

Patient Empowered Education and Research: Integration Study on how to integrate Patient Generated Health Data in Quality Registers

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Background: Healthcare is transformed by the usage of new technologies, like Wearable Devices (WD). Patient generated health data (PGHD) from WDs could be found useful in the management and the research of a chronic disease, like Multiple Sclerosis (MS).

Objective: The objective of the study was to propose a model for the import of PGHD from WDs to the MS Quality Register (MS QR), the main resource for research on MS in Sweden. The study focused both on the medical data that is needed and on the technical challenges that exist in such an implementation.

Methods: Design Science was adopted as a methodology. The context of the study chosen was the MS QR. Participants were interviewed for the technical part and a questionnaire was delivered in order to find the most meaningful PGHD for MS QR. Based on the results, an artifact was created and evaluated from the perspective of the MS QR stakeholders.

Results: The survey was answered by 35 healthcare professionals. The results revealed the factors that WDs can help track for the monitoring of a disease like MS. The interviews revealed several challenges and opportunities, like the legislative or organizational difficulties, but also the opportunities that appear with initiatives towards healthcare innovation. The evaluation triggered an optimization of the technical integration model, demonstrating that simple solutions could solve complex problems.

Conclusion: The import of PGHD in MS QR, is technically possible. Applications should also be added together with WDs monitoring. The choice of model to use, is strongly related to how the data will be used within the organization.

Keywords: Multiple Sclerosis, Patient Generated Health Data, Wearable devices, Quality Register