

INTERVENTION REPORT



Psychological Support Help! Website Report

ON TARGET: Enhancing the future for young people with cancer

ON TARGET is a service evaluation programme funded by Macmillan Cancer Support. Working with patients, the people who support them, professionals, charities and local organisations, the programme aims to assess and enhance the care offered to Teenagers and Young Adults (TYA) with cancer across the South West.

The ON TARGET team has gained a thorough understanding of the needs and wishes of TYA, those who support them and those who treat them. This knowledge has been used to design a programme of interventions intended to improve patient outcomes, increase self-management and reduce future healthcare demands. The selected interventions have been piloted and evaluated. Based on these findings, proposals will be presented to commissioners, the voluntary sector and health care providers to suggest changes to care that will most effectively ensure that “each TYA patient is supported towards re-engagement with life as it would have been without the intrusion of cancer or as the patient decides to recreate it after experiencing the impact of cancer”.

Release: ~~Draft~~ / Final
Version: 1.1
Date: 12-05-15

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1. Executive Summary

This report details the Psychological Support intervention that was co-created and implemented in collaboration between On Target, the existing South West Teenage and Young Adult Service and University Hospitals Bristol Psychological Health Services. The primary objective of this intervention was to co-create a way to provide information and support for level one and two psychological care (as defined in NICE Guidelines, 2004) for TYA from the point of diagnosis through to aftercare, to maximise wellbeing and self-management. Earlier reports (Intervention Evaluation Psychological Support and Interventions Design Integrated Report) provide detail of the analysis, scoping and pilot plans for the Psychological Support workstream (available from www.uhbristol.nhs.uk/tya).

Young people worked collaboratively with professionals using a variety of co design techniques to develop the content, design and functionality for a web based psychological support resource called 'Help I've got cancer'. The website is designed to support young people day and night and is accessible via any device. It also provides a range of multi-media resources for professionals to access to support their work with young people. A key outcome of this intervention has been an increased understanding of how vital it is to undertake this work in genuine partnership with young people if the resource is going to be meaningful for them.

Over the pilot period (12.05.14 – 30.09.14) the website was accessed 686 times using 295 devices. 4370 page views occurred with an average of 6.37 pages per session. There was a return rate of 42.3 %. Feedback was collected via a star rating per page process and free text.

The pilot phase results support further development in partnership with young people and the professionals who work with them. The key next steps identified by the co-creators are:

- To co-create a process to generate and upload young person led content.
- To increase the authenticity of the site with increased ownership by young people (with professional support).
- Increase interactivity of the site to make it more functional, meeting the needs of young people (specifically the use of the tracker).

In terms of the long-term future of the website, short term funding to continue developments after March 2015 has been secured. In the longer term a sustainability plan needs to be put in place by Psychological Health Services and the TYA service team.

2. Intervention Background

2.1 Objectives

The primary objective of this intervention was to co-create a way to provide information and support for level one and two psychological care (as defined in NICE Guidelines, 2004) for TYA from the point of diagnosis through to aftercare, to maximize wellbeing and self-management.

The specific desired outcomes of the intervention were:

- To co-create a website with TYA for TYA.
- To create a solution that would be available to TYAs when they need it (i.e. 24/7).
- To enhance level one and two support, and self-management.
- To enable the delivery of a wide range of information and advice covering as many issues relating to psychological / emotional health as possible, in a variety of ways to support TYA engagement (e.g. video & written).

2.2 Scope of the intervention

This intervention was designed to enhance level one and two support from the point of diagnosis through to post treatment and aftercare. As a result, the intervention designed should be able to be offered to all TYA patients across the south west.

2.3 High Level Design

a) Methodology

One of On Target's guiding principles is to ensure that patients, their network (i.e. the people around them) and professionals are fully involved in the process of assessing and addressing the aftercare needs of TYAs with cancer. Involving healthcare users in the improvement of services is not a new idea, and user participation within the NHS is now well established and considered to be a standard ingredient in creating services which reflect the thoughts and meet the needs of those using them.

Co-creation is however a relatively new methodology and one which fundamentally shifts the focus from professionals delivering care to one in which patients are fully engaged in their own healthcare (Cottam & Leadbeater, 2004). Although a form of participation, co-creation goes beyond seeking just the views of patients and aims to develop a deep and thorough understanding of the complete patient experience. This rich insight forms the basis for re-designing services meaning that patients are central not only to the design of services but are also actively involved in their production and continuous development. This approach allows the power and expertise of patients and professionals to be brought together in order to co-create better health experiences and outcomes (Bate and Robert, 2009).

b) Analysis phase findings

(i) Information gathering

In the analysis phase of the On Target programme, information was collected regarding the aftercare needs of TYA with cancer in the south west. Views were sought from patients, the people in their network and from professionals. Full details of how co-creation was used in this phase, and the findings, can be found in the *On Target: Analysis Phase Consolidated Findings Report, April 2013*.

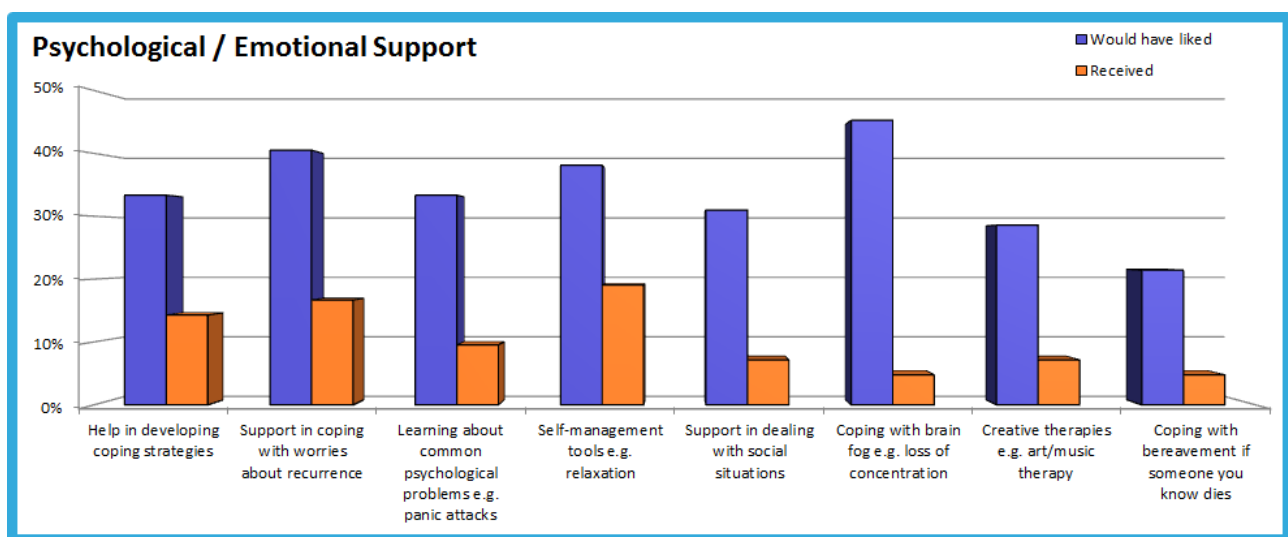
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Following an initial engagement with young people about its design and content, a total of 108 questionnaires were sent out to TYA (known to the TYA clinical service but not previously known to the On Target programme) during August 2012. A total of 42 paper based questionnaires were returned (39% response rate).

Key messages from patients included:

- Fifty five percent of questionnaire respondents did not receive psychological or emotional support (36% did receive support and 9% did not answer the question).
- Of the 36% who did receive this type of support, 57% rated it as either only moderately good or not good.
- Of all eight categories covering psychological and emotional support patient aspirations outweighed actual service delivery in every dimension. See Figure 1 for details.

Figure 1: Psychological Support: Areas in which patients would have liked support compared to what they actually received.



“I would have liked help in coping with loss of concentration and memory (after surgery for brain tumour) but was told the latter was deemed only available for Alzheimer’s patients”.

“I’ve got chemo brain and forget things like hospital appointments. I get really frustrated with myself and would have liked to have known that this could happen at the start of treatment”.

“As my cancer was deemed ‘highly curable’ the emotional impact was not well acknowledged. ‘Why do you need help?’ I still have these thoughts and feelings going on in my head”.

A full report of patient responses is documented in: On Target: Analysis Phase – Patient Report v1.0, January 2013.

(ii) Requirements analysis and prioritisation

After the identification of the requirements collected through information gathering, the need for additional psychological and emotional support was ranked as high priority through the prioritisation process. Two key requirements (140.1 and 695.1) are shown in the Table below. A number of related

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requirements (shown in *italics*) were identified as duplicates of these key requirements and linked to them.

Req. (Ref. No.)	Description	Priority	Patient Benefit Assessment
140.1	Patients should be prepared and supported (together with their network) for the end of treatment and the continuing and evolving impact (psychological and physical) of their cancer experience after completion of treatment	Must	Amber
580.1	<i>TYAs should be supported emotionally</i>		
608.3	<i>Process to assess and respond to fear of recurrence</i>		
636.1	<i>Staff should have the skills necessary to address and assist in minimising the feelings of abandonment described by many young people at the end of treatment</i>		
657.1	<i>Emotional issues surrounding end of treatment should be introduced to, acknowledged and raised with the TYA</i>		
660.6	<i>The TYA service should facilitate discussions around how to cope with end of treatment in the months before it happens</i>		
704.1	<i>TYAs affected by on-going side effects caused by treatment should be offered support to assist them in adjusting to any physical changes</i>		
1352.1	<i>TYA patients should be fully informed about the potential time it may take to recover following treatment</i>		
1750.1	<i>Networkers observe psychological late effects such as body image issues, reduce confidence, fear and dependency which the service should look to address and reduce.</i>		
1751.1	<i>Parents whose children are not newly diagnosed recognise that thoughts and feelings at diagnosis and through treatment are different to those thoughts and feelings that occur later.</i>		

Req. (Ref. No.)	Description	Priority	Patient Benefit Assessment
695.1	TYA patients should have access to a range of therapeutic interventions to help them manage emotional and psychological difficulties	Must	Amber
634.1	<i>TYAs should be offered a variety of services to help them address low mood</i>		

Each key requirement was assessed in terms of its priority for the team to take forward and for the likely direct patient benefit. A full report of the findings of the requirements analysis and prioritisation methodology can be found at: *On Target: Requirements Prioritisation Report v1.0, May 2013.*

It was through this process that a number of On Target 'Core Values' were established: these were considered central to all aspects of the ON TARGET programme and are not unique to any single intervention or element of care (Appendix A).

3. Intervention Design

3.1 Build Process

Further exploration identified some key challenges that would need to be addressed in order to successfully design an intervention to help support the emotional wellbeing of TYA, including:

- Ensuring ready access to level 1&2 psychological support, given the limited resources available to more specialised psychological healthcare.
- The potential distance between patients and treatment centres in the southwest region.
- The stigma attached by many young people to psychological distress.
- The immediacy in which TYA want information, and its availability 24/7.

These challenges suggested a need for a web based intervention. A full report justifying this approach to the intervention can be found in: *Design Phase - Intervention Evaluation Psychological Support v1.0, July 2013*. This initial intervention proposal was presented to a group of young people, networkers and TYA professionals on the 25th June 2013 when the initial design was discussed (Appendix B).

An e-health consultant was approached to discuss how a psychological support website might look, and on 27th August 2013 the first co-creation event was held in the On Target Office, Bristol (Appendix C). The session was facilitated by the e-health consultant and the On Target Psychological Health Workstream leads. Young people that had expressed an interest in working with On Target during the analysis phase, plus anyone identified by the local TYA team as a potential co-creator, were invited to attend. This initial session allowed the group to explore functionality, both for an initial version of the website and for future developments (Appendix D & E).

After collating the discussions about what an initial version should contain, a design studio event was held on the 2nd December 2013 (Appendix F) to shape the 'look and feel' of the site in more detail. Professionals from the TYA service worked with young people to develop the functions, design and content. The session involved the sharing of ideas which were created through a series of tasks requiring collaboration from all those involved. Based on the ideas generated in the co-creation session and design studio event, a prototype website was developed (Appendix G). This served two purposes: firstly, as a tangible example to generate more ideas; and secondly, it contributed to a website specification document.

The initial specification document was created by the e-health consultant to present to a number of companies (Appendix H), with a more detailed version developed for the companies interested in working on the project. (Appendix I).

An agreement was made with Sitekit (www.sitekit.net) to build the pilot website, and host it for one year (Appendix J). Based on the work done previously, a full pilot site was developed for evaluation (Appendix K).

Training on the content management system was delivered to members of On Target on the 22nd April 2014. The format of the training allowed the team to start the initial content upload, without the site being live. After the purchase of the domain name www.tyahelp.co.uk, full content upload and testing, the website went live on the 12th May 2014 (Appendix L).

3.2 Ad Hoc Design Sessions

In order to ensure the design process involved as many stakeholders as possible, ad hoc opportunities were used for discussion with both TYA and professionals. This ranged from email contact for specific advice, to short design sessions at regional TYA clinical team meetings.

3.3 Design Process

The design work was done by a young person that had been through the TYA service and is now working as a graphic designer. The graphic designer attended both the co-design and design studio events and worked closely with the On Target team, e-health consultant and Sitekit to ensure that the designs complemented the content (Appendix M) and were possible within the technical constraints.

3.4 Content

The analysis phase highlighted the topics that needed to be included in the site as a priority (Appendix N), and these were confirmed in subsequent design sessions. The content of the website draws on the theoretical frameworks of motivational interviewing, cognitive behavioural therapy and mindfulness. The content for the site was generated by On Target, the TYA Service Team, Psychological Health Services, the e-health consultant, and a content consultant (TYA patient). All content was quality assured via Psychological Health Services at UH Bristol.

(i) Tracker

During the initial co-design session, the group discussed the usefulness of incorporating a wellbeing tracker into the site. For the purposes of the pilot a 'quick tracker' was developed to provide an example of what could be developed. Using this tool, users can rate their wellbeing using a modified WHO (5) scale (Bech, P., 2012), and the results are compiled in graph form showing scores over time. The site also signposts to MY QuOL-T (Harris *et al*, 2014), which demonstrates a more sophisticated tracking system that can be adapted by the user and to be more age appropriate.

(ii) Images

For the initial pilot site, images were either borrowed from a library held by Bristol Children's Hospital Youth Support Worker or represented by website specific icons.

iii) Video content

On Target worked with JTV Cancer Support (www.jtvcancersupport.com) to generate video content with young people from across the south west. Two sessions were held in Plymouth and Bristol, with four young people. The JTV Filmmaker Coordinator and the young people involved were advised of the areas covered in the website and then engaged in conversation in front of the camera. The editing of the videos was also done by JTV Cancer Support, but they were able to individualise the films, and stylise in a similar way to the website. The videos are hosted by JTV Cancer Support and embedded in to the relevant sections of the website. In view of delays in the editing process, videos were not uploaded to the website until 15th September 2014, so were not present during the whole pilot evaluation phase.

3.5 Accessibility

In line with the On Target core principles, accessibility issues were considered and browsealoud software was installed in the site (www.browsealoud.com/uk/). Features of this include:

- Text-to-Speech
- Spoken & Written Translation in 34 Languages
- Text Magnification
- MP3 Generation
- Written Translations in 74 Languages
- Customisable Options

4. Pilot review

4.1 Pilot Development

(i) Risk Assessment

A risk assessment was done before the pilot evaluation began to ensure the appropriate control measures were put in place to mitigate any potential hazards (Appendix O).

(ii) Change and Quality Control Procedures

In response to the feedback expected during the pilot phase, it was assumed that changes would be requested to the content of the site, and that corrections to content or functionality would be required. A grading system for change requests was established and the process to change content agreed (Appendix P & Q).

Based on the initial feedback received, functionality and design upgrades were made in August and September to ensure usability of version one was acceptable before the end of the pilot (Appendix R & S).

(iii) Recruitment

It was decided that all young people who had contact with the regional TYA service would be invited to register for access. It was hoped this would allow feedback and further development based on suggestions from people at all stages of the treatment journey (from diagnosis to post-treatment). The TYA Specialist Nurses and the CLIC Sargent Social Workers were asked to signpost to the website. The website registration process can be found in Appendix T.

The link for the website was also made available on the TYA service website at UH Bristol (www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/) and on the realshare social networking site for the TYA with cancer in the South West (www.realshare.co.uk). The Teenage Cancer Trust Youth Support Coordinator promoted the website to the young people on the mailing list for the service, and postcards were produced for distribution by staff (Appendix U).

(iv) Outcome Measures

In order to measure the success of the pilot, the following methods were used:

- Website access and utilisation statistics
- Direct feedback was available via the website: users were asked to provide 'star ratings' on each page and there was a facility for a free text feedback mechanism
- Ad-hoc discussion with users as a result of the direct feedback
- Informal discussion/feedback at On Target team meetings and with TYA clinical staff
- An Evaluation session held on the 18th September 2014 at which users were invited to contribute to further co-design of content, appearance and functionality

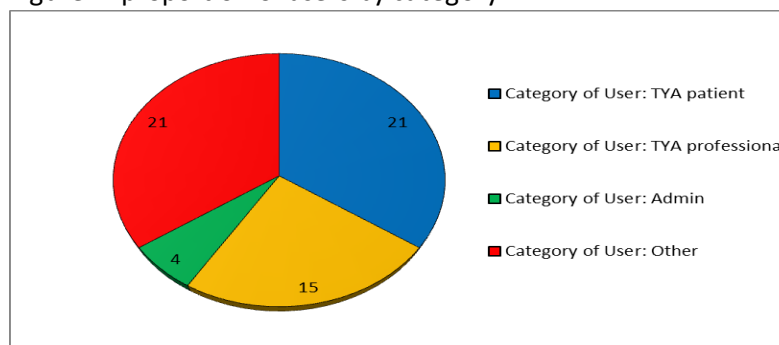
4.2 Pilot Review & Outcomes

The pilot finished at 11:59pm on the 30th September. The website remains available for ongoing use in its current form at www.tyahelp.co.uk.

(i) **Analytics**

During the pilot a total of 57 logons were requested and issued.

Figure 2: proportion of users by category.



'Other' includes: the e-health consultant; staff who may work with TYA but are not specifically TYA staff; TYA's who have not been diagnosed with cancer (e.g. student nurses); and third sector partners/colleagues.

Basic information from website analytics – 12th May 2014 – 30th September 2014.

Times website accessed (sessions)	Number of devices (users)	Page views	Average pages per sessions	Average session length	New visitors	Returning visitors
686	295	4370	6.37	05:55	57.70%	42.30%

(ii) **Page ratings**

Page ratings could be submitted through the site, and were also collected as part of the co-design event on the 18th September (Appendix V).

It should be noted that until the 28th August 2014, the page (star) rating functionality did not have a submit button, so users reported sometimes submitting ratings unintentionally prior to this point.

Average score for each page (1 (lowest score) – 5 (highest score):

Page	Average Rating
Brain Fog	3.3
Breathing Exercises	5
Can't Sleep	2.7
Exercise & Physical Activity	4.5
Fear of Recurrence	3.2
Fertility	5
Glossary	4
Gloucestershire Services	4.5
Isolation	3.4
Low Mood and Depression	1
Meditation	5
Panic Button	5
Peer Support	5

Relationships - partner	4
Search	5
Services front page	1
Sex & Intimacy	5
Sexual Health	4.7
Sexuality	5
Talking About Sex	3.3
Tracker	3.5
Welcome	3.3
Worry & Anxiety	4.1

(iii) Qualitative Feedback

Appendix W shows the collated qualitative feedback collected through the free text feedback mechanism on the website, email and discussion - it also includes comments and any action taken. Feedback fell into four main categories: functionality, design, content and general comments. This information was used both to generate a specification for a website upgrade, and to plan the session held with users and professionals at the close of the evaluation phase.

(iv) Evaluation/co-design session – close of phase one

On the 18th September 2014 an event was held to mark the end of phase one (Appendix X). The event was attended by eight TYA patients, one networker, six professionals and two facilitators who came together to evaluate the website developments to date. Phase one focused on the functionality and design of the site, so this was also an opportunity to start developing ideas for improvements to content. Individual meetings were arranged with young people and professionals who could not attend but who nevertheless wanted to take part; the same topics were discussed. A summary of the discussions that took place can be found in Appendix Y.

(v) Mapping

As well as being mapped against the core values, the project has been mapped against the NHS Outcomes Framework 2014/2015, and Macmillan's Nine Outcomes to demonstrate where quality and efficiency gains might lie (Appendix Z).

5. Intervention Outcomes

5.1 Intervention Sustainability

At the end of phase one a co-created website exists, and funding from the On Target budget has been allocated to ensure that it will be hosted by Sitekit until March 2016. After this time alternative funding will need to be identified to host and maintain the website.

In order to continue its development, resource will need to be secured for professional support to continue to develop the website and to maintain the co-creation approach used. It will only be a useful resource if the young people using it are involved in its future. Currently, the website has an engaged group of young people that have expressed interest in remaining involved in its development.

5.2 Intervention Conclusions

This intervention addresses the requirements of the programme by the successful co-creation of a way to provide information and support for level one and two psychological care from the point of diagnosis through to, an including, aftercare, to maximize wellbeing and self-management. This has been achieved in the following ways:

- The website is available to users at any time, and has been designed to be responsive to all devices (including smart phones, tablets) to increase accessibility.
- This intervention offers level one and two support to all patients, and also allows staff working with TYA to access information and materials at minimal cost.
- Providing the information and advice to patients in this manner supports patients to self-manage. Patients and staff can select the content that is applicable and can choose from a range of self-management exercises.
- As well as text information on a number of topics, users can choose to receive the information through featured videos and mp3 files.
- The process has allowed patients to be fully engaged in the presentation of the site, ensuring that it reflects a design patients have said they would find engaging.
- The ability to engage and fully integrate the patient into service development, demonstrates the ability for TYA to work with healthcare professionals to design and deliver complex interventions. Further evaluation will be required to confirm the wider acceptability of the website and demonstrate its benefit in increasing availability of psychological support to TYA at times of immediate need.

During the pilot, both patients and professionals have been encouraged to register and provide feedback, allowing an initial assessment of the impact the website and of how young people feel in engaging in service development in this way. Throughout the process, opportunities to collect reflective evaluation have been utilised, and the benefits/challenges of working this way have been considered.

'The website will really help people and is something I wish I had when I was diagnosed and during treatment.'

TYA Patient comment

'I really enjoyed helping the TYA team to help other young people like me.'

TYA Patient comment

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The support shown by staff across the south west and the level of referrals being made, indicate that healthcare professionals consider it a valuable resource.

'I think that this is a great site for my patients. I would happily signpost them to it'.

Staff comment

The evidence of sustained engagement by patients suggests that the website, and the approach taken to its development, are useful to TYA's. Work has been undertaken in a way which has engaged a growing group of patients who have been committed to the development of the site, including some previously unknown to On Target. The methodology chosen has allowed the design and construction of an intervention with demonstrable face validity.

5.3 Strengths and Challenges of Co-Creation

Strengths of co-creation	Challenges of co-creation
Working with TYA in this way has allowed a deeper understanding into the patient experience, and as a result has provided rich data.	Challenging others' assumptions about what TYA want from healthcare services, and demonstrating that professional input and patient consultation is not adequate when working with this age group.
This data has afforded the team with a solid evidence base for the intervention designed, and ensured it reflects what needs/wishes of TYA.	Establishing communication channels that work for both patients and professionals. For example, organising events at a time which suits all stakeholders.
Working collaboratively with patients, and their continued commitment to working with us suggests that the website been created in a way that represents how TYA's will engage with their own healthcare.	The process of initially engaging patients, and continued commitment can be challenging as the process can be lengthy and time consuming.
There have been further opportunities for patients because of their involvement in the project - for example, it has offered work experience and material for portfolios / CVs.	Expectation management for both patients and professionals. Professionals have to be mindful about what they are asking from patients, and patients have to understand the constraints in which services are working which may not allow certain ideas to be taken forward.
The process has challenged our own assumptions about what TYA want, and how they will engage in their own healthcare.	Whilst contributing to the overall effective use of funds and resources, the process does result in a transfer of costs to the front end of the development i.e. the analysis & design.
	Managing relationships between the groups of people involved, and individuals within groups.
	TYA can be unpredictable: advance knowledge of availability can be uncertain, particularly when working with young people on treatment.

6. Next Steps

6.1 High Level Design

Phase one has been completed and has had a focus on functionality and design. Based on the feedback and discussions, the recommendation would be to further incorporate young person generated content – both within the core content, and as a way of encouraging young people to deliver information to other young people without it becoming a social media platform. This will benefit young people in two ways: firstly, it will further normalise aspects of the emotional impact of a diagnosis of cancer, and allow indirect peer support; and secondly, it would allow young people to publish relevant information that may help support others.

The suggested next steps would be:

- To co-create a process to generate and upload young person led content.
- To increase the authenticity of the site with increased ownership by young people (with professional support).
- Increase interactivity of the site to make it more functional, meeting the needs of young people (specifically the use of the tracker).

In terms of the long-term future of the website, short term funding to continue developments after March 2015 has been secured. In the longer term a sustainability plan needs to be put in place by Psychological Health Services and the TYA service team.

7. References

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Appendix A – On Target Core Values

CORE VALUES QUESTIONS	
1	Can this intervention be offered to all TYA patients?
2	Does the intervention ensure that the patient's view / voice is central and acted upon?
3	Does this intervention offer sufficient flexibility in its approach so as to meet differences in individual patient wishes?
4	Is this intervention evidence based and have we explored other examples of best practice in this area?
5	Does the delivery of this intervention take account of the challenge to patients of dealing with new experiences?
6	Will we be able to publicise / promote this intervention in a way that helps to demonstrate the needs of TYA with cancer?
7	Will this intervention promote self-management?
8	Can this intervention be applied to patients with cancer in other age groups?
9	Does the information to be offered about this intervention meet the needs and expectations of TYA / networkers?
10	Have TYA / networkers been involved in the creation / design of this intervention?
11	Will the delivery of this intervention respect patients' needs for privacy and dignity?
12	Does this intervention support the patient as they manage the challenge of cancer to their sense of identity?
13	Have we considered all possible ways of delivering this intervention?
14	Are there any specific equity / access issues to consider in the implementation of this intervention?
15	Is this intervention consistent with the future strategic direction of the clinical service and with national policy?
16	Will this intervention be applied at the earliest appropriate point after diagnosis?
17	Is this intervention applicable / transferable across the SW TYA clinical network?
18	Is this intervention sustainable if integrated into the clinical service?
19	Have the appropriate teams been engaged in the design of this intervention (or will they be) and are we clear with whom we are taking its further development forward?

Appendix B – Feedback from Intervention Evaluation

Discussions from Psychological Support presentation

- For those who wouldn't want to talk to anyone – good idea
- Does the quote for maintenance costs inc. updates & additions?
- Show patients on the site who have been through similar things
- Information on speaking to a person face-to-face for psychological support required on site
- Panic button liked
- Staff resourcing?

Facilitation?

1:2:1/group intervention?

Taking in to account most likely time TYA's will access it?

- Having some resources available to all & group/specific information accessible with logon?
- Secondlife-type set up?
- Accessibility?

SN's: most do have means to access internet – are few who don't

Charities have supported patients with buying laptops etc.

Language/literacy accessibility issues?

Appendix C – Co-design Session Plan 27/08/2013

Psychological Intervention
Co Design Event, 27th August
TYA patients and TYA staff

Facilitators : Tim Anstiss, Philippa Spencer, Jen Cheshire
Patients: numbers not yet confirmed (likely to be 5)
Staff: Approx 6
Location : ON TARGET office, Bristol

Session outline:

12.30 Meet, greet, consent & lunch

1.00 Start session

- Introductions
- House keeping
- Group reminders
- Comments box

1. Introduce On Target – where we started, where we are now – (including other pilots ideas)
2. Introduce aim of today –psychological wellbeing
3. Show infographic – highlight key psychological findings
4. Ask group what they think of results? Anything surprise them?
5. Should anything else be on the list? (explore....)
6. How are they currently looking after themselves?
7. What kind of help do they feel they would like, want, need.
8. Explain the idea we have had for an online psych intervention. **Check out what they think of this** (would they use it, how would they use it, what format do they want it in??) **MUSTS and MUST NOTS**
9. Show them Mi Wellbeing - feedback/discussion.
10. If time allows think a bit about feel/design issues (musts/must nots)
11. **Key questions:**
 - Who's interested in further involvement?-
 - Anything that anyone is particularly interested in doing?
12. Summary, next steps and thank yous (I Tunes voucher)

3.30 End

NB: Information to be captured via:

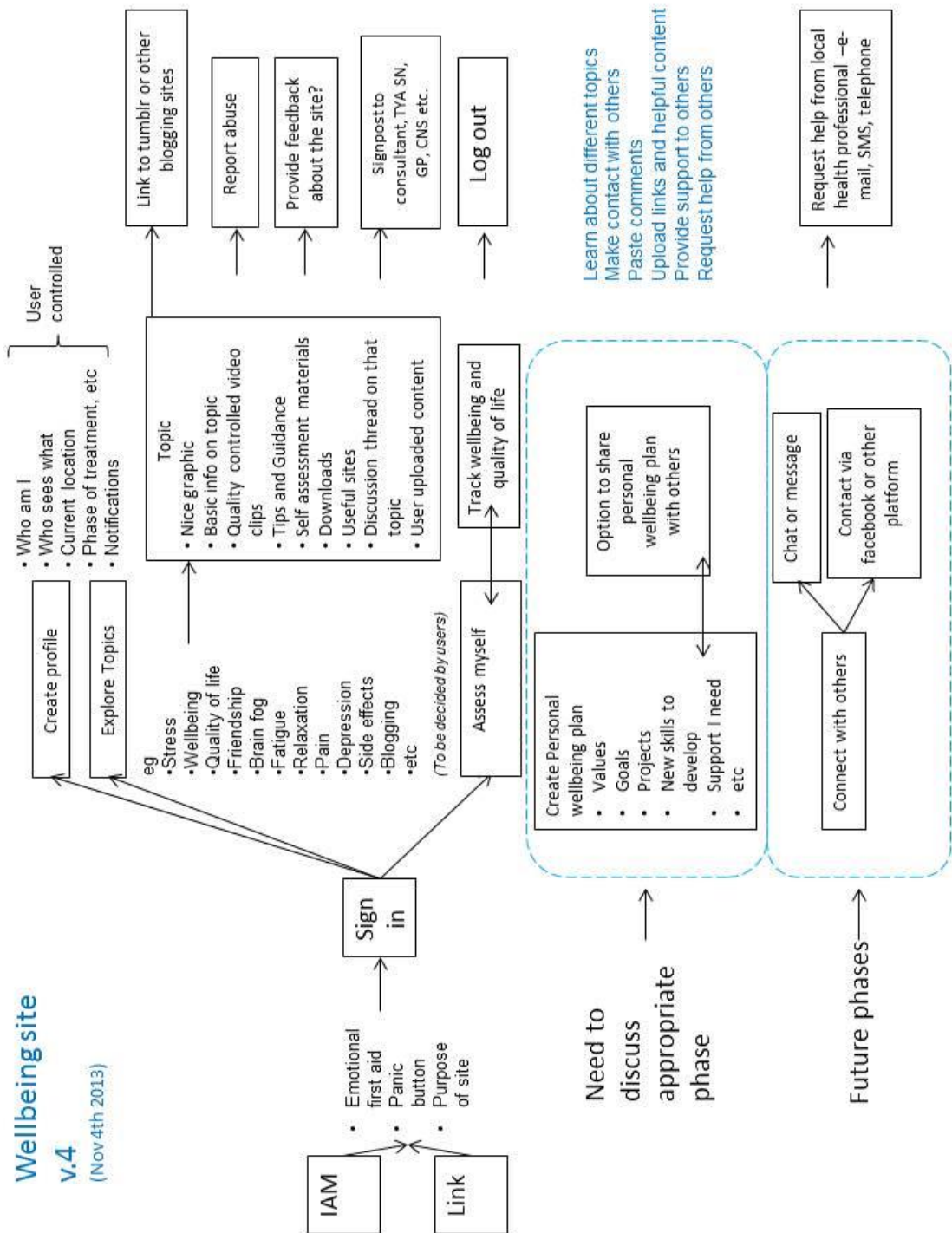
- Flip charting
- Facilitator note taking
- White board
- Comment slips



After a successful first co-design session some of the keys messages we received about creating a psychological support tool were:

- Hints and help from other patients
- Filling in a questionnaire to highlight information that may be useful (for your treatment, age, area etc.) and choose how the information is sorted
- Links to useful websites
- Information for who people can talk to if they are feeling suicidal
- A contact form for people to ask questions
- A date on each page saying when the information was uploaded/updated
- Be able to mark favourite pages
- Statistics on the website use
- Access to the site 24/7
- Something on each page you can say whether it has been useful
- Choose:
 - Whether to receive notifications
 - Whether to have a profile and if anyone sees it
 - Whether to blog
- Option to remain anonymous even if publishing a blog etc.
- Wellbeing tracker
- Information on important topics
- Patients (user group) should be fully involved in any updates/improvements
- Not moderated – but should be able to flag something if it is inappropriate
- Don't try to combine with social networking – people may meet here but communication away from this site
- All information should be available – not given like it is a course

Appendix E – Co-design Website Diagram 27/08/2013



Appendix F – Design Studio Event Session Plan 02/12/2013Error! Bookmark not defined.

Design Studio Workshop

45 minutes Introduction - Problem Definition and constraints

- Assumptions
- Personas
- Pain points
- Constraints

15 minutes Sketch Warm up

- Form 4 teams of 5 people
- Draw circle, square and triangle
- Draw items (Pencil, Bicycle, Chair, House, Person, Argument)

35 minutes Diverge

- 10 minutes Individuals Sketch 6 ideas (persona and pain point)
- 3 minutes (x 5) Individuals present ideas to team mates (persona and pain point)
- 2 minutes (x 5) Team mates critique

35 Minutes Emerge

- 10 minutes Individuals refine one of their best ideas
- 3 minutes (x 5) Individuals present ideas to team mates (persona and pain point)
- 2 minutes (x 5) Team mates critique

45 Minutes Converge

- 25 minutes Team Sketch one idea
- 3 minutes (x 4) Team present ideas to other teams (1 from each team presents to other team)
- 2 minutes (x 4) Other teams critique

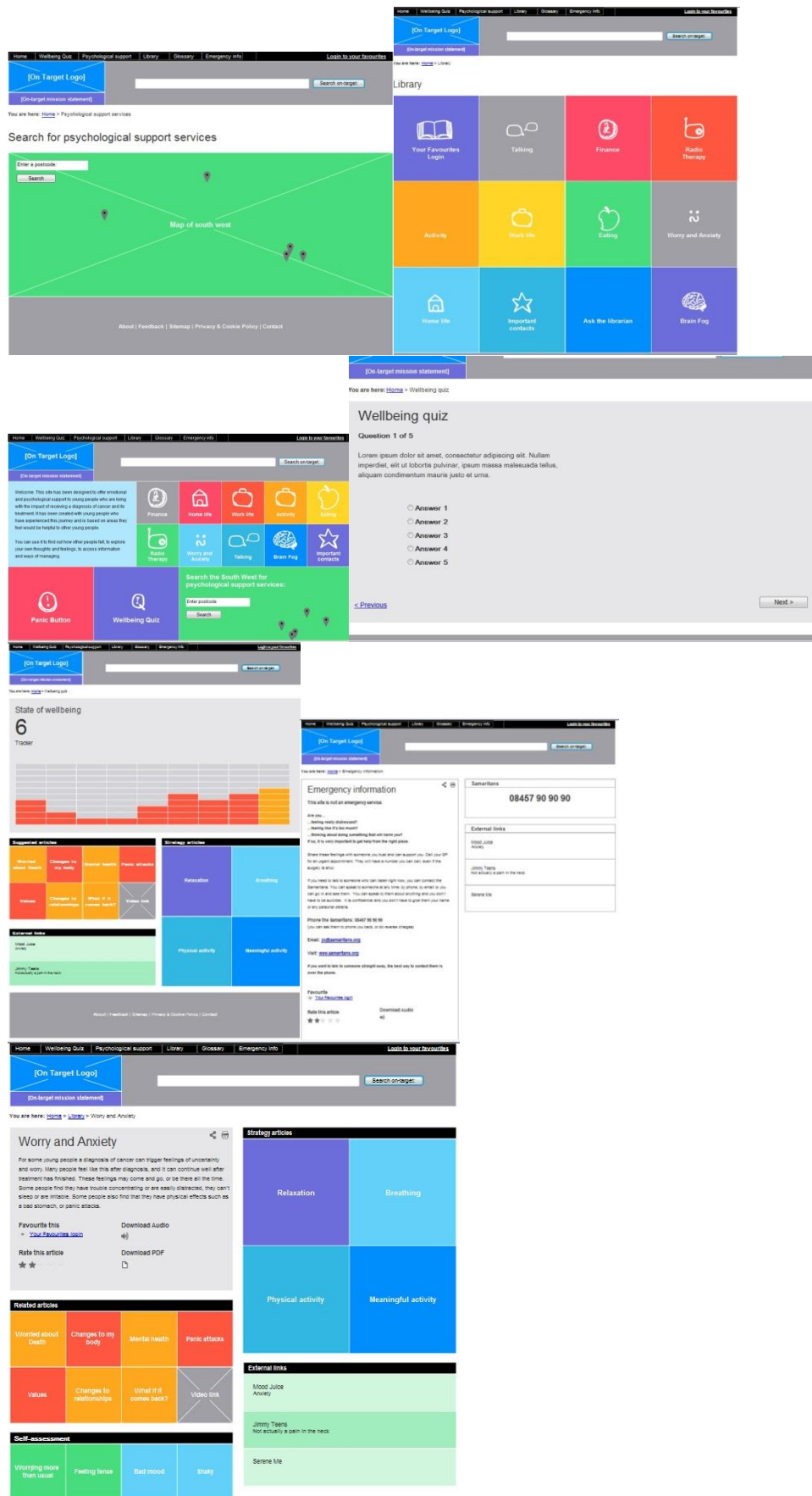
35 Minutes Refine

- 23 minutes Team iterate on their idea
- 3 minutes (x 4) Team present ideas to whole group

Conclusion

Psychological Support: Help! Website Report

Appendix G – Prototype Screenshots



Appendix H – Initial Website Specification

Specification for a web-based Wellbeing Support Platform for Young People with Cancer

Link to demo site: <http://www.cliveghughes.co.uk/ontarget-it03/Home.html>

Desired Features of site	Comment
Responsive design for different phones, tablets, etc	
Accessibility features – font size, colour changes, audio of text, etc	
support for all modern browsers	
24 hour availability	
Ability to search for content	
Ability to save and print page	
Ability to go straight to a particular page via URL	
Administrators able to add content – word docs, video, links, pdf's, audio files, etc	
Users able to rate content – like trip advisor or amazon (but not for other users to see, just the admin team)	
Users can save favourite stuff in a 'briefcase' or on a 'favourites' page	
Navigation bar stays put as you scroll	
Users can take a wellbeing questionnaire each time they visit, and the scores will be graphed so they can see changed over time	
incorporate map of local services	
secure logon / password protected	
search for local services by post-code	
users can provide feedback to admin	

Appendix I – Detailed Website Specification

Functionality

Essential

- Responsive design (mobile/tablet friendly)
- Audio option for text
- Change font size
- Invert colour scheme
- Pages to have own web tag
- Window v.7+ and all Apple OS
- System availability 24hrs
- Video text
- Simple search
- Animated icons
- Print page
- Email page
- Bookmark page
- Personalise colour scheme
- Wellbeing tracker
- Save wellbeing tracker history
- Produce wellbeing tracker graphs
- Email wellbeing tracker results
- Video content/streaming
- Instant feedback mechanism (star system)
- Instant feedback mechanism (free text option to be sent to admin)
- Services map
- User logon
- Admin logon: User logon creation
- Admin logon: Content change


Would like

- Download audio content
- Faceted search
- Tool tip
- Personalised links based on wellbeing tracker results
- Postcode search on services map

Perhaps in future

- QR code

Appendix J – Sitekit Order Form: Website Build



Quotation and Order Form

We are pleased to provide your quotation for products and services as follows:

<p>Customer address</p> <p>On Target Wellbeing Project Bristol Bristol Haematology and Oncology Centre Bristol Royal Hospital for Children Horfield Road Bristol BS2 8ED</p>	<p>Quotation for:</p> <p>On Target Wellbeing Portal - Bristol</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%;">Quote ref.</td> <td>QUO-01773-B2X4-r0</td> </tr> <tr> <td>Valid for 30 days from</td> <td>19th February 2014</td> </tr> </table> <p>Please check all details carefully before signing your order and sending it or faxing it back to us on 0845 166 7299. Please add an official purchase order if required.</p>	Quote ref.	QUO-01773-B2X4-r0	Valid for 30 days from	19 th February 2014
Quote ref.	QUO-01773-B2X4-r0				
Valid for 30 days from	19 th February 2014				

Group / Product Code Product name	Discount	Line total
05 Professional Services / S0504 Sitekit Scoping and Planning	£750.00	£ 750.00
04 Custom Development / S0401 Development based on Sitekit Standard Templates with a bespoke responsive homepage.	£4250.00	£8,500.00
07 Training / P0798/S0709 1 day Sitekit CMS Training		£1,000.00
06 Support / P0698/S0603 Annual Sitekit CMS Application Support for 1 user		£ 750.00
02 Software / P0251 Annual Advanced license fee	£2,500.00	£ 0.00
03 Hosting / P0309 Annual Data Transfer - Shared Hosting - 5GB bandwidth PCM Annual Disk Space - Shared Hosting - 0.5Gb disk space PCM	£825.00	£ 625.00

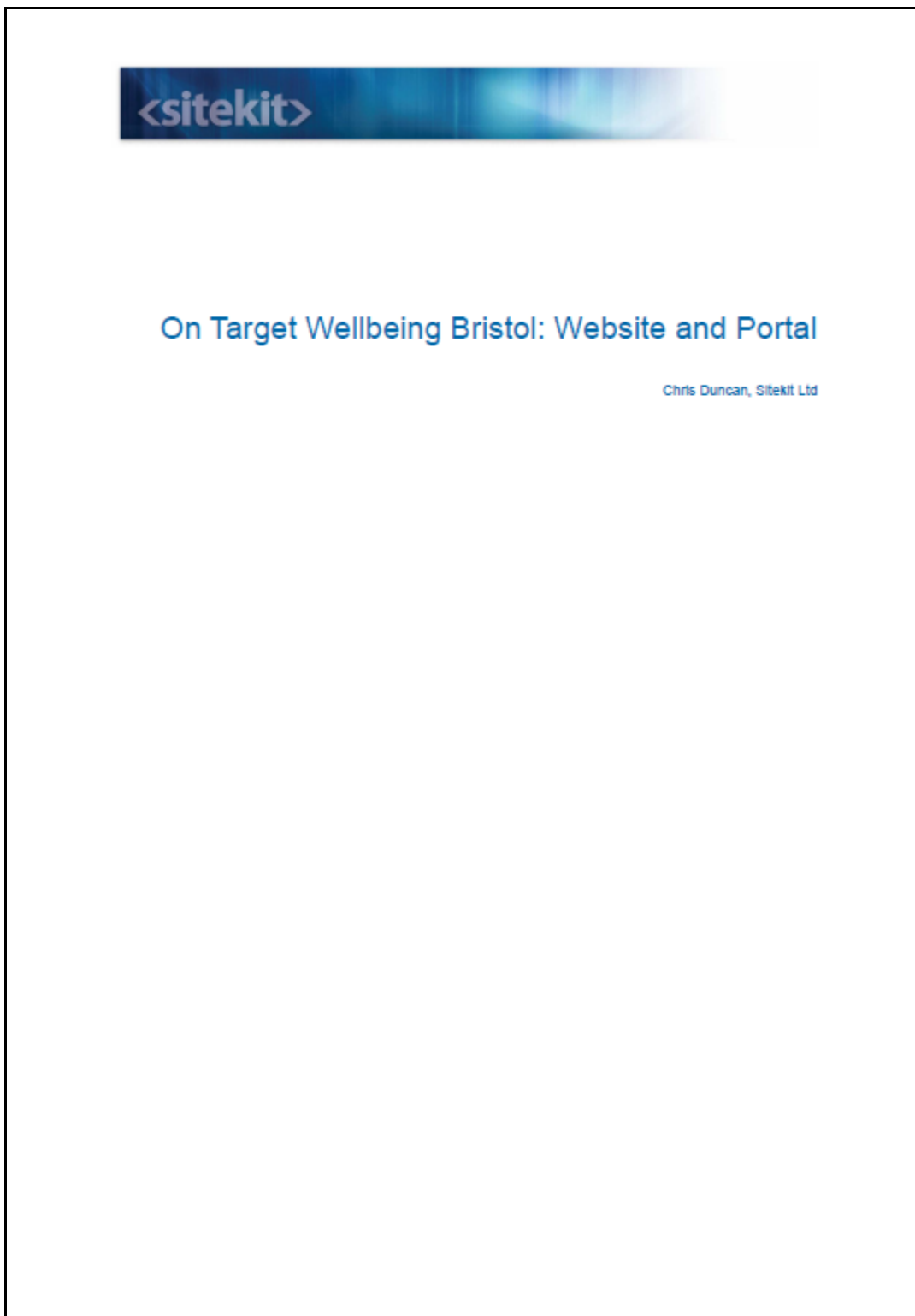
Subtotal:	£11,625.00
VAT:	£2,325.00
Order Total:	£13,950.00

Account / Invoicing details to be completed		
Name:	Payment method:	Invoicing address:
Email:	Purchase Order:	
Telephone:	Will invoices be accepted by Email?	
	Yes/No	

Payment Terms

This order is for a total of £13,950.00 including VAT. I have received, read, understood and agree to be bound by the attached standard Terms of Business, and understand that by signing this order form I am entering into a legally binding

Appendix K – Sitekit User Acceptance Criteria





Document Control V5	
Registered Office	Sitekit Ltd Sitekit House Broom Place Portree Isle of Skye IV61 8HL
Document ID	SKDOC-22-3817
Title	On Target Wellbeing Bristol: Website and Portal
Filename	Sitekit.Solutions.Management.Plan.On-Target-Bristol.2.1
Author	Chris Dunoan
Current Version	0.2
Audience	Client
Document type	Template
Sitekit Role	Management
QMS Controlled Document	No
For QMS Controlled Documents Only:	
Document Owner	Project Manager
Next Review Date	[Next Review Date]
Approved By	[Approved By]
Approval Date	[Approval Date]
Approved Version	[Approved Version]
Customer Code	[Customer Code]
Job Number	2652
Sitekit Company	Sitekit.Solutions
Publisher Rights	© Sitekit Ltd 2014
This document is uncontrolled when printed	

Change Log		
Version & date	By	Changes
1.0 14/03/2014	Sitekit	Creation of doc
1.1 01/04/2014	Sitekit	General additions and amends. Creation of Acceptance Criteria
2.0 22/05/2014	Sitekit	Finalisation of Acceptance Criteria
2.1 06/06/2014	Sitekit	Added document purpose and added item 14 to Acceptance Criteria at request of On Target Wellbeing Bristol

Document Control V5		
Title: On Target Wellbeing Bristol: Website and Portal		
Version: 0.2	Document ID: SKDOC-22-3817	Audience: Client
© Sitekit Ltd 2014	Last Modified: 08/08/2014	Page 2 of 8



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2.2	Desired outcomes	4
3	Acceptance Criteria.....	5
4	Work Governance and Team	5
4.1	Sitekit Solutions Ltd	5
4.2	On Target Wellbeing Bristol	6

Document Control V5		
Title: On Target Wellbeing Bristol: Website and Portal		
Version: 0.2	Document ID: SKDOC-22-3817	Audience: Client
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1 Purpose of this document

- To ensure that the foundation for the project is confirmed and viable
- To understand the purpose and function of the product and who will use it and the desired outcomes
- To define the acceptance criteria, method and responsibilities for the project

2 Work to be undertaken

2.1 Background

On Target is a 3 year programme of work intended to assess and address the Aftercare needs of teenagers and young adults (TYA) with cancer. The programme is developing and evaluating a series of work packages to facilitate and enhance the evolution of a patient's care from its initial focus on cancer diagnosis and treatment, towards cancer survivorship.

Through investigation of the unmet needs of TYAs, a number high priority requirements were identified. It was suggested 55% of patients received no psychological support and there was a significant gap between patient need and availability of information/advice on specific issues. There are number of challenges involved in increasing the provision of psychological support in the south west for this age group. For example:

- Financial constraints
- The geography of the region
- The perceived stigma attached to mental health
- The risk of losing engagement if a service cannot be accessed immediately

Through a process of co-creation, patients and professionals have engaged in the development of an online psychological & emotional support website that focuses on an approach to self-management of common psychological distress areas. This method of delivering psychological support will allow patients to access information and advice in a setting and at a time they choose, and is in line with the wider strategic direction of mental health services. Whilst there are already online resources available, there are few directed at this specific population so engagement is low.

2.2 Desired outcomes

The provision of an intervention that addresses the following high priority requirements:

- Additional psychological support is required across the South West is required to reflect the importance placed on this by patients. To include timely signposting and/or referral to individuals/organisations who are able assist patients in managing persistently low mood and other psychological difficulties including fear of recurrence, perceived late diagnosis, PTSD etc.
- Patients should be prepared and supported (together with their network) for the end of treatment and the continuing and evolving impact (psychological and physical) of their cancer experience after completion of treatment.
- TYA patients should have access to a range of therapeutic interventions to help them manage emotional and psychological difficulties.

The primary objective of this intervention is to provide TYAs with an accessible source of psychological support designed to help them cope with the distress that is known to accompany a cancer diagnosis. This intervention would specifically focus on offering strategies for managing the following key issues; anxiety, low mood, uncertainty (fears about recurrence), brain fog, PTSD, loneliness and change/transition. The intervention would be based on the concepts of resilience, positive psychology, well-being, happiness and self-management and would draw on the theoretical frameworks of motivational interviewing (MI), cognitive behavioural therapy (CBT) and mindfulness.

The specific desired outcomes of the project are:

- The creation of a solution that is available to TYAs when they need it (i.e. 24/7).
- A solution that is better value than traditional psychological interventions.
- A solution that is in line with the national strategy of supported self-management.
- The creation of an intervention that could be potentially rolled out nationally, and customised for the management of other long-term conditions.

Document Control V5		
Title: On Target Wellbeing Bristol: Website and Portal		
Version: 9.2	Document ID: SKDOC-22-3817	Audience: Client
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4.2 On Target Wellbeing Bristol

Name	Role	Role Description
Mike Stevens	Programme Director	Overall responsibility for the programme and final sign-off.
Paul Beynon	Programme Manager	Responsible for the budget/business aspects of the project, and the point of contact in Jen's absence.
Jen Cheshire	Workstream Lead	Principal day to day contact, responsible for managing all aspects of project from On Target Wellbeing perspective. Has authority to sign off milestones. The first point of contact for escalation.
James Matthews	Graphic Designer	Design and creation of custom homepage. Design of innerpage based on Sitekit's standard responsive template format.

Document Control V5

Title: On Target Wellbeing Bristol: Website and Portal

Version: 0.2

Document ID: SKDOC-22-3817

Audience: Client

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Last Modified: 08/08/2014

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Psychological Support: Help! Website Report

Appendix L – On Target Testing Criteria

Desired Feature	Variables / Test Details	Acceptance Criteria	Additional comments
Functional			
Compatibility - Device	Phone - Apple	Page is displayed in optimal format for device being used. With specialised mobile page displayed where appropriate.	Additional check that video content works on Apple products (e.g. adobe flash player may not be supported)
	Phone - Other		
	Tablet - Apple		
	Tablet - Other		
	Desktop - Apple		
	Tablet - Other		
Compatibility - browser	Microsoft Internet Explorer	Page is displayed on all common browsers (including range of recent versions) and each browsers supports all content types	
	Google Chrome		
	Apple Safari		
	Mozilla Firefox		
Design			
Colours	Change		
	Remain as chosen	Colour scheme remains in using the same device	
	Night mode	Colours are converted to 'night mode colour scheme'	
Font Size	Standard	The default font size is displayed when website is first accessed.	
	Variable	Font size can be altered on the website to suit user needs	
Navigation			
Map		Regions link correctly	
Library		Holds links to all pages	
Links		All links / 'click through's' navigate user to expected location of site	
URLs		URLs entered directly in browser navigate the user to the expected section of site.	
Search	Various key word and phrases	Search returns content from webpage and any documents downloaded onto the site. Results can be ordered by relevance (number of times they appear in an article / document) or by date	
'You are here' site map		Each page displays a map location	
Navigation bar		Navigation bar stays put as you scroll	
Interactive features			
Logon	Log in	User has option to log in using secure password to access personalised features.	
	Log out	Personal information (e.g. Well being quiz information is no longer available)	
Ratings		Each page displays an option to provide a rating (out of 5 stars). Feedback is sent only to moderators / admin.	Once a page has been rated the page will save existing user rating
Feedback		Link to feedback directs user to free text form - option available to send to site admin	
Well being Tracker	Save	Holds personal scores from well being questions, with date and score held in tables.	
	Graph	Presents previously saved information in a graph plotting scores from well being questions against time when requested.	
Registration process		User is able to enter email address to begin registration process. Simple validation of address format is carried out and message returned if failed. System notification is received by set admin with hyperlink to activate account contained	
Save Favourites	Marks as saved	Allows pages to be saved and retains confirmation that page has been 'favourited' when it is navigated to at a later date.	
	Collates	Holds personal library of 'favourites' based upon log-on being used.	
Content			
Document download	inc. MS office docs, videos, links, pdf's, audio files	All document types can be accessed or downloaded from the site as required.	
Print page		Provides option to print current page in suitable, printer friendly format.	
Email page		Provides option to email url link to current page with the users default email server.	
Non-Functional			
Availability		Site need to be accessible for users 24 hours a day, 365 days	It's understood that routine maintenance will be required at certain points. During these times a message should be displayed (e.g. This site is currently unavailable due to maintenance, support can be found (add suitable referral point).
Volume	Web Traffic	Site needs to be able handle large volumes of web traffic	
	Content	Website must support large volume of content and downloads	
Security	User	Individual log-ons must be secure with option for user to retrieve password if required.	
	Admin	Only pre-defined admin team can upload content Only admin team can activate/amend/delete users	
Performance		Links are responsive and speed of navigation is suitable for users	IT support maybe required to understand where speed is linked to server issues / connection issue as oppose to webpage

Appendix M – Website Design Moodboard



Health/wellbeing colour's are predominantly natural pastel tones.



Personal Well-being 2012/2013

Personal Well-being 2012/2013



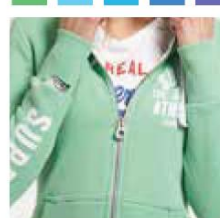
Teenagers (2014) are not afraid of bright warm colours. 10/7 colour palette best reflects this.



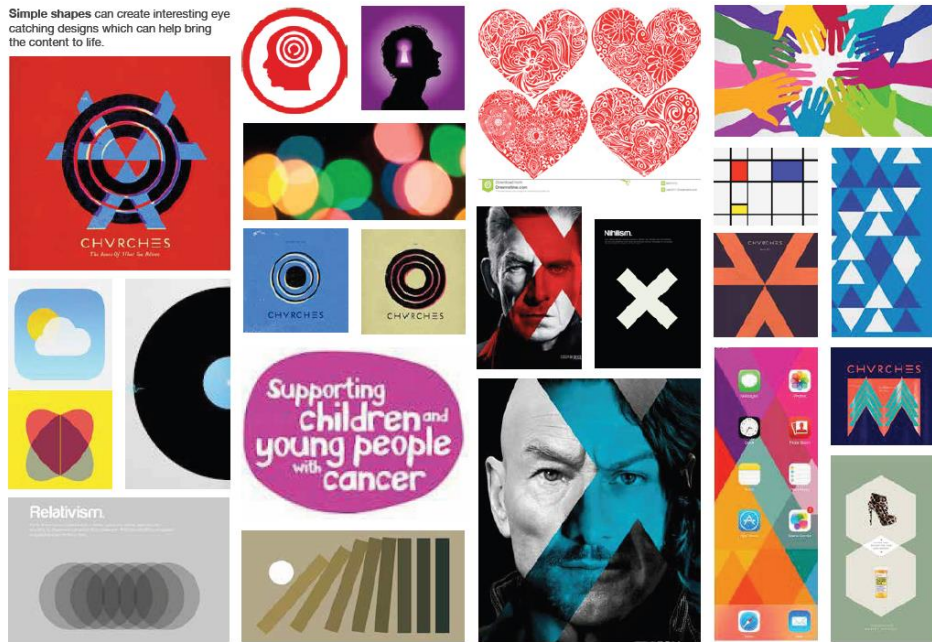
IN AID OF
**TEENAGE
CANCER
TRUST**

teenVOGUE

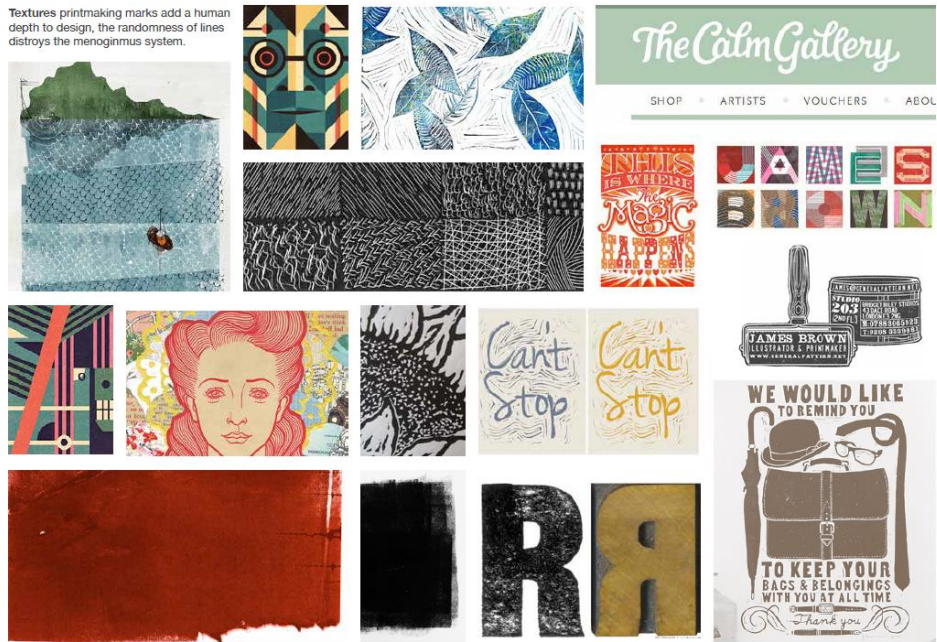
f t g+ b i



Psychological Support: Help! Website Report



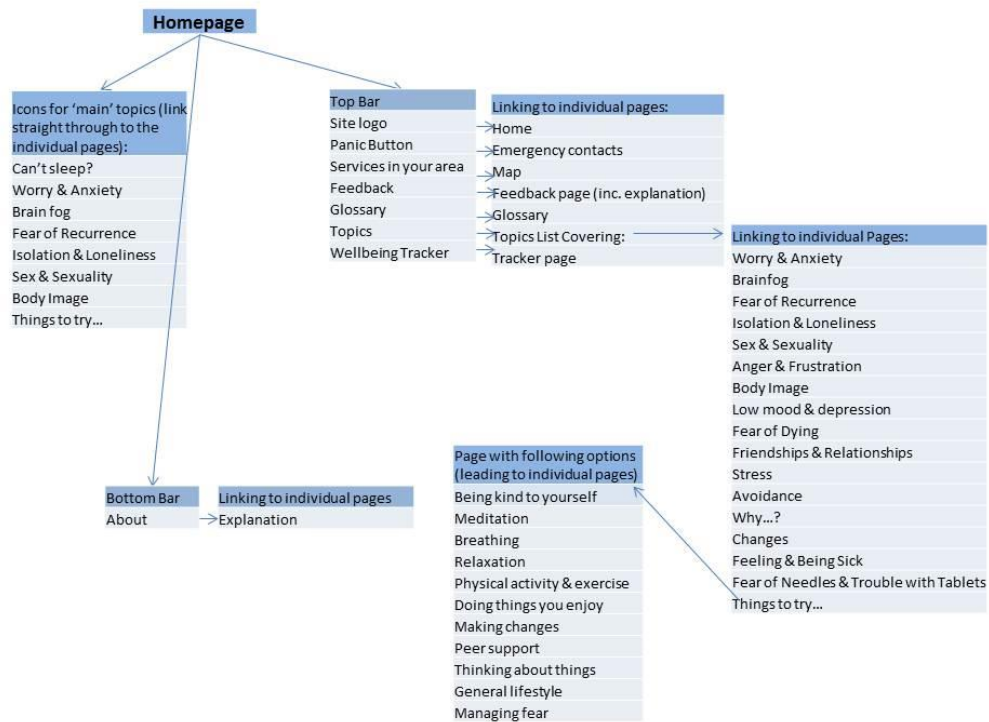
Psychological Support: Help! Website Report



This example best illustrates a good use of shape and colour. In fact the content is quite relevant to our own project.




Appendix N – Website Sitemap



Psychological Support: Help! Website Report

Appendix O – Website Risk Assessment

	Risk Assessment Proforma			Activity: On Target Psychological Support Website Pilot
	Date of activity: TBC	No. Staff: N/A	No. Unknown	

Hazard	Risks of Hazard	Who is at risk	Severity of risk VH/H/M/L/ VL	Likelihood of risk VH/H/M/L/ VL	Control measures put in place (include owner and timescale if appropriate)	Resulting Severity of risk VH/H/M/L/ VL	Resulting Likelihood of risk VH/H/M/L/ VL
Emotional Distress	Risk ranges from upset to suicide	Young People	H	L	<ul style="list-style-type: none"> Content subject to quality assurance processes Feedback mechanism through site Validation through relevant professional Appropriate signposting to emergency services 	M	VL
Accessibility	Language: <ul style="list-style-type: none"> English Level of complexity Visual Impairment	Young People	L	M	<ul style="list-style-type: none"> Encouraging staff to 'work through' the site with patients where appropriate WAI 'AA' Compatible Audio/Video options where possible Content written with teenagers and young adults Validation through relevant professional 	L	VL
Accessibility	Not accessible to those who do not have a compatible device, or those without internet access	Young People	VL	L	<ul style="list-style-type: none"> Providing access within the hospital (e.g. access in Area 61) 	VL	VL
Low numbers	No one uses the site: <ul style="list-style-type: none"> Patients not receiving potential benefit of intervention Discontinued co-creation 	All	H	M	<ul style="list-style-type: none"> Co-creation process used to create content young people have said they would engage with Engagement of staff across the south west in recruiting patients Advertising materials in appropriate places Consideration given to what is asked of patients (i.e. not asking for too much information in registration process) Providing access within the hospital (e.g. access in Area 61) 	H	L
Sustainability	Labour intensive process of site up keep that cannot be matched with current resources	All	H	M	<ul style="list-style-type: none"> Resourcing considered & training of a number of staff in authorising registrations & content management Content subject to quality assurance processes 	H	VL

No moderation	Site being used as a method of alerting healthcare professionals of severe emotional distress	Young People	VH	M	<ul style="list-style-type: none"> Clear messages in site that no one is alerted when panic button is hit/tracker results are low Appropriate signposting to emergency services 	VH	L
Data protection	Third parties accessing personal information	All	H	L	<ul style="list-style-type: none"> Limited personal data requested Sitekit security processes in place Logon access required Datacentre hosting website incorporates industry standard data protection, and is used by other healthcare providers 		
Inappropriate content management	Uploading of offensive/harmful material, or with poor evidence base.	Young People	H	L	<ul style="list-style-type: none"> Access to CMS limited Content subject to quality assurance processes Feedback mechanism through site 	H	VL

Activity Risk Assessment Sign Off			
Risk Assessor Name:		Date of Assessment:	
Risk Assessor Signature:			
Countersignature Name:		Date signed:	
Countersignature Signature:			

VH = Very high
 H = High
 M = Medium
 L = Low
 VL = Very Low

Appendix P – Change Definitions

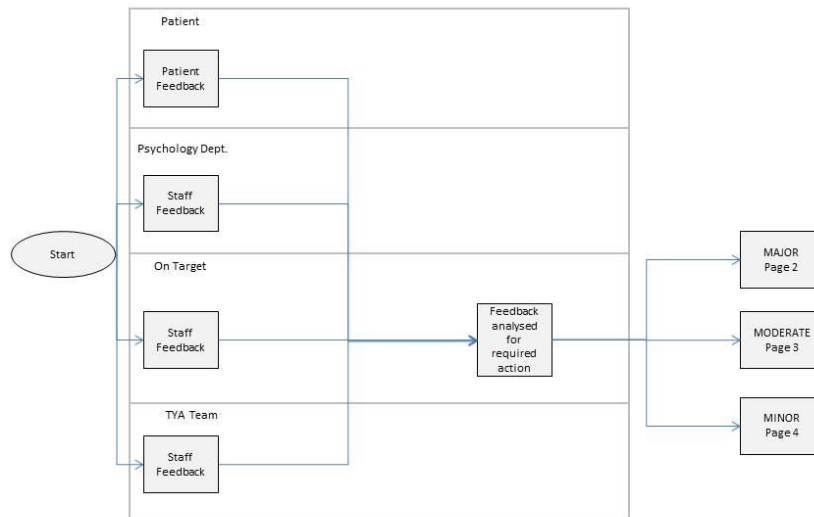
Definitions

<u>Technical Examples</u>	<u>Content Examples</u>
<ul style="list-style-type: none">• Hangs/Crashes complete application• Cannot perform any business processes• Corrupts stored data• Conflicts with legal requirements• Seriously compromises the ease of use of the application• Seriously incorrect behavior encountered	<ul style="list-style-type: none">• Content causes severe distress• Notification content/resources conflict with legal requirements e.g. Copyright
<ul style="list-style-type: none">• Software hard to use but does not prevent the customer from using the product• Does not report information that would be helpful to the user but otherwise does not affect the functionality• Affects some business processes but majority of business processes can be performed• Temporarily display incorrect information but does not mislead the user• Displays unfriendly behaviour that is hindering to the user• Displays cosmetic defects• Displays unfriendly behaviour annoying to the user• Low impact on business processes	<ul style="list-style-type: none">• Notification of research indicating additional content required• Rewording that changes the nature of the content• Additional psychological content• Additional informative/advisory content
<ul style="list-style-type: none">• Displays unfriendly behaviour not annoying to the user• Requested by On Target, but not as a correction	<ul style="list-style-type: none">• Typographical error• Rewording that does not change the nature of the content• Additional content that is not psychological or informative/advisory in nature (e.g. the inclusion of a support service in the directory)

Psychological Support: Help! Website Report

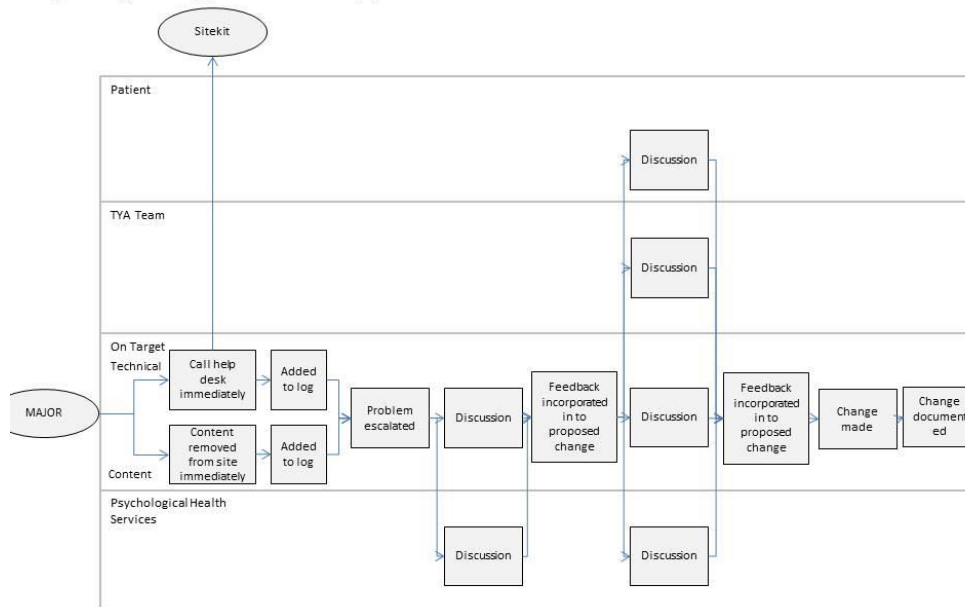
Appendix Q – Change Process

Psychological Support Website QA/Gov Process v0.2



1

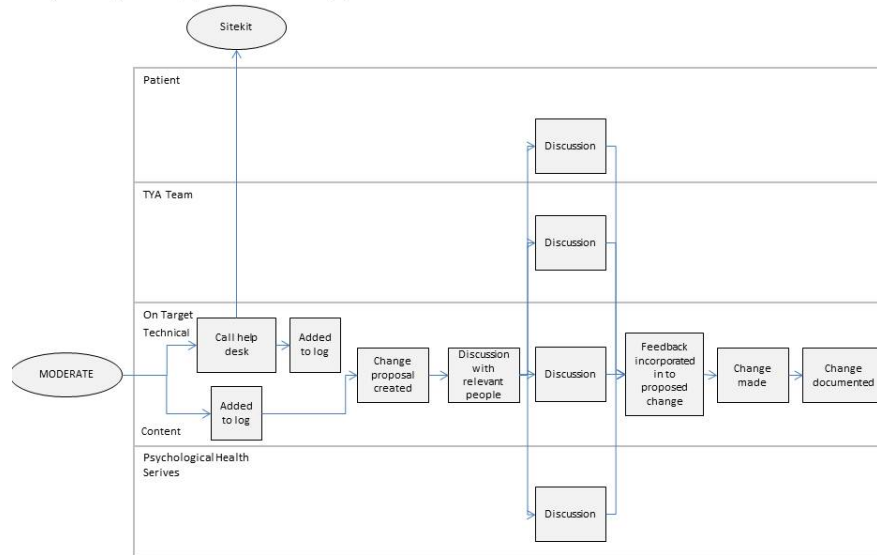
Psychological Support Website QA/Gov Process v0.2 MAJOR



2

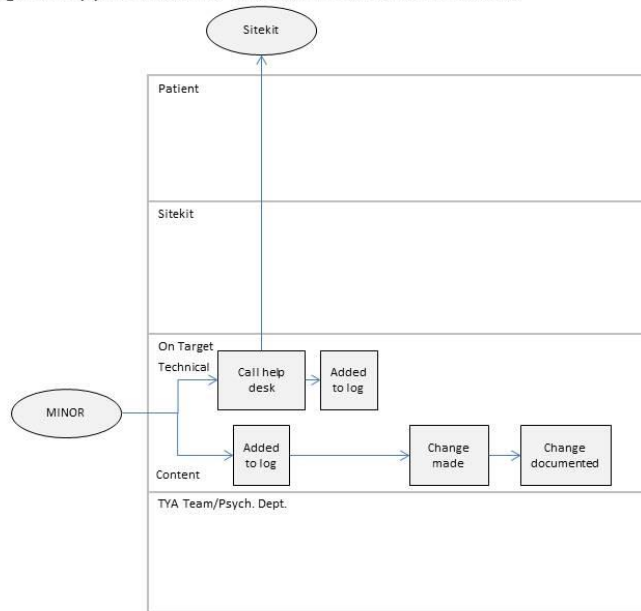
Psychological Support: Help! Website Report

Psychological Support Website QA/Gov Process v0.2 MODERATE



3

Psychological Support Website QA/Gov Process v0.2 MINOR



4

Appendix R – Website Specification: Upgrade

Help: I've got cancer : v1.1

Home page

1. Increase the kerning of the font or un-bold tag line to make clearer.
2. Topic images link to the page (as text).
3. Topic images look like they need to be more centred in their squares?
4. Night Switch feature should be moved to the right hand side of the light bulbs, so that the 'Pick a colour' and 'Night switch' text aligns horizontally. Then move the NHS logos left and centre the '2014 Univer...'
5. Clicking the Night Switch once in Night Mode turns it back to normal mode (colour).
6. In Night Mode remove the white boxes that appear around the bulbs.

iPhone view (Responsive)

7. The light blubs are missing the wire

Topics Page

8. The 'Edit Profile' and 'Log out' should be in their own hash-marked box, separate from Topics.
9. Some Favourites are listed as New Page instead of their page name
10. Distinguishing between links, docs etc. (perhaps bullet points?)
11. Submit option on stars
12. 'How are you feeling?' (worry & depression pages) incorporated in to the main text

Print this out

13. Alignment when printing. Only information printed website name, page URL, breadcrumbs, the article and links.

Panic Button

14. Redesign so the content is easily accessible in an emergency.

Other

15. Tracker visibility on night switch
16. Tracker alignment (on phone)

Map

17. Labels on map

Appendix S – Sitekit Order Form: Upgrade

This is an embedded file – please double click to access.



Quotation and Order Form

We are pleased to provide your quotation for products and services as follows:

Customer address On Target Wellbeing Project Bristol Bristol Haematology and Oncology Centre Bristol Royal Hospital for Children Horfield Road Bristol BS2 8ED	Quotation for: TYA Amendments Quote ref. QUO-01883-G5D5-r0 Valid for 30 days from 1 st August 2014 Please check all details carefully before signing your order and sending it or faxing it back to us on 0845 166 7299. Please add an official purchase order if required.
---	--

Group / Product Code Product name	Quantity	Unit price	Line total
04 Custom Development / S0401 Sitekit Bespoke Development	2	£750.00 / Per day	£1,500.00

Subtotal:	£1,500.00
VAT:	£300.00
Order Total:	£1,800.00

Account / Invoicing details to be completed		
Name:	Payment method:	Invoicing address:
Email:	Purchase Order:	
Telephone:	Will invoices be accepted by Email? Yes/No	

Payment Terms

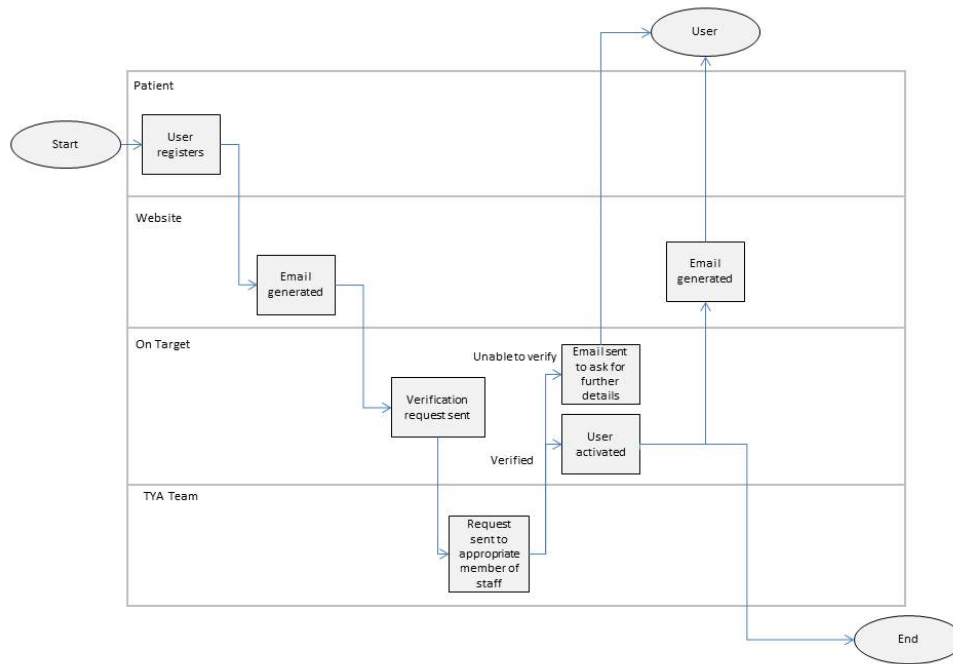
This order is for a total of £1,500.00 including VAT. I have received, read, understood and agree to be bound by the attached standard Terms of Business, and understand that by signing this order form I am entering into a legally binding agreement with Sitekit Solutions Ltd on the basis of the Sitekit Terms of Business as applicable to the items ordered above. The Sitekit Terms of Business, EULA, Support Services and Project Services specifications are available on the Sitekit web site (www.sitekit.net) using the customer extranet login ID which is issued to each customer.

Customer: _____ Signature: _____
Position: _____ Date Accepted: _____

I, the above signed, confirm that I have the full authority of the customer to sign this order form.

Appendix T – Website Registration Process

Website User Registration Process v0.3



Appendix U – Publicity Postcard



Psychological Support: Help! Website Report

Appendix V – Page Rating Results

	5	4	3.5	3	2.5	2	1	Average
Brain Fog	1	2		6		1		3.3
Breathing Exercises	1							5
Can't Sleep	2	1		1	1	6	1	2.7
Exercise & Physical Activity	1	1						4.5
Fear of Recurrence		4		4		2		3.2
Fertility	2							5
Glossary		2						4
Gloucestershire Services	1	1						4.5
Isolation	1	5	1	3				3.4
Low Mood and Depression							1	1
Meditation	1							5
Panic Button	1							5
Peer Support	1							5
Relationships - partner		4						4
Search	1							5
Services							1	1
Sex & Intimacy	2							5
Sexual Health	2	1						4.7
Sexuality	1							5
Talking About Sex	1	1					1	3.3
Tracker		2		2				3.5
Welcome	1	1					1	3.3
Worry & Anxiety	5	6		3				4.1

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Appendix W – Qualitative Feedback

FUNCTIONALITY	
Is it possible when you press the night switch and the screen goes dark, to press the switch (as if to turn it on again) to return to the colour you were using before?	As part of upgrade Aug 2014
Once you click the stars to make a rating, you can't change your mind. E.g. click 4 stars and then wanting to change it to 5 stars - currently you can't.	As part of upgrade Aug 2014
Tracker is not easily visible when using the Night Switch	As part of upgrade Aug 2014
Clicking the topic images should link to the page just like the text does.	As part of upgrade Aug 2014
Clicking the Night Switch once in Night Mode should turn it back to normal mode (colour).	As part of upgrade Aug 2014
Some Favourites are listed as New Page instead of their page name!	As part of upgrade Aug 2014
Add a submit button to Rate content so that I can change the rating if I wish before committing. What happens when I rate content?	As part of upgrade Aug 2014
1 page of info that printed out when I tested wasn't useful. All that really needs to print should be; Website name, page URL, breadcrumbs, THE ARTICLE and links.	As part of upgrade Aug 2014
Possible to have an option for larger size text for those who have poor sight?	Browsealoud functionality
I clicked on devon to look at the services but it just logs me out. Other than that, FAB!!! many thanks	Fixed
What does the Browsealoud button do? (When I click it, it doesn't do anything)	Fixed
Can we have a personalised welcome when user is logged on 'Hello ...'?	Information will be open access - recorded for private area
One area of the map doesn't highlight?	It doesn't need to - kept in map to keep the region geographically representative
The only problems that I have encountered whilst using the site so far (i appreciate that its a pilot) I am trying to rate using the stars but I don't think its working?	It is - functionality improvement as part of upgrade Aug 2014
I esp love the way you can personalise it with colour, and the night switch for those laptop in bed moments.	N/A
Maybe a few drop down boxes could be added or possibly a forum (With an added anonymous area for those that dont want to be named)	Recorded for future discussion
Ask a question/for help option - live - Forum section	Recorded for future discussion
When you click on the tests of anxiety etc symptoms- on my format at the end it just said, if you have any of these you might want to read the info- I wonder if if you are clicking yes to any/many then it should automatically take you through to a bit more info/advice??	Recorded for future discussion
Why are all topics not click-throughable' from the homepage?	Top topics shown on homepage
Is there a mobile version?	Yes
The Fertility clip doesn't play ...I don't know if this is just the Trust computer?!	Yes
Add a Back button after clicking through to a 'Thing To Try' so that you can navigate back to the Topic you were on.	Recorded for future discussion

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DESIGN	
Write the counties names on the map - people may not know where the county is, but will know the name.	As part of upgrade Aug 2014
On the things to try page could you have the 8 options listed in boxes like you have the topics listed in boxes on the home page?	As part of upgrade Aug 2014
The slogan 'Supporting emotional...' is not very clear. I would increase the kerning of the font or un-bold to make it clearer to read.	As part of upgrade Aug 2014
I feel that the Night Switch feature should be moved to the right hand side of the light bulbs, so that the 'Pick a colour' and 'Night switch' text aligns horizontally. Then move the NHS logos left and centre the '2014 Univer...'	As part of upgrade Aug 2014
iPhone view (Responsive): The light blubs are missing the wire!	As part of upgrade Aug 2014
The 'Edit Profile' and 'Log out' should be in their own hash marked box, separate from Topics.	As part of upgrade Aug 2014
Link boxes don't look like links - can this be extended - not easy to read	As part of upgrade Aug 2014
The only thing was that the click through are very close together- is it possible to just put a little space between them to separate them out, and one or two I was not quite sure what I would find on the link, so a slightly longer description maybe?	As part of upgrade Aug 2014
I feel it would be better to have the target, TYA care, Macmillan, UHB' banner at the top of the page so that people immediately know it's a site they can trust and also who runs it?	At bottom following a co- design session. Recorded for future discussion
On welcome note: Un-centre text, to make it more legible.	Fixed
Increase font size of 'Welcome'. Again doesn't necessarily need to be centred.	Fixed
Topic images look like they need to be more centred in their squares.	Fixed
Topics page: Again I wouldn't centre text.	Fixed
Nice icons and areas	N/A
I think it looks amazing and has loads of really useful good information/ links and resources	N/A
I really like the funky idea of being able to chose the colour of the pages and also including the 'night button'.	N/A
Most of all I love the light switch, very useful.	N/A
With regards to the website, from what I have explored, it looks good	N/A
Good font	N/A
It doesn't look NHSy	N/A
Seemed easy to nagivate and looks good	N/A
It would be good to have more drawn images, could you have drawn people/stick people on the pages to make it seem more human?	Recorded for future discussion
Pictures on the different topics that match the picture used for the topic on the welcome page. (E.g. key on welcome page for things to try, but no key on the thing to try page when you click on it).	Recorded for future discussion
Pictures that relate to the info on all pages would be really good.	Recorded for future discussion
All in all, i think the page is very good. Although I would suggest definitely adding some images onto each page for the more visual readers to look at as it becomes more intriguing. Maybe like the images that look drawn to still fit the over all layout. :)	Recorded for future discussion
Improve picture quality of the drawings; at the moment they look pixelated.	Recorded for future discussion
I really like the articles with photos. My suggestion would be more SouthWest relevant local photos/videos/external links to jazz up articles.	Recorded for future discussion
Update the 'hashed lines' to match the current site (not like my hand drawn lines).	Recorded for future discussion
I would add a few major cites for reference. Or even beaches or 'cool locations' to make it TYA friendly.	Recorded for future discussion
Panic Button: The information could do with a redesign so that the content is easily accessible in an emergency. I can give design advice on this if required.	Recorded for future discussion
I recommend Subcategories of Topics should visually be listed as follows (not in a white box). General Lifestyle -Sun Safe -Smoking -....	Recorded for future discussion
Icons - Some appear on page, and some don't - consistency?	Recorded for future discussion
My only other comment is that the site seems a bit one dimensional/ flat with the dotted boxes and I don't know if there is any way that it could be made a bit more engaging...but then I am not a teen so this may not reflect their feelings!	Recorded for future discussion
iPhone view (Responsive): Would be great if the logos were a bit bigger?	Small as pages are already long - recorded for future discussion
In Night Mode remove the white boxes that appear around the bulbs.	Upgrade
Topics page: Increase font size on Topic links to match other links.	Upgrade

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CONTENT	
Low mood and Depression: Says that there are some warning signs to look out for, but not what these are or where to find out about them.	As part of upgrade Aug 2014
Moodjuice pages - some present in landscape & are difficult to read.	Cannot fix
Change 'breathing' to 'breathing exercises (things to try)'.	Fixed
YP Face IT would be a useful additional resource for the Body Image section http://www.yfaceit.co.uk/	Fixed
Service map: Where is Bristol?	Fixed
Tracker: After submitting results, write something encouraging reminding patients to use the My Tracker again in the future and the positives of tracking.	Fixed
Ammend 'Jimmy Teens' to JTV	Fixed
The map isn't very accurate as it doesn't reflect Bristol area – when you scroll over it, it says Somerset....and it isn't until you click Somerset and it goes to the page that it says (inc Bristol).	Fixed
The fertility jimmy teens link- it was a long video- I watched half and it was not useful- mostly seemed to be 2 people saying that they doctors were wrong about their fertility- so it didn't feel like the most appropriate link.	Fixed
The wellbeing tracker is a good way for young people to keep track of how they are feeling – you might want to say that this is private for them (unless professionals be able to see what they are recording?)	Fixed
Isolation and Loneliness: Typo - add 'able' to 'being (able) to see people'	Fixed
Maybe mention which sites are moderated/'safe'	Recorded for future discussion
Nice icons and areas	N/A
I think it looks amazing and has loads of really useful good information/ links and resources	N/A
I really like the idea of the map to find out the services available to an individual in their area. I think that makes it a lot easier for someone to approach the TYA team as they know that there is one available to them. Also, it makes it more confidential to them to find someone to talk to because they don't need to ask around to find a contact number.	N/A
I think the glossary is brilliant to help individuals understand key terms related to cancer.	N/A
Love it. Lots of work gone into it! Love the glossary, love all the topics.	N/A
With regards to the website, from what I have explored, it looks good	N/A
Worry & Anxiety: Spot on!	N/A
Fear of dying: I think this is perfectly written	N/A
Peer support: Great!	N/A
Meditation: Great!	N/A
Relaxation: Great!	N/A
Making changes: Great!	N/A
Your site looks great - interesting content	N/A
Are we allowed to advertise/sell products not affiliated to NHS/Macmillan in connected links (mp3's - get self help)	N/A
I like the way that things have been written in a clear, concise manner and the fact that it is not too wordy	N/A
The info there seems worded clearly.	N/A
I like the local groups that you list under the 'services' tab – I think this makes it feel more personal/close to home	N/A
Visual media is also really good to use – it's also an easy way of keeping things fresh.	N/A
Could you have case studies/stories from young people/videos of young people who have struggled with a topic but share what helped them for others to read/watch on the website under each topic?	Co-design session topic Sept 2014
Time alone card - could you change 'for my very important person' to 'To...' so that they can be used for a variety of people and can be more personal as names can be written in.	Co-design session topic Sept 2014
Any link/ extra info available about 'fear of dying'?	Recorded for future discussion
Have a useful websites page	Recorded for future discussion
Could you have a FAQ about cancer page?	Recorded for future discussion
Could there be a section for moving on after cancer?	Recorded for future discussion
Could you have sections within it; 1) Help! My child has cancer 2) Help! My brother/sister has cancer 3) Help! My friend has cancer 4) Help! Someone I know has cancer (general)	Co-design session topic Sept 2014
Can't sleep: Love the advice - could have a 'find out why' link where they find out why these ideas would be helpful - some YP want to know how/why things work.	Recorded for future discussion
Brain fog: I would break this information into smaller paragraphs, due to the nature of the topic.	Recorded for future discussion
Sex & Sexuality: Need to add a line on sexual 'problems'	Recorded for future discussion
Relationships and Friendships: Need to add peer bereavement.	Recorded for future discussion
Exercise and Physical Activity: I think this needs a bit more	Recorded for future discussion
Talking to people: Could you add TYA team? Local hospital?	Recorded for future discussion
Breathing: Great! Maybe another example here	Recorded for future discussion
Doing things you enjoy: Needs more - could include working with social worker/youth worker to carry on with existing hobbies, and identify new ones to try.	Recorded for future discussion
Glossary: I would add common 'Hospital/doctor terminology' that young people might find confusing.	Recorded for future discussion
Fear of dying - list/links to org's/services that are available - or link through to map.	Recorded for future discussion
Should 'Shine Cancer Support' be included ?- they have a local support group for people in their 20's/ 30's/ 40's	Recorded for future discussion
The bit about fears about dying says There are also organisations and services available where you could speak to someone about your fearsbut it doesn't have any links or tell you where or how to find them!	Recorded for future discussion
I think that there needs to be a bit more information- I understand... you wanted to keep the text down in length, but I wanted more- it seemed to little. Maybe that the extra will be in links and click throughs, but on the pages I have been looking at that did not seem the case for most of the areas.	Recorded for future discussion
Links and signposting is a really good idea. We have lots of information for this age group on our website that you might want to sign post them too: http://www.clcsargent.org.uk/content/information We are currently enhancing our information on post 16 education and employment and I can let you know when this is ready in autumn. We are also planning to launch an online community for young people so perhaps this could be something that you could signpost young people to on the isolation/loneliness page? Again I can keep you updated on this.	Recorded for future discussion
Fear of Recurrence: I would give some suggestions about who to talk to - e.g. GP, TYA team, maybe friends/family, local psychological health services.	Recorded for future discussion
Typo - 'you have you have'	Fixed
(Further) Normalising the symptoms in the third paragraph would be good - just something to say that these can be managed?	Recorded for future discussion

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GENERAL	
I've just come back from an outpatients appointment at Bristol Oncology Centre where my consultant gave me one of the green cards advertising the website etc. I immediately noticed the slogan 'Help! I've got cancer.' I see it is also at the top of the website. I must say, this is a terrible slogan! For a young person who has perhaps just been diagnosed with cancer, this is quite 'in your face' and blunt. I have a brain tumour myself and have been dealing with it for 5 years and I find this slogan a bit much! People with cancer don't want to be reminded of it! Please please change it!	Co-design session topic Sept 2014
I think 'Help I'm a cancer patient' sounds wrong, I can't put my finger on it. I feel that I don't need to be told that I am in need of help. It's like going to Alcoholics anonymous and seeing a sign that says 'I'm a drunk and need help'.	Co-design session topic Sept 2014
It is a brilliant platform to develop in other areas such as other long term conditions for TYA and also adult services. I would definitely signpost patients to it - well done!	N/A
I think that this is a great site for my pts. I would happily signpost them to it.	N/A
It's good that you are collecting feedback from young people on an ongoing basis – the more they think that their ideas can shape the site, the more that they will take ownership of it and the stronger your content will get.	N/A
Are paper copies of the downloads available to young people when they come in/ on wards? Do materials on this website match those available to young people in the hospital?	Recorded for future discussion

Appendix X – Evaluation/Co-design Session Plan 18/09/2014

Session Plan for Co-Design Event: 4 hour (1 hour break)

Need:

Patients and professionals to review the website development to date, and to look at how the website content should be developed.

Aim:

To facilitate discussion/activities about some key areas that have come out of the feedback to date, and evaluate if/how the website is currently being used. Generate some ideas on how future co-ownership and development can be supported.

Objectives:

- ‘You said... We did...’ demonstration on how feedback has been used.
- Gather feedback on some of the pages.
- Discuss if/how the tracker is being used, whether it adds value and how it could be developed.
- Discuss the place of networker support through the website, and how it should be facilitated.
- Vote for if the name should be changed.
- Discuss the inclusion of the patient voice in the content.
- Next steps

Method:

Introduction	10 mins	JC	4-4:10pm
Consent forms given out on arrival (and collected) – ask all to do name badge (already allocated groups). Travel forms given out (to be collected throughout evening). Introduce people, On Target and the session. Housekeeping – loos, fire alarm, break-out. Introduce the ‘Additional comments’ box for anything they don’t want to say out loud/anything they think is important, but don’t have a chance to say. We have a general structure for this evening, but if anyone has something urgent they’ve come with the intention of speaking about – let myself or SD know.			
You said...we did...	10 mins	JC	4:10-4:20pm
Brief summary of the themes that emerged, and powerpoint demonstrating some examples. Chance to discuss after. Why we’re asking for feedback – working to develop. There’s stuff that we’ll have to wait to be able to do, but we’re able to develop as and when people say. Generally things fall in to three categories: functionality, design & content. And as we’re told things, and you’re sending suggestions – if we can do them now, they are being done – or they are being put on the plan for long term development. Functionality <ul style="list-style-type: none">• browsealoud installed so you can change the size of the writing, translate it in to other languages, or have it read out loud.• Rather than just press the star rating and the score is given – have to submit.• Night switch now turns on and off again.• Can now link to pages through the whole icon – not just the wording.			

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<p>Design</p> <ul style="list-style-type: none"> • We've uncentred text to make it easier to read. • DSomeone noticed the lights bulbs didn't have wires on the mobile version. • People asked for pictures on the pages. • And we've reordered images to make them look better. <p>Content</p> <ul style="list-style-type: none"> • Tweaks to wording • Labelling where it's been asked for • If people have suggested links, they go on • And we've started to upload video content, that we've done with young people across the south west. 			
Pages	40 mins	JC	4:20-5pm
<p>Five example pages and one for what else should be included, what should there be less of, and more of. Five minutes on each. (Four groups of one prof & one YP – two group of one prof & two YP). Star ratings and comments section.</p>			
Tracker	30 mins	JC (SD score & scribe)	5-5:30pm
<p>Using green/red cards: Have you used the tracker? Have you used MY QuOL-T? Groups to look at it. General impressions discussed. Specific questions: When might tracking be useful? If you wanted to track, is the 'quick tracker good enough? How could it be improved? (explanation of MY QuOL-T) Should we be looking to make this suitable for young people?</p>			
Networkers	20 mins	JC (SD scribe)	5:30-5:50pm
<p>Introduce with quote. Explain that the scope of this part of On Target has been completely patient focused, but we also appreciate how important it is to know that the people around you are supported. Hard to make a completely new website, but as the information is made open access: What should we do? Should we include specific pages? Links within relationship pages?</p>			
Name	10 mins	JC	5:50-6pm
<p>We've had positive feedback about the name, but there have been a couple of people that the name doesn't work for. Three point likert scale. Ask everyone to place a sticker on an option: 'The name should definitely stay' 'I'm not fussed either way' 'The name should definitely change' Explain speaking to people who couldn't make it too, so when all the results are in we'll be able to establish if we need to do something.</p>			
DINNER	45 mins		6-6:45pm
Young Person led content	20 mins	SD	6:45-7:05pm
<p>Using green/red cards: Ask the question if it would improve the site to have more young person led content. If no: Go to close!</p>			

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<p>If yes: Split in to two groups to discuss two questions</p> <ol style="list-style-type: none"> 1. How might it change the site? Look, feel & content. 2. How can we do it? <p>Two groups including two prof in each and even split of YP – JC & SD to sit with one.</p>			
	20 mins	SD (JC scribe)	7:05-7:25pm
<p>Each group to present their ideas. Full group discussion.</p>			
Closing	20 mins	SD & JC	7:25-7:45pm
<p>Action plan created throughout session & any feedback. Travel expenses collected. Case study participation introduction – forms if interested.</p>			

Resources required:

Comments box	Powerpoint-‘you said’	Example pg’s	Flipchart
Comment slips	Powerpoint-networkers	‘What else?’ pg	Flipchart paper
Stickers	Laptop	Star rating (pg’s)	Pens
Green/red card	Consent forms	Comments (pg’s)	Travel expense
Likert scale	Case study info	YP led content qu’s	Sticky labels

Appendix Y – Evaluation/Co-design Summary 18/09/2014

Notes from the Help! co-design event – 18th September 2014

Tracker

Have you looked at the tracker?	Have you used the tracker?	Have you looked at My Quality?
2/8	1/8	0/8

Tracker use:

I don't like it... get miserable... if say 3/12 low scores... I'd like to forget about how miserable.	What if you feel like crap... it doesn't help.
Not accurate.	Good concept but I'm not keen.
It's just another thing.	Don't think graph is useful... no trend.
Graph isn't representative.	Expect to be miserable... look at working...
Crap if goal is unattainable...	Only if you have a good day...

How it could be improved:

If you grouped & averaged up things that could improve something.	Could be helpful if emotionally.
Eliminate negativity.	Diary maybe good to link with.
Customise... added to...	Link to info – link to what.
Positive purpose.	Could be helpful between things to see change or join things together.
Plug in's – link in to other YP thoughts (see what others are tracking).	Choose chart type, more info and sections? Physical advantages. Maybe have more sections.
Inspirational quotes at the end? Small funny animations? Something to make you smile!	Key & legend are not very clear.
Link with goals.	Log & diary notes.
More than feelings.	Relatable to where you are in your journey (in chemo, in remission...).

To do: Check full tracker graph comes up consistently.

Networkers

- I'm worried about my parent/friend/sibling, what can I tell them/links to support available to them – could be under a section where SW links to worrying about other people.
- More of update later – focus on me – lots of help for others. Doesn't need to be there for a few months – look at Macmillan, TCT...
- If people go online, find crap stuff, should be an expand for others. I know my friends didn't want to ask and my brother. It's a good idea to have a section. Reliable information.
- Depends on point of section – if it's about reliable website can signpost but this was supposed to be one page, could be enough go to...
- Help! My child has cancer. Go to -> reliable websites.
- Do a paragraph from a YP with cancer. Develop up cards from sibling/friend cards.
- Have a signpost at early stage -> first stage, with a 'where to go'.
- How to sit down and have a chat – check the 'what now?' section – Australian website (VB).
- From the point of view as a family, I think it needs a small paragraph saying I need this – this is what I have – more info and a list of websites – reliable that can be visited.

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Panic button

- As other pages – doesn't look as though the page has changed.
- 'Head not good' button as another option instead of panic button? Or 'Head f****d' (too rude probably) or other phrase instead.
- Will it give some ideas? Click on it upset, and get suicide. Rewrite it in terms – emergency/urgent help. Terror button? Distress? Urgent need? Crisis button? Get help? Need help?
- Look at Samaritans website & how to use.
- Emergency information, then click through to less-of-an-emergency information.
- Online vote?

Name change:

It should stay	Not fussed	It should change
1	8	4

Suggestions:

- 'Teenagers and Young Adults rather than TYA'
- 'I've been diagnosed with cancer – support & emotional wellbeing of TYA'
- More pizza.

Cant' sleep section:

1 star	2 star	3 star	4 star	5 star
0	5 (=1x 2 ½)	1	1	0

Suggestions:

- Bullet points need working on. Also 'avoid alcohol and caffeine' before bed or a few hours before? I know, but comes across as all the time.
- Last point separated from bulleted list?
- Explain how & why each thing could help.
- Needs to consider more reasons why people might not be sleeping.
- More conversational
- Use more lighthearted use of punctuation and language. Less full stops. Use the tone a teenager would use. (and agreement statement).
- Upbeat phraseology/calming.
- As if someone is actually talking to you.
- Less direct instructions – can be seen as 'nagging'. Not like your mum/teacher would say it.
- Maybe suggest not looking at the time to encourage not focusing on not sleeping.
- 'Try not to worry about not sleeping' – can this be rephrased or add extra instructions, otherwise instant response is 'how can I not worry?' ... needs more, maybe some advice on how to help get to sleep? More detail on things to do.
- Temperature spelt wrong!
- Suggest the option of sleeping tablets? Pro's & con's?
- Extremely short points, maybe have an 'expand on this' option.
- 'there are things that you can do that may help' or 'there's loads you can do to help!' Promising too much?

Fear of Recurrence:

1 star	2 star	3 star	4 star	5 star
0	2	4	3	0

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Suggestions:

- Specify that these are ‘normal’ or ‘common’ feelings.
- Needs some sort of help/support – links to services, things to try, things to reassure & make you feel better.
- ‘Reassurance on recurrence’ – new name?
- Don’t need ‘however’ (and agreement statement).
- Suggestions of who to talk to – inc. healthcare professionals (and agreement statement).
- Dates for social gatherings – or contact... to find out about socials in your area to meet YP who also have/have had cancer.
- More chatty language.
- Reiterate how common/normal it is to have these thoughts (and agreement statement).
- Less listy – suggest speech bubbles/mind map design.
- How friends/family react after treatment (different) - (and agreement statement).
- Go the extra step, and explain how to deal with the feelings. Stats on how it’s not as often as you think.
- Option of someone’s experience to read – how they faced the situation.
- Talk to someone who’s been through it!
- Could be downloadable content area.

Worry & Anxiety:

1 star	2 star	3 star	4 star	5 star
0	0	2	4	4

Suggestions:

- Really like the questions
- 3rd line down – ‘you have’ typed twice.
- Love the ‘how are you feeling?’ section.
- Typo on ‘how are you feeling?’ section – ‘if you experiencing’ (missing ‘are’).
- Could add one-to-one area (talk to someone).
- Layout needs adjusting. Too much free space, unless space could be filled with more content?
- Perhaps use different colours for the font on the page, instead of just black to make certain text emphasised and differentiate from the other text. It also looks a bit plain.
- Explanations of why you may be feeling like this e.g. because of stress, emotions, different medication people, may be on, as a side effect of sleep deprivation etc. – this might make people feel better about it and not think they are being weak.
- Less listy – mind map the ‘how are you feeling?’ questions – click on one of the questions, and it takes you through to ‘things to try’.

Brain fog:

1 star	2 star	3 star	4 star	5 star
0	1	6	2	0

Suggestions:

- “I got brain fog from the brain fog section!”
- Layout more uniformed.
- Titles in bold? Blends in with the main text.
- Make icons 3D?
- Some examples of what is in the Princess Margaret download (and agreement statement).
- Maybe some things to help bullet points on the page rather than straight to link. Give a few examples then a ‘read more...’.

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- Continuity between topic pages.
- Menu options as tabs? To look more like buttons.
- Larger and/or different font (and agreement statement).
- Font too small/more emphasis needed on title.
- Not enough information in the text about brain fog.
- Too many 'you may's'.
- Too many full stops, doesn't flow.
- "If you're feeling miserable you're not going to go to a Macmillan site and read a load of information – you want something snappy" (Leonardo, 2014) – 'video' added.
- Change text/font size for links to make it clear they are links.
- There is nothing positive/happy about the page.
- Break up the long paragraph of text.
- Use images to make it easy to read.

Isolation:

1 star	2 star	3 star	4 star	5 star
0	0	3 (=1x 3 ½)	5	0

Suggestions:

- More writing, or make the text larger (fits with photo).
- Second bottom line – missing words 'but there ways to this'.
- Below text link 'things to try' so people are aware – they may not scroll down.
- Layout nto be more uniformed and make better use of space.
- *Tick* Video great idea.
- *Tick* Links to other websites.
- Tell you about what each website is about and how they are different.
- Could add a comments box for patients to share advice, tips or support.
- Photo is maybe too much emphasis on the negative?! How to talk to people?! Harder said than done.
- Not sure about top right pic... needs better picture but with same meaning (and agreement statement – yeah, what is that about? Agree).
- "You may..."
- Text not for ants (i.e. too small).
- Link through to fear of recurrence page – because it talks about meeting/talking to people.
- Arrange the information on the page to fill up the spaces.
- Use word art for the topics – less boring font – "makes you think of school".
- Personal stories.
- It tells you to talk yo people in the same situation bit could you give a platform to do that? Or some groups nearby? Rather than focus on social networks, meet in person.

What else?

- What about suggesting that friends & family use the website so you don't have to explain everything yourself.
- List of all types of cancers to click on and get info, and videos maybe.
- Symptoms & side effects – not for everyone, but I like/liked to know.
- Everything needs to be positive, reassurance, no promises (if this makes sense).
- During treatment...
- After treatment...

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- After remission...
- List and links to all other cancer/help related sites and charities. Also help lines (if need to talk whatever the time).
- Going back to school?
 - What happens?
 - Tips
 - How to deal with changes
- Not sure how to phrase – but the good things that come out of bad situations! Holidays? Day trips? New friends? New lease of life? Positives. (with agreement statement – should refer to building on the experience... if you can).
- Catchy sub-categories.
- Things to do in different contexts i.e. neutropenic, disabled activities.
- Confidence knocked:
 - Going back to a work environment/college.
 - Tips for getting back to work (website volunteering links).
 - Online courses.
- ‘How to talk to people’ section.

General

- School work font – can we change it?
- Navigation bar – can text be larger? 3D?
- Keep it fresh & update.
- More colour palette. Change from 1970’s beige paper – graphic based. Random pieces of paper (pin board).
- Elisha’s blog.
- Hope for hopeful page.
- Orange glitch - correct.
- Don’t like beige colour on it.
- Navigation box should be in the green section on side, and should be there permanently.
- Background colour should be different – more appealing to the eye.
- The main font throughout the website should be more fun.
- Mobile version really long – talk to Michelangelo!
- ‘Young people have told us... Young people said...’ – ‘We found...?’!

YP led content

How might it change the site? Look, feel and content.

Font	Language	Creative stuff e.g. animations
Don’t like the beige boxes and the font in the beige boxes.	Lots of spare space.	Navigation box on the colour not the beige.
Less ‘you may’.	More positive! Happy! ‘These things <u>will</u> help’.	Sometimes ‘we’ feel like this – written by YP.
Links to helpful/useful websites	Advice from others	Poems
News page – people can share their stories	Put YP in touch with other YP who have experienced or been through similar things.	Quotes
Links to blogs & blog sites		

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How?

Email link – send in your ideas	Needs moderation	‘Help us develop the website’ tab – polls, ideas.
Make it clear that YP’s ideas & comments/sections for website can be included here. ‘Suggestion box’ on the website.	YP’s writing Collaborative Flexible commitment	Through TYA Emails asking for ideas/additions. More events. YP coming up with ideas/titles.
Regular seminars	Shouldn’t be like Wikipedia where anyone can add/amend – all content to be moderated by a professional (TYA team).	Shouldn’t rely on one fixed group – all TYA.

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Appendix Z – Website Outcome Mapping

	WORKSTREAM	PSYCHOLOGICAL SUPPORT	
		Help! Website	Staff training (MI)
	Intervention		
1	Can this intervention be offered to all TYA patients?		
2	Does the intervention ensure that the patient's view / voice is central and acted upon?		
3	Does this intervention offer sufficient flexibility in its approach so as to meet differences in individual patient wishes?		
4	Is this intervention evidence based and have we explored other examples of best practice in this area?		
5	Does the delivery of this intervention take account of the challenge to patients of dealing with new experiences?		
6	Will we be able to publicise / promote this intervention in a way that helps to demonstrate the needs of TYA with cancer?		
7	Will this intervention promote self management?		
8	Can this intervention be applied to patients with cancer in other age groups?		
9	Does the information to be offered about this intervention meet the needs and expectations of TYA / networkers?		
10	Have TYA / networkers been involved in the creation / design of this intervention?		
11	Will the delivery of this intervention respect patients' needs for privacy and dignity?		
12	Does this intervention support the patient as they manage the challenge of cancer to their sense of identity?		
13	Have we considered all possible ways of delivering this intervention?		
14	Are there any specific equity / access issues to consider in the implementation of this intervention?	Yes - mitigated	
15	Is this intervention consistent with the future strategic direction of the clinical service and with national policy?		
16	Will this intervention be applied at the earliest appropriate point after diagnosis?		
17	Is this intervention applicable / transferable across the SW TYA clinical network?		
18	Is this intervention sustainable if integrated into the clinical service?	Resource dependent	
19	Have the appropriate teams been engaged in the design of this intervention (or will they be) and are we clear with whom we are taking its further development		

KEY

	Meets this core value (relevant issues addressed / mitigated as required)
	There is some uncertainty whether the intervention meets this core value
	Does not currently meet this core value
	Is not applicable to this core value
	Work is insufficiently developed at this stage

WORKSTREAM	PSYCHOLOGICAL SUPPORT	WELLBEING	WORK	NETWORKER NEEDS	PRIMARY CARE ENGAGEMENT, TS & CPs							
	Help! Website	Staff training (MI)	Onwards & Upwards Wellbeing Day	Ward Wellbeing sessions	IAM app	Wellwork Mentoring programme	Early work advice for professionals	Networker feedback questionnaire	Resources for Networker support	Early engagement with Primary Care	Treatment Summaries and Care Plans	Cancer Aftercare Review
DOMAIN 1: PREVENTING PEOPLE FROM DYING PREMATURELY												
INTEVENTION												
NHS OUTCOMES FRAMEWORK 2014/15 (Improvement areas within each domain have been selected on the basis of their relevance to TYA cancer and to the ON TARGET programme)												
Reducing premature mortality from all major causes of death												
DOMAIN 2: ENHANCING QUALITY OF LIFE FOR PEOPLE WITH LONG TERM CONDITIONS												
Ensuring people feel supported to manage their condition												
Improving functional ability in people with long-term conditions												
Reducing time spent in hospital by people with long-term conditions												
Enhancing quality of life for carers												
DOMAIN 3: HELPING PEOPLE RECOVER FROM EPISODES OF ILL HEALTH OR FOLLOWING INJURY												
There are no specific improvement areas applicable to TYA cancer although this Domain is a focus of On Target's work												
DOMAIN 4: ENSURING THAT PEOPLE HAVE APOISITIVE EXPERIENCE OF CARE												
Improving people's experience of outpatient care												
Improving hospital's responsiveness to personal needs												
Improving access to primary care services												
Improving children and young people's experience of healthcare												
Improving people's experiences of integrated care												
DOMAIN 5: TREATING & CARING FOR PEOPLE IN A SAFE ENVIRONMENT AND PROTECTING THEM FROM AVOIDABLE HARM												
There are no specific improvement areas applicable to TYA cancer												

KEY: Work from On Target

Is likely to generate data to demonstrate the value of the intervention in this improvement area

Should have an impact in this improvement area but supporting data will be limited or unavailable

Is unlikely to have an impact (or is not applicable) in this improvement

Work is insufficiently developed at this stage

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WORKSTREAM	PSYCHOLOGICAL SUPPORT	WELLBEING			WORK		NETWORKER NEEDS		PRIMARY CARE ENGAGEMENT, TS & CBS				
		Help! Website	Staff training (MI)	Onwards & Upwards Day	Ward Wellbeing sessions	IAM app	Wellwork Mentoring programme	Early work advice for professionals	Networker feedback questionnaire	Resources for support	Early engagement with Primary Care	Treatment Summaries and Care Plans	Cancer Aftercare Review
MACMILLAN NINE OUTCOMES	INTERVENTION												
	1 I was diagnosed early												
	2 I understand, so I make good decisions												
	3 I get the treatment and care which are best for my cancer and my life												
	4 Those around me are well supported												
	5 I am treated with dignity and respect												
	6 I know what I can do to help myself and who else can help me												
	7 I can enjoy life												
	8 I feel part of a community and I'm inspired to give something back												
9 I want to die well													

KEY: Work from On Target
Meets this outcome
Should have some indirect value in addressing this outcome
Is unlikely to meet (or is not applicable) to this outcome
Work is insufficiently developed at this stage