Changing pediatric cancer care: development and implementation of electronic patient and parent reported outcomes

Schepers, S.A.

Citation for published version (APA):
Chapter 6
Implementation of electronic patient reported outcomes in pediatric daily clinical practice: the KLIK Experience

L Haverman, HA van Oers, PF Limperg, CT Hijmans, SA Schepers, SM Sint Nicolaas, CM Verhaak, AHM Bouts, CJ Fijnvandraat, M Peters, MA van Rossum, JB van Goudoever, H Maurice-Stam, MA Grootenhuis
Clinical Practice in Pediatric Psychology, 2014, 2(1), 50-67
ABSTRACT

Introduction
The use of Patient Reported Outcomes (PROs) in daily pediatric practice is effective in increasing the discussion about emotional and psychosocial functioning. Therefore, we are implementing KLIK: a web based program in which electronic PROs (ePROs) are used. The aim of this article is to describe the KLIK implementation following the methodological recommendations composed by the International Society for Quality of Life (ISOQOL).

Methods
KLIK is intended for all pediatric patients visiting the outpatient clinic and their parents. They complete questionnaires at home via www.hetklikt.nu before consultation. The pediatrician/practitioner discusses the ePROs during the consultation to monitor the patient’s well-being over time, in order to detect problems at an early stage and to provide tailored interventions.

Progress of the KLIK implementation
Since the start of the implementation of KLIK in June 2011, 9 patient groups have started using KLIK. More than 100 professionals followed a training course and over 600 patients are registered on the KLIK website.

Discussion
The implementation of KLIK in daily clinical pediatric practice appears to be feasible and workable. Many pediatricians have shown their interest in using KLIK and we are therefore expanding the use of KLIK in order to make KLIK applicable in different patient groups and hospitals.
INTRODUCTION

In the past ten years there has been a growing interest in the use of Patient Reported Outcomes (PROs) in clinical practice. PROs are based on direct reporting by patients without the intervention of an observer. They include the self-assessment of well-being, functional status, symptoms, and other concerns such as patient needs and satisfaction with care. Health Related Quality Of Life (HRQOL) assessment often includes a patient’s functional status (physical and psychosocial) as well as his or her symptoms. HRQOL questionnaires retrieve information directly from the patient and therefore, can be considered as PROs.

Research in adult patients shows that the integration of PROs in clinical practice generally improves patient-clinician communication; it helps in identifying and discussing HRQOL issues, and adds to improvement of a patient’s health outcomes and satisfaction with care.

Studies on the use of (HRQOL) PROs in pediatric clinical practice are scarce compared to adult practice. De Wit et al. showed that systematic monitoring and discussing of HRQOL in adolescents with diabetes improved their psychosocial well-being and their satisfaction with care. In our hospital, Engelen et al. showed that the feedback of HRQOL via PROs during the consultation with the pediatrician increased the discussion on emotional and psychosocial functioning and improved the identification of emotional problems in pediatric oncology patients. Additionally, the intervention did not lengthen consultation duration.

In these pediatric PRO studies, HRQOL questionnaires were completed at the clinic immediately before the actual doctor’s visit, with patients using stand-alone or touch screen computers. A printed version of this PRO was handed to the pediatrician to be discussed during the consultation. This method was very time consuming and often caused logistical problems because of lack of privacy and room at the clinic. The use of a web-based program could overcome these problems and could contribute to an improvement in the use of PROs in clinical practice.

Therefore, we conducted a new multicenter study, the KLIK (in Dutch: Kwaliteit van Leven In Kaart, in English: Quality of Life in Clinical Practice) study. We developed a website (http://www.hetklikt.nu) and children between 0 and 18 years old with Juvenile Idiopathic Arthritis (JIA) were included. Children and/or their parents completed the HRQOL questionnaires on the website at home. The answers on the questionnaires were schematically converted into a so-called KLIK ‘ePROfile’ (figure 1 and 2). Pediatricians could retrieve these ePROfiles directly from the website during the consultation. This study showed that the use of electronic PROs (ePROs) increased communication on psychosocial topics and increased the pediatrician’s satisfaction with the provided care. In addition, during the KLIK study the use of the website appeared to be feasible.

As a result of the positive findings in both adult and pediatric care and the readiness of our hospital to incorporate systematic attention for HRQOL in clinical practice, we decided to implement the use of the KLIK ePROfile in daily clinical practice for children with various chronic illnesses. The implementation of the use of PROs in daily clinical practice creates new challenges and opportunities for care, as is extensively described in the International Society for Quality of Life Research (ISOQOL) guidelines. These guidelines offer considerations for using PROs.
Chapter 6

Figure 1 KLIK PROfile. A literal representation of the answers.

Figure 2 KLIK ePROfile. Graphic presentation, including norm values.
Implementation of electronic patient reported outcomes in pediatric daily clinical practice: the KLIK experience

in clinical practice, options for designing the PROs, and strengths, weaknesses and resource requirements associated with each option. According to the ISOQOL guidelines, implementing PROs involves a number of methodological and practical decisions. These include: (1) identifying the goals for collecting PROs in clinical practice; (2) selecting the patients, setting of care and timing of assessment; (3) determining which questionnaires to use; (4) choosing a mode for administering and scoring the questionnaires; (5) designing processes for reporting results; (6) identifying aids to facilitate score interpretation; (7) developing strategies for responding to issues identified by the questionnaires; and finally: (8) evaluating the impact of using PROs in clinical practice.

The aim of the current article is to provide a thorough description of the implementation of ePROs in daily pediatric clinical practice following the methodological recommendations and decisions using the guidelines provided by the ISOQOL. In addition, we used our experiences, with the KLIK ePROfile, based upon the study in pediatric rheumatology patients. First, we will outline the eight considerations as provided by the ISOQOL guidelines, illustrated by our intervention (KLIK), and explain why we made specific decisions regarding KLIK. Then we will give insight in the progress of the implementation so far. Finally, we will discuss strengths, difficulties and future goals of the KLIK project. This paper will contribute to the knowledge on how to implement PROs in pediatric practice and eventually make the use of PROs more efficient.

**METHODS**

1. **Identifying the goals for collecting PROs in clinical practice**

In the ISOQOL guidelines several goals for the application of PROs are mentioned; (1) to screen for problems, (2) to monitor progress over time, (3) to facilitate patient-centered care, (4) to function as decision aids, (5) to facilitate multidisciplinary communications, and (6) to evaluate quality of care. In the KLIK project we use ePROs with the purpose to screen and monitor the patient’s well-being. The goal is to monitor children with various chronic illnesses over time, to be able to detect problems at an early stage and to provide tailored interventions before problems increase. We facilitate multidisciplinary communication by providing the KLIK ePROfile to all the members of the multidisciplinary team (e.g. pediatricians, nurses, social workers and psychologists). We also hope to achieve more patient-centered care by providing the KLIK ePROfile to patients themselves. In this way, patients can become more involved in their own care and prepare themselves better before each consultation with their pediatrician.

2. **Selecting the patients, setting of care and timing of assessment**

The ISOQOL guidelines mention different groups of patients for which PROs can be used; patients who can self-report, patients needing assistance with completing PROs, ambulatory patient with or without specific conditions, and patients in inpatient or outpatient care. We assume that all children with chronic illnesses might benefit from the use of the KLIK ePROfile. The recent implementation of KLIK therefore includes all children visiting the outpatient clinic between 0-18 years old. Children aged 8 years or above complete the questionnaires themselves.
Figure 3. Overview of users in KLIK.
### Table I. Questionnaires in KLIK available in December 2012.

<table>
<thead>
<tr>
<th>CHILD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HRQOL Generic</strong></td>
<td></td>
</tr>
<tr>
<td>Pediatric Quality of Life Inventory (PedsQL)\textsuperscript{27,28}</td>
<td></td>
</tr>
<tr>
<td>PedsQL Fatigue module\textsuperscript{43}</td>
<td></td>
</tr>
<tr>
<td><strong>HRQOL Disease-specific</strong></td>
<td></td>
</tr>
<tr>
<td>PedsQL Transplant module: nephrology\textsuperscript{44}</td>
<td></td>
</tr>
<tr>
<td>PedsQL Cancer module: oncology\textsuperscript{45}</td>
<td></td>
</tr>
<tr>
<td>Childhood Health Assessment Questionnaire (CHAQ): rheumatology\textsuperscript{46}</td>
<td></td>
</tr>
<tr>
<td>Dutch Defecation Questionnaire (DDL): gastroenterology\textsuperscript{47}</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with Appearance (SwA): cleft lip\textsuperscript{48}</td>
<td></td>
</tr>
<tr>
<td>Questionnaire Juvenile Idiopathic Arthritis*</td>
<td></td>
</tr>
<tr>
<td>Medication and appearance after kidney transplant*</td>
<td></td>
</tr>
<tr>
<td>Medication and transition questions HIV*</td>
<td></td>
</tr>
<tr>
<td>Questionnaire Sferocytosis*</td>
<td></td>
</tr>
<tr>
<td>Questionnaire Cleft Lip*</td>
<td></td>
</tr>
<tr>
<td><strong>Psychosocial screening tools</strong></td>
<td></td>
</tr>
<tr>
<td>Strengths and Difficulties Questionnaires (SDQ)\textsuperscript{49,50}</td>
<td></td>
</tr>
<tr>
<td>Children’s Revised Impact of Event Scale (CRIES)\textsuperscript{51}</td>
<td></td>
</tr>
<tr>
<td>Child Behavior Checklist (CBCL)\textsuperscript{52}</td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td>Course of Life questionnaire (LVJV/CoL)\textsuperscript{53}</td>
<td></td>
</tr>
<tr>
<td>Questions about school*</td>
<td></td>
</tr>
<tr>
<td>Evaluation of the KLIK ePROfile*</td>
<td></td>
</tr>
<tr>
<td>Open question to the pediatrician*</td>
<td></td>
</tr>
<tr>
<td>VAS pain and VAS wellbeing\textsuperscript{46}</td>
<td></td>
</tr>
<tr>
<td>* self-composed questionnaire</td>
<td></td>
</tr>
</tbody>
</table>
### Table I. Questionnaires in KLIK available in December 2012 (cont.)

#### PARENTS

**HRQOL Generic about child**
- TNO-AZL Preschool children Quality of Life (TAPQOL)\(^{25}\)
- Pediatric Quality of Life Inventory (PedsQL)\(^{27,28}\)
- PedsQL Fatigue module\(^{53}\)

**HRQOL Disease-specific about child**
- PedsQL Transplant module: nephrology\(^{44}\)
- PedsQL Cancer module: oncology\(^{45}\)
- Childhood Health Assessment Questionnaire (CHAQ): rheumatology\(^{46}\)
- Questionnaire Sferocytosis*
- Questionnaire Cleft Lip*

**Psychosocial screening tools about child**
- Strengths and Difficulties Questionnaires (SDQ)\(^{49,50}\)
- Behavior Rating Inventory of Executive Function (BRIEF)\(^{54}\)
- Questionnaire for Behavioral Problems in Children (VvGK)\(^{55}\)
- Children’s Revised Impact of Event Scale (CRIES)\(^{51}\)

**HRQOL Generic about parent**
- TNO-AZL Questionnaire for Adult Health-Related Quality of Life (TAAQOL)\(^{56}\)

**Psychosocial screening tools about parent**
- Distress Thermometer for Parents (DT-P)\(^{57}\)
- Hospital Anxiety and Depression Scale (HADS)\(^{58,59}\)
- Parental Stress Index (NOSIK/PSI)\(^{60,61}\)
- Psychological Assessment Tool (PAT)\(^{62}\)
- Pediatric Inventory for Parents (PIP)\(^{63}\)
- The self-rating scale for post-traumatic stress disorder\(^{64}\)
- Child Vulnerability Scale (CVS)\(^{65,66}\)
- Social Support Scale (ISB)\(^{67,68}\)
- Illness Cognition Questionnaire for chronic diseases (ZCL/ICQ)\(^{68}\)

**Other**
- Evaluation of the KLIK ePROfile*
- Socio-demographic questionnaire*
- Open question to the pediatrician*

#### PEDIATRICIAN

Evaluation of the KLIK ePROfile*
Implementation of electronic patient reported outcomes in pediatric daily clinical practice: the KLIK experience

... (self-report). The validity and reliability of children as informants about their own status using different HRQOL instruments has been supported by several large studies\(^{22,23}\). In the literature, there is a general preference for self-reported PROs compared to proxy-reports, because self-report provides a direct assessment of the patient’s outcome\(^22\). However, young children are not yet cognitively capable to respond themselves\(^20\) and need assistance. Therefore, parents/caregivers complete the questionnaires for children aged 0-7 (proxy-report). For each assessment, the proxy is identified in terms of the relationship to the child (mother/father/other) and reported to the pediatrician.

Depending on the frequency of outpatient visits, children or parents complete the questionnaires on different times based on the process of disease and treatment. We advise to administer the HRQOL questionnaires every three months and the psychosocial questionnaires once a year prior to the hospital visit. To decrease the possible burden of frequent assessment, a condition is built in the website to indicate whether a questionnaire needs to be completed before every consultation, or for example, only once a year. The time interval for completion of the questionnaires is decided by the multidisciplinary team. A targeted measurement strategy is needed for patients with specific illnesses\(^20\), they need specific questionnaires and a specific logistical approach for the use of ePROs.

To improve care for pediatric patients we also acknowledge the importance of the assessment of the burden on parents. To get insight in the parental stress levels and reactions to the uncontrollable aspects of the illness of their child\(^24\) we also included Parent Reported Outcomes in the KLIK ePROfile. The KLIK website enables parents/caregivers of a child to complete questionnaires, for example about their own psychosocial functioning and HRQOL. An overview of whom is able to complete questionnaires on the KLIK website and which members of the team can use that information is provided in figure 3.

3. Determining which questionnaires to use

There are several considerations regarding which questionnaires to use; generic or disease-specific questionnaires, profile or preference-based measures, single or multi-item scales and static or dynamic questionnaires\(^{21}\). The basis of the KLIK ePROfile is a generic HRQOL questionnaire. We included the TAPQOL (TNO-AZL Preschool children Quality of Life)\(^{25,26}\) and the PedsQL Generic Core Scale (Pediatric Quality of Life Inventory)\(^{27,28}\). The TAPQOL is used for parents of children aged 0 to 5 years (proxy-report). The PedsQL self-report form is used for children aged 8 to 18; parents of children aged 6 to 7 complete the PedsQL proxy-report. We chose these questionnaires because they have been proven to be valid, sensitive to changes over time, easy to administer, and well capable of being transformed into an ePROfile. Besides the generic HRQOL questionnaires, there are many other, disease-specific, validated HRQOL questionnaires available in KLIK (Table I). We also included disease-specific HRQOL questionnaires for specific patient groups, because this enables comparison with healthy norm scores as well as with population-specific scores.

Furthermore, questionnaires measuring concepts other than HRQOL, such as coping, illness perception, vulnerability and functional status are available at the KLIK website. In addition,
psychosocial screening-tools are used for diagnostic purposes and are only visible for the psychologist of the specific multidisciplinary team (Table I).

Besides the questionnaires to measure the parent’s HRQOL and psychosocial functioning, a short non-invasive screening-tool that detects the level of parental distress was not available. We therefore developed a screening-tool for parents, the Distress Thermometer for Parents (DT-P)\textsuperscript{29}. This questionnaire was adapted from the DT for adult oncology patients\textsuperscript{30} and added to the KLIK website. In addition, for the use in KLIK, we are working on the translation, validation and feasibility of the Dutch Psychosocial Assessment Tool (PAT) designed for families and children with cancer. We will use the PAT in the inpatient pediatric clinical oncology practice\textsuperscript{31}.

To determine which questionnaires will be used for specific patient groups, a meeting with the multidisciplinary team of the concerning patient group is organized by the KLIK team. The KLIK team consists of 6 psychologists. In this meeting, the members of the multidisciplinary team are involved in the decision which questionnaires should be included in KLIK for that specific patient group. If during the meeting with the multidisciplinary team topics arise that are not captured in already existing questionnaires, the team composes a list with questions on issues they would like to know about their patients or parents. For example for all children using KLIK, questions about school have been added. Also, separate questionnaires have been composed for specific patient groups. For example, questions about medication use in JIA patients, medication-related appearance issues in children with a kidney transplant and questions about transition from pediatric to adult care and sexuality in children with HIV have been added to KLIK (Table I).

In conclusion, we use generic and disease-specific questionnaires. We mainly use profile measures because these measures provide summary scores across a broad range of domains. In addition we use multi-item scales, because they are more reliable, content valid and sensitive than single item scales\textsuperscript{21}. Permission from the developers and/or the publisher was obtained prior to the using of all questionnaires in KLIK. For the use of certain questionnaires, we are obligated to pay a fee.

4. Choosing a mode for administering and scoring the questionnaires

In the ISOQOL guidelines, various options are mentioned for mode of administration and data capture, for example self-administered or interview-administrated (in the clinic) or via mail or telephone (at home). We chose to use a web-based mode including the use of portable devices\textsuperscript{21} for reasons outlined below.

The use of a web-based program can easily overcome problems related to paper-pencil administration at the outpatient clinic, such as lack of space or lack of administrative personal for data entry, and a high risk of missing data. The web-based program can contribute to an improved use of PROs in clinical practice\textsuperscript{16}. Also, it is more convenient for patients and parents, as the timing for data collection is flexible. Another advantage of the use of a website is that the scoring of the questionnaires is conducted automatically.
Figure 4. Homepage of the KLIK website (www.hetklikt.nu).
At the start of the implementation we transformed the research website, used for the KLIK study in children with JIA, into a new user-friendly website with an appealing look for children and adolescents. On the homepage, each patient group corresponds to a button (figure 4). Also, in an informative video on the homepage, including English subtitles, the goal and use of KLIK is explained to parents, children and professionals in only a few minutes. Patients and their parents who are invited to participate in the KLIK project receive an informative letter to introduce the use of KLIK as new standard care at the outpatient clinic, and to inform them how they can register and complete questionnaires on the website. Patients have to go to the website www.hetklikt.nu, select to which patient group they belong, and register. At registration, they fill out the first two letters of their first name and first two letters of their last name, their parent’s email address, their own email address (if applicable), date of birth, gender, consultation date, and they can select their own pediatrician by clicking on his/her picture. They also have to choose a username.

After registration, patients and their parents receive an automatic email from the website containing a password with which they can log in. The KLIK team receives an automatic email for every newly registered patient. One week to three days before the consultation with the pediatrician, patients and their parents receive an automatic email to inform them that the questionnaires are available online. From this moment until the day of the consultation, they can complete the questionnaires. This time frame was chosen to make sure that the pediatrician receives up to date information and discusses the patient’s and parent’s current situation.

After the questionnaires have been completed, the patient and his/her parents can see his/her own KLIK ePROfile. This KLIK ePROfile is also directly available to the members of the multidisciplinary team, who have their own username and password for the website. In case the questionnaires have not been completed yet, one day before the outpatient visit, an automatic e-mail reminder is sent to the patient and parents. One day before the visit, a member of the KLIK team checks which patients have registered and completed questionnaires. Those patients who have not completed questionnaires are contacted by telephone as an extra reminder. The pediatrician or other member of the multidisciplinary team can log in on the website to view the KLIK ePROfile before or during the consultation and discusses the KLIK ePROfile with the patient and his/her parents during the visit.

For the small number of patients without direct access to the internet at home or who did not complete the questionnaires at home, it is possible to complete the questionnaires at the outpatient clinic before the consultation with the pediatrician. They are assisted by a member of the KLIK team and can complete the questionnaires on a regular PC in the outpatient clinic or on a laptop or iPad in the waiting room.

After the consultation, patients and their parents receive an automatic email to thank them for completing the questionnaires and to ask them to fill in the next consultation date with the pediatrician on the website. When this consultation date is entered on the website, parents and/or patients receive an automatic email a few days in advance, reminding them to complete the questionnaires again. In this way, the questionnaires are tied to visits, enabling the members of the multidisciplinary team to monitor changes over time in the patient’s KLIK ePROfile.
Security of the website
The website is designed to be operational for different users. Each user has a unique login name and is automatically given access to a specific secure section of the website. Patients and members of the multidisciplinary team receive very complex and lengthy passwords that cannot be changed. Every patient is linked to his/her own pediatrician/multidisciplinary team and the website only allows the pediatrician/practitioner to see his/her own patients. In this way, the privacy of the patients is guaranteed. Moreover, the website itself is designed to ensure the safety and protection of all data. We have secured the website with a SSL certificate and the information to and from the website is encrypted. In addition, the website server is positioned in a professional data center and is physically secured against fire, forcible entry and vandalism. Professional web-builders are directly available for support of the website in the case of problems or emergencies. In addition, no full names or patient numbers are being used on the website.

5. Designing processes for reporting results

When will results be presented?
The options mentioned in the ISOQOL guidelines for the moment of presenting the PROs are before, during or after a consultation. The questionnaires in KLIK are available a few days before the doctor’s visit. During the visit the pediatrician can retrieve the KLIK ePROfile directly from the website and discusses this with patients and parents. In some patient groups, the KLIK ePROfiles of the patients are discussed during a multidisciplinary consultation.

Where will results be presented?
The results can be presented within or outside the clinical workflow. At this moment, the results are presented outside the clinical workflow. Discussing the KLIK ePROfile is tied to the visit, but the KLIK ePROfile is not integrated into the electronic chart. Pediatricians/practitioners retrieve the KLIK ePROfile from the KLIK website; it is not linked to the existing electronic patient systems. We chose for a web-based application to be able to use the KLIK ePROfile in different hospitals.

How will results be presented?
The PROs can be presented in a numeric and/or graphical presentation and can be presented longitudinal. The development and implementation of the KLIK ePROfile was based on the conclusions presented by Greenhalgh et al. The KLIK ePROfile consists of two parts. The first part is a literal representation of the answers on item level. The second part is a graphic presentation of the ePROs in which the ePROs are presented over time, and the scores on the HRQOL domains are summarized, including norm values. An example of the KLIK ePROfile is shown in figures 1 and 2. As the KLIK ePROfile is printable, it also can also be added to the medical file.

Who will receive score reports?
It is important to determine whether only the members of the multidisciplinary team can see the PROs or also the patients themselves. In the KLIK project, the pediatricians, the members of the multidisciplinary team and patients and parents themselves are able to view the completed questionnaires. The various members of the team can only see the specific questionnaires for their own discipline. The KLIK team can modify on the website which questionnaires can be seen by
Chapter 6

which professional. For example, psychosocial screening questionnaires are only visible for the psychologist. Figure 3 gives an overview of who can complete questionnaires on the KLIK website and which members of the team can use that information.

6. Identifying aids to facilitate score interpretation

It is important that care providers are able to interpret the PROs of the patient immediately. Different options for tools to aid the interpretation are mentioned in the ISOQOL guidelines; a guideline, cut-off scores, reference scores from studies with similar patients, general population with the same condition or from the healthy population, structured interviews, comparison with the patient’s previous score and information about minimally clinically important difference. In the KLIK project, we use different tools to aid the interpretation of the KLIK ePROfile. The answers on the items of the PedsQL and TAPQOL are presented in red when a child reports experiencing problems regarding the subject, orange when the child reports mild problems, or green when a child reports not having problems. It is important to compare individual scores to norm scores if available, or if not available to measure a trend in individual scores over time. We therefore added a graphic presentation of the ePROs; the scores on the HRQOL domains are presented, including norm values. This makes it possible for the pediatrician to compare a child’s HRQOL score to the healthy population score (red line in the graph). Moreover, longitudinal data are also provided by the graphs, allowing the pediatrician to easily compare multiple HRQOL measurements of individual patients and to detect profound changes over time.

For the psychosocial screening questionnaires the cut-off scores are available, and the psychologist can see if the scores are in the clinical or sub-clinical range.

7. Developing strategies for responding to issues identified by the questionnaires

It is important to respond correctly to problems identified by the KLIK ePROfile. In the guidelines three options are mentioned; utilization of disease management pathways, further exploration of PRO issues identified with the patient to gain full understanding and utilization of multidisciplinary team member expertise to address issues. In the KLIK project, we focus on the last two options. Snyder et al. state that training clinicians in the meaning of scores and in approaches to responding to problems is critical before implementing the PRO intervention. All members of the multidisciplinary team are obliged to follow a one-hour training course to get to know how to use the KLIK website and to adequately respond to the patient’s HRQOL outcomes. We invested in a training program for pediatricians/practitioners in the interpretation and use of the KLIK ePROfile. The training course is given by a member of the KLIK team. The training consists of a short theoretical part and an extensive practical part. For the practical part, we use DVD material containing three short patient cases (duration: ± 5 minutes), representing real consultations and actual KLIK ePROfiles. Before the demonstration of each case, the KLIK ePROfile is discussed (‘How would you interpret and discuss this PROfile?’) and the pediatricians/practitioners receive different assignments concerning each case. All of the cases have a specific learning goal, concerning either the general use of the KLIK ePROfile, the use of line graphs or the use of a
decision tree. If children report to have problems pediatricians/practitioners have different options to choose from, for example to give advice or to make a referral to the psychosocial department. After the demonstration of the cases, the skills of the pediatrician depicted on the DVD are evaluated and the pediatricians/practitioners receive a list of key reminders to assist in the use of the KLIK ePROfile\textsuperscript{17,32}. After the training session, the pediatricians/practitioners receive a syllabus, presenting the decision tree, an example of the KLIK PROfile, a paper with a summary of the acquired information (reminders) and theoretical background articles. We developed the decision tree in collaboration with pediatric psychologists, with the aim of supporting communication about the KLIK ePROfile. The decision tree and reminders are also available on the website\textsuperscript{17,32}.

8. Evaluating the impact of the PRO intervention in clinical practice

To evaluate the use of PROs two different options are given in the ISOQOL guidelines; an experimental method or quasi-experimental/quality improvement method, such as observational methods or surveys\textsuperscript{21}. In the research phase of KLIK, we used an experimental design to evaluate and study the use of the KLIK ePROfile; a sequential cohort design\textsuperscript{17,32}.

For the evaluation of KLIK in daily clinical practice, evaluation questionnaires are available at the website. After a patient has used KLIK for one year, the patient and parents are asked to complete the questionnaires about the (use of the) KLIK website and the ePROfile. Pediatricians/practitioners are asked to evaluate KLIK after using KLIK for one year during a focus group meeting. Some multidisciplinary teams evaluate KLIK with pre- and post-test measurements because they want to evaluate the implementation from the beginning.

In addition, within pediatric oncology practice we are currently using a quasi-experimental design to conduct implementation research: the IMPROVE (Implementation of Patient Reported Outcomes Via Electronics in pediatric oncology) study. Different pediatric oncology centers recently started to implement KLIK as part of their standard care for inpatient patients by means of a plan-do-study-act cycle. During this study, KLIK is constantly evaluated and adapted if necessary. To evaluate this new implementation method we monitor the process in terms of registration, uptake-rate, characteristics of the users, facilitating and obstructing factors and satisfaction with the implementation of oncologists, parents and children. As a result we can make meaningful changes in the process to make KLIK-oncology as feasible as possible and patients/parents/pediatrics may directly benefit from these changes\textsuperscript{21}.

PROGRESS OF THE KLIK IMPLEMENTATION

Since the start of the KLIK implementation in June 2011, 12 pediatric patient groups have started using KLIK in daily clinical practice. More groups are scheduled to start using KLIK in the following months. So far, more than 100 professionals followed the training course and over 800 patients are registered on the KLIK website (Table II).

Using KLIK data for research

The implementation of KLIK in daily clinical practice will lead to a very useful database of HROQL and other outcomes of children with chronic illnesses. Before completing the first KLIK questionnaire, parents and children (12 years and older) are asked for their permission to use their data for scientific research. Within the research scope of KLIK all data are stored anonymously. In addition, the database can easily be imported into Excel and SPSS to facilitate statistical analysis.
**Table II. Progress of the KLIK implementation.**

<table>
<thead>
<tr>
<th>Patient group</th>
<th>Start KLIK implementation</th>
<th>Response rate so far</th>
<th>Number of patients registered on the KLIK website</th>
<th>Number of centers participating</th>
<th>Trained professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatology/Immunology</td>
<td>June 2011</td>
<td>259/421=62%</td>
<td>260</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Nephrology</td>
<td>July 2012</td>
<td>66/84=79%</td>
<td>66</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Coagulation diseases</td>
<td>October 2011</td>
<td>101/152=66%</td>
<td>101</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>HIV</td>
<td>November 2011</td>
<td>50/67=75%</td>
<td>50</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>February 2012</td>
<td>42/47=89%</td>
<td>42</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Aftercare IC *</td>
<td>April 2012</td>
<td>19/23=74%</td>
<td>19</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sickle cell disease</td>
<td>April 2012</td>
<td>136/214=64%</td>
<td>136</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Oncology *</td>
<td>June 2012</td>
<td>63/72=88%</td>
<td>63</td>
<td>3</td>
<td>33</td>
</tr>
<tr>
<td>Home Parenteral Nutrition</td>
<td>June 2012</td>
<td>12/21=57%</td>
<td>12</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Sferocytosis</td>
<td>September 2012</td>
<td>15/48=31%</td>
<td>15</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>October 2012</td>
<td>49/250=20%</td>
<td>49</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Cleft-lip</td>
<td>planned start: December 2012</td>
<td>n/a</td>
<td>n/a</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Diabetes</td>
<td>planned start: 2013</td>
<td>n/a</td>
<td>n/a</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>813</strong></td>
<td></td>
<td><strong>112</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* because of newly diagnosed patients, the number of these groups is increasing

The following patient groups are planned to start in 2013: neonatology, inflammatory bowel disease (IBD), congenital hypothyroidism (CHT), eating problems, Hirschsprung’s disease and rehabilitation
DISCUSSION

The results of the pediatric studies\textsuperscript{11,13,18} showed that the use of PROs in daily pediatric clinical practice is effective. Therefore, we decided to implement KLIK in daily pediatric clinical practice. During the implementation of ePROs several issues need to be considered. In this paper we set out the implementation of the KLIK ePROfile in the care for children with a chronic illness based on the considerations formulated in the ISOQOL guidelines.

Based on our experience with the implementation of the KLIK ePROfile in daily pediatric practice, the online application can be considered effective and feasible. Nevertheless, the implementation is a dynamic and challenging process, in which several factors play a role at both the level of the professional, the health care team, the hospital, and the patient\textsuperscript{20,33}. At the level of the professional, time and resource constraints are frequently mentioned obstacles for implementing PROs. Clinicians often share the opinion that a change in clinical practice will automatically be accompanied by an increase in workload\textsuperscript{34}. It is therefore essential that pediatricians realize that the use of the KLIK ePROfile does not lengthen the consultation\textsuperscript{11}. In this study, the consultation with the use of the KLIK ePROfile was shortened by an average of 3 minutes.

At the level of the team, motivation is an important factor. If the medical staff is not enthusiastic about the use of ePROs in clinical practice, implementation is being obstructed\textsuperscript{34}. All members of the team should fully support the use of KLIK. We deliberately involve all team members in the implementation process, by organizing a multidisciplinary meeting to assess which questionnaires to use. The training is also important to make the members enthusiastic and familiar with the website. Pediatricians/practitioners often get more enthusiastic after using the KLIK ePROfile for a while, as they experience the effect of the KLIK ePROfile during the consultation. Since the pediatrician usually discusses the KLIK ePROfile during the consultation, he/she has a key role. It is our experience that patients of those pediatricians who are very willing to actively discuss the KLIK ePROfile are most likely to keep completing questionnaires before every consultation.

At the level of the hospital, the following barriers are present: doubts about the fit within the clinical workflow and reimbursement obstacles\textsuperscript{34}. Regarding the workflow, the KLIK team is very important to guide the implementation process. The KLIK team is available for assistance to all the health care teams using KLIK. Additionally, the KLIK team sends the information letters, calls patients to remind them to complete the questionnaires, and maintains close contact with the web designers. Until now it has not been possible to fit KLIK in the electronic chart, but this is an important future goal. Regarding financial costs, the success of the KLIK ePROfile is dependent on enough financial means, mostly externally funded, to enable the work of all the people involved.

At the level of the patient, language and literacy could be a barrier. To enable the use of KLIK for parents and children for whom Dutch is not their native language, the entire KLIK website is available in English. The ‘main’ questionnaire (PedsQL) is available in eight different languages, the other questionnaires in four or two different languages. The feedback of the KLIK ePROfile to the team is in Dutch. In the near future, illiterate patients will be able to play an audio version of the text on the website. For those patients still experiencing difficulties using the website, a member of the KLIK team will be available to help them at the outpatient clinic. Last but not least, patient
Chapter 6

barriers can be overcome by giving direct feedback to patients after they have completed the questionnaires, for them to understand the goal and motivate them to complete the questionnaires again before their next visit.

Finally, capable web designers are essential, as they are responsible for ongoing adaptation of the KLIK website. There is an increase in the development of commercial software packages to capture electronic PROs, to administer questionnaires, to score data, and to present the results. However, the development of the KLIK website is based on solid research and recommendations supported by members of the ISOQOL21. The website is especially made for pediatric clinical practice. In addition, to simplify the KLIK website, the web designers are working on the development of a KLIK app for smart phones and tablets.

In the upcoming years we will continue to implement KLIK in pediatrics. Pediatricians working with several more patient groups recognize the importance of the KLIK ePROfile and will start using KLIK in the near future: e.g. gastroenterology, cleft-lip, diabetes, neonatology, metabolic diseases and cardiology. Our goal is to implement KLIK for as many patient groups as possible. Moreover, we would like many different hospitals and disciplines to be able to use KLIK.

Besides including more patient groups, we also want to start using KLIK for children in transition to adult care. Transition of adolescents from pediatric to adult care can be challenging35. Transition is defined as a multi-faceted, active process that attends to the medical, psychosocial, educational and vocational needs of adolescents as they move from a child-focused to an adult-focused health-care system 36. KLIK can be used as a tool to fill the gap between the pediatric and adult health care for adolescents. We are therefore working on the validation and collection of norm data for the Dutch PedsQL Young Adult Generic37 and Fatigue module38 and the Course of Life Questionnaire (CoLQ) 39, in order to make it possible to add these questionnaires to the KLIK website. Currently, only children and parents can complete questionnaires on the KLIK website. However, in the near future it will also be possible for teachers and siblings of the patient to provide information via KLIK.

At this point we only use static questionnaires, but we will add dynamic questionnaires, such as computerized adapted tests, in the future. In a multicenter collaboration, we are working on the translation and validation of Patient-Reported Outcomes Measurements Information System (PROMIS) item banks. PROMIS aims to develop self-reported item banks using Computerized Adaptive Tests (CAT) and Item Response Theory (IRT) that are applicable across a wide variety of chronic disorders40,41. By using PROMIS item banks patients or parents only need to answer 4 to 8 items per item bank, so the burden for patients and parents is much lower42. As we assume that these questionnaires will be used frequently in the future, our goal is to integrate PROMIS within the KLIK system.

The most important challenge we will face in the near future is the implementation of the KLIK ePROfile without the intensive support of the KLIK team. During the start of the implementation, the KLIK team supports the multidisciplinary teams tremendously. However, on the long run every department has to be able to use KLIK independently, KLIK has to become a routine in the outpatient clinics.
CONCLUSION

In conclusion, it is a challenge to achieve the optimal use of the KLIK ePROfile in pediatric clinical practice. The first steps of the implementation are made but we still have many future goals. As far as we know, this is the only implemented application for using ePROs that is implemented in daily pediatric clinical practice. To keep providing chronically ill children with tailored care, we will continue to improve the KLIK system and thoroughly evaluate the use of KLIK thoroughly. Only after the evaluating KLIK, we can determine whether it is helpful for patients, parents and members of the multidisciplinary team and whether it is a valuable addition to the daily clinical practice for the different patient groups. Nevertheless, based on our experience, we can state that the implementation of the KLIK ePROfile in daily clinical pediatric practice is feasible, workable and that the users are enthusiastic and optimistic about the use of KLIK. More and more pediatricians want to work with the KLIK system and we are expanding the use of KLIK for different patient groups and hospitals in the Netherlands and abroad. KLIK is available for other hospitals upon payment of a required yearly fee.

With the use of the feasible and effective KLIK website, we can systematically pay attention to HRQOL in pediatric clinical practice, and hope that many children and parents will profit from this application in the future.

Acknowledgements

We would like to thank all the children, parents, pediatricians, psychologists, social workers, nurses, nurse practitioners and all others involved in the KLIK project. In addition, we would like to thank BioMedia/Artsen voor Kinderen for the development of the KLIK website, Zonder Boter for the design of the website, Anne Wiegman for her support of the implementation of the ePROfile in daily clinical practice and Hugo Heymans for his continuous support and inspiration for the care of children with a chronic illness.

Funding

The KLIK implementation is supported by the AGIS Healthcare, Achmea, Fonds Nuts Ohra, KWF Alpes Huzes, De Nierstichting (the Dutch Kidney foundation), Stichting tot Steun and Pfizer BV Pharmaceuticals.


Ref Type: Online Source


