

2016 Learning Engagement Conference

Thursday, October 13th, 2016

8:30am - 9:00am

Engagement: Changing the Culture of Research

Kim Kimminau & Cheryl Jernigan – Present

Brittany Zschoche – Notes

1. Introduction of Charlie Thompson
 - a. iCAN (international children's advisory network)
 - b. www.icanresearch.org
2. Oak mites are terrible
3. Working to change the culture of research
 - a. Engaging youth and family
 - b. Engagement matters, e.g., better patient retention
4. Important consideration: different perspectives of PE
 - a. Patient vs. academia vs. industry
5. Stages at which to engage patients
 - a. Research Q
 - b. Study design
 - i. Process, materials
 - c. Study implementation
 - i. Recruitment, retention
 - d. Ongoing improvement/monitoring trials
 - e. Dissemination of results
 - f. Bottom line: engage early and often
6. What is gained by talking to youth?
 - a. Technologically advanced/input
 - b. Creativity
 - c. Meaningful endpoints
 - d. Level of risk
 - e. Bottom line: improved overall child focus; researchers need to think from family perspective
7. How to elicit feedback
 - a. Prep time
 - b. What to ask, what not to ask
 - c. How to ask
 - d. Group-think; revise Qs together, work with leaders
 - e. USE THE INFO that you gain; act on it
8. Tips
 - a. Make it: engaging, interesting, make it meaningful
 - b. Express gratitude

Q&A

1. Rural aspect: travel component changes recruitment. At Pfizer, using the referral system

Panel Q&A: Changing the Culture of Engagement

1. Cheryl Jernigan, Jeff Ordway, Nancy Davin, Jill Getman
2. Jill: got involved after her daughter had surgery; works to encourage HCP to take it down to another level
3. Nancy: notion of privilege WRT different demographics among patients
4. Jeff: his PCP approached him about joining to prevent others from going through his 2.5 year diagnosis process
5. Cheryl: big data is becoming a big deal