

Wales Cancer Alliance – submission to Health, Social Care and Sport Committee inquiry into the impact of the COVID-19 outbreak on health and social care in Wales

1. The Wales Cancer Alliance (the Alliance) is a coalition of 20 charities working together to prevent cancer, improve care, fund research and influence policy in Wales. During the coronavirus outbreak, we have been supporting people affected by cancer by providing up to date information on cancer treatment and care, as well as maintaining our existing services as much as possible in an extremely challenging financial environment.
2. The COVID-19 pandemic has had a significant impact on cancer services and patients. We support the need for NHS Wales to rapidly adapt to the challenge that COVID-19 poses, particularly to protect the public and manage NHS capacity. However, we are concerned about the impact the crisis will have on cancer survival, patient outcomes and experience.
3. The Alliance has outlined some of the key concerns raised by our member organisations across Wales. We have also set out several areas in which we would welcome further clarification and scrutiny. Our top priorities for the Welsh Government and NHS Wales are:
 - 3.1. Understanding the impact on urgent cancer referrals;
 - 3.2. How people will be encouraged to contact their GP with concerning symptoms;
 - 3.3. The current situation on the development of COVID-free sites to allow cancer treatments to resume in a safe environment;
 - 3.4. Planning for the recovery phase for cancer services, including additional capacity needed to tackle backlogs in diagnostics, cancer screening, and treatment;
 - 3.5. Ensuring continued support for people at the end of life.

Primary care and cancer diagnosis

4. Across the UK, we have seen significant drops in the number of urgent suspected cancer referrals from primary care since the start of the outbreak. In England, we understand that referrals have dropped by 75%, while in Scotland the reduction is 72%. We do not currently have an official comparative figure for Wales. However, from conversations with clinicians, we expect the effect in Wales to be broadly in line with the rest of the UK.
5. This reduction in cancer referrals can be explained by two factors. Firstly, we are concerned that people may be putting off going to their GP with possible cancer symptoms during the coronavirus outbreak, either through fear of exposure to COVID-19 or worry of placing additional burden on the NHS. As we know that early diagnosis is key to improving cancer survival, it is vital that symptoms are still investigated as soon as possible. Even if treatment needs to be delayed, patients will be 'in the system' rather than having to wait for a diagnosis when the current crisis passes.

6. Many GP surgeries are offering appointments over the phone or virtually, which can be accessed easily and securely online. The Alliance has been communicating this in recent weeks but believes more should be done to reinforce the message to the public that their local GP surgery remains open and wants to hear from them if they have any symptoms. We know that NHS England has launched its 'Help Us Help You' campaign aimed at tackling this issue, whilst the Scottish Government has launched a similar campaign, 'The NHS is Open'. It would be very useful to know what actions the Welsh Government is planning in this area.
7. The second factor for the fall in cancer referrals is that some GPs across the UK are setting a higher risk threshold to refer patients than current NICE guidelines recommend. This may be due to a reluctance to send patients to a hospital setting where they might be at risk of contracting COVID-19 or to manage demand on the NHS. It is essential that when a GP decides against an urgent suspected cancer referral, there is appropriate 'safety netting' in place to manage risk and prevent patients falling through the gaps.
8. We are also aware of innovations being accelerated to support referral pathways. In England, FIT tests have been brought in for patients who present with bowel cancer symptoms to help GPs decide who is at higher or lower risk of bowel cancer, helping to prioritise patients who most urgently require a colonoscopy. While it is important that such innovations are brought in safely and appropriately, we would like to see similar measures considered in Wales to support primary care.
 - 8.1. *Can the Welsh Government provide detailed figures on any fall in urgent cancer referrals since the beginning of March?*
 - 8.2. *How will the Welsh Government provide leadership and direction to the NHS to reinforce the message that non-coronavirus health services remain open and that people must contact their GP if they are worried about possible cancer symptoms?*
 - 8.3. *How is NHS Wales sharing best practice and innovations at local health board level, which could have benefit across Wales and beyond the COVID-19 pandemic?*

Planning for a future backlog in diagnostics and cancer screening

5. We have serious concerns regarding the capacity of the NHS to deal with the backlog of cancer diagnostic testing that will be required once services return to relative normality. This will not be helped by the issues in diagnostic capacity that Wales was experiencing before the COVID-19 outbreak, including significant gaps in the diagnostic workforce. Cancer waiting time targets have not been achieved for many years, while international studies regularly place the UK, and Wales in particular, as one of the poorer performing countries for early diagnosis and cancer survival. The growing backlog of cancer diagnoses caused by the response to COVID-19 will require an effective plan to manage this additional demand safely and effectively.

6. On cancer screening, we are similarly worried about a growing and potentially unsustainable backlog. For each month that screening services in Wales are suspended, Cancer Research UK estimates that around 55,600 invitations to take part in the bowel, breast or cervical cancer screening programmes are not being sent out. An accumulating 37,700 people per month are no longer being screened for bowel, breast and cervical cancer following an invite in Wales. Normally, at least 80 patients go on to have a cancer diagnosed through the screening programmes each month in Wales, so right now there are a significant number of early cancers left undetected or prevented before these programmes are reintroduced.
7. Furthermore, important work to optimise bowel screening is currently on hold. The Welsh Government had agreed a plan to lower the starting age from 60 to 50 years, and to bring Wales in line with Scotland on the sensitivity of the test, by April 2023. The first milestone, extending the starting age to 55, was due to take place in April 2020 but has been paused as a result of COVID-19. It is important that a new plan to optimise bowel screening is set out as soon as possible.
8. We welcomed the guidance from Dr Andrew Goodall in his letter to local health boards on Thursday 9 April setting out that they should be planning for a recovery phase for cancer services. Given that the backlog in diagnostic testing is likely to be significant across Wales, we would expect to see what plans are in place to monitor local health boards' compliance of this guidance.
 - 8.1. *What plans are in place to monitor how local health boards are preparing for the recovery phase and the expected backlog of cancer diagnostic testing?*
 - 8.2. *What additional resources will the Welsh Government make available to local health boards and Public Health Wales to help deal with the expected backlog of cancer diagnostic testing and the resumption of the national screening programmes?*

Cancer registration and waiting times

9. We understand the decision to relax cancer waiting times in order to ease pressure on the NHS as it faced the immediate challenge posed by the outbreak. We also understand that cancer registration has been paused as key resources within Public Health Wales have been redeployed to the COVID-19 effort. However, we expect to see both reinstated as soon as possible given that a lengthy pause will affect our understanding of the impact that COVID-19 is having on cancer patients and services. Robust data collection during this period will be vital for our understanding of how COVID-19 has affected cancer patients, as well as in the context of the expected backlog of patients that will require prompt treatment in the aftermath of COVID-19. We would like more information about the Welsh Government's plans to resume their publication.
 - 11.1. *When is the Welsh Government planning to resume the publication of cancer waiting times and cancer registration?*

Communication with patients over delayed treatments

12. Alliance member organisations have been hearing from thousands of patients across the UK who have had their cancer treatments altered, delayed or cancelled due to the outbreak, and we understand the need to balance the risk of contracting COVID-19 against the risk of delaying cancer treatment. We also understand that there are unprecedented capacity challenges across the entire NHS. However, it is unacceptable that some people remain unclear about the reasons for the changes to their treatment.
13. We want to stress that decisions to change treatment plans must always be made with patients, ensuring they understand the reasons for any change and what impact it might have. When patients do have a treatment postponed, it is vital that health and care teams stay in close contact with them in order to monitor any changes to their condition.
 - 13.1. *What guidance is the Welsh Government providing to local health boards on the need to involve patients in decisions on their cancer treatment and to maintain close contact with all patients who have had treatments postponed or cancelled?*

A recovery phase for cancer services and use of clean sites

14. A recovery phase for cancer services in Wales will require the establishment of COVID-free or 'clean' sites, which will be able to provide vital cancer diagnosis, care and treatment. It is critical that these sites have the required equipment and staff available to deliver safe care for patients. We know that several cancer hubs have now been established in England and Northern Ireland to allow certain cancer treatments to go ahead. However, there has been little information about the development of clean sites in Wales. Giving evidence to the Committee on Thursday 30 April, Dr Andrew Goodall suggested that discussions were ongoing but was not able to give any further detail. This must be a top priority for the Welsh Government and NHS Wales to deliver safe environments for cancer treatment and diagnostics, especially as Wales is now at risk of falling behind other UK nations on this issue.
15. To maintain safe environments for cancer diagnostics and treatment, we will need systematic testing for COVID-19 among healthcare professionals and patients. Since a significant proportion of COVID-19 cases are asymptomatic, such testing will need to be widespread and repeated regularly. Testing needs to be rolled out across the healthcare system, with a strategy in place to ensure that high priority sites – including cancer hubs – are prioritised.
 - 15.1. *What discussions have taken place between the Welsh Government, Wales Cancer Network and local health boards to establish COVID-free sites for cancer treatment? What is the timetable for such sites to start accepting patients?*
 - 15.2. *How is the Welsh Government ensuring an adequate supply of equipment and staff to clean sites in Wales?*
 - 15.3. *How will the Welsh Government make sure there is widespread and repeated COVID-19 testing of cancer clinicians, staff and patients to keep settings as safe as possible for cancer treatment?*

Clinical trials

16. Many clinical trials have been halted, with prioritisation given to COVID-19 trials. In some cases, labs and research teams are being redeployed to assist with research and testing for COVID-19, and several research nurses across Wales have been redeployed to the frontline. Where trials are continuing, efforts are being made to reduce the risk of infection. This includes remote follow-up consultations, medicines given in hospital car parks or through the post, and in the case of any complications, treatment ceasing immediately.
17. We understand the need for the above but there is also a concern that long-term disruption to clinical trials could make it difficult for trials to restart. It might also mean patients being denied access to potentially lifesaving or life-extending treatments, which in some cases, may be a final treatment option.
- 17.1. *What plans does the Welsh Government have to ensure that non-coronavirus clinical trials can resume safely as soon as possible?*

Advance care planning

18. We were concerned to hear about the inappropriate approach to DNACPRs taken by some local GP practices at the beginning of the outbreak in the UK. Any conversations around advance care planning must have the patient's wishes at their heart and must be accompanied by appropriate care and support. We welcome that the Welsh Government has clearly set out its position regarding this matter.

Role of specialist palliative care teams

19. Coronavirus has had a significant impact on palliative and end of life care, with people not always able to access the level of care that they might need and would have received before the outbreak. In addition to the measures being taken to reduce the spread of COVID-19, there are capacity issues in the system given the increase in COVID-19 patients not previously known to palliative and end of life services. Specialist palliative care teams – especially those based in the community – are playing a crucial role in providing continued care and should be protected from redeployment wherever possible.
- 19.1. *What support is the Welsh Government providing to ensure that specialist palliative care services can continue throughout the coronavirus outbreak?*
- 19.2. *Has the Welsh Government considered protecting specialist palliative care teams from redeployment to the frontline COVID-19 response?*

Visiting loved ones at the end of life

20. On Wednesday 15 April, UK Health Secretary Matt Hancock outlined new guidance for care homes advising that visits at the end of life should continue wherever possible. We

would welcome clarification from the Welsh Government on what guidance exists for hospitals, care homes, and hospices in Wales in this area.

21. The Alliance has also heard from people who have missed the opportunity to say goodbye to their loved ones who are dying at home due to the restrictions on leaving the house currently in place across the UK. We were concerned to see the First Minister suggest in a recent written answer that it would be a matter for the enforcement authorities to take a view on whether leaving the house for this purpose should be permitted. The Welsh Government should provide clear leadership in this crucial area and update the guidance to allow people to visit relatives who are dying at home.

21.1. *What guidance exists for hospitals, care homes, and hospices in Wales on allowing visits from loved ones at the end of life?*

21.2. *Will the Welsh Government update guidance on the lockdown restrictions in Wales to allow people to say goodbye to relatives who are dying at home?*

The Alliance is comprised of the following organisations:

- Brain Tumour Trust
- Breast Cancer Now
- Bowel Cancer UK
- British Liver Trust
- Blood Cancer Alliance
- Cancer Research UK
- Cancer Research Wales
- Clic Sargent
- Hospices Cymru
- Jo's Cervical Cancer Trust
- Macmillan Cancer Support
- Maggie's
- Marie Curie
- Ovarian Cancer Action
- Myeloma UK
- Pancreatic Cancer UK
- Prostate Cancer UK
- Target Ovarian Cancer
- Teenage Cancer Trust
- Tenovus Cancer Care

The Alliance has a page on its website with helpful resources, information and support for people living with cancer in Wales – <https://walescanceralliance.org/support/>