

NHS Improvement

1. Your details	
Name	Sarah Tranter
Organisation	Pan Birmingham Cancer Network
Email	Sarah.tranter@westmidlands.nhs.uk
Contact Number	07855 236645
2. Details of your project	
Give a description of your project.	<p>The project involves the stratification of patients into risk groups and subsequent allocation to the most appropriate long term follow-up model; medical, nurse-led or postal and telephone survey.</p> <p>3 models of long term follow-up will be developed:</p> <ul style="list-style-type: none"> • Postal survey In conjunction with the West Midlands Regional Children's Tumour Registry • Nurse-led follow up clinics - Run in parallel with medical long term follow up clinics, for medium risk patient <p>Medical follow-up clinics - A development of current practice to allow consultant-led follow up for patients predicted to have the greatest need</p> <p>BCH have recently began working on the National Cancer Survivorship Initiative – Economic Evaluation Exercise (patient questionnaire only) The purpose of this work, is to enable the NCSI to get a retrospective picture of cancer activity and costs for different tumour types in different parts of the country, and to get the patient view on the cost of attending outpatient clinics and whether they have had issues addressed or unaddressed prior to their current appointment.</p> <p>The Late Effects Clinic at Selly Oak is currently being attended by a research assistant each Monday to complete the questionnaire. The results of this will be collected nationally. This has now been completed and submitted to DoH for analysis (information added below)</p>
To what clinical area does your project relate?	Oncology / Haematology Late effects
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	<ul style="list-style-type: none"> • Children and Young People • Self Management
What type of change did your project aim to address (e.g. service redesign, new technology etc).	The aim of this project is to develop a revised model of care which encompasses the patient's follow-up journey from completion of treatment for childhood

	<p>malignancy at Birmingham Children's Hospital through to adult based long term follow up care at Selly Oak Hospital.</p> <p>Further to this work, as part of the National work stream, Birmingham Children's Hospital will investigate the cohort of patient's that have been lost to follow up, with the aim to identify any key indicators or patterns within this group of patients.</p>
<p>What tangible change / tangible outcome have you achieved to date</p>	<ol style="list-style-type: none"> 1. Risk stratification September 2009: Risk stratification designed and applied to current patients 2. Extension of postal follow up service September 2009: All appropriate low risk patients undertake planned discharge to postal follow up. New form designed based on feedback from GPs (see evaluation section) 3. Nurse led clinic A large percentage of medium risk Haematology follow up patients transferred to Nurse Led clinic 4. Introduction of a new departmental "end-of-treatment" summary sheet Sept 2009 This is for use at the completion of active treatment to facilitate the planning of each individuals follow up and late effects monitoring.

<p>What was the purpose of the change and what improvement did it deliver?</p>	<p>The purpose of the changes are to provide the following:</p> <ul style="list-style-type: none"> • Robust mechanisms of follow-up care appropriate to the long-term health needs of the patient • Continuity of patient care from completion of therapy through to adult service • Effective communication between paediatric and adult services to support the transition process • Transfer between models of follow-up of care determined by clinical need and maintained through communication between care providers • Patient /parent involvement in the development of their individual care pathway • Patient / parent empowerment through education, information and involvement
--	---

<p>Did the proposed changes contribute to the achievement of any agreed standards or the delivery of any guidance? If yes please give details and reference where possible.</p>	<p>The stratification of patients into risk groups is in line with recommendations from Wallace et al who proposed levels of follow up for cancer survivors.(BMJ. 2001 Aug 4;323(7307):271-4.) Introduction of an "end-of-treatment" summary is compliant with recommendations for Late Effects MDT with the primary treatment centre for Cancer Peer review (measure 09-7A-124)</p>
---	--

3. How you have implemented your project Risk stratification	
Please describe how your project proposals were implemented.	The clinical team across both the paediatric and adult services worked together to design a risk stratification. 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. 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.
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	None
Were Equality issues identified and how were these addressed	None identified
Who were the champions or key stakeholders and how were they involved in the project?	Clinical staff – Paediatric Oncologists, Adult Endocrinologist, Paediatric and Adult senior nursing staff.

3. How you have implemented your project – Extension to postal follow up service	
Please describe how your project proposals were implemented.	<p>For those patients within the low risk category of the risk stratification, the West Midlands Regional Children's Tumour Registry (WMRCTR) are 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 due to a lack of patient consent, no clinical intervention took place.</p> <p>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.</p> <p>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.</p>
Give details of any additional costs or resource demands that arose, including staffing or new	£15,000 has been supplied by Pan Birmingham Cancer Network to fund a part-time Research Assistant

equipment.	until April 2011. The addition of this post has been invaluable for this area of the project.
Were Equality issues identified and how were these addressed	None identified
Who were the champions or key stakeholders and how were they involved in the project?	<ul style="list-style-type: none"> • West Midlands Regional Children's Tumour Registry – Research Associate and Assistant • Clinical staff – Lead Paediatric Oncologist and wider clinical team in use of discharge packs • GP colleagues within primary care

3. How you have implemented your project – Nurse Led Clinic	
Please describe how your project proposals were implemented.	<p>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.</p> <p>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.</p>
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	<p>Advanced Nurse Practitioner post was initially soft funded, through two different charities. The involvement of the CEO enabled us to gain substantive funding for this post.</p> <p>In addition, the retiring ANP has been funded for one day per week to continue the Nurse led clinic support, until the replacement is fully competent at the end of 2010.</p>
Were Equality issues identified and how were these addressed	None identified
Who were the champions or key stakeholders to engage?	<ul style="list-style-type: none"> • Advanced nurse practitioners within paediatric setting • Paediatric haematologists • Haematology secretaries, in administrative support of identifying and changing over patients into new clinic

4. Evidence of QIPP throughout testing and implementation	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	
Quality including safety - Patient Benefits	Benefits to the patient:- There are a number of benefits to the patients, these include Not having to make unnecessary trips to hospital, being seen away from

	<p>the treatment clinic, valuing the patients time, improving the patients experience and quieter clinics with longer appointment slits with CNS, where increased availability for patient psychosocial needs to be met.</p> <p>These benefits are measured, using clinic data, clinic value audit, patient satisfaction survey, user working group feedback</p>
Quality including safety - Carer Benefits	<p>Benefits are to remove unnecessary trips to hospital, value carers' time and improve the carer's experience This also will be measured using clinic value audits, carer satisfaction surveys, and user working group feedback</p>
Quality including safety – PCT Benefits	<p>The PCT will benefit in two ways Higher quality discharge information benefits GP, providing them with significant education surrounding their patient and Patient consent obtained in all cases prior to FU will enable increased communications between primary and secondary care This will be measured via Letter assessment tool - applied to 20 end of treatment letters pre NCSI & 20 post NCSI and also Evidence of new consent / consent rates / evidence of difficulties associated with lack of consent</p>
Quality including safety – Cancer Centre Benefits	<p>The benefits to the cancer centre are separations of Follow-up and treatment clinics, utilisation of a database as a method of long term follow-up and consent provides contact with higher number of patients, reducing numbers lost to follow-up. These are measured using clinic data, the appointment of a research assistant to maintain the database and evidence of new consent/consent rates/evidence of difficulties associated with lack of consent</p>
Innovation – Patient Benefits	<p>Practical application of a risk stratification tool to FU and the understanding of the impact/effect of being lost to FU this will be measured by the evidence of risk stratification/ measures of patients through each tier of FU and the local "Lost to follow up" work to be used as measure / evidence</p>
Innovation – PCT Benefits	<p>The PCT will benefit in two ways Higher quality discharge information benefits GP, providing them with significant education surrounding their patient and Patient consent obtained in all cases prior to FU will enable increased communications between primary and secondary care This will be measured via Letter assessment tool - applied to 20 end of treatment letters pre NCSI & 20 post NCSI and also Evidence of new consent / consent rates / evidence of difficulties associated with lack of consent</p>

Innovation – Cancer Centre Benefits	The benefits to the Cancer Centre will be the revised follow up questionnaire and increased number of patients on this pathway aids West Midlands Registry in gaining valuable research data. This will be measured by Postal follow up return rates / Postal follow up completion audit / Number of patients on FU
Productivity / cost or savings / effectiveness including the scale of the benefits. Patient Benefits	The patient benefits are Choice for patients and variety in FU models of care works towards ensuring care is being offered in the most appropriate setting and enabling patients to make choices about their care as they see fit by offering additional option should hospital based follow up no longer be an option for them. These will be measured using Clinic value audit and also evidenced by 3 tier model of care / No of patients transferring through tiers / Patient case study
Productivity / cost or savings / effectiveness including the scale of the benefits. PCT Benefits	The PCT benefits are Access for GPs to high quality detailed information about patients measured via the Letter assessment tool
Productivity / cost or savings / effectiveness including the scale of the benefits. Cancer Centre Benefits	Cancer Centre Benefits will be Additional capacity due to the expansion of the scope of the CNS and Training for staff on advanced communication with patients in relation to self management this will be measured using Clinic capacity data and the attendance at ADP course
Prevention – Patient Benefits	Postal questionnaire enables patients progress to be monitored via their GP even though they are not attending hospital this will be measured by looking at the No of patients on postal FU / Audit use of end of treatment summary 5 yrs previous and 6 months after roll out
Prevention – PCT Benefits	Additional education and information to primary care aids GP with early diagnosis of late effects the measure will be assessed using the letter assessment tool / Interaction with GP / Patient case study
Prevention – Cancer Centre Benefits	Consent enables late effects team to call back patients if late effects or early signs of recurrence are suspected from postal follow up or nurse led clinic this will be measured by recording the number of postal FU's that require "file request" or GP letter / action from BCH team

5. Other sources of evidence – Risk stratification	
Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data	The user perspective has been sought by attendance at the Parent and User group at Birmingham Children's Hospital (SPoCC), we gained a qualitative input from the users and parents on project aims and objectives. They have also agreed to look over any patient leaflets and correspondence to give their opinions prior to distribution.

	Patient satisfaction questionnaires are being sent to patients seen with the Nurse-Led clinic and also those actively discharged from routine follow-up since Sept 2009.
Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	Potential yet to be determined
Please present comparisons of base line vs. actual data where relevant	All Data attached separately in the document store
Give an assessment of how your evidence will provide inform & influence service commissioners	To be determined

5. Other sources of evidence – Extension to postal follow up service	
Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data	<ul style="list-style-type: none"> • GP completeness audit • GP questionnaire • Qualitative GP feedback • Q return rates
Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	Will form part of to Economic Evaluation
Please present comparisons of base line vs. actual data where relevant	All Data attached separately in the document store
Give an assessment of how your evidence will provide inform & influence service commissioners	To be determined

5. Other sources of evidence – Nurse led clinic	
Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data	<ul style="list-style-type: none"> • Pre-change baseline clinic questionnaires (both Onc & Haem) • Nurse led clinic evaluation A Clinic value audit is undertaken following the Nurse led Haematology Clinic to obtain a qualitative feedback on whether the patient/carer is satisfied with the appointment and whether they would be happy to attend a further nurse led clinic.
Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	Potential yet to be determined
Please present comparisons of base line vs. actual data where relevant	All data attached separately in the document store
Give an assessment of how your evidence will provide inform & influence service commissioners	To be determined

6. What are the challenges and positive elements of testing	
What other considerations should someone planning to implement these proposals be aware of?	Introduction of a postal follow-up service requires a reliable and robust database and well trained staff to manipulate and analyse the data.
Are there any potential top tips or potential pitfalls?	
Please identify negative elements of the testing and implementation	
Give details of what worked really well throughout the life of the project	To be determined
What are the plans for long term gains	To be determined

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	<p>Sarah Tranter - Service Improvement Facilitator Pan Birmingham Cancer Network Email: Sarah.tranter@westmidlands.nhs.uk Tel: 07855 236645</p> <p>Dr Helen Jenkinson Consultant Paediatric Oncologist Birmingham Children's Hospital NHS Foundation Trust Jenkinson Email: HELEN.JENKINSON@bch.nhs.uk Tel: 0121 333 8411</p>

Cont..... Page 9

Project Evidence cont...

Postal Follow-up

There have been 4 patients discharged onto the postal follow-up from BCH since July 09 and 92 from Adult SOH from Selly Oak. A questionnaire has been developed and is due to be distributed in September to identify whether the patients were happy with the discharge process and if they felt they had sufficient information, support and guidance. This evidence will not be available until Late 2010.

Lost to Follow-up

The Local analysis that Dr Helen Jenkinson is undertaking is still in the process of being completed. This was a huge piece of work that Helen and Ami have been working on for some time. The data has been collated and is currently with the statistician. No information regarding this is currently available at this time. However, Helen may do a poster if the data has been returned in time for the September workshop.

Economic Analysis – Questionnaire

Birmingham took part in the questionnaire side of this project which has now ended. All the patents were interviewed at Selly Oak clinic. There was a 100% completion rate for all 76 patients who attend and this data has been sent to Jonathan White at DOH for analysis as requested.

Nurse Led Clinic

The Nurse Led Clinic began in Mid September 2009 and has been operating on Wednesday afternoons each week with haematology patients. There have been a total of 34 new patients seen during this period. With only 2 DNA's. There have also been 4 patients return for a 2nd appointment during this time period. To gather evidence/feedback from this clinic has proved difficult at times and a number of different methodologies have been tested. We initially gave the questionnaires to the patients to complete immediately after the appointment (7) patients did this. However it was felt that by doing this the patients may not feel they could be as open and honest as they would like to be given the nurse that saw them was handing out the questionnaire and collecting it back. We then tried handing it to them after the appointment and asking them to post it back. (2) Were returned this way.

In February 2010 we then sent the questionnaire out via the post the week after their appointment giving the patient/parent some thinking time. Again only (2) were returned this way.

The Service Improvement Facilitator from Pan Birmingham Cancer Network has also been involved in collating some of the response and most patients were collated in two ways. (11) Were completed by telephone interviews. And (3) were completed during a 1:1 with the patient/parent or guardian after the appointment in clinic.

A total of 25 questionnaires have been completed which is of 73.53% return rate.

The attendance rate at these clinics has also been excellent with only 2 from 36 DNA's which is 5.5% DNA rate.

The questionnaire overtime has been amended slightly so the first 7 patients who completed during clinic are shown separately for this report.

They were asked the following 6 questions with a response of yes/no

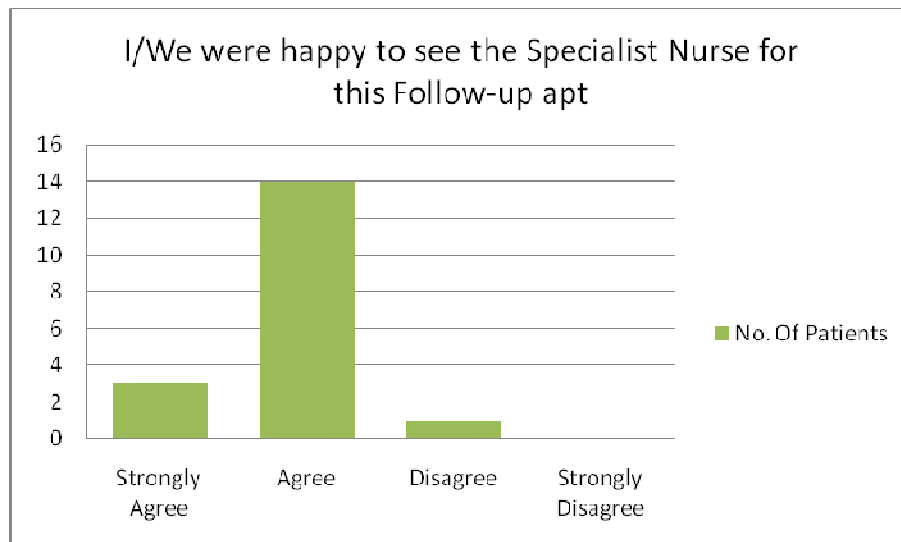
1. Where you happy having a consultation with the nurse
2. Did you feel you could discuss everything you wanted to?
3. Did you have enough time to discuss issues?
4. Did you understand all that was discussed?
5. Did you feel confident about all information received
6. Would you be happy to see the nurse next time?

The results were 100% yes for all questions.

The questionnaire was then amended slightly to try and capture more information.

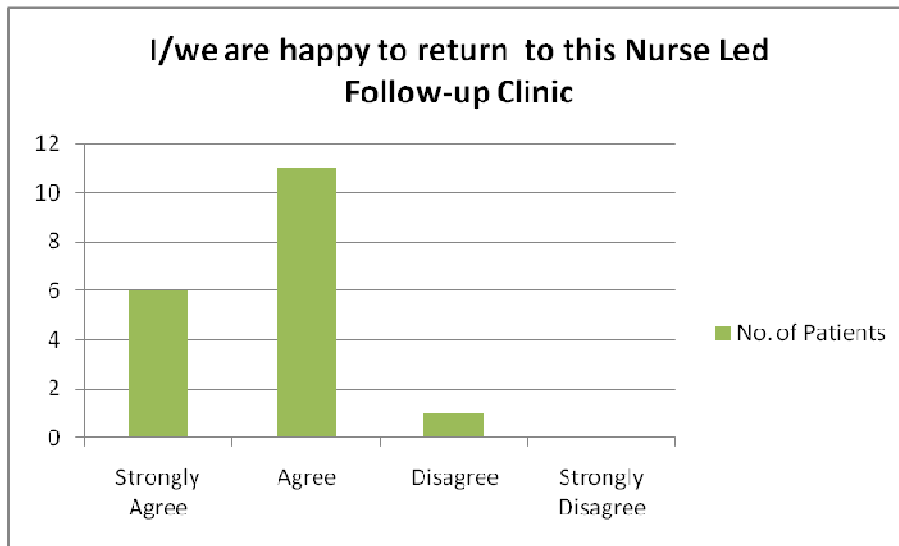
Below are graphs of each of the questions answered by the remaining 18 patients:-

Q1 I/We were happy to see the Specialist Nurse for this Follow-up apt



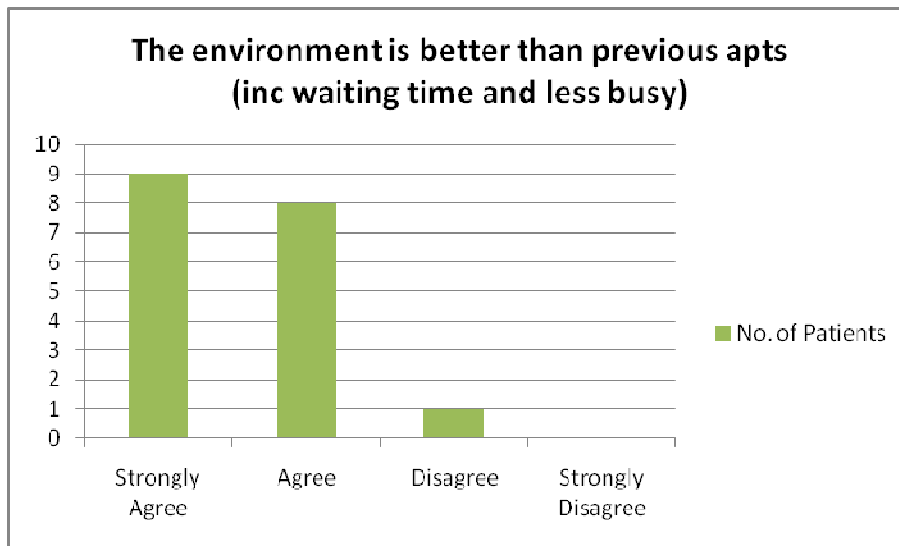
A total of 94.4% either agreed or strongly agreed they were happy to see the Specialist Nurse for their appointment.

Q2 I/we are happy to return to this Nurse Led Follow-up Clinic.



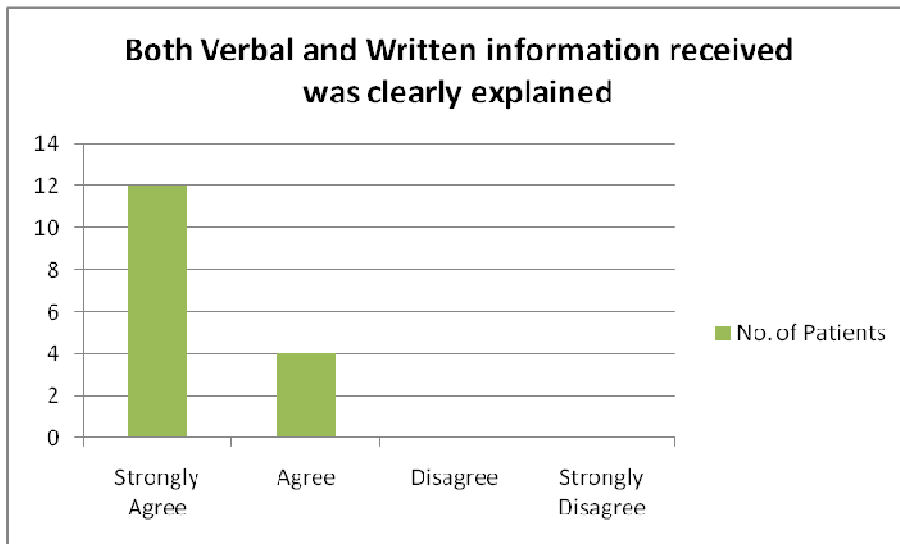
Again a total of 17 which is 94.4% agreed or strongly agreed that they are happy to return to this clinic.

Q3 The environment is better than previous apts (inc waiting time and less busy)



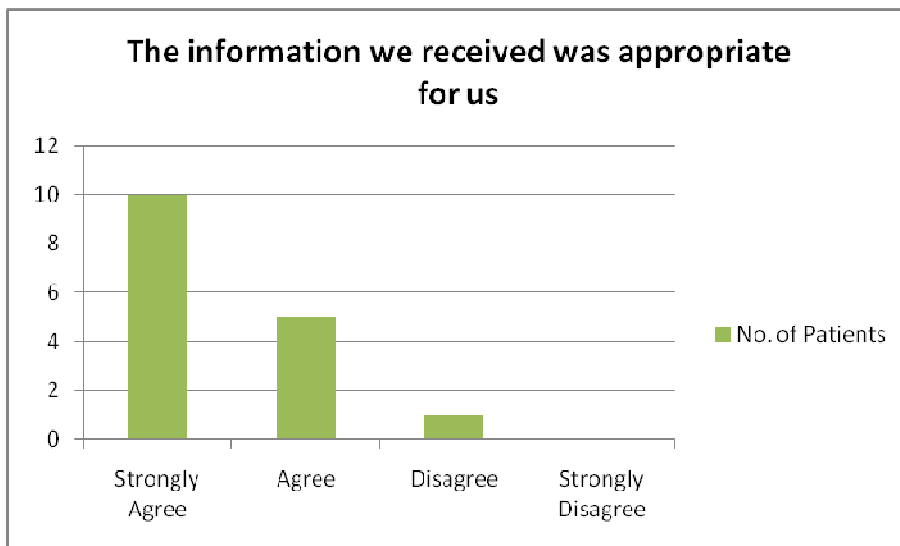
94.4% agreed or strongly agreed that the environment is better than attending previous appointments. This is also reflected in the comments that have been shared.

Q4 Both Verbal and Written information received was clearly explained



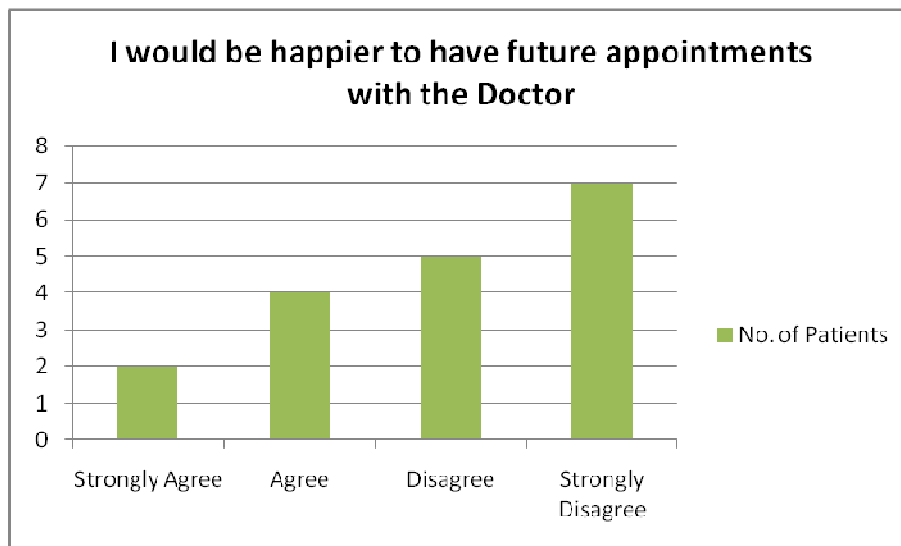
100% of patients felt that the information given was clearly explained. With 66% strongly agreeing. NB. Only 16 Patients answered this question.

Q5 The information we received was appropriate for us



93.75% felt that the information they had been given or discussed was appropriate to them or their child. NB. Only 16 Patients answered this question.

Q6 I would be happier to have future appointments with the Doctor



Only 33.33% of patients felt they would prefer to see the Doctor. With 66.66% more than happy to see the Specialist Nurse.

As part of the questionnaire we also gave people the opportunity to add further comments i.e. any particular areas for improvement, anything they were pleased with and any other comments that they wanted to add. Here are some of the quotes from the patients or parent/carers.

Comments made regarding issues they were pleased with:-

“It’s much better being away from the treatment clinic”

“I felt more comfortable with the Nurse”

“I felt happy to see the Specialist Nurse she was very knowledgeable”

“I felt I had more time with the nurse and it wasn’t as rushed as usual, I also like seeing the same person. She also discussed my Son’s general health and we felt we were able to ask anything that we felt may have been too trivial to ask the Dr as they are very busy”

“We didn’t wait very long for our appointment and it was better being with patients that are in follow-up rather than sitting with patients who are having treatment as this can be very painful and bring back memories”

“The nurse seemed to have more time, she was very open and I felt I could ask lots of questions”

“Seeing the Nurse today has explained the reason why the follow-up appointments are important, it has been very useful. She has given us contact details too if we have any concerns we know who to call”

“I thought it was excellent, all my questions were answered and my son was able to speak to the Dr in private about some concerns he had”

“She was very thorough and gave us information about recent research into Fertility Studies”

“My son was only 18 months when diagnosed and it was explained to him what it was and what happened and will happen in the future her found this very useful”

Comments made regarding areas for Improvement or additional comments

“I would prefer to see the Dr”

"I find it a bit worrying that the blood tests have now stopped I would like this to be done every so often perhaps yearly just to confirm everything is ok"

"It would be nice to see the Dr once in a while, not every visit but occasionally"

"we were still kept waiting for 45 minutes I was not pleased as I thought it was supposed to be quicker"

"The nurse was lovely but some of the information she gave regarding my Childs future was inappropriate as she has special needs, she discussed about if/when my child may have children which is a total in probability. I didn't learn anything I didn't already know, and some things seemed irrelevant"

"It's better being away from the treatment clinic but it's still in Oncology and coming here brings it all back"

During one of the 1:1 questionnaire completions I did, the patients and Dad felt all the information was appropriate however Mom felt she would have not have been as frank with them.

Overview

The feedback from the Nurse Led clinic overall was very positive. It is anticipated that the Clinic will continue to operate for Haematology patients and be offered in the near future to Oncology patients also.