

[COVID Information Commons \(CIC\) Research Lightning Talk](#)



Transcript of a Presentation by Michelle Krzyzanowski (Research Triangle Institute), July 15, 2022

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Transcript Editor: Lauren Close

Transcript

Michelle Krzyzanowski

Slide 1

Hi everyone, I'm Michelle Krzyzanowski. I'm from RTI International and today I will be talking about the PhenX toolkit COVID-19 project.

Slide 2

So I will be talking about three components of the project: the COVID-19 Protocol Library, the COVID-19 Variable Compare Tool, and the COVID-19 Research Collection. But before I get into those, I just want to provide some background.

Slide 3

So what PhenX stands for is consensus measures for phenotypes and exposures. So this project - the entire project has been funded by NHGRI since 2007. It was really driven by the scientific community who contributed and recommended measures that can be used with confidence and cover a variety of research areas.

We promote this idea because study findings always require validation where you would like to compare the studies and make sure that you are essentially getting the same results based on what you're asking.

And, of course, related to that if you have a bigger sample size, you would have more statistical power and more - their validation of the results. And the idea behind PhenX is in support of the National Institutes of Health's FAIR principles, which stands for Findable, Accessible, Interoperable, and Reusable.

Slide 4

So what PhenX is: it is a catalog of recommended measurement protocols. So basically survey instruments and other type of ways of collecting data. It was developed by the scientific community through a consensus based process and it is a web-based resource for a website that is public, fully available, and anyone can use it. What PhenX is not is a new set of standards. It's not a new ontology of the types of exposures. It does not provide any sort of data or bio specimens. It is not restrictive. Obviously investigators can feel free to use other protocols that they so wish to use. And is not proprietary so there is no cost to use the toolkit.

Slide 5

The first component of the COVID-19 project began with the COVID-19 Protocol Library. The goal of this Protocol Library - it was launched in collaboration with the NIH DR2 and it was to provide a listing of all the available COVID-19 measurement protocols that were submitted to NIH so that way people could have easy access to view them, download them, and ideally, use these existing protocols versus developing new protocols. As we know during COVID-19, there was a lot going on in trying to understand the pandemic. Not only the disease itself, but its impact on society. So this is what the library provides. And I also want to point out that, for example, we do have filters and we also have a search option where you could search by keyword for protocols that would [apply] based on your search.

Slide 6

Due to the development of the COVID-19 Protocol Library this informed and led to the development of the COVID-19 Research Collection. There were a lot of protocols in the library but we wanted to provide a more concise collection that was focused on key topic areas that people were focused on from the pandemic. So we end up basing the Research Collection from library instruments we crowdsourced to define the categories. We then had our PhenX steering committee review the categories. We then conducted another round of crowdsourcing to identify protocols for each of the prioritized collections for which are the different categories that were identified. And then the steering committee reviewed the protocols that we identified and we finalized the collection.

Slide 7

So here I'm just showing you the Collection's landing page. As you can see, there are six collections that were formed: Behaviors and Risks; Ethnicity, Race and Demographics; History, Treatment and Outcomes; Information Resources; Psychosocial and Mental Health; and Socioeconomic. And it's also recommended

that researchers who are interested in using these collections for COVID-19 related research also consider using the Social Determinants of Health Core research collection.

Slide 8

Just a quick overview - very brief - if you're to go to any of those collections you would encounter a page similar to this. You'd see the list of available protocols that are part of that and you can see that these protocols in this case are all related to the higher level category of behaviors and risks. And this is just an example of what you were to view if you were to click on a single protocol in this case this is for COVID-19 knowledge attitudes and avoidant behaviors. And the information about the protocol is spread across the different tabs and this includes, you know, description, the actual protocol itself, how to administer the protocol, additional details, resources, references, and so on.

Slide 9

Finally, I would like to present the COVID-19 Variable Compare Tool. Now, there are three functions: the keyword search, side-by-side comparison, and the compare questionnaires. I'm just going to really quickly go over them just because it will be hard a little bit to see the text because I'm trying to show the whole web page. But I do encourage you to when you have a chance to explore the tool yourself.

Slide 10

So the keyword search - fairly straightforward. You type in a keyword and it provides variables at the question level of ones that match your search.

Slide 11

We then have a side-by-side comparison. Again, fairly straightforward you can pick two protocols and compare them side by side and see how much overlap there are between the protocols. And it's also broken down, for example, by identical comparable and related variables. So the identical meaning that they're exactly the same, you know: what is your age - what is your age. Same thing. Comparable is: what is your age versus when you are born. You know, if you manipulate that a bit you can get the same answer. And related are questions that fall under a similar topic but you really can't compare them and that they're not really getting the same exact data.

Slide 12

And then finally we have the Compare Questionnaires which provides a heat map view of the similarity across all the protocols. You can either view them all in a single heat map or you can specifically pick which protocols you want to compare and it can be anywhere from only two up to all of them.

Slide 13

So I'd like to just acknowledge the different groups that contributed to the project. We have our the project scientists from NHGRI. We have our steering committee. There have been 29 research domains, so 29 working groups and member groups that have contributed to PhenX over the years. The IC Liaisons as well as additional Supplements and Specialty Collections that have provided funding for PhenX . And I also want to acknowledge our RTI team: Carol Hamilton who is the PI; Tabitha Hendershot and Wayne Huggins who are Co-Is; and obviously, myself. I was a Co-I for the COVID-19 project.

Slide 14

And feel free to check out the PhenX toolkit website it could be found at the URL listed here on the screen: www.phenxtoolkit.org.