

# Summary of shortlisted nominations: Better Patient Experience Award

This award recognises an individual or team that has delivered measurable improvement in patient experience. This could be at any point of the patient cancer journey.

## 1. Expanding Access to Patient Open Evenings, South West Wales Cancer Centre

South West Wales Cancer Centre treats patients with cancer within the catchment area spanning from Bridgend, as far west as Pembroke, and as far North as Aberystwyth.

SWWCC provides a patient open evening once a month, for patients, relatives and friends to attend prior to starting radiotherapy treatment. The open evening provides patients with general information on radiotherapy, possible side effects and support services available to the patients and their relatives. During the evening those who attend are given a tour of the, often daunting, treatment room and the machinery and equipment used to deliver the treatment. The tour involves patients and relatives being able to enter the control area and see where staff deliver the treatment and helps them to understand and visualise how we will monitor them during their treatment.

Feedback has shown that the evening is of great benefit to both patients and their families and helps to reduce anxiety prior to starting Radiotherapy treatment.

It was recognised that some patients were not attending the open evening due to the long distance they lived from the hospital. The team sought out the option of delivering the open evening to patients remotely, which would alleviate the pressure of making a possible long journey in the evening.

Through staff being trained in the use of Attend Anywhere software, the open evening is now offered to all patients face to face, or remotely. Using Attend Anywhere, patients and relatives can listen to the presentation live, have a virtual tour of the department and have the opportunity to ask any additional questions in a breakout room at the end of the session.

Feedback has shown that providing the option of remotely accessing the open evening has ensured inclusion for all patients, regardless of their demographics.

“Everyone at the Radiotherapy Department and Maggie’s Centre are absolutely wonderful. Many Thanks. Very informative and reassuring. Thank you”

“Very good to meet and find out about treatment. Staff this evening were extremely helpful. It would benefit everyone to attend – well done!”

## 2. Head & Neck Pre-treatment Clinics, Cwm Taf Morgannwg UHB

The Head and Neck Cancer diagnostic pathway is complex involving multiple investigations requiring support and navigation. Additionally the physical and psychological impact and side effects of the cancer at presentation is significant. The Head and Neck Multidisciplinary Team (MDT) have been evaluating the patient experience of their pre-treatment service to ensure it meets the ongoing needs of the population they are supporting in Cwm Taf Morgannwg University Health Board (CTMUHB).

The latest Head and Neck Multidisciplinary guidelines, 2024, noted it is critical that the clinical team help patients to make very difficult decisions, with the provision of clear and understandable information on the risks and benefits associated with treatments offered. The multi professional pre treatment service consists of specialist Speech and Language Therapist, Specialist Dietitian and a Clinical Nurse Specialist. They provide support to patient following a diagnosis of head and neck cancer in:

- understanding their cancer diagnosis
- understanding what happens during cancer treatment
- side effects of cancer treatment including eating and drinking, speech and swallowing
- knowing where to go for advice
- education around good nutrition and providing swallowing exercises
- knowing who and the role of their key worker

For greater understanding on the impact and experience of patients of this pre-treatment service, a before and after questionnaire was sent to patients. 15 patients completed the survey. Quantitative data demonstrated the following:

- Increased confidence in understanding their cancer diagnosis
- Increased confidence in understanding cancer treatment and the side effects of treatment, including nutritional, swallowing and speech
- Increased knowledge in how to seek advice when required
- Decreased level of concern from 6.8/10 to 3.5/10

It was concluded that patient experience did improve as a result of the pre-treatment clinic and therefore the service was meeting its objectives and recent guidelines. The service will be continuously reviewed for experience.

I would like to nominate the Head and Neck Cancer Clinical Nurse Specialist (SLT) and Allied Health professionals (AHP's) involved in the delivery of pre-treatment clinics for the Head and Neck cancer caseload in CTMUHB.

This team strive to offer timely, patient centred, bespoke advice to those diagnosed with head and neck cancer prior to the commencement of treatment. At this clinic appointment the patient will meet members of the Speech and Language Therapy (SLT) team, a dietitian and a CNS in an MDT clinic rather than meeting these individuals separately. The clinic aims to provide the patient, and those close to them, with information, advice and support to empower them to

be prepared for their upcoming treatment, to self manage with support / signposting and to put into practice any particular advice / interventions to support their recovery.

In order to evaluate if the clinic was meeting the needs of patients a patient reported experience measure (PREM) in the form of a questionnaire was provided to patients asking them to rate their confidence in understanding certain aspects of their care prior to the MDT pre-treatment clinic and then a comparison asking them to rate their confidence after their attendance at clinic. A summary of the information can be found here:

[Microsoft Forms \(office.com\)](#)

Confidence in understanding increased in all domains. When asked to rate level of concern pre treatment and compared to post treatment there was significant reduction in the level of concern. The feedback from patients was overwhelmingly positive:

"Full explanations of diet. Having exercises for my swallowing and reassurance around treatment and how it may affect me. Thank you so much for everything your support advice and understanding "

"After all the explaining the treatment is now easier to understand. Thank you"

"Amazing support "

"It has been great to meet the team and have the time to talk "

"I was explained everything I asked. I was given more information to help me through this process. Thank you all for your professionalism, kindness and compassion. "

"Knowing we can contact you with concerns. Everything was explained in terms we understood. Really put my mind at ease. Thank you so much "

The patient feedback confirms the success of these clinics. Ongoing patient feedback will be obtained to ensure that the clinic continues to meet the needs of the patients and their loved ones.

### 3. 24/7 Cancer Treatment Helpline, Hywel Dda UHB

This is a nomination that celebrates the 24/7 Cancer Treatment Helpline Team from Hywel Dda University Health Board. This team is really made of two teams, the Acute Oncology Service (AOS) and the Out of Hours Service. Working together they have pushed organisational norms to partner in providing a local service for cancer patients that is innovative, responsive and value for money.

Around 2015, across the nation, NHS organisations were mandated to provide a 24/7 helpline for patients receiving systemic anticancer treatment to support better management of treatment toxicities. Implementing this presented a number of complex challenges stemming from how existing systems functioned and it was clear change was needed. This began with the building of a SharePoint system where every call taken, across the health board, could be logged and activity and outcomes captured. While this database was still in its formative stages the world was hit by the global pandemic.

The Hywel Dda team worked quickly to bring the centralised SharePoint system up to speed and started using it in 2020 to log daytime calls. With a cancer population shielding and some covid symptoms mimicking toxicities of anti-cancer treatment, the Hywel Dda Team felt that a helpline that was responsive and consistent across the health board was essential. In March 2020 the daytime helpline was moved from each of the four treatment units to one, 0300 number, and was embedded into the Acute Oncology Team for the first time.

During this time conversations began with the Hywel Dda Out of Hours (OOH) team around the overnight element of the helpline. This team already supported the out of hours GP service, providing a palliative care line and professional line, linking patients on the palliative care register and care homes/nursing homes with the out of hours GP. This was a team of experienced call handlers, used to dealing with patients and other healthcare professionals. There was appetite and excitement around how the OOH team and the Acute Oncology Team could work together to improve the patient experience. The OOH team were trained by the Acute Oncology nursing team to use the UKONS triage tool, a nationally recognised tool already in use in the daytime.

In May 2022 the 24/7 Hywel Dda Cancer Treatment Helpline went live!

7 days per week during normal working hours calls are taken by experienced Acute Oncology nurses, and outside of these hours by the OOH Team. The SharePoint system means that this works as one service across the 24 hour period and the Acute Oncology nurses are able to see all overnight/OOH activity and follow up patients appropriately, whether this means calling them at home or visiting them on the ward if they were admitted overnight.

Every month there is a Helpline Governance Group where service leads in Oncology and the OOH Service continue to develop the helpline, learning from patient and staff feedback and using opportunities for continuous improvement. Data around activity and outcomes is captured via the SharePoint system across the 24 hour period and scrutinised each month. Patient experience questionnaires are sent out by email after a call, response rates to date are 25%.

Partnership working with oncology and the out of hours team has improved visibility of the helpline within Primary Care, and benefitted the skillset of GPs in acute oncology scenarios. The acute teams within the hospital sites are now more aware of the helpline and receive SBAR reports following a triage call that needs admission or further assessment. Oncologists and local treatment units are notified of triage calls by an automated SBAR report via the SharePoint system with details of the reason for the call and action taken.

## 4. Cancer Callback Service, Tenovus Cancer Care

In the complex labyrinth of emotions and uncertainty that follow a cancer diagnosis, most people find themselves struggling as they cope with their questions and anxieties. This is particularly true for those who are diagnosed with a later stage diagnosis and need support as they start treatment.

As part of its wider support services offer, Tenovus Cancer Care recognises this critical time and has developed a nurse-led intervention which offers a lifeline to those navigating this time. We call this the Cancer Callback service.

We are putting forward this nomination in recognition of the rapid expansion of this service across Wales. The service is for people undergoing SACT (systemic anti-cancer therapy) referred to us via health professionals, working within Service Level Agreements is unique in Wales, and possibly the UK. The service is complementary to and supportive of the NHS, in that it allows direct patient access to a series of supportive proactive calls to check on their wellbeing and help identify any potential early toxicities during their treatment cycles.

It consists of a schedule of six calls from our highly experienced cancer nurses starting on day five of the first treatment cycle, then day twelve, followed by a further four monthly calls. The nurses carry out an assessment using the UKONS triage assessment tool to identify possible risks to patients following treatment. Should any red flags be raised then the patient will be advised to contact the hospital treating them and the referring team will also be urgently notified by our nurses.

Within this year the offer has expanded from two to five Health Boards, with ongoing work making it likely the offer will be available in six Health Boards and Velindre Cancer Trust by the end of 2024. These developments are led by our Lead Cancer nurse who meets with NHS lead nurses and can provide assurance of the quality and safety of this service. This is a bilingual offer with links to Language Line for support in other languages.

Our nurses handled 6,221 calls and emails in 2023, compared to 3,350 in 2022, demonstrating the level of increase over recent months. At any one time, the service will be supporting an active caseload of 300 clients with this number increasing month on month as more health boards refer to the service. We are currently working with our foundations and trusts team to identify funding for this service as we offer it to the NHS free of charge.

The efficacy of Tenovus Cancer Care's Callback service is not merely anecdotal; it is grounded in rigorous evaluation. Extensive studies conducted by universities in South Wales attest to its value and impact. A recent evaluation outlined the impact of the service and demonstrates a high level of satisfaction for patients as outlined below:

- **95% of clients** found the Support Line nurses "very" knowledgeable and "very" helpful
- **96% of clients** found the Support Line nurses "very" approachable
- **98% of clients** said that they could talk to Support Line nurses about everything they wanted

*"I felt like our calls were a moment to sit down and reflect on where I was going and what I'd been through, and what was normal and not normal about it all. The service allowed me to be open and reflect without putting any burden on my daughter" - Callback Client*

## 5. Nurse Led Post Radiotherapy Clinic, Velindre Cancer Centre

Women treated with pelvic radiotherapy such as cervical or endometrial cancers historically were seen in a consultant led clinic for their first follow up appointment 6 weeks post completion of radiotherapy. At this consultation they would have a clinical examination and a brief discussion as to how they were feeling post treatment, and some were referred to local follow up. Sarah and Tamarha identified that due to the time constraints of the clinic there was not enough time to explore and manage the complex toxicities such as radiation induced premature menopause, radiation induced bowel, bladder and vaginal toxicities and to summarise and explain their diagnosis and treatment received.

Many of the patients are unable to receive traditional HRT as their cancers are hormone driven therefore they discuss other methods of nonhormonal menopause treatment options. Some of these patients are in their 20s, 30s and 40s therefore this has a devastating impact on their quality of life but also fertility, bone, cardiac and psychological health and wellbeing. For patients that can receive HRT they aim to educate and empower patients to make informed decisions regarding HRT delivery methods in line with current NICE guidance. They will then write to the G.P and advise on the type of HRT to be prescribed.

In July 2023 the new Nurse Led Innovative Post Radiotherapy Clinic was launched, the model included 6 one hourly face to face slots with 3 call slots, the call slots are used for follow up test results. All patients are seen face to face with an allocated hour slot whereas previously they had a 10-minute allocated slot in the consultant led clinic.

To date they have seen 93 patients, they are allocated an hour face to face appointment. They are currently in the process of carrying out a patient satisfaction survey/audit . Preliminary results showed that 95% were very/extremely satisfied with the nurse led clinic and 100% of patients felt that Sarah and Tam were able to answer all of their questions and commented that the nurses were “*very professional and knowledgeable in their approach, patient centred care at its best.*”

This new clinic has meant that every patient is provided with the same service and same access to expert advice on the menopause, its symptoms and management whereas prior to this clinic this was not the case due to time constraints. The patient is seen in one clinic slot whereas previously they may have seen the consultant then referred to Sarah and Tamarha for more expert advice in another nurse led clinic, this again improves patient experience as it is all done in one clinic.

To summarise the patient is seen by Sarah or Tamarha (Clinical Nurse Specialist) 6 weeks post radiotherapy. They discuss their diagnosis, treatment and complete an end of treatment summary, they have an internal examination, discuss post treatment toxicities, relevant blood tests i.e. hormone profile to confirm if menopausal, complete a holistic needs assessment and referral back to local follow up where appropriate. Where applicable the patient will receive a follow up call the following week with test results.

Due to the excellent preliminary audit result, they are looking to expand the clinic to offer all gynae patients who have received radiotherapy (not just cervical or endometrial).

## 6. Prostate Active Care Together (P.A.C.T), Hywel Dda UHB

More people are diagnosed and surviving prostate cancer each year and advanced cancer treatment modalities has increased the number of people living with prostate cancer. Despite improvements in survival, not all people affected by prostate cancer are living well. Treatment-related side effects are significant in this population and have important implications which affects quality of life (QOL) and experience.

The Hywel Dda University Health Board (HDdUHB) Prostate Active Care Together (P.A.C.T) programme, led by a multidisciplinary team of Allied Health Professionals (AHPs), encompasses tailored advice on exercise, nutrition, wellbeing and supports self-management of symptoms for people with prostate cancer, to reduce the consequences of cancer / treatment side effects and improve longer term health outcomes and patient experience.

Prior to the introduction of the service, no dedicated rehabilitation service existed and people with prostate cancer had no structured support to manage the consequences of the cancer or side effects of cancer treatment(s).

The delivery model is a paradigm shift away from a medical to a patient centre model of care and supports the development of value-based rehabilitation services to provide the right level of support or intervention, at the right time and by the right person.

Following a holistic health assessment, patients are stratified into patient centred levels of rehabilitation based on their clinical, physical, and psychological needs. Digital platforms are fundamental to the delivery model, improving accessibility within our rural Health Board

Level 1: Supporting people to keep well with self-care and management using a digital held health record.

Level 2: Virtual individual or group consultations that include compassionate conversations, education, shared decision making and brief interventions to build self-care and health, enabling people to live well.

Level 3: Providing complex multifaceted, virtual group-based interventions that support sustainable strategies for health and wellbeing to support patients to live well.

Level 4: Supporting individuals with complex needs on a one-to-one basis, helping them to live well.

Since March 2022, over 800 patients have been supported by P.A.C.T with over 1650 virtual consultations [1:1 and groups]

- 9% declined initial assessment as felt they had no unmet need.
- 9% provided with level 1 support.
- 82% had an unmet need(s) and required level 3 & 4 level support and interventions – management of fatigue, sleep, anxiety, exercise & nutrition.

P.A.C.T was designed to improve the level of care provided to our local population, but also enhances the ways services work together, ultimately leading to further improvement in outcomes and experience for people with prostate cancer.

96% felt P.A.C.T considered & addressed physical, nutritional & psychological needs.

*"I thought I was too old to come to a virtual group at 84, but just shows I'm not too old yet. By having some exercise sessions and been able to manage my fatigue better, I've returned to golf too! Thank you!!"*

Improved patient reported outcomes:

- 67% reported their health was better following access P.A.C.T. Average 9- point positive change in EQ5DL scores representing significant change.
- 62% reported an increase in frequency & intensity of physical activity.
- Reduced number of people reporting that fatigue, sleep, anxiety was impacting on QOL.
- Reduced levels of sarcopenia

Increasing access by delivering services virtually has reduced the burden for people to travel and widened geographical reach, supporting equity in who can access the programme.



## 7. Expansion of Teenage and Young Adult Cancer Service, Teenage Cancer Trust / Cardiff & Vale UHB

In 2019, a Teenage & Young Adult (TYA) Cancer Service Peer Review in Wales revealed that only 40% of young people with cancer were treated at the Principle Treatment Centre and around 50% of young people were referred to the specialist TYA cancer Multi-Disciplinary Team Meeting (MDT), ensuring young people accessed age appropriate care and support services. At such a pertinent age, with influence that lasts a lifetime, the TYA cancer service agreed that service delivery had to look different to meet the needs of young people, wherever they choose to have treatment. The vision was to create an outreach model of Clinical Nurse Specialist and Youth Support Co-ordinator support, to complement the existing youth support co-ordinator role and social worker.

By utilising a targeted approach with clinical teams for TYA multi-disciplinary team (MDT) referrals, referral rates grew significantly and ensured young people can access services they are entitled to in line with Welsh TYA Cancer Standards. Despite growth in MDT referral rates, referral rates to the PTC for treatment remained consistently around 40%; more than half of young people with cancer had treatment closer to home. This demonstrated a need to deliver TYA cancer services differently.

To provide a meaningful offer of TYA services to young patients across the region, Teenage Cancer Trust TYA CNS' was implemented 2022. Initially a pilot for South East Wales, in 2024 the service expanded across West Wales. A team of 3, working as 2 whole time equivalents, ensure young people and their families have specialist support at all stages of their treatment journey – from diagnosis to survivorship or palliation. As a cross cutting team, they work with all tumour groups and site-specific teams along the treatment pathway.

Two youth support co-ordinators (YSCs) work alongside the TYA CNS team and established Young Lives vs Cancer Team to provide a holistic model of care. This team cross Health Board boundaries ensuring a continuity at this critical age. As hospital-based roles, the CNS team travel to local hospitals where young people are receiving their care. This has had significant socio-economic advantages for young people, who now have a local alternative to TYA cancer care delivery – no longer is travelling to PTC the only option. YSCs and Social Workers support care delivery through social events across South Wales as well as offering support in hospitals, remotely and when required, at home.

Core achievements of the service include:

- Development of age appropriate information around cancer support, fertility preservation and post treatment support for patients and professionals.
- Facilitation of end of treatment summaries.
- Implemented survivorship clinics to prepare young people for moving forward, potential late effects (in absence of a late effects service) and psychosocial milestones to expect, as well as providing health promotion, in consultation with primary and secondary care colleagues.
- Implemented TYA post treatment well-being days, covering topics like; relationships after treatment, preparation for late effects, psychological well-being after treatment, vocational support and physical and nutritional rehabilitation.

These services have been highly evaluated by young people and health professionals and we would not be without this expert resource, that has revolutionised the impact of cancer care in Wales for young people with cancer. The final piece of the jigsaw will be to roll out this model for North Wales, ensuring young people have access to this specialist support.

# Summary of shortlisted nominations: Patient & Public Participation & Involvement Award

The winners of this award will demonstrate how meaningful public and patient participation and involvement has helped improve or influence cancer services. This could relate to any part of the cancer pathway.

## 1. Talk CPR – Future Care Planning Cymru, Kat Shelley (in memoriam) & Velindre Talk CPR Wales project team

For people affected by life-limiting and palliative illnesses, talking about Do Not Attempt CardioPulmonary Resuscitation (DNACPR) is an important part of advance care planning. Talk CPR's goal is to encourage conversation about CardioPulmonary Resuscitation (CPR). This can help minimise distress at a later stage.

Kat Shelley was a patient in my palliative care clinic at Velindre Cancer Centre over several years. She sadly died in 2023, and has left a huge void in the world, with so many who loved her very dearly. Kat believed passionately in good advance care planning and talking openly about what happens at the end of our lives. As a patient in her thirties, this was something that she felt was something of a taboo, more so even than perhaps with older people facing the last years of their lives.

She realised and committed a real act of bravery and courage in the last months of her life when she discussed wishing to join a quality improvement project around the topic of openly addressing and declining cardiopulmonary resuscitation (CPR) and discussing its successes versus its drawbacks. She wanted her clinical team to talk openly and honestly to her about what lay ahead. She disliked the sometimes common misconception that cancer settings need to be excessively positive, framing everything in battle language (i.e. fighting or vanquishing the cancers) and by doing so forgetting the information needs of the patient: 'What happens when things *do* get worse'. 'What happens at the end?'

She therefore agreed to film an outpatient consultation with me, where, for the first time the topic of advance care planning and do not attempt cardiopulmonary resuscitation came up in her care journey. In fact, she led on this project and gently steered it, us, the clinical team, and others in terms of what we could and should address, as this is a very delicate topic. She worked with me, the Velindre TalkCPR.wales project team and the Advance & Future Care Planning Strategy Group NHS Wales, to create a video where she and I discuss the ins and outs of this topic area. The video can be found here [https://www.youtube.com/watch?v=SerstX6D\\_CU](https://www.youtube.com/watch?v=SerstX6D_CU) <https://talkcpr.wales/talk-cpr-videos/>. This is the first video we are aware of that features a real life clinic consultation about treatment choices at the end of life, including choices with regard to CPR.

Kat was insistent that this information needed to get better coverage and be shared widely. Within a year, the video has already been seen over 12,000 times, and has got many people interested in the topic of cardiopulmonary resuscitation in palliative illness. We will also be featuring Kat's work for a BBC piece in the run up to Dying Matters Awareness week.

## 2. Shaping Lung Health Checks in Wales, Cwm Taf Morgannwg UHB & National Strategic Clinical Network for Cancer

Targeted low-dose CT (LDCT) screening reduces lung cancer mortality and has been recommended for implementation in the UK. However, uptake of lung cancer screening has been low in Lung Health Check (LHC) activity in England. Reasons for this include:

- fear of a lung cancer diagnosis,
- fatalism regarding treatment options, and
- smoking-related stigma.

Lung cancer disproportionately affects socio-economically deprived groups, amplifying practical barriers to participation including:

- low literacy,
- disability,
- cost of travel or parking, and
- competing social or health priorities.

The LHC Operational Pilot (OP) is a collaboration between Cwm Taf Morgannwg UHB and the NHS Wales Executive Cancer Network, delivering 500+ LDCT screening scans to advance learning in preparation for a future national programme in Wales. The OP is taking place in North Rhondda, an area with exceptionally high levels of socio-economic deprivation.

We overcame barriers to equitable participation by co-designing evidence-based materials to engage and inform the OP's target population with representative patients/members of the public.

We:

- reviewed existing LHC materials and gained permission to adapt these for use in the OP,
- reviewed published literature on barriers to participation in lung cancer screening,
- sought advice from Public Health Wales' Screening Engagement Team and Wales Cancer Network's Patient Engagement and Experience Team, and
- drafted materials for use in the OP.

The existing materials were designed to avoid early disengagement due to:

- practical barriers – “it's free”, “convenient telephone appointment”,

- lack of trust – local GP endorsement and NHS Wales logo,
- fear and fatalism – stepped approach to discussion of lung cancer and positive messaging – “it’s a great way to give your hard-working lungs an MOT”, and
- smoking-related stigma – “no judgments on smoking”.

We further co-developed the materials with patient and public involvement (PPI) via:

- Tenovus All-Wales Cancer Community,
- Health Cancer Research Wales Involving People Network, and
- Wales Cancer Network patient forum.

We incorporated flexibility in how and when representatives contributed according to their preference (e.g. video meeting, via email), and ensured representatives felt heard and valued by creating a friendly, relaxed and jargon-free environment to reduce potential power imbalance.

The following are examples of improvements made to materials driven by PPI:

1. Use of **human stories** to explain the process.
2. **Infographics** were considered useful but those used in NHS England materials were confusing; a simplified version was co-developed with PPI for the OP
3. Most individuals requested basic **information on benefits and risks**, but some wanted more detail. We developed a supplementary [website](#) for the OP with more detailed, evidence-based information.

Finally, we:

- worked with the Plain English campaign to simplify language and avoid jargon, gaining their crystal-mark accreditation,
- developed Easy Read versions to benefit those with lower literacy, and
- made all materials bilingual.

Uptake of the Wales Operational Pilot (OP) has exceeded the highest-performing phase 1-2 Targeted Lung Health Check programme sites in England

All respondents (35/35, 100%) to an experience survey on the OP felt they received “just the right amount of information”. These findings suggest that interventions co-designed with people representative of the target population are likely to be effective in optimising uptake in lung cancer screening and addressing long-standing lung cancer inequalities.

### 3. Unheard: Women's journey through gynaecological cancer, Claire O'Shea (Patient rep), Tenovus Cancer Care, Senedd Cymru

In October 2022 the Senedd's Health and Social Care Committee (the Committee) opened its gynaecological cancers inquiry, which was set up in response to poor patient outcomes.

Early on Tenovus Cancer Care reached out to the Committee to discuss ways in which the voices of women affected by gynaecological cancers could inform the inquiry. Greg Pycroft, Policy and Public Affairs Manager at Tenovus Cancer Care - believing that lived experience from women would complement written evidence submitted by patient advocacy charities and enhance the inquiry process, report and findings - brokered a meeting with Senedd officials. The group agreed to identify and capture on film the stories of women who wanted to share their experiences.

Greg engaged with colleagues at Tenovus Cancer Care, the All-Wales Cancer Community, Jo's Cervical Cancer Trust, Ovarian Cancer Action and Target Ovarian Cancer. Between December 2022 and March 2023 the stories of four women were captured on film by the Senedd's engagement team and submitted as evidence.

In a first for the Committee, three of the four videos were publicly broadcast and watched by Committee Members during the inquiry's first witness session. Tenovus Cancer Care's CEO, Judi Rhys MBE, Lowri Griffiths, and Senedd engagement team manager, Rhayna Mann were invited to react and respond to questions. Staging the evidence this way meant that many of the issues raised by the women in the videos – i.e. medical “gaslighting” or not being listened to were firmly established in the minds of Committee Members.

Using its leadership of the Wales Cancer Alliance, Tenovus Cancer Care also ensured that one of the women affected by cancer, Claire O'Shea, was given a seat around the Committee table to directly respond to questions from Senedd Members.

In response to the evidence gathered by Tenovus Cancer Care and the engagement team, the Committee Chair, Russell George MS said,

“That is more powerful than any written evidence or anything anyone who can sit in front of us can provide. So, thank you to the bravery of everyone who took part in the evidence sessions, talking about their own experiences.”

The four stories scratched the surface of patient experience, but offered powerful evidence, captured, and presented sensitively by the Senedd's engagement team. The stories reflect hundreds of women across Wales with similar disconcerting encounters with parts of the National Health Service.

The strength of their evidence informed the title of the report “Unheard: Women's journey through gynaecological cancer”. The unique nature of the evidence heard by the Committee also attracted media attention, leading to regional and national coverage of the report and recommendations.

The Committee's interest in gynaecological cancer outcomes, and the novel method of evidence gathering hopefully contributed to the Welsh Government making gynaecological cancers one of the three cancer sites for priority intervention during 2023. The renewed interest in "Unheard" in May 2024, and growing patient interest the story has generated should ensure that this area of policy remains under close scrutiny and that positive change is delivered.

From the Chair's foreword of the report 'Unheard: Women's journey through gynaecological cancer':

"This inquiry would not have been possible if women hadn't been prepared to share their stories with us and I would like to pay tribute to Claire, Linda and Judith for their incredible honesty and bravery. We trust that our report and recommendations for improvements will mean that other women will not have to go through what they did."

#### 4. Improving Equity of Care for Metastatic Breast Cancer Patients, Tassia Haines (in memoriam) & campaigning colleagues

I would like to nominate Tassia Haines for her amazing contribution to shining a light on the huge inequity of care that metastatic breast patients are receiving; to changing and improving services for patients with metastatic breast cancer across Wales. Sadly, Tassia died on 10th March this year, so this award would be given posthumously to her husband Nick and the secondary breast cancer community that she supported and was one of.

I met Tassia for the first time back in September 2021, she was going through hell with her diagnosis and treatment yet had the determination to make change and be heard with such passion and relentlessness. She was determined, articulate, super intelligent and hilarious with a joyous and positive outlook that was infectious – despite living with this life limiting illness.

In her 32 years Tassia achieved so much to help others. Her petition and the change that it brought about. Here are just some highlights:

- A petition with over 14000 signatures calling for: change, nurses, a pathway, red flags symptoms awareness and data.
- Metastatic/Secondary breast nurses – Macmillan has recruited two in partnership with Velindre and CTM, with discussions with other Health Boards underway.
- Red flag symptoms to all primary patients – agreed on new Metastatic pathway
- Data collection/audit to gather metastatic patient data – Welsh Government approved plan
- Nominated for petition of the year by the petitions committee Welsh Government
- Established first METUPOK conference in Wales – funded by Macmillan and METUPOK
- Raised huge awareness around secondary breast cancer in Wales, UK and worldwide on social media and media outlets throughout Wales and the UK
- Produced artwork about her treatment and symptom control solutions and shared on all her social platforms
- Gained 70k followers throughout the world sharing her cancer experience, raising awareness, and reaching people who did not feel had a voice to be heard.
- Painted a huge Dragon on a wall in Port Talbot raising awareness of SBC and featured on the BBC programme Who needs Banksy
- Met the Health Minister to talk through the main issues for patients in Wales

Tassia's passion and voice gave others a platform to speak out and not feel alone, isolated and let down.

<https://www.tenovuscancercare.org.uk/news-and-views-listings/the-difference-a-year-makes-new-services-and-support-for-metastatic-breast-cancer-patients-in-wales>

<https://media.service.gov.wales/news/metastatic-breast-cancer-campaigner-meets-health-minister-to-discuss-improvement-in-services>

## 5. QuicDNA – The Patient Voice, Craig Maxwell (Patient rep) & The QuicDNA team

In September 2022, at the age of 40 Craig Maxwell was diagnosed with a rare form of genetic lung cancer, EGFR+, which had also spread to his bones. It is an inoperable, incurable Stage 4 diagnosis.

Genomic analyses are currently requested from tissue biopsy at the lung cancer Multidisciplinary (MDT) meeting. Even with an accelerated 'Optimal Pathway' this takes about 28 days after primary referral. Reporting often takes several more weeks. Only at this stage can future treatment be decided. Craig had two failed tissue biopsies before a gene change in the EGFR gene was detected in his third tissue biopsy. This led to a significant delay in his diagnosis and personalised cancer treatment care, which is not uncommon for lung cancer patients. Craig understood that a blood test at the point of suspicion would have led him to have his personalised cancer treatment care faster. Craig has described the 78 days before he was diagnosed as the "hardest, hardest days I've ever had", adding: "Not knowing what your future holds, knowing you're ill, but having no treatment."

QuicDNA aims to revolutionise lung cancer diagnosis and treatment using a simple blood test for genomic analysis. The liquid biopsy seeks to speed up treatment decision-making by providing early genomic information so that treatment can be initiated earlier.

Determined that he wants patients diagnosed with lung cancer to have the 'best' access to available new innovations and diagnostics to improve cancer outcomes in Wales and wanting to use his experience to change things for patients coming after him, Craig has partnered with the team behind the [QuicDNA real world study](#) in Wales to both fundraise and use his lived experience to highlight the importance and urgency of this work.

Despite his own treatment and prognosis, Craig has devoted his time to working alongside the QuicDNA team in raising awareness and fundraising. Fresh from completing the London Marathon in 2023, Craig attended the QuicDNA launch in Wales to share his experience with attendees. He has since presented alongside QuicDNA team members at the MediWales conference (2023) and the Festival of Genomics (2024) as well as numerous other tv and public appearances. Craig's willingness to share the reality of the impact of his delayed diagnosis alongside the potential offered by introducing QuicDNA to the diagnostic pathway has motivated clinicians across the country to get involved in the work, has increased awareness about the future of liquid biopsies and how accelerated genetic testing can inform treatment decisions. He has also raised awareness among the general public about the symptoms of lung cancer.

In tandem has been Craig's extraordinary fundraising efforts which have seen him exceed his initial £300k target and galvanise a huge community around him to support the cause. As well as contributing to the QuicDNA study, Craig has now established the Maxwell Family Genomics Fund, which will continue to raise funds to support and help the cancer diagnostic pathway for patients in Wales.



## 6. Developing the Breast Unit at Ysbyty Ystrad Fawr, Aneurin Bevan UHB

The new Breast Unit in Ysbyty Ystrad Fawr Hospital successfully opened on the 5 February 2024.

I would like to nominate staff members of the project and operational teams, patient representatives and fund raisers of the breast unit for the Patient & Public Participation & Involvement Award. Their exceptional dedication and unwavering commitment to supporting the breast unit has had a transformative impact on our organisation and the communities we represent.

The project and operational teams have engaged with patients, actively seeking and valuing their feedback, ensuring that their voices are heard throughout our journey. They have fostered an environment of mutual respect, where patients feel empowered to share their experiences and insights, knowing that they are valued members of our team. Notably, the team established a patient reference group, actively engaging with patients throughout the project, via active listening and a genuine commitment to learning from patient experiences. This has played a pivotal role in the development of our service model and unit design, and we have consistently strived to improve breast cancer outcomes and enhance the overall patient experience.

Throughout the planning phase, we actively engaged patients in the process, inviting them to participate in discussions and decision-making regarding the unit's layout and design. This included visits to various sites with the team to gather ideas and insights aimed at improving unit flow and optimizing the patient experience.

One noteworthy instance of patient input was their suggestion to modify patient gowns to enhance dignity. Patients provided valuable feedback on the design of the gowns, leading to adjustments that significantly improved comfort and privacy for those undergoing treatment.

Additionally, patients championed the inclusion of a secondary exit into the unit to enhance convenience, particularly for individuals wishing to avoid walking back through the main waiting area, especially after receiving distressing news. This thoughtful addition was a direct result of patient advocacy for improved accessibility and emotional support.

In addition to working closely with patient representatives we have been supported by the local community who have raised more than £260,000. From cake sales, walks, bike rides, half marathons and more, their innovative fundraising initiatives and collaborative approach, has enabled the project to enhance the building design and furnishings. Patients actively participated in selecting furnishings and design elements to create a welcoming and comforting environment within the unit. Their input helped ensure that the space feels inviting and supportive for all patients and their loved ones. The teams unwavering focus on person-centred care has resulted in significant improvements in the delivery of breast cancer services and overall patient satisfaction.

## Summary of shortlisted nominations: Working Together Award

The winners of this award will be a group or team that demonstrate how deep collaboration has enabled them to better respond to the needs of (suspected) cancer patients. This could be between departments, specialties, across health board boundaries and / or multiple organisations.

### 1. 3D-printed Eye Shields for Radiotherapy, Swansea Bay UHB

Radiotherapy patients receiving cancer treatment to areas in close proximity to the eye require the insertion of a special protective eye shield to protect the lens.

Historically, the Radiotherapy department in Singleton has used high level disinfected patient specific eye shields manufactured by a sole trader. Due to changes to the Medical Device Regulations, this sole trader ceased trading, meaning an alternative product was required.

A procurement process was undertaken to source an alternative product on the market. All products on the market required either chemical or gas sterilisation prior and post patient use. Discussions with infection prevention and Hospital Sterilisation and Decontamination Unit were undertaken and it was established that unfortunately the Health Board did not have the facilities to perform the required sterilisation recommended by the manufacturer. The feasibility of the health board purchasing the required equipment to perform gas sterilisation was explored, however this was not viable.

The Radiotherapy lead reached out to neighbouring Health Boards to enquire if this sterilisation process was available within Wales, however this was not an option.

The Radiotherapy department was faced with a high-risk situation, whereby we could have been forced to no longer offer radiotherapy treatment to those patients who had lesions in close proximity to the lens. Alternative treatment would be surgery where possible.

With a multi-disciplined approach Imaging Specialist Radiographer Anna Iles, Radiotherapy Physics technologist Rhys Jenkins, Medical Physics Expert Mark Edwards, and Maxillofacial Laboratory Services Manager Peter Llewellyn Evans developed a plan to manufacture patient specific eye shields in-house within the Health Board.

A design was created and a sample was 3D printed and approved by Radiotherapy. The Maxillofacial Department agreed to design eye shield moulds, which are used by Medical Physics in Radiotherapy to pour a lead core. The individual lead cores undergo vigorous transmission testing to ensure the protection levels meet specific requirements. Once transmission levels have been approved, the cores are returned to Maxillofacial for an epoxy coating to be applied and a visual check is undertaken to ensure the integrity of the device. The patient specific eye shield is returned to Radiotherapy in order for the patient to commence treatment, and an approved High Level Disinfection process is undertaken prior and post use.

A truly multi-disciplined approach has ensured that the Radiotherapy Department in Singleton is able to continue offering radiotherapy treatment for patients with malignancies in close proximity to the eye.

## 2. Optimising Radiotherapy Services, South West Wales Cancer Centre

The Southwest Wales Cancer Centre (SWWCC) provides specialist oncology services, including radiotherapy (RT), for nearly one million patients, covering a large geographical region with challenging patient cohorts; high proportion of older patients and significant levels of socio-economic deprivation. As always, recruitment is challenging in non-urban areas, with West Wales having some of the lowest numbers of oncologists per capita in the UK. Despite this backdrop, over the past few years the radiotherapy team in SWWCC has become an exemplar of innovation and efficiency, providing local patients with the highest standard of RT treatment. This has been reflected in recent external audits.

This nomination celebrates the outstanding achievements of the multidisciplinary team behind the radiotherapy services at SWWCC who have worked above and beyond their expected roles. It is not possible to list all the brilliant individuals or all the projects. Below are some highlights.

### Streamlined time-to-treat pathway

SWWCC drove continual improvements by focussing on efficiency savings in each element of the pathway. This substantially reduced time to treatments and resulted in SWWCC forming a partnership with Elekta, a leading radiotherapy corporation, to develop novel RT pathway solutions.

Shorter waiting times is good for all patients and results in improved outcomes. Additional capacity generated allows further developments of advanced radiotherapy techniques.

### State-of-the-art Image Guided Radiotherapy(IGRT)

Including:

- Surface-Guided RT –Four matched Linear Accelerators (LINACs) and now a UK reference site for C-RAD, a company that develops this technology.
- Comprehensive motion management: 4D cone-beam CT, abdominal compression, deep-inspiration and end-exhale breath hold
- Advanced breast techniques – Tattoo-less scanning, VMAT internal mammary chain irradiation
- Swansea University MRI collaboration for dedicated radiotherapy planning scans

These developments have been largely driven by non-medical staff members who lead and publish regular structured development plans.

These IGRT developments and innovations allow precise delivery of radiotherapy, benefitting patients by minimising toxic side-effects during their treatment. This also allows SWWCC to open novel RT trials which often require these as pre-requisite.

### Stereotactic Radiotherapy (SABR)

SWWCC has a fledgling but rapidly expanding SABR service with now established lung and oligo-metastatic service. New sites are on track to start in 2024 including Liver, Prostate, Kidney and Pancreas; where SWWCC is likely to be first in Wales to offer this.

Developments have been jointly led by physics, clinicians and radiographers making it a truly MDT effort.

This service for local patients, who hitherto needed to travel further afield, improves the overall patient experience and provides treatment options for patients which may otherwise have none. It also enables participation in national SABR trials.

### Research

SWWCC now has a fully dedicated RT research team and an established research fellow programme. In addition to recruiting to national RT trials, SWWCC was first in Wales to open proton beam trials in breast and head and neck cancers.

Led by Dr Sarah Gwynne and Dr Owen Nicholas, SWWCC also boasts involvement in developing original trials, particularly in Upper GI trials such as PROTIEUS, the first UK proton oesophageal cancer study and GastroSCOPE, a proposed study of RT in stomach cancers.

These research activities improve standards of treatment for all patients, empowers staff, facilitates academic collaborations and attracts external funding.

### Non-medical Clinical Innovations

Including:

- Non-medical treatment planning approval – led by physics, SWWCC has shortened the planning pathway via a novel yet robust approach of delegating this to technologists.
- Palliative RT – Radiographer led service. Sadly now discontinued due to absence of funding, this Pan-Wales pilot programme showed the real value to patients and health boards by reducing the time and cost for urgent palliative RT as evidenced by a Bevan Commission Exemplar report.

### 3. Creating a Regional Malignancy of Unknown Origin (MUO) Service, Swansea Bay UHB / Hywel Dda UHB

We are delighted to nominate the Southwest Wales Malignancy of Unknown Origin Multidisciplinary Team (MDT) for the Working Together Award in recognition of their close collaborative working to enhance patient care.

MUO patients often present complex diagnostic and therapeutic dilemmas. Historically, patients with MUO have faced suboptimal outcomes due to fragmented care pathways and limited access to specialist MUO expertise.

An MUO MDT was established in Swansea Bay in 2015 as part of the Acute Oncology Service supporting such patients presenting to its acute hospitals, this service expanded in 2020 to accept referrals from primary care. There, however, remained a gap in the service for patients in Hywel Dda with MUO. An informal arrangement allowed individual cases from Hywel Dda to be discussed if there were particular diagnostic difficulties, but there remained disparity in the level of service between the Health Boards.

In early 2023 Hywel Dda officially joined the MDT in recognition of this unmet patient need, creating a regional SWW service, thereby ensuring patients across both Health boards have equitable access to the same expertise and care.

The collaboration between SBUHB and HDUHB in the MUO service is characterised by a shared commitment to innovation, partnership, and patient-centred care. There is a broad range of medical, nursing and allied health professional representation within the MDT, with specialists from oncology, care of the elderly, RDC, radiology, histopathology, palliative care and therapeutic radiography creating a truly holistic MDT to meet the complex diagnostic and treatment needs of this patient group.

Beyond its immediate impact on patient care, the MUO MDT has facilitated shared learning and collaboration across organisational boundaries. Clinicians and healthcare professionals from both health boards have benefitted from exposure to diverse perspectives, best practices, and clinical expertise, enhancing their skills, knowledge, and confidence in managing complex oncological cases.

Team members are committed to excellent care tailored to the individual patient and their needs. The team understand the need for rapid, co-ordinated pathways for this complex patient group and work tirelessly to streamline the patient's diagnosis and treatment. There is an ethos of communication outside meetings to avoid delays incurred by MDT waits. There is a camaraderie in the team with staff willing to present and see patients from across health board boundaries including radiology cross cover between organisations in MDT and if necessary, in image guided biopsy services. Clinical Nurse Specialists work across health boards to attend appointments with patients when seen in the regional centre.

Novel ways of working include the use of a Teams channel to track patients through investigations and other MDTs, this is accessible to members from both health boards involved in care, to facilitate movement through the diagnostic pathway and to ensure cases are re-discussed at appropriate time points. We have also introduced MDT discussion summary letters that are sent to referrer and patient GP within two working days to facilitate communication.

The previously unmet need for this service is evidenced by the increasing number of patients referred.

Feedback from a recent MUO MDT support and challenge meeting with SBUHB cancer lead acknowledged the high standard of work and improvements for patients “*Thank you for your commitment to improving the care of cancer patients within your service. It is clear that the service has progressed to an exemplar service due to your hard work, motivation and leadership*”

The combined MUO MDT has revolutionised the care pathway for patients with MUO, resulting in tangible improvements in patient outcomes and experiences. By leveraging the collective expertise and resources of both health boards, the initiative has facilitated timely diagnosis, improved treatment decision-making, and optimised patient management strategies.

## 4. One Wales Medicines Process for Better Cancer Treatment, All Wales Therapeutics and Toxicology Centre (AWTTC)

The One Wales Medicines (OW) process was established in 2015 by the All-Wales Therapeutics and Toxicology Centre (AWTTC), a national organisation that provides advice to NHS Wales on medicines access and optimisation. The OW process assesses the effectiveness of a medicine that is not routinely available in Wales for a defined cohort of patients with an unmet clinical need. This includes medicines that are used 'off-label' and so aren't eligible for health technology assessment by either the National Institute for Health and Care Excellence (NICE) or the All-Wales Medicines Strategy Group (AWMSG).

Clinicians can request access to a medicine for individual patients by submitting an Individual Patient Funding Request (IPFR) but an OW recommendation enables routine access for all patients across Wales who meet the treatment criteria. The process is unique to Wales and is not replicated by the other devolved nations.

Clinicians can ask for medicines to be appraised via the OW process, and AWTTC also identify potential medicines and patient cohorts from analysis of IPFR data. The [One Wales Medicines Assessment Group \(OWMAG\)](#) considers the evidence of clinical and cost effectiveness of the medicine and makes a recommendation to AWMSG for endorsement, and then to Welsh Government for ratification. Health boards are responsible for implementing OW decisions and clinicians are required to collect patient outcomes.

Around half of all OW recommendations are for cancer medicines. Using the OW process, Wales is one of only two countries across the world to approve routine use of dostarlimab for the treatment of stage III rectal cancer with particular mutations (approved 08/23). Dostarlimab has shown to be highly effective in a small clinical trial and is currently off-label for this indication. We have worked with clinicians in Wales to develop eligibility criteria for this treatment and a method for data collection from which we aim to publish outcomes. To date, no patients have progressed after six months treatment. We are working with the manufacturer to provide ongoing data on adverse events as part of their pharmacovigilance requirements and to provide patient numbers to support rebates for this treatment to ensure we get the best price for NHS Wales.

Wales was also the first nation in the UK to make abiraterone routinely available for non-metastatic and locally advanced high-risk hormone sensitive prostate cancer (approved 11/22). Patient outcomes reported to date show 100% overall survival and 100% progression-free survival. For more information on our work visit the [One Wales pages](#).

The One Wales team in AWTTC is a small group of dedicated individuals with diverse backgrounds with years of experience in assessing medicines. We are passionate about our role in supporting the NHS in Wales and responding to the needs of both clinicians and patients.

## 5. Adapting the Welsh Bone Marrow Stem Cell Collection Model, Welsh Blood Service & Velindre Cancer Centre

Stem cell transplantation is the only curative option for many patients with blood cancers (e.g. leukaemia). The Welsh Bone Marrow Donor Registry (WBMDR), part of the Welsh Blood Service, plays a fundamental role in the delivery of stem cell transplantation in Wales and across the globe by supplying blood stem cells from unrelated 'matched' donors for patients. The WBMDR is the sole organisation in Wales that carries out this activity.

The WBMDR achieves this through maintaining a panel of volunteer donors who are 'tissue typed' to allow them to be matched to a patient requiring a transplant. During the 35 years of WBMDR operations, donors on our Welsh panel have provided over 1600 lifesaving stem cell donations for patients across the globe. The WBMDR have also imported over 600 stem cell products from donors elsewhere in the world for patients in Wales that required a transplant.

The WBMDR stem cell collection facilities are situated at the Velindre Cancer Centre (VCC). The rooms, at the VCC, are staffed by WBMDR nurses however they work closely with the many departments within the cancer centre itself such as the 'operations' department, microbiology laboratory, VCC clinical team, facilities department and have a very close relationship with VCC pharmacy.

It is this close relationship with VCC pharmacy that forms the basis of this nomination. Since the events of the global pandemic the WBMDR has needed to change their stem cell collection model to cope with the ever-changing global landscape. None of this would have been possible without the continued support of the VCC pharmacy team that has enabled continued improvement through constant positive engagement in the work of the WBMDR. An example of some of the improvements the WBMDR have been able to put in place with VCC pharmacy involvement are:

The VCC pharmacy were pivotal in the WBMDR maintaining their Human Tissue Authority regulatory licence by working with the WBMDR to install temperature monitoring in the stem cell collection room and aided the WBMDR in working through the issues highlighted by the regulator to ensure that the system remained effective and fit for purpose.

The development and approval of Patient Group Directives for the dispensing of the drugs used for the stem cell collections activity, this removed the requirement for a wet signature on a bespoke prescription that was difficult to acquire from external WBMDR contracted consultants. It would take many days, even weeks to facilitate these signatures and would have to be gained far in advance of the collection activity to ensure there was no delay.

In December 2023 the home care provider that administers the 'stem cell mobilisation' drug to donors before a stem cell collection gave notice to discontinue the service. This is a critical supplier to the WBMDR and without stem cell mobilisation stem cell collection would not be possible. The WBMDR worked hard to find a replacement service provider and worked hard with the VCC pharmacy team to develop a contingency arrangement enabling the WBMDR could continue to collect stem cell and save lives.

The above is a summary of the close working relationship, which has enabled the WBMDR to maintain the highest quality service for donors and patients and together we aim to save many more lives of patients with blood cancer.



## 6. Enabling Research for Better Patient Outcomes, Hywel Dda UHB

It is with great enthusiasm that I nominate the Hywel Dda Research Delivery Teams based at four hospital sites, Bronglais, Withybush, Glangwili and Prince Phillip, for a Moondance Cancer Award. Their exceptional dedication and remarkable achievements in recruiting participants into colorectal cancer studies truly warrant recognition and celebration.

The Hywel Dda Research Delivery Team has demonstrated unparalleled excellence in overcoming significant challenges, associated with the recruitment of patients into colorectal research study, particularly in the notoriously difficult area of endoscopy recruitment.

Endoscopy in Hywel Dda like many hospital departments is an extremely high throughput service with ever-increasing pressures to meet the government targets for cancer investigations, screening and follow-ups. Appointments are time sensitive with limited time for additional discussions or consultations, this makes it challenging to adequately explain the details of clinical trials, address patient concerns and obtain informed consent. Often patients perceive participation in a clinical trial as an added burden, stress or inconvenience, this is particularly prevalent in endoscopy as anxiety and stress related to the personal nature of the investigations adds to their apprehension.

However, the Hywel Dda research teams have overcome these barriers using their exceptional negotiation skills and extensive experience - adopting flexible and considered approaches and adjusting recruitment strategies and schedules to accommodate the dynamic nature of the endoscopy unit. All members of the team clearly understand the anxiety and stress patients experience during endoscopy appointments and are able to empathise with patients to provide compassionate support that enables open communication about clinical trial participation, ultimately placing the needs and preferences of patients at the forefront of all recruitment efforts which has resulted in extraordinary success.

As a result of their unwavering dedication to expanding participation in clinical trials, the research delivery teams have resulted in them not only succeeding in recruiting record numbers of participants directly from the endoscopy units but also enabled them to foster strong collaborative working relationships with the endoscopy teams. These efforts have radically improved research recruitment participation in this setting paving the way for improved outcomes, resulting from research, for patients in the future.