

MINUTES

Community Health Research Exchange

Monday, January 25, 2016

1. Introductions

Members Present in Person	Members Present via Phone
<ul style="list-style-type: none">▪ Anabel Arroyo, Coalition of Community Clinics, Health Scholars Program▪ Alvina Rosales, UCI Stress and Pain Management▪ Dara Sorkin, ICTS CEU Director, School of Medicine, UCI▪ Robynn Zender, ICTS CEU Manager, UCI▪ Sharon Boles, Children and Families Commission of Orange County▪ Jack Light, Caregiver Resources Center, St. Jude Medical Center▪ Marc Lerner, Department of Education	<ul style="list-style-type: none">▪ John Billimek, UCI Health Policy Research Institute, School of MedicineFrank Zaldivar, ICTS Director Integrating Special Populations, Pediatrics, UCI▪ Tommy Servi, Health Smiles Kids, OC▪ Ualani Ho'opai, Health Systems Manager, Primary Care, American Cancer Society▪ Juanita Booker-Vaughns, Healthy African American Families, LA▪ Pluscedia Williams, Healthy African American Families, LA

2. CCRI Awardees/CCRI Presentation Breakfast

A brief mention of this meeting was discussed, in the context of research and evaluation, and other topics.

3. Community partners interested in presenting to ICTS Steering Committee about their agency (including research interests, options, questions)

A call for agencies/organizations to present at Steering committee was put out. Several responses were received.

*IF YOU WOULD LIKE TO SPEAK TO OUR ICTS STEERING COMMITTEE, please call or email Robynn Zender (949-824-3160; rzender@uci.edu)

4. Call for organizations interested in having UCI undergrad student researchers

A call for organizations interested in hosting undergraduate students was made.

*IF YOU WOULD LIKE TO HOST AN UNDERGRADUATE STUDENT OR LEARN MORE ABOUT IT, please call or email Robynn Zender (949-824-3160; rzender@uci.edu)

5. Speaker series 2015-2016

Sharon Boles spoke: Research versus Evaluation

See PowerPoint presentation

Main points:

- Research = hypothesis-driven; purpose to generate new, generalizable knowledge; tightly controlled; dissemination = publication
- Evaluation = to determine the performance of a particular group, program, or policy; goal is to improve and change programs and protocols; improvements directed at a specific population; dissemination of results are to stakeholders
- The many similarities between the two activities often confuse the issue
- When is Evaluation considered Research, and when is it not?

Basically whether a human subjects IRB approval is required (Yes = research;
No = evaluation)

Discussion

Recently proposed changes to the Health and Human Services *Federal Policy for the Protection of Human Subjects*, also known as The Common Rule, has IRB offices re-thinking their IRB protocols. Public comment on these proposed rules closed January 6, 2016. More information about this can be found at <https://www.federalregister.gov/articles/2015/09/08/2015-21756/federal-policy-for-the-protection-of-human-subjects>. Our next speaker, on February 22, is Valerie Sanchez, from the UCI Institutional Review Board to speak with us about these and other IRB-related issues.

Q: How does the definition of Research vs Evaluation impact an organization's eligibility for funds?

A: Possibly no impact. For example, the Commission for Children and Families funds programs for kids age 0 – 5. The new executive director gives great value to program evaluation in order to increase the sustainability of the Commission (to be certain to fund the most effective and impactful programs). Therefore there has been a bigger push toward independent evaluation of programs, and a big increase in IRB applications.

Q: How do smaller organizations manage to conduct evaluation if they do not have a stable infrastructure and/or are inexperienced in evaluation?

A: Organizations must evaluate programs in order to maintain and/or increase their funding, so they must figure it out somehow. Evaluation can also identify areas of critical need that may not be obvious without doing evaluation.

Some resources for such agencies are the CCRI funds offered by ICTS; the Commission can help if the organization is funded by them; or through other connections the organization might have with researchers.

Q: What portion of funding goes into evaluation (within a submitted proposal)?

A: 10% gets cited most often, however this is rarely adequate to evaluate services and programs well. It can be argued that fewer people in need will be served as a result of using funds for evaluation, however, evaluation is mandatory.

Between 15% - 20% is usually a good amount, but it depends on the type of evaluation being done (easily minable data vs. 1:1 patient contact-dependent data, for example). As evaluation becomes more automated with infrastructure put in place, the cost for evaluation decreases each year.

Q: What methods are used for evaluation, if not randomized clinical trials?

A: The difficulty in all studies is in finding or creating a control or comparison group, but figuring out a comparison group is vital. Other options are doing historical comparisons, propensity score matching, quasi-experimental (non-randomized) trials.

Comment: Different cultures have different views of research (such as believing you will be used as a "guinea pig" if you participate), and different ideas of what sorts of information is appropriate to share with patients.

It is important to educate the community (everyone, basically) on the importance of participating in research, share stories of success, perhaps have language in the consent form that explains this (that this trial is only happening because of others that came before us who participated in research studies).

Response: Josh Grill, UCI researcher, studies how to give back to the community of participants, what motivates people to participate, and the “science of participant recruitment and retention”. Also, “what does it mean to ‘provide consent’”.

Response: Consent forms scare people and having a more balanced information sharing that provides the history of how this study came on the shoulders of past studies and past study participants is important.

Response: We are missing large ethnic groups by targeting only English, Spanish, and Vietnamese language speakers. We have a large population of Russian immigrants, also Farsi, Middle Easterners, and others we need to engage.

Q: What are the rates of specific ethnic minorities participation, and how do we improve this?

A: Word of mouth engagement is imperative. Also use of those who are embedded in the culture, such as the model of the Promotoras, is necessary.

Other groups that are difficult to engage are military veterans, and those with substance abuse. Individuals with past experiences with such things is necessary to engage these populations.

Next meeting: February 22, 2016

Speaker: Valerie Sanchez, UCI Office of Research, Institutional Review Board (IRB)