Options for the Interpretation of and Recommendations for Acting on Different PROMs in Daily Clinical Practice Using KLIK

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Options for the Interpretation of and Recommendations for Acting on Different PROMs in Daily Clinical Practice Using KLIK

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Introduction: This paper describes the different ways in which information is being fed back to health care providers (HCPs) using the Dutch evidence-based KLIK Patient-Reported Outcome Measures (PROMs) portal (www.hetklikt.nu). KLIK was initially developed for children with a chronic illness and their parents, and recently expanded for use in adult health care. Patients complete online PROMs at home about their health-related quality of life (HRQOL), symptoms and/or psychosocial functioning before an outpatient consultation with their HCP. PROMs are subsequently converted into an individual KLIK electronic (e)PROfile and discussed during the consultation to facilitate systematic attention for HRQOL.

Methods for PRO Score Interpretation: KLIK includes a variety of different PROMs. The KLIK ePROfile initially consisted of literal representations of the individual PROM items in the European traffic light colors (red, orange, green) and only one graph. Over the years, the KLIK ePROfile evolved into a broader spectrum of feedback options; (1) literal representation of individual items, (2) summary scores, and (3) graphic representations (4 options).

Developing Recommendations for Acting on PRO Results: The primary goal of KLIK is to longitudinally monitor patient and parent self-reported or proxy-reported health outcomes, which means that the focus of KLIK is not mainly on recommending actions for PRO results. However, there are several aids that help interpretation of the KLIK ePROfile and recommendations are given for actions based on PROM scores. The main aid is the KLIK training, which includes a theoretical and a practical part. In the training, 2 tools—a decision tree and a summary of information about the KLIK ePROfile—are given to the HCPs to assist them in using KLIK.

Discussion: Customization of a PROM portal is needed for each different patient group and clinical setting. Because the KLIK website is flexible, every PROM (with good psychometric qualities and permission of the publisher) can be built in. However, implementing and feeding back PROMs in pediatric health care encompasses different challenges, because different versions of the same PROM are needed for children of different ages, as well as proxy and self-report versions.

Key Words: patient-reported outcomes, interpretation, clinical practice, pediatrics

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KEY POINTS

- Customization per patient group and per Patient-Reported Outcome Measure (PROM) is needed (No One Size Fits All).
- Knowledge transfer to the health care providers (HCPs) is essential to lower the threshold for using PROMs.
- Supporting the ongoing implementation process is crucial.
- Rely on existing knowledge from psychometrics, PROM developers, other PROM portals (do Not reinvent the wheel).
- Having capable website builders/IT/technical support is very important, particularly in the feedback of PROMs.

Children with a chronic illness or condition are at risk of having psychosocial problems and a lower health-related quality of life (HRQOL) than their healthy peers.[1,2] Because of repeated hospital visits, surgery, or use of medicines their achievement of developmental milestones is delayed.[3] Therefore, there is a need to give attention to HRQOL and psychosocial issues in daily clinical practice, so that problems can be monitored, identified and discussed and the right interventions can be offered on time. For that reason, the KLIK PROMs portal was developed.

Research on the effect of discussing HRQOL using the KLIK PROfile version one was conducted in pediatric oncology

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(QLIC-ON study). Children or parents completed a generic HRQOL questionnaire on a stand-alone laptop at the outpatient clinic.[4] Answers to the questionnaire (PROfile) were printed and given to the pediatric oncologist. The first development of the KLIK website (www.hetklikt.nu) took place within a pediatric rheumatology study. Children or parents completed questionnaires (PROMs) on the KLIK website at home before an outpatient visit. The answers were converted into an electronic PROfile (KLIK ePROfile) and discussed during the consultation.[5] Both studies concluded that feeding back HRQOL information during the consultation increased discussion of psychosocial and emotional functioning, improved the identification of emotional problems without lengthening the consultation, and increased the pediatrician's satisfaction with the care provided.[6,7]

On the basis of these positive outcomes, KLIK was implemented in daily clinical practice for children with various chronic conditions in different hospitals in the Netherlands starting in 2011. The website homepage was upgraded to a more user-friendly version including an informative video with English subtitles explaining the goal and use of KLIK to parents, children, and HCPs. Implementation was done in line with the decisions and methodological recommendations as presented in the International Society for Quality of Life Research (ISOQOL) guidelines.[8–10]

KLIK can be implemented for any patient group, on request of the multidisciplinary team. Eligible patients and parents receive a letter introducing KLIK as new standard of care. Patients/parents register themselves, receive a password and 2 weeks to 3 days before the outpatient consultation (based on team preferences), they receive an automatic email that they can complete the PROMs online. Automatic email reminders are sent. For patients without home internet access, PROMs can be completed at the outpatient clinic. When patients/parents have completed the PROMs, this information is visible on the KLIK website. When a PROM is completed an automatic email can be sent to the HCPs.

A next step in our research trajectory focused on real-world implementation. Fidelity of real-world implementation of KLIK includes high percentages of: (1) registration, (2) completion of PROMs, and (3) discussion of ePROfiles. Implementation of KLIK in pediatric oncology during treatment appeared to be feasible and satisfactory, but challenging.[11] The website registration by patients was relatively high (86% to 89%), but the completion rate (66% to 85%) and ePROfile discussion were substantially lower (56% to 62%). Several barriers were identified to the intervention [eg, noncompatibility of KLIK in electronic health records (EHRs)], the user (support from colleagues) and the organization (lack of time). A project funded by the Dutch government has recently started to overcome these barriers. Currently over 850 HCPs (eg, pediatricians, nurses, physiotherapists, dieticians, social workers, psychologists) and over 13,000 patients (from over 100 different patient groups) in over 20 Dutch centers are using KLIK. In 2016, the website was further adapted to be usable for adult patient groups. In 2018, the first hospitals outside the Netherlands (United Kingdom, www.klik-uk.org) started using KLIK. Since the start of the KLIK implementation, ~300 PROMs have been built into KLIK. This paper aims to describe both the interpretation of, as well as recommendations for acting on different PRO scores.

METHODS FOR PRO SCORE INTERPRETATION

The PROMs

In the QLIC-ON study,[4] the only PROMs used were generic HRQOL questionnaires. For the pediatric rheumatology study,[5] other more disease-specific PROMs were added to KLIK. Currently, the following categories of PROMs are available in KLIK:

- Generic HRQOL [eg, Pediatric Quality of Life Inventory (PedsQL)[12,13]].
- Disease-specific HRQOL (eg, PedsQL transplant module[14]).
- Daily functioning [eg, Child Health Assessment Questionnaire (CHAQ)[15,16]].
- Cognitive functioning [eg, Behavior Rating Inventory of Executive Functioning (BRIEF)[17]].
- Symptoms [eg, Pediatric Ulcerative Colitis Activity Index (PUCAI)[18]].
- Psychological screening [eg, Strengths and Difficulties Questionnaire (SDQ),[19,20] Hospital Anxiety and Depression Scale (HADS)[21,22]].
- Transition [eg, Skills for Growing Up—Nephrology (SGU-N) tool[23]].

In addition, the following nonvalidated tools are available: (1) a sociodemographic questionnaire, (2) questions about school, and (3) an open-ended question: "Is there anything you would like to ask/tell the person with whom you have an appointment?" The multidisciplinary team selects the PROMs for their patients in consultation with the members of the KLIK team (consisting of research-psychologists). These PROMs were selected because of their good psychometric properties, availability of Dutch normative data, user friendliness, and age range. When Dutch versions of PROMs or Dutch normative scores are lacking, the KLIK team in some cases translates and collects normative data for internationally used PROMs. Sometimes PROMs are not available and the multidisciplinary team and the KLIK team compose a PROM themselves (eg, questions about medication use).

The Reporter

On the KLIK portal, children 8 years and above of age[24] and one or both parents/caregivers (depending on the preference of the multidisciplinary team) complete PROMs. Children complete PROMs about themselves (self-report), parents complete PROMs about the functioning of their child (proxy-report) and about themselves (self-report; Parent-Reported Outcomes); fathers and mothers can complete PROMs separately. Outcomes for these types of PROMs are shown in different tabs in the KLIK ePROfile of the patient which indicate who completed the PROMs (www.hetklikt.nu/englishdemo).

The choice of the self-report versus proxy-report version is mostly based on the age of the child. However, sometimes the child is cognitively or physically incapable of completing PROMs themselves. In these cases proxy-reported PROMs

are automatically offered to parents regardless of the age of the child.

Even though KLIK started in a pediatric setting, KLIK has now been implemented in several adult patient groups (eg, medical psychology, gender dysphoria, coagulation diseases) where patients complete PROMs about themselves (self-report). For children and young adults with coagulation diseases, KLIK is also used for adolescents during the transition to adult health care, providing continued monitoring in the age range 0–30 years.[25]

Since a year, members of the multidisciplinary team have the opportunity to add a free-text note to the KLIK ePROfile of the patient (Clinician-Reported Outcomes).

The KLIK ePROfile

The KLIK ePROfile, based on the input from HCPs,[4,5] initially consisted of literal representations of the individual PROM items in European traffic light colors (red, orange, green) and one graph (Figs. 1A and B). Over the course of implementation, the KLIK ePROfile evolved into a broader spectrum of feedback options. KLIK ePROfiles are now fed back in several ways; (1) literal representation of the individual items, (2) summary scores, and (3) graphic representations (4 options). Feedback of a new PROM is based on the PROM manual, the wishes of the multidisciplinary team and the KLIK team, and the options available on the KLIK website. The website builders, in collaboration with the KLIK team, build the PROM in a way that resembles as closely as possible the way it was originally designed. At this moment they have rough models based on the feedback options described below and they fit a new PROM within one of the existing molds. Table 1 shows an overview of different PROMs with various feedback options. HCPs and patients/parents themselves are able to view parts of the ePROfile.

Literal Representation of the Individual Items

The answers to items are presented in red when a patient reports problems with regard to that topic, orange when the patient reports some problems, or green when a patient reports no problems (Fig. 1A). These traffic light colors are based on the user manual and existing cut-off scores, or on the clinical view of the HCPs and KLIK team. For PROMs with neutral answers without value, individual items are shown in black. Patients, parents and HCPs can see the literal answers.

Summary Scores

For some PROMs, a summary score can be computed. Because there is a calculation, this part of the KLIK ePROfile is not a literal representation of the responses, nor is it a graphic representation. An example of a summary score is the number between 0 and 21 on the anxiety and depression scale of the HADS (see Fig., Supplemental Digital Content 1, http://links.lww.com/MLR/B692, showing summary scores of the HADS), where scores 0–7 are shown in green (normal range) and scores 8–21 in red (clinical range). Scores generated from a Visual Analogue Scale are also part of this element of the KLIK ePROfile (Fig. 2). Patients use a bar to indicate their status, for example, their pain or well-being. In the KLIK ePROfile, this information is only shown to the HCP.

Graphic Representations

In addition to a literal representation and a summary score when available, most of the PROM scores are also fed back in the form of graphs. Mostly these graphs have a PROM score (eg, 0–100) on the *y*-axis and time points on the *x*-axis which are explained using text in the KLIK ePROfile. There is explanatory text under the graph to indicate the direction of the scores (eg, higher scores signify a better

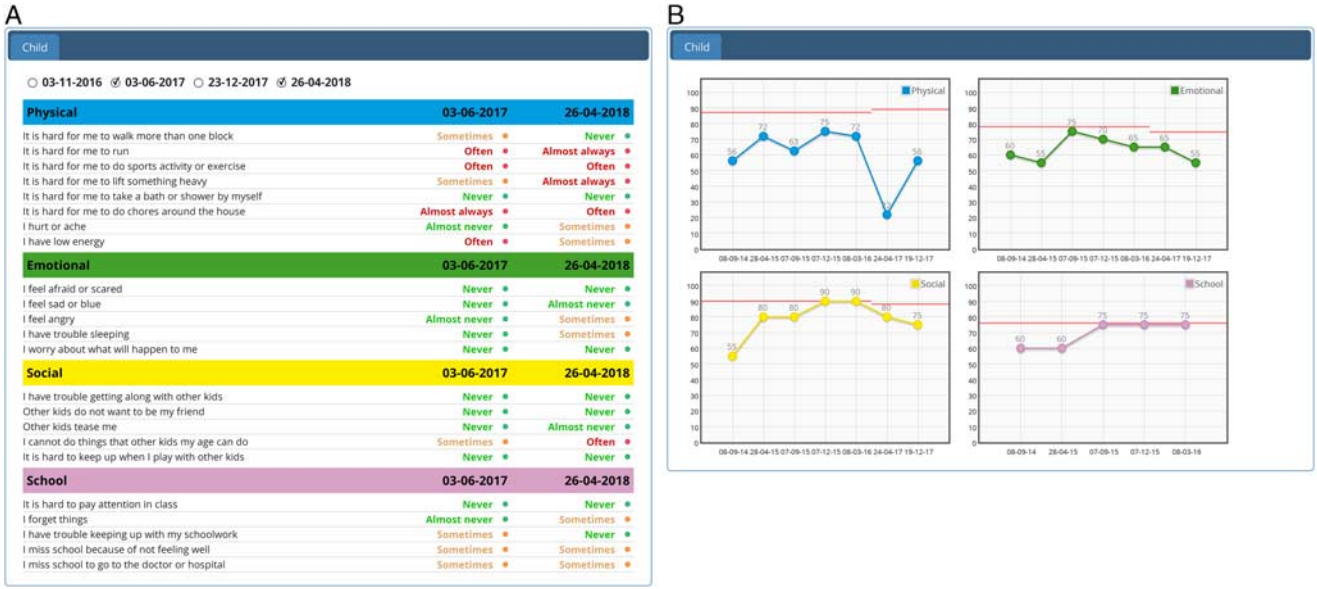

FIGURE 1. A, KLIK ePROfile—literal representation of the individual items on the Pediatric Quality of Life Inventory (PedsQL). B, KLIK ePROfile—graphic representation of the PedsQL, including norm lines that shift to another age category as per age group.

TABLE 1. Examples of How Different PROMs Can be Fed back in the KLIK System

PROM	PROM Category	Literal Representation	Summary Scores	Graphical Representation: Longitudinal Score Line	Graphical Representation: Norm Line	Graphical Representation: Clinical Cut-off/ Diagnosis	Graphical Representation: Pictures
Pediatric Quality of Life Inventory (PedsQL)[12,13] (Figs. 1A, B)	Generic HRQOL	X (23 items)		X	X		
Hospital Anxiety and Depression Scale (HADS)[21,22] (Supplemental Digital Content 1, http://links.lww.com/MLR/B692)	Psychological screening	X (14 items)	X			X	
Child Health Assessment Questionnaire (CHAQ)[15,16] (Fig. 2)	Daily functioning	X (30 items)	X	X			
Child Behavior Checklist (CBCL)[26] (Supplemental Digital Content 2, http://links.lww.com/MLR/B693)	Psychological screening	X (126 items)		X	X	X	
Strengths and Difficulties Questionnaire (SDQ)[19,20] (Fig. 3)	Psychological screening	X (26 items)		X	X	X	
Distress Thermometer for Parents (DT-P)[27,28] (Supplemental Digital Content 3, http://links.lww.com/MLR/B694)	Psychological screening	X (39 or 41 items)		X	X	X	
Psychosocial Assessment Tool (PAT)[29] (Supplemental Digital Content 4, http://links.lww.com/MLR/B695)	Psychological screening	X (~70 items)			X	X	X
MIND Youth Questionnaire (MY-Q)[30] (Supplemental Digital Content 5, http://links.lww.com/MLR/B696)	Disease-specific HRQOL	X (36 items)					X

X indicates that the feedback option is applicable to the specific PROM.
HRQOL indicates health-related quality of life; PROM: Patient-Reported Outcome Measure.

HRQOL). There are several forms of graphic representations used in the KLIK ePROfile:

Longitudinal trend line: the scores of the individual patient over time are presented in a line graph. These individual trend lines are only presented to the HCPs. However, we encourage HCPs to show and explain the trend lines to patients/parents during the consultation. This gives the HCPs an overview of the well-being of the patient and his/her development over time. Depending on the PROM, total scores and/or domain scores (eg, physical or social functioning, Fig. 1B) are shown.

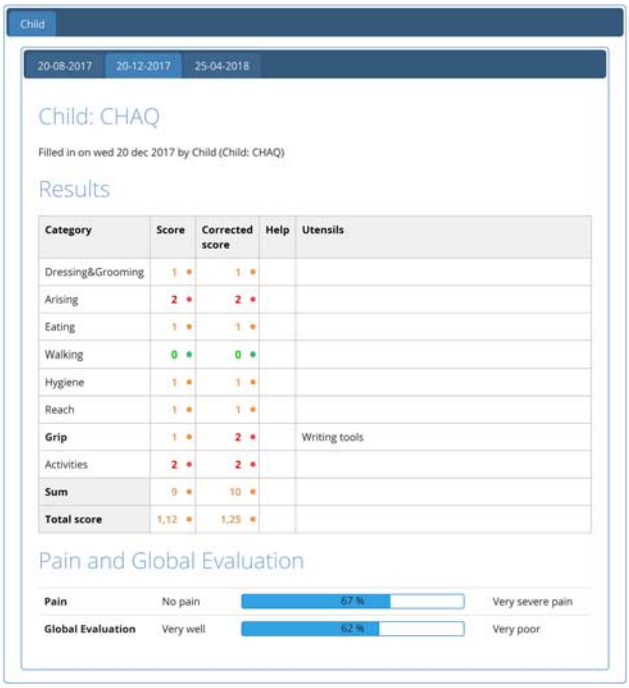

FIGURE 2. KLIK ePROfile—sum scores of the Child Health Assessment Questionnaire (CHAQ).

Norm line: the norm lines (mean scores) are based on the scores of healthy peers (Fig. 1B), the general Dutch population or chronically ill children. For some PROMs we collected the general Dutch population norms ourselves (eg, PedsQL).[27,31,32] The norm line is also only presented to HCPs, because explanation about the meaning is necessary. The norm line is age specific and changes as the child moves to an older age category. When patients have used KLIK for several years, these shifts can be seen in the graphs (Fig. 1B). Furthermore, some PROMs have a gender-specific norm line, when research showed significantly different scores between male and female individuals. In the near future the KLIK ePROfile will be expanded with a disease-specific longitudinal norm line, so that HCPs see if the change over time of an individual patient is alarming or normal for their age and condition.

Clinical cut-off: clinical cut-off scores are available for psychological screening PROMs. When available, the (sub)clinical cut-off points are shown, again only to the HCPs. Some are only presented as a summary score (eg, HADS), however, clinical cut-off scores are mostly presented in graphs in 2 ways; (1) a red norm line showing the clinical cut-off and an orange norm line showing the subclinical cut-off [see Fig., Supplemental Digital Content 2, http://links.lww.com/MLR/B693, showing the graphic representation of the Child Behavior Checklist (CBCL), including clinical and subclinical norm lines][26] or (2) colored areas in green, orange, and red showing a normal, subclinical or clinical score, respectively [SDQ, Fig. 3 and Supplemental Digital Content 3, http://links.lww.com/MLR/B694, showing the literal and graphic

FIGURE 3. KLIK ePROfile—graphic representation of the Strengths and Difficulties Questionnaire (SDQ), including a normal, subclinical, and clinical score range.

representation of the Distress Thermometer for Parents (DT-P), including a clinical score range].[27,28] The feedback for these PROMs was developed in collaboration with the developers of the different PROMs, and resembles the original paper-pencil feedback as closely as possible.

Pictures: for some PROMs, pictures are used in the feedback, which can make the outcomes more easily interpretable. An example is the Psychosocial Assessment Tool (PAT, see Fig., Supplemental Digital Content 4, http://links.lww.com/MLR/B695, which shows the graphic representation using a picture),[29] where families are placed into a low-risk, medium-risk, or high-risk category (visualized as a pyramid with traffic light colors) depending on their scores. Another example is the MIND Youth Questionnaire (MY-Q, see Fig., Supplemental Digital Content 5, http://links.lww.com/MLR/B696, which shows the graphic representation using a picture),[30] a disease-specific HRQOL PROM for adolescents with diabetes. These pictures are shown to HCPs and parents and children, depending on the PROM.

METHODS FOR DEVELOPING RECOMMENDATIONS FOR ACTING ON PRO RESULTS

The primary goal of KLIK is monitoring patients and their parents, which means that the focus of KLIK is not mainly on recommending actions for PRO results. The KLIK ePROfiles are used to facilitate systematic communication about HRQOL and other outcomes. However, there are several aids that help interpretation of the KLIK ePROfile and that provide recommendations for what to do based on PROM scores.

KLIK Training

A 1.5-hour group training session was developed as part of the QLIC-ON study[4] and evaluated and adapted during the KLIK implementation process (as extensively described in Santana et al[33]). This training program is compulsory for every HCP that will use KLIK. Goals of the training are to give HCPs background knowledge about

KLIK and the ePROfile, to raise awareness about the importance of using PROMs in clinical practice, and to become competent in the use of the ePROfile. The training includes a theoretical and a practical part. The theoretical part explains the goals of KLIK and the importance of PROMs, and presents literature on the use of PROMs in pediatrics. During the practical part, video material (consisting of real patient cases) and assignments are used to practice how to interpret the KLIK ePROfile. After showing the videos, the use and interpretation of the ePROfile by the HCP depicted on the video is discussed. At the end of the training session, 2 tools —a decision tree and a summary of information about the KLIK ePROfile—are given to the HCPs to assist them in the use of KLIK. HCPs are stressed to discuss the ePROfile because otherwise patients and parents will become less motivated to complete the PROMs before the next visit.

Psychological Screening PROMs

Feedback on the psychological screening PROMs is only given to a psychologist, as it is presumed that only they have the experience and professional qualifications to interpret the results.

KLIK Evaluation

Every year the multidisciplinary team evaluates KLIK with the KLIK team. The KLIK team starts this meeting with an overview of the implementation process during the past year for that specific patient group (eg, how many patients have registered themselves on the website). Thereafter, HCPs explain how KLIK is used in their consultations, whether they are satisfied with KLIK and the (feedback of the) PROMs that their patients complete, and the reactions they receive from patients/parents. Barriers and facilitators around the implementation process are discussed so that team members can learn from each other's experiences. The meeting ends with plans and wishes for the future. Since February 2018, an online evaluation questionnaire is sent to all team members before these meetings.

DISCUSSION

This paper described both methods for PRO score interpretation, as well as recommendations for acting on PRO scores using KLIK. KLIK can be applied in many different circumstances, because the website is flexible and virtually any PROM (with good psychometric properties and permission of the developer) can be built in. As there are many different ways of feeding back information, the KLIK website can be individualized according to the preferences of the multidisciplinary team and patient group.

For every multidisciplinary team of a specific patient group that starts using KLIK a careful inventory is performed with regard to what is needed and which PROMs are available. The feedback of PROMs in KLIK has several strengths; it can be shown in 3 ways: literal, summary score, and graphical. In addition, the KLIK ePROfile is made easier to interpret by the use of aids (such as the decision tree and the summary of information about the KLIK ePROfile), so that it is visually attractive and therefore child friendly.

There are some limitations of the feedback of the KLIK ePROfile. For example, there are differences in scaling of different PROMs (eg, sometimes scales range from 0 to 100, others 0 to 50) and scoring (eg, sometimes higher scores indicate better functioning, sometimes higher scores indicate poorer functioning) within PROMs and between PROMs. In cases in which both the mother and the father complete the same proxy PROM, these results are represented in 2 separate graphs. This can cause problems, because it may lead to missing time points: for example, at T1 mother completes the PROM, at T2 father, at T3 mother. However, it is not valid to display these 3 time points together in a single graph because of a lack of reliability between reporters.

We are working on different projects to improve and evaluate the use of KLIK and to study the implementation process. A first step in improving the KLIK portal is to make computerized adaptive tests (CATs) available. The pediatric Patient-Reported Outcomes Measurement Information System (PROMIS) item banks have been translated[34] and are now being validated in the Netherlands. By using PROMIS item banks, instead of static questionnaires, patients or parents only need to answer 4 to 8 items per domain. As a result, the burden for patients and parents is reduced. Our goal is to integrate PROMIS into KLIK and provide CATs, by linking KLIK with the Dutch Assessment Center. As with PROMIS CATs patients or parents only answer some items of a domain, providing feedback of these PROMs is challenging. Currently the KLIK team is developing appropriate ways to feedback these results. To help achieve this, several stakeholders (psychometricians, psychologists, HCPs, parents, children) are involved.

A second step in improving the use of the portal is to make PROMs for siblings and teachers available in KLIK, including separate logins and feedback.

Another, third project, is realizing real-time monitoring via KLIK. At this moment we are working on the implementation of a KLIK app in which pain monitoring in childhood cancer care is possible and direct action from nurses will be realized.

A last step in improving the use is to empower patients/parents in discussing their ePROfiles with the HCP themselves. Therefore, an online training is currently being developed for children and parents. These videos will be available at the KLIK website.

Regarding the evaluation of KLIK, in future focus group meetings with HCPs we will discuss the different forms of feedback of PROMs in the KLIK portal and their effectiveness. Depending on the results of these meetings, it might be possible that the current feedback options of PROMs in KLIK will change, according to the suggestions of the different stakeholders. This year, KLIK evaluation meetings have also been held with patients and parents. In these meetings the pros and cons of the KLIK website were discussed and parents and children were asked how the use of KLIK can be improved. The feedback that comes out of these meetings is used to adjust the KLIK website. We are currently in the process of analyzing the data coming from those meetings and the results will be published in the near future.

Although the effectiveness of KLIK has been studied in detail, and much effort has been put into the usefulness of the portal, a high level of implementation is the ultimate final goal. It is important to take barriers of implementation into

account. There are barriers to the broader implementation of KLIK at the level of the HCP, the multidisciplinary team, the organization/hospital, and the patient.[11] For KLIK, there is no connection with EHRs yet. Currently, a front-end integration (hybrid integration) between KLIK and EHRs is being realized. When this has been accomplished, HCPs will not have to log in into 2 separate systems, which will facilitate the implementation process. Issues with regard to privacy of the data and information security present additional barriers.

In conclusion, developing an online PROM portal like KLIK is not sufficient for an effective implementation. Capable website builders are essential, as is knowledge of PROMs, training of the HCPs and supporting the ongoing implementation process. Implementing PROMs in health care encompasses different challenges, and implementation in pediatrics even more, because for children different age-specific versions of the same PROM are needed, as well as proxy-report and self-report versions. Therefore, customization for each patient group and each PROM is needed.

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