



Austin & Repatriation
Medical Centre

Patient Education Project 2

Report on
interviews with
English, Greek and Italian-speaking consumers
and carers about their experience of
receiving colorectal cancer surgery information

Health Issues Centre

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Health Issues Centre is an independent, health policy analysis group which researches consumer perspective's on health. Our aim is to help create a more equitable health care system that is more responsive to users, particularly those who are disadvantaged by the current arrangements.

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1. INTRODUCTION

The PEP2 project aims to evaluate A&RMC's systems for providing education/information to English-speaking (ES) and non-English-speaking (NES) patients, and determine the effects of providing good quality, culturally specific education/information on health outcomes.

As part of Phase 1, a consultation process with consumers was implemented in the first half of 2002. It sought to discover consumer experience of existing pre-operative and discharge information/education for colorectal surgery and their suggestions of how to improve this experience.

Information gained through the consultation process with consumers will be incorporated into developing improved education/information packages in the three chosen languages (English, Italian and Greek) in line with the A&RMC Best Practice Guidelines (BPG). The education/information package will be piloted with a second group of A&RMC patients in the second half of 2002.

Twenty-two A&RMC patients were recruited, consisting of three sub-sets of patients (1 ES, 1 Italian-speaking, and 1 Greek-speaking group). Italian-speaking and Greek-speaking were chosen as these are the two largest non-English-speaking groups that have colorectal surgery at A&RMC.

2. METHODOLOGY

2.1 Qualitative research

Health Issues Centre and the A&RMC used qualitative research methods to gather data from consumers with colorectal cancer about their experiences of information provision from A&RMC.

Different models of research can explore consumer experiences in different ways. Qualitative research methods—in this case focus group interviews and individual in-depth interviews—are particularly useful in understanding the richness of participants' experiences, perspectives and preferences.

In health research, qualitative methods allow researchers to document and interpret the different ways in which consumers make sense of their experiences of health and disease and how these experiences influence health service delivery and health outcomes. Research findings typically are limited to a specific time, place and situation (Patton 1990).

Qualitative methods are considered useful for exploring issues about the experience, access, response to, or understanding of services when little is known about the perspective of the target group. The advantage of qualitative research is its capacity to ask questions that cannot be asked using quantitative research methods. (Howe, Degeling, Hall, 1990: 8). In this case, qualitative research assists the PEP2 project in obtaining an in-detail understanding of factors impacting on information provision; in particular, the constraints to consumer information provision and the usefulness of the information, including situations where information materials were appropriate or inappropriate.

Health Issues Centre researchers, together with the PEP2 project officer, conducted a focus group interview, a small group interview and individual in-depth interviews with consumers (patients and carers) who had been treated for colorectal cancer at the A&RMC during 2000 and 2002.

A decision was taken to include carers as 'surrogate consumers' (Consumer Focus Collaboration (a) 2000: 60). In this case it was considered appropriate to include carers as they were often in receipt of information regarding colorectal cancer and treatment.

A focus group interview is not simply a group interview. Its defining characteristics include: participants are unknown to each other, the interview is one-off and participants respond to each other and less to the facilitator. (Wadsworth 1997: 106) Interaction between the focus group participants means that issues get explored in greater depth than is possible with individual interviews. Participant interaction with each other can also help participants' confidence to express their views (Cooper, Jenkins 1998: 53).

While the content of the discussion is controlled by the questions in the interview guide, participants' interest have priority and often unexplored or unexpected issues arise in discussion.

Consumers who agreed to participate in the project, but did not want to participate in a group setting, were given the option of an individual interview. In-depth interviews involve a series of face-to-face, detailed discussion with consumers, providing opportunities for them to discuss an issue from their perspective.

(Consumer Focus Collaboration (b) 2000: 39). In-depth interviews are particularly useful methods when the information being sought is considered sensitive or confidential, when it's difficult for consumers to get to venues for focus group interviews, or when consumers might not want to participate in a focus group interview.

Consumers were paid \$25 for their participation whether in the focus group interview or the individual interviews. The focus group and group interviews were conducted at the A&RMC. Individual in-depth interviews were conducted at consumers' homes and at the A&RMC.

2.2 Ethics

Ethics approval was sought and received from the A&RMC.

2.3 Consumer recruitment

Interview participants were recruited by the Health Issues Centre, together with the PEP2 project officer, from patient list obtained from A&RMC Outpatients Department.

Recruitment of participants was a two-stage process. Firstly, Health Issues Centre project officers and the PEP2 project officer met with consumers at the A&RMC Outpatients Department during April 2002. Consumers were provided with written information about the purpose of the project and the reasons for the focus group interview and individual interviews. Secondly, Health Issues Centre researchers and the PEP2 project officer contacted consumers via telephone to confirm that they were interested in participating and, if so, negotiating a suitable time and venue.

Eighteen interviews were conducted comprising sixteen individual interviews, one focus group interview with four consumers and one carer, and one small group interview with two consumers.

2.4 Interview questions

Interview questions aimed at understanding consumers' experiences of existing information provision as well as identifying the changes required to information produced and disseminated. Interviews explored the following themes: delivery of patient information; quality of the information received; patients' responses to receiving the written information; design and format of the written information; patients' satisfaction with receiving the information, and use of interpreters.

2.5 Data analysis

Data analysis involved content analysis by reading through the transcripts and coding the data for common themes and concepts (including phrases, descriptions or exchanges between the participants) that appeared during the discussions as these related to the interview questions. Secondly, the data analysis involved open coding, a method based on grounded theory (Patton 1990: 67). This involves coding categories reflecting the content of the data collected rather than the interview guide questions; that is, data that does not pre-fit categories and findings are 'grounded' in the experiential world.

The themes, patterns, categories, descriptive examples and quotations identified through the analysis become the basis of the interpretation of the findings. Interpreting unexpected themes and patterns and considering what they indicate in terms of the project was also critical.

The findings from the analysis are explained. In offering explanations and drawing conclusions it was essential to draw on the research questions, the service delivery arrangements, the participants, the context and the literature review.

2.6 Limitations of the research

This research does not assert to be an authoritative study of all consumers' experiences of existing pre-operative and discharge information/education for colorectal surgery.

Since the study was limited to only three sub-sets of patients (1 ES, 1 Italian-speaking, and 1 Greek-speaking) further research is required to explore the information/education needs of other culturally and linguistically diverse patients. As well, more research is required on carer information needs.

3. DEMOGRAPHICS

Profile of consumers

It should be noted the following demographic data on consumers does not include information on the carers interviewed.¹

Twenty-two consumers were interviewed including eight women and fourteen men with an average age of 68 years.

Of the consumers interviewed ten are English-speaking, seven are Italian-speaking and five are Greek-speaking.

Over half of the consumers interviewed had completed primary school.

Sixty-five per cent of the consumers interviewed are retired.

The majority of consumers (60%) are married.

¹ Ten carers also participated in the interviews.

4. RESULTS

In the presentation of the findings, preferred language spoken, number and gender identify the consumers quoted. Identification of carers corresponds with the consumers they relate to. It is evident that some consumers are more articulate than others when discussing issues. Views contributed by other consumers, although short and less elaborate are also presented to provide a holistic account of consumer examination of issues.

4.1 Existing information

4.1.1 The information consumers received

Consumers reported they received some information when they underwent treatment for colorectal cancer at the A&RMC. Information received was primarily verbal information from their treating clinicians regarding their surgery.

He told me that I had it, and just explained about the surgery and what they were going to do on the surgery part of it, so I was quite happy there. Nothing (to read) at all but the talk I had with him he really covered the operation and what they were going to do. So he didn't give me anything to read but he covered it. (E4, male)

They explained everything as they went along (E3, female)

I don't remember whether it was written but everything was explained.
(Gr.2, male)

They were very good, there were four of them and they explained very well what could happen. They prepared me for the operation and it went ahead. (Gr.5, female)

He said it's very low and he said well you may have to have a permanent bag and you may not, we'll see how we go. (*So did he draw any diagrams?*) Oh no, no. ... I just took it that he knew what he was doing. (E2, male)

Some consumers had received hand written notes and drawings with the verbal explanations.

I had it all drawn out. It was a big picture of the intestines – oh she's lost it, she had it for a long time, exactly where the operation was, it was all explained, very, very well explained. (It.7's sister)

He explained I had cancer and later on I think there was a woman. I went to another room or somewhere, whether it was the same day or not or later on I don't know, I can't remember. She explained it again, she repeated, both people repeated the information. What was going to happen, the operation? (E10, male)

Yes, the day they did the big test a young Chinese doctor over there, I can't think of his name, he was very good, explained it all out. Showed the whole picture of a bowel, where they'd be taking. (E10's wife)

One consumer received pre-operative information by telephone.

The only thing because they didn't have beds, so they rang me here and they told me to prepare myself. So they told me, I can't remember the name, it was two bottles, I drink one 7.00 o'clock and one 12.00 o'clock to clean all my guts so I prepared myself and this is what happened. I bought a bottle from the chemist and I cleaned all my guts and the next day in the morning I went there and straight away had the operation. (Gr.1, male)

It is evident that little written information about the surgery was given to consumers, especially prior to the surgery.

(You didn't receive any information at all?) No. Just interviews with the doctor. (E7, male)

You don't get the written information until after the operation. (E9, male)

Retrospectively, some consumers recalled receiving a letter containing some information on how to prepare for the surgery.

(When you went into the hospital for the operation, did they give you anything to read about the operation?) No. ... Well I had the letter from the hospital I must have had some of this (colonoscopy information sheet) on it. I think it said don't eat or don't do this. (E2, male)

(You're reading the preparation for the surgery?) Yes, some of this must have been in the letter telling me when to go in but not the whole lot, no. *(Do you think this sheet has got more information?)* It's got a lot more information. (E2, male)

4.1.2 Other information received

Those who underwent other treatments for colorectal cancer, such as radiotherapy and chemotherapy, received verbal and/or written information.

The only information I got at the chemo was the doctor at the chemo explained to me what it was and why I was having it. He explained it to me. (E9, male)

Yes, it (the booklet) explained to you the chemotherapy could do this, this and this, and the radiation does this, this and this. Which I found my hair started to fall out when I had the chemotherapy; my hair came out in chunks, which I knew from the beginning it could have happened so I was prepared for it. (It.3, female)

Some consumers felt they hadn't received much information before the surgery compared to after the surgery and other treatments.

(With the bowel surgery or colon cancer surgery, do you think the information you got before and after was as good as what you got from radiotherapy or chemotherapy?) No from the surgery no. It was better from the chemo and radiation I had more information on it. (It.3, female)

They gave me that afterwards. After I had cancer they decided to give me that one, I went to the oncology people; they gave me more information, how it was going and what was going to happen to things and me like that. (It.1, female)

(They didn't give you anything to read about chemotherapy?) Oh, plenty to read. *(Did you read them?)* Certain things you just say Lord keep an eye on me. No good worrying about it. (It.2, male)

Some consumers received post-operative information.

(Did you receive any information in writing?) Yes a sheet with the sketch of a bowel on it, and a list of food to take. (Can you remember who gave you that?) The dietician. (E10, male)

4.1.3 Satisfaction with information

Some consumers were satisfied with the information they received about the surgery.

I was quite happy. I really didn't have to ask any questions really because Dr. X was really good and what not. The staff really covered everything so it was really good. (E4, male).

She was well informed. (It.7's sister)

Many consumers felt the information they received was not sufficient.

He said you'd have to have surgery, that's the only way. But they really didn't explain much in surgery. Like he said to me, you'll go down on the Monday, we're going to be cutting you here and we'll just take it out and cut a bit off and join the rest up, see how it is. I wasn't told much. (It.1, female)

I don't think I got much information as a result of the operation. (E9, male)

Pre-operation (information) was very little. (E9, male)

(What information did you receive when you were told you had bowel cancer?) Not very much. The doctor just said I had colon cancer and that was it. He explained a little bit but not as much in detail. (It.3, female)

I know how the stoma works because I'm a care worker. So I just knew all that, but my Mum and Dad didn't. So here she (the hospital personnel) is trying to explain to us and every five minutes the phone is ringing because other clients are wanting her. As I said there's just not enough information. (It.2's daughter)

4.1.4 Information in languages other than English

One Greek-speaking consumer received verbal and written information in Greek through doctors at the hospital.

There were doctors who used to come and see me and always giving out pamphlets in Greek, and I spoke to them about chemotherapy and they told me that I should go ahead and have it done. ... They gave me books to read. (Gr.2, male)

Ordinarily Greek-speaking and Italian-speaking consumers did not receive information in their respective languages.

The information I was given was in English and it was a bit difficult, the medical words. (It.7, female)

On that day, it sounds like I only received this one, but on the day of the operation I didn't even find out who the surgeon was. (It.4, male)

Unsurprisingly, Greek-speaking and Italian-speaking consumers felt they had not received sufficient information. The problem for this group of consumers is compounded when interpreters were not always available to them. One Greek-speaking consumer reported he hadn't received information in Greek or English. Further, he hadn't had access to an interpreter. He had his daughter with him when he consulted the doctor. Another Greek-speaking consumer said he hadn't received any information in Greek. However, he had received some assistance from a nurse who spoke Greek.

Other Greek-speaking and Italian-speaking consumers reported:

No I had no information, unless they had spoken with my children in English at some stage. (It.4, male)

So an interpreter was there at one stage. She had left because she was running late or the booking had expired. When I went for the results of the colonoscopy she was there and like I said I've given you the story to that. In regards to the explanation of the operation that I had done, absolutely nothing. (It.4, male)

What my husband wants to know is in regards to the second operation (the one for bowel cancer) if things went well or things went bad. Nobody has said anything. (It.4's wife)

(During these times of decision-making, did you ever have an interpreter present or did the hospital provide an interpreter?) No. I had my daughter-in-law. ... The doctors used to speak with my daughter-in-law. (Gr.2's wife)

When Greek-speaking and Italian-speaking consumers had access to an interpreter they reported the exchange of information was good.

With the interpreter they actually had shown us, they had drawn and we had been explained. This was with the interpreter and the doctor. Because I personally don't know my stomach or what it looks like. So three times the interpreter explained from a drawing where it was. They were very good. (It.5, male)

One Italian-speaking consumer and her carer found information provided in their first language more exact and therefore confronting.

We had an Italian specialist, and he really explained exactly and actually whatever he said made us a bit unhappy but at least we knew. *(What did he say that made you unhappy?)* No we were happy, but a bit distressed because he really explained exactly the meaning, which we understood very, very well then. ... Information in English is milder because maybe you don't understand exactly the meaning of it. But when in Italian they tell you exactly what you have, so you really felt. But this was the truth and you wanted to know exactly you know, and we were happy the tumour was different after the chemo. Yes, they said very bad and devastating things, which was shown on the x-ray, then after that it turned out for the best, which we were really happy. (It.7's sister)

4.1.5 Impact of information received

Information currently provided, including pre-operative information, information about the operation and other treatments were found by consumers to be helpful. Some consumers reported it reduced their anxiety.

(You were pretty worried when you were waiting?) Nervous. Really nervous. (So did the information that you received help you with those feelings?) Yeah it calmed me down, so it was pretty good. When I was in I was still nervous, and kept running and forth to the ladies because my nerves were impossible. ... Because I'd been in quite often for operations, but not one like this, not one like cancer. (E3, female)

I did get a little bit anxious prior to going, the last couple of days prior to going, getting readmitted to the operation. But once I was in there and what not and talking to the staff there I calmed down a little bit. I wasn't so anxious about it. ... I was a lot calmer when I was in there. (E4, male)

Well it (receiving information from doctors and nurses) helped in one way because you knew exactly what you were getting, but it worries you to think what you were going to get, but I suppose you find the strength and fight it, after the devastation. (It.7's sister)

(Do you think it was good to know to hear the doctor explain to you before you had your operation?) I think it's good. ... I think it's a good idea you know where you're going. So it's all right. The system works wonderful, we couldn't wish for a better system than we have. That's all I can say. (It.2, male)

After the operation in about three months you'll be back as you are now, you know, back to normal. That was one of his explanations and I thought that was very good. So I took it for granted that everything would go well, which it did. (E2, male)

(In terms of the information that you were given, the first and second time, was it a little easier the second time because you knew what was happening?) It was a lot easier because I knew what I had gone through from the first operation. (It.3, female)

Several consumers believed the availability of information did not help overcome their anxiety.

(Did the information that you got help you reduce your anxiety about the operation?) No. Not a bit. I'm sorry to say. I didn't understand it and I thought you can talk to your blue in the face it won't make me feel any better. Honestly you shut everything out except what you are thinking. You become utterly self-centred. It's a miserable feeling. (E1, female)

When I was there the doctor told me about this (having chemotherapy) and I said no is there something else. He said this is the best treatment and its not going to be without medication tablets. The doctor said no, my hair isn't going to fall out but on the other hand he couldn't give me 100% guarantee. If I had a temperature to call him straight away so they can bring me into hospital. So all these things were scaring me. (Gr.5, female)

(If you think about the patients who are going to have a bowel operation, do you think that it will help them if they receive this information?) It would have helped me understand a little of what was going to happen. *(Would it reduce your anxiety?)* Not really, I don't think. I think you've either got to know everything or nothing at all. If you don't know anything at all, I knew nothing. I just went to sleep and woke up quite surprised. Really surprised when I woke up. (E2, male)

4.1.6 Consumers' assessment of information received

Quality of written materials

Consumers who received written information found the format of most materials good.

I had no trouble with it myself. I can't speak for others but I found it well illustrated, well written. (E9, male)

Information could have been, maybe condensed. I don't know. (E5, male)

Other consumers said the font size was not too small.

It's probably important to have it slightly bigger than smaller (font size). (E1's daughter)

Language and terminology of written materials

Some consumers thought the language used in the information they received was straightforward.

Yeah the instructions (preparation for colonoscopy) down here came with the package. ... Yeah I remember all this, the instructions. That came with a kit whatever you call it. That first one, that's very good. ... They're quite easy to read. (E2, male)

(Did they give you a piece of paper telling you what you should do to prepare for the colonoscopy?) Yes. (From memory, was it easy to understand?) Yes it was. It was explained. (E10, male)

However, other consumers considered the quality of written information received varied, as one consumer said:

Yes I've read that book and then I got sent a little one. The little one we've got out now to read and assess that. That was better than that one, it was easier to read. (E8, female)

Some Greek-speaking and Italian-speaking consumers had no difficulty reading the written information in English.

Yeah, yeah, like I said that one (information about reducing the risk of bowel cancer) is easy to follow, it wasn't hard to understand. ... *(Can you remember when you were reading the information about the preparation for colonoscopy—was it easy to read?)* It sounds pretty easy to me, it wasn't that bad, it wasn't that bad for me, but for others who knows? (It.3, female)

Other consumers, both from English and non-English-speaking backgrounds, reported language and terminology difficulties with some of the written information received.

I didn't read that, (NHMRC guideline) I couldn't understand what the words were. But I think the one they're bringing out is better. (E8, female)

It (NHMRC guideline) was fairly technical and I'm from an engineering area. It's fairly technical. Terrible for some people. (E5, male)

There were some hard words in there you know. ... But I can't remember what they were. (E3, female)

The language was easy to understand. ... About the only time I got stuck on the medical terms was when I was having the chemotherapy, some of the names of the drugs I couldn't even pronounce. The doctors there went through it with me at any rate, through the form and what not and explained to me what the drugs were and what not. So that was all right. (E4, male)

Some consumers reported learning the terminology through the process of treatment and care.

Probably some of the medical terms were a little bit hard to understand, but if you've got an idea, if you've been through what they're talking about when they're giving a diagnosis or something, they mention a medical term and you get to know what they're referring to. (E9, male)

One Italian-speaking consumer described she needed more time to read the information because of the language barrier.

Yeah because some time, I'm going to read a few times anyway. I understand probably the first time but first put in my hands...*(You had to read it again. Is that because it was in English or because you were worried about your health?)* I was worried, don't understand, I have to read a few times. (It.6, female)

4.1.7 Inadequacies of information

Consumers indicated, directly or indirectly, the absence of information in several areas, including alternative sources of information, treatment options and procedures, risks and side effects of treatment, and discharge information.

Alternative sources of information.

Ordinarily the consumers interviewed were not interested in accessing alternative sources of information, and those who did, did not value the information from other sources.

(In that time between when you were diagnosed and you had the operation did you try and find out what was going to happen to you from any other sources such as neighbours or friends or a library?) I think I went to the doctor ...and I asked him, he gave me a rough idea what they did. I took a bit of the bowel. He may have mentioned a bag or something like that, but I don't, I never worried that much. I was worried naturally but I never went to any trouble about finding out. Not only that people lie about it, they never tell you the truth. (E10, male)

That (whether having information available from other sources might have been helpful) is a pretty hard question to answer, because to some people, it may. To other people it just wouldn't. (E9, male)

One consumer expressed he would have liked a second opinion.

I tell you what I would have liked and this is fair dinkum. Go to an independent, of my own choice doctor, and get a second opinion. I really would have liked that. But I don't know it was that quick that I didn't do it. I would have felt a lot better with second opinion, independent second opinion. Someone that didn't know I'd been anywhere first. But then again your own doctor would give it away anyway. (E10, male)

Treatment options and procedures

Most consumers felt that the treatment they had received was the best and the only way to treat their colorectal cancer. Further, they reported not having been involved in the process of decision-making regarding treatment, and or felt they were not capable of deciding treatment options for themselves. Many felt there was no decision to be made because the treatment was essential and there were no alternatives.

That was made for me. The decisions on the chemo and radiation, they were all made for me. (E9, male)

(Did you want to know whether there was another way of treatment apart from the operation?) No I don't think about that because I don't think there's another way to do it. Because if they say operation, you need the operation anyway, probably the best way to do it. (It.6, female)

Well in my case I had to have it. I suppose if I didn't have the tumour in the bowel I suppose there would have been more options I suppose. But with the tumour that was it, I had to have the operation and that was it. (E4, male)

(What made you go and have the operation?) Because I know it was an absolutely certainty, either that or drop dead you know. You have to have it, if they tell you you've got it. (E10, male)

Some consumers were reluctant to agree to the treatment suggested by their clinician, but they felt they had no choice.

The doctors came and they explained to me that I had a tumour and I needed to have an operation straight away. I didn't want to go ahead but the doctor told me to have it done and I agreed to it. (Gr.5, female)

Actually I didn't ask myself, I went back, the information I got once they told me, I went and asked myself, am I going to do it or not. That was my simple question. ... I made a decision just like that, I go ahead. ...Yes to be quite honest I did not want to go ahead with it. Everybody talked me into it, a lot of people talked me out of it. Well I'm still not sure whether I did the right thing or not. Still not sure. (E6, male)

The only option available to some consumers was the timing of the treatment. One Italian-speaking consumer reported having been offered a choice of taking radiotherapy and chemotherapy before or after her daughter's wedding. Another consumer said:

I've got to mention one thing too actually. Before surgery I was asked by the surgeon if instead of surgery, I wanted to take up chemo first. I was asked that information. Then in that case he said I'd do the surgery. (E6, male)

One Italian-speaking woman undertook naturopathy suggested by her daughter as complementary treatment after discussion with her treating clinician. Another consumer decided to only take the clinician's advice after much deliberation.

We have our daughter, she's an only child but she wanted us to have him do the treatments the natural way. She was quite upset; I mean she knew that we would probably go ahead with the operation. She saw herbal teas, what was the other, iron treatment, all sorts of things. So with me being in the middle of course, the doctors they advise the quicker you take the cancer away the better it is for you. On the other hand the family is saying, try it with the herbal medicine first that helps too. But then again, just how long does the herbal medicine take? (E6's wife)

One carer suggested the hospital provide more information on the range of treatment options available to patients.

I felt from my point of view, not being on the receiving end but being a little bit removed from it, the information that I was given about the actual operation was fine. What I thought was perhaps lacking was a clear outline of all the alternatives. So that really they pushed the operation and they didn't say to mum, this is one scenario and if you don't have the operation this and this and this will happen, and this is another scenario if you do have the operation, this, this and this will happen. I just felt that the push was medical, they can fix it with an operation and they wanted her to have it. (E1's daughter)

She also felt the need for more information on treatment procedures.

One of the things that distresses mum is the loss of control over what's happening to her and I think if people knew exactly what steps were going to happen and how long things were going to take, then that loss of control becomes a bit more manageable. If you're told you've got cancer, that's a big loss of control, so it would be nice to have the small things at least under control, like knowing where you're going on a particular day or what procedures are going to be done to you before hand, afterwards.
(E1's daughter)

This need was supported by another consumer's frustration over the treatment process. One Italian-speaking consumer said:

They say I am going to keep the bag for 7 weeks. But until 7 weeks, and it was more than 7 weeks, it was more than 3 months, because they keep changing (the date) to go to have the second operation (to take the bag away). I got so mad. (It.6, female)

Risks and side effects

Some consumers reported the lack of information about side effects of the treatment received.

The one thing you did, you have a meeting two weeks before you go to surgery with the doctor. They tell you things, but they don't tell you, side effects what can happen to you. (E6, male)

A carer thought information on risks involved in the process and side effects should be made more available to patients.

Well I had a few questions, which I did ask the doctors, things like, what was the likelihood of the anaesthetic, because I mean it's a big thing to have an anaesthetic. They did tell me. If you don't ask you don't get told. Its just the same and I think that's a really big issue for young people, they really need to know that there are all sorts of things that can go wrong, apart from the operation, there's the whole issue of anaesthesia. That was never raised, that was never voluntarily mentioned. I had to actually ask. I think that's not good either. ... People need to be treated honestly and they needed to know what the risks are. (E1's daughter)

Discharge information

Many consumers were not satisfied with what happened to them after being discharged from the hospital. They reported not feeling ready to go home, or not having received sufficient information regarding self-care at home.

But then I got home a friend of mine she looked after me because I couldn't do anything, and it's taken about two or three days I had to go back in because I vomit all the time. All green bile and there was a little bucket like that completely full. So she took me back to hospital. (E3, female)

I thought I was a bit early for her to come out, because she had nobody out here, not all the time out here. ... I think it was a bit premature to send her home the way she was. I felt this way. All right she had a family, but many people who live on their own, not everybody has got family help. Even if the nurse was coming around once a day – how often – twice a week, then I think (it was a) devastation if we weren't around. (It.7's sister)

They put me out without knowing if I'm going to eat; I'm going to go to the toilet. To the toilet, I couldn't go to the toilet. I go 15, 20 minutes but nothing happens. They put me out on the eleventh day. I was weak, I didn't eat anything, and I couldn't go to open my bowels. ... Yes they gave us a form. What to eat. Light food and chew it properly, which is what I did, but like I said the first two days I was busy from the food and I can't go to the toilet. They can't throw the people out of the bed if they're not fit properly. (Gr.1, male)

He said to me you've got a hernia now, ... so that's another thing. You really should be telling people that you might get this, because I went home and did a few things that I shouldn't have, and I reckon that's what did it to. (It.1, female)

The quality of discharge information received varied for the consumers interviewed.

It was very hard to read and I've still got it at home I think, I'm sure I have. ... She'd written it very sort of faint. I could hardly read it. (E3, female)

Yes I did definitely get one. My nurse went through it with me before I was sent home. I was not supposed to drive the car for at least six weeks. ... Yeah (I understood what she said). I think I've still got that sheet at home too. She was pretty good the nurse that filled it out. (E4, male)

Timing of information provision

Consumers felt they were often unable to absorb the information at the time it was provided. Some consumers reported having been unable to absorb the information provided because of shock and anxiety regarding their diagnosis. Others talked about physical discomfort associated with surgery and treatment impacting on the information exchange.

Yes I think in my case I was told the next morning I was still a bit doped up. I probably couldn't comprehend exactly what was told to me. I think they could have come a little bit later after the operation to

explain a little bit of what actually transpired, and give you a chance to ask them questions yourself. But at the time I was sedated, it's still vague what they actually said to me. (E9, male)

(So you don't feel you received enough information about what was going to happen?) Well yes, Margaret told us, we had a long talk with her; we spent one hour with Margaret. She told us quite a bit, but I think when at the beginning you're in such a state that you don't take it all up. Probably you don't even want to believe what could happen, you think oh it's just an ordinary operation then its over with. You don't think. (E6's, wife)

He explained to me, but two days after, a day after, if you asked me what he was talking about I would have said I didn't know. At the time you do know and understand, but as soon as they go your confidence goes with them. ... They gave me some information but I'm afraid I was in such a state at the time that I didn't remember and in fact they were talking and I was looking but I wasn't listening. (E1, female)

They explained it reasonably well but I didn't absorb it properly because I went into shock I think. (E10, male)

Certainly in hospital you're half out of your brain anyway. (E5, male)

4.1.8 Verbal communication

Use of verbal communication

All of the consumers reported that verbal communication is the means by which most information is currently conveyed to patients at A&RMC. Further, it is apparent that most consumers prefer this method.

Sometimes the more you read, by the time you've read the last bit you've forgotten what was the first bit. (E1, female)

Oh the written sheets are fine, but it was just a bit more information that I got off the doctors, off the original surgeon from the word go was good. That really did help. (E4, male)

Other consumers particularly appreciated one-to-one communication between patient and clinician.

I honestly think that maybe the surgeon or their assistant could come and spend at least five or six minutes with you and explain to you what actually went on. (E9, male)

It's not paper work that you need, you need somebody, you need a person, you need somebody, my friend who lives with me, or I can talk to my friend. It's all right to read it on a piece of paper then put it away. But this piece of paper won't put its arm around you and say it's all right. (E1, female)

Several consumers thought verbal education should be used to reinforce written information provided to consumers, especially for patients from non-English-speaking backgrounds. Consumers from Italian-speaking and Greek-speaking backgrounds said:

(What about the type of information, is verbal information important or the written information more important?) I think the two. If you talk with me I understand what you say, and if I read I think probably I understand very well, but maybe something. After you go, if I read it reminds me to remember what you say. (It.6, female)

For somebody who doesn't speak English and he or she prefer if somebody else explain to them that's all right yes. It helps them a lot. (Gr.1, male)

Barriers associated with verbal communication

The majority of consumers said they were confused about the content of information in verbal exchanges with clinicians, resulting in frustration, inability to manage self-care, and complications.

A doctor I don't know who it was he was quite nice, and he said to me, just take care of yourself and whatever you do, don't get constipated. I can remember him saying that, and I thought, well how do you don't get constipated? (E1, female)

You can't tell the doctor what actually transpired, you could only summarise what actually transpired. I was led to believe that I was to have radiotherapy and the radiotherapy, I don't know whether there is or whether there isn't, there was some metal placed in a convenient position whereby that they could target through the radiation on the metal or pins or something that was inserted. I don't know whether I've got pins in me back or not, I don't now I wouldn't have a clue. (E9, male)

The operation went well. I was just one of the unlucky patients to get some after effects from it. ... I think about four or five doctors came rushing up to see me to see what was going on. But I did ask Dr. X (treating surgeon) at the time what caused all the pains in the chest and the heart to go into overdrive, and I never got an answer to that question. I saw him about two days later and he said don't worry about it; it was nothing everything is right now. I sat there and said, how about a straight answer, what caused it, it's got me intrigued. He said don't worry about it. So on that part I still don't know what's caused that. (E4, male)

I finished up with a lot of problems now, which we don't know what it is. I was diagnosed after seven days, after surgery with a urine infection. I just kept going and going and going, still going the infection, they don't even know if I have an infection or not, because they say with the catheter you can't have chronic bleeding. ... So I came in with cancer, and I finish up with that problem. But the information you don't get. (E6, male)

Well when he told me there was a cyst there, I wanted to know what sort of cyst it was, how big it was, whether he could do anything with it before I had surgery. He said no. I had a look, I had the colonoscopy, and he said you'd have to have surgery, that's the only way. But they really didn't explain much in surgery. Like he said to me, you'll go down on the Monday, we're going to be cutting you here and we'll just take it out and cut a bit off and join the rest up, see how it is. I wasn't told much. (It.1, female)

Unclear information adds to consumers' distress.

I wanted to know what stage of cancer I have. Being told B, I don't know what that means. ... when I was here for a check-up on the 8th I asked him again. He said it was B and C. ... I didn't understand it anyway, but you know to me it's a new experience. So I didn't know, I guess don't care. I mean I care, but it doesn't worry me any more. At one stage it did. I was really scared that I might die without seeing my

grandchildren and children. I thought I'm all on my own there. (E3, female)

That's what scared me most. They shouldn't have told me it was cancer unless they were 100% sure on my liver. So that really topped the list. (It.1, female)

Terminology in verbal communication

Consumers from English as well as non-English-speaking backgrounds had some difficulties with language and terminology in talking to clinicians.

I tell you something; doctors speak doctor's language. Half the time you don't know what they're talking about, it sounds like 'gobbildy gook'. I think between the doctor and the patient you need an interpreter. I'm not the best-educated person in the world but there are people who are less educated than what I am. They would be completely lost. So that would be something to think about. I know doctors can't speak our language. (E1, female)

Some medical words were too difficult for us. But then we had Patricia who's a daughter and she worked it out very well. But for us on the medical words it was a bit difficult to understand exactly the meaning of it. (It.7, female)

Opportunity to ask questions and discuss treatment/illness

Consumers felt they were not able to ask questions during the consultation time with their clinicians.

Well nearly every time that the doctor came around there's usually a team, they brought around a team of people. As many as six or seven at the end of your bed. (So there wasn't a one-to-one opportunity ... to discuss questions.) No. (E9, male)

One consumer thought patients needed sufficient information to assist them in asking questions of their clinicians.

We were only told at that time you don't know about those things so you can't ask the questions. This is one thing you can't ask the questions because you don't know what's happened. I mean you get told its no problem, that you're seven to ten days in hospital and that's it and you go home, and it takes you time. (E6, male)

Other consumers reported they insisted on asking questions to get the information they wanted.

Well I had a few questions, which I did ask the doctors, things like, what was the likelihood of the anaesthetic, ... if you don't ask you don't get told. ... That was never raised, that was never voluntarily mentioned. I had to actually ask. I think that's not good either. (E1's daughter)

If you ask you get a long way. ... The people who might complain they're not well informed because they don't ask. I ask everything that I thought was necessary for us and then we were getting everything. ... We didn't know (that we could have transport assistance) if we didn't ask. So people have to ask because if you want information you have to ask. It's not there for everybody to read, you've just got to ask. (It.7's sister)

4.2 Consumers and carers

4.2.1 Reactions to cancer

Almost all consumers reported experiencing shock when diagnosed with colorectal cancer.

Trauma, you know. ... That was a shock to me. Now I know what it feels like when you're close to death. Because I was in my unit all on my own in agony. I cried, I couldn't sleep, I wanted to get up and have a drink and I couldn't, I just collapsed and went back to bed. So it was a big experience for me.
(E3, female)

I'd never been in hospital before I had this. I had no idea; I didn't even have a clue. I didn't know what to do, what to take, not a thing. It was just a novelty you know. Mind you that novelty soon wore off.
(E2, male)

Not until they are 60s or into their 70s that they think now my life is my own. Now I can do all I like, because up until then they reared children and they reared grand- children Then all of a sudden your grandchildren have grown up and they are strong and healthy and every thing is OK. You think my life is now my own and then you get cancer. (E1, female)

It devastates you in the beginning, the patient, the family and everybody to live with it, and afterwards you have to live with it and you take all the strength you got. (It.7's sister)

Treatment procedures relating to colorectal cancer also caused anxiety and stress for some consumers.

(So you then got a letter from the hospital saying you'd have to come in and have your operation?) Yes, that was another shock too; it was as quick as lightening. Pensioners wait from 12 months or more. You know, well, it's like watching a vulture land on your fence sort of thing when you get the letter. (E10, male)

That (being told how to use stoma bag after operation) was a bit of a surprise I might tell you. *(Why?)* Well I didn't know anything about it. I'd never mixed with people. (E2, male)

Even now until last week I didn't know whether the bag would go out. (You didn't know last week that they were to reverse it?) No, I just pray to the Lord that it would be taken out because it's not an easy thing to be with. You are at the bathroom every moment of the day, day and night; your system is not normal. (It.2, male)

This operation they have to cut a big part of my bowel. ... Yes they drew pictures. May be they showed me, but I throw away every thing. Don't ask me. ... Because it was very hard part of my life. Because I wanted to forget all about it. ... After the second operation (to take the bag out) I threw every thing away. (It.6, female)

Some consumers talked about managing such anxiety by undergoing treatment quickly, not giving up and not allowing it to affect their lives.

I was thinking like I didn't have to go to a therapist, and the quicker is better, instead of it spreading or whatever. So that's what I was thinking, to do it and get out of there. (Gr.1, male)

I don't know how you'd carry on; as far as I'm concerned they've actually got rid of the cancer in my body. I had treatment, I had chemotherapy and I had radiotherapy. As far as I'm concerned it's gone. I tend to forget all about it. I eat anything and everything. (E2, male)

A small number of consumers, mainly male, appeared not to be worried by the cancer diagnosis and remained calm.

You go in and take a chance I would think, you don't worry. Mind you some people have anxiety problems. Some people have an anxiety problem so they would want to know. (E2, male)

These consumers, however, said their partners/carers did the worrying for them.

(Are you anxious about the operation?) I suppose not really to be honest. ... I don't know why, but it just didn't worry me really for some reason. My poor old sister stressed out. She carried all the stress for me. ... No I wasn't that worried really. (E4, male)

It (the operation) didn't really bother me. ... Because when the day came that's it. ... But the women are different. (Gr.1, male)

I'm not worried about it, but my wife is concerned, worried about this information we don't have. That's a worry because one doesn't know. For me it's not. You can't change it, if its good or bad you can't change it. (It.4, male)

Well my husband when I told him he's worse than me, he nearly had a nervous breakdown over me being sick. What could you do he was just devastated, he was more devastated than me, I mean I thought I've got it, its better that I just try and help myself. (It.1, female)

4.2.2 Not desiring information

Many consumers appeared not to wish for any more information other than what was given to them.

(Do you think it's useful to know what would be happening during the operation?) No. (In terms of any anaesthetics and side effects of the operation?) I wouldn't think so. No I wouldn't think it was necessary. (E2, male)

I don't know. I don't know whether that (pre-operative information about bowel cancer) would have been beneficial or not. Because other people might panic a little bit and get a little bit uptight about it. I think the least you know in those cases the better. (E9, male)

The less you know the better because I look at it this way, not everybody does. You don't lean on somebody else you lean on yourself. The doctor is a doctor but he's not God he's done the best he could. ... *(Did you keep them on the bookshelf?)* No, no don't want things like that, the least you know the better. Get on with your life. (It.2, male)

No, I didn't know anything about it (the operation). You know you've either got to know everything or not much at all. (E2's wife)
(So if you know everything how would you feel?) I might have been very worried. As I say I'd never been in hospital so I had no idea what was going on. (E2, male)

Some consumers described feeling shocked, in denial, and numb when they were told they had cancer. They also tended to refute the information received.

I suffered from shock quite a long time, I did anyway. I couldn't absorb it at first, I couldn't believe it, I kept refusing information I didn't want it, I kept rejecting half the things they told me. Didn't know their head from their elbow. You know you've got the pain and you get worse too. (E10, male)

I didn't even want to read the books I was given, I feel unwell. ... *(Was the information in Greek easy to read?)* Yeah easy. But I didn't want to read it or even know about it. (Gr.2, male)

Some consumers stated they did not want information from support groups because they did not believe it would be useful; they wanted to keep the diagnosis within their family and treating staff.

Most people who have operations they can't really tell you. Describe all the pain, how can you describe your fear, you sleepless nights, you can't describe that. (E10, male)

(Do you think it would be helpful if you met with other people Greek-speaking people who have had a similar thing happen?) I don't want to talk with other people I prefer if I discuss it with my doctors, I tell my family, no I don't want to hear anything. *(Would you like more information in Greek so you can read up about it yourself?)* Please. (Gr.5, female)

Other patients described feelings of denial.

No I don't want that (meeting other patients in a support group if available), the thing is that after I became well I forgot all about it. ... No I just wanted to forget everything. (Gr.2, male)

Well I've got the same mind as him as well because I feel the more you talk about it the more sick you get, you just have to forget it and go on with it. (Gr.2, male wife)

Nevertheless a small number of consumers and carers clearly indicated the desire for more information.

Well the more you know the better prepared you are I think. (E1's daughter)

Yeah more information is better because you can understand it, you know what's going on. At the same time you're aware to pass it on to the children. Like now for instance I'm going through all this, all the information I've got I've packed it away and they can read it through. They've read it through but it's always there for them to go over it. (It.3, female)

As well as participating in their diagnosis and treatment.

Well if they have an anxiety problem they would want to know everything. Mostly I think they would want to know how they're going to be after the operation. Less what's going to happen during the operation, I mean that's entirely up to the specialist surely? But after the operation I would think its important for them to know how they're going to feel, how long it will take to get better etc. (E2, male)

4.2.3 Responses to written information

There were mixed responses by consumers on the written information received. Some consumers paid attention to the information, others tended to be less interested, or ignored the information.

Yes I read it through. (*How did you find the written information you received?*) Quite beneficial. (*Was it easy, difficult to understand?*) Oh easy, quite easy. (E9, male)

I think I got that about a week to ten days (before the operation) after I was sent home (from colonoscopy). So in my case I did get in early which did help to have a read of it (information) yeah. Yeah to have a read of it yeah. ... I went right through it about three times just to make sure I didn't miss anything. (E4, male)

(I read) as soon as I got it. ... So I think that's a good idea for everyone to have. Doesn't matter when you get it. So this cancer business is not to play with it. (E3, female)

(*So when you got all your information about reducing the risk of bowel cancer what did you do with the booklet, did you read it straight away?*) Yeah I read it, explained what you've got to eat to avoid cancer. I read it. I found it pretty easy to understand. ... (*What did you do with the information sheet when you got home?*) I read it and I folded it away. (Someone said to me the other day, they put it on the fridge and forgot about it.) No, what I've done is I've got a folder which I put all the information and all the paperwork which I was given to file away for later on for the kids to read and understand what's going on. (It. 3, female)

Those consumers who indicated they did not want any more information than what was already provided verbally did not pay much attention to written information received. Some consumers believed information would not actually help them; in fact it might cause them more anxiety.

To tell you the truth I didn't take so much notice (of the discharge information about diet) from all the foods because usually we eat the healthy food, I never eat junk food. ... It (information about radiotherapy) doesn't bother me, but for somebody else to read those things (they) start to worry. Better you don't know and that's it. (Gr.1, male)

(*What did you do with those pamphlets that were sent to you?*) Well more or less I put everything, all the paper, what we don't need, in the recycle. We throw nothing away. ... Well, anybody that is interested to read that's a good thing, I'm not saying it's a bad thing. I didn't read very much about it. I said I'm taking my chance, as I said I pray to the Lord that I pull through because it was pretty bad. (It.2, male)

(*What did you do with these pamphlets once you got them?*) Read them and tried to stick to them and then after a little while forgot all about it. Just ignored them. (E10, male)

They gave me something to read. It was all about what they were doing. ... Anyway I was a bit scared. I read the book but probably for my mind it was worse. ... They gave it to me when I was there. What they had to do in the operation before and after. (It.6, female)

Even when the information was in the consumer's first language, it did not make the consumer want to read it.

There were doctors who used to come and see me and always giving out pamphlets in Greek, and I spoke to them about chemotherapy and they told me that I should go ahead and have it done. ... They gave me books to read, but I didn't read much of it because I didn't want to know. (Gr.2, male)

4.2.4 Not asking questions

Many consumers appeared not to want to ask questions, invariably relying on their clinicians to inform them.

No, we don't ask anything. He (the doctor) tell us he's all right, he's going back for a check up again, and now I said to him you're all right, go away the doctor tell me. Come after one year you're very good. (Gr.1's wife)

Most consumers did not ask even if they wanted to know something, fearing the answer.

In my mind I thought I wonder if there's still some (the cancer cell) there. But I thought I'm not going to ask. So I was too scared to ask. In the end I did anyway when I went the first time for a (post-op.) check up. I'd been told the operation went well so it made me happy. (*When you see the doctor each time, do you have time to ask questions?*) I'm sitting there my heart is going bang, bang. I'm too scared to ask. Sometimes I want to ask and then everything goes blank. Who knows what happens next. So that's one thing I have to learn ask questions. (E3, female)

Or they felt shocked and this affected their ability to ask questions.

Yes, I had the thing to ask questions, but at the same time I froze you know. I just froze. What he explained he explained, but then I didn't think to ask. Nothing would come to me and say all these things. I just went blank. Just blank. (It.3, female)

(*Did you feel confident to ask him any questions?*) I was stunned, I'm sitting there and I'm thinking God you know, I couldn't talk to him. He'd come in every day but I was in shock. (It.1, female)

As well as fear and worry, lacking confidence in speaking English made some consumers from Greek-speaking and Italian-speaking backgrounds avoid asking questions.

Anyway if somebody tells me you've got this, you've got that. I say I am in your hands, I don't ask many questions probably because I am afraid, I don't speak very well, they don't understand what I want to say. But I take all the things are coming anyway. ... I don't ask many questions anyway. Probably I want to ask but I'm afraid to say something. (It.6, female)

4.2.5 Reliance on clinicians

Many consumers primarily relied on clinicians for information provision on diagnosis and treatment options.

(Before you had the operation did you find out more information about cancer?) No, only what the doctors and that told me. (E4, male)

(Do you think that primarily you relied on the hospital to provide you with the information?) Exactly. (E9, male)

Most consumers trusted and believed in their doctors' capability and skill.

No, he's not told us, but I know if he needed chemotherapy or something like that, that the doctor would tell me if it has spread, it's not going, he does not need anything. I understand what he tells me. (Gr.1's wife)

I just took it that he knew what he was doing. (E2, male)

(How do you feel that you haven't received any information?) It doesn't matter. Normal. I trust the doctors in the hospital. (Gr.4, male)

Since I had this thing, I had to leave it up to the doctors, to trust the doctors. ... The best information is to believe in the doctors, trust the doctors and to tell myself that I'm going to get well. That's the best information. (Gr.2, male)

As a consequence of trust, consumers left decision-making regarding treatment options to their doctors.

(So were you primarily reliant on the doctors to make those decisions for you?) Absolutely. *(And you were quite happy with that for them to make the judgement about the procedure?)* Yeah sure. Well they prepared you in a pretty good way. They mapped you out as you say, if you needed a bag, they explained to me what the operation was. (E9, male)

Straight away the doctor after the colonoscopy he told me you've got cancer, straight away. I told him I'll leave it to you, you do the best. (Gr.3, male)

I'm so happy with the doctors and I trust them. The gentleman was saying before he's very happy with Dr. X the oncologist who did all three of the operations and I look upon him as a God. (Gr.2, male)

4.2.6 Role of family

Support

In the main, consumers had carers, partners or family members who supported them in different ways. Many family members sought information about cancer or about treatment options, as well as providing physical and emotional support. Some consumers reported strong reliance on family members.

My eldest daughter when I was in hospital, she made it her business to see the ward doctors for everybody that was concerned with the operation. She went and sought out information. (E9, male)

My son he always rang the doctor to find out. (E3, female)

Yes I think every time she (my sister) came to the hospital she grabbed the doctor in charge and the nurses and found out more about it. (E4, male)

Family support is quite apparent with Greek-speaking and Italian-speaking consumers.

When I was in the Austin she was with me all the time on the toilet because I need somebody there. It was necessary, but she was there. (Gr.1, male) I look after him. (Gr.1's wife) So always together, to the doctor, if its for her or for me, its always together. (Gr.1, male)

Because they had everything written down on what they were going to do to me. My daughter was satisfied with all of the information she received. If there was something she doubted or wanted to know, I was asking the specialist to keep her informed. (It.7, female)
I looked everything up, what it was, what was going to happen, all the risks involved and then I just decided whatever God's will. ... (It.7's sister)

(Through) the Internet, (my sister's daughter) she's working in Canberra and she finds out a Naturopath who is working with cancer patients in Canberra. ... So she was so convinced and she wanted her mum to go through that. ... (It.7's sister)

I wanted to know whether his cancer was serious or not. (Gr.1's wife)

You know everything. She knows more about it than I do. (Gr.2, male referring to his wife)

I read some of it because I was so scared of some of the things that could happen to him. The only thing I could (do) was self-encouragement, because at one stage he said I can't go on. I'm going to throw myself out of the window, because the bag used to come undone. (Gr.2's wife)

My wife went to one of the girlfriends whose husband had the same operation. Basically she talked to her about the operation. (It.5, male)

(Did that help?) Yes. It comforted me. (It.5's wife)

Some carers used the information to reassure and help patients in their decision-making about treatment.

I looked at everything... and went through all of it and then with my daughter and my sister we also went through it again. She was well prepared and convinced what she had to go through before all that. (It.7's sister)

I decided then that I would have the operation because the fact that my daughter had written down a, b, c, d, 1, 2, 3, 4, all things that were going to happen, that she knew were going to happen and the doctor drew the illustration of what was going to happen. (E1, female)

One of the carers explained why she had a better capacity to absorb information than the patient.

I was able to understand him (the treating specialist) better because I wasn't suffering from the same immediate shock that she was. (E1's daughter)

Some consumers, however, stated they would rather cope alone with their illness without involving other family members.

Because I was in too much pain. I didn't even speak to my children. I wanted to be alone. Because I've got four children in Cobram and I've got two down here. She's driving me nutty, she rings all the time. Mum go, mum go. I said no leave me alone, so I took my phone off the hook so she couldn't ring me. (E3, female)

We don't tell them, we don't want to worry them. (Gr.1,male)

Family members as translators/interpreters

Family members of the Greek-speaking and Italian-speaking patients often acted as translators/interpreters.

When I don't understand them I have the children and I give it to them and I explain things. *(So all this information was in English. You needed to rely on your children to translate at times?)* Yes I did understand it. I never do anything unless I read it well and somebody explains it to me. (Gr.2, male)

I had a letter but I don't remember what it said. In English? My daughter read them there were about two or three letters. (Gr.5, female)

(Have you had difficulty communicating to the doctors that you needed additional information?) No I don't because I always have my daughter. I don't go on my own. (Gr.5, female)

Many consumers needing interpreters indicated they preferred their relatives to act as interpreters.

I did not have interpreters most of the time. So the only time I had an interpreter was before the operation just once. Because my sister was there. ... I had the interpreter and she did explain everything to me, but I really feel more comfortable with my sister. ...I suppose if somebody could have some of the family, I'm talking overall people, maybe they're more as I said more confidence, but not everyone can have that. (It.7, female)

I prefer my relative, my daughter, or my wife. *(Why is that?)* More trust. ...Because the interpreter maybe—hear it different and tells you different. *(But with relatives and family members you can ask?)* Yes and they explain to you better in plain language. (Gr.1, male)

Nevertheless one Italian-speaking consumer would rather use an interpreter because his son was not able to interpret adequately.

My husband prefers the interpreter because my son speaks some Italian but not all Italian. Sometimes he understands the Italian word and sometimes it not understood. (It.5's wife)

4.2.7 Support needed by patients and carers

Some carers and patients expressed the needs for more social work and counselling services.

Yes, a lot more social counselling because my father had no idea what was happening to him, no idea at all, and there was just so much emotion there it was unbelievable. Depression, the depression was just out his world. He couldn't cope with it and so he just went into a depression and the whole family was affected, the whole family. The bag was breaking ... There's two stoma nurses in the whole Austin Hospital. Two nurses cannot cater for the whole of Victoria basically. So there needs more social counselling and more nurses and more education. (It.2's daughter)

(Would you like to have someone with you to help you remember things or to help you ask questions, like one of your children or a social worker?) I sort of prefer a social worker I think if it had to be. I don't know why because my daughter she's a little bit pushy and I don't like that. ... I've got more confidence in (the social worker) yes. (E3, female)

It seems to me that they (hospitals) don't have a lot (of social workers), that they're not actually going out there and sitting next to people's beds and saying how are you going. ... I had to take on that counsellor sort of person. ... Mum has got somebody and lots of people have got families but there are elderly people who are by themselves. ... Probably some counselling was needed really. (E1's daughter)

This carer also suggested counselling services should be available for family members.

But I think when they see that there's a relative they think OK well the relative can take care of that, and sometimes that's true ... But they don't really take too much notice of the fact that you're turning – that's where probably a social worker or a trained counsellor would be much more useful, just for the morale, the psychological. ... Sometimes the relatives are in a big mess too. So there really needs to be some impartial discussion, a listening post. (E1's daughter)

Some consumers were in need of support at home with household chores as well as physical care.

It's hard my daughter is overseas and my son was only 18 trying to do all my washing, my husband was just hopeless. I had home help for a month, they gave me that so that helped me quite a bit. (It.1, female)

Yeah I could have done with a bit of help from the council. At the time I think nobody explained it to me that I could get the help from the council in the first place. I didn't know about that. (It.3, female)

It was hard you know. I mean he had a bag, he had a draining bag, he had a catheter and he has bleeding from the backside. It was hard. ...He had a very bad time. I often wondered, I wonder how a person male or female, how if you don't have anyone at home. (E6, male wife)

4.3 New information package

4.3.1 What consumers want to know about

Patients and carers while they have differing views of their own health care and health information needs, have indicated several areas of information they wanted to know about. These range from general information and signs of colorectal cancer to treatment options and results to prognosis.

General information and signs of bowel cancer

Consumers expressed the need for information dissemination on the early signs of colorectal cancer to understand their symptoms. One consumer said

Why did it have to happen to me in one way, why is it happening at early age because usually this type of colon cancer comes to an

older person, because at the time I was 48 years of age? So even the doctors were amazed why before the 50 mark, this type of cancer should have been well after the 50.
(It.3, female)

Why has this happened to me? (E5, male)

Yes there must be early warning signs for different things. The earlier you detect it the better it is. Rather than knowing too much afterwards. All right you can reduce the risk, that's part of it. (E2, male)

Treatment options

Some patients needed to know more about treatment options to enable them and their carers to participate in decisions on their treatment.

For instance the surgeon should be able to explain more in detail. More at-length information that you can understand, because in one way they say, you've got colon cancer we can do this or we can do that. But in the long run they didn't give me much information about it. I don't know how to put it. (It.3, female)

Treatment procedures

Some consumers felt it was important to have information about the course and likely outcome of treatment procedures.

(What do you think are the most important things for people to know when they have bowel surgery for cancer?) What the operation involves, what the doctor is going to do to you, how long you'll be in hospital of course, how much pain you're going to get. (E10, male)

Just things like how you're anaesthetized and where you're going to actually go, like when they took her down to theatre, Mum didn't know where she was going, and I had to say, you're going down to the theatre now. ... So just little things like that which the hospital staff takes for granted, which patients don't know would be helpful to know. (E1's daughter)

To know exactly what's happening with them and to know what the doctor is doing and what's going to happen afterwards. (Gr.5, female)

Side effects

Consumers reported the need for information regarding the side effects of different treatment procedures.

What affect the chemo and radiation can have on you. These are things the medical people might not even know themselves. (E9, male)

Results

All consumers wanted to know if the treatment they received was successful.

(What do you think is the most important thing for a patient to know?)

I would think the outcome. *(Of the surgery?)* Yes. (E 2, male)

Well the only question I was going to ask the doctor was how well the operation went which did go well. (E4, male)

The important information would have been that they had taken all the cancer out and it was over and done with. (It.3, female)

Prognosis

Consumers reported lack of clarity regarding their prognosis. None of the consumers felt they had a realistic idea of their prognosis. Some consumers wanted to know what they could expect after the treatment.

How long it will hurt, how long it will take to get better and clear and when he'd be able to get back on his feet etc. The surgery itself you don't know anything about, you go to sleep that's the end of it. (E2, male)

What happens after the operation? (It.6, female)

I wanted to know what stage of cancer I have. (E3, female)

Just the extent of how severe the cancer was at the time. How quickly it had progressed, or was it a slow one. (E9, male)

This information is important to consumers as it provides reassurance as well as helping them plan for future care needs.

What happens in two or three years time, will the cancer have been gone and he will be sort of cured or will he need an operation in say two or three years time. I'm now 79 but then in two years time I would be over 80. Will I be able at that time to take care of him should he then get an operation like this? That's my way of thinking. Or should he go in now while I feel still fit. (E6's wife)

Life expectancy

I'd like to know my life expectancy. (*Did you ask?*) Yes and the GP who wouldn't know a lot obviously said oh well, I might have 12 to 18 months. Even with chemo. That's the impression I got. So it's very, very vague. The whole thing. (E7, male)

My mother was diagnosed with cancer and had colostomy at 65, died at 87. See it doesn't help me I'm a male, different. So I'd like to know the statistics to I could plan ahead. Tell my son, here's where the Deeds are, here's where the Will is. Get rid of this, get rid of that. ... I'd like to see more statistics to help people who think that way. We don't all think that way. (E5, male)

Recurrence of cancer

If you were a younger person in your 30's or 40s or even 50s you'd want to know a bit of information that there's a likelihood of secondary things happening. (E1's daughter)

Once it is over it's a terrible thing I want to know whether it's going to be coming back and able to tell me if it's going to come back or not. (Gr.5, female)

So you want to know what you can do that you help you improve so it doesn't re-occur. So you want to know information about you getting better and when the bag is going to be removed. What you need to do to assist yourself in getting better. To help you recover. (Gr.2, male)

Explanation of technical terms

Some consumers thought technical information and terms used in written information needed to be explained by treating staff.

I think we need more medical terms explained. Medical background.
(E7, male)

The extent of the understanding of the literature, what it actually attains to? I think that's a priority. (E9, male)

Referrals/useful contact numbers

Other consumers thought reference and contact numbers needed to be included in written information.

Or a little handbook that was a quick reference, they could certainly give you all these but a quick reference. (E5, male)

4.3.2 Accuracy of information

Consumers expressed a desire for accuracy with the information provided by a range of clinicians. It was said that there were instances of deceptive and confusing statements in information provided about treatment and care.

Truthfulness

Some consumers wanted information told to them truthfully. They emphasised:

The truth. Tell them kindly and plainly and simply, but don't hold back, tell everything, tell them in a way that they will understand. Make sure that they do understand before you go away. ... But you'd have to get some factual information because that's the only way you can plan ahead for the future. (E1, daughter)

What I want to know myself is that whether the recurrence, whether its going to be 50%, 40% or whether its going to come back, but we want to know the truth not to lie. (Gr.5, female)

I don't know about the doctors. Some of them can be brutally frank which is what you want. (E10, male)

Nevertheless, other consumers felt different about the truth.

The only thing I don't like, I mean here the doctor tells you you've got two weeks to live, you've got four weeks to live. That's not nice. Makes the patient more scared, more thinking. But if tell him nothing maybe he lives longer. ... I prefer not to know. I've done my Will, I know my kids, and I know my wife, so when my time comes it comes. (Gr.1, male)

I don't want to know much. ... Like sometime I think if I go to the doctor and he told me you've got 3 or 4 weeks to live, I don't want to hear that. (It.6, female)

4.3.3 Timing of information delivery

Consumers considered the timing of information delivery requires addressing the differing needs of patients.

I think I would have preferred (having information about surgery) say about three or four weeks beforehand. (E3, female)

I wish I would have had the pamphlet to read at least a couple of months before, so I mean I didn't know I had it then, well I suppose I would have known I don't know. With the pain I had. It's good to read something like that just in case there is something the doctor tells you you've got cancer, so you can prepare yourself. (E4, male)

This consumer thought it most important that consumers had time to comprehend the information they read.

Just make sure they get the time, the more information on the bowel operation and what not at the time and see if they do send them the pamphlets see if they can get them out as quick as they can (before the operation). ... Even if they could get some of these pamphlets from the hospital before they're discharged (from pre-operation) would be a big help too. That's if they're going to get discharged and they've got to come back in a couple of weeks for an operation. (E4, male)

4.3.4 Manner of delivery

Consumers stressed staff input as an important component in providing information. Consumers frequently needed assistance by staff to understand and to process the information and to enable them to identify further questions.

It (being given the information in person) might be a little quicker than posting them out through the mail. ... Because otherwise it goes through the post office everywhere, you have to wait and wait. Sometimes you don't even get it. (E4, male)

I just think to explain everything to them as simple as possible and tell them this is what to expect, or you might even get this, this and this, or this complication can arise. (It.1, female)

This consumer identified treating staff compassion as a crucial component in information exchange.

(What else is important about information giving to patients?) Compassion. ... I think it's important for the people who are doing the operation to perhaps make contact with the patient. (E1's daughter)

4.3.5 Written versus verbal information

Consumers thought written information was as important as the verbal information received.

(What about the type of information, is verbal information important or the written information more important?) I think the two. If you talk with me I understand what you say, and if I read I think probably I

understand very well. But maybe some time after you go, if I read it reminds me to remember what you say. (It.6, female)

One carer indicated some patients might not absorb all the verbal information given to them, therefore written information was something they return to.

Whatever information it is, it has to be written, it has to be in some concrete form because if you just tell it to people they're going to forget, especially elderly people whose memories perhaps might not be quite as good as a younger person's, but given the degree of shock that probably everybody goes through when they hear the word, then some written, concrete information. When the doctor gave mum the diagram and I wrote down the things that he'd said, she actually read that over three or four times at different stages before the operation. (E1's daughter),

And:

But I think the main problem was that mum didn't have anything that she could put it on her bedside table and think I'll read that again later when I feel OK. Then pick it up and go through it and then perhaps do that 10 times. (E1's daughter)

Written information serves as a patient pathway so patients know where they are in the process of treatment and care. The same carer said:

But at least if you had some sort of written material the person who was with you like me would say, look this is where we are in the process now and this is what's going to happen next. (E1's daughter)

Written information is even more important to consumers from Greek-speaking and Italian-speaking backgrounds as some of them experience English language barriers.

Its difficult to know how to ask when you don't speak English, but if you speak a little bit of English, reasonable English you make yourself understand what you really want. But if they've got a pamphlet or something where they say if you need some information you go at the desk such and such, and ask. I think this maybe necessary to have. Because I don't know maybe some people they're afraid or maybe they wait for somebody to come around and tell them which is never going to happen, because they don't know what you need, what we need. So I don't know, it's a bit difficult I think. (It.7's sister)

4.3.6 Information in other formats

One consumer mentioned information on a video would not hold her interest.

(Do you think videos would be useful or is it better with a piece of paper and pamphlet that you can take home?) Yeah but on the video what can you put on the video. Just talking and nothing else. Just a piece of information, instead of written on the paper you see it, somebody is talking to you. There's not much you can do on the video really, is it? (It.3, female)

Format of written information

Consumers analysed the information provided by the A&RMC in terms of language, design, including font size, layout, illustrations, paper size and package model.

Simple language

Several consumers would like printed information written in a language easily understood by readers. They said:

Something written in a pamphlet form puts it into common language, or easy to understand. (E1's daughter)

Better plain because too many people have not been to school, it's different these days. But in our days it's more hard. (Gr.1, male)

In simple (language), people can understand. You go to the library and you've got to understand what this word means before you go there. (It.1, female)

Language and Cultural factors

Greek-speaking and Italian-speaking consumers, raised the importance of addressing language and cultural factors when providing information.

(Would you like to have the printed information in Italian?) Definitely because the kids not always around. (It.7, female)

And the booklet if it was in Italian, it would reinforce what the others were saying and I would have felt more confident. (It.7's sister)

The best information for me was, that when it showed you exactly where the cancer was, and I feel that when the information is in your own language that's the best thing. ... When things are explained to you in your language you understand things better. (Gr.2's wife)

(Do you think you would like some more information about the treatment?) Yes. In Greek. (Gr.5, female)

(Would you like to have that information to be in Italian? Do you think it would be a good idea?) Oh well, yes if you have some books in Italian. ...Probably easier to read Italian. (It.6, female)

Your own language is better. Its more important in your own language but in English its all right when it's not a very important thing. (It.5, male)

Design

Consumers preferred the design of written information to be interesting but simple.

No. But then again they're not trying to make it like a travel brochure; you're not sort of trying to be persuading people to do it. Once you've decided to do it then you just have to follow the instructions. ... It's got to be understandable and clear, so you wouldn't want to make to too jazzed up or people wouldn't know what they were suppose to be doing. (E1's daughter)

(What is the most important thing about printed information?) Simplicity, which is very difficult. (E5, male)

Font size

One consumer mentioned font size should be bigger than normal.

(It is easy to read in terms of the size?) Yeah that one is all right. *(What about this one?)* Yeah that one is OK. I suppose that one there could be a little bit larger in print. Larger in black print. (E4, male)

Layout

Some consumers thought check boxes in written information would be helpful.

Perhaps little check boxes that people once they've done it, they can tick it off and know that they've done it. Because sometimes you're looking at a lot of things, say there are for example, one, two, three, four points there, if your colonoscopy is booked for the morning, if your colonoscopy is booked for the afternoon. So perhaps if you could make it so that people could follow a sequence of instructions and know that they've done it. (E1's daughter)

Diagrams/illustrations

Other consumers thought illustrations in written information would be useful.

See even for example, for people who are having bowel cancer operations, most of them like Mum and I don't even know where your bowel is. So clear diagrams like that, this is the part of your body that's going to be affected would be quite useful. So something along those lines would be really good.
(E1's daughter)

But somebody that may not be conversant with the English language probably they may find illustrations could help. All the illustrations you get it could be confusing too. (E9, male)

However, design should be careful with the use of colour in illustrations.

Black and white will do fine. I think it's only like more terrifying to see the colour. Black and white is more imaginary, you think of the rest of it. Once you see the part where the sickness is, that's fair enough; you never see the entire colour. (It.7's sister)

Paper size

Consumers tended to prefer written information to be produced in pamphlet size.

(What about the size of the pamphlet?) Is it good to fold them (A4 sheet in half like this?) Yes it's easy to read, straight from your hand.
(It.6, female)
Package: leaflets or booklets

Consumers thought written information as leaflets in an appropriate folder or as a booklet would be convenient.

Perhaps the fact that there're multiple bits of paper, perhaps it could be put into some sort of booklets, or like this (looking at examples of loose sheets in a small folder) ... so they're altogether and then you don't have to think, oh where did I put that piece of paper that told me about this or the other. ... If it is a booklet the content should be clearly itemised so patients can pick up quickly what they want to know. ... You don't have to read it all; if you're looking for something specifically you don't have to read it from cover to cover. (E1's daughter)

4.4 Opinions about health services

Consumers' judgment about the services provided by the A&RMC hospital, as well as other services, were sought through the consultation process.

4.4.1 Satisfaction with hospital experience

Most consumers were pleased with the care provided for the treatment of colorectal cancer at A&RMC. Several consumers were very positive about the team of health professionals providing care.

I must say the treatment I've received has been excellent. ... I couldn't be safer than with the hospital staff and the other people that are been concerned with what care they gave me. Especially in palliative care. (E9, male)

The treatment was very good, the nurses were very good. I thought it was very good. I was just an ordinary patient in a general hospital in the Austin, and it was very good. Mind you I'd never been in another one so I didn't know what it was like, or what the other places were like. (E2, male)

Yeah they (hospital and nursing staff) were very helpful. They virtually covered the same thing that the doctor did about it; they were really helpful which made me feel a lot better. (E4, male)

(Dr Z) she was excellent to me. Truly excellent, gave me a lot of confidence in what I was going to do. Because I've never been in hospital in my life, and (another hospital staff) she came in and she talked and talked to us. Don't worry, you get a needle. (E5, male)

Consumers from Greek-speaking and Italian-speaking backgrounds were also satisfied with care received, especially from nursing staff.

Terrific nurse I'll never forget it. She looked after me. ... She looked after me all the time. They were so good to me when I was swelling up. When you're there for so long a time they could get tired of you. (Gr.2, male)

(What about the nursing staff?) Oh they were beautiful, lovely, no problems there at all. As soon as I rang that bell, not that I rang very much, they used to come straight away. They were very caring. (It.1, female)

I was very satisfied with the way that we were treated. We're not very demanding people you know, we know how difficult it is working there and everybody calls. If they treat you fairly reasonably I think you're supposed to be happy. I think without paying anything, if everybody being treated the way she is, they're supposed to be very happy. (It.7's sister)

4.4.2 Complaints

However, some consumers reported variation in the performance of hospital nurses.

Some of the nurses are terrible people. Should be working in Belsen, the concentration camp. (E10 and wife)

Another stated:

(A male nurse) was more interested in that (a female staff) than he was putting a needle in my vein. He missed three times, in the end I

finished up spewing. ... And here's the difference, the next time a Chinese woman did it most of the time, a Chinese woman. Now she was terrific I never even felt the needle going in. That's how good she was. (E10, male)

One Italian-speaking consumer thought the diagnosis and timing of treatment she received was inappropriate.

He gave me an colonoscopy, told me its too big to be removed we'd have to do surgery, it nearly burst that's how bad it got which I reckon was his fault not mine, because he let it go another two or three weeks before he gave me the surgery. It should have been done straight away. ... That's when she (another doctor) told me, well it goes to your lymph glands it spreads to your soft organs like your liver and kidneys and of course that upset me more. So otherwise they don't really come up and say much to you, they used to come in and say hi how are you, you've got this I'll see you later. The doctors at 7.00 o'clock in the morning that's all they used to do you know. (It.1, female)

Some consumers experienced communication problems with some hospital staff.

You don't see enough of the doctors in the morning, they don't listen to you enough, they're too busy, and they don't listen to you. No one listens to you. As soon as you open your mouth they walk away. ... This was after the operation. But they come around, how you feeling, and they're looking over there. (E10, male)

And:

Yeah I don't see enough of the doctors that's a gripe I had, and they didn't listen. When I asked them, this thing it took four days before one of the young nurses, She came along and bought me a pan of salty water and that. I blew me nose out and great blocks came out you know. I was able to breathe and all my problems were over. Those other butchers were tying me down on the bed and all when I complained about me nose, I can't breathe. No one listens to the patient. (E10, male)

One carer commented:

We weren't happy with this hospital; they didn't give us any satisfaction in regards to the operation and the information before or afterwards. (It.4's wife)

Lack of co-ordination among hospital services

An Italian-speaking consumer and her carer identified a problem between medical staff and other services.

The specialist said now you start eating something. She did not say what you could have, and she (catering staff) gave me the normal. (It.7, female)

After the operation you were starving because they starved you before, they starved you after. I think when they bring something out you eat because you're starving, and this was wrong, they brought out a steak, and she ate it and then she couldn't pass it through, she couldn't digest it and she had problems with the bag, and then she started vomiting because she can't pass it through. ... She basically was told to start eating but wasn't told what to eat. ... This is definitely part of seeing it written somewhere in regards to eating special diet things
(It.7's sister)

Early discharge

One consumer felt he was discharged too soon after the operation.

The only thing like I said, they put me out of there too quick. Because I wasn't eating there, I wasn't going to the toilet. They left me. (Gr.1, male)

Another consumer felt she was forced to go home because of the stressful environment in the recovery ward she was in.

I left the hospital too early. The reason was, I don't know whether I should mention this or to write it down, it was because it was like a mad house in there. So I said that I wanted to leave to come home before I went crazy. (*What happened?*) Well it was bad luck where I was before I was the only woman there. ... I found it very hard. I found it extremely stressful. I couldn't tell if they were being overly demanding but the elderly women was constantly ringing the bells and asking the nurses to come and they were not responding and telling them off. I wanted to leave. ... After seven days the doctor didn't want me to leave but I said I had to leave or I'm going to go crazy. (Gr.5, female)

Waiting time and confusion at Outpatient Clinic

One consumer complained about waiting times.

It was only the outpatients I think. ... We arrived there with a letter from my local GP at 11.00 am and arrived home the next morning at 5.30 am., after being seen by a doctor, an intern, at about 12.00 midnight, who wanted to send me in two weeks to a clinic for uterus fibroids, which I have but never have any trouble with, and completely ignored the GP's letter. ... I was lucky (that finally the bowel cancer was diagnosed and treated) but how many people get lost in the public system? (E8, female)

Waiting time at Outpatient Clinics

One consumer complained about waiting times.

It was only the outpatients I think. The local doctor consented to a clinic or something instead of spending 12 hours in outpatients. He said if you're dying you get in first. (*Was that an outpatients or an emergency department?*) The outpatients. We got there at 11.30 and we went home at about 5.30. ... He sent a letter and everything and just said go to the outpatients. That was the only hassle. (E8, female)

4.4.3 Experience with other services

Consumers who had received services from district nurses found them very helpful.

Even the (district) nurses who came home, they were lovely too because she used to work here, and she said to me that's where I worked, so she knew exactly what to do and how to help me. Any problems I used to ring them up, (It.1, female)

The district nurse came twice a week; I found that was a great help.
(E6, male)

Council assistance organised through the hospital was also appreciated.

We got cleaning, she came once a week. ... Yeah it was all organized through the hospital. I got onto the council and they came in. They cleaned my spouting out; I had to pay for it. But still only \$8 an hour, they cleaned the spouting out. What else? We could have had more but we didn't want it. (E6, male)

4.4.4 General Practitioners

Several consumers mentioned contact with their General Practitioners (GPs) during the process of diagnosis and treatment of colorectal cancer. Several consumers were disappointed with the care received from their General Practitioners.

Yes and the GP who wouldn't know a lot obviously said oh well, I might have 12 to 18 months (to live). (E5, male)

(And the faeces were black. And you went to the doctor. So you knew it was dangerous?) I went to my doctor, he gave me some tablets, nothing happened.

(It continued?) After that he gave me different tablets, between that, plus time I go to the hospital with a heart attack... straight away I have an x-ray and found out. And told me you've got cancer. (Gr.3, male)

Other consumers felt the care they had received from their General Practitioner was excellent.

(When you were told that you had cancer you must have worried?) No it was so quick. ... I saw some blood from the back. ...But after two or three days anyway I decided to go to the doctor. I went to my local doctor and she sent me straight away to the specialist. (It. 6, female)

Another patient and her carer found their General Practitioner very good in providing continuity of care.

It was already healing, but as the doctor (GP) said, for every stitch on the outside that healed, there're 10 inside that got to heal. ... I showed him, he looked at it. ...He's a fantastic man. He's quiet and calm, and funny and truthful. Truthful. (E1, female)

So again a lot depends in that instance about whether there's a continuity of the GP's dealing with the patient too. ... I mean if somebody comes in and they haven't had a problem before and they haven't even got GP then its sort of potluck who they get discharged to. But mum had had the same GP for a while. (E1's daughter)

4.5 Views about PEP2

Some consumers offered comments about the project and their involvement.

It's good to help the people you know, it's all right. (Gr.1, male)

If we are able to help in any way then we can we will help. (Gr.2, male)

Very happy. I was able to say some things that I wasn't able to tell anywhere else. (Gr.5, female)

Like I said before it's a very good task to get people, to interview them, they're going to express their feelings, their experience they've gone through for whatever, two or three years you've been having it. Then you can talk to somebody and put it together for somebody else

to read and they are more prepared on what's happening. (It.3, female)

(About receiving PEP2 report) I'd like to know what everybody's ideas are. It will be interesting to know. (It.1, female)

5. DISCUSSION

In preparing this report a conflict becomes evident. On one the hand there is evidence pointing to the absence of comprehensive information having been provided to the consumers interviewed and therefore a need for redress; on the other hand, there is enormous diversity on how, when and with what priority these information needs require to be met in the context of colorectal cancer diagnosis.

The range of information, together with the diversity of colorectal cancer patients' needs means that it is not possible to define a single point at which consumers require information. Rather, it is important that information is available at different times during the course of diagnosis, treatment, recovery and discharge so that consumers can access and use it at the time they decide they need it.

It is important that future information provision strategies emphasise opportunities for consumers to discuss the information received. The availability of written information alone does not sufficiently address consumer information needs about their condition, patient social and emotional issues, and patient decision-making capacity. Verbal education should be available in conjunction with written information.

Themes of the findings can be summarised as follows:

Existing information provision

The consumers interviewed revealed little doubt about consumers needing information. There was very limited understanding by consumers regarding their illness and treatments options, recovery and prognosis. It appears that often consumers had not been assisted by the information they received to understand their condition, including symptoms, diagnostic tests and procedures, treatment options and outcomes.

The quality of information received by consumers about their condition varied according to the clinician they were seeing and whether the consumer was an active seeker of information. The information received was primarily verbal, with little or no written information supporting the verbal advice. Further, consumers reported that often there was no opportunity at any point in time to discuss the information received with treating staff.

Consumers were often not aware of options for treatment, and were provided with little or no information about the relative benefits or effectiveness of the treatments and diagnostic tests and procedures.

Consumers wanted to know about the cause of the condition; in particular, early signs of the disease as well as the possible pathways that the disease might take.

Similarly, consumers needed better discharge information. Consumers stressed the absence of information and assistance regarding management of their condition after discharge.

The absence of information provision was particularly evident with the Italian-speaking and Greek-speaking consumers interviewed. These consumers reported rarely having received written information in their first language as well as the absence of adequate interpreter use in information exchange.

Another interesting issue that emerged was the impact of cancer diagnosis on patient capacity to seek information. There was reluctance by consumers to seek information; that is, there was a primary reliance on their clinicians for information provision regarding their illness and decision-making about treatment options. Colorectal cancer patient passivity needs to be factored in to any implementation of information provision strategies.

Communication

While consumers varied in what they wanted to know and their ability to understand and absorb information, especially due to cancer diagnosis, the majority of consumers expressed the absence of opportunities for them to formulate questions and discuss their illness and treatment options with their clinicians. That is, consumers reported not being given sufficient time or encouraged to participate in decision-making about different treatment options. There was clearly reliance on their clinicians for decision-making regarding treatment options.

Consumers in the consultation process spoke of the difficulty in obtaining timely information; in particular, early diagnosis of the disease, the benefits and risks of particular treatments and discharge information.

Further, consumers often described clinicians/patient information exchanges as confusing. Consumers did not necessarily gain a realistic idea of the processes and likely outcomes of possible procedures and treatments as well as prognosis. Another interesting issue that emerged was consumers' preference for information to be conveyed verbally.

Written information

Nearly all of the consumers consulted who had received written information questioned its relevance. Most of the information received was difficult to read and comprehend and therefore not used. Content usefulness of information prepared is important to stress. It is clear that information prepared will be used if it is relevant to consumers and address the questions that matter to them.

Consumers expressed the need for patients from Greek-speaking and Italian-speaking backgrounds to have information available in their first language, as this would enhance their access to information.

Consumers stressed that the use of jargon, acronyms, technical and medical terminology needs to be avoided as these were confusing to consumers. They suggested that if these were needed to be used, then a straightforward Explanation should accompany their use.

Consumers expressed the need for written information to be prepared in plain English to enable content comprehension by consumers across a wide range of literacy skills.

Consumers expressed a dislike for long, technical information about colorectal cancer and its treatments. There was a clear preference for short, informative pamphlet-size information with diagrams, illustrations, graphics etc. to improve content comprehension.

Some consumers in the consultation suggested the development of a pathway document framed around the most common procedures and treatments—and

providing information about them to help consumers understand and make decisions about them.

Carers

Looking at the information needs of consumers, there is obviously a range of carers' needs that exist at various times. Consumers stressed that the availability of information to carers was very important especially when the patient was not an active seeker of information.

Supports

Many of the consumers expressed little or no knowledge of the range of program services that are available, which might be able to help with social and emotional issues patients experience. Consumers identified information about the availability of social workers and other counselling as being very important, as such services can help patients and carers understand the condition and cope with its effects and treatments.

Consumers also indicated the absence of information available about the availability of other agencies' services, including support groups that may provide further information or support.

General Practitioners

Consumers were extremely concerned with issues relating to their care by General Practitioners; in particular, not being diagnosed early enough or being misdiagnosed.

Some consumers spoke of the difficulty in obtaining accurate, timely information about colorectal cancer, especially information about specific symptoms, from their General Practitioners.

Other consumers indicated the failure of General Practitioners to give general information about the condition; that they were entitled to a second opinion, and about other services available.

Although consumers raised these issues, in the main consumers had good experiences of care; consumers often praised the hospital staff for their standard of care.

6. **RECOMMENDATIONS**

Recommendations are based on the discussions with consumers from the focus group, group interviews and individual interviews.

Content of information

1. That written information includes information on:
 - cause, symptoms, diagnosis;
 - treatment options and outcomes;
 - prevention;
 - recovery and discharge; and
 - social and emotional issues.
2. That written information includes information on all A&RMC services as well as other agencies that provide services for the treatment of colorectal cancer.
3. That written information includes useful contact numbers and references.
4. That written information includes information on alternative sources of information, support groups and counselling services available to patients and carers.

Delivery of information

5. That initial written information on colorectal cancer and its treatment is provided to all patients by their clinician at the time of diagnosis. The following information should be included:
 - information on colorectal cancer;
 - available services, e.g. interpreters, transport assistance, counselling services;
 - a list of questions to ask in subsequent appointments;
 - treatment options, risks involved and side effects;
 - social and emotional issues.
6. That written information is provided at different times during the course of diagnosis, treatment, recovery and discharge. For example, at the pre-operation appointment the following information should be provided:
 - preparation for the operation, operation procedures, post-operative management, care after discharge and other services available;
 - the Patient Pathway document developed by the consumers participating in the A&RMC's CSSP project.

7. That opportunity to discuss written information with staff is available to patients during the course of diagnosis, treatment, recovery and discharge.
8. That verbal education is provided to patients and carers in conjunction with written information.

Linguistic and cultural diversity

9. That written information is prepared in languages other than English.
10. That written information in languages other than English is prepared in collaboration with providers/consumers representing the target groups.
11. That staff ensure that interpreters are used with linguistically and culturally diverse patients in information exchange.
12. That translation of the written information needs to include English technical and medical terms in brackets.

Language

13. That written information utilises plain English.
14. That jargons, acronyms, technical and medical terminology is avoided, and when used is followed by a straightforward explanation.

Format

15. That written information is prepared sequentially possibly encompassing diagnosis, treatment, recovery, and discharge sections.
16. That written information conveys the information clearly through a question and answer/point form format.
17. That the written information includes diagrams, graphs, illustrations, and graphics to assist with reader comprehension.
18. That layout of the written information includes headings relevant to the content.
19. That an easy-to-read font size is used in the written information prepared.
20. That written information is presented in a pamphlet / booklet package.

Carers

21. That written information is provided to carers to support patient involvement in decision-making about treatment options.
22. That opportunity to discuss written information with staff is available to carers during the course of diagnosis, treatment, recovery and discharge.

Divisions of General Practice

23. That A&RMC, in collaboration with Divisions of General Practice, ensures that written information on colorectal cancer for consumer use is available form General Practitioners in the region.
24. That A&RMC, in collaboration with Divisions of General Practice, resources General Practitioners in the region on colorectal cancer diagnosis and treatment services available.

Evaluation

25. That written information prepared includes schedule dates for review and evaluation.

7. REFERENCES

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8. APPENDICES

APPENDIX 1: Interview Question Guide

Delivery of Patient Information

What information did you receive when:

- . You were told you had bowel cancer?
- . Before you had your bowel cancer operation at A&RMC?
- . After you had your bowel cancer operation at A&RMC?

Who gave you the information?

When would be the best time to receive the information?

Did you get information about your bowel operation from any other source?

Quality of the Information Received

When you were told you needed to have a bowel cancer operation what information did you want to know?

After your bowel cancer operation what information did you want to know?

Did you find the information provided comprehensive/useful?

What other information was important, but had not been included?

Did you have an opportunity to discuss the information with a doctor/nurse?

What other (non-written) information did you receive?

Patients' Responses to Receiving the Written Information

What did you do with the written information when you first received it?

When did you read it?

Did you have difficulties reading/understanding the written information?

Did the written information help you prepare questions regarding treatment, recovery etc.?

If you did not receive any written information, what did you do?

Design and Format of the Written Information

What do you think about the presentation of the written information in terms of: size; length of information; language; print quality; illustrations/pictures; and layout design?

Was it difficult/easy to read?

What would you like changed about the design of the written Information?

Patients' Satisfaction with Receiving the Information

Did the information you received help you to:

- . Understand what will happen during the bowel cancer operation?
- . Understand what will happen after the bowel cancer operation and you would go home?
- . Decide/discuss the treatment options?
- . Feel comfortable about undertaking the treatment?

If you did not receive any written information from A&RMC, how do you feel about your experience of the operation?

What other information sources would be supportive?

What type of information did you need for short-term and long-term management of your illness?

Interpreters

How did the interpreter-mediated communication influence your discussion with your doctor/nurse?

What was the availability of interpreters?

Final comments

From all the things discussed, what is most important about the information received?

Is there anything you want to say about the project?

Is there anything you want to say about this interview?