

Response from Cwm Taf Morgannwg University Health Board to the Cross Party Group on Cancer - Inquiry into inequalities and cancer in Wales. Written consultation document

Background

The Cross Party Group on Cancer Inquiry into inequalities and cancer in Wales launched the inquiry in December 2022 in order to:

- 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.

The Cross Party Group will be taking evidence from a range of stakeholders throughout late 2022, and will publish a report with recommendations based on evidence received in Spring 2023.

Responses from Cwm Taf Morgannwg University Board (CTM UHB) and partners to the 7 questions posed are outlined in the following pages.

CTM experiences some of the highest incidence of cancers and poorest survival rates, with high levels of deprivation and lifestyle behaviours associated with cancer.

In response to these challenges, CTM set up multiagency CTM Reducing Cancer Inequalities (RCI) Group which reports into the Cancer Board. The group is chaired by Consultant in Public Health; membership includes partners from Public Health Wales Screening Division, Academia, local and national Cancer Charities, Local Education Authority, Primary and Secondary Health Care the Council for Voluntary Communities and CTM Cancer Business Unit. Members of this CTM RCI meeting were invited to feed in to the Cross Party Group Cancer Inquiry response and the submission includes summarised contributions with embedded documents for fuller reference.

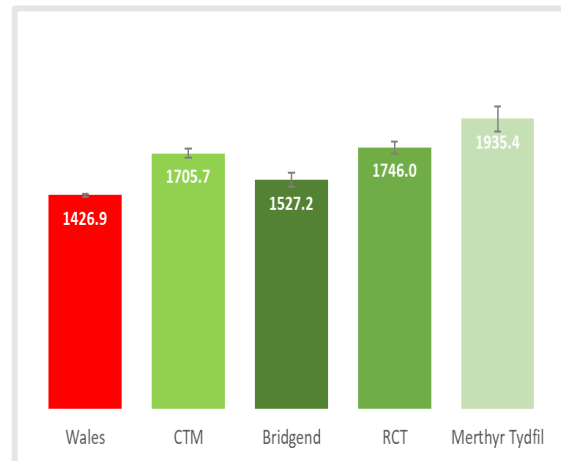
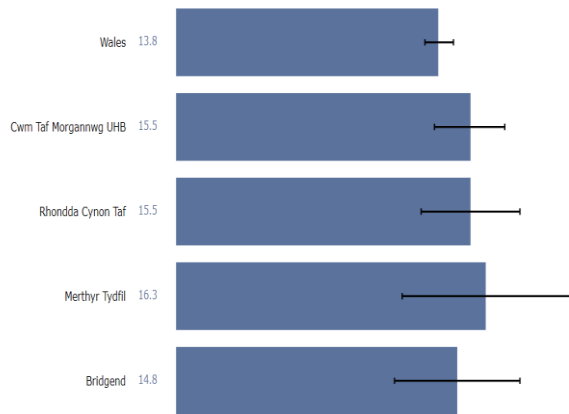
Q1. What are the challenges facing specific groups or communities in Wales with regards to risk factors for cancers such as smoking, alcohol and obesity?

Response- Smoking

Figure 1

Rate of smoking-attributable admissions, ESR per 100k, 2016/17-2018/19, Public Health Wales Observatory

Adults who smoke, age-standardised percentage, persons aged 16+, Wales, Health Board, Local Authority, 2020-2021
Produced by Public Health Wales Observatory using NSW (WG)

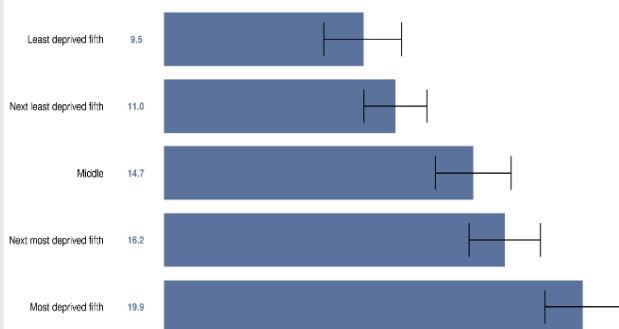
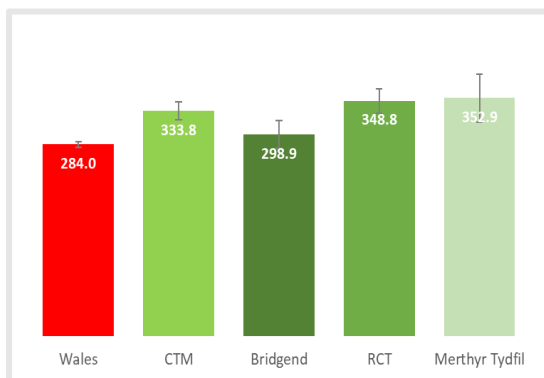


Merthyr Tydfil (MT) in CTM has highest percentage of smokers at 16.3% followed by Rhondda Cynon Taf (RCT) compared to the 13.8% in Wales. Lung cancer rates in MT and RCT are the highest in Wales, with rates in Bridgend similar to Wales. Merthyr has the highest rate of smoking- attributable mortality and smoking- attributable hospital admissions in Wales (2016-18), and RCT the 3rd highest rate¹. This is reflected in the Wales data for smoking prevalence with most deprived areas of Wales being just over double that in the least deprived areas in 2020-21².

Rate of smoking-attributable mortality, ESR per 100k, 2016-2018, Public Health Observatory

Adults who smoke, age-standardised percentage, persons aged 16+, Wales by deprivation fifth, 2020-2021

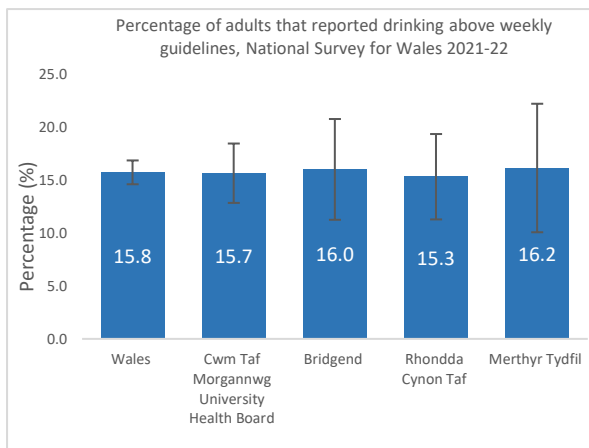
Produced by Public Health Wales Observatory using NSW (WG) & WIMD (2019)
— 95% confidence interval



¹ Liapi S and Slyne C 2023 Risk factors of smoking, alcohol and obesity relating to cancer inequalities. National Survey for Wales (NSW), Public Health Wales (PHW) and Welsh Cancer Intelligence and Surveillance Unit, LPHT at Cwm Tag Morgannwg UHB

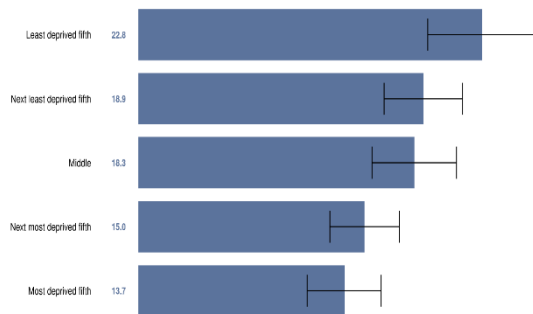
² Lester N 2023, All Party Inquiry into Cancer inequalities. Input from Public Health Wales Observatory and Cancer Analysis Team (OCAT)

Response-Alcohol



Adults drinking above guidelines, age-standardised percentage, persons aged 16+, Wales by deprivation fifth, 2020-2021

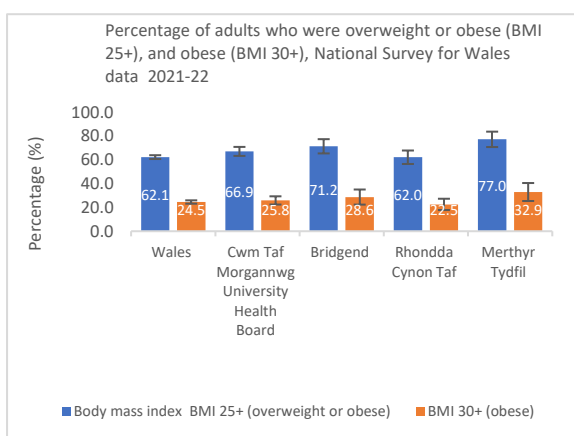
Produced by Public Health Wales Observatory using NSW (WG) & WIMD (2019)
 — 95% confidence interval



15.8% of adults in Wales self-reported drinking above the weekly guideline amount of 14 units of alcohol, compared to 15.7% of adults in CTM, MT at 16.2% was the highest. 18.7% of adults in Wales and CTM do not drink alcohol and highest percentages are seen in MT at 26.6%. Alcohol misuse has been identified as a causal factor for increased risk of cancer and more than 200 other medical conditions¹.

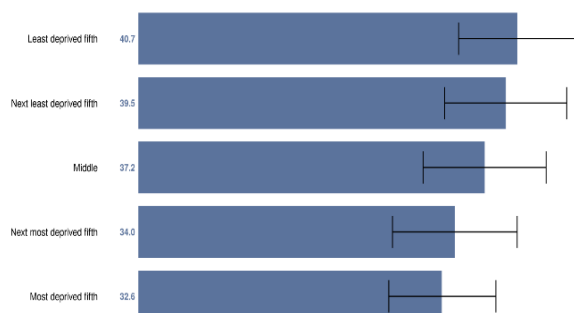
Percentage of people drinking above guideline amounts in the least deprived areas of Wales is higher, at almost 23 per cent, than in the most deprived areas where the figure is just under 14 per cent. However, data on hospital admissions and deaths show the reverse pattern with higher rates in the most deprived areas of Wales. There is suggestive evidence for a multiplicative effect between socioeconomic status (SES) and alcohol consumption, which would imply that higher alcohol consumption poses disproportionately greater health risks for individuals with low SES than for those with high SES².

Response-Overweight / Obesity



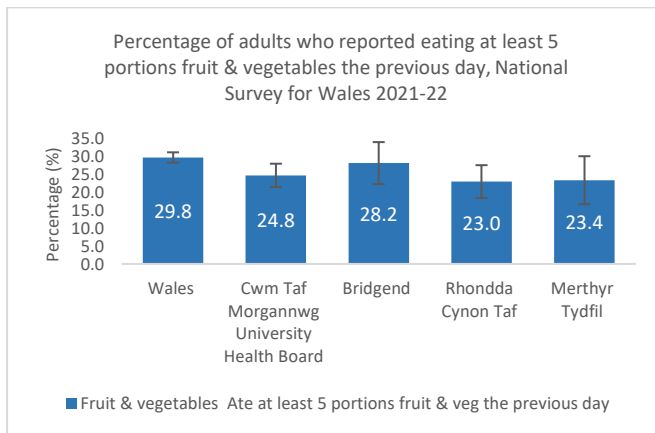
Working age adults of healthy weight, age-specific percentage, persons aged 16-64, Wales by deprivation fifth, 2020-2021

Produced by Public Health Wales Observatory using NSW (WG) & WIMD (2019)
 — 95% confidence interval



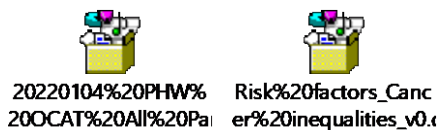
62.1% of adults were overweight or obese (BMI 25+) in Wales, which is lower than 66.9% in CTM. Overweight/obese and obesity rates remain the highest in Merthyr, followed by Bridgend and RCT. Merthyr and RCT have high rates of colorectal cancer which may be linked to poor diet and obesity¹.

Only 37 per cent of working age (16-64) adults reported being of healthy weight. In the most deprived areas of Wales this falls to 33 per cent, with 41 per cent of those in the least deprived areas being of healthy weight².



Consumption of fruit and vegetables is the lowest across the health board in Merthyr and RCT¹.

Fewer than half of adults living in the most deprived areas of Wales are meeting guideline of 150+ minutes of moderate or vigorous intensity activity per week, whilst in the least deprived areas almost two thirds are meeting it. The latest data on cancer incidence shows that the age standardised rate in the most deprived areas was around 20 per cent higher compared with the least deprived areas².



2. What barriers do communities in deprived areas and/or people in low income households in Wales face in accessing:

Response- Barriers faced

An **Ambassador of the Pontyclun Bosom Pals Breast Cancer Support Group** highlights concerns about barriers faced by residents summarised below:

- “barriers more concerning than 12 months ago especially for people in deprived areas who are not physically active, who smoke, drink alcohol and have issues with eating
- low income means cannot afford or just cannot access help needed
- accessing support numbers (contacts) has become difficult
- GP appointments difficult with 18-20 mins waiting times to book appointment
- lack of mobile phones
- serious medical issue detection is not early enough
- hesitancy in accessing support on offer and taking the first step
- more challenges faced with cost of living with heating homes and buying essential foods
- many with underlying conditions shielding for many months and cancer not diagnosed in the early stages
- issues within government, NHS and other bodies has meant that tackling inequalities in cancer has become a massive task

- help available via Foodbanks, for loneliness, wellbeing but dealing with a cancer diagnosis, screening and treatment requires specialists who are desperately needed
- hope that facilities will exist in all areas of Wales for screening, treatments, early diagnosis for all early cancer detection and related disease”³

Allied Therapies – barriers faced

- Regionalisation of services and being unable to travel to different locations around the health board could be a barrier
- As more services moved to virtual, digital availability and literacy
- Promotion therapy self- management if appropriate in terms of prevention and treatment of cancer may be a culture shift for people of CTM, potentially more so in deprived areas and therefore a barrier
- When co-producing new services full patient representation from all demographic areas in ethnicity, deprivation, sexuality is not always available⁴

a. Screening

Response- Accessing screening

The national screening programmes in Wales, provide equitable access and opportunity to take up screening offers based on an individual’s informed choice which has to be consistent with their values and unique circumstances. Declining screening may be a result of interlinked barriers.

Barriers relevant at a national or local level and may be specific to a programme or relate to a community or individual and include:

- logistical or physical challenges driven by economic or environmental factors that reduce access to locations of screening offer
- not receiving information in appropriate formats or languages to ensure availability of necessary knowledge to make an informed choice
- preventative screening may not be a part of their social norm or cultural identity.

Provision of an equal service to all will not support those people from under-served groups who may require additional support to take up their offer of screening. The people of Wales are not all the same including having different barriers and enablers for screening, different levels of health literacy and varying communication needs. Clear demonstrable differences in uptake are seen in data that relate to deprivation, gender and age. Qualitative work carried by the national PHW Screening team, has revealed screening inequities affect different communities and affect them for different reasons, including ethnic minority communities, people in long term care and those with additional communication needs.

The Screening Equity Strategy’s action plan identifies five key areas of focus – Communication, Community and Engagement, Collaboration, Service Delivery and Data and Monitoring. Actions are

³ Hadlow S 2022 Ambassador, Pontyclun Bosom Pals Breast Cancer Support Group, Rhondda Cynon Taf

⁴ Collins R 2023 Rhian Collins Macmillan Allied Health Professional Lead for Cancer, Cwm Taf University Health Board

for a range of organizations, teams and with service user engagement. The published report provides data on uptake and reach of screening in UHBs⁵ - [data report](#).

b. GP/Primary care practice

Response- Barriers faced in GP/Primary care practice

Academic research undertaken in CTM identified:

- 1) Low cancer symptom awareness and negative beliefs about cancer increase likelihood of delays in help-seeking via GP/Primary Care Services and screening. Concerns over wasting the doctor's time were higher in adults from lower socioeconomic groups, resulting in delayed symptom help-seeking. Interviews with adults living in CTM illustrated some of the mechanisms that link socioeconomic deprivation with poor cancer outcomes. Participants described
 - fear of cancer treatment
 - fear of being diagnosed
 - automatic association of a cancer diagnosis with death
 - accessing primary care e.g. time off work
 - lack of confidence in talking to the GP.
 - This research indicates that interventions to improve knowledge of cancer symptoms alone are not sufficient to change help-seeking behaviour in socioeconomically deprived communities, but



Response to The
Cross Party Group on

should also address deep-seated negative beliefs about cancer⁶.

c. Diagnostic services (e.g. endoscopy, imaging)

Response-Diagnostic services

1) **Lung cancer** is the leading cause of cancer death in Wales and CTM. Of the most common cancer types, lung cancer has the widest cancer death inequality, with a gradient of higher mortality in more deprived areas. Differences in mortality between more and less deprived areas has increased over time. North Rhondda was selected within CTM as the target population to pilot the Lung Health Check (or lung cancer screening) due to high levels of deprivation, lung cancer incidence, lung cancer mortality, smoking prevalence and screening inequalities.

A Lung Health Checks operational pilot is being established in North Rhondda with support from the Wales Cancer Network, industry and charity partners. It is a targeted form of screening, and invitation materials and messages, access issues, invitation strategies etc. are all being aimed to maximise uptake. Integrated links with smoking cessation services are a key part of the process. From 2023 it will invite 60-74 year old current- and ex-smokers for a risk assessment of developing lung cancer. Evidence shows a 20+% reduction in lung cancer mortality with targeted screening due

⁵ D Souza S et al 2022 Screening Equity Strategy 2022-2025. Public Health Wales

⁶ Prof. Brain K et al 2022 Response to The Cross Party Group on Cancer – Inquiry into inequalities and cancer in Wales, Cancer Screening, Prevention and Early Diagnosis Theme at Cardiff University, Division of Population Medicine, Cardiff University

to ¾ cases being found at stage 1-2, as opposed to ¾ being found at stage 3-4 through usual



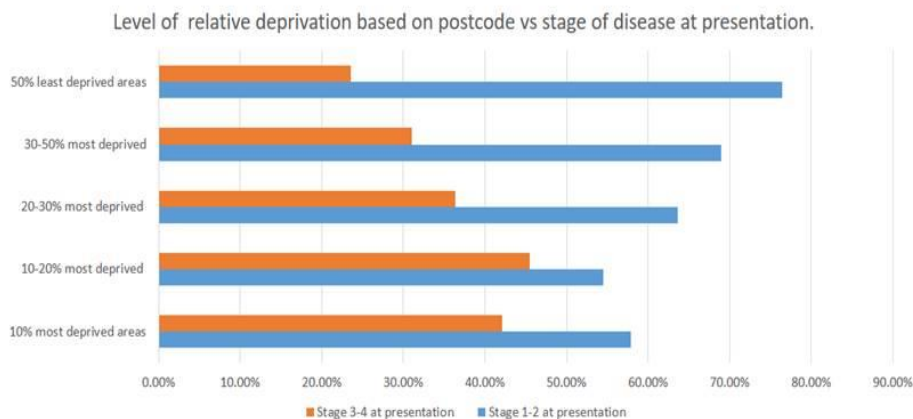
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presentation. 500 participants will be scanned, to find 5-10 lung cancers⁷.

- Only 34% of women in Wales (as at July 2022) with a **Gynaecological cancer** received definitive treatment within 62 days from the ‘point of suspicion’ on the single cancer pathway and of all patients entering the pathway, only 6-7% are actually diagnosed with cancer. However, all patients investigated for suspected cancer require complex, skilled and compassionate care. Optimum management involves co-ordinated teamwork between the primary and secondary care units and the gynaecological cancer centres who provide the Network Gynaecological cancer multidisciplinary team.

A summary of recent CTM response to a national consultation (Health and Social Care, Wales) regarding the experiences of women with symptoms of gynaecological cancer, how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with a gynaecological cancer (to ensure their physical, psychological and practical needs are met) is outlined.

Of the ten areas of response considered (patient centred care, barriers to securing diagnosis, recovery of services within context of extra capacity related to impact of the COVID-19 pandemic, prioritisation of pathways and waiting lists, compared to other cancers, local disparities in backlogs, data disaggregation by cancer type as opposed to pooling and by other characteristics such as ethnicity, adequate priority given to gynaecological cancers (causes and treatments side-effects) action needed to speed up health research and medical breakthroughs in diagnosing and treating in the forthcoming national action plans and planning for new innovations (therapy, drugs, tests) that improve outcomes key local data used in the report are below. Inequalities in stage of disease at time of presentation as related to deprivation and ethnicity particularly relate to inequalities.



An audit carried in CTM during June 2021 to June 2022 showed patients who lived in least deprived areas were more likely to present at an early stage e.g. women presenting with cervical cancer were 50% from the most deprived areas and only 8% from the least derived areas and endometrial cancer, which statistically at national level come from the least deprived areas, in the cohort of patients

⁷ Dr Eccles S 2022 Lung cancer inequalities. Screening pilot. Consultant Respiratory Physician, Royal Glamorgan Hospital, Cwm Taf Morgannwg University Health Board Lung Health Check Wales Clinical Lead, Wales Cancer Network.

assessed in Prince Charles Hospital and Royal Glamorgan Hospital, 50% were from the most deprived areas⁸.

Of the population diagnosed with gynaecological cancer in Bridgend (2021), there were no patients of Black, Asian Minority Ethnic backgrounds, however 20% of the patients diagnosed with cervical cancer and 10% of those diagnosed with endometrial and ovarian cancers were Eastern Europeans (Ukrainian, Bulgarian, Russian, and Polish). Data on the ethnicity of patients has not been routinely available for patients in the population. Late presentation of gynaecological cancer in areas of deprivation and with ethnic minority communities, are typically associated with emotional, practical reasons, symptoms not recognized/confused or service barriers.

CTM UHB Improvement Plan aims to a) promote early recognition of suspicious symptoms and encourage early access to healthcare, campaign to support the engagement of local “cancer champions” with adults b) reinforce and disseminate the information related to early signs of gynaecological cancers available in different languages c) run focus groups and patients’ satisfaction questionnaires to drive patient experience improvement d) clinical psychologist role to be developed on every care site and part of the routine multidisciplinary care e) oncology follow-up to be followed virtual/face-to-face follow-up, guided by the McMillan nurses f) evaluate services for accessible effective and timely diagnostic services g) repatriate the SLA for services for the Bridgend population to ensure an improved quality and equitable waiting times⁹.



Consultation%20on%
20Gynaecological%20

d. Cancer treatments, including innovative treatments and clinical trials

Patients across CTM are offered opportunities to participate in research, and to receive innovative treatments, much of which are undertaken at the cancer centre in Velindre. However, we recognise that our uptake of the offer of research trials is low, and as with other aspects of care, the levels of deprivation are closely linked to willingness or ability to participate. Barriers are likely to be similar to other aspects of care, including geography and travel, literacy and understanding, cultural beliefs and values, to name a few¹⁰.

3. How can deprivation affect the way patients experience cancer services in Wales?

Socio-economic deprivation can result in the following:

- low perceived candidacy to receive healthcare,
- competing life priorities, mean that health may not be a long-term priority for individuals
- exposure to poor cancer outcomes in people’s social networks and local communities may lead to a perpetuating cycle of fatalistic beliefs about cancer

⁸ Cancer team 2022 Prince Charles Hospital and Royal Glamorgan Hospital, 2021-2022 Cwm Taf Morgannwg University Health Board

⁹ Prof Margarit L et al 2022 Health and Social Care Committee Consultation on Gynaecological cancers - December 2022, Cwm Taf Morgannwg University Health Board

¹⁰ Forrester-Paton C 2023 Cancer Clinical Lead, January 2023, Cwm Taf Morgannwg University Health Board

- low symptom awareness
- symptom misattribution (especially for vague symptoms such as unexplained weight loss and persistent tiredness)
- confounding with co-morbid conditions may deter help-seeking⁶.

4. What are the barriers to tackling cancer inequalities in Wales?

- **Cancer awareness initiatives** risk being fragmented, with no or very limited short-term evaluation. This may in part reflect devolved healthcare and issues with sustained funding. A coordinated, top-down approach is needed with robust evaluation of downstream behavioural interventions at multiple levels (individual/provider, community/organisation, wider system). Consideration of inequalities is needed throughout all stages of intervention - from co-design, through to implementation, evaluation and dissemination of results. Additional research, including in large scale data analysis through SAIL, and linked genomic resources is a necessary, and pre-malignant conditions where patients are at higher risk of developing a gynaecological cancer (e.g. endometriosis) should be considered⁹.
- **Understanding of the varying needs and lived experience of populations and sub-populations.**
- **Design and delivery of services across the cancer pathway appropriate to need**
- **Equitable support from cancer charities across geographies and within population groups**

5. What impact has the following had on access to cancer services for different groups:

a. COVID-19 pandemic

Response- COVID-19

The COVID-19 pandemic required a shift in the focus of especially health services to prevention and treatment of COVID-19 cases, hospitalisation and deaths. Normal services in other professions were equally and similarly affected, curtailed or temporarily adapted or stopped in adherence to national guidance. This meant:

- general reduction in availability of and access to GP appointments
- individuals who were immunocompromised or vulnerable were shielding and not presenting with symptoms
- delayed diagnosis
- reduced capacity in diagnostic and treatment services
- delays in seeking a doctor/specialist's opinion.

Early in the pandemic (Summer 2020) interviewees of a screening survey were acutely aware of the strain on the NHS and did not feel worthy of using healthcare resources during this time to treat or investigate their symptoms. As the pandemic progressed, participants expressed a growing frustration that cancer screening and treatment services were being left behind with ever increasing backlogs and waiting lists. Regarding cancer screening, Cancer Attitudes and Behaviours study results showed that almost 1 in 5 participants were less likely to engage in cervical or bowel cancer screening compared to before the pandemic. When discussing concerns about engaging with screening during the pandemic, interviewees described fear of attending healthcare settings (cervical screening only) due to increased risk of COVID-19 infection and uncertainty about how to adhere to social distancing rules.

Worries about wasting the doctor's time, putting strain on healthcare services and not wanting to make a fuss, reluctance to contact the GP due to concerns about COVID-19 and fear of attending hospitals, and described putting their health concerns on hold⁶.

b. Cost of living crisis

Response- Cost of living crisis

Cost of living crisis could mean-

- Not being able to afford healthier diets, particularly for children, can have long-term health and well-being consequences. For example, poor diet in childhood is associated with an increased risk of obesity over the life-course
- Cost and availability of transport is an existing barrier for some people to access services, including health and care. Missing or delaying medical appointments has negative consequences for health and well-being
- Reducing spending on transport can result in people facing social isolation or having to miss important medical appointments¹¹.



221014 Cost of living
- a public health issue

6. What work do you know is happening across Wales to tackle inequalities in cancer care?

Response- Tackling inequalities in cancer

- 1) **CTM Reducing Cancer Inequalities Group Meeting** purpose is to oversee and co-ordinate activity to improve population health outcomes from cancer and reduce inequalities across CTM.



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Some of RCI's actions include:

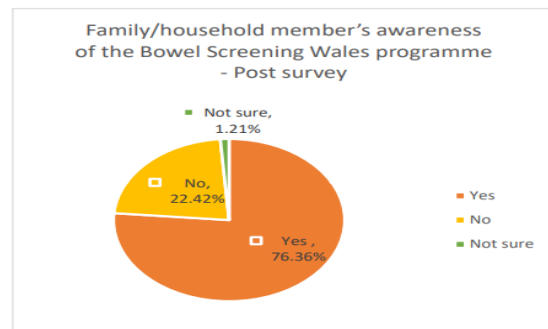
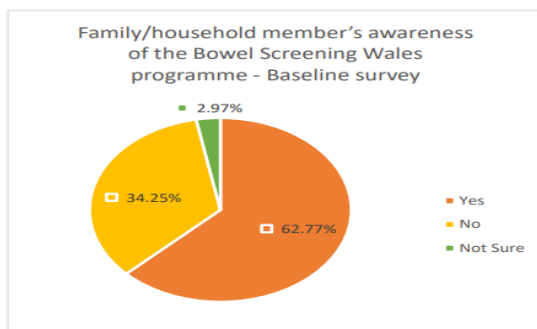
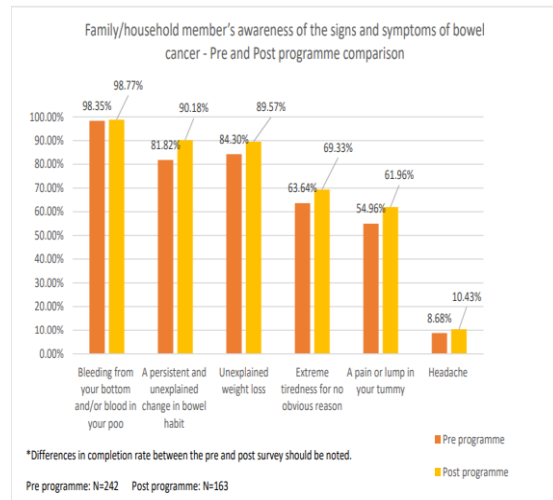
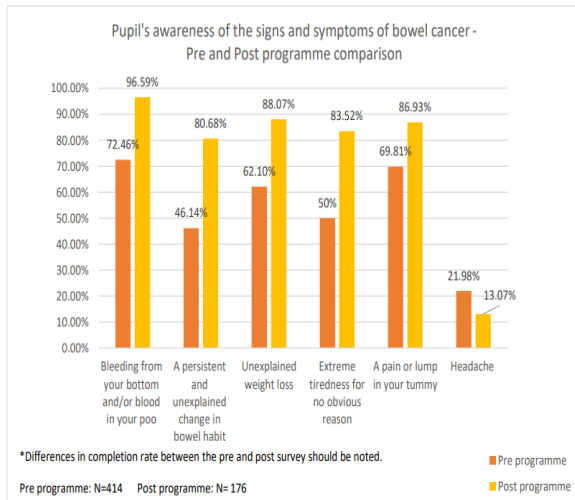
- a report clarifying the **cancer pathway** to support partners in early identification



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- **Co-ordination of the partner agencies** involved in raising awareness of e.g. Bowel cancer. For instance, the Moondance funded pilot delivered in Taf Ely Secondary Schools strengthened partnerships and had a positive impact on knowledge and awareness of bowel cancer symptoms and the screening test. Children participating developed a better understanding of health-harming behaviours that can increase the likelihood of developing bowel cancer and had a better understanding of the symptoms of bowel cancer. The adults within each school community had increased awareness of (early signs of bowel cancer) and bowel screening in the community (family/ households).

¹¹ Roberts M et al 2022 Cost of living crisis in Wales. A public health lens. Public Health Wales



There has been an increase in screening test kit requests by up to 73% in those areas around the six schools during the delivery of the programme in comparison to the same time the previous year.

Replacement Kits Requested Oct 2020 to Feb 2021

Taf Ely		
40	Requested Replacement Kits	
28	Negative	Results of Replacement Kit
2	Positive	
3	Spoilt	
7	Not Return	

Neighbouring Cluster Pair		
59	Requested Replacement Kits	
40	Negative	Results of Replacement Kit
1	Positive	
5	Spoilt	
13	Not Return	

Non-Neighbouring Cluster Pair		
50	Requested Replacement Kits	
34	Negative	Results of Replacement Kit
0	Positive	
2	Spoilt	
14	Not Return	

Replacement Kits Requested Oct 2021 to Feb 2022

Taf Ely		
86	Requested Replacement Kits	
52	Negative	Results of Replacement Kit
0	Positive	
3	Spoilt	
31	Not Return	

% increase = 115%

Neighbouring Cluster Pair		
72	Requested Replacement Kits	
48	Negative	Results of Replacement Kit
1	Positive	
3	Spoilt	
20	Not Return	

% increase = 22%

Non-Neighbouring Cluster Pair		
64	Requested Replacement Kits	
41	Negative	Results of Replacement Kit
2	Positive	
3	Spoilt	
18	Not Return	

% increase = 28%

The pilot has demonstrated that communicating key health messages to children in a school setting provides a pathway for communicating health messages to the wider community which can be further enhanced by parallel community based activity. The health and education partnership created by Moondance has potential to be up-scaled to benefit the wider population of CTM and Wales. It also provides a template to address other areas of health inequalities such as obesity and health literacy.



Moondance School and Community Learn

- **Coalfields Regeneration** – This proposal focuses on areas within CTM HB, in response to where the highest concentration of cancer incidence and deprivation is across Wales. It aims to address capacity building and scaling up activities through a co-production approach to positively impact health inequalities and prosperity for those affected by cancer. Outcomes include increased reach into communities with the greatest support needs through asset-based community development. This would increase early intervention and place-based support, leading to improved quality of life through personalised care and increased self-management capability. Additional benefits include improved awareness and access to other agencies and partner



Coalfields%20Progra
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services (such as housing and financial inclusion services).

- **Bowel Cancer UK**, a partner member of RCI have delivered free 30 minute bowel cancer awareness presentations in the region, delivered by volunteers with an experience of bowel cancer including 4 talks to 76 people in CTM, 22 talks to a total of 429 people across Wales in 2022. Some of these talks were online and available to people nationwide including some CTM residents. Orders from 14 Community Pharmacies for the free community pharmacy toolkit to help raise awareness have been supported.
- **GP endorsement letter** – RCI coordination lead for local communications for GP endorsement letters for Bowel Screening with input from Bowel Screening Wales and Screening & Inequalities Group, working with primary care clinical lead partner and CTM Primary Care Communications
- **Targeted Intensive Community-based campaign To Optimise Cancer awareness (TIC TOC)** a cancer awareness campaign was developed to encourage people living in CTM to visit their doctor with the lesser-known vague cancer symptoms (e.g. unexplained weight loss and tiredness). It combines messages about symptoms, action to take if symptom observed and why importance of early doctor consultation. Messages shared with the public through targeted adverts (e.g. on pharmacy bags, buses, and Facebook) and with local cancer champions who have been specially trained to help support people to visit their doctor with possible cancer



Summary report for
TIC-TOC intervention i
symptoms

- 2) **Public Health Wales (PHW) Screening and Inequalities Group** - chaired by consultant in public health, PHW, the meeting covers messaging for HBs re bowel screening endorsement by GPs, support for Seldom Heard Groups and Other Population Sectors, Equity Action Plan and next steps

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

- Upscale successful interventions and promote good practice
- Use data and equity audits to inform service planning and delivery
- Equitable access to rapid diagnostics
- Health and care organisations should ensure that financial well-being advice and support services are easily accessible to staff¹¹.
- Ambition of 3 in 4 cancers diagnosed early by 2028 will require sustained, multidisciplinary effort
- Interventions to increase equitable access require further development and evaluation
- New cancer early detection technologies such as multi-cancer early diagnostic tests (MCEDs) require careful evaluation to avoid widening cancer inequalities

- Lung Health Check programme requires careful planning and evaluation of the service to ensure equitable, informed participation of high-risk groups for whom there is existing and emerging evidence of inequalities, as well as optimal methods of integrating smoking cessation support contributing to Smokefree Wales by 2030⁶.
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Contributors

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