

# Priority population exploration toolkit:

Protocol for conducting a  
comprehensive evaluation of  
local priority population  
groups.

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# Introduction

Both the Australian and Victorian Cancer Plans place special emphasis on improving cancer care, experience, and outcomes for population groups who experience health inequities related to cancer. [1,2] Inequities in cancer care can occur at any stage of the cancer journey and can be driven by various demographic markers including socioeconomic status (SES), race or ethnicity, sex, disability, sexuality, age, and geographical location.[3] According to the Victorian Cancer Plan 2024-2028, priority populations are defined as:

*“Groups of people who have distinct and varying needs in cancer prevention, screening and care due to factors such as ethnicity, cultural background, geographic location, age, gender, sex, sexual orientation, socioeconomic status, family violence, or disability.” [2]*

To effectively tackle the barriers that drive inequity, knowledge of how cancer care policy, access to services, and a person’s experience of cancer care interconnect with their demographic profile to produce inequity is needed. This document describes a series of examinations that can help contextualise cancer care for priority populations in Victoria and local ICS regions to help identify opportunities to reduce inequity.

The investigations aim to:

- summarise key published recommendations and calls to action for addressing inequities in cancer care for the target priority communities,
- describe how the needs, barriers, inequalities, and outcomes of the priority population group are acknowledged and prioritised in cancer care policy resources throughout Australia and Victoria,
- identify the key actions within cancer care policy resources designed for the priority group,
- summarise the experience of cancer care and survivorship as described by people with cancer from the priority group,
- highlight known barriers and facilitators related to cancer care for the priority population community, and
- understand the data items available to identify the priority group within Victorian cancer related datasets and identify opportunities to improve data capture.

Investigations may include:

- a rapid literature review of published systematic reviews, meta-analyses, qualitative meta-syntheses, and integrated reviews specific to the known barriers to equitable cancer care for the priority population,
- a systematic policy review of publicly available Australian cancer care policy resources relating to cancer care for the target priority population, obtained via advanced Google search,
- an examination of all Victorian cancer related datasets and their data dictionaries to determine whether any data fields are present that can be used to identify the target population group in cancer data, and

- statistical analyses of cancer data to identify potential variations in cancer care, where data fields are available to adequately identify the target population group.

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Please note, not all priority populations will be easily identifiable in existing cancer datasets, and the implications of this lack of visibility should be considered in the absence of identifiable data.

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## Step 1: Rapid systematic literature review

This step outlines how to conduct a rapid systematic literature review exploring current evidence and academic publications related to cancer care specifically for the priority population. This step may or may not be needed, depending on the availability of similar work conducted by other ICS. In some instances, an existing rapid review may benefit from an updated search of the available academic publications to identify any new information and evidence.

### Methods

Rapid systematic literature reviews are used to develop a transparent, repeatable snapshot of academic publications related to a specific research question. The current review aims to summarise information related to the current state of cancer research for the priority population, including patient experience, identified barriers and facilitators to cancer care, gaps in cancer care and research, and any calls to action or recommendations related to improving cancer care for the priority population.

### Academic literature search

The steps below outline how to scope and conduct a robust rapid academic literature search. Having a strong research question and detailed inclusion and exclusion criteria form the backbone of a rapid review. Spending time developing robust inclusion and exclusion criteria prior to conducting the review is highly recommended.

1. Develop the research question(s). It can be helpful to also have a list of key information about the priority population to extract from the included academic publications (e.g., demographics, location, tumour types, etc.)
2. Decide what types of academic references to include. It is recommended that a search includes systematic reviews, meta-analyses, qualitative meta-syntheses, and integrated reviews.
3. Develop key search words and phrases likely to produce relevant results (see Table 1). Include Boolean operators (AND, OR, NOT), truncation (\* or \$, depending on the database), quotation marks for specific phrases (e.g., “radiation therapy”) and wildcards (e.g., tumo?r) to account for possible differences in spelling, terminology or usage in the search. Further information about

using search tools can in a literature search can be found on the University of Melbourne Library website (<https://unimelb.libguides.com/MDResearchProjectLitSearching/strategy>).

4. Develop detailed and specific inclusion and exclusion criteria for assessing manuscript relevance (see Table 2)
5. Conduct an academic search of literature published in Australia or internationally in the last five years across PubMed, Medline and Embase databases. Please note where relevance is unclear, authors should discuss the publication's relevance, and a collective decision made on its' inclusion or exclusion.
6. Upload all search results into Covidence for screening (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available at [www.covidence.org](http://www.covidence.org)). Covidence is an online platform that supports the various stages of a systematic review, from screening to data extraction and bias assessments. Most research databases will have an option that allows for search results to be saved in the appropriate file type for upload to Covidence.
7. Screen uploaded results by abstract using inclusion and exclusion criteria. Where relevance to the priority population using the inclusion criteria is unclear, progress the publication to full text review for further scrutiny.
8. Screen included publications' reference lists by title to identify any potentially relevant literature not captured in the initial primary search of databases.
9. Track inclusion and exclusion results using the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach to systematic reviews (Figure 1).

*Table 1. Search terms used for rapid scoping review.*

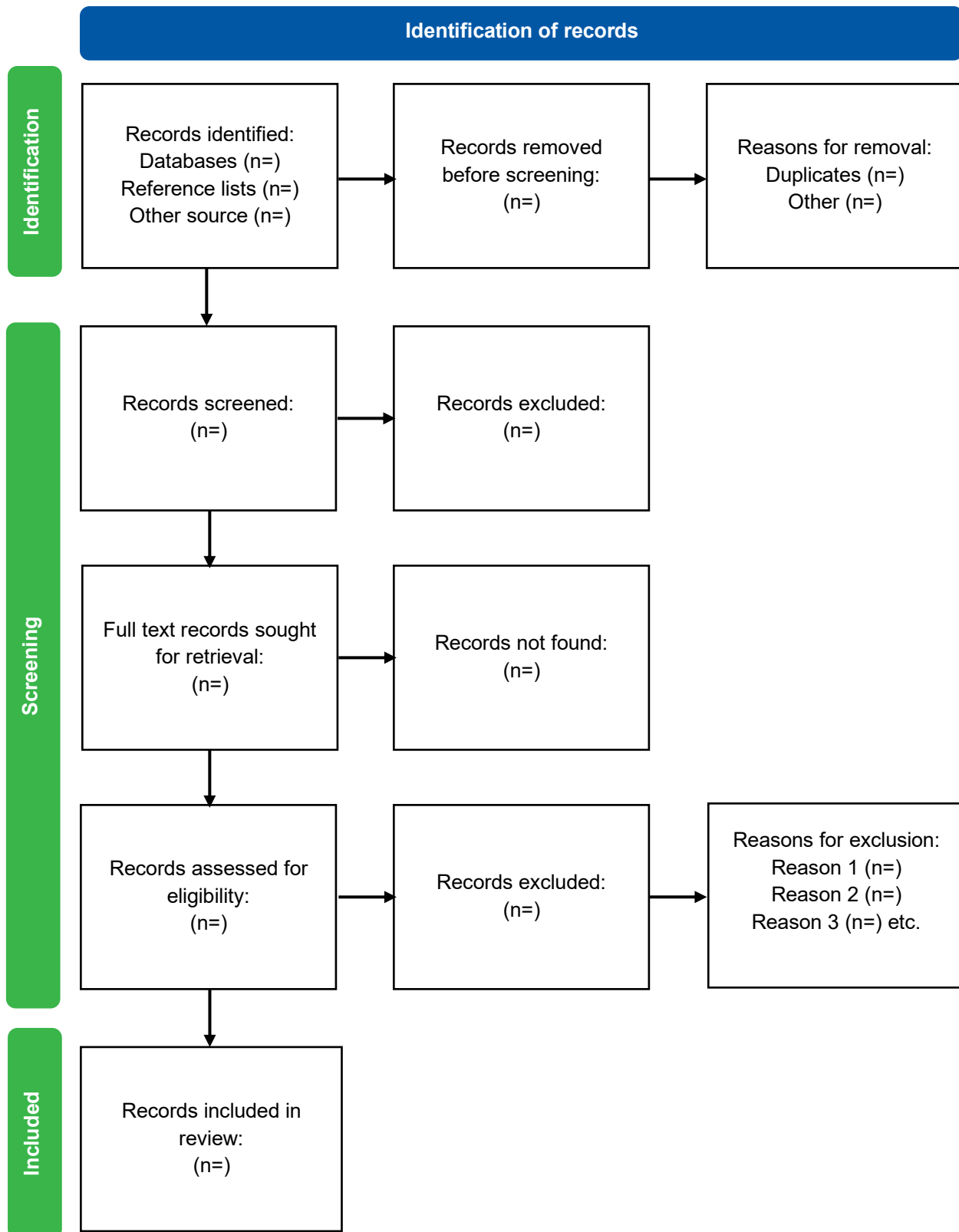
Boolean operator	Key terms	Search string synonyms
	Cancer	cancer OR oncology OR chemotherap* OR (radiation therap*) OR radiotherap*
<b>AND</b>	Systematic review	systematic review OR meta?analys*s OR (qualitative meta?synthes*s) OR (integrated review)
<b>AND</b>	[Target population]	[Select relevant terms]
	<i>e.g., LGBTQIA+</i>	<i>GLB* OR LGB* OR queer OR gay OR lesbian OR bisexual OR transgend* OR transsex* OR nonbinary OR non-binary OR intersex OR (sexual orientation) OR (gender identit*) OR (gender minorit*) OR (gender diverse) OR SOGI</i>

Table 2. Rapid scoping review inclusion and exclusion criteria.

Criteria	Description
<b>Include if:</b>	The publication is a systematic review of one or more aspects of [target population] cancer care and/or their experiences related to cancer care
	The publication is a systematic review examining the perspectives of [target population] people diagnosed with cancer related to their cancer diagnosis, treatment, related health care and/or survivorship experiences
	The publication is a systematic review examining the perspectives of health practitioners related to the care of [target population] people with cancer
	The publication is a systematic review that focuses on [target population] people with cancer as the primary population, or includes [target population] people with cancer as a separate subgroup analysis
	The publication is a systematic review describing the collection of [target population] data for cancer reporting / registries
	The document is in English
	Full text is available
<b>Exclude if:</b>	The publication describes an aspect of [target population] cancer care and/or experiences but is not a systematic review
	The publication has no English version
	The publication focuses on [target population] staff inclusion
	The publication references health and/or cancer care generally but does not specifically refer to the care of L [target population] groups
	The publication focuses on healthcare for [target population] groups but is not cancer-specific
	The publication does not identify the [target population] identity of participants
	The publication refers to participants using an outdated or misleading category and/or descriptor (e.g., for LGBTIQ+, only using a gender binary to categorise SOGI status)

Figure 1. PRISMA diagram template

Source: Page MJ, et al. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71.



## Data extraction and analysis

After all academic publications have been screened in Covidence, identify and extract all relevant information from Covidence into a single Excel document for synthesis using thematic analysis. Make sure the Covidence export settings use the Vancouver referencing style (VICS preferred style) to limit the need for re-formatting in the report.

Study characteristics of the included publications should be documented to provide additional context for the reader to understand the breadth and/or scope of research currently available (see Table 3). A preliminary list of expected themes should be developed before continuing, to provide a base structure for thematic analysis. This list can be expanded or refined as needed during the analysis.

Using thematic analysis, identify common topics present in the review that describes the needs, barriers, inequities, and outcomes related to cancer care for the priority population, expanding the original list of common themes as needed. Where themes are unclear, brainstorming discussions by the authors should be used to reach consensus. After all themes are explored, these should be reviewed and refined as needed to produce a comprehensive but succinct map of existing data related to the priority population. Some themes may naturally fit together to form an overarching category of information.

Examples of categories that might be present across themes could include:

- information related to the current state of cancer research for the priority population,
- data describing the experience of cancer care for the priority population,
- barriers and facilitators to cancer care for the priority population,
- identified gaps in cancer care and research for the priority population, and
- calls to action and recommendations made in relation to the priority population.

Once coding is complete, the data should be organised into their themes and/or related categories for discussion in the results. Where data is identified that relates to gaps and key recommendations, this may suggest opportunities for change within the Victorian cancer system that could be explored. This information should be collated as a list of potential service improvement activities for consideration by the ICS and/or relevant governance groups.

Table 3. Study characteristics of included reviews.

Review details		No. of Reviews
<b>Review type</b>	Systematic Review	
	Qualitative meta-synthesis	
	Integrated review	
	Scoping review	
	[Add other review types as needed]	
<b>Tumour site</b>	Any	
	[List each identified tumour type]	
<b>Population group(s) included</b>	[List all specified groups/subcategories used to describe priority population]	
	e.g., country/region of birth	

## Step 2: Environmental scan of cancer policy

This step outlines how to conduct a systematic environmental scan of cancer policy, guidelines and other relevant health policy in Australia using Google’s “Advanced Search” function. Policy documentation may include cancer plans, strategies, clinical guidelines, pathways and/or frameworks. For simplicity, these documents will collectively be referred to as cancer policy documents.

### Methods

Environmental scans are used to understand the internal and external context in which a system operates. Structured investigations, similar to those used in a systematic review, identify relevant unpublished literature or publicly available program information, including policy.

### Cancer policy document search

The steps below outline how to scope and conduct a systematic web search to identify any publicly available cancer policy, strategy, plans, guidelines, pathways, frameworks, and/or position statements that directly mention the target priority population group.

1. Decide what types of documents to include in the environmental scan. It is recommended the search focuses on national and local webpage resources related to cancer policy, strategy, plans, guidelines, pathways, frameworks, and/or position statements.
2. Develop key search words and phrases likely to produce relevant results (see example Table 4). These terms can be guided by those used in the rapid review in Step 1.

3. Develop inclusion and exclusion criteria for assessing document relevance (see example Table 5).
4. Using the 'advanced search' option, use the search terms to search for relevant cancer policy documents related to cancer care for the priority population.
5. Using the Google Chrome extension [Linkclump](#)
6. extract all results from the first ten pages of search results (excluding paid advertisements) into an Excel spreadsheet. The VICS preferred referencing style is Vancouver, in which all web pages require the date accessed to be recorded. For example:

*Gene Ontology Consortium. The Gene Ontology Resource [Internet]. [Place unknown]: Gene Ontology; c1999-2025. [Last updated 2025 Mar 16; cited 2025 Apr 8]. Available from: <http://www.geneontology.org/>*

7. Evaluate search results by accessing each hyperlink and screening the destination page using the inclusion and exclusion criteria to determine its potential relevance. If the first 10 pages of results fails to identify any known policy documents relating to the cancer care of the priority population, consider conducting a second, broader search.
8. If a second search was conducted, extract the first ten pages of results (excluding paid advertisements) into the same Excel spreadsheet using Linkclump, removing any duplicates.
9. For completeness, ensure all current optimal care pathways published by Cancer Council Victoria that did not appear in the search results are independently sourced for inclusion in the review process.
10. Where relevant cancer policy documents are identified, download and save each document in a single folder for further evaluation. Where policy documents provide only general information or relate specifically to staff and/or patient resources are identified, consider recording these on the spreadsheet for reference but excluding these from additional analyses.
11. For all relevant weblinks, search across each website using the website's in-built search function to identify any additional resources related to the priority population and download relevant resources for further analysis.

*Table 4. Search terms used for Advanced Google search.*

Boolean operator	Key terms	Search string synonyms
	Cancer	cancer
	[Priority population] e.g., LGBTQIA+	[list all versions / naming conventions used to identify the priority population] e.g., LGB* OR (SGM OR "sexual and gender minorit*") OR ("disadvantaged groups" OR "disadvantaged populations")
<b>AND</b>	Policy	"position statement" OR policy
<b>AND</b>	Australia	Australia

Table 5. Environmental scan inclusion and exclusion criteria.

Criteria	Description
<b>Include if:</b>	The health organisation/advocacy group authoring the policy document is in Australia
	The policy document is designed specifically for cancer services settings
	The policy document is in English
	Direct reference is made to [target population] people with cancer in the policy document
	The policy document describes a set of rules for fair and consistent care of [target population] people with cancer (i.e., policy, procedure, protocol/guideline, framework, legislation, or standard)
	The policy document describes the official position and/or areas of focus for an organisation regarding their approach to quality care for [target population] people with cancer in a cancer service setting
	The policy document describes a process to follow when treating [target population] people with cancer
<b>Exclude if:</b>	The health organisation/advocacy group authoring the policy document is outside of Australia
	The policy document has been retired/superseded
	The policy document has no English version
	The policy document focuses on staff inclusion for [target population] people within the organisation
	The policy document references health and/or cancer care generally but does not specifically refer to the care of [target population] people with cancer
	The policy document focuses on healthcare for [target population] people but is not cancer-specific
	The policy document is a subscription-based product that could not be accessed for free
	The policy document is a podcast, webinar, video, or news article
	Reference to the [target population] in the policy document was only found in definitions
	The policy document provides only general information about cancer and cancer care for the [target population]
	The policy document is a training and/or upskilling resource for staff
	The policy document is a patient resource designed to support [target population] people with cancer across their cancer journey

## Data extraction and analysis

Examine all relevant URLs to identify the cancer policy document by type (see Table 6). After categorising the identified publications by type, evaluate the degree to which the priority population was included in each cancer policy document using five stages:

1. **Not included.** The policy resource does not reference the priority population at all
2. **Definitions only.** Inclusion is only present in definitions of patient, consumer, or diverse groups etc.
3. **Acknowledgement.** Specific recognition is made of the priority population, but no details are provided about unique care requirements and/or challenges.
4. **Inclusion.** The policy resource includes a specific subsection dedicated to the health of people with cancer from the priority population and is part of a broader resource for patient care.
5. **Targeted action.** The policy resource is specific to the health care of people with cancer for the priority population.

*Table 6. Cancer care policy document type definitions.*

Document type	Description of policy document included in the category
<b>Policy and/or legislation</b>	Policy document describing a set of rules for fair and consistent care of [target population] people with cancer, including: <ul style="list-style-type: none"> <li>▪ Policies</li> <li>▪ Procedures/guidelines</li> <li>▪ Protocols / frameworks</li> <li>▪ Legislation</li> <li>▪ Standards</li> </ul>
<b>Strategy and plans (priorities)</b>	Policy document describing key areas of focus for improvement as determined by an organisation, including: <ul style="list-style-type: none"> <li>▪ Strategic plans/ directions</li> <li>▪ Submissions to government</li> <li>▪ Policy priorities</li> <li>▪ Health strategies</li> <li>▪ Budget priority resource</li> </ul>
<b>Position statement</b>	Policy document describing the official position of an organisation regarding their approach to quality care for [target population] people with cancer.
<b>Best practice/care guidelines</b>	Policy document describing a research-supported preferred approach and/or process for treating [target population] people with cancer, including: <ul style="list-style-type: none"> <li>▪ Optimal care pathways</li> <li>▪ Best practice guidelines</li> <li>▪ Standards of care</li> </ul>

Cancer policy documents that do not reference the priority population directly or only mentions the group within broader patient/consumer definitions (i.e., Stage 1 and 2), should be recorded but excluded from further analysis. All policy documents that provide specific details about the cancer care of people from the priority population (i.e., Stages 3-5) should be included in the analysis.

Use thematic analysis to identify the type of information contained within the remaining policy documents (see Table 7). Once documents are grouped by theme, data can be examined in relation to national and Victorian contexts. These results will help produce an overview of the current degree of inclusion and support available to the people with cancer from the priority population in Victoria. Using this contextual information, implications for the delivery of cancer care for the priority population can be examined.

*Table 7. Thematic analysis information category descriptions.*

Information category	Description of documents included in the category
<b>Legislative / cultural context</b>	Discusses laws relevant to the document and/or cultural facets of cancer risk and access to care
<b>Priority areas</b>	Includes policy areas deemed a priority by the organisation in improving the quality of care and outcomes for [target population] people with cancer
<b>Position statement</b>	Includes a statement outlining the commitment by the organisation to the quality of care and outcomes for [target population] people with cancer
<b>Key definitions</b>	Includes definitions for terms related to the [target population] group used in the document
<b>Inclusive language</b>	Uses inclusive language throughout the document , particularly when discussing minority groups or politically sensitive terms
<b>Privacy and/or disclosure</b>	Includes details about how the organisation will support disclosures/non-disclosures of status related to the [target population] group
<b>Actions for staff/members</b>	Includes information about and directions for staff behaviours and/or attitudes relating to and towards [target population] people
<b>Resources/training available</b>	Includes specific information about training, policies and/or resources available within the organisation that relate to cancer care for [target population] people with cancer
<b>Inclusion / specialised services</b>	Includes information about specific services available exclusively to [target population] people with cancer

When discussing the findings of the environmental scan, the following structure is recommended:

- Policy document summary
- Policy documents relevant to Victorian cancer services:
  - Cancer policy and legislation
  - Strategy and priorities
  - Position statements
  - Best practice care guides

All included policy documents should be listed in a table for reference (see Table 8) before synthesising the information included. Data summarising the themes from each document can also be reported in a table format (see Table 9).

*Table 8. Relevant documents\* identified by type and stage of inclusion.*

Document type	Stage	Organisation	Resource title	Year published
<b>Policy and/or legislation</b>	Acknowledgement			
	Inclusion			
	Targeted action			
<b>Strategy and priority documents</b>	Acknowledgement			
	Inclusion			
	Targeted action			
<b>Position statements only</b>	Acknowledgement			
	Inclusion			
	Targeted action			
<b>Best practice / care guidelines</b>	Acknowledgement			
	Inclusion			
	Targeted action			

*\*Include direct hyperlinks to each included document in an Appendix at the end of the report.*

Table 9. Overview of document content by type and information category.

Resource Type	Organisation	Resource Title	Legislative / cultural context	Priority areas	Position statement	Key definitions	Inclusive language	Privacy and/or disclosure	Actions for staff/members	Resources/training available	Inclusion / specialised services
<b>Policy and/or legislation</b>											
<b>Strategy and priority documents</b>											
<b>Position statements only</b>											
<b>Best practice / care guides</b>											

## Step 3: Health data and information evaluation

As of 2024, there are substantial differences in the type and availability of data denoting a person's status within the priority population groups identified in the Victorian Cancer Plan 2024-2028. As such, the degree to which data can be explored for the priority population will depend on the type and availability of data related to the target population.

### Methods

Initial investigations should explore the availability and type of data related to the target population. Where available, other data can be used to explore whether variations in access to health services, hospital cancer care or health outcomes are present for cancer patients based on their status within the priority population in focus.

Data dictionaries describing the types of data collected by cancer datasets can be used to understand what data is available. A list of all potential datasets is included in Table 10. This table should be regularly updated with additional cancer datasets as new information becomes available. Using the sourced data dictionaries, any fields that could be used to determine a person's status in relation to the priority population under investigation should be documented in the table. Gaps in each database can then be identified and reported.

Where additional data are available, conducting a retrospective descriptive analysis is recommended to better understand the care received and health outcomes of the priority population being investigated within the target region. This may involve an exploration of:

- The demographic profile of the priority population
- Descriptions of diagnoses and procedures recorded for cancer patients from the priority population
- Statistically significant differences between population groups and subgroups for variables describing the type and quality of cancer care received.

Table 10. Evaluation of data fields and related definitions for datasets accessed by VICS

Dataset	Field	Definition	Code	Descriptor	Coding notes
<b>National Cervical Screening Program</b>	e.g., sex	<i>The biological sex characteristics of a person.</i>	1	Male	<i>Individuals who have male or predominantly masculine biological characteristics, had male sex assigned at birth, or report their sex as male.</i>
			2	Female	<i>Individuals who have female or predominantly feminine biological characteristics, had female sex assigned at birth, or report their sex as female.</i>
			3	Another term	<i>Individuals who have mixed or non-binary biological characteristics (if known), had a non-binary sex assigned at birth, or report their sex using another term. The value meaning of 'Another term' has been assigned to Code 3 for this value domain, which replaces 'Other' and 'Intersex or indeterminate' in previous versions of this element. Terms such as 'indeterminate', 'intersex', 'non-binary', and 'unspecified', etc., are variously used to describe the 'Another term' category of sex. The label 'Another term' is used because a more descriptive term has not been widely agreed within the general community. Additionally, a small number of people do not have a sex of male or female recorded at birth or infancy. The inclusion of 'Another term' as a third response option recognises that across Australian jurisdictions and elsewhere there are a range of options available on birth certificates (such as indeterminate or unspecified).</i>
			9	Not stated / inadequately described	<i>This supplementary value is used to code inadequately described responses and non-responses for sex. It is not to be used on primary collection forms. It is primarily for use in administrative collections when transferring data from data sets where the item has not been collected.</i>
<b>Cancer Service Performance Indicators (CSPI)</b>					

Dataset	Field	Definition	Code	Descriptor	Coding notes
Victorian Admitted Episode Dataset (VAED)					
Victorian Emergency Management Dataset (VEMD)					
Victorian Integrated Non-Admitted Health (VINAH) Dataset					
Victorian Cancer Registry dataset (VCR)					
Victorian Radiotherapy Minimum Dataset (VRMD)					
Victorian Health Care Experience Survey (VHES)					
Australian Health Performance Framework (AHPF)					
Australian Cancer Database (ACD)					
BreastScreen data					
National Bowel Cancer Screening Program register data					
National Cancer Screening Register data					

*\* data code not identified*

## Scope of data analysis

Prior to conducting any analyses, its scope will need to be defined. This includes specifying what data will be included in the analysis as well as what data will be excluded. For example:

- Data analysis will be limited to patients aged 18 years or older who were admitted to a health service within the [ICS region] with a malignant cancer diagnosis (i.e. diagnosis ICD code beginning with C or D), across a five-year period from 2019-2023.
- Admissions for non-melanoma skin cancers (ICD code C44) were excluded from the analysis. A full description of ICD codes and their relevance and/or exclusion from the analysis can be found in Appendix A.
- Admissions for non-cancer treatments where the patient has a pre-existing cancer diagnosis were included in this analysis.
- Where patients received treatment across multiple sites, only admissions at [ICS region] member health services were included in the analysis.
- Private health services located in the [ICS region] were included but not identified in this analysis.

When deciding on whether to examine statistically significant differences across tumour streams (cancer site) in the analysis, conducting a preliminary explorative analysis is recommended to determine whether any notable difference between categories seem worthy of further investigation (e.g., is there a notable difference present in the rate of tumour specific diagnoses for CALD versus non-CALD groups?).

## Determining priority groups and subgroups

Effective analysis will require data to be organised into relevant groups, based on what data is available (e.g., using country of birth (COB) as the primary variable to define CALD status of patients as either “CALD” or “non-CALD”). Depending on the priority group being explored (and its size), the data may be able to be separated into subcategories. However, all categories used in the analysis and any decisions made to define these categories should be clearly documented so that the analysis and group classification can be replicated by others who wish to duplicate or refresh the analysis.

## Deciding on study variables

Deciding on how to examine whether variations in access to health services, hospital cancer care or health outcomes are present in the target region for patients based on the defined population groups will depend on what data is available. In general, the majority population is used as the primary comparison/control group.

As a starting point, exploring variations in care and outcomes within VAED data across seven data categories that relate to access to health services, in-hospital cancer care, and health status/outcomes is recommended. These categories include:

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- First cancer admission via emergency department (ED)
- Chemotherapy treatment
- Palliative care
- Length of stay (LOS)
- Number of procedures per admission
- Number of diagnoses per admission
- In-hospital mortality

For further definitions of how these categories were defined, please refer to Appendix A.

## Statistical analysis

Choosing the appropriate statistical analysis to use will require specialist knowledge of statistics and the data being analysed. In general, chi-square tests are often used to compare categorical variables and Kruskal–Wallis tests for comparisons between continuous variables. The Kruskal–Wallis test is most appropriate when the distribution of the continuous data is skewed (e.g., length of stay data).

*Please note that consulting with the ALIC team or someone with tertiary training in statistical analysis is highly recommended prior to conducting any statistical testing.*

To replicate the statistical analyses conducted by NEMICS for their local CALD population, please email [nemicsadmin@austin.org.au](mailto:nemicsadmin@austin.org.au) with a request for additional information.

When presenting the results of the data evaluation, it is helpful to use a similar structure to that used in a research publication. Please note that the purpose of this analysis is to provide a local snapshot of cancer care for the priority population only and cannot explain why these results may have occurred.

## Step 4: Exploration of patient experiences

This step outlines different ways you can explore patient experiences to better understand how priority populations experience cancer care. Patient experience can be explored via established patient reported experience and patient reported outcome measures (PREMs/PROMs), custom surveys, or targeted focus groups.

### Methods

Initial investigations should explore the availability and type of patient experience data related to the target population. Consideration will also need to be given to relevant access requirements and/or processes involved in obtaining relevant data, and whether ethics will be required as part of the exploration.

## Established patient reported experience and patient reported outcome measures (PREMs/PROMs)

Exploration of patient reported experience and/or outcomes will be dependent on the type and granularity of data available. For example, in Victoria, the Cancer Patient Experience Survey (CPES) is conducted every four years by the Victorian Agency for Health Information (VAHI), on behalf of the Victorian Department of Health. Local health services may have patient experience data available, but these data will likely have distinct limitations to consider within the scope of your investigations and as part of the overall synthesis of information.

When analysing patient experience survey data, consideration should be given to how qualitative and quantitative data are organised and analysed. For example:

1. What data will be used to identify the priority population within the data?
2. If raw data is available, what considerations need to be made for how data are organised and coded?
3. What types of analyses are the data compatible with (e.g., descriptive analyses, statistical analyses, thematic analyses, etc.)?
4. What rules, regulations and/or data agreements need to be considered or referenced before conducting this work?

As with Step 3, it is highly recommended to seek advice from someone with tertiary training in statistical analysis prior to conducting any statistical testing. Likewise, if you are using data from an external organisation (such as the CPES from VAHI), they will likely have specific requirements related to how you handle and use both the data you receive and the analyses you conduct.

## Custom surveys

Before you design any survey, it is important to organise and structure the main purpose and research question the survey should answer. The specific style and focus of any survey will need to be informed by the research question(s) being answered, the target audience, and should comply with ethics requirements of all relevant governing bodies, even if ethics is not a formal requirement.

If you require specific guidance on how to develop a strong survey, NEMICS has a planning guide that can be used to help develop the content and structure of a research survey. It contains three separate sections that will guide you through the different considerations needed to develop a quality survey, including a checklist you can use to cross-check your final survey to make sure it assesses the research question in a clear, concise and consistent way. For more information about this guide, please email [ashley.macleod@austin.org.au](mailto:ashley.macleod@austin.org.au).

## Focus groups

In some instances, it may be suitable to conduct focus group discussions to better understand the experiences of local priority populations. When coordinating focus groups, it is important to consider:

- Who your target audience is, and what limitations may be present in terms of whether they will be able to directly contribute to a focus group
- Whether any community organisations already exist as advocates for the target population group that can be engaged with
- What format the focus group would need to take (e.g., online, in-person, hybrid, on-site, within the community, etc.)
- What specific information you are trying to obtain from the focus groups.

For many scoping activities, focus groups will not be feasible. However, where they are, you will need to review your local Consumer Engagement Framework and any other relevant documents to guide these activities.

## Step 5: Synthesise key messages

Given the many time constraints of local Governance Committees, health service executives, and others likely to show interest in these investigations, it is recommended that key findings from each stage of the analysis is consolidated into a single summary document.

This document should include:

- A brief background on the reasons for exploring the topic
- A summary of any known issues and/or concerns related to the priority population under investigation at a local level
- A description of the types of investigations conducted and why they were used
- High-level summaries of each investigation and key findings
- Information about the limitations of the investigations and any important caveats needed to interpret the results, and
- A synthesised list of proposed recommendations.

The focus of this document (and the broader work conducted) should be to describe the current state of cancer care for the target population. This information can then be used to produce evidence-informed recommendations to improve cancer care locally (or at a statewide level) for the priority population. For further information about this guide or for copies of priority population reports developed by NEMICS that feature in this guide, please contact NEMICS.

# Methodology limitations

While every effort was made to develop a robust methodology for investigating the current state of cancer care for unique population groups, several limitations across each of the analyses should be noted.

## Rapid review limitations

Results from the rapid review of literature will be dependent on the scope and inclusion/exclusion criteria set. For example, using the criteria recommended in Table X will exclude results that are not systematic reviews, qualitative meta-syntheses, integrative reviews, or other review types. As a result, additional reviews and other relevant data may exist that are not included in a scoping review that uses these criteria. Likewise, while the search terms have been developed using a robust range of terms, differences in terminology, usage or abbreviations may differ and as such, there is a risk that documents that use those terms are missed by the search terms. This issue is somewhat mediated by the manual screening of reference lists for all included documents but is worth noting.

## Limitations of the environmental scan of health policy

Resources found in searches using the criteria provided may fail to identify documents that make limited or no reference to the target group/s. In these situations, it may be unclear whether the limited number (or absence) of relevant resources relates to poor search criteria or reflects a lack of cancer policy that recognises the unique challenges and experiences of the target community within healthcare settings. This risk can be mitigated by ensuring all commonly used terminology and abbreviations for the target group are included in the search terms, and by manually investigating publicly available resources from known community group websites.

The environmental scan is also dependent on access to internal policy resources throughout the Australian cancer services setting. While local ICS may be able to request internal policy information from their member health services, it is unlikely that relevant internal policy from other Australian cancer services can be sourced in a timely manner. As such, any health policy review must acknowledge that it provides a summary of publicly available policy only.

## Health data and information evaluation limitations

Analyses for priority populations are likely to be limited by the availability of data collected on the health outcomes of the target group and the identifiers used to determine group status. While work is ongoing to improve access to health data across cancer services, it is vital to recognise when these

evaluations occur (e.g., month and year of evaluation). Highlighting this information will help contextualise any changes to data field collection that may occur in future revisions. For information about which datasets the VICs have access to, please contact the appropriate ICS IMG representative.

Results should highlight that the health data analysis does not capture how individuals experience and/or respond to the collection of specific patient identifiers. Specifically, it should be recognised that some individuals may not choose to disclose their membership to certain population groups for fear of discrimination or reduced access to treatment options. Likewise, many of the priority populations identified in the Victorian Cancer Plan do not have universally agreed definitions or standardised identifiers that can be used to classify individuals across some priority population groups (e.g., LGBTQIA+, CALD groups, disability groups, etc.). As such, all assumptions or categorisations used in the analysis must be detailed in the report, to ensure appropriate transparency.

The recommended data analysis in this methodology does not include exploring correlations between variables. While exploring these relationships could help us better understand whether any of the variations observed are likely to have clinical significance, these investigations sit outside the scope of this work. It is recommended that any work investigating correlations involve consultations with the ALIC team to ensure statistical validity and reliability.

# References

1. Cancer Australia. Australian Cancer Plan. Canberra (AU): Cancer Australia; 2023. Available from: <https://www.australiancancerplan.gov.au>
2. Department of Health and Human Services. Victorian Cancer Plan 2024-2028 optimal and equitable outcomes for all Victorians. Melbourne: Victorian Government, Department of Health and Human Services; 2024. Available at [https://www.health.vic.gov.au/sites/default/files/2024-09/victorian-cancer-plan-2024-28\\_0.pdf](https://www.health.vic.gov.au/sites/default/files/2024-09/victorian-cancer-plan-2024-28_0.pdf)
3. Sarfati D. Why social inequalities matter in the cancer continuum. In: Reducing social inequalities in cancer: evidence and priorities for research. International Agency for Research on Cancer, Lyon (FR); 2019. PMID: 33534471.

# Appendix A: Definitions used for CALD analysis of variables using VAED data

Variable	Definition
<b>Access to health services</b>	
<b>First cancer admission via emergency department (ED)</b>	The rate of first cancer admission via ED was identified as a proxy measure for whether patients had accessed cancer care prior to their ED hospital admission. First admission via ED was established where data for patient admission type was noted as “Emergency admission from ED at this hospital” or “Other emergency admission”.
<b>In-hospital cancer care</b>	
<b>Chemotherapy treatment</b>	Inpatient chemotherapy data were the only cancer treatment type well captured in the VAED. For this analysis, chemotherapy treatment was identified using the Australian Refined – Diagnostic Related Group (AR-DRG) <sup>6</sup> code R63Z (chemotherapy). For this analysis, only patients with one or more admissions with DRG code R63Z were included.
<b>Palliative care</b>	As palliative care is a key component of quality cancer care, variations in palliative care treatment patterns for CALD groups were investigated. The ICD diagnosis code Z515 (Palliative Care) was used to identify admissions with palliative care. For this analysis, only patients with one or more admissions with ICD diagnosis code Z515 were included.
<b>Length of stay (LOS)</b>	While LOS could be influenced by a patient’s clinical condition (i.e., complications), it is an effective proxy for aspects of care delivery such as delays in consulting, coordinating care, or patient acceptance into other services such as a rehabilitation facility, aged care home or community care service. [9] For this analysis, LOS was calculated using only multiday admissions, with same day and overnight admissions excluded.
<b>Number of procedures per admission</b>	The number of procedures per admission was used as a proxy for variation in treatment rigor that could be influenced by variations in treatment planning, by a patient’s clinical condition or patient’s preference. The number of procedures was determined by the count of procedure codes collected in VAED data for each admission. According to <a href="#">VAED Manual Section 3 Data Definitions</a> procedure codes are defined as “ <i>up to 40 Australian Classification of Health Interventions codes reflecting the interventions used for the diagnosis and/or treatment of ill health during an episode of care</i> ”. Interventions include invasive procedures, allied health interventions, etc. For this study, only multiday admissions were considered for this measure.
<b>Health status/outcome</b>	
<b>Number of diagnoses per admission</b>	The number of diagnoses per admission was used as a proxy measure for patients’ overall health, with higher numbers of diagnoses per admission interpreted as an indication of poorer overall health. The number of diagnoses were determined by the count of ICD-10-AM diagnosis codes collected for each admission. According to <a href="#">VAED Manual Section 3 Data Definitions</a> diagnosis codes are defined as “ <i>up to 40 ICD-10-AM codes reflecting injuries, disease conditions, patient characteristics and circumstances impacting an episode of care</i> ”. Only multiday admissions were included in these calculations.
<b>In-hospital mortality</b>	In-hospital mortality can be used as a key indicator for timely and quality care. In-hospital mortality was determined by identifying patient records where mode of separation admission was recorded as a separation by death.

## Appendix B: Links to online resources

Resource	Weblink
Advanced Google search	<a href="https://www.google.com.au/advanced_search">https://www.google.com.au/advanced_search</a>
Advanced search functions (University of Melbourne)	<a href="https://unimelb.libguides.com/MDResearchProjectLitSearching/strategy">https://unimelb.libguides.com/MDResearchProjectLitSearching/strategy</a>
Covidence	<a href="http://www.covidence.org">www.covidence.org</a>
Linkclump (Google Chrome extension)	<a href="https://chrome.google.com/webstore/detail/linkclump/lfpjknckoklfnokkgpkobnkbkmelfej">https://chrome.google.com/webstore/detail/linkclump/lfpjknckoklfnokkgpkobnkbkmelfej</a>
Optimal Care Pathways	<a href="https://optimalcarepathways.com.au/">https://optimalcarepathways.com.au/</a>
PRISMA 2020	<a href="https://www.prisma-statement.org/prisma-2020">https://www.prisma-statement.org/prisma-2020</a>
Vancouver referencing guide	<a href="chrome-extension://efaidnbmninnibpcajpcgiclfndmkaj/https://library.westernsydney.edu.au/_data/assets/pdf_file/0006/1943484/cite_Vancouver.pdf">chrome-extension://efaidnbmninnibpcajpcgiclfndmkaj/https://library.westernsydney.edu.au/_data/assets/pdf_file/0006/1943484/cite_Vancouver.pdf</a>
Victorian Cancer Plan 2024-2028	<a href="https://www.health.vic.gov.au/victorian-cancer-plan">https://www.health.vic.gov.au/victorian-cancer-plan</a>