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

Prof. Dr. Ulrike Ravens-Sieberer,
& the European KIDSCREEN Group

University of Bielefeld
School of Public Health
WHO Collaborating Center for Child and Adolescent Health Promotion
Quality of life assessment in children (WHO)

- 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
Several national instruments are available but international instrument development is rare.

Until very recent no scientifically sound instrument existed to assess QoL/mental wellbeing cross-culturally in children and adolescents in Europe.

International instrument development in children’s QoL/mental wellbeing usually follows a sequential approach.

A simultaneous approach had not yet been conducted.
KIDSCREEN Project

- Fifth EC Research Framework Programme

- European attempt to develop a standardised cross-cultural generic Health-related Quality of Life/ mental wellbeing 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.
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
KIDSCREEN Development Steps

- Literature Review
- Delphi Technique
- Focus Groups

> 3800 families
representative samples
approx. 26,000 families
Completed
# KIDSCREEN Development Steps

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<td>24 Experts</td>
<td>36 Groups, n=146 children, 83 parents</td>
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<td>Identification of HRQoL Dimensions across Instruments</td>
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**Basis for Hierarchical Domain Structure & Definition of Item Banks**
Steps of Questionnaire Construction

**Questionnaire development**
(Literature review, Delphi study, Focus group study)

2505 Items

**Data reduction**
(Elimination of double items, redundancies, linguistic non-adequate statements)

1070 Items

**Cart sort technique**

192 Items

Translation & Harmonisation (D, E, GB, F)

**Cognitive interview**
(n=59 children, n=17 parents)

**Pilot version: 177 Items**
(185 for adolescents)
KIDSCREEN HrQoL Model

KIDSCREEN-HRQoL
FOR CHILDREN, ADOLESCENTS AND PARENTS

Physical Domain
1. Mobility
2. Energy and Relaxation
3. Health and Complaints

Self Perception
4. Body Image
5. Self-assurance
6. Self-Esteem

Psychological Well-Being
7. Positive Emotions
8. Negative Emotions
9. Worries and Stress
10. Satisfact. w. life/ Optim.

Social Functioning
11. Autonomy
12. Opportunity and Quality

Social Relations
13. Home life and Parents
14. Friends
15. Group partic./Social Sup.

Cognitive/School Funct.
16. Concentrat.& Learning
17. Achievement & Relat.

Personal Environment
18. Physical & Home Condit.
KIDSCREEN Development Steps

- Literature Review
- Delphi Technique
- Focus Groups

1. Pilot Draft Questionnaire
   - Forward/Backward Translation
   - Pilot Test
     - > 3800 families

Completed
Pilot Questionnaire

- 159 Items as questions
- Examples: Have you been happy with your health? Have you felt fit and well? Have you felt that people understand you? Have you spent time with your friends?
- 5-point Response Choices: Frequency (never - always) / Intensity (not at all - extremely)
- Time Frame: 1 week
- 8 Domains: Physical, Psychological, Social Relations & Functioning, Self Perception, Cognitive Functioning, Environment
- Languages: English, German, French, Dutch, Spanish
Item reduction using IRT methods

Step 3: Unidimensionality & local independence (MPLUS)
Step 4: Analysis of tracelines (Testgraf)
Step 5: DIF-analysis: countries, age, gender (Zumbo OLR)
Step 6: Model fit of Partial Credit Model (Winmira)

Item reduction using CTT methods

Step 3: Internal consistency reliability
Step 4: Investigation of factor structure (EFA)
Step 5: Internal consistency reliability (repeat)
Step 6: Investigation of factor structure (EFA repeat)

Basic psychometric analysis

Step 1: Item frequencies and distributions
Step 2: Investigation of factor structure (EFA, CFA)

Item reduction using IRT methods

Step 7: DIF-analysis: countries, age, gender (Zumbo OLR)
Step 8: Model fit of Partial Credit Model (Winmira)
Step 9: Item calibration: estimate item parameters (Winmira)

Questionnaire for Survey

International Pilot Data Set n=3834

159 Items

International & National Analyses

52 Items
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 and health monitoring & research

- **KIDSCREEN-10 Index:**
  - very short and psychometrically sound screening instrument can be used in epidemiological studies and surveys
KIDSCREEN Development Steps

1. Literature Review → Pilot Draft Questionnaire → Forward/Backward Translation → Pilot Test → > 3800 families
   - Delphi Technique
   - Focus Groups

2. Telephone Sampling
   - International & National Validation
   - Representative samples
   - Mail Survey

3. Implementation
   - Manual
   - Final Questionnaire
   - Population Norms
European KIDSCREEN- Survey

- Representative Surveys
  (*Telephone sampling & post mail, Schoolsample*)

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

- Per country 1500-1800 families

  total n:
  22,830 Children (8-18 J.)
  16,888 Parents
KIDSCREEN 10 Item Index

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?
Measurement of health and well-being in Europe – the KIDSCREEN-survey*

The KIDSCREEN survey delivers cross-culturally comparable data on well-being of children and adolescents in 13 countries in Europe.

Austria, Czech Republic, France, Germany, Greece, Hungary, Ireland, Netherlands, Poland, UK, Spain, Sweden, Switzerland

The survey measure included also health behaviour, parental health, health services utilization, social support, and many more health indicators. Socioeconomic status was measured with the Family affluence scale.

The countries also administered the Strengths and Difficulties Questionnaire (SDQ).

* The KIDSCREEN project was supported by the EU within the 5th Framework Programme (www.kidscreen.org)
Comparable measurement of ill-mental health and well-being in Europe – Problems and Solution

**Mental health**

**Ill-mental health**
- Limited information: absence of mental disorders in the majority of adolescents.
- Separation of adolescents in two or three groups – no information on their position on a mental health continuum.

**Positive mental health**
- The application of a mental health index besides a measure of mental health problems can give us valuable information on mental health because it covers aspects of psychological well-being.

in addition:
Mental health problems and KIDSCREEN mental health index

Mental health problems:
The SDQ targets four specific problem areas and predicts the probability of a psychiatric disorder. (www.sdq.org)

- I am restless, I cannot stay still for long. (hyperactivity)
- I get very angry and often lose my temper. (conduct problems)
- I have many fears, I am easily scared. (emotional problems)
- I get on better with adults than with people my own age. (peer problems)

Measuring the latent trait:
The KIDSCREEN-Index measures along the mental health and psychological well-being continuum (www.kidscreen.org).

- Have you felt fit and well?
- Have you felt full of energy?
- Have you felt sad?
- Have you felt lonely?
- Have you had fun with your friends?
- Have you got on well at school?
If we compare the self-reported well-being of adolescents in 13 European countries we come to the following results:

(analysis controlled for age) \(F=116.15,71 \ ; p<.001; \text{korr. } R^2=0.132\)
Percentage of respondents with substantially reduced mental well-being according to the KIDSCREEN-10 index.
Well-being among adolescents from 11 European countries and socioeconomic status:

A statistically significant association between the FAS and positive mental health for all countries is apparent. High FAS => high positive health
Mental health problems (disorders) among adolescents from 11 European countries and socioeconomic status

Lower family affluence significantly associated with more child and adolescent mental health disorders

ns = not significant
*  = p<.05
** = p<.01
*** = p<.001
KIDSCREEN index and general health status

ANOVA: $F_{(df=4,21180)} = 1344.409; \ p < .001; \ \text{effect size } d^* = 2.17 \ [1.65^{**}] \ (\text{large})$
KIDSCREEN index and mental health status (SDQ)

ANOVA: $F_{(df=2,13968)} = 1277.133; p < .001$

effect size $d^* = 1.30$ (large)
KIDSCREEN-10 Index: Association with psychosomatic complaints (8-18 years)

Correlation (sumscore) $r = -0.51^{***}$
Impact of Alcohol and Smoking on Health related Quality of Life
12 European countries

T-values QOL (KIDSCREEN-27) adjusted for age & gender

- Physical WB
- Psychol. WB
- Family
- School
- QOL-Index
- Peers

.33
.35
.23
.25
.20

- regular smoking
- regular drinking

effect size „d“ classification: .20=small; .50=moderate; .80=large
Macro-dimension: mental health data and socioeconomic data
Percentage of children reporting low FAS (Unicef-Data) and adolescents’ mental health

Mental health index mean scores by percentage of children reporting low family affluence.
Summary, conclusions and outlook

- The KIDSCREEN-10 Index is a valid and well-tested stable measure for the child and adolescent well-being status …
  - …it’s psychometric properties are tested in a cross-national European health survey, showing a good acceptance, a high reliability and Rasch-scale properties
  - …it also proved to be a valid measure for children and adolescents mental health status
  - …the cross-cultural comparability of results could be demonstrated

- The analyses of the KIDSCREEN data shows the advantages and possibilities of comparable European survey data.
- KIDSCREEN confirms SES findings for child and adolescent mental-ill-health and for positive mental health.
- HBSC analysis for 2006/07 will also look at these connections.
KIDSCREEN Products

- Standard protocols for collaboration and adaptation of KIDSCREEN into other languages/cultures
  - Standard focus group protocol
  - Standard translation protocol
  - Standard protocol for validation-study

- Psychometric results on reliability, validity, national and international norm scores in general as well as in disabled population (inclusion of KIDSCREEN in DISABKIDS survey)

- Documentation/Manuals on how to use instrument and interpret results
  - International and national manuals; Syntax, Norm-data
  - Translations into other languages (15 languages so far)

- Software for computerized application
- CAT-Prototype for psychological well-being
- KIDSCREEN homepage
The KIDSCREEN Questionnaires

Quality of life questionnaires for children and adolescents

Handbook
incl. CD-Rom
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Feelings

Thinking about the last week ...

Has your life been enjoyable?

not at all  slightly  moderately  very  extremely
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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 five 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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More Information: www.kidscreen.org
Thank you!
WHO declared:
Child mental health is a key area of concern (2003, 2005)

- WHO states, that the “development of a child and adolescent mental health policy requires an understanding of the prevalence of mental health problems among children and adolescents“ (2006)

- However, quantifying the burden of mental disorders in children and adolescents in Europe is a difficult task.
Comparable measurement of ill-mental health and well-being in Europe - Problems

A lack of comparable mental health data in Europe:
The variety of prevalences is not only due to real underlying differences but indicates a variety of methodological problems:

- Use of different approaches (questionnaires, interviews), instruments and information sources (child, parent, teacher, combined report); different integration of data; different presentation of results (time frames for calculating prevalence)
- Samples with different age ranges and small sample sizes
  => Lack of national surveys with representative samples
- Lacking cross-cultural comparability of instruments
- Different case definitions (meeting diagnostic criteria, severity)

Similar methodological problems apply to data on socioeconomic status.