

1. Your details	
Name	Ramesh Modasia
Organisation	North London Cancer Network
Email	Ramesh.modasia@islingtonpct.nhs.uk
Contact Number	0207 685 6217
2. Details of your project	
Key Worker Role Final August 2010	
Give a description of your project.	The project aimed to assess the range of enquiries made by cancer survivors into the Long Term Follow-Up Unit (LTFU) at Great Ormond Street Hospital (GOSH) and how a key worker role could support and address these. The project would review the current practice in addressing these enquiries, identify the most appropriate person to fulfil the role of a key worker in the unit and also explore supplementary support to the survivors.
To what clinical area does your project relate?	The project relates to the long term follow up (LTFU) of cancer survivors within the Haematology/Oncology unit at GOSH. This group of survivors are young people who have been treated for childhood cancer (not brain tumours) or who have had a bone marrow transplant, but now are not on any active cancer treatment. They are being followed up on long term basis and during this period they make enquiries to LTFU office as the need arises.
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	GOSH was one of the national test sites as part of the Children & Young People's (CYP) work stream of the National Cancer Survivor Initiative (NCSI) involving the 'living with and beyond cancer' pathway.
What type of change did your project aim to address (e.g. service redesign, new technology etc).	The main focus was on service design and improving communications, incorporating new technology, protocols and innovative ideas into clinical practice, for the benefit of the survivors and family.
What tangible change / tangible outcome have you achieved to date	<p>Apart from this Key Worker Role project, GOSH also led on two other projects, 1) Transitional Care and 2) Survivor Care Plan Record. The initial group exercise produced a baseline patient process pathway through the LTFU unit (Appendix 1).</p> <p>Outcomes of the Key Worker Project achieved to date are:</p> <ul style="list-style-type: none"> • An audit of all enquiries into LTFU over a 6 month period • Ascertainment of the need for and assignation of a key worker role. • Identification of the need to have an easily accessible contact card (for the LTFU unit) and a web site for further information. These are now being developed. • A second audit to evidence the impact of issuing the contact card (contact letters are issued initially until cards are developed).
What was the purpose of the change and what improvement did it deliver?	<p>The main purpose of this work was to assess the needs of the survivors in relation to key worker support and then to explore and implement alternative methodology in routine long term follow up care that could address this need. The role of a key worker can support survivors and parents on issues whilst under LTFU care.</p> <p>Following analysis of the enquiries into LTFU (see Appendix 2), the following improvements have been made:</p>

	<ul style="list-style-type: none"> • The LTFU administrator has been appointed as Key Worker to the survivor, which is unique to GOSH. • Design of a LTFU Contact Card for distribution to Survivors so that future enquiries are made centrally, but also providing useful web links. • Creation of a LTFU website that can address commonly asked enquires and can provide more information and links on living with and beyond cancer. • Access to LTFU is made easier with a central point of contact to the Key worker. Survivors are able to access general and specialised information from the local website.
<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>It has been well documented¹⁻³ that the needs of CYP cancer survivors are considerable and long standing. This work has addressed some of the culture shifts as described in the NCSI vision document⁴, namely:</p> <ol style="list-style-type: none"> 1. The focus on recovery, health and well-being after cancer treatment 2. Assessment, information provision and care planning 3. Supported self-management 4. A shift from a single model to tailored support of follow up care 5. A shift from measuring clinical activity to experience and outcomes for survivors <p>An assigned key worker can assist in positive experience for survivors by directing them to or providing LTFU information as necessary. The local website provides administrative information of the LTFU service and also directs to links for specialised information on late effects of treatment and general advice.</p>

3. How you have implemented your project	
<p>Please describe how your project proposals were implemented.</p>	<p>Following review of the LTFU patient process pathway (Appendix 1), improvement action plans were identified along with three main work streams. A Key Worker Audit was identified as one of the projects.</p> <p>The project was phased as follows:</p> <ol style="list-style-type: none"> 1. Audit enquiries into LTFU over a 6 month period (Appendix 2). 2. Analysis of the nature of all enquiries to the LTFU service and to whom they were directed. 3. Ascertainment of the need for and required skills of a key worker role. 4. Recommendation and implementation of actions to supplement support in addressing enquiries. 5. Repeat audit to confirm impact made by any of the actions implemented (Appendix 3). <p>Access database was created to log enquiries from individual callers. The database was placed on a shared drive, accessible to all working in the LTFU and related Haematology and Oncology services which are known to receive such enquiries. The calls were logged in the system by each recipient, even when they were passed from first recipient to other members of the LTFU team.</p>

	<p>Analysis of the database provided the baseline evidence of</p> <ul style="list-style-type: none"> • The nature of enquiries, their flow within the LTFU and the response and resolutions • need for a key worker role unique to LTFU team at GOSH • distributive resource used in receiving the enquiries and passing to the appropriate person
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	<p>Analysis of the audit showed that considerable resource time was spent on transferring enquiries to the right person who can resolve them. Two action plans were concluded from the evidence. They were:</p> <ol style="list-style-type: none"> 1. Developing and distributing a LTFU Contact Card for the survivors and guardians to enable the enquiries directly and centrally to the LTFU office. 2. Creation of a GOSH LTFU website specific for the long term survivors, addressing commonly asked queries and providing useful information.
Were Equality issues identified and how were these addressed	There were no Equality issues identified.
Who were the champions or key stakeholders and how were they involved in the project?	The project was guided by the Steering Group members composed of GOSH LTFU team which included a Consultant of Oncology and Late Effects, an Associate Specialist in Haematology and Late Effects, a clinical nurse specialist and administrator. External members included survivors and guardians, shared care paediatricians and nurse specialists and a community GP representative. Other members included NHS and local cancer network improvement leads and facilitator and expert advice from the GOSH Child Health Institute. GOSH core team were the champions and key drivers of this project.

4.	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	Evidence collected through the project aligns with the QIPP parameters.
Quality including safety	A key worker is able to provide an improved patient experience by giving direction to an information resource, whilst at the same time being accessible for administrative enquiries or for directing clinical concerns. The LTFU Contact Card enables the caller an easier access. The local website would address common enquiries and provide further specialised information.
Innovation	Developments of a LTFU Contact Card and a local website for the survivors are new products to GOSH to assist the enquirers. The website would be a useful tool to link to further information on issues of living with and beyond cancer.
Productivity / cost or savings / effectiveness including the scale of the benefits.	Once the LTFU contact card is fully developed, it will be issued to all those registered survivors. The card will also have the website address. Survivors will be able to have direct access to LTFU via the central number and directly to the Key worker. Information will be readily available to the survivors via the website.
Prevention	The new Contact Card and website should allow direct access to LTFU

and reduce waiting times for a response.

5. Other sources of evidence

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

Whilst the Contact Card is being developed, letters informing central contact details of the LTFU and the Key worker are issued to the survivors and guardians when making enquiries or attending clinics. 350 letters were distributed during the period the January to July 2010.

A second audit of the enquiries into LTFU for 2 month period (Jun to July 2010) was conducted (Appendix 3). This was done to evaluate the impact of issuing letters about central contact details.

The second audit generated 105 enquiry episodes. It also showed that more enquiries were directed to the Key worker and with reduced enquiries directly to Clinical nurse, doctors and ward administrators.

See comparison results below.

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

Please present comparisons of base line vs. actual data where relevant

This table shows that following issue of contact letters, there is shift to more enquiries being directed to the Key worker and a simultaneous drop in enquiries to other groups. The Secretary group has shown a small increase because there were, at the time of the second audit, patients with serious life threatening problems whose enquiries were directed to a particular haematology secretary for urgent attention of one of the clinicians. The relatively short length of the second audit may also have contributed to this finding.

Enquiry episodes first received by:	Baseline data n = 365	Second audit following issue of contact letters n = 105
LTFU Administrator	43.8 %	61.9 %
Clinicians	13.4%	6.7 %
Nurse specialist	19.5 %	10.5 %
Secretary	16.7 %	20.0 %
Ward administrators	6.1 %	1.0 %

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

The need for funding a key worker to assist survivors' experience of living with and beyond cancer.

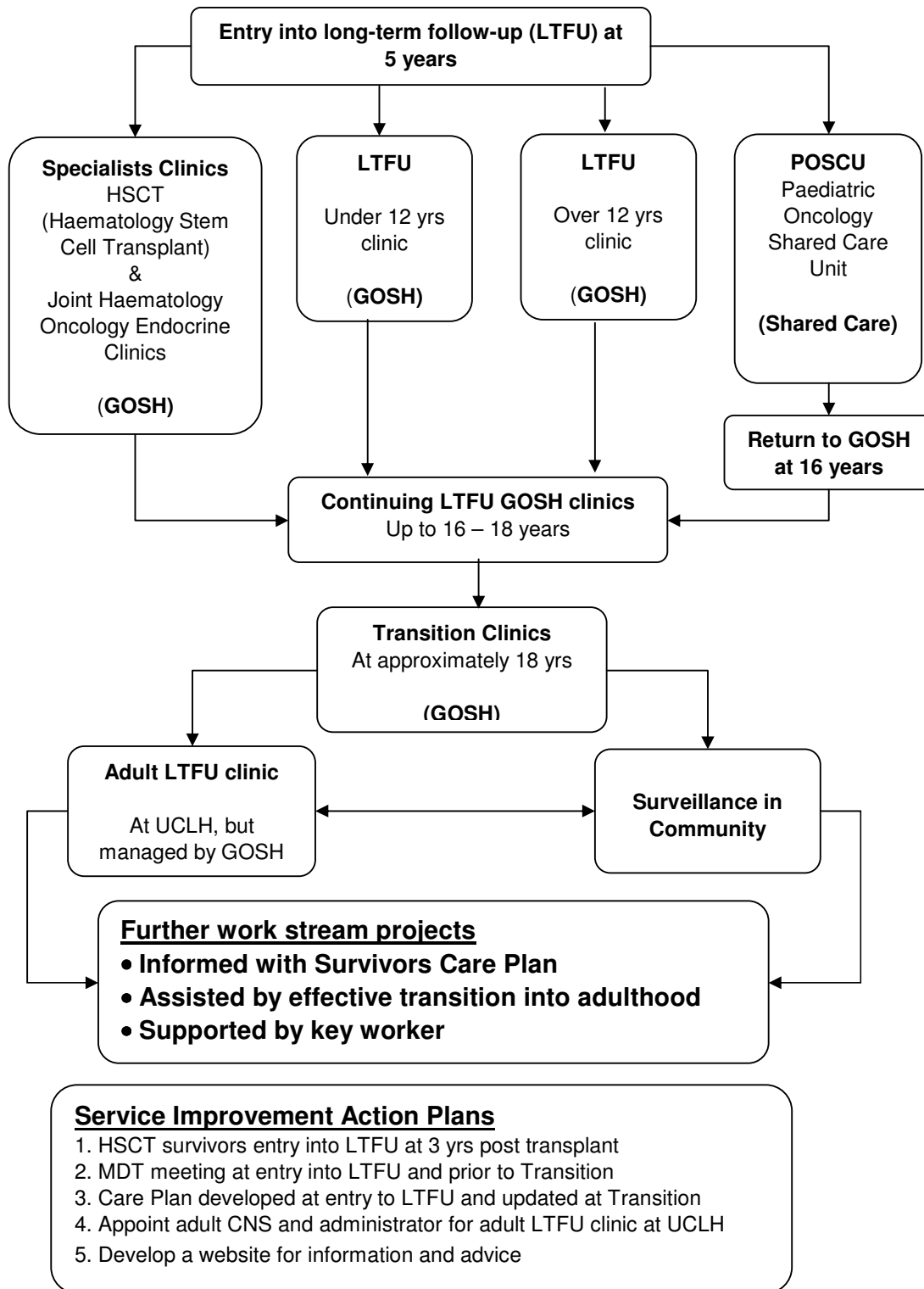
6. What are the challenges and positive elements of testing

What other considerations should someone planning to implement these proposals

be aware of?	
Are there any potential top tips or potential pitfalls?	<ol style="list-style-type: none"> 1. Firm arrangements for cover for absences of the Key worker. 2. Information on the Contact Card for 'out of hours' and emergency situations.
Please identify negative elements of the testing and implementation	In the testing phase, having to record an enquiry in the database may have been challenging for those not directly involved with LTFU. This may have contributed to under reporting of enquiries.
Give details of what worked really well throughout the life of the project	The database was quick to use for the LTFU team and collected large number of calls. It can be easily modified for future audits if required.
What are the plans for long term gains	Long term plans are to continue and improve upon accessibility to LTFU during office hours and ensuring all enquiries are directed to the Key Worker for accurate triaging to the correct personnel.

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	<p>Resources:</p> <ol style="list-style-type: none"> 1. Gibson F, Aslett H, Levitt G, Richardson A. Follow up after childhood cancer: A typology of young people's health care need. <i>Clinical Effectiveness in Nursing</i> (2005) 9, 133-146 – identified (i) need for positive relationship with HCPs; (ii) need for information; (iii) need for communication; (iv) need for parents to be supported; (v) need for HCPs to have appropriate knowledge. 2. NICE guideline publication 2005: Improving Outcomes in Children and Young People with Cancer. 3. George S, Bradbury H. More than my illness: Delivering quality care for children with cancer - <i>CLIC Sargent publication Nov. 2008</i>. Review to support the implementation of the NICE Improving Outcomes guidance. 4. National Cancer Survivorships Initiative, Vision Document – <i>DoH publication January 2005</i>. <p>Contact:</p> <p><u>Alison Leiper</u>: Associate Specialist in Haematology and Late Effects Cancer Treatment, Great Ormond Street Hospital, Leipea@gosh.nhs.uk</p> <p><u>Ramesh Modasia</u>: Service Improvement Facilitator, North London Cancer Network. Ramesh.modasia@uclh.nhs.uk</p>

**Great Ormond Street Hospital for Children NHS Trust
Cancer Survivors Long Term Follow Up Pathway**



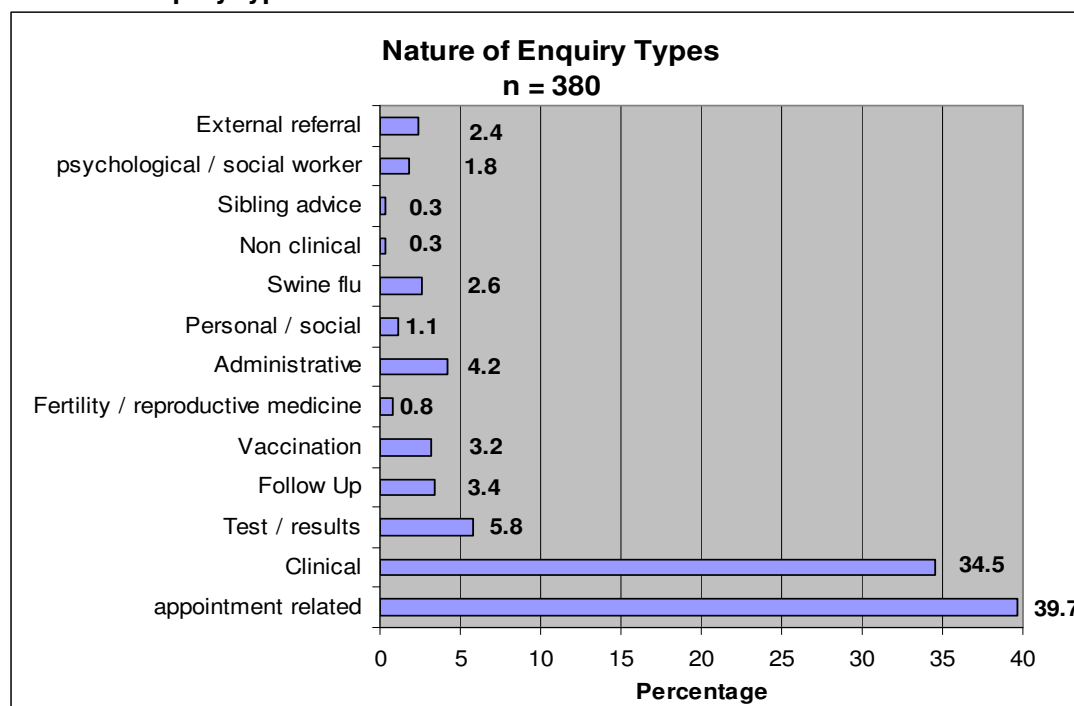
Analysis of the enquiries into LTFU during the period April to October 2009.

Table below summarises that there were:

- 516 entries made in the database, relating to 235 distinct patients.
- Entries were related to 365 separate enquiry episodes (or issues). Some episodes had more than 1 entry in the pathway of resolution of the issue.
- Some patients had more than 1 enquiry episode recorded during the audit period.
- Some episodes were related to more than 1 nature of enquiry.

Total calls recorded	Related to distinct patients	Enquiry episodes with 1 call	Enquiry episodes with 2 calls	Enquiry episodes with 3 calls	Enquiry episodes with 4 calls	Enquiry episodes with 5 calls	Total Enquiry Episodes
516	235	248	89	24	2	2	365

Nature of enquiry types



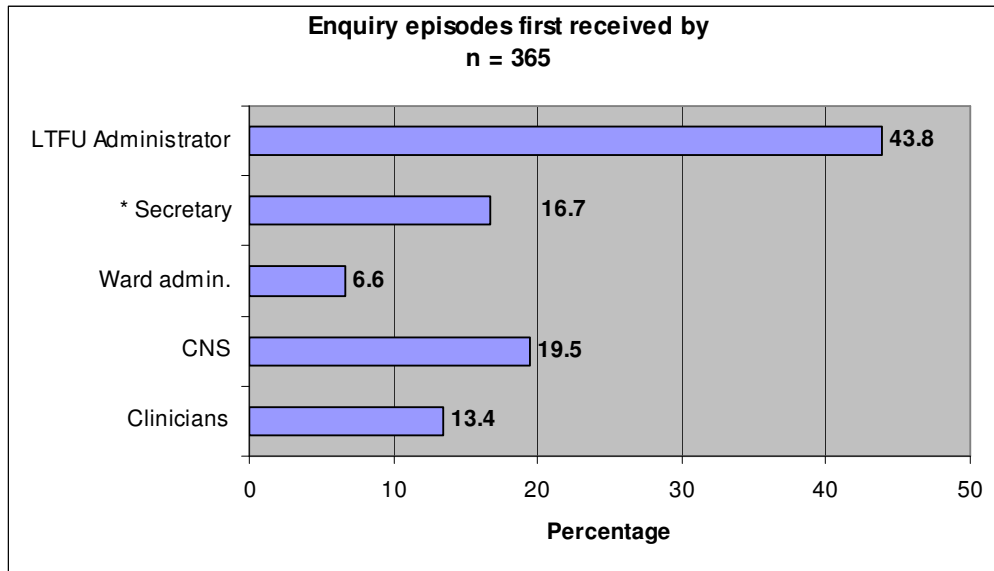
Approximately 40% of the enquiries are related to LTFU appointments, e.g. for changes or confirmations. These are most appropriately dealt by LTFU administrator. Whilst the administrator receives approximately 66% of these enquiries directly, another 34 % of them have to be redirected to the administrator by other recipients.

Appointment related enquiries received by	Clinician	CNS	Ward	Secretary *	LTFU admin.
Total 149	6	11	15	19	98
Percentage	4.0	7.4	10.1	12.8	65.8

* Secretary denotes other secretaries who provide support to clinicians but are not part of LTFU

First recipients of enquiry episodes

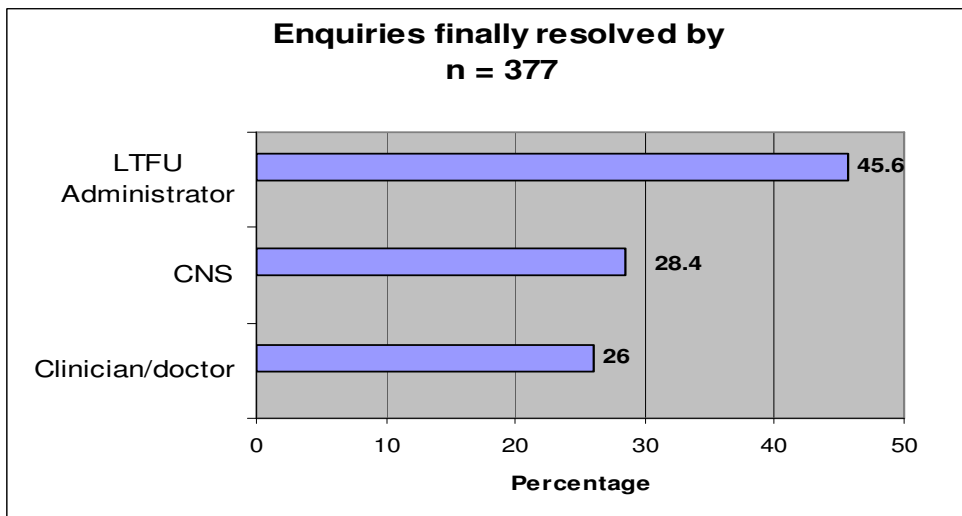
Chart below shows the percentage of enquiry episodes, as first received by various recipients. Secretaries and ward staff have to redirect the enquiries to the appropriate person, invariably via LTFU administrator.



* Secretary denotes other secretaries who provide support to clinicians but are not part of LTFU

Resolution of Enquiries

Analysis showed that LTFU administrator resolved nearly 46% of the enquiries. Others were dealt by either CNS or clinicians.

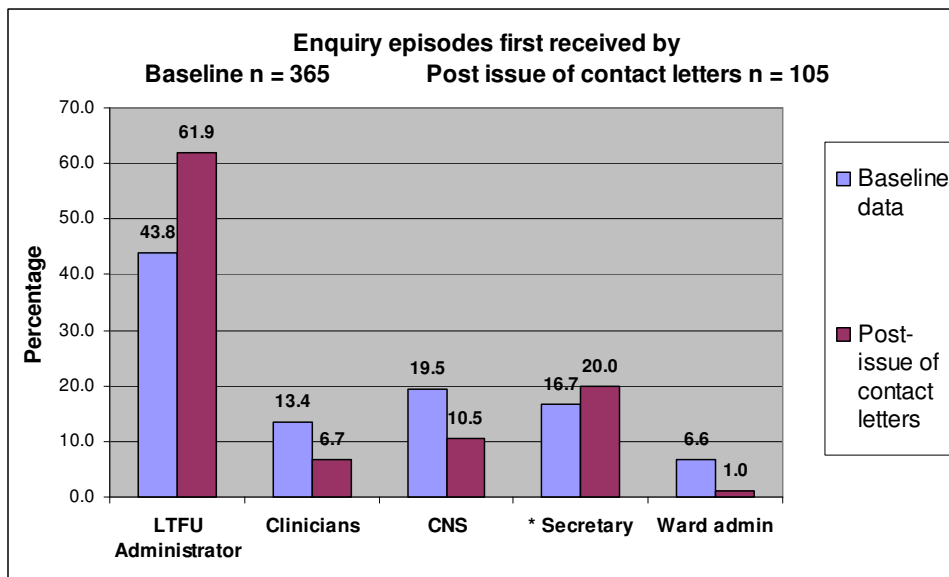


Audit of enquiries into LTFU during the period June to July 2010

Following issue letters informing central contact details to survivors and guardians a second audit of was conducted. 136 entries were recorded in the database comprising 105 enquiry episodes.

Audit: Jun - July 10	LTFU Administrator	Secretary *	Ward admin.	CNS	Clinicians	Total
Number	65	21	1	11	7	105
Percentage	61.9 %	20.0 %	1.0 %	10.5 %	6.7 %	100.0 %
Baseline audit data Percentage	43.8 %	16.7 %	6.6 %	19.5 %	13.4 %	100 %

* Secretary denotes other secretaries who provide support to clinicians but are not part of LTFU



These two sets of data are not subjected to statistical comparison.

1. Your details	
Name	Ramesh Modasia
Organisation	North London Cancer Network
Email	Ramesh.modasia@islingtonpct.nhs.uk
Contact Number	0207 685 6217
2. Details of your project Care Plan and Treatment Summary Record - Penultimate 2010	
Give a description of your project.	The project aimed to develop, test, implement and evaluate a Survivors Care Plan (treatment summary record and care plan) for cancer patients at Great Ormond Street Hospital (GOSH).
To what clinical area does your project relate?	The clinical area of the project is related to the long term Follow up (LTFU) care of non brain tumour survivors followed up at GOSH. This group of survivors are young people who have been treated for childhood cancer including those who have had a bone marrow transplant, but now are not on any active cancer treatment.
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	GOSH was one of the national test sites as part of the Children & Young People's (CYP) work stream of the National Cancer Survivor Initiative (NCSI) involving the 'living with and beyond cancer' pathway.
What type of change did your project aim to address (e.g. service redesign, new technology etc).	The main focus was on service design and improving communications, incorporating new technology, protocols and innovative ideas into clinical practice, for the benefit of the survivors and family.
What tangible change / tangible outcome have you achieved to date	<p>Apart from this Care Plan project, GOSH also led on two other projects, 1) Key Worker Role and 2) Transitional Care. The initial group exercise produced a baseline patient process pathway through the LTFU unit (Appendix 1).</p> <p>Outcomes that are achieved to date are:</p> <ol style="list-style-type: none"> 1. The format of Care Plan was developed in consultation with clinicians, survivors and other stakeholders (including Primary Care clinicians and cancer survivors). It was agreed that a Care Plan would provide core information about: <ul style="list-style-type: none"> • diagnosis • summary of treatment record • potential risks due to late effects of treatment • Follow up plan with on-going surveillance requirements. 2. A baseline evaluation using a questionnaire surveyed survivors and guardians about their LTFU experience and their views on the developed Care Plan (see Appendix 2). 3. Care Plans are now issued at entry to LTFU and at transition, both following MDT meetings which were instituted during the project. At the end of July 2010, 84 Care Plans had been issued and we are continuing with at least 15 new ones issued per month. 4. Following the issue of Care Plans (4 months later), survivors, GPs and parents & paediatric shared care clinicians (where appropriate) are being surveyed to evaluate the usefulness and acceptability of the Care Plan. This will form the evidence for comparison with the baseline.
What was the purpose of the change and what	It has been well documented ¹⁻³ that the needs of CYP cancer survivors are considerable and long standing over many decades.

improvement did it deliver?	<p>The main purpose of this project was to create and test a Care Plan and then implement its use into routine long term follow up care. The Care Plan is individualised summary of clinical record, which whilst satisfying information need, is designed to empower survivors and parents with a higher degree of self management and providing improved experience.</p> <p>Care Plans are now issued routinely at entry to the LTFU and at Transition clinic appointment. A copy of the Care Plan is also provided to the relevant GP and paediatric shared care unit where appropriate.</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>This work has addressed the culture shifts as described in the NCSI vision document⁴, namely:</p> <ol style="list-style-type: none"> 6. The focus on recovery, health and well-being after cancer treatment 7. Assessment, information provision and care planning 8. Supported self-management 9. A shift from a single model to tailored support of follow up care 10. Shift from measuring clinical activity to experience and outcomes for survivors <p>Within follow up after childhood cancer, a typology of young people's health care need¹ highlights the need for information as one of the main concerns. Care Plan provides the treatment information as a record and the risks due to late effects for the future.</p>

3. How you have implemented your project	
Please describe how your project proposals were implemented.	<p>The project implementation was phased as follows:</p> <ol style="list-style-type: none"> 6. Develop a Care Plan in conjunction with stakeholders and Christie Hospital, Manchester 7. Collect baseline evidence of patient/parent experience and views on the Care Plan. 8. Issuing Care Plans to survivors at GOSH and Christie hospital and at other volunteer hospitals. 9. Conduct and evaluate survey of the subjects, four months after they were issued with a Care Plan, to evaluate the benefits and any issues. This would include views of survivors, GPs, guardians and paediatric shared care clinicians (where appropriate).
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	<p>Preparing a Care Plan for a survivor is a time consuming exercise, which involves collating the data from patient notes and other reports of the clinical history. In addition explaining the Care Plans to the patients lengthens the clinic appointments. These should be factored as an additional resource demand.</p>
Were Equality issues identified and how were these addressed	<p>There were no Equality issues identified.</p>
Who were the champions or key stakeholders and how were they involved in the project?	<p>The project was guided by the Steering Group members composed of GOSH LTFU team which included a Consultant of Oncology and Late Effects, an Associate Specialist in Haematology and Late effects, a clinical nurse specialist and administrator. External members included survivors and guardians, shared care paediatricians and nurse</p>

	specialists and a community GP representative. Other members included NHS and local cancer network Improvement leads and facilitator and expert advice from GOSH Child Health Institute. GOSH core team were the champions and key drivers of this project.
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4.	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	Evidence collected through the project aligns with the QIPP parameters.
Quality including safety	Care Plans provide better patient experience through empowerment with information. It satisfies a need for information, which can be referred back to as and when required. Care Plans are provided to the appropriate GP for information and surveillance if necessary.
Innovation	The Care Plan is a new product introduced in routine practice, sharing clinical information with the patient and community physician. There are plans of accessing Care Plans on web based portal system, secured by password protection.
Productivity / cost or savings / effectiveness including the scale of the benefits.	So far 84 Care Plans have been issued to the survivors and at least 15 new ones are issued per month as part of routine clinical practice at GOSH. Care Plans enables a shift from clinic based LTFU care to self management of low risk stratified group. In future this will reduce the need to attend a primary treatment centre and provide LTFU care on alternatively.
Prevention	Care Plans may potentially enable a reduction in emergency admissions due to better distribution informed through Care Plan. Being better informed supports greater degree of self- management and survivors would be more aware of what signs and symptoms to look for related to late effects.

5. Other sources of evidence	
Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data	Baseline evaluation of the Care Plan (Appendix 2) indicated an overwhelming acceptance of the developed Care Plan, affirming it was a good idea and useful. Four months after the issue of the Care, a questionnaire survey is sent out to evaluate the views and usefulness of the Care Plan. Survivors, GPs, guardians and appropriate shared care clinicians are being surveyed. The survey will collate responses relating to GOSH, Christie Hospital and other participating sites. We are now waiting for the survey responses to be returned
Are there any other sources of evidence of how it could affect cost and quality? If yes please give details	Preparation of individual Care Plans is time consuming and delivery needs time to explain during clinic times. Other resource implications are that Care Plans need to be updated, depending on circumstances.
Please present comparisons of base line vs. actual data where relevant	Baseline data is available on Appendix 2. Actual (post introduction of the Care Plan) data awaited
Give an assessment of how your evidence will provide inform & influence service	Care Plan addresses the need of information provision and care planning for the CYP cancer survivors. Summary Care Records are now being made available in many areas of healthcare. Creating Care

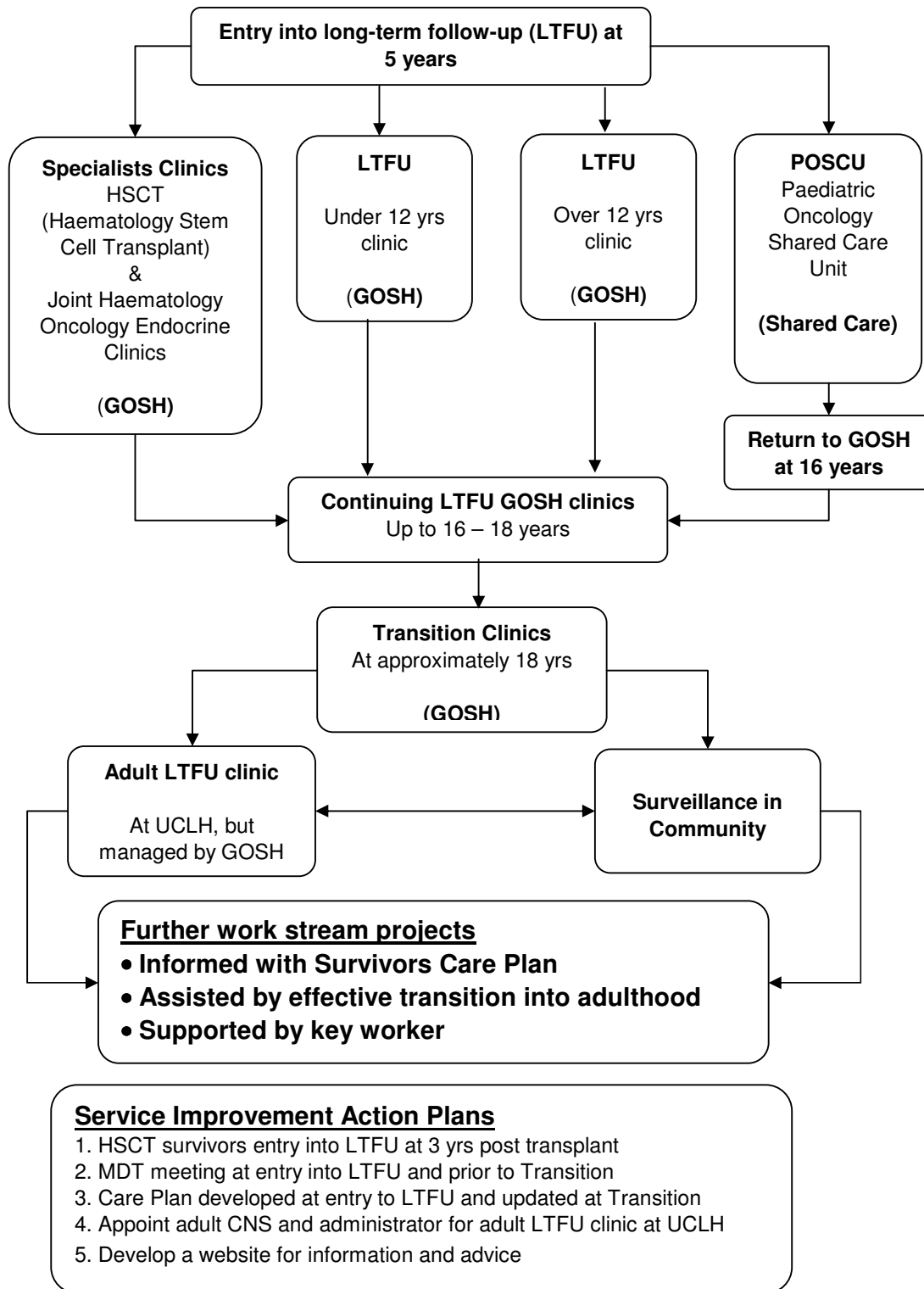
commissioners	Plans needs additional resources, especially at Principle Cancer Treatment Centres.
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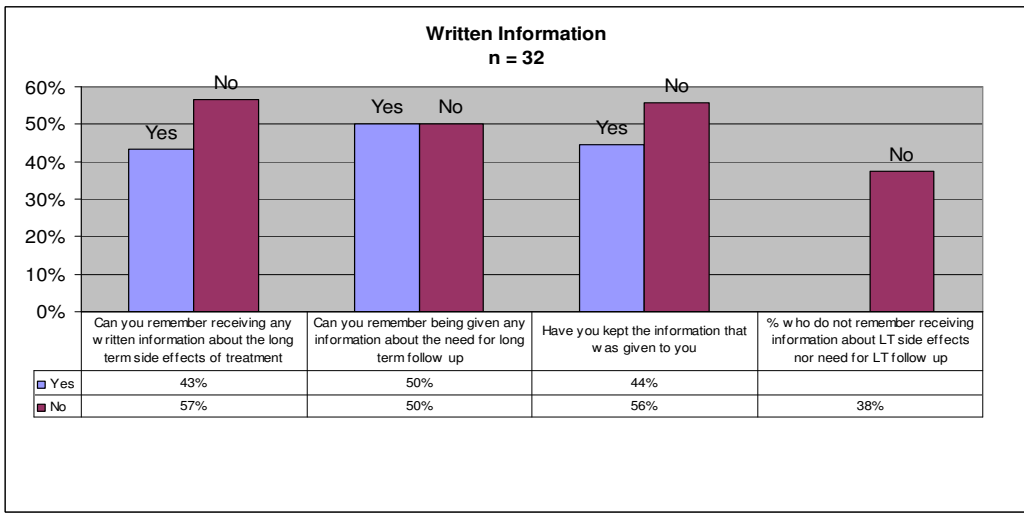
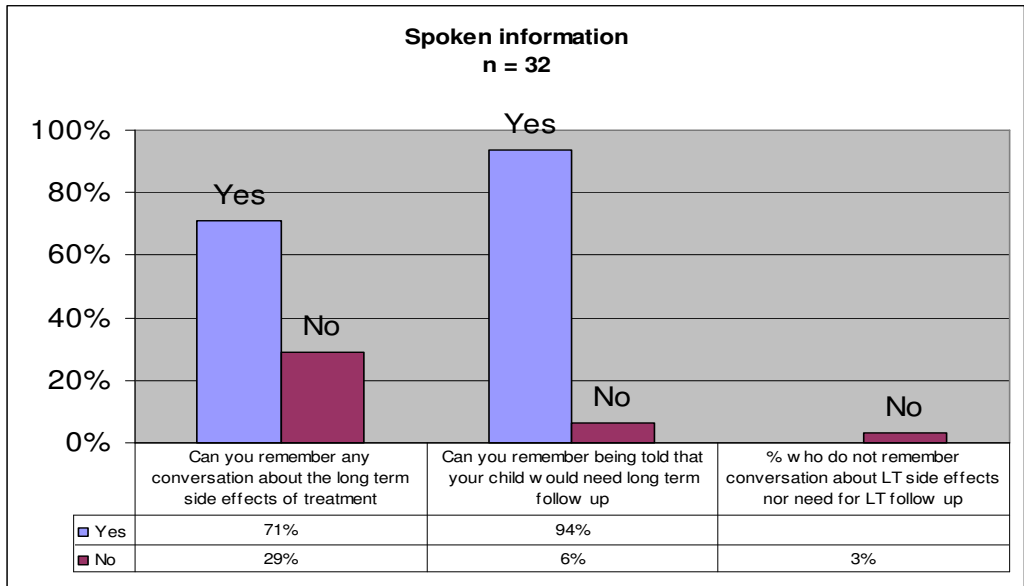
6.What are the challenges and positive elements of testing	
What other considerations should someone planning to implement these proposals be aware of?	Different templates of the Care Plans can be made to improve efficiency in completing the care plan. The more complex treatments will need additional modifications of the care plans (eg for bone marrow transplant survivors).
Are there any potential top tips or potential pitfalls?	It would be helpful to ask the treating clinicians to complete the treatment summary at the end of treatment to decrease the time spend filling in the summary retrospectively on entry to the LTFU service
Please identify negative elements of the testing and implementation	Questionnaire surveys do not always produce adequate returns and responses.
Give details of what worked really well throughout the life of the project	Survivors' and other stakeholders' contributions were very useful in defining the content of the Care Plan. From the outset, the usefulness of Care Plan was recognised. This also bridges the information gap between secondary and primary care.
What are the plans for long term gains	Long term plans are to continue to provide Care Plans at entry to LTFU and at Transition. New agenda is to try to get further resource for preparing Care Plans and delivering them.

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	<p>Resources:</p> <ol style="list-style-type: none"> Gibson F, Aslett H, Levitt G, Richardson A. Follow up after childhood cancer: A typology of young people's health care need. <i>Clinical Effectiveness in Nursing (2005) 9, 133-146</i> – identified (i) need for positive relationship with HCPs; (ii) need for information; (iii) need for communication; (iv) need for parents to be supported; (v) need for HCPs to have appropriate knowledge. NICE guideline publication 2005: Improving Outcomes in Children and Young People with Cancer. George S, Bradbury H. More than my illness: Delivering quality care for children with cancer - <i>CLIC Sargent publication Nov. 2008</i>. Review to support the implementation of the NICE Improving Outcomes guidance. National Cancer Survivorships Initiative, Vision Document – <i>DoH publication January 2005</i>. <p>Contact:</p> <p><u>Gill Levitt</u>: CYP National Clinical Lead, Paediatric Oncologist, Great Ormond Street Hospital, Levitg@gosh.nhs.uk. <u>Ramesh Modasia</u>: Service Improvement facilitator, North London Cancer Network. Ramesh.modasia@uclh.nhs.uk</p>

Appendix 1

**Great Ormond Street Hospital for Children NHS Trust
Cancer Survivors Long Term Follow Up Pathway**





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	Majority wanted in paper form or both (paper and electronic)	
When would be the best time to get this form	Most responded to the end of treatment and start of the long term follow up.	

1. Your details		
Name	Ramesh Modasia	Susan Mehta
Organisation	North London Cancer Network	Great Ormond Street Hospital
Email	Ramesh.modasia@islingtonpct.nhs.uk	mehtas@gosh.nhs.uk
Contact Number	0207 685 6217	0207 813 8127
2. Details of your project Nurse Led Transitional Care Final Report August 2010		
Give a description of your project.	The project aimed to define key features of a model for transitional care after treatment for childhood cancer. The service evaluation of the current nurse led transition clinic at Great Ormond Street Hospital (GOSH) aimed to identify whether young peoples needs were being met.	
To what clinical area does your project relate?	The project relates to the long-term follow up (LTFU) of childhood cancer survivors within the Haematology/Oncology unit at GOSH. Young people who have been treated for childhood cancer (not brain tumours) including those who received a bone marrow transplant, but are no longer on any active cancer treatment attend the long-term follow-up clinic. Young people attend the nurse led transition appointment in preparation for transfer to adult healthcare.	
Specify which part of the NCSI / Survivorship pathway does the change impact upon / improve	GOSH is one of the national test sites as part of Children & Young Peoples (CYP) National Cancer Survivor Initiative (NCSI) involving 'living with and beyond cancer' pathway.	
What type of change did your project aim to address (e.g. service redesign, new technology etc).	The main focus was on service redesign and improvement. Transitional care is being developed in other specialities where young adults have chronic conditions originating in childhood. Incorporating transitional care into long-term follow-up after childhood cancer addresses a previously unmet need.	
What tangible change / tangible outcome have you achieved to date	<p>Nurse led transitional care was one of three projects at GOSH. The project interlinked with the care plan project and the development of the key worker role. The project team produced a baseline patient pathway through the LTFU service and identified the most appropriate stage at which transition should take place (Appendix 1).</p> <p>GOSH started the nurse led transition clinic in 2008 based on the evidence from an unpublished literature review. A nominal group exercise incorporated the views of the transition project team, shared care specialists and young people who use the service and we were able to rank defining features of an effective transitional model of care (Appendix 2).</p> <p>A Questionnaire was developed (Appendix 3) based on the findings in appendix 2 and the literature review. The questionnaire aimed to evaluate the effectiveness of transition, measure patient satisfaction with the service, and measure the effectiveness of the way information is delivered. The draft questionnaire was tested by young people and redesigned according to the findings (Appendix 3). Outcomes achieved to date are:</p> <ul style="list-style-type: none"> • The transition clinic incorporates the features of transitional care as defined by 	

	<p>the stakeholders although psychological support is lacking.</p> <ul style="list-style-type: none"> • Young people found the transition experience informative and satisfactory. The majority of them were able to describe their diagnosis and treatment accurately afterwards. They appreciated being able ask questions and were satisfied with the answers the nurse provided (appendix 4). • Combined face-to-face discussions with written information were most valued (appendix 4). • The survey identified the need to improve information about the transition clinic and contact information for long-term follow-up. A fact sheet about transitional care was developed and will be sent out with each appointment. A LTFU contact card and GOSH LTFU website has been developed.
<p>What was the purpose of the change and what improvement did it deliver?</p>	<p>It has been well documented that the needs of CYP cancer survivors are considerable and long standing¹⁻³. Transition aims to address young peoples' need for healthcare information and support at a critical stage in their development as they move from paediatric to adult healthcare. There is documented evidence that transitional care is necessary for young adults with chronic disease originating in childhood and it should be applied to CYP cancer survivors⁴⁻⁷</p> <p>At transition, survivors are offered information about their past treatment, individual risk for developing late side effects, long term surveillance needs and advice on healthy lifestyle choices. The difference between adult and paediatric healthcare is discussed and young people are informed about who to contact if they have any health concerns relating to past treatment. Young people are able to discuss their concerns in confidence and are encouraged to attend the appointment on their own. Good information aims to empower young people to manage their own health care independently and effectively.</p> <p>To date about 120 survivors have attended a nurse led transition clinic. The feedback from the questionnaire survey supports the value of transitional care. Young people are provided with appropriate written and verbal information about previous treatment, risk for developing problems and living a healthy lifestyle. This should enable them to take responsibility and self manage their own health care in the long term.</p>
<p>Did the proposed changes contribute to the achievement of any agreed standards or the delivery of any guidance? If yes please give details and reference where possible.</p>	<p>The majority of survivors who have had a transition appointment are satisfied with preparation for transfer to adult health care and with the information provided. The new survivor care plan incorporating a treatment summary is a recent addition to the information provided.</p> <p>The changes have addressed some of the culture shifts as described in the NCSI vision document, namely ⁸:</p> <ol style="list-style-type: none"> 11. The focus on recovery, health and well-being after cancer treatment 12. Assessment, information provision and care planning 13. Supported self-management 14. A shift from a single model to tailored support of follow up care 15. A shift from measuring clinical activity to experience and outcomes for survivors <p>GOSH ensures that transition is an integral part of LTFU and can be regarded as a process rather than a final clinic appointment before transfer to adult healthcare.</p>

3. How you have implemented your project	
Please describe how your project proposals were implemented.	<p>Following review of the LTFU patient pathway (Appendix 1), improvement action plans were identified along with three main work streams. Evaluation and improvement of transitional care was identified as one of the projects.</p> <p>The project was phased as follows:</p> <p>10. Define the features of an effective transition model of care.</p> <p>11. Develop a questionnaire to evaluate the effectiveness of the current transition clinic and measure patient satisfaction.</p> <p>12. Initiate the survey, analyse the results of the questionnaire and draw conclusions.</p>
Give details of any additional costs or resource demands that arose, including staffing or new equipment.	<p>At GOSH the clinical nurse specialist (CNS) has taken on the responsibility of developing and running the transition clinics. 8 young people attend 3 clinics a month and each appointment is scheduled to take 45 minutes. All patients are discussed at a multi disciplinary clinic before their appointment. The clinics are now fully booked 2 years in advance due to the demand for transitional care. From November 2009, the new care plan and treatment summary was introduced to young people attending transition clinics and new patients to the long-term follow up service. Care plans are prepared by the CNS and have increased the workload considerably. This has been identified as an additional resource demand. 20 to 25 care plans have to be prepared each month for transition and new patients to long-term follow-up.</p>
Were Equality issues identified and how were these addressed	<p>There were no Equality issues raised. Timing of transition is flexible dependent on individual circumstances of the survivor. Interpreters are used as necessary</p>
Who were the champions or key stakeholders and how were they involved in the project?	<p>The project was guided by Steering Group members comprised of GOSH LTFU team which included a Consultant of Oncology and Late Effects, an Associate Specialist in Haematology and Late Effects, a clinical nurse specialist in late effects and LTFU administrator. External members included survivors and guardians, shared care paediatricians and nurse specialists and a community GP representative. The steering group was supported by North London Cancer network improvement leads. GOSH core team were the champions and key drivers of this project and received valuable advice from Faith Gibson, Professor of Cancer Nursing.</p>

4.	
Quality, Innovation, Productivity & prevention – demonstrate how your project / evidence fits with the QIPP agenda	<p>Evidence collected through the project aligns with the QIPP parameters.</p>
Quality including safety	<p>Transition is able to provide an improved patient experience by preparing young people for a new phase in their survivorship journey as they leave paediatric care and move to adult health care.</p>

	Transition encourages and enables a degree of self-management, yet provides a safe loop of return to LTFU if the need arises.
Innovation	Transitional care is a LTFU service that can be delivered by specialist nurses with expertise in late effects. Transition provides a new value adding intervention in the survivor's journey, living with and beyond cancer. A timely information resource is made available directly to young people, leading to empowerment, and facilitating self-management. Effective transition could lead to long-term follow-up continuing with GP's for young people at low risk for developing late effects.
Productivity / cost or savings / effectiveness including the scale of the benefits.	Since the introduction of nurse led Transition clinic approximately 120 survivors have been transitioned from paediatric to adult health care.
Prevention	<ul style="list-style-type: none"> • Healthy lifestyle is promoted at the transition clinic and some young people have adopted a healthier lifestyle after their transition appointment and over 80% remember discussing healthy lifestyle (appendix 4). • After transitional care 75% of young people understand their treatment and risks for developing late effects. This should enable them to seek timely interventions if they develop problems. • Transitional care and the provision of a long-term follow-up care plan should enable young people to make their own appointments and avoid being lost to long-term follow-up, but it is too early to measure this (appendix 4).

5. Other sources of evidence																													
<p>Have any evaluations of the effects of this change been undertaken? If yes please give details. Please include evidence of qualitative and quantitative data</p>	<p>A questionnaire survey was developed to evaluate the survivors experience of the current Transition clinic provided at GOSH. Seventy questionnaires were sent out to young people who have attended the clinic and a further twelve were contacted via telephone survey. Survey returns are summarised below:</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <thead> <tr> <th style="background-color: #D3D3D3;">SURVEY RESULTS</th> <th style="background-color: #D3D3D3;">POSTAL SURVEY</th> <th style="background-color: #D3D3D3;">TELEPHONE SURVEY</th> <th style="background-color: #D3D3D3;">TOTAL</th> </tr> </thead> <tbody> <tr> <td style="background-color: #D3D3D3;">Sent out / Called</td> <td>70</td> <td>12</td> <td>82</td> </tr> <tr> <td style="background-color: #D3D3D3;">Responses returned</td> <td>38</td> <td>12</td> <td>50</td> </tr> <tr> <td style="background-color: #D3D3D3;">Void responses</td> <td>3</td> <td></td> <td>3</td> </tr> <tr> <td style="background-color: #D3D3D3;">Returned blank / Opted out</td> <td>4</td> <td>2</td> <td>6</td> </tr> <tr> <td colspan="4" style="background-color: #ADD8E6; text-align: center;">% Opt out 6/82 = 7.3%</td> </tr> <tr> <td colspan="4" style="background-color: #ADD8E6; text-align: center;">% Responses including opt out 50/82 = 61%</td> </tr> </tbody> </table> <p>Data was obtained from 31 questionnaires. Questionnaires were returned blank from 4 respondents while 3 respondents did not relate to the transition clinic. There were 12 successful contacts by telephone and 10 agreed to complete the questionnaire verbally.</p> <p>Responses to the questions are graphically displayed in Appendix 4.</p> <p>A thematic evaluation from the comments is summarised below:</p>	SURVEY RESULTS	POSTAL SURVEY	TELEPHONE SURVEY	TOTAL	Sent out / Called	70	12	82	Responses returned	38	12	50	Void responses	3		3	Returned blank / Opted out	4	2	6	% Opt out 6/82 = 7.3%				% Responses including opt out 50/82 = 61%			
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Young people views about the timing and preparation for transfer to adult services

Less than 8% of the respondents expressed concern about moving into a new clinical environment following transition and the comments suggested these were mainly for sentimental reasons.

"Have felt safe knowing I was going to GOS every few years it gave me reassurance"

"GOS was a comfort zone so moving away was unnerving but necessary"

Nearly 87% agreed that 16 -18 yrs was the right time for transition and the majority of the respondents had transition between the ages of 17 to 20.

"I have attended a children's hospital for 12 yrs so now perhaps an adult hospital. I will benefit now I am becoming an adult"

"I feel it should have been arranged when I was much younger although I understand it is a new system"

Taking Responsibility

The majority of survivors (66%) travelled to the hospital with a parent or guardian but 73 % saw the specialist nurse in the transition appointment on their own. About 1/3rd prefer to be seen alone, 1/3rd with parents and 1/3rd did not mind.

"I would prefer my parents with me to listen to what is said in case I don't understand"

"Its not nice talking about your private life in front of your parents"

"I felt more relaxed on my own"

Although most young people travelled to the clinic with a parent or guardian they were all encouraged to attend the appointment on their own.

1/3rd of young people prefer to attend with parents and therefore there is now a more flexible approach. Responses to questions about fertility suggest they can discuss personal issues more comfortably without their parents or guardians present.

More than half (60 %) did not know how to contact LTFU, relying on parental support. This has prompted the design of a LTFU contact card for distribution to the survivors. The card will contain contact details for LTFU. A LTFU website has also been developed. A LTFU fact sheet about transition has been developed and will be sent out before each transition appointment.

Communication

About 78% found it easy to talk to the nurse at the transition clinic. The comments generally illustrated a sense of empathy.

" I have always felt able to ask the clinical nurse about any aspect of my post treatment life and she has always been incredibly helpful"

"Friendly and informative"

"They always show they care. It tends to put the mind at ease and make it a lot easier to talk".

About 75% were satisfied with the discussion and no one stated that they were not satisfied. The majority of comments stated that they found the information detailed, informative, knowledgeable, and thorough and they were able to ask questions.

"Everything was spoken about in detail"

"I learned a lot about my illness and how it affected my family"

"It was thorough and addressed all the issues I had"

About 70% found the transition appointment helpful, but 5% of young people did not

"She expained everything in detail so I knew what to expect when I went to the adult clinic"

"I felt confident before the transition meeting"

About 76% of the respondents were confident about making follow-up appointments in adult services but 7% were not.

" I still need my parents when it comes to appointments because I need the security of them there with me. My illness affected my parents too".

"I am 19 now and mature enough to organise my life".

Information

About 75% of the young people felt they understood the information about their cancer treatment and late effects and a few young people did not understand

"Understand about treatment but not late effects. Quite complicated"

"Not really aware of long-term implications/effects.

Information about treatment and late effects is complex and young people may need a further transition appointment as they reach young adulthood.

About 85% of young people felt comfortable asking questions at the transition clinic appointment and were satisfied that all their questions were answered.

Only 17% of young people thought they knew everything about their past treatment and risk for developing late effects already. 52% agreed that the transition appointment had helped them to fully understand and 30% agreed that the transition appointment had helped them understand a bit.

The comments were variable

"Helped to understand but didn't know anything before the appointment"

My parents talk through everything as I get older"

61% of young people wanted to discuss fertility and 38% did not. The comments suggest that the responses may have been dependent on whether parents were in attendance.

"I am in a relationship with my girlfriend and would have liked to discuss this" (attended with parents)

"Yes I think so but was embarrassed at the time. I was not worried then" (chose to attend with parents).

When asked if the written treatment summary was easy to understand 77% stated that the information was very clear and 23% stated that it was a bit clear. No one stated that it was unclear.

The comments were varied

"Found the information mostly obvious. Some information was relevant"

"It was nice to have something written down to remember"

"Too many technical words on the document"

61% described a face to face discussion combined with a written summary as the most useful way of receiving information. Only 5% would have preferred to only receive written information and 35% would have preferred to only have a face to face discussion. The face to face contact seems to be the most important way to deliver information.

"Good to have it written down but was very good to have to have someone explain what all the long medical words meant"

"face to face discussion and written information equally important"

66% of the young people had never used the written information for other appointments, but 7% had. Comments suggest that this is because no other appointments have been attended since the transition appointment.

	<p><i>"Fortunately I have not had to go to any other hospitals yet"</i> <i>"All sorts doctors, dentists, hospitals"</i></p> <p><u>Lifestyle information</u></p> <p>The importance of a healthy lifestyle may have been discussed at the appointment and the survey aimed to reveal whether the discussion was remembered. We were also interested to know if the discussion had lead to any healthy lifestyle changes.</p> <p>About 85% of the young people remembered discussing smoking, eating healthily and the importance of exercise and keeping fit.</p> <p>1. Smoking A number of young people stated that they <i>"do not smoke"</i>, but one says <i>"I did smoke but stopped after the appointment"</i></p> <p>2. Eating healthily Some young people commented that they were eating more healthily after the appointment <i>"limited sweets and biscuits"</i> <i>"trying to eat more healthily and reduce alcohol intake"</i></p> <p>3. Exercise and keeping fit Of the comments 6 already undertook exercise but had increased it since the appointment. <i>"joined the local gym" "walking a lot more"</i> <i>Already changed my lifestyle but walking more often"</i> A 22 year old commented that it was <i>"Patronising. Know how to eat healthily and exercise properly"</i>.</p> <p><u>Finally</u></p> <p>The survey questioned whether the transition appointment was useful or not. 82% found the transition clinic appointment useful and of those 63.2% found it very useful.</p> <p>Of the 15 comments 12 were very positive. <i>"I found it very useful to have a face to face discussion as it meant I could find out more about my treatment and how it could affect me in the future. Susan was very good at answering my questions and easy to talk to. The information I took away with me also helped as I can use it for reference when I need to"</i> <i>"Your hospital has been fantastic to me as I have grown up each appointment has supported me and my family. These follow-up appointments are really reassuring for me as I grow up and want questions answered. Thank you to everyone who has ever helped me"</i> <i>"Everything was very useful the information sheets, questions and answers, healthcare. It also didn't take too long so it was fine overall"</i> <i>"I liked the fact that I had a chat with the nurse on my own and then invited my mum in. It helped me to understand things myself and also know it affected my mum and family"</i> <i>"I understand that I need a blood pressure check every year and urine check from my GP"</i>.</p> <p>Only 2.7% did not find it useful. <i>"I found the information boring and fairly pointless. I was given a card summarising my medical history which I thought would be useful at the time but I haven't used it since"</i> <i>It was good to get the written information but it could have been explained more fully what it was about and what the next step was"</i> <i>"A necessary end to my treatment at GOS but much of what was covered had been discussed in the LTFU clinic"</i>.</p>
<p>Are there any other sources of evidence of</p>	

how it could affect cost and quality? If yes please give details	
Please present comparisons of base line vs. actual data where relevant	
Give an assessment of how your evidence will provide inform & influence service commissioners	<p>Transitional care is considered important for all young people who have a chronic condition originating in childhood. On this evidence a nurse led transition clinic was developed but there was no robust evidence for transitional care for this patient group.</p> <p>This is a small scale, single centre, audit of nurse led transitional care for young people who have survived childhood cancer. The questionnaire survey provides evidence that young people valued the appointment and were satisfied with the expertise of the clinical nurse specialist who saw them. They preferred a face to face discussion about their treatment and risk for developing late effects and wanted this supported with written information. Healthy life style advice does lead to a change in lifestyle and young people reported that they made changes after the appointment.</p>

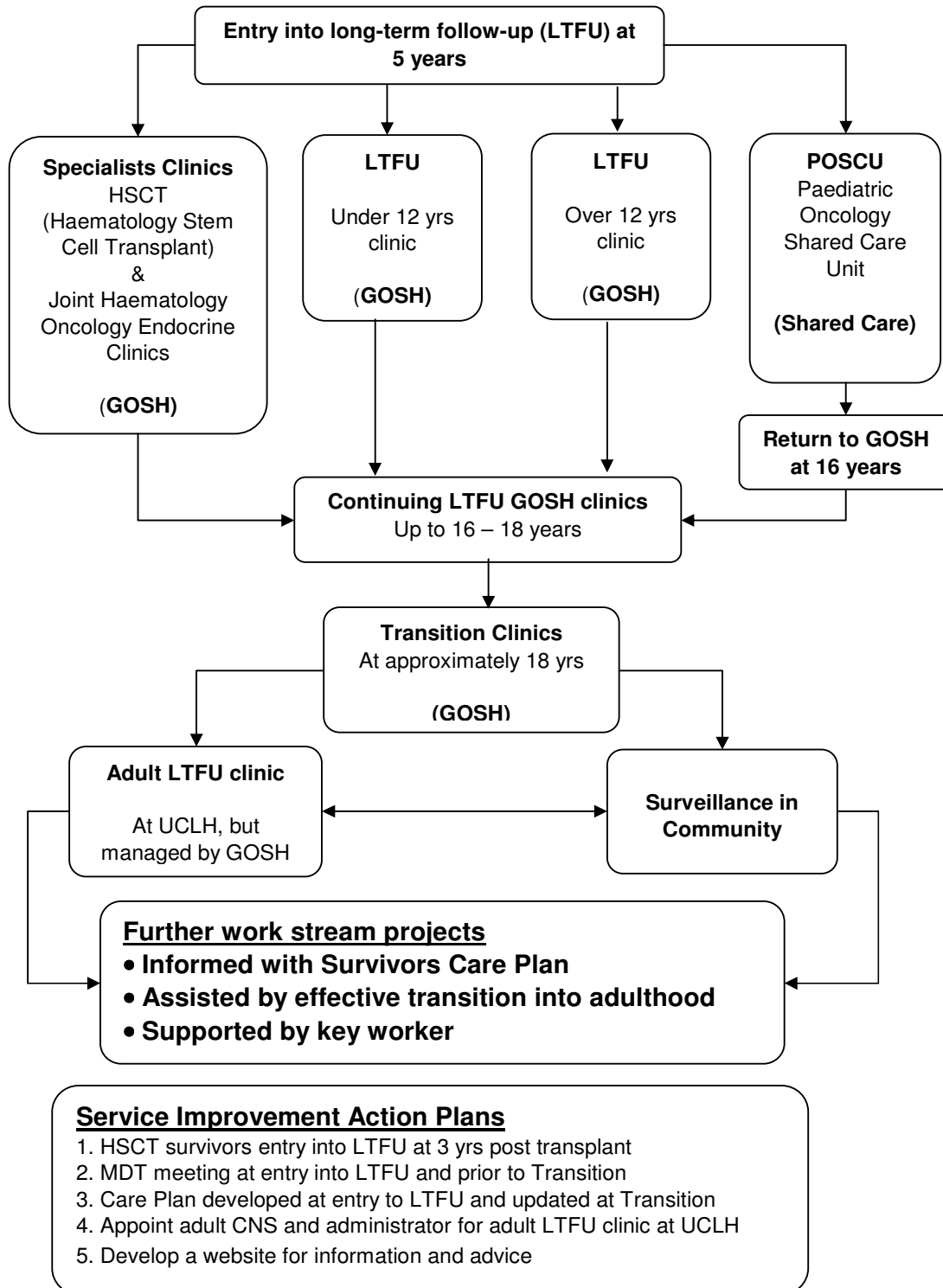
6.What are the challenges and positive elements of testing	
What other considerations should someone planning to implement these proposals be aware of?	The nurse led transition clinic has a resource implication because it takes time to prepare treatment summaries and care plans before the clinic. Each appointment can take up to an hour, allowing for young people to discuss concerns. Each patient is discussed at a multidisciplinary team meeting prior to the appointment, when future long-term follow-up and surveillance is planned. The transition experience was evaluated well by young people. This confirms that young people are satisfied with the service provided by nursing. Young people need to feel confident that their questions will be answered by an experienced clinician and nurses wanting to develop transitional care need to ensure they have the appropriate training and level of specialist knowledge.
Are there any potential top tips or potential pitfalls?	Transition has to be planned for and the appointment should be booked and prepared for in advance. A specific clinic is booked with a maximum number of patients to ensure the workload is manageable. Experienced and appropriately trained nurses are ideally placed to provide transitional care but need to have expertise in late effects of childhood cancer.
Please identify negative elements of the testing and implementation	The questionnaire survey took time to develop, send out and analyse. GOSH was well supported by the LTFU administrator and The North London cancer Network but without this support the project would not have been possible.
Give details of what worked really well throughout the life of the project	We had an active steering group and it was very important to have survivors, parents, members of the LTFU team and Ramesh Modasia from The North London Cancer Network all working together. Eleanor Tyrrell provided CNS support and without her contribution this audit could not have been completed. Eleanor conducted the telephone questionnaires and worked on the treatment summaries and care plans for both this project and the care plan project. Rebecca Yates the LTFU administrator provided invaluable support and formatted the questionnaire and final report and administered the questionnaire survey.

	Team work was most important.
What are the plans for long term gains	Transitional care will continue to be offered to young people in preparation for transfer to adult health care. We are confident that the service we are offering is valued by most of those invited to attend. We have already made some improvements in delivery of the care. We have developed better information and the care plan and treatment summary is now provided to all young people attending the transition clinic. We have developed a website and a patient information leaflet about transition. A contact card has been developed by a member of the steering group. We need to analyse the data from the survey in more depth and consider further improvements to the service according to the data.

7. Relevant contacts or resources	
Please give details of any contacts or resources that could help someone to implement your proposals.	<p><u>Resources:</u></p> <ol style="list-style-type: none"> 9. Gibson F, Aslett H, Levitt G, Richardson A. Follow up after childhood cancer: A typology of young people's health care need. <i>Clinical Effectiveness in Nursing</i> (2005) 9, 133-146 – identified (i) need for positive relationship with HCPs; (ii) need for information; (iii) need for communication; (iv) need for parents to be supported; (v) need for HCPs to have appropriate knowledge. 10. NICE guideline publication 2005: Improving Outcomes in Children and Young People with Cancer. 11. George S, Bradbury H. More than my illness: Delivering quality care for children with cancer - <i>CLIC Sargent publication Nov. 2008</i>. Review to support the implementation of the NICE Improving Outcomes guidance. 12. DoH (2006) Transition: getting it right for young people: improving the transition of young 13. DoH (2008) Transition: moving on well (<i>Gateway reference 8651</i>) 14. Royal College of Nursing (2004) <i>Adolescent transition care: guidance for nursing staff</i>. London: RCN people with long term conditions (<i>Gateway reference 5914</i>) 15. Royal College of Nursing (2008) <i>Lost in transition</i>. London: RCN 16. National Cancer Survivorships Initiative, Vision Document – <i>DoH publication January 2005</i>. <p><u>Contact:</u> <u>Susan Mehta</u>: Clinical Nurse Specialist, Long term Follow up unit, Great Ormond Street Hospital. mehtas@gosh.nhs.uk</p> <p><u>Ramesh Modasia</u>: Service Improvement facilitator, North London Cancer Network. Ramesh.modasia@uclh.nhs.uk</p>

Appendix 1

**Great Ormond Street Hospital for Children NHS Trust
Cancer Survivors Long Term Follow Up Pathway**



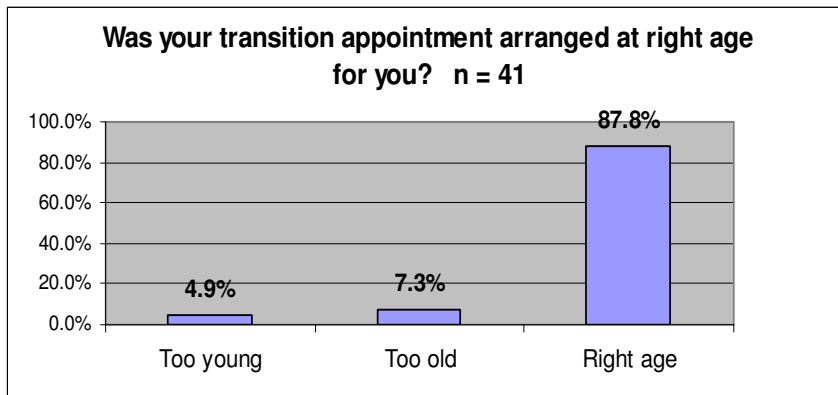
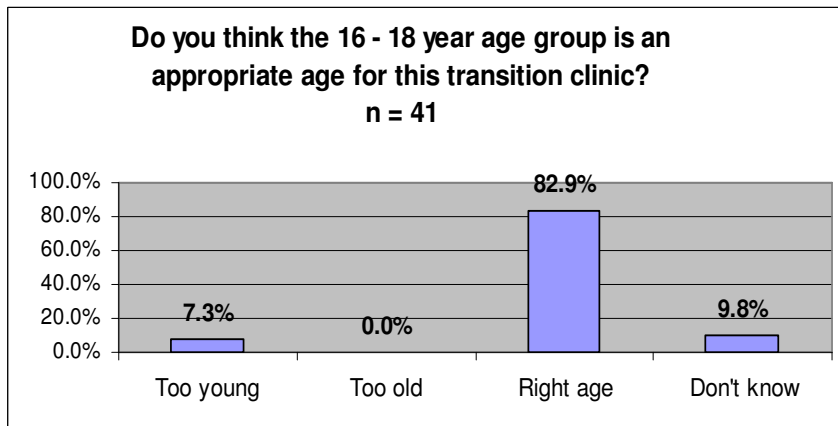
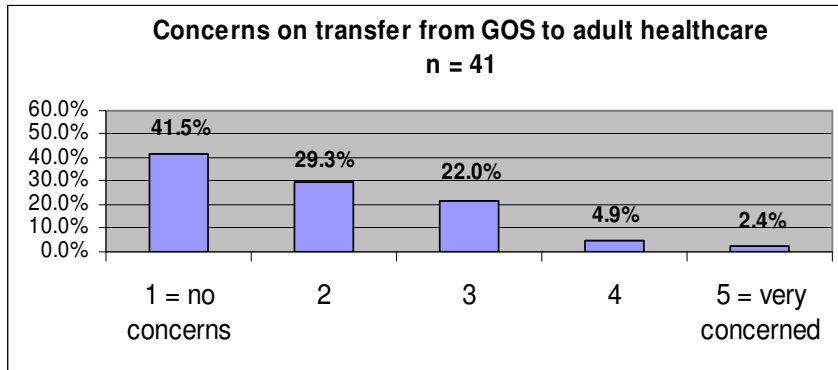
Appendix 2

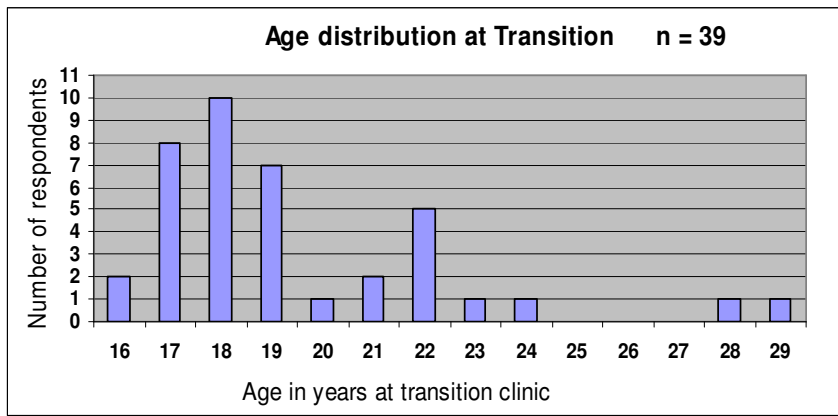
Features of an effective model of transition care
Independent and Safe Environment: - Minimal parental input at this stage; Comfortable "safe" environment for YP - able to be seen alone (without family) and by one health care provider; YP to attend independently so that discussion is directed at them - 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 & 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 YP; Text / e-mail appointment reminders; promote importance to YP 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 YP & 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

Appendix 4

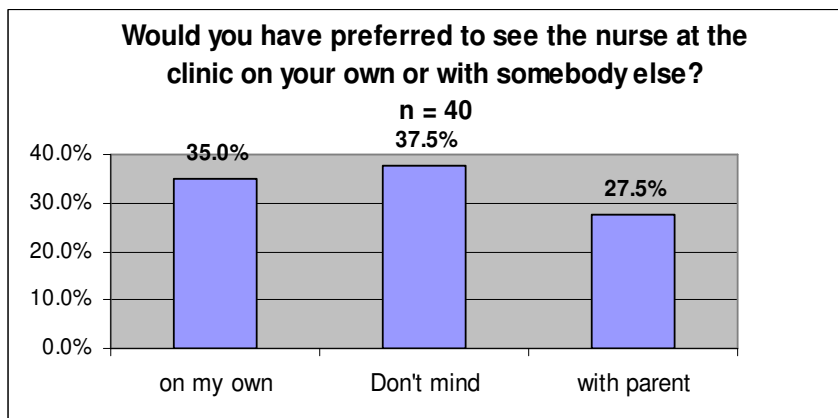
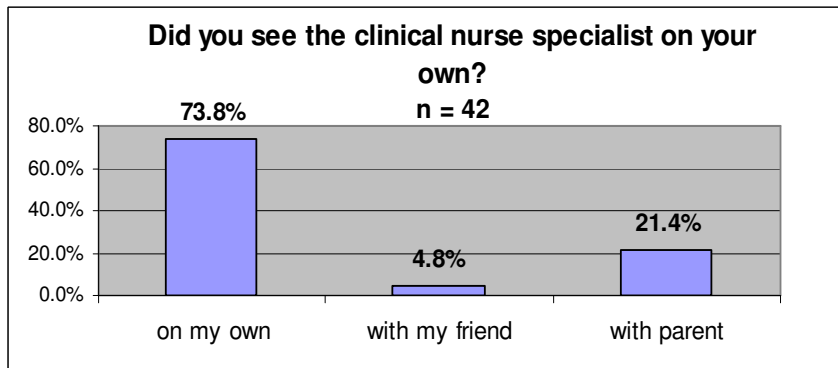
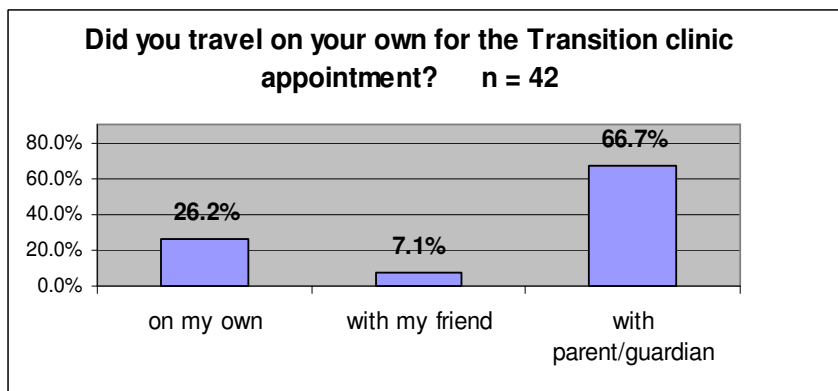
Questionnaire Survey Results

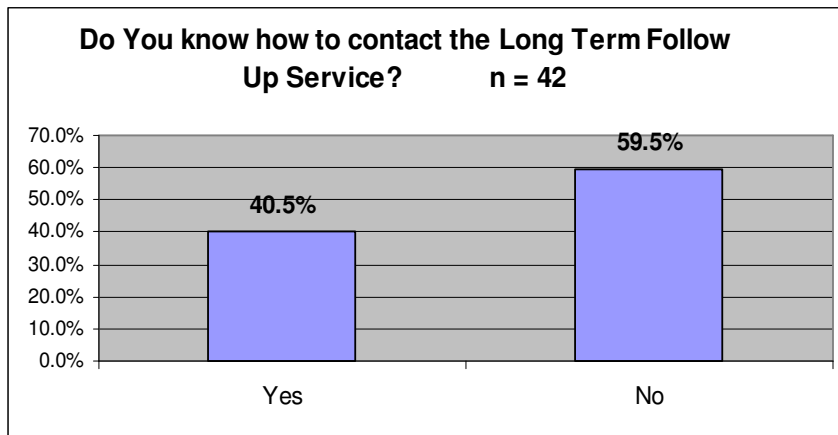
Young peoples views about the timing and preparation for transfer to adult services



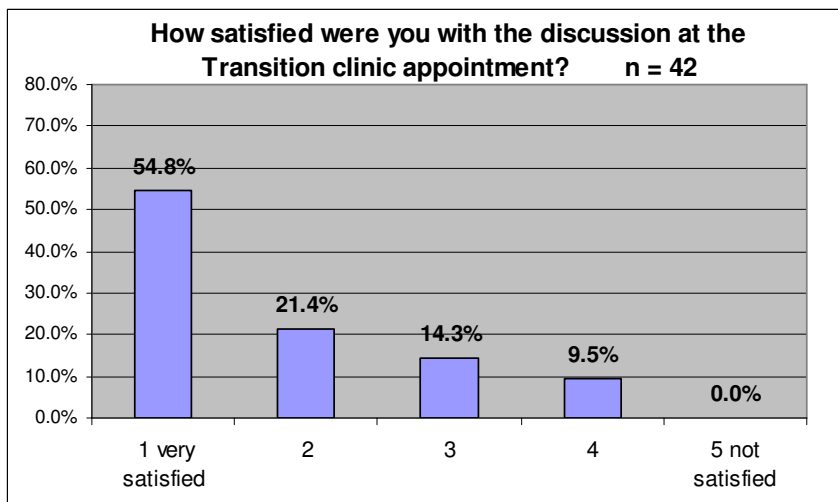
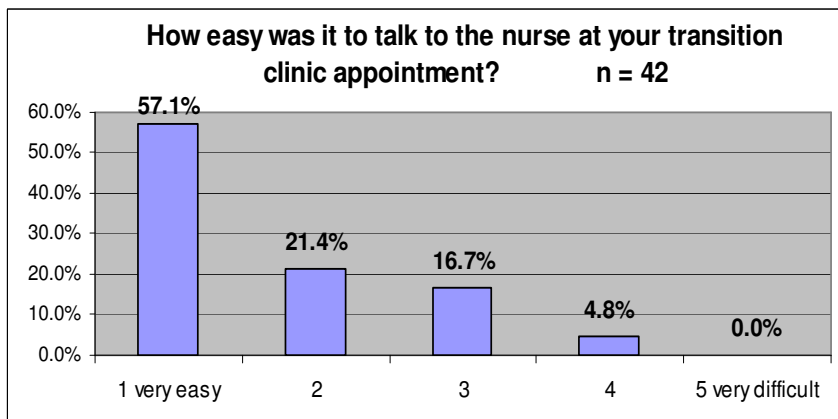


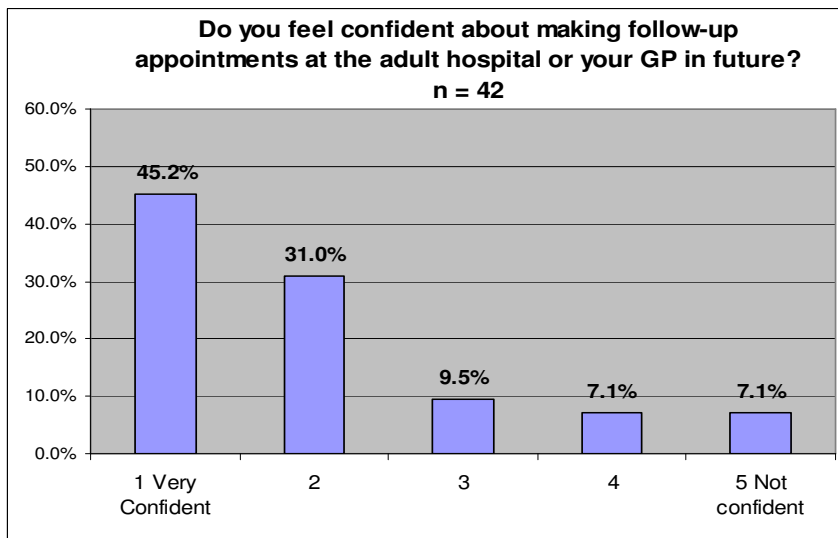
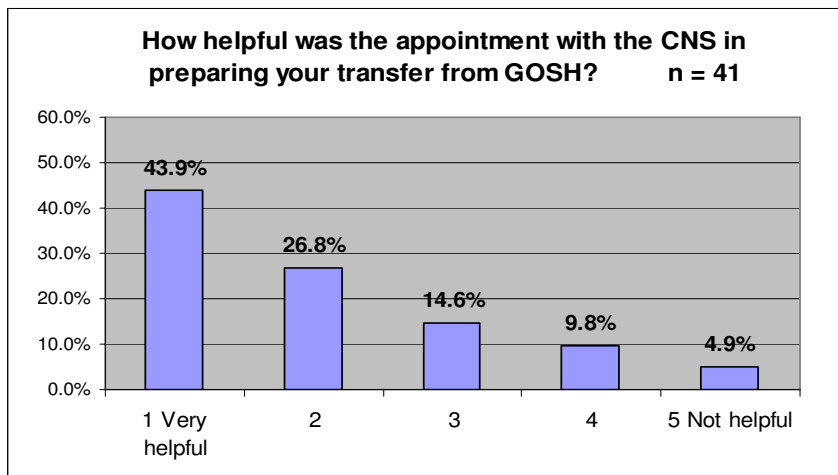
Taking Responsibility



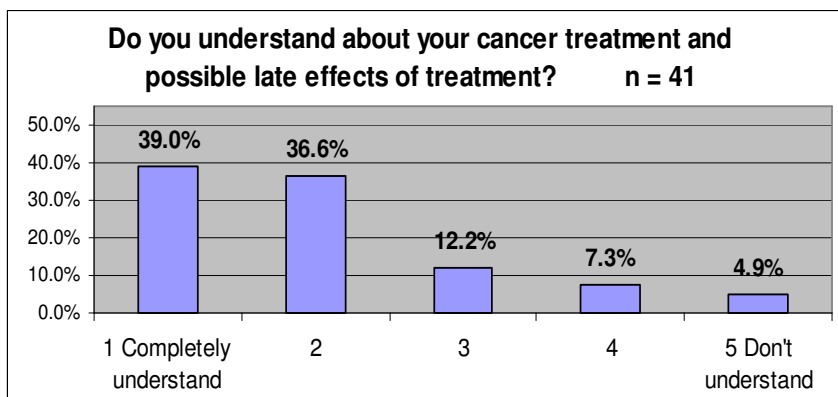


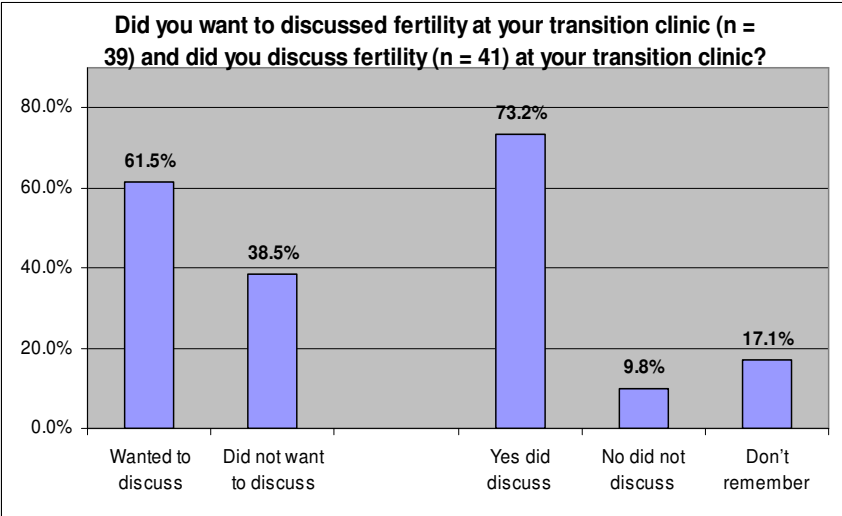
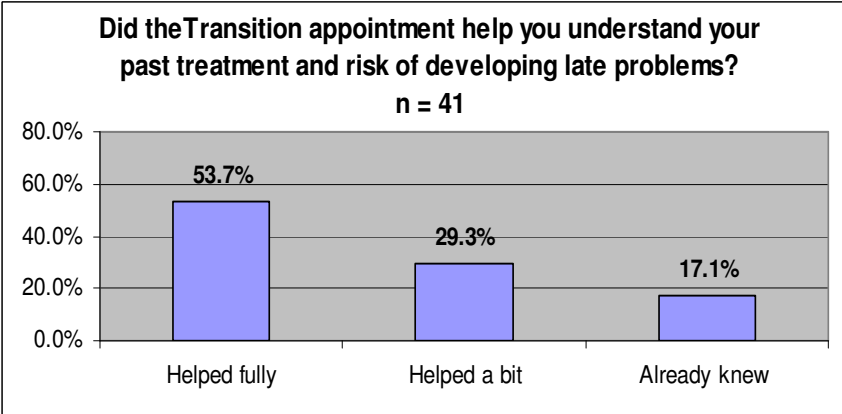
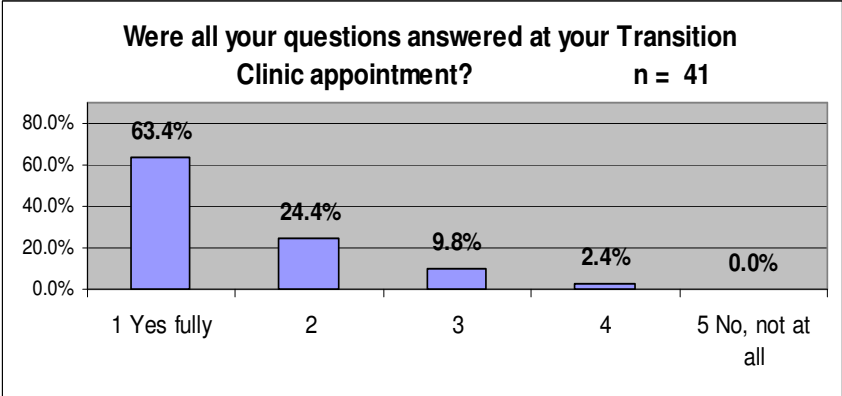
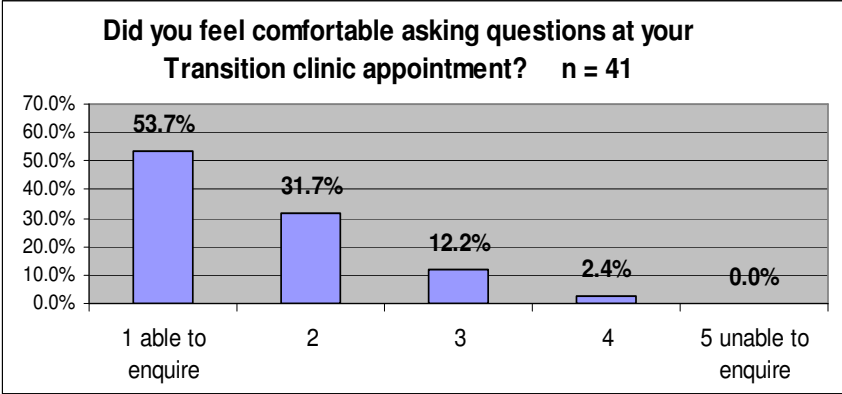
Communication

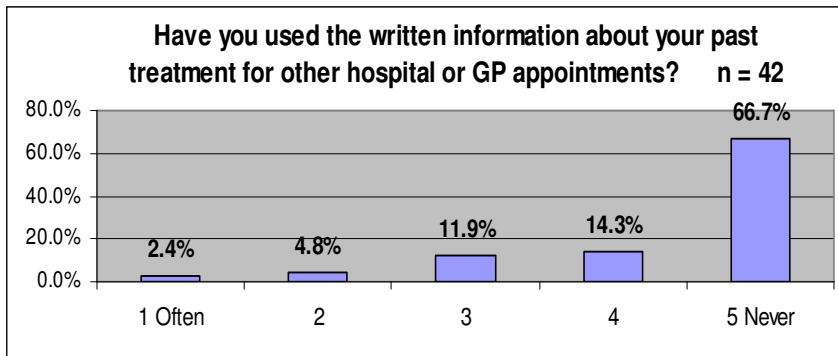
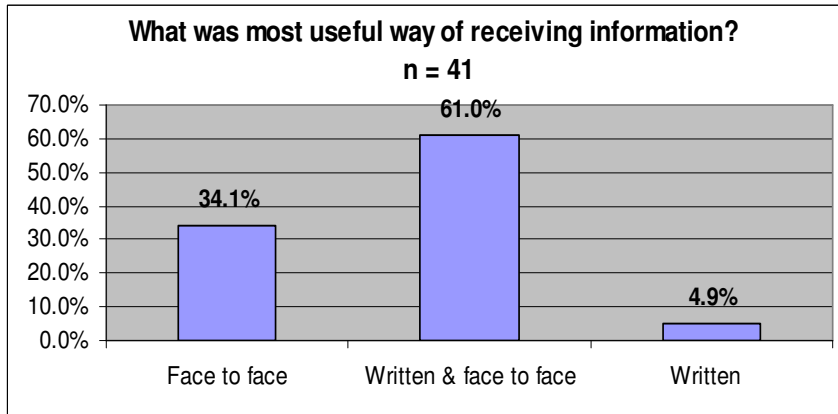
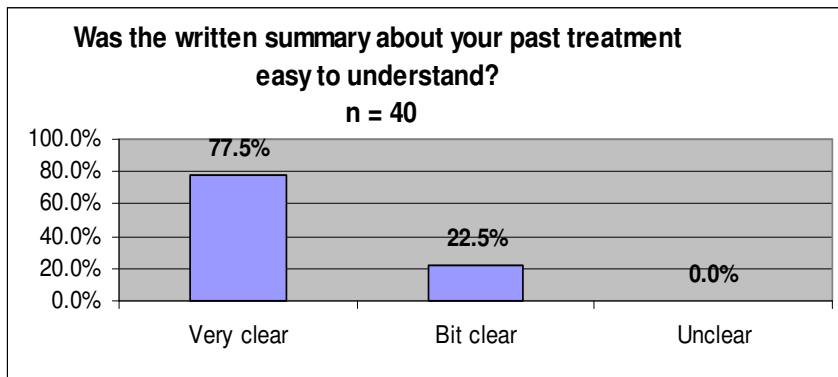




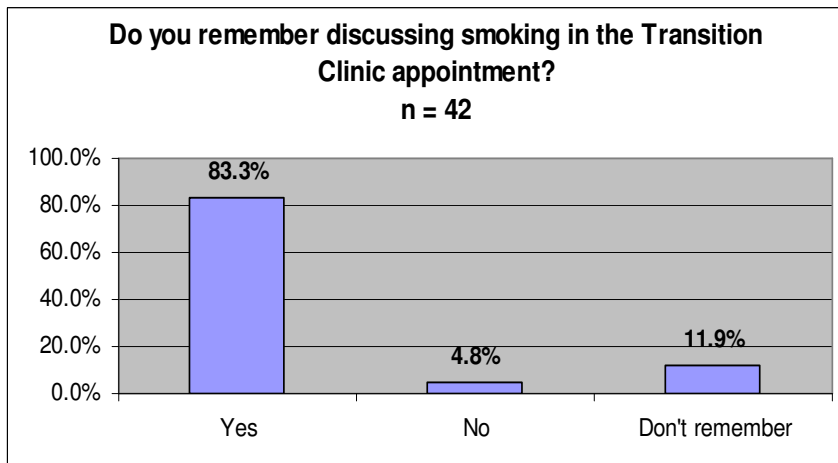
Information

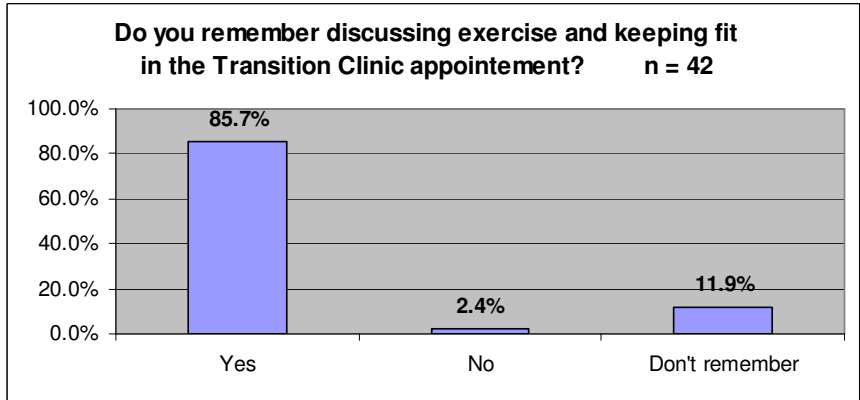
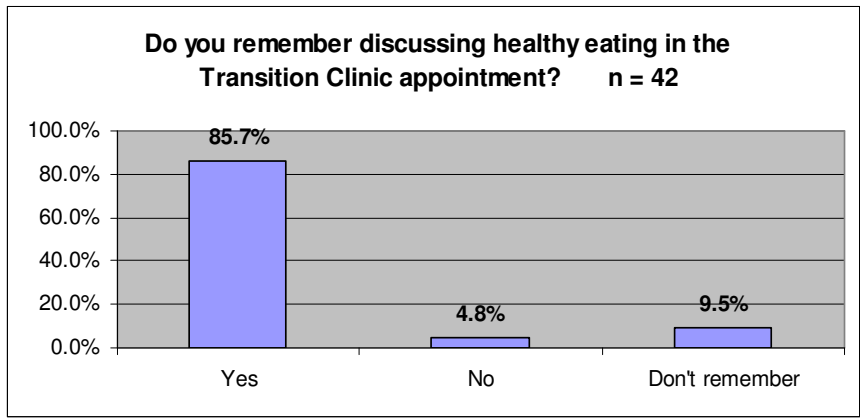






Lifestyle





In conclusion the final overall view on how useful the transition clinic was

