

CPG on Cancer: Spotlight – Children and Young People with Cancer in Wales

Key Details

When: 10:00am-11:00am, Thursday 7th November 2024

Where: MS Teams

Purpose of the Session: To hear from the Wales Cancer Alliance (WCA) subgroup on Children and Young People about the challenges in children and young people's cancer services and discuss what more can be done to better meet the needs of children, young people and their families in Wales.

Topic: This session was focussed on children and young people with cancer in Wales with a presentation from representatives of the WCA Children and Young People.

Agenda:

- Chair Opening & AGM (5 minutes)
- Presentation: WCA Children and Young People (25 mins)
- Q&A (45 minutes)

MSs in attendance:

David Rees MS (**DR**)

Mark Isherwood MS (**MI**)

Dr Altaf Hussain MS

Other attendees:

Simon Scheeres (**SS**), CRUK

Danielle Percival (**DP**), The Joshua Tree

Andrew Reynolds (**AR**), Young Lives vs Cancer

Menai Owen-Jones (**MOJ**), LATCH Welsh Children's Cancer Charity

Lauren Marks (**LM**), Young Lives vs Cancer

Kate Morgan (**KM**), Cardiff and Vale UHB

Dr Philip Connor (**PC**), Cardiff and Vale UHB

Dr Eve Gallop-Evans (**EGE**), Velindre University NHS Trust

Greg Pycroft (**GP**), Tenovus Cancer Care

Rhian Thomas-Turner (**RTT**), Cardiff and Vale UHB

Dr Madeleine Adams (**MA**), Cardiff and Vale UHB

Tracey Burke, Cancer Aid Merthyr

Eirlys Edwards, Sir Gareth Edwards Cancer Charity

Nicola Seneviratne, Cardiff and Vale UHB

Gitanya Naidoo, Cardiff and Vale UHB

Hilary Webb, Blood Cancer UK

Nirushan Sudarsan, Tenovus Cancer Care

Thomas Brayford, Brain Tumour Research

Andrew Seggie, Prostate Cancer UK

Kerri Rowe, Hywel Dda UHB

Helen Long, Cardiff and Vale UHB

Billie-Jo Powell, Cardiff and Vale UHB

Lena Uzunova, Cardiff and Vale UHB

Adam Fletcher, Cancer Research Wales

Lisa Hookway-Jones, Swansea Bay UHB

Anna Capsomidis, Cardiff and Vale UHB

Kali Bernier

Jennifer Lavington, Cardiff and Vale UHB

Emily Hearne, Staff Cymorth yr Aelod | Member Support Staff

Tomos Roberts-Young, Staff Cymorth yr Aelod | Member Support Staff

Kirsty Rees, Staff Cymorth yr Aelod | Member Support Staff

Minutes

Opening and AGM:

- Chair David Rees MS welcomed the speakers and outlined the agenda of the meeting.
- SS held a short AGM, noting that Mike Hedges MS, Rhun Ap Iorwerth MS, and Joel James MS sent through nominations for David Rees MS to continue as Chair and for CRUK to continue providing secretariat for the group. There were no objections towards the above continuing in post for the year ahead.

Presentation:

- MOJ starts the WCA presentation by providing an overview of the services provided to families and children in the South Wales.
- MOJ also introduces the Children's Cancer Leukaemia Group Charity (CCLG) on behalf of representatives who are absent.
- LM gives her thanks to all attendees and covers the agenda of the presentation, as well as providing a background on the landscape of children and young people's cancer and services in Wales.
- LM talks about the Cancer Improvement Plan in Wales and of the unique needs of children and young people with cancer. She explains that the Welsh Government is taking an "age agnostic" approach despite the differences in cancer and care experiences.
- LM raises a question about how the Cancer Improvement Plan will be monitored in relation to children and young people and recommends that there should be a dedicated strategic approach for children and young people with cancer in Wales.

- LM moves on to provide an overview of the commissioning of children's cancer services which are funded via the Wales Joint Commissioning Committee (WJCC) up to the age of 15 and mentions that the WJCC may be looking into teenage services as well.
- LM raises a point that teenage and young adult specifications and standards have not been updated in years and highlights a concern that due to a lack of commissioning, many standards have not been met or rely heavily on the third sector. She notes the outcomes of a recent consultation on the Children's Cancer Service specification which are soon to be published but she expresses concern within the third sector around the provision of psychological support in the revised specifications.
- LM talks about inconsistencies and gaps in care, especially for the 16-17 transitional age group.
- LM ends by pointing out there that a report is due to be issued from Audit Wales on cancer services and she is recommending an urgent review and update of specifications, standards and commissioning arrangements and alignment between children and young people services.
- AR begins by talking on the importance of having effective data on the experiences of children and young people with cancer in service development and in delivering better outcomes. He also notes the challenges with some of the tools and data currently available.
- AR talks about how he would welcome a new approach in Wales to address these key issues and recommends enhancing existing datasets to provide more detailed information on children and young people's experiences and for information to be broken down to useful age groupings, as well as the implementation of an under-16 Cancer Patient Experience Survey (CPES).
- AR highlights the financial impact of a cancer diagnosis on children and young people and their families, particularly through travel costs.
- AR references research from Young Lives vs Cancer which shows disparities between travel costs for those in Wales compared to the rest of the UK, with many patients having to travel outside of Wales for treatment.
- AR recommends the creation of a young cancer patient travel fund with an annual cost of £420,000 to cover the travel costs for every child and young person with cancer in Wales.
- AR finishes by talking about the emotional health and well-being for children and young people with cancer and recommends steps are taken to ensure the availability of accessible emotional psychological support at the point of diagnosis through to post treatment, including that provided by charities, alongside the importance of acknowledging the need for emotional and wellbeing support for family members and to ensure support is available in both Welsh and English.
- AR finishes by recommending a systemic review and focus on children and young people's cancer services and a clear strategic direction with support for their unique needs.

Q&A

- The Chair thanks the speakers and asks participants for any questions.

- SS asks the speakers to elaborate on how a Patient Travel Fund would benefit young patients and their families.
- LM responds by explaining how Young Lives vs Cancer obtained their figures into travel costs and the benefits of removing the financial barrier of travelling for children and young people and their families.
- The Chair asks GP to provide the next question to the speakers.
- GP introduces himself as the Secretary to the Wales Cancer Alliance and his capacity with Tenovus Cancer Care. GP asks what progress has been made within the subgroup and if there is potential for a greater focus on children and young people within the Quality Statement for Cancer in Wales which will be revised in the near future.
- MOJ responds by highlighting the impact of having a coalition of children focused cancer charities coming together.
- LM also responds by pointing out that the age agnostic approach does not work for children and young people and the importance of ensuring that a specific approach, whether as part of a wider strategy or Quality Statement, is to be taken for children and young people specifically.
- PC emphasises the importance of having a focused approach and bringing children's voices into care services.
- KM echoes PC's comments about the importance of the voices of children and young people, particularly those of a transitional age.
- RTT points out that the Wales Cancer Strategy does not specifically cover children and young people. RTT also explains how small services are for children and young people compared to adult services and the consequences of this.
- LM emphasises the importance of platforms such as this group and highlights the differences with prevention in terms of adult and child cancers.
- SS asks if it would be possible for the speakers to elaborate on examples where data in this area of the pathway might be improved and how this would be useful for young patients and their families.
- LM responds by highlighting that cancer in children and young people is unique and their unique needs and data need to be separated as the experiences of children and young people specifically can be obscured if collaborated with other ages.
- The Chair asks if MA could identify the type of data which she thinks would be important to push those agendas forward.
- MA responds by explaining that teenagers who are falling between paediatric and adult services are not only missing out on early phase experimental studies but also standard of care. MA highlights some of the challenges with research and development.
- MA also raises a point about delayed diagnosis and the important of awareness in primary care services surrounding symptoms experienced by children and young people.
- LM expands on this point by explaining that children usually visit primary care services more times than adults to get through the diagnostic journey resulting in more young people being diagnosed in emergency presentation settings.
- The Chair asks LM if there is a specific pathway for children and young people.

- LM asks KM to respond.
- KM explains that there is not a specific pathway and points out that diagnosis often comes extremely late for young people.
- MI talks about his personal experience of having two of his children diagnosed with cancer as young people and the importance of targeting GP practices to ensure a better understanding of cancer presentation in young people. MI asks the speakers if support is standardised or whether it is only available through third sector organisations.
- LM talks about her personal experience of being diagnosed with lymphoma and makes the point that greater awareness would also help children and young people advocate for themselves and create more trust in frontline health services.
- KM responds to MI's question by highlighting that post-treatment support and wider psychological support is almost exclusively provided by the third sector in Wales.
- DP speaks about services in North Wales and the collaboration between hospitals and the third sector.
- EGE introduces herself as an adult clinical oncologist but also treats lymphomas in children and young people. EGE talks about how positive statistic outcomes for young people compared to adults can sometimes hide the impact of a late diagnosis and how it can be months before a diagnosis is received and treatment is started.
- Dr Altaf Hussain MS asks what additional help children and young people have with their education and with any disabilities as a consequence of their diagnosis and treatment. He also asks the speakers whether children and young people are being supplied with Blue Badges.
- LM explains that some children and young people are eligible for Blue Badges through the differing disability criteria but points out that some are only issued for a specific time period and work needs to be done to ensure there is enough designated parking at hospital sites.
- KM talks about the work being undertaken to minimise the disruption to education for children and young people and about the challenges of ensuring there is a continuation of education during treatment and beyond.
- LM echoes these points and explains the importance of getting children and young people back into education if they have had to stop during treatment.
- MOJ highlights the importance of having social workers in terms of easing back into education and aiding families with applying for benefits.
- DP also talks about the impact on siblings and the ripple effect of a cancer diagnosis on families.
- Helen Long makes a point that there are no commission services for Allied Health Professionals (AHPs) and talks about the importance which they have in supporting clinical outcomes, personal experiences and providing support for families, carers and parents.
- The Chair closes the meeting by thanking the speakers and attendees for their contributions.

The meeting closed at 11:06am.

