

Diolch am barhau i roi'r wybodaeth ddiweddaraf i mi am yr adroddiad, rwy'n ei werthfawrogi'n fawr.

Rwy'n ymateb heddiw ar beth fyddai pen-blwydd Mam yn 58 oed. Mae'r negeseuon caredig, negeseuon ar-lein er ei chof a'r blodau hyfryd wrth ei bedd yn dyst i ba mor ddwfn y caiff ei cholli.

Er fy mod yn falch o ddarllen i ddechrau bod y rhan fwyaf o'r argymhellion wedi'u derbyn gan Lywodraeth Cymru, mae gennyf rai sylwadau a heriau a allai fod yn werth eu codi yn y ddadl ar y 15fed o Fai.

Rwyf wedi nodi nhw isod mewn pwyntiau ar wahân yn Saesneg.

Thank you for continuing to keep me updated on the report, I very much appreciate it.

I am responding today on what would have been Mam's 58<sup>th</sup> birthday. The kind messages, online posts in remembrance and the vibrant burst of flowers at her grave a testament to how deeply she is missed.

Although I was initially glad to read that most of the recommendations were accepted by the Welsh Government, I do have some comments and I suppose challenges with regards to their response which may be worth raising at the debate on the 15<sup>th</sup> of May.

I have noted them below in separate points for ease.

### **Claim that the vast majority of patients report high level of satisfaction**

One of the things that stuck with me after reading the response was the claim *that "...the vast majority of those receiving cancer care for gynaecological cancer consistently report high levels of patient satisfaction with the NHS."* Who are these people and what is the methodology of collating this data which results in this claim?

The reason I ask is because I find it hard to believe that many of those who feel let down by the service would have had the opportunity to fill out a survey or contribute to such feedback collation or were in fact physically or mentally able to do so. Unfortunately for some, the realisation that there is no longer any hope of treatment means that they have more important things to be thinking about or, like my mother, became too gravely ill to be able to participate. Although I know she would have given it her all if she had an opportunity that she felt could better the future for others. She did indeed have an opportunity to share with her consultants that she felt let down in an in person meeting, however I doubt that this was logged anywhere in order to contribute to the 'customer service' insight quoted.

For those who were unable to speak for themselves, were their families consulted on to obtain feedback for improvement? Often the families bare a heavy weight when supporting loved ones with Cancer. They see their loved ones in agony, fighting or managing not only the cancer but the everything that comes with it. They run around between countless services, coordinating the GP surgeries, numerous pharmacies (because no one has the drugs in stock when you need them) in desperate hope to obtain the required meds that you are constantly chasing, stressed that if you can't find any you will run out and your loved one will suffer even more. Everything feels difficult because you feel that the services work in silos, don't communicate with each other effectively and it's up to you as a family member to understand what the patient needs and to pull all the services together and repeat the same story several times just to get simple help.

We as a family are fortunate in the fact that we are a close unit who had some grit and drive to run around and try to ensure that we could get things in place, but I still today worry about those who are in the same position as Mam who do not have a family as wonderful as ours to support them. I worry about those who are elderly, aren't mobile or have no family support... I worry to fall ill myself one day due to the failings I witnessed while watching Mam fight her battle... I worry for my own daughter one day.

Lastly on this point I would just like to comment that if you are going through active treatment, then you may think twice before speaking negatively about a service that you are depending on to keep you alive, so I ask the Government how useful is their insight referenced really? By making this claim at the start of the response, they set the tone for the rest of the report to be one which is quite dismissive of there being any issues.

### **Acceptances out of date**

As I have mentioned at the start of my response, I was initially quite pleased to see that the Government had accepted most of the points. This was because I scanned the document looking for the acceptances, this may well be what the Government would hope that most other people do also. I am sure they will be hanging their hat on the fact in any debate that they have accepted the vast majority of recommendations. However, having dwelled upon some of the information the acceptances seem very hollow in their promises.

Firstly, the responses to most of the acceptances are full of jargon that I have no hope of understanding unless I invest most of my time in unpicking and reading other reports and references (that's if I can get hold of them), which I can't. Again, maybe this is what the Government hopes for, that people don't continue to dig that far.

Secondly, some of the responses state that they are already doing what has been recommended. However, the actions that have been committed to or are being done predate the report and so what assurances do we have that what they are doing is still good enough.

### **Recommendation 2.**

Accepted in part because they are already doing it? What they say they are doing predates the report and so how do they know what they are doing is enough, they could be failing at the get go.

### **Recommendation 3.**

This information should be available to the public and can be obtained via an FOI. Regardless of whether they are in the process of changing things. They should show what is currently in place if it's been asked.

### **Recommendation 5.**

Accepted but Objectives or KPIs have not been shared or linked to elsewhere.

### **Recommendation 14.**

Where GPs have failed to refer people who presented to them with potential symptoms, has it been identified what symptoms these were or what the patients' demographics were in case there are assumptions or unconscious bias at play that need to be remedied? For example, a 30 year old woman presenting with abdominal pain and welling being diagnosed with IBS because the likelihood of cancer is lower?

### **Recommendation 15.**

Rejected on the basis that there is "...insufficient resource available to undertake a formal review of this matter within the timeframe requested".

Can the Government not commit to a time frame? Much of this information should be available to the public and can be obtained through FOI requests. Even if what's asked in total here takes longer than the 24 hours where an FOI request can be rejected, then it can be acquired in smaller sections of information by the public.

**Recommendation 20.**

When was this done? Was it done as a result of this report? What exactly has been added, is it sufficient?

**Recommendation 21.**

Can the data sources be cited so we can see them please?

If you have any questions or need any clarification on my points, then please do not hesitate in contacting me.

Kind regards,

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