



Bristol Cancer Survivorship Project

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Background and Context:

- Macmillan Report highlighting unmet needs of cancer survivors
- Cancer Reform Strategy published
- National Cancer Survivorship Initiative (NCSI) launched
- NBT put in a proposal to test self management and alternative follow-up



First Steps

- A complete review of long term support and traditional follow-up was undertaken.
- In the first instance a health needs assessment as well as a focus group, inviting User's to explore unmet needs, was undertaken in four tumour sites:
breast, colorectal, urology and haematology
- We mapped current patient information provision across the pathway and the current follow-up pathways and protocols.
- a new model, based on User's views and the outcome of the review was designed with the aim being explore the quality of support, education, information and follow-up required to meet the needs of cancer survivor's following treatment

Overall Project Aim



To provide interventions that nurture the recovery of everyday life and function, independence, confidence and morale. The approach is to be patient-centred with a strong emphasis on informed choice and personal control

What we tested

- Self management programs consisting of:
 - Big clinics (Living Well Information, support and living well days 4-6 months post treatment in breast, urology, colorectal and haematology)
 - Living Well courses for patients and carers:
 - 10 week courses at Penny Brohn Cancer Care
 - Residential weekend course Penny Brohn Cancer Care
 - Self Management Courses based on CBT 5 week course for breast and prostate patients

Big clinic Living Well days



- Information and support with:
 - Diet and exercise
 - Troubling shooting and what to expect
 - Anxiety and stress management
 - Financial advice
 - Networking with other patients
 - Access to question and answer sessions from clinicians
 - Access to CNS support



Penny Brohn Courses

- **2 x 10 week 'Living well with and beyond cancer' support groups (Jan-March 10)**
- For cancer patients and main supporter/carer
- Facilitated by trained counsellors
- Specialist topic sessions included nutrition; exercise; welfare benefits; reflexology self-help; relaxation techniques



Penny Brohn Courses

2 x residential weekends (May/June 10)

- For patients and main supporter/carer
- Relaxing, calm and safe environment
- Chance to concentrate on own needs, learn relaxation and imagery techniques, demo healthy eating session, group support, gentle exercise

Why?



- User views highlighted gaps in support in current follow-up model
- Current follow-up model still very medically orientated despite being nurse led
- To be able to offer choice in type of support and after care available

What we discovered:



- Different models of follow-up/after care could be used dependant on level of risk of recurrence and levels of intervention needed. These would consist of a combination of:
 - Self Management alone with self referral back into system
 - Self Management with remote follow-up in the form of telephone clinic
 - Self Management and face to face follow-up
 - One of the above plus appropriate surveillance tests

Evidence required



- Increase confidence for clinical teams to move away from a medical model - assurance patients would not get lost to follow-up.
- Equally, proposed changes, would not impact on identifying recurrence of cancer in any way.
- We therefore started the process of gathering audit information on how patients in each tumour group re-presented with recurrence: surveillance examination, OPA or self referral.



Patient Information and data collection

- We also identified there was no information system that allowed collection of all we needed:
 - holistic needs assessment,
 - access and attendance to self management courses
 - alert system if the patient failed to have the appropriate interactions.
- A new IT system was agreed and the idea of the Customer Relations Management System (CRM) was born.

Customer Relations Management System (CRM)

- CRM systems are used by large companies to track important information about their “customers”.
- The system being built and will enable:
 - Summary of episodes by linking to all Trust systems This will include attendance at lifestyle management events and when holistic needs assessment has been done
 - Diary management of lifestyle management events indicating when invites should be sent out to patients
 - Holistic needs assessment via Distress Thermometer recording allowing care plan and reports looking at themes to target Big Clinic topics and other support
 - Completion of treatment care plan for patient and GP
 - Email alerts

Client Relations Management System

[Home](#)

[Events](#) [Client](#) [Location](#)

Welcome to the Client Relations Management system

CRM is used to manage the relationship between the Cancer Unit and their customers
This application will help manage :-

- the chronological history of a client
- Keep a record of all contacts and interactions between the staff and the client
- Ensure that relevant information about the client, or of relevance to the client is to hand during these contacts
- Schedule future calls / contacts with customers
- Record any specific problems
- Ensure that the problem or "case" is handled and tracked appropriately, recording the outcome
- Optionally provide materials & information to customers upon request, or make the relevant information available to customers via a web

Client Relations Management System



Events Client Location

Edit Event

Filter Section

Filter Event Name: Filter Location Name:

Filter Date From: Filter Date To:

Event Name	Contact Name	Contact Number	Date	Start Time	End Time	Location	Room	Description	Modify	Select
Bid Day	Mr Richard Harris	01242 709612	08/07/2010	09:00	17:30	BHH	Function Room		edit	<input type="checkbox"/>
CBT Course	Mr Richard Harris	65548444	15/06/2010	10:30	17:00	Cossham	Board Room		edit	<input type="checkbox"/>
Kidney Cancer Information Day	Mrs Colette Grant	0117 9595189	26/06/2010	09:00	16:30	BHH	Function Room		edit	<input type="checkbox"/>
Penny Brohn Course	Mr Richard Harris	01242 258741	13/06/2010	10:00	16:00	BHH	Function Room		edit	<input type="checkbox"/>

Add New Event

Event Name : *

Contact Number : *

Start Time : *

Location : *

Description : *

Contact Name : *

Date of event : *

End Time : *

Completion of Treatment Care Plan

Submit

Clear

Delete

Name	Richard Harris	Address	46D, Montpellier Spa Road, Cheltenham, Glos, GL50 1UL
NHS Number	1234567891	HRN	F987654
Cancer Site	Skin	Diagnosis	Diagnosis: L443 - Lichen ruber moniliformis
Treatment			
Treatment	<input type="text" value="Please Select"/>	* Other details	<input type="text"/>
Treatment aim	<input type="text" value="Please Select"/>	* Other details	<input type="text"/>
Possible treatment toxicities		* Other Details	<input type="text"/>
<input type="checkbox"/> Diarrhoea			
<input type="checkbox"/> Nausea and sickness			
<input type="checkbox"/> Mucositis			
<input type="checkbox"/> Sepsis (any sign of infection)			
<input type="checkbox"/> Neutropenia			
<input type="checkbox"/> Bleeding			
<input type="checkbox"/> Urinary Tract infections (platinum based chemo)			
<input type="checkbox"/> Other			
Comments	<input type="text"/>		
Alert:			
Symptoms indicating referral back to specialist team	<input type="text"/>		
Actions required by GP:		* Other Details	<input type="text"/>
<input type="checkbox"/> Symptom management			
<input type="checkbox"/> Monitoring			
<input type="checkbox"/> Investigations			
<input type="checkbox"/> Support and advice			
<input type="checkbox"/> Other			
Comments	<input type="text"/>		
Summary of information given to patient:		* Other Details	<input type="text"/>
<input type="checkbox"/> Information prescription			
<input type="checkbox"/> Copy of care plan			
<input type="checkbox"/> Symptom control advice			
<input type="checkbox"/> Symptoms that need checking			
<input type="checkbox"/> Other			
Referral to other services:		* Other Details	<input type="text"/>
<input type="checkbox"/> Information prescription			
<input type="checkbox"/> Copy of care plan			
<input type="checkbox"/> Symptom control advice			
<input type="checkbox"/> Symptoms that need checking			
<input type="checkbox"/> Other			
Key Worker:			
Comments	<input type="text"/>		

Previous surveys :



New Survey

Date of stage : * Stage : *

Distress you have been experiencing over the past week, including today 0 1 2 3 4 5 6 7 8 9 10

Rank <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	Physical Problems <input type="checkbox"/> 1. Your Appearance	Rank <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	Physical Problems <input type="checkbox"/> 2. Bathing or dressing
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 3. Breathing Difficulties	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 4. Passing Urine
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 5. Constipation	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 6. Diarrhoea
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 7. Eating or Appetite	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 8. Fatigue or Tiredness
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 9. Feeling Swollen	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 10. High temperature or Fever
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 11. Getting around (e.g.walking)	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 12. Indigestion
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 13. Sore or dry mouth	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 14. Nausea or vomiting
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 15. Pain	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 16. Sexual Concerns
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 17. Dry, itchy or sore skin	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 18. Sleep and/or nightmares
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 19. Tingling in hands/feet	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 20. Changes in how things taste
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 21. Hot flushes	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 22. Memory or concentration
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 23. Speech problems	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 24. Wound care
Rank	Practical Problems	Rank	Practical Problems
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 25. Caring responsibilities	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 26. Finances, work or housing
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 27. Transport or parking	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 28. Questions about my illness/treatment
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 29. Communication with NHS staff		
Rank	Family Problems	Rank	Family Problems
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 30. Relationship with children	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 31. Relationship with partner
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 32. Relationship with relatives/friends		
Rank	Emotional Problems	Rank	Emotional Problems
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 33. Loneliness or isolation	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 34. Sadness or depression
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 35. Worry, fear or anxiety	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 36. Anger or frustration
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 37. Difficulty making plans	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 38. Guilt
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 39. Hopelessness		
Rank	Spiritual/religious Concerns	Rank	Spiritual/religious Concerns
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 40. Loss of faith or other spiritual concern	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 41. Loss of meaning or purpose of life
<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="checkbox"/> 42. Not being at peace with, or feeling regret about the past		

Highest ranked concerns	Rating	Description and history of problem	Plan of action
<input type="text"/>	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4	<input type="text"/>	<input type="text"/>

Alert

- Records
- Events Enrolled
- Add Event
- Alert - Note - Email
- Distress Thermo
- COT Care Plan

Please select form : Alert Note Email



Filter Section

Select Status All Incomplete Completed

Select Period All Month Week Day

Order By Date Assigned

Date	Time	Assigned	Description	Completed	Status
04/10/2010	10:00	Simon Webberley	Give client details about coming event	✗	Edit
28/10/2010	10:00	Simon Webberley	phone client	✗	Edit

Add new alert

Date : * Time : *

Assign to : *

Description : *

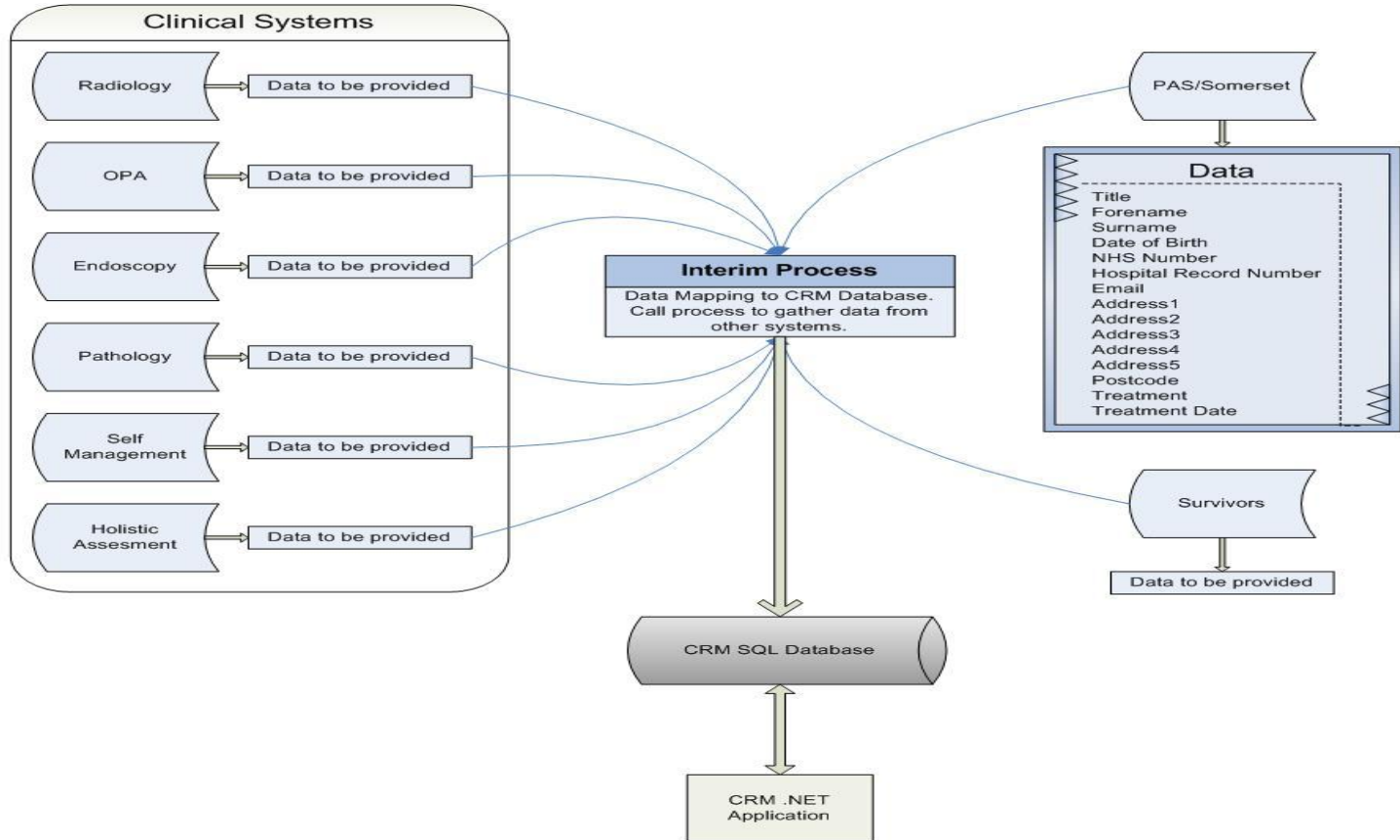
Submit

Please click here to hide/show Audit History

Client Relations Management System

25th April 2010

Data Flow





So far:

- 400 people have gone through interventions with 30 of these being carers
- Uptake for all four tumour sites has been between 60-70%
- There was such an interest in the success of the Big clinics that other teams asked to run them and they are being rolled out across all tumour sites now

Patient feedback:



- **Colorectal Big Clinic Feedback:**
- Exercise programme was useful and the surveillance programme and symptoms to look out for were good
- It has given me the incentive to do more exercise
- To review my diet and exercise
- Change diet and exercise more
- To maintain regular exercise
- Look after my diet more
- Feel more confident to engage in physical exercise

Lung:



- There is support available
- I am not alone
- Diet and travel information great
- To realise that I am not discarded
- Not to be concerned about shortness of breath
- Physio info was good I have learnt you don't have to stop when you feel breathless
- Confidence and how important it is to work through anxiety
- Not as gloomy and outlook is more positive
- Allowances and benefits useful
- Feel there is support
- You can do more than you think
- A very good meeting
- Follow up sessions would be extremely helpful
- Very worthwhile it would be good to have regular sessions

What did the Patients feel they learnt?

Can you list two ways in which your life may change following today's event?

- Being more positive
- Try to be more active
- Start living normally again
- That I can exercise
- To stop using my cancer as an escape
- Exercise with confidence
- Not to make excuses and to start doing housework again
- Go on holiday
- More positive outlook
- Don't panic and give up

What did teams learn?



The most important aspects of learning have been:

- *That we can deliver an alternative model of care for cancer survivors that truly meets their needs safely*
- *That the clinical teams enthusiasm and support is very powerful in implementing change*
- *User input has been invaluable*
- *Collaboration with local partners has been essential adding additional support and choice and has shown that partnership working across care organisations can be successful*

The impact of self management we observed:

- *Patients are clearly able to see what they can and cannot get from health professionals and where the gaps are in terms of their supportive needs.*
- *There was a clear understanding of when they would need specialist advice from the consultant or CNS and what they required additional to this, and that the lifestyle courses went a long way to delivering this.*
- *The support they received from the interaction with other people who had been through a similar experience was invaluable.*
- *We also observed that there are some patients who could not completely self manage and would be at risk which is why differing levels of care and interaction with risk assessment are key.*

CNS feedback:



- All felt that initially it had been a LOT more work – they still had to keep the original system going whilst they made the changes.
- All commented about the administration and IT issues which had clearly been a significant problem.
- The CBT element had involved considerable work with the psychologist.
- However, the positive feedback had made them feel much better about the changes, and they were eager to do more CBT and ‘big clinics’.



Evaluation:

- Qualitative analysis of lifestyle management approaches using focus groups in collaboration with UWE
- Economic evaluation – pilot completed national report available

There were some overarching themes from the focus group evaluations:

- The experiences, needs and issues raised in the pre-intervention group were consistent with the issues raised by participants in the focus groups and some of these had been met through the intervention.
- Consistent professional support and continuity of care was over and over again emphasised as an important component in recovery and in feeling supported. Where this was lacking, people sometimes had particularly poor experiences of care, which could have resulted in very real problems.
- People needed more information about what support was available – preferably written, and the ability to choose information was seen as particularly helpful – one of the good aspects of the ‘Big Clinic’ days.

Continued:



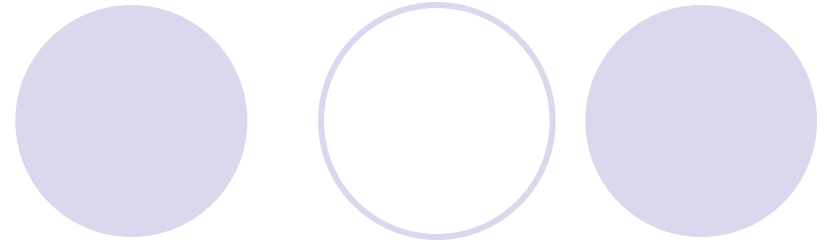
- The courses were greatly appreciated, and people reported having made helpful changes as a consequence of attending, saying that they had more skills and resources to help them recover.
- People differ in their self-awareness, and many said that they were sceptical about the courses' ability to help them prior to having attended. They also felt that more information about what to expect, and, (in the case of the residential weekend), what to bring, would be helpful.
- The combination of the 'big clinic' with plenty of information and the chance to meet with others in a similar situation was definitely seen as helpful, although it is important to be mindful that this may not be the case for all patients, especially if they fall outside the 'normal'



Continued:

- The relaxation exercises were seen as particularly helpful and it was noted that they could be useful if provided before treatment, to help people adjust to radiotherapy or relax during chemotherapy.
- It is also important to note that there were some deficiencies in current routine NHS care that would not be addressed by these courses, and we should continue to be mindful of these, and explore ways of improving patient experience overall.

What we did next:



- Redesigned follow-up protocols to adopt different model incorporating self management
- Enable other cancer teams to replicate model
- Write up of pilot, disseminate and development of commissioned service – in progress
- Plan implementation of alternative follow up model and implement - in progress in colorectal, breast and prostate

2011 plans – testing hypothesis that this model will reduce routine follow up by ..%

- Implement self management/GP care after care model with no secondary care follow-up just remote surveillance in breast, prostate and colorectal
- Telephone follow-up implemented in colorectal and prostate Dec 2010
- Rolling out self management to head and neck, melanoma, Upper GI
- Completion of completion of treatment care plan electronic version by tumour site
- Completion of remote monitoring surveillance system



Summary:

- New model piloted has proved better meets needs and can reduce need for follow-up