

Children, Teenagers and Young Adults

A Wales Cancer Alliance Policy Paper

Summer 2017



Children, teenagers and young adults (0-24yrs): Overview

Children, teenagers and young adults (CTYAs) represent a relatively small proportion of all cancer patients, defined as rare or less common cancers. It is easy for them to be lost in a system not designed for them and without specific focus on their needs. Around 224¹ 0-24 year olds are diagnosed with cancer each year in Wales, with many more on active treatment at any one time. Although survival rates are relatively high, around 80%², there are variations by cancer type and cancer remains the single largest cause of death from disease for children young people³.

It is recognised, most notably in best practice NICE guidance⁴, the particular psychosocial impact of cancer on children and young people. Specialist age-appropriate care is available in Wales and we call for every CTYA with cancer to be offered and have access to these services to improve experiences and outcomes.

Cancer Delivery Plan⁵

After the publication of the Welsh Government's Cancer Delivery Plan in 2012, the Wales Cancer Alliance expressed concern about the very limited focus on CTYAs with cancer and their families. We were therefore pleased to see an increased prioritisation of this in the refreshed plan when it was published in November 2016. We welcomed the recognition of the fact that children and teenagers require a specialised service which takes account of the problems caused by long-term effects and addresses the importance of transition. We were also pleased to see that there was an emphasis on the importance of gathering data on services for children and teenagers. We support the focus on increasing knowledge about patient experience and the decision to consider the extension of peer review to children and young adult services.

However, more detail is needed on how these new proposals will work in practice. The creation of the Wales Cancer Network has provided an opportunity for strengthened engagement but we have yet to see a clear structure for the execution or accountability of the Delivery Plan recommendations.

Background

Unlike adult cancers, the focus for the planning and delivery of cancer treatment for children and young people is based in a few specialised principal treatment centres (PTCs). There is currently one in Wales for children (Children's Hospital of Wales, Cardiff) and one for teenagers and young adults (University Hospital of Wales, Cardiff). Whilst this means that specialist expertise has been developed in these centres, it also means that children and young people are often treated in hospitals hundreds of miles from home.

In Wales, many will receive at least some treatment in an English PTCs: those in North Wales may go to Alder Hey, Liverpool, Manchester or Birmingham. Even children and young people near the PTCs in South Wales may have to travel; for example, those needing bone marrow transplants will go to Bristol. As well as the specialist support that can be provided in PTCs, shared care arrangements also exist whereby patients can

¹ Cancer Research UK 'Teenage and young adults cancer incidence statistics 2012-2014' and 'Children's cancers incidence statistics 2012-2014' [Internet] [Accessed 20 July 2017] Children aged 0-14 all cases in Wales: 87. Teenagers and young adults aged 15-24 all cases in Wales: 137.

² Cancer Research UK 'Teenage and young adults cancer statistics 5 year survival 2001-2005' and 'Children's cancer statistics 5 year survival 2006 - 2010' [Internet] [Accessed 20 July 2017] Children aged 0-14 England and Wales: 82%. Teenagers and young adults aged 15-24 England and Wales: 84%.

³ Public Health Wales. Child deaths in Wales: Patterns and trends report 2016. [Internet]. 2016 [cited 09 May 2017]. Available from: <http://www.wales.nhs.uk/sitesplus/documents/888/CDR%20patterns%20%2B%20trends%20v1%20EN.pdf>

⁴ NICE. Improving Outcomes in Children and Young People with Cancer [Internet] 2005 [cited 09 May 2017]. Available from: <https://www.nice.org.uk/guidance/csg7>

⁵ Wales Cancer Network. Cancer Delivery Plan for Wales 2016 – 2020: The highest standard of care for everyone with cancer [Internet]. 2016 [Cited 09 May 2017]. Available from: <http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

have some elements of their care delivered in designated shared care units, such as Ysbyty Gwynedd in Bangor, Wrexham Maelor Hospital and Glan Clwyd Hospital in Rhyl.

Calls to action

1) Clear policy commitments and accountability frameworks

Defined commitments to understanding and meeting the needs of young cancer patients to ensure there is a clear, coordinated approach to providing high quality services that are accessible to all.

2) National standards to be implemented, measured and reported on

Systems in place to demonstrate a long-term, sustainable and accountable commitment to the recommendations laid out in the 2016 refresh of the Cancer Delivery Plan. Hospitals treating children and young people with cancer should ensure that they report fully and accurately on their services.

In addition to these there are also several specific challenges around supporting younger cancer patients:

- **Early diagnosis:** A greater focus on improving diagnosis of cancer in children, teenagers and young adults is required due to challenges in identifying cancer in this age group. Research is needed to establish optimum routes to diagnosis for children, as the links between particular routes to diagnosis and survival and long term health outcomes have not been sufficiently explored for this age group. In addition to improving the availability of diagnostic testing in primary care settings, it is essential that GPs and other primary care professionals have access to the training and support that they require to feel confident in identifying the signs and symptoms of cancer in children, teenagers and young adults. It is also essential that young people and families are aware of cancer symptoms and empowered to seek help when needed.
- **Access to clinical trials for 16-24 year olds:** Improved access to clinical trials is a direct way to improve patient experience, outcomes and ultimately survival for teenagers and young adults with cancer. However, young people with cancer have very low levels of participation in trials. Figures published in 2014 show only around 30% of teenagers aged 15-19 and 14% of young people aged 20-24 in England, Scotland and Wales enter clinical trials.⁶
- **Survivorship:** It is important to recognise that the survivorship experience for young cancer patients is likely to be different than that of older adults, largely because most young cancer survivors will require additional and long-term support for 50+ years. A significant proportion will also go on to develop other long-term conditions and are at high risk of cancer recurrence in later life. Wider use of patient-held records and summary care plans could help to empower patients in managing their care needs post-treatment and beyond.
- **Palliative care:** Children, teenagers and young adults with palliative and end of life care needs should have access to palliative nursing care 24/7 and access to paediatric advice and support 24/7. Outreach nurse specialists and children's community nurses (CCNs) play a vital role in the coordination of palliative and end of life care and in supporting children to die at home if they choose to. However, outreach nurses are not available in all areas of the country and are very often reliant on charities for funding, whilst there are limited numbers of CCNs in place across Wales. Provision is particularly limited for young people aged 16 to 18, as only children aged up to 16 are eligible for children's services, and only those aged 18 and above are able to access adult palliative care provision. Finally, there is a lack of availability of age appropriate hospice care for 16 to 24 year olds with cancer.⁷

⁶ Fern, L., Lewandowski, J., Coxon, K., & Whelan, J. [Internet]. 2014 [cited 09 May 2017]. Available from: <http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045%2814%2970113-5/abstract>

⁷ Grinyer, A. & Barbarachild, Z. Teenage and Young Adult Palliative and End of Life Care Service Evaluation [Internet]. 2011 [cited 09 May 2017]. Available from: http://eprints.lancs.ac.uk/49234/1/tcteolc_report.pdf,