

Information for people affected by cancer in Forth Valley

October 2005



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Reader Information

Document Purpose	Information strategy for Forth Valley NHS
Authors	Gill Hubbard, Anne Taylor, Nora Kearney
Publisher	Cancer Care Research Centre, University of Stirling
Publication Date	October 2005
Target Audience	Health and local care professionals with an interest in developing an information strategy for people affected by cancer
Further Copies From	cancercare@stir.ac.uk
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Internet Address	http://www.cancercare.stir.ac.uk
Price	Free

Acknowledgements

Thanks to Macmillan Cancer Relief for funding this study, and also Forth Valley NHS and Strathcarron Hospice for their support. Thanks to all the healthcare professionals, patients and carers who participated. Thanks to Sara Walker for providing references and to Jamie Boyd for designing the report.

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Macmillan
cancer relief

NHS
Forth Valley

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Executive summary

1. The Cancer Care Research Centre, University of Stirling carried out a small-scale study over six months in 2005 for Forth Valley NHS in order to contribute towards developing an information strategy for people affected by cancer.

2. A literature review, a postal questionnaire to key clinical personnel and GP surgeries throughout Forth Valley, a focus group with healthcare professionals and focus groups with patients were conducted.

3. Fifty two out of a total of 155 healthcare professionals returned the questionnaire, giving a response rate of 33%. Eleven patients (2 lung, 2 cervical, 4 breast, 2 colorectal, 1 brain) and one carer participated in the patient focus groups; patients had all completed their treatment and were in different stages of follow up. The focus group with healthcare professionals consisted of an oncology consultant, clinical nurse specialists, palliative care nurses and community nursing staff.

4. The overwhelming majority of healthcare professionals (33 out of 52) reported that either they were personally responsible for making sure that information was available or that the team, of which they were a member of, was responsible. Nineteen reported that there was either no-one responsible or that they did not know if someone was responsible.

5. Just under a third (15 out of 52) reported that they did not have any booklets or leaflets for people affected by cancer. Many healthcare professionals (27 out of 52) reported that they had over ten different booklets and leaflets at their disposal.

Action: Consider introducing information officers with specific responsibility for information provision and quality.

6. Most booklets and leaflets were made available to people affected by cancer by healthcare professionals but some were also displayed on shelves and table tops.

7. Patients said that they wanted information to be given verbally and that written information should be given as 'back up.' Healthcare professionals also said that written information should reinforce and complement information obtained verbally rather than act as a substitute for verbal communication.

Action: Ensure that all information is given verbally even if it is also handed out in written form.

8. Another significant source of information and support for patients is other patients.

Action: Continue to develop strategies so that patients can communicate with each other. For example, consider re-arranging the waiting rooms so that some patients can talk together quietly; continue to provide information about support groups and consider expanding the 'buddy system.'

9. Other sources of information for patients were the Maggie's Centre, newspapers and television.

10. Information produced by Cancerbacup, Macmillan and other organisations such as West of Scotland Clinical Network which produces the 'blue booklets' were used. There was not much information used from Marie Curie.

11. Healthcare professionals wanted to give information out in small sections rather than all at once, which was one of the reasons why they liked to use information provided by Cancerbacup and also the 'blue booklets', which were ring binders where information could be slotted in when deemed relevant and appropriate.

Action: Continue with the strategy whereby information is given out in small sections and provided at different times rather than all at once.

12. Healthcare professionals said that they welcomed standardised information because it meant that healthcare professionals across the care system were aware of the information that patients had received and were handing out the same information.

Action: Continue with the strategy of standardising information so that healthcare professionals across the whole system of care provide the same information.

13. Healthcare professionals reported that there was very little internet facilities for patients to use that were available on NHS premises. Some patients however, did access the internet from their own home.

14. Healthcare professionals were concerned that patients using the internet may not be aware of the best sites to access and that in doing random searches, patients can gather information that increases their anxiety, gives them the wrong information and overloads them with too much information.

15. The most common internet sites for healthcare professionals who did use the internet were Cancerbacup and Macmillan.

Action: Recommend high quality web sites for patients and consider introducing more

internet facilities for patients on NHS premises to improve access for those who do not have the internet at home.

16. Some information handed out to patients was of poor quality because it was badly photocopied.

17. Healthcare professionals said that they could not hand out some booklets because they did not have a budget which they could draw on to purchase them.

Action: Introduce a budget so that healthcare professionals can purchase booklets for patients. Make sure that all information, including photocopied material, is of a high standard in terms of presentation.

18. Healthcare professionals reported that there was little information for people who had poor literacy skills, whose first language was not English, or for people with sensory impairment. They also reported that they had no video or audio tapes available to give to patients.

Action: Provide more information for patients whose first language is not English, for patients with a sensory impairment and make sure that all information is written in plain English. Also, consider providing more information in video and audio format.

19. Most healthcare professionals said that they had booklets and leaflets about diagnosis. Giving information about diagnosis and about surgery however, was not always appropriate. This is because most patients said that they wanted information about diagnosis and surgery to be given verbally.

20. Healthcare professionals and patients said that information about radiotherapy and chemotherapy treatments were given verbally but also on paper. Patients said that they found the written information useful.

21. Healthcare professionals said that there was less information about follow up and after-care. Patients said that they wanted more information about what to expect once they had finished their treatments, such as depression and post traumatic stress. Some patients felt 'abandoned' upon completing their treatments. Healthcare professionals agreed that more information about follow up and after-care would be appropriate.

Action: Continue with the strategy of providing information about diagnosis and surgery verbally but introduce more information about after-care and consider introducing more information about support for patients after they have finished their treatments.

22. The questionnaire found that most healthcare professionals reported having information about palliative care although healthcare professionals during a focus group discussion said that more information about end of life care was needed. This was also the case for information about finance/benefits because whilst the questionnaire showed that information was available, healthcare professionals during a focus group said that more information was required. This suggests that whilst information may be available it may not be used. In fact, a key finding from this study is that even though information is available in booklets and leaflets it does not automatically follow that healthcare professionals will hand it out or that patients will read or absorb this information.

Action: Ensure that healthcare professionals do not assume that because information is produced in written format that patients will read or absorb this information or that healthcare professionals will use it. Healthcare professionals may need to re-enforce particular information and alert patients to the fact that this information is readily available.

23. None of the patients said that they wanted information about funerals or wills. They said that they would rather ask if they wanted help with these

matters. Obviously, patients wanted to be told that they were going to be alright. Healthcare professionals admitted that it was difficult giving patients bad news without causing undue and unnecessary anxiety.

24. Patients said that they wanted more information about cancer survivors and success stories.

Action: Give patients more 'good news' stories, such as information about cancer survivors.

25. The findings from the questionnaire show that there is information for family carers. However, patients and healthcare professionals during focus group discussions said that there was very little information specifically for their family members including their children. They said that for those patients who wish to give information to their children, it should be readily available.

Action: Provide information for family carers in order to support them and facilitate their specific needs.

1. Introduction

1.1 The importance of information

Information and communication are crucially important. People affected by cancer rightly expect to have access to relevant information that is clear, at a time and in a form appropriate to them, and to have the opportunity to talk.

Ian Gibson

Chairman, Patient Information Sub-group of the Scottish Cancer Group

The Calman-Hine report (Calman-Hine, 1995), NHS Cancer Plan (Department of Health, 2000), Cancer in Scotland, Action for Change (Scottish Executive, 2003) and the Cancer Information Strategy (Department of Health, 2000) emphasise the importance of providing clear information for patients and the need for good communication between healthcare professionals and patients.

There are several reasons why it is essential that Forth Valley NHS develop an information strategy for people affected by cancer. Previous research indicates that providing high-quality information can improve knowledge and recall, symptom management and satisfaction with services (Mesters et al. 2001) as well as improve psychological and physical well-being (Ream and Richardson 1996) and reduce levels of anxiety (Davison and Degner, 1997; Thomas et al. 2000). In an era where patients are being encouraged to play an active role in making decisions about their care it is imperative that they have at their disposal appropriate and accessible information (Coulter et al. 1999). Research suggests that some patients want as much information as possible and want to be actively involved in making decisions about their treatments, others want information but prefer to delegate decision-making to healthcare professionals and others want minimal information and prefer all decisions to be made by healthcare professionals (Czaja et al. 2003). Recent surveys of patients have found that most of them want to be given as much information about their illness as possible (Jenkins et al. 2001; Meredith

et al. 1996; Wong et al. 2000). Unless healthcare professionals provide patients with good quality information then patients may end up relying on what they read in the newspapers or watch on the television, which may not be necessarily accurate or appropriate.

Clearly more work in relation to the provision of information throughout the UK needs to be achieved since one of the most common complaints by patients with cancer is about poor communication and poor information (National Cancer Alliance, 1996). With this in mind, the Cancer Care Research Centre, University of Stirling carried out a small-scale study over six months in 2005 for Forth Valley NHS in order to contribute towards developing an information strategy for people affected by cancer.

2. Research Aims

The aim of this study was to inform and support the development of an information strategy for people affected by cancer in Forth Valley. The objectives of this study were to:

1. Identify what information is available for people affected by lung cancer, haematology cancers and other cancer types.
2. Obtain the perceptions of people affected by cancer on the current provision of information.
3. Obtain the perceptions of healthcare professionals on the current provision of information.

3. Methods

1. A review of the literature surrounding all aspects of information provision was carried out to provide a comprehensive overview of the research in this area to date.
2. A questionnaire was posted to key clinical personnel and all GP surgeries throughout Forth Valley to ascertain details on who provides information to people affected by cancer, what information is available, in what format and to find out the extent of the use of the internet and internet access.
3. Three focus groups with patients were carried out to explore issues relating to information provision. One focus group with healthcare professionals was carried out to explore their perceptions of the provision of information.
4. The results from the questionnaire and the findings from the focus group discussions were used to make recommendations for the future development of an information strategy for people affected by cancer throughout Forth Valley.

4. Procedures

4.1 Procedure

Ethical approval was granted from COREC. Forth Valley NHS provided approval for the study to be conducted.

The researchers attended meetings with oncology clinical staff, a lead clinician from the community and hospice nursing staff to inform them of the study and to ask for their cooperation for the completion of the questionnaire and to request their attendance at a focus group. Contact details of general practitioners were accessed from the Forth Valley NHS website and the names of other healthcare professionals were accessed through discussion with key professionals throughout Forth Valley. The researchers contacted all GP Practices throughout Forth Valley to inform them of the study and to identify a named GP to send the questionnaire to. Contact details of all oncology staff from across Forth Valley NHS and lists of all community staff were used to administer the questionnaire. Also, the ward manager from Strathcarron Hospice handed the questionnaire to a selection of nursing staff from the ward and day care area. The questionnaire was developed through reviewing the literature, and through discussion with lead cancer specialists and clinicians throughout Forth Valley. The questionnaire was piloted with six clinicians and changes made accordingly. A database was set up using a software package - SPSS - for the analysis of the questionnaire data. The initial return rate of the questionnaire was poor and a second questionnaire was sent out with a letter explaining the importance of the study and to encourage response. An invitation was sent out with each questionnaire asking healthcare professionals to attend a focus group. Healthcare professionals were also contacted via email and telephone and encouraged to attend a focus group. Consent was obtained on the day of the focus group. The discussion was audio-recorded and then listened to afterwards by the researchers to identify emerging themes.

To access patients for the focus groups the clinical nurse specialists and hospice day care staff contacted potential patients and their carers to ask their permission for the researcher to contact them regarding their participation in the focus groups. Once

approval was given, the researchers contacted the individual patient and informed them of the study and either posted out or handed to each patient an information sheet about the study and consent form. The focus group discussions were audio-recorded and the tapes listened to afterwards by the researchers to identify emerging themes and recurrent issues.

4.2 Questionnaire Sample

Table 1 shows who the questionnaire was sent to and the number of healthcare professionals who responded.

Table 1: Questionnaire sample

Who the questionnaire was sent to	Number of returns
All 55 General Practices in Forth Valley	14 (25%)
25 oncology nurses in the acute sector	14 (56%)
47 primary care staff in the community	12 (30%)
20 Strathcarron Hospice nursing staff	5 (25%)
4 consultants from the acute sector and palliative care	4 (100%)
6 health promotion and pharmacy staff	3 (50%)
TOTAL 155	TOTAL 52 (33%)

Of the fourteen oncology nurses in the acute sector, two were lead cancer nurses, six were specialist nurses, three were palliative care nurses and three were oncology support staff nurses. Of the twelve primary care staff in the community, eleven were district nurses and one was a Macmillan community nurse. The consultants were from lung and palliative care. No haematology consultants participated in the study. Whilst we would have welcomed a higher response rate, Table 1 shows that those who returned the questionnaire represent a cross-section of healthcare professionals who care and provide information for people affected by cancer in Forth Valley.

4.3 Patient focus groups sample

Three focus groups were carried out; two took place at one of the district hospitals and one took place at Strathcarron Hospice. Eleven patients and one carer participated in the patient focus groups. The participants were patients with cancer who had all completed their treatment and were in different stages of follow up. Two participants of one focus group were in their 1st year post diagnosis; four participants of a second focus group were one to five years post diagnosis, with two participants suffering from recurrence, and patients attending the third focus group were one to four years post diagnosis. Table two shows the sex, age range and cancer type of the focus group participants.

Table 2: Patients participating in focus groups

Focus group	Sex	Age	Cancer Type
Group 1	Male	60-70	Lung
	Male	60-70	Lung
	Female	60-70	Carer
Group 2	Female	45-55	Cervical
	Female	65-75	Breast
	Male	65-75	Brain
	Female	65-75	Colorectal
Group 3	Female	40-45	Breast
	Female	60-69	Breast
	Female	69-75	Colorectal
	Female	40-45	Breast
	Female	45-55	Cervical

4.4. Healthcare professional focus group sample

Although the researchers had planned to run two focus groups with healthcare professionals, due to the poor response rate, only one was carried out. The focus group consisted of an oncology consultant, clinical nurse specialists, palliative care nurses and community nursing staff. This group is a cross section of clinicians who care for

and provide information to people affected with cancer in Forth Valley.

5. Results

5.1. Who is responsible for information?

A great deal of written and electronic information about cancer is already available. However, it is not necessarily readily accessible to all who need it. At a national level there are no processes in place to ensure that information is accurate, up to date, and comprehensive.

NHS Cancer Information Strategy

Information officers or those responsible for information that is made available to people affected by cancer have overall responsibility to ensure that it is of good quality. Guidelines and tools for assessing the quality of written health information are available to facilitate this process (Plan English Campaign, 2003). Information officers can also liaise with healthcare professionals in order to provide information for people affected by cancer.

Our study found that the majority of the healthcare professionals (33 out of 52) said that either they were personally responsible for making sure that information was available for people affected by cancer or that the team, of which they were a member of, was responsible. In contrast, Strathcarron Hospice had a designated member of staff who was responsible for making sure that information was available. Nineteen healthcare professionals reported that there was no-one responsible for providing information or that they did not know if someone was responsible.

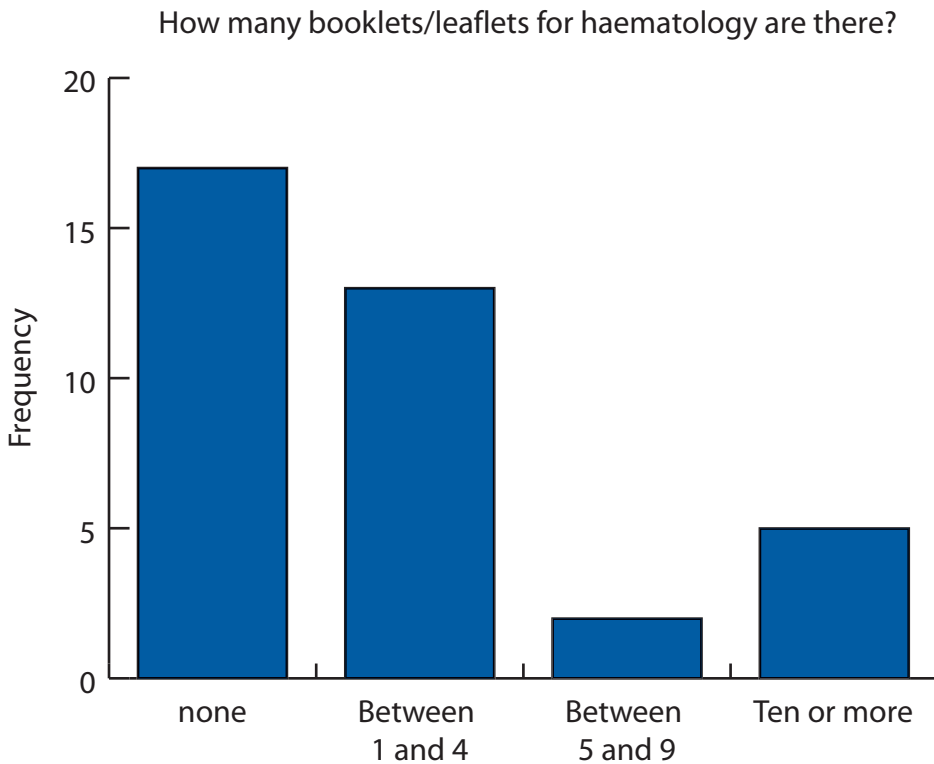
5.2. The amount of information for people affected by cancer

Just under a third (15 out of the 52) of healthcare professionals reported that they did not have any booklets or leaflets for people affected by cancer. Seven of these were GPs, six were district nurses and two were from Strathcarron hospice. From our

study it is not clear why these individuals reported that they did not have information available.

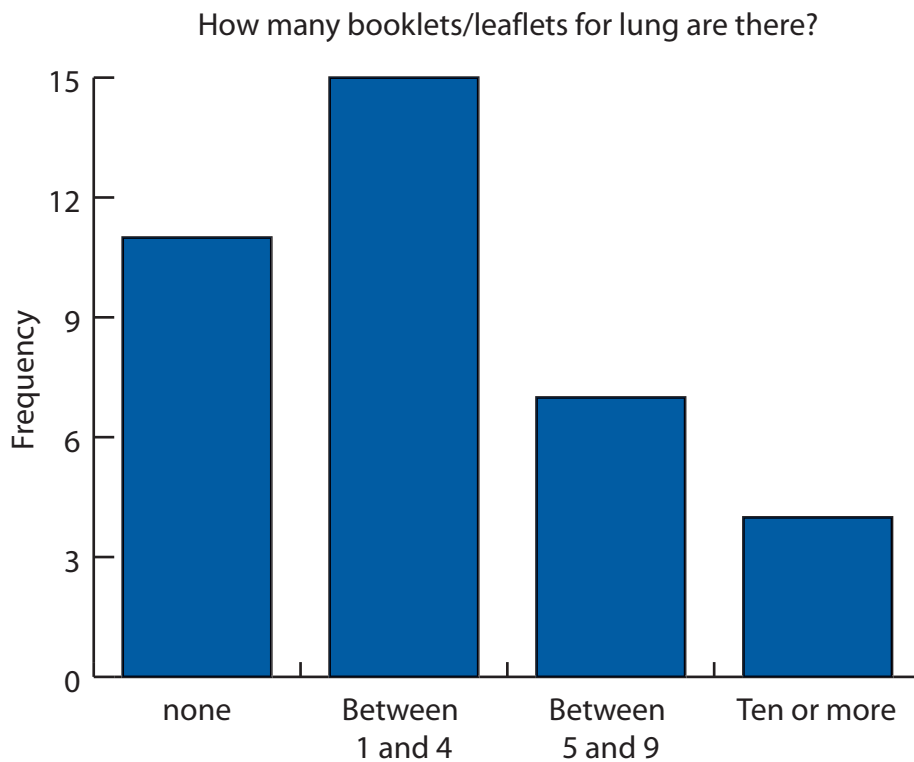
Just over two-thirds (37 out of 52) of healthcare professionals reported that they had information available for people affected by cancer. This means that 37 healthcare professionals were able to provide further information about booklets and leaflets for people affected by cancer, which is why some of the graphs displayed in this report show the responses from 37 healthcare professionals rather than 52.

Graph1a: Frequencies of healthcare professionals reporting the amount of information available for haematology cancers (n=52)



Graph 1a shows that around half of these healthcare professionals (17 out of 37) did not have any information about haematology cancers, a third (13 out of 37) had between 1 and 4 booklets or leaflets, and only two reported having between 5 and 9 booklets or leaflets and 5 out of the 37 had 10 or more booklets or leaflets.

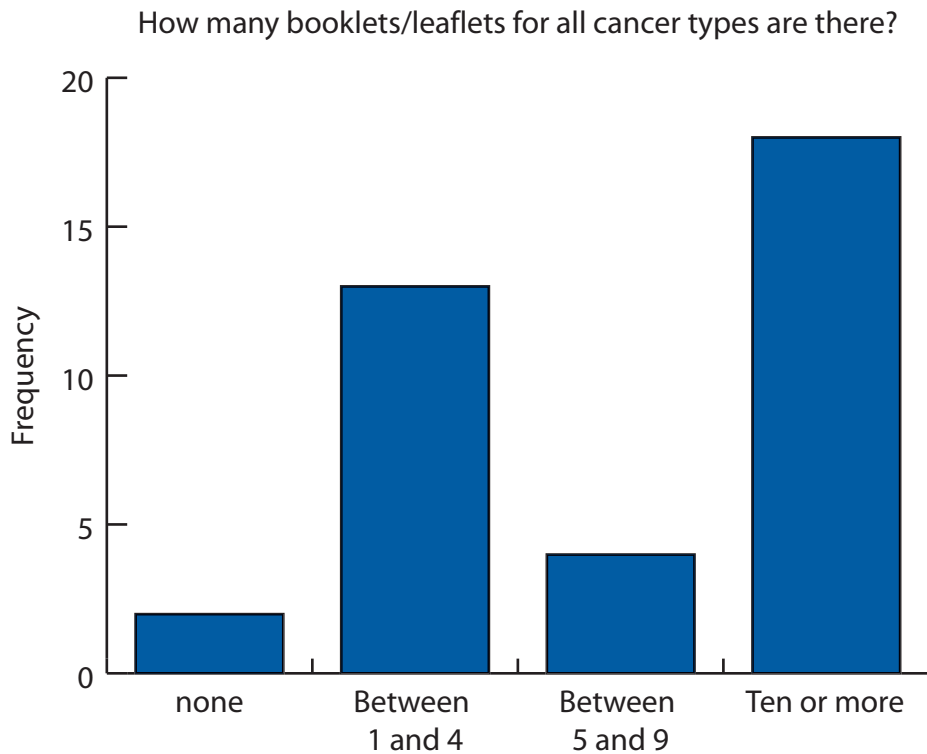
Graph 1b: Frequencies of the amount of information for lung cancer



Graph 1b shows that about a third of these healthcare professionals (11 out of 37) did not have any information about lung cancer, around half (15 out of 37) had between 1 and 4 booklets or leaflets, seven reported having between 5 and 9 booklets or leaflets and 4 out of 37 had 10 or more booklets or leaflets.

Graph 1c shows that only two healthcare professionals did not have any information about all cancer types such as breast and colorectal cancer, around a third (13 out of 37) had between 1 and 4 booklets or leaflets, four reported having between 5 and 9 booklets or leaflets and just over half of the healthcare professionals (18 out of the 37) had 10 or more booklets or leaflets.

Graph 1c: Frequencies of the amount of information for all cancer types



These graphs highlight that the amount of information for different types of cancers varies. The questionnaire did not ask healthcare professionals to document reasons why some types of cancer have more information available than others. However, one possible reason why there was less information about haematology cancer was provided by a haematology clinical healthcare professional during a focus group discussion for the study. She said that booklets and leaflets were only made available to people affected by haematology cancers once a diagnosis had been confirmed, which was usually at the hospital. She therefore did not expect booklets and leaflets about this type of cancer to be readily available at GP surgeries or in the community. Another reason why the amount of information varies between different types of cancer may reflect study bias because there may be less respondents from specialists working with patients with haematology cancers.

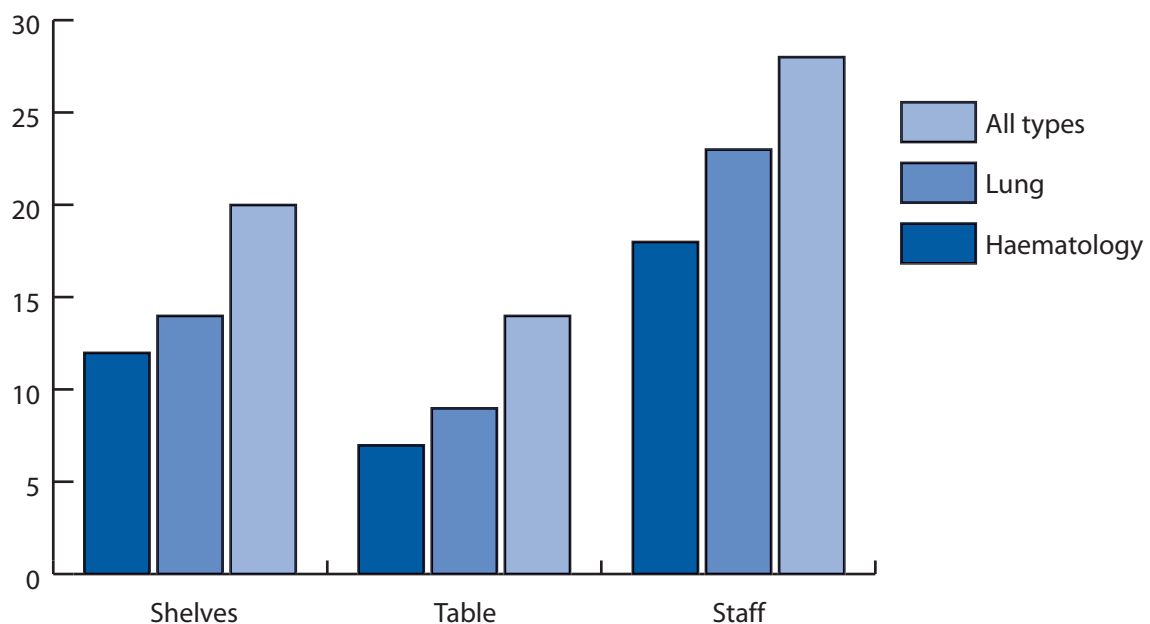
The graphs also show that in total, many healthcare professionals (27 out of 52) had over 10 different booklets and leaflets at their disposal. However, simply having information at hand is not only what is needed to improve communication between healthcare professionals and patients. Previous research for example, suggests that patients

experience a dearth of information although a great deal is theoretically available (Smith, 2000).

5.3. Where people affected by cancer obtain information

Graph 2 shows that most booklets and leaflets were made available to people affected by cancer by healthcare professionals. The graph also shows that information was displayed on shelves and in a minority of cases on table tops. Twenty-eight out of 37 healthcare professionals reported that information about all cancer types such as breast and colorectal cancer, was available from staff compared to 20 and 14 reporting that it was available on shelves and tables respectively. Twenty-three healthcare professionals reported that information about lung cancer was available from staff compared to 14 and 8 reporting that it was available on shelves and tables respectively. Seventeen healthcare professionals reported that information about haematology cancers was available from staff compared to 11 and 6 reporting that it was available on shelves and tables respectively. This evidence emphasises the important role that healthcare professionals directly play in providing booklets and leaflets for people affected by cancer.

Graph 2: Frequencies of healthcare professionals reporting where booklets and leaflets are available from (n=37)



The value of verbal, face-to-face communication between a healthcare professional and patient cannot be under-estimated particularly since patients with cancer prefer to be given information verbally which is then supplemented by written information (Hinds et al. 1995; Mills and Sullivan 1999; Nair et al. 2000) and prefer information based on their own medical records as opposed to general information (Jones et al. 1999). Healthcare professionals who participated in a focus group for the study were aware of the importance of verbal information and perceived that it was a large part of their work. One healthcare professional said that:

'A lot of our work is verbal, with information and support.'

At the same time, since most patients only remember approximately one-tenth of what they are told during a consultation other methods of communication alongside verbal correspondence is also required (Department of Health, 2000). The inability to remember what was being told at the point of diagnosis was made by one of the patients during a focus group discussion:

'At the first consultation I couldn't remember a lot. My husband and I came home quite traumatised but the second one was much better. He [consultant] explained things and was more specific. You need time and he spent a lot of time with my husband and me.'

The importance of verbal communication was re-iterated throughout focus group discussions. Patients for instance, valued the specialist nurses because they were on hand to answer any questions that they had about their diagnosis and treatment. Patients during focus group discussions said that the written information that they obtained was useful 'back up' information to that given face-to-face by healthcare professionals. The following quotations from patients exemplify the extent to which patients valued verbal information and support:

'The staff were fantastic and so supportive right down to the volunteers who made your cup of tea.'

'The nurse explained everything to me and spent a lot of time going over

products and said, "Just call me if there is anything or if you need anything." That was nice just knowing that.'

'Fantastic thing to have someone at the other end of a phone if you need anything.'

Healthcare professionals during a focus group said that written information should reinforce and complement information obtained verbally from healthcare professionals rather than act as a substitute for verbal communication:

'It's given verbally and then I give them my card and say that if they need anything or think of anything then just call me and I give them.'

'You sit and explain it with them and make sure they understand it, then they can contact you if they think of something that they are not sure of.'

5.4. Obtaining information from other people affected by cancer

Previous research has highlighted that 'word of mouth' was the commonest source of information about cancer followed by leaflets, television and newspapers and in a minority of cases the use of the internet (Biley et al. 2001; Carlsson, 2000, James et al. 1999). Focus group discussions indicated that other patients also under-going treatments for cancer were an important source of information. Patients said that they swapped stories with each other in the waiting room and reported that the 'camaraderie' was helpful:

'It was great just knowing that you weren't the only one going through this and it helped you cope and know what to expect.'

'You were seeing the same people each time you were going for your treatment so you built up relationships with them as you went along.'

'The banter was fab, it really did keep you going, talking about everything but cancer, a real camaraderie.'

Our study suggests that patients may also learn about managing their symptoms from other patients. One patient for example, saw another woman's burns to her skin, which made her use a cream during her radiotherapy treatment. Friends and neighbours who had direct experience of cancer were also a source of information for some patients. One patient borrowed a book about cancer from a neighbour who was a cancer survivor and another gained confidence and inspiration when a neighbour informed her that her mother was a cancer survivor of 40 years.

Our study suggests that patients would welcome more details about support groups and contact names of people who have had similar experiences that they could talk to. One patient during focus group discussions said that she had wanted to speak with women of the same age who also had a young family. She used the Breast Cancer Care internet forum and in doing so, had got in touch with two women who were of the same age and also had young children, who she found beneficial to share her experiences with:

'I needed someone who was in the same position as me with young family to discuss things and see how they were doing and coping with things.'

Some healthcare professionals during a focus group said that support groups that they have attempted to establish had not been successful because people had not turned up. Due to the difficulties encountered in setting up nurse-led support groups, healthcare professionals recommended other strategies, such as patients themselves deciding who and when to meet:

'A group of women who met through treatment have got together and they meet regularly.....that's what is meant to be, it has to come from them.'

One healthcare professional said that a 'buddy system' had been introduced on her ward for patients with a haematology cancer so that if patients wished to speak with someone who had been through a similar experience they were able to do so.

Another area that was highlighted as a form of support was the 'Maggie's Centre' where some of the patients and relatives found it an 'oasis' from the busy wards where you could go and sit and relax in a comfortable chair. Patients said that the staff at the Maggie's Centre didn't ask anything but they were there if you needed them for extra information and support.

5.5 Obtaining information from newspapers and television

Focus group discussions for our study highlighted the role of the media in providing information to patients about cancer. Patients during focus group discussions said that newspaper articles were informative about drug treatments and that this information was written in an accessible way. On the whole, they welcomed this type of publicity about cancer because it made members of the public more aware of the disease. They also noted however, that news or stories about cancer could be upsetting to watch. For example, one patient said that her children became upset whilst watching a particular soap opera because one of the characters died of cancer.

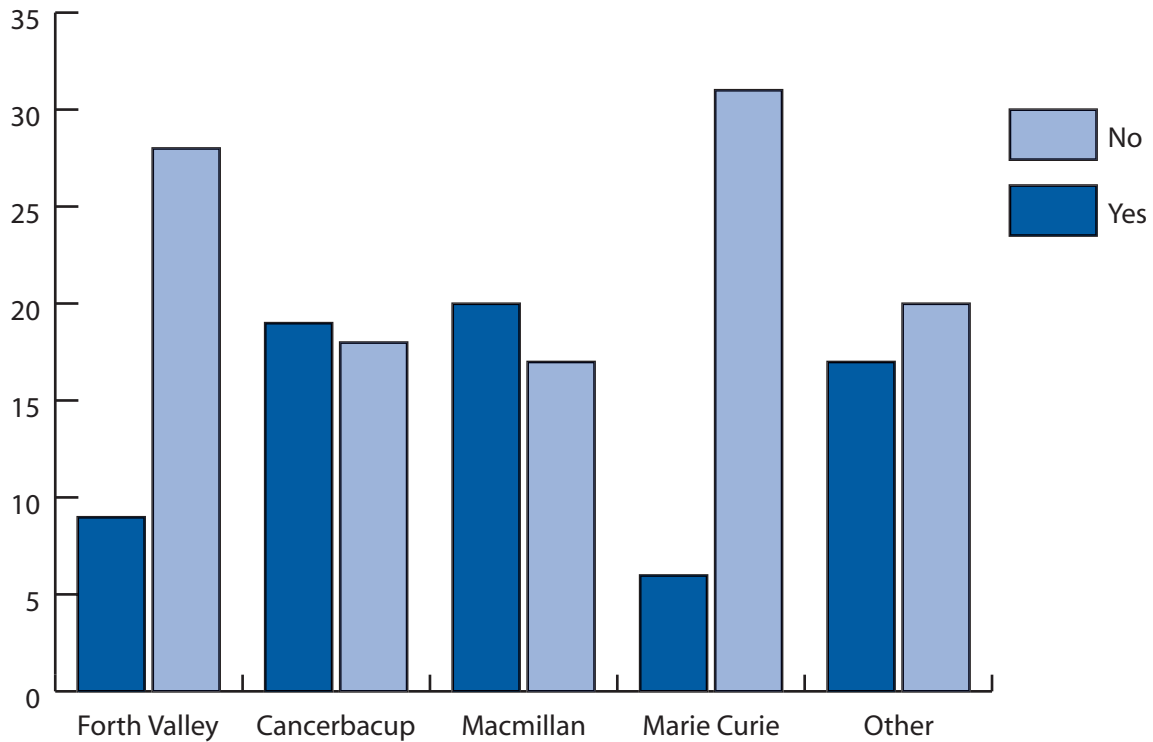
5.6. Organisations that produce information

There is increasing availability of cancer information materials that healthcare professionals and people affected by cancer can access that are produced by a range of organisations including government funded agencies, public and commercial publishers and broadcasters, and software producers. Information comes in a range of formats and with the growth of the World Wide Web patients are able to access a vast and diverse range of information.

Graph 3 highlights that Cancerbacup (19 out of 37), Macmillan (20 out of 37) and other organisations (17 out of 37) provide the majority of information that people affected by cancer receive in Forth Valley. Healthcare professionals reported that the other organisations that they have used include the West of Scotland Awareness project, NHS Health Scotland, Cancer Research UK, West of Scotland Clinical Network, specific

websites for specific cancers and certain appliance and drug companies. The graph also highlights that there was not much information used from Marie Curie, which is mainly about end of life care.

Graph 3: Frequencies of healthcare professional reporting organisations providing information (n=37)



During focus group discussions different healthcare professionals said the following about information provided by organisations:

‘We are very fortunate as many of the companies provide us with free written literature about many aspects of bowel cancer.’

‘Cancerbacup is easy to use and provides information for patients during their chemotherapy and radiotherapy.’

‘We’re using breast cancer leaflets just now, they just give snippets of information that lets the patient read through it and they can ask when they come back about chemotherapy etc.’

‘One of the booklets we just don’t use because it is far too high tech and it just scares the patients so that is why I use Cancerbacup.’

The use of information provided by Cancerbacup was re-enforced by patients during focus group discussions. Patients said that they had received written information about chemotherapy and radiotherapy by nurses prior to their treatment and that this information was photocopies of A4 information sheets provided by Cancerbacup or was information provided in the ‘blue booklet’. Some patients, but not all, had received the ‘blue booklet’ and said that they had not read everything in it but only the parts that they felt were relevant. The use of the ‘blue booklet’ produced by West Of Scotland Clinical Network may explain the relative lack of information produced exclusively by Forth Valley NHS since all relevant information should be provided in this booklet.

Healthcare professionals during a focus group discussion said that one of the reasons why they used Cancerbacup was because information was compartmentalised, which meant that they could provide information to patients when it was appropriate rather than handing them everything all at once. They also said that an advantage of the ‘blue booklet’ was that it was a ring binder, which meant that information could be put in at different times and stages and when the healthcare professional deemed it appropriate to do so. This gave healthcare professionals greater flexibility in relation to giving information out:

‘You can put in the information once you have gone over it with them and they can read it when they are ready.’

‘As the patient goes through their journey, different bits are added in as not all patients will go for chemotherapy or need radiotherapy.’

Healthcare professionals expressed concern that some of the information available was ‘too much’ for patients and that booklets contained information that was not relevant for that particular patient:

‘You sit with a pamphlet and score out sections that are not relevant to that patient before giving it to them it.’

'I wish you could just take out certain chunks of information and give it to them, as they really really do need to know that type of information.'

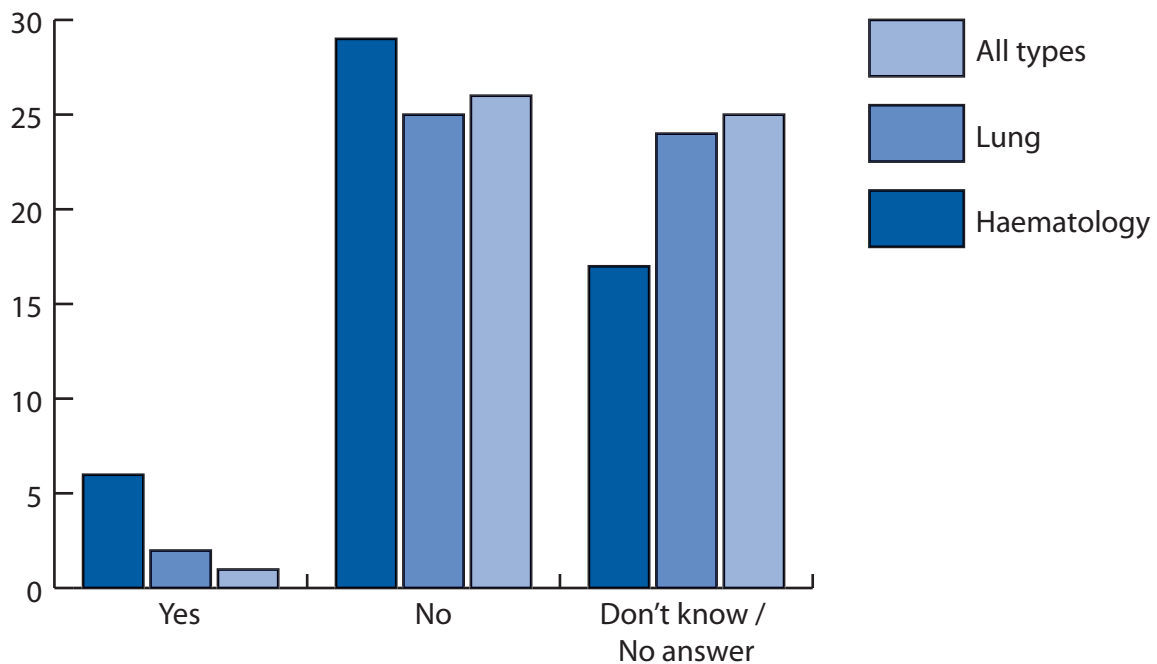
Another concern expressed by healthcare professionals about the use of different sources of information was that patients would not necessarily be receiving the same messages. They said that one of the advantages of introducing the 'blue booklets' in Forth Valley NHS was that information was increasingly becoming standardised, which meant that all healthcare professionals across the care system were aware of the information that patients had received and were handing out the same information. One healthcare professional during a focus group discussion explained one of the advantages of the 'blue booklet':

'The upside is that the information has been standardised so that the patients can go to the hospital, community and the hospice and everyone is telling them the same thing. We have managed to standardise the information which is great.'

5.7. Obtaining information from the internet

Graph 4a shows that the majority of healthcare professionals reported that they had no internet access available for patients and carers, with similar numbers either reporting they did not know if access was available or they did not answer the question.

Graph 4a: Frequencies of healthcare professionals reporting access to the internet for patients/carers (n = 52)



Focus group discussions highlighted that some patients and family carers accessed the internet for information from their own home. For example, one patient said that her husband would find information on the internet and would make a judgement about whether it was best to relay this information to her:

'My husband searched for information but at that time I couldn't and he would throw in different pieces of information through discussions over time. I could probably look at things now.'

Another patient said that she used the internet frequently:

'I couldn't get enough information. I think I was really looking for something to tell me how long I had on this earth.'

Another advised that people should be careful about what they read on the internet because some information was not positive:

'You have to be careful what you read because "click, click" and you can go to secondary cancer and that's not good for you.'

She said that some information on the internet could be quite 'scary'.

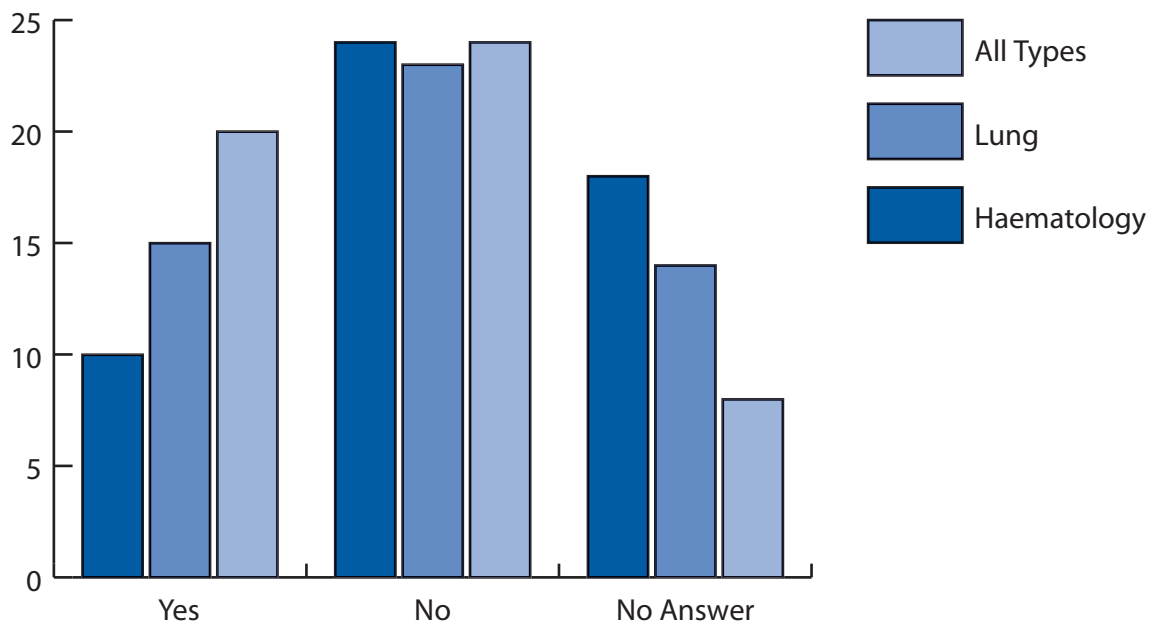
In some cases, internet users may become 'expert patients', with a knowledge of their cancer and the various treatments available which can lead to a feeling of empowerment and control over their situation (Ball & Lillis, 2001; Ferguson, 2000). Also, the importance of sharing experiences online can have a beneficial effect on patients (Powell, et al, 2003). Online virtual communities such as chat rooms and discussion groups have been used by some patients to communicate easily with others and learn more about treatment as well as giving and receiving emotional support. (Eysenbach, 2003 and Ziebland, 2004).

Healthcare professionals during a focus group said that some patients presented them with various treatments and information that they had gathered from specific web sites. This presented a challenge to healthcare professionals who had to spend time in the clinic discussing and clarifying the different treatments with the patient:

'They have such free access and they come back to the clinic and say "Why am I not getting blah blah?" And you have to sit and explain about what is best for them and what is available. It is also a pressure on us to try and keep up to date with all the different treatments that are available.'

Recommending the best sites to access could improve communication between the healthcare professional and patient as neither has to waste time discussing unreliable or irrelevant information (Penson, 2002).

Graph 4b: Frequencies of healthcare professionals reporting downloading information from the internet (n = 52)



Graph 4b shows that less than half of healthcare professionals (20 out of 52) reported downloading information for all types of cancers such as breast and colorectal from the internet, 15 and 10 out of 52 healthcare professionals reported downloading from the internet for lung and haematology cancers respectively.

Table 3 shows the most common sites used by healthcare professionals. The overwhelming majority (45 out of 52) reported that they used the Cancerbacup web site for information. The table also indicates that the Macmillan Cancer Relief web site was used by healthcare professionals (15 out of 52) but to a much lesser extent.

Table 3: Frequencies of internet sites accessed by healthcare professionals (n = 52)

Site	Total reporting use of web site
Cancerbacup	15
Macmillan	5
PatientsUK	3
Roy Castle	2
Cancer Research UK	2

Some healthcare professionals during a focus group said that they downloaded information from the internet for patients:

‘We go on the net a lot and download information on chemos, treatment, so that the patients have that.’

‘I’ll download off certain sites and say “If you want anymore information then you’ll need to contact them and they will send out the information.”’

Healthcare professionals expressed concern that there was a lot of ‘rubbish’ on the internet that would not be helpful for patients. The issue of quality on the internet is a problem as misleading information can be found alongside that which is beneficial (Penson, 2002). They suggested that healthcare professionals should recommend what they perceive as good sites for patients to access if they wished to use the internet. Therefore, healthcare professionals may have to act as gatekeepers or guides to information on the internet as some patients may not be aware of the best sites to access and in doing random searches, patients can gather information that increases their anxiety, or gives them the wrong information.

5.8. Quality of information

Poor quality information may be just as ineffectual at helping patients to gain knowledge and understanding of the disease, symptoms, treatment options and services as having no information provided at all. Misunderstandings can arise from poor quality information to the detriment of the patient. There are a number of tools available to assist in judging the quality and readability of information (Shepperd et al. 1999).

Patients during focus group discussions did not comment on whether the information that they received was well-written but they did point out that some of the information that they received were a photocopy of an article and that sometimes the copy was of poor quality and difficult to read. One patient said that some of the leaflets could be more professionally presented:

‘It could be more professionally presented, there were one or two with some spelling mistakes and if you didn’t know what the sentence was you had to guess as part had been cut off too soon.’

Healthcare professionals during a focus group in our study said that one of the reasons why they downloaded articles and photocopied them was because it was cheaper than purchasing booklets as there was no budget allocated for purchasing information booklets:

‘Information is free for patients but they have to contact the organisation themselves. It costs the health professional to access some of these organisations and we don’t have any budget for materials.’

‘I don’t have a budget for written material, so I need to download information.’

Healthcare professionals said that patients and relatives were able to obtain booklets free of charge from many organisations but healthcare professionals were requested to purchase them. This suggests that a financial imperative as opposed to issues of quality is a reason why some information is used rather than other types of information.

5.9. Information in plain English

‘Though inadequate health literacy skills are common, they often go unrecognized by cancer clinicians and researchers. Insufficient and inaccurate health knowledge, poor numeracy skills, and impaired ability to assimilate new information and concepts often interfere with patient’s ability to communicate with health care providers about cancer screening and treatment.’

Davis et al. 2002

It is incumbent upon the information provider to ensure that information is provided so that patients are able to process and understand it. About 24% of the UK population have poor literacy (Basic Skills Agency, 2003). Previous studies indicate that many healthcare pamphlets for people affected by cancer are produced at too high a reading level (Cooley et al. 1995). Even those patients who can read and write prefer information that is written in plain English and at an early age reading level (Butow et al. 1998).

Healthcare professionals in our study said during a focus group that there was little information for people who had poor literacy skills. They suggested that there should be more information with diagrams and pictures so that people with learning difficulties are also able to have hard copy information:

‘A thing that is never addressed is the fact that some people can’t read and write. You are constantly doing diagrams cause everything is written, some more diagrams would be more helpful.’

‘I agree that more pictures are needed as they work well with patients who have learning disabilities.’

‘Some of the information is too wordy, too scary it completely bamboozles them.’

5.10. Booklets and leaflets written in a language other than English

The overwhelming majority of healthcare professionals (31 out of 37) reported either that they had no booklets and leaflets written in a language other than English or that they did not know if they were available.

This finding echoes that of other studies which have shown that patients who cannot read or speak English are being disadvantaged because virtually all information is produced in English (Cancerbacup). In the census carried out by Forth Valley in 2001, 6,339 people of the total population were from ethnic minorities (Sheehy, 2004). A recent study commissioned by Forth Valley Primary Care Operating Division highlighted that the information needs of people from an ethnic minority background were not being met and one of the key recommendations of the study was that interpreters should be made available (Sheehy, 2004). Forth Valley Trust makes use of the National Interpreting Service, which is accessible on a 24-hour basis (Scottish Executive, 2003) so that interpreters are on hand if required but this service is not designed to translate written information and in our study we did not ask about whether or not this service was used.

5.11. Booklets and leaflets for people with sensory impairment

There are an estimated 2 million people residing in the UK with sight impairment (Royal National Institute for the Blind, 2003). A recent study carried out in Forth Valley found that visually and hearing impaired patients were at a disadvantage because information was not available in the correct format for them (Sheehy, 2004)

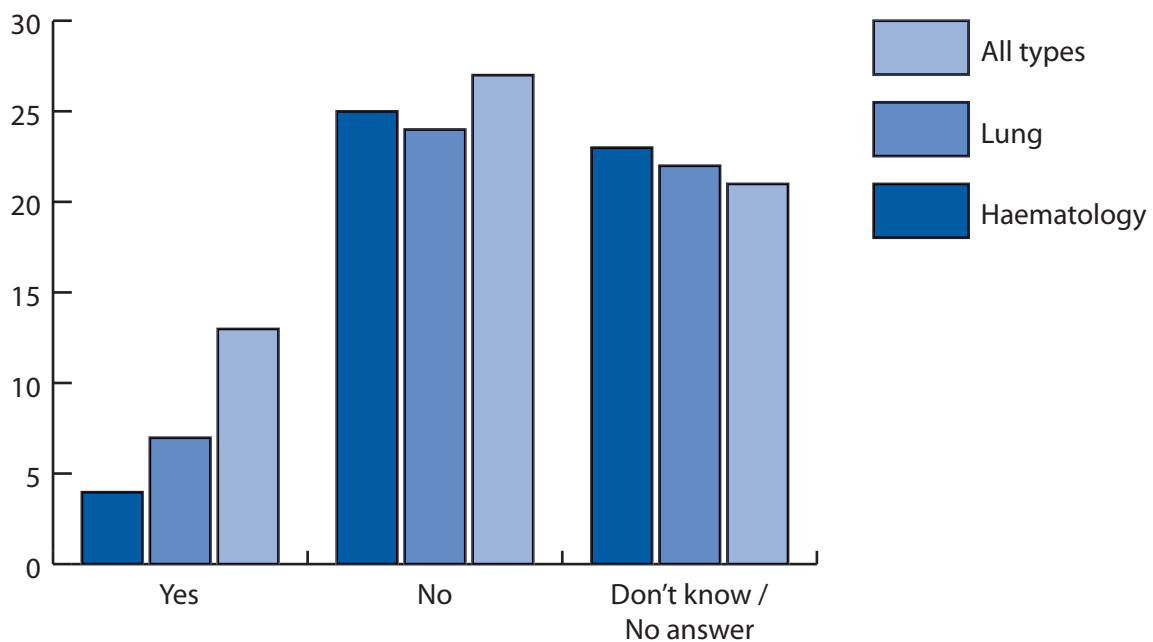
The majority of healthcare professionals (31 out of 37) in our study reported either that they did not have information available for people with sensory impairment or that they did not know if it was available.

5.12 Audio and video material

Previous research suggests that well designed video materials and audio-tapes can be useful additional information within oncology (Tattersall et al. 1994; Tattersall and Butow, 2002; Thomas et al. 2000).

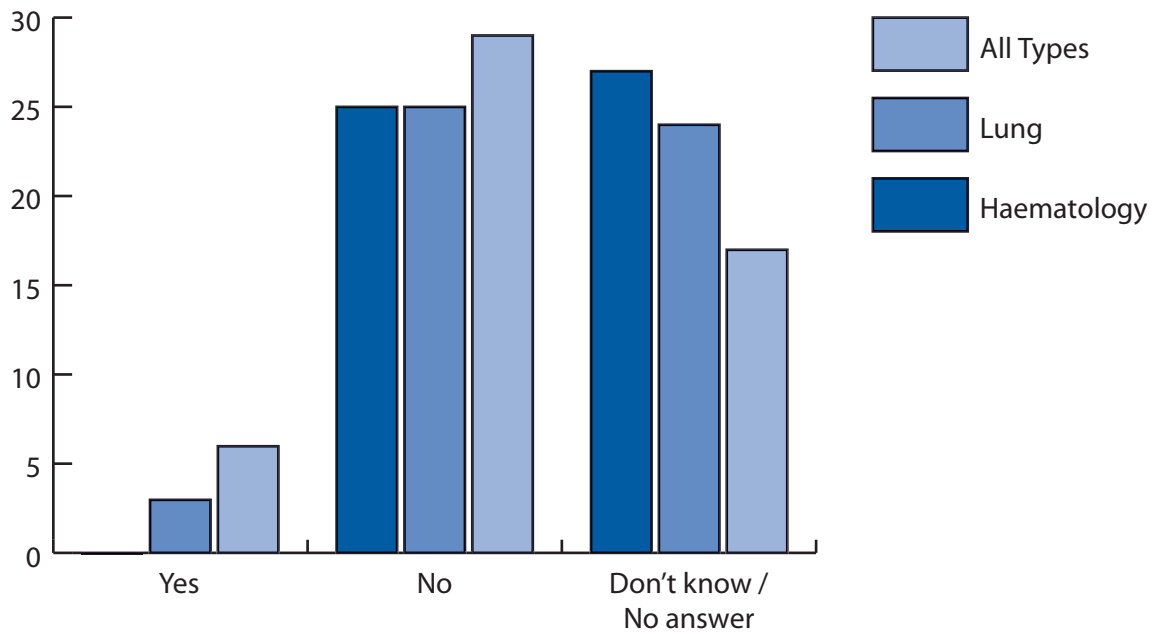
Graph 5a shows that very few healthcare professionals (13, 7 and 4 out of 52) reported having videos available for all types of cancer, lung cancer and haematology cancers respectively. The majority of healthcare professionals reported that they had no videos available, with similar numbers reporting either that they did not know if videos were available to give to patients/carers or did not answer the question.

Graph 5a: Frequencies of healthcare professionals reporting the availability of video tapes for patients/carers (n = 52)



Graph 5b shows that only a handful of healthcare professionals (5, 3 and 0 out of 52) reported having audio tapes available for all types of cancer, lung cancer and haematology cancers respectively. The majority of healthcare professionals either reported that they had no audio tapes available, with similar numbers reporting they did not know if audio tapes were available to give to patients/carers or did not answer the question.

Graph 5b: Frequencies of healthcare professionals reporting information about the availability of audio tapes for patients/carers (n = 52)



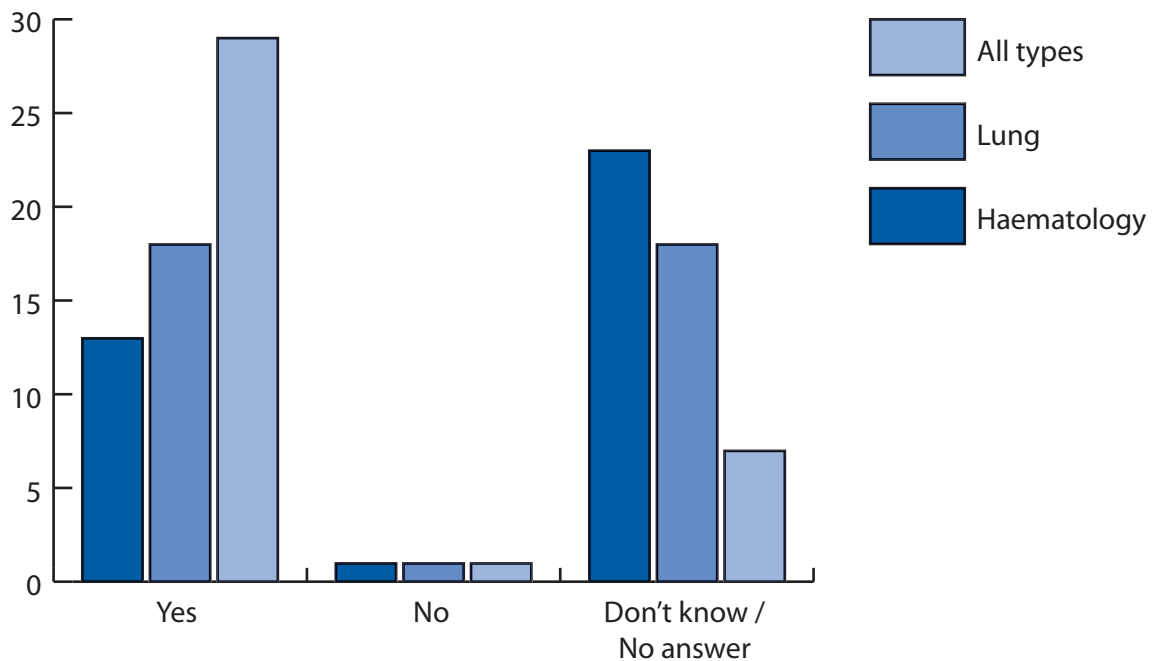
5.13. Information about diagnosis

‘Most patients with cancer want and need detailed information about their diagnosis and about treatment options.’

NHS Cancer Information Strategy

Diagnosis ‘is the process of identifying the disease by the signs and symptoms’ (National Cancer Institute). Graph 6 shows that most healthcare professionals (29 out of 37) reported having booklets and leaflets available about diagnosis for all types of cancer and around half or just less than half (18 and 13 out of 37) of healthcare professionals reported having information available about diagnosis for lung and haematology cancers respectively.

Graph 6: Frequencies of healthcare professionals reporting information about diagnosis (n = 37)



Previous research in Scotland indicates that most patients prefer to be given their diagnosis verbally by a hospital doctor (Meredith et al. 1996). Patients during focus group discussions stressed the importance of verbal information at the point of diagnosis. Some of the patients said that verbal communication was sufficient at that point because they were 'shocked' or 'in a state of shock' and did not wish any further written information:

'I think what we got was enough. He was really very good at explaining what I needed and I didn't need any more information at that point.'

'At that time I couldn't cope with any more information.'

All patients during focus group discussions said that they wanted their diagnosis and discussions about surgery to be conducted face-to-face with the consultant. All patients praised the consultants for spending a lot of time with them to discuss their diagnosis and what treatments they would have. None of the patients said that they had received any written information about surgery and none of them said that they

would have wanted it. One reason why patients said that it was important to receive this information verbally was because surgery varied from patient to patient:

‘Because it’s surgery it is so specific to you that it has to be face to face; written paperwork would be too general.’

Healthcare professionals during a focus group in our study said that nurses did provide written information about surgery for patients and that this was handed out at the nurse’s discretion. They agreed that written information at the point of diagnosis was not always appropriate:

‘If you give them too much too soon they can’t cope with it and they can’t move on for focusing on their disease.’

‘There is written information about breast surgery explaining what they need to know especially post surgery. However, I sometimes leave it until they are in having their surgery as some patients can’t take everything on board at that time.’

Whether or not patients were given written information also depended on whether choices about different treatments had to be made:

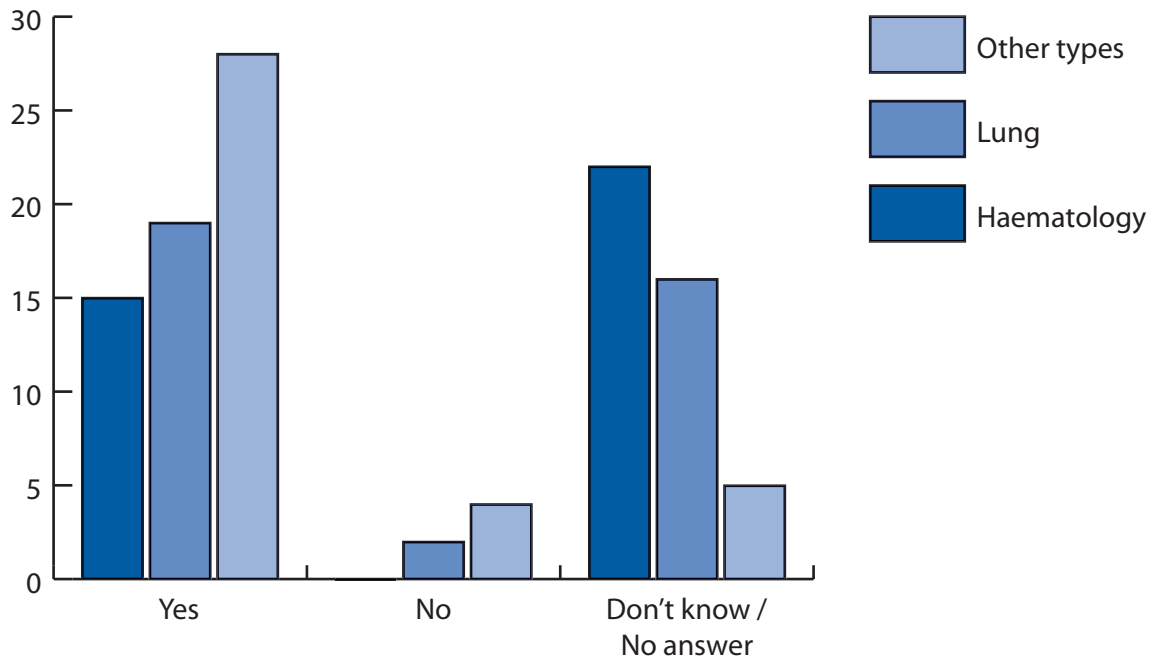
‘It depends on what type of surgery they’re having. If it’s for bowel cancer then there is only one operation; if its for prostate then there could be lots of different operations and procedures. Possibly written information is needed when there is one or more options to consider.’

5.14. Information about radiotherapy and chemotherapy

Graph 7 shows that most healthcare professionals (28 out of 37) reported having booklets and leaflets available about treatment for all types of cancer and around half or less than half (19 and 15 out of 37) of healthcare professionals reported having

information available about treatment for lung and haematology cancers respectively. These figures are similar to those reporting having information about diagnosis.

Graph 7: Frequencies of healthcare professionals reporting information about treatment (n = 37)



Our study found that information about treatment was given both verbally and in writing. Patients during focus group discussions in our study said that they were 'inundated' with written information about chemotherapy and radiotherapy treatments, which they found useful:

'Loads and loads of stuff there explaining the drugs, the side effects, the timing of it, everything was explained in details what to expect.'

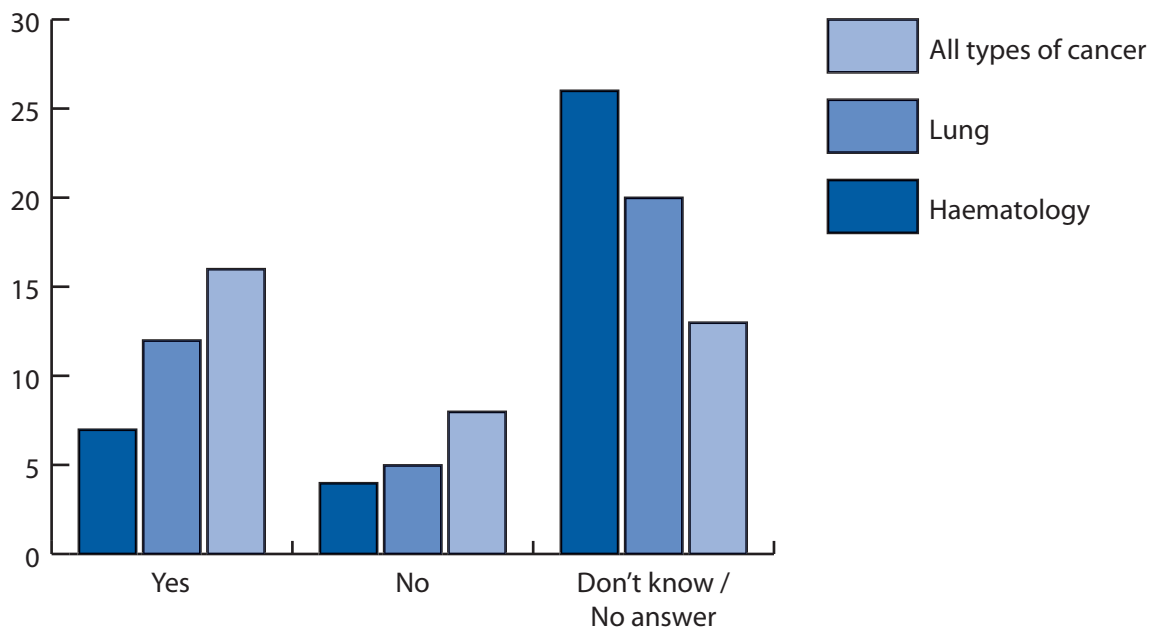
Although most patients said that they had all of the information that they needed about radiotherapy and chemotherapy treatment, one patient said that she was not given enough information about the side-effects of radiotherapy:

'I wasn't told what to expect from my radiotherapy, I was told to apply cream but immediately after my radiotherapy my skin was burned and very blistered, and I was shocked at how bad it looked but within about 10 days it was as good as

5.15. Information about follow up

Follow up is when cancer patients complete their primary treatment and return to the community. They will be looked after by their GP and other members of the primary health care team but, historically, many have also attended for hospital-based follow up.

Graph 8: Frequencies of healthcare professionals reporting information about follow up (n = 37)



Graph 8 shows that around half of healthcare professionals (16 out of 37) reported having booklets and leaflets available about follow up for all types of cancer and a third or less (12 and 7 out of 37) of healthcare professionals reported having information available about follow-up for lung and haematology cancers respectively. These figures show that there is less information available about follow-up than about diagnosis and treatment.

This relative lack of information about follow up was also discussed during the patient focus groups. Patients said that they had received information after their treatments although they said that they would have welcomed more information about what to expect once their treatments were over:

‘No-one tells you what happens next; what to expect. It is very difficult for them [healthcare professionals] to do that but you still don’t know what to expect.’

One patient felt that she had been ‘abandoned’ after major surgery when she returned home. She said that her GP did not know that she had been discharged from hospital until several days after she had already been at home and said that communication between the hospital and her GP should have been much faster:

‘The communication between the hospital and the GP is poor, I felt so abandoned when I got home and it was a few days later that the district nurse and the GP popped in. I wept because I was so relieved to know that there was someone that I could contact if I needed anything.’

Another patient described how she felt vulnerable after the treatments had ended:

‘Everything snowballed and you just go from surgery to treatment and get through each treatment and then there is nothing, your appointments get further apart and you want this but you are still very vulnerable, its strange.’

Other patients described how they felt after their treatments had finished:

‘I have survived longer than was predicted and now you begin to wonder is it coming back? When will it comeback? How will I know if its back? Its like little Gremlins in your head.’

‘The time is getting longer between consultations, we feel a bit isolated.’

‘All the emotions have gone in to the treatment and everything has now finished. You think a headache – is this another tumour?’

The focus group discussions also highlighted a need for information about depression and counselling provision. One patient said that two months after her treatments had finished she started to feel depressed and her GP told her that she was experiencing post traumatic stress. She said that talking to her GP about how she felt made such a positive difference:

'I just started crying and feeling more depressed and more depressed. I went to see the doctor about something else and we chatted about things and I told him how I was feeling and he said that it was post traumatic stress. I took the tablets for a few days but felt better just for talking about it.'

Healthcare professionals during a focus group discussion for our study acknowledged that there was not sufficient information about after-care. They said that patients could be left feeling 'abandoned' at a time when they were 'vulnerable' because they were no longer in regular contact with healthcare professionals or being continuously monitored:

'We back off because they have been in a system where they have been seen every few weeks; had their bloods checked and yeah it must be frightening as they don't have the security anymore.'

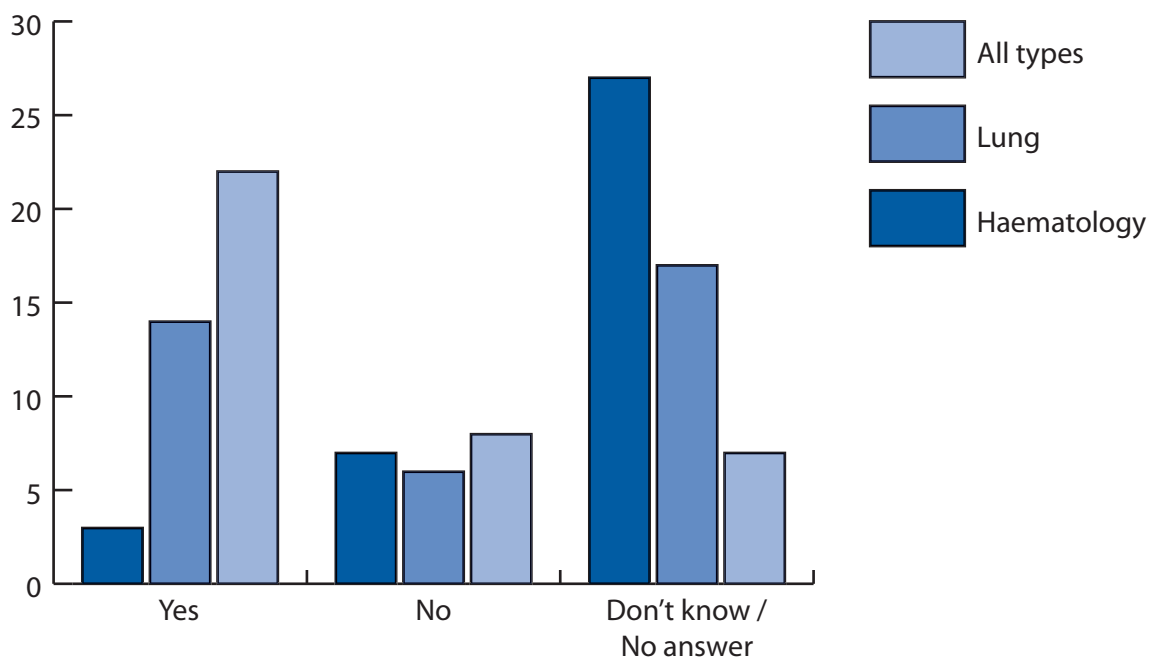
'They are very vulnerable; it's such an anticlimax for them.'

5.16 Information about palliative care

Palliative care 'involves the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments' (NICE, 2004). Graph 9 shows that just under two-thirds of healthcare professionals (22 out of 37) reported having booklets and leaflets available about palliative care for all

types of cancer and around half (15 out of 37) of healthcare professionals reported having information available about palliative care for lung cancer and a very small number (3 out of 37) of healthcare professionals reported having information about palliative care for haematology cancers.

Graph 9: Frequencies of healthcare professionals reporting information about palliative care (n = 37)



Focus group discussions with the healthcare professionals highlighted that they perceived that there was a lack of information about palliative care for patients and their relatives:

‘The issue for me is that I deal with patients at the end stage of life and they either die in the hospital or the hospice or at home but there is a lack of information for relatives at this time and its an area that needs to be looked at.’

‘Non malignant palliative care is neglected, there is a lack of information, having support and information can give them huge help and benefit because there is such a lack of information.’

Healthcare professionals during a focus group noted that introducing services provided at Strathcarron hospice was sometimes difficult because of its association with death and dying. Further discussion about issues associated with death and dying are presented in the following section.

5.17. Giving and receiving bad news

All staff concerned with patient care should be aware of potential problems with communication and be aware that patients often find it difficult to take in information given during consultations, especially just after hearing a diagnosis of cancer or other 'bad news'.

Scottish Executive, 2003

Focus group discussions highlighted that some patients wanted to know everything that there was to know about cancer whereas others said that they did not want negative information. All patients said that they wanted to know more about positive stories and about people who were cancer survivors. Not surprisingly, patients acknowledged that what they really wanted to hear was that they were going to be alright.

'No you just want to be told that, okay you have got this tumour but we're going to do this then blast it with radiotherapy and you have a chance.'

'He said, "It is going to be alright, you have a tumour in your bottom but we can fix that" and that was so reassuring.'

None of the patients, including those that wanted to know everything that there was to know about their cancer, said that they wanted information about issues associated with death and dying such as funeral arrangements and wills. They said that they would rather ask if they wanted help with these matters. Healthcare professionals

during a focus group on the other hand, said that some patients did want information about these issues:

‘The big issues have to be dealt with like wills and funeral arrangements, its not easy but it does help in the long run.’

‘Once people have accepted that they are dying, some people get a lot of pleasure knowing that their funeral is organised and that it has been discussed with the family and that there is no pressure on the family.’

Healthcare professionals during a focus group said that since GPs were usually the first port of call for patients they needed to forewarn patients about the fact that they may have cancer ‘without putting the fear of God in them.’ However, this is tricky since they do not have the necessary information upon which to discuss a patient’s diagnosis until after the patient has been further examined.

One patient during a focus group discussion said that a hospital consultant had told her that her diagnosis could be ‘very serious indeed’. After seeing a specialist consultant and upon further examinations her prognosis turned out to be much better than initially predicted. She said that the first consultant should not have unduly worried her by suggesting that her diagnosis could have been very serious. This was raised by another patient who said that he had been introduced to the Macmillan nurse before he had been told about his full diagnosis from the consultant. He said that he was told that he had a tumour and was then:

‘Introduced to a Macmillan nurse and discussing possible treatments and support from areas such as Strathcarron Hospice before the doctor having all the results.....It is verging on the side of cruelty.’

Our study therefore suggests that there is a fine balance between being overly paternalistic and not informing patients of their potential diagnosis and prognosis and making patients extremely anxious and unduly worried. Healthcare professionals during a focus group discussion said that the only way to get the balance right was to ask patients if there was anything else that they wanted to know:

'I think the only way, because it is really difficult to know how much information patients want, is just to keep on saying is there anything else you want to know.'

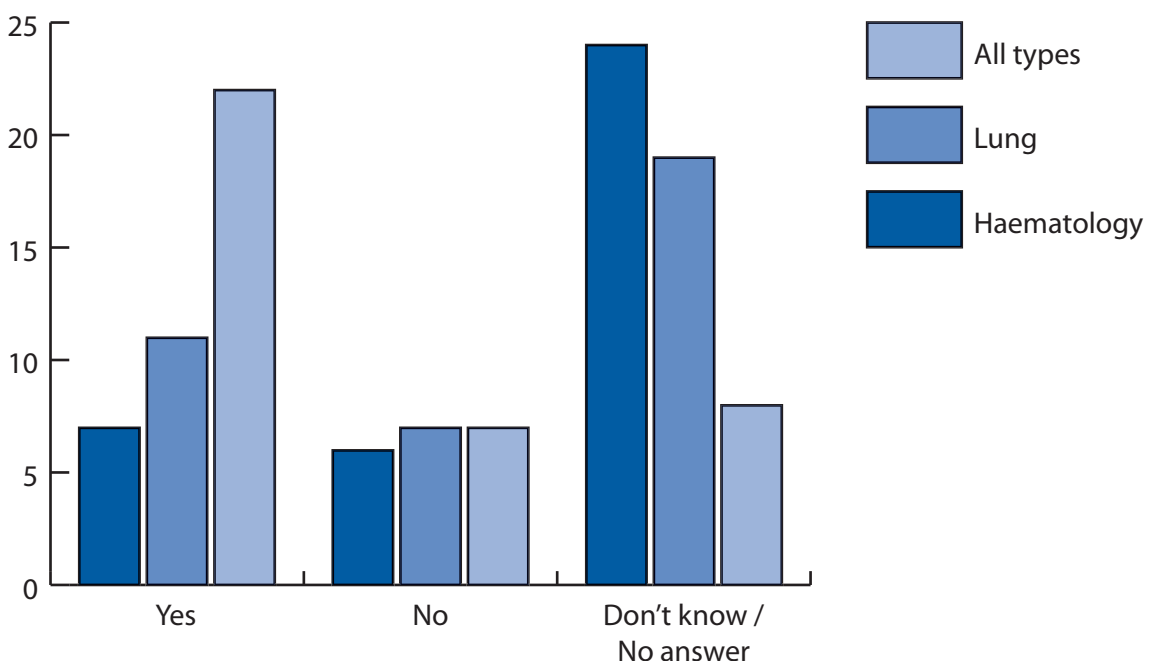
'Do we have to give them everything....if they want to know they will come and ask sometimes it's as if we just take over?'

Healthcare professionals agreed that if a patient's prognosis was poor they 'have to give them the bad news. There's no way round that.'

5.18 Information about finance/welfare benefits

Graph 10 shows that just under two-thirds of healthcare professionals (22 out of 37) reported having booklets and leaflets available about finance/benefits for all types of cancer, and a third or less (11 and 7 out of 37) of healthcare professionals reported having information available about finance/benefits for lung and haematology cancers respectively.

Graph 10: Frequencies of healthcare professionals reporting information about finance/benefits (n = 37)



Despite two-thirds of healthcare professionals reporting having information about finance/benefits, focus group discussions indicated a need for more information about finance/benefits. Healthcare professionals said that it was a difficult subject to raise with patients because patients may be embarrassed to discuss their personal financial situation. They suggested that someone familiar with the welfare benefits system needed to be available to offer patient advice. One healthcare professional said that a welfare advisor was available for patients on the ward where she worked.

The following quotations from different healthcare professionals provide a good indication of some of the difficulties encountered relating to providing financial advice and support to patients:

'I have to be honest, finances are not dealt with, that is such an issue when you are going in and dealing with young couples with young families who have mortgages or self employed people; its not being addressed.'

'The new benefits scheme is there but the problem with it is, that everything gets delayed, we're coming in way down the line and looking at these things and then the patients find out that they have missed benefits and that is really upsetting for them.'

'I know that the oncology unit has Citizen Advice people there certain days a week, finances are a big issue but you really need someone who is, deals with it constantly, they know how to fill in the forms, they know how to word it properly.'

'There is no time to sit and go through all this with the patients, the girls can do a home visit and sit and go through it with the patients and they know what they are doing.'

5.19. Information gaps

Patients during focus group discussions said that they wanted more information about the following topics:

1. Greater emphasis on how radiotherapy treatment can burn the skin and the importance of applying lots of barrier cream.
2. More emphasis on the importance of exercise.
3. Information about diet and nutrition. A healthcare professional during a focus group for our study said that oncologists in Forth Valley had produced a document about nutrition for patients. What we do not know however, is the extent to which this is widely available.
4. Information about travel insurance. Healthcare professionals during a focus group for our study said that it was confusing giving advice about travel insurance because of the 'small print' and details of insurance companies and policies becoming quickly out of date.
5. Contact details for cancer research organisations.

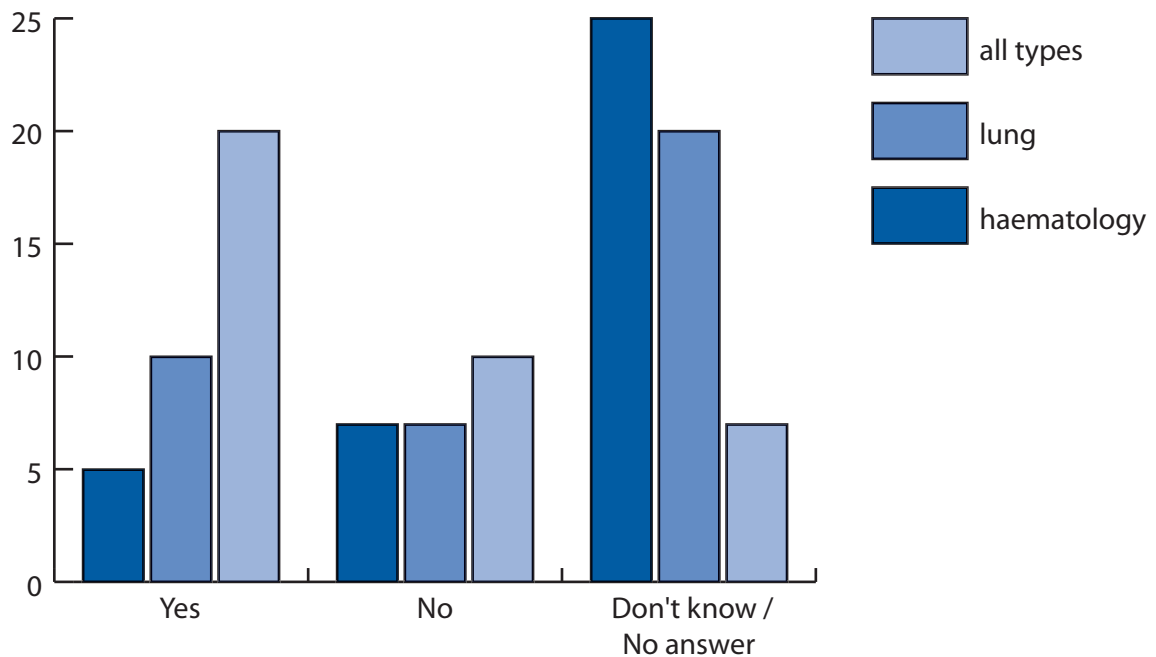
Patients acknowledged that most of this information was already available in the 'blue booklet'. This suggests that healthcare professionals may need to also re-enforce particular information and alert patients to the fact that this information is readily available.

5.20. Information for family carers

Graph 11 shows that over half (20 out of 37) of the healthcare professionals said that there was information for carers of patients with types of cancer, such as breast and colorectal cancer; 10 and 5 reporting that there was information for carers for patients and lung and haematology cancers respectively. However, most of these healthcare

professionals as the graph indicates, either did not know whether information was available for carers or did not answer the question. This is perhaps a further indication that there is a need to gauge a clearer picture of what carers' needs are.

Graph 11: Frequencies of healthcare professionals reporting information available for patients and carers (n = 37)



This lack of information for carers was re-confirmed during focus group discussions with patients, carers and healthcare professionals. Patients and carers said that there was very little information specifically for family carers. They said that family carers read the information that they were given but that they did not have information specifically to support them and facilitate their needs. Patients said that information for their partners, spouses and children would have been beneficial because having cancer affected the whole family. One of them said:

'You're trying to cope for you but you're worried about the impact it's having on your family.'

Some patients did not take information about cancer into their home because they did not wish to 'frighten' their children too much. Others said that their children were

told that their parent had cancer and that they asked questions such as 'Will I get it?' One patient mentioned that the 'blue booklet' did have the name of a book specifically written for children of parents with cancer although others said that they were not aware of this even though they also possessed the 'blue booklet'. The following quotations are from different patients and relate to their children's experiences of cancer:

'Strangely, my eldest daughter said, "that lump you had mum, was it cancerous?" Don't know if she had heard things at school but I thought it was strange and she asked, "will I get it?"

'The consultant said, "it's up to yourself what you tell them, you know your kids better than anyone, you do what you feel is best."

'I didn't tell them because I wanted everything to be as normal in the family as much for my sake but also for them.'

'I just feel it was a shame for my kids as nobody seemed to think about them and there was no information for them.'

Healthcare professionals agreed that it was up to the parents whether children were informed or not and that healthcare professionals should respect their wishes and not be judgemental. Healthcare professionals also stated that most support given to family carers was provided verbally. For example, they advised parents on talking to their children about cancer and on occasions talked to the children themselves if the parents wanted their input. As the following quotations demonstrate, most healthcare professionals said that children should be told about cancer verbally:

'We do that verbally, we give them a lot of support to their husbands and their kids and we give them a lot of advice on how to go about telling the kids, a lot of verbal interaction on how you deal with that.'

'There have been times that I have had to tell the children as the parents just won't do it sometimes, although there is the literature, due to the circumstances you just have to do it verbally as it is so emotive.'

'It would be difficult to put something like that into black and white as every child is so different and everyone's circumstances are so different.'

'Yeah, what age would you write the information for because one child at 5 can have a different intellect from another child at 5.'

'Do you really want to give children lots of information that put it into their minds, it's very hard to work out what's best.'

Healthcare professionals expressed concern about patients and carers being given different information because this could create confusion. They said that it was more appropriate to hand out the same information to both parties:

'You're getting into difficulties if you're giving different information to partners etc. than the patient; more room for confusion; I guess the best thing is to keep things as open as possible.'

6. Conclusion

This study highlights a number of issues that are relevant to developing an information strategy. On the whole, our study suggests that individual healthcare professionals or teams were responsible for the provision of information and there was little indication that designated information officers were responsible. Some healthcare professionals said that they did not have booklets and leaflets for some types of cancer. Unfortunately, our study is unable to report the reasons why they did not have them and there may be valid reasons for this lack of information.

A strong message from this study is the importance of verbal face-to-face communication. Patients obtained most of their information from healthcare professionals verbally and only wanted booklets and leaflets as 'back-up.' Other patients and cancer survivors were another significant source of information who also provided emotional support. Patients also accessed information relating to cancer from newspaper articles, magazines and from television programmes. Healthcare facilities did not appear to provide patient access to the internet although some patients and carers did use the internet from their own homes. This was a challenge to healthcare professionals because patients would present them with information that they had downloaded from the internet that may not be from a credible source. They suggested that healthcare professionals should provide patients with credible web sites to minimise this situation.

The most popular sources of information that healthcare professionals used to give to patients were Cancerbacup, Macmillan and other organisations such as, NHS Health Scotland and West Of Scotland Clinical Network. Information that could be given out in small sections rather than all at once was preferable, which was one of the reasons why healthcare professionals liked to use the 'blue booklet' produced by West Of Scotland Clinical Network and information from Cancerbacup. Some of this information from organisations was downloaded from the internet. The quality of this information was not always up to standard, particularly if they were photocopies of originals. Some healthcare professionals would have welcomed the opportunity to purchase booklets but there was no budget available, which was one of the reasons why they relied on

photocopied material. Healthcare professionals welcomed the standardisation of information so that all sectors of the whole system of care were relaying the same information to patients.

Our study highlights that there was little information for people who had poor literacy skills, whose first language was not English, or who had a sensory impairment. There was also a lack of availability of information in audio or video format for patients. In addition, the study found that there was little information specifically to address the needs of family carers and children.

Booklets and leaflets were available about diagnosis, treatments and palliative care but there was slightly less information about follow up. Most of this information about diagnosis was handed out at a nurse's discretion whereas information about chemotherapy and radiotherapy appeared to be handed out as a matter of routine. Patients said that they would have welcomed more information and support after their treatments had finished. Although the questionnaire results showed that information was available about finance/benefits, focus group discussions indicated that may not be meeting patients' needs. Similarly, the questionnaire found that most healthcare professionals reported having information about palliative care although healthcare professionals during a focus group discussion said that more information about end of life care was needed. This suggests that whilst information may be available it may not be used. In fact, a key finding from this study is that even though information is available in booklets and leaflets it does not automatically follow that patients will read or absorb this information.

Obviously, patients wanted to be told that they were going to be alright. A key challenge therefore for healthcare professionals was giving realistic and appropriate information to patients but that did not cause undue and unnecessary anxiety. Patients said that they wanted more stories about cancer survivors and they did not think that it was appropriate to have information about funerals and wills handed to them. The study found that there was not much information that was provided by Marie Curie, which may reflect some of the difficulties in providing information about end of life care.

7. Recommendations

Based on this small-scale study we recommend the following points be taken into account in the further development of an information strategy for Forth Valley NHS:

- » Appoint information officers with responsibility for providing and monitoring the quality of information.
- » Provide more information for patients whose first language is not English.
- » Provide more information for patients with a sensory impairment.
- » Make sure that all information is written in plain English.
- » Consider providing more information in video and audio format.
- » Introduce a budget so that healthcare professionals can purchase booklets for patients.
- » Make sure that photocopied information for patients is of good copy.
- » Continue with the strategy whereby information is given out in small sections and provided at different times rather than all at once.
- » Continue with the strategy of standardising information so that healthcare professionals across the whole system of care provide the same information.
- » Provide more information for members of a patient's family in order to accommodate their needs.
- » Continue with the strategy of providing information verbally which is then 'backed up' with written information. Ensure that all information is given

verbally even if it is also handed out in written form.

- » Continue with the strategy of providing information about diagnosis and surgery verbally but introduce more information about after-care and consider introducing more information about support for patients after they have finished their treatments.
- » Continue to develop strategies so that patients can communicate with each other. For example, consider re-arranging the waiting rooms so that some patients can talk together quietly; continue to provide information about support groups and consider expanding the 'buddy system'.
- » Ensure that healthcare professionals do not assume that because information is produced in written format that patients will read or absorb this information or that healthcare professionals will use it.
- » Develop the financial advice service by making sure that all healthcare professionals and patients are aware of its existence.
- » Give patients more 'good news' stories, such as information about cancer survivors.
- » Recommend key web sites for patients so that those who feel empowered by using the internet to access information are accessing web sites of the highest quality and limit information overload.
- » Consider introducing more internet facilities for patients on NHS premises.

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