

## Health-related Quality of Life (HRQL)

- › ... Individuals' perceptions of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (WHOQOL group, 1993,1995)
- › ... to gain a better understanding of relevant issues which is essential for optimizing clinical management, planning appropriate care and evaluate specific interventions.

## **Interest in Health related Quality of Life (HrQOL) in Medicine**

- › Increased proportion of persons in need of continuous care
- › Consequences differ widely depending on mediating variables  
Age, gender, social support, coping ....
- › Expanded view of the traditional medical model (morbidity and mortality)

## Objectives of HRQOL measurement

- › Monitoring and evaluation of treatment effects,  
Routine outcome assessment, Quality assurance of care,  
(clinical perspective)
- › Description of well-being and function of populations,  
Identification of needs  
(epidemiological/public health perspective)
- › Comparison of treatment costs and benefits,  
Allocation of resources  
(health economical /health systems perspective)

## Dimensions of HRQL

- › HRQL is a multidimensional construct pertaining to the physical, emotional, mental, social and behavioral components of well-being and functioning
- › Generic and disease specific
- › Focus on adults

## Need for QOL assessment in children ?





## Long-term Implications

- › Increase in prevalence of chronic conditions among children and adolescents
- › Increasing focus on long-term management and prevention
- › Increasing demands on public health policies and health care system

## Requirements for quality of life assessment in children (WHO, 1994)

- › Instruments should be **child-centered**
- › Subjective **self-report** has priority
- › Instruments should be related to age and **developmental** stage
- › Results should be **cross-culturally comparable**
- › Instruments should have a generic core and specific modules
- › **Positive** health-enhancing aspects of QOL should be stressed

## Generic QoL- Instruments for children

### *Examples*

- › **CHQ**  
(Child Health Questionnaire), USA, 1993  
Landgraf et al., 5 -18
- › **CHIP**  
(Child Health and Illness Profile), USA, 1993  
Starfield et al., 11 -17
- › **KINDL-R**  
(HrQoL in Children and Adolescents), D, 1998  
Ravens-Sieberer & Bullinger, 4 - 16
- › **TACQOL**  
Vogels et al., NL, 1998, 6 -15
- › **VSP-A**  
(Perceived Health of Adolescent), F, 1998  
Siméoni et al., 11 – 17
- › **PedsQL**  
(Pediatric Quality of Life Inventory), USA, 1999  
Varni et al., 2 – 18
- › ...

## Available QoL-Instruments

- › Often too long
- › Observer - oriented
- › Not applicable to infants and small children
- › Difficult to use in different age-, culture-, disease-, treatment-groups
- › Several national instruments are available but **international instrument development** is rare
- › International instrument development in children's QoL usually follows a **sequential** approach, not a **simultaneous** approach



## KIDSCREEN Project

### Screening for and Promotion of Health-related Quality of Life in Children & Adolescents - A European Public Health Perspective

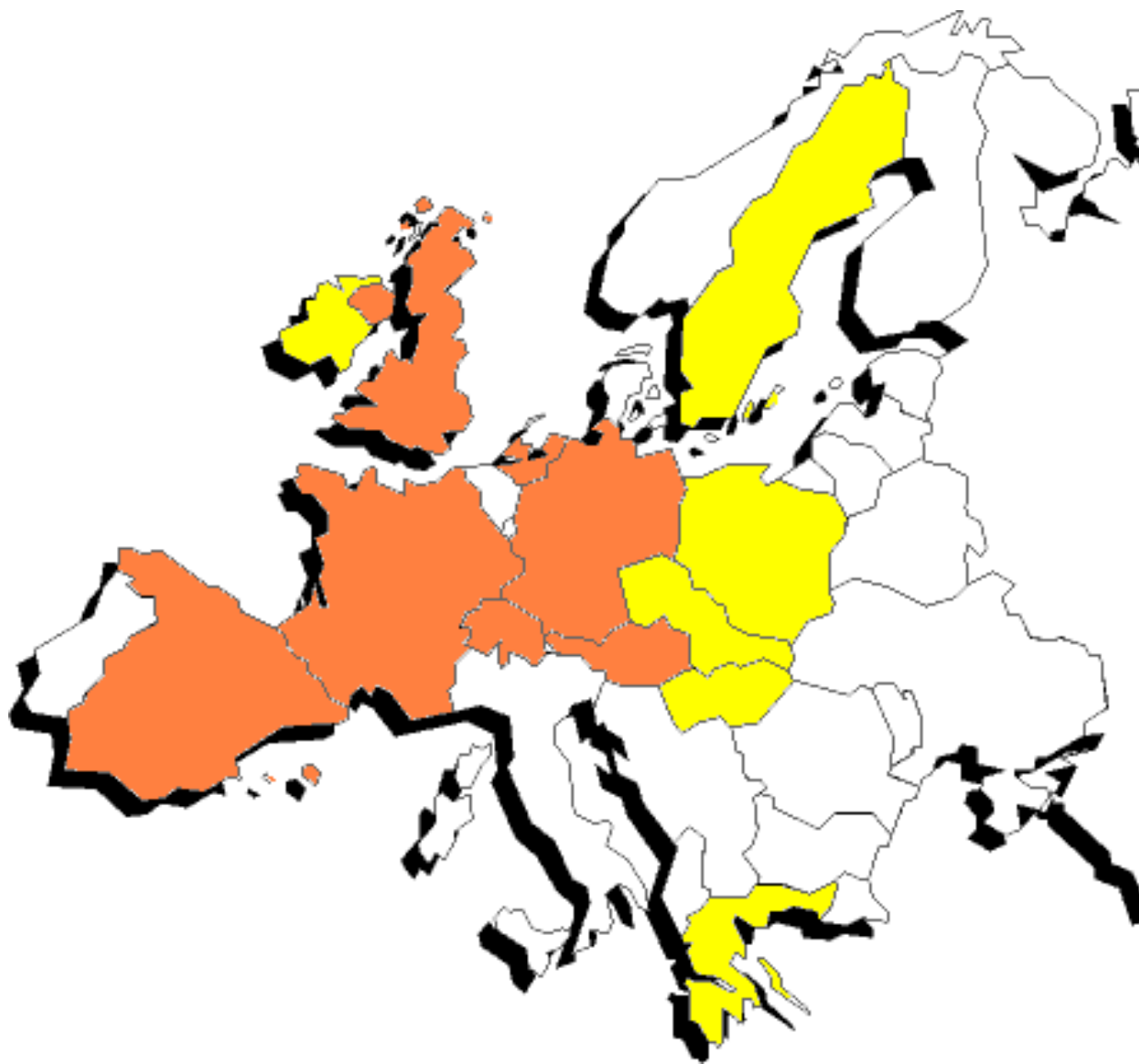
- › Fifth **EC Research Framework** Programme
- › European attempt to develop a **standardised cross-cultural generic Health-related Quality of Life assessment tool** for children and adolescents and their parents.
- › Identification of resources of health and of risks in regard to the perspective of the family
- › **Implementation** in national and **European health services** to plan, monitor, and evaluate health prevention and care.

# Instrument Development

# Project partners KIDSCREEN

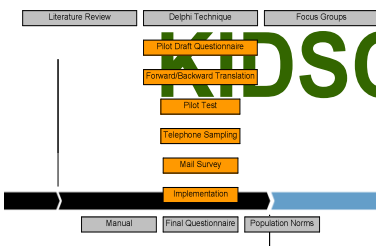
- Germany
- Spain
- Netherlands
- Austria
- UK
- France
- Switzerland

- Greece
- Hungary
- Czech Republic
- Poland
- Ireland
- Sweden



European Commission's grant number [QLG-CT-2000-00751](#)

# HRQoL SCREEN Development Steps



## Literature Review

Identified 10 generic Instruments

Qualitative Instrument Review  
(Rajmil et al. 2004)

Identification of HRQoL  
Dimensions across Instruments

## Delphi Consensus Process

24 Experts

Definition of theoretical  
Domain Structure

Specification of ...

- response options
- time frame, context
- instrument length
- dimensions

## Focus Groups

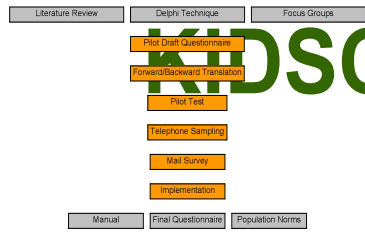
36 Groups,  
n=214 children, 83 parents  
Simult. Conduction (7 countries)  
Duration: 1 1/2 - 2 hours

Qualitative Content Analysis,  
Identification of Dimensions  
Generation of Item Statements

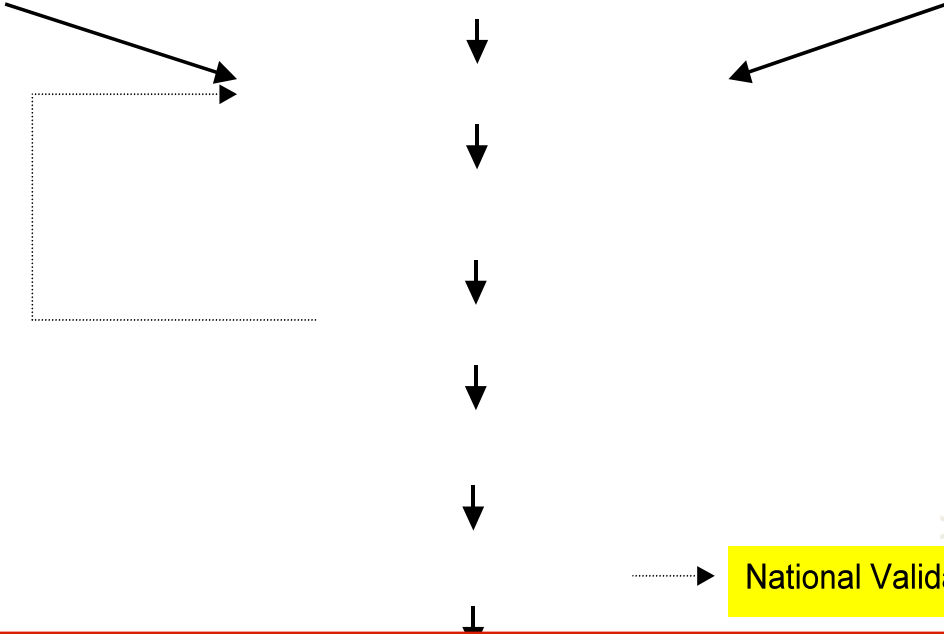
Confirmation of ...

- domains
- response options
- time frames

**Basis for Hierarchical Domain Structure & Definition of Item Banks**



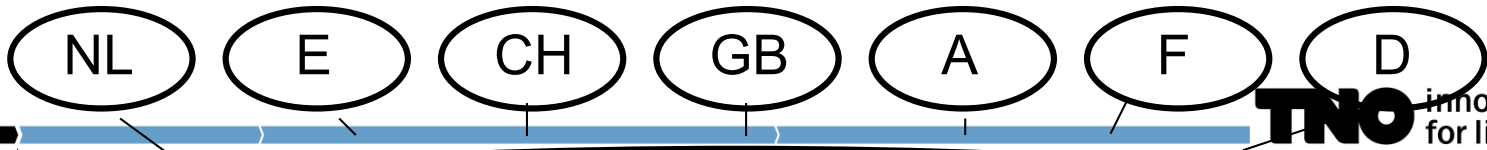
# KIDSCREEN Development Steps



> 3800 families

National Validation





International Pilot Data Set  
n=3834 Children and Adolescents

159  
Items

**Two statistical strategies  
for item reduction**



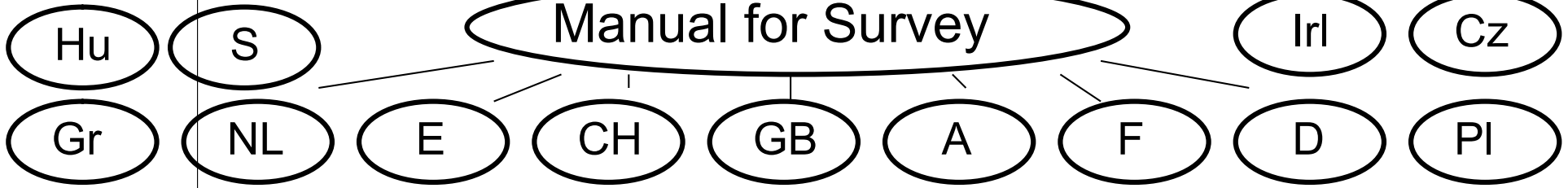
**Modern psychometric methods:**

- 1 : Basic item analyses
- 2 : CFA, EFA
- 3 : Item Reduction via **Item Response Theory Models / DIF-Analysis**

**Classical Testtheory:**

- 1 : Basic item analyses
- 2 : Explorative FA
- 3 : Item Reduction via Methods of Classical Testtheory

Manual for Survey



Data analysis

# KIDSCREEN instruments

(child & proxy versions)

- ▶ **KIDSCREEN-52:**
- ▶ 10 dimensions of HRQOL
- ▶ profile with detailed information, research focused
- ▶ KIDSCREEN-27:
- ▶ 5 dimensions of HRQOL
- ▶ Profile
- ▶ can be used for evaluation purposes in health services, health monitoring & clinical research
- ▶ KIDSCREEN-10 Index:
- ▶ very short and psychometrically sound screening instrument
- ▶ can be used as indicator in epidemiological studies and surveys

**Physical Well-being**  
Have you felt fit and well?  
Have felt full of energy?

**Psychological Well-being**  
Has your life been enjoyable?  
Have you been in a good mood?

**Moods & Emotions**  
Have you felt sad?  
Have you felt lonely?

**Self Perception**  
Have you been happy with the way you are?

**Autonomy**  
Have you had enough time for yourself?

**Parent relation & Home Life**  
Have your Parents treated you fairly?

**Financial Resources**  
Have you had enough money to do the same things as your friends?

**Peers & Social Support**  
Have you had fun with your friends?

**School Environment**  
Have you got on well at school?  
Have you been able to pay attention?

**Bullying**  
Have you been afraid of other girls and boys?

# KIDSCREEN 52-Item Research Version: scale characteristics

Dimensions	items	mean	sd	missing	maxi-	mini-	chron	Rasch-	Rasch-
		0-100	0-100	values	mum	mum	bach	itemfit	itemfit
				%	%	%	$\alpha$	infit msq	infit msq
								min	max
Physical Well-being	5	68,43	18,90	0,4	5,2	<0,1	,78	0.887	1.126
Psychological Well-being	6	76,54	18,30	0,6	9,6	0,1	,89	0.946	1.138
Moods & Emotions	7	78,44	17,23	0,5	8,1	<0,1	,85	0.813	1.225
Self Perception	5	73,36	20,89	0,4	11,5	<0,1	,79	0.885	1.070
Autonomy	5	72,74	20,96	0,3	11,3	0,2	,84	0.896	1.084
Parent Relation & Home Life	6	78,83	19,32	0,8	15,3	<0,1	,88	0.885	1.084
Peers	6	73,68	19,45	0,5	7,4	0,3	,84	0.801	1.264
School Environment	6	66,42	20,88	1,4	4,9	0,2	,87	0.900	1.136
Social Acceptance (Bullying)	3	88,90	16,53	1,4	49,2	0,3	,77	0.924	1.100
Financial Resources	3	71,35	26,69	2,9	24,4	1,8	,89	0.965	1.021

Country A,CH, CZ, D, E, F, GR, HU, NL, PL, S, UK N=21623

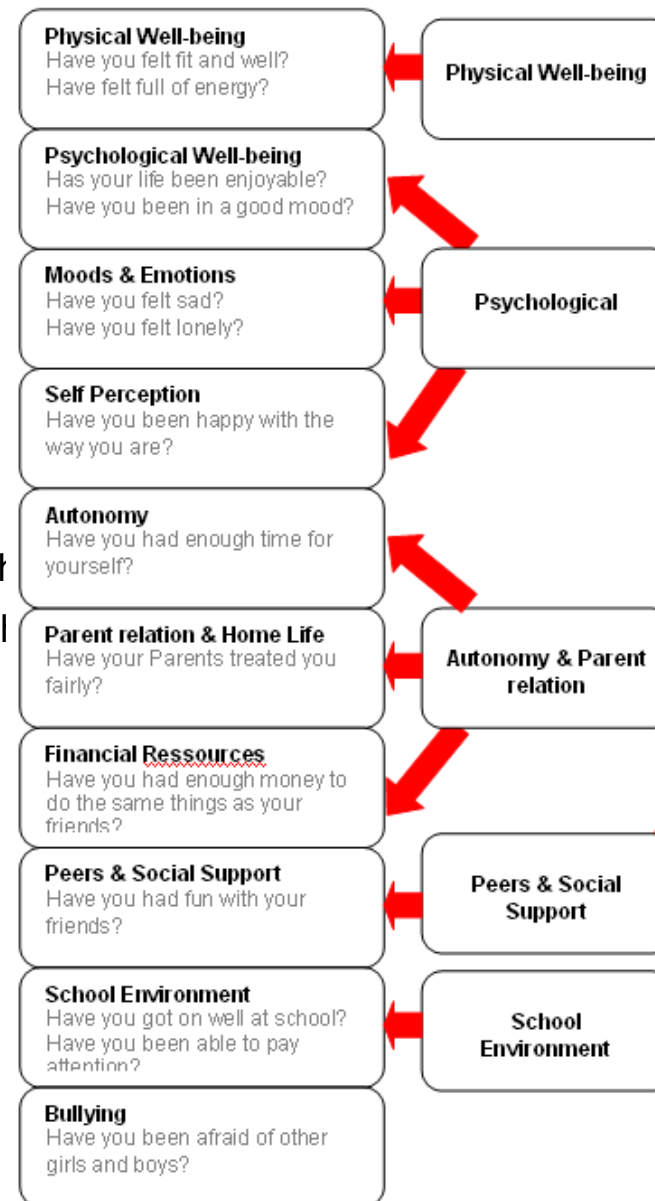
Children & Adolescents

**Cross-cultural** perspective is accounted for in the analysis,  
controll of DIF enables a **culture fair** HrQoL-assessment

# KIDSCREEN instruments

(child & proxy versions)

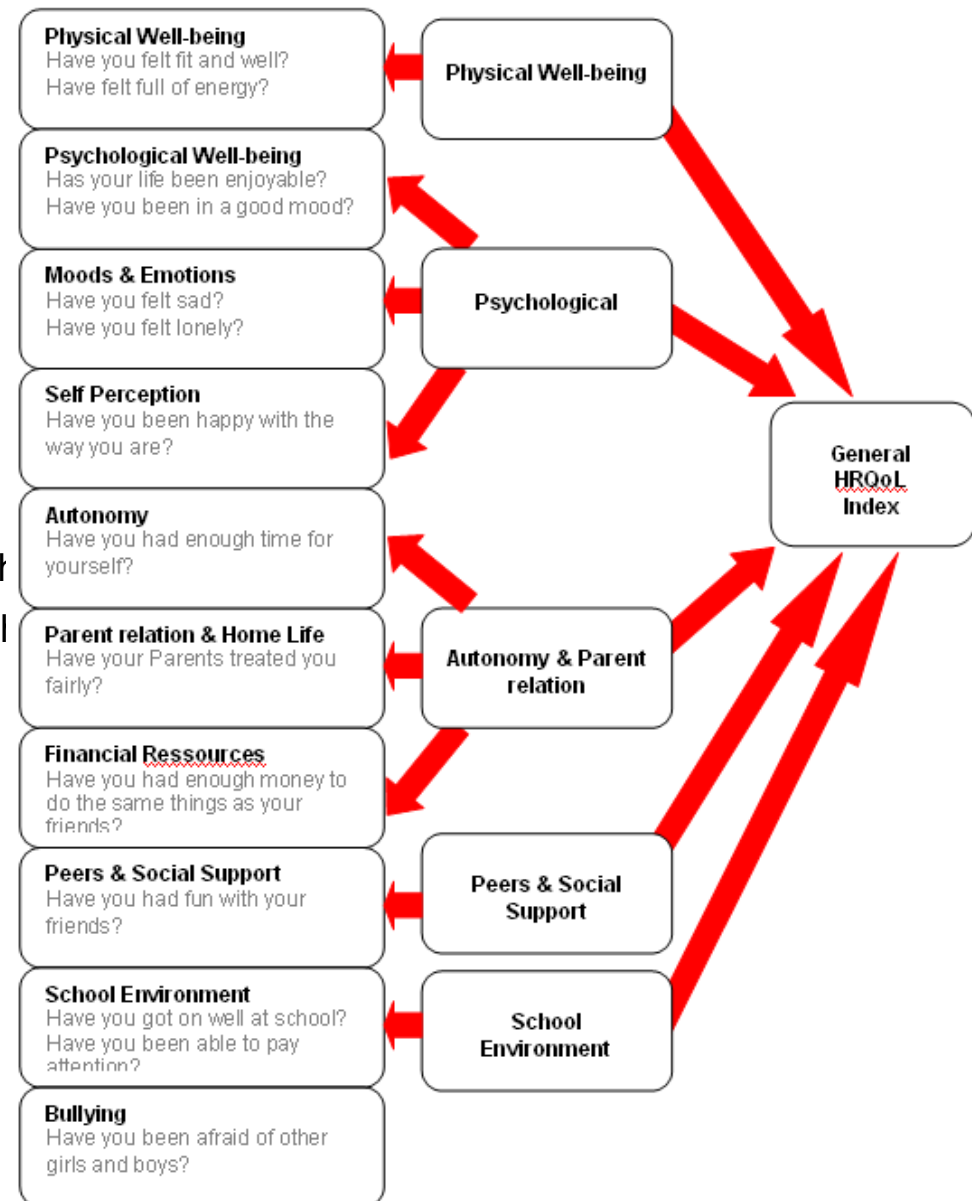
- ▶ **KIDSCREEN-52:**
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- ▶ **KIDSCREEN-10 Index:**
  - ▶ very short and psychometrically sound screening instrument
  - ▶ can be used as indicator in epidemiological studies and surveys



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- › **KIDSCREEN-52:**
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  - › **KIDSCREEN-10 Index:**
    - › very short and psychometrically sound screening instrument
    - › can be used as indicator in epidemiological studies and surveys
- Advantages:** simultaneous European approach, IRT based development, Rasch-scaling, control for DIF



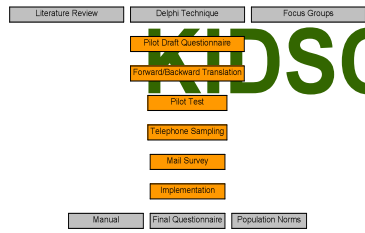
## General Quality of Life

During the past week ...

1. Have you felt fit and well?
2. Have you felt full of energy?
3. Have you felt sad?
4. Have you felt lonely?
5. Have you had enough time for yourself?
6. Have you been able to do the things that you want to do in your free time?
7. Have your parent(s) treated you fairly?
8. Have you had fun with your friends?
9. Have you got on well at school?
10. Have you been able to pay attention?

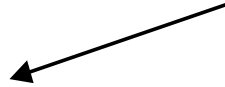
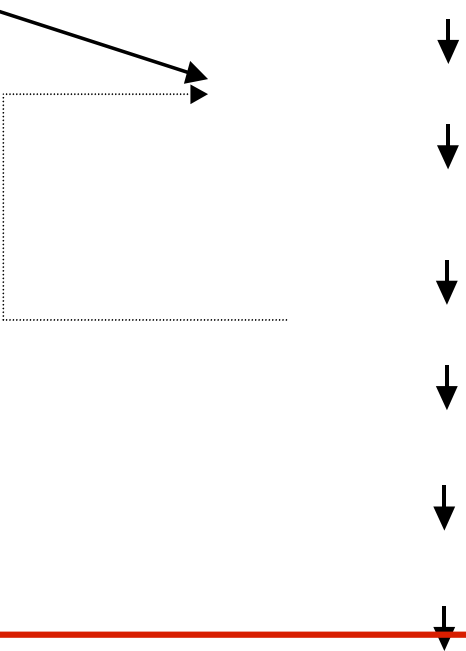
## Results Psychometrics

- › KIDSCREEN Items can be clustered into **stable & psychological meaningful** factors
  - ⇒ valid assessment of quality of life is possible
- › Items form a **Rasch-scale** for every dimension in every country - scales have **high psychometric properties**
  - ⇒ Summation of items is justified; Sum-score gives exhausting information about the items & can be transformed into an interval-scaled measure
- › Control of DIF enables a **culture fair** HrQoL-assessment
- › **Cross-cultural** perspective is accounted for by the analysis



# KIDSCREEN Development Steps

1



> 3800 families

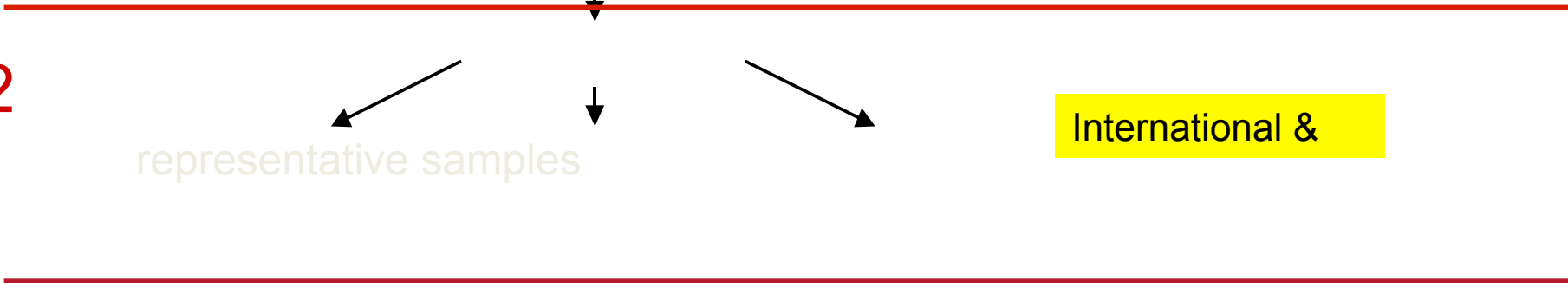
National Validation

2

representative samples

International &

3



# European KIDSCREEN- Survey



## › Representative HI-Surveys

in 13 countries (*Telephone sampling & post mail, Schoolsamples*)

## › Comparison data = ESS (*European Social Survey, Eurostat*)

› Per country 1500-1800 families (6-17 years)

total n:

22.830 Children (8-18 J.)

16.888 Parents

## › The survey included also other

health indicators:

health behaviour, parental health,

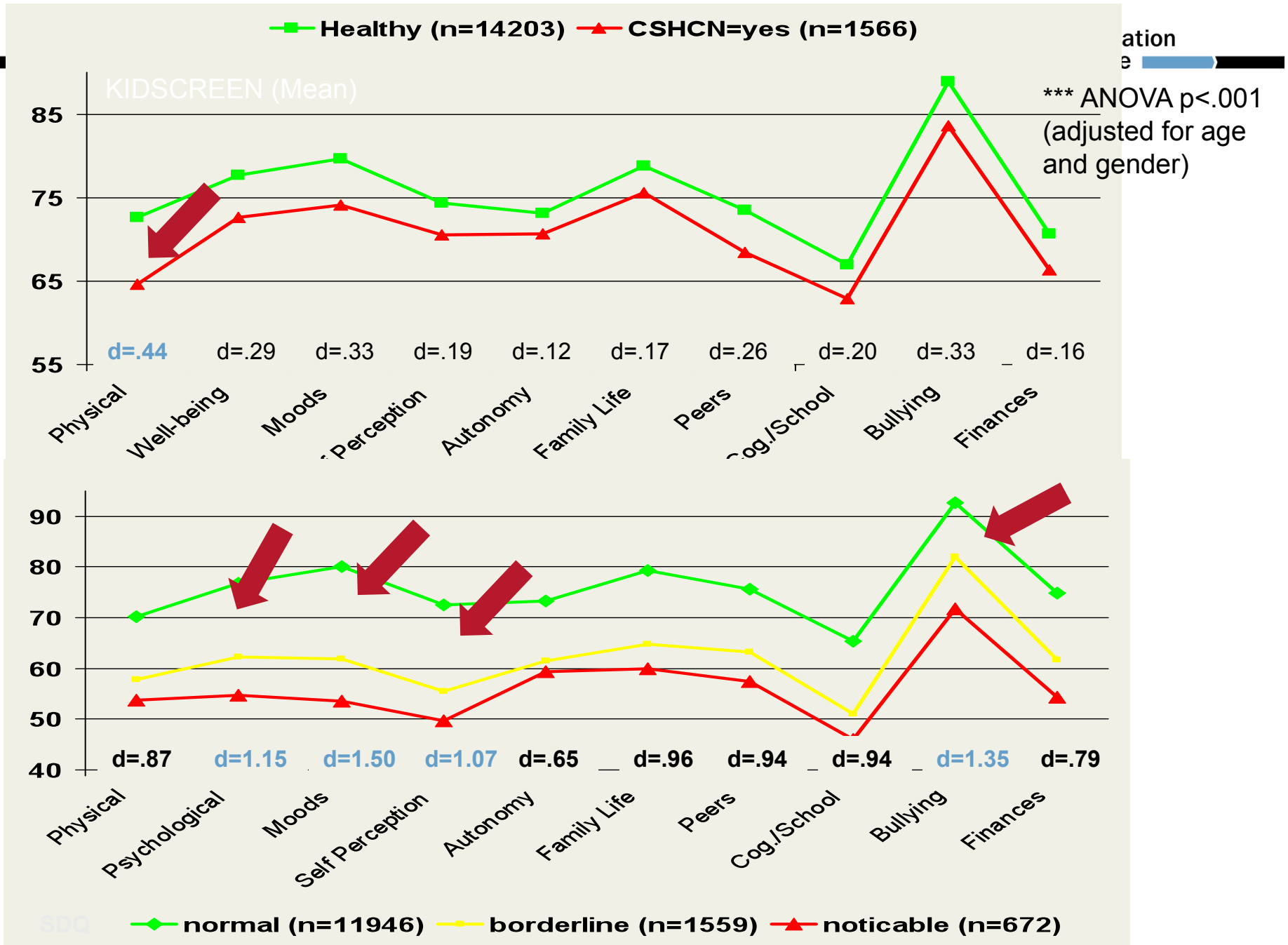
health services

utilization, social support, SES, ....



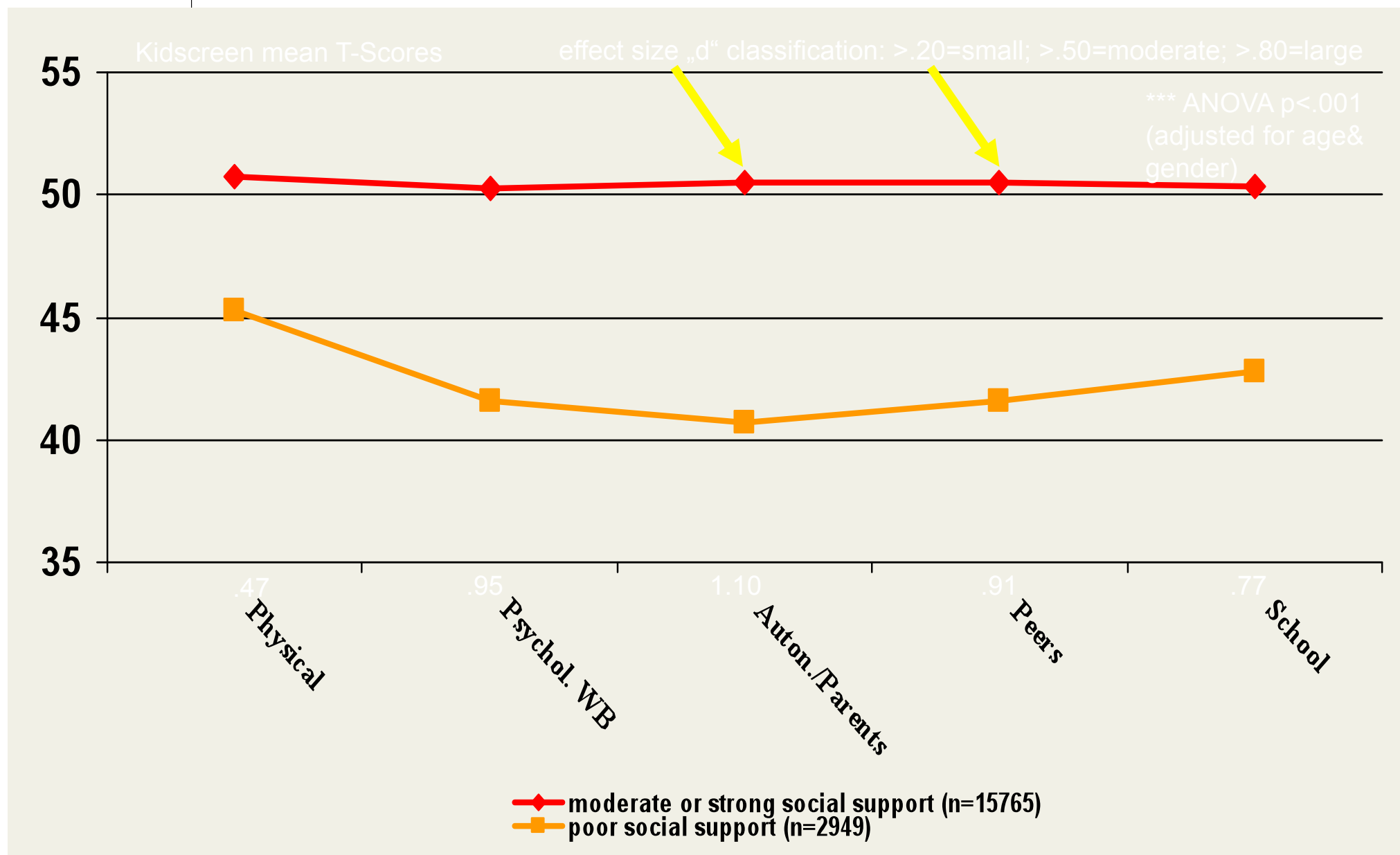
# Epidemiological perspective: results from a European cross-sectional survey

# HrQoL and Health Status

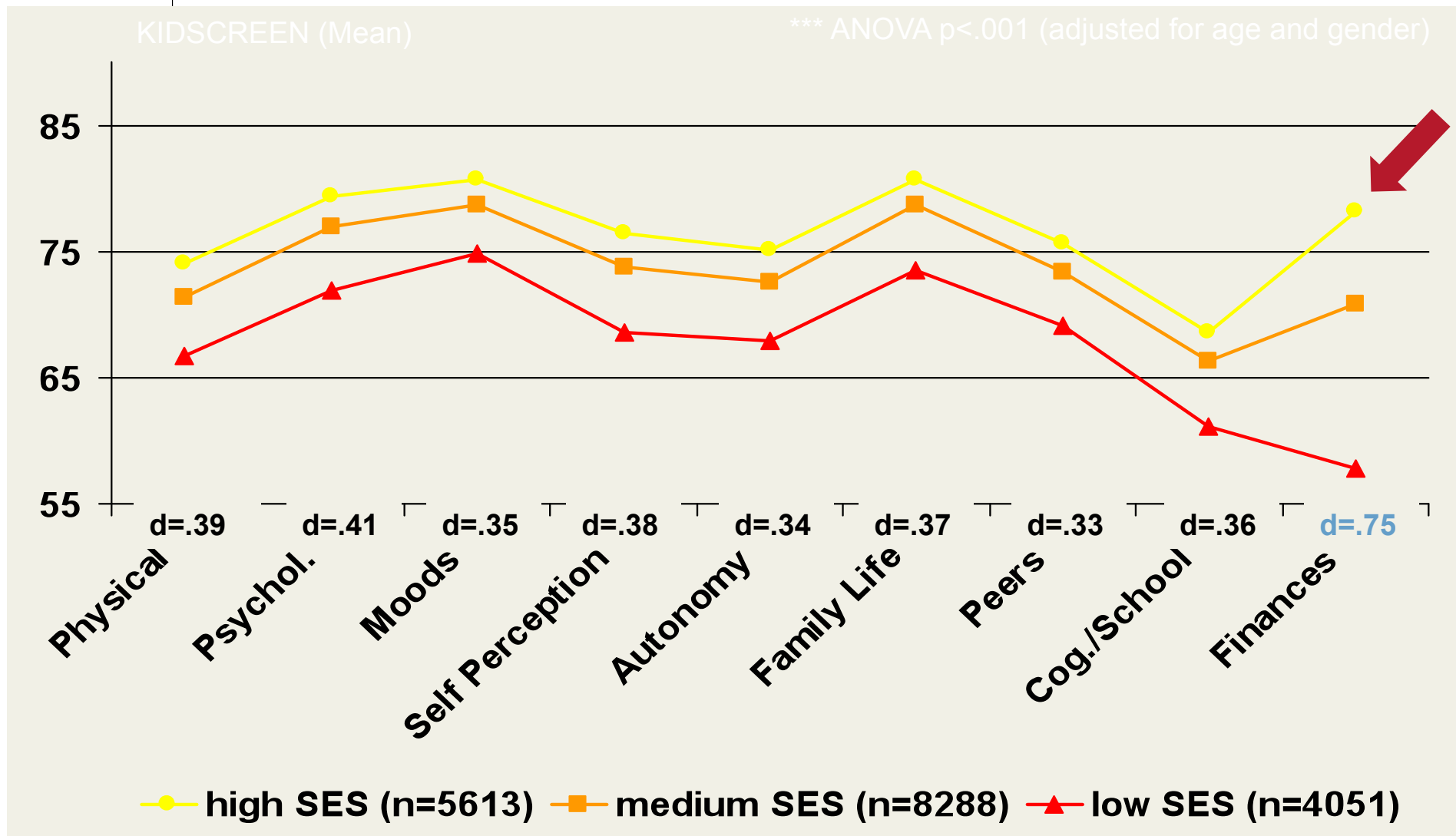


# HrQoL and Social Support

(Oslo Social Support Scale)

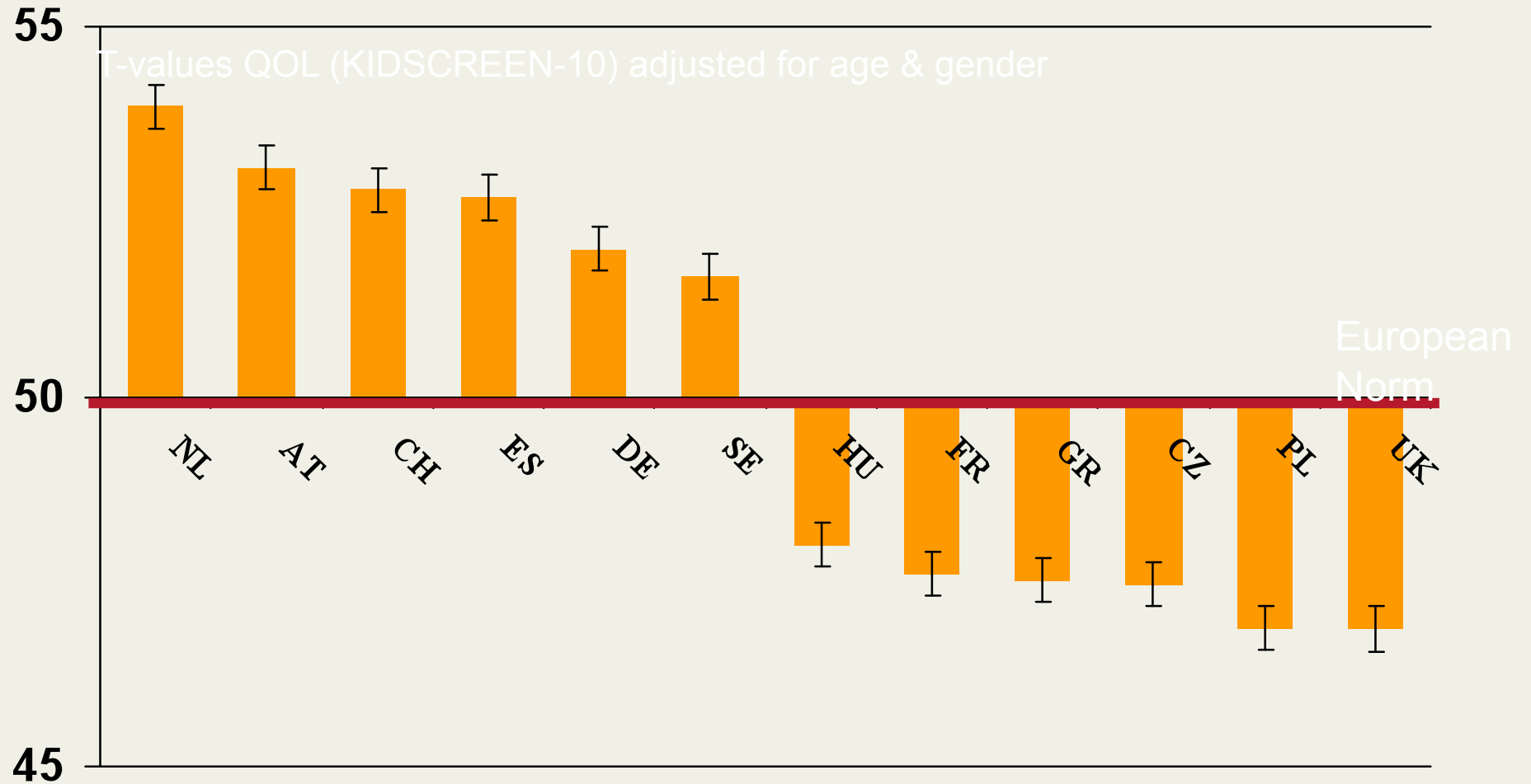


# KIDSCREEN: HrQoL and SES

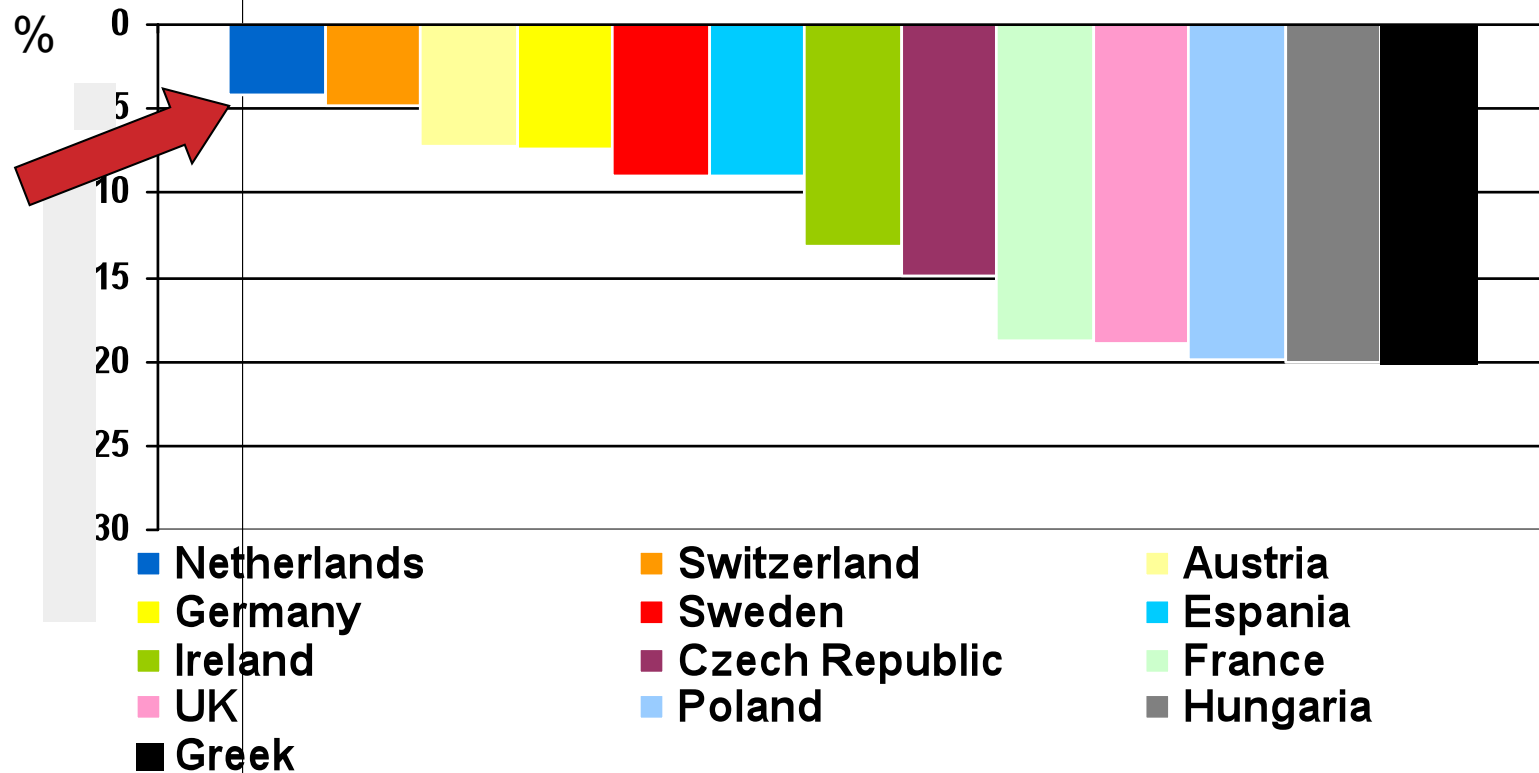


Cohens Effect size SES high vs. low "d": .20=small, .50=medium, .80=large

# HRQoL (KIDSCREEN index) across countries



Respondents with substantially reduced Quality of Life according to the KIDSCREEN-10 index:  
% Population below cut off in 13 European countries



# European cross-sectional study



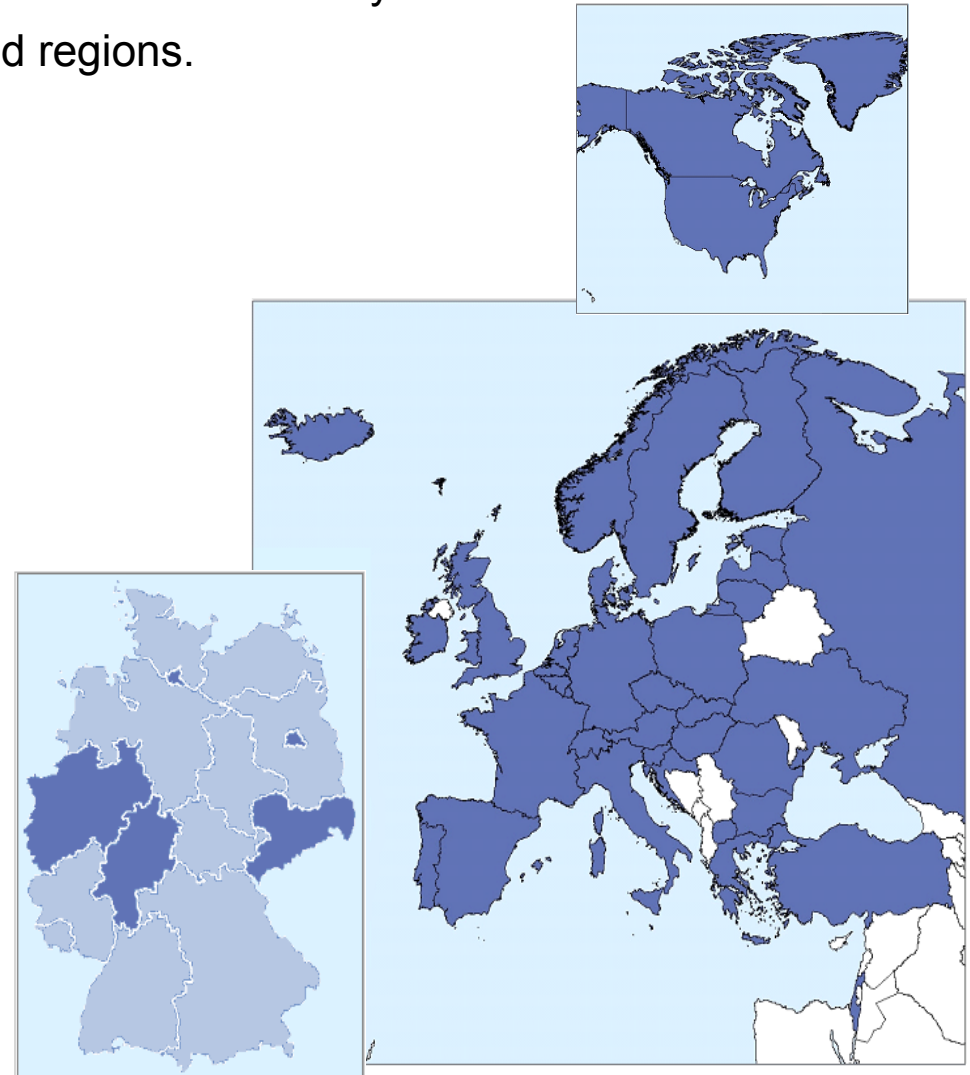
**hb** Health Behavior in  
**sc** School-aged Children  
A World Health Organization Cross National Study

# The „Health Behaviour in School-aged Children“ (HBSC) study

**TNO** innovation  
for life



- › Cross-national research study conducted in collaboration with World Health Organization as a WHO collaborative study. There are now **43 participating countries** and regions.
- › The first cross-national survey was conducted in 1983/84, since then **data collection** has been carried out every four years using a **common research protocol**.
- › most recent survey 2005/06:  
160.000 school children grade 5., 7., 9. (11-15 J.)  
The study aims to gain new insight into the understanding of **young people's health and well-being**, health behaviours and their **social context**.



Indicator of socioeconomic status:  
**Familial affluence assessed through children's  
self report**

The **WHO - Family Affluence Scale (FAS)** asks for material conditions of the households in which young people live:

“Does your family own a car, van or truck?”

“Do you have your own bedroom for yourself?”

“During the past 12 months, how many times did you travel away on holiday with your family?”

“How many computers does your family own?”

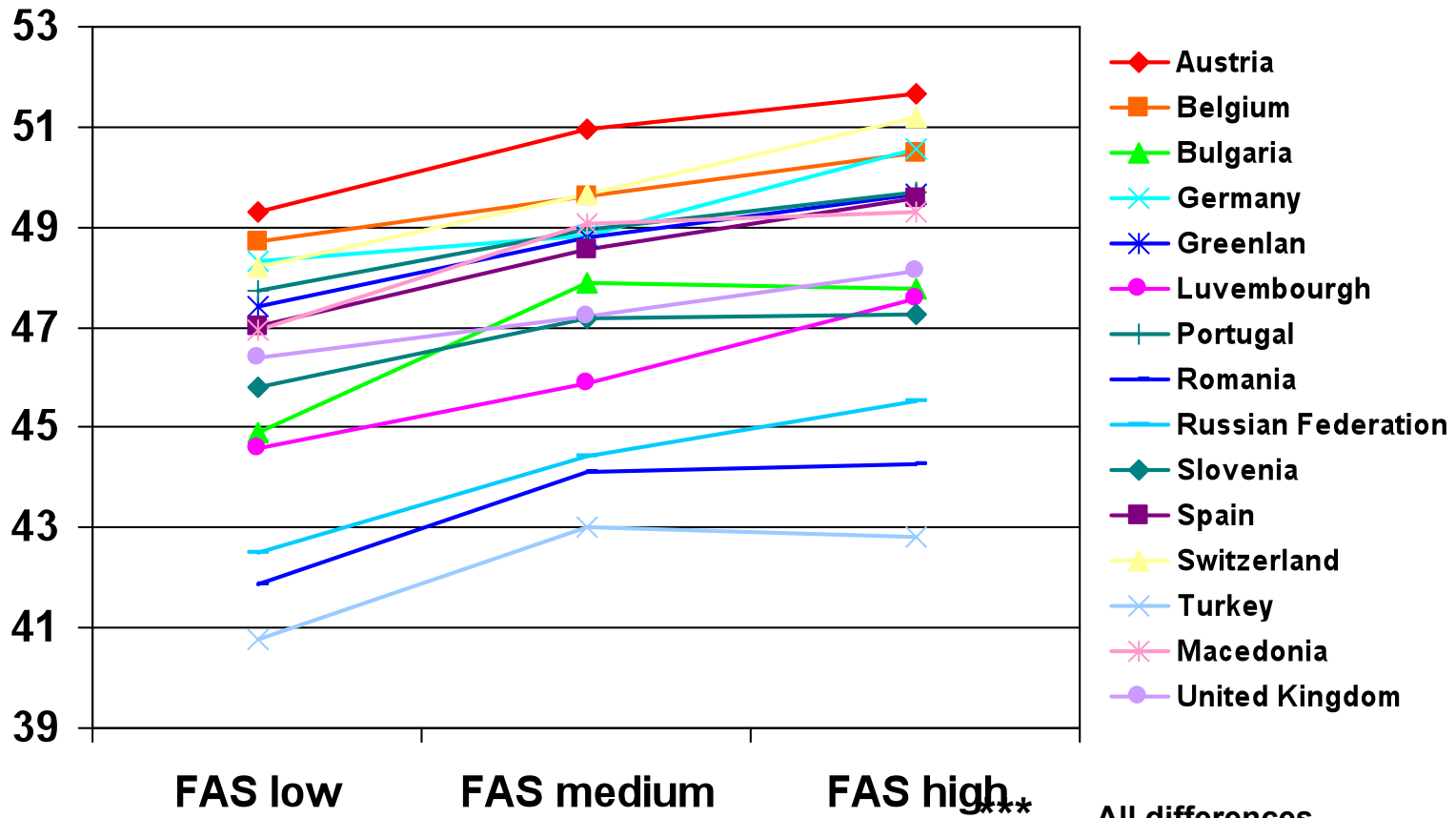
Items are summed up to a weighted score of items, this overall score gives values of **low**, **middle** and **high** family affluence.

# SES differences in children and adolescents health

high FAS => high positive health



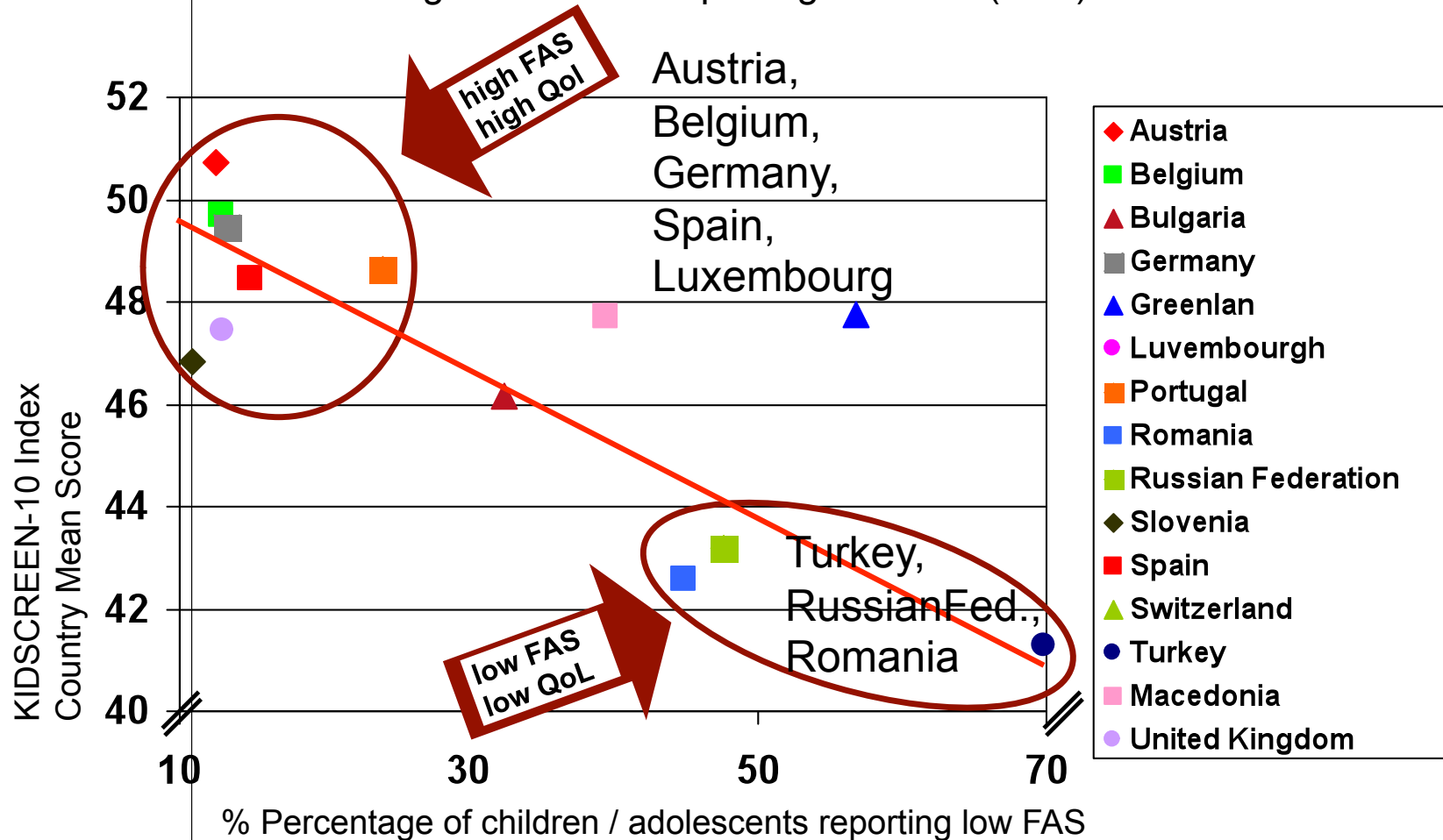
KIDSCREEN-10-Index- mean score (children)



All differences significant at p < .001 except Greenland

KIDSCREEN QoL index mean scores by percentage of children reporting low family affluence. (R=0.74; R<sup>2</sup>=0.54; p<.01)

Percentage of children reporting low SES (FAS) and adolescents' well-being



## **HRQOL in European overweight children and adolescents**

### **Aim:**

To describe the health-related quality of life of children with overweight or obesity in 10 European countries

### **Methods:**

Self-reported height and weight by parents and children  
KIDSCREEN 52-item version self-report (8-18 years)

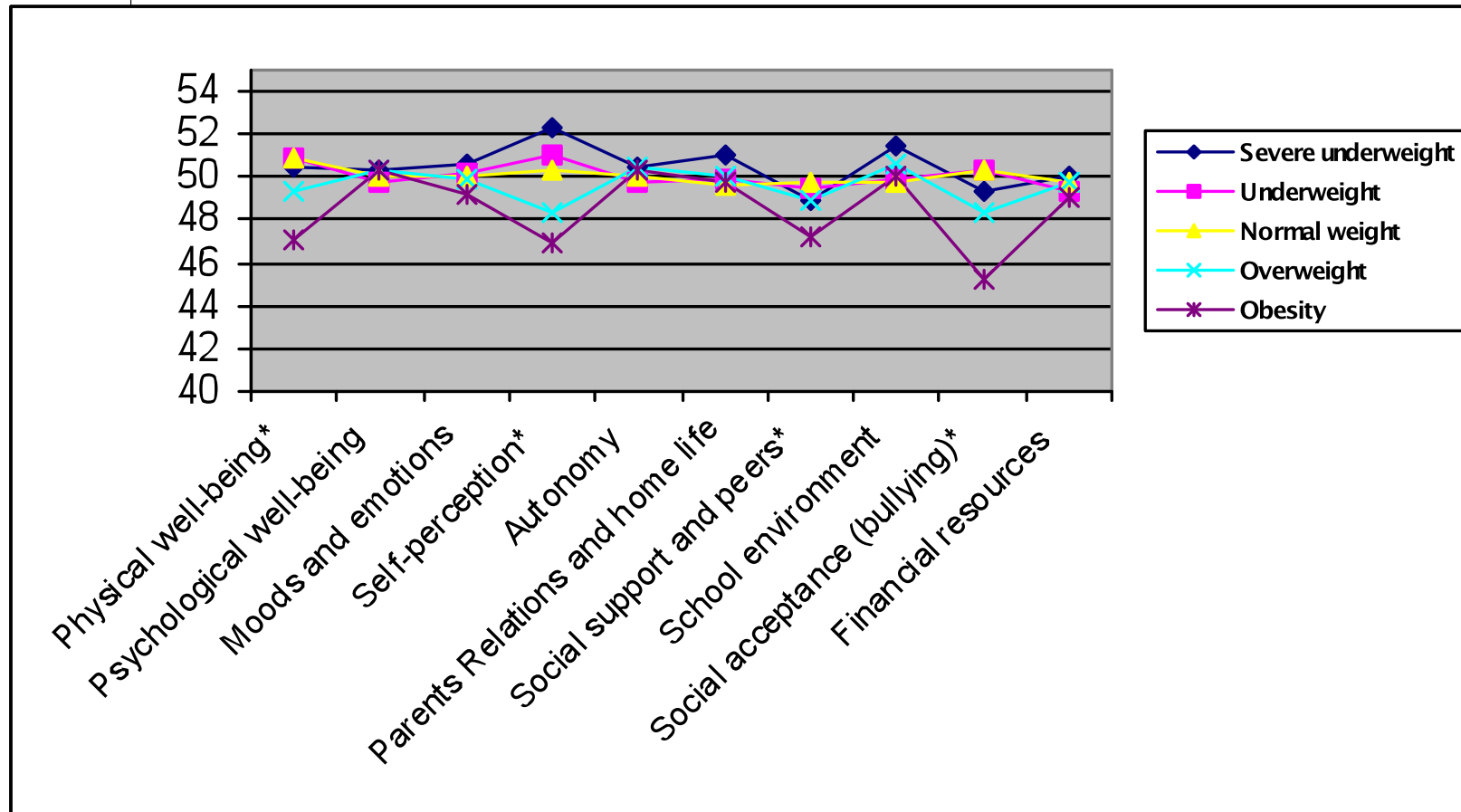
## Prevalence of overweight within Europe

- › Highest rates of obesity are observed in Eastern European countries (Hungary) and southern countries (Spain, Italy and Greece)<sup>1</sup>.
- › Variability related to age and gender
- › Variability within countries

## Prevalence overweight

Country	Severe underweight N (%)	Underweight N (%)	Normal weight N (%)	Overweight N (%)	Obesity N (%)
Germany	44 (3%)	146 (10%)	1115 (74%)	174 (12%)	26 (3%)
Espania	9 (1%)	47 (7%)	508 (71%)	126 (18%)	24 (3%)
Netherlands	51 (3%)	160 (10%)	1186 (75%)	153 (10%)	26 (2%)
Austria	33 (3%)	117 (9%)	927 (74%)	151 (12%)	26 (2%)
UK	14 (3%)	25 (6%)	319 (74%)	55 (13%)	21 (5%)
France	31 (4%)	66 (8%)	659 (77%)	83 (10%)	19 (2%)
Switzerland	46 (3%)	152 (10%)	1119 (76%)	134 (9%)	22 (2%)
Hungaria	55 (3%)	193 (11%)	1224 (70%)	214 (12%)	55 (3%)
Greece	13 (1%)	56 (6%)	695 (76%)	135 (15%)	17 (2%)
Czech R.	32 (4%)	111 (7%)	1182 (75%)	217 (14%)	42 (3%)
Poland	61 (4%)	186 (12%)	1193 (74%)	146 (9%)	18 (1%)
<b>Total</b>	<b>389 (3%)</b>	<b>1259 (9%)</b>	<b>10127 (74%)</b>	<b>1588 (12%)</b>	<b>296 (2%)</b>

## Hrql related to BMI category



## Conclusions

- › Overweight/obesity seems to be negatively related to the hrqol domains: physical activities, self-perception, peers and bullying.
- › In general, girls report a lower hrqol than boys.
- › Children report a higher hrqol in bullying than adolescents.
  - › The Northern European countries reported a significantly lower hrqol when the child is overweight or obese.
  - › In Eastern Europe, a slightly higher hrqol was noted when the child is overweight or obese.

## Kidscreen questionnaire in research

- › About 100 publications

Health-related quality of life, treatment adherence, symptom experience and depression in adolescent renal transplant patients.

• version of KIDSCREEN-52 questionnaire, a cross sectional study.

## Reporting HRQL scores during routine follow-up visits of paediatric oncology patients

(v Engelen et al: *Pediatr Blood Cancer* 2011, 16 may)

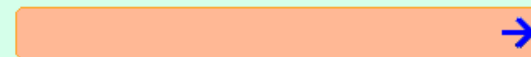
- › investigate effectiveness of providing hrql scores to the paediatric oncologist
- › Children with cancer (94 intervention, 99 control)



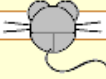
*In hoeverre heb je in de afgelopen week problemen gehad met ...*

**Over mijn gevoelens**

(problemen met...)	Nooit (0)	Bijna nooit (1)	Soms (2)	Vaak (3)	Bijna altijd (4)
Ik voel me angstig of bang	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Verder

\_\_\_\_\_ 



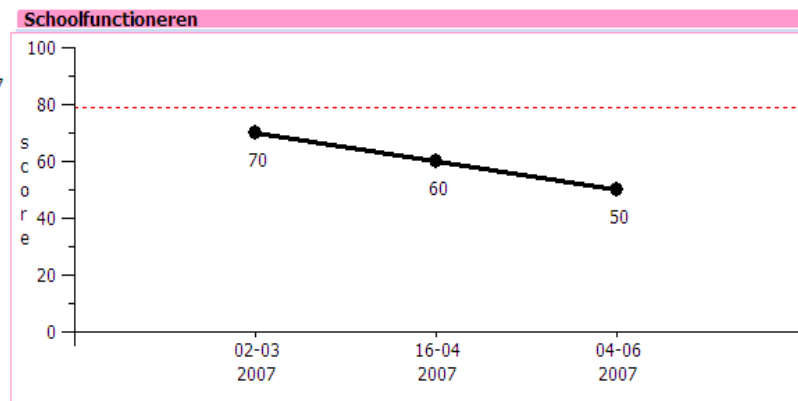
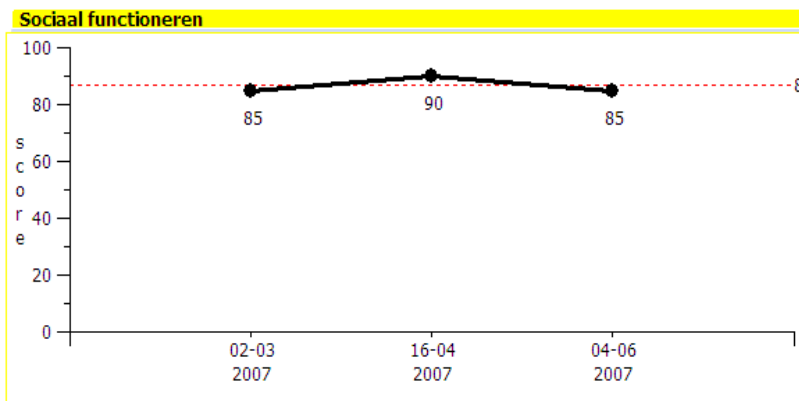
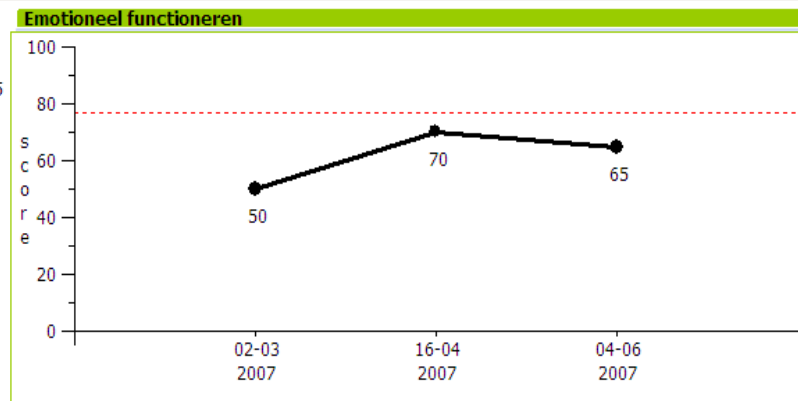
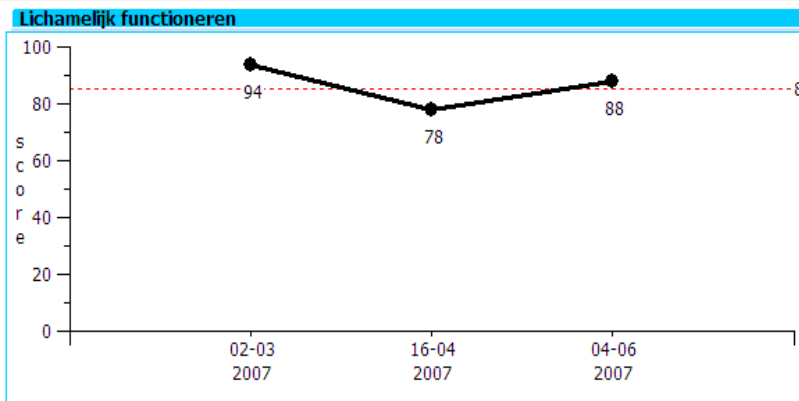
**QLIC-ON Profile**

Responder: 692  
 Name: xx xxx  
 Birthdate: 31-12-1996  
 Completed by: Kind Kind Kind  
 Time period: Last week

**Opmerkingen**

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 -----  
 -----  
 -----

A high score in the graph implies high quality of life



## Results

- › Increased discussion of emotional functioning
- › Increased discussion of psychosocial functioning
- › Better recognition of emotional problems in intervention group
- › Improvement of HRQL in youngest group
- › No effect on duration of the consultation

## Routine outcome measurement

- › In the Netherlands Rom is being implemented in mental health care
- › KIDSCREEN 27 included for children/adolescents
- › Monitoring possible on individual and group level

## KIDSCREEN Deliverables

- › **Standard protocols for of KIDSCREEN into other languages/cultures**
  - › Standard focus group protocol
  - › Standard translation protocol
  - › Standard protocol for validation-study
  
- › National and European **norm scores and cut offs** for the general as well as for a disabled population
  
- › **Documentation/Manuals** on how to use instrument and interpret results
  - › Psychometric results on reliability, validity
  - › International and national Norm-data; Syntax,
  - › translations into other languages



*The KIDSCREEN Group Europe*

# The KIDSCREEN Questionnaires

Quality of life questionnaires for  
children and adolescents

Handbook  
incl. CD-Rom

 PABST

Handbook  
including  
Normdata  
and cut-offs

- › Standard protocols for of KIDSCREEN into other languages/cultures
- › Standard focus group protocol
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- › Psychometric results on reliability, validity
- › International and national Norm-data; Syntax, translations into other languages
- › Software for **computerized application / CAT-Prototype** for mental well-being
- › KIDSCREEN **homepage**

The screenshot displays a questionnaire item on a dark red background. On the left side, there is a vertical panel containing the number '02', a large pixelated hand icon, and a speaker icon. The main content area is divided into three horizontal sections. The top section is labeled 'Feelings'. The middle section contains the text 'Thinking about the last week ...' followed by the question 'Has your life been enjoyable?'. The bottom section features five radio button options: 'not at all', 'slightly', 'moderately', 'very', and 'extremely'. The 'moderately' option is currently selected, indicated by a white highlight around its radio button.

Domain

Time frame

Stem, Item

Response  
option

# More Information: [www.kidscreen.org](http://www.kidscreen.org)

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The screenshot shows a Microsoft Internet Explorer browser window displaying the KIDSCREEN website. The browser's address bar shows the URL <http://kidscreen.diehauptstadt.de/kidscreen/master/index.html>. The website features a header with the European Union flag and navigation links for Home, Contact, and Sitemap. The main content area is divided into two columns. The left column contains a vertical menu with links to Project, Measurement Model, Questionnaires, Language Versions, Conditions of Use, Publications, Service, and Members. The right column contains the KIDSCREEN logo and a detailed description of the instrument, including its purpose and availability. A footer section includes a copyright notice and a link to the DISABKIDS website.

KIDSCREEN / DISABKIDS - Microsoft Internet Explorer bereitgestellt von Robert Koch-Institut

Adresse <http://kidscreen.diehauptstadt.de/kidscreen/master/index.html>

Home / Contact / Sitemap /



**KIDSCREEN**

- :: Project
- :: Measurement Model
- :: Questionnaires
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## KIDSCREEN

### Health Related Quality of Life Questionnaire for Children and Young People and their Parents

The KIDSCREEN instruments are a family of generic quality of life measures that have been designed and normed for children and adolescent aged between 8 to 18 years. It was developed simultaneously in several European countries taking children's concepts of health and well-being into consideration. KIDSCREEN can be used as a screening, monitoring and evaluation tool in representative national and European health surveys.

Three KIDSCREEN instruments are available in child and adolescent as well as parent / proxy versions: **KIDSCREEN-52** (long version) covering ten HRQoL dimensions, **KIDSCREEN-27** (short version) covering five HRQoL dimensions and the **KIDSCREEN-10 Index** as a global HRQoL score. Scores can be calculated for each dimension. T-values and percentages will be available for several countries stratified by age and gender.

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