

Optimising the health and well-being of survivors of childhood cancer: A Long Term Follow-up (LTF) model for the future Summary Report

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Att 1: Predicted numbers of survivors by disease and risk category over time

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Executive summary

Over the past thirty years, significant improvements in the treatment of childhood cancer have evolved, so that today children diagnosed with cancer have a 75% chance of being cured of their disease. However, as survival times have increased, so has the understanding of the long term impacts of the disease and its treatment on the survivor.

Key evidence indicates that survivors of childhood cancer have a mortality rate 10.8 fold greater than the general population. The cumulative effect of chronic health problems in survivors thirty years after diagnosis has been reported as being over 73%. Identified health problems include cardiac problems, second malignancies, infertility, psychological problems and neuro-cognitive deficits. These issues may impact on the survivor's ability to participate in the workforce, establish long term relationships and their own families, as well as their ability to contribute to the wider community.

Until relatively recently, the long term impact of childhood cancer and its treatment on survivors was not well recognised, with services poorly equipped to meet their needs. However, while the evidence of the impact of childhood cancer is now well established, the evidence on the way to best respond to the needs of survivors is more limited.

This service model has been developed by the Paediatric Integrated Cancer Service (PICS) to address a significant service gap in the provision of long term follow-up services for survivors of childhood cancer.

The service model

This service model proposes an innovative model based on a risk adaptive approach, where the level of service is stratified according to levels of assessed risk and need (high, medium and low). Survivors identified at high risk or with high needs will have access to specialist services, whereas those with lower levels of risk or need may be effectively supported by more generalist practitioners, with intermittent access to specialist services.

Using a modelling exercise based on the known number of long term survivors diagnosed since 2000 and the estimated number of young adults who transition into adult services annually, we can estimate the numbers of survivors entering a new long term follow-up program over years. At ten years it is estimated that nearly 800 survivors will access the proposed long term follow-up program within the paediatric-adolescent spectrum of care.

The proposed service model is based on a 'hub and spoke' approach with the aim being to both strengthen generalist services and provide specialist services where needed. A 'wellness and empowering' approach underpins the service model.

The role of the service hub will be to:

- provide leadership and develop strategic partnerships
- develop and trial risk screening and assessment tools, practice guidelines and protocols for both specialist and generalist services
- guide internal service delivery
- offer a secondary consultation role to generalist providers
- develop and implement an information and communication strategy including web-based information and a 1300 number for survivors, family members and service providers

- support and guide survivors' transition into the long term follow-up program and to adult services
- develop and implement a risk management and communication strategy to identify and respond to the needs of 'old' survivors
- lead research opportunities and seek funding support.

The proposed clinical long term follow-up 'spokes' include specialist services within the Children's Cancer Centres, regional services working with local paediatricians, and generalist services such as local paediatricians and general practitioners.

Strong relationships will be developed with adult services to enhance the transition of young adult survivors into appropriate, high quality adult services.

An iterative action research / quality improvement approach will be undertaken to evaluate the appropriateness, effectiveness and acceptability of all elements of the service model. Particular attention will be paid to the stratification criteria for the different levels of need and service access.

In addition, initial research will also be undertaken as part of the risk management and communication strategy for 'old' survivors, diagnosed prior to 2000. This will provide some evidence on current levels of need and service access of long term survivors.

The next steps

This proposal will be forwarded to the Cancer and Palliative Care Unit, Department of Human Services in September 2007.

PICS and the Cancer and Palliative Care Unit will work closely in the future months to identify other sustainable funding streams within the relevant health services or at a departmental level to offset current estimated costs. This may include funding through the Victorian Ambulatory Classification System (VACS) to support the specialist multidisciplinary clinics.

The successful acquisition of ongoing funding provides an important opportunity to develop, implement and evaluate an innovative service model that may be the first such model in Australia. Once effectively trialled, this may serve as a model for other paediatric cancer long term follow-up services nationally and internationally as well as informing the development of long term adult follow-up services for adult survivors of both paediatric and adult cancers.

1. Introduction

'You want their survival – you want them to have a life – but they are never going to have the life that you thought they would have– unblemished. But you want them to be as unblemished by what's happened as you can – that's what you saved them for – to grow up, get married, have kids and do those things in the happiest of ways'.

Parent of long-time survivor

While many survivors of childhood cancer do achieve this parent's wish of a life relatively unblemished by their experiences, there is increasing evidence that long term survival may come at a price. The full impact of cancer and its treatment on the physical and emotional health of survivors may only be realised over the years and may influence the survivors' ability to be active participants in the workforce, to form their own long term relationships and families, and their ability to contribute to the wider society. Unless well managed, survivors' chronic health problems may also result in an ongoing drain on health services.

This service model has been developed to address a significant service gap in the provision of early intervention and long term support and management of survivors of childhood cancer.

It provides an overview of the increasing evidence of the impact of childhood cancer and its treatment on survivors, the predicted levels of need within the Victorian community and current services. It then proposes an integrated service model for the future, an implementation plan and the resources required to achieve this plan over time.

1.1 The Victorian cancer reform agenda

Victoria has a significant cancer reform agenda that seeks to improve the planning and delivery of treatment and support to all cancer patients (adults and children) so that appropriate care is provided in a timely manner as close to the patient's home as possible.

The need for improved delivery of cancer services along with improved outcomes for patients and their families has been identified as a priority for both State and Federal governments and is driven by many factors including trends in population health, workforce issues, the increasing complexity and cost of cancer care and the shift of cancer treatment to the ambulatory setting.

In Victoria, the Integrated Cancer Services have been established to drive change, service improvement and service integration at a local level. There are eight Integrated Cancer Services (ICS) serving the needs of the adult population, three in metropolitan Melbourne and one in each of the five regions of the Victorian Department of Human Services (DHS).

1.2 The Paediatric Integrated Cancer Service

As the only statewide ICS, the Paediatric Integrated Cancer Service (PICS) is a partnership between the Children's Cancer Centres at the Royal Children's Hospital (RCH) and Monash Medical Centre (MMC) and with Peter MacCallum Cancer Centre (Peter Mac).

The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria. The vision for PICS is to *'provide the best care in the best facility as close to home as possible'*.¹

The majority of children with cancer are diagnosed and treated at RCH with a smaller number of less complex children being treated at MMC. Radiotherapy is provided through Peter Mac.

Considerable work has been undertaken by PICS to strengthen services overall, to build the capacity of the MMC Children's Cancer Centre and to enhance links with regional paediatric services.

1.3 Long term follow-up of cancer survivors

Survivors of childhood cancer have been defined as those who are disease free at least two years after the cessation of treatment and / or are at least five years post-diagnosis.

As part of its Vision of Care for 2005-08, PICS identified the need to develop a comprehensive long term follow-up program for Victorian survivors of childhood cancer.

The DHS Cancer and Palliative Care Unit has also recognised that developing and supporting an effective service model for the long term support of survivors of childhood cancer needs to consider broader transition issues as survivors move through childhood, adolescence and into young adulthood. This includes not only the transition into adult services but also the capacity of adult services to be able to respond to the survivors' needs.

2 Method

This service model was developed with key stakeholders within PICS.

2.1 Project objectives

The objectives were to:

- Quantify the level of need and predicted service requirements for current and future survivors of childhood cancer
- Develop a service model that would address these needs in a way that facilitates the optimal use of specialist and generalist services
- Quantify the resources required to meet the needs of the proposed service model
- Develop the business case to support the acquisition of funding for the development and implementation of the proposed service model.

2.2 Project scope

The focus of the Project was to cover those services required by long term survivors up to and including the transition into adult care.

In addition, the Project was to draw on data that was currently available as well as the findings of a recent consultation with young adult / adult survivors and parents of survivors.²

¹ Paediatric Integrated Cancer Service. 2006. The best care in the best facility as close to home as possible. A vision of care and roadmap to guide the Victorian Paediatric Integrated Cancer Service. June 2005 – June 2008.

2.3 Gathering the evidence

The following summarises the key activities undertaken to inform the service model development and the business case.

Advisory mechanisms: This included formal and informal meetings with stakeholders.

Literature review: This included the evidence of the impact of childhood cancer and its treatment on long term survivors, the availability of current guidelines, approaches and service models for the long term follow-up of survivors and barriers to long term follow-up.

Review of other documentation: This included a range of previous PICS documentation such as an earlier literature review on approaches to long term follow-up, a summary of current service models in Australia and a report on a US study tour looking at the management of neuro-cognitive and psychosocial late effects. Other documentation included information and policies to support the transition of young adults from paediatric to adult services.

Review of key demographic and service data: This included the incidence of childhood cancer and the numbers of childhood survivors by tumour group on the Children's Cancer Centre database diagnosed since 2000.

Predicting need: A modelling exercise was undertaken to estimate future service demand based on: the 2004-05 incidence of childhood cancer by different tumour categories; the age of children on diagnosis; the known survival figures over time; the numbers of survivors who would be eligible to enter a long term follow-up program at two years post treatment and the numbers who would remain in a PICS long term follow-up service each year; survivors in the system from 2000.

A review of current services: This included: an audit of the number of survivors being seen at the routine clinics of the MMC Children's Cancer Centre; the numbers of survivors with brain tumours accessing the current long term follow-up clinic; data that indicated the numbers of adult long term survivors currently being followed up within a Children's Cancer Centre; and information on the late effects services for adults offered at Peter Mac.

Consultation with other service providers: In addition to PICS stakeholders, this consultation included consultation with service providers from Peter Mac, the Victorian Paediatric Rehabilitation Service, the RCH GP Liaison Unit and the Managers of both the Western Central and Southern Metropolitan Integrated Cancer Services.

Consumer consultation: The service model drew on the findings of the consultation with long term survivors and parents of survivors. An additional meeting was held with three parents of current survivors of childhood cancer and one adult survivor to discuss the proposed model and gain their input.

2.4 Limitations

A series of limitations should be noted:

- While there is increasing evidence on the long term physical and psychosocial impact of childhood cancer and its treatment on survivors, there is much more limited evidence to inform the development of a best practice service model and interventions to manage this impact.

² Paediatric Integrated Cancer Service. 2007. Long-term follow-up services. Community consultation. Final report. April. Unpublished report. Victorian

- Although we can estimate the numbers of survivors who were diagnosed from 2000, there is limited data on the number or profile of survivors who were diagnosed prior to 2000. It is difficult to accurately estimate the number of these survivors who are currently still within the routine follow-up services of the Children's Cancer Centre, are lost to follow-up or are eligible for transition to adult services.

The level of service need has been calculated on the predicted numbers of survivors diagnosed since 2000. It does not include those survivors diagnosed prior to 2000 who may still be within the paediatric / adolescent spectrum of care.

- The numbers of survivors have been estimated on data from the 2004-05 financial year, with age and tumour group data being available on 157 children from the Children's Cancer Centre database. Of these, 141 were identified as Victorian children or adolescents. On reflection, this figure may be lower than the expected annual number of 160 newly diagnosed Victorian children. The survivor figures used in this document should therefore be seen as a conservative estimate.
- In modelling the required future service capacity it is difficult to estimate the number of survivors who choose not to attend a specialist service, even if recommended to do so. Anecdotal evidence from overseas indicates that 20-30% of survivors may be 'non-attenders'.

The capacity of the proposed clinical service has been based on 100% attendance of survivors diagnosed after 2000. Any 'spare service capacity' will counter the small under-estimation in the initial modelling figures and will also accommodate the needs of survivors diagnosed before 2000, who remain in the paediatric / adolescent spectrum of care.

- The consultations have only included older survivors of childhood cancer (young adults and adults). Gaining input from the needs of younger survivors requires a different approach using a range of child / adolescent activities to elicit their responses. This was beyond the scope of this project.
- The scope for this service model was limited to developing services up to and including transition to adult services. While this has remained the primary focus, it is recognised that a program that strengthens transition of now adult survivors to adult services will impact on these services. This is compounded by a potential back-log of adult survivors currently still within the Children's Cancer Centre system who require prompt transition. This service model identifies some resources to commence progress in strengthening the relevant adult services. It does not address any additional service delivery costs.

Despite these limitations, this report proposes an innovative service model that provides an opportunity to trial and modify specific service approaches and interventions and to address the challenges of transitions into long term follow-up services as well as the transition into adult services.

3 Reviewing the evidence

This section summarises the key evidence from the literature and the consumer consultations, considers the level of need for Victorian survivors of childhood cancer, reviews current services and identifies some of challenges that a new service model will need to address. Finally some key opportunities are identified that may facilitate the development of the service model.

3.1 Childhood cancer in Victoria

Every year approximately 160 children aged 0-16 years are diagnosed with and treated for a childhood cancer in Victoria, through RCH or MMC Children's Cancer Centres³. An estimated 10% of children (n=16) are from interstate.

In 2004-05 141 Victorian children / adolescents were diagnosed with childhood cancer at one of the Children's Cancer Centres. A significant proportion of these children / adolescents will become long term survivors. Table 1 provides the profiles of these children by age group and tumour category.

Table 1: Age and disease profile of children diagnosed in 2004-05

Tumour category	Age on diagnosis						
	0-2	3-5	6-9	10-12	13-16	16+	Total (%)
Brain / CNS tumours	11	3	7	4	2	3	30 (21%)
Solid tumours	12	5	1	8	10	1	37 (26%)
Liquid tumours	13	21	13	9	15	3	74 (53%)
Total (%)	36 (25%)	29 (21%)	21 (15%)	21 (15%)	27 (19%)	7 (5%)	141 (100%)

While there is some variability across years, the following summarises the key data:

- 46% of all children / adolescents are diagnosed at 5 years and under
- 30% of all children / adolescents are diagnosed between 6-12 years
- 27% of all children / adolescents are diagnosed between 13-16 years
- 7% of all children / adolescents are diagnosed at 16+ years.
- Approximately one half of all children / adolescents are diagnosed with liquid tumours (leukaemias, lymphomas)
- Approximately a quarter are diagnosed with solid tumours (e.g. Wilm's tumours, bone cancers)
- About 20% are diagnosed with brain tumours.

Overall it is expected that 75% of children / adolescents will be cured and will potentially experience at least one long term effect of childhood cancer and its treatment.

³ It should be noted that some adolescents 16 years (or younger) may be diagnosed and treated within adult cancer services.

3.2 The long term impact of childhood cancer

With improved survival, there is increasing and evolving knowledge that a significant proportion of long term survivors will experience new health problems as a result of their disease and its treatment. This evidence will further strengthen as the proportion of long term survivors and survival times continue to increase and the knowledge base is expanded.

The following summarises some key evidence from the current literature⁴:

- Survivors of childhood cancer have a mortality rate 10.8 fold greater than the general population
- The risk of late effects increases with increasing length of survival
 - In five-year survivors, up to 60% may have one or more chronic health problems and 20% have three or more problems.
 - The cumulative incidence of a chronic health condition in survivors 30 years after diagnosis has been reported as over 73%.
- In addition to length of survival, other factors that influence risk include:
 - Specific diagnoses e.g. brain / CNS tumours, bone tumours and Hodgkin's disease may increase the risk.
 - The nature, intensity and dose of treatment with those having radiotherapy (with the exception of low dose cranial irradiation), bone marrow transplants and megatherapy at an increased risk.
 - Age at diagnosis with survivors treated at an older age being more likely to report an adverse health condition. Survivors treated at a younger age may be at more risk of some late-effects.
 - Gender with female survivors being at more risk than male survivors.
- The chronic health problems experienced by survivors cover the range of health domains including physical, cognitive and psychological domains (See Table 2). The following highlights some specific problems:
 - Cardiac damage for those who received anthracyclines and / or thoracic radiation
 - Infertility
 - Second malignancies
 - Psychological problems including post-traumatic stress disorders which may only become evident in young adulthood.
 - Neuro-cognitive deficits particularly if survivors were younger, had a brain tumour, or had total body irradiation.

Table 2: The seven health domains impacted by childhood cancer and treatment ⁵

Health domain	Examples of chronic health conditions (late effects)
Growth / endocrine	• chronic health problems such as thyroxine deficiency, growth hormone deficiency and infertility.
Neurological	• cerebral palsy, ataxia/dyspraxia and migraine.
Organ / system	• respiratory problems, organ removal (e.g.

⁴ Wooten. A. 2007. Long-term follow-up project. Literature review. Victorian Paediatric Integrated Cancer Service. Unpublished report.

⁵ Mertens AC, Yasui Y, Neglia JC et al. 2001. Late mortality experience in five year survivors of childhood and adolescent cancer: the childhood cancer survivor study. *Journal of Clinical Oncology*: 19:3 163-72.

	kidney), cardiovascular problems and second malignancies.
Special sense / dental	<ul style="list-style-type: none"> • visual handicap, deafness and dental problems
Intellectual / psychological	<ul style="list-style-type: none"> • learning difficulties, behaviour problems and anxiety/depression.
Cosmetic	<ul style="list-style-type: none"> • obesity and overweight, tissue atrophy and hypoplasia and skin problems.
Orthopaedic	<ul style="list-style-type: none"> • scoliosis, paraplegia/hemiplegia and amputation/endoprosthesis

3.3 Long term follow-up programs / services

With this increasing evidence of long term effects comes an understanding of the need for enhanced long term follow-up for the prevention and / or early detection and management of problems if they arise.

The literature highlights the need for service models to have a strong client focused approach with an emphasis on wellness and health promotion.

While risk does increase with survival duration, there is evidence from the UK to suggest that follow-up service models should be based on the degree of health risk. Wallace et al propose the following three tiered model⁶:

- Level 1:** 'Low' risk e.g. surgery alone and / or low risk chemotherapy
- Level 2:** 'Medium' risk e.g. chemotherapy, low dose cranial irradiation
- Level 3:** 'High' risk e.g. radiotherapy and megatherapy.

The current service models identified in the literature do not appear to discriminate between different levels of need. These international models include the provision of all long term follow-up either through specialist multidisciplinary services or community based services. A range of different approaches were also identified for supporting the transition from paediatric to adult services. This included the identification of the key elements of good transitional care.

There is no clear evidence however to suggest that one long term follow-up service model is better than others. It appears that different models used overseas are shaped by the systemic or economic pressures of each country's health care system. It is likely that to be sustainable, future models in any country need to take these local systemic and economic pressures into account.

⁶ Wallace W, Blacklay A, Eiser C et al. 2001. Developing strategies for long-term follow-up of survivors of childhood cancer. British Medical Journal. 323:271-274.

3.4 Survivor and family perspectives

'We are the first generation of survivors and are really keen to see the next generation of survivors benefit from what we can do'.

Long term survivor

Survivors and parents were keen to see enhanced long term follow-up services for themselves / or their child as well as for future survivors of childhood cancer. This included access to good quality information and accessible services appropriate to needs and developmental age.

3.4.1 Survivors' views

From the survivors' perspective, their needs for information were contingent on their current age. Overall the survivors perceived that there was a dearth of information about long term issues. What information they did gain was gathered from a range of sources including television documentaries, doctors, medical journals or books, support groups run through children's cancer charities such as Camp Quality or an individual nurse manager.

The younger survivors recognised the important role that their parents played as a resource for them, even if they themselves did not want to know all the information. For others it was or had been difficult to talk to their parents about their needs.

Overall the survivors wanted:

- access to a wide range of general information through websites, chat pages, information sheets and regular educational seminars
- specific information about their own medical history for themselves and for other service providers they might access
- access to a 'key contact' to gain information as needed
- an understanding of '*what might lie ahead*'
- specific information about support services or groups available and how to access these services, life insurance, career opportunities and addressing workplace discrimination
- Information about where to direct others for assistance e.g. adult siblings concerns about their own child's risk of cancer.

The survivors also identified the value of gaining information and support through their peers. This would help to normalise the survivors' experiences – '*so you don't feel like a freak*'.

In regard to how services were best offered, key aspects identified by the survivors were that paediatric providers:

- had to have an interest in and knowledge of long term issues
- were able to change their communication style as the survivor moves into adolescence and young adulthood
- were comfortable to address a range of more adult oriented issues e.g. sexuality.

For young adult survivors to transition smoothly into adult services, they needed to be confident that:

- there was proper referral and hand-over of all their information
- the new provider had read their history and did not rely on the survivor providing all the details

- the first appointment was a long appointment to review all long term management aspects and to establish the relationship between the provider and the survivor
- the service had access to a reasonable number of survivors of childhood cancer
- access to a youth worker was available.

3.4.2 Parents' views

From the parents' perspective, access to information was patchy and at times reliant on one provider such as the endocrinologist or an individual oncologist. Only a few had had access to the RCH long term effects booklet.

While the parents had an understanding that the knowledge of long term effects was an evolving one, there was some frustration for the parents of longer-term survivors at the lack or inconsistency of information and '*fudging*' of the information that was available. There was a sense that at each appointment, a new long term effect (actual or potential) was added to the list.

The parents of early survivors (i.e. off treatment 6-18 months) appeared to have limited knowledge of potential long term issues. This may reflect that they had not been given information or that they were not ready to absorb it.

Much of the information that parents had about services in particular was gained by chance through other 'non-cancer' service providers within the hospital or in the community. Parents also talked about the value of peer support, connecting with other parents to gain information and understanding.

The parents indicated that they wanted clear information about:

- the questions to ask
- the long term issues and how to deal with them
- what services they were eligible for and how they could access such services including counselling, rehabilitation and learning disability programs.

Parents were generally supportive (or at least not averse) to long term follow-up being undertaken by more generalist services e.g. general practitioners. However for them to be confident in this they would want to be assured that the generalist providers were linked in with specialist services.

3.5 Predicted numbers of Victorian survivors of childhood cancer

Overall 75% of all Victorian children / adolescents diagnosed with any childhood cancer will be cured of their disease. While disease relapse may occur at any time, the majority of relapses in children and adolescents will occur within two to three years of initial treatment.

Based on the modelling exercise undertaken, we can predict:

- A total of 107 survivors would be eligible to enter a long term follow-up program each year (96 would enter a paediatric long term follow up program with eleven predicted to directly transition into an adult service).
- Of the 96 survivors who enter the paediatric long term follow-up program, 21 will be survivors of brain / CNS tumours, 24 will be from solid tumours and 51 will have had 'liquid' tumours.

- Overall the number of survivors within the paediatric long term follow-up program continues to increase with a steady state being reached at about 10 years (see Table 3)
- An analysis of survivors on the Children' s Cancer Centre database indicates that there are currently 538 survivors who were diagnosed from 2000 – 2005 and are potentially eligible for a long term follow-up program. There will be another cohort of survivors who were diagnosed before 2000 and will still be within the 'paediatric – adolescent' service group.

In addition, we can predict that:

- 46% of survivors diagnosed at age 0-5 years, will enter the long term follow-up program at aged 5-9 years. It will be 10-14 years before they are eligible to transition to an adult service.
- 24% of survivors who are diagnosed at age 13 years and over, will have a relatively short period in a 'paediatric long term' follow-up service. A small number will be referred directly into an adult long term follow-up program two years following completion of active treatment.

The following table summarises the predictions of the number of survivors diagnosed from 2000 by tumour group who would enter a paediatric long term follow-up program over a 15 year time period.

Table 3: Predicted number of Victorian survivors by tumour group over time

Time period	Survivors by tumour type			
	Brain tumours	Liquid tumours	Solid tumours	Total
Number of current survivors on CCC database diagnosed 2000-05 ¹ .	100	336	102	538
Number of survivors predicted to have entered LTF at end of first year of a new paediatric LTF program. ²	110	337	112	559
Number of survivors predicted to have entered LTF at end of five years of a new paediatric LTF program. ²	142	424	158	724
Number of survivors predicted to have entered LTF at end of ten years of a new paediatric LTF program. ²	161	448	174	783
Number of survivors predicted to have entered LTF at end of fifteen years of a new paediatric LTF program. ²	172	409	179	760

¹ includes current survivors over the age of 19 years

² excludes those survivors who will transition into adult services during the time period.

As per 3.3, the type of long term follow-up required may depend on a 'risk assessment' based on the type of tumour, treatment given, and other influencing factors. Table 4 estimates the proportion of all survivors fitting into the three 'risk' categories per annum.

Table 4: Percentage of survivors entering long term follow-up each year by tumour category and level of risk

Tumour type	Number entering LTF*	Estimated % and number of survivors by risk category		
		Low risk	Medium risk	High risk

		%	n	%	n	%	n
Brain / CNS	21	10	2	0	0	90	19
Solid	24	40	10	30	7	30	7
Liquid	51	40	20	30	16	30	15
Total	96		32		23		41

* These numbers are based on the % survival at 2 years post-treatment and exclude those who will transition straight into an adult service.

Across all tumour groups we can estimate that 43% will be identified in a high risk category, 24% in a medium risk category and 33% at low risk.

As there is limited definitive evidence that provides the criteria for stratification of need by different tumour groups, these figures should be seen as 'starting points' to assist in developing the service model. With experience and new evidence, greater clarity about the criteria for such stratification will be gained.

3.6 Current service models for long term follow-up

The follow-up of current long term survivors is undertaken through the Children's Cancer Centres primarily through two different processes.

3.6.1 Routine clinic services

The majority of survivors are seen at regular intervals through one of a number of clinics held each week within either the RCH or MMC Children's Cancer Centre. These clinics see children who are within the early treatment phases, those on ongoing treatment as well as those off treatment. The clinics are staffed by paediatric oncologists and associated medical staff. Other staff such as the nurse coordinators and social workers may be available at these clinics.

It has been estimated that approximately one third of attendees at each clinic are children / adolescents who are off treatment. The audit of the MMC Children's Cancer Centre services affirmed this estimate with 21 out of 68 clinic attendees in a two week period being 'off treatment'. Of these 21 attendees, five had been off treatment for over three years.

Follow-up in these routine services tends to focus on the surveillance for disease relapse. At an anecdotal level, the identification of immediate and long term effects and their management (or referral to other paediatric or adult services) appears to be patchy and may be dependent on the type of effect, the provider's knowledge of the appropriate services to which to refer or the availability of an appropriate service.

3.6.2 Multidisciplinary brain tumour service

Children or adolescent survivors of brain tumours at RCH are seen within a multidisciplinary clinic which is held monthly. These clinics are staffed by a paediatric oncologist, other medical specialists (e.g. radiation oncologist, endocrinologist), a social worker, an

educational advisor and neuro-psychologist. There is also access to a range of other allied health professionals based on need.

Brain tumour survivors are referred to this service one year following the completion of treatment, with the aim being to manage both the immediate and residual impact of the disease and treatment as well as to monitor and manage any long term effects. If children still require more frequent follow-up than the annual visit to the multidisciplinary clinic, this is undertaken in the routine outpatient services.

Approximately 7-8 survivors are seen at each of the multidisciplinary brain tumour clinics and each survivor will see a number of professionals depending on their needs.

Over the past year, a number of initiatives have been developed to strengthen this service. This has included:

- Enhanced coordination
- The introduction of a pre-appointment telephone survey to survivors or their parents to identify current needs and ensure that the right personnel are available within the clinic
- Introduction of the Trackwell screening test for risk of cognitive deficits as part of a broader trial of neuro-cognitive screening
- Negotiating access to other allied health disciplines.

Current challenges in this service include:

- Limited access to some allied health disciplines
- Limited capacity for the education advisor to follow-up educational problems with the survivor's school.

3.6.3 Transition to adult services

Transition to adult services is currently variable and may be contingent on:

- The service providers' knowledge of adult services
- The adult service's capacity and interest to provide appropriate services
- The lack of appropriate services
- The service providers' reluctance to refer and / or the survivors' reluctance to be referred.

Evidence from the adult survivors who participated in the focus group discussions, indicated that they remained formally in the paediatric system well into adulthood with links with specialist adult services now being quite ad hoc. Some had experienced being discharged from the Children's Cancer Centre with a sense of abandonment.

'I have had a number of health problems as well as a range of emotional and psychological issues at different stages – and now I am married and thinking about having children but I don't know where to go for advice.'

Survivor of 15 years

There is evidence that current adolescent / young adult survivors are being better prepared and transitioned into adult services in a timely manner. However limited resources within the adult system, present challenges to both survivors and paediatric service providers.

3.6.4 Adult services

Young adult survivors may be referred back to their general practitioner, to adult services within the related tertiary specialty service for adults or to Peter Mac's specialist long term effects service.

The quality of these adult services is critical given the evidence that:

- chronic health problems continue to increase with increasing survival
- chronic post-traumatic stress symptoms may only come to the fore or be actively acknowledged by the survivor as they progress into the developmental stage of young adulthood.⁷

Routine adult services

Survivors of bone marrow transplants may be referred to an individual adult haematologist or to a major adult haematology service for ongoing care. Similarly survivors of brain tumours may be referred to an individual neurosurgeon / neurologist or to an adult neuro-oncology / neurology service.

Whether seen by an individual or within a specialist clinic, it is understood that these survivors are seen within 'routine' adult services that may deal with a range of patients at different treatment stages. These services are not necessarily oriented towards addressing long term issues with young adults.

Peter Mac late effects clinic

Peter Mac is the only adult service in Victoria that offers specialist services for the management of late effects following cancer treatment for survivors of childhood cancers or adult cancers. This service is a multidisciplinary service based on a 'wellness and empowering' model. The service has expanded significantly in response to demand over recent years.

The Peter Mac late effects service has links with the OnTrac program for the management of adolescents (over 15 years) and young adults with cancer. This facilitates a better understanding of adolescent and young adult needs and referral to OnTrac service personnel as needed.

Anecdotal evidence indicates that some survivors transitioning into this service find it somewhat confronting.⁸

3.6.5 Information provision

Information is currently given to survivors and parents within consultations and through resources such as the RCH long-term effects booklet. Some brief information about long term effects has been included in the recently published information book given to families on a child's diagnosis.

However, as indicated the adolescent / young adult survivors and parents of survivors who were consulted, reported limited access to information. Many were unaware of the RCH booklet.

⁷ Rourke et al, in press. Quoted in Kazak, A, Rourke MT, Alderfer MA et al. 2007. Evidence based assessment, intervention and psychosocial care in paediatric oncology: a blueprint for comprehensive services across treatment. Journal of Paediatric Psychology pp 1-12. Advance Access published July 11 2007.

⁸ D. Ashley. Personal communication.

3.7 Challenges to providing a long term follow-up program

There are a number of challenges that need to be addressed in developing a new service model for survivors of childhood cancer.

3.7.1 The changing service focus

Developing a long term follow-up program requires some shifts in focus including transitioning:

- From a relapse surveillance mode to a wellness, empowering focus and illness prevention.
- From usual clinics to a long term follow-up program.
- Through the survivor's different developmental stages.
- From a 'parent-controlled' focus to an 'adolescent-controlled' focus.
- From paediatric to adult services.

Achieving these changes can be challenging within an acute environment predominantly focused on working with very ill children and their families currently going through treatment. It can also be very confronting for survivors and their families. The establishment of a separate service and good preparation of the survivors and their families is essential to assist in these transitions.

For some survivors and families who have struggled in the past with significant disabilities or other long term effects, an enhanced program provides the opportunity for greater acknowledgement of their needs, better access to strengthened information, improved services and enhanced service coordination.

3.7.2 Meeting diverse information needs

Some parents and survivors have a strong interest in understanding what might be the issues in the future. This may be matched by some ambivalence and a reluctance to take on new and potentially difficult information after the trauma of the disease and its treatment.

From the parents' perspective, they recognised that information about long term effects was potentially difficult. However at both consultations parents indicated that they needed to be provided with at least some information within the 6-12 months following treatment completion.

'My child is quite well now but we still have an overarching need to understand where we go from here'

Parent of recently treated survivor

The challenge for a new long term follow-up service is to be able to provide information in a flexible manner that responds to survivors' and parents' differing needs.

3.7.3 The interface between routine and long term follow-up services

Some survivors will experience immediate or residual impacts of the disease or its treatment, some of which may not resolve and may compound over time, particularly if they are not well managed. At a service delivery level, an overlap is seen between routine follow-up care and the management of the residual impacts and long term follow-up care.

A challenge and an opportunity for service providers is to ensure that early impacts are managed optimally prior to the survivor's transition into long term follow-up services. The developing knowledge base about the assessment, management and referral of survivors with a range of longer term issues may also inform earlier routine follow-up care.

3.7.4 Accessing appropriate adult services

As indicated in 3.6.3, there are limited adult services specifically oriented to the needs of long term cancer survivors. There is also a significant backlog of adult survivors currently within the paediatric service that need early transition to adult services. While some may be able to be referred back to their general practitioner, a significant proportion of these adult survivors may need access to adult specialist services.

This backlog needs to be addressed as a priority as part of the establishment of any new service.

The implementation of the PICS long term follow-up service will result in continuing transitions to adult services which will need to respond to these referrals.

3.7.5 Managing 'old' long term survivors

Consideration has to be given on how to manage the needs of 'old' survivors, particularly those who are not on the current Children's Cancer Centre's clinical database. This includes those who are many years down the track and may be still considered paediatric / adolescent survivors or they may be adult survivors.

There are nearly 540 survivors on the Children's Cancer Centre clinical database who were diagnosed from 2000 – 2005. With slightly lower survival rates, one would expect that there may be between 750 and 900 survivors who were diagnosed between 1990-1999. There may be a further 400 - 500 survivors who were diagnosed prior to 1990⁹.

Communication with 'longer term survivors and families' may be organisationally difficult as at least some may be 'lost to follow-up' or have died. Unexpected communication to the survivors or families may also cause some anxiety or distress.

A preliminary scan of an earlier RCH contact list indicates that there are approximately 2000 names of children / families who were diagnosed before 2000. This includes families whose child died. The figure of 1150-1400 survivors may be a useful starting point for estimating the potential demand¹⁰.

Any new long term follow-up model needs to include a risk management and communication strategy.

3.8 Opportunities to support program development

Balancing the challenges are a number of opportunities.

3.8.1 Increased understanding of the long term needs

The understanding of the physical, cognitive and psychosocial needs of long term survivors is increasing with individual providers, at a service level and at the broader funding and policy levels.

⁹ These figures should be seen as 'best *guesstimates*' only.

¹⁰ Mary McGowan. Personal communication. August 2007.

At the DHS level there is a strong interest in how the provision of long term follow-up services for survivors of childhood cancer may serve as a model for long term follow-up programs for survivors of adult cancers.

3.8.2 Increasing focus on psychosocial needs

There has been an increasing focus on strengthening psychosocial support services for patients and their families as they go through treatment. These strengthened services provide a foundation on which long term follow-up services can build.

In addition, survivors and / or families at high risk of long term psychosocial distress may be identified through the treatment phase and enable greater preventive interventions.

3.8.3 Regional outreach and shared care program

Over the past eighteen months, PICS has established relationships with a number of regional paediatric services to facilitate more local access to support for children and adolescents during their treatment. Over time paediatric oncologists will be supporting six monthly outpatient clinics in regional services across Victoria working with local paediatricians.

These services may provide an opportunity for some long term survivors to access follow-up services locally, and to skill and support general paediatricians to manage these survivors. Increased video-conferencing resources may also provide alternative opportunities to facilitate support for regional providers.

3.8.4 Links with other paediatric services

There are a number of other initiatives that may be of value in the development and implementation of the new long term follow-up service. These include:

- A strong GP liaison unit at RCH and MMC which may facilitate enhanced links with general practitioners
- RCH's strong transition program facilitating the transition of young adults with any health condition to adult services. Linked with this have been the pilot transition initiatives for young adults with spina bifida and cerebral palsy jointly initiated by DHS sub-acute programs and RCH. Through these initiatives stronger adult services have been developed with some initial incentive funding and then some allocation for additional service funding.
MMC also have a similar transition program.
- The Victorian Paediatric Rehabilitation Service which has been recently established to strengthen children's access to short-term goal oriented rehabilitation within both in-patient and ambulatory services. Both RCH and MMC play important roles in this statewide service.

3.8.5 Working with adult services

A number of opportunities arise that may assist both PICS in the establishment of the paediatric long term follow-up program as well as strengthening access to adult services.

Firstly, given their service demand, Peter Mac is developing a new service model for long term follow-up of all cancer survivors. This includes a tiered approach to services with a stronger emphasis on the role of the general practitioner in providing the long term follow-up care for 'lower' risk adults on a shared care basis. A wide range of work is currently underway including GP information, education and communication. Linkage with this

program may provide learnings for PICS, the opportunity to piggyback onto relevant initiatives and to reduce duplication of effort.

Secondly, given their co-location, a potential partnership between MMC Children's Cancer Centre, MMC oncology and other adult services and Peter Mac services at MMC, provides an opportunity to pilot a new model for transitioning survivors to adult services. This could link in with the Southern Metropolitan Integrated Cancer Service (SMICS).

Thirdly given current referral pathways to the haematology and / or neuro-oncology services at the Royal Melbourne Hospital, there may be opportunities to stimulate a stronger interest in a more specialised approach to long term follow-up services for adult survivors of both childhood and adult cancers. There may be potential support through the Western and Central Metropolitan Integrated Cancer Service (WCMICS).

Finally, the work to identify and address the needs of 'older long term survivors' provides a potential opportunity to gain an initial 'snapshot' of the long term impact of childhood cancer on these survivors and their families. This may further inform the development of both paediatric and adult long term follow-up services and provide an opportunity for paediatric and adult services to work together to address these needs through the Integrated Cancer Services.

3.8.6 Research opportunities

Given the limited evidence around effective interventions to support long term survivors, a new long term follow-up program needs to be underpinned by a quality improvement approach, service evaluation and research.

The RCH Children's Cancer Centre has a well established record of both laboratory and clinical research. In the past three years, psychosocial research has been strengthened. This has included trials of:

- a procedural pain management program, *Comfort First*
- a psychosocial assessment screening tool
- a screening tool to identify those at risk of neuro-cognitive problems at key points in the diagnostic and treatment pathway (*Trackwell*).

There are strong links between the Children's Cancer Centres and overseas paediatric oncology services including the Children's Hospital of Philadelphia, the Texas Children's Hospital and Nottingham Children's Hospital. There are potential opportunities for joint research initiatives with these and other international services.

The current research record and these international relationships positions the Children's Cancer Centres well to undertake service evaluation and research as part the long term follow-up program.

The establishment of the Victorian Cancer Agency (VCA) as part of the broader cancer reform agenda, aims to coordinate and promote the rapid translation of cancer research into the clinical setting to improve patient care and outcomes. It is understood that the VCA has indicated some interest in supporting research in clinical service development through the ICS, paediatric and adolescent cancer care and in long term follow-up / late effects.¹¹

¹¹ J. Kearney. Personal communication.

4 Options for the future service model

In developing a service model for the future, key policy directions need to be considered as well as the advantages and disadvantages of different service approaches.

4.1 The broader policy context

There are two key DHS policy documents that need consideration in developing the service model.

Care in your community¹² is a major Victorian Government planning framework that proposes a system-wide strategy for providing patient centred health care in the environment most appropriate to each individual. The framework's emphasis is on care in community settings when it is safe and cost-effective to do so.

Linking cancer care¹³ developed by the DHS Cancer and Palliative Care Unit is the guiding policy for implementing coordinated cancer care. A strong emphasis of this policy is on:

- developing a '*whole of system*' response, working at all service levels
- building relationships between service providers
- developing and implementing agreed protocols and referral pathways across the care continuum
- developing consistent information and communication with patients and between health care providers to facilitate transitions.

Linkages within and between Integrated Cancer Services to support timely access to a range of appropriate services is an important principle.

4.2 The volume of survivors

The data analysis indicates that there are a significant number of long term survivors within the system. Section 3.5 identifies both the number of Victorian survivors by tumour group over time as well as the annual numbers of survivors by disease category and risk level.

The following table identifies the total number of survivors at the different risk levels across all tumour groups over different time periods. It does not include survivors diagnosed prior to 2000.

Table 5: Estimated number of survivors by estimated level of need over time

Time frame	Risk category			Total
	Low risk	Medium risk	High risk	
At end of first year of program	191	135	234	560
At end of five years of program	247	175	302	724

¹² Department of Human Services. 2006. Care in your community. A planning framework for integrated and ambulatory health care. January. Victoria Government Publishing Service.

¹³ Department of Human Services. 2007. Linking cancer care. A guide for implementing coordinated cancer care. February. Victorian Government Publishing Service.

At end of ten years of program	265	187	332	784
At end of fifteen years of program	252	176	330	758

Based on population figures we can estimate that approximately 27% of these survivors will be from regional Victoria.

Providing a specialist service for all of these survivors is likely to be resource intensive. Developing an appropriate service model that responds to this volume and matches the required skill base with the varying needs of survivors presents a challenge.

Attachment 1 provides a series of more detailed tables on the estimated numbers of survivors by tumour group, time interval and by geographical location.

4.3 Advantages and disadvantages of different models

As indicated the evidence (as well as some local experience) identifies two main approaches to the provision of the clinical service component of long term follow-up programs within the paediatric – adolescent spectrum of care.

Each of these models would require the development and implementation of an information and communication strategy for survivors, families and other health professionals. The level of health professional information required may be variable between approaches.

4.2.1 Specialist long term follow-up services

In this model, long term follow-up for **all** survivors is only undertaken through the provision of specialist long term multidisciplinary follow-up clinics as part of paediatric oncology services.

However they are held separately from the usual treatment or early follow-up clinics. Table 4 summarises the advantages and disadvantages of this service model.

Table 6: The advantages and disadvantages of a multidisciplinary, specialist service

Advantages	Disadvantages
Facilitates continuity of care especially if the same clinicians are involved.	Time and resource intensive placing an additional demand on specialist services.
Enables expertise and knowledge to be developed.	Some mismatch between specialist skills and some 'low and medium' risk survivors' needs.
Optimises use of consistent protocols	The volume of survivors will build over time increasing demands on a stretched workforce. 56 – 76 clinics would be needed per annum to review all survivors diagnosed

Advantages	Disadvantages
	from 2000.
Brings a high level of expertise particularly for those survivors with problems or at high risk.	Potentially reinforces a dependency on the specialist service and / or a more illness model
Ready access to a range of specialist services as needed.	May add an unnecessary access burden to some survivors and families in regional Victoria or outer metropolitan suburbs.
Optimises data collection and research.	The burden of accessing a 'centralised specialist service' may outweigh the benefit for long term survivors who are well with no immediate problems.
Most common model currently used at present.	Specialist providers may not be best placed to respond to general health issues such as sexuality and contraception.
Easier to establish more immediately.	Short-term gain in developing an immediate specialist service needs to be balanced against longer term burden.
	Does not strengthen capacity of generalist services.
	Loss of contact with survivors who choose not to attend a specialist service may impact their health over time, and the program's capacity for data collection and research.

4.3.2 Community based model

In this model the clinical follow-up is undertaken with general practitioners or other generalist physicians, who maintain contact with the original paediatric treatment team. Table 7 outlines some advantages and disadvantages of this approach.

Table 7: The advantages and disadvantages of a community based model

Advantages	Disadvantages
Provides more local access for survivors and families.	GPs or other generalist providers may not have the interest or the level of knowledge to support care.
Psychological and social benefits have been reported when moving the service away from the acute setting.	Monitoring and management of complex physiological and psychological needs is time-consuming and may not be easily integrated into a more generalist practice.
Can facilitate a shift to independence and development of stronger relationship with local providers.	May be more difficult to gain multidisciplinary input in an efficient way.
Local provider can provide a more holistic service to address both general	Each GP or generalist paediatrician would see very few long term survivors.

Advantages	Disadvantages
and cancer related health issues.	
Reduced burden on specialist services	More difficult to monitor long term effects, collect data and undertake research.
New MBF items accessible to general practitioners may assist in coordinating care between specialist and generalist services and in accessing community based mental health and other allied health services.	Requires a stronger information and communication strategy with GPs and other generalist providers.
Relatively small numbers of general practitioners with children who survived cancer facilitates a targeted approach to GP education and support.	Tertiary providers must be willing and accessible to provide secondary consultation.

4.3.3 A networked model combining specialist and generalist services

Clearly there are advantages and disadvantages of both the above approaches. In reality a third model may be one that blends elements of both approaches. In such a model a range of linked specialist and generalist clinical services may be available depending on the survivors' needs.

Given workforce issues facing health services overall, increased service funding may not be the only solution. It may be necessary to strengthen the capacity of the overall system to respond to the needs of at least some long term survivors, leaving specialist services to manage those with the most complex needs.

The advantages and disadvantages of this approach are identified in Table 8.

Table 8: The advantages and disadvantages of a networked model

Advantages	Disadvantages
Allows for the needs of survivors to be matched to the appropriate service.	Requires a cultural shift for both specialist and generalist services to work more closely together.
Facilitates local access for survivors and families wherever possible.	Requires an ongoing collaborative approach between providers.
Strengthens the service system overall allowing the specialist services to build their knowledge base and to support generalist providers.	Requires more preparatory work and a longer time-frame to establish the model and the collaborative approach.
Over time may facilitate stronger shared care models for all long term survivors, potentially reducing the burden on specialist services.	If generalist providers and survivors / parents are not adequately supported and prepared, survivors / families may be more reluctant to transition to a generalist provider.
Will build on PICS' current regional	It may not be possible to use the Medical

Advantages	Disadvantages
program.	Benefits Schedule to reimburse both the paediatric oncologist's and paediatrician's time within the same clinic.
Would require a maximum of 1 weekly specialist clinic to manage the volume of survivors diagnosed since 2000 needing access to centralised specialist services.	
Creates strong links between generalist providers and specialist services which will: <ul style="list-style-type: none"> • Optimise role of secondary consultation • Build generalist providers' confidence, skills and knowledge base • Draw on generalist knowledge base appropriately. • Optimise data gathering regardless of where survivor is seen. • Build survivors and families trust in generalist providers • Facilitate referral back into specialist service if needed. 	
Reduces financial and other resource burden on specialist services.	
Develops and trials an innovative model that may have national and international relevance.	
Fits with DHS policy and health service directions.	

4.4 The recommended model

The recommended clinical service model is a networked 'hub and spoke' approach that includes timely transition to adult services.

5 The service model

This section describes the proposed overall service model in more detail.

5.1 Purpose

To develop, implement and evaluate a coordinated and stratified long term follow-up service model that responds to the needs of survivors of childhood cancer and their families in the optimal and most efficient way.

This includes access to a range of clinical, informational and psychosocial services.

A major focus is on strengthening the service system overall (health, education and community services) as well as access to specialist long term follow-up services as required. In addition, attention needs to be paid to the transition of young adult survivors into appropriate adult follow-up services.

5.2 Vision

All children and adolescents successfully treated for cancer (and their families), have access to high quality long term follow-up information, clinical and support services that optimise their well being and their ability to lead a long and productive life.

5.3 Principles

The following principles will guide the development and provision of long term follow-up services to children and adolescents and their families.

Client and family focused principles

- Services will be offered in an empowering and flexible manner that promotes optimal health and well-being and maximises choices and the functional capacity of the child / adolescent, and their family.
- Services are respectful of and accommodate the changing needs of children and adolescents as they mature into young adults and will actively encourage their increasing autonomy and independence.
- Services will be based on a risk adaptive approach, with different levels of specialist or generalist skills available depending on a formal 'risk' assessment.
- Services will be offered in a holistic manner that addresses clinical, developmental / educational and psychosocial needs of the child and adolescent.
- Children and adolescents (and their families) will be able to access information and services as close to home as possible, depending on their needs.
- The survivor and their family will be well informed and prepared for the range of transitions that they may experience including transition into the long term follow-up program, and transition into adult services.

System focused principles

- Services and information will be of high quality, consistent and evidence based.
- Services will seek to contribute to the increasing knowledge base of the long term impact of childhood cancer, through quality improvement, service evaluation and clinical research.
- Using an action research / quality improvement approach (the plan, do, study, act cycle), the service model will be tested, reviewed and modified in response to feedback and evaluation and research findings.
- The general practitioner and other generalist providers will be supported to provide optimal care for their clients in their practice.
- In addition to providing clinical services for children or adolescents at high risk of long term effects, specialist services will provide a range of services (e.g. secondary consultation, professional education and an information and referral hub for survivors and professionals) that will strengthen the service system overall.
- Specialist paediatric services will work in partnership with adult services to optimise the transition of young adults into services that are responsive to their age- and condition-related needs.

5.4 The patient / survivor pathway

The service model is informed by the survivor pathway, visually presented in Figure 1. The following highlights features at key points. This should be taken as a framework only with specific details being developed through agreed protocols as part of early implementation.

If children / adolescents relapse at any point, they return to the treatment pathway.

5.4.1 Routine follow-up (Point A)

Once the child / adolescent is off treatment, they move into routine follow-up as part of current services. The focus is on relapse surveillance, the assessment and management of short-term effects, and referral to other services such as rehabilitation, psychology, educational support. Screening for any current physical, psychosocial or cognitive deficits or future risk is an important component of this routine follow-up.

Depending on the child's / adolescent's disease and treatment, routine follow-up may continue for up to five years. For some, routine follow-up may overlap with long term follow-up services.

5.4.2 Formal review and long term follow-up planning appointment (Point B)

This formal review and long term follow-up appointment takes place within 9 - 24 months of treatment completion and is part of the routine follow-up service. The timing may depend on the follow-up requirements of the disease, any current problems and the survivor / family needs.

This long consultation takes place with the child / adolescent's key consultant and includes a risk assessment (medical, psychosocial, developmental and educational). It provides an opportunity to review past treatment and potential issues for the future.

Information provision includes:

- the provision of the passport of information for the child and family
- discussion about where, how and when long term follow-up should take place
- health promotion and information about community and educational resources.

The long term follow-up service coordinator will be involved in these consultations.

5.4.3 Long term follow-up program (Point C)

Depending on the child / adolescent's risk assessment (low, medium or high) and discussion with the child / adolescent and family, the child / adolescent will be followed up through:

- A specialist multidisciplinary long term follow-up service
- Regional paediatric cancer clinics
- Individual general practitioners or paediatricians.

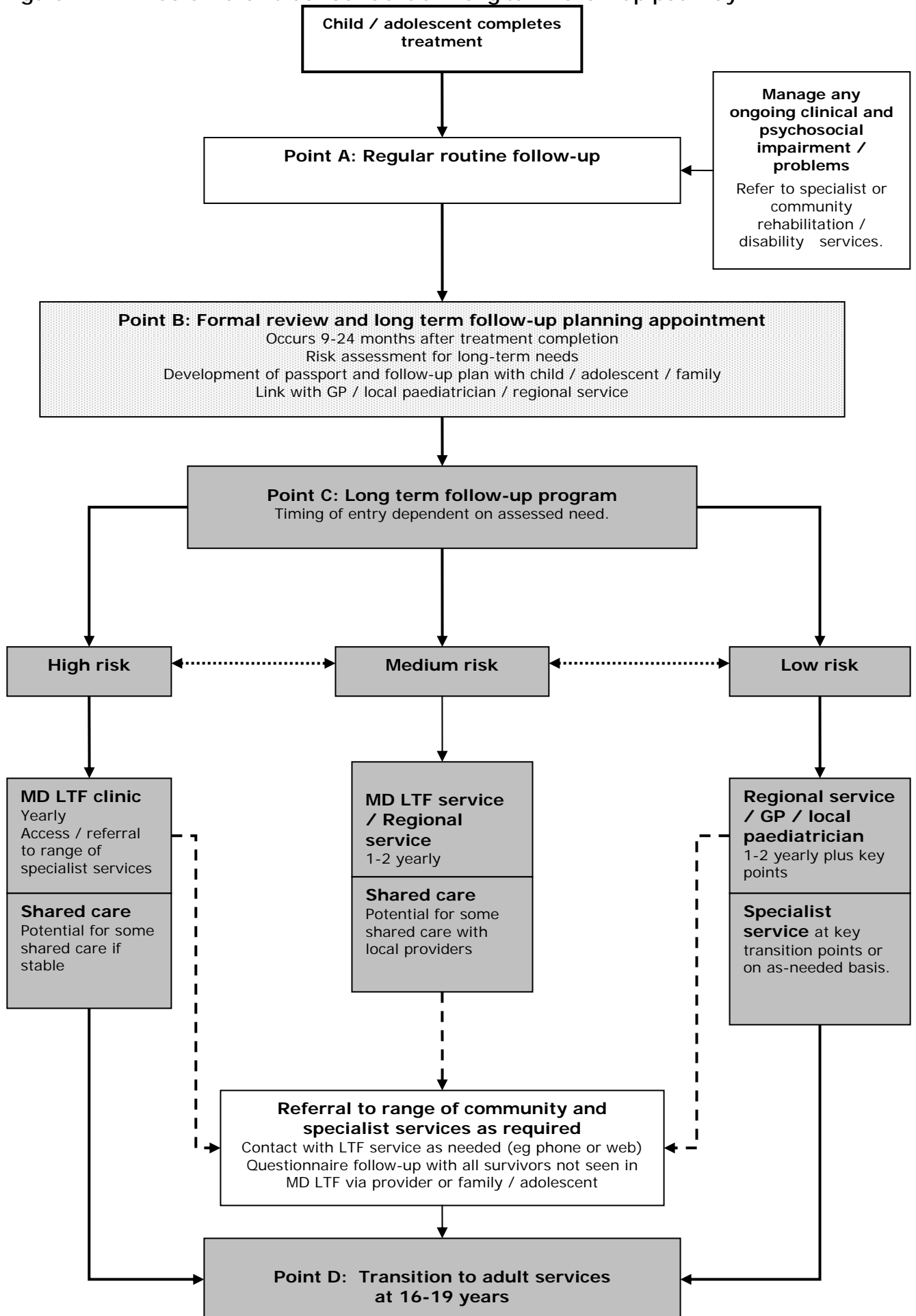
The timing of entry into the long term follow-up program is dependent on a range of factors. Survivors with residual or immediate problems or in a 'high risk' category may enter the specialist long term follow-up service earlier than those with no problems and at lower risk.

All survivors will have some access to a specialist multidisciplinary service. Opportunities for 'shared care' for all survivors between services need to be explored, where appropriate.

5.4.4 Transition to adult services (Point D)

Depending on where the adolescent / young adult receives their long term follow-up care, a specific process may be undertaken to transition their care into appropriate adult services.

Figure 1: PICS Children's Cancer Centre – Long term follow-up pathway



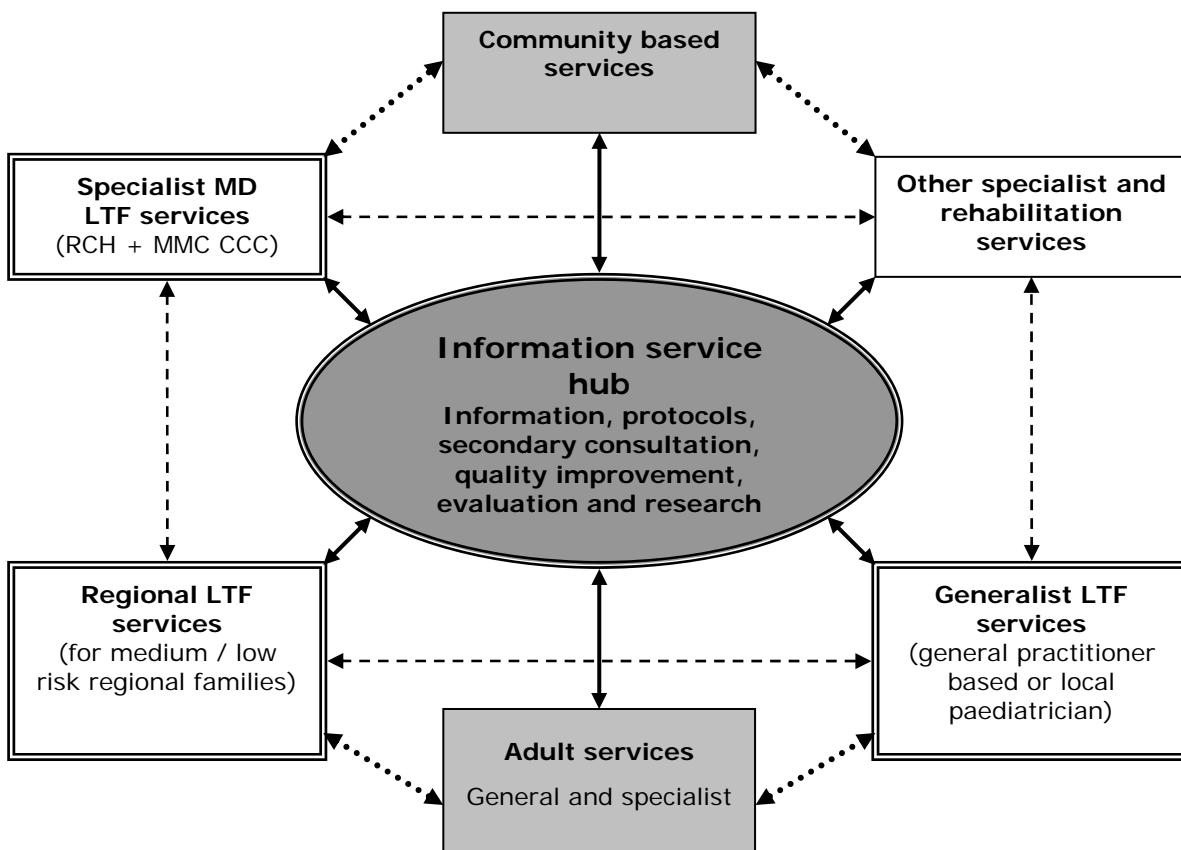
5.5 A 'hub and spoke' and 'shared care' approach

The achievement of the pathway is dependent on having a well-structured and coordinated service system.

The long term service model will be based on a 'hub and spoke' approach, with the hub providing a range of information and support to survivors and service providers. The three levels of clinical service depend on the formal assessment of the survivor's risks. Linkages will be made with other specialist and generalist services as well as with adult services. Flexibility will be introduced into the system to accommodate survivor's needs and to optimise the role of shared care as appropriate.

Figure 2 illustrates the proposed hub and spoke service model.

Figure 2: The hub and spoke service model for long term follow-up services



The following discusses the key elements of the service model.

5.6 The hub service

The hub service will provide a wide range of services and resources to support survivors and their families as well as internal and external service providers. These are outlined below.

Table 9: Key function areas and activities for the service hub

Key function area	Proposed activities
Leadership	<ul style="list-style-type: none"> • Develop strategic directions. • Liaison with key funding and policy stakeholders. • Support / model development for other children / adult services.
Partnerships	<ul style="list-style-type: none"> • Develop consumer participation strategy linking in with parents' advisory group, survivors and adolescent / young adult children's charities e.g. CANTEEN. • Develop / enhance partnerships with other services including: <ul style="list-style-type: none"> ○ Peter MacCallum Cancer Centre late effects services and OnTrac ○ Victorian Paediatric Rehabilitation Service ○ General practitioners and regional services
Clinical service and professional development	<ul style="list-style-type: none"> • Develop / modify the risk screening and assessment tools to be used in the stratified approach. • Develop implement and monitor practice guidelines / protocols. • Provide / facilitate secondary consultation. • Identify and support internal professional development needs. • Guide / develop internal service development. • Develop information resources for GPs and other service providers (available electronically). • Develop and / or link with educational opportunities for range of providers (including paediatricians, GPs, rehabilitation services). • Develop and implement educational strategy for community based child / adolescent / family mental health and other allied health services.
Information and communication strategy	<ul style="list-style-type: none"> • Establish key contact role and 1300 number. • Develop service directory. • Develop information 'fact sheets' for range of issues including transition to adult services. • Develop web page of resources (information and service directory and both professional and survivor oriented). • Develop and implement initial and ongoing communication strategy.
Transition coordination and adult services.	<ul style="list-style-type: none"> • Support / guide the transition process of survivors and families into long term follow-up programs and adult services. • Negotiation with adult services including Peter Mac, WCMICS and SMICS.
Risk management strategy	<ul style="list-style-type: none"> • Develop and implement initial risk management strategy for current 'old' survivors. • Develop mechanisms for informing survivors of new risks as they become known in the future.

Quality improvement, research and evaluation	<ul style="list-style-type: none"> • Identify research opportunities and seek funding. • Develop and maintain central information data base. • Develop and implement service evaluation and quality improvement activities. • Develop and implement survivor feedback mechanisms.
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5.7 The service spokes – clinical services

Based on the risk adaptive approach, the key features of the three levels of clinical service spokes are summarised below. Each service spoke will primarily be an ‘assessment / screening’ service.

Some management may take place by the same service providers or will require referral to a wide range of established services (specialist or generalist services) and wherever possible community based services (see 5.7.5).

The box at the end of each relevant section summarises the estimated numbers of survivors diagnosed since 2000 who will access each service level extracted from data from the tables in Attachment 1. The predicted service requirements are also summarised.

5.7.1 Generalist provider service ‘spoke’ – ‘low risk’ survivors

These are generalist provider based services (paediatrician or general practitioner) for all metropolitan survivors assessed at ‘low risk’ of long term effects with low levels of need.

These providers will be given specific guidance to support them to provide long term follow-up care within the child’s / adolescents’ general health context. This will include protocols, advice and tools on screening clinical, psychosocial and developmental needs and access to secondary consultation.

Children and adolescents may access a multidisciplinary specialist services at key points (maybe 1-2 times during paediatric / adolescent period) and on request.

Estimated service volume

At the end of the first year, an estimated 133 ‘low risk’ survivors diagnosed since 2000 will be managed by local generalist providers. At five to fifteen years, the numbers are estimated to be 170 – 185 per annum.

Generalist providers will also provide a service for relevant survivors diagnosed pre 2000.

Service requirements

These survivors would see current generalist providers through their usual services.

5.7.2 Regional service ‘spoke’ – regional ‘medium’ and ‘low risk’ survivors

This is a service particularly for regional families allowing ‘medium’ or ‘low’ risk children / adolescents to routinely access long term follow-up services locally. Follow-up will be provided by visiting paediatric oncologists from the Children’s Cancer Centres working with regional paediatricians.

The core team will have access to local nursing, social work support and community based services. Some support may be also provided through the long term follow-up service coordinator (nurse or allied health based).

Follow-up care will be supported and guided by protocols and information (as above) provided by the long term service hub. Survivors may access the multidisciplinary specialist service at key points and on request, particularly if they need access to other specialist services.

High risk but currently stable survivors who live in regional Victoria, may also be able to access these more local services as part of a 'shared care' approach with the specialist multidisciplinary service.

Estimated service volume

At the end of the first year, an estimated 97 'low and medium risk' survivors diagnosed since 2000 will be managed by a regional service spoke. At five to fifteen years, the numbers are estimated to be 125– 135 per annum.

An estimated 25-35 'medium' to 'low' risk survivors (diagnosed since 2000) will access a regional spoke in the Barwon South West Region (26% of total) each year.

In the other Victorian regions, the estimated number of 'medium' to 'low' risk survivors diagnosed since 2000 ranges from 15-21 per region in the first program year. Up to 30 survivors will access the service per region each year over 5-15 year time period.

Regional spokes will also support 'medium' to 'low' risk survivors who were diagnosed before 2000 and some shared care for stable 'high' risk survivors.

Service requirements (based on 8 - 10 survivors per clinic)

Over time between 2-4 clinics will be needed per annum in each region to service the needs of regional survivors diagnosed since 2000.

The full capacity is predicted to be 15 regional clinics per annum for long term follow-up survivors.

5.7.3 Specialist service 'spoke' – all 'high risk' and metropolitan medium risk survivors

These clinical services will primarily be available to those children and adolescents who are assessed at 'high' risk and / or have high levels of need. They will also be available to 'medium' risk survivors living in metropolitan Melbourne.

These services would have a multidisciplinary team with the core members being an oncologist / long term follow-up specialist, social work, nursing and an educational advisor who will see all survivors at each follow-up appointment. A neuro-psychologist may be part of the core team for survivors of brain tumours.

The non-core team will be other medical specialists, psychology, neuro-psychology (for non-brain tumour survivors) and the range of allied health professionals who see survivors on an 'as needed' basis identified through screening by core providers.

The 'high risk' services will be delivered at the two major PICS sites.

Although MMC only treats 15% of the population of newly diagnosed children, it is within a health service (Southern Health) which serves 25% of the metropolitan population. 'High' and 'medium' risk survivors who live in the catchment but were treated at RCH may have their long term follow-up at MMC.

Where 'high or medium risk' children are stable, some long term follow-up may take place with a 'shared care' arrangement with the generalist provider (ie GPs or general paediatricians) or the regionally based service spokes.

Estimated service volume

At the end of the first year and based on annual consultation, an estimated 332 'high risk' and metropolitan 'medium risk' survivors diagnosed since 2000 will be eligible for the specialist service. At five to fifteen years, the annual numbers are estimated to be 430-460.

If 'medium risk' survivors are only seen two yearly, the first year figure will reduce by 50 per annum (ie 282) and subsequent time periods by 60 (ie 370-410).

These figures do not include intermittent follow-up for 'low' risk survivors or survivors diagnosed before 2000.

Service requirements (based on 10 survivors per clinic)

In the first year of the new program, the focus will be on strengthening and increasing the capacity of the current RCH brain tumour service.

In Year 2 of the program, approximately **33 clinics** are needed. This allows some capacity to see survivors diagnosed before 2000, or some 'lower' risk survivors (ie those with problems or needing occasional review at key developmental points).

Over time a goal of **4 specialist clinics per month** (n=48 seeing up to 480 survivors per annum) should be set and the capacity of these clinical services to meet need, effectively evaluated.

5.7.4 Other specialist services

Long term follow-up service providers may refer a survivor to a range of currently established specialist medical, rehabilitation, allied health and educational services.

The service hub will work with a range of specific specialist services to optimise their capacity to respond to the needs of these survivors.

The service hub will also establish a strong relationship with the Victorian Paediatric Rehabilitation Program to facilitate the referral of survivors who may benefit from short-term goal based rehabilitation.

5.7.5 Community based services

This is the full range of community and educational services that may provide support to children, adolescents and their families.

The service hub may provide a range of resources and / or training to support these providers e.g. programs for community based mental health workers to provide appropriate counselling for survivors and families.

5.7.6 Adult services

This includes general adult oncology services, specialist adult long term cancer follow-up services and generalist adult service providers (e.g. GPs). Given that the risk of long term effects increase with increasing survival periods, it is likely that a higher proportion of childhood cancer survivors may need access to more specialist services.

The service hub will work with Peter Mac in the short term and with the Integrated Cancer Services in the longer term to establish and strengthen their capacity to provide services for long term survivors as they transition into adulthood.

Priority may be given to working with SMICS to explore the viability of and pilot a transition service (e.g. paediatric and adult physicians / oncologists jointly staffing an older adolescents' / young adults' long term follow-up service) as well as access to an adult service. In addition, working with WCMICS may strengthen current referral pathways and services at WCMICS services (i.e. Royal Melbourne Hospital).

Estimated service volume

At the end of the first year, 44 survivors will be transitioned to adult services. If all 'high' and 'medium' risk survivors (67%) need to access a specialist adult service, an estimated 30 will transition to a specialist service.

At five to fifteen years, the estimated total numbers of survivors transitioning to adult services per annum will range from 46 at five years to 75-80 at years 10-15. Of these, an estimated 31 will need specialist services at five years and 50-55 at 10-15 years.

Currently it is estimated that there are 120-150 adult survivors still being seen within the paediatric environment that need to transition to adult services. An assumption is made that these are likely to be medium or high risk survivors. If 75% need transition to a specialist adult service, this would be 90-112 survivors.

These figures do not include those long term survivors diagnosed before 2000 who are not currently known adults within the paediatric service, but will require transition into general or specialist adult services.

5.7.7 Linking the hub and the 'spokes'

As part of the hub services, a good centralised data system is required to:

- provide ready access to survivor information as needed
- maintain contact details and information on the current status of survivors
- maintain contact details of long term follow-up service providers
- flag the timing of data collection for those survivors not seen within the specialist services and remind external service providers to send information
- support secondary consultation.

In addition, external service providers will be asked to ensure that copies of survivors' clinical tests are forwarded to the central service.

5.7.8 Service model evaluation and research

The evaluation of the service model and other research initiatives will also provide an opportunity to create linkages between the different service levels and with survivors and families.

Initially the evaluation / research priority will focus on the appropriateness, effectiveness and acceptability of the service model with its stratified approach to information and clinical service provision based on assessed needs. This may include:

- Uptake of the different service components.
- Overall morbidity (physical and psychosocial).
- Appropriateness of the stratification criteria and matching services.
- Survivor / carer satisfaction with the services.
- Service provider satisfaction.

In addition, some research will be undertaken to gain an understanding of the needs of the 'old' survivors including:

- Their awareness of long term issues.
- Their current utilisation of health care services.
- Any current health issues.

Identifying ongoing research and funding opportunities is a core role of the hub service.

6 Implementation of the service model

A phased approach is needed for the successful implementation of the model. These three phases may be overlapping dependent on resources and demand.

6.1 Phase 1: Preparatory phase

This predominantly preparatory phase will take up to 12 months and will:

- establish the foundations for the program and the information service 'hub'.
- transition current adult survivors into the appropriate adult generalist or specialist long term follow-up services, working with adult services.
- develop the risk management and communication strategy for 'old' survivors.

The agreed **outcomes** may include:

- An agreed set of policies and protocols to guide the program
- Identification or development of relevant screening tools to be used
- A suite of flexible individualised and general information resources for survivors, families, health care professionals and other service providers
- An active consumer participation strategy
- An active web page and 1300 contact number
- Strengthening of current services
- Preparation of regional services
- An agreed evaluation framework
- Development / modification of an appropriate data collection system
- 80% of all known adult survivors in paediatric services will have been transitioned into an adult service.
- An agreed risk management strategy for 'old' survivors is developed and commenced.

6.2 Phase 2: Early implementation

This will take up to an additional 12-24 months and will include the establishment of:

- one additional specialist clinic per month at RCH (total of 2 a month)
- the secondary consultation service.
- a specialist clinic at MMC – start as 2 monthly service and increase based on need
- pilot of a new / enhanced adult transition service at 1-2 service sites.
- linkage with the regional program to provide regionally based follow-up
- trials of educational programs for community based services e.g. mental health providers.
- full implementation of risk management strategy for 'old' survivors.

The agreed **outcomes** may include:

- 80% of all new survivors are transitioned into an appropriate service
- All current adult survivors and those newly eligible for transition into adult services have done so.
- 'Old' survivor risk management and communication strategy completed.

6.3 Phase 3: Continuing implementation and consolidation

This is an ongoing phase which includes a range of direct and indirect service activities as well as service evaluation and adjustment, further strengthening of long term follow-up services (paediatric and adult) and key research activities.

The agreed **outcomes** may be:

- All program / service elements have been implemented.
- Service model evaluated and new service developments identified
- All survivors transitioned into long term follow-up service appropriately
- Future research outcomes identified.

The potential activities in each of these phases are summarised in Table 10.

Table 10: Proposed activities to be undertaken by implementation phase

Activity category	Suggested key activities		
	Phase 1 Preparation – 12 months	Phase 2 Early implementation – 12-24 months	Phase 3 Ongoing implementation & consolidation
Leadership, strategic directions and partnerships	<ul style="list-style-type: none"> Establish core staff for developing program Finalise strategic directions Develop consumer participation model Develop partnerships with funders, peak bodies and others e.g. Peter Mac service. 	<ul style="list-style-type: none"> Review and modify staffing as needed Review and adjust strategic directions Continue and establish new partnerships as needed. 	<ul style="list-style-type: none"> Review and modify staffing as needed Review and adjust strategic directions Continue and establish new partnerships as needed.
Protocol and policy development	<ul style="list-style-type: none"> Develop policies / protocols for follow-up services and transition to adult services Develop and trial information passport Work with GPs, paediatricians to develop relevant guidelines / resources. 	<ul style="list-style-type: none"> Modify as needed. 	<ul style="list-style-type: none"> Review and modify all policies on basis of experiences and feedback.
Training and education	<ul style="list-style-type: none"> Identify in-house and external training requirements Develop information / training programs / packages 	<ul style="list-style-type: none"> Implement in-house training Promote and implement GP communication Develop and implement information and training for providers such as community based mental health workers. 	<ul style="list-style-type: none"> Continue as needed.
Clinical services	<ul style="list-style-type: none"> Maintain / strengthen current RCH LTF service Optimise transition of adults currently in system to adult services. 	<ul style="list-style-type: none"> Establish new monthly clinic (1) at RCH Plan for and open MMC clinic (2monthly) 	<ul style="list-style-type: none"> Maintain current services Additional clinic (s) established based on need.

	<ul style="list-style-type: none"> • Negotiate required resources for new clinics • Negotiate with current and potentially new adult services re: transition 	<ul style="list-style-type: none"> • Establish LTF services as part of regional clinics • Pilot MMC transition service • Support development of new adult service. 	
Information hub	<ul style="list-style-type: none"> • Develop core information resources for survivors and families, schools and health care providers • Develop web-page • Establish 1300 number • Identify / develop community resource directory. 	<ul style="list-style-type: none"> • Actively promote to survivors and providers • Add to web resources as needed • Provide secondary consultation for service providers • Respond to queries from survivors • Actively use hub as means to respond to needs of 'older' LTF survivors 	<ul style="list-style-type: none"> • Maintain information hub • Provide secondary consultation for service providers • Respond to queries from survivors
QI, research and evaluation	<ul style="list-style-type: none"> • Develop evaluation framework • Develop follow-up questionnaire / process for recording status of all survivors • Develop consumer feedback mechanisms • Seek Ethics approval for evaluation etc • Develop / modify CCC database • Identify early opportunities for research funding. 	<ul style="list-style-type: none"> • Implement follow-up questionnaire with survivors or relevant service providers. • Collect relevant service data in accordance with evaluation framework. • Implement any research activities. 	<ul style="list-style-type: none"> • Evaluate service model based on evaluation framework. • Review and modify model in line with evaluation findings.
Communication and risk management strategies	<ul style="list-style-type: none"> • Develop general communication strategy Develop / implement risk management strategy for 'old' long term survivors. 	<ul style="list-style-type: none"> • Implement communication strategy • Continue risk management as needed. 	<ul style="list-style-type: none"> • Continue as needed.

7 Resource requirements

This section considers the staffing and other requirements needed to develop and maintain the service and information hub, additional resources needed for specific strategies and for the required clinical services.

7.1 Staffing resources

In the initial phase, the staffing resources will be required for the preparatory work. As the program moves into implementation, the level of resources may change as will the required skill base.

Table 11: Staffing requirements and potential roles and skills

Role	EFT	Duration	Proposed roles and skills
Director	0.3-0.4	0.4 in early phase reducing to 0.3	<ul style="list-style-type: none"> • Leadership and strategic planning. • Will guide the development and implementation of the service model. • Communication with funding bodies, partnerships and clinical colleagues. • Will guide development of clinical policies and protocols, support secondary consultation and provide some clinical care.
Project Manager	0.5	Up to 2 years	<ul style="list-style-type: none"> • Responsible for day-to-day development and implementation of service model. • Provides overall management and works in key areas e.g. partnership development, risk management strategy, service evaluation. • Supports other staff. • Works closely with Project Director, PICS Manager and CCC Directors.
Project officer / service coordinator	1.5 – 2 EFT	Up to 2 years and then reduce to 1.5 ongoing	<p><i>Preparatory phase</i></p> <ul style="list-style-type: none"> • Develops and implements specific strategies as well as contributing to overall strategy. • Good mix of project skills, negotiation, verbal and written communication skills (50–70 % of role). • Clinical and service coordination skills • Good knowledge of: <ul style="list-style-type: none"> ○ Health and community services and how to access and navigate through system ○ Understanding of long term follow-up issues • Flexibility in approach to be able to work with children, adolescents, young adults and their families. <p><i>Implementation phase</i></p> <p>There would be less emphasis on project skills (say 30%) with stronger emphasis on</p>

			clinical and service coordination skills and knowledge of health and community services.
Research officer	0.5	Ongoing from Year 2	<ul style="list-style-type: none"> • Ability to coordinate range of research and evaluation activities.
Administrative / data support	0.3-0.5	Ongoing	<ul style="list-style-type: none"> • Provides a range of administrative skills and data handling.

7.2 Resources for specific strategies

While a significant proportion of the required work will be supported by the above staffing resources, some additional resources may be required for the preparatory work, short-term strategies and ongoing activities.

7.2.1 Information hub

This includes resources for:

- Editing and design of low-cost information resources for health care professionals and other service providers.
- Editing and designing of low-cost information resources for survivors and family members including the survivor's passport.
- Web page development.
- Accessing and / or developing a service directory.
- Establishing and maintaining a 1300 number.

7.2.2 Consultation activities

This includes resources for GP consultation and to support a consumer participation strategy.

7.2.3 Educational training programs

Additional funding may be needed to develop specific internal and external educational activities. In particular to develop and trial an educational program to strengthen community based mental health workers in the needs of survivors of childhood cancer.

7.2.4 Quality improvement, service evaluation and research

A minimal level of additional resources has been identified:

- Specialist support in developing the evaluation framework and related evaluation tools.
- The development of new data system to facilitate clinical practice and research.

Further budgetary requirements will be developed as part of any submission to the Victorian Cancer Agency once the VCA guidelines have been released.

7.2.5 Engaging with adult services

This includes:

- A relatively small amount of funding as an incentive to adult services to strengthen their capacity to provide quality long term follow-up services.
- Some funding for the trial of young adult transition service at MMC.

7.2.6 Risk management and communication strategy

The implementation of this risk management and communication strategy for 'old' survivors is likely to require additional resources to:

- Support initial consultation with 'old' survivors.
- Manual trawling of contact listing and accessing medical records.
- Mailing costs and potentially advertising costs.
- Staffing to extract information from clinical records.
- Support forums for 'old' survivors.
- A GP and adult service provider strategy.

Further resources may be needed if this program element develops a stronger research element as identified in 5.7.8.

7.3 The clinical services

This includes the specialist services and regional services.

The following table summarizes the total number of clinics and number of long term survivors seen by year of implementation.

Table 12: Specialist and regional clinics per annum per site

Site	Year 1		Year 2		Year 3		Year 4	
	Clinics (n)	Attendee (n)	Clinics (n)	Attendee (n)	Clinics (n)	Attendee (n)	Clinics (n)	Attendee (n)
RCH ¹	12	120	18	180	24	240	36	360
MMC ¹	0	0	6	60	12	120	12	120
Regional ²	8	64	9	72	13	104	15	120
Total	20	184	33	312	49	464	63	600

¹ based on 10 attendees per clinic

² based on 8 attendees per clinic

7.3.1 Specialist services

A detailed requirement for a specialist, multidisciplinary clinic with the potential to see ten survivors per clinic (7 'high risk' survivors and 3 'medium to low' risk) has been developed (see Table 13). By Year 4, four specialist clinics per month held at either RCH or MMC will be able to see 480 survivors per year.

7.3.2 The regional clinical services

The regional clinics will be staffed by a visiting paediatric oncologist, supported by a local paediatrician and nursing and social work staff from within the regional service.

Table 13: Long term follow-up clinic (for 7 high risk, 3 medium- low risk)

Average time in minutes spent with each MD team member by each clinic attendee													
Core team (all survivors)						Non-core team (sees survivors with identified needs)							Total per child
Key LTF medical	Nsg	SW	Educator	Neuro-psych	Other med specialist x 1 *	Other med specialist x 2	Mental health	Physio	OT	SP	Other		
High risk survivors													
Child 1	15	20	15	15	15		30	30			30		170
Child 2	15	20	15	15	15		30		30				140
Child 3	15	20	15	15	15		30	30					140
Child 4	15	15	20	15	15	30	30		30				170
Child 5	15	15	20	15	15	30				30			140
Child 6	15	15	20	15	15	30					30		140
Child 7	15	15	20	15	15	30						30	140
Med - low risk survivors													
Child 8	25	20	15	15	15							30	120
Child 9	25	20	20	15	15	30							125
Child 10	25	20	20	15	15								95
Administrative work in minutes													
	30	30	30	60	30	30	30	15	15	15	15	300	
Total per discipline	210	210	210	210	180	180	180	75	75	45	75	30	
Hours	3.5	3.5	3.5	3.5	3.0	3.0	3.0	1.25	1.25	0.75	1.25		
Total number of children seen per clinic	10												
Total number of clinics per year					12		24		48				
Total number of children seen per annum					<u>120</u>		<u>240</u>		<u>480</u>				

***Note:** the other medical specialists may be a radiation oncologist, endocrinologist or another speciality

Attachments

Attachment 1: Predicted numbers of survivors by disease and risk category over time

Table 1.1: Number of survivors entering long term follow-up for each yearly cohort

Tumour type	Number of newly diagnosed in 2005	Estimated no: survivors to enter paed LTF per annum - diagnosed in 2004-05	Low risk		Medium risk		High risk	
			%	n	%	n	%	n
Brain / CNS tumours*	30	21	10	2			90	19
Solid tumours**	37	24	40	10	30	7	30	7
Liquid tumours*	74	51	40	20	30	15	30	15
Total		96		32		23		41
Numbers of regional survivors pa based on 27 % of population				9		6		
Numbers of metro survivors pa based on 73% of population				23		16		

* based on 80% survival LTF

** based on 70% survival LTF

Table 1.2: Number of LTF survivors at end of first year of new LTF program (new entries, old survivors and transitions out)

	N	Low Risk		Medium risk		High risk		
		%	n	%	n	%	n	
Brain / CNS	110	10	11			90	99	
Solid tumours	112	40	45	30	34	30	34	
Liquids	337	40	135	30	101	30	101	
Total			191		135		234	
Numbers of regional survivors based on 27% of population				51		36		63

Numbers of metro survivors based on 73% of population	139	98	171
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Table 1.3: Number of survivors at 5 years post-transition by risk category

Tumour type	Estimated number of survivors at 5 years post LTF transition	Low risk		Medium risk		High risk	
		%	n	%	n	%	n
Brain / CNS tumours	142	10	14	0	0	90	128
Solid tumours	158	40	63	30	47	30	47
Liquid tumours	424	40	170	30	127	30	127
Total			247		175		302
Numbers of regional survivors based on 27% of population			67		47		82
Numbers of metro survivors based on 73% of population			180		127		221

Table 1.4: Number of survivors at 10 years post-LTF transition by risk category

Tumour type	Estimated number of survivors at 10 years post LTF transition	Low risk		Medium risk		High risk	
		%	n	%	n	%	n
Brain / CNS tumours	161	10	16	0	0	90	145
Solid tumours	174	40	70	30	52	30	52
Liquid tumours	448	40	179	30	134	30	134
Total			265		187		332
Numbers of regional survivors based on 27% of population			72		50		99
Numbers of metro survivors based on 73% of population			193		136		242

Table 1.5: Number of survivors at 15 years post LTF transition by risk category

	Estimated number of survivors at 15 years post LTF transition	Low risk		Medium risk		High risk	
		%	n	%	n	%	n
		Brain / CNS tumours	171	10	17		
Solid tumours	179	40	72	30	54	30	54
Liquid tumours	409	40	164	30	123	30	123
Total			252		176		330
Numbers of regional survivors based on 27% of population			68		48		89
Numbers of metro survivors based on 73% of population			184		129		241

Table 1.6: Number of survivors across tumour groups: all METRO low and medium risk survivors plus ALL high risk survivors

	Low risk metro (n)	Med risk Metro (n)	High risk - all (n)	Total	Total of metro medium and all high risk
Numbers of new LTF -entering in first year of program plus current LTF	139	98	234	471	332
Numbers of survivors at 5 years	180	127	302	610	430
Number of survivors at 10 years	193	136	332	661	468
Number of survivors at 15 years	184	129	330	643	459