WA COMPREHENSIVE CANCER CENTRE

COMMUNITY CONVERSATION

PREPARED BY

DEB LANGRIDGE & KAT STEWART

CCIProgram

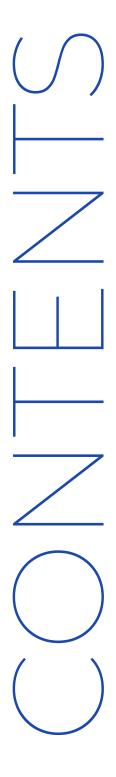
SUMMARY REPORT
OCTOBER 2021







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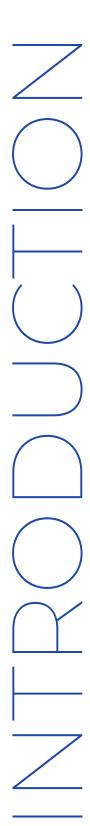
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The Consumer and Community Involvement Program (CCIProgram) was invited to conduct a Community Conversation for Harry Perkins Research Institute as preliminary planning for a new Comprehensive Cancer Centre (WA CCC) in Western Australia (see appendix 1 for further details on the Centre). The CCIProgram delivered the workshop in two formats. Firstly, in-person at the E-Zone at the University of Western Australia on October 13th 2021. And the second, in an online form on November 3rd, 2021.

Thirteen consumers and people with lived experience of cancer and/or a carer of someone with cancer attended the in-person workshop, along with Professor Peter Leedman, the WA CCC Lead and Director of the Harry Perkins Institute of Medical Research (Perkins), his associate Professor Moira Clay, and CCIProgram staff. The online format was a more personalised Conversation, with an attendance of 4 consumers and people with lived experience of cancer and/or a carer of someone with cancer along with CCIProgram staff to facilitate an in-depth exploration of the questions. Both workshops were run using an abridged version of the world café process, with table facilitators staying with their tables/consumers and community members for the entire community conversation. For each event, a brief presentation was given by Prof Peter Leedman on the WA CCC Project to give context to the focus of the Community Conversation (see Appendix 1).

This Summary Report contains the key ideas and thoughts from those who attended the in-person and online workshops, along with an evaluation report and details of the next steps in the CCC Project.

The CCIProgram enjoyed the opportunity to meet and work with Professor Peter Leedman and his team, connecting and involving remarkable people with cancer lived experience. The CCIProgram looks forward to supporting the involvement of people with lived experience at the different stages of the project design and implementation for such an innovative project that poses a paradigm shift in the delivery of cancer care for the WA community.

With thanks,

Deb Langridge

Head, CCIProgram.







Community Priorities for a Comprehensive Cancer Centre in WA Community Conversation 13th October 2021 – 6pm to 8pm Ezone Central (UWA)

Agenda

5.45pm	Registration & refreshments	All
6.00pm	Welcome Acknowledgement of Country Welcome to the workshop Introductions	Deb Langridge
6.15pm	Presentation & questions	Prof. Peter Leedman AO
6.30pm	Process of the evening	Deb Langridge
6.35pm	 Questions and Table discussions What's currently working in Cancer care in WA from a patient's point of view? What are the barriers or challenges to receiving cancer related care in WA from a patient's point of view? What are the solutions/opportunities that the WA Comprehensive Cancer Centre should offer patients and their families? 	All
7.30pm	Main themes and feedback	Table facilitators & attendees
7.45pm	Next Steps and Questions	Prof. Moira Clay, WA CCC
7:55pm	Evaluation	All
8:00pm	Thanks, and Close	Deb Langridge

About the presenters

Deb Langridge
Head, Consumer and Community Involvement Program (CCIProgram)



Deb has worked in the public health and prevention space at all levels of government – Federal, State and Local – and not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of community including access and inclusion, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, children and young people, mental health, health and community services. Deb has been the Chair of Advisory Groups in both, NSW and WA. She works connecting community, government and well-being, also a member of the NSW Commission for Children and Young People's work with the NSW Parliamentary Inquiry on Children and the Built Environment. She was also a representative for WA Local Government on the recent WA Sustainable Health Review.

Professor Peter Leedman AO MBBS, FRACP, PhD, FAHMS



Peter Leedman is the Director of the Harry Perkins Institute of Medical Research (Perkins) and an endocrinologist (hormone specialist) at Royal Perth Hospital (RPH). He is internationally recognized for his research on hormone-dependent cancers (breast and prostate) and more lately on poor prognostic tumours (liver and head and neck cancer). His team is developing new therapies for these solid tumours that they are translating towards the bedside. He is passionate about driving the Perkins to become a global Centre of Excellence, known for its innovative and collaborative approaches to solving some of the more challenging questions in medicine.

Professor Moira Clay

Adjunct UWA, WA Comprehensive Cancer Centre Project



Moira is regarded as one of Australia's foremost experts in health and medical research strategy. She established Moira Clay Consulting in 2013 and has built a strong reputation for adding value to health and research organisations (including medical research institute's; health services; funding bodies; universities; peak bodies) across Australia. In 2018, she was nominated as a Fellow of the Australasian Research Management Society, acknowledging her substantial contributions to research management, and was a speaker at TEDx Fremantle. In 2021, she was appointed Chair of the Advisory Board of the Menzies Institute (University of Tasmania).

KEY QUESTIONS DISCUSSED

What's currently working in Cancer care in WA from a patient's point of view?

Prompts included:

- Access
- Diagnoses
- Navigation of the system access
- Treatment plans
- · Ongoing management and care
- An holistic approach
- · Consideration of mental health and well being
- Access to clinical trials

What are the barriers or challenges to receiving cancer related care in WA from a patient's point of view?

Prompts included:

- What creates the most anxiety?
- Access
- Diagnoses
- Navigation of the system access
- Treatment plans
- Ongoing management and care
- An holistic approach
- · Consideration of mental health and well being
- Access to clinical trials
- State-wide approach

What are the solutions/opportunities that the WA Comprehensive Cancer Centre should offer patients and their families?

Prompts included:

- Integrated care
- Operating theatres
- Day beds
- One stop shop
- Heathy eating, exercise options
- Mental health support
- Whole of family approach
- Access to most up to date trials
- Culturally appropriate services
- State-wide approach

Attendees had approximately 15 minutes to discuss each question with table facilitators noting down key points and table scribes writing down what the attendees said. Facilitators explained key point/s arising at their table (to the whole group), at the end of the discussions.



SUMMARY OF RESPONSES FROM COMMUNITY MEMBERS

What's currently working in Cancer care in WA from a patient's point of view?

Nine themes emerged from the responses to this question:

Treatments and Research Outcomes

- "The treatment" (as opposed to the person being treated)
 - Outcome
 - Survival occurrences
- Survival rates seem good
- Telethon institute the research they're doing there
- The standard of treatment and the speed it can happen

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"Although there was no treatment available when I was diagnosed, they successfully removed all my tumours and I have lived a healthy life ever since"

The expertise available

- Well versed professors
- World-class clinicians are working across Private and Public
- The rest of the world knows more about the expertise available locally than we do
- Ready availability of expert advice and care
- The expertise, advice and accessibility (gives firm foundation) (rare lymphoma)

Availability of treatments and testing

- Choices available/autonomy
 - What type of treatment
 - Where the treatment will be
- We have choices in WA unlike other counties in the world.
- Care can be accessed through both a public and private provider
- Offered multi-disciplinary care
- Surgery choices
- Offering alternative treatments such as a trials



"someone being able to offer me alternatives in an attempt to nip my cancer in the bud"

The speed of care

- Although you might not have private cover, you can still access timely care through the public system with good continuity of care
- Speed of care in public system is adequate
- "Most important point to me is access via the private sector I saw the surgeon within days and had completed the surgery within 28 days I went through the private sector, so they could deal with it very quickly"

The quality of care

- Quality of care is good
- Nursing
- When my daughter was having her leukemia treatment –it was the (paediatric oncology) nursing staff that were amazing and worked well. They went above and beyond – there was a lot of love from the nurses for the kids going through treatment. They found ways to help the children cope.
 - orapports and relationships
 - Used distractions.

"

"from my experience, the general availability towards testing – going from one stage to testing to the next, to the next – every sort of test you can imagine – all was so readily available in Perth – wonderful"

Additional services and collaborations

- Collaboration
 - i.e. Breast cancer clinic
 - Ontinued support from nurse explanations/ "chaperone role"
- Adolescent and Young Adult (AYA) cancer centre

Support group networks

- Outstanding support group networks
 - Cancer Council
 - Melanoma WA
 - Soc it to Sarcoma
- Solaris
 - Private providers are offering a holistic approach to care (Solaris)
- Breast Cancer Care the psychosocial care they offer
 - Breast Cancer Care WA Support Groups

Connections of expertise

- Connections and ability for treatment in small towns (regionally)
- Connections of expertise between doctors/professionals
- Connectedness of people
 - "my oncologist connected me with high profile research in US, the trial was successful and resulted in specific tumour test"

Financial aid

- Generally speaking we haven't had to sell our house, we haven't had to pay for chemo/to see oncologists that's a huge thing –lack of costs associated with care in Australia
 - "little financial output in the nearly 3 years I've been treated"
- Payments from trial to reimburse for parking, petrol ect. "it's a recognition
 of the fact that you're contributing the bigger picture as well, not just your
 own interests

Other points:

- The systems works best if you have confidence and knowledge in how to seek help.
- Models used in Diabetes Care and Cystic Fibrosis works
 - One place
 - Not too much moving
 - Patient goes to one place
 - Good transition between child and adult
 - Proactive ways of dealing with people





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What are the barriers or challenges to receiving cancer related care in WA from a patient's point of view?

16 themes emerged from the responses to this question:

Communication issues as Patients

- Too much information shared by specialists/doctors too little time; much more time is required to share the information we need
- "The system knows what the system knows"
 - Related to this are feelings of trauma, overwhelm and lack of understanding
- Lack of understanding of words used/treatment
- Families not understanding i.e. "lesion" not knowing that means cancer
- Communication is key and it's not good enough overall
- Sometimes doctors/specialists forget to tell you details
- Information given (at diagnosis and with treatment/care options)
 - Too little
 - Not empowering
- Experience of incredibly inappropriate language used by health professionals at diagnoses in the public system



""Tell us when a test is standard"

Lack of holistic care

- Holistic care does not exist in the public system
- The focus is on clinical care and there is no focus on holistic, individualised or tailored care
- More exercise should be incorporated into care
- Spirituality is lacking in all care

Lack of coordinated care

- Care is not coordinated/navigated
- A lack of coordinated care creates barriers
- The patient ends up being the coordinator whether they are capable or not
- Pathways need to be more coordinatedy
- Different treatments at different locations sometimes booked at same time

Exclusion of carers

- Lack of support for carers
- Carers are not included as often and as respectfully as they should, particularly if they are not immediate family

Time issues

- Waiting times
- Timeliness is not prioritised
- 3 hours waiting and then I lost my spot in waiting line
- Waiting 6 weeks for results
- People with colon cancer can't get colonoscopies can't get access to testing – waiting long periods

Physical access challenges

- Difficulty with physical access
- Physical access is rubbish
 - Transport
 - Parking
 - Disability access
 - Signage
- Parking. Very big stressor difficult to get, carpark full, it's expensive, you
 must leave home early to make sure you get there in time, you must
 park far and walk in.

Lack of information given to patients

- Given choices but not enough information to choose
- Don't understand pros and cons of each choice
- Patients need increased knowledge of clinical trials
- Managing side effects
 - o mixed views and limited information
- Problems with getting a diagnosis
 - "it was hard to get a diagnosis in the first place"
- We had to do a lot of asking and following up.

Lack of person-centred care

- What the health professionals feels you need is always prioritised over what you feel you need
- Not treating the person, but treating the cancer
- Fundamental issue those treating don't look through the eyes of the patient
- Lack of understanding
- Connection between people should be prioritised higher than it is
- People should be made to feel like they are a person and not a diagnosis
- People should be empowered to enable a level of control that they deserve
- Brushing off concerns
- questioning about emerging evidence
- side effects/your experience of medications
- Not being heard/specialists having meetings about you, without you.
- "it felt like patients in the adult oncology ward were just a number" staff issues, no real service or warmth or care felt – nobody had time – quick and impersonal

Regional care issues

- Distance to care needs to be addressed, particularly for regional West Australians
- Regional care "it's difficult to deliver care outside of Perth. However,
 Telehealth is not well used or enough this could make a big difference
 to cancer patients not having to fly from regional areas to see a
 specialist."

Cultural barriers to care

- CALD difficulties in understanding information
- Different languages need to be considered
- Cultural appropriateness needs to be addressed

Silos in care

- Siloed specialties
- Primary and tertiary don't communicate effectively
- No sharing of information between doctors
 - O Including rehab, allied health, oncology, chemotherapy

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""Public and Private
sector do not talk to
each other, which
makes it difficult for all
involved"

Poor psychosocial care for patients and carers

- Medical model/ model of care in cancer not working not addressing psychosocial care
 - Not tailored to individual
- Mental health support lacking
- Lack of psychosocial monitoring and support for patient and family members. That's both in paediatric and adult cancers.

Staffing Challenges

- Not enough staff in adult's hospitals as opposed to children's hospitals that contrast shouldn't have to exist/shouldn't be a difference in resources allocated.
- Irregularities in staff/ no familiar faces when arriving for appointments/ seeing different clinicians regularly no rapport built or trust. This creates lack of feelings of care/no relationship established. Adds to anxiety of outcomes of appointments.

Lack of continuity in care

 End of care support required – figuring out what next, what to do with long term issue

Lack of patient advocacy

- Patients and carers sometimes don't know what to ask
- There is no advocacy

Lack of sensitivity

• Wrong ward: "do not put gynaecology patients in maternity ward. Especially the ones with cancer diagnoses, it's insensitive"

Other points made about barriers and challenges:

- As a carer "you have to take time off work, it's a financial struggle when you're caring for someone"
- Lack of hope in outcomes
- "Public care is not predictable and on different days you could get completely different levels of care"
- Sir Charles Gardener Hospital's waiting area is barn-like
- Regime with medications fasting with medications limiting food intake/how to structure routine/eating

What are the solutions/opportunities that the WA Comprehensive Cancer Centre should offer patients and their families?

Sixteen themes emerged from the responses to this question:

Additional support for regional and remote patients

Access to additional resources and services through the Centre

Offer continuity of care

Care coordination/navigation

Psychosocial support readily available

Coordination of treatments and care

Holistic and supported care of the whole person

Understandable and well explained treatment options

Patient centred care

Address cultural barriers

Include carers

Building design features

Improved telehealth services

Peer support and advocacy services

Continued consumer involvement

Food and nutrition (options and information)

Please note: These are not listed in an order of importance.

Additional support for regional and remote patients

- Ensure they have to have the ability to link in with local services/doctor i.e. telehealth services
- Some strategy for providing them/supporting them to find appropriate
 accommodation i.e. Ronald MacDonald or an officer in charge of this.
 Think about the time it takes to get to the city, their normal life they have
 to leave behind. Any top-class facility would need to be looking at how
 they would be supporting country people.
- Accommodation for rural and remote



"I personally don't find telehealth very approached – but we're all becoming more familiar with it. It's been thrust upon us. It will be refined and improve"

Access to additional resources and services through the Centre

- Opportunities for NGO resources and services should be easy to access through the Centre
- Bereavement care must be included
- Hub and spoke model must be implemented (CCC as hub that expands to additional services)
 - Ocommunity Mothers scheme is a good example
- Childhood cancer patient centre one-stop shop multi-disciplinary team trained in effects of cancer i.e. physio who knows how to help, clinical psychologist to help with trauma. Including for adults who'd experienced childhood cancer.

Offer continuity of care

- Continuity of care should include at the end of care
 - End of life
 - Full remission
- Support for patients in figuring out how to transition from managing cancer to what becomes a "chronic disease"
- "survivorship" i.e. survivorship centre how you live a new life
 - Phrased as "living well and beyond cancer"
- Regular staffing/familiar faces

Care coordination/navigation

- Case Workers are needed
 - Navigators
 - Coordinators
 - Cancer Buddies
- "support for transition between child/adolescence and adult cancer care including the patient journey/voice"
- Care coordinator to touch base, prior to, and after clinical consultations
- Navigator assigned to you from day 1
 - Offering spiritual and holistic services
 - Leaving clinicians to support clinical care

Psychosocial support readily available

- "information and assistance for people who have been told they have cancer how they tell their children. Specifically, young children. Support services that are effective for those children"
- Mental health officers/social workers available in the centre

Coordination of treatments and care

- "coordination of treatments e.g. xrays and scans and blood tests prior to appointments to avoid appointments for follow up"
- After business hours treatment area for those who are still working this allows wellness and to have a job

Holistic and supported care of the whole person

- Including access to
 - Pool/access to exercise
 - Psychologist
 - Financial issues
 - Making a will
 - Library
- "specialised cancer services psychiatrist, dietitian, allied health"
- Wellbeing knowledge shared
 - Meditation
 - Complementary services
- Healing Care
- Gym with gentle approaches to exercise staff are experienced and know how to work with cancer patients

Understandable and well explained treatment options

- Balanced evidence-based choices given to patients and carers for treatment and testing options
- Knowing from the beginning what the treatment plan will or might look like
- Personalised care pathway clearly articulated online

Patient Centred Care

- Options must be offered, and laid out in an easy-to-understand way, by someone who actually cares about you as a person
- Personalised care
- Clinicians that allow space for understanding and negotiation when it comes to treatment
- Space to negotiate things (partnership/working for best outcomes)

Address cultural barriers

- Culturally appropriate services
 - Age i.e. young person cancer area
 - Language groups
 - Sensitivity and openness to options
 - Respect to our own decisions
 - Empower where they're at
- Cultural Ambassadors must be available for patients and the organisation itself

Include carers

- Cancer Care = Family support
- Recognition that a patient doesn't need just professional care, but also their family's care.

*see additional notes in "Design"



Building design features

Non-clinical space

- Less clinical/hospital feel calm tranquil building rather than stark white hospital. A nice place to go.
- Artwork
- Soft furnishings
- As relaxed as possible
- Not harsh/clinical looking
- Feels like a hub warmth, depth, texture
- Less like PCH new, bright, soulless feeling causes stress response. Feels like an airport.
- More like PMH smaller spaces, preferable. Has more things on the wall, stuff in the rooms, more warming and homely.
- Not crowded or unequipped
- Big modern buildings are not "like your comfort zone", feel sterile.
 New buildings are designed so preciously designer doesn't want it "spoilt" requires balance between inappropriate and designed so loses sense of comfort.

Space for family and carers

- Space for family members so you don't have to be on your own when you're already feeling tense and unsure
- Flinders Hospice; associated with Flinders Hospital in Adelaide "my sister-in-law referred there, she spent her last 4 -5 days in the hospice – it's the most amazing facility I have ever seen" in design and operation - all rooms were on one side opened to atrium (no matter where you were, there was always an aspect to greenery and fresh air), there were volunteers; there all day, they would come around and offer drinks, toasties etc. - allowed you to eat when you felt like it. The rooms in the upper levels of the building - they would take the patients out in their beds onto a wonderful garden rooftop - designed in such a way that families had their own barriers of live plants. So they could be altogether privately. So comforting to have the fresh air and out in the open was amazing – in a relatively natural environment. ACCESS TO GREEN SPACE and Care animals! - their dog was allowed to come in, there were facilities for them. They had thought about everything to make the family feel safe and secure."



"Somewhere for family to wait – so they don't have to leave the centre, make a drink (adds non-medical aspect to space) – important for mental health "as lot of this journey as I've experienced it is more about the mental aspects – always at the back of your mind is a bit of a worry – anything that can make the building more approachable and comfortable is only going to be good for the patients"

Improved Telehealth Services

- We must exploit telehealth in a more sustainable way
- More consults for shorter periods of time

Peer support and advocacy services

- Peer group/support to share their journey
- Peer support needs to be offered from people with the same diagnoses (not just someone with cancer)
- Patient advocacy services with funding

Continued consumer involvement

- "opportunity to co-design what works for those affected by cancer and their carers"
- People who've had lived experience involved in giving feedback on creation of different levels of care
- "provide focus for cancer consumers and organisations to come together"

Food and nutrition

- Nutrition menu, what time you eat, what you eat: "prescription for wellbeing"
 - Sharing emerging evidence
 - Keeping people informed after they finish care about dietary information
- Cancer patients should have more choice over what they want to eat

Other solutions and opportunities:

- Electronic portal to share information across disciplines and specialities
- Messages of hope
 - Speaking about the research and work being done
 - Emerging research
- Research seminars available for public
- Care available for people without financial security
- Raise the profile of rare cancers
- All types of Cancers must be represented in the new centre
- "develop models of care for cancer"

Summing Up and Next Steps

A number of next steps were discussed at the Community Conversations to highlight how consumer and community involvement would continue to be part of the WA CCC Project. These included;

- A Summary Report of the content of Community Conversations being distributed to all attendees;
- Expressions of Interest taken for attendees at the Community Conversation events who would like to be further involved;
- Additional Community Conversations being planned in 2022 to ensure that people with lived experiences form different backgrounds, cultures and geographic locations have been involved;
- Possibility of 'capturing' the voices of some people with lived experience to heighten the importance and relevance to the WA CCC projects direction and governance;
- In future phases, to establish within the governance of a WA CCC opportunities to ensure people with lived experience are involved in decision making eg Consumer and Community Advisory Group, representation on WA CCC Board, training of Advisory Groups and Board regarding consumer and community involvement.

The CCIProgram will continue to promote and share future opportunities to those who attended the Community Conversation events, together with other networks of those with relevant lived experience.

APPENDIX 1





What is a Comprehensive Cancer Centre (CCC)?

- A truly holistic approach to cancer care that is "one-stop-shop" in principle and in physical practice
 - Strong basic laboratory & clinical cancer research and the translational research that forms the bridge between them.
 - Innovative cancer treatments involving clinical trials, exceptional patient care
 - Cancer prevention and control programs
 - Training and education of health care professionals
 - Cancer information services to the public
 - Community outreach and education
- A range of additional services are available tailored to the patient in a bespoke manner – making each cancer journey quite unique (oncology support specialists in social work, nutrition, nursing, pharmacy, music therapy, massage, exercise etc)

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The Vision

The WA Comprehensive Cancer Centre (WA CCC)

- Seeks to provide the highest level of care in a holistic manner that optimises health outcomes for Western Australians.
- It will embed research and translation of medical discovery into operational innovation enabling WA to be a leader in the provision of integrated cancer services
- It will be a paradigm shift in the delivery of cancer care for the WA community.



What benefits would a CCC give to WA?

- Comprehensive "holistic" patient-centred cancer care
- Research integrated into every aspect of patient journey, underpinning delivery of best cancer care
- Outreach for WA's rural and remote communities and most vulnerable groups
- Part of a national network of CCCs
- Creation of hundreds of new jobs
- Stem the "brain drain"

Potential National Network of CCCs











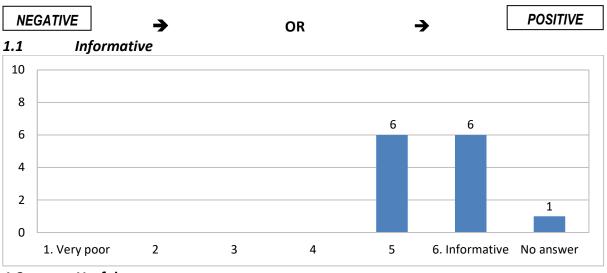
Community Priorities for a Comprehensive Cancer Centre in WA Community Conversation 13th October 2021 - EZone Central

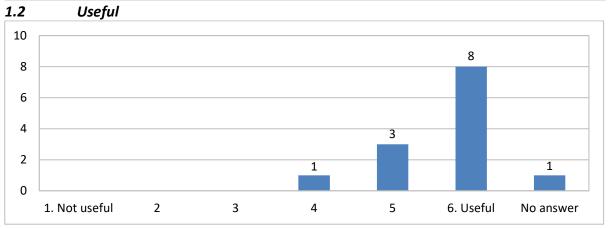
Evaluation Summary

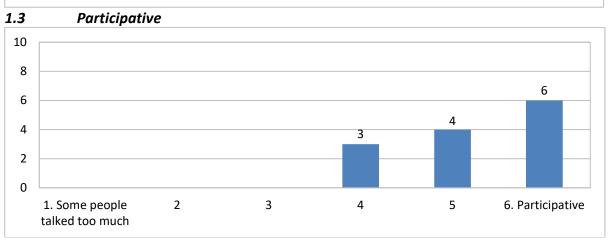
13 Forms completed / 14 attendees

Please tick the responses which best match your view:

1. The Community Conversation was:





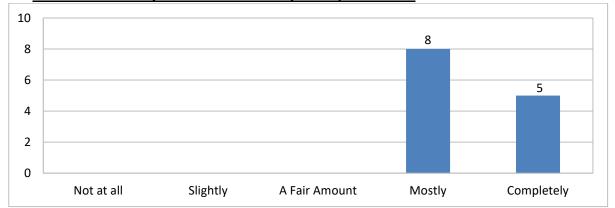




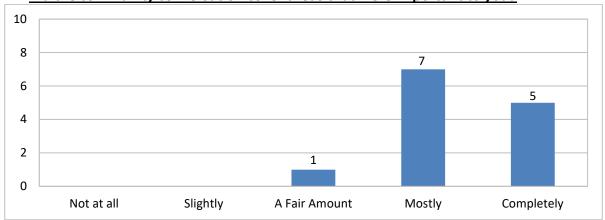






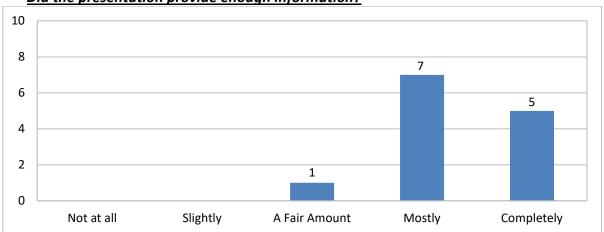


3. <u>Did the community conversation cover areas that were important to you?</u>



If "not at all' please specify what additional information could have been included:

4. <u>Did the presentation provide enough information?</u>

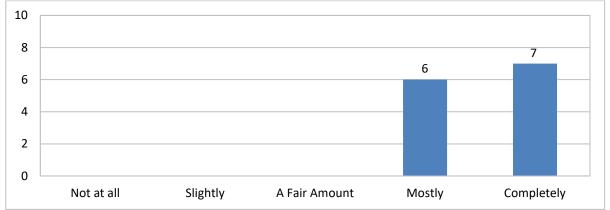




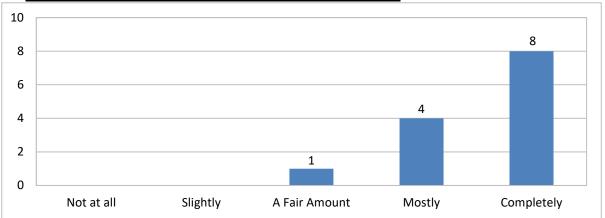




5. <u>Did well were your questions answered?</u>



6. Did you have the opportunity to put forward your ideas?



7. <u>Is there anything else you would like to add?</u>

- Variety of voices
- Great opportunity

8. The <u>best</u> thing about the community conversation was:

- The chance and opportunity to be involved and help shape the vision
- Seeing how passionate Peter and Moira are about this project. It will happen!
- Vision is so positive
- Shared ideas
- Being able to have input on the holistic approach to the Comprehensive Cancer Centre
- Holistic being incorporated
- Hearing the consensus regarding similar issues
- Inclusion (table facilitator) and concise
- Sharing experiences good and bad to get an evaluation of the current state of cancer care in WA
- That it happened

9. The <u>worst</u> thing about the community conversation was:

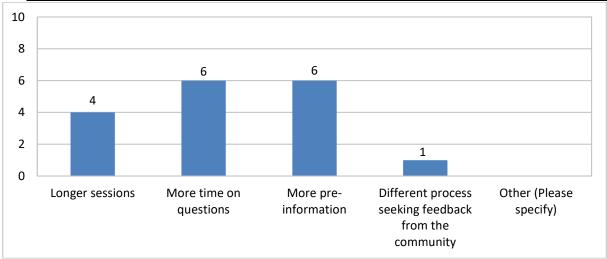
- Need stronger control of 'talkers'
- Not enough time for each person to talk
- Some people don't enjoy hearing other's opinions! (but that's just people)
- Participants were all white, not enough diversity of various sorts
- Not enough time
- That it's taken this long to happen







10. <u>Do you have any suggestions about how we might improve future Community Conversations?</u>



Other (Please specify):

- Needs to be much longer
- Follow up sessions
- Give time for group to introduce themselves to one another build rapport and trust

CONTACT

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