PRIORITY BRIEFING

The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days.

Does the use of a novel telehealth system (MYQuOL-T) to support greater patient involvement in prioritising and monitoring healthcare outcomes improve the delivery of care to individuals with chronic or incurable illness?

Question ID: 3

Question type: Intervention

Question: Does the use of a novel telehealth system (MYQuOL-T) to support greater patient involvement in prioritising and monitoring healthcare outcomes improve the delivery of care to individuals with chronic or incurable illness?

Population: Children and young adults with chronic or life-limiting illness, and their parents/carers, and health care professionals.
Intervention: MYQuOL-T a web-based method for patients to identify, describe, prioritise and monitor problems that are important to them, and to evaluate the impact of therapeutic interventions.
Control: A control group could be children's hospices or teams who do not already use the tool (although as it is freely available on the internet it would not be easy to limit its use). Alternatively, a before and after study design could be implemented.

Outcome: Primary Outcomes:
Quality of life– as measured by comparison against validated generic QOL measures and disease specific measures; patient confidence in outpatient clinics or domiciliary settings – as measured by self-efficacy scoring; communications/ teamwork between patients and healthcare professionals, as measured by qualitative feedback from patients and healthcare professionals about ease of use, timeliness of interventions, & relevance in practice.
Secondary outcomes:
Improved evidence base for QOL of some interventions in health care; greater understanding of patient symptoms/problems and priorities by healthcare professionals; a reduction in emergency hospital/hospice admissions for complications of chronic disease or symptom control

*Please note that the details included in the box are from the original submission and have been edited where necessary for clarity and precision

MYQuOL-T: This tool has been developed with children and young adults receiving palliative care. It provides a visual or graphic display of problems or symptoms of most significance to the patient. Rather than using pre-determined QOL scales, it allows the patient or carer to describe in their own words their current concerns, and accommodates issues that may be physical, psychological, individual or collective, objective or subjective in nature. Relative values are ascribed to each symptom by the patient (see fig 1 at end of question), and an interface allows contemporaneous data entry (fig 2), instant generation of a graphic display of results (fig 3), and web-based access by healthcare providers nominated by the patient. Content and access to data is controlled by the patient/carer and can be used irrespective of contact with a doctor. Data can be entered on a daily or weekly basis, and can be added retrospectively in cases where timely entry is difficult because of competing pressures.

Chronic or life-limiting illness: Chronic conditions are those which remain for a long time and are persistent in nature, they may not cause the individual to live a shortened life but likely enforce limitations on ableness. Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers. MYQuOL-T is primarily designed for those with life-limiting conditions though there has also been interest from clinicians who have patients with a range of chronic conditions.

The Health Problem:

In 2007 the Department of Health reported that approximately 20,100 children aged 0-19 years were likely to require access to palliative care services annually in England. They also estimate that around 2,000 children in the south west strategic health authority need palliative care (24 per 100,000). Government statistics report that one in 20 children are disabled in the UK, this equates to 770,000 disabled children nationally and could potentially represent at least 10,685 disabled children in Devon and Cornwall (143,902 children aged 18 yrs or less in Devon and 69,801 in Cornwall, though this number may be higher as some data suggests Devon has a higher than average prevalence of disability and the Cornwall figures do not include children below school age). The charity also reports that only 1 in 13 disabled children receive a regular support service from their local authority, and over 60% of families with disabled children do not feel listened to by professionals. The majority of children with serious illness or disability are supported within families. A recent review looked at the support available for families with children that have a disability and found that many disabled children and their families report little or no consultation on how their care could be provided.

Guidelines:

National Service Framework for Children, Young People and Maternity Services: Commissioning Children’s and Young People’s Palliative Care Services (2005) also suggests that age and development appropriate services be provided that cover a child’s pain, social, psychological, cultural and spiritual needs, as well as their carers’ support needs. These services should help to promote quality of life and shared decision making.

The National Service Framework for long-term conditions (2005) states that people with these conditions should have a patient-centered service that promotes self-management and integrated assessment. They also state that people living at home should have ongoing access to advice and support (as should their carers) and should use assistive technology to maintain health and improve quality of life. A report by York Health Economics Consortium and the Department of Health Aiming High for Disabled Children (2009) recommend that systems that can record the needs and conditions of children should be fully explored locally and nationally.

NHS Priority:

Regional

SW SHA Priorities framework 2008-11 (please note this has not yet been updated for 2012)

- Expand the use of telecare, telemedicine and assistive technology
- Fully implement the quality requirements of the National Service Framework for Long-term conditions

Local

- NHS Devon – two strategic initiatives: Self care management supporting the most vulnerable children and young people and palliative care for children with life limiting and life threatening illnesses
- Improving self reported experience of patients & users is a priority for Plymouth PCT and Torbay Care Trust

QIPP

Two priorities of the QIPP agenda are adopting best-practice care pathways for LTCs and shifting settings of care.

Existing Research:

Published research

The searches for this topic found no systematic reviews which concentrated on the MYQuOL-T intervention specifically or which concentrated on the effect of telehealth interventions in children with chronic or life limiting illness. There has been one recent systematic review[1] exploring the effects of e-health (interactive websites on internet) in chronically ill patients. The review found 12 studies looking at e-Health websites which included sites that consisted of monitoring, treatment instructions, self-management training and general information and communication between patient and caregiver. The review found small to moderate positive influences on some health outcomes (such as clinical measures of diabetes symptoms), though the authors report that much more research is needed.

Six primary research studies have also recently been conducted focussing on the use of e-health interventions in children with different chronic and life-limiting conditions. Most of the research is aimed at determining how a new e-health intervention might be able to improve patient care and patient and carer satisfaction. One RCT conducted in 2011[2] assessed PediQUEST (a computerised survey that asks about the patients quality of life and symptoms) to see if feedback from this survey could help patients (children with cancer), their parents and care providers communicate better and to see if the feedback influenced the care decisions made. They found that it was generally well received and that parents found it helpful in supplying new information about the psychosocial issues the patient was going through and that it did contribute at least sometimes to their decision to initiate a psychosocial, pain, social work, or palliative care consultation. Also half of the care providers found reports useful when speaking with patients.

There are a number of e-health interventions which ask the patient to report their feelings or experiences generally on pre-specified questions, such as QLIC-ON (a digital health related quality of life questionnaire which provides the clinician with a Patient Reported Outcomes file –PROfile) and KidlQOL[7]. These interventions then provide a health profile which the patient and the clinician can use to try and resolve identified problems during a consultation. In a cohort study on this intervention involving 165 children with cancer, the care providers and parents reported the tool as being useful as they were able to obtain more relevant information from the consultation and were able to concentrate more explicitly on the parent and patient needs or desires[3]. A study on this intervention (or something very similar) has also been conducted with children in Holland with juvenile idiopathic arthritis[4] (the full results from this study have yet to be published).

Another article ‘describes the development of a novel biomedical informatics system that has been designed to allow parents, professionals and children to use a web-based, real-time symptom monitoring system to enable more effective treatments, better pathways of shared care, and more equitable and efficient service delivery for this group of vulnerable children’(children with neuropsychiatric disorders such as ADHD and Autism).[6] They found that the online tool was acceptable to children, parents and clinicians and in some cases seemed to make reporting and monitoring easier and more open/honest.

Importantly, these interventions differ from MyQuOL-T in that they pre-specify the questions/topics that they would like the patient to report on. MyQuOL-T allows the patient to identify their own health-related topics to report on. Similar interventions have been tried before but were mainly before use of the internet was widespread. A systematic review of these interventions was conducted in 2003[8] to provide a critical review of the Patient-Generated Index (PGI), Schedule for the Evaluation of Individual Quality of Life (SEIQoL), Repertory Grid, and Asthma Quality of Life Questionnaire (AQLQ). The review found that the measures were impractical and often did not reach suitable levels of reliability and validity. It also highlighted that such tools did not allow for any form of standardisation that would be useful in estimating population effects, and suggested that patient-generated outcomes measures might only be useful when used alongside standard health related QOL measures. Some research has also been conducted on the use of online diaries to track symptoms of pain in children with chronic pain[5], which in some respects reflects the idea of patient reported outcomes in a less structured way, however, the research does not yet report the impact of using these diaries on the resulting care for the child.

Ongoing research

No ongoing research was identified by the search on this topic.

Feasibility:

The original tool evolved out of patient experience, and was developed with parents/carers of children with life-limiting illness, and healthcare professionals from a range of disciplines working within the children's hospices in the south west. For children and young people living with life-limiting illness, personal involvement in decisions about their health care is crucial, as their unique life challenges are likely to be outside the usual experience of many of their healthcare providers, and subjective outcomes to improve their quality of life are relatively more important in their brief lives.

The original work was funded by a Department of Health grant as part of the £30m investment into projects to improve children's palliative care services (£34k). Although the initial work was based at Children's Hospice South West, several other UK children's hospice teams, paediatric neurodisability consultants, and Together for Short Lives have expressed support for exploring the further development of this concept. Marie Curie have recently provided further funding (£10k) to develop the MYQuOL-T IT platform to support patient empowerment during transition from paediatric to adult palliative care services.

References:

1. Eland-de Kok, P., H. van Os-Medendorp, et al. (2011). "A systematic review of the effects of e-health on chronically ill patients." Journal of Clinical Nursing **20**(21-22): 2997-3010.
AIMS AND OBJECTIVES: We aimed to investigate whether e-health is equal to or better than usual face-to-face care with regard to outcomes on health, quality of life, patient satisfaction and costs. Therefore, we systematically reviewed the literature on e-health in chronically ill patients compared with or as an addition to usual care. BACKGROUND: Interactive websites on internet are increasingly used to inform and treat patients. This type of contact between patients and health care providers, which is called e-health, is easily accessible and particularly interesting for chronically ill patients. DESIGN: A systematic review. METHODS: We searched the databases PubMed, CINAHL, the Cochrane Database of systematic reviews, DARE and CENTRAL for articles published between January 2000-July 2009. RESULTS: The search strategy yielded in total 695 possibly relevant references, which resulted in 12 RCTs after application of the in- and exclusion criteria. Most of the studies were well designed according to the Cochrane criteria for RCTs. The studies are divided into e-health vs. usual

care and e-health as addition to usual care. e-Health consisted of monitoring, treatment instructions, self-management training and general information and communication between patient and caregiver. Most of the studies showed small to moderate positive effects on health outcomes. Cost-effectiveness, quality of life and patient satisfaction were rarely investigated in the included studies. CONCLUSIONS: e-Health interventions for chronically ill patients, offered instead of usual care or in addition to usual care, lead to small to moderate positive effects on primary health outcomes. However, the evidence was not fully convincing, because of the limited number of studies available and the methodological limitations. Further research is needed to confirm the cost-effectiveness of e-health interventions for patients with chronic diseases. RELEVANCE TO CLINICAL PRACTICE: e-Health is a promising tool for treatment and self-management training of chronically ill patients.

2. Dussel, V., B. Neville, et al. (2011). "Routine feedback of patient-reported distress in children with advanced cancer: Provider and family satisfaction with the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) system (311-B)." Journal of Pain and Symptom Management **41 (1)**: 187-188.
Objectives: 1. Identify two ways of evaluating efficacy of a supportive care intervention. 2. Describe three indicators of satisfaction with a supportive care intervention. 3. Provide justification about why study results are encouraging. Background: The Pediatric Quality-of-Life Evaluation of Symptoms Technology (PediQUEST) Study is a supportive care random controlled trial in children with advanced cancer to determine the effect of providing families and providers feedback about patient-reported quality of life and symptoms. Research objectives: To assess provider and family satisfaction with PediQUEST feedback reports. Methods. Children, 2-18 years old, with advanced cancer treated at three large pediatric oncology programs regularly completed the computerized survey PediQUEST and were randomized to have families and providers receive feedback reports or not. Child and parent satisfaction were collected at the fourth and eighth PediQUEST administrations. Providers answered a one-time satisfaction survey at study end. Results. From December 2004 through June 2009, 104 patients enrolled (recruitment fraction: 75%); 98 were analyzable (>1 PediQUEST). Of these, 49 were randomized to feedback; 42 families and 29 families answered the first and second satisfaction surveys, respectively (response rates: 91% and 76%). At the fourth PediQUEST administration, most parents (83%) and children (63%) found the questionnaires relevant and felt summary reports helped them talk to doctors (75% and 52%, respectively). Ninety-six percent of parents said reports helped them understand their child's feelings. Almost all would have liked to continue using the system. Results were stable over time. Providers agreed reports supplied new information about psychosocial issues (61%), but less so about physical symptoms (22%) and thought reports contributed at least sometimes to their decision to initiate a psychosocial (56%), pain (34%), social work (33%), or palliative care (29%) consult. Half the providers found reports useful when speaking with patients.

Conclusion. The PediQUEST feedback system was well received by children, parents, and providers. Summary reports were seen as communication enhancers both within the family and with providers. Implications for research, policy, or practice: Routine feedback of child-reported outcomes enhances aspects of communication about distress in children with advanced cancer.

3. Engelen, V., S. Detmar, et al. (2010). "The effectiveness of Patient Reported Outcomes (PRO's) in pediatric oncology practice: Results from the QLIC-ON study." Psycho-Oncology **19**: S129.
OBJECTIVES: Several studies have shown that children with cancer can experience health related quality of life (HRQOL) problems. These problems are not always systematically discussed or known by their pediatric oncologist (PO). Aim of this study is to develop an intervention to make POs aware of these problems and study the effectiveness in terms of increased referrals and advices, satisfaction and identification and discussion of QoL topics. METHOD: In multicenter sequential cohort study (QLIC-ON) children with cancer immediately after end of treatment participated. Shortly before the first three follow-up consultations with the physician, the child (8-18 years) or parent (about child aged 0-8 years) completes a digital HRQOL questionnaire. The QLIC-ON PROfile is presented to the physician as a PRO in the intervention group, to help identify and discuss HRQOL problems. To maximize the effect of the QLIC-ON PRO POs received a training. RESULTS: In total n = 275 patients (four centres) were approached, n = 190 participated (response 69%) of which n = 80 completed the control and n = 85 completed the intervention period. Most of the parents (74%) and POs (63%) considered the PROfile useful. First analysis showed POs to be more satisfied in the intervention period ($p < 0.05$), to be able to provide more information to parents ($p < 0.05$) and to pay more attention to desires of parents ($p < 0.05$) and child ($p < 0.01$) CONCLUSIONS: The results are promising. Parents and pediatricians are positive about the use of the PROfile. In the future the PROfile can be used for different patient groups and also by different users (e.g. psychologists, nurses or social workers) in clinical practice. With adaptations for internet the PROfile will be easy to implement in clinical practice and helpful in facilitating communication about QoL.

4. Haverman, L., V. Engelen, et al. (2010). "The Quality-of-Life Map (KLIK): The first application of a web-based feedback on the quality-of-life data in children. [Dutch] **78**(6): 220-227.
Introduction. Children with a chronic illness often experience Health Related Quality of Life (HRQOL) problems. These problems are not always known or systematically discussed by paediatricians. For children and parents it is important to pay attention to HRQOL systematically. This is possible with the use of patient-reported outcomes (PROs). The patient completes a HRQOL questionnaire, and answers are summarized in a PROfile. Subsequendy, the paediatrician discusses this PROfile with the patient during the doctor's visit. This is the first study to evaluate the use of online PROs in paediatrics. Www.hetklikt.nu. In the Emma Children's Hospital, the KLIK study is performed in

children with juvenile idiopathic arthritis (JIA). The use of PROs in clinical practice is often confronted with logistical problems. A web-based application can overcome these problems; therefore the website www.hetklikt.nu was developed. With the use of this website, children and parents can complete HRQOL questionnaires at home and paediatricians can retrieve the PROfile online. KLIK study. The KLIK study was launched in August 2008 and examines whether the use of the KLIK PROfile by paediatric rheumatologists has a positive effect on satisfaction with care, communication, advice and referrals. In this multicenter study, the doctor's visit without the use of the profile (control group) is compared to the doctor's visit with the use of the profile (intervention group). The results of the intervention group are compared to the control group. To avoid contamination a sequential cohort design was chosen. Discussion. In the Emma Children's Hospital, profound research was done to realize an application to systematically pay attention to HRQOL issues in daily clinical practice for children with a chronic illness. A web-based PROfile appears to be an appropriate application to achieve this goal.

5. Connelly, M., D. Wallace, et al. (2011). "Tracking of pain in children with daily diaries: What questions should be asked?" Journal of Pain **1)**: P82.
Daily pain diaries frequently are recommended for evaluating chronic pain treatment outcomes. However, there is scant empirical evidence demonstrating which pain characteristics when measured daily provide unique and clinically important information in children with chronic pain. The present study evaluated day-to-day variability of child-reported pain characteristics and assessed the extent of their unique prediction of daily functional limitations. Participants included 20 children (15 female, 5 male) aged 8-17 years with chronic pain (47% chronic abdominal pain, 29% idiopathic musculoskeletal pain, and 24% chronic headache) attending a new patient pain evaluation in a multidisciplinary clinic. During the clinic visit, participants were trained to complete an online daily diary comprising questions about overall worst and average pain intensity, pain location and worst/average intensity at each location (using a body map), frequency of pain episodes and pain exacerbations, duration of worst and total pain, pain affect, and limitations in both routine and more physically demanding daily activities (CALI-21). Participants completed the daily diary from home computers for 30 days (average completion rate = 65%). Hierarchical linear modeling suggested that all measures varied sufficiently from day to day within children to justify daily tracking (ICCs ranging from .37-.73). Pain variables differed in their unique contemporaneous association with activity limitations depending on activity type: For routine activities (e.g., schoolwork, reading), overall average pain intensity, duration of worst pain that day, number of painful locations, and pain affect were significant unique positive predictors. For more physically demanding activities (e.g., gym, sports), only overall worst pain intensity emerged as a significant unique positive predictor. For both activity types, daily ratings of overall pain better predicted functioning compared to intensity ratings by individual location. Findings suggest that different pain

variables may be important to include on daily diaries depending on the functional improvement goals of treatment.

6. Gringras, P., P. Santosh, et al. (2006). "Development of an Internet-based real-time system for monitoring pharmacological interventions in children with neurodevelopmental and neuropsychiatric disorders." Child: Care, Health & Development **32**(5): 591-600.
Few children have a 'pure' diagnosis of neuropsychiatric disorders such as attention deficit hyperactivity disorder or autism. Most have complex, overlapping symptoms, and it is often these associated and common comorbidities that cause as much, if not more impairments, than the core symptoms. Prescribing decisions are therefore complex and made on the basis of eliciting a range of agreed 'target symptoms'. At present, however, there are no agreed systems that allow monitoring of all areas of potential change, and few services are able to monitor symptoms, side effects, impact on family life and individual children's quality of life systematically. At best many clinics use a plethora of paper-based standardized questionnaires, based on individual diagnoses. This article describes the development of a novel biomedical informatics system that has been designed to allow parents, professionals and children to use a web-based, real-time symptom monitoring system to enable more effective treatments, better pathways of shared care, and more equitable and efficient service delivery for this group of vulnerable children.

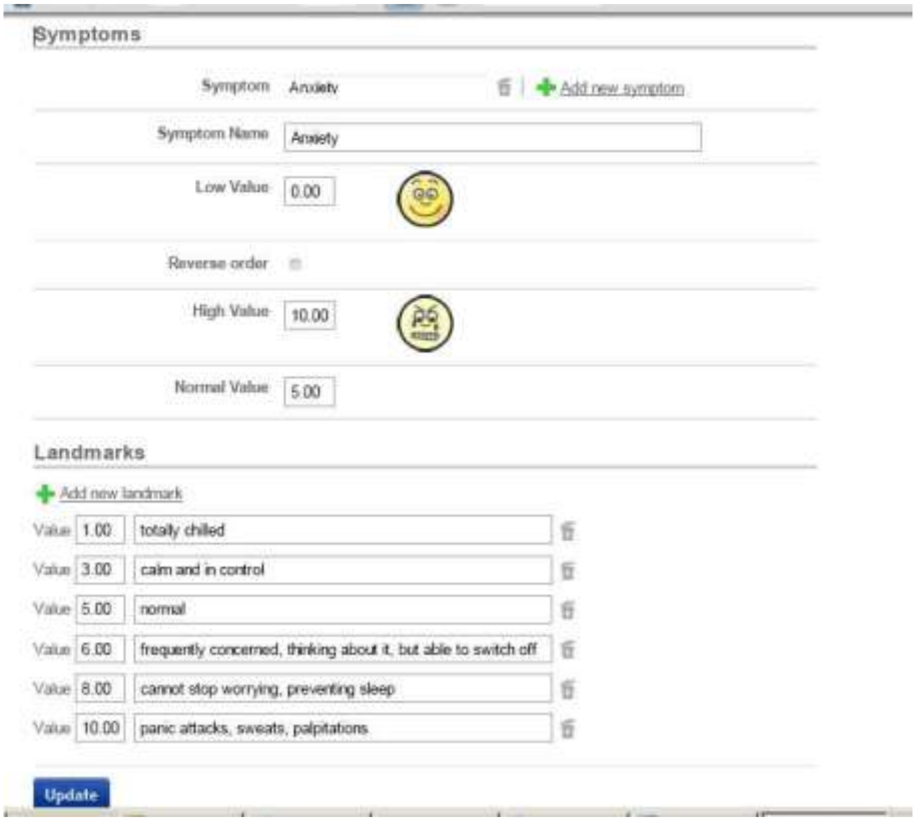
7. Gayral-Taminh, M., T. Matsuda, et al. (2005). "Self-evaluation of the quality of life of children aged 6 to 12 years old: Construction and first steps in the validation of KidIQol, a generic computer-based tool. [French] **17**(2): 167-177.
The KidIQol is a self-evaluation computer-based instrument to assess the quality of life of children aged 6 to 12 years old. This self-evaluation comprises three areas of their subjective quality of life: physical, psychological and social. A computer-assisted tool, composed of 62 items, was developed and set up based upon the results from the evaluation of the initial prototype tool which underwent a series validation steps, tested among children with and without psychological problems. This evaluation lead to the production of a final tool called KidIQuol, which is composed of 44 items. This tool, which utilises computer images to represent real-life situations, is adapted for and accessible to children with a French cultural background aged between 6 and 12 years old. As a generic tool, it could be used among a population of children with various types of handicaps, chronic diseases or psycho-social difficulties.

8. Patel KK, Veenstra DL, Patrick DL. (2003) “A Review of selected patient-generated outcome measures and their application in clinical trials” Value Health 2003 Sep-Oct;6(5):595-603

Patient-generated outcome measures have been developed in an effort to capture the individualistic nature of health-related quality of life (HRQoL). These measures differ from traditional HRQoL instruments in that they allow patients to individually define HRQoL domains or weights. Nevertheless, application of these

measures may be challenging, particularly in a clinical trial setting. The objective of this study was to provide a critical review of the following patient-generated outcome measures: Patient-Generated Index (PGI), Schedule for the Evaluation of Individual Quality of Life (SEIQoL), Repertory Grid, and Asthma Quality of Life Questionnaire (AQLQ). Methods: We conducted a systematic literature review of the Medline and Olga databases and the journal Quality of Life Research and consulted experts. We abstracted data from eligible studies on the instruments' content, psychometric properties, and applicability in a clinical trial setting. Results: The SEIQoL has shown to be reliable, valid, and responsive, but the PGI has not. Both instruments have poor practicality and have not been used in a clinical trial. The Repertory Grid's psychometric properties have not been well studied. The AQLQ is in part patient-generated and has been used in clinical trials. Nevertheless, the practicality of the individualized section is poor owing to the issue of missing data. All four instruments fail to provide a form of standardization needed for estimating population effects in a clinical trial. Conclusion: The applicability of patient-generated outcome measures in a clinical trial setting remains questionable. Patient-generated outcome measures appear to be useful primarily in complementing traditional HRQoL measures, guiding individual patient treatment decisions, and assisting the design of new measures.

Figure 1 – example of patient’s descriptor scale for her anxiety



Symptoms

Symptom: Anxiety

Symptom Name: Anxiety

Low Value: 0.00

Reverse order: ☐

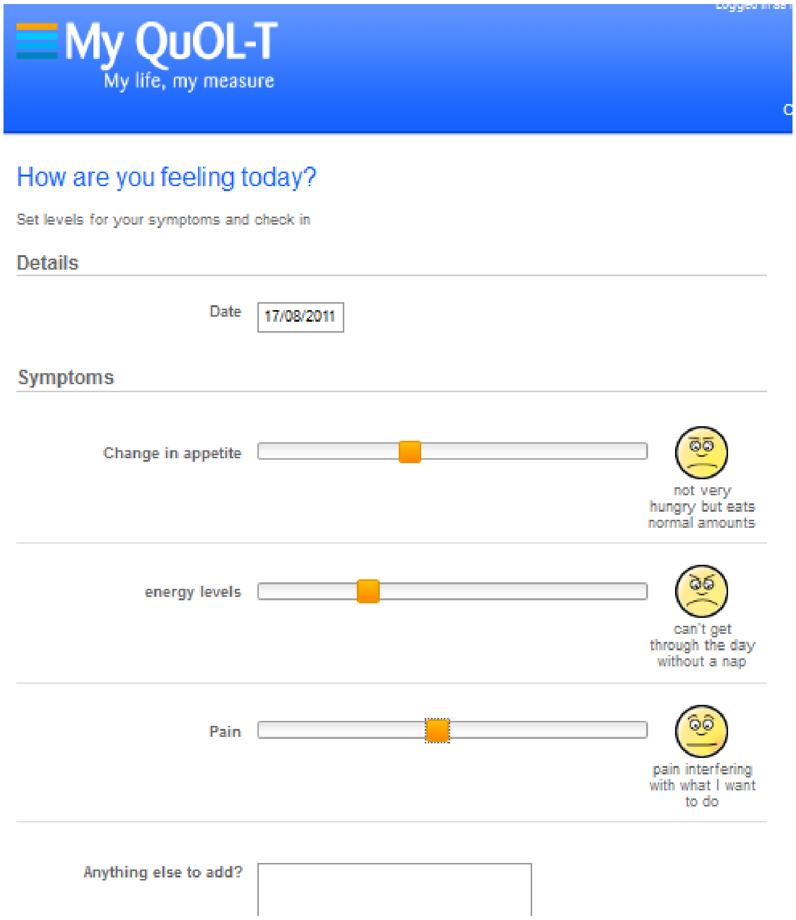
High Value: 10.00

Normal Value: 5.00

Landmarks

Value	1.00	totally chilled
Value	3.00	calm and in control
Value	5.00	normal
Value	6.00	frequently concerned, thinking about it, but able to switch off
Value	8.00	cannot stop worrying, preventing sleep
Value	10.00	panic attacks, sweats, palpitations

Figure 2 – daily check-in to record scores – takes 30sec.



My QuOL-T

My life, my measure

How are you feeling today?

Set levels for your symptoms and check in

Details

Date 17/08/2011

Symptoms

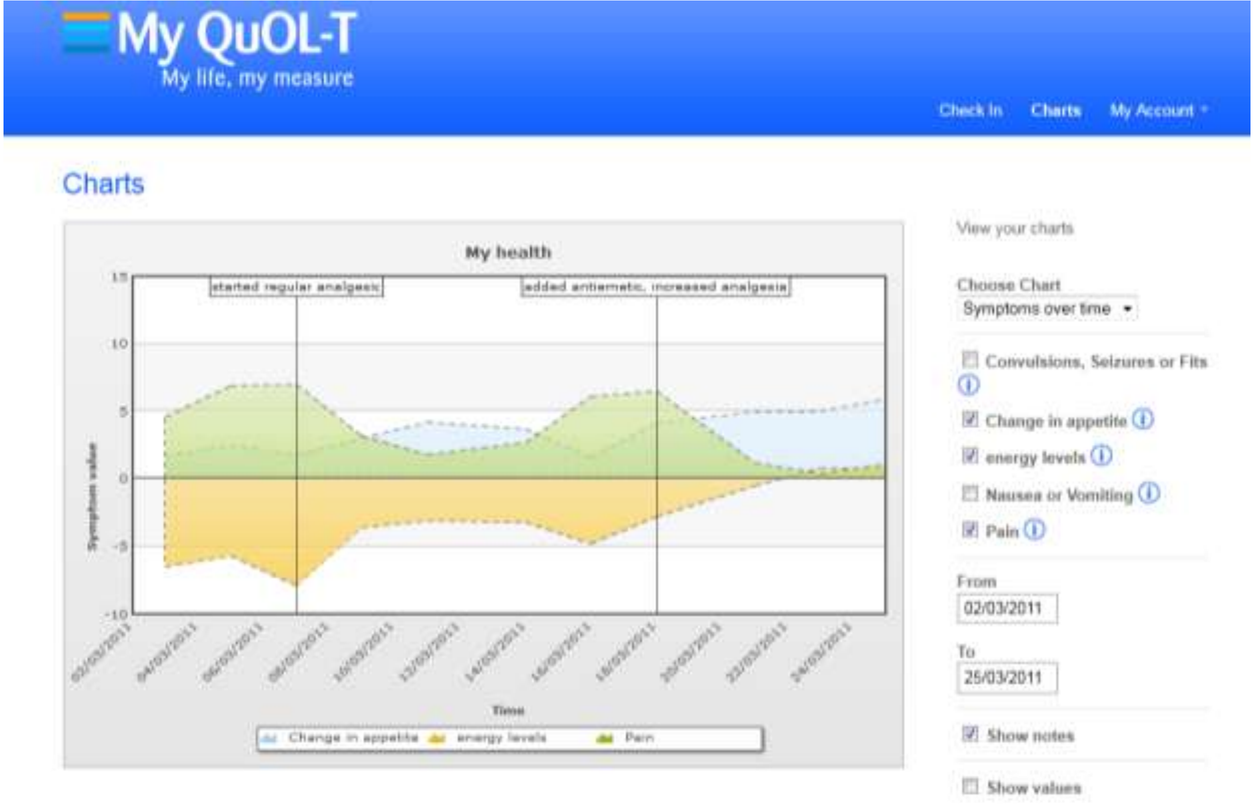
Change in appetite — not very hungry but eats normal amounts

energy levels — can't get through the day without a nap

Pain — pain interfering with what I want to do

Anything else to add?

Figure 3 –graph of results



Charts

View your charts

Choose Chart
Symptoms over time

☐ Convulsions, Seizures or Fits
☑ Change in appetite
☑ energy levels
☐ Nausea or Vomiting
☑ Pain

From
02/03/2011

To
25/03/2011

☑ Show notes

☐ Show values