Perinatal MHRN SIG

September 6, 2017 12-1pm MT

Facilitator: Jean Lawrence

* Check-in: who is on the call
  + Jenn Boggs: KP Colorado, Project Manager IHR; perinatal projects
  + Jean Lawrence: Leading as Arne is out; epidemiologist at KPCO, most work in diabetes in kids, young adults and pregnancy
  + Sam Hubley: Assistant Professor, Dept. of Family Medicine, University of Colorado Anschutz Medical Campus
  + Sona Dimidjian: UC Boulder, Dept. of Psychology and Neuroscience faculty
  + Mark T. Gray: Data Specialist, KP Colorado, IHR
  + Laurel Copeland: Center for Applied Health Research, Baylor Scott & White
  + Wendy Marie Ingram: Postdoctoral Fellow, Department of Epidemiology and Health Services Research, Biomedical Translational Informatics Institute, Geisinger Health System
  + Bobbi Jo Yarborough: KP NW Health services researcher; adolescents with major mental illness and fertility rates
  + Belinda Operskalski: Project manager, KP Washington, general interest in this topic area
  + Greg Simon: KP Washington, AIM study, history of work on safety of ADM during pregnancy, lead investigator for MHRN
  + Rebecca Rossom: Research Investigator, HealthPartners Research Foundation
  + Kelly Young Wolf: KP Northern California, prenatal substance use, K award to look at substance use among pregnant women
  + Lyndsay A. Avalos: KP Northern California, research scientist; K award looking at genetic mutations and folate levels related to perinatal depression, universal screening for perinatal depression, submission to look at mindfulness intervention for perinatal depression
  + Jenn Felder: UCSF postdoctoral research fellow in psychiatry, clinical psychology training at CU Boulder with Sona Dimidjian, prevention of perinatal depression, interests in sleep during perinatal period and birth outcomes, studying digital CBT therapy for insomnia during pregnancy
  + Rachel Vanderkruik: PhD student working with Sona Dimidjian at CU Boulder; note taker for these calls

Discussion Topics:

* Last call: discussion on areas of interest & how align w/ NIMH priorities, some discussion what makes successful in MHRN, and what makes special interest group most useful and impactful. Some thoughts about new studies and resource sharing.
* Mother/Baby linkages – discuss whether data are currently available at participating centers where people working. Interest in linking pregnancy data to infants/live birth and then fetal death records or info on stillbirths, or identifying miscarriages.
  + Some large studies that have included these centers have done linkages (e.g., vaccine safety study, medication for use in pregnancy study). Any centers that are represented here, know what is being done locally or larger multi-center?
  + Southern CA: Perinatal data – linked birth records to mothers records, linkages have changed over time depending what’s available for birth certificate record in state. Also link pregnancy info and outcome (infant delivery/APGAR) back to mother. Have 40,000 deliveries each year now. It is more challenging to link to fetal death records. Have a grant trying to do those outcomes as well. Some fluctuation on birth records from state (e.g., full info from mother) can make linkages easier or harder. Have solid linkage data for babies/moms, less on fetal death that might require more manual review
  + KPCO, how are those records linked?
    - Karthi (data specialist): have local mother/baby link, pulled whenever need data for study. Looking to add a pregnancy mom/baby link to data warehouse...could be ready in a few months, but do not have fetal death. Applicable to all KP sites, not sure who will have access
    - Sona: great advancement!
    - Jenn: VDW table will be created eventually, but not yet...Karthi can find out more detail. Wendy from Geisinger had done some linkages?
    - Wendy: limited about what knows for mom/bay link. Started it in 2010 and have been told that it’s exhaustive for people who are insured by Geisinger. Anytime a mom is seen, it gets brought into EPIC system. Don’t know much about if babies are seen in system, would also know whether or not they have date of death. Updated monthly and linked to SS. If useful to group, Wendy could pull someone in on future calls to discuss further.
    - CESR working group to present linkages on these calls? HCSRN meeting in San Diego, don’t have much info on this
      * Assuming it’s an independent project, not linking to other groups; find someone who is working on this to give an idea of what linkages would look like?
    - Karthi: is on working group – members are clinicians and contribute to data dictionary. Can ask lead programmers when they could present to us to get idea of what linkages entail.
      * Know how linkages could be made across sites for more uniformity and other MHRN sites will be able to potential replicate?
      * Karthi: clinicians are on working group, not sure if code is ready to be presented, but see if we can get some general idea...don’t want to figure out how each site is doing it if there could just be expansion to other sites.
    - Greg: a great development. First step (happening) – defining standard data structure. Doesn’t mean everyone will populate that table, may depend on politics in each site. Once data standard is set, then people in this group can at local research center, make sure it comes a priority. CESR sets standard of what to be done, but then local groups prioritize who will actually do this. We could get more research funded if we do this = key message!
    - Sona: a clear recommended sequence? Local sites having resources to do work we’re talking about now. How helpful to do self-advocacy within site as first step, or is this the work that other more content/clinical substance/grant work becomes part of those proposals?
      * Greg: If developing a data table of mom/baby linkage – that’s a key enabling step. But not sufficient. Still need resource. Step 1) agree on data standard, step 2) let’s build that table & populate linkage table – not an individual grant activity, but that could enable people to write a grant and say that since have the table, grant is now possible.
      * Sona: consistent w/ email Lauren sent that there are no grant mechanisms in place for creating a network database (see email at end of these notes). 1 follow-up Q: people w/in the sites, is there anything this group can do that would help to provide the kind of information to encourage decision makers within sites to support group.
      * Laurrel Copeland: Involved in a partnership in rural area w/ not a lot of competitors, claims include relationship code with mother and see which beneficiary relates to child. Straightforward with claims. In 1984, pediatrician started database w/ actual MRN, kept database with child and mother MRN...not sure how to do it w/o hard work by hand.
      * Karthi: most sites use a version of EPIC and there are some algorithms to pull both mom and baby info out into the table
    - **ACTION ITEM**: Ask CESR group where they are on this, or do they create this type of infrastructures and work w/ stakeholders at sites to get table populated? Or folks with CESR group already committed to populating table
      * Greg: CESR is standard setting body and funder of infrastructure, to build/maintain data. How things get prioritized is a local decision. At KP – resources allocated to this via CESR...this is a priority, put high on the list. At non-KP sites, now a data standard that CESR has created, now have a structure, but they’re not dedicated resources, each site needs to decide if allocate to invest in this. Start this process – Greg will send messages to people and do investigative work to see what people know at his site.
* Previous discussion of sharing of resources – an area for more discussion?
  + Recruitment info, measures, methods of patient engagement, sharing methods for online recruitment, perinatal women as partners
  + Methods for patient engagement for pregnant women as research partners – to inform research strategy...how do this? Karen Coleman doing this for women/families with mental health conditions. Have a group of patients w/ specific condition of interest to see what topics/issues they find important.
  + Have discussed issues of resource sharing?
    - Greg makes offer: we have MHRN intranet or gethub site, have place people can put things. So don’t need to worry about technical issue of where to put it. But does someone who has energy to determine how to organize it? Someone has schema in mind of subfolders to use (e.g., patient recruitment materials, human subjects section for grant application, questionnaires, list of categories and then have people populate)
  + Jenn F: interested in helping out on this in any way. Currently recruiting mom for digital CBT intervention for insomnia, happy to share what people have learned for recruitment/engagement strategies
  + Sona: would be super helpful to share these materials – KPCO team/Jenn B may want to share about stakeholder partnerships/engagement that they have done
  + Jenn B: share some logistical things – how to put in IRB application. The impact that having patient consultants (women in PP period w/ depression) join on study team to design an intervention. Challenges in including patients on teams – what is their role? What will they do? How engage them? Talk with them biweekly, present materials & get feedback. A paid position, they review documents. Changed the way they approached program in many ways. How communicate power of patient consultants...haven’t written it down yet.
  + How recruit them? Did phase 1 – qualitative, focus groups/interviews...many people came in through this way, or referrals from others. A strong bond among women around topic of perinatal mental health. An overwhelming desire for participants to reach out and help as they could.
  + HCSRN: has whole patient engagement group – Leslie Wright; How set up partnerships, how carve out that role for them
* **Next Call**: October 4th – groups can reconvene then. Arne will chair that call. Keep running list of ideas and thoughts and move forward from there.

**Notes from Lauren Hill (NIH/NIMH) on infrastructure funding:**

* To follow-up on the infrastructure-funding question: No NIMH does not have grant mechanisms that would provide funding for infrastructure for a network database.
* NDA staff responded saying that in general NDA can take in appropriate data from qualified researchers regardless of funding source. The agreement any researchers and their institutional official would need to sign to share data in NDA can be found herehttps://ndar.nih.gov/ndarpublicweb/Documents/NDAR+Submission+Request.pdf, ensuring that it's properly consented and de-identified. If you have questions about specific projects or require more specific answers, we may need to consult directly with NDA staff.