

**CLINICAL SUPPORT SYSTEMS PROJECT
AUSTIN CONSORTIUM**

REPORT ON

**INTERVIEWS WITH CONSUMERS AND CARERS
ABOUT THEIR EXPERIENCE OF CARE FOR THE
TREATMENT OF COLORECTAL CANCER**

Health Issues Centre

October 2001

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This report was researched and written by Dr Janet Spink, Senior Policy/Research Officer at 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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REPORT ON CONSUMER AND CARER EXPERIENCE OF CARE

Consumer Involvement in the Clinical Support Systems Project

The Austin consortium has taken a grass roots approach to consumer involvement. This has meant that consumers have been engaged slowly and only those patients of clinicians involved in the project have been approached to become involved. Dr Janet Spink has represented a consumer perspective on the Governance and Implementation Group. She is a senior researcher with Health Issues Centre, with a clinical background in social work. She has been the consumer representative on the National Cancer Strategy Working Party and most recently the newly formed Victorian Cancer Collaboration and also has personal experience of cancer.

The reason for this careful approach to involving consumers in the project was because there was no pre-existing consumer group who could be called upon to participate in the project. Therefore consumer engagement needed to start at the beginning by involving individual consumers. It was also important to make sure that when they did become more actively involved with the system, the system would be appropriately responsive to them. The project did not want to put consumers at risk who were already unwell.

Patients were recruited from clinicians who were already involved in the project. The recruitment process involved discussion with the implementation group and then a letter and information pamphlet to the clinician. A phone call and the faxing of a further letter to the clinician's secretary was made and then if the clinician was willing to suggest patients, a faxed or emailed list was forwarded to the Project Worker at ARMC or Bendigo Health Care.

Patients were recruited in three groups. These groups related to the time of their diagnosis. Group 1 consisted of patients who had been diagnosed in the last 6 months. Group 2 consisted of patients who had been diagnosed in the last 6 to 12 months. Group 3 consisted of patients who had been diagnosed more than 12 months ago. Only one person was recruited for group 1, understandably this is a very difficult time for patients, 14 people were recruited for group 2 and 17 for group 3. Some patients agreed to interviews but became unwell and were unable to attend or have the interviewer visit. Those recruited had a range of diagnosis, care experiences and prognosis. In fact I am very sad to report that one patient who participated died at the end of July.

Once lists of patients were received from clinician's patients were rung and asked if they were interested in receiving information about the project. If they were interested we sent a letter and written information and then rang back a week later and offered them a group or individual interview. Consumers were paid for the interview and any travel they incurred (see separate recruitment document).

Semi-structured interviews were conducted with six small groups ranging from two to five people and totalling 19 consumers, and 14 individual interviews. There were also eight carers/partners present during interviews that contributed to the interviews. The interviews lasted from 60 to 90 minutes. All but one of the individual interviews was conducted at the consumer's home. The other interviews were conducted at ARMC Repatriation campus or CHERC in Bendigo.

Demographic information was collected from all participants. Of the patients 22 were male and 11 female and they ranged in age from 43 to 86 years with most in the 60-80 years age range (24). Many of those interviewed had not completed high school and were employed in skilled trade areas. Most were married with children. Seven patients and two carers were interviewed in Bendigo. Five people originated from the UK, one from Italy, two from New Zealand, one from Hong Kong and one from Greece. Therefore the majority of those interviewed were born in Australia. All spoke English although for three participants it would have been their second language.

The five questions asked were centred on the consumers' experience of care through the medical system. The interview explored:

- The 'ups' and 'downs' of that experience;
- The satisfaction of the consumer with the services provided;
- The perceived clarity of explanations about diagnosis, procedures and treatments;
- Whether and how the consumer sought information from other sources about their condition and its treatment;
- The consumer's knowledge of evidence based medicine and clinical guidelines.

Data Analysis

All interviews were taped (after gaining permission from the participants) and then transcribed by an external transcriber.

The tapes were checked against the transcripts for accuracy. Each interview was coded in relation to the five questions asked (content analysis). A thematic analysis was also carried out which looked for the issues raised by consumers as important in their experience of bowel cancer.

After coding the data it was difficult to decide in what way it was best to present the findings. It was decided to present them in the way the researcher was presented with them by the participants to the research. The participants began with a narrative about their own experience of care including diagnosis, treatment and out patient experience. They then focused on particular issues, which emerged out of that narrative either from the specific issues raised by the participant or from the responses to questions asked of all participants by the researcher. This also fitted well with the *Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients and their families*, 2000, NHMRC. In fact quotes are taken from this document to illustrate the protocols and the patient experience is put along side. It gives life to the guidelines and tells how it really was for some of the patients.

The other themes that emerged included what the patient brought to the experience, dealing with a diagnosis of bowel cancer, the use of multidisciplinary teams and general issues related to communication. These issues are included because the patient cannot experience his or her bowel cancer as a disease to be treated separate from the rest of their physical, emotional and social body. The patient/consumer is more than a diseased bowel and all interventions whether from a surgeon, oncologist, nurse or allied health profession or the hospital system are impacting simultaneously on the patient-consumer.

Some patient-consumers had good experiences of care, others not so good and some experienced both good and bad experiences. The issue of poor

communication between patient and clinician did not appear to be located in any one profession there were stories of both poor and excellent communication in all of the professions involved in patients' care.

Similarly the information received by the patient-consumer about their condition varied according to the clinician they were speaking with, whether a cancer nurse and stoma therapist was available and whether the patient-consumer was an active seeker of information.

Other interesting issues that emerged, were those related to the ideas about cancer- its meaning for the patient and the negative reactions they received from others outside their family. There was some discussion about death and some participants talked about how they were preparing for their own death.

Participants varied in what they wanted to know and their ability to understand and absorb information especially when they were in a shocked and or unwell state. They also varied in what they brought to the care situation in terms of pre-existing medical conditions, courage, ability to stand up for themselves, education and even their sense of humour.

Consumers highlighted a number of issues relating to their care experience that may need to be addressed. They include:

- Being given a diagnosis of cancer with a poor prognosis in an insensitive and inappropriate way,
- Patients being misdiagnosed or not diagnosed early enough;
- Patients not being given sufficient time or encouraged to participate in the decision about whether to have surgery;
- Patients not being automatically told they were entitled to a second opinion;
- Being placed in wards after surgery and witnessing people dying on the same ward;
- Lack of assistance or advice about bowel management after operations; and
- Patients being given limited information when they wanted more.

Although these issues were raised by a number of participants on the whole patient-consumers praised the doctors and nurses (particularly in chemotherapy), cancer nurses and stoma therapists for their caring and playful care. Participants were truly appreciative that medical staff was trying to save their lives. Consequently participants were very pleased to give back to the hospital through their participation in this research.

This report needs to be read keeping in mind that this is a narrative about the experiences of 32 consumers and 9 carers who were asked a particular set of questions and were courageous enough to speak about their experience of care. This report does not put quantitative measures on participant's experiences.

There are lessons to be learnt from all the stories the participants told. These lessons emerged from accounts of the multitude of good procedures that clinicians, nurses, allied health and the hospital system practice in the treatment of bowel cancer. Lessons can also be learnt from those things that were not done well. These "bad" practices remind us all that we must continue to think about ways of improving care for all patients-consumers and carers.

Consumer Reference Group

It is planned to ask those patients who participated in the interviews if they would like to participate in a reference group to work on the consumer contribution to the clinical practice guidelines, consumer pathways and to comment on the consumer report.

Some consumers will be able to represent a number of views and others will have fewer resources. There will be a reference group organised in both Melbourne and Bendigo.

The consumer reference group will be composed of 6-8 participants from the interviews. This group will meet 3-4 times and may also meet with the implementation group to discuss those issues important to consumers. It is planned to set this group up in the next few weeks. Many of the participants interviewed expressed interest in participating.

Please Note:

The words patient, consumer and participant are used interchangeably.

Since the writing of the document the two reference groups have met twice.

The coding used identifies each participant by number. Only the participant has their number.

- ⇒ **pu** means public
- ⇒ **pr** means private
- ⇒ **f** means female
- ⇒ **m** means male
- ⇒ **r** means rural

The Diagnosis

Ability to ask questions and be involved in decision making

Many of the participants said that the decisions were often made for them.

Rural men post 12 months: No that was made for me I didn't have any say so in that, they just came and told me that.

13.purf: I just do what he says. He says do this, do that, go to that – I go. I don't really query because that's his job.

3.pum's wife: He said we'll have to operate straight away. We assumed it was pretty desperate.

Sometimes they thought decisions were made for them because they felt they were not knowledgeable enough to decide, they were worried and frightened or they were overwhelmed by unfamiliar information.

Rural men post 12 months: I just said to the surgeon, I said you know more about it than what I do. You go your hardest...

10.purf: I thought, oh well he knows what he's doing... I just went along with what the doctor advised me... I think the less I know the better... The surgeon said to me, did I want to ask questions... I said no, I'll just leave it up to you. I've got faith in him. I know he'll do his very, very best for me...

12.purf: I had that much thrown at me from different directions, I don't know what was going on half the time.

24.prm: It's a case of acquiring knowledge. You don't really know what to ask the first time. You find your way through.

Sometimes they only felt able to ask one or two questions in the areas that they were confident.

13.purf: Like I asked them straight out, how long I had and they told me 20 years. I was lucky.

9.purm: I always ask them the question, is it going to make me really sick, is my hair going to drop off.

25.prf: I said to him, what are you going to do, where do you cut. He said down your middle and remove it that way

Many felt there was no decision to be made because the treatment had to be done and there were no alternatives.

9.purm: That operation I had, it had to be done.

25.prf: He (the surgeon) really didn't say too much at all... it had to be done didn't it. What could I do I couldn't change anything could I.

5.pum: I think the surgeon explained to me the situation. He said you've got to go, we're going to go and operate on you, you are going to have the bag and things like that...I'm not going to argue

with the doctor. You know he's going to do the best he can. That's about it. That's the system.

19.pufc (For 18.puf): He just said that you've got bowel cancer and you need surgery to remove it, some chemo and maybe some radiation... this is what we're going to do. This is when you're coming into hospital...

23.prm: As far as I was concerned there wasn't any alternative. Nothing to be talked about

22.prm: I don't think there was any choice; I just think the only option was to have it done (otherwise) I would be dead today, of course.

Some participants were unsure as to whom to ask.

9.purm: So you have all these doctors, you don't know whom to ask.

And then the doctors were often very busy.

24.prm: I think getting hold of people is always difficult because they're always busy...

The busyness of the doctor also affected question asking and mutual decision-making. Participants often felt they did not have time to ask or they had waited so long to see the doctor that they would forget what they were going to ask.

27.prf: Unless you write a note for yourself, for when you get there it goes over your head, and you are sitting there reading a book for an hour and a half, and you are so glad to get in there and get out. You forget everything you wanted to ask.

Some people did not ask many questions because they were scared of the answer.

33.pum: Well initially he said he wasn't sure and he was talking about closure and all this sort of stuff and I thought it's scary.

Some people found out vital information indirectly.

25.prf: I think she was just one of the nurses on. I said where would I go to have it done. She said I don't know it depends, Warringal have more intensive care, but I went to Diamond Valley. She said it depends how bad it is or what you'll need afterwards where you would go.

Some participants described how they were able to question the doctors with great success.

29.prf: *The surgeon* encouraged me to have a second opinion; I actually had three other opinions. I went to all sorts of different people in the hope that I might not have to have a bag. So I had to choose whether I wanted to have the surgery with that chance that it would grow very rapidly or if I would prefer to have chemo, which looked as though it would knock the tumor about really badly... So he said he wanted me to discuss that in depth and decide.

7.prm: He came in and explained everything and he put me at ease. He told me what he did and what to expect, that I wouldn't feel anything. Then he asked me if I'd like an epidural and I didn't know

what that was. He said its what ladies have sometimes in the spine to deaden the pain from the waist down. I asked him what after effects or what could happen. He said well you wouldn't have any feelings in your legs and that might not suit you. I said what would you prefer. He said oh well it's not for me to prefer, its for you... so I said I'll have the second one. I'm glad I did.

Some participants described how they were able to question the doctors with less success.

6.pum: I said why continue. It's not doing any good. I said sometimes quality of life is better than quantity. And he gave me an answer, but unfortunately I'm a little bit deaf and I didn't quite hear. I can't remember what he said at the time, but it was to do with quality and quantity, and his opinion was a little bit different to mine.

1.pum: *Re choosing to have radiotherapy.* I said to him well have I still got the cancer. He said well no not really. He said you're clear. This is just insurance, just in case. That's how he carried on, eventually in the end I had it.

Others felt that they were friends with the doctor and it was a conversation, which was mutually enjoyed.

8.purm: The surgeon said, "I cannot remove that, I cannot touch it, he said it could be fatal. He said what we'll do is I'll send *the oncologist* up, he's in charge, so he came up and saw me on the ward with another doctor I forget who it was now. He explained all this new research to me. So anyway he said to me, look you've got two options. Either don't have it or have it. I said well I'm not going to lose anything by having it. So that's the way we looked at it

A few participants reported that their doctor insisted on **them** making decisions.

29.prf: At the end of the session it had been an hour and a quarter, and I said can I just review the things that we've done today, because I want to be very clear so I know what we've covered. When I came to the one about chemo I said, you might organise for me to have chemo after the surgery. He said no, no. I will talk to you about it, and you will decide.

Or that they felt involved in the decision making because they were informed about what was happening.

26.prm: *The surgeon* showed me all the photos, which were taken of my inside, which didn't mean much to me it just looked like a hole in the wall. He explained to me that the cancer had eaten through the wall of the bowel. He did say that we'll have to put a bag on you, but he said its possible you may have to wear that bag for life. I haven't got much room to work, and he says... He said had it been another half an inch lower you would have had to have the bag forever.

Some used family members to find out information.

19.pufc: mum is a bit isolated here and she doesn't know much about medical profession and illness and things, the language might sometimes be a little bit too complicated, out of her reach.... I get it from the doctors then I tell mum, then I tell dad.

Some people were satisfied they were given choices in the decision making process and maybe could have asked more questions.

4.puf: He explained it, he said here's your bowel, it went through the wall into the nodes and these ten were all right and that one had some cancer cells in it... Probably I could have asked a lot more questions than what I did, and I'm sure they would have been answered.

Patient knowledge of evidence-based medicine and clinical guidelines

The majority of those interviewed had not heard of evidence-based medicine or clinical guidelines.

31.puf: I don't think the word was ever mentioned.

One man remembered reading it on the information sheet the project sent him. While another woman clearly knew about evidence and research. She said she had asked the clinicians about the evidence for a particular procedure.

29.prf: My new oncologist said, the best evidence you have that that's not cancer in the lungs is this blood result, and he said it looks as though you've eradicated your disease. You are clear, at the moment it looks as though you're clear.

A number of participants were interested in knowing more about it.

12.purf: It wouldn't have done any harm for me would it?

Quite a number of participants were familiar with clinical trials as they had or were participating in them. No participant had seen the NHMRC Guidelines and all expressed interest in it and took a copy when offered.

Participants had different understandings of what the word 'evidence' meant. Some thought it related to their family history of cancer, genetics or inheritance.

Rural men post 12 months: They talked to me about it but it wasn't much about cancer, they just wanted to know more of your family history.

Others talked about doctors giving them statistics on risk and telling them 'the best thing to do'.

Rural men post 12 months: All *the oncologist* said was that was the best thing to do... It doesn't cure it; it controls it.

33.pum: They said more or less this is the way we've found this treatment is more beneficial we've had more success I think they said we've had more success with reducing the size of the tumours and then removing them rather than going in and chopping it out.

26.prm: *The oncologist*, give me a form to read, it actually stated on it there was a project they were doing, it was only a new project and it would be pretty severe, I didn't have to go through it. But ... if I didn't go through it there was a 50/50 chance the cancer would come

back. If I went through the treatment it reduced to 10% chance. So I said I'll take the odds... Oh I was well informed about it.

1.pum: When I was a bit dubious about having the radiation therapy *the radio-oncologist* drew a little graph out and explained to me that without it I would only have a 60% of re-growth success rate with the radiotherapy he drew another graph, it went up and down. He said it will gradually built up until the last week and go off, and he said you'll have a 90% success rate. So the success rate goes up a lot with the treatment. He did explain all that to me....

One participant reported being given the risks by her doctor but then another health professional disputing that she should have been given the information.

4.puf: One of the doctors did say something. He gave me not as definite as this but more or less if you were at stage one you're got a 90% chance, stage 2 80%. Stage 3 you're down to 70% or 60% or something. But if you have chemo that would put you up to a 70%. They're not the right figures but that was sort of what he said. But when the counselling lady came to me, she was quite upset about that. She said he shouldn't have said that to you because we don't have positive information on that... But I could see what he'd told me worked out that I had about a 70% chance of surviving. Which until he actually said that I thought I had a 100% chance of surviving.

Some participants when asked this question talked about the different sorts of cancer, the value of a special diet, the treatments and procedures they received and issues related to the cause of cancer.

Rural men post 12 months: No well I honestly thought cancer was cancer and that was it, until I was reading the books and so forth and found out there's two sorts of cancer, or there might be more is there?

11.purm: I know when I came out I said is there any special diet for me. He said no just eat what you want to eat that's all there is to it... Eat plenty of vegetables, that is all I know.

28.prf: I think that's the procedure you know, operation, chemo, and radiotherapy.

25.prf: I asked him about what you could do to prevent it or what caused it or everything like that, so he said no one really know for sure. There's no evidence that eating this or not eating that, or doing that or not doing that.

Those who were on clinical trials were not familiar with the word evidence or evidence based medicine.

8.purm: *The oncologist* said to me, we'll give it a go and see what happens. That's all he said. He said are you willing, I said yeah too right I've got nothing to lose. Well what was the word, advanced medicine? That's the way he put it.

Experience of having a delayed or incorrect diagnosis

Several of those interviewed described experiences where they were incorrectly diagnosed

Rural men post 12 months: I had about 8 different doctors check me out there. Anyway finally they admitted me. It was supposedly appendicitis.... The next day he came around to see me and he said you had us fooled, we went and looked at the appendix and said there's nothing wrong. Anyway they took the appendix out (*it was an ulcerated bowel*).

24.prm: The radiologist said oh he's got tumors in his liver. My oncologist said no it's not right you don't. He's had his expert friends look through the CT scan and said no you don't. So you just don't know what to believe.

A considerable number of participants had to visit the doctor or casualty several times or insist on treatment before being correctly diagnosed.

31.puf: I think that perhaps its not picked up very quickly, I'll tell you what I find, a lot of people complain and I did for nearly 12 months that I had what is it, not stress bowel syndrome, irritable bowel syndrome, because I was going to the loo as many as 20 times a day. It wasn't until I saw traces of blood that I said to my Doctor that I really think its time we did something about this.

29.prf: The GP assured me it was some sort of haemorrhoid, which I thought was a little odd because of the nature of the blood because it was very mucousy. So because of that there wasn't any urgency...so I do wonder about her diagnostic skills, because cancer is pretty easy to diagnose.

24.prm: Well actually the year before that I went to the GP with bleeding, and he just laughed and said oh don't worry about, nothing to worry about. So I waited for a whole year. Then I went back to another GP who referred me to *the surgeon* who said I had a bowel tumor. So they surgically removed the bowel tumor...

Rural men post 12 months: Well in my case I was crook (*with pains in the stomach*) for about 9 months. I just kept going to my local doctor all the time...He kept saying no you're constipated. He'd give me more stuff like that. I went like that for 9 months...He kept mucking around, said there was nothing there... Anyway I couldn't stand the pain any more *the son rang the ambulance and he was given a colonoscopy and operated on within the next week for bowel cancer. Also he sacked his GP.*

13.purf: *She knew for 12 months that there was something wrong.* I had all the tests 12 months previously and was told it was all clear. It was only at my insistence through my own doctor that they did them again and found it... I wasn't losing weight I was just losing blood.

4.puf: I'm not criticising my GP... well I still go to him and I'm very fond of him. But he was a bit wrong about this. Because I went to him two months running and said that I was bleeding every time I had a bowel movement.

Sometimes students assist in the diagnostic process.

1.pum: *The surgeon* had students with him. Now the students were asking all sorts of questions... during the questioning it turned out that I was going to the toilet in the morning, several times in the first 2 hours... He said well we'll have a look and see what's going on... nothing to do with a hernia... I think its because they were asking

questions and I was answering more than one question at a time, two or three at a time sort of thing.

Sometimes the delayed diagnosis was due to the person not going and seeking assistance. Sometimes this was due to well-grounded fears about what was wrong with them and their need to choose a clinician who would meet their needs or their desire to deny they were unwell.

12.purf: I was sick for nearly 18 months before I'd even go and see a doctor. I was getting worse all the time. I knew I'd got to that stage. My eldest son came in one Sunday and he was that upset, I knew myself by then I needed help...I told him that if he could find me a woman doctor that I was comfortable with that I'd go. But I said if I went to her once and I didn't like her that's it. So anyway she was nice. So I had all these tests and then I went back to *the GP* and she put her arm around me and said, well look there's one relief she said it's not what you thought it was. I knew but I didn't say it was bowel cancer. Because dad had it and everything was the same exactly. So anyway when she told me about it I just looked at her and I said no that's not right. But I didn't argue with her. I just let it go. Anyway things kept getting worse. It turned out that it was bowel cancer...

Sometimes hospital procedures broke down leading to a delayed diagnosis.

26.prm: During the war I got that amoebic dysentery, and I developed polyps. I can't remember now if it was every year or every two years, *the Repatriation Hospital* use to always send me a letter, and I'd go over and have a colonoscopy every two years. When Kennett come in and split both places up they never sent me any letter any more. It was about 3 years or so when I started to get the blood, one of the polyps had turned cancerous and eaten through the bowel see.

Giving of bad news, the naming of the cancer

Many participants talked about wanting to know the truth about their condition in enough detail with the possible treatment options. They wanted to be told in a sensitive way, at an appropriate time and in an appropriate place.

29.prf: I just want to emphasise the manner in which information is conveyed is so significant as compared to what is conveyed. I mean you can be told like you've got cancer and what it meant to you was *I'm dead in the future*, so I'm going to die from this. If they say these are the ways it can be treated and give you that sense that we're in a position of making decisions here, even if the decisions involve looking at your care in the case of *it being unsuccessful* because all of that is also part of living...I mean the set up of the room...there's a desk which protects them and the patient over there sitting down lower, *the doctor* with the information on this side, if they allotted a little more time than 10 minutes. They can't know what state you're going to be in. It surprised me that *the surgeon* had arranged to ring me. I thought if he thought it was cancer he would have arranged an appointment.

4.puf: I'd like to know what's going on...the doctor who actually told me that the cancer had spread; he told me there are different stages. He said now the best scenario would be that the cancer hadn't spread. Number two would be that it had gone through the

walls but not into the nodes. He said you've got number three, which is the third best alternative that it's gone into the node. It was only afterwards that I found that he only counted four levels. So actually what I had was the second worst. But it sounds a lot better when you say it's the third best.

6.pum: The first doctor that came up was a lady, I had visitors, and she said she wanted to talk to me. So I asked the visitors to leave. She told me what the problem was that it was cancer, and that unfortunately I'd got some spots on the liver...so I said what's the prognosis. It's very hard hitting. 6 months...Kick in the guts pardon me, but it was a kick in the guts. But of course she said I'll come back later and she said I'll bring back another doctor with me... Of course I had to call my visitors back in, sit there with the news that I'd just been told, 6 months to live. It was terrible, terrible. So I had to put on a brave face....

33.pum: Probably the worst... was for my wife when the surgeon rang. *The surgeon* didn't explain it very well, she was quite...abrupt or something. My wife asked her what was wrong and *the surgeon* said well he's got a tumour (in an irritated voice) like as if my wife knew, and she didn't know. She was alone at the time, it wasn't explained...It was like sorry Mr Smith but you're dead, I hate to tell you this you're no longer with us.

Rural men post 12 months: In fact the day I went in there I was the only male there were 12 women. All just like sheep lined up in bed. They scope you and wake you up and they give you a cup of tea and send you home. He just come up to me as soon as I woke up, and said - oh sorry mate, you've got a bit of cancer there, we'll cut it out Thursday. He said come in Thursday we'll chop it out Friday, that's all he said to me.

Some participants described being told in a very blunt way without being given details or support.

Rural men post 12 months: after *the colonoscopy* was over *the surgeon* came out and said to me, sorry but you've got cancer. We'll have to operate, and that was that.

9.purm: What happened I went to primary care and the doctor there... said you've got cancer and you are going to get very sick and that's it. Just bluntly like that. He said what do you think about it. I said what do you want me to think about it, what do you want me to say - I've got cancer. Want me to jump up and down and go 'whoopie.' He sent me home...and he said if you feel crook go to the hospital, the emergency. *He thought he was being given* the see you later treatment.

21.prf: *The surgeon* did a colonoscopy, and a gastroscopy. When I came around that's when he told me. He said you've got bowel cancer. Just like that... and we'll have to operate.

30.pum: The surgeon when he examined me at the hospital he said, yes you have cancer, but he was pretty rude.

1.pum: I think he said, you've got a tumour, that's surgery, boom just like that, as though they do one every ten minutes.

Some appreciated the blunt approach.

32.pum: He took one look at me and said you're as white as a sheet, and he felt my abdomen. He looked up and he said, well I think you've got cancer, just like that. I'm very grateful for what he did.

23.prm: I had the colonoscopy he told me that same day... He said I want to have a chat with you and he did... You can't do much about it, you can put it on a bit of paper if you want or he can tell you. Be blunt and direct and that's the way to go.

Others described good practice of being told they had cancer.

4.puf: *The surgeon* who did the operation ... said afterwards that he'd thought it had all gone well and it was the best possible scenario. But then they tested it and it had gone... through the bowel wall into the ducts, but only into one. He explained it very well but as soon as he'd said it had gone through I got a bit upset... about an hour later my son came in to visit me. I said to the nurse...I don't think I took everything in. Once he said *spread* the brain sort of shut off. She said no problem, and she went off and got the doctor again and he came back and explained it all to my son in detail and drew diagrams. So that was wonderful.

9.purm: Well *the oncologist* before I had chemo he said well you've got cancer and all that sort of thing. He said this is the sort of cancer you've got. Chemotherapy only helps 20% of people. It might help you. The first thing I said when getting the treatment I said I want to know when I'm going to die. He said well 12 months, and if chemo does help it could be 2, 3, 5 years...you like to know what's going to go on.

Some people described being given a misdiagnosis.

24.prm: After the operation *the surgeon* told my wife, bad news he's got secondaries right through his liver, and also his lungs. Then he retracted that later on, the PET scan and the CAT scans are inconclusive, so it doesn't look like I've got anything in my liver...

Some people described doctors wanting them to be more upset about their serious diagnosis when they felt there was nothing they could do.

20.pum: The surgeon...said you've got cancer you know what I mean... Put it this way, I accepted everything as it came along you know. I didn't get upset or excited. Then the other doctor that was looking after me, he said this is pretty serious what you've got. I said I realise that... he said what you've got to know is its very serious. I said I know that. What can you do, you've got to just cop things as they come along you know.

Time for decision making

Little was spoken about being given time to make a decision. Many people believed that there was no decision to be made and they did not want time.

Rural men post 12 months: I was just glad they did it straight away.

One man talked about not having time to think and feeling numb.

7.prm: I didn't really have time to think about asking questions. He did say to me is there anything I'd like to ask. I was sort of numb with the finding out... It's never going to happen to me.

Reaction to Diagnosis

"The diagnosis of bowel cancer affects every person differently. For the majority of people, it will be a difficult time, however some people will manage with little upset to the routine of their daily lives." (NHMRC (2000) Guidelines for the prevention, early detection and management of colorectal cancer, p. 10)

Intermingled with stories about how they were told they had cancer, participants also talked about how they reacted from shock, denial, sadness, anger and depression.

Participants described feeling shocked, alarmed, surprised, numb and scared of dying when they were told they had cancer. Some said they wanted to know their options but felt unable to ask.

25.prf: I suppose I was pretty numb really. I couldn't really react in any particular way...just sort of keep my calm.

24.prm: I was shocked I just wanted to know what my options were...

32.pum: He said you've got cancer... I became quite alarmed I didn't say anything. It's a blokey way of approaching it. I thought definitely I'd die.

1.pum: Well it was a bit of a shock to start with... it's a surprise... I think you must have an attitude of mind when you go in that everything is going to be all right.

Other participants talked about fighting the cancer, not giving up and not allowing it to affect their life. Feeling that they couldn't be told they had an incurable disease, that it seemed so unfair. This was particularly so for participants under 50 years of age.

6.pum's Wife: It also depends on your own character. He wants to fight and give it a run for its money. Where other people to be told that straight out, could have sort of collapsed.

10.purf: I sort of had confidence or faith. I thought all right I've got cancer, but its not going to affect my life.

9.purm: If you've got cancer it's a terminal thing. You do die from cancer. There's nothing I can do. The doctors can't do anything I can't do anything. The only thing I can do is to keep above everything and feel good in myself, my brain and my body Keep on going till the day they take me off the planet ... As I said to mother they're going to take me kicking and screaming.

A number of participants talked about accepting the diagnosis and remaining calm. They talked about waiting to see what would happen.

27.prf: I was a trained nurse so I just automatically accepted it.

13.purf: I've sort of just accepted it, everyone gets something and that was my lot.

20.pum: What can you do, you've got to just cop things as they come along you know...if you've got it you've got it haven't you... I'm still alive and I'm not in any pain.

5.pum: You got to accept what the Lord is offering us ... you fight for your health all the time because you make sure you eat the right food, make sure you don't drink. But when the sickness coming, nothing you can do.

One woman sought many different opinions all through the process taking an active and seemingly objective part in her diagnosis and treatment.

29.prf: I actually went into a state of no emotion at all, it all sort of closed down and I talked very clearly about what options I had with him on the phone.

Others talked about accepting the diagnosis but getting on with their life.

22.prm: I accepted it pretty casually really... when they told me I thought, oh well I've got it. ... I've always been a bit of a fighter myself right from the day I started school. I think you've got to have the right attitude ... you've got to have a hobby...

A number of participants talked about their body "betraying" them.

32.pum: In the initial stages I felt my body has betrayed me, I've done everything right, I looked after myself and it betrayed me.

33.pum: I didn't want it there, its cancer it's going to spread,

Or pretending that it is not there.

20.pum: I don't think about it ... I try to keep my mind off it. That's why I have one of these (a beer) every now and again. It helps with the situation.

Ultimately whatever the participant's reaction there was sadness and loss was related to what was happening to them.

31.puf: We all try to make light of it. I generally try and joke mine off at the time, I say oh jolly good show let's have a party and get the thing removed, but its not what you feel.

Dealing with Bowel Cancer and Associated Treatments

"When you are first told you have bowel cancer, you may or may not understand much else.... some people find it hard to think of anything else for some time.... You need time to collect information, to think about it, and to receive support from your family and friends. This can help you understand the disease and choose the best form of treatment for you" (NHMRC, 2000, p. 15).

Seeking of Information

Some participants were keen to know about their bowel cancer and the treatment options and some did not want to know.

Rural men post 12 months: Of course it's like anything you'd like to know. Especially your own body it's very important... We're so naive on it aren't we.

10.purf: I think the less I know the better... in fact the surgeon said to me, the last time I saw him... did I want to ask questions... I said no I'll just leave it up to you.

Some people believing that information made a difference and others thinking that information would make no difference.

23.prm: You've still got to go in the hospital and have an operation. Still have bowel cancer regardless of what I read. I just think oh forget about it...

Also there were differences in those who actively sought information and those who accessed a small amount or did not want to read information at all.

9.purm: I'm always asking questions... Its like the surgery when they took me in, I'd never had surgery in my life I was scared. I said how do I go to sleep?

33.pum: I had a little book... "*Helping you through bowel cancer*" and I read through it and that was all I wanted to know, I didn't want pictures.

1.pum: I didn't really want to know a lot about it...I think the best thing is not to know.... They can do what they like when I'm asleep....

Often people were ambivalent about how much they wanted to know. This man expresses the dilemma well.

24.prm: I'm interested in the information but I'm not interested in having a great deal of knowledge on this. I just want to know if there's a treatment that might help.

Information would tell them about the status of their cancer and participants were ambivalent about whether they really wanted to know.

Rural men post 12 months: No I didn't want *information*. I thought they've taken it, its gone, its finished with. I hope it doesn't come back. I was bloody glad to be alive.

13.purf: There was an article in *a diet book* about bowel cancer; I just found I couldn't read it. I read it once but I'll probably now pick it up and read it.

33.pum: Someone may have looked it up on the Internet, and...I had a bit of a read and then I threw it away...

Some people accessed information from the Internet, libraries or family and friends.

27.prf: It was the library, the medical encyclopaedia that was good.... I needed to know how long I'd live, what my chances were... what was going on.

9.purm: I've got a friend that's got a computer... She's always on the Internet looking at the cancer and things... and telling me all things.

6.pum: I've got a very good friend and he got on the Internet. He'd phone me up and he said when you go to clinic next time, he said query the doctor and ask what about the thalidomide treatment... You clutch at straws don't you...

32.pum: I've done a bit of research on the Net. A friend of mine... produced a large amount of information. I've studied that, I've gone to the public libraries...

Many participants said they did not have time to seek out information and that maybe information would not really help them or that it might cause them to feel more unwell.

3.pum: I was whipped into hospital and operated on almost immediately... I wouldn't have had a chance of reading anything... If you know what's going on it doesn't worry you so much as if something is happening and you're not sure what it is...

25.prf: I didn't really have time to sit and think about it or anything or get lots of information. Besides what was that going to do... It wasn't going to change what I had was it... Sometimes you can have too much information I think.

33.pum: *Someone associated with his wife's work made a bowel cancer video and gave him the tape "and that was quite good I think I only watched it once but it was quite interesting ...The thing is you don't want to feel sick".*

Some participants were happy to receive information solely from their health professional.

8.purm: I knew what was going on all the time... any of the doctors they said don't be afraid to ask questions. Well I didn't have to ask questions because I knew I was in damn good hands, and I was very confident and had confidence in them.

Others felt that they needed to be given information and it should not be solely reliant on them asking the right questions.

31.puf: I wasn't told that it was cancerous, before or after nor how large the tumor was. Now I didn't ask because I was so stunned, also it was suppose to be so slight... but no there was not a lot of consultation.

Rural men post 12 months: ... you are sort of in the dark to a pretty fair degree all the way through it.

Some had previous knowledge of cancer, trusted the doctor's judgement and/or found that too many ideas were confusing to them.

26.prm: My wife had a breast off about 10 years ago... I didn't bother (*to look for information*), the doctors know more about it than what I do. I find if you ask other people you get that many different ideas or suggestions, its best to forget about it.

Some found it easier and trusted others to ask questions and interpret the information for them.

22.prm: I think Dr. X would answer all the questions, and my wife working with him she use to just go and ask him about different things... he was mainly the big help in it ...

19.pufc: Doctors will start to talk to mum and she just sort of blanks, and that's when I have to jump in. When a doctor will start using big words and terminology *my mum* can't understand, *so* you can't build a rapport between the patient and the doctor... if there's no rapport then the patient is going to close in and they're not going to ask *questions*.

Ability to understand medical terminology (related to asking questions)

The participant's ability to ask questions was related to their knowledge about their own body and how it worked, and their understanding of medicine. They also needed to know about how treatments and procedures are decided upon within the medical system and understand that there is choice, and that what the clinician suggests may not be 100% effective. Many participants (and the community generally) put their trust in the clinician because they are understandably unfamiliar with medical terminology and the latest research. This makes asking questions and understanding the answer difficult for many consumers. One man explains it well when relating it to his own technical knowledge from his work experience as a mechanical engineer.

22.prm: Well yes it is but being in a different business (*he was a mechanical engineer*) I don't understand medical stuff at all. When I look at tablets they're all the same to me, and I don't even try to pronounce them. It's a different field and I'm not interested really. BUT He can describe his hip replacement... I'm lucky I've got tough bones, they drilled them and reamed them with a tapered reamer,... and when you drive the stake..., its not glued in or anything, it is held like a drill on a drilling machine, you just push it up and it stays there... After seeing the *bowel* operation done I would have been in more mess than Mickey the Mouse (if he had tried to do it). It's a very gory thing.

One woman commented on the problem of comprehension in relation to the non-English speaking community.

29.prf: *of an oncologist* . I noticed in his waiting room, many of his clients, *had* English is a second language. So they would be getting the information either through one of their own children, or an interpreter. How are they going to say, no I'm going to see *someone else*.

Choosing clinicians and second opinions

"Choosing the right specialist can be difficult. Some people have no choice...others feel they have no choice" (NHMRC p. 17)

Some participants felt that they were given a choice and others felt they were not given a choice.

22.prm: *The GP* said who do you want to do the job. I said well my wife and son had worked out that Mr. X would be the bloke.

12.purf: I was sick for nearly 18 months before I'd even go and see a doctor... My eldest son came in one Sunday and he was that upset ... I told him that if he could find me a women doctor that I was

comfortable with that I'd go... So anyway she was nice. She (the GP) said I'm going to make the appointment with Mr. X. I said he's a man. She said that's right. I said I don't want to see any men. Anyway she said, no he's very nice and very good. So I went to see him.

Some people reported changing health professionals during the course of diagnosis and treatment because they were not pleased with their treatment.

Rural men post 12 months: I was crook for about 9 months. I just kept going to my local doctor all the time and he kept saying... no you're constipated... He's not my local now.

Some people felt they were not given encouragement to seek a second opinion if they wished.

25.prf: *The surgeon* never ever said well you know you can get a second opinion and see if you decide not to have that surgery or anything... He just said well you've got it and it has to come out... there's no two ways about it...

24.prm: *The GP* has laughed and said ... what are you worried about, there's nothing to worry about... It was silly of me that I didn't go for a second opinion. *Related to bleeding from his bowel*

Others felt it was a more complicated process and they needed assistance in changing clinicians.

29.prf: So they can say it but its not really given as an alternative because they don't facilitate it. Like saying, you can see anybody you wish, well what do you do, look up the Yellow Pages and go... It's just not a real offer to say, you can seek the opinion of anyone you wish when you don't know who you should wish.

Participants varied in their confidence about seeking a second opinion.

27.prf: I think you'd go back to your GP and say I don't like him, send me to someone else.

One woman believed that everyone had the right to a second opinion.

29.prf: He said well you are free to seek any secondary consultation you wish. I thought I don't need anyone to tell me that, you get that when you're born. As a birthright, you don't need a specialist telling you you've got the right to seek an opinion.

Some people felt that there was not the opportunity to seek a second opinion particularly if they had received emergency treatment.

33.pum: once they had operated ... it wasn't any good me getting up and going to another hospital and saying what would you do to me. I didn't feel that I needed to do that. If I'd gone to the doctors and they'd said you've got this and this is what we are going to do to you, give you a colostomy ... I probably would have said ... I'll see someone else. They explained to me if they don't open me, release the pressure on the bowel I'd be in all sorts of trouble... what else can you do?

Some participants felt very confident about their clinician and did not feel the need to ask for a second opinion.

7.prm: I don't think I would have (*asked for a second opinion*) I was confident. I think everybody I saw and what was explained to me... I understood it. So it was explained exactly as I wanted it explained and the consequences.

23.prm: The fellow did say that to me (*you can have a second opinion*). I'm pretty certain he did. But it didn't worry me. I believed what I was told. He in fact showed me photographs after the colonoscopy of what it was... So I believed him.

Once a participant decided they wanted a second opinion there was the problem of finding someone suitable.

29.prf: The other problem I had was I didn't like this oncologist I didn't need him in my life, how do I find one that's not as bad. I don't want to change and find I've jumped from the frying pan into the fire. So its very hard, how do you do research to find out who is nice.

One participant explained that there were certain times when the patient would not be able to choose a clinician or seek a second opinion.

31.puf: I think it depends on your degree of illness too at the time, because I went through a period where I couldn't sign my name, I couldn't speak properly, I couldn't get my thoughts out. I didn't know what I was talking about either. I knew what I wanted to say.

Participants made judgements about their medical professionals on a similar basis to how they made judgements about people in the rest of their life.

22.prm: I didn't worry about it a hell of a lot, as long as I got better again. I suppose that's the way I looked at it. These are the best blokes and they were available and I was quite happy with who I chose... Like I use to employ tradesman, and I would pick them by the way they talk to you... You've got faith in them. But I don't like rude people or doctors that talk down to you... I've dealt with they've all been very supportive... I wouldn't have a bar of them (*if they were rude*). That's why I dumped my GP from that day he was quite rude to my wife. She came with me to make sure that I tell him everything. I'm one of these blokes I go in there and I'd just walk out again and don't say anything.

Expertise of medical profession

Related to choosing a clinician and deciding about a second opinion is whether the patient believes the medical practitioner is expert, skilled and trustworthy.

On the whole participants had great trust and confidence in the expertise of their medical professionals. This trust and confidence was based on the clinician's experience, training and standing as experts in their area of medicine,

3.pum: *The surgeon* told me he'd done over 30 of the same operation as this one. So at least I thought he knows what he's doing.... *Later* But he never said how many were still alive.

8.purm: I didn't have to ask questions because I knew I was in damn good hands, and I was very confident and had confidence in them.

9.purm: They're the experts you've got to trust them...he was happy. So I trust him, to know what he's doing... You can tell... on their faces. When they smile and look at you. You know its right... Well I think being a doctor or a nurse these days, I mean they're truly professionals they're qualified. They've gone through all this. If you can't trust them, who can you trust.

and their manner and reliability.

Rural men post 12 months: Well whatever *the surgeon* has told me has been pretty well spot on.... I call that professionalism.

Rural men post 12 months: I my case I had like a young fellow there, he was a real nice young bloke... he was real good like... he was fair dinkum They'd go and ... explain to Mr X what was going on... He had confidence in them too.

10.purf: Yes. I actually took his advice. I thought oh well he knows what he's doing.

Some people still relied on their medical professional although he/she may have been rude or not know enough about their condition.

21.prf: He said (the GP) look Dot, look at it this way, he was a good surgeon, he did a good operation.

6.pum: They are the medical professional people and you hope they know what they're doing. I feel in my case because it's a sort of an odd cancer, I really feel that at this stage they haven't had a great deal of experience in it.

The need to believe in someone who had the power to save lives was very important. Only one participant mentioned the need for doctors to keep up to date with the latest research.

24.prm: I just think the biggest thing is for these doctors to be able to keep up to date and I think they've got their patients, and I don't know how they find the time to keep abreast of the latest research. I know everybody has sites especially designed for them, for that purpose, and they've probably got a whole range of other things. But I don't think it's tremendously easy for them. Maybe their medical journals could come up with a better way... Rather than having them read through lengthy journal articles, or even just doing research somebody needs to do the compilation of getting all that source material and put it into one place, somebody who knows what they're doing.

Tests and Procedures

There are many tests and procedures that a patient might undergo during their experience of care. The ones mentioned here are those test and procedures specifically mentioned by participants.

Rectal examinations

“Your doctor will examine your rectum by inserting his or her gloved finger into your anus to feel around ... The test is a little uncomfortable...” (NHMRC, 2000, p.19)

There was some distress; pain, unawareness and humour expressed when participants talked about their experience of rectal examinations, particularly the male participants who appeared to feel particularly vulnerable.

Rural men post 12 months: Because to my mind it's the most disgusting bloody test you can go through. It's part of the process, its got to be done. So you just put up with it.... I'd never watch the gay Mardi Gras again.

20.pum: He gave me an inspection... Gee did that hurt. I've never had anything like it in my life... The doctor wanted to do it again up here. I said no thanks very much. He said we'll abort that idea. I said thanks very much it suits me fine.

Rural men post 12 months: Oh I never felt nothing...

22.prm: You laugh about it now. I don't look forward to it but when you go for these examinations you think oh no not again, but it's a joke between the boys and myself at home.

Women were less likely to express negative opinions about this examination although some thought it was worse than a vaginal examination.

29.prf: I've had so many things up me. It's uncomfortable like all of them were.

Sigmoidoscopy

“This test involves your doctor inserting either a flexible or rigid tube into your anus. ... The test may be uncomfortable but should not cause severe pain” (NHMRC, 2000, p19)

A number of men said they experienced pain as a result of this procedure

Rural men post 12 months: He didn't put me to sleep to give me the stunt. It wasn't the most pleasant experience... he just left me hanging on the bed ... I don't know what it was but it wasn't good anyway... Well he took the samples and everything...(a biopsy).

7.prm: He said it was all clear he put the light up. He actually hurt me a fair bit that day, he was gentle but...he caught a few times. But you accept that.

33.pum: You feel a bit violated. You are, but you're letting them do it...They say this might hurt a bit, there was no anaesthetic, I would have liked to be offered.

Barium enema

“A barium enema is a type of radiological (X-ray) investigation for which you lie on a table in the X-ray department...bowel preparation ... a small tube is then inserted into your anus...and a quantity of white liquid- -is poured in...” (NHMRC, 2000, p19)

A number of participants complained about the procedures associated with a barium enema.

Rural men post 12 months: The worst thing for me was then they inserted the plastic hose in my back passage and took X-rays and put this white die through you... I had about 2 feet of that through. While I was there they made me roll over under the big X-ray machine... I said oh gee that's hurting like mad to the nurse. She said I'll tell *the surgeon* that, which she did. I reckon that was the hardest.

Colonoscopies

"A colonoscopy involves inserting a long flexible tube, with a TV-like lens on the end through your anus and rectum...Before the test you will have a bowel preparation....you will be given a sedative..."(NHMRC, 2000, p21)

There was general agreement that the anaesthetic for this procedure is wonderful.

1.pum: That was most odd because everything was going well until he gave me the injection and I don't remember any more. Next thing I know he said I've finished. I thought well I don't know where the time went.

4.puf: But I tell you that is the best anaesthetic in the world when you go for that colonoscopy thing...I can remember they put a little thing in my hand and then the doctor said oh excuse me a minute I just have to take a phone call. I shut my eyes and thought god how long is he going to be with this phone call. I opened my eyes and I was back in recovery. I had no feeling of going to sleep.

But the bowel preparation was considered by some "the worst".

25.prf: It was just the cleaning out of the bowel was the worst... *when you* have to drink that disgusting stuff... that's the worst part of it.

18.puf: That stuff that you've got to drink, make it nicer.

One person reported a colonoscopy that had not gone far enough and so the cancer had been missed.

11.purm: When they did the scan here, the doctor said when they've done the colonoscopy he said they must have got into a black spot and they stopped. If they'd gone another 4 inches or 3 inches they would have found it.

For several people the bowel preparation did not work effectively. This man later developed an abscess, which he attributed to poor bowel preparation

24.prm: I had this stuff to vacate my bowels.... It didn't work... with me it worked like a day later.

CT Scan

“The CT scan (sometimes called a CAT scan) is a special type of X ray.... This painless test usually takes 10-40 minutes” (NHMRC, 2000, p.22)

A number of participants were unclear about whether they had this procedure or what it was called

4.puf: Like a big doughnut machine. I should know the name I've been in it often enough.

Also a number of participants were distressed by the procedure because of bladder difficulties

18.puf: The only thing was when I had to have the CAT scan in Seymour I didn't know what they were going to put up inside me would make me, wee. I didn't take extra underwear. (*Spoken very softly*).

26.pum: Had to take that stuff that cleans you out before you go into it. That was a problem, 20 minutes in that machine and hang on.

Some participants felt claustrophobic.

Rural men post 12 months: I don't like those things, been in one once, claustrophobia.

Rural men post 12 months: That CAT scan was the worst experience of the lot. When they put you up that thing you reckon you're going to choke... you've got your head in that tube... Oh you can't breath or nothing. I thought I was going to die on the table

Some were scared that more cancer would be found.

13.purf: The worst one I found was the scan... it was just that I knew they were looking for it elsewhere. I was an absolute wreck that day... and I sort of thought oh its everywhere but it wasn't... They did stop at one stage and come out and talk to me.

One woman reported that she had blown the machine up!

12.purf: When they put me through this machine I don't know what it was. Something with a big white thing and they had you on your side and it was like having an enema but it wasn't. You had to hold your breath while they did this. Felt like something was blowing up inside. I blew the machine up... the doctor put his face down to mine, he said its not your fault love he said its ours. I didn't know what he was talking about. So when *the GP* come around the next morning she said, you caused a stir down there yesterday.... you blew the machine up.

One woman worked out how to deal with it satisfactorily.

27.prf: I said can I please have a kidney dish because I hate taking it and I might be sick that frightens them and they are nice to you

Blood tests

18.puf: Oh you had to feed the vampires.

Treatment

"If you have bowel cancer there are some decisions to be made regarding what type of treatment to have (or not have).... Your doctor should inform you of the likely impact various treatment choices might have on your quality of life" (NHMRC, 2000, p.25)

Being part of decision making and having choices

Many people reported that they felt they were given no or very few choices and were not involved in decision making particularly when decisions were made about surgery. Some had relatives who had chosen not to have treatment or had left the receiving of treatment too late.

23.prm: No as far as I was concerned I was told what I was told... I didn't argue

11.purm: You've just got to do as you're told.

10.purf: Well I just felt that I didn't have any choice really with the bowel cancer.

30.pum: No he gave me no choice, no nothing. Cut your anus, put a bag for the rest of your life

Some people reported that they had more choices with regard to choosing whether to have treatments like chemotherapy and radiotherapy.

33.pum: I didn't have to it was up to me well. They just said it would be better if you had it if you really want to be sure that everything is honkey dory then have it.

Some people found it easier to decide after they had received treatment about whether they would choose to have more treatment.

25.prf: // I got cancer some place else, I got it really bad I would say to them well ok what's the chances, I've got to have this chemo and all the rest of it and what kind of a life is it going to give me, then I would make a choice about it. I wouldn't be going on and on and on, having all these treatments at the end of it you are still going to die.

27.prf: You don't think you have a choice; the cancer has got to come out, full stop. *BUT* if it got really bad and they told me we don't know how it's going to go in the future. If it comes back in the future they say we don't know whether its worth operating or not, I'd probably say leave me.

Sometimes it seemed easier for the medical practitioner to encourage choice when they were not as sure about the outcomes.

24.prms: *The oncologist* said to me its up to you whether you go on this chemo before you have the surgery. I said I'd like another couple of weeks just to have a break from it. To get over this pain I'm

going through... He doesn't know whether I should have the chemo to prevent that possibility or not.

A number of participants said they wanted more discussion about their choices and for their choices to be related to their individual wishes, age, prognosis and tolerance of the treatment.

31.puf: But this business of treatment for it, I do not think perhaps there's enough discussion about that. I know that I have a very good doctor who I can talk to frankly and he to me. ...But the cancer is growing again... they wanted me to come in December... and I said no way, I'm not going to wreck Christmas it can last a few more weeks. I decided in January I was getting very uncomfortable and I would give it another go, (radiotherapy). I did one week at oncology up there, and it knocked me about so much, mainly that bloody table. God its as hard as that (bangs her hand on the table) and not as wide ... On to it they put what they call a belly board which is about that much higher and has a square like a shoe box cut in the middle to hang this through. I'm 86 and I'm not fit and I found getting on and off that was torture. I had bruises all over my legs. *(She goes on to say)* I told them to tuck it up their jumper. They were horrified. I said I'm not coming back. My doctor and I will fix it between us... I said look I'm not being brave, I'm a coward, I just don't want to be hurt any more. ... If I were 50 I would have persevered and gone through with it. But at my age, hell it's only a palliative thing anyway. It's not going to go away.

It was unusual for a participant to feel that they could decide for themselves (given the choices), and then ask the medical practitioner to do what they wanted.

29.prf: So there was the decision about pre-op or post-op about chemo and radiotherapy and I chose pre-op, partly in my head I just wanted to put off the evil day when I had to have a bag. Partly because three of the four people, the radiotherapist, chemotherapist, surgeon and I had another person ... a diagnostician at Peter Mac., and he said he thought pre-op was better. So I went for pre-op against my own surgeon's wishes, but he was happy to go along with that.

This ability to stand up for oneself was articulated by another woman when she said,

31.puf: We are free to make our own decisions, I was assured of that in the hospital, it's your body, and the nurses constantly told me that.

One woman talked about her family pressuring her to have certain treatments that she did not want. Several other participants talked about the hospital staff convincing them that they should have particular treatments or procedures.

28.prf: When the oncologist told me, I said I don't want it. About a week later, my two boys begging me mum please, please... we need you; we don't want you to go. So a week later I went back to the oncologist and said all right I go ahead ...

1.pum: They then said well you have to have a port put in. I said well I don't really want one of those. They said yes well its good. Wonderful idea, which I suppose it is... there were three or four people convincing me. I said I've come this far I'll go along with it...

One man was quite philosophical about the limited choices he had, saying:

26.prm: I'm a fatalist, what will be will be. It's as simple as that. I looked at it this way I got 5 years and 8 months as an infantryman during the war; I've had several operations in my time. If it's got to be done it's got to be done, simple as that.

Knowing about and dealing with the effects of the procedures and treatment

Some participants were unsure about what the procedures were which they had undergone, or they did not know the results of their surgery or other tests.

30.pum: I didn't know what was going to happen or if I'd survive even the surgery. Actually before surgery I said to the nurses, what are they going to do to me? "I think they're going to cut your bum," she says. "Got to wear a bag," she says. I said "Jesus, there goes my job in St. Kilda".

One woman said the surgeon had taken her lymph nodes but she was unsure as to why this was done.

Other participants complained about the number of tests and procedures they had to endure from different clinicians or the effect of multiple procedures on their state of mind. A male patient when complaining about too many internal examinations says,

26.prm: I said to these buggers I don't know how these gays do it. *The oncologist* said, *the radiologist* will do the finger won't he, I said yes he will do the finger, and when I seen *the radiologist* he said, did *the oncologist* do it, I said yes... I know *the surgeon* is going to do it anyway... There's the three of them doing the one thing ... That is in the one week... I think they should... confer with one another.

27.prf: I've never had a problem with needles in my life, I've had 6 children and three miscarriages, and a few operations and nothing has ever been any bother. But after all the injections in your hand you have a real psychological dread of getting more needles... and I felt cold and miserable.

Some participants appeared to adapt better than others to unpleasant procedures and tests.

Rural men post 12 months: Eighteen months ago if you'd asked me to stand up and let those little Asian student doctors play with my testicles I'd have hunted you. But after the operation you just cop it.

22.prm: *Talking about being examined by a doctor.* No you're prepared when you go down there. I'll go down there and he'll say jump up and I'll have a look at you, and he runs over all the parts. He pushes you and that, then breathing, up around under here he's touching me. It's all part of the thing and well if it happened down there again I'd like him to know about it and be able to tell me about it. Once you've had it you're not looking for it again. *(It refers to cancer)*

9.purm: In hospital they did all that, through the back and whatever else. Millions of needles, I was just constantly on drips. But that's what had to be done... It had to be done.

10.purf: Well I've got to the point now that well one time my body was mine, but now I think I've had so much that it just doesn't worry me....

Others found the side effects of treatment embarrassing.

11.purm: I thought what the bloody hell has happened here. My bowels worked in the night. I had the epidural in here everything was numb down here...I woke up to find everything wet. You feel such a fool at this age.

Psychological strength

A small number of participants talked about the state of mind they needed in order to deal with their bowel cancer, its treatment and the various procedures.

Rural men post 12 months: The biggest thing is after an operation anyway, is to be able to manage your system... one of the things you've got to have is ... a reasonable frame of mind.

9.purm: When I'm in the waiting room up in oncology, there's different people in there and they're all sitting there and they're going to have different things ... They just sit there all morbid and like that. So I always turn around and talk to them... I say how are you going... Just talk to (them), cheer them up a bit.

24.prm: You don't want to become too despondent. If you've got hope, dealing with hope then you can get through, you can do things that you wouldn't otherwise worry about doing... a guide, like a little wall chart or something *of various treatments they have developed would be useful.*

Pre-operative

One person described how important it was for him to have visited the hospital and ward before his operation, to be introduced to people and have the procedures explained to him by a nurse.

7.prm: We were booked in down at Greensborough, Diamond Valley and they closed the day of my operation... we'd been down there and they'd shown me the ward and everyone was introduced. It was lovely. I didn't look forward to it but it put me at ease. Then they sent me to Bundoora over to North Park.

It was also important to participants to be able to receive medical treatment in a timely fashion. Participants had very different experiences of this.

19.pufcarer: Once they diagnosed mum's cancer, they moved fairly quickly that was really good.

7.prm: They said to get there at 11.00 am in the morning of the operation. Sitting around was the only thing I suggest that could be altered. I had to wait till 7.30 that night... they had to fit other operations in so they just asked me would I mind. I said all right. Then they said 2.00, then ... 3.00 you'd definitely be in by 4.30. We went in at 7.30 and come out about ... 12.30 in the morning... You just don't know what to do with yourself.

Anaesthetic

Participants had described the sedative they received for the colonoscopy as “wonderful” and yet many experienced a number of problems with the anaesthetic used for their surgery. Epidurals appeared to present particular problems for the participants interviewed.

10.purf: I was very sick for quite some months after but it wasn't from the actual cancer. They gave me an epidural to start with. It worked apparently for a while but it wasn't killing the pain, as it should have been. So they finished up by giving me morphine and anaesthetic and the two drugs didn't agree. So I was very sick,... I have spoken to three or four ladies who have said I'll never have another epidural. Well it does hurt being put in.

3.pum: I don't know what they did but... for some reason they had to put about 12 needles right up my spine... they broke two inside me... I was conscious when I was having the needles... it was shocking. Because I'd lost a lot of weight naturally and there wasn't much flesh on me for anything to go in.

Some participants reported that they were given a choice about the type of anaesthetic to be used.

Rural men post 12 months: They took me into the theatre and the bloke in there said to me do you want local anaesthetic or do you want us to put you out. I said you can put me out thanks; I'm not interested in watching what's going on.

Surgery and Informed Consent

“The aim of an operation for bowel cancer is to remove the cancer and enough of the tissue around to make sure no part of the primary bowel cancer is left behind” (NHMRC, 2000, p.26)

“Before anyone can operate on you, you must agree to have the operation and this involves providing written consent (NHMRC, 2000, p.27).

Some participants were clearer than others about what the operation involved

20.pum: The surgeon... he give me a thorough examination, anal whatever you want to call it. He said you've got cancer you know what I mean... He said we'll be giving you a bag and we'll be sewing you up in the rear end. So they done the operation first then they done the second one, then they came and saw me and he said, look the cancer is too big, the tumor is too big to operate on. So he said we're going to try and shrink it so as we can operate. '

10.purf: *The surgeon* explained to me, it was like a cauliflower, and he said the cancer was in the stem. So he suggested to me that I have the operation and he'd remove 30 cm of bowel. That's what he did,

33.pum: I had no idea, what operation they were doing I was that far gone, I was pretty high on the pethidine and I just said do it, do what ever you have got to do, get rid of it what ever it is ... I lost a lot of blood in the operation... I asked them why they didn't do a transfusion and he said with the chemo they don't like to do transfusions for some reason. But then the oncologist said why didn't they do a transfusion on me and I said go and ask the surgeons.

21.prf: All *the surgeon* told me was that I had bowel cancer that they'd cut a portion out, and that was it, I wouldn't need any further treatment.

5.pum: They pull your stomach out then they push you back again. They take all the bad parts out of you.

Several people complained about the liquid that they were required to drink prior to a test or operation.

28.prf: That drink (*pre-op for cleaning bowels*) caused me the problems. So I checked into emergency... that drink forced my body system to change, and I just couldn't breath. It was so sore and inside was so painful. That's why I roll all around because I don't know which direction I can be comfortable... The surgeon *should* check it out before they put something in your body, that your body just can't accept.

Most participants knew whether the surgeon had removed all the cancer. They usually were given this information by the surgeon after the operation. Unfortunately a small number of participants were still unclear as to whether all their cancer had been cut out.

3.pum: *The surgeon* said that he'd got it all out and he said they'd checked everything out and everything was negative for the cancer. He said there were a couple of little things just inside, a couple of very small things. He said they took 14 of these out... He took 14 out and most of them were negative but two were positive. So he said I'd probably have to have chemotherapy.

12.purf: It was bowel cancer and they had to take so much out, but I didn't find out much about it because I was in so much pain and everything it just wouldn't sink in. *The GP* ... said they might put a bag in up here. I thought why so far up. For drainage or something... I still don't know how much of the bowel they took out.

9.purm: See I don't know exactly what they actually took out... I don't know what there is inside there, ... he was talking about you might have to have a bag and that's virtually it. I couldn't understand a lot of what was going on... I've got no idea where my liver is.

5.pum: I haven't asked that question. (*if he is cured*) I was looking for that answer last Friday to see if I was in the clear or not, at this stage I don't know.

18.puf: They didn't say, that Chinese doctor didn't say if it was cancer or what it was after the second operation.

Several participants mentioned the effect of the operation on them physically and emotionally.

33.pum: They cut through your stomach muscles and you can't sit up. That goes on for weeks and weeks... its quiet painful actually I was on the morphine for about a week.

Rural men post 12 months: Once you've been on the table I mean what else is there, everybody sees everything.

Rural men post 12 months: So basically what I had in the whole skirmish here was I had three operations. So I mean that side of it was, well I'd say reasonably tough for what had happened.

Having a Stoma-Colostomy

"For some people having bowel cancer there is the chance of having a permanent or temporary stoma... It is recommended that a stoma therapy nurse see all people who might have a stoma before the operation, as well as after" (NHMRC, 2000, p.34).

A number of people reported that they were seen and 'marked' by the stoma therapist before their operation, even when they did not ultimately receive a stoma (bag).

18.puf: *The stoma therapist* drew it all out and showed me. She pencil marked me...being left handed on that side its better for me than on the right.

13.purf: I had it all marked but I didn't need it.

However for some people there was no preparation for a stoma because they had emergency surgery or it was not explained sufficiently to them before their surgery.

12.purf: No I didn't have that. Because everything happened in such a rush I think. There wasn't time to draw anything.

33.pum: I woke up with that, (*the stoma*) that's pretty frightening. I didn't know that was going to happen.

1.pum: He said you've got a bag... that was a surprise when I woke up... He said what we'll do is we'll do a reversal later, in about 6 or 7 weeks time. We'll see how it goes.

One man reported having the stoma placed in the wrong place.

22.prm: I said the left side, I'm left handed and I think that would be the best place to have it. But when I woke up and started to realise what was going on, it wasn't on the left side it was on the right side.

Others reported that they had temporary stomas for varying lengths of time. Sometimes this was for much longer than necessary due to the unavailability of surgeons or infection in their wound.

Rural men post 12 months: I had to wear a bag for a while. *The surgeon* said to me it will only be a matter of a few days and we'll have you back, and we'll put the bowel back again. In the meantime his wife passed away... and that was over 3 months that I had to wear the bag. I suppose it went another fortnight and he gave me a ring to say to come on in...He put the bowel back and sewed it all up.

8.purm: (*Regarding having a bag for 12 months*). Now I asked *the surgeon* about that and he said well look, we were that flat out busy, he said we've had that much surgery to do, we haven't been able to keep up with it, that's why... he said we're understaffed he said it's a shame the way the government are treating us. He said that's why.

1.pum: *The surgeon* said what we'll do is we'll do a reversal later, in about 6 or 7 weeks time. We'll see how it goes...I didn't have a reversal *until...* about 3 days before Christmas...it was 4 months ... there are problems with these bags I might tell you.

24.prm: Then I had a colostomy bag and I've had that reversed just recently, last Tuesday... (*he had it for 9 months*). The reason I didn't get it reversed earlier was because I had a bowel abscess following the surgery, I had an infection. So they were waiting for that to clear up.

A number of participants talked about the relief of not having a stoma or not having it permanently.

22.prm: In the end ... I didn't have to have a bag... it's not the end of the world... You couldn't drink lemonade or anything like that... But when *the surgeon* came in and told me (*he didn't need to have it permanently*) I thought I'd won Tatts you know.

4.puf: No. I was happy with that (*not having a bag*) I would have been a lot more upset. That's a bit of a nightmare.

Others tried to avoid having a stoma.

6.pum: I said please not a bag... My mother died with a bag in, so did a good friend.... It was always in my mind...My mother ... worried about it. She always said to me could I smell it or could I hear it rumbling...

29.prf: So there was the decision about pre-op or post-op... chemo and radiotherapy and I chose pre-op, partly in my head I just wanted to put off the evil day when I had to have a bag. The main reason I was unhappy about it, not that there is not heaps to be unhappy about it... I thought ... that there would be lots of noise and stuff and I thought running a private practice with clients, I wouldn't be able to do that. So I saw it as the end of my career as well.

Some did not understand why they needed to have a stoma.

12.purf: *The GP* said they might put a bag in up here. I thought why so far up. For drainage or something.

30.pum: Why is it I'm going to have a bag all my life.

Other's talked about the life style problems associated with a temporary or permanent stoma and how they had learnt to accept having a stoma and access support.

20.pum: I've had it 12 months now. I can change it in about 10 seconds... I don't get upset about it. After all at my stage of life...I'm lucky I'm still able to keep going and do what I want to do... it's a bit difficult to be bending down all the time

8.purm: I had a few accidents with it when I was out... I was playing in the band one night ... The damn thing come off and it was half full, oh gees I was in a mess. Anyway the people up there that run the dance...they helped me all they could you know to get cleaned up. Not only that, the odour was shocking... *and* was still on my clothes until I came home you know. Couldn't get home quick enough...

5.pum: Yes the bag is on me for as long as I stay. It's the luck of the game... All I know is they done the best they could, and its no good twisting my mind because they are only human being, they're not god. You've got to accept the way things are going... all I know is it's changing my life because I've become depressed... So they do their best and they teach you how to change your bags, and when you start you don't feel like doing it. I thought it will get a bit better we'll give it a go. All of a sudden I said I think we're ready.... In my situation you are not normal.

1.pum: I found out since that there's two people at the bowling club that have bags. They manage quite well... If you can meet somebody that's already got one you just say well how do you get on with this.

31.puf: I have a bag of course... I've had friends who've had colostomy bags for 20 years and they get on all right. But it takes your life over you are never the same again. The whole thing, yes it changes your life completely.

8.purm: They were very good to me they'd send me out three or four boxes of bags you know, every now and then. I had to join this association; I forget the name of it now. I paid \$26 and they supplied me with all the bags I wanted over the 12 months. If I was running a little bit short I just ring the number... I had to change the one on my tummy about every four or five days... you sort of put the bag on and you use a clip to hold them on. Some of the clips were faulty. The Asian lady that measures you up said to me they were having problems with some of them and I said, well I got some of them don't worry.

Ward experiences

Generally participants reported being well looked after on the wards. Some people believing that the public hospital system provided better care than the private system.

1.pum: I was surprised, not being in hospital before in my life I was full of wonderment ... how good the treatment was... The food instead of being canteen food you had a menu.... I thought my god that's better than I have at home...

2.pum: I couldn't speak more highly (*of how well he was treated*). You have a selection (*from the menu*). The nurses couldn't do any more for you. I found it marvellous... Also with the clinical nurse, she was wonderful. She came and explained everything.

20.pum: I couldn't fault the hospital system at all. I even liked the food. It was beautiful... they were bringing around a beer or two and the wine.... The hospital staff were lovely people, the nurses... Put it this way I didn't realise how well looked after you were in hospital. Just like home but it wasn't your own bed and your misses wasn't there.

9.purm: The surgical ward, and the nurses and the hospital were fantastic... The ward where I was ... I got a room by myself, which is very good actually. There was a room across the road and a couple of people I use to take the papers over. There as old digger he'd had his leg taken off. We just chatted along.

Several participants related how they had left presents for ward staff because they appreciated the way they had been cared for.

8.purm: Then when I left the ward ... I took them up a great big container full of sweet lollies... I still see some of the girls.

Several participants were sad that they missed out on meals in hospital following their surgery.

Rural men post 12 months: I was in hospital for 12 days and on the Sunday I had 3 meals there. In the 12 days from the hospital.

One man commented that he had been visited by a number of allied health and medical people but could not remember what they had said while another woman could not remember a whole day of her hospital visit

1.pum: After the first operation I found that I could not remember things for two or three days. Now during those two or three days I had visits from all sorts of helpful people. Such as the cancer risk, home help, all sorts. You know I couldn't for the life of me remember who they were or what they looked like... It would have been better for them to leave a little ticket or see me a bit later...

10.purf: Well after I had the bowel op I had to finish up by going into intensive care... They took me to the ward on the Friday but I don't remember a thing about that, just completely blank.

There were also stories of patients not having a good time in hospital. Some participants described either being at risk of becoming more unwell in hospital, developing pressure sores or actually catching infections in hospital.

29.prf: When I found the woman in the next bed had golden staph. I thought I'm out of here as quick as I can. So they said you can go tomorrow and I said that's not satisfactory, and they sort of looked at me and I said I'm going now.

One woman was in hospital for four months, she had expected to be there for ten days. She had many operations and her wound become infected without having any deep dressings done. She then received the district nurse dressing it daily for 15 months, and it was still being dressed three years later. She also spoke of her GP coming regularly to sit with her while she was in hospital having her wound treated.

31.puf: I had a very bossy nurse on one night; you know how they will make you walk. I was struggling along a passage, and she said – a few more steps and into the bathroom, just a few more steps you can do it. I said – I can't do it, I know I can't do it. Anyway, she had her come 'uppance', because that's the night I think it burst and I vomited all over the place... it was a Sunday night and the whole operating team had to come in, and I think I was in theatre from 11.00 to 1.00... Now that was a period when I think infection could have occurred. *Later she says* I use to say, during that period in hospital I had 6 anaesthetics, 6 trips to the theatre because they always had that thing open...

Several men experienced their wound becoming infected while they were inpatients.

33.pum: After the surgery I got an infection in the whole wound.... I was really sick and they ended up moving me to a room by myself... They didn't know what was wrong and it was a combination I think of low blood count and... an infection... it was the same sort of bug that eats the skin you know when you get ulcers

24.prm: Got a bowel abscess after surgery. I was getting twice weekly drains of that. So I had to go under general twice a week for about 3 months... I think the main reason (*I got it*) was that they give that stuff to clear you out, and it didn't actually clear me out....

One man complained that no one would look at it for some time and then when they did finally look they *"cut it all open again, there and then on the bed, never give me any chloroform or anything or deadened it"*.

Several men complained about their experiences in intensive care. One man did not like being disturbed all the time while the other felt his condition could have been explained to him better.

2.pum: I found in intensive care was the worst of them all. You really just got no peace. ... I was on a drug that happens to put a dye through and also a medication through to thin the blood. It was a gun going off going every 5 minutes with that going and with somebody else moaning or coughing in the ward.

22.prm: I was in intensive care... I got the shivers and the shakes and the jumps, and I was calling them to come and help me and nobody would. I now know why. They'd taken me off morphine... They didn't tell me what it was... Gee that was a terrible experience and I just worried why nobody come and said...

Some people had bad experiences with other patients on their ward.

2.pum: I had a chap he was legally blind, didn't know where he was. It was pathetic to see. He'd just walk around the ward, he'd be on his hands and knees, he didn't know where he was. I use to worry about that.

1.pum: I did have one bad experience in the hospital, which ... did effect me at the time... In the same ward, there was a lady there who was dying of, what's the fluid on the lungs, emphysema. She actually died one night while I was there and that was a horrible night. You could hear her she actually drowned... very slowly drowned. She drowned in her own fluid. Well somebody like that should have been in a separate room being looked after.

26.prm: I was the only male there. I don't think that's really good for a lot of people... I'm not vain or modest or anything... I think it did upset a couple of the women there... One day there I must have fell off to sleep, and one of the chaps come over to me and said better cover your self up

7.prm: But I was in a ward where there was a chap, he had Alzheimer's and he was inclined to hurt himself... once I went to sit on the seat for support and I seen *the man had dirtied the seat*, so I told the nurses and they said to use the other toilet... Well the last three days I was in the ward and that gentleman was right beside me. Couldn't blame him because he didn't know what he was doing. It was unfortunate...

Participants become upset about being transferred between wards.

1.pum: When I went for the bag removal... I went down to surgery, came back and I found myself in another ward all together... It was just a bit of a surprise to find myself in another ward... Nobody said why I was moved or anything... It would have been nice if somebody had of said well we moved you because of so and so.

Some participants commented that they appreciated it when the same doctor cared for them and there was some regularity and continuity to the visits.

Rural men post 12 months: I my case I had like a young fellow.... He was a real nice young bloke. He looked after me all the time. Well they both reported back to *the surgeon who* would come and see you about 3 or 4 times a week. But they'd come every morning at 8.00. He's just like a son to you sort of thing he was real good like.

Several participants complained that nurses were unavailable or overworked when they needed them. One woman complained that she had been vomiting and had diarrhoea most of the night and no one came to her aid. Another man said that because a woman was dying in his ward the nurses were unavailable to empty his bottle and he could not get out of bed.

3.pum: I had a bottle that ... was full up and I didn't know where the hell to empty it. In the end there was a little bowl on the table so I emptied it in there. I called the nurses you see but they were run off their feet. They said we've got an emergency on we'll be back later. Of course it got later and later. I couldn't get out of bed at the time.

A third woman complained that she was not able to contact the nurses because first there was no bell; secondly when she had a bell it did not work and thirdly no one came when it did ring. She became very distressed and wanted to go home.

27.prf: I was moved three times. I wasn't given a bell three times... When I got home I wrote an official letter to the hospital and you don't even get an apology ... all they needed to say is we're sorry this happened to you.

There were a number of negative comments about ward rounds and clinician communication with the patients.

33.pum: It was a bit daunting when the doctors do their rounds 6-8 blokes in suits talking amongst themselves and you feel like you are not part of their conversation and you are the subject...They treat you like you not even there, that's what I found just a couple of times...

Although there were a number of patients who had bad experiences on the whole people were very appreciative of the care they received.

Pain Relief

Most participants reported they had little pain or it was well controlled. There appears to be no reference to pain relief in the Guidelines.

Rural men post 12 months: I had an epidural and I had it in for 7 days. I never felt any pain whatsoever... the only pain I felt when they pulled that out, and they give me one of those little morphine tablets and then it stopped...

Rural men post 12 months: They put ice on me... the epidural was doing the job... No I never felt any pain.

Some participants reported having difficulty with morphine and also making a conscious effort to wean themselves off it.

9.purm: The only thing I did reject is morphine... I just couldn't handle that. It was the walls were just climbing in ... So they gave me an alternative.

12.purf: I was on morphine drip... I didn't want to stay on it for too long.

7.prm: I had pain I'd press the button and you were only given a certain amount *of...* morphine... I tried to stay off it. I gradually got longer and longer before I had to push and I was pleased.

Several people complained of pain, which was not easily treated. One man reported using the hospital pain management clinic and found it very useful

Rural men post 12 months: the only thing I wasn't quite prepared for was the pain afterwards... Back under the testicles and... back up the backside ... I was on these pain killers for about 2 months and my GP said this is no good. So he sent me here to the pain management. In 3 weeks it had done me more good than all the pain killers...

One woman reported a very important discussion she had with her surgeon about pain relief.

29.prf: You need the specialist to be patient. I can remember ringing my surgeon because I had this sudden horror that if I was going to die, he wouldn't give me enough pain relief... so I rang and I was all calm and got put through to him and then I said... I've got a question, and then I started blubbering and blubbering and he just sat there and he said, I'll just wait. He waited and waited... and then he said, I'll tell you all about pain relief the right the way through...

Recovery

Several participants felt that they were sent home from hospital too early. One woman, who was a private patient, felt too weak and in too much pain to go to the surgeon's rooms to have her staples out once discharged. Her GP said that she had been sent home from hospital too soon and came and took out the staples.

21.prf: I was in so much pain, I wasn't fit for anything I was too weak. I just couldn't cope with being driven over to *the surgeon's rooms*

Rural men post 12 months: I had the bowel op; 2 weeks in here... they sent me home... I started to swell up in my legs and ankles and all the rest of it. I wasn't getting rid of the fluids... my bladder gave out, perforated.

Others were able to negotiate their discharge or were readmitted.

23.prm: I had the operation on the Thursday and on ... the Monday; they said you can go home if you want to. I said no I don't want to. I'll wait a bit longer thanks very much.

4.puf: I was home for a day and I got this terrible pain in the groin... I went back to the hospital... and *they* tested me for every single thing that you could ever imagine in your wildest dreams. ... In the end he said we can't find anything that's causing the pain. I said well while I've been lying here in bed *for four days* the pain has pretty well gone away.

Participants said that an important of their recovery process was learning to eat and use their bowels again. Some participants were anxious about eating and using their bowel for the first time after the operation.

7.prm: Anyway I didn't eat before I left hospital virtually... Then they told me to eat and I wasn't game to eat because I didn't know (*what would happen*)... So I had half a sandwich.

Some clinicians warned their patients that it might take time for their bowel to settle down.

26.prm: When they took the bag off though. I was going to the toilet a minimum of 30 times a day. And I still have trouble.

13.purf: Yeah I got told it could take 6 – 8 months to get right

22.prm: Like a bowel operation they reckon your bowel could be out of whack for a long time. Once they've touched it... well they rip it open and they're playing with it. You know, and they reckon it takes months for it to settle down....

Participants often attempted to find their own solutions to managing their bowel with varying success.

7.prm: That's the only problem I've had right along ... I just get that bit bound up. So I take nine prunes of a morning... Then I take liquorice of a night before I go to bed. I am going three to four times a day with no problems.

Rural men post 12 months: I suddenly came to the conclusion that through the operation they cleaned everything out of the bowel. Well you need a certain amount of bacteria to make it work... I finished up on yoghurt. That did make a difference.

12.purf: I had the bowel problem but I was taking Astrolac syrup and Choloxin, Metamucil... Shocking. It still wouldn't work.

26.prm: Even now I probably go 8 times a day. I'm erratic... I've told them about it. I've got tablets and everything, which ... take about 4 or 5 hours to work. But my cure, it's absolutely certain, port wine and brandy fixes me instantaneously. I've acquired a taste for it too. I take a couple for prevention sometimes...If I'm going to play bowls, which I play every Wednesday, and Saturday, I'll have me port wine and brandy before I go and it sees me right out the day.

The erratic nature of some participant's bowel problems caused ongoing concern for some people. Some talked to other patients about possible solutions. Quite a number of participants complained that the surgeon was not particularly helpful

when it came to assisting them with postoperative bowel management especially if they were returning to work.

33.pum: With the surgeons ... they suggest if you are having any problems now using your bowels you should go and see your local doctor and *the GPs* aren't right up with what's what... I thought they would know more about it because they are colorectal surgeons

Rural men post 12 months: I mean from my experience since I've had the operation, you can be all right for a week or two sort of thing then all of a sudden everything goes haywire... Yes it's a bit of a problem to keep pace with it. Because there's no real pattern

21.prf: I said *to her surgeon* I've had trouble with constipation – you shouldn't have. I said well I'm very sorry I have. It was short and sweet and that was it...

The oncology staff on the whole seemed more helpful with bowel control.

22.prm: *The tablets* are available. Yes. I got them on the radiotherapy I think; *the radiologist* put me on them right away. They were very good.

Several people reported that they had worse outcomes from treatment than they had expected, either because their wound became infected or their bowel was leaking.

7.prm: I healed well... until...four days after I was home and I got an infection... All the way down... there was a hole there and there... It was just yellow.

5.pum: When I went last Friday to find out the results about the X-ray they said well you've got a bit of leakage. ... Which is most uncomfortable because I'm up four times a night... cleaning the bag, and wee. It's mighty cold at the moment.

One participant talked about feeling that he had had a good recovery experience although his surgeon had not been helpful.

23.prm: I certainly spoke to the *surgeon* about it... He told me it will get better in due course, your stomach will settle down...I just didn't argue. Maybe I was very relaxed about the whole thing... if its going to happen its going to happen... I was very fortunate, I didn't have chemo or anything at all...And just got better... so I think I'm very fortunate.

Chemotherapy

"This is the treatment of cancer with special anti-cancer drugs. The aim of chemotherapy is to kill all your cancer cells while doing the least possible damage to your normal cells...Chemotherapy can be given either before or after surgery and is usually given by injecting the drugs into a vein." (NHMRC, 2000, p.38)

Participants reported receiving information about both chemotherapy and radiotherapy. One exception was from a man from Bendigo who said he was not warned of the side effects.

4.puf: Yes after they'd explained it all. *The nurse* said if you'd like your children to be here I'll come back again while they're there and explain it all again, and talk to you about what's going to happen... I spoke to the nurses about the fact that I've got six grandchildren... So she gave me some books to explain it to *the grand* children, like story books.

Rural men post 12 months: They told me I was going to go down to Melbourne for chemo and radiotherapy. I was down there for a week ... nobody bothers to tell you what the actual side effects are going to be.

There was also agreement by participants that the environment and nursing staff who worked in oncology were 'wonderful'.

4.puf: The nurses there are just so wonderful. They make it seem like a picnic in the park really. I mean they laugh at people who've lost their hair ... I think it could have been a very gloomy depressing place, but they kept it great. Volunteers coming around with drinks and home made cake. One lady who was into sort of healing, use to make this green cake with green icing because that's a healing colour. I don't know how many people threw up from the green cake.

Participants talked about being a choice regarding whether they had chemotherapy.

24.prm: *The oncologist* said to me its up to you whether you go on this chemo before you have the surgery.

33.pum: I didn't have to it was up to me. They just said it would be better if you had it "if you really want to be sure that everything is honkey dory".

12.purf: He said to me, would you consider having chemo and I said no I wouldn't. He said why... I said no it's too much it makes you that sick. I said... I don't want a bar of it.

"Some drugs used in chemotherapy can cause side effects. The main side effect is diarrhoea, but can also include feeling sick, vomiting..." (NHMRC, 2000, p.38)

Participants described the different sorts of chemotherapy and how it made them feel.

3.pum: I must confess I thought it was wonderful, I was expecting all sorts of horrible things with this chemo.... But it never really affected me...

4.puf: Well its not pleasant. I felt sick all the time I was terribly tired. Your mouth fills up with mouth ulcers. I didn't lose my hair. It's got nasty side effects... I still went on doing my normal thing.

1.pum: I have the chemotherapy, which knocks me off my feet for about a week. I got off my food and lose weight and all sorts... it takes a whole three weeks to recover it really does. The third week I eat everything I can get hold of, and I feel fine. Just as you're standing up straight they knock you over again.

9.purm: My first two days, I felt like a truck hit me but that's about it... hair doesn't fall out or anything.... If anything the hair is growing...

The chemo the drug comes up every day from Melbourne and they just change hands every day and it takes 10 minutes. Some participants talked about the problems of having injections in their hands and for some they would refuse the treatment a second time.

26.prm: My three *fingers* are not worth a crumpet, cold all the time, and I kept saying to them, but they just brushed me off there. I said I reckon they must hit a nerve or something... it just about killed me that chemo I've never been so crook in all my life. The cure was worse than the complaint... I don't think I'd saddle up again, I'd ride it out I think.

27.prf: Its more total misery than anything else. I wasn't sick but I had all the injections in the back of my hand.

"Portal vein infusion is a method of giving chemotherapy straight into the liver" (NHMRC, p.39).

Others talked about the insertion of the catheter for portal vein infusion and the discomfort the catheter can cause. One carer said that the follow-up from the district nurse to flush it out *"had been quite poor"*.

1.pum: They attempted to put the port in... It was the end of week they took me down to surgery... I lay on the table they gave me a local anaesthetic. They cut a hole up here, they cut the slot there (*he is pointing to his chest*) and he spent two hours trying to get the tube to go in and into a vein and he couldn't do that. After about two hours I just about had enough, of laying there on the table being pushed and poked and pulled at... He gave up and stitched it up again. He said now you've got two free scars... I thought well I didn't want those.

18.puf: They put the catheter, in... When it comes out I'll be able to sleep on my tummy and... it's a damn nuisance when you drive it gets in the way of the seat belt.

There was some discussion about the timing of the blood testing before each chemotherapy session. This was linked with longer waiting times if it was done on the day of the chemotherapy, and difficulty in obtaining parking near the centre. Participants were obviously weak and could not always climb the hill nor would they always have someone to drive them to the centre. Some participants tried to have their blood tested earlier but this was not always successful if their blood count was down.

3.pum: Well that's right I had to go in on the Monday. I use to get it (blood tested) done on the Friday and my blood was never right.

One participant reported that the chemotherapy had not been successful.

6.pum: I was having chemo... Then they did the scan... it wasn't doing any good. So they said well the only thing we can do is we'll have to give you stronger chemo... it must be stronger because it really knocked me... It's annoying when you want to try and do things and you can't do it.

Radiotherapy

“Radiotherapy treats cancer by using X-rays to kill or injure cancer cells...This radiation is precisely targeted...Treatment is carefully planned to do as little harm as possible to your normal body tissues” (NHMRC, 2000, p. 39).

Some participants reported feeling very distressed and violated by the procedures associated with radiotherapy. One man thought they should offer a local anaesthetic and make the instruments soft.

Rural men post 12 months: They mark you for the set up of it, and so much is marked on your back, externally. Then there’s an internal mark... that’s the worst part of that...I was face down on the table... everybody else has got the view you haven’t... I got to the stage where they’d do three runs of it... you count the times as to how long before you can get off that table.

33.pum: I had lots of tests at the radiation oncology... I think the examinations were the worst... the radiologist wanted to see where the tumour was like how far... I had one with a thing and they’d blow a balloon to look inside... The instrument had numbers on it and was quite large and it had a condom thing at the end and they pump that up *he describes the different procedures in detail* ... the examinations they were very uncomfortable and I worried that they were doing damage... I thought if they touch it, it might get angry or something... It hurt... because I was still very sore from the operation...

“Radiotherapy can cause temporary side effects, including diarrhoea and nausea (which can be helped by medication) and tiredness. Mild headaches are also quite common.... your skin in the treatment area may become red and sore...” (NHMRC, 2000, p. 39).

Many of the participants talked about the side effects. Most common was diarrhoea and the burns. Participants reported varying amounts of assistance in controlling the diarrhoea and treating the burns, particularly a man from Bendigo.

Rural men post 12 months: I mean nobody explains to you just how graphic that (*the diarrhoea*) can be.... when it hits you between the eyes, out of the blue... By the time it was over and I came back home, the skin had split on my backside. It’s a bit hard to sit on the middle of your back. I had a lot of fun with that to get that sorted out. Lots of baths and lots of Lanolin was the thing that finally sorted it out.

26.prm: They did tell me... I might get a bit of diarrhoea but the bit of diarrhoea for me was 30 times a day. I’d get in the cab to go for my treatment I thought; I hope they don’t hit any red lights along the way. I don’t know how many times I disgraced myself. But that was the only thing that really upset me was disgracing myself at times.

22.prm: those burns I had they were shockers, on my backside, because they come in from the front, underneath and both sides. They zap you for about a few seconds, my god, it done a lot of damage. I mean when you add it all up you’ve only been under it for minutes.

Many participants who received radiotherapy felt that the side effects were explained to them.

33.pum: It was all pretty well explained to me, the radiation... they were really good I knew what was going on the whole time.

Some participants were concerned that the treatment and procedures might make their condition worse.

1.pum: The only concern I had there was whether they would actually burn the bowel past recovery point.

19.pufcarer: They told us that she could end up with some holes developing in the bowel from the radiation therapy.

Several participants had to drive themselves to the radiotherapy or were driven long distances to receive the therapy. This added stress to their situation.

5.pum: I was lucky that I managed to drive myself around. It was pretty hard because I got burned right through out. Blisters everywhere...

18.puf: I stayed with *(my daughter)* she was taking me from North Dandenong to the Austin *every day*.

Prognosis

"The course and likely outcome of a disease, as estimated by a person's doctor or treatment team" (NHMRC, 2000, p. 79).

There was very little discussion by participants about their prognosis. Very few participants reported they had asked their treating doctors about their chance of survival. There also appeared to be cautiousness on the part of the treating team. They were aware that they may not be able to precisely answer the patient's questions.

6.pum: They've kept me informed...the second scan was scarred and my wife said to the doctor...what does that mean. He said well we haven't got a crystal ball but it brings it back to months. They're non-committal...

13.purf: Like I asked them straight out, how long I had and they told me 20 years.

12.purf: That's what I said to her when she was going through all this rigmarole, and I cut her short and said what does that mean. Is it still spreading? She said yes I'm afraid so... I said how long do you think I've got. She said well it could be 12 months or sooner. Then again she said it could be 2 years, could be even longer.

Some people appeared to want to know but were scared to ask.

20.pum: I'd like to know really. I mean I suppose I could easy say to them what's happening. But I know what's happening; they're looking to see if it's got any bigger ... Well if you don't know what's happening it doesn't play on your mind...

Others were told, but not in a manner they felt they could easily understand.

9.purm: It was not long after surgery where everyone had talked to me about the outcome of what's happened... he said it may be 12

months or 2 years...I'd like to find out, if they can precisely, if I'm going to die 12 months or is it going to be 3 years. I mean I've got things to do.

Several patients were very relieved when their surgeon told them that their other internal organs looked healthy.

33.pum: The surgeon told me after the first op ... we had a look at your other organs and they look nice and healthy so that was good, that made me feel good.

Others deliberately took a positive approach to their diagnosis and treatment.

9.pum: I've had the second chance of life. You have to think positive about it. I can't sit around; I've seen a lot of patients sit around moping around. They look like they're waiting to die... I'm just not going to do it.

Several participants commented that although some of their treating team were positive there were others who they would have liked to be more positive even when there was uncertainty.

3.pum: I had to go in every couple of months for a check up, I found the doctors there were very pessimistic. They said to me time and time... that they can't cure cancer, which I knew they couldn't. They said all they can do is slow it down. So it's treatable... I use to come away quite depressed.

24.pum: There's so much uncertainty. My doctor is very good because he's very positive, whereas a lot of doctors and nurses can be very negative. You don't need that. Like one nurse said to me, oh we're only doing this to try and extend your life a bit... when someone says that to you, you think oh god what am I going through all this for just to get an extra week. Whereas another nurse might say, oh quite a lot of patients have been cured from this. Which puts a different spin on it... like the emotions and feelings you carry around have a big impact. It's almost like a placebo effect. The way you think actually enhances your prospects of recovery... the last thing I want to know is, its just extending your life for a little bit.

Experience of clinical trials

"Clinical trials are a vital part of the search to find better treatments for cancer". (NHMRC, p. 41)

A number of participants mentioned that they had been invited to be involved in clinical trials. No participant reported that they had refused. One man received free transportation for his involvement and was very appreciative.

3.pum: They were wonderful. The taxi use to pull up here, take me up... drove me home again.

The only problem he experienced was when he went to the hospital on a Saturday or Sunday for his treatment the staff were extremely busy and did not appear to know what to do.

3.pum: They were absolutely flat out on the Saturday, and we waited for hours and hours... Nobody seemed to know what was going on...

Like the first time they put the thing in my hand and I said that won't work... it shot up all over me.

Some participants reported that they would like to be better informed about the progress and outcome of such trials. Rural patients were less likely to be involved in clinical trials. Usually patients had an opinion as to whether they had been given the placebo.

8.purm: I'm on a case study of one of 36 in Australia.

6.pum: I'm on a clinical trial. They call it NES... Apparently in kidney failure patients they've been using it with success...they use it to help the red cells regenerate a lot quicker. Now they're trialing it on chemotherapy patients because when you have the chemo they explained to me, that it not only kills the good cells but the bad cells... Now one out of five is getting the placebo. The way I'm feeling I think I'm getting the placebo.

4.puf: I don't think I had the drug ... because when you walk to the day care centre where you have your chemo there's ... a much more comfortable room. I did hear a rumour that the people who were actually on this new drug were in this nice luxurious room because they were doing something different. I was in the ordinary day care centre... they never told me to this day whether I was actually getting the new drug or not...

Out patient experiences

Availability of the service

The access to services varied for participants. Some participants from Bendigo had to travel to Melbourne to receive chemotherapy and radiotherapy.

Rural men post 12 months: They told me I was going to go down to Melbourne for chemo and radiotherapy.

One woman from a rural area had to stay with her daughter in Dandenong and travel each day for chemotherapy and radiotherapy because the accommodation for country people was unsuitable.

19.pufc: We checked out the accommodation that the Austin had around there. It wasn't suitable for mum. She would have had to get public transport... there are also steps going into the flats.... the toilets were outside ...If you want to get up through the night. You'd never know who's around... the shops were up a hill and down the road... not having a car and it was in winter, especially someone who is on chemo. They get nausea and weakness.

Several participants thought they were eligible for transport assistance because they were veterans but then found it was not the case.

3.pum: I thought ... it's a terrible long way from here to go over there. She said oh don't you worry about that, they'll be transport ... you're a veteran aren't you. I said yes... Then a little while after she rang and said... because you're a veteran in the English army, no transport... you've got to have a gold or white card or something.

Other participants talked about having to wait for a bed, or a surgeon's appointment before receiving a service. Several private patients talked about the effect on them of the Diamond Valley hospital closing because beds were harder to find.

11.purm's partner: I rang the hospital... she said right get him into emergency. We got him in there at 1.00 in the afternoon; we were still there at 10.45 at night.

21.prf: He said a lot of the surgeons were having trouble getting the patients accommodated in the hospitals... I think he had to wait several weeks before he got a bed for me.

23.prm: It took a while to get between the doctor and *the surgeon* because I wasn't a patient of his. That took probably about 3 week or a month.

Follow up

Some participants talked about the disruption to their lives of constant tests and procedures and the discomfort on too many internal examinations when they went for their check-up.

10.purf: I am to have another colonoscopy... the preparation for that is something I'd rather not have... It's all day Wednesday, and its only fluids and I like milk in my tea, well its black soup and Bonox soup I suppose... Then up and down all night to the toilet... In fact I'm just wishing now that I didn't have to have it because I'm so well I don't want to stop doing what I'm doing.

26.prm: I said to these buggers I don't know how these gays do it. There's the three of them doing the one thing... That's in the one week too you know... because I see the oncologist 6 months, radiation 6 months, and the surgeon 12 months.

Some participants described receiving good outpatient care once they had left the hospital.

6.pum and wife: They sent the assessment people out to the house. Wife So they're going to arrange... to put a rail in there for him to go out that door *and* when he needs a chair and perhaps a hand held shower or something they'll make those arrangements.

26.prm: The Hospital in the Home it was called, they use to come every day, first they'd wash me and bath me and all that sort of thing...

Others relied on their families to care for them.

10.purf: So when I first came home from hospital I'd make sure that *my daughter* was here before I'd have a shower. She'd always stay with me while I had that... that went on for 5 months I think.

Some participants said that they would have liked more follow-ups from the hospital. This included private, public and rural patients.

23.prm: No one came to see me at home... one person once or twice that would be enough. Bit like having a baby, people come and check you for a couple of days. But I had nothing.

19.pufc: The follow up with it has been really quite poor. The RDNS was supposed to come and flush it every 6 weeks, and they don't... The nurse at the hospital said no she's not going to need any district nurse follow up or anything like that. I thought she did... I thought she did need something because out here she's a bit isolated.

10.purf: There was nobody... I had meals on wheels for a week, and then I had home help for a month.

Some participants said they did not want or require follow-up even when they were having problems with their bowels. Some people used their GPs as a support person.

Several participants talked enthusiastically about their follow-up visits to clinicians at the hospital.

Rural men post 12 months: I feel as good as gold everything is going well. I've got all the confidence in the world with *the surgeon*. His staff up there are very good.

Rural men post 12 months: He checks here, under here, around me back, and he said oh your all right I'll see you in 4 months time.

7.prm: I went to see *the surgeon* he said I looked well. I said do you think so and anyway he did.

Others felt the follow-up visits were a waste of time because they had to wait a long time for the clinician and then they had very little time to speak with him/her or be examined.

Rural men post 12 months: You're only there for 5 minutes, he just feels you, oh you're looking good, see you later come back in 3 months that's all he says to you. It's just a waste of time going... You go and sit there for 2 hours before you get in to see him.

28.prf: I haven't seen *the oncologist*, I don't know for how long. Because it seems like I am waiting there longer than I see the doctor. Every appointment is late... and then "oh how are you - oh all right, ok. 6 months". I don't *have an examination*.

Parking and transport

Some participants talked about accessing the services because of transport or parking difficulties. Other participants were able to access taxi vouchers, or were eligible for veteran gold cards.

2.pum: I find it hard to get a park here now. Since there are more people having outpatient treatment here. It's almost impossible to get a park.

4.puf: ...the parking at Austin. It is terrible. The Day Care Centre is up at the top of the big hill. Probably they'll never change this but there's a nice little reserve park out the front. I said this to the doctor actually... I feel good to know that all you healthy young doctors just walk across the door, and when you go through chemo, you park at the bottom of the hill and then trudge up that hill. I said I realise it doesn't help with your deaths from cancer figures because so many

of your customers must drop dead of a heart attack while they're walking up the hill.

8.purm: He said the best thing you can do now if you get into trouble driving, if you can't drive your car he said to get a half taxi voucher. So he said your own doctor will fix that up.

Support and self help groups

Some participants felt support groups would be useful and they would have liked to attend one.

1.pum: Well it would be useful in the context that if you are on your own you don't get to know everything. Everybody has separate problems and you think to yourself well I didn't have that. Then somebody says well I had so and so. You think well I had that. Then they say well I got over that. It gives you a bit more courage.

Two women talked about recovering from other cancers and receiving valuable support from a group.

10.purf: We'd go along and you'd just talk about your experiences, and I realised that a lot of those women have done exactly the same as what's happened to me. Anyway it was great. It turned my mind right over then.

21.prf: We went to the cancer support group ... Marvellous. Marvellous. It makes you put things in perspective.

While several felt that it would not help them at all

33.pum: I didn't want to sit around with a lot of sick people cos I wasn't sick... I wanted to get back to work.

Offering new treatments and hope

A number of participants raised the issue of new treatments, which they had read about or heard on the news. These treatments appeared to be particularly important to those with a more serious prognosis. Participants were obviously interested in new developments in cancer treatments.

9.purm: I want to find out about these new tablets, those X loader or whatever they're called and a few other ones... I mean if I could take tablets for the rest of my life... and it keeps me going, I'd be happy.

6.pum: I did mention before about this miracle drug in Sydney, I said to *the oncologist* ... it any good. I said I'm quite happy, I said my family will move me to Sydney for 12 months to have some treatment if you think it will do good. He was very nice he said, well look whatever they're doing up there we can do down here. He said when you see things like that ... he said they're promoting this drug because they want to get corporate sponsorship.

24.prm: On Quantum and also there was an article in the Herald Sun about some new treatment, and they're not aware of those treatments... I asked *the oncologist* about that and he said, show me the article. He probably knows about the treatment but whether it's suitable or not....

Effect of cancer on their life

Some participants talked about the stigma of cancer and how some people would no longer associate with them because they had cancer.

Rural men post 12 months: They're scared stiff they're going to catch it... people don't understand it, you can try and explain what happens to you, and they nod their heads very knowledgeably and say, oh yes. But they haven't got a bloody clue as to what's going on. You can find a lot of people will automatically wipe you off the slate.

Others talked about whether it was worth altering their life style because of the cancer, especially if their prognosis was poor.

9.purm: I just said to *the doctor* can I still smoke. He goes how far can you walk. I said as far as I want. He goes that's all right. I said can I still have a drink if I want. Yes no worries.... I mean if they say it's a terminal disease, therefore is smoking really going to harm me... I'm dying...

For many it dramatically altered their life style.

5.pum: So it changed my life and then all of a sudden I was so sick I couldn't stay there any more... So we decided to put the property on the market...

24.prm: There's so much uncertainty... like the emotions and feelings you carry around have a big impact. It's almost like a placebo effect. The way you think actually enhances your prospects of recovery...

Several participants were reassured by regular tests to check if the cancer had completely gone.

7.prm: When I went back after 3 months he told me 4 months, and I was pleased. I said what happens after that. He said now don't get ahead of ourselves... That's the only thing worrying me. I want it to come to see there's nothing there...

22.prm: I had a reoccurrence you see... Since then he checks me out on an annual basis and he told me this time he didn't reckon it was necessary to come back. I said well can I come back once a year to see, just to check me out. He said oh yes.

Quality of life and refusal of treatment

A number of participants talked about refusing treatment or adapting their treatment to suit their prognosis. One woman was told she had a limited time to live so she refused chemotherapy and her doctor was sympathetic to her wishes.

12.purf: He said to me, would you consider having chemo and I said no I wouldn't. He said why... I said it's too much it makes you that sick.

Another man who only had weeks to live had decided he would take a short holiday rather than be tied to treatments which were having little effect.

6.pum: We're flying up to Old at the end of June. My wife's brother is up there with his family so we're going up for a week to see them... So we're planning ahead but we're not planning to far ahead... I'm afraid I'm stepping in and saying sorry guys, I'm not going to be in town. You'll have to postpone it... I think I'm entitled to that...

Older participants also were able to say when they had enough of particularly painful treatments. One woman decided not to continue radiotherapy. Another man decided if the cancer reoccurred he would not have chemotherapy again. Another man said that the chemotherapy made him too ill.

31.puf: I said I'm not coming back. My doctor and I will fix it between us. He's assured me. I said look I'm not being brave, I'm a coward, I just don't want to be hurt any more. I'm 86 for god sake... at my age; hell it's only a palliative thing anyway. It's not going to go away, it's going to come back in its own time.

26.prm: I'm 78 next month, if I get it in another 5 years or so I'm not going to worry about going through it again.

2.pum: I was in palliative care ... I was to have 6 weeks of the chemo I only lasted 5 weeks I was that ill with it. They've decided now ... just to see what the progress is from now on in. No more chemo no more radiotherapy... I've got no option. Because they seem to think that at my age, I'm 76 that if I had chemo I was that ill with it... with what I've been through they didn't want to subject me to any more. So they started talking about quality of life. In fact I'm starting to feel a lot better now.

1.pum: I tend to think quality of life is equally as important as quantity of life...

Palliative care

One participant talked positively about the palliative care offered and felt reassured that if he needed a bed it would be available. Another man did not seem to be aware of the palliative care that was available.

2.pum: I had palliative care come in when I came home. Every week... They just watch your progress see how you are... Talk to you and explain things that probably weren't explained to you in hospital.

6.pum: I think most cancer patients that are terminal must have concerns about what's going to happen towards the end. Now if they could come up with some sort of a program, a schedule to say... Well if you get to the stage where you are becoming incontinent or you lose your bodily functions and your bedridden, that such and such we can do for you... At this stage, I think its time you took me away... Who wants to force on your wife, they've got to change dirty beds...

Death

The subject of dying was discussed in several different contexts. Several people had been told that they would die in the next six to 12 months so they talked more personally about their own death.

12.purf: Because when I saw how dad went I thought no I'd hate my kids to see me like that. Euthanasia should be in not out. We should be allowed to die with dignity. Its your body your life.

One man talked about writing to his family and friends because he was finding it difficult to say goodbye.

6.pum: I sat up till 5.00 this morning and I've written 9 pages to the family... They don't know... I've involved in so many things and I have so many friends, that each time I see them I find it very difficult to say good-bye... So not only have I written to the family, I've written letters to my friends. I'm not sending them they're going to be put away till the right time.

Another man talked of his altered consciousness knowing that he would die soon.

9.purm: I've sort of got it in my brain that I am dying I probably will die... you are looking around and everything is different. It's a funny feeling...you just feel strange you're not the same person.

One woman who had been given 12 months to live said her GP communicated with her about it not the specialists.

12.purf: I said how long do you think I've got. She said well it could be 12 months or sooner. She said so if there's anywhere that you would like to go ... I said I don't want to go anywhere. I'll stay with family...

These men and women were not scared of dying but rather they felt they were not ready, they had not done all they needed to do or they were concerned about the burden it might put on their family.

12.purf: Still we're all going to die once, not that we'd like to I suppose. Just take one day at a time. I don't mind dying it's the thought of dying.

6.pum: But the thing is I'm really not afraid of dying... Of course the other thing is, I don't want to go... what I'm going to miss out on. Also if it gets to the serious stage and your body starts to deteriorate I don't want to be a burden on the family...

31.puf: I just don't want to die screaming. I don't want to put it on my family. I think a lot of us when we get older feel that way too. So if I can do it neatly crack a bottle of champagne and go out with style.

For others the discussion revolved around a more distant discussion of life expectancy and death.

Rural men post 12 months: No one can say with any assurance how long you're going to be around.

28.prf: I'm not worried to die. I'm not. I'm a Christian... I know God will look after every step of my life.

26.prm: I'm the opposite, I'm an atheist and I didn't worry one iota either. What will be will be.

Some participants had asked or sought out information related to their own life expectancy and sadly contemplated their own imminent death.

6.pum: So I said what's the prognosis... 6 months...Kick in the guts pardon me, but it was a kick in the guts. It was terrible, terrible.

22.prm: The loss of doing the things I wanted to do was the main thing in front of me, and the family leaving a family. There were a lot of things I hadn't completed and that sort of kept me going. Even when I was at my worst time, I was still building machinery at home, not a lot but just doing a bit each day.

Several participants talked about having nearly died prior to their bowel cancer diagnosis and feeling they had been given another chance.

29.prf: I think this is the grim reapers third try at me.

4.puf: I should have died, and any time that came after that was given time... if I've got 2 years more... I'll have two happy years doing whatever I want to do.

Others were not able to seek out such information.

30.pum: I said to myself, well I'll just leave my life to the doctors they know what they're doing. If I die I've lived long enough anyway and that was it.

And others were confident that their time had not yet come.

3.pum: I never had any doubt in my mind that I wouldn't come through it. I never doubted it. I thought oh yeah I'll have it and I'll wake up and away I go again. I honestly believed that.

One man had written his will and was planning his funeral.

6.pum: In fact the next thing we've got to do is go around looking for funeral parlours...I'm in so many organisations, I would expect to have a big crowd. I'm the youngest of nine, the baby. A lot of the people would probably be elderly, so I want a place that's big enough to seat a large number of people. Of course I also want to find somewhere that's nice to put on some refreshments after... No problem, quite happy to do that.

Education leading to earlier diagnosis/early detection

Many participants talked about earlier detection of colorectal cancer and thought about ways this could occur.

20.pum: If they had *a colonoscopy* every 2 years well, you're pretty right regarding that.

32.pum: Over the years I've heard very little about bowel cancer...why isn't there more?

2.pum: I think anybody over 50 should have it (*a colonoscopy*) because it's nothing really just a general anaesthetic.

Some participants talked about how they were influencing their friends and families to have medical checkups earlier especially if they complained of symptoms.

Rural men post 12 months: I remember one of our members... came to me about a month or so back and said I'm bleeding from the back passage. I said you get to a doctor straight away... So last Friday night we had our meeting and I grabbed him by the scruff of the neck. I said you been to the doctor? He said yes.

25.prf: *The surgeon* said that my daughters should be checked when they turn 40.

A small number of participants predicted that their children might resist such testing even if they were at greater risk.

12.purf: *The GP* told me to make sure that all my children had this test for it because it was hereditary... she said they should have it by the time they're 40 or younger... Knowing them they'll be like me and won't.

One participant thought that GPs should be more alert to the symptoms and be asking their patients questions related to identifying the symptoms of bowel cancer.

1.pum: Going back to the start, is not so much preventative treatment but to know the symptoms. You don't realise that there's something wrong... I think your own practitioner should ... ask if there's any changes and then delve into it... They ought to be asking those other questions... If you get the cancer early enough its only a matter of nipping the damn thing off.

Multidisciplinary teams

The participants were vocal about the various health professionals they had dealt with. On the whole the feedback was positive although there were a number of examples of bad practice and poor communication.

30.pum: All my doctors are quite nice over here, when I come to therapy, hydrotherapy; they're very nice apart from my surgeon.

General comments

A number of participants were very positive about the respectful way the teams of health professionals in particular units treated them and collaborated to provide good care.

Rural men post 12 months: I was more than impressed with the surgeon and his team and the nurses.

10.purf: One thing that I do like about all the doctors... they're all following everything up...I don't really know whether they talk but I know one gets a report from the other.

32.pum: Yes can I say by the time I arrived at the Austin and the time I was treated here, I've always been treated with respect by the doctors.

5.pum: All I can say is thank you for all the doctors and the people involved the nurses, I reckon they done a marvellous job.

One participant was pleased that his clinician consulted with other experts when his radiologist had misdiagnosed tumours in his liver.

24.prm: My oncologist said no it's not right you don't. He's had his expert friends look through the CT scan and said no you don't.

Even when participants had a bad experience with one health professional they were open to praising others who had treated them well.

9.purm: The first doctor (*who told him he had cancer- very insensitively*) he's the doctor but the other people at the hospital... they are just fantastic... Professional.

Some participants found it very useful to have a primary person to speak with especially when the clinicians were very busy and they couldn't remember who they had seen.

1.pum: I had visits from all sorts of people and I can't remember who the devil they were.

Often the cancer nurse or stoma therapist could or did fulfil this role.

It was important to many participants that the medical team did not talk behind the patient's back.

25.prf: I don't like it when they talk about you behind your back. I prefer to be part of it... I'd like to be told at the same time as everybody else knows.

Sometimes the number of clinicians involved was confusing and difficult to manage for some participants.

6.pum: You see that many doctors. *The surgeon* has his registrars and that. Once he gives you away they keep coming and checking on things.

27.prf: One problem I have is the portioning off of people, your oncologist looks after you there, your local GP looks after you and your high blood pressure and the other things. But no one looks at you as a whole person... everyone is a specialty and no one does the whole person... you just are bits and pieces everywhere.

Dealing with disagreements, professional boundaries or differences between health professionals can provide a challenge for some patients.

1.pum: My own doctor... he said "well ethically you should get *the oncologist* to take you off them (*warfarin*)... as far as I'm concerned you don't need them any more. But ... I won't take you off them because it's his job".

2.pum: It was explained to me at the time, that by putting in the port (*for the chemo*) it would be easier for them to take blood (*to analyse the warfarin*). When I went into the vascular wards, none of the nurses would touch the port.

Participants also appreciated the direct speaking of some of the clinicians.

20.pum: The Chinese doctor what was her name... she said to quote her words, "your bum hole is back to normal" I said that's nice to know.

Anaesthetist

Two people reported very positive experiences with the anaesthetist who explained the procedure well and put them at their ease.

9.purm: I'd never had surgery in my life I was scared. I said how do I go to sleep *The anaesthetist says...* I put a needle in there... and I just fell asleep.

7.prm: The anaesthetist come in put me at ease. He told me what he did and what to expect, that I wouldn't feel anything. Then he asked me if I'd like an epidural and I didn't know what that was. *The anaesthetist explained his choices...* I said what would you prefer. He said oh well it's not for me to prefer, its for you... so I said I'll have the second one. I'm glad I did.

One man reported feeling quite upset by his conversation with the anaesthetist.

3.pum: The thing that completely shattered me... I was... waiting for the operation and *the anaesthetist* came along... Anyhow she really laid it on she said, you realise this is a pretty serious operation you are having... because you are old there's a fair chance you are going to have a heart attack... She had me so down that when she finished I said, the way you've spoken about this operation, are you suggesting to me that I don't have the operation. She said oh no, no you've got to have the operation... I said I realise... there's always a risk when you have an anaesthetic... doesn't do my morale any good.

Dietician

Although the NHMRC suggests that genes, age and diet contribute to developing bowel cancer there is no recommendation that patients consult with a dietician. A number of participants reported that they had met with a dietician or would have appreciated a referral.

9.purm: I've had the dietician. We got the diet book. Wanted to know what I was eating and said fantastic you're doing well. Yeah it was good excellent.

Questions arose during the interviews about diet and the value of certain foods.

10.purf: No that was what I was going to ask you, if there is a diet I could go on now to help the bowel.

Management of bowels, overweight and underweight were concerns for a number of the participants. One participant found the dietician useful in helping her to gain weight.

21.prf: He (*the GP*) said I know what I'll do. I'll send you to a dietician... She wanted to know my history sort of thing, why I'd lost all this weight and one thing or another. ... But I'd put on a pound. She was thrilled to bits...

There was also some scepticism expressed by some participants about the value of changing their diet.

18.puf: She tried to get me to have a breakfast cereals, which I hate. Different other foods, well I won't eat them... I think for yoghurt... you've got to be brought up to it. I eat my vegies, but I don't like a lot of strong vegetables.

Especially when some people reported that they had lived healthy lives and now had bowel cancer.

24.prm: I'm one of those people who have looked after myself. I've had a very high intake of fruit and vegetables all my life. I don't drink or smoke, I drink gallons of water and I drink green tea, that's the only drink I have. I use to eat broccoli, brussel sprouts, and cauliflower on the way to work, yoghurt all that sort of stuff. Here I am getting cancer. Do lots of exercise.

25.prf: I'm sort of a little bit sceptical about all of this rubbish... because my husband was the biggest, best eater; he would never eat take-away food... Always use to go to the market and he'd buy the fruit and vegies and everything like that. Look at what happened to him (*he died of stomach cancer*)

Some participants were not keen to change their diet once they had bowel cancer, just as some would not give up smoking because they believed it would make no difference.

GPs

The General Practitioner is a very important partner often instigating the initial referral, providing support and enabling information exchange for many patients.

Patients talked about using their GP to help explain what was happening to them and appreciated the GP's concern for them.

Rural men post 12 months: My doctor at home he's a great chappie he explains everything to you. He's very good indeed... he doesn't buggar about he puts it in plain terms.

12.purf: *The GP is good*, if it hadn't been for her pushing things the way she did I don't think I would have had that operation as soon as I did. She pushed everything. She's still doing it she's very good.

7.prm: When the operation was over and I had to go back to *the GP* he got the skeleton and he showed me and he brought out the books and showed me. Said that's where they operated and that's that.

32.pum: I went to see the family GP. He took one look at me and said you're as white as a sheet, and he felt my abdomen. He looked up and he said, well I think you've got cancer, just like that. I'm very grateful for what he did. He put an immediate phone call through to the Austin and I was transported there

One person thought it would not be useful to discuss her diagnosis with her GP.

25.prf: *The surgeon* gave me a letter... to give to... my local doctor, but he had already told me so what was the point in going to my local doctor, we opened the letter here anyway...

Some patients appreciated their GPs providing extra care for them.

Rural men post 12 months: He was on holidays when I took crook... he rung me up to ask me to come down to have a talk with him... he was very interested in it...

20.pum: *The GP* said it could be polyps just to put me off a bit, to break it to me easy I should imagine. She knew what it was, and she got me straight into the Repat there for an examination.

31.puf: My GP while I was in hospital for that long time, he would come in after surgery at night and sit with me for an hour just to have a chat. The day they had to open this up, and three hours I had dressing it with no anaesthetic or anything, just cleaning it, and he sat here and stayed with me most of the time.

Some participants reported that their GP failed to diagnose the cancer, were insensitive when giving a diagnosis or were rude to a family member. Some of these people decided to change their GP.

Rural men post 12 months: I was crook for about 9 months. I just kept going to my local doctor all the time and he kept saying... no you're constipated. He's not my local now.

24.prm: I went to the GP with bleeding, and he just laughed and said "nothing to worry about". So I waited for a whole year. Then I went back to another GP who referred me to *the surgeon* who said I had a bowel tumour.

9.purm: What happened I went to primary care and the doctor there... said you've got cancer and you are going to get very sick and that's it. Just bluntly like that. He said what do you think about it. I said what do you want me to think about it, what do you want me to say – I've got cancer.

22.prm: I wasn't very pleased with the way my GP performed. He was mucking me around no end... He was quite rude to my wife. She came with me to make sure that I tell him everything. I'm one of these blokes I go in there and I'd just walk out again and don't say anything... He just said to her this day – hey you, out... Kicked her out of the room. She's my wife... I thought from that day on, you're gone mate I wouldn't go back to you again.

19.pufcarer: The local doctor messed around too much and I don't know whether mum explained her symptoms properly to them. But they thought she just had a urinary tract infection... the doctor she saw there didn't even know that she had a colostomy... he didn't even take a urine specimen or anything. Just put her on antibiotics said you've got a urinary tract infection.

One woman showed great loyalty to her GP even when they failed to diagnose her possible bowel cancer early enough.

4.puf: I'm not criticising my GP... well I still go to him and I'm very fond of him. But he was a bit wrong about this. Because I went to him two

months running and said that I was bleeding every time I had a bowel movement... he said... that's just the cause the anti inflammatories. They upset your stomach. The third time I went there and he still said the same. I said look my dad died of stomach cancer, my aunt died of bowel cancer, and I really feel that perhaps I need to take it a bit further. He quite happily gave me a referral, and I went to the hospital and saw *the surgeon* ...when I got the hospital and they give you all the information, I read the symptoms of bowel cancer... and they were exactly what I had. So if he'd perhaps been a little bit aware I could have gone in 3 months earlier.

Nurses

Generally participants spoke highly of the nursing care they received

32.pum: I'm very grateful to everyone. Especially the nurses and district nurses. I owe my life to all those folks.

22.prm: The girls were that beaut.

Participants were less likely to complain about nurses in the public system than the private system.

26.prm: I can't complain about any of the nurses...they were much better here at Austin than ... Warringal. I thought they were more caring, they give me the impression over there, it was just a job. Where here they waited on you hand and foot.

Admission

One participant and his wife related how useful it had been to meet with a nurse prior to admission.

7.prm: I went to the Diamond Valley Hospital and we met a lovely person called Janet. Wife: She rang us and said did we want to go down and have a talk... She took this job of telling people all about the operation. 7.prm: what to expect, measuring for your stocking, everything. Anything I could think of and to ring her if I could think of anything that was worrying me... She was excellent. I was at ease. I was wanting to go. ... She explained anything and everything, things I never thought about... and things, subconsciously I might think of before the operation... I couldn't think of anything that she hadn't told me. I felt so good... I really looked forward to the operation.

On the wards

Most participants reported that they received excellent care from the nursing staff on the wards.

Rural men post 12 months: The treatment and the way they looked after you was phenomenal. Even when you're lying on your back and get crook heels they got a soft mattress and all for me... I reckon I had three nurses to one patient.

32.pum: Now they've got university training and all that... I could ask them questions, they would give me that amount of time to talk with me.

5.pum: Those nurses work day and night... every hour come and check you. Your blood pressure, your connection, your this and

that... I even had a nice box of chocolates and I gave it to the nurses... Best thing in the world you know I think they are, they done a very good job.

A few participants mentioned their negative experiences with nurses, which included the nurse being insensitive or unavailable when the patient needed care.

31.puf: *When talking about a wound which was not healing.* I remember one little Malaysian nurse, "Oh I put my whole hand in", she said, "put a glove on put your whole hand in". I said "Thank you, don't tell me that, I don't want to know". They can be very insensitive at times.

24.prm: One nurse said to me, oh we're only doing this to try and extend your life a bit... when someone says that to you, you think oh god what am I going through all this for just to get an extra week.

Cancer Nurses

Participants who received the care of cancer nurses particularly appreciated them.

33.pum: *She came and talked to us comforted us ... and she was pretty good. It was definitely helpful.*

4.puf: She was very good... She said if you'd like your children to be here I'll come back again while they're there and explain it all again, and talk to you about what's going to happen.

Oncology nurses

Patients consistently talked about the importance of being able to speak with the oncology nurses and appreciating the nurses' knowledge of procedures and treatments.

1.pum: I had a very good talk with the nurse, the senior nurse in the oncology at Heidelberg House. She explained everything, which could happen, all the things that could go wrong... So I went home expecting all sorts of things to happen and nothing happened.

4.puf: I couldn't speak highly enough of the nurses in chemo, they were just wonderful... I spoke to the nurses about the fact that I've got six grandchildren and ... they'd come to visit me in hospital... So she gave me some books to explain it to children, like storybooks.

Royal District Nurse

On the whole participants were pleased to receive the services of the District nurse but one carer was disappointed in the service.

20.pum: We had a district nurse coming every day...checked whether the what's a name was in my arm. Cleaned it all that sort of thing. Checked the battery in the chemo box. Then changed it once a week. Changed the battery once a week.

5.pum: District nurse comes for 2 weeks. She teach us to change the bag... very good indeed

19.pufcarer: After the initial surgery when she was at my place RDNS came out then. That was fine. The follow up (*from the second lot of surgery*) has been really quite poor. The RDNS was supposed to come and flush it every 6 weeks, and they don't come out and flush it. In fact I think they've only done it once.

Stoma Therapist Nurse

There were no criticisms of the stoma therapist nurses. Participants found them helpful, caring, informative and supportive even when they were dreading having a stoma.

6.pum: I said please not a bag... My mother died with a bag in, so did a good friend... Well the stoma therapist marked two around there, and it was either side. I said please – she said no she said this is just a precautionary measure. She said I'll be there and the surgeon will tell me whether he feels it necessary or not. She explained it she said it might only be for a fortnight.

Rural men post 12 months: The stoma sister, she was the one that explained everything ... she's very professional. I call them professional when they tell you.

Usually she visited the patient before their operation.

Rural men post 12 months: In my case the stoma nurse came before the operation and she comes and checks you out and she marks on your stomach where it's going to go. She said we're hoping that you don't have to have one. But I thought oh this is nice, she's putting a little spot here and another spot here, like marking it with texta. So that's where they're going to put it. They make you stand up, where your pants fit and all this sort of stuff.

And then assisted them with the management of their bag after the operation.

20.pum: Oh yeah lovely person yeah... She's a funny person. She came into the ward when I was in the bed after the op and she showed me how to do it all that sort of thing.

Even those who had emergency surgery found her first visit comforting.

33.pum: I was lying there and my parents were coming in and I thought I'm not having that (*the large post operative bag*) and I really was pretty bad. *The stoma therapist* came up and she had a good talk to me and she said oh no this is what we give you when you go home and she made me feel a lot better and we had a good chat and she took me up to another person who had one. It worked out all right.

One participant carer and a participant talked in glowing terms about the excellent follow-up of their stoma therapist.

19.pufc: Excellent. Yeah because she had mum stand up and sit down and bend over. Mark the area that mum thought she would be most comfortable with. Because she's left handed it was better for it to be on this side rather than over here... Her follow up has been excellent... Mum doesn't even have to make an appointment. All she has to do is go to the desk and say is X in. As soon as X can get

time, she'll come and see mum. Any problems mum can get on the phone and talk to her. The stoma therapist has been really good.

22.prm: She talked to me she was beaut. She told me what was going to happen and which side would I like it on... the lady use to come every day for a start, and she got me going on it and that. It worked all right... She was lovely... She got me all these aids as well. She had nice smelling stuff.

Oncology staff

Participants praised the staff that provided oncology services. They reported that they were professional, caring and friendly.

6.pum: The oncology people themselves I go to Heidelberg House for the oncology for the chemo very kind, very considerate people.

6.pum's wife: I must say the oncology staff where you are having the chemo have been wonderful. Haven't they. They are just gems. I don't know how they do it. They are a delight.

3.pum: Let me say that I thought it was wonderful when I had the chemotherapy the people there were friendly, use to go in there and – cup of tea... They never kept us hanging about long...

Some participants mentioned clinicians who they particularly liked.

22.prm: The oncologist was good. I tell you what they are beaut up at that radiology ... He did everything beaut. I've had both those doctors up there but I like him better. There's something about him, he always says how's X going. That's my son.

3.pum: She's a very nice person... she was terrific to me.... Because I was the first person she'd ever done because she said to me, oh well it's the blind leading the blind... She use to chat away and I use to chat away to her... She use to say to me when I was waiting, come on tell me some tales.

26.prm: *The oncologist*, he's very good because I crack dirty jokes with him and everything.

3.pum: *The oncologist*, he's terrific. He goes in and he checked me out and he says "you are doing marvellous. You haven't lost weight or gained weight... your blood is terrific which means that your liver is all right". He said "you look well... I reckon you are going real well". That gives you a lift up...

Participants showed their appreciation for their care with presents usually to the nursing staff.

20.pum: At the radiation place you couldn't wish for nicer people... We bought them all a box of chocolates after the radiation had finished.

8.purm: See at Christmas time I said to my mum, I'd love to do something for the staff in oncology at Heidelberg House. So what I did I got them four Christmas cakes, big Christmas cakes. You should have seen the look on *the nurse's* face when I plonked them on the table in the office. Anyway when I finished the second lot of chemo. I

thought well I've got to take them down something they've been so good to me. I bought a whole heap of chocolate biscuits and that sort of thing and put them in a great big plastic container with a lid on it. Well I plonked that on the table. I said to *the nurse*, I said here you can have these with some coffee.

There was one notable exception. One private patient told a story of how her oncologist had a 10 minute session with her to convey that she had cancer in the liver and lungs and if treatment failed she had only months to live. The woman related how she had attempted to discuss with the oncologist her various choices and he had been quite rude to her on both occasions of her visits. This woman related how scared she was of the clinician even though she was a professional person herself. She sought a second opinion and was very pleased with the new person who told she did not have cancer in her lungs.

29.prf: There were two phrases that he said to me that I felt were just particularly callous.

I said, "Why can't you have a resection of the lungs, because you can have a resection done on the liver. So why can't you have surgery on your lungs."

He said, "Oh you have forgotten your nursing haven't you"...

I thought how rude that is, because this was 30 years ago, and secondly am I likely to think of that at this moment when I'm hearing that I'm about to meet my maker. I thought no don't take any notice of that, that's not the answer to the question.

He said "If I was to ring up Professor X at the Y hospital and say I have a woman here who has a primary in the bowel, secondaries in the liver and the lung, will you do surgery on the lungs? He would organise for me to have a straight jacket put on, and I'd be shipped off to a psychiatric hospital." He said further things like "if I was to do an autopsy on your lungs right now", and this was like within minutes of being told that you are going to die.

I said, "Do you mind, I'm still here".

He said, "if I was to pull your lungs out I'd see there was cancer all through them... I very much want PET scan done to prove that's cancer of your lungs".

I said "you don't want it to prove, you want it disprove it, that's bad news for me."

He said, "Well I want my opinion confirmed".

Some participants appreciated the service more when the appointments were on time.

27.prf: I found *the oncologist* very good too *BUT* He's always late and we always wait.

28.prf: Radiotherapy is always on time, and they schedule it just so beautifully. You know, you go in... its just so quick and good.

Physiotherapist

The physiotherapist played an important part in encouraging patients to begin to walk soon after their operations. One physiotherapist upset a number of the participants by being too energetic.

Rural men post 12 months: The physio came the next day after the operation and they get you up and they make you cough. He made me that crook... Like getting all phlegm up. There was no phlegm there... he'd make you walk up the corridor. Every time you got up the corridor you just felt like vomiting, well I was vomiting. Then he'd

take you back to bed again... Like he use to put all the bags and bottles in your pockets and make you walk. I kept saying no I'm not getting up today I'm too crook.

Rural men post 12 months: You had the same bloke as me I think. A bloke I terms *Speed Gordon*. He'd get you up and race you up the bloody hallway.

10.purf: I thought he was a bit pushy yes. Then he left and I had a girl and she was lovely... I felt perhaps she had more understanding of how I felt.

Other participants reported more positive experiences.

7.prm: But the physios were good. They made me walk straight away. Like as soon as I came out of intensive care... I didn't want to, you say to yourself 'oh no'. They say, come on just lean on me and we'll just go out to the door the door of your room. Of course they'd walk you an extra 20 yards. It was cunning but it was good. It made me better for it.

Priest

Several participants mentioned their belief in god but only one person said they had seen a priest, unfortunately the patient misunderstood the reason for his visit.

9.purm: The priest come in... and he said hello to me and if I needed anything just give him a bell... When he walked in I thought I was dying. You see a priest all of a sudden you go... last rights coming up... Well he didn't say much he just said he was walking the wards and he said 'I just dropped in to say hello'.

Social Worker

Very few participants mentioned the social worker as part of the multidisciplinary team. It was unclear exactly what role the social worker played with those who received her service and it did not appear to be completely helpful. One man had a social worker visit him regularly but he could not understand why he needed to talk about what was happening to him. No rural person mentioned a social worker.

18.puf: She's the one that got me that I can use the taxi.

19.pufcarer: She (*her mother*) could have maybe had a little bit more social worker involvement as far as here at home...

Surgeons

Participants reported both good and poor relationships with their surgeons. Some surgeons appeared to have good relationships with some patients and not so good with others. It was apparent that it was very important for patients to feel that they could trust their surgeon and that the surgeon appeared confident.

10.purf: I've got faith in him. I know he'll do his very, very best for me...

3.pum: He told me he'd done over 30 of the same operation as this one. So at least I thought he knows what he's doing.... 3.pum's wife: He sort of had a confident sort of manner.

One aspect that influenced the patient's relationship with the surgeon was the appointment waiting times and perceived thoroughness of the surgeon's examination. Some participants wondered why they were visiting the surgeon when they received such a brief service.

Rural men post 12 months: You go and sit there for 2 hours before you get in to see him.... He just goes like this, and he feels you around here...you're looking real well, see you later come back in 3 months.

Some reported positively on the thoroughness of follow-up visits.

Rural men post 12 months: He checks here, under here, around me back, and he said you're all right I'll see you in 4 months time.

Participants reported that surgeons had a variety of communication styles. Some participants appreciated the surgeon being straightforward and direct.

33.pum: The surgeon was straightforward. He was probably quite concerned.

20.pum: The surgeon... organised the rest of the proceedings in four weeks... he give me a thorough examination... He said you've got cancer ... He said we'll be giving you a bag and we'll be sewing you up in the rear end.

Others preferred a more explanatory and friendly style.

Rural men post 12 months: He explained what he was going to do and everything else. Told me that I had cancer... he came to me a couple of days after it and he said, now when you go home he said you'll find that it will take ... perhaps 3 months before your bowel will settle down into the right place...

8.purm: Really they were more friends to me than a surgeon because I got to know them pretty good... I saw *the surgeon* only about three weeks ago. I went in and had a yarn to him, sat down at the table.

26.prm: He was terrific. Always asked you how you going and all that.

Participants appreciated it when they thought the surgeon was being truthful with them.

7.prm: He never smiles much, he's a very serious man, but he's down to earth he tells you the truth. That's what I wanted to hear, the truth... I'd never go to anyone else as far as I'm concerned...

One woman said she really appreciated it when her surgeon went "beyond the call of duty" and spent extra time with her.

29.prf: I told him about my fears and he organised for me to contact one of his clients, who was similar age to me and had a colostomy... The other thing he did which I thought was just way beyond the call

of duty. I was having chemo and radiotherapy pre-op and he rang me twice during that period, just to say how are you going.

Participants did not like it when their surgeon did not give them sufficient information.

12.purf: *The surgeon* didn't even tell me that he didn't get it all.

Some participants said they had difficulty with their surgeon who they perceived as unhelpful, unsympathetic, cold or uncaring.

24.prm: I rang the surgeon and I told him that I was under extreme pain. He said you just need to relax, take the pills to make you relax. I took them and it didn't make any difference.

28.prf: Seems like the surgeon is cold. I done a good job on you, that's what he say...There doesn't seem very much care... Walk in and walk out.

One woman thought her problem with the surgeon was because she asked questions. She also related several incidents when he had not responded to her pain, had sent her home too early from hospital and was unconcerned when she was seriously underweight and constipated. She did not think she was receiving the appropriate attention. Her concerns were well founded as she had suffered from other cancers previously.

21.prf: I'm having trouble with the specialist I'm seeing now. Because I'm asking questions... this is why the surgeon and I are not hitting it off...

Some participants believed that surgeons could not be as responsive and caring as other clinicians.

28.prf: I think the surgeon is not as warm as other people anyway because I think they've got a job to do and they get on and do it, whereas a physician or a GP has got an ongoing thing.

30.pum: Yes the surgeon, straight out person, good surgeon... He said, you've got cancer in your anus; we're going to cut it and put a bag for the rest of your life. Nothing else that's it, he says go home. He just examined like production line.

Participants even commented on the surgeon's modesty and the strength of their hands.

4.puf: The surgeon comes in and examines all these little private parts every day. He walked in one day and I was changing my nightie. He was so embarrassed; he jumped out, and said 'oh I'm so sorry I should have knocked'.

32.pum: When the surgeon performed the operation, he actually palpated the area around the tumours. I had no idea how powerful the hands of a surgeon really are. It felt as if he could crush blocks of red gum in his hands.

Training Doctors

Participants were usually pleased to have student doctors involved in their care. Some patients liked the attention of the more junior medical staff and were reassured that they were accountable to a senior medical person.

Rural men post 12 months: I my case I had like a young fellow... He was a real nice young bloke. He looked after me all the time... they'd come every morning at 8.00. *The registrar* was just like a son to you sort of thing.

Rural men post 12 months: *The surgeon* he bought in I think it was 4 or 5 doctors from Melbourne to me. They screened me off. They all had to examine me. Then *the surgeon* explained to them what he had done to me.... They've got to learn and everything else.

One woman commented on the treatment of students by clinicians.

4.puf: What I did mind and found embarrassing was that there was one doctor who would bring in the students to examine you and then he would ask them questions in front of you. I found him very embarrassing because I felt he was making a fool of them in front of me... Like he asked them one time, after the bowel operation "what stage of her diet would you expect her to be now?" I'm looking at them and I'm trying to go like this (raising her eyes to above the bed)- it was over the bed, 'Liquids only'.

One participant reported a less than satisfactory relationship with a training doctor who would not look at his wound, which had become infected and another participant was concerned because his questions were left unanswered

Rural men post 12 months: I told him time and time again that this was hot and sore. But he wouldn't take no notice of it.

Rural men post 12 months: I mean you understand that junior doctors have got to learn and that sort of thing... You can ask them a question but they haven't got an answer. It doesn't do much for you... it leaves you pretty much in the dark.

Communication and Relationship Building

Participants were able to clearly articulate the most important components essential for good communication and relationship building with the health care professional.

The participants wanted professionals who were able to be familiar, positive, reliable, in some cases 'friends', whom the participant could feel 'fond' of during their experience of care. One man talked about how his clinician always visited at the same time, he had confidence in him and he was like "a son" to him. It was important to all participants that the clinician was honest with them about their condition. They also wanted their clinicians to communicate with each other and include them as a part of the team.

7.prm's wife: They both came to me after the operation. *The surgeon* and the anaesthetist and said everything went all right.

These characteristics helped the patient to deal with uncertainty.

8.purm: I treated them all as personal friends. I got on so well with them.... that's the way mum and dad taught us when we were kids to be friends and not enemies.

24.prm: There's so much uncertainty. My doctor is very good because he's very positive.

3.pum: I had finished my 30 doses of chemo she said there you are that's the last one and she said I don't think we'll see you any more. That's the sort of thing you like to hear. Might not be true but at least you know.

29.prf: When asked if she raised a concern regarding the delivery of the diagnosis over the phone she said "I haven't because I am very fond of him. "

31.puf: I even got to the stage with my surgeon that I slapped him on the wrist one day and I said, get your fingers out of my wound. You don't know how strong you are.

Participants did not like clinicians behaving rudely or in an intimidating way towards them. Some of the examples given included a GP asking a patient's wife to leave, a clinician talking to a woman as if she were already dead and a man who was confronted with a diagnosis of cancer as if it was his fault. These participants wanted to be treated sensitively and with respect.

29.prf: It wasn't my own death that terrified me as much as the brutality at which he delivered that information.

Participants wanted the health professional to be interested in them as a whole person, not to just think of them as a diseased bowel. Patients wanted specialists to acknowledge their other health problems. When clinicians did this it encouraged the patient's feeling of trust in the health professional.

The health professional's ability to sensitively give a physical examination was also important to participants. Others participants talked about adapting to repeated rectal examinations, and having to undergo other intrusive procedures in front of a number of health professionals.

The exchange of information was extremely important to all participants. They wanted the health professional to volunteer a wide range of information, to encourage questioning, to listen to them, to be respectful, honest and direct and sensitive to the timing and mode of communication. Participants wanted the health professional to check if the patient had understood what was being said and to involve the family. Many participants involved their carers or partners in the interviews because they provided important information about the family's experience of care. Sometimes family members served as translators or had important personal contacts in the health system.

The patients wanted health professionals to volunteer information and encourage questions.

29.prf: But with that oncologist when my blood wasn't going down I said, what's the normal time and he was very annoyed about that (the question).

Some participants said that they did not know what to ask and they felt they were left in the dark.

28.prf: I can't think any questions; because he's the surgeon what question you can ask him.

Rural men post 12 months: Basically I don't like being put in a mushroom syndrome where you're in the bloody dark.

A small number of participants talked about the clinician's failure to hear that they were in pain or distressed.

31.puf: They don't listen. I said to them, I don't think this will work, it's only a small bag you know and it comes out there, it doesn't go all through there.

Clinicians needed to check whether the patient had understood and heard what was being said.

6.pum: He gave me an answer, but unfortunately I'm a little bit deaf and I didn't quite hear. I can't remember what he said at the time.

12.purf: I didn't find out much about it because I was in so much pain and everything it just wouldn't sink in.

Participants found it reassuring when they were given detailed written, verbal and or visual information about what would happen to them, when and what the side effects were.

13.purf: They drew me pictures; showed me where it was and what they were going to do.

Rural men post 12 months: *The surgeon explained all that to me. He explained what he was going to do and everything else. He was very straightforward, very good.*

33.pum: I remember getting stuff to read...they were pretty good at explaining... I understood what they were saying. It was horrifying but I understood what they were saying

Many participants reported that they would have appreciated more verbal, written or visual information.

20.pum: I don't think they did explain it enough, in as much as I didn't really know what they were going to do.

Patients appreciated being given constructive assistance in reducing or dealing with side effects of treatments and procedures. It provided them with some security in a very insecure environment.

6.pum: When I started oncology, the first day I went to oncology I had the fear of god in me because you hear all these nasty things about chemo making you sick. But the first day they take you into a room and they give you a private consultation, I had my wife with me. They go through the procedure of chemo and all the side effects you can get and what you can do, and you can't do... they gave me a booklet and information. Said I'd lose my hair and possibly will get mouth ulcers how to treat it. Rinse my mouth out four times a day with salt water, and dental hygiene. Every night I go to bed I say to my wife I can't come to bed yet love I've got to do my ablutions... Oh dear I've got to take pills, clean my teeth, rinse my mouth out.

They also wished to be encouraged to be involved in a conversation with the health professional about their diagnosis, treatment and ongoing care.

32.pum: I was actually able to hold a conversation with the doctors and they explained to me, they explained the effects the trials overseas, and the efficiency of the methods they use here.

They wanted to be able to properly understand what was happening to them so they could deal with it physically, emotionally and socially.

Rural men post 12 months: Most people want to know how the hell they're going to get around it and get over it. What are you going to do how are you going to face it.

A number of participants commented on the long time that they had to wait in the waiting room for appointments. They also commented on the short amount of time that they had to discuss their condition with the health professional. One woman had two contrasting experiences. The first of a ten-minute consultation in which she was told she would probably die only to discover the consultation was over when the doctor left the room. The second similarly important consultation the woman reported that the surgeon allowed over an hour to discuss all issues.

The timing of the provision of different pieces of information was also important to participants. Participants said there were certain times when they were more able to hear bad news and or remember details. They needed information to be given in chunks and they needed to be provided with support and reassurance.

The physical space in which communication occurs, particularly the delivery of bad news is very important to participants. Not only do they require private space, not during visiting hours and adequate time, but they also want the clinician to position him or herself more equally, not looking down or standing over the patient. Rather sitting and talking with the patient. Some participants felt that being given bad news over the phone was not appropriate.

29.prf: The oncologist sat behind a desk with a very high chair that was padded. We sat on lower seats... so you feel you are way below him... My own surgeon often sits at a desk beside me and discusses it, and has sweets and minties

Some participants reported that they had never been hospitalised nor had they had an anaesthetic. This meant that they had needs for specific information and reassurance about hospital procedures. For example one man needed to know how he would be put to sleep because he had never had an anaesthetic.

What the patient brings to the experience

It is important to acknowledge and understand what the patient brings to their experience of care when considering relationship building and communication between patient and health care professional.

A number of participants talked about experiencing severe stress prior to becoming unwell. One woman lost both her husband and mother. Another man described having to move house, work pressures and having serious marital problems. Several participants were caring for spouses who had serious illnesses or had recently died. A number of participants thought their own experience of stress had contributed to them becoming ill.

Other participants described being very well all their lives and not being able to draw on the experience of being ill to cope with their current situation.

5.pum: I was never sick in my life.

7.prm: Well when you've never had anything wrong, it's a shattering experience in a way.

There were other participants who had experienced a number of illnesses including prostate cancer, breast cancer, cataracts, and ovarian cancer. Some people had appendectomies, cholecystectomies, strokes, hernia operations, vascular disease, diabetes; one person even had necrotising fasciitis. Several men said they had fought in the Second World War. Participants also talked about family members who had died of various cancers. Many of the participants were over 60 years of age; quite a number smoked or had smoked during their lifetime.

Participants varied in their confidence and ability to stand up to the medical profession, ask questions and feel that they could equally be involved in decision making about their own care.

21.prf: I didn't ask questions because I came from England... It's forbidden sort of thing, to query doctors and specialists what they say you see.

29.prf: Then I went back to my surgeon and discussed all the options and he encouraged me to get a second opinion

19.pufcarer: Mum won't say boo, she won't say if she's in pain, she won't say if she's uncomfortable she'll just lie there.

4.puf: I'm a fairly shy person and I don't like to say to the doctor look I think you're on the wrong track but I had to say it

Some of the participants were used to seeking medical assistance as soon as they noticed problems while others put off seeking help and sometimes underestimated how unwell they were.

20.pum: I'd had this going on for probably 5 years. I knew practically that I had it do you know what I mean, but I was too scared to go to the doctors, because I've never been in hospital in my life.

Rural men post 12 months: I was supposed to go up to Cooma shearing. I love it up there sort of a holiday... you can do trout fishing and that on the weekend. I rang the boss and said I won't be able to come for a week I'll see the doctor and he'll give me a tablet...He said its just not right you'll have to go *and* see a specialist...Then I had to be honest with him...It gets you that way well eventually... I've got to be treated.

Many participants exhibited great courage in the way they dealt with negotiating pre-existing conditions, the system, their diagnosis, treatments and poor prognosis.

Rural men post 12 months: They told me I was going to go down to Melbourne for chemo and radiotherapy. It burnt... the first week I was down there... I only lasted the week and they said well we're talking you off it all and we'll send you back home for a week... I said to my

wife, I don't really know what's going to happen with this but I'm going to follow it through, 4 ½ weeks and get it over and done with...

9.purm: Just take each day as it goes by. But don't mope around and think about it all the time. Because I think if you do that it wears your system down it really down.

31.puf: The day they had to open this up... with no anaesthetic or anything, just cleaning it... it was, what do they call it, debriding. Scraping bits off and cutting bits off. But it was all dead flesh you see, so I guess that's why I didn't hurt very much. But it went on for 3 hours... It was awful. And the result of it is I feel I never want to go inside a hospital again.

4.puf: I just take the attitude that the cancer is all gone I'm not going to get it again. Going to the chemo I said it's just something I do. Like I go to Safeway in the morning, I go to chemo in the morning.

Several participants said that their religion helped them deal with their illness.

28.prf: Prayers are very good, it makes you more calm.

Participants described how being unwell meant they were reliant on their partners in new ways, which had an effect on their self-esteem and challenged them to confront their fears.

7.prm: The only thing you don't feel a man for a start because I had to have mum washing me in the shower... I said to the nurse, will I wet the bed. She said don't worry about wetting the bed; she said you won't wet the bed. Isn't it funny? It's just a male sort of thing.

20.pum: I was too scared to go to the doctors, because I've never been in hospital in my life. I was that scared that I didn't want to front up to the situation... my mother died in hospital, my father died in hospital. My mother-in-law died in hospital and it just frightened me.

Some participants said that they did not have a clear understanding of how their body worked and where the different organs were. This made it more difficult for them to understand information they were given about their condition, treatment and prognosis.

9.purm: I've got no idea where my liver is... showing me the x-rays and the scans would have been good to say, well there's your spots, there's your lesions.

18.puf: I don't know what the insides are.

Many participants used humour to talk about their experience of care.

4.puf: One lady who was into sort of healing, use to make this green cake with green icing because that's a healing colour. I don't know how many people threw up from the green cake.

Rural men post 12 months: On our ward, three of them were bowel cancer. The other fellow he had his leg chopped off. I thought Jesus I'm lucky, he's got no leg up here like. It's gone. In fact it started off below his knee and they done it four times, its up here on his thigh the last one he got. I thought how lucky can you be.

29.prf: Think of me, (*she is pointing to the scars on her abdomen*) I had there, now there to there. My husband said you've got to have a little tatty done here saying 'no right turn' and one here for my appendix. He said, now all we need to do is a splenectomy, to complete the picture because that would be across there.

Family and Carers

Families and carers are intimately involved in the whole experience of care. Some participants expressed concern and wanted to protect their families from stress related to their diagnosis and treatment. Several participants thought that it upset their families more than it upset them. They described how their families dealt with the news and treatment.

6.pum: I told my wife when she came in... Anyway the family came in and we decided at that stage that we wouldn't say anything... So we battled on for the rest of the week... That Saturday night we invited all the family around the table. I said to them, all right I've got some news. Told them the news. I said all right if you want to scream, cry, do whatever you want to do. Do it now and then its out. Let's forget about it. I said we take it as it comes and we do the best fight we can do. Yeah they were upset. But they've been very supportive.

Rural men post 12 months: Yes it knocks them around more so than it does you actually in that sense. Because when you are in the situation you basically know what you are going to do what's going to happen and you know how you feel, but they don't.

10.purf: Well one daughter I don't know really what the other two think, but one daughter seems to talk more about it than what the other two girls do.

20.pum's Wife: No I was so shocked, I was so shocked you know. I just couldn't think. My mind sort of went blank.

Family members became quite engaged in the care, information gathering process or advised on the best clinician for the patient to see.

4.puf: *My daughter* came in with me the first time I saw the doctor and I think at one stage he had to excuse himself and went outside and I'm sure he was reading up a medical dictionary to get the answers to some of the things she was asking.

10.purf: Beforehand I was on my own. Then each time I went back afterwards there was a daughter with me.

Carers became very involved in monitoring their partner's pain and nausea, and assisting in their care whilst also accompanying them to the hospital for treatment. Other family members wanted the participant to share family holidays.

11.purm's partner: As soon as I wake up in the morning the first thing I do is ask him, have you got any pain. It's the first thing.... I know when he goes pale that's when I know there's something wrong with him.

12.purf's husband You know what they're going through... Being kicked around. They like to say some things to you that they would never say otherwise. The way they are. You've got to handle all that... Well you can see it in her face.

20.pum wife: I always go in with him. 20.pum: Oh yeah it's a bit of comfort do you know what I mean. Takes a bit of the stress away too.

Some participants described not having partners or family to speak with about their condition or not wanting them to accompany them. One woman said that her husband had denied she was ill. Another man said that his wife had passed away while he was having surgery. He had some family support.

21.prf: I can't speak to my daughter... Several times she said I don't want to know, I don't want to know.

26.prm: Everybody said to me this one is an absolute invalid. That upset me really... I didn't bring the wife today, I didn't tell her... of course she'd answer the questions and not give me a chance to answer...

27.prf: My husband more or less took the attitude, you're ok I don't want to think anything further along these lines... He was panic stricken when the operation took place ... I don't think he wants to deal with it.

8.purm: *My wife* passed away by this and I never saw her any more after I had surgery, she was cremated.

Another outcome for families was that the patient become more vocal about making sure the rest of the family sought early screening tests.

20.pum: If you've got any children it pays to get them to check themselves out...

Conclusion

The experiences of care documented in this report include patient's positive experiences of good practice and their experiences when the practice could be improved. Patients were particularly appreciative of the work of the oncology staff, stoma and cancer nurses, and the medical staff on the wards. Some patients spoke about the excellent relationship they had with their health professional who provided them with good information. Metropolitan patients on the whole felt that access to services was adequate, except for parking problems. Rural patients could not access radiotherapy in Bendigo.

One strong message emerging from the interviews with patients was that it is necessary for all health professionals to start where the patient is and to remember whose body it is that is being treated. It is also important that the health professional repeatedly checks that the patient understands what is being said to them. The patient's individual need for complexity and desire for involvement in decision-making must be investigated so that the health professional can provide appropriate individualised care.

A person receiving care for the treatment of colorectal cancer wants to be treated with respect and as a whole person, not a sick bowel. This belief is expressed well by this final quote.

29.prf: On numerous occasions I had to go for scans and stuff, and they'd come in and say, "oh what's wrong with you?" I hated that, absolutely hated that ... To one of them I said, "well do you want to

hear about my whole life or just the sick bowel?" I was sick of them asking me, "why are you here?" And that's all they want to know. I think when you first go to health professional they should take it upon themselves to actually have an interest in you as a whole person.

FINDINGS AND RECOMMENDATIONS

The findings and recommendations from the consumer interviews can be summarised under a number of headings.

Issues Raised	Findings	Recommendations
Decision-making	<ol style="list-style-type: none"> 1. Decisions appeared to be made for patients particularly around the decision to have surgery. People were often told there was no alternative or choice. 	<p>People should be given the choice of a second opinion, alternatives and the evidence and risks associated with particular treatments.</p>
	<ol style="list-style-type: none"> 2. Many people had limited ability to ask questions because they were unfamiliar with the disease. 	<p>People need to be educated about their body, colorectal cancer, given guidelines, assistance in asking questions and also involve the family in this process.</p>
	<ol style="list-style-type: none"> 3. The apparent power differential between clinician and patient needs to be acknowledged as this effects patient's ability to ask questions and be equally involved in decision making. 	<p>A cancer nurse/advocate can be used effectively to support and represent patient needs. Clinicians can be educated to become more aware of different communication styles.</p>
	<ol style="list-style-type: none"> 4. Patients did not always have a choice of health professional. They wanted someone they could trust, have confidence in, was reliable, on time, 	<p>Always offer the choice of a second opinion, a list of names of possible clinicians, their experience and area of specialty.</p>

Issues Raised	Findings	Recommendations
	polite, and up to date with their research knowledge. It is a patient's right.	
Information Provision regarding diagnosis, treatment and side effects	5. Many patients felt the doctor was too busy or they did not know who to ask for information	More proactive use of the Cancer nurse in the provision and explanation of information; a hospital policy that enables doctors to make enough time to speak with patients; education of clinicians in different communication styles; provision of orientation for patients to the hospital and what to expect.
	6. Some patients were given bad news inappropriately. Patients said they wanted the clinician to be truthful, detailed, sensitive, and to deliver it in an appropriate place and time. It is important that clinicians understand patient's various responses, which include shock, denial, sadness, anger and depression.	Use of the Cancer nurse and ensuring a family member is present to aid questions and explanation; education of clinicians in communication, hospital protocols related to delivery of bad news (See NHMRC Guidelines for Breast Cancer).
	7. Many patients were not given the evidence or risks of a particular treatment.	As a matter of course patients are given the latest evidence regarding treatments and procedures.
	8. Some patients reported being given an incorrect diagnosis, not being diagnosed early enough and/or in an untimely fashion	As a matter of course clinical guidelines should be used by health professional; GPs and casualty doctors are regularly educated in recognising the signs and symptoms for the detection of colorectal cancer; the promotion of a public education program into the early

Issues Raised	Findings	Recommendations
		warning signs and risk factors associated with colorectal cancer; Training for clinicians in communication of bad news.
	9. Often patients were not given time to make or think about a decision. Some people appeared to be coerced into doing what the clinician thought was best.	Education for clinicians into communication related to informed consent and joint decision-making.
	10. Patient's suffered embarrassment, discomfort, pain, claustrophobia, and violation from multiple tests, procedures and treatments.	That clinicians be fully aware of each patient's possible distress, treat patient's sensitively, fully inform patient's about tests and side effects, do not underestimate effects and communicate with other clinicians regarding the numbers of tests to be done on one patient.
<p>Information Seeking</p> <p><i>Patients bring a variety of life experiences, courage, humour and education to their experience of colorectal cancer.</i></p>	11. Patient's ability and skill at seeking information varied enormously and was related to their ability to understand what was being said, how familiar they were with their body, their ability to be assertive, and their ability to know what to ask.	Clinicians be aware of actively encouraging choice, providing detail, providing sufficient time, providing access to different information mediums (spoken, written, visual), providing questions for the patient to ask, encouraging the presence of a cancer nurse, advocate and or family member, ensuring that an interpreter is present if required. Clinicians need to provide the evidence, the risks, and the guidelines. Clinicians need to make sure the patient fully understands what they are agreeing to. This is an ethical responsibility.

Issues Raised	Findings	Recommendations
	<p>12. Some patients wanted to be able to choose not to have treatment this related to their personal wishes, age, prognosis and tolerance of treatments. Some patients also wanted further treatment when clinicians may have given up.</p>	<p>Clinicians fully discuss all options as many times as necessary.</p>
	<p>13. People wanted to be properly prepared for the anaesthetic, surgery, pain relief and other possible procedures.</p>	<p>Pre admission nurses could be used to explain what will happen for all admissions; patients are provided with choices as regards pain relief and anaesthetic.</p>
	<p>14. People wanted to be properly informed about the results of surgery.</p>	<p>Hospital procedures should ensure that the patient and family are fully informed several times about the results of surgery; Clinicians receive training in effective information provision.</p>
<p>Experience of Care</p>	<p>15. Ward experience: Patients reported concerns about infection, people who were dying on their ward, mixed sex wards, unexplained transfers between wards or people who should have been on another ward.</p>	<p>Review ward allocation in relation to having male and female wards and also appropriate diagnostic mixes of patients. Monitor infection control.</p>
	<p>16. Discharge experience: Some people were discharged too soon or without adequate district nurse follow-up leading to their readmission or infection.</p>	<p>Review discharge-planning procedures.</p>
	<p>17. Post-operative bowel management: Many patients needed assistance with post treatment bowel management.</p>	<p>Review the clinical guideline and hospital procedures regarding appropriate post operative and post treatment bowel education and support.</p>

Issues Raised	Findings	Recommendations
	<p>18. Discussion of prognosis and death. Some patients had bad experience of this.</p>	<p>Review the clinical guideline and hospital procedures regarding delivery of bad news; provide further education in this for health professionals.</p>
	<p>19. Absence of support and self-help groups: Many patients would have appreciated having access to a self-help or support group.</p>	<p>The hospitals work towards assisting in the setting up and maintaining such groups.</p>