

**The Mary Tyler Moore Vision Initiative Workshop on Data**

**May 7, 2024**

**Seattle, WA**

**Title: Data Harmonization, Standardization, and Collaboration for Diabetic Retinal Disease (DRD)**

*Accelerating the development of new indications, therapies, and regulatory pathways*

**Objective:** To outline best practices and specific considerations for building a large, shareable MTM Vision data lake, including methods for clinical data standardization and harmonization of 'omics analyses.

**Location:** **Seattle Central Library** (Level 4, Meeting Room 1), a short 0.4 mile (9 minute) walk from the Seattle Convention Center. Seattle Central Library Address: 1000 4<sup>th</sup> Ave, Seattle, WA 98104.

**Date and Time:** Tuesday, May 7, 2024 from 10:30am – 1:00pm Pacific Time.

**Workshop Structure:** 30 min for each major topic, with 1-2 presentations, a panel discussion and then time for focused group interaction guided by pre-specified questions.

---

**AGENDA:**

**10:30 AM**

**1. Setting the stage (10 min.)**

Introductions and Welcome

- **S. Robert Levine, MD**, Founder and CEO, Mary Tyler Moore Vision Initiative
  - Major goals of MTM Vision.
- **Michael Chiang, MD**, Director, National Eye Institute, National Institutes of Health
  - Importance of data harmonization, standardization, and collaboration.

**10:40 AM**

**2. Building a data lake (30 min.)**

- Speaker: **Aaron Lee, MD MSCI**, Associate Professor of Ophthalmology, University of Washington, PI of NIH's Bridge2AI AI-READI project
- Panel Moderator: **Jennifer Sun, MD, MPH**, Science Co-Director, Mary Tyler Moore Vision Initiative; Associate Professor of Ophthalmology, Harvard Medical School; Chair, Diabetes Initiatives, DRCR Retina Network
- Panelists:
  - **Sally Baxter, MD, MSc**, Assistant Professor of Ophthalmology, University of California San Diego
  - **Drew Lewis**, Co-Founder/President, Estenda Solutions, Inc.
  - **Paolo Silva, MD**, Assistant Chief of Telemedicine, Betham Eye Institute, Joslin Diabetes Center; Associate Professor of Ophthalmology, Harvard Medical School

- Topics for Consideration:
  - What are the important considerations in data acquisition for clinical data, images, and 'omics data?
  - How do we structure the data lake to best promote future sharing of this resource?
  - Who will contribute to the data lake? How does this relate to other ongoing efforts?
  - What are the qualifications that will make data/cohorts eligible or ineligible for participation?
  - Will the data lake be centralized or decentralized?

**11:10 AM**

**3. Data standardization (30 min.)**

- Speakers: **Kerry Goetz, MS**, Associate Director, NEI Office of Data Science and Health Informatics and **Brian VanderBeek, MD, MPH, MSCE**, Assistant Professor of Ophthalmology, University of Pennsylvania Scheie Eye Institute
- Panel Moderator: **Thomas Gardner, MD, MS**, Science Co-Director, Mary Tyler Moore Vision Initiative; Professor of Ophthalmology and Visual Sciences, University of Michigan
- Panelists:
  - **Michelle Hribar, PhD**, DATA Scholar, National Eye Institute; Associate Professor of Ophthalmology and Medical Informatics and Clinical Epidemiology, Oregon Health & Science University
  - **Emily Chew, MD**, Director of the Division of Epidemiology and Clinical Applications, National Eye Institute
- Topics for Consideration:
  - What will it take to standardize the data in the MTM Vision data lake?
  - To which common data element models should MTM Vision data be mapped (e.g. CDISC, OMOP, etc.)?
  - What are the considerations in mapping clinical trial/study data vs electronic health record datasets?
  - What is the status of other major ophthalmic data efforts in terms of standardization and are there opportunities to collaborate with these groups?
  - What are the potential use cases for reuse of the data that are collected?

**11:40 AM**

**4. Break & Lunch (15 min.) [working lunch to continue during discussion]**

**11:55 AM**

**5. Standardization of sample collection, characterization, and storage and 'omics analyses for ocular tissues and fluids (30 min.)**

- Speaker: **Jeffrey Sundstrom, MD, PhD**, Assistant Professor, Pennsylvania State College of Medicine
- Moderator: **Patrice Fort, PhD, MS**, Director, Mary Tyler Moore Vision Initiative Biorepository & Resource Center; Associate Professor of Ophthalmology and Visual Sciences, University of Michigan.
- Panelists:
  - **Vinit Mahanjan, MD, PhD**, Professor of Ophthalmology, Stanford Medicine
  - **Stephen Kim, MD**, Phyllis S. and William B. Snyder Chair and Retina Division Chief, Vanderbilt University Medical Center
  - **Remko Bakker, PhD**, Director CardioMetabolic Diseases Research, Boehringer Ingelheim

- Topics for Consideration:
  - What ‘omics analyses should be performed/encouraged for ocular tissues and fluids in eyes with DRD?
  - What are the best ways to encourage collaboration between groups performing ‘omics research in ophthalmology?
  - What are the considerations in creating ‘omics datasets that will ensure harmonization of data and the ability for easy sharing?

**12:25 PM**

**6. Opportunities for collaboration with NIH, FDA, foundations, international organizations, and industry (30 min.)**

- Panel Moderator: **S. Robert Levine, MD**, Founder and CEO, Mary Tyler Moore Vision Initiative
- Panelists:
  - **Thomas Brunner**, President and CEO, Glaucoma Research Foundation
  - **Ulrich Luhmann, PhD**, Biomarker Experimental Medicine Leader, Translational Medicine Ophthalmology, Roche Innovation Center
  - **Tunde Peto, MD, PhD**, Professor of Clinical Ophthalmology, Queens University Belfast, EA Study of Diabetic Eye Complications Study Group; ESAB
- Topics for Consideration:
  - How can MTM Vision coordinate efforts with NEI and FDA to encourage the standardization of ophthalmic data and build shareable data warehouses for ophthalmic efforts?
  - How can we strengthen existing or build new collaborative efforts with NIH, regulatory agencies, industry, and international organizations that encourage data standardization and sharing of datasets?
  - Are there potential RFAs that would be of interest to NEI and/or NIDDK around the creation of data lake resources? Are there any funding mechanisms available from regulatory bodies for these types of activities?
  - How do we incentivize data sharing across clinical practices and academic centers? Are there NIH initiatives that can be developed to encourage a data-sharing culture?

**12:55 PM**

**7. Summation and next steps (5 min.)**

- **Jennifer Sun, MD, MPH**, Science Co-Director, Mary Tyler Moore Vision Initiative; Associate Professor of Ophthalmology, Harvard Medical School; Chair, Diabetes Initiatives, DRCR Retina Network

**1:00 PM**

**8. Thank you and invitation to MTM Vision Fall Symposium**

- **S. Robert Levine, MD**, Founder and CEO, Mary Tyler Moore Vision Initiative

***Thank you for participating today!***

We hope to see you again for  
**The Mary Tyler Moore Vision Initiative Annual Symposium on Curing Vision Loss from Diabetes**  
 November 11 – 12, 2024 for  
 Ann Arbor, Michigan