



Bethany Kwan: Tweet @docvock and @COPRHCon with #COPRH21

Bethany Kwan: Download Dr. Vock's handout here: https://coprhcon.learningtimesevents.org/wp-content/uploads/2021/05/COPRHcon_Handout-Template_DMV_notes.pdf

David M Vock: Happy to take any questions or comments. We'll see how fast I can type . . .

Brad Morse he/him/his: Hi DocVock! How do you think about community engagement when using existing or secondary data? Is this a concern?

David M Vock: This is a really important aspect! Certainly stakeholders and the broader community can and should be engaged in the research and hopefully were engaged during the initial data collection. Even if not, stakeholder engagement can be used throughout the design.

David M Vock: I'd be curious also to hear others' perspective on community engagement particularly those who work in that space more routinely than I do

Bethany Kwan: I've been leading stakeholder engagement in research on use of secondary health data for research. Here are some video materials we've developed to use in the context of patient stakeholder engagement - introducing use of patient health data for research and discussing security and privacy concerns
<https://mountainscholar.org/handle/10968/6173>

Bethany Kwan: <https://mountainscholar.org/handle/10968/6174>

Cole Hooley: What strategies have you used in the past to identify possible secondary data sources? Before I engage in primary data collection, I will often wonder if we could use an existing dataset. But not sure what the most efficient ways are to search for those datasets in areas that are new to the team.

Rachael Kenney (she): I think that engaging the community in interpreting the results could be really insightful and uncover things that weren't considered.

David M Vock: Some strategies that we've employed to keep summaries of existing data sources which research in our group have access to. But I agree it is always a challenge to keep up with this

David M Vock: I'm curious if other organizations have developed more formal ways of indexing available existing data rather than just using a google doc like we do

Russell Glasgow: I really appreciate the initial list of issues to keep in mind- both pro and con in using secondary/EHR data... one issue that strikes me is the interrogation/ absence of data on some key issues.... I would appreciate your thoughts on supplementing these data with either other data- especially things like PROs related to social determinants of health and patient preferences.... Going forward maybe we can also lobby for more consistent inclusion of such pt.-centered data in the EHR (and as you point out- consistent, systematic inclusion)

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Bethany Kwan: There are a few large national data networks that enhance access to existing clinical data that may be of interest, including <https://pcornet.org/data/> and <https://www.actnetwork.us/National>

David M Vock: Certainly preference likely not to be documented very well and many patient-reported outcomes are hit or miss at best. To the extent that you could supplement it might be worthwhile but that strikes me as really challenging. Contacting previous patients is challenging as we are discovering first hand.

Cole Hooley: Thanks @Bethany!!

Lisa Schilling (she, her, hers): Re: catalogue of potential data sources- check this out. It takes an estimated full-time FTE so we did not proceed but it may have improved since- NYU Data Catalog: <https://datacatalog.med.nyu.edu/>

Data Catalog Collaboration Project: <https://www.datacatalogcollaborationproject.org/>

Bethany Kwan: I also like <https://www.ohdsi.org/> OHDSI uses the OMOP common data model, which has standards for integration of PROs

Cole Hooley: Thanks @Lisa!!

David M Vock: Great resources all! Thank you so much!

Wendy: CPT codes to capture social determinants of health have been added effective 1/1/21 but don't know the extent to which these are being used. <https://www.icd10monitor.com/social-determinants-of-health-and-2021-e-m-code-changes>

Bethany Kwan: Intrigued by record linkage? A session later today digs into the details <https://coprhcon.learningtimesevents.org/21d2s6d/>

Bethany Kwan: That's fantastic, Wendy! Very helpful.

Art Davidson: Also check out this site for the latest on development of value sets and messaging capabilities related to SDoH from HL7: <https://confluence.hl7.org/display/GRAV/The+Gravity+Project>

Bethany Kwan: In the next session this morning, Track 2 has LOTS of great talks on using EHR data, population-based data, claims data, and digital health data for research.

Bethany Kwan: Then this afternoon, Track 2 breakouts will cover data quality assessment, record linkage, natural language processing and mining social media data

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