



**SWEDISH INSTITUTE FOR DISABILITY RESEARCH**  
**LINNAEUS CENTRE HEAD GRADUATE SCHOOL**

# **Persons with Usher syndrome, some aspects of health**

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# SWEDISH INSTITUTE FOR DISABILITY RESEARCH

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## LINNAEUS CENTRE HEAD GRADUATE SCHOOL





# Audiological Research Center

C. Möller, Professor in Audiology and Disability Science. Research about Deafblindness and Usher syndrome.

B. Danermark, Professor in Sociology.  
Communication and Disability.

B. Lyxell, Professor in Psychology.  
Cochlear implant (CI).

K. Möller, Medicine Doctor.  
Activity and Participation in Deafblindness.



C. Henricson, Doctoral student

Speech and language development in children with Usher type 1 and CI. Cognitive functions in adults with Usher type 2.

M. Wahlqvist, Doctoral student

Psychosocial health in Usher syndrome.

H-E. Frölander, Doctoral student

Cognitive development in children with early deafblindness.

B. Rönnåsen, Doctoral student

Communication development in children with Alström syndrome.

M. Ehn, Doctoral student

Importance of environmental factors in Usher syndrome.



# The Usher database

National Swedish register including individuals with Usher syndrome

- All three types included
- Audiograms and visual tests
- Genetics
  
- Swedish National Public health questionnaire, "Health on equal terms"  
HADS – Hospital Anxiety and Depression Scale

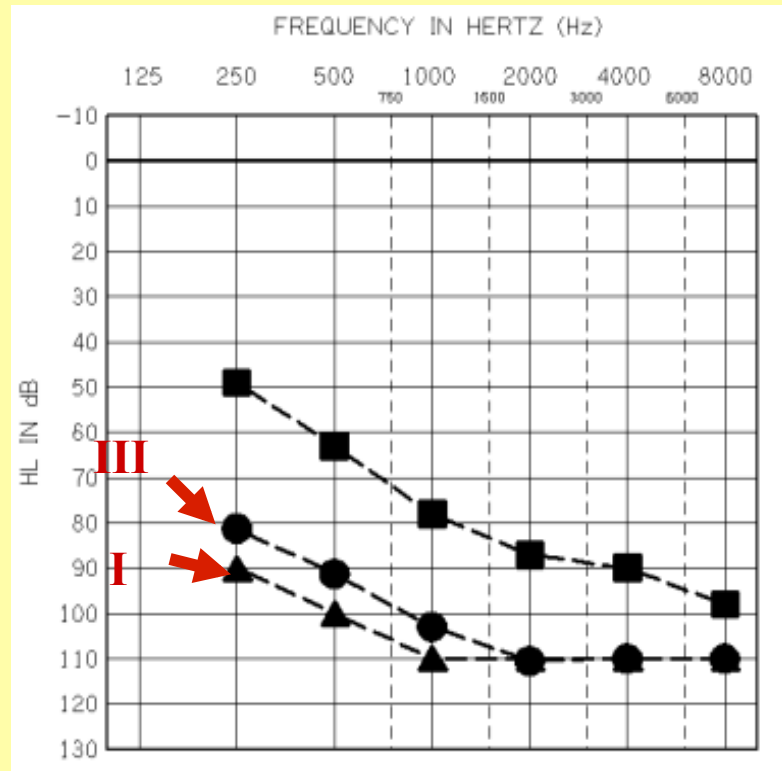
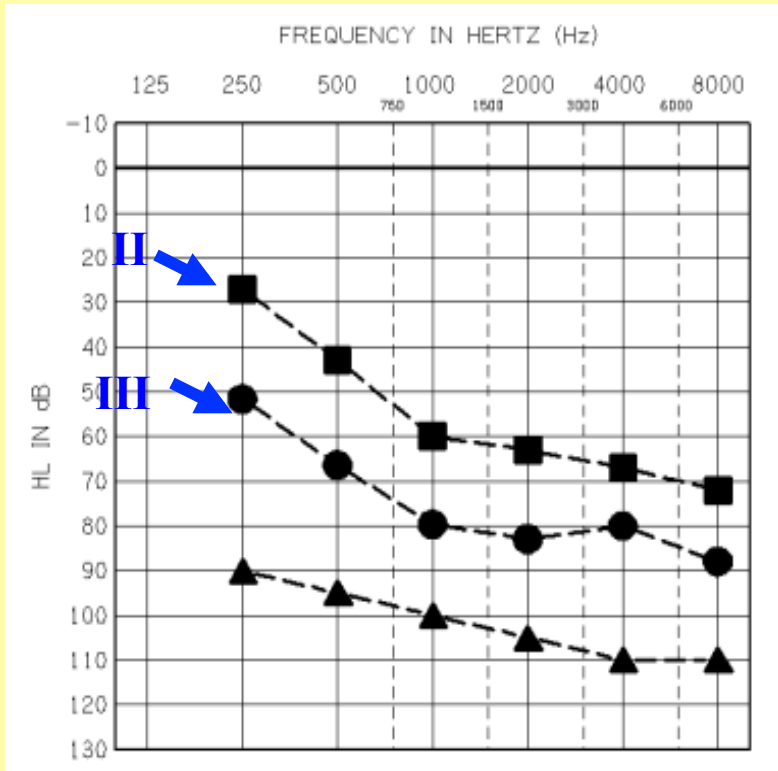
Reference population

- Swedish Public Health Institute
  
- Swedish sample, cross section of the population in Sweden, includes individuals with and without disability

# Hearing impairment, Usher type 1, 2 and 3

4-9y

40-49y

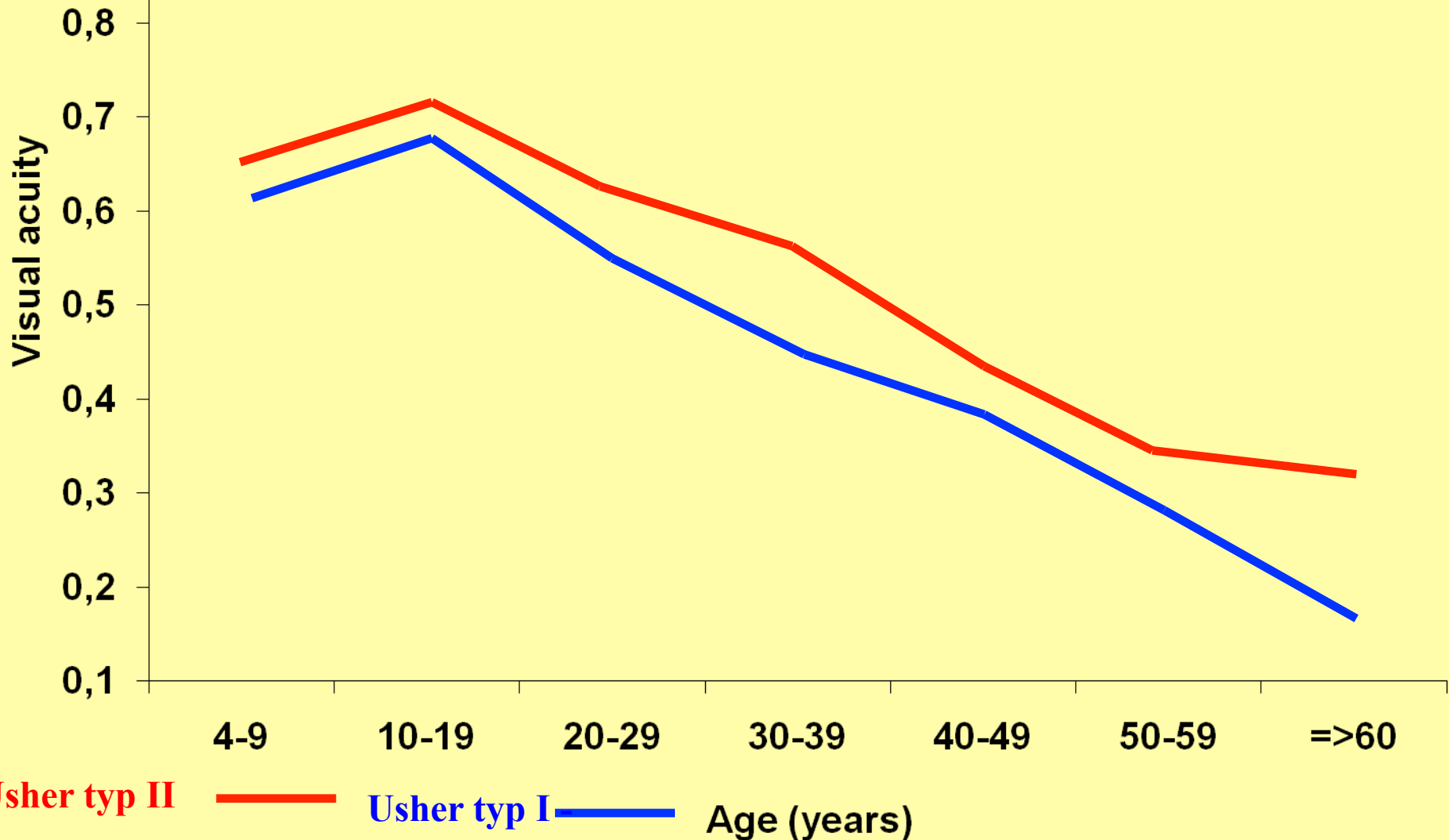


- Usher type II
- Usher type III (USH3)
- ▲- Usher type I

- Usher type II
- Usher type III (USH3)
- ▲- Usher type I



# Visual acuity in a life course perspective





# Teenage





# 20-40 years



# 40-50 years





# Health among persons with Usher syndrome

## Study 1

Physical and Psychological Health among persons with deafblindness due to Usher type 2

## Study 2

Physical-, Psychological Health and Social relations among persons with Usher type 3

## Study

Usher type 1, Health

Swedish National Public health questionnaire, "Health on equal terms", and HAD-scale

## Study 4

Lifestrategies



# Study 1

“Physical and Psychological Health among persons with Deafblindness due to Usher syndrome type 2”

(Wahlqvist et al. 2013)

Swedish National Public health questionnaire, “Health on equal terms”, and HAD-scale

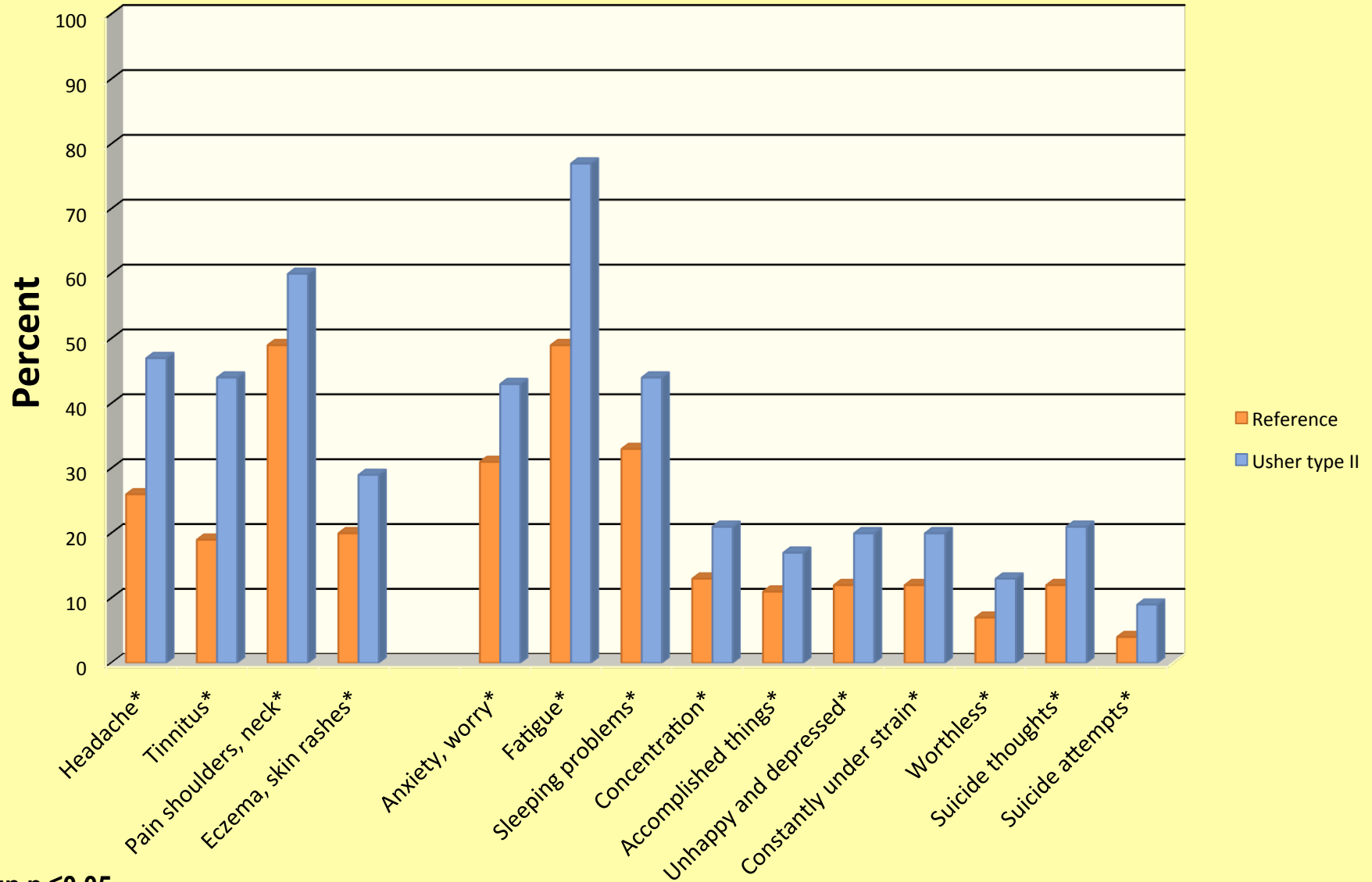
The aim was to describe physical and psychological health among persons with Usher type 2, and to explore if there was differences between men and women compared to a cross section of the Swedish population



# Population

	USH2	Reference
Number	96	5738
Age (mean)	55	58
Age(min - max)	18-84	23-91
Women (%)	53	56
Genetic diagnose	59%	
PTA4 best ear	73db	
Visual field (mean)	4 ( $<10^{\circ}$ )	
Visual acuity (mean)	0,4	

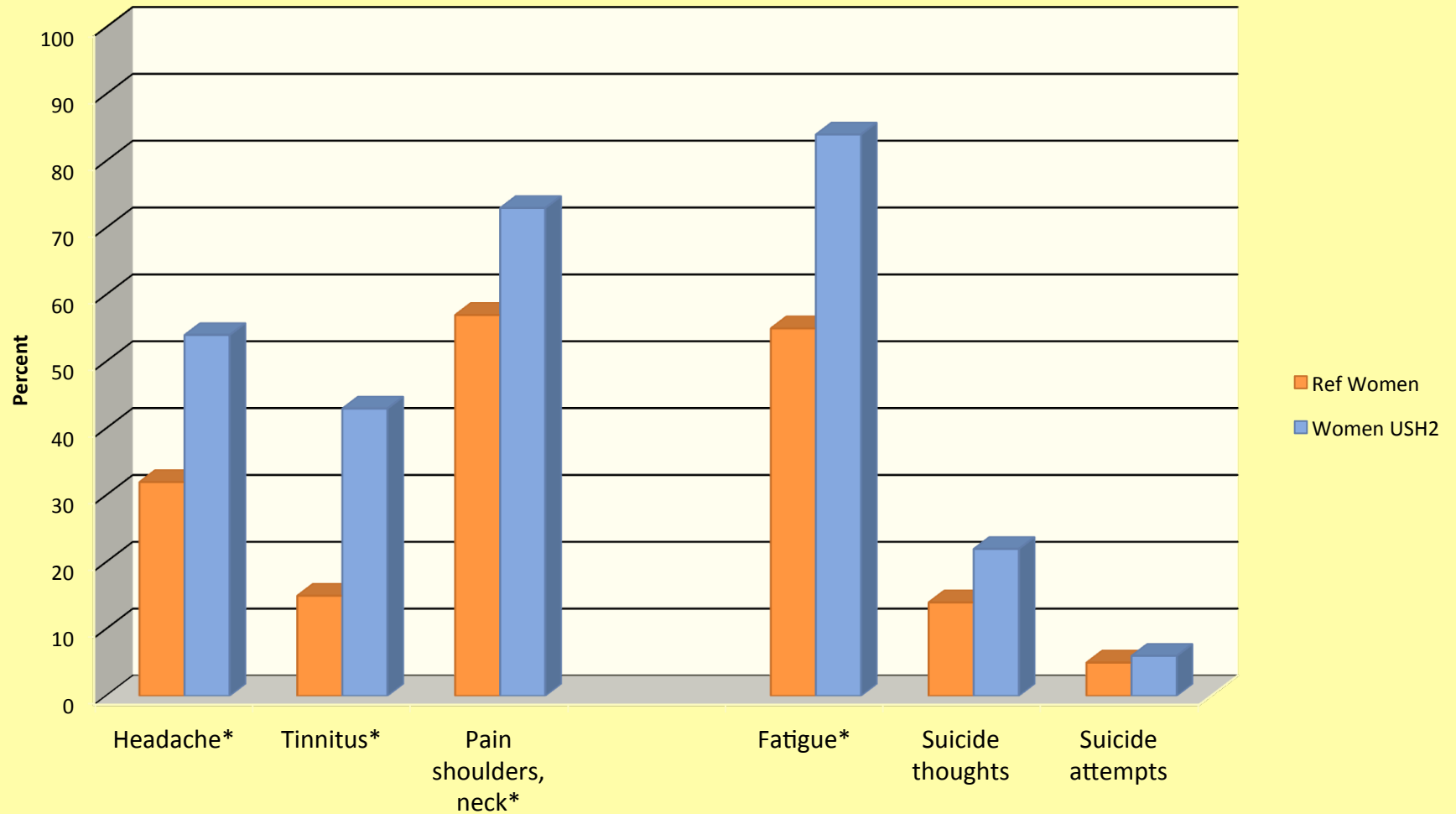
# Physical and Psychological Health



\*Sign  $p \leq 0,05$

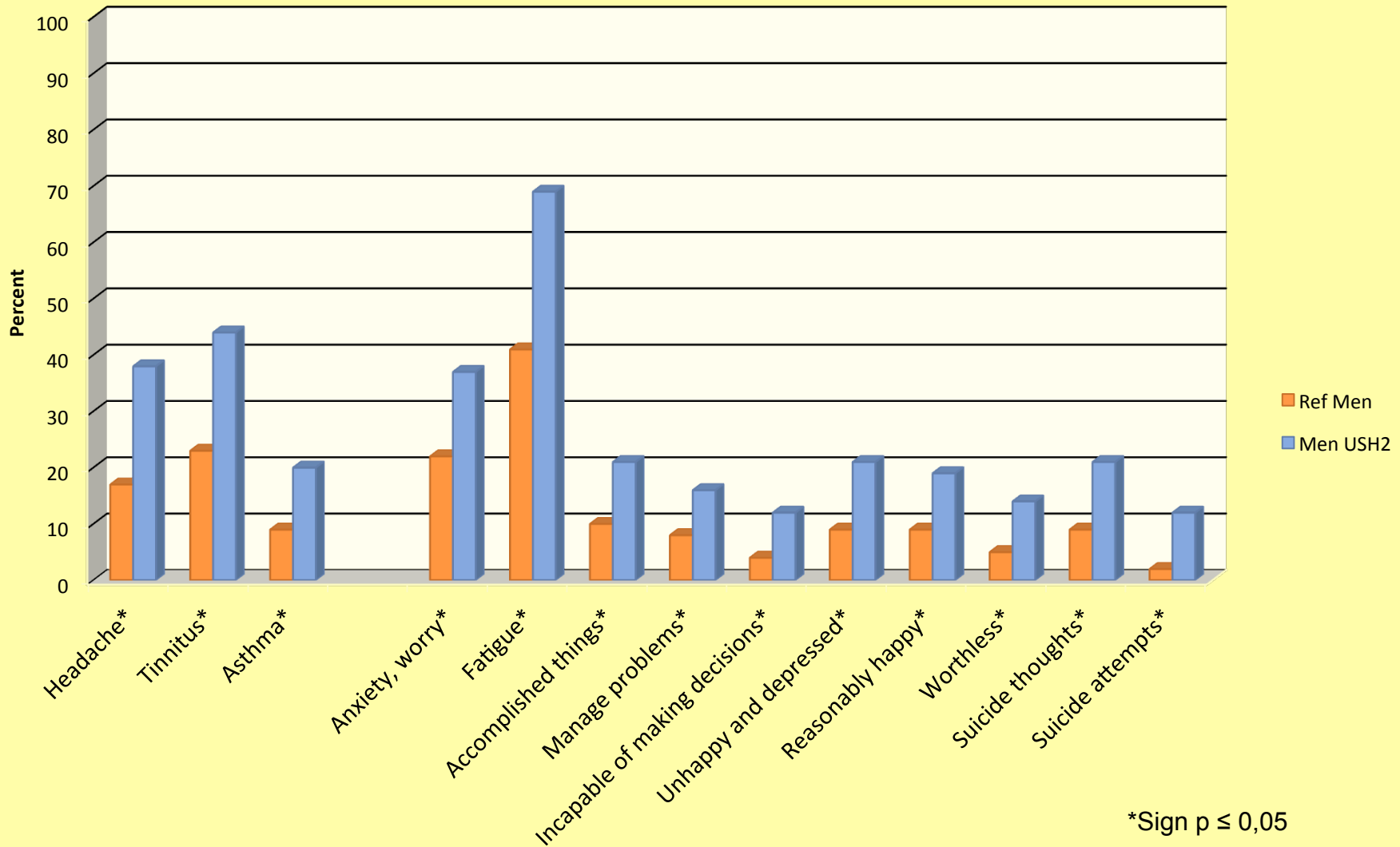


## Physical and Psychological Health



\*Sign  $p \leq 0,05$

## Physical and Psychological Health





# Conclusions

Persons with USH2 have more problems with physical and psychological poor health than a cross section of the population in Sweden.

Problems with:

Headache, fatigue, feelings of worthlessness, suicide thoughts and suicide attempts

Small difference between men and women with USH2

Men with USH2 have more problems with psychological poor health than men in the reference



## Study 2

The aim was to describe and analyze data on vision and hearing impairment, physical-, psychological health and social risk among persons with USH3

15 persons with USH3

Mean age 41 years

11 women and 4 men

Swedish National Public health questionnaire, "Health on equal terms", and HAD-scale



# Preliminary conclusions

Physical problems related to pain (headache, neck/shoulders and back pain)

Psychological problems due to fatigue, sleeping problems, stress and worry

Suicide thoughts and attempts

Social withdrawal and a general mistrust in others



# Study 3

Health among persons with USH1

Swedish National Public health questionnaire, "Health on equal terms", and HAD-scale

Adjustments of the material

DVD, USB, large font, better contrast

Pilot

Sent out to 85 persons with USH1, response rate 71 %

Analyzes will begin autumn 2014





# Study 4

Research event 26-27 of April 2013

Invited persons with USH2, Audiological Research Center, University Hospital, Örebro, Sweden

14 participants

9 men and 5 women

Group interviews

Life strategies

- When life has been difficult...

Hearing assessments and cognitive tests



# What can this research lead to?

- Evidence-based practice
- Prevent physical and psychological poor health
- Platform to gain resources



Thanks!

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