



## Response to the Anti Racist Wales Action Plan Inquiry

October 2023

Tenovus Cancer Care is a Wales-based charity giving help, hope, and a voice to everyone affected by cancer. Our services offer information, advice, and specialist support to people living with cancer, and their loved ones.

We are committed to listening to the real experiences of people affected by cancer in Wales to drive the changes that make a difference.

We understand how cancer can impact every aspect of life and how it affects families and friends too.

Our advocacy work plays a critical role in getting the right care and support for everyone. It is informed by Wales-specific cancer data, the services we offer, and the real experiences of people affected by cancer.

Tenovus Cancer Care is here for everyone affected by any type of cancer. We prioritise and focus our campaigning and policy activity on those areas we believe we can have the most impact – including in this instance, the inquiry into the Anti Racist Wales Action Plan being conducted by the Senedd's Social Justice and Equality Committee.

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Tenovus Cancer Care welcomes the inquiry. Given the nature of our work in Wales, our comments relate to the section of the Anti Racist Wales Action Plan covering Health, and in particular ethnicity, data and health inequalities (encompassed within Health priority action 5)<sup>1</sup>.

We encourage the Committee to scrutinise the pace of setting up the NHS Health Inequalities working group and its effectiveness in identifying barriers to tackling health inequalities. It has taken our persistence, on behalf of BAME people with cancer to put the collection of ethnicity data by NHS Wales – a significant, system-wide, omission - on the working group's agenda.

Equality in access to healthcare is something we are passionate about at Tenovus Cancer Care. So last year, when Cancer Research UK data covering England revealed

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<sup>1</sup> <https://www.gov.wales/sites/default/files/pdf-versions/2022/7/3/1658919769/anti-racist-wales-action-plan-contents.pdf> (page 130)

that ethnicity can impact on many different stages of a person's cancer journey, we wanted to understand the situation in Wales.

The English data found that for most cancer types, cancer incidence was lower amongst non-white minority ethnic groups<sup>2</sup>. However, another paper highlighted<sup>3</sup> that being from a minority ethnic group would make it more likely that diagnosis of a number of cancer types happened at a later stage. That paper concluded that this was due to a wide range of reasons, including lower screening uptake and poor symptom awareness. Our insight and evidence team decided to investigate whether ethnicity has an impact on the stage of diagnosis in Wales. After all, if ethnicity has an impact on the stage of diagnosis in Wales, NHS decision makers and managers would be able to start planning interventions to attempt to close the gap.

As is the case for many charities, Tenovus Cancer Care is entirely dependent on publicly available data, and in this instance our colleagues searched for ethnicity data sets we could apply to this issue. We were unable to find any.

We made Freedom of Information (Fol) requests to the 7 Health Boards to help us better understand what ethnicity data is available for cancer patients. From the Fol requests we made we discovered that one health board is collecting ethnicity data for as little as 15% of its cancer patients. The highest was at 55%. Information from Cancer Research UK states that in 2017 ethnicity data was captured for about 94% of cancer patients in England<sup>4</sup>.

Tenovus Cancer Care brought this issue to the attention of the Minister for Health and Social Services in March 2023 (Appendix 1). The Minister responded in the following month that she was directing Digital Health and Care Wales to examine the issue.

Follow up correspondence arrived in June 2023 (Appendix 2). The Minister informed us:

“I am advised that by reviewing the ethnicity data on the cancer data set, it does show that the capture and reporting of ethnicity is an issue as you have indicated. On average across Wales 50% of the records have no ethnicity recorded. It is therefore acknowledged that this is an important issue and wider than cancer records.”

“I have asked our Digital Director and our Equalities team to review how best we can develop our national policy on this and implement this as a priority action.”

The issue will now be raised at the new NHS Health Inequalities Group that is tasked “to maximise the impact the NHS in Wales in tackling health inequalities in Wales”. Within the Group's terms of reference, the top priority is “a) Reviewing data sets and taking action to respond to gaps.”

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<sup>2</sup> Delton C et al. Differences in cancer incidence by broad ethnic group in England 2013–2017. *British Journal of Cancer* (2022); 126:1765–1773; <https://doi.org/10.1038/s41416-022-01718-5>

<sup>3</sup> Fry A, et al. Relationship between ethnicity and stage at diagnosis in England: a national analysis of six cancer sites. *BMJ Open* (2023); 13:e062079. <https://bmjopen.bmj.com/content/13/1/e062079>

<sup>4</sup> Delton C et al. *British Journal of Cancer* (2022); Differences in cancer incidence by broad ethnic group in England 2013–2017. 126:1765–1773; <https://doi.org/10.1038/s41416-022-01718-5>

While we welcome recognition of the problem and a commitment to rectify the issue, we question why it has taken the persistence of a relatively small cancer charity for this to happen? Why was it not picked up by the NHS Health Inequalities Group earlier, since the issue of accurate ethnicity data within the NHS seems of critical importance to the health and care system in Wales as data becomes an increasing determinant of planning fundamental to its remit.

We believe that NHS Wales must prioritise and rectify the issue, drawing upon the experience and best practice developed by NHS England. We hope that the Social Justice and Equality Committee shares this objective and uses this case study to scrutinise this area of Welsh Government work.

We also believe that the Welsh Government must set delivery targets for capturing ethnicity data at the most appropriate point of a person's cancer journey, with performance matching or exceeding NHS England. This could be part of future anti racism action plans, and we would welcome any consideration by the Committee.

NHS Wales staff must be supported to ensure they have the training and confidence to capture ethnicity data, and to respond to enquiries from members of the public concerning the need for and use of the information. This would align with the health workforce priority action within the current anti racism action plan.

We also feel strongly that Welsh BAME people, representing communities from across Wales, must be included and involved in the development and delivery of the activities addressing the issue of ethnicity data. Co-production is an important principle of critical importance to any new national policy and associated activity delivering the policy goals. We hope to meet with the Welsh Government's health Digital Director and if a meeting does occur, we will be making this point.

We remain concerned that if this issue is allowed to stagnate, people with cancer from BAME communities from across Wales will be underserved and health inequalities allowed to persist. We would welcome an opportunity to discuss these issues with the Social Justice and Equality Committee should the opportunity arise during this inquiry.



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Eluned Morgan MS  
Minister for Health and Social Services  
Welsh Government  
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17 March 2023  
Our Ref: BAMEData/MinHSS/01  
Your Ref:

Dear Eluned

**Re: Capturing BAME data on the new cancer informatics solution**

Thank you for taking the time out of your busy schedule to speak to Tenovus Cancer Care at our recent Welsh Labour Conference stand, giving us the opportunity to raise concerns we have regarding the collection of BAME characteristics of Welsh patients within the new cancer informatics solution. We wish to follow up that conversation with this letter and welcome your thoughts.

We understand that the BAME protected characteristics of Welsh patients with a cancer diagnosis are not being captured and recorded in a systematic way on the new cancer informatics solution alongside other personal details such as home address, sex and age. We have made enquiries and only around 10% of Welsh BAME patients with a cancer diagnosis are currently having their ethnicity captured, while in England the figure is 92% and there is a clear understanding and rationale for the remaining 8% - this is largely down to this cohort being admitted as an emergency.

We have verified this situation with colleagues working within the NHS and we have been informed that whilst capturing this data is aspirational it is not on the current priority list given the challenges of switching the system over. Whilst we understand that a huge amount of work has gone into developing and integrating the system and this process is far from complete.

It is the perfect opportunity to examine and act on the issue of data capture now since it may become more challenging to act retrospectively. We would welcome you and your officials taking this opportunity to explore the rationale for not prioritising BAME data capture. Given the insight we are increasingly being presented with BAME communities do much worse than their white counterparts across many health areas, including cancer.

Census 2021 data published in November last year<sup>1</sup> demonstrates an increase in the number of BAME people in Wales. Problems associated with healthcare inequalities based on ethnicity could also be

<sup>1</sup> StatsWales. (2022) Ethnic group, national identity, language and religion in Wales (Census 2021). <https://www.gov.wales/ethnic-group-national-identity-language-and-religion-wales-census-2021.html>

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increasing unless we start capturing data to recognise these problems now. We cannot fix what we do not understand.

Being unable to interrogate the cancer data of BAME communities within Wales means we will be compromised in our ability to fully understand and act upon equitable access to cancer services throughout the pathway with an eye on improving cancer outcomes.

A copy of this letter has also been sent to the Minister for Social Justice since responsibility for equalities and human rights falls within her portfolio.

We look forward to your response and hope this situation is resolved and the capturing of BAME data is prioritised.

Yours sincerely

**Judi Rhys MBE**  
**Chief Executive**  
**Tenovus Cancer Care**

cc.  
Jane Hutt MS, Minister for Social Justice

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## Appendix 2

**Eluned Morgan AS/MS**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref BAMEData/MinHSS/01  
Ein cyf/Our ref EM/00968/23

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19 June 2023

Dear Judi,

Further to my letter of 17 April, I am now able to provide a more substantive reply and apologise that it has taken longer than I had hoped to be able to do so.

I am advised that by reviewing the ethnicity data on the cancer data set, it does show that the capture and reporting of ethnicity is an issue as you have indicated. On average across Wales 50% of the records have no ethnicity recorded. It is therefore acknowledged that this is an important issue and wider than cancer records.

An NHS Health Inequalities Group has been established to maximise the impact of the NHS in Wales in tackling health inequalities. Health inequality experienced by Black, Asian and Minority ethnic patients is a core area of focus for this group. The group is currently conducting a gap analysis to identify what data currently exists and could be used to inform action on health inequalities.

I have asked our Digital Director and our Equalities team to review how best we can develop our national policy on this and implement this as a priority action.

I will write to you again when we have made some progress.

Yours sincerely,

**Eluned Morgan AS/MS**  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.