

## The Hand Eczema Core Outcome Set (HECOS) Initiative

Dear Patient,

Millions of people worldwide suffer from hand eczema. Researchers therefore investigate how to ease the burden of this condition, but they need the assistance of patients to make sure that their findings are indeed helpful. We invite you to participate in HECOS, an initiative that aims to develop a core outcome set for future hand eczema trials.

### What is a core outcome set and why do we need it?

While medical knowledge about the prevention and therapy of hand eczema continues to grow, it faces a big obstacle: Study results are often not fully comparable. As an example, imagine you want to know how ointment A works in reducing hand eczema. There are three trials investigating the effects of ointment A; each trial includes 100 patients. Trial 1 shows generally positive results, trial 2 finds no effects, and trial 3 observes negative effects in most patients. How can we make sense of these findings?

One interpretation could be that ointment A has no effect on hand eczema – the positive and negative results in trial 1 and 3 occurred by chance. But when we look closely at the three studies, their design may be the reason for the different results. To assess the effect of the ointment,

- Researchers in trial 1 asked the patients if their skin condition improved or worsened.
- In trial 2, a dermatologist assessed how many patients still had hand eczema after treatment.
- Trial 3 measured health-related quality of life.

Knowing this, it is *possible* that ointment A improved the patients' skin condition but not quite enough to result in eczema-free hands. An explanation for the reduced quality of life might be that the ointment was uncomfortable to apply or too greasy.

However, these are only speculations. We cannot be certain about the effects of ointment A because the trials are too different from each other. We need standardised measurements that are applied in every hand eczema trial. Such a standard is called a core outcome set. An outcome is the concept that is measured in trials (in our example: skin condition, presence of hand eczema, quality of life).

### How can I participate?

We need patients who help us decide which outcomes are important enough to be part of the standard. You are invited to participate in an online survey that consists of 4 to 7 rounds. The goal of this procedure is that all participants finally reach an agreement about the most relevant outcomes. The survey will be available in several languages.

To become a member of this consensus panel, please complete the attached registration form and send it to [Henriette.Roensch@tu-dresden.de](mailto:Henriette.Roensch@tu-dresden.de). If you have a deeper interest in the scientific methods of HECOS, you will find more information at <http://cs-cousin.org/hecos>.

***Your contribution to enhance hand eczema research is highly appreciated.***

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