

# TECHNOLOGY BRIEF

## PROM

### iscorEB (instrument for Scoring Clinical Outcomes for Research in Epidermolysis Bullosa)

#### Description

Epidermolysis bullosa (EB) is a family of rare genetic blistering skin disorders characterized by fragility of skin and mucosa. Severe forms of EB can dramatically affect the mucosal membranes (mouth, eye, airway, etc.), internal organs (gut, kidneys, heart) and lead to severe anemia, poor nutrition and stunted growth. Severely affected patients have a decreased life expectancy due to severe infections or invasive skin cancer.

While EB is often viewed as a “skin disease,” it effectively involves the entire body. Affected patients, particularly those with severe sub-types, can suffer from non-skin complications such as growth failure, low blood counts, feeding difficulties, heart and renal disease, and/or osteoporosis. EB decreases quality of life, and in many cases, shortens life expectancy. Current treatment aims to promote patient well-being by helping with wound healing and monitoring and treating secondary complications.

There is significant innovation occurring in EB treatment in search of new therapeutics. In order to assess the benefits and adverse impacts of such interventions, well-developed, validated measures of clinically relevant and patient-important outcomes are required. To date, there are very few validated tools enabling researchers and clinicians to assess the disease severity and to monitor changes over time.

To address the current lack of outcome measures, Dr. Elena Pope has developed iscorEB (instrument for Scoring Clinical Outcomes for Research of Epidermolysis Bullosa) that quantifies the disease severity from both, clinician and patient/family perspective.

#### Therapeutic Area

- Epidermolysis bullosa

#### Advantages

- The iscorEB can be used for research purposes or in regular clinical practice to monitor disease progression.
- Patients can also use the patient only sub-score by themselves to monitor changes over time.
- This research tool can be used as a sole outcome measure in interventional trials.

#### Additional Information

- Available in various languages.
- Publication doi: 10.1111/pde.12317

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