



Royal College  
of Physicians

Coleg Brenhinol  
y Meddygon (Cymru)

# Cancer care at the front door

## The future of acute oncology in Wales

Supporting healthcare  
professionals in Wales  
to develop high-quality  
acute oncology services

January 2023



# Foreword

Every year, thousands of people come into contact with acute oncology services (AOS) in the Welsh NHS. This includes people who receive an emergency cancer diagnosis at the front door of the hospital, as well as those people living with cancer who suddenly become seriously ill, either because of their illness itself or because of complications with their treatment. In an ideal world, these patients would receive high-quality care at the front door from specialist clinicians who understand the complexity of cancer, its complications and treatments, and the devastating effect that the disease can have on people's physical, emotional, financial and mental wellbeing.

However, these specialist services are often under-resourced, understaffed and overstretched. The Royal College of Physicians (RCP) has worked with clinicians across Wales to come up with this briefing. Collaboratively written, with case studies from every health board and different professional groups, it aims to set out the importance and benefits of AOS, encouraging senior NHS leaders and decision-makers to invest in these crucial teams. Working with the Wales Cancer Network as it develops a clear national vision for AOS in Wales, it is now up to our health boards to take the lead and work collaboratively to improve patient care.

## **Dr Olwen Williams OBE**

Vice president for Wales, RCP

Consultant in sexual health and HIV medicine

We have produced this resource to support our colleagues working in AOS across Wales, not only specialist nurses, but therapists, doctors and other allied health professionals. There is something for everyone, including educators, policymakers, service planners and health and care professionals involved in AOS and related specialties (palliative care, acute medicine and emergency medicine in particular).

As part of this project, the RCP held an online roundtable workshop with national professional bodies (including royal colleges and specialty societies), third sector organisations and national clinical leads in Wales. We also carried out structured interviews with more than 20 health and care professionals working in AOS across Wales, and we have used these conversations to inform our recommendations.

We wanted to ensure that the voice of clinicians delivering acute oncology services was heard, and that patients were at the centre of a collaborative piece of work that enables and encourages service change and investment. It's important that we reduce variation in outcomes and patient experience across health boards and trusts; wherever a patient lives in Wales, they should be able to access excellent AOS. Our incredible staff are at the heart of what we do: time and time again during interviews, we heard that recruiting and retaining specialist staff is absolutely vital, and a truly multidisciplinary team is key to high-quality patient experience. Communication and education were also strong themes, as well as consistent funding and business support for clinical leaders.

## **Dr Hilary Williams**

Consultant medical oncologist, Velindre Cancer Centre  
Wales Cancer Network lead for acute oncology services  
Regional adviser for south-east Wales, RCP

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# Glossary of terms

<b>AHP</b> – allied health professional	<b>MSCC</b> – malignant spinal cord compression
<b>AMU</b> – acute medical unit	<b>MUO</b> – malignancy of unknown origin
<b>ANP</b> – advanced nurse practitioner	<b>RCP</b> – Royal College of Physicians
<b>AOAU</b> – acute oncology assessment unit	<b>SACT</b> – systemic anti-cancer therapy
<b>AOS</b> – acute oncology service	<b>SAS</b> – staff, associate specialist and specialty
<b>CNS</b> – clinical nurse specialist	<b>SDEC</b> – same-day emergency care
<b>CUP</b> – cancer of unknown primary	<b>TYA</b> – teenage and young adult
<b>DGH</b> – district general hospital	<b>UHW</b> – University Hospital of Wales
<b>IO</b> – immunotherapy	<b>VCC</b> – Velindre Cancer Centre
<b>MDT</b> – multidisciplinary team	

# Key ask

**By the end of 2023, health boards should publish their plans for developing and investing in high-quality, patient-centred acute oncology services as part of their organisational response to the forthcoming national cancer plan for Wales.**

These plans should meet the service standards and principles of care developed by the Wales Cancer Network and follow an agreed format and template

so that plans can be compared and health boards held to account on their delivery. Plans should include long-term investment in more specialist staff to ensure cross-cover and a sustainable, resilient service, protected time for service provision and education, a multidisciplinary team approach across primary care, acute medicine, palliative care and oncology, closer regional collaboration, and a focus on reducing health inequalities across Wales.

**The following organisations and stakeholders were invited to contribute to the stakeholder workshop on 10 May 2022 and/or to review the report findings and recommendations once written. The RCP would like to thank everyone involved.**

Association of Cancer Physicians, Association of Palliative Medicine, British Dietetic Association, Cancer Research UK, Chartered Society of

Physiotherapy, Macmillan Cancer Support, RCP specialty advisers for acute internal medicine, medical oncology and palliative medicine, Royal College of Emergency Medicine, Royal College of General Practitioners, Royal College of Nursing, Royal College of Occupational Therapists, Royal College of Paediatrics and Child Health, Royal College of Radiologists, Royal College of Speech and Language Therapists, Society for Acute Medicine, Tenovus Cancer Care.



# Recommendations

**The Welsh government should work with NHS delivery bodies to:**

## Service development

- 1 provide long-term funding for the expansion of acute oncology services (AOS)
- 2 integrate AOS with same-day emergency care (SDEC) services to prevent admissions
- 3 ensure that all AOS have a multidisciplinary approach
- 4 develop hot clinics and virtual wards to reduce length of stay and facilitate earlier discharge
- 5 ensure that all patients with malignant spinal cord compression (MSCC) have rapid, coordinated access to services and treatment
- 6 support and develop access to immunotherapy (IO) toxicity services for all AOS teams
- 7 ensure that AOS teams have access to regular malignancy of unknown origin (MUO) and cancer of unknown primary (CUP) multidisciplinary team (MDT) meetings
- 8 carry out a full options appraisal for the role of a national treatment support helpline
- 9 invest in community AOS to speed up discharge, avoid admission and reduce length of stay
- 10 invest in digital innovation and remote monitoring of patients
- 11 implement the patient-held all-Wales cancer treatment summary
- 12 provide business case and project management support to service leads
- 13 invest in the NHS estate and workforce to improve facilities and upskill staff
- 14 facilitate faster, more equitable access to diagnostics and prehabilitation services

## Workforce

- 15 ensure that every hospital with an acute take has a senior clinical lead for AOS
- 16 ensure that all core team members have protected time in their job plans for AOS

- 17 support district general hospitals (DGHs) with senior oncologist sessions for patient care and medical education
- 18 recruit more clinical nurse specialists (CNSs) to each hospital site to ensure cross-cover
- 19 continue to build strong relationships between palliative care, acute medicine and AOS
- 20 ensure that all AOS teams have administrative, data and digital support
- 21 develop and support the role of staff, associate specialist and specialty (SAS) doctors in AOS teams
- 22 invest in and expand the numbers of specialist allied health professionals (AHPs) working in AOS
- 23 develop and support the role of physician associates and nurse consultants in AOS teams
- 24 invest in developing specialist AOS nurses who work in the community

## Education and training

- 25 ensure that AOS team members have protected time for education and training
- 26 support oncology to work with other specialties to upskill acute medical teams in AOS
- 27 raise awareness and understanding of acute oncology with other health and care teams

## Communication

- 28 continue to support AOS teams with strong pan-Wales networks and shared learning
- 29 agree a timetable for establishing data flows into a central AOS repository
- 30 collect accurate, comprehensive data to help measure outcomes and improve the service
- 31 continue to improve communication between primary care and specialist services
- 32 consider the role of a direct advice line for clinicians working outside oncology.

# Cancer care at the front door

Half of us will be diagnosed with cancer at some point in our lives.

When people think about cancer treatments, they might think about undergoing surgery or receiving chemotherapy, radiotherapy or immunotherapy as part of a planned care pathway. This treatment would usually take place in an organised way, perhaps during weekday hours, in a specialist centre.

But what happens when an emergency arises? What happens if you suddenly become very sick because of your cancer treatment, or a complication arises overnight or during the weekend? What happens if a cancer diagnosis is made during a visit to a hospital emergency department?

**This is called acute oncology, and it is part of the unscheduled care pathway.**

There are acute oncology services (AOS) in every district general hospital (DGH) in Wales. However, in many cases, the service consists of a single specialist nurse, working singlehandedly on weekdays, 9am–5pm. **This means that if these nurses take annual, study or sick leave, the service simply does not exist.** While the [Welsh government's quality statement for cancer](#) states that 'fully integrated acute oncology services [should be] available in all acute hospitals', there is no definitive set of requirements or definition of what AOS should look like, and senior decision-makers in health boards often don't know what AOS are, or what the benefits might be to patients and the wider health and care system.

**More than one-third of Wales' cancer cases are diagnosed when people arrive at hospital in an emergency.**

Acute oncology service (AOS) patients are those with cancer and urgent care needs:

- > due to a new/relapse diagnosis of cancer
- > due to a complication or side effects of their cancer treatment
- > due to a complication of an existing cancer.

There is an unplanned and unmet service need across much of Wales, which means that cancer patients can have a very poor experience when attending emergency departments. However, early review and rapid assessment by the right team can lead to quicker discharge and help to avoid readmission, while open and honest conversations with patients and their families can make a real difference to the quality of patient experience. In fact, high-quality AOS can keep people out of emergency departments, avoid unnecessary admissions and allow people to stay at home for longer.

**Health boards must now prioritise and invest in acute oncology services.**

One-third of British inpatient admissions for cancer are avoidable and a further third could be avoidable with an ambulatory care model. Yet most people who die of cancer will have an emergency hospital admission in their last year of life. Around one in six will experience three or more admissions. An acute cancer admission often means that a patient's condition is getting worse, but we know that only around one-quarter of acutely unwell cancer patients are asked about palliative care, and if this is not discussed during their first hospital admission, they are 50% less likely to die at home.

## **Patient access to acute oncology depends on where you live.**

Patients who live in large cities such as Cardiff or Swansea will invariably receive a different standard of care from the service that can be provided in more rural areas, including mid- and west Wales. While dedicated acute oncology assessment units for every part of Wales would reduce variation in care, this model is currently impossible due to limited financial resource and a chronic shortage of oncologists, specialist nurses and therapists across huge swathes of the country.

Where dedicated acute oncology assessment units (AOAUs) are not yet viable, health boards must at minimum ensure that AOS expertise is integrated into acute medical units (AMUs) and same-day emergency care (SDEC) units. In the longer term, the Welsh government must work with the NHS executive for Wales and health boards to consider how best to improve access to high-quality specialist AOS for everyone in Wales, regardless of where they live.

## **What next?**

Health boards should now prioritise the development of high-quality, well-staffed, patient-centred AOS. An acute emergency can be terrifying for the patient and their family, and having reliable, specialist expertise on hand at the front door of their local hospital could make a massive difference to the experience of people living with cancer. Services should work towards extended hours, overnight provision and weekend working; a 24/7 AOS provision in every part of Wales should be the gold standard, although this is currently impossible due to staffing and resource constraints.

Immunotherapy (IO) includes a group of medicines that stimulate the immune system to target and kill cancer cells. It is a game-changer for patients, but the adverse side effects can be challenging to manage for non-specialists. [Regional IO toxicity services](#) will offer 24/7 support through the existing triage support line and enhanced emergency care in south-east Wales.

In the future, closer working relationships between acute medicine, community teams and palliative care will become even more important. Providing preventative care closer to home will reduce hospital admissions and keep people healthier at home and living well in their community for longer. Ensuring that more health professionals outside specialist palliative care – especially in nursing and acute medicine – have basic symptom control skills will ensure better care and reduce patients' length of stay in hospital. There should be clear access to rapid decision-making on spinal surgery.

More involvement and better communication with primary and community care will improve patient flow and help to prevent acute presentations and hospital admissions in the first place; ensuring that GPs and the primary care team have the skills and understanding to treat some acute oncological presentations will enable and support patients to stay at home for longer.

There is strong peer-to-peer support and networking across AOS in Wales: the new NHS executive for Wales and the national clinical networks should ensure an aligned voice and a commitment to clinically led, people-centred change. This should take into consideration the circumstances of those patients who live in Wales under the care of a Wales-based primary care practice, but receive their oncology care at a hospital in England. Cross-border arrangements should ensure that there is good communication and collaborative working to ensure that nobody falls through the gaps.

Most importantly, patients and their support networks should be at the centre of these changes. Using accessible patient-held health records, they should be empowered to make informed decisions about their care and treatment. As soon as possible after diagnosis, the patient should be equipped with the understanding and resources to know what to do in the event of an acute episode, where to go and who to contact, so that they can advocate for themselves and their loved ones in an emergency. Ultimately, AOS should be about improving the experience of cancer care at the front door: that is, keeping people out of hospital and getting them home as quickly as possible.

**' More education around MSCC is needed for both patients and their primary care team. A lot of patients with metastatic breast cancer are diagnosed in the emergency setting with a scan, but it would be such an improvement to patient care if something could be done before they become unwell enough to use the emergency route.'**

– patient living with cancer



# The story until now

AOS in Wales have developed very rapidly in the past 10 years.

AOS in Wales have received significant investment and support from Macmillan Cancer Support. In most parts of Wales, AOS are nurse led with an on-site presence from Monday to Friday. The [cancer delivery plan for Wales 2016–2020](#) committed ‘*health boards to further develop acute oncology services, ensuring they comply with national standards and work to expand them to 7-day provision.*’

**‘ We need to provide more services in the community. We need faster, more equitable access to diagnostics, prehabilitation services and holistic support. We need safe, equitable, robust out-of-hours and emergency unscheduled care and advice for all AOS patients.**

– GP

## Are AOS meeting the 2016 standards?

In 2018, a Wales Cancer Network steering group [peer review report](#) assessed the quality and performance of AOS against the 2016 [all Wales national standards for AOS](#). The peer report found that:

- > there was insufficient time allocation for senior clinicians acting as clinical leads
- > administration support for the services was variable
- > there was clear evidence and some excellent examples of education and collaborative working
- > poor access to patient records was causing a risk to patient safety
- > relationships between teams were improving, but this was hindered by poor flow of clinical information and access to patient notes, particularly out of hours
- > access to a 24-hour telephone advice line should potentially be centralised

- > further work was needed to identify possible models for 7-day working
  - > an all-Wales approach to flagging cancer patients attending acute services should be considered
  - > the all-Wales AOS database should be integrated into the Welsh Clinical Portal
  - > better collaboration and communication between health boards and cancer centres was needed
  - > ‘door to needle’ time response for neutropenic sepsis could be improved
  - > recruitment of an MSCC regional coordinator should be considered in south Wales
  - > patients would benefit from closer working between primary care and AOS
  - > work should continue to improve the collection of patient experience and feedback.
- [All-Wales peer review report 2018: Acute oncology service](#)



In December 2020, the [Nuffield Trust provided advice](#) on the proposed model for non-surgical tertiary oncology for south east Wales. Their report stressed the need to expand ambulatory care at VCC, develop acute oncology plans for each local health board as ‘a priority’, invest in an enhanced research hub at UHW, improve referral pathways, build a network with a common dataset (supported by a workforce strategy) and take the opportunity to plan integrated cancer services. Perhaps most importantly, the Nuffield Trust noted that ‘solutions to the immediate issues facing cancer services across the region, and at VCC in particular, are required now, rather than at an indeterminate point in the future’.

In March 2021, the [Welsh government quality statement for cancer](#), which replaces the cancer delivery plan for Wales, committed to ‘*fully integrated acute oncology services [that] are available in all acute hospitals.*’ Health boards and trusts are responsible for planning and delivering cancer services in line with this quality statement, supported and enabled by the new NHS Executive for Wales and the Wales Cancer Network Board, which will set out a rolling, 3-year implementation plan.

### **Key messages from a joint Royal College of Radiologists, RCP, Association of Cancer Physicians paper on AOS, 2020**

- > AOS are vital for providing consistent and high-quality care for patients, for optimising clinician time and expertise, and for ensuring the best use of NHS resources.
- > Meeting the complex needs of acutely presenting oncology patients across a wide variety of clinical contexts is challenging and deserves to benefit from the same strategic and operational clinical leadership that is already available to site-specific cancer teams.
- > A clearly defined role for consultant oncologists within AOS is essential for ensuring effective clinical leadership and oversight.

- > The rising incidence of cancer in an ageing population with multiple health conditions will require a multiprofessional approach to care, with AOS providing the critical cancer oversight for the majority of emergency cancer admissions.
- [Acute oncology: Increasing engagement and visibility in acute care settings](#)

In writing this report and designing these recommendations, we interviewed more than 20 health and care professionals working in health boards and trusts across Wales. We held a 2-hour online workshop with stakeholders from royal colleges, professional bodies, specialty societies and the third sector, and during the review process we worked with Macmillan Cancer Support, Tenovus Cancer Care and Cancer Research UK to ensure that patient groups and networks were consulted.

During our structured interviews with health and care professionals, we identified six key themes:

- > We need to recruit and retain high-quality specialist **staff** in AOS.
- > We need better **communication** across the health and care system.
- > We need to embed changes to the **education** and training of oncologists.
- > We need to **raise the profile** of AOS with colleagues across the health and care sector.
- > We need to **reduce regional variation**, especially in more rural and remote areas.
- > We need to expand and invest in **multidisciplinary team working**, especially allied health professionals (AHPs).

During our workshop in May 2022, there was firm agreement that national service standards and recommendations would have to strike a balance between being aspirational and being realistic.

Regular reviews of the national standards for AOS should be commissioned, to allow ambitious new objectives as services develop, treatments advance and our understanding of AOS best practice grows.

### What are the challenges facing AOS?

*The following findings are taken from a 2018 peer review of AOS in Wales. All are still relevant.*

- > Low and variable rates of spinal surgery for patients with malignant spinal cord compression (MSCC) compared with UK and England standards
  - > Lack of clarity around the service provision for spinal surgery in south Wales
  - > Lack of clear long-term funding for several teams
  - > Lack of funded consultant sessions (particularly for oncology consultant-led care for malignancy of unknown origin (MUO))
- > Variable access to cancer of unknown primary (CUP)/MUO multidisciplinary team (MDT) discussion
  - > Although teams had led improvement in door-to-needle time for administration of antibiotics, the majority of patients do not receive antibiotics within an hour of arrival at hospital.
  - > Inconsistent data collection via standalone database.
- All-Wales peer review report 2018: Acute oncology service



# The national picture

AOS are not delivered in a vacuum. They are part of a complex health and care system, working closely with urgent and unscheduled care teams with links into primary care, community teams, palliative medicine, acute medicine and emergency medicine.

## **Acute oncology services are currently very fragmented.**

When health boards are investing in AOS, they should consider how their plans align with Welsh government policies and strategies, including the principles of [value-based healthcare](#) as well as:

- > [A healthier Wales: long term plan for health and social care](#)
- > [National clinical framework: a learning health and care system](#)
- > [Six goals for urgent and emergency care: policy handbook for 2021 to 2026](#)
- > [The quality statement for cancer](#)
- > [Improving health and social care \(COVID-19 looking forward\)](#)
- > [NHS quality and safety framework](#)

We also know that [health inequalities are a growing problem in Wales](#). In 2019, [Macmillan Cancer Support](#) found that ‘people living with cancer in the most socio-economically deprived areas are 20% more likely to have their cancer diagnosed at a late stage and face almost 25% more emergency admissions in the last year of life compared to people in the least deprived areas’.

## **‘Tackling poverty cannot be seen as a singular issue and that is why we take a government-wide, long-term approach in Wales.’**

– Welsh government, September 2022

Poverty causes illness and poor health and will have a tangible impact on AOS across the country. Poor access to public transport and digital technology continues to have an impact on patient care. Addressing the factors that cause ill health and

disease in the first place should be a central focus for all public bodies and we have called on the Welsh government to publish a cross-government action plan to tackle inequalities and poverty.

**‘People in deprived areas generally present later and more often via emergency departments with complications arising from cancer. They have reduced access to clinical trials and often need more targeted support and expertise. The increased integration of care into the community and primary care and the timely clinical care that AOS provide will benefit more deprived patients.’**

– [Acute oncology: Increasing engagement and visibility in acute care settings](#)

In the meantime, AOS teams should consider how their plans fit with the wider NHS Wales principles outlined in the [public health outcomes framework](#) and the [value-based healthcare strategy](#). The need for behaviour change, access to better data and measures of patient outcomes and experience, improvements to communication and digital care all overlap with the aims of the [six goals programme](#), and the expansion of AOS will give health boards the opportunity to meet the aspirations set out by the Welsh government around:

- 1 coordination, planning and support for populations at greater risk of needing urgent or emergency care
- 2 signposting people with urgent care needs to the right place, first time
- 3 clinically safe alternatives to admission to hospital
- 4 rapid response in a physical or mental health crisis
- 5 optimal hospital care and discharge practice from the point of admission
- 6 home-first approach and reduced risk of readmission.

# Key principles of acute oncology in Wales

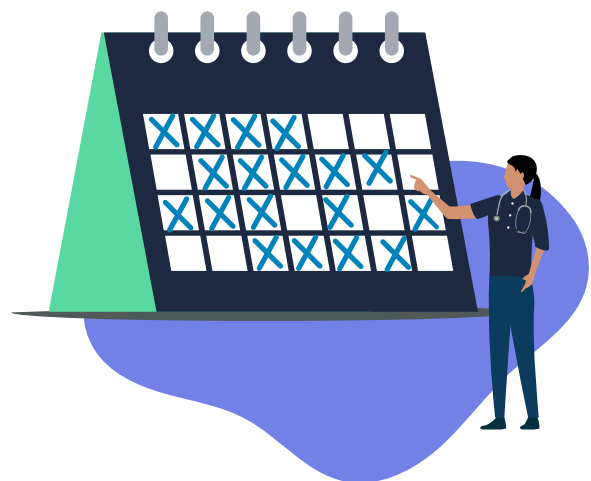
**'Planning for the next decade, acute oncology is more relevant than ever. The pressure on urgent care services is unrelenting in the face of a rising cancer incidence in an older and multimorbid population.'**

**– Acute oncology: Increasing engagement and visibility in acute care settings**

These eight overarching principles of acute oncology in Wales have been developed to help teams deliver the best possible care, place patients at the heart of decision-making and align with wider NHS Wales and Welsh government strategies, including the six goals of urgent and emergency care, A healthier Wales and the national clinical framework.

AOS across Wales should work towards meeting these principles:

- 1 Provide care that is tailored to the individual and their goals.
- 2 Put the patient and their support network at the centre of decision-making and help them to develop strategies of self-management where possible.
- 3 Ensure that the acute oncology team is multidisciplinary, with dedicated AOS time in their job plans to enable the effective delivery of care.
- 4 Ensure that the acute oncology team is skilled in managing cancer emergencies and has robust access to specialist oncology support and expert decision-makers.
- 5 Work with other teams to provide same-day alternatives to admission, rapid assessment, diagnosis and treatment where possible.
- 6 Put in place clear clinical pathways with primary care, urgent and unscheduled care, and other appropriate specialties to ensure effective and timely patient care.
- 7 Have 24/7 access to clinical information and patient records for all health and care professionals.
- 8 Have digital systems and protected staff time in place to capture acute oncology data, activity and outcomes.



# Developing the acute oncology service

## **What is acute oncology?**

### **How should it be delivered?**

Acute oncology means different things to different people.

**' Acute oncology is as important as site specialty oncology. It's what matters to patients. It makes the difference between a good life and a good death.'**

– consultant oncologist

Broadly speaking, however, it helps patients with cancer who are admitted to hospital with a complication of their cancer or side effects of their cancer treatment (eg chemotherapy, radiotherapy or immunotherapy), or those who receive a new diagnosis of cancer at the front door. Put simply, AOS treats the acute episode, not the cancer itself.

**' Acute oncology is about supporting the on-call medical team in district general hospitals [to improve patient care]. It can reduce pressure on the acute take.'**

– consultant oncologist

**' We need to get better at asking what will make a real difference to the outcomes and experience of a patient and their family. AOS should be about improving patient experience.'**

– palliative care consultant

A cancer patient in a crisis is often going through one of the worst experiences of their life. They may be seriously ill, frightened and unsure about the future.

**' My role is to support and advise the medical team about admitted patients who have become unwell because of their cancer treatment, or perhaps they have received a cancer diagnosis at the front door, or they have developed an oncological emergency. We also support patients and their families directly, and we liaise with Velindre.'**

– clinical nurse specialist

Many hospital teams managing admissions at the front door, whether through an emergency department, a minor injuries unit, a medical assessment unit or any other unscheduled referral pathway, will not necessarily have the expertise required to make decisions about the care for someone with cancer, especially as treatments become more complex and specialist.



## Finding the balance between general and specialist care

Acute oncology is about complex decision-making and the provision of specialist acute care and advice at the front door of the hospital. However, oncology is increasingly outpatient based, so when a patient with cancer becomes seriously unwell, they may find themselves at their local acute hospital or DGH with no easy access to specialist oncological advice.

**‘Modern cancer care has become an outpatient field. People with cancer who [present] as emergencies [at the front door] require urgent assessment of complicated problems and rapid decisions about the most appropriate interventions. Well-organised AOS can lower the number of people needing admission, reduce length of stay, improve quality of treatment and help to train the next generation of clinicians. Core principles are the promotion of education, awareness and early access to specialised oncology input, as well as more integrated ways of working between oncology and acute specialties.’**

– Swansea Bay University Health Board AOS expansion business case, November 2021

### What does a good AOS look like?

*The following findings are taken from a 2018 peer review of AOS in Wales. All are still relevant.*

- Good relationships with other specialties, such as admission and triage departments, palliative care, haematology, oncology and primary care
- A quick and accurate response to administering antibiotics to patients with suspected neutropenic sepsis
- A fast response to diagnosing MSEC and providing a surgical opinion within the optimum time
- Providing a diagnosis and treatment plan for unknown cancers

- 24-hour telephone advice service to provide one standard of care with an out-of-hours package
  - Cross-cover arrangements across sites (admission units)
  - An automated flagging system to identify potential patients
  - The provision of education and training
  - Dedicated time of a clinical lead
  - Administration and data collection support
  - Evidence of audit and service improvement
- [All-Wales peer review report 2018: Acute oncology service](#)

## Working with other acute care teams

AOS are often underfunded and understaffed; it is not unusual to have a single specialist nurse covering the entire hospital. This needs to change. In south Wales, for example, consultant oncologists are based at specialist centres in VCC and Singleton Hospital, and most acute oncology happens at the front door of DGHs.

**‘Expanding and resourcing the service has been a real ongoing challenge for us. A lack of funding is a key issue. Recently we’ve seen some investment [across the health board], but now the recruitment of both doctors and nurses is becoming a bigger problem.’**

– consultant oncologist

**‘Each local health board needs to develop a plan for oncology support for unscheduled cancer patient admissions and acute oncology assessment of known cancer patients, with inpatient admission as an option.’**

– [Nuffield Trust, 2020](#)



Front-door triage must have strong links with the AOS team; where possible, hospitals should invest in AOAs that provide SDEC, staffed by nurse specialists and AHPs, with clinical input from senior decision-makers on the ground. Where SDEC services are being developed in hospitals across Wales, acute oncology should factor into these plans.

**'In an ideal world, there would be specialist cancer support at every district general hospital. Medical assessment units should have dedicated oncology beds managed by the AOS nurses, with access to emergency diagnostics and treatments. But in reality, that's very hard to achieve.'**

– GP

**'We're very interested in how we can build acute oncology into SDEC. It's an entirely new way of working for us. There's a lot that comes through the emergency department that we could treat in an ambulatory unit, if we had a robust pathway and scoring system in place. One day, in the distant future, we could even have AOS nurses in the community who could assess patients at home.'**

– clinical nurse specialist

**'Each health board needs to ensure that there is a plan for providing oncology advice and support for patients admitted via A&E, and for acute oncology assessment of known cancer patients presenting with symptoms/toxicities, with inpatient admission provided as an option on a district general hospital site if needed. The assessment service model should provide for multidisciplinary input, in particular from palliative care, specialist nursing and allied health professionals.'**

– [Nuffield Trust, 2020](#)

### **What is same-day emergency care (SDEC)?**

SDEC is the provision of same-day care for emergency patients who would otherwise be admitted to hospital. Under this care model, patients presenting at hospital with relevant conditions can be rapidly assessed, diagnosed and treated without being admitted to a ward and, if clinically safe to do so, will go home the same day that their care is provided.

**'Hopefully in a few years, there will be an AOS assessment unit in all three hospitals in north Wales. The assessment unit in Ysbyty Gwynedd has been a great success, but only because we have taken opportunities when we can. There's no longer-term strategic plan. It can be exhausting.'**

– consultant oncologist

Velindre Cancer Centre's assessment unit's unique multidisciplinary approach leads to a reduction in length of stay, with the unit having an average 4-hour stay. 61% of patients seen on the unit are discharged on the same day. The assessment unit and the service provide an opportunity for clinicians with an interest in acute oncology (AO) to undertake leadership and development within AO.

– [Acute oncology: Increasing engagement and visibility in acute care settings](#)





## Acute oncology assessment units (AOAUs)

Health boards should be planning ahead to accommodate the growing numbers of people who are likely to receive a cancer diagnosis over the coming years. Many of these patients will at some point need specialist emergency cancer care at the front door of their local hospital. Identifying AOS patients can be complex; every health board should work towards having at least one AOAU in their area, with agreed referral protocols where extra specialist input is needed.

**'If I could wave a magic wand, I'd want enough staff and resource to always have an AOS specialist at the front door. That's how we make the biggest impact and avoid problems developing, because we'd have someone with expert knowledge involved from the start. We need to get cancer patients to the right place, first time – it could be many different places, but the most important thing is that there is AOS in DGHs to support these patients and work with other hospital teams to provide high-quality care.'**

– clinical nurse specialist

**'Cancer patients in crisis don't want to go to the emergency department. They want to see a doctor who understands their case.'**

– consultant oncologist

**'The definition of acute oncology is so open to interpretation. Do we just concentrate on treatment and disease complications? Should we rule out surgical admissions? Should we rule out obvious site-specific cancers and refer them to the relevant team? Should we see all patients with cancer who are admitted? It's a very difficult balancing act.'**

– advanced nurse practitioner

**'What happens if a patient has back pain and they are triaged to a smaller local hospital, then it turns out to be a spinal cord compression? Or they have a bad reaction to their cancer treatment that seems straightforward, but it's actually immunotherapy toxicities, which can be very serious?'**

– clinical nurse specialist

**'Every health board should have a flagging system, based on the 2018 service specification, but some teams are so short-staffed that they simply ignore it. It's just a lack of resource.'**

– advanced nurse practitioner

AOS teams should be able to signpost patients towards emotional and wellbeing support, access to benefits advice and other relevant information. AHPs can support ambulatory care by taking a rehabilitative approach that can prevent readmission. There should be a big role for hot clinics and virtual review: AOS teams should avoid admitting patients where possible.

## A safe, comfortable environment for patients in crisis

Hospitals should offer a safe and comfortable environment for patients in crisis. The experience of receiving treatment in an acute emergency would be improved by ready access to food and water. Some people will have caring responsibilities and need support; others should be offered the opportunity to talk about their worries or concerns, especially if their health has deteriorated significantly, or they might want privacy in a safe space. While a full holistic needs assessment may not be appropriate in an acute emergency, the human elements of a good patient experience are still important, and hospitals should strive to embed the elements of the 'what matters to me conversation', even during a crisis.

## Caring for children and young people with cancer

Teenagers and young adults (TYAs) diagnosed with cancer often experience prolonged and convoluted diagnostic pathways compared with children and older adults; TYA patients often have multiple visits to primary care and hospital emergency departments before being diagnosed. It has been estimated that 38% of new TYA cancer referrals are emergencies, with 7% having their first presentation via emergency departments; after diagnosis, they will still present to their local emergency department and AOS team if they become acutely unwell with complications of cancer treatment. The Wales Cancer Network TYA Cancer Site Group Youth Advisory Forum has created principles of communication for health professionals working with young people with cancer and encourages all health professionals to use them.

## Available everywhere, to everyone who needs it

AOS are patchy across Wales. In some areas, the care provided to patients is well resourced, with access to nurses, doctors and therapists. In other areas, the service is provided by a single nurse with no clinical support or cross-cover. It may be aspirational at this stage, but the NHS should aim to ensure that high-quality AOS is available everywhere, to everyone who needs it.

**' I do feel like patients down here [in west Wales] get a raw deal. We do feel a bit abandoned, in a way. It would be nice to have a clinical lead down here. Sometimes I do feel anxious about giving advice without seeing a patient. It worries me.'**

– clinical nurse specialist

AOS teams also need protected time or extra staff resource to collect and input data on activity and outcomes. This might be difficult to achieve, but

it is essential to ensure that we develop a learning system. This must be linked to work being done for the national clinical framework and by Digital Health and Care Wales to develop a national data resource. Ultimately, we should move away from manual collection and input of data by improving the flow of information to a central AOS repository.

**' Improving pan-Wales communication between the NHS, the independent sector and the third sector is important. The development of IT systems to support a repository would be beneficial in supporting inequalities and for people who are in a rural area of Wales.'**

– RCN Wales evidence

Ultimately, while AOS should aim for a 24/7 approach, this is unachievable with current levels of resource and staff. A resilient 5-day service could aim to reduce admissions at the weekend, with a 24/7 triage line to refer cancer patients in crisis to the safest place, and clear pathways to allow discharge over the weekend. However, AOS teams should aim towards providing a 7-day service as soon as possible, with incremental improvements in staff capacity and financial resource.

**' Acute oncology teams provide multidisciplinary clinical expertise to support the care of acutely unwell cancer patients, avoiding hospital admissions where possible. However, while two-thirds of cancer centres provide a dedicated unit for assessment and admission of acutely ill cancer patients during standard working hours, only a quarter can provide a 24/7 service.'**

– Royal College of Radiologists. Clinical oncology: UK workforce census report 2020

## **‘Massive distances apart’**

There is only one consultant oncologist working in Hywel Dda University Health Board, who is based in Bronglais. With no overall clinical lead for oncology, cancer patients in west Wales attending emergency departments at Withybush, Prince Philip or Glangwili hospitals will be seen by a clinical nurse specialist (CNS), with no access to MUO or CUP clinics. A speciality doctor in Swansea Bay University Health Board provides some remote support for the nurses, but there is no doctor on the ground to see patients.

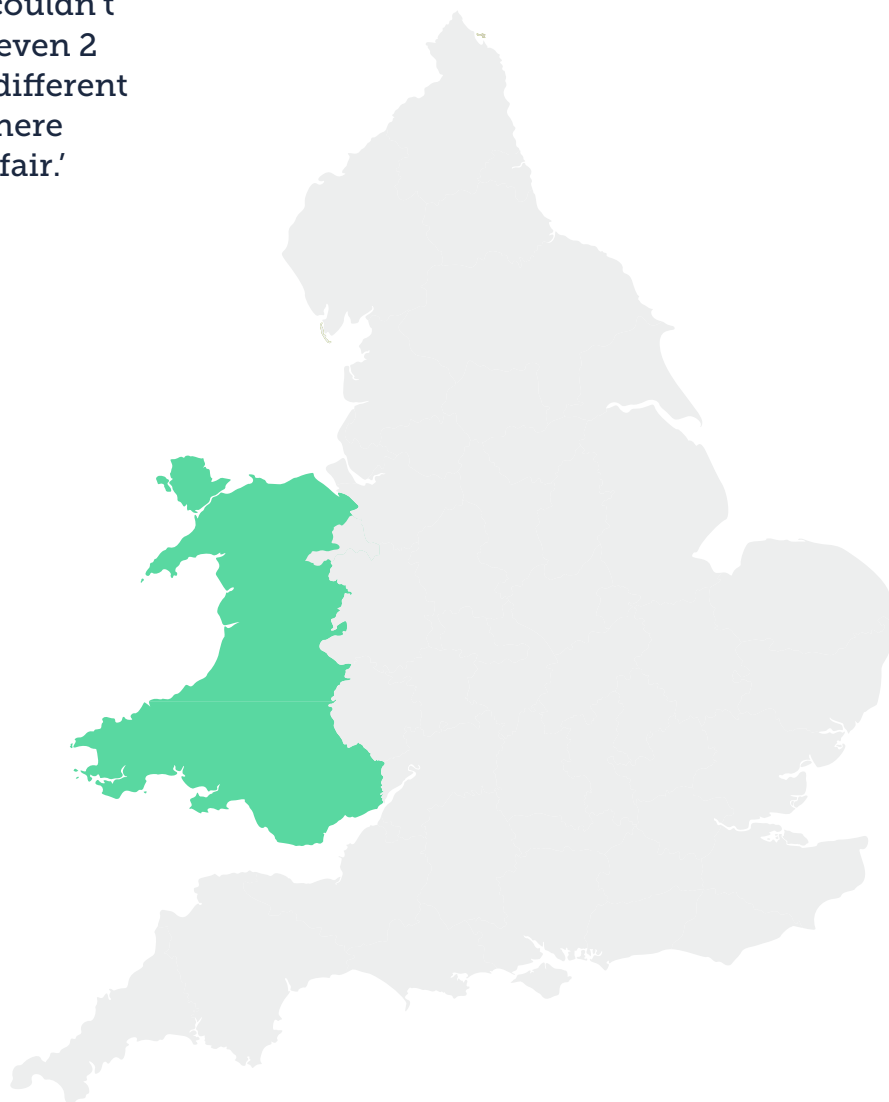
**‘It would be good to have some face-to-face sessions with a doctor. Perhaps a ward round in person, where we could go through all the patients. But then, where do they go? We have hospitals in Llanelli, Carmarthen and Haverfordwest, massive distances apart. You couldn’t do all three in a single day, or even 2 days. Patients are receiving a different standard of care because of where they live, which doesn’t seem fair.’**

– clinical nurse specialist

**‘A lone medic [in west Wales] could quite easily get overwhelmed by the work and the travel. On the other hand, it would be interesting from an educational perspective and very helpful to have more of a medical presence in some of the more remote and rural hospitals.’**

– senior clinical fellow

Both doctors and nurses told us that the AOS team in west Wales can get stuck in the middle of the conversation between acute care, AOS and tertiary care. Hywel Dda and Swansea Bay university health boards should come to a formal agreement around funding and staffing for MUO/CUP clinics and senior clinical support for the AOS nursing team in west Wales.



# Developing the acute oncology team

'Ultimately, it's about people, and not just doctors. You need good nurses, AHPs, diagnosticians, radiologists, geneticists. Attrition is a big problem. We need to get better at looking after our staff and building a high-quality MDT workforce.'

– trainee doctor

## What should the team look like?

An acute oncology team should be multidisciplinary, with specialist knowledge, access to a senior expert decision-maker and a clear focus on clinical leadership. Protected time for education and training for all AOS team members is essential; this should be undertaken using a multidisciplinary approach. Core team members (with protected time for AOS in their job plans) should include:

- > nurse specialists
- > clinical lead
- > AHPs
- > AOS coordinator
- > administrative support
- > data and digital support.

All AOS teams should have rapid, coordinated access to MSCC services, as well as to advice and support from an IO toxicity service. MSCC services should include spinal surgery opinions and protected capacity to operate. NHS organisations should consider whether to recruit MSCC coordinators at a regional level in Wales.

**MSCC coordinator role:** The role involves coordinating the ongoing care of adults with MSCC and the diagnostic investigations of people at risk of developing MSCC who present with relevant symptoms. An MSCC coordinator should be available 24 hours a day, 7 days a week, acting as a single point of contact for healthcare professionals to liaise with.  
– [NICE quality standard \[QS56\]](#)



'We need to ensure that patients are going for MSCC surgery when appropriate and in a timely manner. In Wales, we've never invested in MSCC coordinators, which puts pressure on the system and staff. Decisions aren't being made quickly, communication is too slow, and we're often missing our NICE targets. It's a big risk.'

– allied health professional

### What is immunotherapy?

Immunotherapy (IO) is a drug treatment for some types of cancer that helps the immune system to recognise and attack cancer cells. Checkpoint inhibitors (a type of IO drug) block certain proteins that stop the immune system from attacking cancer cells, and so allow the immune system to attack the tumour. IO treatments have changed the landscape of cancer care and allow some patients to live without measurable signs of cancer for a reasonable length of time. However, IO toxicities can be life-threatening, permanent and, in some cases, fatal. This area of cancer treatment has advanced quickly, and there have not always been clear patient pathways, so an IO toxicity service for south-east Wales has been developed with Welsh government SDEC funding. The team is:

- > developing clear, consistent pathways to manage IO toxicities
- > providing national leadership in education, research, audit and service development
- > updating and maintaining IO toxicity guidelines
- > developing ambulatory pathways to reduce the number of patients admitted to hospital with IO toxicity
- > supporting pathways for new IO treatments.

### 'The nurses are amazing'

'Quality nursing is the thing that matters most. It's what makes the difference, especially in improving access to services. We need to get better at attracting and keeping good nurses.'

– trainee doctor

'Attitudes have improved. People are less dismissive of AOS nurses now. They are more supportive of the work that we are doing, and they welcome our input.'

– clinical nurse specialist

Some services in Wales are run by CNSs, others by advanced nurse practitioners (ANPs). Some nursing teams provide cross-cover for colleagues in other hospitals within the same health board, some are based exclusively on one hospital site. In some cases, they are the only clinician with specialist AOS knowledge in a hospital. They are patient facing, providing expert advice to other hospital teams, as well as emotional and practical keyworker support for patients and their families.

Health boards should consider investing in nurse consultant roles, particularly where AOS teams do not already have a senior clinical lead in post. A strategic approach to workforce planning is needed; it is difficult to plan the future cancer workforce when the available vacancy data are patchy and not up to date. Ultimately, to enable long-term sustainability in the health and care system, we need to know how many staff are needed to keep pace with patient demand. This means publishing workforce data in an open, transparent and accessible format, based on what we know about current actual and future likely patient demand and workforce supply, and setting out a range of short-, medium- and long-term solutions to grow, train and retain the workforce, accompanied by the necessary funding.

**' To understand how many nurses and nursing staff are needed in the NHS, indicators of patient need and workforce pressure such as vacancy rates, agency spend and workload pressure should be considered.'**

– [Nursing in numbers 2022, RCN Wales](#)

**' The nurses in Hywel Dda are amazing; they give us really comprehensive summaries of the patients who have been admitted there, some of whom we know about, some we don't. They liaise with us and the medical team locally and keep the lines of communication open.'**

– consultant oncologist

In the context of acute oncology, there must be enough people in the team to provide cross-cover when staff take leave. There is a risk that, without cross-cover, the service simply collapses when the CNS is off site, which means that patients cannot access care and other teams cannot rely on it.

**' We need to future-proof these services: it's short-sighted not to provide cover, because without the AOS nurse, there isn't an AOS service.'**

– clinical nurse specialist

**' We are a close-knit team; while we work completely independently and separately across the three sites, as a team of CNSs we do coordinate and communicate with each other, although we don't provide cross-cover. We tried, but it was impossible. The CNS post at the Princess of Wales was vacant for 18 months, which meant that there was no AOS there at all. Velindre would triage a patient on the treatment helpline and send them to hospital, but there was no CNS with AOS expertise to see them when they got there. It's inequity of access for patients.'**

– clinical nurse specialist

**' AOS is a safety net, and unless you're able to provide a reliable service every day, people won't use it because they need to be able to rely on it, and things won't get flagged the way they should.'**

– trainee doctor

## **'We don't have enough doctors'**

Face-to-face support is vital: every team needs a clinical leader. In most cases this is a doctor, but health boards should consider the potential role of nurse consultants in the future where appropriate.

**' Delivery of an AOS requires strong and effective oncology leadership, clearly defined consultant AO roles and responsibilities alongside resources, training and supported structures are essential to delivering excellent patient care and service improvement for cancer care.'**

– [Acute oncology: Increasing engagement and visibility in acute care settings](#)

Most services in Wales have a clinical lead, but some don't, and where there is no clinical lead, the rest of the team can sometimes feel adrift and unsupported.

**' Acute oncology nurses and trainees benefit from working with each other and they both benefit from working more closely with the consultant oncologists. It can reduce overall consultant workload because some of the more straightforward medical decisions can be made and actioned by the trainee. It's not a hierarchical system, it is very much a team approach.'**

– consultant oncologist



' Health boards need to invest in timetabled, protected time for consultant acute oncology sessions so they can see patients and teach trainees. Just a couple of ward rounds a week to train, educate and support colleagues on the shop floor, especially with difficult cases.'

– consultant oncologist

' Ideally though, you would want a consultant doctor with two or three AOS sessions a week in each district general hospital, working as part of a multidisciplinary team to review patients and support the specialist nurses with teaching and development.

– consultant oncologist

' Having a physical face-to-face presence with decent cross-cover is very important, as is investing in teaching, developing the profile of the service, and ensuring keyworker and emotional support for patients who need help navigating a very complex system.'

– consultant oncologist

There are big recruitment challenges across the specialties of medical and clinical oncology.

' Workforce is a big problem. We might have the money for more doctors, but the people aren't there. The team is still relatively small and until recently, there was no cover for nursing leave. When you're trying to build a really good service, it's very difficult if there's no consistency. People need to be able to rely on us, and without cross-cover, there's a single point of failure: that's a big challenge.'

– consultant oncologist

' Staffing is the biggest barrier to developing the service. We have only recently recruited a second nurse for the service in Ysbyty Glan Clwyd, and trying to run an AOS, see triage patients, see CUP patients and do my clinics single-handedly has been tough going. That's down to both funding and staffing challenges.'

– clinical nurse specialist

' We simply don't have oncologists waiting in the wings to fill these jobs. We've got to be honest and transparent and consider different ways to staff oncology medicine in district general hospitals: are we using specialty doctors effectively? How about upskilling other CNSs and ANPs?'

– consultant oncologist

' Staffing is the biggest challenge we face. We don't have enough doctors. On one single day, I might be responsible for the assessment unit, a ward round, an MDT meeting and the new patient clinic. If everything goes smoothly, I can manage. If there's an emergency, that's when it becomes an issue.'

– consultant oncologist

' Recruitment is tricky. There is a shortage of oncologists, and it's even harder in rural areas. But that shouldn't stop other parts of Wales applying for the funding and making the business case. If you don't have the money in the first place, you can't recruit the people.'

– consultant oncologist

To get people home more quickly, patients should receive specialist review by a senior oncologist with a wide range of oncology expertise, ideally on a daily basis. This does not have to mean hospital admission, but could include hot clinics with tertiary specialist referral as appropriate.



## ‘AHPs should be core members of the AOS team’

### **An MDT approach in action at Velindre**

Therapy services cover inpatient, outpatient, radiotherapy review clinics and chemotherapy units within VCC. Therapists also liaise regularly with teams in local health boards to ensure good communication and seamless continuity of care. The patient is at the centre of the multidisciplinary team and each patient should contribute to their goal setting. All therapy interventions are aimed at maximising patient safety and wellbeing, functional ability, and the quality of life of both the patient and their carers.

There are currently very few specialist AHPs working in AOS in Wales, despite the challenging physical complications of many cancers and the key role that AHPs play in enabling people to live well with cancer in the community. Health boards should invest in developing this particular workforce, given their contribution to improving patient experience, reducing length of stay and preventing hospital admissions. Recruiting specialist AHPs can be difficult due to historic underinvestment: while upskilling staff will take time and resource, there should be clear referral pathways to generalist AHP teams in the hospital, who should be supported with AOS training.

‘Therapy intervention in acute oncology not only helps to avoid admission into hospital, it also reduces length of stay and facilitates earlier discharge. We can help patients to self-manage their health by providing earlier intervention with fatigue, pain or breathlessness, and it can really enhance their quality of life. That’s what’s key to improving the patient experience.’

– allied health professional

‘Patients are presenting at a later stage, especially post-pandemic, and the need for AHPs to improve quality of life will only increase. AHPs should be core members of the AOS team: we make a real difference to patient outcomes.’

– allied health professional

‘Having a dedicated ward would allow us to bypass the emergency department. We’d need more oncologists and ANPs and it would be amazing to offer a 7-day service, but that’s reliant on funding and staff. We’ve now got an occupational therapist, physio, dietitian and funding for speech and language therapy input in our team, and they have made a world of difference already. They are able to get people home quicker, we’re taking more risks because they’re being assessed by the therapist, and it’s improved the quality of our multidisciplinary case-based discussions.’

– advanced nurse practitioner



## **‘How can we show that we’re providing value-based healthcare without the data to back it up?’**

AOS teams need clinicians, but they also need administrative, data and digital support. As the implementation of the Welsh Clinical Portal gathers pace, and new cancer patient information becomes available to healthcare professionals across Wales, the NHS should invest in data collection and measuring outcomes so that teams can use this information in real time to improve services.

## **‘Acute oncology is dealt with by lots of different specialists’**

Patients deserve a joined-up approach. Core AOS team members might be based at the front door of a DGH, but the wider service includes primary care, community teams, specialist oncologists at regional cancer centres and palliative care. There should be strong links with SDEC units, emergency departments and medical assessment units, with AOS factored into service planning at the hospital front door. Clear communication between professionals is crucial.

**‘Everyone thinks that cancer is only dealt with by oncologists, but actually it’s not. It’s dealt with by lots of different specialists, and GPs have to build a relationship with all of them which is why it’s really positive that primary care is becoming more involved with AOS.’**

– GP

**‘Specialist palliative care should be part of every acute oncology team: a lot of AOS patients sit across both services, especially MUO patients, many of whom are essentially palliative from diagnosis.’**

– palliative care consultant

**‘We can contact the community resource team for ambulatory patients, although records are not yet on the same digital platform, which makes things more difficult. That’s supposed to be happening quite soon though. Digital working will make the transfer of patients much easier because everyone will have access to the same information. Communication is a big thing.’**

– clinical nurse specialist

In an ideal world, palliative medicine should be a core part of the AOS team, but this must be funded, and trainee numbers increased to account for changes to medical training and the curriculum. The NHS should think more strategically about how palliative medicine and AOS teams could work together, especially in the community. Palliative care services are currently very stretched, with much of their AOS input being ad hoc and informal, based on good personal relationships between teams.

**‘A good working partnership between the acute medical unit (AMU) and acute oncology service (AOS) can result in a significant improvement in patient care together with opportunities for admission avoidance and early discharge.’**

– Acute care toolkit 7: Acute oncology on the acute medical unit

## Haematology and AOS

' Haematology malignancy needs investment too. All of our daycare areas across Wales are too small and understaffed. When teams in Cardiff discharge patients after intensive chemotherapy regimens, we are frequently told that the patient's local centre has no capacity to care for them between cycles of treatment, so they often come back to us for follow-up. Even other large treatment centres are struggling. Haematology must be remembered within acute oncology – leukaemia, lymphoma, myeloma etc are also cancers and often need much more urgent care.'

– consultant haematologist

Building good relationships is absolutely crucial. The importance of having the time to develop closer working with other teams and build stronger links with the other specialties in acute medicine and general medicine cannot be overestimated. (This is, of course, in the context of consultant workforce shortages across all of the medical specialties, including acute medicine: there is no easy source of clinicians.) AOS teams should consider how they can be part of the induction process for trainee doctors who rotate every 6 months through a different specialty.

' I really enjoyed meeting people and building those relationships. The medical teams wanted our input and support, and they were very grateful that the service was starting up. It was really helpful that we both had connections from previous roles that we could use to build networks, especially given that junior doctors rotate regularly, so we needed to embed new ways of working with the consultant physicians and grow those relationships'

– clinical nurse specialist

Visiting oncology consultants through outreach AOS can enhance local provision of care for patients, help define appropriate local pathways within non-elective care and provide education to healthcare practitioners outside of cancer centres.

– Acute oncology: Increasing engagement and visibility in acute care settings

## How has the pandemic affected AOS?

AOS kept going through the pandemic; however, a big impact was felt in the education and training of doctors-in-training who move through different placements, and primary care felt that it was more difficult to build relationships and drive shared work forward.

' Pre-COVID, we ran educational sessions to raise awareness of acute oncology, but a lot of that stopped overnight when the pandemic hit. It's an ongoing battle and very time-consuming, especially when doctors-in-training move around so much. The reality is that we're often just firefighting, given the rise in patient demand at the moment.'

– consultant oncologist

' Change takes time. Everything takes longer than you'd think. It was easier when we were face to face, but sometimes it feels like primary care is out of sight, out of mind.'

– GP

Changes to the specialist oncology training curriculum will have a big impact on AOS. All registrars will now be required to practise some acute oncology as part of their training, which should lead to a bigger AOS medical workforce in the future. This learning should be shared with other professionals and specialties in an MDT approach to education.

' Acute oncology is now part of the new medical and clinical oncology curriculum. That means covering the acute oncology take, managing oncology emergencies, providing oncology advice to other healthcare professionals, being part of an acute oncology service, managing the acute oncology team. It's mandatory. Time needs to be ring-fenced for acute oncology training, and that cannot just take place in a cancer centre. You have to gain experience working in a DGH setting. Working in a specialist cancer centre will not be enough. We need to show that we are helping to reduce the workload of the acute take at DGHs, and trainees should be supporting nurses with training and education as well as providing clinical advice.'

– consultant oncologist

# Developing the future of acute oncology in Wales

As an immediate priority, we recommend that AOS services receive more long-term funding, more staff and more support for business planning.

' For every service we've set up with no additional resource, we've stretched ourselves even thinner, sometimes to breaking point. But what's the alternative? Waiting for funding wouldn't get anything done. It's a difficult balance.'

– consultant oncologist

' It would make a huge difference if there was a clear process for seeking funding for a new idea, with central administrative and project management support for developing a business case, instead of expecting clinicians to do this on top of a heavy clinical load. There are so many hoops to jump through, even to set up or expand services that are well established in other health boards. It's just so frustrating.'

– consultant oncologist

' Medical training is very clinically focused, but management is an important part of the consultant role, and I find it very challenging to know how to build a business case and design new job descriptions, for example'

– consultant oncologist

Workforce planning will be key to the success of expanding AOS in the future.

Wales lacks a strategic approach for developing the cancer workforce. Data on vacancy rates are inconsistently published and often not centrally held – this makes reliable and strategic decision-making on the future nurse workforce extremely challenging

– [Macmillan Cancer Support, 2021](#)

We also recommend that AOS teams are encouraged to work towards building more community provision of acute oncology, which could reduce admissions and speed up discharge. AOS, primary care and palliative care teams should share learning and best practice examples of admission prevention in the community.

**' There's an argument for outreach AOS in the community, which might stop patients coming into hospital in the first place. The problem is that people arrive at the front door of the hospital, and if they're seen by a non-specialist, they get admitted by default.'**

– advanced nurse practitioner

**' Palliative medicine goes where the patients are. It's the outlying hospitals, the community patients, they are the ones who AOS needs to reach. Around a fifth of acute hospital beds are occupied by people who have some sort of cancer-related problem, and a lot of those admissions might have been avoided with more proactive AOS community care. Closer working between AOS and specialist palliative care teams in acute hospitals is so valuable: it should be embedded in the design of acute oncology services.'**

– palliative care consultant

There is a big role for primary and community care working with palliative medicine to share learning and best practice. Clinical networks and communities of best practice should work across Wales to support each other and develop new ways of working. Ultimately, most people would rather be at home, and as more people are living with cancer as a chronic condition, AOS teams should be supported to allow patients to live well for longer in the community. This will mean closer working with the third sector and AHPs, who can help with signposting to community services and support groups. Therapists working in the community should be enabled through education and training to support cancer patients in the community.

**' We need better regional integration on the more specialist issues, like the immunotherapy toxicity service. I am trying very hard to build stronger links between the three specialist centres in Velindre, Singleton and Rhyl. I believe that collaboration is going to be the way to make progress. It's about mutual support'**

– consultant oncologist

**' Collaboration is key. Velindre hosts a lunchtime AOS meeting for health boards in south-east Wales to look at complex cases, metastatic spinal cord compressions, and other acute oncology presentations, which really helps to build relationships with the health boards. We want to make those a central hub for advice and support, with formal notes made by the AOS coordinator. If we don't have that meeting, things do tend to fall apart. The challenge now is to increase engagement and attendance from the AOS teams across south-east Wales to ensure shared learning.'**

– allied health professional

**' The ideal model would give both patients and clinicians access to that specialist information: a one-stop shop for someone who is unwell as a result of their cancer or their cancer treatment. We'll be working closely with NHS 111 Wales, primary care, emergency care – we have to have good links. Possibly – and this is a big step – in the future, we may want to explore a national model, that is, a central helpline number, funded jointly by the health boards, especially overnight and weekends.'**

– clinical nurse specialist



## Working in partnership with the third sector

Tenovus Cancer Care is collaborating with Betsi Cadwaladr University Health Board and Hywel Dda University Health Board, and more recently Swansea Bay University Health Board, to provide a telephone call-back service for patients receiving systemic anti-cancer therapy (SACT). Patients are referred, with permission, to the call-back service. A Tenovus Cancer Care nurse calls the patient at a fixed time to provide advice and support, raising awareness about SACT side effects and giving people the confidence to approach the agreed health board team at an earlier stage with any concerns, instead of waiting until it becomes an emergency. The UKONS (UK Oncology Nursing Society) oncology/haematology 24-hour triage rapid assessment triage tool is used by the nurses when assessing clients and initial contact is followed by several more calls over the next few months. Nurses use holistic needs assessments to identify physical, emotional and practical needs, as articulated by the patients, and offer referrals and signposting to other services.

Feedback suggests that the service offers effective and welcome reassurance, professional information and support, and practical advice on side effect identification and management. Importantly, it encourages seeking help for alleviable side effects. Listening skills and emotional support provided by the Tenovus Cancer Care support line nurses during telephone calls have led to patients reporting a sense of relief, of not feeling so alone, and that the calls have lifted their day and improved their coping abilities. Staff are generally rated highly for knowledgeability, helpfulness and approachability, and conversations are reported to reduce anxiety about treatment and side effects.

It was uplifting to hear the enthusiasm for innovation and the future of AOS care in Wales from the nurses, doctors and therapists that we interviewed. A key theme that emerged from our research was the desire for more collaboration, regional working and shared learning. From virtual clinical advice sessions to the management of highly specialist cancer treatment side effects, from the idea of a central 24/7 helpline for patients and clinicians to shared MSCC coordinators, everyone was very keen to explore new opportunities for working together to improve patient care and expand AOS to more people.

**'I've really enjoyed the challenge of the past few years. It's unpredictable, and you never know what's coming through the door. I'm glad I never gave up: things don't happen straightaway, and it's taken us a long time to get to this point, but we've managed it. It is worth being patient.'**

– advanced nurse practitioner



# Acute oncology in action: The stories told by staff

**'I'm really proud of the MUO team and how far we've come. It's such a lovely MDT; it's very patient-focused and it's so interesting'**

I've been a consultant oncologist in Swansea for 10 years. I didn't do any AOS as part of my training; it wasn't really a thing back then. It was in 2015 that the first AOS business case was funded – three clinical nurse specialists and an MUO MDT. Palliative care was very involved. I think they were doing a lot of ad hoc acute oncology at the time. A couple of years later, I was clinical lead for oncology and inherited AOS and MUO overnight – it was passed to me after other staff left the organisation.

To begin with, I did the MUO work myself and to my surprise, I found I really enjoyed it. But I was single handed. We needed to stabilise the service, so if I was on leave, the on-call consultant would cover the MDT and referral. Eventually the MUO work was recognised in my job plan. The MUO MDT meets once a week and includes three AOS nurses who act as keyworkers, as well as pathology, radiology, oncology, primary care and palliative care. We've also set up an MUO clinic to see patients, and we've been awarded money through the Moondance Foundation for a radiographer to speed up treatment pathways. I now have colleagues to help me.

We've sometimes had to be creative with how we fund things. We've got a management team that's really flexible and positive about letting us move money around to build the team organically. I'm really proud of the team and how far we've

come. It's such a lovely MDT; it's very patient-focused and it's so interesting. There's a really good community of practice in Wales now. The Wales Cancer Network has a MUO-CUP working group which provides peer support.

MUO can feel like the poor relation, but we have a fantastic team of people who really see the value in this work and want to provide excellent patient care to those people who might previously have fallen between the gaps in the system. I can't believe we went this long without an MUO service really. Patients would have been bounced around the system. Their experience and outcomes would have been much worse in some cases.

We offer clinical advice to the Hywel Dda AOS nurses, but we're not funded to provide an MUO service. We're keen to create a joint MUO MDT in the future though, and we're costing that now. It's complex. Under a long-term agreement, we provide cancer services to Hywel Dda, but where there's new and innovative work, like an MUO service, we need to agree separate funding with them. It's very difficult. We don't want to ignore Hywel Dda patients, and I will discuss them outside of MDT on an ad hoc basis, but there is no formal arrangement in place. Because of the case mix in Swansea, we know that there must be patients who would fit into an MUO service if it existed in west Wales.



The challenge now is what that MUO service looks like across four sites. There is an oncologist based in Bronglais, but she has no capacity to support any other hospitals, so where do you base the MDT and the MUO clinic? Other health boards in Wales have identified a non-oncology AOS lead in their health board, but Hywel Dda have not managed to find anyone yet. Getting patients in west Wales access to our MUO service is an absolute priority.

In terms of AOS, we have three nurses with consultant review once a week at Morriston. For a while we had clinical fellows on the service, but we didn't have enough time to mentor and support them. More recently, we've been able to allocate some consultant and specialty doctor time and now we have three funded sessions a week in Morriston to support the AOS nurses on a 5-day rota.

Pre-COVID, we ran educational sessions to raise awareness of acute oncology, but a lot of that stopped overnight when the pandemic hit. It's an ongoing battle and very time-consuming, especially when doctors-in-training move around so much. The reality is that we're often just firefighting, given the rise in patient demand at the moment, and we're expecting Morriston to get busier when the acute medical take consolidates on one site.

For years, we were under the impression that the plans included a specialist cancer centre on the Morriston site. More recently, we've learned from the new chief executive that there's no funding for a new centre, and we'll be staying at Singleton where the vision is for a centre of excellence with cancer surgery on the Singleton site. It was a real blow at the time, but at least it was honest feedback which means we can plan ahead, and I do feel we are being heard.

The Swansea Bay reorganisation includes lots of SDEC and we felt that we needed more specialist nurses on the ground to support the medics with expert decision making. We also need to set up hot clinics to see patients within a few days of discharge from SDEC. To deliver this, we're recruiting senior nurses and physician associates, and we're putting in place a senior AOS nurse manager to lead the nursing team and develop the hot clinic model. Finally, we've had 15 consultant oncologist sessions funded as part of the redesign of acute medicine, which will hopefully give us some flexibility and stability to expand and develop AOS. It's really exciting.

We're also hoping to create a clinical navigator role to triage patients by phone, sending them to either the emergency department or ambulatory care in Morriston, or the assessment unit in Singleton. Those calls currently come into the on-call registrar, which isn't the best use of their time. Once this is all bedded in, we will look at introducing 7-day working in line with other services.

Recruitment is tricky. There is a shortage of oncologists, and it's even harder in rural areas. But that shouldn't stop other parts of Wales applying for the funding and making the business case. If you don't have the money in the first place, you can't recruit the people. At least with the funding in place, I can slowly start to build the team, appointing good people as they become available. In some ways, that's more sustainable because the team grows organically and isn't reliant on one person: it means that we've built resilience into the service.

### **Dr Sarah Gwynne**

Consultant clinical oncologist, Singleton Hospital  
Clinical lead for oncology  
Swansea Bay University Health Board

# 'GPs need oncology teams to be very explicit and direct and tell us what they want from us'

I am the primary care clinical lead for cancer for Swansea Bay. My job came about through a 5-year, Macmillan-funded project to develop the links between primary and secondary cancer care. Now I'm employed by Swansea Bay to develop cancer referral pathways and to represent and feed back to primary care about what's happening in cancer care.

I am a salaried GP working in Bridgend. Most GPs aren't involved with acute oncology. If a patient becomes unwell, and they have cancer, we may have discussions with an AOS team. But quite often they will go directly to their specialty team with any questions or concerns.

We need better communication between oncology teams and primary care teams. We're currently working on an all-Wales cancer care treatment summary, which is held by the patient and moves between primary and secondary care. Those of us in primary care need to know who to contact and what to look out for: things change so rapidly in cancer care that GPs can't hope to be up-to-date with every side effect of every new treatment, so it's all about communication.

GPs need oncology teams to be very explicit and direct and tell us what they want from us. We don't need every single detail about the patient's treatment, just what might be expected from us and any information that might help us to deliver good patient care, especially about the prognosis of the patient. GPs often receive very complicated, lengthy letters from secondary care with a request for action buried deep within the document, but increasingly it's very difficult to pick out what's important, especially when we are so pushed for time in primary care. What we need is contact information – where do we go if we're not sure about something? What if there's an emergency?

Secondary and tertiary care colleagues don't necessarily understand what the day-to-day workload looks like in primary care. A lot of the decisions we make as GPs about treatment and medications are influenced by the bigger picture, which is why we need secondary care to be very clear in their communications with us. I've learned in this job that specialist colleagues are quite approachable, and if I have a question, it's okay to email them. It's all right to get in touch.

Of course, it goes both ways. I've sat in oncology clinics. They fit a lot of information into a short appointment, and we all need to appreciate that everyone is working hard. Nothing is easy or straightforward and we all need to try and understand each other's roles a little bit more so that we can help each other as best we can. Patients are reassured and receive better care if the GP understands what's going on in their specialty treatment.

Change is slow. Things take time. We've done pilots, but the pandemic has really slowed us down, and everyone's short staffed. It would be really helpful to have better community support for some of our patients. The triage helplines can be busy; sometimes they divert people to their GP, who doesn't always know the back story. One day, it would be great to have specialist acute oncology nurses based in the community for example, like the team working in community palliative care who can provide expert advice locally.

Everyone thinks that cancer is only dealt with by oncologists, but actually it's not. It's dealt with by lots of different specialists, and GPs have to build a relationship with all of them, which is why it's really positive that primary care is becoming more involved with acute oncology services.

**Dr Gemma Eccles**

Macmillan GP cancer lead  
Swansea Bay University Health Board

# 'I've been very impressed with the curiosity in Bangor, and the enthusiasm to try new ideas, pilot innovation and learn something new'

Betsi Cadwaladr University Health Board is geographically very large, with three separate acute oncology services. In Ysbyty Gwynedd, there is a dedicated named consultant on the rota every day to provide on-call support to the acute oncology assessment unit, working with the nurses who lead the service. During the pandemic, we wanted our patients to bypass the emergency department, so we developed a separate entrance with three beds where we would assess acutely unwell patients and then either admit or discharge them or refer them to other services, so that they didn't have to go through ED.

Staffing is the biggest challenge we face. We don't have enough doctors. On one single day, I might be responsible for the assessment unit, a ward round, an MDT meeting and the new patient clinic. If everything goes smoothly, I can manage. If there's an emergency, that's when it becomes an issue.

I have always been interested in digital health and innovation. We've been working on a project to monitor cancer patients remotely through a smart watch and an app, so that we can intervene before they get so sick that they might have to be admitted. We've focused on frequent attenders who often come in with treatment side effects. Everyone has been really enthusiastic about the idea, and very willing to provide advice and support.

It's still quite unusual to have a dedicated assessment unit for acute oncology and haematology. I trained in France, and acute oncology doesn't really exist there. I've been very impressed with the curiosity in Bangor,

and the enthusiasm to try new ideas, pilot innovation and learn something new. There is an attitude among clinicians here that if it can be done in principle, we should give it a go.

Being part of a team and listening to feedback from colleagues is vital. I'm mentoring three nurses to become advanced nurse practitioners. I really think it's super, it's really fulfilling to see people developing and growing their responsibilities. We have just recruited our first physician associate, which is very exciting. My colleague will lead on medical education for the doctors, and I will lead on the mentoring and support for nurses, AHPs and physician associates. A lot of my research is not only medical, it's about having a healthy lifestyle, so it's important to have a multidisciplinary approach from the start.

We need to invest in training people locally and adapting their job role to the best of their ability. We need better equipment: our laptops are prehistoric. Where we've secured new equipment, we haven't been able to get IT to install the software to make it work. Yes, we need more staff, but it's not just about personnel, it's about the whole environment and allowing people to work at their very best. If everything works well in their surroundings, people will stop looking elsewhere for a new job. They will grow and develop if you give them the opportunity. That's how you retain staff.

## Dr Pasquale Innominato

Consultant medical oncologist, Ysbyty Gwynedd  
Betsi Cadwaladr University Health Board

# ‘It’s crucial that we simplify the system and improve access to specialist advice when a GP has a seriously unwell cancer patient’

I have been the Velindre Macmillan GP lead since 2016, working closely with the acute oncology services (AOS) team in VCC, and I’m the Macmillan GP adviser for Wales. Every health board has a GP cancer lead or facilitator: we hold away days where primary care leads from across Wales get together to discuss innovative projects and share learning to improve services.

In my Velindre role, I’m working to improve communication between primary and specialist care, especially the language we use for prognosis and treatment. I’ve also developed primary and community care education sessions, working with Cardiff University and Macmillan to deliver evening and face-to-face learning.

I’m leading work to develop all-Wales treatment summaries that provide clear, understandable and patient-held information, which was a commitment in the 2016 cancer delivery plan. We’ve piloted this in Swansea, with highly positive feedback. The idea is not new: various teams have been using these for a while, but now we want to roll out an all-Wales version that can be recognised and used easily by anyone working in NHS Wales. We’re now working on linking IT systems for a second pilot and considering how we can minimise digital exclusion.

Change takes time. Everything takes longer than you’d think. It was easier when we were face to face, but sometimes it feels like primary care is out of sight, out of mind. Consultant colleagues from Velindre have taken part in our educational events, and we’ve publicised the AOS app, but getting the message out to primary care on the ground is quite tough. There are so many things we need to know, and it’s wider than just GPs – it’s practice nurses, paramedics, physiotherapists and many other professionals. A single learning event won’t attract everybody, and we are reliant on people in a practice spreading the learning when they return to work. We often send newsletters, but it’s one of many emails that people receive.

It’s crucial that we simplify the system and improve access to specialist advice when a GP has a seriously unwell cancer patient. It would be good if primary care could join specialist AOS MDT team meetings. Most cancer patients spend the majority of their time outside hospital, and those who have a longstanding relationship with their GP might present to primary care before they ring a treatment helpline. For patients without a clear treatment pathway, GPs might spend a lot of time ringing around for advice before the patient ends up going to the emergency department (ED), where they might have a terrible experience because of the pressures on acute hospitals.

A direct advice line for clinicians would help. If a patient rings the treatment helpline with chemotherapy sickness, they might get told to contact their GP for medication. But without the full treatment history, I won’t know what to prescribe. Even better, the clinical team at Velindre could ring an ex-directory number for the GP practice and leave a message for the GP. I know people are busy, but it’s not fair on patients and relatives if they are left to ring around in an emergency for help. We’re hoping that e-prescribing will make this easier when it comes in.

The issue with Consultant Connect is that it’s best for generic advice. Many cancer patients are on a very specific pathway, and their oncologist might not want someone else suggesting treatment options. If I need advice, I’ll email the named consultant. If there’s no response I’ll go through the main switchboard, then the AOS team, then maybe the registrar on call. It is hard to get the right information and I don’t have the time allocated to chase up every single patient. There’s no clear process, which means that when I need specialist advice, it’s happening in a very unstructured way.

Fundamentally, the issue is that there isn’t a one-size-fits-all emergency pathway for cancer patients. The hospital AOS nurses are very helpful, and it would be

good to work more closely with them and develop a process for flagging potential admissions before arrival, whether that is at ED or an assessment unit. In an ideal world, there would be specialist cancer support at every district general hospital. Medical assessment units should have dedicated oncology beds managed by the AOS nurses, with access to emergency diagnostics and treatments. But in reality, that's very hard to achieve. When there are ambulances queuing outside, ethically it's difficult to ringfence beds for a single specialty.

We need a change in mindset to provide more services in the community, accompanied by a massive publicity campaign to inform and educate people about the different types of health professional they can see. We need faster, more equitable access to diagnostics, prehabilitation services and holistic support, eg named key workers with specialist knowledge. We need safe, equitable, robust out-of-hours and emergency unscheduled care and advice for all AOS patients.

Communication between professionals could be improved: for example, if a patient is in a clinical trial, there's no guarantee that their GP will be informed. On the other side of the coin, I don't need pages and pages of case history for my specialist colleagues: I just need to know the patient's current treatment, prognosis and any action required from the primary care team. The important information should be highlighted at the top of the patient's notes, not buried several pages in. When the system feels broken, sometimes it feels like climbing Mount Everest to make these changes, but there is often an easier, more efficient way of doing things.

### Dr Elise Lang

GP adviser for Wales, Macmillan Cancer Support  
Macmillan GP cancer lead, Velindre Cancer Centre  
Interim lead, primary care cancer framework,  
Wales Cancer Network

## 'Developing these services needs senior input and proactive clinical leadership'

I'm a consultant medical oncologist. As a doctor-in-training, I worked mainly here in north Wales and carried out outreach ward rounds. That's how I got interested in acute oncology, and how I came to set up a service for cancers of unknown primary (CUP), which was the first in Wales.

There have been named AOS nurse practitioners in hospitals in north Wales for around a decade, and I set up other AOS services in Ysbyty Gwynedd off the back of that and within existing resources, so it was quite straightforward. The downside is that we were making do. I don't think we've ever moved away from patching together the service. Expanding and resourcing the service has been a real ongoing challenge for us. A lack of funding is a key issue. Recently we've seen some investment in Wrexham, with some consultant acute oncology sessions funded there, but now the recruitment of both doctors and nurses is becoming a bigger problem.

There's only one clinical nurse specialist at each of the three acute hospitals in Betsi Cadwaladr University Health Board, supported by a consultant clinical lead. That means that if the CNS takes study, sick or annual leave, the service shuts down. There's recently been a push to try and increase staffing and some sites are now starting to recruit administrative support – but ideally there should be two nurses at each site as well as an administrator to support the team, especially with data collection. (In Bangor the CNS does it, which is not a good use of clinical time.)

None of the medical oncologists at Ysbyty Gwynedd have protected time for acute oncology. The biggest barrier in setting up AOS for north-west Wales has been limited resource and capacity. I didn't have any administrative or managerial support to put together the business case and supporting documents for the CUP service and the assessment unit, despite having other clinical duties and responsibilities. It was a poor

use of my time, and it's slowed down the process. Trying to achieve change is really difficult and the funding system is really opaque.

Because we couldn't get funding, we just got started anyway and built the service quietly in the background, with hard graft and by asking for favours. I would have preferred to do it with a business case, but nobody was interested. The problem is that now it is set up, people think we can manage without extra help. For every service we've set up with no additional resource, we've stretched ourselves even thinner, sometimes to breaking point. But what's the alternative? Waiting for funding wouldn't get anything done. It's a difficult balance.

Historically, we are measured on how quickly we treat diagnosed cancers coming through the scheduled pathways, so that has always taken priority. There is no scrutiny on how we treat the side effects of those treatments, which is still a major issue. If someone is admitted out of hours, or the AOS nurse is on leave, then the patient ends up in ED or AMU. Yes, there's a safety net, but it's not high-quality patient care and experience.

During the pandemic, we set up patient self-referral assessment unit in Bangor, 9am–5pm on weekdays to triage patients by phone call and keep them out of hospital. We found that we reduced ED and AMU admissions and helped to bypass primary care where appropriate. In those patients who were admitted, there was a reduced length of stay. We were able to do this because there were fewer inpatients during COVID-19, so we could reallocate nursing staff; then we collected the data and used them retrospectively to prove the effectiveness of the unit. There was never a formal business case.

Hopefully in a few years, there will be an AOS assessment unit in all three hospitals in north Wales. The assessment unit in Ysbyty Gwynedd has been a great success, but only because we have taken opportunities when we can. There's no longer-term strategic plan. It can be exhausting.

It would make a huge difference if there was a clear process for seeking funding for a new idea, with central administrative and project management support for developing a business case, instead of expecting clinicians to do this on top of a heavy clinical load. There are so many hoops to jump through, even to set up or expand services that are well established in other health boards. It's just so frustrating.

Developing these services needs senior input and proactive clinical leadership. You need someone who is willing to really push to get things done, while being prepared to wade through treacle to improve services with limited support. Cancer patients in crisis don't want to go to the emergency department. They want to see a doctor who understands their case; they should be able to call us directly and ask for advice.

Health boards need to invest in timetabled, protected time for consultant acute oncology sessions so they can see patients and teach trainees. Just a couple of ward rounds a week to train, educate and support colleagues on the shop floor, especially with difficult cases. After all, our acute oncology nurse practitioners are amazing. We really ask a lot of them and I'm not sure we give them the credit for everything they do and achieve.

Acute oncology is as important as site specialty oncology. It's what matters to patients. It makes the difference between a good life and a good death. It's so exciting to know that the Welsh Cancer Network is pushing acute oncology forward – it's something I feel passionately about.

### Dr Anna Mullard

Consultant medical oncologist  
Acute oncology lead, Ysbyty Gwynedd  
Betsi Cadwaladr University Health Board



# ‘It would be helpful to have more of a medical presence in the more remote and rural hospitals’

When I had my initial interview to become a specialty doctor in Singleton, the panel were very keen on the fact that I had very recently been a medical registrar and was open to working in acute oncology. I didn't start working in AOS straightaway, but after a while, I started doing a ward round once a week at Morriston to bolster the acute oncology service we were offering patients there.

I'm currently the named clinical lead for AOS in Hywel Dda. I do two virtual sessions with the AOS nurses to discuss complex cases and provide them with senior support. Previously some of that was being done by the on-call registrar, so it helps to reduce their workload. There are oncology doctors covering the inpatient ward at Bronglais Hospital in Aberystwyth, although I provide virtual senior input when they're on leave. There are six or seven AOS nurses covering the four hospitals in Hywel Dda.

During one of my virtual sessions with the AOS nurses, they'll bring complex cases for discussion, then we try and do some teaching and shared learning afterwards. The CNSs often struggle to get away from the wards and attend those meetings though, so we may need to revisit the set-up and decide on the best way forward with them.

Giving specialist advice sometimes feels like banging my head against a brick wall. Quite often with oncology patients in west Wales, we rely on the medical and surgical teams locally to provide equitable care, but there's no guarantee that they will take specialist clinical advice from the AOS nurses in Hywel Dda, which has been discussed with myself. Some of this comes back to education, both in Swansea and in Hywel Dda.

We don't have AOS-specific therapists at the front door, although we do have therapists on the inpatient ward in Singleton who do assessments. There's no specialised oncology assessment unit in

Swansea at the current time, although there should be improved SDEC under the new model of acute care at Morriston, with AOS nurses on site. I believe we're going to have around 30 beds for oncology and haematology in Singleton under the new plans for Swansea Bay (with no capacity for 'outlier' patients), so we'll have to be careful about which patients we admit under specialist oncology services going forward. We hope to establish hot clinics and to expand the workforce with more physician associates/CNSs: we're aiming for a full 5-day service in Morriston in the short term.

If every hospital had an acute oncology assessment unit, one of the risks is that the cancer service would become overwhelmed with acute patients, when many of these could actually be managed by the on-call general medical team with input from specialists. This would free up tertiary bed space for urgent chemotherapy or radiotherapy. Having an AOS CNS on the ground means that there should always be someone who can physically see patients and update their treating consultant.

However, in an ideal world in west Wales, they would be supported by a doctor doing a ward round at least once a week in their hospital: maybe travelling between more remote sites. I would enjoy doing some in-person reviews of patients in west Wales, but I'm also very aware that a lone medic could quite easily get overwhelmed by the work and the travel. On the other hand, I think it would be interesting from an educational perspective and very helpful to have more of a medical presence in some of the more remote and rural hospitals.

## Dr Nia Jackson

Senior clinical fellow in oncology  
Swansea Bay University Health Board



# 'Acute oncology is now part of the new medical and clinical oncology curriculum [and] we need to show that we are helping to reduce the workload of the acute take at district general hospitals'

I chair the specialist training committee for medical and clinical oncology in Wales. When the curriculum was combined last year, creating the oncology common stem, the two specialties worked together to ensure an increase in the amount of acute oncology in specialty training.

Acute oncology is not just about managing patients within a tertiary cancer centre; it's also about supporting the on-call medical team in district general hospitals and reducing the pressure on the acute unselected take. Hopefully, in a few years we'll start seeing consultants who have actually trained in acute oncology rather than falling into it by accident; so far, we've developed it locally depending on funding and opportunity.

The AOS model that we have developed in Wales is very nurse-led, partly because of staffing cost and workforce challenges. So far, the model has worked well, and allowed us to set services up more quickly than otherwise might have been, because of previous chronic underfunding of training and consultant posts in cancer in Wales, but even if we had the money to appoint doctors to develop acute oncology services, the oncology medical workforce is still developing into these roles.

My experience of having AOS nurses in Morriston has made a huge difference; they can see cancer patients in person and update the doctors in Singleton, providing important continuity and support for medical teams managing oncology patients in Morriston. The nurses in Hywel Dda are amazing; they give us really comprehensive summaries of the patients who have been admitted there, some of whom we know about, some we don't. They liaise with us and the medical team locally and keep the lines of communication open.

Ideally though, you would want a consultant doctor with two or three AOS sessions a week in each district general hospital, working as part of a multidisciplinary team to review patients and support the specialist

nurses with teaching and development. That would be really good for training; if there is a visible presence on the ground in a hospital, people are more likely to approach them and involve them in improvement and medical education.

Acute oncology is now part of the new medical and clinical oncology curriculum. That means covering the acute oncology take, managing oncology emergencies, providing oncology advice to other healthcare professionals, being part of an acute oncology service, managing the acute oncology team. It's mandatory. Time needs to be ring-fenced for acute oncology training, and that cannot just take place in a cancer centre. You have to gain experience working in a DGH setting. Working at Velindre, or at Singleton in a specialist cancer centre will not be enough. We need to show that we are helping to reduce the workload of the acute take at DGHs, and trainees should be supporting nurses with training and education as well as providing clinical advice.

Trainees will benefit from the different approaches in each cancer centre across Wales. Oncology trainees in Swansea have scheduled AOS sessions within their timetables, including consultant-led ward rounds in Morriston, MUO clinic and MDT meetings. We'd love to do something similar with Hywel Dda hospitals, but that's not feasible at the moment as our presence there is all virtual. Acute oncology nurses and trainees benefit from working with each other and they both benefit from working more closely with the consultant oncologists. It can reduce overall consultant workload because some of the more straightforward medical decisions can be made and actioned by the trainee. It's not a hierarchical system, it is very much a team approach.

## Dr Rachel Jones

Chair, specialty training committee for medical and clinical oncology  
Consultant medical oncologist Swansea Bay University Health Board

# 'Closer working between AOS and specialist palliative care teams in acute hospitals is so valuable'

Specialist palliative care should be part of every acute oncology team: a lot of AOS patients sit across both services, especially MUO patients, many of whom are essentially palliative from diagnosis. In fact, many palliative care teams were often doing something that looked a little bit like acute oncology before acute oncology had ever been thought of, and the AOS service in Swansea was partly modelled on what we'd been trying to do with palliative medicine in the acute hospitals.

For a small specialty, our national network is strong. There is a palliative and end-of-life care national clinical lead and a pan-Wales implementation group. Because palliative medicine is connected with almost every specialty, it's difficult to organise structured engagement with any one area of medicine. Palliative medicine is not just about cancer: clinically, more patients have palliative care needs that don't have cancer than the ones that do, and we don't always meet those patients' needs because we struggle with staffing and resource.

We need to help more people understand what acute oncology is. It causes a lot of confusion, especially when the service is not staffed properly so you can't rely on having cover every day of the week. Agreeing a standardised model of care will be helpful in achieving parity of care everywhere. A hub and spoke model might work as long as the outreach is strong enough and it's clinically led.

At a national level, we've had years of under-investment in the NHS and it's really showing. We need updated facilities, more beds, more staff, better social care. We've got a situation that's just not working, but everybody's trying their best. At a local level, we need health boards

to recognise that end-of-life care should be a key priority for investment, and better health economics support with data collection, audit and QIPs. How can we show that we're providing value-based healthcare without the data analysis to back it up?

We need to get better at asking what will make a real difference to the outcomes and experience of a patient and their family. How can palliative medicine and AOS come together to agree the outcomes we should be measuring? We have a growing workforce crisis in palliative medicine, but with better data, we could make more informed decisions and better use of the limited number of staff we have.

Palliative medicine goes where the patients are. It's the outlying hospitals, the community patients, they are the ones who AOS needs to reach. Around a fifth of acute hospital beds are occupied by people who have some sort of cancer-related problem, and a lot of those admissions might have been avoided with more proactive AOS community care. Closer working between AOS and specialist palliative care teams in acute hospitals is so valuable: it should be embedded in the design of acute oncology services.

## Dr Gwenllian Mair Davies

Clinical lead for palliative medicine  
Swansea Bay University Health Board

## Dr Gemma Lewis-Williams

Co-clinical director for palliative medicine  
Betsi Cadwaladr University Health Board

## Dr Idris Baker

National clinical lead for palliative and end of life care,  
Swansea Bay University Health Board

# 'We need to get better at looking after our staff and building a high-quality MDT workforce'

I've worked in more than 10 hospitals in different training posts over the past decade, so I've seen lots of different ways of developing services, including acute oncology, which I enjoy because it's interesting and diverse.

All our admissions in Velindre are acute oncology patients, so we're a bit different. At University Hospital of Wales (UHW), there is a flag system upon admission, which picks up all those patients who have ever been diagnosed with cancer and refers them to the MDT for review. It's over-sensitive because it's not time limited and it picks up everyone, regardless of why they have been admitted that day, but it's better to err on the side of caution. If someone with a history of prostate cancer comes in with back pain, the AOS team should spot if there's any connection between new symptoms and a historic diagnosis.

The system is different in other district general hospitals, often because of a lack of staff. Most other hospitals do not have a functioning flag system. They simply don't have the resource. If there is only one specialist nurse based at a hospital, it's not fair on them. There isn't the cover when they take leave, which means that things slide. AOS nursing can be difficult; it's very independent. Quality nursing is the thing that matters most. It's what makes the difference, especially in improving access to services. We need to get better at attracting and keeping good nurses.

There is now an oncology registrar at UHW every weekday morning, supported by an admitting consultant, with out-of-hours telephone support. I've been getting some very positive feedback from the medical and surgical teams about seeing us and knowing that someone is there. It reduces the workload of the medical and surgical on-call teams and means that reviews are done earlier.

AOS is a safety net, and unless you're able to provide a reliable service every day, people won't use it because they need to be able to rely on it, and things won't get flagged the way they should. Half done is almost worse than nothing at all. If an oncology service doesn't have proper multidisciplinary input, it just makes life more complicated. I worked in one hospital where the AOS team only had a presence for 3 days a week, which wasn't enough to cope with the workload, so reviews were often delayed, and people didn't bother making the referrals in the first place.

Ultimately, it's about people, and not just doctors. You need good nurses, AHPs, diagnosticians, radiologists, geneticists. Attrition is a big problem. We need to get better at looking after our staff and building a high-quality MDT workforce.'

## Dr Ruth Stone

Specialty registrar in clinical oncology  
Velindre Cancer Centre



# 'The success of these projects will depend on the drive and momentum of clinicians working together'

There's a beautiful synergy between what we can do at Velindre and what our health board colleagues can do. In Velindre, we've developed a very holistic model with the therapies, palliative care and oncologists all working together in the same assessment unit and ambulatory space, led by ANPs. It would be great to have a similarly holistic approach with access to oncology expertise in our local health boards.

In an ideal world, patients would ring the triage helpline for advice on where to go. Patients should be assessed initially in an emergency department if the acuity necessitates this, and if appropriate they should be able to get holistic input from allied health professionals, either in an assessment unit or an inpatient ward. As long as there is an ongoing dialogue between professionals, and a robust pathway to move patients around the hospital if their condition changes, then we don't need a one-size-fits-all approach. The long-term goal is to get patients to the right place, at the right time, first time round. We need better regional integration on the more specialist issues, like the immunotherapy toxicity service.

There is a risk that we lump all of the very difficult, complex problems together under the heading of 'acute oncology', and we make no progress because it feels so big that nobody knows what to do with it. If I could wave a magic wand, I'd bring everyone together and portion out the work, so that everyone was clear on who was leading what, and how they should work with each other.

The challenge is finding oncologists to take consultant sessions in the health board. There is a lot of pressure from the health board executive teams to employ oncologists on the ground, and I absolutely agree with that approach. But we have to be realistic. We simply don't have oncologists waiting in the wings to fill these jobs. Instead, we've got to be honest and transparent about the situation and consider different ways to staff oncology medicine in district general hospitals: are we using specialty doctors effectively? How about upskilling other CNSs and ANPs?

I am trying very hard to build stronger links between the three specialist centres in Velindre, Singleton and Rhyl. I'm often contacting my north Wales colleagues saying 'This meeting exists, do you want to join it? Can we collaborate?'. It's vital that we encourage people who are really passionate about a 'once for Wales' approach to be as involved as possible. The success of these projects will depend on the drive and momentum of clinicians working together. I believe that collaboration is going to be the way to make progress. It's about mutual support.

## Dr Ricky Frazer

Consultant medical oncologist  
Velindre Cancer Centre

# 'As therapists, we screen patients who come into the AAU to identify their needs, reduce admission and provide early intervention'

Four years ago, Velindre secured Macmillan funding for allied health professional time on our acute oncology assessment unit. We have very much taken an MDT approach, and now the therapies team is completely integrated into the patient care that we deliver at the front door.

Therapy intervention in acute oncology not only helps to avoid admission into hospital, it also reduces length of stay and facilitates earlier discharge. We can help patients to self-manage their health by providing earlier intervention with fatigue, pain or breathlessness, and it can really enhance their quality of life. That's what's key to improving the patient experience.

Velindre has an ANP-led assessment unit, with the ethos being a multidisciplinary holistic approach. As therapists, we screen patients who come into the assessment unit to identify their needs, reduce admission and provide early intervention. We carry out a small number of community visits: we'd like to expand those alongside our therapy-enhanced discharge service. We are still a very fragile team. We've grown over the years, but we are still fairly small for the services we're trying to deliver. Seven-day working is an ambition for the unit, because people still require assessment and possible admission on a weekend.

We've worked hard to educate other healthcare professionals about the roles and the value of having AHPs on the unit. Four years down the line, we've proved our value and integrated ourselves as part of the MDT. Our role is to look at the bigger picture: treating patients holistically is absolutely key to preventing admission. After all, we aim to maintain safety, independence and quality of life. Patient experience has been very positive, and we get valuable feedback from the patients. To the outsider, it might look like an occupational therapist providing a commode is just giving them a piece

of equipment. But the commode might prevent a night-time fall, therefore avoiding a hospital admission, which in the longer term, will have a positive impact on the individual's quality of life. A significant proportion of AHP time is also dedicated to non-pharmalogical symptom management like breathlessness, fatigue, pain and anxiety, which are side effects of both diagnosis and treatment.

Collaboration is key. Velindre hosts a lunchtime AOS meeting for health boards in south-east Wales to look at complex cases, metastatic spinal cord compressions, and other acute oncology presentations, which really helps to build relationships with the health boards. We want to make those a central hub for advice and support, with formal notes made by the AOS coordinator. If we don't have that meeting, things do tend to fall apart. The challenge now is to increase engagement and attendance from the AOS teams across south-east Wales to ensure shared learning.

Initially, it was a big challenge to find space to house us all. You want the whole team to be co-located to enable those MDT discussions: that's important. On any given weekday, there are medics, ANPs, nursing staff and a healthcare support worker, plus the visiting palliative care team and AHPs.

We need to develop more specialist AHP knowledge in the health boards. When a patient is discharged home, they face a postcode lottery in accessing follow-up support from therapies. The digital infrastructure needs work too: patients don't always come in with a transfer letter, so we have to spend time chasing the health boards for their medical and surgical history. That's about improving processes and pathways and collecting the right data to make the case for investment. If we can measure the right outcomes, it's much more powerful to develop the service further.

Transport is another challenge. Moving patients between sites in a timely manner, particularly on the weekends, can be difficult, and delays can have a huge impact on patient outcomes and experience.

Ideally we'd also have access to an MSCC coordinator for every health board. We need to ensure that patients are going for surgery when appropriate and in a timely manner. In Wales, we've never invested in MSCC coordinators, which puts pressure on the system and staff. Decisions aren't being made quickly, communication is too slow, and we're often missing our NICE targets. It's a big risk.

Things have changed massively over the past 10 years. AHPs in AOS were hidden a decade ago. Patients weren't as complex and treatments weren't as advanced as they are now. We've come a long way, but there are still challenges

to ensure that AHPs are core to every AOS team. Patients are presenting at a later stage, especially post-pandemic, and the need for AHPs to improve quality of life will only increase. AHPs should be core members of the AOS team: we make a real difference to patient outcomes.

#### Kate Baker

Macmillan therapies manager  
Velindre Cancer Centre

#### Cathryn Lewis

Macmillan clinical lead for occupational therapy  
Velindre Cancer Centre

#### Kate Williams

Specialist physiotherapist  
Velindre Cancer Centre

## 'The definition of acute oncology is so open to interpretation: it's a very difficult balancing act'

As the advanced nurse practitioner in the Cardiff and Vale acute oncology service, I took on this role in 2015 managing the AOS nursing team and I am involved in developing the enhanced AOS business case for south-east Wales. Seven years ago, when I started, there was quite a frosty relationship between Cardiff and Velindre. Building those networks and relationships has been difficult, but we've managed to build bridges and there are a lot of people on both sites who want to make things better for patients.

We set up a forum of AOS nurses across south-east Wales to start networking, communicating and building relationships across the region. It was tricky at times, and there was pushback from some people who did not agree that AOS should be a nurse-led service.

A big challenge is that the sites are so close to each other. Many cancer patients would rather go to Velindre when they are acutely unwell, but when they phone the treatment helpline, perhaps the assessment unit is full, or they are too sick, so they are sent to ED. Psychologically I think it's quite difficult for local patients to accept that they cannot just go to Velindre when it's so close.

Having a senior clinical decision-maker on the ground will certainly help some patients, especially those with disease progression, or new cancers, or treatments. The business case in south-east Wales now has funded oncologist sessions, and changes to the oncology training curriculum mean that we now have a visiting registrar during the week, which has been good. It's helped the relationship with Velindre. But the downside is that some nurses feel they've lost autonomy. So now it's about finding a new way of working and adapting to change.

If we need an urgent decision, we can dial into the lunchtime Velindre AOS meeting on Microsoft Teams. We work closely to agree a plan of action by email with site-specific oncologists if one of their patients is admitted to UHW, and we have palliative care consultant input once a week, which is valuable. We've talked about holding early morning meetings to touch base, but there aren't enough hours in the day. More collaborative working with a consultant oncologist presence would have benefits.



The vision is for UHW to have an inpatient ward, whether it's a cancer ward or joint with haematology, and I'd like us to have day-case facilities. We've just started an outpatient clinic – a hot clinic – for patients who need to be seen, but don't need to go to Velindre or the ED. We're trying to do it in bite-sized chunks, so we don't get overwhelmed.

Having a dedicated ward would allow us to bypass the ED. We'd need more oncologists and ANPs and it would be amazing to offer a 7-day service, but that's reliant on funding and staff. We've now got an occupational therapist, physio, dietitian and funding for speech and language therapy input in the Cardiff and Vale AOS team, and they have made a world of difference already. They are able to get people home quicker, we're taking more risks because they're being assessed by the therapist, and it's improved the quality of our multidisciplinary case-based discussions. And if we had a magic wand, we'd have a regional MSCC coordinator for south-east Wales.

It's important to manage expectations and be patient. It's been a long journey; I thought everything would happen more quickly than it has. I wasn't prepared for some of the setbacks we've faced. We're in a better place now though, with data, secretarial and project support, which frees up our clinicians to see patients. In the future, I'd like more technical and digital support for the team. I'd like to recruit more junior nurses to support patients and admin staff to capture patient experience.

When we appointed to our new nursing posts, I recruited a CNS from a neighbouring health board, which has left their AOS team in trouble. It's just shuffling chess pieces, and there's a whole workforce issue with doctors and nurses that just needs to be addressed by government.

We need more doctors: we need more palliative care input. And there's an argument for outreach AOS in the community, which might stop patients coming into hospital in the first place. The problem is that people arrive at the front door of the hospital, and if they're seen by a non-specialist, they get admitted by default. We're developing a virtual ward, an SDEC service that manages some of the medical emergencies as outpatients.

I once heard someone say that 'acute oncology is everything that nobody else wants to do with cancer for the acutely admitted patient'. The definition of acute oncology is so open to interpretation. Do we just concentrate on treatment and disease complications? Should we rule out surgical admissions? Should we rule out obvious site-specific cancers and refer them to the relevant team? Should we see all patients with cancer who are admitted? It's a very difficult balancing act.

### Jane Whittingham

Advanced nurse practitioner  
Cardiff and Vale University Health Board



# 'In the future, I'd like everyone in the hospital to know who we are and how to contact us'

I'm the clinical lead for acute oncology in Swansea Bay, with one AOS session at Singleton and one at Morriston. I've always had an interest in acute oncology and feel quite strongly that cancer patients often get a bit of a raw deal when they're admitted. Medics at the front door don't always know too much about highly specialised cancer treatments and people can be a bit afraid of making the wrong decision.

We are a fairly rapidly expanding acute oncology service. In Swansea, we work across Singleton and Morriston. We haven't got a physical presence at Neath Port Talbot at the moment because that's largely outpatient and rehabilitation services. We act as a liaison service for people who are admitted into Morriston when their specialist team is in Singleton: we provide advice and support both to the front door team and the patient's named oncologist. It's crucial to provide constant updates and maintain links with their treating team.

We have a flag system to identify when our patients are admitted, and we've started outreach into the emergency department to provide oncology-specific advice about acute oncological presentations. The health board is currently redesigning acute medical services and developing ambulatory care, and I'm hoping that the AOS team will have a bigger role in the new structure.

There is an active MUO service that sees patients admitted through the medical and surgical takes, and an MOU MDT meeting once a week. I try and bring people back to that weekly clinic if possible, instead of asking them to stay in hospital waiting for an MDT outcome. I'd also like to develop hot clinics, which would help to reduce length of stay while providing a safety net.

There's a good appetite to improve things in acute oncology in Swansea at the moment. It's a good time to try and influence things. The postgraduate

training curriculum has recently changed to include more acute oncology for specialty registrars, so that's a big driver for positive change.

Workforce is a big problem. We might have the money for more doctors, but the people aren't there. The team is still relatively small and until recently, there was no cover for nursing leave. When you're trying to build a really good service, it's very difficult if there's no consistency. People need to be able to rely on us, and without cross-cover, there's a single point of failure: that's a big challenge.

Inpatients are generally really pleased to see someone from the oncology team: it's really nice to be able to build relationships with the medical teams and make a real difference to the patient experience. We're still working out where we slot into the diagnosis pathway for cancers that aren't MUO, where the pathways vary across site-specific teams. We're also focusing on more ambulatory care and reducing length of stay, but it's not always clear where the boundaries sit. Where does AOS finish, and where do site-specific services begin? Having that oversight of all the different services is quite difficult – and if it's complicated for us, how bad is it for patients? We know that acute medics are incredibly busy, so we're looking at how we can be more involved with giving bad news and supporting patients with new cancer diagnoses.

We have our own workforce gaps in AOS, but so does every team, and it's about patient ownership. This is definitely something that we really need to iron out and it's going to be a challenge. Emergency departments are simply not set up to do follow-up care or provide ongoing treatment. Ideally, patients discharged with investigations pending should be given a key worker point of contact to help them navigate the system. There are so many different types of cancers, and we need to put some time into mapping out all of the different pathways that exist.

We work closely with Hywel Dda University Health Board and we are trying to set up an MUO service with them. We provide the CNSs with virtual medical support sessions because there aren't any oncologists based at Prince Philip, Glangwili or Withybush hospitals. We want an equitable service for the whole of south-west Wales, but we need to work out how to do that in Hywel Dda across four remote hospitals with recruitment and retention issues. We communicate well with the AOS nurses, but ideally, we'd like to provide on-site senior support for those hospitals in the future. Having a physical face-to-face presence with decent cross-cover is very important, as is investing in teaching, developing the profile of the service, and ensuring keyworker and emotional support for patients who need help navigating a very complex system.

In the future, I'd like everyone in the hospital to know who we are and how to contact us. We should be a well-known team. I would like us to have cover throughout the week, including when people are sick and on holiday. I would like to have a more equitable service across Swansea Bay and Hywel Dda for both AOS and MUO. I would like us to have access to hot clinics, so that people can go home and come back when needed, rather than being stuck in hospital. I would like us to try and ambulate patients where we can. We should be able to bring

people in once a day for IV treatments or clinical review and avoid hospital admission as the default. The biggest barriers, though, are a lack of workforce and physical space: hopefully this will improve when the acute medical service redesign goes through during the next year or so.

There are only so many hours in the week. The challenge is to decide what needs to be done, and how things should be prioritised, so we're not promising things we can't deliver. We need to involve senior trainees in more strategic meetings. Medical training is very clinically focused, but management is an important part of the consultant role, and I find it very challenging to know how to build a business case and design new job descriptions, for example.

I'd advise anyone with an interest in acute oncology to get as much exposure as possible, as early as possible. Training is a short period of time, and there's no need to rush into becoming a consultant. Take the time to do leadership and management training. There are lots of opportunities out there.'

#### **Dr Allie Shipp**

Clinical lead for acute oncology  
Swansea Bay University Health Board

## **'I can have five patients admitted for the same thing, and every case will be different'**

I've spent most of my career as a nurse working in cancer care, and when I became an AOS CNS, the biggest surprise was how many patients are diagnosed with cancer at the front door. More than a third of cancers in Wales are diagnosed in the emergency department. My role is to support and advise the medical team about admitted patients who have become unwell because of their cancer treatment, or perhaps they have received a cancer diagnosis at the front door, or they have developed an oncological emergency. We also support patients and their families directly, and we liaise with Velindre.

Back in 2015, Cwm Taf Morgannwg University Health Board appointed two band 7 AOS nurses for the Royal Glamorgan and Prince Charles hospitals with a lead consultant on each site, a band 4 administrator and an MSCC coordinator. Since then, the Princess of Wales hospital has moved into the health board with a band 7 nurse and a clinical lead. The original two nurses have reduced their hours, and a band 6 nurse is covering this shortfall across both sites. The band 4 post has been vacant for a couple of years, so we have 2 years' worth of data waiting to be put into the system.

We are a close-knit team; while we work completely independently and separately across the three sites, as a team of CNSs we do coordinate and communicate with each other, although we don't provide cross-cover. We tried, but it was impossible. The CNS post at the Princess of Wales was vacant for 18 months, which meant that there was no AOS there at all. Velindre would triage a patient on the treatment helpline and send them to hospital, but there was no CNS with AOS expertise to see them when they got there. It's inequity of access for patients.

When we set up the service across the health board, we found that there was an informal system set up where patients with MUO and CUP would be seen by the clinical lead and a palliative care nurse. We began by making ourselves known to the respiratory team, then the wider medical teams. We attended all the MDTs that we could find to present our plans for AOS. We networked across the hospital and with Velindre, set up a website and an intranet page, and started seeing patients about 3 months after we took up post.

I really enjoyed meeting people and building those relationships. The medical teams wanted our input and support, and they were very grateful that the service was starting up. It was really helpful that we both had connections from previous roles that we could use to build networks, especially given that junior doctors rotate regularly, so we needed to embed new ways of working with the consultant physicians and grow those relationships. I learn

something new every week: I can have five patients admitted for the same thing, and every case will be different. The patients and their families will deal with it differently.

We're now seeing the effect of COVID-19. Patients are presenting with advanced disease. Some are not even making it as far as Velindre for the first consultation, let alone chemotherapy. We had a patient recently who died within 10 days of being told she had cancer.

There's no cover when I'm on leave. That has been the biggest challenge, and it feels as though we are set up to fail from the start. Nobody seems to understand or want to accept that. When a new service is set up, the funding might be agreed for one CNS, but you need at least two to cover leave. We've also been through three administrators because they move onto more senior roles. We need to future-proof these services: it's short-sighted not to provide cover, because without the AOS nurse, there isn't an AOS service.

My relationship with the Velindre on-call team has improved over the years, which is really good. People are more supportive of the work that AOS nurses do, and they welcome our input.

### Karen Wingfield

Clinical nurse specialist, Royal Glamorgan Hospital  
Cwm Taf Morgannwg University Health Board



# 'With experience comes confidence, but you can't learn that if you're in an environment where you feel unsafe'

The way that we work has recently changed, because we've started doing triage (SACT helpline) as well as our on-site AOS work. We used to have a single clinical nurse specialist at each of the four hospitals in Hywel Dda University Health Board (HDU), but now we've got some extra help because we've taken on the triage phoneline and we're working weekends and bank holidays. We do have to cross-cover for each other: sometimes I am in one hospital in the morning, and I travel to another hospital for the afternoon. With Bronglais Hospital we tend to offer telephone cover because it's such a distance, but we will go down to Withybush Hospital in Pembrokeshire if needed. It's a lot of travelling.

It's a lot to ask of the team, but we've always just done it. It was just what was expected, we just managed. But it's becoming more problematic. We're a lot busier these days, more people know about us, and we've got a much bigger caseload. And if the triage helpline is busy, we have to start picking up those calls too.

We've never had access to MUO/CUP MDT meetings, and we've never had a clinical lead. We've always had to fend for ourselves and find space in any MDT that we could. There are more pathways now, so that is slightly easier, and we have much more specialty oncology support from Singleton, which is really positive and helpful. We didn't have any of that before, we really struggled to be honest. It's still not ideal – patients do miss out because there are no clinics, and no one to see them in person. Nobody takes ownership of those patients in HDU.

I think the triage service (SACT helpline) takes us away from the AOS: we don't have AOS cover on every site any more, because we're covering the phones. I have to spend some of my days on the triage call line, which means I can't see patients on site while I'm doing that, so someone could go most of the week in hospital without seeing an AOS specialist and there's less continuity of care.

Previously, patients would ring the chemotherapy unit if there was a problem, but the lines were often busy, or there was nobody available to answer the phone. So, we have developed new pathways and it works better now, but I still think it takes us away from providing acute oncology care. A national helpline with a central rota could be more effective because it could be done from anywhere; we shouldn't be taken away from our day job to do it. But we are currently recruiting for a lot more staff, so there is light at the end of the tunnel, although some aren't starting until the very end of the year because we've only just appointed them.

We don't have a clinical lead in the health board. That's a big problem for us and I don't think enough has been done to recruit one. It's hard to say whether we need an oncologist on the ground because we're so used to just getting on with it. I quite enjoy the autonomy, but when we have difficult cases, it would be nice to have that expert advice and support from an oncologist. You could be in hospital in HDU with cancer for months and never see a specialist doctor. The nurse-led AOS teams are brilliant, but you're still missing out. If you're admitted to Singleton, you're normally on an oncology ward with a whole team of experienced oncology nurses and doctors to see you every day. Here, if you're lucky, you'll see an acute oncology nurse. And it's a lot for the nursing staff to handle: the diagnosis talk, the treatment options, the end-of-life conversations.

It would be good to have some face-to-face sessions with a doctor. Perhaps a ward round in person, where we could go through all the patients. But then, where do they go? We have hospitals in Llanelli, Carmarthen and Haverfordwest, massive distances apart. You couldn't do all three in a single day, or even 2 days. Patients are receiving a different standard of care because of where they live, which doesn't seem fair.

The underlying issue is that there's nobody we can discuss patients with locally. Some individual doctors are responsive and willing to offer advice. But a lot of them don't answer emails. There's nobody to bounce ideas with; we could ring the on-call registrar or colleagues at Singleton, but they're so busy that we don't always want to bother them if it isn't an emergency, and they're not funded to have those conversations anyway, so it feels a bit like asking for a favour. I always just used to get on with it, but now things seem to be getting a lot more complicated. Patients are more poorly. It puts the resilience of the service at risk, because as more junior nurses start in post, they are less willing to take those decisions without support. They feel more vulnerable. With experience comes confidence, but you can't learn that if you're in an environment where you feel unsafe.

I think the whole team struggles with moving between sites and manning the phones. There's no continuity, you don't know where you are from one day to the next. It's stressful worrying about fitting it all in; it's so daunting trying to cover three sites by yourself. It's the pressure. It has affected team morale. But there are new people starting soon, so we'll get there.

I do feel like patients down here get a raw deal. We do feel a bit abandoned, in a way. It would be nice to have a clinical lead down here. Sometimes I do

feel anxious about giving advice without seeing a patient. It worries me. Occasionally the admitting team will make decisions about a patient's care that I wouldn't have made; sometimes they might not follow my advice. At times I have to really fight to get a patient admitted, ringing every team I can to get them in, which increases my workload and puts pressure on me. It feels sometimes like the medics ask for my advice as a tick-box exercise, because they're not going to follow it, whatever I say. They want to see an oncologist, but there isn't one, so the anger is misdirected really. Some doctors are happy to see us and will take our advice, but they're in a small minority.

A few years ago, we did a lot of work to raise our profile across the health board, but there's such a turnover of junior doctors and locum consultants, then we went into the pandemic, we lost staff, people went on leave. Most recently, we've taken on triage, so we simply don't have time for education and awareness raising any more. With so much moving about between sites, I no longer know everyone in the hospital, and that's makes a difference. If you have a relationship with a team, they are more likely to listen to you, but often they can't even get hold of us any more.

### Jessica Bowden

Clinical nurse specialist  
Hywel Dda University Health Board

## 'Let's forget the past – let's move forward and build something we can all be proud of'

With four acute hospital sites in Aneurin Bevan University Health Board (ABU), we struggle to staff four front doors with only three nurses. We're recruiting for a bigger team, which will help, but the long-term challenge is how we provide equity of care for AOS patients with limited resources. We provide cross-cover for each other at the moment with three senior nurses across four sites, although we're going up to six nurses (four senior, two junior) plus a senior nurse manager very soon. It's a complex situation. Do we put one senior nurse in each of the four hospitals? But some hospitals will have a more acute intake than others, and so

the workload will be different: more intense, more pressurised in that hospital, so is that fair?

Over the coming months, as the business case for south-east Wales is rolled out, we're planning to recruit therapists to the team. There's so much to decide about the model of care. What happens if a patient has back pain and they are triaged to a smaller local hospital, then it turns out to be a spinal cord compression? Or if they have a bad reaction to their cancer treatment that seems straightforward, but it's actually immunotherapy toxicities, which can be very serious?



In an ideal world, perhaps a single take for ABU patients would work, but in reality, for our health board, that's virtually impossible. The definition of AOS is so broad, and the critical care centre is not an appropriate setting for an assessment unit, it doesn't have the bed capacity. Neither can we concentrate the AOS take at one of the local hospitals, because the specialties simply aren't there.

We don't currently have an acute oncology assessment unit, but there is now a same-day emergency care (SDEC) unit that's just opened at the Grange. We're very interested in how we can build acute oncology into SDEC. It's an entirely new way of working for us. There's a lot that comes through the emergency department that we could treat in an ambulatory unit, if we had a robust pathway and scoring system in place. One day, in the distant future, we could even have AOS nurses in the community who could assess patients at home.

We can contact the community resource team for ambulatory patients, although records are not yet on the same digital platform, which makes things more difficult. That's supposed to be happening quite soon though. Digital working will make the transfer of patients much easier because everyone will have access to the same information. Communication is a big thing.

If I could wave a magic wand, I'd want enough staff and resource to always have an AOS specialist at the front door. That's how we'd make the biggest impact and avoid problems developing, because

we'd have someone with expert knowledge involved from the start. We need to get cancer patients to the right place, first time – it could be many different places, but the most important thing is that there is AOS in DGHs to support these patients and work with other hospital teams to provide high-quality care. Patients should be able to go to one place and have access to all the specialties: SDEC has to play a big role in this.

It's even possible the Velindre model could work. There's some talk of developing a specialist cancer centre at Nevill Hall Hospital (NHH), so perhaps there could be a Velindre-style acute oncology assessment unit at NHH, with patients transported by ambulance to the Grange if they deteriorate. In some ways, that would be easier for ABU to design because it's all one health board.

We're in a positive place at the moment. There's the south-east Wales business case, there's funding, people are giving AOS some attention. I think AOS is where palliative care was 15 years ago if I'm honest. So, let's get excited about what the future can be! Let's forget the past – let's move forward and build something that we can all be proud of.

#### Claire Gilfillan

Clinical nurse specialist  
Aneurin Bevan University Health Board

#### Kay Wilson

Lead nurse for acute oncology services  
Aneurin Bevan University Health Board

# 'It's unpredictable, and you never know what's coming through the door'

I'm a surgical nurse by background. Three years ago, I was working as an oncology advanced nurse practitioner and I was asked to cover for an AOS colleague who went on sick leave, then left the job – so I completely fell into acute oncology by accident, but I absolutely love it. I'm now the clinical lead for AOS across all three sites in north Wales, and I'm based at Ysbyty Glan Clwyd (YGC).

The sites in north Wales work really separately, and very differently from each other. Our catchment areas are so different. At YGC, we've recently employed another CNS to work full time in acute oncology; we have 20 inpatient beds shared between oncology and haematology. Our triage unit has been in place for some years. It used to be on the treatment day unit, but we moved during the pandemic. We have seven chairs, plus a bed for query spinal cord compression patients and an isolation room: it's a really busy assessment unit. We also take all the radiotherapy patients for north Wales, so we're at capacity every day. Ysbyty Gwynedd has 15 inpatient beds, a treatment day unit and a three-bed assessment unit with one CNS. In Wrexham, there are two CNSs but no inpatient beds.

Staffing is the biggest barrier to developing the service. We have only recently recruited a second nurse for the service in YGC, and trying to run an AOS, see triage patients, see CUP patients and do my clinics single-handedly has been tough going. That's down to both funding and staffing challenges. The service in YGC is ANP led (as opposed to CNS led), which makes a difference because it means that there are very few occasions when I need to get a consultant involved (although consultant colleagues have been amazing and very supportive). Once this round of recruitment is done, we should have three, maybe four nurses and a healthcare support worker in the team. We don't have much therapy input, but we have a physiotherapist and an occupational therapist on site in the cancer centre and they are always very willing to see patients in triage.

Next, we want to look at improving the facilities in our triage area and expanding the service to cover longer hours. We struggle to cover 5 days at the moment, never mind 7-day working. We're working with the emergency department to streamline admissions and improve patient experience, and we're developing a better relationship with the medical on-call team because they can see that we are trying to help and support them with the acute take. The key thing has been building relationships with the front door team, reviewing and repatriating oncology patients as quickly as possible and being a point of contact to help sort out any issues.

I've really enjoyed the challenge of the past few years. It's unpredictable, and you never know what's coming through the door. I'm glad I never gave up: things don't happen straightaway, and it's taken us a long time to get to this point, but we've managed it. It's worth being patient.

I do feel quite strongly that AOS should be ANP led where possible. I know that's not always easy, but with fewer doctors, it's something that we may need to look at. An ANP can prescribe, see their own patients, hold their own clinics. It takes a lot of the workload off the doctors: in triage, a patient can come in, I can clerk them, do their bloods, do initial investigations, prescribe antibiotics and fluids and order further investigations. Then it just needs a senior medic to come down, review the imaging and give a decision on whether they're admitted or discharged.

## Nia Blackborow

Advanced nurse practitioner, Ysbyty Glan Clwyd  
Nursing clinical lead for AOS, Betsi Cadwaladr  
University Health Board

# 'We are leading a national piece of work to review what SACT helplines look like, and how we should develop them in the future'

I'm a specialist nurse for the systemic anti-cancer therapy (SACT) services based at Velindre, with a key role in leading and developing the 24-hour helpline. I'm also employed 1 day a week currently for the Wales Cancer Network (WCN) as clinical lead nurse for SACT and acute oncology.

The guidelines say that patients should have 24-hour helpline access to specialist advice if they are experiencing toxicities or they feel unwell following treatment. The model across Wales is very varied with different standards of provision, and the WCN is leading a national piece of work to review what SACT helplines look like, and how we should develop them in the future. There's no single best practice model, so we're aiming to align standards across Wales.

Quite often, it's not just patients with SACT issues who phone the helpline, it's anyone with an acute oncological emergency, but the SACT nurses don't always have the clinical assessment tools to help. In some cases, these helpline services are 20 years old, and they've never been adapted or developed to provide that wider clinical advice. Many SACT

helplines are receiving more calls, perhaps because patients can't get through to their GP, or they don't want to go to their local emergency department. The problems are becoming more complex. The system needs proper governance and more investment. We've struggled to access high-quality data, especially where people are working off bits of paper because they lack staffing resource. Done well, these helplines can reduce admissions and avoid lengthy hospital stays.

The ideal model would give both patients and clinicians access to that specialist information: a one-stop shop for someone who is unwell as a result of their cancer or their cancer treatment. We'll be working closely with NHS 111 Wales, primary care, emergency care – we have to have good links. In particular, we need to explore how we can best support triage services overnight and at weekends.

## Rosie Roberts

Clinical lead nurse for SACT and acute oncology, Wales Cancer Network  
Specialist nurse, Velindre Cancer Centre



# ‘Young people with cancer say that communication with health professionals sometimes falls short’

Teenagers and young adults (TYAs) diagnosed with cancer often experience prolonged and convoluted diagnostic pathways compared with children and older adults. Clinicians are less likely to consider the possibility of a malignant diagnosis in this age group at initial presentation. One in 200 TYAs will be diagnosed with cancer, which remains the leading cause of non-accidental death for this age group. Consequently, TYA patients often have multiple visits to primary care and A&E before their cancer is diagnosed. It has been estimated that 38% of new TYA cancer referrals are emergencies, with 7% having their first presentation via emergency departments.

In Wales, young people aged 16–24 years with a cancer diagnosis can choose to be treated in the TYA Principal Treatment Centre (PTC) or they can remain under the care of their local hospital, in line with the Welsh TYA Cancer Standards. The PTC for mid- and south Wales is based at University Hospital of Wales, Cardiff. Young people often choose to travel to the PTC to access specialist services. However, these patients will still present to their local emergency department and AOS team if they become acutely unwell with complications of cancer treatment.

Unlike paediatrics, TYA cancer services are not commissioned in Wales as they are in England and Scotland. TYA patients are cared for by many medical and surgical teams and, as a result, the management pathways for young people can become disconnected. Local AOS teams support

admissions of young people in local hospitals within hours, supporting appropriate complication management. There are currently no TYA specialist NHS staff within Wales advocating for young people when they are admitted outside the PTC. Acknowledging this gap, we are piloting a TYA specialist nurse in south-east Wales with charitable support to improve the experience for young people, support care coordination and provide TYA expertise. We want to provide a more robust and impactful TYA cancer network that will work with designated hospitals across Wales to provide specialist local support to patients and their local clinical teams.

Through our youth forum, young people with cancer have highlighted areas where communication with health professionals falls short of their needs and the needs of their families. As a consequence of this work, the Wales Cancer Network TYA Cancer Site Group Youth Advisory Forum has created principles of communication for health professionals working with young people. We are asking all health professionals working with young patients to adopt them.

## Dr Clare Rowntree

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## Bethan Ingram

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# Educating, improving, influencing

Through our work with patients and doctors, the Royal College of Physicians (RCP) is working to achieve real change across the health and social care sector in Wales. We represent 40,000 physicians and clinicians worldwide – educating, improving and influencing for better health and care. More than 1,600 members in Wales work in hospitals and the community across 30 different clinical specialties, diagnosing and treating millions of patients with a huge range of medical conditions. We campaign for improvements to healthcare, medical education and public health.

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## Useful resources and further reading

- Macmillan Cancer Support. *Cancer nursing on the line: why we need urgent investment to end the workforce crisis*, 2021.
- Nuffield Trust. *Advice on the proposed model for non-surgical tertiary oncology services in South East Wales*, 2020.
- Royal College of Physicians and Royal College of Radiologists. *Cancer patients in crisis: responding to urgent needs*, 2012.
- Royal College of Physicians. *Acute care toolkit 7: Acute oncology on the acute medical unit*, 2013.
- Royal College of Radiologists, Royal College of Physicians and Association of Cancer Physicians. *Acute oncology: Increasing engagement and visibility in acute care settings*, 2020.
- Royal College of Radiologists. *Clinical oncology: UK workforce census report*, 2021.