

Voices from the frontline:

Challenges facing cancer clinical nurse specialists right now



We've had ten years of decline, ten years of no meaningful investment and now we're struggling to hold a workforce together. There's not enough money to deliver the services that are required, so the NHS long-term plan is fine as an aspiration, but it's worthless until there is serious investment.

Macmillan Lead Cancer Nurse, South East region

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The clinical nurse specialist is often viewed as a luxury or a privilege. Organisations should recognise the importance of good cancer care and recognise the value of the role of the CNSs within that...and reflect that in the nursing strategy agenda ...We are haemorrhaging our specialist nursing workforce and losing that wealth of experience.

Lead Cancer Nurse, retired in February 2019, South East region

Foreword

Every year nearly 300,000¹ people in England receive a cancer diagnosis. Hearing 'you have cancer' is an extremely challenging moment in a person's life, and having a fully trained professional by your side helps make sense of the diagnosis and provides support through the treatment journey and beyond.

As more people are being diagnosed with cancer, and more people are living longer with more complex conditions, the role of the specialist cancer nurse in supporting them navigate complex care and support pathways should not be underestimated.

The increasing number of people diagnosed with cancer and the increased complexity of treatments, puts enormous demands on our workforce and yet the support we provide nurses is not adequate. Continuing professional development (CPD) is essential for health and care professionals to provide effective care for their patients.

Providing CPD is critical because it enables staff to build their knowledge and skills in an increasingly complex world of treatments and side effects. CPD helps drive collective innovation across the NHS and ensures best quality care for people with increasingly complex needs. CPD is a basic requirement for a nurse to remain on the professional register, and most importantly, keeps patients safe.

But we know that increasingly, many nurses are facing barriers to accessing essential CPD. To better understand what is happening we asked cancer nurse specialists to tell us about their experience in the last year.

This is what they told us: in the NHS today, there is little protected funding and almost no protected time for professionals to undertake CPD. Time and again we heard of the 'catch 22' whereby cancer services seeking to fill specialist adult cancer nursing posts are struggling to find nurses with the right experience to do the job whilst general adult nurses are not able to secure the funding or time to gain specialist skills they need to secure a specialist role.

We have waited many years for a strategy in England to deliver a credible plan for ensuring the NHS has the workforce required to meet patient need. In June 2019 an Interim People Plan was published, setting out the broad direction of travel, but this plan lacks crucial detail on both the shape and size of the workforce that will be needed and how the NHS will deliver and fund the required growth. The lack of systematic approach to planning the supply and development of specialist cancer nurses has resulted in a stretched workforce, with Macmillan's 2017 census highlighting vacancy rates, down banding of roles and an ageing workforce in this group. The picture we are uncovering in relation to CPD significantly compounds our concern. We found no evidence of the concerted action required to reverse the vacancy rates we have highlighted but rather forewarning of greater trials yet to come.

In this vacuum of national leadership specialist cancer nurses have done what nurses always do – kept going as best they can, sometimes even overlooking their own education and training, to keep caring for people living with cancer. Cancer nurse leaders, too, are working tirelessly and creatively to raise the profile of cancer care to encourage people into the profession, to support specialist nurses in their roles and to keep delivering the best possible care.

The national approach to supporting the cancer nursing workforce to date has been short sighted. Without safeguarding the time and resource for professional development, not only will individual professionals feel undervalued and under strain; innovation and quality improvement will suffer too. More people are being diagnosed with cancer and more people are living longer with more complex conditions, and the role of the specialist adult cancer nurse in



Fran Woodward

Executive Director of Policy and Impact



supporting them to navigate complex care and support pathways should not be underestimated. As we seek to meet the ambitions of the NHS Long Term Plan for England and to deliver fully personalised care for people living with cancer, it has never been more important to unleash the creativity and productivity of the people who work in and run the NHS.

Macmillan will continue to do all we can to build and sustain the specialist cancer nursing workforce, utilising our own charitable resources and experience. But we can't do it alone. We stand ready to work with colleagues across the NHS to ensure that our hard-working cancer workforce gets the support it deserves.

The Government needs to support initiatives to tackle the big CNS shortfall. We need to address it now, not in five years' time. ▶

Macmillan lead cancer nurse, South East region

A note on this report

Between March and April 2019, we carried out telephone interviews with 16 Macmillan Professional and non-Macmillan Professional Lead Cancer Nurses across England. These interviews focused on individuals' experiences in leading cancer nursing teams, the challenges they and specialist cancer nurses face in accessing CPD opportunities and the impact this has on planning for the future.

In addition, we commissioned an online survey of Specialist Adult Cancer Nurses. The fieldwork took place between 28th May – 2nd July 2019 and 350 responded. We are extremely grateful to all the nurses who took the time to share their experiences.

Please note that in this report 'CNS' refers to a (cancer) Clinical Nurse Specialist.

In this report, we will be referring only to the 268 people who responded to our survey in England. To be classed a specialist cancer nurse for this research, nurses had to spend at least 50% of their time in patient facing activity and have a documented training record in cancer care.



The role of a cancer Clinical Nurse Specialist

A clinical nurse specialist (CNS) is an advanced practice nurse who can provide expert advice related to specific conditions or treatment pathways. CNSs provide leadership in the advanced practice of nursing to achieve quality and cost-effective patient outcomes as well as provide leadership of multidisciplinary groups in designing and implementing innovative alternative solutions that address system problems and/or patient care issues. They are clinical experts in evidence-based nursing practice within a specialty area, treating and managing the health concerns of patients and population.

We don't have the right workforce to match the patients' needs, forget expectations. We can't meet those basics to be able to provide, not gold standard, but even silver or bronze, and that impacts on patient experience.

Lead Cancer Nurse, South East region

Executive summary

The NHS nursing workforce is at breaking point, with vacancies reaching 40,000² and near intolerable pressure being placed on many professionals. The causes of this crisis are multifaceted, and so too must the response be. Whilst there is no single silver bullet which can reverse current trends and much more needs to be done to grow the workforce, we also need to do more to support and retain existing nursing staff. We know too that lack of development and learning support is a commonly cited reason for nurses leaving the profession. Ensuring that nurses are up to date and able to deliver the best possible care is also fundamental to patient safety and quality of life. For these reasons, we believe prioritising CPD is critical in creating a fit-for-purpose NHS workforce.

Key findings

Specialist cancer nurses and lead cancer nurses report three main barriers to accessing CPD. These are a lack of **protected time**, **funding**, **and locally available courses**.

Protected time

- Only a third (36%) of the specialist cancer nurses we surveyed had protected study time to access and attend CPD training.
- One in five (22%) CNSs had taken annual leave to undertake CPD.
- Individual workload is the biggest single barrier affecting professionals being able
 to take time to access and attend training in the last 12 months, with over half (58%)
 agreeing this was the case. Without backfill for clinical commitments many nurses
 are unable or unwilling to undertake CPD.
- Of the specialist cancer nurses who faced barriers accessing CPD, 49% felt their workload had got worse in the last two years.



One in five (22%) CNSs took annual leave to undertake CPD

Funding

- 43% of specialist cancer nurses cited lack of funding as the main barrier to accessing CPD in the last 12 months.
- Many trusts are not ringfencing budgets for CPD for cancer nursing.
 We discovered that funding from charitable or professional grants accounts for over half (54%) of the overall funding for CPD.
- One in five (22%) specialist cancer nurses have self-funded their CPD.

Availability

- A quarter (25%) of survey respondents reported that availability of CPD training has worsened over the past two years. Around half (48%) felt it was about the same.
- One third (33%) of specialist cancer nurses reported being unable to access CPD in the last 12 months because of a lack of local courses.
- Nearly half (45%) reported that this was a worsening problem.

In the interviews, cancer lead nurses told us they face significant problems in recruiting to CNS posts. There is no clear route to becoming a CNS and general adult nurses are struggling to find the funding or time to train to become specialists. This means there aren't enough candidates with the necessary skills and experience for the specialist roles.

We heard that CPD is essential to the delivery of high quality personalised care for people living with cancer.

- Over three quarters (76%) of respondents to our survey were clear that having more time for CPD would help them improve care for people living with cancer.
- A significant minority (44%) feel that their workload is negatively affecting the quality of care they can give to cancer patients.

Nurses' morale

- A sizeable minority (39%) disagreed that their current workload is manageable.
- Whilst 44% said that the current workload is negatively affecting their morale.



76%

of respondents said that having more time for CPD would help them improve care for people with cancer.

Key recommendations

- The Secretary of State for Health should ensure that the NHS has the sustainable nursing workforce required to deliver the care people living with cancer need.
- NHS England, NHS Improvement and Health Education England should urgently deliver a costed cancer workforce plan. This must be based on realistic estimates of the workforce numbers that will be required to meet the needs of people living with cancer.
- The Chancellor should support this plan by providing the long-term investment needed in the upcoming emergency budget.
- NHS England, NHS Improvement and Health Education England must urgently boost the supply and retention of the general adult nursing workforce. This is necessary to ensure all nurses have backfill for their clinical commitments to undertake CPD; and to ensure a pipeline for specialist nursing roles.
- The Health Education England CPD budget should be restored, as a minimum, to its former highest level of £205m (as at 2015/16), with immediate effect.
- Funding for CPD for cancer CNSs and for succession planning to support nurses to become cancer specialists should be ringfenced in Trust budgets. Without this investment, the commitment in the NHS Long Term Plan to deliver personalised care for everyone diagnosed with cancer in England will not be met.
- Health Education England, NHS
 England, alongside local Integrated Care
 Systems and Cancer Alliances, should
 be accountable for ensuring that nurses
 across England have equal access to
 relevant CPD to end variation in access.
 Neither geographical location nor lack of
 charitable trust funding should prevent
 access to CPD.

- There should be clear and supported professional development pathways for a nurse to become a cancer CNS. Health Education England, NHS England, Integrated Care Systems and Cancer Alliances should work together to support this at local level.
- Integrated Care Systems, Cancer Alliances and local Trusts should give priority to workforce planning, including providing structured support programmes for the development of general adult nursing staff to gain insight and experience of cancer nursing.
- Integrated Care Systems, Cancer Alliances and local Trusts should take a person-centred skill mix approach to workforce planning to ensure cancer CNSs are able to focus on working at the top of their scope of practice in delivering the complex and specialist care they are trained to provide. This means having the right number of both specialist and support staff in the workforce.
- Integrated Care Systems, Cancer Alliances and local Trusts should be aware of the potential risks to both safety and quality of patient care if the current trend towards down-banding continues.
- Trusts should be more flexible in the use
 of the existing experienced workforce, for
 example utilising flexible or part time
 working for those nurses near or at
 retirement age to ensure they can work
 with new or aspiring specialist adult
 cancer nurses before they leave
 the NHS.

A shortfall in nurses

Highest vacancy rate 15 vacancies per 100 filled roles



Lowest vacancy rate 0 vacancies per 100 filled roles.

Chemotherapy nurses

Highest vacancy rate 11 vacancies per 100 filled roles



Lowest vacancy rate 1 vacancies per 100 filled roles.⁴

Specialist cancer nurses

Introduction

Increasing need for cancer care

By 2030 we anticipate around 3.4 million people will be living with a cancer diagnosis in England³ and the health and care system will need to cope with this increased need. This need must be met through the NHS Long-Term Plan⁴, which is set to be delivered by 2028. In addition, the number of people alive five or more years from initial diagnosis is predicted to more than double to 2.2 million between 2010 and 2030⁵. The system will also have to address increasingly complex care needs as people continue to live longer with multiple conditions. It is vital that clinical outcomes are not the only focus, as quality of life and a good patient experience are cornerstones of excellent cancer care.

With the story of cancer changing, our health and care system must meet the challenge of ensuring that everyone living with cancer has access to care and help that meets all their needs.

The NHS workforce crisis

The general and specialist cancer nursing workforce are key to delivering the right care to people living with cancer. Therefore, the workforce must grow in step with demand to be able to meet this need. However, the Interim NHS People Plan², published in June 2019, warned that shortages in nursing are the single biggest and most urgent issue to be addressed. Currently, one in ten nursing positions in the NHS in England are unfilled, leaving a shortfall of around 40,000 nurses.



people in England will be living with a cancer diagnosis by 2030.²

Macmillan's 2017 census of the cancer workforce in England gives a snapshot of the state of the current cancer care workforce, including cancer CNSs and chemotherapy nurses⁶. It found that there is variation in vacancy rates across the country, with rates as high as 11 for every 100 filled roles for specialist cancer nurses in some Cancer Alliances.

This means that where you live, or the type of cancer you have, can impact on your access to key specialist health professionals. There is considerable variation across England when looking at the ratio of specialist cancer nurses to newly diagnosed patients for different cancer types.

We also know that the proportion of specialist cancer nurses who are over 50 years old has risen from 33% to 37% since the last census in 2014, and that there is variation across the country in the age profile of the workforce. This highlights the need for urgent action to ensure plans are in place to train new nurses and keep the workforce sustainable in the long term.

Government action in practice

In January 2019, NHS England published its 'Long Term Plan' (LTP) which sets out to redesign patient care for the next decade. The explicit commitments for cancer care include improving rates of earlier diagnosis and survival outcomes, and delivery of personalised care to ensure everyone with cancer gets the right support. To support this, the Plan commits that by 2021 everyone diagnosed with cancer will have access to a Clinical Nurse Specialist or a Support Worker to help deliver a needs assessment, a care plan and health and wellbeing information and support. This is important to ensure that the clinical and non-clinical needs of everyone with cancer are identified and addressed.

These commitments demonstrate that providing high-quality cancer treatment and care will continue to be a priority for the NHS in the next decade. However, the Plan does not set out in enough detail how the service

can guarantee it has the workforce necessary to meet the commitments made. Proposals have been made in both the LTP and the subsequently published Interim People Plan⁷ to increase the recruitment and supply pipeline of the nursing workforce, with ambitious targets for reducing the nursing vacancy rates from 12% to 5% by 2028. Crucially, however, there is a lack of clarity as to how the required investment in workforce will be funded.

Independent analysis has demonstrated that almost all of the £20.5bn extra a year for the NHS, announced by Theresa May in 2018, risks being swallowed up by maintaining business as usual, rather than contributing to funding improvements⁸. Arms-length bodies, including Health Education England who will be tasked with supporting the growth of the workforce, have yet to receive the additional funding they need to support the NHS Long Term Plan commitments.

We are concerned that the current workforce is not able to cope with patient need now, let alone in the future when need increases. Without significant action, if current trends continue, the current nursing shortfall is set to more than double to 70,000 Full Time Equivalent nurses in five years' time9. And even with action, the Interim People Plan is only proposing to fill 40,000 vacancies. That simply takes us to a position where in five years' time we will have only filled today's nursing vacancies, not grown the workforce for the future. Therefore, meeting the ambitions of the long-term plan will require additional specific workforce funding to be delivered.

Too little attention has been given to supporting and retaining the existing nursing workforce, and more nurses are now leaving the professional register than are joining it. A lack of access to CPD is cited to be a primary reason for nurses leaving the profession, with 58% of exit interviews stating they left because of "few opportunities to access training and development opportunities" 10.

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Continued Professional Development: CPD explained

CPD and personal development provides the opportunity for staff in pay bands 5 to 9 to access a wide range of education to support improvements in patient outcomes and to develop staff confidence and competence in new interventions and techniques. It is not optional, it is a requirement to stay as a registered nurse.

CPD can take the form of higher education provided by an accredited institution, which often results in the acquisition of a formal qualification (such as a Master's degree). Nurses are also able to select specific university modules, rather than an entire course.

CPD also encompasses learning outside of the higher education sector. This can include in-house training, conferences, webinars, online learning modules, reading and mentoring.

Requirements

The Nursing and Midwifery Council (NMC) requires nurses to undertake 35 hours of CPD relevant to the scope of their practice every 3 years, and of the 35 hours, atleast 20 hours must have included participatory learning. Examples of participatory learning can include attending a conference, taking part in a workshop or attending a relevant training course.

Keeping pace with advances: The importance of continual professional development

CPD¹¹ is invaluable to the specialist cancer nursing workforce, allowing them to develop their skills to respond to the needs of people living with cancer in a rapidly changing treatment landscape. New and emerging treatments alongside the rise in personalised medicine are increasingly altering how we view and treat cancer. For some people living with cancer this means they will live longer with cancers that previously had short-term survival rates. They live with their cancer as a chronic condition. For others, this will mean receiving treatments, such as immunotherapies and CAR-T cells, with complex and still emerging side effects. The increasing availability of genomic testing will mean that treatment can to be personalised in ways we haven't been able to before, and those with inherited risk of cancers will have greater access to surveillance and treatment opportunities.

All of this requires that the specialist cancer nursing workforce has access to regular and specific education and training opportunities to ensure they continue to maintain the levels of expertise required to provide the best care, and support people living with cancer to make the right treatment choices for them. People living with cancer have a range of holistic needs extending far beyond clinical treatments, and specialist cancer nurses also provide invaluable support to ensure the range of emotional, psychological and practical needs are met.

A lot of CPD can now be done online, however, an interactive, face to face experience is still the preferred method of learning for many nurses. A mix of CPD formats need to be available.

Cuts to CPD

Despite this, CPD for nurses has not been prioritised. Since 2015, Health Education England's (HEE) CPD funding for nurses, midwives and allied health professionals has been cut by over 60%¹² since 2015/16, with recent estimations stating that investment in education and training has dropped to just over 3% of total health spending in 2018/19. This is £2 billion lower than if spending had grown in line with the rest of health spending over time.¹³ A budget for workforce development was not included in the new £20.5bn funding settlement set out by the Government in 2018.¹⁴

As pressures on NHS finances have grown, Trusts have been investing less in their people.

Against this background, accessing CPD has become more difficult for nurses. The latest statistics from the Nursing and Midwifery Council show that the number of nurses who failed to meet CPD requirements for revalidation went up by almost 50% during the last financial year.¹⁵

While the Interim NHS People Plan contains a pledge to restore funding for CPD, this is to take place over five years. This will only bring the level of funding back to where it was six years ago, whilst demand has only increased.

Cancer nurse specialists paint a challenging picture of the impact of this disinvestment in CPD through the stories they have shared with us.

Education will always be pushed back and will become less of a priority when you've got a ward that you can't staff effectively.

We just haven't got a pursing

We just haven't got a nursing workforce at the moment to allow people to get the education that is needed.

Macmillan Lead Cancer Nurse, South East region

Our findings: Not enough protected time for training

Only a third (36%) of the specialist cancer nurses we surveyed had protected study time to access and attend CPD training, and finding time to study was also identified as a significant problem by the lead cancer nurses we spoke to in more depth.

Too much workload pressure

The NHS nursing workforce is heavily under strain with around 40,000 vacancies listed across the service. 16 The resulting increased pressure this places on the existing workforce can have numerous consequences, ranging from poor morale, greater risk to safe patient care, poorer patient experience and reduced opportunity for nurses to take up CPD.

Our survey found that individual workload had been by far the biggest barrier to professionals' ability to access and attend training in the previous year, with over half (58%) agreeing this was the case. Nearly half (49%) felt that this had worsened in the last 12 months.

Time and again we heard that nurses are unable to step back from clinical commitments because there was no backfill for their role.

'Accessing training has become more difficult. We can put on training but people aren't released off the ward to attend. Services are extremely busy so the capacity and time to release staff is difficult. There is no spare capacity.'

Macmillan Lead Cancer Nurse, North West region

We heard that this is the case across the nursing profession but that the situation is exacerbated for CNSs because of the autonomous, often unique nature of their position within a service. Quite simply, a number of lead cancer nurses reported that many specialist cancer nurses are unable to allow themselves the time and space for education and training.

'CNSs are very autonomous and find it difficult to release themselves. A sole nurse running a service cannot afford to take two days off for training.'

Macmillan Lead Cancer Nurse, North West region

'Staff are very stretched...the clinical caseload is heavy so they will always prioritise that.'

Macmillan Lead Cancer and Palliative Care Nurse, North West region

We heard too that often nurses are having to study in their own time. This can be particularly challenging for specialist adult cancer nurses in a day job which can be incredibly physical and emotionally demanding. One in five (22%) of the nurses responding to our survey reported having to take annual leave to access CPD.

'In my Trust there's a policy where 50% of study time is given by the Trust and 50% would be in the individual's own time. Some people aren't willing to make that sacrifice when they're working 50 hours a week and then having to study. Nurses are giving so much on the shop floor now, week in and week out, [that] the motivation to study, to train, to develop, begins to wane a bit, and you're physically and emotionally exhausted.'

Macmillan Lead Cancer Nurse, South East region

'Staffing capacity was restrictive...you could only release one person at a time to study because there wasn't capacity in the service to allow for more frequent studying. This was only for their university time; any additional study was in their own time.'

Former Deputy Lead Cancer Nurse, retired in August 2018, South West region

'It's the inability to take time away from work. It's either taking study leave or taking annual leave because these modules can be intense.'

Macmillan Lead Cancer Nurse, South East region

In-house training in reality

Whilst several Trusts are providing in-house training opportunities to save time and money, in reality, workload pressures make this difficult to deliver. We heard that sometimes staff are not released even for half day or shorter sessions, and that the specialist staff also lack the time to step back from clinical commitments to share their knowledge.

'[With] lots of the in-house training...
frequently people didn't turn up that were
booked on it, because they couldn't be
released. And they're essential training
things that they needed to do for their
role.'

Former Macmillan Lead Cancer Nurse, North West region



Whilst several Trusts are providing in-house training opportunities to save time and money... we heard that sometimes staff are not released even for half day or shorter sessions.

We didn't have the budget to send nurses externally to do their foundations in cancer care or to learn more about certain aspects of cancer, so we're compensating by doing a lot more in-house training and using our clinical nurse specialists and our clinical teams to provide the education that we can't afford.

In house training can be quite limited and involves taking staff away from their normal day jobs which means losing the capacity for clinical delivery because the people, trainers and teachers are all away from the patient groups.

Head of Cancer Nursing, London region

We had some budget for cancer but it wasn't ring-fenced around development and education. It would cover everything from training, employee salaries, equipment, IT, general supplies etc.

It was always a challenge accessing budgets to support cancer nursing education.

Former Lead Cancer Nurse, Northern region

The funding scramble

It was widely acknowledged by lead cancer nurses that funding is now a significant barrier to nurses accessing the CPD they need both to become specialist cancer nurses and to maintain and to continue to develop their knowledge and skillset in and beyond the specialist cancer nurse role; and 43% of respondents to our survey agreed that this was the case.

In the last 12 months, less than half (45%) of respondents to our survey had received funding for CPD from their Trust, and most (54%) had received funding from charitable or professional grants. Sadly, over one in five (22%) nurses had self-funded their CPD.

Decreased funding for cancer nursing education

A significant minority of respondents felt that CPD funding had changed in the last two years, with most of those (79%) who had received funding from their Trust stating that funding had decreased.

'We had some budget for cancer but it wasn't ring-fenced around development and education. It would cover everything from training, employee salaries, equipment, IT, general supplies etc. It was always a challenge accessing budgets to support cancer nursing education.

Whilst there was some learning beyond registration available, the reduced HEE budget affected the more formal academic university-based training.

Nurses are being asked to work at very senior autonomous levels, and with it comes credibility when it is supported by a really strong academic background. Not being able to access training impacts on nurses being able to fulfil the wider remit of being a clinical nurse specialist and feeling like a true expert.'

Former Lead Cancer Nurse, Northern region

No ringfenced funding for learning essential skills

Many lead cancer nurses noted difficulties in accessing central Trust resource, stating that there was no ring-fenced funding for cancer nurses' CPD.

'There's been a lot of cuts to the NHS and our hospital is not in a very good state financially. The opportunities for fully funded education are few and far between. The people that I line manage are able to attend a conference or a single study day maybe 2 or 3 times a year. It is quite limited.'

Macmillan Lead Cancer Nurse, South East region

Some noted that specialist cancer nurses could not access CPD as the Trust was prioritising other areas – we heard numerous times that investment was being directed to advanced nurse practitioners (ANPs) and generalist rather than specialist training. Whilst ANPS may be part of a multidisciplinary team providing care for people living with cancer, they provide different care to specialist cancer nurses. A specialist cancer nurse may be available to a patient across the care pathway, offering continuity of care and support to address a range of holistic care needs, whereas an ANP typically offers specific interventions during an episode of care.

'For cancer nurses within our organisation, our training and development fund has been decimated.

All of the training budget for nursing in our division goes to advanced nurse practitioners, so we have no budget left for our clinical nurse specialists to finish their Master's programmes or for any training and development, apart from mandatory training. An increase in central budget would have a massive impact on being able to complete Master's as not everyone can self-fund.'

Head of Cancer Nursing, London region

'There's only ever been generic budgets that are either held at the Trust level or within divisions. Some have an allocation for training. It's much more difficult now for staff to access training and development funds. Nurses can access certain courses like non-medical prescribing because it's highlighted as a priority at the Trust. We also get allocated places each year for advanced nurse practitioner training.'

Macmillan Lead Cancer and Palliative Care Nurse, North West region

The funding scramble

A number of lead cancer nurses commented that funding was often piecemeal, which is problematic for nurses requiring sustained funding to support them through a Master's degree. Often nurses are forced to apply for funding module by module meaning that they lack security and it takes longer to complete education and training than it necessarily should.

'The overall budget has gone down by about 40% which impacts on the cancer budget. It's taking nurses a long time to do courses because people will be able to get the money for one module to make a start, but they can't finish the course in the normal way you'd expect.'

Lead Cancer Nurse, London region

'We had 60 specialist nurses but enough HEE budget for one person for one course. We could only apply for one module at a time, not a full course. The funding was massively reduced... Nurses were scrambling around, trying to find money, module by module.'

Former Deputy Lead Cancer Nurse, until August 2018, South West region

Alternative funding sources: charitable and personal

Our interviews confirmed the results of our survey, with many lead cancer nurses telling us that members of their team had received education and training that was primarily funded by charitable grants or the nurses themselves, rather than by the Trust.

'People often fund their own education and that's difficult, not everyone can. There are many people who are the only breadwinner or not in a position to spend, it's quite discriminatory.'

Lead Cancer Nurse, London region

There's a decrease in budget which means CNSs are less supported to do MSc modules, which they are increasingly being required to do. An increase in funding would mean more access to modules but also sends out the important message that we're supporting you to do something we've asked.

Someone I managed couldn't get funding for an MSc module from the Trust. She got a charitable grant but still had to pay a fair amount of the cost.

Macmillan Lead Cancer Nurse, South East region



Macmillan investment in the cancer CNS workforce

Our research found that Macmillan funding is increasingly proving to be a lifeline for many specialist cancer nurses, filling the CPD budget black hole. Last year, we secured almost 700 new Macmillan nurse posts, increasing our total number of nurse posts to over 6,400. Across the UK, they provided personalised care to over 880,000 people living with cancer.

In 2018, we invested £76 million in health and social care professionals, including spending over £830,000 on professional grants. We also delivered learning and development courses to nearly 17,000 professionals.

'We tend to use Macmillan training and Macmillan grants to access support for those CNSs. Macmillan have been very supportive of any needs that we've had. Even our non-Macmillan CNSs have been able to put a grant forward. If we didn't have Macmillan support, it would take most options for training off the table.

I've had to use Macmillan funding for succession planning where I knew It was going to be high risk, because our Trust won't support until someone's leaving, they don't really put in any extra funds to succession planning.

There's no allocated study budget for training cancer nurses instead we find cost savings from somewhere else. Maybe we've had a vacancy in the team for quite some time or somebody's on long term sick so there's an opportunity to use that money. I don't know what the world would have looked like if we didn't have external financial support for CPD.'

Leader Cancer Nurse, Northern region

Macmillan continue to do all we can to support the cancer workforce, increasingly plugging the gaps.

There's no allocated study budget for training cancer nurses instead we find cost savings from somewhere else. Maybe we've had a vacancy in the team for quite some time or somebody's on long term sick so there's an opportunity to use that money.

I don't know what the world would have looked like if we didn't have external financial support for CPD.

Lead Cancer Nurse, Northern region

We're a very big cancer centre so there's a lot of buzz and there are charitable funds to use for CPD. Smaller district general hospitals are in a much, much worse position and that's why I run my education programme to cover those hospitals because they don't have anything else. If we can get them in on our programme, then that's a start, isn't it?

There's an inequity issue, teaching hospitals have more money and that helps staff for education, whereas it's much harder for smaller Trusts.

Lead Cancer Nurse, London region

Local variation in availability of training

We heard that the location or type of Trust a nurse works in can impact on the availability of and access to education and training. A third (33%) of our survey respondents reported being unable to access training because of a lack of local courses, and nearly half (45%) reported that this was a worsening problem.

Teaching hospitals or specialist centres often find it easier to fund CPD, for example by using their associated charitable funds, than district hospitals who do not have the advantages that come with being a teaching trust.

As left, accessing local CPD opportunities appears to be an issue. Under half (46%) agreed that there are local CPD training opportunities they can access if needed (26% disagree). Professionals in regions other than London were more likely to disagree.

The location of a Trust matters too – if there is no local training available and travel is required, this can make it harder to release staff because of the length of time they might be gone and because of additional costs for travel or accommodation. Over a third (36%) of CNSs responding to our survey disagreed that they were supported to attend CPD if they need to travel outside their geographic region.

'The Trust will fund some of the travel expenses, but not always accommodation. Most of my team like to stay fairly local. We need more equitable availability and standards of courses at a national level.'

Lead Cancer Nurse, South West region

'If I have local training offered at hospitals around me I'm much more likely to release staff to go because then someone can go in the morning for half a day. A lot of it is about, "Is training full day or half a day?", "What am I losing in terms of service hours for that individual?", and, "How far are people needing to travel to do it?""

Leader Cancer Nurse, South East region

Trusts in this position are trying to counteract this with more in-house provision but some lead cancer nurses felt that whilst there is a role, or sometimes a necessity, for in-house training, it can't always offer the quality of experience that nurses need.

'We normally want to send people externally to do a chemotherapy nursing module, but we can't afford it. Instead we run a one-day in-house study day which won't have the same impact as four and a half days taught with an assessment. You do your best but you can't replicate the quality.'

Lead Cancer Nurse, London region

We had to bring nurses into a Band 6 role without the appropriate qualification, and then train them whilst they're in post. People can't access the training before they become a CNS... There wasn't really any L&D for non-specialists, there's a pressure of time and accessing a programme.

The onus was placed on the individual to get funding for those courses because we had so little centrally...we need to recruit in but we're not growing enough nurses at staff nurse level, so there's not going to be enough people to grow into specialist nurses.

Former Deputy Lead Cancer Nurse, South West region

Succession planning

Planning for the future was a major preoccupation for all the lead cancer nurses we spoke to, and often a cause of real worry. Everyone reported that whilst we know the specialist adult cancer nursing workforce has an ageing profile, there has been no systematic strategy to ensure the NHS has a cohort of trained and experienced nurses to replace them.

Consequently, lead cancer nurses identified that it was becoming harder and harder to find appropriately skilled and experienced nurses to move into specialist adult cancer nursing roles. Put simply, a significant and damaging dearth of educational opportunities for general adult nurses means there is no training before specialist level.

'It's a catch-22, unless they can get into a specialist role they won't be released to go do the training, never mind the funding. Opportunities like that are absolutely vital for generic nurses [who] might have an aspiration to work in cancer. But because people don't invest in you until you're in a specialist role you can't even reach that specialist role.

We've got masses of CNSs over 50, and when we come to recruit rather than retain we may struggle because there is a deficit out there. The lack of CPD means you haven't got the people with the skills to take these roles. We need to sometimes recruit staff at a junior level and develop them because they're not as equipped as we want them to be.'

Macmillan Lead Cancer and Palliative Care Nurse, North West region Equally, staffing pressures across the services mean nurses are also not exposed to cancer care and services for to gain experience and insight in situ.

'We are struggling to recruit onto the ward. If our staffing numbers were right in the first place then you can have 5 to Band 6s working with the specialists so they've started that understanding of specific tumour groups and would be exposing them to go into study days. You usually have to learn on the job, and on the go. It's not easy but we don't have people coming in ready-made.'

Lead Cancer Nurse, South East region

The specialist adult cancer nurse role is complex and highly autonomous requiring skills, competencies and experience across both clinical and leadership and management functions. The consequences of this lack of investment and planning are vacancies that can't be filled or appointing nurses that do not meet the full range of requirements and developing them in role. Whilst this might be a workable compromise if Trusts are willing and able to provide the required development once nurses are in post, there is a risk to the quality of care that can be offered to people living with cancer during this transition.

'Nurses on wards tend to be the staff that we will need to train and support to come into CNS roles with the right skill set. But it's much more difficult for ward staff to get cancer training compared to CNSs.

I have concerns with specialist cancer nurses leaving through retirement and am particularly worried about the quality of care that we're offering because new CNSs are not as experienced and supported. In our bigger teams, it's not too bad because you've got other CNSs to support a new person but in small teams with only 1 or 2 CNSs it's possible they will retire very near to each other, and then where's the support for new people coming?'

Lead Cancer Nurse, Northern region

There should be systematic planning and a clear development pathway for new specialist adult cancer nurses. Planning should include smarter, more flexible use of the current experienced workforce, for example utilising flexible or part time working for those nurses near or at retirement age to ensure they can work with new or aspiring specialist adult cancer nurses before they leave the NHS.

'We need a proper workforce structure with appropriate learning and development to develop all levels of staff. Senior nurses aren't doing as much mentoring as they could. I'm past retirement age so I could retire. I've been asking our organisation what I can do about developing someone but haven't been told or supported to do that. Some senior managers can be short-sighted about what exact experience and knowledge you need and just think it's about filling the gap. But there is going to be a massive gap our senior cancer nurses go.'

Macmillan Lead Cancer and Palliative Care Nurse, North West region 'The initial learning is from your peers and the clinicians, reinforced with education, a lot of it is applied practice. We need to look at those who are retiring to come back and in what capacity to avoid losing those skills completely and to build support for the newer staff. If someone has the energy in them and wants to come back, what can we offer them so their skills can be passed on.'

Lead Cancer Nurse, South East region

It was also felt that due to general pressures in services there was less opportunity for junior nurses to be exposed to cancer care to see if it would be a career they would like to pursue. The lack of opportunities for rotational training was mentioned by several lead cancer nurses as a barrier to junior nurses gaining exposure and experience of cancer care.

'What I see is nurses on the wards here who might be interested in either becoming a palliative care nurse specialist or cancer nurse specialist but there is no way of them trying it out. We need to have a real formal process where there's a route for people to become a specialist nurse, I think there needs to be some sort of educational process rather than just getting a Master's.'

Lead Cancer Nurse, London region

'General nurses don't have as many opportunities to specialise into cancer care as they used to. Now there's less and less exposure and with so many staff cuts generalists can't afford the time to spend with specialist adult cancer nurses and the specialist teams themselves are too busy and struggle to take people to shadow.'

Lead Cancer Nurse, Northern region

A cancer nurse remarked that there was a level of 'guilt' associated with recruiting into specialist cancer nursing roles, because they knew it meant taking a nurse away from another service that would be more stretched without that individual.

[In] my experience over the last couple of years, recruiting to the post has got harder and harder for the right quality of staff. And basically, you're just robbing another area when you do get somebody who's decent. So, then another area is short, and they have to try and recruit.

Former Macmillan Lead Cancer Nurse, North West region

We need CNS development roles, encouraging Band 5 and 6s to think about cancer nursing specialism and to provide robust career progression pathways.

If nurses want to go from a Band 6 to a Band 7, it's dependent on their experience, there isn't any formal process for progression. I worked at a hospital with a CNS development programme. I hope that would be more common nationally.

Macmillan Lead Cancer Nurse, South East region

Career development pathways

The lead cancer nurses we spoke to were resolute on the importance of structured pathways for both individual career development and the security and sustainability of the specialist nursing pipeline. They also felt like a nationally recognised competency framework would also help the NHS to support a career progression strategy.

'A development pathway is really important to retaining the workforce.'

Macmillan Lead Cancer Nurse, South East region

Many gave us examples of informal opportunities they are creating in their own Trust to promote and grow the cancer nursing specialist workforce and ensure teams have the skills and competencies needed to provide the best cancer care for patients (see left).

'I'm concerned that the nurse specialists' skill mix is quite junior. It takes experience to feel confident with certain aspects of cancer care. We need to target nurses working directly in cancer care but also nurses on the peripheries who are caring for cancer patients in non-specialised areas.

We need to grow our own and motivate junior members of the team to identify their own career pathway. It shouldn't be random, there must be a career pathway for nurses to understand how to get to a CNS role in a two or three years and so tailor their education and their training to link in with that.

Each Trust has to look at how to develop basic cancer knowledge for Band 5 nurses so they have the confidence to apply for a Band 6 specialist role. I'm currently applying for a Band 5 associate nurse specialist post that rotates between four cancer specialities. They'll develop core competencies so they could apply for a Band 6 CNS post.

We're starting to hold cancer care study days, called 'The Cancer Patient Journey' to upskill generalist nurses on how patients are diagnosed, referred, tested and given cancer treatment options. Now that generalists have more awareness of the role they might feel more confident to apply for the post. There was a lot of nurse specialists on the day so the staff understood the extent of how broad the CNS role is and how much the CNS becomes a patient advocate and an enabler in speeding parts of the cancer journey. A lot of them were amazed and surprised how proactive the CNS had to be to avoid delays. It's an unsung role, without the CNS the patients would struggle. The feedback from staff was about feeling empowered and informed to recognise aspects of the care that they may not have previously recognised and to be able to contact the CNSs if they're concerned about a patient.'

Lead Cancer Nurse, South West region



Measuring professional skills: The Macmillan competency frameworks

Macmillan has commissioned the development of 2 complimentary competency frameworks to support services and individuals to better meet the needs of people living with cancer.

The Macmillan Competency Framework for Nurses (previously published in 2014) has recently been updated¹⁷ and now includes a toolkit with case vignettes to ensure that the framework implementation is relevant and easy to use for all nurses working in frontline clinical practice, education, management, or commissioning.

Macmillan has also sought to clarify the competencies that are needed in the wider workforce to address common unmet holistic needs of people living with cancer. Competencies have been developed using National Occupational Standards (Skills for Health) for posts from level 1 (entry level) to level 8 (consultant level) setting out what each level role will do to address common unmet need. The competencies also form a framework that may be used to assess existing levels of competency within teams and to identify possible solutions e.g. Learning & Development or new roles.

frameworks are going to be increasingly valuable so nurses can see the type of training and CPD needed to fulfil that role.

Former Lead Cancer Nurse, Northern region

It's so important we define roles and acknowledge the importance of the clinical nurse specialist role in patient care. CNSs are being replaced by the nurse practitioner role.

It needs to be better defined and have central support and acknowledgement otherwise the importance of those roles will be lost.

Former deputy Lead Cancer Nurse, until August 2018, South West region

Getting the skill mix right

In the modern healthcare team everyone has a role to play and making best use of the spectrum of roles across a service helps ensure that each professional uses their time and skills in the most targeted, effective way to deliver care for people living with cancer. Macmillan therefore encourages service planners to look at the workforce from the perspective of what patients need rather than an arbitrary focus on roles or titles.

However, we do not support the dilution of skill mix due to cost pressures or the inability to train the right number of given professionals. Systematic substitution of specialist cancer nurses with other roles raises the risk of losing the specialist skills cancer services needed to provide quality patient care. Some of the lead cancer nurses we spoke to raised concerns that services are using lower banded staff or Advanced Nurse Practitioners instead of specialist cancer nurses, and that this may risk the quality of holistic care for people living with cancer.

'Trusts with tight budgets have to be careful with cancer support workers or with Band 5 or 6 nurses because they're not a cheaper version of specialist adult cancer nurses. [Additionally] whilst we're wanting to massively expand our advanced nurse practitioners, often that's to the detriment of CNS posts and then we've got a gap in CNS support. Then those Advanced Nurse Practitioners or care practitioners need the support of the CNSs for the patients they're seeing.'

Macmillan Lead Cancer and Palliative Care Nurse, North West region Part of the solution to this is to more clearly define the clinical nurse specialist role and provide a competency framework setting out the skill mix required across teams to deliver quality cancer care.

'There was an internal drive that all Band 7s be titled, "Advance Nurse Practitioner" and to do the advanced practice courses, rather than cancer specific courses. Advanced practice nurses were pulled into cancer diagnostics and patient follow-ups because of pressures with capacity and cancer performance. A lot of them didn't have the capacity to do a traditional cancer nurse specialist role like implementing a holistic needs assessment.

There's no clear or equal definition for the clinical nurse specialist role.

It's so important we define roles and acknowledge the importance of the clinical nurse specialist role in patient care. CNSs are being replaced by the nurse practitioner role. It needs to be better defined and have central support and acknowledgement otherwise the importance of those roles will be lost.'

Former deputy Lead Cancer Nurse, until August 2018, South West region It's very dispiriting to ask people to work in a specialist area but then not give them the specialist education they need. Sometimes staff confidence is affected if they feel they haven't had some education and I think patients can pick up when staff are not quite sure about things.

Lead Cancer Nurse, London region

Learning to make things better for people living with cancer

Patient experience

Specialist cancer nurses are clear that the failure to support nurses with CPD impacts on both individual professionals' feeling of value and job satisfaction but also the quality of care that can be provided to people living with cancer.

Over three quarters (76%) of respondents to our survey were clear that having more time for CPD would help them improve care for people living with cancer.

Quality improvement

Continuing to invest in the ongoing education and training of our cancer nursing workforce will pay dividends in the future. Lead cancer nurses told us how important CPD is to ensure specialist cancer nurses are equipped to provide the quality care and leadership the NHS needs at a time when more and more is needed from cancer nurses.

'I think what's been expected of the cancer nursing workforce is much more, so essentially, you're needing people with higher level skills than you did before. Cancer nurses are actually being asked to man the clinics now, do follow ups, all that, you need some more assessment and diagnostic skills and things like that...'

Former Macmillan Lead Cancer Nurse, North West region

We are still finding that the complexity of patients' needs is so great that it's hard to keep up with demand. The patient population is growing and the number of nurse specialists is not growing alongside that. We are helping patients to understand self-management.'

Head of Cancer Nursing, London region

Continuous development is also crucial for quality improvement and innovation within the NHS – creating and capitalising on opportunities to be more efficient and deliver services better.

'We need to be making sure that we've got an appropriately skilled workforce by preparing people for the roles and making sure they've got the right competencies to deliver a service.

One of our lung cancer nurse specialists wants to develop their role to support a changing service. But we can't get any funding through the hospital or regionally to financially support her through the university courses she needs to gain those competencies. If the funding isn't there we just couldn't evolve that service as we'd want to. This is about improving the patient experience and patients getting through the health system more quickly, but in a supported way. We wouldn't be able to do that with the current staffing and structure of that team.'

Lead Cancer Nurse, Northern region

The landscape in which cancer care is delivered is constantly evolving – services are integrating, more care is set to be delivered out of acute settings, and the NHS must grasp the opportunities offered by new technologies and advances in treatments. Nursing staff need to be equipped with the knowledge to translate this into the best possible patient care.

We have a less well-educated workforce, and that's bound to impact on the quality of care and patient experience. Treatments are more sophisticated and technical and side effects more challenging. You can't expect generalists to build upskilled to that level to care for cancer patients safely. That's just an unrealistic expectation.

Macmillan Lead Cancer Nurse, South East region

If nurses are having less development and education, it will directly impact how well they support their patients and how well informed they are with regard to that patient group.

Head of Cancer Nursing, London region

The effect on nurses' morale

We heard that specialist cancer nurses are not immune to the pressures that much of the NHS workforce is currently experiencing and are often worn down by trying to deliver the best possible service for people living with cancer in the face of decreasing resource and rising patient need.

Respondents to our survey reported that whilst over all they feel valued and supported (60% agreed this was the case), a worrying picture is emerging regarding the impact of workload on both professionals' morale and their confidence in the quality of care they can deliver. A sizeable minority (39%) don't feel their current workload is manageable and nearly half (44%) feel that their workload is negatively affecting their morale. Nearly half of specialist cancer nurses also report that their workload is negatively affecting the quality of care they can give.

'It's challenging always keeping people on the upbeat given the pressures on the nurse specialists... because of the workforce shortage, particularly in oncology, which I think they find really challenging when the patient can't get an oncology appointment in a quick timely fashion, or an appointment has been cancelled...they're bearing the brunt of that so sometimes they can feel helpless because it's something they can't fix.

But the Trust is fantastic at celebrating and promoting meaningful recognition, we're tweeting and celebrating lots of really good things that are going on, for me it's all about valuing staff and what they do, and making them feel valued, its core to everything.

We've had ten years of decline, ten years of no meaningful investment and now we're struggling to hold a workforce together. There's not enough money to deliver the services that are required, so the NHS long-term plan is fine as an aspiration, but it's worthless until there is serious investment.'

Macmillan Lead Cancer Nurse, South East region

'Morale is pretty low. Staff don't feel valued because of the pressure on them from all sorts of different angles. Stress comes from the overwhelming caseload but also because CNSs deal with a lot of distress. People are off work from stress that hasn't being managed well in the workplace.

The NHS doesn't just need money. We are a larger population living longer but with multiple long-term conditions. The NHS needs an engaged workforce, that feels valued and at the moment they just feel battered.

Without an engaged workforce the NHS won't exist, it's as simple as that really.'

Macmillan Lead Cancer Nurse, South East region Unless nursing is seen as an attractive career there'll be ongoing recruitment problems. Over time, that affects senior specialist posts and that's what we're beginning to see now.

The problem was mainly at a ward level, but now it's starting to affect senior posts.

Lead Cancer Nurse, London region

Conclusion

Specialist cancer nurses provide essential care and support for people living with cancer but without investment in nurse training and education, the sustainability of this workforce is under threat, with deeply concerning consequences for the safety and quality of patient care.

Macmillan is clear that the commitments in the Long-Term Plan to deliver personalised care and improve outcomes for people living with cancer will not be met without concerted action to ensure the workforce has the skills, competencies and capacity to deliver care in an increasingly complex environment. We are therefore calling on the government, NHS England, Health Education England and every Trust to commit to the following actions:

- The Secretary of State for Health should ensure that the NHS has the sustainable nursing workforce required to deliver the care people living with cancer need.
- NHS England, NHS Improvement and Health Education England should urgently deliver a costed cancer workforce plan. This must be based on realistic estimates of the workforce numbers that will be required to meet the needs of people living with cancer.
- The Chancellor should support this plan by providing the long-term investment needed in the upcoming emergency budget.
- NHS England, NHS Improvement and Health Education England must urgently boost the supply and retention of the general adult nursing workforce. This is necessary to ensure all nurses have backfill for their clinical commitments in order to undertake CPD; and to ensure a pipeline for specialist nursing roles.
- The Health Education England CPD budget should be restored, as a minimum, to its former highest level of £205m (as at 2015/16), with immediate effect.

- Funding for CPD for cancer CNSs and for succession planning to support nurses to become cancer specialists should be ringfenced in Trust budgets. Without this investment, the commitment in the NHS Long Term Plan to deliver personalised care for everyone diagnosed with cancer in England will not be met.
- Health Education England, NHS
 England, alongside local Integrated Care
 Systems and Cancer Alliances, should
 be accountable for ensuring that nurses
 across England have equal access to
 relevant CPD to end variation in access.
 Neither geographical location nor lack of
 charitable trust funding should prevent
 access to CPD.
- There should be clear and supported professional development pathways for a nurse to become a cancer CNS. Health Education England, NHS England, Integrated Care Systems and Cancer Alliances should work together to support this at local level.
- Integrated Care Systems, Cancer Alliances and local Trusts should give priority to workforce planning, including providing structured support programmes for the development of general adult nursing staff to gain insight and experience of cancer nursing.
- Integrated Care Systems, Cancer
 Alliances and local Trusts should take
 a person-centred skill mix approach to
 workforce planning to ensure cancer CNSs
 are able to focus on working at the top of
 their scope of practice in delivering the
 complex and specialist care they are

trained to provide. This means having the right number of both specialist and support staff in the workforce.

- Integrated Care Systems, Cancer Alliances and local Trusts should be cognisant of the potential risks to both safety and quality of patient care if the current trend towards down-banding continues.
- Trusts should be more flexible in the use
 of the existing experienced workforce, for
 example utilising flexible or part time
 working for those nurses near or at
 retirement age to ensure they can work
 with new or aspiring specialist adult
 cancer nurses before they leave
 the NHS.

'Unless nursing is seen as an attractive career there'll be ongoing recruitment problems. Over time, that affects senior specialist posts and that's what we're beginning to see now. The problem was mainly at a ward level, but now it's starting to affect senior posts.

A decade ago being a CNS was seen as the pinnacle of your career, but it's not seen like that now. There's no financial incentive and now more people don't understand the CNS role so that affects recruitment.

I'm worried about nurses retiring. We have a retire and return policy but we're not doing enough or being flexible enough roles to keep them.... We brought in Band 4 support workers to release capacity of the specialist staff and provide the service differently, but there comes a point where you just need more nurses.'

Lead Cancer Nurse, London region

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