VCCC ALLIANCE DATA STRATEGY 2024-2029

Health Equity

21 February 2025

Contents

Background

1. Vision

The vision of the VCCC Alliance 2024-2029 Strategy (the Strategy) is to save lives through the integration of cancer research, education and patient care driven by improvements in prevention, detection, treatment and survivorship for all. Building on progress and achievements resulting from the programs established in the Strategic Program Plan 2021-2024 (SPP), the VCCC Alliance will continue working to decrease the cancer burden and further improve outcomes for all cancer patients in Victoria. All Victorians should have access to world-class cancer care closer to home, fast-track to new therapies, better care through upskilling of health workers, and benefit from utilisation of new technologies to link data particularly between primary care and hospital to improve early detection. Patient-centred care will be championed to be at the forefront in each Victorian health service, helping hospitals care for complex cancer patients facing intersecting disadvantages. Clinical research will be embedded into routine care, and new models trialled for early palliative care for regional Victorians with cancer.

The VCCC Alliance will achieve this vision by working on five strategic areas:

1. Collaborative research - bring the best minds and organisations together to turn research into better cancer outcomes.
2. Data and technology - drive better sharing of data and knowledge, and use of technology, so patients benefit from latest evidence and advance.
3. Equitable care and outcomes - ensure ALL patients have access to optimal care.
4. Patient-powered - integrate diverse consumer perspectives to improve research and care.
5. Leadership and learning - upskill, support and inspire the cancer workforce to deliver world-leading outcomes.

2. Purpose

This document presents the health equity data strategy for the current phase of the VCCC Alliance. Although it outlines the strategy and activities in the health equity strategic pillar – equitable care and outcomes, the principles are applicable to all projects and activities across all the VCCC Alliance strategic goals as equity is one of the key tenets of the VCCC Alliance to strive for equitable access to cancer care and outcomes for all Victorians affected by cancer. Current activities and projects outlined in the Health Equity program are mapped to the Victorian and Australian Cancer Plans, together with potential future undertakings.

While the health equity program takes an intersectional approach to health equity, this document outlines strategies in three priority population groups as outlined in the Strategy: (1) Aboriginal and Torres Strait Islander communities[1], (2) culturally and linguistically diverse communities (CALD), and (3) rural and regional populations (see Figure 1).

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[1] Aboriginal is used in throughout this document to represent Aboriginal and Torres Strait Islander population.

3. Data strategy guiding principles

A guiding principle for collection of data is predicated on the premise that data be collected at the 'source of truth' and only once whenever possible. This translates to capturing data at the coalface or embedded into routine business practice. Datasets should be developed based on how routinely and frequently the data will be utilised to contribute to up-stream reporting and research. Data collection should not be an additional burden on already the stretched health workforce, and should be based on key performance indicators (KPI) that will elicit buy-in from users and encourage contribution.

All VCCC Alliance programs and projects should ensure a core foundation is in place for the collection of robust data to support evidence-based research, education and consumer activities. The following are guiding principles to enable the VCCC Alliance to properly capture accurate and robust data to report on the wellbeing of cancer patients:

Table 1. VCCC Alliance health equity data guiding principles.

1.	Data should be relevant, complete, and high-quality.
2.	Data collection should be streamlined and integrated into VCCC Alliance programs and projects captured as part of business practice or embedded into project plans.
3.	Data to be collected should be routinely utilised and be able to contribute to reporting and research.
4.	Datasets should be constructed so that they align with outcomes, benchmarking or key performance indicators (KPIs).
5.	Datasets should be driven by stakeholders based on outputs or outcomes they see as beneficial to them.
6.	Datasets should be collectively determined to ensure there is equitable input from all stakeholders.

Internal and external reporting protocols will be developed for all VCCC Alliance health equity projects. Collection of data will be structured first and foremost based on reporting on KPI's, either to the Department of Health or leadership groups (eg. VCCC Alliance Board, Health Equity Advisory Group). For the broader VCCC Alliance strategic pillars, a reporting process will be embedded into each strategic pillar that will allow information on equity to be streamlined and captured as part of business practice as much as possible. Similar principles apply to equity projects undertaken by VCCC Alliance member organisations. Ideally, a health equity dataset will consist of a mandatory minimum dataset and a wider full dataset based on specific programs or projects.

Health Equity Program data governance

As part of the new strategy, all projects undertaken or funded by the Health Equity Program (ie. Collaborative Projects), will adhere to the principles in Section 3 Data strategy guiding principles, and will be stipulated as part of the deliverables to in all collaborative agreements. The Health Equity team will collaborate to have more of a hands-on approach (where possible) and be part of the project governance enabling more input into the design of data capture, implementation and to actively engage and monitor progress of projects.

VCCC Alliance strategic pillar data governance

In the new VCCC Alliance strategic goals 2024-2029, each pillar should have an equity lens incorporated into all projects and activities. The first step in this is to capture accurate data within projects. To achieve this, the Health Equity team can advise and guide each program on the best practice to include equity into work plans and projects. This could be through having a member of the Health Equity team attend meetings of the other strategic pillars monthly. The onus is on program managers to ensure that equity is incorporated and reported as part of workflow. There will be a gradual integration of equity (via the Cancer Equity Framework – see below).

VCCC Alliance members data governance

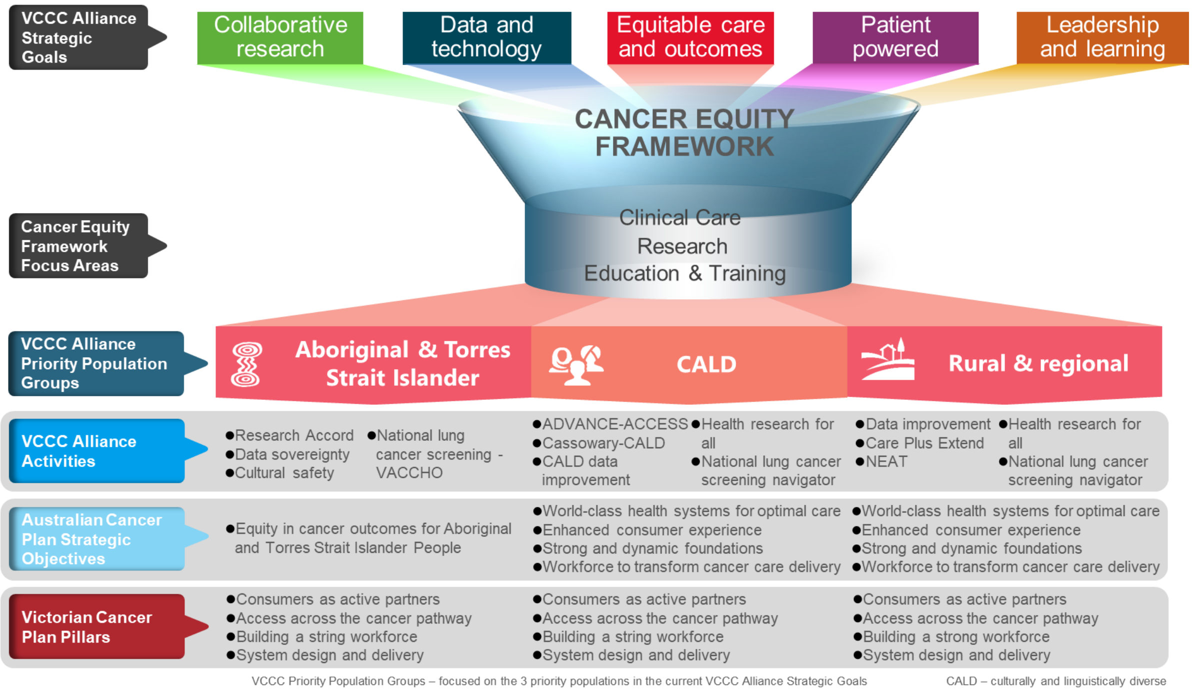
For VCCC Alliance members, the Health Equity team will help guide and influence the inclusion of equity and capture of data on equity for projects or activities that the VCCC Alliance are involved in, wherever possible. Identification of data and processes will be generated through discussions via project managers or principal investigators, with health service health information managers or business intelligence units, to ensure relevance and feasibility of collecting data and reporting on these initiatives.

Equitable Care and Outcomes

The VCCC Alliance strategic goal is for all patients have access to optimal care. The aims are to ensure that people and systems are equipped and enabled to improve cancer outcomes for all Victorians, particularly underserved populations, and Aboriginal and Torres Strait Islander Peoples. All Victorians affected by cancer should also have access to timely palliative care to improve quality of life. Equity and diversity should be embedded into all VCCC Alliance programs underpinned by the captured of relevant data.

Equity will underpin all VCCC Alliance strategic goals, and each strategic pillar will inculcate equity as a key component in activities undertaken to deliver on the overall strategy. This is illustrated in Figure 1. All data equity initiatives will be guided by their alignment to the Cancer Equity Framework (CEF). One of the guiding principles of the CEF is based on evidence and data. The Data strategy guiding principles (Section 3) will guide data collected for CEF activities. The CEF is further elaborated in Cancer Equity Framework section below. Improving more equitable access to cancer prevention, treatment and supportive care for priority populations are the priority areas in both the Victorian Cancer Plan and Australian Cancer Plan. The VCCC Alliance strategic goals and data strategy are well aligned to both plans particularly for Aboriginal and Torres Strait Islander, CALD and rural and regional communities (see Figure 1, Victorian Cancer Plan, Australian Cancer Plan and Table 2 below).

Figure 1. VCCC Alliance health equity data strategy for each priority population group and alignment with the Victorian Cancer Plan 2024-2028 and the Australian Cancer Plan



VCCC Alliance Priority Population Groups	Aboriginal & Torres Strait Islander	CALD	Rural & regional
VCCC Alliance Activities	●Research Accord ●Data sovereignty ●Cultural safety ●National lung cancer screening - VACCHO	●ADVANCE-ACCESS ●Cassowary-CALD ●CALD data improvement ●Health research for all ●National lung cancer screening navigator	●Data improvement ●Care Plus Extend ●NEAT ●Health research for all ●National lung cancer screening navigator
Australian Cancer Plan Strategic Objectives	●Equity in cancer outcomes for Aboriginal and Torres Strait Islander People	●World-class health systems for optimal care ●Enhanced consumer experience ●Strong and dynamic foundations ●Workforce to transform cancer care delivery	●World-class health systems for optimal care ●Enhanced consumer experience ●Strong and dynamic foundations ●Workforce to transform cancer care delivery
Victorian Cancer Plan Pillars	●Consumers as active partners ●Access across the cancer pathway ●Building a string workforce ●System design and delivery	●Consumers as active partners ●Access across the cancer pathway ●Building a string workforce ●System design and delivery	●Consumers as active partners ●Access across the cancer pathway ●Building a strong workforce ●System design and delivery

VCCC Priority Population Groups – focused on the 3 priority populations in the current VCCC Alliance Strategic Goals

CALD – culturally and linguistically diverse

Strategic areas of data improvement

1. Streamlined and consistent dataset for priority groups. Data collected for Aboriginal and Torres Strait Islander, CALD, and regional populations should be standardised and quality improved to enable more robust analysis.
2. Data linkage. Data collected for health equity projects could be linked with external datasets to investigate correlation with health service data.
3. Benchmarking. Data collected should help to identify gaps in health access and outcomes, monitor progress over time and identify priority areas for disparate populations. The use of benchmarking establishes a standard for assessing performance. Real-time assessment (eg. dashboards) improve timeliness or types of support services provided to disparate population groups. Longer term monitoring of equity activities will contribute to quality improvements in prevention and screening initiatives and access to cancer health services for priority populations.

4. Cancer Equity Framework

The CEF is designed to enable health services, the cancer workforce and cancer researchers to embed an equity lens into their core work and address inequities in service delivery and cancer outcomes (see Figure 2). Establishing a shared language and understanding of the underlying drivers of health inequities, the CEF calls for action in 3 areas – (1) clinical care, (2) research, and (3) education and training. It proposes culture change as a continuous cycle of action where leaders, the cancer workforce, consumers, and community work together to understand and strive to address the underlying drivers of health inequities. In addition to improving equity for patients, equity also involves organisational and cultural diversity, and effecting change through education and introducing a safe environment in which the healthcare workforce can operate and function.

Guiding principles

1. Acknowledging the ongoing impacts of colonisation and historic discrimination
2. Understanding intersectionality
3. Building common understanding and shared vision
4. Taking a systems approach
5. Developing a diverse workforce
6. Using evidence and data to inform change
7. Being patient centred
8. Being trauma informed

Guiding principles are based on cancer care and control plans, and strategies to address persistent discrimination and barriers in the health system.

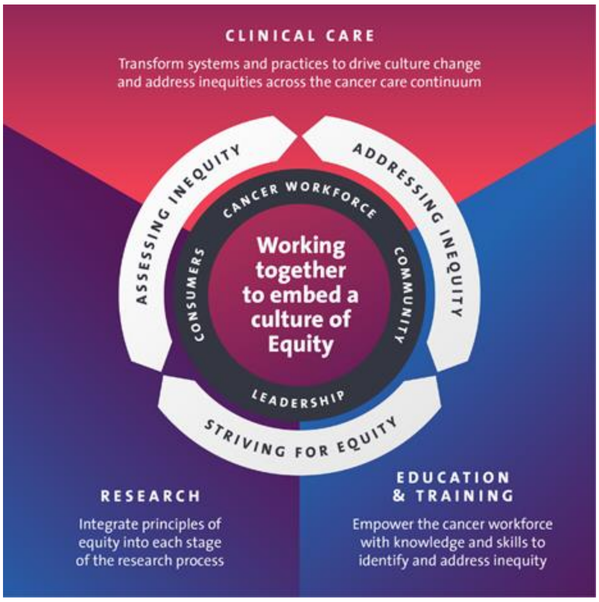
Assessing inequity is a key component of the CEF. To advance health equity it is essential to investigate patterns in health disparities and identify the underlying drivers (root causes) of unwarranted variations in cancer survival, life expectancy, morbidity and quality of life for different population groups. Effective data collection and analytics are necessary to implement and sustain organisational change and promote health equity (Doherty et al 2021).

There is a need to capture better data on priority populations in health services and to understand the broader impact of social, cultural, and environmental determinants of health on cancer outcomes for these populations. Central to this is determining what data is missing to enable better understanding of the needs and experiences of different communities and building data infrastructure to collect and act on this data (Linfield Z et al, 2023). This requires working closely with priority populations to inform what information to collect, and how to act on that information.

Better equity data will enable identification of diversity (patients and workforce), process (policies, guidelines, training), systems (software and hardware), and report (government, projects, communications).

To pilot the operationalising the CEF, the VCCC Alliance will fund six projects in the three action areas in identified priority populations (Table 4 and Table 5).

Figure 2. Cancer Equity Framework



5. Victorian Cancer Plan

In 2023, the Victorian Government sought consultation for its cancer strategy over the next four years to identify priorities to improve cancer outcomes for all Victorians. The cancer plan aims to continue with the same 5 priority action areas of the previous Victorian Cancer Plan (2016-2020) where a key focus was on achieving health equity across the cancer system so that the unique needs and experiences of every person are recognised and people are not disadvantaged by who they are, where they live, or their level of resources.[2] A new Victorian Cancer Plan 2024-2028[3] was launched in September 2024. Priority areas in the plan over the next 4 years are for greater equity in access to cancer prevention, treatment and supportive care. There is also a need for renewed focus on cancer screening and early detection. Figure 1 shows how the VCCC Alliance strategic goals and activities align with four pillars of change in the Victorian Cancer Plan. The Health Equity program can identify activities and projects within these four pillars (see Table 2).

6. Australian Cancer Plan

Cancer Australia launched the Australian Cancer Plan in 2023 and is designed to improve cancer outcomes for all Australians, particularly for those groups whose health outcomes are poorest. Achieving equity in cancer outcomes will be a fundamental measure of success for the plan and will align Australia with global calls to improve cancer outcomes for all people.[4]

Five Australian Cancer Plan strategic objectives align with the VCCC Alliance strategic goals and impact on this data strategy (Table 2). Under Strategic Objective 4, the Australian Cancer Plan has laid out

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[2] Victorian Government, Victorian cancer plan 2016–2020 - Improving cancer outcomes for all Victorians, (Melbourne: Victorian Government, 2016).

[3] Victorian cancer plan 2024–2028, Victorian Government, 2023, accessed 16 September 2024, https://www.health.vic.gov.au/health-strategies/victorian-cancer-plan

[4] Cancer Australia, Australian Cancer Plan (Summary), (Surry Hills, NSW: Cancer Australia, 2023).

implementation considerations for priority populations. For people from culturally and linguistically diverse (CALD) backgrounds, there are 2 priority areas:

- Improved data collection and linkage to better identify people with a diverse background who are at greatest risk of poor cancer outcomes.
- Improved data collection to understand cancer screening participation rates and targeted programs to improve health literacy and participation rates across specific communities.

One of Cancer Australia's key area of action is the development of an agreed National Cancer Data Framework where a draft was prepared for public consultation which closed in November 2024. The design and implementation of the framework is heavily predicated on a report by Cancer Council Australia in mapping the Australian cancer data ecosystem and describing a vision and steps in achieving a cancer data maturity strategy.[5] A mature data system would have the ability to produce a routinely updated national master linked dataset contributed by state, territory and Commonwealth data collections, held in a secure research environment accessible by accredited and accountable analysts and researchers, with simplified data custodianship and further capacity to link collections such as quality clinical registries. The framework will be guided by the principles of the various Australian Government data strategies, three of which are:

- Aboriginal and Torres Strait Islander data sovereignty - Aboriginal and Torres Strait Islander leadership is integral in data collection, management, and use of Indigenous data.
- Australian cancer data is an asset to drive value in healthcare - Australia has a cancer data ecosystem that is accessible through modern infrastructure, enables collaboration and is used to inform policy and health service delivery, to drive economic value, support innovation and overall improvement in cancer outcomes.
- Patient-centred and inclusive - data are used to ensure treatment and care are patient-centred to deliver the best outcomes and improved equity for all Australians. A specific focus on hard-to-reach, under-represented communities, including minority groups and remote and rural communities, will be a feature of the system.

To this end, the VCCC Alliance health equity initiatives and data strategy are well placed to contribute to activities to realise the framework to further enhance our understanding of improving access to prevention, treatment and supportive care for priority populations. It is intended that the framework will set the strategic direction for comprehensive cancer data collection, management, use and reporting in Australia including consideration of a benchmarking system. An agreed minimum cancer dataset that can be expanded upon will ensure comprehensive and consistent approach to data collection by states and territories, and public and private entities, including agreement to key quality indicators to monitor optimal and equitable care through networked cancer services including the uptake of the Optimal Care Pathways.

Table 2. Alignment with VCCC Alliance Health Equity program with the Victorian Cancer Plan 2024-2028 pillars of change and the Australian Cancer Plan strategic objectives.

Victorian Cancer Plan	Australian Cancer Plan	VCCC Alliance Health Equity program
Pillar 1. Consumers as active partners - the cancer pathway should be designed to meet the diverse and intersecting needs of people affected	**Strategic Objective 2.** Enhanced consumer experience.	Working closely with consumer groups, the Health Equity program will strive for better diversity across all consumers to promote appropriate representation of patients accessing cancer and health services.

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[5] Cancer Council Australia, *Developing a National Data Strategy for Cancer: A Report for Discussion* (Cancer Council Australia, October 2023 2023), https://www.cancer.org.au/assets/pdf/developing-national-data-strategy-for-cancer.

by cancer, families, carers and communities.		
Pillar 3. Optimal access across the cancer pathway - timely access to high-quality and high-impact prevention, early detection, treatment, clinical trials and support services.	**Strategic Objective 3.** World-class health systems for optimal care.	Equitable access to clinical care and support services will be a focus of the Health Equity program. Projects include improving participation in lung cancer screening for priority populations, more equitable access to clinical trials in primary care and optimal time to access palliative care. Clinical care under the CEF will also touch on certain areas in the Optimal Care Pathway (see supplementary **Error! Not a valid result for table.**) including better identification of CALD patients to access supportive care and also receive optimal cancer care.
Pillar 4. Building a strong workforce - ensure high-quality cancer prevention, screening, care, support and research	**Strategic Objective 5.** Workforce to transform the delivery of cancer care.	Education and training will underpin the VCCC Alliance health equity program. Building on previously funded projects, training and educating the cancer workforce will continue through the use of an equity assessment tool for nurses in the regions. Development of learning resources will enable better identification of priority populations. Promoting and facilitating implementation of the *marra ngarrgoo, marra goorri* the Victorian Aboriginal Health, Medical and Wellbeing Research Accord Victorian Aboriginal Research Accord Project (VARAP) - VACCHO with cancer researchers will help increase the number Indigenous researchers.
Pillar 5. System design and delivery through research, data and intelligence - improve data and intelligence capabilities, and leverage existing assets, technology and research to strengthen the cancer pathway.	**Strategic Objective 4.** Strong and dynamic foundations.	The VCCC Alliance funds Data Connect which links datasets from primary care, acute care, administrative and cancer registry data to examine cancer across the continuum of care. Through further collaboration, the Health Equity program aims to work more closely with Data Connect to better identify CALD and other priority populations diagnosed with cancer prior to diagnosis while attending primary care clinics.
-	**Strategic Objective 6.** Achieving equity in cancer outcomes for Aboriginal and Torres Strait Islander Peoples.	VCCC Alliance will support development of Indigenous data sovereignty and governance modules to improve on data captured on the Indigenous peoples. Broadening partnerships with VACCHO[6] and local ACCOs[7] will support implementing protocols for participation in the national lung cancer screening program.

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[6] VACCHO - Victorian Aboriginal Community Controlled Health Organisation

[7] ACCO - Aboriginal Community Controlled Organisations

Supplement

Table 3: Mapping VCCC Alliance health equity activities against the Victorian Cancer Plan 2024-2028 and Australian Cancer Plan 2023

Victorian Cancer Plan	Australian Cancer Plan	Current Activity	Potential Future Activity [8]	Priority population [9]
Pillar 1 – consumers as active partners	Strategic Objective 2 - enhanced consumer experience	Consumer engagement and being consumer led is integral in all activities undertaken by the VCCC Alliance. Health equity activities aim to adhere to the VCCC Alliance Model of Consumer Engagement.		
Pillar 3 – optimal access and care across the cancer pathway	Strategic Objective 3 - world-class health systems for optimal care Strategic Objective 6 - achieving equity in cancer outcomes for Aboriginal and Torres Strait Islander Peoples	• National Lung Cancer Screening Program • Care Plus Extend • Cassowary-CALD • ADVANCE-ACCESS	Understand and implement learnings from the CALD identification project to better identify CALD groups and Indigenous status. This could lead to better identification of these priority groups to encourage participation in clinical trials and the National Lung Cancer Screening Program.	• Aboriginal and Torres Strait Islander • CALD • Regional
Pillar 4 – building a strong workforce	Strategic Objective 5 - workforce to transform the delivery of cancer care	• Health Research for All • NEAT • We Can	Develop education resources/tools to train health professionals from learnings gained from all projects, including training workforce to be more culturally aware when capturing for CALD and Aboriginal and Torres Strait Islander people.	• Regional • CALD
Pillar 5 – system design and delivery through research, data and intelligence	Strategic Objective 4 - strong and dynamic foundations	• Cassowary-CALD • CALD identification audit	Future activities include collaborations with Data Connect, Cancer Australia and Victorian Agency for Health Information (VAHI) to link primary care data with acute care for clinical trial participation. Expansion of the CALD identification project piloted to other health services and collaboration with Australian Institute of Health and Welfare (AIHW), Australian Bureau of Statistics (ABS), Cancer Council Victoria (CCV) for standardised and improved data collection on CALD and Indigenous status.	• Aboriginal and Torres Strait Islander • Regional • CALD

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[8] Activities relate only to data specific activities to be undertaken under the health equity program and do not include activities to inculcate a culture of change in the wider context of the CEF.

[9] CALD – culturally and linguistically diverse.

Table 4: VCCC Alliance health equity data improvement work plan aligned to the Victorian Cancer Plan 2024-2028

Victorian Cancer Plan Pillar	Victorian Cancer Plan Actions	Collaborative Projects[10]	VCCC Alliance Led Projects[11]	Activity (current and planned)	Outcome	Priority population
Pillar 1 – consumers as active partners	• Improve and promote accessible information to consumers	All projects	All projects	• Adherence to consumer engagement model. Use of consumer engagement toolkit and checklist. • Data collected to demonstrate intersectional diversity and impact on VCCC Alliance projects.	• Consumer voices are embedded in all VCCC Alliance Collaborative Projects and VCCC Alliance led projects.	• All
	• Collect, monitor and respond to consumer feedback in care, service delivery and system design • Improve access to appropriate services and care for priority populations		CALD identification audit	• Develop education resources/tools to improve health literacy of consumers (patients, patient family, carers) in CALD data collection.	• Improvements in CALD data collection.	• CALD
Pillar 2 – empowering Victorians to prevent cancer	Not applicable	None	None	None	None	None
Pillar 3 – optimal access and care across the cancer pathway	• Improve timely and equitable access to screening and diagnostic services, focusing on priority populations	National Lung Cancer Screening Program[12]	-	• Engage and support VACCHO in developing screening resources	• Aboriginal and Torres Strait Islander population supported to participate in screening program in culturally safe and	• Aboriginal and Torres Strait Islander

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[10] Collaborative Projects – projects funded by the VCCC Alliance Health Equity Program which are led by VCCC Alliance members. The Health Equity team will have oversight through governance groups for each project. For a summary of Collaborative Projects, see Appendices.

[11] VCCC Alliance led projects are projects or activities where the Health Equity team leads the development of strategy, governance, implementation and evaluation.

[12] VCCC Alliance is a partner. VACCHO will have overall oversight and management of the project.

Victorian Cancer Plan Pillar	Victorian Cancer Plan Actions	Collaborative Projects[10]	VCCC Alliance Led Projects[11]	Activity (current and planned)	Outcome	Priority population
	• Support implementation of the National Lung Cancer Screening Program				appropriate ways leading to greater use of lung screening services.	
	• Support initiatives to increase access to palliative care	Care Plus Extend	-	• Expansion of a model of early palliative care (Care Plus) for people in underserved communities and people with target cancers.	• Increased proportion of Victorians with targeted cancers in collaborating regional areas receiving early palliative care more than 6 months prior to death.	• All • Regional
	• Ensure Victorians have access to the latest cancer treatments and clinical trials	Cassowary-CALD	-	• Adapt Cassowary trial program to facilitate CALD patients to participate in primary care-based cancer clinical trials.	• Development of optimised trial protocol and processes for CALD participation in primary care-based cancer clinical trials.	• CALD • Regional
	• Drive delivery of optimal cancer care through uptake of Optimal Care Pathways	ADVANCE-ACCESS	-	• Develop patient-driven strategies and implement pilot to improve access to symptom support services for CALD cancer patients.	• Strategies to improve access to symptom support services CALD cancer patients available to cancer sector to adapt and pilot in other healthcare settings.	• CALD
	• Improve the availability of culturally responsive screening and care services for Aboriginal and Torres Strait Islander people living in Victoria	-	Indigenous data sovereignty and governance modules	• Development of Indigenous data sovereignty and governance policies at ACCOs.	• Culturally safe and appropriate collection of Indigenous status, leading to better and more complete datasets.	• Aboriginal and Torres Strait Islander
Pillar 4 – building a strong workforce	• Enhance partnerships between clinical, academic and research institutions to support innovation and the workforce of the future	Health Research for All	-	• Development an online platform offering tools and educational resources to embed equity practices and training for researchers.	• Resources to embed equity into practices and training, readily available for Australian health researchers.	• All

Victorian Cancer Plan Pillar	Victorian Cancer Plan Actions	Collaborative Projects[10]	VCCC Alliance Led Projects[11]	Activity (current and planned)	Outcome	Priority population
	• Strengthen capability within the healthcare workforce to improve linkages across the cancer pathway	Nursing Equity Assessment Tool - NEAT	-	• Improve health equity data quality, collection and use of the nursing equity assessment tool (NEAT) in the regions. • Pilot framework across multiple sites (including regional). • Resource page made available on WeCan website.	• Improved workforce understanding of drivers of health equity and better identification of patients at risk of poorer outcomes due to other social determinants of health.	• All • Regional
		A navigator model of care for lung cancer screening	-	• Development of a navigator model of care with community partners. • Pilot the navigator model including resource tools.	• Better opportunities for CALD and regional patients to access lung cancer screening.	• Regional • CALD
		-	CALD identification audit	• Develop education resources/tools to train health professionals in collecting CALD data. • Implementation of education resources for health professionals.	• Cancer care workforce trained and supported to collect more accurate and comprehensive CALD data.	• CALD
	• Build a strong and supported Aboriginal and Torres Strait Islander workforce	-	Implementation of VACCHO Cancer Journey Strategy and Victorian Aboriginal Research Accord	• Support VACCHO in developing resources / protocols to implement the Accord. • Pilot implementation of the Accord[13].	• Increased research roles filled by Aboriginal or Torres Strait Islander researchers. • Establishing culturally safe and appropriate ways to engage meaningfully engage Aboriginal and Torres Strait islander	• Aboriginal and Torres Strait Islander

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[13] *marra ngarrgoo, marra goorri* the Victorian Aboriginal Health, Medical and Wellbeing Research Accord Victorian Aboriginal Research Accord Project (VARAP) - VACCHO

Victorian Cancer Plan Pillar	Victorian Cancer Plan Actions	Collaborative Projects[10]	VCCC Alliance Led Projects[11]	Activity (current and planned)	Outcome	Priority population
					people in health and medical research.	
Pillar 5 – system design and delivery through research, data and intelligence	- Improve access to clinical trials in regional and rural areas - Improve understanding of cancer outcomes through expanded linked data	Cassowary-CALD	Expansion of CALD identification audit	- Collaboration to improve identification of CALD cohort for primary care clinical trials in linking health service data with primary care data via Data Connect. - Integrate primary care data by developing protocols and governance for linking data for CALD communities from primary care data through to diagnosis, treatment and end of life care (ie. OCP Steps 1 to 7). This could be done via Data Connect, PLIDA, etc.	- Improve capture of CALD data in primary care. - Improve utilisation of CALD data to identify potential CALD primary care clinical trials participants. - Linking with other social determinants of health data eg. education, income and social protection, housing, etc. - Primary care data and health services linked to enable better access to clinical trials in primary care.	- CALD
	- Improve access to cancer screening data to increase screening participation rates	-	Support for development of Indigenous data Sovereignty and Governance modules at ACCHOs	- TBC	- TBC	- Aboriginal and Torres Strait Islander
		Nursing Equity Assessment Tool - NEAT	Linkage to Victorian Cancer Patient Experience Survey	- Explore concordance of validated patient-reported outcome measures (PROMs) with Victorian Cancer Patient Experience Survey. - Report on correlation of NEAT-PROMs and Victorian Cancer Patient Experience Survey.	- Greater insights into real world patient experience compared with targeted interventions.	- Regional

Victorian Cancer Plan Pillar	Victorian Cancer Plan Actions	Collaborative Projects[10]	VCCC Alliance Led Projects[11]	Activity (current and planned)	Outcome	Priority population
		-	Cancer Australia National Cancer Data Framework and Minimum Dataset	- Engage with Cancer Australia to elevate the importance of data collected on priority groups particularly CALD. - Engage Cancer Australia and AIHW in the development of minimum dataset for health equity indicators.	- Contribute to feedback and consultation of the draft National Cancer Data Framework. - Review development of benchmarking in health equity.	- CALD - All
			Benchmarking for health equity	- Development and validation of health equity indicators used to benchmark standards in health equity. - Convene committee or working groups to develop standards including a consensus list of indicators for benchmarking.	- Develop indicators for benchmarking in health equity.	- All
		-	CALD identification audit	- Expansion of the CALD identification project piloted to other health services. - Collaboration with AIHW/ABS/CCV on a minimum CALD dataset.	- Improvements in CALD data collection.	- CALD

Appendices

There are currently a number of health equity projects underway at the VCCC Alliance and member sites funded by the Victorian government. The following summarises these projects as well as highlighting activities or new projects that will be undertaken under the 3 priority population groups as described (see Purpose).

Aboriginal and Torres Strait Islander

Cancer and other neoplasms were the leading broad cause of death for Indigenous Australians, accounting 23% of total deaths. Age-standardised death rate due to cancer and other neoplasms have increased for Indigenous Australians, while the rate for non-Indigenous Australians declined. However, incomplete identification of Indigenous status in the data has led to substantial limitations in cancer data quality, data availability and data stewardship prevented a comprehensive assessment of these disparities, where the true difference in cancer incidence between Indigenous and non-Indigenous Australians are likely underestimated. [14]

National Lung Cancer Screening Program - VACCHO

Currently no lung cancer screening programs exist specifically for Aboriginal and Torres Strait Islander people. Lung cancer screening for Aboriginal and Torres Strait Islander Peoples will be developed and applied using an equity lens alongside the national Lung Cancer Screening Program (LCSP). Aboriginal and Torres Strait Islander participation to guide the codesign must be applied at the core of program design rather than a post hoc alteration to the mainstream program. The program has already been endorsed by key organisations. VACCHO will lead the development of a pilot trialling resources and education materials for communities, health services, ACCOs and primary care physicians to ensure appropriate referrals into the LCSP. This pilot has been funded by the Department of Health. Key documents drafted (two-page project summary, terms of reference, protocol, and budget).

Activity
1. Develop a collaborative lung cancer screening program between VACCHO, the VCCC Alliance and other relevant stakeholders (e.g., people living with lung cancer, Aboriginal and Torres Strait Islander researchers with expertise in cancer, economist). 2. To provide a culturally appropriate lung cancer screening program within an ACCO context by piloting lung cancer screening program in two ACCOs (one metropolitan, one regional setting) within Victoria. 3. To develop and implement a collaborative lung cancer screening program that recognises Aboriginal and Torres Strait Islander definitions of health and wellbeing and culture. 4. Align dataset with outcomes for the national Lung Cancer Screening Program but also aligns with the principles of Indigenous Data Sovereignty and governance of the collection, management and use of Aboriginal and Torres Strait Islander data.

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[14] Australian Institute of Health and Welfare & National Indigenous Australians Agency. Aboriginal and Torres Strait Islander Health Performance Framework (accessed 2 March 2025), https://www.indigenoushpf.gov.au/measures/1-08-cancer

Cultural safety training

Evidence-based culturally responsive and community-led are critical in transforming cancer outcomes for Aboriginal and Torres Strait Islander people. Through a meaningful partnership with VACCHO, there is a commitment to implement the Victorian Aboriginal Cancer Journey Strategy, with a strong focus on cultural safety, research governance, and data sovereignty.

Data sovereignty

Working with Victorian Cancer Registry who have submitted a NHMRC Partnership Grant with a range of organisations including VCCC Alliance. This project will focus on data linkage using Person Level Integrated Data Asset (PLIDA). Looking at cancer screening, treatment and outcomes for 3 priority populations - Aboriginal and Torres Strait Island Peoples, people with a disability and regional, including the intersection of these. This will be done by embedding Aboriginal and Torres Strait Islander voices, perspectives, and leadership, in all aspects of cancer control to support service delivery, data governance, education and research.

Culturally and linguistically diverse

A recent conference report published by the Australian Multicultural Health Collaborative (AMHC) and the Federation of Ethnic Communities Councils' of Australia (FECCA) indicated that there is still a dearth of information regarding Australia's multicultural population citing a lack of nationally consistent and accurate collection and reporting of data.[15] Delegates agreed that Government, research institutions and health services need to recognise and address the underrepresentation of multicultural communities in surveys, national datasets and research. It was recommended that the following be acknowledged and addressed:

- Need for more specific indicators as opposed to broad categories like 'culturally and linguistically diverse'.
- Involve communities in identifying correct descriptors of diversity.
- Survey question/s addressing diversity should depend on the purpose of the survey as it is difficult to find a universal question/indicator to capture the nuances of diversity (such as language spoken at home or country of birth).
- Learn from other countries, such as the UK and US, in designing questions and addressing ethnicity and intersectionality.
- Optimise data linkage and building capacity to analyse diverse health data.
- Recognise the urgency and importance of addressing the lack of inclusion of diverse identities in health data.

Current VCCC Alliance initiatives aim to improve access to services as well as outcomes for people with culturally and linguistically diverse (CALD) backgrounds. In September 2023, the VCCC Alliance hosted a roundtable discussion bringing together a range of stakeholders interested in improving the quality and quantity of health service data about CALD people. Participants included consumers, researchers, statisticians, data analysts, data and health information managers, patient quality and diversity managers, health service professionals, public health officials, and standards and regulatory compliance policy makers. Also present were representatives from all VCCC Alliance member health services and consumers,

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[15] Australian Multicultural Health Collaborative, *National Multicultural Health and Wellbeing Conference 2023 - Summary Report* (Canberra, 2023), https://fecca.org.au/wp-content/uploads/2024/04/FECCA-AMHC-Conference-Summary_v11-web.pdf.

the Australian Bureau of Statistics (ABS), Australian Institute of Health and Welfare (AIHW), Victorian Cancer Registry, Integrated Cancer Services, Monash Partners Comprehensive Cancer Consortium, and the Victorian Department of Health. A key focus of the day was to discuss issues relating to collecting data on the CALD community. Presentations in the morning were followed by a breakout session where participants were allocated into five groups and deliberated on key priorities and actions that could be undertaken to answer questions regarding the CALD communities.

CALD Patient Identification Project

Resulting from the roundtable, the VCCC Alliance funded a pilot project at one health service (Austin Health) with the support of the North Eastern Metropolitan Integrated Cancer Service (NEMICS), to provide more accurate classification of the CALD population by reviewing how healthcare systems identify patients from CALD communities. The project looked to:

- Identify of deficiencies and constraints in the current methods of data collection.
- Review and refine definitions for CALD patients.
- Identify critical touchpoints to prioritise and streamline data collection efforts.
- Identify gaps in resources, knowledge, and training.
- Assess the frequency and comprehensiveness of reporting.

The main aim of the project was to make recommendations for improving consistency and comparability of collecting existing data standards for CALD by integration of standardised CALD data collection into health services. AIHW and ABS were involved as observers. AIHW is keen to promulgate standardised national data standards for CALD. One pathway is via the National Health Information and Data Standards Committee (NHDISC). NHDISC is the committee that endorses national data standards (eg. for inclusion in hospital administrative datasets) and provides advice to the AIHW for its work in developing and maintaining national health data and information standards and related national health information infrastructure, in the context of the National Health Information Agreement (NHIA). The NHIA is an agreement between the Australian Government and state/territory government health authorities, established to coordinate the development, collection and dissemination of health information in Australia, including the development, endorsement and maintenance of national data standards.

Activity

1. Adoption of the validated methodology resulting from the CALD project to other health services, commencing with cancer services of VCCC Alliance members.
2. Provide the evidence to support adapting hospitals data collection systems to implement a standard dataset of CALD data variables.
3. Advocate for the inclusion of standardised, evidence based data standards for CALD cancer population across all health services nationally, commencing with VCCC Alliance member health services.
4. Establish and maintain engagement of national and State agencies eg. Australian Institute of Health and Welfare (AIHW), Australian Bureau of Statistics (ABS), Victorian Agency for Health Information (VAHI) and the Victorian Cancer Registry (VCR) in developing standardised collection of CALD data.
5. Get onto the work program of the NHDISC by approaching the Victorian representative on the Committee via VAHI and working towards presenting a paper to NHDISC (jointly with the AIHW).
6. In line with the CEF community of practice, convene annual forums for members and interested stakeholders to come together to discuss progress and issues relating to collection of CALD data.

ADVANCE-ACCESS - CALD Symptom Support Service Access Cancer Project

The timely management of treatment related side effects is a critical part of cancer care for cancer patients. In many hospitals, clinical nurse consultants (CNCs) and symptom and urgent review clinics (SURC) (which we have termed "symptom support services") provide these services for patients. They are a port of call for patients who require reviews outside of scheduled medical appointments and allow for the timely management of side effects or complications from cancer treatment. Accessing symptom support services have been shown to reduce ED presentations, prolonged admissions and healthcare costs. There is data showing low rates of utilisation of symptom support services by patients from a CALD background, which along with many other factors, contribute to the poorer health outcomes for this priority population. Thus, there is urgent need to explore and address the issues surrounding the inequity.

CLEAR-ACCESS is a multi-site exploratory qualitative study exploring the experiences of patients and carers with cancer who are from a CALD background, specifically, the Vietnamese, Mandarin, Greek and Arabic speaking communities and how and from whom they seek advice for the management of treatment related side effects. Health care professionals including GPs and interpreters as well as community representatives will also be interviewed to develop a multi-faceted understanding of the complex issues surround accessing symptom support services for people from a CALD background. CLEAR-ACCESS will provide critical early data to understand, identify and generate targets for intervention to address issues of access to care. Building on this, ADVANCE-ACCESS aims to partner with patients, carers and health care professionals to co-design interventions to improves access to symptom support services. Finally, DELIVER-ACCESS will implement and evaluate patient and system-level interventions to deliver equitable cancer care and improve patient outcomes for people from a CALD background.

Activity
1. Collect and analyse SURC usage data amongst patients from a CALD background across seven Victorian hospitals, both metropolitan and regional
2. Partnering with patients from a CALD background to co-design interventions to improve access to symptom support services.
3. Pilot and evaluate interventions in clinical settings, collecting data regarding their utility, capacity and feasibility to improves access to symptom support services for patients from a CALD background).

National Lung Cancer Screening Program navigator - CALD

Healthcare providers and bicultural workers needs to facilitate implementation of the planned a potential national lung cancer screening for multicultural communities culturally and linguistically diverse communities.

Evidence demonstrates lower participation in existing breast, bowel and cervical screening programs for CALD communities. The planned National Lung Cancer Screening Program (NLCSP) will be implemented in Australia on 1 July 2025 and will target high-risk people (e.g., aged 50-70 years, current high-level smoking or having quit in <10 years). Higher smoking rates for some CALD communities, and the link between stigma and tobacco smoking, means that CALD communities will need additional support, information and resources to participate in lung cancer screening for healthcare providers to participate and play a significant role in the recruitment and engagement through the NLCSP pathway. Preliminary interviews with stakeholders (n=13) from multicultural organisations representing service delivery, community engagement, and policy perspectives showed that stakeholders had very poor awareness that an NLCSP was being considered, and stakeholders recommended engagement of multicultural communities to design and deliver a culturally appropriate NLCSP.

This project is underway at the University of Melbourne, Peter MacCallum Cancer Centre and Cancer Council Victoria led by A/Prof Nicole Rankin. This project will conduct qualitative interviews (n = 40) with health care professionals working in primary and community organisations and bicultural workers, peer-to-peer workers and interpreters that provide care and support to CALD communities within Australia's healthcare system. Outcomes from qualitative interviews will inform the development of a needs assessment NLCSP survey tool and pilot the implementation of a navigator model of care to document how best to facilitate implementation of a culturally appropriate NLCSP.

Activity

1. Inform the development of tailored implementation tools, materials, resources and/or strategies which (a) support primary care in the implementation of lung cancer screening for CALD communities; and (b) support CALD communities in engaging in lung cancer screening and tobacco cessation. The developed implementation tools or strategies will be informed by the reflected need expressed by stakeholders within qualitative interviews and/or the needs assessment and developed in collaboration with key partners.
2. Undertake appropriate evaluations assessing reach, effectiveness, acceptability, and implementation of developed implementation strategies in supporting engagement and participation of lung cancer screening for CALD communities.
3. Engage with key stakeholders of the NLCSP (i.e., Cancer Australia, National Cancer Screening Register, Lung Cancer Foundation) to advocate for the need for appropriate data collection systems to ensure systems can adequately measure participation and outcomes of NLCSP for CALD communities.

Cassowary-CALD

Diagnosing cancer in general practice is complex and some cancers are more challenging than others to identify and diagnose when they present symptomatically in primary care. General practitioners play an essential role in the management of cancer via provision of comprehensive and continuous care, from diagnosis until the end of life. Identification of CALD or priority populations will enable implementation of better values-based care where environmental, social and financial costs matter on delivering health outcomes.

Identifying adaptations required to facilitate patients from CALD communities to participate in primary care-based cancer clinical trials. The primary objective is to contribute to the evidence base available for researchers to effectively adapt primary care-based cancer clinical trials to facilitate participation from CALD communities. Specifically, this project will take a newly funded trial (the Cassowary trial) and use it as an exemplar to understand what is required to adapt it to make it accessible to a specific CALD population.

Activity

1. Explore what adaptations to the existing Cassowary trial protocol are needed from community, healthcare provider and researcher perspectives to improve engagement and participation by people from the Chinese community.
2. Explore what adaptations to the existing Cassowary trial protocol are needed from community, healthcare provider and researcher perspectives to improve engagement and participation by people from the Chinese community.
3. Develop a modified protocol for the Cassowary trial that is designed to improve engagement, accrual and retention of Chinese participants.
4. Pilot this adapted protocol to assess its acceptability and feasibility from patient, general practice health professional and researcher perspectives.
5. Quantify the resources required to implement CALD-enabling strategies into a trial protocol and associated tools.

CALD Researchers Network

Improving equity in research is a small project led by Prof Christobel Saunders. Prof Jen Phillips and Dr Vijaya Joshi are investigators on this project building a network of researchers interested or involved in CALD communities to enhance capacity, engagement and professional development.

Activity

1. Improve research workforce capacity and capability to understand the benefits of developing robust data collection across basic science, translational research, clinical trials and health services research.
2. Develop training strategies and policies to help deliver the information and insights needed for better data capture that will lead to inform research practice and health literacy to drive improvements in diagnosis, treatment and care. As data capacity, capability and skill develop within the workforce, this should have a flow-on effect on developing and strengthening community and engagement.

Rural and regional areas

Care Plus Extend

The Care Plus service focuses on supporting the person with cancer as well as their family and friends. A multidisciplinary team works together to ensure a cancer patient’s physical, psychological, social, spiritual and cultural needs are met. Care Plus also provides advice, support and education to family and friends. It is a model of early palliative care designed to overcome known barriers and enable equitable access for patients and families to this service. This service was rolled out across a few metropolitan health services based on evidence to implement standardized, timely palliative care for people with cancer, to improve health outcomes and reduce acute hospitalisation at the end of life. One of the priority goals in the Victorian Cancer Plan is to increase the proportion of patients who die from cancer who received specialist palliative care within 12 months before their death. The Care Plus Extend project will measure the clinical effectiveness, benefits and any barriers of Care Plus Extend delivered to people with three cancer types in regional and metropolitan settings.

Activity

1. Determine the effectiveness of Care Plus Extend on improving quality of care for people with Sarcoma, Lung Cancer and Colon Cancer.
2. Improve timely management of symptoms and quality of life, and reducing acute hospitalisations and Emergency Department (ED) presentations.
3. Ensuring access to care does not differ according to gender, ethnicity, socioeconomic status or geographic location of residence.

Nursing Equity Assessment Tool - NEAT

Disparities in cancer incidence, complex care needs, and poor health outcomes are largely driven by structural inequities stemming from social determinants of health. A nursing complexity checklist (the Nursing Equity Assessment Tool - NEAT) to support rapid identification of people at risk of poorer outcomes, enabling timely support and intervention. The NEAT tool has already been demonstrated acceptability and feasibility in one metropolitan cancer centre in Victoria.

Activity

1. Regional cancer nurses will be involved in design of training resources to support implementation of the NEAT as a component of usual nursing care.

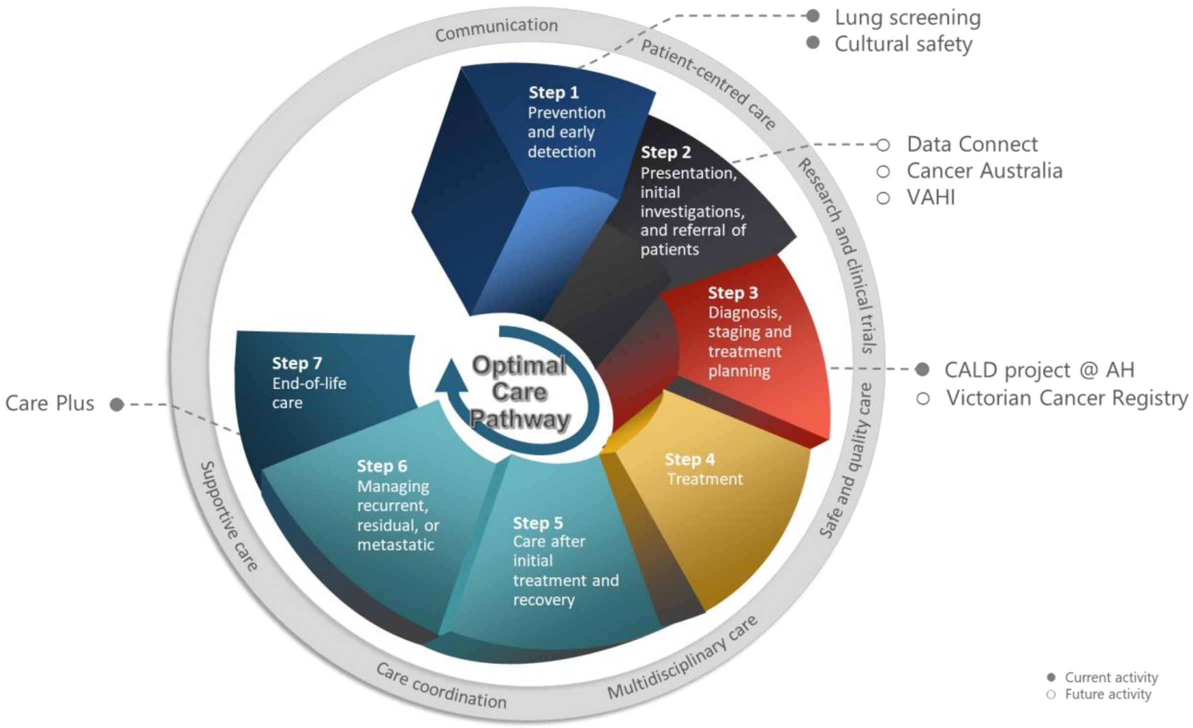
2. Explore concordance between specific NEAT items and validated patient-reported outcome measures (PROMs).
3. Ensuring access to care does not differ according to gender, ethnicity, socioeconomic status or geographic location of residence.

Optimal Care Pathways

The framework of the nationally endorsed Optimal Care Pathways (OCP) was designed to provide consistent, safe, high-quality and evidence-based care for people with cancer. There are currently 25 OCP for various tumour streams.[16] Cancer Australia has published the National OCP Framework.[17] The clinical care focus area highlighted in the CEF will utilise this framework. The CEF will identify and provide mitigations for drivers of disparities in service delivery and outcomes across the whole cancer journey. Data strategy principles will complement the clinical care pathways in the CEF, leading to implementation of a consistent dataset for all priority populations that can be more easily shared and linked, while facilitating analysis.

For cancer patients to realise better outcomes from their cancer journey, the data strategy for clinical care is mapped to each of the 7 steps described in the OCP (see Figure 3). Current VCCC Alliance activities are mapped to each of the steps (closed circles ●) with potential future projects (opened circles ○). This provides a holistic view of how each of the current projects or activities relate along the continuum and helps identify gaps that future projects should be addressing.

Figure 3. VCCC Alliance key equity activities in relation to the Optimal Care Pathways



The VCC Alliance is already involved in activities correlating to stages of the OCP (see Table 5). Future VCCC Alliance activities or projects will try to address every stage in the OCP to help address difficulties faced by

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[16] Optimal care pathways, Department of Health, Victoria. (accessed 21 March 2024) https://www.health.vic.gov.au/health-strategies/optimal-care-pathways

[17] National Optimal Care Pathways (OCP) Framework, Cancer Australia. (accessed 10 December 2024) https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-optimal-care-pathways-framework

priority groups at each step and how access to health services can be improved across the entire cancer patient journey. We acknowledge there are several projects and activities with priority populations occurring across the cancer sector. While the current data strategy only maps those within the VCCC Alliance, ongoing efforts will be made to link all resources.

Table 5: Mapping VCCC Alliance health equity activities to the Optimal Care Pathways (OCP)

OCP Step	Current Activity (Population Group and Projects)	Potential Future Activity
Step 1 – prevention and early detection	Aboriginal and Torres Strait Islander Peoples: • NLCSP – VACCHO	To be determined during the planning phase 2024-2029.
	CALD: • NLCSP – CALD	To be determined during the planning phase 2024-2029.
Step 2 – presentation, initial investigations, and patient referral	CALD: • Cassowary-CALD	Collaborations with Data Connect, Cancer Australia and Victorian Agency for Health Information (VAHI) to link primary care data with acute care.
Step 3 – diagnosis, staging and treatment planning	CALD: • CALD identification project	Expansion of the CALD identification project piloted at Austin Health to other health services to improve access to cancer services for CALD patients, and to support better analysis of data collected upon diagnosis and treatment for this cohort.
	CALD: • NEAT	To be determined during the planning phase 2024-2029.
Step 4 – treatment	CALD: • CALD identification project	Identification of CALD patients through better data collection will enable better understanding of how patients can receive equitable treatment and better navigate through the patient journey.
	CALD: • ADVANCE-ACCESS	Strategies to improve access to symptom support services for CALD cancer patients.
Step 5 – after initial treatment and recovery	No health equity projects currently underway.	To be determined during the planning phase 2024-2029.
Step 6 – managing recurrent, residual or metastatic	There are currently no health equity projects.	To be determined during the planning phase 2024-2029.
Step 7 – end-of-life care	All: • Care Plus Extend	The Care Plus Extend program supports the person with cancer as well as their family and friends during this phase of the cancer patient journey will be expanded to three cancers and rolled out in regional centres.

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