

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 24

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

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## **Response from Macmillan Cancer Support to the Health and Social Care Committee's consultation on the waiting times backlog**

Macmillan Cancer Support welcomes the Committee's decision to undertake this important inquiry. As we approach two years since Wales first went into lockdown, the pandemic continues to significantly impact the ability of the NHS in Wales to deliver non-COVID services, and the Committee is right to focus on the impact this has had on people waiting for a diagnosis or for their treatment to start.

We have welcomed the numerous and significant investments announced by the Welsh Government since the start of the pandemic to help to tackle the backlog in non-COVID care. Much of this funding has been aimed at increasing capacity within cancer services, specifically around diagnostic equipment and surgical capacity. But we also desperately need the right workforce in place to be able to make use of these investments – this is why a focus on retention and long-term investment in the cancer workforce is so vital.

We have set out some further comments below across several areas, but for any additional information please contact

## **The scale of the backlog in cancer services**

We know that cancer services in Wales are continuing to come under significant pressure as a result of the pandemic, with widespread impacts on health boards' performance against the Suspected Cancer Pathway target and a small number of disruptions to cancer surgeries.

It is important to understand the levels of demand that local health boards are currently facing. September 2021 saw the highest number of cancer referrals in Wales since the Suspected Cancer Pathway was first introduced, with 14,965 people entering the system.<sup>i</sup> For context, the average number of monthly referrals pre-pandemic was around 13,200. In addition, for most of 2021 the number of first cancer treatments taking place each month has been consistently higher than previous years, indicating a system that is overstretched and working tremendously hard.

In the context of wanting to see more people present with potential symptoms and help facilitate earlier diagnosis, this increase in activity is a very welcome sign. However, the knock-on impact is that cancer services are exceptionally busy trying to ensure people receive a diagnosis and start treatment as soon as possible and within the 62-day target.

Gynaecological, head and neck, urological, and lower gastrointestinal cancers are the four key tumour sites where waiting times performance continues to be of significant concern. For example, of the 86 people who commenced treatment for gynaecological cancer in October, just 27 (less than a third) started within the 62-day target.<sup>ii</sup>

In addition to concerns about the system's ability to meet this heightened demand for cancer care, there have been widely-reported concerns throughout the pandemic about those people who may have put off presenting at primary care with a potential symptom of cancer due to fears of COVID or not wanting to "burden" the NHS. In July 2021, we estimated there could be over 4,000 people in Wales who had missed a cancer diagnosis due to the pandemic.<sup>iii</sup> We do not have a more recent update to these figures, but the increased number of referrals entering the system since March 2021 means the overall backlog in diagnoses should have come down significantly since our last estimate.

Unfortunately, evidence does suggest that many of the people now coming into the system are being diagnosed with cancers that have progressed to a later stage – with worse outcomes as a result. Macmillan's welfare benefits advice teams in Wales reported a worrying 20% increase from 2019 to 2020 in the number of 'Special Rules' (DS1500) applications they reported seeing – this is an application to the Department for Work and Pensions for people with fewer than six months to unlock or expedite access to welfare support.<sup>iv</sup>

## **Inequalities within the backlog**

The Committee's inquiry is also considering the extent to which inequalities exist in the backlog. Whilst this is an area that requires further investigation and evidence, we know that even before the pandemic there were persistent gaps in cancer survival between the least and most deprived areas of Wales. Looking at the most recent five-year survival rates published by the Welsh Cancer Intelligence and Surveillance Unit, for some cancers – such as colorectal – the survival gap between the least and most deprived parts of Wales is really significant. For other tumour sites such as breast and lung, the deprivation gap is smaller but has widened in recent years, which is of serious concern.<sup>v</sup>

We also know that many of the most deprived parts of Wales and the UK have been badly hit by the pandemic, both in terms of deaths per capita and the knock-on impact of coronavirus cases on the NHS and its ability to deliver cancer care and other services.

## **Investing in the health and care workforce**

The health and care workforce is by far the largest factor when considering how we can both tackle the waiting list backlog and support those people who have been waiting for diagnosis or treatment. Even before the pandemic this was a significant issue, with notable gaps in the diagnostic workforce in Wales as well as in the specialist cancer nurse workforce. The pandemic has only exacerbated the pressures that the health and care workforce was already under.

Recent research from Macmillan suggests Wales will need an 80% increase (166 additional posts) in the specialist cancer nurse workforce in Wales by 2030 in order to keep up with expected demand.<sup>vi</sup> And even before the pandemic, our 2017 census of the cancer nurse workforce in Wales highlighted concerns around succession planning, with 74% of breast CNSs likely to retire in the next 10 years.<sup>vii</sup>

Access to continuing professional development (CPD), structured career pathways, flexible working, and fair pay are also hugely important components of the staff retention challenge facing the Welsh Government. Of these, protected access to CPD and having structured career pathways are particularly important in ensuring that generalist nurses who want to specialise are able to do so by developing their knowledge and practice.

The Royal College of Nursing in Wales has been calling on the Welsh Government for several years to start publishing nurse vacancy rates in line with other UK nations. This is something that Macmillan supports, as it is incredibly difficult to start to address some of these issues without a baseline picture of where we are at.

## **Mental health support**

Put simply, the best way to reduce mental health support needs resulting from long waiting lists is to reduce the waiting lists as quickly as possible. The biggest challenge created by lengthy waiting lists for people with a suspected cancer will generally be the substantial uncertainty and anxiety this causes. We now have more people waiting on the Suspected Cancer Pathway than before and with that the system is struggling to diagnose and treat them within the 62-day target. People on a waiting list tend to mind less about the wait, but more about the uncertainty and lack of communication about how long they will wait and what they can do in the meantime.

What we do know from people who are currently held on a waiting list, is that a point of contact within the system is vitally important. We frequently talk about the role of the key worker or support worker roles following a diagnosis of cancer, but having an assigned point of contact from the outset of joining the suspected cancer pathway can also help to ease some of the uncertainty and anxiety. Another key issue to consider is that many people will not actually know they are a cancer diagnostic pathway – they might be awaiting a scan or a biopsy for something they haven't contemplated is cancer.

For those waiting for treatment to start, clear communication from health boards amidst potential disruption from COVID is crucial. If extreme pressures do result in disruption to cancer treatments, it is absolutely imperative that anyone whose treatment is affected is actively communicated with and monitored by health boards. In such circumstances, health boards should also be working across regional footprints where appropriate to ensure treatment can be rearranged as soon as possible.

## **Supporting the wider needs of people living with cancer**

Many of the non-medical needs of people living with cancer – such as financial, emotional, or practical concerns – are ones that have been exacerbated by the pandemic. This has ranged from people having to cope with the financial impact of a cancer diagnosis at the same time as a family member losing their job due to COVID, to people not being able to support their loved ones at hospital appointments.

One of Macmillan's key priorities in Wales as we continue to adjust to living with COVID and its effect on NHS services, is to ensure the principles of holistic, personalised care aren't lost amidst local health boards' efforts to tackle the backlog. We know that people living with cancer need this kind of support now more than ever and we would like to see a strong focus from the Welsh Government going forwards to ensure these important non-clinical needs are met.

The financial cost of cancer in particular has been exacerbated for many by the economic impact of the last two years. Even before the pandemic, the 2016 Wales Cancer Patient Experience Survey – delivered by a partnership between Macmillan and the Welsh Government – found only 48% of people felt they had been given adequate signposting and information about financial help and benefits.<sup>viii</sup> Compounding this, COVID has had a devastating impact on many people's livelihoods and financial situations.

Macmillan has also carried out some recent research on the financial cost of cancer for people in Wales and across the UK - the key findings of this research are as follows:

- 87% of people with cancer in Wales experienced some kind of financial impact from their diagnosis. For those affected, this reached an average of £734 a month on top of their usual expenditure.
- More than one in three people with cancer in Wales (38%) were severely financially affected by their diagnosis.
- Almost one in four (24%) experienced extra costs of travelling to and from their appointments. 23% saw their household bills rise following their diagnosis.

These financial pressures can have wide-ranging effects including anxiety and stress, a decline in physical health and missed hospital appointments. Cancer charities in Wales including Macmillan, Tenovus Cancer Care, and Maggie's all have welfare benefits advice services in place to assist anyone who may be struggling with the cost of cancer.

### **The effectiveness of messaging and engagement with the public about the demands on the service and the importance of seeking care promptly**

The biggest challenge for cancer services in the first few months of the pandemic was the sudden decline in people presenting at primary care with potential symptoms – leading to the worrying backlog of missed cancer diagnoses. Therefore, the fact that cancer referrals have been consistently at or above pre-pandemic levels for the majority of 2021 is very encouraging.

However, there are several pieces of learning we can take from the staggering 63% drop in cancer referrals in April 2020 and the subsequent push to reassure people that they must still contact their GP with any concerning symptoms.

For instance, we would have liked to have seen the Welsh Government's 'Keep Wales Safe'/'Diogelu Cymru' campaign have a much stronger focus on urging those with

potential cancer symptoms to seek help from their GP. Part of this campaign covered information about accessing NHS services in Wales, but this focused primarily on the appropriate use of accident and emergency units, the Welsh Ambulance Service, primary care and other services. What was needed in addition to this was a strong push from the Welsh Government to reassure people that primary care wanted to hear from them with any potential cancer symptoms.

### **The contribution the third sector can make in providing peer support and information to patients waiting on an NHS waiting list**

There is a hugely important role for the third sector in Wales to play in supporting those waiting for NHS services. From the perspective of cancer services, Macmillan's Support Line operates seven days a week on 0808 808 00 00 and can help with questions or concerns about cancer, coronavirus, money or work, or absolutely anything that might be worrying somebody. We also have dedicated welfare benefits advice services and information hubs based in hospitals across Wales, and operate a 'Telephone Buddies' scheme which matches people diagnosed with cancer with a trained volunteer to act as a listening ear and source of support. There are of course numerous other support lines, initiatives and projects run by other cancer charities operating in Wales that can provide much-needed support, advice or a listening ear to people on a waiting list.

It is vitally important that NHS cancer services and the other parts of the system supporting people with cancer actively and systematically refer people onto third sector organisations. With the significant increase to the cost of living and the long-term disruption a cancer diagnosis often has to people's financial circumstances, it is important that the system makes use of the third sector's capacity to assist with some of the social and economic challenges brought on by a cancer diagnosis.

## References

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<sup>i</sup> Number of patients entering the single cancer pathway by local health board, numbers starting treatment and performance accounting for suspensions, June 2019 onwards, Welsh Government. Available at: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times/Monthly/pre-February-2021>

<sup>ii</sup> Suspected cancer pathway (closed pathways): The number of patients starting their first definitive treatment and those informed they do not have cancer by local health board, tumour site, age group, sex, measure and month, Welsh Government. Available at: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times/Monthly>

<sup>iii</sup> "I put off calling the GP': Thousands of cancer diagnoses 'missing' in Wales since start of pandemic", ITV Wales, July 2021. Available at: <https://www.itv.com/news/wales/2021-07-06/i-put-off-calling-the-gp-thousands-of-cancer-diagnoses-missing-in-wales-since-start-of-pandemic>

<sup>iv</sup> "Covid: Cancer worry as claims for end-of-life help rise in Wales", BBC Wales, October 2021. Available at: <https://www.bbc.co.uk/news/uk-wales-58769347>

<sup>v</sup> Cancer Survival in Wales, 2002-2018. Welsh Cancer Intelligence and Surveillance Unit. Available at: <https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/>

<sup>vi</sup> Cancer nursing on the line: why we need urgent investment across the UK, Macmillan Cancer Support, September 2021. Available at: <https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/4323-10061/cancer-nursing-on-the-line-why-we-need-urgent-investment-in-the-uk>

<sup>vii</sup> Cancer workforce in Wales: a census of cancer, palliative and chemotherapy speciality nurses and support workers in Wales in 2017, Macmillan Cancer Support, 2018. Available at: [https://www.macmillan.org.uk/\\_images/cancer-workforce-in-wales-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017\\_tcm9-326409.pdf](https://www.macmillan.org.uk/_images/cancer-workforce-in-wales-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017_tcm9-326409.pdf)

<sup>viii</sup> Wales Cancer Patient Experience Survey 2016, Welsh Government & Macmillan Cancer Support, July 2017. Available at: <https://gov.wales/sites/default/files/publications/2019-01/wales-cancer-patient-experience-survey-2016.pdf>