

## CONFERENCE ABSTRACT

# Eliciting moral values of stakeholders in the development of a web-based QoL-instrument for people with severe mental health problems: The case of the QoL-ME

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**Purpose:** The aim of this study is to elicit moral values of stakeholders in the development of a web-based QoL-instrument for people with severe mental health problems.

**Context:** Quality of Life (QoL) is an important outcome measure in mental healthcare to evaluate the effect of interventions. It is important to investigate whether the current domains in QoL-assessment suffice or whether supplements (add-ons) are needed, capturing patient empowerment and social changes. To contribute to the evaluation of innovations, and to enhance substantiated policy decisions in the allocation of resources, we are developing a web-based, personalized, patient-friendly and easy to administer QoL-instrument: the QoL-ME. However, technology is value-laden. It is argued that moral values of stakeholders play a significant role in shaping technologies [1] and that they can intentionally be incorporated in their design [2]. In order to recognize and feedback these values, the different visions of all stakeholders into the development and utilization of the QoL-ME should be taken into account. In the development of the design of the instrument stakeholders' values are therefore systematically elicited to be able to explore how these perspectives can be translated into choices for technical design.

**Methods:** To elicit the stakeholders' values heterogeneous focus groups (n=3) and workshops (n=2) were held with patients (n=19) and healthcare professionals (n= 12). Participants were asked for their views on apps in general, (QoL) questionnaires, and ethical values they considered relevant in for the design of the web-based QoL-ME. In addition, semi-structured interviews were conducted with QoL-researchers (n=6) to assess what values play a role in current face-to-face QoL-assessments. Finally, semi-structured interviews were conducted with representatives of an insurance company (n=1) and a policy maker (n=1). They were asked for their perspective on the use of QoL-ME for their organization.

**Results and discussion:** Stakeholders largely agree on the ethical values that are relevant for the development and utilization of the QoL-ME: Privacy, autonomy, trust, accessibility, efficiency and intimacy. For patients privacy is an issue when it was related to data-security, ownership of data and

the ability to use the QoL-ME on their own device. The QoL-researchers and some patients mentioned that a personal relationship between them is essential to build trust and to share intimate information, although some patients claim that sharing this information with an anonymous device would be easier. Patients feel that transparency and control (autonomy) over sharing their data is a prerequisite for trusting the device. Stakeholders agree that control over the topics of the QoL-assessment would make it more efficient, more interesting and less time consuming for patients. Healthcare professionals and some patients warn that the QoL-ME might not be accessible for computer illiterate users, or users with no access to computers or mobile phones. Both representatives of the insurance company and the policy maker were not so much interested in the content or form of the QoL-ME, but stressed the need for the instrument to meet the user requirements for proper QoL-assessment set by the field.

It seems that stakeholders largely agree on which ethical values play an essential role for the development and utilization of the QoL-ME. The next step in the design process is to explore how we can translate these perspectives into choices for technical design.

#### References:

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