ABSTRACT BOOK ABSTRACTS



QUALITY OF LIFE, QUALITY OF CARE, AND PATIENT SAFETY

DEVELOPMENT OF A STANDARD DATASET FOR THE DOCUMENTATION OF PSORIASIS: A DELPHI APPROACH WITH PSORIASIS EXPERTS

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Introduction: Outcomes measurement is a major component of modern psoriasis management in practice. However, full electronic monitoring and documentation systems are rare.

Objective: The current project aims to develop a standard dataset including clinical- and patient-reported-outcomes for the documentation of psoriasis in practice. This dataset will later be integrated in an electronic monitoring and documentation system.

Material and Methods: The selection of outcomes instruments was based on a systematic literature review. Consensus of instruments and other patient information was achieved by a Delphi process with 26 psoriasis experts in three online Delphi rounds and one in-person meeting. Most of the questions were standardized, but also open questions were included to state reasons of choice and to enlarge the dataset. Furthermore, the expert meeting was informed by results of three patient focus groups (n=14) and results of a quantitative survey concerning the status quo of dermatologist experts' instrument use in practice (n=15).

Results: The consensus approach resulted in a dataset of 65 variables, divided in a minimal (18 variables), optimal (32 variables) and optional (15 variables) dataset. E.g. the minimal dataset includes variables like comorbidity, therapies, adverse events and a clinical instrument. The optimal dataset contains e.g. rehabilitative and stationary services and various clinical and patient-reported-outcomes. Summarizing, the data can mainly be grouped in master data, general status and anamneses data, anamneses of psoriasis, status of psoriasis, diagnostic and comorbidity, therapies and patient reported outcomes.

Conclusions: The inclusion of two more methods in addition to the experts' consensus approach allowed a broad view and discussion for the development of the dataset. The dataset will be used for documenting psoriasis in practice and builds the basis for an electronic monitoring- and documentation system. Some of the electronic outcomes instruments are under development or are already developed (PASI, BSA, DLQI, PBI).





