

Proposing an Ethical Foundation for Access to Patient Data through “Care Everywhere” and “Happy Together”: A Case of Novant Health

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INTRODUCTION

Novant Health is one of the ten largest health systems in the country. As a not-for-profit health system operating in North Carolina, South Carolina, Virginia and Georgia with 15 medical centers, nearly 2,700 beds, 436 physician clinics, and over 4.4 million physicians visiting a year, the organization’s decisions impact a tremendous number of patients. Balancing a positive impact and continuing to keep abreast of new technological advances while maintaining patient’s autonomy which includes privacy and confidentiality is becoming increasingly more challenging. As electronic health records (EHRs) (e.g., the widely used health record system, EPIC) continue to evolve through the addition of new modules with enhanced capability, ethical boundaries involving interoperability and data sharing continue to be tested.

As a staff member of North Health’s population health department (Care Connections), my role is to coordinate various pay-for-performance and quality-based incentive programs which are add-on contracts to standard fee-for-service contracts both of which are aimed at partnering with the payor towards shared goals. Our team focuses on a myriad of different goals which can be simplified as reducing total cost while improving quality of care for patients. Much of our work is handled through closing preventative healthcare “gaps in care” which can occur during transitions between different care facilities and treatments. Emergency department and inpatient discharge calls, medication adherence programs, social work support, diabetic education, COPD programs, partnership with skilled nursing facilities and triage. For example, while following up on an ED visit or inpatient discharge, a nurse can check a patient’s medical record to ensure they have a PCP to reduce likelihood of unnecessary ED visits and determine if any preventative health gaps are incomplete. The nurse can not only provide follow-up to the recent visit to a facility but also help the patient schedule the needed preventative screening. The same holds true if a social worker, diabetic educator, or COPD navigator speaks with a patient. If health maintenance gaps are identified, they can submit a referral to the care coordination team to assist the patient in scheduling an appointment that will close the gap, ultimately with a focus on giving each patient the best healthcare possible.

One of the most effective benefits of the EPIC platform is sharing patient records with other providers. This can be done by sharing medical records with other providers operating on the EPIC platform through a module called “Care Everywhere” and with other non-EPIC system providers in a module called “Happy Together.” However, recently, the roll-out of the Care Everywhere and Happy Together modules have prompted a heated debate on when and how the patients’ medical records that our organization have can be accessed and utilized by the outside organizations. Any healthcare organization utilizing the EPIC platform and these modules, I

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believe, will experience the same challenges. In the most fundamental level, the two ethical principles, beneficence and autonomy, are deemed in conflict with each other.

ON BEHALF OF BENEFICENCE

As we all know, the principle of beneficence, broadly construed, requires that we should act in the best interests of the patients we are treating. Assume that the service provided is done with good intent, the care coordinators and clinicians view the act of accessing and obtaining patient records from outside providers through EPIC as a patient-centric duty and in the best interest of the patient. They do feel, I assume, a personal responsibility to provide the best care at the top of their license to each patient they contact. Accessing their records remotely through EPIC does help the patient scheduled for the necessary preventative screenings such as mammograms, colonoscopies, cervical screens, chlamydia testing, well-child checks, A1C testing and compliance, vaccinations, and adolescent well-care visits. Non-compliant patients with overdue screenings are often unaware that they are overdue for a specific screening. By accessing their outside records through EPIC, the nurses and care coordinators are improving the lives of patients, their families, and the community. Furthermore, accessing their outside records will help improve outcomes, extend lives, diagnose cancer earlier, and ultimately reduce health care expenditures for that specific subset of the population. In the end, the data sharing is particularly beneficial for the patients because a great number of people are “healthcare illiterate” due to the overwhelming complexity of the U.S. healthcare system and to the fact that many of the patients are too busy to keep track of their health records and appointments in their busy lives.

THE PROBLEM OF PATIENT AUTONOMY

On the other hand, the ethical principle of autonomy requires that the health providers respect competent patients’ thoughts, intentions, and actions in the sense that their wills are not coerced and their decisions should be the product of fully informed consent. In our case, the competent patients aware of the harms and benefits of the data sharing and the consequences of their allowance of it should endorse our organization to let the outside corporations access their medical records. However, the problem is that it is not all clear whether the patients have granted such permissions.

Many organizations require all patients to sign HIPAA forms and other documents to access services of their providers. Those forms often have broad statements allowing the sharing of medical information on a need-to-know basis, such as law enforcement, subpoenas and some other various reasons. In some cases, the patients can say that they signed the forms without fully realizing the harms and benefits of the treatments or procedures and the consequences of their actions. If true, it may be suggested that the best option to ensure the patient autonomy is to acquire the explicit form of informed consents from the patients by providing the patients with a full range of information with great details, to inform them whenever new information arrives, and to notify the patients, every time, whether they want their records to be shared or not. However, this is practically not possible and not recommended either. The reason for that is that this way of obtaining the informed consent may terrify the patients to the extent that they are discouraged to consent to any procedures. It should be noted that most patients are healthcare-illiterate, as mentioned above, and that a very few of them are health law experts or medical doctors. In the end, the treatment procedures will be delayed. As a result, the procedure of informed consent may work against the health providers’ beneficent intent. If so, what would be the best way of obtaining the patient consent in the manner of not foregoing the provider’s beneficent concern?

A PROPOSED SOLUTION

What seems to be fortunate is that, based on my understanding, Novant Health has a more stringent form of medical record access policy than other organizations. Trusting in the rigor of the system, I propose the following.

First, the patients must be Novant Health patients within, say, the last three years, and signed the HIPAA release form any time within the three years. To determine whether an individual is the system’s patient or not, I argue that they must have received medical services at any of the Novant Health’s facilities and locations. However, a form signed within the last three years and that signed beyond the three-year period seem to require different justifications for action.

Second, the location in which the HIPAA was signed should be taken into consideration. For example, the form signed at a hospital ER or urgent care unit could be viewed as signed under a significant amount of duress, while a form signed at a primary care provider or specialist appointment acts is considered less of a burden to consent. Thus, if the patients sign the HIPAA form in the ERs or urgent

care units, the ER doctors or attending physicians or medical residents who are directly treating the patients (not physician assistants or nurses) should countersign the form within 24 hours after the patients sign. When the doctors' signatures are not obtained within 24 hours, the form should be voided.

Third, the Novant Health should develop a separate form that the patients can sign to allow Novant Health both to share their information with outside organizations and to access the records from outside providers for the purpose of improving better health outcomes. The physicians and care coordinators must fully explain the beneficent nature of the information sharing, not every technical content-detail of it. For example, the medical experts of Novant Health may find, in their best of knowledge, the preventive and critical care proven to be effective in improving the health outcomes and wish to involve outside research organizations. Also, the information sharing reduces health care expenditures by removing the care gap. In addition, utilizing the outside vendors helps the patients keep their medical records and appointments secure while assisting in identification of opportunities to improve a patient's health.

Last, there should be a limit who can access the patient information and disseminate it to whom. In our case here, a member of our team should only be allowed to access the records from outside providers through EPIC and be given the privilege to share the patient information with other organizations.

The situation is extremely sensitive and complex due to the technological advances within healthcare. As technology continues to rapidly advance and evolve, ethical dilemmas will present themselves, forcing health leaders, ethicists, and health systems to determine how to utilize the technology and what limitations or policies are needed. Given that there are no clear-cut ethical solutions for these problems, I have proposed the four recommendations which may provide, at least, an ethical foundation for access to patient data through Care Everywhere and Happy Together.