Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar **Canserau gynaecolegol**

This response was submitted to the Health and Social Care Committee consultation on Gynaecological Cancers

GC 17 Ymateb gan: | Response from: Sadie Jones, Canolfan Ymchwil

Canser | Sadie Jones, Wales Cancer Research Centre

I would like to thank you for the opportunity to represent the Wales Cancer Research Centre in this enquiry.

My name is Dr Sadie Jones and I am an Academic Consultant Gynaecology Oncology Surgeon in the University Hospital of Wales in Cardiff. Until recently, I chaired the Wales Gynaecology Oncology Multi-Disciplinary Research Group and now represent early stage researchers in the CreSt initiative of the Wales Cancer Research Centre. I have 13 years experience of clinical academia in Wales and was indeed, lucky enough to be one of the first candidates appointed to the Welsh Clinical Academic Training (WCAT) programme back in 2010. I have a deep understanding of how Wales performs not only in terms of developing and growing clinical academics but also how it performs at running research, particularly in relation to gynaecology oncology. I hope you will consider my following written evidence in your enquiry.

With particular reference to your investigations around '*the extent to which gynaecological cancers and theirs causes and treatments (including side effects), are under-researched, and the action needed to speed up health research and medical breakthroughs in diagnosing and treating gynaecological cancer'*. Latest figures demonstrate that only 1:5 patients with cancer in Wales are offered the chance to participate in research in Wales. In gynaecology oncology specifically, this figure is though to be closer to 1:20. Studies also consistently demonstrate Wales as one of the poorest performing developed countries in the World in terms cancer survival outcomes, particularly in gynaecology. Interestingly although unsurprisingly, research and clinical outcomes are linked. Studies repeatedly demonstrate that the more research that takes place in a health board or hospital, the better the outcomes for patients. It is estimated that cancer survival in Wales could be improved by 4% if our healthcare system increased its clinical research activity. Given that sadly 9000 people die per year from cancer in Wales, this could save 350 people annually. Clearly, these are figures that Welsh Assembly Government and associated responsible bodies could directly strive to improve.

Of course, resource is what is required, which may initially seem difficult to justify in research when NHS services are under such immense pressures already. However, when research is at the core of cancer service delivery, continual incremental improvement in patient outcomes will follow, helping to increase the flexibility and resilience of cancer pathways. This will ultimately serve to reduce waiting lists more quickly as well as offer patients the very latest treatments and interventions that research provides. Unfortunately, research is typically first sacrificed when demands on services outweigh resource. Research is frequently seen as an optional add-on rather than an integral part of providing a high quality service for patients. This is a required shift in culture that again, Welsh Assembly Government and associated responsible bodies could drive. The resource required includes more jobs for research nurses and protected academic sessions for doctors and other healthcare professionals conducting and developing research, it also includes space. I will offer gynaecology oncology in UHW (the largest gynaecology cancer centre in Wales) as an example. We currently have 6 gynaecology oncology trials running, two of which we are the highest recruiter in the UK. We have a further 3 benign Gynaecology trials open. We have one excellent research nurse running these trails who is exhausted, increasingly demoralised and close to burnout. None of the consultants leading the trails have funding from the health board for research, they either do it as a 'hobby' or have secured external funding themselves that is by no means permanent and requires frequent reapplication which is demoralising. We have no office space. Meetings are either done online or in the coffee shop, the joy and benefits of mingling with like-minded people, sharing ideas and problem solving does not exist. The lack of staffing resource means that despite several opportunities, new clinical trials cannot be opened because we do not have the capacity to deliver. It also means that other trials are not achieving recruitment targets or closing down. The impact of this goes further than the direct impact on the patients. Wales will increasingly become unappealing amongst the

international communities as a location for opening trails. We will not be approached by international studies and will lose credibility. The consequences of this are clearly significant and far reaching. Healthcare professionals are people with bright minds, enthusiastic to learn, improve things and do their best. People like that want to work in environments where they can grow and develop and be proud to work. We already have huge recruitment issues in Wales as well as high attrition. Declining academia and research will further fuel this. An active, supported research environment with clinical academic programmes would counteract this.

Wales needs to work on making itself more attractive as a region in which to open academic and industrial clinical trails. Barriers that currently exist in Wales that prevent efficient delivery of trials need to be broken down. As an example, I currently lead on one of the biggest surgical oncology clinical trails in the UK. Opening Wales as a recruiting centre first is important not only for Welsh patients, Welsh credibility but also the success of the trial (the centres of the lead investigators are typically the highest recruiting centres). However, because of complex contracting issues within and between healthboards, despite chemotherapy in Rhonda Cynon Taff being overseen by Swansea Cancer Centre the complex process of trial opening needs to take place at each of the hospitals in the healthboard in order to provide all patients with access in that area. This process should and could be much simpler and some initiatives are developing to facilitate this such as 'One Wales' but they are in their infancy and need to be more abundant.

There is remarkably and fortunately, still a lot of interest in Welsh Gynaecology Oncology research. The Gynaecology oncology multi-disciplinary group (MDRG) had more than 30 attendees from across Wales at meetings including, doctors, scientists, nurses, physiotherapists, trainees, psychologists, dieticians amongst others. Unfortunately the group was at its relative infancy when the MDRG structure was changed. It did however demonstrate the enthusiasm that exists and therefore the potential for change and growth. I genuinely believe we have the energy, skills, tenacity, and people to put Wales on the map in the world of research in gynaecology oncology. We simply need:

- Clear vision with achievable focused aims
- Resource (staff, time and space)
- Supported structure (supported groups with clear aims such as increasing research participation in general)
- Training opportunities for bright new sparks
- Effective mentorship programmes to guide new and early career researchers and support senior researcher
- Increased efficiency in processes around research delivery e.g 'One Wales'.

Regards *'The priority given to planning for new innovations (therapy, drugs, tests) that can improve outcomes and survival rates for women.* Of course, as we prioritise research we will prioritise all this for our patients. Active clinical trials open for patients to participate in means they will access the state not the art treatments. However, in Wales we also have the ability to lead new oncology research. We have scientists in Cardiff and Swansea leading world class research developing new ways of delivering anti-cancer drugs using viruses and nanoparticles, we have surgeons and clinicians leading clinical trials assessing state of the art techniques in the surgical delivery of anti-cancer treatments, we have psychologists leading research helping us understand why patients don't engage with cervical screening and more. We need to recognise these strengths as a community and bring them together as programmes of research where possible to ensure their maximum potential is realised. Establishing funded programmes of research needs to be prioritised in Wales to further ensure Welsh patients are accessing state of the art cancer treatments, means of diagnosis and care in general.