# ALL THINGS BEING EQUAL?

## Inquiry into cancer inequalities in Wales caused by socio-economic deprivation

**Cross Party Group on Cancer**

**June 2023**

## CHAIR'S FOREWORD

I am certain if any of us should be told the difficult news that we have cancer, we would hope to have as good a chance as anyone else at beating the disease. Obviously, the type of cancer, how early it is diagnosed, and the treatment options available to us will all play a factor. But it should not be the case that where we live, how much money we earn, our ethnicity, age, gender or sexual orientation should make a tangible difference.

That it does should be unacceptable to us all. Who we are and where we live can have an impact on our chances of getting cancer, how likely we are to survive, as well as the care and support we might receive.

Health inequalities are not a new thing, nor are they exclusive to Wales. The COVID-19 pandemic shone a light on how the direct and indirect harms of the virus were not felt uniformly across society. We now need as much focus on how and where inequalities exist in cancer too.

We know that to beat cancer, we need research into better ways to detect and treat the disease, rapid implementation of innovations in the NHS, and the right care and support wrapped around patients. But that needs to be available for everyone. If we were to achieve our shared goal of improving cancer survival and care, but in doing so saw little progress, or even greater gaps, between different groups, we could not consider that success.

A new cancer plan for Wales sets the direction for how we can improve cancer survival, outcomes, and patient experience. Delivering it must take place through the lens of tackling inequalities too, in order to ensure the benefits are felt by all.

One issue we found in this work was how little data are available on the different aspects of cancer inequalities. We have focused on deprivation as that is where the data are most available. But we need a better understanding of how different groups experience cancer in different ways. This will be vital for us to know we are on the right track and hold our leaders to account.

This is the second inquiry the Cross-Party Group on Cancer has undertaken while I have been chair. Our previous one, on cancer waiting times and the impact of COVID-19, helped keep cancer high on the political agenda during the height of the pandemic. We need to do the same again, demonstrate that cancer inequalities are avoidable and unfair, and bring the whole community together with a united vision for change.

I am immensely grateful to everyone who contributed to this inquiry. We heard from a range of people, including academics, charities, clinicians, researchers and, most importantly, people affected by cancer. The written and oral evidence we received, alongside the input from patient panels, helped shape our understanding of both the challenge and potential solutions.

Finally, my thanks to Cancer Research UK for their continued support as secretariat of the Cross-Party Group, as well as helping to co-ordinate this inquiry.

To anyone who shares our ambition to tackle cancer inequalities, we are ready to work with you to deliver the change needed across Wales. The challenge might be hard, but we simply cannot afford to fail.

**David Rees MS**

**Chair, Cross-Party Group on Cancer**

## CONTENTS

## ABOUT THE CROSS-PARTY GROUP ON CANCER

The Cross-Party Group on Cancer (CPGC) is a group of Members of the Senedd from across the political spectrum. The Group seeks to facilitate discussion between Members of the Senedd, medical professionals, charities, and those affected by cancer. The CPGC aims to identify ways to improve cancer outcomes and patient experience in Wales, and to campaign for those improvements.

The Chair of the CPG is David Rees MS. The membership of the CPGC includes:

- Rhun ap Iorwerth MS
- Mike Hedges MS
- Mark Isherwood MS
- Joel James MS
- David Rees MS

Meetings of the CPGC are attended by other stakeholders, including third sector organisations, healthcare professionals, industry, and people affected by cancer. The CPGC is supported by Cancer Research UK, who provide the secretariat to the Group.[1]

## ABOUT THE INQUIRY

In October 2022, the Cross-Party Group for Cancer launched an inquiry into inequalities and cancer in Wales. The Group sought to gather evidence from policy and health experts, to hear from leaders in understanding and reducing poverty and inequalities, and to understand the needs of people in deprived communities across Wales who have been affected by cancer.

While cancer inequalities can exist for a range of different demographic groups, this inquiry focused on the impact of deprivation and geography on inequalities as this is where the data are strongest. This does mean that we do not have as clear a picture, or strong recommendations, on cancer inequalities due to ethnicity, sex, gender identity, sexual orientation or disability.

The Group received oral evidence at 3 sessions, where we heard from 8 witnesses, followed by a call-out for written evidence where we had 21 responses. We surveyed people affected by cancer, through the Cancer Research UK Involvement Network and through Tenovus Cancer Care's All Wales Cancer Community.

This final report sets out the evidence we received, identify where and how inequalities exist across the cancer pathway in Wales, and provide actionable recommendations.

### *Aims of the inquiry*

- Understand the impact that inequalities, and particularly deprivation, have on patient experience, access to cancer services, cancer incidence and cancer outcomes in Wales.
- Provide recommendations to the Welsh Government, NHS Wales, and other public bodies to tackle inequalities across the cancer pathway, and in particular the impact of poverty and deprivation on patient access and experience.

## EXECUTIVE SUMMARY

1. Health inequalities exist when there are avoidable, unfair and systematic differences between different population groups.[2] They can be found between different demographics and characteristics, including ethnicity, age, sex, gender identity, sexual orientation, disability, as well as socioeconomic status.[3]

2. These can impact every stage of the cancer pathway, including prevalence of cancer risk factors, screening uptake, access to health services, and patient experience. These all contribute to stark differences in cancer incidence and outcomes in different population groups.

3. Understanding the root causes of cancer inequalities, who they impact, and how to eliminate them, is complex and multi-faceted. We need to do more to fully understand cancer inequalities[4]. Currently, the data available for many population groups on several cancer metrics are outdated, limited, or non-existent.

4. This inquiry, from the Cross-Party Group on Cancer, seeks to understand where cancer inequalities exist based on deprivation in Wales. This report outlines the evidence we have received, including the voice of people affected by cancer themselves. We have sought to provide actionable recommendations for the Welsh Government, NHS Wales, and others. If we want to succeed in reducing cancer inequalities, organisations from across the cancer community, with different roles and expertise, will need to have a laser-focus on our shared ambition.

5. Deprivation levels vary across Wales. Swansea Bay and Aneurin Bevan University Health Boards contain the highest proportion of the most deprived zones (27% each), but also 25% and 16% of the least deprived zones, respectively. Powys Teaching Health Board contains only 6% of the most deprived zones in Wales.[5]

6. **If you live in a more deprived community in Wales, you are more likely to get cancer**. Cancer incidence rates in the most deprived group in Wales are 19% higher than in the least deprived (2017-2019).[6] It is estimated that there are around 2,000 extra cancer cases each year in Wales attributable to deprivation.[7] That's more than 5 extra new diagnoses per day that could be avoided if the rates of cancer in sites where it is higher for the most deprived were the same rates as for the least deprived. Lung cancer contributes half of these extra cases, with almost 1,000 extra cases linked to lung cancer being more common in more deprived populations.

7. **If you live in a more deprived community in Wales, you are more likely to die from cancer.** In Wales, cancer mortality rates are 55% higher in the most deprived populations compared to the least deprived (2021).[8] For all cancers combined, five-year net survival is 17 percentage points lower in the most deprived group compared to the least deprived (2014-2018).[9]

8. Around 4 in 10 cancer cases could be prevented each year in Wales, over 7,200 cases each year. Smoking and excess weight are the two biggest preventable causes, responsible for around 3,100 and 1,000 cancer diagnoses in Wales respectively.[10]

9. **More deprived communities in Wales still have higher rates of smoking, overweight and obesity.** Smoking rates are more than four times higher in the most deprived quintile compared to the least deprived quintile in Wales (2021-2022).[11] In 2003-2004, the absolute deprivation gap

for smoking prevalence in Wales was 22 percentage points.[12] Today, the gap persists at 17 percentage points (2021-2022).[13]

10. Overweight and obesity prevalence is higher in the most deprived quintile compared to the least deprived quintile in Wales (2021/22).[14] In 2003-2004, the absolute deprivation gap for obesity prevalence in Wales was 10 percentage points.[15] Today, the gap persists at 9 percentage points (2021-2022).[16] If current obesity prevalence trends continue, adult obesity prevalence is projected to increase from 29% in 2015 to 37% by 2040 in Wales for the most deprived group.[17] For the whole population, there will be almost as many obese people as people of a healthy weight in Wales by the 2040s if current trends continue.[18]

11. When people experience concerning symptoms that could be cancer, it is important that they contact their GP. However, we heard of multiple barriers that can affect someone seeking help from primary care in a timely manner, particularly within more deprived populations:

    - Knowledge and understanding of signs and symptoms
    - Attribution of symptoms to other existing medical conditions
    - Ongoing management of other medical issues
    - Ease of booking an appointment with a GP
    - Ability to dedicate time to attend an appointment, due to taking time off work and/or caring responsibilities
    - Social and cultural influences on help seeking
    - Negative beliefs about cancer, particularly fear, fatalism and that it is a 'death sentence'
    - Belief that they are not worthy of receiving help, e.g. due to having smoked

12. **If you from a more deprived community in Wales, you are less likely to be participate in cancer screening.** Similar barriers exist for Wales' three cancer screening programmes: bowel, breast, and cervical screening. Data from 2020-2021 demonstrates there is a deprivation gap in uptake for breast screening (19 percentage points),[19] bowel screening (15 percentage points),[20] and cervical screening (12 percentage points)[21] between the most and least deprived groups.

13. The UK National Screening Committee now recommends lung screening targeted at 55 to 74 year olds at high risk of lung cancer. [22] Wales does not yet have a lung screening programme. However, a pilot is due to launch this year in Cwm Taf Morgannwg University Health Board. A full national roll-out needs to happen at pace, with specific consideration given to people from deprived groups, who are both more likely to benefit from lung screening, whilst at the same time, less likely to participate.

14. Many of the contributors to our inquiry highlighted how socioeconomic deprivation can create barriers to health services in a way that others might take for granted. This might include where it becomes too difficult to attend appointments, due to travel, or where someone might have no choice but to prioritise other needs above their health, such as work and finances. This can lead to missed appointments, delayed diagnosis and treatment, and ultimately could impact survival and other outcomes. Evidence also points to it being more difficult for more deprived populations to access primary care and book appointments.[23] This can affect both receiving a timely diagnosis for cancer, as well as receiving ongoing support from a GP post-diagnosis and treatment.

15. **Data on cancer inequalities in Wales remain incomplete, meaning that we do not have a full understanding of why someone is more likely to die from cancer if they are from a more deprived population.** There is a lack of available data to understand the impact of deprivation on outcomes in secondary care. Routine data on stage at diagnosis, cancer waiting times, and cancer treatment data are not broken down by deprivation quintiles.

16. However, staging data by Health Board shows that there is some geographical variation in the proportion of cancers diagnosed at later stages in Wales. In lung cancer, for example, 60% of cases are diagnosed late in one Health Board, compared to 72% in another (2017-2019).[24]

17. The Suspected Cancer Pathway was established in 2019, with a target of at least 75% of patients starting their treatment within 62 days of their cancer being suspected. The target has not been met since it was introduced in February 2021 and performance has been steadily declining. While there are no data available on the deprivation gap for cancer waiting times, there is large variation between Health Boards. In 2022, performance against the Suspected Cancer Pathway target ranged between 47% and 65%.[25]

18. Currently, there are no routinely reported data on the cancer treatment people in Wales receive that provides breakdown by deprivation level. There is evidence of variation in the treatment received between more and less deprived populations for different cancer types in other countries,[26] but it is unclear whether similar variation is seen in Wales.

19. The Cancer Improvement Plan includes actions focused on new ways to deliver services and care using regional cross-Health Board approaches, such as regional diagnostic hubs and regional treatment hubs.[27] While these will likely lead to increased capacity and, it will be hoped, improved performance and outcomes, it is also important that consideration is given to their possible impact on inequalities. If patients are required to travel further to access some services that might normally be found in their local hospital, it may create additional barriers for more deprived groups, which could have the unintended consequence of exacerbating cancer inequalities.

20. We heard that for patients at end of life, accessing out of hours palliative care can be difficult. This can lead to people ending up in A&E as a result, most commonly for working age women and those from more deprived areas.[28]

21. It is important that cancer patients receive the right information and support, not just about their diagnosis and treatment, but also to address the additional needs that cancer can create. One area in particular is the financial cost of cancer, with on average £891 a month additional costs, associated with loss of earnings, increased travel for appointments, and higher energy bills.[29] These costs will be more keenly felt by people from more deprived groups, particularly during the cost of living crisis, as well as risking driving more people into poverty.

22. Participating in clinical research can offer patients the opportunity to receive new and innovative cancer treatments. For some patients, particularly those with later stage cancers, a clinical trial might offer a final treatment option. Consultation respondents told us that there is often a lack of diversity in trial participants, with more deprived groups less likely to take up an offer to be in a trial. Many of the barriers are similar to accessing health services, as well as structural issues in the NHS in capacity, which may be more apparent in some Health Boards.

23. **It is shocking and unacceptable that we have found that cancer patients in more socioeconomically deprived populations are more likely to experience worse outcomes**. There is a deprivation gap both in someone's chances of developing cancer, as well as dying from it. The Cancer Improvement Plan provides a short-term roadmap on how we can provide the best cancer care in Wales to improve survival and cancer experience. Those responsible for its implementation must been keenly focused on how cancer inequalities can be addressed, including in the delivery of new measures which could risk unintended consequences and exacerbating inequalities.

## SUMMARY OF RECOMMENDATIONS

| No. | Chapter | Recommendation |
|---|---|---|
| 1 | Cancer inequalities in Wales | The Welsh Government, NHS Executive, Wales Cancer Network, and Health Boards must continue to make tackling cancer inequalities a top priority, including in planning and delivery of services and new innovations. |
| 2 | Cancer inequalities in Wales | The Health Minister should provide an annual report to the Senedd on the Welsh Government's efforts to tackle cancer inequalities. |
| 3 | Cancer inequalities in Wales | In the implementation of the Cancer Improvement Plan, the Wales Cancer Network must set out how new initiatives either help reduce cancer inequalities, or outline steps to be taken to mitigate risk of exacerbating inequalities. |
| 4 | Cancer inequalities in Wales | Health Boards should establish, where not already present, a multi-agency working group focused on tackling cancer inequalities within their area. |
| 5 | Cancer inequalities in Wales | The Welsh Government, Public Health Wales and Wales Cancer Network should commit to the collection and publication of better data on cancer inequalities, including on ethnicity, age, sex, gender identity, sexual orientation, and disability. |
| 6 | Cancer inequalities in Wales | NHS Wales should commit to routinely providing cancer waiting times, staging data and treatment activity, and other published cancer data, by levels of deprivation, wherever possible. |
| 7 | Preventable risk factors for cancer | As well as taking action to achieve the existing Smoke-free 2030 target, the Welsh Government must set a subsequent smoke-free target of 5% or less smoking prevalence in Wales for all socio-economic groups, including the most deprived. The exact date for the target should be based on modelling. |
| 8 | Preventable risk factors for cancer | The Welsh Government should continue to implement its tobacco control strategy, with a clear focus on how to reduce inequalities in smoking prevalence. |
| 9 | Preventable risk factors for cancer | The Welsh Government, through its Healthy Weight Healthy Wales strategy, must focus on targeted initiatives for those most at risk of overweight and obesity, including people in the most deprived socioeconomic groups. |
| 10 | Preventable risk factors for cancer | The Welsh Government should urgently introduce legislation on the healthy food environment, including restricting retail price promotions of food and drink high in fat, salt and sugar. |

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| 11 | Preventable risk factors for cancer | Public Health Wales and local immunisation teams should work closely with local communities to identify barriers, tackle myths and stigma, and encourage uptake of the HPV vaccine, particularly in groups less likely to participate. |
| 12 | Awareness, attitudes, and help seeking | The Welsh Government and Public Health Wales should invest in regular cancer awareness campaigns, which seek to address cancer inequalities, and focus on signs and symptoms of cancer alongside tackling barriers to contacting a GP, with proper evaluation. |
| 13 | Awareness, attitudes, and help seeking | The Welsh Government and Public Health Wales should consider awareness campaigns to support understanding of cancer risk factors and address barriers to cancer screening for some population groups. These could be community-based. |
| 14 | Cancer screening | The Welsh Government should commit to expanding the existing targets for cancer screening uptake to include targets for improving uptake among groups less likely to participate, including those from more deprived areas. |
| 15 | Cancer screening | Public Health Wales should deliver targeted actions to improve informed uptake among more deprived groups in all three cancer screening programmes. |
| 16 | Cancer screening | The Welsh Government and Public Health Wales should ensure that evidence based improvements for cancer screening are rolled out at pace. |
| 17 | Cancer screening | The Welsh Government should commit to a timetable, and begin preparations, for the national roll out of a targeted lung screening programme, incorporating evidence from pilots already run in other parts of the UK. This must include specific consideration on how to encourage uptake from people from less likely to participate. |
| 18 | Accessing health services | The Welsh Government, Wales Cancer Network and Wales Ambulance Service should conduct an urgent review in patient transport options for cancer tests and treatment, including supporting existing community organisations. |
| 19 | Accessing health services | Primary care and cancer services should consider how they can offer flexibility in appointment times to ensure that people who find it more difficult to take time off work or use public transport are less likely to miss appointments. |
| 20 | Accessing health services | Health Boards and primary care should, wherever appropriate, offer the option of either a virtual or face to face appointment to suit personal circumstances and avoid additional costs for patients. |

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| 21 | Accessing health services | The Welsh Government should commit to working in partnership with a range of stakeholders, including the third sector, to deliver personalised care in out-of-hospital settings. This approach will ensure that existing services and community resources can be better utilised to support diverse communities of people living with cancer. |
| 22 | Accessing health services | When delivering new pathways and increased regionalisation of services, the Wales Cancer Network and Health Boards must consider the impact on some patients' ability to travel and ensure mitigations are available. |
| 23 | Accessing health services | Health Boards should ensure patients at end of life have a single point of contact for out of hours palliative care. |
| 24 | Cancer experience and support | The Welsh Government and Health Boards should ensure that everyone with cancer has a supportive conversation with a health professional that addresses their individual needs and connects them to local statutory and voluntary support. |
| 25 | Cancer experience and support | Health Boards should routinely collect data on how many Holistic Needs Assessments are conducted and how many written care plans are made with patients. This data should be made available by demographic group. |
| 26 | Cancer experience and support | Health Boards should routinely signpost patients to advice services that can address financial concerns, including from the third sector, following a cancer diagnosis. |
| 27 | Cancer experience and support | Health Boards must ensure that patients receive accessible cancer information, regardless of language and literacy level, including appropriate signposting to third sector organisations. |
| 28 | Research and innovation | The Welsh Government and Health and Care Research Wales should invest in research into what works in tackling known inequalities in cancer, as well as learning what works elsewhere across the UK. |
| 29 | Research and innovation | The Welsh Government and Health and Care Research Wales should explore ways to increase equity to access clinical trials. |
| 30 | Research and innovation | Health and Care Research Wales should consider how to support patients who might need to travel long distances to participate in clinical trials. |

## WHAT ARE CANCER INEQUALITIES?

Health inequalities exist when there are avoidable, unfair and systematic differences between different population groups.[30] They can be found between different demographics and characteristics, including ethnicity, age, sex, gender identity, sexual orientation, disability, as well as socioeconomic status.[31] Where they occur, differences in a range of health outcomes can be observed. They impact every stage of the cancer pathway, including prevalence of cancer risk factors, screening uptake, access to health services, and patient experience. These all contribute to stark differences in cancer incidence and outcomes.

Recent reports have shown where inequalities in cancer exist for people from more deprived groups for some cancer types.[32] People from ethnic minority communities[33, 34] and people with learning disabilities[35] are all more likely to be diagnosed at a later stage for certain cancer sites. People from more ethnically diverse areas[36], people with a learning disability,[37] and men,[38] are less likely to participate in screening programmes, and we know that the cervical screening system creates several barriers for trans men and non-binary people's access to appointments.[39]

Research also shows there are significant inequalities in patient experiences of cancer care, with a poorer average rating of care being reported by people from Asian, Black, Mixed and Other backgrounds compared to White respondents (survey categories) in England.[40] LGBTQIA+ people also have poorer experiences in the healthcare setting than heterosexual groups,[41] with research by Macmillan Cancer Support showing that LGBT+ people face poor communication and felt excluded from decision making in their experience of cancer care.[42]

The COVID-19 pandemic shone a light on health inequalities, highlighting that the direct and indirect effects and harms of the disease were not felt equally across society.[43] However, health inequalities have been observed for decades before COVID-19 arrived. As far back as 1980, the Black Report highlighted the differences in mortality rates across different social groups.[44] More recently, reviews by Professor Sir Michael Marmot, first in 2010[45] and followed up in 2020[46], found worrying and increasing gaps in life expectancy. Critically, these reviews demonstrated that tackling health inequalities was not simply down to health services, but tackling the wider determinants of health, including poverty, housing and infrastructure.

It is important not to oversimplify health inequalities. Humans are complex. Our identities will be shaped by more than just one characteristic, which in turn will impact our experiences and how we behave in different circumstances. For many people, there is an intersectionality at play that will drive the health inequalities that they experience.

Conversely, there is still much to uncover about how and where inequalities exist in cancer outcomes and experience. Data tend to be more widely available on the differences between different socioeconomic groups. As a result, this inquiry, and its final report, focuses more on the impact of deprivation and geography than it does on other demographics. That is not to say that other characteristics are unimportant. Indeed, we need more data to better understand where health inequalities exist and the potential solutions to address them.

## CANCER INEQUALITIES IN WALES

***Around 2,000 extra cancer cases each year in Wales are attributable to deprivation, the equivalent of more than 5 extra diagnoses a day.***

***Cancer death rates are 55% higher in the most deprived Welsh populations compared to the least deprived.***

Every day, 54 people are diagnosed with cancer in Wales[47] and 25 people die from the disease.[48] The number of cancer cases in Wales is projected to rise by more than a quarter, to around 24,800 new cases per year by 2040.[49]

Deprivation levels vary across Wales. NHS Health Boards in Wales are made up of 'zones'. Each zone is ranked by level of deprivation, which is used to assign the zone to one of five groups – or 'quintiles' – with an increasing level of deprivation between each quintile.[50] However, a zone in the least deprived quintile can still have people facing high levels of deprivation living in that zone.

There is large variation between Health Boards in the proportion of zones they contain that are in the most deprived quintile, ranging from 6% to 27%.[51] Swansea Bay and Aneurin Bevan University Health Boards contain the highest proportion of the most deprived zones (27% each), but also 25% and 16% of the least deprived zones, respectively. Powys Teaching Health Board contains only 6% of the most deprived zones in Wales.

When considering cancer outcomes broken down by deprivation, an uncomfortable truth emerges: that where you live can impact your chance of developing cancer and dying from it.

Cancer incidence rates in the most deprived group in Wales are 19% higher than in the least deprived (2017-2019).[52] It is estimated that there are around 2,000 extra cancer cases each year in Wales attributable to deprivation.[53] That's more than 5 extra new diagnoses per day that could be avoided if the rates of cancer in sites where it is higher for the most deprived were the same rates as for the least deprived. Lung cancer contributes half of these extra cases, with almost 1,000 extra cases linked to lung cancer being more common in more deprived populations.

There are more cancer deaths in more deprived populations than less deprived. In Wales, cancer mortality rates are 55% higher in the most deprived populations compared to the least deprived.[54]

More deprived groups also have worse cancer survival compared to the least deprived.[55] For all cancers combined, five-year net survival is 17 percentage points lower in the most deprived group compared to the least deprived (2014-2018).

For colorectal cancer, five-year net survival is 15 percentage points lower in the most deprived group compared to the least deprived (2014-2018). For breast cancer, five-year net survival is 12 percentage points lower in the most deprived group compared to the least deprived (2014-2018).[56]

While cancer inequalities of this nature are not unique to Wales, there should be a strong consensus that these differences are unacceptable and must be tackled. However, how that can be achieved is complex and challenging.

A recent report from the Welsh NHS Confederation in partnership with the Royal College of Physicians suggested that much of the drivers on our health and wellbeing sit outside of healthcare services.[57] The report reinforces the point that the NHS alone does not have the levers to reduce inequalities and argues for a cross-governmental approach to tackling health inequalities.[58]

Like the rest of the UK, people in Wales are dealing with the cost of living crisis, immediately following the COVID-19 pandemic, which has played a significant effect on our society. Several of the contributors to our inquiry highlighted that support is no longer only requested by those in receipt of benefits, but increasingly by people in work who are still struggling to make ends meet. Worryingly, we heard too many examples of where this has affected people's experiences of cancer.

We welcome that tackling health inequalities remains a stated priority of both the Welsh Government and NHS Wales. The Cancer Improvement Plan for NHS Wales 2023-2026, published in January 2023, details an ambition to improve cancer outcomes and reduce health inequalities.[59] Everyone involved in its implementation must have a laser-focus on how the plan's actions can be delivered in a way that seeks to address cancer inequalities in Wales, so that no matter where you live or how much money you earn, you have the best chance of beating cancer.

We also heard from Cwm Taf Morgannwg University Health Board, who in response to the challenge of inequalities, have established a multi-agency Reducing Cancer Inequalities Group for the Health Board, which reports to the Wales Cancer Network Board. The membership includes Health Board staff, clinicians, public health consultants, academics, third sector organisations, and the local education authority. Other Health Boards should examine this approach and consider replicating to identify opportunities to tackle cancer inequalities within their own region.

### *Data on inequalities*

Understanding the root causes of cancer inequalities, who they impact, and how to eliminate them, is complex and multi-faceted. We need to do more to fully understand cancer inequalities[60]. Currently, the data available for many population groups on several cancer metrics are outdated, limited, or non-existent. Data availability also varies along the cancer pathway, with data on inequalities particularly limited some aspects such as staging data and treatment activity.

These gaps limit our ability to comprehensively identify, understand, and act on inequalities. The best available data are on socioeconomic deprivation, but even for this demographic there are gaps in the evidence.[61] We also know that there are major inequalities based on geography in Wales, with people's experience of getting cancer[62] and their cancer outcomes[63] can vary depending on where they live. However, we do not yet have a full and complete understanding of where cancer inequalities exist, including how they may intersect, for example, the experience of someone from an ethnic minority community living in a more deprived area. This report can only mark the start of the conversation on cancer inequalities.

Some of these data may be available but not accessible to those seeking to tackle inequalities. In other cases, the relevant data may not be collected yet. It is essential that we get to grips with this as soon as possible, otherwise our efforts to ensure everyone has the best possible chance of beating their cancer will be hampered.

***Recommendations***

1. The Welsh Government, NHS Executive, Wales Cancer Network, and Health Boards must continue to make tackling cancer inequalities a top priority, including in planning and delivery of services and new innovations.
2. The Health Minister should provide an annual report to the Senedd on the Welsh Government's efforts to tackle cancer inequalities.
3. In the implementation of the Cancer Improvement Plan, the Wales Cancer Network must set out how new initiatives either help reduce cancer inequalities, or outline steps to be taken to mitigate risk of exacerbating inequalities.
4. Health Boards should establish, where not already present, a multi-agency working group focuses on tackling cancer inequalities within their area.
5. The Welsh Government, Public Health Wales and Wales Cancer Network should commit to the collection and publication of better data on cancer inequalities, including on ethnicity, age, sex, gender identity, sexual orientation, and disability.
6. NHS Wales should commit to routinely providing cancer waiting times and other published cancer data by levels of deprivation, wherever possible.

## PREVENTABLE RISK FACTORS FOR CANCER

***Smoking rates are more than four times higher in the most deprived quintile compared to the least deprived in Wales.***

***For the most deprived quintile, 33% of the adult population is obese, compared to 20% in the least deprived.***

Around 4 in 10 cancers could be prevented each year, over 7,200 cases in Wales annually.[64] Smoking and excess weight are the two biggest preventable causes, responsible for around 3,100 and 1,000 cancer diagnoses in Wales respectively.[65]

However, the prevalence of these risk factors is not equal across the Welsh population, with a strong link between deprivation and unhealthy behaviours that increase cancer risk. This is a big driver to the disparity in cancer incidence across different socioeconomic groups.

Efforts to prevent cancers from first occurring will play a key role in wider ambitions to tackle health inequalities.

### *Smoking*

Today, 13% of the Welsh adult population smokes.[66] Smoking is known to cause 15 different types of cancer, including some of the more common cancers – lung and bowel – as well as some of the most difficult to treat – pancreas, stomach and oesophageal.[67]

However, smoking rates vary significantly across levels of deprivation. In the most deprived quintile, 22% of adults smoke, while this is only 5% in the least deprived.[68] In fact, smoking rates are more than four times higher in the most deprived quintile compared to the least deprived quintile in Wales (2021-2022).[69] In 2003-2004, the absolute deprivation gap for smoking prevalence in Wales was 22 percentage points.[70] Today, the gap persists at 17 percentage points (2021-2022).[71]

At one of our evidence sessions, Suzanne Cass of ASH Wales shared that smoking rates tend to be higher among very specific population groups, including long-term unemployed, routine and manual workers, people living with severe mental health illness, homeless people, people in contact with the criminal justice system, looked after children, and LGBT people.

Research funded by Cancer Research UK found that people who smoke from more deprived socio-economic backgrounds are more likely to access stop smoking services but are less likely to be successful in their smoking cessation attempt.[72]

In July 2022, the Welsh Government published a new strategy, *A smoke-free Wales: our long term tobacco control strategy*, with the ambitious aim of achieving a smoke-free Wales by 2030. This would be defined as less than 5% of the population smoking.[73] Its first theme focuses on reducing inequalities, while the first two year delivery plan includes actions that are targeted at specific groups. There are also population-wide measures, such as implementing smoking cessation support in hospital settings, based on the Ottawa model.[74]

Modelling by Cancer Research UK in 2020, before the most recent tobacco control strategy was launched, set out that on current trends, Wales was not likely to hit a smoke-free target until 2037. To achieve a 2030 target, the pace of change in smoking rates would need to increase by 40%.[75] Due to data limitations and availability, the report was unable to model the deprivation gap in smoking. However, based on data from England, Scotland and Northern Ireland, the report demonstrates that

those living in the most deprived areas in Wales could take longer to achieve the smoke-free target compared to those in the least deprived areas. Consideration should be given to setting a subsequent smoke-free target of 5% or less smoking prevalence in Wales for all socio-economic groups, including the most deprived quintile. The Welsh Government should conduct modelling for what date this ambitious target should be set at.

### *Obesity*

In total, 62% of the Welsh adult population is overweight or obese.[76] The deprivation gap for obesity alone, where BMI is 30+, is significant. For the most deprived quintile, 33% are obese, compared to just 20% of the least deprived.[77]

The Child Measurement Programme offers a worrying picture in childhood obesity. The programme was disrupted due to the pandemic but the most recent full results for 2018/19 showed that more than 1 in 4 children aged 4-5 were overweight or obese. The deprivation gap in childhood obesity has increased from 4.9% in 2012/13 to 6.9% in 2018/19.[78]

Wales has the highest rate of obesity among 4-5 year olds in Great Britain.[79] Cancer Research UK analysis projects that there will be almost as many obese people as people of a healthy weight in Wales by the 2040s if current trends continue.[80] It is projected that 32% of the Welsh population – 870,000 people – will be obese by 2040, just marginally fewer than the 34% – 920,000 people – of a healthy weight. The percentage of overweight and obese adults in Wales is projected to increase from 59% in 2015 to 66% – a 12% relative increase – by 2040. That equates to around 1.8 million overweight and obese people in 2040. It is projected that those from the most deprived backgrounds in Wales would be almost two-thirds more likely to be obese than those of the least deprived backgrounds.[81]

In the most deprived group in Wales, if current trends continue, 37% of adults will be obese by 2040, compared to 29% in 2015.[82]

Excess weight is linked to 13 different cancers, including breast, bowel, pancreatic, oesophageal, and ovarian, among others. Tackling the rising trend of overweight and obesity is a complex challenge, with many environmental factors influencing individuals' behaviour. Our food and drink environment has a huge impact on the way that we shop and consume foods, for example.

The Welsh Government's *Healthy Weight Healthy Wales* strategy was published in 2019. It is made up of four national themes to reduce overweight and obesity in Wales: healthy environments, healthy settings, healthy people and leadership and enabling change. The ten-year strategy is being delivered through a series of two-year delivery plans.[83] Reducing inequalities will play a key role throughout this work.

In June 2022, the Welsh Government ran a consultation on creating healthy food environments, including a number of legislative measures such as restricting price promotions on food and drink high in fat, salt and sugar (HFSS), as well as promotions based on location in retail areas. The Obesity Alliance Cymru (OAC), made up of charities and health bodies, agreed that such a measure would support efforts to tackle obesity by making the healthy choice the easiest choice to make.[84]

There will be some understandable concern that implementing measures to remove price deals on certain products during a cost of living crisis will disproportionately impact low income families. However, there is evidence that those who make most use of price promotions tend to buy more unhealthy food.[85] Such promotions encourage overconsumption rather than sensible stockpiling.[86]

Given the deprivation gap in obesity in Wales, restricting price promotions on HFSS products will likely benefit both the waistlines and the wallets of the most deprived groups.

### *HPV*

Exposure to certain infections causes around 640 cancer cases in Wales every year.[87] One such infection, human papillomavirus (HPV), is known to cause almost all cases of cervical cancer, as well as some head and neck, vagina, vulva, penis, and anal cancers.[88]

Thanks to research, some of which was conducted in Wales, there is strong evidence that the HPV vaccine works and will save lives. One such study found that the bivalent Cervarix HPV vaccine reduced cervical cancer rates by 87% in women in their 20s in England who were offered it at age 12 to 13.[89]

The HPV vaccine is now offered to all girls and boys in Wales aged 12 to 14, in school years 8 and 9. However, Jo's Cervical Cancer Trust highlighted disparity in uptake of the HPV vaccine across the UK, including those living in areas with high levels of social deprivation[90], some ethnicities[91], and those previously excluded or not in school.[92] Jo's Trust also raised concern that uptake of the HPV vaccine is currently lower than it was pre-pandemic, calling for action to target to improve uptake levels.

***Recommendations***

7. As well as taking action to achieve the existing Smoke-free 2030 target, the Welsh Government must set a subsequent smoke-free target of 5% or less smoking prevalence in Wales for all socio-economic groups, including the most deprived. The exact date for the target should be based on modelling.
8. The Welsh Government should continue to implement its tobacco control strategy, with a clear focus on how to reduce inequalities in smoking prevalence.
9. The Welsh Government, through its Healthy Weight Healthy Wales strategy, must focus on targeted initiatives for those most at risk of overweight and obesity, including people in the most deprived socioeconomic groups.
10. The Welsh Government should urgently introduce legislation on the healthy food environment, including restricting retail price promotions of food and drink high in fat, salt and sugar.
11. Public Health Wales and local immunisation teams should engage with local communities to identify barriers, tackle myths and stigma, and encourage uptake of the HPV vaccine, particularly in groups less likely to participate.

## AWARENESS, ATTITUDES, AND HELP SEEKING

Most cancers will be diagnosed following a patient seeing their GP.[93] As such, it is important that people understand the signs and symptoms of possible cancer, and act on them in a timely way by contacting their GP. Early diagnosis remains the best way to maximise chances of survival, meaning that any delays to help seeking can have a detrimental impact on outcomes.

Throughout our inquiry, we heard about the multiple barriers facing people in seeking help from their GP when they experience concerning symptoms. Broadly, these included:

- Knowledge and understanding of signs and symptoms
- Attribution of symptoms to other existing medical conditions
- Ongoing management of other medical issues
- Ease of booking an appointment with a GP
- Ability to dedicate time to attend an appointment, due to taking time off work and/or caring responsibilities
- Social and cultural influences on help seeking on help seeking
- Negative beliefs about cancer, particularly fear, fatalism and that it is a 'death sentence'
- Belief that they are not worthy of receiving help, e.g. due to having smoked

These factors were shown to disproportionately affect people from lower socioeconomic groups.[94] Professor Kate Brain and her team at Cardiff University highlighted several studies indicating the link between deprivation to help seeking behaviour.

> *"Adults who smoke and live in socioeconomically deprived communities, including deprived regions in Wales, are less likely to access healthcare services for possible cancer symptoms, especially lung cancer symptoms."* [95]

Some of the responses we received from patient surveys and panels reinforced this:

> *"Having to take time off from work made it difficult. An evening or weekend appointment would have meant seeking help at an earlier stage rather than waiting until being so ill that symptoms could no longer be ignored."* [96]

The COVID-19 pandemic may have widened inequalities in help seeking behaviours.[97] It severely disrupted access to healthcare services during lockdowns. The COVID-19 Cancer Attitudes and Behaviours Study (CABS), run by Cardiff University, found that nearly half of participants who experienced potential cancer symptoms reported not contacting their GP for any symptoms during the first six months of the pandemic.[98] There were several reasons why many stayed away from primary care in particular:

- Worries about wasting the doctor's time
- Putting strain on healthcare services
- Not wanting to make a fuss
- Fear of attending hospitals

Before and since the pandemic, public awareness campaigns have been run to raise awareness of common symptoms and encourage people to contact their GP. Most recently, both Cancer Research Wales and Cancer Research UK ran campaigns in 2021 to support recovery from the disruption of COVID.

However, while mass media campaigns can help raise population awareness, their effects are not always equal across different groups, running the risk of exacerbating inequalities, as well as their effect often being short lived.[99] It is therefore important that particular groups, including those from deprived areas, are targeted in an effective way in order to encourage timely help seeking when concerning symptoms are experienced.

***Recommendations***

12. The Welsh Government and Public Health Wales should invest in regular cancer awareness campaigns, which seek to address cancer inequalities, and focus on signs and symptoms of cancer alongside tackling barriers to contacting a GP, with proper evaluation.
13. The Welsh Government and Public Health Wales should consider awareness campaigns to support understanding of cancer risk factors and address barriers to cancer screening for some population groups. These could be community-based.

## CANCER SCREENING

***The deprivation gap in cancer screening uptake in Wales is 19 percentage points for breast screening, 15 percentage points for bowel screening and 12 percentage points for cervical screening***

Cancer screening involves testing apparently healthy, asymptomatic people for signs of the disease. It can save lives by finding cancers at an early stage or, in some cases, preventing them. Screening normally involves a specific test and if cancer is suspected, a pathway to further diagnostic tests is provided.

*Existing cancer screening programmes*

Wales has three cancer screening programmes: bowel, breast, and cervical screening. Each has recommended by the UK National Screening Committee (UKNSC), which will include specific criteria regarding who is eligible to participate. This will be based on the potential benefits and risks of cancer screening – weighing up the positive impact on cancer mortality, against the potential for overdiagnosis, overtreatment, and other risks. The Welsh cancer screening programmes are run via Public Health Wales.

Taking part in cancer screening is a personal choice. However, there are concerning differences in uptake of cancer screening based on deprivation.

For breast screening, uptake is 19 percentage points lower in the most deprived populations compared to the least deprived (2020-2021).[100]

For bowel screening, uptake is 15 percentage points lower in the most deprived populations compared to the least deprived (2020-2021). Following the introduction of a new faecal immunochemical test (FIT) for bowel screening from January 2019 in Wales, there was an overall increase in screening uptake, but major variation in uptake still exists between the most and least deprived groups.[101]

A similar trend is seen for cervical screening, with a difference of 12 percentage points between the most and least deprived groups (2020-2021).[102]

Public Health Wales have developed a Screening Equity Strategy.[103] It highlights that some people might take an active decision to not participate in screening, but for others, they are unable to take up their offer for screening due to several barriers. Some of these barriers are more keenly felt by more deprived populations. These can include:

- Ability to attend screening appointments, due to travel, work or other challenges
- Information and language barriers, which can affect understanding of screening
- Social and cultural norms

Public Health Wales' strategy includes plans to target groups where uptake is low using evidence based interventions. In their submission, Cancer Research Wales outlined that targeted letters from GPs can increase uptake among some groups. Cancer Research UK provide a good practice guide on reducing inequalities in screening for healthcare professionals.[104] Jo's Trust called for a more accessible self-sampling test to encourage uptake of cervical screening among more deprived populations.

During the COVID-19 pandemic, cancer screening programmes were paused during the early months. The CABS study at Cardiff University found that during the pandemic, almost one in five people were less likely to engage in cervical or bowel screening than before.[105]

*Lung screening*

Last year, the UKNSC recommended that lung screening should be implemented across the UK. This followed an evidence review which found that targeted 55 to 74 year olds at high risk of lung cancer and offering a low dose CT scan, would detect more early stage lung cancers and save lives.[106]

Wales does not yet have a lung screening programme. Cwm Taf Morgannwg University Health Board (CTM) intends to set up a pilot this year. The pilot will take place in North Rhondda, due to its high levels of deprivation, lung cancer incidence and mortality, smoking prevalence, and screening inequalities. Invitations will be sent to 60-74 year old current and ex-smokers. Following a risk assessment of developing lung cancer, 500 participants will be scanned, with the expectation that around 5-10 lung cancers will be identified.[107] The pilot will then be evaluated to inform how the Welsh Government and Public Health Wales can roll out lung screening across the whole of Wales.

While the Cancer Improvement Plan includes an action related to the pilot, it does not commit to a timeframe for a full national roll out of lung screening.[108]

Given the higher prevalence of smoking in more deprived areas, lung screening could help address cancer inequalities. However, as Professor Brain told the CPGC, there is a paradox that more deprived populations are most likely to benefit from lung screening but also least likely to participate. Consideration must be given, both in the pilot and national roll out, as to how to encourage uptake from people in lower socioeconomic groups.

***Recommendations***

14. The Welsh Government should commit to expanding the existing targets for cancer screening uptake to include targets for improving uptake among groups less likely to participate, including those from more deprived areas.
15. Public Health Wales should deliver targeted actions to improve informed uptake among more deprived groups in all three cancer screening programmes.
16. The Welsh Government and Public Health Wales should ensure that evidence based improvements for cancer screening are rolled out at pace.
17. The Welsh Government should commit to a timetable, and begin preparations, for the national roll out of a targeted lung screening programme, incorporating evidence from pilots already run in other parts of the UK. This must include specific consideration on how to encourage uptake from people from less likely to participate.

## ACCESSING HEALTH SERVICES

***In 2022, performance against the Suspected Cancer Pathway of patients starting treatment within 62 days of their cancer being suspected ranged from 47% in the worst performing Health Board compared to 65% in the best.***

***The national target is 75%. No Health Board has achieved this since it was introduced in 2019.***

Many of the contributors to our inquiry highlighted how socioeconomic deprivation can create barriers to health services in a way that others might take for granted. This might include where it becomes too difficult to attend appointments, or where someone might have no choice but to prioritise other needs above their health, such as work and finances. This can lead to missed appointments, delayed diagnosis and treatment, and ultimately could impact survival and other outcomes.

In both written and oral evidence, several themes were raised as significant barriers for some people to access the health services they need – time off work, travel to appointments, and digital accessibility.

### *Taking time off work*

For some people in low income jobs, the ability to attend appointments during work hours may be more difficult and/or could lead to loss of income. This may include people working shifts, who are self-employed, and people in more casual work. Medical appointments are often inflexible in their timing. Following a cancer diagnosis, a patient will likely have to attend multiple appointments over a prolonged period, depending on their treatment plan. Recovery from some treatments can also affect someone's ability to work for a period of time. The CPGC heard anecdotal evidence of patients who had decided to delay their cancer treatment for these reasons, which could impact their outcomes.

> *"My husband has been working since he was 16. Recently diagnosed with stage 4 bowel cancer … A tragic situation- still working now, although he really deserves a rest as he is undergoing palliative chemotherapy."* [109]

### *Travel for appointments*

If patients rely on public transport, then it can be more difficult to get to medical appointments, particularly if they take place in a specialist cancer centre a long way away. This will be particularly true when receiving some treatments, including chemotherapy or radiotherapy, which can require attendance at hospital for several days over a number of weeks. For those living in rural areas, or find their communities poorly served by public transport, this challenge can be particularly difficult.

The Welsh Ambulance Services NHS Trust provide non-emergency patient transport service, with the eligibility criteria including receiving oncology treatment and have additional medical needs.[110] However, not all patients will be able to access this service. There may be additional support locally, including from some third sector organisations, but this will not be universal.

**CASE STUDY: CANCER AID MERTHYR TYDFIL**

Cancer Aid Merthyr Tydfil provide a range of services for local cancer patients. This includes a free door-to-door transport service to attend cancer appointments, including for treatment. It is around 20 miles from Merthyr Tydfil to the Velindre Cancer Centre, where patients may be required to regularly travel for their treatment. This service relies on volunteer drivers. Each year, the charity provides transport for up to 300 patients.[111]

*Digital accessibility*

Virtual consultations and appointments have become a more regular occurrence for many of us since the pandemic. While not suitable for every appointment, it might be that some patients are expected to attend a GP or outpatient appointment on the telephone or online.

It is important to recognise that virtual appointments may work well for some people, particularly in reducing travel requirements and time away from work.

However, several respondents also pointed to virtual appointments being less accessible for some people, including some in lower socioeconomic groups. Reasons given included:

- Digital literacy levels
- Access to technology
- Cost of broadband and mobile data

It is important that patients have a choice for how to attend appointments and consultation to suit their circumstances, wherever appropriate.

Audit Wales' report *''Time for Change' – Poverty in Wales'* describes exclusion from public services as a key component of experiencing poverty in Wales. The report sets out 'I statements' that may be experienced by those in poverty. Some of these can have direct implications for their ability to receive information and seek help for concerning symptoms that may be cancer:

- I am unable to register for health, dental and care services
- Transport is unreliable and I find it difficult to access and/or afford transport
- I do not have a computer, a SMART phone and/or tablet
- I do not have access to the internet at home
- I find it difficult to access the essential public services I need
- I find it difficult to get the advice and information I need to help me
- I feel marginalised by the services I seek help from[112]

*Access to primary care*

In addition, the National Survey for Wales has shown that getting a primary care appointment was more difficult for some groups:

- 22% of people living in material deprivation wanted an appointment but hadn't got one
- 23% of those with a limiting long-term illness said they couldn't get an appointment.[113]

People living in material deprivation are also less likely to be satisfied with the care received at their last GP appointment (80%) than those who are not deprived (87%).[114] Commonly cited reasons included difficulty making an appointment, and appointments not available at convenient times.

As well as the importance of primary care in diagnostic pathways, GPs will also play an important role in providing support for patients after a cancer diagnosis. However, the latest Wales Cancer Patient Experience Survey results showed that in 2021, only 31% of respondents said they had definitely received enough care and help from their GP after leaving hospital. However, the survey did not find a correlation based on deprivation for this question.[115]

The patient panel for our inquiry shared examples of a lack of follow up care from GPs:

> *"Once the potential Cancer was suspected, my loved ones was effectively handed over to the Hospital clinical team and all my discussions were with them. There was no follow-up by GP or any meaningful support from the GP team." [116]*

### *Access to secondary care*

There is a lack of available data to understand the impact of deprivation on outcomes in secondary care. Stage at diagnosis, cancer waiting times, and cancer treatment data are not broken down by deprivation quintiles.

However, there is evidence of significant variation geographically in Wales, with performance between Health Boards varying considerably on some measures. Staging data by Health Board shows that there is some variation in the proportion of cancers diagnosed at later stages. In lung cancer, for example, 60% of cases are diagnosed late in one Health Board, compared to 72% in another (2017-2019).[117]

The Suspected Cancer Pathway was established in 2019, with a target of at least 75% of patients starting their treatment within 62 days of their cancer being suspected. The target has not been met since it was introduced in February 2021 and has been steadily declining.[118] There is significant variation between Health Boards in cancer waiting times performance. In 2022, performance against the Suspected Cancer Pathway target ranged between 47% and 65%.

Early diagnosis can improve cancer survival. For example, bowel cancer is the fourth most common cancer in Wales[119] and causes around 970 deaths per year.[120] When diagnosed at the earliest stage, more than 9 in 10 (94%) people with bowel cancer in Wales will survive their disease for five years or more, compared with around 1 in 10 (9%) people when the disease is diagnosed at the latest stage.[121] While all Health Boards need to improve, the variation between them on performance and outcomes paints a worrying picture. More capacity in diagnostic services is required.

Currently, there are no routinely reported data on the cancer treatment people in Wales receive that provides breakdown by deprivation level. There is evidence of variation in the treatment received between more and less deprived populations for different cancer types in other countries,[122] but it is unclear whether similar variation is seen in Wales.

> *"Nearest test centre was a 2.5-hour journey one way. Nearest treatment centre was 1.5-hour journey one way. Limited public transport meant my husband also had to take time off work for appointments & treatments" [123]*

The Cancer Improvement Plan includes actions focused on new ways to deliver services and care using regional cross-Health Board approaches, such as regional diagnostic hubs and regional treatment hubs.[124] While these will likely lead to increased capacity and, it will be hoped, improved performance and outcomes, it is also important that consideration is given to their possible impact on inequalities. If patients are required to travel further to access some services that might normally

be found in their local hospital, it may create additional barriers for more deprived groups, which could have the unintended consequence of exacerbating cancer inequalities.

*End of life care*

For patients whose cancer is advanced and not curable, palliative and end of life care plays an incredibly important role in maintaining quality of life, dignity, and a good death.

Marie Curie Cymru told the CPGC that there is a particular problem accessing out of hours end of life care, with too many people ending up in A&E as a result. This was most common for working age women and those from the most deprived areas of Wales.

Problems associated with accessing emergency end of life care out of hours include difficulties obtaining medicines, care packages being delayed or unavailable and a reliance on community nursing services. Gaps exist across Wales in terms of availability of 24/7 telephone support for people at the end of life, despite this being a NICE recommendation.[125]

> *"I have secondary breast cancer and have trouble walking, bending, standing for long periods of time. I am only 57 and have worked all my life until I was diagnosed in 2017, I now feel like I don't want to go out as everything is so expensive i can't afford to go on holiday or do things I would like to do before I die. Everything is such hard work down to claiming benefits with all the form filling all the time. […] I don't drive so I rely on public transport or wait for one of my children to help when they are not working. Everything is going up food, petrol, gas, electric sometimes I feel like why am i even bothering. I'm not even entitled to the £650 cost of living payment because i get the ESA that are not entitled to it."*[126]

***Recommendations***

18. The Welsh Government, Wales Cancer Network and Wales Ambulance Service should conduct an urgent review in patient transport options for cancer tests and treatment, including supporting existing community organisations.
19. Primary care and cancer services should consider how they can offer flexibility in appointment times to ensure that people who find it more difficult to take time off work or use public transport are less likely to miss appointments.
20. Primary care and cancer services should, wherever appropriate, offer the option of either a virtual or face to face appointment to suit personal circumstances and avoid additional costs for patients.
21. The Welsh Government should commit to working in partnership with a range of stakeholders, including the third sector, to deliver personalised care in out-of-hospital settings. This approach will ensure that existing services and community resources can be better utilised to support diverse communities of people living with cancer.
22. When delivering new pathways and increased regionalisation of services, the Wales Cancer Network and Health Boards must consider the impact on some patients' ability to travel and ensure mitigations are available.
23. Health Boards should ensure patients at end of life have a single point of contact for out of hours palliative care.

## CANCER EXPERIENCE AND SUPPORT

A cancer diagnosis means more than just receiving treatment. It can lead to additional emotional, social, and financial needs, all of which require support and information to be available and accessible to patients.

The latest results from the Wales Cancer Patient Experience Survey found that 91% of respondents rated their overall cancer care as 7 or more out of 10. However, the survey also highlighted areas where patients were not receiving the care and support they need. Only 37% of patients said their healthcare team completely discussed with them or gave them information about the impact cancer could have on their day-to-day activities, such as work life or education.[127]

Being provided with a written care plan, undertaking a holistic needs assessment, and having a named key worker or clinical nurse specialist can all help ensure that cancer patients are able to receive the support they need, including signposting to third sector organisations, who might provide welfare benefits advice and emotional support.

Interestingly, the survey found that patients from the most deprived quintiles were more likely to report having been offered a written care plan, find it easier to contact their key worker, and being offered opportunities to discuss their needs and concerns.[128] Given so much of our inquiry has found where the needs of more deprived populations not being met, these results are welcome. We know that healthcare professionals will be working as hard as possible to deliver the best possible care for their patients. It is essential that this support is maintained for all. Where there are opportunities for further improvement in support, Health Boards and the Wales Cancer Network must work with clinicians and patients to deliver these.

### CASE STUDY: IMPROVING THE CANCER JOURNEY POWYS

Macmillan Cancer Support have trialled 'Improving Cancer Journey' (ICJ) initiatives across the UK. Since January 2020, Macmillan have been working in partnership with Powys County Council and Powys Teaching Health Board to deliver an ICJ approach in Powys.[129]

The aim of ICJ is to embed personalised support in the cancer pathway and enable equitable support. There are several key components to the approach:

- Proactive: all patients diagnosed receive a letter within 6 weeks offering an appointment with a support worker
- Co-produced: people with lived experienced and local service leaders are involved with the design of the service
- Systematic: concerns identified by a holistic needs assessment, such as housing, money or fatigue, have a route into other services
- Integrated: it is not about signposting but practical help and support, including shared data between organisations

ICJ has been run in Glasgow, which has a high proportion of patients living in deprived areas, many of whom have greater levels of need. It successfully overreached into the most deprived populations, leading to higher uptake from these groups.[130]

One area where support is vital is addressing the financial impact of a cancer diagnosis. Macmillan Cancer Support reported that, even before the current cost of living crisis, 83% of people with cancer in the UK experienced some kind of financial impact from their diagnosis. For those affected, this

reached an average of £891 a month, on top of their usual expenditure.[131] These costs are associated with a person's ability to continue to earn income through work, alongside possible increased costs due to travel to medical appointments and higher energy bills due to feeling the cold more during treatment or being at home more than usual.

Such costs have a double whammy in relation to inequalities. Those from more deprived populations will feel the impact of these costs more keenly, perhaps due to low income, little to no savings, or being in a job without sick pay.[132] Conversely, the financial cost of cancer can have the effect of driving more people into poverty.

Marie Curie Cymru have found that people in Wales are more likely to experience poverty at the end of life than in any other UK nation, with 6,600 people dying in poverty in Wales in 2019.[133]

> *" I have lung cancer on immunotherapy, to give me longer hopefully but cannot be cured. I am not putting on heating, using blankets to keep warm. Not eating as well as I should as food is so expensive."*[134]

The Cancer Improvement Plan recognises that cancer patients will be impacted by the current cost of living crisis. One of its actions includes bringing together the Wales Cancer Network, Health Boards, Trusts and the third sector to provide better access to all patients to advice on welfare benefits by September 2023.[135]

***Recommendations***

24. The Welsh Government and Health Boards should ensure that everyone with cancer has a supportive conversation with a health professional that addresses their individual needs and connects them to local statutory and voluntary support.
25. Health Boards should routinely collect data on how many Holistic Needs Assessments are conducted and how many written care plans are made with patients. This data should be made available by demographic group.
26. Health Boards should routinely signpost patients to advice services that can address financial concerns, including from the third sector, following a cancer diagnosis.
27. Health Boards must ensure that patients receive accessible cancer information, regardless of language and literacy level, including appropriate signposting to third sector organisations.

## RESEARCH AND INNOVATION

Research into cancer provides the best route to understand the disease, as well as identifying new ways to detect, diagnose and treat it. Research can also focus on population health, including how to address the preventable risk factors of cancer. It can increase our understanding of the barriers facing some people in engaging with primary care and cancer screening. Research will play a key role in how we can tackle cancer inequalities in Wales.

### *Access to clinical trials*

Participating in clinical research can offer patients the opportunity to receive new and innovative cancer treatments. For some patients, particularly those with later stage cancers, a clinical trial might offer a final treatment option.

The Wales Cancer Patient Experience Survey found that in 2021, only 20% of respondents had been offered a discussion about taking part in cancer research. This was slightly lower than in 2016, when 23% of patients reported discussion opportunities to participate in cancer research.[136]

In their evidence, ABPI Cymru reported a significant lack of diversity in participants in clinical trials across the UK. This means that some groups and communities are underserved by research.[137] Cwm Taf Morgannwg University Health Board told the CPGC that patients are offered opportunities to participate in research, with this normally taking place at the Velindre Cancer Centre. However, uptake is often low, and the most deprived populations are the least likely to participate.[138]

Mandy Edwards, CRUK Senior Research Nurse for Wales provided evidence to the CPGC about what the key barriers can be for some patients being able to participate in clinical trials. Some of this mirrors the previously described issues in accessing health services. However, there are also some structural issues that could increase geographic inequalities in clinical research.

- Distance and cost of travel, particularly if the only place to take part in a trial is the Velindre Cancer Centre in Cardiff or The Christie in Manchester
- Challenges getting accessible information and support to understand clinical trials
- Local health service capacity to deliver requirements for trial participation, e.g. imaging scans in a quick turnaround time
- Gaps in the oncology workforce, which might limit opportunities for principal investigators to be available in some hospitals, particularly in rural areas.[139]

Cancer Research UK highlighted that there are opportunities to learn from the adaptations made to clinical trials during the height of the pandemic, which could make cancer trials more accessible and inclusive. This includes decentralised delivery, such digital consultations and administering some treatments in participants' homes or GP practices. Such changes might not be suitable for all aspects of every trial, but they offer an opportunity to widen access to clinical research to more people, including those less likely to participate.

### *Existing research in Wales on cancer inequalities*

Many of the contributors to our inquiry highlighted initiatives taking place in Wales to better understand cancer inequalities and the interventions that could address them. It is important these are properly supported, and their findings shared so that any improvements can be implemented at pace.

Some of these initiatives that have run or continue to operate in Wales include:

- TIC-TOC (Targeted Intensive Community-based campaign To Optimise Cancer awareness) - a feasibility study of a public awareness campaign designed to help adults living in deprived communities recognise vague cancer symptoms in South Wales[140]
- ICJ (Improving the Cancer Journey) Powys – embedding equitable patient support in the cancer pathway[141]
- Coalfields Community Champions Project 2023-2028 – a project targeting some of the most deprived areas within Cwm Taf Morgannwg University Health Board to provide non-clinical support through community champions[142]
- ABACus (Awareness and Beliefs about Cancer) – a randomised controlled trial testing a health check intervention in socioeconomically deprived communities.[143]
- Talking Trials – an exploration of clinical trial perceptions among black, Asian and minority ethnic communities[144]

***Recommendations***

28. The Welsh Government and Health and Care Research Wales should invest in research into what works in tackling known inequalities in cancer, as well as learning what works elsewhere across the UK.
29. The Welsh Government and Health and Care Research Wales should explore ways to increase equity to access clinical trials.
30. Health and Care Research Wales should consider how to support patients who might need to travel long distances to participate in clinical trials.

## CONCLUSION

This inquiry has sought to better understand how and why some groups within the Welsh population are more likely to experience worse cancer outcomes.

It is shocking and unacceptable that we have found that cancer patients in more deprived populations are more likely to have an experience of cancer. There is a deprivation gap both in someone's chances of developing cancer, as well as dying from it.

We are grateful to everyone who has participated in this work, to help us identify some of the causes and the potential solutions to address this issue. It will require all of us to work together – Welsh Government, Senedd Members, NHS Wales, third sector, researchers, and other bodies – if we are to make a difference.

Our inquiry was always going to be limited by the data available on cancer and inequalities. As such, we have focused more on where inequalities exist due to deprivation and geography. But we know that this will go far deeper and the intersectionality between different demographics will mean that some people face a much more difficult time following a cancer diagnosis.

The Cancer Improvement Plan provides a short term roadmap on how we can provide the best cancer care in Wales to improve survival and cancer experience. Those responsible for its implementation must been keenly focused on how cancer inequalities can be addressed, particularly in the delivery of new measures which could risk unintended consequences and exacerbating inequalities.

The only way we will beat cancer is if we can ensure that everyone has the same chances, no matter who they are and where they live.

## APPENDIX A: INQUIRY TERMS OF REFERENCE

*Aims of the inquiry*

- To Understand the impact that deprivation and inequality have on cancer incidence, access to cancer services and cancer survival in Wales.
- To provide recommendations to the Welsh Government, NHS Wales, and other public bodies to tackle inequalities across the cancer pathway, and in particular the impact of poverty and deprivation on patient access and experience.

*Objectives*

- Invite and take evidence from a range of stakeholders – looking at impact of income poverty and deprivation through the lens of:
    - prevention of cancers
    - seeking help with signs and symptoms
    - screening
    - access to primary care and diagnostic services
    - access to treatment
    - access to innovations
    - access to information and support
    - palliative and end of life care
    - access to clinical trials
- To understand the patient experience, to hear from less-well represented groups.
- To understand what work is taking place across Wales to redress inequalities in order to better health outcomes
- To make recommendations to Welsh Government, NHS Wales and other bodies based on this evidence

## APPENDIX B: WRITTEN EVIDENCE SUBMISSIONS

We are grateful to the following organisations and individuals who submitted written evidence to our inquiry:

- ABPI Cymru Wales
- Brain Tumour Research
- Cancer Aid Merthyr Tydfil
- Cancer Research UK
- Cancer Research UK Campaigns Ambassador
- Cancer Research Wales
- Cardiff University School of Medicine – Screening, Prevention and Early Diagnosis Theme (led by Professor Kate Brain)
- Cwm Taf Morgannwg University Health Board
- Jo's Cervical Cancer Trust
- Less Survivable Cancers Taskforce
- Macmillan Cancer Support
- Mandy Edwards, CRUK Senior Research Nurse for Wales
- Marie Curie
- Pontyclun Bosom Pals
- Young Lives Vs Cancer

We are also grateful to Tenovus Cancer Care and Cancer Research UK for their support in enabling people affected by cancer to be heard within this inquiry.

Respondents were asked to answer the following questions, where possible, in their submissions:

1. What are the challenges facing specific groups or communities in Wales with regards to risk factors for cancers such as smoking, alcohol and obesity?
2. What barriers do communities in deprived areas and/or people in low income households in Wales face in accessing:
    a. Screening
    b. GP/Primary care practice
    c. Diagnostic services (e.g. endoscopy, imaging)
    d. Cancer treatments, including innovative treatments and clinical trials
3. How can deprivation affect the way patients experience cancer services in Wales?
4. What are the barriers to tackling cancer inequalities in Wales?
5. What impact has the following had on access to cancer services for different groups:
    a. COVID-19 pandemic
    b. Cost of living crisis
6. What work do you know is happening across Wales to tackle inequalities in cancer care?
7. What action would you like to see Welsh Government, NHS Wales and other bodies take to tackle the inequalities that exist in cancer in Wales?

## APPENDIX C: ORAL EVIDENCE PARTICIPANTS

The Cross Party Group ran three sessions to hear oral evidence for the inquiry from the following participants.

*Launch of the inquiry: 27 October 2022*

- Chaired by David Rees MS
- Speakers:
    - Dr Steffan Evans, Head of Policy (Poverty), Bevan Foundation
    - Lowri Jackson, Royal College of Physicians

*First evidence session: 1 December 2022*

- Chaired by Huw Irranca Davies MS
- Speakers:
    - Suzanne Cass, Chief Executive, ASH Cymru
    - Judi Rhys, Chief Executive, Tenovus Cancer Care
    - Julie Bishop, Director of Health Improvement, Public Health Wales
    - Richard Pugh, Head of Partnerships, Macmillan Cancer Care

*Second evidence session: 8 December 2022*

- Chaired by David Rees MS
- Speakers
    - Kate Brain, Professor of Health Psychology, Cardiff University
    - Tracey Burke, Principal Manager, Cancer Aid Merthyr Tydfil
    - Gerard McMahon, Head of External Affairs, Bowel Cancer UK
    - Jon Antoniazzi, Associate Director of Policy and Public Affairs, Marie Curie

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