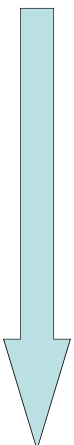


1. Your details	
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2. Details of your project	
Give a description of your project	<p>The project has adopted a two stage approach :</p>  <p>Phase 1:</p> <ul style="list-style-type: none"> Who needs the service? What is currently being provided for them ? Who is providing it ? What do patients want & What do professionals think patients want ? Who is actually able to contribute to the service ? Define the optimal service model based on patient and professional expectation and the available resources <p>Phase 2:</p> <ul style="list-style-type: none"> Negotiate resources to deliver the model as agreed Pilot the model Evaluate the model Adjust and implement the final model of care
To what clinical area does your project relate?	The principal focus of the project is to explore models of care for young adult survivors shared with secondary care but there are aspects which also address the need for continuity of follow up for survivors, transition to adult services and survivor care plans
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	Shared Care
What type of change did your project aim to address	This is a service design / development project
What tangible change / tangible outcome have you achieved to date	<p>The key findings identified to date are as follows (the background to the 4 main data gathering exercises is summarised in section 3 below) :</p> <p><u>Survivor Questionnaire</u></p> <ol style="list-style-type: none"> 1. Over half of survivors (58%) who responded to the questionnaire had attended a clinic in the previous 12 months : <ul style="list-style-type: none"> - 75% had been seen at their local hospital - About a half of the survivors were still being seen by the paediatric team (note : median age of responders = 26 years) - 68% believed that the primary purpose of their clinic visit was to follow up after their previous treatment - Fewer than 10% of survivors thought they had a care plan. 2. 76% believed that they should continue to attend a follow up clinic every 1–2 years as the preferred model for their ongoing care : <ul style="list-style-type: none"> - 76% wished to be seen by a specialist doctor - 15% would be willing to be seen by a specialist nurse.

3. The four factors identified by survivors as having most influence on their preference for location of care were:
 - Confidence in the knowledge of the professionals (46%)
 - Continuity of care by / relationship with (the professionals) (19%)
 - Ability to fit appointments around other commitments (15%)
 - Ease of travel (13%)
4. 72% of those attending clinic did so by private transport and of those who reported difficulties (37%) with travel to clinic, over half (61%) related this to parking problems.
5. Approximately 70% of survivors would be willing to travel for up to 60 minutes to attend a suitable clinic (59% for up to 90 minutes)
6. The top five responses to questions about health problems or other issues that survivors indicated they would like to discuss or receive information about were (in order of frequency):
 - Psychological / emotional issues
 - Fertility
 - Physical issues
 - Diet and exercise
 - Information about previous treatment
7. 69% of patients provided additional free text comments. These could be broadly grouped as follows (expressed as % patients who responded in this way - note that some responses could be coded in more than one category):
 - No problems / general satisfaction with past / current care (35%)
 - Wish for more information, predominantly expressed as need for website and other on-line communication tools (30%)
 - Difficulties with / criticism of current care (28%)
 - Suggestions about / wish for more flexible and individualised care (22%)
 - Wish for contact with other survivors / support groups (15%)
 - Wish for access to ad hoc advice, mainly as a telephone help line (13%)
 - Other comments (13%)
8. Quotes

"Use of the internet where possible, supported by a telephone help line so that people can make contact with specialists between follow up appointments if necessary."

"I often felt unsure who to go to after my treatment finished...GP thinks I should go to specialist and specialist says I can go to GP."

"Stop telling me I have no health care needs now I am cured. I feel I have ongoing problems that result from my cancer treatment..."

"I see an endocrinologist at Hospital [A] and a neurologist at Hospital [B]: However I feel the communication between the two hospitals could be better."

"I would like to see a front sheet on my notes with a précis of my condition. Last time...the poor A&E doctor spent 2 hours trying to work out my medical history. Mostly doctors give up and ask and that drags it all back..."

“A system similar to NHS Direct whereby I can phone day or night with concerns and be referred to a specialist if necessary...this helpline should be cancer specific and linked to professionals who specialise in the effects of cancer.”

“I feel I had the best cancer treatment when I was diagnosed. But I was a child and now I am an adult and it is hard to get seen if you have a problem. Maybe GPs should be better informed about cancer and it's after effects...”

“Although I am satisfied with today's service I would look forward to any further action being taken to improve and help the NHS with cancer after care.”

Focus Groups

1. What Issues are Important to Survivors?

The following topics / issues emerged as important in the discussions but were not prioritised :

a) Physical Issues

Need to know more about physical late effects – confidence in knowing what you can do

b) Psychological Issues

- Need more psychological support & support to talk about treatment
- Peer support important – helpful to meet others, especially with the same disease of treatment

c) Information about Previous Treatment

All survivors need a treatment summary – feedback to patients on treatment they had or why things have happened

d) Fertility

Difficult to get information; needs to be provided at the right age (puberty or later); needs to be relevant to the individual

e) Employment and Education

Patchy experience of information and support – often poor

2. What Issues Should be Addressed by a Late Effects Service ?

Each of the 2 groups was asked to identify their top five issues :

a) Three topics were common to both groups, namely :

- Information about physical aspects of late effects
- Psychological / emotional wellbeing
- Use of complementary therapies¹

b) Four other topics emerged as priorities (two in each group)

- Fertility
- Information about previous treatment
- Employment advice
- Information about support groups

¹ The place of complementary therapies was discussed further. Many people felt that once treatment had finished 'you were just abandoned'. Complementary therapies may be a way of continuing 'positive' treatment to aid full recovery and assist with general well being.

3. What Happens at Follow up Clinics now?

Variable experiences were discussed. There was an emphasis on the:

- Reassurance of a physical examination
- Importance of staff being properly acquainted with previous treatment and problems

"Seems to be random x-rays / scans / blood test depending on which doctor happens to see you"

"Big black hole, a load of follow up appointments, no doctor reading your past history....."

4. Concerns about Transition to a Late Effects Service

Themes emerged which related to:

- Need for this to be staffed by people who understood the issues
- Presence of others who had had similar experiences
- Convenience in terms of location and timing of clinics

"Evening would be better"

5. Provision of Information

- a) Information and advice about non medical issues was often difficult to access or inaccurate.

"Wrong information given by doctor – real world is tough on cancer survivors"

- b) There was strong identification with the use of technology to provide signposting (to other services), information, support that does not require a face to face visit and peer support. A web based forum could provide this.

- c) It was felt that clinics should be used to discuss individual issues and perhaps an enhanced physical examination.

Professional Survey

1. The professionals' consensus view supported :

- the need for treatment summaries
- use of care plans
- a risk based plan for follow up following assessment in a specialist survivorship clinic
- open access for survivors to continue to obtain expert advice

and recognised that :

- no assumption should be made about knowledge of potential late effects made available to survivors by parents

2. The professionals did not confidently support the statement that "It is safe and effective to offer survivorship care in a shared care setting"

3. Quotes:

- a) Responses to the statement that "Most parents will explain what they were told at diagnosis (about the late effects of treatment) to the survivor when he / she is old enough to understand" included:

"probably explain something but is it enough/what the YP would want to know about?"

	<p><i>“parents (are) probably over protective and may impart inaccurate information”</i></p> <p><i>“I doubt they remember, if they were ever told”</i></p> <p>b) Responses to the statement that “All survivors should be given a written summary of the treatment they received together with recommendations for their future care” included :</p> <p><i>“They should, but they don't. Major resource implications here”</i></p> <p><u>Geographic Analysis (see Appendix A)</u></p> <p>The data show that a step wise improvement in (reducing) travel times can be obtained by increasing the number of sites at which survivorship clinics are provided but :</p> <ol style="list-style-type: none"> 1. Only a three centre (or greater) model for the delivery of care would meet the majority of patients expectations to travel less than 60 minutes to access a suitable clinic 2. There is no clear advantage of a 5 site model over a 4 site model
<p>What was the purpose of the change and what improvement did it deliver?</p>	<p>There is a long history of effective paediatric shared care in the South West, between the Principal Treatment Centre (PTC) in Bristol and Paediatric Oncology Shared Care Units (POSCUs) in district hospitals across the region. Follow up after completion of treatment is provided at POSCUs, supported with a programme of outreach clinics by paediatric oncologists, endocrinologists etc. from the PTC. This continues until patients are no longer considered eligible for care in paediatric units (between 16 and 18 years) but from that time, transition into adult services remains a challenge and, when achieved, this is usually in relation only to one component of care (e.g. endocrinology) and it is difficult to maintain an ongoing overview of the needs of these patients, many of whom have potentially complex multi-system issues.</p>
<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>As above, the project is in a Data Gathering / Analysis phase and is scheduled for implementation in 2011. The design of a service which can provide specialist support on a shared care basis is consistent with the principles of the CYP IOG (NICE 2005)</p>

3. How you have implemented your project

Please describe how your project proposals were implemented.

The main mechanisms used during the data gathering were :

Survivor Questionnaire

- a) 601 patients were identified as potentially eligible for the study of whom 245 (41%) were confirmed as eligible to be approached with a questionnaire.
- b) 67 out of 245 (27%) of those sent a questionnaire submitted a response: ethical committee approval dictated that survivors could be contacted only once.
- c) Younger survivors (age \leq 24 years), those who were less than 20 years from original diagnosis, and those with a previous diagnosis of leukaemia and lymphoma were more likely to have been sent a questionnaire in the first place. There was no difference in age at diagnosis or gender between the recipients and non recipients.
- d) Older survivors (\geq 25 years), those treated for CNS tumours, and women were more likely to respond to the questionnaire. There was no difference in age at first diagnosis or in duration of follow up between responders and non responders.

Focus Groups

31 out of the 67 patients (46%) who responded to the questionnaire expressed an interest in attending a focus group of whom 10 (32%) actually attended one of two meetings (held in Plymouth and Exeter). In addition 3 parents attended.

Professional Survey

- a) The Professional Cohort invited to take part in the study, were identified with the support of the local members of the steering group. This cohort was derived from individuals who are already, or may in the future, be involved with the provision of care to adult survivors of cancer in childhood and / or the treatment of older teenagers and young adults with cancer at hospitals in the Peninsula.
- b) The questions set for the questionnaires were established using a modified Delphi technique to ascertain consensus with statements governing the needs of survivors and the design of a late effects service.
- c) 31 out of 47 (66%) of those sent a questionnaire responded in round 1. Only those who responded in round 1 were eligible for involvement in round 2.
- d) 22 out of 31 (71%) responded in round 2.

Geographic Analysis

In order to inform the design of a future service to provide long term follow up to survivors in the Peninsula, the home postcodes of 209 out of the 245 patients sent a questionnaire (85%) were included in a geographical analysis (the 36 postcodes excluded were from the questionnaires returned "Addressee Unknown"). The geographical analysis computed travel times (using private transport) and distance from each of the 5 possible locations for late effects clinics in the Peninsula Cancer Network.

Give details of any additional costs or resource demands that arose, including staffing or new equipment.	None to date. Actual vs Plan Project Costs for Phase 1 are included in Appendix B.
Were Equality issues identified and how were these addressed	None to date.
Who were the champions or key stakeholders and how were they involved in the project?	<pre> graph TD PSGroup[Project Steering Group] --- MikeStevens[Mike Stevens (Project Oversight & Core Team)] MikeStevens --- CoreTeam[CORE TEAM] MikeStevens --- KeyStakeholders[KEY STAKEHOLDERS] subgraph PSGroupMembers [Project Steering Group Members] direction TB PSGroupMembersList["Liz Alsbury (Totnes) Dr Karin Bradley (Bristol) Dr Liz Crowne (Bristol) Dr Sian Harris (Truro) Dr Corinne Hayes (Exeter) Dr Catherine Lissett (Torbay) Michelle Narey (Bristol) Louise Taylor (Exeter) Dr Paul Ward (Plymouth) plus Judi Tapp & Patricia Morris"] end CoreTeamList["Rachel Cox (Clinical Lead) Ruth Elson (Clinical Nurse Specialist) Hugh Bishop (SpR Paediatric Oncology) Paul Beynon (Project Manager) Cathy Gane (Young Person's Involvement Worker)"] KeyStakeholdersList["Mary Barnes (ASWCS (Host) Network & Service Improvement Lead) Jonathan Miller (Peninsula Network Lead) NHS Improvement Collaborating Clinicians Study Participants"] </pre>

4. Evidence of QIPP throughout testing and implementation	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	The Project is currently in a data gathering phase and it is during the next phase i.e. Design, that the findings to date will be translated into requirements for the new service. It is these requirements that will then be assessed / mapped against the QIPP criteria plus other standard prioritisation criteria e.g. MoSCoW (Must Do, Should Do, Could Do, Would Do) to ensure that all agreed/essential components are included in the Pilot phase.
Quality including safety	The project will build on the experiences gained from a designated young adult follow up service already running in Bristol where a separate clinic is open to all patients aged ≥16 years of age, ≥5 years from diagnosis and at least 3 years from last treatment. This clinic sees all patients who are under the direct supervision of the PTC (i.e. those based in or close to Bristol) including those treated for solid tumours, brain tumours, leukaemia and those who have undergone BMT. At the first visit all survivors are offered an individualised assessment of risk and recommended investigations in the context of an education programme to provide appropriate information about the value of continuing follow up. On this basis, survivors are offered an opportunity to continue follow up in the young adult survivor clinic; be transferred to their GP or to another appropriate physician; or to be discharged from further review with the opportunity to contribute to an intended postal follow up system. An important aspect of the existing clinic is the role played by the nurse specialist who sees patients individually, provides healthy life style advice, and monitors compliance with appointments for other investigations, medication etc. A Late Effects MDT has also been initiated which will serve as the MDT for the entire CTYA network in line with Children's Measures (09-7A-111)

Innovation	The stated aim of the project is to test the following hypothesis that “ <i>EFFECTIVE</i> long term follow up can be delivered with high levels of <i>SATISFACTION</i> in a shared care setting under the guidance of the principal treatment centre and the support of staff with specialist knowledge”. This statement encapsulates an aspiration to provide a service which is underpinned by specialist expertise, is available locally and meets patient expectations.
Productivity / cost or savings / effectiveness including the scale of the benefits.	No data are yet available for these parameters but the project will evaluate the preferred service model by seeking measures of patient and professional satisfaction and will work closely with commissioners to ensure that the model proposed is seen to be affordable and appropriate in its scope and geographical location.
Prevention	Although not directly applicable, we hope this project will improve the health of survivors and limit / prevent morbidity by ensuring education about healthy lifestyle and offering early interventions

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	The project will be undertaken in two phases as described in Section 2. The baseline assessment / data gathering is underway which includes the principal components described in Section 3.
Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	We intend to collect data on the benefits of the new service configuration by addressing issues such as : <ul style="list-style-type: none"> – implementation of care plans – profiling predicted risks against the follow up plan offered / accepted by survivors – assessing patient satisfaction and knowledge of their health needs – measuring possible improvement in quality of life following access to the service – assessing increased awareness of the service in primary and secondary care
Please present comparisons of base line vs. actual data where relevant	The measures for the Analysis stage of the project are included in Appendix C
Give an assessment of how your evidence will provide inform & influence service commissioners	Once the baseline data are available, we will utilise this information to create possible models for the delivery of care based on survivor preference, professional expertise and interest, and geographical constraints. A meeting has been arranged for 07-09-10 to share the findings of the study with the Project Steering Group and to clarify interpretation and implications prior to the next CYP National Workshop on 23.9.10. The models will be presented to commissioners, to the Peninsula Cancer Network, to Trusts, and to user representatives before implementing a pilot of the preferred model and evaluating its effectiveness and user satisfaction. We will also ensure that our findings are shared and discussed with primary care with whom there is an important interface.

6.What are the challenges and positive elements of testing

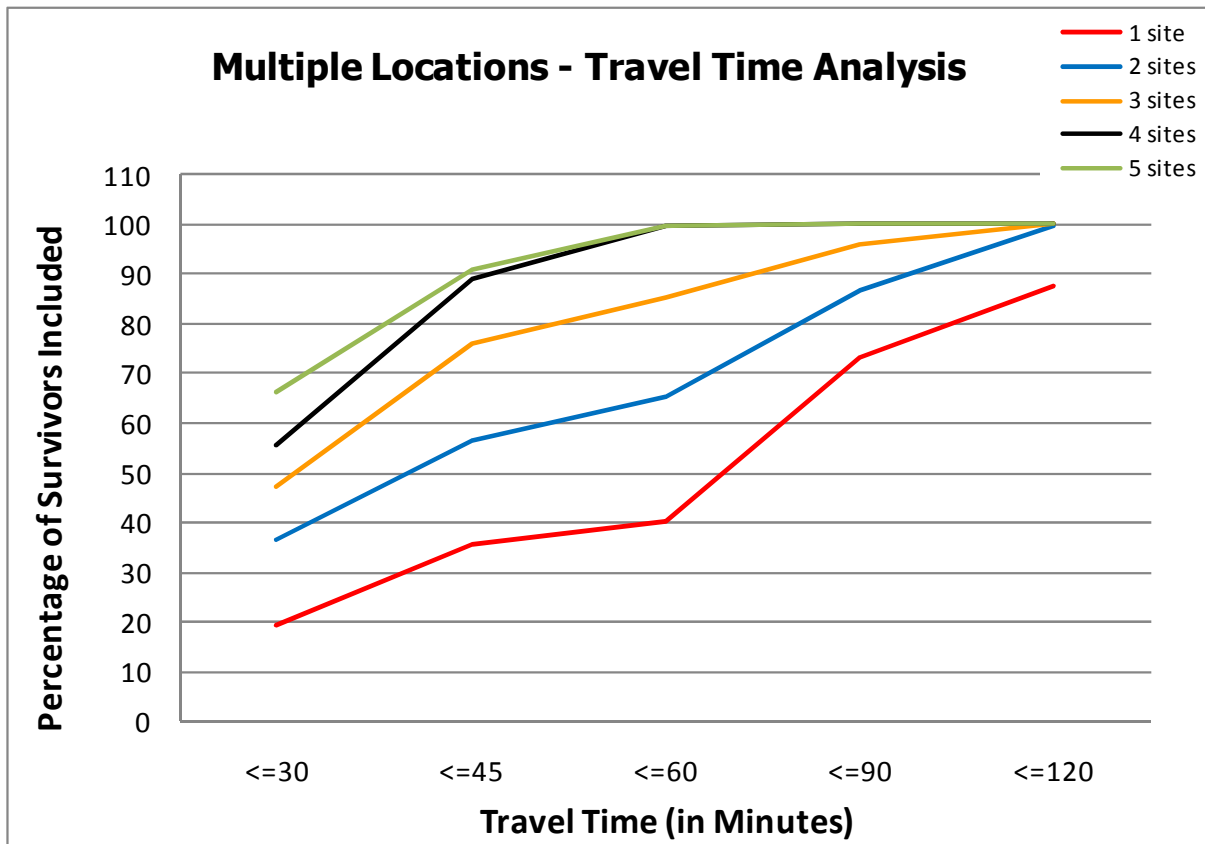
What other considerations should someone planning to implement these proposals be aware of?	We will cross correlate the findings of this study with plans for the location of designated shared care centres for the SW regional TYA cancer service.
Are there any potential top tips or potential pitfalls?	<p>Early engagement with the cancer network is important to reinforce strategies for engagement with adult services who may continue to see this as a paediatric issue.</p> <p>We had difficulty in deciding whether Research Ethics Committee approval was necessary for our work. We decided in the end to seek such approval as we felt we were taking the project beyond straightforward service evaluation and would be approaching patients who had lost contact with our service and staff who may have had no prior contact with this group of patients. Earlier clarity about the distinction between research and service evaluation / development would have been helpful.</p> <p>The introduction of a late effects MDT has helped clarify some aspects of the detail of this project and the project has, in turn, clarified the further development of the late effects clinics being run in Bristol. The involvement of the Project Manager in all aspects of the survivorship service has been very helpful in maintaining this cohesion.</p>
Please identify negative elements of the testing and implementation	None identified to Date
Give details of what worked really well throughout the life of the project	To be determined
What are the plans for long term gains	We hope the benefits of this project will help us build towards a more cohesive approach to survivorship in general

7. Relevant contacts or resources

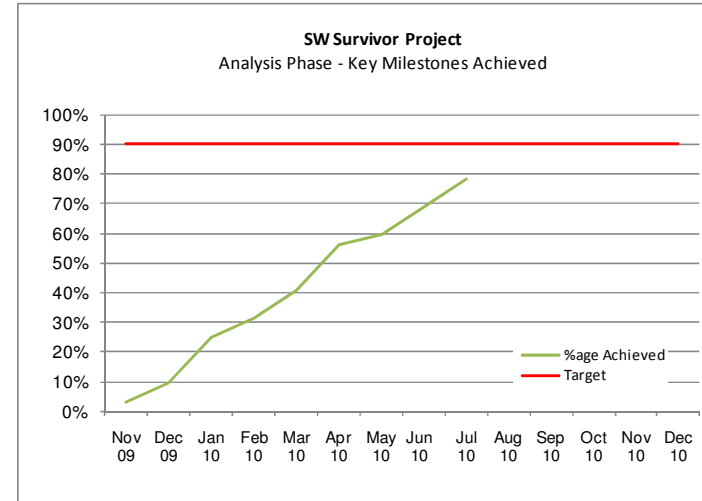
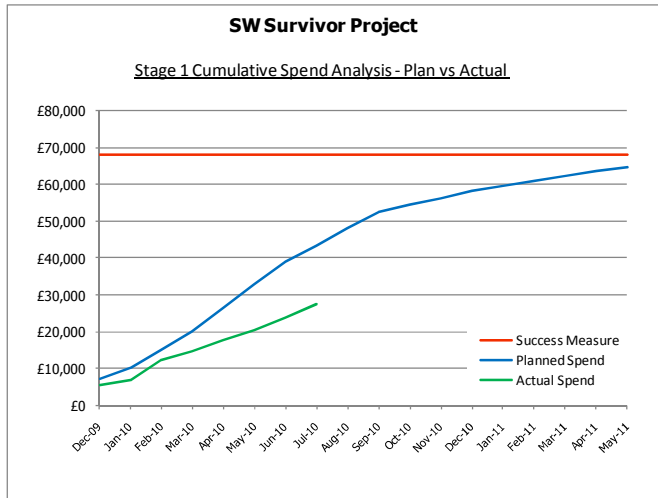
Please give details of any contacts or resources that could help someone to implement your proposals.	<p>Prof. Mike Stevens</p> <p>Ruth Elson</p> <p>Dr Hugh Bishop</p> <p>Paul Beynon</p>
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Appendices

A Geographic Analysis Graph



B Analysis Phase - Project Management Measures



C Analysis Phase – Project Measures

