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Santana, MJ, Haverman, L, Absolom, K orcid.org/0000-0002-5477-6643 et al. (4 more authors) (2015) Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Quality of Life Research*, 24 (7). pp. 1707-1718. ISSN 0962-9343

<https://doi.org/10.1007/s11136-014-0903-5>

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Title:

Training Clinicians in How to Use Patient Reported Outcome Measures in Routine Clinical Practice

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Training Clinicians in How to Use Patient Reported Outcome Measures in Routine Clinical Practice

ABSTRACT

Patient-reported outcome measures (PROs) were originally developed for comparing groups of people in clinical trials and population studies, and the results were used to support treatment recommendations or inform health policy, but there was not direct benefit for the participants providing PROs data. However, as the experience in using those measures increased, it became obvious the clinical value in using individual patient PROs profiles in daily practice to identify/monitor symptoms, evaluate treatment outcomes and support shared decision-making. A key issue limiting successful implementation is clinicians' lack of knowledge on how to effectively utilize PROs data in their clinical encounters.

The implementation of PROs in patient care represents a significant change to clinical practice of individual clinicians and health organisations. Using a change-management theoretical framework, this paper describes the development and implementation of three programs for training clinicians to effectively use PRO data in routine practice. The training programs are in three diverse clinical areas (adult oncology, lung transplant and paediatrics), in three countries with different health care systems, thus providing a rare opportunity to pull out common approaches whilst recognizing specific settings. For each program we describe the clinical and organisational setting, the program planning and development, the content of the training session with supporting material, subsequent monitoring of PROs use and evidence of adoption. The common successful components and practical steps are identified, leading to discussion and future recommendations.

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Patient-reported outcome measures (PROs) were originally developed for comparing groups of people in clinical trials and population studies, and the results were used to support treatment recommendations or inform health policy, but there was not direct benefit for the participants providing PROs data. However, as the experience in using those measures increased, it became obvious the clinical value in using individual patient PROs profiles in daily practice to identify/monitor symptoms, evaluate treatment outcomes and support shared decision-making. A key issue limiting successful implementation is clinicians' lack of knowledge on how to effectively utilize PROs data in their clinical encounters.

The implementation of PROs in patient care represents a significant change to clinical practice of individual clinicians and health organisations. Using a change-management theoretical framework, this paper describes the development and implementation of three programs for training clinicians to effectively use PRO data in routine practice.

The training programs are in three diverse clinical areas (adult oncology, lung transplant and paediatrics), in three countries with different health care systems, thus providing a rare opportunity to pull out common approaches whilst recognizing specific settings. For each program we describe the clinical and organisational setting, the program planning and development, the content of the training session with supporting material, subsequent monitoring of PROs use and evidence of adoption.

The common successful components are identified, leading to discussion and future recommendations.

INTRODUCTION

Patient-reported outcome measures (PROs) are defined as: “any report of the patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else”¹. PROs include validated questionnaires that assess the impact of the disease and treatment from the patient’s perspective.

PROs were originally developed for comparing groups of individuals in clinical trials and population studies. The results were used for treatment recommendations or to inform health policy. As the experience in using these measures increased it became obvious that there is a clinical value in using individual patient PROs profiles in daily practice to give clinicians standardized information on patient problems to identify/monitor symptoms, evaluate treatment outcomes and support shared decision-making.²⁻⁸

Recently, PROs became widely accessible to clinicians via electronic/online reporting with new developments towards integration with Electronic Health Records (EHRs) via patient portals.² The integration of PROs with clinical data in EHRs offers innovative opportunities of including patient perspective in Big Dataset for analysis and rapid learning from combined biological, clinical and treatment information. The importance of PROs is increasingly recognized as an essential part of drug safety reporting, Comparative Effectiveness Research and patient-centred outcomes approaches.³⁻⁶

However, these innovative opportunities can only be realized if practicing clinicians understand the values of PROs in patient care and start collecting and utilizing the information in their daily work. The barriers to implementing the use of PROs in routine clinical care⁷ included scepticism about the validity of patient self-report, unfamiliarity with PROs, preference for physiologic measures, and uncertainty how to interpret the information and make it actionable in clinical care.⁸ More than two decades of methodological development of PROs⁹ and the accumulation of experience in the use of PROs in a variety of clinical settings have reduced these barriers. A key problem that still limit successful implementation is clinicians' lack of knowledge on how to effectively utilize PROs data in their clinical encounters with patients^{10,11}.

We describe the development and implementation of three programs for training clinicians to effectively use PRO data in routine practice, aiming to identify the key components for successful clinician training. The training programs are in three diverse clinical areas (adult oncology, lung transplant and paediatrics), in three countries with different health care systems, thus providing a rare opportunity to pull out common approaches whilst recognizing specific settings.

METHODS

From a theoretical perspective, the implementation of PROs in patient care represents a significant change to clinical practices of individual clinicians and health organisations. Changing health care systems is known to be a challenge¹². The stages of the change process, namely dissemination, adoption, implementation, continuation¹³ can be applied

specifically to the process of using PROs in clinical practice, recognizing local organizational and clinical issues.

The training of clinicians represents the first steps in dissemination. Grol¹⁴ suggests a model for implementing changes in clinical practice, recommending a combination of theoretical approaches: 1) educational (adult experiential learning in small interactive groups); 2) epidemiological (evidence-based guidelines); 3) marketing (recognizing the needs of the target audience to adapt training); 4) behavioral (reviewing performance, providing feedback/reminders); 5) social interactions (opinion leaders, support to care providers); 6) organizational changes to support innovation. Educational, epidemiological and marketing approaches are effective at the dissemination stages, marketing and social interactions at adoption, and behavioral and organizational approaches at implementation¹⁴. We use this framework¹⁴ to describe the development and implementation of the three programs.

RESULTS

For each program we describe the clinical setting, the training and development, the content of the training session with supporting material, subsequent monitoring of PROs use and evidence of adoption.

1. Adult Oncology Department, UK

Clinical setting

The oncologist training session was performed in a tertiary cancer centre in UK. An interactive session was designed aiming to encourage effective use of the PROs data in clinical encounters, which was evaluated with 3 oncologists and 60 patients in a pilot before-after study. Patients completed a cancer site-specific PROs questionnaire on

touchscreen computers before chemotherapy appointments. Color-coded graphs of the results were immediately given to the doctors to use in the consultation (see Figure 1a and 1b). Initially, the doctors received basic description the PROs, the graphs and a 'Quick reference guide'. After 10 patients per doctor, the interactive training session was conducted, and further 10 patients participated. Consultations were audio-recorded and content analyzed to determine how the PROs data were used.

Training planning and development

The doctor training session was based on feedback received from oncologists during previous PROs studies^{10;11;15-17}. The training structure and content was based on a national communication skills program for oncologists using role plays¹⁸⁻²⁰, which provides a supportive environment to practise skills and share experiences. In order to have a more standardised content compared to role plays and to reduce the duration of the session, we used videos/ 'trigger tapes' of simulated consultations with oncologists using PROs.

Content and supporting materials

The training was designed as a 3-4 hour session, organised at a time when all three oncologists could attend in order to facilitate group discussion.

The session was divided into 3 main parts:

- A didactic overview (15 minutes) covering the evidence supporting the value of PROs and the challenges of using PROs in clinical practice.
- Describing the development the PROs used in the study and a reminder of the clinical interpretation of PROs and graphs, using real patient cases. Oncologists were asked to review and discuss the graphic results.

- An interactive session was the core component of the training (approximately 2-2.5 hours). Clips from the ‘trigger tapes’ were shown, the facilitators guided questions and discussions emphasizing key learning points.

The main supporting materials were the ‘trigger tapes’ plus decision aids in the form of locally adapted guidelines on managing emotional distress and fatigue.

Five scenarios for the ‘trigger tapes’ were based on real oncology consultations, selected to illustrate typical patient cases (patient with symptom improvement responding to treatment, patient with depression, patient with multiple problems) and to highlight ways PROs can be used by clinicians (assess treatment effects, detect problems, help structure the consultation). The most relevant sections were selected, resulting in 3-7 clips from each scenario. Table 1 shows one scenarios of a patient with multiple problems describing the clinical summary, PROs data and key learning points.

Training manuals were produced for the session, including key information on the evidence base, the PROs and the patient scenarios. Specific local guidelines were developed suggesting clinical actions and referral pathways to manage emotional distress and fatigue, as oncologists previously reported uncertainty in dealing with those issues ²¹.

Oncologists were encouraged to share their experiences of using the PROs. The discussion points focused on: different ways to effectively introduce PROs into clinic consultations, how to share the information with patients to support decision making, solutions for dealing with multiple PROs problems and management of emotional, financial and social issues.

Monitoring PROs use

The oncologists gave a positive feedback via an evaluation questionnaire after practising their skills. Seeing other oncologists using PROs via the DVDs was particularly valued, providing ideas how to use the information. Early analysis of the content of the audio-recorded encounters suggested increased discussion of physical function and pain following the training.²²

Adoption and Implementation

In response to the clinical needs, an integration of the PROs with Electronic Patient Records was developed and currently evaluated.

2. Lung transplant department, Canada

Clinical setting

The training session for transplant specialists was designed for a randomized trial where chronic lung disease patients completed the Health Utilities Index (HUI) at every outpatient visit and the graphically presented results were shared with clinicians²³⁻²⁵. At every visit, discussions amongst patient, family and team members were audio-recorded to assess communication, the role of HUI and how the information contributed to care plans.

Training planning and development

The transplant healthcare team (respiratory physicians and allied healthcare providers) participated in the selection of PRO measure and in the design of the HUI score card and other supporting material to ensure the effective use of the data. The team members identified barriers to successful implementation (time-constraints, confidence in interpreting PRO data, ability to deal with symptoms unrelated to transplantation), which informed the training content.

Content and supporting materials

Each training session was scheduled for an hour. During the first month ad-hoc training took place because the familiarization process prompted questions that were resolved on the spot.

The training session provided clinicians with background knowledge about the evidence supporting the use of PROs in chronic disease management, the design of the trial, described the chosen PRO measure and gave examples of its use in practice.²³⁻²⁵

The session had 3 parts:

- Overview - a formal presentation introducing the evidence base and the HUI measure to the team.
- Familiarization with the measure: Attendees completed the proxy HUI with results fed back to the audience in an aggregated fashion, allowing them to understand the scores.
- Acquiring practical skills - Interpretation of the scores, understanding clinically important difference, what to do when a score is abnormal, and developing an algorithm to guide potential actions. In an interactive session, clinical cases of real patients with different problems were discussed. The cases included a summary of the medical history, longitudinal graphical presentation of the HUI score card and linkage of the scores to clinical parameters. Table 2 displays two such clinical cases. Clips from the audio- recording were used to illustrate how to communicate with patients issues that were not directly related to transplant, especially emotional problems (considered difficult to discuss by team members).

The supporting materials used included: the HUI proxy questionnaire, the case studies and selected audio-tape recordings. In addition, a reference card was developed as an aid memoir, including the scoring system, guidance on clinically important changes and suggested actions, and relevant contact information. The quick card was tailored to team needs and to the size of their white coats pockets.²³⁻²⁵

Monitoring PROs use

During the first month, clinicians completed the proxy version at every visit after seeing the patient. The comparisons between patients' and clinicians' scores were discussed at the team's weekly meetings. Clinicians scored patients lower than the patients themselves, proving the importance of adding the patient perspective. Subsequently, at the monthly team rounds the use of PROs was reinforced by presenting clinical cases to encourage adoption and respond to queries.

Clinicians completed two questionnaires regarding the usefulness of the HUI measure in routine clinical care- at baseline (expectations) and at the end of the study (evaluation).

They found the information was valuable and have subsequently incorporated the use of the HUI in the routine clinical care of their patients.²⁵

Adoption and Implementation

The PROs data is used in daily practice and included in the local lung transplant database. The integration with Electronic Patient Records is under development.

3. Paediatric hospital, The Netherlands

Clinical setting

The training session was designed as part of the implementation of PROs in pediatric practice (www.hetklikt.nu) at the Emma Children's Hospital in Amsterdam, the KLIK

project. Children and/or their parents completed the questionnaires on the KLIK website at home. The responses to the questionnaires were graphically represented into a KLIK 'ePROfile' (Figure 2 and 3). Pediatricians retrieved these ePROfiles directly from the website during the consultation²⁶.

Training planning and development

The KLIK training was based on a program used in a paediatric oncology study (QLIC-ON)²⁷, and involved a multidisciplinary team from different paediatric oncology centres: five researchers, four clinical psychologists and one paediatric oncologist. The QLIC-ON training had two parts: an individual and a group training. The individual training consisted of 1-hour interview and a PROfile instruction. The interview explored oncologist's views of their clinical roles and directed the focus to the subject of the study: identifying and discussing problems. The PROfile was introduced and explained with respect to layout, content, interpretation and use. The group training aimed to describe the development of the PROfile, the theoretical background and practice with the use of the PROfile. In developing the current training, we realized that it was time consuming for paediatricians to have both individual and group training sessions. We chose to rebuild the training into a 1-hour group training with a theoretical and practical parts, including video material.

Content and supporting materials

Goals of the training included providing paediatric oncologists with background knowledge about the PROfile, fostering awareness of the importance of the use of PROs in paediatric oncology and achieving competence in the use of the PROfile in clinical

practice. A Training Manual was created to enhance effective use of the PROfile in clinical practice.²⁸⁻²⁹

The theoretical part of the training included a presentation elaborating on literature concerning PROs of children with chronic illnesses and the definition of PROs. The video material contained three short patient cases, representing real consultations and actual KLIK ePROfiles. Before the presentation of each case, the KLIK ePROfile was shown for discussion. The pediatricians received different assignments concerning each case. If children reported problems, pediatricians had different options to choose from: for example, give advice or refer to the psychosocial department. After the presentation of the cases, the use and interpretation of the PROfiles by the pediatrician depicted on the DVD were discussed for key learning points.

Two supporting tools help pediatricians interpreting the ePROfile. These tools, available at the KLIK website, were:

- A paper with a summary of the information assisting the use of the KLIK ePROfile^{26;30}
- A decision tree as an aid for interpretation of the PROfile. This tree distinguishes three steps:
 - Identify: Is there a HRQOL problem?,
 - Discuss: What is the problem exactly?,
 - Take action: Is it necessary to refer?

After the training session, the pediatricians received a manual including the handouts, presenting the decision tree, the summary, an example of the KLIK ePROfile, and theoretical background articles^{16;31-34}.

Monitoring PROs use

After using KLIK website for one year, pediatricians participated in a focus group. Professionals were positive about the use of KLIK and recognize the value added, although they sometimes forget to discuss the ePROfile. They felt that parents and patients do not mind completing the questionnaires and benefit from using KLIK.

Adoption and Implementation

The KLIK program has been adopted by 8 pediatric centres and is being used by over 2000 children and over 200 healthcare providers (95 paediatricians, 32 nurses, 9 social workers, 30 psychologists, 11 dieticians, 49 physiotherapists, 5 occupational therapists, 2 speech therapists, 7 secretaries). The motivation of the multidisciplinary team was an important factor for this success, plus targeted initial support by the KLIK team. Patients were given direct feedback after they completed the questionnaires, helping them to understand the goal and motivating them to complete the questionnaires again. In these past 3 years, an average of 70% of the patients/parents completed one or more questionnaires prior to the consultation. Since the start of the implementation, there have been around 7600 consultations.

Table 3 summarizes the programs and clearly demonstrates the application of the theoretical framework with the “marketing approach” used at planning development, “epidemiological” and “educational” approaches for the main training and “behavioural intervention” (reminders, performance feedback) for adoption.

DISCUSSION

The three described programs confirm that clinicians with different professional background can be successfully trained and effectively use PROs in clinical practice using brief programs to help them interpret and act on PRO data.

This paper makes two new contributions to existing guidelines for using PROs in clinical practice.³⁵ The first is demonstrating the value of using a theoretical 'change management' framework to guide planning, content, delivery of the training program, subsequent monitoring/feedback and adoption. This ensures a systematic approach covering all important change process components. The second contribution is the description of specific practical ideas how to design and implement a successful clinician training programme.

Bringing together experiences from different training programs in three countries, with different healthcare systems and different specialties and being able to demonstrate the common successful components is a strength of our approach.

Based on the theoretical framework and the details of the three programmes, we can make several key recommendations:

- It is essential to engage the clinicians at the planning stages to identify concerns, barriers and needs. Although common barriers to using PROs have been known for long time⁷ specific local issues must be identified and addressed. The stakeholders should be involved in the choice of PROs, graphic presentations and design of supporting aids.
- The training session has to be brief, timed to fit with existing organisational practices. Training options should be flexible, group or individual, and e-training

sessions may be required. Group training supports exchange of knowledge and experiences. Ideally, in the future PROs training can be accredited as part of standard medical education programs.

- The most successful element of the training was the experiential problem-based learning using video/audio clips and real patient cases, allowing clinicians to see how to refer to the PRO data, and how to act on it. This approach addresses the main barriers identified by a systematic review of professionals' experiences with PROs, namely valuing, making sense of the data, and using it to make changes to patient care.⁸
- Implementing decision-support aids was an essential facilitator (local guidelines on referral pathways, online decision tree, quick reference card). The easy access to the decision-aids on the website worked well in the pediatric setting and is an approach recommended for the future.
- Proactive behavioural feedback after the training and during adoption was an effective measure in the lung transplant and the paediatric program. Incorporating the feedback within existing team meetings is necessary.
- PRO are particularly useful for engaging multidisciplinary teams as they allow sharing of patient experiences across different specialties (doctors, nurses, psychologists). Training of the multidisciplinary team is likely to achieve better results. This is well demonstrated within the pediatric program in the Netherlands.

The implementation of PROs is a dynamic and challenging process, in which several factors play a role at individual (professional, patients, relatives) and system level³⁶. We focused here on clinician training, but wish to acknowledge the importance of other factors, namely:

- Patients/participants engagement and training in using PROs is of paramount importance for successful PRO implementation. It is possible to achieve good participation with online symptom reporting.³⁷ In qualitative interviews exploring patients attitudes, they clearly state that if they see their PRO data being used by clinician and influencing their care, this will encourage continued participation.
- The practical organisation and ongoing support for collecting and integrating PRO data in patient records and in the clinical workflow is a necessary step. Online, from home, data collection is here to stay but it requires robust information technology support as part of the health organization structure and policy.
- At the stages of adoption and implementation of innovations social interactions, using opinion leaders and specific organizational changes also become the key to success.

CONCLUSION

Brief, adult learning programs teaching clinicians how to use and act on PROs in clinical practice are a key steps in supporting patient engagement and participation in shared decision-making. Researchers and clinicians from different clinical areas should

collaborate to share ideas, develop guidelines and promote good practice in patient-centered care.

ACKNOWLEDGEMENTS

We are grateful to our colleagues for their interest and participation in the training sessions. Dr. David Feeny has a proprietary interest in Health Utilities Incorporated (HUInc), Dundas, Ontario, Canada. HUInc distributes copyrighted HUI materials and provides methodological advice on the use of HUI. The other co-authors report no other conflicts of interest in this work.

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Table

[Click here to download Table: Table 1 Oncology Summary of DVD scenarios.docx](#)

Table 1 Oncology Summary of DVD scenarios

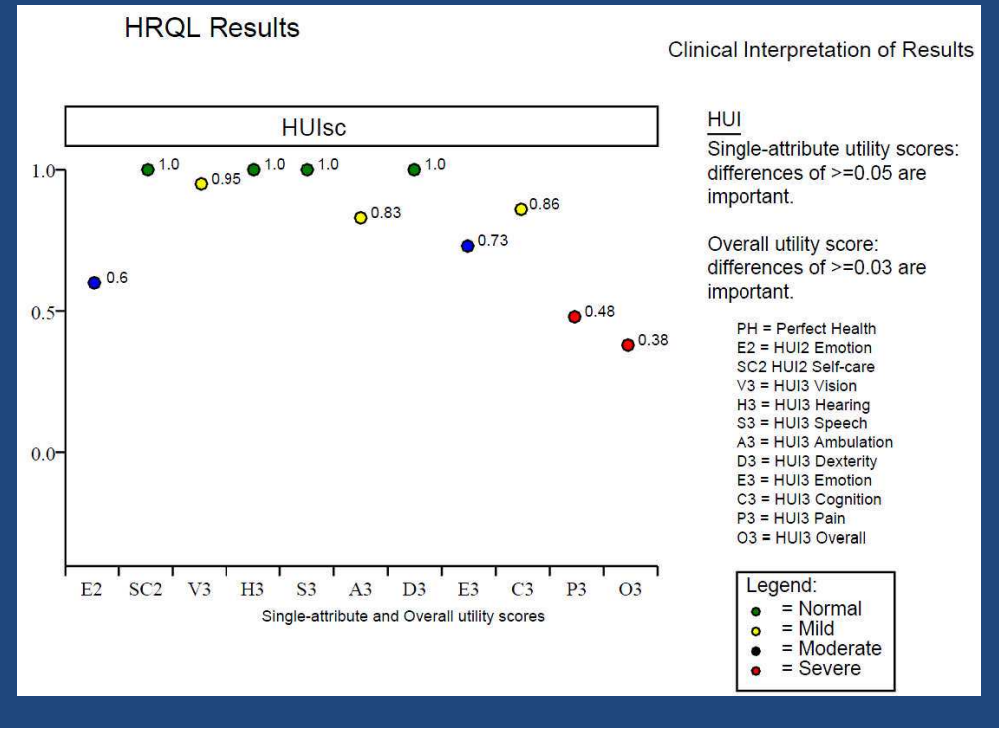
Scenario	Brief synopsis	Utility of PROMs
A	A 51 year old woman with advanced breast cancer on palliative chemotherapy. She is tolerating treatment well with signs of response but developing depressive symptoms (insomnia, anorexia and high depression score on HADS)	Screening for emotional distress/ depression
B	A 63 year old man with metastatic leiomyosarcoma on palliative chemotherapy. He is tolerating treatment well. This is reflected in the questionnaire scores showing very few problems.	Help to make consultation more efficient
C	A 70 year old lady with advanced ovarian cancer. She has undergone bowel surgery which has resulted in a formation of a stoma. She has multiple symptoms and problems and this is manifested in the questionnaire scores.	Help structure consultation by prioritising important issues.
D	A 45 year old woman with advanced breast cancer who has recently started on third line chemotherapy. She has symptoms which limit her physically. She is unable to work resulting in financial concerns, poor social and role functioning.	Questionnaire to help detect problems
E	A 68 year old woman with advanced bowel cancer. She has completed 3 months of palliative chemotherapy during which she has had significant improvement in her symptoms. Her restaging CT scan has shown that the appearance of her cancer has not changed very much (stable disease).	Monitoring and assessing treatment effect

Table 2 Two patients with lung transplants

Clinical Cases																																						
Case 1																																						
69 year old male lung transplant on a complex medication regimen. The HUI revealed serious memory problems																																						
Visits	HUI score card	Action																																				
Visit 1	<div data-bbox="443 555 1444 1300"> <p>HRQL Results</p> <p>HUIsc</p> <p>Clinical Interpretation of Results</p> <p>HUI Single-attribute utility scores: differences of ≥ 0.05 are important. Overall utility score: differences of ≥ 0.03 are important.</p> <p>PH = Perfect Health E2 = HUI2 Emotion SC2 HUI2 Self-care V3 = HUI3 Vision H3 = HUI3 Hearing S3 = HUI3 Speech A3 = HUI3 Ambulation D3 = HUI3 Dexterity E3 = HUI3 Emotion C3 = HUI3 Cognition P3 = HUI3 Pain O3 = HUI3 Overall</p> <p>Legend: ● = Normal ● = Mild ● = Moderate ● = Severe</p> <table border="1"> <caption>Single-attribute and Overall utility scores</caption> <thead> <tr> <th>Attribute</th> <th>Utility Score</th> <th>Severity</th> </tr> </thead> <tbody> <tr> <td>E2</td> <td>0.6</td> <td>Mild</td> </tr> <tr> <td>SC2</td> <td>0.85</td> <td>Mild</td> </tr> <tr> <td>V3</td> <td>0.59</td> <td>Mild</td> </tr> <tr> <td>H3</td> <td>0.71</td> <td>Mild</td> </tr> <tr> <td>S3</td> <td>0.67</td> <td>Mild</td> </tr> <tr> <td>A3</td> <td>0.83</td> <td>Mild</td> </tr> <tr> <td>D3</td> <td>1.0</td> <td>Normal</td> </tr> <tr> <td>E3</td> <td>0.73</td> <td>Mild</td> </tr> <tr> <td>C3</td> <td>0.32</td> <td>Moderate</td> </tr> <tr> <td>P3</td> <td>0.48</td> <td>Moderate</td> </tr> <tr> <td>O3</td> <td>-0.04</td> <td>Severe</td> </tr> </tbody> </table> </div>	Attribute	Utility Score	Severity	E2	0.6	Mild	SC2	0.85	Mild	V3	0.59	Mild	H3	0.71	Mild	S3	0.67	Mild	A3	0.83	Mild	D3	1.0	Normal	E3	0.73	Mild	C3	0.32	Moderate	P3	0.48	Moderate	O3	-0.04	Severe	Care plan modified with involvement of patient and family member to address the cognition problem. The plan included change of immunosuppressant, addition of pillbox and increased frequency of follow up calls from transplant nurse.
Attribute	Utility Score	Severity																																				
E2	0.6	Mild																																				
SC2	0.85	Mild																																				
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O3	-0.04	Severe																																				

Visit 2

After three weeks



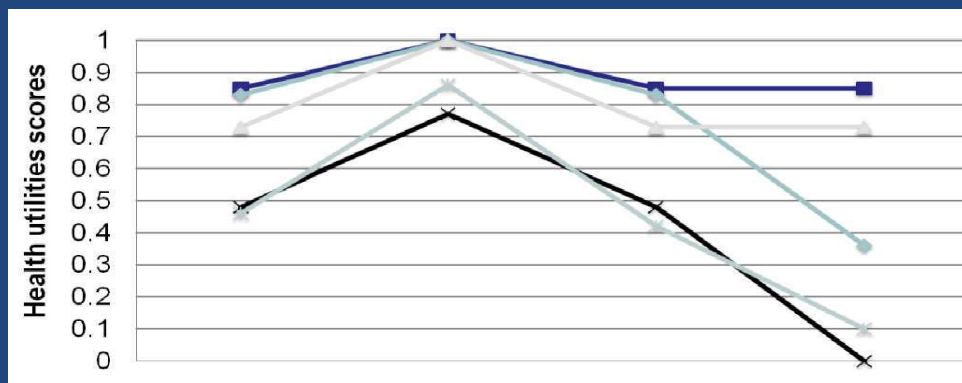
The team reviewed the general improvement and focused on the emotional issues. The care plan includes referral to the psychologist.

Case 2

34 year old female, suffering cystic fibrosis, listed for lung transplant.

The following graph represents the trajectory of the patient from pre-transplant to post-transplant and death, correlating the overall HUI score to the FEV1% pred.

HRQL scores and FEV1% pred vs. transplant time



	Pre-transplant	4 Months	6 Months	16 Months
Self-Care	0.85	1.00	0.85	0.85
Ambulation	0.83	1.00	0.83	0.36
Emotion	0.73	1.00	0.73	0.73
Pain	0.48	0.77	0.48	0.00
Overall HUI3	0.46	0.86	0.42	0.10
FEV1%pred	54	86	71	22

The training was focused on the trajectory emphasizing that the overall HUI score revealed the worsening condition before the clinical parameter

Table 3 Overview of the three programs based on theoretical approaches

	Theoretical approach and intervention	Oncology	Lung transplant	Multiple pediatric patient groups
Planning and development of the training	Assess the needs of the target group Involve key stakeholders <i>Marketing approach</i>	Based on the feedback from 20 oncologists from previous research	Co-created in collaboration with the transplant multi-disciplinary team	Developed by multi-disciplinary team: 5 researchers, 4 clinical psychologists and 1 paediatric oncologist
	Identify obstacles Address concerns <i>Marketing approach</i>	Physicians concerns: 1. Time constraints - Apprehension about visit length 2. Competence in interpretation of the PRO information 3. Ability to deal with wide range of symptoms (beyond cancer symptoms and side effects)	Physicians concerns: 1. Time constraints - time spend in training and increasing visit time 2. Competence in interpretation of the PRO information 3. Ability to deal with wide range of symptoms (unrelated to transplantation)	Physicians concerns: 1. Time constraints Time spend during training sessions 2. Competence in interpretation of the PRO information 3. Ability to deal with wide range of symptoms
	Problem-based interactive learning <i>Educational approach</i>	Built on communication skills training widely adopted in UK at the time		

<p>Content of the training</p>	<p>Evidence-based learning</p> <p><i>Epidemiological approach</i></p>	<p>Didactic overview</p> <ul style="list-style-type: none"> -The evidence base supporting the value of PROs in clinical practice -The challenges -Overview of the PROs used 	<p>Didactic overview</p> <ul style="list-style-type: none"> -The evidence base supporting the value of PROs in clinical practice -The challenges -Overview of the PROs used 	<p>Didactic overview</p> <ul style="list-style-type: none"> -The evidence base supporting the value of PROs in clinical practice -The challenges -Overview of the PROs used
	<p>Small group interactive learning</p> <p><i>Educational approach</i></p>	<p>Familiarization with the PRO measure</p> <p>Clinical interpretation of PROs and graphical presentation using patient cases</p>	<p>Familiarization with the PRO measure</p> <p>Attendees completed the HUI and results were fed back to the audience to support the clinical interpretation of PROs and graphical presentation using patient cases</p>	<p>Familiarization with the PRO measure</p> <p>KLIK ePROfile was introduced and explained with respect to layout, content, interpretation and use</p>
	<p>Problem-based learning</p> <p>Small group interactive learning</p> <p><i>Educational approach</i></p>	<p>Interactive session</p> <p>-DVDs were developed of 5 simulated consultations with oncologists and actors using PROs. The scenarios were based on real oncology visits from previous studies, and selected to show</p>	<p>Interactive session</p> <ul style="list-style-type: none"> - Clips from audio-recordings were used to discuss real clinical cases of patients with different problems The case scenarios were based on patients' clinic visits and selected to 	<p>Interactive session</p> <ul style="list-style-type: none"> -DVD material was developed, containing two short patient cases (5 minutes), representing real consultations and KLIK ePROfiles. -Before the demonstration of each

		<p>situations identified by oncologists as potential obstacles.</p> <p>-Clips from the simulated oncologist-patient encounters were shown together with the medical history and the PRO graphs. The facilitators guided discussions and questions surrounding key learning points.</p>	<p>illustrate potential obstacles.</p>	<p>case, the KLIK ePROfile of the cases were discussed.</p> <p>-</p> <p>Pediatricians/practitioners receive different assignments concerning each case.</p> <p>-Pediatricians skills depicted on the DVD were discussed.</p>
Supporting materials	<p>Reminder systems</p> <p><i>Behavioural approach</i></p>	<p>Decision-support</p> <p>Developed local guidelines (emotional distress, physical function/fatigue) linking PRO scores with specific actions and available local services (with contact information)</p>	<p>Decision-support</p> <p>A memory aid (a quick reference card) included:</p> <p>-scoring systems for the measure</p> <p>- guidance on clinically important changes</p> <p>-relevant contact information</p>	<p>Decision- support</p> <p>Online decision tree to aid interpretation and actions</p>
		<p>-Training manual</p> <p>-DVD with examples of using PROs</p> <p>-Local guideline maps for existing support</p>	<p>Selected audio-recordings to illustrate how to communicate HUI scores with patients</p>	<p>-Training manual</p> <p>-DVD of two cases using KLIK ePROfile</p> <p>-Online decision tree</p>

		services (emotional distress and fatigue)		
Duration of the training sessions	Adapting change proposal to local needs Ito fit with busy clinical practice <i>Marketing approach</i>	One 3-4 hour session with 3 oncologists	One-hour group training Further learning presentations	One-hour group training
Monitoring PRO use after the training	Audit and feedback on performance Monitoring practice <i>Behavioural approach</i>	The oncologists completed a questionnaire before and after the training session as part of the evaluation process. An end of study interview covered their experiences with using PROs and views on the training.	-Case presentations at weekly meetings were used to encourage adoption and to collect clinicians views on the usefulness of collecting PROs -Clinicians completed the HUI proxy version at every visits after seeing the patient during the first month -Healthcare providers completed a questionnaire assessing the usefulness of patient data in clinical care after the visit with the patient	-During the studies, the paediatricians complete a questionnaire after the training session as part of the evaluation process -A yearly evaluation with patients by the use of questionnaires -A yearly evaluation with the health care providers by the use of focus groups
Adoption and	Creating organisational conditions to improve	In response to the clinical needs an integration with	The use of PROMs is adopted locally. Patients	Implemented initially in oncology, then across

Implementation	care <i>Organisational approaches</i>	Electronic Patient Records was developed and will be implemented.	complete PROMs at enrolled as pre-transplant, during the waiting time as well as after transplantation. The PRO data is included in the local lung transplant database. The integration with Electronic Patient Records is under development and will be implemented.	over 8 paediatric hospitals. -Over 2000 children are now using the KLIK ePROfile -Over 200 health care providers are trained in the use of the KLIK ePROfile
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Figure 1a. Example of graphical output of QuEST PROM data

Questionnaire Summated Scales - Longitudinal Charts

[Display Subscales](#)[Display Alerts Only](#)

Subject Name	Subject Number	Unit Number	BirthDate	Gender
Anonymous Subject	4	Not Given	Not Given	N

Key:

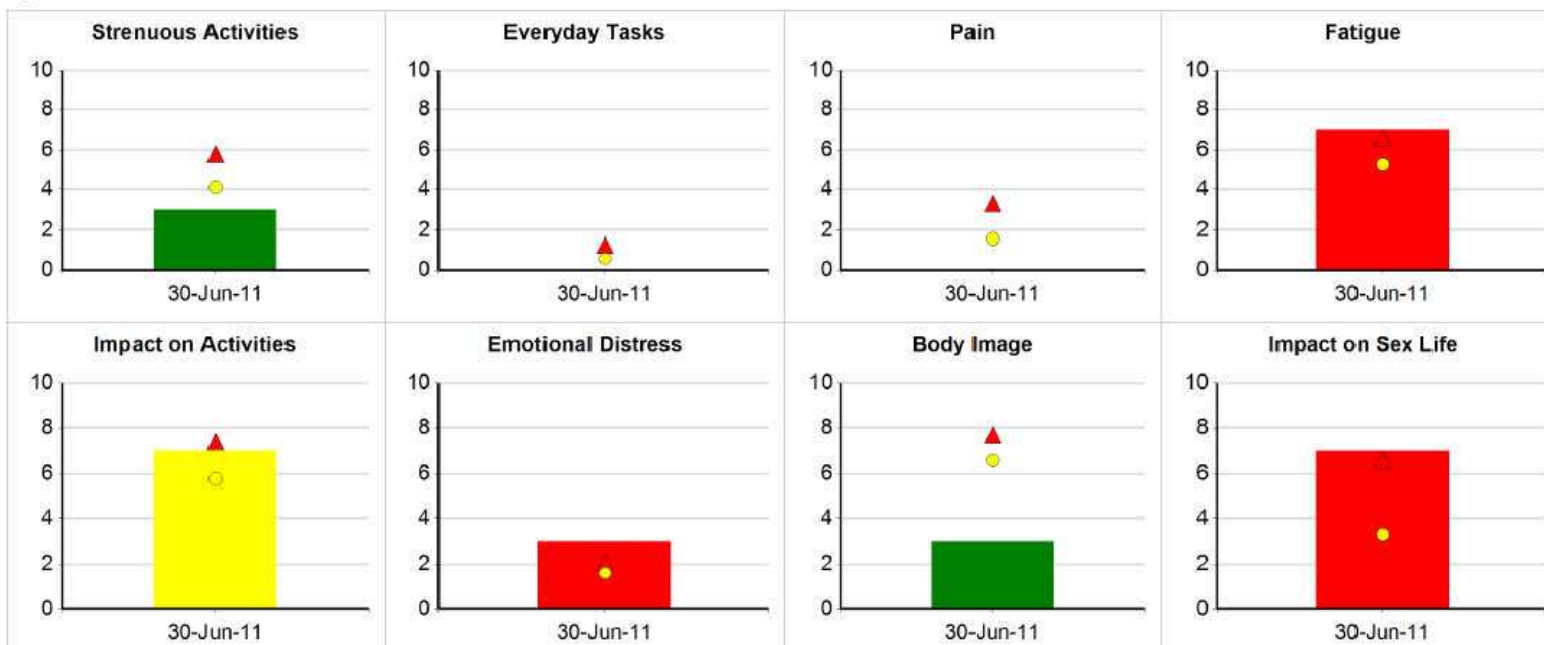
— Alert Limit



- - - Normal Limit



QuEST- Br



Key: No bar/Green = no/mild problem, Yellow = moderate problem, Red = severe problem

Figure 1b. Example of graphical output of QuEST PROM data

Questionnaire Charts

[Display Subscales](#)

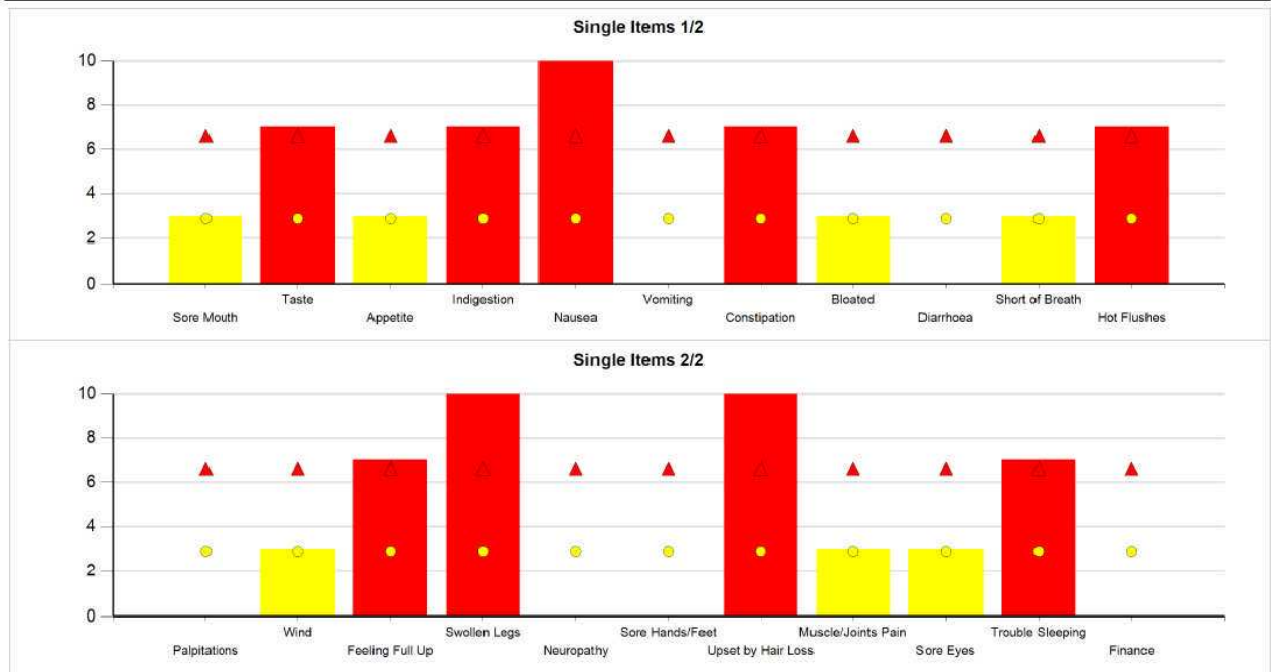
[Display Alerts Only](#)

Subject Name	Subject Number	Unit Number	BirthDate	Gender
Anonymous Subject	5	Not Given	Not Given	N

Key:

— Alert Limit ▲

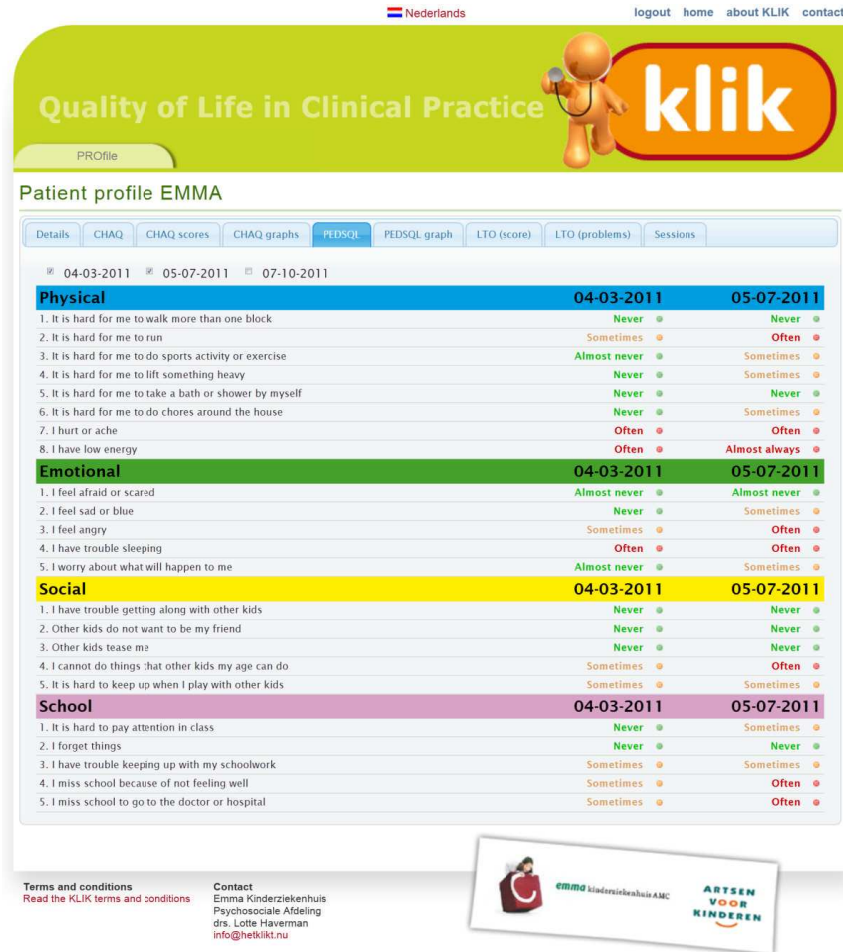
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Figure

[Click here to download Figure: Figure 2 literal representation of the KLIK PROfile for pediatric patients.docx](#)

Figure 2 literal representation of the KLIK PROfile for pediatric patients



Figure

[Click here to download Figure: Figure 3 graphical representation of the KLIK PROfile for pediatric patients.docx](#)

Figure 3 graphical representation of the KLIK PROfile for pediatric patients

