

National Assembly for Wales

[Health and Social Care Committee](#)

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from Annie Mulholland - CDP 38

Annie Mulholland

I am grateful for the opportunity to comment on the implementation of the Welsh Government's Cancer Delivery Plan and to provide evidence and a response from a patient's perspective.

I was diagnosed with advanced and incurable ovarian cancer in March 2011. I presented few symptoms of ovarian cancer but despite this the GP considered there was an urgent need for a referral and this would be dependent upon an ultrasound examination. I was told by my GP that diagnostic screening by the NHS could take up to 12 weeks and he asked whether I wished to have a scan at the Spire Private Hospital. I opted for a private test which I had the following day and my GP was then able to refer me to a gynecologist whom I saw some 10 days later. The process from first GP consultation to diagnosis and surgery took 8 weeks rather than up to 18 weeks had I relied on NHS Wales for early diagnostic testing.

My GP was extremely thorough and I was treated with great care and professionalism by all staff at Llandough Hospital and the Velindre Cancer Centre where I received my initial chemotherapy treatment.

Sadly my experience at the Velindre Cancer Centre was not entirely positive and I believe this is due to the current funding model that requires the cancer centre to go cap-in-hand to a patient's health board to obtain drugs, second opinions and referrals to clinical trials. This creates an unfair and bureaucratic health service. By casual observation I concluded unreasonable demands were made on front-line staff and this puts them under stress and ultimately puts patients at risk.

In May 2011 I was referred to an oncologist who was just about to commence maternity leave. Consultations for the first three months of my treatment were provided by an oncologist who was not a gynae specialist, which I believe is a requirement by NICE, but an abdominal specialist. At the end of her term as a locum the consultation I received was provided by a number of staff including a pharmacist and a clinical specialist nurse. I found it very distressing, as they were not qualified to answer some of my questions or provide appropriate advice during the consultation.

For some reason I did not receive the correct prescription of chemotherapy. The locum consultant said there had been an 'admin error' and by the time this was

realised I was told I would not be able to have dual-agent chemotherapy which is the gold standard recommended by NICE. I had started single agent chemotherapy and was to add the second agent at the third cycle. I was told at this stage that there was no available provision to receive the second agent until August of that year. In hindsight I believe the Velindre should have made provision for me to receive the prescribed drugs.

I received thorough follow-up visits over a two-year period following chemotherapy but I noted that my own consultant was under pressure because she had been required to take on patients from a colleague who was by then on maternity leave. This has long been a concern, not only because I was worried for the wellbeing of my consultant, who quite frankly looked ill on occasions, but equally for the risk of errors that might affect the patients' wellbeing.

It was in May 2013 that I heard about a drug that was available elsewhere in Wales and in England. The IPRF system is deeply flawed because there are no clear criteria as to which patients qualify for exceptional drugs and the health boards have the ability to interpret the loose guidelines provided by the Welsh Government as they see fit. This results in a grossly unfair system whereby patients in the same hospital don't have access to the same range of drugs and the oncologists are put in the unacceptable position of providing contradictory advice to patients because it is based on the funding constrictions of their health board rather than what would be good for them.

I asked some very direct questions of my oncologist and clearly put her in a very difficult situation. I asked why the drug Avastin had not been discussed after diagnosis and why it had not been considered at first relapse. I have only discovered at a meeting at the Welsh Assembly Offices last month that my health board, Cardiff and the Vale, is very unlikely to fund exceptional cancer drugs whereas had I lived in Neath I would have been guaranteed Avastin. Access to these drugs is haphazard across the whole of Wales and has been described by the current Minister of Health as a 'postcode lottery'. The Chief Medical Officer, Dr Ruth Hussey announced on a TV documentary about Avastin that 'she was sorry'. However, these drugs have a direct influence on how long a patient will live and their quality of life and I don't think it's acceptable to just be sorry and to perpetuate a deeply flawed system hoping that the patients won't notice. I don't necessarily think the Welsh Government should need to resort to additional taxation to fund its NHS but rather it should prioritize its spending. The news recently that the Government had spent £52M on a failing airport valued at £34M, which they must now maintain, must be beyond the belief of any cancer patient who has been refused treatment or drugs that would maintain their wellbeing and keep them alive.

My oncologist acknowledged that I was medically suitable for the drug Avastin. I'd heard of a clinical trial which would have funded the cost of the drug alongside chemotherapy, medical care and a contribution towards my travel costs. To my astonishment my health board refused to endorse the recommendation even though it would surely have been a saving for them as the cost of my care over a 2-year period would have been covered by the trial and not the board.

I find it difficult to describe the distress I suffered when I realised I lived in the wrong postcode in Wales, that the 5-year cancer survival rates in Wales were poorer than other parts of the UK, and then I received the final blow of a senseless refusal to allow me to participate in a clinical trial.

For the sake of my psychological wellbeing I felt I had no option but to move to England to access better care and hopefully enjoy a longer life span. I then realised that I wouldn't have to move. I would just need to identify a 'primary address' in England which I have done and I have now just completed my second line of chemotherapy along with Avastin which I would not have received had my treatment continued in Wales. I will continue the course of Avastin for as long as it is doing some good. I'm aware of many other cancer patients who have either moved from Wales or have obtained addresses in England to access better care. Having a 178 mile border with England and good transport links from east to west makes this feasible for many Welsh patients even though it is not desirable.

I am bitterly disappointed as a member of the electorate that Wales now has 5-year cancer survival rates at a par with the worst and least developed countries of the European Union. This is deplorable given one of the former Health Ministers, Edwina Hart, promised the electorate in 2008 that by the year 2015 Wales would have 5-year cancer survival rates commensurate with the best in Europe. This would have required some direct interventions such as Cancer Awareness-Raising Schemes, GP Training, investment in diagnostic screening, development of radical surgical techniques, along with access to treatment and drugs that are available in the best centres in Europe. It would also be reasonable to make provision for patients with rarer cancers who wish to access specialist services the option of travelling to a centre of excellence even if it is outside Wales.