

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from CLIC Sargent – CDP 27

Inquiry into progress in implementing the Cancer Delivery Plan: CLIC Sargent

Introduction

1. CLIC Sargent is the UK's leading cancer charity for children and young people and as such we play a key role in providing care and support to the children and young people diagnosed with cancer in Wales each year.¹ We are there every step of the way:
 - **During treatment** – providing specialist nurses, play specialists, Homes from Home
 - **In hospital & at home** – offering specialist social care and support in the community – services for young people, holidays, grants, helpline
 - **After treatment** – helping survivors, supporting those bereaved.
2. We welcome the opportunity to respond to this inquiry into progress made to date in implementing the Welsh Government's Cancer Delivery Plan. There is much to welcome in the delivery of this plan, including the ambition to ensure health services in Wales are among the best in the world and that anyone in Wales diagnosed with cancer should expect to receive high quality services. However, we believe there is not sufficient focus on the needs of children and young people with cancer and their families in Wales. There are few mentions of children and none at all of teenagers and young adults (aged 16 to 24) in the plan. The fact that this group of patients is small means that it is even more important to ensure there is a clear, coordinated approach to ensuring high quality services are accessible to all. However, at present there is a risk that the Cancer Delivery Plan will represent a missed opportunity for children and young people.
3. **CLIC Sargent is a member of the Wales Cancer Alliance and we endorse the points raised in their response.**

Children and young people

4. Most cancers which affect children (0 to 16) differ from those affecting adults. They occur in different parts of the body; appear differently under the microscope and respond differently to treatment. The spectrum of cancer types in young people (16 to 24) covers firstly a large proportion of the patients who experience one of a small group of cancer types which, although relatively rare in the overall population, are common within this age group. Secondly, there are a minority who develop one of the many cancer types typical of older adults but for various reasons they occur in this situation at an unusually young age.
5. Children and young people's needs differ according to their developmental stage (emotional, social, psychological and physical) and the need to consider the impact on the wider family of a cancer diagnosis. Indeed, across the age spectrum,

¹ There are around 170 new diagnoses in Wales each year in the 0-24 age-group.

children are as different from each other as they are from adults. Therefore a holistic approach to needs assessment is an essential part of service design.

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6. The terms of reference for the inquiry are to examine the progress made in implementing the Cancer Delivery Plan in Wales in relation to a set of key questions. Our response will focus on the following key questions with regards to children and young people between the ages of 0 - 24:
 - Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016
 - Whether patients across Wales can access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner

Is Wales on course to deliver the Cancer Delivery Plan by 2016?

7. **Lack of focus on children and young people with cancer creates a delivery risk** – When the Cancer Delivery Plan was published, CLIC Sargent raised concerns that successful delivery would be placed at risk due to a lack of sufficient focus on children and young people within the document. In particular, we flagged the lack of any commitments to address the specific needs of teenagers and young adults within the plan.
8. As stated above, most cancers that affect children and young people differ from those which affect older adults. 170 children and young people are diagnosed with cancer each year in Wales, with approximately 25% not expected to survive their disease. Unlike adult cancers, the focus for the planning and delivery of cancer treatment for children is based in a few very specialised principle treatment centres (PTCs), of which there are currently 19 in the UK and one in Wales (Children's Hospital of Wales, Cardiff). Whilst this means specialist expertise has been developed in these centres, it also means that some children are treated in hospitals hundreds of miles from home.² As well as specialist support that can be provided in PTCs, shared care arrangements also exist whereby patients can have some elements of their care delivered in designated shared care units, including Ysbyty Glan Clwyd.
9. As cancers in children and young people are less common, it is necessary to take an all Wales approach in order to ensure equitable access to services for all young cancer patients. It is not appropriate for services to be led at a local level as the patient populations will be too small. In addition, there must be clear national oversight and accountability to ensure that high-quality services are in place for all children and young people affected by cancer in Wales.
10. Consequently, a 'one size fits all' approach to implementation of the Cancer Delivery Plan, which does not overtly address particular areas of concern, barriers to delivery and opportunities to build on best practice for children and young people, is much less likely to lead to successful delivery. If the outcomes and performance measures of the Cancer Delivery Plan are to be delivered by 2016, swift action must be taken now to create a more targeted approach to delivery for

² The impact of travel on children, young people and families was explored in a report by CLIC Sargent published in 2010 entitled [A Long Way from Home](#)

children and young people.

11. Due to the rarity of childhood cancer, we believe an all Wales approach is critical to ensure equitable access to high-quality services for all patients. It is also essential that the Welsh Government puts in place a robust system for monitoring and ensuring standards are adhered to. **We recommend that the Welsh Assembly should publish an action plan which sets out the way in which they implement the Cancer Delivery Plan for children and young people during 2014-16.** This plan should draw on existing best practice guidance including NICE *Improving Outcomes in Children and Young People with Cancer* guidance.
12. **Lack of data on patient experience for children and young people creates a delivery risk** – It is regrettable that the recently published Wales Cancer Patient Experience Survey did not capture the experiences of patients who are under 16. Patient experience is rightly valued within the health system in Wales, however, children do not have this opportunity to share their experiences and the lack of information about the current state of patient experiences of children under the age of 16 is a significant barrier to improvement. Without national patient experience data it is difficult to develop meaningful indicators to drive improvements in children’s cancer patient experience.
13. Although the Wales Cancer Patient Experience Survey did include 16 – 24 year olds, the number of young people responding to the survey is low. One reason for this might be that the survey is not age appropriate and that young people find it difficult to engage in an adult survey. The Cancer Patient Experience Survey which is operated by the NHS in England has consistently shown that TYA with cancer report poorer patient experiences than older adults. For example the last three the survey has found young people to be less positive than older patients, and the 2013 survey found that younger patients were the least positive group on over 50% of scored questions (23 of 41). Consequently, it is critical to gauge whether this is also the case in Wales, and to take action to address any inequality of patient experience for TYA.
14. **We recommend that the Welsh Government should develop an age appropriate Wales Cancer Patient Experience Survey which captures the experiences of 0 – 25 year olds with cancer.**
15. **Lack of progress on key working and survivorship for TYA** – Although, the key working role is adopted relatively well within Paediatric Oncology services, there is a missing link in terms of key worker support in Wales to those in the 16 – 24 age range. In some cases social workers are taking on this role by default – which is not ideal in terms of the medical support and co-ordination that young people require – particularly in palliative phases of their disease.
16. In addition, provision of survivorship support for young cancer patients remains largely in the hands of national and local voluntary sector organisations and would benefit from a co-ordinated approach at a national level.
17. **We recommend that the Welsh Assembly should take action to address the deficit in key worker and survivorship support for TYA with cancer.**

Can patients across Wales access the care required in an appropriate setting?

18. **Teenagers and young adults (TYA) with cancer are not accessing the care**

they require, in appropriate settings – Despite the fact that national standards for the management of TYA have now been put in place, minimal progress has been made to increase access to the specialist support available to the 16 – 24 age group. TYA multi-disciplinary teams exist in South Wales and in the Clatterbridge hospital on the Wirral (to which North Wales young people would be referred). The recommendations that all TYA diagnosed with cancer should be referred to the TYA MDT's is not being complied with in many cases. For example North Wales Cancer Network has identified 10 young people who have been diagnosed with cancer in the past year who have not been referred to the TYA MDT. Analysis of this information is on-going to identify why this is the case.

19. In order to ensure effective delivery of the Cancer Delivery Plan for TYA, it is essential that action is taken to ensure that the recommendation for referral to specialist age appropriate care and support to be enforced.

CLIC Sargent in Wales

20. CLIC Sargent currently contribute to the funding of three Clinical Nurse Specialists and a Paediatric Social Work post supporting patients in shared care arrangements throughout North Wales. We also fund a Young Persons Social Worker for the North Wales region. We also have a Young Person's Outreach Team in South Wales consisting of two Young Person's Social Workers supporting 16-24 year olds affected by cancer. In South Wales we also fund a Paediatric Neuro-Oncology Nurse Specialist Key Worker. All children and young people registered with CLIC Sargent receive financial grants of a minimum £170 per individual. We cover the paediatric principal treatment centre in Cardiff as well as supporting patients in shared care arrangements in Bangor, Wrexham and Rhyl.