

Undergraduate Thesis Prospectus

Improved Characterization of Patient Phenotypes for Advanced Heart Failure
(technical research project in Computer Science)

Patient Data versus Patient Privacy
(sociotechnical research project)

by

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technical project collaborators:

On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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STS advisor: Peter Norton, Department of Engineering and Society

General Research Problem

How is the increasing use of software affecting relationships between healthcare consumers, providers and payers?

In healthcare, information technology offers numerous advantages of cost and efficacy, but introduces new risks, including rising patient-to-caregiver ratios, displacement of personal care, and compromises of patient privacy. With electronic medical records (EMR), healthcare providers can more easily manage and access patient information. One systematic review of 7 studies found that patient satisfaction was mostly neutrally or positively affected by physician EMR use in the exam room (Irani et al., 2009). Automation of error prevention functions in hospitals can reduce medical errors that can harm patients (Aron et. al, 2011). Telemedicine depends upon and generates patient data. To manage claims, insurers use software to process patient data.

Improved Characterization of Patient Phenotypes for Advanced Heart Failure

How can an algorithm designed for one point of care measurement be adapted to accept more?

The technical advisor for the project is Josephine Lamp, a PhD student who works with Professor Lu Feng in the Computer Science Department. In the ESCAPE trial, (The ESCAPE Investigators and ESCAPE Study Coordinators*, 2005), demographic and clinical data was collected on patients with advanced heart failure. Venous and arterial pressures were measured at baseline and discharge for many patients. The current model

designed and described in Lamp et. al, is a Multi Value Decision Diagram that accepts a single point of care measurement as one of its many inputs. I seek to modify the model so that it will accept more than one measurement in the hopes that it helps the model better classify patients into categories based on the severity of their heart disease. I will learn all I can about prior work, modify the algorithm and test the results for validity. If successful, the model may be more accurate and of better use to clinicians who undertake the difficult task of making prognoses and treatment plans for this patient population.

Patient Data versus Patient Privacy

How are patient advocates, privacy advocacies, insurers and data brokers competing to draw the line between legitimate uses of patient data and invasion of privacy?

Big data can improve healthcare outcomes and save money in an economic sector accounting for about 17 percent of U.S. GDP. United Healthcare, a health insurance company that serves employers. It offers a Health Plan Manager that helps its clients optimize employees' use of their health insurance (UHC, 2017). IQVIA, a data broker and analytics firm, claims its products can safely accelerate drug trials without compromising privacy (IQVIA, n.d.). The Electronic Frontier Foundation is an advocate of data privacy, including the privacy of medical data (Schwartz et al., 2020). With data mining techniques and models, hospitals can optimize resource allocation, thereby reducing costs (Kraft, 2003). Kirlidog and Asuk (2012) developed a data mining method for detecting health insurance fraud.

Fernández-Alemán et al. (2013) assembled an extensive review of research on the security and privacy of electronic health records. In a study of patients' attitudes

about data privacy, Kim, Joseph, and Ohno-Machado (2015) found “a great deal of concern” that digitization would “worsen” privacy and security. They report that “consumers show willingness to share health information electronically,” but “they value individual control and privacy.” Healthcare professionals, however, have been caught between competing demands that may deter them from prioritizing the privacy of patients’ data. According to Lapke, Garcia, and Henderson (2016), “healthcare providers do not place privacy as a high priority”; instead, most “prioritize personal and organizational gain as well as mitigating personal and organizational loss over privacy of EMRs.”

Health records vendors extol the benefits of ample collection and distribution of patient data. During the 2020 pandemic, Epic Systems, the largest vendor of electronic medical records systems, asserted that “Patients’ critical health information—including medications, problem history, allergies, and infections—informs how providers care for them, ensuring that they receive personalized care even when treated at a different organization” (Epic Systems, 2020). Yet hospitals have objected to the cost of compliance with the privacy regulations governing patients’ records, particularly those imposed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA, 1996). In a 2017 report, the American Hospital Association complained that “the timing and pace with which regulations are released make regulatory compliance challenging and generates additional burden” (AHA, 2017).

Leading advocates of strict privacy standards for patient data include the American Civil Liberties Union (ACLU), Electronic Privacy Information Center (EPIC),

and Patient Privacy Rights (PPR). In 2009, as Congress was developing incentives to promote digitization of health records, these three advocacies joined a larger alliance called Coalition for Patient Privacy (CPP). That year, in a letter to Congress, CPP contended that “consumer trust is essential to health IT adoption and participation, and only attainable with privacy” (Katz, 2009). In part due to the coalition’s influence, the resulting HITECH Act (“Health Information Technology for Economic and Clinical Health Act”) included significant privacy safeguards (Public Law 111-5, 2009).

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