

Innovating for Improvement

Guided Online Self-Help for Cancer and
Depression in Adolescents (GOSH CAN)

Great Ormond Street Hospital



About the project

Project title: Guided Online Self-Help for Cancer and Depression in Adolescents (GOSH CAN)

Lead organisation: Great Ormond Street Hospital

Partner organisations: Institute of Child Health, Macmillan Cancer Support, London Cancer, University College London Partners and University College Hospital London.

Project lead/s: Dr Anna Coughtrey and Prof Roz Shafran

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Part 1: Abstract

Background

Depression in young people with cancer is common but neglected. Every year over 2000 young people aged 13-24 years are diagnosed with cancer in the UK. These young people have an increased risk of depression following diagnosis, and throughout treatment and remission. However, depression often goes undiagnosed and evidenced based psychological therapies are rarely provided. There is evidence that guided self-help, including online cognitive behavioural therapy (CBT) is an effective low-intensity treatment for mild-to-moderate depression in young people, but such interventions are not routinely used in paediatric cancer services. This project will enable vulnerable young people to access high quality, evidence based psychological therapies that improve depression and quality of life.

Aim

The aim of this project is to improve the recognition and care of the mental health needs of young people with cancer through the development and continual iterative testing of a guided online self-help treatment package. The package provides evidence based guidance for the self-management of depression and is delivered online so that adolescents can access treatment on wards, from home or in between appointments.

Setting

The initiative was implemented in collaboration with Great Ormond Street Hospital, the young people's cancer service at University College London Hospital, and CLIC Sargent. It was delivered by a multidisciplinary group of research and clinical staff and the development and use of the website was driven by significant input from young people and clinical staff.

Learning and impact

During the set-up phase we held three focus groups with key stakeholders to ensure that we held shared goals and aspirations for the project. This work helped us identify the key areas of potential for the project (improving access, normalising symptoms and providing information and support, and reducing loneliness and isolation) whilst also identifying potential barriers including risk management, suitability of the package for young people with terminal diagnoses and involvement of parents.

One of the challenges we faced was gaining the support of the local NHS clinical team, and this initial scoping work was crucial in identifying areas of concern in order to have open conversations about the aims and scope of the project. This was done through 20 in-depth interviews with members of staff to better understand their reservations and scope areas of collaboration. The results of this work were then subsequently discussed with the local NHS clinical team, and are currently being written up for publication in a peer-reviewed journal. From these findings we mutually agreed that the intervention package would not be suitable for implementation at UCLH

where there is a great deal of support from multidisciplinary teams for young people with cancer. Instead, from our interviews with young people and their families, we identified a greater need for our intervention package through third sector organisations such as CLIC Sargent, who offer support to young people who often live far from face-to-face services or those who do not have access to a young people's cancer service. This was a significant point of learning for us, which shifted our efforts from implementing our intervention at UCLH to working more closely with CLIC Sargent and Macmillan to scope key areas of implementation.

Although there are evidence based self-help materials for the treatment of depression, the overall aim of the project was to develop an online treatment package. The website was developed using a plan-do-study-act (PDSA) approach by making iterative improvements to the website with significant input from the users. The intervention is now live as a website and can be shared with young people. The intervention is unique in its content and structure. Although the intervention is based on cognitive behavioural therapy (CBT) principles, the content has been significantly modified with examples suggested by users, including blog posts written by one user. From the qualitative data on the use of the intervention, we have also found that the users preferred a flexible pick-and-choose style of delivery, which allows for more ownership and empowerment of the user, than the linear approach traditionally offered in CBT.

In the initial stages of the project we anticipated that the most important learning would be to demonstrate pre-post effectiveness in terms of reduction of distress after using the website. The evaluation of the intervention was done using quantitative pre-measures and post-measures collected from 19 users. On average, the users reported lower levels of distress and low mood and anxiety after using the website. However, there is large variability between participants, and the small sample size does not allow for valid interpretations of statistical comparisons.

Throughout the course of the project, we have discovered that although evaluation of pre-post distress is relevant, evaluation of the usefulness and acceptability of the project is more meaningful and important as it provides information about how access does/does not work and will ensure that the website is sustainable beyond the lifespan of the project.

Overall, throughout the course of this project, we have learned that there is a need and scope for our intervention. Users have reported positive feedback on the idea and the delivery of the intervention. Therefore, we aim to continue conversation with third sector charities to work on the sustainability of the intervention website.

Key learning points:

- Sufficient time and resources are needed in the development phase in order to create a shared vision across all stakeholders and to ensure any reservations or concerns are adequately addressed.
- The greatest potential for the successful implementation of an online intervention is to use it as a *first step* in treating depression.

- It is important to implement the intervention in a setting where the need is greatest, and it may be necessary to adapt implementation strategies during the lifespan of the project.
- Evaluation of usefulness and acceptability are more meaningful than more traditional pre-post evaluations of outcomes in order to ensure sustainability.

Part 2: Progress and outcomes

Summary of Development Work

The development of a website of self-help resources for young people with cancer and depression was led by clinical psychologists at Great Ormond Street Hospital (Professor Roz Shafran and Dr Anna Coughtrey) and at University College London Hospital (Professor Deborah Christie) along with significant input from medics including Dr Rachael Hough. We were also supported throughout the project by advisors from the Quality Improvement team at Great Ormond Street Hospital and in the initial stages received input from University College London Partners.

In the first phase of the project, our main focus was on the *development* of an innovative solution to improve access to evidence based interventions for depression for young people with cancer. We worked closely with young people, families and professionals to develop an online package for mild mood difficulties through experience based co-design. It is delivered online and based on cognitive-behavioural therapy principles. The intervention is modular so that young people can focus on the topics most relevant to their individual needs. The package consists of the following eight modules:

- Learning about the distress (psychoeducation about depression, normalising symptoms and discussing the links between depression and cancer)
- Problem solving (with cancer relevant examples)
- Doing something to feel better (activity scheduling)
- Relaxation and mindfulness (with links to other resources and including video/audio recorded scripts)
- Thinking differently
- Self-esteem and body image
- Plans for coping
- Managing the future

The content of the modules was based on the MATCH-ADTC protocol (Chorpita & Weisz, 2009), which we adapted to be used for guided self-help and to be used online using PDSA methodology.

The key adaptations we have made to the guided self-help materials have been to personalise them e.g. through including cancer-specific examples. This is important because it suggests that the approach itself (e.g. helping young people increase daily activities, and identify and address unhelpful cognitions) does not need to be specific to cancer. This has important implications for spread as it suggests that we can generalise the findings to other long term physical health conditions.

Therapist guidance was provided to young people throughout the intervention via telephone calls, texts, instant messages or email according to patient preference.

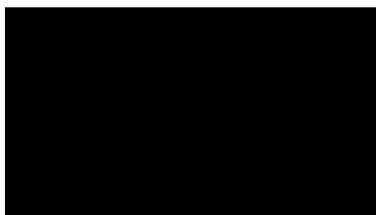
Qualitative Evaluation of Website Development

We conducted three focus groups and twenty individual interviews with staff and one focus group and 20 individual interviews with young people with cancer. In order to engage with a range of professionals and services, we interviewed the following staff groups: psychiatrists and clinical psychologists, clinical nurse specialists, ward nurses, play therapists, oncologists and haematologists, and professionals from third sector organisations.

A summary of the key themes emerging from this data is included in appendix 1. The main message was to 'keep it simple' and use the website as a basic first step that may lead to young people accessing face-to-face support. In general, young people and staff thought that the modules focusing on problem solving and doing something to feel better were likely to be more valuable than thinking differently, which may not be as relevant for this population.

Young people and staff also suggested a number of interesting and important avenues which the intervention could include in the future. These included: a forum (carefully monitored), a high degree of interaction, modules on the fear of relapse and death and dying, sexuality and relationships and a strong narrative component, including a video diary which would allow young people to record their experiences along the cancer journey. As a team we agreed that although these are important aspects, they have traditionally fallen outside of evidence-based practice. We therefore linked out to existing resources in these areas rather than creating new materials to address these issues. Although the intervention itself could include modules on these topics in the future these would potentially need further evaluation.

Video of Development Work



Evaluation for Measuring Impact

During the evaluation of impact phase we conducted a case series of 19 young people aged between 13 and 24 years used the website to evaluate it's impact on their low mood. Participants completed validated, widely used self-report measures of depression, mental health and quality of life before and after their use of the website. The measures were selected because they are routinely used in mental health services and in oncology settings and included the following:

- The Distress Thermometer: This is a validated measure included as part of the holistic needs tool for people with cancer (Cancer Action Team, 2007).

Patients are asked to rate their distress on a scale from 0-10 and indicate the areas which are most significantly causing them distress. The distress thermometer was completed by all participants.

- Participants over the age of 18 completed a measure of low mood (the PHQ-9) and anxiety (GAD-7) routinely used in adult improving access to psychological therapies services.
- Participants under the age of 18 completed two measures of depression and anxiety (SDQ and RCADS) which both form part of the minimum data set for mental health services for children and young people.
- Quality of life was assessed using the Peds QL for participants under the age of 18 and the WSAS for participants over the age of 18.

Traditional models of psychological therapy have required patients to complete a set number of treatment sessions covering topics in a sequential format. More recently, there has been a move towards modular interventions whereby patients and therapists decide collaboratively which topics are most appropriate and in which order they should be completed, which in turn improves outcomes. To reflect this shift in practice, participants in this project were not restricted in their use of the website. Therefore participants completed a range of topics in varying order.

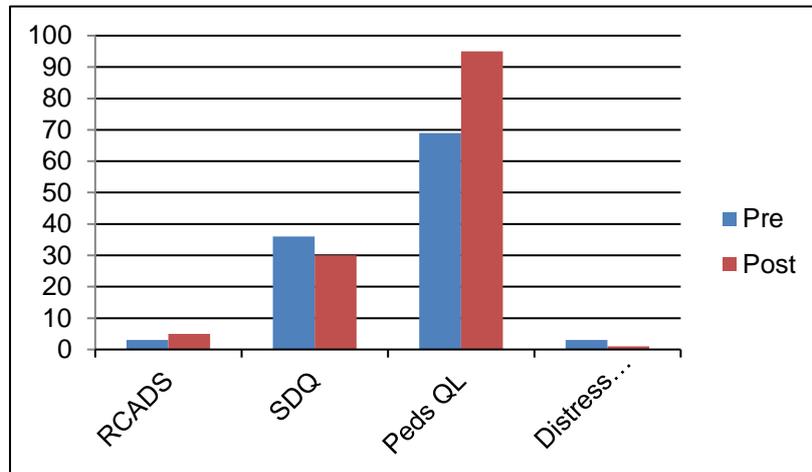
Results of Case Series

To date 19 participants have used the website and 16 have completed post-measures (three participants are currently continuing to use the website). The majority of participants reported some improvement in mood following use of the website, however as the case illustrations demonstrate, change in pre-post scores was sometimes variable and difficult to delineate from changes in physical health.

More meaningful, and of interest, is the qualitative data and data on the usefulness of the website. In particular, it is of note that participants used the website in a range of ways – some choosing to complete all modules on a weekly or fortnightly basis whereas others selected the most appropriate modules and completed them in a shorter time period. The most popular modules were: doing something to feel better (37%), relaxation (27%), problem solving (18%), and learning about distress (18%).

Case 1: Matthew

Matthew is a 15 year old boy with a diagnosis of leukaemia in remission. Matthew completed two modules of the website over 11 weeks: 'doing something to feel better' followed by 'managing the future.' His pre and post scores on the measures are shown below.

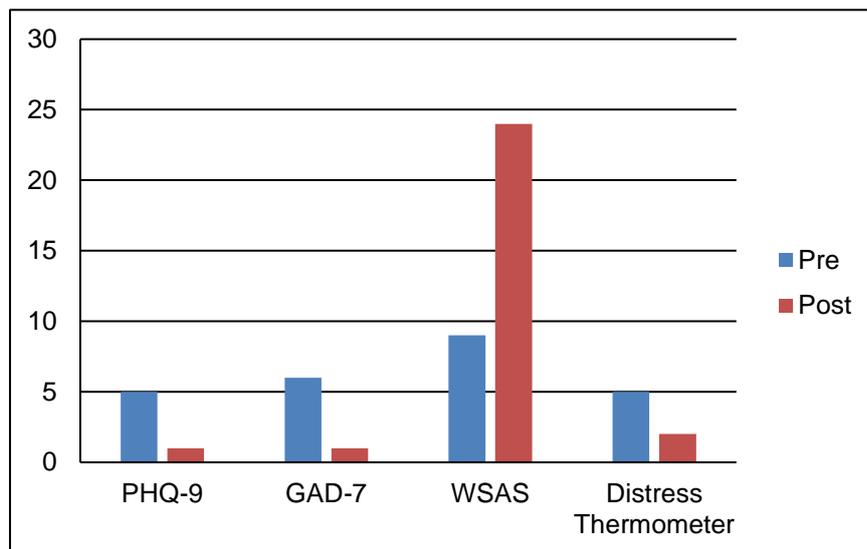


Matthew reported slight improvements in mood (demonstrated by a reduction in scores on the SDQ and Distress Thermometer) and an increase in quality of life (demonstrated by an increase in scores on the Peds QL).

Matthew gave the following feedback: *“it helped me think of things to do apart from the same thing over and over to change my mood.”* He said that the least useful aspect was “thinking of the things to do myself as sometimes when in a low mood I can’t be bothered to think of things to do” and suggested it would be helpful to *“offer pre-selected things to do as well as the activity sheets where you can think of your own things to do.”*

Case 2: Matilda

Matilda is a 20 year old Female with a diagnosis of acute lymphoblastic leukaemia in maintenance. Matilda completed eight modules of the website over 8 weeks in the following order: 'learning about distress', 'problem solving', 'doing something to feel better', 'relaxation', 'thinking differently', 'self esteem and body language', 'plans for coping' and 'managing the future'. Her pre and post scores on the measures are shown below:

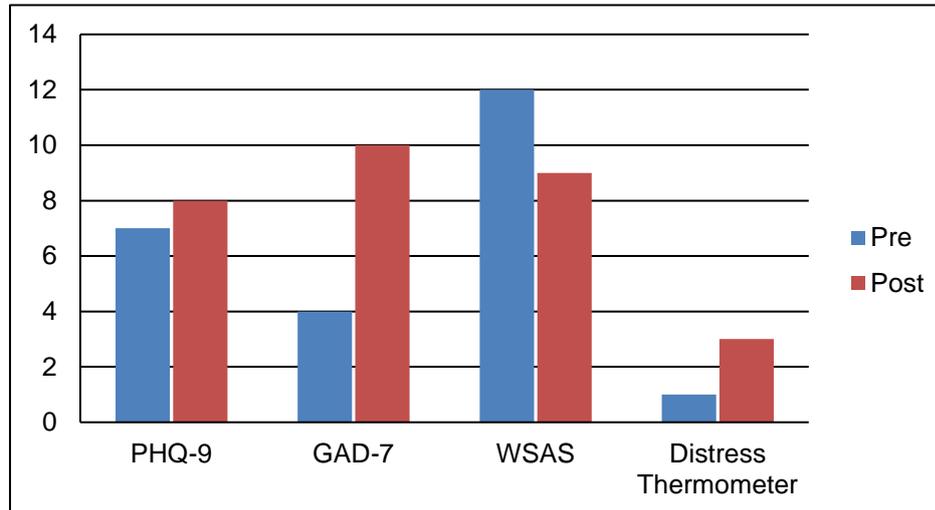


Matilda reported improvements in mood and general anxiety (demonstrated by a reduction in scores on the PHQ-9, Distress Thermometer and GAD-7) and an increase in quality of life (demonstrated by an increased scores on the WSAS).

Matilda gave the following feedback: *"If there's anything that bothers me, I will try and refer back to what I learned."* She said *"I wish I would have had access to [the website] sooner as I was going through the intense part of my treatment because you know, there are times when you're sat in the hospital and it would be something to cure the boredom but something that is helpful at the same time."*

Case 3: Sally

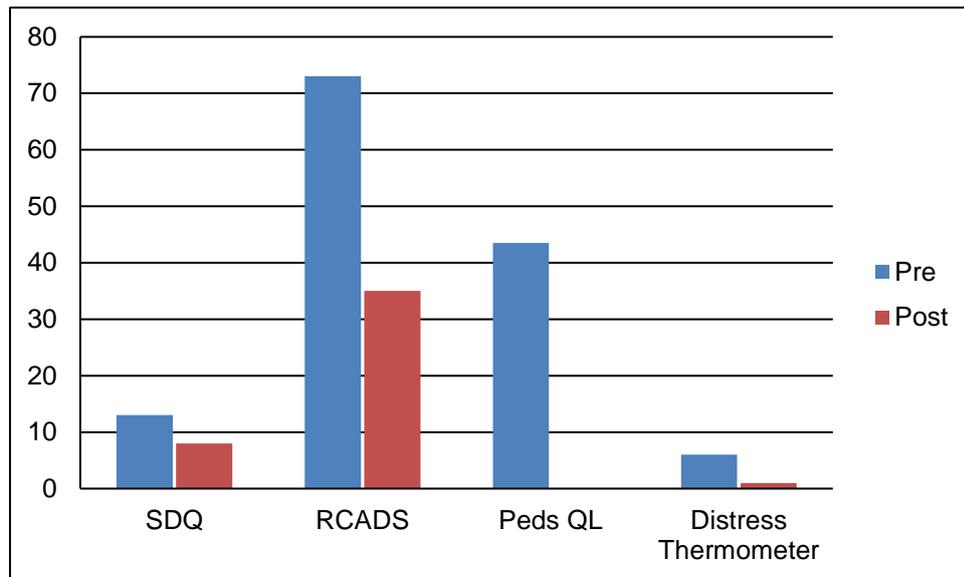
Sally is a 19 year old Female with a diagnosis of Hodgkins lymphoma in remission. Sally completed eight modules of the website over 19 weeks in the following order: 'learning about distress', 'problem solving', 'doing something to feel better', 'thinking differently', 'plans for coping', 'managing the future', 'relaxation' and 'self esteem and body image.' Her pre and post scores on the measures are shown below:



Sally reported an overall deterioration in mood and general anxiety (demonstrated by an increase in scores on the PHQ-9, GAD-7 and Distress Thermometer) and in quality of life. Sally explained that this was in part due to a deterioration in her physical health and explained that she may have had greater benefit from the website had it been offered to her sooner. She said she valued the focus on practical things she could do to address low mood: *"[The best thing was] that it was useful long-term and simple to do. It doesn't try and diminish the importance of the problem but gives practical things to do about it."*

Case 4: Rachel

Rachel is a 17 year old young woman with a previous diagnosis of acute myeloid leukemia. Rachel had received the 'all clear' prior to starting using the website. Rachel completed eight modules of the website over seven weeks in the following order: 'problem solving', 'thinking differently', 'relaxation', 'plans for coping', 'managing the future', 'doing something to feel better', 'learning about distress', and 'self-esteem and body image'. Her pre and post scores on the measures are shown below:

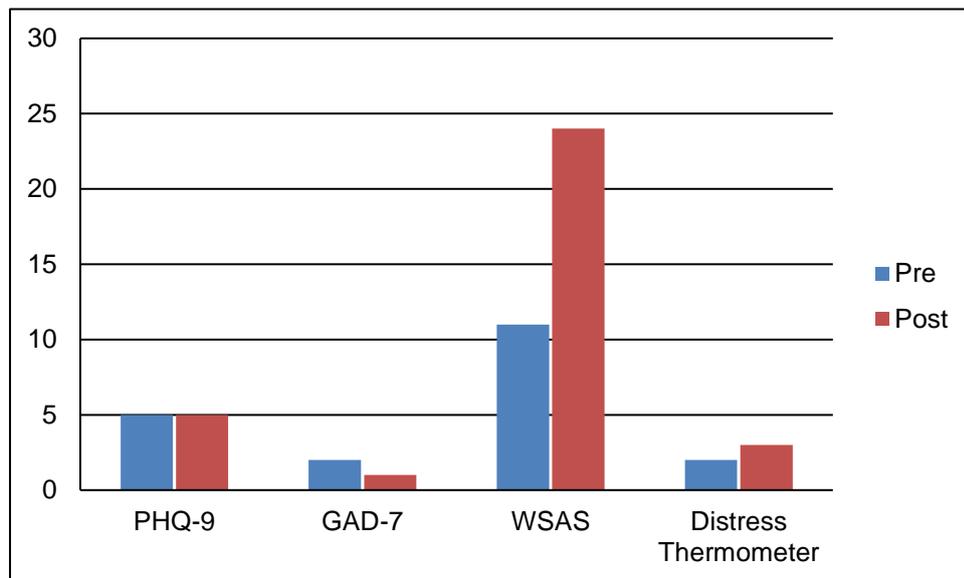


Rachel reported an overall increase in mood (demonstrated by a decrease in scores on the SDQ, RCADS and Distress Thermometer). Unfortunately Rachel did not complete the Peds QL following completion of the website so impact on quality of life cannot be assessed.

Rachel gave the following feedback about the website: *“Using the website helped me to reflect on how, when I was going through my diagnosis and my treatment.... how I could have looked at things in a different way.”* She explained: *“When I was going through my treatment I just sort of had a routine. But the website made me think that, if I had the website when I was going through my treatment, there were different things that I could actually do, to improve my mood, rather than just sort of getting stuck in a cycle of waking up and think ‘oh I’ve got this to do today’ and ‘this is gonna happen’.”*

Case 5: Mike

Mike is a 24 year old young man with a diagnosis of Burkitt's lymphoma in remission. Mike completed 7 modules of the website over thirteen weeks in the following order: 'Self esteem and body image', 'doing something to feel better', 'thinking differently', 'plans for coping', 'learning about distress', 'managing the future' and then repeated 'doing something to feel better.' His pre and post scores on the measures are shown below:

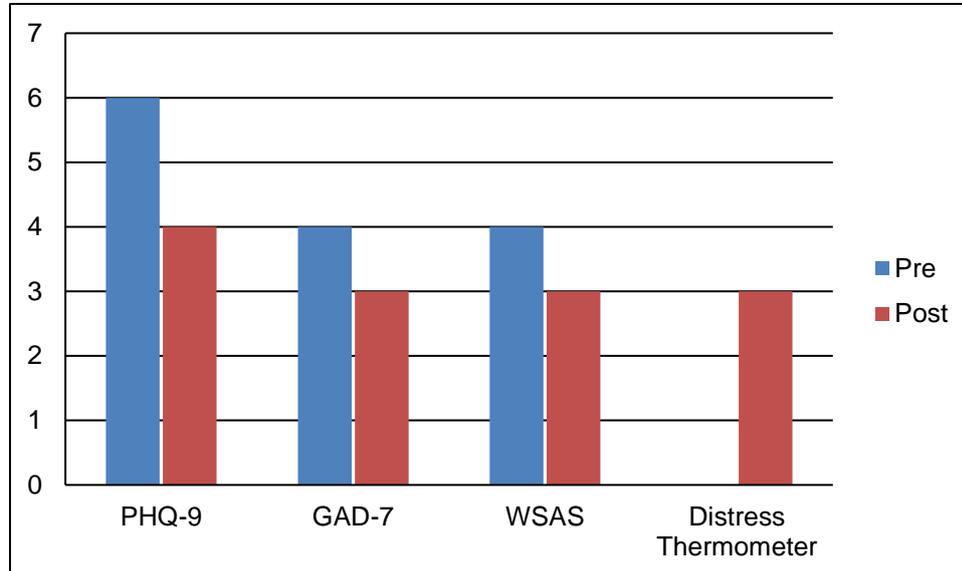


Mike reported minimal changes in mood (demonstrated by a small increase in scores on the distress thermometer, a small decrease in scores on the GAD-7 and no change in PHQ-9 scores). However, Mike reported an increase in quality of life (demonstrated by an increase on the WSAS).

Mike gave the following feedback *"I liked the scenario in the beginning where the person DECIDED to be more positive."* However, *I'm not completely sure if I agree that positivity and happiness is always a decision in every situation. It will be somewhat unfair to ask a cancer patient who may be in severe pain to smile more and act more happy as it might just not be possible for them.* He suggested that the module could be improved by *"[writing] somewhere to highlight that it's okay if a cancer patient isn't feeling positive or finding it difficult to do positive acts."*

Case 6: Emily

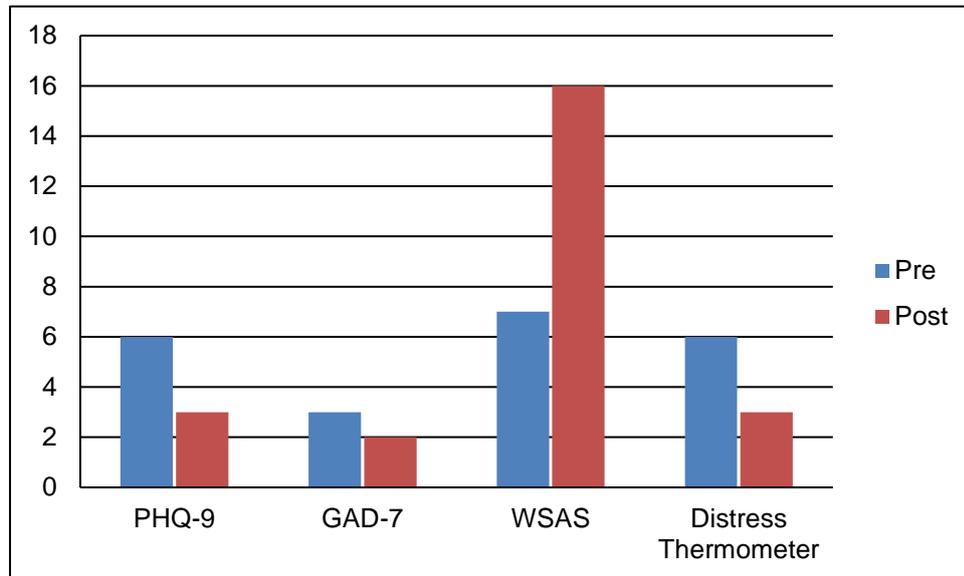
Emily is a 19 year old Female currently undergoing treatment for Hodgkins lymphoma. Emily completed one module of the website over 4 weeks: 'Self esteem and body image'. Her pre and post scores on the measures are shown below:



Emily reported an improvement in mood over the four week period (demonstrated by a decrease in scores on the PHQ-9 and GAD-7). However, contrastingly, she reported an increase in distress (demonstrated by an increase in scores on the Distress thermometer) and a decrease in quality of life which could potentially be attributed to her decrease in physical functioning during treatment. She gave the following feedback on the module she completed: *'The video on how to carry yourself in conversation to show a positive attitude and present yourself in a happy and interested manner was particularly helpful. The key points on what acting sad and down highlights why people should want to try to be happy were most useful. I also like that acting happy was related to any other skills such as math, because it is a skill to harness.'*

Case 7: Danielle

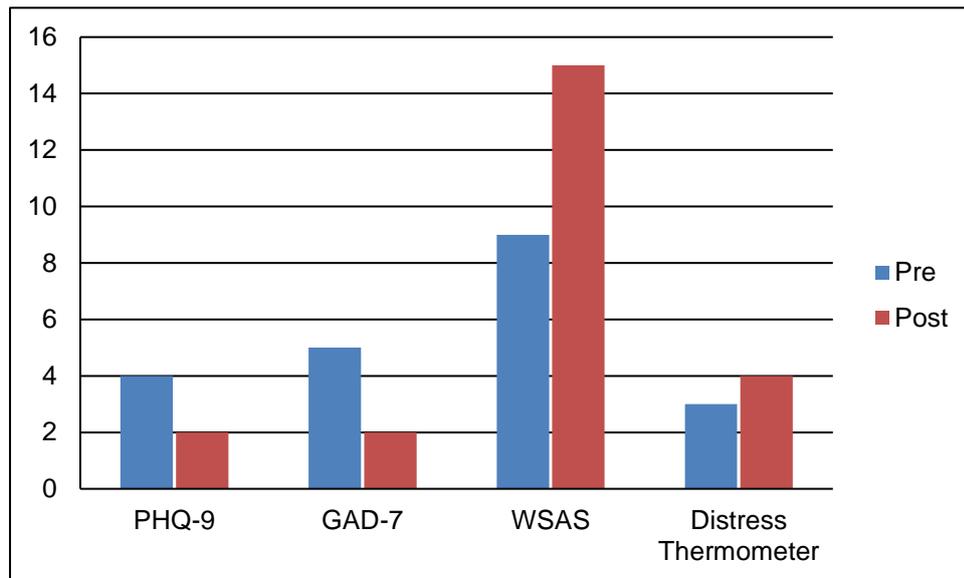
Danielle is a 22 year old Female with a diagnosis of Craniopharyngioma in remission. Danielle completed the following two modules of the website over five weeks: 'Learning about distress' and 'problem solving.' Her pre and post scores on the measures are shown below:



Danielle reported a general improvement in mood (demonstrated by a decrease in scores on the PHQ-9, distress thermometer and GAD-7) and increase in quality of life (demonstrated by an increase in scores on the WSAS). Danielle explained that she found the thinking-feeling-doing section most helpful as 'it made me think about how when in a negative mood everything becomes negative and spirals.'

Case 8: Sam

Sam is a 20 year old young man with a diagnosis of osteosarcoma who used the website following completion of treatment. Sam completed eight modules of the website over 4 weeks in the following order: 'learning about distress', 'problem solving', 'doing something to feel better', 'relaxation', 'thinking differently', 'self-esteem and body image', 'plans for coping' and 'managing the future.' His pre and post scores on the measures are shown below:

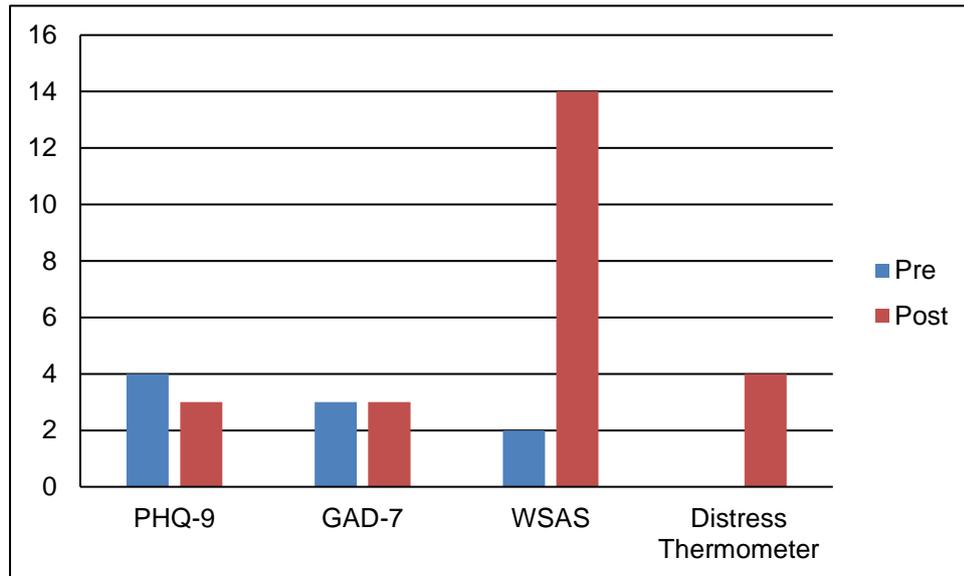


Sam reported an improvement in mood (demonstrated by a decrease in scores on the PHQ-9 and GAD-7), and quality of life (demonstrated by an increase in scores on the WSAS). However, he indicated a slight increase in distress (measured by the distress thermometer). This may be in part due to facing some difficulties in reintegrating into everyday life following completion of chemotherapy.

ES gave the following feedback about the website: *"it was most useful and well structured. It's very easy to use, understand and much more interactive and that's good especially for new generations of boys and girls."*

Case 9: Mia

Mia is a 24 year old young woman with a diagnosis of Hodgkins lymphoma in remission. Mia completed eight modules of the website over four weeks in the following order: 'learning about distress', 'problem solving', 'doing something to feel better', 'thinking differently', 'self-esteem and body image', 'plans for coping', 'relaxation' and 'managing the future.' Her pre and post scores on the measures are shown below:

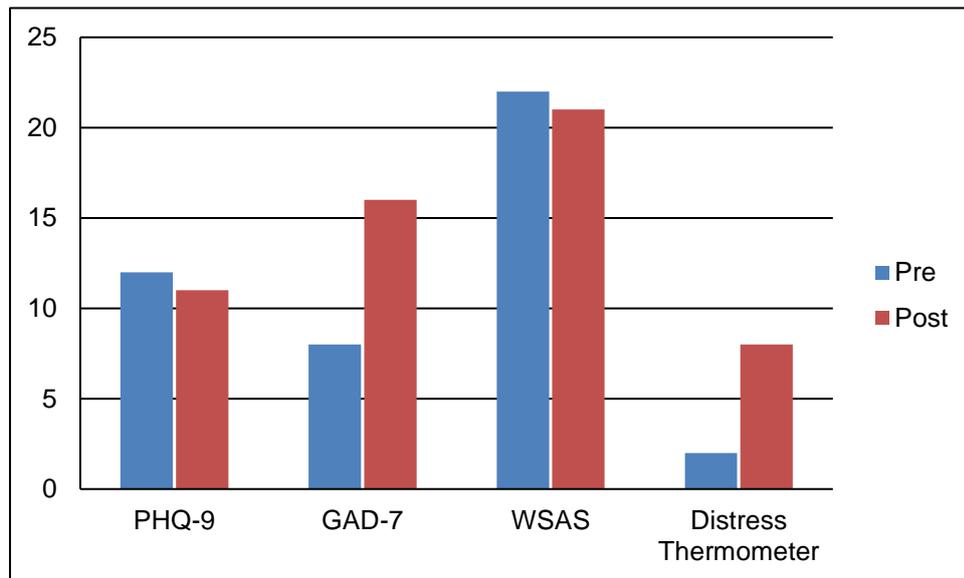


Mia reported a slight improvement in mood (demonstrated by a decrease in scores on the PHQ-9) and a large increase in quality of life (demonstrated by an increase in scores on the WSAS). However, Mia also reported an increase in distress (demonstrated by the increase in score on the distress thermometer).

Mia explained that the most useful component of the website was: *"The comparison between my thoughts, feelings and actions when I am in a good mood vs. a bad mood. It was good to see them directly compared - it made me question why I should allow my behaviour to change at all!"*

Case 10: Irene

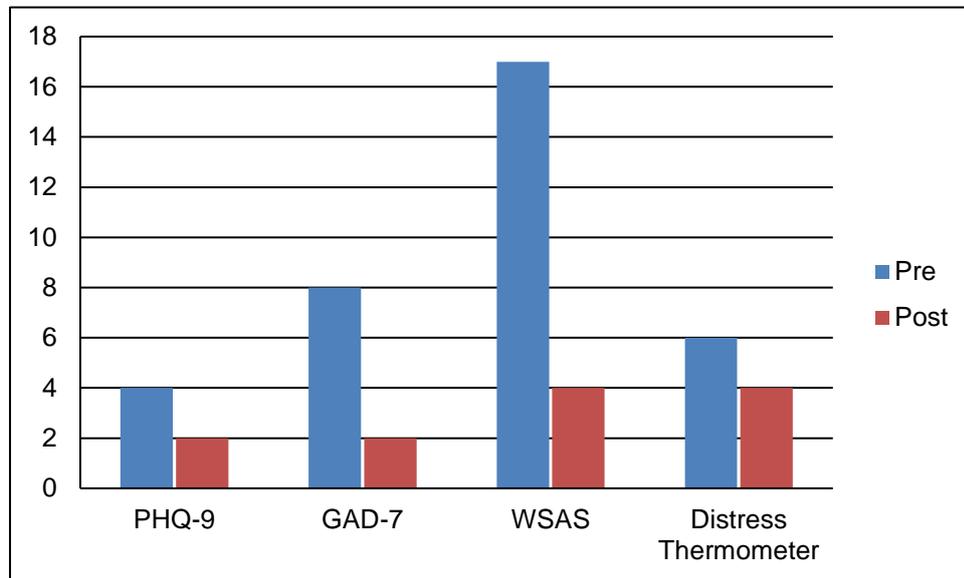
Irene is a 20 year old Female with a diagnosis of Hodgkins lymphoma. She had finished treatment when she started using the website and was told she was in remission when she completed the post-measures. Irene completed two modules of the website over three weeks in the following order: 'learning about distress' and 'problem solving.' Her pre and post scores on the measures are shown below:



Irene reported a slight improvement in depression (demonstrated by a decreased score on the PHQ-9), however, she reported an increase in distress (demonstrated by an increase in scores on the distress thermometer) and also an increase in general anxiety (demonstrated by an increased score on the GAD-7). In general Irene explained that she would have preferred face-to-face input for her difficulties. However, she said: *"the solutions to the bad feelings were really good."*

Case 11: Louise

Louise is a 24 year old young woman with a diagnosis of Rhabdomyosarcoma in 5 year remission. Louise completed two modules of the website over six weeks: 'learning about distress' and 'problem solving.' Her pre and post scores on the measures are shown below:

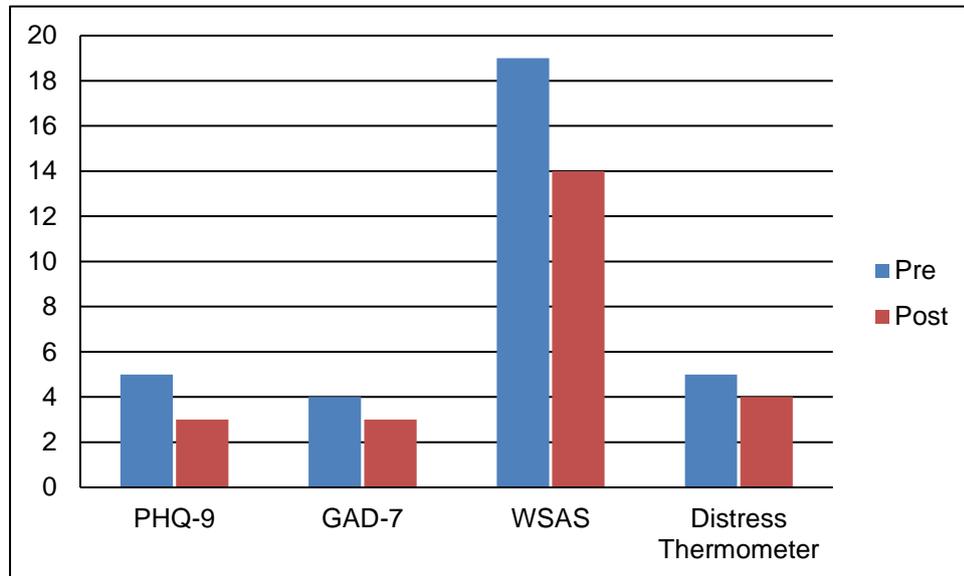


Louise reported a general improvement in mood (demonstrated by decreased scores on the PHQ-9, distress thermometer and GAD-7) but also a large decrease in quality of life (demonstrated by a reduced score on the WSAS).

Louise gave the following feedback about the intervention being online: *“I was a bit sceptical at first. Without the face to face contact you feel like you’re doing it on your own but actually because it was talking about young people with cancer, it felt very targeted and personal in that way. And I found it much easier than I thought I would and much more able to do.”*

Case 12: Mark

Mark is a 21 year old young man currently receiving treatment for Oligodermoglioma. Mark spent one week using the website focusing on only one module: 'managing future.' His pre and post scores on the measures are shown below:

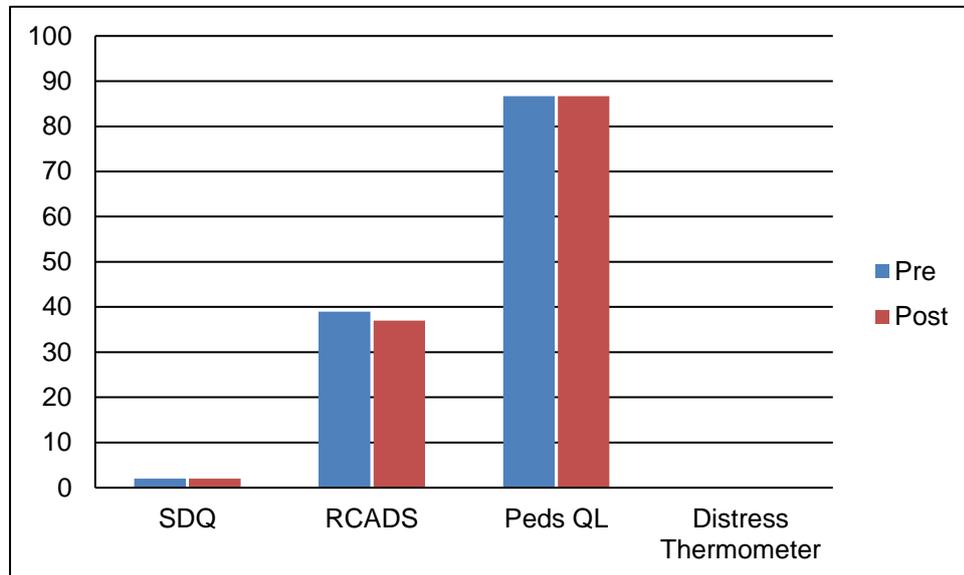


Mark reported an improvement in mood (demonstrated by decreased scores on the PHQ-9, distress thermometer and GAD-7). However, Mark also reported a decrease in quality of life (demonstrated by a reduced score on the WSAS) related to a decrease in functioning due to the limiting factors of cancer treatment.

Mark explained: *"[The course] would be good as an addition to [face to face]. So it'd be good for somebody to begin on the website and then have somebody to talk to afterwards....I think at that stage people they obviously have a lapse between their treatment at some point and the initial diagnosis where they might begin to think too much about the problem and become distressed so if they had something like a website to then prepare them for the treatment and sort of build up their self-esteem about the problem then it would be most helpful instead of in between treatments."*

Case 13: Jack

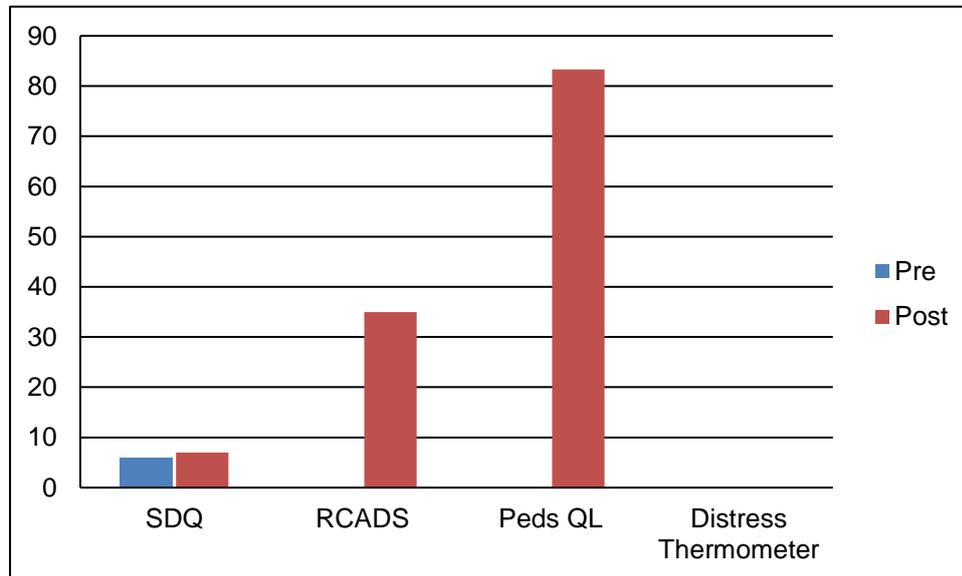
Jack is a 13 year old boy with a diagnosis of malignant rhabdoid tumour. Jack is currently in long-term follow up and completed the 'relaxation' module of the website only. His pre and post scores on the measures are shown below:



Jack reported no change in any of the measures. This may be because Jack only completed one module of the website; however he appeared to value learning about relaxation techniques: *"It was great to be given the opportunity to practice using the video as well as with recordings. I really really liked this module."*

Case 14: William

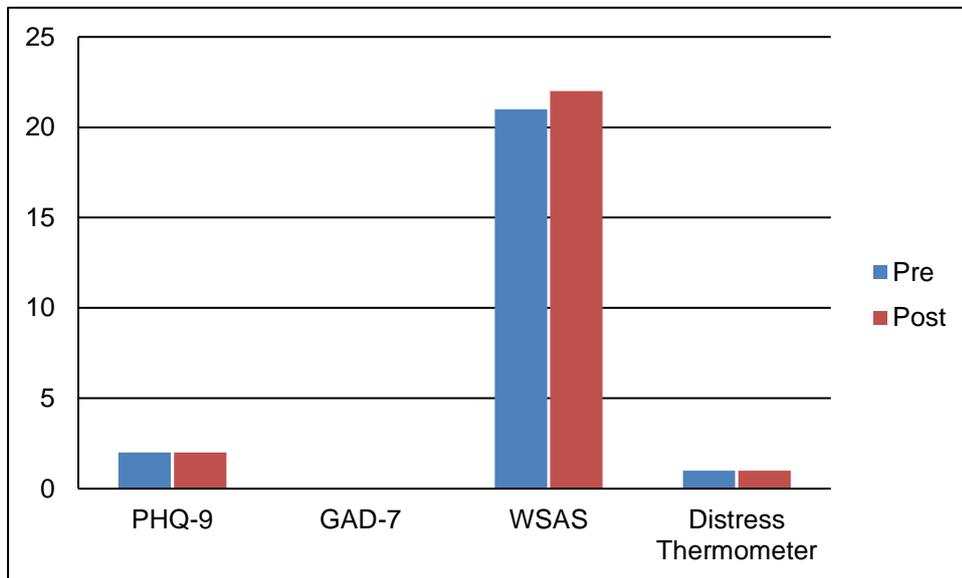
William is a 15 year old boy with a diagnosis of Rhabdomyosarcoma. William is currently in long-term follow up and completed the relaxation module only. His pre and post scores on the measures are shown below:



William reported no change in the SDQ or Distress Thermometer and did not submit pre-measures were taken for RCADS or the Peds QL. The lack of change may be due to low levels of distress at the start of treatment. William gave the following feedback following completion of the module: *"[the relaxation module] made you concentrate on a place which you would relate to being relaxing which was helpful in being calm."*

Case 15: Harry

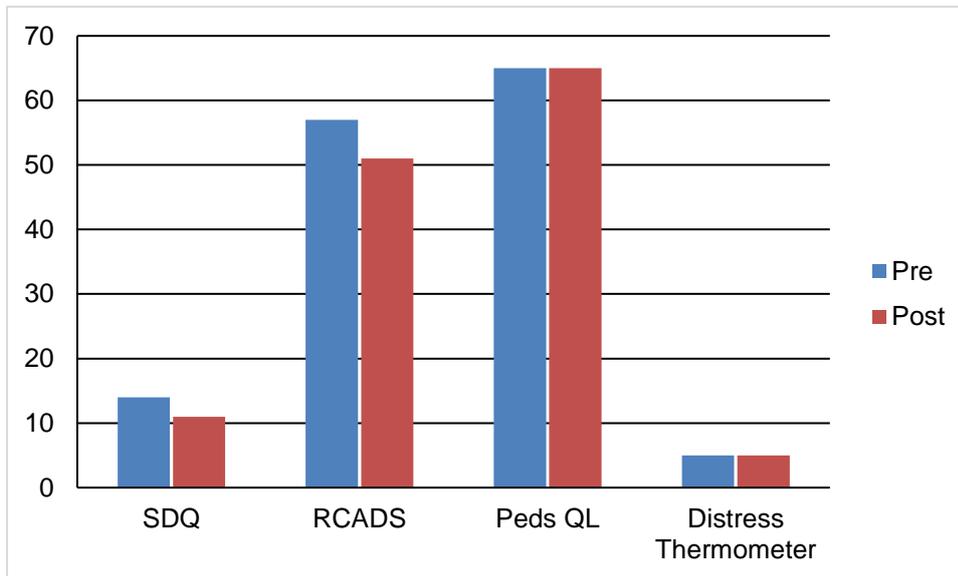
Harry is a 17 year old boy with a diagnosis of Wilms tumour in long-term follow up. RR completed the 'problem solving' module only. His pre and post scores on the measures are shown below:



Harry reported no change in any of the measures which may be due to low levels of self-reported distress at the start of the intervention. He said: *“[the problem solving module] allows you to make decisions which benefit you and you feel are best at that moment in time.”*

Case 16: Toby

Toby is a 14 year old boy in long-term follow-up for acute lymphoblastic leukaemia. Toby completed the 'problem solving' module of the website. His pre and post scores on the measures are shown below:



Toby reported a non-clinically significant improvement in mood following use of the website (demonstrated by a slight decrease in both the SDQ and RCADS), however there was no change in quality of life or level of distress (demonstrated by the Peds QL and Distress Thermometer). Toby gave the following feedback about problem-solving: *"It was good the way in which it can be applied to big decisions or tiny everyday problems in the same way. I think it'd be a great routine to get myself into when struggling to make decisions."*

Case 17: Julia

Julia is a 18 year old woman with a diagnosis of Hodgkins lymphoma. Julia has recently finished treatment and has completed the following five modules to date: 'learning about distress', 'problem solving', 'doing something to feel better', 'plans for coping' and 'relaxation.' Julia is still currently using the website.

Case 18: Richard

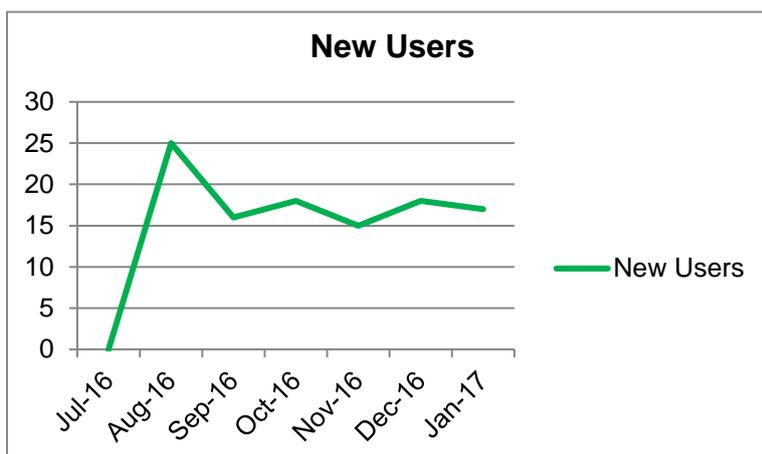
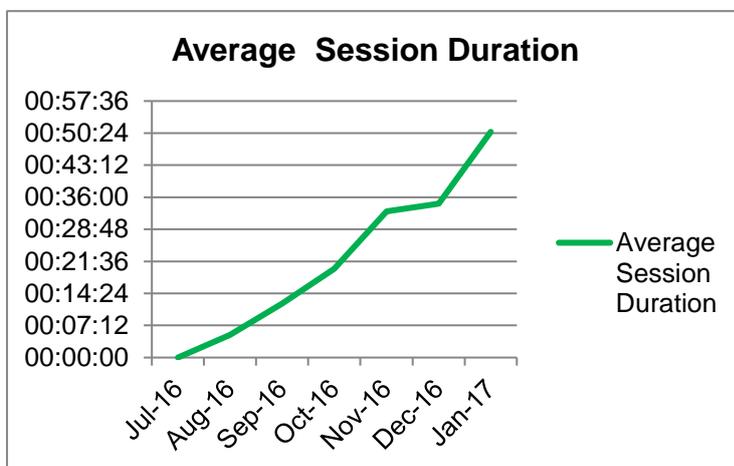
Richard is a 20 year old young man with a diagnosis of T Cell cancer, currently in maintenance. Richard has completed four modules of the website to date: 'managing the future', 'relaxation', 'self-esteem and body image' and 'doing something to feel better.' Richard is still currently using the website.

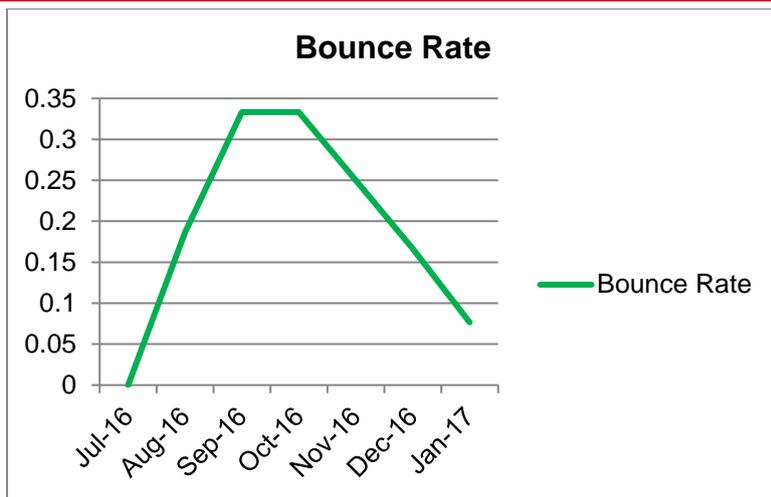
Case 19: Jessica

Jessica is a 14 year old girl currently receiving treatment for neuroblastoma. Jessica has completed the 'relaxation' module and is currently continuing to use the website.

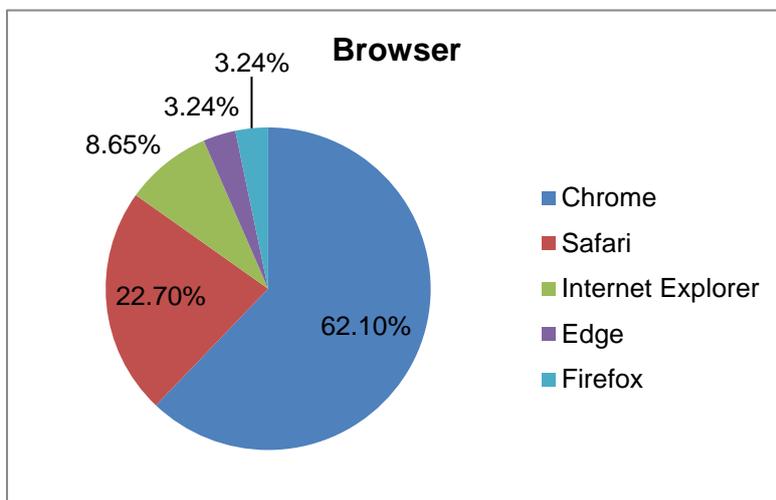
Website use and acceptability

99 unique users interacted with the website between July 2016 and January 2017 with 818 unique sessions during this time period. This suggests that we had a much wider reach than the 19 participants who formally completed pre and post measures. The graphs below show how the average session duration and number of new users increased with each PDSA cycle. The bounce rate decreased following completion of the development phase in early autumn 2016. The average session duration increased from 5:03 minutes when the website was first launched in August to 50 mins 41 seconds in January 2017.





The website was accessed on a range of browsers which has implications for sustainability and spread.



We also received quantitative feedback on the modules from all users of the website. Young people were asked to rate the module from 1 (very bad) to 5 (very good). The average ratings for the modules are:

- Learning about distress: 3.78
- Problem solving: 4.36
- Doing something to feel better: 3.67
- Relaxation: 4.60
- Thinking differently: 4.00
- Self-esteem and body image: 3.10
- Plans for coping: 4.50

- Managing the future: 4.00

Outputs

We have shared learning from the project at the Association of Behavioural and Cognitive Therapies in New York in October 2016 and at the Teenage Cancer Trust Global Cancer Conference in Edinburgh in December 2016.

We have submitted a systematic review of mental health interventions for young people with cancer to *Clinical Psychology Review* and are currently writing two additional papers for publication in relevant peer-reviewed journals: (1) a qualitative analysis of the mental health needs of young people with cancer from the perspectives of patients and staff; and (2) a paper detailing the development of the intervention and its potential for wider use.

Part 3: Cost impact

The development work in this project highlighted the importance of providing the guided online self-help in addition to care as usual. This is both because the intervention is designed for mild-moderate symptoms of depression only and because clinicians and young people were concerned that the intervention could potentially be looked at as an opportunity for cost-saving. This was not the intention of the project and the guided online self-help is not designed to replace existing face-to-face services offered at UCLH and across the UK.

The economic case for CBT and self-help in young people without cancer is well established, therefore a further economic analysis of our website was considered beyond the scope of this project. However, we believe that the costs of the ongoing running of the website will be relatively low. The guidance can be provided by a Band 6 worker (approximately 15 mins per week per patient) and this could be incorporated into routine contact e.g. if it is provided by clinical nurse specialists or social workers. There is likely to be a nominal cost for the ongoing development and maintenance of the website. We will continue working with our third sector partners to explore avenues for future funding for the continued monitoring of the website to ensure patient safety.

It is worth noting for others interested in doing similar work that the costs associated with the development and initial implementation of this online resource go beyond that requested from the Health Foundation funding. The largest additional cost was that of staff time, which was covered by Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health. In particular, the development phase was more intensive than we anticipated and required a greater than anticipated input from all team members. We would recommend that other future Innovating for Improvement teams fully consider the time commitment of senior members of staff and ensure that their input is sufficiently planned for and included in the funding.

Part 4: Learning from your project

The aim of this project has been to improve the recognition and care of the mental health needs of young people with cancer through the development and continual iterative testing of a guided online self-help treatment package. We have achieved this aim and have developed a product in the form of a website that is live. Our partners at third party organisations such as CLIC Sargent and Macmillan have been instrumental in our successes, through their continuous support in advocating and raising awareness for our project to the young people in their networks.

We think that one of the key contributing factors to the projects success was how we worked as a team. We all contributed unique skills which enabled us to problem solve effectively when we encountered difficulties and see unique and different solutions, for example when recruitment was slow. Perhaps more importantly we all had a shared passion for making a difference to mental health in this vulnerable population and this enthusiasm meant that we were able to champion change and maintain enthusiasm and momentum in the face of difficulties.

Our project involved three organisations at the start (and increased as we formalised our links with charities). Initially one of the difficulties we faced was in navigating multiple organisational boundaries and procedures including opening a grant code to access the funding and obtaining ethical and local R&D permissions. We found this stage of the project time consuming and demoralising, but being able to be honest with our Springfield consultant and increasing the frequency of our team meetings to maintain momentum helped us stay focused. Although technically we did not require NHS ethics, we would certainly recommend obtaining ethical permission for Quality Improvement projects which cross organisations as this was often the first hurdle to gain access to different services. We also considerably underestimated the time needed for the set-up phase; allowing an extra month for this would have allowed us to 'hit the ground running' when we started development.

One of the challenges that has persisted throughout the project has been gaining the support of the local NHS clinical team after ongoing conversations to address concerns. This in turn negatively impacted our recruitment, as the staff remained unwilling to share our project with the patients under their care. As a result, we changed our strategy of recruitment, focusing our efforts on close collaboration with our third sector partners. As a team we have reflected on why it has been difficult to engage with our local clinical team. We framed this project as an 'Quality Improvement' project, naively believing that others would share our enthusiasm for the chance to do something different that ultimately might improve the service we deliver. However, in the current climate where mental health services are under considerable strain and pressure, we think that clinicians who are working hard and doing their best potentially may find the term 'Quality Improvement' offensive as it suggests that they are doing something 'wrong', thus placing them in a defensive position. This is particularly relevant as this project was essentially about introducing what should be routine clinical practice into routine clinical practice. This has led to important learning for us for our other projects; we have found that talking about projects to 'enhance' practice are more acceptable to clinicians.

Partly due to the challenges highlighted above, the way that we thought about this as

a project changed throughout the year. In particular we thought that the development phase of the project would be much faster. However, in reality we discovered that it was beneficial to invest time at this stage to ensure that we created a website that was meaningful and useful to young people. In future projects we would make sure we planned for significant time for development, particularly when using co-production methods.

Key learning points:

- It is not acceptable to pathologise distress in young people with cancer. Additionally the website is appropriate for use by all young people with cancer, rather than only those who have mild-moderate depression symptoms. Rather than solely measuring pre-post change in distress, measures of usefulness and acceptability are more important.
- The website is best conceptualised as a resource rather than an intervention. This allows young people to ‘dip in and out’ of different modules, take control over their own mental health and removes concerns about who has clinical responsibility for the young people who use the website. This is important in terms of scalability and spread.
- Young people are interested in sharing their stories and engaging with other young people with cancer. Therefore we have included options for sharing experiences on the website and this has increased user ratings of the website.
- The key adaptations we have made to the resources have been to include cancer-specific examples. This has important implications for spread as it suggests that we can generalise the findings to other long term physical health conditions. We are currently exploring using a similar approach in young people with epilepsy, drawing on learning from this project.

Advice for others:

- Be passionate about what you are doing and share this with others whenever possible. However, be mindful of the unique challenges in each clinical setting and think about the language you use to promote your project.
- Allow a longer time scale for set-up, development and recruitment as this is often when the most valuable learning occurs.
- Focus efforts on furthering successful collaborations and think about sustainability from the start.
- Try all avenues to overcome challenges, but do not be afraid to change strategy and revise aims when necessary.

Part 5: Sustainability and spread

Sustainability: Young people will continue to have access to the website beyond the lifetime of the project. The website will continue to be hosted by University College London. This means that UCLH and our charity partners will be able to continue to share the website and its contents with young people ensuring that the access to the evidence based materials is sustained. We will continue to use Google Analytics to monitor the use of the website on a monthly basis.

We have the continued support of Practice Wise who hold the copyright for the written materials in the MATCH manual. We will therefore continue to promote the use of the website through various channels including to other cancer services throughout the UK.

One challenge going forward is the sustainability of provision of any guidance a young person may want whilst using the website. We have been worked closely with clinical nurse specialists at UCLH who have been largely supportive of the guided online-self-help intervention. We have also built relationships with play therapists and activity coordinators at the hospital. In addition, we have worked closely with CLIC Sargent, whose support workers provide support to patients and families. Therefore, the sustainability of the website can be taken forward by the support workers or clinical nurse specialists to act as 'coaches', and we can offer training to these staff members if necessary. We have also offered the online package to the local NHS clinical team.

Spread: We have made links with psychologists working in South West England who use similar online materials to support young people with cancer. We have also formalised our links with Macmillan and CLIC Sargeant who will continue to inform young people across the UK about the resource. Our charity partners have been extremely supportive of the project and have shown interest in continuing the work beyond the funding provided by the Health Foundation. We have offered the online package to our partners and will offer support to them in making a business case. In addition we will continue to promote the website to other cancer services e.g. through our links with mental health networks for young people with long-term physical health conditions.

Outputs: We have shared learning from the project at an invited keynote at the Association of Behavioural and Cognitive Therapies in New York in October 2016 and via a poster presentation at the Teenage Cancer Trust Global Cancer Conference in Edinburgh in December 2016.

We have submitted a systematic review of mental health interventions for young people with cancer to *Clinical Psychology Review* and are currently writing two additional papers for publication in relevant peer-reviewed journals: (1) a qualitative analysis of the mental health needs of young people with cancer from the perspectives of patients and staff; and (2) a paper detailing the development of the intervention and its potential for wider use.

Appendix 1: Resources and appendices

Summary of qualitative data

Key feedback from staff members:

One size doesn't fit all

Participants talked about the complex nature of distress in young people with cancer e.g.

“Depression in young people with cancer is much more complex and it is difficult to operationalize those complexities.” Symptoms often fluctuate in response to changes in physical treatment and varies at different stages of the cancer journey: *“It is very variable and can change day-to-day much more than you might see in depression [in young people without cancer].”*

Learning: There is a need for any intervention to be flexible and personalised. Participants preferred a model where young people could select topics relevant to them from a range of resources, over a linear module based approach.

Distress is completely understandable

Almost all participants explained that distress is a common and understandable reaction e.g. *“young people go under the duvet, which is a very very common place...it's like just shut your mind and just get through it and I think that is very appropriate. That seems to be completely understandable.”* It is important to validate young people's experiences and *“normalise but don't patronise.”* Participants were also clear that it is important that we don't over-label a normal reaction to a difficult situation and instead that it is vital that the intervention *“allows young people to define their own emotions, rather than us defining it for them”*.

Learning: We will include information about distress in a way that validates young people's experiences and allows them to make their own decisions about what is a 'normal' emotional reaction. Materials which externalise the cancer and distress may be most appropriate.

A 'stepping stone' intervention

There was agreement that a website could not replace the enormous therapeutic benefits of forming a therapeutic relationship through face-to-face therapy and that *“there is a huge amount of value in simply being with them through the whole journey.”* One participant said: *“we must keep human contact”*.

Learning: The website may have most benefit for those young people who do not/or cannot currently engage with face-to-face services and act as a 'stepping stone', signposting to other resources and raising awareness of face-to-face services. The website will be offered in addition to, not instead of usual care.

Connecting with others

Many participants talked about relationships and the importance of engaging with others where possible. One concern was that an online intervention may increase

isolation and therefore it is important that the package encourages young people to 'get back into their lives' when appropriate. Young people face various challenges in doing this, both practical and emotional, and participants provided detailed examples in this area. Information and support about how to manage these challenges, for example by gradually increasing social contact may be useful.

Participants also highlighted how the cancer can lead young people to have a different perspective on their lives as a result of the experience: *"Some say 'I wouldn't change what has happened, which I always find is very remarkable, and somehow it's the cancer that gives them the confidence to do A, B and C.'"*

Learning: A solution focused, future oriented approach is likely to be most beneficial. We will include links to blogs and other resources which may be relevant to young people.

Ownership and empowerment

A number of participants highlighted that one challenge of being diagnosed with cancer as a young person, is the often sudden need to become dependent on others during a time when they had been forging independence. One participant said: *"I think the things that cause the distress are the inability to be achieving the goals that are part of adolescence."*

Learning: Participants were keen that young people would have control over the intervention and could opt in and out of the different topics. Young people can choose which resources are relevant and useful for them.

Key themes from patients and carers:

There is a need for an accessible resource on mental health

All respondents have expressed support for a website that offers resources to cope with distress or low mood. *"I found that of all elements of my treatment, the finding help for mental health side of things was definitely the most difficult thing that I had to push most for."*

Participants found that having resources online makes sense as people/teens spend a lot of time online.

The majority of participants have said that if they had the option, they would use it at some point during their cancer journey. When they would use it depends on the individual.

Learning: We need to make the website flexible rather than linear, and easily accessible regardless of particular service.

Stepping stone to face to face support

Some of the respondents have expressed that they would welcome having resources available online as they feel uncomfortable or awkward talking about distress face to face: *"Sometimes you don't feel as comfortable talking to someone face to face. Personally for me, I would rather have it online than face to face"*

because I did have a counsellor in school and one point and I felt that it was sort of awkward, because I don't find it easy to talk to people face to face."

Others have expressed a preference for face to face. Most respondents who have expressed a preference for online therapy have been boys, whereas most respondents who have expressed preference for face to face are mostly girls: *"I would find it better to do it face to face. I don't know why, but I don't really like to chat over a phone or a computer."*

"At the moment we're on the waiting list, and that's just to get the first initial assessment. Once you have the initial assessment you could be waiting for months."

"In my experience so far of talking to [child] about mood or whatever, is that it's quite difficult, so I would hope that this would be something that she would want to engage with, and I think particularly if it could lead to an introduction, as she says, to having face to face stuff, I suspect even by Skype, then that would be good."

Change to website: Therefore, the website may be most useful for those young people who do not/or cannot currently engage with face-to-face services and act as a 'stepping stone', signposting to other resources and raising awareness of face-to-face services. It will be offered in addition to, not instead of usual care.

Used in conjunction with face to face support

One young person also suggested that the website with resources and exercises would be useful to have in conjunction with face to face therapy and could serve as a follow-up or maintenance of face to face therapy: *"I think I'd find this really useful if I'd just come out of a counselling thing or something and I'd left it for a couple of days, and then I went on here [website] and worked through some of these exercises and then it reinforced ... it kind of backed up what I'd been doing in my counselling really."*

Change to website: As above, we see this as an additional resource that can be used by young people in addition to their usual care. We hope that it will encourage young people to seek face-to-face support if necessary.

Flexibility

Although the majority of respondents have expressed that they would find a website most useful at the beginning of the cancer journey, others have expressed that they would use it all the way through and especially after treatment, when they cannot access the same level of support from the hospital or treatment centre anymore.

In addition, respondents have expressed a range of situations when they would access the website, for example, at the hospital or at home. It depends on how they are feeling that particular moment: *"When you are here you are given chemo which makes you feel like you don't want to do anything"* and how much distractions they experience from the environment. For example, some find hospitals distracting, whereas others find home distracting.

Learning: Therefore, there is a need for any intervention to be accessible at any point and from anywhere.

Concerns about the term ‘treatment’

Some parents have raised the concern about using the word ‘treatment’ as it feels negative or might imply that these kids have emotional problems. However, some young people think it is the right word to use.

Change to website: We have changed ‘treatment’ to ‘resources’ and reconceptualised the purpose of the website.

Need for resources for parents/carers

All parents have mentioned that they would love a similar, but separate, resource for parents/carers or have a section on the website for them, which provides information about cancer, side effects of medication, financial aspects, and how to talk to their children about cancer and mental health.

Parent: *“I question myself sometimes how I deal with it. Am I being too hard on [child]? Am I being too easy? It’s just having that bit of guidance. Parents are just as confused as the children.”*

Young people also agree with the idea of having something to support parents/carers: *“It would be good also for other people to have support, so I’d have really liked my friends to be able to talk about it, or my little brothers, or my mum, instead of them being like ‘we’re the rocks for her’, like ‘we can’t let our guard down at all.’”*

However, the preference is for a parent website or section is that it is separate from the young person’s materials.

Change to website: We will explore the option of linking to a parent website or resources for parents.

Striking differences in support offered in different treatment centres

One striking difference from the interviews so far, is the variability of the level of support young people have received from their treatment centres. Most people we spoke to at UCLH have felt well supported by the team and were aware of services and points of support if they needed them. However, other people we have spoken to who have been treated in other areas have mentioned lack of support or patronizing comments from clinical staff.

Person from Hub: *“When you get here, they give you 8 million bits of information and you know you can speak to anybody, therapists or what have you, and it seems it is very well contained here.”*

Person from elsewhere: *“I sort of mentioned it to my consultant and he said ‘aw it’s just part of the parcel’ but I mentioned it to some doctors at the end and one laughed at me, prescribed me a relaxant, like they just gave me some pills and said ‘any blood tests you have from now, just have these and don’t drive.’”*

“I think it’s just kind of assumed that everyone’s going to feel pretty crap, while they’re on treatment and, don’t necessarily say uhhh anything about it.”

Learning: Resources may be needed more by other hospitals than the team at UCLH

Need for content specific to cancer

Some of the resources used in young people without cancer are not realistic for those with cancer. For instance, behavioural activation needs to be adapted because going out and doing activities is unrealistic when the young person is on treatment and feels tired. Instead, it is important to add sections in that encourage trying out new hobbies, or suggesting activities that can be done privately or sitting down. In addition, it is normal that mood may fluctuate from one day to the next, and it is important to emphasise realistic goal setting depending on the mood of the day: “the week after treatment, if I had a shower, I was doing well, but then the other week, I was going back to university and seeing my friends”.

Other useful sections that young people have highlighted include:

Dealing with relationships: “When I first got diagnosed they were all like ‘oh let us know if you need anything’, but further into my treatment it seemed like they weren’t too bothered or they were ‘oh you’re going back in again, ok then’. So I think it would be help to have something on how to deal with changes in relationships and friendships.”

After treatment has finished: “I think that’s when it really hit me, like when I first finished my treatment.[..] Just because the cancer treatment is over, doesn’t mean that cancer is over.”

“He [doctor] was really positive about it [discharge], like you’d expect, but I wasn’t really expecting him to say it, and actually I kind of didn’t feel ready to leave all the support and stuff that I had through the hospital, even if it was just [..] knowing I had the follow-ups to go to were kind of quite important to me. And then suddenly it just completely stopped.”

Change to website: Therefore, it is important to adapt or develop materials that specifically deal with these areas.

Social network and hearing others’ stories

All respondents (young people and parents) have expressed that they would like to be able to chat to or hear about other people’s experiences (both young person and parent experiences). Suggestions to incorporate this include instant chats, forums, and blogs: *“You would be able to talk to other people who are going through the same things as you. You could share experiences; you would be able to cheer other people up which would make you feel better about yourself, so I think that would actually be quite useful as well.”*

Change to website: As other charities have moderated forums as well as collections of stories in place, we have decided to link to these existing forums and stories instead of setting up our own. In addition, we will link to existing blogs written by young people with cancer.