Small Towns Cancer Planning Toolkit

A guide to health literacy community-based participatory approach to reduce cancer mortality in small towns

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Abbreviations and acronyms

ABCD Asset-Based Community Development

CFA Country Fire Authority

CWA Country Women's Association
RSL Returned Servicemen's League

U3A University of the Third Age

Introduction

People living in regional and remote areas have higher cancer death rates. Those in rural areas may also have greater health literacy needs. Inadequate knowledge of health and health services, poor relationships with health care providers, and low motivation for managing health may contribute to poor cancer outcomes in rural and remote towns.

This toolkit is a product of the Small Towns Cancer Plan project funded by the Western Alliance. To achieve the overall goal of improving health literacy, this project had three objectives:

- To utilise local resources and wisdom about effective ways to engage local people in stimulating local dialogue and mutual support related to stages in the cancer journeyTo build partnerships between regional organisations, local district health services, and community members
- To build on community strengths to improve cancer awareness and access to care.

This toolkit offers a potential model for organisations to address questions such as:

How can we identify health literacy needs in relation to cancer services in a small town using limited resources?

How can communities respond to big health issues such as high cancer mortality?

How can local councils, district health services, integrated cancer services, and primary care partnerships work alongside community members to address local needs?

How can we identify people who are less engaged and what could the community do to support them?

This toolkit describes some guiding principles and suggested steps to an organisation-supported, community-led approach to address cancer outcome disparities in small towns. It builds on the foundational values of equity, partnership, and consumer enablement that are already embedded within the strategic directions of local and regional organisations.

This is not a definitive model for community-based approaches in health literacy, but a suggestion that could be adapted to local circumstance. It can be used as a starting point for organisations to develop and build a team which would go on and discover its own path following the strengths and the needs of each town.

Background and how to use this kit

This manual outlines some phases and general principles for using a community approach to identify and respond to issues relating to access and engagement with cancer prevention and treatment.

Step 1 outlines the process of building a local team. It contains general principles and tips in recruiting local leaders and building the structure, however, details may differ according to the local context.

Step 2 describes the process of communicating key concepts to team members. This includes key principles of health literacy and community-development that underpin this model.

Step 3 describes the first task of the newly formed team, which is to define their target groups.

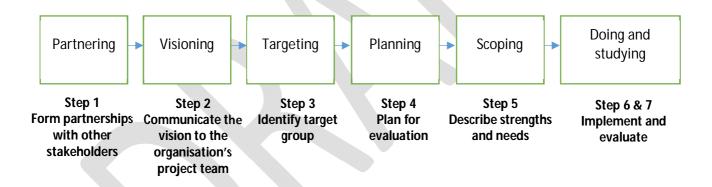
Step 4 describes the process of planning for evaluation.

Step 5 is a step-by-step guide to conducting a situational analysis.

Step 6 describes the process of implementation.

At the end of each Step the relevant resources are summarised in corresponding Appendices.

Overview of the Ophelia Small Towns Cancer Strategy



Step 1: Build a team

The purpose of Step 1 is to form a core partnership with other regional organisations, and recruit local organisations, with the final goal of forming an Implementation Team. The recruitment of local leaders could be an ongoing process as contacts recommend additional contacts and so on.

The proposed model is as below:

Figure 1.1. Governance of the Ophelia Small Towns Cancer Strategy



Why do Step 1 of the Small Towns Cancer Strategy?

- Helps build a sustainable team
- Allows all key beneficiaries of the project to have a sense of ownership

Step 1 activities are:

- 1.1 Establish a project team
- 1.2 Identify roles and responsibilities of team members

Activity 1.1 Establish a project team

This activity will identify and recruit people to participate in the Core Partnership Team and Implementation team

Consider the following as you undertake this activity:

- 1. Who are the relevant regional organisation and leaders who are likely to be regional leaders in community-based cancer prevention?
- 2. Who are the local health service providers that are likely to be interested in cancer prevention?
- 3. Who are likely to be the target groups? Which a community groups would reach these groups? Who are the leaders of these groups?

Getting started on recruiting a team

It is difficult to know in advance, or to make generalizations about the best places to find people with an interest in joining the local teams. The lead regional organisations may have contact with key people in the town, and local health services may know of enthusiastic local people. In addition we found that the libraries in small towns had lists of local organizations. It is important to think broadly, enthusiastic team members can come from diverse and unpredictable organizations.

Activity 1.2 Identify roles and responsibilities of team members

This activity identifies the roles and responsibilities of each team member

Consider the following as you undertake this activity:

- 1. Who will lead the project overall?
- 2. Who will act as a key leader and liaison for all the team members in the Core Partnership and in the Implementation Team?
- 3. Who will provide expertise about the project focus?



Figure 1.2. Example of roles of responsibilities of team members

Team members

Regional health organisations e.g. Integrated Cancer Service, Primary Care Partnerships [Core Partnership]

Local health organisations e.g. District health service [Core Partnership and Implementation Team]

Local leaders e.g. president of U3A [Implementation Team]

Roles and Responsibilities

- Initiate and organise meetings
- Provide training, support and resources to local leaders
- Lead situational analysis
- Initiate and lead in co-design workshop
- Ensure local organisations focuses on supporting community leaders
- Recruit and engage local leaders
- Provide training, support and resources to local leaders
- Plan and implement situational analysis
- Lead the planning and implementation of health interventions alongside community leaders, until community leaders are ready to take lead
- Engage community members to take action in health
- Implement some parts of the situational analysis under leadership of organisations.
- Communicate the best ways to engage someone or to implement something to the Local Team
- Carry out planned activities in the community

Tips: Who are the local leaders?

Local leaders could be identified from the following:

- Referred by local health care providers
- Community group leaders from a community directory (e.g. President, Treasurer, Secretary or Contact Person)
- Expressed interest to be contacted after participating in a survey or interview
- Public notice of a workshop (e.g., this may attract a cancer survivor or a family member, or any individual with a strong interest in this area)

Further reading and resources:

Appendix 1: Background information on Small Towns Cancer Strategy and Ophelia Grampians

Appendix 2: Ethical considerations before starting the project

Step 2: Communicate key concepts

The purpose of Step 2 is to define project aim and scope.

Why do Step 2 of the Small Towns Cancer Strategy?

- Provides a clear vision of the project
- Allows all team members to have a sense of ownership and purpose within the project

Step 2 activities are:

- 2.1 Communicate key concepts of health literacy and community-driven model to team members
- 2.2 Identify the project focus and scope and how it aligns with organisation or group strategic plans

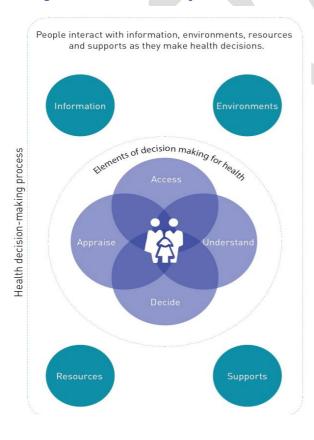
Activity 2.1 Communicate key concepts of health literacy and community-driven model to team members

The output of this activity is a clear vision statement for the project that includes the concepts of health literacy and asset-based community development

Consider the following as you undertake this activity:

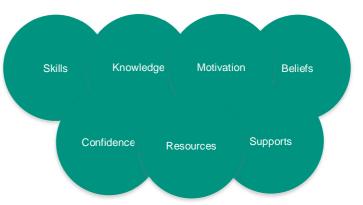
- 1. What are the health literacy needs that are relevant to cancer prevention and treatment engagement in this town?
- 2. What are the benefits of involving the beneficiaries of the interventions in the planning, recruiting and implementation of the interventions?
- 3. Which aspects of community engagement aligns well with your organisation strategic direction?

Figure 2. Health literacy and health decision-making process



Health literacy =

The personal characteristics and social resources people need



to engage in effective decision making about their health and the health of their family and community

Activity 2.2 Identify the project aim and scope and how it aligns with organisation or group strategic plans

The output of this activity is a clear statement of the project's aim and scope

Consider the following as you undertake this activity:

- 1. Are there known issues regarding engagement with cancer prevention and treatment in this region?
- 2. What are the key drivers for high cancer mortality or incidence in the region?
- 3. Do the organisations have to meet strategic priorities or quality standards about these engagement issues or health outcomes?
- 4. What is the timeline, budget and resources for this project?

Further reading and resources:

Asset-based community development. https://resources.depaul.edu/abcd-institute/resources/Pages/tool-kit.aspx

Or just Google "ABCD Institute", go to Resources, read through Toolkit

Step 3. Define target groups

The purpose of Step 3 is to define the target group(s).

Why do Step 3 of the Small Towns Cancer Strategy?

- Identify the at-risk groups for engagement
- Allow more targeted approach during data collection

Step 3 activities are:

- 3.1 Identify at-risk groups from local and regional data
- 3.2 Identify at-risk groups from local and regional staff members

Activity 3.1 Identify at-risk groups from local and regional data. The output of this activity is a list of target groups

Consider the following as you undertake this activity:

- 1. Which group has the highest cancer mortality or incidence in this region?
- 2. Which group has the lowest cancer or health service engagement and usage in this region?

Activity 3.2 Identify at-risk groups from local and regional staff members

The output of this activity is a list of community group leaders that could reach the target groups

Consider the following as you undertake this activity:

- 1. Which groups are likely to be most difficult to engage when it comes to cancer prevention or treatment?
- 2. Who are the community leaders of these groups?

Identification of the target group could be an iterative process. Further definition of the target group or new target groups may also surface during the interviews of community members.

Case study:

Men's Shed Walking Sessions

The need: Men may be reluctant to seek medical attention. This could lead to a delay in cancer diagnosis, amidst other health risks.

The solution: The Men's Shed organised a walk involving laps around the oval prior to their weekly meeting. At the workshop, they decided to build on this by opening the invitation to the public, and to utilise this informal meeting opportunity to increase awareness about cancer screening events.

Case study: Targeting rural men in cancer screening and awareness

Need, as defined by data: National and state data suggest that people residing in rural areas, especially men, have higher cancer mortality rates.

Need further described by community members: Farmers are particularly difficult to engage in cancer prevention and screening measures.

Strategy: Target community groups for men, such as sports clubs, Men's Shed, RSL, CFA. Other community groups for older men and women such as U3A, CWA were also considered.



Step 4. Plan for evaluation

The purpose of Step 4 is to develop an evaluation plan

Why do Step 4 of the Small Towns Cancer Strategy?

- To define what success looks like
- To determine what needs to be measured and monitored, at which time points, by whom

Step 4 activities are:

- 4.1 Identify key outcomes that would be taken as 'success'
- 4.2 Define the roles and responsibilities of team members to carry out evaluation

Activity 4.1 Identify key outcomes that would be taken as 'success'

The output of this activity is a list of outcome criteria and indicators that would show how successful the project has been

Consider the following as you undertake this activity:

- 1. Was your intervention undertaken/conducted as expected? (process evaluation)
- 2. Did your intervention achieve its objective? (outcome evaluation)
- 3. Did your intervention influence your ultimate aims? (impact evaluation)

Activity 4.2 Define the roles and responsibilities of team members to carry out evaluation

The output of this activity is a table of roles and responsibilities on evaluation

Consider the following as you undertake this activity:

- 1. When would the outcomes be monitored, and by whom?
- 2. Who will prepare the evaluation report?

Tips: Planning for evaluation before you start

Understanding what success look like early on could help the team members identify the best interventions and partnerships at the workshop.

Figure 4. An example of an evaluation plan for an intervention to increase cancer awareness among men

Process evaluation		
Intervention activities	How is success measured	
Men's health night	Number of people attending,	
-	Attendee's satisfaction with the	
	event	
Outcome evaluation		
Intervention objective	How is success measured	
To increase awareness of cancer screening	Interview participants to determine if their information needs have been met.	
	Before and after survey on attitudes and beliefs about cancer prevention and screening.	
Impact evaluation		
Ultimate aims	How is success measured	
Empowerment of men to take care of their own	Number of men's groups involved in	
health	the partnership	
Sustainable support from regional and local	Support of community leader(s) as	
organisation	part of the strategic plan of regional	
	and local organisations	

Tips: What does success look like?

Your team may want to consider success in terms of changes at the individual, organisation, or community level. For example:

- An improvement in cancer screening knowledge (individual)
- An increased engagement of GPs with community (health organisation)
- An increase in openness to discuss cancer within a group (community)

Step 5. Describe strengths and needs

The purpose of Step 5 is to map the strengths and needs of the town involved.

Why do Step 5 of the Small Towns Cancer Strategy?

- To map the avenues of opportunities for implementation
- To discover and engage community leaders
- To determine the strengths and needs of the town

Step 5 activities are:

- 5.1 Identify regional data on the causes of cancer mortality in the region
- 5.2 Conduct surveys to identify what people think might be problems with cancer services and what might stop people's engagement with these services
- 5.3 Conduct interviews to identify issues with cancer services and engagement with these services

Activity 5.1 Identify regional data on causes for cancer mortality in the region

The output of this activity is a list of possible risk factors for high cancer mortality in the region

Consider the following as you undertake this activity:

- 1. What is the local, regional and state data on cancer prevalence, incidence and mortality?
- 2. What is the prevalence of cancer-related risk factors in the region, for e.g., fruit and vegetable consumption, participation in cancer screening, overweight and obesity, sunprotection behaviour, at-risk level of alcohol consumption or smoking?
- 3. What is the cancer treatment participation or completion rate in this region?

Tip: Answering these questions will involve referring to several data sources. Usually regional cancer services will already have information about local risk factors and groups as well as who uses services. They may be the best source of information.

Activity 5.2 Conduct surveys to identify issues with cancer services and engagement with these services

The output of this activity is a list of factors relating to strengths, threats, opportunities and need in relation to cancer prevention and treatment in the town

Administer the survey attached in **Appendix 3**. Try to achieve representativeness of all major demographic groups in the town, with special attention to those at risk e.g., men, farmers, elderly.

At the last page of the survey, provide an option for survey participants to leave their contact details to be involved in an interview or workshop.

Tip: Setting up a poster and collection box at the local hub of the community, e.g., library, information centre, could be a good way of collecting surveys. However, the best way to get responses to a survey is to get people to fill it in there and then. This could be done at community events or going door-to-door of the retail businesses along the main street.

Health literacy

Health literacy is likely to be a determinant for the cancer risk behaviours in small towns.

If resources are available, a full profiling of the town according to the Ophelia process (see Ophelia Brief Toolkit, Ophelia Additional Resource and Template) can be very useful.

In cases where this is not feasible, we have included the concepts of health literacy within the questions in a Survey developed with cancer prevention in mind (Appendix 4).

Activity 5.3 Conduct interviews to identify issues with cancer services and engagement with these services

The output of this activity is a list of factors relating to strengths, threats, opportunities and needs in relation to cancer prevention and treatment in the town

Conduct interviews with community leaders. A suggested script for the interview is found in **Appendix 4**. You can print out **Appendix 5** to take notes at each interview. At the end of the interview, offer an invitation to the workshop.

Tip: Online directory of community groups that may be available at local council or regional organisational websites is a great place to recruit interviewees.

Connecting with people

Interviews and surveys are not just tools to gather information. This is an important step in forming connections with community leaders.

The conversation started at interviews and surveys could be continued, with their consent, through periodical phone calls (e.g. once a month initially) to acknowledge their unique strategic position to engage target group, open discussion on what they could do, and the resources the organisation could offer to support them.

Possibly as a result of such ongoing conversations, Men's Shed has redefined its group beyond a hobby group, to one that focuses on men's health.

Figure 5. Example of strengths and needs of Avoca and Beaufort

 Community spirit Friends and family Word of mouth Connections Clubs and groups 	OpportunitiesCommunity and support groupsInformation and awareness
NeedsTransport and accessibility	ThreatsApathyFearMisconception

Further reading and resources:

Appendix 3: Template for survey

Appendix 4: Script for interview

Appendix 5: Interview form



Step 6. Plan for implementation

The purpose of Step 6 is to develop a plan for interventions.

Why do Step 6 of the Small Towns Cancer Strategy?

- To consult all stakeholders for ideas to solve the identified problems
- To develop short, medium and long term goals
- To develop an immediate action plan for the short term goal

Step 6 activities are:

- 6.1 Determine the target audience and recruitment strategy for the workshop
- 6.2 Prepare for the workshop
- 6.3 Conduct the workshop

Activity 6.1 Determine the target audience and recruitment strategy for the workshop

The output of this activity is a plan that specifies who you are going to engage and how you are going to engage them.

Consider the following as you undertake this activity:

- 1. Who do you need to engage? You will want to engage those who have access to or great influence over your target group, those who best understand the issue, or most likely to have been involved in making the necessary changes to improve health. Think about engaging:
 - Health care providers
 - Community leaders
 - Those who participated in survey or interviews

Activity 6.2 Prepare for the workshop

The outputs of this activity are a confirmed recruitment plan for the attendees, completed materials for presentation, confirmed arrangement on roles and responsibilities of team members during the workshop, finalised arrangements with travel, date, venues and catering.

Consider the following as you undertake this activity

- 1. When is the best time of the day to engage your target group?
- 2. How many printed copies of the handouts do you need?
- 3. Do you need to send background information to the attendees prior to the workshop?
- 4. Will you have the audio-visual equipment that you need?

Tips on recruiting for the workshop:

- Make a telephone call, drop in for a chat, and perhaps follow up with email, to extend a personal invitation to survey and interview participants
- Place public advertisements in prominent places, although this may not be very effective in small towns

Tips on organising for the workshop:

- Start early as organising a mutually convenient time between all core partners may take longer than you thought.
- Don't forget to organise catering, nametags (write names in large, easy to read, print), stationary.
- Example of handouts can be found in **Appendix 6 and 7**.

Tips on preparing for the workshop presentation:

- Compile regional data into a few slides (see Example in **Appendix 8**).
- Analyse numeric data from the survey into averages.
- Categorise narrative survey responses and interview responses into Strengths, Needs, Threats, Opportunities.

Tips on facilitating the workshop:

The workshop's aim is to allow community members <u>to be listened to</u>, to prioritise actions, and to develop goals and plans. Any strategies or techniques that could effectively achieve these aims are good options. The ideas generated should be projected on screen or written on a flip chart so that the group can discuss and prioritise.

Activity 6.3 Conduct the workshop

The output of this activity is your notes and a list of solutions generated at the workshop, at least one (relatively) short term intervention selected for practical and detailed planning, and an action team identified to follow up with the plan.

An example of the script for the workshop is found in **Appendix 9**.

Outline of the workshop:

- 1. Start with a summary of the members of Core Partners and Local Team, the overall aim of the workshop, and a brief presentation (about 15-20 mins) on the Strengths and Needs of the town.
- 2. Small group discussion to generate ideas
- 3. Large group discussion to consolidate all ideas and prioritise short, medium and long term goals
- 4. Select one intervention for detailed practical planning, and an action team to plan and implement this intervention.
- 5. Summary of what has been achieved

Further reading and resources:

Appendix 6: Brainstorming handout

Appendix 7. Planning handout

Appendix 8. Workshop presentation example

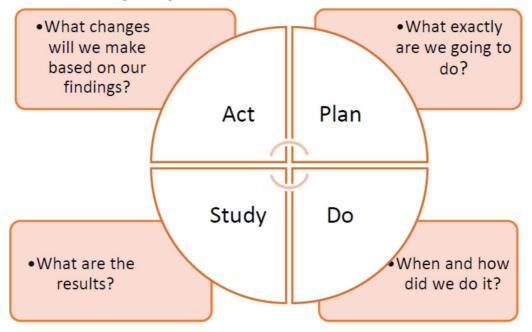
Appendix 9: Workshop script



Step 7. Implement, evaluate and repeat

The purpose of Step 7 is to implement the intervention, evaluate the process and outcome of intervention, and to develop next steps. It is part of the widely-used quality improvement process where team members engage in a *plan-do-study-act cycle* (Figure 7) that can be repeated as often as necessary.

Figure 7. Plan-do-study-act cycle



Why do Step 7 of the Small Towns Cancer Strategy?

- Allows you to consider the findings from Step 6
- To refine strategies to better achieve goals
- To foster partnerships between team members

Step 7 activities are:

- 7.1 To implement the intervention and evaluation plan
- 7.2 To determine future intervention plans

Activity 7.1 To implement the intervention and evaluation plan

The output of this activity is an evaluation report

Consider the following as you undertake this activity:

- 1. What needs to be measured as indicators of success?
- 2. Who will be measuring them?
- 3. Who are the targets for the report?
- 4. Who will prepare the report?

Activity 7.2 To determine the next intervention plan

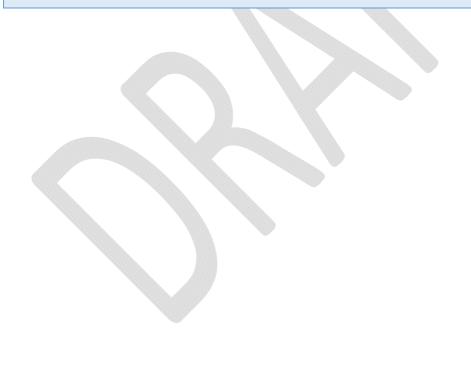
The output of this activity is an action plan for the next intervention

Consider the following as you undertake this activity:

- 1. What were the lessons learnt from the previous intervention plan?
- 2. Should the current intervention be built on for further refinement and wider implementation, or should the team move on to another intervention?
- 3. Are there better ways to achieve the outcomes and impact of the intervention?

Case study: Men's night at Beaufort

This event aimed at facilitating community conversations around cancer among men. Beaufort APEX club, VFF Beaufort and Beaufort and Skipton Health Service volunteered to coordinate this project with support from Grampians Pyrenees Primary Care Partnership. At the event, healthcare professionals facilitated conversations around cancer affecting men, and free health checks were provided. During the conversations, several community members gave an off-the-cuff talk about Pedal For Prostate, a cycling fund-raiser event for the Prostate Cancer Foundation of Australia. Another community member spontaneously shared his personal experience with suicide and the need for support and help from mates as well as health services.



Attachments

Appendix 1. Background information on Small Towns Cancer Strategy Pilot Project and Ophelia Grampians

Appendix 2. Ethical considerations

Appendix 3. Survey

Appendix 4. Script for interview

Appendix 5. Interview form

Appendix 6. Brainstorming handout

Appendix 7. Planning handout

Appendix 8. Workshop presentation example

Appendix 9. Workshop script