CARE CULTURE & DECISION-MAKING INNOVATION COLLABORATIVE:

NAM Working Group on Technologies to Enhance Person, Family, & Community Engagement
January 17, 2019 Meeting Highlights

MEETING FOCUS: Engagement of the health care system leadership, resources, and partnerships for the creation of an equitable health system in which technology enables seamless engagement of patients, families, clinicians, and community resources as partners on behalf of transformative progress in health and health care.

Motivating questions:
1. *Purposes*: What is the potential for technologies to advance equity and the empowerment of persons, families, and communities in health and health care? What is the potential for technologies to tactically enhance the equitable personalization and quality of medical decisions?
2. *Practices*: Which examples best illustrate transferable lessons on how to achieve success and avoid harm?
3. *Strategies*: What core tenets and resulting interdisciplinary actions are necessary to build a future environment of equitable, technology-enabled, participatory health and health care?
4. *Improvements*: What gaps and issues need to be urgently acted upon to avoid harm and achieve progress, and what stakeholders or disciplines must be involved in this action?

Outcomes anticipated: Continued refinement of the scope, aim, and underlying themes of three discussion papers.

REPRESENTATIVE OBSERVATIONS

Discussion of draft: Technologies facilitating a person-centered model of information exchange

- This paper emerges from the concern that today's fragmented, poorly protected, and impersonally managed health data silos are colliding head-first with a consumer market that borrows from advertising and technology business models to influence user behavior. The goal is to move towards a future where ongoing technological innovation could allow cross-institutional care teams to seamlessly share data and care plans with patient consent or facilitate creation of apps and wearables that gently nudge better behavioral choices to reverse decades of sedentary habit-building cues. (MS, LS)

- The goal of the paper is to define cross-sector approaches to data management that centers individuals as the agents of their experience. It is to portray a broader landscape through a focus on the ubiquity and centrality of personal data, showing that it is no longer prudent nor possible to envision health and health care in a silo. In arguing for the benefits of person-centeredness in data use and health tech design, development, and deployment, the writing group will cast it not just as ethically and morally right but also as a competitive advantage. (MS, LS)

- In the United States, the patient is not generally the direct purchaser or payer for health care. Adding a consideration of the payer sector brings up questions about who is the "customer" in a model of information exchange. (S. Badlani)

- There are new concerns about protection of direct health information; a pending patient access bill states all clearinghouse data should not be HIPAA-covered. There is the potential to create a framework for the ethical use of data across sectors, with attention paid to questions of interoperability and ethical use there. Shifting the perception to regard errors in data as medical errors, and coding them accordingly, might prompt action. (LKH)

- This brought up the topic of existing standards like HIPAA, the HITECH Act of 2009, and ONC standards released in 2011, 2013, and 2016, which are not widely utilized. The challenge is to resolve the inherent tension between data as a public good and the bottom-line interests of the tech companies who are best positioned to leverage that data. (SB; AC; SL)

Discussion of draft: Technologies as core to the state infrastructure addressing health disparities

- This paper looks to address the lack of a national electronic surveillance or registry system for health disparities; this leads to a fragmented system that relies heavily on unstructured data, is highly subjective with varying degrees of semantic consistency, and typically has errors and limited consistency because data are manually inputted. (TC, GD)

- New technology does not always lead to better outcomes; health information exchanges do not necessarily improve function. It is important to think about global standards, like those being put out by AHiMA, and consider how the metrics can be transformed into state standards. (TC)

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- The ACA tried to build in standards for technology, in Section 1561, but not a single state is using common standards. A consumer-directed exchange seems to be the best way of ensuring state and federal collaboration, but there's been no ongoing conversation about how to do it. That has led to states and federal agencies spending millions to create algorithms on SES and social determinants that are vendor-led and not reproducible, leading to wasted effort and resources. (AC)
- There are substantial issues driving state disparities; what we see reflected in differential health outcomes is driven by differential access to health care, difference in the kind and quality of care delivered, disparity in Medicaid expansion and rollout, etc. Authors were cautioned against recreating the same access and disparity problems we see in the physical world in the digital arena. For true scaling of digital health to provide broad access and maximum effect, coverage and payment by private and public payors are a must, and work is ongoing to create billing codes to facilitate this. Giving digital health tools to public health workers and FQHCs is good, but not sufficient to achieve scale. Some states with the highest need also have the most acute coverage issues (i.e. uninsured in Medicaid non-expansion states). It is important to insure that new tools are developed specifically with all populations, including the vulnerable, in mind so that the tools are relevant and accessible to these groups. (JR)
- Over-reliance on AI/ML (Artificial Intelligence/Machine Learning), where the learning data sets may have historical bias, might result in promoting continued disparities, because historical prejudice is being "baked in": the difference between profiling and risk adjustment is slight. Having a human involved in the process of building these complex systems is important. "Automating Inequality" by Virginia Eubanks describes this in more detail. (LKH, STI).
- Information on a wide range of social determinants is not found in neat boxes in EHRs, meaning it is difficult to share and compare across settings. There is a potential for a consumer-designated app using a FHIR API to do this, but so far this potential has not been realized. (JM)
- In these papers, it is necessary to establish a vision for the role of people as central actors in health care, and describe it from various perspectives, with particular attention given to making sure it functions for those who face other barriers, such as low digital literacy or who are non-native English speakers, etc. (MQ)

Discussion of the draft: Technologies tailored to engagement throughout the lifecycle
- There is an emerging realization that social determinants are essential in a complete approach to health, yet disparities and structural disempowerment persist, transmitted from paper processes to the data and code of our health systems and health relevant technologies. To realize an equitable future, we must articulate goals through a humanitarian lens and on a foundation of equity, anchoring these tenets into the design and implementation of health relevant technologies. These technologies allow us an opportunity to bring technology and health into people's lives, rather than attempt to fit our growing diversity through the narrow gates of a health care system. (JM, STI)
- The focus of this paper is on changing the frame from, "What data could have changed this negative outcome" to "What actions taken based on this data could have changed it." It is one thing to have accurate measurement of data presented in an actionable way for leadership and frontline providers, but it is different for the data to be presented in a way that empowers persons and families. This paper discusses getting data transparency to a point where people receiving health care are empowered, and are not reliant on providers or health system leadership to take action to improve care. (JM)
- Caution was raised that new technologies can be deployed well or deployed poorly. Using TeleDoc as an example, it is scaling up telehealth care for people with colds who want unnecessary antibiotics but not for the problems that really need more access (chronic disease such as diabetes), and is providing fragmented rather than coordinated care. Telehealth has enormous potential, but current market forces aren't necessarily scaling the best uses of telehealth or serving the populations most in need. (JR)
- In addition to talking about using data to address disparities from an architectural, systems-level perspective, it is also important to think about innovation, around the use of those data and by whom, and how to bring those innovations out to the people who can use them. Three recent use cases of innovation were presented, ranging from drones delivering medical supplies in Rwanda, to using predictive analytics to call Ubers to get patients to dialysis, to analytic models being supplemented by a human visit to identify gaps in public transport in Baltimore. (SP)
- Sylvia Trujillo shared her experience caring for a relative with a genetic illness. As someone who works at the AMA, with a high degree of education, good health literacy, and experience in navigating the compilation of health care delivery services, she believes that simple health literacy on the part of patients is not the issue. Rather, it is the issue of frictionless

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integration and coordination within health care system: we need to build solutions that feature user centered design. Her problems accessing care were the same ones that low-income people with low levels of education would have. She strongly suggested framing the discussion to make clear the <u>system</u> has a deficit, not the humans who are using it. (ST)

- The role of data standards is critical. Medical forms have extensive duplication, and theoretically it is possible to have a standard form that enables auto-population. This could be applied to creating a standardized tool to measure SDOH. However, a lack of interoperability between systems means it is not currently feasible. Technologically, it's simple, but consensus needs to be built, and entities such as the VA have an outsize role in catalyzing tech companies to change. (AC)

<u>Afternoon Discussions about Overarching Themes:</u>
- Current implementation of a consent model is fundamentally coercive. In the model most familiar to patients, if they opt out, they can't use the service (such as Gmail or Facebook, etc.). HIPAA functions differently, but most patients don't know this—they may assume they have to agree to all potential uses of their data or the doctor will deny them service. (JNS)
- Addressing patient/consumer protections is an important consideration when talking about consent. For example, the Genetic Information Nondiscrimination Act (GINA) protects genetic data form being used against individuals for health insurance purposes, but long-term care insurance is not mentioned. (SP)
- Underserved populations have a sense of urgency in addressing disparities and are willing to participate in research. But leaders have to acknowledge that there are barriers to this participation. Underserved populations have less power, even if the individual is health-literate, so it is important to consider how to change the system to reduce the power imbalance. (SE)
- The group should consider examples of power-sharing, such as allowing families of hospitalized patients to call for a rapid response team, which have been successful. (LKH)
- When creating AI/ML models, the people designing the technology need to clearly consider racism and bias, and take active steps to ensure existing disparities are not replicated. These disparities are reflected in existing datasets that will be used to train the machine learning, and humans will need to be involved in the process, although determining at what stage and how is still a matter of debate (KF, MS, STI)
- It is important to listen to patients without judging. There is a distinction between equity and equality: our American assumption that "everyone is created equal" ignores the reality that everyone is not coming from the same starting point. A health system that treats everyone the same—equally—will not result in the same level of outcome for all—equity. There is a need to learn from other countries operating with fewer resources than the U.S., which has shown that health care spending is not the same as offering access or improving outcomes. Finally, transparency is the key to success, and in its absence we have chaos. (JW)
- Vulnerable populations must have access to new technologies, and we must also guard against allowing novel tools like telemedicine to exacerbate existing disparities (if the newer technology allows a lower standard of care). One topic that has not been mentioned is workforce diversity, which will be as important in new digital systems as it is now. We need doctors, health system leaders, and tech developers who look like the patients being served. (JR)
- In this discussion, it is important to decouple data from technology. Technology is a thing that's purchase, used, and adopted; data is information that can be used for many things. There is a need for an advocate for the disenfranchised, for someone who has access to data to solve ongoing problems. Finally, there is an unanswered question about the philosophical approach to the call to action contained in these papers: writing groups need to answer the question of what is the desired end result, and how to target these papers to speak to those who have the ability to take action. (AC)
- The papers need to explicitly state that our economic system has shifted to what has been called <u>surveillance capitalism</u>, based on the circulation of information and the profitability of behavior prediction. Secondly, all the papers should pay attention to the ways that disparities can be exacerbated outside the health care system; health-relevant technology does not exist in a vacuum. Similarly, these papers need to realize the scope of health equity, and realize it must be addressed at the level of data inputs and development of technology, and in the implementation. Finally, the authors were invited to think creatively—if a new predictive algorithm was being developed, what would community-lead algorithmic design look like? Data literacy is learnable; what else could be done to make it as inclusive as possible? (KF)

COLLABORATIVE ACTIVITIES FOR CONSIDERATION

Reflect on content of this meeting. Resume writing group calls, include suggestions from this meeting in the process of writing the discussion papers.

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