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POSTER ABSTRACT

Development of an electronic patient reported outcome and an electronic case report form to assess and present health in young people visiting Youth Health Clinics

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Background: In Sweden, Youth Health Clinics (YHC) offer care for young people, age 13-25. Early detection of poor health in young people is important to avoid long-term lower quality of life. The overall objective was to develop an electronic health report system, for use in assessment of young people's health, to identify health-risks in early stages, to increase health, and quality of life.

Methods and Results: The project had a participatory research approach on consultative level, with different stakeholders; young people 16-23 years old, YHC healthcare professionals, and an expert panel. An Information Technology (IT) company took part in the hands-on development of the health report system. The project included three sub-studies.

Sub-study I: Interviews with 15 young people, explored their opinions on using electronic Patient-Reported Outcome (ePRO) at the YHC, what to include, and how to design an ePRO. The participants were positive to use an ePRO and had suggestions for design and content. These results affected the content and design interface of the ePRO and the summary of its results in an electronic Case Report Form (eCRF).

Sub-study II: The study consisted of two parts; a) Development of the Youth Health Report System: A literature search and consultative expert panel discussions formed the base of inclusion of validated questionnaires for an electronic Health Report Form (eHRF). b) Usability evaluation of the eHRF and the eCRF: The usability was evaluated with four young people, three YHC healthcare providers and seven participants in an expert panel. Data from interviews and a usability questionnaire were analyzed accordingly. Both the eHRF and the eCRF were found usable for YHCs. The participants informed on improvements in further development and contributed to the use of the eCRF. Thus, the revisions were made and an education program for healthcare professionals was created.

Sub-study III: The Youth Health Report System's electronic Evaluation Questionnaire (eEQ) and the eCRF were assessed for feasibility in a YHC clinical setting. Eleven YHC healthcare

professionals participated in semi-structured interviews. Quantitative data were collected from the eEQ, from 54 young people.

Conclusion: The participation of young people, YHC healthcare professionals and expert panel contributed with a wide perspective that directly contributed to both content and design in the development of the Youth Health Report System for YHC. The system was found usable and feasible to use in future effect studies.

Lessons learned: Differences in YHC governance organization required a pragmatic project design. The recruitment of young people was affected by the Corona-pandemic, commitment challenges and drop-outs. Some healthcare professionals were unfamiliar with computers and digital Health and Welfare Technology (HWT). This project contributes with knowledge about developing HWT for young people and how it can be used in clinical work.

Next step: is to evaluate if the Youth Health Report System leads to improved health, health-related behavior and quality of life compared to treatment as usual.