

P-06-1294 Dont leave metastatic breast cancer patients in Wales behind, Correspondence – Petitioner to Committee, 04.12.23

Dear Jack and committee members,

Firstly, thank you to Jack Sargent for applying pressure for me to meet with the Health Minister. I am pleased to report it was a positive interaction and her support for the points raised have massively aided our work moving forward and I sincerely hope the engagement will continue. Also, thank you to the committee team members for the continued support for improving metastatic breast cancer (MBC) In Wales. After 6 months since the petition was discussed, we have managed to make many strides forward. However, we are still disappointed with the lack of transparency, urgency and collaboration from the Welsh Executive.

On September 19th we hosted an awareness 'launch' event for patients and Senedd members. We promoted the MBC 'Red flag' infographics for use in Welsh and English and launched Wales's first MBC pathway, which included an end of treatment (EoT) summary, including the infographics for increased awareness of the risk of MBC. There was a delay in approving the MBC pathway from the Cancer board and it was due to be approved on November 24th, but we are yet to hear of the outcomes. The Wales Executive website does not include the meeting minutes which lead to the pathway rejection on September 12th, nor does it include the new pathway or meeting minutes from November 24th. How can we empower patient voices when we do not have the information readily available? What can the Government do to ensure better transparency from the Cancer board and achieve the outcomes from these meetings?

Over the past few months, I have had the privilege to meet with a few cancer board members and I am extremely disturbed by the lack of communication and consistency within the group. For example, I met with Bethan Hawke (Lead nurse for patient experience and engagement) on November 22nd and was advised the best way to get the EoT implemented was to go through the Cancer Site Group (CSG). As far as I am aware the EoT summary had already been signed off by the CSG on July 12th as part of the MBC pathway which I believe Bethan was working on. How are members of the Cancer board unaware of such important information? Patients are concerned how the EoT and MBC symptom infographics will be implemented within the NHS when top level executives are unaware of them, despite our tireless awareness efforts. Communication is just one of the reasons patients share a lack of trust of the system. What can the petitions committee do to ensure the knowledge within the Cancer board is consistent and they are all adequately informed?

Additionally, the Health Minister shared our excitement for the 28-day target within the pathway from point of suspicion (PoS) to start of treatment in our meeting. Unfortunately, Professor Tom Crosby announced during the patient lead MBC conference that the Cancer board had removed the number of target days from PoS from the MBC pathway so 'they' would approve it (After the CSG had approved it with the 28 day target). I was led to believe the Cancer board are answerable to the Welsh Government. Which leads to my next question, who are the 'they' the board members are referring to for approval? And when will the target number of days return to the pathway if it was approved? There needs to be a target, as it stands this reaffirms to us patients that our lives still do not matter.

The Health Minister shares our sentiment for allowing third sector support for SBC CNS's access to every patient, as does Bethan. Bethan confirmed they will work with Marguerite Holloway (Head of

MBC Wales MacMillan) to approach lead nurses with the case for 3rd sector support within their Health Boards to allow MBC patients access to a dedicated SBC CNS. What can the government do to ensure these meetings will take place urgently?

There is growing concern as the post for overseeing the national audit in Wales remains unfilled since the departure of Marianne Dillon at least 3 months ago. The lack of urgency to fill this position is extremely concerning as Wales has nobody to represent us on the board of the audit from the Royal College of Surgeons, overseeing the data collection for MBC patients. How can the government ensure this role will be filled as a matter of urgency as the mandate for data collection on MBC patients has been failed to be met for many years now? Without a lead, we will not achieve this, and this shows we are moving backwards on progression with data. Furthermore, what evidence do we have that the implementation of the 'new CaNISC' has been proven more effective for data collection thus far?

As petitioner, I am willing to expand on any points raised from my experience over the last 6 months to any representative from the health and social team. As reported, there is a clear communication blockage between the patients and government which is slowing down progress. I hope the petitions committee will be able to continue to aid us in seeking the answers to the points above. I would like to politely enquire if we can expect to have some of the answers above by January 2024? On the day-to-day experience from the patient there has still been little tangible change for us, and we are running out of time. Please help us.

Yours sincerely, Tassia Haines