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**WE ARE
MACMILLAN.
CANCER SUPPORT**

THINKING DIFFERENTLY

Macmillan's vision for the future
cancer workforce in England

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Foreword



Dr Fran Woodard,
Executive Director of Policy and Impact,
Macmillan Cancer Support

The number of people living with cancer is growing. With treatment options advancing and survival rates increasing, more people than ever before are living longer after a cancer diagnosis. However, many of these people are not living well. Around one in four people experience poor health or disability following treatment¹, and many people are now living with multiple long-term conditions. This poses a significant challenge for the cancer workforce, who are dealing not only with rising demand but also with increasing complexity.

This increase in the number of people with cancer and the increase in the complexity of the disease is happening against a backdrop of one of the most significant financial challenges in the history of the NHS. In November 2016, almost a third of hospital trusts were expecting to miss their financial targets in the third quarter of the year, suggesting that the pressures on the NHS in England to achieve cost savings and demonstrate cost-effectiveness of investment are only going to increase over the coming years.²

While none of these issues are new to the NHS, past experience shows us that workforce considerations are often forgotten, coming as an afterthought to service redesign rather than driving it. As a result, the lack of a strategic and sustainable approach to recruiting, training and retaining the cancer workforce over a continued period is already beginning to impact on patient care.

Macmillan has been supporting the development of the cancer workforce for more than 40 years. In 2014 we set out our position on the cancer workforce in the discussion document *Working Together*.³ Since then, we have engaged with staff on the frontline who are facing these challenges on a day-to-day basis. By doing this we can build a better understanding of what the future cancer workforce needs to look like.

We believe that the workforce needs to be equipped with the capacity, confidence and skills to identify and address holistic needs, to tailor follow-up care and support people to self-manage. In order to balance the current financial constraints in the NHS and boldly move towards innovative new approaches, we believe that the solution needs to include improving career paths to and through specialist roles; improving use of skill mix and pursuing new kinds of cost-efficient roles; whilst finally, enhancing the skills, confidence, and ways of working for existing staff.

This new approach to the cancer workforce needs to be owned and driven at a national, regional and local level. A new national strategic vision for the cancer workforce, as recommended in the Cancer Strategy for England, is urgently needed to set the level of ambition, while local organisations and bodies must drive the change needed in each local context. Doing nothing is no longer an option – without a sustainable cancer workforce, the NHS simply will not be able to deliver high-quality, safe and effective care to everyone living with cancer in the future.

‘The lack of a strategic and sustainable approach to recruiting, training and retaining the cancer workforce over a continued period is already beginning to impact on patient care.’

1. Executive summary

Achieving world-class cancer outcomes – a strategy for England 2015-2020 states that Health Education England should work with partners to develop a strategic vision for the future cancer workforce. In light of this recommendation, this report sets out Macmillan's own vision for the future cancer workforce⁴, using examples of projects and programmes we have led or been involved in to illustrate the need to think differently about the workforce. It makes recommendations at both a national and local level, recognising that both are vital to achieving lasting and sustainable change. It focuses predominantly on England, although many of its themes may also have relevance across the devolved nations.

Macmillan's vision is for a cancer workforce that can deliver patient-centred care and support which is holistic (ie, focusing not just on medical needs but also on wider factors such as emotional, social and financial needs). This should be based on understanding the core needs of people living with cancer and the access they need to other services that will contribute to their care.

In setting out our vision, this report examines the current challenges facing the cancer workforce. These include gaps in key roles such as Clinical Nurse Specialists (CNSs), inefficient use of specialist skills, and poor coordination and communication leading to lack of support both for recovery and at end of life.

Through a series of service examples that illustrate how Macmillan is working to address these challenges, we outline five ways of addressing workforce challenges that can support the NHS to think differently about the cancer workforce. They are as follows:

- 1 Improving career pathways to and through specialist cancer roles.
- 2 Improving skill mix and introducing new types of cost-efficient roles.
- 3 Enhancing the skills and confidence of existing staff, and communication between them.
- 4 Improving ways of working.
- 5 Exploring how new ways of understanding the cancer population can be utilised to support workforce planning based on need rather than tumour type.

While Macmillan has an important role to play in developing and supporting the future cancer workforce, we cannot achieve transformational change alone. Without a coherent national framework, the health and care system risks continuing to make fragmented, incremental progress. It should not miss this unique opportunity to shape

and sustain the future cancer workforce and achieve high-quality, coordinated, holistic, patient-centered care. Solutions will be unique to each local context and will require the input of a variety of local stakeholders, including Cancer Alliances, Sustainability and Transformation Plans (STPs) and local NHS providers.

Recommendations:

This report makes three key recommendations:

- Health Education England must play a critical role in leading the development of a strategic vision for the cancer workforce, and it is vital that they work closely with partners across the health sector, including NHS England, to do this.
- The Department of Health needs to hold Health Education England to account and ensure that there is a strong, strategic focus on workforce across the NHS, and that the vision for the cancer workforce aligns with this wider work.
- To ensure people living with cancer experience well-coordinated continuity of care, Local Workforce Action Boards, Sustainability and Transformation Plan Leads and Cancer Alliances need to:
 - work closely with providers to help translate the national vision in a way which works for local health economies, and
 - adopt an approach to service redesign which begins with a clear understanding of the workforce gaps based on patient need and consider the five ways of addressing workforce challenges outlined on page 6.

The content of this report is based on the expertise and insight of professionals and people affected by cancer. This report should drive debate and discussion on this important topic, and its conclusions should be considered by stakeholders across government, ‘arms-length bodies’ such as Health Education England and NHS England, and the NHS itself. We also hope that it will provide ideas and inspiration for those leading workforce transformation locally and enable professionals on the frontline to improve outcomes and experiences for people living with cancer.

2. Introduction: what do we mean by the cancer workforce?

Many different professionals provide support for people with cancer. Cancer care may be all of, or only part of, a person's job. Some are specialists, for example oncologists and CNSs, who spend most of their time working specifically to support people with a cancer diagnosis, while others, for example GPs and practice nurses, are supporting people with a range of different conditions.

Some professionals focus on diagnosis, others on treatment and recovery or end of life, while some work across the whole cancer pathway. There is a range of different roles in a variety of settings including information specialists, allied health professionals, pharmacists, district nurses, social workers, end of life care facilitators, support workers and care assistants. Volunteers and people affected by cancer, including carers, also have an important part to play in the cancer care team.

We recognise the vital contribution made by each and every professional and non-professional across the cancer pathway, including social care professionals and welfare benefits advisers. However, the scope of this report focuses predominantly on the healthcare workforce, with a specific focus on how the needs of people affected by cancer have and will change. We do not focus on the diagnostic and medical workforce, such as radiologists and surgeons, as much work has already been conducted in this area, although many of our recommendations are likely to apply for these roles. Similarly, we do not focus on end of life, although many of the challenges and solutions we identify align with our experience in this area.⁵



3. What is Macmillan's vision for the future cancer workforce?

Our vision

Our vision is for a workforce that can deliver holistic, patient-centred care and support. It is based on understanding the needs of people living with cancer and the access they need to other services that will contribute to their care.

In developing a new approach to workforce planning, we believe that determining what roles will be required in the future must be based first on our understanding of the needs of people living with cancer. This includes understanding how these needs are changing and how they will continue to change over time. Only then can we establish what competencies and skills will be necessary to meet these needs, and therefore what roles will be required. It will also enable us to understand how services should be redesigned to develop a better skill mix within specialist teams.

We must ensure people living with cancer experience continuity of care, which is well-coordinated and responds to their individual needs. Delivering truly patient-centred care means ensuring that people are supported before, during and after treatment.

Cancer is a complex disease, and it can be distressing for people to deal with a multitude of different people and organisations during their journey. This is often made more difficult if these organisations are not coordinated and individuals have to repeat their story over and over again. For example, one breast cancer patient told us, 'Nothing seemed to be joined-up.' She highlighted the fact that she had been given two different diagnoses from two different doctors and had to chase up results herself. If services are not coordinated a further risk is that people may not be able to access services at the appropriate time.



'We must ensure people living with cancer experience continuity of care, which is well-coordinated and responds to their individual needs.'

Providing coordinated, person-centred care means not only delivering the best treatment at the right time, but also ensuring the workforce has the skills, time and capacity to meet someone's holistic needs. Achieving this will only be possible if staff are utilising their skills appropriately. This would be the right thing for people affected by cancer and it would also make the NHS more sustainable, as healthcare professionals would be operating at the top of their skill set and issues would be addressed early before they reach crisis point.

However, in its current form, this is a vision that the cancer workforce often cannot achieve. Growing caseloads, roles not being replaced when staff leave, and prioritisation of cost-effectiveness over quality are issues frequently highlighted by professionals. Many report that it is becoming more difficult to provide the high-quality care they want for patients. We hear cases of highly qualified specialists such as CNSs being asked to provide cover on wards in order to fill shortfalls in posts elsewhere in the system.

At Macmillan, we also hear from people living with cancer who tell us how this is impacting on their care. While people hugely value the staff who support them through their cancer experience, we still hear too many cases of people falling between the gaps, being unable to navigate complex systems of care once they leave hospital, and being unsure of who to contact for support.

We believe that a key part of addressing the challenges facing the cancer workforce is a fresh, strategic approach to workforce planning. Many commentators have highlighted the fragmentation in the NHS' current approach to workforce planning. It involves a multitude of bodies and does not allow local organisations the flexibility they need to adapt to the changing priorities of national policy-makers.⁶

'We believe that a key part of addressing the challenges facing the cancer workforce is a fresh, strategic approach to workforce planning.'

The lack of a strategic approach to the cancer workforce was recognised in the Cancer Strategy for England when it called for Health Education England to 'work with NHS England, charities and others to develop a vision for the future shape and skills mix of the workforce, required to deliver a modern, holistic patient-centred cancer service⁷...'

We believe that this recommendation is essential in delivering our vision for the cancer workforce. While individual trusts and their partners have a significant role to play in finding innovative solutions, the transformational change required by the *Five Year Forward View* and the Cancer Strategy for England mean that national leadership is vital. Without a coherent national framework, we risk continuing to make fragmented, incremental progress. We must not miss this unique opportunity to shape and sustain the future cancer workforce so we can achieve the vision of high quality, coordinated, holistic, patient-centered care.

Health Education England, working closely with the Department of Health, NHS England, and other strategic partners need to use the opportunity presented by the cancer strategy to set a clear level of ambition for the bodies who will be responsible for supporting cancer workforce planning at a local level. These include Local Workforce Action Boards and Cancer Alliances. With STPs now published, and the cancer strategy already being implemented, it is imperative that clear progress is made in the next year. As our recent report *Warning Signs*, on the implementation of the cancer strategy outlined, failing to address the cancer workforce is one of the biggest risks to achieving the ambitions of the Cancer Strategy for England by 2020.⁸

4. What are the cancer workforce challenges and how can they be addressed?

The number of people living with cancer is growing and the needs of people living with cancer are changing. We are also faced with a variable and uncertain workforce supply within a challenging funding environment. We are seeing the increased pressures the cancer workforce is under – dealing with ever-growing caseloads that are increasingly complex – while there are often also gaps or vacancies in key roles. The challenge for providers to quantify the quality of support they provide to patients, particularly in a target driven culture which has a strong focus on cost-effectiveness, is ever present.

We are inevitably concerned about the impact this has on people living with cancer. Without the right workforce in place, they may not be treated as early as they should be and may not have the support they need to optimise their quality of life after treatment. They may not always know who to contact for support nor how best to do so. We know they do not always have enough time to talk through all their concerns or be supported with non-clinical issues, such as financial support.⁹ If we do not address these issues now, there is an increasing likelihood that the NHS

will not be able to provide the right quality and standard of care for future generations of people with cancer.

While Macmillan does not employ professionals directly, we are well placed to see how these current challenges are taking a toll on individual professionals. They are often under increasing levels of stress and are not given the time and space for career development and training. Alarmingly, professionals tell us that their time can be taken up by tasks which do not make best use of their specialist roles. Many are finding it increasingly difficult to deliver the level of quality they would like, without the time and space to improve services for cancer patients.

On top of this, there is a real danger that the impact the current challenges are having could ultimately lead professionals to think about leaving their roles. With evidence showing a third of nurses are due to retire in the next 10 years,¹⁰ these challenges could exacerbate the uncertainty of supply.

Challenge

Gaps in key roles

The Cancer Strategy for England identified 'significant workforce deficits, particularly in diagnostic services, oncology and in specialist nursing support'. Many providers are now consistently breaching the target for patients to receive their first treatment within 62 days of being referred, and it has been suggested that this is linked to pressures on the diagnostic workforce.¹¹ However, the diagnostic workforce is not the only area of workforce feeling the pressure.

Clinical Nurse Specialists

Analysis by Macmillan published in 2012 estimated that there was a gap of 3,400 CNSs across the UK.¹² If this gap is left unaddressed and survival rates increase, we have estimated there could be a deficit of 7000 posts by 2030.¹³

CNSs undertake a significant range of roles, from performing assessments to helping patients understand their treatment and its effects, as well as playing a crucial role in improving services. They often take the role of a key worker, ensuring that people living with cancer feel supported throughout their cancer journey. Our previous report, *Working Together*, highlighted

data from the Cancer Patient Experience Survey (CPES) which suggested that good patient experience is strongly associated with access to a CNS.¹⁴

We also know from the 2013 CPES in England, however, that one in 10 patients do not have access to a CNS.¹⁵ Anecdotal evidence suggests that this situation is not likely to improve given the current pressures faced by the workforce. Many Macmillan CNSs have reported a rise in colleagues leaving the profession and a growing tendency not to replace these roles, or to replace them on temporary contracts.

Allied health professionals

This is also true for the allied health professional (AHP) workforce. AHPs, such as dietitians, physiotherapists and speech and language therapists, deliver a range of services which support patients before, during and after treatment. For instance, dietitians support patients with issues such as managing weight change and swallowing difficulties. Physiotherapists and occupational therapists can assess functional issues (such as altered vision or neurological function) caused by the late effects of cancer treatments.

The Cancer Strategy for England identified that many patients ‘do not have sufficiently early access to AHP support’.¹⁶ While there is a lack of up-to-date data on this component of the workforce, anecdotal evidence suggests that there has been a reduction in the number of specialist rehabilitation posts in cancer multi-disciplinary teams.

This means that many patients are missing the valuable and specialised support these roles can offer.¹⁷ In addition, there is variation in the types of AHP roles choosing to specialise in oncology. This means that while people with cancer may be able to access a speech and language therapist, it could be more difficult for them to access a physiotherapist or occupational therapist.

‘Many patients are missing the valuable and specialised support AHP roles can offer.’

Thinking differently

Developing and promoting career pathways, to and through, specialist cancer roles

If all people with cancer are to be able to access specialist health professionals, including CNSs and AHPs with a cancer speciality, we need to both increase retention of qualified and experienced staff, as well as ensure that there is a sustainable supply of people able to enter the profession.

Enabling generalists with an interest in cancer to develop their skills is one way in which we can create a pipeline of professionals to fill current and future gaps. To address this, Macmillan has been exploring ways to help develop the next generation of CNSs and AHPs through our role development programme, Macmillan Explore. The flexibility of the programme allows professionals to develop in a way that fits with their own busy schedules.

Macmillan Explore

Developed by Macmillan, this e-learning programme supports qualified professionals who wish to increase their knowledge, skills and professional confidence in cancer care. The aim of the programme is to support generalist nurses to gain the knowledge and experience they need to apply for specialist posts, although the programme can also be used by current CNSs to refresh or enhance their knowledge. During the pilot of the programme, more than 200 people registered for the course.

Macmillan Explore includes four key modules exploring topics designed to support roles in cancer care teams. They are called, 'Increase your knowledge about the cancer pathway', 'Macmillan services to help you, your patients and their carers', 'Managing yourself', and 'Increase your knowledge about key elements of the specialist role'. The programme also includes telephone mentoring support.

The purpose of Macmillan Explore is to help and support professionals to:

- further develop their skills and knowledge about cancer,
- enhance their current practice,
- become more competent and confident practitioners,
- improve patient care,
- equip them to consider a specialist practitioner role in the future, and
- to increase the confidence of newly appointed CNSs or AHPs working in oncology.

'I know that the quality of the course will be so beneficial to me in my formative years in post. I have found it all I was hoping for and more.'

Pilot course delegate



In addition to training and development programmes, career pathways can also be developed and promoted through the use of competency frameworks. The lack of a recognised career pathway for AHPs wishing to specialise in cancer, along with the need to build more capacity in this part of the workforce, has led Macmillan to develop a competency framework for AHPs working in cancer. This framework sets out the various levels of competence for AHPs working with people living with cancer, and can provide a framework for informing the development of the AHP workforce at an individual, organisational and commissioner level.

Encouraging retention of staff will also be hugely important, as will looking at the potential of retired professionals as volunteers. If the cancer workforce is to retain its staff for as long as possible, it is important that staff experience is positive, and that staff are valued. This issue is a matter that Macmillan has explored previously as part of our work on patient experience. Our 2015 report, *The people behind cancer care*, gathered stories from both patients and staff.¹⁸ One of the quotes it included from an emergency practitioner highlighted issues around retention of staff, stating, 'Even newly qualified nurses, only in the job 18 months, are already quitting because it's miserable.'

That report found that staff experience was not only important to improve retention but, crucially, that it is also directly related to the experience of patients, with happier staff leading to a greater likelihood of happier patients. The report found that in trusts where staff were more likely to recommend their trust as a place to work or receive treatment, the cancer patient experience was also more positive. It concluded, 'Clearly staff are aware of the quality of care they are providing and this is what drives and motivates them'.

Next steps

We believe that initiatives such as those described in this section can go some way to addressing supply issues. However, this alone is not enough to address the wider issue of the growing gaps in CNS and AHP numbers. Therefore:

- **Cancer Alliances should work with local stakeholders to identify and support the promotion of cancer as a specialism in their local area. They should recognise programmes such as Macmillan Explore as opportunities for enhancing the knowledge of generalists, thereby relieving some of the pressure on the cancer specific workforce.**

- **As part of its vision for the future of the cancer workforce, it is vital that Health Education England examines the issue of supply more broadly, aligning with wider plans for the nursing and AHP workforce, as part of the *Five Year Forward View*. It should ensure that there is a sustainable pipeline of people entering the profession. In addition, it will be important that Health Education England considers (as far as is possible) any impact Brexit may have on future workforce supply.**
- **We believe that all organisations – from Health Education England, to Local Workforce Action Boards and individual trusts – have a responsibility to ensure that career pathways and retention are considered as a priority in any workforce planning.**

Challenge

Inefficient use of specialist skills

The pressures faced by CNSs and AHPs every day mean that they are increasingly unable to offer the level of support they would like as a key worker. Many feel this is partly due to the increasing numbers of people living with cancer, but also the growing

complexity of the cases they see. One Macmillan CNS told us that their time is ‘increasingly stretched’ and that it is taken up by ‘doing non-specialist tasks’, particularly as CNSs can ‘rely less and less on admin/general colleagues as they are increasingly disheartened and overwhelmed’.

With pressures also growing in the wider workforce (the increase in demand for nurses outstripping supply in the wake of the Francis report in 2013 being one example), many CNSs are also being asked to fill gaps in other areas rather than use their specialist cancer skills. Anecdotal evidence suggests that CNSs have been asked to cover shifts in the Emergency Department and work on wards – some even have to spend time pushing beds around the hospital.

One AHP told us, ‘so many things I have to do do not need to be done by a highly skilled [professional], however they have to be done. I need to be able to target my specialist skills, and not at the photocopier.’

Wider workforce pressures combined with many staff not being able to fully utilise their specialist skills has created a situation which urgently needs addressing to avoid further negative impact on patient experience of care and outcomes.

Thinking differently

Supporting services to develop better skill-mix within specialist teams, including adopting new types of roles where appropriate

Whilst an increase in specialists is needed to help address the current gaps, we know that simply increasing numbers is not the most effective or sustainable way to address the changing needs of people with cancer. Many professionals have highly specialised skills, which are not always necessary to address the day-to-day concerns of patients.

For instance, CNSs have the skills needed to play a key role in responding to feedback and driving service change. However, many of our professionals tell us that they find it hard to make time for this given their increasing caseloads. In addition, some of the support a patient may need to help coordinate their care, such as rebooking appointments, may not always require a CNS intervention. Macmillan has explored a solution for this through working with Imperial College Hospital to develop a navigator role. This new 'single point of contact' role means that rather than having to wait to speak to a CNS, patients are able to speak to someone who can address their particular concerns or escalate them to the appropriate person.

Utilising new roles which make the best use of different levels of skills can relieve pressure on CNSs, allowing them to spend time using their skills

for the tasks best suited to their specialist qualifications and experience. It can also provide a more flexible and responsive service for patients.

Trained support workers are another new role Macmillan has been exploring. These roles work alongside registered practitioners to support people with cancer who have non-complex needs. While the specifics vary, the overall aim of their role remains the same: to offer the right post-treatment support to patients at the right time, and to support people to manage their own care. For instance, support workers can coordinate care or provide a single point of access in order to allow patients to easily re-enter the system when they need to. In addition, they can provide appropriate advice and escalate any issues to a specialist where necessary. The role, which is focused on a partnership with the patient, allows the support worker to empower the patient to self-manage – which is ever more important as people live longer with the consequences of cancer treatment.

'My Macmillan support worker helped me understand my feelings and emotions a bit more. They also helped me with the transition from being a cancer patient to a more normal lifestyle and routine again.'

Person with cancer

Macmillan support workers making a difference in cancer aftercare

The feedback from people living with cancer who have received support from a Macmillan support worker has been extremely positive and reinforces the need for this type of role. Our evaluation showed that many felt they would not have received appropriate care and support in dealing with the consequences of their cancer and its treatment without access to a Macmillan support worker.

When Gemma took on the role of Macmillan cancer support worker at University Hospitals, Bristol, she had the skills and capacity to rethink how cancer rehabilitation and support services were being delivered. One of her many initiatives involved introducing a one-click e-referral system allowing CNSs to refer patients to her easily and efficiently. She also established regular, well-attended, health and wellbeing events, and supported a successful scheme to help patients boost their fitness in advance of surgery.

‘The real positive about my role is the amount of time I am able to spend with patients – it’s something CNSs simply don’t have,’ says Gemma. ‘Patients can always access our service, and they find this reassuring.’

Next steps

Macmillan support worker roles are now in place up and down the country, implementing changes in patient follow-up and supporting CNSs and AHPs to manage bigger caseloads. Some areas have reported between 25% and 40% of clinicians’ time being freed up.¹⁹

Macmillan’s experience of developing new roles has been positive, and we will continue to drive the rollout of this model. This aligns with the direction of current thinking on NHS workforce as the *Five Year Forward View* identified new roles as a key way in which

the workforce needs to adapt to be sustainable in the future.

However, there is still significant variation in the extent to which new roles are being adopted across the NHS.

- **In looking at a vision for the future cancer workforce, Health Education England needs to closely consider how new roles can support the existing workforce. It also needs to set a clear expectation that workforce planning should consider new roles when looking at how the workforce can best address patient need.**

- **The specific design – and success – of new roles will depend heavily on local context. Therefore, Local Workforce Action Boards, Cancer Alliances and trusts will need to work closely together to encourage innovative thinking about how best to use new roles and skill mix to meet the specific workforce challenges they are facing.**

Challenge

Poor coordination and communication

The NHS is already struggling to maintain the level of cancer care that people have received in the past. This is exacerbated by the fact that, for example, seven out of ten people with cancer (70%) are also affected by one or more other serious long-term conditions.²⁰ Multi-morbidities mean that they may be receiving care within acute, primary and community settings and that they will be in contact with a variety of professions including both cancer specialists and generalists.

More people are living longer after a cancer diagnosis. But, unfortunately, that does not mean that those people are living well. Research estimates that 625,000 people have one or more physical or psychological consequence

of their cancer or its treatment,²¹ and one in five people have unmet needs after their cancer treatment has ended.²²

'[I was] left completely to fend by myself. When I found it difficult to cope emotionally, I did contact the cancer care team but as a cancer survivor was told I was out of their remit.'

Mandy, 71, person with pancreatic cancer

With patients having a wide range of needs, it is vital that these are identified and that the services to support them are available and well-signposted. This is particularly important in the first few months after treatment has ended. However, we know that many people struggle to access the timely and effective support they need at this point in the pathway. There are many reasons why people living with cancer are not currently able to access the services they need. For example, we know health and social care professionals are not always equipped to discuss financial issues or to signpost to relevant information,

advice and guidance.²³ We also know the challenges this can bring through our work in end of life care, in which a variety of professionals and multiple agencies are required to work together across organisational boundaries to provide patient-centred care.

Both people living with cancer and professionals often highlight poor coordination and communication between organisations as a root cause of this difficulty in accessing services. This tends to be particularly the case between primary and secondary care providers, but also between health providers and local authorities too.

‘I now know at this time that there was probably more help available. However people in our state don’t really have the time or the energy to go and ask for help. I know that might seem strange, but it would be better if the help could come to us. Then we would get everything that we need.’

**25-year-old person
with lung cancer**

A lack of consistency in the services provided, coupled with uncertainty over roles and responsibilities, mean that people with cancer often fall between the gaps. Currently, responsibility for coordinating the care of people with cancer outside of hospital is variable and inconsistent.

Mandy, who was diagnosed with pancreatic cancer, told us how a lack of support and poor coordination of care after a complex operation to treat her cancer, affected her physically and emotionally. Mandy received some support from her local cancer care team, however the support provided was insufficient and she described feeling ‘very much alone’.

Thinking differently

Enhancing the skills and confidence of existing staff, and communication between them

The need for generalists and specialists to work together is increasingly important as cancer becomes more complex and more people live with multi-morbidities and need to access different services.

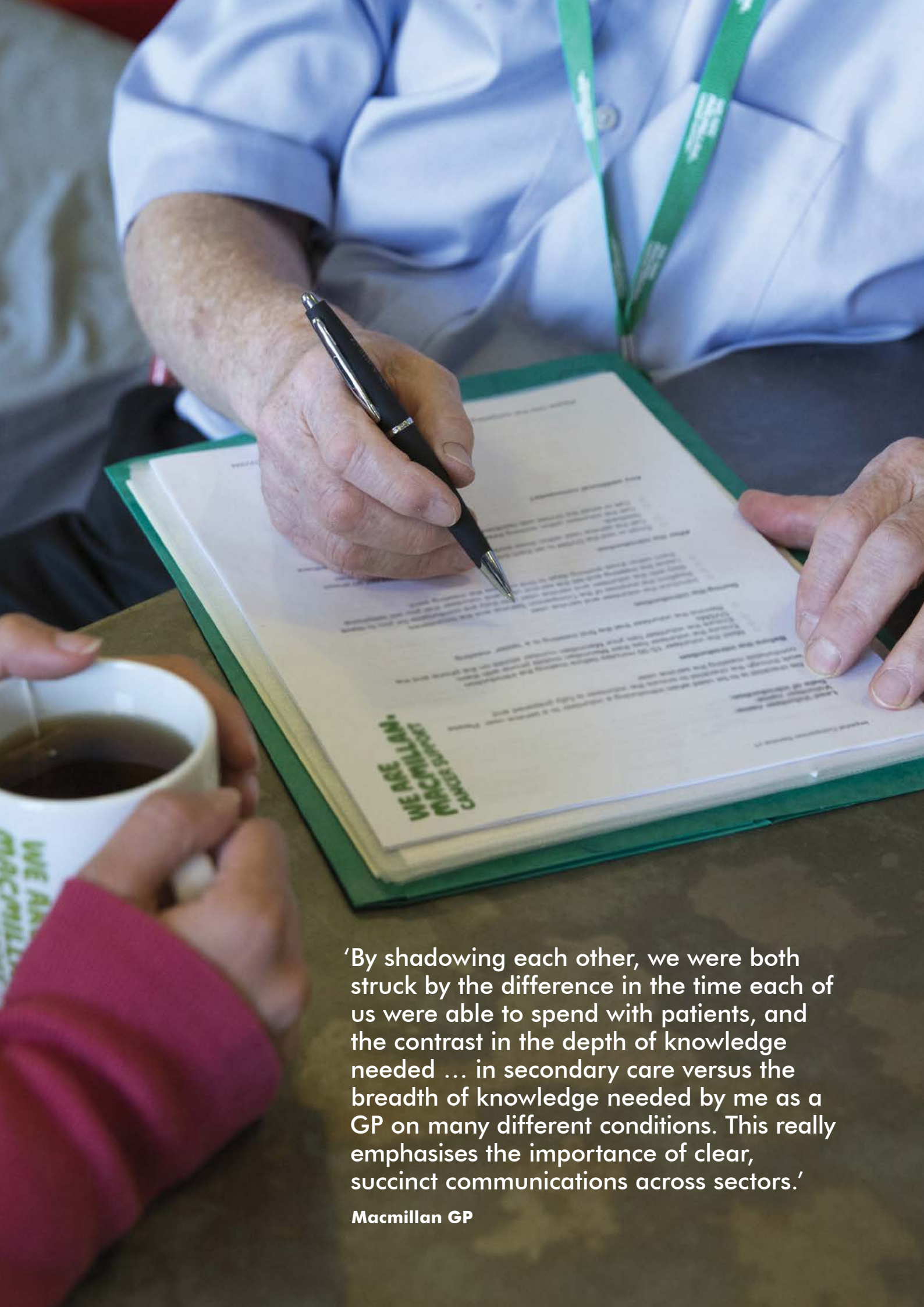
One way to improve coordination and communication is to increase professionals’ knowledge of cancer and of each other’s roles, whether they are specialist or generalist. Macmillan has been exploring this through our work in primary care.

A spotlight on primary care

Through Macmillan's **Practice Nurse Course**, which uses the skills of practice nurses in managing long-term conditions, staff are equipped with the knowledge they need to apply their existing skills to cancer patients specifically. Our offer to practice nurses is focused not only on improving knowledge but also confidence. An evaluation of the programme found that participants felt it gave them 'the confidence to see cancer patients, whereas previously they would not have had any input'.²⁴ It uses Macmillan's unique insight and position as a facilitator to deliver a transformational course with an opportunity for service redesign, building relationships and improving outcomes within the local health economy. Many nurses said that it led to a change in their attitude towards cancer patients.

The importance of using and building on existing skills in the workforce is demonstrated through our work with the **Macmillan Cancer Improvement Partnership** in Manchester (MCIP). This partnership was launched to improve cancer outcomes in Manchester and 90% of Manchester's GP practices chose to participate. As well as improving systems, procedures and the provision of information, clinical and non-clinical staff cancer training was key. Sessions were run for GPs, practice nurses, district nurses, community nurses, health care assistants, practice managers, receptionists, secretaries and a variety of other administrative roles. Practices involved in the programme contributed to an increase in the number of new cancer cases treated after a suspected cancer referral. The combined Manchester average detection rate of 50.4% now exceeds the England average (48.4%).²⁵

Through our **Medical Communities of Influence**, a network of medical professionals, including around 200 GPs, we have recognised the value of improving relationships between generalists and specialists and building understanding of each other's roles. A number of GPs and consultants have undertaken a Macmillan shadowing day called, 'A day in each other's shoes'. Participants have reported that the day revealed interesting insights. Consultants discovered that GPs actually see patients with cancer relatively infrequently in surgeries, while GPs learned that MDT meetings are extremely pressured with just a few minutes allowed for the discussion of each case. This improved understanding has resulted in improved communication, as well as the potential for effective coordination of care.



'By shadowing each other, we were both struck by the difference in the time each of us were able to spend with patients, and the contrast in the depth of knowledge needed ... in secondary care versus the breadth of knowledge needed by me as a GP on many different conditions. This really emphasises the importance of clear, succinct communications across sectors.'

Macmillan GP

Next steps

Whilst these solutions may not work for every local health system, we believe that the principles underpinning them should be considered when shaping the future workforce.

- **When developing a national vision for the future cancer workforce Health Education England must take into account the different roles of generalists and specialists and consider how the existing skills of the workforce can be utilised and enhanced.**
- **When determining how best to respond to workforce challenges in their area, Cancer Alliances and Local Workforce Action Boards should use insight from projects and programmes that demonstrate how existing staff can achieve their full potential and improve communication between care settings.**

Thinking differently

Improving ways of working

As well as utilising existing skills and competencies, we can also innovate in the way the existing workforce is currently working. With cancer becoming more complex, the services people need to access become more varied. For instance, someone may need to access long-term financial support, housing advice, or support for mental health issues. One of the key problems for patients in being able to access these services is a lack of coordination between health services and those provided by the local authority. Workforce needs to be a driving factor in service redesign. Macmillan has explored ways of doing this in Scotland, as part of our Improving the Cancer Journey programme.

‘Back up, before and even in the immediate post-operative period, was nonexistent. The operation was done in London and nothing was arranged for support, either medically or psychologically. I became very ill [...] the stress of travelling all the way to London [for follow-up consultations] and waiting around for hours had just been too much.’

Mandy, 71, person with pancreatic cancer

Linking people with cancer to the holistic support they need

The Improving the Cancer Journey (ICJ) programme involves a team based within the local council working with local health services. They proactively reach out to patients who have been newly diagnosed with cancer and offer them a meeting with a Link Worker who can help assess any unmet needs and direct people towards the relevant services. Since the project launched in February 2014, more than 4,100 newly-diagnosed people in Glasgow have been contacted, and there have been just over 2,400 referrals into the service.²⁶

A 44-year old person with breast cancer was quick to praise the ICJ programme. 'With both of my cancers removed I was one of the lucky ones. But why couldn't I pick myself up and get on with my life? I had totally lost my confidence.

But things started to change when I received a letter from the ICJ programme offering their support.

My Link Worker came to visit me and carried out a needs assessment. The assessment showed that I would benefit from support to exercise, from talking therapy, and from massage to improve my mobility. My Link Worker then arranged for me to attend gentle Tai Chi classes at my local support centre, as well as a massage therapy session and several weekly talking therapy sessions. It was great to have someone who patiently listened to my thoughts and fears and suggested coping strategies.

ICJ has allowed me to carry on with my life happily and with greater confidence. It has helped prepare me to deal with the future, whatever that may hold for me.'

'ICJ has allowed me to carry on with my life happily and with greater confidence.'

44-year-old person with breast cancer

Next steps

The evaluation of the Improving the Cancer Journey programme has found that it has transformed cancer care in Glasgow, helping those most in need when they need it most. It has become a beacon of excellent inter-organisational practice for others to follow. What's more, the components of its success – strong leadership, strong buy-in from partners, and a highly-skilled workforce practising within a clear process – are reasonably straightforward to identify and follow.²⁷

Given that the focus of many vanguards, new models of care and STPs is on broader service redesign and integration of health and social care, it is essential that the cancer workforce is considered as an important part of this. To organise the cancer workforce around the needs of the patient, there needs to be a strategic focus on new ways of working, that do not look exclusively at the health service but also at organisations across the local economy, and particularly local authorities.

- **Health Education England should use the strategic cancer workforce review to set a clear direction that emphasises the importance of using workforce effectively to deliver services across organisational and sectoral barriers as part of their local workforce planning.**
- **While it might not be possible to replicate the exact model used for Improving the Cancer Journey everywhere, Local Workforce Action Boards and Cancer Alliances should incorporate the principles from such programmes when considering how to design the workforce in their area.**

5. What more can we do to achieve transformational change?

We believe that there are practical ways that organisations can begin to tackle these workforce challenges, and this report has illustrated some of the projects Macmillan is involved in to help do this. However, achieving transformational change will require the system to build on individual projects and be more ambitious about redesigning the workforce.

‘Achieving transformational change will require the system to build on individual projects and be more ambitious about redesigning the workforce.’

Thinking differently

Exploring whether the cancer workforce could be designed better in future using Macmillan’s Three Cancer Groups model

Every person with cancer is different and treatment and support should be personalised to individual needs. However, identifying similar needs for groups of cancers could help to guide thinking as to what interventions, conversations and skills are required to move towards more personalised care. Macmillan has undertaken exploratory work framing three groups of cancer, and is keen to explore the potential to improve workforce planning through grouping parts of the workforce using this model.

This model provides a high-level view of potential care requirements. We believe there is a possibility that, if the workforce were designed in this way, skills and competencies could be more aligned to need, and capacity could be used more efficiently. This could also have the potential to ensure greater operational resilience and workforce flexibility, ultimately improving outcomes and the care that people with cancer experience.

A new approach: the Three Cancer Groups

Macmillan's Three Cancer Groups analysis aimed to generalise the more than 200 existing cancers into groups that are primarily based on survival data in order to facilitate service design.

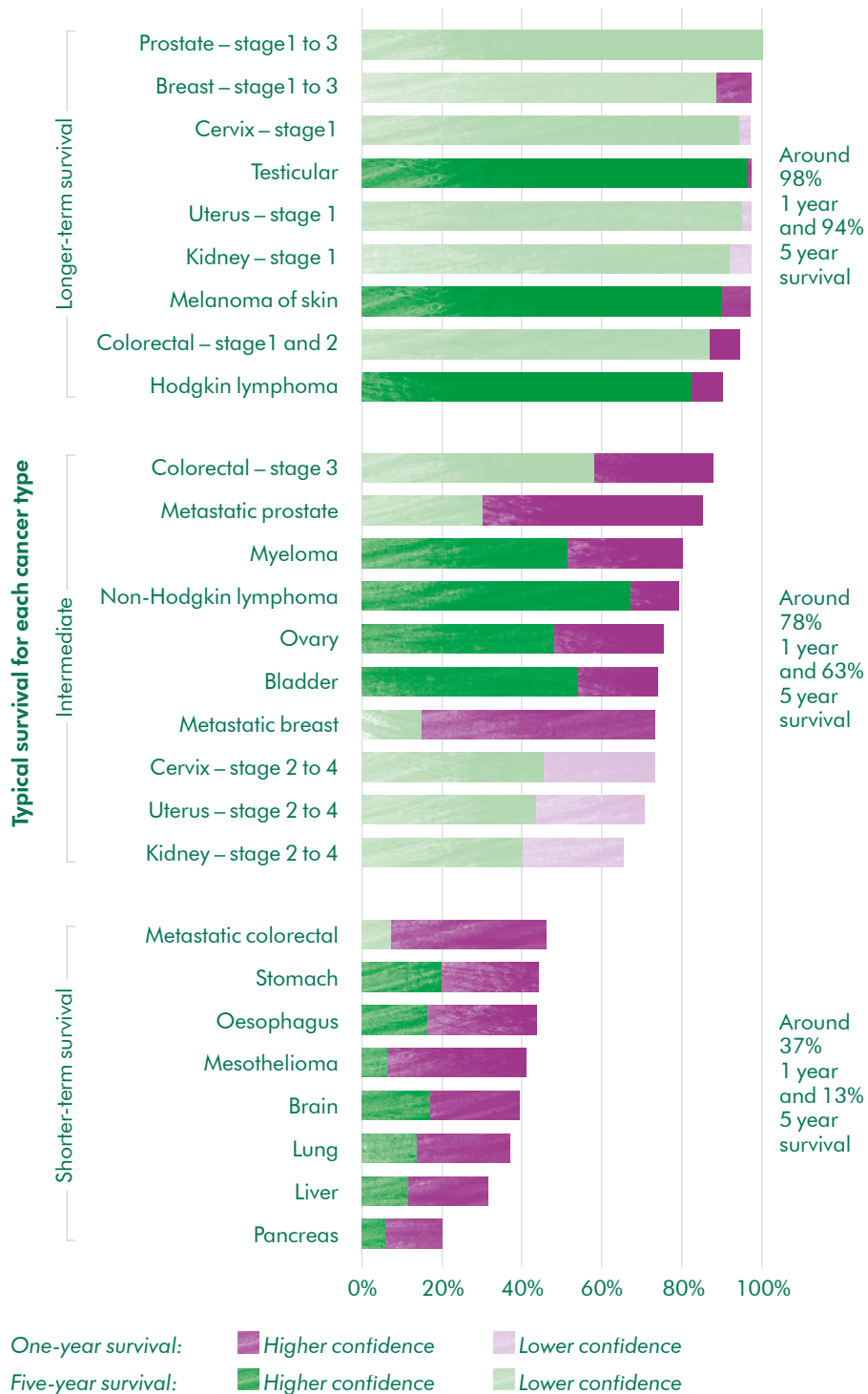
The three types of cancer identified were:

- The longer-term survival group which includes cancers where 80% of people live five years or more and many go on to live at least a decade.
- The shorter-term survival group includes cancers where fewer than 50% of people survive a year.
- The intermediate survival group experience moderate survival where one year survival is over 50% but less than 90%.



Figure 1

Variation in survival rates between the three cancer groups²⁸



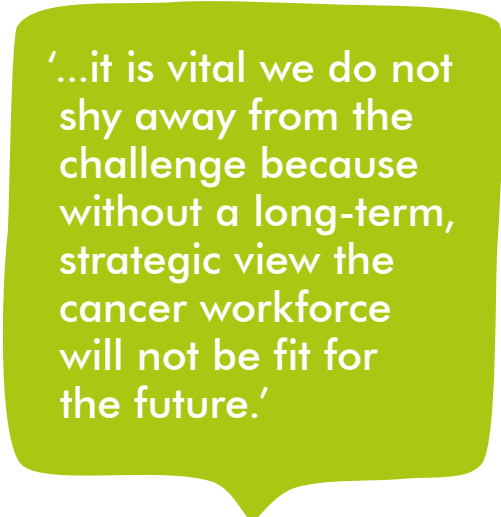
6. Conclusion

Addressing the challenges facing the cancer workforce will be one of the most ambitious tasks in implementing the cancer strategy. However, it is vital we do not shy away from this challenge because without a long-term, strategic view the cancer workforce will not be fit for the future.

At Macmillan, we have an acute understanding of the vital role the cancer workforce plays in delivering the best care and outcomes for people living with cancer. We are inspired by the drive and ongoing commitment of our professionals who are proud to play a part in thinking differently about these important issues, and who play a pivotal role as catalysts for change within the NHS.

While Macmillan has an important role to play in developing and supporting the future cancer workforce, we cannot achieve transformational change alone. All parts of the system must take responsibility for providing a workforce which can deliver high-quality care and support for future generations of people living with cancer.

Without a coherent national framework, the health and care system risks continuing to make fragmented, incremental progress. We must not miss this unique opportunity to shape and sustain the future cancer workforce which can achieve the vision of high-quality, coordinated, holistic, patient-centered care. Solutions will be unique to each local context and will require the input of a variety of local stakeholders, including Cancer Alliances, STPs and local NHS providers.



'...it is vital we do not shy away from the challenge because without a long-term, strategic view the cancer workforce will not be fit for the future.'

7. Recommendations

This report makes three key recommendations:

- Health Education England must play a critical role in leading the development of a strategic vision for the cancer workforce, and it is vital that they work closely with partners across the health sector, including NHS England, to do this.
- The Department of Health needs to hold Health Education England to account and ensure that there is a strong, strategic focus on workforce across the NHS, and that the vision for the cancer workforce aligns with this wider work.
- To ensure people living with cancer experience well-coordinated continuity of care, Local Workforce Action Boards, Sustainability and Transformation Plan Leads and Cancer Alliances need to:
 - work closely with providers to help translate the national vision in a way which works for local health economies, and
 - adopt an approach to service redesign which begins with a clear understanding of the workforce gaps based on patient need and consider the five ways of addressing workforce challenges outlined in this report. These are as follows:
 - 1 Improving career pathways to and through specialist cancer roles.
 - 2 Improving skill mix and introducing new types of (cost-efficient) roles.
 - 3 Enhancing the skills and confidence of existing staff, and communication between them.
 - 4 Improving ways of working.
 - 5 Exploring how new ways of understanding the cancer population can be utilised to support workforce planning based on need rather than tumour type.

References

- ¹ Figures quoted from expert consensus collated as part of Macmillan Cancer Support (2013) Throwing light on the consequences of cancer and its treatment. Consensus was reached by consulting with a range of UK experts in the field, including members of the National Cancer Survivorship Initiative (NCSI) Board, the NCSI Pelvic Cancers Project Steering Group, the Consequences of Cancer and its Treatment Collaborative (CCaT) and other leading researchers and professional societies. Macmillan Cancer Support, Throwing light on the consequences of cancer and its treatment. Available from: http://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf [Accessed August 30 2016]
- ² The Kings Fund (2016) Quarterly Monitoring Report 21: NHS faces difficult winter as demand for care increases <http://qmr.kingsfund.org.uk/2016/21/>
- ³ Macmillan Cancer Support (2014) Working Together – Challenges, Opportunities and Priorities for the UK's Cancer Workforce http://www.macmillan.org.uk/_images/aa
- ⁴ Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: a Strategy for England 2015-2020
- ⁵ <http://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/specialist-care-at-home.html>
- ⁶ The Health Foundation, Fit for purpose? Workforce policy in the English NHS, March 2016
- ⁷ Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: a Strategy for England 2015-2020
- ⁸ Macmillan Cancer Support (2017) Warning Signs (report to be published February 2017)
- ⁹ <http://www.macmillan.org.uk/information-and-support/organising/money-worries>
- ¹⁰ Marangozov R, Williams M, Buchan J, July 2016, Institute for Employment Studies, The labour market for nurses in the UK and its relationship to the demand for, and supply of, international nurses in the NHS <http://www.employment-studies.co.uk/resource/labour-market-nurses-uk-and-its-relationship-demand-and-supply-international-nurses-nhs>
- ¹¹ NHS England (2016) Provider-based Cancer Waiting Times for October 2016; Cancer Research; Science Blog: Cancer waiting times: what's causing the delays? (October 2016) <http://scienceblog.cancerresearchuk.org/2016/10/13/cancer-waiting-times-whats-causing-the-delays/>
- ¹² Macmillan Cancer Support (2014) Working Together – Challenges, Opportunities and Priorities for the UK's Cancer Workforce http://www.macmillan.org.uk/_images/workforcediscussiondoc_tcm9-295356.pdf Internal Macmillan analysis based on Frontier Economics. One to one support for cancer patients: A report prepared for DH. December 2010 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216683/dh_122521.pdf Number of nurses required is calculated based on assumptions around the appropriate size of caseloads (caseloads vary by speciality). Numbers projected forward to 2030. Includes Lung, breast, urology, upper gastrointestinal, gynaecological, lower gastrointestinal, haematology, head & neck, brain & central nervous system and skin. Macmillan Cancer Support (2014) Working Together – Challenges, Opportunities and Priorities for the UK's Cancer Workforce http://www.macmillan.org.uk/_images/workforcediscussiondoc_tcm9-295356.pdf

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- ¹³ Macmillan 2013 internal analysis based on previously published estimates
- ¹⁴ Macmillan Cancer Support (2014) Working Together – Challenges, Opportunities and Priorities for the UK's Cancer Workforce http://www.macmillan.org.uk/_images/workforcediscussiondoc_tcm9-295356.pdf
- ¹⁵ Cancer Patient Experience Survey (2013) <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey>
- ¹⁶ Independent Cancer Taskforce (2015) Achieving World-Class Cancer Outcomes: a Strategy for England 2015-2020
- ¹⁷ National Cancer Action Team (2012) National Cancer Rehabilitation Workforce Comparative Report
- ¹⁸ Macmillan Cancer Support (2014) The People Behind Cancer Care – Patient and Staff Stories <http://www.macmillan.org.uk/documents/aboutus/research/inclusionprojects/the-people-behind-cancer-care.pdf>
- ¹⁹ See Nursing Times (14 June 2016) Offering the right post-treatment support to cancer patients - and at the right time https://www.nursingtimes.net/macmillan/offering-the-right-post-treatment-support-to-cancer-patients-and-at-the-right-time/7005475_article. For more information see Evaluation of Phase 1 of the One-to-One Support Implementation Project Baseline Report Macmillan Cancer Support
- ²⁰ Macmillan Cancer Support. The burden of cancer and other long-term conditions. April 2015 www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf. Research commissioned by Macmillan Cancer Support from Monitor Deloitte
- ²¹ Macmillan Cancer Support. Throwing light on the consequences of cancer and its treatment. 2013. London; Armes J et al. Patients' supportive care needs beyond the end of treatment: A prospective, longitudinal survey. Journal of Clinical Oncology.2009. 27:36 6172-6179
- ²² Armes J et al. Patients' supportive care needs beyond the end of treatment: A prospective, longitudinal survey. Journal of Clinical Oncology.2009. 27:36 6172-6179
- ²³ Macmillan Cancer Support (2017) No Small Change (report to be published February 2017). For more information see Macmillan Cancer Support: Make Money One Less Worry <http://www.macmillan.org.uk/information-and-support/organising/money-worries> (accessed January 2017)
- ²⁴ Cancer as a long-term condition: Practice nurse pilot evaluation (May 2013) http://www.macmillan.org.uk/documents/aboutus/health_professionals/primarycare/newslettermay2013/cancerasalongtermconditionfullevaluationreportfinal2.pdf
- ²⁵ Macmillan Cancer Support (September 2016) Macmillan Cancer Improvement Partnership in Manchester MCIP http://www.macmillan.org.uk/_images/mcip-brochure_tcm9-301553.pdf
- ²⁶ Patient contact and referral data collected by ICJ Glasgow Service
- ²⁷ Edinburgh Napier University (2016) Evaluation of Glasgow Improving the Cancer Journey Programme http://www.macmillan.org.uk/_images/Glasgow-improving-the-cancer-journey-programme-full-evaluation_tcm9-301271.pdf
- ²⁸ White R, McConnell H, Maher J. Three cancer groups; explaining the different complexity, intensity and longevity of broad clinical needs. Poster session presented at: Cancer Data and Outcomes Conference 2016: Using data to drive services; 2016 June 13-14; Manchester UK. Available at: http://www.macmillan.org.uk/_images/three-cancer-groups_tcm9-297577.pdf
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When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support you through. From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We'll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

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