2021 Election for Board Director

**Candidate**
Rachel Richesson

**Professional Title And Affiliation**
Professor, University of Michigan Medical School

**Personal Statement**
I consider AMIA my professional home. The knowledge and insights that I have gained from fellow AMIA members and AMIA-sponsored meetings are immeasurable. AMIA meetings and communication channels have given me a forum to share my work and ideas, find collaborators, ask questions, and learn. Through the AMIA organization and activities, I have amassed a rich professional network of peers, mentors, advisors, and friends that have informed and aided my career goals, motivated me to face new challenges, and offered me opportunities to contribute to advancing the field of informatics through science, education, and policy. As an AMIA Board Member, I would like to contribute to the health and well-being of AMIA to ensure that it will continue to develop informatics students and professionals that can address emerging health problems and inequities. I bring perspectives around pragmatic (embedded) clinical research, data standards, and inclusion of patients as critical stakeholders, users, and enablers/sponsors of standards-enabled clinical research.

My perspectives derive from my roots in public health and recognition of the need for clinical research to advance our understanding of health, disease, and intervention, and ultimately to improve population health. Informatics can improve not only the efficiency and conduct of research (especially through methods to embed research into health care activities without burdening busy clinicians), but also the widespread dissemination and integration of research results into practice – potentially reducing the adoption time for evidence-based practices from years to days. The AMIA organization and its many talented members can support the growth in informatics workforce and infrastructure, and the evolution of informatics practice and policies, to realize the vision that every patient – whether at the smallest clinic in the smallest town or at the largest or most prestigious academic medical center – can benefit from data-driven and personalized care - informed with current and relevant knowledge – at the precise time and place it is needed.

Data standards are vital to realize this vision. This includes standards for how we collect and exchange data, as well as standards for representing knowledge in ways that it can be integrated into health information systems for meaningful action. There are numerous data standards and many approaches to standards adoption. Despite their potential value, clinicians’ frustration with documentation and systems is undeniable. New research showing that some EHR user features can help ease this burden and reduce workload provides source of
hope that future systems that can improve health. Balancing provider needs with the potential public impact of standardized data collection in a complex ecosystem is a challenging dilemma that AMIA should help inform. I believe my knowledge and experience with data standards can help AMIA navigate this ongoing challenge.

I also believe that the informatics-driven transformation and improvements of health will be enabled by patients and consumers and I see that the evolution of AMIA will be strengthened with their input and engagement. In my work with rare diseases research, I witnessed the power of patient advocacy to accelerate - and transform – biomedical research. I believe that patients and healthcare consumers can make similar impacts in health informatics and the adoption of data standards. Warner Slack noted (1997) that patients are the most underutilized resource in health care. I agree and further envision that patients to be an important force toward optimizing EHR systems for care and research. With access to their clinical data via the 21st Century Cures Act and subsequent regulations, patients and health consumers will become recognized EHR “users” (via patient portals), will take more responsibility for their care, and ultimately will be the evaluators of the “value” of care (via patient outcomes and alignment with preferences.) To advance the mission of transforming and improving health through informatics, AMIA will need to engage with patient advocates and be thoughtful of patient users and impacts. I can help facilitate this with my affiliation (as volunteer) with HL7 Patient Empowerment Workgroup (PEW), which is committed to bring the patient perspective and patient-centered use cases into the standards development process. The HL7 PEW is driving innovation and representing an important user base, and I would be honored to liaise and facilitate collaboration between AMIA and these very important perspectives and stakeholder groups.

**Informatics Interests**

My informatics interests coalesce around the goal of making clinical research more efficient and relevant. 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., with automated clinical decision support tools) of effective practices and interventions.

**AMIA Engagement and Participation**

I joined AMIA as a student in 2000, and am grateful for the many professional development and leadership opportunities I have had in the areas of informatics research, education, and policy. Over the past 20 years, I have submitted and presented many posters, papers, and panel presentations at AMIA conferences and annual symposia, and have served as a reviewer for many of these conferences. 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).

I also contributed to the AMIA 10x10 professional education program by developing a CME eligible online course (“Data Standards for Learning Health Systems”) and offering it four times during 2017 – 2019.

**Participation in other organizations**
I am an active member of the Health Level Seven (HL7) standards development organization, and am currently the vocabulary facilitator for the Patient Empowerment Working Group.

I was inducted into the American College of Medical Informatics (ACMI) in 2014, and chaired the Program Committee for the ACMI Winter Symposium (“Collaborative Science: Informatics Challenges for Data and Knowledge Integration”) in February 1-4, 2018. Scottsdale, AZ. I served on the ACMI Election and Nominations Committee (2016-2018).

My past organizational memberships include the Clinical Data Interchange Standards Consortium (CDISC), the American Public Health Association (APHA), and the World Wide Web Consortium (W3C), Health Care and Life Science Interest Group (HCLS).

**Education and Experience**
I have formal training in Public Health (MPH, 1995) and Biomedical Informatics (MS, 2000, and PhD, 2003) from the University of Texas Health Science Center at Houston. 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 help define the field of Clinical Research Informatics, co-editing the first textbook with that title (Springer 2012 & 2019). I directed the use of data standards in multinational multi-site clinical research and epidemiological studies, including the NIH Rare Diseases Clinical Research Network (RDCRN) and The Environmental Determinants of Diabetes in the Young (TEDDY) study. I was co-chair of the RDCRN Standards and Registry Committees, and interacted with standards development organizations (e.g., HL7, CDISC, IHTSDO, LOINC) 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.

I have implemented and evaluated SNOMED CT and RxNorm in research settings, and explored the coverage of these coding systems for various research projects. As part of the PCORnet Coordinating Center, I helped develop and promote standardized approaches for cohort identification using EHRs in clinical and health services research. Currently, I co-lead the EHR Core for the NIH Health Systems Research Collaboratory, which is developing generalizable methods for pragmatic clinical trials (embedded within health systems and using EHR data and systems). I also co-lead the Mobilizing Computable Biomedical Knowledge (MCBK) collaboration of diverse stakeholders working toward an ecosystem where computable knowledge can be used safely and at scale to improve health.

**Recent Publications**


**Honors and Awards**

Fellow of the American College of Medical Informatics (FACMI), 2014.

University of Texas Dean’s Scholar Award, 2016.
Evidence of Strategic Thinking/Experience in Activities of AMIA or another non-profit or institution

I have served on 2 different AMIA committees (Publications Strategy Task Force, Journals and Publications Committee) that report to the AMIA Board.

I worked with other AMIA members and staff to submit responses and opinions on behalf of AMIA. In 2014, Dr. Phillip Payne and I submitted a response to NOT-ES-15-002 (“Making Data Usable – A Framework for Community-Based Data and Metadata Standards Efforts for NIH-Relevant Research”) on behalf of AMIA. Along with other AMIA members, I contributed to the following responses from the AMIA Public Policy Committee:


Contributions to Activities that Support Diversity, Equity, and Inclusion

I have had the opportunity to work for two different universities that have made organizational commitments to diversity, equity, and inclusion. At the Duke University School of Nursing (DUSON), under the strong leadership of Dean Marion Broome, I witnessed deliberate action and subsequent organizational and cultural changes toward diversity and inclusion, several years before many other schools adopted such approaches. I was fortunate for the experience to participate in these organizational changes through my role on the Faculty Search Committee. I helped to draft procedures, documentation, and evaluation plans that would ensure that our processes for screening, interviewing and evaluating faculty candidates did not disadvantage candidates from under-represented races or ethnic backgrounds. As a committee and a school, we deliberately changed how we searched and evaluated candidates, and inserted explicit points throughout the process for thought and reflection– to ensure that we were aware of biases that might influence how we interact with and assess applicants and faculty that represent diverse – and often non-traditional – academic or faculty backgrounds. To move toward retaining a diverse faculty, our Dean and leadership set the tone and expectation for an inclusive environment. We added a “statement” to our annual faculty evaluation about contribution to the principles of diversity, equity, and inclusion that are embraced by our university. This was a step to stimulate thinking and reflection about the values of diversity equity and inclusion, and has served to build an organizational culture that appreciates these values. After a few years’ time, I witnessed acceptance and ultimately an embrace of this “diversity statement” as an opportunity for personal growth and professional responsibility to contribute time, thought, and energy toward these values and ideals. Dean Broome routinely hosted events to raise awareness of diversity and promote personal, professional and organizational achievements of faculty/staff from diverse background and regular “diversity conversations”. Through my participation in these events, I have watched the
conversation shift from diversity (goals and targets) to inclusion and now to equity (DEI). I am new to the University of Michigan, but already I see that we have dedicated resources to promote DEI principles across the university – most departments having one or more designated DEI facilitators with creative ideas for activities that stimulate reflection and action around DEI values among faculty, staff, and students. My experience in multiple organizations has shown me that organizational and cultural change requires intentionality and takes time, discussion, and iteration. AMIA leadership has committed to principles of diversity and inclusion. I am excited to support new and existing strategies, including AMIA’s high school scholars and first look programs, that can attract new AMIA members from diverse backgrounds and nurture future leaders.

Looking outward, AMIA and its members have tremendous potential to impact health equity. One important component of health equity is the need for research findings and innovation (e.g. predictive algorithms, decision support) to be relevant to different and diverse populations. To be relevant, the data used to build these insights must reflect patients from diverse races and ethnicities. Recruiting diverse patients into research studies has been a known issue in clinical research for decades, and remains a challenge despite the many policy, research and community approaches to address. There is growing clarity (facilitated by many AMIA members) that failing to include data from African Americans in the development of data-driven and technology-enabled health care innovations can cause harm and increase health disparity. AMIA can impact health equity by promoting informatics practice standards that ensure that diverse patients are represented in research and that we actively look to assess the impact of informatics applications on diverse and vulnerable populations.