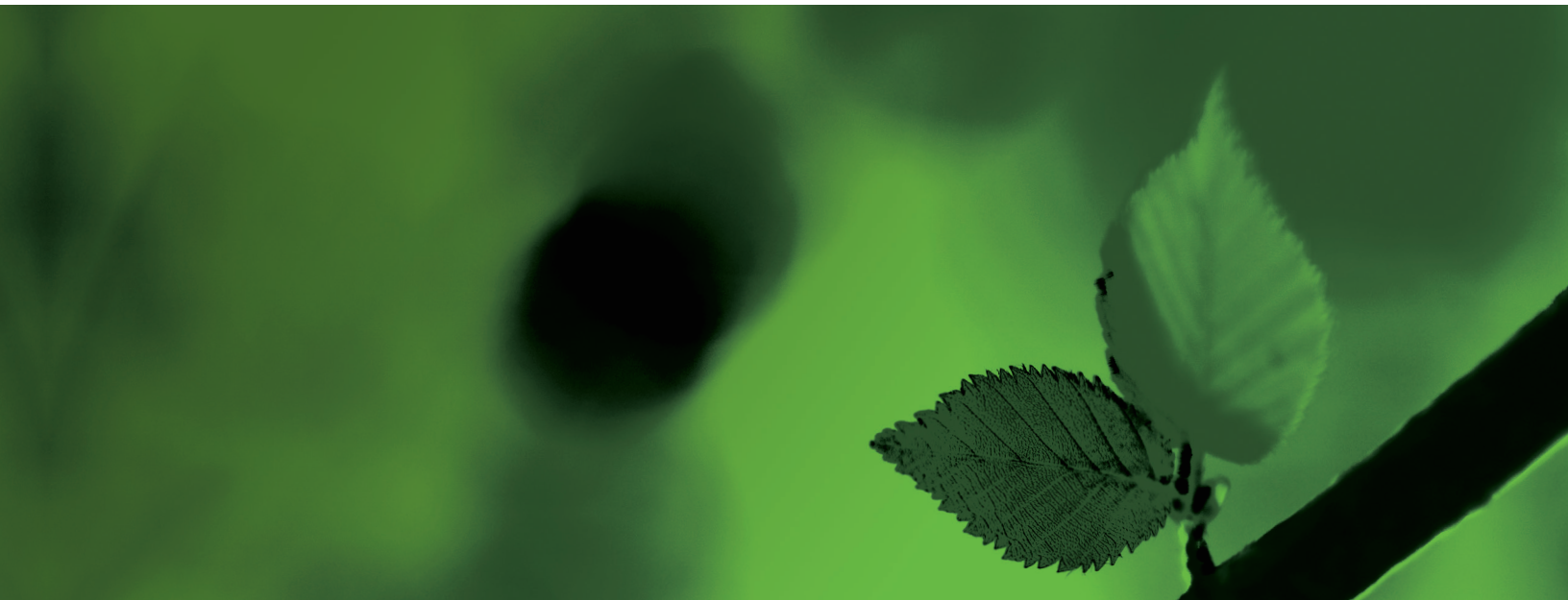


ARRESTING CANCER:

Using community-based participatory approaches to improve cancer screening and awareness with formerly incarcerated men and women



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We would like to thank the many contributors to our community-based cancer-focused project. Our diverse project team, who participated through all the steps of development and implementation, directly contributed to its success. We honour the project participants, for their honest and generous insights, and all the voices who together created this project with the sole purpose of improving the health and well-being of previously and currently incarcerated individuals. We acknowledge all who contributed to the writing and editing of this how-to-manual, a truly collaborative effort, reflecting the spirit and participatory practices of the project documented in these pages.

Why did we write this manual?

This manual describes the community-based model and participatory approaches used to develop and pilot materials and workshops to address early cancer screening and awareness for previously incarcerated men and women. We hope that other organizations will find our manual useful when initiating similar projects designed for marginalized populations, or any other community-based health-related project. This manual does not advocate for a one size fits all approach. What worked for us may not work for all – sensitivity to the local context and participant population is imperative for successful project design and implementation.

Who should use this manual?

- Health, community, or correctional organizations working with currently or previously incarcerated men and women;
- Organizations or individuals interested in community-based participatory approaches in project design and delivery;
- Organizations interested in developing cancer screening and awareness projects;
- Academic individuals or institutions interested in community-based research;
- Current or future health care providers; and/or
- Instructors and students of health disciplines.

BACKGROUND

Who are we?

The Collaborating Centre for Prison Health and Education (CCPHE) operates in the Faculty of Medicine at the University of British Columbia (UBC). The centre was established in 2006 to encourage and facilitate collaborative opportunities for health, education, research, and advocacy to enhance the health and social well-being of individuals in custody and those transitioning back into their communities.¹

Why did we develop a cancer screening and awareness project with formerly incarcerated men and women?

During previous health education research projects, the CCPHE built strong working relationships with two organizations: Women in2 Healing (Wi2H), and Long-term Inmates Now in the Community (L.I.N.C.). Both organizations have community-based networks of formerly incarcerated men and women. Health care has been identified as a critical issue for the communal and individual well-being of this population and CCPHE aims to collaboratively address health issues that have been identified by the community.

This manual is dedicated to the memory of Lora Kwandibens, a member of the Ojibway Nation, who spent many years as an adolescent and young adult inside correctional institutions. Lora was a passionate member of the Wi2H participatory health research projects; she encouraged us to apply for funding to improve cancer education and cancer screening for incarcerated people because she knew that cancer prevention and cancer screening is not given priority among prison populations. Lora was diagnosed with breast cancer at the age of 41. She died at of metastatic breast cancer in February 2013, leaving behind her six-year-old son.

At the time of Lora's breast cancer diagnosis, three other previously incarcerated women were also dealing with diagnoses of invasive breast cancer. Momentum to develop a community-based participatory cancer screening and awareness project was a direct result of the devastating life experiences that late cancer diagnosis causes, and the specific impact of cancer on individuals with incarceration history.

Reaching out: A university-community partnership


Application for funding

In order to address this community-identified need, the CCPHE, in partnership with Wi2H and L.I.N.C., applied for funding from the Public Health Agency of Canada. In 2012, we received funding to conduct a two-year project that focused on promoting participation in available cancer screening and early detection programs for breast, cervical, and colon cancer with formerly incarcerated men and women.

Project objectives

The project collaborators developed the following project objectives:

1. Increase the awareness of the importance of cancer screening and early detection amongst previously incarcerated men and women in British Columbia (BC). The project focused on screening and early detection of breast, cervical and colon cancer, consistent with the BC Cancer Agency screening projects.

- 
2. Identify and decrease the barriers that previously incarcerated men and women face when participating in cancer screening and early detection programs in BC.
 3. Activate previously incarcerated men and women to direct their own care in cancer screening and early detection and to increase their trust in health care providers.
 4. Promote a dialogue on the feasibility of national uptake of similar cancer screening and early detection initiatives for previously incarcerated men and women in the community and within correctional institutions.

COLLABORATIONS

Building a collaborative project team

We used purposeful and participatory approaches when selecting the project team, in order to represent a myriad of voices from varying perspectives. The project team refers to the academic team, the project staff team and the Project Advisory Committee.

Academic team

The multi-disciplinary academic team included expertise from medicine, nursing, education, criminology, and counselling psychology and was responsible for development and evaluation of the project.

Project staff team

Under the guidance of the academic team, the project staff team was responsible for the day-to-day operation and implementation of project activities. The team consisted of two UBC-based project coordinators and four part-time community-based (CB) and UBC-based project assistants. Three members of Wi2H and L.I.N.C. were hired as the CB project assistants as they brought first-hand experience and front-line perspectives to the development, implementation, and evaluation of the project. There was an equal representation of individuals with and without incarceration history on the staff team.

Project Advisory Committee

The Project Advisory Committee (PAC) was an external committee that provided strategic guidance to this project and other CCPHE projects. They joined the academic and project staff teams for quarterly meetings to provide advice and feedback. The PAC also provided guidance for dissemination and implementation of the project findings. The PAC consisted of a diverse representation of key policy stakeholders, community, health, and corrections organizations, and previously incarcerated individuals.

The collaborative project team was responsible for developing, delivering and evaluating the project. The following diagram illustrates the collaborative aspects of the project planning process (Figure 1).

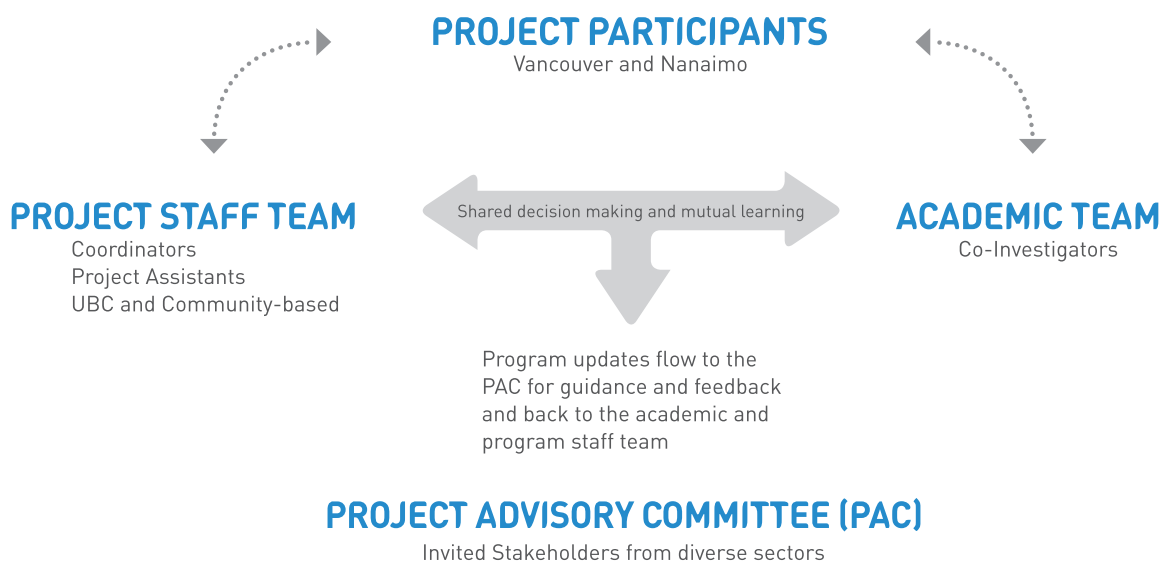


Figure 1: The collaborative aspects of the project planning process

GUIDING VALUES AND PRINCIPLES

Articulating guiding values and principles

During the initial phase of the project, the academic team, project staff team, and PAC met to articulate and to agree upon values and principles that would guide all aspects of the project activities. At the heart of our conversation was our desire to embody respect for the knowledge, insights, and experience of our community participants and to promote reciprocal learning and capacity building among all members of the project.

Core guiding values

The values that we agreed up for this project included:

Partnership – Equal participation of all relevant stakeholders

Voice – Opportunity and encouragement for all to share opinions and ideas

Active Listening – Willingness to hear and acknowledge what others have to say

Respect – Acknowledgement and recognition that everyone has ideas and experiences of value to offer

Reciprocal Learning – Willingness to learn from one another

Cultural Respect – Indigenous and ethnic cultural awareness, sensitivity, and competence

Transparency – Honesty and accountability in all actions

Principles of community-based research (CBR)

Throughout the project, we adopted elements of community-based research (CBR). We recognized that men and women who have incarceration history and who have had to re-integrate into their communities are best situated to speak to these challenges. CBR is defined as “a partnership approach to research that equitably involves community members, practitioners, and academic researchers in all aspects of the process, enabling all partners to contribute their expertise and share responsibility and ownership.”²

CCPHE’s previous work demonstrated the receptive enthusiasm of currently and formerly incarcerated men and women to participate in projects where they were partners in all aspects of the project from the design and development through to implementation, evaluation, and dissemination. The project aimed to involve members of the community to affect change, not only for themselves, but also for the larger community and for those who are currently incarcerated.

The core CBR principles we chose to adopt were as follows:²⁻⁵

- **Build on community strengths and resources:** The insights, resources, and strengths that communities possess are invaluable to the process of developing community-based projects. Focusing and building on these invites a strengths-based approach rather than a “deficit mentality” approach, which focuses only on weaknesses. A strengths-based approach allows for deeper conversations about the capabilities and strengths of the different partners, enabling all involved to be supported throughout the process and set-up for success.
- **Capacity building:** Creates educational and skill-building opportunities for all partners involved in a project. Project-specific training for community members such as research, computer, group facilitation, or leadership enabled individuals to be active and equal members of the team.

- **Community-based partnerships:** Community-based partnerships bring together those affected by the issue with those who have relevant skills and experience, thereby bridging expertise, experience, and wisdom between the organization(s) leading project development and community members involved. This approach ensures the issues being selected and addressed are relevant and responsive to the community's identified needs, and that community members are brought into the project as partners from the onset.
- **Iterative:** An iterative approach allows researchers or the project team to flexibly integrate new practices into the project. The reflective nature of community-based research or projects incorporates a continuous analysis of what is taking place, followed by revisions prior to moving forward into the next phase or activity. This cyclical pattern of analysis, reflection, and revision provides an opportunity for everyone to contribute to and learn from the project's successes and challenges.
- **Participatory:** Participatory approaches help to ensure that all voices are heard and shared decision-making is implemented, fostering meaningful involvement of all stakeholders throughout the project. Communities, organizations, and individuals are involved or consulted at all levels of the project, establishing the structure for the active participation of those affected by the issue.
- **Reciprocal learning:** Knowledge exchange takes place by actively engaging everyone in the development, implementation, and evaluation in the project. Everyone learns from each other in an exchange of information and shared experiences. Knowledge sharing activities, such as debriefings, group meetings, information exchange activities, and feedback opportunities, may be built into a project in order to enhance reciprocal learning opportunities.

Ethical principles

Community-based projects initiated at UBC require an application to the Behavioural Research Ethics Board (BREB) to ensure the project is guided by the core principles of research ethics: respect for persons, concern for welfare, and justice. The underlying value of the research ethics review is respect for human dignity. With this in mind, we received the UBC BREB certificate and adopted the following ethical principles:

- **Free and informed consent:** Our project was described in detail in a written consent form which was discussed with participants to ensure that they chose to voluntarily participate from an informed perspective. Participants had an opportunity to ask questions for clarification, and to ask for assistance if literacy barriers were present. In addition, we reiterated that participants could withdraw at any time.⁶
- **Minimal risk:** Our project was designed to minimize risks no greater than those encountered by our participants in their everyday life. In addition, some benefits were anticipated for participants, such as increased health knowledge and positive relationships between participants, and between participants and staff/presenters.⁶
- **Privacy and confidentiality:** Privacy is respected if participants can control the use of their personal information through consent to personal data collection or disclosure of information. Confidentiality refers to the responsibility of the organization, institution, and researcher to safeguard the personal information of research participants. Many participants knew each other prior to this project, such that their identity was not anonymous or confidential. We asked participants to keep confidential the information shared during group discussions.⁶

DESIGN AND DEVELOPMENT

This section describes the sequence of events that contributed to the collaborative project design and development.

Step 1	Working together as a project staff team
Step 2	Inviting previously incarcerated men and women to participate in the project
Step 3	Communicating with participants
Step 4	Identifying existing cancer screening and awareness strategies and materials
Step 5	Receiving feedback from participants about existing strategies and materials, and how we could make them more relevant for the project
Step 6	Planning the workshops, based on participant feedback

Step 1: Working together as a project staff team

The newly hired project staff team, from diverse backgrounds and with differing knowledge and expertise, recognized that they needed to clarify their roles and responsibilities and to establish organizational and project guidelines and structure.

Grounded in CBR principles, the team encouraged inclusive participation of all members, reciprocal learning, shared decision-making, and capacity building. The ability to build strong working relationships and work collaboratively was critical to the team's success.

Reflection:

It was evident to me right from the start that everyone had something to offer, and that these differing skills and areas of insight were recognized and appreciated by the other team members. I truly feel that the project would have been about half as successful had it not been for the diverse representation on the team. – RENEE, PROJECT COORDINATOR

Team guidelines: a training and protocol manual

A training and protocol manual was written to clarify the roles and responsibilities for each team member and to establish organizational and project guidelines. The project staff team was the driving force behind training and protocol manual. The manual was not intended to be a static document but an iterative manual, to be revised as the team learns and reflects on the procedures within the project and the roles of the team members. Topics in the training and protocol manual include:

- Team structure, roles, and responsibilities;
- Communication expectations;
- Guidelines for positive, productive meetings;
- Details on how to collect data ethically and accurately;
- Money handling procedures and the implementation of a log book to be signed by two team members per transaction; and,
- Safety protocol for travelling to workshops or to collect data.

Team meetings: a way to build trust and create reciprocal learning opportunities

Weekly team meetings allowed the team to stay connected, discuss the project, plan upcoming activities, and address potential challenges. However, the weekly meetings were also a time to build trust between

team members. We started each team meeting with an around-the-room check-in activity – team members drew an ‘Angel Word’ (e.g. trust, creativity, compassion) from a box and incorporated the word into his or her check-in.⁷ This activity allowed people to reflect on the word and share what it meant for them at that time. It allowed a deeper interpersonal connection to form between team members, which ultimately impacted our abilities to trust each other. The meetings were grounded in open communication, honesty, and always ended with a positive reflection about the project or the meeting.

The team meetings were also an opportunity to learn from each other because the team brought different, but complementary, strengths to the project. For example, the CB project assistants with incarceration history were familiar with issues that many of participants faced on a daily basis. Participants were willing to talk with, and give honest feedback to, the CB project assistants, whom they might know personally and because they shared similar experiences to their own. The CB project assistants helped other project team members understand the complexity of participants’ lives. The team meetings provided a respectful venue to discuss these issues.

Reflections:

Weekly team meetings were an integral part of my experience within the project. Along with assigning roles/tasks and reporting progress as things went forward, they provided an ongoing opportunity to share knowledge and ideas while learning about each other on a deeper level. I learned to recognize team member’s communication styles and an awareness of my own communication style. Being aware of the impact on others, and the possibility of communication style variances creating misunderstanding or clouding the message. The trust and safety that was fostered within the team was crucial to identify and resolve any misunderstanding or tensions that arose. Some aspects of this project were new uncharted territory to all of us, and with that came areas of stress. The meetings provided an arena that allowed us to recognize the signs in other members and ourselves leading to a quick and effective opportunity to debrief and share our challenges. All of this learning and finding a rhythm to work collaboratively came fairly quickly because of the nature of the meetings – we built in time to connect personally (check-in) as well as time for project-related business. —WENDY, COMMUNITY-BASED PROJECT ASSISTANT

Building a level of trust and cooperation between everyone involved on the project was evident throughout the term of the project. This ongoing trust and cooperation became more evident and stronger over time. It allowed participants to feel more confident to discuss and share personal stories, many of which would almost certainly not have been shared with others easily because of a lack of trust that incarceration instills in people. It was tremendously gratifying to witness this phenomenon which was almost like the slow but steady opening of a flower from bud to bloom. —LARRY, COMMUNITY-BASED PROJECT ASSISTANT

Shared decision-making

The team promoted shared decision-making in planning the project. It is important to acknowledge the difference between the project coordinators’ full-time position at the university and the CB project assistants’ part-time position. The CB project assistants attended weekly team meetings where we discussed the design, development, implementation, and evaluation of the project; however they were not at the university site to participate in decisions on a daily basis. This structure posed inherent challenges to equitably involving all members in all decisions; however every effort was made to involve all team members in all decisions whenever possible.

Capacity building

Opportunities for capacity building for team members were incorporated throughout the project. The CB project assistants were trained in data collection and focus group facilitation, thus building their research skills. They also presented during the workshops, delivering health information from a community perspective, thus building their confidence and public speaking skills. Team members also presented the project findings at two national conferences.

Step 2: Inviting previously incarcerated men and women to participate in the project

How did we invite participants to join the project?

The three formerly incarcerated CB project assistants were central to the success of enrolment in Vancouver. Information about the project was shared largely by word-of-mouth and participants were often invited through the CB project assistants' personal networks. All interested participants were guided through a consent form, and consented to participate by signature. The personal histories and connections of the CB project assistants formed a foundation of trust between the participants and the academic and project team. We also witnessed that strong connections were formed between participants, and likely contributed to participant retention. A total of 54 previously incarcerated individuals enrolled as participants in the project in Metro Vancouver.

In Nanaimo, we were less able to rely on previously established social networks for participant invitations because the CB project assistants had fewer personal connections there. Through a combination of new strategies we enrolled 76 participants in Nanaimo, where the enrolment processes differed from that in Vancouver. Firstly, enrolment in Nanaimo was strongly driven by word-of-mouth from a former Vancouver project participant who moved to Nanaimo and was keen to remain involved. His leadership and peer influence contributed a great deal to the high volume of participants. His success clearly demonstrates the importance of having formerly incarcerated individuals who support the project as partners within the community. Secondly, Nanaimo is a small city with well-connected community organizations. The project coordinator contacted a shelter and halfway house in the area and they were able to disseminate information about the project to their clients. Enrolment took place at the central downtown library which was ideal as most of the participants lived within walking distance.

Who were the participants?

The participants were previously incarcerated individuals, of whom 65% were men and 35% were women. Their ages ranged from 25 to 66 years. The total time participants had spent incarcerated varied from less than one year to over 20 years. 19% were married or common law (the remainder were single, divorced or never married), 23% self-identified as Aboriginal, and 42% lived in transition housing such as a shelter, halfway house, or recovery house.

Step 3: Communicating with participants

How did we communicate with participants?

Multiple communication strategies were needed to communicate effectively with the participants. Ongoing communication was needed to keep participants involved and to create a sense of community. However, maintaining communication with participants was an ongoing challenge that had no simple solution. For example, some participants lived in unstable housing, thus communicating with them was often difficult. Participant communication strategy therefore included several components: email, mail, phone, peer outreach, and Facebook.

Communication methods

- Individual: Email, phone, mail
- Peer outreach: Face-to-face, email, phone
- Group: Closed Facebook group

Email/Phone/Mail: We communicated with participants through a variety of methods. We realized early on that if we relied solely on email, we would miss people with limited computer access or low computer skills. Phone calls turned out to be one of the most successful methods of contacting participants in both Vancouver and Nanaimo because people often kept the same cell phone number even if their home address or email address changed.

Peer outreach: The three CB project assistants, who continue to be actively involved in their community, communicated with participants through their personal networks, and by email, phone, or face-to-face. Peer outreach also took place between participants. It was evident that some participants were very involved in the project, and often encouraged their peers (other participants) to attend the workshops.

Reflection:

The importance of peer outreach became clear right from the beginning of the project. The fact that we were people with incarceration experience made it so that we were viewed by potential participants as “peers.” This made it much more likely that participants wanted to be involved, and made it easier for participants to trust that it would be beneficial to them. Another factor was our involvement in outreach projects working with incarcerated populations before this project was started. We were therefore in a position to know many individuals with incarceration history and were held in high esteem by many for our dedication to this kind of work. —LARRY, COMMUNITY-BASED PROJECT ASSISTANT

Facebook: A closed Facebook group allowed participants to discuss workshop material as well as general health information and questions. The project staff team used Facebook to post upcoming workshops, events, and information about the project. The Facebook group was a user-friendly way to communicate with many participants on an ongoing basis.

What we learned

- Several communication strategies were needed to communicate with participants;
- Phone calls to each participant, though time consuming, fostered personal connections between project staff and participants, and was an effective way to communicate with participants;
- Facebook was a successful way to reach the participants who were computer literate and had computer access;
- Peer outreach was the most effective way to successfully enrol participants into the project. Once they were enrolled, it seemed less important that peers did the contacting about project details such as workshops.

Step 4: Identifying existing cancer screening and awareness strategies and materials

We identified existing cancer screening and awareness strategies and materials for breast, cervical, and colon cancer. We also searched for information about barriers to screening with hard to reach populations, and effective screening interventions and promotion strategies. While the search primarily included programs and activities within British Columbia (BC), we also included examples from other provinces and the United States. This information helped us to develop a framework for the project and informed what strategies and materials we would present to the project participants.

We investigated two types of client-directed interventions to promote cancer screening: ones that increase the likelihood of participation and ones that reduce barriers to cancer screening.⁸

Interventions that increase the likelihood individual participation in cancer screening:

- Reminders: sent via mail or email to encourage screening or to advise people they are due for screening;
- Incentives: small rewards to encourage people to seek screening or to encourage others to seek screening;
- One-on-one education: communicating in person or via telephone about indications, benefits, and general information about screening;
- Group education sessions: same information as one-on-one education, but in a group setting;
- Mass media: print, TV, radio, or magazine campaigns to communicate educational and motivational information regarding cancer screening.

Interventions that reduce barriers to cancer screening:

- Reduce client out-of-pocket costs: providing bus tickets for transportation;
- Reduce structural barriers: transportation access, offering extended hours and/or services in alternative settings, and simplifying administrative procedures (i.e. scheduling assistance or translators).

Step 5: Receiving feedback from participants about existing strategies and materials, and how we could make them more relevant for the project

Based on the information gathered during our initial search, the project team selected samples of existing pamphlets, posters, reminder cards, videos, and campaign events to bring to our participants for advice during a feedback session. The goal of the feedback session was to work together with project participants to adapt or re-design cancer screening and awareness materials for the project, appropriate for men and women with incarceration history, ultimately shaping the plans for the project design. The three hour feedback session was facilitated by six members of the project team, three of whom were previously incarcerated.

Participants provided advice on how to make the cancer screening materials more relevant to them. It was important to hear from the previously incarcerated participants to understand what would motivate them to get screened.

After a brief introduction, the project team presented cancer statistics, risk factors, and signs and symptoms for breast, cervical, and colon cancer. The participant feedback session was then divided into three sections:

1. Cancer Screening Videos

- We played two minute excerpts from five short videos promoting cancer screening;
- Participants had approximately three minutes immediately following each video to fill out a feedback form;
- Facilitators encouraged group discussion about the video. Two project team members documented the comments from the verbal discussion.

2. "Design Your Own" Pamphlets and Reminders

- Participants formed three small groups to provide feedback on existing cancer screening pamphlets for breast, cervical, and colon cancers;
- Facilitators asked five questions to prompt discussion about preferences. The small group discussions were audio recorded;
- In groups, participants then designed their ideal cancer screening pamphlet by drawing and listing facts and information that were important to them. The participants spent the last ten minutes presenting their design to the whole group.

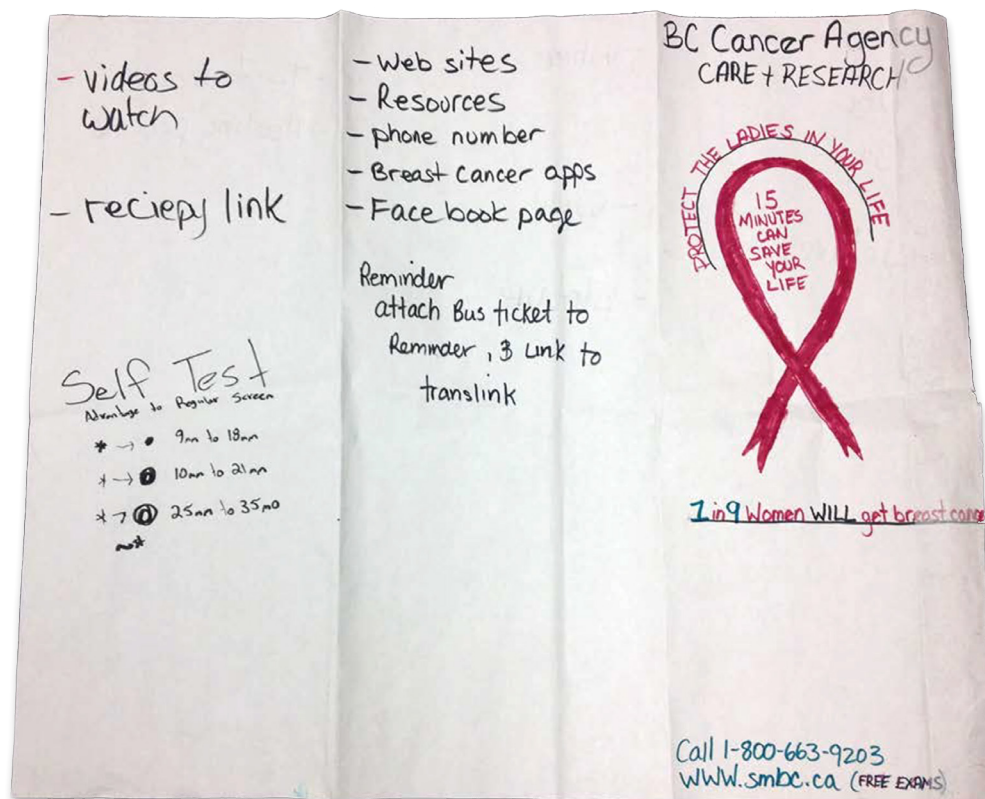


Figure 2: Example of 'Design Your Own' pamphlet. This group of young men wanted to share information about cancer screening with the women in their lives, remind women that screening is free, and attach bus tickets as a way to reduce out-of-pocket expenses.

3. Cancer Screening Outreach and Campaigns

- Participants remained in their small groups and two project team members presented four types of cancer screening campaigns;
- Facilitators asked four questions to elicit feedback from participants on each campaign. The small group discussions were audio recorded.

Based on information gathered at this session, the project team worked with a graphic designer to adapt or re-design cancer screening and awareness print materials to be responsive to the participants' preferences.

Participant feedback on cancer screening materials

- Provide facts that show the seriousness of cancer, but also provide messages to show that people can overcome cancer;
- Provide pertinent screening information such as where to get screened and that screening is free;
- Create materials that evoke emotion;
- Personal testimonials with pictures of 'real people' had the most impact;
- Minimize barriers to screening by providing bus tickets and a link or phone number to bus schedules.

Project staff team feedback on workshop logistics

- Hold the workshop in a central place near transit. Consider that many participants may not have access to a vehicle;
- Allow a little extra time for each of the planned activities. The group session was popular and many people wanted to contribute their suggestions;
- Organization is key to a successful event. If various methods of evaluation are used and many forms of data are collected, assign who is responsible for each role during the event;
- A catered lunch of casual sandwiches was a popular choice. Familiar catering choices provide a relaxed atmosphere during the break.

STEP 6: Planning the workshops, based on participant feedback

Based on feedback from the participants at the cancer feedback session described above, the project team planned the workshops topics. Three areas were identified as priorities and formed the topics for the subsequent workshops.

1. Navigating the Health Care System

In order to successfully engage in cancer screening, individuals must have access to a family physician, and know how to navigate the cancer screening programs relevant to them. In order to achieve our objective of increasing screening rates among participants, we needed to inform people of how to find a family doctor, and also how to create a positive relationship with a family doctor. Therefore, we decided that the first workshop should highlight these two key issues. A detailed description of the workshop can be found on page 26.

2. Cancer Prevention (reducing your risk)

Although many cancers are not preventable, when lifestyle factors are modified, individuals can reduce their risk of cancer significantly. Participants were interested in learning more about what they can control in their lives through their life choices. A detailed description of the workshop can be found on page 30.

3. Cancer Screening

Based on feedback from the session, it was evident that there was a lack of clarity regarding screening programs that exist in BC, as well as who should have what screening test done and when. In order to clarify some of these questions, the project team planned a workshop focused on general cancer screening. A detailed description of the workshop can be found on page 34.

An iterative approach to project design

From the outset, participants helped to shape and re-shape the project content and delivery style. They decided which health resources, and cancer screening and prevention materials would be used throughout this project. The participants also provided feedback on workshop activities and content during the focus group discussions held at the end of each workshop. The project team took this feedback and used the suggestions to inform and plan the next workshop. The feedback – positive or negative – was always constructive in helping the team plan new “iterations” of the project. The project team also brought participant feedback to the PAC in order to continually guide the direction of the project from the ground up.

IMPLEMENTATION

Grounded in CBR principles, the workshops were planned iteratively and collaboratively. Workshop activities were generally planned after the previous workshop was completed and participant feedback was analyzed. The feedback provided valuable information and insights for the project team to plan the subsequent workshops.

Workshop materials, resources, and tools

The project team, participants, and our partner organizations collaboratively adapted or designed strategies (including materials, resources, and tools) to encourage participation in cancer screening and early detection and to encourage participants to actively manage their own health.

1. Health resource binder
2. Memo-to-Myself
3. Online health forum
4. Cancer screening and prevention reminder cards with bus tickets
5. Posters
6. Cancer awareness wristbands with outreach information card
7. The Basic Shelf Cookbook
8. TV Trainer resource
9. *Cancer Walks Free* documentary film

1. Health resource binder

At each workshop participants received health resource handouts tailored for the specific workshop topic: Navigating the Health Care System, Cancer Prevention, and Cancer Screening. The health resource binder provided space for supplemental information that could not be covered during the two-hour workshop. At every workshop, participants received an information insert for their binder.

Reflection:

By involving men and women with incarceration history in all phases of the project, they were able to provide insight into what type of workshops and resources they wanted. They requested resource material that they could use as a reference after the workshops for themselves or to share with others. It was inspiring to witness how participants wanted change, but they also wanted to be part of the change process. —DEBRA, PROJECT COORDINATOR

Why did we use this strategy? Participants requested action-oriented workshops that encouraged them to improve their own health. The reference material in the health resource binder served as a reminder of what was covered during the workshops, and as encouragement to actively participate in their own health care.

What we learned: Participants were keen to take home written information after the workshops. Print materials were especially useful to participants given that many had low computer literacy and therefore were unlikely to access online resources. Participants gathered resources for themselves, and also for friends and family members.

2. Memo-to-Myself ⁹

The Memo-to-Myself was introduced to support the intention to change over the course of a month. At the end of each workshop, participants were asked to reflect on what they had just learned, and before leaving the workshop, to set two health goals that they could work towards over the next month. Participants wrote down in duplicate their two health goals; one copy was placed in a self-addressed envelope, which was sent as a reminder two weeks after the workshop; the second copy was placed in an envelope anonymously. A summary of all anonymous responses was mailed two weeks after the first reminder. The two mailings served as prompts for participants to carry out their predetermined health goals.

Why did we use this strategy? The Memo-to-Myself was introduced to encourage goal setting, promise-keeping, and reflective learning. The mailed-out summaries of responses were intended to provide a sense of community support and accountability: participants were reminded that their peers were also working towards common goals.

What we learned: We gathered feedback on the Memo-to-Myself during the focus group discussions held after each workshop. While the Memo-to-Myself generally had a positive impact, the responses about their usefulness were varied. Some did not find the memos useful, but others revealed different ways in which Memo-to-Myself was useful to them, by acting as a reminder to complete their health goal. Many letters were returned due to participants moving; therefore some did not receive their reminders.

Quotes:

I do [find the Memo-to-Myself useful] – mine sits on my night table and I look at it every so often. It's a good reminder that I have a goal; I plan sometimes to get back and follow it again.

—PREVIOUSLY INCARCERATED PARTICIPANT

The Memo-to-Myself was useful because I actually did follow through with it, and when I received it in the mail, I was like, right on! Yes, I remembered to do this, I've already done it. And I felt really good about it. —PREVIOUSLY INCARCERATED PARTICIPANT

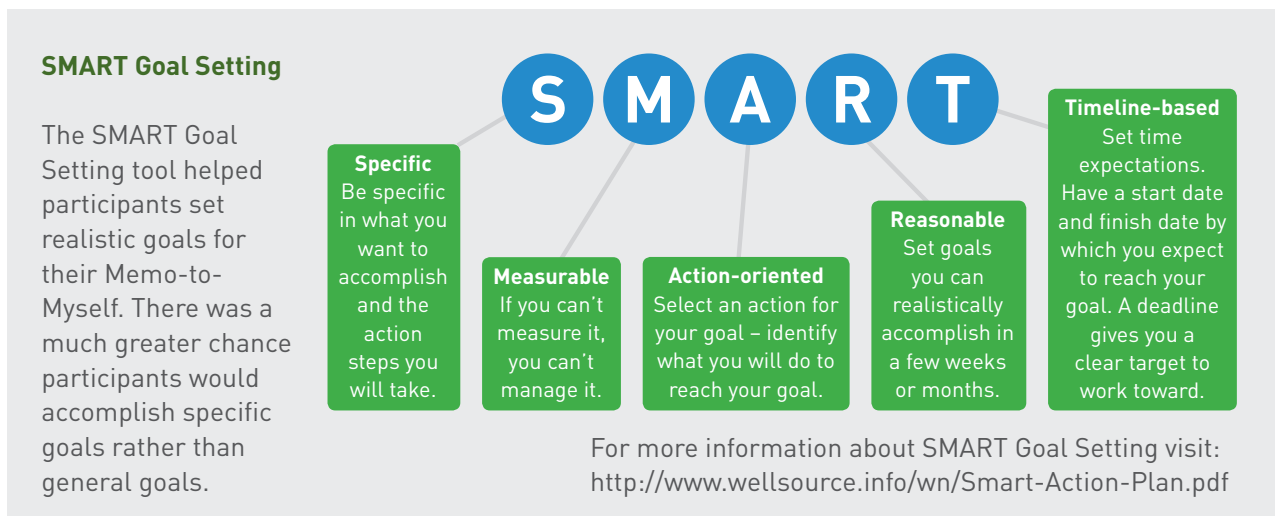


Figure 3: The SMART Goal Setting tool helped participants set realistic goals for their Memo-to-Myself.

3. Online health forum

We created an interactive online forum with several health-related ‘chat rooms’ – one of which was cancer-focused. Participants could talk with their peers, ask medical questions which were answered within the week by a medical resident, or ask questions to the academic team or the project staff team. The online forum aimed to give participants a sense of direction over the kind of information they required answers to and provide a space to safely discuss health-related topics.

Why did we use this strategy? We wanted to create an interactive space for participants to share and learn about cancer and health-related topics, but we also wanted to use the data from the online forum as part of our project evaluation. In order for the forum to be approved by UBC BREB as a qualitative data collection tool, it had to be built on a secure site that would protect participants’ identities with computer generated user names and passwords. The online health forum was housed on a UBC server and accessible through the CCPHE website.

What we learned: Use of an online forum may be of minimal value if the site is not user friendly with simple log-in procedures. Participants had difficulty using this online health forum and uptake was low. Potential factors for low uptake included a lack of computer skills, financial constraints such as not being able to afford the cost of a computer or computer time, a transient lifestyle, and/or living in accommodation without computer access. We were driven by the need to build and evaluate a tool that would be approved by the UBC BREB. However, many participants had difficulty accessing the online forum – such as getting their user name and password, logging into the forum, or losing the information after they received it. In response to these barriers, we held a ‘tutorial’ on how to navigate the forum. While the tutorial helped somewhat, the online forum was not an effective way to engage participants.

4. Cancer screening and prevention reminder cards with bus tickets

We customized three reminder cards about breast, cervical, and colon cancer with a message designed to speak to participants. The tag line “So much is beyond our control. Take control of what you can. Get Screened” was developed by the CB project assistants. They explained that this motto spoke to the common experience of individuals feeling a lack of control inside prison, and their opportunity to take control once outside. The reminder cards also included practical information such as who should be screened, how often, why, and a phone number to call for an appointment or to ask for more information. The tag line on the reverse side of the card read, “So much is beyond our control. Take control of what you can. Reduce your risk” and included five steps to reduce the risk of cancer: quit smoking, be active, eat well, drink less alcohol, and get screened for cancer. We worked closely with the Screening and Promotions Manager at the BC Cancer Agency to ensure we included the most up-to-date screening and prevention guidelines. We attached two bus tickets to the reminder cards as a way to reduce participant out-of-pocket expenses while traveling to and from a cancer screening appointment.

Reflection:

The “take control” tag line addresses two key issues I have dealt with since leaving prison, and see many peers struggle with too. While in prison, patients are careful about what they reveal to health care providers because it is often reported in their files by security-minded officers and used in various ways affecting their placement within the institution and release outcomes. Inmates are very aware of the effects misinformation can have on their lives. It is discouraged that people challenge the established standard. This fosters a deep feeling of lack of control around health issues. Institutionalized individuals become accustomed to being judged as less competent, less intelligent, and generally less valuable. Upon reintegration it is often an ongoing struggle to find one’s voice and re-learn how to effectively be heard. –

WENDY, COMMUNITY-BASED PROJECT ASSISTANT



Figure 4: Three customized reminder cards for breast, cervical, and colon cancer with the tag line “So much is beyond our control. Take control of what you can. Get Screened.”

Why did we use this strategy? During the feedback session, participants said that personal testimonies were an effective way to convey the importance of cancer screening. Participants wanted to see ‘real people with real messages’ because their stories would be a source of motivation and inspiration. Based on this feedback, we chose two project participants and one CB project assistant, each with incarceration history, to be photographed for the reminder cards and to share a message about how cancer screening diagnosed his/her cancer early.

Participants also suggested we include two bus tickets with the reminder cards as a way to minimize the transportation costs to travel to the screening location. The majority of participants were unemployed (56%) with almost half living on welfare or disability. Many of the participants still lived in unstable housing, such as a halfway house or shelter. This strategy aimed to minimize economic barriers that impede participant access to cancer screening.

What we learned: Participants said they preferred to receive the reminder cards by regular mail rather than by email. They indicated that they liked receiving mail and would be more likely to pay attention to information if they received a paper copy. However, many of the reminder cards were returned because participant addresses were outdated. While we followed-up with telephone calls or emails, we could not always get in touch with participants due to a variety of reasons such as unstable housing, recidivism, parole conditions, and/or relapse.

Reflection:

Participants found that the reminder cards were right to the point, offering a good brief of essential information regarding the three types of cancer. The individual quotes from project participants regarding personal experiences with cancer added elements of trust and reality to the cards and the project.

— LARRY, COMMUNITY-BASED PROJECT ASSISTANT

5. Poster

We created two posters featuring nine participants and one woman, Lora Kwandibens, with incarceration history who had recently died of metastatic breast cancer. Lora was the inspiration for this project. Surrounding the central photo are headshots of the participants, along with quotes about cancer and cancer screening. The quotes were pulled from short interviews with the participants about their experiences of cancer, personally, or among friends and family.

Why did we use this strategy? The posters were available for participants to take after the Cancer Prevention and Cancer Screening workshops. Many took several copies to post in places they live, work, or frequent. The posters were engaging to participants because they recognized their peers and were interested in their stories.

What we learned: Participants were enthusiastic about having their pictures and stories on the posters. They were keen to share their stories about cancer and screening to contribute to awareness among their peers by being the ‘real people with real messages.’ Though some of the participants had tough stories about dealing with cancer inside prison, their quotes for the posters were decidedly motivational and focused on the benefits of catching cancer early by screening.



Figure 5: Two posters with pictures of CB project assistants and project participants and their personalized cancer screening message.

Reflection:

The poster produced through this project features messages by people with incarceration experience in real language encouraging others to get screened. By not using generic models, it provides real people and identifiable situations. The pictures are large, the words are minimal. Overall, it delivers a message succinctly, in a format that could easily be displayed inside prisons to reach those who are incarcerated, which is a fundamental long term goal of the project. —WENDY, COMMUNITY-BASED PROJECT ASSISTANT

6. Cancer awareness wristbands with outreach information card

Each participant who attended the Cancer Screening workshop received three brightly coloured wristbands with the message “CCPHE – Take control – it’s your health. Get screened.” The colours matched those on the reminder cards, and therefore represented the three types of screenable cancers. As an awareness campaign and a form of peer outreach, we attached an information card stating: “Keep one. Pass two on. Tell family and friends about the importance of breast, cervical, and colon cancer screening. Help spread the word.”

Why did we use this strategy? Wristbands are a popular and low-cost way to create awareness for cancer screening. By giving participants three wristbands and encouraging them to pass two on, we hoped it would create opportunities for conversation about what participants had learned during the workshop and the importance of cancer screening.

What we learned: The wristbands were well liked at the workshops, and many participants wore them home. Compared to the reminder cards, participants seemed more likely to gift the wristbands to others.



Figure 6: Tri-coloured wristbands were used as a cancer awareness strategy and a form of peer outreach.

7. The Basic Shelf Cookbook¹¹

The Basic Shelf Cookbook (2011) was designed by the Canadian Public Health Association for people living on a low budget. Most of the suggested ingredients have a long shelf life and few require refrigeration. The recipes are quick and easy to make and require a minimum of cooking experience and equipment.

Why did we use this strategy? Since over half of our participants are living on welfare or disability, this cookbook provided tips on how to plan meals, save money when shopping, and prepare low-cost, nutritious recipes. The cookbook was chosen as a way to illustrate that healthy eating does not need to be expensive and time consuming. The cookbook was available to participants at the Cancer Prevention workshop, which included a presentation on tips for healthy eating.

What we learned: The cookbooks were highly valued by participants, who intended to use them for personal use, or to share with their housemates. Participants appreciated that the cookbook was targeted to eating on a budget, unlike most cookbooks.

8. TV Trainer resource

The TV Trainer was adapted from a resource created by the Provincial Health Services Authority Workplace Health, Health Promotion program. It included exercises that could be done in a small space and without equipment. The exercises were printed on a small card with stretches and strengthening activities to be done during each commercial break while watching TV.

Why did we use this strategy? We anticipated that participants might not have access to many fitness resources, so we focused the discussion of physical activity on what you can do at home or throughout the day to increase activity. Setting the stage with prison exercises, which many participants related to, exemplified the message that staying active requires minimal resources.

What we learned: Participants were less interested in information about physical activity than about other topics like diet and cancer screening. In general, participants noted that they were already quite active with walking and biking frequently.

9. *Cancer Walks Free* documentary film

A documentary was produced about cancer screening and individuals with incarceration history. The film highlighted issues that both individuals with incarceration history and health care practitioners encounter when dealing with each other. The content for the 12-minute film was developed during a three hour 'sharing circle' where participants shared their feelings and experiences about cancer screening, their relationship with their health care providers, and what they would like to see happen regarding cancer prevention and screening for currently or formerly incarcerated men and women. Six participants agreed to be profiled in the film, and were interviewed individually on camera. A physician who worked inside a women's prison for 16 years also shared her perspective.

Why did we use this strategy? The documentary aimed to raise awareness about cancer screening amongst previously incarcerated individuals. Another goal was to convey to health practitioners the unique perceptions, fears, and cancer risk factors for individuals who have spent time incarcerated. By presenting the individuals' and the doctor's perspectives, the documentary also aimed to increase understanding and compassion between health care providers and individuals with incarceration history.

Cancer Walks Free is available online: <http://www.youtube.com/watch?v=vJKloTHFAko&feature=youtu.be>

What we learned: Short films as educational tools are well received among previously incarcerated men and women, health care providers, instructors, and the general public. Posting the documentary on-line makes the film available for larger audiences beyond the project itself. Film is an especially engaging medium for delivering information about cancer screening since it is able to convey emotions and personal stories that enrich the facts and figures.

Reflection:

Making a film about cancer awareness and prevention among people with incarceration experience was important to me because I have incarceration experience and I am a cancer survivor. Like most people with prison experience the fear of going to a doctor is very overwhelming. The fear of judgement kept me from going to a healthcare provider even when I knew that something was not right. Until a friend of mine was diagnosed with stage 4 cancer after she fought with doctors that she knew something was wrong it was too late to save her life. I learned from her experience that it is important to get tested early and that testing can save your life. My friend passed away and today I want to make sure that no one else with incarceration experience has to go through what she and her family did. —MO, DIRECTOR OF *CANCER WALKS FREE*

Workshop delivery styles

Each of the three workshops included a variety of approaches to engage participants in learning. In the workshop planning, we purposely used different types of delivery styles to appeal to participants' diverse learning styles. Feedback from participants revealed that they preferred presentations in which there was a combination of expertise on specific health topics and personal experiences from their peers. Each workshop used a combination of the approaches that are described below.

1. Community organization: Representatives from local community organizations presented components of the workshops relating to health education and health promotion. The CB project assistants with incarceration history were involved in tailoring the material and messages to ensure the acceptability of the material by the participants.

2. Health care provider: A physician or medical resident presented on topics from a medical perspective. The health care providers added value to the workshops by providing basic disease physiology information, and by providing the participants with an opportunity to ask medical questions.

3. Peer-led: The CB project assistants presented components of the workshops, including health information contextualized by personal anecdotes. Because they have a history of incarceration, they spoke from a community-based perspective and represented the voice of the participants.

4. Experiential learning: Experiential learning activities involved active participation, as opposed to a conventional lecture-style form of information delivery. Participants practiced useful skills and participated in a variety of games, activities, and lively discussions.

Reflection:

We found that icebreaker games are extremely important! Each workshop began with one or two icebreaker games. These were engaging, often funny, and created a sense of community and light-heartedness to begin the workshops. They were also useful in establishing a trusting space. There are many to choose from. —

RENEE, PROJECT COORDINATOR

5. Multimedia: Different forms of information delivery were used to provide visual interest, mainly PowerPoint presentations and YouTube videos. Laptops were available to participants at one workshop for practicing online skills.

6. Interactive theatre activity (“Rainbow of Desire”): We explored health and social issues in the context of prison health by fostering communication around emotionally difficult issues through a facilitated theatre exercise. Rainbow of Desire¹⁰ explores those internal voices within us that complicate relationships between groups and individuals. This technique honours both sides of the story, highlighting different perspectives, creating an opportunity for dialogue, without polarizing the community into ‘us and them’.

Before you finalize your workshop plans, here are some key considerations:

- Have you created workshop objectives as a way to stay focused during your planning process and as a way to measure your success?
- Have you incorporated an icebreaker or team/community building activity?
- Have you allowed sufficient time for transitions between activities?
- Have you incorporated time for question and answer or discussion periods with the speakers?
- Do you have a way for people to give feedback? (i.e. feedback form, online survey, focus group)
- Do the project team members know what their roles and responsibilities will be at the workshop?
- Do you have snacks and beverages arranged? (We found this to be critical!)
- Will participants have something to “take away”? (i.e. information and/or hard copy resources)
- Do you have a way of following up with the participants? (i.e. contact list/sign in sheet)
- Do your participants have a way to follow up with you? (i.e. business cards, contact information on handouts)

Workshops

WORKSHOP 1: NAVIGATING THE HEALTH CARE SYSTEM

The Navigating the Health Care System workshop was developed because previously incarcerated men and women told us that not having a family doctor, and deeper factors such as unhealthy relationships, stigma and mistrust, were barriers to achieving their health goals. Participants told us that they needed skills, information and resources in order to successfully navigate the health care system. Due to a number of factors, incarceration does not set people up for success regarding accessing health services. Relationships between health care providers and previously incarcerated individuals are not always simple or positive. Therefore, the project team decided that it would be beneficial to expand the invitation to include health care providers in addition to the project participants. The planning of this workshop addressed the above issues.

Reflection:

We found that participants liked having health professionals at this workshop to answer questions and to hear their concerns. By introducing each team member and their role in the project, the participants knew who was in the room, their expertise, and that they could ask questions to any team member at any time. —DEBRA, PROJECT COORDINATOR

Workshop Objectives

- Improve relationships between previously incarcerated individuals (participants) and health care providers;
- Decrease barriers to accessing health services;
- Provide information on how to navigate the health care system; and,
- Encourage participants to leave with a health action plan related to the workshop topic.

Workshop Delivery Styles

- Community organization
- Health care provider
- Interactive theatre activity
- Multimedia

Workshop Resources

- Handouts for health resource binder
- Memo-to-Myself

Workshop Activities

1. **Health care provider presentation:** Dr. Ruth Elwood Martin, a family doctor and former prison physician, discussed how to find a family doctor and provided a demonstration of how to search online for doctors accepting new patients. She also highlighted the importance of building a trusting relationship with a family doctor, and how one might go about doing this. She emphasised patient rights, and the process of how to make a complaint if one were to have a negative experience with a health care provider. There was ample time left for questions, which was very beneficial, as the presentation sparked much discussion.

Quote:

“I found it very interesting to see the doctor’s side because we don’t really think how doctors feel and what their fears are and what they feel at work, so it’s nice to see an aspect of both sides”

—PREVIOUSLY INCARCERATED PARTICIPANT

Alternative option

Involving a prison physician or an experienced physician like Dr. Martin in a workshop may not be realistic or necessary, for many contexts. In Nanaimo, a post-graduate family practice resident, Dr. George Francis, was delighted to be invited to give the workshop presentation. Post-graduate medical residents often enjoy being involved in extracurricular health-related community-service experiences and they offer a wealth of knowledge. They also might have more flexibility in their schedules than practicing physicians.

- 2. Interactive theatre activity - Rainbow of Desire:**¹⁰ David Diamond, co-founder and artistic director of Theatre for Living (www.headlinestheatre.com), asked workshop participants to share their experiences of a previous negative health care experience while in prison. One situation was selected by the group to use in the demonstration. Two volunteers were invited on stage: a former prison physician, and a participant, who took on the roles of prison physician and a formerly incarcerated person seeking medical advice. The Rainbow of Desire activity explored the internal voices of both ‘actors’ by drawing out each character’s fears and desires in the context of this particular scenario. Diamond invited members of the audience to offer additional fears or desires by coming on stage to embody them, taking the shape of what those fears and desires might look like. The activity highlighted a “rainbow” of fears and desires (Figure 7). Diamond then engaged the audience in a discussion about their interpretations of the scene, and people commented on the emotions of both characters. The activity allowed new perspectives to emerge, which elicited empathy from both groups for both sides of the issue.

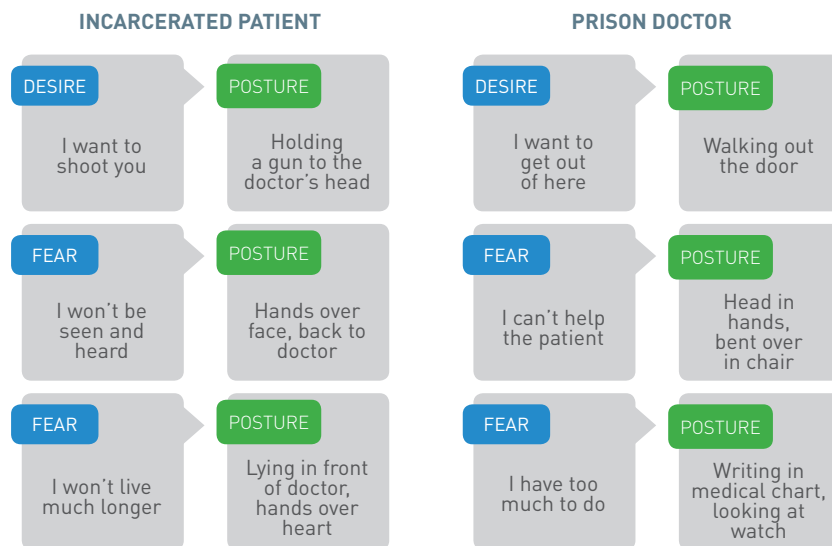


Figure 7: Rainbow of Fears and Desires for Incarcerated Patient and Prison Doctor

Reflection:

The physician was at one time a prison health care worker. The participant was a long-term inmate with many years of incarceration. The participant typified one of the most problematic issues facing persons with incarceration experience: a very low opinion of health care services, described as being “generally a complete waste of time”. She described health care inside the walls as “creating feelings of helplessness and frustration.” Emotional feelings led the participant to dread going to health care even when she knew that she was experiencing symptoms indicating possible serious health issues. Through the Rainbow of Desire activity, both the participant and the doctor shared feelings of fear, frustration and a near total lack of ability to accomplish any constructive dialogue under the influence of those feelings. Virtually everyone in the audience was deeply affected by the role playing and felt the strong emotional feelings that were created. Both players reported that they felt the exercise allowed them to recognize the other individual’s similar feelings. This realization led to a willingness to try to create a dialogue based on a mutual respect for each other. The audience recognized the importance of the catharsis that occurred between the players and how witnessing and experiencing this could lead to more effective relationships between participants and other people. —LARRY, COMMUNITY BASED PROJECT ASSISTANT

Alternative option

Having a theatre expert, such as David Diamond, present at a workshop might not be possible for many groups. A good alternative could be to have a skilled facilitator or mediator to enable a similar activity or discussion to explore the two sides of a situation and discuss peoples’ unique experiences.

What we learned

- Previously incarcerated participants and health care providers reported increased awareness and understanding of each other’s perspectives;
- Participants suggested that the Rainbow of Desire technique or a similar activity such as a facilitator-led improvisation would be beneficial to use in training current and future health care providers;
- Participants valued learning practical ways to improve their experience in navigating the health care system and relating to health care providers;
- People respond well when given an opportunity to have their voice heard, as evidenced in the theatre exercise, where everyone was able to contribute their thoughts on the topic;
- The interactive theatre activity was an effective learning tool, as evidenced in a noticeable shift in the levels of compassion that were being expressed;
- Bringing groups together that are often disparate (in our case, health care providers and previously incarcerated individuals) is challenging, but provides an opportunity to build trust between them.

A following quotes are from the focus group discussions after the workshop.

Quotes:

“There were some ‘aha’ moments – learning moments...because it’s both the health care providers and the inmates that need to give and take, they both need to be more relaxed, more open”

—HEALTH CARE PROVIDER PARTICIPANT

“I’m going to look into getting health care...this has opened my mind. Health should be first, before anything” —PREVIOUSLY INCARCERATED PARTICIPANT

“I felt like I was re-living every day of my work. I work in a Downtown Eastside clinic. A lot of people come in looking for a family doctor, and they are very desperate and angry and they’re at a point where they are basically holding a gun at me. How can we then check our behaviours or our reactions, in interacting with community members?” —HEALTH CARE PROVIDER PARTICIPANT

Reflection:

Guys call to tell me that the Navigating the Health Care System workshop has made them think, like re-thinking their demeanour when handling interpersonal conflicts. We are giving people opportunities and education, which is the road to freedom. —LARRY, COMMUNITY-BASED PROJECT ASSISTANT

WORKSHOP 2: CANCER PREVENTION

The Cancer Prevention workshop was designed to provide knowledge and skills to reduce the risk of cancer. Since cancer prevention encompasses so many personal health behaviours, our workshop was designed to be fast-paced and interactive to maximize the coverage of health information. The project team invited two provincial organizations, the BC Cancer Agency (BCCA) and the BC chapter of the Lung Association (Quit Now BC) to collaborate with us on the development of the workshop. For several weeks, the project team communicated regularly with community health educators from both organizations to tailor their pre-existing workshops to the needs of our participant community, as identified by the project assistants with incarceration experience. The educators' familiarity with community resources was invaluable. The workshop had several components that provided a comprehensive look at how to reduce one's risk of cancer.

Workshop Objectives

- Increase knowledge of the basic science and physiology of cancer;
- Enhance understanding of the risk factors for cancer;
- Share skills and tools to be healthy; and,
- Support participants in achieving attainable health goals.

Workshop Delivery Styles

- Community organization
- Experiential learning
- Peer-led

Workshop Resources

- Carbon monoxide monitor (Quit Now BC)
- Fitness equipment (pedometers, resistance bands, exercise balls)
- Fitness Challenge
- Healthy gift basket (prize)
- The Basic Shelf Cookbook¹⁰
- Handouts for health resource binder
- Memo-to-Myself

Workshop Activities

- 1. Cancer education presentation:** The presentation by the community health educator from BCCA combined facts and disease prevalence rates with practical lifestyle modifications to reduce cancer risk. The discussion touched on nutrition, physical activity, alcohol, and sun safety in ways that were relevant and appropriate to our participants. For example, because many participants had restricted incomes, the project team encouraged the educator to focus on eating healthily on a budget, rather than promoting the benefits of eating expensive anti-oxidants like berries, and to suggest low- and no-cost ways to increase physical activity. This session was engaging and interactive, because the presenter posed questions to the participants that started dynamic brainstorming discussions and she provided opportunity for participants to ask practical questions, which further stimulated the conversation.

Quote:

"I liked it today because I felt that I was in more control of what I could do...like diet, exercise, quitting smoking and the cutting down the drink and all the things that would help you to counteract any cancers starting. The information we received today...it was not overwhelming, it was something that I understood right away and something that I could control myself." —PREVIOUSLY INCARCERATED PARTICIPANT

2. **Health risks of tobacco presentation:** The presentation from Quit Now BC’s educator focused on smoking, how it relates to cancer risk, and practical methods to help participants quit, including available no-cost community quit smoking services, such as a helpline that connects clients with nicotine replacement therapy and motivational coaching. The presentation concluded with an experiential learning activity, in which participants used a carbon monoxide (CO) monitor (similar to a breathalyser machine) to read the amount of CO in their lungs. Participants discussed with the educator what their reading meant, and how it related to their cigarette use and lung health.
-

Quotes:

“I got a lot of positive stuff today about the healthy diet, exercising and about the smoking. I’ve got to quit smoking, I’ve been a smoker for 55 years and it’s gotta come to a halt. I found out lots of information here on what’s the right stuff to eat and where to go for smoke cessation projects, so I found the whole thing interesting and helpful to me.” —PREVIOUSLY INCARCERATED PARTICIPANT

“I think that part of what made the workshop successful today was everybody knows you shouldn’t smoke, or you should use sunscreen, but I think that they gave us a bit of a solution, they didn’t just tell us what you should and shouldn’t be doing; they gave us a solution, they gave us a tool, tools to get there.”

—PREVIOUSLY INCARCERATED PARTICIPANT

3. **Team-building and experiential learning exercise: “*Crossing the River*” game:** The health educators facilitated the ‘Crossing the River’ game, a fun activity that illustrates goal-setting and peer support and was well received by workshop participants.

‘Crossing the River’ game: Each person identified one goal that he or she wanted to set related to reducing their cancer risk. Examples included decreasing smoking by five cigarettes per day, going for a walk with a friend once per week, or eating a piece of fruit with breakfast. All participants wrote their goal on a sticky note and placed their sticky note on a square of carpet, which was referred to as a ‘stepping stone.’ Meanwhile, the educators laid out two long ropes that represented a river. To play the game, one person put down his or her ‘stepping stone’ at the edge of the ‘river’ and announced the health goal. The following person put one foot on the existing stepping stone, and placed his or her stepping stone ahead. Every participant then followed in a line, putting down stepping stones to pave the way across the ‘river.’ If a stepping stone was not underfoot, it washed away. The game required discussion, planning and cooperation, so as to not lose stepping stones or let anyone ‘fall in the river.’ By reading aloud their goals, participants took ownership of and accountability for their goal. The team approach to crossing the river represented the peer support that is often needed to accomplish health goals.

Materials required: Two three meter ropes, sticky notes, and squares of carpet (alternatively write on paper plates for the ‘stepping stones’), and markers.

Reflection

Everyone had a good time working on this exercise and it was especially rewarding to see participants working with each other, staff working with participants and expert guests who brought the activity to the workshop. No one was left out and this fostered cooperation, planning and a deeper trust, sharing, and cooperation between everyone involved. —LARRY, COMMUNITY-BASED PROJECT ASSISTANT

4. **Peer-led presentation #1 - *Marnie's Health Tips***: The peer-led component of the workshop was an original presentation led by one of the CB project assistants about nutrition and physical activity, which Marnie researched, developed and presented. Her PowerPoint presentation contained practical, simplified nutrition tips, such as using your thumb, palm and fist to estimate appropriate portion sizes. Marnie described the dramatic health improvements she had experienced since leaving prison by changing her eating habits, framing the nutrition tips as essential components of her personal success story. The presentation was personable and relatable, and provided both knowledge and inspiration to the participants. Focus groups following the workshop revealed that Marnie's presentation was the preferred component of the workshop.
-

Quote:

"It's easier to hear from your peers, as someone who's actually really experienced it and not somebody who's read it in the textbook... it to me touches home when one of my peers talks about stuff."


—PREVIOUSLY INCARCERATED PARTICIPANT

5. **Peer-led presentation #2 - *Prison Exercise by Larry***: Larry reflected with the group on the importance of exercise while incarcerated, and the innovative ways to do so in prison. Participants shared their stories about working out in prison with limited resources, which led to a discussion about how people can find easy ways to exercise in their daily lives without having to buy a gym membership or fancy equipment. For example, Larry shared that when he was incarcerated, he used to stand in a doorframe and push with the backs of his hands into the frame, or push with his palms into the doorframe, causing isometric contractions. This exercise activity is something that is easy to do anywhere. Larry's presentation was critical in making the BCCA presentation about the importance of exercise relatable to the participants, while offering practical tips on how to incorporate more physical activity into their lives. To complement his presentation, Larry created a handout called Any Port in a Storm: How to Exercise with Limited Opportunity and Equipment. The handout included a reflection on how Larry found innovative ways to exercise while in prison.
-

Reflection:

Access to proper exercise equipment can be very difficult for incarcerated individuals as well as those recently released back into the community. By demonstrating how easy it can be to get a good workout in virtually any environment I hoped to provide participants with knowledge that could be put to good use daily without prohibitive costs. The benefits associated with a healthy workout routine are numerous. Proper exercise allows the individual to maintain a healthy, trim and good looking physique or body. This is a tremendous boost for individual self-esteem, helps deal with laziness, and is an effective way to deal with boredom too. There is much to be said for the old adage that a healthy body spawns a healthy mind. —LARRY, COMMUNITY-BASED PROJECT ASSISTANT

6. **Fitness Challenge**: The purpose of proposing the fitness challenge, and providing the equipment was to reduce barriers that had been identified by the CB project assistants regarding physical activity. These barriers include: lack of interest or motivation; lack of resources/equipment; lack of knowledge about fitness and exercise; and no one to be accountable to. The project team designed a fitness challenge to encourage participants to set goals and track their physical activity on a tracking card over the following month. We suggested that participants buddy up with a friend or acquaintance to increase motivation and



accountability in achieving their goals. For example, commit to going for a walk with that person twice per week! We presented our challenge alongside handing out activity equipment. Participants selected an exercise ball, a pedometer, or resistance bands, whatever equipment suited them best. Simple instructions accompanied the equipment. As an added motivation, everyone who completed a health challenge card was entered into a draw. The prize was a gift basket, which contained a selection of healthy snacks.

What we learned

- Participants valued receiving practical tools and ideas on how to implement changes and achieve their health goals;
- Community health educators bring valuable knowledge and expertise about community health resources;
- Participants were responsive to peer-led presentations and activities;
- Timing is important. Leave enough time for transitions between activities and speakers, as well as a buffer in case interactive activities run over;
- Allow sufficient time for discussion and questions following presentations and activities;
- Comprehensive communication strategies are essential to ensure workshops are well attended; The project team used email, Facebook, peer outreach, email, and phone calls for maximum reach. (Please see the communication section for more details)

WORKSHOP 3: CANCER SCREENING

Screening rates among previously incarcerated individuals are low when compared with population cancer screening rates. Therefore, implementing a workshop that focused on cancer screening was identified as an important topic to accompany the cancer prevention workshop. There are three cancer screening programs in BC: breast by mammograms; cervical by Pap tests; and colon by FIT (Fecal Immunochemical Test).

Workshop Objectives

- Increase awareness around breast, cervical and colon cancer screening;
- Increase number of participants who participate in cancer screening;
- Increase general cancer awareness (signs, symptoms, and changes to be aware of relating to other cancers);
- Identify barriers and fears regarding screening;
- Dispel myths relating to cancer screening; and,
- Provide information about screening in a number of different modes (video, lecture, small and large group discussions).

Workshop Delivery Styles

- Community organization
- Experiential learning
- Health care provider
- Multimedia
- Peer-led

Workshop Resources

- Computer demo of how to find a family doctor (College of Physicians and Surgeons of BC website)
- 'Dodging the Barriers' game
- Sample colon cancer screening kit (FIT test)
- YouTube clips (screening methods)
- Cancer awareness wristbands with outreach information card
- Handouts for health resource binder
- Memo-to-Myself

Workshop Activities

1. **Screening education presentation:** A health educator from BCCA gave a short PowerPoint presentation on the guidelines for breast, cervical, and colon cancer. She also included some information on general cancer awareness such as what changes to look for and be aware of in your body. She illustrated the importance of getting screened by presenting facts and prevalence rates, which highlighted the effectiveness of screening for catching and treating cancer early.
2. **Discussion groups:** The three CB project assistants facilitated small group discussions, during which they asked participants to share what they had learned so far, and what information they would share with family and friends. The discussion facilitated deeper learning and integration of the information. The CB project assistants also facilitated discussion about peoples' barriers (past and anticipated) regarding screening, which encouraged dialogue about ways to overcome these barriers. The discussion also laid the foundation for the 'Dodging the Barriers' game.

3. **Team-building and experiential learning exercise - ‘Dodging the Barriers’ game:** The BCCA health educator passed around a small toy to participants to represent a “barrier” that they face or have faced related to being screened for cancer. The facilitator roped off a section of the floor, and everyone announced their barrier (for example, “fear”) and tossed the toy into the roped area. Participants then paired up: one member of the pair closed their eyes while their partner directed them through the channel, telling them where to step so they would avoid stepping on a barrier and having to start over again. Both partners had a chance to participate. The BCCA health educator concluded the exercise by describing how people experience all sorts of barriers to getting screened for cancer. The game illustrated that sometimes all you need is the support from someone you trust to guide you around the barriers and help you reach your goal.

Materials required: Rope, small toys that don’t roll away (like beanbags)

Reflection:

The ‘Dodging the Barriers’ game shows that people experience all sorts of barriers to getting screened for cancer, and it can be difficult to motivate yourself to be screened when there are so many barriers ahead of you. Sometimes all you need is support from someone you trust to guide you around the barriers and help you reach the end point. For example, female friends could schedule time to get a mammogram together, or someone could accompany their parent to an appointment to pick up a FIT kit. There will be noise in the background distracting you from accomplishing the task of getting screened. Sometimes you can tune it out, but other times the noise will get you off track. You can always start the process of getting screened again.

—ALEX, PROJECT ASSISTANT



Figure 8: Project assistants, Alex and Wendy, at one of the cancer screening info stations.

Quote:

“I think [it allowed us to] basically move past any fears or misconceptions that I may have about screening and having the procedures done, and share that information with you know, friends and family.”

—PREVIOUSLY INCARCERATED PARTICIPANT

- 4. Screening info stations:** Small groups rotated between three stations where each of the three screening procedures, mammogram, FIT, and pap tests, are described in detail. A YouTube video of what to expect during each procedure was shown, with opportunities to ask questions. At the colon screening station, a FIT test kit was available for people to see. The hope was that by seeing the screening materials, some of the unfamiliarity and/or fear would be removed, thereby increasing the likelihood that people would engage in this test. Given that a family doctor is required in order for cancer screening and/or follow-up of results in BC, we also incorporated five minutes into the first station for a discussion of how to find a family doctor. Using laptop computers, the facilitator demonstrated how to find a doctor that was accepting new patients on the College of Physicians and Surgeons of BC website (<https://www.cpsbc.ca>). We also provided information on where participants could go for each of the tests.

What we learned

- Cancer screening education needs to be designed to decrease fear around the unknown of what cancer screening is and what it means;
- Misinformation about cancer screening existed among some participants. For example, many thought a colonoscopy was the only way to screen for colon cancer;
- Teaching a practical skill such as demonstrating how to find a family doctor online, and allowing time for participants to practice doing it online themselves, shows individuals how they can take action for their own health care;
- Providing basic information on screening locations and how to book an appointment is a step towards reducing barriers to cancer screening.

Where do you go for a...

Pap test? You can get one at a family doctor’s office, walk-in clinic, or nurse practitioner clinic in BC.

Mammogram? Visit a mammogram clinic. There are many around the Lower Mainland. A family doctor or clinic is required for follow-up, as well as a BC care card number.

FIT test? You can do it at home! First you get a referral from a doctor, then pick up the kit at a lab. You collect the sample at home, and then return the sample to the lab.

Tip: The BC Screening Mammography Program offers a mobile screening van, which goes to convenient public places. For groups of women, arrangements may be made for the van to come to requested locations. The BC Cancer Agency offers this service to marginalized or difficult to reach women. The Screening Mammography Program can be contacted at 1-800-663-9203.

For the most up-to-date information about cancer screening in BC, please visit www.bccancer.bc.ca

EVALUATION

An evaluation plan was developed during for the funding proposal stage of this project. The plan, which included five objectives with the expected results, success indicators, and data collection tools, provided a roadmap for the team to evaluate the project. However, in keeping with the participatory nature of the project, the specific data collection tools, questionnaires, and focus group questions were developed in partnership with the academic team, the project staff team, and the PAC once funding was received.

Evaluation methods

The project team decided to use a multi-method approach to evaluation that included both quantitative and qualitative methods of data collection.

1. Survey questionnaires, pre- and post-project
2. Workshop attendance
3. Workshop satisfaction Likert scale surveys
4. Focus group discussions
5. Project team reflections

1. Survey questionnaires

- Demographics
- Knowledge about cancer and cancer screening guidelines
- Health behaviours
- Cancer screening behaviours

Prior to participating in any of the project activities all participants were surveyed by the CB project assistants or the project coordinators. The surveys were completed with the assistance of a project team member. Although the surveys were self-explanatory, we found that the participants generally welcomed the opportunity to complete their survey with the project assistant or coordinator and deliver responses verbally rather than in writing.

The demographic survey included questions about participants' age, education, housing, ancestry, gender, and number of year incarcerated. The remaining surveys examined the participants' knowledge and attitudes towards health care providers; cancer knowledge and screening guidelines; health behaviours such as eating and physical activity habits; and, cancer screening behaviours such as whether screening rates increased after participating in the project. Participants were also surveyed on all these issues at the end of the project.

2. Workshop attendance

Each participant signed the attendance sheet when they arrived at the workshop and when the workshop was complete. The attendance record allowed us to monitor how many people were in attendance throughout the project.

3. Workshop satisfaction Likert scale surveys

A six-question survey was given at the end of each workshop asking participants general questions about whether they found the workshop useful; if they learned something new about their health; if they would share the information with friends and family; and if people inside prison would find the information useful. We also included two questions about whether the participants found the Memo-to-Myself useful and if they achieved at least one of their health goals they had set at the previous workshop. We used a five-point Likert scale that allowed participants to express how much they agreed or disagreed with the statement.

4. Focus group discussions

We held small focus group discussions after each workshop. We asked participants to provide feedback on the workshop delivery style, content, materials, and if they thought the workshop would be useful for people who are currently in prison. This recorded information was transcribed and used to inform and improve future workshops.

5. Project team reflection

Weekly team reflections allowed the project staff team to iteratively provide feedback about the project details, including data collection, safety protocol, and workshop delivery and content.

Who collected the data?

Survey questionnaires

The CB project assistants and the project coordinators conducted the survey questionnaires in the community. In the Greater Vancouver area, the surveys were done in various locations in Mission, Surrey, New Westminster, and Vancouver. In Nanaimo, all surveys were done at the Nanaimo Public Library in one or two private rooms.

Prior to conducting the survey questionnaires, the project coordinators held a skill-building session to ensure the CB project assistants were familiar with the procedures required to collect information ethically and accurately.

Safety was a priority when we were in the community. Therefore, protocols were put in place to maximise safety of the project staff and participants. We established a buddy rule, ensuring no one did project activities on their own, such as conducting surveys with participants, handling cash, and travelling to and from workshops.

Focus group discussions

Members of the academic team and the project staff team conducted 30-minute focus group discussions after each of the workshops. A member of the academic team skilled in the facilitation process held a skill-building workshop with the project staff team to discuss effective facilitation. Building facilitation capacity benefited our project staff team members and the effectiveness of project delivery.

Prior to each workshop, we held a short meeting to hand out the facilitator packages which included the Focus Group Instruction Guide with focus group questions, an audio recorder, the workshop satisfaction Likert scale surveys, the Memo-to-Myself with the SMART Goal Setting handout, and pens. Facilitators were asked to introduce themselves and go through the focus group discussion guidelines before starting the discussion.

Each facilitator emphasized the following guidelines prior to starting his or her focus group discussion:

- Everyone's views were welcomed and important;
- We asked that the information discussed remain confidential and not be discussed outside the group;
- If quotes from participants were used later, they would not be identified by name or location to protect the identity of the speaker;
- We asked that participants only discuss what they would be comfortable saying in a public setting;
- All voices were to be heard, so the facilitator would step in if too many people were speaking at once or to make sure that everyone had a chance to speak.

**Focus group tips:**

- Check that the recorder is on during the focus group. Take a moment early in the discussion to ensure that your recorder is recording. Have a project staff member available to assist the facilitator if needed.
- Have each participant state their name every time they speak and to pass the recorder to the next speaker, instead of having it on the table. This will produce a clearer recording and thus ensure more accurate transcribing.
- If the discussion is going well the focus group discussion can go for an additional five-to-ten minutes past the allotted time – all comments are valuable. Participants are free to leave at any point in the discussion.

SHARING WHAT WE HAVE LEARNED

Sharing what we have learned with the public, health care providers, researchers, and local and national stakeholders has been an integral part of this project, especially during the second year. The main vehicles of knowledge dissemination included:

- Health Beyond Bars: Towards Healthy Prisons in Canada, a conference and public forum hosted by the Collaborating Centre for Prison Health and Education (CCPHE)
- *Cancer Walks Free* documentary film
- Arresting Cancer: Using community-based participatory approaches to improve cancer screening and awareness with formerly incarcerated men and women, this 'how-to' manual

Our findings were also shared at multiple times during the project through multiple venues including:

- Project Advisory Committee (PAC) meetings
- Media engagement activities
- Academic conferences, meetings, and publications

Health Beyond Bars: Towards Healthy Prisons in Canada: The CCPHE hosted a two-day dissemination conference and public forum at the University of British Columbia, Vancouver, British Columbia, on February 20-21, 2014. The event brought together 132 attendees from diverse backgrounds, including health care providers, individuals with incarceration history, policy and decision makers, academic researchers, and community, health, and correctional professionals. All participants in this project were invited to attend the conference and the public forum where the project team presented the findings, and what we learned from engaging in community-based participatory processes together. Five previously incarcerated project participants chose to speak at the conference about their personal health narrative and involvement in this project. Sharing their stories reminded us of the challenges, the pain, and the courage that breathes within the work that calls us together to create a healthy community.

The Health Beyond Bars conference objectives were as follows:

- Include relevant stakeholders and sectors in a conference that will highlight participatory approaches to preventive prison health;
- Disseminate findings from the CCPHE participatory prison health projects;
- Promote a national dialogue on the feasibility of uptake of similar preventive health initiatives for individuals with incarceration experience in the community and within correctional institutions;
- Foster collaborative networking and dialogue opportunities between conference participants in order to improve the health of incarcerated individuals and those who are integrating back into the community.

Conference proceedings will be available on the CCPHE website by fall 2014 at <http://www.ccphe.ubc.ca>

Cancer Walks Free: This 12-minute documentary film aimed to raise awareness about cancer screening amongst previously incarcerated men and women. The film also aimed to convey to health care providers the unique fears and cancer risk factors that individuals with incarceration history face. *Cancer Walks Free* was used as a method of knowledge dissemination because of its ability to reach a broad audience, including project stakeholders and the general public. The film was first screened at the Health Beyond Bars public forum and had a significant impact on the audience, which was comprised of community

members, health care providers, academics, and individuals with incarceration history.

Audience members shared the following quotes after viewing *Cancer Walks Free* and participating in the public forum:

“The film hit home for me the prevalence and dangers of untreated or late detected cancer both within the community and behind bars. It serves as a reminder of the health inequities and barriers to care that people with incarceration experience endure.”

“I think the most valuable part of the public forum was the diversity among attendees and their backgrounds and organizations. The number of people that showed up and participated was a demonstration of people’s basic humanity and interest in a very tough topic.”

Cancer Walks Free is available to view online:

<https://www.youtube.com/watch?v=vJKloTHFAko&feature=youtu.be>

Project Advisory Committee (PAC) meetings: Quarterly PAC meetings provided a venue to disseminate knowledge to committee members, who were key policy stakeholders, community, health and corrections professionals, and formerly incarcerated previously incarcerated individuals who were committed to our project. The PAC met multiple times throughout this project allowing for feedback and advice from the PAC as we moved forward. PAC members benefited from the information we shared directly with them and whenever possible, they would share what we had learned within their organizations.

Media engagement activities: Media dissemination strategies included a 60 minute interview on Vancouver Co-operative Radio, CFRO, with one academic team member and one CB project assistant. The interview coincided with the Health Beyond Bars conference and public forum and brought attention to this project’s collaborative work with formerly incarcerated men and women.

Academic conferences, meetings, and publications: In order to share our learning with health researchers, health care providers, and policymakers, members of the project team have presented at national and local academic conferences and meetings. Whenever possible, the CB project assistants have co-presented with other project team members as their voices, experience and insights enrich the impact of the presentations. We plan to submit articles to peer-reviewed academic journals to further share the knowledge we have gained during our project. All team members who contribute to the writing of the articles will be included as co-authors.

CONCLUSION

This project illustrates the value of using a community-based model and participatory processes when engaging formerly incarcerated men and women in a cancer-focused project. Engaging in participatory processes empowers formerly incarcerated men and women to effect change, not only for themselves and their peers, but also for the larger community. Our findings showed that the men and women who participated in this project were motivated to engage in discussions on cancer screening and participate in awareness activities. They were also keen to share the information they learned with their friends and families, and to contribute to the health and well-being of individuals who are still incarcerated. Working within community identified areas for intervention, we hope this project becomes more meaningful to the population that it serves. We truly hope that individuals and organizations will be able to use the learning and experiences we have shared in our manual for planning their own community-based participatory projects.

THE COLLABORATIVE PROJECT TEAM

This project was made possible through the collaborative efforts of the academic team, the project staff team, and the Project Advisory Committee.

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