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INCLUDING PATIENT-GENERATED HEALTH DATA IN ELECTRONIC HEALTH RECORDS – A SOLUTION FOR CGM-DATA

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Background and Aims: Patients with diabetes and health personnel do not have an optimal way of interacting. Health personnel must use multiple ICT systems, such as third-party companies' services, to access health-related data from diverse vendors' CGM platforms and Electronic Health Record (EHR). Furthermore, other health-related data like physical activities, quality of life or well-being is often discussed but rarely stored inside the EHR system. We propose a future-proof architecture for diabetes medical consultation using the HL7 Fast Healthcare Interoperability Resources (FHIR) standard.

Methods: We designed a service, based on Tidepool, that combines generic data (e.g., sleep, physical activity, diet), disease-specific data (blood glucose, carbohydrate intake, insulin doses), PROMs (e.g., PAID, SF-36, PHQ-9) and exchange these data according to FHIR.

Results: Profiling information from CGMs or generic data like physical activities using the FHIR standard impose some new design choices. The FHIR standard permits the use of observations, making it technically possible to exchange such data. However, even with unequivocal data exchange, there are multiple ambiguities in storing patient-generated health data (PGHD) in EHRs, including ethical questions regarding responsibility, maintenance and versioning. Thus, the question: Who is responsible for the validity of such data? Remains open since multiple possible answers exist, such as the patients, healthcare systems or device producers.

Conclusions: Health-related data (e.g., CGM data, PGHD) are often obtainable exclusively via proprietary systems slowing clinical practice. A future-proof architecture based on FHIR standards may provide a comprehensive picture for patients and health personnel for diabetes medical consultation.