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Quality of life in children and adolescents: a European public health perspective

Summary

Objectives: The measurement of health-related quality of life (HRQOL) is increasingly important as a means of monitoring population health status over time, of detecting sub-groups within the general population with poor HRQOL, and of assessing the impact of public health interventions within a given population. At present, no standardised instrument exists which can be applied with equal relevance in pediatric populations in different European populations.
The collaborative European KIDSCREEN project aims to develop a standardised screening instrument for children's quality of life which will be used in representative national and European health surveys. Participants of the project are centres from Austria, France, Germany, Netherlands, Spain, Switzerland, and United Kingdom. By including the instrument in health services research and health reporting, it also aims at identifying children at risk in terms of their subjective health, thereby allowing the possibility of early intervention.
Methods: Instrument development will be based on constructing a psychometrically sound HRQOL instrument taking into account the existing state of the art. Development will centre on literature searches, expert consultation (Delphi Methods) and focus groups with children and adolescents (8–17 years). According to international guidelines, items will be translated into the languages of the seven participating countries for a pilot test with 2100 children and their parents in Europe. The final instrument will be used in representative mail and telephone surveys of HRQOL in 1800 children and their parents per country (total n = 25200) and normative data will be produced. The potential for implementing the measurement tool in health services and health reporting will also be evaluated in several different research and public health settings. The final analysis will involve national and cross cultural-analysis of the instrument.
Results: The international, collaborative nature of the KIDSCREEN project means it is likely to provide many challenges in terms of producing an instrument which is conceptually and linguistically appropriate for use in many different countries, but it will also provide the opportunity to develop, test and implement the first truly cross-national HRQOL instrument developed for use in children and adolescents. This will help to contribute to a better understanding of perceived health in children and adolescents and to identify populations at risk.

Key-Words: Quality of life – Children – Survey – Public health – Generic measure – Health reporting.

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Monitoring the health status of the population is one of the main activities of public health research. In those European Countries, in which representative health surveys are routinely administered, health status is assessed through classical health indicators, derived from the biomedical model. However, as stated early in the World Health Organization (WHO) definition of health, health can also be viewed as a subjective representation of function and well-being[1]. The WHO definition holds an important expansion of the view of health, which is not only understood by somatic indicators, but also comprises how a person feels, psychologically and physically, and how she or he manages with other persons and copes with every day life[2–4]. This perceived health is known as health related quality of life (HRQOL). HRQOL is described as a multidimensional construct covering physical, emotional, mental, social, and behavioural components of wellbeing and function as perceived by patients and/or other individuals[2,5,6]. The WHO Quality of Life Group extends this definition and includes the cultural perspective: quality of life is defined as an individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns[7].

While quality of life research in adults has progressed over the past years, health-related quality of life research in children is a recent field. As was the case in the adult area, but with a delay of about a decade, 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 90s, and still going on, consists of constructing and developing quality of life measures for children. The third phase, which just recently began (about 1995 and later), concerns the application of these measures in clinical and epidemiological studies.

Including HRQOL instruments in public health surveys allows researchers to monitor population health status over time, to detect sub-groups within the general population who might be at risk for poor HRQOL, and to assess the impact of public health interventions within a given population. At present, no standardised instrument exists which can be applied with equal relevance in pediatric populations in different European populations, although subjective health is increasingly used as a measure of health status in national health surveys[8,9] and in international studies measuring perceived health indicators such as the WHO Cross-National Study: Health Behaviour in School aged Children[10,11].

Methodological considerations and instrument development to date

Research reflecting the children's point of view about well-being, perception and behaviour is so far only available in rudimentary form[12]. Recent overviews of health-related quality of life measures for pediatric patients have appeared from Eiser and Morse[13], Harding[14], Bullinger and Ravens-Sieberer[15], Marra et al.[16], Spieth and Harris[17] and Rosenbaum and Saigal[18].

Only a few, but an increasing number of generic questionnaires exist which assess HRQOL in children and adolescents. This has to do with several difficulties: Firstly, it can be explained particularly by the earlier doubts as to whether children are able to express opinions, attitudes and feelings about their HRQOL reliably[19]. To understand the concept of HRQOL or to value aspects of one's own health and well-being is determined by the age, maturity and cognitive development of a child. Recent research shows that children are able to report on their well-being and functioning reliably if the questionnaire is appropriate to the child's age and cognitive level. In younger children another impediment may be the child's difficulty with reading and writing. To resolve this problem some authors have developed questionnaires for different age groups. Further, the use of new assessment methods (e.g., different answer categories, using "smilies" or pictograms), especially for younger children, has proven to be useful[12].

Another critical point concerns the dimensions are relevant and necessary to describe the concept of HRQOL in children and adolescents. Authors agree that HRQOL is a multidimensional construct, which is documented by several national and international studies for adults[12]. Whether children would emphasise the same dimensions as adults is not clear, but it can be assumed that this is at least partly determined by the child's age. One shortcoming of the theoretical discussion and construction of questionnaires is that children are rarely asked to express their point of view. Increasing emphasis is being given to considering the child's point of view as equally or more relevant than that of experts or the results of literature reviews.

Instruments to assess quality of life have been developed mainly in the adult area. In the children's area attempts at construction of generic measures exist but only few instruments conform to the quality standards that had been set by international quality of life assessment projects with regard to translation, psychometric testing, and norming[18,20]. Among instruments which have been developed with a conceptual background and using psychometric techniques are the Child Health Questionnaire (CHQ)[21,22], and newer developments such as the TACQOL[23], VSP-A[24] and the

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KINDL-R[25]. Such instruments are increasingly used today to assess the quality of life in children in clinical research at a national and international level[26]. However, items for these questionnaires have been generated within one country. Cross-cultural instrument development should, as defined by the WHOQOL group[27], use a primary consensus on relevant dimensions and items of quality of life for certain age groups within each of the different countries. These items can then be reviewed and included in a cross-culturally developed questionnaire[28].

When analysing the results of public health surveys which include HRQOL measures for children and adolescents, it is important to take into account determinants of children's perceived health such as the physical, cultural and social environment[29], social stressors[30], health behaviours[31], and psychosocial processes such as coping and social support[22]. These factors have to be included as either determinants or moderator/mediator variables in the design of health surveys together with quality of life as a dependent variable. As a consequence children and adolescents at risk in terms of their subjective health can be identified. These children can be offered intervention programmes, which should be evaluated subsequently.

The KIDSCREEN project aims at a collaborative European development of a cross-culturally standardised screening measure for children's and adolescents' HRQOL which can be used in representative national and European health surveys.

The KIDSCREEN project

The project "Screening for and promotion of Health Related Quality of Life in Children and Adolescents – a European Public Health Perspective" (acronym: KIDSCREEN) is part of to the programme "Research and Technological Development Activities of the Generic Nature" in the area public health as described in the EC work programme within the 5th Framework Programme 'Quality of Life and Management of Living Resources' and is funded by the European Commission for three years. It started on February the 1st, 2001 and involves seven European countries: Austria, France, Germany, Netherlands, Spain, Switzerland, and the United Kingdom.

The project consists of three main phases: instrument development and testing, instrument application in large public health surveys, and an implementation phase in which the possibility of using the instrument in different settings will be tested. The whole project is based on 11 work packages. While the study centre is responsible for co-ordination and communication during all work packages and project phases, each participating centre is alternatively responsible of the contents of different work packages. The project centre is located at the Robert Koch Institute (RKI), a central institution of the Federal Ministry of Health, in Berlin, Germany. One of the main tasks of the RKI is the analysis of the health situation in Germany.

Throughout the project the study co-ordination centre and the project partners work closely together. The partners have experience both in conducting public health surveys as well as in HRQOL research in children and adolescents. Additionally there will be a continual exchange of expert knowledge with the DISABKIDS project[32] participants (a European partner project to develop questionnaires to assess quality of life in children and adolescents with disabilities and their families).

The instrument development phase

The development of the questionnaire is based on literature reviews, expert consultation (e.g., the Delphi method), and children's focus groups in all participating countries to identify dimensions and items of HRQOL which will be suitable for inclusion in the new instrument and relevant to respondents in all countries.

The first task was to perform a *literature review* of the development and use of generic quality of life measures for children and adolescents in public health settings. This literature review provided an initial identification of relevant dimensions and available assessment methods for the project.

In two comprehensive literature searches using Medline and Psychlit with a search tree involving, on the highest level, (a) "child" or "adolescent" in association with the terms "public health" or "health survey" or "health reporting" or "epidemiology" and on the second level (b) "quality of life" or "health status" or "well-being" or "psychosocial" in addition to "instruments" or "assessments", a total of 9029 abstracts were identified. Using a priori evaluative criteria, these abstracts were judged by an expert group on child health and quality of life using a rating system. Results indicated that only 4% of this literature were relevant for quality of life in health surveys. However, an additional 40% of the abstracts identified concepts and assessment instruments that dealt with determinants of quality of life. Descriptive cross-sectional studies were the most common type of study; within the epidemiological literature, representative health surveys were rare. From a public health perspective only a few countries have conducted comprehensive surveys of child health. National surveys differ widely in the methods and study designs applied, so that quality of life information is difficult to compare across countries. Available instruments to assess quality of life in generic as well as disease or

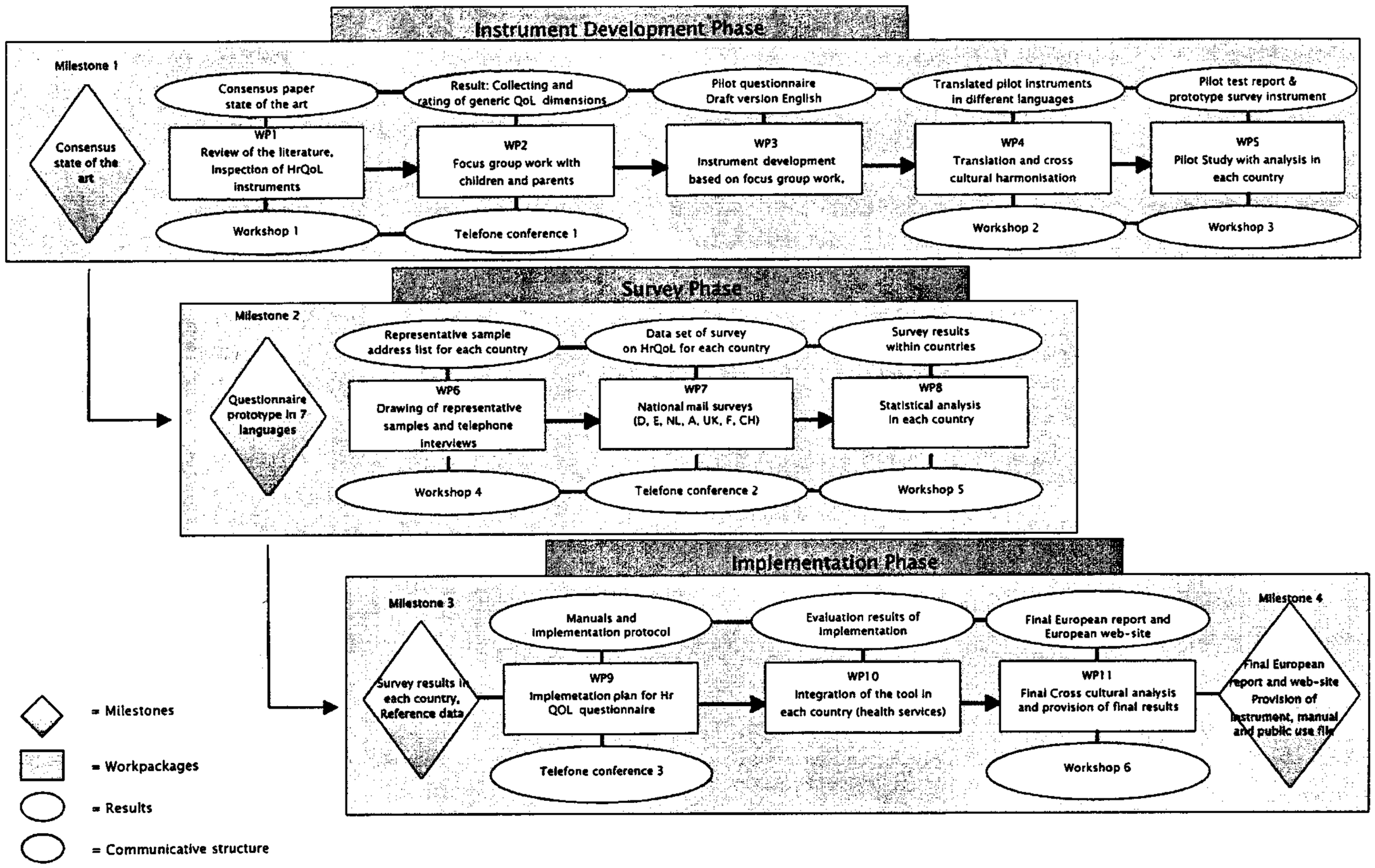

Figure 1 Management structure – KIDSCREEN project

condition specific terms were identified and rated according to the psychometric data provided (reliability, validity, and sensitivity of the instruments located) and the nature of the application.

For the second step of the instrument development phase, a *Delphi method* was used to determine the degree of consensus among experts regarding the conceptualisation and operationalisation of HRQOL for children, and to identify preliminary content for the new measure at the dimension level. The Delphi technique is a method to determine the extent to which experts or lay people agree about a given issue[33]. By means of repeated interrogations a consensus should be reached. The Delphi process in the KIDSCREEN project consisted of three rounds of questionnaires administered to a multidisciplinary group of 24 experts from seven European countries. The first Delphi round consisted primarily of open questions, and later versions of the questionnaire were based on expert responses to this round. The questionnaire was divided into three broad sections dealing with conceptualisation and operationalisation of HRQOL, as well as questionnaire construction and content. Analysis of first round responses was largely qualitative. In the second and third rounds, consensus was considered to be reached when at least 90% of experts either agreed or disagreed with a given item. Responses were received from 20 respondents in the three rounds. Agreement was reached that the new instrument should be a multidimensional, profile measure with 30–49 items covering five to eight dimensions, and taking 10–15 minutes to complete. Agreement was also reached on eight specific dimensions to be included in the questionnaire: psychological well-being, self-esteem, body image, cognitive functioning, mobility, energy/vitality, social relations, and family/home function. The consensus was generally against having an individualised questionnaire.

The results of the literature review and the Delphi process provided a preliminary structure for the following phase of *focus groups* with children (8–17 years) to identify relevant quality of life dimensions and acceptable wording. Six focus groups are being performed in each country with a minimum of four children/adolescents in each group (8–9 years, 12–13 years, 16–17 years: girls and boys each, n=24). Separate focus groups are performed in girls and boys and by age group. The participants were preferably recruited from different schools or similar institutions. Where possible, the children taking part in the focus groups were not supposed to know one another, and researchers were asked to try

to include different socio-economical levels in the groups. Parents of children of a similar age (or occasionally parents of the children who participated in the focus groups) were also asked for their opinions on what might be most important elements of quality of life for their own children using a standardised questionnaire in the different countries.

Focus group work is currently ongoing and is going to result in a list of items and dimensions, pictures and response scales for the questionnaire. These materials will be sent to all participants who are asked to rate the items with regard to clarity, relevance, and appropriateness. Final item selection will be performed in a second Delphi study. The outcome of this process will be the English pilot version of the HRQOL questionnaire, which then has to be translated into the languages of all participating countries. International translation guidelines will be followed which include two forward translations by native speakers of the target language, one backward translation by a native speaker of the source language and comparison between the back-translation and the original version. In addition, quality ratings by other independent raters regarding the clarity, use of colloquial language, and semantic equivalence of translations will be involved. An important aspect is the comparability of answers scales across countries, and in this case it is intended to use Thurstone scaling exercises and/or visual analogue methods to examine the interval propriety of rating scales across countries. A manual in which the translation process and particularly the changes in translation to achieve semantic equivalence with the original version will be prepared by each participating country. After this translation procedure a pilot questionnaire version should be available in the different languages. Furthermore, a questionnaire of the parent version for ethnic minorities has to be translated and utilised in each country.

The translated questionnaire will be included in a pilot study with 300 children per country as well as their parents (two age groups, three socio-economic levels, and both genders) to provide a preliminary validation of the questionnaire. Children included in the survey will be contacted in conjunction with health officials through routine medical examinations in schools. The process and result of this pilot test will be documented, analysed, and reported by each participating national centre, and a cross-European analysis of the data will be conducted (n=2100 children and n=2100 parents). In addition to common psychometric analysis, item response theory and structural equation modeling will be performed to determine the optimal item and scale characteristics of the questionnaire.

The survey phase

The final instrument is going to be used in representative mail and telephone surveys of HRQOL in children and adolescents. At least 1800 interviews with both parents and children in each participating country are to be realised. Data collection consists of three parts: a) the sampling representing the main population parameters (quota sample), b) carrying out a sample survey consisting of short telephone interviews with parents and children by the principal centre and c) the detailed standardised mail questionnaire which will be sent to both parents and children in the seven European countries.

The sampling by telephone will be carried out using a CATI-supported random-digital-dialing management system to avoid distortions of the sample survey and to control the characteristics of the quota sample. Representative quota sampling was selected as the best sampling procedure, owing to positive experience in most European countries. The selected parameters reproduce the structure of the population in each participating country and represent the respective population. The distribution of the parameters will be taken from the national statistics in each participating country to achieve the correct proportion of each stratum: children's age (two age groups), gender, and type of area. Families will be asked via telephone interview to participate, to give their written informed consent, and to respond to a mailed survey.

The mail survey of parents and children using the translated, psychometrically tested and extended questionnaire is going to be carried out by the participating countries. To increase the response rate, each participating country will send two reminders to the parents to ask for the questionnaire and will provide incentives for children. It is expected that using a combined procedure of sampling by telephone and mail surveys distributed by each national centre will lead to an optimal response in the sample survey. Non-response in the mail surveys of participating countries requires a retrospective representative weighting of the data according to the parameters of the population. Statistical analysis across countries will use correlational and structural equation modeling for the global data set.

Implementation phase

Modes of implementation of the new measure is going to be discussed among all national partners in the implementation phase of the KIDSCREEN project. On the basis of the survey data collected, round table discussions with health services officials will be initiated in order to tailor possibilities for each nation to implement the instrument in health promotion programmes on the basis of the identified children at risk. The implementation phase has included preparation

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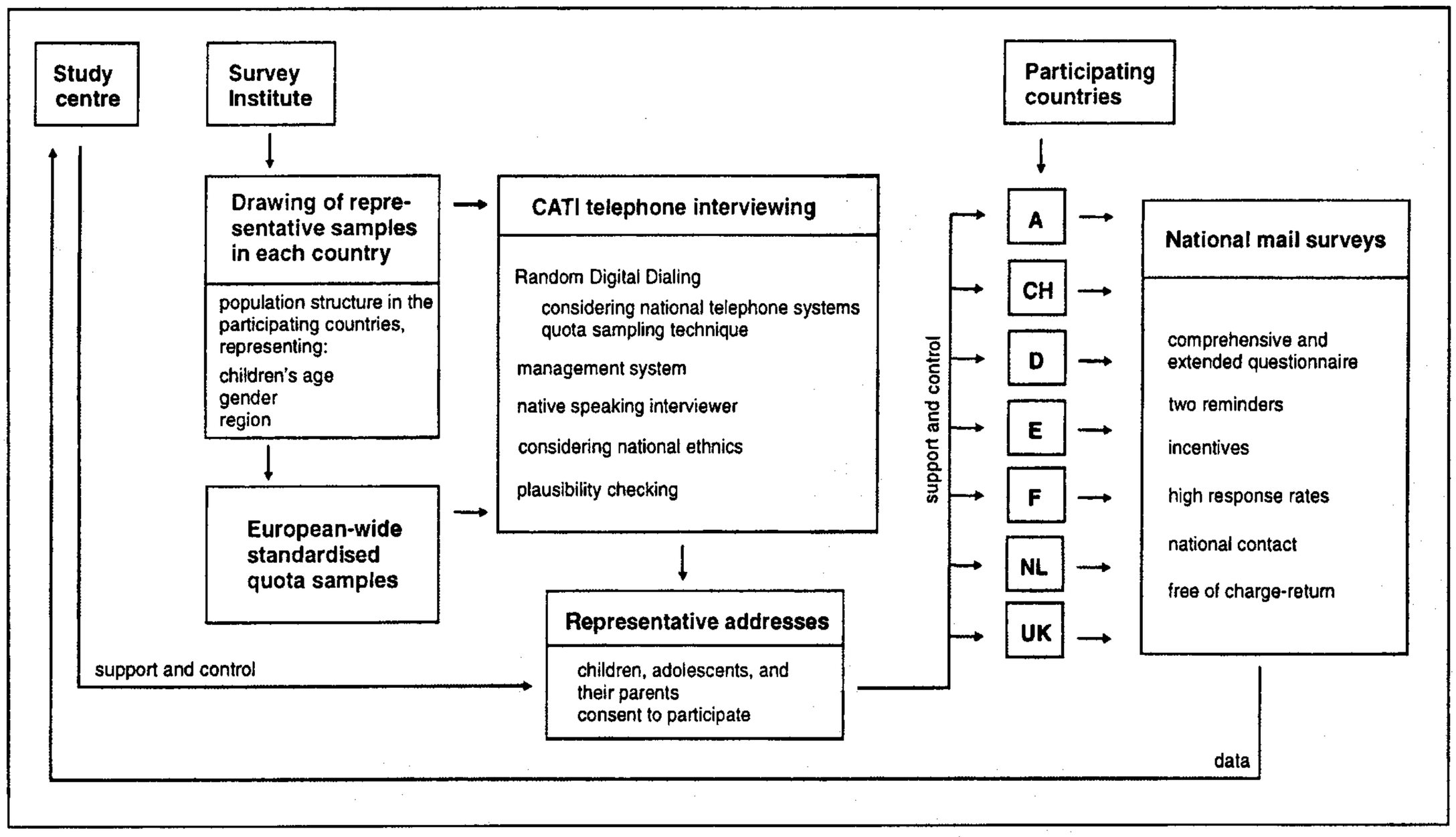

Figure 2 Overview of sampling and data collection – KIDSCREEN project

of user friendly guidelines and user manuals in view to facilitate practical use of the instrument. Those will be made available via modern communication technologies.

One implementation per country (e.g., local health reporting, or quality of life screening instruments in routine school health examinations) will be conducted. The countries are rather free to choose the form of implementation they feel will be most appropriate or useful in their particular locale. Suggestions for implementation to date include use of the instrument as a screening tool in a primary care centre in deprived areas to detect children at risk, or evaluation of health promotion programmes for teenagers.

Discussion

HRQOL is one of the major descriptors and outcome criteria that has been discussed in the health care systems in recent years. Quality of life of children and especially children at risk however is yet an under-researched area. To fill this gap, the development of a generic HRQOL measure is warranted. It should meet an European standard in which the children's self report and parental perception of their children's health is included. The importance of subjective measures of well-being and function (i.e., subjective health) has increased over the past decade. Especially for children and adolescents it is important to know how they view their lives and how they rate their function and well-being. Screening and early intervention is necessary and dependent upon an instrument to monitor populations as well as to identify population subgroups at risk. For children and adolescents with known health problems it is important to understand the impact of their health conditions on health-related quality of life in order to plan, act upon and improve prevention and care.

The project contributes to European policies by providing information about the types and distribution of quality of life impairments (nationally as well as Europe-wide). By giving each country and centre the possibility to be involved already at the item construction phase of the current project, a truly international collaborative effort is made. European added value consists in having at hand a cross-cultural comparable and usable instrument, which will be easy to use and to apply. To devise an instrument to assess quality of life for children and adolescents in major European languages makes it easier on a national and international level to communicate the approaches to and experiences with monitoring representative populations, with health promotion as well as with communication about improvement possibilities.

Providing a quality of life assessment measure, the KIDSCREEN project adds an important dimension in health assessment and health monitoring. Such a screening instrument may also serve as a prototype for further application of

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quality of life health surveys in other countries. Thus, the project attempts to contribute to a transfer of existing knowledge about quality of life assessment in health surveys to other regions of the European Union, which are yet less experienced in the quality of life assessment. A continued implementation of a standardised HRQOL measure in health reporting is even more important, since the KIDSCREEN study design does not include follow-up data to analyse the time stability of the perceived quality of life and health.

In sum the contribution to public health research of the KIDSCREEN project exists on several levels: 1. the provision of a standardised instrument available in several languages for European countries to routinely monitor subjective health and well-being of the children in the European Union; 2. to screen for and early detect possible impairments in well-being and function in children, which can be the basis of early interventions; 3. to identify social and behavioural determinants of health (e.g., socio-economic factors and health behaviours, acute and chronic health conditions); and 4. the assessment of the relative impact of such quality of life assessment on monitoring the health of children and adolescents in the European region.

Zusammenfassung

**Lebensqualität bei Kindern und Jugendlichen:
eine europäische Public-Health-Perspektive**

Fragestellung: Das von der EU geförderte Projekt trägt den deutschen Titel „Screening und Förderung der gesundheitsbezogenen Lebensqualität von Kindern und Jugendlichen in Europa – eine Public-Health-Perspektive". Das Projekt wird von Deutschland aus geleitet und in Zusammenarbeit mit sieben europäischen Ländern (Deutschland, Schweiz, Österreich, Frankreich, Spanien, Grossbritannien und die Niederlande) durchgeführt. Im Mittelpunkt steht die Entwicklung eines standardisierten Untersuchungsinstrumentariums zur krankheitsübergreifenden Erfassung der gesundheitsbezogenen Lebensqualität von Kindern und Jugendlichen im Alter von 8–17 Jahren sowie deren Familien. Das Untersuchungsinstrumentarium wird nach Entwicklung in den jeweiligen Ländern in repräsentativen Gesundheitssurveys eingesetzt, wobei ein Fokus der Untersuchungen die Identifizierung der Gesundheitsstörungen von Kinder und Jugendlichen darstellt.

Methoden: In einem ersten Arbeitsschritt erfolgt die Entwicklung eines Untersuchungsinstrumentariums zur populationsbasierten Erfassung gesundheitsbezogener Lebensqualität von Kinder und Jugendlichen. Das Untersuchungsinstrumentarium wird mit Hilfe von Experten aus dem Gesundheitsbereich generiert, zusätzlich werden Kinder und Jugendliche hinzugezogen und bezüglich relevanter Themen befragt. Der so entwickelte Fragebogen wird nach internationalen Richtlinien in die Sprachen der teilnehmenden Länder übersetzt und in einer Pilotstudie getestet. In einem zweiten Arbeitsschritt werden sieben repräsentative Erhebungen zur gesundheitsbezogenen Lebensqualität und zum Gesundheitszustand bei je 1800 Kindern/Jugendlichen und ihren Familien in jedem Land durchgeführt. Nach Auswertung dieser Umfrage wird in einem dritten Schritt das entwickelte Untersuchungsinstrumentarium in die nationalen Gesundheitsstrukturen implementiert und auf europäischer Ebene vorgestellt und evaluiert.

Ergebnisse: Die Studie möchte dazu beitragen, aktuelle Informationen zur Kinder- und Jugendgesundheit sowohl auf europäischer Ebene als auch in den einzelnen Ländern zu gewinnen. Ziel ist es auch, diejenigen Kinder und Jugendlichen zu identifizieren, bei denen ein besonderer Interventionsbedarf besteht. Die Ergebnisse sollen dazu beitragen, Hinweise für die Richtlinien zukünftiger Gesundheitspolitik in Europa zu geben.

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The KIDSCREEN Project: Screening for and Promotion of Quality of Life in Children and Adolescents - A European Public Health Perspective

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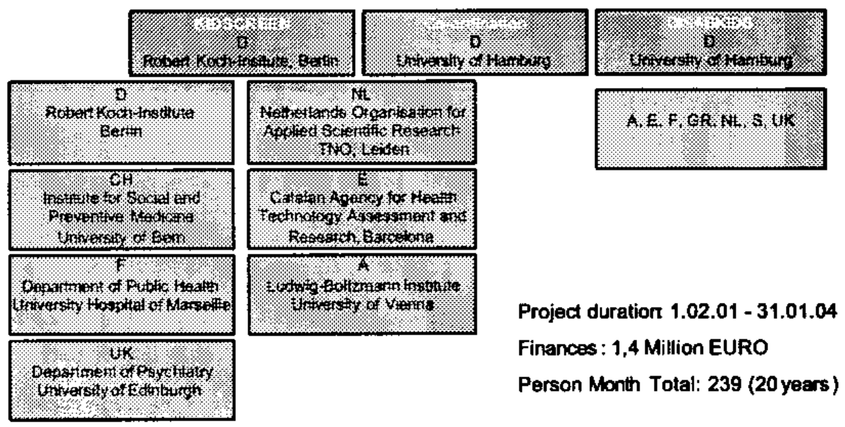
1. Background

The KIDSCREEN project is a favorably reviewed EC-Project within the 5th Framework-Programme Quality of Life Management of Living Resources, offered within the sub-programme Activities of a Generic Nature, Area Public Health. KIDSCREEN is funded for three years, started February 1st, 2001, involving seven European countries: D, E, GB, F, A, NL, CH.

European Co-operation



Project duration: 1.02.01 - 31.01.04
Finances: 1,4 Million EURO
Person Month Total: 239 (20 years)

2. Objectives

The project aims at a co-operative European development of a standardized screening instrument for children's quality of life which will be used in representative national and European health surveys. It also aims at identifying children at risk at terms of their subjective health to suggest early intervention possibilities by including the instrument in health services research and health reporting.

3. Method and Project Phases

KIDSCREEN - Project Phases

- **Phase I ⟹ Instrument Development**
  Literature Review, Delphi Method, Focus Groups
- **Phase II ⟹ Survey**
  National Representative Investigations in the Respective Countries (N = 12600)
- **Phase III ⟹ Implementation**
  in National and European Health Systems

11 Workpackages

Instrument development pertained to construct a psychometrical sound HrQol instrument taking into account the existing state of the art by using literature searches, expert consulting and Delphi Methods. Items of the instrument were developed by conducting focus groups with children (8-17 years) to identify acceptable items and relevant QoL dimensions.

According to international guidelines items were translated into languages of the participating countries and a pilot instrument was obtained which will be tested in 300 children in each country. Item response theory and structural equation modeling are used to determine the optimal item and scale characteristics of the questionnaire in addition to common psychometric analysis.

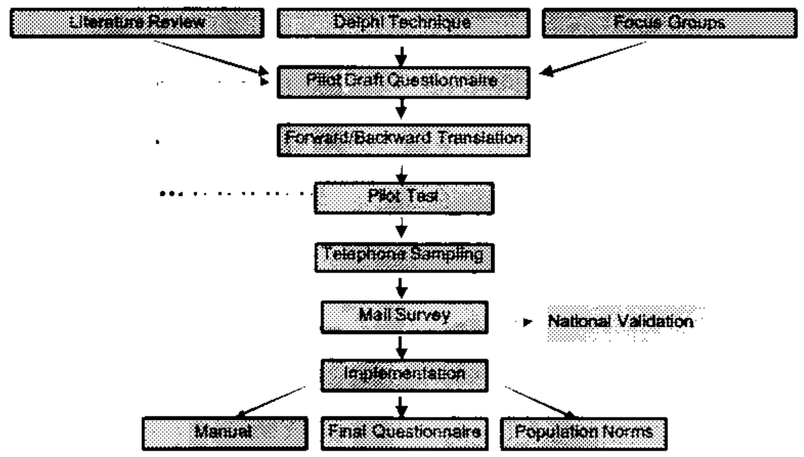
[1] C. Bisegger, A. Clément, B. Cloetta, S. Detmar, A. Futh, A. Gosch, M. Herdman, A. Kindervater, K. Phillips, U. von Rüden, M.-C. Simeoni, E. Verrips. The KIDSCREEN project cooperates closely with the partner project DISABKIDS.

4. Expected Results

The final instrument will be used in representative mail and telephone surveys on HrQoL in 1800 children and parents per country (n total = 12.600), and norm data will be provided. The potential implementation of the instrument tool in health services and health reporting will be planned, tested and evaluated. The final analysis will involve national and cross cultural -analysis of the instrument.

It is expected that the KIDSCREEN project will contribute to a better understanding of perceived health in children and adolescents in Europe and will contribute to planning, carrying out and evaluating innovations in the health care field.

KIDSCREEN Development Steps



5. Contact

News, continuing documentation and publications of work from the project is available on the KIDSCREEN homepage at: www.kidscreen.org