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Foreword

Macmillan first established the clinical nurse specialist role in the 1970's, and the total reported through the 2014 census shows we currently have 1305 hospital based adult cancer care posts called Macmillan nurses across the UK. We have therefore long been a strong advocate for the role specialist cancer nurses play in supporting people affected by cancer, ensuring they receive timely person centred care. Recent cancer patient experience surveys in England and Wales have provided evidence that patients who had a named Clinical Nurse Specialist (CNS) in charge of their care reported more favourably on aspects of their experience^{1 2}.

It is therefore fitting, that we have commissioned the first UK wide census of the hospital-based specialist cancer nurse workforce to provide a robust picture of the numbers and location of these nurses across all four of the UK nations. This report presents the findings of the census in Scotland.

In completing this census, we have relied on our partners in the NHS to provide this information and have been heartened to receive tremendous support for our approach with the census having a 100% response rate in Scotland. We have learnt a lot about the workforce and how it is changing to respond to environmental, demographic and policy challenges.

However there are two themes that emerge strongly across Scotland (as well as in the UK-wide census), as things we need to respond to soon:

 Our specialist cancer nurse workforce is ageing. Almost one third of the specialist nurses are aged 50-59 and half are aged between 40-49. While the age profile of the specialist cancer nurse workforce may not be an immediate cause for concern, there is a clear need for a focus on succession planning to ensure suitably qualified nurses are ready to take over as the current workforce retires.

• There is considerable variation in the provision of specialist cancer nurse expertise for those with different cancer types. While some of this can be explained by the level of need, this does not appear to explain all of the variation this census found. While the needs of many cancer patients can be fulfilled by the generalist workforce, those with complex needs often require the support of a specialist cancer nurse. This census would suggest that access to this support is not equally available to all those who need it, with some locations and cancer types having markedly better provision than others.

While the data in this report is presented at cancer network level, it is also available at board level on request. Macmillan would welcome the opportunity to work with providers and workforce planners to support planning to address these challenges.

Janice Preston Head of Macmillan Services for Scotland

Lynda Thomas Chief Executive Macmillan Cancer Support

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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 by cancer type and locality in order to inform commissioning intentions and workforce planning.

The first two censuses in England in 2007³ and 2008⁴ were developed and led by the cancer network nurse director 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. In 2014, Macmillan Cancer Support commissioned the census working with Mouchel (the partner of the Centre of Workforce Intelligence).

The 2014 census of specialist adult cancer nurse workforce 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 is the first UK-wide census to take account of the significant differences in policy and delivery of cancer care in Scotland, Wales, and Northern Ireland, as well as England. The data has been presented in separate reports and should be interpreted in light of the relevant national context.

The Information Services Division (ISD) in Scotland also provides a variety of information on staff employed in NHS Scotland from NHS Board HR and payroll systems. According to ISD in September 2014 there was the whole time equivalent of 248 cancer clinical nurse specialists in Scotland. This is an increase of 46% compared to in September 2009. This data is available by specialty, band, age, sex, contract type and NHS region and board.¹⁶

Whilst this document offers information regarding the ratio of hospital-based specialist cancer nurses to incidence of cancer and two-year prevalence in Scotland, it does not represent guidance on an appropriate caseload. It merely demonstrates variance of provision of these hospital-based posts by tumour type to provide workforce planners with the information they need to make decisions about how best to meet the needs of the cancer population.

1.2 Methods

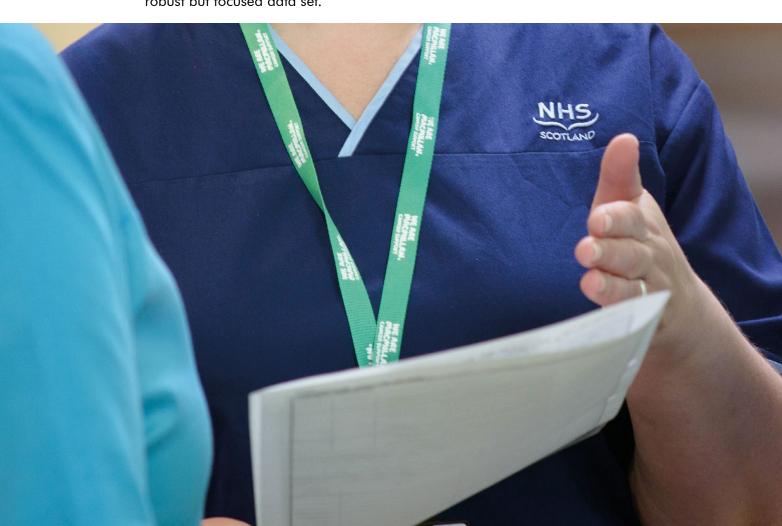
Following support from the Chief Nursing Officers Directorate, within the Scottish Government, the census was rolled out across Scotland. The census day was the same (April 24th 2014) as in the rest of the UK but the data collection period was from May 28th–July 16th 2014. This was to ensure consistency across the four countries, but facilitate time to provide complete returns.

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

Given that this is the first time the census has been carried out in this form in Scotland, the emphasis was on ensuring a robust but focused data set. The data was primarily collected using a bespoke spreadsheet with drop down menus. However, some responses were received in a standard spreadsheet format.

Areas of enquiry were informed by the previous four censuses undertaken in England.

Areas of practice are broadly based on the NICE Improving Outcomes Guidance definitions⁷. Consistent with 2011 the areas of practice include Acute Oncology Services 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 service⁸.



As in previous years of the England census there was the facility to record the post as being supported by the charity Macmillan Cancer Support. All posts are recorded as whole time equivalents (WTE) in adult cancer care where 1 WTE is equivalent to a 37.5 hour week.

Additional information was collected on age and gender of post holders and on vacant posts. Data was also collected on posts that reported supporting 'cancer of unknown primary.'

Spreadsheets were returned from Health Boards and some further checking and completion was undertaken to ensure complete records were provided where possible. Data was returned electronically from Health Boards to Mouchel for analysis. One month was given for returns to be made, with a further extension to enable appropriate dissemination and support for returns. Collection was completed by 16th July 2014.

Census process:

- Project Team and Mouchel agree census tool design and data fields
- Spreadsheet and instructions for completion were sent out to health boards
- Data entry completed at health board level
- Completed spreadsheets returned to Mouchel
- Records checked for completeness and accuracy with respondents as appropriate
- Analysis by Mouchel and project Team
- Analysis and production of data tables for review and identification of key findings
- Report production

N.B. The data was supplied by NHS Boards from Management Information. It does not form part of an Official or National Statistics publication, and therefore has not been thoroughly quality assured to meet the standards set out in the UK Statistics Authority's (UKSA) Code of Practice for Official Statistics.

1.3 Selection criteria

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

Inclusion criteria were kept consistent with previous census where possible.

Inclusion criteria: all nurse posts that:

- treat, support and manage the health concerns of adult cancer patients and work to promote health and wellbeing with 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 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 and non patient facing roles
- work "as and when required" e.g. bank and agency staff
- are community nurse specialists
- work with paediatrics or 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 (CNS) which have a specific job title and a subset of specialist adult cancer nurses.

The definition used by ISD Scotland is similar – a clinical nurse specialist (CNS) is a registered nursing professional who has acquired additional knowledge, skills and experience, together with a professionally and/or academically accredited post-registration qualification (if available) in a clinical specialty. They practice at an advanced level and may have sole responsibility for a care episode or defined client/group. ISD Scotland also exclude staff working "as and when required" e.g. bank and agency staff and those in band 1 to 4. The key differences are they only include those paid by the NHS Board and they only include those with a CNS job title.16

2. Context and background

The vital role of cancer nurse specialists in delivering good care for patients in Scotland has long been recognised by the NHS and Macmillan. We hope that this, the first ever census of cancer nurse specialists across Scotland, will build on ISD data and help cancer care planners make the best decisions for the growing number of people with cancer in the country.

Scotland's population and geography presents each area with differing challenges in delivering the best cancer care. For example, almost half of all new cancer diagnoses in Scotland are in the West of Scotland Cancer Network.⁹

The North of Scotland Cancer Network must provide care to patients living in very sparsely populated rural areas. Some cancer nurse specialists, particularly in rural areas, work across the primary and acute sectors.

Across Scotland there has been an increased focus on the CNS role as a strategic coordinator of care, using their skills and experience to support patients with complex needs. Indeed a number of those included in the census of specialist adult cancer nursing workforce are Advanced Nurse Practitioners.

There are currently an estimated 220,000 people in Scotland living with a cancer diagnosis and this number is expected to reach almost 360,000 by 2030¹⁰. Many more people are surviving cancer. While this is good news, it also means there are more people than ever before in need of support coping with the long term impact cancer can have on many aspects of their lives, from physical side effects to emotional and even mental health problems.

Macmillan is working across Scotland to ensure patients get the support they

need from the most appropriate source at the time they need it. This means ensuring those with complex care needs can access support from a CNS or other cancer specialist very quickly. It also means ensuring those with other kinds of support needs, such as financial problems, emotional issues or practical support needs, are referred to the person or organisation best placed to help them.

Macmillan welcomes the growing use of the Holistic Needs Assessment to identify the support needs of patients, as well as the programme of health and social care integration announced by the Scottish Government last year.

The Scottish Government's partnership with Macmillan on the Transforming Care after Treatment programme is also helping to embed new ways of working that will help bring health and social care together to better meet the wider needs of people affected by cancer.

We believe a more rounded approach to supporting people with a cancer diagnosis will improve their experience.

However while we recognise cancer patients may have many support needs a cancer nurse specialist may not be best placed to fulfil, there is no doubt of the vital role they play in supporting many patients. The variation in specialist adult cancer nurse posts across cancer types and aeographical areas indicates there is work to be done to ensure all cancer patients have equally good access to a specialist nurse when they need one. We hope the census will be used in conjunction with ISD data to help cancer care planners across the country make decisions on how to direct resources to ensure the needs of the growing cancer population in Scotland can be best met.

2.1 Headline findings

Total specialist adult cancer nurse workforce

The census of the specialist adult cancer nurse workforce in Scotland achieved a response of 100% from all Health Boards in Scotland.

The total reported specialist adult cancer nurse workforce for the 3 Scottish Cancer Networks in 2014 was 265 WTE.

The most common area of practice was breast cancer specialists (19% of WTE) and acute oncology service (AOS) (17%), this was followed by lung cancer specialists (14%).

34 % of the total specialist adult cancer nurse workforce WTE in Scotland was reported as providing cover for cancers of unknown primary (CUP). The main areas of practice providing this cover were AOS (23% WTE), lung (18%), and other (18%).

Clinical Nurse Specialists

The largest group by job title was Clinical Nurse Specialist equivalent to 180 WTE (68%) of the total workforce.

In total 71% of Clinical Nurse Specialists were banded at AFC Band 7, with 25% below this at Band 5 or 6 and only 3% above this at Band 8A or 8B.

Macmillan specialist adult cancer

32% of the specialist cancer nurse population in Scotland are titled Macmillan Cancer Support posts.

Vacancies

This census was the first specialist cancer nurse census to collect data on vacancies. The vacancy rate reported among specialist cancer nurses appears to be similar to the vacancy rate found in those working in human health and social work activities as reported by the Office for National Statistics vacancy survey¹¹.

Workforce characteristics

Data on the age profile of filled posts, highlights that over one third of the total specialist cancer nurse workforce in Scotland were reported as being over 50 years of age, with one post holder under 30 years of age. The proportion of the workforce over 50 years of age is highest in urology (72%), malignant dermatology (55%), brain and central nervous system (57%) and colorectal (42%).

Ratio of nurses

When provision of specialist adult cancer nurse posts is mapped to incidence of cancer in Scotland, the ratio varies from 84 new cases of sarcoma to each nurse and 349 new cases of upper gastrointestinal cancer to each nurse.

When provision of specialist adult cancer nursing posts is mapped onto the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010), the ratios vary from 103 in lung cancer to 394 in malignant dermatology.



3. 2014 census results

This section presents detailed data collected in the census supporting headline findings.

Table 1: Total specialist adult cancer nursing workforce by area of practice, and Cancer Network, WTE, Scotland, 2014.

Table 1 shows the total provision of the specialist adult cancer nursing workforce across the 3 Cancer Networks by reported area of practice. The area of practice with the largest proportion of the workforce is reported as breast, accounting for about 19% of the total reported workforce followed by acute oncology service (about 17%) and lung (14%).

Cancer Network	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	Other	Grand Total
North of Scotland	20.6	1.5	14.7	10.6	3.2	2.0	3.0	7.0	2.0	0.9	2.5	1.0	3.0	10.2	82.3
South East Scotland	12.7	1.0	18.8	8.7	4.1	7.0	3.0	6.0	0.8	1.0	3.3	2.4	5.5	1.0	75.2
West of Scotland	11.1	1.0	17.5	14.7	2.6	5.4	5.1	25.0	2.5	1.0	3.0	2.0	8.0	8.7	107.5
Total	44.4	3.5	51.0	34.0	9.9	14.4	11.1	38.0	5.3	2.9	8.7	5.4	16.5	19.9	265.0

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

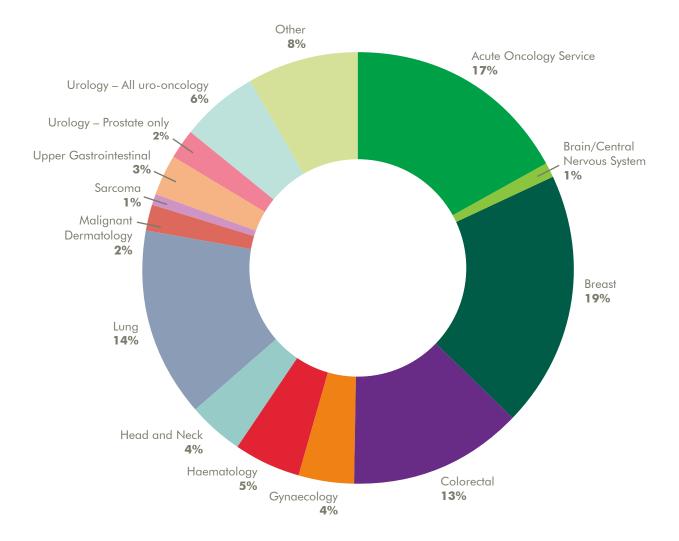


Table 2: Clinical Nurse Specialist workforce by area of practice, Cancer Network, WTE, Scotland, 2014

Table 2 shows only the cancer specialist nurses with a CNS job title across the 3 Cancer Network by reported area of practice. The area of practice with the largest proportion of the CNS workforce is reported as breast, accounting for about 21% of the total reported workforce, followed by lung (17%).

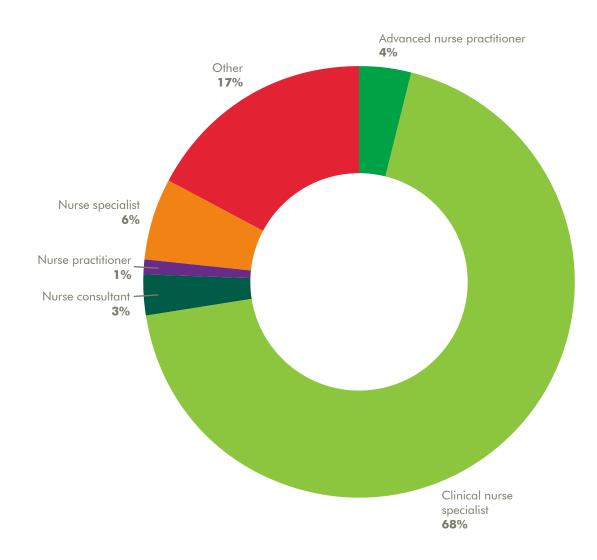
Cancer Network	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Other	Grand Total
North of Scotland	11.4	1.5	12.9	5.0	2.6	1.0	3.0	5.0	2.0	0.9	1.6	0	3.0	8.9	58.8
South East Scotland	2.5	1.0	15.4	7.3	3.1	4.0	3.0	6.0	0	1.0	3.3	2.4	5.0	0	54.0
West of Scotland	8.1	1.0	10.3	7.6	2.6	2.0	4.1	20.5	1.5	1.0	1.4	2.0	5.5	0	67.5
Total	22.0	3.5	38.6	19 9	8.3	7.0	10.1	31.5	3.5	29	6.3	4 4	13.5	8.9	180.3

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

Table 3 shows the total numbers of WTEs by job title across the area of practice, with the largest proportion of the workforce reported as CNSs working in breast (15% of the total reported WTE). The smallest proportion of the reported workforce (with a job title) is Nurse Practitioners (1% of the total reported WTE).

Area of practice	Advanced nurse practitioner	Clinical nurse specialist	Nurse consultant	Nurse practitioner	Nurse specialist	Other	Total
Acute oncology service	7.7	22.0	4.8	1.0	6.2	2.8	44.4
Brain/central nervous system	0	3.5	0	0	0	0	3.5
Breast	1.0	38.6	0	2.9	1.8	6.7	51.0
Colorectal	1.0	19.9	0	0	4.6	8.5	34.0
Gynaecology	1.0	8.3	0	0	0.6	0	9.9
Haematology	0	7.0	0	0	1.0	6.4	14.4
Head and neck	0	10.1	0	0	0	1.0	11.1
Lung	1.0	31.5	0	0	0	5.5	38.0
Malignant dermatology	0	3.5	0	0	0	1.8	5.3
Sarcoma	0	2.9	0	0	0	0	2.9
Upper gastrointestinal	0	6.3	0	0	0.9	1.6	8.7
Urology – Prostate only	0	4.4	0	0	1.0	0	5.4
Urology – All uro-oncology	0	13.5	1.5	0	0	1.5	16.5
Other	0	8.9	1.0	0	0	10.0	19.9
Total	11.7	180.3	7.3	3.9	16.1	45.8	265.0

Fig. 2: Total specialist adult cancer nursing workforce by job title, WTE, Scotland, 2014.





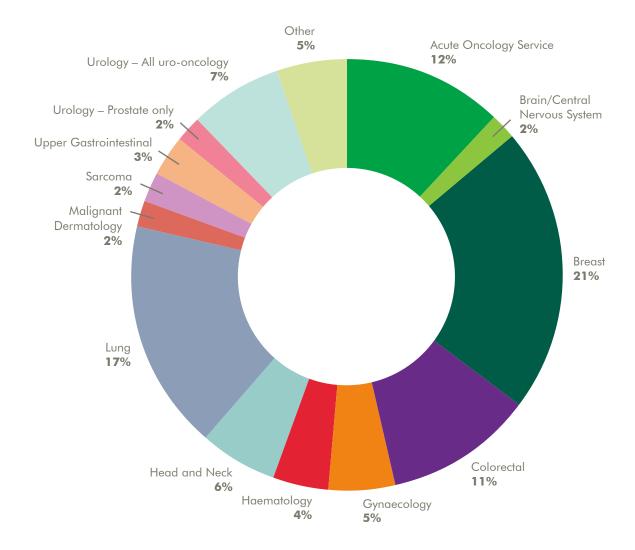


Table 4: CNS workforce by AfC banding and area of practice, WTE, Scotland, 2014.

The largest proportion of the reported WTE are Band 7 posts accounting for 71% of the total reported CNS WTE. The largest reported CNS WTE are band 7 posts in the breast area of practice with about 21% of the total reported CNS WTE.

Area of practice	AfC Bands 5 & 6	AfC Band 7	AfC Bands 8a & B	Not known	Total
Acute oncology service	4.6	16.4	1.0	0	22.0
Brain/central nervous system	0	3.5	0	0	3.5
Breast	15.9	22.7	0	0	38.6
Colorectal	6.9	11.0	2.0	0	19.9
Gynaecology	1.4	6.9	0	0	8.3
Haematology	1.0	5.0	1.0	0	7.0
Head and neck	3.6	5.5	0	1.0	10.1
Lung	2.8	28.7	0	0	31.5
Malignant dermatology	0	3.5	0	0	3.5
Sarcoma	0.6	2.3	0	0	2.9
Upper gastrointestinal	0	6.3	0	0	6.3
Urology – Prostate only	2.4	2.0	0	0	4.4
Urology – All uro-oncology	4.5	9.0	0	0	13.5
Other	2.1	5.8	1.0	0	8.9
Total	45.8	128.5	5.0	1.0	180.3

Fig. 4: Total specialist adult cancer nursing workforce by Agenda for Change banding, percentage, Scotland, 2014

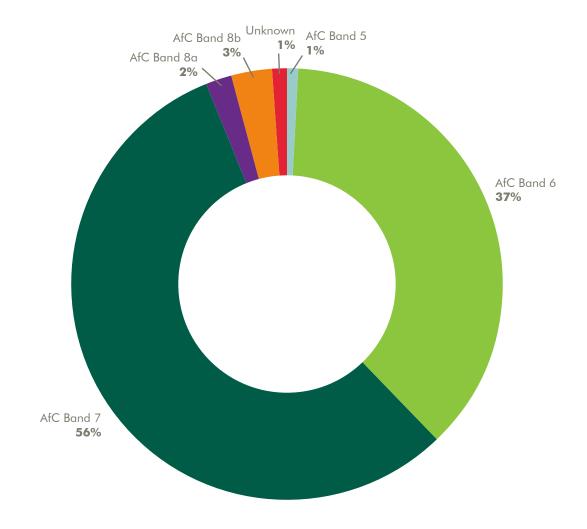


Table 5: Macmillan specialist adult cancer nurse workforce WTE, Scotland, 2014

Table 5 shows the total number of posts that have Macmillan Cancer Support in the job title. Macmillan WTEs accounted for 32% of the 265 total WTE.

Macmillan Cancer Support posts	WTE
Macmillan CNS	56.4
Other Macmillan cancer specialists	29.6
Total	86.0

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

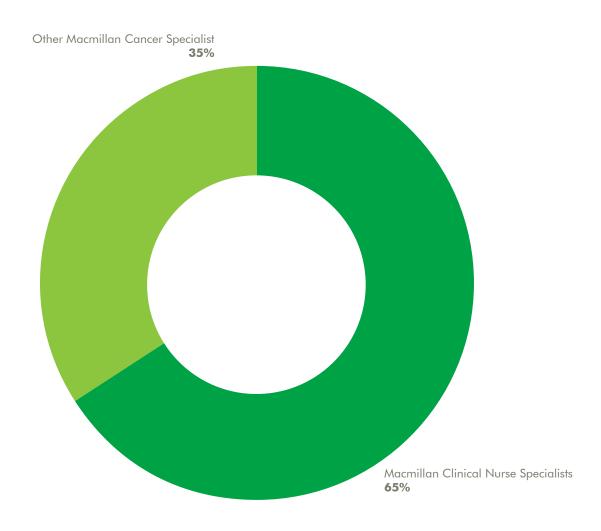


Table 6: Macmillan Cancer Support specialist adult cancer nursing workforce by area of practice, WTE, Scotland, 2014

	Macmillan WTE	% of total WTE
Acute oncology service	29.8	35
Brain/central nervous system	0.5	1
Breast	9.9	12
Colorectal	6.8	8
Gynaecology	2.4	3
Haematology	2.0	2
Head and neck	4.0	5
Lung	8.8	10
Malignant dermatology	2.5	3
Sarcoma	0.9	1
Upper gastrointestinal	2.7	3
Urology – All uro-oncology	2.5	3
Urology – Prostate only	1.0	1
Other	12.3	14
Total	86.1	

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

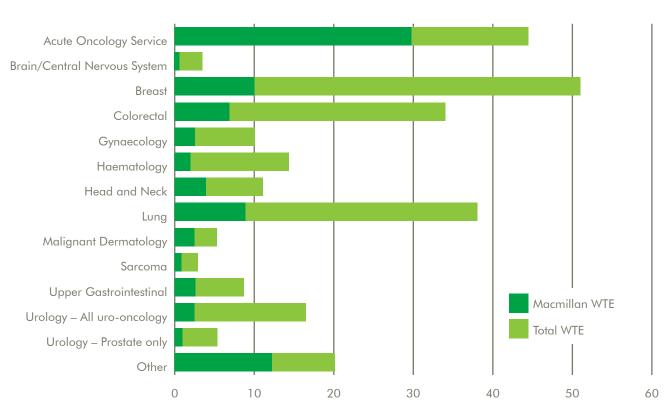


Table 7: Total specialist adult cancer nursing workforce, by gender, WTE, Scotland 2014

Table 7 shows the reported WTE by gender. The majority of reported WTE are females populating 94% of the total reported WTE.

Gender	WTE	% of total (WTE)
Female	244.4	94%
Male	14.0	5%
Declined	0.0	0%
Not known	0.5	0%
Total	258.9	100%

Table 8: Total specialist adult cancer nursing workforce by area of practice and gender, WTE, Scotland, 2014

Area of practice	Female	Male	Declined	Not known	Total
Acute oncology service	39.9	2.5	0	0	42.4
Brain/central nervous system	3.5	0	0	0	3.5
Breast	50.0	0	0	0	50.0
Colorectal	32.0	1.0	0	0	33.0
Gynaecology	9.9	0	0	0	9.9
Haematology	13.4	1.0	0	0	14.4
Head and neck	11.1	0	0	0	11.1
Lung	36.0	1.0	0	0	37.0
Malignant dermatology	5.3	0	0	0	5.3
Sarcoma	2.9	0	0	0	2.9
Upper gastrointestinal	8.7	0	0	0	8.7
Urology – Prostate only	5.4	0	0	0	5.4
Urology – All uro-oncology	11.0	5.5	0	0	16.5
Other	15.3	3.0	0	0.5	18.8
Total	244.4	14.0	0	0.5	258.9

Table 9: Total specialist adult cancer nursing workforce, by Agenda for Change banding, and gender, WTE, Scotland, 2014

Table 9 shows the reported WTE by gender and AfC banding. The majority of reported WTE are females at Band 7 (58%). The proportion of male and female reported WTE as band 7 were about the same (51% and 58% respectively). The WTE reported as Band 8a and above shows a higher proportion of male WTE when compared to female WTE against the total WTE by gender (about 21% and 4% respectively).

Gender	Band 5	Band 6	Band 7	Band 8a	Band 8b	Band 8c	Band 8d	Band 9	Not known	Total
Female	1.6	89.6	140.6	6.0	4.8	0	0	0	1.9	244.4
Male	0	4.0	7.1	0.4	2.5	0	0	0	0	14.0
Declined	0	0	0	0	0	0	0	0	0	0
Not Known	0	0	0.5	0	0	0	0	0	0	0.5
Total	1.6	93.6	148.1	6.4	7.3	0	0	0	1.9	258.9

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

In the United Kingdom there were 2.4 vacancies per 100 employee jobs overall and 2.4 vacancies per 100 employee jobs in human health and social work activities between April and June 2014¹¹. In this census, in Scotland, we found 7 vacant posts out of 302 filled jobs. This is equivalent of 2.3 vacancies per 100 filled jobs. The rates are not directly comparable; however, this suggests that there may be a similar rate of vacancies.

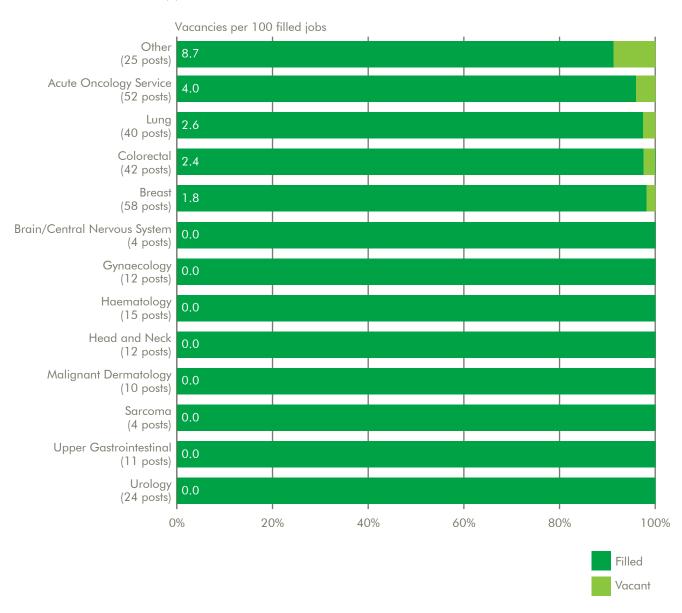


Table 10: total specialist adult cancer nursing workforce, reporting cover for cancer of unknown primary, WTE, Scotland, 2014

Table 10 shows the total WTE who were reported as covering cancer of unknown primary. 34% of the total WTE (filled and vacant posts) were reported as covering cancer of unknown primary. However 11% of the total WTE (filled and vacant posts) were reported as not know if the post covered cancer of unknown primary.

Does the post/post holder cover cancer of unknown primary?	WTE
Yes	91.4
No	144.8
Not known	28.8
Total	265.0

Table 11: Total specialist adult cancer nursing reporting cover for cancer of unknown primary by area of practice, WTE, Scotland, 2014

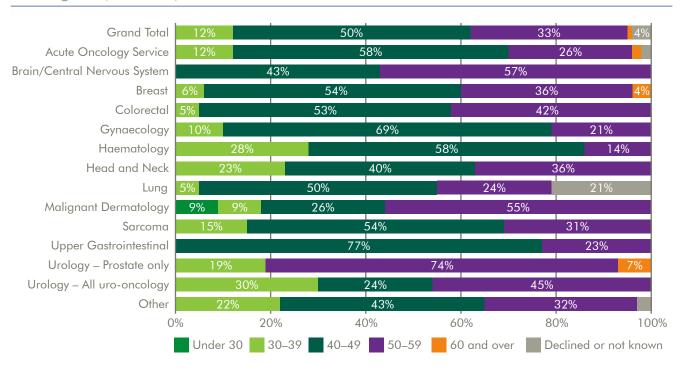
Area of practice	WTE	% of CUP workforce (WTE)
Acute oncology service	21.2	23%
Brain/central nervous system	0	0%
Breast	11.5	13%
Colorectal	12.7	14%
Gynaecology	1.0	1%
Haematology	2.0	2%
Head and neck	3.1	3%
Lung	16.2	18%
Malignant dermatology	0	0%
Sarcoma	0	0%
Upper gastrointestinal	4.0	4%
Urology – Prostate only	0	0%
Urology – All uro-oncology	3.5	4%
Other	16.2	18%
Total	91.4	100.0%

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

Table 12 shows the age profile by area of the total reported WTE by area of practice and age band. The highest WTE is reported as age 40-49 (50% of the total reported WTE). Only 1% of the total reported WTE were reported as age 60 and over.

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	Other	Percentage of total
Under	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
30	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.5)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.5)
30–39	16.2%	0.0%	9.9%	5.9%	3.3%	13.2%	8.6%	6.6%	1.6%	1.4%	0.0%	3.3%	16.5%	13.5%	12.0%
	(4.9)	(0.0)	(3.0)	(1.8)	(1.0)	(4.0)	(2.6)	(2.0)	(0.5)	(0.4)	(0.0)	(1.0)	(5.0)	(4.1)	(30.3)
40–49	18.9%	1.1%	20.8%	13.4%	5.2%	6.4%	3.4%	14.0%	1.1%	1.2%	5.1%	0.0%	3.1%	6.2%	50.0%
	(24.6)	(1.5)	(27.2)	(17.5)	(6.8)	(8.4)	(4.5)	(18.3)	(1.4)	(1.6)	(6.7)	(0.0)	(4.0)	(8.2)	(130.6)
50–59	13.0%	2.4%	21.1%	16.1%	2.5%	2.4%	4.7%	10.4%	3.4%	1.1%	2.4%	4.7%	8.8%	7.2%	33.0%
	(11.1)	(2.0)	(17.9)	(13.7)	(2.1)	(2.0)	(4.0)	(8.9)	(2.9)	(0.9)	(2.0)	(4.0)	(7.5)	(6.1)	(85.1)
60 and	26.2%	0.0%	60.7%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	13.1%	0.0%	0.0%	1.0%
over	(0.8)	(0.0)	(1.9)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.4)	(0.0)	(0.0)	(3.1)
Not known	10.8% (1.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	84.1% (7.8)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	5.2% (0.5)	4.0% (9.3)
% of total	16.4%	1.4%	19.3%	12.7%	3.8%	5.5%	4.3%	14.3%	2.0%	1.1%	3.4%	2.1%	6.4%	7.3%	100.0%
	(42.4)	(3.5)	(50.0)	(33.0)	(9.9)	(14.4)	(11.1)	(37.0)	(5.3)	(2.9)	(8.7)	(5.4)	(16.5)	(18.8)	(258.9)

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



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

It is important to put the variation in the distribution of specialist cancer nurses into the context of the varying levels of need. It is impossible to do this 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) and onto the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010).

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, Scotland, 2014

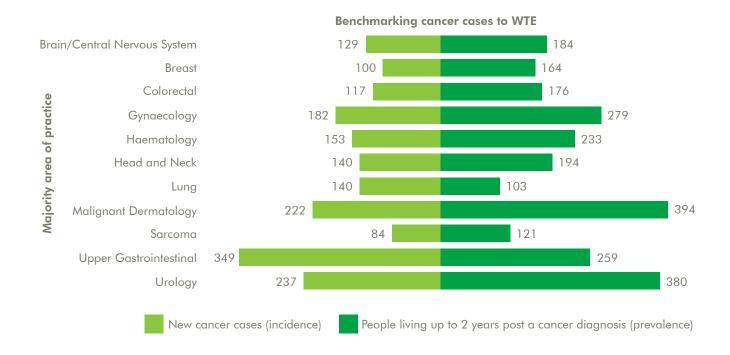
	New cancer cases (incidence) ¹² per WTE	People living up to two years post cancer diagnosis (prevalence) ¹³ per WTE
Brain/central nervous system	129	184
Breast	100	164
Colorectal	117	176
Gynaecology	182	279
Haematology	153	233
Head and neck	140	194
Lung	140	103
Malignant dermatology	222	394
Sarcoma	84	121
Upper gastrointestinal	349	259
Urology	237	380

Source: Two-year prevalence data sourced from National Cancer Intelligence Network. 2014. Macmillan-NCIN work plan – Cancer prevalence: All malignant neoplasms combined and cancer types, 20-year cancer prevalence for the period 1991-2010, by nation, UK. Data sourced and presented in collaboration with the Welsh Cancer Intelligence & Surveillance Unit (WCISU), Information and Services Division (ISD) Scotland and the Northern Ireland Cancer Registry. For cancer definitions see appendix.

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

The figure below shows the variation in the ratios across tumour types. For new cancer cases upper gastrointestinal has the highest ratio of cases per WTE. For two-year prevalence malignant dermatology has the highest ratio.

This difference mainly reflects the differences in short term survival between these two cancers. This also highlights the complexity of the issue and the sophistication needed in workforce planning.



5. Observations and areas for further exploration

This is the first census of the specialist cancer nursing workforce in Scotland, and builds upon the ISD data and therefore provides a baseline. Macmillan continues to develop new posts such as Support Workers, to support Clinical Nurse Specialist and Advanced Nurse Practitioner posts to optimize their expertise. Support Worker roles being piloted in Macmillan's One-to-One support programme are demonstrating that they can release as much as 30% of CNS capacity.



Summary

Future planning and recommendations

With an estimated 220,000 people currently living with a cancer diagnosis in Scotland, and that number expected to reach close to 360,000 by 2030¹⁰, the need for careful planning to ensure we can meet the needs of the cancer population is clear.

Workforce planning will be crucial in achieving improvements in outcomes, and the specialist adult cancer nursing census is a valuable tool to inform decision making around the role of workforce in ensuring the delivery of the best possible cancer services for people in Scotland.

There are inequities in provision of specialist nurse expertise for those diagnosed with different cancer types, as well as some degree of variance across geographical locations. Evidence from all the recent National Cancer Patients Experience Survey England and Wales reports ¹² pointed towards provision of specialist nurse expertise as an important indicator of the quality of cancer services and the experience of care reported by patients.

Workforce planners and service developers may, therefore, be interested in examining more closely the ratio of specialist nurses to new cases of cancer within their localities along with data from the first ever Scottish patient experience survey when the results become available in 2016.

Proposals for future work

In thinking about the future specialist 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 more people with multiple health issues. Multiple morbidities are becoming the norm, with many people with cancer also living with two or more other conditions¹⁴.

In this context Macmillan is developing thinking about what the cancer care teams of the future need to look like. They will need to be more flexible, working with people living with cancer to identify their concerns and support them in managing their own care. The specialist cancer nurse workforce will be a key part of a whole system of care that will be needed to support the growing numbers of people living in the community after a cancer diagnosis.

The plans of Macmillan Cancer Support in Scotland include:

- Identifying how best to optimise the specialist cancer nurse workforce, building on the success of introducing skill mix in our One- to- One Support pilots, where support workers have been demonstrated to release CNS time for more complex care¹⁵.
- Re-establishing a Role Development Programme that will support nurses wishing to establish themselves as specialists in cancer care
- Look at developing new roles that will support people with complex care coordination at key points in their care pathway
- Mapping interventions that specialist nurses offer across different cancer patient pathways to determine best practice
- Funding system re-design projects including the Glasgow-based Improving the Cancer Journey and the Scotlandwide Transforming Care After Treatment programme. These are aimed at better identifying and meeting the medical, emotional, financial and practical needs of people who've had a diagnosis of cancer, promoting better working between hospital-based teams and community health and social care teams.
- Continuing the Specialist Cancer Nursing Census on a bi annual basis

Macmillan will continue to explore the use of markers other than incidence and two-year prevalence to help estimate the true caseload of specialist nurses, such as the volume of patients seen by a multidisciplinary team.

Additionally, Macmillan will continue to work with its partners, the Cancer Networks, the Scottish Government and charitable organisations to provide robust data regarding the important nursing element of the specialist adult cancer workforce and to address inequities wherever they are identified.



Acknowledgements

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References

- 1. NHS Wales, Welsh Government and Macmillan Cancer Support. Wales Cancer Patient Experience Survey National Report January 2014. http://wales.gov.uk/docs/dhss/publications/140117canceren.pdf (accessed January 2015)
- 2. Department of Health. Cancer Patient Experience Survey 2014 National Report. https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey-national-report-pdf/file (accessed July 2015)
- 3. Trevatt, P., Petit, J., Leary, A., 2008. Mapping the English cancer clinical nurse specialist workforce. Cancer Nursing Practice; 7(3), 33–38.
- 4. Trevatt, P., Leary, A., 2009. A Census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales. *European Journal of Oncology Nursing*; 14(1), 68–73.
- 5. Warwick, M. Trevatt, P. Leary, A. 2010. Clinical Nurse Specialists in Cancer Care: Provision, Proportion and Performance. A census of the workforce in England 2010.
- 6. National Cancer Action Team. Quality in Nursing, Clinical Nurse Specialists in Cancer Care; Provision, Proportion and Performance a Census of the cancer specialist nurse workforce in England 2011. NCAT, 2010.
- 7. National Institute for Health and Care Excellence. Cancer. http://www.nice.org.uk/GuidanceMenu/Conditions-and-diseases/Cancer (accessed September 2014)
- 8. National Chemotherapy Advisory Group (NCAG). Chemotherapy services in England: Ensuring quality and safety. August 2009.
- 9. Cancer incidence by place of residence in 2013. ISD Scotland. Annual incidence.
- 10. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. Br J Cancer 2012; 107: 1195–1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015. The distribution across the nations taken from Maddams J., Thames Cancer Registry, personal communication. See also Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009.101: 541–547.
- 11. Office for National Statistics. 2014. VACS02: Vacancies by industry. http://www.ons.gov.uk/ons/rel/lms/labour-market-statistics/august-2014/dataset--claimant-count-and-vacancies.html (accessed September 2014)
- 12. Information Services Division Scotland.2014. Cancer incidence and mortality in Scotland by site/type of cancer, sex and year of diagnosis/registration of death: 2003-2012 https://isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2014-04-29/cancer_incandmort_summary.xls (accessed August 2014) and personal correspondence with the Information Analyst at the Information Services Division (ISD) of NHS National Services Scotland (August 2014).

- 13. 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
- 14. Macmillan Cancer Support. Working together: Challenges, opportunities and priorities for the UK's cancer workforce. June 2014.
- 15. Macmillan Cancer Support. 2014. Evaluation of phase 1 of the one-to-one support implementation project. http://www.macmillan.org.uk/Documents/AboutUs/Research/Research/Researchandevaluationreports/OnetoOneSupportPilotReportFinal.pdf
- 16. ISD Scotland. Nursing and Midwifery Workforce. http://www.isdscotland.org/Health-Topics/Workforce/Nursing-and-Midwifery/ (accessed September 2015)

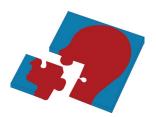
Appendix

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



Mouchel



National Forum of Gynaecological Oncology Nurses



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