THE CASE OF NEED FOR INVESTMENT IN SOUTH WEST AFTERCARE

SWAftercare: A service for young adult survivors of cancer in childhood

SUMMARY

To further develop the SWAftercare service in line with national recommendations, investment is required to meet the following key priorities:

- Lack of access to the current service by patients from Devon and Cornwall (for whom no alternative exists) and therefore inequity of care by area of residence

- Lack of access to the current service by TYA patients treated under adult clinical care models (for whom no alternative exists) and therefore inequity of care by age and treating team

- The development of a full range of models of care in line with National Cancer Survivorship Initiative recommendations for all children and young people surviving cancer in the SW

- The capacity to ensure that all eligible patients are offered an expert Aftercare review, ensured a comprehensive risk assessment to inform an agreed model of future care, and provided with a central point of contact for advice about future needs

- To address a major unmet need of survivors attending the service – the lack of psychological support.

This paper offers:

- A background to the bid including a summary of clinical justification, description of national policy and the views of clinicians and patients

- A brief description of the existing service

- Characterisation of patients eligible for Aftercare and the complexity of their clinical needs.

- A model which defines the necessary service development

- Reference to national work on health economic outcomes

- Justification for the resource requested
## CONTENTS

1. **Background**  
   1.1. Clinical justification for a designated Aftercare service  
   1.2. Clinical evidence for complications relating to cancer treatment  
   1.3. NICE Guidance and Peer Review Standards  
   1.4. The National Cancer Survivorship Initiative  
   1.5. Views of Patients and Professionals in the South West  

2. **The South West Aftercare Service**  

3. **Characteristics of patients eligible for Aftercare**  

4. **Clinical complexity**  

5. **Unmet Need**  

6. **Geographical access**  

7. **Service capacity required**  

8. **Health Economic Considerations**  

9. **Resource Requirements for Service Development**  
   9.1. Current resources  
   9.2. Resource investment required  

Appendix  
   [A] The agreement of 10 core principles defining Aftercare:  
   [B] The definition of four models of care  
   [C] The development and publication of an interactive care pathway
1. Background

1.1. Clinical justification for a designated Aftercare service

Overall survival rates for children with cancer have continued to improve over the past 20 years and now approach 80% at 5 years from diagnosis: the majority of these patients are likely to be cured and will become long term survivors. It is known that over 60% of this expanding cohort of survivors have at least one adverse late effect of cancer treatment and that a significant number experience real or potential consequences of the disease or its treatment which will present as medical, psychological, educational or social difficulties both during childhood and later in adult life.

Emerging data confirm patterns of morbidity that necessitate evaluation of all survivors within a specialist Aftercare setting in order to risk stratify individuals to determine future patterns of care. Risk stratification requires a full assessment of treatment exposure and established complications of treatment (treatment summary). It is clear that some patients with low risk profiles can be discharged from hospital based follow up whilst others, with high risk profiles, require ongoing specialist health care interventions.

The lack of an established adult programme into which childhood cancer survivors can transition requires support for a service that can undertake expert risk stratification, ensure individualised care planning and holistic needs assessment in liaison with appropriately informed adult services, and offer patients accurate and up to date information about their future health care needs.

Traditionally, the only model of care for survivors was a specialist, consultant led service delivered from a designated paediatric oncology Principal Treatment Centre (PTC). Difficulties with this model are that it represents a centralised ‘one size fits all’ approach that did not take into consideration the varying needs of different groups of patients and included inconsistent arrangements for transition to local adult services. There have also been inadequate efforts made in the past to educate and empower patients themselves and to engage primary care in supporting those with less complex needs. As a consequence, a significant minority of patients are lost to follow up before appropriate care plans are made; this includes some with the potential for significant future health problems.

The concept of ‘informed self management ‘(i.e. where an appropriately informed patient relies principally on health care in the primary sector with the possibility of advice from and, if necessary, re entry into, a specialist Aftercare service) is being increasingly promoted. It is a concept supported by patients and represents an opportunity to reduce healthcare utilisation within the secondary and tertiary sectors.

1.2. Clinical evidence for complications relating to cancer treatment

There is extensive evidence from the literature to illustrate the profile of complications experienced by childhood and teenage cancer survivors. This includes data from at least two large international cohorts of survivors (one British and one from the USA, each enrolling over 12,000 individuals and following their progress over time) as well as a number of single institution studies. Health related concerns vary according to treatment exposure but include: risk of second cancer (and the need, in selected cases, for augmented cancer screening programmes); impaired fertility; cardiovascular and metabolic disease characterized by cardiomyopathy, coronary artery disease, hypertension, unfavourable lipid profile, obesity and early onset diabetes; reduced lung function; impaired kidney function;
endocrine damage including hypopituitarism requiring life long hormone replacement and specialist endocrinology support; and neurocognitive problems. Results of more recent studies indicate a pattern of accelerated or premature ageing and there is an increasing body of evidence to suggest that risk based screening offers the potential to identify and treat some conditions that, if detected early, should preserve health and longevity.

In response to this situation, clinical guidelines have been developed in many developed countries to guide the screening and management of childhood cancer survivors. Guidelines developed by the Children’s Cancer and Leukaemia Group are used as standard of care by SWAftercare and elsewhere in the UK.

The psychological and social implications of life threatening illness in childhood are not insignificant and are often inadequately addressed. Many patients experience disadvantage from the educational and social impact of their disease and some have specific neurocognitive and sensory deficits.

1.3. NICE Guidance and Peer Review Standards
The NICE Improving Outcomes Guidance for children and young people (CYP) with cancer (2005) mandated the provision of long-term clinics for survivors, staffed by professionals with the relevant expertise. The subsequently introduced paediatric peer review measures require the presence of a Late Effects (now more appropriately called ‘Aftercare’) MDT and set specific requirements about aspects of its function. Measures for TYA (teenage and young adults) include the need to provide all survivors with a treatment summary and risk based care plan.

The Aftercare MDT reviews all patients newly referred to the existing Aftercare service. It ensures that a full treatment summary is available for each patient, undertakes a risk assessment of need, and confirms the care plan agreed once a patient has been seen and assessed.

1.4. The National Cancer Survivorship Initiative
The NCSI originated from the Cancer Reform Strategy (published in 2007) and is a partnership between the Department of Health, Macmillan Cancer Support and NHS Improvement. In January 2010, the NCSI published a vision document summarising a range of evidence that the current follow up arrangements for cancer patients were not meeting all survivors’ needs following treatment, and did not provide value for money. A series of workstreams, including one focusing solely on the needs of children and young people, were established to address these findings. NHS Improvement has supported the delivery of the NCSI through the piloting of models of improved care and support for adults, young adults and child survivors in clinical test communities around the country.

The SWAftercare service at UH Bristol has been closely involved in the NCSI CYP workstream, initially as one of ten national test sites and subsequently as one of four national prototype sites. The work undertaken by SWAftercare looked at a shared care model for Aftercare and contributed to the collection of data to support the final conclusions of the NCSI CYP workstream (“Children and young people living with and beyond cancer. Designing and implementing pathways to benefit patient aftercare: Continuing to build the evidence”) October 2011 and to a report from the York Health Economics Consortium (“Review of Cancer Survivorship Services for Children and Young People – refining the evidence”) August 2012. This latter publication offers a health economic analysis in favour of the NCSI model of care.
The work of the NCSI CYP work stream has led to three key outcomes (see Appendix); ten core principles defining Aftercare; four possible models of care; and to the development of an interactive care pathway for children and TYA survivors.

NHS Improvement has continued to direct a 2 year programme of work (‘The Spread’) to introduce the CYP strategy nationally, utilising the agreed pathways and ensuring that all children’s and TYA services deliver Aftercare according to the core principles and within the agreed models of care.

1.5. Views of Patients and Professionals in the South West

The SW Young Cancer Survivors Project (undertaken 2009-2011 and funded by NHS Improvement) aimed to collect information from and about patients and professionals to inform the design and evaluation of an Aftercare service for young adult survivors of childhood cancer resident in the Peninsula Cancer Network.

Patients indicated a need for further information and expressed concerns about the adequacy of ongoing care, particularly after graduation from paediatric services. Views are illustrated by the following quotations:

“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 me .....and that drags it all back...”

“A system similar to NHS Direct whereby I can phone 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 its after effects...”

The professionals involved supported a consensus view on: the need for treatment summaries; the use of risk based care plans following assessment in a specialist Aftercare clinic; and open access for survivors to continue to obtain expert advice (even if discharged from hospital based follow up).

Importantly, the professionals also recognised that no assumption should be made about the knowledge of potential late effects made available to survivors by parents – i.e. that notwithstanding any work done with parents at or after the time of a child’s diagnosis, young people themselves need to be given an opportunity to understand the implications of their disease and its treatment. This underlines the importance of a transition approach as young people become old enough to acquire and utilise this information.
2. The South West Aftercare Service
The current agreed policy is that all patients treated for cancer within the South West Paediatric Oncology Service (includes individuals diagnosed between birth and 18 years 364 days treated by paediatric oncologists within the SW shared care network) who are:

- ≥16 years of age and
- ≥5 years from first cancer diagnosis and
- ≥3 years from completion of last treatment

are to be referred to the Aftercare Service for ongoing follow up and long term care.

In addition, there is an option for the referral to the Aftercare service of any patients who are

- ≥11 years and <16 years of age and
- ≥5 years from first cancer diagnosis and
- ≥3 years from completion of last treatment

This clinic predominantly sees Bristol patients and increasingly is the pathway followed by local survivors of leukaemia and some solid tumour patients, otherwise patient follow up (until the age of 16 years) remains the responsibility of the patient’s treating consultant and is delivered either in Bristol or, as appropriate, by the shared care teams at one of the seven designated paediatric oncology shared care units (POSCU) across the South West. Transition pathways are being developed for this group to prepare for the eventual transfer to the over 16 year old Aftercare clinic and a programme of patient led work books for transition are being used in Bristol. These are designed from existing materials for use in transition and in line with National transition policy.

This document relates to survivors aged ≥16 years and to the resources required to deliver their care.

All such patients are discussed and prioritised at the Aftercare MDT prior to their allocation to an Aftercare clinic.

All patients are reviewed at a pre-clinic planning meeting at which the details of their treatment exposure and the presence of other relevant factors are assessed. This maximises the efficiency of each consultation and supports a full risk assessment from which an individualised care plan is formulated.

Each risk stratified care plan is approved at the Aftercare MDT after the initial assessment.

3. Characteristics of patients eligible for Aftercare
New referrals to the SW paediatric oncology service each year range between 120 – 130 new diagnoses. Assuming an average of 125 patients and estimated survival of 75 - 80% at 5 years from diagnosis, approximately 94 - 100 patients would become eligible for entry to the Aftercare programme each year.

Based on cancer registry data from 2007 / 2008 for regional incidence and on NCIN survival data 2013 122 TYA patients per year would be expected to be alive 5 years from diagnosis within the SW. Some of these are known to the Paediatric services but the majority would be new activity for the Aftercare service and their entry point into the service would vary between tumour sites reflecting the diverse needs of this group for care planning and holistic needs assessment. Recognising that impact of treatment is likely to be different in this group in comparison to paediatric survivors and that holistic needs assessment will take
place from diagnosis (TYA MDaT and On Target programme) smaller numbers will require regular clinic attendance. However, all survivors will require some level of support and estimates suggest:

- 122 patients require MDT discussion
- 25 (20%) patients level 3 requiring regular clinic attendance
- 51 (42%) patients require some element of remote monitoring/ intermittent clinic attendance
- 46 (38%) patients level 1 requiring self-management, who may require rapid re-entry back into the service

For childhood survivors there is a large population of patients who have not previously been able to access the Aftercare service. An audit performed by the South West Childhood Cancer Research Registry in 2012 identified 1980 patients first diagnosed at age <18 years, who were at least 5 years from first diagnosis, still alive and currently aged ≥16 years: of these only 356 (18%) had had recorded contact with the Bristol Aftercare service.

A diagnostic profile demonstrated a relative deficit in the proportion of patients with brain tumours seen by the Aftercare service:

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Leukaemia</th>
<th>Solid Tumour</th>
<th>CNS Tumour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>1980</td>
<td>614 (31%)</td>
<td>950 (48%)</td>
<td>416 (21%)</td>
</tr>
<tr>
<td>Known to SWAftercare</td>
<td>356</td>
<td>160 (45%)</td>
<td>146 (41%)</td>
<td>50 (14%)</td>
</tr>
</tbody>
</table>

This deficit was also greatest in those aged ≥25 years (all diagnoses). The age profile of the patients known to the Aftercare service was younger than that of the eligible population (median 24.4 vs. 29 years for those not known to Aftercare) and only 192/752 (25%) of those currently aged <25 years were known to Aftercare.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Age 16 - &lt;25 years</th>
<th>Age ≥25 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>1980</td>
<td>752 (38%)</td>
<td>1228 (62%)</td>
</tr>
<tr>
<td>Known to SWAftercare</td>
<td>356</td>
<td>192 (54%)</td>
<td>164 (46%)</td>
</tr>
</tbody>
</table>

There were no significant differences in distribution of patients by gender or by age at first diagnosis. However, the data showed that patients known to the Aftercare service were less distant from their diagnosis and were more likely to have been treated since 1990.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>1980</td>
<td>832 (42%)</td>
<td>792 (40%)</td>
<td>356 (18%)</td>
</tr>
<tr>
<td>Known to SWAftercare</td>
<td>356</td>
<td>100 (28%)</td>
<td>167 (47%)</td>
<td>89 (25%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Diagnosed &gt;20 years previously</th>
<th>Diagnosed 10 – 20 years previously</th>
<th>Diagnosed &lt;10 years previously</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>1980</td>
<td>1010 (51%)</td>
<td>752 (38%)</td>
<td>218 (10%)</td>
</tr>
<tr>
<td>Known to SWAftercare</td>
<td>356</td>
<td>139 (39%)</td>
<td>160 (45%)</td>
<td>57 (16%)</td>
</tr>
</tbody>
</table>
4. Clinical complexity
Patients attending the Bristol Aftercare service from April 2011 – March 2012 were subject to detailed audit. Data was available for 231 patients (> 95% of those who attended during that time) of whom 32% were being seen for the first time.

All patients were risk stratified using the (nationally agreed) Wallace classification where Level 1 is low risk and Level 3 is high risk. Only a minority (12%) fell into the low risk group.

Of note, 15% were survivors of bone marrow transplantation and 13% had had a brain tumour – groups known to be amongst those with the highest level of risk. These two groups represented 72% of all Level 3 patients.

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Total</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allogeneic BMT</td>
<td>0</td>
<td>2</td>
<td>32</td>
<td>34</td>
<td>16%</td>
</tr>
<tr>
<td>CNS Tumour</td>
<td>2</td>
<td>3</td>
<td>23</td>
<td>28</td>
<td>13%</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>16</td>
<td>47</td>
<td>16</td>
<td>79</td>
<td>37%</td>
</tr>
<tr>
<td>Solid Tumour</td>
<td>6</td>
<td>59</td>
<td>4</td>
<td>69</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>Totals</td>
<td>26</td>
<td>111</td>
<td>76</td>
<td>213</td>
<td>100%</td>
</tr>
</tbody>
</table>

Two measures of complexity of care (now being collected within the NCSI reporting structure) are: a) the extent to which patients are already known to other clinics:

and b) the number of patients being referred to other clinics after review in Aftercare:
This assessment of complexity is further highlighted by data, which show the number of investigations undertaken in the Aftercare clinic:

The data confirmed that, overall, 88% of patients had a Treatment Summary and 54% possessed an adequate Care Plan. As Care Plans are generated only after first assessment in the Aftercare clinic, this figure applies only to the 68% attending for follow up (i.e. 79% of those expected to have a care plan, did so). National targets are 100% for both criteria and this continues to be the subject of routine audit. (2012/13 audit figures demonstrate that 96% patients now have treatment summaries within the Aftercare service and 73% have a care plan.)

Thirteen (of 15 patients approached) were recruited to a clinical trial or study.

5. Unmet Need
Despite the action taken by the Aftercare service, the clinicians involved also record significant unmet needs – it was notable that 13% of patients seen were considered to need formal psychological intervention despite attempts to access and utilise resources outside the service: many more would benefit from the availability of psychological support in directing self management strategies and in addressing educational and cognitive deficits associated with treatment.
6. Geographical access
Travel time and access to the clinical service was explored with patients resident in Devon and Cornwall as part of the SW Young Cancer Survivors Project (undertaken 2009-2011). The great majority (76%) believed that they should continue to be attend a follow up clinic every 1 – 2 years and 76% wished to be seen by a doctor with specialist expertise in this area.

The four most important factors influencing 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%)

The majority (72%) of those attending clinic did so by private transport and of those who reported difficulties (37%) with travel to clinic, over half related this to parking problems at hospital sites.

Seventy seven percent of patients indicated that they would be prepared to travel for up to 60 minutes in each direction for access to an appropriate Aftercare clinic. No patient resident in Devon and Cornwall could access the Bristol Aftercare clinic within 60 minutes although this is possible for the majority (but not all) of patients resident in the north of the region.

Analysis based on post code of residence (undertaken by South West Cancer Intelligence Service) modeled the delivery of care at one or more hospital sites across Devon and Cornwall to see how this travel time target might be achieved. The figure below shows that, to achieve the target of 77% of patients accessing an Aftercare clinic within 60 minutes travel time, it would be necessary to deliver care from at least three centres.
More detailed analysis confirmed that care delivered from Exeter, Plymouth and Truro represented the best model. It is clear that, until clinics are established in these localities, access to Aftercare services for patients in Devon and Cornwall will be inequitable as SWAftercare clinics are currently only delivered in Bristol.

An audit by the South West Childhood Cancer Registry (SWCCRR) undertaken in 2004 suggested that 31% of all long-term survivors within the paediatric oncology programme aged >17 years were resident in Devon and Cornwall. There is no reason to believe that this proportion will have changed to any significant degree since the date of the audit and this implies that approximately one third of patients eligible for Aftercare have geographically inequitable access to the service.

7. Service capacity required

In determining the necessary capacity for the Aftercare service, the following information was ascertained, based on data available at August 2012, and certain assumptions were made:

1. 356 patients are already known to the service, of whom 231 attended in the year 2011-12. Overall, it is expected that approximately 80% of existing patients will continue to attend clinic and the service is working towards the achievement of a national target of 20% reduction in hospital based follow up in line with NCSI expectations.

2. Previous audit data show that approximately 75% of returning patients are booked to re attend annually (with 25% bi-annually or at longer intervals).

3. Approximately 95 new patients aged of 16 – 18 years will meet the eligibility criteria for referral to the Aftercare service each year: all should be seen for risk assessment and care planning.

4. Approximately 122 new patients treated under TYA services will meet the eligibility criteria and all will require risk assessment and care planning with 25 (20%) requiring on-going follow up.

5. Current practice suggests that patients who, on the basis of risk assessment are considered likely to fulfill eligibility for ‘managed self care’ (this applies to most Level
1 and some Level 2 patients), will still need to be seen at least once more before discharge from the service can be implemented.

6. Data from the South West Childhood Cancer Research Group indicates that there are 1980 patients who could be eligible for SW Aftercare, of whom 356 are known to the service. Amongst these is a ‘backlog’ of approximately 560 patients, aged 16 – 25 years, known to be alive and eligible for the Aftercare service but who have not yet been assessed. It is for this group that active efforts to engage with Aftercare are most likely to be beneficial. It is unlikely that all patients who have been lost to follow up will be easily traceable and some may not wish to engage with the concept of Aftercare. It is assumed, therefore, that 60% (336) may be successfully traced and accept an invitation to be seen (subject to the offer of a clinic location within a reasonable travel time from their home). Within the proposed service model, it is suggested that this backlog could be addressed, and all patients risk assessed, within 3 years.

7. Capacity in each clinic, based on the current availability of medical staff resource, is for 12 booking ‘slots’. Each follow up patient is booked into 1 slot but each new patient is booked for 2 slots.

The model utilised to calculate the necessary increase in service capacity is shown in Table 1 and the number of clinics needed within the Peninsula is seen in Table 2 and these will need to be distributed between the 3 sites – Exeter, Plymouth and Truro.

This indicates how the service should develop over 5 years in order to meet the demands both of new patients entering the Aftercare programme as they evolve from treatment, and of the backlog of patients currently aged < 25 years and not yet seen for risk assessment and care planning.

The number of additional clinics required by the service increases (from the current baseline of 36) by 10 in 2013-14 to a total of 46 in the year, peaking at 69 a year in 2015-16 and settling to between 55-60 by 2018.

As approximately one third of patients eligible for Aftercare are resident in Devon and Cornwall, it is proposed that at least this proportion of clinics should be delivered between Exeter, Plymouth and Truro. This is a conservative estimate as patients from Devon and Cornwall are more likely to be represented amongst the backlog of patients yet to be seen by the Aftercare service.

The NCSI proposes nurse led clinics as an alternative model of care for lower risk patients. These are being piloted by SWAftercare for Bristol based patients but currently there is insufficient Clinical Nurse Specialist resource to permit this development for within the Peninsula. Nevertheless, it is estimated that approximately 10-15% of all patients would be suitable for nurse led clinics should this resource become available throughout the region in the future. This, and the developing role of the Care Coordinator, will have an important impact on the adequacy of existing medical staff resources to support an increasing number of clinics, at least in the first two years of the proposed service model after which medical staffing resources may need to be reviewed.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>New patients eligible for Aftercare</td>
<td>95</td>
<td>190</td>
<td>95</td>
<td>190</td>
<td>95</td>
</tr>
<tr>
<td>New patients from current backlog (to be integrated over 3 years)</td>
<td>114</td>
<td>228</td>
<td>111</td>
<td>222</td>
<td>0</td>
</tr>
<tr>
<td>Follow up appointments from existing patient</td>
<td>231</td>
<td>131</td>
<td>326</td>
<td>185</td>
<td>532</td>
</tr>
<tr>
<td>Follow up appointments from patients in the backlog cohort seen in the previous year</td>
<td>0</td>
<td>0</td>
<td>114</td>
<td>114</td>
<td>111</td>
</tr>
<tr>
<td>Totals</td>
<td>440</td>
<td>550</td>
<td>646</td>
<td>711</td>
<td>849</td>
</tr>
<tr>
<td>Additional Slots Required / year (baseline = 432)</td>
<td>118</td>
<td>279</td>
<td>393</td>
<td>288</td>
<td>232</td>
</tr>
<tr>
<td>Additional Clinics Required / year (baseline = 36)</td>
<td>10</td>
<td>23</td>
<td>33</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>TOTAL CLINICS/YEAR PROVIDED ACROSS SERVICE</td>
<td>46</td>
<td>59</td>
<td>69</td>
<td>60</td>
<td>55</td>
</tr>
</tbody>
</table>
### TABLE 2

<table>
<thead>
<tr>
<th>SW Aftercare - Clinic Slots Estimate</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Year 4</th>
<th>Year 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients slots needed</td>
<td>82</td>
<td>64</td>
<td>82</td>
<td>64</td>
<td>82</td>
</tr>
<tr>
<td>New entries to system</td>
<td>32</td>
<td>64</td>
<td>32</td>
<td>64</td>
<td>32</td>
</tr>
<tr>
<td>New entries from backlog</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Follow ups from new entries</td>
<td>0</td>
<td>32</td>
<td>19</td>
<td>64</td>
<td>96</td>
</tr>
<tr>
<td>Additional follow ups for backlog</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patients seen</td>
<td>32</td>
<td>64</td>
<td>63</td>
<td>96</td>
<td>123</td>
</tr>
<tr>
<td>Totals</td>
<td>32</td>
<td>64</td>
<td>64</td>
<td>63</td>
<td>96</td>
</tr>
<tr>
<td>Clincis Required - for new patients</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Clinics Required - for &quot;new&quot; follow-up patients</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Clinics Required - for &quot;new&quot; &amp; follow-up patients</td>
<td>8</td>
<td>10</td>
<td>13</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>Totals</td>
<td>32</td>
<td>64</td>
<td>64</td>
<td>63</td>
<td>96</td>
</tr>
</tbody>
</table>

**Parameters**

<table>
<thead>
<tr>
<th>Slots Required per Appointment</th>
<th>New</th>
<th>Existing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slots Required</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

**Existing Patients**

- Percentage Seen each Year: 80%
- Number at 2013: 0

**New Patients**

- Estimated New Patients: 32

**Clinics**

- Slots per Clinic: 8
- Clinics per year: 36
- Slots per year: 288

**Patient Backlog**

- Estimated Number: 752
- Number Already Known: 192
- Number not Accessing Service: 0
- Percentage Likely to Accept Invoice: 60%
- Estimated New Patients: 0

**New Patient catch-up by year**

<table>
<thead>
<tr>
<th>Year</th>
<th>Catch-up Percentage</th>
<th>Catch-up Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>34%</td>
<td>0</td>
</tr>
<tr>
<td>Year 2</td>
<td>38%</td>
<td>0</td>
</tr>
<tr>
<td>Year 3</td>
<td>38%</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>0</td>
</tr>
</tbody>
</table>

NB for TYA patients additional capacity will be required for 25 new patients per year to clinic as repeated attendees (122 requiring needs assessment and care planning)
8. Health Economic Considerations

A specific evaluation has not been carried out the SWAftercare service and it is acknowledged that most measures of long-term health benefit from the programme may not be realised on an individual basis for a number of years. However, as part of the South West Young Cancer Survivors Project, data from SWAftercare was contributed to a national health economic evaluation undertaken by the York Health Economics Consortium. This work, built around two clinical scenarios for the delivery of Aftercare, highlighted the complexity of the approach involved. Its key conclusions are summarized below in text taken from that report – with qualifying comments relating to this bid shown in italics:

- Changes in activity *(i.e. the transfer of patients from hospital based follow up to managed self care)* will not necessarily happen quickly and it is important that proper assessment procedures are followed before survivors are risk stratified into lower risk levels;
- The additional cost of initial assessments *(including the re engagement of patients currently lost to follow up)* is likely to be significant, particularly in applying risk stratification to services that have yet to do so. It is important that hospital providers and commissioners discuss how best this can be achieved and whether there is any need for pump-priming to support this activity. Without these assessments, it will be difficult for the new pathways to develop;
- When survivors are risk stratified, it may release capacity within hospital-based services to allow for more survivors to receive aftercare. Given the likely growth in the number of survivors in the coming years, it is important that there is spare capacity in the system to allow for this. This will not therefore result in actual cost savings to the hospital service but should allow greater efficiency to be generated;
- Commissioners need to take into account the additional costs of care provided in the primary and community care settings when survivors are effectively ‘discharged’ from hospital care;
- In considering the way in which hospitals are reimbursed for their provision of aftercare, it may be worth considering alternative forms of currency. The use of tariffs can create perverse incentives and it may be appropriate that some form of community or whole systems tariff is developed to take account of a service that is increasingly provided across the different sectors of the health economy, rather than just in hospital settings. Personalised budgets for aftercare could also be an option worth considering;
- The introduction of functions such as care coordination and liaison with a key worker should allow for a better quality aftercare service to be developed. These functions could be provided within existing staffing resources if time is freed up through risk stratification, and so they need not necessarily require new appointments to these roles *(this depends on the adequacy of existing staffing and the availability of staff to meet the anticipated increase in activity associated with re engagement of patients lost to follow up and the increasing number of survivors entering the aftercare system)*. More organised care should mean that survivors are followed up more systematically which should result in better outcomes. Although it will be some time before this hypothesis can be tested, it is important that the concept of better outcomes for survivors is maintained as one of the key drivers for these changes. If these improvements happen without significant extra cost it would indicate that they are cost effective.
9. Resource Requirements for Service Development

9.1. Current resources
The Aftercare service is an outpatient service. Current staffing consists of:

- 0.4 wte Clinical Nurse Specialist (Ruth Elson) – note that this is part of a 1.0 wte post but 0.6 wte of this post is allocated to the paediatric endocrinology service for the endocrinological support and investigation of paediatric oncology patients.

- 1.0 wte Care Coordinator (Divya Bassi) – the post holder is currently appointed on a fixed term contract to the end of March 2014 supported by funds from NHS Improvement.

- 0.4 wte Consultant Paediatric Oncologist sessions (shared between Professor Stevens and Dr Cox)

- Secretarial support within the existing paediatric haematology oncology secretarial team.

9.2. Resource investment required
In order to support the proposed increase in clinical activity identified in section 7, the resource investment requested from 2013-14 includes support for:

- Clinical Nurse Specialist (0.6 wte) from 1.4.14
  Justification – to extend the introduction of the service (via outreach clinics) to patients resident in Devon and Cornwall; to contribute to the provision of a designated key worker role to all patients.

- Clinical Psychologist (0.6 wte) from 1.4.14
  Justification – to support the development of self-management strategies and promote discharge from hospital based follow up; to address unmet clinical need for the psychological support of individual patients (there is currently no psychological resource available to the Aftercare service)

- Care Coordinator (1.0 wte) from 1.4.14
  Justification – to coordinate Aftercare clinic bookings, provide patients with required pre clinic information and take action to minimise DNA rates; coordinate pre clinic planning meetings; support Aftercare MDT meetings and implement the actions relating to outcomes agreed; to contribute to the provision of a designated key worker role to all patients; to maintain routine audit of all Aftercare clinic activity and generate appropriate reports, including monthly submission of clinical activity data to NHS Improvement; to maintain the SWAftercare email account and act as a ‘Hub’ for contact by patients (and their other medical attendants) seeking advice and information about Aftercare issues.

As the service expands it is likely that additional consultant time will be required within the next 5 years.

R Cox
December 2013
Appendix

The work of the NCSI CYP work stream has led to three key outcomes:

[A] The agreement of 10 core principles defining Aftercare:

1. All cancer survivors should expect to have informed choices in relation to services provided for them and that these will be provided through an established aftercare multidisciplinary team.
2. All Aftercare services are based on consistent, defined patient pathways.
3. All Aftercare is based on safe risk stratified levels of care endorsed by clinicians.
4. All cancer survivors should have access to the appropriate models of Aftercare which is ‘right for them’ and in line with the national Quality Standards of National Institute for Health and Clinical Excellence (NICE).
5. All cancer survivors can expect to be given a Treatment Summary and Care Plan at the end of their treatment and at all stages of transition.
6. All cancer survivors should have access to a care co-ordinator function to streamline their care.
7. All cancer survivors should have pre-planned and pro-active transition arrangements at all stages of their Aftercare.
8. All cancer survivors, who are clinically safe to self-manage will be provided with comprehensive information and be involved in a remote monitoring and / or alert system(s) which prompts screening investigations.
9. All cancer survivors “experience feedback” should be routinely monitored and directly influence commissioning decision-making.
10. There will be a minimum 20% reduction in hospital based Out-Patient appointments.

[B] The definition of four models of care

The consultant led model
Traditionally, follow up and aftercare for cancer patients have been provided by medical consultants which may be within a tertiary treatment centre. However, with the exponential increase in the number of young adult cancer survivors, as well as supporting patient choice and the need to repatriate patients back to their local hospital as early as possible, this model of care may no longer be viable, sustainable or appropriate. In order to overcome this, alternative models of follow up care have been developed and prototyped.

The shared care model
The shared care model is a professionally led shared care pathway with a clinical specialist and clinician at a local hospital or GP in the community in conjunction with a clinician at the Principal Treatment Centre (PTC). The care coordinator function is vital to the success of this model by identifying and providing the best clinical care for the survivor.

The nurse led model
The nurse led model may include a face to face clinic appointment, telephone follow up or postal follow up. This model of care is proving very beneficial particularly with patients transitioning from young adult to a late effects or adult services.

The supported self management model
The supported self management model gives the survivor the ability to actively participate in their follow up care therefore empowering the patient and building confidence so the patient has the ability to make decisions concerning their recovery within a supported environment. Care coordination, treatment summary and care planning and remote monitoring / recall systems are vital for this model to be ‘best practice’. Survivors need and require robust stable systems in place to allow for rapid re-entry back into the survivorship pathway at any juncture.

---

1 Children and young people living with and beyond cancer. Designing and implementing pathways to benefit patient aftercare. Continuing to build the evidence. NHS Improvement October 2011
The development and publication of an interactive care pathway

This has been published in two versions – one for children and one for TYA patients. The paediatric pathway is illustrated here but is best viewed on the website (see link below).

Paediatric aftercare pathway

An interactive version of these pathways can be accessed from the NHS Improvement website at: