

## **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 76**

**Ymateb gan: | Response from: Cymorth Cancer Macmillan | Macmillan Cancer Support**

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## **Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor Initial priorities identified by the Committee**

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrsgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

### **C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?**

**Q1. Which of the issues listed above do you think should be a priority, and why?**

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The health and social care workforce, including organisational culture and staff wellbeing

Macmillan is pleased to see the health and social care workforce listed as an initial priority for the Committee. The pandemic has both highlighted and exacerbated the pressures that the health and social care workforce has been under for years, many of whom are struggling to cope with excessive workloads and unable to get the professional development and support they need. As we begin to recover from Covid, the cancer workforce in Wales is exhausted, facing a significant backlog in diagnostics and treatment, and worried about what this winter may bring.



One key member of the cancer workforce that Macmillan would like to highlight to the Committee is the specialist cancer nurse. Specialist cancer nurses' clinical expertise, leadership skills and advanced diagnostic and communication skills can speed up a patient's recovery, prevent readmissions, and join up services to tackle inequalities in care. They are unique in their balance of clinical and non-clinical skills built up over several years' training and experience, providing people with a single point of contact for all their needs and playing an essential role in coordinating and leading teams to deliver personalised care.

Macmillan has recently published a new report, ['Cancer nursing on the line: we need urgent investment across the UK', which](#) focuses on the challenges facing specialist cancer nurses and what steps governments across the UK can take to ensure we have enough of them to meet the expected increase in demand over the next decade.

For Wales, we estimate that if the number of specialist cancer nurses stays at current levels an additional 166 specialist nurses will be needed to deliver comprehensive care and support for the anticipated 230,000 people that will be living with cancer in 2030 – an increase of around 80%. The cost of training and developing specialist cancer nurses to deliver this increase is estimated at £12.2 million. This includes £5.8 million on advanced training to become a specialist cancer nurse and £6.4 million on undergraduate training to create a new generation of nurses to replace those who become specialists. Future employment costs for the additional 166 specialist cancer nurses in 2030 are estimated to be £10.2 million per year.

In addition to this call for investment, our report also recommended that health boards and trusts in Wales guarantee time and ringfence funding to allow nurses to access CPD, that the Welsh Government directs HEIW to develop a cancer-specific workforce plan, and that the Welsh Government and HEIW create and fund an optimised career development pathway for general adult nurses to become clinical nurse specialists.

We would be happy to provide further information to the Committee on this issue and will be responding to the separate call for evidence specifically on the health and social care workforce. In terms of key groups and stakeholders that might be beneficial for the Committee to engage with, we would suggest hearing directly from specialist cancer nurses and other key parts of the cancer workforce in addition to local health boards, trusts, and HEIW.

## **Blaenoriaethau allweddol ar gyfer y Chweched Senedd**

### **Key priorities for the Sixth Senedd**

**C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:**

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

**Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:**

- a) health services;**
  - b) social care and carers;**
  - c) COVID recovery?**
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### **Gwasanaethau iechyd**

#### **Health services**

##### **Palliative and end of life care services**

We know that more people are surviving and living beyond a cancer diagnosis, but approximately 9,000 people still die every year from the disease. We also know that most of us will need to access palliative and end of life care at some point in our lives – whether for us or a loved one, and that demand for these services is expected to rise significantly in the coming years. The pandemic has highlighted the importance of high-quality palliative and end of life care services, and the importance of talking openly about death and dying, but it has also led to new pressures including a greater demand for end of life care in community settings. With the development of the new National Programme for End of Life Care, the next few months and years will be key in setting a direction for palliative and end of life care services in Wales, and we believe that issues around end of life care could and should form part of the Committee's work over the sixth Senedd.

Specifically, exploring inequalities in access to palliative and end of life care would be a worthwhile piece of work for the Committee. For instance, we know that people from certain communities from across the UK often have a poorer experience of palliative and end of life care: people from the most deprived areas are less likely to access the care they need, more likely to experience hospital admissions in the last months of their life, more likely to die in hospital, and are generally less satisfied with the care they receive. There is also a generally low uptake of palliative and end of life care amongst people from BAME groups, with potential factors including poor communication healthcare professionals and patients, language barriers, and cultural perceptions and preferences around death and dying. [New research](#) details the challenges that specialist

palliative care services in the UK have faced in meeting the needs of people from ethnic minority groups during the pandemic – especially with regards to restricted visiting and communicating with patients and families.

However, Wales-specific data on inequality in access to and experience of palliative and end of life care services is lacking. We believe that an inquiry or a shorter programme of work from the Committee could shine a light on this important issue and encourage the Welsh Government to prioritise investigating and improving the situation.

Another area where the Committee may be able to make a positive difference is around the shift towards more deaths at home that we have seen over the course of the pandemic. Between March and September 2020, England and Wales saw a staggering one-third increase in the number of people dying at home compared to pre-pandemic levels. The majority of these deaths were unrelated to coronavirus. A lack of resource and capacity in community care can make it incredibly difficult for professionals to meet the demand for palliative and end of life care at home, and during the pandemic this has often meant family members having to take on more responsibilities in this area. We have called on the Welsh Government to make investment in community palliative and end of life care services a priority, and would welcome the Committee including this important issue within its forward work programme.

For both of the above issues, key groups and stakeholders for the Committee to engage with could include hospices and people living with cancer and any other conditions that may require access to palliative and end of life care – particularly those from the aforementioned communities.

### **Approaches to personalised care – going beyond treatment**

Delivering high-quality cancer services in Wales is about much more than the treatment that people receive. The non-medical needs of people living with cancer – ranging from financial concerns to heightened anxiety or difficulty carrying out daily tasks – are so important in protecting a person’s health, wellbeing and quality of life before, during and after their treatment. As we see new developments in the treatment of cancer, more people are surviving or living well with the disease for longer periods of time to the point where cancer can be considered a chronic disease. This also has a knock-on impact on the extent to which a cancer diagnosis can impact on a person’s work, finances, mental health, and day-to-day activities.

Despite substantial efforts and commitment from the Welsh Government we have not been able to embed personalised care as a common experience for most people living with cancer in Wales. For example, Macmillan invests heavily in providing benefits advisers across Wales and we work with other charity partners to ensure there is access to good advice, but this is still not an integrated part of care planning even though financial worries may be the most pressing concern for a person.

The most recent Cancer Patient Experience Survey, carried out in partnership with the Welsh Government, found that only 48% of people felt they had been given adequate signposting and information about financial help and benefits. Only 49% felt their family was equipped with the

right information on how to care for a loved one at home. Under the 2016-2020 cancer delivery plan, access to a named key worker is mandated, but over a quarter felt it was difficult to contact this individual. We also know that people with a cancer diagnosis often face the 'carrier bag' effect, where they are overloaded with flyers and information but do not have an appropriate person on the other end of the phone who knows them and their treatment. [Recent research from Macmillan](#) suggests people with cancer in Wales still frequently feel 'lost' in the complex health and care system.

The Committee would be well-placed to undertake a focused piece of work examining:

- Current provision available and consistency of policy application
- Long-term trends in cancer and how to support a larger population appropriately
- Potential recommendations for the Welsh Government to update its position on personalised care needs in Wales

The Committee could consider linking this work in with other major long term conditions such as heart disease and stroke to examine how we meet the non-clinical demands of people with major and potentially life-limiting conditions. The Committee could hear directly from people living with cancer currently (for instance the North Wales Cancer Patient Forum, or Macmillan support groups), and welfare benefits advisors who can provide real life stories of the impact of good personalised care and where provision might be lacking.

## **Adfer yn dilyn COVID**

### **COVID recovery**

#### **Tackling the backlog in cancer diagnostics and treatment**

Although the seven initial priorities identified by the Committee are all important and worthwhile areas in their own right, we would have liked to see the extensive backlog in non-COVID treatment – specifically cancer - included on the list.

In July 2021 [we estimated](#) that there were around 4,200 "missing" cancer diagnoses in Wales as a result of the pandemic – this was based on the number of diagnoses we would normally expect to see and the number of actual diagnoses taking place since April 2020. Although we expect this number to have reduced slightly given the number of people entering the Suspected Cancer Pathway (SCP) each month is now consistently at or higher than pre-pandemic levels, this is still a substantial diagnostic backlog and will undoubtedly lead to worse outcomes for those who are yet to be diagnosed. When these people do eventually enter the system, it is likely their cancer will be at a more advanced stage and potentially less treatable as a result.

Macmillan has welcomed the funding announced by the Welsh Government so far to tackle waiting lists across cancer and other non-COVID health conditions, but it is imperative that this funding is monitored and adjusted as required to allow local health boards to ensure timely treatment across all tumour types. We believe the Committee has a crucial role to play in

monitoring this situation and ensuring that cancer services recover from the pandemic as urgently as possible.

## **Unrhyw faterion eraill**

### **Any other issues**

#### **C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?**

#### **Q3. Are there any other issues you wish to draw to the Committee's attention?**

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##### **Strategic approaches to delivering care for major conditions**

Following the Welsh Government's 'A Healthier Wales' strategy, the publication of quality statements and the phasing out of existing delivery plans began to take place in 2021. The development received significant scrutiny from organisations representing major conditions, with a large number expressing reservations with the new approach by the Welsh Government.

Macmillan and others, through the Wales Cancer Alliance, highlighted significant concerns about reducing the amount of policy direction set out by Welsh Government under the 2016-2020 Cancer Delivery Plan. By opting for a high-level set of principles for health boards in the delivery of cancer services through the quality statement, we fear that the drive and impetus for improving outcomes for people living with cancer and delivering consistent improvements in their wider-care needs may be lost.

Macmillan would welcome committee scrutiny on the implementation of quality statements following 'A Healthier Wales' and a temperature check on how much they will influence the strategic development of services relating to major conditions. In the fourth term, the Health and Social Care Committee examined the implementation of the first Cancer Delivery Plan. We feel a short inquiry of this nature would provide useful scrutiny at this early point in the implementation of the Welsh Government's policy intention.