

2016 Learning Engagement Conference

Thursday, October 13th, 2016

Youth Patient Panel

Charlie Thompson, Patients, Kim Kimminau & Cheryl Jernigan – Present
Brittany Zschoche – Notes

1. Panelist introductions
2. Motivation to help
 - a. Bouncing among meds, side effects
 - b. Once found solutions, realized there could be improvements made to the system
3. What can others learn from you?
 - a. Using DNA for research
4. What have you learned that's surprised you?
 - a. Diseases vary widely among kids, and treatments are drastically different for kids vs adults; can't find clinical trials for children
 - b. It's important to be proactive in trying drugs
5. Advice to teams developing research with kids
 - a. Don't beat around the bush or sugar coat, no fluff; be direct
 - b. Having the disease and going through treatment is an incredibly maturing experience; kids are resilient and can deal with more than what you think they can
 - c. Children's feedback is valid and language matters (having hallucinations vs child thinks he's having hallucinations)
 - d. Run lots of tests especially if symptoms aren't tangible, physical
6. What are some ways you've helped researchers in the past?
 - a. Modernizing and improving assent/consent forms
 - b. Wristband improvements
 - i. Children often have sensitivity issues
 - ii. They get torn off, discarded
 - c. Reviewed form re: mental health status, suicide risk – make sure it's appropriate but doesn't cross any boundaries (e.g., suicidal ideation: it's not planting seeds or numbing to ask too much, better to ask than to not ask).
7. Q&A from audience
 - a. What are your thoughts on the privacy of your data? How it can help researchers? (We are in a much more digital age and your EMRs could be very useful to researchers.)
 - i. Clinical trials have more hoops for privacy; couldn't disclose actual birthday
 - ii. Said medical record can't be used against me in a harmful way; altruistic – if can be used for the good of someone else, if it can reduce the pain of someone else, then by all means take it
 - iii. Using data as cross reference for other kids, harder to get consent since both kids and parents have to consent – additional roadblock
 - iv. "We don't want kids to go through what we've had to go through"
 - b. Parents and patients can be reluctant to participate in trials. What advice do you give us to recruit more patients?
 - i. Pull on heartstrings, e.g., help a sick child
 - ii. Follow up, follow through, and the sharing of information – especially with rare diseases, it's good to connect; beneficial if you can improve someone else's life

- iii. Parents care about their kids more than anything – advice to include the child in the discussion; kids are usually more open-minded
 - iv. Bring in someone who helped develop the study/trial
- c. What research projects would you like to see?
 - i. How technology can be introduced/help; new technologies
 - ii. Education
- d. What are your opinions about paying participants to participate in research?
 - i. It's greedy to help someone; it's a reward in and of itself to help reduce someone else's pain
 - ii. Depends on the depth of the study; travel, extra visits, etc. warrant compensation, and time is money for the parents who are losing time to take kids to research
- e. How would you use data from research? Do you think kids would want to use it?
 - i. Taking medications with unknown side effects – de-identified data would work for that
 - ii. Akin to social networking, use this to find kids like me
 - iii. Again, clinicians will have to believe what kids say about side effects – DeID data here would help
- f. Do youth patients from other countries have similar perspectives?
 - i. Yes; it's been interesting seeing all viewpoints
 - ii. Some countries transition kids to adult care at age of 16
- g. Are any of you interested in research as a career?
 - i. Being in the medical field would be too emotional for me; interested in engineering – biomedical engineering
 - ii. Joining teen advisory board at CMH has shown me that everyone here and at hospitals is making an impact; that's shown me that I want to be in the medical field to make an impact
 - iii. I want to be a neurosurgeon based on the number of surgeries I've had – I feel I could relate to the patients
 - iv. I'm planning to go to medical school, growing up I never thought I would, grew more interested with each visit to a medical professional; I want to make a difference for other kids