

QUALITY OF LIFE, QUALITY OF CARE, AND PATIENT SAFETY

DEVELOPMENT OF THE ELECTRONIC PATIENT BENEFIT INDEX FOR A DIGITAL MONITORING AND DOCUMENTATION SYSTEM FOR PSORIASIS

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Introduction: Outcomes measurement and treatment goals are major components of modern psoriasis management in practice. However, full electronic monitoring and documentation systems are rare.

Objectives: The objective of the current project is to develop a platform of electronic devices for the management of clinical and patient-reported outcomes (PRO) in psoriasis. One component is to develop and test the electronic Patient Benefit Index (ePBI) for psoriasis.

Materials & Methods: After developing a standard data set for documenting psoriasis in practice, electronic clinical and patient reported outcome tools were developed, as e.g. the PBI App and web version (Swiss4ward). The PBI consists of two questionnaires (Patient Needs, Patient Benefits) resulting in a PBI score. The ePBI including the questionnaires, different result sections and paper based examples of graphs and cockpits showing possible results was tested cognitively and developed iteratively in 4 rounds with 11 patients. Furthermore, 39 dermatologists and 213 patients were asked about their acceptability of documenting patient needs and benefits in a standardized online survey. The survey instrument was developed on the basis of 3 focus groups with 14 patients. Further feasibility and acceptability testing is ongoing.

Results: The ePBI is totally developed by conducting cognitive interviews and can be shown on the conference. Dermatologists and patients with psoriasis show a high acceptance of recording patient needs and benefits. E.g. 87% and 87.5% of the patients would be willing to answer questionnaires about their needs and benefits. 100% and 85.7% of the dermatologists would also be willing to collect these data from their patients.

Conclusions: The ePBI is a usable and acceptable instrument for documenting patient needs and benefits. It will be included in a digital monitoring and documentation system for psoriasis. In a next step validity testing and the development of more opportunities to show results is planned.