

Data ownership and use of data aggregators in clinical care (#IS071)

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Abstract Body

Type 1 diabetes (T1D) is increasingly becoming a “digital disease” for which persons with diabetes (PwD) generate hundreds of continuous glucose monitoring (CGM), insulin dosing, carbohydrate intake, exercise, sleep, and other physiological datapoints per day. These data have value to the PwD themselves in addition to the providers giving medical advice, companies looking to improve algorithms and products, and third-party researchers aiming to better understand T1D care. The desire to share data and grow knowledge is counter-balanced against the need to secure protected health information, prevent breeches in privacy, and obstruct malicious actors. Digital data is generally available to PwD and their providers via manufacturer-based websites and uploaders. These platforms, however, require individual providers to learn and maintain a growing number of accounts, a process which is prohibitive outside specialty diabetes centers. Third-party data aggregators hold the potential to homogenize data sharing and visualization among PwD, providers, and researchers, but move data control outside of the companies creating and improving the devices. In this talk we will discuss data ownership and the pros and cons of data aggregators getting at the question, “Whose Data Is It Anyway?”