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Title

LEAD (Lower Extremity Amputation Dataset): Outcome of a Global Consensus

Coauthors

None

Summary

ISPO, funded by USAID through UNOPS in support of ATscale, facilitated a global consensus process to develop a core dataset which could be used, and is to be promoted around the globe. The LEAD was completed in the second half of 2021 and is now in the process of being rolled out and pilot study.

Introduction/ basics

ISPO International, with the support of USAID, ATScale and UNOPS has undertaken an international consensus to develop the LEAD (Lower Extremity Amputation Dataset) for people undergoing lower-limb amputation and prosthetic rehabilitation.

Currently, there is a large amount of variability in data domains collected about people with lower limb absence, including in the areas of research, national registries and in smaller data sets at the regional and centre level. To facilitate more uniformity to allow combination of datasets, more robust comparisons and a better standard of reporting to allow clear interpretations, the LEAD has been developed. Other recommendations include domains useful for development of a registry

Material method; implementation/ process

A scoping review of data sets related to lower limb absence and rehabilitation and related assistive products was undertaken. As part of the strategy semi-structured interviews about limb loss and prosthetic rehabilitation registries and data sets were conducted as a first step. Subsequently a global consensus process of multidisciplinary clinicians, users, policy makers and researchers who have established a set of recommended data elements, based on their real-world experience and knowledge of outcome measure utility and applicability was established.



Results

The LEAD and its data dictionary as well as the recommendations for data management, data collection, compliance with privacy legislation, stakeholders, funding, registry design and other matters related to development of a patient registry will be shared with the audience.

Discussion/ conclusion; conclusion for the practice

The LEAD can be included in routine clinical practice at an international level and will assist in providing data to make the case for continued and increased investment into lower limb prosthetic provision and rehabilitation.

References

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