2024 Election for Board Director

Candidate: Rachel Richesson

Professional Title & Affiliation

Professor, University of Michigan Medical School

Personal Statement / Short Biography

I have formal training in Public Health (MPH) and Biomedical Informatics (MS and PhD). I have been a faculty researcher and educator at 3 different universities. In my current position as Professor in the University of Michigan Medical School Department of Learning Health Sciences, I teach classes on data standards, system interoperability, and technical and social infrastructures to support biomedical discovery and learning health system activities.

For many years, I worked as part of a data coordinating center for clinical trials and networked research, and used this experience and my participation in AMIA working groups and conferences - to develop the Clinical Research Informatics textbook (Springer 2012, 2019 and 2023). I led data standardization efforts for several multi-national multi-site clinical research and epidemiological studies, including the NIH Rare Diseases Clinical Research Network (RDCRN). I was co-chair of the RDCRN Standards and Registry Committees, and interacted with standards development organizations to represent the perspectives of both clinical research and rare diseases. I helped design and implement the RDCRN Contact Registry for over 150 rare diseases. I have over a decade of experience with patient registries and engagement of patient advocacy organizations in research and serve on the advisory boards for several registry programs. Over the past 3 decades, patient advocacy organizations have transformed research processes and outcomes, and I am excited at the possibilities for patient-led innovation and transformation of health care through technology that I see in my current service with the HL7 Patient Empowerment Work Group.

I look forward to the opportunity to continue my service as an AMIA board member for a second term. I particularly want to continue to advance the work of the AMIA Journals & Publications Committee and the HL7 Partnership. The need to transform our health care system is enormous and urgent, and will only be achieved with modernized and standards-based EHR systems and a workforce of professionals that can optimize and leverage these systems to generate new knowledge (through research, including observational research and embedded pragmatic clinical trials) and deliver this knowledge when and where it is most needed. I believe AMIA should continue to lead and support the education, training, and policy initiatives around the development and implementation of data standards necessary for a national learning health infrastructure. My experience from multiple collaborative research networks, data standards development, and use of EHR data in pragmatic clinical trials gives me a unique perspective to realize to this vision. Further, I see tremendous and unrealized opportunity to engage patients both as users of EHR systems and the ultimate stakeholders of learning health systems in the science, education, and the practice of informatics.

Please describe your leadership skills and experience, inside and outside of AMIA

I have directed the implementation of data standards for many multi-site and multi-national clinical research and epidemiological studies, including the NIH Rare Diseases Clinical Research Network (RDCRN) and The Environmental Determinants of Diabetes in the Young (TEDDY). I was co-chair of the RDCRN Standards and Registry Committees, and interacted with standards bodies and other organizations (e.g., HL7, CDISC, IHTSDO (SNOMED), LOINC) to represent rare disease needs. I worked with the Patient Centered Outcomes Research Network (PCORnet) to develop approaches to use EHR data and systems in research, with emphasis on data quality assessment and validation of computable phenotypes. Currently, I lead the EHR Core for the NIH Health Systems Research Collaboratory, which is developing methodologic guidance for using EHR data and systems in pragmatic clinical trials. I also serve as Vocabulary Facilitator for the HL7 Patient Empowerment Group, which projects patient voice in standards development and promotion.

Please describe your experience and accomplishments in informatics

I have over 100 peer reviewed journal publications and conference papers and have served on numerous AMIA committees and scientific program committees. I hold an academic position in the rank of professor and have been selected to serve on various NIH and federal grant review committees. My reputation for excellence in informatics is best illustrated by my election as a Fellow of the American College of Medical Informatics in 2014.

I am most proud of my work developing training and infrastructure for clinical research. For many years, I worked as part of a data coordinating center for clinical trials and networked research, and leveraged this experience and my participation in AMIA working groups and conferences - to help define the field of Clinical Research Informatics, co-editing the first textbook with that title (Springer 2012) with updated versions in 2019 and 2023. I helped design and implement the RDCRN Contact Registry for over 150 rare diseases. I have over a decade of experience with patient registries and engagement of patient advocacy organizations in research and serve on the advisory boards for several registry programs.

Share any unique skills or perspective you bring to this role

My informatics interests coalesce around the goal of making clinical research more efficient and relevant for clinicians and patients. This includes the use of EHR data for research and methods for generating real-world evidence from pragmatic clinical trials embedded in health care systems. I am passionate about the need to leverage and apply data representation standards that can enable the rapid aggregation of data for more powerful studies that will generalize to individuals and populations in the real world, as well as knowledge representation standards that will facilitate the dissemination and adoption (e.g., through automated clinical decision support tools) of effective practices and interventions.

Please describe your teamwork experience and skills

I am a team scientist. I have experience from multiple collaborative research networks and participate in consensus-based standards development organizations. I thrive in multi-disciplinary and multi-stakeholder environments. I value and respect opinions and perspectives from others.

Having served a prior term on the AMIA Board of Directors, I recognize that I represent members of the organization and must act with loyalty to and in service of the AMIA organization.

AMIA Engagement and Participation
AMIA member – More than 20 years
It was my honor to be elected and serve as member of the AMIA Board of Directors from 2021-2024. I served as Board Liaison to the AMIA Journals & Publications Committee, which uses standardized metrics and interviews with editors to assess their performance and the value, relevance, and responsiveness of AMIA-affiliated journals. I also supported the committee to develop a process for evaluating existing journals for endorsement by AMIA to support provide AMIA members a trusted source of biomedical informatics research. This process was used to designate the Journal of Biomedical Informatics as an AMIA-endorsed journal and moving forward provides a mechanism to expand the portfolio of AMIA-endorsed publications so that members continue to see AMIA as the trusted source for informatics knowledge and research in emerging areas. I have also served as Board Liaison to the AMIA-HL7 Partnership, supporting the FHIR App Competition in the AMIA Annual Symposium and exploring opportunities for training around HL7 data exchange standards and workforce development for FHIR implementation.

Prior to my service on the AMIA BOD, I have held a number of service committee positions over the years, including: Clinical Research Informatics Working Group (Secretary, 2010-2012), AMIA Leadership Task Force (2105), AMIA Academic Forum, Publications Strategy Task Force (2016), AMIA Journals and Publications Committee (2018 â€" 2021), Morris Collen Award Selection Committee (2018), Planning Committee for the AMIA Policy Invitational Summit (2016), Contributor/writer for the AMIA Health Policy Principles and Positions document around data standards (2016), and the AMIA Advisory Group on Health IT Standards (co-Chair, 2016-2017). I also served on the JAMIA editorial board (2013 -2015). I have supported the planning and content of AMIA conferences and symposia by serving on the Scientific Program Committees for the AMIA Clinical Research Informatics Summit (2010 & 2013, Track Chair in 2011) and the AMIA Annual Symposium (2012 & 2014).

Areas of Expertise
Clinical Research; Clinical Trials; Electronic Health Records; Interoperability; Knowledge Representation; Registries; Research