

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gynllun Llywodraeth Cymru i drawsnewid a moderneiddio gofal a gynlluniwyd a lleihau rhestrau aros](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [Welsh Government's plan for transforming and modernising planned care and reducing waiting lists](#)

PCWL 08

Ymateb gan: | Response from: Tenovus Cancer Care





Tenovus Cancer Care Response to the Welsh Government's plan for transforming and modernising planned care and reducing waiting lists

This response is formed by Tenovus Cancer Care, using the views and feedback of staff across the organisation, including those that work directly with people affected by cancer.

It is also formed by the opinions of those on our All-Wales Cancer Community – a community of people affected by cancer who are part of a community through Tenovus Cancer Care. Part of their involvement in this community is to contribute to policy consultations and support Tenovus Cancer Care to raise awareness of issues that affect them directly.

Overall, Tenovus Cancer Care welcome the focus of Welsh Government's proposal for planned care. This is a much-needed strategy to help the NHS and its partners tackle the backlog of planned care appointments, which has impacted greatly on people affected by cancer. This plan gives an overarching view of the approach that will be taken. In order for it to be successful, detail on how this will be implemented and achieved should be outlined in the new Cancer Services Action Plan, which is due to be published in the Autumn. The publication of this action plan cannot be delayed as it is vital if lives are to be saved and we at Tenovus Cancer Care are keen to work with the Welsh Government and the Wales Cancer Network Board to develop this.

We understand that the COVID-19 pandemic had a significant impact on the NHS and that there is catching up to do to get services running as they were before 2020. In May 2020, the *British Journal of Cancer* found that over a thousand fewer new cases of three common cancers were diagnosed in Wales in 2020 compared to 2019, equivalent to a reduction of 15 percent.¹ Extensive alterations to healthcare routes to diagnosis, increases in later-stage diagnoses and an increase in the number of undiagnosed patients with new cancers have and will continue to occur as a result of the pandemic. We therefore understand that managing expectations of what can be achieved needs to be considered and communicated effectively to people across Wales. However, we also believe that there should be a strong focus on finding solutions to both quickly and effectively address the backlog of people waiting to be seen, whilst ensuring that those newly coming into the system are not delayed by this. Clear messaging is essential in reassuring people where they are in the system and what they can expect next.

Tenovus Cancer Care welcomes using innovation to tackle the backlog and establish more efficient ways of working going forwards. Whilst we feel that using approaches such as digital and telephone appointments is a positive step forwards, this could cause concern and confusion for some people accessing the NHS. Many people struggled with mixed messaging during the pandemic about whether they should come forward to get checked. The Welsh Government and NHS must clearly communicate with people that any approach will be assessed against people's needs and is not one size fits all, but something that will be used for the benefit of both the NHS and patient. People should continue to receive person-centred care that meets their needs, no matter how long they wait.

The suggestion of patient initiated follow up needs careful consideration. The COVID-19 pandemic has proved that in Wales, people tend to not want to bother their doctor and now that people know how much pressure the NHS is under post-pandemic, they may be hesitant to initiate such follow ups. Not everyone is equally comfortable to chase up these appointments. The suggestion of patient initiated follow ups also does not fit in with the theme of regular communication for people on

¹ <https://phw.nhs.wales/news/study-finds-significant-reductions-in-cancer-diagnoses-in-wales-during-the-covid-19-pandemic/>

where they are on the referral pathway and next steps. The messaging needs to be clear.

Tenovus Cancer Care Recommends:

Welsh Government should devise a campaign to communicate with the public what they are doing to address planned care in Wales. This should cover:

- How they will address the backlog for planned care
- Plans for ways of being more efficient such as by using digital technology, but not at the expense of receiving quality, person-centred care
- How they will ensure that new people coming through the NHS system are not delayed by addressing the backlog
- Highlighting that communication between the pathway and the person is one of Welsh Government's points in the care plan so that people should be better informed of where they are on a pathway and what the next steps are
- What people can do if they feel they are not getting the communication or care that they need, including information on the Community Health Councils and planned changes going forwards
- Supporting people to wait well by signposting to services that could support them whilst they are waiting for the next steps in the NHS referral pathway. This could include referral/signposting to other NHS services, community-based services or the third sector.

We also recommend that the Welsh Government should utilise and build upon the support it has from the Third Sector to significantly broaden its messaging reach. For example, by developing joint campaigns on promoting the signs and symptoms of cancer and on preventative behaviours such as the use of sun cream, stopping smoking, maintaining a healthy weight as well as promoting screening and encouraging people to attend appointments; highlighting that cancer is not necessarily a death sentence and that if caught early it is treatable.

We are one amongst many charities working in Wales who could support with the efforts to reduce the backlog of planned care through alleviating pressure on existing NHS services.

For example, Tenovus Cancer Care will seek to work with the Wales Cancer Network as it starts to review provision of Systemic Anti-Cancer Therapy (SACT) support as our Tenovus Cancer Care call back service is a vital lifeline to patients who have just started treatment and a well-regarded service by Clinicians.

In addition, Tenovus Cancer Care have a newly launched counselling service for people across Wales who are affected by cancer. There will be many people going through this who are anxious and would like to speak with someone about their

experiences, to gain some reassurance and support or simply for a listening ear. Mental health and wellbeing support will be critical for the recovery of the NHS in Wales and is particularly important for people who have been affected by cancer during the COVID-19 pandemic and the difficulties that they faced during this period.

Tenovus Cancer Care welcomes Welsh Government's plans to develop a national framework for social prescribing to embed access to prevention services and wellbeing activities into referral pathways. Sing With Us' choirs are an initiative established in Wales by Tenovus Cancer Care to provide social support and improve mental wellbeing amongst those affected by cancer, whether patients, the bereaved, family member, carers or health care staff. Research has already demonstrated that these choirs can reduce depression and anxiety amongst participants and improve social support networks and quality of life. Whilst they do not cure disease, there is some evidence that participating in these activities can reduce levels of stress hormones and enhance immune activity.²

Moving care closer to home

Moving care closer to home is a theme throughout and is an approach that Tenovus Cancer Care supports, but there are some concerns about the feasibility of achieving this.

Over a period of many years many local hospitals and health facilities have been closed across Wales, with diagnosis, treatment and care being centralised in bigger hospitals in towns and cities. General hospitals have become increasingly under threat; for example, the repeated threat of closure of Worthybush Hospital in Pembrokeshire. Powys no longer has a general hospital, forcing people to travel long distances to access the care that they need. For some, this care is often far over the border into England. For example, people affected by cancer often travel from Powys to Cheltenham or Birmingham and back every day for cancer treatment because they are unable to access this closer to home. This places additional financial, physical and emotional stress on these people compared with those that don't have to travel so far to access the same care. People affected by cancer who are eligible to claim money back on travel and parking for hospital appointments have told Tenovus Cancer Care that they have not seen their travel claim amount increase during the cost of living increase in 2022; leaving those travelling by car to pick up the price difference. The NHS is free at the point of use, but the distance people must travel (and decide to mitigate for missing work and other arrangements etc.) means that this is a hidden cost for people.

Moving care closer to home not only provides immediate benefits for the local population, but it also provides the opportunity to gather data and information to

² Tenovus Cancer Choirs Study: the Benefits of Singing for Those Affected by Cancer - Full Text View - ClinicalTrials.gov

assess the needs of that population. Tenovus Cancer Care recently undertook work to assess lung cancer and inequalities across Wales and were unable to include Powys in this assessment due to the lack of information available. This is because people must travel out of area to receive the care and support that they need. We are therefore not getting a clear and accurate picture of the health needs of the population to effectively design services and support people in this area and in other areas of Wales where access to healthcare is also difficult.

By enabling people to access care closer to home we will have a more accurate picture of the different inequalities that exist across the country and how we can address people's needs in a more targeted way.

Tenovus Cancer Care welcome using innovation in order to help bring care closer to home and one of our many offers is mobile cancer support in the community. Cancer patients in Wales can travel up to 150 miles for treatment. Every round trip to hospital can cost nearly £70 and if someone relies on public transport, these journeys can take many hours. Our mobile support units cut journey times to hospital, making receiving treatment less stressful and less expensive for cancer patients. Despite this, our offer of mobile support units is often not taken up by health boards. Tenovus Cancer Care encourage Welsh Government to support health boards to actively seek out and utilise such available support to ensure cost savings and benefits for people that need to access those services. This joint working is something that is desired by both sectors, as stated in the article published on NFP Research: 75% of healthcare professionals see the potential of developing closer working relationships with charities since the COVID-19 pandemic.³

Prioritisation of diagnostic services/Diagnosing cancer early

Tenovus Cancer Care welcome the formation of a Diagnostics Board. However, for this to be meaningful, it should be for more than "input" as is outlined in this plan. In order to achieve outcomes for people across Wales, the Diagnostics Board should have a programme of work and evidence that this is aligned with other agendas, such as the National Endoscopy Programme.

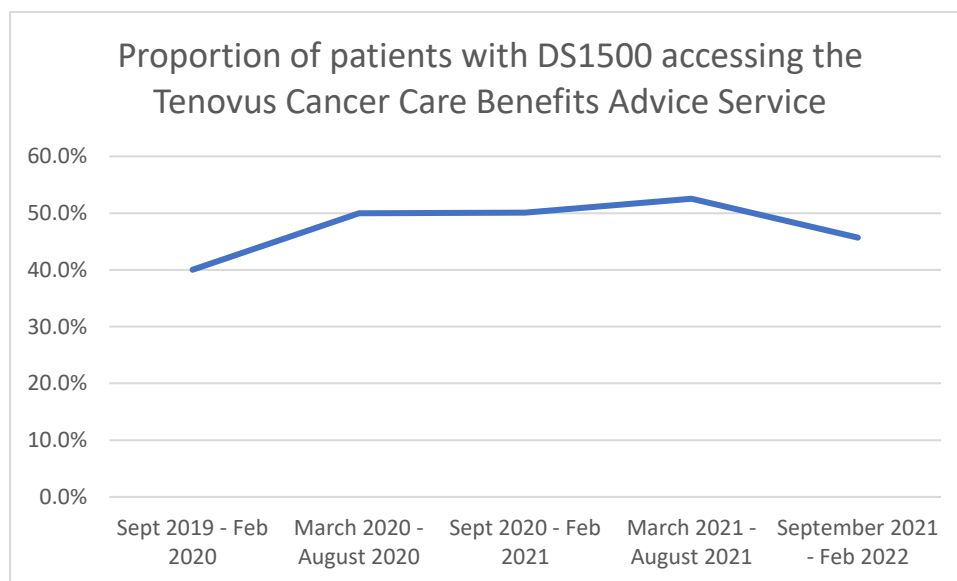
The disruption caused to people affected by cancer during the pandemic⁴ may mean an increase in emergency presentations of cancer. From our own service provision, we saw a large increase in the proportion of patients with DS1500 accessing our benefits advice service.

In the 6 months immediately prior to COVID-19, 40% of the patients accessing our benefits advice service were in possession of a DS1500 (indicating that they were unlikely to survive beyond the next 6 months). This increased to 50% in the first 6 months of the pandemic and peaked at 52.5% in the March – August 2021 period.

³ Charities during the pandemic: 5 observations from healthcare professionals | nfpResearch

⁴ <https://www.macmillan.org.uk/get-involved/campaigns/we-make-change-happen/we-shape-policy/covid-19-impact-cancer-report.html>

This proportion has been decreasing since this peak but has yet to return to pre-pandemic levels.



Tenovus Cancer Care feel that it is important for the Welsh Government to take some responsibility for this, rather than laying the blame on “patients deciding not to come forward” as outlined in this action plan. People were told to ‘stay at home, protect the NHS’ and therefore it is inevitable that people would have stayed away and not sought advice.

Screening was paused for several months, which in the world of people affected by cancer is not a “very short time”. This will have had an impact on the number of people being diagnosed with cancer at a later stage.⁵ It is unfair to suggest that these delays are down to patient behaviours. Later diagnosis in these circumstances is a result of the system not being able to carry out diagnostics such as endoscopies and having to instead put in place hurried solutions around the use of sensitive FIT tests (FIT in symptomatic) in primary care. Tenovus Cancer Care feel that Wales should use this hindsight as a learning opportunity to now quickly adopt new and emerging technologies, which are backed by evidence from pilots. These radical and innovative solutions are important to get the NHS in Wales to a stage where it can build back better than before, not just to how things were pre-pandemic. The health system was fragile before the pandemic and Wales must be better prepared for possible similar disruptions in the future.

At the end of the forward (page 1) the plan states that during COVID “more people than ever have been checked and treated for cancer” yet official figures show that the number of patients referred for cancer treatment in April 2020 dropped by more than 51% compared to the previous month and at this stage charities had already warned of a cancer “timebomb” due to Covid-19 disruption.⁶ In a separate release,

⁵ Millions in UK miss cancer screenings, tests and treatments due to Covid-19 | Cancer | The Guardian

⁶ Coronavirus: Big drop in cancer referrals in Wales - BBC News

and as experienced by our own benefits team, Macmillan also stated that in 2021 the number of terminally ill people accessing end-of-life benefits has increased during the pandemic, with a warning of more evidence of a growing "cancer backlog"⁷.

In addition, about 3,500 cancer patients had been reported as "missing" from treatment services since the start of the coronavirus pandemic.⁸ Tenovus Cancer Care was one of many cancer charities that called for a recovery plan for cancer services back then and Wales is still waiting for this to be drawn up.

The new cancer recovery services plan must be drawn up with the third sector as soon as possible if Wales is to make its approach to planned care a success.

Less Survivable Cancers

Tenovus Cancer Care are pleased to see that cancer is being looked at as a whole disease area – that there is not a focus on high volume cancers at the expense of other cancers. Tenovus Cancer Care have been campaigning to raise awareness of the less survivable cancers, which are closely correlated with inequalities. The less-survivable cancers: Lung, liver, brain, oesophageal, pancreatic and stomach, have an average five-year survival rate of less than 20%. These six cancers account for over 69,000, and no less than 42% of the cancer deaths in the UK each year.⁹

Covid-19 has brought huge challenges to the health service, unlike anything we have previously experienced. This has had a serious and deeply concerning effect on people with cancer, with an alarming drop in cancer diagnoses and, in many places, backlogs building for vital diagnostic tests, treatments and surgery.¹⁰

For people who have one of these six less survivable cancers, early and fast diagnosis is critical to detecting the cancer at a stage when curative treatment is possible. However, these cancers often present with vague symptoms or are asymptomatic and are therefore hard to diagnose. As a result, three quarters of people with these cancers are diagnosed at a late stage and less than 16% of people diagnosed will survive five years or more. This was a serious problem before the pandemic. Covid-19 has now exacerbated this problem and we know that people will be diagnosed with cancer even later due to the disruption to health services.¹¹ Urgent referrals for possible cancer were 25% of the normal rate at the peak of the pandemic and, even now (date), are only at 75% the expected rate.¹²

⁷ Covid: Cancer worry as claims for end-of-life help rise in Wales - BBC News

⁸ Covid: 3,500 'missing' from cancer services in Wales - BBC News

⁹ <https://lesssurvivablecancers.org.uk/about-us-2/>

¹⁰ <https://www.bbc.co.uk/news/uk-wales-54195580>

¹¹ <https://phw.nhs.wales/news/study-finds-significant-reductions-in-cancer-diagnoses-in-wales-during-the-covid-19-pandemic/>

¹² <https://www.pancreaticcancer.org.uk/wp-content/uploads/2021/04/APPG-report-The-Impact-of-Covid-19-on-Pancreatic-Cancer-Treatment-and-Care-in-England.pdf>

Lung cancer is the biggest cancer killer in Wales.¹³ One-year survival rates lag slightly behind those for England and Northern Ireland. In addition, five-year relative survival for lung cancer in women in Wales is 10%, which is below the average for Europe (16%). In men the survival rate is 5%, which is also below the average for Europe (12%)¹⁴

In August 2021 there were around 8,600 urgent referrals for suspected cancer in Wales, 9% fewer than the same time the previous year whereas lung cancer referrals were down 26% in August compared to the same time in 2019. During the lockdown in April, there was a 72% drop in lung cancer referrals compared to the previous year.¹⁵

Smoking cigarettes is the single biggest risk factor for lung cancer. It is responsible for more than 70% of cases.¹⁶

Of the most common cancer types, lung cancer has the widest cancer death inequality, with a gradient of higher mortality in increasingly deprived areas.¹⁷ The size of the differences in mortality between more and less deprived areas has increased over time.

Whilst we welcome action being taken to address lung cancer survival in Wales, we feel that there is already enough evidence to justify the need for lung health checks and targeted screening, which is currently being consulted upon by the UK Screening Committee. If they make recommendations for nations to develop and implement a Lung Screening Programme, we expect Wales to move at pace to put in place a comprehensive and optimal framework to deliver this new programme which will save many lives across Wales.

Tenovus Cancer Care Recommends:

- The Welsh Government to support the implementation of the proposed Lung Health Check pilot in Cwm Taf Morgannwg and once the UK Screening Committee has made recommendations about a comprehensive lung cancer screening programme – for Welsh Government to work with its NHS partners to deliver this at pace. Rolling this intervention out will have a huge impact on cancer outcomes for people in Wales.

¹³ <https://www.uklcc.org.uk/sites/default/files/2021-12/An-overview-of-the-impact-and-priorities-for-lung-cancer-in-Wales.pdf>

¹⁴ Lung cancer survival statistics | Cancer Research UK

¹⁵ <https://news.cancerresearchuk.org/2020/11/20/covid-19-referral-drop-fears-for-lung-cancer-patients-in-wales/>

¹⁶ [https://www.nhs.uk/conditions/lung-cancer/causes/#:~:text=develop%20the%20condition.-,Smoking,carcinogenic%20\(cancer%2Dproducing\).](https://www.nhs.uk/conditions/lung-cancer/causes/#:~:text=develop%20the%20condition.-,Smoking,carcinogenic%20(cancer%2Dproducing).)

¹⁷ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/deprivation-gradient>

Leadership and Patient Experience

The announcement regarding the establishment of the new NHS Executive has just been made¹⁸. This new function of NHS Wales will bring together senior teams within Welsh Government alongside key national NHS bodies which collectively should have the levers to drive improvement and put in place accountability structures for ongoing innovation and improvement in service delivery. Whilst the NHS in Wales has a difficult few years ahead to repair and rebuild, to be held to account on the care they deliver to their populations

Welsh Government itself has highlighted the role of the Executive as being essential in futureproofing the health system, stating that it's central purpose will be to support the NHS to deliver improved quality of care to people throughout Wales, resulting in better and more equitable outcomes, access and patient experience, reduced variation and improvements in population health¹⁹.

There is now an expectation that we will see a step change in performance, especially in relation to cancer waiting times and access to diagnostics and screening.

We know that there were thousands of people who went undiagnosed with cancer in 2020 and 2021. This strategy is vital in ensuring that no matter what the prognosis of these people is, they must receive the best possible treatment, care and support to enable them to navigate their pathways and achieve the best possible outcomes.

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¹⁸ Written Statement: Update on setting up an NHS Executive for Wales (18 May 2022) | GOV.WALES

¹⁹ *ibid*