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Methodological innovations and stakeholder involvement in core outcome sets for skin diseases: a survey of the C3 working groups

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To the Editor,

Skin diseases, ranging from common conditions like acne to rare disorders, often lack standardized outcomes and measures. This absence of uniformity in outcomes complicates the comparison of research findings across disease processes, impedes pooling of data and meta-analyses within disease areas, and hence hampers the delivery of optimal patient care. The development of core outcome sets (COS), minimum sets of outcomes that are to be collected in all studies of a given disease or condition, is an attempt to overcome this problem by standardizing outcomes and their associated measures [1, 2].

Historically, the generalizability of COS has been limited by insufficient stakeholder involvement. In some cases, COS have focused narrowly on the clinical manifestations of dermatologic conditions as defined by physicians, often neglecting the perspectives of other essential stakeholders such as patients and caregivers [3]. Moreover, projects have often involved experts predominantly from Western countries, leading to a lack of geographic diversity in these initiatives.

Recognizing these limitations, several COS projects have expanded stakeholder involvement. UPGRADE and COMPPASS, for instance, have sought global representation by including participants from countries like Australia, Canada, Germany, and South Africa. Furthermore, groups like HISTORIC, OCOMEN, and HOME have incorporated novel Delphi methodologies and iterative feedback mechanisms, actively engaging a broader array of stakeholders including sufficient numbers of patients (Table 1). Efforts such as those by ACORN and OVAMA to actively involve a range of stakeholders have not only led to more representative COS but have also paved the way for greater uptake in clinical practice. In addition, it is crucial to highlight the need for training materials for patients and patient representatives, a factor that plays a vital role in ensuring meaningful and effective engagement in the development of core outcome sets.

In conclusion, the move toward methodological innovation and broader stakeholder involvement in COS development promises a more standardized and globally accepted approach to developing COS. Inclusion of a broad range of stakeholders and active involvement

of these in the COS development process will ensure greater generalizability and hopefully improved uptake of COS.

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