Victorian Integrated Cancer Services

My Cancer Diagnosis Explained

Assisting with Patient-Centred Care

State-wide Project report, May 2020

For more information, contactus@wcmics.org.au

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Acknowledgements

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.

Table of contents

Executive summary

Key messages:

- In accordance with the state-wide adoption of the Optimal Care Pathways (OCPs), a cancer diagnosis summary (the 'My Cancer Diagnosis Explained' (MCDE) summary) was co-designed to provide written information specific to individual patients and their carers.

- The MCDE summary is designed to complement existing patient-centred care, programs and policies that health services may already have in place.

- The summary helps to increase access to services and equity of health outcomes for a diverse range of patients and carers with varying levels of health literacy.

- It provides a template and guide for state-wide standardisation of communication to cancer patients, and one which any health service working across any tumour stream can choose to adopt.

The 'My Cancer Diagnosis Explained' project builds on 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 titled *Development and implementation of a Suite of Individualised Patient Information tools (2018*) found that cancer patients consistently report wanting more, and specific, information about their cancer diagnosis. The pilot project set out to provide information specific to patients about their diagnosis and services available to them.

A recommendation from the pilot project was to take the concept to a state-wide project funded through the Victorian Integrated Cancer Services. The deliverables being develop resources for people diagnosed with pancreatic cancer and head and neck cancers and an implementation guide.

This project aimed to develop an individualised cancer information resource called the 'My Cancer Diagnosis Explained' (MCDE summary), to supplement the verbal communication between a clinician and the patient at the time the patient is informed of a cancer diagnosis. An implementation guide was also developed to assist any clinician, quality improvement team or project officer who wants to implement the MCDE summary into a clinical area.

The MCDE summary supports the 'diagnosis and next steps' conversation with patients by:

- helping clinicians to deliver specific information about the cancer diagnosis

- enabling effective communication that meets each patient's needs

- linking the patient to information and services that can help them

- ensuring the patient is informed and can therefore be actively engaged in decisions about their health

- providing the patient with take-home information they can refer to and reflect on after the consultation.

The content of these new resources was co-designed by patients and clinicians across the state, with consideration of the health literacy levels of most of the Australian population.

1. Background context

Cancer is the leading cause of the total burden of disease in Australia[1] and has a significant impact on a person's physical, emotional, and social well-being. The steady progress made in many areas (including early diagnosis, improved treatment methods and higher survival rates), has resulted in an increased prevalence of cancer and its recognised 'status' as a chronic condition. All of these factors have made the management of care for cancer patients more complex.

Since clinicians are involved in diagnosis, treatment and follow-up, many and various clinicians are involved[2]. This results in a complex healthcare system, to which patients need to continually adapt if they are to successfully navigate through its many paths. This complexity can lead to sub-optimal care that can result in discontinuity and fragmentation of care. Therefore, we need to address this to ensure that health care delivery is more patient-centred[3].

Patient-centred care (the concept of making sure that people are involved in and central to their care) is recognised as a key component for delivering high quality integrated care. When healthcare professionals and services give patient-centred care, it puts the patient at the 'centre' of their healthcare. Literature shows that the 'patient-centredness' of cancer care can be improved in many ways. One way is to provide patient-centred communication, which is essential to providing high quality patient-centred care[4].

The burden of cancer demands that we understand and improve how patients, families, and health care professionals communicate. To do so, the project referred to the recent pilot project (2018) and the following five main drivers in the development of patient information for cancer healthcare settings:

1) the National Safety and Quality Health Service Standards (the policy context)

2) the Optimal Care Pathways in cancer care

3) patient-centred communication

4) health literacy as a determinant of patient engagement

5) co-design of improvements in health information and health outcomes (including participation of patients).

Each of these are explained below.

The National Safety and Quality Health Service Standards

The eight National Safety and Quality Health Service (NSQHS) Standards[5] provide a nationally consistent

statement of the level of care patients can expect from health services.

Of these eight standards, the '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 respond to the input and needs of patients, carers and patients.

It also recognises and accepts that patient partnerships in health care are integral to the development, implementation and evaluation of health policies, programs and services, and considers that partnerships with patients and patients are central to patient-centred care.

Developing patient information for cancer healthcare (such as the MCDE summary) meets the following action items under two action areas of this Standard:

Partnering with patients in their own care

- **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

- **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

Optimal Care Pathways

The Optimal Care Pathways[6] (OCPs) describe the optimal cancer care for specific tumour types. They outline the patient or patient journey, identify specific steps or critical points along the care pathway, and make recommendations about care at each point.

Optimal Care Pathways also provide guidelines for communication between clinicians and patients.

The pathways have been endorsed by the National Cancer Expert Review Group (NCERG), Cancer Australia, Cancer Council of Australia, and the Australian Health Ministers Advisory Council (AHMAC).

As a key principle underpinning the OCPs is patient-centred care, the OCPs recommend that the lead

clinician should:

- offer individualised cancer information which 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 a written copy of this plan

- provide the patient and carer with information about:

  – possible side effects of treatment

  – self-management strategies

  – emergency contacts.

The OCPs state that communication should be:

- individualised

- truthful and transparent

- consistent

- in plain language (avoiding complex medical terms and jargon)

- culturally sensitive

- active, interactive and proactive

- ongoing

- inclusive of patients and their families.

As such, developing a resource that provides information about a person's cancer diagnosis and available support services aligned to the OCP recommendations.

Patient-centred communication

The communication between a clinician and patient at the time of diagnosis is a crucial first step in that person's cancer journey. Although complex medical information about diagnosis and treatment is provided to patients, this is often in isolation of any supplementary written information. In addition, patients may not comprehend all of the information they receive during their appointment and may not recall all of it afterwards. Various studies estimate that patients remember only 14-40% of the information provided verbally[7].

The recent pilot study focused on improving patient-centred communication by providing lung and colorectal cancer patients with written information specific to their cancer diagnosis.

Clinicians (Medical Oncologists, Surgeons, Radiation Oncologists and Cancer Nurse Coordinators) who found that providing written information was beneficial at time of diagnosis stated:

"Providing patients with a personalised plan is fantastic."

"It provided a segue for patients to ask questions."

"Provides patients with information to take away, as they may be still processing the information heard."

"It is simple and clear and provides a clear outline of processes in lung diagnosis."

"The summary is a good way of providing documentation, but not sure if it genuinely enhances the understanding of all the processes involved to the patient."

"It provides a consistent structure to how I communicate and the information I give patients."

Similarly, feedback from the patient survey (pre and post pilot) identified that:

- the number of people who received spoken and written information about their cancer diagnosis increased from 46% (pre-pilot) to 80% (post-pilot) (Figure 1).

- the number of people who received individualised written information increased from 29% to 80% (Figure 2).

Figure 1. Format of information patients received (N=22)

Pre-pilot
In what format did you receive information about your cancer diagnosis?
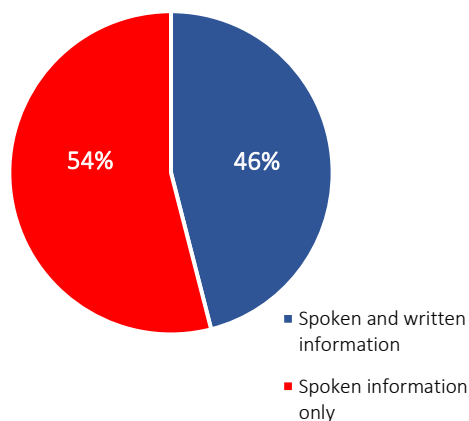
- Spoken and written information
- Spoken information only

Post-pilot
In what format did you receive information about your cancer diagnosis?

- Spoken and written information
- Spoken information only

Figure 2. Nature of information patients received (N=22)

Pre-pilot
What type of information did you
receive about your cancer diagnosis?

Post-pilot
What type of information did you
receive about your cancer diagnosis?

Pre-pilot chart: 29% Individualised written information, 71% Generic written information

Post-pilot chart: 20% Individualised written information, 80% Generic written information
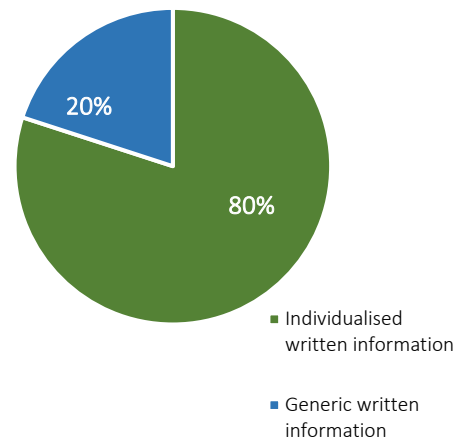
Individualised and written information improves a patient's recall of pertinent medical information, which results in better adherence to recommended treatment plans. Therefore, this project (as recommended in the pilot project) continues to emphasise that patient-centred communication is essential to providing high quality patient-centred care.
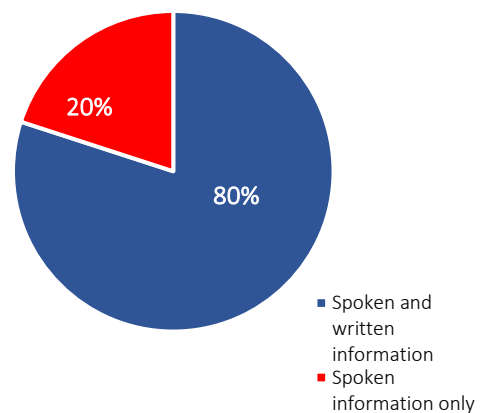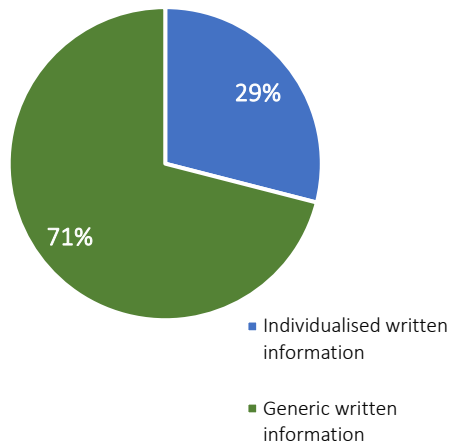
Health literacy as a determinant of patient engagement and health

The Australian Commission of Safety and Quality in Health Care[8] states that only about 40% of adults have the level of health literacy needed to meet the complex demands of everyday life. Low health literacy is associated with higher rates of hospitalisation and emergency care, poor treatment compliance and adverse outcomes generally[9].

To facilitate improvement and reduce barriers to healthcare, the ACSQH recommends that healthcare providers:

- recognise the needs and preferences of individual patients and patients

- assume that most people have difficulty understanding and applying health information and concepts that are complex

- use a range of interpersonal communication strategies to confirm that information has been

delivered and received effectively.

These recommendations are relevant not only when interacting with patients and patients, but also when developing patient-centred material.

Co-design of improvements in health information and health outcomes (including participation of patients)

Co-design refers to the design of a service or product that involves people who use or are affected by that service or product[10] and is now used in many sectors. In healthcare, co-design seeks to bring together managers, clinicians, patients and their representatives to share their experience, resources, and knowledge to improve work practices, products and services. Involving much more than just consultation, all participants are seen as an expert in their field, and are invited to offer advice in different forums and formats.

Co-design is recognised as an element of high-quality healthcare which leads to improvements in health care and health outcomes. The success of the pilot project was underpinned by a rapid co-design process, that highlighted the importance of partnerships between health services, clinicians, patients, families, carers and patients. Active participation of people who were likely to be affected by the outcomes of the project contributed to its success and supports the same approach for future projects, as follows:

"As healthcare itself moves towards a better focus on the individual patient, both patients and healthcare workers can benefit from having an equal say in genuinely co-designing care to deliver a better experience and better health outcomes overall."

Medical Oncologist (state-wide workshop)

2. About the project

Project rationale

The 'My Cancer Diagnosis Explained' (MCDE summary) state-wide project builds on the pilot project titled *Development and implementation of a Suite of Individualised Patient Information tools to empower and inform cancer patients* (2018) led by Western and Central Melbourne Integrated Cancer Service in collaboration with Southern Melbourne Integrated Cancer Service and Hume Regional Integrated Cancer Service.

The pilot project identified that verbal communication supplemented by written information specific to the individual's cancer diagnosis (i.e. the MCDE summary) resulted in patients reporting an improved level of satisfaction with their hospital experience. Additionally, results indicated that the resource provides a consistent structure for conducting a consultation, and actively engages the patient in shared decision-making. Thus, a key recommendation of the pilot project was for all tumour streams to adopt the MCDE summary in order to achieve a state-wide standardised approach to providing patient information.

Project aim

The project aims to:

- make information about a cancer diagnosis specific to the patient

- make information about cancer services available and easy to understand to all Victorian cancer patients.

Project objectives

- To develop a standard resource to be given to patients at the time of their cancer diagnosis which provides written information that is specific to the patient.

- To develop a standardised communication tool to help cancer clinicians explain a specific cancer diagnosis.

- To engage relevant stakeholders in order to identify their needs and receive their input into the content and design of the resource.

- To co-design evidence-based information tools that will supplement and reinforce verbal communication between clinicians and patients at the time of a cancer diagnosis.

- To help achieve patient-centred communication and improve levels of patient satisfaction.

Project scope

The project scope was to develop two patient information resources (one for head and neck cancer and another one for pancreatic cancer), both of which would subsequently be rolled out state-wide.

Inclusions

- Devolved co-design and testing (by three Integrated Cancer Services) of the resources in English, at an appropriate health literacy standard.

Exclusions

- Development of resources in languages other than the selected languages.

- Paediatric cancer streams.

- Development of resources specific to Aboriginal and Torres Strait Islander Australians.[*]

Project governance

Project Steering Committee

The Project Steering Committee, a forum for the exchange of ideas, was accountable for the MCDE project. Its function was to provide oversight and general guidance of the project and ensure the project objectives and key deliverables were achieved.

Steering Committee Members

- The manager of the sponsor ICS

- 2 ICS managers

- 1 Department of Health and Human Services (DHHS) representative

- 2 pancreatic cancer patient representatives

- 2 head and neck cancer patient representatives

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[*] departure of this project was due to recommendation from the Chief Aboriginal Health Advisor, Victorian DHHS, to allocate adequate time to engage and co-design with Aboriginal and Torres Strait Islander Australians. The departure was supported by DHHS, VICS network, and the Project Steering Committee members on 11/02/2020.

- 5 clinical representatives

- 1 Cancer Council Victoria (CCV) representative

- 1 project lead

Project oversight structure

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        │   Sponsor    │
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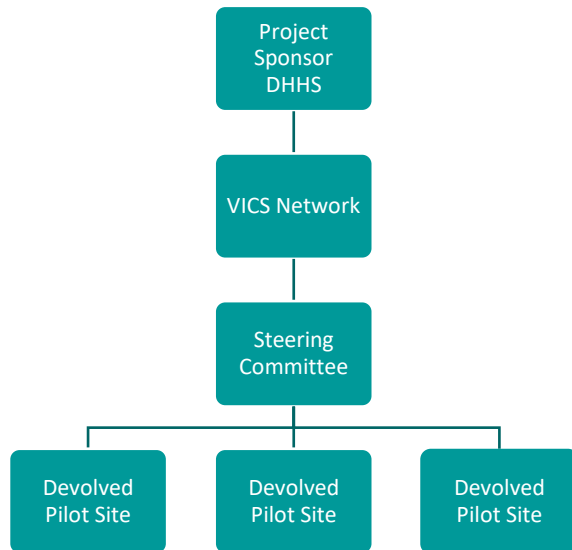
Devolved pilot sites

The pilot sites functioned as test sites by engaging with their stakeholders to assess the MCDE summary with for its 'usability' and 'look and feel', and providing recommendations for its development.

Participating ICSs

- Barwon South Western Integrated Cancer Service (BSWRICS)

- Grampians Integrated Cancer Service (GICS)

- Hume Regional Integrated Cancer Service (HRICS)

Participants at each pilot site were comprised of:

- project lead

- managers and project managers from the participating ICS

- health service staff/clinicians and patients from the participating ICS

Project stakeholders

The major stakeholders were:

- DHHS – Cancer Strategy and Development

- tumour stream heads of unit

- patients and carer representatives

- nurse coordinators

- other clinicians and/or managers

- health service quality improvement managers

- health information services managers.

See Appendix B for further information about the engagement of these and other these stakeholders.

3. Methodology and development of the MCDE summary

The MCDE project was a mixed methods project using a collaborative methodology, which included conducting:

- a scoping literature review to identify and map the components underpinning published definitions of patient-centred communication

- qualitative surveys of key stakeholders (patients, carers and clinicians)

- focus groups comprised of patients and clinicians, and conducted by the participating ICS, to co-design the MCDE summaries for patients with Head and Neck and Pancreatic cancer.

The collaborative methodology

BSWRICS, GICS and HRICS were invited to participate in the project.

Co-design testing of the summaries was devolved to the participating ICS in order to:

- extend the reach of the resources

- identify the needs of stakeholders across the state

- develop a resource that suits most people in Victoria.

Development of the MCDE summary

The MCDE summary was developed in phases (see Appendix A for a detailed timeline of development), which allowed for different approaches to collect feedback, and the opportunity for wide stakeholder consultation.

Stage 1: Review and consolidation

A rapid review of the pilot study was carried out to identify which recommendations to implement. A literature appraisal on patient-centred communication was also conducted to identify themes that align to the eight National Safety and Quality Health Service (NSQHS) Standards, and the health services' quality standards.

Stage 2: Co-design of MCDE summary

Phase 1: Conduct state-wide survey

Clinicians and patients across Victoria participated in surveys (N=56) so that the project could identify the

information a patient needs at the time they are told of their cancer diagnosis. The results informed the design and content of the preliminary MCDE summary.

Phase 2: Devolve co-design testing to participating ICSs

The three pilot sites engaged with their stakeholders to assess the look and feel of the preliminary MCDE summary and to understand how their health service could adopt it. They held focus groups or consulted with their clinicians and patients, to collect feedback on each section of the preliminary MCDE summary. The feedback from the three ICSs was collated by the leading ICS and used to inform a co-designed MCDE summary.

Testing sites

Integrated Cancer Service	Health Service
Barwon South Western Integrated Cancer Service (BSWRICS)	Barwon Health
Grampians Integrated Cancer Service (GICS)	Ballarat Health Services
Hume Regional Integrated Cancer Service (HRICS)	• Albury Wodonga Health/Albury Wodonga Regional Cancer Centre (AWH/AWRCC) • Goulburn Valley Health (GVH) • Northeast Health Wangaratta (NHW)

Phase 3: Review outcomes and templates

The Victorian Integrated Cancer Services Network (VICS), comprising ICS managers and clinical directors, was asked to provide feedback on the co-designed MCDE summary. Each ICS provided comments on all the sections of the summary, which informed the content of the draft MCDE summary.

Phase 4: Finalise two MCDE summary

The Project Steering Committee were invited to provide further comments about the content and the 'look and feel' of the draft MCDE summary. A plan-do-study-act (PDSA) cycle was used to develop the final version of the summary.

The following resources were developed:

- MCDE summary in English for head and neck cancer (see Appendix C)

- MCDE summary in English for pancreatic cancer (see Appendix D)

- Editable MCDE summary template (see Appendix E)

Stage 3: Develop Implementation Guide

The MCDE Implementation Guide (see Appendix G) was developed to support the implementation of the MCDE summary into normal clinical practice. It includes five tips for enhancing the impact of an implementation strategy and facilitating the uptake of the MCDE summary. It also explains the important elements of good communication, and contains useful information and resources to help readers think about when and how they could use the MCDE summary in their clinical practice.

The VICS network was invited to provide feedback on the MCDE summary and on the content of the guide, and this feedback was used to inform the development of the guide. The content of the preliminary guide was reviewed by the Project Steering Committee through an iterative process, and their feedback informed the development of the final guide.

4. Consultation summary

The MCDE summary resources were developed following an extensive consultation process, which included seven feedback activities that were conducted between August 2019 and February 2020. A total of 183 feedback interactions took place where people provided feedback on the content and usability of the MCDE summaries, as shown in Table 1 below:

Feedback activity	Date	Number of Patients	Number of Clinicians	Number of SC members	Number of ICS Directorate and clinical directors
State-wide survey	Aug 2019	21	35		
Peter Mac CLEEG (Consumer Literacy Education & Evaluation Group)	Aug 2019	5			
Pilot site testing	Oct-Nov 2019	15	16		3
Project Steering Committee testing	Dec 2019			14	
ICS Devolved Focus group consultation	Nov-Dec 2019				13
VICS consultation	Jan-Feb 2020	21	16		10
Project Steering Committee final feedback	Feb. 2020			14	
Total number of feedback interactions		62	67	28	26

Table 1. Feedback activities August 2019-February 2020

Collation of feedback

The feedback received from each feedback activity was captured in a tracker (see Appendix F), which:

- captured and tracked suggestions/changes for each section of the summary

- identified repeat feedback

- reminded the project's decision-makers to accept or reject feedback as feedback was received.

Incorporating feedback

The consultation process provided valuable and comprehensive feedback, most of which was accepted. The MCDE summary was updated following each feedback activity to reflect the comments provided in that feedback activity. Each updated version of the MCDE summary was then used to gather feedback in the subsequent feedback activity.

Assessment of feedback

- Feedback was either accepted, partially accepted or not accepted depending on the criteria described in the table below.

- While considerable effort was made to use all of the comments and suggestions, where there were divergent opinions and suggestions, those that had most consensus was accepted. (Most of these differences in opinion were due to different requirements of local health services.)

- If the feedback reflected local requirements of a health service, the alternatives or workarounds that fell under the "Accepted" criteria were made.

- All feedback relating to 'typos' was accepted.

- None of the feedback relating to typos sent via pdfs was captured in the tracker.

Feedback was either accepted, partially accepted or not accepted as follows:

Status	Reasons for decision
Accepted	• within scope of the project • endorsed by SC
Partially accepted	• feedback was accepted in part based on the "Accepted" and "Not Accepted" criteria • appropriate alternatives or workarounds that fell under the "Accepted" criteria were made
Not accepted	• not within scope of the project • not endorsed by SC • it was provided at an earlier feedback activity and a decision had been made at that time

5. Project outcomes and key learnings

Project outcomes

The key outcome was a succinct resource (the MCDE summary) that supports and complements the clinician's 'diagnosis and next steps' conversation with patients.

The MCDE summary:

- contributes to the clinician's ability to improve patient-centred communication and health outcomes and empowers health providers to ensure that care is optimised

- provides a clear and consistent state-wide way for clinicians to engage patients in their healthcare

- is a cost-effective intervention that complements the information verbally given to the patient at the time of diagnosis

- provides a consistent way of explaining the diagnosis to a patient, which benefits both the patient and clinician

- supports effective patient-centred communication and shared decision-making

- as shown in Figure 3, fits naturally into the cancer patient's journey and complements other resources available in Victoria.
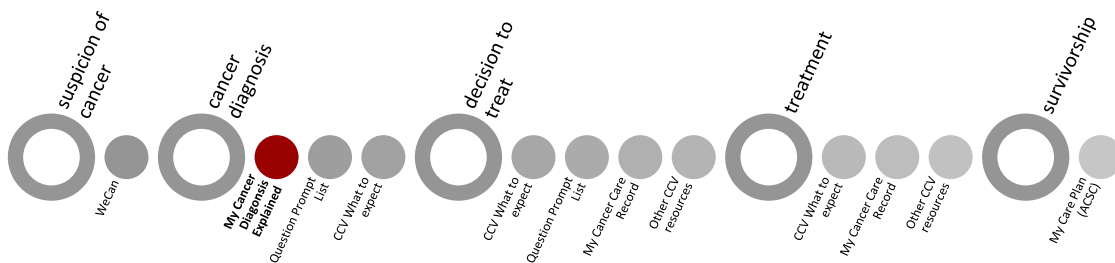

Figure 3. The MCDE summary in a patient's cancer journey (see References for hyperlinks to the resources)

Key learnings

- Patients want to receive information that is specific and individualised to their cancer journey.

- To produce acceptable and appropriate resources that meet stakeholder needs, a project needs both sufficient time and end-user involvement (i.e. co-design).

- Co-design methodology is important when developing patient-centred solutions, as it brings

together the 'user-centred orientation' and a collaborative change process.

- A state-wide project involves meeting the quality assurance and ethics requirements, as well as accommodating the processes of multiple health services whilst ensuring they align with the project's objectives.

- Developing an MCDE summary for Aboriginal and Torres Strait Islander patients requires:

  – due consideration of the principles of self-determination

  – adequate time for co-design with the stakeholders.

6. Conclusion

The project showed that to develop an effective state-wide resource such as the MCDE summary, a collaborative methodology is essential. Healthcare providers and supporting bodies are increasingly using quality improvement collaboratives such as this one to achieve large-scale improvements and increase the reach of medical and healthcare innovations.

The devolved process was also a valuable methodology to extend the reach of the MCDE summary within a short time. It allowed for the sharing of local experiences and needs, and problem-solving of common areas of concern. Thus, it was a valuable process to develop a resource that satisfies most requirements, despite the significant and complex challenge of aligning different interests of diverse stakeholders.

The MCDE summary complements the patient-centred care programs and policies that a health service may already have, while providing Victoria with a way of standardising communication to patients. In doing so, it helps to reduce health inequity and assists to increase access to services for a diverse range of patients with varying levels of health literacy.

7. References

1   https://www2.health.vic.gov.au/about/health-strategies/cancer-care/victorian-cancer-plan; (accessed 30th March 2020)

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Optimal Care Pathway for people with head and neck cancers, Cancer Council Victoria, 2016 (accessed 30th March 2020) https://www.cancer.org.au/content/ocp/health/optimal-care-pathway-for-people-with-head-and-neck-cancers-june-2016.pdf

7   Kessels R.P.C., Patients' memory for medical information, (2003), Journal of the Royal Society of Medicine, 96(5), 219-222.

8   Australian Commission on Quality and Safety in Health Care; Health Literacy National Statement https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf (accessed 30th March 2020)

9   Batterham R. W., Buchbinder R., Beauchamp A., Dodson S., Elsworth G. R. and Osborne R. H., (2014) "The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health

literacy profiling and community engagement to create and implement health reform." BMC public health BMC public health, vol. 14, no. 694, pp. 1-10.

10 Experience Based Co-design - A toolkit for Australia, made available by the Australian Healthcare and Hospitals Association (AHHA) and Consumers Forum of Australia (CHF), 2017: (accessed 30th March 2020) , https://ahha.asn.au/experience-based-co-design-toolkit

Hyperlinks

1. WeCan
   https://wecan.org.au/

2. My Cancer Diagnosis Explained
   https://www.wcmics.org/downloads

3. Question Prompt List
   https://www.petermac.org/sites/default/files/media-uploads/00051_Patient_Question_List_PRINTFINAL_160128_0.pdf

4. What to expect- Cancer Council Victoria ((CCV)
   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/

6. My Care Plan- Australian Cancer Survivorship Centre (ACSC)
   https://www.mycareplan.org.au/

8. Appendices

Attached separately:

Appendix A: Timeline of project implementation

Appendix B: Stakeholder engagement

Appendix C: Head and Neck cancer MCDE

Appendix D: Pancreatic cancer MCDE

Appendix E: Editable MCDE

Appendix F: Feedback Summary

Appendix G: MCDE Implementation Guide