

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 39

Ymateb gan: | Response from: Abbvie



SeneddHealth@Senedd.Cymru

Dear Committee Clerk

Re: Priorities for the Sixth Senedd

We are contacting you in response to your consultation on the priorities for the Health and Social Care Committee for the Sixth Senedd with a request that the committee takes the opportunity to look at **the needs of people living with blood cancer in Wales to ensure parity between blood cancers and solid tumour cancers.**

Blood cancers are the fifth most prevalent cancer in Wales, accounting for over 10% of all cancer cases diagnosed,¹ and the third biggest cancer killer.² During the five-year period 2013-17, there was a total of 10,350 incidences of blood cancer in Wales, an average of 2070 incidences per year.³ Over 250,000 people are currently living in the UK with a blood cancer diagnosis; all of whom have been at an increased risk during the COVID-19 pandemic.⁴

Last year, a policy roundtable was organised and funded by AbbVie in collaboration with the Blood Cancer Alliance (BCA).

The roundtable brought together members of the Blood Cancer Community, including representatives from patient organisations, clinicians, nurses, policymakers, and Members of the Senedd (MSs). The purpose was to discuss how the next national cancer policy presents an opportunity to set an ambition for the continued improvement of Blood Cancer services in Wales, reflecting the unique needs of people living with blood cancers.

Recognising the impact of the COVID-19 pandemic on cancer patients and services, the meeting also provided the opportunity to highlight current issues such as access to care and treatment closer to home and the importance of shared decision making. I attach the report of the discussion and recommendations for your consideration.

The key areas of consideration identified at the roundtable, which we believe should be included in a future committee inquiry include:

- Parity between blood cancers and solid tumour cancers, reflecting the need for relevant support to haematology services and ensuring future cancer policy for Wales does not focus solely on strategies relating to solid tumour cancers.

¹Welsh Cancer Intelligence and Surveillance Unit: Cancer Incidence Statistics by Cancer Type in Wales Available at: https://publichealthwales.shinyapps.io/Cancer_incidence_in_Wales_2001-2017/ Last accessed December 2020

²Welsh Cancer Intelligence and Surveillance Unit: Cancer Mortality in Wales Available at: https://publichealthwales.shinyapps.io/wcisu_cancer_mortality_in_wales_2017/ Last accessed December 2020

³Welsh Cancer Intelligence and Surveillance Unit: Cancer Incidence Statistics by Cancer Type in Wales Available at: https://publichealthwales.shinyapps.io/Cancer_incidence_in_Wales_2001-2017/ Last accessed June 2020

⁴Cancer Research UK, The immune system and cancer. Available at: <https://www.cancerresearchuk.org/about-cancer/what-is-cancer/body-systems-and-cancer/the-immune-system-and-cancer> Last accessed: April 2021

- Blood cancers, unlike solid tumours, are often not treatable with surgery or radiotherapy. Setting targets for equitable uptake of innovative medicines, will continue to drive improvements in blood cancer patient outcomes across Wales.
- Addressing the demand for a joined-up cancer workforce plan; meeting recruitment challenges, providing access to specialist expertise and the expansion of the 'Hub and Spoke' model of service delivery to better support service provision across rural Wales.
- A model of patient-centred, shared decision-making between patients, their healthcare team, and their supporters, with the aim to deliver improved patient experience and outcomes, should be at the centre of future cancer policy for Wales.

We understand that the Welsh Government is now developing an implementation plan to follow their Cancer Quality Statement which was published in March 2021, and we therefore believe that it would be timely for the committee to input to that process. The recently published Northern Ireland Cancer Strategy includes a strong focus on haematology services, referencing their close association to oncology services, the aim to provide an integrated approach to addressing capacity pressures as the NHS looks to tackle the backlog.

We look forward to working with the committee over this Senedd term.

Yours sincerely

[Redacted signature]

Government Affairs Manager – Oncology



Abbvie Ltd

Abbvie House

Vanwall Business Park

Maidenhead

Berkshire

SL6 4UB

[Redacted contact information]

[Redacted contact information]

abbvie.co.uk

[@abbvieuk](https://twitter.com/abbvieuk)

Recognising Blood Cancers within the next Cancer Delivery Plan for Wales

Virtual Policy Roundtable Discussion during Blood Cancer Awareness Month

September 2020

Overview

To ensure the development of the next Cancer Delivery Plan for Wales reflects the needs of people living with blood cancers, and to mark the end of Blood Cancer Awareness Month, a policy roundtable was organised and funded by AbbVie in collaboration with the Blood Cancer Alliance (BCA).

Blood cancers are the fifth most prevalent cancer in Wales, accounting for over 10% of all cancer cases diagnosed,¹ and the third biggest cancer killer.²

The roundtable brought together members of the Blood Cancer Community, including representatives from patient organisations, clinicians, nurses, policymakers, and Members of the Senedd (MSs). The purpose was to discuss how the next Cancer Delivery Plan presents an opportunity to set an ambition for the continued improvement of Blood Cancer services in Wales, reflecting the unique needs of people living with blood cancers.

Recognising the impact of the COVID-19 pandemic on cancer patients and services, the meeting also provided the opportunity to highlight current issues such as access to care and treatment closer to home and the importance of shared decision making.

Key areas for consideration include:

- Parity between blood cancers and solid tumour cancers, reflecting the need for relevant support to haematology services and ensuring future cancer policy for Wales does not focus solely on strategies relating to solid tumour cancers.
- Blood cancers, unlike solid tumours, are often not treatable using surgery or radiotherapy. Setting targets for equitable uptake of innovative medicines, will continue to drive improvements in blood cancer patient outcomes across Wales.
- Addressing the demand for a joined-up cancer workforce plan; meeting recruitment challenges, providing access to specialist expertise and the expansion of the 'Hub and Spoke' model of service delivery to better support service provision across rural Wales.
- A model of patient-centered, shared decision-making between patients, their healthcare team, and their supporters, with the aim to deliver improved patient experience and outcomes, should be at the center of future cancer policy for Wales.

Hearing from the Blood Cancer Community

Dawn Bowden, MS (Welsh Labour) and Member of the Senedd's Cross Party Group on Cancer, chaired the roundtable. She welcomed the discussion as an important opportunity for the blood cancer community to build consensus in shaping recommendations that will inform a more detailed blueprint for blood cancer services across Wales, informing the next Cancer Delivery Plan.

Bethan Hawkes, Wales Cancer Network (WCN), provided an overview of the priorities of the Wales Cancer Network, citing the impact of the pandemic on cancer services, and sharing information regarding the roll out of the Single Cancer Pathway, equitable access to services, national roll out of the Rapid Diagnostic Centre's (RDCs) and the drive to deliver person centered care through optimised patient pathways.

¹ Welsh Cancer Intelligence and Surveillance Unit: Cancer Incidence Statistics by Cancer Type in Wales Available at: https://publichealthwales.shinyapps.io/Cancer_incidence_in_Wales_2001-2017/ [Last accessed December 2020]

² Welsh Cancer Intelligence and Surveillance Unit: Cancer Mortality in Wales Available at: https://publichealthwales.shinyapps.io/wcis_u_cancer_mortality_in_wales_2017/ [Last accessed December 2020]

Nusha Haghpanah, Policy and Public Affairs Officer, Anthony Nolan, presented on behalf of the Blood Cancer Alliance, sharing the experiences of people living with blood cancer in Wales. She focused on the challenges in diagnosis, and the different cancer patient pathway for blood cancers as opposed to solid tumour cancers.

Nusha advocated the importance of shared decision making, ensuring blood cancer patients get the practical and psychological support they need. She also outlined the importance of securing access to the best medicines as a priority to treat people living with blood cancers, as unlike solid tumours, are often not treatable using surgery or radiotherapy.

Dr Clare Rowntree, Clinical Director Haematology, Cardiff and Vale UHB, and Chair NCRI Acute Lymphoblastic Leukaemia Clinical Studies Group, shared her clinical experience, by welcoming the rapid pace of innovation in the field of blood cancer research. Dr Rowntree welcomed the increasing number of new innovations in treatment, now available for people living with blood cancer, but set out the challenges these new technologies bring, in terms of healthcare professional capacity to adapt to these changes, and the urgent need for additional pharmacy and cancer clinical nurse specialist (CNS) support.

To reduce service variation across Wales, and provide equitable access to specialist expertise, she advocated for expansion of the 'Hub and Spoke' model of service delivery, giving all patients the option of where they receive their care and treatment, as well as access to specialist multidisciplinary team (MDT) support, regardless of a chronic or acute diagnosis.

Roundtable participants collectively discussed the key themes arising from the presentations in order to build consensus and inform recommendations, relevant to raising the parity of blood cancer care to parallel that of solid tumour cancers within the next Cancer Delivery Plan for Wales.

Discussion focused on the need for improved awareness of blood cancers, earlier diagnosis, access to psychological support, the importance of shared decision making between the patient and their healthcare team and access to medicines. The need for actionable strategies to better implement national data collection, research, and workforce planning, were also considered, with the aim to provide equitable access to services and innovation, for all people living with blood cancer in Wales.

Consensus Building

Parity for Blood Cancers

The lack of parity between blood cancers and solid tumour cancers was a key point of concern. Differences regarding the awareness of symptoms, diagnostic facilities, access to care, treatment, and support services, and haematology workforce resourcing, further exacerbate the disparity of blood cancer services across Wales.

The difficulties of applying the Single Cancer Pathway to people living with chronic or relapsing blood cancer, particularly at later stages of their disease were also highlighted, reflecting that the targets do not address the needs of blood cancer patients, and that haematology services deliver care outside the model of solid tumour cancers.

Since the roundtable the Senedd Cross Party Group on Cancer's (CPGC) Report on the Single Cancer Pathway has been published.³ Disappointingly the report made no reference to blood cancers and several recommendations referred to data collection for tumour sites only. There is therefore opportunity to work with the CPGC on ensuring that both the Single Cancer Pathway and the next Cancer Delivery Plan for Wales acknowledge the unmet needs of people living with blood cancers.

Recommendation: As the fifth most common cancer in Wales¹ and the third biggest killer,² it is vital that the next national cancer plan gives parity to blood cancers, reflecting the unique unmet patient and service needs, and does not focus solely on strategies relating only to solid tumour cancers.

Recommendation: Relevant and specific diagnosis and treatment targets for acute and chronic blood cancers, across the Single Cancer Pathway should be considered, recognising blood cancers are not screened, staged, and treated as solid tumour cancers are.

³ Available at: https://www.cancerresearchuk.org/sites/default/files/cpgc_-_the_single_cancer_pathway_november_2020_full_report.pdf [Last accessed December 2020]

Raising Awareness to Support Earlier Diagnosis of Blood Cancers

There was strong consensus that action should be taken to support the challenges of late diagnosis of blood cancers. Diagnosing blood cancers can be complex; symptoms such as bruising, back pain or fatigue are often misunderstood or misdiagnosed. For many acute cancers diagnosis occurs in the emergency setting, and for chronic blood cancers, following multiple visits to the GP or through unrelated routine blood tests. In both situations, late diagnosis can have a major impact on a person's quality of life and long-term outcomes.

Recommendation: To achieve more timely diagnosis of blood cancers, raising awareness of symptoms through provision of tailored education for primary care practitioners, will support GPs in identifying the symptoms of blood cancers earlier.

Recommendation: Providing greater access to, as well as maximizing capacity of, rapid diagnostic centers (RDCs), and phlebotomy services in the community, through accelerated primary care, or direct patient, referrals will support the Single Cancer Pathway target to diagnosis.

Enhanced Access to Dedicated Emotional and Psychological Support

There was also strong consensus regarding the need for people living with blood cancers to receive better access to emotional, and psychological support, not just at the point of diagnosis, but throughout the blood cancer care pathway, including when patients are on 'watch and wait'. The most recent Welsh Cancer Patient Experience Survey, revealed that patients with blood cancers scored significantly lower in terms of accessing support from their dedicated key worker or CNS,⁴ which can have significant impact on a patients' positive experience.⁵ Variability in support can be dependent on whether patients receive their care through haematology or oncology services, therefore ensuring equity between the two will offer optimal patient care.

Recommendation: The same support opportunities should be provided for all people with a blood cancer diagnosis, including access to a named CNS, regardless of whether they are treated in a haematology, or an oncology clinic.

Recommendation: Signposting, by healthcare teams, to resources available from blood cancer patient organisations can provide holistic support to patients and their supporters.

A Model of Patient-Centered Shared Decision Making

To ensure people living with blood cancer can access the care they require, a model of shared decision making between patients, their healthcare team, and their supporters could be further embedded into routine clinical practice. Evidence demonstrates that people who are more engaged in decisions about their care and treatment, feel more empowered to manage their own health and as a result experience more favorable health outcomes.⁶

Recommendation: A model of patient-centered, shared decision-making between patients, their healthcare team, and their supporters, with the aim to deliver improved patient experience and outcomes, should be at the center of the next national cancer plan.

Equitable Access to Medicines as a Key Pillar of Cancer Treatment

Blood cancers, unlike solid tumours, are often not treatable using surgery or radiotherapy. This means that the treatment needs for people living with blood cancers is more dependent on the development of, and access to, innovative medicines. Currently medicines reviewed by NICE and in the Cancer Drugs Fund are routinely made available to patients in Wales. In England, the Government has made a commitment to reform the Cancer Drug Fund (CDF) into an Innovative Medicines Fund (IMF)– it is important that the Welsh Government understands the implications of these changes and adapts to ensure that there is no unnecessary variation in access for patients in Wales.

Recommendation: Access to medicines should form a key pillar of the next national cancer plan.

⁴ NHS Wales: National Report Wales Cancer Patient Experience Survey 2016 Available at: <http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/170705national-reporten.pdf> [Last accessed June 2020]

⁵ Leukaemia Care: My CNS Matters Available at: <https://media.leukaemiacare.org.uk/wp-content/uploads/cnsreport.pdf> [Last accessed June 2020]

⁶ NHS England Shared Decision Making Available at: <https://www.england.nhs.uk/shared-decision-making/why-is-shared-decision-making-important/shared-decision-making-to-improve-health-outcomes/> [Last accessed June 2020]

Recommendation: Setting targets within the next national cancer plan for equitable uptake of innovative medicines, will continue to drive improvements in blood cancer patient outcomes across Wales.

Recommendation: The Welsh Government should engage closely with NHS England to consider the impact of proposed reforms to the Cancer Drug Fund (CDF) evolving into the Innovative Medicines Fund (IMF) in England,⁷ and introduce measures/resources to ensure continued access to approved medicines in Wales.

Haematology Workforce Planning, Clinical Trial Support and Data Collection

Workforce planning is critical to meet current demand and future need. Concerns were raised around the lack of consultant haematologists and CNS's, and the need for Local Health Boards (LHBs) to prioritise recruitment to support healthcare teams with their current high caseloads.

Innovation in cancer research, evolution to personalised treatments and the changing face of solid tumour cancer care, will also impact on haematology services, requiring a more joined up approach to their delivery.

The lack of robust digital infrastructure and ability to collect blood cancer patient data across NHS Wales has been a consistent source of concern and prevents further inward investment into clinical research and trials in Wales.

Recommendation: The next national cancer plan will need to address the demand for a joined-up cancer workforce plan, meeting recruitment challenges, and addressing the variance in service delivery for blood cancer patients across all Wales commissioning; providing access to specialist expertise through MDT's, and the expansion of the 'Hub and Spoke' model of service delivery to better support service provision across rural Wales.

Recommendation: Investment into digital infrastructure and data collection across Wales, will continue to drive improvements in blood cancer patient outcomes. Supporting the expansion of the NHS Wales Haematological Malignancy Data Solution 'Haem Base' across the LHBs and extending across the range of blood cancers types will facilitate further collection and assessment of clinical and patient reported data in real-time.

Impact of COVID-19 to Blood Cancer Services

The rapid and coordinated action across the NHS and the cancer community in response to COVID-19 has continued to ensure the safety of at risk, and immunocompromised blood cancer patients, whilst best managing available NHS resources.

Recommendation: To restore standards of care, address the resultant backlog, and prioritise patient access to blood cancer services, embedding the positive innovation switches, offers to streamline some cancer services, implement care closer to home and further recognise patient preference for their care.

Conclusion

The recommendations set out in this report reflect a collective response to support the development of a meaningful cancer strategy on behalf of blood cancer patients in Wales. There was strong consensus that the current Cancer Delivery Plan does not meet the specific needs of people living with blood cancer and that the next Cancer Delivery Plan presents an opportunity for the Welsh Government to lead the rest of the UK in developing a national approach which meets the needs of all cancer patients.

For further information regarding the work of AbbVie and the Blood Cancer Alliance in Wales, please contact:

████████████████████ Government Affairs Manager, Haematology & Oncology, AbbVie Ltd
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Blood Cancer Alliance

E: BloodCancerAlliance@atlas-partners.co.uk

⁷ Conservative Party: Get Brexit Done Unleash Britain's Potential Available at: https://assets-global.website-files.com/5da42e2cae7ebd3f8bde353c/5dda924905da587992a064ba_Conservative%202019%20Manifesto.pdf [Last accessed June 2020]

Policy Roundtable Attendees

- Dawn Bowden MS
 - Bethan Hawkes
 - Nusha Haghpanah
 - Dr Clare Rowntree
 - Sinead Ward
 - Dr Georgina Webb
 - Judi Rhys
 - Richard Pugh
 - Chris Walden
 - Charlotte Martin
 - Stephen Scowcroft
 - John Greensmyth
 - Daniel Cairns
 - Mark Edwards
 - Helen Allen
 - Sheldon Donovan
 - Prof. Christopher Fegan
 - Dr Ceri Bygrave
 - Dr Sumant Kundu
 - Dr Phil Webb
 - Prof Alex Tonks
 - Dr Deborah Roebuck
 - Gail Grant
 - Dr Ray Johnston
 - Nerys Evans
 - Cathy Owens
 - Harry Thompson
- Welsh Labour
 - Wales Cancer Network
 - Antony Nolan
 - Cardiff & Vale UHB
 - AbbVie, Oncology Director
 - Welsh Conservative Health Researcher
 - Tenovus Cancer Care
 - Wales and South West England, Macmillan Cancer Support
 - Blood Cancer UK
 - Leukaemia Care
 - Lymphoma Action
 - CLL Support
 - Myeloma UK
 - Welsh Patient representative
 - Welsh Patient representative
 - Welsh Patient representative
 - Cardiff & Vale UHB
 - Cardiff & Vale UHB
 - Hywel Dda UHB
 - Velindre NHS Trust
 - Cardiff University
 - AbbVie, Oncology Government Affairs
 - AbbVie, Head of Government Affairs
 - AbbVie, Oncology Medical
 - Deryn Consulting
 - Deryn Consulting
 - Deryn Consulting

Policy Roundtable Apologies

- Anthony Davies
 - Sally Lewis
 - Rhun ap Iorworth
 - Andrew RT Davies
 - Jayne Bryant
 - Dr Catherine Bale
 - Beryl Roberts, CNS
 - Dr Steve Knapper
 - Dr Hanadi Ezmigna
- Welsh Government
 - Welsh Government
 - Plaid Cymru
 - Welsh Conservatives
 - Welsh Labour
 - Betsi Cadwaladr UHB
 - Betsi Cadwaladr UHB
 - Cardiff & Vale UHB
 - Cwm Taf Morgannwg UHB