



Australian Government
Cancer Australia



National Service Delivery Framework for Adolescents and Young Adults with Cancer



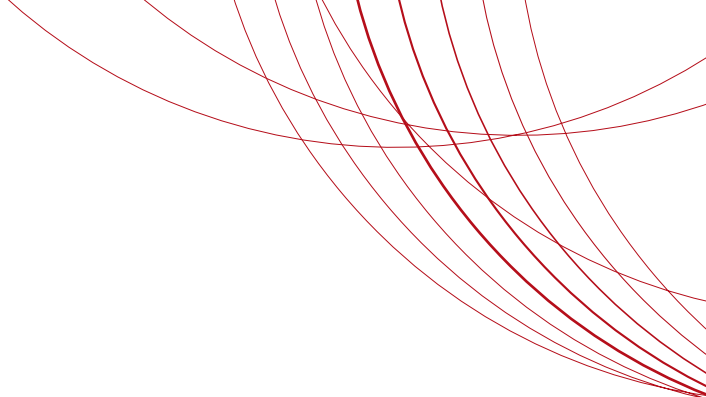
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Australian Government (2008) through Cancer Australia in collaboration with CanTeen
National Service Delivery Framework for Adolescents and Young Adults with Cancer

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**National Service
Delivery Framework**
for Adolescents and
Young Adults with Cancer

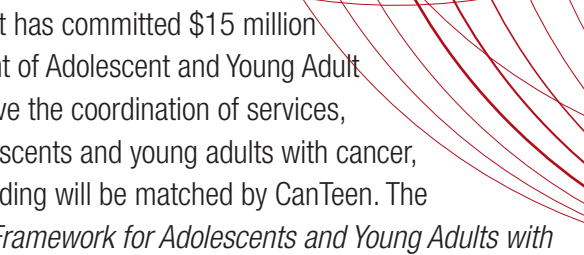


Foreword

For all people, cancer is a significant life event and even more so for adolescent and young adults. Our young people are adapting to crucial developmental tasks of psychosocial, physical and sexual maturity. Furthermore, they are also acquiring skills needed to carry out adult roles, taking responsibility for their own life style choices with increased autonomy from parents and, developing relationships with peers and partners. To add a cancer diagnosis on top of such rapid change significantly compounds an often demanding stage. The care and support required during this time includes sensitivity, responsiveness and effective coordination of services in order to respond to the complete needs of adolescents, young adults, their partners and families.

CanTeen and Cancer Australia jointly developed the *National Service Delivery Framework for Adolescents and Young Adults with Cancer* with the invaluable and substantive input from consumers, health professionals and personnel from the state, territory and Commonwealth governments, who are all committed to the delivery of best practice care. This document sets out a National Framework for adolescent and young adults with cancer that articulates the coordinated service delivery that meets their particular needs.

While the Framework has been developed specifically for adolescents and young adults, the method of taking a national approach to the development of quality models of care may be generalised for other populations requiring a targeted approach. Successful implementation of the *National Service Delivery Framework for Adolescents and Young Adults with Cancer* calls for leadership across all areas of health care and will require resources in workforce, training, and data systems.



The Australian Government has committed \$15 million to support the development of Adolescent and Young Adult Cancer Networks to improve the coordination of services, support and care for adolescents and young adults with cancer, and their families. This funding will be matched by CanTeen. The *National Service Delivery Framework for Adolescents and Young Adults with Cancer* will support the Adolescents and Young Adults Cancer Networks by providing a foundation for best practice care for adolescents and young adults with cancer.

We look forward to the successful implementation of best practice care for our young people.



Dr Andrew Young
CanTeen

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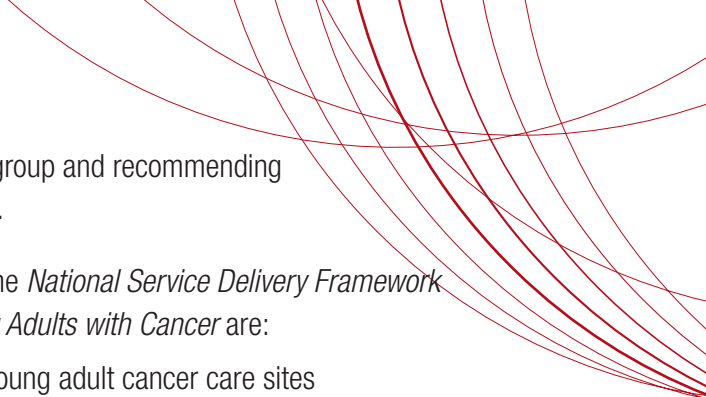
Executive summary

The *National Service Delivery Framework for Adolescents and Young Adults with Cancer* provides a national framework for quality local cancer care for adolescents and young adults. It is the result of collaboration by key stakeholders from around the country—adolescents and young adults affected by cancer, private and public sector oncologists, surgeons, epidemiologists, researchers, educators, general practitioners, nurses, psychologists and clinicians with experience in paediatric and adult cancer care.

Cancer Australia brought together key stakeholders to form the National Reference Group for Adolescents and Young Adults with Cancer. At its first meeting, in May 2007, the reference group identified ways to reduce the impact of cancer on young Australians affected by cancer. They recommended the development of a national service delivery framework. Following this meeting, CanTeen, a consumer support organisation for adolescents and young adults with cancer, approached Cancer Australia to work in partnership with it to develop the framework.

In developing the framework, CanTeen and Cancer Australia consulted consumers, health professionals and service providers across Australia, the Cancer Australia Advisory Council and the intergovernmental Strategic Forum established by Cancer Australia. They reviewed the National Service Improvement Framework for Cancer and state and territory cancer plans, as well as similar adolescent and young adult service improvement frameworks in the United Kingdom and New Zealand.

The framework focuses on the service delivery needs of adolescents and young adults affected by cancer to optimise equitable outcomes for this group. It follows the adolescent and young adult cancer journey, identifying



the specific needs of this group and recommending a cancer service response.

The five key elements of the *National Service Delivery Framework for Adolescents and Young Adults with Cancer* are:

- lead adolescent and young adult cancer care sites
- access to support services and clinical trials
- comprehensive assessment at diagnosis
- coordinated care to empower adolescent and young adult decision making
- expert multidisciplinary teams skilled in adolescent and young adult cancer care.

Scope

The Australian Government has recognised the need to develop an improved model of care for adolescents and young adults affected by cancer. The 2005 Senate Community Affairs References Committee report *The cancer journey: informing choice* recommended that Cancer Australia consider the particular difficulties confronted by young people with cancer.

With this mandate, Cancer Australia established the National Cancer Reference Group for Adolescents and Young Adults with Cancer. In May 2007, the reference group prioritised the development of the National Service Delivery Framework for Adolescents and Young Adults with Cancer. The framework was developed after reviewing the best evidence available nationally and internationally and consulting adolescent and young adult consumers, health professionals, cancer support organisations, and researchers across Australia.

Objectives

The aim of the framework is to maximise survival and quality-of-life outcomes for young people affected by cancer and to enhance supportive care services for them and their families. The framework:

- focuses on aspects of service delivery most likely to significantly improve survival rates of young people and to enhance the short- and long-term quality-of-life outcomes for them, their families and carers
- articulates a model for the care of young people affected by cancer, based on the best available evidence
- sets an aspirational national framework for achievement over five years.

Limitations

The framework has three major limitations:

- It does not detail the staffing and infrastructure investment requirements, which will be set out in a companion document after agreement on a national service framework.
- It does not calculate improved health or quality-of-life outcomes.
- It does not dictate how states or territories might build on unique local initiatives to achieve quality adolescent and young adult care.

Key elements

Improving the model of care for adolescents and young adults affected by cancer involves five key elements:

- lead adolescent and young adult cancer care sites
- access to support services and clinical trials
- comprehensive assessment at diagnosis
- coordinated care to empower adolescent and young adult decision making
- expert multidisciplinary teams skilled in adolescent and young adult cancer care.

Definitions

'Adolescents and young adults' (AYA) have been defined as a term for the purposes of the AYA Framework. In addition, 'cancer services' have been defined to categorise the formalised AYA cancer care sites.

Adolescents and young adults

In the context of the framework, whenever the term 'adolescents and young adults' is used, it is generally meant to refer to young people between 15 and 25 years of age. It is used interchangeably with the term 'young people'. At an individual level, a clinician may determine that someone outside the age range falls into the category of an adolescent or young adult in order to provide access to care services. The clinician will make the decision based on the type of cancer and the physical, psychosocial, and emotional needs of the young person with cancer.

As much of the literature uses the acronym AYA to mean 'adolescent and young adult', this framework sometimes uses the acronym before common nouns to mean relevant to or applying to adolescents and young adults. The plural form of the acronym is also used in tables to mean 'adolescents and young adults'.

Cancer services

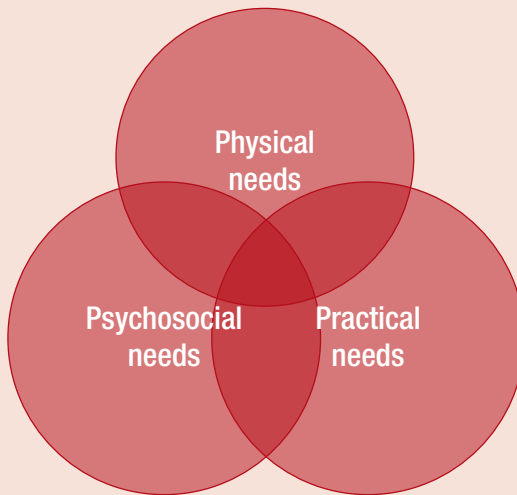
Cancer services are all organised networks of clinicians and other health professionals, encompassing, primary, secondary, and tertiary care, with recognised skills and competencies in adolescent and young adult care in the public or private sector. Cancer services integrate general practitioners, cancer centres, units, and networks to deliver high-quality, effective services for adolescents and young adults.

Needs of young people with cancer

While Australia has already recognised the particular needs of children affected by cancer, it is now responding to the distinct needs of adolescents and young adults affected by cancer. Both paediatric and adult oncology and haematology services currently provide cancer care for this age group, but existing services within these sectors may not be meeting their needs appropriately. This framework aims to bring together paediatric and adult cancer care providers to build expertise in adolescent and young adult health to improve AYA cancer care.

Young people with cancer have unique health needs that affect their quality of life, their long-term health, and their engagement in society, education, and employment. Health professionals working with young people with cancer must be conscious of these physical, psychosocial, and practical needs.

Figure 1 Needs of young people with cancer



Physical needs

Fertility

Young people with cancer need to understand how cancer treatments may affect their fertility and how to maximise the potential preservation of that fertility. When a treatment plan may threaten or affect future fertility, young people need to consult a fertility counsellor to explore their future fertility options.

Nutrition

Young people with cancer need to understand how cancer treatment may affect their nutritional requirements. During adolescence young people grow rapidly and have to come to terms with a new body image. Dieticians may help young people with cancer understand their food choices and how best to support healthy growth and development.

Acute toxicity

Young people with cancer who are receiving intensive chemotherapy or radiation therapy may experience side effects and need high-dose analgesia, complex nutritional support, prolonged antibiotic treatment, and multiple blood product transfusions. They require age-specific information about toxicities. The multidisciplinary management of side effects must take account of age-specific responses to toxicities.

Mobility and cognitive function

Cancer therapies may affect mobility, cognitive function, or both. Some young people with cancer need to have access to professionals who can help them optimise their mobility and cognitive function both during and after treatment. Similarly, a permanent change in mobility or cognitive function may mean that young people need help to readjust their career or hobby objectives.



Late effects

Young people undergoing cancer treatment need to have their risk of late effects assessed at the completion of treatment and to be monitored over time to proactively address issues that may impair their long-term physical function. Late effects include impaired endocrine function, cardiac and neurological impairment, cognitive decline, psychological effects, and increased risk of developing a second cancer.

Survivorship

Survivorship begins when the cancer treatment has ceased. Young people then have to adjust to the cessation of intensive treatment; to adapt, or re-engage in, former activities, hobbies, and sport; and to cultivate a general sense of health and wellbeing. Young people with cancer report that their needs in survivorship are not being met.

Psychosocial needs

Emotional, cognitive and personal

Adolescents and young adults are in a transformative stage of their psychological development, which affects their social behaviour. As young people become increasingly independent, they make decisions about sexual relations, alcohol, drugs, and peer interactions. Young people diagnosed with cancer are not immune from the psychosocial pressures common to those aged between 15 and 25. In addition, the cancer experience will further shape psychosocial and psychosexual identity.

Health professionals must be able to discuss issues with young people openly and honestly and provide support when needed. Young people whose cancer

is incurable have a unique set of age-related psychosocial needs associated with facing mortality.

Fortunately, the majority of young people diagnosed with cancer are expected to survive. They will move on from the challenges of cancer to face the challenges of adult life. Health professionals are responsible for ensuring that young people with cancer optimise their psychosocial and psychosexual development.

Peers

Social interactions are highly significant to young people. They need to engage with their peers during and after cancer treatment. During hospital stays, adolescents and young adults would like to be with others their own age. After treatment, young people may need help to find opportunities to cultivate peer support or to re-engage with peers with whom they have lost touch.

Families and carers

Adolescents and young adults affected by cancer may be dependent on their families or other carers (including partners) during the course of their cancers. The debilitating illness or death of a young person has a profound effect on people close to them. Being attentive to these relationships is important in service delivery.

Spiritual

The need for appropriate spiritual or pastoral care is often discussed in conjunction with palliative care. Access to such support may be relevant to young people with cancer and their families and carers throughout the cancer journey.



Existential

Existential issues include questions of life and death, life direction, purpose and meaning. At a stage of life when their peers have a sense of invincibility, young people affected by cancer can find it confronting to have an illness that may result in death.

A cancer experience may compel a young person to re-envision their life and live with greater purpose or to feel hopeless and therefore require significant psychosocial support. Confronting existential issues may require specific support from skilled professionals.

Grief and loss

Grief and loss support is needed for young people facing an incurable illness and for their families and friends.

Within families, the needs of siblings, in particular, must be addressed. Friends and the wider community can also be affected and may also require support. Services should be tailored and responsive to individual family needs, including their spiritual and cultural needs.

Practical needs

Educational

Young people attending school or university and who are undergoing cancer treatment might need help to keep up with classes or with reintegration into the classroom. This may require additional educational assistance, and involve liaising with teachers or school administrators, or talking to the school community about cancer.

Vocational

The intensity of cancer treatment may have a significant impact on young people's ability to find or maintain work. They may need help with discussing leave with their supervisors or with their reintegration into the workplace once they are ready to return to, or start, work. Some may need help with choosing appropriate career options after treatment.

Financial

The financial costs of undergoing cancer treatment are significant. Young people with cancer may incur costs for medical treatments, pharmaceutical products, supportive therapies, and transport. Additionally, it is sometimes impractical for them or their parents or carers to maintain paid employment during treatment, resulting in significantly reduced income.

Rural and regional

Rural and regional access to care is important in all cancer services. According to the Australian Institute of Health and Welfare's report, *Young Australians: their health and wellbeing 2007*, 68 per cent of young people live in major cities, 21 per cent in inner regional areas, 9 per cent in outer regional areas, and 2 per cent in remote and very remote areas. To meet the need for access, innovative methods of providing ongoing care with well-defined linkages across rural, regional, and urban boundaries need to be determined and formalised to enable young people with cancer who live in rural and regional areas to receive quality care through lead AYA cancer care sites and locally.

Cultural

Attention to cultural needs is important in all cancer services. Healthcare providers must recognise the cultural values, beliefs, and language barriers that may influence service effectiveness. Cultural needs should be considered in consultation with young people and their families to optimise service design and delivery.

Service delivery

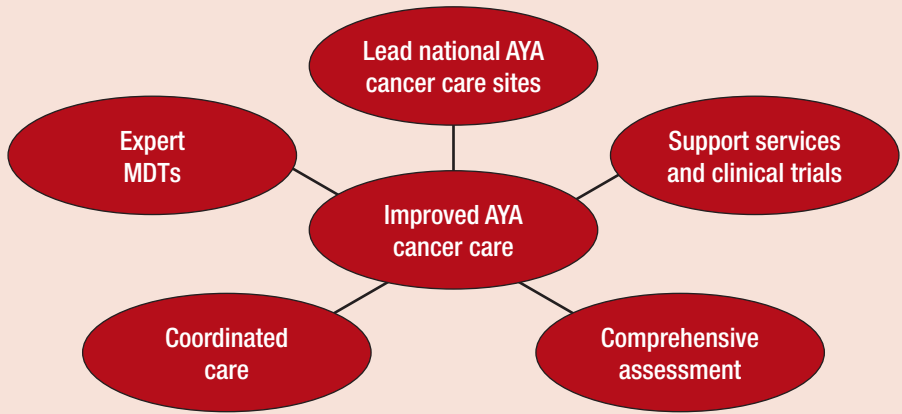
This component explores in detail the essential elements of the framework, including the service delivery response that aims to address the needs of young people with cancer.

General principles

With the aim of addressing the key needs of adolescents and young people affected by cancer, the national service delivery framework is based on the following general principles:

- establish a nationally mapped network to deliver high-quality cancer services for adolescents and young adults through lead sites with robust linkages to local care
- increase access to adolescent and young adult support services and increase access to and enrolment in clinical trials
- provide the opportunity for every adolescent and young adult to be assessed at diagnosis by medical and psychosocial clinicians skilled in adolescent and young adult care
- facilitate access to care coordination for every adolescent and young adult throughout the cancer journey and involve them in decision making about their treatment and support options
- ensure that multidisciplinary teams (MDTs) have the expertise to manage adolescent and young adults with cancer.

Figure 2 Key elements of improved adolescent and young adult cancer care



Lead adolescent and young adult cancer care sites

Lead adolescent and young adult cancer care sites are at the centre of a network of improved service delivery to young people with cancer. Sites will be established nationally, with age-appropriate facilities to treat and support 15- to 25-year-olds. The minimum population served by the lead adolescent and young adult site will be approximately two million, but such a network could serve a population of up to four million. This is likely to translate to six lead adolescent and youth adult sites around the country. Lead adolescent and young adult sites will have access to the full range of therapeutic options, as well as paediatric, adolescent, and adult cancer specialists.

Support services and clinical trials

The lead adolescent and young adult cancer sites will serve as the base for the psychosocial support teams. Other treating facilities in the network may call on the sites for expert support for treatment or support services. The sites will provide expert advice linkages for local practitioners and direct support

as required. Lead adolescent and young adult sites will offer clinical trials for young people, with robust links to other institutions caring for young people in the network.

Comprehensive assessment at diagnosis

Every young person is entitled to a comprehensive needs assessment at diagnosis. The comprehensive assessment includes both a medical and a psychosocial assessment. The comprehensive assessments will take place at a lead adolescent and young adult site. However, the place of subsequent treatment will be considered on a case-by-case basis, depending on tumour type and supports required. The psychosocial assessment will be conducted by a member of the psychosocial MDT, based at the lead site. The medical component will be conducted by a medical MDT with speciality in the tumour stream. The medical MDT will take advice from relevant medical specialists located throughout the network. Treatment plans will be developed based on both components of the assessment. A key clinical worker will be designated to share the treatment plan and any options with the young person with cancer.

Coordinated care

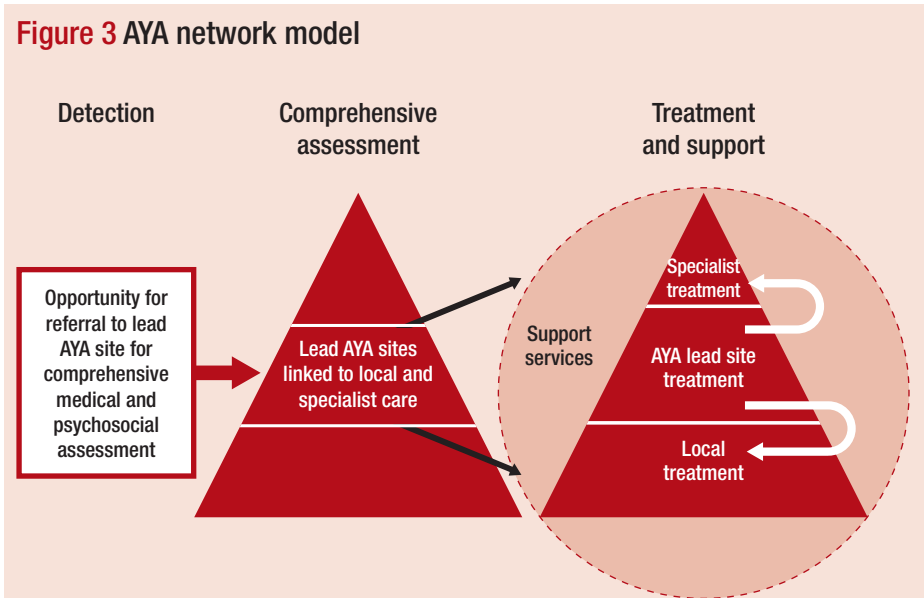
Central to the improved model of care is better care coordination across treatment settings—local, national lead sites, and specialist care. This will be discussed in detail below (see ‘Care coordination’).

Expert multidisciplinary teams

Multidisciplinary care through an MDT will be offered to adolescents and young adults with cancer. The improved model of care incorporates both medical and psychosocial MDTs. Medical MDTs will represent tumour-specific expertise. Psychosocial MDTs will care for adolescents and young adults across the range of cancers. The teams will be integrated, with a designated

lead adolescent and young adult clinician as the interface between the MDTs. A designated clinician will be assigned responsibility for the treatment plan. Expert MDTs will be discussed in detail below (see 'Multidisciplinary care'). Figure 3 gives an overview of the AYA network model.

Figure 3 AYA network model



AYA cancer journey

Figure 4 depicts the elements of the AYA cancer journey. The AYA needs described in tables 1 and 2 (below) are distilled from a number of sources, including AYA consumers, the National Service Improvement Framework for Cancer, the National Reference Group for Adolescents and Young Adults with Cancer, key service providers, and state and territory cancer plans (see ‘Key evidence papers informing AYA cancer journey’ referenced at the end of this document).

Figure 4 Elements of the AYA cancer journey

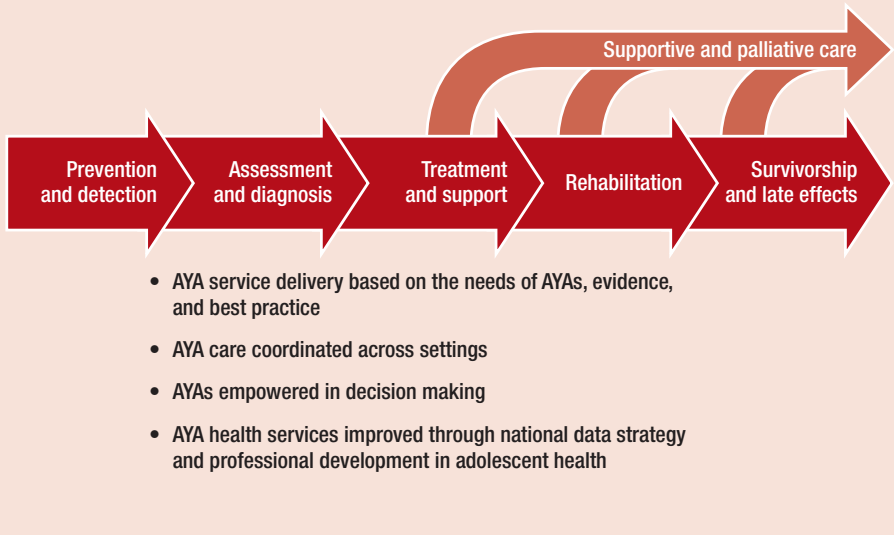


Table 1 addresses AYA needs by making recommendations that will improve the delivery of AYA services and help ensure equitable outcomes at specific stages of the cancer journey.

Table 1 Addressing AYA needs at specific stages of the cancer journey

Specific stage	AYAs need:	National Service Delivery Framework
Prevention and detection	<ul style="list-style-type: none"> a better understanding of cancer and how to minimise their cancer risks over a lifetime 	Mechanisms will be formally established to link AYAs to ongoing public health initiatives on cancer risks and preventative vaccines
	<ul style="list-style-type: none"> to have their cancer found as early as possible 	Cancer services will provide expert advice, identifying AYA cancer risks and symptoms
Assessment and diagnosis	<ul style="list-style-type: none"> their support needs (and those of their families and carers) recognised promptly and attended to throughout the cancer journey 	Cancer services will provide the opportunity for all AYAs to receive a comprehensive needs assessment at diagnosis
	<ul style="list-style-type: none"> an explanation of their cancer journey, including the support available to them 	Cancer services accepting responsibility for treating AYAs will provide a treatment plan for the cancer journey
	<ul style="list-style-type: none"> to be told honestly and clearly about their care treatment options 	Cancer professionals will communicate appropriately with AYAs and their families and carers about the treatment plan
	<ul style="list-style-type: none"> access to accurate information about their cancer and support services for themselves and their families and carers 	Cancer services will provide accurate information on AYA cancers and services via a customised national AYA cancer website

Specific stage	AYAs need:	National Service Delivery Framework
Treatment and support	<ul style="list-style-type: none"> access to appropriately skilled medical multidisciplinary teams for themselves, their families and carers 	Cancer services will determine the membership of each medical multidisciplinary team (MDT) and base those on tumour stream and evidence
	<ul style="list-style-type: none"> to know that their treatment plan complies with the best available evidence 	MDTs of tumour stream experts will review treatment plans in line with the best available evidence
	<ul style="list-style-type: none"> access to disease-appropriate expertise, regardless of where they live 	MDTs of tumour stream experts will advise on treatment plans via telemedicine, where necessary
	<ul style="list-style-type: none"> to understand clinical trial and to be able to participate in those, where appropriate 	Cancer services will provide links to a database of open clinical trials with benefits, risks and outcomes of participation described to AYAs
	<ul style="list-style-type: none"> access to age-appropriate care environments 	Cancer services will provide age-appropriate care environments at lead national AYA cancer sites
	<ul style="list-style-type: none"> to have access to information for themselves, their families and carers on possible psychosocial issues that may arise during treatment 	Cancer services will provide access to a psychosocial MDT including a psychologist, social worker, physiotherapist, and educational or vocational adviser based on need
	<ul style="list-style-type: none"> access to the best and most appropriate care, regardless of where they live or their cultural or linguistic backgrounds 	Cancer services will provide rural and regional access to AYA services and cultural and linguistic support where required
Rehabilitation	<ul style="list-style-type: none"> to limit the impact of the cancer on their daily lives and that of their families and carers 	Cancer services will address AYA rehabilitation needs, including those needs involving families and carers
	<ul style="list-style-type: none"> access to support that will allow them to maintain a maximum level of independence and physical, psychological and social functioning 	Cancer services will provide an up-to-date local AYA support service directory for ongoing professional and peer support

Specific stage	AYAs need:	National Service Delivery Framework
Supportive and palliative care	<ul style="list-style-type: none"> • symptom control and supportive management throughout their illness and timely and integrated access to palliative care 	Appropriate symptom control and support will be available and palliative care services will be introduced early, particularly for those with progressive disease
	<ul style="list-style-type: none"> • need support in discussing their prognosis and in issues related to end of life for themselves, their families and carers 	Cancer professionals will communicate with patients and their families and carers about palliative care options
Survivorship and late effects	<ul style="list-style-type: none"> • to have a record of their treatment for future reference 	AYAs will receive a full record of their treatment from cancer services—both in hardcopy and in electronic form Cancer services will liaise with GPs and local care providers in order to be involved in the survivorship plan, which will anticipate and address late effects
	<ul style="list-style-type: none"> • to know what may happen to them at and following the completion of treatment 	Cancer services will provide consistent discharge plans documenting the full range of health needs and screening plan in hard copy and electronically
	<ul style="list-style-type: none"> • peer and professional support as part of survivorship 	Cancer services will connect AYAs to peer and professional support networks
	<ul style="list-style-type: none"> • information about and help dealing with the uncertainty and fear of recurrence and side effects of treatments and disease 	Cancer services will liaise with GPs and local care providers for follow up care with an AYA survivorship plan to anticipate and address late effects

At various stages of the cancer journey, young people with cancer will have the specific needs that are set out in Table 1. In addition, at all stages of the cancer journey they will have particular needs in relation to care coordination and decision making, and health services. Those needs are set out in Table 2 (below).

Table 2 Addressing AYA needs throughout the cancer journey

All stages services	AYAs need:	National Service Delivery Framework
<p>Care coordination and decision making services</p>	<p>AYAs and their families and carers want to experience cancer treatment across settings as seamlessly as possible</p> <p>AYAs need to be empowered to make decisions, but in the context of the legal responsibilities of their parents and guardians</p>	<p>A clinical professional will be designated to assist AYAs navigate the system and will communicate options, identify support resources, and share information across treatment settings with them</p> <p>Cancer care professionals will share information about risks and benefits of treatment options with AYAs in a timely manner and with respect for their privacy</p>
<p>Health services</p>	<p>AYAs need cancer professionals who understand adolescent health and developmental needs</p> <p>AYAs need to see increased participation in clinical trials for their age group over time</p> <p>AYAs need good shared care protocols to be able to be treated close to home when possible</p> <p>AYAs need reliable data collection at a national level to improve treatment efficacy over time</p>	<p>Cancer services will work with medical and health professional groups to promote professional training in adolescent health</p> <p>Cancer services and professional research groups will work to reduce barriers for AYA participation in clinical trials</p> <p>Cancer services will establish shared care protocols for AYA collaborative care</p> <p>Cancer Australia will work with lead national sites to develop a consistent minimum dataset for AYA cancers</p>

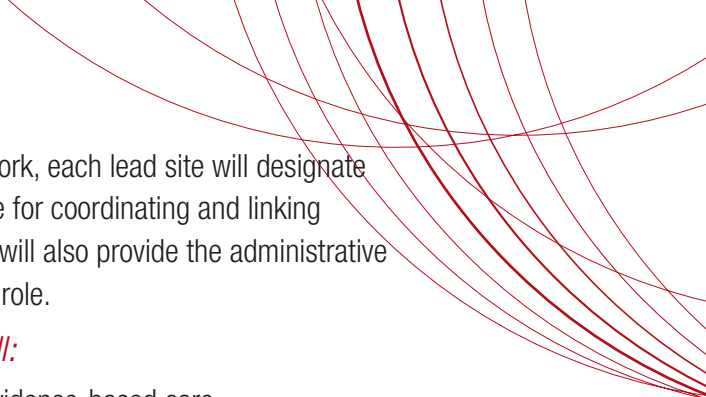
Lead AYA cancer care sites

Lead AYA cancer care sites will feature age-appropriate care facilities. These facilities will be specifically designed to treat 15- to 25-year-olds, but their use will be subject to clinical discretion related to tumour type and maturity.

The AYA cancer care sites will ideally be located at a campus with major adult and paediatric hospitals or at an adult hospital with strong linkages to a paediatric facility, and will provide access to the range of medical therapies and paediatric and adult cancer specialists. Adolescents and young adults see themselves more as adults than as children and would prefer AYA units to be co-located with adult facilities. Paediatric centres that support adolescents and young adults need to be aware of this preference.

The AYA cancer sites will act as centres of excellence for the network. Other treatment facilities will be able to call on professionals at the lead sites for expert advice on treatment or support services. The psychosocial MDTs will be based at each lead AYA site, interacting remotely with young people requiring care closer to home. AYA clinical trials will be coordinated by the lead AYA sites.

The sites will be designed and run to facilitate peer interaction among adolescents and young adults who need hospital care. Education facilities will be set up with computing and internet connections. Young people will have contemporary and age-appropriate spaces for relaxation and suitable spaces will be set up for their family and friends. The Teenage Cancer Trust units in the UK provide examples of age-appropriate environments for young people. Adolescents and young adults should be engaged in the design of services for the lead AYA cancer sites and networks.



To bring together the network, each lead site will designate a lead clinician responsible for coordinating and linking the network. The lead site will also provide the administrative support necessary for this role.

The lead clinician will:

- ensure high-quality, evidence-based care
- communicate with comprehensive assessment MDTs
- provide leadership within the AYA network
- coordinate AYA research and clinical trials
- promote AYA health education and training opportunities
- support formalised links to local settings.

Access to support services and clinical trials

Rural and regional access must be considered in any cancer delivery service in Australia. Young people with cancer who live far from any medical care facility face additional burdens, such as the need to travel for certain treatments and the corresponding dislocation from home support networks, and logistical concerns related to arranging accommodation and travel for their families and carers. Key clinical workers should ensure that rural and regional young people have full access to existing resources and support for travel and accommodation. Additionally, when possible, MDTs should consider telemedicine, videoconferencing and other innovative methods of providing ongoing AYA care.

Detailed information on access to clinical trials can be found in the 'Clinical trials, research and data' section on page 35.

Comprehensive assessment at diagnosis

All young people will benefit from a comprehensive assessment at diagnosis to ensure all their needs are met and their follow-up care is coordinated.

Comprehensive assessment refers to a medical multidisciplinary team with expertise in tumour specific care and psychosocial multidisciplinary teams with expertise in adolescent and young adult health.

Care coordination

Care coordination is central to improved AYA cancer services. A role will be designated to assist young people to navigate the system, communicate options, identify support resources, and share information across treatment settings. For the purpose of the framework, this role will be referred to as the ‘key clinical worker’. The key clinical worker will have the expertise and training to manage the care needs of young people and their families as they move between care settings along the cancer journey. The role is necessarily broad and will depend upon individual need, total caseload, geographical spread of the services, and pre-existing AYA services and resources. Key clinical workers need to be involved with the young person as soon as possible after presentation so they can ensure that care is coordinated from the beginning—starting with the comprehensive needs assessment—and throughout the cancer journey.

This role will be held by someone who has the skills and knowledge to provide clinical information and answers to improve a young person’s capacity to make informed decisions about their care. The key clinical worker will have sufficient experience in adolescent health to contribute to care planning and will possess clinical expertise to respond to ad hoc inquires. Coordinated care aims to furnish the young person with an understanding of the decision-making process and their options, with their associated implications, so that the young person’s perspective is reflected throughout their cancer journey.

A key clinical worker will:

- provide care navigation throughout the cancer journey
- be assigned to the case at comprehensive assessment
- attend medical MDT and psychosocial MDT meetings
- empower young people to make informed decisions
- access answers to clinical questions and resources for clinical needs
- liaise across network boundaries.

This role will be based at a lead site and will liaise with the relevant medical MDT and the psychosocial MDT, as well as with local care providers and general practitioners where relevant. When young people with cancer move or travel interstate for treatment, the key clinical worker will liaise with other key clinical workers across state lines to maintain quality care. Key clinical workers have the responsibility to share options with young people with cancer in a timely manner and with respect for their privacy.

The key clinical worker may change as care needs vary across the cancer journey.

Multidisciplinary care

There is increasing evidence that multidisciplinary care improves cancer outcomes through timely and appropriate consultation, reduced timeframes from diagnosis to treatment, facilitated communication among health professionals with differing expertise, and increased participation in available clinical trials. Multidisciplinary care is typically conducted through a Multidisciplinary team (MDT).

Medical multidisciplinary teams

The constitution of the medical MDTs for AYAs will vary by cancer type. Typically, a medical MDT will include professionals from medical oncology, radiation oncology, palliative care, pathology, radiology, surgery, nursing, and a key clinical worker who can liaise across treatment settings.

The medical MDT will have tumour-specific expertise. Medical MDT composition at any one point along the cancer journey will vary, reflecting individual needs of AYAs as well as the expertise of particular team members. MDT membership should be explicit, with defined responsibility for clinical and managerial leadership and adequate administrative support.

Psychosocial multidisciplinary teams

The constitution of the psychosocial MDTs does not vary by cancer type but rather by a young person's psychosocial needs, which will be determined at diagnosis through a comprehensive needs assessment. The psychosocial MDT will care for young adults with a range of cancers.

Typically, a psychosocial MDT will include the treating oncologist or haematologist, the general practitioner, the psychologist, the social worker, the education or vocation adviser, the activities coordinator, workers in supportive and palliative care, and a key clinical worker who can liaise across treatment settings. External resources that may be engaged in specific cases include a fertility specialist, dietician, occupational therapist, pastoral care or spiritual adviser, physiotherapist, and psychiatrist.

Table 3 (below) shows the core members of the MDT at various stages in the AYA cancer journey.

Table 3 MDT members along AYA cancer journey

Engagement of clinicians and other health professionals across cancer care continuum	III	Assessment and diagnosis	Treatment and support	Supportive and palliative care	Survivorship and late effects
Comprehensive Assessment Medical MDT					
Lead AYA clinician		*			
Medical clinicians For example, oncologist/haematologist, radiologist, surgeon, pathologist, specialist nurses		*			
Key clinical worker		* **			
Comprehensive Assessment Psychosocial and Supportive MDT					
Psychosocial clinicians For example, psychologist, social worker, education adviser or vocation adviser, youth worker or activities coordinator, palliative care worker		**			
External consultants For example, fertility specialist, counsellor, dietician, occupational therapist, pastoral care, psychiatrist, physiotherapist		**			
Palliative and supportive care clinicians For example, palliative care clinician, nurses from inpatient and day care units, specialist nurse, specialist pharmacist			**		
General practitioner		**			
Outreach nurse				**	
Endocrinologist					**

Note: The table is for illustration only. Individual cases will vary.

* As member of medical MDT

**As member of psychosocial MDT

Health professionals

Health professionals skilled in adolescent and young adult health and cancer care are an essential component of the framework and will bring the expertise required for improved AYA cancer care. Health professionals involved in AYA care are pivotal in meeting AYA needs for the best possible outcome. The professional development needs of health professionals caring for adolescents and young adults are described below.

Professional development

Health professionals working with AYAs with cancer should have the opportunity to develop skills in adolescent health. A three-tiered approach to training modules for all disciplines working with AYAs is presented below. It is recommended that each health professional working in the lead AYA cancer care sites have at least basic level training in adolescent health. Over time, as the curriculum and opportunities for rotations are established, all medical and health professionals working in MDTs should have proficient or advanced level training.

Basic level training

Basic training is based on a generic teaching resource in adolescent health. It will cover general psychosocial, ethical, and societal aspects of managing cancer in young people. Basic training will include online training modules catering to a wide spectrum of disciplines working with adolescents and young adults. The Coventry University online course in the UK is an example of basic level training.

Proficient level training

Proficient level training covers topics related to adolescent and young adult health and oncology. The oncology training would emphasise how cancer in this age group differs in epidemiology, biology, clinical management and

outcomes. Proficient level training modules should be coordinated through agreements among departments, universities, and colleges.

Advanced level training

Advanced training would provide specialist training in AYA oncology. Existing professional training material for AYA cancer care requires further development and refinement of existing training modules in an Australian context. Health professionals interested in working with young people could arrange rotations with lead AYA sites as part of their advanced level training. In time, advanced training would include opportunities for exchanges and fellowships.

Collaboration with existing institutions

A number of institutions to develop and support professional training in adolescent health already exist in Australia, both as clinical departments of adolescent medicine and as dedicated teaching and training institutions:

- Department of Adolescent Medicine, Princess Margaret Hospital
- Department of Adolescent Medicine, Monash Medical Centre
- Department of Adolescent Medicine, Westmead Hospital
- Centre for Adolescent Health, Royal Children's Hospital, Melbourne
- NSW Centre for the Advancement of Adolescent Health, Children's Hospital at Westmead
- Youth Consultancy Service, Royal Prince Alfred Hospital, Sydney.

In addition, training could be offered through online courses. Cancer Australia has contracted the Centre for Innovation in Professional Health Education and Research at the University of Sydney to develop online professional

development packages for oncology health professionals. Cancer Learning (www.cancerlearning.gov.au) provides access to a single Australian directory to guide health professionals in their professional development. A major aim of Cancer Learning is to consolidate the rapidly growing variety of evidence-based learning activities, resources and information available from both within Australia and from overseas. All listed resources pass through a transparent evaluation process which is available on the site.

AYA health specialisation

Developing specialist knowledge and skills in adolescent health has the potential to improve outcomes for young adults as treatment and supportive care plans are developed to meet the needs of young and early adult people affected by cancer. Undertaking further research into this area will improve the evidence of AYA treatment and outcomes in both the short and long term.

Recruitment, retention, and self-care

Health workers caring for young people with cancer sometimes absorb the traumatic stress of those they serve, putting them at risk of high stress levels and compassion fatigue. The stress and burnout experienced by health professionals can also be detrimental to the effectiveness and productivity of the organisation.

To recruit and retain high-calibre professionals to work with adolescents and young adults, lead AYA sites will actively create a work culture that supports the health, safety, and wellbeing of its staff. Lead sites will encourage health professionals working in the field of AYA cancers to heed warning signs and engage in self-care to avoid burnout. Lead sites will communicate policies and procedures and implement training programs to enable health professionals to effectively deal with these issues.

Clinical trials, research, and data

Currently there is very little participation of adolescents and young adults in clinical trials. This results in limited evidence available about the best treatments for AYA cancer care and minimises the opportunities for best practice care. Similarly the lack of AYA specific data prevents identification of AYA improvement over time and reduces our ability to compare ourselves, nationally and internationally. Due to relatively small and dispersed numbers of adolescents and young adults diagnosed each year a coordinated effort is required to involve adolescents and young adults in clinical trials, prioritise AYA research priorities and, strengthen AYA data. This section describes a coordinated approach to these critical elements.

AYA clinical trials and research

Improved AYA research and participation in clinical trials is pivotal to attaining better long-term outcomes for AYAs with cancer. Whenever appropriate, AYAs with cancer should be treated on age-specific open multi-centre clinical trials. Garnering a critical mass of young people with cancer is a challenge, since the number of potential participants is relatively small. Therefore, lead AYA sites will serve as the centre for clinical trials in each state. They will work to increase participation by opening available trials to young people with cancer and by dedicating clinical trial resources for use by multiple institutions treating AYA cancers.

Addressing the lack of clinical trials available to adolescents and young adults requires clinician and researcher leadership and a focused strategy. Prioritisation will be based on clinical need, the likelihood of improving outcomes for young people with cancer, available resources and opportunities, and a demonstrated absence of access to trials. The strategy needs to include

a survey of existing treatment patterns and availability of clinical trials at a state and national level. Existing resources, including clinical oncology groups and researchers, should be involved in developing solutions.

As the majority of 15- to 25-year-olds are treated in the adult cancer system, dedicated resources and institutional advocacy are critical to increasing their participation in clinical trials. In the adult cancer system adolescent and young adult trial participation is low when compared to the participation rates of those in paediatric institutions. This needs to be addressed in order to best ensure improved outcomes for adolescents and young adults with malignant conditions.

Collaborative model

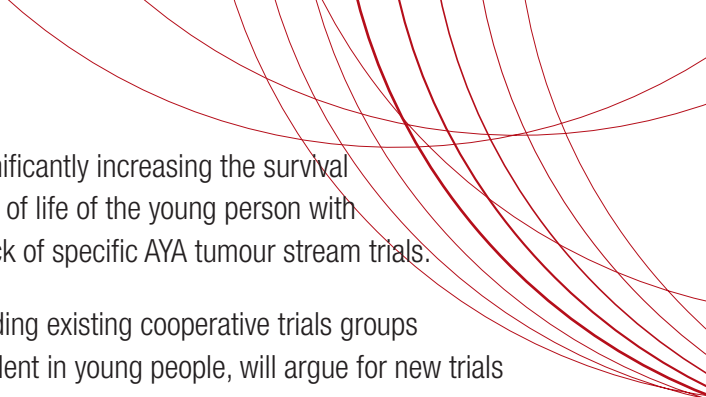
The capacity to conduct clinical trials is central to the definition of a lead AYA cancer care site. Lead AYA cancer care sites will coordinate improved access to clinical trials for adolescents and young adults.

Lead AYA cancer care sites will offer clinical trials for adolescents and young adults and link to other institutions caring for them. The sites will house staff to cover multiple institutions treating young people on open trials (for example, a clinical trials research nurse and ethics coordinator).

Lead AYA care sites will sign up to collaborative trial groups and promote cross-appointments to increase AYA clinical trial access. They will also coordinate to maximise their ability to recruit young people onto clinical trials and to direct resources efficiently and effectively.

Dedicated resources

Resources are essential to optimise AYA participation in clinical trials. To offset competition for limited resources, funds at lead AYA cancer care sites will be earmarked for AYA studies. The funds will be allocated on the basis of clinical



need, the likelihood of significantly increasing the survival time and long-term quality of life of the young person with cancer, and the current lack of specific AYA tumour stream trials.

Professional groups, including existing cooperative trials groups focusing on cancers prevalent in young people, will argue for new trials for common cancers found in this age group.

Education and advocacy

To assist with education and awareness, an online database of clinical trials open to young people with cancer will be made available. This online resource will include education in the benefits of clinical trials in language appropriate for young people. Defined treatment protocols will be included where available for various tumour streams, with or without open trials.

Cancer Australia, in collaboration with the University of Sydney and the National Health and Medical Research Centre Clinical Trial Centre, is improving AYA access to information about cancer clinical trials on a consumer website.

AYA cancer data

Improving AYA cancer service delivery depends on reliable and widely available data collection on treatment strategies to prove and disprove their efficacy. Cancer registration currently contains limited clinical data on comorbid conditions, cancer stage, treatment approaches, recurrences, and other outcomes. Clinical registration could include these data, as well as data on clinical trial participation and exposure to multidisciplinary care, palliative care, and psychosocial support.

National AYA registration

The case for national data collection on AYA cancers is compelling. AYA cancers constitute a relatively small cohort of cancers. Because case numbers will not be adequate at a state level, national aggregation of cases will be needed to gain an accurate picture of outcomes. Registering and aggregating data on cancers in 15- to 25-year-olds will be addressed through Cancer Australia's national data strategy.

AYA minimum dataset

A team of expert AYA clinicians will work, in partnership with consumers, to define an AYA minimum dataset (MDS) that complements the generic national cancer MDS, with additional fields specific to adolescent and young adult cancers to gain consistency across states and territories. The dataset would be proposed to the National Health Data Standards Committee to approve the dataset and its definitions.

The MDS may incorporate data on comorbid conditions, cancer stage, approaches to treatment, recurrences, clinical trial participation, and exposure to multidisciplinary care, palliative care, and psychosocial support. Cancer Australia could act as the steward for this process and act as a conduit to the National Health Data Standards Committee.

Data monitoring and research

An AYA data oversight committee will be formed to monitor AYA cancer service delivery and outcomes, and to promote research. Research efforts would highlight Australian AYA health outcomes on various cancer treatment protocols and monitor national outcomes in light of international benchmarks. The committee would oversee a program of work that could include research efforts based at lead AYA cancer care sites to track short and long-term quality of life impacts. The committee would work closely with existing research groups.

Identified gaps

To improve service delivery for adolescents and young adults with cancer, many barriers need to be removed. This section lists some of those barriers and makes recommendations for reducing or eliminating them as impediments to improving the way cancer care services are delivered to young people.

Lack of consistent and accessible data

Recommendation: *Develop a consistent minimum dataset for AYA cancers as well as considering AYA clinical data as a special category in Cancer Australia's national data strategy.*

Inadequate evidence on new approaches

Recommendation: *Fund AYA clinical research fellows to develop the evidence base on efficacy of new approaches to AYA cancer care.*

Undetermined impact on workforce

Recommendation: *Engage workforce planning experts to help determine the impact on the availability of trained staff across all disciplines to ensure the provision of a sustainable, high-quality AYA network service.*

Unclear career development pathways

Recommendations: *Map teaching and training pathways across all health disciplines working with adolescents and young adults with cancer. Work with experts and institutions in adolescent health to determine the training required to ensure that all health professionals working with young people with cancer have appropriate opportunities to develop and continually advance their skill sets and knowledge.*

Fragmented website information

Recommendation: *Develop a web portal for young people with cancer to provide consumers and service providers with up-to-date information on AYA cancer, services, and AYA clinical trials.*

Developing an AYA web portal will be an ongoing, iterative process. It will need to expand over time and maintain the capacity to be customised to address local needs.

Lack of dedicated and coordinated resources

Recommendation: *Invite a subcommittee of Cancer Australia's National Reference Group to serve as the AYA service reference group, which would assist in implementing the National Service Delivery Framework for Adolescents and Young Adults with Cancer. Its responsibilities would include:*

- *working with key stakeholders including departments of health and human services across the country to implement the national framework*
- *assisting with the design and planning of lead AYA sites*
- *reviewing and updating the national framework based on national and international trends and research*
- *linking to local implementation and coordinating across the networks to share best practices.*



*Lack of evidence of AYA outcomes,
service quality and effectiveness*

Recommendations: *Monitor and evaluate AYA service quality and effectiveness to continually improve service delivery to young people with cancer. Work with experts and governments to determine quality performance indicators to help build the evidence of improved outcomes for young people with cancer, and improved quality of service delivery in areas of comprehensive assessment, psychosocial support, care coordination and multidisciplinary medical and support teams. This would involve benchmarking across sites, systems and services, monitoring AYA participation in clinical trials, collaborating with youth support groups, ensuring the national data strategy incorporates AYA needs and advocating improved AYA cancer care at the state and national level.*

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