

DATA SEGMENTATION IN ELECTRONIC HEALTH INFORMATION EXCHANGE:
POLICY CONSIDERATIONS AND ANALYSIS

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EXECUTIVE SUMMARY

The issue of whether and, if so, to what extent patients should have control over the sharing or withholding of their health information represents one of the foremost policy challenges related to electronic health information exchange. It is widely acknowledged that patients' health information should flow where and when it is needed to support the provision of appropriate and high-quality care. Equally significant, however, is the notion that patients want their needs and preferences to be considered in the determination of what information is shared with other parties, for what purposes, and under what conditions. Some patients may prefer to withhold or sequester certain elements of health information, often when it is deemed by them (or on their behalf) to be "sensitive," whereas others may feel strongly that all of their health information should be shared under any circumstance.

This discussion raises the issue of data segmentation, which we define for the purposes of this paper as the process of sequestering from capture, access or view certain data elements that are perceived by a legal entity, institution, organization, or individual as being undesirable to share. This whitepaper explores key components of data segmentation, circumstances for its use, associated benefits and challenges, various applied approaches, and the current legal environment shaping these endeavors.

Data segmentation in the health care context can support granularity of choice with respect to the following:

- What specific data are eligible for exchange (from individual data elements to defined categories of data, such as all behavioral health records);
- Who has access to the information (from individual providers to other health care entities);
- Under what circumstances access is granted (*e.g.*, emergency access, treatment, *etc.*); and
- For what period of time access is granted (*e.g.*, unlimited, one-time access, *etc.*)

Collectively, these decisions reflect a set of information management preferences that theoretically could be executed by a number of parties, including individual patients, health care providers, provider organizations, or other legal entities. At present, however, these determinations are rarely made by the individual, and the question of who actually should have authority to determine and apply such preferences has emerged as a significant issue.

The impetus for protecting personal health information through the use of data segmentation is partially rooted in state and federal privacy laws addressing stigma and social hostility. Frequently cited laws such as the federal Confidentiality of Alcohol and

Drug Abuse Patient Records regulations (Part 2) vigorously protect specific health information from exchange without patient consent. Additionally, a host of less well-recognized, but equally stringent, state laws protect a broad range of information, for example health data related to minors or incidents of sexual violence. Other justifications for the use of data segmentation in protecting health data include long-recognized principles of patient autonomy and the need to encourage greater patient trust and participation in the health care system.

Data segmentation provides a potential means of protecting specific elements of health information, both within an EHR and in broader electronic exchange environments, which can prove useful in implementing current legal requirements and honoring patient choice. In addition, segmentation holds promise in other contexts; the electronic capture of data in structured fields facilitates the re-use of health data for operations, quality improvement, public health, and comparative effectiveness research.

When discussing various data segmentation options in the health care context, several challenges also arise. These include:

- *Technical considerations, including the use of structured data.* Legacy systems and provider documentation practices (e.g., reliance on free-text fields) often result in the recording of unstructured data. This scenario can complicate segmentation, which relies on the documentation of information in a structured and codified manner that can be managed through the application of rules engines and other intelligence systems.
- *Defining “sensitive information.”* Pre-determining categories of information can ease the implementation of segmentation – both technically and logistically – but many patients express a strong preference for systems that enable them to convey their personal preferences more fully.
- *Consumer engagement.* Some approaches to segmentation would require and support deeper engagement on the part of the patient in determining and assigning segmentation preferences. These require consideration not only of the capacity of patients in this respect, but also their motivation to assume responsibility for the potentially daunting tasks associated with assigning and recording such preferences.
- *Provider reluctance.* At present, providers play a critical role in obtaining, documenting and honoring patient preferences with respect to personal health information. They also rely on the availability of accurate and relevant health information in order to provide appropriate and high-quality care. Segmentation policies must address the needs and concerns of providers as well as patients, including their concerns regarding quality and safety of the care provided, workflow implications, and liability.

Despite these issues, and largely due to existing legal requirements, electronic exchange with some level of data segmentation has succeeded to varying degrees in the U.S. The more developed solutions at this point are in very early stages, however, and others tend to enable segmentation only in contained environments. Varied segmentation policies,

practices and applications have emerged, including the following:

- *Patient-controlled segmentation models.* In these models, patient preferences are recorded or entered by the patient and applied as information is exchanged. PHRs and health record banks are the primary examples of such models. However, this approach only allows patient control over a copy of his / her health record (not the provider's documentation) and cannot guarantee that patient preferences will be honored once the information is released to another entity.
- *Individual provider-controlled models.* These models allow providers to act as patient proxies in recording patient preferences with respect to data sharing. Communication between patient and provider is critical to the success of these models, as is provider willingness. Some systems have successfully supported the exchange of information according to patient preferences, but typically operate as closed systems and do not permit segmentation preferences to extend to other settings.
- *Other systems, including organization-controlled models, hybrid models and innovative tools.* These systems often enable segmentation of information according to one or more jurisdictional, organizational or individual patient directive. Pilot programs are also in development to enable the use of consent management systems in exchanging health information between systems. When developing organizational policies, exchanges have indicated that receiving the input of key stakeholders, including consumers, is vital to success.

Other industries and international health information exchange efforts also offer promising examples and insight regarding data segmentation. Social networking sites in particular can illustrate how the public views privacy and the amount of granular control over personal information individuals generally prefer. International health information exchange efforts also can offer examples of ways to approach various issues related to data segmentation.

It is clear that enabling patient expression of preferences with respect to data sharing is critical to supporting consumer engagement. While consumer demand for segmentation tools may not be high at the present time, there is growing concern over the increasing availability of health information, which on its own or in combination with other data types might be used in ways not supported by individual patients and consumers. Notably, the advent of personalized medicine and increased availability of genetic information has been perceived by many as significantly changing the privacy discussion. Absent the ability to segment out specific data points within an EHR, the only alternative may be for entire health records to be exchanged routinely. This practice likely would lead consumers to engage in more privacy protective behaviors, thereby compromising achievement of better patient care and engagement in their health and health care. It could also diminish the overall utility of electronically-captured data for purposes other than direct care delivery.

As such, it will be important for policy makers to consider various approaches to moving not only the discussion, but also the meaningful realization of data segmentation,

forward. Data segmentation efforts to date have explored a variety of approaches that show some early, but limited, success. To accelerate this forward momentum, we would suggest, among other pursuits, the following:

- *Build a Bridge to Greater Autonomy:* Rely on policy levers that will move us closer to the goal of supporting individual, subjective preferences for information management;
- *Provide Direct Financial and Other Support to Stimulate Change:* Consider various means of supporting the development of segmentation-enabling processes and technologies; and
- *Generate Evidence:* Given the significance of the transformation from paper to electronic means of data capture and sharing, establish and execute on a set of updated research priorities.

We support the idea of casting a wide net in search of appropriate means of providing patients more granular control over the exchange and use of their identifiable health information, and point to the efforts underway in other countries as evidence that this is a worthwhile endeavor. While still a challenge, data segmentation holds promise for accomplishing the ultimate goal of accommodating the needs and desires of the multiple stakeholders engaged in the electronic exchange of health information.