Federal and State Laws Impacting Data Sharing

Health

Federal Laws

45 CFR 160, 164, as amended, and Subparts A & E

Since it is a national mandate to improve health care and efficiency while reducing costs, and to use technology (through Electronic Medical Records (EMR), Electronic Health Records (EHR) and Health Information Exchanges (HIE)), to its utmost to reach these goals, it is essential for all systems to work together. That means sharing appropriate information to avoid redundancies and to think differently how the human services and health systems can help each other. One hypothesis is that if the systems are in tandem, the health system can decrease the reliance on high-cost medical care and procedures, including emergency room care. It has been shown that families with problems paying their rent and housing-related expenses experience higher rates of emergency hospitalizations than other families.[1] Social needs (including but not limited to shelter, food, utilities) are directly leading to worse health, and the social needs are as important to address as the medical conditions. The medical field and practitioners are not capable to address the patient's social needs, which is why the systems must work together. If a person does not have food to eat, they are more likely to be in poor health. Conversely, a person's health improves and the person's health needs and costs decrease if they have nutritious food, adequate and affordable housing, transportation assistance and gainful employment.[2] Health and human services must work together to achieve affordable health care and wellness for our citizens.

Volumes have been written about the Health Insurance Portability and Accountability Act (HIPAA) but in a nutshell, there are 3 purposes for this federal law:

1. It was the beginning of the creation of a uniform standard for processing electronic health care claims in the United States. The HITECH amendment to ARRA built on this processing standard by providing financial incentives for the creation of electronic health records. This was the "portability" purpose so that if a patient moved, the new medical provider would understand and use the same uniform standard.
2. It established a minimum set of privacy rules that all health care providers (as well as health plans and clearinghouses) must follow when handling patient information, giving patients greater control over how their individual health information is used. This was the first part of "accountability". This was to encourage people to truthfully share information with their medical providers without fear that the information will be broadly distributed to other persons.
3. It established new standards for protecting the security of patient information, or the second part of "accountability".

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[1] Bushel, Gupta, Gee and Haas. *Housing Instability and Food Insecurity as Barriers to Health Care Among Low-Income Americans*, Journal of General Internal Medicine, 2006.

[2] *Health Care's Blind Side: The Overlooked Connection between Social Needs and Good Health*, Robert Wood Johnson Foundation, December 2011.

Cross-system information sharing can make all the systems be more effective and efficient in performance, cost savings and revenue reductions. Whether it is the SNAP program and the determination of whether the applicant is an "able bodied adult without dependents" and is capable of working; or the Medicaid system, greatly expanded in enrollment under the Patient Protection and Affordable Care Act, it is essential for the health and public service system to share information when permissible by law. When a child is placed into the foster care system, the state becomes the responsible party for that child and it is essential for the child welfare system to have both basic and complete health and treatment information regarding the child to prevent a health emergency or tragedy and to prevent the inefficient retesting and re-examinations, and even sometimes re-immunizations, which take up caseworker time to arrange and cause expends unnecessary fund expenditures. The corrections system is another example of where readily available and timely health and treatment information can provide better, continuous care for inmates in the state's care and save money by avoiding repetitive and unnecessary costs.

The following outlines the Health and Insurance Portability and Accountability Act (HIPAA) of 1996 and how it is supportive of information sharing with other systems:

- The federal protections are not to interfere with patient access to or the quality of health care delivery[3]
- It is carefully balanced to avoid creating unnecessary barriers to the delivery of quality health care[4]
- Sharing is encouraged if the prohibition would result in unnecessary interference with access to quality health care or certain other important public health benefits of national priorities[5]
- Permitted to share to the individual or designee of individual[6]
- Permitted to share for treatment, payment or health care operations[7]
- Treatment includes the provision, coordination or management of health care and related services among health care providers regarding the individual[8]
- Lengthy list of exceptions to the privacy protections and the requirement for a written authorization
    - Permission to share if required by state law, including to human services entities and the courts[9]
    - An exception for a court order or subpoena with prior notice to the individual[10]
    - Clear description of the elements of and required statements in an appropriate authorization[11]
- Encourages policies and procedures on how protected health information is used, disclosed, and requested for specific purposes[12]

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[3] HHS/OCR guidance
[4] 45 CFR §160
[5] HHS/OCR guidance
[6] 45 CFR §164.502(a)
[7] 45 CFR §164.506
[8] 45 CFR §164.501
[9] 45 CFR §164.512(a)
[10] 45 CFR §164.512(e)
[11] 45 CFR §164.508(c)(1) & (2)
[12] 45 CFR §164.502(b)(1)

- Encourages policies and procedures to develop reasonable criteria for determining what is the "minimum necessary" protected health information to accomplish purpose of request[13]
- Policies and procedures should identify persons/classes of persons who need access to information to carry out job duties, categories or types of protected health information needed, and conditions appropriate to such access.[14]

A governmental entity that administers the Medicaid and other benefit programs (e.g. healthcare coverage including but not limited to coverage for physical health, mental health, and drug use disorders; TANF; SNAP, etc.) and other human services (e.g. housing, employment, child welfare, mental health, etc.) could decide that the entire entity should be designated as the covered entity under HIPAA, so that information can be shared between different individuals within the organization providing services to the same person, on a need-to-know basis and only the minimally necessary information.[15] This type of integrated, multi-service public agency is the legal entity, with one director, various disciplines, and a centralized administrative unit. The agency needs to have one set of policies and procedures and provides integrated services. The agency's confidentiality notice, provided to all clients as soon as possible, is shared within the integrated, multi-service public agency. Clients or patients could be provided an opportunity to "opt out" and restrict information sharing by designating a particular type of service information not to be shared with other systems. In addition, the agency provides a specific authorization for certain information to be shared, including the protection of the location of an abused person, domestic violence, HIV and AIDS information, and alcohol and drug use disorder treatment services.

In this situation, HIPAA permits the sharing of protected health information within the agency without requiring specific and separate authorizations under all of the applicable federal laws for the purposes of treatment and other related health services. The HIPAA definition of treatment permits a provider to offer or coordinate social, rehabilitative, or other services as long as they are associated with and related to the provision of health care.[16]

As for barriers to information sharing, HIPAA was enacted to make it easier for individuals to share health information electronically and thus the word "Portability" in its title. It is interesting to note that the law in many ways has stopped the sharing of information with practitioners of health services and practitioners working with an individual in other fields and systems. Instead of seeing the protections as a part of the treatment process and the multi-disciplinary practice, HIPAA has become the "Red Light" of information sharing, even though the law does not prohibit information from being shared. Instead, policy makers must work together to protect the confidentiality rights of the individual and make the information sharing easier among the people working with a particular individual to provide services to that person.

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[13] 45 CFR §§164.502(b)(1); 164.514(d)(4)
[14] HHS/OCR guidance
[15] HHS/OCR guidance
[16] Federal Register, Volume 65, No. 250, December 28, 2000/Rules and Regulations at 82628

The following outlines what are commonly viewed as barriers that HIPAA presents to the efforts of sharing health information with other systems:

- Federally-mandated foundation for the protection of personal health information, and the confidentiality and privacy of such information
- Strong privacy protections regarding the sharing of protected health information unless authorized by the individual
- No uniform authorization for an individual; instead, each covered entity has its own and separate authorization for an individual to sign
- Fear of violation of the federal law and disclosing protected health information inappropriately but for positive intentions
- Does not make clear that "treatment" for many federally-funded recipients in multi-systems may involve services from these other systems to meet the "social determinants of health"
- Does not make clear what is the "minimum necessary" protected health information to fulfill a request since it is based on the circumstances of the particular request and the individual's situation

But there is no language in the HIPAA laws, regulations or official clarifications by the Department of Health and Human Services Office of Civil Rights that states that personal health information can never be shared. Instead, it is a process to determine if the information is protected by HIPAA; if protected, can it be shared under the Privacy Rule or do you need a signed authorization by the patient to share the information; how to share the minimally necessary information, and then how to keep the information secure once shared.

So, the first question is what health information is protected by HIPAA. First, it must be information that could be used to identify the individual patient, or protected health information. Such "individually identifiable health information"[17] includes both the demographic information about a patient (name, address, employer, etc.) and the medically related information (diagnosis, treatment, condition, medications prescribed, etc.). It includes past, present or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present or future payment for the provision of health care to an individual.

As a general rule, all individually-identifiable health information is confidential and protected. The next question is when can protected health information under HIPAA be disclosed and shared? There are 3 general circumstances when such information can be shared:

1. For treatment, payment and health care operations—this circumstance is important when dealing with individual case information, especially when looking at "treatment."[18] Examples of "treatment" include the provision, coordination, or management of health care and related services for an individual by one or more health care providers (between doctors, nurses, medical technicians, hospital social workers, hospice workers), including consultation between providers regarding a patient and referral of a patient by one provider to another.[19]

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[17] 45 CFR §160.103
[18] 45 CFR §160.506
[19] 45 CFR §160.506

Examples of “payment” activities include such things as billing and collections, utilization review, reviewing health care services for medical necessity determinations, coverage, justification of charges, and determining eligibility and coverage.[20]

Examples of “health care operations” include quality assessment and improvement, credentialing and peer review, compliance, auditing services, business planning and development, legal services, training health care and non-health care professionals, accreditation, certification and licensing.[21]

2. For other purposes if the patient has authorized the disclosure—this circumstance is also important when working with an individual in different systems. If there is a trust relationship between the individual and the caseworkers in the different systems to work together for the benefit of the individual, it will be much easier to obtain the authorization.[22]

3. For certain public and research purposes, even if the patient has not authorized the disclosures. This circumstance is basically for research, planning and program effectiveness and not case-specific situations.[23]

And then there are the additional exceptions to the rule, where protected health information can be shared without authorization:

1. Victims of abuse, neglect or domestic violence[24]
2. Judicial and administrative proceedings[25]
   - Court or administrative tribunal order
   - Subpoena if certain assurances regarding notice to individual and ability to request a protective order is provided
3. Law enforcement purposes[26]
   - Required by law (court orders, court-ordered warrants, subpoenas)
   - To identify or locate a suspect, fugitive, material witness or missing person
   - In response to request for information about victim or suspected victim of a crime
   - To alert law enforcement of a person’s death if there is a suspicion that criminal activity caused the death
   - When health care provider believes that protected health information is evidence of a crime that occurred on its premises
   - When health care provider is providing care for a medical emergency not occurring on its premises, when necessary to inform law enforcement about the commission and nature of a crime, the location of the crime or crime victim, and the perpetrator of the crime.
4. Required by law[27]

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[20] OCR/HHS Guidance
[21] OCR/HHS Guidance
[22] 45 CFR §160.506
[23] 45 CFR §164.514(a) & (b)
[24] 45 CFR §164.512(c) & (f)
[25] 45 CFR §164.512(e)
[26]45 CFR §164.512(f)
[27] 45 CFR §164.512(a)

5. Public health activities[28]

    Examples include:

    - Public health authorities for prevention and controlling disease, injury or disability

    -Government authorities authorized to receive reports of child abuse and neglect

    -Entities, products and activities subject to the Food and Drug Association (FDA)

    -Individuals who may have contracted or been exposes to communicable disease when notice is authorized by law

    -Employers in compliance with Occupational Safety and Health Administration or similar State law
6. Public health activities[29]
7. Decedents (funeral directors, coroners, medical examiners)[30]
8. Cadaveric organ, eye or tissue donation[31]
9. Serious threat to health or safety[32]
10. Specialized government functions[33]
11. Workers' compensation[34]
12. Research (under a number of stringent circumstances)[35]

Whether the information can be shared under one of the 3 general circumstances of the HIPAA Privacy Rule or under one of the 12 exceptions, the information should be provided only to a person who has a "need to know" the information for legitimate purposes and to the minimum extent necessary. In addition to the "need to know" rule, and when providing the information outside of the traditional "treatment" circumstances (for example physicians, nurses, and other health practitioners); the information shared should be limited to the" minimum necessary". Therefore, there must be careful thought as to what information is needed and why the information is needed (and only for legitimate purposes).[36]

[28] 45 CFR §164.512(b)
[29] 45 CFR §164.512(f)
[30] 45 CFR §164.512(g)
[31] 45 CFR §164.512(h)
[32] 45 CFR §164.512(j)
[33] 45 CFR §164.512(k)
[34] 45 CFR §164.512(l)
[35] 45 CFR §164.512(i)
[36] HIPAA is a federally-mandated minimum standard. If a federal or state law is applicable to the information and requires a more stringent standard of confidentiality and conditions and requirements to share information, then the higher standard must be met.

State Laws

CGSA § 19A-25 and 19a-25-1 et seq.

State law requires the confidentiality of records procured by the Department of Public Health or directors of health of towns, cities or boroughs.[37] This includes all information, records of interviews, written reports, statements, notes, memoranda or other data, including personal data. This also includes information obtained and collected by staff committees regarding issues including but not limited to morbidity and mortality, maternal mortality, disease prevention and control, etc.

The Department of Public Health cannot disclose identifiable health data, except as minimally necessary, to the following: (1) to healthcare providers in a medical emergency to protect the health, life, or well-being of the person with a reportable disease; (2) to healthcare providers, the local health director, another state or public health agency, or other persons as necessary for disease prevention and control or to reduce morbidity or mortality; and (3) for medical and scientific research. The disclosure can only take place upon the execution of a written agreement, which provides for the protection of the data, among other things.

[37] CGSA § 19A-25