LACK OF CURRENT CLINICAL RESEARCH IN AREAS VERY RELEVANT TO PATIENTS AND CLINICIANS IN DYSTROPHIC EPIDERMOLYSIS BULLOSA.

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A lack of current clinical research in areas very relevant to patients and clinicians is a significant concern, particularly in conditions like Dystrophic Epidermolysis Bullosa (DEB). The recent Priority Setting Partnership (PSP) in DEB has provided an ordered list of research priorities for patients and clinicians that we compared with registered randomized clinical trials (RCTs) to assess if current research is aligned with the needs of patients and clinicians.

**BACKGROUND**

Setting a research agenda that covers patients’ needs is important when research is difficult and resources limited, as is the case for rare disorders such as Dystrophic Epidermolysis Bullosa (DEB). The recent Priority Setting Partnership (PSP) in DEB has provided an ordered list of research priorities for patients and clinicians.

**OBJECTIVES**

To assess how many of the current registered clinical trials of any kind of intervention in DEB match some of the top-ten prioritized uncertainties identified during the PSP in DEB.

**RESULTS**

We found 26 registered studies, which cover 4 of the 10 uncertainties identified. We did not find any ongoing trial aimed to answer six of the ten prioritized uncertainties about the treatment and management of patients with DEB.

**DISCUSSION**

Our study highlights a lack of clinical research in areas that are very relevant to patients and clinicians and likely to provide answers soon, such as therapy of itch, syndactyly treatment, and early skin cancer detection and management. Limitations of our research are that not all patients and clinicians might agree on priorities described by the PSP, and that some research might be ongoing but not included in RCTs registries.

**CONCLUSION**

Our study shows a mismatch between the research needs perceived by patients and clinicians and current research. These results should encourage the creation and funding of new international research teams to study the more neglected areas of DEB therapy.

**REFERENCES**