Research data management in healthcare: Current challenges and trends

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The medical sector generates large amounts of structured and unstructured data on a daily basis, including 1) health data such as medical images, laboratory results, questionnaire scores, treatment details and 2) healthcare (administrative) data such as hospital admission/transfer/discharge, demographics, disease registries, billing accounts, appointments, and schedules. Clinical environments are arguably among those producing the largest quantity of data, but their potential remains relatively untamed from a Big Data and artificial intelligence perspective, due in part to legislative constraints, ethical considerations and data governance hurdles. We will review these challenges and present current trends in Research Data Management (RDA), including the FAIR principles as well as emerging standards and good practices in RDA that can potentially lead to innovative Big Data approaches in healthcare. The PULSAR collaborative platform for data-driven health research at Université Laval will also be presented.