

***Grampians Integrated Cancer Services***

***Cancer Service Improvement Survey***

**Summary Report**

**May 2011**

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# Grampians Integrated Cancer Services Cancer Service Improvement Survey

## Introduction

This report's purpose is to present the main findings of a survey conducted by the Grampians Integrated Cancer Services (GICS), in partnership with the Central Highlands Primary Care Partnership, and the University of Ballarat. The aim was to gauge the opinions and attitudes of consumers of cancer services in the Grampians region, in relation to a series of themes and topics derived from *"The experience of the cancer journey for patients and their carers in the Grampians Region"*. It is an account of a comprehensive investigation, employing a range of qualitative methods, analysing the experiences, as they were perceived, of over 250 people touched by cancer. Patients, family members, carers and health care staff attended a series of forums, focus groups, community activities or personal interviews, sharing their experiences about what worked well and what not so well, and personal recommendations regarding the development and improvement of cancer services in the region. They also told of the people and service aspects that they valued, and the uplifting experiences, such as the sense of community they encountered along the way.

The survey study was undertaken to consolidate the findings of the initial investigation. Qualitative methods provide excellent means of deriving tentative hypotheses about a topic; researchers reason inductively about what might be 'going on' for people who have participated in the interviews. Their strengths are related to the openness of the research agenda, ensuring that there is not premature closure on the issues, as investigators generalise from previous studies in other communities, from their theoretical analyses, and from clinical insight. Inviting consumers to voice their views ensures that hidden, neglected, or avoided aspects are aired and novel perspectives are given due consideration. The themes suggest further areas for consideration and deeper exploration, which in turn can be reported back to the key stakeholders, as a catalyst for further change and evaluation, in a process known as action research.

The potential drawbacks of qualitative approaches include the possibility of overstating singular views. One person might express a fascinating or potentially highly informative view. For example, she might praise the support received from a particular service or condemn aspects of the treatment received, pointing to its shortcomings. The question then becomes just how widespread that particular perspective is shared by others. Conclusions based on singular sources of evidence form foundations of unknown reliability and thus have to be considered cautiously until they are demonstrated to have wider applicability to or consensus among other consumers.

This report was undertaken to build greater confidence in the preliminary findings from the initial report. By feeding back a summary of the main themes

to a broader representation of the consumer groups, the extent and depth of their agreement or disagreement with these themes was gauged. The findings provide a snapshot of their attitudes and opinions, confirming many of the conclusions and clarifying others. They provide a firmer base for GICS to improve patient outcomes through ongoing planning for development and improvement of services in the region.

While the findings reported here increase the reliability of the main report's conclusions, it has to be recognised that this study too has limitations. First and foremost, the sampling techniques employed rely on convenience methods. The participants were all volunteers who responded to invitations posted on GICS website, and published in newsletters, etc. These methods of publicising a study ensure that willing and motivated individuals will respond; those who are too busy, stressed or unwell to take part are less well represented. Thus the results are not as reliable as those that fully random sampling techniques might provide and the validity of generalisations has to be treated with some caution. Nevertheless they do represent a step forward and improve our confidence in the value of the initial conclusions.

The limitations of the original study also apply here. A number of hard-to-reach consumer groups are not well represented in the initial study. For example, very young consumers are under-represented, as are groups from CALD backgrounds. So too, Aboriginal and Torres Strait Islander peoples are not included among the community representatives that were part of the original study. As these groups are likely to have unique perspectives on the extent and quality of cancer services that they receive, it remains an important goal for future studies to capture their unique experiences and improve our understanding of their perspectives.

A further comment is warranted concerning the separation of the views of public and private patients. While it was initially anticipated that their experiences would be different and that it would be important to capture any distinctions, in practice it proved far more difficult to differentiate these perspectives than we had anticipated as there is not a clear boundary between the two systems. People often crossed between the two with considerable ease and frequency. Often they were unaware of having made the crossing, as the two were not as clearly differentiated in their eyes as they might be in the minds of professional health carers. It remains for future work in this area to address the question with greater focus and attention than in our initial investigation.

These limitations are noted not to devalue the project's worth. They simply serve to highlight the central message of action research: it is not an end in itself; each step represents a little progress, illuminating the path we need to take, and providing the raw materials for sustaining that journey. Along the way, new questions are raised and become the raw material for further work, with the ultimate aim of improving the quality of cancer services provided in the Grampians region.

## Methodology

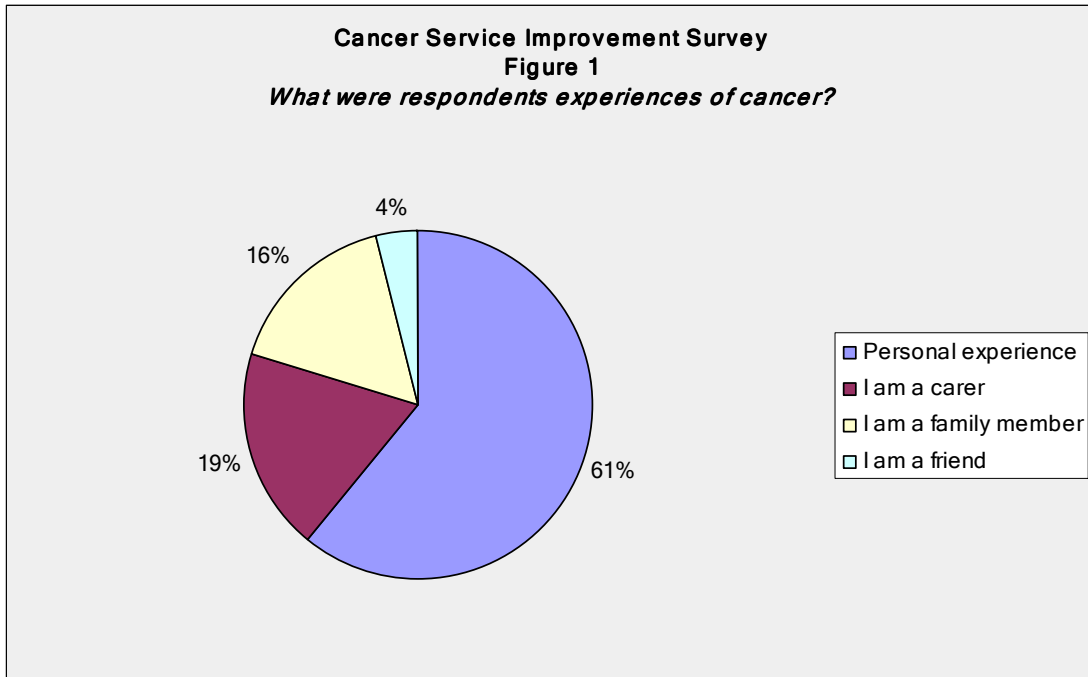
Following the extensive community consultation process, involving over 250 participants, the major themes identified in the interviews, focus groups, and community forum settings were collated. Subsequently, a survey was undertaken of the opinions and attitudes of cancer services consumers in the Grampians region using these themes to create items for a short questionnaire. A set of 14 items were prepared, encapsulating broad issues raised by the contributors. Each item consisted of a single affirmative statement, accompanied by a four-point Likert-type response scale, ranging from *Strongly Agree* to *Strongly Disagree*. There was also a *Don't Know/Not applicable* option. Participants were invited to indicate which of the response options best fitted their opinions in relation to each specific item.

The short survey was distributed in two forms. The first was through the internet. Links to Monkey Survey web-pages were posted on the GICS internet site and visitors were invited to participate in the survey by clicking on the links and filling out the questionnaire. The second method involved sending a traditional hardcopy, pencil-and-paper version of the questionnaire to individuals and groups on the GICS mail lists and inviting them to participate by returning the questionnaire in a self-addressed, post-paid envelope that was provided. Both methods involved snowballing techniques to recruit participants, and thus the sample is one of convenience rather than being a more representative stratified random sample. The degree to which the sample is biased by extraneous factors is unknown, and this point should be borne in mind when reading the report. Both versions of the survey were approved for use by the Human Research Ethics Committee of the University of Ballarat before they were distributed to interested parties.

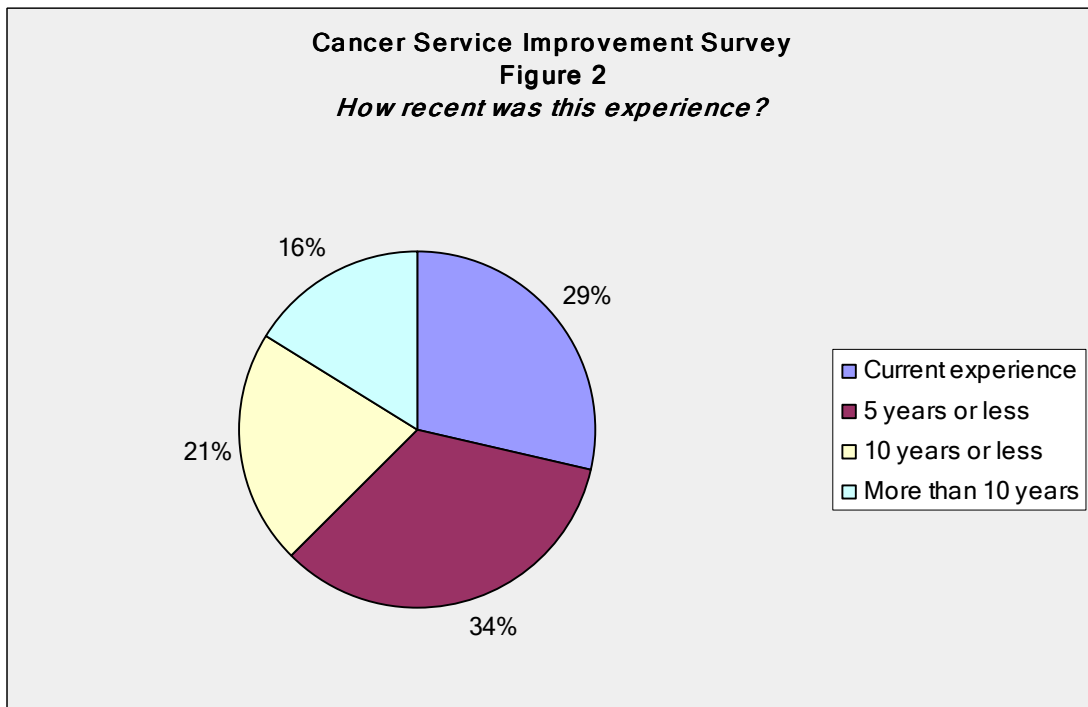
Altogether, there were 81 surveys in usable form that were returned to the investigators. Of these, 22 were returned online and 59 were returned by post. Participants were asked to provide their postcodes, as a way of checking the geographical distribution of responses. Two people did not provide this information and the remaining 79 responses indicated that the participants were widely distributed throughout the Grampians region, with the majority from urban areas within the region, including cities and towns. Of these, 28 lived in the Ballarat urban area. No other aspects of demographic details were collected in order to keep the survey length to an absolute minimum.

### What were Respondents' experiences with cancer?

Of the 81 respondents, 48 (81%) had or were still having a personal experience of cancer; 15 (19%) indicated that they were carers, and 13 (16%) said they were family members. Another 3 (4%) were friends of someone directly experiencing cancer. These proportions are illustrated in figure 1



Participants differed in the length of time they had been experiencing cancer, either directly or indirectly. For 23 (29%) individuals, the experience was current. For 27 (34%) the experience was less than five years, and for another 17 (21%) it was less than ten years. Over ten years was reported by 13 (16%) participants. The proportions are summarised in Figure 2.



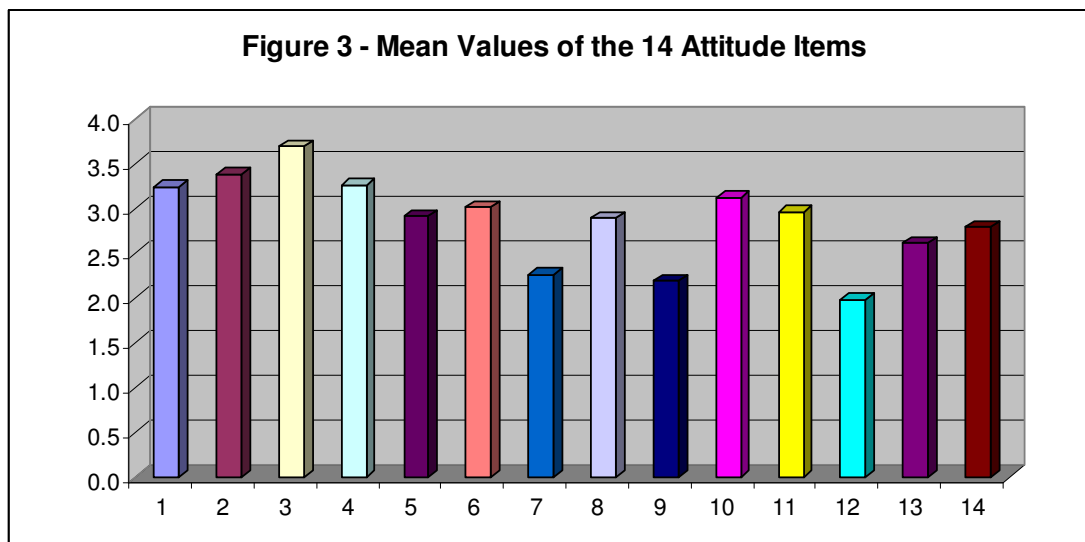
## Attitudes to Services in the Grampians region

Initially, the responses to all 14 items were entered into spreadsheets for statistical analyses. Means and standard deviations for the whole sample on all 14 items were calculated and are presented in Table 1 and Figure 3.

It can be seen that on the whole, perceptions of cancer services in the Grampians region were favourable. People tended to agree with the positive items. For example, item 1, *I valued the services provided locally in the region*, had a mean value of 3.2, indicating that on average the participants agreed with this statement. On the other hand, they tended to disagree with the negatively worded items, such as *I spent too much time waiting in the cancer care treatment system*. Here the mean value was 2.3, indicating that on average the participants disagreed with this statement. Some items, which it had been anticipated would raise criticism, on average, did not elicit agreement. An example was *Doctors' and therapy appointments are scheduled inconveniently*, which had a mean value of 2.2. However, mean values for the whole sample often disguised large within-group variation. Therefore analyses providing a breakdown of each item are provided later.

**Table 1: Means and Standard Deviations by Item**

Item	Mean	SD
I valued the services provided locally in the region	3.2	0.9
Local staff make a special contribution to the standard of care given	3.4	0.7
I would like to see all treatment for cancer given locally	3.7	0.6
Local services have improved a lot in the last decade	3.3	1.0
Delays in cancer diagnosis and treatment occur in the Grampians region	2.9	0.9
I was satisfied with communication between myself and my doctors	3.0	0.9
I spent too much time waiting in the cancer care treatment system	2.3	0.8
Information about treatment from my medical team satisfied my needs	2.9	0.8
Doctors' and therapy appointments are scheduled inconveniently	2.2	0.9
Patients' wishes should be given more consideration in decision making	3.1	0.8
I should have seen a Social Worker much earlier in my cancer treatment	3.0	0.9
Transport options for treatment in the Grampians region are adequate	2.0	0.9
I was left to find out too many things by myself	2.6	1.0
Medical staff need more training on working with clients	2.8	0.9



## Did the method of participation impact on the results?

As a preliminary check, it was important to compare the two forms of participation, on-line and pencil-and-paper, to establish if any differences were evident. In order to compare responses, the sample was split into two subgroups, depending on the method of participation. Means and standard deviations on each of the 14 items were then calculated for the two subgroups; the results are presented in Table 2.

One-way Analyses of Variance (ANOVAs) were performed, comparing the mean scores of the two subgroups. The F statistics and probabilities for each comparison are also listed in Table 2. It can be seen that while the first item, *I valued the services provided locally in the region*, approached significance ( $p = .088$ ), in fact none of the items reached the threshold for significance. This single item can be attributed to random variation and it can be inferred that the null hypothesis, there are no differences between the two methods of responding, should not be rejected. In essence, it appears that the participants are drawn from the same population and the rest of the statistical comparisons can be conducted on the whole sample with the two subgroups collapsed into one.

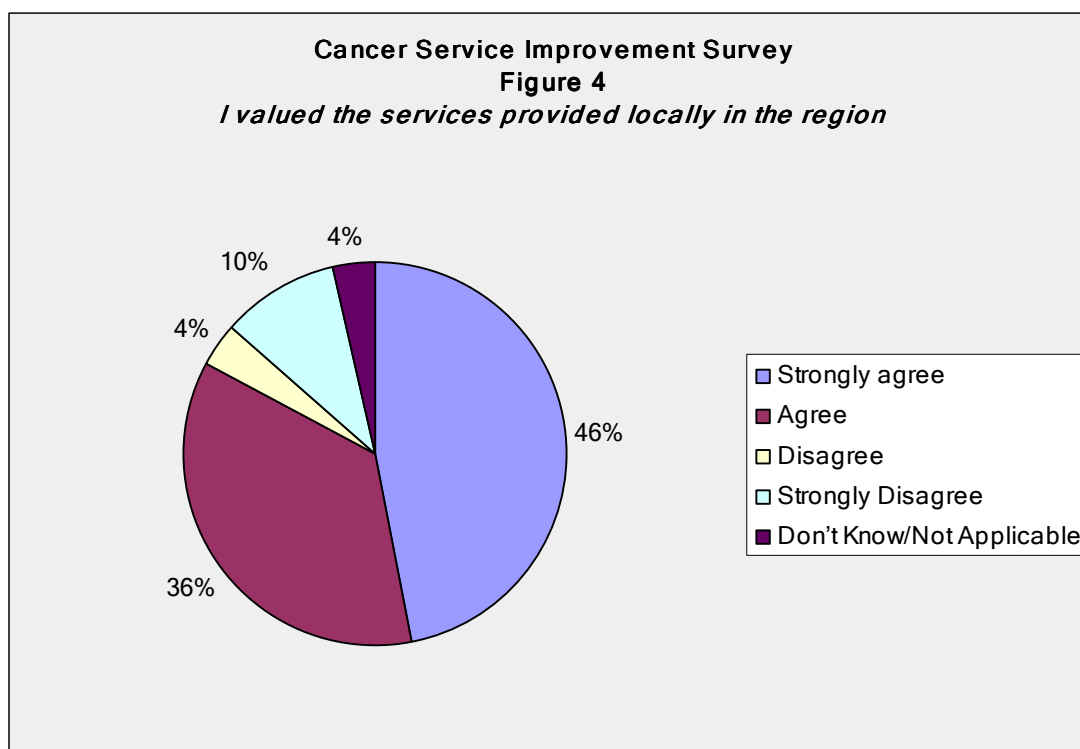
	<b>Item and source</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>	<b>F</b>	<b>P</b>
1	Website Response	21	3.7	0.5		
	Hard copy Response	56	3.1	1.0	2.99	0.088
2	Website Response	21	3.4	0.5		
	Hard copy Response	51	3.4	0.8	0.17	0.68
3	Website Response	22	3.5	0.5		
	Hard copy Response	57	3.7	0.6	1.83	0.18
4	Website Response	17	3.4	0.6		
	Hard copy Response	46	3.1	0.8	2.12	0.151
5	Website Response	17	2.9	0.7		
	Hard copy Response	48	2.9	1.0	0.03	0.862
6	Website Response	17	3.0	0.9		
	Hard copy Response	54	3.0	0.9	0.0	1.0
7	Website Response	17	2.2	1.0		
	Hard copy Response	48	2.3	0.8	0.02	0.884
8	Website Response	18	2.9	0.9		

	Hard copy Response	54	2.9	0.8	0.01	0.933
9	Website Response	19	2.2	0.8		
	Hard copy Response	48	2.2	1.0	0.01	0.926
10	Website Response	17	3.1	0.7		
	Hard copy Response	55	3.1	0.8	0.15	0.70
11	Website Response	17	3.1	0.7		
	Hard copy Response	41	3.0	0.9	0.18	0.67
12	Website Response	19	2.2	0.7		
	Hard copy Response	40	1.9	0.9	1.99	0.164
13	Website Response	19	2.6	1.0		
	Hard copy Response	55	2.6	1.0	0.02	0.884
14	Website Response	19	2.9	1.0		
	Hard copy Response	52	2.7	0.9	0.74	0.394

## Analyses by item

## Attitudes towards the services provided locally in the region.

1. <i>I valued the services provided locally in the region</i>		
Answer Options	Response Percent	Response Count
Strongly agree	46.9%	38
Agree	35.8%	29
Disagree	3.7%	3
Strongly Disagree	9.9%	8
Don't Know/Not Applicable	3.7%	3
	<b>100.0%</b>	<b>81</b>
	<i>Mean</i>	3.2
	<i>SD</i>	0.9



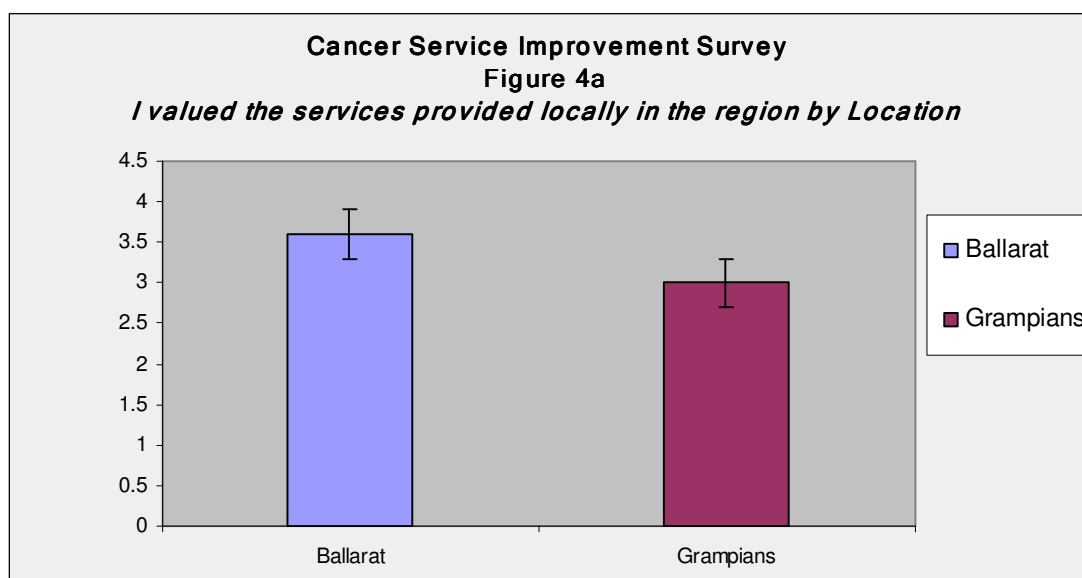
Almost half (46%) *strongly agreed* with this statement. A further 36% *agreed*, making a total of 86% who expressed favourable attitudes to the services provided locally. On the other hand, 4% *disagreed*, and 10% *strongly disagreed*, indicating that a sizeable minority did not share this positive attitude and did not value the services provided locally in the region.

### Did the responses to this item differ by location of the respondent?

In order to establish if the opinions of respondents from the Ballarat region and those from other areas of the Grampians differed, two subgroups were formed, based on the post codes they provided. The responses to each item were broken down by this category. These figures are presented in table 1a below. Mean ratings were calculated, and a one-way Analysis of Variance was performed. The results were significant,  $F(1, 76) = 6.04, p = .016$ . Both subgroups expressed agreement with the view that they valued the services provided locally in the region. However, on average, the participants from the Ballarat district provided higher ratings than did those from the broader Grampians region. The means are compared in the following figure (4a).

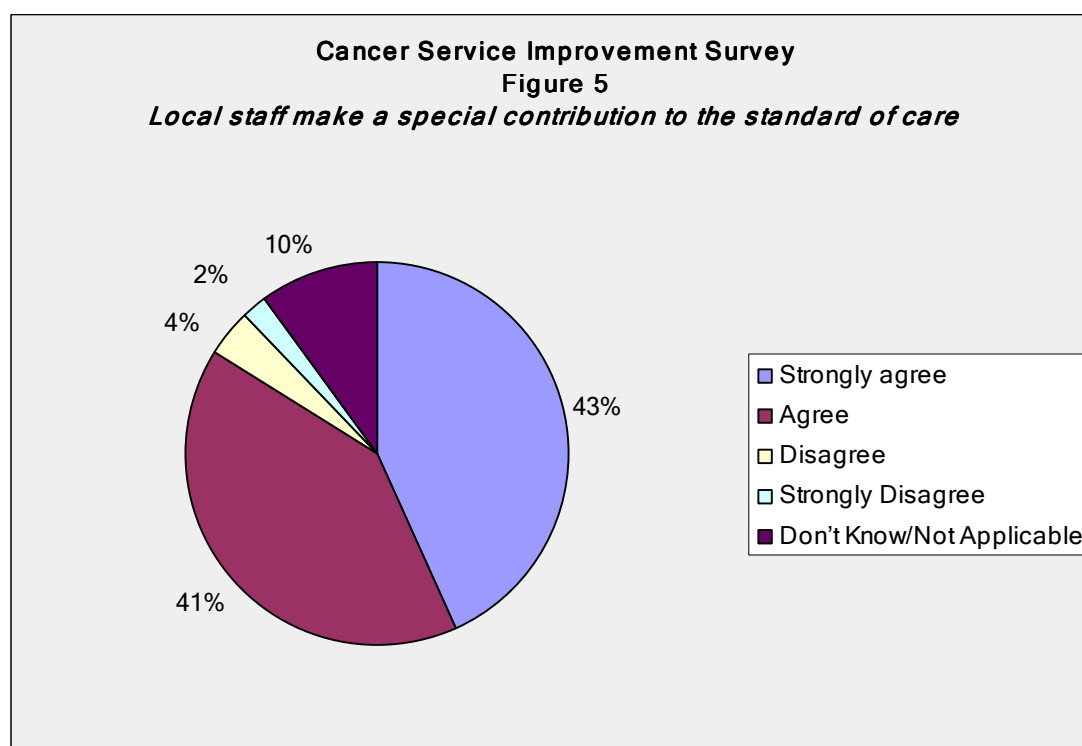
It should be noted that this was the only comparison by location that produced significant differences. Each variable was analysed in the same manner but there were no other effects to be reported.

<b>1a. I valued the services provided locally in the region by Location</b>		
<b>Answer Options</b>	<b>Ballarat</b>	<b>Grampians</b>
Strongly agree	63.0%	41.2%
Agree	33.7%	39.2%
Disagree	3.7%	3.9%
Strongly Disagree	0%	15.7%
	<b>100.0%</b>	<b>100%</b>
	<i>Mean 3.6</i>	<i>Mean 3.0</i>
	<i>SD 0.6</i>	<i>SD 1.0</i>



## Attitudes towards the local staff in the region

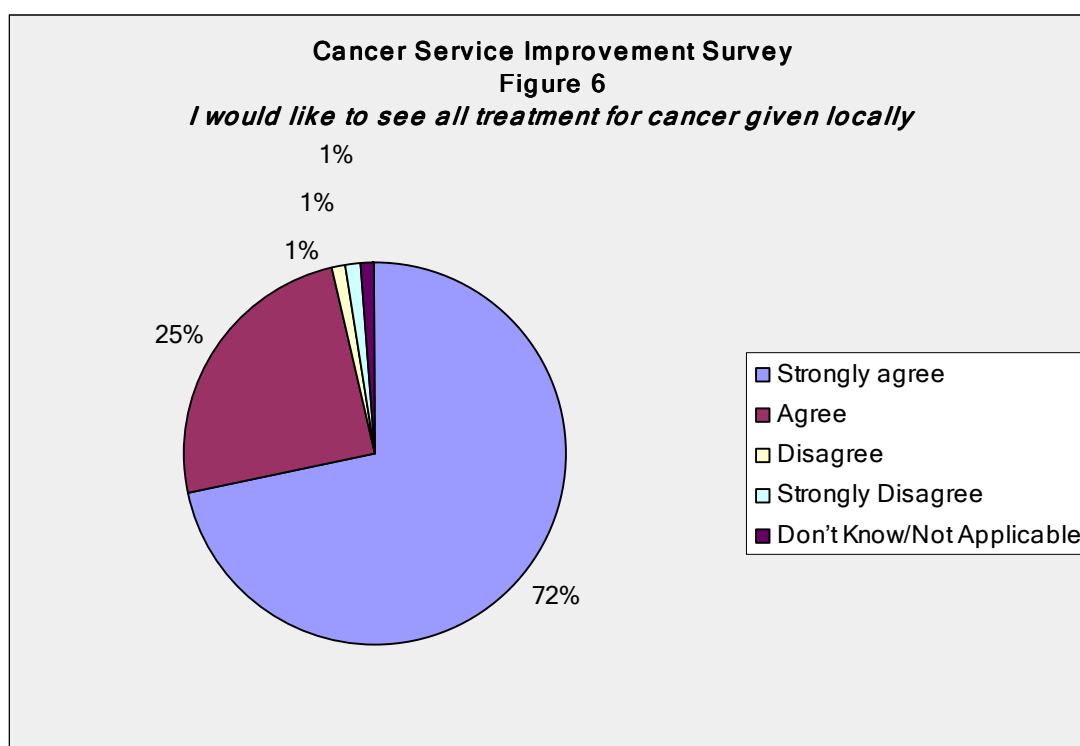
<b>2. Local staff make a special contribution to the standard of care given</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Strongly agree	43.2%	35
Agree	40.7%	33
Disagree	3.7%	3
Strongly Disagree	2.5%	2
Don't Know/Not Applicable	9.9%	8
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.4
	<i>SD</i>	0.7



Support for local staff was favourable; 43% indicated that they *strongly agree* with that statement and a further 41% indicated that they *agreed*. The number expressing negative attitudes was very low, at 6% or 5 individuals. These findings are consistent with the conclusions drawn in the main Report, where positive comments about the efforts of local staff going beyond the call of duty were made frequently and spontaneously. It is also worth noting that the final category attracted a number of *not applicable* responses because some people had not received treatment directly, e.g., friends and family members.

## Preferences for cancer treatments to be given locally

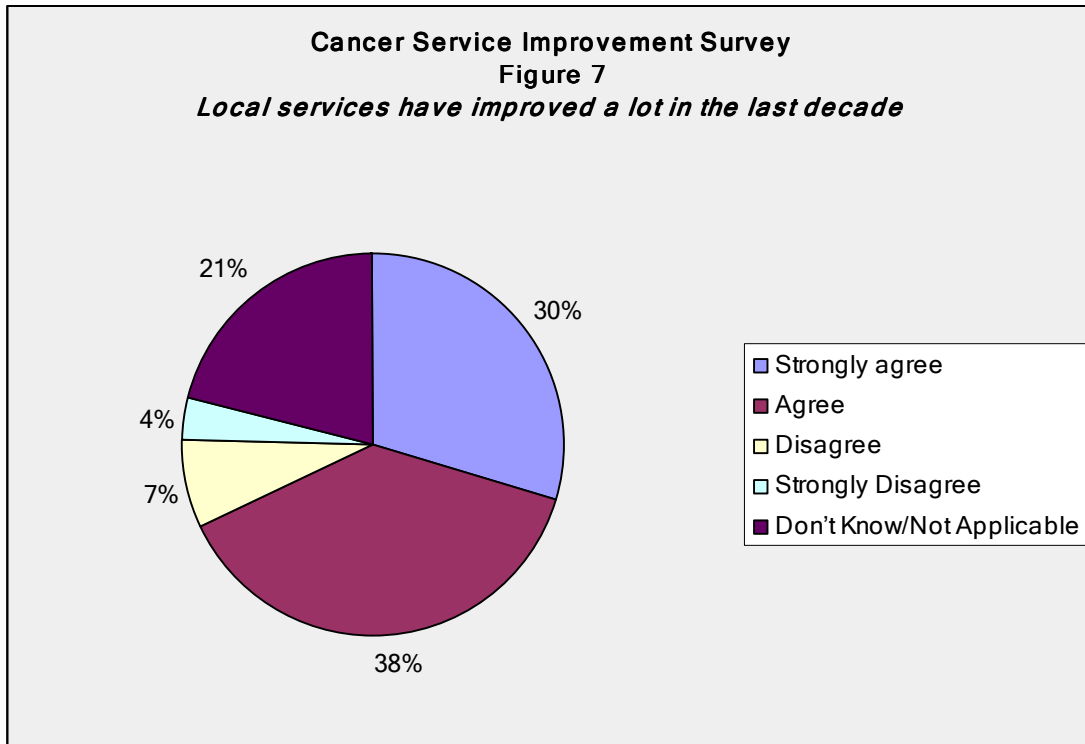
<b>3. I would like to see all treatment for cancer given locally</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Strongly agree	71.6%	58
Agree	24.7%	20
Disagree	1.2%	1
Strongly Disagree	1.2%	1
Don't Know/Not Applicable	1.2%	1
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.7
	<i>SD</i>	0.6



Participants indicated overwhelming preferences for all cancer treatment to be given locally. Over 70% stated they *strongly agreed* and a further 25% indicated that they *agreed* with this statement. Again, these preferences were consistent with conclusions drawn from the community engagement study, with many participants expressing in focus groups and community Forums a strong preference for this development, whilst also recognising that government funding is stretched already and it would be unrealistic to expect comprehensive services would be available in every rural town in the region.

Perceptions of improvements to services

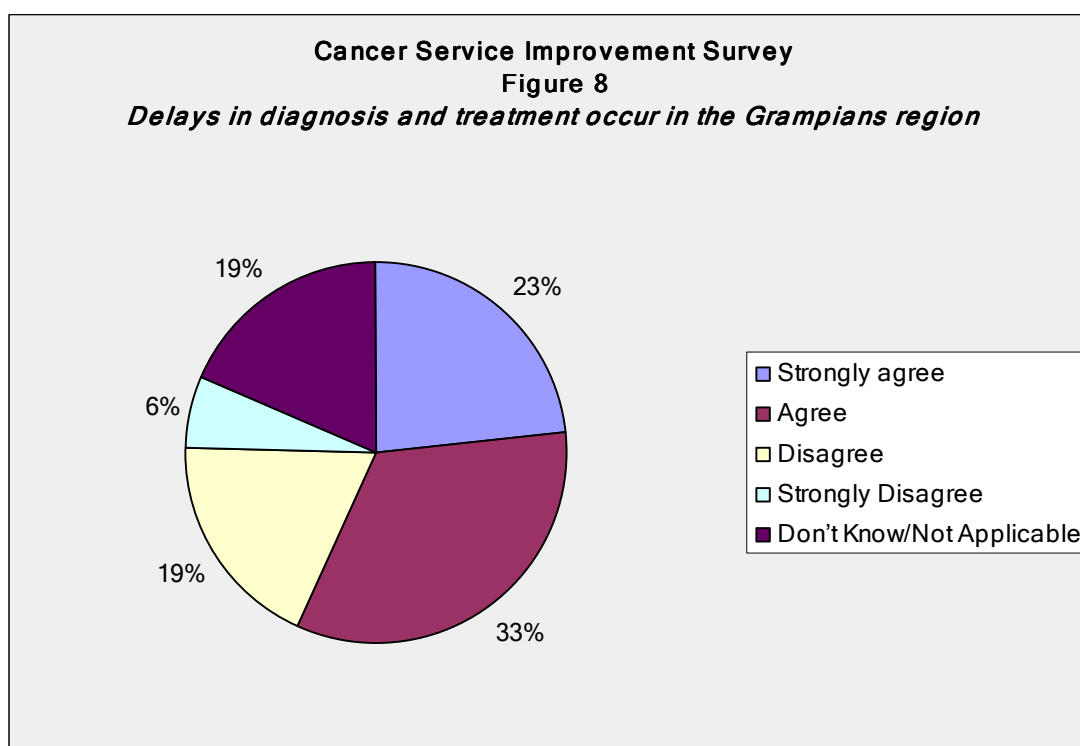
4. Local services have improved a lot in the last decade		
Answer Options	Response Percent	Response Count
Strongly agree	29.6%	24
Agree	38.3%	31
Disagree	7.4%	6
Strongly Disagree	3.7%	3
Don't Know/Not Applicable	21.0%	17
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.3
	<i>SD</i>	1.0



While a majority of participant *agreed* (38%) or *strongly agreed* (30%) with this statement, there was a large number of respondents who stated they did not know or that the item was not applicable to them, because they did not have the historical perspective to be able to judge accurately. Many had been affected by cancer within the last five years or were currently so affected, which explains this figure. Over 10% or 9 individuals *did not agree* with this view. These attitudes have to be seen in light of preference for more services to be provided locally, as the two responses often accompanied each other.

## Timeliness of services

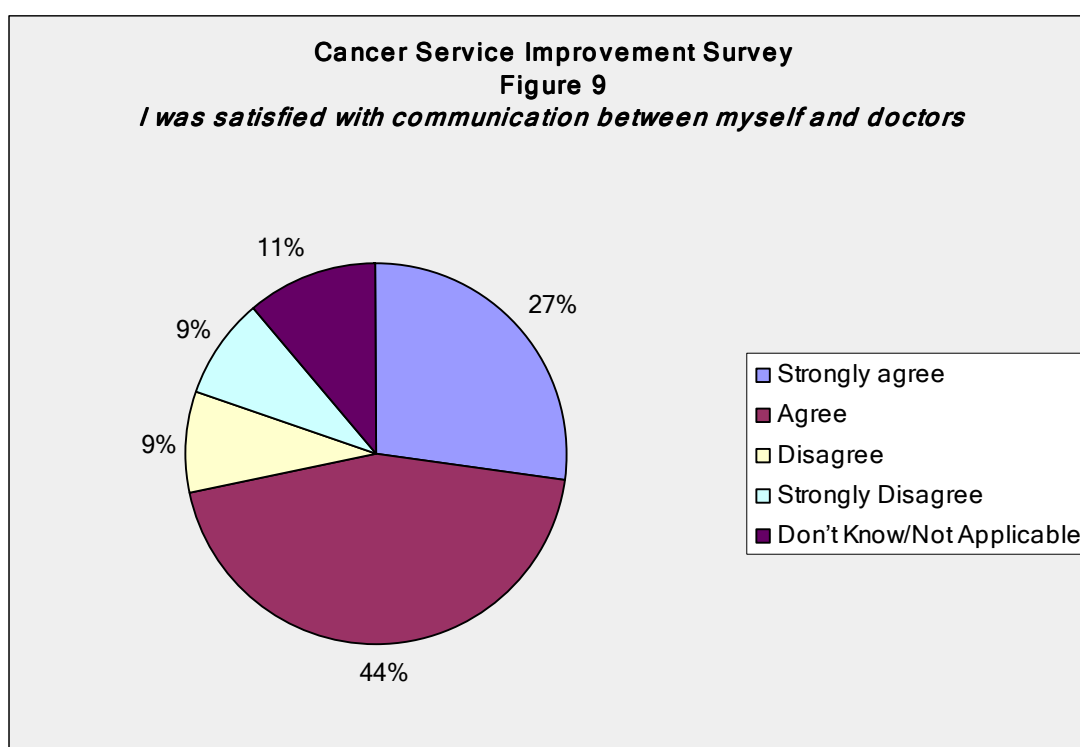
<b>5. Delays in cancer diagnosis and treatment occur in the Grampians region</b>		
Answer Options	Response Percent	Response Count
Strongly agree	23.5%	19
Agree	33.3%	27
Disagree	18.5%	15
Strongly Disagree	6.2%	5
Don't Know/Not Applicable	18.5%	15
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	2.9
	<i>SD</i>	0.9



A little over half the participants concurred with this statement; 23% *strongly agreed* and 33% *agreed* that delays in cancer diagnosis and treatment had occurred in the Grampians region. While a quarter of the sample did not share this perception, with 19% indicating that they disagreed and 6% stating they strongly disagreed, a further 19% said that they did not know or the item was not applicable to them. Thus the proportion of those able to answer the item who concurred with the statement is significantly higher than the summary data indicate.

## Patient-Doctor communication

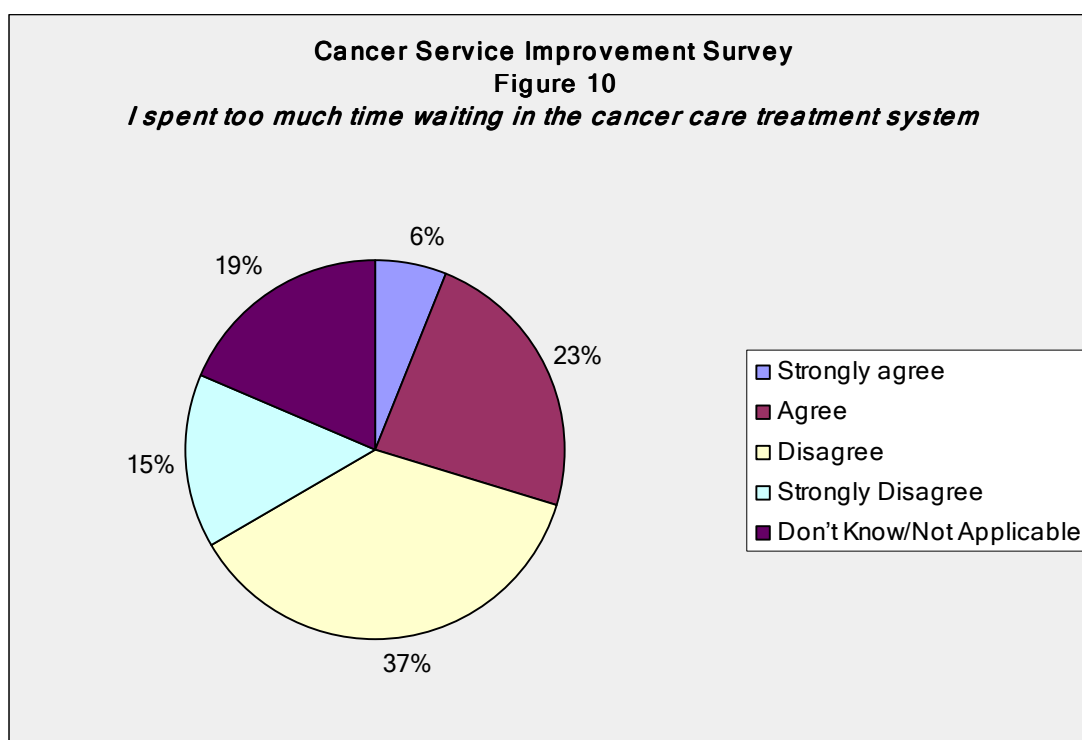
9. I was satisfied with communication between myself and my doctors		
Answer Options	Response Percent	Response Count
Strongly agree	27.2%	22
Agree	44.4%	36
Disagree	8.6%	7
Strongly Disagree	8.6%	7
Don't Know/Not Applicable	11.1%	9
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.0
	<i>SD</i>	0.9



There was strong support for this statement, with 27% stating they *strongly agreed* and a further 44% stating they *agreed* with it. A total of 18% *did not agree* with the view, however, and a further 11% stated they *did not know* or that the item was *not applicable* to them.

### Attitudes towards waiting in the cancer care treatment system

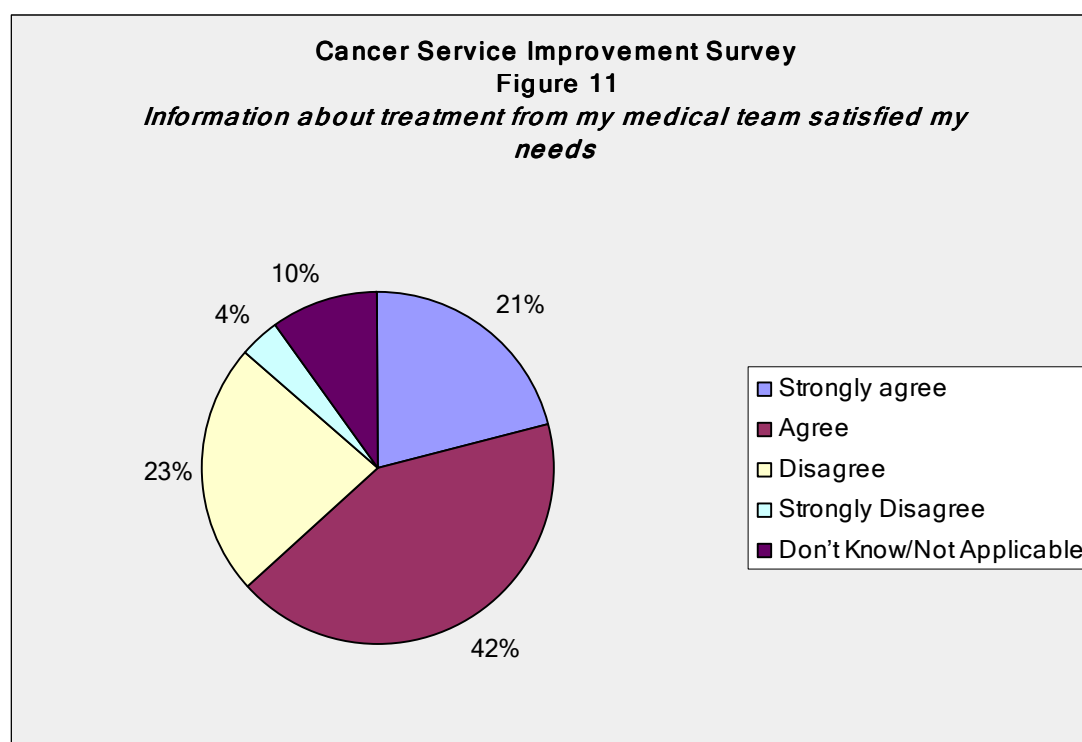
10. I spent too much time waiting in the cancer care treatment system		
Answer Options	Response Percent	Response Count
Strongly agree	6.2%	5
Agree	23.5%	19
Disagree	37.0%	30
Strongly Disagree	14.8%	12
Don't Know/Not Applicable	18.5%	15
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	2.3
	<i>SD</i>	0.8



Over one quarter of the participants *agreed* or *strongly agreed* that they spent too much time waiting in the cancer care treatment system; 23% *agreed* while a further 6% *strongly agreed* that they spent too much time waiting. The majority did not agree, however, with 37% *disagreeing* and 15% *strongly disagreeing*. Nearly 1 in 5 people (19%) *did not know* or thought the item was *not applicable* to them.

## Attitudes towards information provided

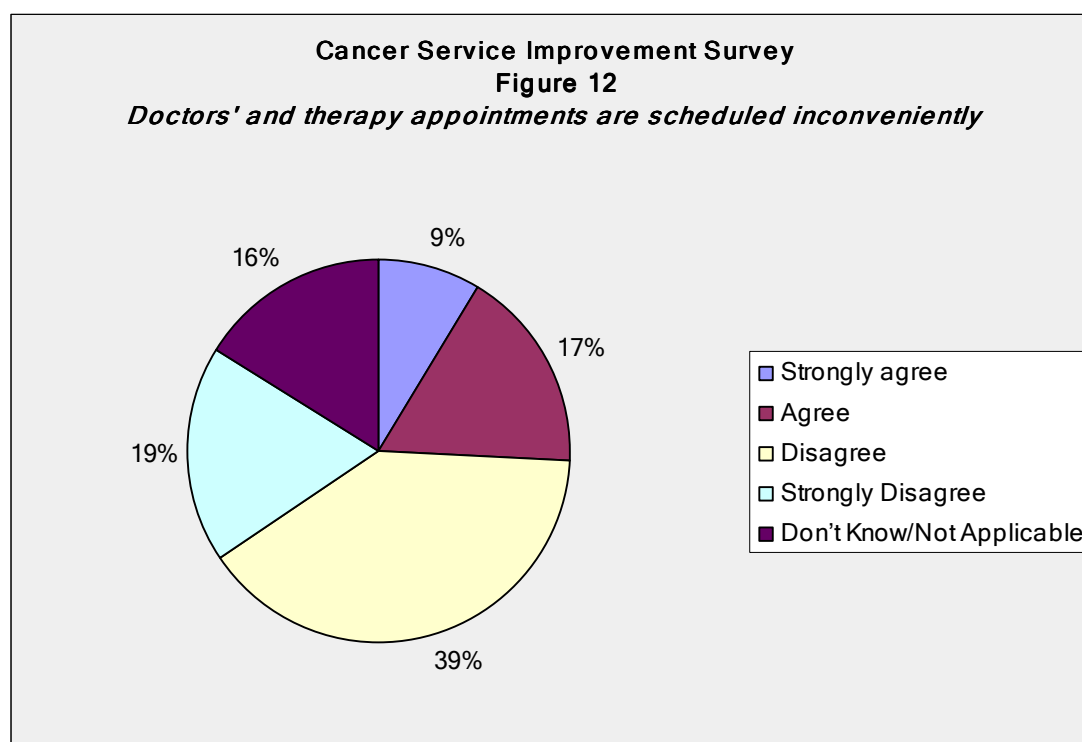
<b>11. Information about treatment from my medical team satisfied my needs</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Strongly agree	21.0%	17
Agree	42.0%	34
Disagree	23.5%	19
Strongly Disagree	3.7%	3
Don't Know/Not Applicable	9.9%	8
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	2.9
	<i>SD</i>	0.8



Agreement with the statement *Information about treatment from my medical team satisfied my needs* totalled 63%; 21% *strongly agreed* and 42% *agreed*. A quarter of the sample demurred, with 23% *disagreeing* and 4% *strongly disagreeing*.

## Perceptions regarding scheduling of appointments

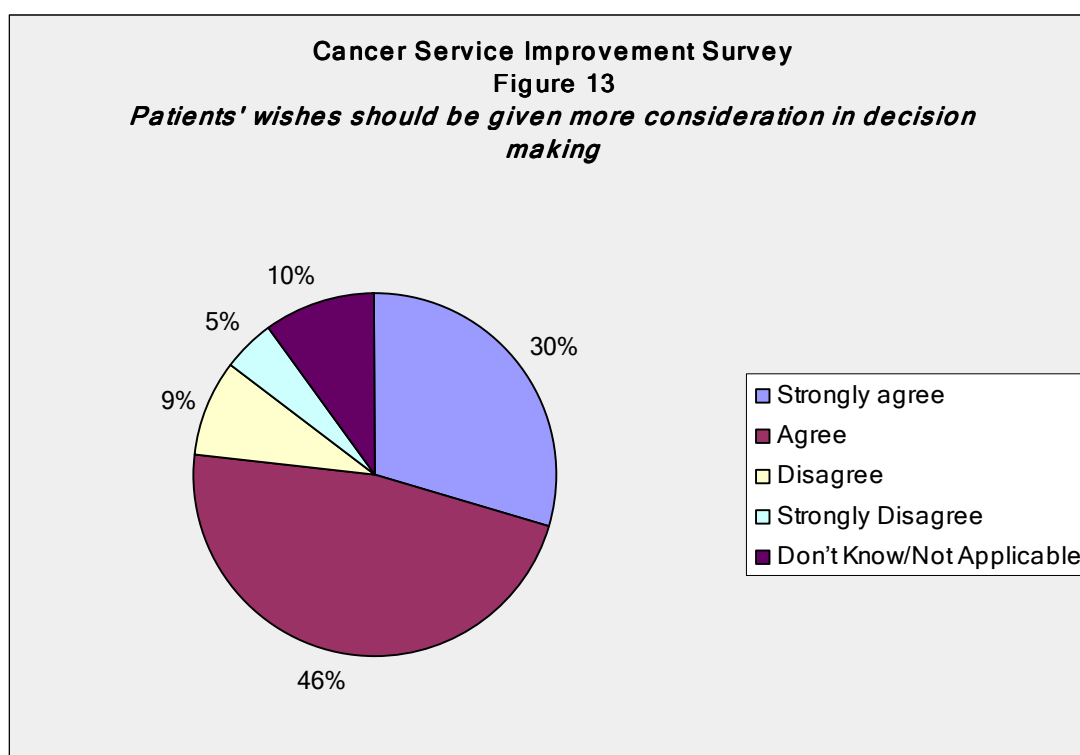
12. Doctors' and therapy appointments are scheduled inconveniently		
Answer Options	Response Percent	Response Count
Strongly agree	8.6%	7
Agree	17.3%	14
Disagree	39.5%	32
Strongly Disagree	18.5%	15
Don't Know/Not Applicable	16.0%	13
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	2.2
	<i>SD</i>	0.9



A total of 26% *agreed* with this statement. Of these, 9% stated the *strongly agreed* and 17% *agreed*. Of the 58% who did not agree, 39% *disagreed* and 19% *strongly disagreed*. *Don't know* or *not applicable* was endorsed by 16%. On first examination, these data appear to contradict the conclusions reached in the community engagement Report. However, over one quarter of the sample did agree, which is a sizeable minority experiencing these difficulties, so their needs cannot be ignored.

## Preferences regarding participatory decision making

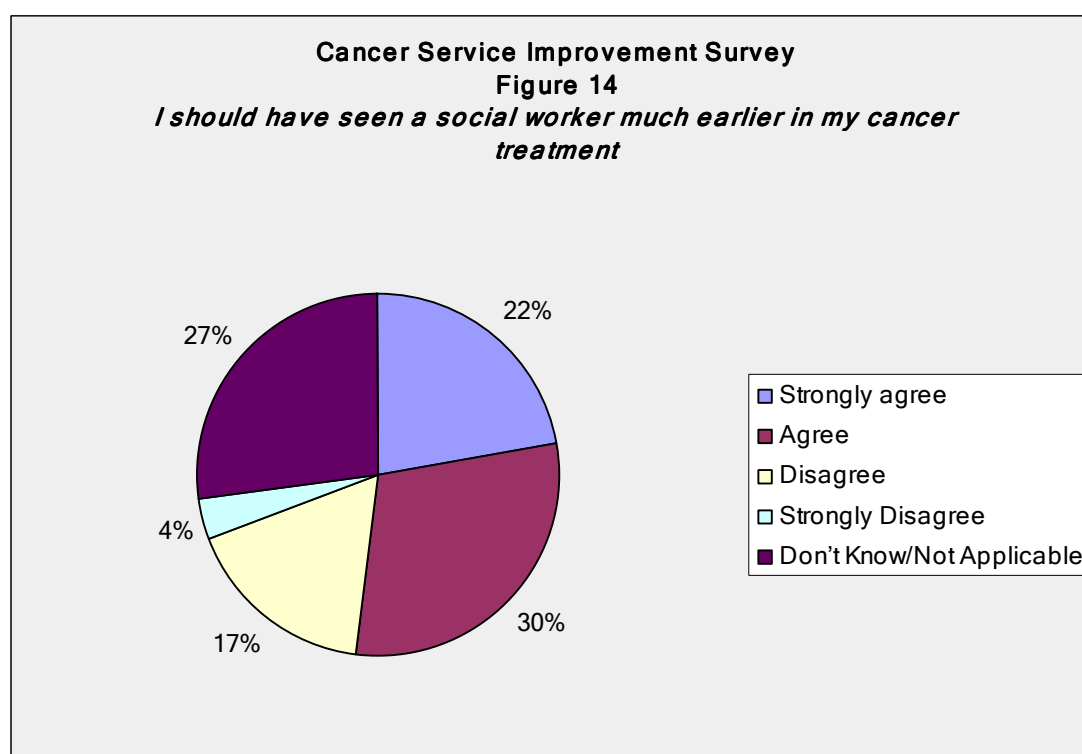
<b>13. Patients' wishes should be given more consideration in decision making</b>		
Answer Options	Response Percent	Response Count
Strongly agree	29.6%	24
Agree	46.9%	38
Disagree	8.6%	7
Strongly Disagree	4.9%	4
Don't Know/Not Applicable	9.9%	8
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.1
	<i>SD</i>	0.8



Participants' preferences regarding participatory decision making were made clear by their responses to this item. Over 75% *agreed* (46%) or *strongly agreed* (30%) with the statement that *patients' wishes should be given more consideration in decision making*. Interestingly 14% *did not agree* with this view. The reasons for these views were not investigated so it is not possible to offer any explanations for these preferences. Further work on this aspect is recommended.

## Views regarding early referral to social workers

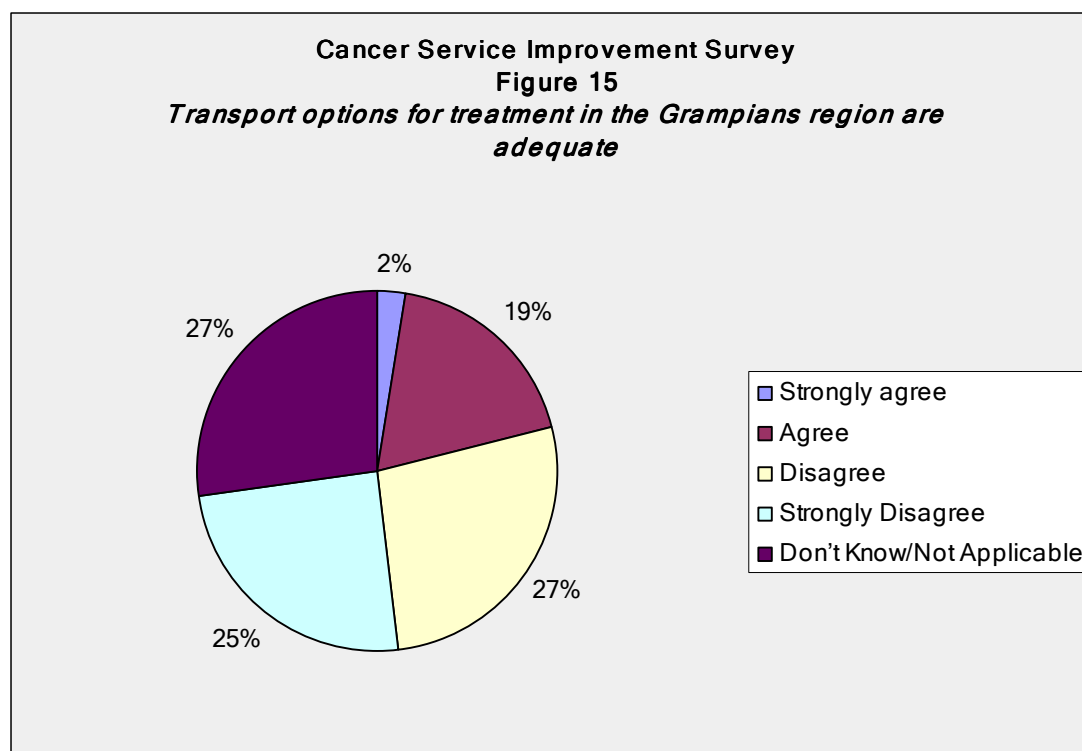
14. I should have seen a Social Worker much earlier in my cancer treatment		
Answer Options	Response Percent	Response Count
Strongly agree	22.2%	18
Agree	29.6%	24
Disagree	17.3%	14
Strongly Disagree	3.7%	3
Don't Know/Not Applicable	27.2%	22
	<b>100%</b>	<b>81</b>
	<i>Mean</i>	3.0
	<i>SD</i>	0.9



Early referral to social workers was endorsed by just over half the sample. Over one fifth (22%) indicated that they *strongly agreed* with this statement and a further 30% *agreed*. While 17% *disagreed*, and 4% *strongly disagreed*, which is a sizeable minority, the balance of views in favour of early referral was quite marked. In relation to the comments recorded in the final Report, it is clear that many people valued the contribution of social workers to their supportive care and only appreciated its worth once they were receiving it and had overcome their own initial prejudices towards accepting the psycho-social support that this group of health professionals is able to offer those affected by cancer.

## Views regarding transport options in the Grampians region

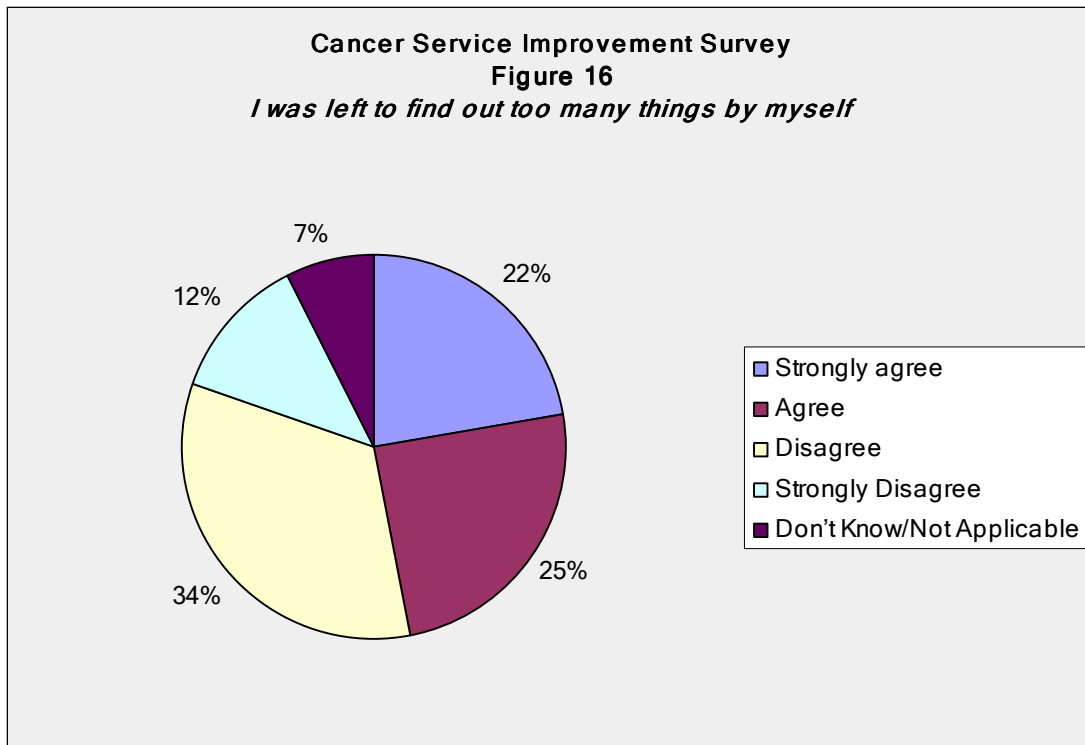
15. Transport options for treatment in the Grampians region are adequate		
Answer Options	Response Percent	Response Count
Strongly agree	2.5%	2
Agree	18.5%	15
Disagree	27.2%	22
Strongly Disagree	24.7%	20
Don't Know/Not Applicable	27.2%	22
<b>answered question</b>		<b>81</b>
		<b>2.0</b>
		<b>0.9</b>



More than half the sample disagreed with this point of view; 27% *disagreed* and 25% *strongly disagreed*. With a further quarter of the participants stating that they *did not know* or believed the item was *not applicable* to them, the figures are even starker than at first encounter. It is clear that many respondents would have agreed with comments made at the forums and focus groups criticising the poor transport services and their integration throughout the Grampians region.

Perceptions of information needs support

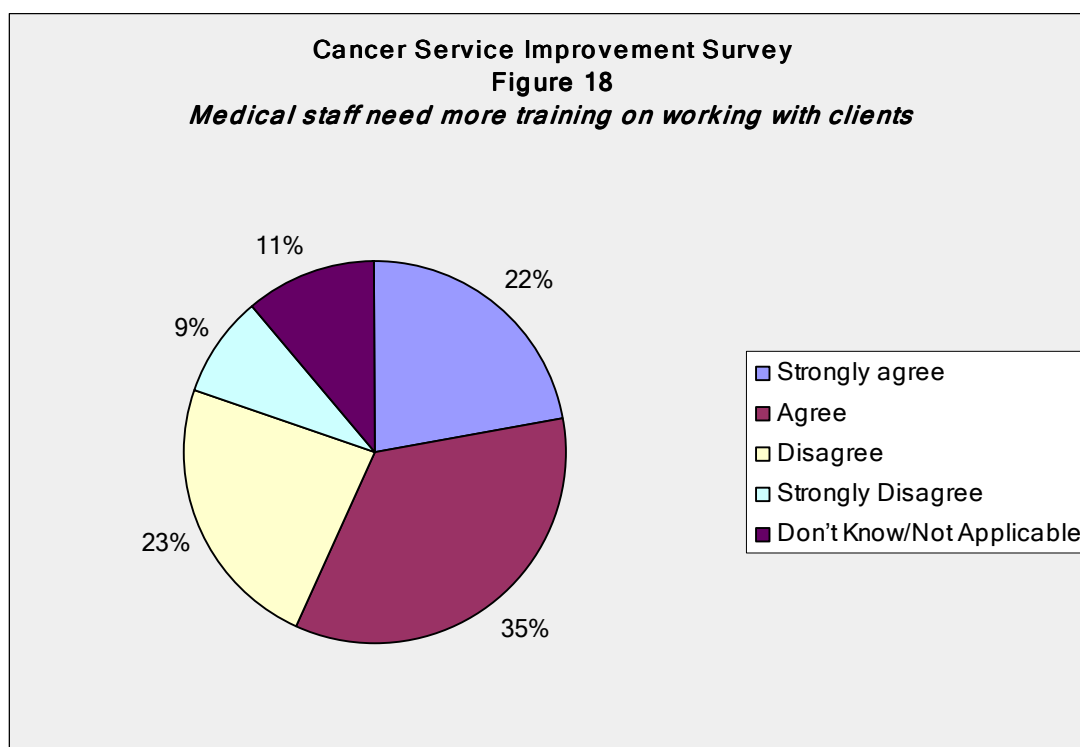
16. I was left to find out too many things by myself		
Answer Options	Response Percent	Response Count
Strongly agree	22.2%	18
Agree	24.7%	20
Disagree	33.3%	27
Strongly Disagree	12.3%	10
Don't Know/Not Applicable	7.4%	6
<b>answered question</b>		<b>81</b>
		<b>2.6</b>
		<b>1.0</b>



Responses to this item indicate that opinions regarding information needs support were sharply divided. Almost half the sample *agreed* (25%) or *strongly agreed* (22%) with the statement, while 46% *disagreed* (34%) or *strongly disagreed* (12%) with it. Only 7% stated they *did not know* or the item was *not applicable* to them. These views reflect the range of opinions expressed in the forums and focus groups. People often raised the view that if anything they were given too much information initially and that timing of information provision was as important as the volume of information provided. Not having the necessary information at the required time meant people had to seek it out for themselves, as this item suggests.

## Attitudes regarding staff training on working with clients

17. Medical staff need more training on working with clients		
Answer Options	Response Percent	Response Count
Strongly agree	22.2%	18
Agree	34.6%	28
Disagree	23.5%	19
Strongly Disagree	8.6%	7
Don't Know/Not Applicable	11.1%	9
<b>answered question</b>		<b>81</b>
<i>Mean</i>		2.8
<i>SD</i>		0.9



While the dedication and commitment of so many health care professionals was commented on explicitly in the focus groups and forums, there were also many comments made about the inadequacies of some practitioners' communication with patients, carers and families. Numerous spontaneous comments were made that some doctors need to devote greater professional development to doctor-patient communication skills. The responses to this item appear to reflect those views. Altogether, 22% *strongly agreed* and 35% *agreed* with the proposition that medical staff need more training on working with clients. While a third of the sample did not share these views, with 23% saying they *disagreed* and 9% saying *strongly disagreed*, the complexity reveals the mixed experiences of communication with their doctors that the respondents had encountered.

## Additional Qualitative Comments

Participants were invited to add any further comments they wished at the end of the survey questionnaire. A total of 36 offered no comments at all. For reasons such as not having had first hand experiences of the services, 8 participants declined to comment further.

There were 16 separate comments complimenting the quality of services they had received, praising the expertise of local health professionals, and identifying strengths of the local services. For example, one person wrote, *"My treatment by surgeon and hospital staff were kind and caring."* Another indicated, *"My treatment program at [hospital treatment centre] was very caring, well organised, and all the staff deserve top marks to their dedication to all the cancer patients I met."*

There were also 27 comments that raised complaints about services or staff. Poor communication and information provision was the target of 5 comments, such as, *"Very little information was given about the end stages of cancer. No-one told the family members how bad it would be for my dad."* Other comments reflected on the time wasted because of poor service co-ordination. One person wrote, *"1) I guess it's unavoidable, but I have waited for up to 5 hrs (that was once, other times 2 hrs) with my mother for her allocated appointment to see the doctor for 5 mins (he was so behind he had to rush through the appointment)."* The other comments all pertained to complaints about service quality, such as, *"Some nurses don't care or don't know."*

Finally, there were three comments relating to views about how services could be improved to meet growing demands and encourage client self-management, such as, *"It would be wonderful for more local hospitals to be able to service chemotherapy etc to save travelling."*

## Concluding Comments

The survey provides a helpful snapshot of consumers' views on cancer services in the Grampians region. While it was relatively simple in design and scope, the results are revealing with regard to the complex nature of the experiences of those touched by cancer in this region. The average ratings, as captured by the means for each item, are only part of the story they tell. A breakdown of the distribution of responses for each item helps reveal the inherent complexity. With some items, there is overwhelming support for the views the statements express. For example, people were almost unanimous in expressing the view that they valued the services provided locally in the region. Similarly, they were equally vocal in expressing their gratitude for the special contribution to the standard of care made by local staff. Both of these findings echo the sentiments expressed in the focus groups and local forum meetings. People are, broadly speaking, proud of and loyal to their local health care providers. These attitudes are reflected also in the views expressed around preferences for seeing all treatment for cancer provided locally. There was also satisfaction expressed in the improvements seen in the provision of local services over the last decade. Perhaps there was also a degree of pride in that accomplishment.

The theme emerging from these attitudes is the central role that 'place' plays in the experiences and identity of people in the Grampians region. As a result, health care provision represents an important reservoir of social capital, and is a key factor in ensuring the sustainability of regional and rural communities. Government policies that promote the viability and development of local services are thus pivotal in the long-term vitality of our regional areas.

The dark side of living more rurally is also reflected in responses to a number of items. A majority agreed that delays in diagnosis and treatment occur in this region. Sources of these perceived delays, if they can be substantiated with objective evidence, need to be identified and addressed, if satisfaction with cancer services in the Grampians region is to improve. Similarly, waiting appears to be endemic in the health system, as nearly two-thirds of the sample agreed with the view that they spent too much time waiting. As one respondent wryly remarked, "You don't get called a patient for nothing". Scheduling of appointments was seen as less problematic, on average, but again a sizeable minority felt they experienced inconveniences as a result of poor scheduling. This problem was exacerbated by the relatively poor transport infrastructure throughout the region. This problem is particularly difficult for people who are sick and often disabled as a result of their cancer, and who cannot drive their own vehicles as perhaps they might have done when they were well. Whilst these limitations were often seen as part of the bigger picture when it came to living in country regions, the double effect on those touched by cancer contributed significant additional burdens to their load.

Relationships with staff were the focus of several items and again the complexity of people's experiences were reflected in the range of responses as much as in the average scores. For example, a significant proportion agreed that earlier referral to social workers would have benefitted them.

These views confirmed some of the statements made at focus groups and forums, highlighting the valuable contribution that these professionals make to comprehensive health care. Identifying psycho-social support care needs earlier in the treatment process, and ensuring reliable referrals to appropriate sources of supportive care would likely benefit the overall performance of the health care system in the Grampians region, as it is well documented that patients whose needs in this domain are met show improvements on a broad range of outcome indicators, include better survival rates and lower utilisation of services.

Finally, despite the reported support for health care professionals commented on earlier, there was one area that was singled out for criticism. The interpersonal aspects of the doctor-patient relationship were, for many participants, below par. Nearly one fifth expressed dissatisfaction with the communication that they had with their doctors. Nearly three quarters agreed that patient wishes should be given more consideration in decision making, which reflects the quality of the communication process. Many felt they were left to find out too many things by themselves, reflecting further aspects of their dissatisfaction with communication. Ultimately, these attitudes were reflected in participants' views regarding medical staff's need for more training on working with clients. Over half the participants agreed that this would be a good idea. The interesting point here is that improving communication would be a relatively easy and inexpensive way to increase satisfaction with cancer services in the Grampians region. Most participants recognised that it was unrealistic to expect the government to provide linear accelerators for every hospital throughout the region. They also thought it far more reasonable, though, to be treated with the dignity and respect that a genuine patient-centred model of care would promote.