KIDSCREEN-52 quality of life measure for children and adolescents

Ulrike Ravens-Sieberer†, Angela Gosch, Luis Rajmil, Michael Erhart, Jeanet Bruil, Wolfgang Duer, Pascal Auquier, Mick Power, Thomas Abel, Ladislav Czemy, Joanna Mazur, Agnes Czimbalmos, Yannis Tountas, Curt Hagquist, Jean Kilroe and the European KIDSCREEN Group

This review describes the development and reports first psychometric results of the European KIDSCREEN-52 generic health-related quality of life questionnaire for children and adolescents. The KIDSCREEN-52, including ten dimensions, was applied in a European survey involving 12 countries (i.e., Austria, Switzerland, Czech Republic, Germany, Greece, Spain, France, Hungary, The Netherlands, Poland, Sweden and the UK) in 22,110 children and adolescents aged between 8 and 18 years of age. Questionnaire development included besides literature search and expert consultation, and focus group discussions with children and adolescents. After definition of dimensions and collection of items, a translation process following international translation guidelines, cognitive interviews, and a pilot test were performed. Analysis regarding psychometric properties showed Cronbach α ranged from 0.77 to 0.89. Correlation coefficients between KINDL[R] and KIDSCREEN-52 dimensions were high for those assessing similar constructs (r = 0.51–0.68). All KIDSCREEN-52 dimensions showed a gradient according to socioeconomic status and most dimensions showed a gradient according to psychosomatic health complaints. The first results demonstrate that the KIDSCREEN-52 questionnaire is a promising measure of health-related quality of life assessment in European children and adolescents.

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†*Author for correspondence*
Child and Adolescent Health, NG3, Robert Koch Institute, Seestraße 10, 13353 Berlin, Germany
Tel.: +49 304 547 3436
Fax: +49 303 531
RavensSiebererU@rki.de

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Health-related quality of life (HRQOL) is increasingly acknowledged as an important health outcome measure in both pediatric and epidemiologic research. HRQOL is generally conceptualized as a multidimensional construct encompassing several domains. This follows from the widely accepted definition of health put forward by the World Health Organization (WHO) as the state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity [1]. The WHO Quality of Life Group extended this definition by referring to the idea that quality of life is also concerned with the individual's perception of their position in life in the context of the cultural and values systems in which they live, and in relation to personal goals, expectation, standards and concerns [2,3].

The conceptualization of HRQOL supports a subjective, multidimensional and comprehensive model of health. This represents an expanded view of the traditional medical model that assesses health primarily through physical outcomes. There is growing interest in the inclusion of HRQOL outcome measures in the evaluation of the efficacy of medical treatment, the utility of health services, and for monitoring health in a population. Furthermore, monitoring population health status should permit the tracking of health trends, thus identifying inequities in health, planning preventive strategies and, consequently, the improvement of population health.

There is a substantial body of HRQOL research using both generic- and disease-specific measures with adults [4,5]. It has been only

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recently that health professionals have focused on quality of life assessment in children and adolescents [6,7]. In some cases, HRQOL questionnaires addressing adults were modified for the use in children. However, much of this work is not directly applicable to measuring child HRQOL due to several reasons. Besides similar dimensions such as physical and psychologic well-being, different dimensions of HRQOL are relevant for children (e.g., family, school and peers). Changes in children's emotional and cognitive development have to be recognized and addressed, and reading skills have to be considered. In general, children are often regarded as unreliable respondents [8–10], and for this reason early attempts to rate children's HRQOL were based on data provided by mothers or other proxy reports. In recent years, studies have shown that children and adolescents are able to answer HRQOL questionnaires reliably if their emotional development, cognitive capacity and reading skills are taken into account [10].

Another shortcoming has been that most HRQOL questionnaires for children and adolescents have been generated within one country and subsequently translated into other languages [11,12]. The crosscultural adaptation of existing questionnaires, although a reasonably quick and practical means of obtaining HRQOL instruments in other languages, has several weaknesses when it comes to obtaining crossculturally equivalent measures [13]. In order to avoid these problems, several authors have recommended the simultaneous development of instruments in different countries [14]. The World Health Organization Quality of Life Group recommended that the simultaneous approach should include exploration of the relevant dimensions of HRQOL for inclusion in the questionnaire by age group and across different countries, and that initial scale content should be based on content generated by focus groups in different countries [15].

The KIDSCREEN project was funded by the European Commission to produce the first instrument using this methodology for use in children and adolescents [8]. The aim of this review is to give an overview on the development steps and initial psychometric results of the KIDSCREEN-52 HRQOL questionnaire. Such psychometric results are scale properties, partial evaluation of reliability (internal consistency), and of validity obtained in a survey performed in 12 European countries (i.e., Austria, Switzerland, Czech Republic, Germany, Greece, Spain, France, Hungary, The Netherlands, Poland, Sweden and the UK).

Method

Development of the KIDSCREEN-52 HRQOL questionnaire for children & adolescents

The KIDSCREEN-52 generic HRQOL questionnaire for children and adolescents was developed as a self-report measure applicable for healthy and chronically ill children and adolescents aged between 8 and 18 years. The generation of the questionnaire was based on literature reviews, expert consultation (Delphi method [16]), and children's focus groups in all participating countries to identify dimensions and items of HRQOL which were relevant to respondents in all countries [8].

The aim of the Delphi study was to elicit expert opinions and determine the degree of expert consensus on aspects of the conceptualization and operationalization of HRQOL. In total, 24 experts (psychologists, pediatricians, sociologists and health services researchers) agreed that the HRQOL questionnaire should cover a multidimensional concept, reflecting the respondent's own view of their state of health. The specific dimensions of HRQOL which should be included (e.g., psychologic well-being, self-esteem, body image, cognitive functioning, mobility, energy/vitality, social relations and family/home function) cover aspects of physical, mental and social health. Agreement was reached that the questionnaire should aim to measure HRQOL in largely healthy children, thus more emphasis was given to the inclusion of psychosocial domains, and less to domains of physical functioning or symptoms such as pain.

In the focus group study, a total of 214 children or adolescents discussed different aspects of their perceived quality of life. In each country, six focus groups were performed, consisting of four to six participants stratified by age and gender. Two interviewers followed a protocol of instructions concerning the content, interviewer behavior and setting during the sessions. The content to be discussed included 26 questions ranging from open questions (e.g., When do you feel good?) to very narrow questions (e.g., What activities do you like to do in your free time?). In addition, different response scales and timeframes were selected from existing questionnaires, and children and adolescents were asked to decide which they preferred. In general, children and adolescents favor tick boxes combined with verbal descriptors over other response formats used in HRQOL questionnaires. Furthermore, a timeframe referring to the last week is acceptable for both children and adolescents.

In summary, 2505 statements were derived from focus groups with children, rewritten into an item format and reduced in a first step following international guidelines [17], and in a second step, using a card sort technique. The first step involved the removal of redundant and inappropriate items ~~by three centers (The Netherlands, Germany and the UK). In~~ the second data reduction step, the participating centers were asked to rate the remaining 1.070 items for applicability, clarity and importance. As a framework, a card sort technique was used similar to that used in cognitive psychology [18,101]. This technique reduced the items while taking into account the dimensions of quality of life those children/adolescents and families deemed to be important as an underlying theoretical model. In each dimension, the cards were divided into a number of categories according to certain common features, and substandard items were rejected. In each category, the items were ranked according to how well they represented the dimension. As a result of the card sort technique, 185 suitable items for the KIDSCREEN Pilot measure were identified.

To transform the questions into final items for a questionnaire format, an item-writing panel was assembled by the participating centers. The criteria set by the panel included: items should give rise to answers that inform on respondents' state or behavior and be amenable to a rating scale; reflect the meaning

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conveyed in the domain definition; be applicable to people with a wide range of conditions; be framed as a question instead of a statement; reflect the discussion that took place in focus groups; and should make use of wording suggested by focus group participants. A decision to have a 5-point response scale for frequency and intensity was reached within the Delphi process [16] and focus group study where a decision was also made on answer categories referring to frequency of occurrence and intensity of statement.

A resulting pilot measure was translated into languages of the participating countries according to international guidelines (WHO [19] and International Quality of Life Assessment [20]) using intercultural harmonization sessions. The first step employed a forward–backward–forward translation technique. Within each country the original English pilot draft was translated twice by two independently working translators into the respective language (national forward translations). Next, all items of the two independent versions were compared in order to generate a single corrected reconciled version for each item (national reconciled forward translations). The items of these national reconciled forward translations were then backtranslated (national backward translation) in order to be subsequently compared with the items of the original English pilot draft. This comparison was designed to provide the final versions for the national questionnaires (national final forward translation). Thereafter the degree of conceptual equivalence among the respective national final forward translations was checked on an international basis to reach crosscultural harmonization. A telephone conference was held to resolve inadequate concepts of translation, as well as discrepancies between alternative versions. A pretest, followed by cognitive debriefing, took place in the respective countries to ensure the feasibility of the ~~Pilot~~ questionnaire. In the pretest it was shown that children older than 8 years of age could read, understand and answer all the items without problems. After that, agreement on final item formulation was made in a meeting in which all countries participated.

From the multinational KIDSCREEN Pilot test, the study sample used for further item reduction analysis consisted of 3019 children and adolescents aged between 8 and 18 years who filled in the questionnaire in schools (with the exception of The Netherlands where questionnaires were filled in at home). The average age of all children and adolescents was 12.7 years, with a standard deviation of 2.6 years. Of the children and adolescents, 48.8% were female and 50.8% were male. Distributions by age and gender are comparable across countries.

The statistical analyses using the pilot test data for the item reduction was divided into four major steps to determine the measure's optimal item and scale characteristics:

- Confirmatory and exploratory factor analysis, and item reduction with methods descending from Item Response Theory [21,22]
- Principal component analysis and item reduction with methods rooted in the Classical Test Theory [23]
- Comparison of the results of both methods, including theoretical considerations, and item reduction of the combined version using methods of Item Response Theory
- Improving the scales' predictive validity by examining the item function across countries, age groups and gender [24].

After these item reduction steps [25], the final KIDSCREEN-52 questionnaire consisted of 52 items assessing ten HRQOL dimensions:

- Physical well-being: explores the level of the child's/adolescent's physical activity, energy and fitness
- Psychologic well-being: examines the psychologic well-being of the child/adolescent, including positive emotions and satisfaction with life
- Moods and emotions: covers how much the child/adolescent experiences depressive moods and emotions, and stressful feelings
- Self-perception: explores whether respondents perceive their bodily appearance positively or negatively; body image is explored by questions concerning satisfaction with looks as well as with clothes and other personal accessories
- Autonomy: looks at the respondents' opportunities to create social and leisure time
- Parent relations and home life: examines relationships with parents and the atmosphere at home
- Social support and peers: examines the nature of the respondents' relationships with other children/adolescents
- School environment: explores the child's/adolescent's perceptions of their cognitive capacity, learning and concentration, and their feelings about school
- Social acceptance (bullying): covers the aspect of feeling rejected by peers in school
- Financial resources: assesses the respondents' perceptions of their financial resources

The KIDSCREEN-52 HRQOL questionnaire assesses either the frequency of behavior/feelings or, in fewer cases, the intensity of an attitude. Both possible item formats use a 5-point Likert response scale, and the recall period is 1 week. Scores are computed for each dimension (for each dimension items are equally weighted) and are transformed into T-values with a mean of 50 and a standard deviation of 10; higher scores indicate higher HRQOL and well-being. The generic KIDSCREEN-52 HRQOL self-report measure is available in English, German, Dutch, French, Spanish, Czech, Polish, Hungarian, Swedish and Greek.

European KIDSCREEN survey: subjects & settings

To test the robustness and properties of the crosscultural KIDSCREEN measure, a European survey on HRQOL in children and adolescents was performed. The data was collected involving 12 European countries (i.e., Austria, Switzerland, Czech Republic, Germany, Greece, Spain, France,

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Hungary, The Netherlands, Poland, Sweden and the UK) with representative national samples obtained for each participating country, taking into account sex, two age groups (8–11 and 12–18 years) and region.

Two approaches for sample selection were used: in the first approach (e.g., Austria, Germany, Czech republic, Spain, France and The Netherlands), address sampling was conducted via computer-assisted telephone interviews. Questionnaires were sent by post to families who had agreed by phone to participate, and these were filled in at home and sent back to the national centers in a prepaid envelope. Two reminders were used. In the second approach (e.g., Czech Republic, Greece, Hungary, Poland, Sweden and the UK), the sample was obtained in schools that were representative for the country as a whole in terms of type (private vs. public, rural vs. urban). The pupils filled in the questionnaires during classtime and took a copy of the parents' questionnaire back home with them. The representativeness of each national survey was assessed in the following way: KIDSCREEN respondents were compared not only with the reference population (provided by Eurostat, European Statistics) but also with eligible contacted people who did not accept to participate (refusers). Overall, results indicate no noticeable deviation from the reference populations and between participants and refusers.

Measures

To address the properties of the measure in terms of convergent and construct validity, several other measures were included in the survey, in addition to the KIDSCREEN-52. Convergent validity was assessed through the comparison of KIDSCREEN-52 dimension scores with the KINDL^R, a known and validated questionnaire measuring similar concepts.

The generic KINDL^R questionnaire is an instrument developed in Germany from focus groups with children and adolescents [26]. The revised KINDL^R is based on the self-report of children and adolescents, includes 24 items which cover six dimensions of quality of life (e.g., physical, psychologic, self-esteem, family, friends and functional aspects) for three age groups (4–7, 8–12 and 13–17 years). The self-administered 8–12 year and 13–17 years of age versions, as well as the parent version were included in five participating countries (i.e., Austria, Czech Republic, ~~germany~~, Greece and Spain).

To address construct validity measures of determinants of HRQOL, familial socioeconomic status and psychosomatic health complaints were applied.

To assess familial socioeconomic status the Family Affluence Scale (FAS) [27] was used, a socioeconomic indicator addressed to children populations, includes family car ownership, having their own unshared room, the number of computers at home, and times the children spent on holiday in the past 12 months. The FAS was collected in seven categories (from 0 the lowest, to 7 the highest FAS category) and was recoded into three groups in the analysis (low FAS level [0–3], intermediate [4,5], and high FAS level [6,7]).

To assess psychosomatic health complaints the Health Behavior in School-aged Children (HBSC) psychosomatic complaints symptom checklist [28] was used. Psychosomatic health complaints, such as headache, stomach ache, backache, dizziness, irritability/bad temper, feeling nervous, feeling low or sleeping difficulties, are serious health problems, not only for adults but also in adolescents and children. The HBSC psychosomatic complaints symptom checklist is a self-administered brief screening instrument which asks children and adolescents

Table 1. Response rate and sociodemographic characteristics of the KIDSCREEN sample.

	Total	AT	CH	CZ	DE	ES	FR	EL	HU	NL	PL	SE	UK
n	**22295**	**1529**	**1746**	**1603**	**1773**	**917**	**1083**	**1194**	**3297**	**1911**	**1720**	**3354**	**1983**
Response rate (%)	*78.9*	*64.5*	*72.1*	*100*	*77.6*	*47.2*	*45.3*	*100*	*92.6*	*97.8*	*72.1*	*100*	*77.0*
Children													
Mean age (years)	9.57	9.73	9.87	9.50	9.81	9.77	9.55		8.76	9.45	10.26		9.36
Age range (years)	8–11	8–11	8–11	8–11	8–11	8–11	8–11		8–11	8–11	8–11		8–11
Adolescents													
Mean age (years)	14.27	14.25	14.49	14.85	14.68	14.74	14.42	14.66	13.78	14.54	15.06	13.65	14.08
Age range (years)	12–18	12–18	12–18	12–18	12–18	12–18	12–18	12–18	12–18	12–18	12–18	12–15	12–18
Female (%)	53.1	54.3	53.9	49.7	51.4	50.4	51.8	59.9	58.5	52.0	55.6	49.0	50.0
All (socioeconomic status)*													
Low FAS (%)	22.6	14.5	11.2	49.2	11.6	20.1	8.4	37.6	29.9	10.2	38.0		13.2
Medium FAS (%)	46.2	49.6	46.3	41.4	48.2	50.6	44.2	45.0	46.8	49.3	48.3		39.2
High FAS (%)	31.2	35.9	42.5	9.4	40.2	29.3	47.4	17.4	23.2	40.5	13.7		47.6

*FAS: Family Affluence Scale (0–3 = low; 4–5 = medium; 6–7 = high).
AT: Austria; CH: Switzerland; CZ: Czech Republic; DE: Germany; EL: Greece; ES: Spain; FR: France; HU: Hungary; NL: The Netherlands; PL: Poland.

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Table 2. Scale descriptives, internal consistency, scaling success ~~and Rasch measurement item fit~~ of the KIDSCREEN-52 dimensions.

			Scale descriptives					Internal consistency reliability	
Scale	No. items	n	Mean	Standard deviation	Missing (%)	Floor (%)	Ceiling (%)	Cronbach's α	Cronbach's α range*
Physical well-being	5	21266	49.94	9.88	2.47	0.06	5.24	0.80	0.75–0.86
Psychologic well-being	6	21488	49.92	9.87	1.45	0.08	9.64	0.89	0.85–0.91
Moods and emotions	7	21386	49.83	9.70	1.92	0.04	8.24	0.86	0.80–0.89
Self-perception	5	21484	50.17	10.18	1.47	0.10	11.59	0.79	0.71–0.84
Autonomy	5	21505	50.11	10.14	1.37	0.18	11.29	0.84	0.79–0.86
Parent relation and home life	6	21328	50.13	10.16	2.18	0.13	15.45	0.89	0.85–0.90
Social support and peers	6	21283	49.88	9.95	2.39	0.29	7.45	0.85	0.81–0.87
School environment	6	21299	50.05	10.14	2.63	0.19	4.90	0.87	0.81–0.88
Social acceptance (bullying)	3	21496	50.13	10.16	1.41	0.32	49.10	0.77	0.61§–0.83
Financial resources	3	21183	50.19	10.21	2.85	1.83	24.46	0.89	0.82–0.91

*Range across countries.
‡~~Minimum–maximum across items.~~
§France.

about the frequency of occurrence of eight psychosomatic health complaints. Items are added together to generate an index of psychosomatic health complaints score. The symptom checklist was included in all countries.

Statistical & psychometric analysis

Various psychometric aspects were studied, including feasibility, reliability, and convergent and construct validity. Feasibility was examined by analyzing the proportion of missing items and the distribution of scores of the KIDSCREEN dimensions (floor and ceiling effects). Floor and ceiling effects were considered to be present when 15% of respondents had the minimum or maximum possible scores on a given dimension, respectively [29].

The internal consistency of the KIDSCREEN-52 dimensions was calculated using Cronbach's α [30]. α coefficients of 0.7 or higher were considered acceptable. Pearson correlation coefficients were computed to analyze convergent validity between KIDSCREEN-52 dimensions and the KINDL^R. Convergent validity was considered to be demonstrated when correlations between comparable dimensions were significantly higher than correlations between theoretically different dimensions and of reasonable magnitude. Correlation coefficients between 0.1 and 0.3 were considered low, those between 0.31 and 0.5 moderate, and those over 0.5 were considered high [31].

Construct validity was further evaluated based on previously developed hypotheses regarding age, gender, familial socioeconomic status (FAS), and psychosomatic health of children and adolescents (e.g., on the background of existing literature it was expected that older children would have poorer HRQOL [32,33] and that girls would report lower HRQOL in few dimensions such as psychologic well-being than boys [34]). Construct validity was assessed by calculating Cohen's effect sizes (ES; d) [35]. Effect sizes of 0.2–0.5 were considered small; those between 0.51 and 0.8 moderate, and those over 0.8 were considered large.

Results

Sample characteristics

The final survey sample included 22,296 children and adolescents. Response rates varied across countries, from 45.3 to 100% according to the sampling approach taken with a higher response rate in school samples. TABLE 1 shows the sociodemographic characteristics of the final sample, overall and by country. The mean age for the overall child sample was 9.6 years, and for the adolescent sample, 14.3 years. There were slightly more females than males in both samples. In terms of age and gender, the child and adolescent samples were broadly similar across all participating countries.

Psychometric properties

Scale description & reliability

TABLE 2 shows psychometric characteristics of the ~~KIDSR-CEEN~~-52 HRQOL questionnaire dimensions for the overall sample, and for reliability, the range across countries. There were no or very few floor effects in any dimension, but there were some ceiling effects, particularly in the dimensions of social acceptance (bullying; 49%), financial resources (24%), and relationship with parents and home life (15%). Cronbach α for the overall sample ranged from 0.77 to 0.89. For only one scale (social acceptance [bullying]) was Cronbach's α below 0.70 in one country (France).

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Table 3. Convergent validity of the KIDSCREEN-52. Pearson correlation coefficients of the KIDSCREEN-52 dimensions and the KINDL[R].

	KINDL scales					
KIDSCREEN-52 dimensions	*Physical (r)*	*Emotional (r)*	*Self-esteem (r)*	*Family (r)*	*Friends (r)*	*School (r)*
Physical well-being	0.53	0.44	0.47	0.28	0.38	0.39
~~Psychologic~~ well-being	0.45	0.60	0.57	0.47	0.49	0.44
Moods and emotions	0.48	0.59	0.52	0.48	0.47	0.48
Self-perception	0.41	0.44	0.51	0.37	0.38	0.50
Autonomy	0.35	0.43	0.41	0.38	0.43	0.32
Parent relation and home life	0.36	0.48	0.47	0.68	0.41	0.41
Social support and peers	0.26	0.47	0.38	0.22	0.61	0.17
School environment	0.37	0.42	0.49	0.40	0.36	0.63
Social acceptance (bullying)	0.18	0.29	0.18	0.20	0.32	0.16
Financial resources	0.21	0.28	0.27	0.34	0.24	0.28

n = 4001–4551. Correlation coefficients between 0.1 and 0.3 were considered low, those between 0.31 and 0.5 moderate, and those over 0.5 were considered high.

Convergent validity

TABLE 3 shows the results of the convergent validity analysis. KIDSCREEN-52 HRQOL and KINDL[R] dimensions generally showed a moderate level of correlation, but for the expected relationships, the KINDL[R] physical functioning correlated highest with the KIDSCREEN-52 physical well-being dimension (r = 0.53). The KINDL[R] Emotional Functioning and Self-Esteem Scales scored highest with the KIDSCREEN-52 psychologic well-being (r = 0.60 and r = 0.57), moods and emotions (r = 0.59 and r = 0.52), and the self-esteem scale scored high with the self-perception dimension (r = 0.51). The KINDL[R] family scale correlated highly with the KIDSCREEN-52 parent relations and home life (r = 0.68). Finally, the KINDL[R] school functioning scale correlated highest with the KIDSCREEN-52 school environment dimension (r = 0.63). As expected, the KIDSCREEN-52 financial resources dimension correlated with none of the KINDL[R] scales. In addition, social acceptance (bullying) showed low coefficients in almost all analyses, with the exception of the friends scale of the KINDL[R].

Determinants of HRQOL

Age, gender & socioeconomic status

TABLE 4 shows mean T-values for the KIDSCREEN-52 dimensions stratified by age, gender and socioeconomic status. In general, all HRQOL scores were lower in adolescents than in children, with moderate effect sizes (d) for the physical well-being (d = 0.48), psychologic well-being (d = 0.45), self-perception (d = 0.61), and school environment (d = 0.58) dimensions. Girls reported lower HRQOL than boys, with moderate differences in physical well-being (d = 0.32) and self-perception (d = 0.49). No differences by gender were found in the parent relations and home life, social support and peers, school environment and social acceptance (bullying), and financial resources dimensions. A gradient in KIDSCREEN-52 for all dimensions was found according to the socioeconomic status (FAS) of children and adolescents. Effect sizes between those in the high and low FAS categories ranged from 0.11 in the dimension of social acceptance (bullying) to 0.76 for the financial resources dimension. All dimensions other than social acceptance (bullying) had an effect size of 0.3 and above.

Psychosomatic health complaints

TABLE 5 shows correlations between KIDSCREEN-52 dimension scores and the Psychosomatic Complaint Index. Most correlation coefficients were low-to-moderate. High and moderate correlations were found between the Psychosomatic Complaints Index and the KIDSCREEN-52 moods and emotions (r = -0.53), psychologic well-being (r = -0.47), and self-perception (r = -0.45) dimensions.

Discussion

The KIDSCREEN-52 HRQOL questionnaire ~~(APPENDIX)~~ is the first instrument for children and adolescents to be developed simultaneously in several different countries, and it exemplifies a continuation of strategies applied to develop crosscultural applicable instruments.

Besides a literature search and expert consultation, questionnaire development steps included focus group discussions with children and adolescents and their parents for the generation of relevant dimensions and items. This method of development has a number of strengths, particularly of ensuring that different perspectives are taken into account during instrument development, avoiding the imposition of possible cultural biases as regards to instrument content, and permitting valid crosscultural comparisons.

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More requirements for questionnaire development were met, such as following scientific approaches of item reduction and international translation guidelines, as well as performing cognitive interviews with children and adolescents and conducting a pretest in all countries. The item generation achieved by conducting simultaneous focus group discussions and following a card sort technique for item reduction ensures that the content of the KIDSCREEN-52 dimensions will be important for all participating European countries. Furthermore, following international translation guidelines guarantees a crosscultural conceptual equivalence of all items. This conceptual equivalence was achieved not only by using a forward–backward–forward translation technique but by having repeated international harmonization conferences by telephone to ensure conceptual equivalence of the measure. In a further step, cognitive interviews with children and adolescents helped to finalize the KIDSCREEN Pilot questionnaire.

The European KIDSCREEN Pilot test was essential to support the theoretical and questionnaire structure and items generated in focus group discussions. The results of more advanced statistical analyses, such as structural equation modeling and item response theory, are described elsewhere [36] but show that the ten KIDSCREEN-52 HRQOL questionnaire dimensions enable crosscultural measurement on an interval-scaled level by satisfying the assumptions of the Rasch model and display no differential item functioning.

The final KIDSCREEN-52 HRQOL questionnaire for children and adolescents includes ten dimensions covering physical, psychologic and social aspects of HRQOL. The importance of perceived psychologic well-being is underlined by the three dimensions psychologic well-being, moods and emotions, and self-perception derived by the combined procedure of questionnaire development. Furthermore, the test development has shown that financial resources are relevant for children's and adolescents' HRQOL. This dimension explores whether the child/adolescent feels that they have enough financial resources to allow them to live a lifestyle which is comparable with that of other children/adolescents and provides the opportunity to do things together with their peers.

The KIDSCREEN-52 HRQOL questionnaire was tested in a large number of children and adolescents in a European sample, in a survey involving national representative samples.

Table 4. Differences in KIDSCREEN-52 dimension scores by age, gender and socioeconomic categories (FAS).

	Age			Gender			FAS			
	Children mean (SD)	*Adolescents mean (SD)*	*Effect size*	*Girls mean (SD)*	*Boys mean (SD)*	*Effect size*	*Low mean (SD)*	*Medium mean (SD)*	*High mean (SD)*	*Effect size (High vs. low)*
Physical well-being	53.75 (9.99)	48.55 (9.66)	0.52	48.54 (9.79)	51.69 (10.03)	-0.31	48.1 (10.8)	50.29 (9.71)	51.68 (9.74)	0.36
Psychologic well-being	53.40 (9.39)	48.67 (9.93)	0.47	49.40 (10.22)	50.72 (9.71)	-0.13	47.6 (10.13)	50.12 (9.69)	51.39 (9.54)	0.39
Moods and emotions	52.16 (10.00)	49.16 (9.90)	0.30	48.78 (10.00)	51.36 (9.85)	-0.26	47.85 (9.55)	49.83 (9.42)	50.95 (9.39)	0.33
Self-perception	54.55 (9.78)	48.29 (9.57)	0.62	47.94 (9.92)	52.43 (9.60)	-0.45	48.09 (10.07)	50.28 (9.99)	51.49 (9.91)	0.34
Autonomy	51.56 (9.72)	49.40 (10.06)	0.22	48.90 (10.01)	51.26 (9.86)	-0.24	47.99 (10.49)	50.07 (10.14)	51.13 (9.82)	0.31
Parent relation and home life	52.66 (9.21)	48.96 (10.13)	0.37	49.64 (10.31)	50.43 (9.66)	-0.08	47.48 (10.37)	50.03 (10.03)	50.91 (9.61)	0.34
Peers and social support	50.68 (10.11)	49.76 (10.00)	0.09	50.39 (10.06)	49.61 (9.98)	0.08	47.83 (10.19)	49.67 (9.79)	50.79 (9.87)	0.30
School Environment	54.53 (10.49)	48.24 (9.26)	0.63	50.43 (9.88)	49.59 (10.16)	0.08	47.71 (10.13)	50.06 (10.17)	51.06 (10.12)	0.33
Social acceptance (bullying)	47.52 (10.60)	50.91 (9.64)	-0.34	50.23 (9.97)	49.64 (10.08)	0.06	49.01 (10.57)	49.75 (10.16)	50.01 (10.02)	0.10
Financial resources	48.87 (10.49)	50.42 (9.81)	-0.15	49.84 (9.99)	50.18 (10.04)	-0.03*	45.21 (10.34)	49.88 (9.92)	52.86 (9.56)	0.74

Range of n = 17437–21550. All standarized mean differences are statistically significant at less than 0.01 level except * = < 0.05. Effect size (d): 0.20 = small; 0.50 = moderate; 0.80 = large.

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Table 5. Correlation between KIDSCREEN-52 dimensions and the Psychosomatic Health Complaints Index.

KIDSCREEN-52 dimensions	Psychosomatic Health Complaints Index (r)
Physical well-being	-0.42
~~Psychologic~~ well-being	-0.47
Moods and emotions	-0.53
Self-perception	-0.45
Autonomy	-0.37
Parent relation and home life	-0.41
Social support and peers	-0.25
School environment	-0.38
Social acceptance (bullying)	-0.20
Financial resources	-0.23

Range of n = 20503–21008. All correlations are significant at p = 0.001.
Correlation coefficients between 0.1 and 0.3 were considered low, those between 0.31 and 0.5 moderate, and those over 0.5 were considered high.

Classical psychometric analysis confirmed the instrument's ability for sound measurement with sufficient psychometric properties. Instrument reliability was good, with Cronbach's α coefficients of 0.7 or above for all dimensions in all language versions (except for one dimension in one country).

Following the WHO definition of health and HRQOL, an attempt was made to analyze the validity of the physical, psychologic and social constructs of health by correlating the KIDSCREEN-52 with a similar instrument to assess HRQOL, the KINDL^R. A comparison of the KIDSCREEN-52 dimensions and the KINDL^R scales showed the highest correlations for all similar concepts/dimensions (e.g., KIDSCREEN-52 physical well-being dimension and physical functioning scale of the KINDL^R). This refers to a satisfying convergent validity, which means that measures that should be related, are in reality related. Theoretically expected low correlations (divergent validity) were, in fact, found for the KIDSCREEN-52 financial resources dimension with all KINDL^R scales. Only the low correlation between the KIDSCREEN-52 dimension social acceptance (bullying) and the school functioning scale of the KINDL^R needs to be explained further.

The association between the KIDSCREEN-52 HRQOL questionnaire and KINDL^R is not attributable to an overlap of item content since the KIDSCREEN-52 was generated in different European countries. However, even though the initial results of KIDSCREEN-52 validation have been promising, more convergent validation studies using other HRQOL questionnaires are desirable.

The KIDSCREEN-52 HRQOL questionnaire discriminated well in the hypothesized direction between age groups, gender and socioeconomic categories. In several studies, a lower HRQOL was found in adolescents in comparison with children [32,33]. More differentiated results of the present study show that children display a significantly higher physical and psychologic well-being than adolescents, they perceive their bodily appearance more positively (self-perception), and they have more positive feelings about school (school environment). In other dimensions, such as how they perceive their financial resources and autonomy, or how satisfied they are with relationships with other children/adolescents (social support and peers), no differences between children and adolescents were seen.

In general, girls were found to show a lower HRQOL in comparison with boys [34]. In the present study, this was supported in only two dimensions: girls perceive their own body appearance more negatively and are more concerned with looks as well as with clothes (self-perception), and they report a lower physical well-being than boys.

Social class gradients associated with self-reported health status were found for both children and adolescents [37,38]. As expected, in this study individuals with a high familial socioeconomic status report significantly higher HRQOL for most of the KIDSCREEN-52 dimensions than less affluent children and adolescents (exception: social acceptance [bullying]). The highest difference was found in their perception and satisfaction with financial resources.

Finally, the KIDSCREEN-52 dimensions psychologic well-being, moods and emotions, and self-perception correlated at a moderate-to-high level with the Psychosomatic Complaints Index: children and adolescents with more psychosomatic complaints reported a lower psychologic well-being, reported more depressive moods, emotions and stressful feelings, and they perceived their own body appearance more negatively in comparison with individuals with fewer psychosomatic complaints. This means that the KIDSCREEN-52 instrument may be sensitive to such psychosomatic complaints, whereas the sensitivity to physical diseases, pain and/or prevalent (self-reported) chronic conditions needs to be investigated in future studies.

In summary, the KIDSCREEN-52 HRQOL questionnaire for children and adolescents achieves most of the attributes proposed by the Medical Outcomes Trust Scientific Committee [39], although more studies are needed in order to improve score interpretation for its use in clinical practice. The instrument discriminated well in a theoretically expected way between children and adolescents with different sociodemographic and health characteristics, meaning that it would be useful in both epidemiologic and clinical settings.

Using a HRQOL profile based on dimension scores can provide detailed information about impairments in certain HRQOL domains and can stimulate intervention strategies, and in the long run prevention activities. Problematic HRQOL domains can be identified; whereas an overall score is difficult to interpret since different health patterns may result in similar overall scores [40,41]. Furthermore, different dimensions or scales of a HRQOL instrument display different degrees of sensitivity towards changes in HRQOL following therapeutic interventions. Thus, the use of a profile instrument is more valid for pre- and postinterventional measurements than a global

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valuation score [42]. However, to optimize this, cut-off scores will be developed for the dimensions and their relevance will be tested in future studies.

As mentioned, one limitation of the study was that no clinical information could be gathered. In the future, the KIDSCREEN-52 HRQOL questionnaire needs to be tested in clinical settings where clinical diagnoses and information about the severity of conditions is available. Such future analyses will allow response patterns associated with those conditions to be identified and established.

The international, collaborative nature of the KIDSCREEN project provided many challenges in terms of producing an instrument conceptually and linguistically appropriate for use in many different countries. By giving each country the opportunity to be involved as early as the item construction phase, the KIDSCREEN-52 is the first crossnational developed HRQOL instrument for use in children and adolescents. To date, items and dimensions are relevant to European children and adolescents of the participating countries, and enable a better understanding of perceived health in children and adolescents. But whether this may hold true for children and adolescents from other countries still has to be seen.

Expert opinion

While quality of life research in adults has progressed over the past years, HRQOL research in children is a recent field. As in the adult field, but with a delay of approximately 10 years, the development of quality of life research in children has occurred in three waves. The first wave in the late 1980s was concerned with how to assess quality of life in children as a theoretical concept, especially with regard to differences from adult quality of life concepts. A second phase beginning in the early 1990s, and still going on, consists of constructing and developing quality of life measures for children. The third phase, which began 10 years ago (from 1995 onwards), concerns the application of these measures in clinical and epidemiologic studies.

Including HRQOL instruments in public health surveys allows researchers to monitor population health status over time, detect subgroups within the general population who might be at risk of poor HRQOL and to assess the impact of public health interventions within a given population.

To date, many HRQOL questionnaires have been developed for different pediatric populations, but only a few for healthy children and adolescents. Most were developed within one country, and some were adaptations of adult instruments. Meanwhile, it is common practice to use different sources for questionnaire development and this includes in particular the focus group approach with the target group of interest: children and adolescents.

The KIDSCREEN-52 HRQOL questionnaire for children and adolescents has been developed as a standardized instrument which can currently be applied with equal relevance in pediatric and healthy populations in different European populations.

Five-year view

In the next 5 years, in our view, existing questionnaires in the field of HRQOL in children and adolescents will be translated into other languages following international translation guidelines. More HRQOL instruments will be included in clinical and epidemiologic research because perceived health will become a more important outcome variable in the face of the limitations of medical outcomes. It will be accepted practice to include both medical indicators of health and perceived well-being in clinical and epidemiologic studies. Methodologic research will be stimulated to optimize questionnaires and their utility, and efforts will be made to develop personal computer versions to assess HRQOL in a child-friendly and easy way. Questionnaire formats will be developed to reliably examine HRQOL in younger children.

In research, efforts will be made to agree on the necessary dimensions of HRQOL in children and adolescents, to describe the trajectory of HRQOL from childhood adolescence in

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Key issues

- Health-related quality of life (HRQOL) questionnaire development including literature searches, expert consultation and focus group discussions with children and adolescents is required to generate important items and dimensions.
- Translation of the preliminary questionnaire following international translation guidelines (two forward, one backward translation, international harmonization, cognitive interviews with children and adolescents) is needed.
- The item reduction process includes the following methods of classical test theory and item response theory, and Rasch approaches.
- The KIDSCREEN-52 health-related quality of life (HRQOL) questionnaire is for children and adolescents, aged between 8 and 18 years, with 52 items covering ten dimensions of HRQOL.
- Use of the KIDSCREEN-52 HRQOL questionnaire for children and adolescents is used in 12 European countries in surveys together with determinants and another HRQOL instrument.
- Calculation of standard data for the participating countries is possible (T-values with a mean of 50 and standard deviation of 10).
- Good internal consistency of the KIDSCREEN-52 dimensions (α = 0.80–0.89 [except a = 0.77 social acceptance {bullying}]), requires satisfactory correlation with dimensions of another validation instrument.
- Most *a priori* hypotheses regarding age, gender, familial socioeconomic status and psychosomatic complaints of children and adolescents were satisfactorily confirmed.

different subgroups, such as girls and boys, and describe the impact and changes of different determinants on HRQOL in childhood and adolescence.

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Affiliations

- *Ulrike Ravens-Sieberer, PhD, MPH*
  Child and Adolescent Health, ~~NG3,~~ Robert Koch Institute, Seestraße 10, 13353 Berlin, Germany
  Tel.: +49 304 547
  Fax: +~~49 303 531~~
  Ravens-SiebererU@rki.de
- *Angela Gosch, PhD*
  Child and Adolescent Health, ~~NG3,~~ Robert Koch Institute, Seestraße 10, 13353 Berlin, Germany
  Tel.: +49 304 547
  Fax: ~~+49 303 531~~
- *Luis Rajmil, MD*
  Agència d'Avaluació de Tecnologia i Recerca Mèdiques, Barcelona, Spain
  Tel.: +34 932 594 223
  Fax: +34 932 594 201
  lrajmil@aatrm.catsalut.net
- *Michael Erhart, Dipl Psych*
  Child and Adolescent Health, ~~NG3,~~ Robert Koch Institute, Seestraße 10, 13353 Berlin, Germany
  Tel.: +49 304 547
  Fax: ~~+49 303 531~~
  ErhartM@rki.de
- *Jeanet Bruil, PhD*
  TNO, Prevention and Health, Leiden, The Netherlands
  Tel.: +31 715 181 705
  Fax: +31 715 181 920
  J.Bruil@pg.tno.nl
- *Wolfgang Duer, PhD*
  Ludwig Boltzmann-Institute for Sociology of Health and Medicine, University of Vienna, Vienna, Austria
  Tel.: +43 142 774 8284
  Fax: +43 142 774 8290
  wolfgang.duer@univie.ac.at
- *Pascal Auquier, MD*
  Department of Public Health, University Hospital of Marseille, Marseille, France
  Tel.: +33 491 324 474
  Fax: +33 491 797 520
  pascal.auquier@medecine.univ-mrs.fr
- *Mick Power, PhD*
  Department of Psychiatry, University of Edinburgh, Royal Edinburgh Hospital, Edinburgh, UK
  Tel.: +44 131 537 6578
  Fax: +44 131 447 6760
  mjpower@staffmail.ed.ac.uk
- *Thomas Abel, PhD*
  Social and Behavioural Health Research, Department of Social and Preventive Medicine, University of Berne, Berne, Switzerland
  Tel.: +41 316 313 512
  Fax: +41 316 313 430
  abel@ispm.unibe.ch
- *Ladislav Czemy, PhD*
  Prague Psychiatric Centre, Prague, Czech Republic
  Tel.: +42 266 003 272
  Fax: +42 266 003 270
  csemy@pcp.lf3.cuni.cz
- *Joanna Mazur, PhD*
  Department of Epidemiology, National Research Institute of Mother & Child, Warsaw, Poland
  Tel.: +48 223 277 325
  Fax: +48 223 277 325
  epid@imid.med.pl
- *Agnes Czimbalmos, PhD*
  Health Promotion and Development Centre, Child Health Department, Budapest, Hungary
  Tel.: +36 14 288 239
  Fax: +36 14 288 241
  agnes.czimbalmos@oefi.hu
- *Yannis Tountas, PhD*
  Institute of Social and Preventive Medicine, Athens, Greece
  Tel.: +30 107 482 015
  Fax: +30 107 485 872
  chsr@med.uoa.gr
- *Curt Hagquist, PhD*
  Karlstad University, Karlstad, Sweden
  Tel.: +46 547 002 536
  Fax: +46 547 002 523
  curt.hagquist@kau.se
- *Jean Kilroe, PhD*
  13 HSE, Programme of Action for Children, Dublin, Ireland
  Tel.: +35 318 682 942
  Fax: +35 318 682 943
  Jean.Kilroe@mailr.hse.ie
- *European KIDSCREEN Group*

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Appendix. Examples of the KIDSCREEN-52 HRQOL questionnaire for children and adolescents (aged 8–18 years).

1.	**Examples: physical well-being dimension**					
	Have you felt fit and well?	not at all	slightly	moderately	very	extremely
	Have you been physically active (e.g., running, climbing or biking)?	not at all	slightly	moderately	very	extremely
2.	**Examples: psychologic well-being dimension**					
	Has your life been enjoyable?	not at all	slightly	moderately	very	extremely
	Have you felt satisfied with your life?	not at all	slightly	moderately	very	extremely
3.	**Examples: moods and emotions dimension**					
	Have you felt that you do everything badly?	never	seldom	quite often	very often	always
	Have you felt under pressure?	never	seldom	quite often	very often	always
4.	**Examples: self-perception dimension**					
	Have you been happy with the way you are?	never	seldom	quite often	very often	always
	Have you felt jealous of the way other girls and boys look?	never	seldom	quite often	very often	always
5.	**Examples: autonomy dimension**					
	Have you had enough time for yourself?	never	seldom	quite often	very often	always
	Have you been able to choose what to do in your free time?	never	seldom	quite often	very often	always
6.	**Examples: parent relations and home life dimension**					
	Have your parent(s) had enough time for you?	never	seldom	quite often	very often	always
	Have you been able talk to your parent(s) when you wanted to?	never	seldom	quite often	very often	always
7.	**Examples: social support and peers dimension**					
	Have you had fun with your friends?	never	seldom	quite often	very often	always
	Have you been able to rely on your friends?	never	seldom	quite often	very often	always
8.	**Examples: school environment dimension**					
	Have you enjoyed going to school?	never	seldom	quite often	very often	always
	Have you got along well with your teachers?	never	seldom	quite often	very often	always
9.	**Examples: social acceptance (bullying) dimension**					
	Have you been afraid of other girls and boys?	never	seldom	quite often	very often	always
	Have other girls and boys made fun of you?	never	seldom	quite often	very often	always
10.	**Examples: financial resources dimension**					
	Have you had enough money to do the same things as your friends?	never	seldom	quite often	very often	always
	Have you had enough money for your expenses?	never	seldom	quite often	very often	always

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