

'Let's Talk About Cancer'

*A pop up shop pilot
project in
Melbourne's West*



Sunshine cancer pop up shop. Image credit: Tessa van der Riet

North Western Melbourne PHN acknowledges the participation and contributions of Cancer Council Victoria, Western Health, and IPC Health



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1 Abbreviations

AHPC – Australian Health Policy Collaboration

CALD – Culturally and Linguistically Diverse

CCV – Cancer Council Victoria

DHHS – Department of Health and Human Services (Victoria)

GP – General Practitioner

IPC Health – Improving and Promoting Community Health

NFD – Not further defined

NMSC – Non-melanoma skin cancer

NWMPHN – North Western Melbourne Primary Health Network

NHS – National Health Service (England)

TIS – Translating and Interpreting Service

UK – United Kingdom

“Fabulous idea. Came in to ask a question about my mother who has breast cancer and was given lots of information from the nurse. I think there should be lots more shops like this.”

– Participant, Sunshine shop

“I had a young lady come in who admitted to just wanting to see what the shop was about. I ended up having a really long conversation with her about her cancer and how overwhelmed she still felt. We linked her in with the Healthy Living after Cancer Program and Cancer Connect (telephone-based peer support) and advised as to how to get some psychological counselling. After a few tears she felt very relieved she was going to get some help.”

– Pop up shop cancer nurse

2 Background

2.1 Introduction

Cancer outcomes in Victoria are improving, with the all-cancer five-year survival rate reaching 69% in 2016. However, cancer remains the leading cause of death in Victoria, and Aboriginal and Torres Strait Islander Victorians continue to die of cancer at rates significantly higher than that of non-Indigenous Victorians.

The Victorian Cancer Plan 2016-2020 identifies an increase in early diagnosis through screening and early detection, and the reduction of cancer risks through primary prevention, as priority areas for the Victorian Department of Health and Human Services (DHHS).¹

Research suggests that a combination of public education about symptoms and empowerment to seek medical advice, as well as support at the primary care level, could enhance early presentation and improve cancer outcomes.²

An innovative cancer initiative, the ‘Get to know cancer’ pop up shop, was trialled in the United Kingdom in 2012 and 2013. The individual cancer pop up shops were located in local shopping strips or centres, in a non-medical environment. The shops were staffed by specialist cancer nurses, public health nurses and volunteers.

The UK project was commissioned in response to regional and ethnic disparities in cancer outcomes and lower rates of cancer survival in the UK compared with other countries in Europe. These disparities and survival rates were linked to later stage presentation for cancer and lower screening rates, with consequent lower survival rates. The UK pop up shop sought to address cancer disparities

¹ Department of Health and Human Services 2016, *Victorian cancer plan 2016-2020. Improving cancer outcomes for all Victorians*, State Government of Victoria, Melbourne.

² Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J, Hiom S & Wardle J 2009, *Public awareness of cancer in Britain: a population-based survey of adults*, *British Journal of Cancer*; Volume 101 S18–S23.

through a community-facing project that promoted the importance of early diagnosis by raising awareness of the importance of stage of diagnosis on survival rates and that allowed for the delivery of cancer messages in a non-medical format.

The key findings of the NHS model on evaluation were:

- Visitors felt confident they knew the symptoms of cancer in general but knew less about symptoms of specific cancers
- The shop was well-received and encouraged people to talk about cancer in a non-clinical environment conveniently located in the community
- That the format encouraged people to visit their GP with symptoms indicative of cancer³

Following the success of the UK shops, DHHS proposed a trial of similar shops and commissioned North Western Melbourne Primary Health Network (NWMPHN) to develop, implement, and evaluate two cancer pop up shops in the Western suburbs of Melbourne. NWMPHN was provided with a one-off grant for this purpose.

2.2 Project Objectives

The objectives set by DHHS at the start of the project were to:

- Test the appropriateness and acceptability of the pop up shop model in Victoria
- Increase the early diagnosis of cancer
- Increase understanding and awareness of the risk factors, signs, symptoms and causes of cancer
- Deliver positive health messages to local communities
- Reduce fear and stigma associated with cancer
- Focus on the hard to reach / culturally and linguistically diverse (CALD) / lower socio-economic populations

A positive change in knowledge about cancer, prevention strategies and screening at a population level was hypothesised to increase early stage presentations and decrease cancer incidence through modification of lifestyle factors.

If the project was implemented effectively, the expected outcomes were to:

- Improve knowledge of cancer risk factors, screening, and prevention in the community
- Change individuals' health seeking behaviours
- Increase uptake of cancer screening programs

2.3 Cancer pop up shop model

A 'pop up shop' is a short-term shop supported by advertising or other promotion. The format is designed to generate interest and attention for a brand or organisation and is a means to reach populations directly without the expenses of an ongoing shopfront.

³ E Scott, L Boyd, E Wallace, E Ream, J Armes; Evaluation of the 'Get to know cancer' pop up shop initiative (London, 2013): Jo Armes, *European Journal of Public Health*, Volume 23, 2013

The Melbourne cancer pop up shop was based on the UK 'Get to Know Cancer' pop up shops with some minor changes. The mix of specialist cancer nurses, community health nurses and volunteers remained the same, as did the location in areas of easy access. The pop-up shop model allowed for an open-ended range of cancer conversations among a diverse population. Some of the differences between the Melbourne model and its UK predecessor are outlined in the methods section of this report.

2.4 Partnerships

A fundamental aspect of the Melbourne 'Let's Talk About Cancer' pop up shops was the development of a partnership approach between a range of organisations with an interest in decreasing the impact of cancer in Melbourne's West. A collaboration between DHHS, NWMPHN, Cancer Council Victoria (CCV), Western Health, and Improving and Promoting Community Health (IPC Health) was formed to develop and implement the cancer pop up shops in Melbourne.

Department of Health and Human Services

DHHS is a department of the Victorian Government that works to enhance the health, wellbeing and safety of all Victorians so that they can lead a life they value.

Through DHHS, the Victorian Government invests in a range of reforms and actions to reduce cancer incidence and mortality, improve access to quality detection, screening and treatment services and to enhance the quality of life of those affected by cancer. This approach to cancer control encompasses specific programs across:

- The prevention, detection, diagnosis and treatment of cancer and its precursors
- The ongoing management of cancer, rehabilitation, and the provision of end-of-life care
- Cancer research and its application
- Cancer-related policy, the organisation of services, planning and service development, and
- Innovation, quality improvement and evaluation

The need for improved delivery of cancer services along with improved outcomes for patients and their families has been identified as a priority for both state and federal governments.

DHHS was the project sponsor of the pop up shop pilot project, with funding and oversight responsibilities.

North Western Melbourne Primary Health Network

NWPHN is an Australian Government health agency with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes and improving the coordination of care to ensure patients receive the care that they need at the right time and in the right place.

Among others, NWMPHN's goals are to:

- Respond to local and national priorities to reduce the burden of disease and improve population health outcomes
- Improve integration and coordination of care across the continuum

NWMPHN does this by identifying and understanding the priority needs in the region and supporting, developing, innovating, coordinating and measuring service responses to address priorities. NWMPHN

works closely and collaboratively with federal, state, and local governments and other health agencies and providers.

NWMPHN was the lead agency in the development and implementation of the cancer pop up shop project in part due to its close links with healthcare providers and cancer services in the region. NWMPHN employed a project manager who was responsible for the day to day organisation and management of the project.

Western Health

Western Health is the largest provider of hospital care services in the western suburbs of Melbourne, managing three acute public hospitals and a wide range of community-based services. It is the largest integrated health provider in the fastest-growing region in Victoria.

Western Health provided the core specialist nursing staff to the Pop up shop project. One nurse staffed the shop in Sunshine for all four weeks and two nurses job-shared the Caroline Springs shop, providing continuity amongst an otherwise rotating workforce of volunteers and other nurses. The Western Health nurses were from Ambulatory Cancer Services – Day Oncology, and the Symptom Urgent Review Clinic. Both nurses had over ten years of acute clinical experience and provided expert advice, information and support to members of the public. The nurses contributed their extensive oncology and haematology experience and their knowledge of services available in the region. One nurse was able to speak multiple languages other than English, which was desirable but not essential to the nursing skill-set. The Western Health nurses received training from CCV in assisting with cancer-related enquiries from the public.

Western Health is home to an award-winning volunteer program, with over 600 volunteers, many of whom speak languages other than English. Western Health provided 25 volunteers experienced in providing information to the public. Within the volunteer pool helping in the pop up shops, they spoke 12 languages other than English. Volunteers underwent training prior to the start of both shops. Management and rostering of volunteers was undertaken by Western Health's manager of volunteers, who worked extensively with the project manager in the lead up to both shops.

Cancer Council Victoria

Cancer Council Victoria is an independent, not-for-profit organisation with an international reputation for innovative work in cancer research, prevention and support. CCV plays a leading role in reducing the impact of all cancers on all people.

As part of their support arm, CCV offers an information and support telephone line staffed by experienced cancer nurses. Nurses talk about the effects of specific types of cancer and can explain what will happen during processes like chemotherapy, radiotherapy or other cancer treatments. They do not give individual medical advice. CCV provides a broad range of support services such as financial and legal support, peer support programs, a holiday break program, a wig service and many more.

CCV provided nurses from their information and support line, training and advice to the Cancer Pop up shop project. Nurses were rostered on to the pop up shop Tuesdays to Fridays, and provided expert advice, information and support to members of the public as well as referral to CCV and other health services and programs.

CCV provided training to the two Western Health nurses, including time spent shadowing CCV nurses staffing their information and support line, and to the volunteers from Western Health before each of the two shops.

A range of CCV information resources were provided at the shop. These included a large range of brochures in English, Aboriginal-specific resources and resource packs, and multilingual translations of cancer resources.

IPC Health

IPC Health is a community health organisation based in Western Metropolitan Melbourne, delivering primary health care, practical health promotion and primary prevention initiatives to diverse communities with complex health and social needs with six principal sites and over 400 staff, IPC Health predominantly services the local government areas of Brimbank, Hobsons Bay and Wyndham. IPC Health provides quality health care accessible to all who need it, with a priority towards those who experience disadvantage and greater health disparities.

For the cancer pop up shop program, IPC Health provided staff from their youth and women’s health team and their living well team to provide in-shop consultations and referrals to prevention services.

The youth and women’s health team influence the health and wellbeing of community members to make informed choices about their health. Their role includes educating and promoting the uptake of free Government funded cancer screening initiatives such as cervical screening, mammogram via BreastScreen, bowel cancer screening and chlamydia testing.

The living well team work with clients in the early stages of chronic disease and those with risk factors for chronic disease and work to improve their capacity for self-management.

IPC Health also provided a clinical psychologist for debriefing of all staff involved in the cancer pop up shop.



A Western Health volunteer speaks with the public. Image: Tessa van der Riet

2.5 Project management

Direct day-to-day project management was undertaken by NWMPHN.

A part-time project manager was employed to develop and implement the project over a period of one year from September 2017.

The project manager was involved in all aspects of the shop from location, to design and implementation, including development of documentation, budget development and management, contract oversight, partnerships, media, and stakeholder relationships. The project manager was day-to-day manager of the two shops, interactions with staff and volunteers and undertaking activities not included in their position descriptions.

The project manager provided updates on the status of the project and tracked progress against anticipated outputs and outcomes. Regular meetings were held with the NWMPHN manager and with DHHS to ensure continuity of direction and update the Department on budget and operational matters. The project manager collected feedback from stakeholders, shop participants, nurses and volunteers.

NWMPHN provided considerable in-kind support through a range of teams and individuals. The project manager was line-managed and supported by a NWMPHN manager with other cancer responsibilities and who provided assistance and expertise to the project. Other supporting staff included cancer project officers, media and communications team, finance and contracts team, Health Systems Integration manager, Aboriginal liaison, and administration staff.

2.6 Governance

The table below outlines the make-up of the project team and partner organisations, and their key responsibilities.

ROLE	ORGANISATION	PROJECT RESPONSIBILITIES
Project Sponsor	DHHS	<ul style="list-style-type: none"> • Advise on top-down objectives and vision for the project as required • Oversight of project • Chair of steering group
Lead agency	NWMPHN	<ul style="list-style-type: none"> • Fund holder, budget management, management of project risks • Project Manager <ul style="list-style-type: none"> ○ Contracts management ○ Shop design ○ Printed materials development and design ○ Shop management ○ Stakeholder management ○ Data and analysis ○ Report writing • Implementation and reporting • Pop-up toolkit development

ROLE	ORGANISATION	PROJECT RESPONSIBILITIES
		<ul style="list-style-type: none"> • Contract development and oversight • Media and communications
Steering Group	DHHS, NWMPHN, Cancer Council Victoria, Western Health, consumer representative, volunteer representative (Western Health), academic (University of Melbourne)	<ul style="list-style-type: none"> • Provide expert advice on cancer and project management • Review of plans and documents • Monitoring and evaluation • Consumer feedback
Partner organisations	Western Health	<ul style="list-style-type: none"> • Provide nursing staff for pop up shop • Provide volunteers • Provide resources • Train volunteers • Manage Western Health nurses and volunteers • Participate in steering group
	Cancer Council Victoria	<ul style="list-style-type: none"> • Provide nursing staff for pop up shop • Train Western Health nurses and volunteers • Provide information resources • Manage CCV nurses • Participate in steering group
	IPC Health	<ul style="list-style-type: none"> • Provide community health nurses and Living Well coaches • Provide resources • Provide clinical psychologist for staff debriefing and counselling • Participate in steering group

2.7 Steering Group

The project steering group was convened in July 2017 to oversee the development, operation and evaluation of the two pilot pop up shops.

This group consisted of representatives from all participating organisations, a volunteer representative, a consumer representative/Aboriginal Liaison Officer, and a senior academic. The steering group brought considerable experience across government, primary health, acute health, community health, nursing, cancer and prevention fields. The project steering group was fortunate to hear a presentation from Dr. Jo Armes of the University of Surrey, who was involved with the original NHS project. Dr. Armes evaluated the NHS project and provided information on the strengths and limitations of the project to the steering group.

Meetings were held bimonthly and chaired by DHHS. Location was alternated between DHHS and NWMPHN, with a single meeting held at Western Health following training at their campus.

Final decision making on strategic direction rested with DHHS, with due consideration given to the strategic advice provided by the steering group.

Out of session decision making was required in instances where input or advice was sought from the steering group members between scheduled meetings.

2.8 Budget

NWMPHN was provided with a one-off grant of \$209,800 to enable the development, implementation, and evaluation of the pilot project. A further \$20,000 was provided during the project to fund the development of a resource toolkit. Budget was included for staffing costs including nurses, expected project implementation costs, and overheads. A financial acquittal of the project will be provided on completion of the project.

An indicative sample budget is contained in the *Pop Up Shop Resource Toolkit*.

“I spoke with a lady in her 60s who let me know that she had never screened before in any program (breast, cervical or bowel), and said that her main barrier was the embarrassment and anxiousness, but also not knowing where to go. We provided her with information, some education on the importance of screening and risk factors, and she left saying she would read it all, and felt more prepared and able to follow up and make the necessary appointments.”

– Pop up shop cancer nurse

3 Methods

3.1 Adaptation of shop model

The model chosen for the project was that of a short-term consumer-focused shop to promote greater cancer awareness, uptake of screening and access to timely cancer care in a non-medical environment.

The Melbourne project was inspired by the UK ‘Get to know cancer’ shops outlined in the introduction, however there was no access to their resources and only limited transfer of knowledge through websites and publications.

The UK shops aimed to reduce fear of cancer and promote the importance of early diagnosis by raising awareness that survival rates are improved when cancer is diagnosed early. The shops also focused on increasing awareness of common cancer symptoms and prevention of cancer through healthy living. The shops included BMI measurement and blood-pressure checks, which were not included in the Let’s Talk About Cancer shops as it was decided that the provision of health checks could mean the shops were interpreted as a health service. The Melbourne ‘Let’s Talk About Cancer’ shops also had a stronger multicultural and multilingual focus than the UK shops, and were based in malls rather than shopping strips.

The Melbourne cancer pop up shops provided information, support and referral, with any participants requiring treatment or diagnosis referred on to appropriate services within the local community. The Melbourne cancer pop up shops also had a wide focus across a range of cancer topics.

The physical space of the shop was designed to be friendly and inviting, non-threatening, and non-medical, and the UK shops were used as inspiration for the design. Bright colours and simple motifs were used to convey this idea as well as couches to sit and have a conversation. Tea, coffee and fruit were available to encourage people to stay, relax and have a conversation.

3.1 Shop location

Two trial sites were chosen in Melbourne's west in areas of high relative deprivation and culturally and linguistically diverse populations. The location was informed by maps sourced from the Australian Health Policy Collaboration⁴ (AHPC) and the demographic consultancy Id.⁵ The AHPC maps illustrated cancer outcomes for a range of cancers and screening measures, and mapped risk factors including obesity, sedentary behaviour and tobacco use. The Id demographic consultancy utilised Australian Bureau of Statistics data on measures of deprivation and cultural and linguistic diversity.

Mapping information was used in conjunction with the availability of shop sites to guide decisions on shop location. Another factor impacting shop location was distance from Western Health's volunteers, many of whom rely on public transport, and on this basis some of the more distant sites were excluded from consideration.

A total of nineteen possible candidate shopping areas in Melbourne's west were identified and considered. Each of these sites was visited and inspected by the project manager to determine their suitability.

Shop selection was significantly constrained by the availability of commercial real estate for short term lease. This prevented a proactive approach to site selection as many of the larger and busier shopping areas had few retail vacancies and would not consider a 6-week lease even if a space became available. A considerable amount of time was spent by the project manager liaising with real estate agents and shopping centre managers. Malls in Melbourne frequently sell centre-of-mall temporary leasing in pedestrian areas, and leasing managers were keen to lease these spaces to the project. Some negotiation and detail were required in order to explain the necessity of a quiet private space for sensitive cancer and health conversations.

A Sunshine location was considered most suitable for the first shop and this was secured in November 2017 for a February 2018 lease. Following the conclusion of the Sunshine shop it was proposed that a site with higher footfall was desirable. A search for the second shop took close to 3 months, resulting in a shop in the Caroline Springs CS Square shopping centre.

3.2 Design

In order to ensure a high-quality and attractive space, NWMPHN worked closely with a design agency experienced in public health campaigns (Plural Agency). This process was initiated early in the project development phase.

An initial concept design was presented to Western Health volunteers to ensure community acceptability and to test the 'Let's Talk About Cancer' name and draft design with a diverse audience.

The agency developed a logo and colour scheme and initial designs. These were presented to the Steering Group who provided feedback. The concept was designed to be inviting to all communities. This was supported through signage, with the 'Let's Talk About Cancer' front-of shop design containing translations of the ten most widely spoken languages in the City of Brimbank, and the primary logo artwork being in English, Vietnamese, and Hindi.

Following an iterative process of development and refinement, a set of designs and files were produced, and these were then printed and installed. The artwork was printed on high quality poster material to enable multiple installations and ongoing reuse. The decision to allow the ability to reuse of designs and materials was made to decrease the marginal cost of any additional shop. Further use of materials may require reprinting, customisations, translations, or further alterations.

⁴ Australian Health Policy Collaboration. 2017. Australia's Health Tracker by Area, 2017. Accessed November 2, 2017. <http://www.atlasesaustralia.com.au/ahpc/atlas/atlas.html>

⁵ .id. 2017. .id Community Profile. Accessed October 26, 2017. <https://profile.id.com.au/>



Example interior design image. Credit: Plural Agency.

3.3 Shop operation

Each shop operated for four weeks. The shop leases included an additional week for set up and a week for pack down.

The shop in Sunshine operated from 6 February 2018 to 3 March 2018 and was open from 10 am to 4:30 pm daily Tuesday through Saturday.

The shop in Caroline Springs operated from 3 June 2018 to 30 June 2018 and was open from 10 am to 4 pm daily Tuesday through Saturday. The shop did not operate on the Saturday of the long weekend due to staffing constraints.

The Sunshine shop was a large (approximately 90 square metres) and situated within the Sunshine Plaza shopping mall. The position of the shop was highly visible from the escalators ascending from the car park. The shop was decorated using furniture and painting a large wall. Internal semi-soundproof partitions were hired and used to create an internal space for private nurse consultations, data-entry and office work. The mall contained an Aldi supermarket and a mixture of low-cost variety and food retailers and had a low footfall relative to other malls in Melbourne's west. However, it also had a high vacancy rate and was eager to work with the project. The shop required temporary flooring to cover a defect in the shop floor and lacked internal toilets but was otherwise satisfactory. Car parking was available in mall parking, and all-day car-parking-tickets were supplied by the mall for use by staff.



Sunshine pop up shop, operating in February 2018. Image: George Darroch

The Caroline Springs shop was a large former deli site in Caroline Springs at CS Square mall. It was approximately 70 square metres in size. Internal semi-soundproof walls were installed for privacy and to create a nurse work and consultation space. The rear of the shop contained a storage area, a former freezer-room, and a kitchenette and toilet. The storage area was converted into a resource-storage room, and the freezer-room was converted into a makeshift office. This shop had a relatively higher footfall and was located at an entrance adjacent to a Coles supermarket. Car parking was available for staff and volunteers. The short-term lease manager for the mall management company had a family experience with cancer and was keen to provide a site for the project.

Health and safety were an important consideration in the shop model and fit-out. Shops were inspected and audited for safety by a NWMPHN occupational health and safety officer. Where hazards were identified, they were eliminated (for example unsafe flooring was repaired) or isolated (an electrician turned off a circuit for the duration of the shop).

For personal safety, nurses and volunteers were advised to only engage in activity within the scope of their position descriptions, for example, nurses and volunteers were not expected to lift heavy boxes or open or close the shop. Staff and volunteers were trained in strategies to disengage from people or activity that made them uncomfortable or unsafe, and phone numbers of mall security and the project manager were displayed prominently. A minimum of two staff were always present in the shop.



Caroline Springs shop in Caroline Springs, operating in June 2018. Image: George Darroch

3.4 Volunteers

Volunteers were positioned at the front of the shop to greet and engage members of the public and encourage them to enter. Volunteers could explain the purpose of the shop, the resources available and that nurses were available for more detailed and specific conversations about cancer or to answer questions. The volunteers were a friendly face to help direct flow to nurse interactions and to help people wait if the nurses were already occupied.

Volunteers were recruited from Western Health's large and well-established volunteer program. Volunteers were chosen with experience working in the Sunshine Hospital Patient Information Centre and as volunteers in cancer wards. These volunteers had received previous training and had a positive record of volunteer work within Western Health. This experience gave the volunteers confidence and experience in interactions with the public.

A volunteer position description was developed from Western Health's 'Patient Information Centre' position description, which focused on assisting the public in a medical environment. Approximately 25 volunteers were engaged across the two shops. Volunteers were chosen on the basis of their skills, suitability, and availability. Volunteers also had considerable linguistic diversity and spoke 12 languages other than English. Fluency in languages other than English was a considerable assistance with helping the public to access the shop and find cancer material in their language.

CCV provided 'Listen and Refer' training to the volunteers from Western Health before each of the two shops. The training was tailored to this particular project and conducted over a half-day at Western Health. Listen and refer training is designed to enable members of the public to be able to lend a sympathetic ear to people affected by cancer, and then send that person to the most appropriate

source of information or support. This empowered volunteers to confidently provide appropriate information and refer on to available nurses or other health professionals when issues were beyond their scope of practice.

Each volunteer was required to commit to at least two shifts of 2 hours each week during the Sunshine shop, and two shift of 3 hours each week during the Caroline Springs shop. Volunteers were rostered around their availability across the 4 weeks of shop operation.

Volunteers handed out brochures on the cancer pop up shop to passers-by, informing them of the shop and inviting them to come in. Brochures distributed to the public in this way were counted as a proxy for an interaction. Approximately 4000 brochures were distributed to passing public at the Sunshine shop, and 2500 brochures were distributed at the Caroline Springs shop. During the operation of the Sunshine shop volunteers were able to walk freely in all areas of the mall, allowing them to interact with the public and distribute brochures. This was not possible at the Caroline Springs mall where it was viewed as undesirable, and volunteers were constrained to a small area immediately in front of the shop. As a result of these changes, volunteers had fewer opportunities to engage the public at Caroline Springs.

3.5 Staffing – nurses

Nurses were the core information provider of the pop up shop model. Western Health, Cancer Council Victoria, and IPC Health all provided nursing staff to the project.

Western Health were contracted to supply the lead nurse to each of the shops. The nurses were chosen by the Western Health nurse unit manager as experienced cancer nurses with a broad cancer knowledge and good people skills who were interested in exploring this different style of communicating directly with members of the public. Each nurse worked from Tuesday through Saturday each week and provided continuity for the shop.

CCV supplied nurses on Tuesday through Friday each week on a rotating basis, with one cancer information nurse attending each day. These nurses all had experience working on CCV's cancer information and support line. This meant a range of nurses with differing experiences were able to apply their skills to the shop. CCV nurses were also able to talk about and provide resources or referral to other CCV programs and services.

The core role of the nurses was to provide information, support and advice to the public and refer on to appropriate medical or community services where needed. Nurses provided general information and avoided specific medical information, in accordance with training provided by CCV. This protected nurses and participating organisations from exposure to medical liabilities or responsibilities.

The development and implementation of a contract for services between NWMPHN and Western Health took several months. This was in part due to the nursing work being outside of the ordinary work of Western Health cancer nurses, and a desire to ensure that risk to all organisations was minimised. The nursing contract was finalised in the week before operation of the Sunshine shop. A variation to this contract was made following the Sunshine shop to allow for a second shop, and this took additional time.

3.6 Health promotion and prevention activities

IPC Health provided community public health nurses from 10 am - 12 pm twice during each week of operation. These nurses had experience in providing information about health interventions such as screening, healthy living, exercise and nutrition programs. These nurses also supported CCV and Western Health nurses in providing general health information to the public.

CCV provided public health staff, and IPC Health their health promotion staff to the project. During the operation of the Sunshine shop efforts were made to incorporate an explicit smoking cessation focus on a single day of operation, and CCV staff were engaged. During the operation of the Caroline Springs shop advertising was made that emphasised smoking cessation, but no additional staff were enlisted. An Aboriginal-focused cancer day was held at the Caroline shop, but this was poorly attended.



A Western Health nurse speaks with members of the public. Image: Tessa van der Riet

3.7 Media and promotion

The shop was supported by a range of media and promotion channels.

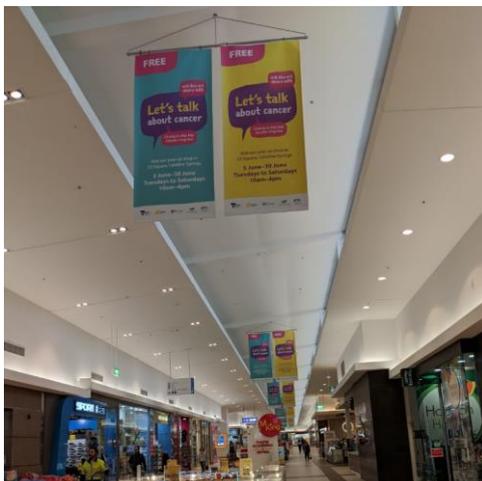
The shop was featured in local newspapers with large circulations in the surrounding area. Journalists were invited to the launch of the Sunshine shop, which resulted in a story in the local paper.

Social media was essential to increasing the reach of the shop. For this purpose, Facebook was chosen as the primary medium. Posts with interesting visual content were made on a regular basis to ensure that Facebook's algorithms recognised the site as an active one, and to increase the reach of the site among the public. In order to increase reach, paid Facebook advertising boosts were used, which returned increased engagement and was considered to be cost-effective by NWMPHN's communications team. This strategy was successful, with posts achieving excellent results. Two example posts are shown below.

A video was commissioned by the NWMPHN to document and illustrate the operation of the shop, and to allow for promotion across a range of channels. The video was made by a professional videographer and is available for viewing and re-use through the resource toolkit supporting this shop. The video was used in Facebook posts, and posts utilising the video had over 21,000 views on Facebook. This was the most successful post across both shops.



In-mall marketing was secured as part of the lease agreement with CS Square mall in Caroline Springs ahead of the second pop up shop. The roof hangings were installed along the length of the mall, and the floor coverings were installed at two entrances. These came at an additional cost of \$3300, which included printing and installation. Participant feedback was positive about their usefulness in increasing awareness of the shop. However, several participants fed back that they had been unable to find the shop initially and suggested directional signage or clear wording specifying the internal location.



3.8 Ethics approval

Ethics approval was obtained from the DHHS Human Resource Ethics Committee. The project was determined to be in the committee's low or negligible risk stream. The following documents were required for approval:

- Study protocol
- Participant information
- Participant consent form
- Curriculum vitae of investigators
- Copy of questionnaires and data collection tools
- Letters of support
- Copy of participant recruitment script

Approval was granted in January 2018. An amendment to the ethics application was made in April 2018 to allow nurses to collect more structured data, with minor revisions to forms. This revision was accepted provisionally in May 2018, with full approval in June 2018 before the commencement of the Caroline Springs shop.

Materials developed to support the ethics application are included in the *Pop Up Shop Resource Toolkit*.

3.9 Data collection

The two shops employed a mixed-methods approach to data collection. Data collection processes and collection forms changed from the Sunshine shop to the Caroline Springs shop based on feedback and the ability to analyse the data collected. The evolution of the data collection is described in detail below.

The data collected in the Sunshine and Caroline Springs shops was gathered through a range of methods, including paper form-based visitor surveys, nurse notes, computer-based nurse records, and volunteer forms.

These were supplemented with counts of shop brochures distributed and feedback collected from nurses, volunteers, and managers. De-identified data on the number and subject of callers to CCV's 13 11 20 information line was also supplied by CCV.

As the two shops employed different data collection methodologies, the information from each shop is not directly comparable.

3.9.1 Volunteer data collection (Sunshine)

Volunteers collected data on numbers visiting the shop, resource use, and numbers of nurse conversations. The form completed by volunteers recorded demographic data on age, ethnicity, gender and postcode of people visiting the shop. Participants were asked about their experience of cancer and to describe their satisfaction with the shop, whether they felt respected and listened to, and whether they intended to take any action following their visit. Those who indicated an intention to act were asked a follow up question about those actions. These activities and categories were unprompted.

Data collection from volunteers at the Sunshine shop was recorded by hand on a paper form and entered into a Microsoft Excel spreadsheet analysed by NWMPHN. The volunteer data collection form is included in the *Pop Up Shop Resource Toolkit*.

3.9.2 Nurse notes (Sunshine)

During the Sunshine shop, nurses were encouraged to take notes following each conversation with a member of the public. The purpose of the notes was to capture relevant information about the participant, their cancer experience, and to record conversation topics and outcomes.

Notes were completed by nurses in most but not all cases. The notes were predominantly handwritten and were not structured in a consistent way, leading to variability in information captured, style, length, and legibility. These notes were read and entered into a Microsoft Excel spreadsheet by the project manager and were coded and analysed for themes by an external consultant.

Issues and results from the Sunshine shop lead to an extensive re-working of data capture prior to the Caroline Springs shop to facilitate a more structured data collection.

3.9.3 Nurse data collection (Caroline Springs)

For the Caroline Springs shop, a modified version of CCV's nurse data-collection fields used in their telephone interactions was used to develop a more structured form. This was also informed by the common conversation topics from the Sunshine shop. The form was tested with Western Health and CCV nurses for suitability and utility.

The new nurse data collection form recorded demographic information, as well as the types of interaction and outcomes, which were moved from volunteer data collections. Nurse-recorded outcome data and cancer-relationship questions were added to the data recording template. All data entry was made via a simple electronic form that directly linked to a database. Two laptop computers were hired to facilitate easy and quick data entry immediately following each nurse conversation. Nurses were trained in data collection via this form and requested to complete the form immediately, rather than wait until later in the day when some information may be lost. Volunteers assisted member of the public to wait if nurses were temporarily busy with data collection. This approach considerably improved the consistency and completeness of data collected.

The nurse data collection form is included in the *Pop Up Shop Resource Toolkit*.

3.9.4 Volunteer record of interaction (Caroline Springs)

The volunteers were given a simple form in the Caroline Springs shop to record the quantity and type of volunteer interactions.

The form recorded the volunteer's name (for quality control purposes), the date of entry and four 'tick boxes' to indicate whether the volunteer; engaged in a conversation, referred the person on to the available nurses, provided information brochures, or engaged in another activity such as a non-cancer conversation or asking the person to return to the shop.

Volunteers were given an open text field to write about any interesting or notable interactions and provide context to their interactions. These forms were entered into a Microsoft Excel spreadsheet by a trained volunteer, with oversight from the project manager. The form for volunteer record of interactions is included in the *Pop Up Shop Resource Toolkit*.



A Western Health nurse and volunteer speak with a member of the public. Image: Tessa van der Riet

“This shop is a great idea. I needed to ask questions about my sister’s experience with cancer and was given lots of information about prevention for myself and daughter. I feel reassured about my sister’s outcome and was very glad to talk with the nurse about my concerns for her.”

– Participant, Sunshine shop

4 Results

As previously noted, data collection methods were altered following the Sunshine shop. As a result, the information from each shop is not directly comparable, and data and graphs presented below should be read with this in mind.

4.1 Shop entry

In the Sunshine shop there were 169 recorded nurse consultations over 20 days of operation, representing an average of 8.5 nurse consultations per day. These conversations and information sessions ranged from approximately one minute to almost an hour in length, with most taking five and ten minutes. In addition, over 4200 brochures were given to members of the public.

In the Caroline Springs shop there were 243 recorded nurse consultations over 19 days of operation. This represents an average of 12.8 nurse consultations per day. In addition, over 2500 brochures were given to members of the public.

A total of 794 public-volunteer interactions (conversations and nurse or information referrals) were recorded at the Caroline Springs shop, representing 42 each day. These consisted of conversations about prevention, survivorship, other cancer related topics or referrals onto an available nurse. These referrals and interactions are discussed in further detail below.

Public interactions were largely initiated by volunteers and nurses. Members of the public were asked if they would like to talk about cancer, or whether they would like to learn about reducing their cancer risk. Members of the public responded readily to questions about whether they were up-to-date with their screening.

In cases where the member of the public came into the shop without encouragement or prompting, there was often a compelling reason for entry such as a personal cancer experience or the perception of possible cancer symptoms.

Volunteers and nurses encountered members of the public who spoke little or no English. In some cases, a nurse or volunteer was able to speak the same language as the person and were able to converse with them and talk about simple cancer topics, as well as provide material in-language. In cases where the nurse or volunteer was able to ascertain what language was spoken they were able to provide the person with cancer prevention or screening information in that person’s language and direct them to CCV services through the 13 14 50 Translating and Interpreting Service.

4.2 Demographic information

The majority of those visiting the shop were female, making up 62% of participants in the both the Sunshine and Caroline Springs shops. At the Caroline Springs shop, 2.1% of visitors were recorded as couples made up of male and female visitors.

The age distribution of visitors peaked among those aged 51-70 years, with approximately 39 percent of visitors to the Sunshine shop and 42 percent of those visiting the Caroline Springs shop in this age group.

Figure 1. Age distribution of the Sunshine shop. (n = 64)

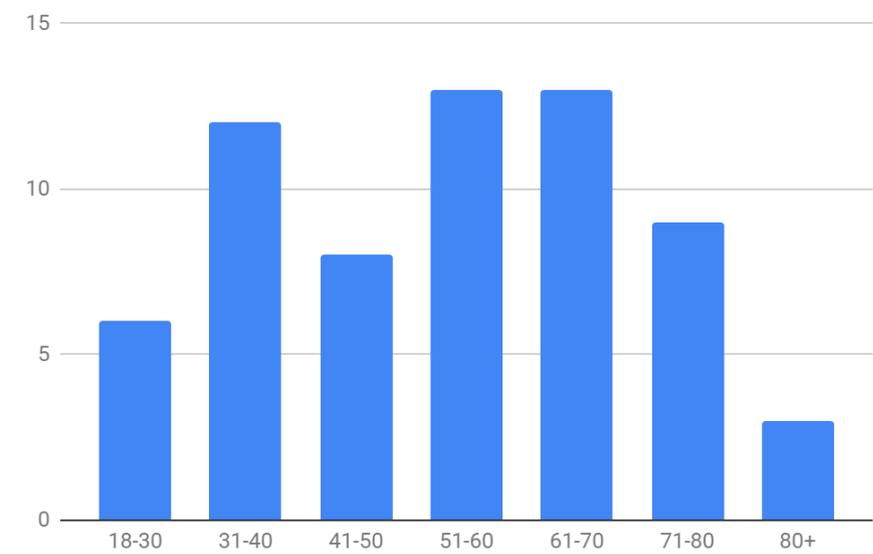
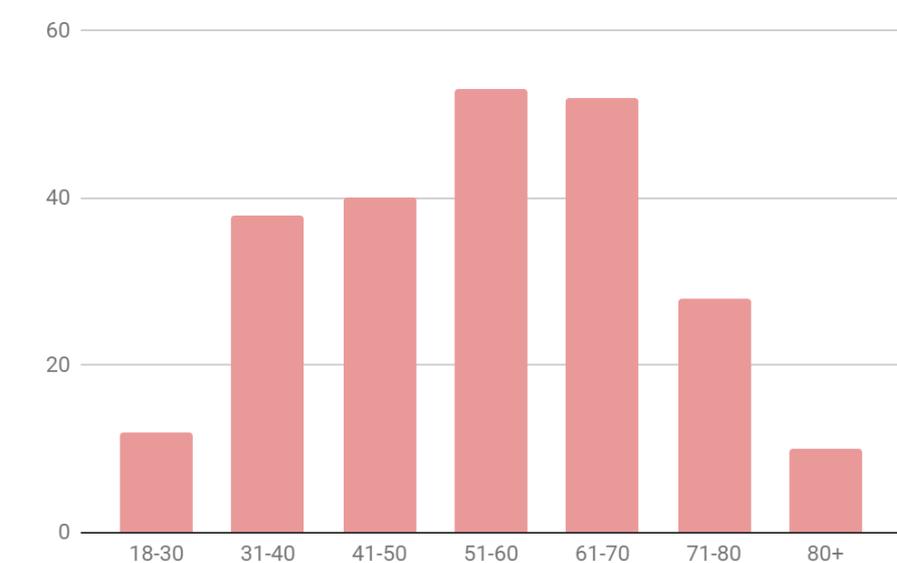


Figure 2. Age distribution of Caroline Springs shop. (n = 234)



The clear majority of those visiting either shop were from the closest suburbs, as indicated by the postcodes data collected. The visitors to each shop were largely participating in their ordinary shopping and business. During the Sunshine shop postcode data was asked of participants by volunteers, and in the Caroline Springs shop postcode data was recorded by nurses.

Figure 3. Sunshine shop postcode data. (n = 61)

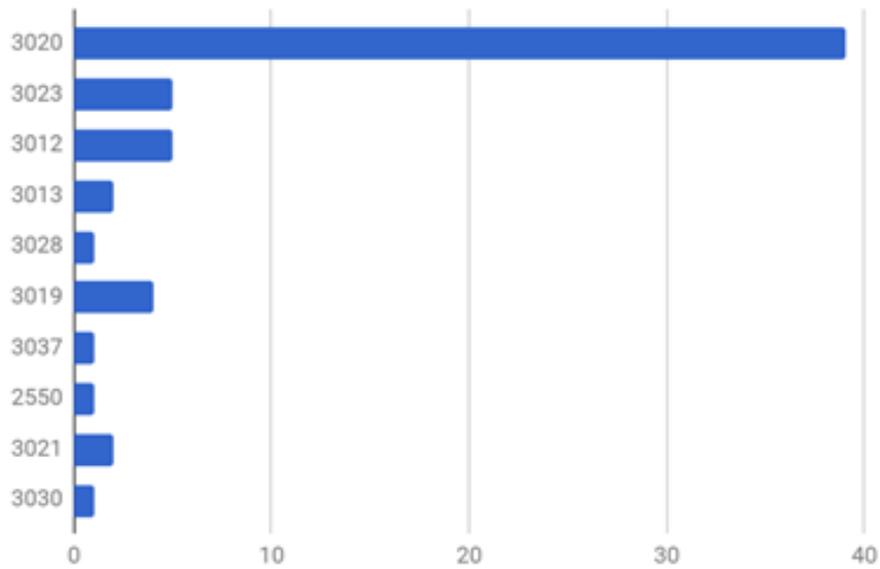
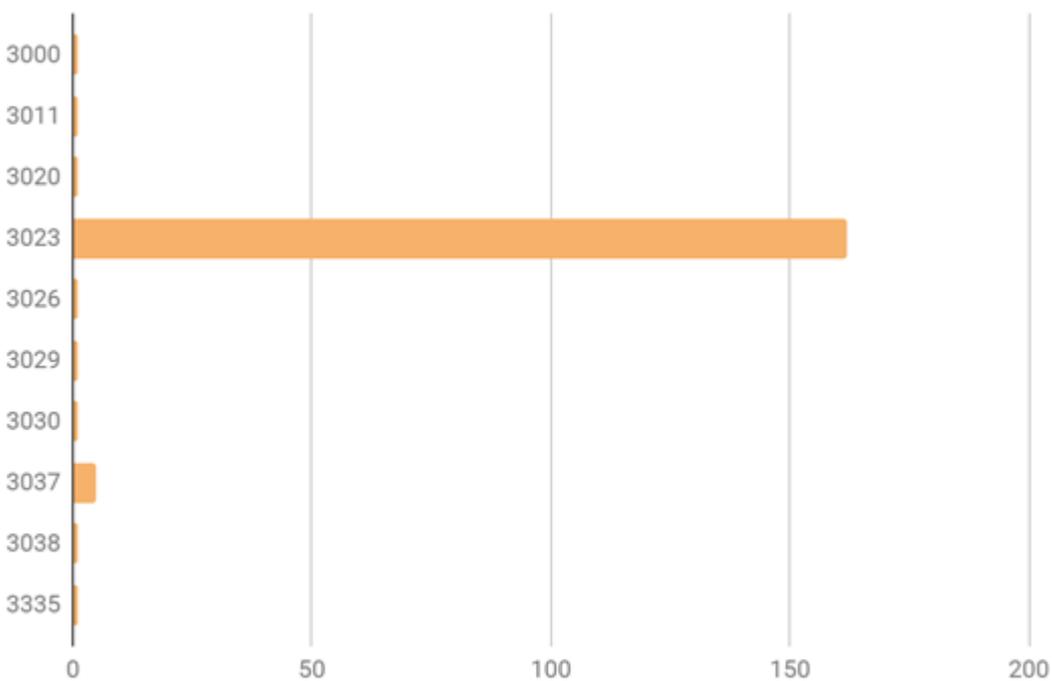
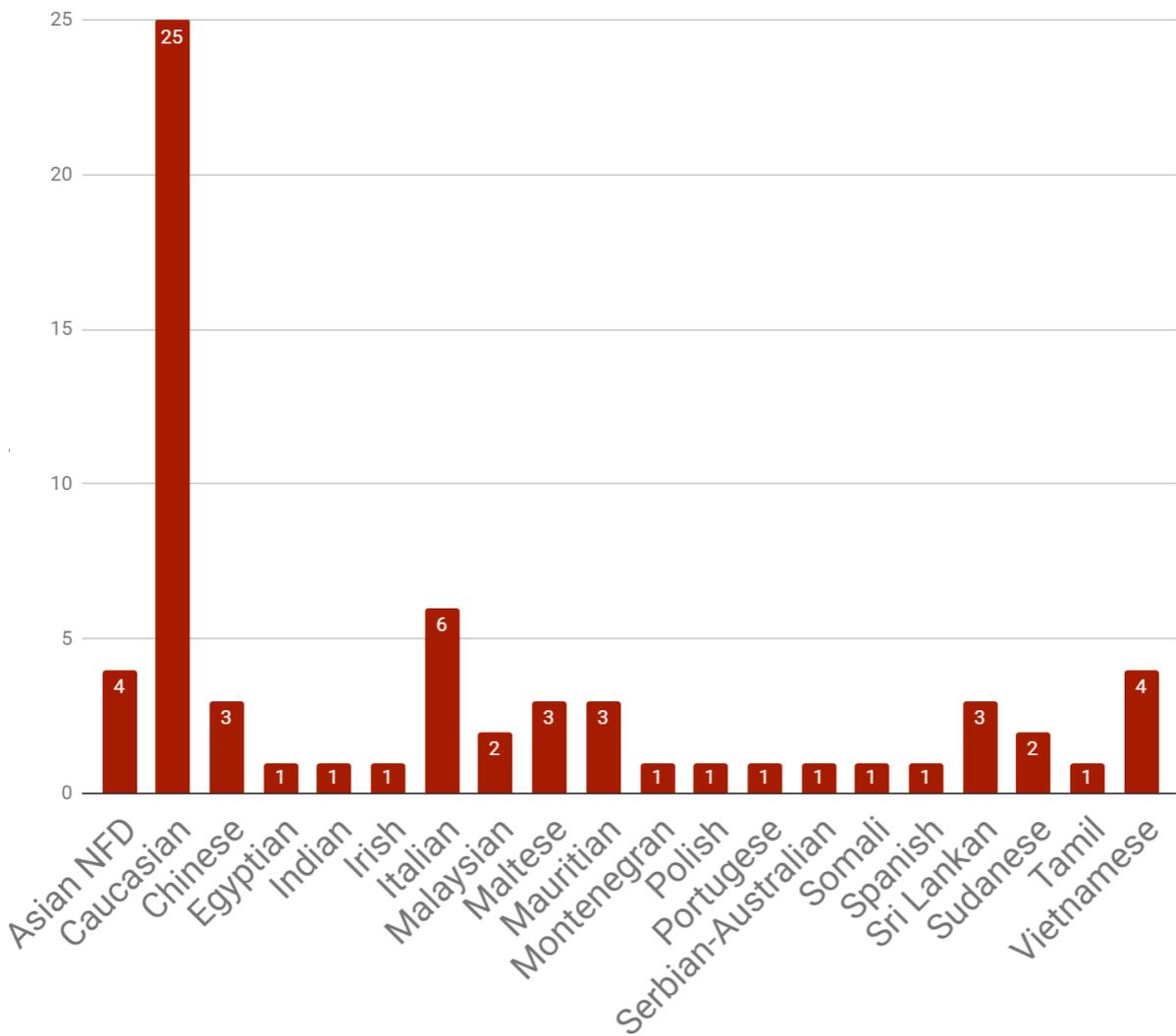


Figure 4. Caroline Springs shop postcode data. (n = 189)



There was significant diversity of ethnicity seen in both shops, as shown in the following graphs. The largest single ethnic identification in either shop was European, with 22 separate ethnicities recorded in Sunshine shop and 27 separate ethnicities recorded in the Caroline Springs shop. There were no shop participants who were interviewed by volunteers or spoke to nurses who were recorded as identifying as Aboriginal or Torres Strait Islander. Volunteers recorded the following ethnicities of visitors to the Sunshine shop below.

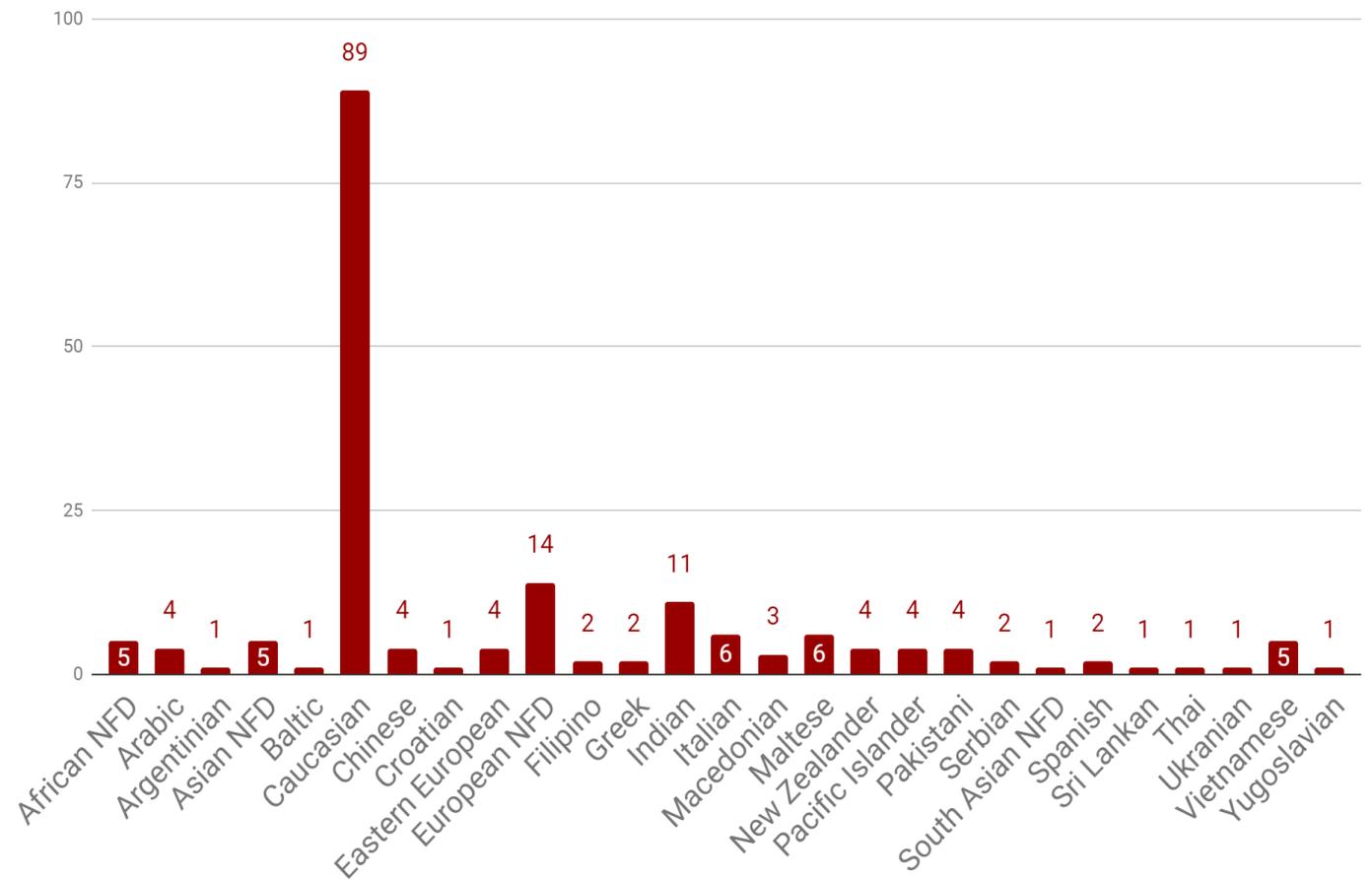
Figure 5. Ethnicity of visitors to Sunshine shop. (n = 66)



(Asian NFD – Asian: not further defined)

Nurses recorded the ethnicities of those visiting the Caroline Springs shop and these are displayed below. Because of differences in data collection the results are not directly comparable but represent the diversity of visitors to the shops.

Figure 6. Ethnicity of visitors to Caroline Springs shop. (n = 184)



(African NFD – African: not further defined.
 Asian NFD – Asian: not further defined;
 European NFD – European: not further defined
 South Asian NFD – South Asian: not further defined.)

Cancer information brochures were given out in a variety of languages. These included Vietnamese, Mandarin Chinese, Italian, Greek, Maltese, Spanish, Russian, Serbian, Burmese, Karen (Myanmar ethnic minority), Arabic, Filipino, Hindi and Punjabi. Brochures were also given out which enabled direct referrals to CCV through the Translating and Interpreting Service. The number of brochures given out in each language was not recorded.

4.3 Shop use

4.3.1 Shop acceptability

During the Sunshine shop 67 participants were interviewed by volunteers as they left the shop. Participants were asked about their experience of the shop, and their intention to act (recorded below). They were asked to state how much they agreed with four questions below, on a five point Likert scale.

“This shop was useful to me”:	4.78
I felt listened to and respected:	4.97
I have the information I need to take action:	4.85
I intend to take action after leaving this shop: 4.25	4.25

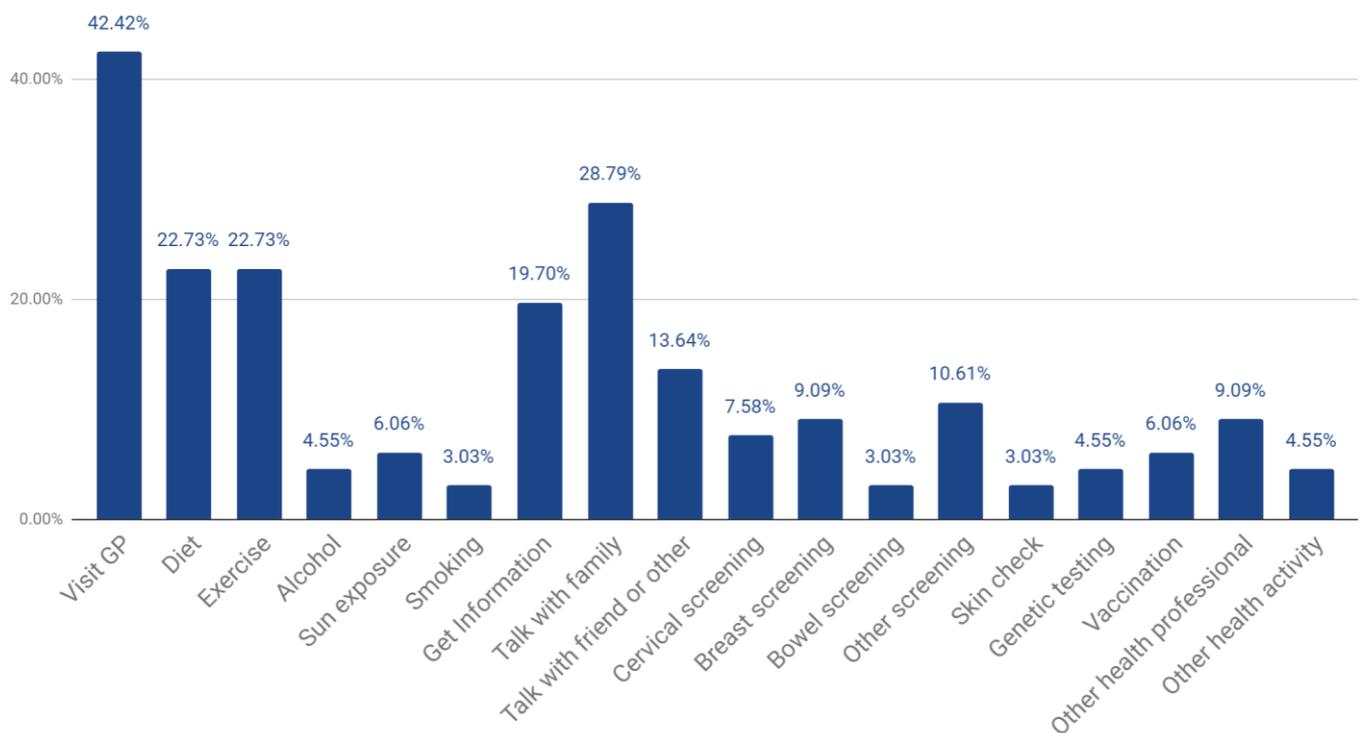
These results indicate a high degree of acceptability of the shop format and activities conducted. The results also reflect very well on the staff and volunteers involved.

4.3.2 Intention to act

The participants in the Sunshine shop were asked about their intention to act, with 78.8% indicating that they intended to act after leaving the shop. Intended actions were recorded, with multiple answers possible. The results of the intention-to-act question are displayed below.

This survey was included as part of the nurse data collection in the Caroline Springs shop. Unfortunately, an unintended consequence was that very few results were recorded as most nurses entered data on their encounters after participants had left the shop, which meant there was not an opportunity to ask these questions.

Figure 7. Indication of action by visitors to the Sunshine shop. (n = 56)



(Note that multiple intended activities were possible.)

4.4 Referral to service

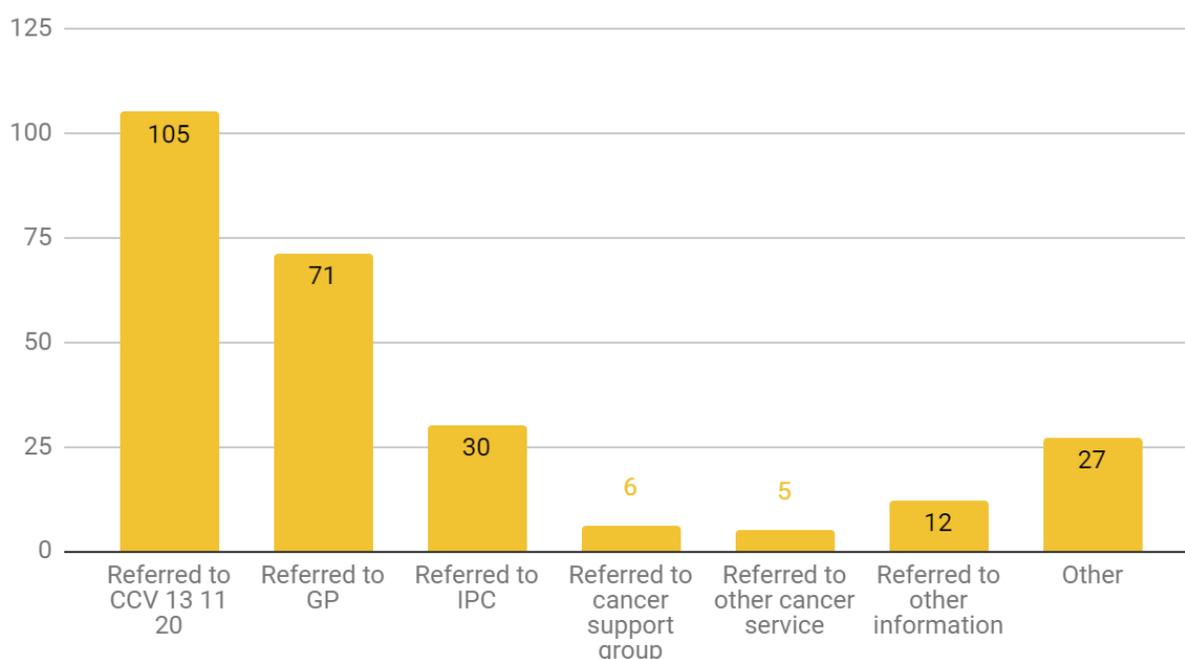
The operating model of the cancer pop up shop excluded the provision of medical advice and emphasised the importance of directing participants to services and care. For this reason, one of the main activities of the nurses was making referrals to cancer and other support services.

In the Caroline Springs shop, from 243 nurse conversations, 256 referrals to services were generated. Referrals to screening were categorised separately and in addition to this number (below). Clearly, many people were referred to multiple services and programs. Where the participant was interested in further information about a cancer topic, or sought support for cancer issues, they were frequently referred to CCV. This was the most common category of referral, with 105 referrals to CCV during the Caroline Springs shop.

The presentation of possible cancer symptoms was a strong driver for people entering the shop, often expressed through a high level of concern. A number of individuals entered with moles or other abnormalities on their skin. In each case the person was referred to their GP and given information about skin clinics and symptoms of skin cancer. People with other possible cancer symptoms were given a strong recommendation to see their GP in the near future and discuss their symptoms and concerns with them. Two examples of such people were a man presenting with blood in his stool, and a man with unresolved reflux issues and unexplained back pain which he believed could result from bone cancer.

Current cancer treatment and dealing with the direct and indirect effects of cancer also drove entries into the shop. The side effects of cancer treatment were frequently discussed with nurses. Discussion regarding altering treatment plans or other medical issues were directed back to appropriate health professionals, but nurses did provide valuable advice, support and information for visitors and were able to direct them to resources and services, including support groups where appropriate. Figure 8 below details the referrals made from the Caroline Springs shop.

Figure 8. Referrals to service, Caroline Springs shop. (n = 256)

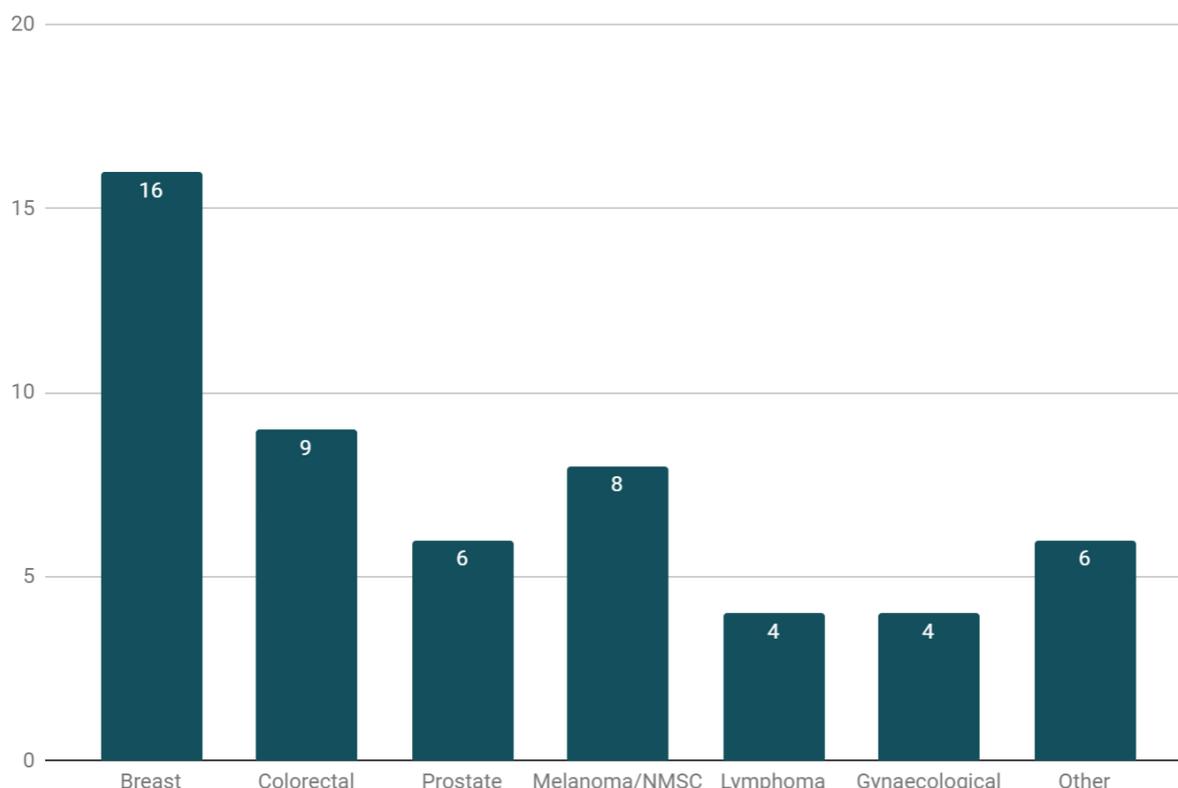


(Note that multiple referrals were possible.)

Participants in the Caroline Springs pop up shop were asked by nurses about their current or historic cancer status, or the participant revealed this in conversation. A total of 53 current or previous cancers were recorded across 48 participants. This represents approximately 20% of all entrants to the shop. The majority of cancers recorded aligned with the most prevalent cancers – breast, prostate, colorectal and skin cancers, as shown below in Figure 9.

Figure 9. Current or historic cancer types of visitors to the Caroline Springs cancer pop up shop.

(n = 53)



(Note that multiple cancer types were possible)

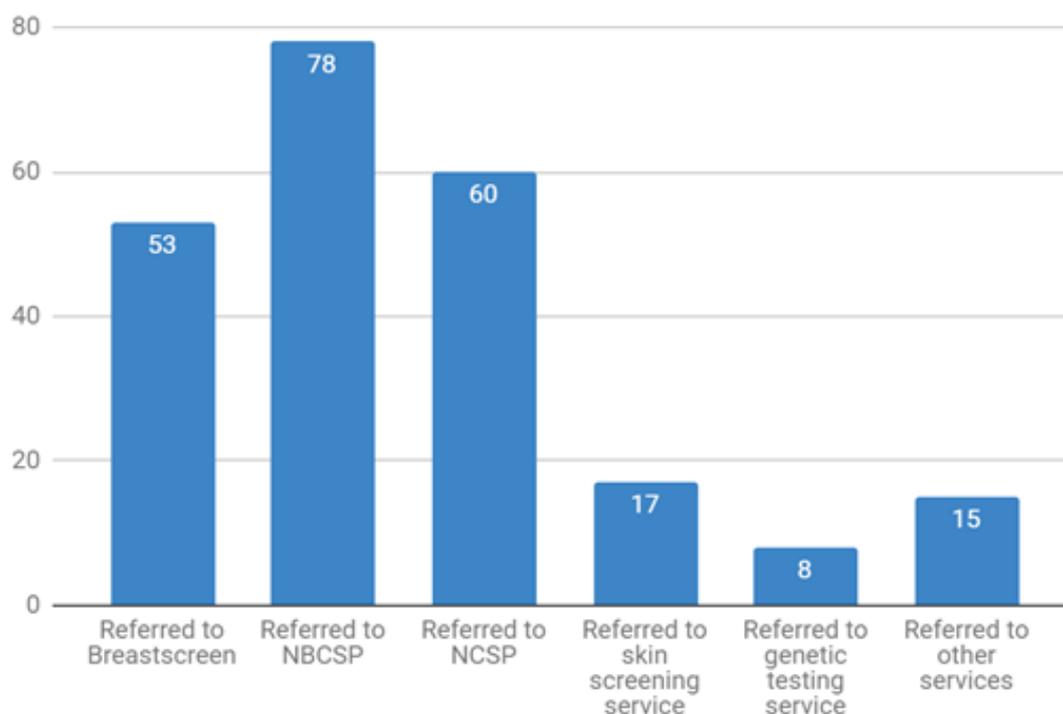
4.5 Screening

Of 243 nurse conversations in the Caroline Springs shop, 231 referrals to screening were recorded. Visitors of all types requested basic information about screening services, including web addresses and phone numbers. Some were interested in screening for skin cancer and how to contact and enrol with a skin check clinic. They were counselled on the options and told about the skin checks available through GPs. Many of those who discussed cancer screening with the nurses were not up to date with all their screening, had lapsed or had not begun their cancer screening. Others had not received a National Bowel Cancer Screening Program kit due to incorrect or out-of-date information and were provided with a number to call to request a new kit. Use of the bowel-screening kit was a subject of discussion, with staff explaining its correct use.

In some cases, the person had aged-out of screening programs and was seeking an explanation for their exclusion or way to enrol in screening. In these cases, the person was given information and advice on health promotion and how to talk with their GP about referral to screening services. In one

case, a group of teenagers asked for information about screening and were given brochures. The following week the mother of one of the teenagers told a nurse that she had been asked by her daughter to enrol in breast screening and had subsequently done so. A larger number of self-directed screening inquiries were seen at the shop in Caroline Springs. Figure 10 details the range of referrals to screening made in the Caroline Springs shop.

Figure 10. Referrals to screening, Caroline Springs shop. (n = 231)



(Note that multiple referrals were possible.)

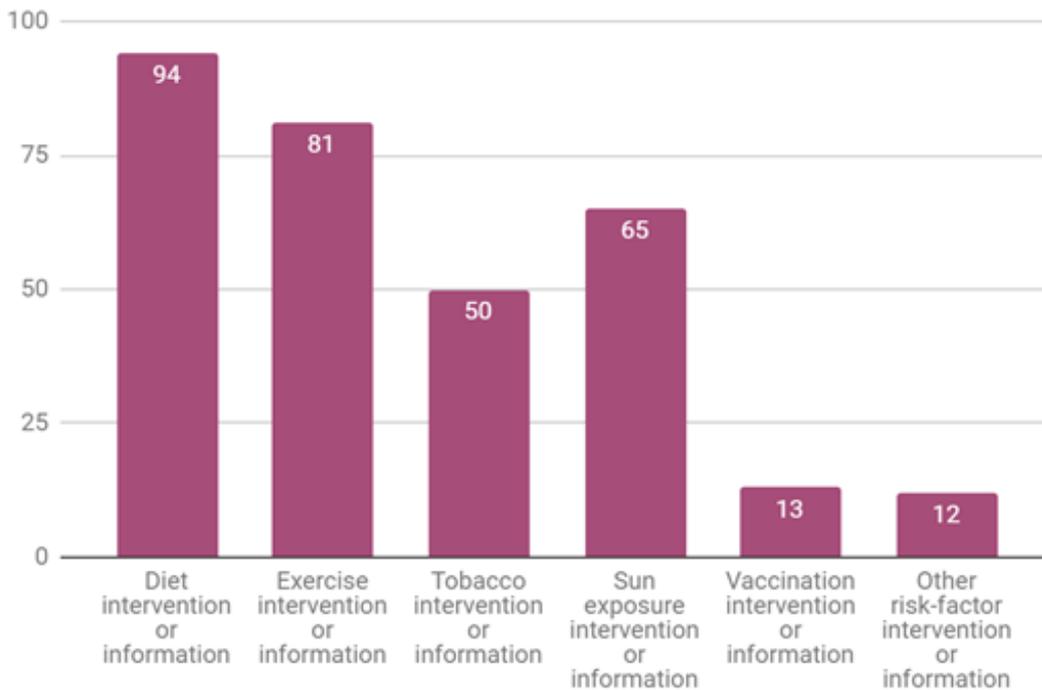
4.6 Reducing cancer risk

A large number of those entering the shop expressed interest in reducing their cancer risk, with 315 cancer risk reduction topics discussed in 243 nurse conversations. Diet-related information or discussion of interventions was the most common cancer risk related topic, with 94 discussions. This was followed by exercise-related information or discussion of interventions, with 81 discussions. Together, these two topics made up just over half of all reducing cancer risk discussions.

Visitor-directed enquiries were frequently general in nature and did not relate to any specific risk factor. Nurses asked questions about their habits and offered relevant information. IPC Health nurses were particularly focused on conversations involving prevention and lifestyle modification. IPC Health staff were able to refer participants to their organisation’s free exercise, diet, and smoking cessation services. As Western Health and CCV nurses became familiar with their services, they also increased their referrals to IPC Health.

Many visitors were given information or referral to one or more lifestyle modifications, as shown in figure 11 below.

Figure 11. Lifestyle modification information and interventions conversations, Caroline Springs shop. (n = 315)



(Note that multiple interventions or information topics were possible.)

4.7 Family and concern for others

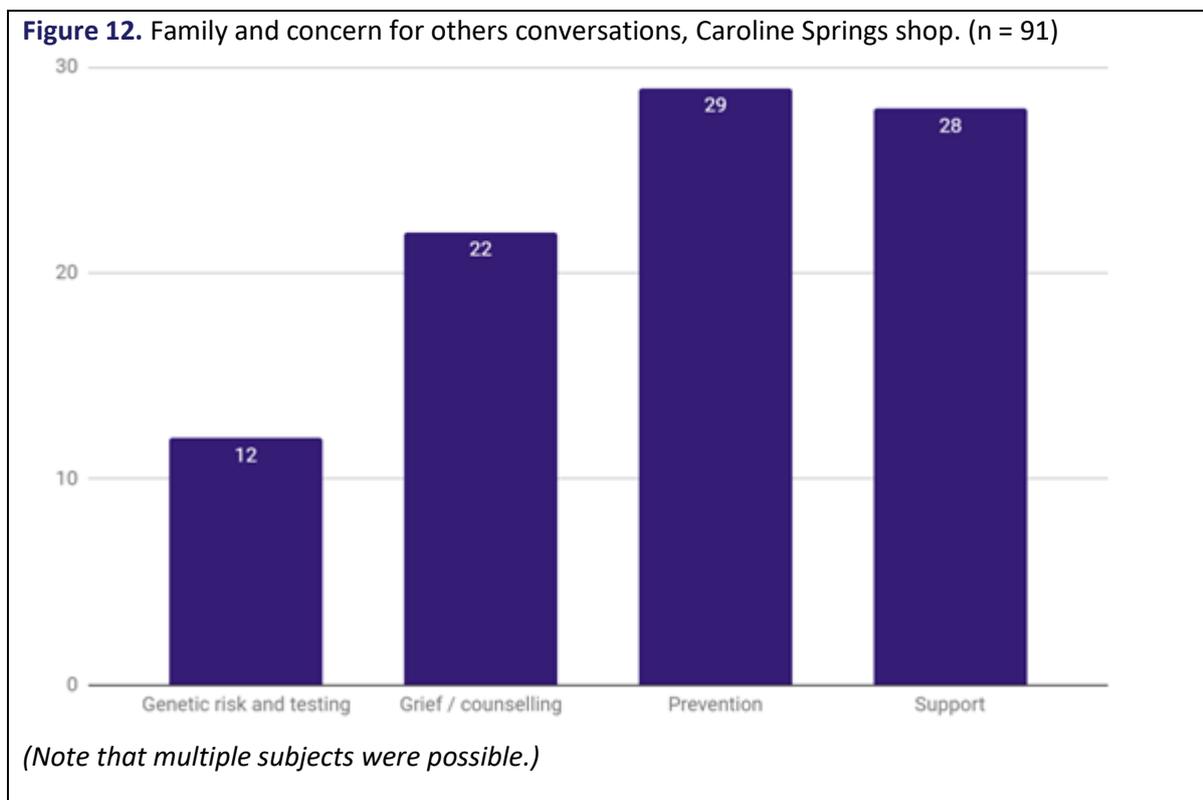
Cancer in the family was a leading cause for entry to the shop. Approximately 10% of those entering the shop were seeking assistance in understanding the cancer of a loved one. This was assisted by provision of information about cancer types and directing these people to cancer resources. Many of the questions asked by the public were well-informed and were directed at gaining further knowledge and context for a diagnosis. Where a possible family history of cancer presented to the nurse, this was discussed, and the person was given information about talking this over with their GP and possible genetic testing if appropriate. The majority (57 of 91) of these conversations were directed towards support or prevention directed towards a family member.

There were several visitors to each shop who were currently affected by the cancer diagnosis of a loved one living outside Australia. In one case, a Chinese-Australian woman sought advice about the practicality of bringing her cancer-affected father from China to Australia. As a result of her research work in other countries, a nurse was able to advise that this would be disruptive to her father's support and care, and that the standard of cancer medicine in China has improved markedly in recent years. Another visitor was highly distraught and sought an opinion on his wife's diagnosis and files in Pakistan. The nurse was able to explain the nature of the shop, and that a second opinion was only possible with the assistance of a referral to an Australian doctor. The participant did not appear to consider this a satisfactory outcome but was grateful for being heard. While these were not a primary subject of the shop, they illustrate some of the diversity of cancer topics addressed.

Of 91 conversations involving family or others with cancer, there were 22 which involved dealing with grief. Many Victorians are affected by the loss of a loved-one due to cancer, and this was reflected in the cancer conversations had by visitors to the shop. These conversations provided visitors with an opportunity to discuss important issues with a health professional. In one case, a woman expressed at

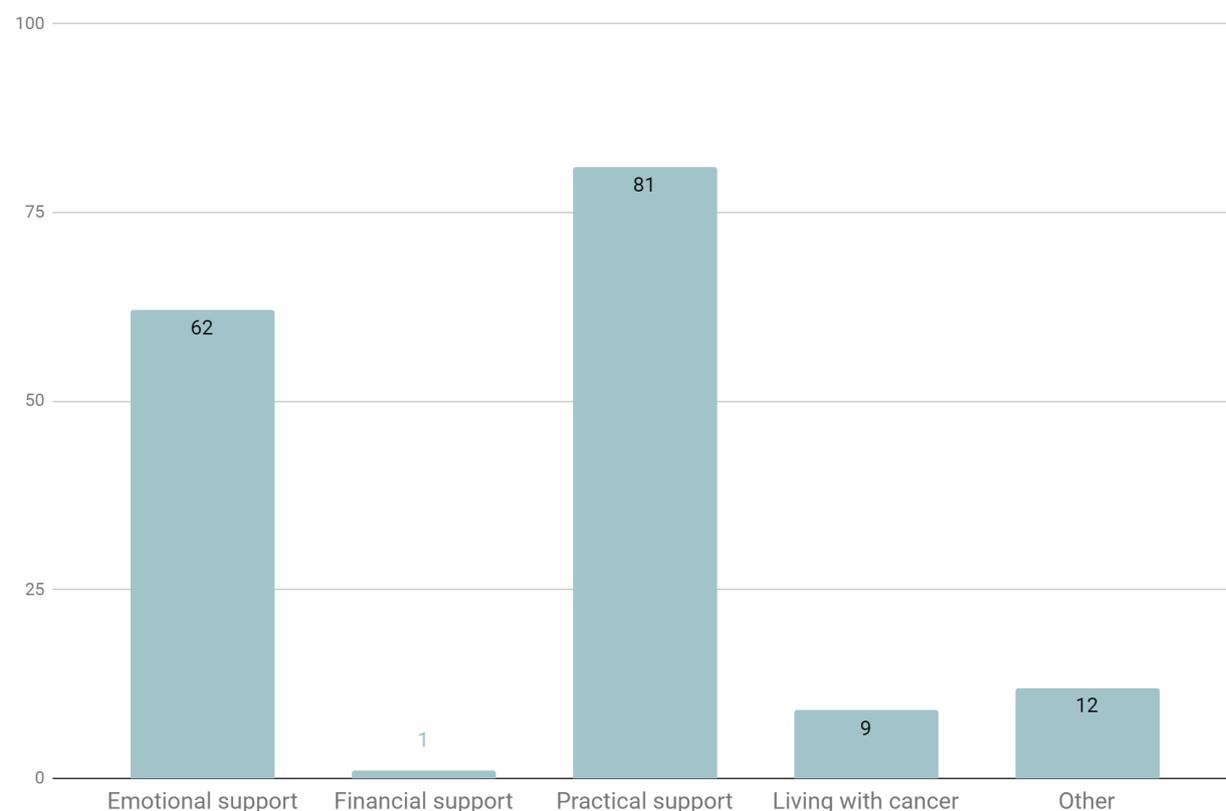
length her anger at the perceived mistreatment of her husband who was terminally ill with chondrosarcoma and appeared to find the conversation and provision of counselling information useful. In many other cases, the conversations themselves were therapeutic in nature. Visitors were offered the opportunity to connect with CCV specialist counselling and peer-support services, and these were accepted in some cases.

Figure 12 shows the common topics of conversation covered under family and concern for others in nurse-participant consultations.



Of the 243 nurse conversations, 165 involved discussion around provision of support. The large majority of these covered emotional support topics (81 of 165) and practical support topics (62 of 165). These were large and varied subject areas, and covered topics as diverse as healthcare navigation and continuity of care, distrust of doctors due to belief in alternative medicine, managing medical anxiety due to survivorship, a history of domestic violence and communicating with younger children about a cancer diagnosis.

Figure 13. Support-related nurse conversations, Caroline Springs shop. (n = 165)



(Note that multiple subjects were possible.)

4.8 Reach

4.8.1 Cancer Council Victoria call data

Following the operation of the shop, a request for data was made of CCV for the number and type of calls from the primary postcodes recorded by visitors to either shop. This gathered call numbers for the month prior to operation, the month of operation, and the month subsequent to operation. The data was de-identified in accordance with CCV's data policies.

In the month prior to the operation of the Sunshine shop, CCV reported 14 calls from the postcodes adjacent to the shop. This increased to 34 calls in the month of operation, and 30 calls in the month following. Prior to the Caroline Springs shop CCV reported 10 calls from the surrounding postcodes. This increased to 34 calls in the month of operation, and 20 calls in the month subsequent to its operation. While it is not possible to definitively attribute the additional calls from these postcodes, the increase is suggestive of impact from the shop and people following up on cancer concerns.

Figure 14. Number of calls to CCV from primary postcodes recorded in the Sunshine shop. (n = 70)

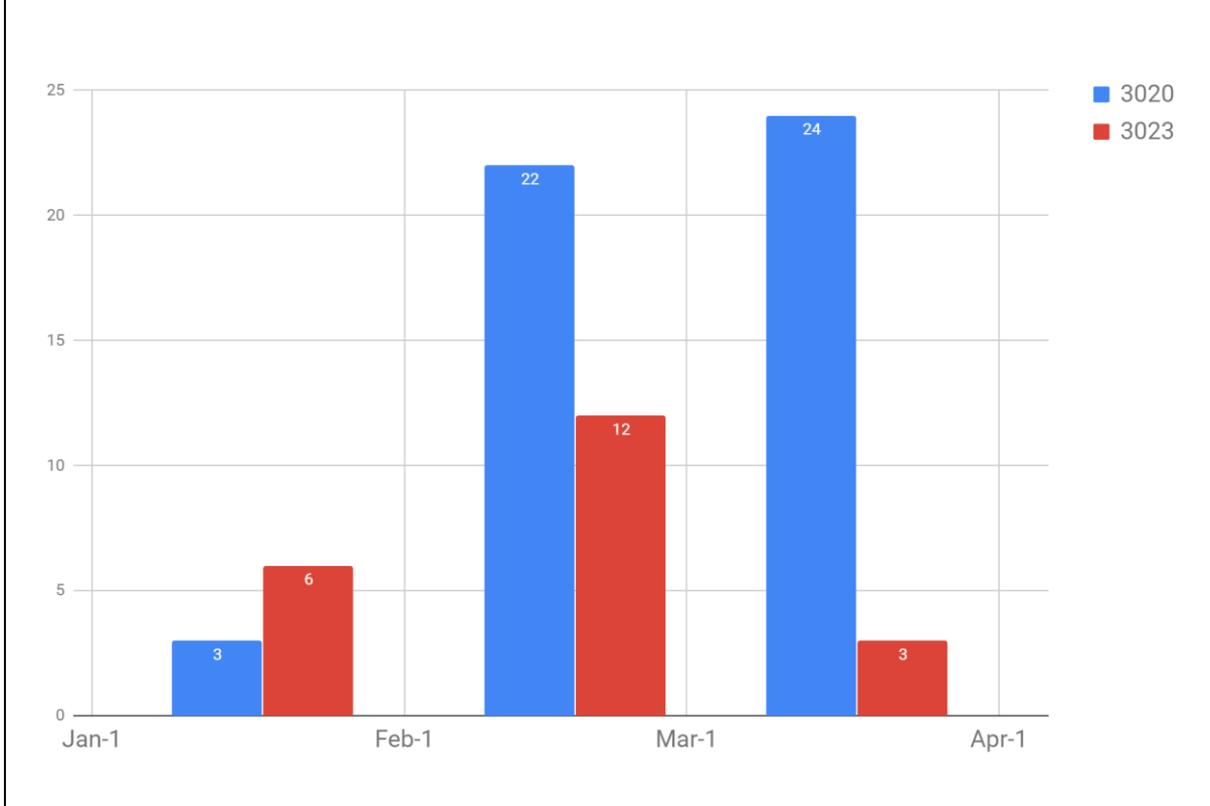
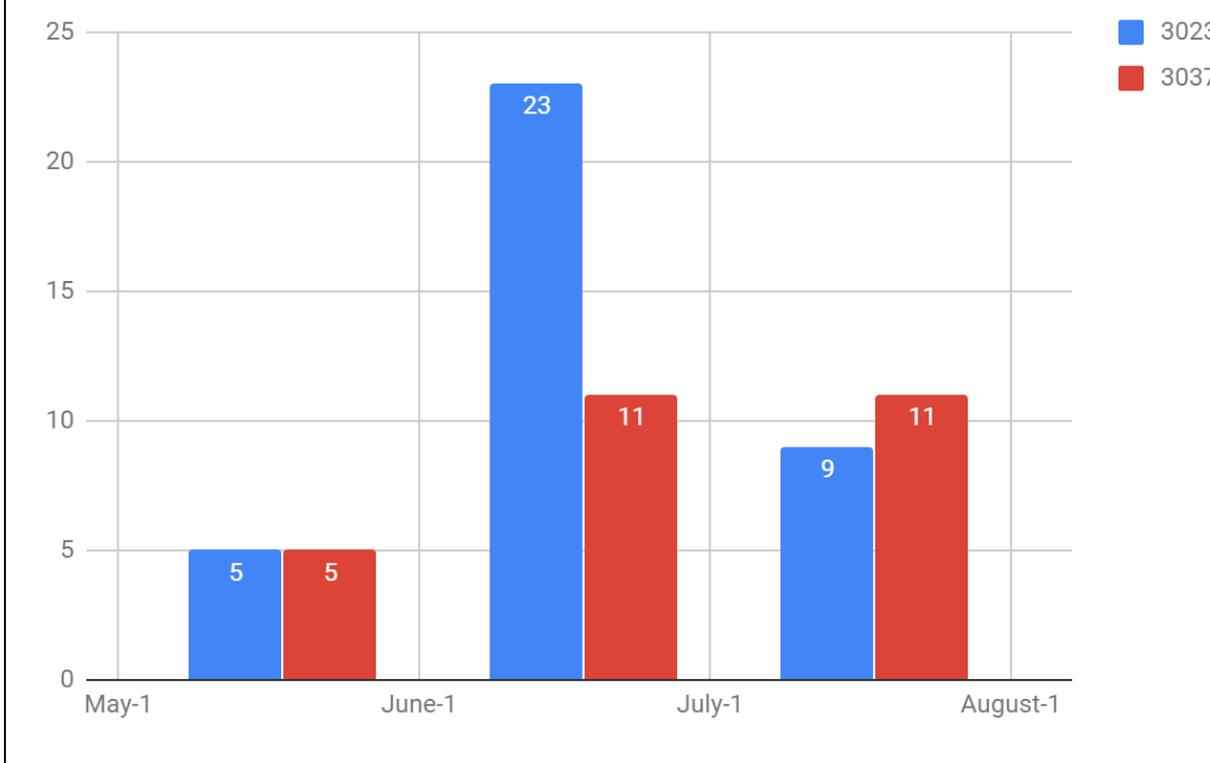


Figure 15. Number of calls to CCV from primary postcodes recorded in the Sunshine shop. (n = 64)



CCV provided information on the subject of calls made to their information and support line from the primary postcodes associated with the two shops, aggregated across the three months requested (closer detail was not available). The largest number of calls made to CCV from these postcodes were for support or advice on practical issues, with 27 calls from postcodes associated with Sunshine shop, and 26 calls from postcodes associated with the Caroline Springs shop. This was followed closely by psychological and emotional support, with 22 calls from postcodes associated with Sunshine shop, and 10 calls from the Caroline Springs shop.

Figure 16. Subject of calls to CCV from primary postcodes recorded in Caroline Springs shop. (n = 70)

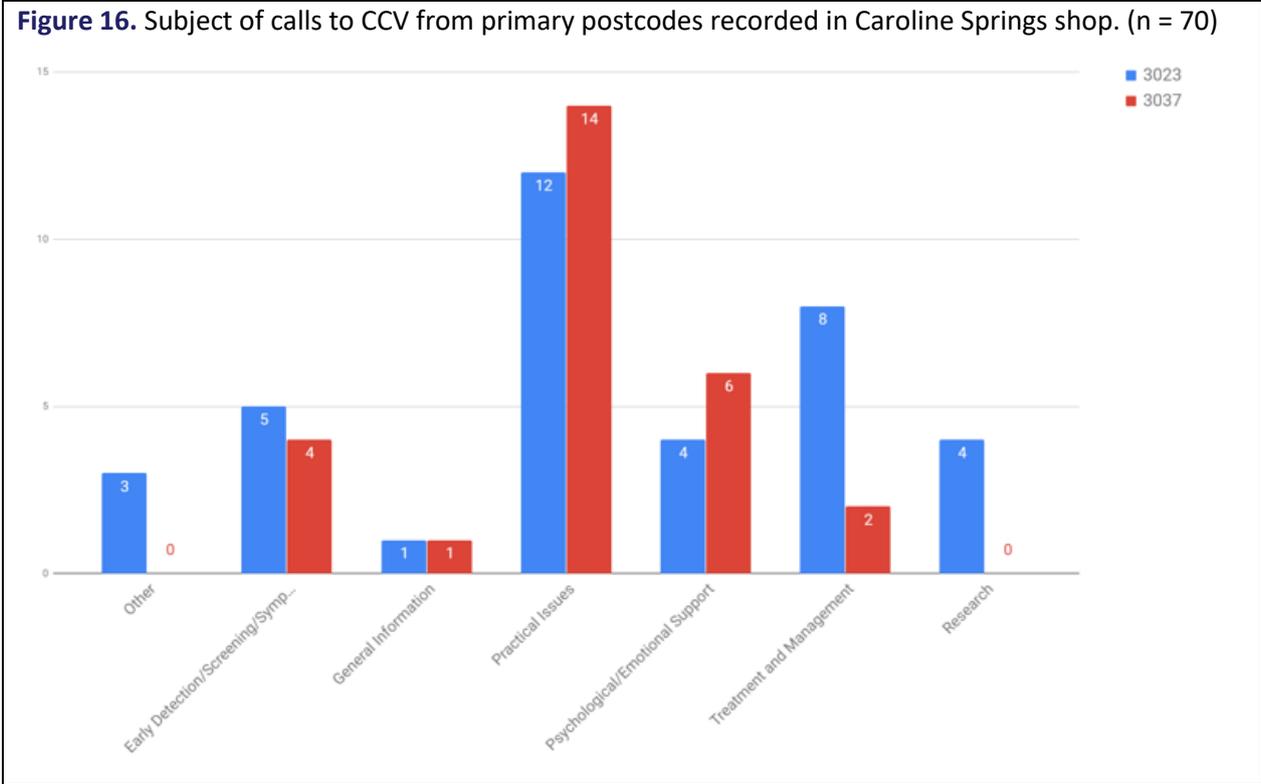
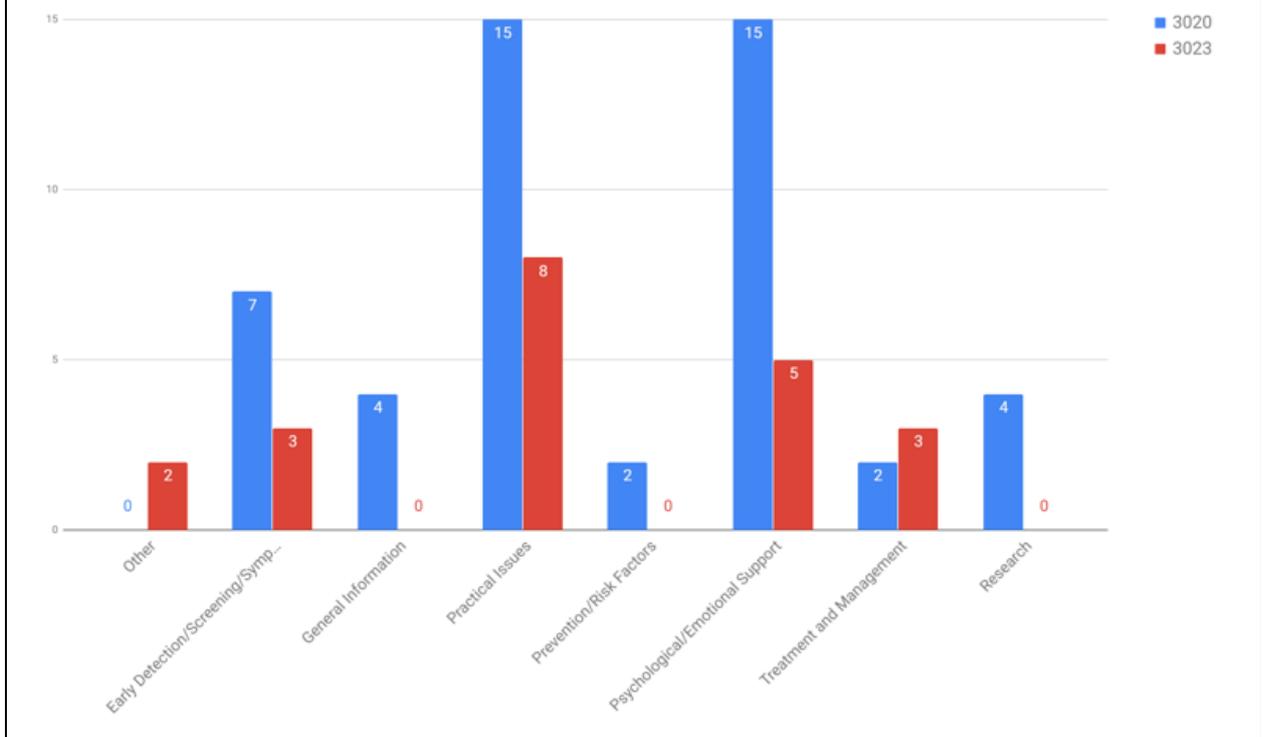


Figure 17. Subject of calls to CCV from primary postcodes recorded in the Caroline Springs shop. (n = 64)



4.8.2 Breastscreen Victoria data

Following the Caroline Springs shop Breastscreen Victoria were asked to supply data about referrals to their service from primary postcodes related to the shops. This data is not yet available and will be provided to the DHHS when it has been provided.

4.8.3 Communications and marketing results

Extensive use was made of social media to promote the shop and ensure that it reached the diverse audiences targeted. Facebook was chosen as the primary medium for engagement, and content was produced. This was supported by targeted advertising to the postcodes surrounding either shop.

This resulted in many posts with large reach. Five posts had over 5000 views, with a total of 76,082 views of Let’s Talk About Cancer Facebook posts. This was significantly more than expected based on audience response to other NWMPHN social media content. The most successful posts were of the Let’s Talk About Cancer video, which received 21,469 views, and of the ‘Let’s Talk About Quitting’ invitation and graphic, which received 9344 views. These posts achieved 238 and 155 likes respectively, and there was a cumulative total of 813 likes on posts by the page. Content was shared by the public 205 times and 34 comments were made on posts.

The shop was also supported with traditional media. The Brimbank and North West Star Weekly published an article based on NWMPHN’s press release for the shop launch. The newspaper has a circulation of 72,158. The Melton Star Weekly was invited to the Caroline Springs shop and produced an article with a prominent image on Page 3. The newspaper’s weekday circulation is 47,550.

The Caroline Springs shop was advertised with internal advertising within Caroline Springs mall. This supported the shop and raised its profile. Indicative feedback from the public indicated that the advertising made the shop much more prominent and increased awareness, but the scale and degree was not measured. Approximately 50 posters and several hundred brochures were supplied by

NWMPHN to Brimbank Council before the Sunshine shop for distribution to libraries and community facilities. Before the Caroline Springs shop 30 posters and 300 brochures were distributed to Melton Council for placement in libraries and recreation facilities.

The use of local and ethnic radio was considered by the NWMPHN media team but was decided against because of constraints on staff resources and time. This may be an avenue for future promotion of pop up shops.

“This shop is a story-telling shop. People come here, and they tell every kind of cancer story.”

– Pop up shop cancer nurse

5 Discussion

5.1 Operation

5.1.1 Acceptability of shop format and presentation of cancer

Early in the planning of the shop the steering group discussed the naming and format of the shop. This included discussions of the use of the word ‘cancer’ and its potential to cause alarm and prevent entry and discussion of health topics. It was decided that use of the word ‘cancer’ would ultimately help to destigmatise the disease and reduce fear by encouraging open discussion of the disease. Conversely, concealing the purpose of the shop could potentially reinforce stigma.

Both shops engaged a large number of the public in cancer-based conversations. Those who used the shop found them useful and informative, and volunteers and nurses indicated that they had many positive interactions with the public, and that these were consistent across many cultural groups. This and the results from those interviewed at the Sunshine shop support the acceptability of the shop format and its application to cancer.

While there were large numbers of people who entered the shop, it is not possible to determine the attitudes and reactions of those who did not enter the shop. Some people may have found the concept of having a conversation about cancer disturbing or confronting.

The shop format was specifically designed to be multicultural, with signage emphasising linguistic diversity and inclusion. This helped account for its reach among diverse communities in Melbourne’s West. A strength of the shop was the contribution of culturally and linguistically diverse volunteers and staff. Their linguistic and cultural understanding assisted with making the shop accessible, and in providing a ‘bridge’ that allowed the person to come in and feel comfortable. When the staff or volunteer was able to speak or understand the participant’s language they were also able to assist in providing information materials in that language. This helped to contribute to the goal of increasing equity of screening and access of cancer treatment.

This reach could have been extended through greater engagement and connection with cultural and community organisations in Melbourne’s west prior to the shops. If future shops are operated these should aim to incorporate a significant degree of linguistic and cultural diversity.

5.1.2 Demographics of visitors

People who visited the pop up shops tended to be highly concentrated in the immediate areas surrounding the shop, as seen in the postcode data. This suggests that a large geographical distance is not necessarily needed between pop up shops to attract an entirely new population of people. The large majority of those entering the shop did so because of being approached by a volunteer or nurse and were undertaking shopping or ordinary business.

The shops had a concentration of visitors between 50 and 70 years of age. This may reflect several factors. There is an increased incidence of cancer in those above 50 years of age. Those in their 50s,

60s, or 70s are likely to be aware of the likelihood of cancer and have greater motive to take action to seek advice or assistance with cancer. They are also more likely to have known a family member or other person who has had cancer. The opening hours of the shop may have impacted on those attending. People of retirement age may have been more likely to be present in shopping malls during the day when younger people are often at work, lessening their likelihood of engagement.

Most visitors to both shops were women. Women are recorded as having greater health seeking behaviours than men in many contexts.⁶ The larger numbers of female visitors may have also reflected a greater number of female nurses and volunteers in the shop. Most of the nurses working at the shop were women, as were most volunteers. However, the volunteers and nurses did not notice a large difference in the gender composition of those visiting on days when there were male nurses or volunteers, and this was also confirmed by the project manager.

There was considerable ethnic diversity in both shops, and this reflected the ethnic composition of the postcodes surrounding the shops. Demographic information from the Caroline Springs shop was less clear than in the Sunshine shop. In the Sunshine shop volunteers were instructed to ask the public for their self-identified ethnicity. In the Caroline Springs shop nurses completed the ethnicity question based on their conversation, without necessarily asking people to self-identify their ethnic group. This may have resulted in less clarity through inferred ethnicity.

5.1.3 Shop operation

The Sunshine shop was operated in the month of February, and despite several days above 35 degrees, the temperature inside air-conditioned shopping mall and the shop remained comfortable and did not appear to impact shop operation. The Caroline Springs shop was run in June, and this had a measurable impact on staff and volunteer experience. The shop was located adjacent to a mall entrance, which meant that large volumes of cold damp air entered the shop each time the automated doors opened. Days were short, darker and cold. This impacted staff and volunteer energy and morale, and volunteer absences were frequent. Noise from shopping trolleys and a 'Thomas the Tank Engine' miniature train also affected the operation of the Caroline Springs shop on some days.

Volunteers also emphasised that the success of each shop was not due entirely to the level of activity in the shopping centre but was also the result of having a quiet and comfortable space to talk with the public.

Security and staff safety were a consideration for shop operation, and procedures were put in place to manage safety. Both shops were in shopping centres which had security guards, and their numbers were displayed prominently, and staff instructed to call them for any reason. In both shops staff experienced the entry of visitors who made them feel uncomfortable, and in one case a security guard was called to escort a person from the shop, which happened efficiently and safely. This was not an aspect of shop operation that was expected and reinforced the need to keep staff and volunteer safety paramount. Shop location within malls and season of operation should be considered in order to maximise pedestrian flow and staff and volunteer comfort. Safety should be emphasised in planning, and staff and volunteers given instruction in contacting security and escalating a situation to ensure their safety.

5.1.4 Staffing and nurse data collection

The importance of selecting the right nurses and volunteers cannot be overstated. Successfully engaging the public is both a skill and a talent. It is important that nurses and volunteers have a positive and welcoming attitude. At the same time, it is important that they do not act in an overly

⁶ James A Smith, Annette Braunack-Mayer and Gary Wittert. 2016. 'What do we know about men's help-seeking and health service use?' *Medical Journal of Australia*, 184:2, pp. 81-83.

forward way that makes people uncomfortable or seem to be too eager to get people into the shop. Staff and volunteers with experience and who enjoy interacting with the public are of great value to a shop and it is important that they receive support and training to enhance and practice these skills.

An illustration of this occurred one morning when all volunteers were absent due to illness or other commitments and only one nurse was present. This nurse had considerable experience in providing information in public environments such as festivals and engaged the public with friendly questions about their screening or cancer knowledge. The nurse was able to use these skills to bring in the public. Over a two-hour period, 17 nurse-public conversations were recorded. This represented the busiest single period during the operation of either shop.

Several factors likely contributed to the increase in activity, including the nurse having conversations that volunteers may have had, but it does demonstrate the potential impact of staff selection.

In the Caroline Springs shop nurses were asked to record information about the participant interaction in a computer-based data collection form. This was performed consistently, and overall reached a high standard. Because the data entry was performed after the participant had left the nurse conversation, there was no opportunity to engage them further on questions. An unintended result was that questions about participant's impression of the shop and intention to act which were not asked by most nurses, with only 52 of 243 data entries recording at least one of these questions. This section had almost uniform entries of the highest possible score. Due to low numbers and unreliable quality, this data has not been reported. Consideration should be given to the creation of a short card-based feedback form allowing participants to rate their experience in subsequent shops.

Data collection during subsequent shops should be informed by the need to create a simple and consistent data-collection protocol, which is well understood and appropriate for the staff or volunteers asked to use it. Materials used in the collection of data are contained in the *Pop Up Shop Resource Toolkit*.

5.1.5 Shop utilisation

At the Sunshine shop, volunteers were encouraged to move outside the shop and engage the public. There was a high-degree of volunteer-public interaction, with conversations about cancer and other topics initiated out of the shop. These were then transferred into the shop, with participants shifting to a nurse for a more detailed and rich conversation. In a few cases the public were not willing to speak directly with a nurse and instead chose to take an information brochure. Members of the public rarely entered the shop without encouragement. Most members of the public chose to use the couches in the open areas for conversations with nurses. The private consultation area was used rarely but was typically utilised for conversations that were deeply personal, contained private or sensitive information, or involved conversations about grief or loss.

Feedback from nurses and volunteers indicated that members of the public were frequently confused about the nature of the shop. The shop was marked by large signage in bright colours emphasising that the shop was about cancer. This signage also emphasised that the shop was free. Despite this, it was not clear to everyone what the shop was or why the volunteers and nurses sought to engage the public. This was reflected by several members of the public attempting to give cash donations at the shop (members of the public attempting to donate were referred to CCV's phone number and website and given information about their services).

In the last week of operation of the Caroline Springs shop, the nurse on duty trialled moving the information stall to the entrance, which did appear to be effective at bringing people into the shop. This made it clearer that the purpose of the shop was the provision of information and may be a consideration for any future shops. This might also be accompanied by the distribution of information brochures or altering shop promotion brochures so that they contain cancer screening and prevention information.

The Sunshine shop was located in a mall with a relatively low number of shoppers and entrants but high levels of vacancy. This demonstrates the logical conflict between vacancy and availability, with availability generally highly-restricted in desirable high-traffic malls and shopping strips. This may be mitigated through cooperative relationships with the large mall operator groups, including Scentre (formerly Westfield), Stockland, Lendlease, and Vicinity and more flexibility over where and when to run shops. Each group runs multiple malls across Melbourne and are frequently willing to work with reliable organisations with high-quality pop up shops that add to their malls.

5.2 Cancer discussions

Members of the public indicated to nurses and volunteers that the shop was a space in which they felt comfortable having conversations they would not have with a doctor. An example of this was a case in which a person of European descent revealed to a nurse that they believed that their abnormal bowel test results were the result of a sexually transmitted infection. They believed this may have been the result of the activity of their partner and were considering ending that relationship. The person had felt they were unable to discuss this with their GP. The nurse was able to provide information in the native language of the person and explain that the results were not the result of any infection, and the person was sufficiently relieved that they expressed that they would no longer end their relationship.

Other conversations or interactions with the public revealed that people were putting off desired or needed interactions with the medical system. These included delayed or avoided screening activities. An example of this was a woman who entered the shop concerned about a new sun spot on their face. This woman had not had a cervical screen in many years and had never had a breast screen but had completed a bowel screen. Discussions like these highlight the importance of knowledgeable staff able to confidently engage on a wide range of topics.

The greater number of conversations in the Caroline Springs shop is likely to be attributable to a range of factors. The shop was in a busier shopping mall which offered a greater opportunity for interactions. The nurses and volunteers involved in the shop had gained experience through their operation of the Sunshine shop and gained additional skills in interacting with the public in this unique setting. The shop was also better supported with local and in-mall advertising, and a large Facebook campaign. These may have made the public more familiar with the concept and receptive to the messages used. Finally, the demographics of the shop differed, and the different populations may have responded differently to the messages presented.

Community and cultural organisations based in Melbourne's west were invited to participate in the Caroline Springs shop. Prior to the shop, letters, posters, and brochures were sent out to 48 organisations to invite their leaders and members to visit the shop and enjoy 'tea and coffee and cake'. Unfortunately, this was not a successful exercise, as no organisations responded to the invitation. To ensure greater participation from community and cultural organisations it is important to engage and leverage existing relationships. This may be possible where the project manager or other staff have extensive local experience or deep connections with the communities in which the shops are based, but where this is not possible relationships might be developed over several months, and the use of intermediary staff or organisations may be necessary.

Similarly, the shop manager organised and promoted several prevention-focused and Aboriginal-focused mornings and days. These were supported with Facebook posts and advertising, and staff from CCV and IPC Health were in attendance to support these. Despite the effort put in, they did not connect with the populations affected. Closer connection with Aboriginal health and community organisations is recommended, as is a broad approach that facilitates nurses engaging in prevention conversations as part of the wider cancer conversation.

5.3 Replication

5.3.1 Replication of shop in other environments

This trial has shown that the pop up shop concept is suitable for replication in other environments. The model was applied to two locations within Melbourne's west that were ethnically and culturally diverse, and with differing socio-economic profiles. The response of the community was positive and the diverse entry to the shop suggests that it would be well received in other locations. Members of the public indicated to staff and volunteers that they were keen to see more of the shop, in other locations. Several people asked volunteers why the shop was temporary and expressed that it should be permanent. Volunteers themselves were keen to see another shop and asked the project manager for the next location.

It is suggested that if the shop is run again that an organisation with existing cancer-nursing or cancer-information capacity may be a good fit. All organisations involved in the project maintained a high degree of cooperation and facilitated their staff's involvement in the shop. However, as a coordinating agency, the NWMPHN lacked internal nursing or volunteer capacity and had to contract out to partner organisations. There were high in-kind contributions required of the lead agency, notably from the communications team and the contracts and finance team. The external nature of nursing and cancer-information staff also meant that the project was subject to the rosters and needs of other organisations. The use of internal capacity may eliminate or mitigate these factors.

The ability to run such a shop is predicated on the availability of vacant real-estate in suitable high-traffic locations. These conditions are not predictable in a particular location, but with a greater geographic spread it may be easier to source appropriate shops. A regular repetition of pop up shops across diverse locations would increase the reach of the project and ensure that the resources involved in its production were utilised effectively. Management of any future shops by an organisation with a statewide reach may be advantageous.

Set-up and development costs represent a large proportion of the overall costs incurred by the lead organisation. These included design and communications work, oversight and training, and the employment of a project manager to develop and evaluate the shop model. These costs could be minimised with replication of standard elements within the model. This would prevent the need for reinvention and duplication of work. While this model resists an 'assembly line' approach, there is considerable scope to replicate the shop and its component elements.

5.3.2 Replication of shop with other diseases

During the initial stages of planning, the steering group discussed the inclusion of cardiovascular diseases within the shop model due to several overlapping risk factors, including overweight and obesity, dietary risks, lack of physical exercise, and tobacco. It was decided by the steering group that a singular focus on cancer would allow for a stronger disease-specific approach and a clearer call to action for the public. It was also envisioned that this would help reduce the stigma and fear surrounding the word 'cancer.'

The pop up shop model may be suitable for replication with other diseases. This is particularly so for widespread non-communicable diseases which have confusion or fear associated with the disease. These could include; cardiovascular diseases, stroke, chronic kidney disease, diabetes, depression and anxiety, and dementia. Communicable diseases associated with stigma, such as viral hepatitis, may also be suitable. Each contributes significantly to Victoria's burden of disease and are worsened by a lack of understanding about prevention, screening and diagnosis, and treatment.

5.4 Recommendations

The following recommendations are suggested for future pop up shop projects, based on the findings of the 'Let's Talk About Cancer' pop up shops:

- That DHHS considers further pop up shops for cancer outreach and dissemination of care and screening at other locations across Victoria.
- That the shop model continues to focus on priority populations, particularly areas containing significant CALD populations and/or high levels of deprivation.
- That further efforts are made to expand and diversify engagement with community organisations.
- That shops are run in high traffic locations, primarily shopping malls, and strong consideration is given to location and season of operation.
- That an emphasis on being a safe, welcoming, non-medical environment is maintained.
- That volunteers continue to be a key element of any future pop up shops.
- That volunteers and nurses continue to receive high-quality training in cancer conversations and referral.
- That the multi-organisation partnership model is continued and developed.
- That this model be implemented by an organisation with internal cancer nurse capacity, or in close partnership with such an organisation.
- That DHHS investigate the possibility of running pop up shops for diseases other than cancer.

A number of practical recommendations about the model of operation are provided:

- That consideration is given to the shop being run for three weeks rather than four.
- That signage is refined to further advertise that the shop is free.
- That materials and signage continue to reflect the cultural and linguistic groups represented in the target location.
- That heating and cooling are considered in shop selection.
- That volunteers and nurses have access to private space within the shop.
- That shops are located close to transport options.
- That shops are supported by a strong social media presence and Facebook advertising.
- That data collection is further refined to reflect lessons from the Melbourne shops.

NWMPHN has developed a *Pop Up Shop Resource Toolkit* to allow other organisations to adopt the model for use in their own contexts and communities and learn from the experience of running the Melbourne shops.

5.5 Summary

The 'Let's Talk About Cancer' pop up shop was a DHHS-commissioned pilot project to trial a new method of promoting cancer messages and increasing uptake of screening and care.

The project investigated the feasibility and usefulness of a 'pop up shop' to support greater cancer awareness in Victoria and increase screening and use of cancer services. The two 'Let's Talk About Cancer' pop up shop demonstrated that the model was viable. The two shops demonstrated a large

reach, high degree of acceptability, and positive feedback from a diverse audience in two Melbourne suburbs.

Although Victoria has a high level of quality care for cancer, there remain inequalities in access to screening and care. Language and cultural barriers remain considerable barriers to access of services and are responsible for worsened outcomes compared to non-CALD populations. Real and perceived financial barriers can reduce access to primary and cancer care, particularly for migrant populations.⁷ By situating the pop up shop in the local community, the shop allowed the public to talk and seek information in a comfortable environment.

Over 8 weeks of operation, the two pop up shops attracted over 420 participants who actively engaged in nurse conversations, who may not otherwise have accessed support, information or medical services. The shops also reached tens of thousands of Melbourne residents through social media, newspapers, advertising and the distribution of brochures and resources. The shop was able to refer on people who had lapsed from screening services and provide a point of contact for people affected by cancer who were unaware of available support services. The shop also facilitated a large number of conversations about prevention and related topics.

The pop up shop model proved highly acceptable to the community and received high levels of approval. At each shop thousands of people were given cancer messages directly and through promotional activity. A large number of people were given information or assistance to access cancer screening services and were engaged in prevention conversations and referrals.

The shop proved its value in two locations with high concentrations of cultural and linguistic diversity. The shops were well received across diverse audiences and patronised by a range of ethnic and linguistic groups.

This shop showed the value of a partnership model for the implementation of a pop up shop. Each of the contributing organisations brought expertise and resources to the project that added in a synergistic manner. The combination of experienced cancer nurses and trained volunteers meant that the public were able to access cancer information and support in a non-medical community environment.

This project was the first time the pop up shop model has been applied in an Australian context and contains a range of important learnings and lessons. These have been captured in the *Pop Up Shop Resource Toolkit* which has been developed by NWMPHN for use by health services interested in running a cancer pop up shop.

The cancer pop up shop model is a useful addition to Victoria's approach to reducing the risk of cancer and increasing uptake of screening for early detection of cancer.

⁷ Federation of Ethnic Communities' Councils of Australia, 2010. 'Cancer and Culturally and Linguistically Diverse Communities', Canberra.



Image: Tessa van der Riet