

NHS Improvement

1. Your details	
Name	Andrea Slater
Organisation	The Christie NHS Foundation Trust
Email	Andrea.slater@christie.nhs.uk
Contact Number	0161 918 7362
Document revised	13/5/2010
	11/6/2010
	14/7/2010
	6/8/2010
2. Details of your project	
Give a description of your project.	<p>The Christie Hospital Treatment Summary / Care Plan is a new service innovation that aims to improve information for our Teenage and Young Adult cancer survivors.</p> <p>The purpose of the change is central to the governments National Cancer Survivorship Initiative (NCSI), which endeavours to improve care and support for people living with and beyond cancer.</p> <p>The project builds on work being undertaken at The Christie to provide a personalised treatment summary and late effects follow-up care plan including;</p> <ul style="list-style-type: none"> • Diagnosis • Stage • Treatment (including chemo and XRT doses) • Summary of potential Late Effects and the importance of follow up needed post disease specific surveillance <p>The intention is that this summary will be individualised and concise, and copies will be held by the patient, cancer centre, and general practitioner. It is thus available for any future health care consultations in primary, secondary or tertiary settings in the United Kingdom or abroad</p> <p>The Teenage and Young Adult (TYA) groups' contributions to steering group discussions include; <i>'GPs need more and concise information', 'knowing what to expect takes out some of the worry', 'be good to have something you can take with you when you move'</i></p> <p>Outcome to date: Delivery of Treatment Summaries by 3 clinicians at The Christie commenced in Dec 2009 and is a continuous process.</p>
To what clinical area does your project relate?	
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	
What type of change did your project aim to address (e.g. service redesign, new technology etc).	
What tangible change / tangible outcome have you achieved to date	
What was the purpose of the change and what improvement did it deliver?	

<p>Did the proposed changes contribute to the achievement of any agreed standards or the delivery of any guidance? If yes please give details and reference where possible.</p>	<p>The proposed changes contribute to the guidance and vision proposed in the Department of Health (DH) (NCSI) Vision document.</p>
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3. How you have implemented your project	
<p>Please describe how your project proposals were implemented.</p>	<p>The Christie has worked closely with Great Ormond Street Hospital to define the Treatment Summary / Care Plan document (TS/CP), following much discussion and input from stakeholders.</p>
<p>Give details of any additional costs or resource demands that arose, including staffing or new equipment.</p>	<p>At The Christie the key stakeholders include patients, Y.O.U staff, NHS Improvement and the Cancer Network, and representatives from these areas were all invited to participate in the project steering group.</p>
<p>Were Equality issues identified and how were these addressed</p>	<p>The phased approach of the project is to:</p> <ol style="list-style-type: none"> 1. Develop a Treatment Summary/Care Plan in conjunction with GOSH 2. Collect baseline evidence of patient experience and views on the Treatment Summary/Care Plan. 3. Issue Treatment Summary/Care Plans to survivors at Christie Hospital and GOSH and at other volunteer hospitals. 4. Conduct a survey of the subjects, six months after they were issued with a Treatment Summary/Care Plan, to confirm the benefits.
<p>Who were the champions or key stakeholders and how were they involved in the project?</p>	<p>The Baseline Questionnaire and Treatment Summary/Care Plan were approved by hospital governance and the medical records committee. No equality issues were identified.</p>

4. Evidence of QIPP throughout testing and implementation	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	To ensure effectiveness and appropriateness of the project we measure the value of the intervention and ensure there is continuous re-assessment and ongoing refinement.
Quality including safety	The patient will receive a clear, brief, written summary of the type, doses and duration of chemotherapy/radiotherapy (including site) received and any possible late toxicities. Primary Care will receive a summary of potential late effects and the importance of follow up needed for post disease specific surveillance. Cancer care centres will retain clear information about previous treatment and any health care professional involved in the management of any subsequent health problem.
Innovation	The Treatment Summary/Care Plan is a new service innovation that aims to improve communication and provision of information for our Teenage and Young Adult cancer survivors.
Productivity / cost or savings / effectiveness including the scale of the benefits.	The primary benefit of this quality information will improve patient support, choice, self-management and potentially benefit their use of NHS services. It may improve patients' uptake to appropriate follow-up care, improving clinic attendance and reducing DNA rates.
Prevention	The Treatment Summary / Care Plan aims to inform and empower the survivor. It improves self management and should help identify future signs and symptoms and what to look for in relation to late effects of treatment.

5. Other sources of evidence	
Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data	<p>The project is now being tested in the Young Oncology Unit at The Christie. Testing commenced Dec 2009 and is ongoing.</p> <p>A baseline questionnaire survey of survivors has been conducted to evaluate what they were told or what they remembered about late effects of treatment.</p> <p>30 Teenage and Young Adults received questionnaires;</p> <ul style="list-style-type: none"> • 15 x completed treatment < 5 years ago • 15 x completed treatment 5 – 10 years ago <p>The baseline questionnaire examined:</p> <ul style="list-style-type: none"> • Spoken and Written Information - What they remember of being told, or receiving in writing, information about long term side effects of treatment and the need for long term follow up. • Experience of obtaining information - How they rate the information obtained from various sources. • Treatment Summary and Care Plan – Comments on a blank TS/CP and its usefulness. <p>Test progress to date:</p> <ul style="list-style-type: none"> • Baseline questionnaires – 30 done and evaluated

	<ul style="list-style-type: none"> • Treatment Summaries – 42 done and 29 given – test deadline extended to try and obtain more • Other YOU clinicians hadn't really got on board much with TS delivery, mainly produced and delivered by Dr Ed Smith. Two further consultants now starting to deliver (Martin McCabe and Jo Tomlins) • Treatment summary delivery is time consuming and requires a fair amount of effort (though this should improve with practice and improved templates). The effort required should ultimately reap rewards for both patients and care providers. • Six further national Test Sites are helping to increase the numbers of TS given – total is approx 100 at the moment. • Presented baseline findings and current project progress at the CYP national workshop meeting in London on 24th March 2010. Conclusion and comments – patients and guardians <ol style="list-style-type: none"> 1. are generally well informed 2. want more information 3. find the treatment summary / care plan a good idea • SIAN meetings June 15th and July 20th –post project evaluation discussed • Poster presentation required for CYP national meeting in London Sept 23rd 2010. • Kate Pye now working with Faith Gibson and helping devise and co-ordinate post-project questionnaires and evaluation – almost ready to send out. • Post project questionnaires sent out to 17 x Christie patients and their GPs- date for return to Kate by 16th Aug. Kate sent questionnaires to all care professionals who completed the Treatment Summaries. <p>(baseline results - see Appendix A)</p>
<p>Are there any other sources of evidence of how it could affect cost and quality? If yes please give details</p>	<p>Ongoing evaluation:</p> <ul style="list-style-type: none"> • Data collection sheets contain patient details and comments section for final evaluation. • Monthly report from all test sites of numbers of TS/CP delivered to patients. • Creation and revision of templates as required. <p>Early feedback includes the following points:</p> <ul style="list-style-type: none"> • The time and resources required to complete and deliver TS/CP are substantial, especially for patients with complex cancer histories. • There is a lack of a dedicated resource to do this, on an already busy unit • Longer clinic times are required for discussing the summaries • There is a requirement for creation of templates – increases time and effort • Engagement of all clinicians is vital to success and not all required clinicians engaged in the project
<p>Please present comparisons of base line vs. actual data where relevant</p>	<p>Post-test evaluation is to be performed by NHS Improvement approx 6 - 12 months following care plan delivery. Questionnaires will be sent to patients, parents, GPs and healthcare providers. Kate Pye now working with Faith Gibson and helping devise and co-ordinate post-project questionnaires and evaluation – almost ready to send out.</p> <p>This will be compared to the baseline evaluation.</p>

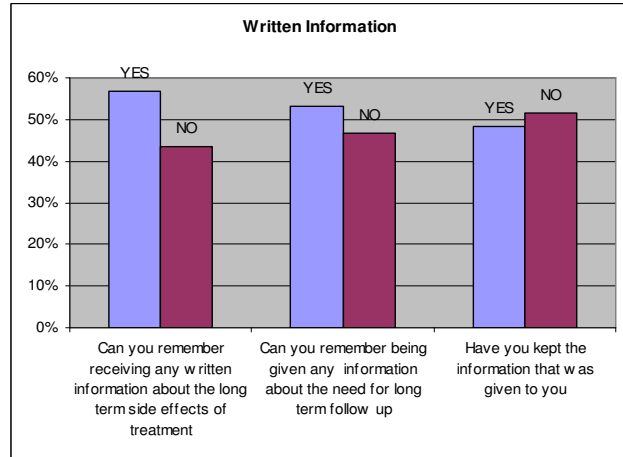
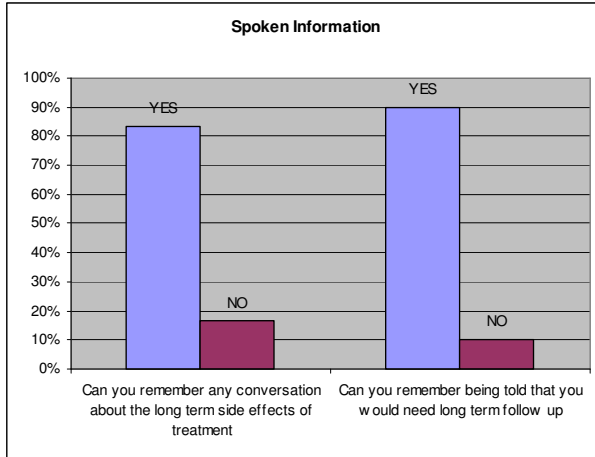
Give an assessment of how your evidence will provide inform & influence service commissioners	
6. What are the challenges and positive elements of testing	
What other considerations should someone planning to implement these proposals be aware of?	Awareness of time and resources necessary to complete and deliver Treatment Summary / Care Plan.
Are there any potential top tips or potential pitfalls?	Early engagement of clinicians is vital.
Please identify negative elements of the testing and implementation	Most of TS/CP delivered by one consultant, other clinicians not fully engaged with project. Numbers of TS/CP delivered in project timeframe lower than estimated.
Give details of what worked really well throughout the life of the project	Acceptance of the TS/CP by the patients
What are the plans for long term gains	

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	<p>Clinical Lead: Dr Ed Smith Consultant in Clinical Oncology Ed.smith@christie.nhs.uk</p> <p>Project Manager: Andrea Slater Andrea.slater@christie.nhs.uk Tel: 0161 918 7362</p> <p>Project Administrator: Martine Tempest-Mitchell Martine.tempest-mitchell@christie.nhs.uk Tel: 0161 918 7127</p>

Appendix A

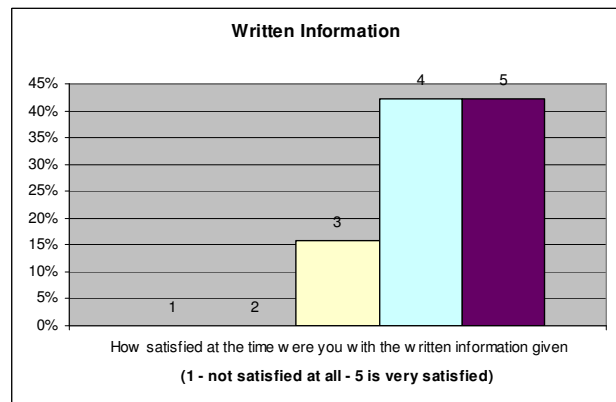
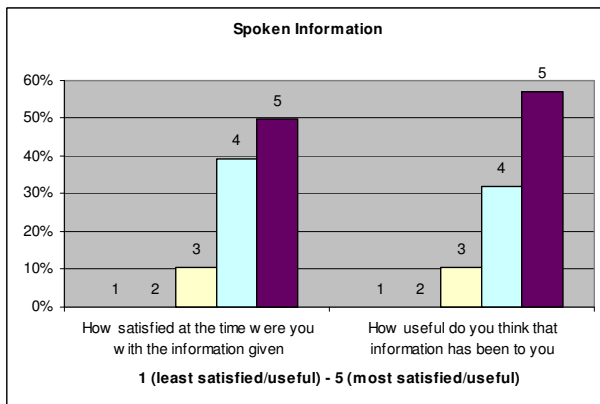
The following baseline results are combined for the two groups.

Spoken and Written Information: What they remember of being told, or receiving in writing, information about long term side effects of treatment and the need for long term follow up.



A higher percentage of respondents remembered receiving spoken, rather than written, information about the long-term side effects

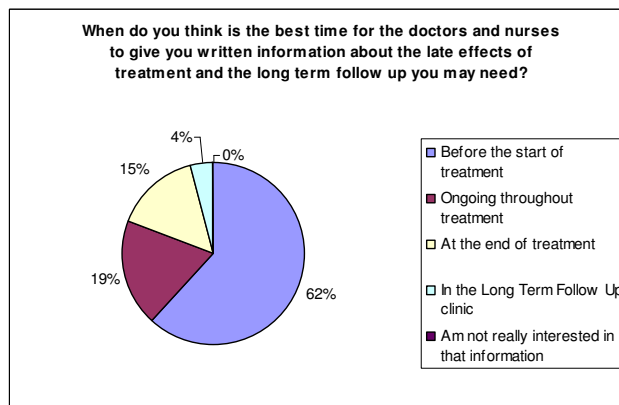
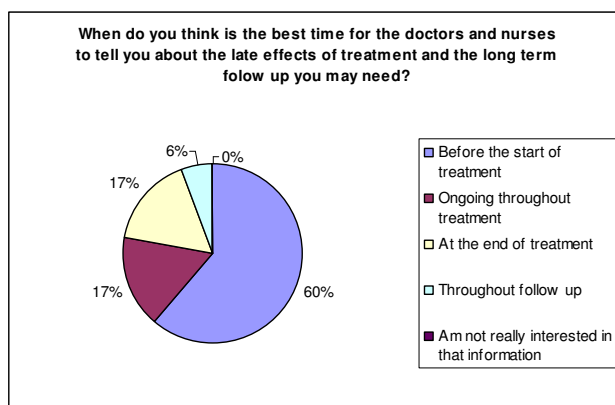
- Spoken YES 83% NO 17%
- Written YES 57% NO 43%



Satisfaction with information at the time was high and fairly even, whether this was spoken or written

Satisfied scores 4 and 5

- Spoken 89%
- Written 84%



The majority of respondents believed that the best time to tell them about late effects and follow up is *before the start of treatment*

- Spoken 61%
- Written 62%

Understanding the information was the same whether it was spoken or written

- | | ALL | SOME |
|-----------|-----|------|
| • Spoken | 59% | 41% |
| • Written | 58% | 42% |

Mood improvements after receiving the information was noticeably higher for those receiving written information

- | | Felt better | Felt upset |
|-----------|-------------|------------|
| • Spoken | 45% | Spoken 24% |
| • Written | 70% | Written 5% |

23 – 25% were not bothered about the information at all (spoken or written)

Experience of obtaining information: How they rate the information obtained from various sources.

Ways of getting information were wide and varied in usefulness.

- The most useful methods of obtaining information were mainly from the cancer doctor, nurse or someone else at the hospital.
- Next was information from the internet, conferences, relatives or friends.
- Some information was obtained from GPs, though this was not ranked as useful as information from the hospital.
-

Treatment Summary & Care Plan: Comments on a blank Treatment Summary/Care Plan and its usefulness.

- 89% of respondents would find a TS like this very useful (scores 4 and 5)
- 100% respondents would not mind their GP viewing the *technical bits* of the TS
- 68% respondents would not need someone to go through the TS with them
- 88% respondents would like the TS at the end of treatment before long term follow-up
- 96% thought the layout was easy to follow
- 93% thought the length and detail was about right
- 96% said that the follow up care plan was important to them
- 63% preferred paper copies of the TS
- 33% preferred to have both paper and electronic copies of the TS

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2. Details of your project	
Give a description of your project.	<p>The Christie Hospital Survivorship Programme project is a new service innovation that aims to improve information and support for Teenagers and Young Adult (TYA) cancer survivors. The work is part of the National Cancer Survivorship Initiative (NCSI) and The Christie is one of the test sites for the Children and Young People (CYP) work stream.</p> <p>TYA groups contributions to steering group discussions include; <i>They 'want 'Information in an interactive format', and 'others may ask questions that I hadn't thought of'.</i></p>
To what clinical area does your project relate?	
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	
What type of change did your project aim to address (e.g. service redesign, new technology etc).	
What tangible change / tangible outcome have you achieved to date	Completion of the first two Survivorship Education Courses; Course 1 delivered over a period of 8 weeks (Feb 17 th to Apr 14 th 2010), one x 2 hour session per week. Course 2 changed to two x Saturdays (May 22 nd and July 3 rd 2010).
What was the purpose of the change and what improvement did it deliver?	<p>The purpose is to provide an educational Survivorship Programme that includes the following sessions;</p> <ul style="list-style-type: none"> • Relationships and body image • Anxiety, coping strategies and risky behaviours • Late effects of treatment • Fertility • Finance – mortgages, insurance, benefits • Education • Employment • Life skills and keeping healthy <p>The programme will be offered to those who have received potentially curative treatment for cancer.</p>
Did the proposed changes contribute to the achievement of any agreed standards or the delivery of any guidance? If yes please give details and reference where possible.	The proposed changes contribute to the guidance and vision proposed in the Department of Health (DH) NCSI Vision document.

3. How you have implemented your project	
Please describe how your project proposals were implemented.	<p>The project has been piloted for patients from the Young Oncology Unit, The Christie. The testing phase is in progress and the first course commenced on February 17th 2010.</p> <ul style="list-style-type: none"> • The structure, content and speakers for the course were

	<p>explored, discussed and defined.</p> <ul style="list-style-type: none"> • The venue for the first course was chosen to be The Christie Hospital. Catering was provided and a local Starbucks also provided refreshments during each course session. • Publicity for the course included posters, flyers and personal letters of invitation to approx. 200 x current and former patients of the YOU. • Course administration included; <ul style="list-style-type: none"> ○ venue and catering bookings ○ order stationary requirements ○ preparation of resources, attendee information file, meeting room, speaker and attendee requirements ○ organisation of speaker fees, travel arrangements and expenses claims ○ registration of attendees <p>The next course was held over two x Saturdays (May 22nd and July 3rd 2010) - 10am – 4pm with 2 x coffee breaks and lunch.</p> <ul style="list-style-type: none"> • The new venue is the Best Western Willowbank Hotel, Fallowfield. Room, AV facilities, catering, refreshments and some stationary all supplied within total cost (£1260) • Sessions revised following Course 1 evaluations. • Time of sessions shortened to adapt to new time schedule. • All course admin as per first course including liason with attendees <p>The programme requires considerable funding for venue, catering, speakers and other resources. We have received a very welcome, considerable donation of £25,000 from Aon to fund future survivorship courses at The Christie. Discussions between The Christie, Aon and MUFC are currently in progress to see how they can offer further support, resources and funding assistance.</p>
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	<p>Costs to date are;</p> <p>Course 1 £3,468.60 Course 2 £2,339.96</p> <p>(see Appendix A)</p>
Were Equality issues identified and how were these addressed	No equality issues were identified. Care was taken to identify and address any special requirements for the attendees or session contributors.
Who were the champions or key stakeholders and how were they involved in the project?	<p>The key stakeholders are the patients, the YOU staff, NHS Improvement and the Cancer Network – all are invited to be represented on the project steering group.</p> <p>The Christie Crew social group were invited to attend the course and provide feedback for evaluation purposes.</p>

4. Evidence of QIPP throughout testing and implementation

<p>Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda</p>	<p>Session and speaker evaluations of the first two courses are very positive so far.</p>
<p>Quality including safety</p>	<p>The Survivorship programme aims to provide relevant, sufficient and timely information that will inform, support and empower survivors in relation to many aspects of their lives that have been affected by treatment for cancer. The aim of this is to improve the quality of patient</p>

	<p>care and self-management. The information given to the attendees will be of a high quality through utilising professional expertise and resources.</p> <p>Examples of feedback from first two sessions include;</p> <p><i>“The survivorship programme helped me in many ways. Primarily it gave me a better understanding of what help was available after having cancer, as well as being able to use the folder as a handbook to refer to short and long term. It also gave me vital contacts to get in touch with which really helped a lot and on the whole I think it’s a brilliant idea!”</i></p> <p>It was felt to be excellent to have the benefit of expert speakers and there were plenty of opportunities to ask questions. It was easy and comfortable to talk to speakers in breaks.</p>
Innovation	<p>It is intended that the information given will answer many of the questions that patients have, in an easily accessible interactive forum, and attendees will have the opportunity, and be encouraged, to ask questions. This additional method of information provision is used alongside current methods of delivering information in order to improve patient engagement, acceptance, and understanding.</p> <p>Examples of feedback from first two sessions include;</p> <p><i>“Good to have an interactive session in which the attendees can participate, discuss, speak their views, be listened to and offered advice”.</i></p> <p><i>“...hearing that people have similar worries; sharing of anxiety experiences; learning how to combat anxiety with coping and relaxation techniques; knowing that a relaxing environment helps mood and confidence”.</i></p>
Productivity / cost or savings / effectiveness including the scale of the benefits.	<p>It is hoped that the programme will inform patients as well as empower them to take ownership of their lives in survivorship, as well as offering advice on attending clinics and approaches to other aspects of their lives that may be touched by their previous diagnosis. The primary benefit is that quality information will improve patient support, choice, self-management and potentially appropriate access to NHS services.</p>
Prevention	<p>The programme hopes to identify issues and problems that the survivor may encounter, and provides them with the knowledge and resources for resolution or coping strategies.</p> <p>Patient quote regarding the Information File: <i>“Love it, really good and useful, always refer to it.”</i></p>

5. Other sources of evidence

<p>Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data</p>	<p>Pre course;</p> <p>Questionnaires are given to each course attendee to assess their course expectations and their current state of mood, body image, social behaviour, physical activity and any risky behaviour.</p> <p>The pre-course questionnaires have not yet been audited.</p> <p>Ongoing;</p> <ul style="list-style-type: none"> • Evaluation of session content, speaker and venue at end of each session by all attendees. • Identify number of attendees per session – maintain register of attendance. • Feedback from speakers. • Discussion forum with attendees post course. • Feedback from Steering Group.
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Course 1 - 16 young people enrolled for the course, although attendance at each session fluctuated because the course had a 'dip in, dip out' style – ranged from 4 – 10, average attendance 8.

Course 2 – 20 enrolled, 16 attended Part 1 and 10 attended Part 2

The age range age of attendee was from 16 to 32 years, with the average age of 21 years for both courses.

Geographical location of attendees was markedly different for the two alternative course formats. Course 1 (weekday evenings) had only 1 out of 12 attendees from outside the Greater Manchester boundaries (8%); Course 2 (weekend) had 9 out of 20 attendees from outside the Greater Manchester boundaries (45%).

Time out of treatment (total 22 attendees);

- 10 were <1yr,
- 10 were >1yr
- 2 were on maintenance treatment for Leukaemia.

(see Appendix D for Attendance charts)

Post course;

Six months after the course the same questionnaires will be completed again to evaluate any changes. Further monitoring of progress is advisable as the evaluation time frame is quite restrictive and valuable information would still be emerging 12 months to 5 years post attendance

Lessons learned from the first course will be incorporated into the next one. All evaluation charts and comments have been sent to the contributors and these will be taken into consideration.

Further points raised at the Steering Group meeting are;

- Session length will be shortened to 75 mins per session
- It was invaluable having a YOU social worker attend most sessions, the young people (and Carol) found this very useful
- It is good to open the sessions with familiar faces from the YOU.
- The "Coping with Cancer workshops" need to be later in the course (day 2) as the group needs time to become comfortable with each other prior to such emotive discussions.
- The "Coping with Cancer workshops" need to be more directed and not just audience driven. There were a lot of issues and questions that were not answered or resolved during the session.
- Relationships – sexuality not touched upon, may need to consider this for next course.

Session and speaker evaluations of the first two courses are very positive so far. The steering group met on July 13th and the following points were discussed;

- All session feedback from the attendees and speakers is important to the development of the programme and future changes should always be according to the requirements of the survivors. We need to listen to what they want from the course, what works well and what needs improving.
- Some elements of the course need more discussion and

consideration as to how they can best provide the information the young people need, with an approach that they will find useful, interesting and they can engage in. The evaluation comments will be taken into consideration for all sessions in order to make these improvements.

- Comments made in the meeting include
 - Remove Benefits, Nutrition and Relationships / Anxiety from programme – put information in folder about benefits and nutrition
 - Relationships etc – These need to remain in the programme somehow but there is not enough time to do this properly in the current format and workshop style. May be better in a lecture style with a more structured session including patient videos.
 - Sessions have to be generalised and we cannot answer all individual concerns and questions in the time we have. The expectations of the attendees may be too high?
 - Nutrition – this is important when on treatment but may not be as important for our survivors. Information about healthy eating could be put in the information file.
 - The YOU patient support network already covers many aspects of the course to a certain point. Nutrition, benefits etc may be very relevant to include in a programme for other hospitals that do not have the expertise and support network that we have on the YOU.
 - The programme aims to attract young people that may not engage with the YOU staff as well as they could.
 - Format of two x Saturdays works well but the day is very rushed and contains a lot of information with not much time for relaxation, questions and engagement.
 - There needs to be some form of icebreaker at the start of the course.
 - It is invaluable having Carol (ClicSargent YOU social worker) attend the course, for the attendees and for Carol herself. It would be useful to have more YOU staff attend the next course to be available for any queries and concerns the attendees have and to learn from the speakers.
 - Ed felt that there should be no upper age limit for attendees.
 - If the format of the course is appropriate (lecture style) then partners could attend if they wished. If there are workshop sessions with more interaction and personal issues then it was felt that partners should not be included in these.
 - The hotel venue and catering was excellent, although we do need to have disabled access / toilets and they had none.
- Suggestions for the format of the next course included a pre-course social event and a residential weekend. These were discussed but no decision made as yet.

Further evidence includes discussions with the Christie Crew members (as a focus session – June 30th 2010); compilation of comments received from attendees and contributors, and evaluation of the pre and post project questionnaires to complete full evaluation.

(For session evaluations for the first two courses see **Appendices B and C**)

Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	To ensure effectiveness and appropriateness of the programme we will measure the value of the intervention and ensure there is continuous re-assessment and ongoing refinement. Feedback is to be provided on the cost of implementation and resources required to the NCSI CYP work stream. This will be part of the evaluation process.
Please present comparisons of base line vs. actual data where relevant	
Give an assessment of how your evidence will provide inform & influence service commissioners	

6. What are the challenges and positive elements of testing	
What other considerations should someone planning to implement these proposals be aware of?	The programme requires considerable funding for venue, catering, speakers and other resources. Promotion and publicity of the course requires a systematic approach and engagement by the staff and users.
Are there any potential top tips or potential pitfalls?	
Please identify negative elements of the testing and implementation	Some elements of the course need more discussion and consideration as to how they can best provide the information the young people need, with an approach that they will find useful, interesting and they can engage in. Sessions have to be generalised and we cannot answer all individual concerns and questions in the time we have. The expectations of the attendees may be too high? The YOU patient support network already covers many aspects of the course to a certain point. Nutrition, benefits etc may be very relevant to include in a programme for other hospitals that do not have the expertise and support network that we have on the YOU.
Give details of what worked really well throughout the life of the project	Engagement and enthusiasm of contributors and course attendees. Early feedback and comments are very positive and helpful. 2/6/2010 - MUFC's new shirt sponsor Aon have kindly made a donation of £25,000 to support the survivorship programme
What are the plans for long term gains	

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	Clinical Lead: Dr Ed Smith Consultant in Clinical Oncology Ed.smith@christie.nhs.uk Project Manager: Andrea Slater Andrea.slater@christie.nhs.uk Tel: 0161 918 7362 Project Administrator: Martine Tempest-Mitchell Martine.tempest-mitchell@christie.nhs.uk Tel: 0161 918 7127

Appendix A

Costs to date

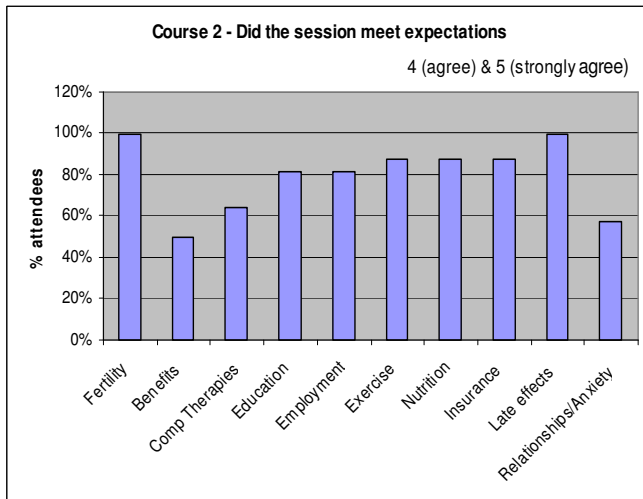
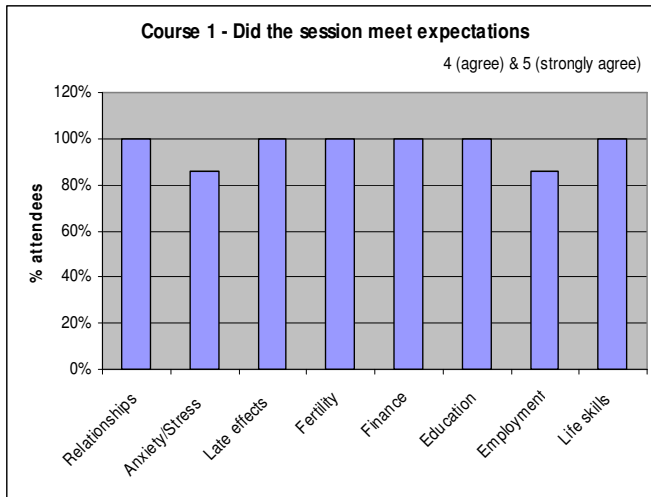
Survivorship Programme

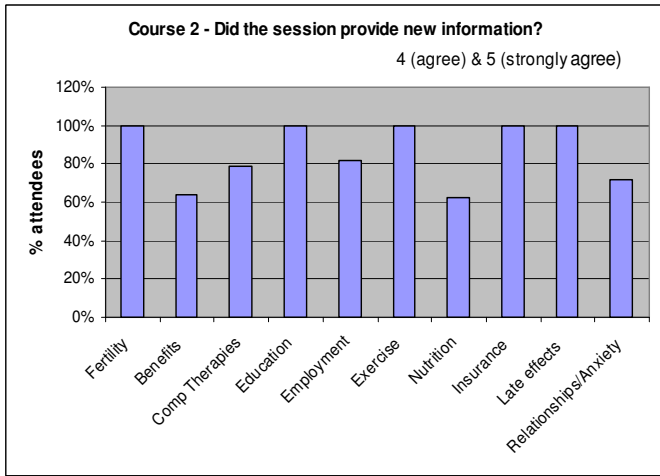
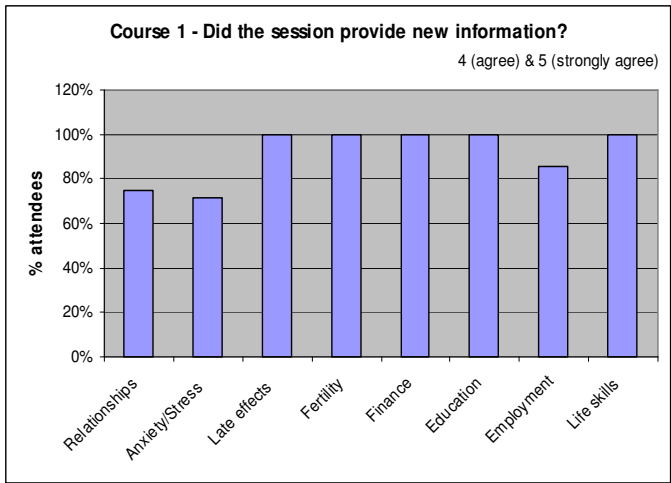
Course 1	Costs									
	17th Feb	24th Feb	3rd Mar	11th Mar	17th Mar	24th Mar	31st Mar	14th Apr		
Room hire + AV technician	£ 200.00	£ 200.00	£ 200.00	£200.00	£200.00	£200.00	£200.00	£200.00	£200.00	£1,600.00
Catering	£ 115.00	£ 96.00	£ 68.00	80.00	92.00	96.00	96.00	92.00	92.00	735.00
Stationary	£ 59.77	£ -	£ -							59.77
Speaker fee				£300.00				£150.00		450.00
Travel expenses				£127.00	£269.93			£ 52.00		448.93
Hotel expenses				£ 55.20	£ 62.10			£ 57.60		£ 174.90
	£ 374.77	£ 296.00	£ 268.00	£762.20	£624.03	£296.00	£296.00	£551.60		£3,468.60

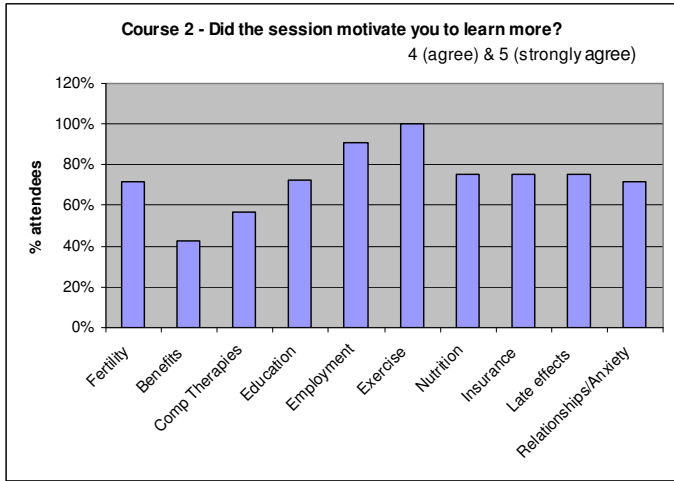
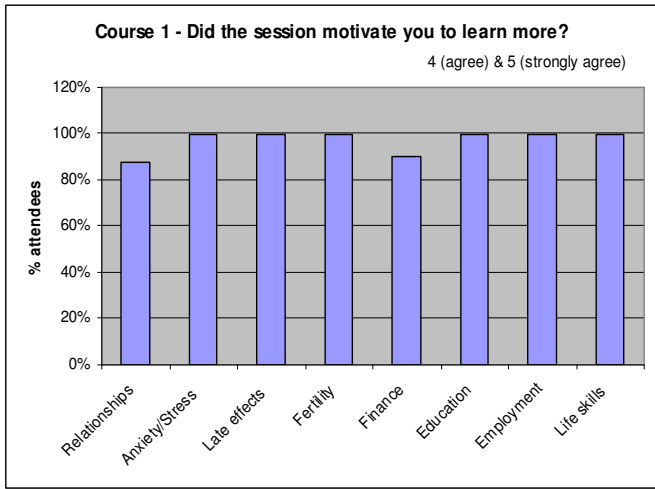
Course 2	May 22nd	July 3rd	
Room hire + AV technician	600	660	
Catering			
Stationary			
Speaker fee	£300	£150	
Travel expenses	£94.54	£411.22	
Hotel expenses		£124.20	
	£994.54	£1,345.42	£2,339.96

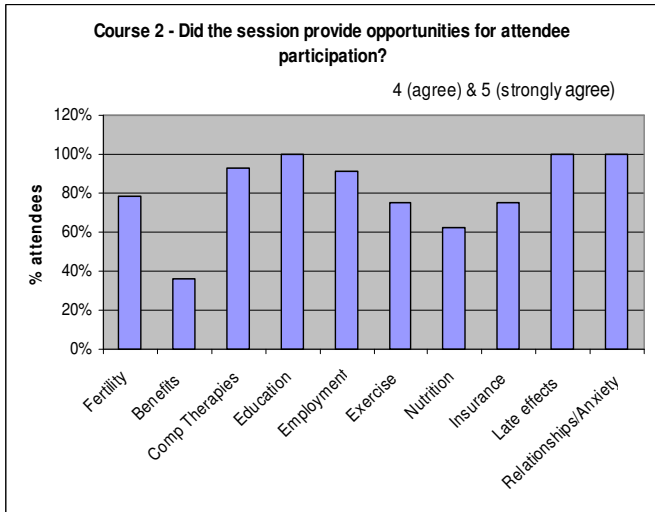
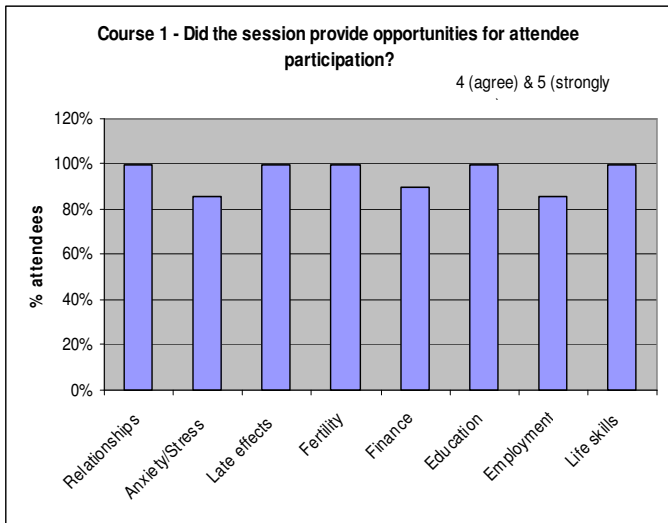
Appendix B

Courses One and Two Session Evaluation Charts



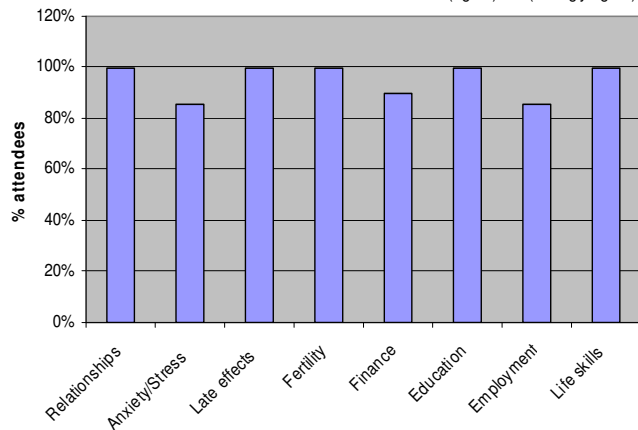






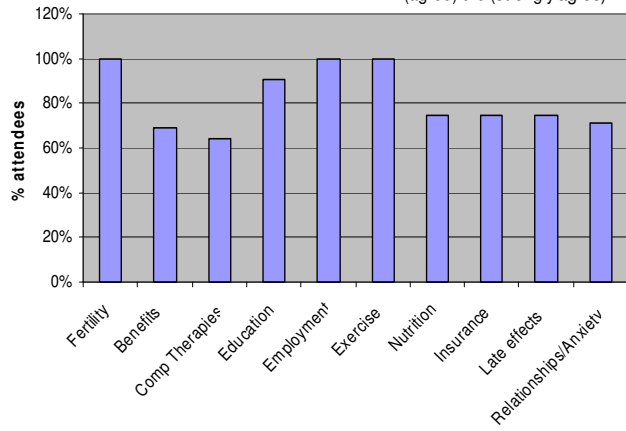
Course 1 - How satisfied were you with the suitability and level of material to the delegates attending?

4 (agree) & 5 (strongly agree)



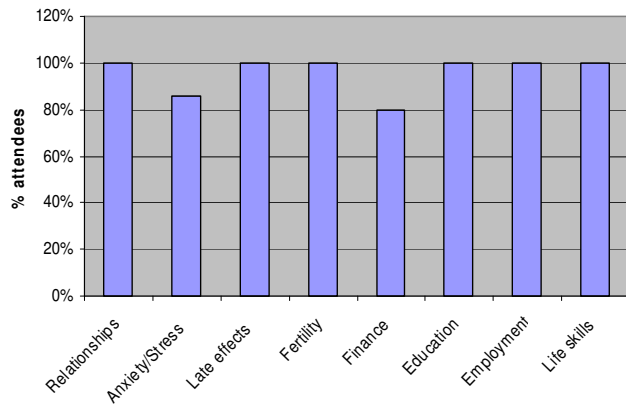
Course 2 - How satisfied were you with the suitability and level of material to the delegates attending?

4 (agree) & 5 (strongly agree)



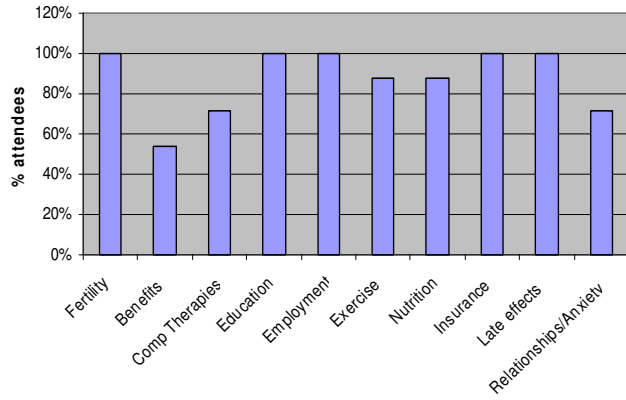
Course 1 - How satisfied were you with the effectiveness of the speaker(s)?

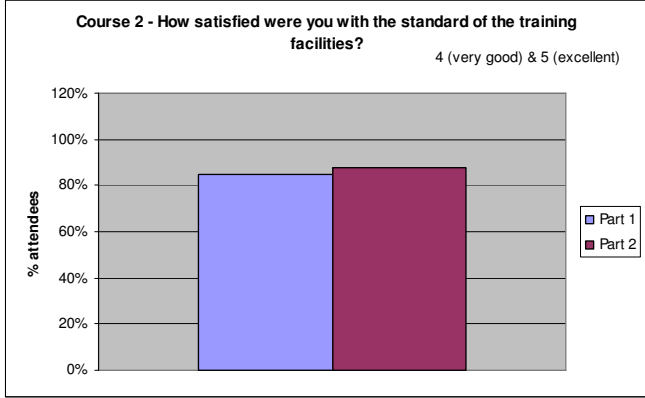
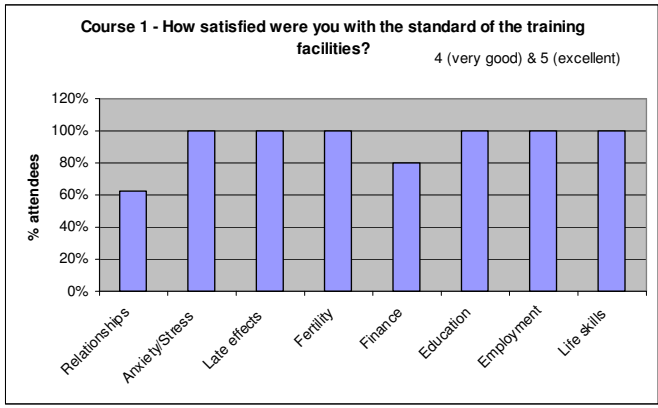
4 (agree) & 5 (strongly agree)



Course 2 - How satisfied were you with the effectiveness of the speaker(s)?

4 (agree) & 5 (strongly agree)





Appendix C

Survivorship Programme

Qualitative Feedback and Comments

<p>Dates / time</p>	<p>8 weekday evenings Didn't mind coming every week and it wasn't difficult to commit to the whole course because of the "dip in dip out" style. The 6pm start is difficult because of the rush hour traffic and longer travel times; late finishes at work/ college; tiredness and family demands. Weekends may be easier for people to attend, though a full weekend course could result in information overload, so 2 x Saturdays could be a good idea.</p> <p>Two x Saturdays It is easier for attendees who cannot attend regular eve sessions because they have to travel from a distance. Format of two x Saturdays works well but the day is very rushed and contains a lot of information with not much time for relaxation, questions and engagement. One belief is that weekend sessions may have a detrimental effect on the cumulative group process for the "coping with cancer" workshop sessions.</p>
<p>Venue</p>	<p>Christie Venue and travel distance ok; would be a problem if lift not working; no variety with catering; Starbucks refreshments very good.</p> <p>Willow Bank Hotel Venue good, food excellent; room a little difficult for some group activities.</p>
<p>Sessions (general)</p>	<p>Course 1 Quantity of information was okay - didn't need more or less of anything. Timing ok, though some felt sessions were a bit long and perhaps required more breaks. It was felt to be excellent to have the benefit of expert speakers and there were plenty of opportunities to ask questions. It was easy and comfortable to talk to speakers in breaks. It is invaluable having the YOU social worker and other YOU staff at the session to engage with and learn from the speakers and attendees. They are also a useful contact for further help and support requirements that are picked up during the course. Some sessions are not appropriate for everyone – eg education. Simultaneous education / employment sessions could be run so the attendees have a choice. Quote from course attendee; <i>"The survivorship programme helped me in many ways. Primarily it gave me a better understanding of what help was available after having cancer, as well as being able to use the folder as a handbook to refer to short and long term. It also gave me vital contacts to get in touch with which really helped a lot and on the whole I think it's a brilliant idea!"</i></p>

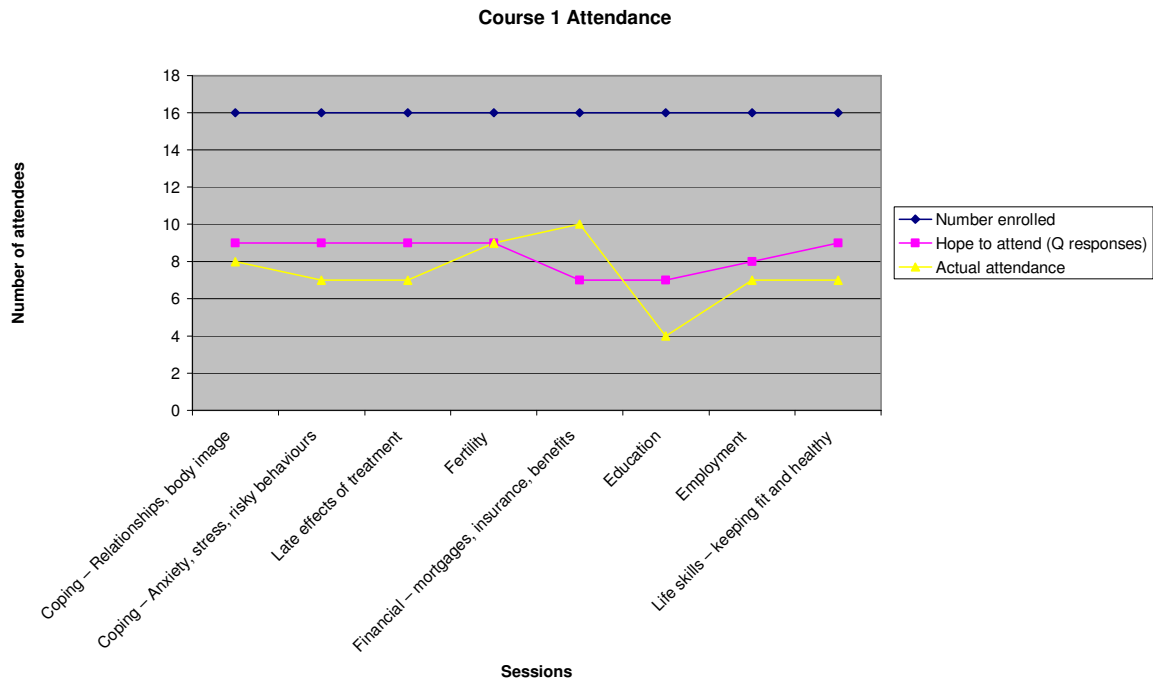
	<p>Course 2</p> <p>Some elements of the course need more discussion and consideration as to how they can best provide the information the young people need, with an approach that they will find useful, interesting and they can engage in.</p> <p>Sessions have to be generalised and we cannot answer all individual concerns and questions in the time we have. The expectations of the attendees may be too high?</p> <p>The YOU patient support network already covers many aspects of the course to a certain point. Nutrition, benefits etc may be very relevant to include in a programme for other hospitals that do not have the expertise and support network that we have on the YOU.</p>
Relationships / body image	<p>Good to have an interactive session in which the attendees can participate, discuss, speak their views, be listened to and offered advice. Useful aspects included talking and listening to peers who have similar situations; discussing problems; thinking of ideas to help future patients.</p> <p>Workshop style session - should always come later in the course and needs an ice breaker.</p> <p>Course 2 (combined with Anxiety)</p> <p>Session remains a little vague. It needs to remain in the programme but the format needs to change. There isn't enough time to do this properly in the current workshop format, it may be better in a lecture style with a more structured session including patient videos. Inclusion of <i>Body Image</i> and <i>Sexuality</i> need consideration for future courses.</p>
Coping – stress/anxiety	<p>Useful aspects – hearing that people have similar worries; sharing of anxiety experiences; learning how to combat anxiety with coping and relaxation techniques; knowing that a relaxing environment helps mood and confidence.</p> <p>The session needs to be more directed and not just audience driven. Lots of questions remained unanswered or resolved.</p> <p>Should always come later in the course and needs an ice breaker.</p> <p>It may help to go through more techniques/strategies in a more interactive way.</p>
Fertility	<p>Very useful session – presented well and clearly states with stats and diagrams what the infertility chances and options available are. The speakers are excellent and the information given is useful and relevant. Some attendees say this session is their main reason for course attendance.</p> <p>Course 1</p> <p>Format good – relaxed and engaged audience, though still required more time at end for questions</p> <p>Course 2</p> <p>In this format the session had some issues because the time was too short for the amount of information requiring delivery. The atmosphere was not as relaxed – session was 1st of the course (mistake) and room layout possibly not conducive to audience engagement.</p> <p>One suggestion for improvement was to maybe divide male and female.</p>
Late Effects	<p>Very useful session, useful aspects included the depth and presentation of information given (useful to find out links between condition and symptoms) and the division of late effects by body parts.</p> <p>It is an emotive and difficult subject to come to terms with and needs a longer debrief time.</p> <p>May need more detailed specialist info for some areas and info about differences in the problems caused by localized radiation and TBI.</p>
Benefits	<p>Attendees thought that this session was full of important information and advice,</p>

	<p>especially for those about to return to work, but the presentation was uninteresting, slow and static. The subject is confusing and some attendees were left feeling unsure which bits were relevant to them and what the process for application should be.</p> <p>It may be that the Benefits session would actually be more timely for our young people when they are having treatment rather than at this stage of their survivorship.</p> <p>It may be best to take out the session and give the attendees the information in the Info File.</p>
Mortgages	<p>This session was not helpful as presented by Nat West Bank (Course 1). It was felt it may be more relevant in future courses to talk about finding a place to live (mortgages, buying and renting). This has long term relevance and the majority of the attendees could possibly be too young for this info at this time.</p> <p>The session could be dropped and information given in the Info File.</p>
Insurance	<p>Very useful and informative session presented by an excellent speaker who engages well with the audience and provides lots of useful tips and handy contacts.</p> <p>Some attendees felt that they were still unclear about how to approach getting insurance and felt that there could have been more recommendations of good insurance companies.</p>
Education	<p>A well presented session, very useful and informative. Useful aspects included small group work; attendee participation; shared experiences and opinions; discussion with peers in same situations; information about approaching new teachers, classmates etc.</p> <p>One suggestion was that this may not be relevant to many of our young people, as they could have passed the education stage. The session could be combined with the employment session and any extra info could be given via the Info File.</p>
Employment	<p>A well presented session, very useful and informative, excellent speaker. Useful aspects included what to put on CV; personality typing.</p> <p>May need more about disability on CVs</p>
Exercise	<p>Useful aspects - how to get back into exercise and know how much to do; to know about fatigue and how exercise can help; to know that 30 mins doesn't have to be in one go.</p> <p>Session could be more interactive</p>
Nutrition	<p>Session provided a useful healthy eating guide, though this was not felt to tell the attendees anything they didn't already know.</p> <p>Needs more cancer specific diet, but this is more important when on treatment and perhaps is not as important at this survivorship stage.</p> <p>Session could be dropped and put info about healthy eating into Info File.</p>
Complementary therapies	<p>Useful aspects of session included the knowledge of what is available and the benefits of complementary therapies.</p> <p>This may be a good session to finish 1st day</p>
Information File	<p>Love it, really good and useful, always refer to it.</p>
Course Admin	<p>We require a systematic course invitation to all people who've received treatment in past 5 yrs.</p> <p>Use text / email system during registration to assist with response rates.</p> <p>Consider max number of people on each course – may be too large for some group activities.</p> <p>Need pre-course ice breaker, it's a little intimidating to arrive alone and some felt it would be useful to have partners attend.</p>

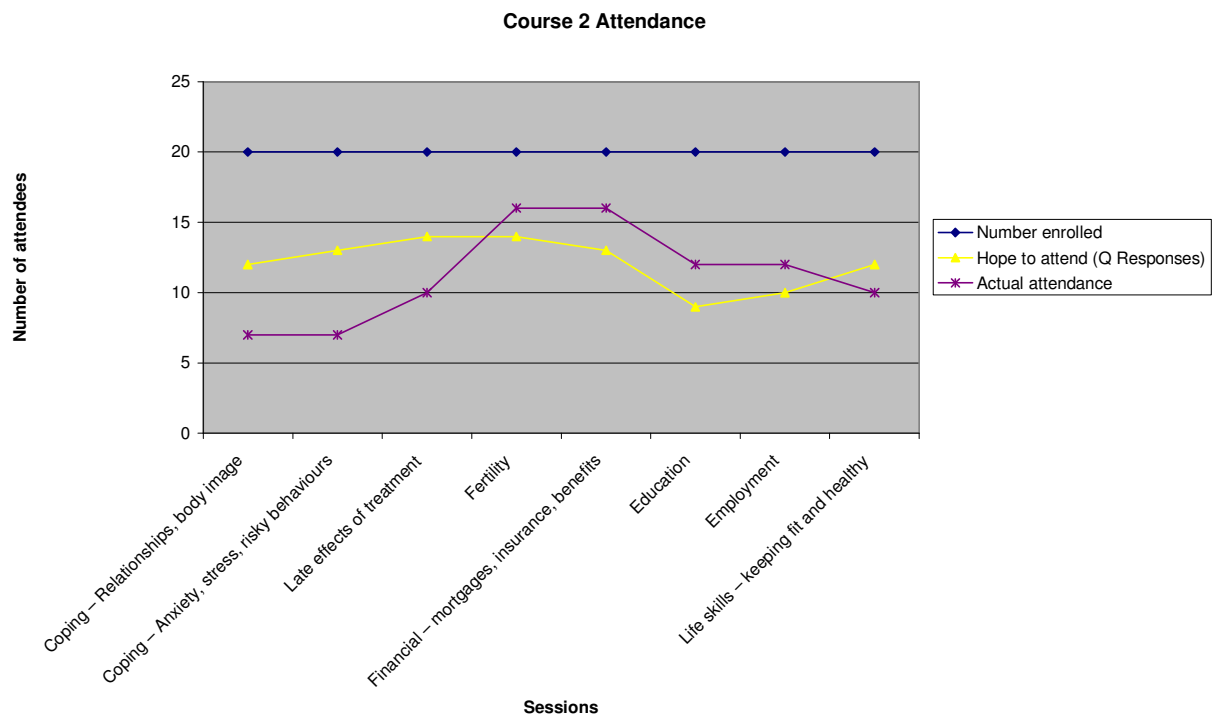
Appendix D

Survivorship Programme

Attendance Charts

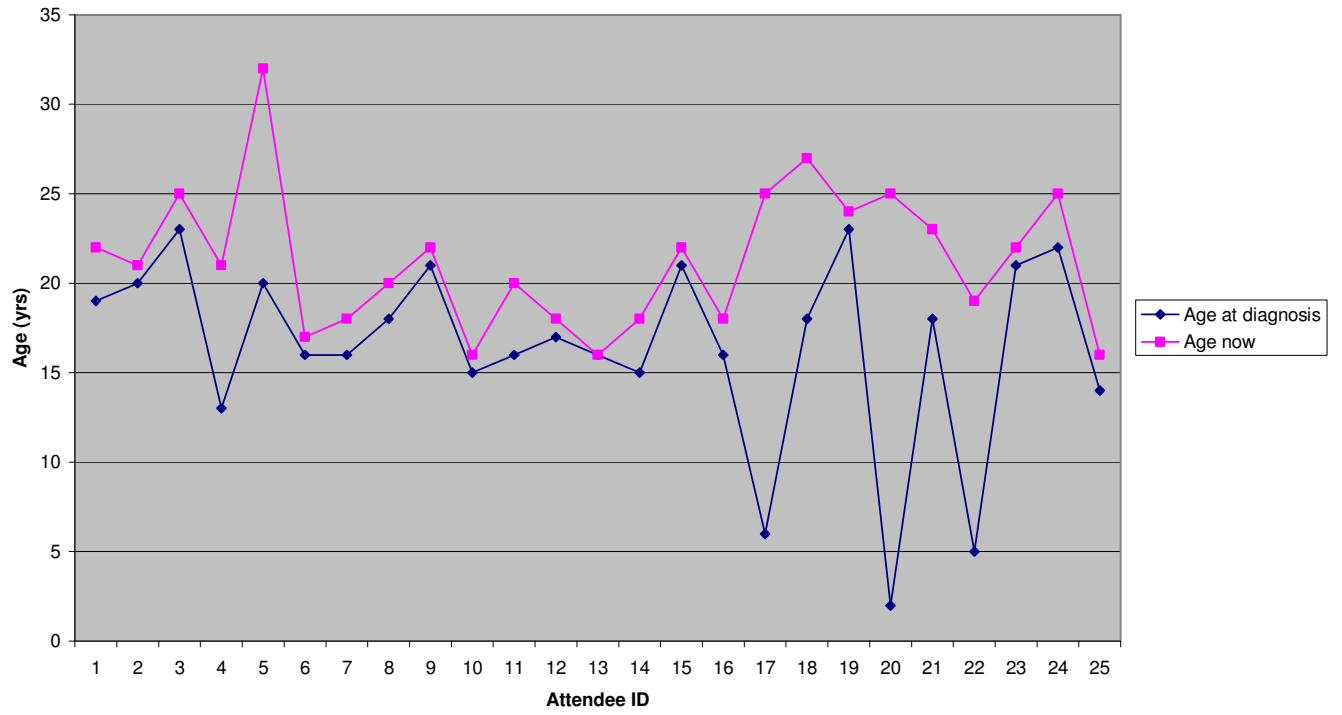


Course 1 12 people attended some / all of course (4 enrolled attendees DNA for whole course)



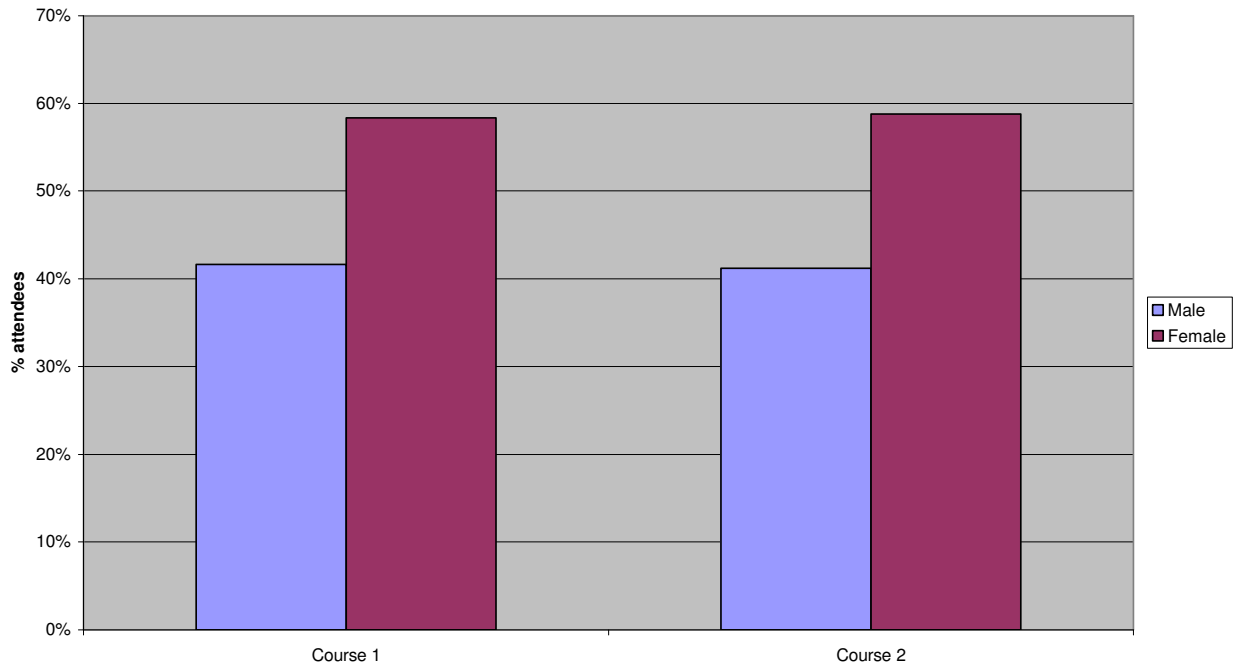
Course 2 17 people attended some / all of course (3 enrolled attendees DNA for whole course)

Age of attendees - Courses 1 & 2



Average age for both courses was 21 years.

Gender of attendees Courses 1 & 2



Geographical location of attendees

