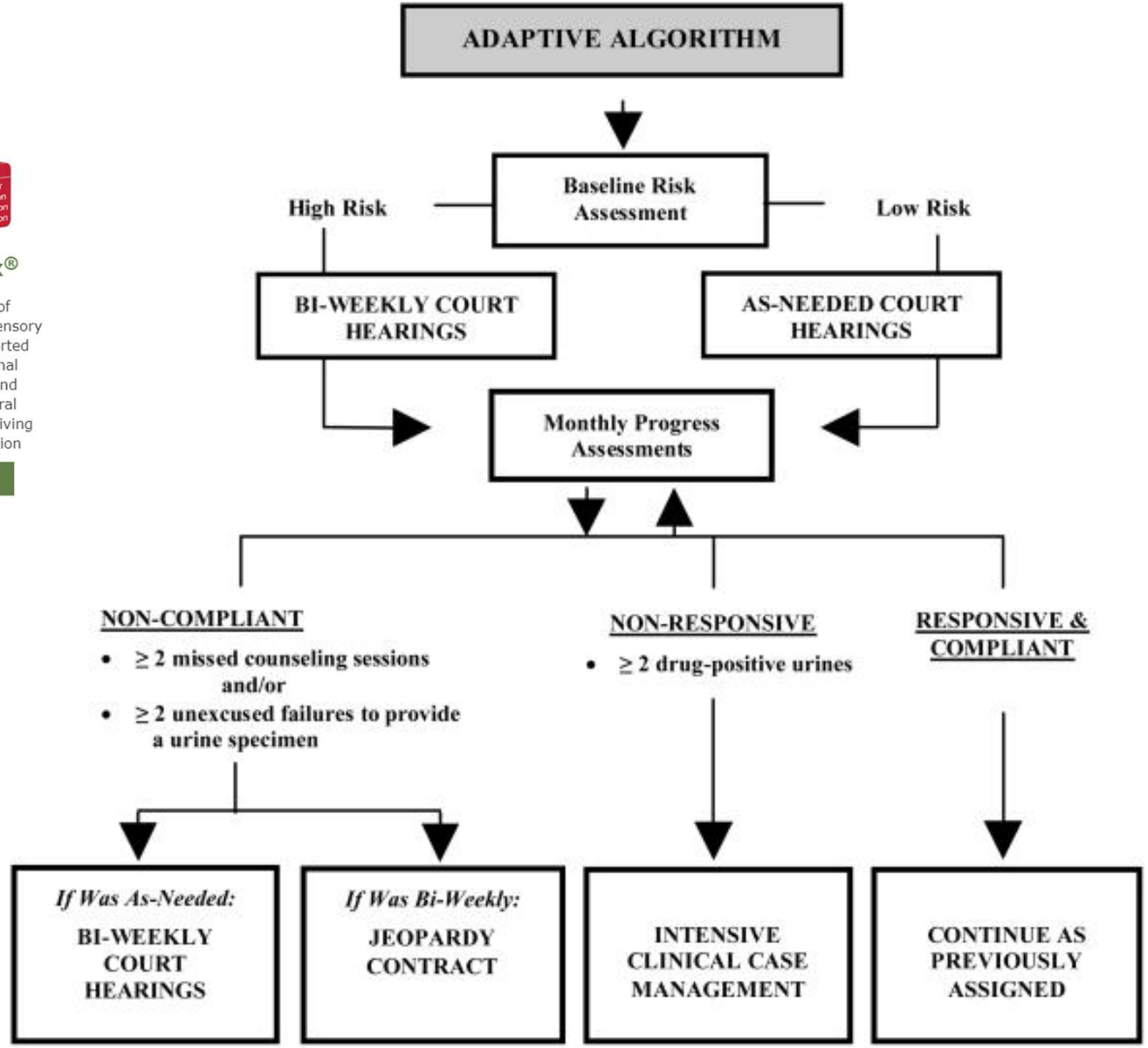
Performance tests of cognitive, motor, and sensory function and self-reported measures of emotional function for adults and children in the general population and those living with a chronic condition

READ MORE

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



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



Marlowe, et al., Adaptive programming improves outcomes in drug court: An experimental trial. *Crim Justice Behav*. 2012 Apr 1; 39(4): 514–532.

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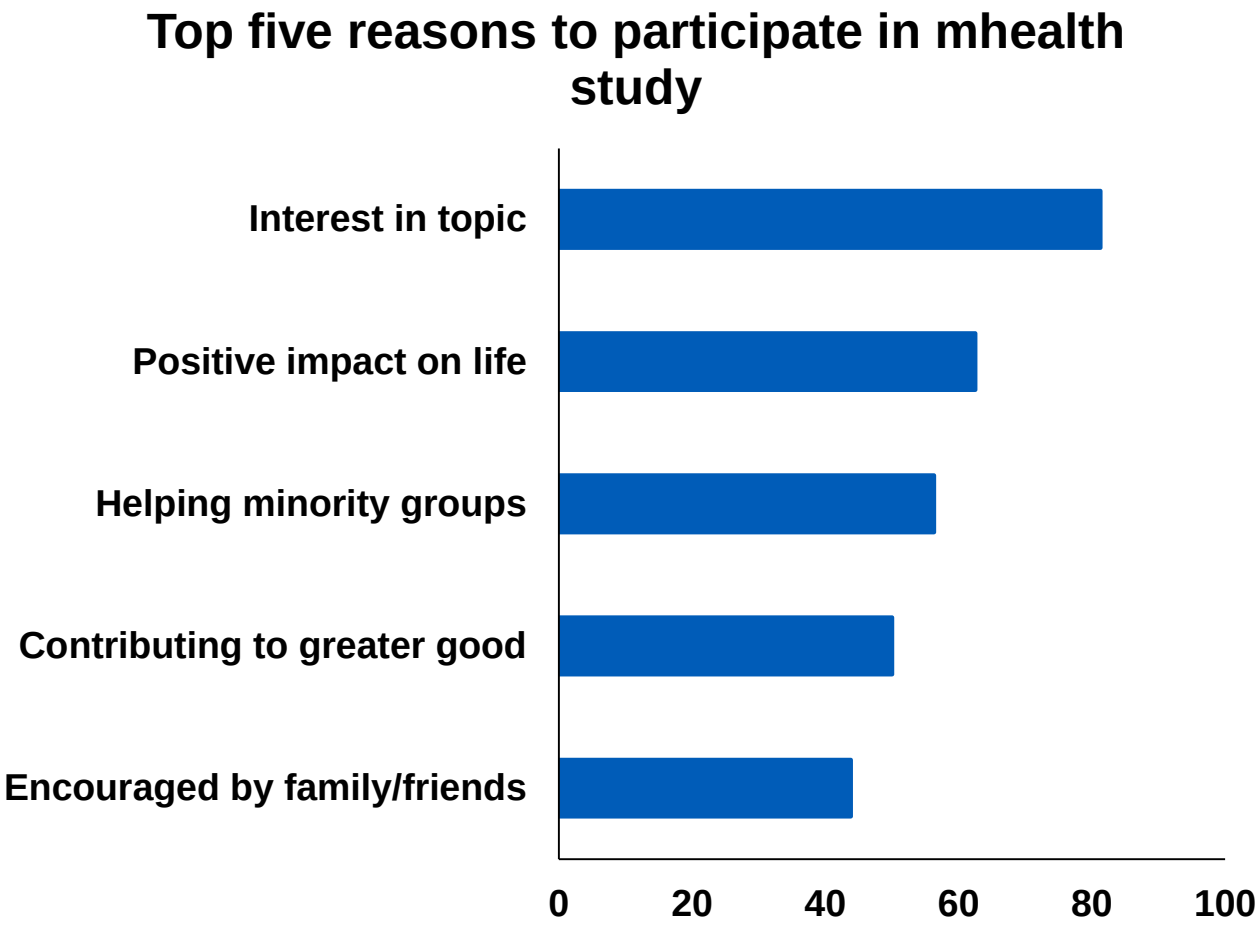
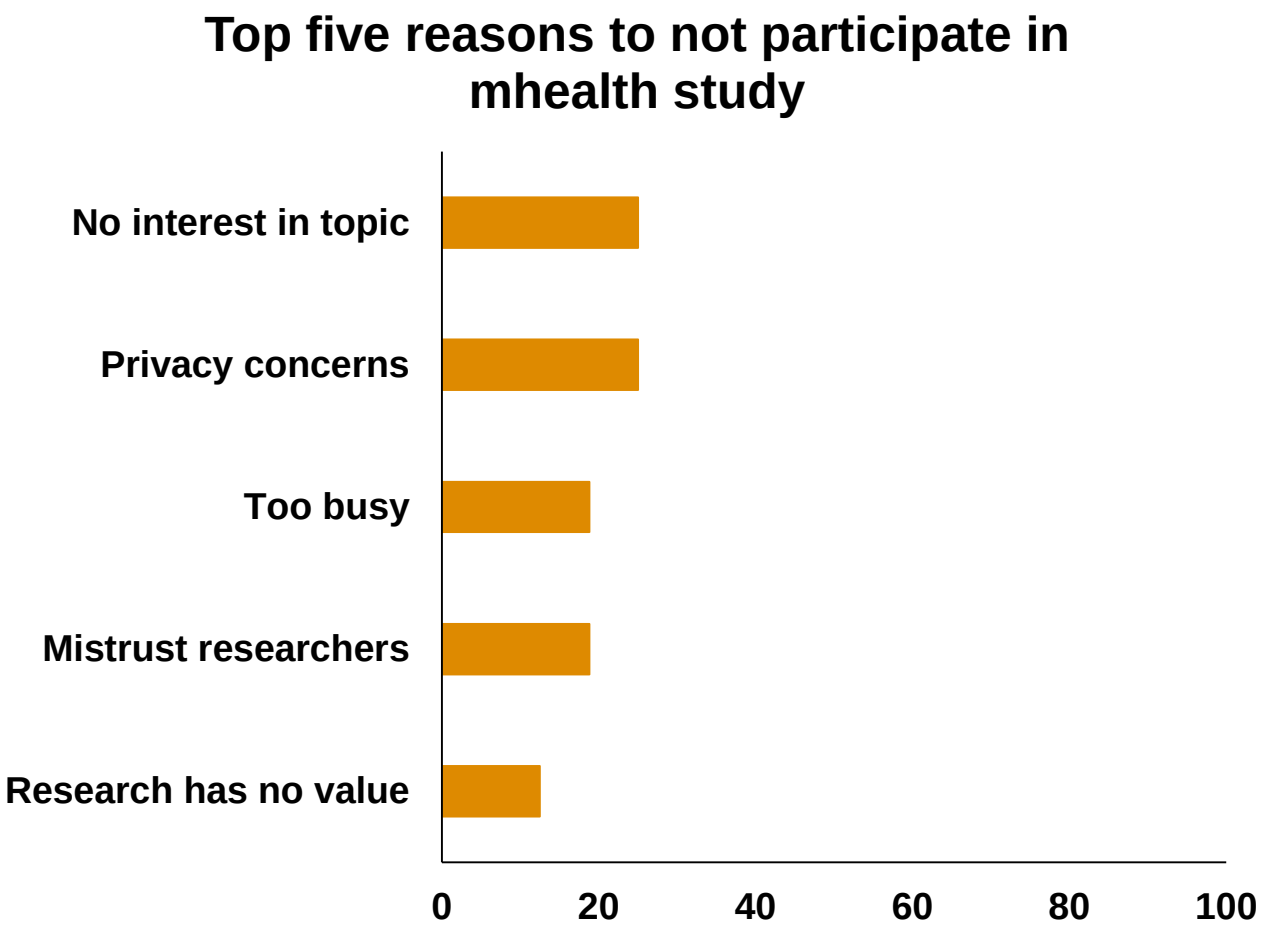
Research participation





Andrews, M., et al. Dispelling Myths on Participation and Engagement of Minorities in Community-Based Behavior Change Research Using Mobile Health Technology. Under Review.

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Research participation

"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."

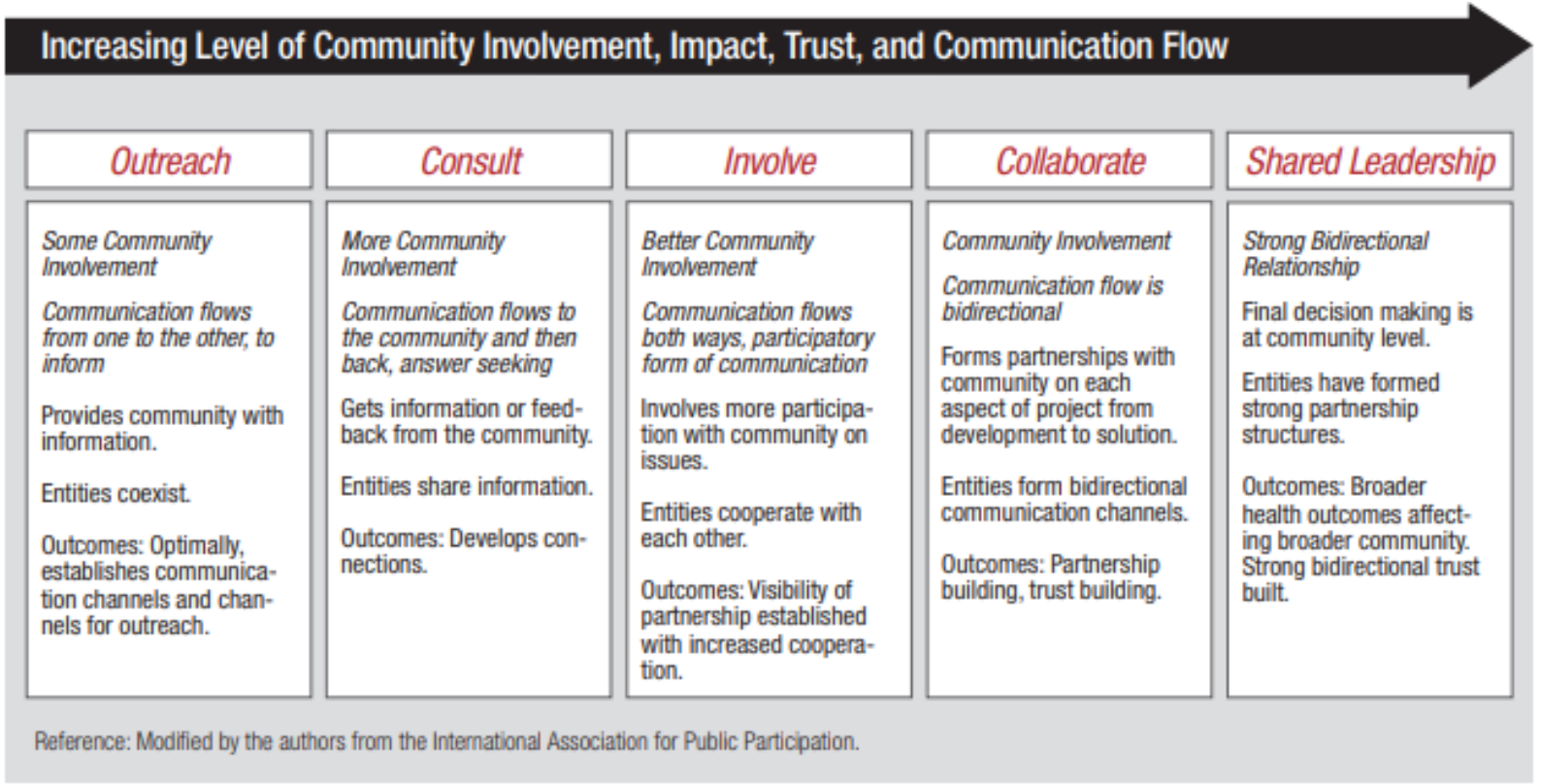

Figure 1.1. Community Engagement Continuum

https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

"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."

Andrews, M., et al. Dispelling Myths on Participation and Engagement of Minorities in Community-Based Behavior Change Research Using Mobile Health Technology. Under Review.

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

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