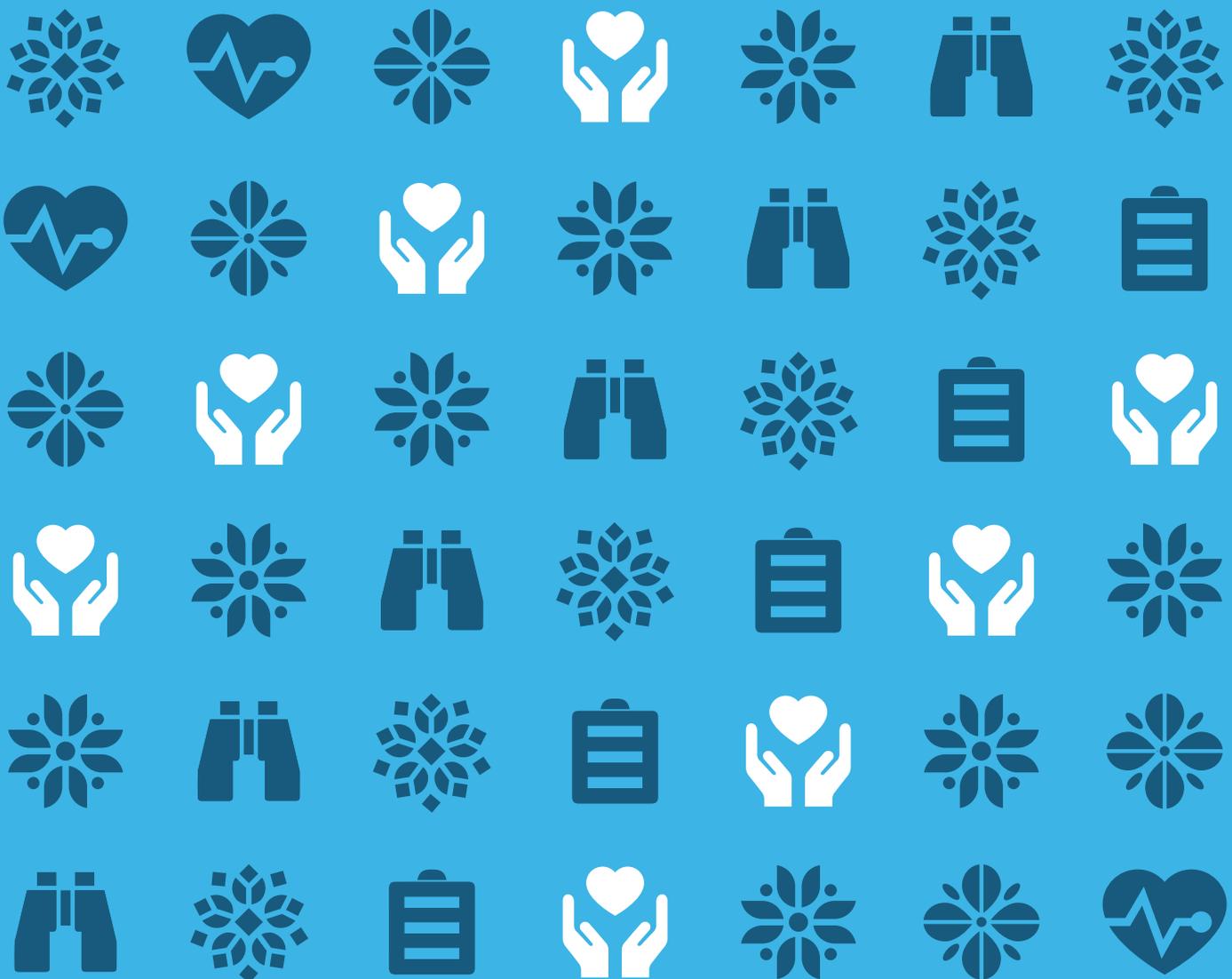


Optimal care pathway for adolescents and young adults with cancer

FIRST EDITION



Optimal care pathway for adolescents and young adults with cancer

FIRST EDITION

Endorsed by



Australian Government
Cancer Australia



Statement of acknowledgement

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

This work is available from the Cancer Council website <www.cancer.org.au/OCP>.

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Welcome and introduction

The *Optimal care pathway for adolescents and young adults with cancer* has been developed with the aim of improving the outcomes and the experiences of care for young people with cancer.

Although cancer is rare in young people, it disproportionately contributes to the burden of disease and disease-related death within young Australians, with outcomes lagging behind those achieved in children and adults. While the diagnosis and treatment pathway for any patient with cancer is complex, this is even more apparent for young Australians who may be supported by healthcare services that straddle across adult, paediatric, public, private, metropolitan and regional settings.

The treatment aspects of optimal care are the same irrespective of age, but there are a range of unique considerations for young people as the timing of ill health coincides with a critical time period for their growth and development. Thus, a cancer diagnosis has the potential for far-reaching consequences including impacts on physical growth, mental health, peer and family relationships, establishment of new social roles, education and vocation attainment, and achieving independence.

Reflective of the distinctive needs of this population, investments by both state and federal governments have led to significant progress in developing specialist age-appropriate care for young Australians diagnosed with cancer. The development of this optimal care pathway builds on work by Cancer Australia and Canteen within the *National service delivery framework* (2008) and was specifically recommended as one of the key items in the subsequent *Australian youth cancer framework* (2017), both of which promote a national vision for quality adolescent and young adult cancer care.

This optimal care pathway has been designed to complement the existing cancer-specific optimal care pathways, ensuring that current, emerging and future developmentally significant health issues are addressed in conjunction with their cancer treatment.

This pathway acts as a reminder for health professionals of their responsibility to consider a young person with cancer not just in the context of their disease but equally in the context of their life stage. In addition, it may support health services in order to inform service delivery that is responsive to the needs of young people and their support networks.

Its development has been guided by a National Expert Working Group consisting of national leaders in oncology and adolescent health and is underpinned by strong engagement and consultation with young people and community partners. We thank them all for their generous contributions.



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Summary

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

This quick reference guide provides advice to health practitioners and service planners on optimal care for adolescents and young adults (AYA) with cancer, across the cancer continuum. Refer to the relevant cancer-specific optimal care pathways on the Cancer Council website <www.cancer.org.au/OCP>. The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials. For AYA with cancer, timing of ill health coincides with a critical period for their growth and development, also demanding unique developmental considerations that are applicable across all steps of the care pathway.

This quick reference guide provides a summary of the *Optimal care pathway for adolescents and young adults with cancer*.

Key considerations to support optimal care for AYA with cancer

- **Model of care.** Optimal AYA cancer care is a hybrid patient-centred model of care that supports the individual's emerging or established autonomy while being adaptive to the involvement of parents/carers and significant others. Care becomes family-inclusive versus family-focused.
- **Care environment.** An age-appropriate hospital environment will provide the patient with a sense of control, offer access to positive distractions as well as access to social (non-professional) supports. The environment should promote a sense of normalcy and ability for the AYA to continue to achieve tasks, as well as include age-appropriate activities.
- **Care coordination.** AYA with cancer prefer an individualised approach that acknowledges and responds to their competing psychosocial commitments. A dedicated AYA care coordinator provides information, emotional support, empowerment, patient advocacy and development of health literacy, with a physical presence at key time points throughout the care continuum.
- **Communication.** Effective, age-appropriate communication from youth-friendly healthcare providers is a primary indicator of quality AYA health care. Youth-friendly communication training should be a requirement for staff working regularly with AYA.
- **Understand your patient.** A cancer diagnosis during this stage of life has the potential for far-reaching consequences including impacts on physical growth, mental health, peer and family relationships, establishment of new social roles, education/vocation attainment, and achieving independence. Understand and incorporate these unique considerations in all decision-making processes about treatment and ongoing care with AYA.

Please note that not all patients will follow every step of the pathway.

Step 1: Prevention and early detection

Prevention

Encourage AYA to:

- reduce UV exposure
- get vaccinated for human papillomavirus (if not undertaken during childhood)
- avoid smoking
- reduce alcohol intake
- promote physical activity and healthy eating.

Risk factors

In the absence of a familial cancer predisposition syndrome (CPS), most cancers in the AYA population are sporadic without known causes.

There is an increased risk of developing a second cancer during early adulthood as a result of exposure to chemotherapy and/or radiation therapy during childhood.

Early detection

There are currently no standardised screening tools that increase early detection while reducing the risk of mortality (without undue risk to the healthy population) in new cancer diagnoses in this group. However, screening AYA may be beneficial for some cancer sub-types such as cervical, breast or colorectal cancer, particularly if they have a CPS.

Checklist

- Recent weight changes discussed and the patient's weight recorded
- Alcohol intake discussed and recorded and support for reducing alcohol consumption offered if appropriate
- Smoking status discussed and recorded and brief smoking cessation advice offered to smokers
- Physical activity recorded
- Referral to a dietitian considered

Step 1: Prevention and early detection continued

Screening recommendations

- AYA with a known familial CPS or family history of cancer at a young age should be aware of the importance of screening and early detection and encouraged to follow evidence-based recommendations.
- AYA survivors of childhood cancer should follow evidence-based guidelines that include reducing modifiable cancer risk factors and, if applicable, cancer risks associated with initial disease and treatment, such as secondary malignant neoplasms.

Checklist

- Referral to a physiotherapist or exercise physiologist considered
- Education on being sun smart considered
- Referral to tertiary a familial cancer service for those with known cancer predisposition
- Referral to cancer survivorship service for AYA with a history of childhood cancer

Step 2: Presentation, initial investigations and referral

Presentation

Cancer in AYA presents with a broad spectrum of signs and symptoms, the most common being the presence of a lump or swelling, extreme fatigue and pain. Barriers to timely diagnosis include the rarity of AYA cancer and low index of suspicion, the frequent development of non-specific symptoms, low health-seeking behaviours and a lack of cancer awareness among AYA.

Primary and emergency care providers should seek and promote education/awareness campaigns to understand both the types of diseases seen in AYA, as well as the presenting signs and symptoms to improve time to diagnosis.

Referral options

At the referral stage, the GP or other referring doctor should advise the AYA and, if applicable, their family about their options for referral, waiting periods, expertise, if there are likely to be out-of-pocket costs and the range of services available. This will enable informed choice of specialist and health service.

If cancer is suspected, the GP should have telephone discussions with a health service that has expertise in managing AYA cancer when planning tests and investigations to confirm or exclude a diagnosis of cancer.

For those AYA with a confirmed diagnosis in primary care, the GP should strongly consider referral to a cancer centre with expertise in managing AYA cancers, particularly in the case of paediatric-like cancer types, rare and complex diagnoses and those AYA with complex psychosocial risk.

Communication

The GP's responsibilities include:

- explaining to the AYA and/or their family who they are being referred to and why
- supporting the AYA and/or their family while waiting for specialist appointments
- informing the AYA and/or their family that they can contact Cancer Council on 13 11 20.

Checklist

- Signs and symptoms recorded
- Discussion with a tertiary service undertaken
- Age-appropriate supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Patient notified of support services such as Cancer Council 13 11 20
- Referral options discussed with the AYA and, if applicable, their family including cost implications

Timeframe

Timeframes for completing investigations and referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timeframes for appropriate consultations and treatment in AYA may improve clinical and patient-reported outcomes.

Step 3: Diagnosis, staging and treatment planning

Diagnosis and staging

Work-up should be undertaken by a cancer centre with multidisciplinary experience in managing AYA cancers with access to clinical trials. At times, this may be within a paediatric tertiary cancer centre. This is particularly important in rare tumours, advanced-stage disease or those requiring complex and/or multidisciplinary diagnostic evaluation.

Diagnostic tests and investigations should be informed by evidence-based guidelines or, ideally, as determined by enrolment in the relevant clinical trial. Results should be interpreted by clinicians with experience in the relevant AYA cancer.

Genetic testing

A higher incidence of CPS has been seen in many cancer types in AYA compared with adult populations.

Consideration for referral includes those AYA with:

- atypical age at the time of diagnosis
- excessive, unanticipated toxicity to standard therapy
- family history of childhood/early-onset cancers and/or presence of hereditary factors
- presence of multiple primary cancers
- congenital anomalies or intellectual disabilities associated with a recognised CPS
- diagnostic clues strongly associated with a CPS (e.g. triple-negative breast cancer).

Fertility

- An individualised infertility risk assessment is made by the healthcare team at the time of confirming the prospective treatment plan and is documented
- Discussions about fertility risk and potential interventions such as preservation are part of the informed consent process at the time of diagnosis to facilitate decision making.

Treatment planning

All diagnostic work-up and prospective treatment planning via a disease-specific multidisciplinary meeting (MDM) should happen before starting treatment.

Members of the multidisciplinary team (MDT) must be able to show appropriate expertise/experience in AYA cancer.

Concurrent referral should be made to an AYA-specific MDT that works in partnership with the disease-specific MDM. An AYA MDT will discuss the clinical and supportive care aspects of care, bringing a disease-specific, age-appropriate, psychosocial focus to prospective treatment planning.

Research and clinical trials

AYA are under-represented in clinical trial enrolment, having the lowest rates of participation of any age group. Clinical trial discussions should be part of the MDM agenda for all AYA and be documented. Access to trials may involve referral to or collaboration with an external paediatric or adult cancer centre.

Communication

In collaboration with the AYA care coordinator, the lead clinician's¹ responsibilities include:

- establishing if the AYA has a regular or preferred GP and, if they do not have one, encouraging them to find one
- exploring information preferences and providing age-appropriate written information about the diagnosis, treatment, treatment intent and prognosis
- providing a treatment care plan including contact details for the treating team and information on when to call the hospital
- discussing how they wish to have their family engaged in confidential and private discussions
- discussing the benefits of multidisciplinary care and gaining consent before presenting their case at an MDM.

Discussions around prognosis should be revisited with AYA over time as they become more accustomed to their diagnosis.

Checklist

- Diagnosis confirmed
- Performance status and comorbidities measured and recorded
- Referral to an AYA-specific MDT made
- Patient discussed at an MDM and decisions provided to the GP, AYA and family as applicable
- Clinical trial enrolment considered
- Age-appropriate supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- Patient referred to support services (e.g. Cancer Council) as required
- Treatment costs discussed with the AYA and, if applicable, their family

Timeframe

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timeframes for appropriate consultations can reduce distress.

¹ Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 4: Treatment

Establish intent of treatment

- Curative
- Treatment with uncertain or poor prognosis
- Anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- Symptom palliation

Treatment options in AYA also need to consider the increased risks of late effects and both disease and non-disease related mortality.

Whenever possible, AYA diagnosed with cancer should have a carefully planned path to enrolment in clinical trials for their specific disease.

Palliative care

Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis. Representatives from the palliative care team should be considered core members of the AYA MDT. For more, visit the Palliative Care Australia website <www.palliativecare.org.au>.

Communication

The lead clinician and team's responsibilities include:

- discussing treatment options with the AYA and, if applicable, their family and including the intent of treatment as well as risks and benefits
- communicating the treatment plan to the AYA's GP.

Checklist

- Intent of treatment established
- Risks and benefits of treatments discussed with the AYA and, if applicable, their family
- Treatment plan provided to the GP
- Treating specialist has adequate qualifications, experience and expertise
- Supportive care needs assessment completed and recorded, and referrals actioned
- Early referral to palliative care based on need

Timeframe

Timeframes to treatment should be informed by evidence-based guidelines (where they exist).

Step 5: Care after initial treatment and recovery

Needs at this time include individualised information and advice, counselling and psychological support, and social support/relationships.

AYA with cancer experience the adverse effects of cancer and its treatment at a dynamic time point, impacting on or delaying key developmental milestones. These effects can persist well beyond the completion of treatment.

Provide a treatment summary to the GP, AYA and, if applicable, their family outlining:

- the diagnosis
- staging, grading and/or risk stratification
- the treatment protocol, including clinical trial enrolment if applicable
- chemotherapy (if applicable), including cumulative doses
- radiation therapy, as applicable
- significant morbidities and/or adverse events experienced during treatment
- fertility preservation strategies if applicable
- the treatment end date
- contacts at each speciality service where care was delivered

Provide a follow-up cancer surveillance schedule, including tests required and timing.

Provide a process for rapid re-entry to medical services for suspected recurrence.

Cancer survivorship

At the end of cancer surveillance, a periodic evaluation with a focused history, physical examination and risk-based screening should be facilitated. High-priority targets for consideration include secondary cancers, cardiovascular and respiratory toxicity, endocrine screening and neurocognitive screening.

The survivorship plan should also cover:

- timing for surveillance of potential primary and secondary malignant neoplasms
- timing of evidence-based screening recommendations for potential late effects, tailored to the AYA's disease, treatment and age at diagnosis
- wellbeing, primary and secondary prevention health recommendations that align with chronic disease management principles.

Checklist

- Treatment and follow-up summary provided to the GP, AYA and, if applicable, their family
- On completion of follow-up, a survivorship summary provided to the GP, AYA and, if applicable, their family

Step 5: Care after initial treatment and recovery continued

AYA with a low risk of late effects should be transitioned to their GP with documentation; those with medium risk should be seen within a shared-care model between a cancer survivorship service and their GP. Those with a high risk of late effects (e.g. bone marrow transplant, high-dose chemotherapy and radiation therapy) should remain engaged in dedicated cancer survivorship care.

Communication

The lead clinician's responsibilities include:

- explaining the treatment summary follow-up and survivorship care plan to the AYA and, if applicable, their family
- providing information about secondary cancer prevention and healthy living
- discussing the follow-up care plan with the AYA's GP.

Checklist

- Age-appropriate supportive care needs assessment completed and recorded at both time points and referrals to allied health services actioned as required

Step 6: Managing recurrent, residual or metastatic disease

Detection

Most residual or recurrent disease will be detected via routine follow-up or by the AYA presenting with symptoms.

Treatment

Evaluate each patient for whether referral to the original MDT is appropriate. Treatment will depend on the location and extent of disease, previous management and the AYA's and, if applicable, family's preferences.

Clinical trials

The treatment team should support the AYA to participate in research and clinical trials where available and appropriate. Trials in relapsed refractory cancer for AYA are more readily available but are also more specialised and resource-intensive.

Advance care planning

Advance care planning is important for all AYA but especially those with advanced

disease. It allows them to plan for their future health and personal care by thinking about their values and preferences. This can guide future treatment if the AYA is unable to speak for themselves.

Palliative care

Palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication

The lead clinician and team's responsibilities include:

- explaining the treatment intent, likely outcomes and side effects to the GP, AYA and, if applicable, their family
- maintain open and candid communication with the AYA at all times.

Checklist

- Treatment intent, likely outcomes and side effects explained to the GP, AYA and, if applicable, their family
- Age-appropriate supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
- Advance care planning discussed with the AYA and, if applicable, their family
- Early referral to palliative care if appropriate
- Routine follow-up visits scheduled

Step 7: End-of-life care

Palliative care

Consider a referral to palliative care. Ensure an advance care directive is in place. The treating team need to be aware that the AYA and their family may not have the same level of acceptance.

Communication

The lead clinician's responsibilities include:

- being open and candid about the prognosis and discussing palliative care options with the AYA and, if applicable, their family
- establishing transition plans to ensure the AYA's needs and goals are considered in the appropriate environment.

Checklist

- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Referral to palliative care
- Advance care directive in place

Visit the guides to best cancer care webpage <www.cancercareguides.org.au> for consumer guides. Visit the optimal care pathways webpage <www.cancer.org.au/OCP> for the optimal care pathways and instructions on how to import them into your GP software.

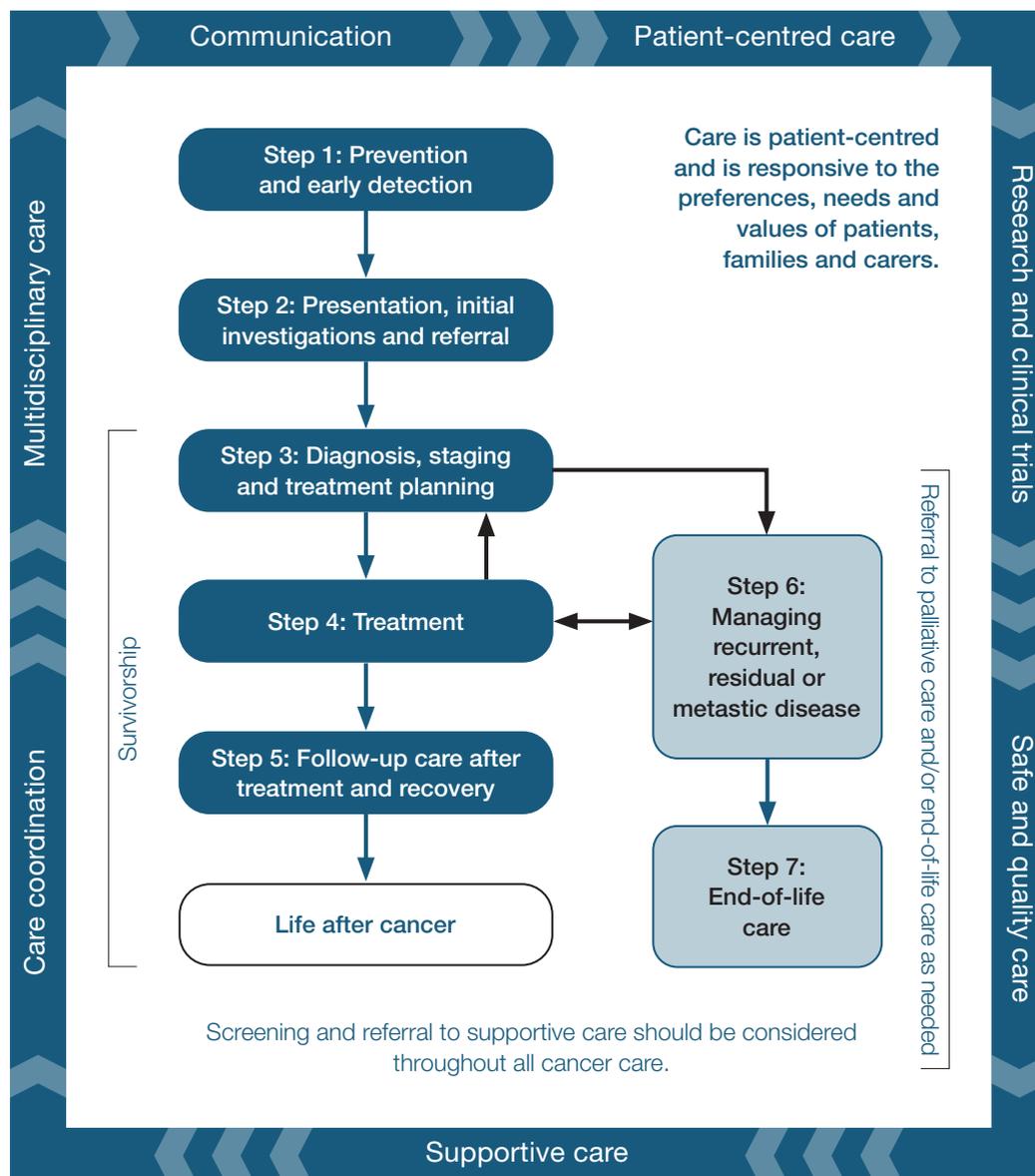
Intent of the optimal care pathways

Optimal care pathways map seven key steps in cancer care. Each of these steps outlines nationally agreed best practice for the best level of care. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (e.g. the type of cancer, when and how the cancer is diagnosed, prognosis, management, the patient's decisions and their physiological response to treatment).

The principles underpinning optimal care pathways always put patients at the centre of care throughout their experience and prompt the healthcare system to deliver coordinated care.

The optimal care pathways do not constitute medical advice or replace clinical judgement, and they refer to clinical guidelines and other resources where appropriate.

Figure 1: The optimal care pathway



Optimal care pathway resources

There are three resources for each pathway: an optimal care pathway, a quick reference guide for health professionals and a guide to best cancer care for patients, carers and families.

Optimal care pathways

This optimal care pathway is designed for **health professionals and health services**. However, **patients and carers** may find useful information in this version to help understand the processes their treating health professionals are following.

This resource aims to:

- assist health professionals to provide optimal care and support to patients with cancer, their families and carers
- provide optimal timeframes for delivering evidence-based care
- emphasise the importance of communication and collaboration between health providers and people affected by cancer
- assist and inform new health professionals or trainees who are entering the cancer care workforce
- provide value to health systems to identify gaps in current cancer services, bring about quality improvement initiatives and improve how services are planned and coordinated. Adherence to the pathways should be measured wherever possible.
- Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways.



Quick reference guides

The quick reference guides are for health professionals and health services. They provide a summary of each optimal care pathway for health professionals and patients.

The quick reference guides include:

- optimal timeframes within which tests or procedures should be completed
- checklists with indicators related to recommendations in the optimal care pathway.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the quick reference guide for this optimal care pathway.



Guides to best cancer care

The guides to best cancer care are **consumer** resources that help patients understand the optimal cancer care that should be provided at each step. Carers, family and friends may also find the guides helpful.

The guides to best cancer care:

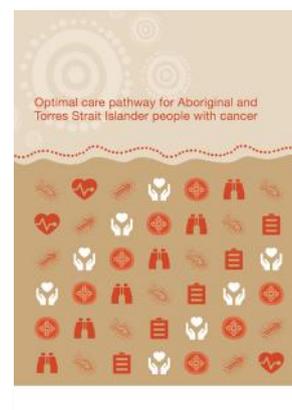
- include optimal timeframes within which tests or procedure should be completed
- include prompt questions to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask
- provide information to help patients and carers communicate with health professionals
- are available in eight languages.

Visit the Cancer Council's website <www.cancercareguides.org.au> to view the guides to best cancer care.

Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* provides a tool to help reduce disparities and improve outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer. This resource can be used in conjunction with the optimal care pathway for each cancer type.

Visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>> to view the optimal care pathway for Aboriginal and Torres Strait Islander people.



Scope

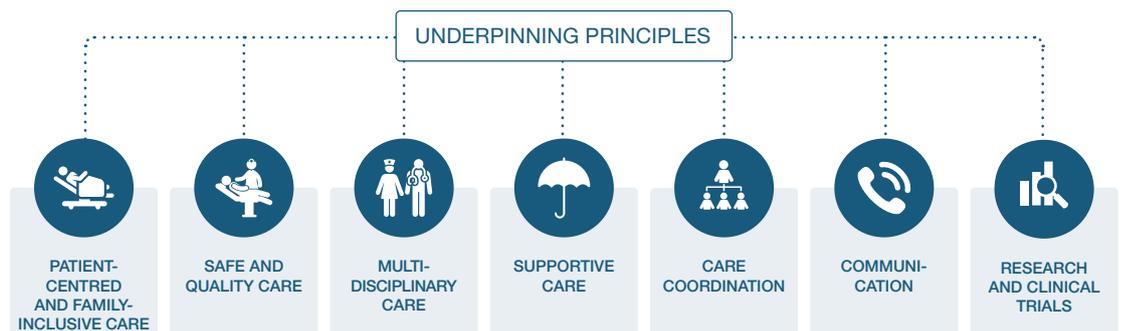
Internationally, the age definition of adolescent and young adult (AYA) oncology is varied and influences the data referenced in this pathway. Within the Australian context, AYA are defined as those aged between 15 and 25, aligned with a focus on key adolescent development.

The abbreviation AYA is used throughout this pathway to refer to adolescents and young adults.

Principles of the optimal care pathway

The seven principles of care define appropriate and supportive cancer care that is the right of all AYA and those caring for and connected with them.

Figure 2: The seven principles underpinning the optimal care pathway



Principle 1: Patient-centred and family-inclusive care



Patient-centred and family-inclusive care informs and involves AYA in their care and respects and responds to the preferences, needs and values of AYA, families and carers.

AYA cancer occurs at the interface between paediatric and adult cancer services.¹ The AYA cohort does not comfortably fit within the family-centred (paediatric), nor disease and patient-focused (adult), models of care.² While limiting important discussions and decision making to parents and caregivers may be appropriate for young children, this approach may threaten the autonomy and emotional wellbeing of an emerging adult. Conversely, the presumption of autonomy and mature decision making, which characterises clinical interactions in adult medicine, and the tendency to focus on the disease more than the person, may neglect the critical psychosocial impact of cancer and treatment on the AYA.³ Ideally healthcare providers should adjust their approach to meet the needs of AYA while also acknowledging the wide heterogeneity of life experiences within this age group.⁴

Health services providing AYA cancer care should adopt a hybrid patient-centred model of care that supports the individual's emerging or established autonomy – a model that can adapt and be receptive to the involvement of parent/carer and significant others according to the life stage⁵ and wishes of the AYA. Care becomes family-*inclusive* versus family-*focused*, modelling the strengths of both paediatric and adult medicine approaches to care.

Referral choices and informed financial consent

AYA and their families have the right to receive the information they need to be able to make an informed decision on where to be referred for treatment. Treating specialists and practitioners should clearly explain the costs or how to find out the costs of services, tests and treatment options upfront to avoid consumers experiencing 'bill shock'.

At the time of referral, the general practitioner (GP) or other referring doctor should discuss the different options for referral, waiting periods, expertise, if there are likely to be out-of-pocket costs and the range of services available. This will enable patients to make an informed choice about their specialist and health service. Referral decisions influence the care patients receive along the pathway and the direct and indirect costs they and their carers may incur. Different referrals have different costs:

- referral to a public hospital, which may involve some costs
- initial referral to a private specialist with associated costs, with the option of ongoing treatment in a public hospital at any time
- referral to a patient's choice of practitioner for immediate and ongoing private hospital management with associated costs.

All AYA and their family should be made aware that even though public hospital health care is 'free' to all Australian citizens and most permanent residents of Australia, there are still associated direct costs such as:

- over-the-counter medication and prescriptions
- wound dressings
- travel costs
- parking fees
- tests that are not covered by Medicare.

A cancer diagnosis and treatment may affect the AYA and their family's income. This is an indirect cost associated with cancer. Social work support is essential to help AYA and their families deal with this issue. AYA and/or their family should be advised to consider the impact of private care with significant out-of-pocket expenses if financially constrained. Specialists in private practice need to explain costs at the start of each new treatment to acknowledge the cumulative out-of-pocket expenses that patients can incur.

It is also important to note that for AYA with cancer, services such as those that meet their unique psychosocial needs are generally provided within the public system, and linkages between the private and public sector need to be defined to ensure those needs are met and a consistent approach to care is provided. Clear referral pathways to public services for psychosocial care should be developed within the private sector.

For more information on informed financial consent see the Cancer Council's *Standard for informed financial consent* <www.cancer.org.au/health-professionals/resources/informed-financial-consent>.

Financial counselling services can provide advice on dealing with financial difficulties. These services can be accessed publicly (via social workers at hospitals, financial counsellors at neighbourhood houses or rural financial aid), privately or through cancer support services such as local charity groups or social work services.

For practical and financial assistance, AYA and/or their family may consider Cancer Council's financial services <www.cancer.org.au/support-and-services/practical-and-financial-assistance>.

Links to other services are provided in the resource list at the end of this document.

Shared care

Shared care for AYA between a cancer specialist and primary/secondary care health professional is delivered in two or more settings by two or more professionals. The primary care provider is usually a GP but can include nurses and allied health practitioners. In some instances, care for AYA with cancer may be shared between a tertiary referral centre and a secondary health service closer to home. Shared care can be delivered throughout the care pathway including during treatment, follow-up care, survivorship care and end-of-life care. Shared care offers several advantages to patients, including the potential for treatment closer to home and more efficient care with less duplication and greater coordination.

Telehealth can enable efficient shared care and should be explored for all patients and offered where safe and practicable. AYA in some rural or remote locations may access specialists via telehealth consultations funded under the Medicare Benefit Scheme. GPs working in rural or remote locations should be aware of specialist multidisciplinary teams with facilities to reduce the travel burden and costs for patients.

Principle 2: Safe and quality care



Hospitals and health professionals are responsible for providing safe and quality care.

Professional development in AYA care

The unique needs of AYA with cancer demand a professional development approach that facilitates a wider understanding beyond the requirements of either a paediatric or adult oncology provider. AYA need to be reassured that health professionals are knowledgeable and competent to deliver age-appropriate care. The demand for specific education programs in AYA cancer is an identified and welcomed need of the oncology community.⁶⁻⁹ Demand for professional development is more important for the large cohort of AYA who are treated in centres that may not have a dedicated AYA service.²

Position statements outlining education requirements for providers¹⁰ have now been further refined¹¹ to delineate skills, knowledge, attitudes and communication competency requirements. Important topics in an AYA cancer education program include:⁷⁻¹²

- AYA cancer epidemiology, biology and treatment
- foundations in general AYA health and the impact of cancer on normal biopsychosocial development
- AYA-specific assessment tools and their application
- legal and ethical issues in AYA cancer care
- providing effective age and culturally appropriate communication
- understanding professional boundary issues in the context of AYA cancer care
- late effects of cancer for AYA, including fertility and mental health considerations.

Strategies to facilitate education include:

- supporting opportunities for staff to experience a specialised AYA cancer service as a means of consolidating skills and developing competency
- using professional competency standards and endorsed position statements to inform institutional AYA cancer professional development pathways and connection to state and national networks of AYA expertise
- promoting access to formal, evidence-based, interprofessional AYA cancer postgraduate programs
- promoting and supporting access to AYA conferences and collaboration with professional groups to cultivate relationships and continuous learning.

Data-driven quality care

Collecting and analysing data relevant to AYA cancer care is necessary to inform evidence-based high-quality care.¹³ Unfortunately, enrolments in clinical trials for AYA remain lower than other age groups,¹⁴ while gaps in high-quality literature persist in areas of supportive care research in AYA such as mental health and wellbeing,^{15,16} digital health,^{17,18} physical activity,¹⁹ primary care,²⁰ adherence²¹ and fatigue.²²

To promote data-driven care, health services should:

- demonstrate active participation in international collaborations and partnerships in developing clinical trials, key performance indicators, datasets and in evaluating interventions through large cohort studies²³
- contribute resources towards the monitoring and reporting of national/international datasets for AYA cancer, including the evaluation of patient outcomes¹³
- ensure all outcome measures to evaluate effectiveness of interventions are well defined and appropriate to age/developmental stage
- provide institutional mechanisms for sustainable monitoring and evaluation of data to inform quality improvement activities in AYA cancer care^{13,24}
- encourage and promote research into longitudinal studies with age-appropriate, patient-reported experience and outcome measures to assess interventions over time²⁵
- include AYA specific sub-groups that sit within existing adult protocols, particularly in areas where it is not feasible to have AYA-specific research²⁶
- provide an institutional environment and resources that actively promotes and supports multidisciplinary research into AYA cancer.

Patient-reported experience and outcome measures

Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) should be incorporated into routine AYA cancer care.

PREMs are used to obtain patients' views and observations on aspects of healthcare services they have received. Patient experience data is collected for specific services and then relayed to service providers to instigate improvements in patient services.

PROMs measure aspects of a person's health status such as symptoms, quality of life and needs and are collected directly from patients either online, via a smartphone or through paper-based means.

Collecting PROMs, and then instigating an appropriate clinical response, has been shown to prolong survival, reduce health system use and improve patients' quality of life.

Health services should ensure well-defined, age-appropriate patient-reported outcome measures validated within this cohort are considered to inform optimal care.

Principle 3: Multidisciplinary care



Multidisciplinary care is an integrated team approach that involves all relevant health professionals discussing all relevant treatment options and making joint recommendations about treatment and supportive care plans, taking into account the personal preferences of patients.

Multidisciplinary care improves patient outcomes. Cancer Australia's 'Principles of multidisciplinary care' provide a flexible definition, allowing services to vary implementation according to cancer type and the service location and context. The principles stipulate:²⁷

- a team approach that involves core disciplines that are integral to providing good care, including general practice, with input from other specialties as required
- communication among team members about treatment planning and follow-up plans
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution (for AYA this may be via referral)
- care delivery in accordance with nationally agreed standards
- patient involvement in decisions about their care.

Key considerations and components of AYA multidisciplinary cancer care include:

- unique specialised teams that meet the needs of the AYA at critical time points, including at diagnosis when establishing the treatment plan, during treatment to meet supportive/psychosocial care needs, during survivorship and/or end-of-life care²⁸
- considerations such as fertility, sexual function and identity, educational and vocation advisors, nurse navigators/coordinators and mental health, and disruption to education and employment.^{9,29}

See Appendix C: 'Members of the AYA multidisciplinary team' for core members of an AYA multidisciplinary team.

Multidisciplinary meetings, often called MDMs, should be based on the principles outlined above.

For more information on the principles of multidisciplinary care and the benefits of adopting a multidisciplinary approach, see Cancer Australia's 'Principles of multidisciplinary care' <www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care/all-about-multidisciplinary-care/principles-multidisciplinary-care>.

Principle 4: Supportive care



Supportive care is a vital part of any cancer treatment program. Supportive care deals with issues that emerge for AYA, their families and carers from the effects of the cancer diagnosis and its treatment. It is made up of all the services, information and resources they need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis. Meeting the supportive care needs of AYA with cancer is one of the most essential indicators of quality AYA cancer care.³⁰

AYA are a heterogeneous group, with variability in psychosocial development, maturity and life experience, all within a single cohort.² A diagnosis of cancer occurs at a time of critical transformation in growth, development and identity formation.³¹

Key supportive care needs identified during this period include social relationships and supports;^{32,33} age-appropriate information, healthcare facilities and communication;^{25,34} education/vocational support;³³ and mental health needs.

Key review points

The treatment team should assess AYA (and, if applicable, their family) for supportive care needs at these key stages:

- initial presentation or diagnosis
- the beginning of treatment, a new phase of therapy or a new treatment modality
- significant change in prognosis
- rites of passage such as final exams, formals/graduation, birthdays and other missed opportunities that may lead to increased distress or anxiety
- if an AYA is found to have an underlying germline genetic mutation predisposing to cancer
- end of treatment
- throughout survivorship as any new issues emerge
- during transition to an adult service (if applicable)
- following significant adverse events
- diagnosis of disease recurrence or treatment failure/refractoriness
- significant change in, or development of, new symptoms
- transition to end-of-life care
- other time points based on clinical judgement.

Assessment tools

Assessment tools in supportive care should be evidence-based, age-appropriate for the AYA cohort and applied by clinicians with experience in their implementation. Some examples of AYA-specific tools include:

- HEEADSS assessment^{35,36}
- AYA psychosocial screening tools^{37,38}
- the adolescent young adult psycho-oncology screening tool (AYA-POST)³⁹
- an assessment tool and care plan specifically focusing on end of treatment and survivorship, the Adolescent and young adult oncology psychosocial survivorship care process manual, used widely in Australia.⁴⁰

Health services should also consider the use of patient-reported outcome measures, validated within AYA, to facilitate supportive care assessment.

Following assessment, it is important that a care plan is developed in collaboration with the AYA and, with consent, circulated to the wider team,³⁷ which may include external services providing care such as radiation oncology or surgery.

Educational and vocational needs

A diagnosis of AYA cancer and its treatment can disrupt education and vocation pathways⁴¹ and make reintegration after treatment challenging.⁴² AYA report difficulties in employment, educational attainment⁴³ and financial stability and describe the feeling of being 'left behind' by their peers.³³ For many AYA, there are significant delays to achieving pre-diagnosis educational or vocational goals.⁴⁴ Support for education and career development is a significant need in this population.^{32,44-46} AYA who receive formal assistance describe feeling more supported and remain engaged in work and studies,^{44,47} a factor critical to optimising long-term success.^{48,49}

Educational and vocational interventions should include:

- referral at diagnosis to a dedicated education and/or vocational support person, ideally within the context of a formal program,⁴⁷ as well as for those entering a survivorship program
- school re-entry for adolescents, as applicable, remaining part of the prospective care plan
- supporting efforts/interventions that promote continued engagement with school and/or work during treatment.

Exercise and nutritional needs

Diagnosed at an early age, AYA survivors will experience many years of life living with elevated risks of health problems⁴¹ including risk of relapse, secondary cancers and metabolic syndrome. Some of these are modifiable risk factors that can be mitigated through promotion of exercise and healthy nutrition.⁵⁰

During treatment, AYA frequently experience malnutrition⁵¹ and may negatively influence outcomes.⁵² Effective nutritional support can reverse malnutrition associated with disease and treatment and improve quality of life,⁵³ although nutritional interventions are not always provided appropriately.⁵¹ AYA with cancer also report significantly worse physical health than their matched peers.⁴³ Physical activity and nutrition during treatment has been described by AYA as serving a positive physical and psychological function.⁵⁴

A diagnosis of cancer, however, can be a barrier to achieving adequate levels of exercise and nutrition,^{52,55–57} and access to age-appropriate exercise and nutritional supports have been described as significant unmet needs.^{25,34,46,51,58} Exercise and nutritional interventions promote weight loss⁵⁹ and healthy dietary behaviours in AYA.^{60,61} Physical activity programs following cancer treatment appear to accelerate improvements in cardiorespiratory fitness in AYA, while exercise during cancer treatment has been shown to be feasible and safe in other age groups, with possible benefits on fatigue and quality of life.⁶²

Health services should be able to demonstrate:

- an inpatient environment that promotes physical activity⁴¹
- real-time access to dietitians and exercise physiologists or physiotherapists with experience or knowledge in AYA developmental needs²⁹
- age-appropriate physical activity programs that meet the preference of AYA; these may not necessarily be hospital-based⁵⁸
- the development, advocacy and implementation of health policy that supports healthy eating and physical activity⁵⁰
- access to resources and systems (including assessment tools) that address the physical and psychosocial barriers to physical activity and nutrition experienced by AYA.^{63,64}

Informational needs

High informational needs are consistently identified in AYA with cancer and their families but often remain unmet.^{25,34,46,65–67} High levels of unmet informational needs are associated with reduced health-related quality of life⁶⁸ and an increased level of psychological distress.^{34,69} Unmet needs can remain consistent over time⁶⁵ and may also be a contributing factor to treatment non-adherence.⁷⁰ Reduced patient engagement is also associated with unmet informational needs,^{34,71} and interventions that promote therapeutic engagement and resilience may improve this.⁷² Strategies that reduce psychological distress may also reduce unmet informational needs.³⁴ Significant differences in informational needs have also been demonstrated in AYA compared with the adult cohort.⁶⁶

To meet the informational needs of AYA and their families, health services should:

- provide access to developmentally appropriate information, tailored to the young person's learning needs, at critical time points including diagnosis, new phase of treatment or new treatment modality, end of treatment, transition and survivorship
- focus on a variety of modalities for learning, including face-to-face, peer-to-peer, online and social media components
- provide resources and strategies that aim to alleviate psychological distress and promote patient activation and engagement
- explicitly target and prioritise information sharing with poorly engaged AYA
- acknowledge that a hybrid model of both patient- and family-centred care may be necessary to meet this need
- be aware of and respond to the unique needs of AYA and their families with cultural and linguistic diversity (see Appendix A).

Psychological needs

The trajectory of rapid psychological and emotional growth during the AYA years is a critical but complex part of normal development.³¹ Disruptions in this trajectory, coupled with a greater physical burden, risk of neurocognitive sequelae of disease and treatment, fear of relapse, changes in body image, infertility risk, impact on sexual health and development, social disconnection and disruptions to education all contribute to psychological distress.^{29,73,74} Within the general Australian population, those between the age of 16 and 24 have the highest proportion of mental health or behavioural conditions.⁷⁵ AYA with unique pre-existing neuropsychological profiles (e.g. autism spectrum disorder) are also vulnerable groups who may need increased supports to facilitate accurate assessment and communication, support adherence and reduce the impact of cancer and treatment on the patient.⁷⁶ Special population groups, as outlined in Appendix A, as well as AYA with intellectual disability, may also experience higher incidence of distress and demand increased support.

Consequently, compared with healthy controls and other cancer groups, there is an increased risk for psychological distress^{16,66,77,78} and poorer self-reported mental health⁴³ in AYA with cancer, which for many continues throughout survivorship.^{79,80} Up to one-third of all AYA with cancer (and their parents) in Australia may experience moderate to severe anxiety/depression.⁸¹ There is also a higher risk of anxiety and mood disorders in survivorship¹⁶ and symptoms of post-traumatic stress disorder.^{74,81} Access to psychological counselling and support services is rated as very important by AYA with cancer;⁸² however, many may not receive adequate psychological care, intensifying the problem.^{31,73}

Interventions and preventative strategies for providing optimal psychological care include:

- for all new diagnoses, using psychosocial assessments such as HEEADSS and AYA-POST to determine referral for at-risk AYA for psychological/psychiatric supports^{39,83}
- providing a neuropsychology assessment in young AYA (< 21 years) for risk populations such as those with a history of a central nervous system tumours and those who received craniospinal radiation therapy and/or intrathecal chemotherapy²⁹
- offering tailored, developmentally appropriate interventions to address psychological needs, which may include peer interactions, creative expression (e.g. art and music therapy), promoting AYA-clinician interactions with increased decision making, promoting physical activity, individual coaching and engaging technology⁸⁴
- involving mental health clinicians with experience in AYA cancer care as part of the multidisciplinary team (they should be accessible throughout the cancer care continuum)
- providing patients exhibiting emotional distress (e.g. depression and anxiety) or pre-diagnosis mental health conditions (e.g. autism spectrum disorder) with timely access to specialised mental health teams²⁹
- having AYA with pre-existing intellectual disability, and their family/carers, collaborating with the health service to develop tailored care plans⁸⁵
- including long-term mental health surveillance in survivorship.⁷⁹

Practical needs

Supporting practical domains, such as within the home environment, transportation and financial security,³¹ are an important need and area of concern for AYA with cancer.⁶⁶ These needs continue after treatment⁸⁶ and are more often unmet for AYA treated in adult centres versus the paediatric setting.⁴⁶ Threats to the management of practical needs due to a diagnosis of cancer may re-establish a reliance on parents at a point of emerging independence.³³ Financial distress has been associated with poorer quality of life and social wellbeing in AYA with cancer.³³

Effective management of practical needs includes:

- timely referral to both social workers and AYA coordinators at the time of diagnosis
- undertaking a psychosocial assessment at the time of diagnosis to guide practical support needs and interventions, including those promoting financial self-efficiency
- assessment of practical needs during treatment, at relapse (if applicable), coming off treatment and in survivorship.

Principle 5: Care coordination



Care coordination is the responsibility of every professional, both clinical and non-clinical, who works with patients, their families and carers.

Seamless care coordination is essential for patients to successfully navigate the complex health system. Care coordination is a comprehensive approach to achieving continuity of care for patients. It aims to ensure care is delivered in a systematic, connected and timely way that promotes efficiency and reduces the risk of duplication and over-servicing to meet the medical and personal needs of patients.

Effective care coordination for AYA is a comprehensive whole-of-system approach encompassing multiple aspects of care delivery.⁸⁷ Central to this, however, is the role of the AYA care coordinator. An AYA coordinator provides continuity in what is often a fragmented and complex healthcare system.^{88,89} AYA with cancer prefer an individualised approach that acknowledges and responds to their competing psychosocial commitments;⁹⁰ these needs may be distinct to the adult cancer population.⁶⁶ In an era of personalised medicine and increasing complexity of treatment, effective care coordination will become more important.⁹¹

Optimal AYA care coordination provides information, emotional support, empowerment, patient advocacy and development of health literacy, with a physical presence at key time points throughout the care continuum.^{88,89,92} Using a cancer coordinator has been shown to proactively orientate patients to resources tailored to their needs⁹³ and improve patient satisfaction.⁹⁴ It is considered a critical component of a specialised, AYA cancer service.^{4,30}

Health services providing AYA cancer care should:

- allocate resources for a dedicated patient coordinator as part of their strategic and business plans¹³
- prioritise these resources at critical time points in the care continuum
- gather stakeholder perspectives on institutional barriers to optimal AYA care and expectations of the role when developing local care coordinator position descriptions⁹⁵
- ensure a realistic caseload limit due to the increased and varied psychosocial demands of this cohort⁹⁰
- ensure integration with the wider network of AYA healthcare workers and expertise.

It is important to note that in low-volume health services that do not have a dedicated AYA coordinator, there should be a responsible member of the team who is clearly defined to provide this role. This may often be the AYA's GP.

Principle 6: Communication



Everyone employed in the healthcare system is responsible for ensuring the communication needs of AYA, their families and carers are met.

Effective communication is a complex but crucial element of an optimal AYA model of care.^{2,11,63} Effective and creative communication from youth-friendly healthcare providers is a primary indicator of quality care and facilitator of information sharing from patient-reported experience measures.^{25,96}

In a cohort of 'digital natives', communication should also embrace a digital-enabled culture of targeted communications and interventions.^{17,97} This approach has demonstrated early success in this population⁹⁸⁻¹⁰⁰ but remains to be implemented and evaluated at scale.¹⁷

For many healthcare providers, however, communicating with AYAs with cancer can be a difficult process³¹ and, as such, is a key topic in AYA cancer professional development and training.¹⁰

Challenging topics and time points in communicating with AYA include prognosis, fertility, sexual health, sexual and gender diversity, financial supports, end of treatment, transition, survivorship and end-of-life care,¹⁰¹⁻¹⁰⁴ as well as mental health and drug use/abuse. Complex topics such as these will also require an assessment of health literacy to enhance communication.¹⁰⁵

Strategies to enhance effective communication include:^{2,10,31,98,106}

- communication that is respectful of the emerging autonomy of the younger AYA
- culturally and age-appropriate communication that retains the professional boundary of the clinician
- use of tools that support assessment of health literacy and reinforcement of learning,¹⁰⁵ such as the teach-back method¹⁰⁷
- discussions that incorporate peer supports, family members and/or partners as desired by the AYA
- where applicable, directing discussions towards AYA without excluding parents
- providing a 'time alone' model with younger AYA
- tailoring the communication to meet the individual AYA's needs
- allowing time to process information and promote active listening
- embracing technology-based, digital interventions in communication
- promoting a risk-reduction approach that facilitates two-way dialogue
- facilitating and promoting clear referral pathways to other age-appropriate resources wherever possible
- youth-friendly communication training as a mandatory professional development requirement for those working regularly with AYA
- being aware of and responding to the unique needs of AYA and their families with cultural and linguistic diversity (see Appendix A).

Principle 7: Research and clinical trials



Research and clinical trials play an important role in establishing the efficacy and safety of diagnostic, prognostic and therapeutic interventions, as well as establishing the role of psychological, supportive care and palliative care interventions.¹⁰⁸

While enrolment in clinical trials correlates with improved overall survival,^{109,110} it is not the single end point; there are many other benefits to the patient, the institution and the AYA cancer community. Clinical trial enrolment provides access to: investigational therapies; biobanking of specimens to promote basic, translational and clinical research within a cohort of patients with unique tumour biology; and cancer control, epidemiological and supportive care studies.¹¹¹ Benefits of clinical trials also include:¹⁰⁹

- having a standardised protocol and guideline (including dosing and toxicity support)
- access to a wider network of experienced AYA clinicians
- demand for precise tumour staging and evaluation
- the oversight for timeliness of therapy administration, compliance and toxicity reporting.

Unfortunately, AYA are under-represented in clinical trial enrolment,¹⁴ having the lowest rates of participation of any age group. This may have contributed to slower improvements in survival relative to younger children and older adults. Lack of clinical trial enrolment has been shown to be an independent predictor of relapse when compared with childhood cancer in some disease sub-groups.¹¹² To date, both in Australia and internationally, some effort, but little progress, has been made to increase trial participation, particularly in the older AYA group.¹¹³ Emblematically, the lowest point for clinical trial accrual overall occurs at the peak age prevalence of AYA cancer.¹⁰⁹

Barriers to AYA enrolment are multifactorial and occur at the system, institution and individual level.¹⁴ As such, the desire to increase AYA participation in clinical trials continues to be a key recommendation for providers and policymakers.^{13,24,29,41}

Increasing participation in clinical trials includes allocating resources, infrastructure, workforce, advocacy in trial design and/or strategies towards:^{9,14,26,111,114–116}

- broadening the age eligibility of current and prospective clinical trials
- greater flexibility for paediatric institutional age limits to increase access for older AYA
- increasing the number and availability of trials in the AYA cohort
- paediatric–adult communication and collaboration, including joint AYA tumour boards, governance and cross appointments, and referring on, if appropriate, to where the clinical trial may be open
- appointment of clinical trial investigators as part of the AYA multidisciplinary team
- understanding the decision-making processes for AYA to enrol on clinical trials
- improving access to and content of age-appropriate patient education resources
- professional development opportunities that support how best to advise AYA patients in clinical trial participation
- examining other potential institutional barriers within the health service.

Health services should also strive to implement policies and procedures that facilitate equitable access to clinical trials for all patients, including culturally diverse patients, regional patients and those from Aboriginal or Torres Strait Islander communities.

Supporting the delivery of optimal care for AYA with cancer: further considerations

This section provides further information and guidance about unique concepts in AYA cancer care, addressed under three main themes: health system approaches, developmental considerations and medical considerations. This information is likely to be relevant across all steps in the care pathway.

Unique health system approaches

The following considerations outline unique demands of the health service to ensure the delivery of optimal AYA cancer care. A good example where health services have been specifically developed in Australia with the aim to meet these challenges is the national network of Youth Cancer Services. The Youth Cancer Services were established in 2010 in Western Australia, New South Wales, Queensland, Victoria and South Australia, with outreach to Tasmania, the Northern Territory and the Australian Capital Territory to provide oversight of specialised hospital-based treatment and support services for young people with cancer. In addition to providing high-quality, age-appropriate cancer care, Youth Cancer Services provide leadership and support to other health professionals and services. This enables young people to access high-quality care, highly skilled teams, resources, research and support within cancer service networks across Australia.

Environment and approaches to care

A diagnosis of cancer places the AYA in an environment that is not aligned to their life stage or expectations. A lack of age-appropriate facilities in healthcare environments has been consistently identified as a critical, unmet need.^{25,117} The environment contributes to the culture of AYA cancer care (both positive and negatively), particularly the care beyond immediate clinical needs.¹¹⁸

Research suggests that hospital environments can facilitate optimal AYA care through three main strategies: providing the patient with a sense of control, access to positive distractions,¹¹⁹ and access to social (non-professional) supports.¹²⁰

Development of the healthcare environment should promote both a sense of normalcy and the ability for the AYA to continue to achieve tasks and include age-appropriate activities. This includes:^{1,3,4,9,41,96,118,119,121,122,123}

- collaborating with, and visits to, high-volume cancer centres that provide AYA cancer care to support informed planning of inpatient and outpatient settings for AYA cancer care
- encouraging co-design with AYA cancer patients in planning and development of physical environments
- ensuring that private, therapeutic conversations can be undertaken safely when required
- encouraging use of contemporary decor and age-appropriate interior design that disrupts the homogeneity of standard hospital environments

- actively promoting the personal ownership of particular environments, particularly in the inpatient setting (e.g. using personal items such as pillows, throws and photos)
- providing a dedicated area that promotes social interaction and peer relationships in both inpatient and outpatient settings that is both temporally and spatially located away from paediatric and adult patient populations
- providing appropriate support for privacy when needed, such as private bathrooms and bedrooms, particularly within the inpatient environment
- providing access to positive distractions for AYA, such as high-speed internet, music and IT infrastructure (health services should be able to adapt to changes in AYA preferences)
- providing flexible care that is aligned to individual versus hospital routines such as later bedtimes, 'sleeping-in', flexible visiting hours and dedicated time to socialise with peers.

It is also important to acknowledge that the environment of a dedicated AYA cancer unit in a large metropolitan tertiary service is not directly translatable to smaller (particularly regional) health services. Downscaling the essential elements (while maintaining key clinical aspects and approaches to AYA care discussed herein) may be a viable alternative⁴ while also supporting care closer to home.

Centralised care

In AYA cancer, decisions around location of care can vary according to the disease, local psychosocial supports and the institutional facilities.²⁹ The rarity of some tumour types may be best managed by high-volume, specialised centres with appropriate expertise and experience in treating cancer in this population.¹ There may also be an advantage from centralised review, volume effect and/or treatment facility type in some tumour types seen in AYA.^{124–133}

Centralised review and evaluation (including age-appropriate psychosocial evaluation) is recommended for all new diagnoses²⁹ (particularly those requiring systemic and/or multimodal therapies) and should incorporate an AYA cancer MDM.

Centralised care is recommended for AYA who:

- need extensive diagnostic evaluation¹⁹⁵
- have advanced-stage disease¹⁹⁵
- require complex inpatient and ambulatory therapies¹³⁴
- who are diagnosed with disease groups such as bone and soft tissue sarcomas¹³⁵
- develop cancer during pregnancy
- have complex paediatric-like cancers²⁹
- have significant pre-existing comorbidities.

Primary care engagement

The GP is often the first encounter with a healthcare provider for AYA with cancer. Throughout the cancer care continuum, the GP provides an educational and counselling role, as well as a coordination of referrals.¹³⁶

The GP may be used pre-diagnosis,¹³⁷ but their ongoing role during cancer treatment in AYA is uncommon,^{20,136} and efforts to encourage a shared care model between the cancer service and primary care during active treatment may not be effective.¹³⁸ Despite this, there is a willingness from GPs to engage after treatment and provide an active role during survivorship, including providing care for AYA survivors of childhood cancer.^{139–141} Coordination between the GP and the cancer service is seen as a key component of survivorship care. The GP is also best placed to continue the management of pre-existing comorbidities and some treatment-related sequelae as defined by the cancer service, as well as referrals for AYA and their family for psychosocial or practical support.¹⁴² There is also the critical role in psychosocial support of the family: the GP often knows the family and patient history well,¹⁴² describing themselves as ‘caring for patients with cancer versus providing cancer care’.¹³⁹

Barriers to engagement with primary care include AYA who do not have an existing or solid relationship with a GP, mistrust established during the diagnostic period, inadequate GP training in AYA needs and oncology, the lack of a clearly defined role for the GP, limited access to guidelines/protocols, and ineffective or delayed communication from the cancer service.^{139,140,143}

Strategies to facilitate engagement with primary care include:^{139,143}

- proactively encouraging those AYA who do not have a GP to identify and access one
- encouraging younger AYA to access their own Medicare card to support their autonomous engagement with their GP
- including the GP as part of the healthcare team from the point of diagnosis
- encouraging the patient to maintain regular visits with their GP, including for managing any comorbidities
- encouraging additional training for GPs around the unique needs of AYA and AYA cancer
- directly contacting the GP immediately following diagnosis, any changes in prognosis, at the end of treatment or the need for palliative care referral
- providing summarised documentation during treatment
- providing direct electronic and phone communication channels with primary care, including rapid referral processes to reduce delays to diagnosis
- developing interventions that avoid placing the responsibility of communication on the patient (this may include providing a shared care plan or shared access of the patient’s electronic medical record)
- providing a treatment summary and survivorship roadmap to the GP at the end of treatment
- identifying the pathway of communication and handover of care with the AYA at the end of treatment and through survivorship.

Collaboration between paediatric and adult sectors

Optimal AYA cancer care requires bridging the 'AYA interface' through collaboration and is a critical function of an effective AYA program. The clinical setting may also determine the access (or barriers) to clinical trials.^{14,114,144} Research suggests the influence of the adult or paediatric site and approach to care may also determine outcomes (e.g. where some AYA cancers are best treated on paediatric protocols)¹⁴⁵⁻¹⁴⁸ and that formal, collaborative programs may improve outcomes such as access to clinical trials.¹⁴⁹

Survival, however, is not the unique end point; services also need to bridge the unique biopsychosocial needs of this group¹⁵⁰ to ensure optimal quality of life following treatment.

To improve collaboration across paediatric and adult cancer settings, health services should demonstrate:

- a dedicated program for transition of adolescent patients¹⁵¹
- the development of joint tumour boards to discuss new AYA diagnoses to determine the optimal treatment site, not only for overall survival but quality of survival and the patient experience of treatment^{26,150}
- the provision of cross-campus appointments of key personnel including oncologists, AYA coordinators and allied health staff
- a systems-level approach to clinical trial governance across both the adult and paediatric sector, including facilitated craft groups to support relationships.²⁶

Transition of health care between services

Transition is 'an active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centred to adult-oriented healthcare systems.'¹⁵²

Transition from the paediatric to the adult healthcare sector occurs as adolescents are becoming more independent.¹⁵³ This can be a vulnerable time point not without its inherent risks, including challenges of treatment non-adherence, disengagement from health care and loss to follow-up.¹⁵⁴ Compounding this is the issue of whether the adult service is able to manage the needs of the AYA,¹⁵⁵ with the intensive supportive care needs provided by the paediatric cancer service generally not replicated in the adult sector. A landmark paper noted that only 18 per cent of childhood cancer survivors report adequate follow-up specifically related to their cancer diagnosis and treatment,¹⁵⁶ warranting a collaborative and careful approach.

An effective transition program provides seamless continuity of high-quality care¹⁵¹ that includes:

- decisions around location of adult care for childhood cancer survivors; for example, diseases or therapies with a high-risk of late effects (e.g. central nervous system tumours or haematopoietic stem cell transplantation) may be best placed in an adult oncology tertiary centre, while low-risk patients may be better placed with their GP, when supported by appropriate documentation¹⁵⁷
- avoiding transition at vulnerable developmental or disease time points such as at relapse or when entering palliative care⁴¹
- avoiding transition close to stressful life events such as final high school exams
- a clearly identified patient navigator and written information to support transition¹⁵⁸⁻¹⁶¹
- an early and gradual process (with a defined time point for transfer from the paediatric service) whereby the adolescent (and their family) can become more independent and confident with the decision¹⁵⁸
- anticipatory educational opportunities that enable the AYA to advocate for risk-based cancer follow-up¹⁵⁷ (AYA with higher perceived vulnerability and understanding of late effects are more likely to engage with cancer-related healthcare visits)¹⁶²
- education opportunities that promote self-management based in understanding of the differences between paediatric and adult health care¹⁵¹
- a treatment summary (including cumulative doses and complications of treatment) and a tailored clinical surveillance roadmap
- a joint clinic appointment with both paediatric and adult providers in anticipation of and immediately prior to transfer.¹⁵⁹

Importance of co-design in AYA cancer care

Co-design is a method of human-centred design where new approaches to services are created with the people who use or deliver those services.¹⁶³ Co-design in health care involves patients and carers working in partnership with staff to improve services.¹⁶⁴

Co-design is widely used in healthcare research¹⁶⁵ and service improvement.¹⁶⁶ In health care, co-design demands a radical reconceptualisation of the role and responsibility of the patient.¹⁶⁴ Co-design can inform patient and provider education and policies and enhance service delivery¹⁶⁷ by offering a richer, deeper understanding of what consumers know and feel.¹⁶⁶ Co-design in research can also reduce the misalignment between the researcher's aims and the end-user needs to create meaningful benefits for patients.¹⁶⁵

In the unique field of AYA cancer, patients and their families will, over time, acquire a deep experience that, with support, will equip them to contribute to improving all aspects of patient care.²⁴ The perceptions and priorities of physical and psychosocial care of the AYA may be distinct to that of the healthcare provider.^{168,169} Co-design has been a feature of the development of Youth Cancer Services in Australia.¹¹⁷ In time, the focus on embedding co-design in practice may in fact be preferable to simply collecting more data on the patient experience.¹⁶⁴

Services caring for AYA with cancer should adopt co-design methodology in their practices in both AYA research and service improvement. This should also incorporate and acknowledge the experience of bereaved families.

Unique developmental considerations

Ethical and legal concerns

Treating cancer in AYA poses unique legal and ethical dilemmas that challenge AYA, clinicians and families. Care is required when considering the emerging autonomy of younger AYA tasked with the complexities of treatment decision making. Supporting active participation in treatment decision making can increase a sense of control, increase autonomy and promote adherence to treatment.^{170,171} Unresolved discord in treatment decision making may affect family cohesiveness and the AYA's self-management.¹⁷⁰

Ethical and legal issues experienced in the care of AYA with cancer include:¹⁷²

- emerging autonomy and treatment decision making
- consent and/or assent
- privacy and confidentiality
- genetic testing (particularly in adolescents tested for older adult-onset cancer risk)
- fertility preservation
- truth telling in the context of poor prognosis
- treatment adherence, care refusal or abandonment (particularly in the context of patient and parent discord)
- participation in early-phase clinical trials
- decision making in end-of-life care.

Health services should ensure the following:

- All adolescents are encouraged to actively participate in treatment decision making.
- Clinicians have strategies in place to support young people's capabilities to engage in decision making in ways that they are comfortable with.¹⁷³
- Ethical and legal advice should be available to the service in real time to support decision making.
- Age-appropriate patient information and consent forms should be available for all clinical trials and research involving AYA.
- Advance care planning should be instigated early in the setting of relapse or poor prognosis in a way that is well supported and acceptable to the young person and allows health services to provide best care.
- There should be an individualised approach for younger AYA to support participation in decision making.
- The application of an arbitrative model to resolve decisional conflict between the AYA and the parent in a balanced way.¹⁷⁰
- Duty of disclosure and honest communication is strongly encouraged.

Body image

AYA is a period of key identity development where body image plays a central part.¹⁷⁴ Factors associated with negative body image in AYA with cancer include weight loss/gain;¹⁷⁴ major disfiguring surgical interventions; changes to hair, nails and skin (including scarring); being female;^{174,175} presence of central lines and tubes; and impaired physical, cognitive and sexual functioning.^{1,174,176,177} These changes are not always systematically addressed by the health care team.¹⁷⁶

Impaired body image may lead to a loss of identity,^{177,178} social avoidance¹⁷⁴ and impact on the ability to develop relationships.¹⁷⁹ These changes may contribute to distress for AYA with cancer⁸¹ and be a source of low self-esteem.¹⁸⁰ The potential impact on body image in AYA may even contribute to treatment decisions and adherence to therapy.¹⁷⁶

To address the impact of body image, health services should:

- provide assessments and offer in-depth discussions to at-risk AYA about the values, concerns and risks of body image¹⁷⁴
- offer anticipatory guidance, education and the opportunity to explore potential body image changes throughout treatment¹⁷⁴
- promote psychological coping mechanisms such as positivity, self-compassion and humour¹⁷⁶
- provide surveillance, health promotion and early interventions to reduce the impact of impaired body image during treatment and in survivorship¹⁷⁵
- offer educational and psychological care that enhances self-confidence and esteem
- allow flexibility in established clinical routines that may exacerbate issues of body image such as undressing for clinical examinations and procedures.

Sexuality and sexual health

Developing sexuality, interest and orientation is an important part of adolescence and young adulthood^{41,181} and a core component of a young person's evolving identity. Sexual health is a vital aspect of health-related quality of life in AYA.¹⁷⁹ A diagnosis of cancer during the AYA period can have a significant negative impact on certain domains of sexual function¹⁸² and psychosexual development.¹⁸³

Discussions regarding sexuality and sexual health in AYA cancer care are often overlooked,¹⁰¹ despite evidence that sexual intimacy remains common among AYA during treatment.¹⁸⁴ Without appropriate counselling, some risk-laden behaviours may potentially exacerbate complications of therapy.¹⁰⁶ AYA providers in paediatric services describe barriers to communication such as lack of knowledge, discomfort and parental presence.¹⁰³ Further disparity exists for sexually and gender-diverse AYA, due to issues such as fear of disclosure,¹⁸⁵ lack of inclusive talk by providers¹⁸⁶ or safe spaces for conversations.²⁹ Unmet needs described by AYA related to sexuality include fertility concerns, sexual communications, dealing with side effects, dating and disclosure to partners.¹⁸³ Research has also demonstrated that up to 50 per cent of young adults report problems with sexual functioning in the first two years after a diagnosis of cancer.¹⁸⁷

Strategies to ensure needs relating to sexuality and sexual health are met include the following:

- The range of sexual health topics should be addressed confidentially with the young person alone, without their parents or partners. It may also be appropriate to have subsequent discussions with parents or partners if desired by the AYA.
- Sexuality should form part of the multidisciplinary care, initial assessment and history taking for all AYA.⁶³
- Sexual health discussions directed at AYA include promotion of safe sex during treatment, pregnancy risk, potential impact of cancer and treatment on sexuality and sexual function, fertility issues, approaching discussions with their sexual partner and where to access further information.^{41,70}
- Incorporate the described unmet needs from the literature regarding sexuality into AYA screening tools and care plans.¹⁸³
- Implement education and support needs for providers to improve sexual health communication¹⁰³ and referral to appropriate services.
- Use modelling systems such as Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) to inform and facilitate discussions with AYA around sexuality.
- Use an AYA program / treatment team that can provide additional education and supports beyond that of the primary treatment team.¹⁸⁸
- Use inclusive and non-heterosexist language when discussing sexuality for all AYA.²⁹
- Have clear referral pathways if identified concerns regarding sexuality and sexual health lie outside the expertise of the team.

See Appendix A: 'Special population groups' for more information on sexually and gender-diverse AYA.

Fertility preservation

The effects of cancer and its treatment on fertility are well documented.^{189–191} AYA with cancer express a high level of concern about reproductive risk^{192–196} and consider it a priority issue.²⁵ AYA value the opportunity to discuss fertility and preservation at the time of diagnosis^{197,198} and subsequently into survivorship.

Despite this, the issue of fertility remains an unmet need for many patients,^{25,45,195,199} while variations in clinical practice impede timely implementation of interventions that may optimise fertility.²⁰⁰

Barriers to discussions, documentation and/or referral may be attributable to:

- the clinician's knowledge base and perceived comfort in having discussions²⁰¹
- patient factors such as sexual maturity, prognosis or current relationships²⁰¹
- time demands and competing clinical priorities (e.g. diagnostics and starting treatment)²⁰²
- lack of robust educational materials^{201,202}
- lack of a dedicated AYA program in the health service or access to specialist input²⁰³
- health practitioner indecision in younger AYA and the appropriateness of the conversation
- lack of access to fertility specialists.

Optimal oncofertility care for AYA includes the following:^{29,63,204–206}

- An individualised infertility risk assessment is made by the healthcare team at the time of confirming the prospective treatment plan that is documented.
- Discussions about fertility risk and potential interventions such as preservation are part of the informed consent process at the time of diagnosis to facilitate decision making.
- All AYA and, where applicable, their families, who express an interest in fertility preservation are referred to a dedicated fertility service with experience in AYA cancer.
- Where clinically feasible, referral occurs before starting gonadotoxic therapy.
- Fertility experts are recognised as part of the AYA treatment team.
- Age-appropriate educational material is available for AYA and their families.
- Fertility preservation interventions are delivered within the context of evidence-based guidelines with appropriate clinical and ethical governance.
- Any techniques and technologies where the efficacy for future fertility cannot be demonstrated are clearly communicated to the patient.
- Results regarding semen analyses and tissue biopsies are communicated to the patient and/or family as soon as possible in case there is potential for a secondary procedure.
- Discussions regarding fertility are addressed again at end of treatment and continue during consultations in survivorship.
- Access to psychosocial supports are made available as part of the fertility consultation.

Adherence to treatment

Poor adherence to cancer therapy in AYA is a contributing factor to poorer outcomes including inferior response to therapy, infection, relapse and death.²⁰⁷ Large population-based studies show that AYA are more likely to consider breaking therapy than adults,²⁰⁸ while one-third to one-half of all AYA with cancer may be non-adherent with oral medications.²⁰⁷

Excluding issues such as cultural and linguistic diversity, poor adherence may often be difficult to predict. Barriers described in AYA with cancer include the developmental context of adolescence with its accompanying sense of invulnerability to side effects of treatment,¹⁵⁴ and poor understanding of the disease and perceived value of adherence. Other factors include reduced support and level of protectiveness from significant others, poor emotional wellbeing, high family incongruence²⁰⁷ and a poor bond between the AYA and their healthcare provider.²⁰⁹ Reduced adherence to oral chemotherapy in children and young people has also been associated with sociodemographic factors including low household income, low parental education and households without mothers,²¹⁰ emphasising the importance of pre-emptive social work involvement.

Currently, there are limited studies that demonstrate methods to improve adherence in AYA with cancer.^{21,207} Despite this, current strategies that show promise include:^{21,29,41,70,211–214}

- assessing the individual's level of development, maturity and health literacy when developing a treatment plan
- exploring family relationships and role delineation for medication administration
- exploring family, peer and healthcare provider relationships as potential barriers or enablers to adherence
- delivering ongoing, anticipatory patient and family education, particularly on the perceived value of 'life-saving' treatment and assessing the person's understanding of this
- seeking out interventions or referrals that promote self-esteem, self-management and psychological wellbeing
- encouraging the AYA to develop treatment routines (e.g. to pair medications with regular activities)
- promoting patient and healthcare provider alliance
- identifying and offering safe individual choices to facilitate some sense of control and mastery
- simplifying schedules and tailoring treatments that meet the person's needs and immediate priorities
- being aware of the impact of change and providing increased resources at these time points, such as the time of transfer to adult services or for significant life events
- thorough psychosocial assessment to identify and ameliorate any potential financial barriers to adherence
- seeking out and using, where available, validated methods of adherence monitoring such as electronic systems
- investigating mechanisms to routinely assess and monitor adherence in AYA, including drug monitoring
- electronic reminders may benefit some subgroups; for example, in a randomised controlled trial daily text messages improved adherence in adolescents with poor baseline adherence.²¹⁵

Social media and cyber safety

AYA are pervasive users of technology and the use of social media is a ubiquitous and integral part of their communication.^{216,217} Social media shows significant potential in AYA cancer prevention²¹⁸ to facilitate health communications, support emotional wellbeing²¹⁹ and foster an environment of care continuity beyond the hospital clinic.²¹⁷ Given the relatively low number of AYA with cancer in any country, the potential globalisation and sharing of knowledge provided by social media is potentially of great benefit to AYA with cancer.⁹⁸ Through the support of online peer to peer interactions, AYA may feel less socially isolated and more empowered to be involved in their care.²²⁰ There is growing evidence for clinicians to incorporate social media strategies into their clinical practice in order to optimise clinical care.¹⁸

However, health services also need to be aware of the impact of cyberbullying and its negative mental health impacts in this age group,^{221,222} particularly those at greater risk such as gender and sexually diverse youth.²²³ AYA with cancer may also be at risk of impulsive posting of their health information online without appreciating the potential consequences of sharing this information.²²⁰ A lack of guidance from the healthcare team may also result in the AYA accessing negative or damaging information about their individual disease, treatment and outcome.²¹⁷

Health services should be able to demonstrate:

- development of institutional social media accounts to help provide education and broaden the access to reliable and reputable information
- active engagement with AYA regarding self-care, accessing appropriate online sources of information and the importance of considering how they share their health information online and understanding their digital footprint
- strategies that incorporate the internet and social media platforms as part of the psychosocial assessment process
- discussion with parents, caregivers or family regarding AYA consent of any health information shared online or to fundraise.

Substance use in AYA

The period of adolescence and young adulthood is when many young people experiment with using particular substances such as alcohol, tobacco, marijuana and other drugs.²²⁴ This remains an issue for AYA undergoing cancer treatment.¹⁸⁴ Furthermore, this period has the highest risk of substance use disorders.²²⁵ Substance abuse during this time is associated with negative outcomes such as altered decision making and poor emotional functioning.²²⁶

Normalising peer status, social rituals, increasing confidence, masking self-consciousness or simply as a method of coping are some reasons why AYA with cancer may continue to engage in substance use.^{29,41,227,228}

Substance use (and abuse) may present a barrier to treatment adherence, lead to comorbidities that impact on care and outcomes, decrease immune function, impede symptom assessment and management, impair mental health and add an increased risk to the potential late sequelae of treatment, including secondary cancers.^{224,227}

Health services should:

- assess all AYA for substance use at diagnosis with the use of a validated tool
- explore the AYA understanding of substance use
- use supportive and non-judgemental communication strategies to encourage disclosure and discussion about substance use
- carefully consider and discuss with the AYA issues of confidentiality and duties of care and disclosure in discussions about substance use
- explain the contraindications of specific substances in the context of cancer care as well as more generally
- provide health promotion and risk reduction strategies (if applicable)
- repeat assessment at other critical time points, both during and completing treatment, as well as in survivorship.

Dedicated, experienced staff (e.g. AYA cancer care coordinators) should use these time points as 'teachable moments' when AYA are at heightened receptivity and conducive to lifestyle change.^{224,229}

Unique medical considerations

Differences in tumour and host biology

Tumour genomics and biology may differ in AYA compared with adult cancer,⁹ and in some histotypes, unique tumour and host characteristics specific to AYA may influence poorer treatment response and prognosis,^{1,230} particularly when compared with their paediatric or adult counterparts.²³⁰⁻²³²

There are also unique pharmacokinetic and pharmacodynamic factors in this age group that may impact on efficacy and toxicity of chemotherapy and biotherapy dosing.^{9,233,234}

Unfortunately, there is still limited understanding of this unique biology. Strategies to overcome this barrier may include:^{233,235}

- contribution to central registers of germline and malignant tissue in AYA in order to understand and elucidate the fundamental differences
- promotion of pharmacokinetic research in AYA cancer
- increased trial enrolments in AYA cancer.

Genetic predisposition to cancer

A small but critical number of AYA will have an underlying cancer predisposition syndrome (CPS).²³⁶ Large-scale studies of adult cancers show pathogenic germline variants present in approximately 8 per cent of patients,²³⁷ while in children this number is closer to 10 per cent.^{238,239} Recent data suggest that early-onset, predominantly older adult-like cancers in the AYA cohort demonstrate a likely pathogenic or pathogenic germline mutation as high as 21 per cent, while in cancers common to AYA, this number is approximately 13 per cent.²⁴⁰ Higher incidence of CPS in AYA has been demonstrated in many cancer types, including colorectal,^{241–243} breast^{244,245} and sarcoma.²⁴⁶ A CPS may be more common in AYA as other factors such as lifestyle, environment and mutational burden are less likely to be of influence at a younger age.²⁴⁷

Early identification of a CPS in an AYA patient may facilitate individualised (or alternative) treatment plans to improve prognosis or reduce late complications, offer potential cancer surveillance options for early identification of secondary cancers as well as support potential at-risk relatives.^{236,248} All AYA with a new diagnosis of cancer should be assessed for CPS risk. Criteria that merit consideration for referral include:^{236,249}

- atypical age at the time of diagnosis
- excessive, unanticipated toxicity to standard therapy
- family history of childhood/early-onset cancers and/or presence of consanguinity
- presence of multiple primary cancers
- congenital anomalies or intellectual disabilities associated with a recognised CPS
- diagnostic clues strongly associated with a CPS (e.g. triple-negative breast cancer).

The optimal approach to genetic predisposition in AYA includes:

- an integrated approach that addresses issues such as genetic counselling; cancer prevention, surveillance and treatment; psychosocial support; and ethical issues²³⁹
- utilisation of evidence-based decision support tools²³⁶ and current published guidelines²⁵⁰ to guide assessment on all AYA with a new diagnosis of cancer and referrals for those patients with potential risk²³⁶
- encouraging provider training in CPS to increase awareness and examining potential for access to a 'tele-genetics' service within tertiary cancer centres for regional or resource-limited health services²⁴⁷
- supporting education for genetic counsellors in youth-friendly approaches to counselling that meet the needs of AYA²⁵¹
- pursuing the role of a genetic counsellor with experience in working with young people as part of the multidisciplinary cancer team to improve access to genetic services for eligible patients²⁴⁷
- recognising the importance of tailored, developmentally sensitive genetic counselling, particularly for younger AYA,²⁵² with psychosocial support available for both the patient and the family^{253,254}
- recognising that genetic testing and counselling comes with psychosocial and ethical challenges²³⁶ and should be underpinned by a youth-friendly,²⁵⁵ institutional clinical and ethical governance framework.

Optimal care pathway

The aim of this pathway is to help guide system safety and responsiveness to the unique needs of AYA diagnosed with cancer. Patient care does not always occur in a linear process but depends on the particular situation (e.g. the type of cancer, when and how the cancer is diagnosed, prognosis, management, patient decisions and the patient's physiological response to treatment).

This optimal care pathway is intended to complement the cancer-specific optimal care pathways, acting as a tool to identify areas for health services and health professionals to improve the quality and safety of care provided to AYA. The information presented at each step is also complemented by the preceding sections in this document regarding principles of care and unique considerations.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type (where published).

Seven steps of the optimal care pathway

- Step 1: Prevention and early detection
- Step 2: Presentation, initial investigations and referral
- Step 3: Diagnosis, staging and treatment planning
- Step 4: Treatment
- Step 5: Care after initial treatment and recovery
- Step 6: Managing recurrent, residual or metastatic disease
- Step 7: End-of-life care

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of AYA cancer.

1.1 Prevention

Primary prevention campaigns in reducing sun exposure have been successful at reducing the incidence of melanoma,²⁵⁶⁻²⁵⁸ while the human papillomavirus (HPV) vaccine has been shown to protect against cervical pre-cancer in AYA females;²⁵⁹ its use has been the first global strategy for eliminating a cancer as a public health problem.²⁶⁰ Adherence to established nutritional and physical activity cancer prevention strategies may prevent diseases in AYA such as colorectal and breast cancer;^{50,261,262} unfortunately these modifiable cancer risk factors remain prevalent in this cohort.^{263,264}

Health services and government health departments should actively promote recommendations with proven efficacy in cancer prevention to the general AYA population. This is of greater importance in AYA survivors of childhood cancer. Preventative strategies should mobilise AYA, encourage a social media presence, support evidence-based behavioural and informational interventions, and recognise the voice of the AYA in delivering change.^{218,265-268}

Risk factors

In the absence of a family history, most cancers in the AYA population are sporadic, without identified aetiology.²⁹ The percentage of germline pathogenic variants and cancer predisposition in the AYA cancer cohort, however, is significant and growing,^{9,239} particularly in those AYA with cancer sub-types that usually occur in older adults.²⁴⁰ Familial cancer syndromes seen in AYA include, but are not limited to, hereditary breast and ovarian cancer syndrome (BRCA 1+2), Li-Fraumeni syndrome (leukaemia, sarcomas), familial adenomatous polyposis syndrome (colorectal cancer) and Lynch syndrome (colorectal and ovarian cancer). Other lifestyle risks, as already discussed, include excessive exposure to UV/sunlight (melanoma) and the presence of HPV (cervical cancer).²⁹ There is also an increased risk of developing a second malignant neoplasm during early adulthood as a result of exposure to chemotherapy and/or radiation therapy during childhood.²⁶⁹

1.1 Risk reduction

All AYA should be encouraged to reduce their modifiable risk factors such as reducing UV sunlight exposure, avoiding smoking, reducing alcohol intake, accessing HPV vaccination, maintaining a healthy weight, eating a healthy diet and promoting exercise.

1.4 Early detection

Cancer in AYA is rare, and there are currently no standardised screening tools that increase early detection while reducing the risk of mortality (without undue risk to the healthy population) in de-novo cancer in this group.^{270,271} However, screening AYA may be of benefit for some cancer sub-types such as cervical, breast or colorectal cancer, particularly if they have a cancer predisposition syndrome.²⁹

Screening recommendations:

- AYA with a known high-risk cancer predisposition syndrome or family history of cancer at a young age should be aware of the importance of screening and early detection and encouraged to follow evidence-based recommendations.
- AYA survivors of childhood cancer, with the support of their GPs, should follow evidence-based guidelines that include reducing modifiable cancer risk factors and, if applicable, cancer risks associated with initial disease and treatment such as secondary malignant neoplasms.

Step 2: Presentation, initial investigations and referral

This step outlines the standards of care when establishing a diagnosis and/or referring to other health or supportive services.

2.1 Signs and symptoms

Cancer in AYA presents with a broad spectrum of symptoms²⁷¹ and, compared with paediatric and adult cancers, often experience a prolonged pathway to diagnosis.¹ Barriers to timely diagnosis include the rarity and heterogeneity of AYA cancer and low index of suspicion, the frequent development of non-specific symptoms, low health-seeking behaviours and lack of cancer awareness among AYAs.^{29,272,273} In some tumour types, rapid diagnosis may in fact be a poor prognostic indicator.²⁷⁴ Tumour biology, versus diagnostic timeliness, is more strongly associated with treatment response and outcomes.²³⁰

When examined across all AYA cancers, the most common presenting signs and symptoms include presence of a lump or swelling, extreme fatigue and pain, although the observed variation in time to seeking help following the onset of symptoms is too short to enable specific, targeted awareness campaigns.²⁷¹

Despite this, efforts to expedite diagnosis may benefit some sub-groups²⁷⁵ (resulting in early-stage diagnosis and improved survival) and lead to reduced psychological distress.¹

Recommendations at this time point include:

- establishing robust communication and referral systems between primary and secondary/tertiary care²⁷²
- encouraging the importance of safety-netting of AYA in primary care²⁷⁶ (the process of monitoring a patient until their symptoms are explained)²⁷⁷
- targeting those sub-groups where early diagnosis may improve outcomes²⁷⁸
- education/awareness campaigns for primary and emergency care providers to understand both the types of diseases seen in AYA, as well as the presenting signs and symptoms. An example of this is the *Early detection of cancer in AYA cancer guideline*, developed by the Clinical Oncological Society of Australia.²⁷⁹

Improving primary care and AYA symptom awareness of cancer to facilitate early diagnosis has been identified as a research priority by AYA with cancer.²⁸⁰

To view the full clinical optimal care pathway and specific presenting signs and symptoms for each cancer type (where published), visit the Cancer Council website <www.cancer.org.au/OCP>.

2.2 Initial referral

The GP should have telephone discussions with a health service that has expertise in managing AYA when planning tests and investigations to confirm or exclude a diagnosis of cancer. This may also be applicable for regional cancer centres planning complex investigations in AYA. In some cases, it may be preferable to defer complex diagnostic testing to the referral centre.

For those AYA with a confirmed diagnosis in primary care, the GP should strongly consider referral to a cancer centre with expertise in managing AYA cancers, particularly in the case of paediatric-like cancer types, rare and complex diagnoses and those AYA with complex psychosocial risk.

Referral to high-volume centres with multidisciplinary expertise in AYA sarcoma is strongly recommended in managing soft tissue and bone sarcomas.¹³⁵

Referral for a suspected or diagnosed cancer should include the following essential information to accurately triage and categorise the level of clinical urgency:

- clearly marked as urgent or non-urgent according to findings and clinical condition
- important psychosocial history and relevant medical history
- family history, current symptoms, medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- notification if an interpreter service is required.

Cancer centres that manage AYA should be able to provide clear referral criteria and pathways for GPs.

2.2.1 Timeframe for referring to a specialist

Timeframes for completing investigations and referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timeline for appropriate consultations and treatment in AYA may improve clinical and patient-reported outcomes.²⁷¹

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type.

2.3 Support and communication

2.3.1 Supportive care

The GP should consider a rapid psychosocial assessment at this time point to identify the needs of the AYA and their family, including emotional support. The assessment should also be undertaken to identify any potential barriers to accessing the referral centre within the planned timeframe. Referral to appropriate support services should be made as required. See validated supportive care tools mentioned in Principle 4: 'Supportive care'.

2.4.2 Communication with AYA, carers and families

The GP is responsible for:

- providing AYA and, if applicable, their families, with information that clearly describes where they are being referred, the reason for referral and the expected timeframes for appointments
- requesting that they notify them if the referring centre has not been in contact within the expected timeframe
- supporting the patient while waiting for the specialist appointment.

All interaction should align to the standards outlined in Principle 6: 'Communication' and 'Referral choices' in Principle 1.

For additional information on supportive care and needs that may arise for different population groups, see Appendix A.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer and for planning subsequent treatment. The guiding principle is to have close and sustained interactions between appropriate multidisciplinary team members who are responsible for determining the treatment plan.

3.1 Specialist diagnostic work-up

Although it may vary depending on the diagnosis, work-up should be undertaken by a cancer centre with multidisciplinary experience in managing AYA cancers with access to clinical trials. At times, this may be within a paediatric tertiary cancer centre. AYA experience is particularly important in rare tumours, advanced-stage disease and those requiring complex and/or multidisciplinary diagnostic evaluation.¹³⁴

Diagnostic tests and investigations should be informed by evidence-based guidelines or, ideally, as determined by enrolment in the relevant clinical trial. Imaging should be interpreted by a radiologist with experience and expertise in the relevant AYA cancer. Diagnostic laboratory investigations should be interpreted by a pathologist with experience in the relevant AYA cancer. Clinicians involved in the diagnostic work-up should participate in the diagnostic/treatment planning MDM.

All AYA cancers should be well described according to ICD-O topography and morphology coding and, whenever applicable, molecular and genetic features. The complete diagnostic profile should be clearly documented in the medical record.

3.1.1 Timeframe for completing investigations

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations can reduce distress. Diagnostic delays still occur beyond the primary care evaluation and referral. In some populations prolonged diagnostic intervals have been shown to continue even after the AYA has had their initial consultation with their oncologist and may be due to timely access to appropriate diagnostics;²⁷⁶ cancer services need to be aware of this issue.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type.

3.1.2 Genetic testing (family risk)

See the section 'Genetic predisposition to cancer' for more information on the rationale and recommendations for genetic testing in AYA with cancer.

3.1.3 Pharmacogenetics

Pharmacogenetics describes how individual genetic differences can lead to differences in the way certain medicines interact with the body. Variability in response, and adverse drug reaction risk, is a feature of modern therapies (e.g. systemic anti-cancer care), some of which may include a prominent genetic component.²⁸¹ Using pharmacogenetics as a clinical tool to guide drug selection and dosage adjustments may be an effective and potentially cost-saving risk-mitigation strategy.²⁸² Personalised medicine is an evolving field in AYA cancer and at present is limited to a small range of diseases. However, when applicable, this approach will guide health services to prescribe the most appropriate therapies at the optimal dose from the beginning of treatment.²⁸³

3.1.4 Biobanking

Age-related molecular features in AYA cancer remain poorly understood.²⁸⁴ Consideration should be made at the time of diagnosis to seek consent for tumour biobanking for research purposes,¹⁰⁹ to examine these age-related differences in areas such as the biology of disease control, host immune response and susceptibility to late toxicities.²⁸⁵ Biobanking will facilitate research in AYA cancer sub-types that have traditionally been under-represented¹⁰⁹ and to study the complexity and heterogeneity of rare cancers.²⁸⁶ The cancer service should be able to demonstrate access to biobanks with ethically collected, high-quality, well-described biospecimens that also collaborate with external institutions to harmonise collection processes and encourage rapid translational research in AYA cancer.

3.2 Staging, grading and risk stratification

Staging, grading and/or risk stratification is a critical element in treatment planning for all AYA at the time of diagnosis. It must be assessed by a current, internationally recognised, peer-reviewed classification tool, ideally within the context of a clinical trial, and clearly documented in the patient's notes.

There should also be institutional guidelines for all aspects of staging, grading and/or risk stratification when reporting new diagnoses to cancer registries.

For further details, visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type.

3.3 Performance status

Performance status is a central factor in cancer care and should be clearly documented in the patient's medical record. Performance status should be measured and recorded using an established scale such as the Karnofsky scale or the Eastern Cooperative Oncology Group (ECOG) scale.

Well-defined, patient-reported outcome measures validated in AYA should also be considered. These often vary from functional performance status and through direct symptom reporting, and may inform more effective care when used together.²⁸⁷

3.4 Treatment planning

3.4.1. Key considerations beyond treatment recommendations

Please refer to the 'Principles of care' section that outlines some of the key concerns at diagnosis for AYA, including developmental, health system and biological considerations. Central to this will be providing developmentally appropriate support for decision making.

3.4.2 Timing of the multidisciplinary team meeting

All diagnostic work-up and prospective treatment planning via a disease-specific MDM should occur before starting treatment. However, immediate treatment is often required before a full multidisciplinary team ratifies details of the treatment plan. Results of all relevant investigations and access to images should also be available prior to discussion at an MDM.

3.4.3 Responsibilities of the multidisciplinary team

The MDM requires administrative support in developing the agenda for the meeting, for collating patient information and to ensure appropriate expertise around the table to create an effective treatment plan for the patient. The MDM has a chair and multiple lead clinicians. Each case will be presented by a lead clinician (usually someone who has seen the patient before the MDM). A member of the team records the outcomes of the discussion and treatment plan in the patient record and ensures these details are communicated to the AYA's GP and other primary care providers, as applicable. The team should consider the patient's values, beliefs, developmental and cultural needs as appropriate to ensure the treatment plan is in line with these.

3.4.4 Members of the multidisciplinary team meeting at diagnosis

The multidisciplinary team should be composed of core specialties (e.g. oncology, haematology, pathology, radiology, surgery, nursing, pharmacy, psychosocial and clinical trials) who can demonstrate appropriate expertise and experience in AYA cancer. MDMs are generally tailored to the diagnosis. An AYA coordinator should be available for any MDM presenting AYA patients at diagnosis. The team should ideally incorporate input and attendance from both paediatric and adult oncology providers.

3.4.5 Role of an AYA-specific MDM at diagnosis

Concurrent referral should be made to an AYA-specific multidisciplinary team (as previously discussed) that works in partnership with the disease-specific MDM.⁴¹ An AYA multidisciplinary team that has capacity to present regular case discussions is an essential element of the service.⁹ An AYA MDM will discuss the clinical and supportive care aspects of care, bringing both a disease-specific and age-appropriate, psychosocial focus to prospective treatment planning.⁴¹ The Youth Cancer Services in Australia is a good example of implementing a model of care and team developed to facilitate AYA-specific MDM discussions.

See Appendix C: 'Members of the AYA multidisciplinary team' for more information.

3.5 Research and clinical trials

Patients should be encouraged to participate in research or clinical trials where available and appropriate. Clinical trial discussions should be part of the MDM agenda and be documented. For those who do not meet eligibility criteria, or where a clinical trial is not open, the patient should follow the most recently completed and published 'standard of care' treatment protocol offering the best possible outcome.

Access to trials may involve referral to or collaboration with an external paediatric or adult cancer centre.

See Principle 7: 'Research and clinical trials' for more information.

3.6 Support and communication

3.6.1 Supportive care

A comprehensive, multidisciplinary, age-appropriate supportive care assessment is undertaken and documented at the time of diagnosis.²⁹ This assessment should align to each of the principles of care previously described within this document, to help support prospective treatment planning.

3.6.2 Fertility preservation and contraception

Access to fertility information and preservation services is a priority issue for AYA with cancer.²⁵ See 'Fertility preservation' and 'Sexuality and sexual health' in the principles of care section for more information.

3.6.3 Communication

In discussion with the AYA and, as applicable, their family, the lead clinician and AYA coordinator should undertake the following:

- establish if the AYA has a regular or preferred GP and, if the patient does not have one, encourage them to find one
- explore information preferences and provide age-appropriate written information about the diagnosis, treatment, treatment intent and prognosis
- provide a treatment care plan including contact details for the treating team and information on when to call the hospital
- discuss how they wish to have their family engaged in confidential and private discussions
- discuss the benefits of multidisciplinary care and gain the patient's and/or parent's consent before presenting their case at an MDM.

Discussions around prognosis should be revisited with AYA over time as they become more accustomed to their diagnosis.^{102,288}

All interaction should align to the standards outlined in Principle 6: 'Communication'.

Step 4: Treatment

Step 4 addresses key aspects of care when treating AYA with cancer. Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways for each cancer type.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- curative
- treatment for AYA with uncertain or poor prognosis²⁸⁹
- therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

The treatment intent should be established within the initial MDM, documented in the patient's medical record and conveyed to the AYA and their family.

4.2 Treatment options

AYA may tolerate more intensive therapy, have better organ function and experience fewer comorbidities that may limit treatment options in older patients.²⁹⁰ Increased treatment intensity may favour outcomes in some disease groups²⁹¹ and should be considered where it demonstrates improved outcomes with an acceptable side effect profile.²⁹ As previously discussed, there are also unique pharmacokinetic and pharmacodynamic factors in this age group that may impact on efficacy and toxicity of chemotherapy and biotherapy dosing.^{9,233,234} Treatment options in AYA also need to consider the increased risks of late effects^{292, 293} and both disease²⁹⁴ and non-disease related mortality²⁹⁵ associated with this age group.

Whenever possible, AYA patients should have a carefully planned path to enrolment in clinical trials for their specific disease.

4.2.1 Surgery

Surgery plays a critical role in many common AYA cancers, such as sarcomas, central nervous system tumours, breast cancer, colorectal cancer and thyroid cancer. The surgeon is considered a core member of the multidisciplinary team and participates in the diagnostic/treatment planning MDM. Surgical interventions in emerging AYAs (e.g. limb-sparing procedures in bone sarcomas) need careful planning because they may lead to greater late effects than in older AYAs or adults.²⁹ When considering the location of surgery in AYA cancers, level of complexity and the institutional volume or case load of patients should be considered, alongside services that encourage and support speciality AYA care under a multidisciplinary team structure with an active clinical trials focus and access to rehabilitative services. Surgical volume effect in speciality referral centres may have a positive association with outcomes in areas such as sarcoma or central nervous system tumours.^{130,131} Institutions without appropriate case load and service capability should have established processes for routine referral to high-volume centres.

4.2.2 Radiation therapy

Radiation therapy is indicated for treating many AYA cancers. However, the use of radiation therapy in AYA with cancer (dependant on dose, field and technique) has been associated with increased risk of second malignant neoplasms mortality,²⁹⁴ cerebrovascular disease,²⁹⁶ infertility¹⁸⁹ and pulmonary, cardiac and thyroid dysfunction.²⁹⁷ AYA who have received radiation therapy as part of their treatment plan will need ongoing engagement with a survivorship service. Radiation therapy planning should be discussed within the context of the diagnostic/treatment planning MDM where the radiation oncologist is considered a core member of the diagnostic/treatment planning multidisciplinary team.

4.2.3 Systemic therapy

Evidence-based supportive care guidelines should be followed to mitigate the potential toxicities of systemic therapy in the treatment of AYA cancer, and every attempt should be made to maintain dose intensity unless contraindicated.^{1,29} Less complex components of systemic therapy could be administered within a shared care, telehealth-based model for AYA from appropriately-equipped and staffed regional centres. As previously discussed, the service needs to be aware of the risk to treatment adherence in AYA, particularly in the administration of systemic oral therapies and supportive care medicines in the home, as well as those AYA on long-term, targeted oral therapies for disease control.

4.2.4 Haematopoietic stem cell transplant (HSCT)

AYA have higher HSCT-associated treatment toxicities compared with children, and some studies suggest an increase in graft-versus-host disease (which may be attributable to adherence to supportive care medicines).²⁹⁸ Despite AYA having higher physical wellbeing and activity outcomes than older adults, HSCT can have a greater impact on personal development, autonomy and maintenance of social contacts,²⁹⁹ with reports of lower social functioning of long-term survivors of HSCT undertaken during AYA.³⁰⁰ Despite the multidisciplinary input and intensity of HSCT therapy, AYA still report unmet informational needs, needs that differ from older adult recipients of HSCT, demanding an age-appropriate approach from an AYA multidisciplinary team.

4.3 Rehabilitation

Physical deficits from disease and/or treatment in AYA, at a time of developing autonomy and independence, can have a devastating impact.⁴¹ Unmet physical needs in AYA with cancer have been shown to be an important predictor of distress,⁶⁹ while AYA with greater levels of physical burden may be more vulnerable to poor adjustment to diagnosis and poorer psychosocial outcomes.³⁰¹

Rehabilitation may be required at any point of the care pathway. All members of the multidisciplinary team have an important role in promoting rehabilitation. Team members may include prosthetists, orthotists, occupational therapists, speech pathologists, dietitians, social workers, psychologists, physiotherapists, exercise physiologists and rehabilitation specialists.

High-risk groups in AYA that require referral to specific rehabilitation programs include those undergoing neurosurgery, bone sarcomas (and subsequent limb salvage or amputation), HSCT (and deconditioning) and avascular necrosis in those receiving high-dose steroids for haematological malignancies.⁴¹

See Principle 4: 'Supportive care' for more information on exercise.

4.4 Place of care

As previously discussed, care directed by a tertiary referral centre specialising in AYA cancer should be considered for those with advanced-stage disease, complex inpatient and ambulatory therapies,¹³⁴ specific disease groups such as bone and soft tissue sarcomas,¹³⁵ cancer during pregnancy, complex paediatric cancer types in young adults²⁹ and those with high pre-existing comorbidities. Centralising care may also be the determinant for increasing access to clinical trials and novel therapies that would otherwise be unavailable.⁹

4.5 Palliative care

The emerging trend in AYA cancer of standardising care to meet the unique psychosocial and supportive care needs of the patient provides the opportunity and rationale for early collaboration with palliative care services where appropriate.³⁰² Regular, early and routine assessment should be undertaken to determine referral to a palliative care program.³⁰³ Triggers for referral should include those with advanced cancer, current high symptom burden and/or AYA undergoing therapies associated with high levels of physical and psychological distress (e.g. HSCT) despite their curative intent. Referral should not be based solely on prognosis.

Involvement of a specialty palliative care service for AYA with cancer is associated with fewer intensive care admissions at end of life, more advance care planning and fewer in-hospital deaths.³⁰⁴

Early integration with a multidisciplinary palliative care program (with age-specific provider training) should be offered, as required, across the whole care continuum and complement the existing supportive care program of an AYA-specific cancer service. Representatives from the palliative care team should be considered core members of the AYA cancer multidisciplinary team.

Step 5: Care after initial treatment and recovery

AYA with cancer experience the adverse effects of cancer and its treatment at a dynamic time point, impacting on or delaying key developmental milestones.⁸⁰ These effects can persist well beyond the completion of treatment.

AYA survivors report difficulties in employment, finances, education and relationships.³³ Compared with their healthy peers, AYA with cancer can experience significant burden as long-term survivors including:

- increased long-term, non-cancer mortality risk²⁹⁵
- increased risk of secondary malignant neoplasms³⁰⁵
- increased risk of all-cause mortality²⁹⁴
- higher hospitalisation rates^{306,307}
- higher self-reported measures of poor health³⁰⁸
- poorer psychosocial functioning²⁹
- increased risk of cerebrovascular events.²⁹⁶

5.1 Transitioning from active treatment

The period immediately after completing treatment and early post-treatment can be particularly challenging for AYA cancer survivors.³⁰⁹ It has been described as a time of feeling abandoned by the healthcare team,³⁰⁹ a hiatus in (cancer) care,³¹⁰ and feeling underprepared for the issues they experience³¹¹ at a time when they feel 'neither sick nor healthy'.⁸⁰

At the end of treatment, nearly all AYA still experience at least one physical, emotional and practical concern and often do not seek help, with many accepting this as a normal burden of cancer survivorship.⁸⁰ Needs at this time for AYA include individualised information and advice, counselling and psychological support, and social support/relationships, different needs than experienced by older adult survivors.³¹²

Recommended strategies during this period include:^{80,310,311,313}

- integrated, systematic screening during acute and follow-up care to identify medical and psychosocial issues
- increased consultation time with their oncologist at the end of treatment
- targeted, age-appropriate and accessible information on topics that meet the identified needs
- discussing strategies and referrals to support a return to education and/or employment
- discussing nutrition and physical activity and providing referrals as indicated

- ensuring careful planning and navigation for younger AYA transitioning at the end of treatment to an adult health service
- identifying the AYA's preferred GP (or encouragement to engage with one) and discussion of their role during follow-up
- the key role of key AYA workers/navigators in the health team at the end of treatment
- professional development opportunities and specific and direct guidance for healthcare providers involved at this time point.

5.2 Follow-up care

5.2.1 Cancer surveillance

After completing initial treatment, the AYA should be provided with a treatment summary and a surveillance roadmap. These documents are key resources for the AYA and their healthcare providers and can be used to improve communication and care coordination.

The treatment summary should include:³¹⁴

- the date of diagnosis
- the age at diagnosis
- the type and, if applicable, site, of cancer, its histology, staging, grading and/or risk stratification
- date and type of any surgery
- the treatment protocol, including clinical trial enrolment if applicable
- chemotherapy (if applicable), including agents administered and cumulative doses
- radiation therapy, as applicable, including all radiation fields, dose of radiation of at-risk organs and target volumes, as well as age at first dose
- significant morbidities and/or adverse events experienced during treatment
- fertility preservation strategies if applicable
- the treatment end date
- contacts at each speciality service where treatment was undertaken.

The surveillance roadmap may cover a period of five or more years depending on disease and should include timings for clinical reviews, tests and investigations required after completing treatment. The roadmap is tailored according to the AYA's diagnosis and treatment and, ideally, is determined by the respective clinical trial protocol. Copies should be provided to the GP to support a shared model of care with the cancer service.

5.2.2 Cancer survivorship

Following surveillance, a periodic evaluation with a focused history, physical examination and risk-based screening (based on diagnosis and treatment) should be facilitated.²⁹ High-priority targets for consideration in AYA cancer survivorship screening include secondary cancers, cardiovascular toxicity, respiratory toxicity, endocrine screening and neurocognitive screening.³¹⁵ Evaluation should be lifelong and adhere to evidence-based screening recommendations.

The survivorship plan should also cover, but is not limited to:

- timing for surveillance of potential primary and secondary malignant neoplasms
- timing of evidence-based screening recommendations for potential late effects, tailored for the AYA's disease, treatment and age at diagnosis³¹⁵
- wellbeing, primary and secondary prevention health recommendations that align with chronic disease management principles.

Place and responsibility of care in AYA survivorship should be risk stratified. Those with low-risk of late effects can be transitioned to their GP with documentation; those with medium-risk should be seen within a shared-care model between a cancer survivorship service and their GP; while those with high-risk of late effects (e.g. HSCT, high-dose chemotherapy and radiation therapy) should remain engaged in dedicated cancer survivorship care.²⁹

5.2.3 Optimising wellbeing and preventing subsequent cancer development

Not smoking, eating a healthy diet, being sun smart, avoiding or limiting alcohol intake and other substances, being physically active and maintaining a healthy body weight may help reduce the risk of second malignant neoplasms.

Cancer survivors should be encouraged to reduce modifiable risk factors for recurrence as well as other chronic diseases. Ongoing coordination of care between providers should also deal with any comorbidities, particularly ongoing complex and life-threatening comorbid conditions.

5.3 Research and clinical trials

Like many other facets of AYA cancer care, the period at the end of treatment and survivorship remains under-researched.^{15,74}

Health services should encourage AYA cancer survivors to take part in research or clinical trials where they are available and appropriate. These might include studies to understand survivors' issues, to better manage treatment side effects, or to improve models of care and quality of life. It is important that survivorship models of care are continually evaluated for clinical effectiveness³¹⁶ and to ensure the needs of the AYA are met.²⁷³

5.4 Support and communication

5.4.1 Supportive care

Validated screening tools should continue to be used during both surveillance and survivorship, as a standard of care. See supportive care tools mentioned in Principle 4: Supportive care'. For more information on supportive care and needs that may arise for different population groups, see Appendix A.

5.4.2 Communication with the AYA and their family

The lead clinician responsible for care (themselves or by delegation) should take responsibility for:

- explaining the model of post-treatment care and the roles of health professionals involved in post-treatment care including the role of general practice
- explaining the treatment summary, surveillance and survivorship roadmaps
- discussing the development of a shared follow-up and survivorship care plan where a model of shared follow-up care has been agreed
- discussing how to manage any of the physical, psychological or emotional issues identified
- providing information on the signs and symptoms of recurrent disease
- preparing the AYA for the psychosocial concerns that often arise after coming off treatment and options for accessing support as needed
- providing contact details of the care team involved.

All interaction should align to the standards outlined in Principle 6: 'Communication'.

5.4.3 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the GP about:

- the patient's progress
- the follow-up care plan
- potential late effects
- supportive care requirements
- any shared care arrangements
- clarification of various roles in patient care
- a process for rapid re-entry to cancer services if there are other concerns.

Step 6: Managing recurrent, residual or metastatic disease

AYA who present with recurrent, residual or metastatic disease should be managed by a multidisciplinary team and offered timely referral to appropriate physical, practical and emotional support.

Step 6 is concerned with managing refractory disease or relapse. The likelihood of relapse depends on many factors usually related to the type of cancer, the stage of cancer at presentation and the effectiveness of treatment. Some cancers cannot be eradicated even with the best initial treatment. But controlling disease and disease-related symptoms is often possible, depending on the clinical situation.

6.1 Signs and symptoms

Signs and symptoms will depend on the type of cancer initially diagnosed. They may be discovered by the AYA or by through routine surveillance in the post-treatment period.

6.2 Multidisciplinary team

Managing relapse or refractory disease in AYA is often complex and should therefore involve all the appropriate specialties in a multidisciplinary team including palliative care. Care for all AYA with relapse or refractory disease should be directed by a tertiary cancer centre with experience and expertise in managing AYA cancer. The Youth Cancer Services in Australia is a good example of a unique team developed to facilitate AYA-specific MDM discussions at this time point.

6.3 Treatment

Treatment will depend on the type of cancer, location, extent of recurrent or residual disease, previous management, and the preference of the AYA and/or their family.

All patients should be discussed within an MDM to develop an appropriate treatment plan. MDM discussions at the time of relapse should:³¹⁴

- include decisions about clinical trial availability (these may not be available onsite)
- present all the information about the success rate of conventional relapse plans, regardless of prognosis
- be prepared to respond to potential complementary and alternative options
- maintain open and candid communication with AYA at all times
- incorporate palliative care involvement.

6.4 Support and communication

6.4.1 Supportive care

A number of specific challenges and needs may arise at this time for AYA:

- an increased focus on emotional and psychosocial support, exploring the AYA and their family's strengths, with a focus on enhancing quality of life
- the potential isolation from normal support networks, particularly for AYA from regional and rural areas

- decline in mobility or functional status as a result of recurrent disease and/or its treatment (referral to physiotherapy or occupational therapy may be required)
- due to the increased toxicities of many relapse protocols, referral to services that may not have been indicated in up-front treatment (e.g. fertility).

See supportive care tools mentioned in Principle 4: Supportive care'. For more information on supportive care and needs that may arise for different population groups, see Appendix A.

6.4.2 Communication

The lead clinician should ensure there is adequate discussion with AYA and their family (as appropriate) about the diagnosis and recommended treatment. Supporting the AYA at this time point includes eliciting their values and being candid about prognosis, treatment intent, benefits, risks and uncertainties.³¹⁷ All information is sensitively provided to the AYA and their family, in age-appropriate language and within a supportive environment.

6.5 Advance care planning

Advance care planning (and documentation) should be developmentally appropriate and reflect the values of the AYA.³⁰² Tools such as the Voicing my CHOICES advance care planning guide for AYA should be considered as a tool to facilitate open and honest communication at this time point.^{318,319} This tool has been culturally adapted to the Australian context and evaluated by healthcare providers as a helpful strategy to guide difficult, sensitive conversations.³²⁰ Timing of the discussion around advance care planning should be early, on a 'what if' basis, rather than left to the point of end-stage disease.³²¹

6.6 Palliative care

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on the AYA's need and potential for benefit, not solely on prognosis.

See section 4.5 'Palliative care' for more information.

6.7 Research and clinical trials

The treatment team should support the AYA to participate in research and clinical trials where available and appropriate. Trials in relapsed refractory cancer are more readily available but also more specialised and resource intensive.

See Principle 7: 'Research and clinical trials' for more information

Step 7: End-of-life care

Step 7 is concerned with maintaining the AYA's quality of life and meeting their health and supportive care needs as they approach the end of life, as well as the needs of their family.

Some AYA with cancer will reach a time when active treatment is no longer appropriate. The team needs to share the principles of a palliative approach to care when making decisions with the patient and their family or carer. End-of-life care is appropriate when the patient's symptoms are increasing, and functional status is declining.

7.1 Multidisciplinary palliative care

In addition to specialised, age-appropriate palliative care nursing and medical specialties, the treating team may consider seeking additional expertise from these professionals:

- clinical psychologist
- social worker
- pain specialist
- pastoral or spiritual carer
- bereavement counsellor
- music therapist
- art therapist
- home and community-based care.

The AYA care coordinator should remain engaged with the AYA and their family during this time.

There is some evidence that AYA with cancer continue to access intensive treatment at end of life,^{322,323} and that many families have a poor understanding of the AYA's individual end-of-life preferences such as place of death and access to life support.³²⁴ Discussions and decision making for end of life, including advance care planning, should be family-centred and instigated early in high-risk populations. While preferences in AYA with cancer at end of life are not yet well defined in the literature, the demand for an age-appropriate healthcare environment (often preferencing the home), offering a sense of normalcy and promotion of honest discussions, have been reported in this age group.³²⁵

7.2 Research and clinical trials

Although challenging by nature and under-represented,^{326,327} well-defined clinical research in palliative care is necessary to improve patient care and encourage clinically meaningful differences,³²⁸ including at end of life. The treatment team should support the patient to participate in high-quality research and clinical trials where available and appropriate.

7.3 Support and communication

7.3.1 Supportive care

See supportive care tools mentioned in Principle 4: 'Supportive care' and Step 6.4.1 of 'Managing recurrent, residual or metastatic disease'.

7.3.2 Communication with the AYA

AYA often express a desire to be engaged in early end-of-life discussions, tailored to the individual, and provided by a healthcare team confident and skilled in this area. These discussions can facilitate conversations before a 'crisis point' has been met in their care.³²⁹ As discussed, the treating team need to be aware that the AYA and their family may not have the same level of acceptance.³²⁴

This is one of the most challenging areas in communication with AYA – using education and training tools to develop a framework and expertise for discussion may be beneficial.

All interaction should align to the standards outlined in Principle 6: 'Communication'.

7.3.3 Communication with the GP

The patient's GP, who often has an established relationship with the AYA and their family, should be kept fully informed by the treating team and involved in major developments in the patient's illness pathway.

7.3.4 Communication within the treatment team

The cancer service should provide a regular mortality and morbidity meeting to review patient deaths as an important event for discussing cases, contribute to the governance of patient safety (and potential system changes), facilitate peer support and explore and clarify individual and team learning.⁴¹

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Advance Care Planning Australia

Allied Health Professions Australia

Australian New Zealand Children's Haematology
Oncology Group

Australian College of Nursing

Australian Medical Association (VIC)

NSW Cancer Institute

Australian Cancer Survivorship Centre

Australian New Zealand Society of Palliative
Medicine

Cancer Nurses Society of Australia

Canteen

Clinical Oncology Society of Australia

Cook Children's, Fort Worth, Texas

Medical Oncology Group of Australia

Oncology Social Work ANZ

Queensland Child and Youth Network

Redkite

Royal Australian College of Physicians

Royal Australian College of General Practitioners

Australian Youth Cancer Services

Appendix A: Special population groups

Aboriginal and Torres Strait Islander AYA

Cancer is the third leading cause of burden of disease for Aboriginal and Torres Strait Islander people. While Australia's cancer survival rates are among the best in the world, Aboriginal and Torres Strait Islander people continue to experience a different pattern of cancer incidence and significant disparities in cancer outcomes compared with non-Indigenous Australians.

For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life–death–life.

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people, and unique connection to culture, highlight the need for a specific optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Ensuring this pathway is culturally safe and supportive is vital to tackling the disparities for Aboriginal and Torres Strait Islander people.

Published in 2018, the optimal care pathway for Aboriginal and Torres Strait Islander people with cancer³³⁰ provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer across the cancer continuum.

In addition to the key principles underpinning cancer -specific pathways, these are the key concepts that are fundamental to Aboriginal and Torres Strait Islander health:³³¹

- providing a holistic approach to health and wellbeing
- providing a culturally appropriate and culturally safe service
- acknowledging the diversity of Aboriginal and Torres Strait Islander peoples
- understanding the social determinants and cultural determinants of health.

View the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>> on the Cancer Australia website. To view the consumer resources – Checking for cancer and Cancer: What to Expect, visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-people>>.

Culturally diverse communities

For people from culturally diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in people from culturally diverse backgrounds, and this can affect their understanding and decision making after a cancer diagnosis. In addition to different cultural beliefs, when English language is limited, there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients.

A professionally trained health interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those with a non-Anglo culture, and members of the treatment teams should pay particular attention to supporting these patients.

The Australian Cancer Survivorship Centre has developed a glossary of more than 700 cancer terms in nine different languages. The multilingual glossary has been designed as a resource for professional translators, interpreters and bilingual health professionals working in the cancer field. The glossary is a unique tool that enables language professionals with access to accurate, consistent and culturally appropriate terminology. Visit the Peter Mac website <www.petermac.org/multilingualglossary> to see the glossary.

AYA with disabilities

Disability, which can be physical, intellectual, sensory or psychological, may have existed before the cancer diagnosis or may be new in onset (occurring due to the cancer treatment or incidentally). AYA cancer survivors have a greater prevalence of disability compared with their healthy peers,³⁰⁸ and adjusting to life with a disability adds another challenge to cancer care and survivorship.

In general population data (15–64 years of age), barriers that prevent people with disabilities from accessing timely and effective health care include:³³²

- physical limitations
- competing health needs
- the trauma of undergoing invasive procedures
- potential barriers associated with obtaining informed consent
- failure to provide assistance with communication
- lack of information
- discriminatory attitudes among healthcare staff.

In caring for AYA with disabilities and a cancer diagnosis, the Australian Institute of Health and Welfare disability Flag (a series of standardised questions) should be used at the point of admittance to correctly identify and meet the additional requirements of a person with disability. Facilities should actively consider access requirements, and health practitioners should make reasonable adjustments where required.

AYA who have a permanent or significant disability may be eligible for support or funding through the National Disability Insurance Scheme. More information can be found on the NDIS website <www.ndis.gov.au>.

AYA experiencing socioeconomic disadvantage

In general, people in Australia from lower socioeconomic groups are at greater risk of poor health, have higher rates of illness, disability and death, and live shorter lives than those from higher socioeconomic groups.³³³ People experiencing socioeconomic disadvantage are less likely to participate in screening programs, more likely to be obese, less likely to exercise and much more likely to smoke, which are all risk factors for cancer. In 2010–2014 age-standardised cancer incidence rates were higher in the lowest socioeconomic areas compared with the highest socioeconomic areas for all cancers combined.³³⁴

Because of their life stage, AYA with cancer are also at particular risk of the economic burden of cancer treatment,³³⁵ negatively impacting on the cancer experience.³³⁵

Socioeconomic status and low health literacy are also closely correlated. Therefore, effective communication with patients and carers is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults).³³⁶

Consideration should be taken for cancer patients experiencing socioeconomic disadvantage to reduce their risk of being underserved for health care.

Rural and remote AYA

Across all ages, there is a disadvantage for rural/remote cancer patients in high-income countries of approximately 5 per cent in overall survival.^{337,338} This rural/metropolitan disparity has also been demonstrated in Australia, including some cancer types within the AYA population.³³⁹ The ‘tyranny of distance’ can negatively affect not just physical health but the psychosocial outcomes for AYA with cancer.³⁴⁰

Reasons behind the rural/remote disadvantage may include associated delays to diagnosis being less amendable to treatment,^{340,341} lower socioeconomic status³³⁹ and the burden of travel.^{338,340} Indigenous Australians are also more likely to live in remote areas. Preliminary outcome data in Indigenous AYA with cancer is difficult to interpret due to small numbers and reliability of classification of Indigenous status,³⁴² however, older Aboriginal and Torres Strait Islander people with cancer are known to have inferior survival.

Strategies for health services include:

- providing visiting specialties to regional services
- promoting shared care with secondary healthcare services closer to home
- seeking opportunities for telehealth-led consultations and tele-trials for AYA
- using an AYA navigator for regional patients to coordinate care and reduce travel burden.

Sexually and gender-diverse AYA

Exploring sexuality, relationships and gender identity are important aspects of AYA development.³⁴³ Sexually or gender-diverse groups include, but are not limited to, people who identify as lesbian, gay, bisexual or transgender, collectively ‘LGBT’. There is no universally agreed upon initialism to describe this community, with other terms such as queer/questioning (Q), intersex (I), asexual (A) and pansexual (P) often included, as well as a plus symbol (+) indicating inclusivity of other identities not explicitly mentioned.

Currently, there is a gap in the understanding of LGBT AYA who experience a diagnosis of cancer during this phase of their life.¹⁸⁵ It is known that LGBT patients experience healthcare disparity broadly, due to minority distress, victimisation, stigma, discrimination and cultural and social norms that prioritise heterosexuality.³⁴⁴ This disparity is experienced through diagnosis and treatment of cancer in the adult population.²⁹

In LGBT AYA generally, there is a greater incidence of bullying and victimisation,²²³ which has been demonstrated to lead to a disproportionate incidence of cancer-related health risk behaviours compared to the general AYA population, including substance abuse and sexual risk behaviours.^{345,346} Both during and following treatment, there is also recognised disparity in the level of psychological distress experienced by LGBT patients (a minority group who already experience significant mental health issues) compared to the wider population.^{101, 347-349}

Evidence also suggest that there are several cancers may also disproportionately affect LGBT patients as a result of behavioural risk factors, decreased rates of screening and prevention and healthcare discrepancies.^{29,350-352}

There may also be significant challenges for gender-diverse AYA undergoing treatment for some cancers (e.g. a potential increase in gender dysphoria for a transgender male diagnosed with breast cancer) and the psychological impacts when gender affirming interventions such as hormone-replacement therapy or surgery needing to be paused or delayed during treatment.

The reported experience of LGBT patients in adult cancer care demonstrate significant challenges, including issues of disclosure, fear of homophobia, navigating a hetero-centric healthcare system and inadequate support groups.³⁵³ Disclosure is likely a more critical issue in AYA if they have not yet shared their identity with their family and community,¹⁸⁵ particularly in an age of shared electronic medical records. Although expressing a willingness to learn, healthcare providers in cancer care generally have limited knowledge of LGBT issues³⁵⁴ and in general medicine have been shown to rarely engage in inclusive language when discussing sexuality with teenagers.¹⁸⁶

Health services providing optimal care to AYA with cancer should:

- offer healthcare provider training on issues of minority distress and healthcare disparity for LGBT; unique cancer risks, engagement in health prevention and surveillance; and social and cultural competency such as understanding heteronormative bias and importance of inclusive language for all AYA^{185,186,353,355}
- adopt institutional implementation of LGBT-inclusive practices^{29,356}
- encourage and acknowledge the importance of partners in the cancer journey and recovery process³⁵⁷
- acknowledge and be aware of the potential for increased mental health distress and offer access to additional psychosocial supports
- ensure sexual orientation, gender identity, pronouns and names are incorporated in patient record demographics³⁵⁶
- promote LGBT AYA research and collaboration with key stakeholder groups, practising a co-design model to inform and implement high-quality care.¹⁸⁵

Appendix B: Complementary therapies

Complementary therapies may be used together with conventional medical treatments to support and enhance quality of life and wellbeing. They do not aim to cure the patient's cancer. Instead, they are used to help control symptoms such as pain and fatigue.³⁵⁸

The lead clinician or health professional involved should discuss the AYA's use (or intended use) of complementary therapies not prescribed by the multidisciplinary team to assess safety and efficacy and to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base. A transparent and honest discussion that is free from judgement should be encouraged.

While some complementary therapies are supported by strong evidence, others are not. For such therapies, the lead clinician should discuss their potential benefits and use them alongside conventional therapies.³⁵⁹

If the AYA (or their family if applicable) expresses an interest in using complementary therapies, the lead clinician should consider referring them to health providers within the multidisciplinary team who have expertise in the field of complementary and alternative therapies (e.g. a clinical pharmacist, dietitian or psychologist) to assist them to reach an informed decision. Costs of such approaches should be part of the discussion with the patient and family and considered in the context of evidence of benefit.

The lead clinician should assure AYA who use complementary therapies that they can still access a multidisciplinary team review and encourage full disclosure about therapies being used.



More information

- See the Clinical Oncological Society of Australia's position statement *Use of complementary and alternative medicine by cancer patients* <https://www.cosa.org.au/media/1133/cosa_cam-position-statement_final_new-logo.pdf>.

Appendix C: Members of the AYA multidisciplinary team

The multidisciplinary team may include the following members:⁹

- AYA nurse coordinator/navigator
- AYA program lead
- AYA medical oncologist/haematologist clinical lead
- social worker
- mental health specialist
- physiotherapist and occupational therapist
- art and music therapists
- exercise physiologist
- palliative/supportive care clinician
- dietitian
- educational/vocational advisor
- fertility/sexual health clinician
- clinical trials representative.

Resource list

For AYA, families and carers

Advance Care Planning Australia

Advance Care Planning Australia provides national advance care planning resources for individuals, families, health professionals and service providers. Resources include a national advisory service, information resources, a legal forms hub and education modules.

Telephone: 1300 208 582

Website <www.advancecareplanning.org.au>

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre has developed information resources and events to help people move from initial treatment to post treatment and beyond, including those receiving maintenance treatments. While they do not provide clinical advice, they connect with a range of providers to enable improved care.

Telephone: (03) 8559 6220

Website <www.petermac.org/cancersurvivorship>

Beyond Blue

Beyond Blue provides information about depression, anxiety and related disorders, as well as about available treatment and support services.

Telephone: 1300 22 4636

Website <www.beyondblue.org.au>

Cancer Australia

Cancer Australia is a specialist agency within the Australian Government's Health portfolio, providing national leadership in cancer control across all cancers, for all Australians.

Cancer Australia's purpose is to minimise the impact of cancer, address disparities, and improve the health outcomes of people affected by cancer in Australia by providing national leadership in cancer control.

Cancer Australia achieves this by developing and promoting evidence-based best practice cancer care; providing consumer and health professional cancer information; funding priority cancer research; and strengthening national cancer data capacity.

Cancer Australia provides accessible, evidence-based information about cancer for people affected by cancer, carers and their families through the Cancer Australia websites, resource library and video content.

Website <www.canceraustralia.gov.au>

Cancer Council's Cancer Information and Support Service

Cancer Council 13 11 20 is a confidential telephone support service available to anyone affected by cancer. This service acts as a gateway to evidence-based documented, practical and emotional support available through Cancer Council services and other community organisations. Calls will be answered by a nurse or other oncology professional who can provide information relevant to a patient's or carer's situation. Health professionals can also access this service.

Telephone: 13 11 20 – Monday to Friday, 9.00am to 5.00pm (some states have extended hours)

Website <www.cancer.org.au/about-us/state-and-territory-councils>

Cancer Council's Cancer Connect

Cancer Connect is a free and confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience. A Connect volunteer can listen with understanding and share their experiences and ways of coping. They can provide practical information, emotional support and hope. Many people newly diagnosed with cancer find this one-to-one support very beneficial.

For more information on Cancer Connect call Cancer Council on 13 11 20.

Cancer Hub

Canteen, Camp Quality and Redkite are working together to provide Cancer Hub, designed to help families impacted by cancer more easily access the practical and emotional support they need, when they need it. Cancer Hub received funding from the Australian Government.

Website: <www.cancerhub.org.au>

Cancer Institute NSW

The web portal provides clear and simple information for those who have been diagnosed with cancer. It includes checklists and information on treatment and support that is available in eight languages (Arabic, Vietnamese, Greek, Korean, simplified Chinese, traditional Chinese, Spanish and Italian) in web, audio and video formats.

Website <www.cancer.nsw.gov.au/general-cancer-information/cancer-support/support-for-communities/multicultural-communities>

Canteen

Canteen helps adolescents, young adults and parents to cope with cancer in their family. Canteen offers individual support services, peer support services and a youth cancer service, as well as books, resources and useful links.

Telephone: 1800 835 932 to talk to a health professional about information and support for young people or 1800 226 833 for other enquiries.

Website <www.canteen.org.au>

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

Website <www.cancer.nsw.gov.au/general-cancer-information/cancer-support/coping-with-cancer/physical-wellbeing/eating-well>

Guides to best cancer care

The short guides help patients, carers and families understand the optimal cancer care that should be provided at each step. They include optimal timeframes within which tests or procedures should be completed, prompt lists to support patients to understand what might happen at each step of their cancer journey and to consider what questions to ask and provide information to help patients and carers communicate with health professionals. The guides are located on an interactive web portal, with downloadable PDFs available in multiple languages.

Website <www.cancercareguides.org.au>

headspace

headspace is the National Youth Mental Health Foundation providing early intervention mental health services to 12–25-year-olds. Headspace can help young people with mental health, physical health (including sexual health) alcohol and other drug services, and work and study support.

Website <www.headspace.org.au>

Look Good, Feel Better

A free national community service program, run by the Cancer Patients Foundation, dedicated to teaching cancer patients how to manage the appearance-related side effects caused by treatment for any type of cancer.

Telephone: 1800 650 960

Website <www.lgfb.org.au>

Quitline

Quitline is a confidential, evidence-based telephone counselling service. Highly trained Quitline counsellors use behaviour change techniques and motivational interviewing over multiple calls to help people plan, make and sustain a quit attempt. Quitline is a culturally inclusive service for all, and Aboriginal counsellors are also available. Health professionals can refer patients to Quitline online or via fax.

Telephone: 13 7848

Website <www.quit.org.au> or the relevant website in your state or territory

Redkite

Redkite provides the practical, emotional and financial support for families who have a child with cancer aged 18 or under.

Website <www.redkite.org.au>

Sony Foundation You Can Initiative

The You Can initiative is a partnership with Canteen and the Australian Government to establish a network of youth cancer centres. In particular, the Sony Foundation provides free accommodation to regional AYA who require treatment in metropolitan cancer centres.

Website <www.sonyfoundation.org/youcanstay>

Youth Cancer Services

Youth Cancer Services are hospital-based multidisciplinary teams providing care and support for 15–25-year-olds with cancer. There are five Youth Cancer Service lead sites across Australia, such that all young people with cancer should have access to age-appropriate psychosocial care. Youth Cancer Services are funded by the Australian Government, Canteen and state health departments. The website provides information for patients and healthcare providers on Youth Cancer Services and many aspects of cancer treatment and life after cancer for young people.

Website <www.canteen.org.au/youth-cancer>

For health professionals

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre provides expertise in survivorship care, information, support and education. Its purpose is to support and enable optimal survivorship care.

Telephone: (03) 8559 6220

Website <www.petermac.org/cancersurvivorship>

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a guide for clinicians containing evidence-based strategies to support clinicians to understand and fulfil their responsibilities to cancer patients. This guide is particularly relevant to Steps 3 to 6 of the optimal care pathway. The guide is titled NSQHS Standards user guide for medication management in cancer care for clinicians.

Australian & New Zealand Children's Haematology/Oncology Group

ANZCHOG is the peak professional body for paediatric oncologists, nurses and allied health staff caring for children and adolescents with cancer and their families. ANZCHOG offers information on clinical trials, research, biobanking, and clinical guidelines relating to cancer in children.

Website <www.anzchog.org>

Cancer Australia

Cancer Australia provides evidence-based information for health professionals including guidance, cancer learnings, cancer guides, reports, resources, videos, posters and pamphlets.

Website <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority.

Website <www.cancer.org.au>

Canteen

Canteen helps adolescents, young adults and parents to cope with cancer in their family.

Canteen offers individual support services, peer support services and a youth cancer service, as well as books, resources and useful links.

Telephone: 1800 835 932 to talk to a health professional about information and support for young people or 1800 226 833 for other enquiries.

Website <www.canteen.org.au>

eviQ

A clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment.

Website <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment.

Website <www.nhmrc.gov.au>

Youth Cancer Service

Youth Cancer Services are hospital-based multidisciplinary teams providing care and support for 15–25-year-olds with cancer. There are five Youth Cancer Service lead sites across Australia, such that all young people with cancer should have access to age-appropriate psychosocial care. Youth Cancer Services are funded by the Australian Government, Canteen and state health departments. The website provides information for patients and health care providers on Youth Cancer Services and many aspects of cancer treatment and life after cancer for young people.

Website <www.canteen.org.au/youth-cancer>

Glossary

advance care directive – voluntary person-led document that focuses on an individual's values and preferences for future health and medical treatment decisions, preferred outcomes and care. They are completed and signed by a competent person. They are recognised by specific legislation (statutory) or common law (non-statutory). Advance care directives can also appoint the substitute decision-maker(s) who can make decisions about health or personal care on the individual's behalf if they are no longer able to make decisions themselves. Advance care directives focus on the future health care of a person, not on the management of his or her assets. They come into effect when an individual loses decision-making capacity.

advance care planning – the process of planning for future health and personal care, where the person's values, beliefs and preferences are made known so they can guide decision making at a future time when that person cannot make or communicate their decisions.

alternative therapies – treatments used in place of conventional medical treatment.

care coordinator – the health provider nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and the location and care in which care is being delivered.

complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

end-of-life care – includes physical, spiritual and psychosocial assessment, and care and treatment, delivered by health professionals and ancillary staff. It also includes support of families and carers and care of the patient's body after their death.

genomics – the study of multiple genes and their relationships with one another.

indicator – a documentable or measurable piece of information regarding a recommendation in the optimal care pathway.

lead clinician – the clinician who is nominated as being responsible for individual patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

metastatic disease – cancer that has spread from the part of the body where it started (the primary site) to other parts of the body.

multidisciplinary care – an integrated team approach to health care in which medical and allied health providers consider all relevant treatment options and collaboratively develop an individual treatment plan for each patient.

multidisciplinary team – comprises the core disciplines that are integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

multidisciplinary team meeting – a meeting of health professionals from one or more clinical disciplines who together make decisions about recommended treatment of patients.

optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care for all people affected by cancer.

performance status – an objective measure of how well a patient can carry out activities of daily life.

primary care health professional – in most cases this is a general practitioner (referred to as such within this document) but may also include general practice nurses, community nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists and Aboriginal health workers.

spiritual care – the aspect of humanity that refers to the way people seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

supportive care – care and support that aims to improve the quality of life of people living with cancer, cancer survivors and their family and carers and particular forms of care that supplement clinical treatment modalities.

survivorship – a person is considered a cancer survivor from the time of diagnosis, and throughout their life; the term includes individuals receiving initial or maintenance treatment, in recovery or in the post-treatment phase.

survivorship care plan – a formal, written document that provides details of a person's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up, surveillance, and strategies to remain well.

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