IMPLEMENTING A NURSE-LED SURVIVORSHIP CLINIC

—

A GUIDELINE

Australian Cancer Survivorship Centre

Peter Mac

Peter MacCallum Cancer Centre
Victoria Australia

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Author: Australian Cancer Survivorship Centre

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Publisher: Australian Cancer Survivorship Centre. Locked Bag 1, A'Beckett Street, Melbourne, Victoria 8066

p: (03) 8559 6220 e: contactacsc@petermac.org

www.petermac.org/cancersurvivorship

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Contributors

Anna Beaumont, Australian Cancer Survivorship Centre

Nella Combe, Australian Cancer Survivorship Centre

Kate Cridland, Australian Cancer Survivorship Centre

Prof Michael Jefford, Australian Cancer Survivorship Centre

Trish Joyce, Peter MacCallum Cancer Centre

Helana Kelly, Australian Cancer Survivorship Centre

Nicole Kinnane, Peter MacCallum Cancer Centre

Tracey Mander, Australian Cancer Survivorship Centre

Yvonne Panek-Hudson, Peter MacCallum Cancer Centre

Reviewers

Prof Raymond Chan, Flinders University

Annie Chuang, Royal Women's Hospital

Dr Fiona Crawford Williams, Flinders University

Marc Diocera, Peter MacCallum Cancer Centre

Natalie Goroncy, Peter MacCallum Cancer Centre

Justin Hargraves, Bendigo Health Cancer Centre

A/Prof Mahesh Iddawela, LaTrobe Regional Hospital

A/Prof Gemma McErlean, University of Wollongong

Prof Catherine Paterson, Flinders University

Kerry Shanahan, Royal Melbourne Hospital

Dr Carla Thamm, Flinders University

HOW TO USE THIS GUIDELINE

The Australian Cancer Survivorship Centre (ACSC) has developed this guideline in conjunction with clinicians from Peter MacCallum Cancer Centre (Peter Mac) and other health services with expertise in survivorship and nurse-led clinics.

This resource provides health professionals and organisations with a framework to design and implement a sustainable nurse-led survivorship clinic. It is a generic guideline and can be adapted to suit the needs of patients and health services.

The elements of this guideline can be progressed in any order and simultaneously. Components can also be used to support a business case or research project.

Prior to initiating a nurse-led survivorship clinic, engage with organisation leadership and key stakeholders to ensure the initiative aligns with the organisation's strategic plan, and discuss available support and resourcing.

The ACSC has expertise and resources available to assist in the development of new models of survivorship care, resources are available at www.petermac.org/cancersurvivorship. We welcome inquiries from health professionals or services: email contactacsc@petermac.org

SECTION 1: INTRODUCTION AND OVERVIEW

1.1: Cancer survivorship

A 'cancer survivor' is anyone who has been diagnosed with cancer from the time of diagnosis to end of life, and includes those living with incurable and/or advanced cancers.[1]

There are over one million Australians living with or beyond their cancer diagnosis[2] and this is expected to increase in the future due to advances in early detection, better treatments and ageing of the population.[2]

Living with and beyond a cancer diagnosis can be difficult, and effects of cancer and its treatments can continue to impact on the health and wellbeing of survivors, caregivers, family and friends. This may include experiencing ongoing side effects or late effects; fear of cancer recurrence; or other physical, emotional, financial and social aspects.[3]

Cancer survivors commonly report unmet needs. A systematic review of Australian cancer survivors indicated that psychosocial issues were the most prevalent.[4] The five most commonly reported unmet needs were fear of cancer recurrence, uncertainty about the future, stress, worrying about loved ones, and accessing information and support services.[4]

Cancer survivorship care often refers to the care provided after treatment completion when patients are in follow-up and/or receiving maintenance therapy. This can be a difficult time for patients and carers. Many feel unprepared and unsupported while adjusting to life beyond a cancer diagnosis, and may still be experiencing side effects. Research indicates it is important to provide survivorship care as it positively impacts long-term health outcomes for patients and carers.[3,5,6]

It is essential that survivors understand what to expect following treatment and are provided with the right information and support at the right time.[1]

The five components of quality survivorship care are[5,6]:

1. prevention and surveillance for recurrent and new cancers – assessing the risk of recurrence of primary cancer and the development of new cancers
2. surveillance and measurement of physical effects – late or long-term effects related to cancer and its treatment
3. surveillance and management of psychosocial effects – late or long-term effects related to cancer and its treatment
4. surveillance and management of chronic medical conditions – consideration of chronic medical conditions, either pre-existing or at risk of, and their impact on cancer and its treatment
5. health promotion and disease prevention – importance of improving overall health and wellbeing.

For more on these components, refer to section 3.2.

1.2: Models of survivorship care

Traditional models of survivorship and follow-up care have predominantly been medically led and hospital-based, with a priority on detecting recurrence and new cancers.[7,8] These models have had limited focus on symptom management, health risk behaviours, health promotion and managing comorbidities.[7,8]

Other models of survivorship care have been trialled, including shared care, general practitioner (GP)-led and nurse-led.[7–9] Research indicates that these models are feasible, acceptable and equivalent alternatives to medically led follow-up care, and may have more economic benefits and use fewer resources when compared to specialist-led models.[7–12] These alternative models have shown other benefits, including an increase in primary care involvement in cancer care and improved coordination between primary and secondary care services.[8]

1.3: Benefits of nurse-led, cancer survivorship care

Nurse-led models of care are managed by specialist cancer nurses across multiple settings and evidence supports the effectiveness of these models.[7-9]

Specialist nurses are knowledgeable and skilled clinicians and ideally placed to provide survivorship care. Nurses provide a holistic and person-centred approach to care and can recognise and manage toxicities, psychosocial distress, coordinate care efficiently, promote behaviour change and support self-management.[10,13] Nurse-led models can be delivered in person, or by telephone or telehealth to suit the needs of patients and health services.[7,8]

When compared to specialist led care, nurse-led models have demonstrated at least equivalent outcomes, or at times better outcomes, in health-related quality of life. There are equivalent outcomes in survival, detection of cancer recurrence and psychological morbidity, with potential economic benefits.[7–12]

Nurse-led survivorship models have demonstrated patient acceptability and increased patient satisfaction.[8] Additionally, nurse-led models are a potential solution to managing increasing demand on the health system, which is experiencing an increasing number of cancer survivors with increasingly complex issues.[8]

When developing a nurse-led model, consider how it will work in collaboration with primary care. Defining the roles and responsibilities of tertiary and primary care providers and communication pathways is recommended.

This guideline outlines the steps and considerations when establishing a nurse-led survivorship clinic. This includes developing a model of care and appropriate supporting systems, logistics, governance, reporting and evaluation. Incorporating these factors will ensure the clinic is measurably effective.[8]

SECTION 2: PREPARATION AND INITIAL SET-UP

2.1: Project planning

Review survivorship standards and framework

Use an appropriate framework to ensure the nurse-led survivorship clinic is designed in alignment with evidence-based standards.

The ACSC, funded by the Victorian Government, conducted a literature review, environmental scan, Delphi study and expert consensus meeting to answer the question: 'What quality criteria do survivorship experts consider to be important in achieving optimal cancer survivorship care?'. This led to the development of the Victorian Quality Survivorship Care Framework. This framework and editable Policy Template will be helpful in the clinic's development, governance and measuring outcomes.

In addition, reviewing the following documents is recommended when preparing to set up a new clinic:

- Cancer Australia – Principles of Cancer Survivorship
- Clinical Oncology Society of Australia – Model of Survivorship Care
- Australian Government – Australian Cancer Plan
- the relevant cancer plan in your state or territory.

Assess the environment

Before considering any changes to existing practice and processes, assess the current environment. Various factors at an organisational level can influence the progress and success of implementing the clinic. Consider the following factors and their potential impacts:

- the organisation's strategic plan and priorities – will the clinic model, aims and objectives align with organisation's strategic plan?
- timeliness – is the timing suitable for the organisation and are there other organisational priorities that need to be resolved before proceeding?

It is also important to understand the way survivorship care is currently being delivered and the impacts of continuing in this way. This will assist in formulating a compelling case in support of improvement and change. It may also be beneficial to explore whether other departments within your hospital provide nurse-led clinics and to learn from their experiences.

- Understand how survivorship care is currently being delivered – for example, is all follow-up care delivered by medical specialists?
- Understand the impact of continuing to deliver survivorship care in the same way, for example:
    - patients not receiving comprehensive survivorship care
    - patients experiencing unmet needs
    - delayed discharge from medical clinics
    - clinic running costs, clinic physical/virtual capacity, and other logistics (e.g. clinic booking systems)
    - empty episodes of care.

It is important that clinical leadership teams drive this practice change. Discussion at this level was crucial to fortify support and begin the first steps of setting up a survivorship model in the myeloma service. Learning from streams with well-established survivorship models and hearing firsthand how patient health and wellbeing can be improved ignited enthusiasm, support, and passion to explore a similar model for the myeloma population. Our clinical leaders were committed to optimising the patient's health and wellbeing throughout all phases of the disease which enabled and empowered us to make this practice change.

Nurse Practitioner, Myeloma.

Gain stakeholder support and engagement

Implementing a new clinic requires the support of key stakeholders and a team effort to prepare, implement and sustain. Identify and engage stakeholders early. Likely key stakeholders include nurses delivering the clinic, medical staff, hospital executives, consumers and administration staff.

- Complete a stakeholder analysis and identify those needed to endorse and support the initiative.
- Discuss the initiative and ideas with key stakeholders.
- Consider early engagement with consumer stakeholders.

Developing a broad outline of the model of care at this time (e.g. clinic mode and operating hours, target patient cohort and patient pathways) may be helpful when engaging with stakeholders and exploring funding opportunities.

In addition, engaging with other health professionals involved in survivorship clinics and exploring opportunities to observe their programs can offer valuable insights while fostering collaboration and professional relationships. If you require assistance finding someone to connect with, contact the ACSC for information about programs and networks.

Taking our clinic from an idea to implementation required significant effort and time in the planning phase. It depended on medical support, executive support and the senior nurse in the team taking on the role of project lead. It was also essential to have a few champions withing the team to share the workload and maintain momentum. What initially started out as small meetings, formalised into several focus groups with broad stakeholder representation to inform implementation. This approach ensured all perspectives were considered, helping to identify enablers and barriers, address potential challenges and ultimately increase the likelihood of success.

Clinical Nurse Consultant, Gynae Oncology.

Develop project aim and objectives

Develop a project proposal outlining the rationale for the new clinic and why it should be prioritised and supported by the executive and clinical service. Include how it will assist the organisation to meet its strategic objectives.

The proposal should describe how the clinic will improve the patient experience, and how the benefits of the clinic will outweigh the costs and resources required to establish it. Include information about issues with the existing model and processes, motivation for change, aims and objectives, anticipated benefits and any potential risks.

The project aims and objectives should be kept 'high-level' at this time and establish why the initiative has merit. A clear aim and set of goals will ensure focus and alignment to the objectives as the project progresses. They should be developed in consultation with key stakeholders and aligned with the organisation's strategic plan.

Use clear, unbiased evidence to support your case when considering:

- how the clinic will meet the needs of patients
- how the clinic will meet the needs of the health service
- the overall aim of the project and the desired outcome/s
- the elements within and outside the scope of this initiative.

Explore short-term and long-term funding opportunities

Understand the costs required to set up the clinic as a financially sustainable service. They are important for the short- and long-term goals of the clinic. This information will also be useful for developing grant proposals or a business case for ongoing funding.

- Consider if a business case proposal is required for set-up and ongoing funding. See APNA building a business case resources.
- Explore any grant sources that can assist with short-term funding (e.g. philanthropic, research, industry, government).
- Develop a draft budget for the clinic with assistance from the finance department. Include ongoing expenses (salaries, clinic equipment, operating expenses) and revenue sources (e.g. Medicare Benefits Schedule or Activity Based Funding).

2.2: Clinic design

Defining the patient cohort, clinic aims and objectives and expected clinic activity will assist in understanding what is within and outside of the scope of the clinic, and assist with evaluation.

Define target patient cohort

Define the patient cohort and eligibility/referral criteria.

- Develop specific inclusion criteria for the clinic
- Outline any relevant exclusion criteria (e.g. certain comorbidities, cancer stage).
- Specify the number of patients to be seen in the clinic each week/month/year.

Define clinic aim and objectives

Clearly define a purpose statement for the clinic and how it will be achieved.

- Outline what the clinic is aiming to achieve for patients, clinical service and organisation.
- Develop SMART (simple, measurable, achievable, realistic, time-bound) objectives to meet the aim.
- Outline key milestones and when they will be achieved.

Develop key performance indicators

Key performance indicators (KPIs) should be developed with the priorities of the clinic in mind, and can be used to evaluate the clinic during implementation and beyond. Consider developing KPIs relating to the patient and carers, clinicians, the clinic itself and the healthcare system.[14] KPIs may relate to implementation, clinical effectiveness, economic or research aspects of the clinic. Some examples include:

- clinic to be operational by [month, year], with [number] of appointments available each week
- >90% of eligible patients to be referred/directed into the clinic stream by [month, year]
- >80% of patients to complete the assessment tool/s prior to attending clinic
- >90% patient satisfaction with clinic, as evaluated by patient survey after attending clinic (consider use of promotor score and other validated patient experience scales)
- all billable patient encounters are captured and billed (or activity counting within Activity Based Funding models)
- referral rates to relevant allied health and specialist services
- after one year of operation, outcome data is published or presented at a national conference.

2.3: Supporting systems and logistics

In the preparation phase of a nurse-led survivorship clinic, supporting systems, logistics and resourcing should be planned to ensure the clinic meets the needs of the patients and health professionals, functions well, and is cost effective and sustainable.

Communicate early with the administration team about clinic space and the development of booking templates to discuss optimal use of available clinic space.

Determine clinic mode and operating hours

Describe how and when the clinic will operate, for example:

- the days of the week and hours that the clinic will operate
- if the clinic will operate in parallel with medical, allied health and other nursing clinics, or be stand-alone
- if the clinic will be delivered in person, telehealth, telephone or combination
- the number of patients to be seen in the clinic
- how much time is needed for each consultation, including preparation and documentation (recommend considering 60-90 minutes for first consultation and 30-60 minutes for subsequent consults).

Identify clinic requirements

Describe the facilities required for the clinic, for example:

- whether there is a secure and safe space to run the clinic – this may require a formal request to start a new clinic
- whether there are any additional technology requirements, including any additional training
- the process and system for managing patient records
- the equipment required for patient assessment and care delivery.

Identify human resources

Decide which human resources are needed.

- Determine the nursing full time equivalent (FTE) needed to run the clinic.
- Ensure more than one nurse is able to run the clinic so continuity and sustainability are maintained in the event of staff leave or turnover.
- Identify if additional human resources are needed to ensure nursing staff can work to their full scope of practice (e.g. administration).

Consultations are offered both in-person and via telehealth to accommodate patient preferences and mitigate travel time and costs. The design of our clinic was determined by several factors, including staff and room availability, and alignment with existing medical clinics, as our patients remain on long-term maintenance therapy. This alignment ensured that all patients are discussed in our pre-clinic huddles with the multidisciplinary team, facilitating discussion about their needs, including the ordering of medications and investigations. Additionally, this approach supported ongoing promotion and awareness of the clinic and maintained a steady flow of referrals.

Nurse Practitioner, Myeloma.

Consider appointments and billing

Describe how patients are booked into the clinic and informed of appointments.

- Identify if there is an existing clinic booking template or if a new one is required.
- Identify administrative support required to coordinate appointments and source information required for the consultation.
- Determine if and how patients will receive appointment reminders.
- Determine how clinic consultations will be billed, and sources of funding (e.g. Activity Based Funding or Medicare Benefits Schedule.

> With organisational support we set up a nurse led gynae-oncology post-treatment clinic. We contacted specialist clinics to establish a template to book clinical nurse consultant telehealth appointments as well as utilizing an existing template. We utilised the existing administrative support to make the bookings with patients receiving an SMS reminder. We confirmed the clinic consultations would be billed through National Weighted Activity Unit (NWAU) activity funding - recommend this clarification be undertaken prior to commencing any clinic.
>
> **Clinical Nurse Consultant, Gynae Oncology.**

Develop a communication plan

Early and clear messaging about nurse-led follow up is recommended for patients, health professionals and administrative staff. Outline how the clinic will be promoted to patients, medical staff, allied health, nursing and primary care to ensure the clinic is embedded as part of normal processes and patients move into the clinic at the agreed timepoint.

- Communicate to patients and health professionals information about the clinic, its purpose and what to expect, including referral criteria.
- Consider methods for communicating the clinic to hospital colleagues, formal and informal.
- Consider if any promotional materials or flyers are required, as well as communication via organisational electronic mediums.

2.4: Staff and scope of practice

Nurse-led clinics are delivered by advanced practice nurses such as clinical nurse specialists, nurse consultants and nurse practitioners. Each advanced practice nurse level has an associated scope of practice and regulatory and legislative frameworks that apply.

For the clinic, scope of practice should be developed collaboratively with the nursing and medical teams. Any extensions of current scope of practice should be approved by the nursing executive or organisational equivalent.

It is recommend that the Australian Nursing and Midwifery Board's professional standards and Decision-making framework for nursing and midwifery and the International Council of Nurses Guidelines on advanced practice nursing are consulted when developing the scope of practice.

When defining the scope of practice, consider medication management, ordering of investigations, referrals, and the expected experience and qualifications of the nurses in the clinic.

Consider capability and training

Advanced practice nurses already have advanced knowledge and skills relating to their area of expertise; however, there may be additional skills or capabilities to consider relating to survivorship or long-term follow-up.

Education in cancer survivorship is recommended. The ACSC has a Cancer survivorship introductory course available on eviQ for health professionals. It is recommended that the Cancer Nurses Society of Australia EdCaN framework is reviewed.

Any capabilities or training requirements can be included in a position description if it is being created, or as part of the staff training requirements.

- Create position descriptions, clearly outlining roles and responsibilities in the clinic, including survivorship capability and reporting lines.
- Identify related human resource policies and planning, such as remuneration and reward, mandatory training, leave, performance management and other related human resource functions.
- Ensure there are ongoing training or professional development opportunities for staff.

Provide staff support and mentoring

Providing in-depth survivorship consultations can pose a risk to staff welfare due to the nature of the content discussed. All involved should be aware of the risks and staff should be proactive in self-care, wellbeing and seeking support to ensure a safe work environment.

- Consider regular opportunities or times to discuss patient care and debrief if needed.
- Identify any programs the organisation offers to staff regarding support and mentorship (e.g. clinical supervision).
- Consider other opportunities to provide a safe and supportive work environment for staff.
- Consider engaging a nurse mentor who has experience in nurse-led clinics and their evaluation.

During the early phases of our clinic, we held regular meetings with key health professionals involved in its delivery. These meetings, held every one to two weeks and kept intentionally brief, provided an opportunity for debriefing and peer support during this change in practice. They also allowed us to address issues in real time, workshop solutions and implement and evaluate changes promptly, often by the following week.

Nurse Practitioner, Myeloma.

SECTION 3: DELIVERING THE CLINIC

3.1: Patient pathways

Patient pathways describe the way patients move into, through and out of the clinic, including discharge criteria and planning.

The creation of a flow chart may be helpful to visualise this and assist in communication with stakeholders.

Describe clinic entry – referral pathway

Describe the process for how patients will access the nurse-led clinic.

- Determine who can refer patients to the clinic (e.g. medical, nursing, allied health, ward staff).
- Outline the process for referring patients who meet eligibility/referral criteria.
- Determine how referrals will be received, assessed and triaged, and by whom (nursing or administration).

Determine follow-up schedule

Use tumour stream and survivorship evidence-based follow-up guidelines to determine the follow-up schedule while in the clinic. Examples are:

- National Optimal Care Pathways
- relevant tumour stream clinical guidelines
- hospital department-specific guidelines.

Outline the patient follow-up schedule, including when patients are referred to the clinic, appointment frequency and discharge criteria back to the medical team or GP.

Patients should not require a medical review when being seen in the nurse-led clinic. However, if your patients also need to attend medical consultations while being seen in the nurse-led survivorship clinic – for example they are receiving maintenance therapy or have higher risk of complications – consider how consultations will be scheduled and aligned to minimise hospital visits.

Develop escalation criteria

Identify potential clinical scenarios and establish escalation criteria to ensure patients receive the care that they require, and support staff in decision-making and communication.

Patients may present with signs of disease progression, a new late effect, significant changes in symptoms or pathology, medication side effects or acute illness, and require escalation to the medical team for care for a short time or ongoing.

Document the following clinical pathways and escalation criteria to the medical team where:

- disease progression is suspected, or a significant late effect identified
- a clinical finding or deterioration in the patient's condition occurs
- the patient is acutely unwell.

We have a consult template to assess symptoms post treatment with agreed escalation criteria. For example, a patient presented four months post-treatment for cervical cancer with pain. Pain assessment was undertaken with additional urinary symptoms identified. The patient was concerned about cancer recurrence. We discussed symptoms, potential causes and need for further investigations. As per agreed criteria, significant new symptoms and suspected recurrence required escalation to the radiation consultant. Investigations were ordered and disease surveillance scans brought forward. Scans identified new left hydroureteronephrosis resulting in referral to urology for stent insertion and request for a tissue sample. The patient resumed medical follow-up with scheduled phone symptom assessment from nurse consultant.

Clinical Nurse Consultant, Gynae Oncology.

Plan clinic exit – discharge

Ideally, patients will complete their follow-up in the clinic and be discharged to primary care for ongoing care at a predetermined time. This will avoid the clinic reaching capacity and being unable to accept new referrals. Discharge planning should begin as soon as the patient enters the clinic. There may need to be consideration regarding how to manage complex discharges.

To facilitate discharge, communication with both the patient and GP should start early.[15] Additionally, establish clear discharge criteria and a process for identifying and managing complex discharges.

If there is a significant change to a patient's health status while in the clinic, patients may move from nurse-led to medical follow up for short-term or ongoing care.

At the first appointment, we ask the patient whether they have a GP and ensure that we have the correct contact details on record. We also ask when they last saw their GP and inquire about their availability, as we will need their involvement in the goals and care plan created in the consultation.

If the patient does not have a GP or if they express concerns about their GP's suitability, or access to appointments, we take the time to discuss this further.

We explore the qualities that make a good GP for the patient, what is important to them and provide guidance about how to find a new GP if needed

Nurse Practitioner, Myeloma.

Discharge to GP for follow-up

After the patient completes follow-up in the nurse-led clinic, subsequent care will usually be managed in the primary health setting with the GP.

To facilitate discharge planning to primary care, early identification of a suitable GP is recommended. If the patient does not have a suitable GP, working with the patient to identify a suitable GP should be a priority. Educate patients about the role of the GP and establish a collaborative approach with the GP in managing the patients' health needs from the time of clinic entry. The ACSC patient resource 'How your general practice can support you to live well' can assist patients to understand the role of the GP in survivorship care.

Consider the following before discharging to a GP:

- Discuss with the patient that if they remain stable, they will be discharged and monitored by their GP, including that there will be a process for referral back to the treating team if required.
- Discuss discharge to GP with the treating doctor.
- Arrange a telehealth review with the GP and patient to assist with transition; if not possible, a phone call to the GP is recommended.
- Send a letter to the GP in advance to inform them of the discharge plan.

At the time of discharge, the following points should be clearly documented and communicated to the GP through the survivorship care plan (see section 3.2) and/or a comprehensive letter:

- the primary contact person(s) from the treating team and contact details, ideally listed at the top of all communications
- recent medical history and treatment, including major toxicities, persistent side effects (physical, psychosocial) and social considerations
- specific issues to monitor, and frequency of monitoring
- where to send copies of results/communication to the treating team, if expected details regarding a rapid re-entry pathway to the hospital.

Document a rapid re-entry pathway into the hospital for the GP

To support the GP to provide survivorship care following discharge, develop and document a rapid re-entry pathway to the treating hospital. Ensure this plan is communicated with the GP and patient prior to discharge.

When developing and documenting the rapid re-entry pathway for the GP, consider:

- what issues/results need to be escalated back to the hospital team
- the most efficient method for GPs to contact the hospital team, including who to contact and expected timeframes to receive a response
- whether patients will need a new referral to be seen by the hospital team again.

3.2: Survivorship consultation

The consultation should be patient-centred, emphasising shared decision-making, goal-setting and encompassing the principles of quality survivorship care. It should be grounded in evidence through adherence to clinical guidelines and available research, and use validated tools for needs assessment and symptom grading. When developing the clinic consultation, partnering with consumers is recommended.

Consider the role of the GP and primary care in providing comprehensive survivorship care while in the nurse-led clinic and in the context of eventual discharge to the GP (outlined in section 3.1).

While the patient is being seen in the nurse-led clinic, outline and communicate to the patient and the GP, the roles and responsibilities of the nurse, GP and patient regarding:

- managing persistent symptoms, regular medications and comorbid illnesses
- regular screening for other health problems and cancers through screening programs or blood tests
- health promotion initiatives and referrals to allied health and community supports.[15,16]

> Our patients attend a one-off post-treatment survivorship consultation. We communicate the outcome of the consultation through a letter to the GP and send them a copy of the after-treatment care plan.
>
> We inform patients that ongoing medications are required to be prescribed via the GP. If patients indicate they are not participating in national screening programs, we encourage them to enrol and include a recommendation in the GP letter for follow-up.
>
> Bone health post pelvic radiotherapy is critical for gynae oncology patients, as there is risk of insufficiency fracture. We recommend the GP arrange a baseline bone density scan post treatment, noting this is earlier than the usual 70-year age risk factor.
>
> **Clinical Nurse Consultant, Gynae Oncology.**

Principles of quality survivorship care

Incorporating the Institute of Medicine's five principles of quality survivorship care is recommended when developing the clinic model.[5] Below are some examples of each principle, the complete list can be found in the publication Cancer Survivorship care quality domains and proposed indicators (see Box 2).

Surveillance, screening and risk reduction strategies

- Apply recommended screening for surveillance and detecting recurrence, including timeframes.
- Apply recommended cancer risk reduction strategies and population cancer screening guidelines.

Assess and manage physical effects

- Use a systematic approach to symptom assessment with standardised assessment tools and/or disease or symptom-specific assessment tools.
- Use recommended care plans for issues identified (e.g. investigations, medications, therapy, referrals, management strategies).

Assess and manage psychosocial effects

- Use a systematic approach to symptom assessment with standardised assessment tools and/or disease or symptom-specific assessment tools including fear of cancer recurrence, anxiety and depression, fatigue, financial toxicity, employment, intimacy/sexuality.
- Use recommended care plans for issues identified (e.g. investigations, medications, therapy, referrals, management strategies).

Assess and manage chronic medical conditions

- Work with primary care providers to screen for and manage other chronic medical conditions.
- Work with primary care providers to manage medications.

Promote health and prevent disease

- Assess modifiable health behaviours and provide recommendations (e.g. alcohol, smoking, sun exposure, obesity, exercise, diet).
- Assess vaccination history and provide recommendations.

Complete a needs assessment and set goals

Cancer survivors commonly report unmet needs; a number of validated tools can be used to screen for unmet needs and common symptoms. These tools are self-reported questionnaires known as Patient Reported Outcome Measures (PROM) and Patient Reported Experience Measures (PREM).

When selecting an appropriate tool, define the purpose of the tool and identify those commonly used in the patient population for disease-specific issues. Ensure tools have been validated in routine care as many may have been designed for clinical trials.

Tools should be completed prior to the clinic consultation so results can be used to inform care plans and set goals.

Implementing an appropriate PROM/PREM in the clinic requires selecting a suitable tool for the patient group that screens for commonly experienced symptoms. Develop a process for administering, ensuring the outcomes are actionable within the scope of the clinic and add value.[17]

An essential component of inviting patients to complete PREM and PROM, is using the information in their clinical review, and discussing goals the patient would like to achieve. These may be short term goals, like going on a cruise, or long-term goals such as improving overall strength and fitness or working on their relationship with their partner. Actively discussing information and goals the patient has shared both demonstrates that you value and see importance in their experience and can identify ways to support patients to achieve their goals.

Nurse Practitioner, Allogeneic bone marrow transplant follow-up clinic.

It may also be helpful to consider PROM/PREM tools commonly used in survivorship listed below:

- National Comprehensive Cancer Network (NCCN) Survivorship Assessment (Patient version) – see page 31 of NCCN Clinical Guidelines Survivorship Version 2.2024
- NCCN Distress Thermometer and Problem List – NCCN Distress Management Guidelines
- Short-Form Survivor Unmet Needs Survey
- Cancer Survivors Unmet Needs
- Edmonton Symptom Assessment System (ESAS) – Revised.

Also, disease-specific quality of life tools may be used, such as those produced by the European Organisation for Research and Treatment of Cancer (EORTC) and from the Functional Assessment of Chronic Illness Therapy (FACIT) suite.

When the tool(s) has been decided, develop a process for administering and integrating it into the consultation. For example:

- any existing hospital systems that can be leveraged to reduce administrative time
- the process for how the tool will be used in the clinic, including administering, scoring and documentation, considering those with additional language, cultural and literacy needs
- how outcomes can be used to set SMART goals with the patient in clinic.

To support our post treatment consultation, we send patients the Distress Thermometer and Problem List to complete prior to the appointment. Mostly patients return these via email. The completed checklist is used to guide our consultation alongside our symptom assessment.

Clinical Nurse Consultant, Gynae Oncology.

Refer patients to health services as needed

To manage health concerns or unmet needs identified in the clinic, patients may benefit from being referred to allied health or specialist medical services. This may include physiotherapy, exercise physiology, dietetics, occupational therapy, psychology, social work, spiritual care, or specialist referrals such as endocrinology, cardiology or neurology as examples. Consider the availability of hospital, non-government organisations and community-based services.

- Identify the issues most likely to be identified in the clinic and the health professionals or programs commonly referred to for management.
- Define the criteria and process for making the referrals and if an extension to the nurse's scope is required to generate referrals.
- Inform health professionals or services if an increased number of referrals is expected from the clinic.

Develop a survivorship care plan

Survivorship care plans (SCP) are formal, written documents that provide details of the cancer diagnosis and treatment (e.g. a treatment summary would be included, if available), potential late and long-term effects, recommended follow-up, surveillance and strategies to remain well.[6]

Developed with the patient and communicated to all other health professionals involved in the survivor's care, SCP can facilitate communication and the allocation of responsibility for various elements of survivorship care.

The ACSC has developed long and short SCP templates, which are available for download (Resources and tools – Peter MacCallum Cancer Centre).

Other SCP options include:

- 'MyCarePlan', an online SCP generator at mycareplan.org.au – Create your cancer survivorship care plan online for specific cancer types - early stage melanoma, uterine cancer (endometrial), non-Hodgkin lymphoma (diffuse large B-cell), early stage breast, early stage bowel and localised prostate.
- Any 'inhouse' generic and disease-specific templates care plans within your health service.

Consider the following when developing an SCP for the clinic.

- Identify an existing SCP template and adapt as required.
- If there are ongoing reviews in the clinic, decide if the SCP will be updated or a new plan generated at subsequent visits.

Provide appropriate resources

Educational resources are important for patients to understand common issues related to survivorship and learn more about managing symptoms, as well as promote autonomy and empower individuals to be active participants in their own healthcare.

Information should be provided to all patients, be evidenced-based and tailored to the patient's needs (e.g. format, literacy level, language).

The ACSC has many resources available for cancer survivors on its website:

- Common Survivorship Issues Directory
- Survivorship resources – videos, fact sheets, podcasts and tools Life after treatment resources – Peter MacCallum Cancer Centre
- Disease specific survivorship resources – bowel, breast, diffuse large B-cell lymphoma, endometrial, Hodgkin lymphoma, early-stage melanoma and prostate
- Survivor stories – Peter MacCallum Cancer Centre
- Survivorship information in other languages and for specific groups (e.g. Aboriginal and Torres Strait Islander people, Adolescent and Young Adult, LGBTIQA+, paediatrics) Survivorship in specific populations – Peter MacCallum Cancer Centre.

Consider the following when reviewing information that will benefit patients.

- Identify resources that may be appropriate for the clinic (e.g. ACSC survivorship information including disease-specific resources, information produced by other organisations).
- Decide which educational materials will be provided to all patients (e.g. Cancer Council Living well after cancer booklet and available resources relevant to cancer type).
- Decide which education materials will be provided when specific issues are identified in the clinic.

Document the consultation

Documentation of the consultation and the SCP is important for communication, reporting and evaluation purposes. It may be helpful to discuss needs and options to facilitate reporting of data with the organisation's medical records team.

- Consider using a standardised template to document the consultation in the medical record.
- Develop a standardised process for documentation and correspondence to the patient, GP and medical team following each consultation.
- Define how the documentation will be provided (e.g. electronic, paper-based, both).
- Decide with the patient their preferences for who receives their SCP (e.g. GP, treating doctor/s, other specialists).

SECTION 4: GOVERNANCE, REPORTING AND EVALUATION

Optimal nurse-led care requires that all staff are aware of and implement patient safety processes according to local hospital policy as well as a process for ongoing evaluation and improvement.

Reviewing the Victorian Quality Survivorship Care Framework and Policy Template may be helpful when considering components of governance, reporting and evaluation.

4.1: Evaluation and improvement

Clinic evaluation should be considered in the planning phase and should encompass both formative and summative evaluation. Formative evaluation begins early on and aims to monitor and improve processes as the clinic is being developed and implemented. Summative evaluation usually occurs after implementation to assess the impact and outcomes of the clinic and should be aligned with the clinic KPIs.[17]

A regular, systematic approach to evaluation against evidence-based criteria is recommended. Consider collecting both qualitative and quantitative data and a variety of PROM/PREM tools.

Embedding an evaluation framework is recommended. This may require ethics approval.

Use data collection tools and processes

Use evidence-based frameworks and validated tools for data collection and evaluation. Implementation, acceptability, evaluation and improvement frameworks are freely available. Some organisations have preferred frameworks or may have resources to develop a customised framework. Examples of frameworks include:

- Implementation: Action, Actor, Context, Target, Time
- Acceptability: Theoretical Framework of Acceptability
- Evaluation: The Donabedian Model
- Quality improvement: Plan, Do, Study, Act.

In addition to screening for unmet needs and common symptoms, PROM/PREM tools can be used for evaluation purposes. Tools can be used to understand what is important to the patient, evaluate outcomes of healthcare, and measure quality care at both the individual and service level.

When developing the evaluation plan, consider:

- what is important to evaluate
- which evaluation framework/s will be used
- which tools will be used to collect data, how and when they will be administered
- who will collect the data, and how it will be analysed and shared.

Evaluate the clinic - outcome measures

The impact of the clinic can be demonstrated by:

- number of eligible patients referred to the clinic
- patient activity and delivery mode of clinic consultation
- number of patients discharged to GP follow-up at the discharge time
- patient experience and satisfaction with service
- nurse satisfaction survey
- reduction in unmet needs
- stakeholder feedback of clinic (e.g. GP, oncologist, allied health)
- adherence to evidence-based follow-up schedules and care.

Evaluate the clinic – process measures

Measure the way processes work to deliver the desired outcome, for example:

- number of patients completing PROM/PREM before the consultation
- information resources provided
- referrals to other health professionals/services
- patients escalated or referred back to the medical team and rationale
- cost analysis (e.g. nurse-led versus oncologist-led)
- adherence to population-based cancer screening programs.

4.2: Reporting

Regular reporting to the organisation and relevant stakeholders is critical to monitor the effectiveness of the service. Consider the following processes.

- Identify and understand governance processes for reporting the clinic outcomes, including revenue/billing.
- Outline how and when reports will be provided to various stakeholder groups and hospital executive.

The gynae-oncology specialist-nurse-led survivorship clinic aims to address supportive care needs, provide survivorship care plans (SCP) and customise information. Women attend the nurse-led consultation three to six months post curative intent treatment. We sought to evaluate patient perspectives of the service.

A purpose-designed online survey assessed satisfaction, perceived value and appropriateness of the service. The survey included a Likert scale, limited option and free-text questions. All women who attended the clinic within the previous 15 months were sent a survey link via text message, without reminders. As a quality assurance project, ethics approval was not required.

Results indicated that specialist-nurse-led survivorship consultations are a highly rated opportunity to address post-treatment needs and concerns, and the SCP considered a useful information tool.

Clinical Nurse Consultant, Gynae Oncology.

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