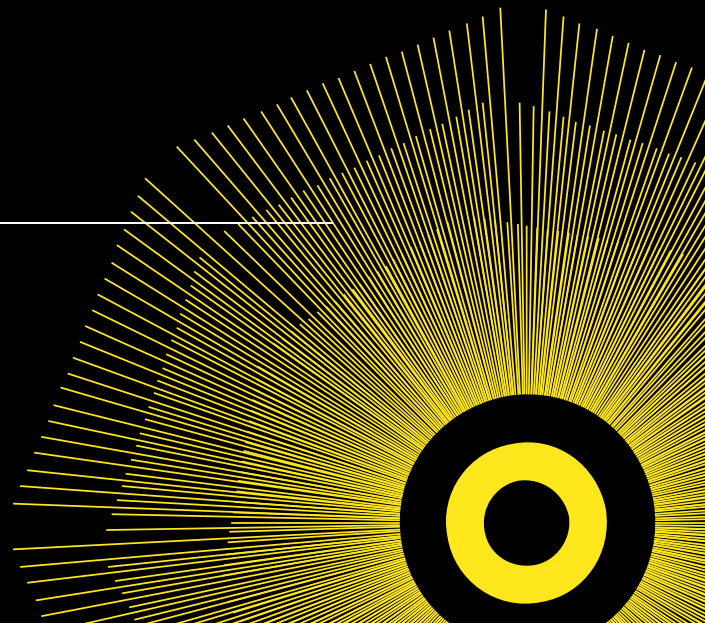


Shine 2012 final report

‘My QuOL-T’ promoting patient and carers’
priorities in care

Children’s Hospice South West



Part 1. Abstract

Project title: My QuOL-T: Promoting Patient and Carers' Priorities in Care

Lead organisation: Children's Hospice South West (CHSW)

Partner organisation: University of West of England (UWE)

Lead Clinician: Dr Nicola Harris

Abstract

Long-term or life-limiting illness in children and young people is an increasing issue as advances in medical technologies sustain those with long-term conditions for longer. Children and young people receiving palliative care support for such illnesses often have complex health symptoms requiring treatment, with multi-faceted consequences which impact on their and their families' health and wellbeing. Contact with health professionals can be sporadic and often continues over extended periods. It can be difficult for professional carers to know, at any particular time, which issues are most important for the child and family. It can also be difficult for those living with a long-term condition to describe the experience from their perspective. As a result it is difficult to measure the health related quality of life experienced by these families. This in turn has an impact on decisions about resource allocation and usage. My QuOL-T (Measure Yourself Quality of Life Tool) was developed to assist patients in communicating their concerns and symptom patterns to the clinicians caring for them. This tool could offer families affected by childhood life limiting conditions a means of focussing attention on symptoms or behaviours important to them rather than those deemed important by clinical and professional staff.

This project sought to evaluate the use of My QuOL-T in the children's palliative care setting.

My QuOL-T is a web-based application that helps patients (or parents) to identify, describe, prioritise and monitor health related problems or symptoms that are important to them, using their own words and scoring system. Issues identified may be physical, psychological, individual or collective, objective or subjective in nature. The tool was developed with children and young adults and has evolved from patient experience. The patient registers on a secure website, defines which 'problems' they want to measure. They can include as many or few problems, and score them as frequently, as they wish. As scores are entered, charts are generated giving a visual time-based display of their data.

These patient-generated data, in a clinically accessible format, can be shared electronically with the patient's chosen professionals. The process facilitates feedback from patients to their professionals, and has the potential to aid timely evaluation of the impact of therapeutic interventions. Further, it creates opportunities to improve communication with services for patients when at home.

We used a mixed methods approach to the evaluation, which included face to face interviews, the completion of a Family Empowerment scale at T=0, T+3months, and T+6 months if time allowed, and evaluation of user-generated symptom scores and patterns of use of the website over the course of the study.

The project involved three hospices covering a geographical area. Seven local MyQuOL-T Champions were trained to recruit and support families and hospice staff in delivering this project.

The study was approved by the Faculty Research Ethics Committee of University of West of England in Jan 2013.

What we achieved:

We

- re-developed the website to accommodate the study, and for researchers to access anonymised data.

- recruited and trained local Champions to familiarise them with data collection and storage processes, provide opportunities to explore the capabilities of the website, and to encourage project team networking .
- informed other relevant professionals within CHSW about the study and My QuOL-T website through training sessions for the multidisciplinary care team members at all sites
- recruited 32 participants to the study
- collated data on 2442 days of website use
- recorded an improvement in self-rated empowerment scores by participants
- demonstrated the utility and ease of use of the website
- recognised support for this approach to improving patient participation and partnership with healthcare amongst the study participants, and identified areas for future development.
- presented the study at two national and one regional conference, with international presentation in Montreal due in September 2014.

Challenges we have encountered include:

- Managing communication across the geographical distance between the hospices.
- Streamlining project processes across organisations involved (Hospice, University and IT developers)
- Informing and involving local clinicians and practitioners
- Protecting time for project during a period of unprecedented clinical demand.
- Unpredictable events: in a team of 10, 3 changed roles within their organisation and one experienced a bereavement. These impacted on meeting deadlines and delivering results for the project.

These were overcome by:

- Additional hospice visits by project manager
- Production and distribution of a quarterly newsletter; distribution of business cards and information leaflets for clinicians and practitioners involved with families enrolled on the study.
- Monthly meetings for project management team, and ad-hoc email, telephone and Skype contact between team members
- Flexibility and commitment amongst remaining team members – and one replacement champion mid-study – to ensure that the study proceeded to schedule.

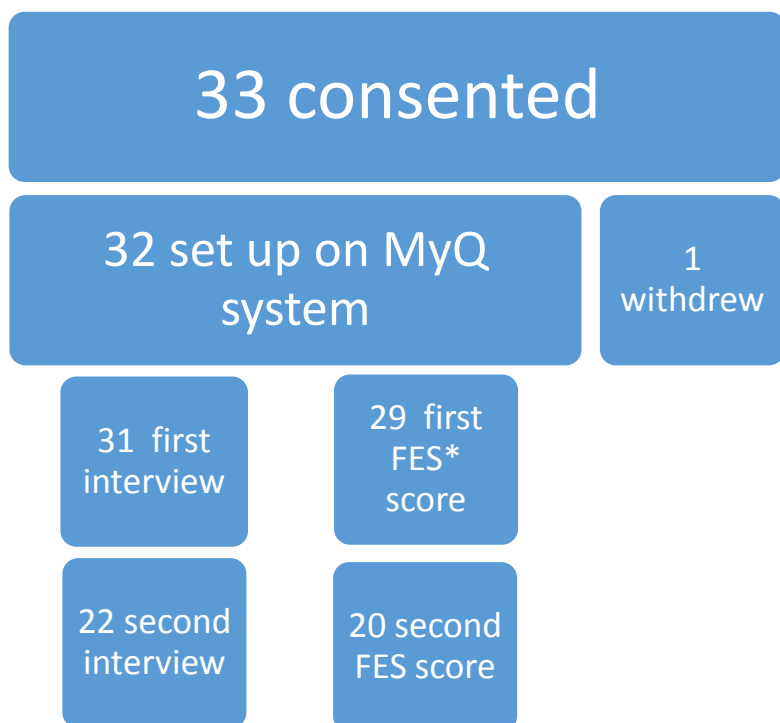
Part 2. Quality impact: outcomes

The My QuOL-T website had already been developed in basic form prior to the start of the SHINE 2012 study, and the first three months included significant changes to reflect feedback from previous users, plus the development of methods to monitor use of the programme by users enrolled on the study. This allows anonymised review of patterns of use by families and by professionals when the data are analysed. All families using the hospice services are encouraged to use My QuOL-T for as long as they wish.

The study was conducted across 3 hospice sites, with local champions leading the recruitment and patient support in each location.

Primary data were from three sources:

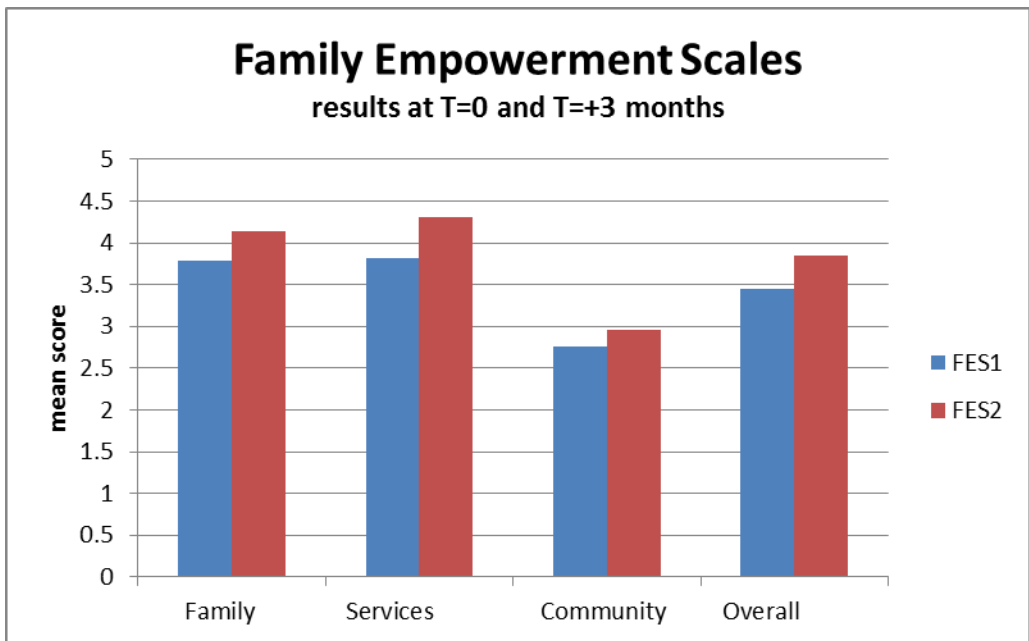
1. quantitative evaluation via review of website data
2. completion of empowerment scales
3. semi-structured interviews.



1: Evaluation of website use demonstrated that the tool was used by the majority of individuals who were given a demonstration and/or initial set-up (23/32, 72%). Average duration of use by the 23 users was 106 days (range 2-301), and many participants have continued to input data into the system after the end of the study period (from Feb 2014). Further details of website use can be found in appendix 3

2: The local champions asked the families to complete a Family Empowerment Scale [FES] (Koren et al 1992) when joining the project, and after three months. In several cases both parents choose to complete their own form independently, rather than having one response as a family. The FES can be seen in appendix 4.

Overall, FES scores from all participants showed an increased in empowerment across all three categories over time. Improvements were most marked in relation to empowerment related to the child's services, followed by empowerment related to their own family. The smallest increase was recorded for community related issues (see chart below).



3: We also assessed the impact of MyQuOL-T via semi-structured interviews with family users at the start of the project, and again after 3 months.

Initial interviews demonstrated recurring themes including ease of use of the website, rapid inputting of data, and the usefulness of the graphic display. Some families also commented on overcoming their initial fears of putting personal information on-line. Many could see the potential benefits of sharing information with health and social care professionals.

Subsequent interviews with participants who had used the tool confirmed the value of an on-going record over time, the usefulness of the tool to explore patterns or correlations in their child’s symptoms or behaviour, and the ability to share data with professional colleagues who could then provide appropriate support. See appendix 5 for further quotes from interview findings, and appendix 6 for an outline of factors influencing the use of MyQuOL-T identified during the study.

For further details of the impact of this intervention, please see case studies in Appendix 7

Part 3. Cost impact

This project was designed primarily to improve the quality of care rather than to reduce its cost. Cost measures have not been established for the MyQuOL-T project. Such cost-benefit analysis would require a much larger study examining the impact of better communication and information sharing on service access and service effectiveness (interventions, use of clinical time etc).

My QuOL-T generates an immediate visual summary of the trend over recent days/weeks for problems of greatest importance to the patient/parent, so a rapid review of the data may save significant consultation time as key areas are pre-identified, impact of interventions evident and improvement/worsening known in advance. With time, patient tailored clinical visit intervals could replace visit-by-routine. The ability to be responsive to patient need should both improve patient care, and the cost-effectiveness of outpatient services.

There will be some time requirements for staff training, but the site is quite intuitive and some patients have set themselves up to use the site without any difficulty, so it may well be that this demand on staff time is fairly minimal. Furthermore, the increased efficiency generated by more effective targeting of staff resources to patient need means that any additional demand on staff time can be recouped.

On starting to use MyQuOL-T there may be an initial increase in demand for support from healthcare providers as previously unrecognised unmet patient/family needs are brought to attention. However, the benefits from improved communications, shared decision-making and patient empowerment should ultimately result in earlier intervention and more tailored support for children and families, a reduction in treatment or interventions that do not demonstrate improvement, improved compliance with arduous treatment regimens, and an improved patient experience, so overall one could anticipate a reduction of demand for support as well-being and confidence improve. Thus overall health costs should reduce.

Unfortunately, there are perverse incentives in the current NHS funding structure as health care resourcing is often related to patient attendance rather than improvements in self-care. This sentiment has already been shared within professional meetings describing MyQuOL-T, and may regrettably limit its uptake more generally within the health service.

The website is owned by Children's Hospice South West. Running costs include webhosting fees and IT support, totalling £2960 per year. We do not anticipate charging fees for website use to patients or their carers, nor to professionals using the site for patient care. However, it does have the potential to be used for audit, research and service evaluation. This will incur additional costs as the site will need to be adapted to retain and anonymise information for these purposes, and we would anticipate covering the running costs by setting appropriate charges for this use.

Part 4: Learning from your project

The primary objective of this project was to demonstrate a more person-centred approach to care, with improvements in efficiency, effectiveness, and timeliness of support. We also wished to embed these approaches and resulting improvements into normal service provision in the future.

What went well:

- Enthusiastic support from local MyQuOL-T Champions, who were effective at persuading other hospice team members to identify prospective study participants; rapidly understood how to explain the study and the importance of gaining informed consent; were able to overcome their own concerns about their IT skills and demonstrate the tool effectively to others, and who became a valued resource for families and team members throughout the study period.
- Presentations to the full team at all sites ensured all care team members were aware of the study and could see its potential to improve care and communications with children and families using our service
- Excellent liaison with our IT partner to ensure that website design and functionality was appropriate for our families to use, and also met our requirements for data extraction.
- The project team met regularly to review progress, consider challenges as they arose, and think proactively about long-term sustainability of MyQuOL-T and dissemination of results from the outset.
- The hospice and university have strengthened an academic partnership, with UWE colleagues providing guidance, training and support for the introduction of MyQuOL-T and evaluation of its impact. Training enabled champions to have the confidence to recruit participants, conduct interviews, organise and collate questionnaire data, and review results. Several champions expressed an interest in ongoing involvement with innovation and development projects within the hospice during their study interviews. All of these support a positive approach to service development in the future, and the development of a research culture within the hospice.
- To our knowledge, use of the Family Empowerment Scale in the UK, or in hospices, has not been reported previously. We have demonstrated that it was adaptable for our purposes, sensitive enough for our needs, and acceptable to families.

What was challenging:

- We hoped to demonstrate more efficient, effective and timely provision of hospice support to families, and although there were instances of increased responsiveness to family's needs, it was difficult to demonstrate this more widely within the time frame of the project. We decided to focus on evaluating empowerment of families and qualitative feedback about MyQuOL-T use. We are satisfied that we have anecdotal evidence of improvement in their experiences both during and after using MyQuOL-T.
- Combining research work with clinical demand – the study coincided with an unprecedented increase in clinical workload at one hospice, which delayed the initial recruitment of children and families.
- Three of six Champions changed their roles within the hospice during the course of the project – one moved from clinical care to staff education, a second took on increased managerial responsibilities, and another retired from regular work, joining the nursing bank. However, their enthusiasm for the role was infectious, such that one member was quickly replaced, and another maintained her commitment to the study despite her new situation, demonstrating a very positive approach to the study.
- The hospice with the smallest caseload and staffing establishment was geographically (200 miles) and clinically more isolated than the two larger hospices. The project manager visited the larger hospices weekly in conjunction with clinical duties, and the smaller hospice every 2 months specifically for the purposes of the MyQuOL-T study. The lack of opportunity to maintain the enthusiasm and momentum in the smallest unit, which was also facing demands on staff time, is reflected in lower levels of patient recruitment and data return.

- The hospices have limited IT facilities, which had a negative impact on the study. In all units, wi-fi accessibility was almost impossible during the recruitment phase of the study, which meant demonstrating the website or setting patients up to use it whilst resident in the hospice proved very challenging. This was addressed by local champions visiting families at home, but this built-in delays and was very time-consuming.
- The population of children most likely to use the tool were those whose condition was unstable or whose treatment was changing, and this group was most likely to require emergency admission to hospital. A number of families found that these repeated interruptions to the normal pattern of their lives provided a major distraction to study participation, and although enthusiastic about the concept, it was impractical to continue to use the site.
- Engagement of professionals outside the hospice was challenging. Although there were a number of presentations at departmental meetings, and regional and national conference posters and presentations, it proved difficult to get professionals to register with the site, making it difficult to demonstrate the full potential benefits of this approach to improving communications. This issue has been identified as the focus for forthcoming work to embed MyQuOL-T in practice.

What would we do differently?

- Build in more project manager time at the more isolated and least accessed site, to maintain project momentum and maximise opportunities for recruitment and support for champions and study participants.
- Insist on fixed sessional commitment for champions from hospice management. It was difficult to protect time for project work when the challenges of staff shortages and workload demands put pressure on management, and clinical care was always prioritised over other obligations.
- Invest more in the website development, to allow full functionality of the site on tablets and smartphones. This would partly mitigate the difficulty in engagement with professionals, as it would enable families to take their child's progress charts to clinic and demonstrate the value of the data they have been recording.

Part 5. Plans for sustainability and spread

We considered it crucial to ensure the sustainability of the project within Children's Hospice South West from the outset. The creation of "Champion" posts within each hospice means that we have a cohort of experienced and enthusiastic individuals familiar with the website and willing to enrol future families, train colleagues, and sustain the use of this approach as a part of normal practice within our hospice environment. Running costs for IT support have been covered for the next two years. The MyQuOL-T tool will remain accessible to users after the duration of the SHINE 2012 study, and we would encourage families to continue to use this for as long as they wish.

Beyond CHSW, we have been actively addressing the potential for the use of this tool in other settings. From early in the project we maximised the opportunities to share this work with regional colleagues and at national meetings, such as the South West Paediatric Club, Children's Cancer and Leukaemia Group (CCLG) Friends and Family National Conference, CCLG National Scientific Meeting, and a variety of local educational events and network meetings around the country. As a result of this publicity, the core team members have been invited to attend a national meeting in April 2014 of researchers interested in using IT initiatives to support patient empowerment. This SHINE project has been accepted for presentation at the International Palliative Care Congress in Montreal in September 2014.

Other ongoing initiatives include an approach by the local MacMillan "On-Target" project for Teenage and Young Adult Cancer services, who are seeking a user-friendly mechanism for recording wellbeing, and feel that our approach fits the bill nicely – this potential use will be explored further during the spring of 2014.

A further key to future sustainability of this concept is through patient networks, such as the patient/carer support groups that exist for a variety of conditions. The project leader has already been approached by two separate groups to deliver a presentation at their local meetings, fuelled by current participants on this study who are impressed by the concept and potential benefits of MyQuOL-T and wish to share their experiences. This dissemination process may be slow, but if driven by patient demand may be more successful than direct approaches to health care professionals.

Prior to the start of this study, we were approached by the True Colours Trust to consider the potential for developing the tool to assist the provision of palliative care support in the developing world. We intend to build on the results and evidence base gained through the SHINE 2012 process to return to TCT and consider this prospect in more detail in the future.

If this concept is to be extended beyond CHSW, additional resources will be required to develop the website further to accommodate large scale use, and to inform health care professionals and patients about it.

Please attach any leaflets, posters, presentations, media coverage, blogs etc you feel would be beneficial to share with others

Appendix 2: References

Appendix 3: Website use, and examples of data input and output

Appendix 4: Family empowerment Scales: data, and questionnaire

Appendix 5: quotations from interviews

Appendix 6: Outline of Factors Influencing Use of MyQuOL-T

Appendix 7: Case studies

Appendix 8: My QuOL-T poster and sample newsletter

Appendix 9: presentation of mid-point results to Children's Cancer and Cancer and Leukemia Group Annual Scientific Conference (27/1/14, plenary session, Manchester)

Appendix 2: References and Further reading

Empowerment:

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321

Herbert, Gagnon, Rennick, O'Laughlin A Systematic Review of Questionnaires Measuring Health-related Empowerment *Res Theory Nurs Prac* 2009 23(2):107-32

Nachshen: Empowerment and Families: Building Bridges Between Parents and Professionals, Theory and Research *Journal on Developmental Disabilities* 11(1) 2005

Patient Generated Outcome Measures:

Paterson C. Measuring outcome in primary care: a patient-generated measure, MYMOP, compared to the SF-36 health survey. *British Medical Journal* 1996 312:1016-20.

McGee H, O'Boyle C et al. Assessing the quality of life of the individual: the SEIQoL with a healthy and a gastroenterology unit population. *Psychol Med* 1991 Aug; 21(3) 749-59

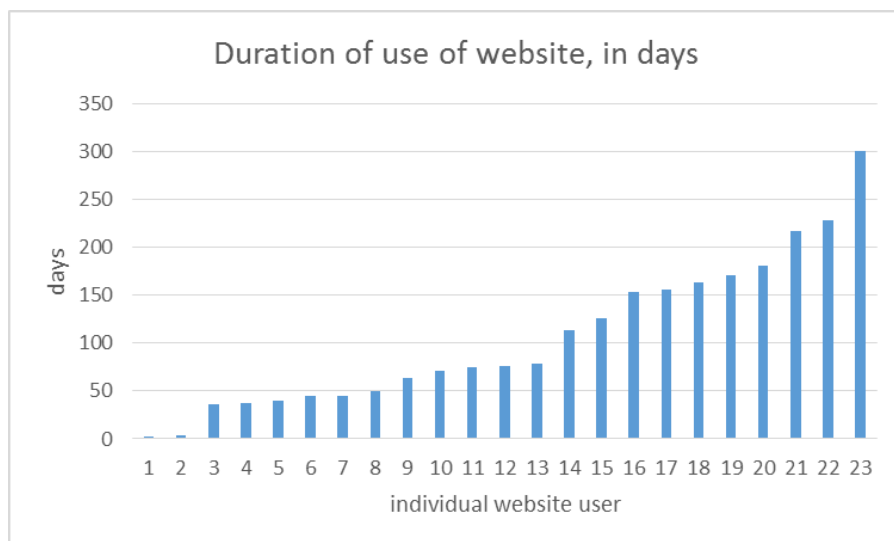
Ruta DA Garratt AM et al. A new approach to the measurement of quality of life. The Patient-Generated Index *Med Care* 1994 Nov;32(11):1109-26

Appendix 3 – Data from Evaluation of Website Use

32 study participants registered on MyQuOL-T site and identified priorities

23 participants used site to monitor their identified priorities

Average duration of use = 106 days (range 2-301)



Non users: 9

- 4/9: child in and out of hospital so inconsistent access to site
- 3/9: too busy
- 1/9: computer “out of action” so internet access difficult
- 1/9: withdrew from study

Priorities identified: 114 in total, by 32 families

Most families chose 2 or 3 parameters to record (range 1-15)

Parameters were created or modified using free text in 37/114 (32%)

Scales were personalised using free text in 64/114 (56%)

The most common parameters within this study group were:


- Seizures: 24/32
- Constipation: 9/32
- Pain: 6/32
- Sleep problems: 6/32

Sharing access: 26/32 identified and shared access with a healthcare professional

- Most commonly, 2 professionals with access, most commonly hospice medical and nursing staff.
- Range 1-8, including children’s community nurses, clinical nurse specialists, consultants, social workers.

Website Use in Practice:

1. Example of data input page: having identified the priorities, the bar and descriptors act as a visual analogue scale, with the descriptors changing when the button is moved. The smiley faces are based on the Wong-Baker faces chart for use with young children, and change appropriately in tandem with the sliding bar scale.



My QuOL-T
My life, my measure

[Links](#) [Check In](#) [Charts](#)


How are you today?


Set levels for your priorities and check in


Details

Date

Priorities

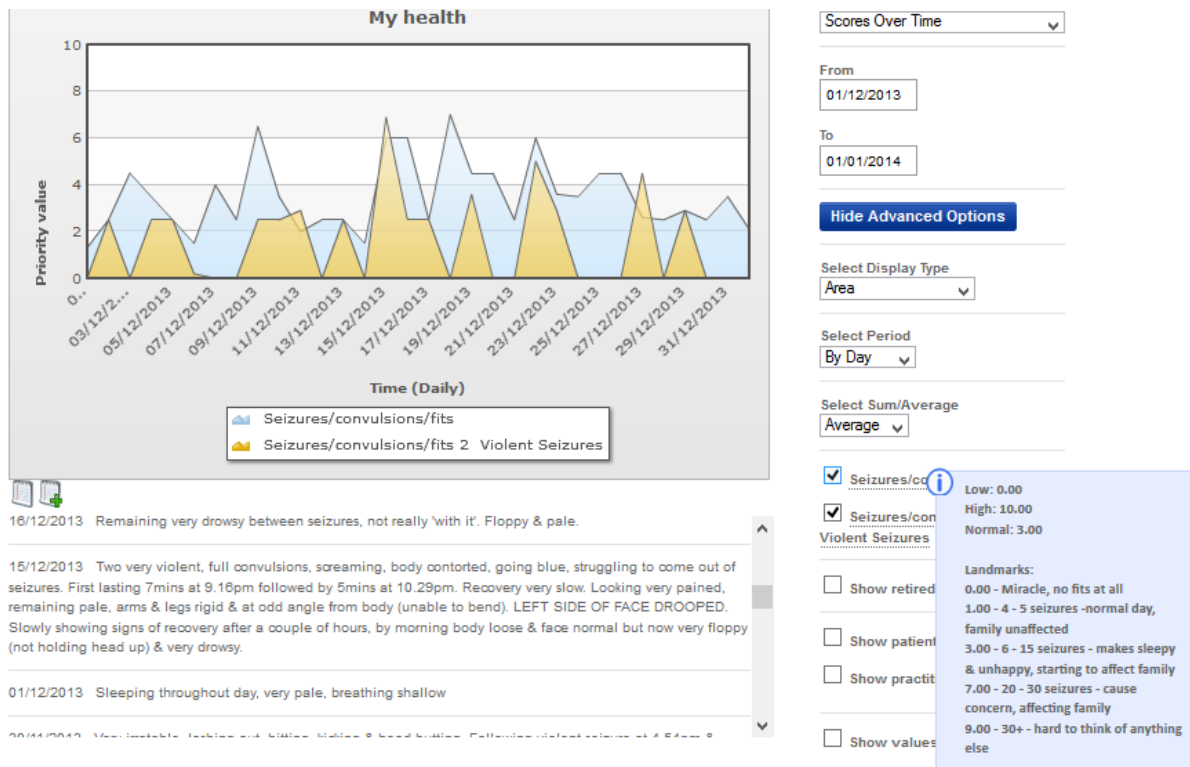
Breathing problems 
short of breath on exertion, recovering fully at rest

Loss of independence 
Severe - need assistance for daily tasks

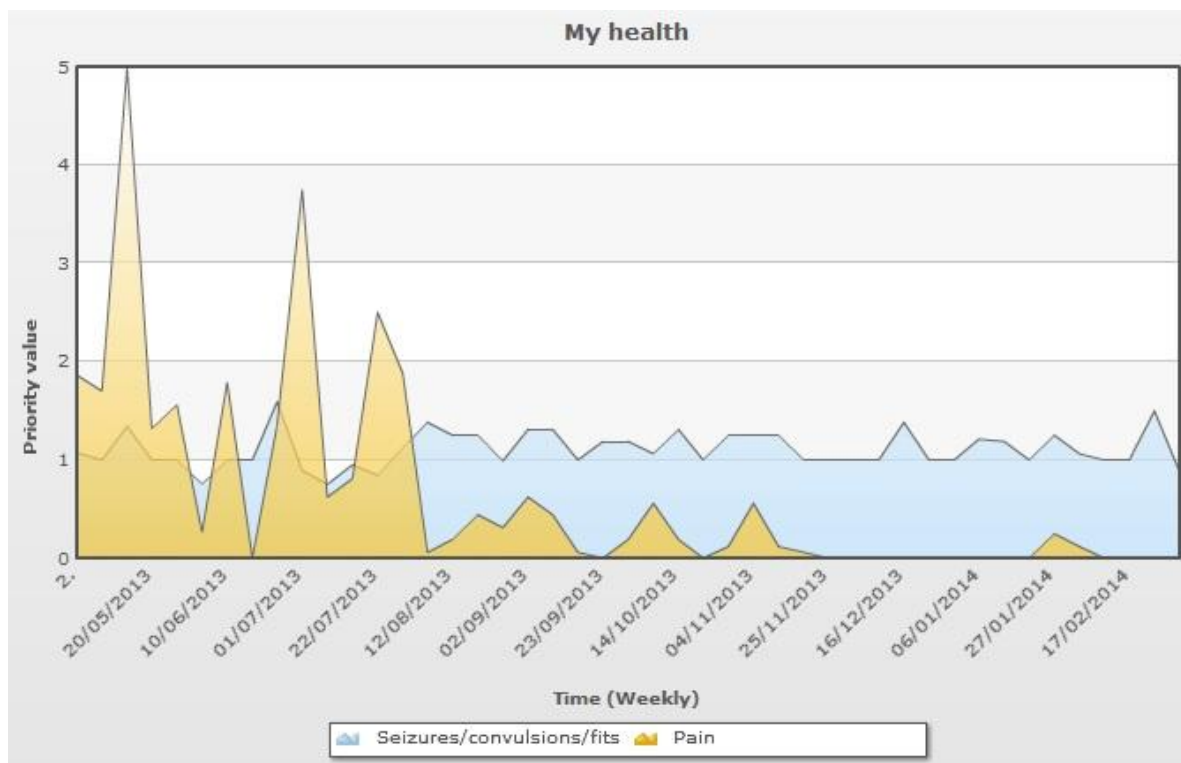
Anxiety 
Moderate, gets in the way of doing normal things

2. Example of personalised scales and use of diary notes to add detail:

This little girl with severe learning difficulties and epilepsy had two different types of seizure, described and quantified by her mother on the personalised scale shown below. The diary notes add significant detail. This level of information helps the hospice staff to prioritise support for families when life at home becomes particularly stressful or exhausting.



3. Example showing graphic output display: for this teenager with severe neurodisability, pain control and seizures were both problematic. Her mother felt uncertain whether pain exacerbated seizures, or seizures caused exacerbation of pain, but was convinced that the two were related. Pain management was initially very challenging, but it became clear over time that this could be controlled, and exacerbations of pain and seizures were not linked. Her neurologists continue to struggle with effective seizure control, but parents report that her quality of life has improved as her pain has largely settled.



Appendix 4

Study Code.....

Date.....

FAMILY EMPOWERMENT SCALE

These questions ask about several areas of your life—your family and your child’s services. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer “Never”. Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking of your own situation. Feel free to write any additional comments at the end and write on the back if you need more space.

<i>ABOUT YOUR FAMILY...</i>	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
1. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child’s disorder.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5
<i>ABOUT YOUR CHILD’S SERVICES...</i>	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
13. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
14. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
15. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
16. I am able to make good decisions about what services my child needs.	1	2	3	4	5

17. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
18. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
19. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
20. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
21. I know what services my child needs.	1	2	3	4	5
22. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
23. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
24. Professionals should ask me what services I want for my child.	1	2	3	4	5
ABOUT YOUR INVOLVEMENT IN THE COMMUNITY.	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
25. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
26. I get in touch with my MP when important legislation or policy issues concerning children are pending.	1	2	3	4	5
27. I understand how the service system for children is organized.	1	2	3	4	5
28. I have ideas about the ideal service system for children	1	2	3	4	5
29. I help other families get the services they need.	1	2	3	4	5
30. I believe that other parents and I can have an influence on services for children.	1	2	3	4	5
31. I tell people in agencies and government how services for children can be improved.	1	2	3	4	5
32. I know how to get agency administrators or legislators to listen to me.	1	2	3	4	5
33. I know what the rights of parents and children are under the special education laws.	1	2	3	4	5
34. I feel that my knowledge and experience as a parent can be used to improve services for children and families	1	2	3	4	5

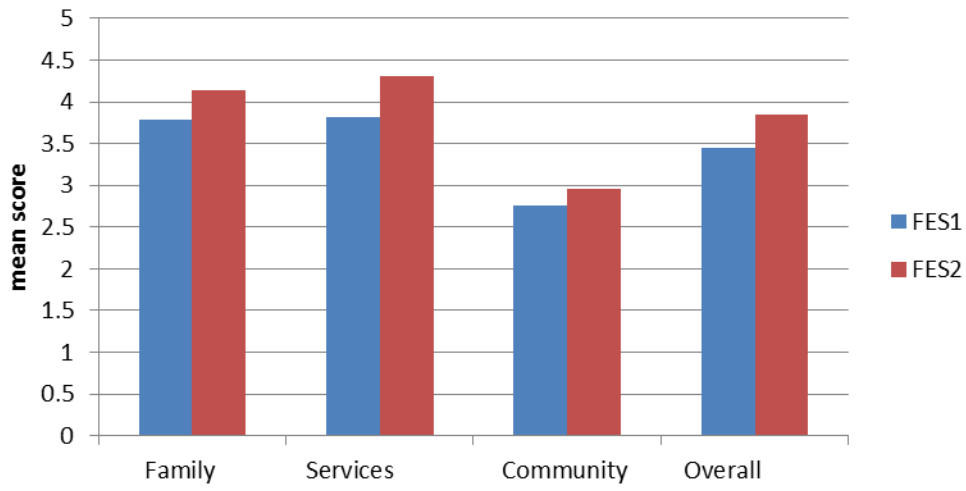
COMMENTS _____

Appendix 4 – Family Empowerment Scales data

Study ID	FES1				FES2			
	Family Q1-12	Services Q12-24	Community Q25-34	Overall Q1-34	Family Q1-12	Services Q12-24	Community Q25-34	Overall Q1-34
CF01	4.08	3.75	4.3	4.03				
CF02	3.25	3.75	2	3.05				
CF02	2.75	3.58	1.9	2.79				
CF04	3.6	4.8	3	3.88	4.5	5	3.1	4.26
CF05	4.33	4.41	2.1	2.23	4.25	4.83	3.4	4.2
CF06a	4.58	4.83	4.6	4.67	4.91	5	4.7	4.88
CF06b	3	3.4	3.5	3.29				
CF07	4.5	3.25	2	3.32	4.66	5	2.2	4.19
CF08	4.58	4.33	2.8	3.97	4.83	4.66	2.9	4.2
CF09	4.5	4.25	4.4	4.38	4.75	4.58	3.9	4.44
CF10	3.16	2.41	1.7	2.47	3.91	3.58	2.8	3.47
CF11	3.25	3.33	1.8	2.85	4.08	4.16	2.7	3.7
CF12	3.66	3.66	3	3.47				
CF13	4.16	4.08	3.1	3.82	4.08	4	3.3	3.82
CF14	4.08	4.66	2.3	3.76	4.16	4.25	2.4	3.67
CF15	4.41	4.25	2.5	3.79				
CF16	4.33	3.27	1	2.69				
CF17	2.75	2.33	2	2.38				
LBH01	2.66	3.95	3.9	3.57	3.41	4.5	4.1	4
LBH02	2.25	2.8	1.3	2.28	2.75	3.58	1.9	2.79
LBH05	4.08	3.75	2.4	3.52	4.25	4.25	2.7	3.79
LBH06	4.5	3.3	1.2	3.11	4.5	3.58	1.6	3.32
LBH07	4.08	4.6	2.5	3.95				
LBH08	3.83	3.83	3.9	3.85	4.08	4.58	3.4	4.05
LBH10	3.75	4	4.5	4.05	3.83	4.08	4.3	4.05
LBH11	3.75	3.91	3.4	3.7	3.5	4.5	2.3	3.5
LBH13	4.66	3.75	2	3.55	4.08	3.75	2.4	3.38
LBH14	3.91	4	2.3	3.47	4	4	2	3.41
LBH18	3.83	3.75	2.5	3.41				
LH01	3.33	4.5	4.8	4.17				
total	113.6	114.48	82.7	103.47	78.53	81.88	56.1	73.12
Mean	3.79	3.82	2.76	3.45	4.13	4.31	2.95	3.85
Median	3.455	3.815	3.05	3.45	3.83	4.29	3.3	3.835
Mode	4.08	3.75	2		4.08	5	3.4	4.2

Family Empowerment Scales

results at T=0 and T=+3 months



Appendix 5: Key quotes from interviews

1. Ease of use of MyQuOL-T:

“Very easy to set up, using it every day. I enjoy using it, and it is easier than phoning someone to tell them how (my daughter) has been. It’s quick, I do it in the evening. I’m on the computer doing my emails anyway, and a few minutes to do this is fab. Very easy to use, and I am not a technical-type person” (Parent A 10)

“I use it every day. It was easy to add a new priority after we started. Also easily used by respite carers” (parent B11)

“I set up a reminder on my phone, and do it every day. I will definitely continue after the study is over. I am glad I joined in (the study)” (parent A1)

2. Empowerment:

“It has made me quite confident, so I can phone up and say “look we’ve had a bad few weeks with (her) pain” whereas before I wouldn’t do that, I would just sit and suffer.” (Parent A10)

“Really helpful, it helps to highlight (my daughter’s) needs both to us and to others” (parent B11)

“This has given us the courage to say, look, we’re doing this, you’ve got to listen to us” (parent B10)

“It gives you the weight, it gives you the backing when you can see something in black and white and show them and say look, this shouldn’t be happening, because without monitoring it they’ve only got your hearsay, your word, for how things are going” (parent B1)

3. Communication:

“I’m not good at phoning and asking for help. I don’t want to think that (my daughter)’s that bad that she needs it. But if they can see what is going on (at home), it’s good if people phone you, it’s easier to accept help than to ask for it.” (parent A13)

“Useful to allow others to see what’s going on with her at home, I don’t think when you tell the doctors they really understand. And you can see when she’s having a run of good days too, and that’s great.” (parent B11)

“I wanted it to “put away” how things have been, rather than carry that information around in my head” (parent A11)

“It helps to get organised, so much better than the scraps of paper we used to have in the past” (parent B6)

“Looking at the graph has given us clues about what is going on in her world” (parent B10)

“The MyQuOL-T email alerts trigger a phone call from (the hospice) team and they talk things through with me, very useful” (parent A10)

4. Clinical Impact:

“Very good to see patterns. Took the graphs to the doctors, showed when we started a new medicine and her seizures went up, and then when she came off they came back down again, really self-explanatory. Showed it to (Dr X), it made a difference because he managed to take her off that medicine and start a new one.” (parent C5)

“My community nurse is registered on it and that proved very useful – she can see things and will call me up, and also she was able to take the graphs to get an extra night’s support from continuing care panel because they could see “the medical evidence”. (parent A10)

“It was very useful to see progress over months with the graph – I hadn’t realised how things had all settled down over that time, and how that related to his VNS (vagal nerve stimulator)” (parent A5)

“We could see correlation between starting the patch (for pain relief) and improved sleep for (our daughter), and the impact this has had on the whole family.” (Parent A2)

“I am using it as online diary (for bowel movements and increased picosulphate in response) – “when you see it in black and white, you do actually know what is happening.” (parent B10)

Appendix 6 – Outline of Factors Influencing Use of MyQuOL-T

Factor	Positive influence	Negative influence
1. Inputting data	<p>Establishing a routine for data entry.</p> <p>Having an easy to access platform e.g. using a mobile device</p> <p>Feeling the priorities chosen are meaningful.</p> <p>Having the support of a local Champion.</p>	<p>Not getting started.</p> <p>Poor or interrupted internet access.</p> <p>Being away from home e.g. during a hospital admission.</p> <p>Forgetting password.</p> <p>Not being able to see charts and therefore so not getting the reinforcement of a visual display.</p> <p>Having a system that already works well enough, e.g. diaries.</p>
2. Child's condition	<p>A long-term condition where there are symptoms which can be described and represented by the sliding scale priorities within a predictable range.</p>	<p>An episode of severe illness.</p> <p>A period of stability where the condition does not change – meaning there is no change to report.</p> <p>Where there is no further treatment identified or available, for example when the 'terminal' palliative phase is entered.</p>
3. Level of coping resources	<p>Managing day to day.</p> <p>Ability to ask for and readiness to accept help.</p>	<p>Feeling overwhelmed by demands and unable to take on anything more.</p>
4. Relationship with health professionals	<p>If family trusts the professional and thinks they can help.</p> <p>Where the tool helps coordinate communication e.g. between school and home or between carers and parents.</p> <p>When professionals initiate contact having received an alert.</p>	<p>Feeling of being a nuisance so not wanting to ask for help.</p>

<p>5. Perceived value of MyQuOLT-T; to child, to self and to health professionals</p>	<p>To child: Where the parent feels a therapy, treatment or service will be made available for their child if they can provide evidence for its need. E.g. VNS or extra respite care.</p> <p>Where the parent feels it gives them an insight in to the child's world.</p> <p>To self: To find patterns and links between symptoms and behaviour.</p> <p>To help represent their child's needs to others.</p> <p>To provide a summary of their child's condition over time, rather than as a snapshot.</p> <p>To have somewhere to record information and prevent worrying about forgetting it.</p> <p>Feeling that it bolsters courage and confidence.</p> <p>When it offers positive feedback and helps parents 'notice the good days'.</p> <p>To health professionals: If professionals sign up to the system and opt to receive alerts.</p> <p>If professionals show an interest in the information generated.</p>	<p>To child: Where the parent feels that there are no treatment options that can be offered.</p> <p>Where the parent feels the child may be upset by completing the scale.</p> <p>To self: When not 'getting anything from it' – new information or insights.</p> <p>When completing is 'a chore'.</p> <p>When regarded as too 'simplistic'.</p> <p>To health professionals: Passive: if professionals show no interest</p> <p>Active: if professionals discourage use.</p>
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Appendix 7 – case studies

Case study #1

A is now 11 years old, and suffered pneumococcal meningitis in infancy. She recovered but was left with significant hypoxic neurological deficit, such that she now has severe learning difficulties, frequent seizures, and spastic quadriplegia. She cannot swallow safely and so is fed via gastrostomy, but has frequent aspirations and resulting chest infections necessitating hospital admission. She is a very vulnerable child, and is totally dependent on others for all care.

A's mother started to use My QuOL-T to record her seizures on a 1-10 scale, with her normal defined as a score of 2, with 6-8 fits per day. During the summer, A's seizures increased steadily despite increases in her usual medication, and with resulting poor sleep, and leading to increasing levels of maternal depression.

The graph of her average seizure frequency (fig 1) was shared with her children's community nurse, who used it to support mother's request for additional respite care provision funded by the local authority. This was granted at the end of August, and although seizure control remained challenging, the impact on mother's mental state and ability to care for her daughter at home is clearly visible, and sustained, on the MyQuOL-T graphs (fig 2).

Case study #1, Figure 1 -

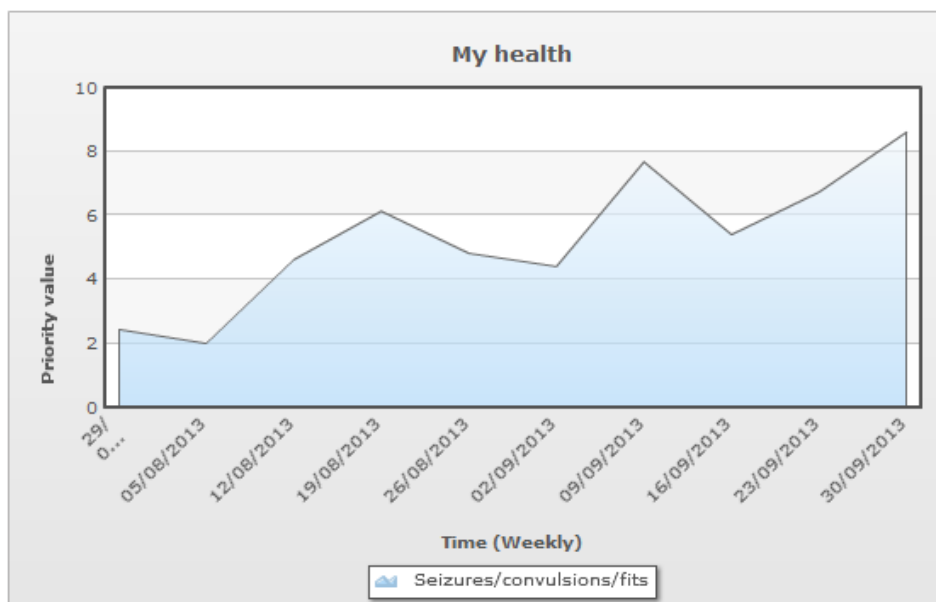
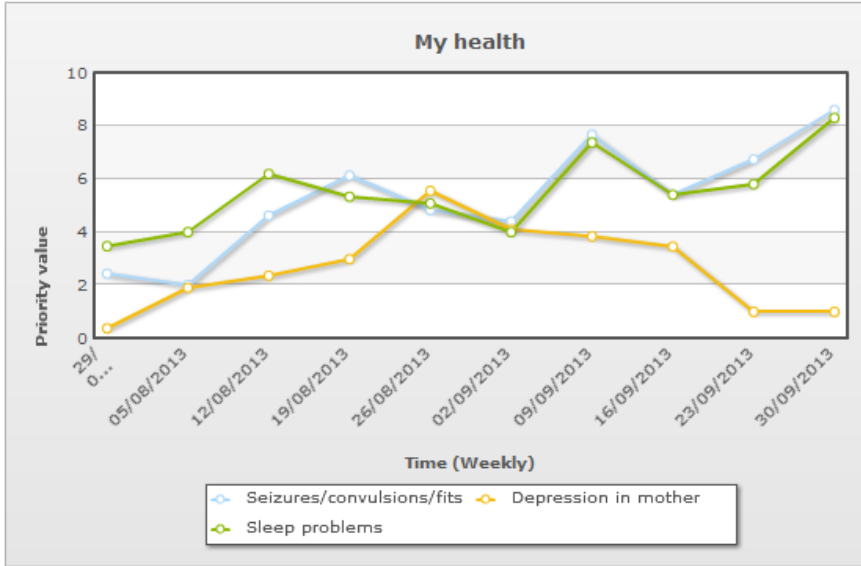


Fig 2: ongoing impact of increased social care support

My QuOL-T
My life, my measure

[Links](#) [Choose Patient](#)

265B94C3 Charts

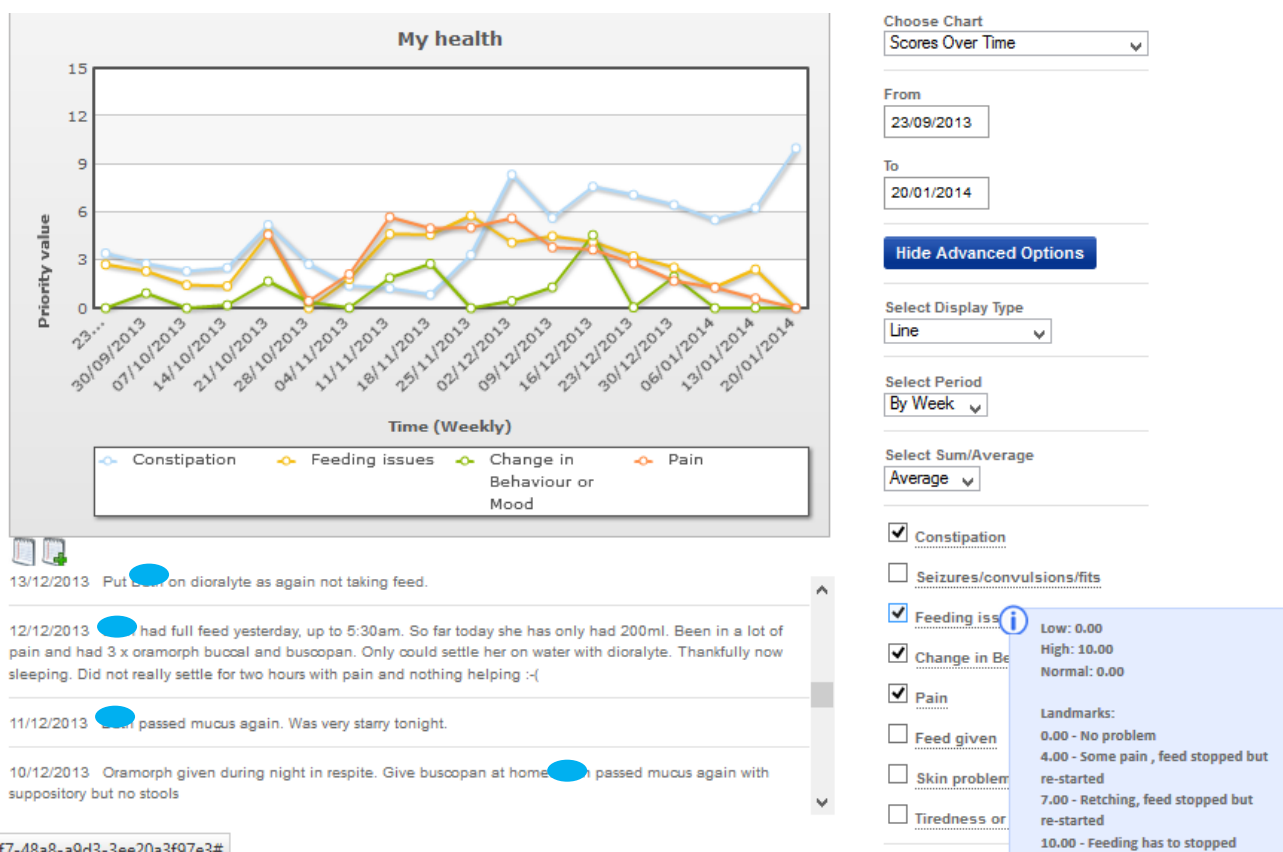


Case study #2

B is a 22 year old with cerebral palsy, severe learning difficulties and epilepsy, and longstanding problems with nutrition and feeding. She is now having increasing episodes of pain, but has been difficult to determine the cause of this, potential causes including gut dysmotility, constipation, and pain from contractures or musculoskeletal causes. She has variable mood, seeming unsettled at times, but it was not clear if this was simply in response to pain, or to other influences. She has been losing weight.

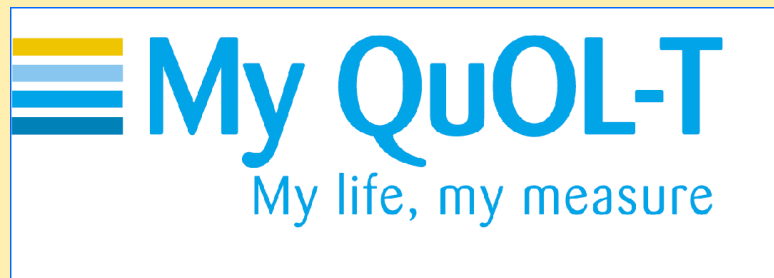
Her mother started to use MyQuOL-T to record her feeding and bowel activity, and look for correlation with pain. Over time it became clear that the pain scores more closely mirrored feeding problems than constipation, and that changes in her mood or behaviour were unrelated to anything to do with her gut. Ongoing management has focussed on trying to maximise her feed intake by adjusting feed rates and constituents, and managing her constipation with appropriate laxative use, but addressing environmental causes of her mood changes through appropriate sensory activity. She remains thin, but her weight has stabilised.

This figure shows the patterns of correlation over time. The diary notes give additional detail concerning her day-to-day care.



She remains cared for at home, with intermittent support from the hospice whilst in transition to adult services. As she is not a frequent attender in our unit (due to her age), the ability to support her via MyQuOL-T and monitor her progress has been helpful to her mother, and ensures ongoing continuity of care.

Appendix 8 – MyQuOL-T 5 steps poster and newsletters

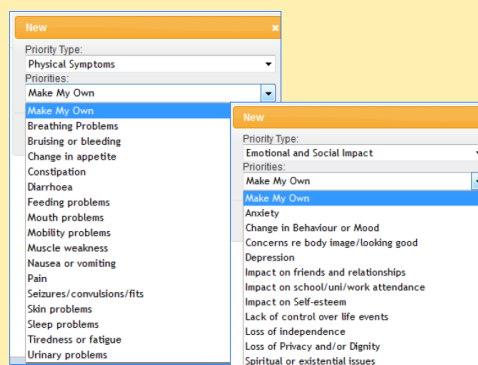


AN INNOVATIVE WAY TO IDENTIFY, DESCRIBE, MONITOR AND SHARE WHAT MATTERS MOST TO YOU OR YOUR CHILD, AND YOUR FAMILY

1. IDENTIFY YOUR PRIORITIES:

Ask yourself:

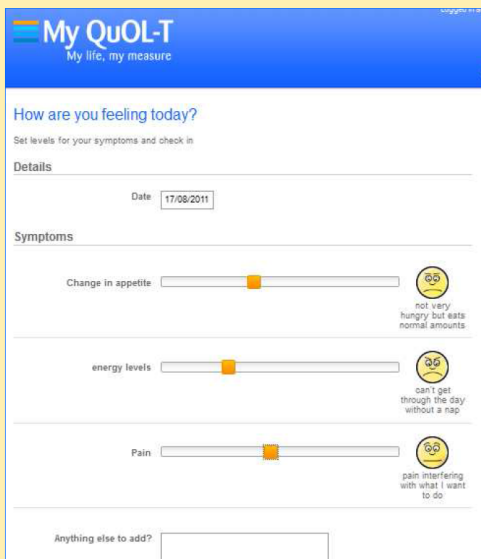
- “WHAT IS AFFECTING MY QUALITY OF LIFE THE MOST?”
- “WHAT COULD BE IMPROVED THAT WOULD MAKE THE BIGGEST DIFFERENCE TO ME, OR MY FAMILY?”
- “WHAT IS STOPPING ME FROM DOING WHAT I WANT TO DO TODAY?”



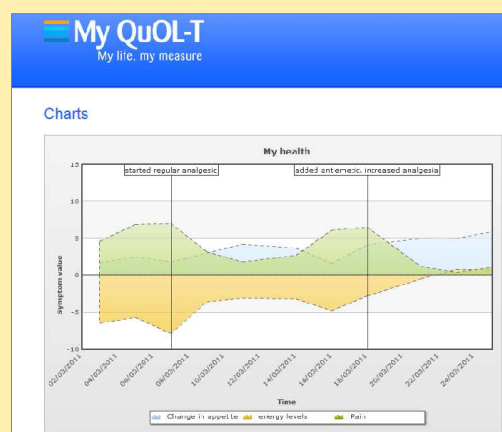
2. DESCRIBE HOW MUCH IMPACT IT HAS ON YOU OR YOUR FAMILY

3. CHECK-IN AND RECORD HOW YOU FEEL EVERY DAY

0.00	Not at all
1.00	Slightly - but not bothered by this
3.00	Moderately - limits some activity or concentration
7.00	Severely - markedly affects activity or concentration
9.00	Overwhelmingly - unable to think of anything else



4. MONITOR CHANGES OVER TIME



5. SHARE YOUR CHARTS WITH YOUR HEALTHCARE TEAM, OR KEEP THEM PRIVATE—IT'S UP TO YOU

CREATED by Dr Nicky Harris, IT SUPPORT by Agile Medeware, MY QuOL-T is owned by Children's Hospice South West

Meet the team:

Project lead

Dr Nicky Harris, CHSW

Local Champions:

Little Bridge House:

Jess Oliver & Rosie Hosford

Little Harbour:

Nicola Isbell & Berny Morcom

Charlton Farm:

Chris Baird & Sarah Norman

Core Project Management Team

Dr Nicky Harris, Palliative Care Paediatrician, CHSW

Dr Antonia Beringer, Senior Research Fellow, UWE

Prof Margaret Fletcher, UWE & University of Bristol

Josh Helmink, Agilemediaware (web design and IT support)

For further information, contact

nicky.harris@chsw.org.uk

Welcome to the SHINE "My Quality" Study Newsletter, April 2013.



Calling all families attending CHSW hospices!

- Is this you? Jumping through hoops, juggling your child's needs and trying to keep everything on the go?
- Do you keep a diary to keep track of everything? Or an A4 folder?!
- Does your computer act as a lifeline to the outside world?



If this sounds like you, please keep reading!

My QuOL-T is a new development which evolved from listening to the experiences of people attending our hospices. Children and their immediate family members are best placed to know what makes the biggest difference to their quality of life. This web-based programme allows you to identify, describe in your own language, and monitor the priorities that make the most difference to your family's wellbeing, and you can share these with your hospice support team should you choose. The system is free, confidential, controlled by you the user, and currently under evaluation as part of the SHINE programme (see below.)

If you would like to join us in this attempt to improve the service we provide, please contact anyone on the list to your left.



From Left: Berny Morcom, Nicola Isbell, Chris Baird, Jess Oliver, Antonia Beringer, Nicky Harris, Sarah Norman, Rosie Hosford.

SHINE Study Update: Against tough competition, we secured funding from the Health Foundation in November 2012 as part of their SHINE programme for innovation in healthcare. We were the only successful hospice-based application in the programme, and one of only 4 projects specifically supporting children's services, so we were delighted! The study involves using My QuOL-T for as long as you wish, and an informal interview and questionnaire at the start and 3 months later about your experience, and whether or not you found it useful. We will be seeking 40 families to take part in the study over the next 6 months, and the first few have already agreed to take part. If you would like to participate, please talk to your CHSW contacts, or one of the SHINE My QuOL-T champions at your local hospice. Thank you!



Appendix 9 –presentation of mid-point results to National Children’s Cancer and Leukaemia Scientific Meeting, 27.1.14, Manchester Conference Centre.

[2014 Manchester CCLG.ppt](#)