

# Assessing Quality of Life Using FHIR – How to Combine Patient Reported Outcome with Patient Generated Data for Better Compliance

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**Abstract.** Quality of life (QoL) is affected by environmental influences and varies between patients. A combined measurement through Patient Reported Outcomes (PROs) and Patient Generated Data (PGD) may enhance the detection of QoL impairments by a longitudinal survey. Leveraging different approaches of QoL measurement techniques, the challenge is to combine data in a standardized, interoperable way. We developed an app (*Lion-App*) to semantically annotate data from sensor systems as well as PROs to be merged in an overall analysis of QoL. A FHIR implementation guide was defined for a standardized assessment. To access sensor data the interfaces of Apple Health or Google Fit are used instead of integrating various provider directly into the system. Since QoL cannot be collected exclusively via sensor values, a combination of PROs and PGD is necessary. PGD enable a progression of QoL which offers more insight into personal limitations whereas PROs give insight about personal burden. The use of FHIR enables structured exchange of data while personalized analyses might improve therapy and outcome.

**Keywords.** Quality Of Life, FHIR, Interoperability, Patient Reported Outcome, Patient Generated Data

## 1. Introduction

To detect personal deviations in Quality of Life (QoL) a longitudinal survey and good compliance is necessary. This may be achieved by combining subjective Patient Reported Outcomes (PROs) with objective Patient Generated Data (PGD). Merging two measurement techniques, standardization and therefore interoperability are important [1].

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## 2. Methods

Currently measurement techniques of QoL have the limitation that the absence of behavioral reference and no longitudinal monitoring may exhibit a response bias [2].

Therefore, an app (*Lion-App*) was conceptualized and implemented for a continuous measurement of QoL. PROs and PGD needed to be uniformly structured to be combined.

## 3. Results and Discussion

In *Lion-App* QoL is gathered through a sensor-based survey of daily activities and PROs about symptoms. All is structured through HL7 FHIR as it utilizes LOINC or SNOMED codes to further use data semantically interoperable in computations or health care delivery. Therefore, data from PROs and PGD can be matched by the same semantic annotation for a joint analysis independent of their data source. A FHIR implementation guide was developed to define resources for a standardized assessment.

Our concept is based on the use of private devices for a universal applicability across different hardware with supporting the operation systems of Android or iOS. Instead of implementing interfaces to various providers, Apple Health and Google Fit have been prioritized to access and ingest sensor data. User centered development of the app showed positive results for applicability and acceptance of the app [3]. A basic requirement for measuring QoL through PROs and PGD is a compliant patient. A purely objective survey through sensors (PGD) can extend the survey by behavioral reference, but it cannot replace the subjective assessment of the personal burden (PROs). For this reason, a combination is necessary to enable reliable, longitudinal QoL tracking. With the automated behavioral analysis in combination with PROs and mapping of the data to QoL, trends can be identified at an early stage. To use data in medicine, it must be semantically coded in a uniform way, for example by using HL7 FHIR. To date, no such systems are known to collect QoL in oncology, which is why it was decided to publish the structure of our approach in an implementation guide as the concept may be reused by other members of the scientific community.

## 4. Conclusion

In summary, it is technically possible to implement a system for the combined measurement of QoL. By using the communication standard of HL7 FHIR, mobile collected PROs and PGD can be combined and further used in health care systems.

## References

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