Cancer Council Western Australia

Carers Australia WA

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Community Conversation Forum
After cancer treatment ends…
Where to from here?

OUTCOMES REPORT

Wednesday, 24 August 2016
The Rise Community Centre, Maylands

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Introduction

Consumers, carers and community members with experience of cancer survivorship gathered for a Community Forum on Wednesday, 24 August 2016 at The Rise Community Centre in Maylands.

The Forum was a partnership event cosponsored by the Cancer Council WA (CCWA), Health Consumers Council (HCC) and Carers Western of Australia (CWA).

The aim of the Forum was to provide consumers with an opportunity to articulate what's important for engaging people after cancer treatment ends.

The key aspects of the format for the Forum were:

- Attendees were given a short time to reflect about their experiences and what they would like to share with others;
- The groups used a digital platform to input their responses to the discussion questions;
- In three separate 15 minute sessions (i.e. one question per session), participants provided responses to the discussion questions; and
- The final session involved groups using the 'like' function to prioritise their responses to the final discussion question.

By the end of the Forum, the participants had:

- Considered the current situation with a panel of speakers;
- Heard updates on the services currently available from HCC, CWA and CCWA;
- Shared their experiences of access to support services and information after treatment had ended;
- Articulated what would make the 'biggest difference' for people after treatment ends; and
- Agreed on the next steps.

See Appendix C for registrant and attendee information.
See Appendix D for a summary evaluation of the Forum.

Thanks to Will Bessen of Tuna Blue Facilitation for planning, facilitation and reporting of this forum

TUNA BLUE

Executive Summary

The attendees participated in two workshop sessions over a series of short 15 minute bursts, focused on:

1. Their experiences of access to support services and information after treatment had ended
2. What would make the biggest difference after treatment ends

The key responses from each workshop session are outlined below.

Common experiences in regards to **Access to Support Services** were:

- Clients often have to personally navigate the complexity of the system and coordinate their own access to support services
- Having a strong, understanding relationship with a GP was helpful in navigating the process
- Clients often experience a feeling of isolation and uncertainty post treatment dependent on the information or advice they are provided
- Access to support groups and online groups are helpful and well received
- Specific supports that are helpful included dieticians, health coaching and wellness, alternative or complementary therapies and specialist Clinics.
- There is a need for longer term, ongoing and more holistic support after treatment
- Support for carers and families is important
- Clients find it difficult to understand and plan for treatment due to referral gaps, blockages and shortcuts; Survivorship Plans were raised as a useful tool for communicating between health professionals
- The cost of accessing ongoing support services is sometimes prohibitive
- Barriers to access include long waiting times, oversubscribed support group and restrictive referral criteria.

Common experiences in regards to **Access to Information** were:

- Clients are not given adequate information or guidance on where to find information post treatment, and have to personally research and obtain suitable information
- More readily available and specific information is desired on topics such as mental, emotional and reproductive health, as well as practical guidance or logistical information on low cost pharmacy options, cheap parking and travel insurance requirements
- Accessing information from peers in support groups and other settings is a popular method

- It is important to consider the accessibility of information provided in brochures or by phone for clients who have grown accustomed to information delivered face-to-face at appointments during their treatment phase
- Clients not feeling involved in the treatment process is an issue to accessing suitable information
- Time poor clinicians not giving enough information to clients is a challenge
- GP's without adequate knowledge of treatment options and processes is an issue (e.g. Chronic Disease Management planning)
- Uncertainty between tests or visits is an issue for clients, especially long waits for post treatment follow-ups and information
- Treatment plans / lists of post treatment options are useful in addressing the uncertainty for clients and provide a sense of control
- Access to information for carers and opportunities for carer input is important

The most common suggestions for **What Would Make the Biggest Difference** were:

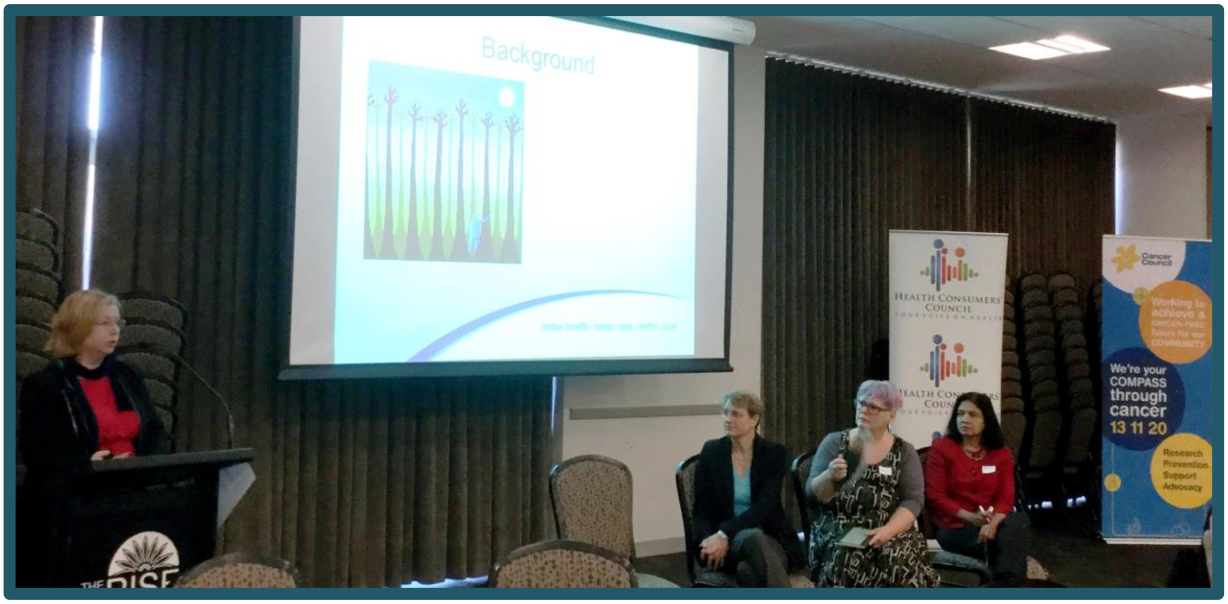
Response	Likes
➢ Increased opportunities to meet other cancer patients and survivors through support groups and forums as a way to share experiences and learn from each other, and to normalise the experience and address isolation	49
➢ More consistent information after treatment, especially to build an understanding of the long term effects of cancer treatment	31
➢ Better communication and coordination of services between health professionals	30
➢ Increased focus on psychological, mindfulness and wellness support programs	17
➢ Improved knowledge and communication skills of health professionals	16
➢ Greater involvement of carer and family feedback and provision of the necessary support for them	16
➢ Greater recognition and respect for the patient as a person during and after treatment	13
➢ Increased information on what's available and where to access services (i.e. lists or directories)	11
➢ More career and work integration assistance for cancer survivors post treatment	11
➢ Better use of e-health records as an underutilised communication tool	9
➢ Greater acknowledgement that cancer treatment includes a range of services other than just surgery, chemotherapy and radiotherapy	5

Panel Discussion

To set the scene Ms Violet Platt, Co-Director and Director of Nursing of the WA Cancer and Palliative Care Network provided a state-wide update, noting that the WA Cancer Plan provides a policy basis for all clinical service delivery related to cancer care including life after cancer treatment. For the 70,000 Western Australians living after a diagnosis of cancer, treatment is often a long term chronic condition, and people have to learn to navigate living with, during and after cancer. Violet provided a brief overview of a number of initiatives including the Cancer Survivorship Collaborative.

Violet then joined a panel that included Ms Karen Taylor – Survivorship Cancer Nurse Specialist, Ms Lencie Wendon – Breast Cancer Survivor and Ms Anjali Abbot – Carer of her daughter with rare cancer.

All members of the panel shared their work and experiences providing personal insights on system challenges, ongoing management and how they are coping with the long term effects of cancer treatment both physically and mentally. This discussion helped set the scene and centre table discussions and input into the workshop process.



Workshop One: Access

The participants worked in small groups to consider the following focus questions:

> *Drawing from your own experience as a cancer survivor or carer…*
>
> *What can you tell us about **access to support services** after cancer treatment ended?*
>
> *What can you tell us about **access to information** after cancer treatment ended*

Most Common Responses

The most common themes from responses were:

Access to Support Services

- ➢ Clients often have to personally navigate the complexity of the system and coordinate their own access to support services
- ➢ Having a strong, understanding relationship with a GP was helpful in navigating the process
- ➢ Clients often experience a feeling of isolation and uncertainty post treatment dependent on the information or advice they are provided
- ➢ Access to support groups and online groups are helpful and well received
- ➢ Specific supports that are helpful included dieticians, health coaching and wellness, alternative or complementary therapies and specialist Clinics.
- ➢ There is a need for longer term, ongoing and more holistic support after treatment
- ➢ Support for carers and families is important
- ➢ Clients find it difficult to understand and plan for treatment due to referral gaps, blockages and shortcuts; Survivorship Plans were raised as a useful tool for communicating between health professionals
- ➢ The cost of accessing ongoing support services is sometimes prohibitive
- ➢ Barriers to access include long waiting times, oversubscribed support group and restrictive referral criteria.

Access to Information

- ➢ Clients are not given adequate information or guidance on where to find information post treatment, and have to personally research and obtain suitable information
- ➢ More readily available and specific information is desired on topics such as mental, emotional and reproductive health, as well as practical guidance or logistical

information on low cost pharmacy options, cheap parking and travel insurance requirements

- Accessing information from peers in support groups and other settings is a popular method
- It is important to consider the accessibility of information provided in brochures or by phone for clients who have grown accustomed to information delivered face-to-face at appointments during their treatment phase
- Clients not feeling involved in the treatment process is an issue to accessing suitable information
- Time poor clinicians not giving enough information to clients is a challenge
- GP's without adequate knowledge of treatment options and processes is an issue (e.g. Chronic Disease Management planning)
- Uncertainty between tests or visits is an issue for clients, especially long waits for post treatment follow-ups and information
- Treatment plans / lists of post treatment options are useful in addressing the uncertainty for clients and provide a sense of control
- Access to information for carers and opportunities for carer input is important

See Appendix A for the detailed responses from participants.

Workshop Two: What Would Make the Biggest Difference?

The participants worked in the same small groups to consider the following question:

What would make the ***biggest difference*** *to you after cancer treatment ends?*

Most Common Responses

The most common themes from responses were:

	Response	Total Likes
➢	Increased opportunities to meet other cancer patients and survivors through support groups and forums as a way to share experiences and learn from each other, and to normalise the experience and address isolation	49
➢	More consistent information after treatment, especially to build an understanding of the long term effects of cancer treatment	31
➢	Better communication and coordination of services between health professionals	30
➢	Increased focus on psychological, mindfulness and wellness support programs	17
➢	Improved knowledge and communication skills of health professionals	16
➢	Greater involvement of carer and family feedback and provision of the necessary support for them	16
➢	Greater recognition and respect for the patient as a person during and after treatment	13
➢	Increased information on what's available and where to access services (i.e. lists or directories)	11
➢	More career and work integration assistance for cancer survivors post treatment	11
➢	Better use of e-health records as an underutilised communication tool	9
➢	Greater acknowledgement that cancer treatment includes a range of services other than just surgery, chemotherapy and radiotherapy	5

Most ‘Liked’ Responses

The most ‘liked’ individual responses were:

	Response	Likes
➢	Better information on support and treatment at all stages (i.e. before and after treatment)	6
➢	More opportunities to meet other cancer survivors and learn about what services and doctors work (crucial for addressing isolation and normalising the experience)	6
➢	Increased access to support groups	6
➢	Increased access to services such as counselling, support groups, exercise and meditation	5
➢	Being able to share experiences with others and share ideas and feedback about things that can help	5
➢	Better communication between health professionals	5
➢	Better use and development of e-health and Advanced Care Directives	5
➢	Improved coordination of services between hospital, community, public, private, NGOS; It's not about reinventing the wheel as there are a lot of good wheels out there	5
➢	Improved GP knowledge and education on services and information	5
➢	More information and advice on the side effects of the treatment	5
➢	More psychological support for patients	5

See Appendix B for the detailed responses from participants.

Summary and Next Steps

The data represented in this report reflects the thoughts and experiences of those in attendance on the day. It is clear that although there are a number of initiatives and service providers working towards improving outcomes for cancer survivors and their carers there remains substantial challenges in reaching this goal.

The opportunity to hear these voices has been valuable and the information gathered will go some ways to informing organisation and systems issues into the future. In particular this document will be utilised as below.

- The feedback from this event will be provided to the WA Expert Advisory Cancer Group, the WA Cancer & Palliative Care Network, the Survivorship Collaborative and be utilised by Cancer Council WA, Health Consumers Council and Carers WA
- Those attendees who registered interest in becoming a consumer or carer representative will be followed up either by the Health Consumers' Council or Carers WA for access to training opportunities
- There is a clear mandate from feedback from the day that people would like more opportunity to provide further input into the WA Cancer Plan.
- Further thinking will be undertaken to increase diversity of representation in future forums

Cancer Council WA, Health Consumers Council and Carers WA thank all participants for their valuable contributions to this forum.

Sandy McKiernan, Cancer Council WA

Pip Brennan, Health Consumers Council

Dean Beissel, Carers WA

Appendix A – Detailed Responses Workshop One

The responses in full detail and listed under the cluster headings.

Access to Support Services

Clients often have to personally navigate the complexity of the system and coordinate their own access to support services

- I could contact the Breast Cancer Nurse but I had to initiate contact
- As an allied health professional I knew how to access the information, but I believe this would be very difficult for someone else
- Had to look for support services
- Had to start my own support group
- Have to be personally proactive or you can get lost and then the treatment gets delayed
- Need to take charge of your own health care
- Needed someone to help me navigate the system and guide me in the right direction
- No umbrella or key person to help you access services
- Had to drive my own access to get support for comorbidities
- Self-access to support services is more likely than being referred to them by a health professional
- The patient has to take charge of some aspects of treatment and be proactive
- Writing your own Survivorship Plan is critical
- Word of mouth was best way to get info

A feeling of isolation and uncertainty post treatment dependent on the information or advice a client is provided

- Access is dependent on the information you're provided
- Need to talk to the right person
- Received no advice on when to stop support services or treatments
- No follow up regarding support groups
- No one to talk to who understands, felt very isolated
- Not enough time to ask questions at follow up appointments
- Felt like a sausage factory
- Felt restless and living in limbo
- Uncertainty post treatment is the biggest issue
- Not sure of where the treatment was going unless you asked the question

Access to support groups and online groups are helpful and well received

- Access to peer support at any time was great
- Access to support group via BCNA was very useful but had to find through internet
- Active on online groups which helped

- Breast Care offering support and counselling
- Support group in specialist cancers was helpful
- Support groups have been a lifesaver
- Psychological support was also great

Specific supports that were helpful included dieticians, health coaching and wellness, alternative or complementary therapies and specialist Clinics.

- Complementary and integrative therapies were helpful
- Dietitian was very useful to cover off what was and wasn't able to be eaten for bowel cancer
- Eating well and dietician support is important
- Health coaching and wellness was helpful
- Health coaching program was very helpful
- Alternative supports were very helpful
- Offered financial and taxi support but it was not needed
- Physiotherapy and lymphedema management was offered when concerns were raised and both were helpful and available when needed
- Silver chain services were good
- The brilliant service of the Menopause After Cancer Clinic needs to be better resourced as they are terribly overworked but are the only service that specialises in this area
- Timing of CCWA retreat day was very suitable when in the middle of treatment
- Good support team and all the doctors were good mates which was positive
- Good cohesive medical team meant that care could progress quickly

Support for carers and families is important

- As a carer I would've appreciated some additional support
- GP offered mental health services to my family which was wonderful to know there was something available for them
- Carer support from people who understood the carer’s situation
- Support for family members is important
- It’s important to look after yourself as a carer
- Family and friends’ support was essential
- Advocating as the carer with GPs and other health professionals was often very difficult
- As a carer I was keen to find out what was available and be involved
- Carers WA and Red Cross were referring

Difficulty understanding and planning for treatment due to referral gaps, blockages and shortcuts; Survivorship Plans were raised as a useful tool for communicating between health professionals

- A treatment and care summary would be very useful for planning but was not available

- Wanted a summary of treatment for travelling but was unable to obtain from oncology health professional and my GP was not able to do except where the patient was on-sent by other oncology professionals
– my GP didn't have the required information about the care provided and so end result was sub optimal
- Hard to plan as to what financial support is there
- Access to allied health services needs to be made available without complicated referral processes
- Appointments not happening to schedule was a challenge
- Don’t get easily referred onto other services by oncology staff
- Was directed to the Breast Cancer Nurse, who I met only once
- Follow up care was missing which meant not recognising the side effects
- Seeing a doctor that you haven’t seen before is always a problem
- Having a Survivorship Plan can help share information between health professionals
- Radiologist had to advise on other support services
- Radiologist suggested that I access a physiotherapist

Prohibitive cost of accessing ongoing support services

- Can’t always afford support services
- Can’t get cover for all services
- High costs of services is difficult
- The ongoing costs of follow up treatment makes some services difficult or impossible to access

Having a strong relationship with an understanding GP was helpful in navigating the process

- The GP provided Plan was good
- Having a good GP helps
- Having a good GP, who you can trust is very important
- Seeing a GP is better than the specialists if you get a good GP
- A trusting GP was very helpful
- My GP was good to advise that he could provide help with no need for costly regular visits to others
- GP has been helpful in assessing mental health and referring for psychological support
- The GP does not always get feedback from specialists
- GP’s don’t have much knowledge at the follow-up stage
- GP often just refers back to the specialist
- GP support varies so they all need the same information on support services available

Barriers to access included long waiting times, oversubscribed support group and restrictive referral criteria

- Age can limit your access to service
- Breast cancer gets better access than other cancer types
- Difficulty in accessing specific supports
- It’s been a long time since diagnosis and I now have limited access to programs
- The opportunity for social support not part of the structure
- Support groups are over subscribed
- The ABC catalyst show was seen by many and raised the need for exercise that wasn't discussed by my hospital or medical staff
- Long waiting times to access counselling services
- DSP is hard to get

Need for longer term, more holistic ongoing support after treatment

- Would like more long term support
- Now when my kids are older they still have challenges, so there is a need for supporting young people a long time after cancer treatment ends
- ‘Living with cancer’ is a good term to describe that life will never be the same after treatment
- Being left with a lot of health issues post treatment was challenging
- A focus on quality of life should be a high priority
- Focusing on quality of life is important
- Oncologist didn't take a holistic approach

Other comments

- Access to life now only known through Catalyst
- Environment is dominated by non-survivors
- Need to better understand what may be a problem so that users can work out what is needed
- Online support was disrupted by negative people
- Received a brochure in the mail from the Cancer Council WA
- Social workers are not sure of what is available
- Solaris Care provided some information about support services
- Some needs are the same regardless of type of cancer
- The Breast Cancer Survivorship Care Plan needs to be rolled out on the front line (yes it's on the WA Health website but it needs to be promoted)
- Valued information sessions about how and where to access services
- Discrimination in the private system when coming from the public
- Access in the public system was slower than the private

Access to Information

Clients not given adequate information or guidance on where to find information post treatment, and have to personally research and obtain suitable information

- Being guided online to useful sites would be more helpful than just trying on your own
- I couldn't access the information even with inside knowledge
- Google can be informative but not good for diagnosis
- Have to do your own research to find services
- I had to ask for the information to be sent to me
- Information only seemed to be available when the patient asked the questions, so how do you know what questions to ask?
- It is almost impossible to find out information
- Just hearing things for first time even today
- Lack of information means scrambling to find out what is available
- Left high and dry once treatment ends
- Doctors letting go and taking back personal control is an important aspect of care and information
- Lots of information at the beginning and through treatment but nothing afterward
- Need to know that information is available so that it can be effectively sought out
- No information given on where to get information
- Used Google and local newspapers for information
- Vacuum of information between surgery and other treatment when I needed to know 'what next?'
- Wasn't given adequate information about side effects by doctors and if you can't find anything yourself then where do you go?
- What does MDT care really mean when you personally have to drive it
- Why do I have to go online to get the information I need
- Going to oncology units and seeking the information yourself
- Having a personal contact to 'welcome' me to the cancer journey and give me information about what's available would be ideal
- Information could be a portal to what support services people are eligible for rather than just an information leaflet about cancer and treatment options

More readily available and specific information is desired on topics related to the medical treatment such as mental, emotional and reproductive health, as well as practical guidance on topics like low cost pharmacy options, cheap parking and travel insurance requirements

- The information was too broad and didn't go into detail about specific needs
- Practical information for patients would be helpful e.g. the hospital pharmacy is low cost and the community pharmacist is much more expensive to fill your relevant script
- Informational focus was on physical health, and therefore other issues such as mental and emotional health can be neglected
- Important to address anxiety and other issues related to cancer treatment, such as reproductive problems

- Information and pointers about nurturing and nourishing oneself would be helpful
- More information is needed about eligibility for mobility allowance
- Need to know about travel insurance requirements for overseas travel so informed decisions can be made
- No information for emotional support
- No information or late information on support such as cheaper parking etc.
- Sexuality and fertility information is not forthcoming easily
- Shouldn’t matter about whether you want to have children or more children, sexuality and fertility conversations need to happen early and before decisions are made
- Information on transport between hospitals wasn’t clear
- Surgeon gave simple advice about life decisions after cancer
- Things have changed over time, back in 2003 there was little information and by 2010 things had improved a lot and very specific information was available, particularly on eating which was very helpful with my throat cancer
- Information about efficacy of treatment is difficult to obtain (e.g. efficacy of radiotherapy BEFORE you make treatment choices)
- Information about recurrence is missing; needed to know what to look out for, at what point do I need to follow up and at what point should I be worried
- Does information on genetic testing increase anxiety unnecessarily? Information needs to be personalised
- The only information I've found on Aromatase Inhibitor is in the USA via Blogs
- No information on side effects
- No information about longer term side effects
- Some services give good information early but most provide it late

Accessing information from peers in support groups and other settings is a popular method

- Learnt more about after effects by talking to other patients than information
- Best source of information is other people
- Most information is sourced from going to sessions where other patients are
- Nice to connect with someone who has been through what you have been through and can talk about side effects
- Support groups are a good way to share experiences and information
- Support groups are a great avenue for seeking information from others who have been through this

Need to consider the accessibility of information provided in brochures or by phone for clients who have grown accustomed to information by face-to-face appointments during their treatment phase

- Brochures are not always going to be read by someone with cancer
- Access to information very is challenging as it takes a lot of time to digest
- Accessibility for hearing and speech impaired people is not well done, challenging to have conversations

- Given 8 different phone numbers for financial counselling and then the cost was $300 which was prohibitive
- Information only supplied through the mail meant I couldn't relate to the information, as it was targeted towards a younger patient
- People with cancer get used to appointments, so it’s really important to provide information to people in the way they will understand it after the face-to-face period

Clients not feeling involved in the treatment process is an issue to accessing suitable information

- Clinical staff don't listen
- Clinicians don't see the person; constantly fobbed off
- My job is to ask questions and yours is to answer (clinician)
- Difficulties experienced with getting a second opinion
- Confidentiality used as an excuse to not share information
- For some providers it is just a job and the care factor is in question
- Patient needs to be more involved in communication in the treatment setting (i.e. patient, doctor and nurses all involved in communication)
- Patient should be part of a three-way conversation with the nurse and doctor
- Seem to be part of a production line with no concern for afterwards
- Support and information on what to expect after surgery that tailors care should be part of admission and consent process at the start of the journey
- Should be "informed consent"

Time poor clinicians not giving enough information to clients

- Staff are normally good for information but are under the pump if required to help further
- Clinic and GP visits are too short
- GP is often too busy
- People don't always get an explanation of the possible after effects by oncology staff
- Some people are lucky when they have good clinicians who provide suitable advice
- What you get depends on who you see
- You feel guilty asking questions when your GP is too busy
- Empower social workers to be more active in support and information

Uncertainty between tests or visits is an issue for clients, especially long waits for post treatment follow-ups

- Coping with test days is hard, waiting for those results is really difficult, waiting for test day is one of the worst things
- Major anxiety in between tests
- One year is a long time for a follow up visit
- Treatment follow up comes too late
- Emotional support needs to come earlier in the treatment journey.

Treatment plans and lists of post treatment options are useful in addressing the uncertainty for clients and provide a sense of control

- Getting a plan / summary about what was happening that could be given to other services was very useful
- Having things organised gives the patient control over the information
- List of post treatment options would be very useful as this will provide a sense of control
- Need the knowledge to plan
- Told ‘don't put the cart before the horse’ but needed to know what was coming
- Uncertainty is the biggest issue faced in terms of what to expect and what you need to build a better understanding of
- Understanding what will happen will allow people to make decisions about the big things like moving house, major holidays or retirement
- Knowing that every week is different is the most important information
- No continuity
- Seeing a different person every time is difficult

GP’s without adequate knowledge of treatment options and processes (e.g. Chronic Disease Management planning)

- GP often has no idea and asks the patient or carer what to do
- GP services are not fully up to speed with CDMS
- GP wasn't even advised about the treatment until a CDM plan was needed to take up Life Now exercise
- GPs are not always aware of how to complete CDM plans for Life Now
- You often know more than they do and there is anxiety in knowing that
- GP is a key resource for information

Access to information for carers and opportunities for carer input is important

- Access to information for carers is important
- Having a key person to assist in filling out forms really helps
- Having independent information sources in hospitals is important (e.g. whiteboard at end of bed that is open for family to use as a communications tool)

Other comments

- How do you find out about different costs of public vs private?
- Huge gap between public and private services
- No scanning post diagnosis because at a population level this has been seen not to be effective but can this be individualised? There is often huge anxiety in the absence of screening and can be delays in diagnosing recurrence of cancer

Appendix B – Detailed Responses Workshop Two

The responses in detail and grouped under the 'most common' cluster headings are.

Increased opportunities to meet other cancer patients and survivors through support groups and forums as a way to share experiences and learn from each other, and to normalise the experience and address isolation (49 likes)

Response	Likes
• More opportunities to meet other cancer survivors • Important, as you can learn a lot from others about what services and doctors work • Crucial for addressing isolation and normalising the experience • Needs trained, supported facilitators with good succession planning	6
• Increased access to support groups	6
• Increased access to services such as counselling, support groups, exercise and meditation	5
• Being able to share experiences with others and share ideas and feedback about things that can help	5
• Being able to connect with others with similar cancer experiences	4
• More opportunities to talk to someone else who has been through chemotherapy so that you can better understand the side effects	4
• Get involved and participate in research programs	3
• Recurrent theme of isolation and lack of connections	3
• Getting people together to talk about positive outcomes	3
• Being helped to live in the moment and appreciate each day by surrounding yourself with positive people	2
• Connecting with others who have a similar cancer journey	2
• Having a disease specific support group has been the best support I have received since my diagnosis	2
• Attendance at a Breastcare forum was the best thing I did and it was wonderful to be with all those people; it gave me a different perspective	1
• Avoid negative friends	1
• Having an exercise group and connecting to people	1
• Connect to social groups and stay healthy with diet, exercise and social connections	1
• Peer support who can empathise and understanding from other people that 'get it'	0

More consistent information after treatment, especially to build an understanding of the long term effects of cancer treatment (31 likes)

Response	Likes
• Better information on support and treatment at all stages (i.e. before and after treatment)	6
• More information and advice on the side effects of the treatment	5
• Ongoing education and support afterwards as some aftereffects last for years	4
• Ensure information is provided as required over the long term and not all given at diagnosis when the patient is in shock, overwhelmed, and only able to take in the immediately relevant information necessary to get through the treatment • Fine line between too much and not enough that depends on the individual	4
• Expand the definition of ‘after cancer’ to include people living with cancer and the ongoing effects of treatments	4
• Better understanding of what the chemotherapy does and what you need to be careful about, especially long term effects	3
• Having access to ongoing services	3
• Ongoing support over the longer period after treatment has finished	2

Better communication and coordination of services between health professionals (30 likes)

Response	Likes
• Better communication between health professionals	5
• Improved coordination of services between hospital, community, public, private, NGOS; It's not about reinventing the wheel as there are a lot of good wheels out there.	5
• Better continuity of care over the long term, so you don’t have to keep explaining your story over and over to different health professionals.	4
• Better management of clinic appointments as follow up appointments don’t run to time • Also more respect given to patients is very important.	4
• Better communication between public and private health care systems	3
• improved connection through the different specialist areas, making MDTs work towards multidisciplinary therapies not treatment	2
• To be assigned a health professional who follows up according to your need (i.e. health professional initiated instead of patient initiated)	2
• Summary of what has occurred and what is happening so that anyone can see where the patient is at (medical personnel need to look at it not keep asking the patient)	2
• We need a system that can accommodate a changing and fluctuating clinical workforce	2
• Continuity of care and keeping access to people who know you is important	1
• Clinical areas better collaborating in overall care as there are cut-off points	0

everywhere!	
• Comorbidities need to be better supported and communication between GPs and treatment team needs improvement through the use of treatment plans	0

Increased focus on psychological, mindfulness and wellness support programs (17 likes)

Response	Likes
• More psychological support for patients	5
• Help getting fit and healthy again as the number one priority, including eating better, ongoing counseling, setting life goals and stopping thinking about cancer	4
• To value wellness as much as health and understand anxiety as a condition	3
• Better access to support and mindfulness sessions	2
• Volunteer gave a hand massage during chemo which felt so good and I felt cared for • Support at that time is good and having a buddy assigned to you during chemotherapy is helpful	2
• Mindfulness classes are helpful	1
• Access to a therapy dog and ability to have access to public transport as the dog isn't able to come into services	0

Improved knowledge and communication skills of health professionals (16 likes)

Response	Likes
• Improved GP knowledge and education on services and information	5
• Improved communications skills training for health professionals will help improve how we feel supported; little things make a big difference	4
• Increased knowledge levels of all staff, especially frontline; even as simple as being aware of parking support	3
• Having skilled health professionals not trainees for cancer patients will ease anxiety (all other services as well)	2
• Ensuring clinicians have the right support so they can provide the right care	2

Greater involvement of carer and family feedback and provision of the necessary support for them (16 likes)

Response	Likes
• Both patient and carer feedback needs to be listened to more	4
• Support the carer and the spouse, as the diagnosis can affect them more than the patient, especially for carers with other commitments as well. • Timely and effective information to better help them care and feel part of a	4

team	
• Include and question carers in all aspects of care and feed that feedback into the decision making process	3
• Address survivor and carer fatigue, no one celebrates the carers' involvement in the outcomes	3
• Better acknowledgement that depression occurs for patients and carers	2

Greater recognition and respect for the patient as a person during and after treatment (13 likes)

Response	Likes
• Understanding the patients perspective when communicating and providing services	3
• To be regarded as more than a statistic or a patient	3
• Respect for the patients time and energy in the transaction and treating the whole patient, starting from reception through to the phlebotomists,	2
• Funding differences between aged care and DVA and HACC needs to be better integrated to focus on the family / carer / patient as a whole not as individuals	2
• Be treated as a person rather than just focusing on the physical aspects	1
• Didn't like the word 'released'	1
• What's the difference between a patient and a person?	1
• A directorate of patient journeys in the hospital as there is currently no way that the system recognises opportunities to improve patient experience	0
• Recognising the person behind the rare cases and provide the support that is needed, not be seen as a case for a journal	0

Increased information on what's available and where to access services (i.e. lists or directories) (11 likes)

Response	Likes
• Provide a list of things that can help you get through, from the big stuff down to the daily issues. • Increased information about where to get these services	4
• Knowing where you can get proper support	3
• More awareness of what is available, which links back into accessing information and support services	2
• The 8 week Cancer Council mindfulness based stress reduction course is excellent; could this program be integrated into the Survivorship Care from the treating institution rather than the consumer having to try and find out about it in the community?	2

More career and work integration assistance for cancer survivors post treatment (11 likes)

Response	Likes
• More career assistance in terms of return to work or a change of career	4
• Better education of employers regarding cancer • Important as most employers have no understanding of the ongoing issues after treatment and expect you to be 100%	4
• Help for dealing with return to work integration	3

Better use of e-health records as an underutilised communication tool (9 likes)

Response	Likes
• Better use and development of e-health • Also includes Advanced Care Directives	5
• Importance of e-health record as a communication tool that is under utilised	4

Greater acknowledgement that cancer treatment includes a range of services other than just surgery, chemotherapy and radiotherapy (5 likes)

Response	Likes
• Acknowledging that cancer treatment is not only focused on surgery, chemotherapy and radiotherapy	2
• An understanding in the community that treatment includes a range of services because of side effects, with increased access to nutritionists and GPs after 'main treatment'	2
• Medical treatment works as well as the other support	1

Other comments

Response	Likes
• Knowing the importance of self-care	3
• Policy or control for programs where people have colds or flus that are contagious	3
• Could cancer nurses be funded to provide survivorship services under Activity Based Care funding arrangements for hospitals?	3
• Getting a clear understanding of what the diagnosis is	2
• Days like today are good but need to be longer as getting everyone’s comments would be very useful	1
• Don't worry about the small things	0
• Increased information and education on setting boundaries	0

Appendix C – Registrant and Attendee Information

Registration process

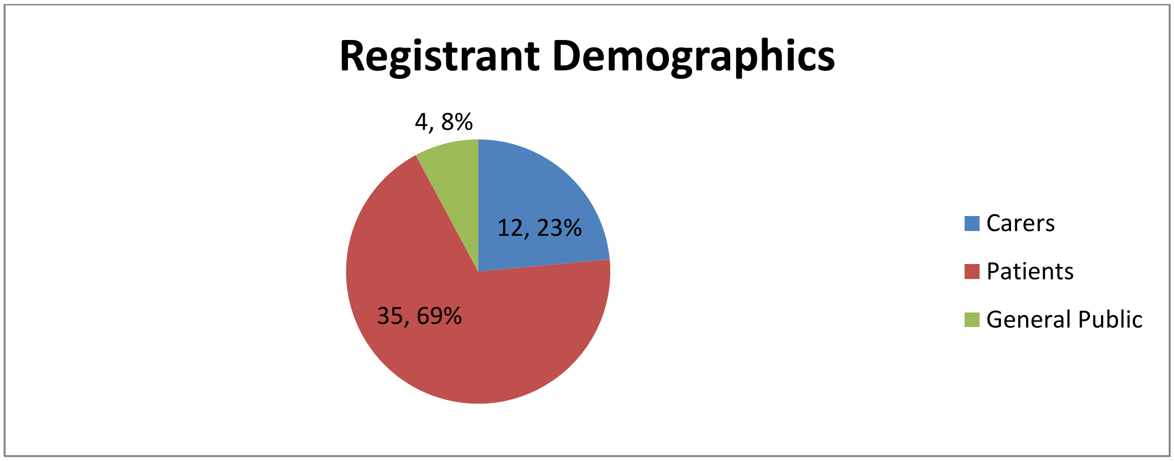
Wide dissemination of the event through all three organisations took place over a six week period. Registrations were taken online via Cancer Council WA website or via calling our 13 11 20 phone service.

Marketing of the Event

Social media and organisation websites were primary marketing opportunities, as well as dissemination to health professionals via the Survivorship Collaborative and other health professional networks. Information on the event was provided to Cancer Council WA Hospital Volunteers (SCGH and FSH).

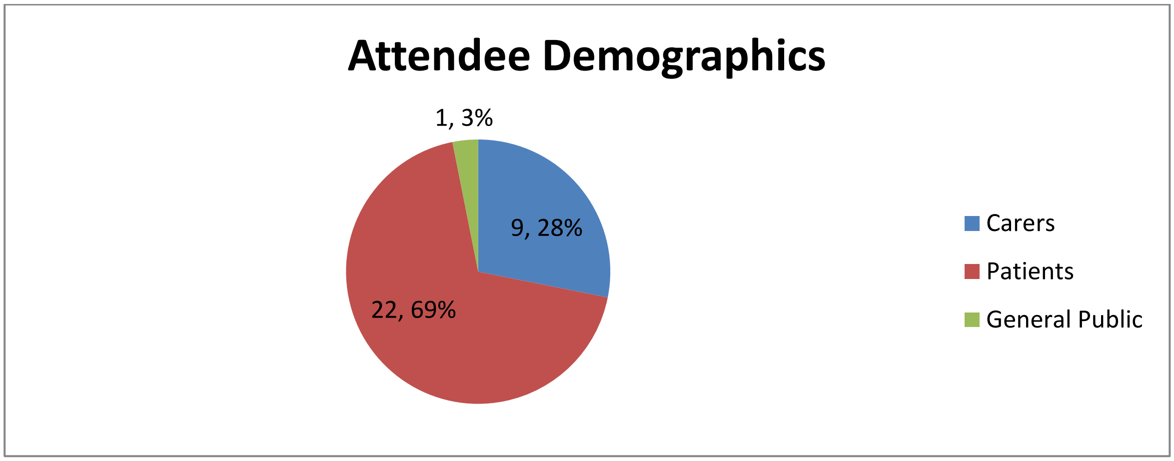
Registrations

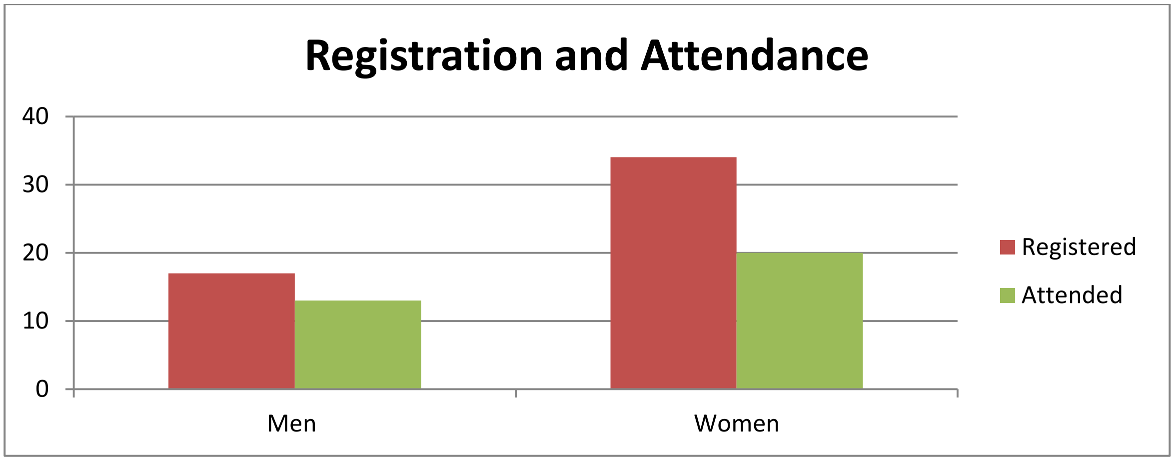
At close of registrations 51 participants were registered, with 67% women, 33% men. Of those registered 69% were people with a diagnosis of cancer, 24% identified as a carer and 8% as general public.



Attendance

On the day 64% of those registered attended, with a higher retention of male attendance than female, and carers to patients





Appendix D – Forum Evaluation

The overwhelming majority of feedback from the Forum was positive, with 93% of attendees believing the event was run well. Those that attended really enjoyed the opportunity to contribute to cancer service planning. An additional benefit was the networking and socialising that attendees really appreciated.

Review of the evaluation data suggests that attendees not only enjoyed the day but increased knowledge about support and involvement in a number of domains.

Community supports

- *Before* - 50% of attendees had a limited knowledge of Cancer Council, Health Consumers Council and Carers WA services before the consultation.
- *After* - 90% of attendees had improved their knowledge of the services offered by the three organisations after the consultation.

Involvement in cancer service planning

- *Before* - 76% of attendees did not have any knowledge of how they could contribute to cancer service planning prior to the consultation.
- *After* - 77% had a clearer understanding of how they can give strategic feedback after the consultation.

Format of the Forum

- 83% of attendees agreed that the Introductory Q&A helped set the scene for the consultation.
- 83% of attendees agreed that the consultation questions allowed them to effectively provide feedback about their experience.

Venue and catering

- 96% of attendees felt the venue was easy to get to and the catering was to a good standard.

Other feedback

- 23% of attendees provided additional feedback that the session could have been longer.
- 53% of attendees stated they would access services and become more involved in social support groups as a result of the consultation.