

**Focusing on the Views of
Cancer Patients**

**Report of the Cancer Patient
Meeting Held on the evening
of 30th January 2007.**

**Report written by Steve Powell
and Catherine Oakley**

List of Facilitators

Many thanks to the 21 staff who helped to facilitate the event:-

Catherine Oakley	Lead Cancer Nurse
Tim Jackson	Network Nurse Director, South East London Cancer Network
Steve Powell	Cancer Auditor
Martha Sankey	Patient Representative
Jean O'Shaughnessy	Health Information Centre
Barbara Gallagher	SWLCN
Elizabeth Crocker	Head and Neck CNS
Sarah Houston	PALS
Colin Smith	WPCT
Wilfred Carneiro	Equality & Diversity
Margaret Adjaye	Equality & Diversity
Geraldine Walters	Director of Nursing
Val Thomas	Cancer Clinical Directorate Lead
Rachel Lissauer	General Manager, Cancer
Anne-Marie Conneally	Service Manager, Oncology, Haematology, Palliative Care
Ronak Unjia	Assistant General Manager
Nina Kenyon	Macmillan Information Officer
Ed Mew	MDT Co-ordinator
Sarah Henderson	Macmillan Urology CNS
Harriet Backhouse	Macmillan Lung Cancer CNS
Richard Billington	Radiology
Caroline Esty	Macmillan OT

Contents

Item	Page
Contents Page	2
Introduction	3
<u>Topic Tables Details</u>	<u>3-10</u>
➤ (Including)	
➤ Topic 1 – Patient Core Information Pack	4
➤ Topic 2 – Patient Health Promotion Day	5,6
➤ Topic 3 – Cancer Care Facilities/Environment	7,8
➤ Topic 4 – Home Support	9
➤ Topic 5 – Needs of friends and family	10
Feedback and Evaluation	11
Appendices	12

Summary

A cancer patient meeting was held on the 30th January 2007 at St George's Hospital. The purpose of the meeting was to feed back results of previous patient focus group and survey work and detail how this had been taken forward. Further aims were to gather additional patient views about the service and identify patients who may wish to participate in a cancer patient working group.

131 people attend the meeting including patients (n=84) carers, friends and relatives (n=26) and staff (n=21). Patient views were gathered via 5 topic tables covering issues previously identified in patient involvement work. These identified the following key issues for patients:

Cancer Care Facilities <ul style="list-style-type: none">○ Overcrowded clinics and chemotherapy bay○ Issues with food and cleanliness○ Knowledge of cancer patient issues by staff working on general wards○ Would like opportunity to have chemotherapy at weekends/evening
Patient information <ul style="list-style-type: none">○ Patients felt having someone to talk through the pack with them was helpful.○ "drip-feeding" of the information over time was most effective○ Advice on lifestyle and diet should be included.
Home Support. Need more: <ul style="list-style-type: none">○ Information and support to manage symptoms○ Emotional support○ Benefits advice○ Dietary advice – healthy living○ Practical help – around the home
Needs of Family and Friends <ul style="list-style-type: none">○ Friends/family currently support each other○ Need advice on practical aspects getting time off work, benefits, travel, parking costs○ Need counselling/Emotional support including support for children○ Would like support from other carers e.g. support groups
Health Promotion day <ul style="list-style-type: none">○ Most would like to attend○ Felt the day would provide info/support○ Would prefer the day to be tumour specific TOP Four sessions <ol style="list-style-type: none">1. Cancer Treatments2. Exercise and fatigue management3. Where to from here? Help at the end of treatment4. Diet

Evaluation of the evening was positive with 92% of patients and carers rating the evening as either excellent or very good. 25 participants indicated they would like to be involved in a patient working group, which is being taken forward by the Lead Cancer Nurse. It is anticipated that issues highlighted at this patient meeting will be taken forward by the cancer team in partnership with patients.

Introduction

The cancer Directorate Board at St. George's Hospital meets monthly. The meeting is attended by lead doctors and specialist nurses. The patient voice is currently heard at this meeting via cancer nurses. During 2005/06 patient views were gathered from 333 cancer patients and 19 carers through focus groups, questionnaires and a colorectal patient meeting. Actions taken forward from this work by individual cancer teams and facilities include:

- Introduction of Citizens Advice Benefits Service
- Patients now offered a copy of their GP letter
- Improvement in the quality of hospital food
- Improvement in cleanliness
- Informing cancer patients of parking concessions
- Offer all cancer patients written information
- Set up education programmes for general nurses
- Reorganised chemotherapy booking system to reduce the time that patients wait for treatment.

A Cancer Patient Evening was hosted on the 30th January 2007 in the Lanesborough Wing Restaurant area at St. George's Hospital. The purpose of this meeting was to feed back previous user involvement work, further explore issues patients had identified through topic tables and to identify patients interested in establishing a patient group to work with the cancer team.

131 people in total attended the event.

- 84 Patients
- 26 Carers/Friends/Relatives
- 21 Members of staff (Facilitating)

A breakdown of the patients' demographics reveals they were treated by the following tumour-specific teams:-

Tumour Types	No of patients
Breast	15
Lung	2
Colorectal	25
Gynae	6
Upper GI	2
Urology	16
Haematology	6
Head and Neck	2
Skin	6
U/K	4
Total	84

Age ranged from 24-87, with a mean age of 64½ yrs. (Mode 53yrs)

The average time since initial diagnosis for the 84 patients was 27 months or 2¼ years.

Opening Presentations

Dr Val Thomas, Clinical Cancer Director, opened the evening and welcomed all to the event. Following this, Catherine Oakley, Lead Cancer Nurse at St. George's Hospital, delivered a 10 minute presentation, entitled "Listening to Cancer Patients – What have we learned so far?"

Topic Tables

A steering group had previously agreed 5 areas of importance highlighted during patient involvement work. These areas or topics included, patient information, health promotion, the environment, home support and needs of friends and family. In order to explore how needs related to these 5 issues may be addressed topic tables were set up as part of the patient meeting reported here.

Patients and carers/friends/relatives were seated at 10 tables (approx 10 per table). The 21 Health Care professionals facilitating the event were split in to groups of 2 and 3 and assigned one of 5 topics. Facilitators moved between tables in a designated order to ensure all patients had an opportunity to comment on each of the 5 topics. Each facilitator had a sheet of flip chart paper to which they affixed post-it notes, written by each patient about a particular question. This was to ensure each of the patients/carers, even those who are naturally quieter in a group situation, were able to make a contribution. For those who did not find it easy to use the post it note system, the facilitators assisted and wrote agreed comments for them.

Each of the topic tables findings are summarised below. The key themes of patients' responses are listed, with appropriate direct quotes and further information where necessary:-

<i>Topic Table 1: Patient Core Information Pack (This is the pack that all patients should be given at diagnosis – the pack includes (not an exhaustive list) information on Cancer in general (South West London Cancer Network), "help with the cost of cancer" (Macmillan), help with travel costs/expenses (St.Georges) and information specific to the patients tumour-type (various). A sample of the pack was available on each table.)</i>	
Key Theme	Direct Quotes and Further Info
Most patients had not received the pack.	10 said Yes, 68 No
Most patients prefer to look at the pack between 2 and 4 weeks after diagnosis.	"...as I had to adjust to the news of my diagnosis"
Some patients indicated that the information is overwhelming and too voluminous	"Too much information. After being told of cancer – shock! Can't take it all in"
Some patients indicated that having a professional to talk through the pack with them is their preference.	1. "The pack is not helpful. Talking to somebody is more helpful" 2. "If the nurse can help going through the information this would be good"
Further to above, 'drip-feeding' the information over a period of time is more effective	1. "Too much to absorb in one go" 2. "The method of delivering info should vary e.g. group meetings"
Patients found the Macmillan Information helpful	"Macmillan financial support booklet very useful – not for every patient, but generally"
Numerous patients thought advice on diet and lifestyle should be included in the pack	"A simple nutrition guide – e.g. red meat bad for colon Cancer, dairy bad for hormonal Cancers etc."

Topic Table 2: A patient health promotion day
(Patients were asked if they thought this was a good idea and what they would expect from such a day.)

Key Theme	Direct Quotes and Further Info
<p>Most patients indicated they would like to attend such a day</p>	<p>44 (79%) said yes, 6 (11%) No, 6 (11%) maybe. Those undecided said it obviously depends on the time and day.</p>
<p>Patients felt that a Patient Health Promotion day would be beneficial - Patients wanted to learn more about Cancer the disease.</p>	<p>1. "To learn more about cancer, and also to meet and talk to people going through the same thing as you" 2. "Would like to learn what to ask"</p>
<p>Patients felt a health promotion day would enable them to support, and be supported by, other patients</p>	<p>1. "I would like to help others – come as 'a survivor'" 2. "Yes to get more info on support in the community"</p>
<p>Patients felt a health promotion day would enable them to keep abreast of new treatments</p>	<p>1. "...important to know what's going on in all areas of Cancer. I may need to know in the future" 2. "...To keep abreast of new treatments, trials and hospital facilities – be able to pass on the information to other patients through a patient support group"</p>
<p>Reasons most commonly cited for not being interested in a day, aside from physical impairment, were that the day might be too generic (patients would prefer it to be tumour-specific) and concerns over travel & parking costs.</p>	<p>Other concerns: 1. "I would rather have 1 to 1 info. You would have to sit through a lot that is not relevant" 2. "I want information when it's relevant – e.g. on discharge"</p>
<p>Patients indicated that they would like the study day to be held during the week rather than at a weekend</p>	<p>29 (49%) Daytime, 20 (34%) Evening, 7 (12%) Saturday, 3 (5%) Anytime</p>
<p>Patients indicated the four sessions which they would most like to make up the day to be:</p> <p>1. Cancer Treatments (55) - <u>60%</u> 2. Benefits of exercise and how to manage tiredness (54) - <u>59%</u> 3. Where to go from here? Help at end of treatment (41) - <u>45%</u> 4. Diet (40) - <u>43%</u></p>	<p>92 completed forms – full breakdown is shown in Fig 1 below. Numbers in brackets here denote how many patients chose that session as one of their preferred four.</p>

<p>Other suggestions by patients as to what else could make up such a day include :</p> <ul style="list-style-type: none"> - Hearing other patients' experiences - Tumour-specific support groups - Section on employment issues - What to believe about what you read in the press 	
<p>There was a general feeling that any study day (or most sections of) should be tumour-specific.</p>	

Fig 1 Full Breakdown of which subjects would most interest patients on a health study day

Cancer Treatments	55	60%
Benefits of exercise and how to manage tiredness	54	59%
Where to from here? Help at end of treatment	41	45%
Diet	40	43%
What is cancer?	33	36%
How can I help myself cope with my diagnosis and treatment	33	36%
Clinical Trials	32	35%
Relationships with family, colleagues etc.	26	32%
Topical Issues – what's in the press?	22	24%
Where to find further info	21	23%

Topic Table 3: Cancer care facilities/Environment
(Patients were asked to give their opinion on the environment where they were treated - clinic, ward or day unit)

Key Theme	Direct Quotes and Further Info
<p>Most patients who attended an outpatient clinic thought their environment was overcrowded</p>	<ol style="list-style-type: none"> 1. "Oncology clinic waiting room – Staff were (and are) wonderful, but the waiting room is too small and in dire need of refurbishment and redecoration – compare it with other waiting rooms!" 2. "Patients often accompanied by people who took the chairs intended for patients" 3. "Dressings clinic waiting area was the corridor"
<p>Patients who attended Allingham Day Care felt the environment was overcrowded</p>	<ol style="list-style-type: none"> 1. "Allingham ward – Chemo unit overcrowded on Fridays. Not enough chairs whilst having chemo (but staff fantastic)" 2. "Allingham ward day care chemo – found the ward warm and very rushed"
<p>Patients who stayed on Cavell ward found the environment noisy</p>	<ol style="list-style-type: none"> 1. "Cavell ward – atmosphere was not calm, sleeping was difficult anytime" 2. "Cavell ward – was terrible, very noisy. Nurses fantastic"
<p>Feeling about the cleanliness of the wards was varied, although bathrooms and toilets were commonly a problem</p>	<ol style="list-style-type: none"> 1. "Ward – wonderful, very clean" 2. "Toilets were dirty - Cavell ward" 3. "Cavell ward was generally fantastic, nurses excellent, but bathrooms awful" 4. "Caesar Hawkins ward – clean ward...Nurses excellent" 5. "Gunning ward – Kept clean – dusted every day" 6. "Rodney smith ward brought in fragranced oils and change was amazing. Patients so much happier when smell was better"
<p>Cancer patients on general wards felt their care could have been more specialised</p>	<ol style="list-style-type: none"> 1. "(Environment) insensitive – sense of avoidance. 2. "(Environment) without emotion and understanding" 3. "It was not just a ward for cancer patients and some of the nurses did not know that they should not touch the arm where the lymph nodes had been removed" 4. "Care on the general wards was OK, but you did not feel you got specialised care"

<p>There were many positive comments received about staff in various areas of the hospital</p>	<ol style="list-style-type: none"> 1. "Chest clinic very professional. Humour. Views valued" 2. "Allingham ward was great when receiving Chemo. So friendly...nurses were great, nothing was too much trouble for them" 3. "Ruth Myles ward – I found the ward very pleasant to stay in. The staff were wonderful and the nursing care was excellent" 4. "Cavell ward – Doctors and nurses 1st Class" 5. "Caesar Hawkins ward – nurses excellent"
<p>When responding to how the environment should be, patients thought it should be more spacious and have a calmer atmosphere. (A few mentioned that an upgrade of the Oncology waiting room would be desirable)</p>	<ol style="list-style-type: none"> 1. "Ideal environment would be spacious to give impression of being calm and unhurried" 2. "More space! Quiet and calm, regular cleaning" 3. "Oncology clinic waiting room – Considering the seriousness of a cancer diagnosis and the fear that engenders, this clinic should receive top priority to improve"
<p>They would also like to see an improvement of the food in terms of choice and quality</p>	<ol style="list-style-type: none"> 1. "Food could have been better – more alternatives" 2. "...e.g. Fruit/organic snacks in chemo rather than yoghurt full of "e's" – being Cancer patients we watch the additives"
<p>The option to be treated on the Allingham Day care unit in the evening or on a Saturday</p>	<p>Of 25 patients, 22 thought this was a good idea. The majority, 16, would be happy with either a Saturday or an evening.</p>

**Topic Table 4: Home support
(Patients were asked about their need for care and support outside of the hospital environment)**

Key Theme	Direct Quotes and Further Info
<p>Quality of information provided prior to going home from hospital: Of 51 patients, 28 thought this was good, 23 thought there was room for improvement.</p> <p>Of those where the information was good, most patients felt that having specialist staff (inc.Macmillan nurses) facilitated smooth discharge</p> <p>Issues included no information given, and no opportunities presented to take up support at home.</p>	<p>1."The Intermediate Care team visited twice a day for 3 weeks"</p> <p>2. "Given very good info on what is expected at home after chemo sessions, from both ward staff and Macmillan nurse"</p> <p>3. "The information I received from Macmillan nurses was very helpful on going home and afterwards"</p> <p>4." Specialist nurse info and home support by phone. Very helpful"</p>
<p>The areas patients would have liked more support with were :</p> <ul style="list-style-type: none"> • Managing symptoms, :- mostly short-term but some long-term • Emotional support, • Benefits advice, • Dietary advice (healthy living) • Practical support (in home, shopping etc.) 	<p>"Phone numbers and contacts for incontinence pads"</p> <p>"I was told by district nurse to buy my own pads from chemist for leaking bladder"</p> <p>"I had a hysterectomy – Info on how to get back to having a normal sex life"</p> <p>1. "Would have liked to be able to contact agency etc. when feeling lonely"</p> <p>2."Counselling after prostate surgery"</p> <p>"Being told that I didn't have to give up my home as I could have applied for benefits"</p> <p>"What symptoms to look out for – what to eat, how to exercise to improve speed of recovery"</p> <p>"Home caring – cooking, shopping"</p>
<p>Only a few patients received support from HCPs as most support was from friends and family</p>	<p>Emotional and practical support both provided in the main by friends and family.</p>

Topic Table 5: Needs of friends and family (Patients and carers were asked about carers needs)	
Key Theme	Direct Quotes and Further Info
In responding to how a diagnosis of cancer had affected family, friends and local community.	All patients mentioned family and friends were understandably shocked and quite frightened. However, they did also note that friends and family were in the main supportive, and the cancer diagnosis had helped in some instances to bring the family closer together.
Where do family and friends get support :	<ul style="list-style-type: none"> • Mostly family and friends support each other (31/57 responses of this nature) • 6/57 said “no support” • Only 15/57 said they got support from Health care professionals • 6/57 said they got support from church • 4/57 said via the internet (including online support groups) • 2/57 said their friends and family didn’t need support • 3/57 said support groups & information centres
The additional support patients feel their friends & family would find helpful include :-	<ul style="list-style-type: none"> • (8/38) Advice on practical issues – getting time off work, benefits, travel, parking costs. • (8/38) Counselling/Emotional support including support for children • (6/38) Support from other carers – e.g. support group
Patients were asked whether they felt their religion and/or their beliefs helped them with a diagnosis of cancer	<ul style="list-style-type: none"> • 43/53 patients said Yes (37 of these religion, 3 believing in ‘inner strength’, 1 belief in humanity, 1 belief in fate and 1 believer in Yoga practice being beneficial) • 9/53 patients said no (with 1 ‘don’t know’)

Feedback and Evaluation

Evaluation forms were distributed to gauge patients' views on how interesting, informative and enjoyable they found the evening. 78 completed evaluation forms were returned. Feedback was extremely positive.

- 72/77 (1 left blank) responders (**93%**) felt the organisation before the event was "Excellent" or "Very Good"
 - 74/77 (**96%**) felt the organisation during the event was "Excellent" or "Very Good"
 - 70/78 (**90%**) felt the venue was "Excellent" or "Very Good"
 - 67/75 (**89%**) felt the refreshments were "Excellent" or "Very Good"
 - 69/77 (**90%**) felt the evening was ran sensitively
 - 69/76 (**91%**) felt their views were valued enough
-
- **69/75 (92%) rated the evening as either "Excellent" or "Very Good"**

Next Step

25 of the patients indicated they would like to be part of a cancer patient working group. A "start-up" meeting for the group was held on the 17th May at which initial hopes and expectations (by both patients and staff) for the structure and contribution of the patient group were sought. In addition, a further 29 patients said they would like to be consulted by post or email about the cancer service in future.

Conclusion

The patient meeting was a success and generated useful data to inform the development of cancer services at St George's. It is envisaged that these issues and the patient agenda will be taken forward by the cancer team in partnership with a new patient working group.

Appendix 1 – Topic table questions

1. Core Information Pack

- Did you receive a copy of this pack?
- If you did receive a copy when did you look at it?
- Did you find the information pack helpful and if so why?
- Did you find the information pack unhelpful and if so why?
- Should anything else be included?
- What is your general view of the pack?

2. Patient Cancer Information Day

- Would you attend such a day?
- If yes, why would you like to attend?
- If such a day wouldn't interest you, why not?
- What time of the day would suite you best?
- Please indicate on the separate sheet (details below) provided which 4 sessions would be of most interest to you?
- Should anything else be included?

Please indicate which 4 sessions would interest you most	
1. What is cancer?	
2. Cancer Treatments	
3. Clinical trials	
4. Diet	
5. Benefits of exercise and how to manage tiredness	
6. Relationships with families, colleagues friends and healthcare professionals – sexuality- talking to family members	
7. Topical issues – what's in the press?	
8. Where to find further information	
9. Where to from here? Help at the end of treatment	
10. How can I help myself cope with my cancer diagnosis and treatment?	

3. Cancer Care Facilities/Environment

- How did you find the environment where you received your Cancer care? (Please specify the area)
- What would you like the environment to be like?
- If you have received cancer chemotherapy treatment as an outpatient would you like an option to be treated
 - In the evening?
 - On a Saturday?

4. Home Support

- Was the information provided prior to your going home from hospital helpful?
- What additional information would have been helpful?
- Did you need more support at home?
- What other support at home would have been helpful?

5. Needs of friends and family

- How has a diagnosis of cancer affected families, friends and local communities?
- Where do family/friends get support?
- Would additional support for family/friends be helpful? If so what?
- To what extent do religion/beliefs affect how you cope with a cancer diagnosis?