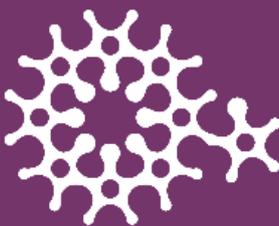


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Integrating shared care teams into cancer follow-up care models

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Key Messages

- Cancer follow-up care is predominantly provided by specialists in acute care settings; however, this model does not adequately address the supportive care needs of people diagnosed with cancer.
- Integrated, shared care models for cancer follow-up care have been promoted as an effective and cost-effective way to capitalise on the expertise of a range of healthcare providers required to meet patients' needs. In Australia, issues of accessibility for patients living in geographically remote areas, or those from diverse cultural backgrounds, or with financial difficulties are known barriers to accessing follow-up appointments. An integrated shared care model for cancer follow-up care will improve the patient journey, but this model is not widely implemented.
- Integrating cancer follow-up care across primary and acute care settings requires coordination and communication between different clinicians and health services. The use of nurse navigators for patients with complex chronic disease has demonstrated ability to improve communication across health providers and improve the patient journey. Nurse navigator roles are not specific to cancer, and specialist cancer nurses who can assist in care coordination only exist for certain cancer types. Mapping of the cancer care coordination workforce across local health districts will identify gaps in roles and services that can impact on equity of health care delivery.
- Where shared care follow-up does occur, there is a lack of clarity around the composition of multi-disciplinary teams and how care is coordinated. Collection of data regarding the utilisation of case conferencing, shared medical records, and referrals to allied health or community services for cancer survivors would facilitate benchmarking against optimal cancer care pathways, and provide guidance for future service planning. No national or state-wide data is available to understand current patterns of follow-up cancer care. Linking data from existing local health services or hospital data, Medicare Benefits Scheme data and electronic health records is required.
- A national clinical governance framework would assist the implementation of shared care models more broadly and provide guidance on adapting to suit a local context. Continued evaluation of the framework will enhance the sustainability of the shared care model. Stakeholder consultations, ongoing data collection on patterns of care, and annual reporting can identify the requirements for continuous improvement of the framework.

Executive Summary

With increases in cancer survival rates, over 1 million Australians are living with cancer and require ongoing follow-up care after treatment. Shared care follow-up models which incorporate a multi-disciplinary team wrapped around the patient can improve the patient experience and health outcomes. There have been several guidelines and recommendations for the implementation of shared care follow-up models developed across Australia. Despite recognition of the benefits of shared care, these models have not been implemented consistently. Little is known about where shared care services are being delivered, the roles of the healthcare providers involved, and the subsequent outcomes.

The current workforce of cancer care coordinators, specialist cancer nurses, primary care nurses, general practitioners (GPs), and allied health providers have the scope and ability to assist cancer specialists to deliver shared care; however, limited guidance exists on the required tasks of each team member and appropriate communication pathways. While Medicare items relating to chronic disease management can be utilised to assist in shared care for cancer, information is lacking on their utilisation. Additionally, current fee-for-service funding structures may not allow for adequate administration to assist in care coordination aspects of care and could be improved through values-based funding models.

Several existing sources of data could be used to understand the delivery of shared care follow-up models across different jurisdictions, such as primary care data held by Primary Health Networks and local general practices, administrative data from the Medicare Benefits Schedule, and clinical hospital data. However, this data is not linked together, and is currently not used for the purposes of understanding cancer care delivery. Without data to understand existing practices and identify gaps in services, it is challenging to make improvements to the implementation of shared care models.

This issues brief highlights the gaps in knowledge relating to the implementation of shared care cancer follow-up models in Australia. It focuses on some of the key considerations for implementing shared care including the need to collect primary care data regarding the use of shared medical records and allied health referrals, and link this to patient health outcomes data to evaluate current patterns of service delivery; mapping of the health care workforce involved in delivering shared care follow-up to identify gaps in services that can impact on equity; and developing national clinical governance frameworks that enable continued monitoring and quality improvement.

Background

There are six key phases of a cancer journey (Figure 1), with long-term follow-up care being increasingly important as cancer survival rates improve (Australian Institute of Health & Welfare, 2021b).



Figure 1: Phases of the cancer journey

In Australia, over 1.1 million people are living with cancer. With advancements in cancer detection and treatment, this is expected to rise to 1.9 million people by 2040, with the majority being long-term cancer survivors (AIHW, 2021b, Cancer Council, 2018).

Cancer survivors are at increased risk of developing other chronic conditions, as well as experiencing ongoing psychosocial impacts, placing additional pressures on the healthcare system and social services to provide adequate follow-up care (Lisy et al., 2019, Mayer et al., 2017, Tan et al., 2019).

This growth in health care utilisation by cancer survivors will be exacerbated by an ageing population and raises concerns about the ability of the health system to provide adequate care (Rana et al., 2019). Cancer specialists are required to provide follow-up care for cancer survivors for several years after treatment, placing an unsustainable workload burden on the current oncology workforce as the number of newly diagnosed cancer patients increases.

Cancer follow-up care already represents a substantial cost to the healthcare system in Australia (Goldsbury et al., 2018). This will continue to increase as the population of cancer survivors grows. Implementing a cost-effective and holistic model of cancer follow-up care will help to reduce healthcare costs, alleviate pressure on the health system, and improve the patient journey. The standard role of general practice and acute care in delivering care throughout the cancer journey is shown (Figure 2).

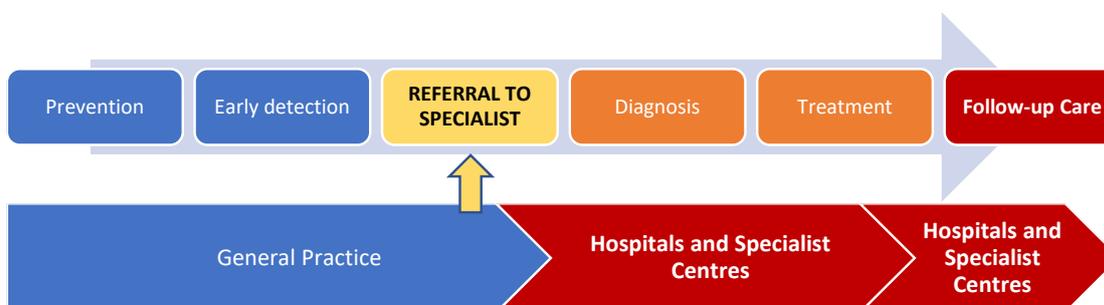


Figure 2: Care setting across the cancer journey in current specialist-led models

In Australia, cancer treatment is provided by oncology specialists (oncologists and haematologists) in acute care cancer centres, most often located in major metropolitan areas (Hunter et al., 2019; Jefford et al., 2013).

Follow-up care is also traditionally provided by oncology specialists, focusing heavily on medical surveillance and excluding consideration of psychosocial issues and health promotion required for quality cancer follow-up care (Nekhlyudov et al., 2019). This means that patients are experiencing significant financial distress and have unmet psychological and emotional needs (Chan et al., 2019; Paul et al., 2017; Van Der Kruk et al., 2021). These holistic aspects of cancer follow-up care are better addressed by clinicians outside of the acute setting. The use of shared care follow-up models to transfer the patient's care back into general practice is shown (Figure 3).

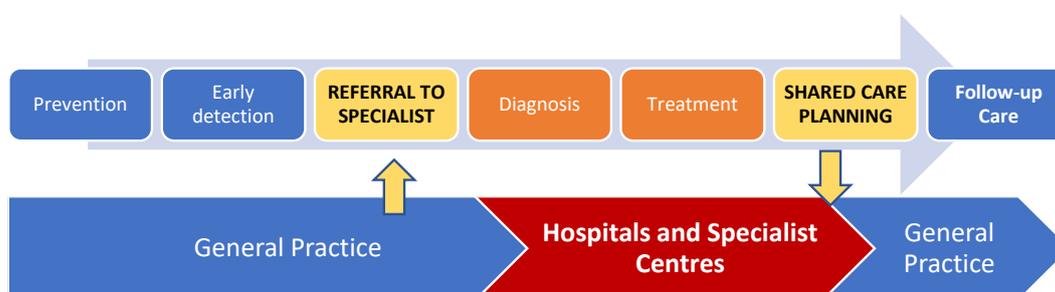


Figure 3: Care setting across the cancer journey with shared care models

What is shared care?

Shared care which incorporates a multi-disciplinary team can improve the effective delivery of quality cancer care by integrating health services which increase comprehensiveness and continuity of care. Shared care can be more easily tailored to individual patient circumstances and has been shown to reduce the financial and workforce burdens on the acute care system and improve quality of life for patients (Bosch et al., 2009; Weaver et al., 2014; Halpern et al., 2015). Shared care teams are designed to be wrapped around patients throughout the cancer journey and may include providers from both acute and primary care settings including GPs, nurses, social workers, allied health providers and oncology specialists as can be seen in Figure 4 (Cancer Australia, 2022).

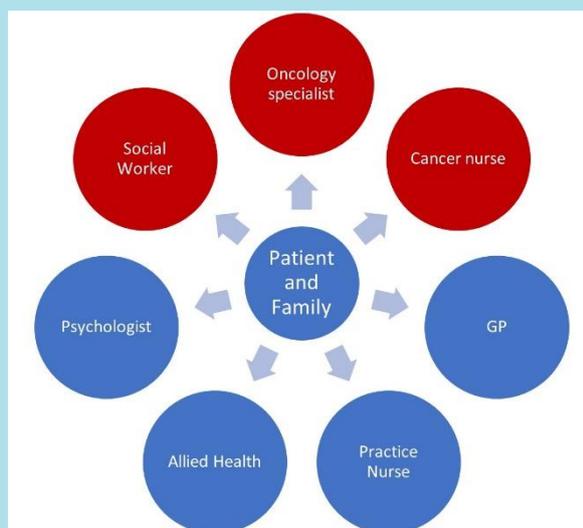


Figure 4: Healthcare providers involved in the multi-disciplinary care of cancer patients across acute and primary care settings

Accessing traditional cancer follow-up care can be difficult for patients living in rural locations or from diverse cultural backgrounds (Gunn et al., 2021). Follow-up care appointments require individuals to travel to a metropolitan centre, and often specialists located in metropolitan areas are not aware of the unique needs of cancer survivors living in rural settings (Gunn et al., 2013; Hunter et al., 2019). Similarly, cancer survivors from culturally and linguistically diverse or indigenous backgrounds have a greater need for information and explanations about cancer follow-up care requirements and may have difficulty navigating the health system in traditional models of care (Scanlon et al., 2021; O’Callaghan et al., 2016; Meiklejohn et al., 2018; Ristevski et al., 2020). An integrated shared care model for cancer follow-up care can address access barriers and improve the patient journey, but this model is not widely implemented across Australia.

A multi-disciplinary shared care approach to cancer follow-up has been recognised as an important component in a number of key state and national documents including guidelines, principles, and cancer plans (Cancer Australia, 2020b; SA Cancer Service, 2018; Vardy et al., 2019; Victorian Government, 2020; Cancer Institute NSW, 2022). The safety, benefit and cost-effectiveness of a shared care model of follow-up for early breast cancer and low-risk endometrial cancers has been identified by Cancer Australia, who in 2020 released clinical practice guidelines, but have not yet released guidance for other types of cancer (Cancer Australia, 2020b; Cancer Australia, 2020a). In 2019, the Clinical Oncology Society of Australia (COSA) released a guide for quality shared care follow-up for all cancer types.

COSA guide for quality cancer follow-up care

- A multidisciplinary approach should be implemented to enhance coordination
- Pathways of care should be tailored based on individual needs and clinical factors
- Follow-up care should support wellness and healthy lifestyles as well as medical surveillance
- Healthcare teams should develop a treatment summary and care plan when transitioning out of active treatment
- Cancer patients should receive equitable access to services, while minimising unnecessary use of healthcare services and resources (Vardy et al., 2019).

This model has informed the development of other state frameworks (SA Cancer Service, 2018; Victorian Government, 2020), however there is no evidence that existing guidelines or frameworks for shared care follow-up are being translated into practice. Further consideration of the implementation of best practice cancer follow-up care models is also timely given the Australian Cancer Plan currently being developed by Cancer Australia (Cancer Australia, 2021).

Effective implementation of integrated shared care for cancer follow-up nationwide is necessary to improve the patient experience equitably. However, a number of barriers to implementing this routine cancer follow-up care result in unsystematic and uneven availability of shared care follow-up models (Lisy et al., 2021). The key barriers include poor communication between acute and primary care; limited referral pathways; resistance to change of medical practitioners; lack of time, resources, and clinical staff; and the challenge of covering large geographical areas and vulnerable

population groups (Bergin et al., 2020, Senate Community Affairs References Committee Secretariat, 2005).

Barriers to implementing integrated shared care follow-up

Poor communication between care providers

Communication between specialists, primary care providers, nurses, and allied health is hampered by a lack of clarity about who delivers which aspect of the cancer follow-up care in a multi-disciplinary team (LaGrandeur et al., 2018; Radhakrishnan et al., 2019). For example, primary care providers report not receiving communication about the transfer of survivorship care and what responsibilities they need to take on (Dossett et al., 2017). This can result in aspects of quality follow-up care being missed and patients receiving fragmented care.

While electronic medical records can assist in defining tasks for team members, such as care plan templates or electronic medical records that can be accessed across different sites, they are not available to all healthcare providers (Taggart et al., 2021). The time taken to manually develop shared care plan documents introduces errors. For example, missing paperwork is a significant barrier to communication between providers that is known to hinder the implementation of integrated shared care (Trankle et al., 2019).

Acute care settings are increasingly using electronic health records which can be effective to transfer information, but patient information may not be documented in a way that GPs can understand what is required of them. The expansion of the My Health Record platform to hold shared care plans for cancer could improve communication between acute and primary care. Additionally, shared care teams require an enhanced understanding of the standard responsibilities for quality care that is agreed upon by all team members. The development of guidelines for multi-disciplinary shared care would help to support this, which can then be personalised for an individual health service.

Referral pathways to allied and community health are limited

The current uptake of and referral to holistic psychosocial support by specialists and GPs is insufficient (Lipworth et al., 2021). There are no established referral pathways for GPs to refer to oncology relevant allied or community health providers within the cancer follow-up care model (Mizrahi et al., 2021). Without clear guidelines to delineate patient referral options, and pathways to support GPs to carry out their role within shared care models, clinicians have reported lacking confidence to deliver follow-up cancer care (Lisy et al., 2021; Emery, 2014). Referral pathways must include allied health providers, community health services and allow for rapid access back to specialist care. Allied health professionals are an integral part of the cancer follow-up care team, providing specific professional knowledge to manage treatment-related side effects and assisting patients in returning to normal living (Cancer Australia, 2022). For example, exercise programs delivered by qualified allied health professionals are safe and effective at improving adverse physical effects and quality of life among cancer survivors (Cormie et al., 2017). However, not all patients are referred to exercise professionals. For instance, in an Australian study of 40 patients with brain

cancer, 77% of participants were referred to physiotherapists with 60% of patients taking up the referrals. But no participants were referred to exercise physiologists, psychiatrists, financial counsellors, or advocacy organisations (Langbecker and Yates, 2016). This highlights the gap in providing adequate holistic care to cancer survivors.

Community health services and non-government organisations also deliver psychosocial support to cancer survivors, reducing the burden on the health system, and improving patient health and quality of life (Eakin et al., 2020). However, guidance on when or how to refer patients to local community services is lacking (Lim et al., 2017). In 2016, a study in the Northern Territory found that cancer survivors commonly accessed community services and allied health services, but participants were not asked how they were referred to these services (Parikh et al., 2021). Evidence on provision and uptake of referrals to community services in other Australian states is lacking and there is no foundation from which to understand current practice. Lack of information about referral to psychological support services is an issue of particular concern, with groups of patients with high psychological needs, such as survivors of brain tumours, reporting problems accessing such services (Langbecker and Yates, 2016).

The process of referring patients to appropriate follow-up services is made difficult by the lack of integration of allied and community health services into existing care pathways. Clear pathways that identify patient needs and subsequent connection to appropriate allied health and community support will ensure that patients are provided quality follow-up care (Nekhlyudov et al., 2019). Reassuring patients that healthcare providers are available to support holistic aspects of care is important for patient satisfaction (Meiklejohn et al., 2017). Ensuring GPs have rapid re-access to hospital also reassures the patient that care will be provided if a serious issue arises (Lisy et al., 2020). Implementing shared care follow-up into routine practice to support the patient journey will require clear referral pathways that include allied health and community services. HealthPathways South Australia is an online tool that provides South Australian GPs with easy access to local referral resources for specific health conditions, with an established pathway for referring cancer patients for pain management (SA Health, 2022). This online portal, developed in partnership with state government and local Primary Health Networks (PHNs), could be expanded to incorporate allied health referrals for follow-up care, with similar programs developed in other states.

Attitudes and resistance to change traditional follow-up models

Implementation of shared care follow-up between acute care specialists and GPs can be hampered by the medical professional's willingness to adopt new models of follow-up care. It has been reported that oncologists perceive an unwillingness by GPs to participate in cancer follow-up care or that they do not have adequate training to assist in follow-up care (Schütze et al., 2017; Lisy et al., 2020; Coschi et al., 2021). Cancer patients also prefer to have follow-up care delivered by specialists rather than GPs, reasoning that additional training may be required for GPs to be involved in shared care models (Brennan et al., 2011; Baravelli et al., 2009).

Shared care models of follow-up are favoured when the patient and GP are provided with clear guidelines and information about the shared care model (Emery, 2014; Schütze et al., 2017; Ngune

et al., 2015). GPs themselves appear to be happy to be included in the broader multi-disciplinary team providing follow-up cancer care as long as they are given all the necessary information to provide care (Lawrence et al., 2016). All healthcare providers involved in cancer follow-up care need to be supportive of shared care models for implementation to be effective. Increasing awareness of the benefits and clear processes for implementing shared care models needs to be circulated among all healthcare providers. The development of national frameworks and discipline-specific information endorsed by peak bodies or professional colleges can help to shift negative attitudes and resistance to change.

Implementing shared care follow-up across large geographical areas

Cancer survivors living in rural and remote areas experience difficulties accessing follow-up care appointments (Van Der Kruk et al., 2021; Gunn et al., 2021). In Australia, 40% of cancer services are based in metropolitan areas, 30% in rural and 30% in remote locations (Hunter et al., 2019). In 2005, only 20% of regional hospitals administering cancer care had a resident medical oncology service, 7% had a radiation oncology unit, and 6% had a resident surgical oncologist. Only 24% of regional hospitals involved in cancer care reported a dedicated palliative care specialist and 39% identified a dedicated oncology counselling service (Underhill et al., 2009). This lack of specialist cancer services in rural areas requires cancer patients living in non-metropolitan areas to travel extensively for cancer treatments and follow-up care.

In 2010, the Australian Government invested in a network of new regional cancer centres to help improve cancer survival outcomes for patients living in rural, regional, and remote areas (PM&C, 2010). The 2010 regional cancer centre initiative focused on expanding chemotherapy and radiotherapy services into non-metropolitan areas, engaging the private sector to fill service gaps, and developing other models of care such as shared care, regional outreach services, and telehealth services (Hunter et al., 2019). However, limited scoping of the delivery of cancer care in rural and regional areas has been conducted since the introduction of the regional cancer centre initiative.

In 2016, mapping of healthcare organisations across the public and private health sector identified 295 organisations delivering cancer care services across Australia (Hunter et al., 2019). Of the cancer care organisations identified, only 75% provided supportive care or follow-up care services (Hunter et al., 2019). Where supportive care is provided, it occurs through hospital in-patient or outpatient services, rather than community-based services (Pinkham et al., 2021). Since local, regional, and rural health services are not well integrated into follow-up care practices, patients living outside of metropolitan centres are still required to travel to metropolitan areas for cancer follow-up appointments. The implementation of shared care models which leverage local GPs and community health services would help to reduce the need for cancer survivors to travel for follow-up care and improve the patient experience.

Not every cancer survivor will need rigorous follow-up or access to a broad range of healthcare professionals, but that does not mean that individuals do not have their own needs which traditional follow-up care models fail to consider (Koczwara, 2020). A personalised approach to care in which cancer survivors follow individual pathways based on their needs could use healthcare resources

more efficiently than providing a standard model for all cancer survivors (Alfano et al., 2019). Personalised pathways of follow-up care seek to optimise coordination between a range of health providers based on the personal needs of the individual (Tremblay et al., 2021). However, this still requires quality follow-up care services to be available to all cancer patients regardless of circumstance and geographic location.

Lack of time, resources, and staff to provide quality cancer follow-up care

Low levels of adequately trained staff and lack of time within the current workforce are known barriers to quality, evidence-based healthcare and will impact on effective implementation of integrated shared care cancer follow-up models (Lisy et al., 2020; Lisy et al., 2021). Specialists lack the time and resources needed for addressing matters beyond immediate medical needs (Brennan et al., 2014; Beesley et al., 2020), meaning that they do not have the capacity to provide their patients with non-acute holistic care. Resource constraints and appropriate remuneration have also been identified as barriers to the provision of cancer follow-up care in general practice (Meiklejohn et al., 2016; Johnson et al., 2014). Additional support to perform administrative tasks such as managing correspondence, scanning and storing documents, and scheduling appointments, is required to effectively implement shared care models (Lisy et al., 2021).

A care coordinator or patient navigator role has been shown to successfully support the implementation of shared care models by assisting in communication between healthcare providers, managing appointments for patients, and documenting patient medical records. In Western Australia, a state wide cancer nurse coordinator service was implemented in 2006 to facilitate navigation of the cancer care system for patients and families (Monterosso et al., 2016). Unlike cancer nurses based in acute care settings, the nurse coordinator moves with the patient across acute care and primary care settings, and conducts tasks related to patient education and multi-disciplinary clinical care (Monterosso et al., 2016). This cancer nurse coordinator role has been seen as a fundamental element of quality follow-up care in WA. However, it is not known how broadly this role is implemented, and the availability of staff to assist GPs and specialists in the care coordination aspects of follow-up care may vary across other Australian states and territories.

Key recommendations for cancer care coordination roles have been developed (Clinical Oncology Society of Australia, 2015), providing guidance for workforce planning and scope of practice, taking into consideration qualifications, capabilities, responsibilities, and key performance indicators (Clinical Oncology Society of Australia, 2015). The COSA statement on cancer care coordination has yet to be actioned, but the proposed activities need to be supported for effective implementation of integrated shared care follow-up. State governments or local PHNs will need to conduct a comprehensive audit of current cancer care coordination or patient navigation positions to inform opportunities for expansion.

Health system structures that support shared care follow-up

Using Medicare items for Chronic Disease Management

Administrative data collected through the Medicare Benefits Schedule (MBS) does not provide information on whether Medicare items are being used for cancer follow-up care or other health conditions, but rather contains administrative information on claims, benefits paid, patients and service providers. Integrated shared care follow-up involving specialists, GPs and allied health providers can be planned under the MBS items for Chronic Disease Management (Department of Health, 2014). Chronic Disease Management items enable GPs to plan and coordinate the care of patients with chronic or terminal conditions, including patients who require multidisciplinary, team-based care from a GP and at least two other healthcare providers.

Medicare rebates are available to GPs for the following services:

- Preparing a management plan for a patient who has a chronic or terminal medical condition with or without multidisciplinary care needs (Item 721)
- Coordinating the preparation of Team Care Arrangements for a patient who has a chronic or terminal medical condition and requires ongoing care from a multidisciplinary team of at least three health or care providers (Item 723)
- Reviewing a GP Management Plan (Item 732)
- Coordinating a Review of Team Care Arrangements (Item 732)
- Contributing to a multidisciplinary care plan (Item 729 and 731)

Cancer patients who have their follow-up care managed by their GP are also eligible for Medicare rebates for certain allied health services on referral from their GP (Department of Health, 2014). Patients can be referred for up to five allied health services each calendar year. Thirteen allied health professions are funded under the Chronic Disease Management program including Aboriginal and Torres Strait Islander health practitioners, audiologists, chiropractors, diabetes educators, dietitians, exercise physiologists, mental health workers, occupational therapists, osteopaths, physiotherapists, podiatrists, psychologists, and speech pathologists (Department of Health, 2014). Five Medicare funded allied health sessions are insufficient to adequately manage cancer follow-up care as patients are instructed to visit exercise physiologists, dietitians, and psychologists and are likely to have comorbid chronic health conditions (Allied Health Reference Group, 2019). Alternative sources of public funding are not available to patients who require more than five allied health appointments, and many patients seek private services, resulting in additional financial burden (Allied Health Reference Group, 2019). Increasing the number of rebated allied health sessions for people with cancer and complex medical conditions is needed.

The collection of MBS data is not designed for service evaluation or quality improvement but could be linked to other routinely collected clinical data. MBS data linked with other clinical patient data can identify the type and quantity of healthcare services accessed or healthcare costs. Additional primary care data is required to understand how many Chronic Disease Management Plans are

specific to cancer follow-up, and to assess the proportion of total cancer survivors who have their follow-up care being managed by a GP.

Additional data on the number of allied health services used by cancer survivors in a calendar year is also required to understand the number of referrals that would be adequate for patients. Cancer specific primary care data, collected by general practices and PHNs, needs to be reviewed to understand current practice and evaluate the appropriateness of follow-up cancer care in general practice.

Telehealth can improve access to shared care follow-up across geographic regions

The uneven distribution of cancer care services across Australia prevents many cancer survivors from accessing follow-up care close to home. However, increasing the use of telehealth appointments throughout the COVID-19 pandemic has allowed the use of technology to deliver care close to home and reduce patient out-of-pocket costs (Koczwara, 2020). Alongside telehealth appointments between healthcare providers and patients, telemedicine interventions such as videoconferencing between a GP and oncologist or nurse-led telephone programs, can be effective for addressing the psychosocial and physical effects of cancer in the follow-up care period (Chan et al., 2021).

The North Queensland Tele-Oncology Network has allowed rural and remote cancer patients living in Queensland to access specialist cancer care delivered via telehealth (Sabesan et al., 2012). In this model, consultations with an oncologist are performed via videoconference with support from local GPs, nurses, and allied health providers. The Townsville Cancer Centre uses videoconferencing technology to oversee the management of patients from rural and remote towns of the Townsville and Mt Isa Health Service Districts. The tele-oncology model has been used to deliver chemotherapy treatment remotely with the help of trained nurses and has been safe, feasible, acceptable to patients and healthcare providers, reduces waiting times for patients, and saves money for the health system (Sabesan et al., 2012). To date, telehealth videoconferencing involving two health providers has been used only during cancer treatment and limited evidence is available for the use of tele-oncology in follow-up care.

Telehealth can form an important component of follow-up cancer care by addressing some of the current challenges with care, including minimising or eliminating the financial impact of travelling to appointments (travel, parking, accommodation), particularly for regional and rural patients; reducing the impact that face-to-face appointments have on work and family commitments; and improving access to care provided by allied health and primary care, which more fully meets the needs of cancer survivors. Cancer nurses are well placed to assist with telehealth-facilitated cancer follow-up care (Brunelli et al., 2021). However, while cancer nurses have positive attitudes towards the use of telehealth for cancer follow-up care, actual use is low (Brunelli et al., 2021). While COVID-19 has resulted in rapid uptake of telehealth services by GPs, specialists, nurse practitioners, and allied health providers (Burbury et al., 2021), the capacity of the cancer nursing workforce to use telehealth to deliver follow-up care is not well understood (Brunelli et al., 2021; Chan et al., 2021). Data identifying barriers and enablers to telehealth use by cancer nurses can provide important

lessons for the ongoing expansion and utilisation of telehealth services for cancer follow-up care beyond the pandemic.

Specialist cancer nurse models improve quality cancer care

Particular types of nursing models, such as nurse navigators or cancer care coordinators, are generally based in acute care settings and have limited involvement in cancer follow-up care (Freijser et al., 2015). Specialist cancer nurses play a similar role and are commonly available for breast and prostate cancer patients in both private and public hospital settings but are less common for other cancer types. These specialist nurses are known to improve the quality of life for patients, patient experience, and coordination of care; however, the roles predominantly focus on support during the diagnosis and treatment phases of cancer care and not on long-term follow-up (Mahony et al., 2019; Fleure and Sara, 2020).

The McGrath Foundation currently has 145 McGrath Breast Cancer Nurses across Australia representing 38% of the national breast care nursing community (McGrath Foundation, 2020). Evaluation of the McGrath nurse model shows that access to a McGrath nurse improves the cancer experience for patients and healthcare providers, and there are cost savings to the health system when cancer patients have early access to a McGrath nurse due to reduced health service utilisation (Mahony et al., 2019). While the McGrath Foundation has developed a breast nursing model of care to enhance and standardise supportive care practices and deliver best-practice care to patients across Australia (McGrath Foundation, 2020), there is scope for the breast care nurses to play a greater role in follow-up care (Mahony et al., 2019).

The Prostate Cancer Foundation of Australia (PCFA) has 54 specialist nurses located in 48 health services across Australia. As with McGrath nurses, the role of the PCFA nurses is to provide patient education and coordination of care and while the PCFA model of care provides access to follow-up care support, there is scope for these roles to develop further, into post-treatment surveillance programs and nurse-led survivorship care (Fleure and Sara, 2020).

McGrath and PCFA specialist cancer nurses are funded jointly through the respective non-government organisations fundraising efforts and federal government investment. Federal government funding has also assisted in the establishment of four specialist lung cancer nurses, one cancer care telehealth nurse providing support to lung cancer patients, and six specialist ovarian cancer nurses. Federal government funding for specialist cancer nurses to support patient care in other cancer types is absent. The limited number of federally funded specialist cancer nurse positions means that cancer care predominantly relies on the state funded nursing and care coordination workforce. Particular services such as nurse navigator supports are perceived to be particularly in need of greater funding (Lipworth et al., 2021). Resource limitations are also exacerbated by limits in the number of healthcare professionals who have the training necessary to provide the specialised care that cancer patients need. While workforce distribution issues are common in all disciplines, the shortage of specialist cancer nurses and nurse navigators compromises the delivery of best practice care (Mahony et al., 2019; Brims et al., 2022).

Improving the coordination of follow-up care through funding models

A major barrier to the coordination of cancer patients care following treatment is the current Medicare funding model which provides fee-for-service reimbursement. Ineffective administrative processes such as having difficulty accessing paperwork, and the time taken to coordinate a patient's follow-up care, can fall to a GP, nurse, or specialist without allocated, funded time (de Witt et al., 2020; Haynes et al., 2018). Value-based care reforms that support health outcomes over cost would encourage more coordinated and efficient cancer follow-up care. Value-based funding can take into consideration the long-term nature and ongoing health appointments that are required after cancer treatment and provide block funding for periods of care rather than each individual episode of care (Lipworth et al., 2021). A block or bundled payment model issues a single payment to providers or their facilities for all healthcare services a patient received during a predetermined episode of care to treat a disease, rather than the traditional fee-for-service model.

For example, the Department of Veterans' Affairs (DVA) Coordinated Veterans' Care (CVC) Program is a healthcare team program designed to improve care and reduce unplanned hospital admissions and re-admissions through a coordinated model of care (Grosvenor Management Consulting, 2015). Within this program, GPs are paid to enrol patients onto the CVC program and to provide comprehensive and coordinated care with the assistance of their practice nurse. The CVC program then allows GPs to claim fees through Medicare at initial assessment and at completion of a 90-day period of care (reviewing the care plan). The program targets five chronic conditions (congestive heart failure, coronary artery disease, pneumonia, chronic obstructive pulmonary disease, and diabetes) where improved coordinated care has the potential to reduce healthcare utilisation but does not include cancer care. It has been found that the CVC Program promotes collaborative teamwork between GPs and other healthcare providers and encourages GP engagement in care planning. This program not only reimburses GPs for the coordination of care but has also resulted in reducing unplanned hospitalisations and improving quality of life for patients (Grosvenor Management Consulting, 2015). Reforming and implementing a bundled payment model, based on the CVC program, would improve the coordination of follow-up care for non-veterans and all patients with cancer.

Established guidelines for shared care follow-up are inconsistent

Despite the endorsement of shared care follow-up to improve patient care, implementation of shared care follow-up models across the country is inconsistent and patchy (Lipworth et al., 2021). Consequently, not all patients are receiving quality follow-up care. The Victorian Department of Health have developed Optimal Care Pathways which provide specific recommendations for delivering care across the patient journey for 18 cancer types (Cancer Council Vic, 2021). The optimal care pathways recommend shared follow-up care involving the joint participation of specialists and GPs in the planning and delivery of follow-up care (Cancer Council Vic, 2021). The optimal care pathways have national acceptance and government support although they are not legislated or otherwise mandatory. For implementation, optimal care pathways or other shared care clinical practice guidelines require cooperation across different health sectors, and incentives for health

services or PHNs to adapt current practice. As yet, limited assessment has been done on widespread implementation of Optimal Care Pathways or clinical practice guidelines in relation to shared care follow-up.

Conflicting, unclear, or vague guidelines about cancer care can lead to ambiguity among primary care providers about what is best practice (Cruickshank and Barber, 2019; Shell and Tudiver, 2004). Consistent advice on shared care follow-up for all cancer types is needed to ensure quality care provision. Cancer Australia’s evidence-based guidelines for early breast cancer or low-risk endometrial cancer could be used to inform generic guidelines for the delivery of quality shared care. However, broad principles can make it difficult for individual health services to identify opportunities for change in their existing practice. COSA’s principles for quality cancer follow-up care do not provide specific advice on what each member of the multi-disciplinary shared care team should do to provide the quality follow-up care to their patients (Vardy et al., 2019). A framework which lists the actionable tasks for each member of a shared care team, tips for communication across health settings, how to use appropriate MBS items, and shared care planning documents is required. Figure 5 provides an example of a shared care follow-up model that can be adapted and integrated into practice in local services.

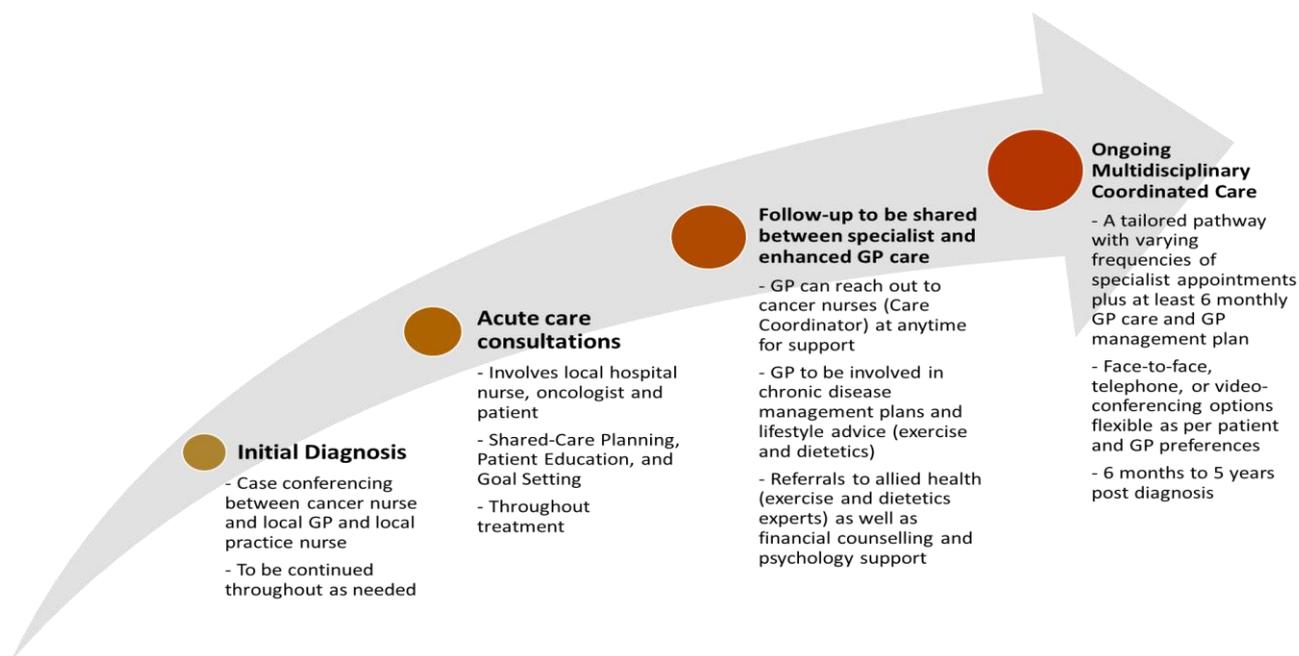


Figure 5: Shared Care Follow-up Model with examples of practical tasks listed

Monitoring & evaluation of integrated shared care follow-up

Although the provision of cancer follow-up care changed rapidly during the COVID-19 pandemic with increased implementation of shared care models, changes were not uniform across the country

(Chan et al., 2020). For instance, during the pandemic cancer patients were unable to visit their cancer service for their follow-up appointments and reported having their follow-up care conducted by their GP, while other post-treatment appointments were conducted using telehealth, and some non-urgent surveillance consultations were delayed (Chan et al., 2020). The value of the rapid changes to practice cannot be recognised without more detailed understanding of where and how shared care models are being utilised. The implementation of shared care follow-up models needs to be monitored and continually evaluated to ensure patients are receiving quality, evidence-based care. The collection of accurate and high-quality data on service delivery models, multi-disciplinary team involvement, workforce distribution and scope of practice, and patient outcomes is essential to inform continued improvement of cancer follow-up care services. Measures to evaluate shared care follow-up include improved survival, reduced risk of recurrence, reduced risk of new cancers, improved quality of life, improved functional outcomes, improved patient experience, minimised health-care utilisation, and lower costs to cancer survivors and healthcare systems.

Workforce distribution of health providers involved in cancer follow-up care

The capacity of the current health workforce to deliver shared care cancer follow-up is poorly understood. Without an understanding of current practices and resources, barriers to the implementation of shared care models cannot be adequately addressed. The availability of data relating to workforce composition and the providers involved in current shared care models for cancer follow-up is required to provide a foundation for future resourcing requirements for the growing population of cancer survivors. A lack of the required staff to support a shared care team approach (oncologists, cancer nurses, GPs, allied health providers) can impact the delivery of quality follow-up care and result in poorer health outcomes and patient experience. Supply must be able to meet patient demand to maintain high standards of cancer follow-up, particularly with a growing number of cancer survivors (Trapani et al., 2021).

Mapping of the Australian health workforce involved in delivering cancer care has previously been carried out through non-compulsory self-report surveys distributed by professional bodies (Lwin et al., 2018; Underhill et al., 2009; Cancer Nurses Society of Australia, 2022). For example, an Australian medical oncologist workforce survey was conducted in 2016 to map and understand the challenges facing the workforce; however, only 354 members of the Medical Oncology Group of Australia completed the survey, just 57% of the 620 medical oncologists registered with AHPRA (Lwin et al., 2018). The Cancer Nursing Society of Australia (CNSA) has also conducted a workforce mapping project which aims to understand where cancer nurses are located and to identify barriers to their involvement in cancer care (Cancer Nurses Society of Australia, 2022). This national survey again relies on nurses' willingness to participate and is unlikely to capture the full breadth of understanding required to improve health service delivery. This method allows for gaps in information and hampers future service planning without an accurate understanding of current workforce distribution. More robust data on nurses, allied health, and primary care providers' involvement in cancer follow-up services could be included in the Australian Institute of Health and

Welfare's National Health Workforce Data Set. This information is needed to map workforce availability and match increasing patient needs.

Shared care models of follow-up which increase the involvement of primary care allow for general practice nurses to become involved in some tasks such as care-coordination. A workforce survey of 3,750 primary care nurses conducted in 2020 identified that 40% of the nurses felt they could do more with their current skills and knowledge, and 54% had suggested to their manager that they could undertake more complex clinical activities (APNA, 2020). A greater understanding of workforce distribution and availability to take on complex care is required to enable underutilised staff such as general practice nurses to take on a greater role in cancer follow-up care.

Over the last 20 or more years there has been critical maldistribution of the health workforce resulting in shortages of GPs, nurses, allied health providers, and oncologists in regional and rural areas (Armstrong et al., 2007; Joyce et al., 2006; Koczwara et al., 2012; Murphy et al., 2015; Deloitte Access Economics, 2019). The National Health Workforce Data Set provides accurate statistics on the number of health professionals working in Australia, the headcount and full-time equivalent positions, the distribution across states and territories, and services provided, but does not drill down into the specifics required to understand the workforce involved in cancer follow-up care. The establishment of an Australian cancer workforce registry could be used to track workforce trends and provide the information required to efficiently allocate human resources for more effective implementation of shared care follow-up (Srivastava et al., 2021). Cancer Australia could develop a cancer workforce registry by considering the World Health Organization's Minimum Data Set for Health Workforce Registry (WHO, 2015) and adapting to ensure the multidisciplinary nature of cancer care is reflected (Srivastava et al., 2021). The establishment of a cancer workforce registry at the national level can then be utilised along with the Australian Cancer Plan to determine future workforce requirements.

Clinical data is underutilised and evaluation is lacking

There is currently no comprehensive data on where shared care follow-up models are being implemented, which healthcare providers are delivering shared care, and consequent patient outcomes. This lack of information means that it is not possible to tell if shared care models are meeting patient needs, or how they could be improved. Improved collection and utilisation of clinical data could help to identify the resources and workforce needed to provide shared care follow-up to a growing population of cancer survivors.

There is a lack of guidance as to where relevant cancer follow-up care data can be found or accessed and how it can be linked to other routinely collected patient data. A range of routinely collected administrative and clinical health data from acute care and primary care settings could be used to evaluate the impact of shared care follow-up models on patient outcomes and patient satisfaction. The Australian Cancer Database is compiled from population-based cancer registries within each Australian state and territory and provides information on cancer incidence and mortality, and patient level information such as age, sex, country of birth, geographic location, and socio-economic status (Australian Institute of Health & Welfare, 2021a). However, for cancer follow-up care these

registries provide no useful information, but there may be scope to add items to the registries for additional benefit. Data on long-term treatment side effects, comorbid diseases, disability, other healthcare outcomes and cost of healthcare delivery could be added to cancer registry data collections to monitor the performance of follow-up care models.

Cancer Australia's National Cancer Data Strategy was developed in 2008 recommending that data be linked across the public and private health sectors, and across jurisdictions for effective service monitoring and supporting patient care. It also suggested that supplementary data collection such as ad hoc surveys could be undertaken to supplement existing routinely collected information (Cancer Australia, 2008). Since then, Cancer Australia has undertaken key activities to bring together cancer data from across a range of sources, including the National Cancer Control Indicators framework and website, and the national collection of cancer data on stage, treatment and recurrence (STaR) project¹ (Cancer Australia, 2022b). However, data collection and reporting relating to cancer follow-up care remains lacking. An updated national data plan needs to be developed by Cancer Australia to continue to optimise the quality of cancer data collection and data linkage and provide usable information for understanding shared care follow-up models.

Primary care data

There are currently no systematic mechanisms for collecting or analysing primary care data that help in understanding variations in patient management for cancer follow-up care (Swerissen et al., 2018). General practices collect a range of clinical data in patient management systems that would be invaluable to the understanding of shared care cancer follow-up. This data currently remains the property of individual practices, with access to the data also provided to PHNs and the Australian Institute of Health and Welfare. For example, the Practice Incentives Program – Quality Improvement incentives collect data on ten general practice items that support an understanding of chronic disease management. This could be expanded to collect information relevant to cancer care in primary care settings. POLAR (<https://polargp.org.au/polar-gp/>) is another source of primary care data that could be utilised to understand the management of cancer follow-up in general practices as researchers can apply for access to subsets of de-identified general practice data (Outcome Health, 2020).

South Eastern Melbourne PHN is collaborating with researchers at Monash University to use the primary care data in POLAR to understand the cancer patient's primary care journey (Outcome Health, 2020). The data collected by PHNs could be expanded to include items specific to cancer follow-up. This data then needs to be utilised by PHNs to understand shared care follow-up practices and inform quality improvements within local health services.

While data on clinical care delivery and patient health outcomes is routinely collected in acute and primary care settings, linkage of this data to understand cancer care follow-up practices is not occurring. Primary care data and acute care medical records can be linked from across different

¹ Cancer Australia's National Cancer Control Indicators (NCCI) website is a national resource that brings together national data across a set of indicators from prevention and screening through to diagnosis, treatment, psychosocial care, research and outcomes. NCCI enables users to see interconnections and relationships across cancer control, and to monitor national trends and benchmark internationally. STaR is a multiphase, multi-year project with key national data collected on cancer stage at diagnosis, survival by stage at diagnosis and system-wide treatment activity reported on the NCCI website.

sources as a single patient identifier is commonly used across a healthcare system. Further linkage with administrative data and national health surveys can enrich our understanding of shared care follow-up models.

Patient Reported Outcomes

Data used to assess the quality of health service delivery does not consider the patients' perceptions of their health and experiences. However, there is increasing support for the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) to assist in monitoring and evaluating the quality of cancer care (Nguyen et al., 2021). A core set of PROMs which can be used to standardise the assessment of cancer survivors concerns during follow-up have been developed in Australia (Ramsey et al., 2021). Engaging clinical stakeholders to implement routine collection of PROMs can ensure that cancer follow-up care models are meeting the needs of cancer survivors (Bamgboje-Ayodele et al.). Furthermore, routine collection will provide data that can be used to guide the implementation of shared care follow-up and make comparisons across health services.

Without tailoring multidisciplinary shared care pathways to individual needs, cancer survivors can miss out on necessary care. PROMs could be used to determine a patient's need for further support. Collecting PROMs electronically and linking to electronic patient health records will provide the multidisciplinary team involved in shared care follow-up with the information to provide tailored advice to individual patients. The successful utilisation of PROMs in clinical practice is dependent on the creation of robust electronic platforms for recording and sharing data, and training staff to effectively utilise PROMs (Bamgboje-Ayodele et al., 2022). The core set of PROMs for cancer follow-up care (Ramsey et al., 2021) should be incorporated into routine data collection for cancer survivors across acute care and primary care settings.

Conclusion and recommendations

Integrated shared care for cancer follow-up wraps care around the cancer survivor and family and has the potential to improve the patient journey and experience. Guidelines and principles for the implementation of shared care follow-up models exist in Australia but are not routinely implemented. Workforce availability and barriers to care-coordination need to be addressed for shared care models to be implemented effectively and to provide equitable cancer follow-up care. Additional collection of clinical data is required to monitor and evaluate optimal shared care approaches.

Recommendation 1: Consistent data collection and linkage of data across primary and acute care is needed to ensure quality shared care

Primary care data is difficult to access, and information specific to cancer follow-up care practices is not consistently measured or monitored. Therefore, it is difficult to determine whether shared care

follow-up models are being implemented and resulting in improved patient outcomes in standard practice.

The collection of data that measures relevant patient outcomes as a result of shared care follow-up models is required to ensure quality care is being delivered. Linkage of data across primary care and acute care settings is required to monitor utilisation of chronic disease management plans, referrals and utilisation of allied health, patient adherence to follow-up appointments, and rapid referral back to specialist care.

Recommendation 2: The roles within multi-disciplinary shared care teams should be defined

Multidisciplinary team members require an understanding of their role within the care team. Detailed shared care guidelines which list the tasks required would help to support this. Improved communication and role clarification can also be achieved through multi-disciplinary team meeting, shared care planning, and recording of information in electronic health records. Greater investment in information technology systems, or changes to the ability of My Health Record to create shared care plans, would enable timely and dynamic communication between hospital-based cancer centres and community-based general practices, nurses, and allied health professionals.

Professional awareness and knowledge of shared care models broadly should be improved. Key stakeholders such as RACGP, RACP, and CNSA should support the development of a standard description of roles and tasks required to support shared care teams. This can include links to further education opportunities for different health professionals.

Recommendation 3: Understand the workforce available to provide shared care follow-up and assist with care-coordination

Mapping of the health workforce and understanding the allocation of time and resources dedicated to cancer follow-up care is needed to ensure shared care models are sustainable. Developing a cancer workforce registry would provide the information required to monitor and evaluate the health workforce role in shared care follow-up.

Care coordination is a crucial component of shared care follow-up resulting in improved patient experience. State governments or local PHNs will need to conduct a comprehensive audit of current cancer care coordination positions to inform opportunities for expansion. Nurse navigators, specialist cancer nurses, GPs, and primary care nurses are all suitable positions to provide care coordination if adequate funding and resources are provided.

Recommendation 4: Referrals to allied health and community services should be included in follow-up care pathways

Shared care follow-up models need to incorporate a range of allied health and community service providers relevant to the individual cancer survivor needs. Having clear referral pathways and easy communication between multidisciplinary team members will enable GPs to refer their patients to

appropriate resources. Online directories of local allied health providers specialising in oncology could be developed in partnership with state government and local PHNs.

To support comprehensive quality care for the cancer survivor, funding to support access to allied health should be prioritised by increasing the current referral limit of five appointments funded by the Medicare Benefits Scheme for chronic disease management.

Recommendation 5: Governance frameworks and appropriate funding structures should be developed for shared care models

Existing shared care follow-up guidelines and principles of care have not been integrated into practice consistently across Australia. A national governance framework for shared follow-up care is required which would help address the fragmentation of care experience by cancer survivors. Cancer Australia should work with peak bodies including the RACGP and cancer specialist groups such as COSA, to develop practical guidance on the delivery of shared care follow-up that can be adapted to suit a local health service context. The current development of the Australian Cancer Plan provides an opportunity to link shared care follow-up with wider cancer policy reform.

Additionally, alternative funding structures to the current fee-for-service model should be considered to incentivise quality follow-up care. Consideration should be given to block funding based on periods of care where funding is provided to meet the needs of the patient. In concept, this could resemble the principles of the Coordinated Veterans' Care Program and needs to be trialled to ensure shared care follow-up pathways are supported and viable. Over the long term, the fee-for-service payment system needs to be improved so that GPs are rewarded for coordinating and delivering complex care.

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