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Specialist adult cancer nurses in Wales

A census of the specialist adult cancer
nursing workforce in the UK, 2014

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Foreword

This is the first census of specialist adult cancer nurses undertaken in Wales, providing accurate information on their numbers and locations. This is part of a larger census covering all of the UK.

In June 2012 the Welsh Government published *Together for health – cancer delivery plan for NHS and its partners*¹, placing person-centred care at the heart of its vision. There is no doubt that the cancer Clinical Nurse Specialist (CNS) has a key role to play in ensuring this aspiration becomes a reality.

Macmillan first established the CNS role in the 1970s. In this 2014 census we recorded over 3,500 hospital-based specialist adult cancer nurses across the UK, of which 1,305 have Macmillan in the job title. We have long been a strong advocate for the role that specialist adult cancer nurses play in supporting people affected by cancer, and ensuring they receive timely and person-centred care. The recent Wales Cancer Patient Experience Survey (2013)² has provided evidence that patients who had a named CNS in charge of their care reported more favourably on aspects of their experience.

In completing this census, we have relied on our partners in the NHS to provide information and have been heartened to receive excellent support for our approach. In a time of considerable change and financial constraint, the census returned a 100% response rate in Wales and a 97% response rate across the UK.

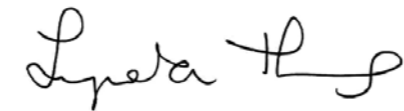
We have learnt a lot about the workforce and how it is changing to respond to environmental, demographic and policy challenges. These challenges are different in the four nations of the UK, and so the data presented in this report should be interpreted in the light of the local context.

However, there are two themes that emerge strongly across the UK, as things we need to respond to soon:

- Our specialist cancer nurse workforce is ageing. In some areas of practice in some parts of the UK, our data suggests that as many as half of the nurses currently providing cancer care are over 50. It is likely that the majority of these will retire in the next five to 10 years.
- There are variations in the provision of specialist adult cancer nurse expertise for those diagnosed with different cancer types or requiring specialist support, and across geographic locations. Further investigation is required to understand the pathways and place of care for cancer patients in terms of diagnosis, treatment and after care.



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1. Introduction

1.1 Background

The specialist adult cancer nursing census was originally designed to map the specialist adult cancer nursing population in England by cancer type and locality in order to inform commissioning intentions and workforce planning.

The first two censuses in 2007³ and 2008⁴ (the latter included some data from Wales) were developed and led by the cancer network nurse directors and colleagues before they handed over management to the National Cancer Action Team (NCAT) and Mouchel Management Consulting Limited, who led on the 2010⁵ and 2011⁶ censuses respectively. Further iterations expanded data collection to include role title, banding and geography.

Macmillan commissioned the 2014 census working with Mouchel Management Consulting Limited (supported by the Centre of Workforce Intelligence).

The 2014 census has leant on the significant experience and expertise provided by the continued involvement of three senior cancer nurses and healthcare scientists/professional colleagues: Professor Alison Leary and Paul Trevatt, who had developed the original census, and Steve Candler.

It may be useful to read this document in conjunction with other resources such as *Excellence in cancer care: The contribution of the Clinical Nurse Specialist. NCAT 2010*,⁷ *One-to-one support for cancer patients*. A report prepared for the Department of Health by Frontier Economics⁸.

While this document gives the ratio of specialist adult cancer nurses to cancer incidence and two-year prevalence in Wales, this does not represent guidance on appropriate caseload or indeed the total number of specialist adult cancer nurses required.

It merely acknowledges variation in the provision of these posts across different areas of practice, with a view to stimulating further discussion and exploration of circumstances and local arrangements. The information should also be read in conjunction with the Wales Cancer Patient Experience Survey².

This report aims to present a detailed description of the current specialist adult cancer nursing workforce across Wales so that it can be used as a resource to support workforce planning and service development. Macmillan would welcome the opportunity to work with partners to address specific challenges, with the aim of ensuring that everyone affected by cancer has the best outcomes possible and experience of care through access to a specialist adult cancer nurse.

1.2 Methods

This census was primarily based on the approach adopted for previous censuses, in particular the work undertaken by NCAT in the 2011 census⁶.

Given that this is the first time the census has been fully supported in Wales, the emphasis was on ensuring a robust but focused data set. Data was collected over an eight-week period between April and June 2014. However the workforce numbers collected were a snapshot of the population on the day of the census, 24 April 2014. The data was primarily collected using a bespoke spreadsheet with drop-down menus.

Areas of enquiry were informed by the previous censuses undertaken in England and reviewed to ensure compatibility with the Welsh system.

Areas of practice were broadly based on the NICE Improving Outcomes Guidance definitions⁹. Consistent with the 2011 census⁶, the areas of practice included 'acute oncology services' (AOS), as it was recommended in the 2009 NCAG report *Chemotherapy services in England: Ensuring quality and safety* that all hospitals with emergency departments should establish this service¹⁰. Acute oncology services are particularly important in Wales as they are supported in the Welsh Government's *Together for health – cancer delivery plan*¹. Published in 2012, the plan sets out the Welsh Government's expectations of NHS Wales, working with its partners, in tackling cancer up to 2016. This document underpins cancer policy in Wales and provides a crucial focus on the implementation and delivery of person-centred care consistently throughout Wales.

As previously, the census identified whether the posts have Macmillan in their job title.

Additional information was collected on the age and gender of post holders and on vacant posts. Data was also collected on posts that reported cover for 'cancer of unknown primary' (CUP).

All posts are recorded as whole time equivalents (WTE) in adult cancer care, where 1 WTE is equivalent to a 37.5 hour week.

Spreadsheets were returned by lead cancer nurses or senior cancer nurses in hospital trusts and health boards. Some further checking and completion was undertaken to ensure complete records were provided where possible. Nurse Directors, NHS Lead Cancer Nurses and Directors of Nursing were involved as appropriate to collate and validate the relevant data.

Data was returned electronically to Mouchel for analysis. One month was given for data to be returned, with a further extension to enable appropriate dissemination and support for returns. Collection was completed by 13 June 2014.

Census process:

- Project team and Mouchel agreed census tool design and data fields
- Spreadsheet and instructions for completion were sent out to lead cancer nurses or equivalent in each trust, health board or hospital across the UK
- Data entry completed at trust/health board level
- Completed spreadsheets returned to Mouchel
- Records checked with respondents for completeness and accuracy as appropriate
- Analysis by Mouchel and project team
- Data tables produced for review and key findings identified
- Report



2. Context and background

1.3 Selection criteria

The census is aimed at hospital-based specialist adult cancer nurses working in adult cancer care only.

Inclusion criteria were kept consistent with previous censuses where possible.

Inclusion criteria: all nurse posts that:

- treat, support and manage the health concerns of adult cancer patients and work to promote the health and wellbeing of the patients they care for (including post holders who perform a role in education, research and audit in adult cancer care)
- deliver predominantly secondary care
- are registered (Agenda for Change – AfC – bands 5 to 9 only)
- are funded by any source (e.g. NHS, charity, pharmaceutical)
- are vacant posts as well as those filled on 24 April 2014

Exclusion criteria: posts that:

- specialise only in chemotherapy, radiotherapy, palliative care, pain management or non-patient facing roles
- work 'as and when required', e.g. bank and agency staff
- are community nurse specialists
- work in paediatrics or with teenagers and young adults
- are research nurses

All posts reported that met the inclusion criteria are referred to as specialist adult cancer nurses. In this report we also refer to Clinical Nurse Specialists (CNSs), which have a specific job title and are a subset of specialist adult cancer nurses.

In Wales, health boards/trusts have a responsibility to assign a named key worker to every person diagnosed with cancer as set out in the Welsh Government's *Cancer delivery plan*¹ published in June 2012. The plan also sets out a clear requirement to deliver person-centred care, ensuring that all patients' needs are assessed holistically, a written care plan is produced and that a copy of that plan is given to the patient. This requirement has subsequently been reinforced by the inquiry carried out by the National Assembly for Wales Health and Social Care Committee during 2014. This recommends that the Minister for Health and Social Care provides an update to make sure progress is being made by health boards in ensuring that the requirements set out in the *Cancer Delivery Plan* for all patients to be assigned a key worker and provided with a written care plan are met by 2016.

The cancer specialist workforce will be pivotal to the achievement of this commitment.

This is the first Wales-wide census of the specialist workforce. In Wales, just over 19,000 people are diagnosed with cancer every year¹¹ and an estimated 130,000 people are currently living with or beyond cancer – around 4% of the population. Socioeconomic inequalities and deprivation are helping to drive the high burden of ill health and mortality from cancer in our society. If current trends continue, this figure will increase to 220,000 by 2030 – almost 7% of the population¹². This increase is largely due to improvements in survival and detection, and a growing and ageing population in Wales.

The first national Wales Cancer Patient Experience Survey (WCPES) was published in January 2014 and, like those previously undertaken in England, clearly demonstrates the correlation between access to a CNS and a better patient experience².

The Wales cancer patient experience survey reported that patients who were allocated a Clinical Nurse Specialist were more positive about their care and experience in 59 out of 74 questions. Patient comments revealed high levels of satisfaction with all nursing specialities, with a high volume of comments praising the dedication and skill of specialist nursing staff. Patients valued having a central point of contact, perceived their care to be of a high standard and felt supported by their CNS throughout their active treatment. However, there were a smaller number of patients who reported some difficulties contacting their CNS and these patients often attributed their CNS' lack of availability to inadequate nurse staffing levels¹³.

Health services in Wales are provided by seven health boards and Velindre NHS Trust. The size of the geographic area covered and the split between urban and rural areas varies across the health services. The need for effective information, support and care coordination has never been more important. Nor has the need for care that better enables and supports more active self-management by patients and their carers, throughout the cancer pathway and beyond.

This report, which will be distributed directly to partners, is intended to be used by managers, leaders and clinical teams as a resource for sharing information, and for stimulating discussion about the provision and deployment of specialist nursing support for cancer patients in their health boards/trusts and localities.

This should include reviewing opportunities for role and service redesign and succession planning, and should contribute to the national debate regarding the development and maintenance of a comprehensive understanding of the cancer workforce.

This baseline will also support a greater focus on specialist support for specific tumour sites. For example, lung cancer has been identified as an area of focus for Welsh Government and NHS partners during 2015/16, as a priority for improving outcomes. The recent development of AOS and the inclusion of the specialist AOS workforce in the census, in support of this development, are key to understanding how this service can be supported as recognised in the *Cancer delivery plan* with a view to delivering fast, effective care.

Given Macmillan's projections that there will be 220,000 people in Wales living with and beyond cancer by 2030¹² and, in view of the fact that some will have multiple co-morbidities, it is important to understand the implications of change in the cancer population on the specialist adult cancer workforce. This means identifying and understanding transition points in order to better understand patients' needs at each point in the pathway, and recognising that an individual's need for specialist intervention will be different at various points in the pathway.

There is overwhelming evidence that having a CNS is a powerful positive factor in patient experience and leads to joined-up care. Therefore, maintaining, utilising and, where needed, increasing the specialist workforce is essential.

2.1 Headline findings

Total specialist adult cancer nursing workforce

The census of the specialist cancer nurse workforce in Wales achieved a health board or trust response rate of 100%.

The total reported cancer specialist nurse workforce for the two current Welsh Cancer Network areas in 2014 was 184.3 WTE.

Breast cancer is the most common area of practice (21.6% of specialist adult cancer nurses' WTE). This was followed by colorectal (13.5%) and lung (12.2%) cancer specialists.

A total of 26 specialist cancer nurses were reported as providing cover for CUP (17.6% of the 79% of specialist cancer nurses where CUP status was recorded). Eight of these CUP nurses had AOS as their main area of practice. Four had colorectal, four had lung and four had upper GI cancer as their main area of practice.

Clinical Nurse Specialists

CNS was the most common job title with 145.9 WTE (79.1% of the specialist cancer workforce).

81.4% of CNSs were banded at AfC band 7, with 17.3% below this at band 5 or 6 and only 1.4% above this at band 8.

Macmillan specialist cancer nurses

21% of the specialist cancer nurse population in Wales are titled Macmillan Cancer Support posts.

Vacancies

The vacancy rate reported among specialist adult cancer nurses in Wales appears to be relatively lower than the vacancy rate found in those working in human health and social work activities, as reported by the Office for National Statistics vacancy survey in the UK¹⁴.

Workforce characteristics

Data on the age profile of filled posts highlights that nearly half of the specialist cancer nurse workforce in Wales were reported as being over 50 years of age, with no post holders under 30 years of age. The proportion over 50 is lowest in lung (8 out of 19 WTE with known age), urology (8 out of 20) and malignant dermatology (3 out of 8). This highlights the need for careful workforce succession planning.

Ratio of nurses

When provision of specialist adult cancer nurse posts is mapped against incidence of cancer in Wales, the ratio varies from 61 new cases in brain/central nervous system cancers, to 181 new cases in cancer urology.

When provision of specialist adult cancer nursing posts is mapped against the number of people living up to two years post cancer diagnosis (two year prevalence in 2010)¹⁵, the ratios vary from 73 in lung cancer to 288 in urology.

3. 2014 census results

This section presents detailed data collected in the census supporting headline findings in Wales, and highlights data on networks, tumour sites, banding, age, gender, vacant posts and support for CUP.

Table 1: Total specialist adult cancer nursing workforce by area of practice WTE, Wales, 2014

Breast cancer is the area of practice with the largest proportion of the workforce (22% of the reported WTE), followed by colorectal (14%) and combined urology (11%).

Majority area of practice	Wales	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only*	Urology – All uro-oncology*	Total
	Wales	13.3	4.8	39.9	24.9	10.9	11.3	10.0	22.4	7.5	2.0	16.4	5.0	16.0	184.3

*The urology specialist adult cancer nurse workforce has been split into two groups to identify the size of the specialist prostate cancer workforce. A majority area of practice of 'Urology – prostate only' was defined as a nurse post where 95% or more of the time the nurse spends in adult cancer care is in prostate cancer or suspected prostate cancer. 'Urology – All uro-oncology' is the rest of the urology specialist adult cancer nurse workforce who spend less than 95% of their time in adult cancer care in prostate cancer or suspected prostate cancer. This definition is designed to identify only the most specialised nurses, as a generalist urology nurse may expect to see frequent cases of prostate cancer given the high incidence of prostate cancer. It can be difficult for lead cancer nurses to accurately and consistently classify nurses, so the data should be used to build a general picture of the urology workforce rather than to draw detailed quantitative conclusions.

Fig. 1: Total specialist adult cancer nursing workforce by area of practice WTE, Wales, 2014

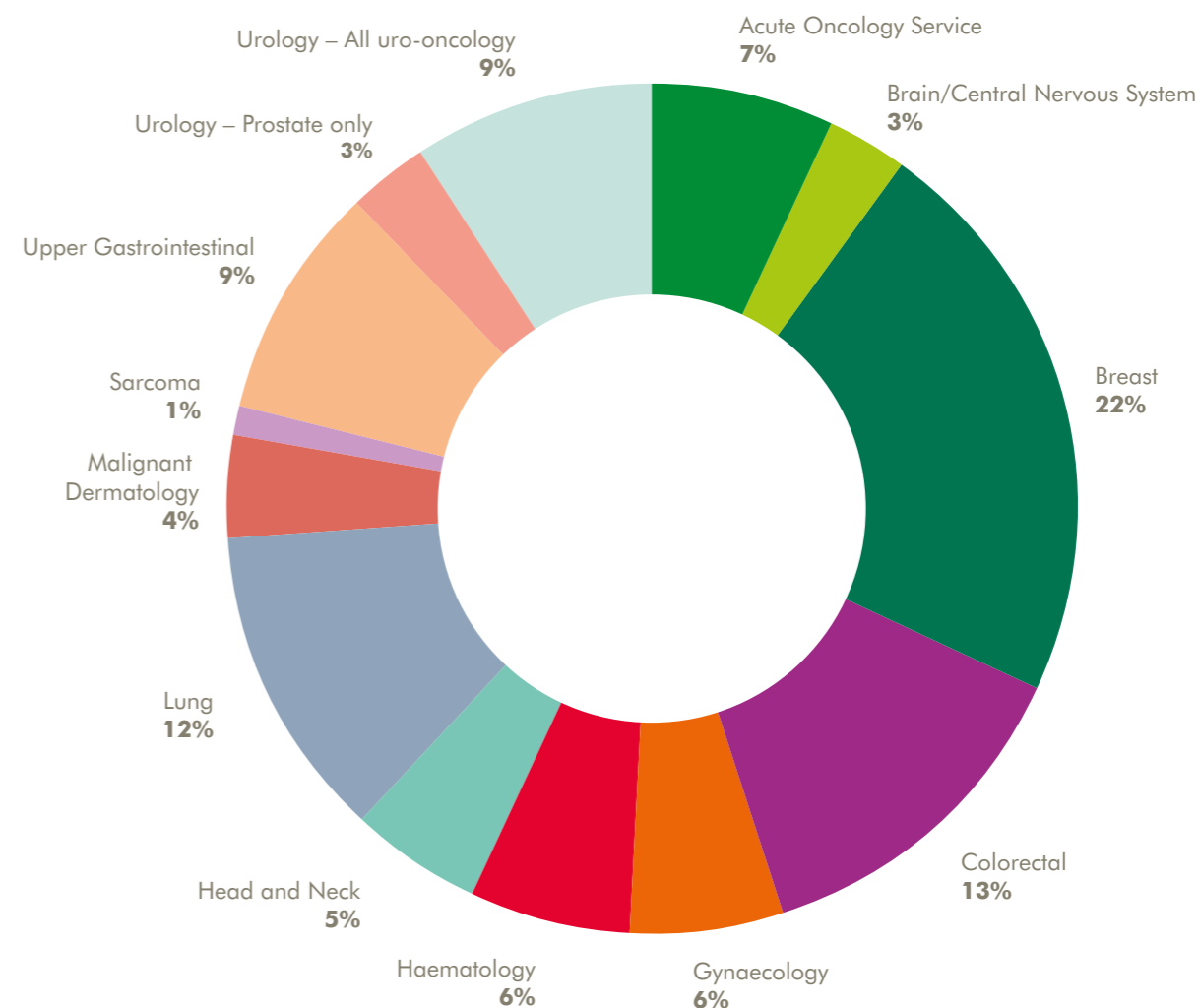


Table 2: Clinical nurse specialist (CNS) workforce by area of practice WTE, Wales, 2014

Table 2 shows only the specialist cancer nurses with the job title 'CNS' by reported area of practice. The area of practice with the largest proportion of the CNS workforce is reported as breast, accounting for 23% of the total reported CNS workforce, followed by lung (15%).

Majority area of practice	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Total
Wales	5.8	4.8	33.3	15.9	8.3	10.4	9.0	21.4	7.5	2.0	12.4	2.0	13.0	145.9

Fig. 2: Total CNS workforce by area of practice (%), Wales, 2014

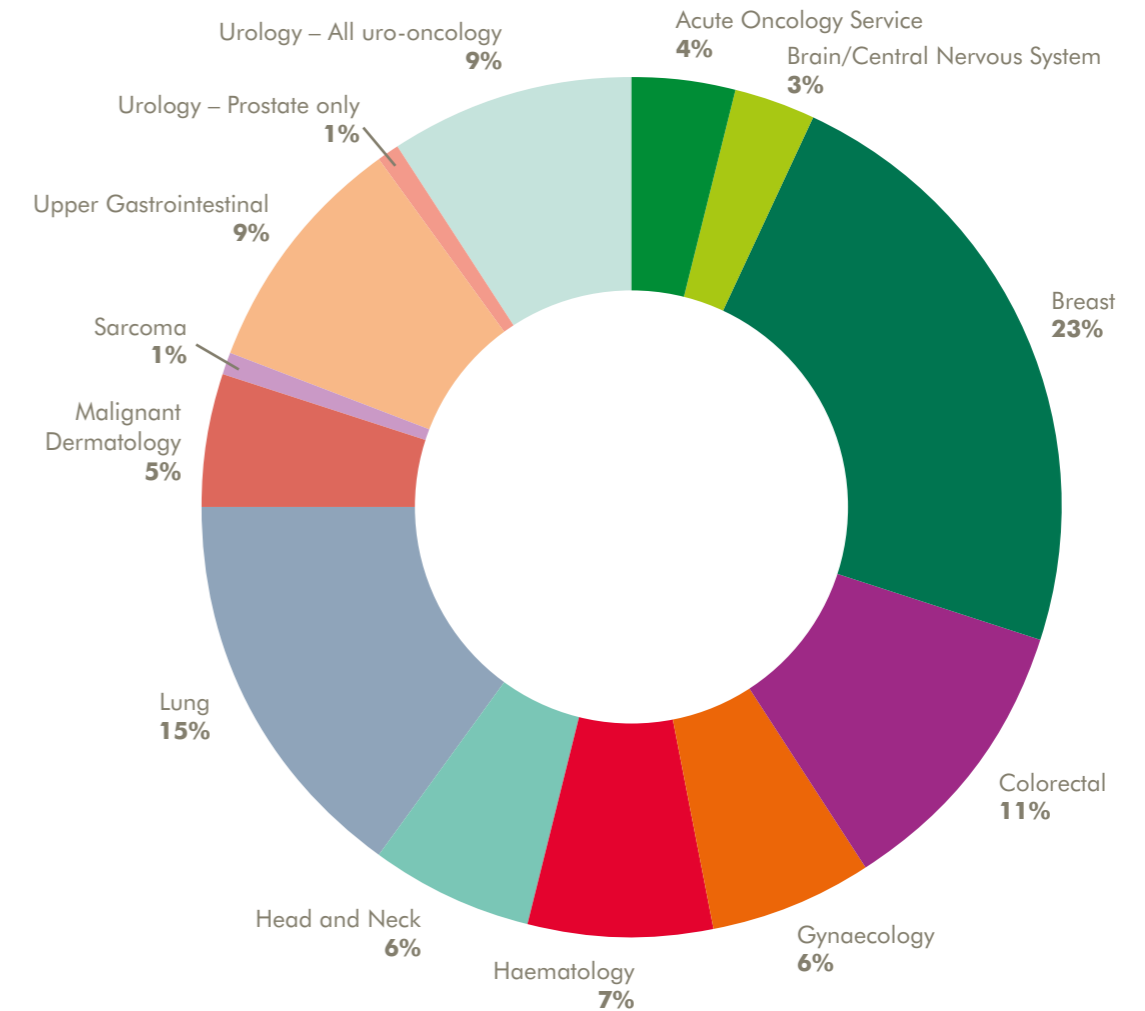


Table 3: Total specialist adult cancer nursing workforce by job title and area of practice WTE, Wales, 2014

The largest proportion of the workforce reported as CNSs work in breast cancer (about 18% of the total reported WTE). The census found no nurse consultants in Wales.

Area of practice	Advanced nurse practitioner	Clinical nurse specialist	Nurse consultant	Nurse practitioner	Nurse specialist	Other	Total
Acute oncology service	5.0	5.8	0	0.9	0.6	1.0	13.3
Brain/central nervous system	0	4.8	0	0	0	0	4.8
Breast	0	33.3	0	4.0	1.0	1.6	39.9
Colorectal	3.0	15.9	0	2.0	1.0	3.0	24.9
Gynaecology	0	8.3	0	1.6	0	1.0	10.9
Haematology	0.9	10.4	0	0	0	0	11.3
Head and neck	0	9.0	0	0	1.0	0	10.0
Lung	0	21.4	0	0	0	1.0	22.4
Malignant dermatology	0	7.5	0	0	0	0	7.5
Sarcoma	0	2.0	0	0	0	0	2.0
Upper gastrointestinal	2.0	12.4	0	2.0	0	0	16.4
Urology – Prostate only	1.0	2.0	0	1.0	1.0	0	5.0
Urology – All uro-oncology	2.0	13.0	0	1.0	0	0	16.0
Total	13.9	145.9	0	12.4	4.6	7.6	184.3

Fig. 3: Total specialist adult cancer nursing workforce by job title WTE, Wales, 2014

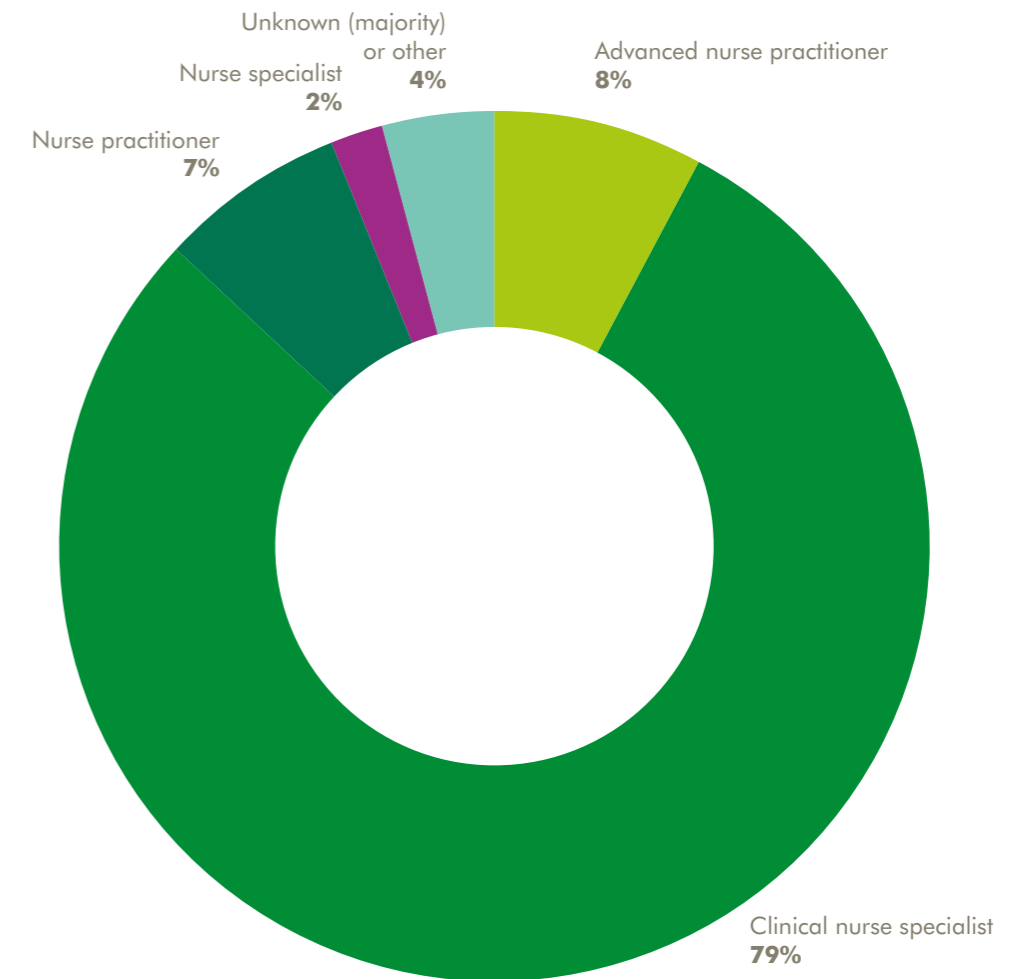


Table 4: CNS workforce by Agenda for Change (AfC) banding and area of practice WTE, Wales, 2014.

The largest proportion of the reported WTE is band 7 posts, accounting for about 81% of the total reported CNS WTE. The largest reported CNS WTE is band 7 posts working in the breast area of practice, with about 17% of the total reported CNS WTE.

Area of practice	Band 5 & 6	Band 7	Band 8a and above	Not known	Total
Acute oncology service	0	5.8	0	0	5.8
Brain/central nervous system	0	4.8	0	0	4.8
Breast	8.0	25.3	0	0	33.3
Colorectal	1.6	13.3	1.0	0	15.9
Gynaecology	1.5	6.8	0	0	8.3
Haematology	2.0	8.4	0	0	10.4
Head and neck	2.5	6.5	0	0	9.0
Lung	4.0	17.4	0	0	21.4
Malignant dermatology	1.0	5.5	1.0	0	7.5
Sarcoma	0	2.0	0	0	2.0
Upper gastrointestinal	2.6	9.8	0	0	12.4
Urology – Prostate only	1.0	1.0	0	0	2.0
Urology – All uro-oncology	1.0	12.0	0	0	13.0
Total	25.2	118.7	2.0	0	145.9

Fig. 4: Total specialist adult cancer nursing workforce by AfC banding (%), Wales, 2014

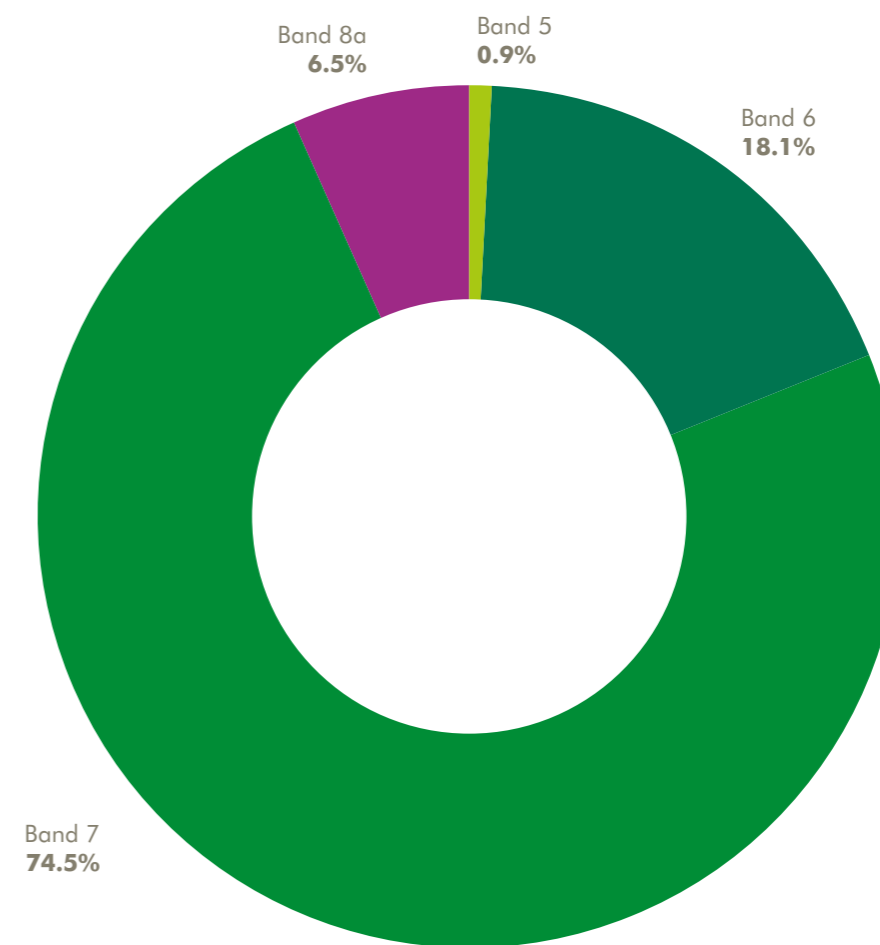


Table 5: Macmillan specialist adult cancer nurse workforce WTE, Wales, 2014

Table 5 shows that there are 38.7 WTE with Macmillan in the job title

Macmillan Cancer Support posts	WTE
Macmillan CNS	32.7
Other Macmillan cancer specialists	6.0
Total	38.7

Fig. 5: Specialist adult cancer nursing workforce Macmillan Cancer Support posts, CNS and other, percentage, Wales, 2014

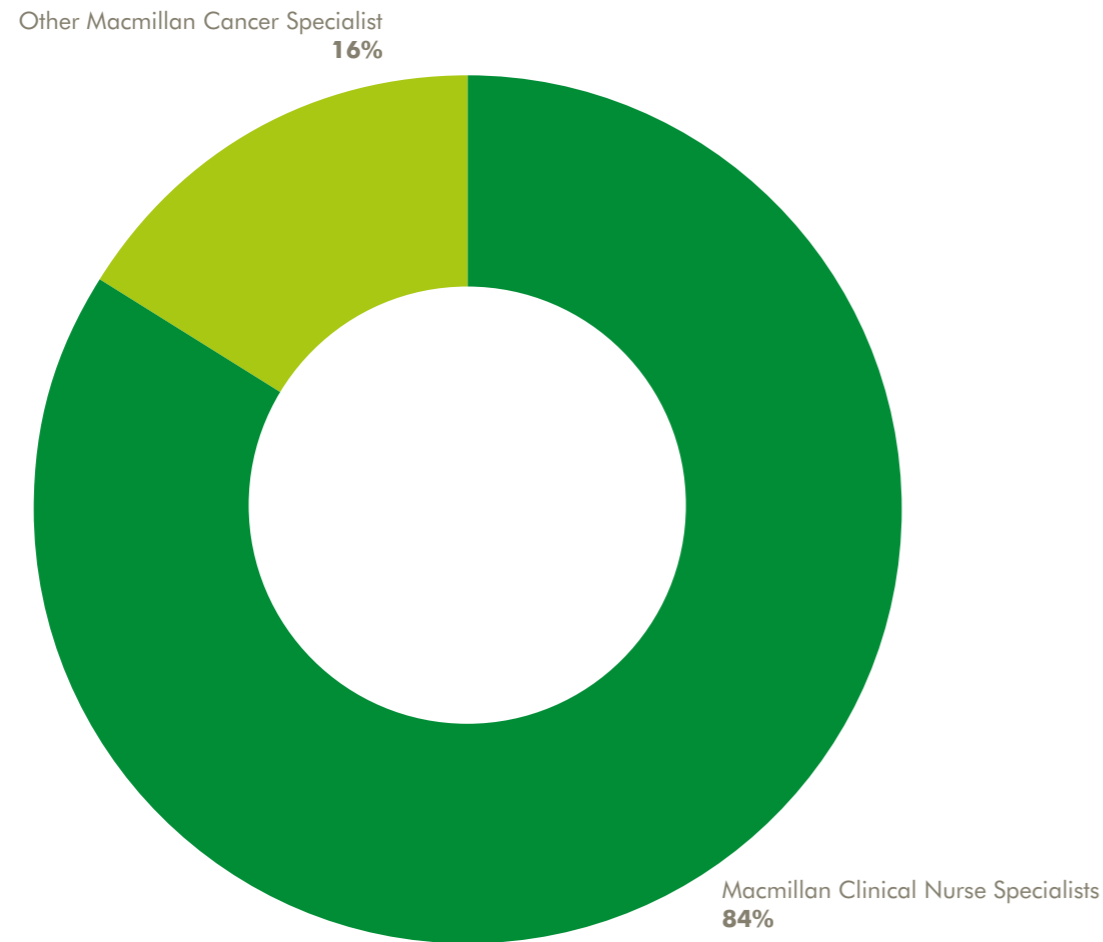


Table 6: Macmillan Cancer Support specialist adult cancer nursing workforce by area of practice WTE, Wales, 2014

	Macmillan WTE	Total WTE
Acute oncology service	0	13.3
Brain/central nervous system	0.9	4.8
Breast	6.6	39.9
Colorectal	1.9	24.9
Gynaecology	6.0	10.9
Haematology	1.0	11.3
Head and neck	4.5	10.0
Lung	8.8	22.4
Malignant dermatology	1.9	7.5
Sarcoma	1.0	2.0
Upper gastrointestinal	3.0	16.4
Urology – All uro-oncology	2.0	16.0
Urology – Prostate only	1.0	5.0

Fig. 6: Macmillan Cancer Support specialist adult cancer nurse workforce as a proportion of total specialist adult cancer nursing workforce, by area of practice WTE, Wales, 2014

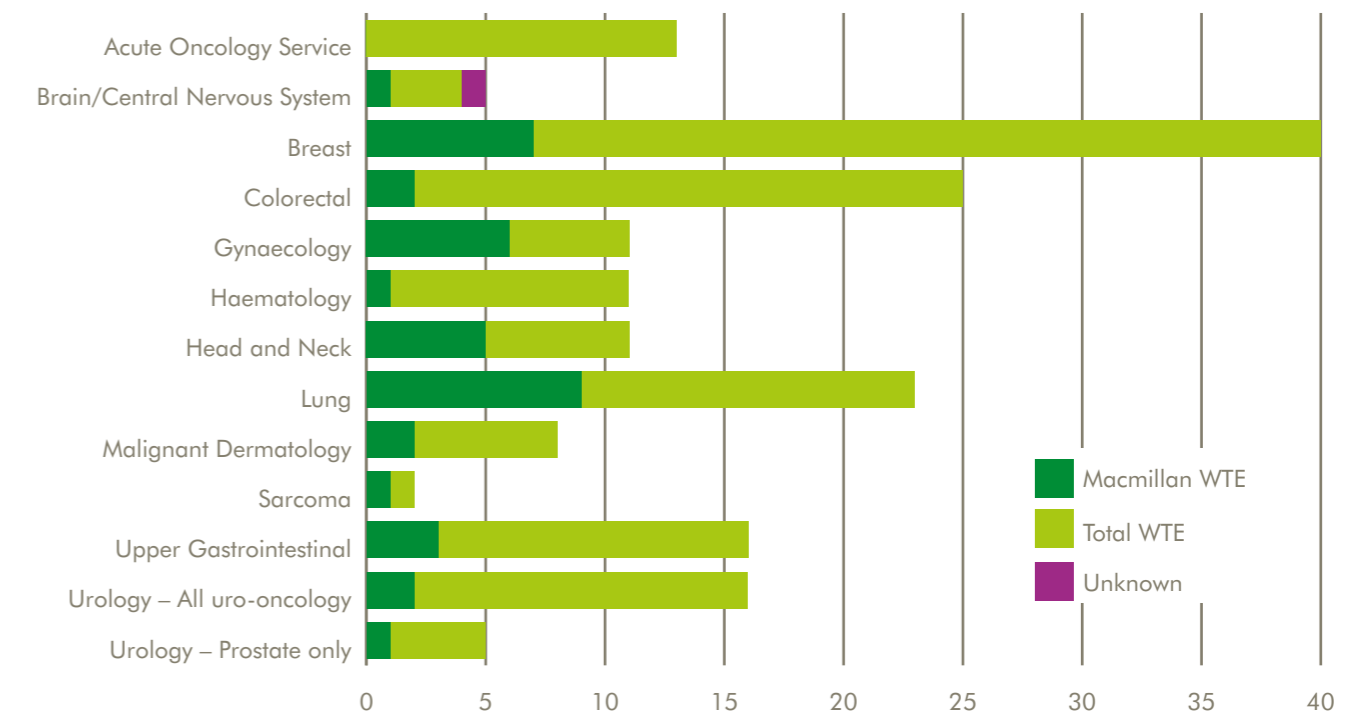


Table 7: Total specialist adult cancer nursing workforce WTE by gender, Wales, 2014

This is the first time this data has been collected and reported. The majority (96%) of filled specialist adult cancer nurse posts are held by females.

Gender	WTE	% of total (WTE)
Female	174.5	96.22%
Male	6.9	3.78%
Declined	0.0	0.00%
Not known	0.0	0.00%
Total	181.3	100.00%

Table 8: Filled specialist adult cancer nurse posts by area of practice and gender WTE, Wales, 2014

Area of practice	Female	Male	Declined	Not known	Total
Acute oncology service	11.4	1.9	0	0	13.3
Brain/central nervous system	4.8	0	0	0	4.8
Breast	39.9	0	0	0	39.9
Colorectal	24.9	0	0	0	24.9
Gynaecology	9.9	0	0	0	9.9
Haematology	11.3	0	0	0	11.3
Head and neck	9.0	1.0	0	0	10.0
Lung	21.4	0	0	0	21.4
Malignant dermatology	6.5	1.0	0	0	7.5
Sarcoma	2.0	0	0	0	2.0
Upper gastrointestinal	16.4	0	0	0	16.4
Urology – Prostate only	4.0	1.0	0	0	5.0
Urology – All uro-oncology	13.0	2.0	0	0	15.0
Total	174.5	6.9	0	0	181.3

Table 9: Total specialist adult cancer nursing vacancies by AfC banding (WTE), Wales, 2014

Band	Band 5	Band 6	Band 7	Band 8	Total
No. of vacancies in Wales (WTE)	0	0	3.0	0	3.0

Fig. 7: Total specialist adult cancer nursing vacancies per 100 jobs by area of practice, Wales, 2014

In the United Kingdom there were 2.4 vacancies per 100 employee jobs overall in April and June 2014, and 2.4 vacancies per 100 employee jobs in human health and social work activities¹⁴. In this census, for Wales, we found three vacant posts out of 193 filled jobs. This is equivalent of 1.6 vacancies per 100 filled jobs. The rates are not directly comparable, however, this suggests that there may be fewer vacancies among specialist adult cancer nurses in Wales than there are in the overall UK job market.

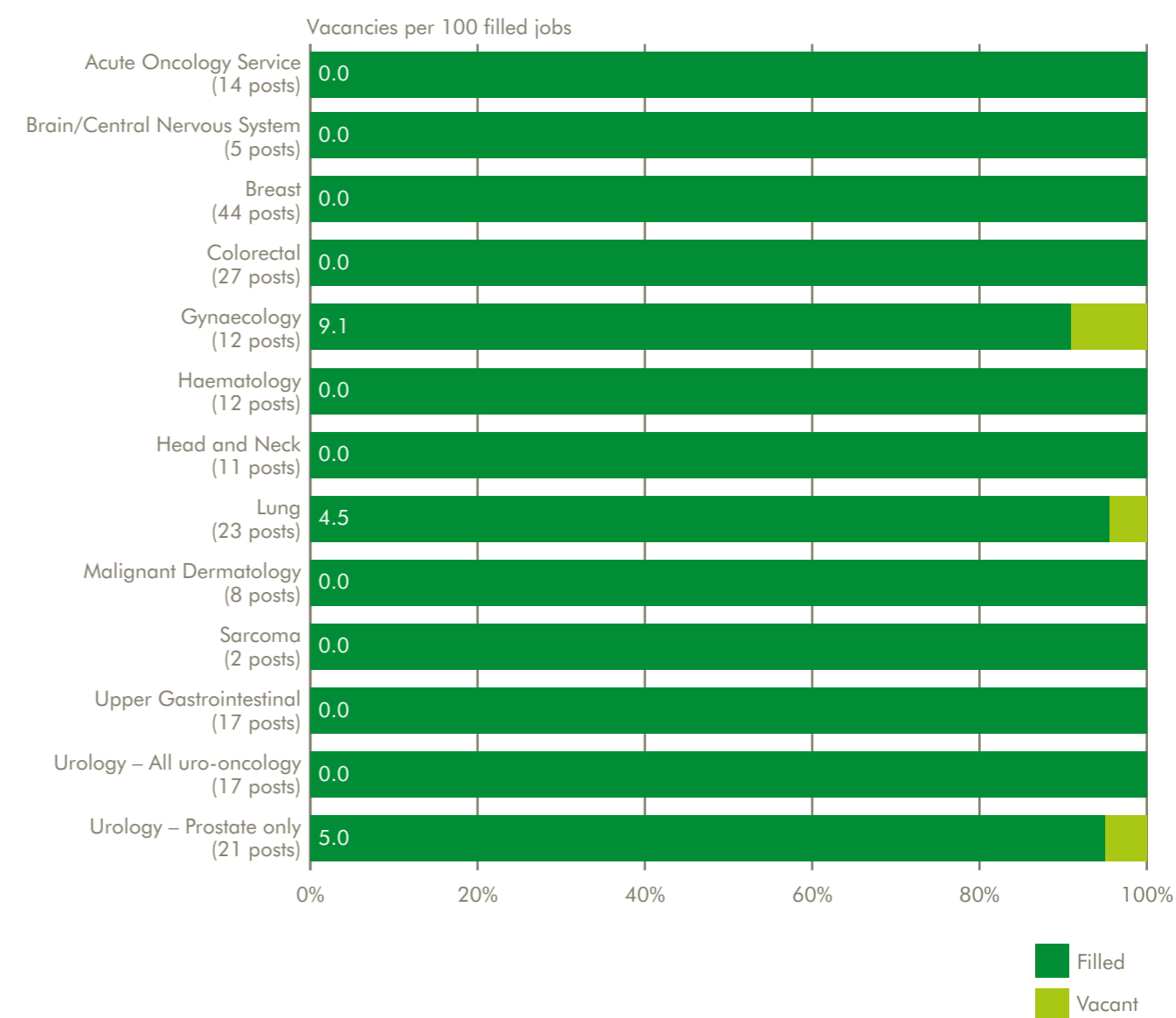


Table 10: Specialist adult cancer nursing workforce reporting cover for cancer of unknown primary (CUP) WTE, Wales, 2014

Table 10 shows that, of the 79% WTE where coverage of CUP was known, 18% covered CUP.

Does the post/post holder cover cancer of unknown primary?	WTE
Yes	25.6
No	120.0
Not known	38.8
Total	184.3

Table 11: Specialist adult cancer nursing reporting cover for CUP by area of practice WTE, Wales, 2014

Table 11 shows that 31% of nurses who cover CUP work in acute oncology services. The other nurses who cover CUP come from a variety of specialisms.

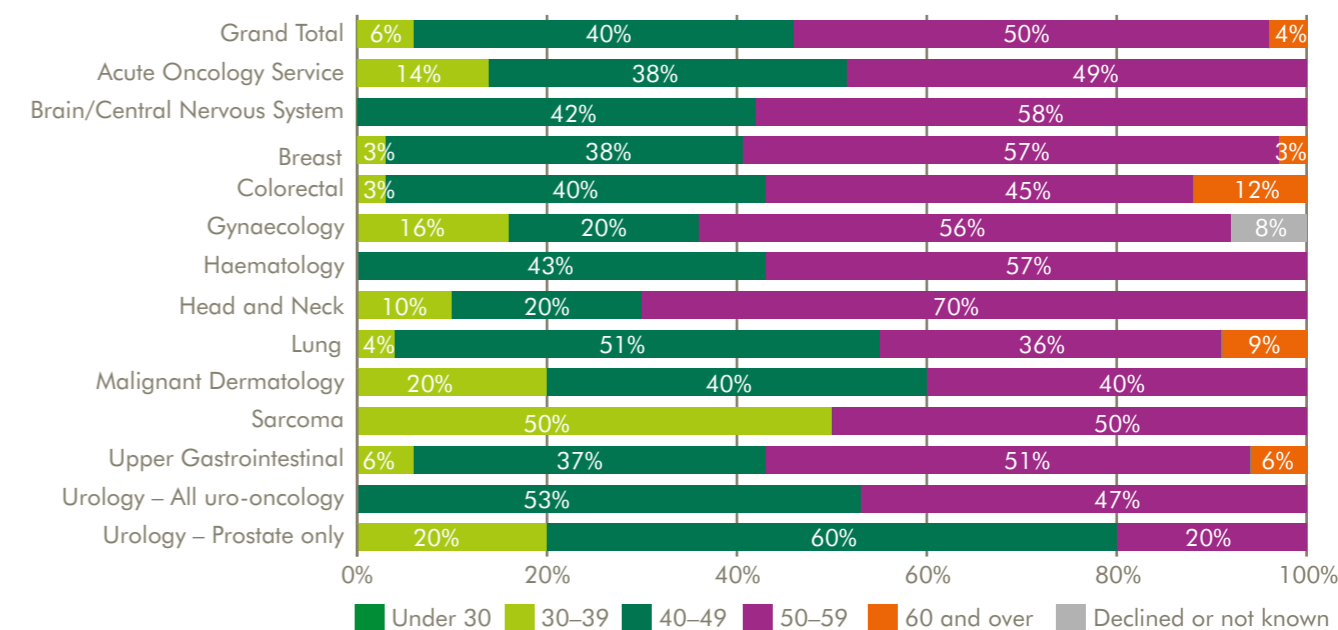
Majority Area of practice	WTE that cover CUP	% of all nurses covering CUP (WTE)
Acute oncology service	7.9	30.7%
Brain/central nervous system	1.0	3.9%
Breast	0	0.0%
Colorectal	3.9	15.2%
Gynaecology	2.0	7.8%
Haematology	0.9	3.3%
Head and neck	1.0	3.9%
Lung	4.0	15.6%
Malignant dermatology	0	0.0%
Sarcoma	0	0.0%
Upper gastrointestinal	4.0	15.6%
Urology – Prostate only	1.0	3.9%
Urology – All uro-oncology	0	0.0%
Total	25.6	100.0%

Table 12: Specialist adult cancer nursing workforce by area of practice and age banding WTE, Wales, 2014

Table 12 shows the age profile of the total reported WTE by area of practice and age band. Out of the 96% of filled WTE where age is known, the most common age range is 50 to 59 (52% of WTE). The second most common group is those aged 40 to 49 (41% WTE). Only 0.5% of reported WTE were age 60 and over, and no nurses were reported as being under 30. The high proportion of older nurses may indicate a future retirement bulge.

Age range	Acute oncology service	Brain/ nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Percentage of total
Under 30	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0%
30–39	15.8% (1.8)	0.0% (0.0)	8.8% (1.0)	6.3% (0.7)	13.7% (1.6)	0.0% (0.0)	8.8% (1.0)	7.0% (0.8)	13.2% (1.5)	8.8% (1.0)	8.8% (1.0)	8.8% (1.0)	0.0% (0.0)	6.3% (11.4)
40–49	6.9% (5.0)	2.8% (2.0)	21.1% (15.2)	14.0% (10.1)	2.8% (2.0)	6.7% (4.9)	2.8% (2.0)	15.2% (11.0)	4.2% (3.0)	0.0% (0.0)	8.3% (6.0)	4.2% (3.0)	11.1% (8.0)	39.8% (72.2)
50–59	7.2% (6.5)	3.1% (2.8)	25.2% (22.6)	12.4% (11.1)	6.1% (5.5)	7.1% (6.4)	7.8% (7.0)	8.4% (7.6)	3.3% (3.0)	1.1% (1.0)	9.3% (8.4)	1.1% (1.0)	7.8% (7.0)	49.6% (90.0)
60 and over	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	100.0% (0.8)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.4% (0.8)
Declined	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0%
Not known	0.0% (0.0)	0.0% (0.0)	14.3% (1.0)	42.9% (3.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	28.6% (2.0)	0.0% (0.0)	0.0% (0.0)	14.3% (1.0)	0.0% (0.0)	0.0% (0.0)	3.9% (7.0)
% of total	7.3% (13.3)	2.6% (4.8)	22.0% (39.9)	13.8% (24.9)	5.4% (9.9)	6.2% (11.3)	5.5% (10.0)	11.8% (21.4)	4.1% (7.5)	1.1% (2.0)	9.0% (16.4)	2.8% (5.0)	8.3% (15.0)	100.0% (181.3)

Fig. 8: Filled specialist cancer nursing workforce by majority area of practice and age banding WTE, Wales, 2014



4. Ratio of specialist adult cancer nursing workforce to incidence and two year-prevalence

It is important to put the variation in the distribution of specialist adult cancer nurses in the context of the varying levels of need. It is impossible to do this while fully taking into account the many aspects of need and service design. However, as a very crude measure, we have mapped WTE onto new cancer cases (incidence in 2012)¹⁶ and onto the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010)¹⁵.

However, there are many caveats to this approach – most notably the fact that new cases of cancer are recorded by the resident address of the patient, and not by the cancer unit in which they are diagnosed or treated. These ratios do not, therefore, reflect the caseload of the specialist nurse, nor do they demonstrate the variations in the level of support needed depending on the type and stage of cancer.

Table 13: Range of ratios of incidence and two-year prevalence per WTE by area of practice, Wales, 2014

	New cancer case (incidence) per WTE	People living up to two years post cancer diagnosis (prevalence) per WTE
Brain/central nervous system	61	102
Breast	70	126
Colorectal	101	135
Gynaecology	108	161
Haematology	125	166
Head and neck	71	101
Lung	113	73
Malignant dermatology	97	163
Sarcoma	100	117
Upper gastrointestinal	105	74
Urology	181	288

Source: Two-year prevalence data¹⁵ sourced from National Cancer Intelligence Network. 2014. Macmillan-NCIN work plan – 20-year cancer prevalence for the period 1991–2010 by cancer type for each UK nation. Data sourced and presented in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry. For cancer definitions, see appendix.

Source: Incidence data sourced from personal correspondence with the Senior Statistician, Welsh Cancer Intelligence & Surveillance Unit¹⁶

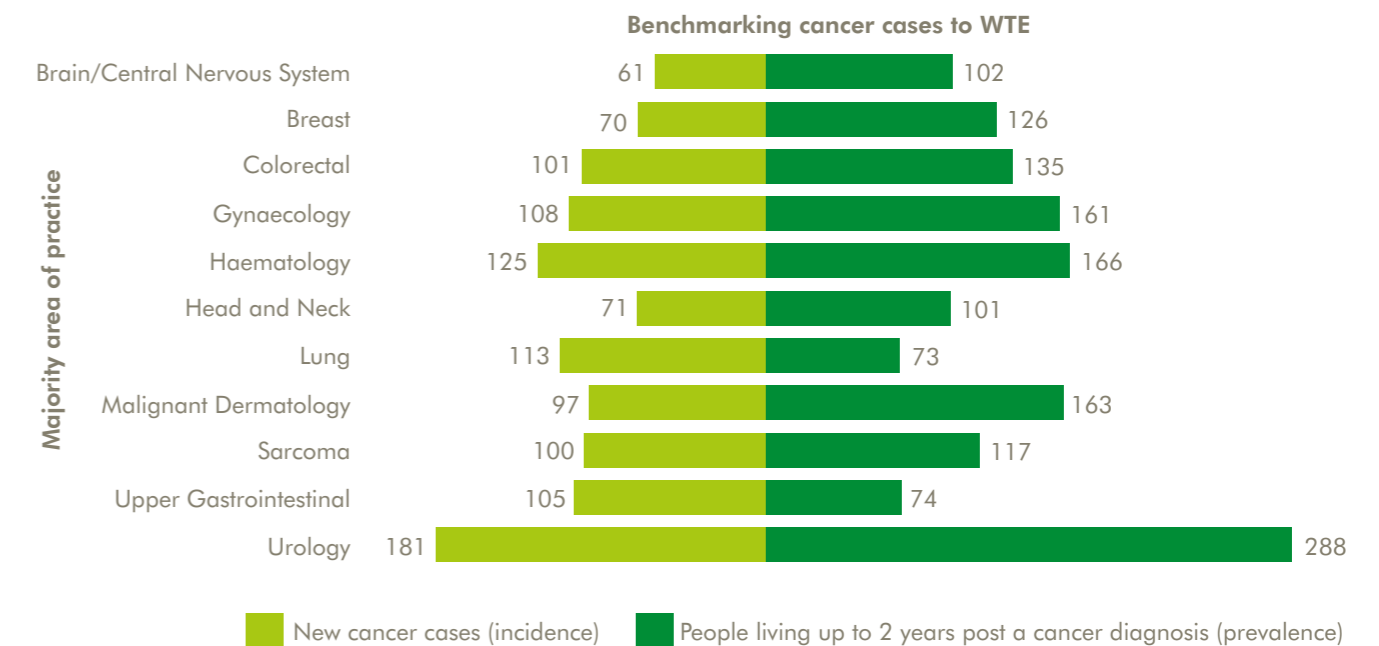
Table 13 and Figure 9 provide a benchmark for reviewing new cancer cases and prevalence for local services, and for reviewing the patient pathway while recognising that diagnostic, treatment and aftercare services may be provided by different teams in different geographical locations.

The requirements of the specialist adult cancer nurse workforce will be significantly affected by where care is provided. It should also be recognised that there is currently a variation across Wales in the provision of specialist adult cancer nurses.

Fig. 9: Specialist adult cancer nursing workforce ratios against incidence and prevalence for Wales overall, WTE, 2014

The figure below shows the variation in the ratios by tumour type. For both measures, urology has the highest ratio of cases per WTE. This is based on the assumption that urology nurses are responsible for a diverse cancer population, including large numbers of prostate cancer cases, as well as bladder, kidney, testicular cancer and carcinoma in situ cases.

The differences in the pattern seen in the ratio of new cases and people living up to two years post a cancer diagnosis mainly reflects the differences in short-term survival. This also highlights the complexity of the issue and the level of sophistication needed in workforce planning.



5. Observations and areas for further exploration

This is the first complete census of the specialist adult cancer nursing workforce in Wales, and therefore provides a baseline for further analysis including use of data available from the recent Wales Cancer Patient Experience Survey.

This baseline will also support a greater focus on certain tumour sites. For example, lung cancer has been identified as one of five top priority areas for Welsh Government and NHS partners. This is because the number of cases in women has increased by one-third over the last 10 years, with lung cancer also accounting for 22% of all cancer deaths in 2013¹¹. This census found 22 WTE specialist adult cancer nurses in Wales who specialise in lung cancer.

This census identified 13 WTE specialist adult cancer nurses working in acute oncology services (AOS) in Wales. AOS nurses deliver a fundamental service to those who require assessment and treatment for the consequences of current cancer treatment (generally systemic anti-

cancer treatment) or consequences of the disease itself. The further development of AOS is key to ensuring that the Cancer delivery plan provides fast, effective care, and continues to be a development supported by Macmillan across Wales.

The variation in the area of practice of posts holders covering cancer of unknown primary (CUP) suggests that there are no clearly agreed care pathways. Further work may be required to establish how best to meet the needs of people with CUP and how to support the CUP workforce.

Macmillan continues to develop new posts such as support workers to support CNS and advanced nurse practitioner posts to optimise their expertise. Support worker roles are being piloted in Macmillan's 'One-to-One Support' programme and other services, and are demonstrating that they can free up specialist nursing capacity as well as improve patient care¹⁷.

Summary

Future planning and recommendations

Those responsible for delivering services will undoubtedly be expecting value for money as well as high-quality services for patients. Workforce planning will be crucial in achieving improvements in outcomes, and this census is a valuable tool to inform the drive for world-class cancer services.

A national approach to workforce planning may be appropriate, as well as local service intelligence, and this may be a good time for Macmillan to contribute to this important aspect of work.

There are some differences in the provision of specialist nursing expertise for those diagnosed with different cancer types, as well as some degree of variation across different geographical locations. Evidence from all the recent National Cancer Patients Experience Survey Reports, including the one carried out in Wales, suggests that specialist nursing expertise is an important indicator of the quality of cancer services and the experience of care reported by patients.

Providers may wish to examine the ratio of specialist nurses to new cases of cancer within their localities more closely, along with data from health board/trust level, Wales Cancer Patient Experience Survey results and other sources, such as the National Cancer Peer Review programme. This may provide valuable information for health board/trust cancer annual reports and delivery plans, which are required to be submitted to Welsh Government annually. Macmillan service development teams may be able to support this analysis.

Proposals for future work

In thinking about the future specialist adult cancer nursing workforce, Macmillan has published a discussion document to encourage consideration and debate about how best to respond to the challenges facing the UK's health and social care systems. As people live longer, the incidence of cancer and other long-term conditions continues to rise, leading to an increase in the number of people with multiple health issues. Multiple morbidities are becoming the norm, with many people with cancer also living with two or more other conditions¹⁸.

In this context, Macmillan is exploring what the cancer care teams of the future should look like. They will need to be more flexible, working with people living with cancer to identify their concerns and supporting them to manage their own care. The specialist adult cancer nursing workforce will be a crucial part of a whole system of care that will be required to support the growing numbers of people living in the community after a cancer diagnosis.

Macmillan's plans include:

- identifying how best to optimise the specialist adult cancer nursing workforce, building on the success of introducing skill mix in our One-to-One Support pilots, where support workers have been demonstrated to free up CNS time for more complex care¹⁷;
- re-establishing a role development programme that will support nurses wishing to establish themselves as specialists in cancer care;
- developing new roles that will support people with complex care co-ordination at key points in their care pathway;
- mapping interventions that specialist nurses offer across different cancer patient pathways to determine best practice; and
- continuing the specialist adult cancer nursing census every two years.

Macmillan will continue to explore the use of markers other than incidence and two-year prevalence to help understand how nursing numbers relate to patient numbers, such as volume of patients seen by a multidisciplinary team.

The patient comments recorded within the Wales cancer patient experience survey were analysed by the University of Southampton and its findings were published in November 2014.¹³ This report provides further insight and understanding of the impact that a Clinical Nurse Specialist has on patient experience and outcomes. It is hoped that the Wales Cancer Patient Experience Survey will be repeated so that comparative analysis with the baseline data published in January and November 2014 can be undertaken to help inform developments and monitor progress of the implementation of the Welsh Government Cancer Delivery Plan.

There are also plans to continue to explore the complex CUP pathway and the key role that specialist adult cancer nurse can play here.

Acknowledgements

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Appendix

Cancer definitions used calculating the ratio of specialist adult cancer nursing workforce by incidence and two-year prevalence

Majority area of practice	Cancer types used in the ratios
Brain/nervous system	Incidence is based on brain and nervous system (C47, C70–C72, C75.1–C75.3), two-year prevalence is based on brain, nervous system and eye, including benign neoplasm (C47, C69, C70–C72, D33)
Breast	Breast with in situ (C50,D05)
Colorectal	Colorectal with anus (C18–21)
Gynaecology	Gynaecology (C51–C58)
Haematology	Haematology (C81–C85, C88, C90–C96)
Head and neck	Head and neck with thyroid (C00–C14, C30–C32, C73)
Lung	Respiratory (C33–C34, C37–C39, C45)
Malignant dermatology	Skin – malignant melanoma (C43)
Sarcoma	Sarcoma (C40–C41, C46, C48–C49)
Upper gastrointestinal	Upper GI (C15–C16, C22–C25)
Urology	Urology including prostate and testicular (C60–C68) and bladder in situ (D09 in the incidence data and D090 in the two-year prevalence)

The census and report is endorsed by the following bodies:



British Association of Head and Neck Oncology Nurses



National Lung Cancer Forum for Nurses



Breast Cancer Care



National Colorectal Cancer Nurses network



British Association of Urological Nurses



United Kingdom Oncology Nursing Society



Centre for Workforce Intelligence



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National Forum of Gynaecological Oncology Nurses

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