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“You don’t get called a patient for nothing”

Engaging Cancer Patients and Their Carers: The Grampians Experience



University of Ballarat
Learn to succeed



Acknowledgements

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The Executive Committee, Grampians Integrated Cancer Services

www.gics.com.au

Presentation Aims

- Explore the rationale for consumer engagement in cancer treatment services,
- outline processes for consumer engagement and identifying the needs of consumers,
- summarise main findings, documenting the themes and issues raised,
- identify key recommendations regarding consumer participation in cancer care in the Grampians region.

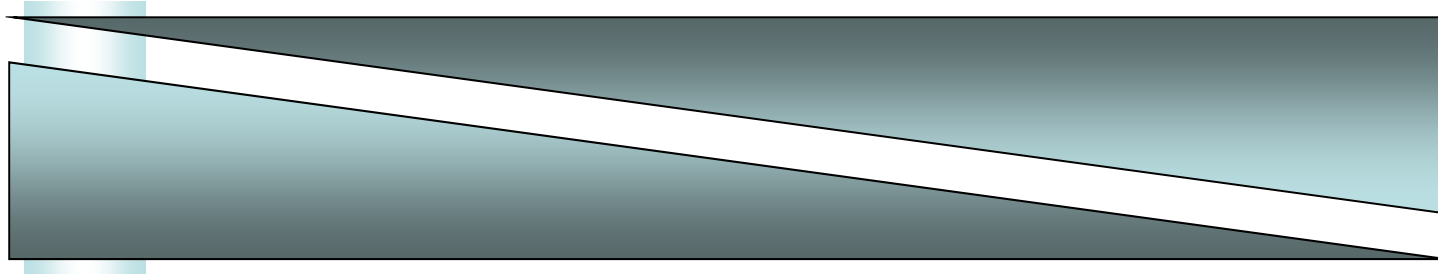
Why Consumer Engagement

“Strategies used by governments to connect with and involve people who make direct or indirect use of the health system in the development and implementation of policies, programs and services”

(Department of Health, 2009a)

Why Consumer Engagement

Assimilation of those priorities and needs to policy?



Accommodation of policy to those priorities and needs?

Consumers as key stakeholders in a complex decision-making process.

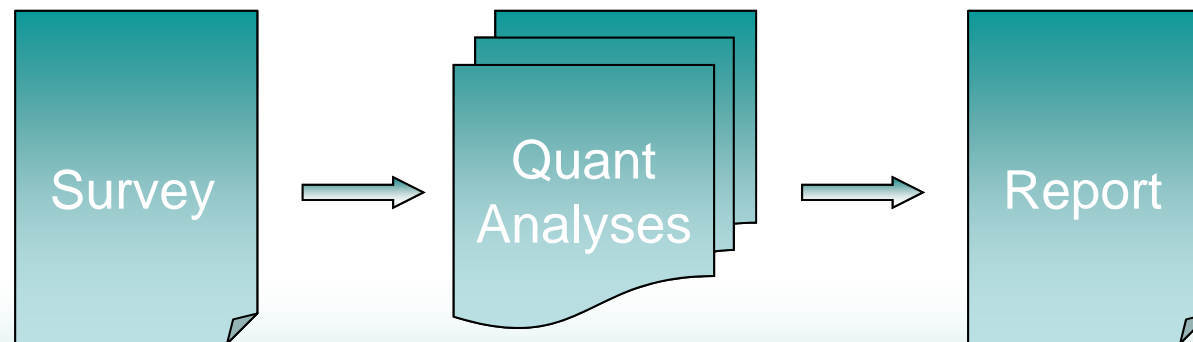


Processes Adopted

- Listening to the voices of consumers:



- Sounding the depth and extent of views:



Engaging with our Community

Help us plan for Cancer Services in your Region

- Are you a cancer survivor, patient or carer?
- Would you like to influence the way these services are provided in your region?
- We invite you to a Regional Forum to contribute your thoughts about the planning and delivery of cancer services that meet the needs of cancer patients, survivors and carers in the Grampians Region.

We will be "Engaging with our Community" through regional forums, focus groups and case studies and will be coming to a venue in the Grampians Region on the following dates:

Date	Venue	Time
11 March 2010	East Grampians Health Service Ararat	5.30 - 7.00
18 March 2010	Stawell Regional Health	XX
24 March 2010	GICS 804 Sturt Street, Ballarat	2.30 - 4.00
25 March 2010	Wimmera Health Care Group, Horsham	XX
31 March 2010	GICS 804 Sturt Street, Ballarat	5.30 - 7.00
XX	West Wimmera Health Service, Nhill	XX

To register your interest and confirmation of venue OR if you are unable to attend a forum but would like to participate in a focus group or case study, please contact Laura Liversage at the University of Ballarat on 5327 9841 or email: community@gics.com.au

"Engaging with our Community" is funded by GICS and is a collaborative project between:



Connecting cancer care,
driving best practice
and improving patient
outcomes

Information on GICS can be found
on its website: www.gics.com.au

Name: _____

Address: _____

Phone: _____

Email: _____

I can attend

Please send me more information
on the Regional Forum in my area.

I cannot attend regional forum but
would like to participate in a focus
group or case study



Processes Adopted

- **Changing Knowledge and Attitudes**
 - Informing consumers of the agencies' work
 - Staff professional development
 - Providing informational resources to consumers
 - Keeping cancer in the public eye
- **Changing Consumer Behaviour**
 - Involvement of consumers in agency activities
 - Advocacy training and skill building for consumers

Listening to Consumers

- Qualitative components: over 250 people took part in the activities
 - Reasonably good coverage; some groups less well represented.

Better Coverage of:

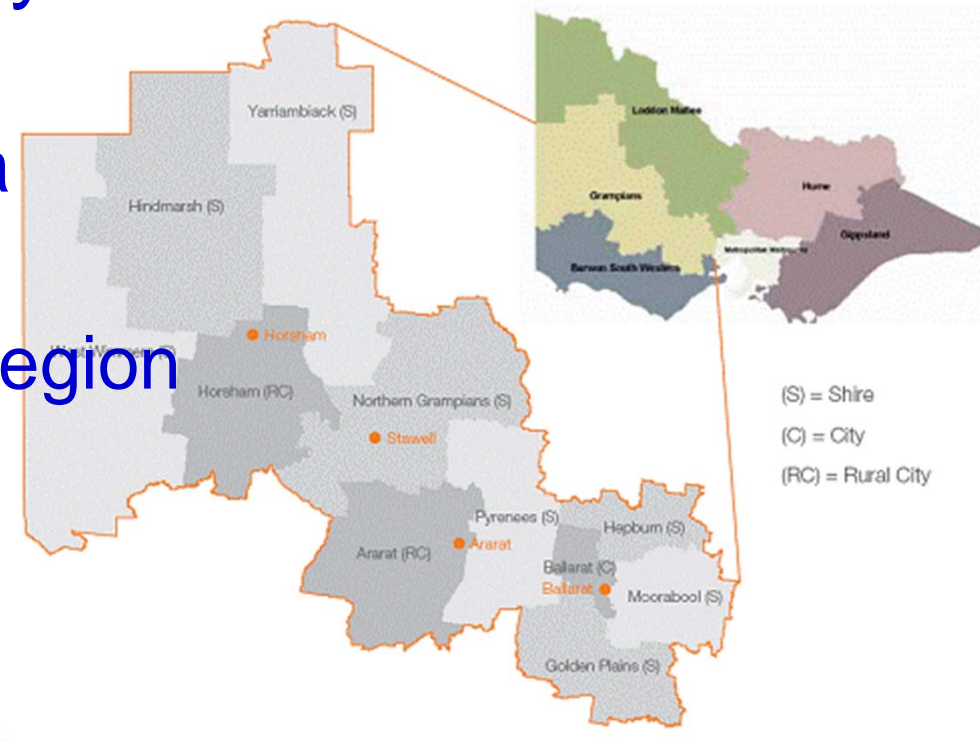
- Gender balance
- Tumour streams
- Place of residence
- Older age groups

Poorer Coverage of:

- Young people
- CALD groups
- ATSI groups
- Rare tumours

Listening to Consumers

- Quantitative part: 81 respondents to an opinion survey of identified issues
 - 28 from the Ballarat area
 - 53 from the Grampians region



Identifying What Worked Well



- Local services valued despite limitations
- Dedication and commitment of staff – deeply appreciated
- As well as convenient, reliable, etc., being treated locally is a ‘statement of identity’
- Improvements to services welcomed but limitations still very apparent
- Palliative care services praised

What Can Be Done Better



- Delays related to service delivery
- Patient-doctor relationships criticised
- Poor transparency around options and decisions
- Better scheduling could be achieved easily
- Balancing information needs and timing
- Referral to support groups often neglected

Persisting Difficulties



- Financial burden of cancer
- Limited financial support during treatment
- Transportation and distance from services
- Co-ordination of public transport
- Parking and accommodation difficulties
- The personal cost to carers and families
- Information about local support groups

Consumer Recommendations

- Summarises around 20 recommendations:
 - ☑ Provide feedback to services in the region on the excellent work they perform
 - ☑ Support health care staff who are making personal contributions to the quality of cancer care in the Grampians region
 - ☑ Encourage governments to continue the process of decentralising services

Consumer Recommendations

- ☑ Continuing professional development in patient-doctor relationships needed
- ☑ Promote palliative care services and educate the community on its benefits
- ☑ Patient-centred care: needs transparency, openness and accountability on the part of health practitioners

Consumer Recommendations

- ☑ Patient-centred care needs promotion within and outside the organisation
- ☑ Use IT better - create efficiencies, improve scheduling and reduce complex form filling
- ☑ Greater community participation should be encouraged where possible
- ☑ Access to relevant information, needs to be timely and self-directed, not all-or-none

Consumer Recommendations

- ☑ Provide appropriate specialised referral services in the Grampians
- ☑ Provide information about support groups
- ☑ Train support group officers to improve the effectiveness of support groups
- ☑ Allow consumers to make informed choices about attending

Consumer Recommendations

- ☑ Encourage government policy initiatives in relation to the financial burdens involved
- ☑ Expand accommodation services
- ☑ Incorporate carers' needs in broader treatment planning

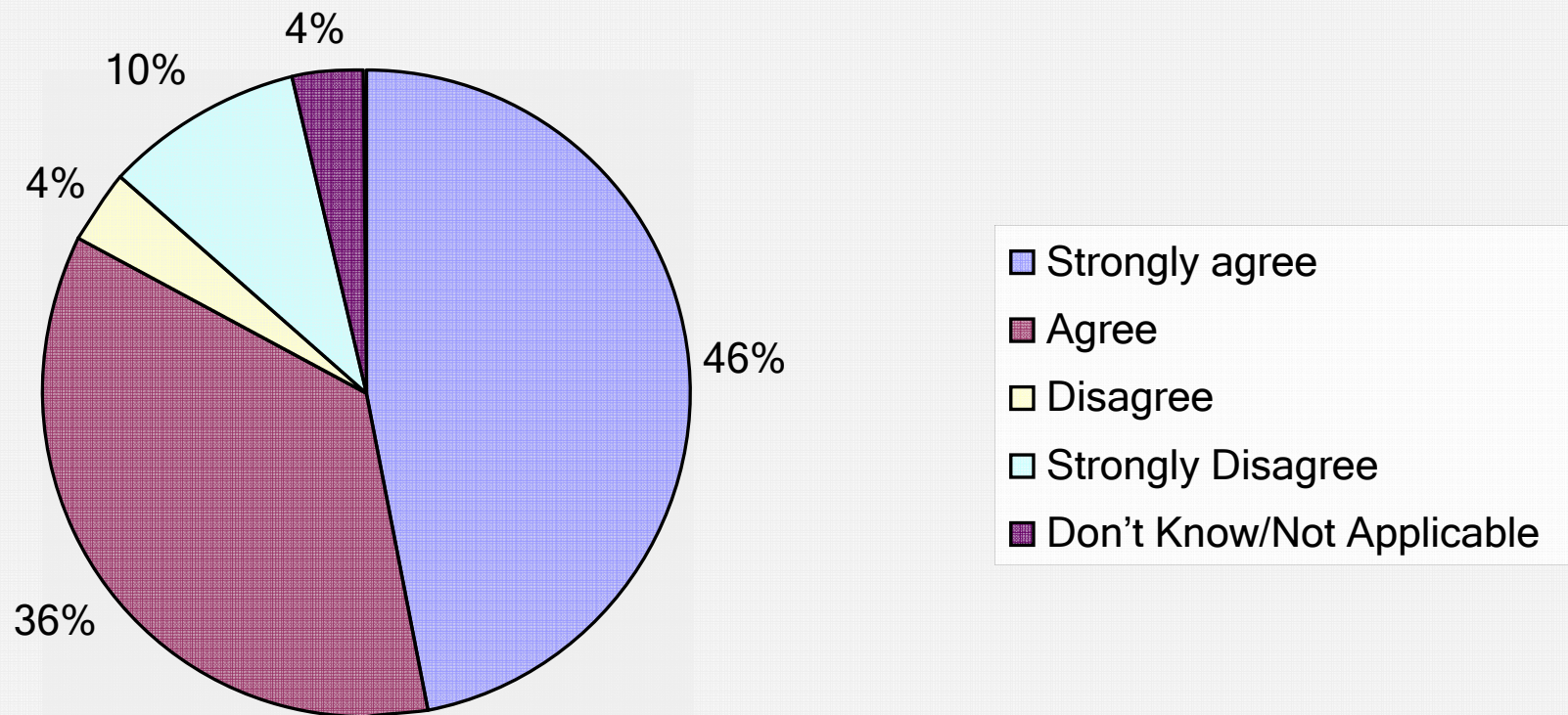
Consumer Survey

- Quantitative analyses allows for digging deeper into the depth and extent of views
- Do we have one voice speaking over the top of others? Are views widely shared?
- Time for one example – *The level of satisfaction with services provided locally*

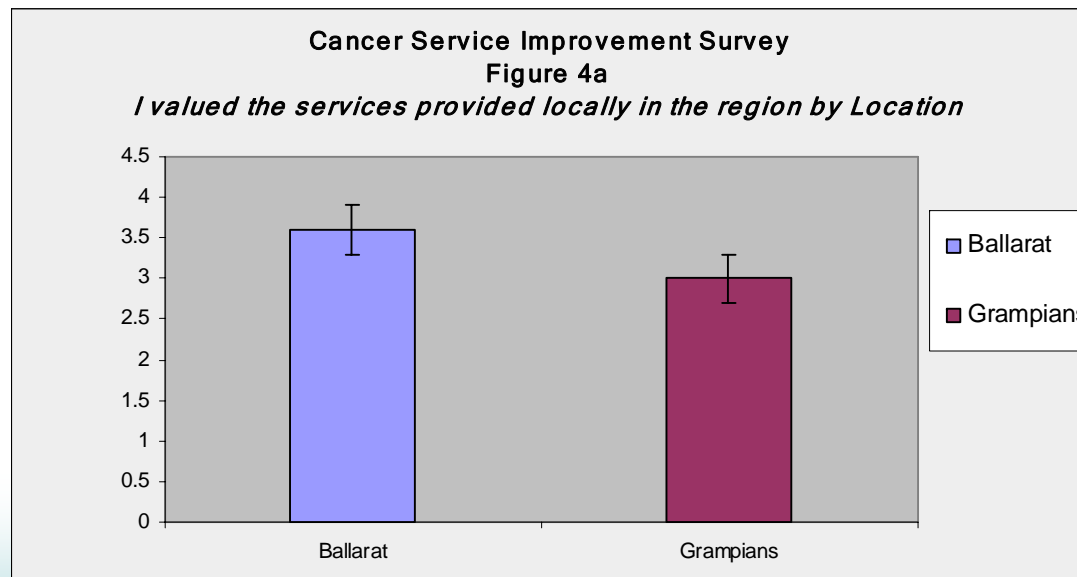
Cancer Service Improvement Survey

Figure 4

I valued the services provided locally in the region



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



Ballarat Regional Integrated Cancer Centre

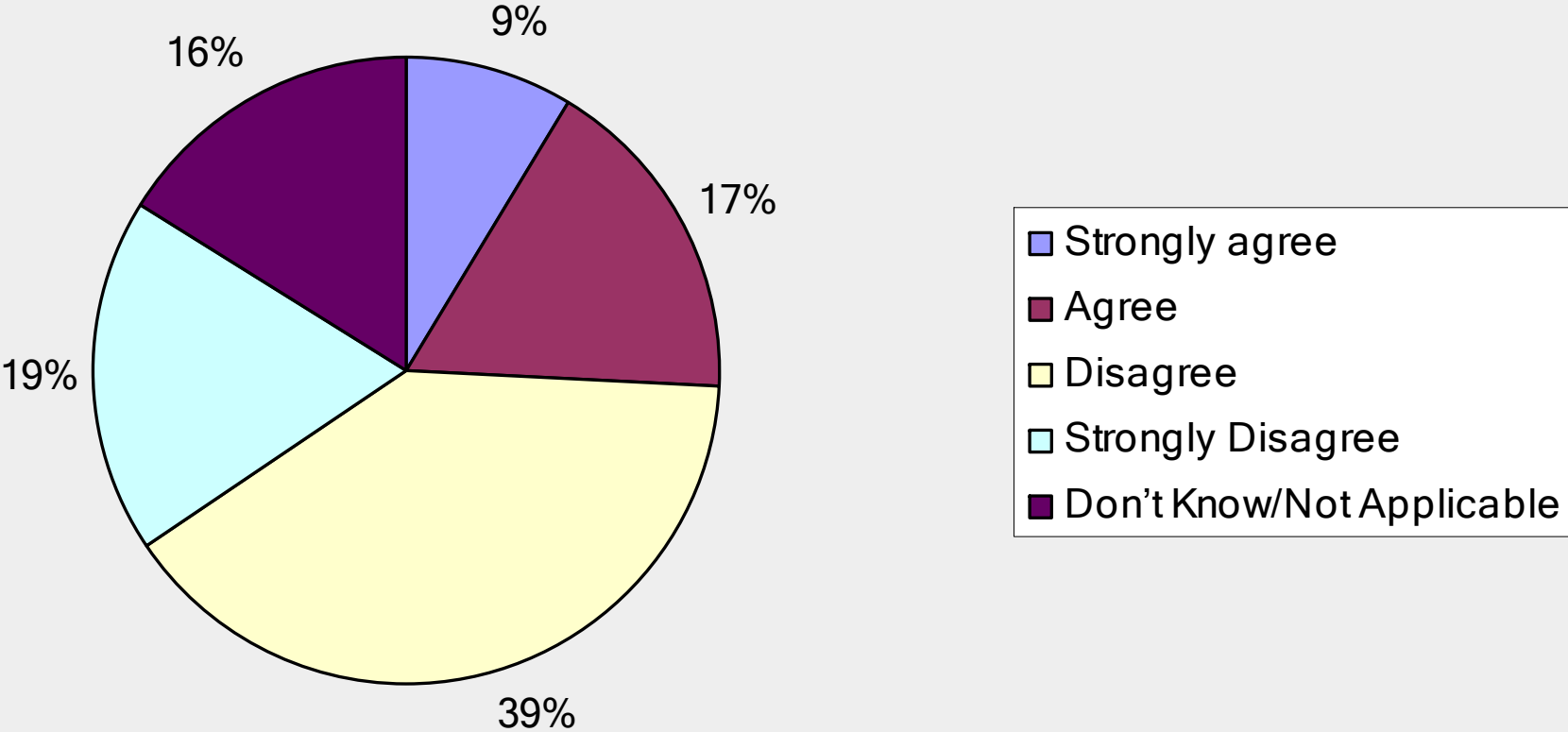


Grampians Regional Integrated Cancer Centre

Cancer Service Improvement Survey

Figure 12

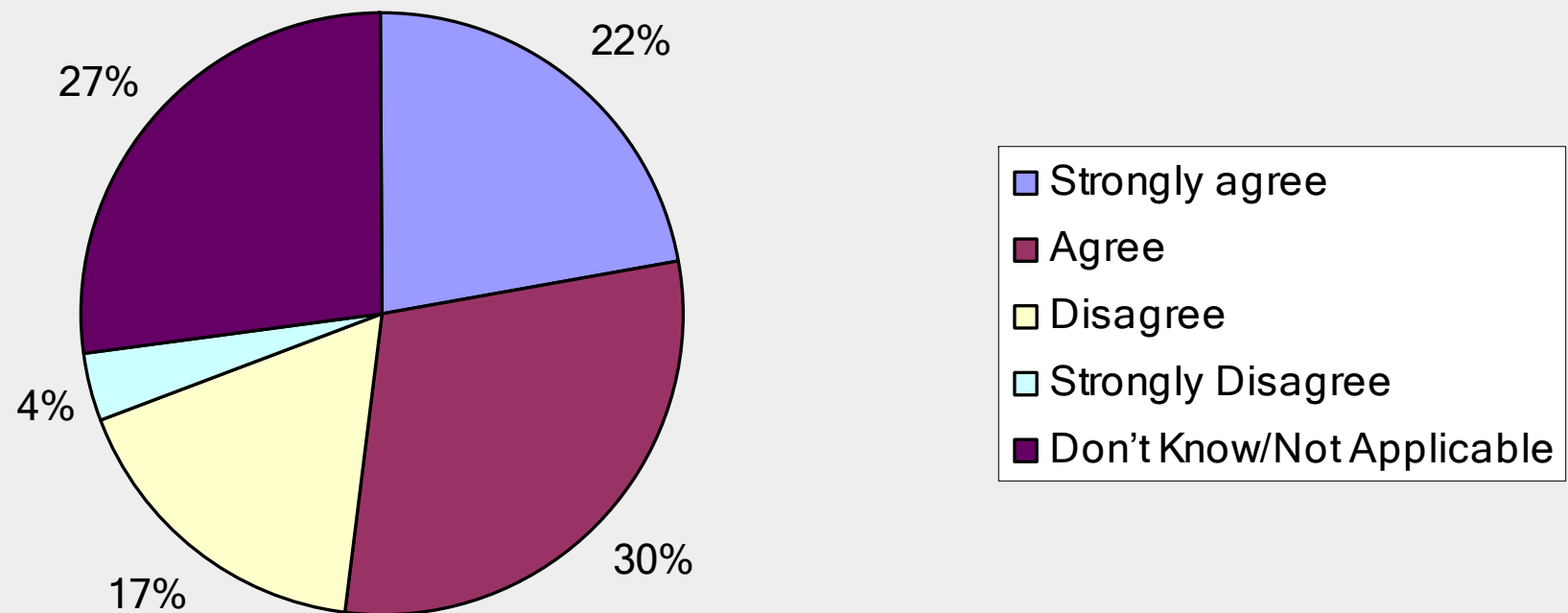
Doctors' and therapy appointments are scheduled inconveniently



Cancer Service Improvement Survey

Figure 14

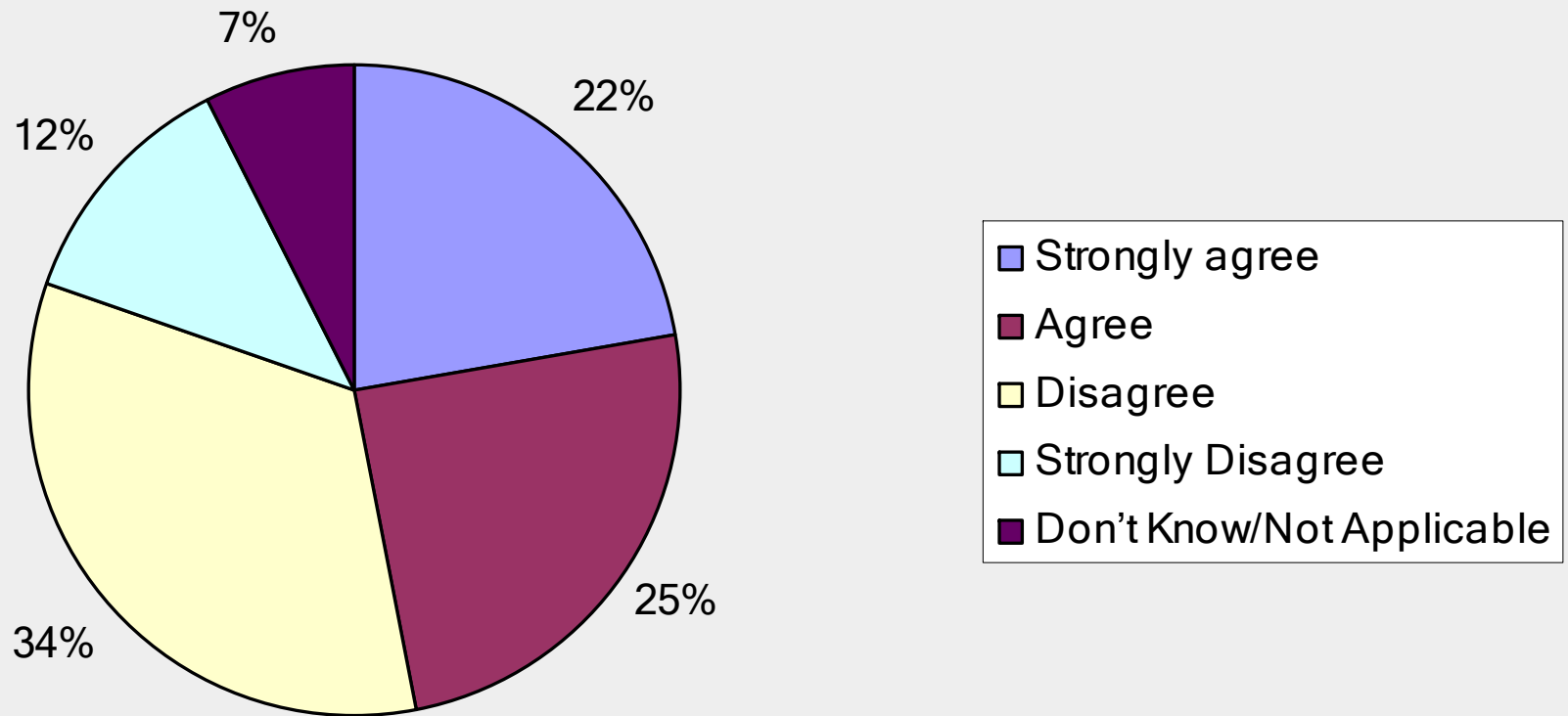
I should have seen a social worker much earlier in my cancer treatment



Cancer Service Improvement Survey

Figure 16

I was left to find out too many things by myself



Personal Stories

- A collection of 50 personal stories about their journeys with cancer told by people from the Grampians region
- These will be posted progressively on the GICS website for visitors to browse
- A selection of the stories will be collated in booklet form and published

A Personal Story

- Sue, 68 y.o., non-Hodgkin's lymphoma - commenting on the value of supportive care to people living in the country:

“A lot of people may need telephone support, because they live on their own or their family is not close by. Not every-body wants to see somebody face-to-face”

Conclusions

- The findings of the work we have done are available from GICS website
- They represent the first iteration of the action research model
- Need to continue the process to ensure change is embedded
- Engagement seen as central to supportive health care in cancer