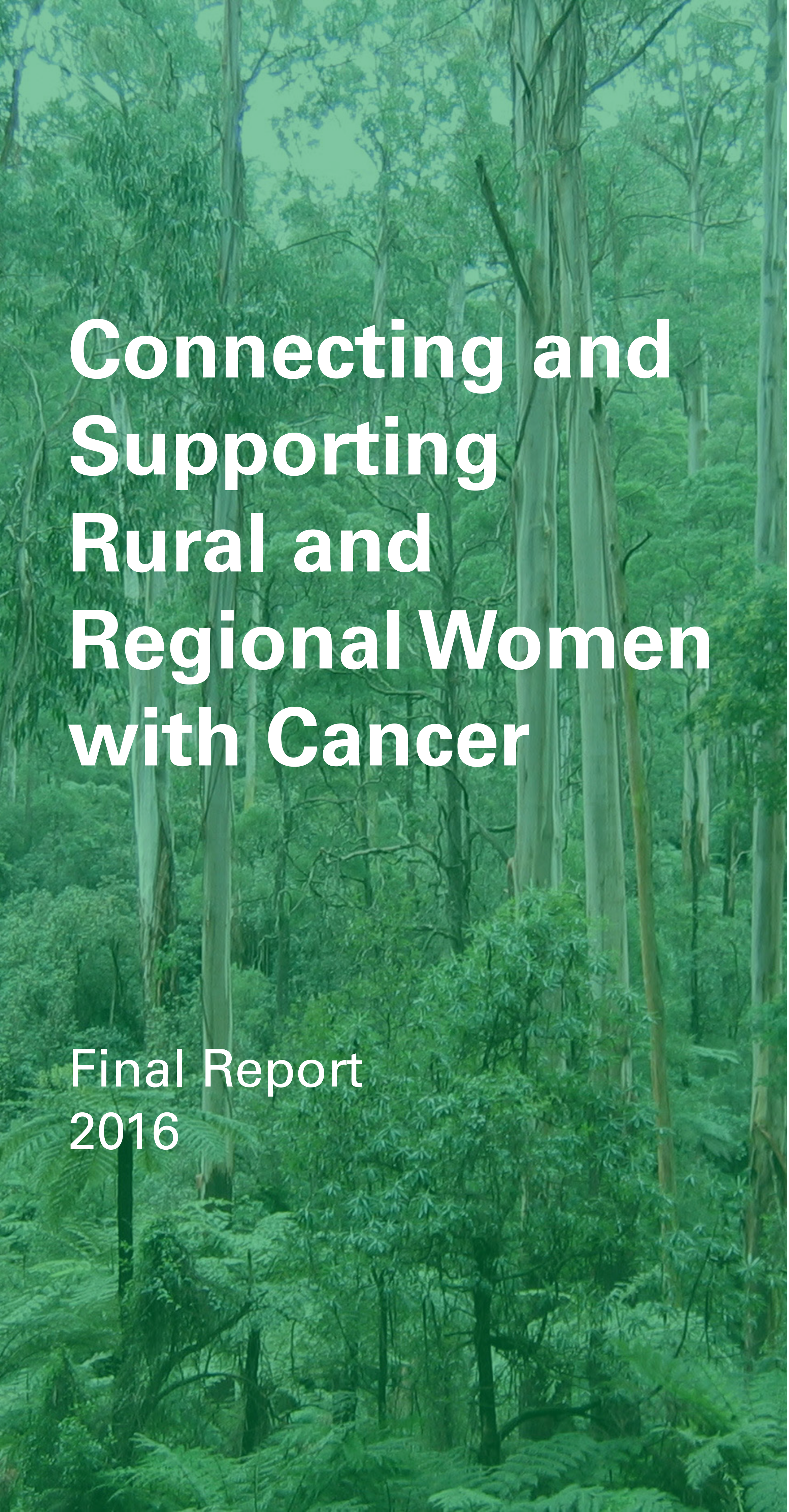

Connecting and Supporting Rural and Regional Women with Cancer

Final Report 2016

Lead Agency

BreaCan
GYNAECOLOGICAL & BREAST CANCER SUPPORT

A service of Women's Health Victoria

Partners

BSWRICS
Barwon South Western Regional Integrated Cancer Service

Grampians Integrated Cancer Service (GICS)

Funded by

VICTORIA
State Government

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Project Steering Committee

Barwon South West Region Integrated Cancer Service
    Sue Riches
    Marita Reed
    Rebecca Steele

Grampians Integrated Cancer Service
    Keiran Murrihy
    Glenn Reeves

BreaCan
    Lee Kennedy
    Catherine Watts

Consumer representatives
    Angela
    Fae

Authors

Lee Kennedy
Fiona McRae
Marita Reed
Glenn Reeves
Sue Riches
Rebecca Steele

Additional editing by

Alison Hughes

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Executive summary

The Victorian population is growing and ageing at a rapid rate, with this increase more pronounced in regional areas of the State. The survival rates of people diagnosed with cancer are also increasing, creating a greater need for post-treatment follow-up and supportive care.

In response to these issues, the Department of Health & Human Services provided funding to BreaCan to conduct an analysis of the information and support needs of women with cancer in the Grampians and Barwon South Western region. BreaCan is a unique statewide information and peer support service for women who have been diagnosed with breast and or a gynaecological cancer however women with any cancer diagnosis were included in this project. To conduct this project, BreaCan formed a partnership with Barwon South Western and Grampians Integrated Cancer Services. In Victoria, Integrated Cancer Services (ICS) comprise the Victorian Cancer Clinical Network, combined with clusters of hospitals and associated health services that deliver services for people with all types of cancers within a geographic area. The range of services include public hospitals, community-based services, general practitioners and other primary health organisations, private hospitals and supportive care services. The role of the ICS is to build relationships, implement 'best practice' models of care, improve the efficiency and effectiveness of cancer care and monitor systems and processes to improve performance.

A literature review was undertaken initially and a consultation plan developed to ensure women's opinions and experiences informed the process. In an effort to reach disadvantaged communities, a dual consultation process was conducted: focus groups undertaken in local areas with populations of high socio-economic disadvantage (Colac in BSW and the Ballarat suburb Lucas in Grampians region); and a survey across both regions. A total of 46 people affected by cancer participated in focus groups while 130 respondents completed the survey. In addition, a survey of service providers was conducted, with 170 respondents.

A number of key themes emerged from the consultations, including:

1. The importance of connecting with people who shared a similar experience;
2. The significant role performed by local general practices;
3. The absence of a central repository for accessing cancer information and support;
4. The consumers' preference to receive information in a setting where questions and issues are addressed; and
5. The range and quality of information and support provided for women with cancer is not the same across the different tumour streams.

While none of these could be described as surprising it is important to note that despite the sector's awareness of these issues, there continue to be gaps in and barriers to accessing information in these areas.

The following recommendations have been developed for implementation in response to the main issues arising from the project.

1. Broaden access to peer support options for women with cancer in rural and regional areas;
2. Collaborate with general practice to raise awareness of the information and support needs of patients diagnosed with cancer;
3. Increase awareness of state-wide cancer support websites (either existing or in the process of development) by improved promotion of these initiatives;
4. Identify opportunities for the provision of local information hubs where they do not exist; and
5. Provide education (regular and targeted) for service providers about non-clinical issues for people diagnosed with cancer.
   Only the first recommendation has a proposed implementation plan developed as further discussions with relevant stakeholders would be required for their implementation.

Peer support can be both formal and informal and take many forms, including phone calls, emails, referrals or connection to relevant services or information, text messaging, online forums, group meetings, going for walks together, and sharing a cup of tea. This type of support complements and enhances other health care services by creating the emotional, social and practical assistance necessary for staying healthy and managing the impact of cancer. At BreaCan, extensively trained and well supported peer support volunteers are rostered to respond to women's queries, providing support and a strong message of hope.

For the purpose of this project, 'information' refers to verbal (speaking and discussion) and written material (e.g. brochures and booklets) relating to a cancer experience such as facts, statistics and descriptions. Support is defined as: encouragement, practical assistance, comfort, and understanding relating to a cancer experience.

1. Introduction:

In December 2014, Breacan in partnership with the Integrated Cancer Services of Barwon South West and Grampians commenced the *Connecting and Supporting Rural and Regional Women with Cancer* project to better understand the support and information needs of women affected by cancer in rural and regional Victoria. To gain insight into the experiences of these women, the project partners undertook a consultation with consumers and service providers, which will inform the project's recommendations. The implementation of this project occurred alongside two other relevant projects being undertaken in the Grampians region: Grampians Integrated Cancer Service was involved in a series of consultative forums as part of its "Cancer Conversations" initiative; and Deakin University in partnership with GICS, commissioned by DHHS, was completing "Project Ophelia", a health literacy focused consultation with cancer stakeholders.

The Problem:

Reduced geographic access to treatment and support is a known factor in producing poorer health outcomes. Many women diagnosed with cancer can feel "lost in translation" a feeling that can be multiplied by the geographic isolation of living a long way from major treatment centres.

The Opportunity:

This project aligns with one of the Victorian Action Plan support priorities; creating better experiences for cancer patients and carers. Support which improves a person's self-efficiency, wellbeing and social supports is known to assist them to better manage the stressors accompanying cancer. Identifying and proposing recommendations on how best to provide relevant information and support to women affected by cancer living in rural and regional Victoria could potentially reduce the adverse effects resulting from a lack of access to support services.

Key Objectives:

- To understand the diverse experiences and needs of women living with cancer in the Barwon South West and Grampians region, especially people who are older, on low incomes and from culturally and linguistically diverse backgrounds, as they face greater barriers finding and accessing information and support;
- To develop an understanding of existing support services and needs of service providers caring for women living with cancer in Barwon South West and Grampians region;
- To develop a **sustainable and transferable model** of information and support for women living with cancer in rural and regional Victoria; and
- To provide a set of recommendations that improves access to information and support for women living with cancer in rural and regional Victoria.

2. Background

2.1. Overview of literature review:

A review of the literature, focusing on enablers of and barriers to rural and regional women in accessing support and information, was completed by The Connecting and Supporting Rural and Regional Women with Cancer Project. The literature reviewed included: peer reviewed journal articles accessed by searching academic databases, and government reports and rural and regional Australian research obtained by conducting a desktop review. A summary of the main points emerging from the review of the literature has been grouped into the following themes, barriers and opportunities, with the detail of the Literature Review presented in Appendix I.

Themes:

- People living in rural and regional areas face a number of barriers to accessing and utilising information and support
- The demand for support can be dependent on the attitudes and health seeking behaviours of people from rural and regional areas with a cancer diagnosis
- Limited knowledge about existing services in addition to a lack of coordination can impede access to services in country areas
- A range of practical support is required by rural and regional women (including transport, accommodation, financial, childcare and home help)
- There are many benefits associated with peer support
- Innovative approaches to technology can increase the provision of information and support
- Poor literacy is a barrier to accessing and utilising information and support services
- Service providers can act as enablers to women accessing supportive care services.

Barriers:

- Limited knowledge about services, lack of coordination between support services, poor health literacy and higher levels of poor social determinants of health rated highly as major barriers to rural and regional people's ability to access information and support
- Service providers may not be able to adequately respond to the needs of women because of time constraints, heavy workloads and role limitations
- Lack of support for consumers can contribute to poorer outcomes (i.e. emotional and psychological)
- Some rural and regional people miss out on services because they do not perceive these services to be important to them.

Opportunities:

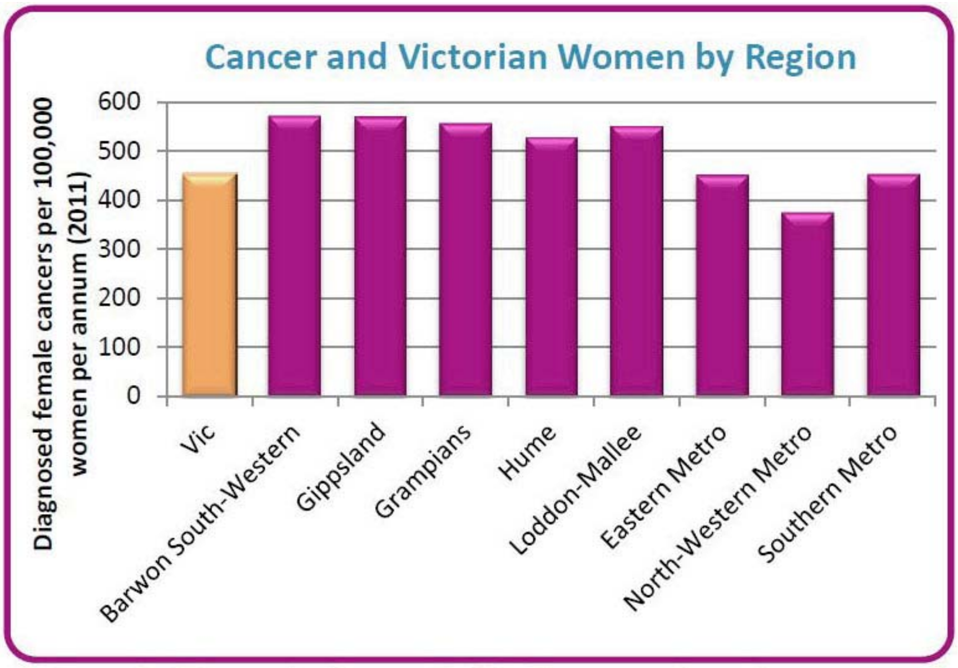
- Access to supportive care including support and information has broad benefits across the health and wellbeing spectrum
- Developing local options which allow women to maintain their privacy and / or anonymity
- Breast Care Nurses and Cancer Coordinators play an important role in connecting rural and regional women to support services
- Availability of supports vary from very little to strong informal networks
- Peer support is important for rural and regional women living with cancer
- It is important to target people from disadvantaged backgrounds to ensure they receive support services.

2.2. Profile of the regions

About the regions

Regional Victorian women face a higher rate of cancer diagnosis than their metropolitan counterparts (Figure 1). For example, the incidence rate of cancer in women in the Barwon South-Western region in 2011 was 5% higher than the statewide rate, representing 117 per 100,000 more women diagnosed with cancer in this region.

Figure 1: Incidence rate of cancer in Victorian women by region



The survival outcomes for Victorian's diagnosed with cancer are improving, creating a greater need for post-treatment follow-up supportive care. However, the 5-year survival rate for those diagnosed with cervical and ovarian cancer is 8% lower in non-metropolitan compared to metropolitan Victoria.[1]

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[1] Cancer Council Victoria (2012). *Cancer Survival in Victoria 2012*. Retrieved from http://www.cancervic.org.au/downloads/cec/cancer-survival-victoria-2012.pdf

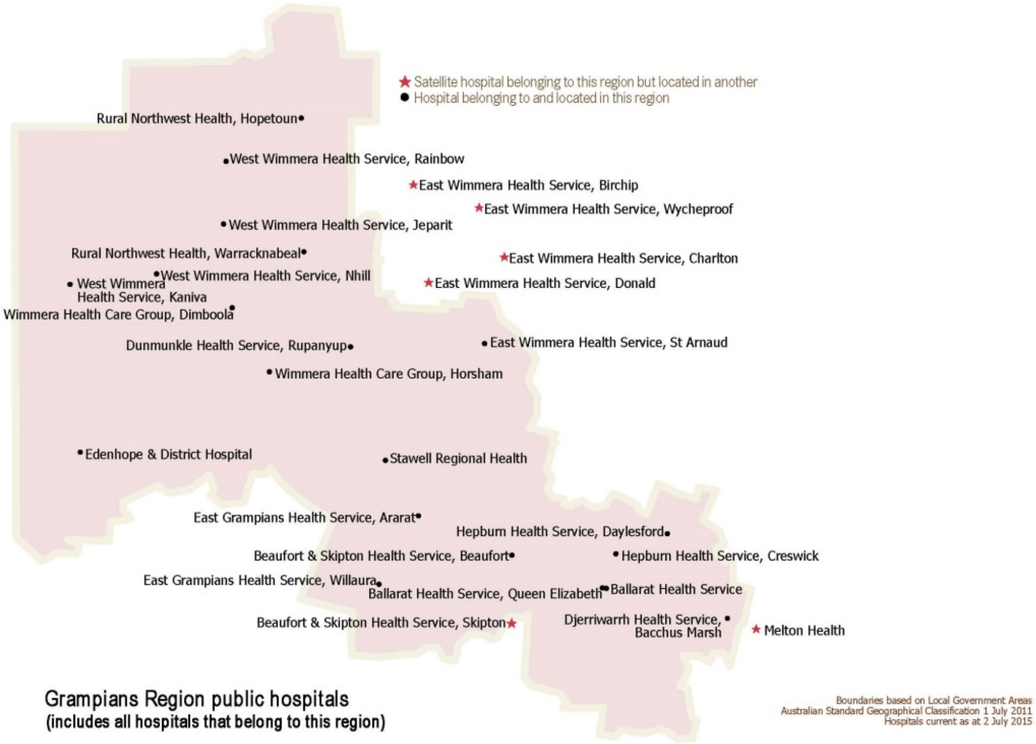
Barwon South Western (BSW) Region

The BSW Region is one of eight Department of Health & Human Services' regions, stretching from the tip of Queenscliff Heads in the east to the South Australian border in the west. The estimated population in 2015 was 380,000, which is expected to increase at a higher than average annual rate of growth (1.3%) compared to the regional Victoria average of 1% (Regional Development Victoria: cited in BSWRICS annual report).

Grampians Region

The Grampians Region covers the area from Bacchus Marsh in the east to the South Australian border in the west, and from Patchewollock in the north to Lake Bolac in the south. The Region is geographically diverse including the Grampians, remote farming communities, the major regional city of Ballarat and smaller communities of Horsham, Stawell and Ararat.

The Grampians Region covers an area of 47,980 square kilometres, contains eleven local government areas and is one of eight Department of Health & Human Services' regions.



Grampians Region public hospitals
(includes all hospitals that belong to this region)

Boundaries based on Local Government Areas
Australian Standard Geographical Classification 1 July 2011
Hospitals current as at 2 July 2015

SEIFA

To understand disadvantage in both regions, the project referred to the SEIFA (Social Economic Index of Disadvantage by Area) which measures the relative level of socio-economic disadvantage based on a range of Census characteristics. A higher score on the index means a *lower* level of disadvantage. The index is used to obtain a general view of the relative level of disadvantage in one area compared to others and is used to advocate for an area on the basis of the relative level of disadvantage. (See Appendices II and III: Heat Map for BSW and Grampians Regions). The areas identified to have high social disadvantage in the BSW Region were: Colac, Corio / Norlane, Camperdown, Lismore, Cressy, and Heywood. The areas identified to have high social disadvantage in the Grampians Region were: Suburbs of Ballarat (Wendouree West), Avoca, Stawell and St Arnaud.

2.3. Other relevant initiatives

In the Victorian cancer arena, information and support is currently provided in a variety of approaches. Examples of existing approaches include but are not limited to:

On-line:
- Consumer portal of the Optimal Care Pathways.
- Cancer Council Victoria (CCV) Email Service which provides a forum for consumers to email a nurse with a question, with a reply sent back within 2 business days.
- CCV Online Communities which provides information, online forums and blogs regarding cancer.
- CCV Directory of Services providing practical support and information including cancer treatment centers, palliative care, respite care, support for living at home, emotional support,

information about cancer, and services for carers. This is currently being updated and due for release in March 2016.
- Better Health Channel provides information regarding cancer types and a Service and Support Directory; the latter covers a broad range of health and support services including cancer support groups. This information is also available as an app.
- CanTeen provides an online peer support service and also provides a range of information and other counselling and support service information online for Adolescents and Young Adults affected by cancer.
- Warwick Cancer Foundation provides peer support and wellness escapes for young adults with cancer.
- Range of other online services from cancer specific organisations including Cancer Council Victoria and Integrated Cancer Services as well as blogs, and online support groups.
- BreaCan provides peer support by phone, Skype and in person, provides access to a specialist library with free postage, offers information sessions on medical wellness and creative topics and trains and supports peer support volunteers.

Telephone:
- Cancer Council phone service (13 11 20) which operates Monday to Friday from 9.00 a.m. to 5.00 p.m. and provides information, counselling and referrals. The phone line is staffed by experienced cancer nurses with oncology qualifications. Besides information provision, this service also connects the caller to cancer support groups and other community resources.
- CCV Cancer Connect provides one on one peer support via the phone. Consumers are linked with trained volunteers who also have a similar experience in terms of cancer type, cancer treatment, age and family circumstances. Selected volunteers then call the consumer at home when convenient.

Face to face:
- CCV ‘Find a Support Group’ allows consumers to search for local support groups and also provides information on phone and online cancer support groups. CCV also provides training and support to group leaders.
- On Trac provides a service for adolescents dealing with a cancer diagnosis.
- CanTeen provides young people with access to counselling, camps and recreation days and allows young people with similar experiences to meet and form relationships.

There are a number of organisations providing information regarding specific cancer types, support services, clinical trials and access to online, telephone and or face to face support groups, including but not limited to:
- Lung Cancer Network;
- Ovarian Cancer Australia;
- Leukemia Foundation;
- Breast Cancer Network Australia;
- Australian Lung Foundation; and
- Australian Cancer Survivorship Centre.

In summary, a number of services and supports are provided in both the BSW and Grampians regions for people experiencing a specific cancer. These services, however, are limited in resources and or geographical coverage, which create difficulties for people seeking support. While online and telephone services are more readily available, there are limited options for face to face to support.

3. Methods

Consultation Methodology

Consumer and community participation is central to improving health outcomes, providing and maintaining high quality and effective healthcare.[2] The Connecting and Supporting Rural and Regional Women with Cancer Project was committed to working in partnership with consumers, carers, health facilities and service providers to ensure the consumer voice was heard when developing strategies and determining priorities. A position of “doing it with them not for them” was adopted by the project, recognising that meaningful engagement of rural and regional women required consultative activities that suited their expectations while fulfilling the auspice organisation’s remit to provide opportunities that enable women to express their opinions and comment on their experiences around information and support. The women who participated in the various consumer engagement strategies expressed a desire for their views and suggestions to be taken forward in this report in order to create better experiences for all women diagnosed with cancer in the future.

The methods undertaken to engage with a broad range of consumers and service providers are captured in following table.

Table. 1. Overview of Engagement, Consultation and Collaboration Initiatives

Community Engagement Consumer promotion, communication and engagement with service providers and consumers				
Community consultation				**Community Collaboration**
Scoping Interviews with local connections N = 6	Focus Groups Attendees N = 42	Consumer Survey N = 130 Service Provider Survey N = 170	GICS Cancer Conversations with consumers	Round Table Luncheons with consumer and service providers N = 54
April	June – July	July – August	External project	September

3.1. Community engagement

Community engagement was essential to the success of the project, with a number of strategies used to engage a variety of consumers and service providers.

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[2] SA Health, (2006). Consumer and Community Participation Guideline. Retrieved from http://www.countryhealthsa.sa.gov.au/LinkClick.aspx?fileticket=ikmj6TDFPt0%3D&tabid=675.

Consumer engagement

Strategies undertaken to achieve community engagement, included:

- Posting flyers in local venues such community health, supermarkets, libraries and neighborhood houses
- Requesting local GPs, clinicians, nurses and other health professionals to promote project events
- Promoting the project and events to local cancer support groups
- Presentations given to advisory groups (BSWRICS, GICS and BreaCan) about the project.

The most successful strategy for engaging with rural and regional women with cancer was a personal invitation via email or post. In the survey, 53% received the survey via email or post. Most attendees for the consumer forum were personally invited or found out about the community forum via their local support group.

The project team spent a few months engaging with key service providers about the project. These service providers sent invitations to women on behalf of the project. Invitations were also sent to consumers from BSWRICS, GICS and BreaCan.

Focus groups were conducted as part of the community forums held in Colac and Ballarat. These events offered a range of benefits for attendees, including: wellbeing presentation, lunch, presentation on consumer participation, and the opportunity to have their say about information and support experiences via focus groups (See Appendix IV: flyer and running sheet for Colac forum). This event was well attended and well received in Colac.

Fewer attendees signed up for the community forum held in the Grampians Region. This may have been due to the following reasons:

- The conduct of a range of recent consumer participation events in Grampians including: Cancer Conversations and Project Ophelia; and
- A small number of personal invitations sent to women living with cancer due to a limited mailing list.

The agenda and program for the Ballarat event was amended as only nine people were registered and subsequently attended. (See Appendix V: flyer and running sheet for Ballarat forum).

Service Provider engagement

Service providers were invited to participate in the project via a survey distributed by email and post. GPs received a hard copy survey with a post reply paid envelope, which resulted in the participation of 116 GPs (64% of respondents for the Service Provider Survey) in the two regions. This was a very positive response from GPs. The other service providers received an email with a link to the survey and accounted for the remaining 36% of respondents. Emails to service providers were not personally addressed, and this could have affected the final response rate.

Round Table Luncheon (Geelong and Colac)

The key to engaging both consumers and service providers for these events was a personal invitation, along with follow-up from either health service management or the project to find out if people were attending. The events were very successful with 52 attendees. (See Appendix VI: Round Table Summary).

3.2. Community consultation

The *Connecting and Supporting Project* conducted consultations with women living with cancer and service providers to develop an understanding of information and support experiences of women living with cancer.

3.2.1. Scoping interviews

Prior to developing our approach to community participation with women living with cancer and service providers, a number of pilot interviews were conducted in the two regions. The purpose of these interviews was to determine an appropriate community consultation approach and trial data collection instruments as well as build an understanding of existing services, gaps in service provision and develop strategies for gathering input from consumers and service providers.

Participants
Preliminary interviews were conducted with six service providers and two consumers across the two regions to better understand the landscape of the two regions, as well as existing supports and gaps in information and support.

3.2.2. Consumer consultation

To achieve consumer consultation within two vast regions of Victoria (Barwon South West and Grampians), the project team recognised the need to use a two-pronged approach for collecting information:

- Narrow and deep (focus groups); and
- Wide and shallow (survey).

Narrow and deep

The narrow and deep approach was aimed at targeting women with specific characteristics: older age cohorts, low-socio economic status and culturally and linguistically diverse backgrounds. Women from disadvantaged backgrounds are generally recognised as hard to reach groups for purposes of research, including survey participation. This project, however, was committed to capturing data that would provide insights into the information and support experiences of women from disadvantaged backgrounds. Focus groups were selected as a suitable method and subsequently held in areas with a high SEIFA index, with the intention of engaging women from disadvantaged communities (BSW: Colac, and Grampians: Lucas, Ballarat). Local venues were further chosen for the conduct of these focus groups, providing an intimate and supportive environment and reducing the barriers to participation for this targeted group of women.

Wide and shallow

The wide and shallow approach refers to reaching out to all women with a cancer experience in the two regions to participate in the project via a survey. The aim of this approach was to ensure all women who wished to participate in the project had an opportunity to be involved.

3.2.2.1. Focus groups

The project team arranged two community forums in local government areas that had evidence of accessibility to women who were older, low socio-economic status and from culturally and linguistically diverse backgrounds. The Community Forums provided an opportunity for women living with cancer to express their opinions about information and support they received and, to provide an opportunity for women to connect and discuss wellbeing following a cancer diagnosis. The Community Forums were held in Colac and Lucas, a suburb of Ballarat. (See Appendices VII & VIII: Focus group notes for Colac and Bendigo).

Participants
Within the Community Forum, focus groups were conducted with 42 consumers in six different focus groups (four groups were conducted in Colac and two groups were conducted in Ballarat). There were 37 women with a cancer experience and five support people (son, carer, daughter, and a friend). The women living with cancer, included a range of different cancer types: kidney, cervical, breast, brain, eye, melanoma, multiple myeloma, leukemia and lymphoma, and neo-endocrine. Attendees did include women who were older and younger, women with high and low socio economic backgrounds, and a few women who were culturally and linguistically diverse.

3.2.2.2. Consumer Survey

A survey was developed over the course of two months, factoring in information derived from the project literature review and included a combination of validated and new questions. The survey was reviewed by academics, consumers, and service providers. The survey collected demographic data, asked consumers to rate the importance of different types of information and support, and to rate satisfaction with different types of information and support. (See Appendix X: Consumer Survey).

The consumer survey was distributed to women in the BSW and Grampians regions via a number of methods including email and post from a range of different people and organisations (BreaCan, BSWRICS, GICS, Cancer Council Victoria, Breast Care Nurses, Cancer Link Nurses, Support Groups), via social media, advertisements in local newspapers, and health professionals.

Participants
The consumer survey was completed by 129 consumers (Grampians: 43, BSW: 86).

3.2.3. Service Provider consultation

Service Provider Survey
The Service Provider Survey was developed over the course of two months, factoring in information obtained from the literature review and included a combination of validated and new questions. The survey was reviewed by academics and service providers. The survey asked service providers about the types of information and support they offered women living with cancer, and sought to understand service providers’ perceptions about the provision of information and support for women living with cancer. (See Appendix XI: Service Provider Survey).

The service provider survey was distributed by post to GPs and via email to all other service providers. Other service providers included surgeons, social workers, nurses including cancer nurses and oncologists.

Participants

The service provider survey was completed by 170 service providers.

3.3. Community collaboration

An important aspect of The *Connecting and Supporting Project* was working with women living with cancer and service providers to develop options for improving information and support.

Round Table Luncheons

The “Round Table” Luncheons were held as a form of community collaboration, to:

- Share findings from the community consultations with the community;
- Seek community feedback and impressions regarding community consultation findings; and
- Work together with the community to develop options for improving information and support for rural and regional women living with cancer.

The two Round Table luncheons were held in the BSW region: one in a regional centre (Geelong) and the other in a rural area (Colac). (See Appendix VI: Round Table Summary)

Participants

Women living with cancer and service providers were invited to attend the Round Table luncheons. A total of 52 participants attended across the two events:

Attendee type	Geelong	Colac	Total
Consumer	15	17	32
Service Provider	9	11	20
Total at each event	24	28	52

3.4. Limitations

Limited timeframes and resources saw a two-pronged strategy utilised to maximise the project’s reach and exposure: narrow and deep and broad and shallow in order to achieve maximum reach across the two regions. Small focus groups were held in disadvantaged areas and surveys distributed across the two regions.

By using this strategy, the project captured a proportionally larger number of women with cancer from lower socio-economic areas but was unable to replicate this for other targeted groups: Aboriginal and Torres Strait Islander women and CALD women. Additional efforts would need to be deployed to engage CALD and Aboriginal and Torres Strait Islander women living in the region, and would need to be undertaken in consultation with appropriate key community liaison roles to fully ascertain the support and information needs of these groups.

Contributing to the lower numbers attending either focus group or round table discussions in the Grampians were other cancer consumer engagement events including: Cancer Conversations being led by GICS and the Deakin / GICS collaborative project, Ophelia. Due to the similarities between the Cancer Conversations consumer engagement initiative and the Connecting and Supporting rural and regional women project, advice was sought, resulting in a decision to hold both Round Table discussions in the Barwon South West Region. With permission from GICS, key outcomes from Cancer Conversations have been made available for this report.

4. Findings

Of particular note was the high involvement of GPs. General Practice clearly plays an integral role in rural communities. The high level of engagement from GPs was not expected however it highlighted the importance of their role in rural regional Victoria and one that should be considered important for building onto in the future.

There was reasonable reach to women geographically, but responses were predominantly related to breast cancer as this is the most developed part of the service system. Across all domains, there were clear differences between experiences of women with breast cancer and other cancers. Breast cancer nurses appear to be the critical difference as their coordination role and their continuity of care appear to have a very positive effect.

Peer support options have emerged strongly as most women identified shared experiences to be very important. Currently, availability of peer support options in rural and regional areas is limited to some support groups. There is also a clear preference for face to face support, perhaps related to the fact that emotional and psychological support are rated as highly important. Non clinical information and support was also rated as highly important but consumers and service providers reported difficulty in accessing these resources and supports. Given that survivorship approaches are relatively new this is perhaps not surprising.

Technological solutions were still not considered the preferred (or available) mode for information provision and support in many situations. This reflects both the digital divide with many not comfortable in the digital world as well as issues relating to broadband availability in some areas. Service providers could be conduit to this information for those whose access is limited.

Service providers indicated their willingness and availability for providing information and support but indicated they’d like to be better informed about non clinical topics and options.

5. Discussion and analysis

A number of themes and perceived gaps in information and support emerged from the various forms of consultation. The first two of these are overarching and are;

- the importance of emotional support and
- the disparity in the type and level of support available to those diagnosed with breast in comparison to other cancers.

Further themes are outlined with a summary of the key evidence presented in the box, followed by a discussion which leads to recommendations.

High importance: emotional and psychological support

In both the focus groups and surveys consumers rated emotional and psychological support of high importance, yet it was an area of relatively low satisfaction. This is perhaps evident given the gaps in provision of mental health services in the general community that are well documented. It is also known that cancer survivors may have a higher need for this kind of support. Two further issues could be explored further and include: i) who needs this support and ii) how best to provide those supports.

Understanding consumer needs and preferences requires examination as is it not always easy to determine who needs extra support and in what form. Some social indicators can assist in the process of identifying people who are likely to have emotional or psychological needs such as those with a history of mental health, without immediate support options, in financial difficulties, and younger people. The use of validated tools such as the distress thermometer are useful but experienced service providers report it is at times difficult to make accurate judgments about an individual's capabilities; as those perceived to have strong coping strategies may have high levels of unmet need and vice versa. Further work on theories such as the relationship between emotional support needs and a person's "sense of coherence" or ability to make sense of the world, may lead to a better understanding of needs and risks.

In the meantime, it is essential to try to ensure that people's needs are assessed early and often so that issues are picked up in the early stages and dealt with in a planned manner rather than as an emotional crisis requiring immediate unplanned action. General practice was seen as particularly important in terms of early identification and referral pathways to appropriate care

Discussions with consumers have identified that there are a wide range of ways of getting support including; informal ones such as family, friends, faith networks, and peers as well as more formal ones such as peers, support groups, online groups, social workers and psychologists. It is clear that access is one of the most significant issues for those outside main regional centres. It has also become evident that different people need different things at different times.

Women with breast cancer have high levels of satisfaction

The higher levels of satisfaction of the women participating in this project who had a breast cancer experience is testament to the advocacy of women over the past decade and the subsequent responsiveness of the service system. As the cancer that affects the greatest number of women, it can be expected that a range of information and supports are available for this cohort. While there are still unmet needs amongst women with breast cancer, especially for those from rural and remote areas, the range and quality of information and supports are clearly better than those for people with other cancers. There are many lessons to be learnt from the excellent options available for breast cancer survivors so that women diagnosed with other cancers can enjoy similar service levels.

In some instances, the disproportionate levels of service availability creates negative perceptions of the breast cancer services as some service providers and consumers are aware of significant unmet need in other tumour streams. Discussions with stakeholders have identified a range of options to try to redress the balance within scarce resources. Options identified have included better use of the practice nurse and district nurse roles, and training of more peer support volunteers.

Peer Support: The evidence in both the literature and the responses captured by rural and regional women in the consumer survey and focus groups found peer support to be important and beneficial. Connecting with someone with a similar experience was welcomed by the respondents across all stages of a cancer pathway i.e. at diagnosis (64%) during treatment (69%) and post treatment (77%). Aside from the preferred face to face contact (80%), peer group support was the next favoured option (52%). Mixed approaches to peer support including telephone, telephone and video conferences could further address issues around privacy and / or isolation. For women who do not have the more common cancers, including younger women, the project found there were very limited options for peer support in country areas.

Many consumers felt that connecting with others in the same situation was or would be beneficial. Those who had the opportunity to meet with peers discussed its importance in normalising their situation whether at diagnosis, during treatment or beyond. A number of those who had not had the opportunity to meet peers recognised it would have been beneficial and would recommend it to others.

Discussion with stakeholders identified a number of options that could be implemented to improve the situation. Introducing patients to each other, coordinating survivor treatments post treatment, promoting the existing services such as Cancer Connect, BreaCan and others, setting a place for survivors to register for contact and providing support for trained peer support volunteers were all suggested.

Providing a range of options, both formal and informal, that respond to differing and changing needs would be required, as would consideration of the needs of women particularly in remote areas. Travel assistance or technology may be of further assistance.

General Practice: For some women, their General Practitioners (GPs) provided excellent information (56%) and support (58%), others thought their GPs could be more aware of available information and support. While shared care with general practices is important in rural areas to reduce travel and time spent away from home, the literature identified constrained schedules and workload as barriers to the provision of care by service providers. Interestingly, results from the service provider survey reported that GPs *do* have time to provide women with information (77%) and inform them about support services (73%), but they would like to be better informed about some topics so that they can provide appropriate information (80%) about where women can go to obtain more information and access support services (83%).

The importance of general practice for women in rural regional areas with an experience of cancer was very clear throughout this project. Consumers spoke of this important relationship and the response rates of general practice in the project also reflected a high level of engagement on this issue. This can partly be explained by the level of local access of practices compared to the distance to specialists, but another contributing factor could be that information and support sit well with general practice, complementing the consumer's need for treatment. Nevertheless, access to information and support on nonclinical issues was cited by both consumers and general practice as not being satisfactory. The growing rates of cancer survivorship combined with the predicted rise in cancer incidence and prevalence rates also point to the growing importance of the general practice role in cancer care. This will be true across the continuum of care from prevention, diagnosis, treatment and survivorship.

Developing clear roles and responsibilities for general practice and the cancer treatment team in this context will be important as will the development of algorithms and guidelines in relation to cancer to support general practice and tools for communication, risk stratification (identifying those with greatest need), and referral. In addition, the general practice experience with chronic disease approaches will be particularly important here. The relationships between Primary Health Networks (PHNs) and local Clinical Networks will be key to this, as will access to regular education opportunities such as cancer survivorship.

Central information site: The consultations found there was limited knowledge about how to find information and support services and no (known) central space / repository for information and support. Service providers similarly would like to be better informed about where women can go to obtain more information and access support services: GPs (83%) other service providers (68%). In the focus groups, areas of particular interest for more support included; work, finances, travel assistance and issues that arise after treatment. Women reported low satisfaction with these types of non-clinical topics in the survey. Grampian's Cancer Conversations consumer consultations found access to information and support beyond specific treatment was largely unmet. Emotional and practical living assistance were identified along with support to make financial and work adjustments. Better promotion of services available and ease of navigation were comments common to consumers across both regions.

Not knowing where to find information and support was an issue for both consumers and service providers. This is not a new finding as it has been discussed in the sector for some time. Many consumers have noted that accessing appropriate support services seems to be ad hoc and often relies on contact with a key individual, often a nurse. Women with breast cancer were more likely to have received this information through the Breast Cancer Nurse.

It should be acknowledged that a number of attempts have been made to address this gap in the past, without success. Discussions with stakeholders have identified a number of structures and processes that would need to be in place to successfully address this in the future.

The most important of these is linking to an existing successful directory with its own profile and an established process for regular updates. Another essential element would be a partnership with Integrated Cancer Services as local contacts. From a user point of view, a number of features would need to be in place to ensure good take-up of a localised Integrated Cancer Service contact and information directory . The most obvious of these are the basic elements; user tested, easy to use and up to date. Plain English was seen as important given Australia's low health literacy rate and in acknowledgement of the needs of women with low basic literacy. In addition, features such as the ability to search by type of cancer, type of support and local area. These searches would also need to be printable so that service providers such as GPs can provide relevant information to their patients and people can look up the information for themselves, or friends and family, when they have access to computer or broadband.

Digital inclusion is also an important consideration. Realising that older Australians are less likely to have computers and know how to use them, and that many rural areas do not have reliable access to the internet means that care needs to be taken to make digital solutions possible and workable.

Avoiding duplication was also seen as important but it should not be forgotten that currently information on all cancer support options cannot be obtained from a single location. Providing links to information already in existence will be important. Being aware of all the information is available is also important so posters, bookmarks and other resource materials will be essential.

Information Hubs: information provided face to face (80%) and written information (61%) were the top two preferences reported by rural and regional women. In order to reach people with disadvantaged backgrounds service providers supported a concept of services and consumer events being held in local venues close to where they live. Timing of information is important; too much information at one time - particularly at diagnosis when there is a range of emotions occurring- can be overwhelming. Information provided in lay terms and specific to type of cancer is preferred. Support champions such as the McGrath nurses are seen as an excellent source of information and support. Accessing a broad array of available literature and having someone available to answer / clarify queries in a local central space was put forward as the ideal by women participating in focus groups.

Consumers had a very strong preference for face to face information. Many discussed the importance of being able to participate in a dialogue so that the information could be immediately discussed and clarified. Some found the group setting of a forum worked well for them, some mentioned support groups and others learnt a lot from someone else in a similar situation. Family and friends were cited as strong sources of information and support.

In thinking about approaches to respond to this gap, the costs of providing face to face support to rural areas was acknowledged. Having time for questions built into sessions with health professionals was seen as important but complementing this with trained peer support volunteers was seen as more viable. Discussion with stakeholders identified a range of ways improvements might be possible with this is mind. One of these was the idea of having set times when local information hubs such as those at treatment centres were attended by trained peer support volunteers. Another was to consider a visiting van or bus like the mobile library that also had the addition of trained peer support volunteers.

Service Provider Education (non-clinical issues): Consumers perceived a range of non-clinical topics to be highly important including: emotional and psychological support (81%), communicating with family and friends (76%), exercise (72%), diet (67%) financial support and entitlement (65%), intimacy and sexuality (55%). The literature identifies a lack of knowledge about services available for referral by service providers and varying skills for identifying needs and tailoring and timing support interventions. Women participating in the focus groups also reported limited knowledge of service providers in regard to the support available for women with less common cancers. While service providers currently provide information and support on a range of topics they did indicate that they would like to be even better informed about some topics so they can provide up-to-date and relevant information.

Service providers, especially GPs were generally less satisfied with information relating to non-clinical aspects of cancer clients' needs. This included practical information on finances or travel assistance. Increasing the profile of CCVs new service and provision of survivorship training in rural settings were discussed as potential options to address this issue. The centralised website suggested earlier would also help ameliorate this.

Drawing from these findings, a number of options stand out as meeting the previously mentioned project benefits. These include: increasing Peer Support options, improving GP involvement, creating a central website that lists relevant support services, creating local information hubs (where they do not exist) and service provider training in non-clinical cancer issues.

6. Recommendations

The 2015 Connecting and Supporting Rural and Regional Women Project captured a range of data and information to inform key stakeholders including Department of Health & Human Services' Cancer Strategy and Development, BreaCan Advisory Group, Integrated Cancer Services (both regional and metropolitan) and Primary Health Networks on the gaps in existing supports and resources and opportunities for improvement.

The recommendations are in line with the principles outlined in the Victorian Cancer Services Framework, emphasising:

- multidisciplinary cancer care to ensure effective and efficient patient management;
- maximum geographic access for patients and their carers / families; and
- high quality and safe cancer services.

Principal recommendations

1. Broaden access to peer support options for women with cancer in rural and regional areas

   1.1 Train and support local peer support volunteers (local is defined as within an hour or two's drive)
   1.2 Increase awareness of existing peer support options
   1.3 Investigate innovative approaches to extend the reach of peer support options.

2. Work more closely with General Practice to raise awareness of the information and support needs of patients diagnosed with cancer

   2.1 Inform General Practices about available information and support
   2.2 Educate general practices in topics they would like to receive additional information
   2.3 Explore tools for assessing non-clinical needs of people with cancer in general practice.

3. Increase awareness and quality of statewide websites (either existing or in development) that list relevant support services by improving promotional initiatives

   3.1 Increase user friendliness (lay language, search function).
   3.2 Develop websites and test with people affected by cancer
   3.3 Develop marketing and resource material for rural context
   3.4 Include maintenance.

Other recommendations

4. Identify opportunities for local information hubs where they currently do not exist

5. Provide education (regular and targeted) for service providers about non-clinical issues for people experiencing a cancer diagnosis

7. Proposed Implementation for a transferable and sustainable model of rural peer support

Current Regional Situation

Peer support is accessed within the two regions mostly via support groups, there is some access to telephone and online peer support options, while some women accessed peer-to-peer support incidentally (cousin, friend of friend, etc.) However, there was a strong indication from rural and regional women in the BSW and Grampians region that they would like greater access to a range of peer support options.

Whilst many respondents of the consumer survey highly valued support gained from attending support groups, others indicated that support group(s) they have access to are not the right fit for them (or they are not interested in support groups). Respondents to the consumer survey also indicated a high preference for receiving support via 'face-to-face' followed by 'with a peer group' while other options for receiving support were rated low.

Telephone and online options may have been rated low because women had not utilised them, making it difficult for them to rate these options highly for receiving support. If a reason for limited uptake is due to rural and regional women not having the opportunity to utilise these telephone and online support options, it may be beneficial for these options to be further explored for future implementation as these options have the potential for overcoming geographic barriers and privacy issues. There is a strong case for increasing the profile of existing peer support options through the proposed centralised website.

The evidence suggests that rural areas will have an expanding and aging population, with an increase in the prevalence of people with cancer. As such, there will be a need for expanded supportive services in regional and rural Victoria in order to meet this increasing demand. Decentralisation should therefore be encouraged and promoted. Expansion of peer support programs and services such as the BreaCan program to regional and rural areas would provide an opportunity to address the disparity in available services and resources between metropolitan and rural Victoria.

Increasing peer support, aligns closely with the Victorian Cancer Action Plan, Victorian Optimal Care Pathways and BreaCan's strategic objectives by creating better experiences for cancer patients and carers. By extending this "bond of common experience" where peer support has been shown to improve a person's self-efficacy, wellbeing and social supports, rural and regional women will be better able to manage their issues in the future. Potentially, this may reduce long term care costs by assisting with early identification of supportive care and information needs.

The implementation of a broader women's peer support model also addresses key challenges outlined in the Victorian Health Priorities Framework 2012 – 2022: Rural and Regional Health Plan which includes reducing the disparity in health behaviors and outcomes, improving health literacy, and ensuring service design and capacity meets population demand and regional characteristics.

The attached implementation plan aims to outline a process to improve the information and support available to women in the form of peer support.

Pilot Project Implementation Plan

Objective

To provide comprehensive information and peer support services to regional and rural Victorian women diagnosed with cancer, their family and friends. The service will provide high quality, region specific information that is regarded by local women as relevant, useful and accessible.

Intervention

In partnership with regional cancer care service providers, BreaCan's unique model of information and support would be extended into a rural setting to increase local support options for women affected by cancer not just those with breast and gynaecological cancers. A variation on the hub and spoke model using the expertise of BreaCan and local partners (primarily health services) in Victorian regional centres would utilise existing resources to minimise duplication.

Qualities that make BreaCan's model unique in the Victorian cancer landscape

A number of organisations, some small and local and others statewide or national, provide support and information for women diagnosed with cancer. However, a unique quality of the Victorian BreaCan model is that the volunteers are all women who have had their own cancer experience and they provide tailored support based on women's expressed need. These volunteers receive extensive training followed by ongoing supervision, debriefing and education. There has been strong support for the model which is by women for women.

Many people diagnosed with cancer feel "lost in transition" at the end of their treatment, a feeling that may be magnified by geographic isolation of rural / regional living. Peer support volunteers are in a unique position, different to most healthcare providers, in that they can provide empathy and non-clinical assistance from a first-hand perspective. This complements the medical model and has been shown to support survivorship and wellbeing.

Training and support

The BreaCan model

At the core of the BreaCan service model is the provision of experiential support by trained peer support volunteers. Following recruitment and eligibility process, volunteers undergo a comprehensive training program prior to commencement. Peer support volunteers are trained in a wide range of skills from communication, self-awareness and information provision to emotional and practical support, ethics and confidentiality. They are also provided with ongoing support such as debriefing and professional development.

Provision of peer support is integral to the delivery of BreaCan's services. The knowledge and experiences of trained peer support volunteers enables BreaCan to offer high quality, responsive and supportive care for women with a breast or gynaecological cancer in a safe and welcoming environment. The provision of comprehensive training provides a solid foundation for building a skilled volunteer workforce to ensure the ongoing and successful delivery of BreaCan's services. A clear and thorough recruitment process is an essential first step in the BreaCan approach. Information sessions, pre-requisite criteria, application, interview and group work are used to ensure peer support trainees are of a high standard.

A six week training program has been developed using a range of medical experts, health professionals and members of BreaCan's staff and volunteer workforce. Delivery of the content is supported by provision of educational resources and self-directed learning activities. An online training portal has also been developed to support the completion of learning activities and facilitate access to online resources.

The program is structured around six modules which are interrelated and designed to build on the knowledge and skills gained from previous modules. The modules include:

Module 1 – Introduction to BreaCan and volunteering
Module 2 – Understanding cancer
Module 3 – Building communication skills
Module 4 – The cancer journey
Module 5 – Exploring diversity
Module 6 – Information provision and preparing for volunteering

BreaCan Post Training Support Approach / Modules:
Initial training is followed by a three month orientation period and after the peer support volunteer has "graduated" they are then rostered regularly and asked to attend at least two of the three scheduled in-services each year.

Peer support volunteers always have access to staff support – even in an outreach context. This ensures that liaison with partners / health professionals is undertaken by a staff member and that debriefing is available. Volunteers are always provided with the opportunity to debrief at the end of a session and can access further support by phone, if required.

The Volunteer Coordinator monitors a volunteer's health status and general circumstances and incorporates this information into rostering on an ongoing basis. Throughout the year volunteers have opportunities to meet as a group. Some of these are social events to celebrate the work of the volunteers.

Peer support volunteers, as previously stated, have themselves been diagnosed with cancer and in offering support to others may become distressed and are emotionally susceptible. BreaCan is sensitive to this and within a strong support system, provides debriefing, support and feedback on a regular basis which will be extended to regional volunteers by a trained staff member centrally located. Alternatively, if face to face support is required then it will be incorporated as part of the pilot model i.e. local access to appropriate counselling.

The BreaCan model would be adapted to make it accessible in rural and regional areas depending on the location and the services available. It is critical that there is a strong local leader to partner with. A range of models using the BreaCan approach will help to ensure local improvements in access to information and support with assistance from BreaCan and building on existing services.

Pilot Aims:
As a first stage it is proposed to roll out this pilot project in two rural regions. The pilot aims to implement a transferable sustainable model of peer support in identified areas across two regional ICS boundaries. The pilot should consider a mix of one larger regional centre and one small rural centre per region.

Project Governance:
A pilot Project Steering Committee will be established combining representatives from across the regional areas. Of critical importance for "on the ground" engagement will be representatives from local health services and general practices. Video conferencing will be the meeting platform of choice to contain the travel required for participants.

Project Scope:
The project scope will include

- Two regional areas (per existing R / ICS boundaries) and two targeted sites within the two regions
- Concentrate on a peer support model involving volunteers who have had a cancer experience to address one of the major themes elicited from the needs analysis.

Project Promotion:
The project is now aware that the ways women access information about services available in country areas differs in nature from women living in a metropolitan location. A marketing plan would be developed to reflect these differences.

Project Challenges
Common but not unique to the health sector, local resources are likely to be already stretched. Funding for training and in-service would have to be in addition to current arrangements. Local support roles may find it difficult to have time released to participate as key contacts, so backfill resources will need to be incorporated in the project budget.

How would the pilot model operate?

- Development of partnership agreements to address and ensure best practice re recruitment, training, delivery, service provision, ongoing training and support

- Following consultation with key stakeholders, BreaCan and participating health services, ICS and PHN would be engaged in discussions on how to best match the pilot aims with local expectations for targeted rural and outreach models

- Project plans for each site are developed and signed off by the local steering committee

- BreaCan provides ongoing leadership in peer support for women and cancer and provides ongoing support / expertise to service providers

- Participating health services identify a key person in a relevant role to seek interested volunteers

- Local support person recruits peer support volunteer/s in collaboration with BreaCan

- Volunteers attend training with relevant sessions face to face and at least one at BreaCan then via a VC platform (Health Direct)

- Volunteers then could be utilised at local appropriate events and other supported scenarios. Regular in-service training would be provided by BreaCan along with opportunities to get together with other volunteers. Day to day support including debriefing and supervision would be provided by local support person, backed up by BreaCan.

Evaluation

Project / program evaluation is a critical aspect of the accountability and sustainability for this initiative and will be included as part of the project plan. This will include a formative, process, impact and outcome evaluation.

8. Appendices **(abridged)**

I: Literature Review

II: Barwon South Western Region Socioeconomic Index

III: Grampians Region – Relative Socioeconomic Disadvantage

IV: Colac forum invitation and running order

V: Ballarat forum invitation and running order

VI: Round Table Summary

VII: Focus group notes – Colac

VIII: Focus group notes – Ballarat

IX: Project Findings

X: Consumer Survey

XI: Service Provider Survey

Appendix I: Literature Review

Exploring the barriers rural and regional people face in accessing information and support.

Prior to commencing a needs analysis of the BSW and Grampians region to understand the information and support experiences of rural and regional women living with cancer, a literature review was conducted to explore the barriers faced by rural and regional people in accessing support and information.

The literature review includes both peer reviewed journal articles found using academic databases and other literature obtained via a desktop review including reports and research conducted in rural and regional Australia.

Introduction

It is important that people diagnosed with cancer have access to supportive care which can be obtained through a variety of mechanisms (Department of Human Services, 2009, p.5) including support and information.

Benefits associated with supportive care include better emotional and psychological health and improved medical outcomes through better adherence to treatment including faster recovery, along with fewer post-hospital complications, enhanced self-care and greater ability to cope with difficult treatments (Supportive Care Policy, 2009, p.5). Research indicates that people living in rural and regional areas of Australia have relatively poorer survival rates (AIHW, 2007; Fox & Boyce, 2014,) and poorer access to services including supportive care. The literature suggests it is likely that a lack of access to supportive care is one of many factors contributing to poorer emotional and psychological health, and therefore poorer medical outcomes and lower survival rates.

According to the literature, rural and regional people face a number of barriers to accessing and utilising information and support, including: attitudes and health seeking behaviours, availability of support & support services, limited knowledge about services and service coordination, poor health literacy and higher levels of poor social determinants, and barriers faced by service providers.

Attitudes and health seeking behaviors

Research indicates that attitudes and health seeking behaviors of rural and regional people living with cancer can act as a barrier and enabler to utilisation and demand for support services (Gunn et al., 2013).

Psychological and emotional support

- Perceptions about psychological and emotional support are important: Some rural and regional people miss out on services because they do not perceive them as being important (Gunn et. al., 2013), other rural and regional people value a range of different types of psychological and emotional support, including: lay community support (Duggleby et al., 2011; Verde et al., 2004), peer support and professional support (Verde et al., 2004).
- Awareness of specific concerns of rural women living on properties, including: “separation from family and friends during a time of great vulnerability for treatment; the need to travel long distances for support and follow-up services, and extra financial burdens which can combine to cause strain on marital relationships and family cohesion (McGrath, Part 1: 1999, p.43)”
- Importance of conversation: some rural and remote women have a “strong need for support and conversation (McGrath et al., Part 1: 1999, p. 41)”.

Practical support

- A range of practical support is required by rural and regional women: transport, financial assistance/advice, accommodation, childcare, home-help etc. (Verde et al., 2004; Health Issues Centre, 2009; Goldstein & Underhill, 2007; Women's Health Grampians, 2006).
- There is a need for support regarding travel and accommodation for treatment, either with transportation or accommodation itself or financial reimbursement (Verde et al., 2004; Health Issues Centre, 2009; Goldstein & Underhill, 2007).
- A lack of access to palliative care services, with referrals to these services frequently made too late (Duggleby et al., 2011; Women's Health Grampians, 2006).

Local services

- Lack of privacy: some women living with cancer do not want to access local support services due to privacy reasons (Church & Curran, 2000; Gunn et al., 2013; Verde et al., 2004)

Limited knowledge about existing services and service coordination

Limited knowledge about existing services and a lack of coordination between services can act as a barrier to accessing services.

- A lack of information about services for consumers
- Unmet navigation needs, information about support services needs to be accessible and easy to navigate (Gunn et al., 2013; Women's Health Grampians, 2006)
- A lack of coordination between services (Gunn et al., 2013; Women's Health Grampians, 2006; Drury & Inma, 2010)
- Breast Care Nurses and Cancer Coordinators play an important role in connecting rural and regional women to support services (Women's Health Grampians, 2006; Drury & Inma, 2010; Goldstein & Underhill, 2007; Duggleby et al., 2011).

Availability of support

Rural and regional women living with cancer require a range of different types of support (informal, professional, peer support, innovative approaches), which may be difficult to access because of the barriers.

Informal support

- Some rural and regional women living with cancer have access to strong informal support networks such as family, friends and/or the community (Duggleby et al., 2011; Gray et al., 2003; McGrath, 2000; Verde et al., 2004)
- Some women living with cancer do not experience strong informal support networks, and consequently should be targeted for support (McGrath, 2000)
- Some people rely on family and friends for support largely due to the absence of alternative support (McGrath, 2000 p. 142)."

Professional support

- Rural and regional women need access to psychosocial services (Gunn et al., 2003; Women's Health Grampians, 2006)
- Informal support networks need access to psychological support (Gray et al., 2003; McGrath, 2000)
- Counselling is recognised as an effective service to assist people with cancer deal with emotional trauma but access to and affordability of counselling services can be an issue in rural areas (Verde et al., 2004).

Peer Support

- Peer support is important for rural and regional women living with cancer (Solberg et al., 2003; McGrath, 2000; Gray et al., 2003; Church & Curran, 2000)
- There are many benefits associated with peer support: minimize fears, normalize experiences, offer a survivorship perspective, shared understanding, learn from one another and reduce isolation (Gray et al., 2003; Solberg et al., 2003; Church & Curran, 2000)
- Ideally peer support should be with someone who shares a similar experience (Church & Curran, 2000)
- Professional support can assist with the delivery of peer support (Gray et al., 2003; Church & Curran, 2000).

Innovative approaches to providing support and information

- A rise in innovative approaches for provision of information and support such as the use of telephones and audio conferencing technologies (Solberg et al., 2003; Curran & Church, 1999; Davis, 2008)
- Innovative technologies can be utilised to provide information, peer support, telehealth, shared care and much more (Davis, 2008; Fox & Boyce, 2014)
- Use of technologies can overcome geographic barriers and privacy issues (Church & Curran, 2000)
- It is important that innovative technologies are accessible to those who are in most need of support such as people from disadvantaged backgrounds (Smith et al., 2008).

Poor health literacy and low socio-economic background

According to the literature, a barrier to accessing and utilising information and support services is poor health literacy (Gunn et al., 2003; Martinez-Donate, et al., 2013; Smith et al., 2008) and low socio-economic background (Dixon & Welch, 2000; Smith et al., 2008).

- It is important to target people with disadvantaged backgrounds to ensure that interventions and support services reach populations "where the greatest health gains may be obtained (Smith et al., 2008, p. 60)."
- Patient "navigation programs and adoption of health literacy best practices among systems and providers could contribute to improved cancer care delivery and cancer-related outcomes among rural populations (Martinez-Donate et. al., 2013 p.580)."

Barriers faced by service providers

Service providers can enable women to access supportive care services. However, there are barriers that prevent service providers from providing information and support for women living with cancer.

Service providers are not able to respond to the needs of women due to:

- Time limitation and workload (Women's Health Grampians, 2006)
- Differing perceptions about: their role in supportive care and support needs for women with cancer (Women's Health Grampians, 2006; Lee, 2007)
- A lack of knowledge about services available for referral (Women's Health Grampians, 2006; Lee, 2007)
- Varying skills for identifying needs and tailoring and timing support interventions (Women's Health Grampians, 2006; Lee, 2007)

Shared care with general practitioners is the way forward, particularly in situations where patients need to travel long distances to see specialists (Fox & Bryce, 2014).

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Women s Health Goulburn North East, 2010. Exposed: a literature review of the issues of women's cancers in Australian Indigenous communities. Wangaratta, Vic: 1-52.
URL: http://www.whealth.com.au/documents/publications/whp-exposed_a_literature_review.pdf

Cancer Action Victoria, 2014. Empowering Rural Consumers Project Report. Cancer Australia Supporting People with Cancer Grant.

To develop competencies for consumer involvement in advocacy in rural areas of Victoria by training consumers (CALD people, Aboriginal and Torres Strait Islander people, refugees, people with disability) to be trainers for other consumers who can then advocate for people with cancer in their local community. There were 7 trainers representing 4 regions.

The *train the trainer program* focused on three main areas:

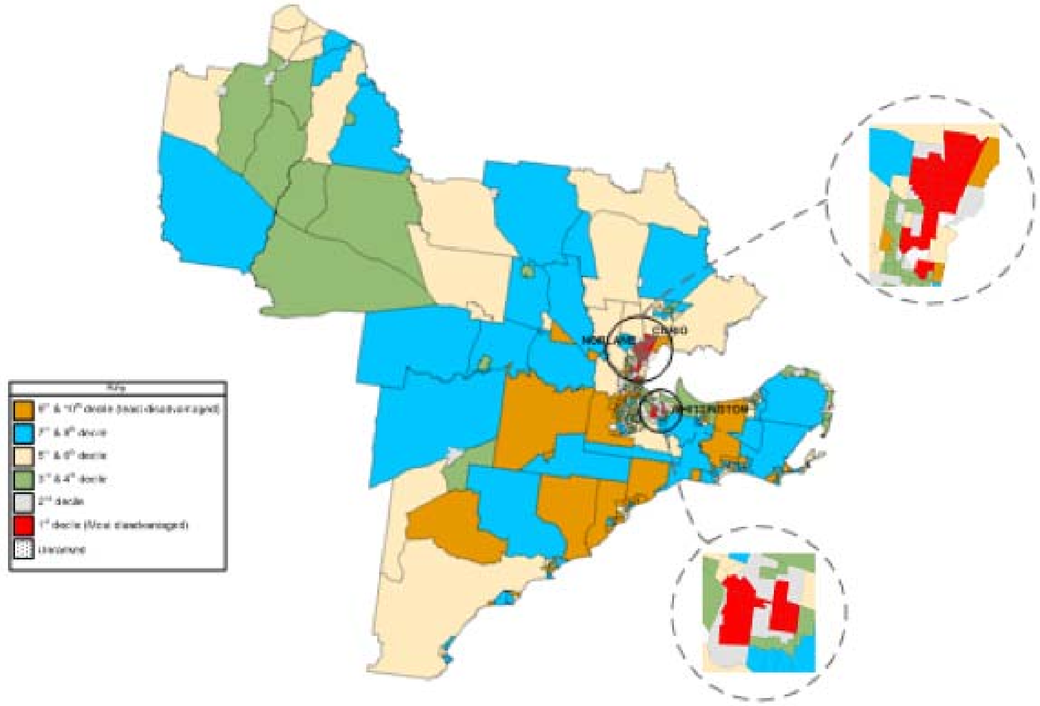
- The development of facilitation skills
- Understanding and familiarising with the training content
- Organisational and logistical aspects of delivering training.

Key findings:

- The need for strong governance
- Open communication channels
- Selection of a project officer and consumers to participate
- Early involvement of key people in rural areas.

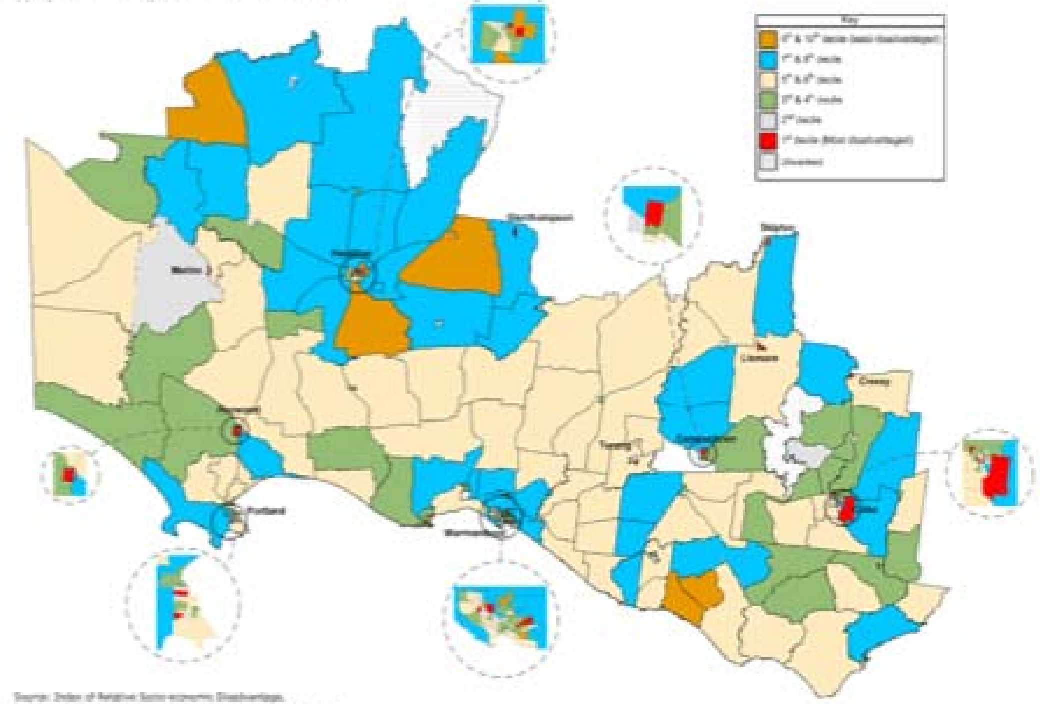
Appendix II: Barwon South Western Region Socioeconomic Index

Mapping of disadvantage, G21 (excluding Colac-Otway), 2006



Source: Index of Relative Socio-economic Disadvantage,
Census of Population & Housing 2006, Australian Bureau of Statistics

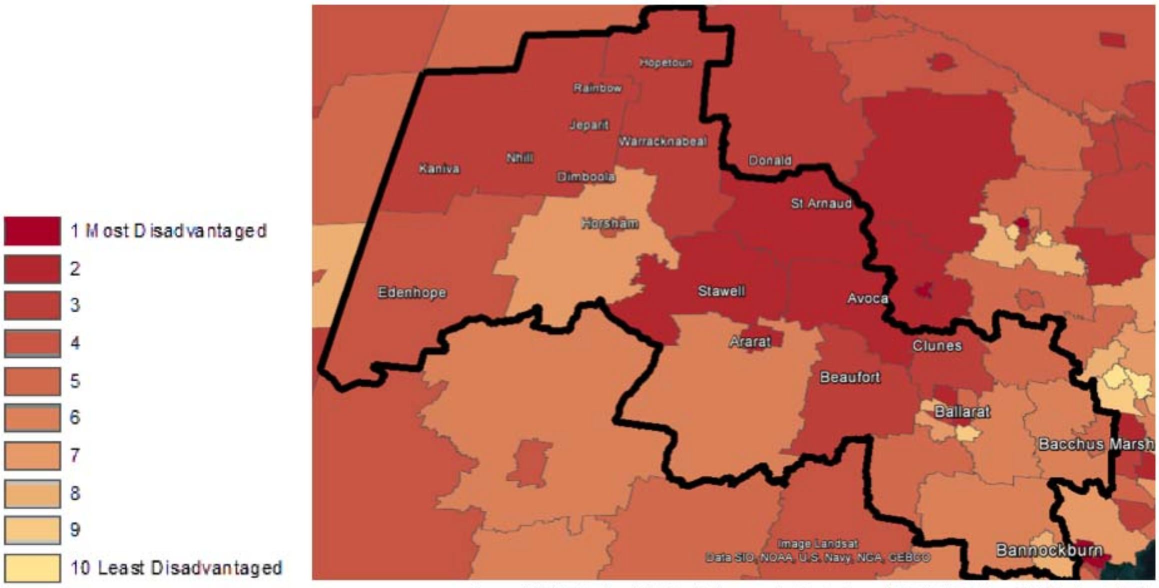
Mapping of disadvantage, Great South Coast, 2006



Source: Index of Relative Socio-economic Disadvantage,
Census of Population & Housing 2006, Australian Bureau of Statistics

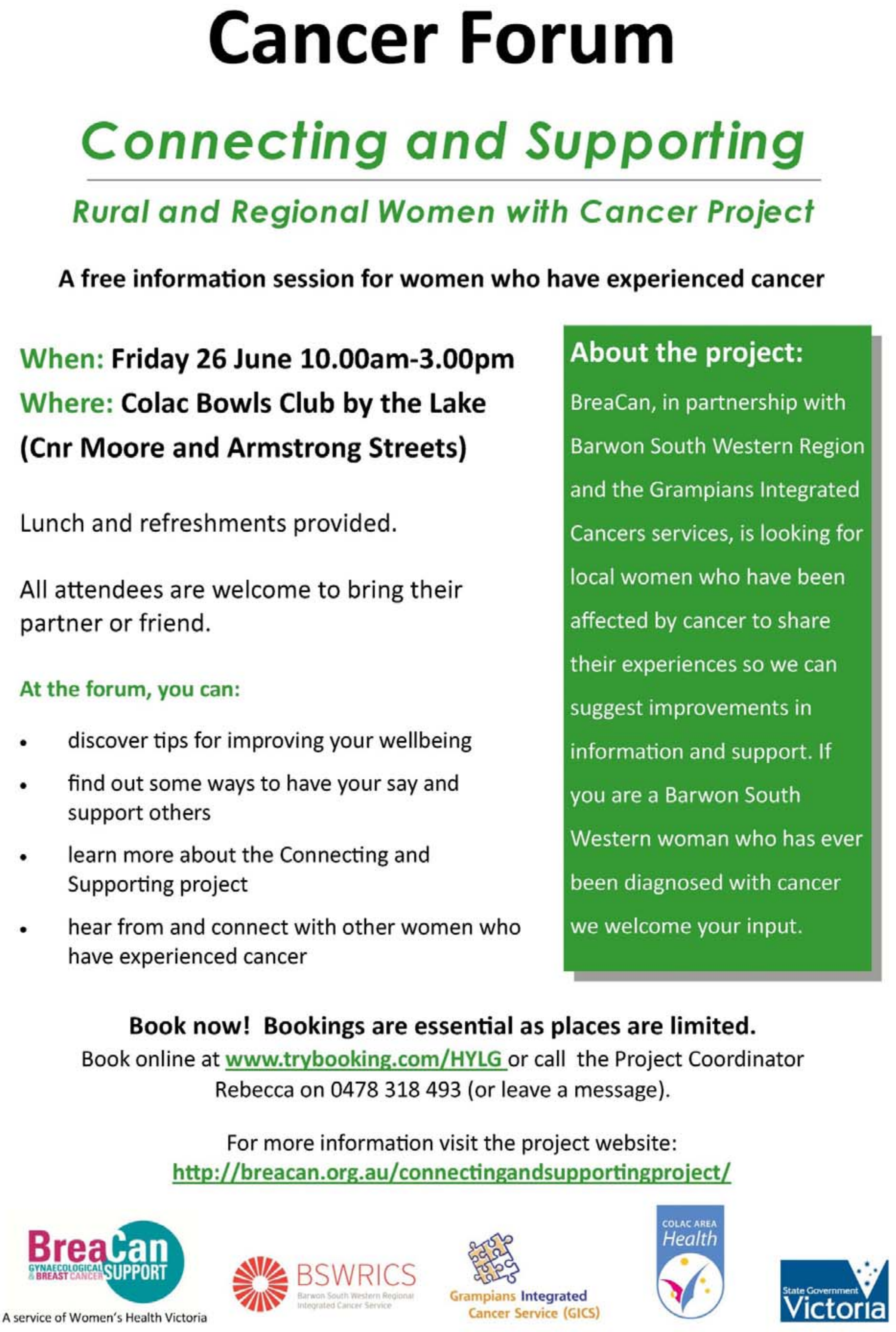
Appendix III: Grampians Region – Relative Socioeconomic Disadvantage

Grampians Region - Relative Socioeconomic Disadvantage



Source: ABS, SEIFA Index of Relative Socioeconomic Disadvantage, 2011, Statistical Area 2 (SA2), Google Earth

Appendix IV: Colac forum invitation and running order



Cancer Forum

Connecting and Supporting

Rural and Regional Women with Cancer Project

A free information session for women who have experienced cancer

When: Friday 26 June 10.00am-3.00pm
Where: Colac Bowls Club by the Lake
(Cnr Moore and Armstrong Streets)

Lunch and refreshments provided.

All attendees are welcome to bring their partner or friend.

At the forum, you can:

- discover tips for improving your wellbeing
- find out some ways to have your say and support others
- learn more about the Connecting and Supporting project
- hear from and connect with other women who have experienced cancer

About the project:

BreaCan, in partnership with Barwon South Western Region and the Grampians Integrated Cancers services, is looking for local women who have been affected by cancer to share their experiences so we can suggest improvements in information and support. If you are a Barwon South Western woman who has ever been diagnosed with cancer we welcome your input.

Book now! Bookings are essential as places are limited.
Book online at www.trybooking.com/HYLG or call the Project Coordinator Rebecca on 0478 318 493 (or leave a message).

For more information visit the project website:
http://breacan.org.au/connectingandsupportingproject/

BreaCan Gynaecological & Breast Cancer Support
A service of Women's Health Victoria
BSWRICS Barwon South Western Regional Integrated Cancer Service
Grampians Integrated Cancer Service (GICS)
Colac Area Health
State Government Victoria

Connecting and Supporting

Rural and Regional Women with Cancer Project

COLAC FORUM

Friday 26 June 10am-3pm

Time	Session	Presenter
10:00am - 10.05am	Welcome	Marita Reed, Service Development Manager BSWRICS
10.05am - 10:15am	Introduction to the Connecting and Supporting Project	Lee Kennedy, BreaCan Manager
10:15am - 10:25am	Peer Support	Fiona McRae Team Leader, BreaCan Programs
10:25am -10:40am	Local Service Update	Geoff Isles, CEO for Colac Area Health
10:40am - 12:00pm	Wellness Workshop	Tara McKinty, Co-Founder/Counsellor The Sanctuary Counselling Centre
12.00pm - 12:40pm	Lunch	
12.40pm - 1:00pm	Power of the consumer voice Q&A	Fae Lovell, member of BSWRICS Consumer Advisory Group Marita Reed, Service Development Manager BSWRICS
1:00pm - 1:55pm	Focus Groups	Lead by BreaCan, BSWRICS & Colac Area Health
1:55pm - 2.25pm	Connecting and Supporting Project Survey	
2.25pm - 2.45pm	Focus Groups – key points of discussion	
2.45pm - 3:00pm	Meditation and Music	Tara McKinty Co-Founder/Counsellor The Sanctuary Counselling Centre

A service of Women's Health Victoria

Appendix V: Ballarat forum invitation and running order

Cancer Forum

Connecting and Supporting

Rural and Regional Women with Cancer Project

A free information session for women who have experienced cancer

When: **Wednesday 8 July**
10.00am-3.00pm
Where: **Ballarat Community Health**
Lucas Site, 12 Lilburne St.

Lunch and refreshments provided.
All attendees are welcome to bring their partner or friend.

At the forum, you can:

- discover tips for improving your wellbeing
- find out some ways to have your say and support others
- learn more about the Connecting and Supporting project
- hear from and connect with other women who have experienced cancer

About the project:

BreaCan, in partnership with Barwon South Western Region and the Grampians Integrated Cancers services, is looking for local women who have been affected by cancer to share their experiences so we can suggest improvements in information and support. If you are a Grampians woman who has ever been diagnosed with cancer we welcome your input.

Book now! Bookings are essential as places are limited.

Book online at www.trybooking.com/IAKL or call the Project Coordinator Rebecca on 0478 318 493 (or leave a message).

For more information visit the project website:
http://breacan.org.au/connectingandsupportingproject/

A service of Women's Health Victoria

Agenda

Connecting and Supporting Project: Ballarat Forum

Wednesday 8 July 10am-1pm

Time	Session	Presenter
10.05am-10:10am	Welcome & Introduction to the *Connecting and Supporting Project*	Lee Kennedy, BreaCan Manager
10:10am-10:20am	Get to know you activity	Everyone
10:20am-11.20am	Your say: Information and Support (focus groups)Wellness Workshop	Lead by BreaCan, BSWRICS & GICS
11.20am-11.50am	Fill-out survey	
11.50am-12pm	Self-care strategies	Lead by BreaCan
12pm-1pm	Lunch & learn about Ballarat Community Health Smoothie Bike, walk & check out the display table.	Lead by Ballarat Community Health

Appendix VI: Round Table Summary

Connecting and Supporting

Rural and Regional Women with Cancer Project

"Round Table" Luncheons – September 2015

Introduction

The *Connecting and Supporting Project* held two "Round Table" Luncheons, one in Geelong on Tuesday 15 September and another in Colac on Wednesday 16 September.

During the past 6 months, the *Connecting and Supporting Project* has conducted community consultations in the form of interviews, focus groups and surveys. These community consultations have been conducted in the Barwon South West and Grampians region to develop an understanding of the experiences, needs and gaps in information and support for rural and regional women living with cancer.

The "Round Table" Luncheons were held as a means of community collaboration, to:

- Share findings from the community consultations with the community
- Seek community feedback and impressions regarding community consultation findings
- Work together with the community to develop options for improving information and support for rural and regional women living with cancer.

Women living with cancer and service providers were invited to attend the events. There were 420 service providers invited (320 of these were GPs). All service providers received an email invitation, except for GPs who received a posted invitation. Women living with cancer were invited via personal mail (post or email) and promotion of the event via clinicians and poster displays in treatment centres.

Attendees

There was a total of 52 attendees at both events:

Attendee type	Geelong	Colac	Total number of attendees
Consumer	15	17	32
Service Provider	9	11	20
Total at each event	24	28	52

- Geelong attendees: 24 (15 consumers and 9 service providers)
- Colac attendees: 28 (17 consumers and 11 service providers)
- Consumers (total from both events): 32
- Service providers (total from both events): 20 attendees

Service providers

A range of service providers attended both events:

Type of service providers	Organisations
Radiotherapy Nurse Chemotherapy Nurse Clinical Coordinator Clinical Nurse Educator Assessment officer for Aged Care GP Psychiatrist Counsellor Manger of Allied Health Mangers of clinical and supportive care departments	BSWRICS Colac Area Health Colac Otway Shire Otway Medical Clinic South West Healthcare Barwon Health The Sanctuary Counselling Centre

Consumers

Women living with different types of cancer attended, and the length of time since diagnosis also varied.

Community feedback and impressions regarding community consultation findings

Key findings from community consultations were presented and discussed by attendees. Feedback included:

- Surprised that a high portion of respondents (Service Provider Survey) indicated that it is within their role and they do have time to provide information about cancer related topics and support services (Colac & Geelong).
- Not surprised that a high proportion of women were less satisfied with information about non-clinical topics (Geelong).
- A nurse commented that it is important to keep in mind that often only 1/3 of information given to cancer patients is retained and it is particularly difficult for cancer patients to retain information at the time of diagnosis (Geelong).
- Difficult to get clinicians to tell women about support groups (Colac).
- Form of support: many women do not use the internet or have email addresses (Geelong & Colac).

Rating options for improving information and support

All attendees were given an ‘Option Rating Sheet’ which listed five options for improving information and support for rural and regional areas. These 5 options were developed based on community consultation findings with members of the Project Steering Committee Meeting and BreaCan staff at a workshop. At the Round Table Luncheons, attendees were asked to rate these options from most important or “most like to see happen” (rated 1) to least important or “least like to see happen” (rated 1). The options with the lowest score were rated most important.

Options for improving Information and Support	**Colac score (rating of importance)**	**Geelong score (rating of importance)**
1. Create a statewide website that lists relevant support services	81 (4)	50 (2)

2. Create local information hubs where they do not currently exist	57 (1)	58 (4)
3. Increase peer support options	63 (2)	46 (1)
4. Work more closely with general practice	59 (3)	51 (3)
5. Education for service providers about non-clinical issues for people with cancer	98 (5)	78 (5)

Similarities between both areas

- Both areas rated “Increase peer support options” and “Work more closely with general practice” within the top three most important options.
- Both areas rated “Education for service providers about non-clinical issues for people with cancer” as least important.

According to the ‘Option Rating Sheet’: “Increase peer support options” and “Work more closely with general practice” are considered to be highly important options; “Education for service providers about non-clinical issues for people with cancer” is a less important option.

Difference between option ratings for both areas

- “Create local information hubs where they do not currently exist” was rated as most important at the Colac event, yet it was rated fourth at the Geelong event.
- “Create a statewide website that lists relevant support services” was rated second most important at the Geelong event “and fourth at the Colac event.

There is only so much we can infer from this, but it is interesting that this contrast exists between an event held in Geelong (a regional town) and an event held in Colac (a rural town). This difference may be a coincidence or it may be due to:

- An older population, who are less likely to use the internet
- Poorer internet access in Colac compared to Geelong

Comparing consumers and service providers

The ‘Option Rating Sheet’ included a question asking who was completing the sheet (woman living with cancer, service provider, both). Unfortunately, 17 attendees did not complete this section of the ‘Options Rating Sheet’. Of those who did: Service provider (11), Consumer Both (2). As only two people selected the option ‘both’ (a service provider and a women living with cancer), these results have not been included.

Options for improving Information and Support	**Service Provider (rating of importance)**	**Consumer (rating of importance)**
1. Create a statewide website that lists relevant support services	33 (4)	38 (2)
2. Create local information hubs (where they do not currently exist)	29 (2)	45 (4)
3. Increase peer support options	32 (3)	24 (1)
4. Work more closely with general practice	25 (1)	39 (3)

5. Education for service providers about non-clinical issues for people with cancer	30 (5)	64 (5)

- Both consumers and service providers rated “Increase peer support” and “Work more closely with general practice” as the top 3 most important options.
- Both consumers and service providers rated “Education for service providers about non-clinical issues for people with cancer” as the least important option.

Development of options for improving information and support

After rating the five options for improving information and support, attendees were divided into groups (by choice) to further discuss one or two options for improving information and support for rural and regional women with cancer. A facilitator led each group and notes were taken.

Each group discussed the following points:

1. What is good about this option?
2. What is not good about this option?
3. Local knowledge: how could this option work in your local area and other rural and regional areas in Victoria?

The following notes were made about each option:

Option 1. Create a state-wide website that lists relevant support services

Geelong		
1) Why is this option good?	**2) Why might this option not be good?**	**3) Local knowledge**
• It is statewide: • Consumer choice (re: local services) • Can check for mum, family members • 24 / 7 access • Helpful for service providers assisting patients from elsewhere • Future focused • Cheaper than printing • Clinicians can be the middle person	• Assumes computer knowledge • Rural access to broadband: big issue • Will not work if it gets out of date • Ensure private patients are in the loop • Impersonal • If it is not easy to use, it needs to be user friendly (test with women)	• Local services must update / maintain • Needs local computer training • Needs hubs because some don’t have a computer and cannot always make support group meetings

Colac		
1) Why is this option good?	**2) Why might this option not be good?**	**3) Local knowledge**
• Lots of people could use it • Consistency of information would be easier to update • Can be used by people / family who can help (from other regions) • Private for people who do not want everyone to know about their situation • 24/7 access	• Not having someone to help interpret the information • Not much use if it is not up to date • Broadband access is patchy • Assumes people have a computer and they can read • Concern about comprehensiveness • Validation of information	• Printable options • Trusted providers of information involved • User friendly • Search by location • Human element – ring this number • Feedback about this • Broadly advertised • Cancer knowledge, not just support

Option 2. Create local information hubs where they do not currently exist

Geelong		
1) Why is this option good?	**2) Why might this option not be good?**	**3) Local knowledge**
• It could be a reliable place to go • Somewhere people know they can get correct information • People could get bits of information when they need it	• If people go there and cannot be seen or need to wait a long time to talk to someone • People could get too much information, they tend to take in 1/3 of what has been said and too much information can be overwhelming	• Accessible for anyone diagnosed with cancer (does not matter how long ago they were diagnosed) • Peers who have experienced cancer and been trained could look after the information hub (they understand and they get it) • Advocates could be within the information hub, who not only give information but assist with applications for financial support and entitlements (e.g. navigating Centrelink, accessing super), social welfare • Info hubs could be in hospitals • A warm comforting, friendly place

Colac		
1) Why is this option good?	**2) Why might this option not be good?**	**3) Local knowledge**
• Information van - More personal for friends and family, and people with cancer - Covers rural areas • Information Desk - Otway Health - CAM, GPs • Information on the internet can be very difficult to understand and navigate • Information library • Non-confronting • Internet sites need to be user friendly	• Information to be kept up to date • Some businesses may not want to have information in their shops • Trading hours may limit access	• Information van would cover more rural and regional sites • Reduces financial, time, emotional impact of having to drive to major centres • Would be good to have more local forums • Cancer Concierge would be great to have – as long as they are well trained and their knowledge is up-to-date • People presume that everyone has internet access

Option 3. Increase peer support options

Geelong		
1) Why is this option good?	**2) Why may this option not be good?**	**3) Local knowledge**
• Offers an option for those who are receiving their care in the private sector / hospital • Allows you to share experiences, talk with someone else who has been through the same thing (VIP) • Peer support offers you the option of receiving information / support in different ways – group, one-on-one	• Need training • Getting/giving advice – especially medical advice • Creates uncertainties • In groups sometimes there is one person who takes over • Comparison between people (cancer / treatment) which can be unsettling – training could assist with this	• Local knowledge is handy – peer support person is from the same area • Not having to travel to far • Informal setting works well – e.g. talking over lunch / coffee • Have an Information Centre (van) that comes to us • People stay in units for extended periods of time and are isolated – good time to access support

Colac		
1) Why is this option good?	**2) Why may this option not be good?**	**3) Local knowledge**
• Source of support • Receive information about treatment • Someone to talk to • Understanding for how you feel • Helps you know what to expect • Friendships (like a family) light heartedness	• Can come into contact with: - Negative people - People focused on their own experience • Some people might not know what a support group is like • No one to support the people providing peer support	• All types of cancer need access to peer support • Some people might not want one-on-one • A peer support person for family members – family need someone to talk to • Someone to follow up with people after peer support interaction (particularly after the first time)

Option 4. Work more closely with general practice

Geelong		
1) Why is this option good?	**2) Why may this option not be good?**	**3. Local knowledge: how could this option work in your local area & other rural and regional areas in Victoria?**
• GP know the patient / family whole situation • Practice manager may be able to help – know what's available, especially at first point of contact • Not always • GP kept informed • When could they go – O.C. Pathway	• Constant battle to engage GPs / rooms • Not always first, not automatic part of screening • Public: more standard care • Private: specialist has full contact	• Portal of guest accommodation • Portal can fill avoid between diagnosis and treatment • Contact with initial diagnosis • Reflected in distress – unknown • Depending on cancer – time taken

Colac		
1) Why is this option good?	**2) Why may this option not be good?**	**3. Local knowledge**
• Keeps doctors in the loop so that they can help with other aspects of a patient's healthcare and social situation – means they can look after a person fully • Gives patients confidence in the treatment and that someone is looking after you • Accessibility: the GP is easily able to be accessed and they can call the specialists	• Impact on lifestyle = people get fatigued of seeing a doctor all the time • Sometimes the GP is not sensitive to a person's situation = becomes a bad experience	• More doctors • Make sure GPs are more accessible: reception staff know you have cancer and therefore can always get you in

Option 5. Education for service providers about non-clinical issues for people with cancer

Geelong		
1) Why is this option good?	**2) Why may this option not be good?**	**3) Local knowledge**
• Holistic care, need to look after the whole person including issues such as: - finances (can't work yourself and your partner needs to care for you limiting their ability to work) • Travel / accommodation (regional areas) • Emotional needs (self/ carer / family) • If it can be improved it reduced stress considerably	• Executing change is not easy, requires process improvement • Identify needs – how to use supportive care screening tools • Assess needs – resourcing • Action needs – referral pathway options are known • Different service providers have different processes and different challenges • Challenge for service providers to acknowledge issue and option doors to improve the current processes	• Information sessions

Colac		
1) Why is this option good?	**2) Why may this option not be good?**	**3) Local knowledge**
• Hearing personal stories • Possibility of looking at wellness too • Beyond diagnosis: cancer is one element of one's life • Importance of coordination with other providers • Acknowledging post treatment needs • Link to care places • Longer consultations	• SP might not have time / be their role • SP might be more likely to not refer • Looking at options for other cancers	• PHN to get together relevant providers, having identified a "go to" person

Appendix VII: Focus group notes – Colac

	Group 1	Group 2	Group 3
1.) How would you describe the <u>support</u> you received following your cancer diagnosis? Cues: Where from (local, regional) Who from (clinicians, community members, family, friends) When received (during treatment, after treatment)	• Anam Cara – For people with cancer or carers • Michelle contacted me • Google - Not good – close down - Not well • Michelle – Shire – how do you know otherwise • Do you need support - Hospital - Home help – what it's about <u>Hospital</u>'s shire and visits • Not peer support for general • Family & Friends – sometimes • Sometimes Friends – sometimes • Cancer Council – cancer buddy… • Strange talking to someone you don't know over the phone – strange • But would like the option – who is the connector? • How do you find out about support?	• Surgeon and Nurse • GP / Surgeon / Other - Nurse bag with it all together • Family Friends • Support group • Surge of love at start but tapers off • Phone support good because anonymous • Phone call from peer 4 – 5 times (could be more) • Counsellors available locally • Timing – missing the vital	• Very early gap between being told you have cancer and then seeing a specialist – What do you do? • Need to understand I get support straight away (ie. Does waiting for an appointment make a difference) • Take another set of ears to all appointments to listen and ask questions • Everyone should have access to nursing support like BCNs from diagnosis • Having to go through treatment alone is terrible – especially when treatment goes for a long time • Approaching a support group can be really hard – what would make this easier? - Taking a friend • Colac support group is great - We have a laugh - Share stories – often funny • Lots of handouts all at once • Being diagnosed with less common cancers can be really hard – meeting others can be good (especially in same situations) • Shared experiences – the same or similar across different cancers, waiting for results, appointments, fear of it coming back, etc. • Waiting – being left in the dark – keep people up to date with what is going on • Moving car / parking • Let people know that waiting is inevitable and take things to do

	Group 1	**Group 2**	**Group 3**
2.) How would you describe the <u>information</u> you received following your cancer diagnosis? Cues: Where from (local, regional) Who from (clinicians, community members, family, friends) When received (during treatment, after treatment)	• 100 Michelle's • A lot of other things going on • Got you to where you needed to be and when you needed to be there • No information – many years ago • Need specialised?? • GP – Information • Recommended to see Marg Vesey • Cancer Council (Social Worker) • GP – got a fantastic • ALCC – great with information • Public system – told you everything you needed • Info about all help I needed • Never went into anything unknown • Now days – good treatment breast cancer • Lack? for other cancers • Poor info about treatment (radiation) – ALCC wa/feed through • Gynae cancer – radiation poor informed (told it was like an x-ray) • No nurse or info • Info in writing – not just verbal • Salvation Army (food, bills) • St Vinnies (helped with bills) • Cancer Council • Andrew Love • Travel is a huge problem • Red Cross and Lions (need more with travel) • Parking pain	• Drs and Nurses gave written and verbal • BCNA magazine • My journey kit from hospital • Lack of information for some cancers • Getting information is one thing, reading it is another • Timing – sometimes it's all too much • After surgery more open • Some brochures are scary eg sentinel • Time for questions – written answers • Having another set of ears • Drs could ask people about the information level they want	

	Group 1	**Group 2**	**Group 3**
3.) Were their barriers to receiving information and support? Cues: Issues with accessing support and information: Time (Work, Family), Travel required, Too much information, How to find out what is available?		• Health professionals busyness • Being spoken down to • Anonymity could help some • Being used to being carer – not being cared for • Feeling guilty • Time / tiredness • Travel – everything was plus 4 hours (Melbourne round trip) • Costs • GP place for information • Specialists provide info about local options • Prosthesis • Working in with routine / appointments	
4.) Any suggestions for improving information and support for rural and regional women living with cancer?	• Need someone to come to me • Lack of support for other cancers • Support group tend to be older • Perfect run – Michelle • GP needs to have all the information • Doctors not to give you a time limit • Information (pay) concern • Support Group • Needs to know about opportunity • Someone needs to tell you what is available • Breast cancer – given bag with information	• Linking up – buddying with someone who's been through it/going through it (Could Nurses identify) • Linking up by phone – a check in call • Home visit from nurse/person with list (forums) of supports (tools) available (support options) • Improvements Now • Local services places for specific questions • Better travel support • Assistance with decision making – acknowledging people felt insecure not seeing specialist • GP and Specialists • Making links for after effects • Handing on the baton	• At diagnosis know about cancer support group / someone who has been through what you have been diagnosed with

Appendix VIII: Focus group notes – Ballarat

	Group 1	Group 2
1.) How would you describe the support you received following your cancer diagnosis? Cues: Where from (local, regional) Who from (clinicians, community members, family, friends) When received (during treatment, after treatment)	Support received from: • Husband / family • Breast Care Nurse • Council – home help • Specialist psychologist Where support was received: • Rare Cancers – One National body - single nurse • Facebook/phone • InstaPeer – Peer • Stupid cancer (American site) • Facebook friends – international • Peer Support Groups • Mothers cancer club Timing of support • Support from nurse during chemo o In the meantime aunty took notes • Finding peer support can take too long • Offered peer support at key times (early) • Diagnosis by phone – not okay. High drama, no support • GP could provide face-to-face • GP needs to be careful what they say • Family present • Helped to have someone there after diagnosis to help with shock / questions • Need more cancer nurses who coordinate/info and support/ check in (knowing how to deal with ports) • PCEHR for emergency • Note book or diary with suggestions	• No practical support • Support from Melbourne Leukaemia Foundation • Multiple Myeloma Support Group – wasn't for me • Good community support • And support to deal with overwhelming support • Felt alone • Support groups – *meet others years down the track – 'a relief' 'I was going to survive'* • Friendship from support group • Friends – lost – didn't know what to do • Friends were not helpful (even people who have been there before)

2.) How would you describe the information you received following your cancer diagnosis? Cues: Where from (local, regional) Who from (clinicians, community members, family, friends) When received (during treatment, after treatment)	• Didn’t get information about chemo • Can be too much information • Needs to be plain English • Some brochures had all the bad news up-front (worst case scenario) – instead of recommendations • Combination of verbal / hard copy • Lack of information about impacts of chemo in complex cases (eg. disability, or kidney issues) o results in less options o limited research that is relevant • Doctor Google – Recommend not to look up at all (this wasn’t okay) • Make sure diagnosis is written down • Recommend / come up with advice about good sites / good process • Internet can provide information to save hospital visit (increase independencies) Whom information was received from • Surgeon – explained in plain English • BCN – be more readily available • Aunty who wrote things down • Oncologist • Ballarat Cancer Centre staff • Brochures • Cancer day / forum	• Leukaemia – had to go out of my way to find another person o Nothing from GP o Very little information • Only received verbal information from Oncologist – no written information • Dr Google → multiple myeloma. Bone marrow • Angela Meaney – Leukaemia Foundation • Need specific info • Personal nurse – under clinical nurse – provided very good information. • Not wanting information • 2005 breast cancer → information overload • Also, was Christmas, difficult with services • Lots of direction from GP • Good GP, specialist → good services • Private treatment • Nursing background – understood • Internet • GP – info for melanoma o Very good o Verbal, but very good – spent the time explaining things • BreastScreen – very good • Breast Care Nurse was excellent – assisted with forms and came with me to appointments (NSW) • Support group: o Source of support o Practical information • Not linked to Angela (from the Leukaemia Foundation), but another person worked • Support – not offered • Linked to social worker and nurses • Ballarat Hospice: o linked in early o family support

		o counsellors o practical o carer respite o stigma attached to ‘end of life’ • Free massage sessions
3.) Were their barriers to receiving information and support? Issues with accessing support and information: Time (Work, Family), Travel required, Too much information, How to find out what is available?	Important for others to know: • Information / support re chemo effects • Cancer nurses for all • Seeing different people all the time – improve continuity of care. • Variety in cancer support groups • Heads up re composition of the group • Cancer and chat	• How do you find out about support services, especially if you have to travel to Melbourne? (eg Red Cross / Traveler’s Aid / Council) • Or get treatment in another direction (eg. family/friends are somewhere else) • Nurses being available for all cancers • *GPs important – especially afterwards. They can be really helpful to explain the medical terms / experiences, and also to link in to local services.*
4.) Any suggestions for improving information and support for rural and regional women living with cancer?	• Knowing what’s available • Centralised information place • Awareness of school restrictions • Improvements for carers information and support, especially when there is no known cure o One woman’s support group have organised a BBQ to get their partners to meet and get to know each other • Generic “My Journey” kit – journey forward, support services • More focus on survivorship o Cancer nurse or cancer forum o Self-management ▪ Yoga ▪ Gentle exercise ▪ Peer support	Want: • Opportunity to connect – similar cancer experience • Someone who will listen, share story and understand • Other person outside family • Finished treatment – where to now? o Support group o Connect with someone in a similar situation o Conferences – still seeking information, these are very good o Work, finances Want during treatment: • Felt isolated – would have been nice to have the opportunity to speak to someone at the time • Unknown - need for someone to connect peer support o Boundary – so isolates people • Leukemia Foundation – phone forum • Phone group – could be good • Online group – some want • Work and finances

Appendix IX: Project Findings

1. Scoping interviews

Key themes were identified from the interviews, particularly in relation to gaps in information and support, including:

- Central space for finding out about available information and support services
- Increased peer support options
- Services and consumer engagement events need to be held close to where people diagnosed with cancer live, if people from disadvantaged backgrounds are to be reached.

2. Consumer consultation

2.1. Focus group findings

Participants were asked about their support experiences. The themes identified were:

Support	
Common sources of excellent support:	Aspects or sources of support that could be improved:
• Family and friends (practical and emotional support): excellent for some, limited support for others • Support Champion: Breast Care Nurse, Cancer Nurse, GP • Support groups: great for some (support and practical information), not for all • Cancer organisations: Cancer organisations for rare cancers (national group), Leukemia Foundation, Cancer Council, Andrew Love Cancer Centre, GP	• GPs: need to be more aware of available information and support services • Increase options for finding out about available information and support • More focus on support after treatment, work and finances, travel assistance • Limited options for peer support (especially women with less common cancers, and younger women) • Limited support for women with less common cancers

Participants were asked about their information experiences. Key themes were identified:

Information	
Common sources of excellent information:	Aspects or sources of information that could be improved:
• Clinical champion: Breast Care Nurse, Cancer Nurse, GP • Support groups: great for some (support and practical information), not for all • Cancer organisations: Cancer organisations for rare cancers (national body), Leukemia Foundation, Cancer Council, ALCC	• Timing is important; too much information can be overwhelming. Provide people with a list of available information and ask people about the type of information they require at this point in time • Needs to be in lay terms and specific to your type of cancer • Some information is very negative • Need for a combination of verbal and written information • Limited information for women with less common types of cancer

*** Definitions of information and support provided**

Information includes:
verbal (talking and discussion) and written material (e.g. brochures and booklets) relating to your cancer experience such as facts, statistics and descriptions.

Support includes:
encouragement, assistance, comfort, and understanding relating to your cancer experience.

2.2. Consumer Survey findings

Participants

The consumer survey was completed by 129 consumers (43 from the Grampians and 86 from the BSW)

Demographics:

- 81% over the age of 50 (39% of respondents within the age bracket 65+)
- 56% have a Health Care Card
- 31% achieved Primary School attainment and some High School
- 75% Breast Cancer and 25% Other (6% ovary, 4% bowel & 15% other)
- 70% 1-5 years since diagnosis (1-2 years 23%)
- 45% received treatment in a public hospital, 25% private, 29% a combination, Unsure 1%
- 25% of respondents travelled more than 100 km for treatment.

Survey Questions 16, 17 and 18

Respondents rated a range of topics from not at all important to very important from their perspective. Additionally, respondents were asked to rate their satisfaction with information they received about a range of topics.

Importance rating by respondents	Topics	Quite a bit / very important	Quite a bit / very satisfied	Not at all / a little bit satisfied
High importance	**Cancer Type**	94%	78%	5%
	Treatment	96%	81%	6%
	Immediate side effects	89%	70%	12%
	Long-term side effects	88%	57%	19%
	Emotional and psychological support	81%	51%	20%
Moderate importance	**Communicating with family & friends**	76%	54%	21%
	Support for family & friends	73%	25%	25%
	Cancer support organisations	72%	65%	18%
	Exercise	72%	54%	23%
	Diet	67%	45%	26%
	Financial support & entitlements	65%	46%	38%
	Peer support options	63%	39%	31%
	Car parking	68%	39%	33%
	Accommodation assistance	60%	61%	38%
	Travel assistance	60%	52%	26%

Importance rating by respondents	Topics	Quite a bit / very important	Quite a bit / very satisfied	Not at all / a little bit satisfied
Low importance	**Local community organisations**	59%	47%	29%
	Spirituality or religion	54%	38%	35%
	Intimacy or sexuality	55%	35%	28%
	Complementary therapies	50%	38%	38%
	Fertility	24%	29%	45%
	Childcare	2%	29%	48%

Key Points:

- Clinical information was rated of high importance by most respondents
- Emotional and psychological support (81%) was rated the most important topic after the clinical topics
- Childcare and fertility was rated the least important topic. This is likely to be age related as the majority of respondents were older. Importantly, they were also the topics with the highest levels of dissatisfaction.

Survey Questions 21 and 23

Consumers were asked how they received information and what their preference was for receiving information:

Form	How information was received (% of respondents)	Preference for receiving information (% of respondents)
Face-to-face	84%	80%
Booklet or pamphlet	75%	61%
Recommended website	29%	45%
Google	32%	27%
Information session	23%	49%
Telephone	21%	36%
DVD	11%	24%
Email	9%	22%

Key Points:

- Most common methods for receiving information: face-to-face and written material
- Preferred options for receiving information: face-to-face and written material
- Least preferred options for receiving information: email, DVD, google and telephone.

Survey Question 19

Top 7 sources for receiving valuable INFORMATION

Source	**Proportion (%)**
Surgeon	78.57%
Oncologist	76.38%
Cancer Nurse	72.13%
Nurse	61.74%
GP	55.74%
Radiologist	46.77%
Cancer support organisations	44.44%

*The top 7 sources are the same for both regions

Survey Question 25

Consumers were asked to rate the importance of different types of SUPPORT (multiple responses were allowed)

Types of support	**Proportion rated highly important (%)**
Physical needs	87%
Psychological needs	88%
Social needs	79%
Spiritual needs	49%

Key Points:

- Most respondents rated physical, psychological and social needs as highly important.

Survey Question 27

Consumers were asked to rate levels of satisfaction for different types of support, particularly when aligned with importance

	How satisfied were you with support for:	
Types of support	**% highly satisfied**	**% low satisfaction**
Physical needs	65%	20%
Psychological needs	54%	23%
Social needs	44%	30%
Spiritual	29%	24%

Key Points:

- Satisfaction for all types of support could be improved.

Survey Questions 31 and 33

Consumers were asked how they received support and what their preference was for receiving support

Form	**How support was mostly received**	**Preference for receiving support**
Face-to-face	75%	80%
Peer group	20%	52%
Telephone	25%	36%
Forum	21%	33%
Online	10%	25%

Key Points:

- Big mismatch in preference for peer support vs how received
- Face-to-face is the most popular form of receiving support, followed by peer group.

Survey Question 35

Consumers were asked if they would have liked the opportunity to connect with someone with a similar experience at the following time points:

Time	Response	Proportion (%)
At diagnosis	Yes	64%
During treatment	Yes	69%
After treatment	Yes	77%

Survey Question 36

Received information or support from a rural or regional service:

	% of women that received information and support from rural and regional services
Yes	77%
No	23%

Key Points:

- Most people have accessed information and support from a rural or regional service

Survey Question 37

Top 7 sources for receiving valuable support

Source	% of respondents that received valuable support
Family members or friends	86.29%
Oncologist	73.17%
Surgeon	72.58%
Partner	68.85%
Cancer Nurse (e.g. Coordinator, Breast Care, Cancer Specialist)	66.13%
GP	58.40%
Nurse	56.64%

Key Points:

- Family and friends are clearly the most important supports
- The top 7 sources are the same for both regions.

Survey Question 38

Interested in accessing information and support from:

Accessing information and support	Yes	Maybe	No
My local town or suburb	51.64%	19.67%	28.69%
My nearest regional city	41.82%	20.91%	37.27%
Melbourne	24.53%	21.70%	53.77%

Key Points:

- 50% of the respondents are interested in receiving information and support locally
- nearly 30% of respondents are not interested in accessing information and support locally
- 25% of the respondents are interested in accessing information and support in Melbourne.

Questions about importance of Peer support options (connecting with someone with a similar experience)

	Percentage	
Not important	6.35%	🟥
A little	8.73%	🟥
Somewhat	16.67%	🟥
Quite a bit	19.05%	🟥
Very important	43.65%	🟥
N/A (not relevant to me)	5.56%	🟥

How did you receive support for your cancer experience?

Face-to-face discussion

	Percentage	
Not at all	1.59%	🟥
A little	7.94%	🟥
Somewhat	15.08%	🟥
Quite a bit	33.33%	🟥
A lot	42.06%	🟥

Online (webinar or online forum)

	Percentage	
Not at all	66.67%	
A little	11.71%	
Somewhat	11.71%	
Quite a bit	7.21%	
A lot	2.70%	

Telephone

	Percentage	
Not at all	26.05%	
A little	24.37%	
Somewhat	24.37%	
Quite a bit	17.65%	
A lot	7.56%	

2.3. Cohort Comparisons

The following identifies any responses that were significantly different between different cohorts – between the regions, with and without health care cards, types of cancer, and relative distance travelled.

Regional Differences (BSW and Grampians)

Demographics:

- Some High School: higher for BSW (14%) than Grampians (42%)
- High School certificate: higher for Grampians (30%) than BSW (14%)
- Health Care Card: higher for BSW (65%) than Grampians (37%)
- Women with breast cancer: higher for BSW (81%) than Grampians (65%)

Information:

Rated high satisfaction with the information received about:	**Barwon South Western**	**Grampians**
Cancer support organisations	80%	66%
Diet	66%	79%
Car parking	14%	34%
Communicating with family and friends	68%	42%
Long term side effects	54%	62%
Support for family and friends	19%	33%

Support:

- Spiritual needs: respondents rated spiritual needs to be more important in BSW (54%) than Grampians (40%)
- Physical needs: respondents rated higher satisfaction with support for physical needs in BSW (63%) than Grampians (51%).

Health Care Card vs No Health Care Card – key differences

Demographics:

- Some High School: higher % of respondents with a Health Care Card (39%) than without a Care Card (10%)

Information received – rated quite a bit and a lot:

- Booklet or pamphlet: lower for respondents with a Health Care Card (68%) than those without a Health Care Card (83%)
- Google browsing: lower for respondents with a Health Care Card (20%) than those without a Health Care Card (45%)

Preference for receiving information – rated very good and excellent:

- Booklet or pamphlet: lower for respondents with a Health Care Card (68%) than those without a Health Care Card (83%)
- Google browsing: lower for respondents with a Health Care Card (20%) than those without a Health Care Card (45%)

Breast Cancer vs Other types of cancer – key differences

Survey Question 17 : Survey respondants indicated they were quite a bit and very satisfied with the information received about the following topics

Information about	**% respondents with breast cancer**	**% respondents with other types of cancer**
Your cancer type	83%	63%
Immediate side effects	73%	55%
Long-term side effects	60%	44%
Emotional and psychological supports	58%	32%
Spirituality or religion	27%	15%
Support for family and friends	53%	35%
Cancer for support organisations	69%	46%
Local community organisations	48%	33%

How would you rate the following methods for receiving support?:

- With a peer group: high for women with breast cancer (70%) than other cancers (49%).

Form of support received – rated quite a bit and a lot:

- Face-to-face discussions: higher for women with breast cancer (81%) than other cancers (62%)
- Online webinar: lower for women with breast cancer (7%) than other cancers (26%).

Connecting with someone with a similar experience:

- At diagnosis: higher for women with breast cancer than other cancers
- After treatment: higher for women with breast cancer than other cancers.

Consumers' responses when asked "Do you feel you currently lack support"

- Yes and somewhat: lower for women with breast cancer (33%) than women with other cancers (59%).

Travelled over 100km for services vs less travel

Information – quite a bit or very important

- Travel assistance: rated more important by women travelling more than 100km to services (70%) than others travelling less of a distance to services (42%)
- Accommodation assistance: rated more important by women travelling more than 100km (71%) to services than others travelling less of a distance to services (34%).

Information satisfaction – rated quite a bit and very satisfied

- Accommodation assistance: higher for women travelling more than 100km to services (50%) than others travelling less of a distance to services (25%).

Form of information received – quite a bit and a lot:

- Information session (e.g. form or support group): lower for women travelling more than 100km to services (12%) than others travelling less of a distance to services (26%).

Form of support received – rated quite a bit and a lot:

- Online (webinar or online forum): higher for women travelling more than 100km to services (20%) than others travelling less of a distance to services (10%)
- At a forum: lower for women travelling more than 100km to services (15%) than others travelling less of a distance to services (26%)
- With a peer group: lower for women travelling more than 100km to services (10%) than others travelling less of a distance to services (25%).

2.4. GICS Cancer Conversations project key findings

As noted in the Introduction, Cancer Conversations was a consumer consultation led by GICS. Their consumers identified the following regarding information and support.

Generally:

- To be treated as a whole person not just treating the cancer
- Support preferably from one person they can trust and rely on to provide them with the information, and to guide them through the options they need to consider

- Support from the time of diagnosis to the completion of the journey. There are gaps in support: between diagnosis and starting treatment, at the time of discharge, and during recovery
- To be part of a well-coordinated health system which is connected, able to transfer information correctly, and be consistent in testing / interpretations and treatment practices
- For health professionals to have the communication skills required to listen and hear what patients and their support people are saying
- Better promotion of services / facilities
- Greater assistance for peer support either individually or in a group for all cancer streams.

Access:

- Information and support beyond the specific treatment process which would include such things as: financial, emotional, practical living assistance, lifestyle / work adjustment needs
- Information and support that is timely and specific to needs / not too much and not too little
- Information and support that is equally accessible, regardless of public or private patients, low or high profile cancer, live in regional or rural Victoria.

3. Service Provider Survey

The service provider survey was completed by 170 service providers, comprising 37 from the Grampians Region and 129 from the BSW Region.

Types of service providers

- GPs (64% of respondents), also cancer nurses, oncologist, surgeons (36% of respondents)
- 116 GPs (47% from the Grampians and 53% from the BSW region)
- 64 Other service providers including cancer nurses, oncologist, surgeons and social workers.

GPs and other service providers – key differences

Service providers were asked which topics they provide information about and topics they do not provide information about:

GPs most commonly do not provide information about the following topics

Topics	**Do not provide information (%)**
Financial support and entitlements	63%
Spirituality or religion	55%
Complementary therapies	51%
Child care	55%
Peer support	28%

Other Service providers most commonly do not provide information about the following topics

Topics	**Do not provide information (%)**
Child care	71%
Spirituality or religion	49%
Financial support and entitlements	45%
Complementary therapies	45%
Diagnosis	40%
Fertility	39%
Peer support	36%

Key point:

- Common topics that all service providers do not provide information about include: child care, spirituality or religion, financial support and complementary therapies.

	Other service providers		**GP**	
Common topics	**Not part of my role**	**I don't provide this information**	**Not part of my role**	**I don't provide this information**
Child care	39%	33%	37%	18%
Financial support and entitlements	31%	14%	26%	37%
Complementary therapies	26%	19%	39%	12%
Spirituality or religion	35%	25%	37%	19%
Peer support	19%	17%	23%	5%

The service provider survey asked service providers if they make local referrals.

Response	**GP**	**Other service providers**
Yes	69%	75%
No	31%	25%

Key point:

- Most service providers refer women to rural and regional support services.

Service providers were asked about the availability of support services

Perceived availability of support services		
	Low availability	**High availability**
Psychological needs	40.72%	11.98%
Spiritual needs	42.17%	30.12%
Physical needs	21.34%	66.46%
Social needs	41.32%	47.90%

Key point:

- According to respondents for the service provider survey, there is low availability of services for all support needs, particularly psychological needs.

Statements about providing information and support for rural and regional women living with cancer were included in the service provider survey.

Statements referred to from the survey		**GPs**	**Other service providers**
I am the **right person** to:	Provide information for many topics	71%	70%
	Inform about support services	87%	79%
I have time to:	Provide women with information	77%	79%
	Inform about support services	73%	77%
I would like to be better informed:	About some topics so I can provide women with the information	80%	66%
	About where women can go obtain more information and access support services	83%	68%

Key point:

- Responses to these statements indicate that service providers (GPs and other service providers) would like to be involved with provision of information and support for women living with cancer.

4. Key correlations found between consumer and service provider data sets

There is a correlation between the topics women living with cancer are not satisfied with and the topics both GPs and other service providers do not provide information about.

	GP	**Other service providers**
Topics consumers rated Low satisfaction	**Don't provide info about this topic**	**Don't provide info about this topic**
Child care (48%)	55%	71%
Fertility (45%)	17%	39%
Financial support and entitlements (38%)	63%	45%
Complementary therapies (38%)	51%	45%
Spirituality or religion (35%)	55%	49%
Peer support (31%)	28%	36%

Key point:

- Service providers commonly do not provide information about all the low satisfaction topics (identified by respondents within the consumer survey), except for fertility.

5. Community collaboration

Round Table Luncheons

Feedback and impressions regarding community consultation findings.

Attendees were asked for their feedback regarding community consultation findings. Feedback and impressions regarding the findings included:

- Surprise that a high portion of respondents (Service Provider Survey) indicated that it is within their role and they do have time to provide information about cancer related topics and support services. (Colac and Geelong)
- Not surprised that a high proportion of many women were less satisfied with information about non-clinical topics. (Geelong)
- Challenges regarding the amount of information provided to cancer patients and that it is important to keep in mind that often 1/3 of information given to patients is retained and it can be especially difficult for cancer patients to retain information at the time of diagnosis. (Geelong)

- Difficult to get clinicians to tell women about support groups (Colac)
- Form of support: many women do not use the internet or have email addresses (Geelong and Colac).

Rating options for improving information and support (see table below)

At the Round Table Luncheons attendees were asked to rate some options for improving information and support. These options were identified by project partners following data analysis at a workshop utilising investment logic.

Attendees rated options from most important or "most like to see happen" (rated 1) to least important or "least like to see happen" (rated 5).

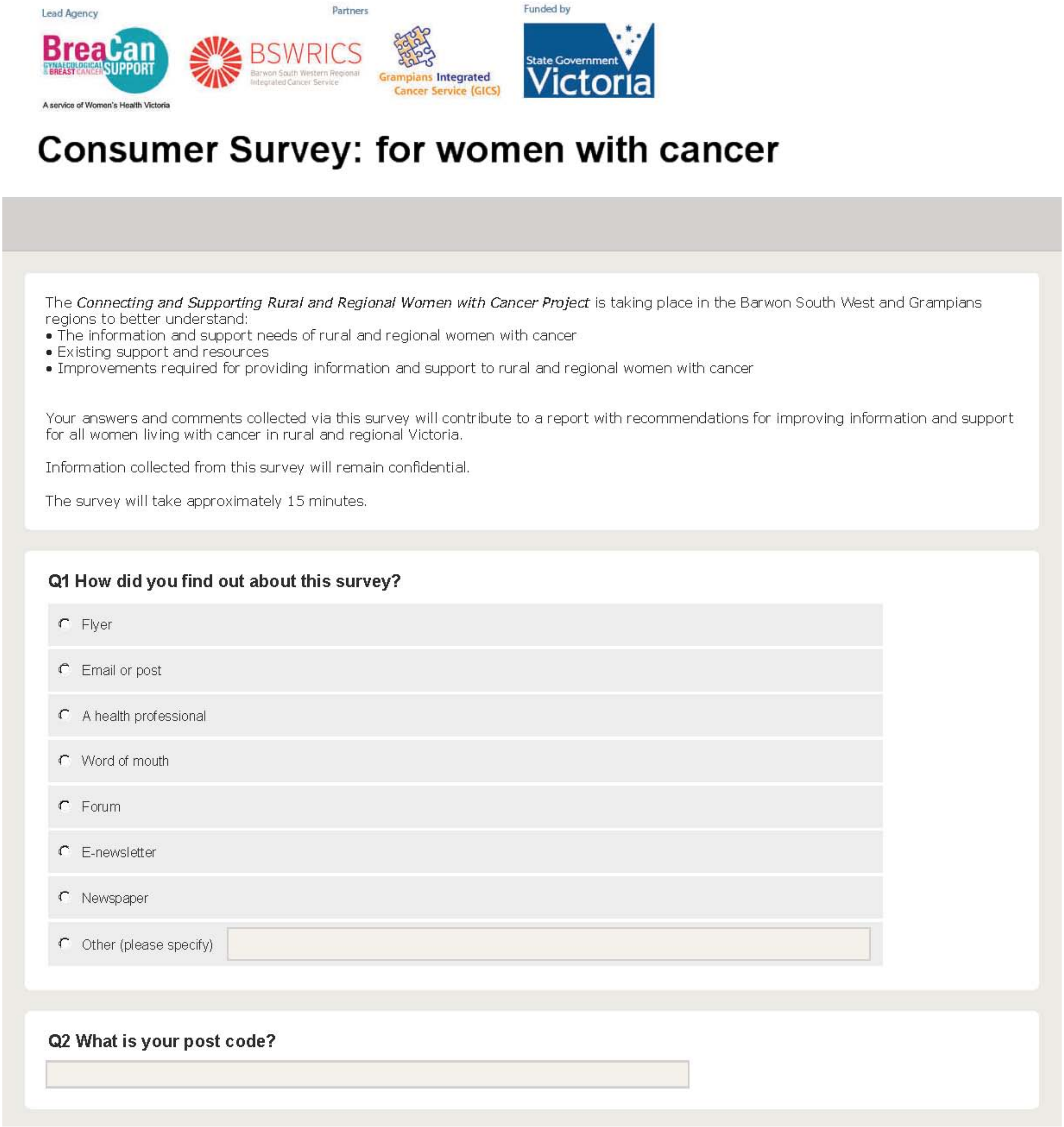
Options for improving Info and Support	**Colac score (rating of importance)**	**Geelong score (rating of importance)**
1. Create a statewide website that lists relevant support services	81 (4)	50 (2)
2. Create local information hubs where they do not currently exist	57 (1)	58 (4)
3. Increase peer support options	63 (2)	46 (1)
4. Work more closely with general practice	59 (3)	51 (3)
5. Education for service providers about non-clinical issues for people with cancer	98 (5)	78 (5)

Combined results identify "Increase peer support options" and "Work more closely with general practice" as the most important options.

One difference that was noted between the sessions was the rating of "Create local information hubs where they do not currently exist" and "Create a statewide website that lists relevant support services". Whilst "Create a statewide website that lists relevant support services" was rated 4th at the Colac event, it was rated 2nd for the Geelong event. In contrast "Create local information hubs where they do not currently exist" was rated 4th in Geelong and 1st in Colac.

There is only so much we can infer from this, but it is interesting that this contrast exists between an event held in Geelong (a regional town) and an event held in Colac (a rural town). Cancer information is more readily available at Andrew Love Cancer Centre however it may be also due to an older population who are less likely to use the internet, differences in education levels between the groups, and/ or poorer internet access in Colac compared to Geelong.

Appendix X: Consumer Survey



Consumer Survey: for women with cancer

The *Connecting and Supporting Rural and Regional Women with Cancer Project* is taking place in the Barwon South West and Grampians regions to better understand:

- The information and support needs of rural and regional women with cancer
- Existing support and resources
- Improvements required for providing information and support to rural and regional women with cancer

Your answers and comments collected via this survey will contribute to a report with recommendations for improving information and support for all women living with cancer in rural and regional Victoria.

Information collected from this survey will remain confidential.

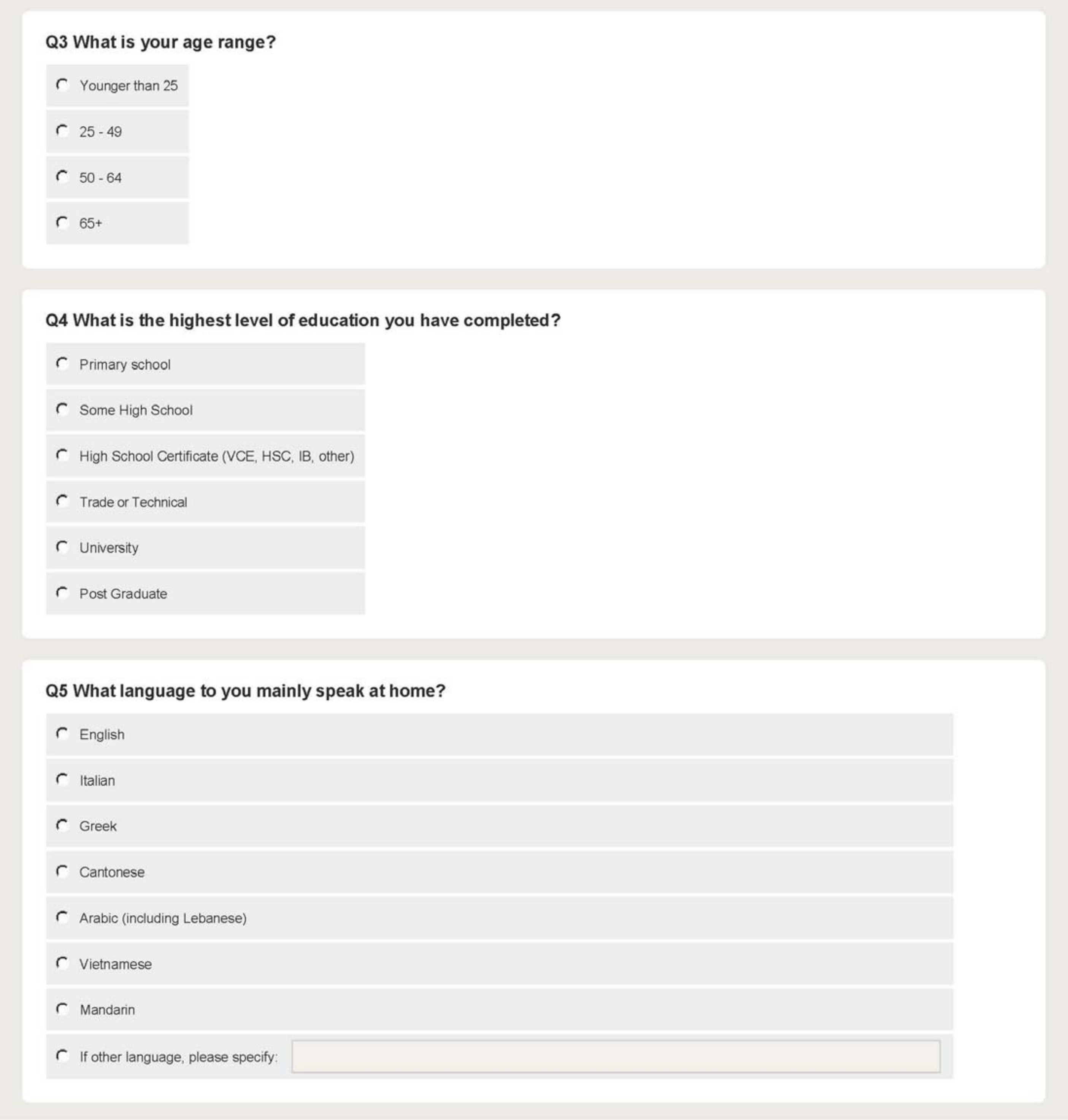
The survey will take approximately 15 minutes.

Q1 How did you find out about this survey?

○ Flyer
○ Email or post
○ A health professional
○ Word of mouth
○ Forum
○ E-newsletter
○ Newspaper
○ Other (please specify) ____________

Q2 What is your post code?

____



Q3 What is your age range?

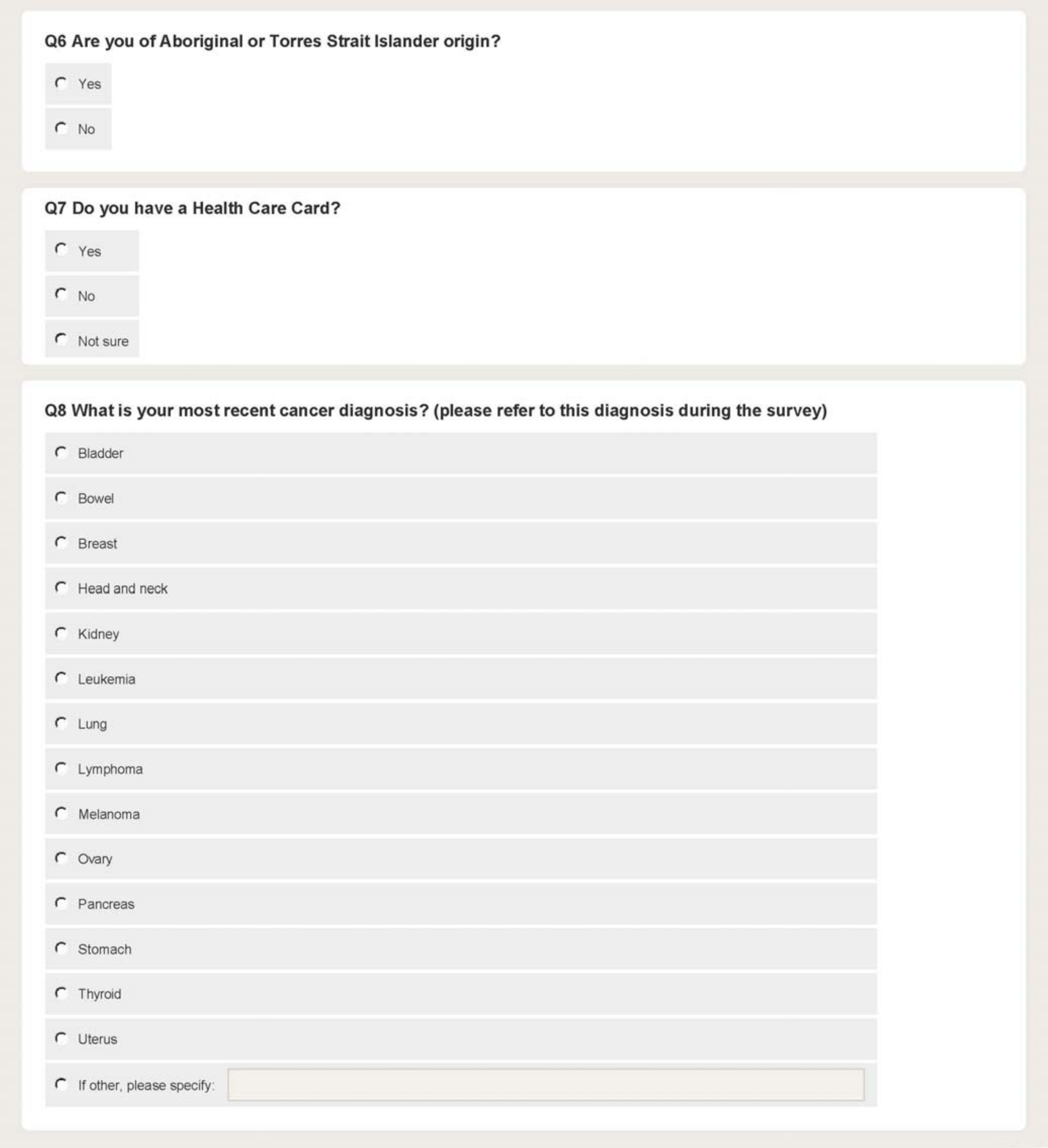
○ Younger than 25
○ 25 - 49
○ 50 - 64
○ 65+

Q4 What is the highest level of education you have completed?

○ Primary school
○ Some High School
○ High School Certificate (VCE, HSC, IB, other)
○ Trade or Technical
○ University
○ Post Graduate

Q5 What language to you mainly speak at home?

○ English
○ Italian
○ Greek
○ Cantonese
○ Arabic (including Lebanese)
○ Vietnamese
○ Mandarin
○ If other language, please specify: ________



Q6 Are you of Aboriginal or Torres Strait Islander origin?

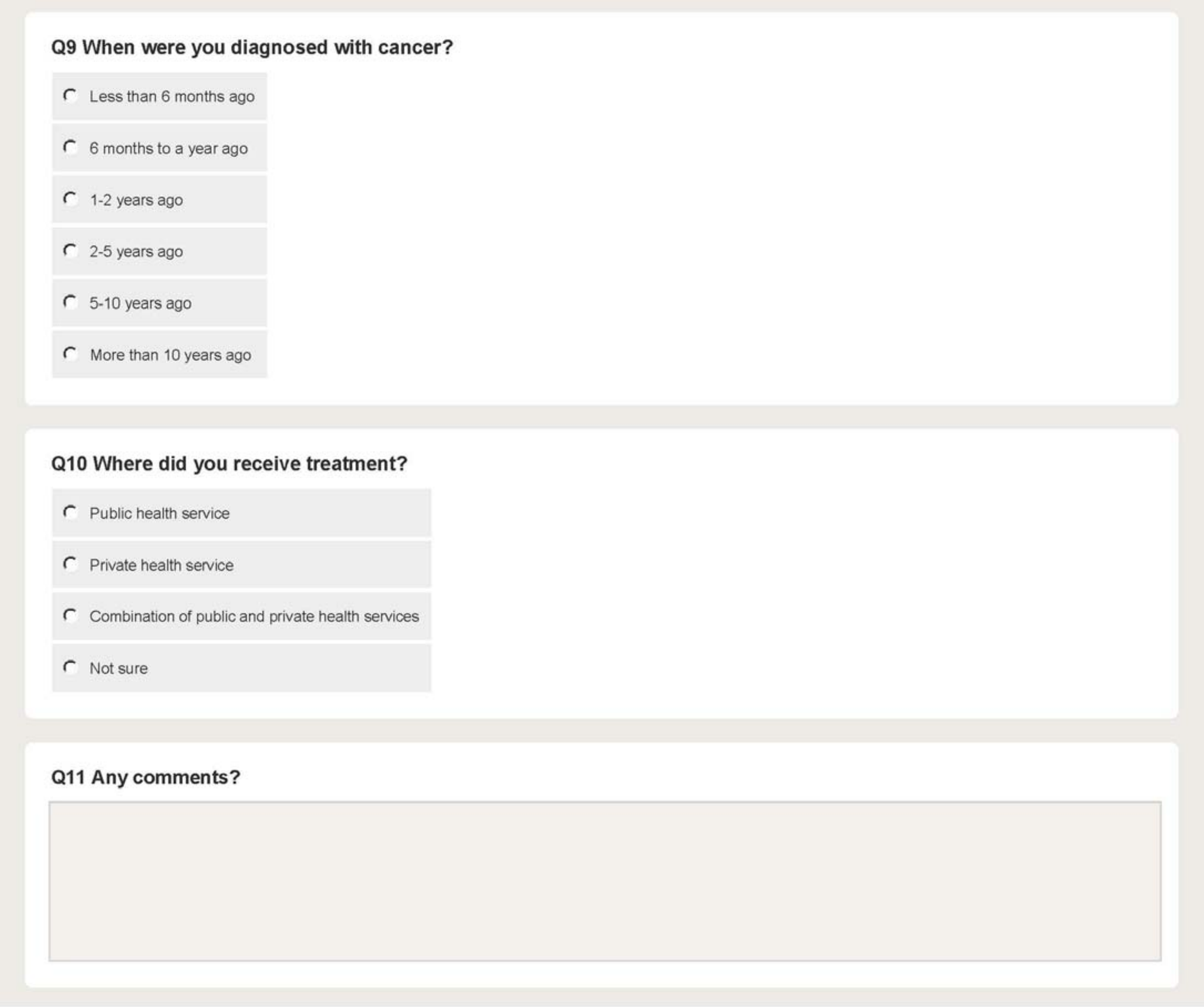
- ○ Yes
- ○ No

Q7 Do you have a Health Care Card?

- ○ Yes
- ○ No
- ○ Not sure

Q8 What is your most recent cancer diagnosis? (please refer to this diagnosis during the survey)

- ○ Bladder
- ○ Bowel
- ○ Breast
- ○ Head and neck
- ○ Kidney
- ○ Leukemia
- ○ Lung
- ○ Lymphoma
- ○ Melanoma
- ○ Ovary
- ○ Pancreas
- ○ Stomach
- ○ Thyroid
- ○ Uterus
- ○ If other, please specify: ☐



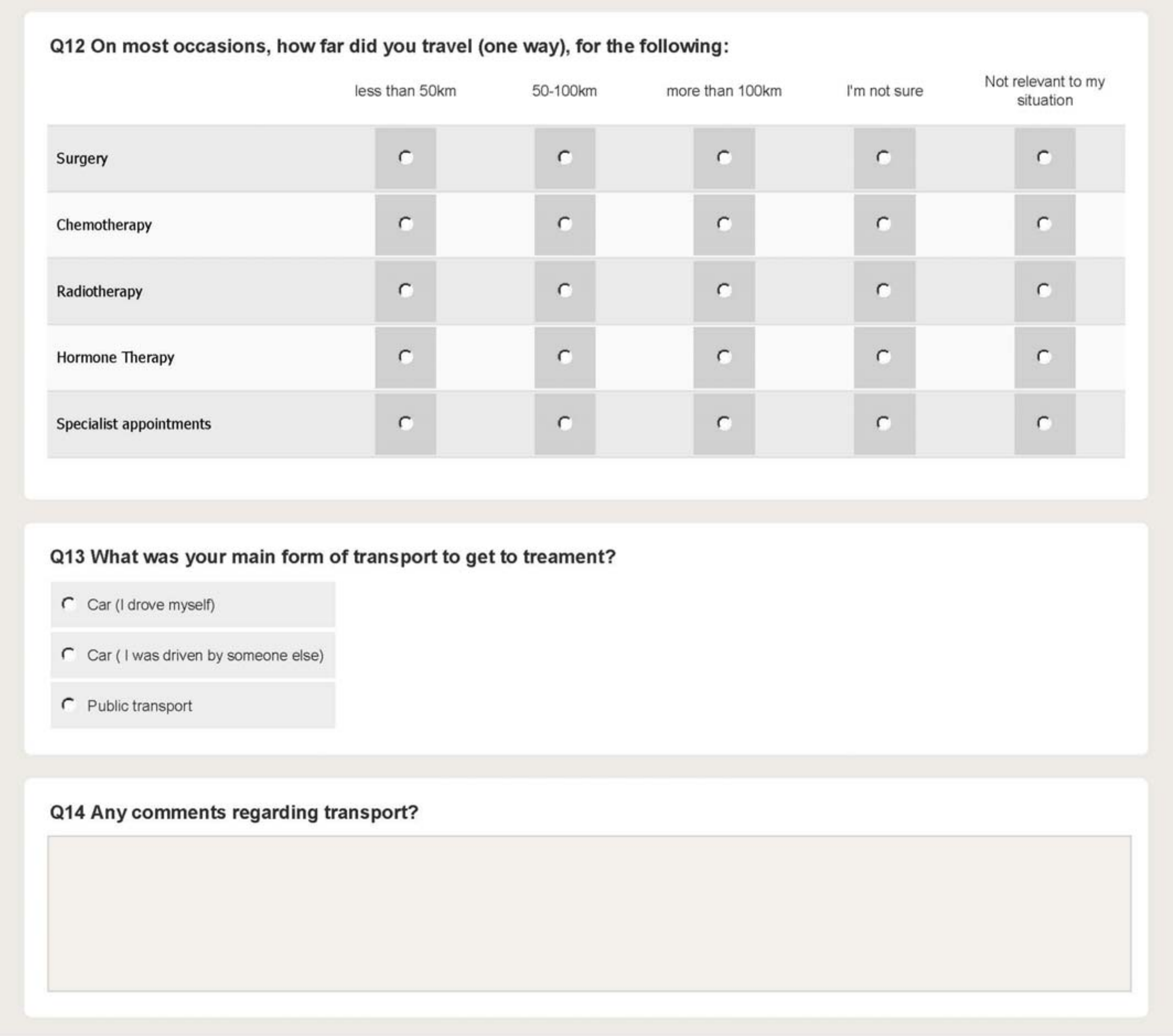
Q9 When were you diagnosed with cancer?

- ○ Less than 6 months ago
- ○ 6 months to a year ago
- ○ 1-2 years ago
- ○ 2-5 years ago
- ○ 5-10 years ago
- ○ More than 10 years ago

Q10 Where did you receive treatment?

- ○ Public health service
- ○ Private health service
- ○ Combination of public and private health services
- ○ Not sure

Q11 Any comments?



Q12 On most occasions, how far did you travel (one way), for the following:

	less than 50km	50-100km	more than 100km	I'm not sure	Not relevant to my situation
Surgery	○	○	○	○	○
Chemotherapy	○	○	○	○	○
Radiotherapy	○	○	○	○	○
Hormone Therapy	○	○	○	○	○
Specialist appointments	○	○	○	○	○

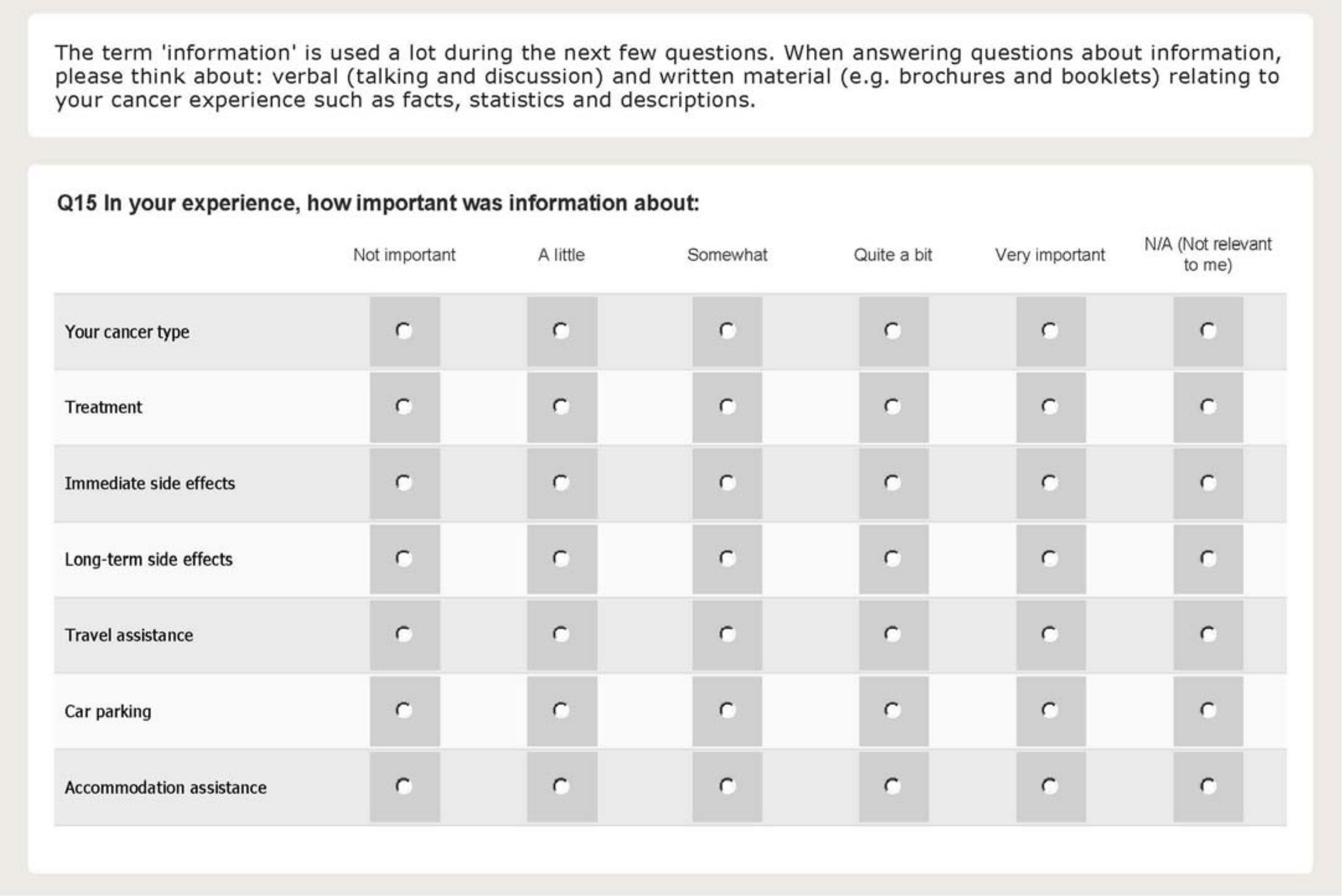
Q13 What was your main form of transport to get to treament?

○ Car (I drove myself)

○ Car (I was driven by someone else)

○ Public transport

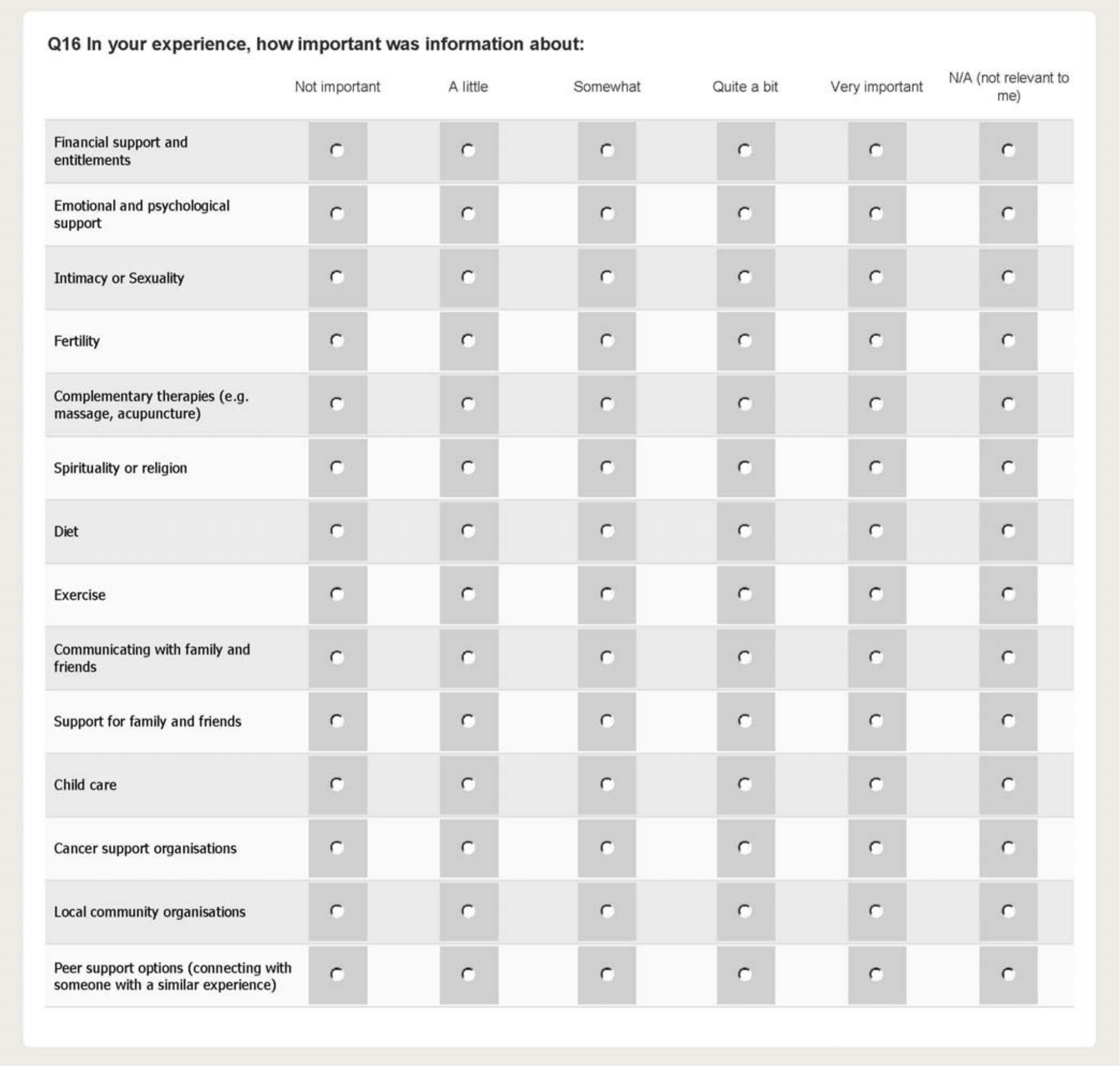
Q14 Any comments regarding transport?



The term 'information' is used a lot during the next few questions. When answering questions about information, please think about: verbal (talking and discussion) and written material (e.g. brochures and booklets) relating to your cancer experience such as facts, statistics and descriptions.

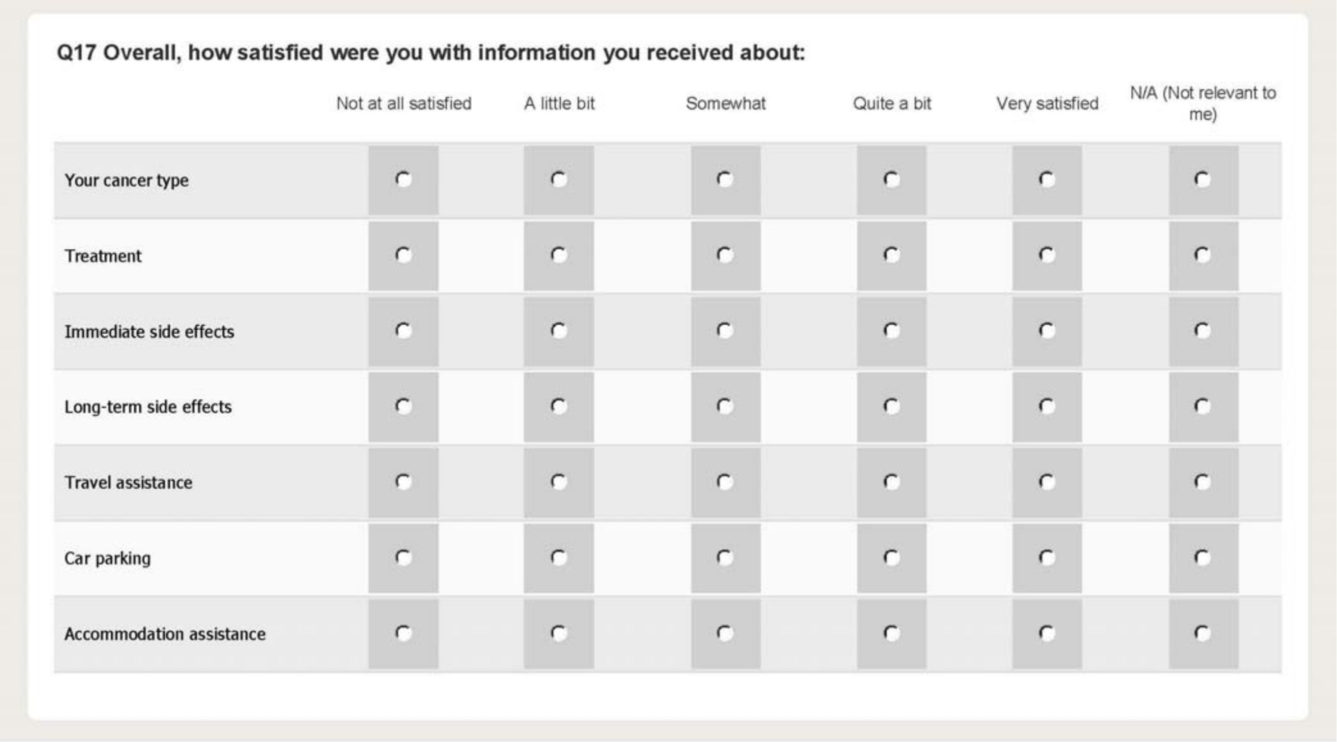
Q15 In your experience, how important was information about:

	Not important	A little	Somewhat	Quite a bit	Very important	N/A (Not relevant to me)
Your cancer type	○	○	○	○	○	○
Treatment	○	○	○	○	○	○
Immediate side effects	○	○	○	○	○	○
Long-term side effects	○	○	○	○	○	○
Travel assistance	○	○	○	○	○	○
Car parking	○	○	○	○	○	○
Accommodation assistance	○	○	○	○	○	○



Q16 In your experience, how important was information about:

	Not important	A little	Somewhat	Quite a bit	Very important	N/A (not relevant to me)
Financial support and entitlements	○	○	○	○	○	○
Emotional and psychological support	○	○	○	○	○	○
Intimacy or Sexuality	○	○	○	○	○	○
Fertility	○	○	○	○	○	○
Complementary therapies (e.g. massage, acupuncture)	○	○	○	○	○	○
Spirituality or religion	○	○	○	○	○	○
Diet	○	○	○	○	○	○
Exercise	○	○	○	○	○	○
Communicating with family and friends	○	○	○	○	○	○
Support for family and friends	○	○	○	○	○	○
Child care	○	○	○	○	○	○
Cancer support organisations	○	○	○	○	○	○
Local community organisations	○	○	○	○	○	○
Peer support options (connecting with someone with a similar experience)	○	○	○	○	○	○



Q17 Overall, how satisfied were you with information you received about:

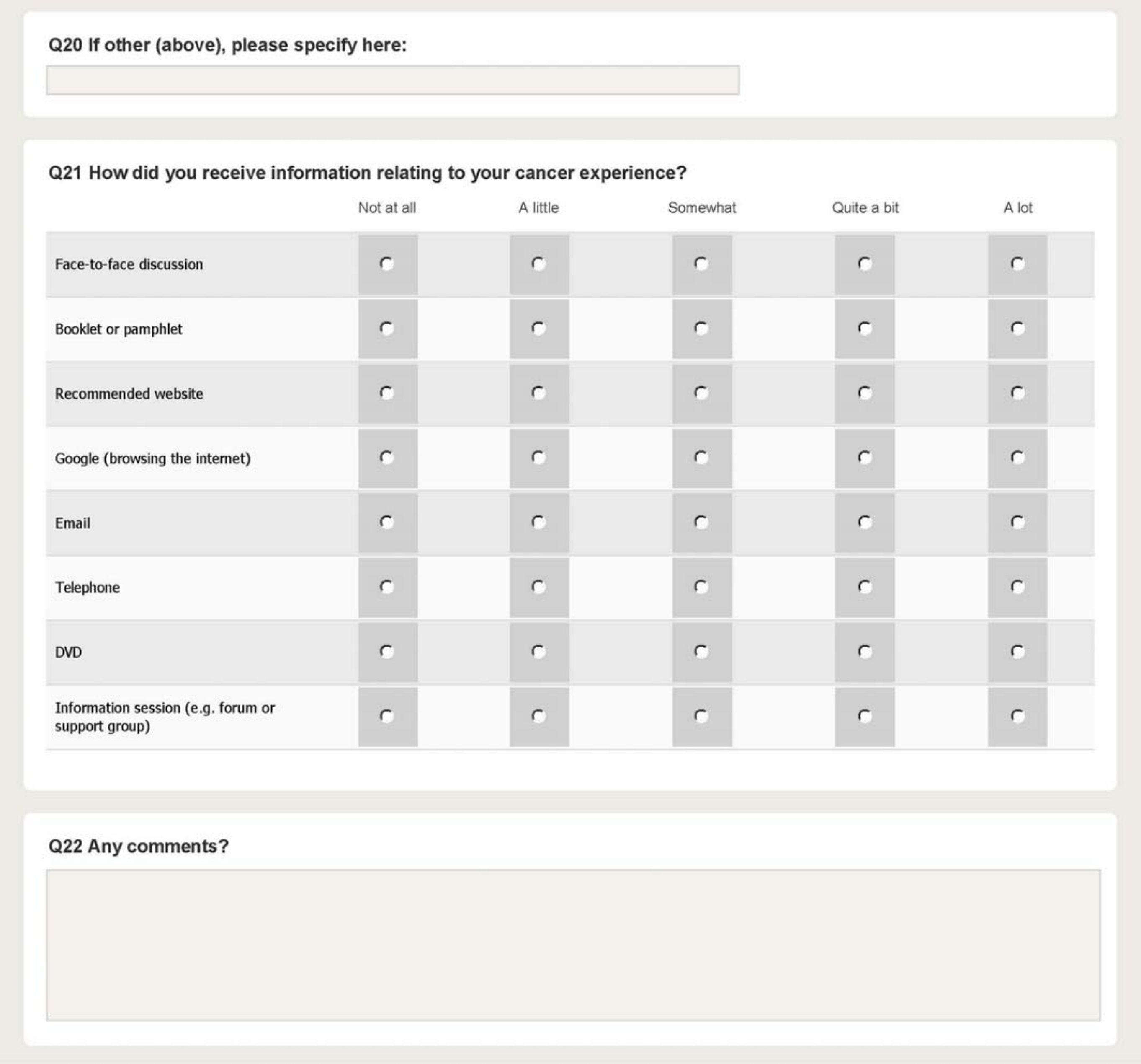
	Not at all satisfied	A little bit	Somewhat	Quite a bit	Very satisfied	N/A (Not relevant to me)
Your cancer type	○	○	○	○	○	○
Treatment	○	○	○	○	○	○
Immediate side effects	○	○	○	○	○	○
Long-term side effects	○	○	○	○	○	○
Travel assistance	○	○	○	○	○	○
Car parking	○	○	○	○	○	○
Accommodation assistance	○	○	○	○	○	○

Q18 Overall, how satisfied were you with information you received about:

	Not at all satisfied	A little bit	Somewhat	Quite a bit	Very satisfied	N/A (Not relevant to me)
Financial support and entitlements	○	○	○	○	○	○
Emotional and psychological support	○	○	○	○	○	○
Intimacy or Sexuality	○	○	○	○	○	○
Fertility	○	○	○	○	○	○
Complementary therapies (e.g. massage, acupuncture)	○	○	○	○	○	○
Spirituality or religion	○	○	○	○	○	○
Diet	○	○	○	○	○	○
Exercise	○	○	○	○	○	○
Communicating with family and friends	○	○	○	○	○	○
Support for family and friends	○	○	○	○	○	○
Child care	○	○	○	○	○	○
Cancer support organisations	○	○	○	○	○	○
Local community organisations	○	○	○	○	○	○
Peer support options (connecting with someone with a similar experience)	○	○	○	○	○	○

Q19 When reflecting on my whole cancer experience, I received valuable information from:

	Not at all	A little	Adequate	Quite a bit	A lot	N/A (I didn't have contact with this person)
Nurse	○	○	○	○	○	○
Cancer Nurse (e.g. Cancer specialist, Coordinator, Breast Care)	○	○	○	○	○	○
Oncologist	○	○	○	○	○	○
Radiologist	○	○	○	○	○	○
Surgeon	○	○	○	○	○	○
GP	○	○	○	○	○	○
Social Worker	○	○	○	○	○	○
Psychologist or Counsellor	○	○	○	○	○	○
Dietitian	○	○	○	○	○	○
Speech Therapist	○	○	○	○	○	○
Occupational Therapist	○	○	○	○	○	○
Physiotherapist	○	○	○	○	○	○
Community or District Nurse	○	○	○	○	○	○
Community worker	○	○	○	○	○	○
Cancer support organisation	○	○	○	○	○	○
Other (please specify below)	○	○	○	○	○	○

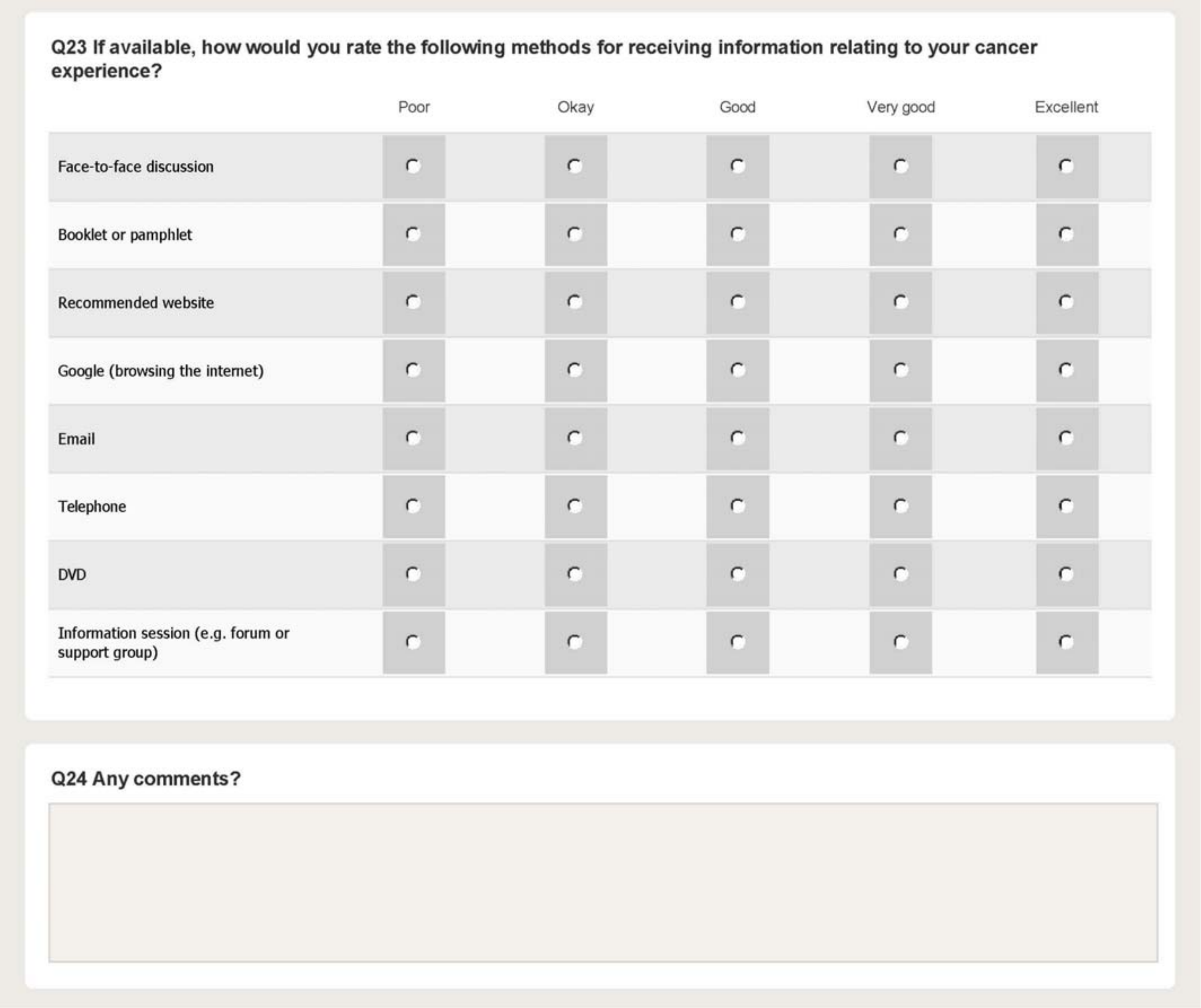


Q20 If other (above), please specify here:

Q21 How did you receive information relating to your cancer experience?

	Not at all	A little	Somewhat	Quite a bit	A lot
Face-to-face discussion	○	○	○	○	○
Booklet or pamphlet	○	○	○	○	○
Recommended website	○	○	○	○	○
Google (browsing the internet)	○	○	○	○	○
Email	○	○	○	○	○
Telephone	○	○	○	○	○
DVD	○	○	○	○	○
Information session (e.g. forum or support group)	○	○	○	○	○

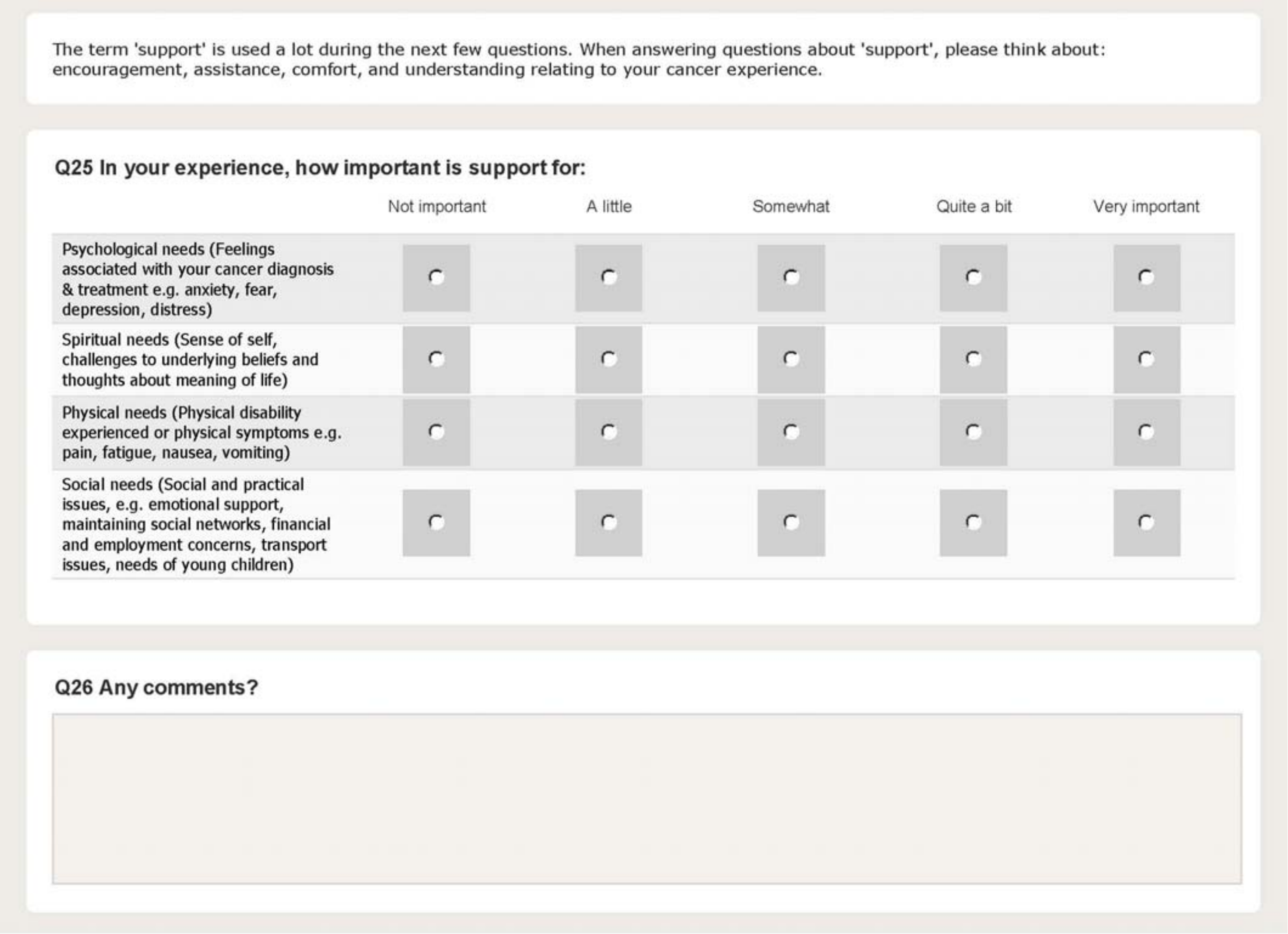
Q22 Any comments?



Q23 If available, how would you rate the following methods for receiving information relating to your cancer experience?

	Poor	Okay	Good	Very good	Excellent
Face-to-face discussion	○	○	○	○	○
Booklet or pamphlet	○	○	○	○	○
Recommended website	○	○	○	○	○
Google (browsing the internet)	○	○	○	○	○
Email	○	○	○	○	○
Telephone	○	○	○	○	○
DVD	○	○	○	○	○
Information session (e.g. forum or support group)	○	○	○	○	○

Q24 Any comments?

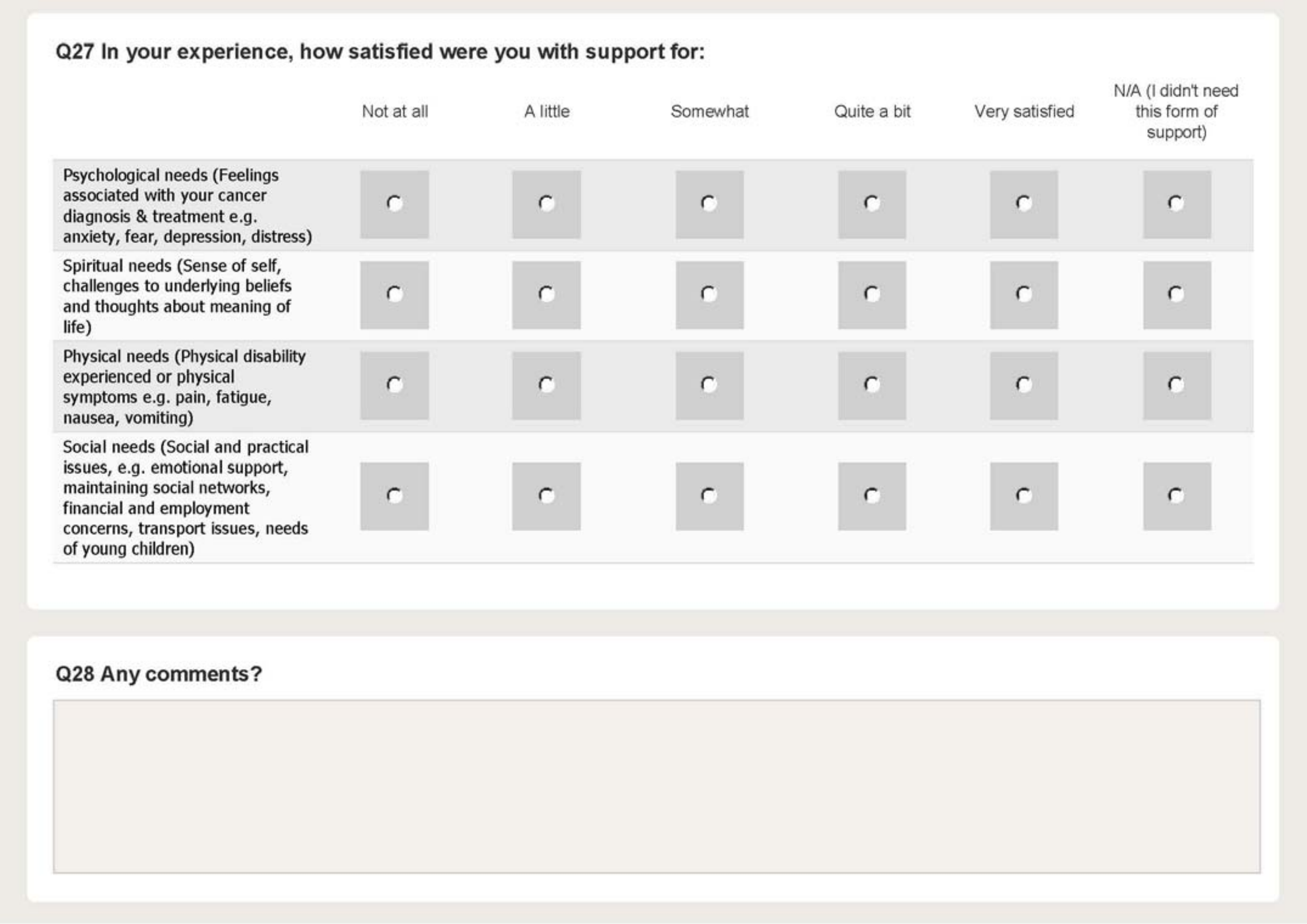


The term 'support' is used a lot during the next few questions. When answering questions about 'support', please think about: encouragement, assistance, comfort, and understanding relating to your cancer experience.

Q25 In your experience, how important is support for:

	Not important	A little	Somewhat	Quite a bit	Very important
Psychological needs (Feelings associated with your cancer diagnosis & treatment e.g. anxiety, fear, depression, distress)	○	○	○	○	○
Spiritual needs (Sense of self, challenges to underlying beliefs and thoughts about meaning of life)	○	○	○	○	○
Physical needs (Physical disability experienced or physical symptoms e.g. pain, fatigue, nausea, vomiting)	○	○	○	○	○
Social needs (Social and practical issues, e.g. emotional support, maintaining social networks, financial and employment concerns, transport issues, needs of young children)	○	○	○	○	○

Q26 Any comments?



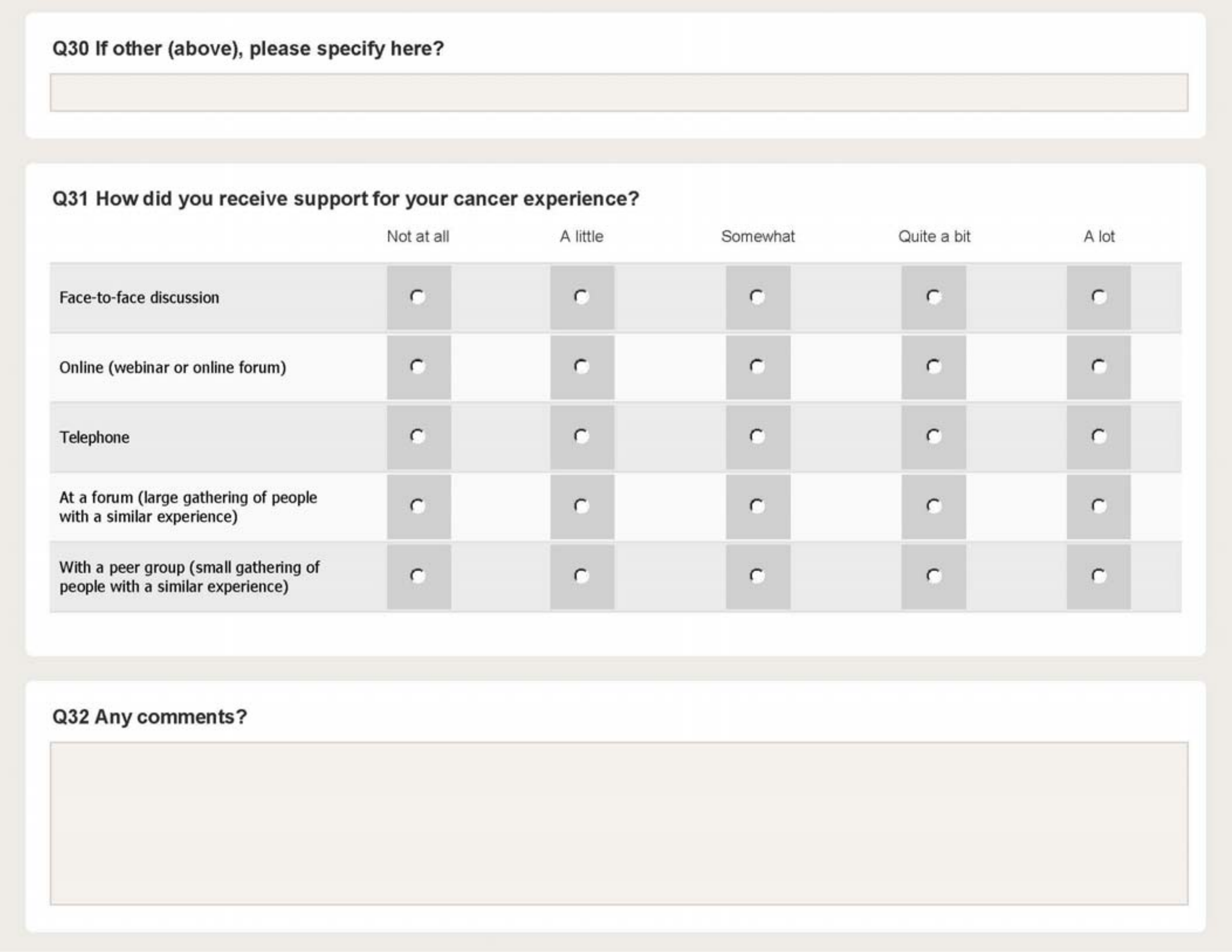
Q27 In your experience, how satisfied were you with support for:

	Not at all	A little	Somewhat	Quite a bit	Very satisfied	N/A (I didn't need this form of support)
Psychological needs (Feelings associated with your cancer diagnosis & treatment e.g. anxiety, fear, depression, distress)	○	○	○	○	○	○
Spiritual needs (Sense of self, challenges to underlying beliefs and thoughts about meaning of life)	○	○	○	○	○	○
Physical needs (Physical disability experienced or physical symptoms e.g. pain, fatigue, nausea, vomiting)	○	○	○	○	○	○
Social needs (Social and practical issues, e.g. emotional support, maintaining social networks, financial and employment concerns, transport issues, needs of young children)	○	○	○	○	○	○

Q28 Any comments?

Q29 When reflecting on my whole cancer experience, I received valuable support from:

	Not at all	A little	Adequate	Quite a bit	A lot	N/A (I didn't have contact with them)
Nurse	○	○	○	○	○	○
Cancer Nurse (e.g. Coordinator, Breast Care, Specialist Cancer)	○	○	○	○	○	○
Oncologist	○	○	○	○	○	○
Radiologist	○	○	○	○	○	○
Surgeon	○	○	○	○	○	○
GP	○	○	○	○	○	○
Social worker	○	○	○	○	○	○
Psychologist or Counsellor	○	○	○	○	○	○
Family members or friends	○	○	○	○	○	○
Partner	○	○	○	○	○	○
Local community worker	○	○	○	○	○	○
Support group	○	○	○	○	○	○
Peer support (connection with an individual with a similar experience)	○	○	○	○	○	○
Wellness program	○	○	○	○	○	○
Religious/spiritual person	○	○	○	○	○	○
Other person (please specify below)	○	○	○	○	○	○

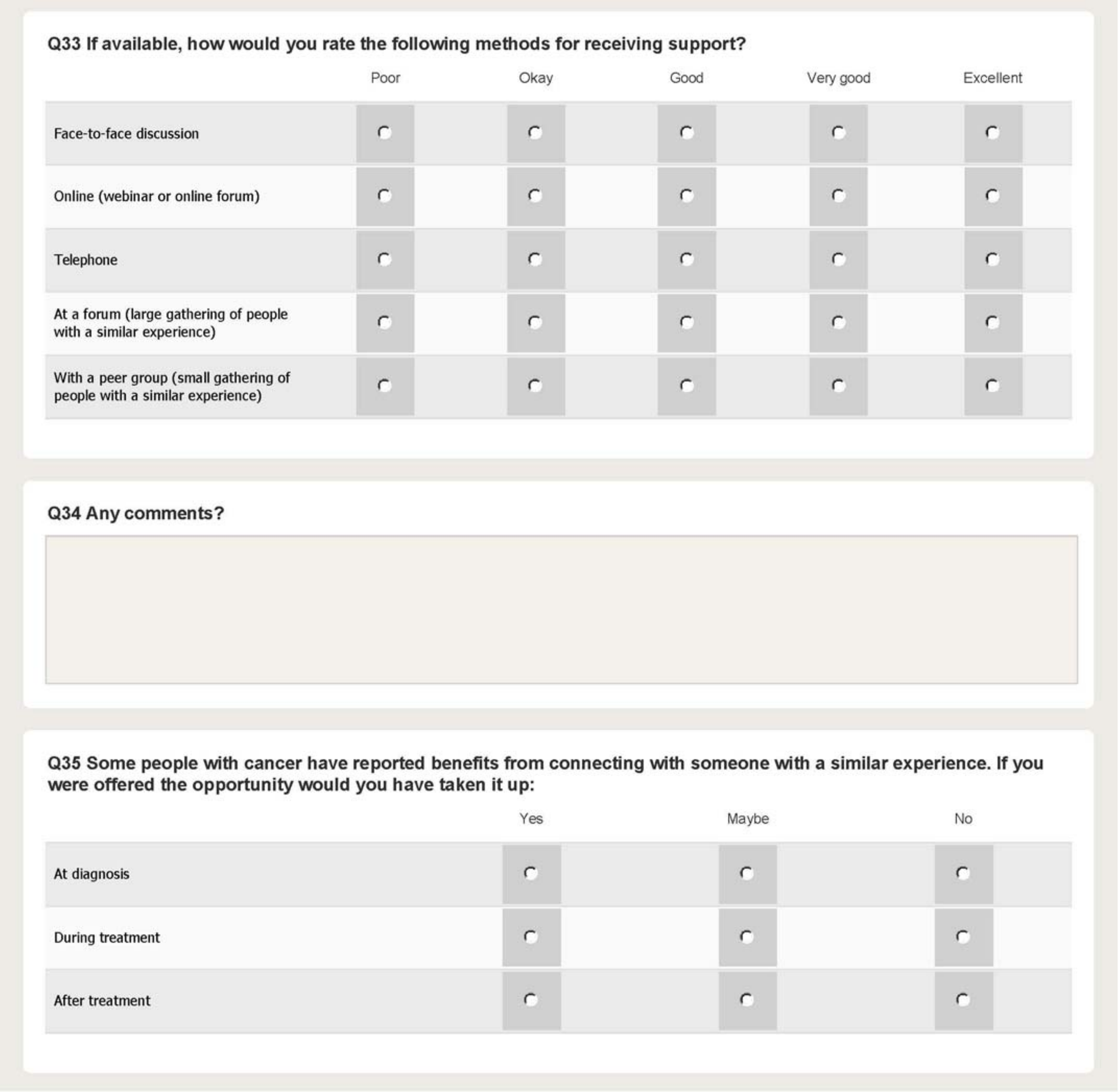


Q30 If other (above), please specify here?

Q31 How did you receive support for your cancer experience?

	Not at all	A little	Somewhat	Quite a bit	A lot
Face-to-face discussion	○	○	○	○	○
Online (webinar or online forum)	○	○	○	○	○
Telephone	○	○	○	○	○
At a forum (large gathering of people with a similar experience)	○	○	○	○	○
With a peer group (small gathering of people with a similar experience)	○	○	○	○	○

Q32 Any comments?



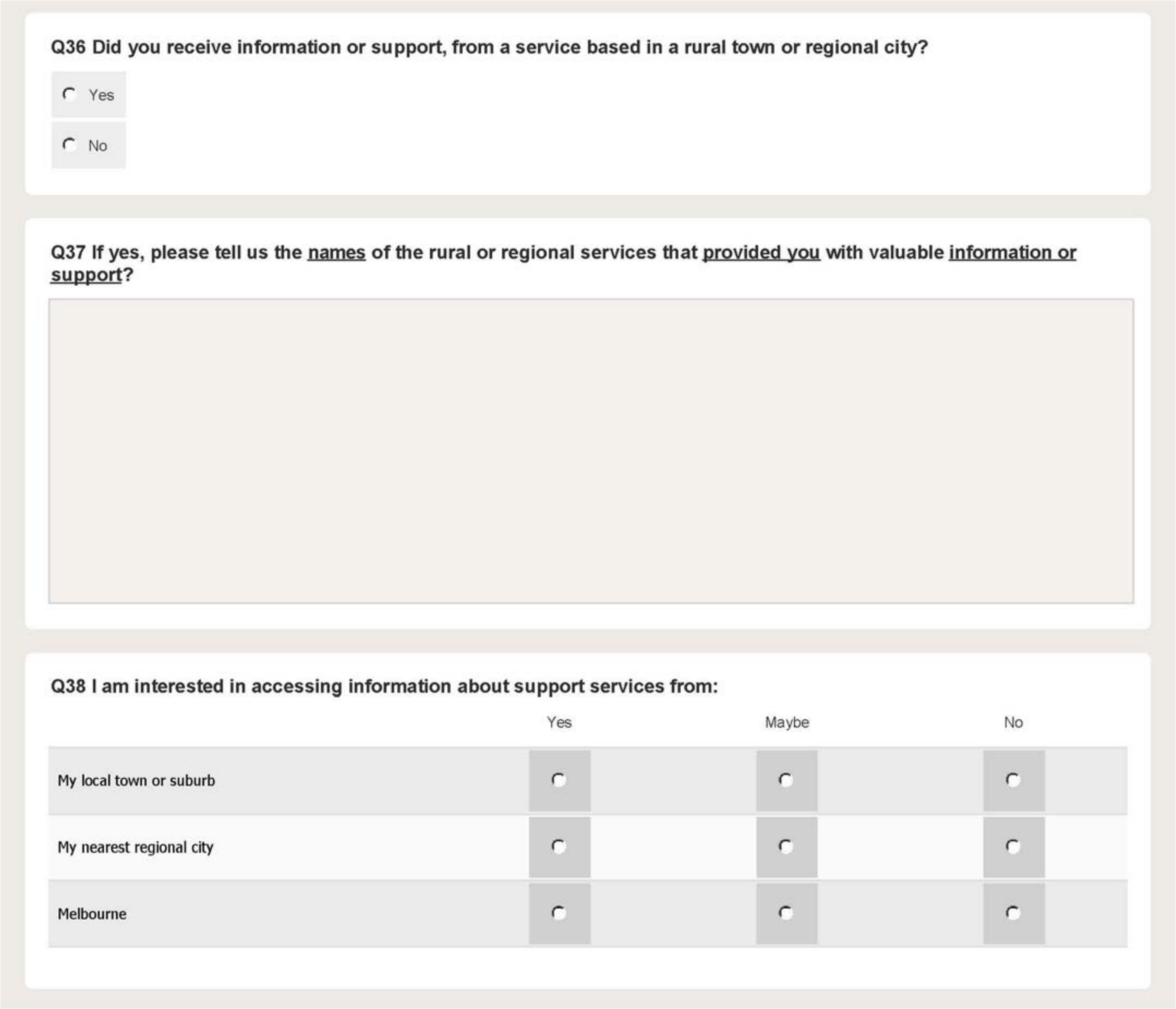
Q33 If available, how would you rate the following methods for receiving support?

	Poor	Okay	Good	Very good	Excellent
Face-to-face discussion	○	○	○	○	○
Online (webinar or online forum)	○	○	○	○	○
Telephone	○	○	○	○	○
At a forum (large gathering of people with a similar experience)	○	○	○	○	○
With a peer group (small gathering of people with a similar experience)	○	○	○	○	○

Q34 Any comments?

Q35 Some people with cancer have reported benefits from connecting with someone with a similar experience. If you were offered the opportunity would you have taken it up:

	Yes	Maybe	No
At diagnosis	○	○	○
During treatment	○	○	○
After treatment	○	○	○



Q36 Did you receive information or support, from a service based in a rural town or regional city?

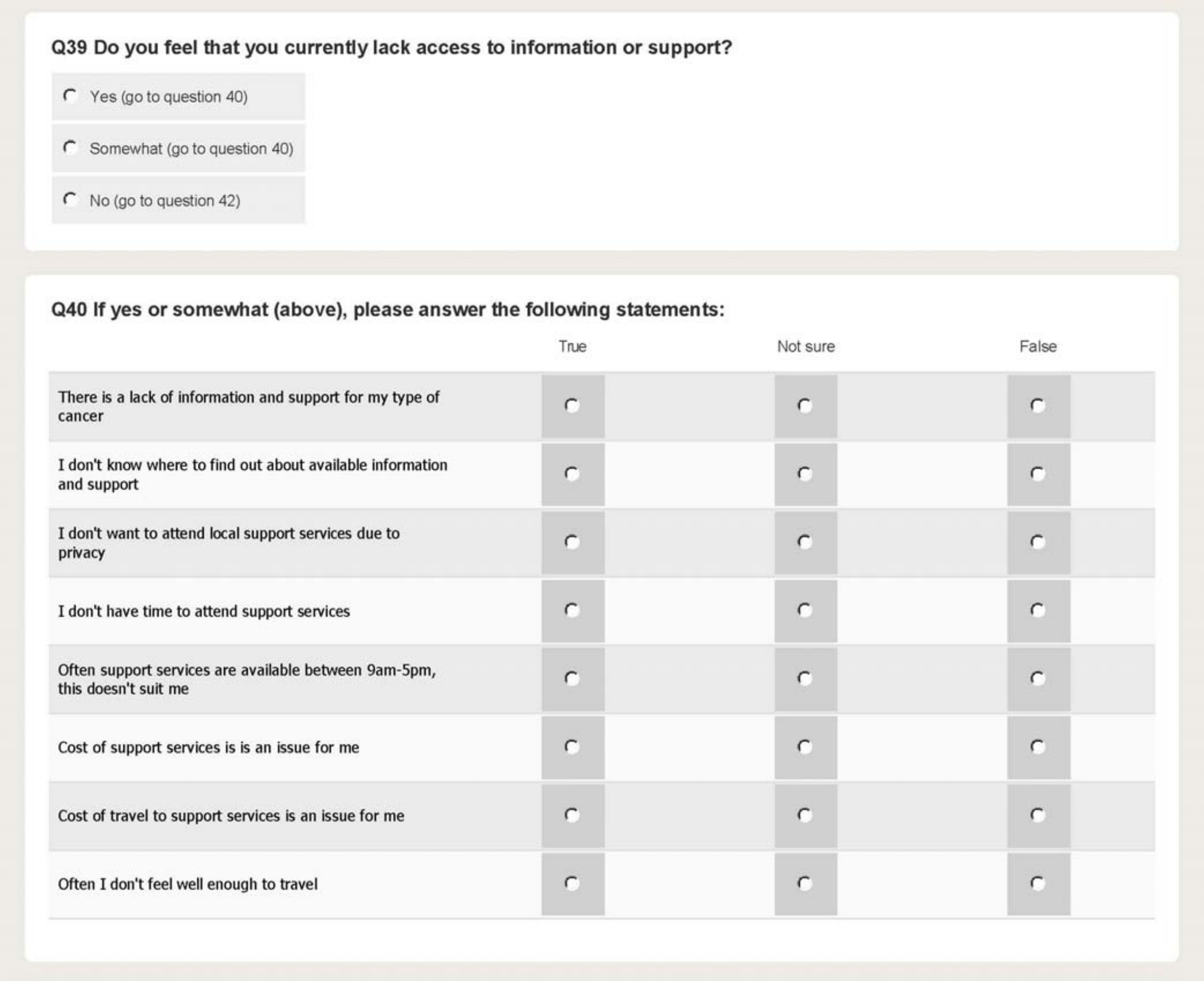
○ Yes

○ No

Q37 If yes, please tell us the <u>names</u> of the rural or regional services that <u>provided you</u> with valuable <u>information or support</u>?

Q38 I am interested in accessing information about support services from:

	Yes	Maybe	No
My local town or suburb	○	○	○
My nearest regional city	○	○	○
Melbourne	○	○	○



Q39 Do you feel that you currently lack access to information or support?

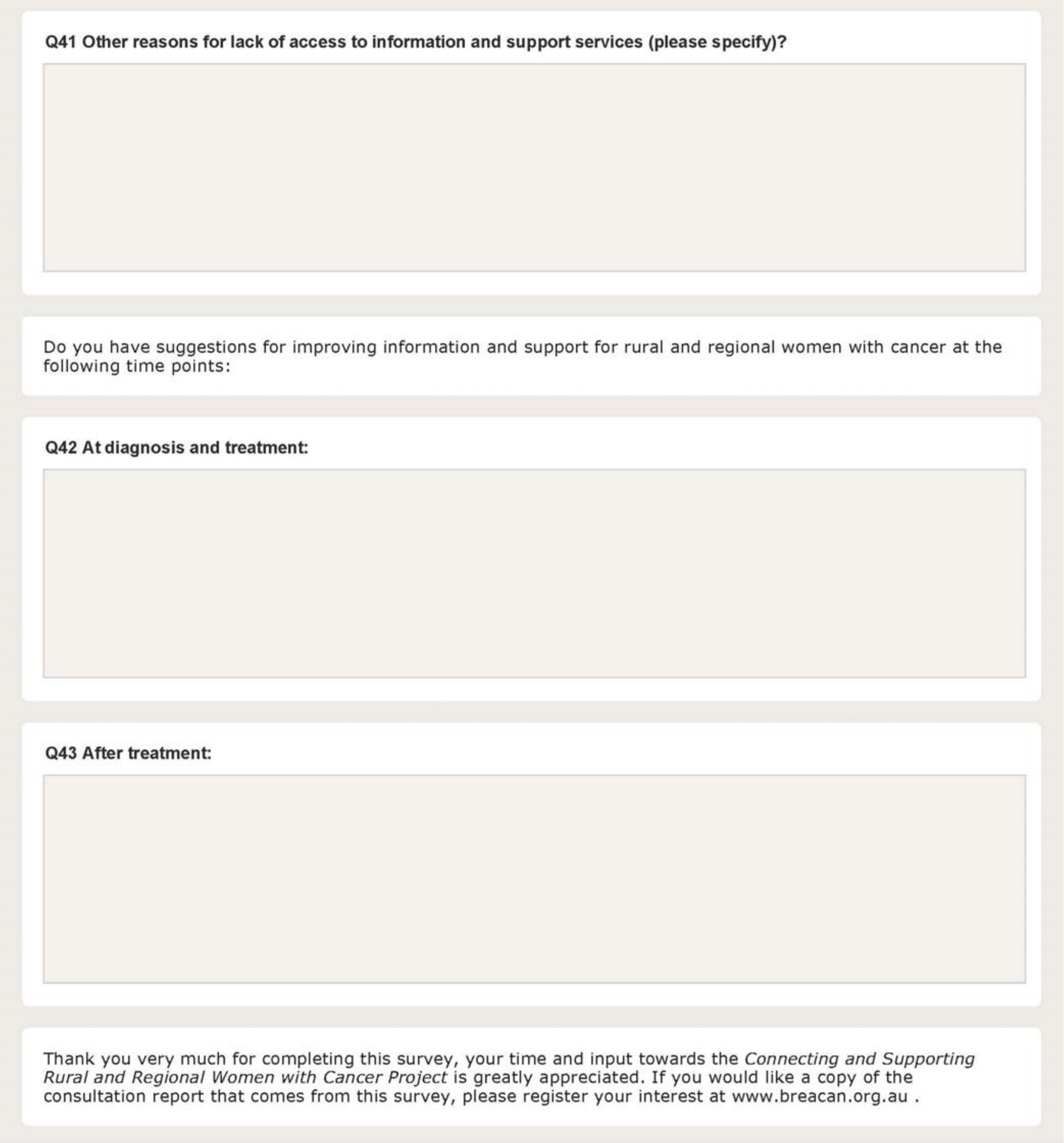
○ Yes (go to question 40)

○ Somewhat (go to question 40)

○ No (go to question 42)

Q40 If yes or somewhat (above), please answer the following statements:

	True	Not sure	False
There is a lack of information and support for my type of cancer	○	○	○
I don't know where to find out about available information and support	○	○	○
I don't want to attend local support services due to privacy	○	○	○
I don't have time to attend support services	○	○	○
Often support services are available between 9am-5pm, this doesn't suit me	○	○	○
Cost of support services is is an issue for me	○	○	○
Cost of travel to support services is an issue for me	○	○	○
Often I don't feel well enough to travel	○	○	○



Q41 Other reasons for lack of access to information and support services (please specify)?

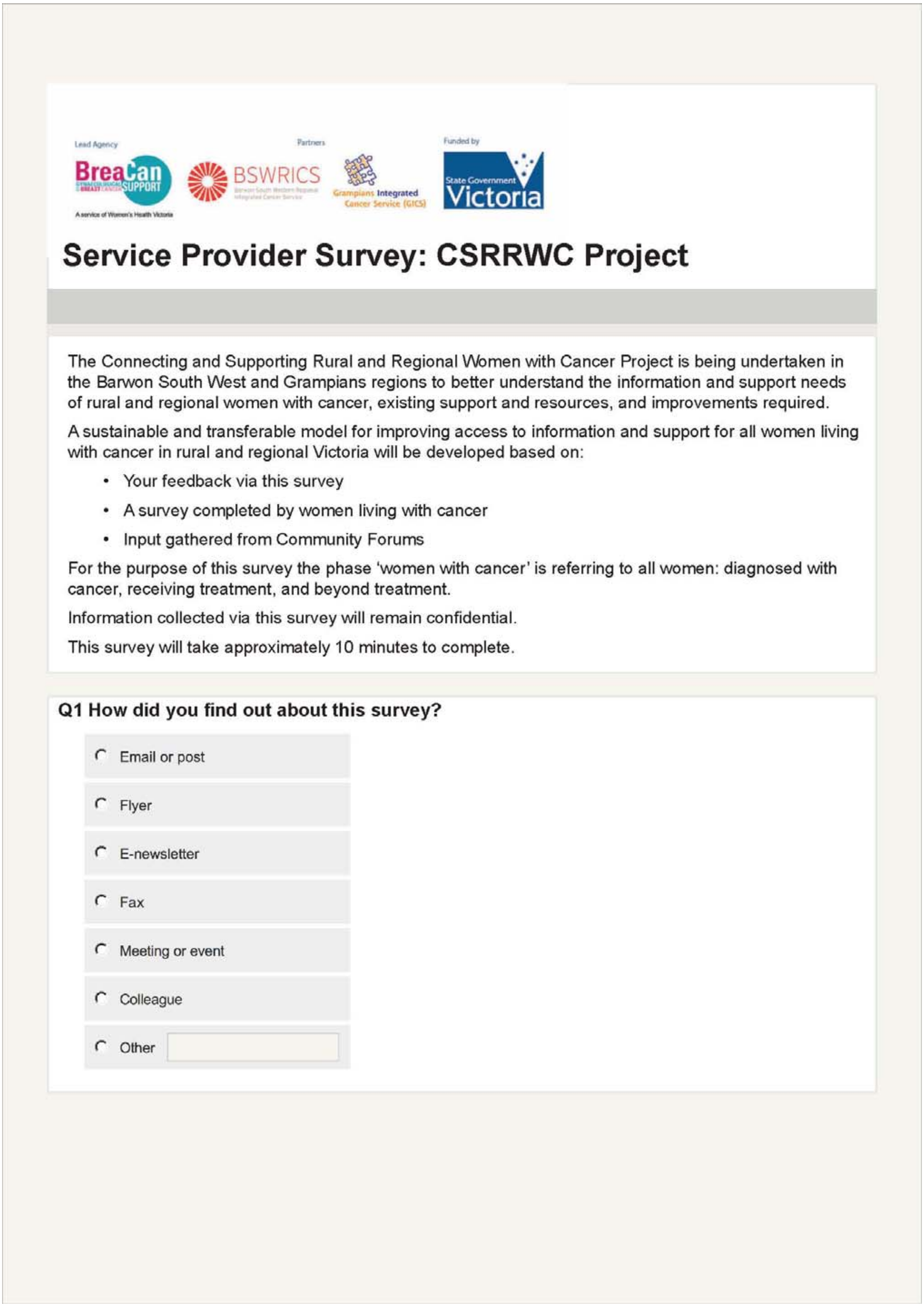
Do you have suggestions for improving information and support for rural and regional women with cancer at the following time points:

Q42 At diagnosis and treatment:

Q43 After treatment:

Thank you very much for completing this survey, your time and input towards the *Connecting and Supporting Rural and Regional Women with Cancer Project* is greatly appreciated. If you would like a copy of the consultation report that comes from this survey, please register your interest at www.breacan.org.au .

Appendix XI: Service Provider Survey



Service Provider Survey: CSRRWC Project

The Connecting and Supporting Rural and Regional Women with Cancer Project is being undertaken in the Barwon South West and Grampians regions to better understand the information and support needs of rural and regional women with cancer, existing support and resources, and improvements required.

A sustainable and transferable model for improving access to information and support for all women living with cancer in rural and regional Victoria will be developed based on:

- Your feedback via this survey
- A survey completed by women living with cancer
- Input gathered from Community Forums

For the purpose of this survey the phase 'women with cancer' is referring to all women: diagnosed with cancer, receiving treatment, and beyond treatment.

Information collected via this survey will remain confidential.

This survey will take approximately 10 minutes to complete.

Q1 How did you find out about this survey?

○ Email or post

○ Flyer

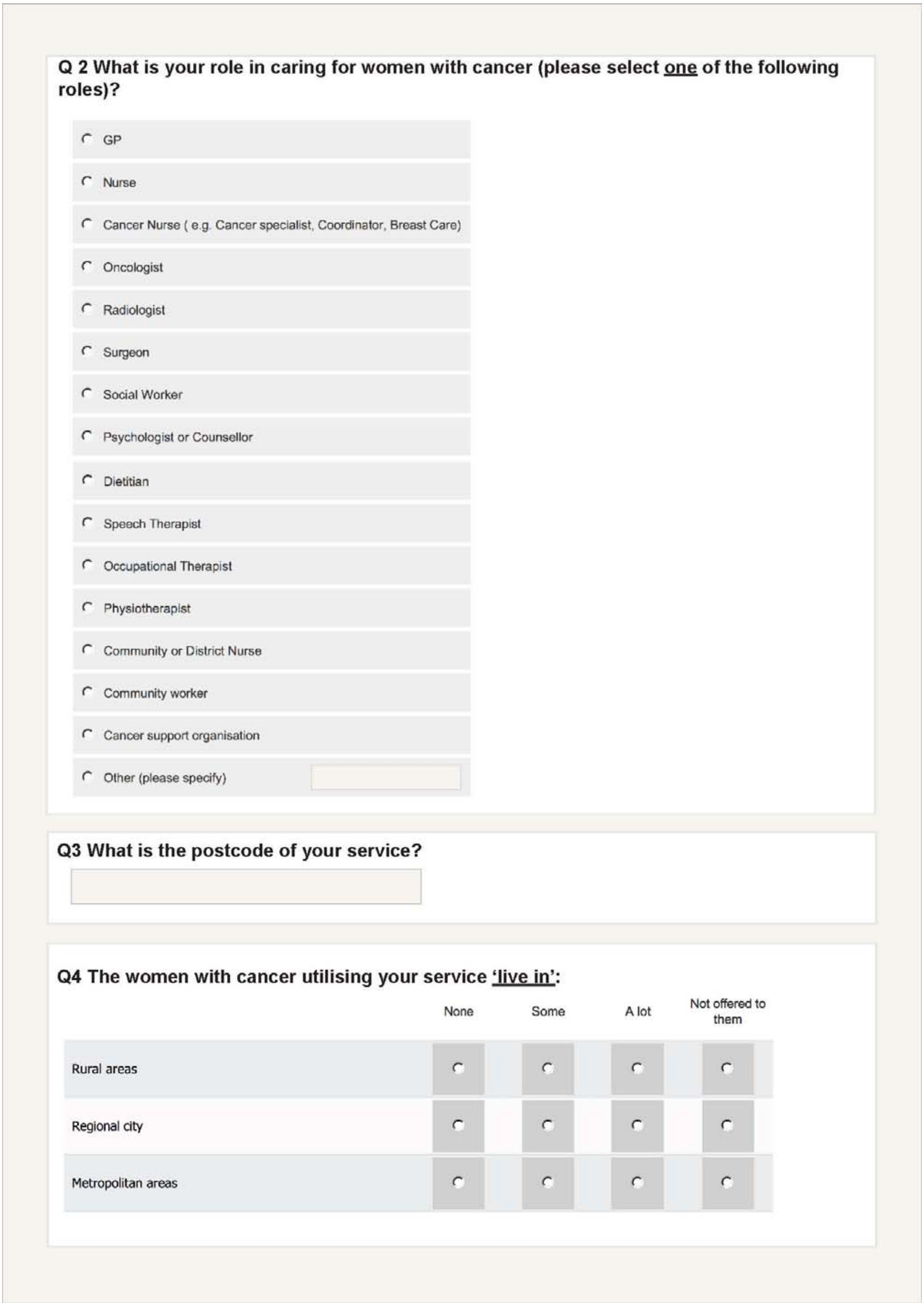
○ E-newsletter

○ Fax

○ Meeting or event

○ Colleague

○ Other ________



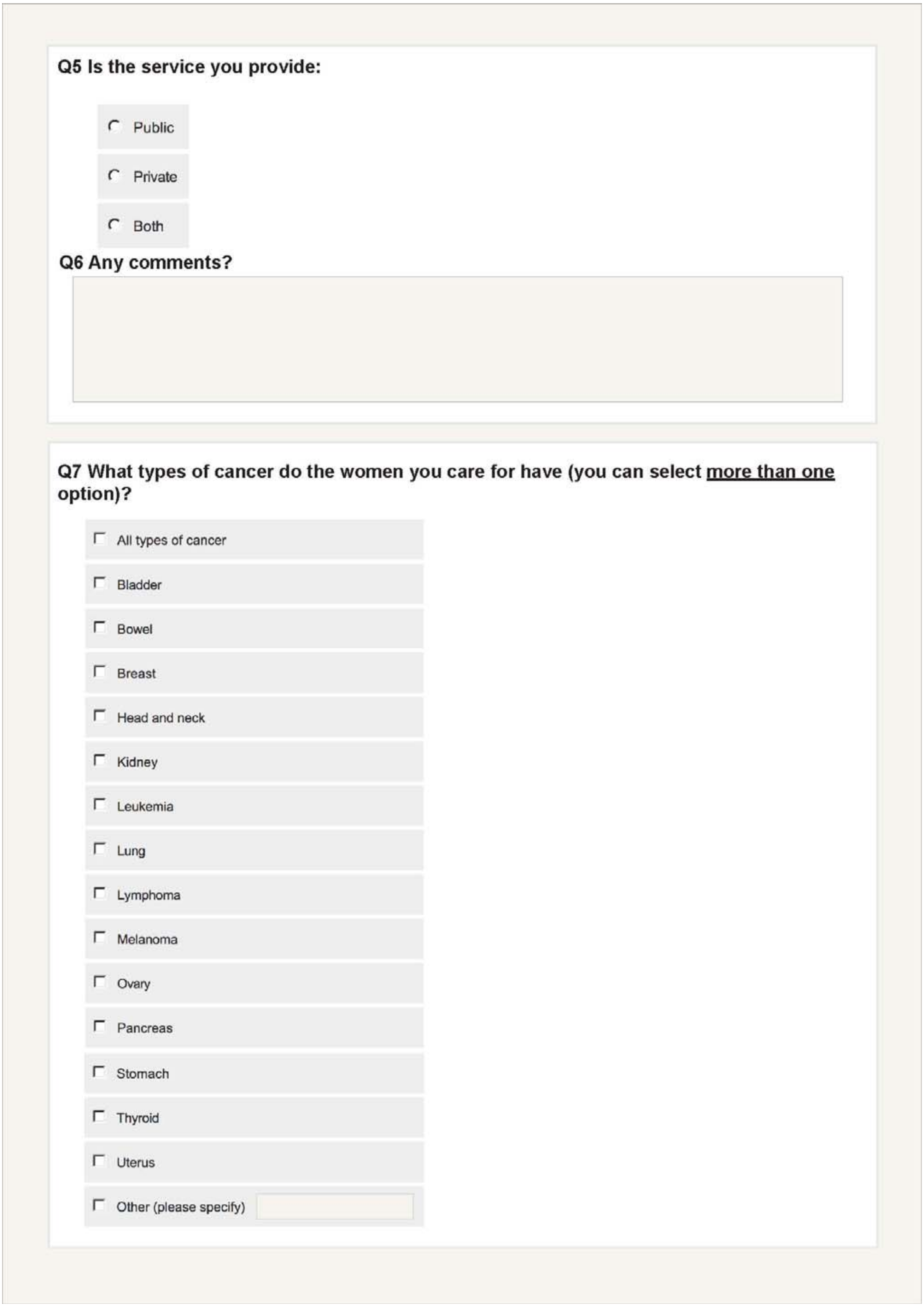
Q 2 What is your role in caring for women with cancer (please select one of the following roles)?

○ GP
○ Nurse
○ Cancer Nurse (e.g. Cancer specialist, Coordinator, Breast Care)
○ Oncologist
○ Radiologist
○ Surgeon
○ Social Worker
○ Psychologist or Counsellor
○ Dietitian
○ Speech Therapist
○ Occupational Therapist
○ Physiotherapist
○ Community or District Nurse
○ Community worker
○ Cancer support organisation
○ Other (please specify)

Q3 What is the postcode of your service?

Q4 The women with cancer utilising your service 'live in':

	None	Some	A lot	Not offered to them
Rural areas	○	○	○	○
Regional city	○	○	○	○
Metropolitan areas	○	○	○	○



Q5 Is the service you provide:

○ Public

○ Private

○ Both

Q6 Any comments?

Q7 What types of cancer do the women you care for have (you can select more than one option)?

☐ All types of cancer

☐ Bladder

☐ Bowel

☐ Breast

☐ Head and neck

☐ Kidney

☐ Leukemia

☐ Lung

☐ Lymphoma

☐ Melanoma

☐ Ovary

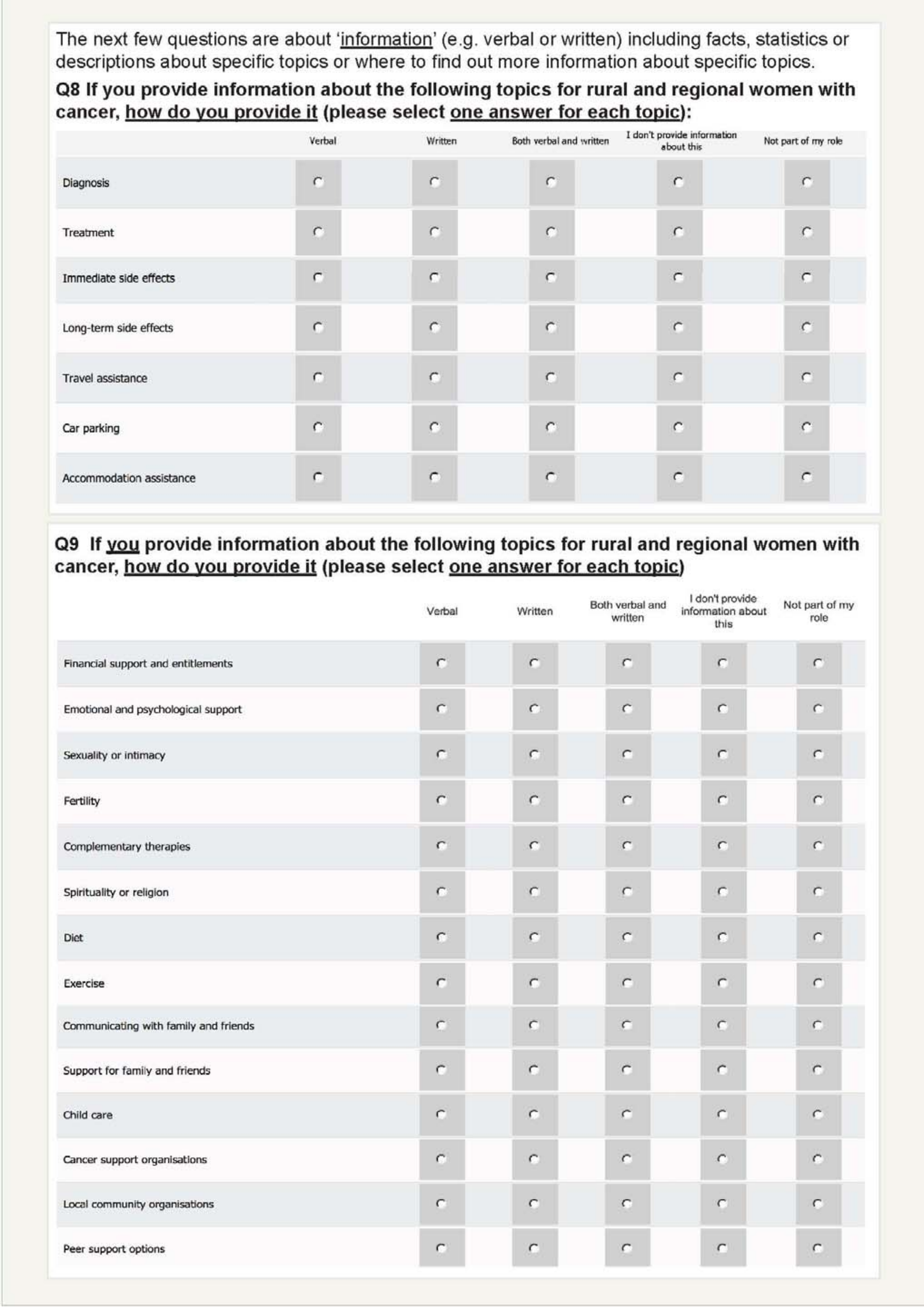
☐ Pancreas

☐ Stomach

☐ Thyroid

☐ Uterus

☐ Other (please specify)



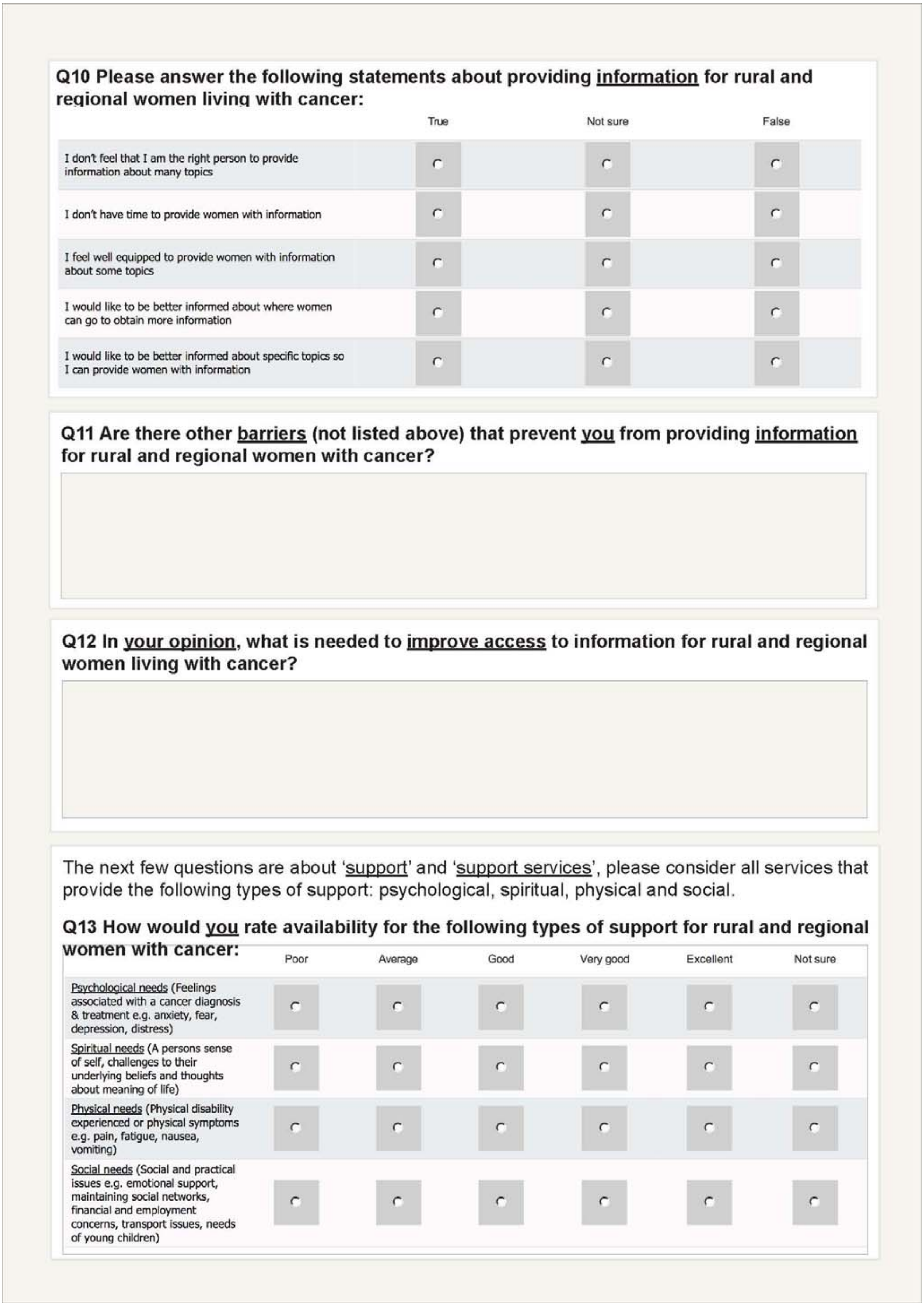
The next few questions are about '<u>information</u>' (e.g. verbal or written) including facts, statistics or descriptions about specific topics or where to find out more information about specific topics.

Q8 If you provide information about the following topics for rural and regional women with cancer, <u>how do you provide it</u> (please select <u>one answer for each topic</u>):

	Verbal	Written	Both verbal and written	I don't provide information about this	Not part of my role
Diagnosis	○	○	○	○	○
Treatment	○	○	○	○	○
Immediate side effects	○	○	○	○	○
Long-term side effects	○	○	○	○	○
Travel assistance	○	○	○	○	○
Car parking	○	○	○	○	○
Accommodation assistance	○	○	○	○	○

Q9 If <u>you</u> provide information about the following topics for rural and regional women with cancer, <u>how do you provide it</u> (please select <u>one answer for each topic</u>)

	Verbal	Written	Both verbal and written	I don't provide information about this	Not part of my role
Financial support and entitlements	○	○	○	○	○
Emotional and psychological support	○	○	○	○	○
Sexuality or intimacy	○	○	○	○	○
Fertility	○	○	○	○	○
Complementary therapies	○	○	○	○	○
Spirituality or religion	○	○	○	○	○
Diet	○	○	○	○	○
Exercise	○	○	○	○	○
Communicating with family and friends	○	○	○	○	○
Support for family and friends	○	○	○	○	○
Child care	○	○	○	○	○
Cancer support organisations	○	○	○	○	○
Local community organisations	○	○	○	○	○
Peer support options	○	○	○	○	○



Q10 Please answer the following statements about providing information for rural and regional women living with cancer:

	True	Not sure	False
I don't feel that I am the right person to provide information about many topics	○	○	○
I don't have time to provide women with information	○	○	○
I feel well equipped to provide women with information about some topics	○	○	○
I would like to be better informed about where women can go to obtain more information	○	○	○
I would like to be better informed about specific topics so I can provide women with information	○	○	○

Q11 Are there other barriers (not listed above) that prevent you from providing information for rural and regional women with cancer?

Q12 In your opinion, what is needed to improve access to information for rural and regional women living with cancer?

The next few questions are about 'support' and 'support services', please consider all services that provide the following types of support: psychological, spiritual, physical and social.

Q13 How would you rate availability for the following types of support for rural and regional women with cancer:

	Poor	Average	Good	Very good	Excellent	Not sure
Psychological needs (Feelings associated with a cancer diagnosis & treatment e.g. anxiety, fear, depression, distress)	○	○	○	○	○	○
Spiritual needs (A persons sense of self, challenges to their underlying beliefs and thoughts about meaning of life)	○	○	○	○	○	○
Physical needs (Physical disability experienced or physical symptoms e.g. pain, fatigue, nausea, vomiting)	○	○	○	○	○	○
Social needs (Social and practical issues e.g. emotional support, maintaining social networks, financial and employment concerns, transport issues, needs of young children)	○	○	○	○	○	○

Q14 Do you refer women with cancer to rural and regional support services?

○ Yes ○ No

Q15 If yes, which rural or regional support services do you refer women with cancer to (please list them)?

Q16 Please answer the following statements about informing rural and regional women about <u>support services</u>:

	True	Not sure	False
Providing information about support services is not part of my role	○	○	○
There is a lack of local support services	○	○	○
I don't know which support services to refer women to	○	○	○
I don't have time in my role to provide information to women about support services	○	○	○
I don't have time in my role to keep up with changes to support service	○	○	○
I am very aware of available support services	○	○	○
I would like to be better informed about available support services	○	○	○

Q17 Are there other barriers (<u>not listed above</u>) that prevent <u>you</u> from informing rural and regional women with cancer about <u>support services</u> ?

Q18 In your opinion, what is needed to improve access to support services for rural and regional women living with cancer?

Thank you very much for completing this survey, your time and input towards the Connecting and Supporting Rural and Regional Women with Cancer Project is greatly appreciated.

BreaCan is a statewide support and information service dedicated to helping women living with breast and gynaecological cancers, their families and friends from diagnosis, during treatment and beyond.

PHONE	1300 781 500
EMAIL	breacan@breacan.org.au
WEBSITE	www.breacan.org.au

POSTAL ADDRESS
GPO Box 1066
Melbourne VIC 3001

BREACAN RESOURCE CENTRE
Queen Victoria Women's Centre
210 Lonsdale Street
Melbourne VIC 3000

BreaCan is a service of Women's Health Victoria, a statewide women's health promotion, information and advocacy organisation.

BreaCan acknowledges the support of the Victorian Government