**From:** Heather Hufstedler <heather.hufstedler@uni-heidelberg.de>
**Sent:** Friday, February 4, 2022 12:06 AM
**To:** Pena, Andressa Z <azp12@pitt.edu>; Meetings <Meetings@hl7.org>; HL7Headquarters <hq@hl7.org>
**Subject:** Re: Consortium Invite: Assessment of Data Standards' Demands

Hi, good morning.

Thank you for sending these invitation, Andressa.

To whom it may concern at FHIR, we would value involvement from your team in the March 11th meeting. So, if you could please get back to us within 2 weeks as to whether this would be possible, that would be great. If not, there may be other opportunities to connect down the line.

Best wishes,

Heather

**From:** Pena, Andressa Z <azp12@pitt.edu>
**Sent:** Monday, January 31, 2022 3:01:39 AM
**To:** Meetings@HL7.org; hq@HL7.org
**Cc:** Heather Hufstedler
**Subject:** Consortium Invite: Assessment of Data Standards' Demands

Good morning Dear HL7,

I hope this email finds you healthy and safe. My name is Andressa. I am an intern with the ReCoDID consortium. Heather, in cc, is the program manager for WP3.1 on data standards and harmonization. We are looking forward to connect with you to move an idea forward.

**Current work:** Our consortium ReCoDID is entirely focused on infectious disease data. One work package is mainly focused on pooled individual-level data from several studies. In another work package, we are exploring the current implementation of causal inference/quasi-experimental methods, as well as, the methods researchers are implementing to account for measurement errors and missing data. Currently, we are documenting present-day practices but also shining a light on a few examples where these methods could be improved.

In this work package, of data harmonization and standardization, Heather Hufstedler had the great pleasure to work with other stakeholders over the last 2+ years, conducting their own IPDMAs and standardizing data sets, discussing current practice and future possibilities for data standards related to observational or nested observational infectious disease studies.

**Your contribution:**

* Current issues: While implementing these data standards with our own data *and* as we work to create standardized CRFs for use in future studies, we have seen tradeoffs (rather than pros and cons) of each data standard. And unfortunately, uptake in other smaller, less well-funded studies may be low due to cost of lack of understanding of the standards. One positive thing that has come out of Covid is that many more researchers, even outside the infectious disease field, have realized the importance of sharing, harmonizing and standardizing individual-level data. But without resources, where do smaller studies begin to understand what is best for them without wasting more resources? As more attention is paid to all of us, what can we do improve currently-existing standards to accommodate specific needs of infectious disease observational studies.

* The work envision: Two main malleable ideas: the first idea is to discuss and collectively publish, similarly to a [methods](https://nam12.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.sciencedirect.com%2Fscience%2Farticle%2Fpii%2FS2352827319301545%3Fvia%253Dihub&data=04%7C01%7Cazp12%40pitt.edu%7Cb465f18489ab4e72862408d9e119e7f0%7C9ef9f489e0a04eeb87cc3a526112fd0d%7C1%7C0%7C637788324574204439%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C2000&sdata=3mIDR1AXIkm9zMN%2FurWvbLpbKBn2Wd%2Fa%2ByN8eoZudxQ%3D&reserved=0) article our colleague published, the tradeoffs of each standard. The second idea, we make suggestions on how the current data standards can be improved for observational infectious disease studies. Nothing groundbreaking or set in stone, but we hope to identify data standard to help all stakeholders.

* When: We are meeting virtually to discuss these issues on **March 11th, 2022 from 14:00-18:00 CET**. We already have commitment from 5 standards—Maelstrom, CDISC, LOINC, SNOMED and a division of OMOP. We would love for you to join us.

If you can join, please let us know and we will send you a calendar invitation along with the agenda and information for a 3-slide presentation for all, by February 15th.

We are looking forward to connecting with you.

Andressa Pena

MPH Graduate Candidate, IDM-PEL/Research Specialist III

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