

**P-06-1294 Don't leave metastatic breast cancer patients in Wales behind –
Correspondence from the Petitioner to the Committee, 03 November 2022**

Dear Jack and committee members,

I would like to start this letter with the biggest heartfelt thank you for the work and representation you have given so far on behalf of metastatic breast cancer (MBC) patients. Unfortunately, the health minister's response in both the letter and speech failed to address the key issues which were presented from the petition and open letter.

My concern is the information which was presented in the health ministers' response is not in line with the standards of care we are calling for. Quite simply her expectations of MBC patients receiving support and a satisfactory standard of care from a multi-disciplinary team are just not being met. The [national optimised pathways](#) highlighted in her letter do not include MBC, but only a pathway for primary breast cancer. I call into question how these expectations can be measured when there is no existing MBC pathway? Who is accountable for this pathway not existing?

The health minister highlighted in her speech that the Welsh Cancer Network will be reviewing MBC services and will consider a series of recommendations. What are these recommendations? how will they lead to better patient care? How will the success of this be measured? How and in what time frame will this be implemented?

The health minister's speech also stated there are specialist nursing roles being introduced in a South West Wales cancer centre and in a North Wales cancer centre. However, these nurses are not the same as the dedicated MBC nurses which we are calling for. These roles need to be in accordance with the [NICE guidelines](#), be patient led and focus just on the unique issues brought forward from the [leading cause of death in women 35-64](#) in the UK. It needs to be recognised that the holistic needs and support of these individuals require a solely dedicated nurse for MBC. The nurses referenced in the health minister's speech currently look after other groups of patients and fulfil different roles. What evidence is there that patients are having all their holistic needs addressed and how do they feel supported? 277 MBC patients and care givers in Wales have signed our [open letter](#) which agrees they are not receiving this care and desperately need it.

The health ministers speech referenced the promised audit on MBC patients will start “next year” in 2023. [In 2021 it was promised it would have been started in 2022](#), who is accountable that this has not yet happened? I fear this will be another empty promise, as Data collection was mandated in 2012 and promises were made to rectify this in 2019. What is the Welsh Government going to do to ensure this audit starts while patients continue to die? Furthermore, the £11 million investment in a new cancer information system is welcomed, but can the health minister confirm data analyst roles will be included? If not, who will extract the data we need from the new system and who will be responsible to ensure the information is recorded?

Finally, I would like to address the health minister's encouragement to remind people they have the power to help prevent breast cancer through living a healthy life and through screening. Younger women are increasingly being diagnosed with Breast Cancer and MBC remains to be the leading cause of death in women 35-64 despite these women leading normal lives. Additionally, over half of this age group

are too young to qualify for screening according to the national screening guidelines. The public response from this statement has been one of absolute devastation and leaves questions on the clarity of the health ministers' level of understanding of the facts from patients and health professionals alike.

The patients and health professionals of Wales need to have faith that the Welsh government can grasp and address the differences between primary and metastatic breast cancer. How can you as a committee members take this further? And what can we do to move forward and restore our faith in this system.

Yours sincerely,

Tassia Haines