Involving Consumers in the Cancer Epidemiology Network

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We dedicate this report to the memory of Annie MacKinnon and Maria Jose Roderigues Melo

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Abbreviations

Cancer Council Western Australia Cancer Epidemiology Network (CCEN)

Consumer and Community Health Research Network (CCHRN)

Consumer Advisory Council (CAC)

Introduction

In this report, we summarize our experiences of involving consumers in a program of research on cancer epidemiology. The Cancer Council Western Australia Cancer Epidemiology Network (CCEN) was an initiative designed to support and encourage cancer epidemiology and prevention research in Western Australia. Funding enabled employment of a post-doctoral researcher from 2016 to 2019 to facilitate the network and its research activities.

The aim of the CCEN was to foster multidisciplinary collaboration in cancer epidemiology and prevention research to reduce the risk of cancer in Western Australians.

An important aspect of the CCEN plan was to involve consumers in directing, supporting, advising and contributing to research projects. Consumer involvement is compulsory requirement for most funding agencies such as the cancer council and the national health and medical research council. Therefore, the CCEN worked with the Consumer and Community Health Research Network (CCHRN) to form a Consumer Advisory Council (CAC) whose key areas of involvement were:

- Planning and organizing a community conversation for the general public
- Fostering consumer-researcher relationships to support research projects
- Building capacity for future consumer-researcher collaborations

Members of the council not only shared their lived experience and views of cancer, but also learned about their potential impact on the direction of cancer epidemiology and prevention research, particularly in Western Australia.

In this report we describe the process we followed to form our CAC and conduct CAC meetings and other consumer events. We also discuss some of the items our CAC provided feedback on and report a summary on of the online evaluation survey on the effectiveness of our CAC. Future research groups who are planning in forming their own CAC could use this as a model.

Establishing a CCEN Consumer Advisory Council

With advice and support from the CCHRN, we established a CAC designed to support CCEN in Western Australia. The CCHRN coordinated the promotion and advertisement of the positions available via their website, e-newsletter and social media channels, as well as the membership application process. Applicants interested in being a part of a new consumer group within the CCEN were required to complete an Expression of Interest, outlining their relevant experience and motivation for applying.The CCHRN interviewed potential members, plus their references and provided a summary to the CCEN project coordinator. Nine consumers were selected, their contact details passed onto the CCEN and were then contacted via an invitation email including details about the first meeting. Consumers were appointed for a three-year period between 2016 and 2018 and are listed below

1. Margaret Wood (Chair of the CAC)
2. Annie MacKinnon
3. Shannon Simpson
4. Catherine Woulfe
5. Maria Jose Roderigues Melo
6. Ann D'Orsogna
7. Yvonne Parnell
8. Adrian Gallo
9. Alizee Bourgault

The goal of the CAC was to enable the CCEN to develop a partnership in which consumers, community members, and researchers work together to make decisions about research properties, goals, methodologies, questions, and dissemination of results (see Appendix One for terms of reference). In particular, the CAC was formed to provide and/or facilitate:

- Consumer and community perspectives on research undertaken by CCEN members
- Links between consumers, the community and researchers within the CCEN
- Advice and expertise on consumer and community issues and priorities for cancer epidemiology research
- Advocacy on behalf of consumers and the community
- Advice on avenues of disseminating research results
- Evaluation and reports on consumer and community participation in the CCEN
- Feedback on strategic planning and governance structures relating to consumer and community involvement in research

Planning for a Consumer Advisory Council Meeting

Meetings were tentatively scheduled every four months depending on the demand of agenda items from both researchers and the nominated chair of the CAC. The project coordinator sent a doodle poll listing possible times and dates for a meeting to all members. The day/time that had the highest number of available participants was then chosen and members were notified via email about the date/time of the next meeting. Two weeks before the meeting, the project coordinator sent the agenda and directions on how to get to the location of the meeting (See Appendix Two for an agenda template). A quorum of 50% of council members and 50% of researchers was needed to hold a meeting. In the absence of a quorum, the project coordinator would contact the chairs of the CAC and researchers informing them about the absence of a quorum and asking for input on whether the meeting should be cancelled and rescheduled to a different date. If the chairpersons decided to proceed with the meeting, then any discussion or decisions requiring ratification by the CAC was either done at the next meeting or approved by CAC chair if it was urgent.

Consumers were offered an honorarium of $30 an hour for the meeting they had attended, which was paid in cash. These payments were offered to acknowledge their contribution of time and any associated out of pocket expenses (e.g. parking, transport, childcare). The honorarium process required considerable development in consultation with the Finance Department. We were insistent that this was an honorarium and should not require an invoice from the consumers. With the support of Curtin University Consumer Advocate and other key individuals within the Faculty of Health Science a process was developed and used for the CCEN Consumers. The final process is outlined in Appendices 3 and 4.

In addition to CAC members and CCEN researchers, occasional international and local visitors were invited to attend in order to observe how consumers were involved in our project. We also welcomed PhD students interested in possible strategies to recruit participants to their research project to attend these meetings.

Things to consider when organising a meeting

- Bring copies of the agenda meeting and other meeting related documents
- Ensure the meetings are not too formal and keep them quick
- Prepare the agenda and meeting papers in plain language when possible
- Ensure that the meetings run on time
- Provide refreshment for the meetings
- Hold meetings in the evenings to accommodate the schedules of working consumers
- Ensure that meeting locations are close to public transport and that free parking is available
- During discussion avoid using scientific jargon or abbreviations
- Ensure that the meetings are chaired alternately between the CAC and researchers co-chairs

Image 1. Members who attended one of the Consumer Advisory Council meetings: [Front row from left to right: Terry Boyle (Researcher), Jennifer Stone (Chair of the Researchers), Kristina Kjaerheim (International visitor), Lin Fritschi (Researcher), Ann D'Orsogna (Consumer). Back row from left to right: Matthew Govorko (PhD student), Ben Horgan (Consumer advocate), Ellie Darcey (Researcher), Sonia El-Zaemey (Project coordinator), Liz Milne (Researcher), Catherine Woulfe (Consumer), Margaret Wood (Chair of the CAC), Maria Melo (Consumer)]

Consumer Advisory Council Contribution

The CAC contributed to our project in several ways. In brief, they have:

- Provided feedback on grant applications
- Provided feedback on plain language summaries of grant applications
- Acted as consumer representatives on projects led by the researchers
- Participated in some of the research meetings led by the researchers
- Provided input on priorities for cancer prevention research
- Provided input on strategies to recruit participants to research studies
- Given advice on study documents including participant invitation letters, information sheets, and questionnaires
- Provided input on workshop and networking event planning and they also participated in these events.
- Advised on avenues of disseminating research results

Planning for the "community conversation about cancer prevention"

On Thursday 2nd June 2016, the CCEN researchers held a meeting with the CAC to plan for a community conversation about cancer prevention. The purpose of the community conversation was to hear community members' opinions and views on the focus and direction of cancer prevention research in Western Australia. Before the meeting with the CAC, the CCEN researchers drafted three questions (see below) which would be used at the community conversation to find out what the community thought should be a priority in cancer prevention research in Western Australia.

The three questions that the CCEN developed were:

1. What factors should we consider when deciding which cancer to study/research? E.g. how common it is, what the survival is, etc.

2. What factors should we consider when deciding which risk factor to focus on for cancer prevention?

3. What factors should we consider when deciding which population group to focus on for cancer prevention?

During the meeting, the CAC amended these questions, and also provided input about how to organise, promote and run the community conversation meeting. Below is some of the feedback provided, some of which could be useful for other groups when planning a community conversation:

- One of the CCEN researchers should give a 10-minute (maximum of 10 slides) presentation at the start of the community conversation to summarize the aims of the research, explain any terms, and provide some background information. For our community conversation, this background information was about cancer statistics in Western Australia and cancer prevention case studies (lung cancer and cervical cancer).
- The presentation should clearly specify what the focus of the community conversation is. For our community conversation, this meant being 100% clear that the focus of the community conversation and the CCEN is cancer prevention, not treatment or survivorship.
- Avoid jargon and do not assume people will understand commonly used scientific terms e.g. 'factors', 'risks'
- Facilitators to collate the priorities from each group, and put a list up for the consumers to prioritize the most important ones through 'Dot-mocracy'. 'Dot-

mocracy' is a concept from D'Arcy Holman where the consumer group will choose where to place the dots, for example 1 dot for three priorities, or 3 dots for 1 priority

- The community conversation should not have too many people, as it will be difficult to manage the session. Aim for 20 to 30 people.
- The community conversation is recommended to have a World Café format. You can find out about the World Café procedure using this link http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/
- Community members attending the community conversation should not be told beforehand which questions will be asked.
- Hold the community conversation in the evening to allow people who work to attend.
- Food and an honorarium (out of pocket expense) should be provided to community members for attending the meeting

After deliberation, the following questions were decided for the consumer conversation meeting to be held on Monday 25th July 2016.

1. Based on your knowledge or experience, what cancers would you like to see researched?

2. What specific things in your life do you think cause cancer?

3. Are there particular groups in the community that you would like to see us focus our research on?

Community conversation

Introduction

The community conversation about cancer prevention research was held on Monday 25 July 2016, 7-9 pm, at the Cancer Council Western Australia Seminar Room at Gordon Basford House in Shenton Park in Perth.

The community conversation specifically focused on the prevention of cancer within communities in Western Australia and did not discuss the treatment of cancer or survivorship issues.

This interactive conversational forum encouraged community members to discuss and share their personal views on addressing the focus on cancer prevention research in Western Australia, with the aim of using this information to ensure consumers' voices were included when designing and undertaking cancer prevention research for the CCEN.

Summary of the Community Conversation

Twenty-six people attended the community conversation. This included nineteen community members, which included some of CAC members and seven facilitators. The facilitators were: Anne McKenzie and Hayley Haines from the Consumer and Community Health Research; Associate Professor Alison Reid, Dr. Jennifer Stone, Dr. Terry Boyle, and Dr. Renee Carey, who were all CCEN Chief Investigators; and Dr. Mutsa Gumbie, the initial CCEN coordinator. Three of the CAC attended this meeting: Adrian Gallo, Catherine Woulfe and Margaret Wood.

The community members were adults who registered to attend the meeting and either had cancer, knew someone who had cancer or was interested in preventing cancer. Community members were recruited via dissemination of a flyer (see Appendix five) through various online networks that included the CCHRN's "Involving People in Research" website (www.involvingpeopleinresearch.org.au), Twitter "@InvolvingAus" and Facebook "Involving Australia" and the CCEN twitter handle (@Cancer_Epi_WA). The community conversation was also promoted on Curtin FM and 6 PR radio stations.

Workshop attendees were provided with a handout that included the process of the forum and questions (see Appendix six). Participants were seated at three tables, each of which had 1-2 facilitators. Refreshments were provided for participants and participants received an honorarium from the CCEN for their attendance.

Anne McKenzie opened the event by reflecting on the importance of consumer engagement to inform research directions and giving an overview of how the

community conversation would run. Dr. Terry Boyle then gave a 10-minute presentation outlining the CCEN, the aims, and focus of cancer prevention, a brief overview of cancer statistics in Western Australia, and the three questions to be discussed at the community conversation. The three questions were: (1) ‘Based on your knowledge or experience, what cancers would you like to see researched?’; (2) ‘What specific things in your life do you think cause cancer?’; and (3) ‘Are there particular groups in the community that you would like to see us focus our research on?’.

Each table then discussed the three questions for about 20 minutes each. Facilitators noted down participant responses and emerging themes for each question. Feedback and opinions that were out-of-scope but contributed to the discussion were noted down and included as suggestions for further research. CCEN researchers were able to provide information and clarification to participants during the community conversation. Priority voting on the topics noted down for Question 2 was conducted at the end of the community conversation as a strategy to identify the most important themes.

Image 2. Anne McKenzie opening the event and explaining the forum process

Themes Identified from the Community Conversation

Question 1 – Based on your knowledge or experience, what cancers would you like to see researched?

Responses that related to which cancers the participants thought prevention research should focus on included:

- **Prostate cancer**
  - Long malignancy
  - Men don't seek help
  - More screening
  - Quality of life post-treatment (quantity of years versus quality of years)
- **Brain cancers/tumors**
  - Have a great impact on people's lives
  - Poor survival
- **Childhood Leukaemia**
  - Unknown cause
  - Difficult treatment that is likely to have a lifelong impact
- **Breast cancer**
  - 50's or 60's age group
  - Known treatment
- **Less 'sexy' cancers**
  - More research on less studied cancers
- **Cancers affected by similar exposures**
- **Hereditary/genetic cancers such as breast cancer**
- **Not me-specific cancer- but similarities between them and those that share the same cell biology**
- **Occupational cancers**
  - To do with newer exposures
  - exposures since the 1970s
  - Exposure to radiation from x-rays; is there an excess risk
- **Treatments from other diseases that might cause cancer**
  - Medications
  - Chemotherapy
- **Cancers caused by illegal drug use (ice, meth, etc.)**
- **Rare Cancers**
  - Shouldn't be determined by money to be made from treatment, rather an objective determination to socio-political benefit, not just economics
- **Metastatic pathways**
  - What makes cancers metastatic
  - Why do they spread in unusual places e.g. brain, or areas without much blood circulation- this would aid in better detection rather than the full body scan, e.g. leukemia/lymphatic cancers
- **Childhood Cancers**
  - What is the gap in the failure to treat the 10% of cancers that are non-curable
  - What don't we know about the non-curable 10%
- **Comorbidities based research**
  - Cancer and diabetes

- Cancer and other conditions that may not allow chemotherapy/treatment

- **Cancer Survivorship and mental health**
  - What contributes to psychosocial health and survival?
- **'Subtle' cancers**
  - Those that don't have obvious signs
  - Could develop biomarkers
- **Late diagnosed and poor prognosis cancers**
  - Ovarian
  - Pancreatic
  - Liver
- **Cancers linked to low vitamin D and other diseases, like multiple sclerosis**
- **Cancer linked to low-level chronic factors** e.g. oral health, diet, environmental exposures
- **Cancers that are increasing in the population/ Top 5 cancers**
  - Make more of an impact for the population
  - Studying the top 5 cancers will most likely cover other cancers anyways
- **Other exposures that cause lung cancer that is non-tobacco related**
- **Bowel/colorectal cancers**
  - Diet and lifestyle

Question 2 – What specific things in your life do you think cause cancer?

Responses that related to which specific things participants thought caused cancer included:

- **Drugs/medications for chronic conditions**
  - Pain medication
  - Anti-depressants
  - Side effects of medication use
  - Increased use of antibiotics
  - Effects of poor digestive flora
  - Statins
- **Kids not playing outside**
  - Not allowed to rough play, not always true
  - In public schools, it is an increasing problem
  - Only additional programs
- **Hormonal imbalance**
  - Increased oestrogen in the sea
  - Beef industry pumped with hormones
- **Does the weakened immune system cause cancer?** (From colds/flu, stress, diet, lack of exercise and headaches)
- **Cancer survivorship (as mortality is already studied) – what makes them survive?**
- **Those who don't smoke getting lung cancer**
  - Mesothelioma
  - Asbestos
- **Sun – sunscreen**
  - Men over 40 not protecting themselves because the damage was already done
  - Insufficient exposure to sun/vitamin D
- **Plastic surgery** – botox

- **Foreign items in the body**
  - IUD's
  - Tattoos
  - Vaccinations especially at a young age
  - antibiotics
- **Diets**
  - Paleo diet- could it be harmful or beneficial
  - Swapping between diets- constant swapping/changing of cellular level chemicals
  - Fats: eating too much and the wrong kind of fats
  - Excess sugar and salt leading to obesity
  - Junk food
  - Lack of understanding of causes and what is healthy
  - Alcohol
  - Lack of nutrition
  - Over-exercise (extreme exercise e.g. bodybuilding) and undernutrition
  - Food allergies
  - Steroids, supplements
  - Dehydration
  - Microwave meals
  - Caffeine
  - How many vitamins are enough or too much?
  - GM Foods
- **Education on early life to help mothers**
  - Baby formula and reduced breastfeeding
  - Exposure in womb
  - Diet during pregnancy
- **Hidden exposures**
  - Things added in manufacture processes
  - Are certain processes harmful
  - Lack of protection e.g. paint
- **Circadian rhythms**
- **Will cancer ever be solved? maybe focus on reducing deaths**
- **Environmental factors cause clusters of cancers?**
  - Power lines
  - High chemical concentrations in soils
  - Insecticide on fruit and vegetable
  - Pesticides (household and commercial)
  - Pollution in the air especially in cities or developing areas
  - Chemicals in beauty products, cosmetics, hair dye, soaps, makeup, hair products, shellac (UV light)
  - Mould in old buildings – air conditioners
  - Volatile Organic Compounds (VOC): industrial paint, carpet, rubber, raw building products, pipe, new clothes, furniture
  - Poor soil – not enough nutrients so can't fight the cancer
  - Second-hand smoke
  - Diesel exhaust (start to like the chemical smell)
  - High levels of estrogen
  - Heavy metals- iron, cadmium, mercury
- **Sedentary lifestyle: physical inactivity**
- **Stress**
  - Reactions inside body
  - This impacts on healthy lifestyle
  - Free radical damage-oxidative stress
  - Emotional trauma
  - Negativity

- Excessive exercise

- **Radiation from modern technology**
  - Mobile phone
  - Wifi
  - Microwave
  - Computer, iPads, tablets, blue tooth, X-boxes
  - X-rays
- **Age**
  - Is it just we are living long enough that our bodies are giving up and cancer has time to kill
- **Gut health**
  - Constipation
- **Genetic factors**
  - maternal and paternal
  - Human nature
- **Agriculture**
  - How fish are farmed
- **Occupational exposure**
  - Workplace chemicals
  - Breaking down computers to take out harmful chemicals and valuable parts

Question 3 – Are there particular groups in the community that you would like to see us focus our research on?

Responses that related to which particular groups in the community consumers thought cancer prevention research should focus on included:

- **Different age groups – across all ages**
  - More diagnoses in younger – school/education
- **Point of diagnosis and before** – average age of diagnosis
- **Men** – particularly young males
- **Occupational**
- Office (sedentary work)
- Shift work
  - Working long hours
- **Males over 50** – particularly for skin cancer
- **Long-term medication users** e.g. Dexys, Ritalin
- Those with comorbidities e.g. obesity
- Mental health
  - Chronic health conditions e.g. back pain and heart disease
- **Alternative medicines** (versus **traditional**)
- **Children/ young adults/ teenagers**
- **Pregnant women** (also **preconception**)
- **Poorer** / **underprivileged/ low socioeconomic status** (socially or medically disadvantaged) / **overprivileged** (poor versus rich)

- **Migrants** (1st and 2nd generation) and new migrant populations
- **Healthy populations** (meeting 6 health promotion messages) – what cancers do they get?
- **Role of a male in family/health behaviors** – how do males look after themselves?
- **Survivors (cancer)**
  - What do they have in common?
    - Genetic factors
- **Rare cancers** – populations most likely to get
- **Indigenous groups**
    - Change to 'western' lifestyle
- **Culturally and Ethnically Diverse groups**
  - Ethnicity or genetic?
    - acculturation
- **Homeless people**
- **Male versus Female**
- **Vaccinated**
- **Ageing/pensioners**
- **Single people** (look after themselves)
- **Occupations** – outdoor occupations
- **'At-risk' populations**- those identified as being at higher risk
- **'Gamers'**
    - Unhealthy lifestyle: lack of sleep, physical inactivity, lack of sunshine and poor diet
- **Remote and regional communities**
- **Those undertaking risky behaviors without cancer**
  - Smokers
  - Ex-drug users and/or recreational drug users
    - Young alcohol users

Priority Themes

The consumers were given 5 dots for voting, to place against the responses they gave from Question 2, to determine what should be prioritized. The themes with more than 5 votes were as follows (see Figure 1).

Figure 1: Priority themes from Question 2 (with more than 5 votes)

The following are the counted votes for themes identified from Question 2 (votes in brackets):

1. Diet (11)
2. Medications/Drugs (8)
3. Stress (8)
4. Insecticides (7)
5. Chemical exposure (7)
6. Modern Technology (6)
7. Sedentary lifestyles (6)
8. Genetics (5)
9. Hormones/Food additives 5)
10. GM Foods (4)
11. Obesity (4)
12. Comorbidity: other illness/immune system (4)
13. Water: chemicals treating water (3)
14. Allergies (2)
15. Circadian rhythms (2)
16. Power lines (2)
17. Chemicals in soil (2)
18. Alcohol (2)
19. X-rays (2)
20. Asbestos/industrial products (2)
21. Sun exposure (1)
22. Lack of breast feeding (1)Second-hand smoke (1)
23. Exposure at different life stages (1)
24. Beauty products (0)
25. Pollution (0)

Image 3. Consumers deciding what's important in cancer prevention research

Suggestions for the future

Consumers raised the following research topics for future cancer prevention research:

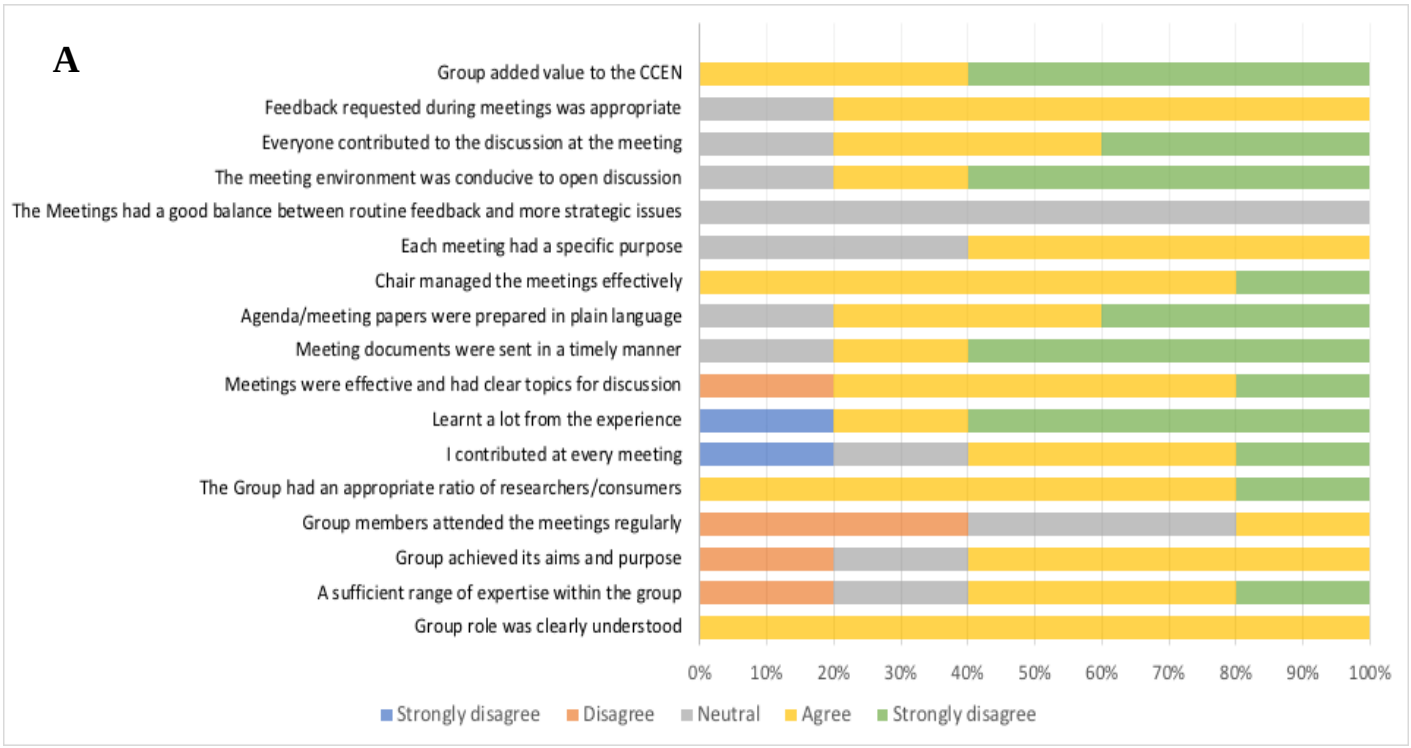
1. Relationship between personal behaviour and lifestyle (how many years of certain high-risk behaviours e.g. smoking, drinking alcohol, occupational exposure) prior to cancer diagnosis
2. Relationship between low vitamin D levels and cancer incidence (e.g. www.sedstudy.org)
3. Has the prevalence of smoking in the younger generation dropped?
4. Create the option for younger population groups to screen for colon or breast cancer with doctors (option to pay)
5. Create a national primary and high school program that is compulsory and educates on diet, healthy lifestyle, coping with stress, yoga, meditation, improvement of quality of life

Consumer Advisory Council and Researchers Group Evaluations

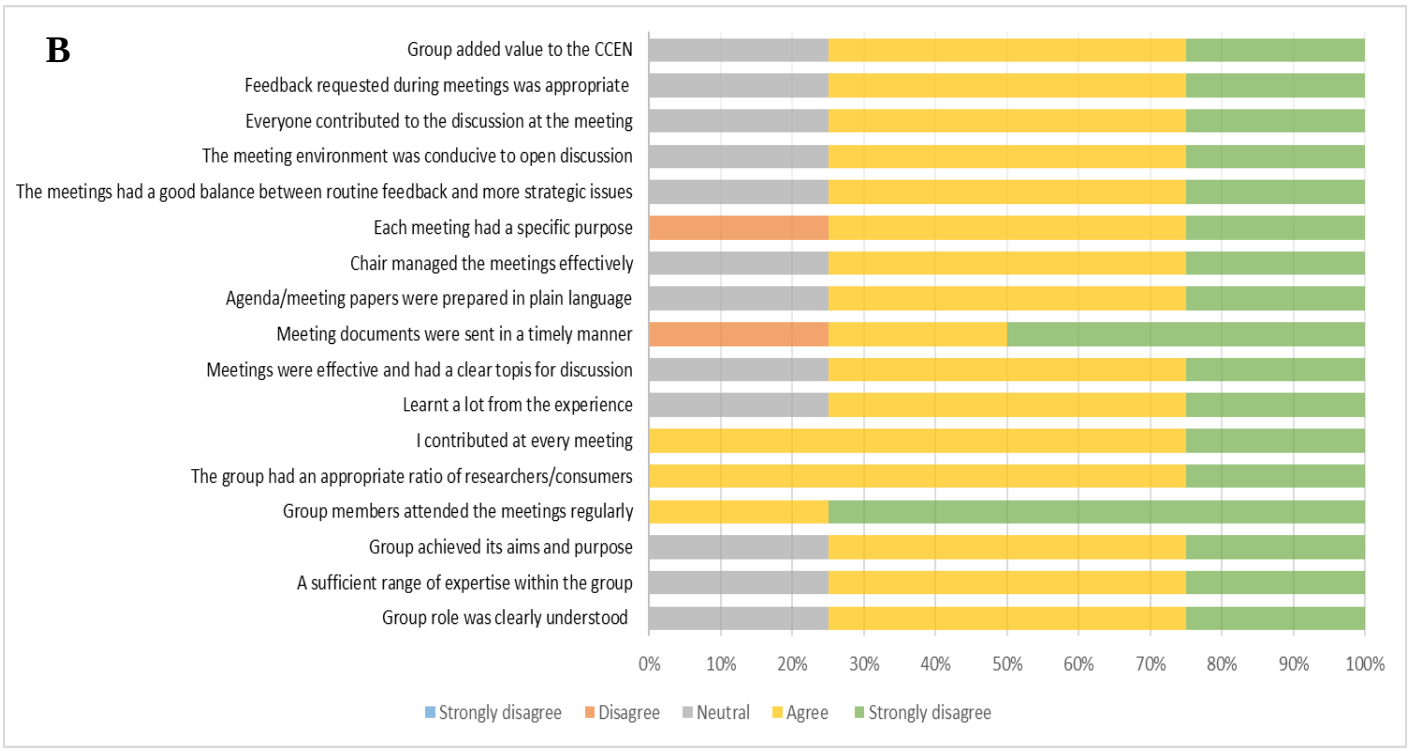
In December 2018, the Consumer Advocate Ben Horgan, from CCHRN, conducted an online survey about the effectiveness of the council from the point of view of both the researchers and the consumers. Four consumers and five researchers completed the survey. The survey included questions on members' knowledge and understanding of their role function according to the terms of reference as well as questions on the structure and size of the council and the effectiveness of the meetings. The online platform Survey Monkey was used to administer the survey. A 5-point Likert scale of agreement was used in most of the questions with response options generally ranging from strongly disagree to strongly agree (see Appendix seven for the full survey).

The majority of the members (consumers and researchers) provided positive responses indicating that they had knowledge and understanding of their role in the functions, that the expertise of the group members was fully utilized in achieving the terms of reference, that the council size and structure was appropriate and that the group's meetings were effective (See Figure 2 for the responses of the researchers and consumers).

Figure 2: Evaluation survey responses to the effectiveness of CAC by researchers (A)



and consumers (B)



In addition to the Likert scale responses, the members provided suggestions and additional comments in response to the following open-ended questions.

1. **Could you recommend anything to better utilize council member's skills?**

Consumer 1: "We were certainly included and consulted so no improvement necessary".

Consumer 2:" Possibly more frequent presentations"

Researcher 1: "The topic was probably too broad for meaningful engagement on a general level. However, for individual projects and questions, I think the council was really helpful."

2. **What would you suggest to improve the Advisory Group's size and structure?**

Consumer 1: "I found the size (number) really comfortable. The structure worked very well in my opinion with both two Chairs - one Researcher and one Consumer Chair."

Researcher 1: "I think it was a good size, difficult to have much bigger. I'd like to know about alternative structures, we followed the advice of the consumer experts and it seemed to be ok."

3. **Any additional comments or suggestions?**

Consumer 1: "Was really interesting research and the Researchers are such warm friendly people who made the committee very enjoyable."

Consumer 2: "The meeting places are usually difficult to get to"

4. **Any additional comments or suggestions**

Consumer 1: "This was a fantastic initiative that was very successful. It worked very well to have quite a few researchers present at the meetings and there were really interesting talks by researchers, great group discussions and feedback. Everyone had a voice and contributed enthusiastically".

Consumer 2: ". Meeting up in person with these fabulous researchers who are doing this amazing work really is such a privilege. Also being alongside other like-minded consumers was wonderful and I met up with Annie McKinnon as a result of this committee which was wonderful."

Some things to consider when forming CAC and organising meetings

- Have a short presentation in each meeting by one of the researchers
- Ensure that meeting locations are easily accessible
- Make sure the meetings have specific themes to allow for meaningful engagement
- Appoint a Chair to represent the consumers and a Chair to represent the researchers
- Avoid forming a large group (e.g. >10) otherwise it will be hard to manage

Conclusion

The council worked very well and it has provided significant benefit to CCEN. The CAC helped researchers to understand the value that consumers can bring to research and to work out what aspects of research can benefit most from collaborations. The CAC helped in setting the research agenda, which helped to fully tailor research to be more relevant to community needs. This report will be available to the public, and distributed to relevant research organisations to ensure that the communities' priorities inform future research into the cancer preventions and will be distributed to researchers who are interested in setting up their own CAC to use this a guide.

Appendices

Appendix One: Terms of Reference

Vision
Enhance quality and relevance of cancer epidemiology research through consumer and community involvement

Purpose and Aim
The CCWA Cancer Epidemiology Network (CCEN) Community Advisory Group (the Advisory Group) has been established to enable the CCEN to develop partnerships in which consumers, community members and researchers work together to make decisions about research priorities, goals, methodologies, questions, and dissemination of results.

Terms of Reference
The Advisory Group will provide input and/or facilitate:

- Consumer and community perspectives on research undertaken by CCEN members
- Links between consumers, the community and researchers within the CCEN
- Advice and expertise on consumer and community issues and priorities for cancer epidemiology research
- Advocacy on behalf of consumers and the community
- Advice on avenues of disseminating research results
- Evaluation and reports on consumer and community participation in the CCEN
- Feedback on strategic planning and governance structures relating to consumer and community involvement in research

Appendix Two: Meeting Agenda Template

CANCER COUNCIL (WA) CONSUMER ADVISORY COUNCIL MEETING

Date/Time:

Address:

Parking information:

Public transport information:

Apologies:

Attendees:

Agenda

5:00-5:10. **Welcome and introduction**
New Consumer Council Members:
Visitors:

5:10-5:20 Topic/Presentation

5:20-5:30 Topic/Presentation

5:30-5:40 Topic/Presentation

5:40-6:00 Topic/Presentation

Appendix Three: Cash advance procedures to pay advisory committee participants at the meeting - Curtin University- School of Public Health:

1. Researcher requests a cash advance from the School of Public Health business manager, by email with copy to Health Transactions (hth.transactions@curtin.edu.au). Information to be included in the email is as follows:
    - Reason required –
    - The amount required
    - The account to be credited
    - Cost centre number to be debited

2. Once the school business manager provides approval, Health Transactions will organise the cash advance to be deposited into the researcher's personal bank account.

3. Researcher completes a Cash Disbursement Form documenting each payment to a participant preferably with signature (See appendix three).

4. At the end of the meeting, if any money is left as a result of absent of a consumer the researcher will return the unused money to Curtin via Curtin Epay https://payments.curtin.edu.au/home/menu

5. The Researcher then emails Curtin Epay the receipt (for unspent money) and the signed cash disbursement form to Health Transactions.

Appendix Four: Cash Disbursement Form.

Project Title: _____
Script account number # ____
Principal Researcher: ____

Date of Meeting: _____

Participant Name	Amount	Signature

Appendix Five: Recruitment flyer for the Consumer Conversation

Cancer Prevention Forum

25th July 7pm - 9.15pm

Interested in cancer prevention and want to make a difference to cancer research? Share your ideas

The Cancer Epidemiology Network want to hear what consumers and community members think!

Venue

Cancer Council WA,
Gordon Basford House,
Bedbrook Place, Shenton Park

Payment and light supper provided

We reserve the right to make changes to the event and the right to determine the confirmed registration list.

RSVP by 20th July at www.involvingpeopleinresearch.org.au

Curtin University

Cancer Council Western Australia

THE UNIVERSITY OF WESTERN AUSTRALIA

TELETHON KIDS INSTITUTE Discover. Prevent. Cure.

Appendix Six: Agenda for the Consumer Conversation

Monday 25th July 2016
7pm – 9.15pm

Agenda

7.00pm	Registration and supper	All
7.15pm	Welcome and introduction	Anne McKenzie
7.20pm	Presentation and questions	Terry Boyle
7.40pm	What's the process of the forum?	Anne McKenzie
	1. Based on your knowledge or experience, what cancers would you like to see researched?	All
	2. What specific things in your life do you think cause cancer?	All
	3. Are there particular groups in the community that you would like to see us focus our research on?	All
8.45pm	Facilitator feedback and questions	Table facilitators
8.55pm	Priority voting	All
9.10pm	Evaluation	All
9.15pm	Close	All

Thank you for attending

Anne McKenzie

Anne's key role is to support and facilitate active consumer and community involvement in the research and teaching programs at the Schools of Public Health at Curtin University and The University of Western Australia and the Telethon Kids Institute. She has a long history as a consumer advocate and has been involved on numerous state and national health-related committees. She established and occupied the role of Parent Advocate at Princess Margaret Hospital for Children, Perth, Western Australia. Anne is a life member and former Chairperson of the Health Consumers' Council WA and a senior consumer representative for Consumers Health Forum of Australia. Her early collaborations with counterparts in the UK led to the development of innovative training programs that built capacity in researchers, consumers and community members and promoted the work of the Program.

In 2015 Anne was appointed Member of The Order of Australia (AM) for her "Significant service to community health through consumer advocacy roles and strategic policy research and development". This richly deserved honour recognises many years of dedication to ensuring the consumer and community voice is heard in health and medical research.

Terry Boyle

Dr Terry Boyle is a cancer epidemiologist whose research focuses on the role that physical activity and sedentary behaviour play in cancer risk, cancer survival and cancer survivorship. He received his PhD in Epidemiology in 2012 from The University of Western Australia, and is now based in the School of Public Health at Curtin University. Terry recently spent two years working at the BC Cancer Agency in Vancouver, Canada, and returned to Western Australia earlier this year.

Appendix Seven: Advisory Group evaluation

The Cancer Council of WA Cancer Epidemiology Network Community Advisory Group
Self-assessment

Purpose: To review and assess member's knowledge and understanding of their role and function according to the Terms of Reference. Please answer the following questions honestly, all responses are anonymous.

Section 1: Terms of Reference and Role

I was familiar with the Group's Terms of Reference?

- ☐ I am not aware of them
- ☐ I have heard of them but don't know them
- ☐ I have read them once or twice
- ☐ I have read them and understand them

From my perspective all members understood the Group's Terms of Reference

- ☐ No one on the Council knows about them
- ☐ A few Council members know about them
- ☐ The majority of Council members know about them
- ☐ All Council members know about them

The Group's activities were driven by the Terms of Reference

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ neutral
- ☐ Agree
- ☐ Strongly Agree

From my perspective the Group achieved its Aims and Purpose

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ neutral
- ☐ Agree
- ☐ Strongly Agree

The Role of the Group was clearly defined and understood.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Agree
- ☐ Agree but think they could do be made clearer
- ☐ Strongly Agree

From my perspective the expertise of the group's members was fully utilised in achieving the Terms of Reference.

- ☐ Strongly disagree
- ☐ Mildly disagree

- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

If you disagree: What would you change to improve better utilisation of council members skills:

Any additional comments or suggestions:

Section 3: Membership

The Group contained a sufficient range of expertise to make it effective.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Agree
- ☐ Agree but think they could do better
- ☐ Strongly Agree

The Group's size and structure are appropriate?

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

If you disagree: what would you change to improve the Council's size and structure:

Any additional comments or suggestions:

Section 4: Meetings

The Group's meetings were effective?

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

Group's members would attend meetings regularly:

- ☐ Strongly disagree, many people frequently miss meetings
- ☐ Mildly disagree, only a few people frequently miss meetings
- ☐ Neutral
- ☐ Agree, majority of people attend regularly
- ☐ Strongly Agree, all members attend regularly

The agenda and meeting papers were well prepared.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree
- ☐ Strongly Agree

The Chair manages the meetings effectively.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

The meetings run on time.

- ☐ Never on time
- ☐ Very rarely
- ☐ Neutral
- ☐ Most of the time
- ☐ Always

The Group's meeting had a good balance between routine information and more strategic issues.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

If you disagree: what would you change:

The atmosphere at the Group's meetings were constructive

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

Everyone contributes to the discussion at the meeting.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

From my perspective the Group added value to the Network.

- ☐ Strongly disagree
- ☐ Mildly disagree
- ☐ Neutral
- ☐ Agree
- ☐ Strongly Agree

Any additional comments or suggestions

Thank you for your participation!