

*Written Testimony of Christopher Alban, MD  
Physician at Epic, an electronic health records developer in Verona, WI*

Thank you for the opportunity to share our customers' experience in building and growing a network of electronic health records exchange that stretches across the country.

In 2008, our first customers went live on Care Everywhere, Epic's interoperability platform. We built Care Everywhere to meet a simple use case – wherever patients go for care, whether across the street or across the country, their charts should go with them. We found that the best and most sustainable way to achieve this goal is a simple model in which data is requested by the organization that needs it directly from the organization that holds it, without the intervention of a central intermediary or the need for manual release.

In working with our early adopters, we quickly realized that part of the foundation of an exchange network is trust. Trust is not created by technical certifications or attestations, but by the existence of social institutions that are known to operate fairly. Put differently, while technical standards are a practical requirement, they are not the foundation for trust. Trust is founded on a shared belief that every participant is playing according to the same set of rules, and, if that agreement is violated, that there is appropriate recourse available.

From these simple principles, our customers have grown a network covering hundreds of hospitals and thousands of clinics including academic medical centers, county and community hospitals, independent medical groups, Federally Qualified Health Centers, and some of the largest integrated health systems and networks in the country.

Each month, 350,000 patient records are exchanged on this network, and that equates to about 2.2 million standard documents received per month. And these numbers have been growing fast, more than doubling every year.

Our customers and their partners have developed a governance model that satisfies their needs and alleviates the underlying concerns when sharing patient data. They are happy to share this model in the hope that it will inform the future of health information exchange in our country.

First, a set of rules must be established describing good network behavior. In the context of Care Everywhere, these are outlined in a document called "The Rules of the Road," or RotR. Its intent is similar to that of the DURSA, which it predates. Every participating organization is required to agree to these rules, and they are binding in the sense that agreement to them represents a contractual obligation to every other participant. Like the DURSA, the RotR assume a basic legal framework subsuming HIPAA. HIPAA lays out the basic circumstances under which patient information may be exchanged between covered entities, and this foundation simplifies the exchange by building atop policies to which every participant (as covered entities or business associates) is already bound.

The RotR describe the rights and responsibilities of participants in the network. Briefly, the responsibilities include safeguarding both patient information and the technical means of accessing the network, ensuring appropriate role-based access to the exchange, and not discriminating between requestors of information based on business needs. Specifically, under Care Everywhere's RotR, every participant must be willing to exchange patient information equally with any other participating covered entity, without playing favorites or discriminating against business competitors. It is also the right of every participating organization to request evidence supporting the appropriateness of requests for patient information, and the duty of the requestor to provide it when requested.

A constraint on information exchange that has been crucial to the success of Care Everywhere is that, of the circumstances allowed under HIPAA to release patient information, only treatment purposes are supported. This greatly reduces the complexity of the trust relationships involved.

Just as important to the fabric of trust as the RotR and the legally binding agreement to them has been the development of an oversight body with jurisdiction over the Care Everywhere information exchange. Under Care Everywhere, this body is called the Governing Council, and its main purpose is to safeguard the RotR by providing a grievance process available to any participant who believes the RotR have been disobeyed or abused.

The Council is comprised of elected representatives from member organizations. The Council has developed, and the participants have approved, a set of procedures to follow in order to resolve any grievances between participants. It also sets up guidelines for possible sanctions against a party found to be operating against the letter or spirit of the RotR, including suspension of a particular user's access to the exchange, suspension of the organization from participating, or in the worst cases contemplated, complete disconnection from the exchange.

The exchange has operated for nearly five years with no formal grievances filed. This is a testament to the efficacy of the RotR and the Governing Council in establishing a framework of meaningful trust between participants. With a common understanding of good network behavior, any questions or complaints have been answered to the satisfaction of the organizations involved.

One additional feature of Care Everywhere deserves attention because of its importance in allowing an exchange to develop that crosses regional, political, and legal boundaries. Each record-holding organization determines what, if any, patient authorization will be required in order to respond with a patient's information to a requester. It is not the responsibility of the requesting organization to interpret the requirements, nor is it the responsibility of a third-party, centralized Health Information Exchange or a legal entity to determine those requirements for the record holder. This gives each record-holding organization confidence that their legal and policy obligations will be met. Our customers have found that this approach allows them to be comfortable with cross-state exchanges, and almost all participants have had at least one cross-state exchange.

Here, in simple form, are some examples of different patient authorization policies that various individual participating organizations have developed to date, though this is not an exhaustive list:

- All requesting organizations must provide patient authorization, using the record-holding organization's form, before a record will be released, assuming the patient hasn't authorized the release prospectively.
- Certain organizations, determined by the record-holding institution, do not need to provide such authorization, whereas others do.
- Organizations within the record-holder's state do not need to provide such authorization, whereas others do.
- No covered entity abiding by the RotR (requiring an immediate treatment relationship) must provide such patient authorization.

This ability of an organization to set its own patient authorization policies enables rapid growth of the network, where membership is now nearly automatic among Epic's customer base.

To summarize, the features of governance most strategic to the success of Care Everywhere over the last five years have been:

- A single set of Rules of the Road that governs good network behavior
- A representative Governing Council whose responsibility it is to safeguard those rules and settle grievances
- A focus on information exchange for treatment purposes only and directly between covered entities
- The self-determination of record-holding institutions with regard to the rules around patient authorization for release of information

We thank you for the opportunity to share our customers' experience in this important area, and we're proud to represent these trailblazing health care organizations in their work to make sure that clinicians have the most complete information possible to treat patients.