NATIONAL CANCER SURVIVORSHIP INITIATIVE

Providing the evidence to achieve improvements for patients

CHILDREN & YOUNG PEOPLE CANCER SURVIVORSHIP

NHS

NHS Improvement

CANCER

DIAGNOSTICS

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An initial series of case studies and learning from the Children and Young People Test Site Community including:

- A three tiered model of care provides follow-up options for childhood cancer survivors in Birmingham
- Improving the lives of young people throughout and after their cancer treatment
- Transition care
- Transforming the traditional model of late effects follow-up

The Children and Young People Survivorship workstream is one of seven workstreams within the overall National Cancer Survivorship Initiative - which is a five year strategy with the Department of Health, Macmillan and NHS Improvement working in partnership to improve the care, patient experience and support for those living with and beyond a cancer diagnosis and treatment.

Contents

Foreword

Making progress ... achieving our vision

The NCSI Vision for future survivorship care outlines five shifts, which are needed in the approach to the care and support for people living with and beyond cancer (Department of Health 2010).

These five shifts include:

1. A cultural shift in the approach to care and support for people affected by cancer, to a greater focus on recovery, health and well-being after cancer treatment;
2. A shift towards holistic assessment, information provision and personalised care planning, in recognition that future care needs to be directed by individual risks, needs and preferences;
3. A shift towards support for self management, based on individual needs and preferences, an approach that seeks to empower individuals to take responsibility for their condition supported by clinical assessment, support and treatment;
4. A shift from a single model of clinical follow-up to tailored support that enables early recognition of the consequences of treatment or further disease;
5. A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures in aftercare services.

This shift, we believe, will improve overall quality of life, allow young people to live a healthy and active life, to enhance future autonomy and achieve their life goals. Our aim is to maximise health and well-being and minimise the long-term effects of therapies. Underpinning these shifts in care is a re-think about the way we prepare young people to take responsibility for their lives, as well as the focus and delivery of follow-up care. Developing new approaches to care and support is the focus of our nine clinical test sites.

The piloting and evaluation of new approaches to deliver care will be the key to our success in being able to achieve our vision. Included in this document is an update on progress to date through a series of 'improvement stories' from the nine clinical test sites and one non-clinical test site.

Elements of improving self-management, describing and evaluating service innovation and detailing the skills of the cancer workforce feature throughout our test site work. With the on-going support of service improvement teams, clinical teams are working with young people and their parents/carers in both the development and testing of these new initiatives. As always with service improvement work, progress varies, but individual achievement has been significant. Building the principles for post-treatment care is being realised through the sustained hard work of those delivering through clinical test site activity. We can be confident that the evidence to achieve change is within our grasp.

Department of Health (2010) National Cancer Survivorship Initiative Vision. Department of Health, London.

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Introduction

The Children and Young People Cancer Survivorship work is focused on testing models of care to identify principles and 'prototype' models for further testing.

The overall objective is to improve the provision of care and support for children and young people surviving cancer; and to importantly improve the overall support to parents and carers. To achieve this objective we are testing models of care in relation to clinical and non clinical services and support based on the follow priorities:

- The development of survivorship treatment plans (individual to the needs of each child or young person).
- The development of survivor pathways with a particular focus on key stages of the care pathway, namely transition.
- Appropriate follow-up models – including shared care and nurse led follow-up.
- Identifying those patients at low, medium and high risk as a consequence of late effects following surgery, chemotherapy and radiotherapy.
- Continuing support throughout care in terms of education needs.
- Dealing with non-clinical issues to ensure a 'normality' of life following a cancer diagnosis and treatment.

There are nine clinical test sites and one non clinical test site.

The four children and young people working principles are:

Principle 1
Personal, risk-stratified care.

Principle 2
A shift to informed self management.

Principle 3
Easy access to universal and, where necessary, specialised services appropriate to their needs.

Principle 4
Realistic/evidence-based/cost effective 'models of care'.

Cross cutting themes include:
- Risk stratification methodology
- Nurse competencies
- Evaluation exercise
- Evidence review
- Pan Thames – model of care work
- Lost to follow up
- Sharing of learning and progress.

Global measures are:
- 100% care plan for all children and young people cancer survivors
- Reduction in inappropriate follow-up appointments
- Reduction in unnecessary emergency admissions/reduction in unnecessary inpatient admissions.

Children and Young People Cancer Survivorship Test Sites 2008/10

1. Yorkshire Cancer Network/St James' University Hospital, Leeds
2. Sheffield Teaching Hospitals NHS Trust
3. The Christie NHS Foundation Trust
4. Birmingham Children's Hospitals NHS Foundation Trust
5. Bristol Royal Hospital for Children and South West Paediatric Oncology Shared Care Network
6. Cambridge University Hospitals NHS Foundation Trust
7. CLIC Sargent
8. Great Ormond Street Hospital for Children NHS Trust
9. The Royal Marsden Hospital NHS Trust
10. Brighton and Sussex University Hospitals NHS Trust

Additional Care Plan/Treatment Summary Test Sites

11. Newcastle upon Tyne Hospitals NHS Foundation Trust
12. The Leeds Teaching Hospitals NHS Foundation Trust
13. Alder Hey Children's NHS Foundation Trust
14. Cardiff and Vale NHS Trust
15. University College Hospitals London NHS Foundation Trust
16. The Royal Marsden Hospital NHS Trust

Birmingham Children's Hospital NHS Foundation Trust

A three tiered model of care provides follow-up options for childhood cancer survivors in Birmingham

Project details

In March 2009, Birmingham Children's Hospital (BCH) embarked on a journey of redesign with their patients who are on long term follow-up. Having been accepted by NHS Improvement as a national test site, the Trust aimed to design and test a three-tiered model of care for their long term survivors. The intention was to offer a range of care options dependent upon the health needs of the patient. There are a number of partners in the project each providing a unique contribution. The working group from BCH is supplemented by:

- West Midlands Children's Tumour Registry (WMCTR) who provide the postal questionnaire service
- Clinicians from University Hospitals Birmingham who provide the adult service for this group of patients
- Pan Birmingham Cancer Network who provide service improvement support.

Current baseline situation

Working closely with their partners on the project, BCH began by assessing the current services offered and collecting baseline measures. A process mapping exercise was completed to analyse gaps in service provision. Great variation was identified in the services and possible improvements discussed. It became clear that the pathway for follow up of patients relied heavily on the different working patterns and medical viewpoints of the individual clinicians. Follow up care was predominantly offered through hospital based care within consultant-led clinics with only a small number of patients being discharged by individual clinicians, some of who were transferred to a GP postal questionnaire system. Oncology patients did so within specific follow up clinics but this was not the case for haematology patients. This cohort returned to a treatment clinic setting with the consequence of long waiting times and being surrounded by patients still undergoing treatment.

A questionnaire was distributed to patients and parents in follow-up within both oncology and haematology clinics, which provided the following information:

- 94.5% of all parents/patients felt it appropriate to return to hospital for their follow up appointments.
- Whilst 43% of haematology responses showed they were unhappy with coming to treatment based clinic settings, 84% of oncology patients who had already experienced designated follow up clinics would be unhappy to return to treatment clinics for follow up care.
- 81% of all responses felt it was essential to see a consultant during their follow up appointment.

In addition to this questionnaire, an audit was undertaken with all patients who had seen the clinical nurse specialist (CNS) for their follow up appointments within the adult services at University Hospital Birmingham (UHB). The results were extremely positive with a 100% of responses received stating they were happy with their consultation with the nurse. They were confident with the information received and would be happy to see the nurse for their next appointment. The survey also collected qualitative data and examples of responses received are below:

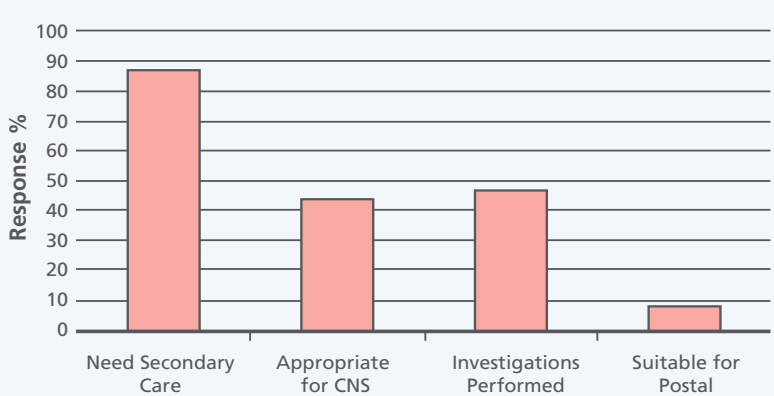
"Much more relaxed seeing the CNS as seeing a doctor evokes memories of painful treatments."

"The CNS gave me more information and reassurance than I have had in a long time."

"We found she was very helpful - and felt she had time to listen to us."

"The CNS was very attentive and discussed all of the issues we raised in detail."

Figure 1: Clinic Audit Value



Clinical appointment value

A further audit was designed and completed by the clinicians within the follow up clinic (see graph on page 6). This was designed to determine how they perceived the clinical value of the appointment and the need for the patient to return to consultant led care. The results identified that 87.5% of the patients who attended follow-up within the audit period needed secondary care. This meant that 12.5% of patients were considered suitable for an alternative form of follow up. Furthermore, 43.75% of those audited were considered by the clinicians to be appropriate for nurse-led care.

Nurse led clinic was born

Through analysis of this baseline information, it was clear that there was a large cohort of patients who would benefit from a quieter, more attentive designated follow up within a nurse led clinic setting. It was also apparent from the questionnaire responses and the variation between oncology and haematology clinics that it would take some time for the parents and patients to be comfortable with these changes This meant that there was need to monitor patient satisfaction with any changes closely.

Risk stratification

The clinical team across both the paediatric and adult services worked together to design a risk stratification model (see table above). This categorised patients into three clear groups according to their risk of late effects. All low risk patients would be discharged from secondary care follow up and placed on postal follow-up.

Figure 2: Risk stratification

Level 1 postal follow-up

Treatment group:

- Stage I and II Wilms tumour
- Low risk chemotherapy (i.e NOT received anthracyclines or alkylating agents)

Tumour groups:

- Surgery alone
- Low stage neuroblastoma
- Germ cell tumours
- Melanoma
- LCH
- Retinoblastoma

Level 2 nurse led follow-up

Treatment group:

- Standard risk ALL in first remission (regimen A and B)
- High risk ALL in first remission excluding patients with CNS disease at presentation or undergoing BMT in first remission

Level 3 clinician led follow-up

Treatment group:

- Multi-agent chemotherapy, anthracyclines, alylating agents, platinum agents
- Radiotherapy
- Myeloablative high dose chemotherapy with stem cell rescue

Tumour groups:

- Brain tumours
- All other non-CNS solid tumours not in level 1 or 2

Medium risk patients would transfer to follow up within a nurse led clinic; and high risk patients would continue to be seen by a consultant.

Evidence of successful testing

Testing is launched

As a result, in September 2009, a nurse led clinic was set up within BCH. For the testing period, this clinic focuses only on haematology patients This group had previously been identified as having the highest disadvantage within their current setting. The nurse led clinic has run successfully now for five months, with early feedback from patients showing that they are happy to return to this setting. The education to these families and evaluation of the improvements made will continue through to the end of the testing period. With only a few patients booked in per clinic, the families are given more time, attention and support to discuss their treatment and possible late effects. The focus is heavily on encouraging patients' self-management and raising the awareness of their own health. Psychosocial support is now more readily available for the parents and siblings, in a calmer and more time-generous setting.

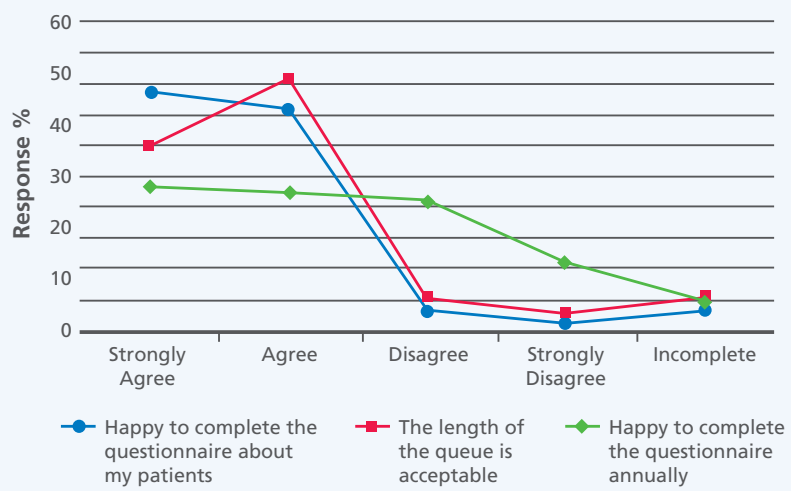
Postal follow up

For those patients within the low risk category of the risk stratification, the West Midlands Regional Children's Tumour Registry (WMRCTR) is working with the project to enable follow up of those patients through primary care. WMRCTR have run a service for 19 years, whereby they have sent out questionnaires to GPs. These questionnaires collect health and social information on survivors of childhood cancers. Previously the results of the postal questionnaire were utilised only for research purposes and no clinical intervention took place.

The registry records patients on their database for the whole region, which includes individuals that have not been seen at BCH. Focusing on the BCH patients, most of the patients on postal follow up were those that had moved out of the area and thus could not return to BCH for follow up appointments, or have defaulted out of the follow up service through non-attendance. Very few patients had been actively put onto postal follow up through a process of planned discharge.

An assessment was undertaken into the rate of returns of the information from the GPs. In 2008, 81.5% of questionnaires sent were received back having been completed within primary care; and 2009 provided a similarly high figure of 76.8%. With return rates higher than many of the registries in the UK, it was clear that we needed to keep our primary care colleagues satisfied with any changes made to the services.

Figure 3: GP Survey Results



An audit of the completeness of the returned questionnaires identified a number of questions which were often unknown by the GPs. Many of these are related to the social information which whilst necessary for research purposes were not required for clinical assessment. A new questionnaire was designed based on the responses of the GPs. This questionnaire was sent out to 100 GPs on the database to gain their thoughts and opinions on this mode of follow up (see graph above). The following results were received from these GPs:

- 94% of GPs stated they were happy to complete the postal follow up forms for their patients.
- 90% felt the length of the questionnaire was acceptable.
- 59% were happy to complete the questionnaire annually (as opposed to previous three yearly issue).

With the support of primary care, in both their satisfaction with the means of involvement and an acceptable level of returns, the final check was to ensure that the information received through this route was accurate. A data validation exercise was completed. This compared the GP information we had received again the Cancer Intelligence Unit's HES data. The result of this data validation exercise was very positive – a sample 5% of all the patient matches were analysed in detail and identified that in 100% of cases the GP information was entirely accurate; and in fact in 25% of cases, we received more detailed information from the GP than we would receive through the HES data.

From September 2009, a new discharge pack was designed by the project's lead clinician and a launch of the new pathway of discharge was spread to the wider team at BCH and UHB. With patient consent and information of postal follow up, it equips the patient and family with education around their planned discharge to postal follow up. To date, six patients have been actively discharged through these means and an evaluation of this revised pathway will begin in March 2010, six months after testing began.

While planned discharge at BCH has shown improvement, the introduction of a research assistant at the Cancer Registry and more structured and detailed evaluation of these clinics and patients has already identified a significant number of patients who will be appropriate for postal follow up after their move to adult services.

The risk stratification and three-tiered model of care have allowed BCH and UHB to provide patients and parents with a range of follow up which is more appropriate to their needs. By reducing unnecessary visits to hospital and giving patients a higher level of value to their appointments, both improved quality and productivity are anticipated as a result of this testing.

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Brighton and Sussex University Hospital NHS Trust

Model of care

Project details

The Royal Alexandra Children's Hospital (Brighton and Sussex University Hospitals (BSUH) NHS Trust) has provided shared care for children with cancer with a number of Primary Treatment Centres. Traditionally, long term follow up of the children and young adults has reverted to the Primary Treatment Centre (PTC) and this has required families making the journey to London. The aim of this project was to establish a local model of long term follow-up for childhood cancer survivors. This service re-design project would contribute to the achievement of the Cancer Service Guidance 2005 – Improving outcomes with children and young people that states:

"The principle that under pins the guidance is that of age appropriate, safe and effective services as locally as possible."

The project has involved a BSUH paediatrician and adult endocrinologist/haematologist establishing a joint clinic to review long term follow-up patients. They have worked together with a clinician from the Royal Marsden Hospital to test a service that achieves a smooth transition from paediatric to adult services structured by age.

Initially clinic appointments have been offered to patients known to the local paediatric shared care service but the aim would be to offer the service to all childhood cancer and young adult cancer survivors within the network, for example young adults aged 16-20 previously treated by adult oncology services who would not currently have access to the type of clinic described.

Testing has been conducted alongside the Royal Marsden NHS Foundation Trust and the Bristol University Hospital's model of care.

Evidence of successful testing

The project seeks to establish a new service designed to meet the specific need of survivors of childhood cancer, in this way it will improve the quality of services for this patient group

Safety – it is hoped that establishing a local long term follow-up service may reduce the number of lost to follow up patients. As part of the project we have tried to quantify the number of people who might require this service. The Cancer Registry has traced 400 childhood cancer survivors living in Sussex and as a Hospital Trust we are aware of 180. These patients are of significant risk of developing problems later on in life and their clinical outcomes are improved if the problems are diagnosed and treated at an early stage.

Clinical effectiveness – we would aim that BSUH provides long term follow-up care that is as a minimum, of a comparable quality to that provided by the Royal Marsden. Improvements in clinical care and transition for all cancer patients will arise through closer collaboration between the BSUH paediatrician and adult endocrinologist/haematologist. During the testing period the numbers of patients seen has been small and so an audit of clinical care will take place towards the end of the pilot period.

The adult endocrinologist and the paediatrician are also keeping a 'learning diary' to capture the experience during the project

"One thing we discussed after clinic was that paediatricians in general tend not to discuss with patients issues related to sexuality and libido. But, these are clearly very important to the 'survivors' as they grow up, and are something we frequently manage in the 'endo' clinic. With one patient, I had asked him previously about this and he said he had no concerns, but today he admitted he did have some concerns, and we had a very helpful discussion about the possible hormonal/psychological causes, including possible psychological reactions to his previous cancer diagnosis, that could be causing this. We agreed a way forwards.

I also learnt from this that young patients may not understand the term 'libido' so I'm going to paraphrase this in future!"

Adult Endocrinologist

Patient experience – the project will provide patients with greater choice as to where to receive their long term follow-up treatment. They will be able to make choices to fit in with their lifestyle and preference. Feedback from patient interviews indicates that 100% of patients attending local long term follow-up clinics would prefer being seen at the Royal Alexandra Children's Hospital (RACH) rather than the Royal Marsden due to the reduced travel involved and for some for more emotional reasons.

> Having cancer has made me a more positive person. I missed a lot of school but I have become determined to overcome this. Coming here makes it easier because I can go back college after the clinic. When we go to the Marsden it takes all day.

17 year old boy

> There's a funny smell at the Marsden that I just don't like. It's not unpleasant but makes me feel funny. I suppose it might be memories.

13 year old girl

The patient questionnaires have also shown that:

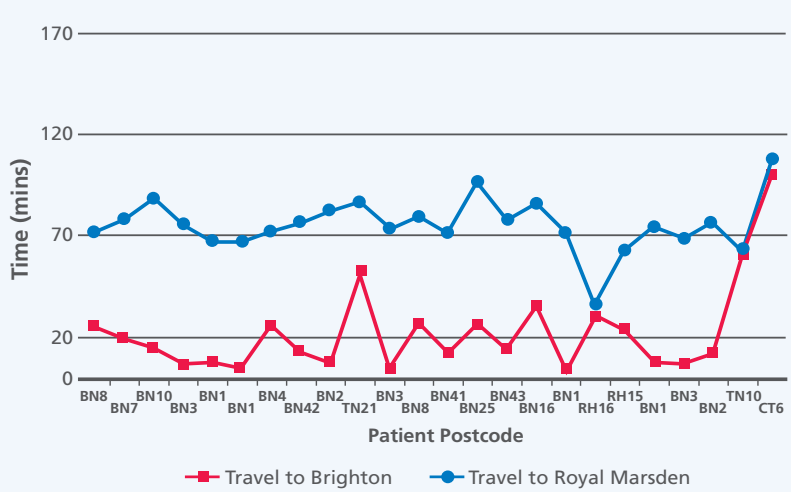
- 33% of patients who attended BSUH clinic talked about having issues other than health related problems. Difficulty in education and employment, feeling different and problems with relationships were the main areas. 25% would want the opportunity to talk about these things in a clinic environment.
- 42% had health related issues to do with weight.
- 13% have problems with depression.
- 13% have fertility concerns.
- 33% would rather be seen in an adult outpatients department (first clinics were held in the Paediatric Hospital but subsequent clinics will be held in adult outpatients).
- 100% would prefer to be seen in Brighton rather than in London because of the shorter/easier journey.

> I like the cross over – seeing Dr Taj and Dr Anne here – and then when I'm older Dr Anne and the adult people.

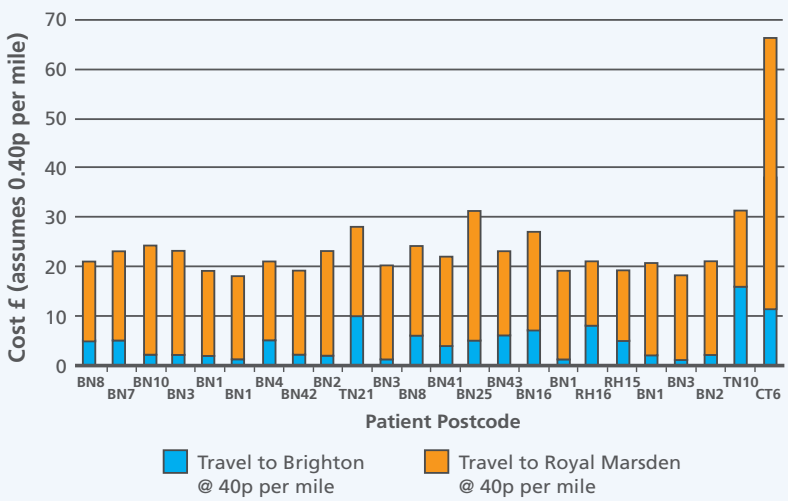
14 year old girl

Productivity/cost – an assessment of patient travel distances, duration and costs has been undertaken This indicates that on average, the journey times, distances and costs of patients travelling to the RACH are 70% less than if they had attended clinic at the Royal Marsden in London.

Brighton and Sussex University Hospitals NHS Trust - Patients potential travel time to long term follow-up clinics



Brighton and Sussex University Hospitals NHS Trust - Patients potential travel costs to long term follow-up clinics



Results

It was decided to collect the (Did Not Attend) DNA and re- booking rates during this project and this is on going. To date these are on a par with the rates that existed at the RMH prior to the project starting. But the numbers are so small that they may not be significant. We will have to await the end of the pilot period.

We are in the process of assessing RACH and RMH costs and income for LTFU clinics to see which the most cost effective model is. There may also be savings associated with BSUH not having to pay for as many London consultants to deliver clinics from Brighton.

An annual audit of LTFU patient's care against LTFU best practice guidelines /treatment protocols (this has yet to be undertaken). This would ascertain whether as a minimum, the same quality of LTFU care can be provided by the local centre as the PTC.

We are planning to continue with the BSUH LTFU clinics planned for this year. We review the project plan after each clinic to ensure the plan reflects new knowledge and learning. However, long term implementation will depend on the outcome of the national project.

Top tips

- Ensure that you have Primary Care Trust (PCT) support from the beginning. The PCT were initially concerned that the project might increase demand so it took a while to work the issue through with them.
- Engage with the cancer network which may be able to provide data or service improvement support to the project.
- Identify early on clinicians within the adult service who will act as the survivorship lead within their specialty. This may not be an adult oncologist – ours are an adult endocrinologist and haematologist.
- Be clear about the patient group you will focus on i.e. long term follow-up patients currently seen in London, lost to follow-up patients etc.
- If establishing a new service, start small and review plans after each clinic. Be prepared to be flexible and to change your approach.

Resource implications

- Funding for long term follow-up clinical nurse specialist.
- Access to appropriate psychology support for patients (patient interviews have identified this as a big gap in the existing service).
- Service improvement project support for process mapping and re-design plus undertaking patient interviews.

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University Hospitals Bristol NHS Foundation Trust

South West young cancer survivors project

Project details

The principal focus of the service design /development 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.

Phase 1:

Who needs the project?

What is currently being provided for them?

Who is providing it?

What do parents want?

What do professionals think parents 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

Phase 2:

Negotiate resources to deliver the model agreed

Pilot the model

Evaluate the model

Adjust and implement the final model of care

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.

A previous audit undertaken in the South West looked at the follow up status of survivors aged 17 years or over. Of 895 patients, 47% were still receiving follow up within the paediatric shared care network, 10% had been formally transferred to an adult service, 11% had moved out of the region, but 32% were apparently lost to follow up. Fewer of the older survivors (age ≥ 22 years) were being followed up (41% 'lost' vs. 17% of those aged 17 – 21 years) and survivors of brain tumours, who might be expected to have the greatest need, showed the largest loss to follow up (46% 'lost'). These data highlighted the unsatisfactory nature of services for survivors despite well established and high quality shared care arrangements for paediatric care. The key points were that patients were being inappropriately followed in paediatric services, not being adequately transitioned into adult care and that too many patients were lost to follow up without any formal process by which the need for continuing follow up was being assessed or discussed.

The project addresses key issues incorporated in the NICE IOG for Children and Young People with Cancer published in 2005 and reflected in the Children's Cancer Measures published 2009, specifically the project seeks to ensure that:

1. **Survivors are able to access specialist ('safe and effective') care as locally as possible.**
2. **There should be 'robust and appropriate surveillance' for survivors.**
3. **There should be good communication in achieving transition between paediatric and adult services.**

Evidence of successful testing

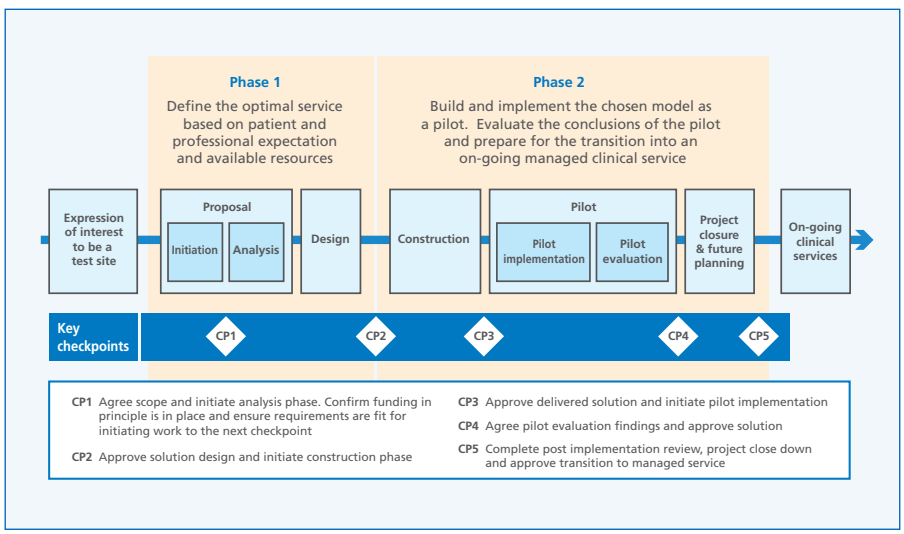
The project will build on the experiences gained from a designated young adult follow up service already running in Bristol where a separate clinic is open to all patients aged ≥16 years of age, ≥5 years from diagnosis and at least 3 years from last treatment. This clinic sees all patients who are under 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).

The stated aim of the project is to test the following hypothesis that '**effective** long term follow up can be delivered with high levels of **satisfaction** 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.

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.

The project will be undertaken in two phases. The baseline assessment is underway which includes three principal components:



- A review of the current status of long term follow up activity amongst young adult survivors, their knowledge about the need for long term follow up, and their engagement with it (or otherwise). The two key mechanisms for gaining insight into the views of survivors will be a paper based questionnaire and a series of focus group workshops.

  We will also explore (using a Delphi analysis) attitudes to the provision of long-term follow up care amongst professionals in the region as this may impact on the acceptance of the model by the young adult survivors.

- The South West Cancer Intelligence Service (SWCIS) will facilitate geographical mapping based on post code of residence, to explore the optimal location of the long term follow up 'hubs' in terms of patient travelling time.

Data for each of these components will be available by September 2010.

We intend to collect data on the benefits of the new service configuration by addressing issues such as:

- 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.

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. 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.

Top tips

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.

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.

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.

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Cambridge University Hospitals NHS Trust

Improving the lives of young people throughout and after their cancer treatment

Project details

Background

The journey through cancer diagnosis, its treatment and after effects is fraught with obstacles which can impede a young person's ability to return to a functional life. Many of these are well known and appreciated by professionals but some may not be expressed by the young people at the time and so their importance may be underestimated. We undertook a series of pilots in cancer survivorship for children and young people based on the feedback we had received at user involvement groups or in response to a known clinical need. The key areas identified by the young people were:

- Need for increased access to knowledge relevant to their cancer and its effects in a means accessible to them.
- Increased information about fertility and increased options for fertility preservation.
- Need for individualised psychological support.
- Increased information about exercise and what they were allowed to do.

The key area identified by clinicians working in late effects was:

- Late effects database and summary of treatment with dates for future investigations.

Teenagers and young adults attending a series of fatigue workshops

Aims

As a result several pilot schemes were set up to investigate the specific needs, examine gaps in provision and, working with a group of young adult survivors, innovate new ways to provide solutions to those gaps. This also led to empowering the young people with the belief that their needs were being addressed and they could help to do something about it. The pilots are:

- A teenage and young adult cancer website for information in an age appropriate setting (www.cforward.org.uk).
- An assessment of fertility information and practical service provision.
- An assessment of a unique psycho-oncology service which is mirrored from paediatrics to adult services (see diagram on page 17).
- An exercise initiative (assessment, fatigue workshops, DVD)
- A late effects database (Onolog™) led by Dr Anny Wong (not included in this document).

The purpose of these projects was to improve the quality of life and well being of young people throughout and after their treatment and to address the guidance set out in the Improved Outcomes Guidance for Children and Young People with Cancer (2005) and in line with several aspects of the cancer reform strategy. In addition we assessed the fertility advice and practical steps given to all patients over a year compared with the joint college guidance on fertility for cancer patients (2007).

Evidence of successful testing

Several testing areas were undertaken in line with the pilot schemes. Initially young patients and their families were asked to attend a group meeting to confirm priorities for future work which is where the pilots evolved. Several young people volunteered to work and co-lead projects to ensure patient relevance and as an innovation of care delivery.

Further testing included:

- Questionnaires about areas of need for information.
- Assessment of exercise tolerance prior to illness, at diagnosis, on treatment and current (with time from treatment if relevant) which is currently being repeated both for new patients and to review how the interventions helped since first assessment.
- Assessment of concordance with joint college guidance on fertility (in the knowledge it was written for adults not those under 16).
- Assessment of needs for psychological support, how and where it was delivered and any gaps identified to assess for future service development.

Findings and resulting developments

1: Information delivery

The website went live in July 2009 having ascertained which areas were of need to patients (central point of contact for information, all relevant numbers and weblinks in one place, knowledge about the teenagers and young adults (TYA) service and team). Further testing and questioning ascertained that this had been seen as an improvement, for many patients had replaced folders of sheets of paper but still lacked information they would like access to including important information for the end of treatment such as immunisations, insurance advice, how to get back into education and revisiting fertility concerns. These areas are now being taken forward at the next user involvement group to design key survivorship 'tools' to get back into life. These should be added in 2010 and a reassessment of improvement made.

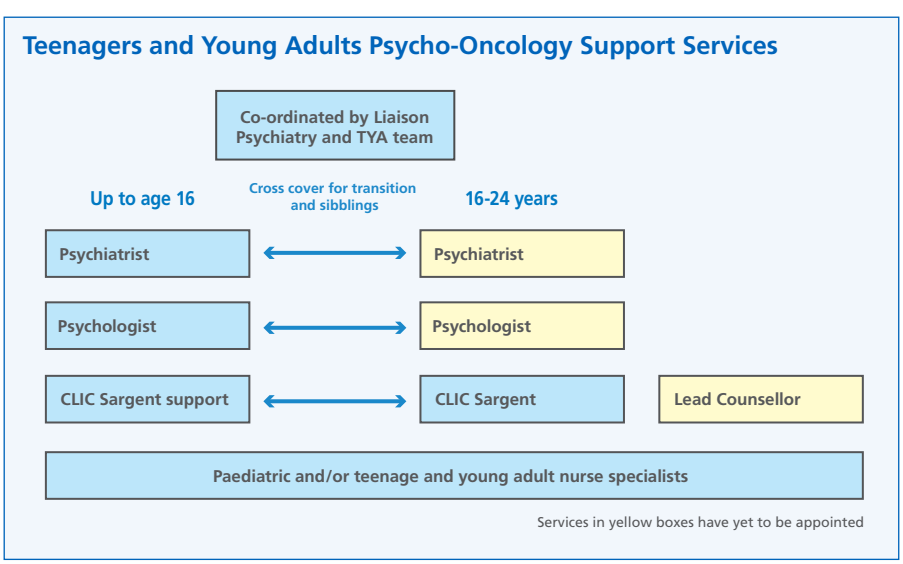
2: Fertility assessment

The first assessment showed that the guidance was well followed for men over 16 but that there were gaps for women of all ages (particularly under 16). This has led to the establishment of a TYA fertility team which can refer young women within less than four days for urgent advice (often the same day as the request). This is being done by experts within reproductive medicine in combination with interested TYA oncology clinicians or nurse specialists. The reassessment of concordance with joint college guidance in 2010 will establish how much of a difference this has made. In addition new techniques have been employed (in line with new developments in reproductive medicine) which have retained the fertility in at least three new female patients in 2009 who would previously have been rendered infertile.

The initial user involvement survey highlighted that infertility is not adequately addressed for most patients (over 80%) regardless of how well the joint college guidance was followed. This was because most patients felt they could not process the long term implications of the affect on fertility by their cancer/treatment as they had so much else to process at the same time. However, even within a few weeks this subject kept coming up in their minds and surfaced repeatedly at follow up clinics even after treatment. However less than 5% of survivors felt able to ask about fertility at such appointments as they felt they should be grateful for being alive and were not sure when/where to ask the questions. A late effects clinic is being set up as well as a 'New Beginnings' series of workshops for those near/at the end of treatment.

3: Psycho-oncology service

A structure (see diagram below) was devised to cover the range of psychological needs for those in children's and adult services including those who would transition from one



group to the next. To date only the posts in blue have been appointed but the others are to be appointed in 2010. An assessment of psychological need showed that approximately a third of patients in the TYA age group (13-24) required additional support from those other than nurse specialists. The ratio of need was almost 2:1 female:male. The most common reasons for need were of anxiety, difficulty dealing with diagnosis or palliative diagnosis or depression, post traumatic stress, compliance issues with very few cases of parasuicide or severe clinical depression. The flexibility of the service in those under 16 led to no gaps in care required. However, significant gaps were identified in those over 16 (mostly psychology but also some psychiatrist time gaps). Psychiatry was only available to those over 16 in a crisis. The apparent success of the under 16 model suggests that once appointed the over 16 model should also work well.

4: Exercise initiative

An initial survey of young people showed that many wanted information on exercise which was not being provided and that they were often covert about any exercise they undertook. They were keen to help with a DVD which gives specific help to patients with particular issues (e.g. bed bound, chair bound, poor balance after brain surgery or limb prosthesis). It also gives personal stories from young people and general advice on fatigue management.

The initial assessment of need also showed fatigue management was an issue for young people so a series of fatigue workshops have been run. These assess the levels of activity possible before diagnosis and during (and after if relevant) treatment. Over 85% of young people found this helpful as did 95% of the parents (many of whom did not realise the severity of their child's fatigue or how they could help). In 2010, a reassessment of those who took part in the 2009 workshops will be undertaken to see if there has been progress. The two patients assessed so far have noted an increased ability to do more of what they want to do by modification of their behaviour and including light exercise.

Top tips

Our greatest achievements have come from directly following the needs and requests of our young patients and survivors; generally, if they are not keen on an idea it probably will not work, and vice versa.

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The Christie NHS Foundation Trust

Survivorship education programme

Project details

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) workstream.

The purpose is to provide an educational survivorship programme over a period of eight weeks, one x 2 hour session per week.

The sessions include:

- 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.

The programme will be offered to those who have received potentially curative treatment for cancer. The proposed changes contribute to the guidance and vision proposed in the Department of Health (DH) NCSI Vision document.

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.

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.

TYA groups contributions to steering group discussions include;
They 'want 'Information in an interactive format', and 'others may ask questions that I hadn't thought of'.

Evidence of successful testing

The survivorship programme will provide clear information and advice in relation to aspects of life affected by cancer survivorship. The aim of this is to improve the quality of patient care and self-management. The information given to the attendees will be of a high quality through utilising professional expertise and resources.

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.

The project aims to provide relevant, sufficient and timely information that will inform, support and empower survivors. This additional method of information provision is used alongside current methods of delivering information in order to improve patient engagement, acceptance, and understanding.

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.

Results

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 17 February 2010.

Pre course attendee questionnaires, investigating user satisfaction and any noticeable changes to patients' mood and their social, physical and risky behaviours, will be used as a baseline for evaluation.

Post course – some time after the course the same questionnaires will be completed again to evaluate any changes (timeframe probably 12 months but yet to be confirmed). Further monitoring of progress is advisable as the evaluation time frame is quite restrictive and valuable information would still be emerging 12 months to five years post attendance

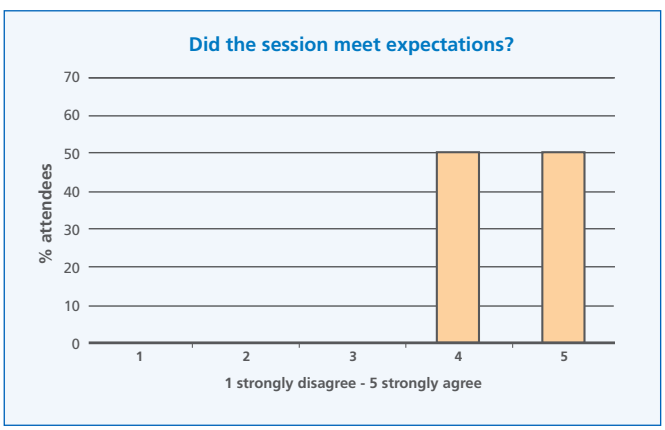
Session evaluation will be through the use of questionnaires. The session format, content and speakers will be evaluated by all attendees at each session.

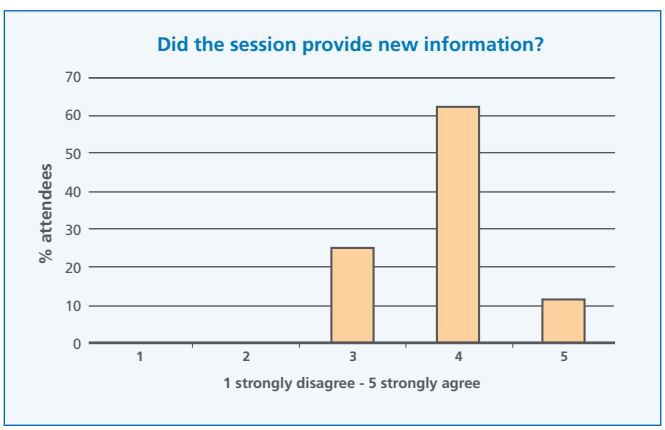
Feedback is to be provided on the cost of implementation and resources required to the NCSI CYP work stream. This will be part of the evaluation process.

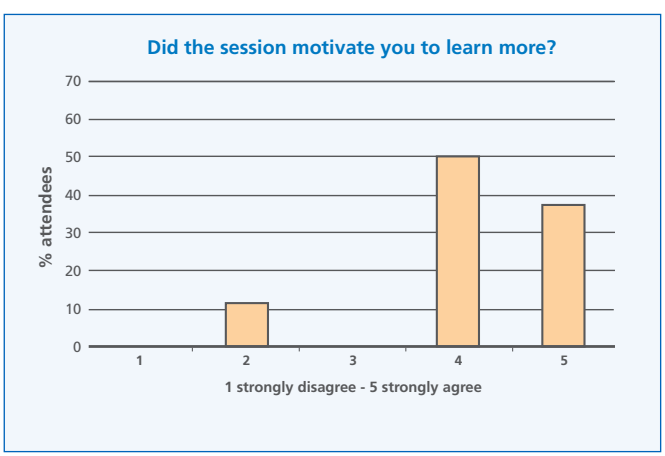
Early evaluation and top tips

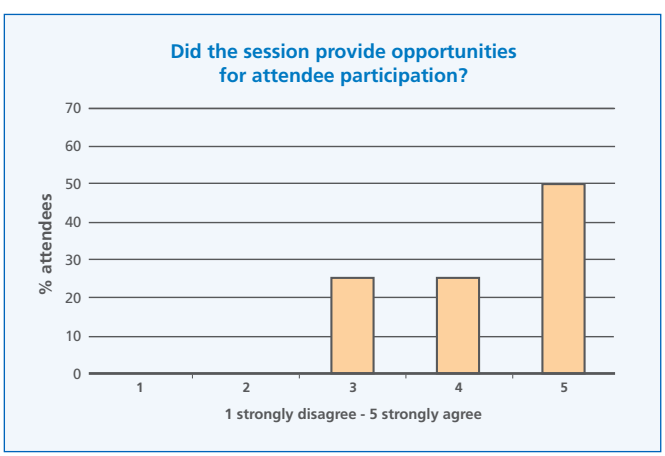
- Early session evaluation looks promising.

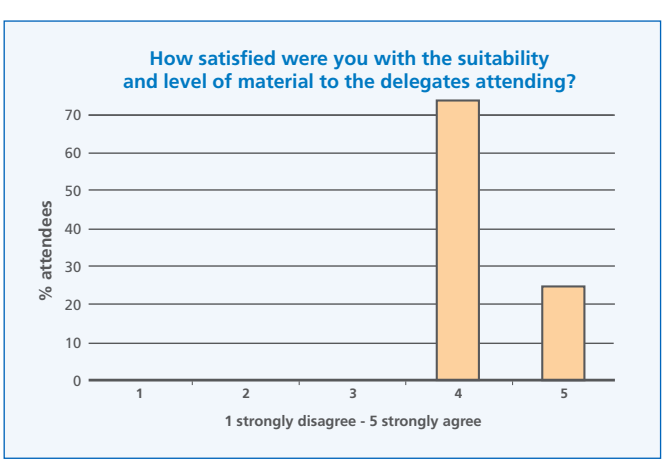
Session one evaluation charts:











	Actual comments
Which part of the session did you feel was especially useful and why?	Discussing problems and thinking of ideas to help future patients.
	Helping for the future, patients etc and discussing problems that everyone shared
	Talking to other peers in the same situation
	Discussions with other patients
	Discussing other peoples problems, learning that everyone has similar problems and how they went about them
	First part - small group idea was good. Felt confident enough to talk. Even though I don't feel I learnt much, I enjoyed discussing my experience and listening to others. Break/snack was nice and relaxed.
	When we were split into groups and able to discuss our own individual experiences/ emotions
	Hearing other people talk about their situations

- 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.

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The Christie NHS Foundation Trust

Treatment summary record and survivor care plan

Project details

The Christie Hospital treatment summary/care plan is a new service innovation that aims to improve information for both patient and GP. The purpose of the change is central to the government's National Cancer Survivorship Initiative (NCSI), which endeavours to improve care and support for people living with and beyond cancer.

The project builds on work being undertaken at The Christie to provide a personalised treatment summary and late effects follow-up care plan including:

- Diagnosis
- Stage
- Treatment (including chemo and XRT doses)
- Summary of potential late effects and the importance of follow up needed post disease specific surveillance.

The Teenage and Young Adult (TYA) groups' contributions to steering group discussions include:

'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.'

The proposed changes contribute to the guidance and vision proposed in the Department of Health (DH) (NCSI) vision document.

Evidence of successful testing

The Christie has worked closely with Great Ormond Street Hospital (GOSH) to define the treatment summary/care plan document, following much discussion and input from stakeholders. 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

The phased approach of the project is to:

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.

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.

The primary benefit of this quality information will improve patient support, choice, self-management and potentially benefit their use of NHS services.

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.

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. It also may improve patients' uptake to appropriate follow-up care, improving clinic attendance and reducing DNA rates.

There are an additional six test sites nationally who are participating with the testing.

Results

The project is now being tested in the Young Oncology Unit at The Christie. The testing phase is in progress December 2009 – April 2010.

A baseline questionnaire survey of survivors was conducted to evaluate what they were told or what they remembered about late effects.

30 teenage and young adult subjects received questionnaires:

- Completed treatment <5 years ago (x 15)
- Completed treatment 5-10 years ago (x 15)

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.

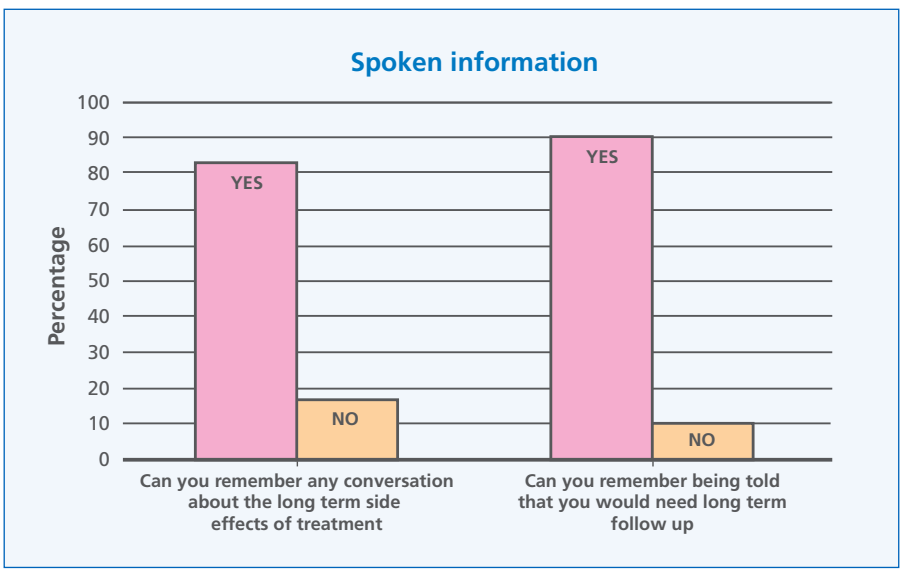
A higher percentage of respondents remembered receiving spoken, rather than written, information about the long term side effects.

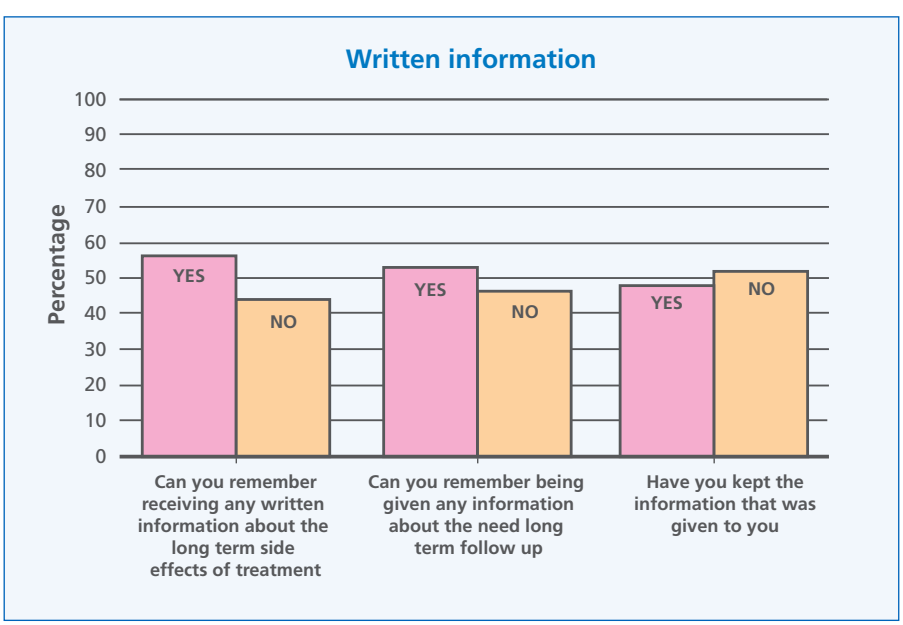
Spoken	YES 83%	NO 17%
Written	YES 57%	NO 43%

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.

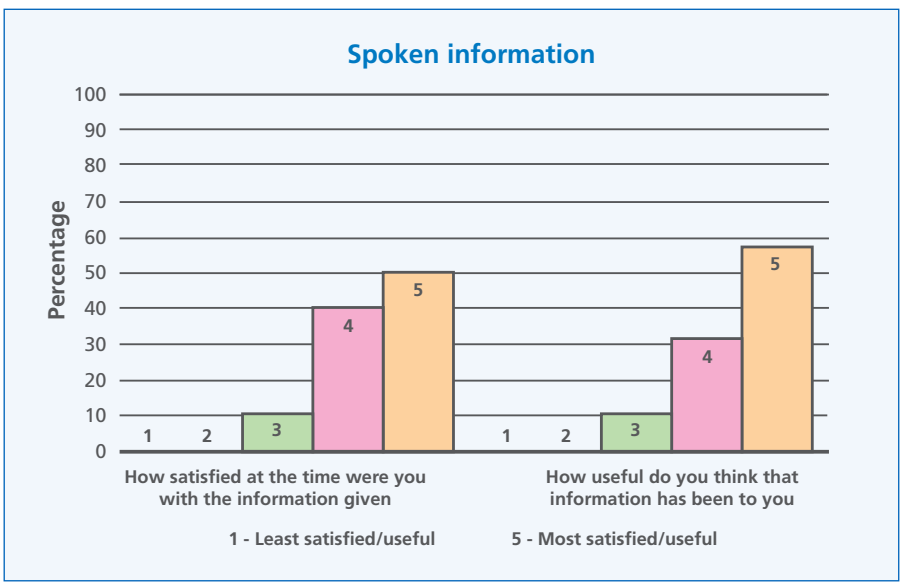
	Felt better	Felt upset	
Spoken	45%	Spoken	24%
Written	70%	Written	5%

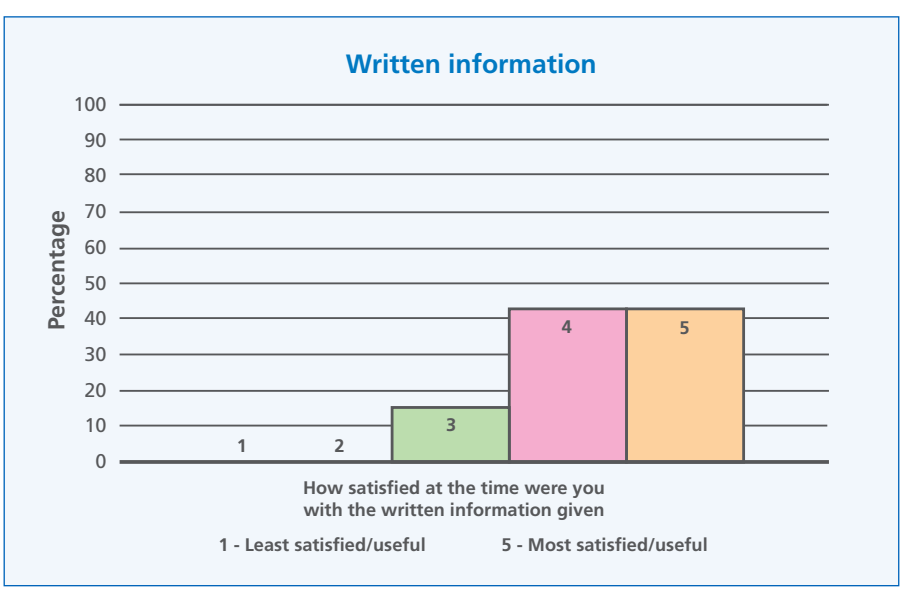
23-25% were not bothered about the information at all (spoken or written).

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 and care plan
Comments on a blank treatment summary/care plan and its usefulness.

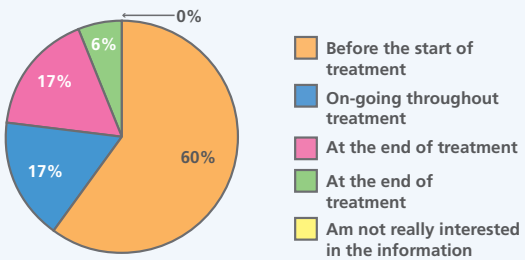
- 89% of respondents would find a TS like this very useful (scores 4 and 5).
- 100% respondents would not mind their GP viewing the technical bits of the TS.
- 68% respondents would not need someone to go through the TS with them.
- 88% respondents would like the TS at the end of treatment before long 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.

Post-testing evaluation is to be performed by NHS Improvement approximately six months following care plan delivery, details to be confirmed. This will be compared to the baseline evaluation.

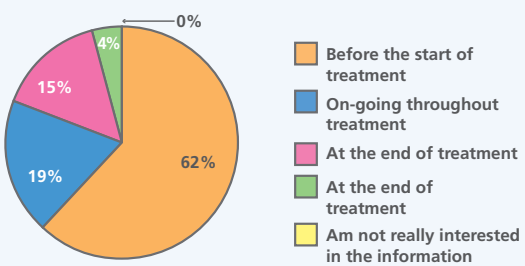
Early evaluation and top tips

- Awareness of time and resources necessary to complete and deliver treatment summary/care plan.
  - Time it takes to complete them, especially follow up patients with complex histories
  - Lack of dedicated resource on a busy unit
  - Delivery of TS/CP can take a long time – longer clinic time required.
- The requirement for creation of templates.
- Early engagement of clinicians.

When do you think is the best time for the doctors and nurses to tell you about the late effects of treatment and the long term follow up you may need?



When do you think is the best time for the doctors and nurses to give you written information about the late effects of treatment and the long term follow up you may need?



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CLIC Sargent

The impact of cancer on a child's world

Project details

Background

CLIC Sargent was commissioned to carry out this study by the Children and Young People's workstream, as part of the National Cancer Survivorship Initiative (NCSI).

Definition

There are several definitions of cancer survivorship. Children and young people have told CLIC Sargent they should be regarded as a survivor from day two, the day after diagnosis. This simple definition echoes the scope of survivorship described by the NCSI as being "anyone living following a cancer diagnosis". A survivor is therefore anyone "living with and beyond cancer".

Approach

Survivors aged 7 to 13 living in England were invited to tell CLIC Sargent about the impact of cancer on their world. The children were offered the option of giving their views in person at an activity afternoon or by completing a postal activity pack:

- 49 children took part in six activity afternoons held in locations across England
- 41 children completed and returned a postal activity pack.

The study has gathered rich quality narrative from six focus groups and the children's postal activity packs, which combine written and illustrated contributions from children living with and beyond cancer.

The method used to consult children at the activity sessions was independently evaluated.

> "Well, my family is scared that my cancer might come back and they tell me that if it comes back I would not survive. My mum doesn't like it when I play action games and throw myself about because she thinks if I knock myself the cancer might come back."

Ben, age 9, six years post treatment - Wilms Tumour

Evidence of successful testing

Findings Summary

Children have highlighted a number of intertwining issues that stem from their cancer diagnosis and treatment, the impact of which can be far reaching and affect many aspects of a child's life. The issues raised by children are encompassed within the six broad headings below:

- The Effects of Cancer and Treatment
- School Life
- Friendships
- Home and Family Life
- Hospital
- Information and Public Awareness.

Improving the survivorship experience for children

Cancer and treatment has a marked impact on many survivors of childhood cancer in both the short and long-term.

Children have told CLIC Sargent that they recognise cancer has changed their lives, limiting some opportunities which would be considered the norm for children of their age.

Children said that where possible they have adjusted to accommodate the impairments caused by their illness and treatment so that they can get on with life. Many feel optimistic and confident they will achieve their aspirations for the future.

Despite this optimism, inevitably the negative impact of a cancer diagnosis often leads to children having additional support needs, which for some are not being met.

It was clear from the views expressed by children that for many of them joint working and planning across medical, education and social care services had at times been poor. This had resulted in an uncoordinated approach to their support, particularly in the case of those off treatment. The result was that children missed out and fell behind at school, struggled to maintain friendships and found it difficult to be part of wider social groups and networks

Activity Two - Your letter/artwork

Your letter/artwork for Professor Mike Richards

> Being treated with cancer has made me less independent, less confident and I don't like trying or doing different things. It also affects my mum and dad as well because I need them more than usual.

Lucy, age 13, two years post treatment - Medullablastoma

The issues raised by children in this report describe the challenges they face in achieving what they want from life. Children living with and beyond cancer need timely and appropriate support to enable them to meet these challenges and accomplish educational achievement, social achievement and emotional stability. In doing so children will be allowed to realise the Every Child Matters outcomes and reach their full potential.

Providing children and their families with ongoing personalised support packages and information will help to improve the experience of children throughout their cancer journey.

The following actions are integral to the successful delivery of a personalised support package for children living with and beyond cancer and their families:

a) All children and their families participate in developing a personal assessment and care plan at the point of diagnosis to include clinical, emotional, social, and practical support.

b) A named key worker or support coordinator is appointed to lead and monitor the delivery of the care plan from the start of the child's treatment through to long term care.

As part of a personalised assessment and care plan, the following areas highlighted by children need to be considered:

Be healthy

- Appropriate information and support is available on how children can maintain fitness levels and live a healthy lifestyle.
- Information on cancer and treatment is available for children and families to enable them to make informed decisions.
- The child's family supports their wish to lead an active and healthy lifestyle.
- Children are included in active games and physical education classes at school.
- Children are encouraged to continue attending social groups.

Stay safe

- The whole family are offered support
- Children feel safe in their surroundings
- Care professionals are child friendly, and have positive attitudes and working practices
- The hospital and other care environments receiving children are bright and welcoming.

Enjoy and achieve

- Children are supported to help them maintain school attendance.
- Children receive academic support in school.
- Children are supported to help them maintain academic progress whilst away from school.
- Children are supported to maintain friendships through school and other peer social groups outside school.
- Children are provided with treatment at home or close to home.

Make a positive contribution

- Children's ability to make a positive contribution is recognised.
- Organisations listen to the views of children and act on what they've heard.
- Children are actively involved in making decisions that affect them.
- Children are able to participate in developing new information and services which aim to support them.

Achieve economic wellbeing

- Academic, social and emotional support for children is available from diagnosis, to allow the child to reach their full potential in the long term.

> Please take all this information into account and do good with it.

Daisy, age 12,
ten years post treatment

CLIC Sargent

Policy project

Background to CLIC Sargent

CLIC Sargent is the UK's leading children's cancer charity. CLIC Sargent provides a wide range of services and a large number of care professionals to look after children and young people with cancer, and their families. We are delighted to be a part of the National Cancer Survivorship Initiative's children and young people's workstream.

Project details

Ensuring the holistic needs of young cancer survivors aged between 11 and 19 are effectively met by generalist and non-clinical policy, guidance and services for children and young people, comprising specific initiatives targeting those with special needs or disability.

Survivorship is a particularly significant issue for children and young people (CYP) with cancer. As more and more children go on to survive cancer, longer term adverse effects of treatment may become apparent and the duration of the life beyond cancer could be 50 years or more. The issues facing CYP living with and after cancer can be very different to those experienced by adults. When cancer hits at an earlier stage of someone's life, education can be affected and starting out in work can be a challenge. Young people's bodies are growing during their cancer treatment and there can be more physical and hormonal effects later in life. There are also many practical issues that affect survivors of childhood cancer which affect survivors of both adult and childhood cancer, such as employment, financial difficulties, insurance and information.

It is CLIC Sargent's assessment that at present little is understood about the overall picture of what guidance, practice and policy exists around the provision of generalist services for CYP with cancer and whether their needs are adequately being met. This policy review therefore aims to look at this overall picture and make recommendations as to what further policy change, training, awareness, information and research may be required to better meet these needs. CLIC Sargent, the UK's leading cancer charity for children and young people, is leading this policy review work as part of the children and young people's work stream of the National Cancer Survivorship Initiative (NCSI).

More specifically, the policy review will:

- Identify all relevant guidance and policy in the provision of services for children and young people with SEN, disabilities, complex health needs, mental health and other needs.
- Highlight gaps in current policy and guidance when it is applied to young cancer survivors.
- Assess what resources are needed in order for the full range of service providers to be able to effectively deliver best practice to this group – such as additional information or training.
- Propose key areas of policy and guidance which the workstream may wish to develop or influence others to develop.
- Produce a report, including a version which is accessible to young people.

The purpose of the policy review is to map policy for general children's services which cover young people with cancer, to identify gaps and to make recommendations for change to ensure such policy best meets the needs of young cancer survivors.

The policy review will enable the NCSI and the children and young people's workstream to:

- Take a genuinely holistic view of meeting the needs of young cancer survivors.
- Identify potential areas of policy and guidance that should be developed to shape service priorities.
- Influence the development of non cancer specific services but for the benefit of young people with cancer.
- Ensure that there is no duplication of effort with other workstreams and other policy initiatives.

At present, a lack of information and understanding means that young cancer survivors may not be able to take advantage of the opportunities presented by non-cancer specific Government initiatives and policy. By providing an overview of this, including a version accessible to young people, will empower young cancer survivors as well as highlighting gaps and areas for further work.

The CYP workstream of the NCSI seeks to ensure that children and young people who have or have had cancer have equal opportunities to achieve the five Every Child Matters outcomes. CLIC Sargent's policy review will empower young cancer survivors to access and increase their awareness of non-cancer specific Government initiatives which may better ensure their broader psycho-social needs are met.

Evidence of successful testing

The project improves quality of care by making recommendations to plug policy and guidance gaps, it is anticipated that new policy or guidance will be created to support general services for young people, such as schools, Connexions, youth clubs etc. to understand cancer survivors needs better.

Results

CLIC Sargent, as the UK's leading charity for children and young with cancer, intends to use the findings of the policy review to inform its ongoing policy and campaigning work. CLIC Sargent is committed to ensuring children and young people who have or have had cancer are enabled to return to a normal life as quickly as possible and that their holistic clinical, educational, social, emotional, practical and financial needs are met as an ongoing part of survivorship care and support.

This policy review aligns well with a major piece of work that CLIC Sargent has been leading to ensure children and young people with cancer receive the best possible holistic care and support in the community – the More Than My Illness review of the community based clinical and non-clinical care and support needs of children and young people with cancer and their families, published February 2009. CLIC Sargent will shortly be publishing a follow-up to this report which will recommend key elements of support that aim to improve the long-term life opportunities of young people with cancer aged 16-24 by improving access to high quality community-based services.

In addition, it is anticipated that further research will be undertaken to evaluate further the psycho-social and economic late effects of childhood cancer. This research, coupled with the findings from the policy review, will provide a good springboard to plug existing policy gaps and better meet the needs of young cancer survivors. CLIC Sargent will be working with the NCSI CYP workstream on an ongoing basis to ensure the needs of young cancer survivors are effectively addressed.

Top tips

The issue of reviewing policy as opposed to policy implementation has been a significant challenge for the policy project. Whilst policy often comprises laudable aims and objectives, these are often compromised by lack of proper implementation and / or evaluation. In addition, such issues are compounded by the fact that there often exists geographical disparity in policy implementation, and most notably on issues such as special educational needs.

The review is therefore seeking to make use of anecdotal evidence as to how policy is implemented whilst focusing more specifically on policy itself. The review will also attempt to identify which 'boxes' young survivors may fit into to best meet their needs, e.g. learning difficulties, SEN, physically disabled etc.

It is also worth being aware that the review can only give a 'snapshot' of current policy which often changes at a significant pace with new policy and guidance being released all the time.

Where possible, the review has attempted to give an indication of the direction of travel for certain areas of policy but clearly this will also be impacted by the result of the imminent General Election.

CLIC Sargent is hoping to be in position to take forward further research to evaluate further the psycho-social and economic late effects of childhood cancer. This research, coupled with the findings form the policy review, will provide a good influencing strategy to the government to plug policy gaps.

Resources

CLIC Sargent's report *More Than My Illness* recommends a new model of joined up service delivery for children and young people with cancer (and other complex health needs) that spans the health, education and social care sectors. It provides a toolkit for commissioners which will help them ensure that every child's care and treatment is coordinated, and that they are able to safely leave hospital and spend more time at home during their treatment. More Than My Illness aims to support the full implementation of the NICE (National Institute for Health and Clinical Excellence) Guidance Improving Outcomes for Children and Young People with Cancer.

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Great Ormond Street Hospital for Children NHS Trust

Transition care

Project details

The project involves the evaluation of current transition care offered via nurse led transition clinic to cancer survivors at Great Ormond Street Hospital for Children NHS Trust (GOSH). GOSH is one of the national test sites as part of Children and Young Peoples (CYP) National Cancer Survivor Initiative (NCSI).

The project addresses service improvement and aims to incorporate new ideas and protocols into clinical practice. The purpose of the improvement change is central to the governments NCSI, which endeavours to improve care and support for people living with and beyond cancer.

The proposed study will contribute to the guidance and vision proposed in the DH NCSI Vision document enabling survivors prepare for adulthood with relevant information, personalised care planning based on treatment record and self management and independence.

Measures to collect evidence of successful testing

Young survivors who attain the age of around 16 to 18 years are offered a transition clinic appointment to prepare them for future follow up at an adult hospital setting or with their GP in the community. At transition, survivors are offered information about late side effects, long term surveillance needs, advice on healthy lifestyle, fertility, etc. It also provides an opportunity to the survivors to talk confidentially of any other issues. Since the development of the care plan (separate project), these are now issued at transition, though similar information had been provided at GOSH in the current setting.

Good information empowers survivors, supporting self-management and independence, which improves patient experience and quality of care. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences.

The phased approach of the project is to:

1. Define the features of an effective transition model of care. This would be achieved through normative exercise with wide stakeholders. This will form the baseline evidence.
2. Develop a survey questionnaire for those who have undergone transition to evaluate the current transition care and check that it meets the best practice as defined above.
3. Distribute questionnaire and analyse to support benefits.

Stakeholder focus group (physical and virtual) was conducted to define features of an effective model of transition model care. A survey questionnaire is being developed at the moment.

Results

Features of an effective model of transition care

Independent and safe environment: Minimal parental input at this stage; Comfortable 'safe' environment for young people (YP) - able to be seen alone (without family) and by one health care provider; YP to attend independently so that discussion is directed at them - not parents. Previous research has shown that YP like professionals to speak directly with them; Clinic should provide ability to improve self confidence; Age appropriate environment; Confidentiality; clinic environment where no questions are barred e.g. sex, drugs, relationships, etc.; Transition should empower YP to take more control of their own health care.

Written information/advice/ treatment/risk/health education: Patient education, provide written treatment summary and offer; expert advice/information about treatment and risk of late effects; Transition needs face to face discussion and written information - fact sheet, summary, health education, contact details; Information - re Late Effects; Information Leaflets; Information easily transferable to new health care teams in new health provider trusts.

Flexibility in transition service: On site but not necessary in clinic; age appropriate discussion; Referred to dedicated Transition service after age 16, but referral determined by individual development; Dedicated clinic - Clinic appointment needs time; Longer appointment, preparation before clinic; Appropriate timing of transaction (likely needs to be patient specific); Transition may have to be a spectrum of care - some patients may need one appointment; some may need more.

Clinician competency:
Clinician with good general training in Late Effects/Endocrine; Education for clinician - Clinician needs to be expert and able to communicate with adolescents. Needs knowledge about Late Effects and access to patient notes.

Communication across pathways:
Good communication between 'sending' and 'receiving' health care teams; Good referral pathways; New health care provider has an easily identifiable service to receive referral; representatives from both present.

Attendance and reminders of appointments:
Good attendance by young people; Text/e-mail appointment reminders; promote importance to young people for their benefit; modern form of communication.

Resource:
Clinic - Adequate resources i.e. time, patient information, etc. ; Must be feasible with our currently available resources; Funding and support of management to develop service.

Contacts:
Ability to contact health care professional post clinic; Easy access of patient to staff and information; Ability to contact HCP post clinic by young people and other health care professionals, e.g. community based.

Transitioning:
Education for patient adult health services; preparation for change from child to adult care; Education for patient, healthy life style, social health, fertility; Discussion re: employment, higher education, insurance, pension, etc. Administration:- need of an administrator; Database.

Patient Group Forums:
Ideally Group (long term survivors) activities and Support Groups
Key Worker:- Need of a key worker role.

Psychological support/assessment - siblings:
Opportunities to talk and support.

Support for parent/carer:
Possibly parental education about separation as child grows older.

Survey questionnaire is being developed and it is hoped that its analysis would provide evidence of the benefits of a transition care.

Points to consider

There is some overlap of this project and that of the care plan as both involve providing relevant information to survivors to become better informed ad equipped in self management.

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Great Ormond Street Hospital for Children NHS Trust

Treatment summary record and survivor care plan

Project details

The project involves the development, testing and implementation of a treatment summary record and survivor care plan of cancer survivors at Great Ormond Street Hospital for Children NHS Trust (GOSH). GOSH is one of the national test sites as part of Children and Young Peoples (CYP) National Cancer Survivor Initiative (NCSI).

The project addresses service redesign and improvement and aims to incorporate new technology, protocols and innovative ideas into clinical practice. The purpose of the improvement change is central to the governments NCSI, which endeavours to improve care and support for people living with and beyond cancer.

The proposed changes contribute to the guidance and vision proposed in the DH NCSI Vision document. The project aims to provide information and personalised care planning, based on treatment record, individual risks and needs. For this project, GOSH has worked closely with Christie Hospital at Manchester, which is involved with the adult workstream of NCSI.

Evidence of successful testing

Measures to collect evidence

Following cancer diagnosis, treatment and remission, most of the survivors remain in long term follow-up (LTFU), which involves regular clinic attendance (annual or even less frequent). Good information empowers survivors, supporting self-management and independence, which improves patient experience and quality of care. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences.

The phased approach of the project is to:

1. Develop a care plan in conjunction with Christie Hospital
2. Collect baseline evidence of patient/parent experience and views on the care plan.
3. Issuing care plans to survivors at GOSH and Christie Hospital and at other volunteer hospitals.
4. Conduct survey of the subjects, six months after they were issued with a care plan to confirm the benefits.

The format of the care plan was developed in consultation with clinicians, survivors and other stakeholders. It was agreed that essentially a care plan would provide information about:

1. Diagnosis
2. Summary of treatment record
3. Potential risks due to late side effects of treatment
4. Follow up plan
5. On-going surveillance requirements e.g. regular tests or checks.

This in itself addresses a current gap as there is lack of such comprehensive record held by patients, their GP and even the long term follow up clinical team. Care plans should provide improvements in clinical effectiveness and patient experience. Though empowered into self-management, there is a safety loop of easy return to long term follow up as and when needed.

A baseline questionnaire survey of the survivors and guardians was conducted to evaluate their LTFU experience and their views on the developed Care Plan form. This would form the 'before' improvement story, prior to issue of care plans.

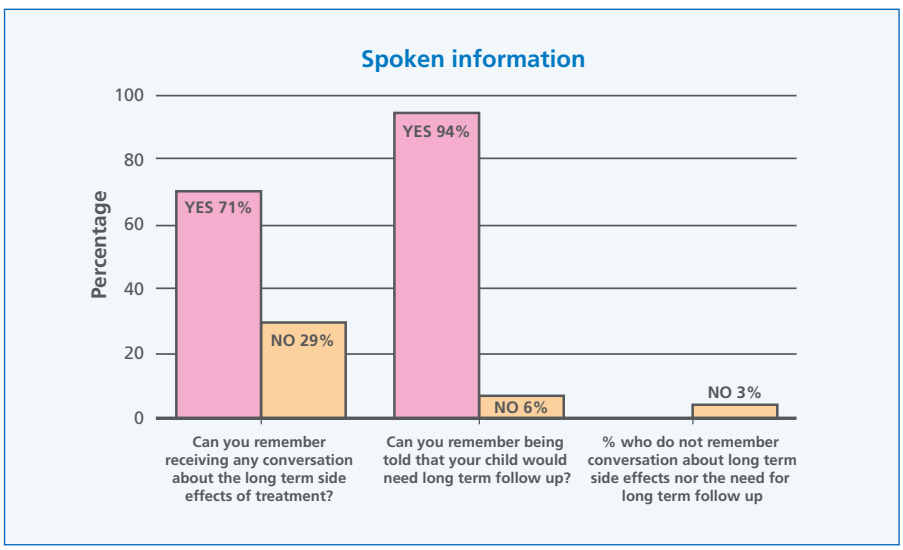
Care plans are now being distributed to new entrants into long term follow-up and at transition. These subjects will be surveyed at six months after receiving the care plans to evaluate the 'after' improvement story. This will start in July 2010.

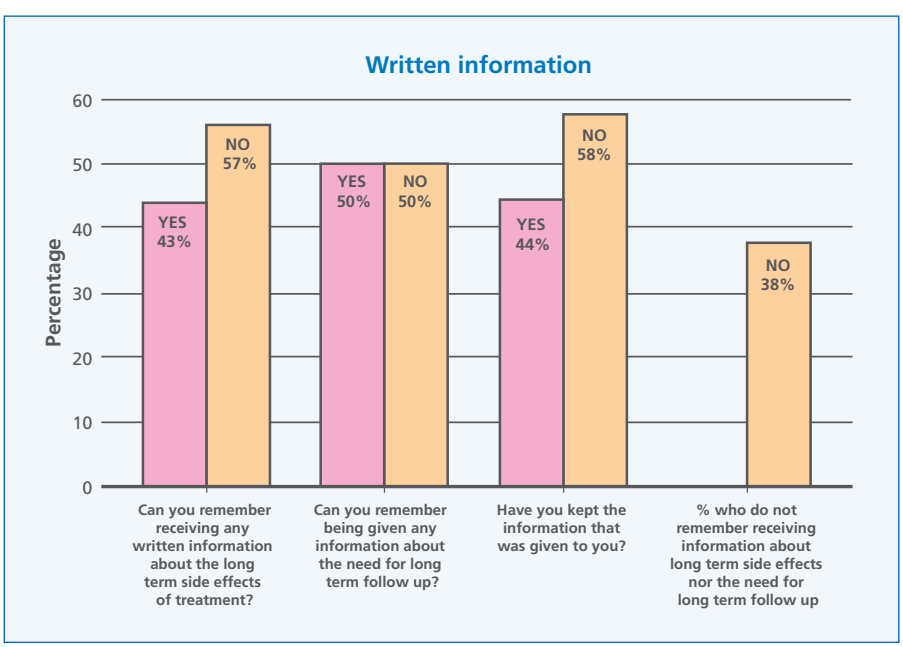
Results

Baseline questionnaire survey attempted to evaluate:

1. **Spoken information:** What they remember and told about long term side effects of treatment and the need of long term follow up.
2. **Written information:** What they remember of receiving any form of written information about long term side effects of treatment and the need of long term follow up.
3. **Experience of obtaining information:** How they rate the information obtained from various sources.
4. **Treatment summary and care plan:** Comments on a blank care plan and its usefulness.

32 subjects were surveyed – 15 over 18 years age; 9 in age group 12-18 years and 8 guardians for age group below 12 years.





Respondents scored highly on remembering a conversation about the long term side effects and the need for follow up.

There was no significant difference between those who claimed remembering receiving written information and those not remembering receiving written information. However, 38% claimed not to remember receiving information about the long term side effects and the need for long term follow up. This reinforces the need to provide a comprehensive care plan as an important event in patient experience and the necessity to reference this in future consultations.

Experience following receiving of spoken or written information:
High positive scores were recorded following receipt of information on questions about satisfaction, understanding of the information and being confident about asking further questions.

Best time to provide information	Spoken information %	Written information %
Before the start of treatment	43	38
Ongoing throughout treatment	24	23
At the end of treatment	12	12
In the long term follow-up clinic	21	27
Not interested in that information	0	0

Common ways of obtaining useful information that were highly rated were the patient's doctor and nurse, followed by information booklets and the internet.

Response to treatment summary and care plan form	Yes %	No %
Would you find a written summary like this useful?	81	8
Does technical information on it bother you?	0	100
Would you need someone to go through it with you?	31	69
Is the layout easy to follow?	100	0
Is there enough detail?	92	8
How would you like to receive the form?	0	0
When would be the best time to get this form?	0	0

Points to consider

Whilst it is essential to record the core information in the care plan, it may be useful to modify for local considerations e.g. a varied version for bone marrow transplant survivors.

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University Hospitals Birmingham NHS Foundation Trust

Lost to follow-up

Project details

The project aims to identify the risk factors for patients becoming lost to follow-up and the impact of being outside a specialist service.

A definition of lost to follow-up is:
'A patient that does not receive appropriate monitoring for the complications of his or her primary disease or its treatment through omission.'

The purpose of the project is to determine the size of the population at risk and the risks patients may be exposed to. If patients at risk can be offered an appropriate service, the quality of their long term outcome may be improved. Patients not being followed may be at risk of significant late effects which may affect the quality or length of life.

Evidence of successful testing

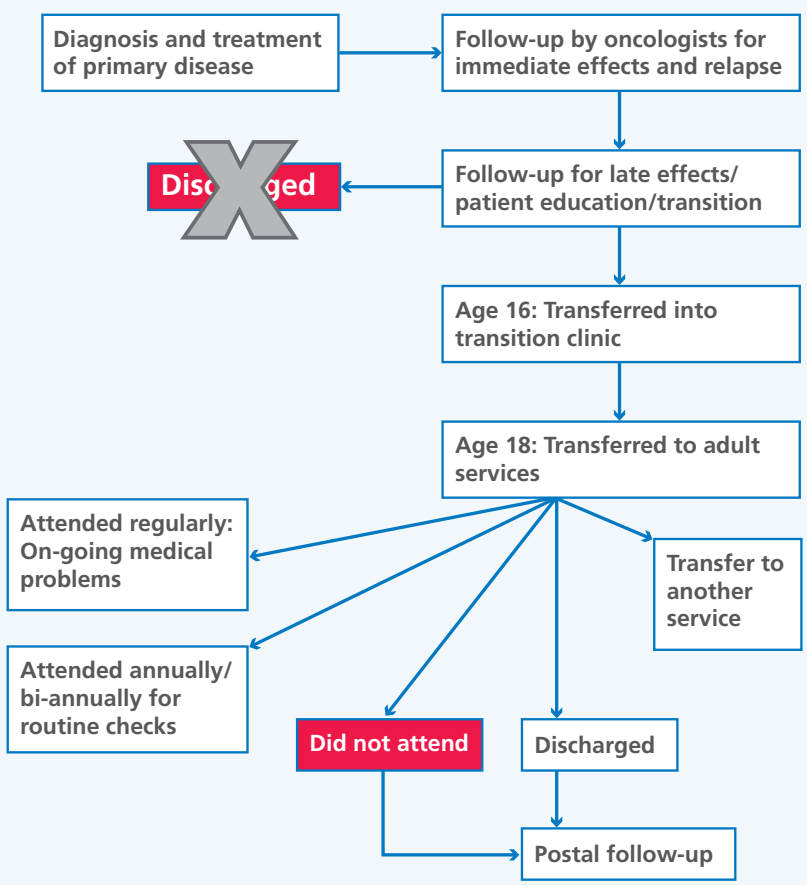
Information related to those lost to follow up is being explored from three sources:

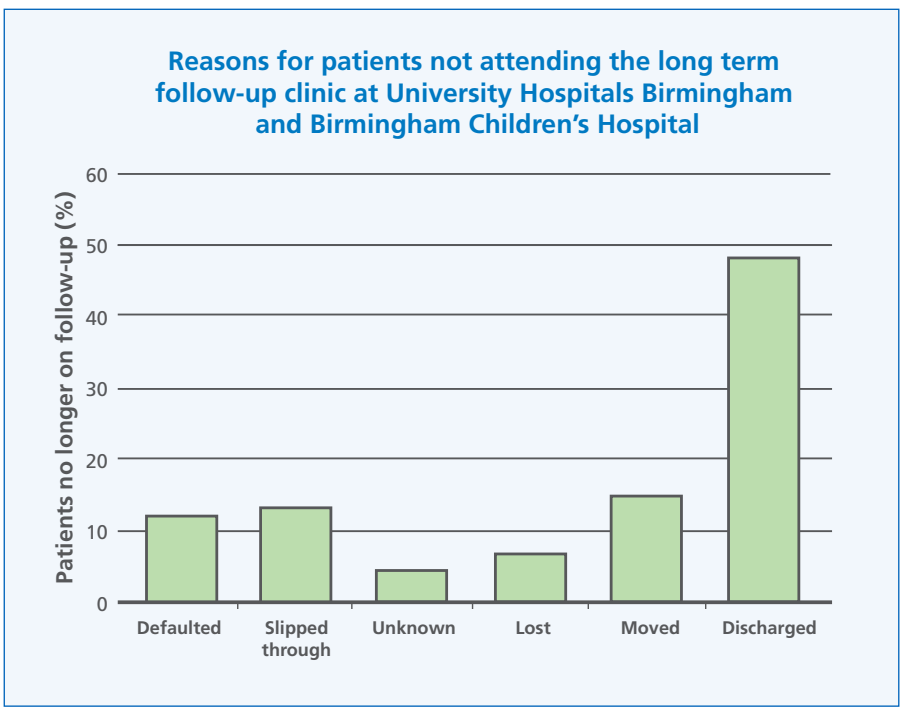
- Late effects service at Birmingham Children's Hospital (BCH) and University Hospital Birmingham (UCH)
- Late effects data base held at BCH
- British Childhood Cancer Survivors Study – University of Birmingham.

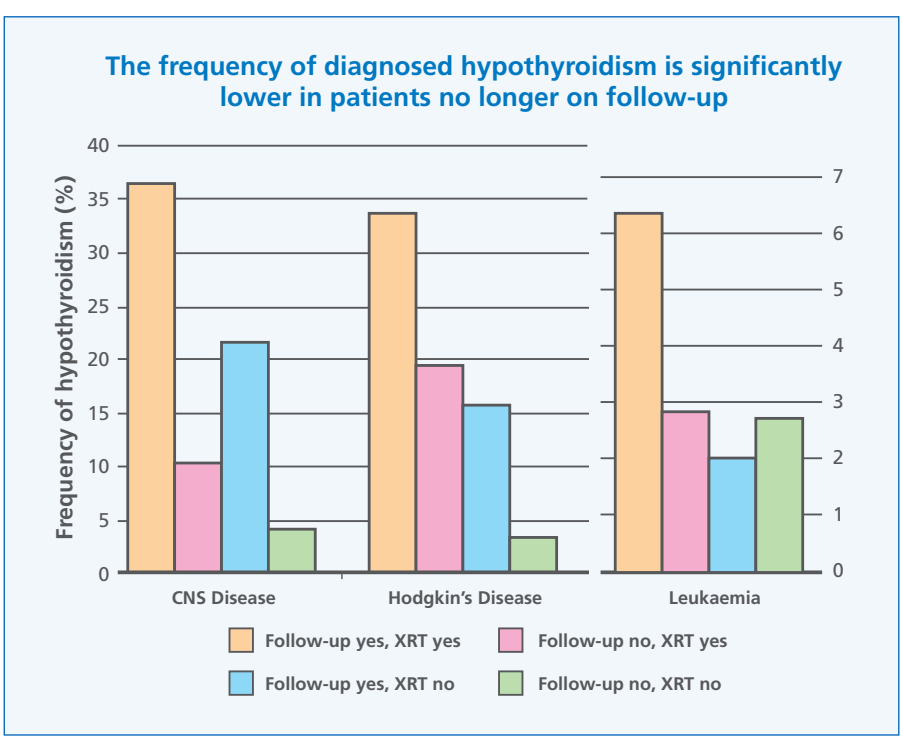
Reasons identified for those becoming lost to follow-up include:

- Change of environment
- Change of personnel
- Change of patient / parent dynamic
- Change of role of patient.

The lost to follow-up patient journey







Costs of assessment for those no longer on follow-up are likely to be significant. The costs will be defined by proposed economic modelling. If local factors can be identified they will be addressed to determine whether they improve compliance with follow-up.

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The Royal Marsden NHS Foundation Trust

Life after cancer: Helping our patients lead normal lives

Project details

We aim to give our cancer survivor patients the best possible chance of recovery from their diagnosis, not only by providing the highest levels of clinical care, but support that will enable them to lead as normal lives as possible. We believe that offering the best possible educational and psychological support is key to ensuring our patients and their families feel confident in their ability to self-manage through childhood and transition from paediatric to long term adult follow-up care.

Supported by NHS Improvement, we are testing the benefits to patient experience of introducing a clinical nurse specialist to our late effects set up, combined with developing a psychological screening tool to ensure those with psychosocial difficulties are not missed, improving access to appropriate psychological therapy services.

Paediatric Psycho-Social Screening Tool for Late Effects: Age 8-12

Patient ID:____ Gender: M or F Date:_____ Age 8-12 version 2

Please follow steps 1 to 6 on this page

1). Please circle the number (0-10) that best shows how much you have been **worrying** or **feeling upset** about things in *the past week, including today.*

10 9 8 7 6 5 4 3 2 1 0

Lots of worry/upset

No worry/upset

2). Please circle the number (0-10) that best shows how much you have had trouble with your **memory and learning** in the *past week, including today.*

10 9 8 7 6 5 4 3 2 1 0

Lots of trouble with my memory and learning

No trouble with my memory and learning

3). Please tick anything that has been a **problem** for you over the *past week including today:*

My family, friends & school life:

- ☐Getting on with my parents
- ☐Getting on with other grown ups
- ☐Getting on with other children
- ☐Getting on with my brothers/sisters
- ☐Making friends
- ☐Taking part in activities
- ☐Going to school
- ☐Doing my homework
- ☐Bullying

How I feel:

- ☐Being scared about things
- ☐Being nervous about things
- ☐Feeling sad
- ☐Feeling worried
- ☐Getting angry
- ☐Feeling different to others
- ☐The way I look
- ☐Feeling bad about myself
- ☐Feeling lonely
- ☐Feeling panicky
- ☐Feeling nothing at all

Problems with my body:

- ☐Pain
- ☐Feeling sick
- ☐Feeling tired
- ☐Sleeping
- ☐Difficulty breathing
- ☐Eating

Memory/Learning:

- ☐Remembering things
- ☐Learning things
- ☐Paying attention

4). Please circle the **biggest** problems for you (up to 4 problems)

5). Are there any other things you have been worrying or feeling upset about in the past week including today? If so, please write in the space below:

.....
.....
.....
.....
.....
.....
.....
.....

6). FINALLY, would you like to talk to someone about any of these worries? YES ☐ NO ☐

The need for psychosocial support in late effects

The psychosocial late effects from childhood cancer are well documented in academic literature, as are the benefits of nurse-led clinics. (see References). If undetected and untreated, the initial impact of psychosocial problems on social development and education in childhood can continue into adulthood, significantly affecting quality of life through their effects on employment and personal relationships. This impact can be even greater in patients with cognitive impairment resulting from treatments such as cranial radiation.

As part of our baseline evaluation, our late effects project co-ordinator gathered information on patient experience from attending clinic sessions and conducting interviews. This proved fruitful, highlighting a need to improve methods of imparting information on diagnoses and their long term effects, together with a formal process for identifying and addressing psychosocial needs. In addition, we hope our improvements will help to reduce the DNA rate in the young adult clinic at St George's Hospital, where patients are transferred at the age of eighteen.

Evidence of successful testing

Moving towards nurse-led support during late effects clinic sessions, our doctors spend as much time educating patients on lifestyle issues and responding to non-health related questions, as they do monitoring their health. The introduction of a clinical nurse specialist (CNS) to our late Effects clinics will provide a focused setting in which patients can receive information and advice. The CNS will also provide emotional support, helping to identify any psychosocial needs that might benefit from specialist psychological input. Transition clinics for patients within two years of transfer to young adult services will be set up to ensure the process runs smoothly, keeping them informed and supported in preparation for this change.

> Planning for transition from paediatric to adult-orientated healthcare is crucial. In order to achieve this smoothly, patient education is vital. It can be accomplished by improving awareness of late effects due to cancer therapy among patients, their families and empowering the patient. They should be able to take charge of their long term follow up. Lack of knowledge about long-term risks is a major barrier to delivery of optimal care to cancer survivors.

Dr Gul Bano, Consultant Endocrinologist and Senior Lecturer in Clinical Endocrinology, St George's Hospital, London

Identifying psychosocial needs

In the management of psychosocial needs, the National Comprehensive Cancer Network (NCCN) recommends a model that includes screening for distress and psychological needs. It has been found that patients respond well to the distress thermometer (Gessler et al, 2008) and we have based our tool on the NCCN distress thermometer and problem checklist, focusing on the late effects domains of 'family, friends and school life', 'how I feel', 'problems with my body', memory and learning' and 'practical issues' for 18 years and above. Psychosocial screening tools have been adopted for use in adult oncology, but have not been used in a late effects paediatric oncology setting. Our tool incorporates both psychosocial and cognitive late effects. The latter focuses on the most common cognitive difficulties (Gross-King, Booth-Jones & Couluris, 2008), a feature not included in other brief paediatric screening tools.

Our aim is ensure our screening tool distinguishes effectively between those patients with and without psychological problems, focusing on the correct domains and validating it against existing and reliable measures of depression, anxiety, behaviour, etc.

The paediatric psycho-social screening tool for late effects

Age-appropriate versions of the screener have been designed according to specific age groups, in addition to parent proxy versions, to ensure maximum inclusion of children, such as younger age groups and those with cognitive impairment. Test screening will take the form of patient interviews with our psychologists following their outpatient appointment.

Patients and parents/caregivers follow steps 1 to 6 on the screener:

Steps 1 & 2
Worry and memory thermometers pinpoint whether a need exists, establishing the extent of worry or upset, as well as problems with memory and learning (0 meaning none, 10 meaning lots).

Step 3
Checklist of specific areas responsible for worry/upset.

Step 4
Checklist of the main areas of worry/upset (up to 4).

Step 5
Checklist of any other problems not mentioned on checklist.

Step 6
Request for help.

Step 7
An action plan is completed by the clinical nurse specialist to implement psychological support, if needed.

Results

To date, we have undertaken our baseline evaluation. Screening tool documentation is awaiting research and development and ethics approval. We plan to commence testing in Spring 2010.

Funding has impacted on staffing resources and, consequently, the start date of the project. The Project co-ordinator and assistant psychologist are in post. However, recruitment of a clinical nurse specialist is still underway. To avoid further delays, the project co-ordinator has undertaken the baseline evaluation.

Top tips

- Use face to face interviews for service evaluation, if possible.
- Preparation, particularly when interviewing patients, is crucial.
- Ensure team is kept informed of all strands of the project, not just their own.

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> As the survival rate increases, so does the population of children and young people at risk of a wide range of psycho-social difficulties. There is a need to provide routine psychological screening as well as screening for physical problems in the late effects population.

Eiser, 2007

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Sheffield Children and Young People Cancer Survivorship Test Community

Telephone reminder system

Project details

The Sheffield Children and Young People Cancer Survivorship Test Community have piloted a system of telephone reminders to young people prior to their follow-up appointment to see if this improved clinic did not attend (DNA) rates. This included those who attend the LEC. The anticipated benefit of this service redesign and new technology is to identify if there has been an improvement in concordance with follow-up, reduction in wasted appointment time.

There are already examples of similar telephone reminder pilots in different departments within Sheffield Teaching Hospitals (STH) and we liaised with the service development team to initiate this service. We collected information on DNA rates prior to implementing this initiative and again for the duration of the new service and compared the differences.

The service improvement and evaluation projects in Sheffield build on the recommendations of the Children & Young People's Improving Outcomes Guidance (C&YP IOG) and had both the North Trent Cancer Network and the Yorkshire and the Humber Specialised Commissioning Group (SCG) support. Our project plan forms a subset of the network wide action plan which has been approved by local SCG.

Evidence of successful testing

- The clear improvement in DNA rate will increase patient concordance with follow up and reduce wasted appointments.
- In real terms the DNA rate dropped from 120 missed appointments to about 60 missed appointments, i.e. 60 more cancer survivors received planned care. This was based on a full year and is the difference between the two DNA rates applied to the number of total appointments in that period.
- The clear improvement in DNA rate will increase patient concordance with follow up and reduce wasted appointments

There were a few limitations:

- Insufficient preparation and engagement of patients.
- Options for an opt out facility.
- Suitability for patients with hearing dysfunction, learning disabilities, or speech disorders. All these issue have now been addressed.
- Opt-out is primarily at three levels.

We can opt-out a whole specialty (like hearing services), opt-out a whole clinic (by excluding the clinic code from the extract, or opt-out an individual using NTR. The only option prior to appointment is if the specialty is set to ask the question. Otherwise it depends on the patient requesting the opt-out. The Trust decided to go for an inclusive version for a number of reasons.

Evidence on the effect on quality and productivity/cost includes:

- Overall the mean DNA rate reduced by >50%.
- In real terms the DNA rate dropped from 120 missed appointments to about 60 missed appointments, i.e. 60 more cancer survivors received planned care.
- This was based on a full year and is the difference between the 2 DNA rates applied to the number of total appointments in that period.
- Financially the LEC recovered ~ £6-7k in otherwise lost tariffs.
- Implementation costs for the Trust are in the order of £80k. Revenue cost is around £50k per annum but is volume dependent.

Results

- Prior to the intervention our mean DNA rate was 12.3% but was highly variable and we could only be confident (to three standard deviation) that it would not be above 44%.
- The interventions happened in two stages and now the mean DNA rate is currently 5.3% and we can be confident that it will not go above 28%.
- Financially the LEC recovered ~ £6-7k in otherwise lost tariffs.
- Overall the mean DNA rate reduced by >50%.

This service has been implemented and will be monitored and audited in April 2010.

Top tips

- The long-term sustainability of this reminder system and its continuing impact on DNA rate has yet to be established.
- Future monitoring is needed to be confident about long-term recommendations.
- The limitations as mentioned on previous page.

Resources

The system used is called Remind+ and is provided by Telephonetics VIP

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Sheffield Children and Young People Cancer Survivorship Test Community

GPs view on the acceptability and usefulness of treatment summaries and care plans

Project details

The Sheffield Children and Young People Cancer Survivorship Test Community are evaluating GPs opinion on the usefulness of the summaries in understanding the survivor's individual late effects risk and health needs. We will use summaries and care plans evaluated at other test centres. With these particular late effects risks in mind, we will also ask the GPs to identify areas of care which they would be confident to manage. We plan to use examples from different tumour groups so for example, a childhood cancer survivor, and crossing into the adult workstream, possibly breast and prostate cancer survivor summaries and care plans since statistically these are more likely to be seen in general practice. We will do this in collaboration with the Academic Unit of Primary Care and in teaching sessions around the Network where reasonably possible.

The aim is to determine GPs opinion on the usefulness of the summaries in understanding the survivor's individual late effects risk and health needs and to identify areas of survivorship care in which GPs would be confident to manage.

The anticipated benefit of enhancing the service and improving communications between secondary and primary care is to make recommendations on how best to relay late effects risk and surveillance plan to general practice and key skills GPs can offer to build a shared-care plan.

The service improvement and evaluation projects in Sheffield build on the recommendations of the Children & Young People's Improving Outcomes Guidance (C&YP IOG) and has both the North Trent Cancer Network and the Yorkshire and the Humber Specialised Commissioning Group (CSG) support. Our project plan forms a subset of the Network wide action plan which has been approved by local SCG

Evidence of successful testing

- Improves transfer and effective use of information clinical information.
- Safety and clinical effectiveness – Appropriate transfer and use of clinical information will help to ensure that health problems that may be related to cancer treatment are recognised as such and managed appropriately.
- Patient experience – Patients desire good continuity of care and to be dealt with by well informed and confident professionals. The effective sharing and use of clinical information will facilitate this.

This project will be implemented by testing the improved process with GPs to assess effectiveness and appropriateness of proposed improvement . To date there is no available evidence of the effect on quality and productivity cost.

Results

Project is still 'live' therefore no results are available.

Resources

- NCSI – Assessment and care planning workstream.
- Locally through the late effects executive at Sheffield Teaching Hospital
- Regionally – network for service design
- Macmillan Community of Influence.

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Sheffield Children and Young People Cancer Survivorship Test Community

Summary of roles, responsibilities and training needs of survivorship and late effects nurses

Project details

The Sheffield Children and Young People Cancer Survivorship Test Community are:

- Determining what core competences nurses require to meet the needs of young people living with and beyond cancer.
- Establishing clinicians' and managers' views of the ideal roles and competences of the post given the recent national developments in survivorship.
- Evaluating the existing roles and responsibilities of nurses across the country who care for patients beyond the end of treatment.

The anticipated benefit of this work is to make recommendations for competences for nurses who are involved with children and young adults with cancer. This work may inform academic training agencies in the development of tailored courses for survivorship nurses.

The increase in survival rates in cancer care for children and young adults up to the age of 25 years is approximately 75%. However, patients can also experience accumulated disabling consequences due to their cancer or the long term side effects of their curative treatments. This can include physical, emotional and social implications that can impair their quality of life. (DoH 2005)

The side effects of the cancer diagnosis or its treatments can occur at any time following treatment and we therefore need to consider how we as health care providers monitor and treat this group of patients.

Nurses have an important role to play in the development and provision of long term follow up services (Chesterfield 1999), (Ball 2005 and DoH 2007), especially in non-medical interventions such as psychosocial support and information giving. These are potentially highly skilled roles due to the complex nature of the long term follow up sequelae. Nurses can be involved in monitoring physical effects of treatments and identifying psychological morbidity and the social challenges a cancer diagnosis can have on patients well after their treatment ends (Loescher et al 1990).

It would be useful to have a competence framework for nurses working with long term follow up cancer patients in this age group as it will benefit:

- The patients, who would receive equitable and consistent care.
- Nurses as they can plan their roles and services to suit the needs of the patients.
- Employers as they can plan and implement services more effectively.

At present there is no competence framework for nurses or medical staff involved in the care of cancer patients beyond the end of treatment. This project focuses on nurses.

The Royal College of Nursing has developed guidelines for nurses working in other specialities and it is anticipated that this project will create a framework for nurses working in late effects care for teenagers and young adults.

This project will address issues related to competences in long term follow up care (including late effects surveillance and issues of survivorship), and identify specific training implications for this group of care givers.

This project is built upon the recommendations of the Children & Young People's Improving Outcomes Guidance (C&YP IOG) and has both the North Trent Cancer Network (NTCN) and the Yorkshire and the Humber Specialised Commissioning Group (SCG) support. This proposal forms a subset of the network wide action plan which has already been approved by local SCG

The IOG recommends a key worker and for this service improvement programme, we have interpreted the key worker to be a nurse (with extent of responsibilities depending on grade). Apart from service improvements, this proposal includes workforce initiatives with the intention that we contribute to the understanding of what skills and knowledge are required in the workforce for delivery of appropriate care for cancer survivors.

Evidence of successful testing

- Achieving a service designed to meet the particular requirements of this client group is challenging. The development of competences for nurses aims to create efficient services carried out by nurses with the appropriate skills and expertise. It could also help managers view service design in a different way, especially in terms of the role and grade of the nurse required for a particular purpose.

- **Quality**: Providing a framework for professional development will ensure that nurses working in late effects have the appropriate skills to provide a quality service and are given the opportunity to develop them. It can also be used to design and benchmark current and new late effects services by outlining the potential scope of the nurses role.
- **Safety**: Ensuring nurses have the appropriate skills and expertise is essential to patient safety.
- **Clinical effectiveness**: The framework can be used to ensure nurses are being used appropriately to deliver care safely, efficiently and of a high standard. The framework can be used to plan and develop services ensuring nurses are appropriately trained to carry out their role.

Evidence of the effect on quality and productivity/cost

There is currently no evidence available for the effect on quality and productivity as this is not being explored within the remit of this project. It is anticipated that the project outcomes will enable effective and appropriate planning and delivery of services.

Results

The project does not aim to explore the effects of the change by carrying out pre and post evaluations. However, the scoping exercise will enable identification of current and 'desired' roles and skills for nurses working with young cancer survivors which will be useful to those evaluating current care and developing future services.

Competence frameworks have been developed for other areas of nursing, many have been endorsed by the RCN. However there are currently no competency frameworks for nurses working with this patient group.

The project outcomes will be disseminated through local and national bodies and groups including the Royal College of Nursing, Childrens Cancer and Leukaemia Group, European Symposium on Late Complications after Childhood Cancer, Cancer Action Team, and Cancer Networks.

Top tips

Implementation will depend on clinical needs of services and this will differ from setting to setting. The competences are framed at a choice of clinical responsibility e.g. band 6, 7 or 8 and we recommend service design users these proffered levels of skill for adaptation in their own clinical environmental setting with agreement from local commissioning services.

Resources

Royal College of Nursing competence framework
NHS Improvement
Childrens Cancer and Leukaemia Group
Department of Health
Cancer Action Team

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Yorkshire Cancer Network

The Community Cancer Portal: Transforming the traditional model of late effects follow-up

Project details

The vision

The Yorkshire Cancer Network (YCN) supports two integrated national test site projects that aim to develop and test a supported self-care approach to the management of long term survivors of childhood and adolescent cancer.

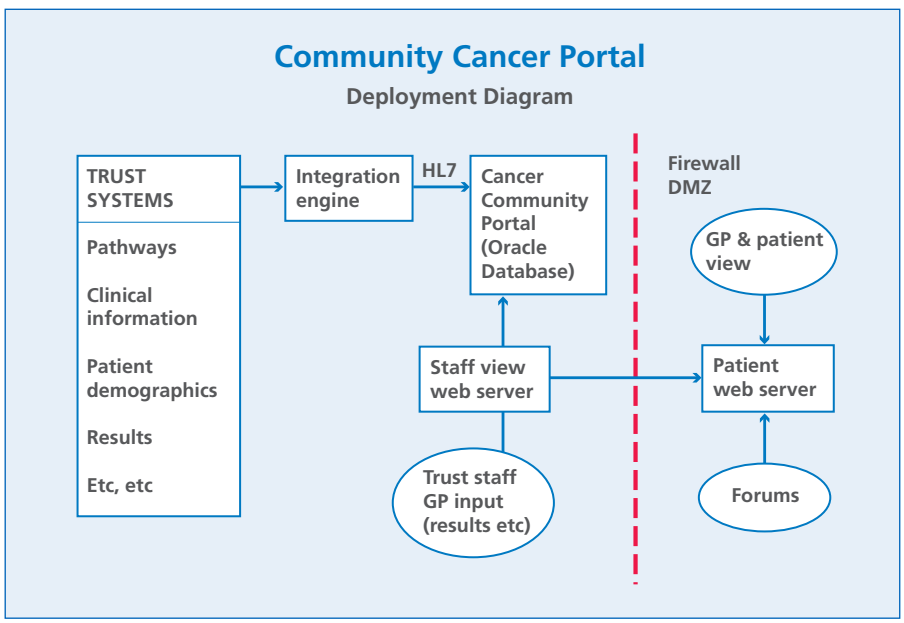
The vision is one that mirrors and supports the '5 Key shifts' at the core of the National Cancer Survivor Initiative's vision and the clear direction of travel outlined within the Cancer Reform Strategy. The aim is to move away from the traditional tertiary management of patients (currently based at Leeds Teaching Hospitals NHS Trust) to one that allows appropriate patients to take control of their care and be increasingly managed within their own community with primary care support.

As well as allowing care and clinical monitoring to be delivered close to the patient's home, the aim – again, in line with national policy direction - is to ensure the patient is sufficiently empowered to ensure they experience greater control, ownership, understanding and peer support throughout their follow-up.

The approach

The YCN initiative comprises two integrated components namely the development of a clear, sustainable and safe shared-care pathway and also the development of a Community Cancer Portal (CCP).

The CCP is an e-platform that will not only allow seamless communication and information exchange between the tertiary centre and any future primary-care based partners in follow-up but also between patients themselves and the tertiary team. Finally it will facilitate peer support for patients via on-line chat fora.



The primary focus of the first year of the project has been in developing the CCP – without which the proposed radical pathway of follow-up care will not be possible.

Evidence of successful testing progress

February 2010 witnessed the first live demonstration of the CCP. The demonstration by IT and clinical colleagues from Leeds Teaching Hospitals NHS Trust was a culmination of one year's work by them on behalf of the YCN.

In addition to showing that the technology does indeed work, the demonstration also clearly showed the CCP's future capability to:

- Communicate securely between tertiary, secondary and primary care.
- Communicate securely between tertiary care and the survivor.
- Automatically generate survivor cancer care plan/pathways.
- Automatically generate treatment summaries.
- Automatically generate alerts regarding planned surveillance tests.
- Simply sign-post on-line information resources for both patients and shared care partners.
- Provide a secure chat-room for improved peer support.

Throughout the development of the CCP it has been of primary importance to ensure that the portal has the ability to be rolled-out to any other interested centre with the absolute minimum of expense and requiring only modest local IT development. The system has been developed using Snomed codes and a common HL7 interface – essentially allowing 'plug and play' adoption by any other centre.

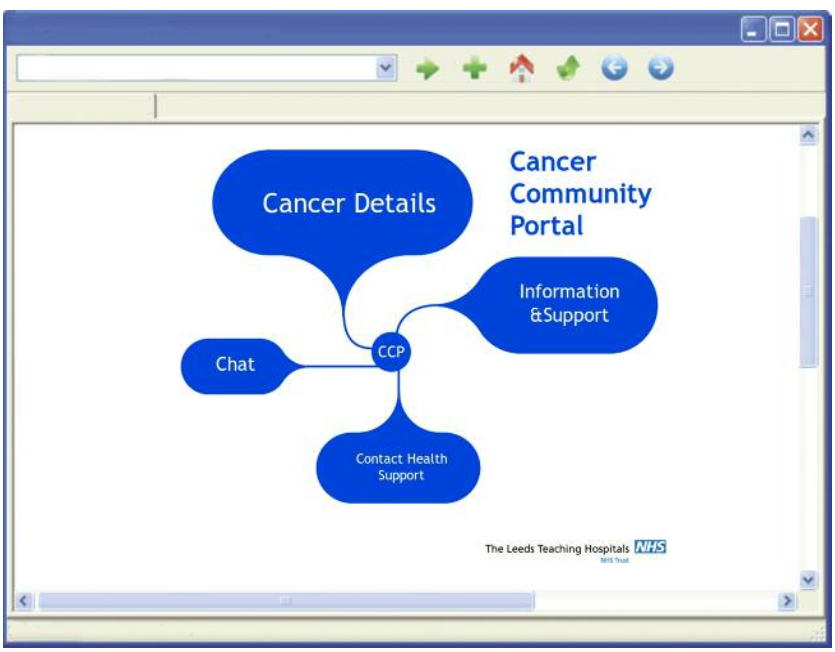
The Leeds Teaching Hospitals NHS Trust developers have also ensured that the CCP is based on an E.A.V. model. This allows the user to directly add data items as they are required without having to wait for IT development staff assistance – thereby cutting down the on-going IT support required to run the system and maximising local flexibility.

Screen shot of home page

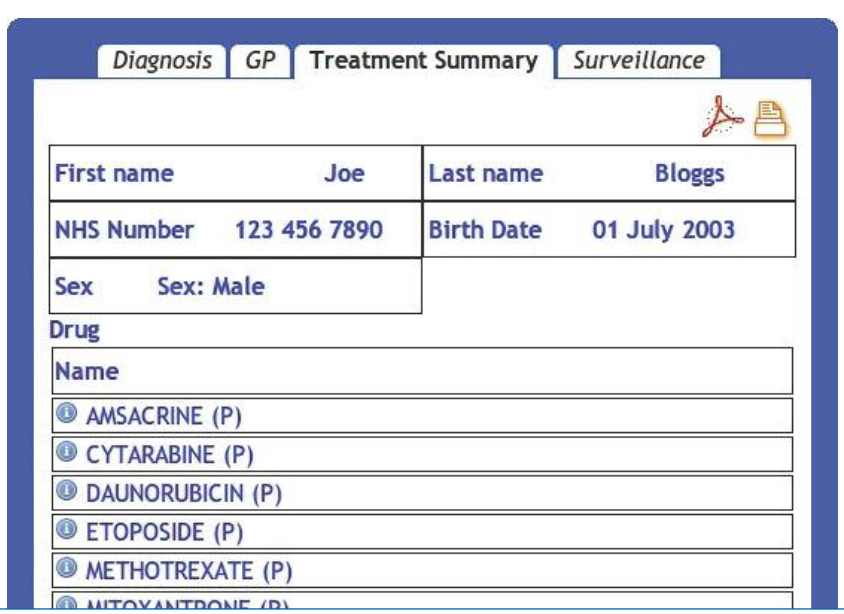
This demonstrates the four key components of the patient /GP view:

1. **Cancer details**, containing all diagnostic, treatment, morbidity and on-going surveillance details including comprehensive survivor care plan.
2. **Information and support** with information regarding drugs, treatments, complications of therapy and support to maximise quality of life and function.
3. **Chat** fora to provide secure peer support.
4. **Contact Health Support** immediate e-mail to the long-term follow-up service that will monitor the CCP every working day of the year.

Screen shot of the Community Cancer Portal - Staff view



Screen shot of the Community Cancer Portal - Patient view summary



Anticipated benefits

The Late Effects Project Steering Group anticipates a significant number of benefits to both patients and the wider health community from the implementation of the new pathway that will be enabled via the CCP.

These benefits have been mapped against the QUIPP (Quality, Innovation, Productivity and Prevention) framework to ensure that the anticipated transformation of follow-up care clearly delivers against the key criteria that commissioners will be expecting.

Specific measures have been developed for each of the above anticipated benefits and will be utilised to evaluate both the CCP and the implications of a shared-care pathway throughout the next 18 months.

Benefits				
	Patient/carer	**Primary Care**	**Commissioners**	**Cancer Centre**
Quality	• Choice over model of follow up • Possibility of care closer to home • Better co-ordinated care • Peer support via CCP.	• Follow up tests co-ordinated • Direct access to care records/treatment plans.	• Possibility of care closer to home.	• Treatment plans for all patients • LTFU able to focus support on patients most in need • Comprehensive outcomes data.
Innovation	Web access for patient to: • LTFU support • Care history/plans • Information.	Web access for GP to: • LTFU support • Care history/plans • information.		
Productivity	• Possibility of continuing care and follow up tests undertaken closer to home.		• Tests undertaken more cost-effectively in community.	• LTFU team able to support greater number of patients • Fewer tests undertaken at Cancer Centre • LTFU skills targeted on patients most in need • No unnecessary outpatient visits for tests • Maximum use of information technology.
Prevention	• Cancer survivor care plan developed with all patients.			

Economic modelling

Inevitably, given the radical nature of a shift away from an entirely tertiary-based care to one of shared care with primary care, there will need to be an understanding of the likely economic consequences for all parties involved. To this end, the YCN have started to capture the salient interventions that occur across current pathways in order that these can be costed. Once this is completed, it is hoped to be able – possibly as part of a national pilot – to model the economic consequences of any shift to shared care. With this evidence a commissioning framework can be developed that supports shared care without compromising the quality of tertiary care and that also reflects and rewards the tertiary team's on-going support to shared care partners.

Top tips

- Harness, encourage and support clinical leaders.
- Get explicit support for the project at the very highest level eg YCN Board at the outset.
- Develop IT projects in liaison with experts – don't go it alone.
- Constantly reflect to ensure your project is in line with national policy direction.
- Never forget the politics.
- Don't give up. Even IT within the NHS can sometimes come good.

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Additional ongoing children and young people test sites

Cambridge - Oncology

Testing to assess the efficacy of the oncology database in planning surveillance and long term follow-up for patients. This IT system is linked directly to the CCLG follow-up guidelines (2nd Edn, April 2005) which will make it possible to track timing of investigations and clinical reviews according to an individual's needs.

Progress

150 treatment summaries have been uploaded to the data base which will enable efficacy of the system to be undertaken.

Great Ormond Street - Key worker

Progress

Six-month audit of enquires into LTFU is now complete.

Following analysis of the enquiries into LTFU unit, two actions have been planned.

1. LTFU Contact Card

To facilitate all enquiries to the key worker, it was decided to create a Contact Card that can be issued to all survivors. This will enable an easier and informed access to LTFU, rather than accessing via a number of variable personnel.

2. Local web site

A local informative web site is planned to address commonly asked questions and also provide links to other useful sites.

Sheffield - Users' views on Transition Service

Schedule and formally evaluate transition service for childhood cancer survivors who move from the children's hospital to the adult hospital setting and find out how this process can be modified and improved.

Sheffield - Telephone follow-up

User acceptability of a low intervention follow-up service - Using the risk-stratified model proposed by Wallace et al (BMJ 2001). Childhood cancer survivors in our centre identified as low risk of late effects, already receive telephone Follow Up from the Macmillan Late Effects Clinical Nurse Specialist.

We are uncertain how satisfactory this group of 'young people' find this service and whether or not they have experienced a sense of abandonment since moving to telephone follow-up. It is also possible that this population of young people, despite being at low risk of late effects still have a need for supportive follow-up.

Sheffield - Psychological Service

Pilot early psychological intervention for improving concordance with follow-up

Summary

At this stage of the testing, we can already see that there are some specific themes emerging from the work of our test sites.

These themes include:

- Care plans/treatment summaries are a basic requirement.
- There is a need to reduce and remove meaningless follow-up appointments.
- It is important to make the best use of technology when designing follow-up for patients.
- A shift is needed in terms of the 'language' we use in relation to individuals living with and beyond cancer.
- No one size fits all – care and support needs to be based on individual requirements.
- It is essential we provide a robust body of evidence at the end of the testing phase to inform the commissioning of future services.
- Real commitment is needed to make change happen.

Some of the challenges are around the following:

- Ensuring we all maintain a clear focus and making sure we deliver tangible outcomes.
- Ensuring we all keep to time scales in the run up to September 2010.
- Ensuring we continue to share the learning.
- Ensuring we make sure we continue to build a robust body of evidence to inform services in the future.

Acknowledgements

The children and young people testing work would not have been possible without the commitment, hard work and enthusiasm of the many individuals and teams working within our test sites.

I would like to take the opportunity to express our thanks and appreciation for their support, expertise and co-operation from the start of this initiative.

For example:

Members of our Children and Young People Steering Group

Members of our Children and Young People Clinical Reference Group

The Clinical Leads, Service Improvement Leads and Facilitators and Project Managers from all of those sites working with us on this initiative

Members of the team from CLIC Sargent and The Teenage Cancer Trust

Members of the DH Cancer Policy Team (in particular Claire Bache with whom we have worked closely with during this initiative)

My NHS Improvement colleagues within the Communications and Marketing Team, the NHS Improvement System Team and the secretarial and administrative input that helps to support this work

Finally (but not least) thank you to my colleague Judi Tapp, National Improvement Lead for her attention to detail and her support.

We look forward to continuing to work with you all during the coming months.

Thank you again to everyone involved.

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Leading on behalf of NHS Improvement the Children and Young People workstream

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