

# LYHTY – Functioning and challenges in equality and accessibility among people with short stature

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# People with short stature

- People who are significantly shorter than peers, and who as adults are shorter than 140–150 cm.
- Over 400 various medical conditions leading to short stature, such as genetic diseases, chromosomal aberrations, hormone deficiencies or developmental disorders.
- In Finland there are more than 1000 individuals with short stature due to inherited skeletal diseases

# People with short stature in Finland and in Lyhty study

Inclusion criteria:

- In Finland the most common skeletal diseases causing short stature are
  - Diastrophic dysplasia (DD)
  - Achondroplasia
  - Cartilage-hair hypoplasia (CHH) – which is more common in Finland than in any other country
- In addition, people with short stature caused by Osteogenesis Imperfecta (OI) are included. OI is caused by mutations in the genes affecting both the quality and quantity of the main protein in bone leading to bone fragility as the predominant symptom.



# Purpose?

## **The project is running in 2016–2017**

1. to gain new information about functioning and disability of people with short stature as well as their challenges in accessibility and equality
2. to test feasibility of operationalized questions of the comprehensive musculoskeletal post-acute ICF core set, and
3. to find out associations between functioning and accessibility in individuals with short stature.

# Why?

## **Benefits for people with rare diseases, professionals and organizations are**

- Unique national and international data for advocacy work to improve health and social services of short people and people with rare diseases
- better understanding of functioning of short people in relation to environmental factors and their influence on accessibility and equality, and
- lessons learnt of usability/feasibility of comprehensive client-oriented, ICF-based questionnaires, to guide national and international evaluation research.

# Why?

The comprehensive and holistic data collection and analyses among one target group will expand understanding of how to evaluate functioning and its connections to accessibility and equality.

We produce new data of the life situations of short people with the aim to guide improvement of their health and social services.





# How?

1. First, categories of the comprehensive musculoskeletal post-acute ICF core sets were operationalized to questions and the draft questionnaire was then prepared. (February–March 2016)
2. Secondly, 15 short statured people were invited to in-depth individual interviews. They also completed the draft questionnaire which was then revised based on the received feed-back. (April–July 2016)
3. Thirdly, the final postal questionnaire will be sent out. The aim is to reach out to all over 7 years old people with short stature due to the four diagnosis in Finland and to receive 60 % of the inquiries back. (August–September)
4. Inquiry and process of analyzing. (August–November 2016)
5. Report by the end of February 2017.

# Study partners

- Invalidiliitto ry – The Finnish Association of People with Physical Disabilities
- HYKS lastenkliniikka – Helsinki University Central Hospital, HUCH Pediatrics
- Lyhytkasvuiset – Kortväxta ry (Finnish association for people with restricted growth, and their families and friends)
- THL – The National Institute for Health and Welfare
- Kehitysvammaliitto – The Finnish Association on Intellectual and Developmental Disabilities

In collaboration with

- OI-yhdistys ry – The Finnish Osteogenesis Imperfecta Association
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TERVEYDEN JA  
HYVINVOINNIN LAITOS



Kehitysvammaliitto

# Lisätietoja

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