

1. Your details	
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Give a description of your project

To test a multidisciplinary long term follow up “model of care” to achieve smooth transition from paediatric to adult services structured by age. The model will be evaluated with the Royal Marsden (used as a baseline model)and the Bristol Trust (hub and spoke model)

To what clinical area does your project relate

Paediatric Oncology: Survivorship

Specify which part of the NCSI/ Survivorship pathway does the change impact on/improve

Late Effects Long term Follow Up

What type of changed did your project aim to address

Service redesign. Royal Alexandra Children’s Hospital (RACH) oncology services have been provided on a shared care basis with the Royal Marsden NHS Foundation Trust, which is the Primary Treatment Centre for Sussex, However in the 1970’s the majority of children were treated either at Great Ormond Street or Brighton. Plus some children also being referred a number of different centres including Barts, Southampton, UCLH and The London Hospital.

What tangible change / tangible outcome have you achieved to date

BSUH had established a local model of Long Term Follow up for childhood cancer survivors.

All long term follow up has traditionally taken place at the Primary Treatment Centres and this work has established 2 new clinics in the Royal Alexandra Children’s Hospital that take place with a consultant from the RMH in attendance with a paediatrician from the RACH in Brighton. These have taken place in July 2009, Jan 2010 and July 2010. These clinics are modelled on the service offered to GOSH children who are seen in Brighton in up to 3 annual clinic (although in 2009 and 2010 only 1 GOSH clinic has taken place). An adult endocrinologist and haematologist have been in attendance in order to learn about Late Effects but also to meet the young people who would be moving to the adult service in the future.

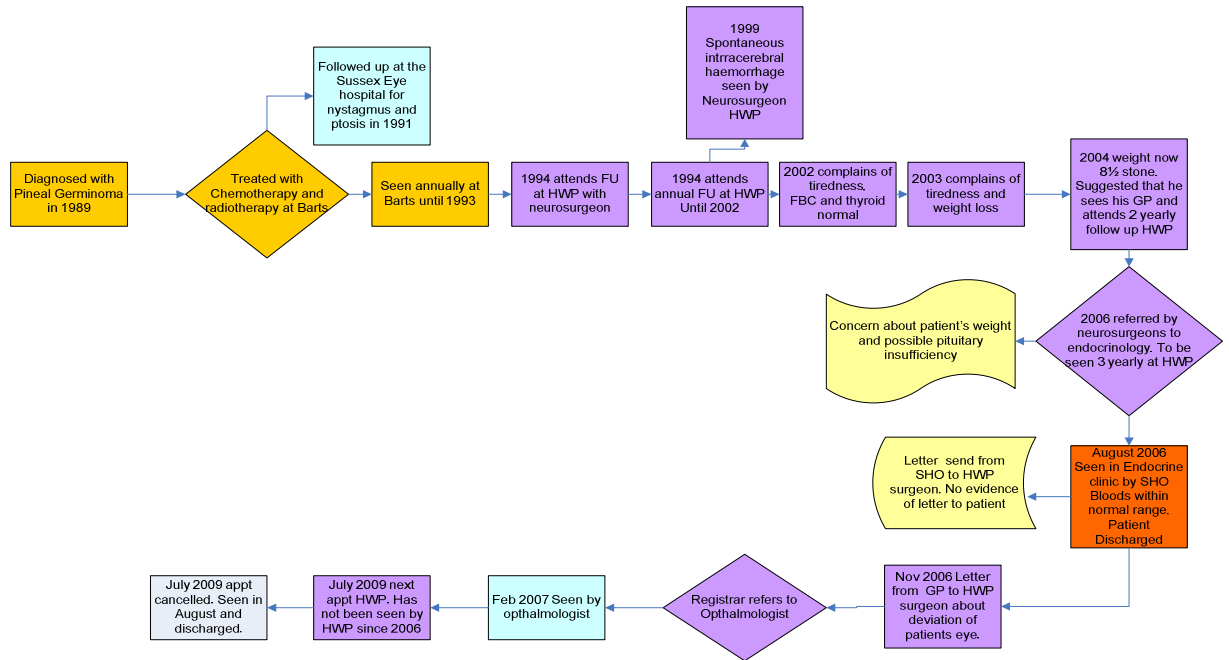
Two adult endocrine late effects clinics have taken place – One in the RACH with young adults who will be seen in the future in the adult service. This gives the patients the opportunity to meet the adult clinician in an environment that they feel comfortable in alongside the paediatrician with whom they have a relationship. The second took place in the main OPD with the paediatrician in

attendance with the endocrine consultant. A third clinic is to take place in the adult hospital in September 2010. Three clinics a year are planned for service.

An adult haematology/ paediatric clinic was envisaged but due to capacity issues this has not occurred.

The Thames Cancer Registry has provided evidence that 683 children and young people up to the age of 20 were diagnosed with cancer between 1985 and 2003 of whom 68% were recorded as alive- suggesting that at least 450 childhood cancer survivors in the region. Obviously there will have been some geographical mobility but this will have been both in and out of the area. By looking through old treatment cards and the PAS system BSUH staff have identified 193 childhood survivors who have had some kind of contact with Brighton and Sussex Universities Hospital Trust (BSUH). The paediatric clinician examined notes that were available and identified patients who were being seen in adult clinics who would be more appropriately seen in a Late Effects clinic Eg a 30 year old who had a brain tumour removed when he was 10 years old and had his oncology treatment at St Bartholomew's Hospitals. He has been seen by the neurosurgeon who conducted the original operation. During his patient journey he had been referred to an endocrine clinic and a number of tests were conducted which were negative and the patient discharged. The tests conducted were not detailed because the clinician did not have experience of Late Effects. This patient has been invited to attend a Late Effects clinic in September 2010. (Case study 1). Consultants with patients who are childhood survivors have been contacted and asked if they would agree to have their patients attend adult Late Effects clinics. Of this group 73 adult patients have been identified as needing Late Effects follow up.

Case study



What was the purpose of the change and what did it deliver

Patients were having to travel long distances for their Long term follow up care. The concern for the clinicians was that patients would DNA and be lost to follow up because of travel and time costs. The families of children and young adults with special needs and disabilities as a result of their cancer of treatment find the travel costs and disruption onerous.

Chart 1

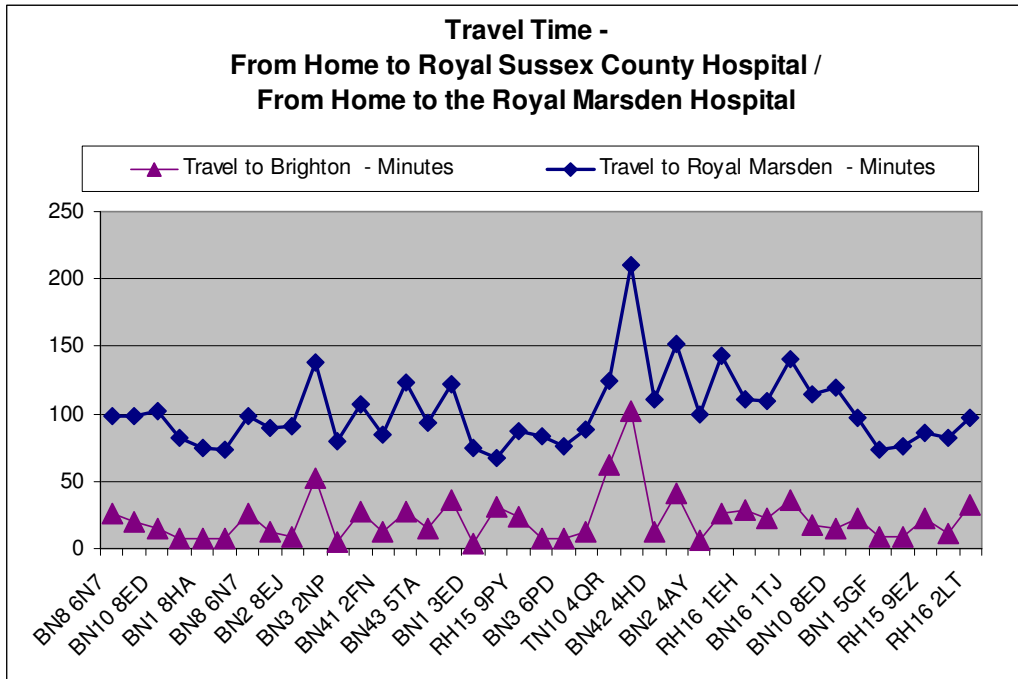


Chart 2

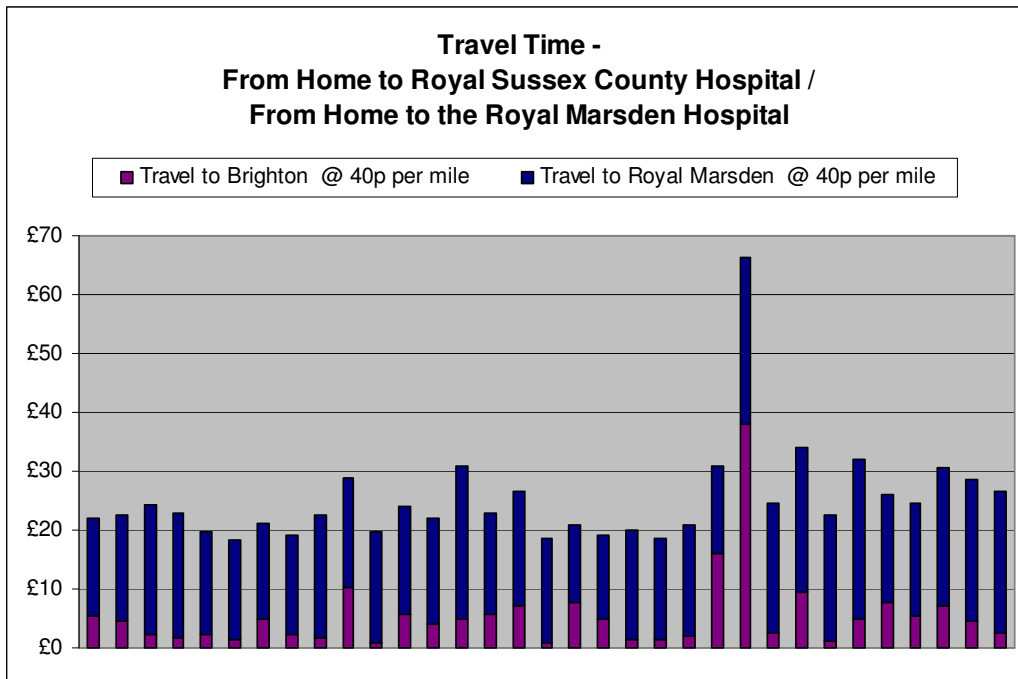


Chart 1 and 2 show the travel times and cost for each patient attending the RMH and Brighton based on post code measurement. This has assumed that patients will be driving to the hospitals. We did not measure public transport costs. Travelling to Brighton is cheaper and more convenient for the patients.

A number of the young people interviewed also liked being seen closer to home because they did not have to miss so much school/ college. *“ Coming here make it easier because I can go back to college after the clinic. When he go the Marsden it takes all day”* 17 Year old boy

It was also envisaged that a local service would provide more flexibility for patients and their families. Transition to the adult service is an example of this. A 17 year old girl seen at the Children’s Hospital in one of the new RMH/ RAH clinics stated that she wanted to be seen at the adult OPD. *“ I don’t like sitting their with all those babies looking at me”*. She now has an appointment for the adult clinic where the paediatrician will be in attendance with the adult endocrinologist. We also had a couple of 21 and 22 year olds who when interviewed said that for the moment they preferred to be seen in the Children’s Hospital. *“ I like it here, I like Dr Davidson and I like the little kids in the waiting room, they make me laugh. I like Dr Crown and everything here is nicer than St Helier- they talk to me better here “* (22 year old male). The local service has shown that it can be flexible to accommodate patients. The attendance of the adult clinician in the paediatric setting allows for the relationships to be formed which seem to be key to attendance in long term follow up. *“ 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.

It is also envisaged that provision of services can be not only flexible but also provide a robust service for patients. In an attempt to map our current services it has been evident that our service is complex and follow up and long term follow up arrangements have been arranged in a rather ad hoc way, partly dependent on patients’ original primary treatment centre. An audit of 30 sets of notes of patients believed to be lost to follow up was undertaken. 12 (40%) had been discharged as there was no suitable service for them to attend, 9 (30%) were lost between the shared care arrangements eg It states in one set of notes written in Brighton that the patients next appointment would take place in Southampton and in one year they would return to Brighton. There is no correspondence evident to show that either appointment took place. The remaining 9 (30%) became lost to follow up because their consultant either in shared care or at a PTC left the establishment.

During this project the administration of patient information has moved from being paper based to being held on a data base and the administration of clinics has become more robust. This change in itself will lead to a more efficient service.

Patients also assumed that it would be easier to arrange their follow up and that they would be seen in a more timely manner if the service is provided locally. *“ I had to push for an appointment having not been seen for 3 years. Having a local service would make it easier to be seen. I know the name of the lady in the booking team so even knowing that makes it less remote”* Mother of a 14 year old.

Did the proposed changes contribute to the achievement of any agreed standards or the delivery of any guidance? If yes please give details and reference where possible

Cancer Service Guidance 2005 Improving outcomes with Children and Young People

“The principle that underpins the guidance is that of age-appropriate, safe and effective services as locally as possible.”

Manual for Cancer Services 2008 Children’s Cancer measures

Please describe how your project proposals were implemented

A steering group/project group was established. Membership – Adult endocrinologist, paediatrician, Senior manager of RAH, Cancer Network SIL, BSUH SIF, Patient Access manager. PCT, have been invited but have only attended the first meeting. We had a patient representative who was willing to attend but the timing of meetings has always been a problem as his job requires travelling to London. We have used him as a resource for feedback.

- The Paediatrician and BSUH SIF attended the RMH steering group meetings as the projects are connected.
- A process mapping session has been undertaken which highlighted issues to do with transition and paper based administrative system.
- Baseline DNA data was collected from the RMH about Brighton and Hove attendances.
- Data has been obtained from the Thames Cancer Registry.
- A patient questionnaire was devised and piloted at a GOSH shared care clinic June 2009. The questionnaire was adopted by RMH to use in their clinics so that we get similar information. This has been used in all subsequent children and adult Late Effects clinics.
- Travel time and costs to patients have been calculated.
- Because of the small number of patients coming to these clinics all children/ adults attending have been interviewed using the questionnaire as a prompt . RMH has conducted face to face interviews on a sample group
- Two in depth interviews have taken place in patients homes. One patient had been lost to follow up and eventually found themselves in the system with Late Effects and the other a 17 year old girl with some late effects symptoms but had always attended Follow up.
- Because we have no extra resources for new clinics the service has been set up within current templates. Patient details are now on a data base, Prior to the project Follow up services were organised from a paper diaryA late effect leaflet has been devised and piloted. It has been adopted by the RMH team.Admin systems are in place for the organisation of the clinics

Give details of additional cost or resource demands that arose, including staffing or new equipment?

- The project needs to employ a nurse to undertake the organisation of the clinic, audit the clinical outcomes and be a presence at the clinics. There have been delays in the employment to this post which has caused problems. In July 2010 the job has been advertised and it is hoped that a nurse will be in post by October.
- Administrative resources need to be found across paediatric and adult services to service the clinics
- A Late Effects Leaflet has been developed for patients and is being piloted. If the project continues then funding for print costs will need to be found.

If the project is a success the number of patients will increase and more clinic resource will be required. Capacity in adult haematology is unable to cope with increased demand. Alternative ways of providing for these patients needs to be found. (This is under discussion within the haematology service)

During the course of this project the number of patients needing Late Effect follow up has been identified.(see Table 3)

Table 3

	Level 1	Level 2	Level 3	Total
Number of Children under 16	4	30	5	39
Number of Adults	4	43	26	73
Total	4	73	31	113

The capacity in clinics is inverse to the demand. Three adult Late effects clinics provides for approximately 21 patients a year .Which leaves 52 patients without follow up(48 if the level 1 patients are excluded). Whereas the paediatric clinics can provide for the children requiring follow up as they currently run as all day clinics. The demand for the adult places will increase year on year. Currently there are around 40- 50 children still in the monitoring phase assuming the majority of these will survive roughly 7-8 patients per year will enter LTFU services per year from the current BSUH service. A similar number will graduate from paediatric services to adults. Assuming no patient in adult services die over the next 10 years then local BSUH adult survivor numbers will grow by 70 whereas the paediatric population will remain the same. So without attempting to find lost to follow up patients or offering a service to a wider population than just BSUH we will have 150 adult survivors.

It has been evident that some of the patients who have attended the adult Late Effects clinic had required further follow up within the endocrine service. This demand on the service is being monitored.

The referral criteria agreed in July 2009 *Referral criteria to adult clinics*

It was proposed that these should be any patient who requires ongoing clinical care who is a childhood cancer survivor, with the general assumptions being that when patients reach the age of 18:

- Level 1 patients are discharged back to primary care for monitoring
- Level 2a patients are seen every five years
- Level 2bs and Level 3s will receive annual follow-up.

- Patients who received radiation treatment will generally be referred to the adult endocrine service
- Patients who were treated for leukaemia would be referred to the adult haematology service.

It was acknowledged that there will be some patients whose follow-up need will not fit into these broad categories particularly those with psycho/social issues.

During the course of this project discussions have taken place to the development of Clinical Nurse Specialist conducting clinics and therefore freeing up the clinicians to see the Level 3 patients and the more complex Level 2 patients. This would need to be costed but it is envisaged that this would be a part time post and the nurse would see Level 2 patients and the level 1 patients with other needs.

Were equality issues identified and how were these addressed

Low income groups and the disabled travelling to London can cause significant difficulties. It is hoped that providing a service closer to home will assist these groups in particular (See Chart 1 and 2 about cost to patient and times)

“ I like coming here but you could do with some sweet machines – it’s better for dad because he gets REALLY STRESSED going to the Marsden as he doesn’t drive” 11 year old boy.

Two patients with Learning difficulties were brought to clinic by social service carers and they said that coming to the RACH was easier for their service and also that the parents were more likely to come to the clinic as well because taking morning off work was more acceptable than having to take the whole day.

Who were the champions or key stakeholders and how were they involved in the project?

- The Sussex Cancer Network did not have the manpower to support this project. They donated 10K for SIF and project support which is provided by a BSUH member of staff.
- The adult oncologists were not engaged with this project but an adult endocrinologist and haematologist working alongside the paediatrician have been the project champions.
- The PCT commissioners are waiting until the end of the project to make a decision about commissioning. They are key stakeholders and

it would have been beneficial to have them on board from the beginning.

- Patients from RMH willing and wanting to attend a more local service.
- Local endocrine clinician willing to refer their patients to the adult Late Effects Service

Evidence of QIPP throughout testing and implementation
Quality, Innovation, Productivity and Prevention (patient involvement)-
Demonstrate how your project/evidence fits with the QIPP agenda

The project has attempted to meet the specific needs of survivors.

Quality including safety

An audit of the LTFU patient's care against LTFU best practice guidelines/ treatment protocols has been undertaken. It was envisaged that the patients attending the RACH would receive the equivalent care that they would have received at a primary treatment centre. A audit was undertaken during August 2010 by the paediatric clinician (appendix 4). 47 sets of notes were analysed for compliance to protocols. 28 (60%) Patients had received anthracyclines as part of their treatment and the expectation would be that they would receive an echo 5 yearly and 28(100%) were compliant. 5(11%) patients who had had a kidney removed as part of their treatment would expect to have their blood pressure taken at each clinic appointment, their urinalysis and Urea and Electrolytes tested. 2(40%) patients were compliant for all tests, 4 (80%) patients had 2 of the tests.

While conducting this audit it was evident that the patients who did not receive the tests were patients who had presented with complex needs. For example, a patient who had a Wilms tumour as a baby and is now 17 years old is presenting with cardiac problems. The focus of the appointment was more on this than her original diagnosis and surgery, the test for U/Es were not carried out. The process of conducting the audit was an important part of the testing. The presence of a project nurse to assist in the preparation of the clinics will improve the adherence to guidelines and protocols.

When the project nurse is employed it is envisaged that this type of audit would be part of her role.

At the CYP conference in March 2009 it was stated that the project should measure understanding of the young people as to what condition they have been treated for and what the treatment entailed and if they knew how long they had been off treatment. 37 (93%) of those interviewed knew their diagnosis but 8(10%) did not know what sort of treatment they received – not knowing if they had any form of chemotherapy or radiotherapy. Attendance at the clinics has improved the knowledge of the young people and made them aware of the importance of Long term follow up. One young man (age 17)who was a baby when diagnosed said that each time he attended he learnt a little bit more about what had happened to him. The questionnaire did not go into detail about the patients understanding but it could be deduced from some of the patients comments is that the knowledge gained is incremental.

14 year old girl *“ I don't want to come here, but I know I have to and I do learn more “*

The patient interviews had shown that the local model with both children and adult services can provide flexible care for patients. Some young adults under 18 have expressed a strong preference to be seen in an adult setting and this has been accommodated.

“ I don't want to sit in a waiting room with all those babies looking at me” 17 year old girl.

Alternatively there are some young adults where the move at 18 to an adult service would be inappropriate and they can continue to be seen at the Children's Hospital. In the Learning Diaries being kept by the clinicians the paediatric oncologist has said

“Two patients described the way in which their original diagnosis was communicated quite vividly. In both cases (1983 and 2005) it would seem they were effectively treated as adults initially; it is not clear whether they had opportunities to discuss the impact of the distress they felt at the time or later.

One young man (18 and a half) who was attending on his own without his parents for the first time told us how he felt he needed to understand his treatment and subsequent problems for himself although he had previously been happy for his parents to be in control - “ well I was treated as and adult at the beginning. I remember my mum telling that I would need “special treatment” but she hadn't used the word cancer and then I went to this specialist adult centre and they told me I could die and I had cancer. Then I was referred to the Royal Marsden children's centre and I liked being in a children's hospital” I thought his case illustrated how a cancer diagnosis in adolescence can effectively “arrest” normal emotional maturation and that we need to be sensitive to this when planning transition.”

The process of conducting this project is altering the way in which the clinicians are approaching the care of their patients who are not yet in Long term follow up which is improving the quality of care given.



Safety

Establishing a local LTFU service may help to reduce the number of lost to follow up patients. These patient are at significant risk of developing problems later on in life and their clinical outcomes are improved if the problems are diagnosed and treated and an early stage.

Younger patients of school age have also expressed views saying that they are more likely to continue to attend LTFU if they see the relevance and if the risks of Late Effects are explained to them. Patients when interviewed talked about learning a little more each time they visited. One 17 year old said that until he was 16 he didn't really listen to what was going on but he does now and had learnt at that visit about the treatment he had received. He had been a baby when diagnosed and had no memory of his treatment.

The feedback on the information that has been sent to them prior to their clinic visits has been very positive. 100% thought it was clear and informative. The younger teenagers interviewed have also asked how they will be followed

up if they attend university or move away from home. This development is very positive that they are considering staying in Follow up..

Experience

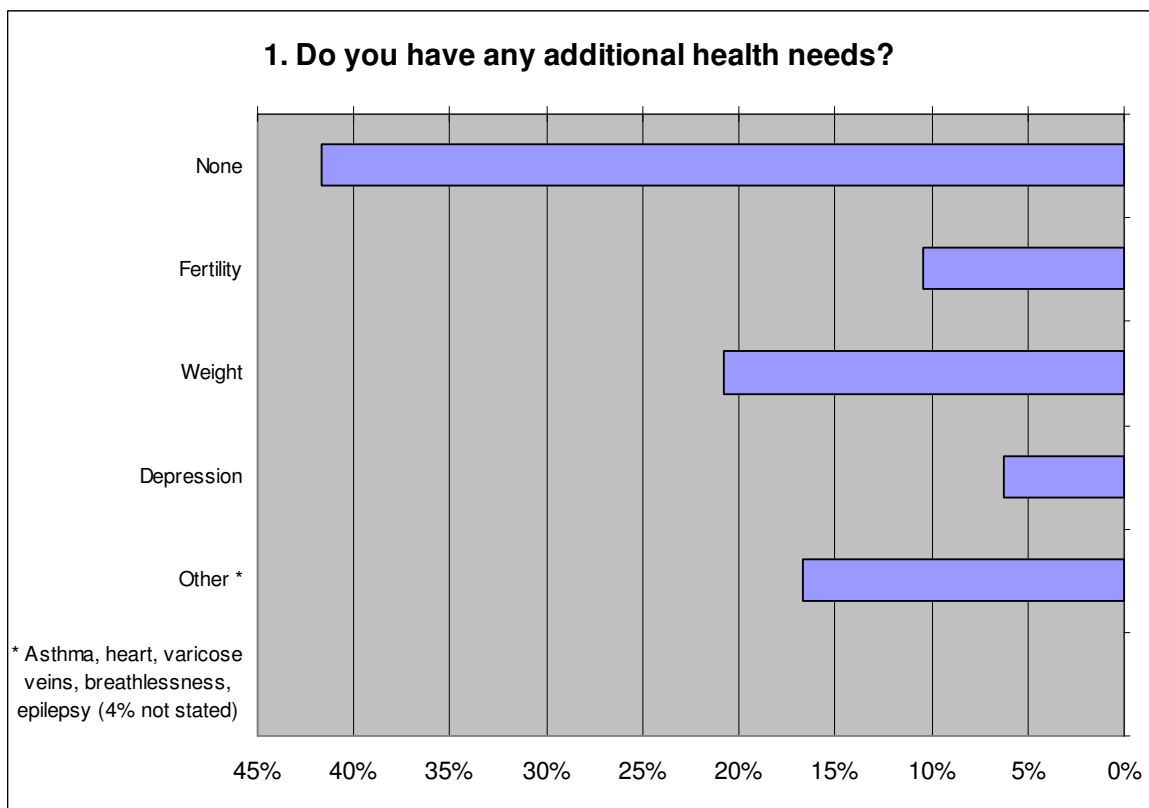
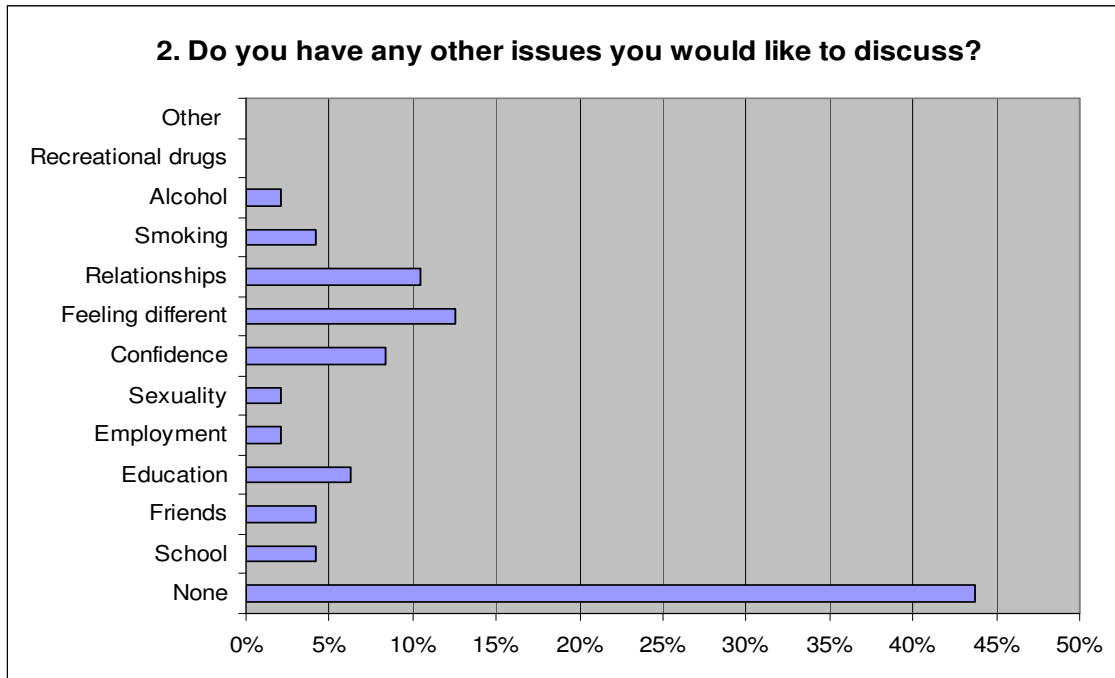
(please see appendix 1 for complete breakdown of questionnaire replies)

41 (66%) of patient attending clinics agreed to complete the questionnaire. 37 of whom were happy to have a face to face interview using the questionnaire as a prompt.

100% (41 completed questionnaires) of all patients interviewed prefer to be seen nearer to home. For those in education the service has meant less time off school or college.

They have expressed positive views of being seen by Mary Taj in Brighton and meeting the adult doctors that they will come across when they are older. A number of parents talked about the importance of the relationships that they have with the doctors. One patient was a baby at diagnosis and is now 17. Mum said *“ I like to come for reassurance. These doctors are specialist and you wouldn't get that with a GP. My GP would be anxious and so would I. Mary has seen him many times so there is a relationship. I know he can't remember but each time he learns a little more”*

It is helpful to come to clinic to find things out that I didn't know”. Girl age 14 and Mother said –“Coming to Brighton is good because I know Anne. She was there at diagnosis and all the way through. At the Marsden she is a number but here she is a person. At the Marsden it feels like a tick box. Also coming here cuts out a middle stage. We see Mary and then she says she will write to Anne to organise something. But here it can just happen.”



A third of patients have expressed a view that they would like the opportunity to talk to someone about issues other than their immediate health needs. An attempt to measure a gap in need was attempted through conducting the questionnaire. 47% (15) expressing concern about depression, feeling different

or difficulty with relationships. 21% have concerns about their weight – either under or over, and how this affects the way they feel about themselves. However without a control group we are uncertain as to whether this would be similar for any group of teenagers and young adults.

A psychologist who is temporarily attached to the adult endocrine team through “soft” (pharmacology) money to assess need was referred a patient and this is what she entered in the Learning Diary.

Patient O. I saw this female patient recently. There was a key unresolved issue which affected her original consultation (aged 13) running throughout her family dynamics and has affected all her subsequent relationships. Unusually this has not affected her illness and disease management/outcome (although she did have very high blood pressure in her appointment with Dr Crown!?) However it could have. The patient's distress has turned in part to some anger plus a desperate need for resolution. I am seeing her one more time in two weeks and may also involve her partner. This is not for active treatment but closure. She was very surprised she had been asked about her psychological status and was desperate to talk. I do feel patients like these are carrying and have carried a huge disease and illness burden and to not offer psychological intervention around this is inadequate, however, separate unrelated psychological trauma cannot get processed whilst managing major illness and it is clear that his service should offer intervention aimed at these issues.

The service that we are operating does not provide a psychology service. What the clinicians are able to do is refer to the local CAAMHS service for psychological support. It is also envisaged that a clinical nurse specialist would be able to provide some of the support that is required by the patients who may not require the intensity of a psychology referral but need the space to talk about other issues.

These were the thoughts of the adult endocrine nurse specialist who attended one of the adult clinics

I thought the late effects clinic was an effective and much needed consultation for both the patients and the clinicians.

It was apparent that most had a variety of unresolved issues relating both to the experience of their illness and its sequelae.

Looking at this from a Clinical Nurse Specialist standpoint it would be useful the CNS to follow up the patients by telephone/e-mail within a week or so once the impact of their "revisit" had hit.

It may be more appropriate for them then to explore possible support mechanisms (planned information pack) with a better insight into what may/may not be useful.

The CNS can then provide an ongoing link to any desired support in a more informal way.

This service is essential to transition as well as late effects.

On a personal level I found the experience of being part of the team immensely rewarding but restricting, as it felt unfinished for the reasons

*documented above.
I hope these comments are useful.*

Innovation

The main innovation for this project is not just the local provision of care closer to the patients home but the flexibility of what the consultants have attempted to provide. The reflection that has taken place by the clinicians at each clinic about how they have provided this local service and affected how they will proceed in subsequent clinics and the care in which they treat their current patients. The patient interviews have shown that the local model with both children and adult services can provide flexible care for patients which was the stated aim of this project.

31/3/10

- 1. . It was very helpful seeing patients together – in terms of developing the service it would also be ideal if we could plan for other specialists eg renal or Gynae to also be available for selected patients to avoid multiple clinic visits for complex patients*

LEARNING DIARY 31/03/10

- *Emotion*
 - *Talking about memories of diagnosis / treatment was very emotional – distant yet vivid – very painful*
 - *Unmet needs for support – esp psychological*
 - *'Post-traumatic stress'?*
- *Transition*
 - *Talking about transition; attending +/- parents*
 - *Importance of age/stage-appropriate information*
- *Information*
 - *Clear information about diagnosis / treatment / possible consequences of treatment*
 - *Would be optimal to back up verbal information with written pack as planned*
- *Uncertainty*
 - *We're uncertain about the optimal / necessary FU / potential outcomes of treatment*
 - *Risk of over-medicalising 'ex-patients'*
 - *Balance with need to gather information about late effects to help inform management of future cohorts of patients*
- *Team working*
 - *Really helpful to tackle questions together – between us we could field most of their queries / concerns*
 - *Our expertise was complementary - & we learnt from each other*
- *Patient priorities & perspective*
 - *They assume survival & worry about other issues (e.g. body image; dry mouth [from radiotherapy] affects teenage kisses;*

'next step' / transition). In the same child, it was also very encouraging to see how positive the effect of very major spinal surgery had been on his health & outlook. Another patient's situation was less positive - again a child with significant disabilities as a consequence of treatment - we realised how little support is available once these patients are no longer 'children', also how tricky it is to arrange things when people are outside our immediate catchment area - it's a challenge for any 'late effects' clinic to co-ordinate all the medical & psycho-social needs of these patients..... Finally, tricky for me, as the 'new comer', to start to gain the trust of the patients / parents / carers, when they've known Gill & Anne for ever - re-emphasises the importance of transitional clinics rather than abrupt transfer of care.

Productivity

Costs to patient- an assessment of patient travel distances, duration and costs has been undertaken (See Table 1 and 2). 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.

Costs of delivering LTFU clinics - We are in the process of assessing RACH and RMH costs and income for Long Term Follow Up clinics to see which is the most cost effective model. There may also be savings associated with BSUH not having to pay for as many London consultants to deliver clinics from Brighton. We calculate that this is a saving of £2000 per clinic based on the cost of the GOSH clinics where we have an agreement for up to 3 per year.

Further analysis of DNA rates - Numbers of BSUH patients are small so it is difficult to compare BSUH numbers with London Centres like the Royal Marsden. However, DNA rates for both clinics are being monitored.

Chart 4

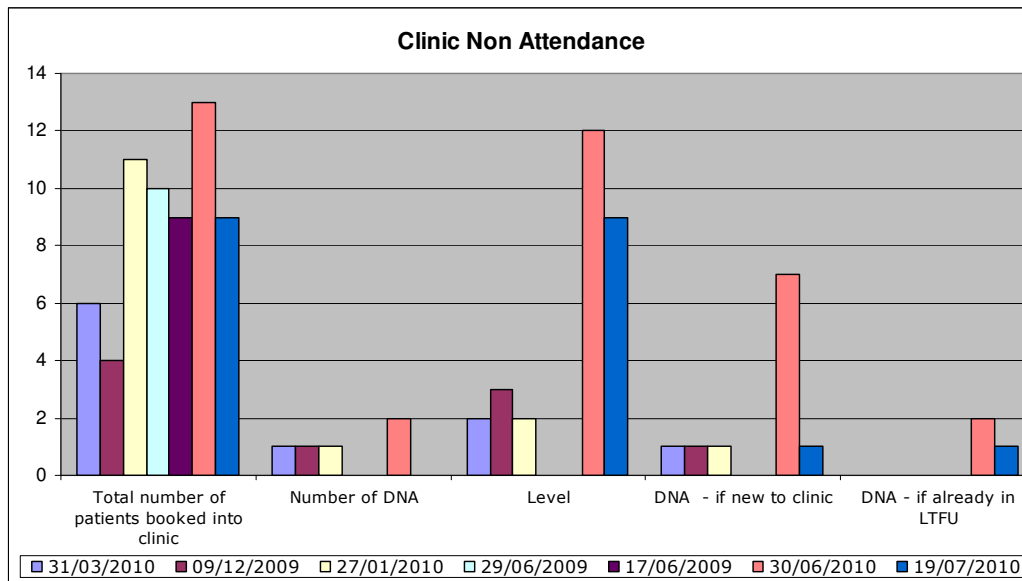


Chart 4

Shows the Number of DNA's for each clinic. The DNA's for the clinic that took place on the 30/6/2010 and the 19/7/2010 were high but the patients that had been invited to attend and who DNA'd were the group who have not been in any long term follow up for a number of years. The administration team were uncertain whether the contact details were correct for the patients so we are unclear as to whether they received the details of appointments. All the patients who have been in long term follow up either at the Royal Marsden/ GOSH or locally had a much smaller DNA rate – 3 in total.

Prevention

By providing a local and flexible service to patients where early screening can identify any health issues and refer if necessary to specialist services locally. Patients with psychological difficulties can be referred to the local CAHMS service. Health education is an important aspect of a Late Effects Service. It is evident that clinicians are suggesting local resources to patients eg under 16 free swimming at the local swimming pool, and a local charity that provides sailing courses.

One adult patient who was seen in the first adult Late Effects clinic was referred to a psychologist who is temporarily able to provide a limited service. She was able to access this service very soon after her clinic appointment. The psychologist has also been asked to contribute to the Learning diaries (see above).

This patient was in her 40's and had attended a number of adult OP clinics for conditions related to her original treatment but had never had access to Late Effects Clinics. It could be argued that her psychological difficulties that have affected her and her relationships could have been less burdensome if she could have received help earlier.

An in depth interview was conducted with a 38 year old patient who was lost to follow up and emerged in an adult endocrine clinic. He had been referred to the endocrine service and it is evident that his problems stem from the treatment that he received as a child. He talks about how these late effects have damaged his life and relationships. (See appendix for full interview)

Below is an extract from his interview.

How has having cancer as a child affected your life?

“The tiredness associated with it has been difficult. But I have always just had the attitude that I should live with it and just get on with it. I have been tired the whole of my life

I have been to GP's about it and work medicals but it has never been pursued. It is the one issue that I have mentioned to every GP that I have ever seen. It was only at a works medical recently that someone picked up on this and referred me to Dr Crown. I look really young and I mentioned this to the work doctor as well as about the tiredness.”

Did you feel that your education/ work suffered?

“Again the tiredness. I had to achieve at school and work hard to make up for the time off. But I’ve always been quite focussed; It did mean that what little energy I had was focussed on work. It’s meant that in order to get an education all my energy was used up and I didn’t go out.

I now think that I have been passed over as far as promotions are concerned because I look so young no one takes me seriously. I now know that this is as a result of hormone deficiency. So I suppose work has suffered but not the quality of my work but my work life.”

***Has it affected you physically/ emotionally/ psychologically?
Would you be prepared to share this.***

*“I think that I have probably been depressed on and off for years. The tiredness affects relationships. Even at university what little energy was spent trying to get through the work. There was no energy to spend socialising and eventually people stop asking you.
It’s the same at work. You can work and then when people go out you haven’t got the energy and then they stop asking.”*

This gentleman also talked honestly about his teen age self and how he would really have had to have been persuaded to remain in long term follow up. The relief of being discharged for him and his family he described in a way that was almost physical. His physical difficulties, depression and relationship difficulties stem from his treatment of his childhood cancer and if a service

Patient Involvement

Every patient that attended the clinic was given the opportunity to be interviewed about their experience of clinics. (See Appendix 1). 66% 41 questionnaires were completed and 37 had a face to face interview took using the questionnaire as a prompt.

. Patient interviews – two in depth interviews were conducted in patients homes. 16 patients were contacted but only 2 agreed to be seen. One was a 38 year old man who had been referred to the endocrine service and it is evident that his problems stem from the treatment that he received as a child. He talks about how these late effects have damaged his life and relationships. The second interview is with a 17 year old girl who has moved from Long term follow up to Late effects with no break. She has some late effects but is confident because she knows that these are being addressed (see appendix)

A patient representative was approached to be on the steering group but was unable to attend because of his work hours.

Patients who were referred from the Marsden were asked whether attending Brighton was something that they would like to do. So there was “buy in” from the patients.

Other sources of evidence

All discussed above

Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data.

See above for this information.

Because some of the patients are seen annually and the timescale for this project is limited it has been impossible to evaluate the service one year on. Patients have given their views about the clinics and these have been very positive. However the effectiveness of signposting patients and intervening at an earlier stage is a long term aim to measure.

Mapping of our service and understanding the demand has been very useful and will help in the discussions with commissioners as to how to continue and provide a service for childhood cancer survivors.

Are there any other sources of evidence of how it could affect cost and quality? If yes please give details.

See above for the evidence about future demand.

We will continue to monitor DNA and re-booking rates. The RMH data showed that in 2008 DNA rates of patients from Brighton and Hove were 4. They were unable to provide data about patients in the Sussex area. This number is very small and difficult to compare against. In our new service patients who attended who had been in follow up at the RMH or GOSH the DNA rate was only 3 patients in the year. (See above). The new service has provided for patients who have not been in follow up and were new to the service the figure was 8. It is this group that is causing concern and we will have to look at how many times we offer a patient an appointment when we have such a limited provision in clinic and we do not want to waste capacity.

Please present comparisons of baseline data vs actual data where relevant

See above

Give an assessment of how your evidence will provide inform and influence service commissioners

We are hoping to show that repatriating RMH patients to Brighton will reduce costs. That some GOSH patients can be seen in the adult clinics which will reduce the number of shared care clinics and make considerable savings. That seeing patients in a specialist Late Effects Long term follow up clinic will ultimately reduce inappropriate use of other resources because signposting will be timely and effective. This evidence needs to be collected longer term as the timescale of the project is too short to measure this effect when patients only attend annually.

The qualitative evidence from the interviews is powerful and the reduction in cost to patients by 70% in financial terms and the softer benefits of not missing school are considerable.

What are the challenges and positive elements of testing

Challenges

Timescale too short

RMH figures not necessarily helpful as a baseline measurement

Positive elements

Monitoring the effectiveness of the clinics has led to positive reflection

Collecting data about the quality of provision was new and beneficial.

Patients views have influenced the clinicians.

Cancer registry figures were invaluable

Process mapping identified administrative shortfalls early on in the project and work took place to resolve these. Don't underestimate the need for administrative support

What other considerations should someone planning to implement these proposals be aware of?

Are there any potential top tips or potential pit falls

- Ensure that you have 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 that you will focus on i.e. LTFU 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
- Administrative support is key especially when providing as service across the adult and children divide. This needs to be resolved early in the project

Please identify negative elements of the testing and implementation

- Too short a timescale when patients only attend annually – it is difficult to measure the impact.
- The original measures of DNA rates may not be meaningful at the end of the project.
- Not having a nurse in post has prevented the audit of clinical measures to take place. The clinician is having to do this piece of work.

Give details of what worked really well throughout the life of the project

The softer qualitative information from the Learning Diaries and the patient interviews. The consultants reflections on the effectiveness of the clinics led to changes and improvements over the lifetime of the project.

What are the plans for long term gains?

The service is taking place under the consultants' current templates. No extra resource has been identified to expand the provision of the service.

The mapping of the demand has shown that we cannot under current templates provide a service for all the adult childhood survivors that require follow up. A clinical nurse in post would allow the consultants to concentrate on the patients with the greatest need and complexity. It is envisaged that this nurse could provide a service for both adult and children who are cancer survivors.

The referral criteria states that level 1 patients would be discharged into the community under the care of a GP. Support and education for GPs is required and PCT engagement would need to take place in order for clinicians to feel confident about this move. Care plans for patients need to be adopted

The Haematology department are discussing the provision of long term follow up for childhood survivors. It is envisaged that a similar joint clinic will be established initially in the children's hospital. This will enable the adult haematology clinician to learn from the paediatric clinician.