

***My Cancer Diagnosis Explained***  
*Implementation Guide*

Published by the Western & Central Melbourne Integrated Cancer Service (WCMICS)  
on behalf of the Victorian Integrated Cancer Services.

We acknowledge the Traditional Owners of Country throughout Australia and their  
continuing connection to the land, sea and community. We pay our respects to them  
and their cultures and to Elders past and present.

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# ABOUT THIS IMPLEMENTATION GUIDE

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## Target audience

This guide has been written for any health professional, quality improvement team or project officer who wants to implement the 'My Cancer Diagnosis Explained' summary (MCDE summary) into a clinical area. Using the guide will help to improve the amount and quality of information given to people when they receive a cancer diagnosis.

The MCDE summary is a resource that you can use to provide individualised written information at the time a patient is first told of their cancer diagnosis.

## Purpose of this guide

This guide aims to:

- build health professionals' understanding of the MCDE summary, so you can use the MCDE summary as part of your usual clinical practice
- enhance health professionals' capability to deliver the MCDE summary and provide effective communication that meets each patient's needs
- support health professionals to deliver information about a cancer diagnosis
- explain how to successfully implement the MCDE in your health service, by including:
  - ↳ Five tips for enhancing the implementation of the MCDE summary
  - ↳ Useful information and resources, including the important elements of good communication, to help your team improve their use of the MCDE summary.

## How to use this guide

This guide is designed so that you can read and action any of the implementation steps in isolation to the other steps.

## A patient-centred implementation

As the MCDE summary is designed to provide patient-centred care, this guide complements the patient-centred programs and policies that your health service may already have.

## Implementation timeframe

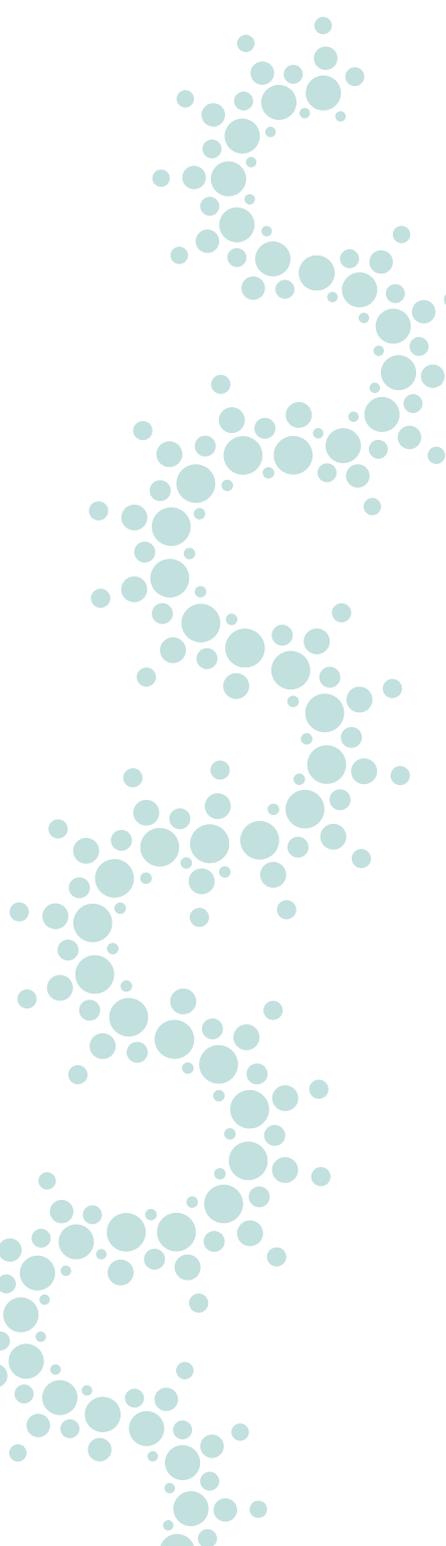
The length of time health services requires to implement the MCDE summary may vary, as the process depends on the health service you provide, how ready your organisation is, and the available resources. Typically, implementation will take 6 months or longer.

***The 'MCDE summary' complements the patient-centred programs and policies that your health service may already have.***

## 5 steps to implement 'My Cancer Diagnosis Explained' summary

To successfully implement My Cancer Diagnosis Explained, you need a cancer specific MCDE summary that is ready to be put into practice, such as the example in Appendix 1. In the sections that follow this list of steps, there is detailed advice and handy tips to help you build the MCDE summary into your usual clinical practice.

*The following 5 steps will help you implement your MCDE summary.*



1

### Identify the need and plan

- Identify an area of need and any gaps; analyse issues; customise and prioritise solutions.
- Obtain executive sponsorship to proceed with the program of work. This includes all the usual aspects of project planning and management.
- Build a strong case for change by collecting qualitative and quantitative data that will help you develop key messages (a 'call to action') to motivate staff and engage stakeholders.

2

### Build consensus

- Prepare a strategic vision that defines what success will look like, and obtain clinical, managerial, and administrative consensus of this vision.
- Adopt a structured approach to implementation by appointing a designated Project Lead, supported by a Sponsor (senior health service executive) and a Clinical Lead (visible clinical leader).

3

### Understand local requirements

- Tailor a solution that aligns to your existing health service's policies and processes and will meet your local requirements.

4

### Raise awareness

- Raise awareness of the implementation project by issuing frequent and clear communication.

5

### Measure the progress

- Monitor and evaluate the progress regularly.
- Share and discuss information you have obtained with local team members to identify any barriers to implementation, and possible solutions.

# EXECUTIVE SUMMARY

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## Purpose

This Implementation Guide provides clear steps and tips to support the local implementation of the 'My Cancer Diagnosis Explained' summary (MCDE summary) given to patients after being diagnosed with cancer. The MCDE summary provides easy-to-understand information that is patient-specific.

This guide contains two sample MCDE summaries as examples (see Appendix 1 Head and Neck Cancer, and Appendix 2 Pancreatic Cancer MCDE summary), and a 5-step process to successfully embed the MCDE summary into your usual clinical practice.

## Context

Before implementing the MCDE summary, consider your local health service requirements, resources or clinical setting context, and what you want to achieve. Although this guide is designed to complement your existing health service policies, procedures and processes, success depends on organisational readiness and organisational priorities.

## The background to MCDE summary

'My Cancer Diagnosis Explained' consolidates the work completed in the pilot project led by Western and Central Melbourne Integrated Cancer Service in conjunction with Southern Melbourne Integrated Cancer Service and Hume Regional Integrated Cancer Service.

The pilot project (2018), concluded that cancer patients want more—and better—information about their health, healthcare and treatment options, and they want that information to be specific to them.

One output of the project was a resource co-designed by consumers and health professionals that provides patients and carers with individualised information about the cancer diagnosis. Supplementing the verbal communication between a clinician and a cancer patient, each MCDE summary provides the patient with written information they can take home.

***The content  
and design  
of the MCDE  
summary meet  
the domains of  
health literacy.***

# INTRODUCTION

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## Background

Communication between a patient and health professional at the time of diagnosis is a crucial first step in the patient's cancer journey, yet the significance of clear and accessible communication is often overlooked. Instead, complex medical information about diagnosis and treatment is often provided to patients verbally, but without any supplementary written information. This occurs at a time of significant stress for the patient when there is limited time for detailed discussion and questions.

Lack of 'take home' information at this time can exacerbate emotions such as disbelief, anxiety, fear, anger and sadness. In addition, most patients find it difficult to comprehend all the information they are told during the appointment, and even more difficult to recall it afterwards. Studies estimate that patients only remember between 14% and 40% of the information provided verbally<sup>1</sup> and poor patient recall is identified as a barrier to active participation in decision-making<sup>2, 3</sup>. For patients with low health literacy, this may lead to disengagement with health professionals, which in turn may result in low treatment compliance and poor health outcomes<sup>4</sup>. It is estimated that 60% of people in Australia have less-than-adequate levels of health literacy, which presents a significant challenge for those delivering health services.

Patients need and want written information specific to their cancer diagnosis, and studies suggest that providing comprehensible written information increases patients' overall satisfaction with the care provided by health professionals<sup>4,5</sup>. But despite this, providing patients with individualised written information, including treatment plans, is not standard practice across Victoria's health services. And while it is true that some health professionals do provide written information to patients, the methods and quality of delivery are inconsistent.

## Policy context

### **National Safety & Quality Health Service Standards<sup>6</sup>**

The eight National Safety and Quality Health Service (NSQHS) Standards provide a nationally consistent statement of the level of care consumers can expect from health services.

Standard 2, 'Partnering with Consumers Standard', recognises the importance of involving patients in their own care and providing them with clear communication. The aim of this Standard is to ensure that health services are responsive to patient, carer and consumer input and needs.

*Implementing the MCDE summary meets the following Standard 2 action areas:*

### **Partnering with patients in their own care<sup>7</sup>**

#### **Action 2.6**

Sharing decisions and planning care: Patients receive safe and high-quality care by being involved in decisions and planning about current and future care.

#### **Action 2.7**

Sharing decisions and planning care: Health professionals work with patients to enable them to be partners in their own care.

### **Health literacy<sup>8</sup>**

#### **Action 2.8**

Communication that supports effective partnerships: Consumers receive the information they need in a way that is appropriate for them.

#### **Action 2.10**

Communication that supports effective partnerships: Consumers receive the information they need to get the best health outcomes, and this information is easy to understand and act on.

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<sup>6</sup> The National Safety and Quality Health Service (NSQHS) Standard 2 can be accessed via

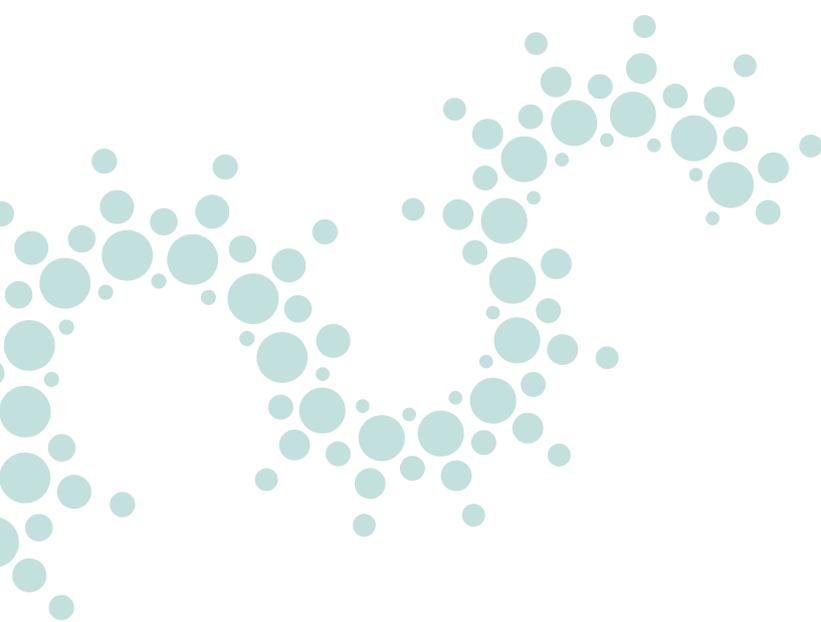
<https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard>

<sup>7</sup> Action 2.6 and 2.7 can be accessed via

<https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/partnering-patients-their-own-care>

<sup>8</sup> Action 2.8 and 2.10 can be accessed via

<https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/health-literacy>



## Optimal Care Pathways

The Optimal Care Pathways<sup>9</sup> (OCPs) describe the key steps in a patient's cancer journey and detail, for 15 cancer types, the expected standards of care at each stage. By stipulating consistent standards for each stage in a patient's cancer journey, the OCPs aim to improve patient outcomes, experiences and the quality of care.

The OCPs were developed by consulting with a wide range of expert health professionals, multidisciplinary teams, peak health organisations, consumers and carers. It was subsequently endorsed by the National Cancer Expert Reference Group (NCERG).

Each OCP includes three resources:

- for health professionals: a detailed clinical Optimal Care Pathway
- for general practitioners: quick reference guides
- for patients: a 'what to expect' guide, that helps patients and their carers understand the cancer care pathways and what to expect at each stage throughout their care.

## OCPs and patient-centred care

A key principle underpinning the OCPs is patient-centred care: healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. In addition, there is growing evidence of the importance of partnerships between health services, health professionals, patients, families, carers and consumers<sup>10</sup>. These elements of high-quality healthcare can lead to improvements in care and outcomes<sup>11</sup>.

Providing cancer patients with information about their diagnosis and available support services can improve a patient's understanding of their health.

Therefore, the OCPs recommend that the patient's lead health professional should:

- offer individualised cancer information that meets the needs of the patient and carer
- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes, and provide the patient with a written treatment plan
- provide the patient and carer with information about:
  - ↳ Possible side effects of treatment
  - ↳ Self-management strategies
  - ↳ Emergency contacts.

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<sup>9</sup>Further information about the OCPs can be accessed via

# PURPOSE

The 'My Cancer Diagnosis Explained' (MCDE summary) aims to give patients information about their diagnosis so they have a better understanding of their care, and the steps they will take after diagnosis. Each section of the MCDE summary contains information that patients should receive at the time of diagnosis, and which should supplement the information their health professional gives them verbally during the consultation.

The health professional informing the patient of their diagnosis needs to be familiar with the information that needs to be included in each section of the MCDE summary.

The MCDE summary allows the clinician to provide the patient the following written information:

- the cancer diagnosis
- details about the stage of their cancer
- a diagram on which the health professional marks the location of the cancer
- what happens next (tests needed and other health professionals the patient may need to see)
- main points discussed in the consultation
- where to find more information.
- questions they may want to ask their doctor.

***The MCDE summary provides a consistent structure of the information provided to patients and sets a minimum standard of communication and patient engagement.***

The MCDE summary provides a consistent structure of the information provided to patients and sets a minimum standard of communication and patient engagement. These are both important, especially as health professionals often have limited time for conversations about complex health matters. Sample MCDE summary are in Appendices 1 and 2.

## **Benefits of providing the MCDE summary to patients**

There are several benefits of routinely providing the MCDE summary to patients:

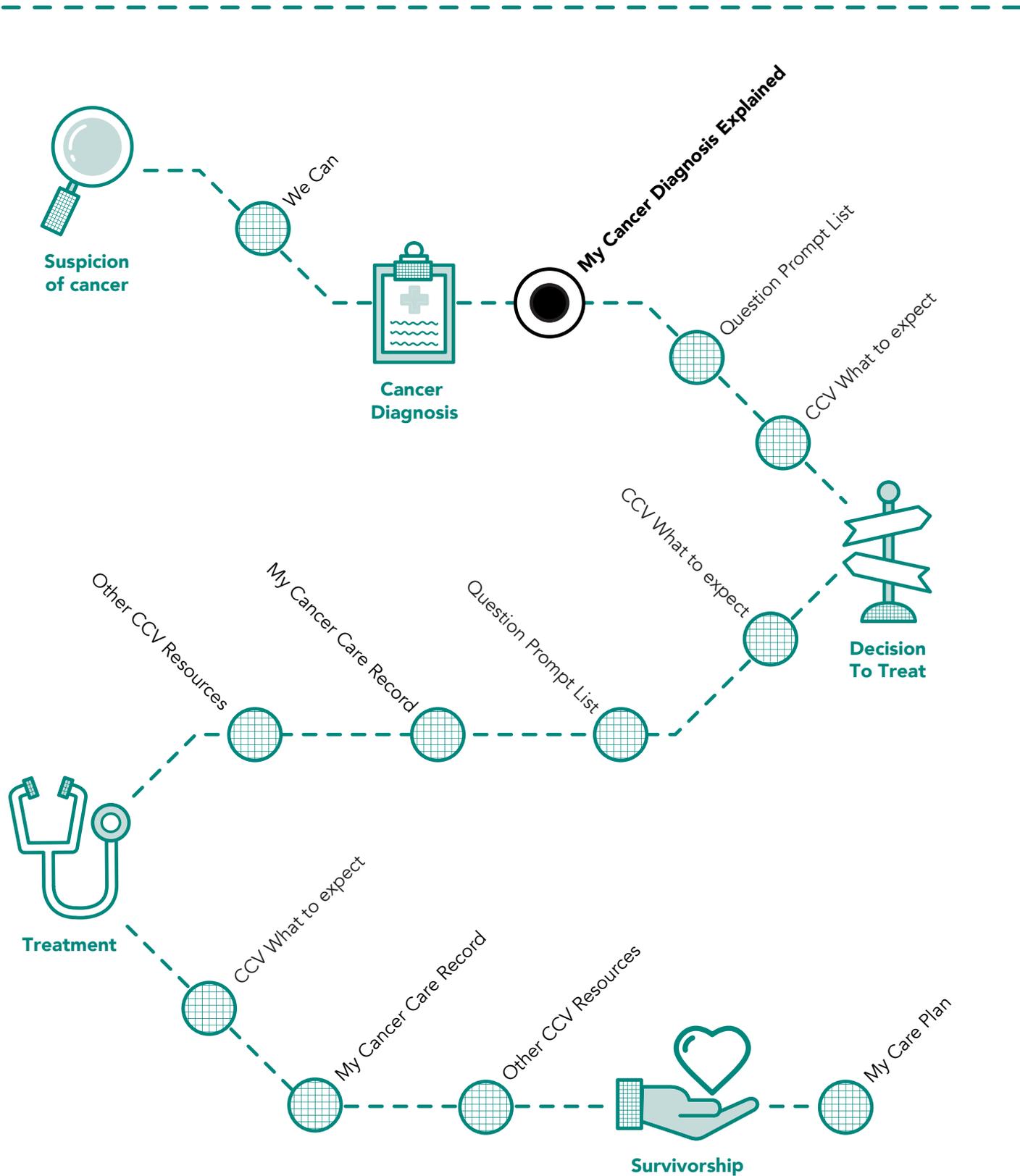
- Patients receive information that is specific and individualised to them.
- Being informed about their cancer increases patients' overall satisfaction with the care provided by their health professionals.
- Patients are more likely to retain information and can refer to and reflect on that information after the consultation.
- Patients are more likely to understand complex medical information about their diagnosis and treatment.
- An informed patient is more likely to be actively engaged in shared decision-making.
- Patients are more likely to comply with treatment and therefore experience better health outcomes.
- Health professionals have a clear and consistent framework for informing patients.

**Diagram 1**

*Resources available for patients affected by cancer*

Diagram 1, below, shows:

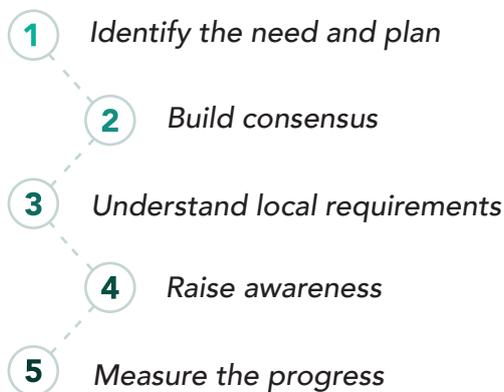
- when to give patients the MCDE summary
- how the MCDE summary complements other resources available for people affected by cancer.



## 5 Steps to Implementation

Implementation is the process of turning strategies and plans into actions that bring about a desired change.

There are five steps to implement a change successfully. Jump to whichever step you are ready to follow:



### Step 1. Identifying the need and plan

Before you begin, take time to identify and clarify the issue and the proposed solution. This step is about defining fundamentals: what problem needs solving, who will be involved, and what will be done. It includes all aspects of project management planning.

Work with the whole team to identify current issues and potential solutions.



Thoroughly map existing local processes so you:

- understand how patients will interact with your health service throughout their care and when the MCDE summary can be given to them
- mitigate the risk of the patient not receiving the MCDE summary.

### Project Management Plan

Create a project management plan in which you clearly document the following items that need to be developed:

#### *Rationale, objectives and governance*

- a business case that explains the need for the change in your organisation
- a clear aim for the implementation project, and specific objectives
- the scope of the implementation project (specify what is in and out of scope)
- sponsorship and governance for the implementation project

#### *Project team*

- the key stakeholders who need to be involved
- the roles and responsibilities of the project team

#### *Implementation*

- timelines for the implementation project
- a communication plan
- a risks and issues log

#### *Evaluation*

- the evaluation approach, including key questions and data that you will collect and measure.

# step 2.

## Step 2. Build Consensus

### Agreement & Buy-in from Health Service Staff

Because change often leads to resistance, involve your stakeholders during all stages of the project to achieve:

- early buy-in
- successful program design
- long-term support for the program

Therefore, in many ways, stakeholder buy-in can be regarded as the glue that binds together all the project's elements, ensuring that the change will happen and that it will be a success.

Achieve clinical, managerial, and administrative consensus by clearly articulating the strategic vision and creating the means to support the proposed changes.



Strengthen the case for change by collecting and analysing qualitative data (e.g. Cancer Patient Experience Survey, patient and clinician surveys) and quantitative data (e.g. medical record audit). As well as helping people understand the need and relevance of the change, this information can form the basis of the project team's key messages about the project.

When building the case for change, answer the following questions:



- What is the current situation ('as is')?
- What is the desired state? ('to be')
- What is changing (including behaviours)?
- Why are we changing? What are the consequences of not changing?
- What's in it for those who are required to change (the likely benefits)?
- Who will the changes impact and what impact will they have?
- What are the measures of success and what will success look like?

### Reasons for resistance & overcoming resistance

Resistance may come from nursing and medical staff, who may be used to working in a deeply ingrained health service culture.

To overcome this resistance:

- determine who will be completing the MCDE summary for patients, and conduct a thorough analysis of established responsibilities and processes. Then reorganise roles and tasks appropriately, so you are not just adding tasks to roles that may already be overloaded.
- in all your leadership communication, explain why following new policies is a priority.



# step 2.



Another common pocket of resistance for a project such as the 'My Cancer Diagnosis Explained' may come from the IT department, as they usually have a large workload. To overcome this resistance, have senior management communicate the priority of the MCDE summary, and, if your health service decides to integrate the MCDE summary into their electronic medical record system, involve your IT department in every stage of the project.

## Form the local implementation team

Adopt a structured approach to implementation by establishing:

- a designated Project Lead
- a Sponsor (senior health service executive) who will support the Project Lead
- a Clinical Lead (visible clinical leader) who will also support the Project Lead
- an implementation team comprised of clinical and administrative staff from key departments in the health service.

With the assistance of senior management, the Project Lead should identify the members of the implementation team, keeping in mind that this group will be responsible for:

- ensuring that the MCDE summary is used in the health service
- reporting the progress and results to the senior management team.

The implementation will be successful only if the clinical team is actively involved and demonstrates genuine commitment and ownership of the project.



Members of the implementation team will need to have some of their time freed up so that they can attend regular meetings and conduct other work related to the implementation.

*Consider including the following stakeholders in the local implementation team:*

- Executive Sponsor – ideally the General Manager, Director of Nursing or designee
- Clinical/Change Champion – a senior clinician who can champion the initiative and help engage local clinical staff (e.g. Pre-Admission Clinic, Out-Patients Clinic, ward area)
- Process Owners – the staff members responsible for completing the MCDE summary for patients
- Project Lead – a committed and enthusiastic individual who will be the focal contact point for the implementation team at the lead site, and report to the senior management team
- Patients, family members and other community members.

# step 2.

## *When establishing a local implementation team:*

- appoint staff who are interested in the project and keen to improve overall outcomes for patients
- involve stakeholders who can influence and engage colleagues, and advocate on behalf of the project
- actively involve patients and carers, as they can provide a different and valuable perspective particularly when identifying possible solutions
- welcome project team members warmly, make the most of their interest and enthusiasm, encourage each person to take an active role, and allow different team members to own and control relevant aspects of the project.

## **Reporting progress**

The implementation team should regularly report on the project's progress and outcomes, as specified in the governance section of the Project Management Plan. Typically, each area of the implementation team prepares a report, which the Project Lead compiles into a single report and presents to senior management.

## **Accommodating local variations**

Local implementation will most probably vary at each site in order to accommodate variations in local resources and different levels of service provision.

## **Change Champions and Process Owners**

Change Champions and Process Owners need to be motivated and engaged, as they play a key role in the implementation of the project.



### **Change Champions**

Change Champions should be leaders from the different professional groups (e.g. members of the medical and nursing staff) in your health service.

The role of the champions is to:

- educate their respective professional groups
- advocate for the benefits of implementing the MCDE
- represent and advocate for their respective groups in the implementation team's meetings and decisions

After the planning, pilot and implementation stages, Change Champions also work to sustain the changes and improvements.

### **Process Owners**

Process owners are the staff members who fill in the MCDE summary for patients. Typically, a single staff member is responsible for completing several or most of the components.

*The implementation team must decide:*

- who is involved in filling in the MCDE summary for patients?
- who has ultimate responsibility for the information included in the MCDE summary?

## Step 3. Understand local requirements

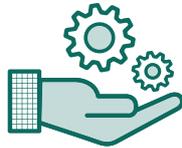
# step 3.

This step involves clearly defining the change to take place, modifying local practices, and measuring the outcomes. With each activity, the project team must consider local needs and resources in order to encourage buy-in and ownership and create a MCDE summary that suits the local setting.

### *This involves:*

- identifying people involved in changing local practices
- providing these people with appropriate resources
- providing feedback to local teams
- having stakeholders review the MCDE summary
- making minor amendments to adjust for the clinical setting and a patient's current condition. Appendix 3 contains useful information about how you can adapt the MCDE summary to your local requirements.

### Options to Consider



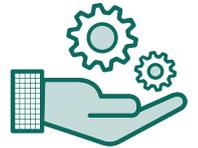
#### **Ethics review?**

When developing your plan, you must consider the ethical implications of your engagement activities. Determining the appropriate review depends on your project's level of risk. Each activity falls into one of the following risk categories: high risk research; low and negligible risk research; or quality assurance and audit.

To decide whether ethics approval is required:

- find out if the local health service considers the project a Quality Assurance or Research Project
- contact the Ethics Department at your health service for advice and support on which ethics review pathway to follow.

If necessary, allocate additional time for this process.



#### **Electronic or paper-based format?**

Determine which format of the MCDE summary will best meet the requirements of your health service and local setting. Whichever format you use, incorporating a local method to capture metrics will help you to evaluate the project.

##### *Paper-based*

A paper-based MCDE summary is best printed on tear-off pads.

The pads can be made available to:

- Clinical Nurse Consultants and/or care coordinators incorporating the MCDE summary into their work plan and practice
- administrative assistants and/or Multi-Disciplinary Team coordinators who identify newly diagnosed patients and can attach patient labels to the MCDE summary before the appointment
- clinicians in their clinic rooms, so they can use the MCDE summary as required.

##### *Electronic*

An electronic format allows clinicians to edit the MCDE summary electronically, print it for the patient, and email it to the patient. You will need approval from the local forms committee to make the MCDE summary available through the local health service's Electronic Medical Record (EMR).

## Step 4. Raise awareness

# step 4.

One of the primary goals of patient-centred care is to integrate patients as partners in the care team, and the MCDE summary helps to achieve this. However, introducing the MCDE summary will involve some minor and more substantial changes in the way people do their work, so all staff involved in this initiative need the awareness and knowledge to participate effectively and follow appropriate processes.

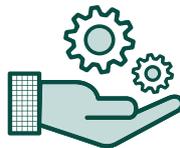
To help your health service adopt the MCDE summary and use it effectively, local implementation will need to include ongoing education for patients and health professionals about the purpose of the MCDE summary. For example, you could display a poster in the staff area and a patient-focused one in the patient waiting area.

Situations to consider in the education include what to do when staff members encounter a patient who has a MCDE summary previously completed by another member of staff, and when a patient who is aware of the MCDE summary asks their clinician to complete one for them.

To increase their sense of ownership and involvement, involve people from the beginning of the project. Sending out regular communications about the change to the local team and all related stakeholders will help them stay involved.



### Options to Consider

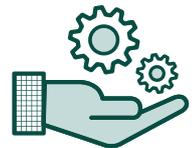


#### Patient education

Patient education can increase the occurrence of shared decision-making.

Examples of patient education:

- clinicians can use the 'teach back' strategy with patients during the appointment
- patients can be directed to online resources
- patients can be given patient resources (e.g. the MCDE summary in a pack, What-to-expect)
- the MCDE summary can be available in the Patient/Family Resource Centre.



#### Clinician education

Successful implementation of the MCDE summary relies on clinicians and members of key departments clearly understanding the MCDE summary's purpose.

Examples of clinician education:

- grand rounds presentations
- in-service training (in person, via webinars, using expert speakers or consultants)
- presentations at multi-disciplinary team meetings
- updates in newsletters and emails sent to health professionals.

# step 5.

## Step 5. Measure the progress

Evaluation is an integral component of quality improvement. As well as providing specific information relating to the project, undertaking formal evaluation of the project can also deliver important information that adds to the body of knowledge about the theory of implementation processes and complex change processes.

Quality improvement projects, such as implementing the MCDE summary, are undertaken in many different settings and the knowledge gained from these projects can help increase our understanding of implementing effective change.

Each time the MCDE summary is introduced into the care of a patient, it should be considered an opportunity for us to learn and improve the patient's experience of care.



### Evaluation may include:

- patient and carer surveys to collect information about the impact of the implementation project
- clinician surveys to collect information about their experience and awareness of the implementation project
- regularly conducting a local review and sharing the results with the local team members
- discussions of any local barriers to implementation in order to identify solutions
- collecting positive feedback from carers and staff and sharing this with the local team and management to demonstrate the benefits of the implementation.



***Local leaders need to maintain their support of, and encouragement to, the staff involved so that the initiative is sustained and becomes part of local policy and practice.***

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# HYPERLINKS

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2. My Cancer Diagnosis Explained  
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3. Question Prompt List  
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<https://www.cancer.org.au/about-cancer/cancer-pathways-what-to-expect.html>
5. My Cancer Care Record  
[https://www.nemics.org.au/page/improving\\_cancer\\_care/My\\_Cancer\\_Care\\_Record/](https://www.nemics.org.au/page/improving_cancer_care/My_Cancer_Care_Record/)
6. My Care Plan- Australian Cancer Survivorship Centre (ACSC)  
<https://www.mycareplan.org.au/>

# APPENDIX 1

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## APPENDIX 1 Head and Neck Cancer MCDE summary

# Head & Neck Cancer

## My Cancer Diagnosis Explained

A personalised summary for me to keep

Please affix patient ID label here

My key hospital contact is:

Name:

Phone:

To be completed by clinician upon diagnosis:

Clinician name:

Role:

Date completed:

What is my diagnosis? \_\_\_\_\_



Stage:

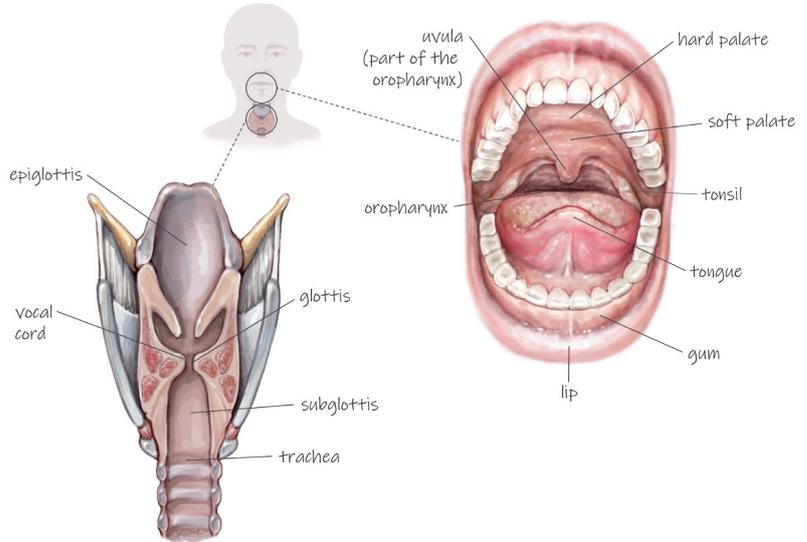
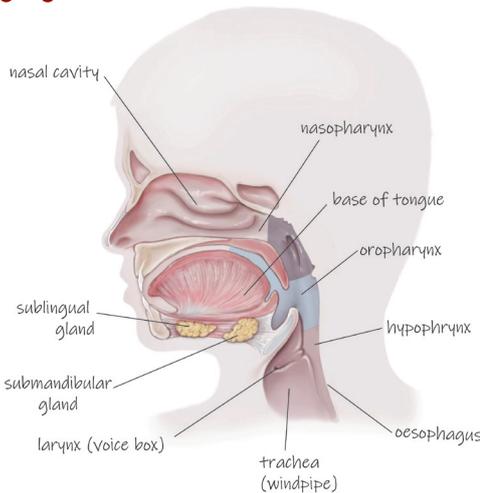
Stage tells me if/how much my cancer has spread. (It helps doctors to work out the best treatment options.)

Early Cancer: Stage 1 or 2 cancers are small (less than 4cm in size) that have not spread.

Advanced Cancer: Stage 3 or 4 cancers are bigger (more than 4cm), and have grown into nearby tissue, spread to lymph nodes, or spread to other parts of the body.



Location:



What happens next?

I may need the following test(s) and/or scan(s): \_\_\_\_\_

I may see one or more specialists below to discuss my test results and treatment options, the possible side effects and risks and benefits of treatment.

These are some key clinicians who together make up my Multidisciplinary Team

Medical Oncologist

treats cancer using drug therapies such as, chemotherapy, targeted therapy or immunotherapy

Radiation Oncologist

treats cancer using radiotherapy

Surgeon

removes the cancer and nearby tissue during surgery

Cancer Nurse

helps to navigate appointments, and provides care and follow-up

Palliative Care Consultant

helps people with cancer gain good quality of life

Other

Top 3 points we discussed today:

- 1.
- 2.
- 3.

My to-do list:

clinician to use teachback

Insert barcode here

## Where can I find more information?

### General Practitioner (GP):

GPs can be a helpful source of support and advice and can refer to other support services if required, such as:

- Dentist/ Prosthodontist
- Palliative Care
- Physiotherapist
- Speech Pathologist
- Social Work
- Audiology
- Dietitian
- Exercise Physiologist
- Psychology
- Occupational Therapist

### Online information:

[www.beyondfive.org.au](http://www.beyondfive.org.au)  
[www.wecan.org.au](http://www.wecan.org.au)  
[www.cancerpathways.org.au](http://www.cancerpathways.org.au)

### Information and support:

Cancer Council nurses can answer any questions about the effects of cancer and provide information on local support and other community resources. Call a Cancer Council nurse on 13 11 20 or visit [www.cancer.org.au](http://www.cancer.org.au)

### Cost consideration:

When going to hospital, there are different costs for treatment. Even with private health insurance, there may be out of pocket costs for medical appointments, tests, medications, accommodation, travel, and parking. I can discuss these costs with my GP, clinician, or private health insurer to understand what will be covered. Visit [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au) for more information.

## Questions I may want to ask:

Asking questions can sometimes help in understanding and making decisions about health

### About my cancer:

- Is my cancer slow or fast growing?
- How serious is my cancer?
- Is it possible to cure or control my cancer?

### About scans and other tests:

- What will this test involve?
- What are the benefits and risks to me in having this test?
- Will the test results make any difference to the decision on what type of treatment I have?
- What are the costs of scans and tests?

### About my treatments:

- What treatments are available to me?
- What difference will this treatment make to my quality of life (eg. can I work)?
- How much will treatment cost? How can the cost be reduced?
- What are the possible side-effects of treatment?
- Are side-effects of treatment temporary or permanent?
- Can they be prevented or controlled?
- What if this treatment does not work?
- I would like some time to make a decision. Will that make any difference?
- Who are the members of my treatment team?
- Can I get a second opinion?
- Are there any clinical trials suitable for me?

My notes: (e.g. what I need to do between appointments, next appointment etc.)

# APPENDIX 2

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## APPENDIX 2 Pancreatic Cancer MCDE summary

# Pancreatic Cancer

## My Cancer Diagnosis Explained

A personalised summary for me to keep

Please affix patient ID label here

My key hospital contact is:

Name:

Phone:

To be completed by clinician upon diagnosis:

Clinician name:

Role:

Date completed:

What is my diagnosis?



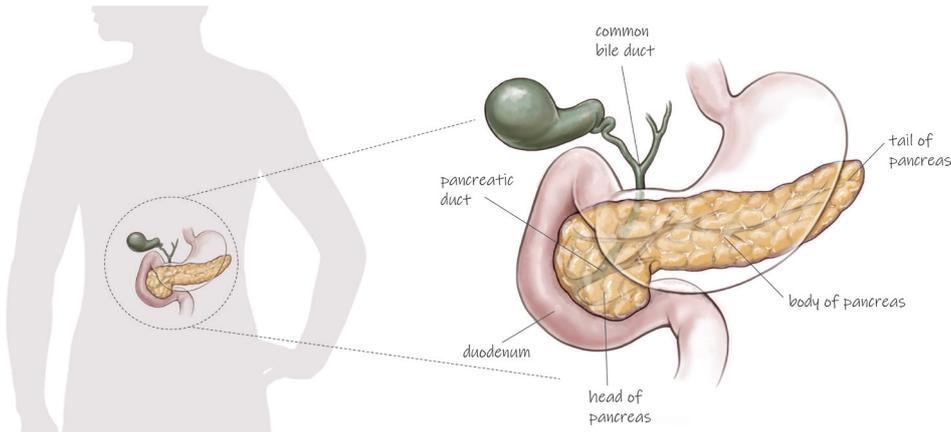
Stage:

Stage tells me if/how much my cancer has spread. (It helps doctors to work out the best treatment options.)

- Early stage resectable: Cancer is found only in the pancreas.
- Borderline resectable: Cancer has either spread to lymph nodes or organs near the pancreas, such as the duodenum or common bile duct, or is large but has not spread to nearby organs.
- Locally advanced: Cancer has grown into nearby major arteries. Cancer may or may not be in the lymph nodes.
- Metastatic: Cancer has spread to other organs, such as the liver, lungs or lining of the abdomen.



Location:



What happens next?

I may need the following test(s) and/or scan(s): \_\_\_\_\_

I may see one or more specialists below to discuss my test results and treatment options, the possible side effects and risks and benefits of treatment.

*These are some key clinicians who together make up my Multidisciplinary Team*

- Medical Oncologist**  
*treats cancer using drug therapies such as, chemotherapy, targeted therapy or immunotherapy*
- Surgeon**  
*removes the cancer and nearby tissue during surgery*
- Palliative Care Consultant**  
*helps people with cancer gain good quality of life*
- Radiation Oncologist**  
*treats cancer using radiotherapy*
- Gastroenterologist**  
*treats diseases that affect the gut and performs endoscopy, colonoscopy and biopsy*
- Cancer Nurse**  
*helps to navigate appointments, and provides care and follow-up*

Top 3 points we discussed today:

- 1.
- 2.
- 3.

My to-do list:

clinician to use teach back

Insert barcode here

## Where can I find more information?

### General Practitioner (GP):

GPs can be a helpful source of support and advice and can refer to other support services if required, such as:

- Palliative Care
- Exercise Physiologist
- Physiotherapist
- Endocrinologist
- Social Work
- Psychology
- Dietitian
- Occupational Therapist

### Online information:

[www.pancare.org.au](http://www.pancare.org.au)  
[www.pansupport.org.au](http://www.pansupport.org.au)  
[www.unicornfoundation.org.au](http://www.unicornfoundation.org.au)  
[www.cancerpathways.org.au](http://www.cancerpathways.org.au)  
[www.wecan.org.au](http://www.wecan.org.au)

### Information and support:

Cancer Council nurses can answer any questions about the effects of cancer and provide information on local support and other community resources. Call a Cancer Council nurse on 13 11 20 or visit [www.cancer.org.au](http://www.cancer.org.au)

### Cost consideration:

When going to hospital, there are different costs for treatment. Even with private health insurance, there may be out of pocket costs for medical appointments, tests, medications, accommodation, travel, and parking. I can discuss these costs with my GP, clinician, or private health insurer to understand what will be covered. Visit [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au) for more information.

## Questions I may want to ask:

Asking questions can sometimes help in understanding and making decisions about health

### About my cancer:

- Is my cancer slow or fast growing?
- How serious is my cancer?
- Is it possible to cure or control my cancer?

### About scans and other tests:

- What will this test involve?
- What are the benefits and risks to me in having this test?
- Will the test results make any difference to the decision on what type of treatment I have?
- What are the costs of scans and tests?

### About my treatments:

- What treatments are available to me?
- What difference will this treatment make to my quality of life (eg. can I work)?
- How much will treatment cost? How can the cost be reduced?
- What are the possible side-effects of treatment?
- Are side-effects of treatment temporary or permanent?
- Can they be prevented or controlled?
- What if this treatment does not work?
- I would like some time to make a decision. Will that make any difference?
- Who are the members of my treatment team?
- Can I get a second opinion?
- Are there any clinical trials suitable for me?

My notes: (e.g. what I need to do between appointments, next appointment etc.)

# APPENDIX 3

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## APPENDIX 3

How to build your own 'My Cancer Diagnosis Explained' summary

# How to build your own 'My Cancer Diagnosis Explained' summary

Engaging and empowering patients in their health care

## Health Literacy Key Principles

When developing the 'My Cancer Diagnosis Explained' it is important to remember that all patients and carers may have difficulty comprehending health information and that you should communicate in ways that anyone can understand.

The following suggestions will help you to reduce the complexity of the information and increase a patient's understanding of health information:

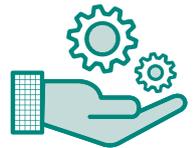


- use [health literacy standards](#) (grade 6)
- provide simple and clear information
- make everything easy to understand
- use simple language (no jargon)
- use short, simple and direct sentences.

## Step 1: Individualise patient information

Individualised patient-information a person receives may vary from one health service to another, depending on the service provision of the health service. Ideally, the content of the 'My Cancer Diagnosis Explained' MCDE summary (the MCDE summary) should align to the requirements of the health service.

## Consider



### Content

Limit to essential information

- Summarise main points
- State the information as clearly and simply as possible
- Provide information about other sources
- Use a conversational style, using active voice
- Include information that is relevant and meaningful to the patient, for example:
  - ↳ Cancer diagnosis
  - ↳ Stage and location of cancer
  - ↳ Tests/scans to be completed and future appointments to confirm diagnosis
  - ↳ Treatment options and side effects
  - ↳ Support
- Who to contact in hospital
- Other resources
- Support groups
- Out-of-pocket costs
- Prompt questions for follow-up

### Design ('look and feel')

- Use a simple design, free of clutter and distractions
- 4 – 5 main points (use bulleted lists or bold etc)
- Use a clear typeface, like Arial
- Use type size 12 point or larger
- Use action-orientated graphics and balance with use of white space to provide a break for the eyes
- Limit to 1-2 pages
- Use headline and titles
- Do not use full justification of text

## Step 2: Stakeholder engagement

Engage and consult with health professionals, patients and carers. They will be able to provide advice about what information to include. Active involvement from clinicians will build advocacy for the use of the MCDE summary.

### Suggestions:

- seeking feedback from any clinical roles and department staff likely to use the MCDE summary
- setting realistic timeframes for seeking agreement (it is an iterative process)
- holding a workshop to brainstorm and agree on the content of the MCDE summary with active participation from all stakeholders.

## Step 3: Develop and review the resource

- Develop the MCDE summary in accordance with your health service's forms policy.
- After the stakeholders have agreed to the content, use page design software such as Microsoft Publisher or Adobe InDesign to create the MCDE summary.

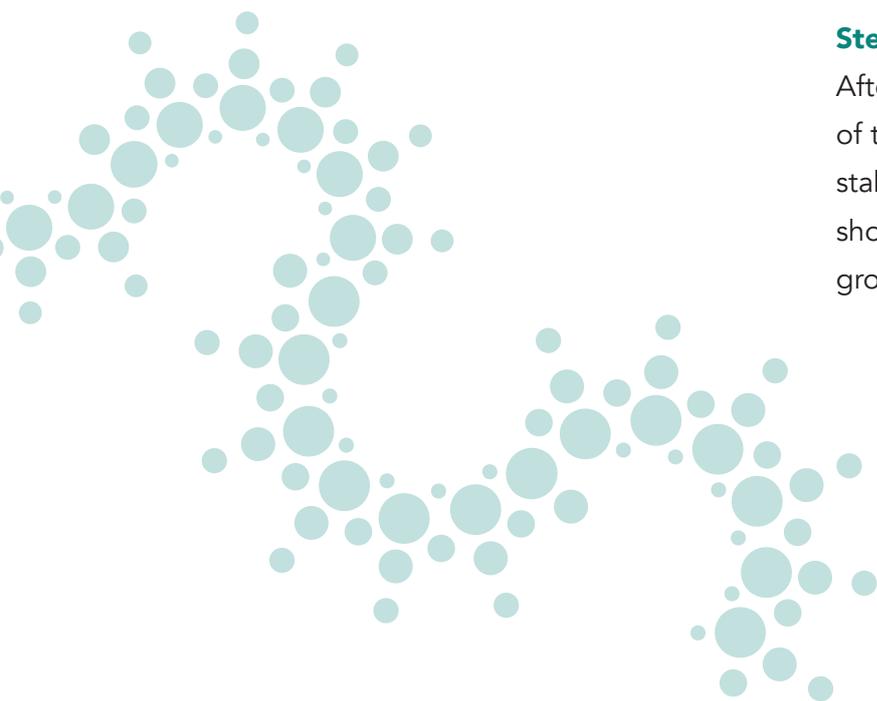
Seeking feedback from the end users (clinicians and patients) will help to ensure the MCDE summary will meet end users' needs. Creating the MCDE summary is an iterative process, and you might update the MCDE summary many times.

### Examples of the type of feedback to ask for:

- clarity of the information
- suitability of the information
- utility of the MCDE summary
- process of delivering the MCDE summary.

## Step 4: Approval of the MCDE summary

After the review process, share the final version of the MCDE summary with the relevant stakeholders for a 'final quality review'. This should include representatives of all stakeholder groups, including end users and managers.



# Template Cancer

## My Cancer Diagnosis Explained

A personalised summary for me to keep

Please affix patient ID label here

My key hospital contact is:

Name:

Phone:

To be completed by clinician upon diagnosis:

Clinician name: *Template\_Name*

Role: *Template\_Role*

Date completed: XX/XX/XXXX

What is my diagnosis? \_\_\_\_\_



Stage:

Stage tells me if/how much my cancer has spread. (It helps doctors to work out the best treatment options.)

INSERT STAGE DESCRIPTION

INSERT STAGE DESCRIPTION

INSERT STAGE DESCRIPTION

INSERT STAGE DESCRIPTION



Location:

INSERT ILLUSTRATION

PLACE HOLDER  
PLACE HOLDER



Insert barcode here



What happens next?

I may need the following test(s) and/or scan(s): \_\_\_\_\_

I may see one or more specialists below to discuss my test results and treatment options, the possible side effects and risks and benefits of treatment.

*These are some key clinicians who together make up my Multidisciplinary Team*

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Surgeon

*removes the cancer and nearby tissue during surgery*

Palliative Care Consultant

*helps people with cancer gain good quality of life*

Radiation Oncologist

*treats cancer using radiotherapy*

Cancer Nurse

*Helps to navigate appointments, and provides care and follow-up*

Other

Top 3 points we discussed today:

- 1.
- 2.
- 3.

My to-do list:

clinician to use teach back

## Where can I find more information?

### General Practitioner (GP):

GPs can be a helpful source of support and advice and can refer to other support services if required, such as:

- INSERT AVAILABLE SUPPORT SERVICES
- INSERT AVAILABLE SUPPORT SERVICES
- 
- 

### Online information:

INSERT WEBSITE URLS

### Information and support:

Cancer Council nurses can answer any questions about the effects of cancer and provide information on local support and other community resources. Call a Cancer Council nurse on 13 11 20 or visit [www.cancer.org.au](http://www.cancer.org.au)

### Cost consideration:

When going to hospital, there are different costs for treatment. Even with private health insurance, there may be out of pocket costs for medical appointments, tests, medications, accommodation, travel, and parking. I can discuss these costs with my GP, clinician, or private health insurer to understand what will be covered. Visit [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au) for more information.

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### About my treatments:

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- How much will treatment cost? How can the cost be reduced?
- What are the possible side-effects of treatment?
- Are side-effects of treatment temporary or permanent?
- Can they be prevented or controlled?
- What if this treatment does not work?
- I would like some time to make a decision. Will that make any difference?
- Who are the members of my treatment team?
- Can I get a second opinion?
- Are there any clinical trials suitable for me?

My notes: (e.g. what I need to do between appointments, next appointment etc.)

