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Challenges, opportunities and priorities
for the UK's cancer workforce

June 2014

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Foreword



By 2030, there will be four million people living with and beyond cancer across the United Kingdom.¹ Each person deserves the very highest standard of diagnosis, treatment, care and support. They should get that regardless of who they are, where they live, or what type of cancer they have. Sadly, though, UK survival rates are amongst the worst in Europe and there remain unacceptable variations in care.²

The UK's health and social care systems are facing unprecedented challenges. As people live longer, the incidence of cancer and other long-term conditions continues to rise, leading to more people with multiple health issues. Multiple morbidity is becoming the norm, with many people with cancer also living with two or more other conditions.³

Traditional approaches to cancer care that use a single disease framework cannot keep up with current and future demand for services and do not adequately meet the needs of people with more than one condition.

All of this is taking place in a time of financial constraint and economic uncertainty. Health and social services are feeling the pressure to do more, with less. The clear need for continued investment in cancer specialist posts must be balanced with innovative approaches to the way care is provided, enabling efficient service delivery within stretched resources.

Each part of the UK faces its own challenges and barriers, relating to the age and health of the population, education and training, employment rates and political structures. However, failure to adequately meet the current needs of all people with cancer is common across each of the four UK nations. All governments have an important role to play in setting and realising objectives that deliver the highest standard of care for all people diagnosed with cancer across the UK.

The UK needs a better understanding of the changing needs of people with cancer, at every stage of the cancer pathway, and new models of cancer care that will help the UK's cancer workforce provide the best possible support. It's vital we have a flexible workforce that is responsive to the individual needs of people at different stages of the cancer pathway and who may have multiple conditions.

At Macmillan, we are thinking carefully about these issues and talking with people affected by cancer, professionals, the voluntary sector, workforce planners, decision makers and governments about the challenges, opportunities and priorities for the UK's cancer workforce. This report captures what we have heard from you to date.

This report is the start of a conversation. Macmillan needs to continue this discussion and would value your contribution. Please contact us with your thoughts, comments and questions. It's only by continuing to work together that we can develop and support the right workforce to meet the changing needs of all people affected by cancer.


Ciarán Devane

Ciarán Devane
Chief Executive
Macmillan Cancer Support

We all need to think differently about the way we work, the way we invest in services, and the way we approach cancer care. Together, we can ensure high-quality, person-centered, cost-effective care for every person with cancer across the UK.

GET IN TOUCH

 @Mac_PolicyDept

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1 The changing story of cancer

For too long, we have focused on cancer as only having two outcomes: cure or death. This is no longer the case. More people than ever are living with and beyond cancer. In turn, these people need support during and after treatment that meets their ongoing and varied needs, so they can live with cancer as a long-term and fluctuating condition.

Surviving cancer is not always the same as living a full and healthy life. There are often long-term consequences of treatment that require ongoing care and support. At least 500,000 people in the UK are facing poor health or disability after treatment for cancer, which is one in four of the current population of people living with cancer.⁴ This places an increased and varied demand on health and social care services, as each individual's needs are different and will vary at different stages of treatment.

A greater understanding of the needs of people at different stages of the cancer pathway, new technology and advances in treatment, will all impact on the skills and competencies required from cancer care teams.

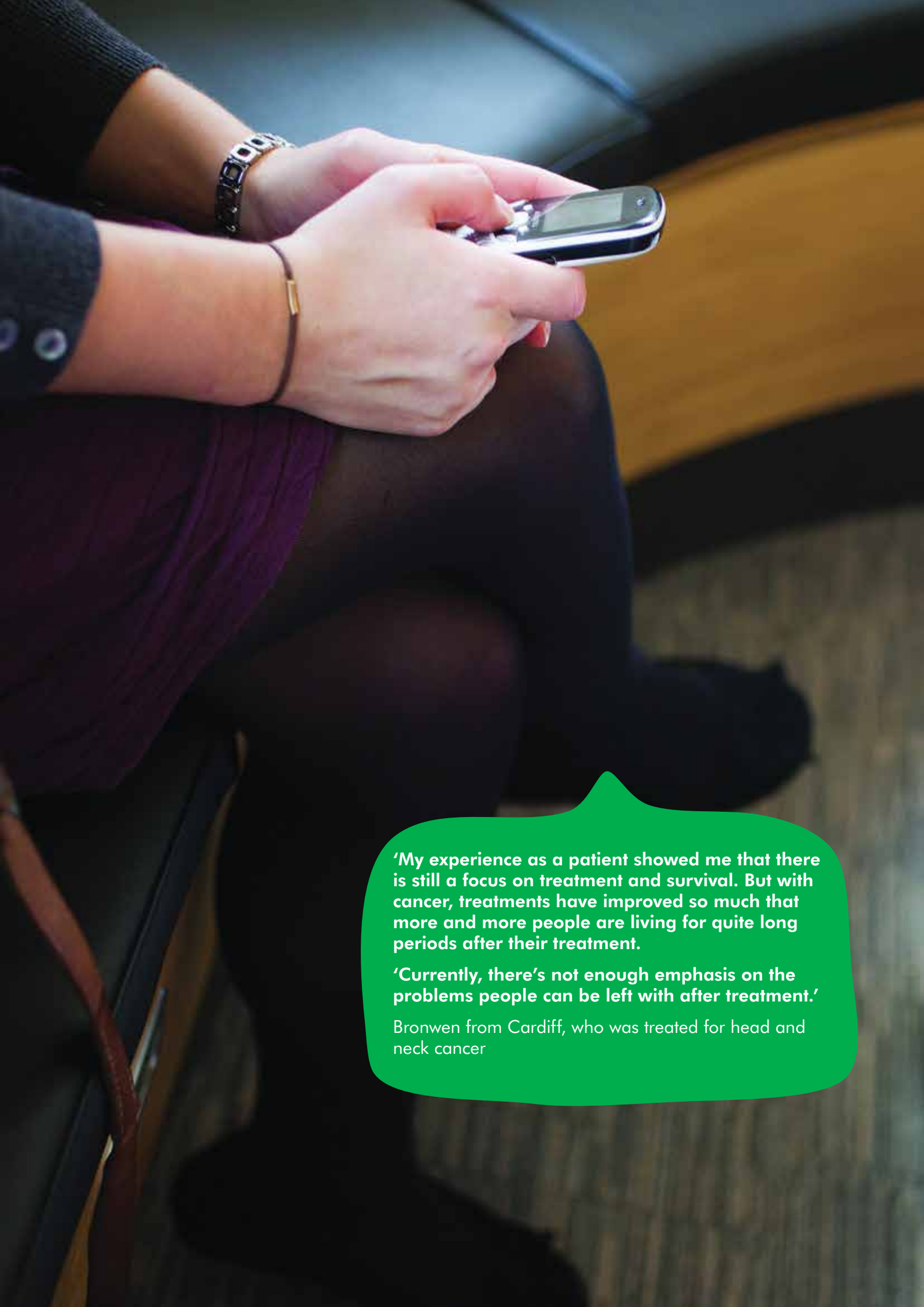
The long-term consequences of cancer and its treatment are both mental and physical. They include mental health issues, sexual and reproductive difficulties, chronic fatigue, lymphoedema, urinary and gastrointestinal problems, and ongoing pain.



By 2020, almost one in two people will get cancer in their lifetime ...



... but nearly four in ten of those will not die from it.



'My experience as a patient showed me that there is still a focus on treatment and survival. But with cancer, treatments have improved so much that more and more people are living for quite long periods after their treatment.'

'Currently, there's not enough emphasis on the problems people can be left with after treatment.'

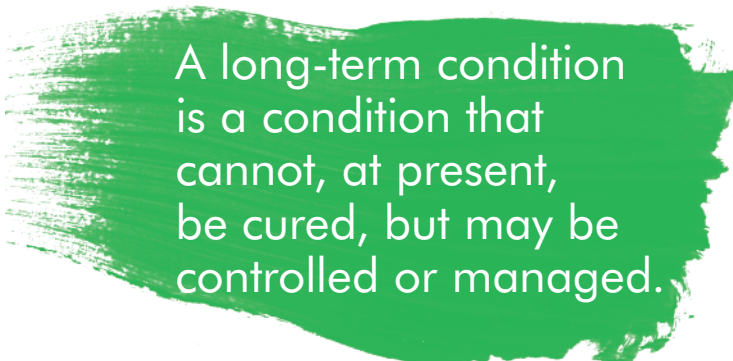
Bronwen from Cardiff, who was treated for head and neck cancer

2 The impact of changes in the UK's population and health

As the UK's population grows and health needs change, its health and social care systems are having to support more people, with more varied and complex needs.

Over the next 25 years, the general population is projected to increase by 9.6 million people,⁵ and the number of people living with and beyond cancer is expected to rise from two million today to four million by 2030.⁶

Long-term conditions are on the rise



A long-term condition is a condition that cannot, at present, be cured, but may be controlled or managed.

As people live longer and treatments become more advanced, there is a greater proportion of the population living with one or more long-term conditions. Treatment and management of long-term conditions is costly for health and social care services. In England, the management of long-term conditions accounts for 50% of all GP appointments, 64% of all outpatient appointments and 70% of all inpatient hospital bed days; this equates to an estimated 70% of the country's total health and social care expenditure.⁷

With more people living with cancer as a long-term condition, cancer care teams are moving away from a sole focus on preventing death and treating illness towards maximising quality of life and promoting independence and self-management.

Multi-morbidity has become the norm

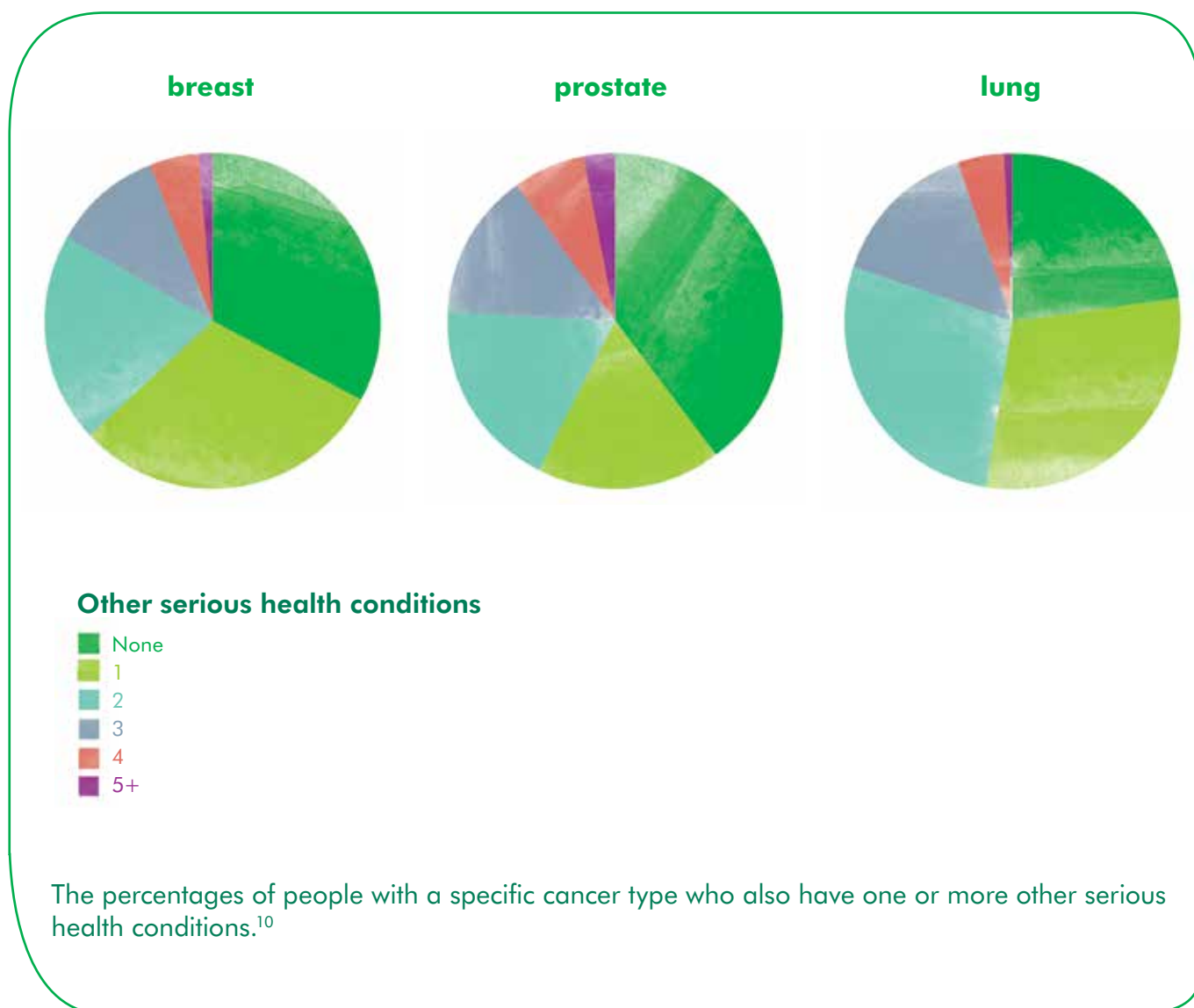
It is becoming the norm, rather than the exception, that people are living with multiple long-term conditions. The number of people with co-morbidities in England is set to rise from 1.9 million in 2008 to 2.9 million by 2018.⁸

For people with cancer, living with another serious health condition can be particularly difficult. It can make their cancer harder to treat and significantly reduce their overall quality of life.⁹

The health and social care system must improve the way it treats and supports people with multiple conditions, otherwise costs will rise as outcomes fall. Failure to consider the impact of a treatment on other conditions, including the interaction of medications, poses a real threat to outcomes. Duplication of tests, failure to share results, different follow-up appointments for different conditions and individuals having to repeat their story time and again all result in unnecessary costs and a poorer care experience.

While there is a continued need for specialist health services and interventions, there is also a growing role for community based services. With the appropriate clinical, emotional, financial and practical support from health and social care professionals, carers and volunteers, many more people with cancer could self-manage their own conditions.

People living with cancer and other morbidities



To achieve this, specialists and generalists need to work together with people affected by cancer to identify and plan each individual's care and treatment needs. In addition, skills must be developed further and the understanding of cancer as a long-term condition improved

across the entire workforce. Generalists need to learn some specialist cancer skills, and cancer specialists need to develop a more generalist perspective of people's health and lives.

An ageing population

In common with other European countries, the UK has an ageing population. There are currently more people of pension age in the UK than there are children under 16, and by mid 2037 a projected 1 in 12 people will be aged over 80.¹¹

- The ageing population will impact on the health and social care workforce in a number of ways. The number of people aged over 65 who are living with cancer is set to treble by 2040. At this time, older people will account for 77% of all people living with a cancer diagnosis – an increase from 63% in 2010.¹²
- Older people are more likely to have one or more long-term conditions. This can increase the complexity of their care and support needs. Common co-morbidities include dementia, diabetes and obesity, as well as conditions affecting the cardiovascular, respiratory and gastrointestinal systems.¹³
- UK cancer mortality rates in the older population are not improving as quickly as in the younger population.¹⁴ In addition, the UK has some of the worst five-year survival rates in Europe for cancer among people aged 75 or over.
- Around 1 in 8 people over the age of 60 are caring for someone with cancer.¹⁵ Many older carers may have a long-term condition of their own, meaning they require more support to maintain their own health and wellbeing while caring.
- Because the UK's population is ageing, its workforce is ageing too. This is particularly noticeable in some sectors, including community care, where district nurses have a higher average age than other types of nurses.¹⁶ In addition, fewer new nurses are being recruited than doctors.¹⁷ This could have major implications for the future workforce supply, if posts are not filled as workers reach retirement.
- The skills and experiences of the older workforce may become increasingly important and result in more people of retirement age taking on voluntary and advocacy roles to support people with cancer.

3 Finding the right skill mix in cancer care teams

Governments across the UK have recognised the need for dedicated support for people with cancer. In Wales, local health boards and trusts have a responsibility to assign a named key worker to every person diagnosed with cancer.¹⁸ In England, the coalition government committed to continue the 2010 Labour government's five-year pledge to ensure every cancer patient receives dedicated nursing.¹⁹

But to truly deliver on these promises of dedicated nursing for everyone with cancer, we still need to find ways of using care teams more effectively and efficiently. We also need to think carefully about the skills and capacity of the non-cancer specialist workforce, and their role in supporting people with cancer.

'We believe that an individual's needs are best met through a series of interactions with different professionals, at different points in their cancer journey.'

'Each individual's cancer pathway is different, so it follows that the workforce roles involved in their care will be different.'

Jacqueline Goodchild, Workforce Programme Manager, Macmillan Cancer Support

Clinical nurse specialists

Clinical nurse specialists are a central part of multi-disciplinary teams, providing technical expertise and practical support, and facilitating communication between care settings and professionals. There is a strong correlation between access to a clinical nurse specialist and good patient experience outcomes.²⁰

There are simply not enough clinical nurse specialists to meet the current, let alone future, demand for their services. In 2010, it was estimated that an extra 1,234 posts such as clinical nurse specialists were required in England to meet demand for support for the six major tumour groups.²¹ Extrapolated across all tumour types and across all four nations, this equates to an additional 3,400 cancer dedicated posts. Macmillan has committed to work with health bodies to close the gap between supply and demand for cancer specialist posts across all regions.²²

However, meeting support needs is not as straightforward as simply filling the specialist gap. We need a better understanding of the level of specialist and generalist care required to adequately meet the needs of people living with and beyond cancer, and those at the end of life. This will then help to ensure that the appropriate level of specialist support is provided to all people diagnosed with cancer.

A multidisciplinary team (MDT) is a group of doctors and other health professionals with expertise in a specific cancer. Together, they discuss and manage an individual's care, and plan the treatment that's best for them.

Providing cancer care in a different way

While clinical nurse specialists are well placed to provide one-to-one support, the gap in the supply and demand of clinical nurse specialists means they cannot always be the named key worker or play the coordinating role.

Importantly, though, some of the work undertaken by clinical nurse specialists or named key workers, such as coordinating care and signposting to services, does not always need to be performed by a specialist. At different stages of the cancer journey, different skill levels are required. This means there could be a real opportunity to utilise other workers, including those who are unregistered but trained, to provide support in different ways.

As well as being cost-effective and enhancing the skill mix of care teams, this way of working could potentially free up the time of specialists so they can provide their specialist support to more people with cancer. Therefore, we need to develop a better understanding of the support that could be provided by non-cancer specialists during the cancer journey. We also need to be clear on the care and support which can only be provided by a cancer specialist.

'You can't have one person who does it all, but you can have better communication between specialists. It is about a holistic needs package of care for that patient, so it is about individualising care plans and using different people's expertise.'

'I think it's about professional respect as well. There used to be a bit of "us and them" between the hospital and the community, and I think that needs to go.'

Karen Burnet, Cancer Research UK Senior Research Nurse, Macmillan focus group, December 2013

4 Better communication, coordination and cooperation can lead to better outcomes

'The big picture is that with cancer numbers going up, the money is not going up. We really have to challenge the traditional ways of doing things and be innovative in how we communicate between teams.'

'Once a patient moves on, whatever speciality you're in, there's a very poor information flow about what happens to them next. I find this very difficult.'

Dr Chris Fosker, Clinical Oncology Consultant, St James' Institute of Oncology, Macmillan focus group, December 2013

Cancer treatment can be complex and disjointed, span across two or more hospitals, health boards and trusts, and involve various professionals, including surgeons, oncologists, allied health professionals, nurses and social workers.

Too often, we hear of people falling through gaps in the system, having to try and navigate their own way, and not knowing where to get the right information or how to access support services that may be available. This extends beyond clinical treatment, as there are many other pressures on people affected by cancer. For example, work and financial worries, caring responsibilities and anxiety may require intervention and support services, including social care.

People with cancer, carers and professionals speak of the frustrations of a system that is fractured and does not lend itself to seamless and efficient care. Systems that do not speak to one another, complex funding arrangements and poor transitions between services cause distress and frustration. Many people living with long-term conditions report that they have experienced poorly coordinated care,²³ which can lead to poorer outcomes and a negative patient experience.²⁴ A lack of coordination and communication can also have a huge impact on people at the end of life and prevent them from dying in the place of their choosing.

There is consistent rhetoric from governments and health and social care leaders around the need for better integration of health and social care services, often with a focus on integrated planning and funding as a means to improve the coordination of services. Northern Ireland has an integrated health and social care system; Scotland is moving towards full integration by 2015; and the Social Services and Wellbeing Bill in Wales, which comes into force in 2016, promotes integration of care and support between local authorities and health services.

The coalition government has also placed a significant emphasis on improved coordination and integration through its health and social care reforms. The Health and Social Care Act 2012 sets out a number of measures to promote joint working, including the establishment of clinical commissioning groups in England to lead on the integration of health and care commissioning. In addition, the Care and Support Bill sets out a duty on local authorities in England and Wales to promote the integration of services.

In England, a key development has been the establishment of health and wellbeing boards to encourage health and care commissioners to work together to improve the health and wellbeing of local people and develop joint health and wellbeing strategies for localities. However, the new commissioning arrangements have seen a split in responsibility between NHS England, clinical commissioning groups and local authorities, which means a significant amount of coordination will be required to ensure people receive joined-up care across the cancer pathway.

People with long-term conditions will inevitably use services over a longer period of time, which means it is vital that the cancer workforce helps to provide coordinated care. We must facilitate better communication and team working, particularly at transition points of care.

'Communication is an interesting and important challenge. It's not just communication between professional and patient, but communication between professionals, and breaking down those traditional barriers.'

Christopher Ward, Managing Director, Oakview Associates, Macmillan focus group, December 2013

5 Better support for individuals, carers and volunteers

Individuals, carers and volunteers play a huge role throughout the cancer treatment and care pathway. Although their role can be very different from that of health and social care professionals, it is no less important.

When thinking about the future needs of the UK's cancer workforce, we must take into account the roles of individuals, carers and volunteers as unsalaried and often unrecognised members of cancer care teams. They must be acknowledged and empowered, supported and valued as partners in care.

Shared decision making and supported self-management

A person with cancer is an integral part of their own care team. Treatment should be assessed and planned with the person and not simply 'done to' them. When properly supported, individuals can and often want to play a role in their own care, resulting in improved health and wellbeing outcomes.

Shared decision making can also improve people's care experience, safety and engagement with professionals and reduce the cost of health and social care.²⁵ Shared decision making takes place when professionals, people with cancer and their carers work together to look at options for treatment and care.

'One of the biggest challenges will be the coordination of services for people with cancer. I think workforce has to include everyone, not just the specialists doing the treating.'

Dr Chris Fosker, Clinical Oncology Consultant, St James' Institute of Oncology, Macmillan focus group, December 2013

This way of working helps individuals to:

- be involved in decisions about their treatment and care
- understand any treatment and care options available to them based on the expertise and evidence provided by clinicians and other sources of information they have accessed
- make good decisions so they can get the treatment and care that is best for their cancer and their life.

Shared decision making is not yet a reality for every person with cancer. Only 72% of respondents to the most recent Cancer Patient Experience Survey in England said they were definitely involved as much as they wanted to be in decisions about their care and treatment; in Wales the figure was a similar 71%.²⁶



In Wales, only 58% of respondents said they had been offered the opportunity to discuss their needs and concerns to help create a care plan. The type of tumour a person has also dramatically affects whether someone receives a care plan or not, with 80% of people with a brain or central nervous system cancer receiving a plan and only 37% of people with a urological cancer benefiting from a plan.²⁷ Overall, less than a quarter (22%) of cancer patients in Wales receive a written care plan,²⁸ despite the Cancer Delivery Plan for Wales requiring all health boards and trusts to provide one.²⁹

Governments and health and social care bodies have a role to play in prioritising shared decision making. A positive step is NHS Scotland's recent adoption of the first cancer patient experience quality performance indicators, one of which will measure shared decision making.³⁰

Effectively involving and empowering individuals in shared decision making requires strong communication skills and time. Professionals should have access to appropriate training around communication, motivational interviewing and coaching for behavioural change, and be given the necessary time to involve individuals in treatment decisions and care planning.

HOPE: a self-management programme for cancer survivors

The HOPE programme, developed by Coventry University and Macmillan Cancer Support, is a group self-management programme for cancer survivors that is underpinned by positive psychology theory and practice.

It aims to increase people's ability to manage aspects of their health by improving goal motivation and planning. Already, across the UK, it has had a positive impact on quality of life issues for people living with and beyond cancer, including negative feelings, cognitive problems, fatigue and accessing financial support.

'I strongly believe that courses such as this one would benefit many tens of thousands of cancer survivors and help them to see that life can be wonderful again, and to never to give up hope.'

HOPE programme participant

With the right support, the majority of people with long-term conditions can actively manage their health.³¹ For those living with and beyond cancer, supported self-management techniques are extremely important in managing the impact of their conditions and any consequences of treatment such as fatigue. They also require fast access back into the care system if they have concerns or notice signs of recurrence.

The UK's cancer workforce needs to support and enable people to safely and effectively self-manage their own long-term conditions. This will allow people with cancer to control the impact of their condition on their life and help to reduce unnecessary hospital admissions as well.

The Mandate from the coalition government to NHS England sets an ambition to make 'measurable progress towards making the NHS among the best in Europe at supporting people with ongoing health problems to live healthily and independently, with much better control over the care they receive.'³² The governments in Scotland, Northern Ireland and Wales are similarly committed to prioritising supported self-management.

Carers

'Working with professionals is about sharing the care. We both have a role to play.'

Jean, a carer

Across the UK, there are more than one million people providing unpaid care and support for a family member or friend with cancer.³³ They are a vital part of the care team, providing practical, emotional and financial support, and in some cases performing healthcare tasks, with an economic value of £14.5 billion.³⁴

Nearly half (46%) of those caring for someone with cancer say it affects their emotional and mental health, and one in six (13%) say it causes physical health issues such as lack of sleep and digestive problems.³⁵

Many carers do not recognise their role as a carer, and many professionals in health and social care settings fail to identify or recognise carers. As a result, many carers are missing out on support that could help them to maintain their own mental and physical health and wellbeing as they continue to provide unpaid care. Without this support, carers are more likely to reach crisis point and develop their own care needs, placing further strain upon the health and social care system.

Carers need to be better recognised and empowered as partners in care. We need to make sure they are supported in their caring role so they can provide effective care and maintain their own health and wellbeing.

Key to achieving this is making sure health and social care services are available for the person they care for. This will help to prevent carers from becoming overburdened and forced to take on tasks they are uncomfortable with. Where appropriate, carers should have access to training to help them safely and comfortably perform caring tasks, if they want to do this. The Carers Strategies (Wales) Measure and NHS England's Commitment for Carers are examples of positive steps taken by governments to better identify and support carers. However, there is much more we can do.

'In two months, we were simply swept into this medical world. Despite accompanying Pam to every clinic and consultation, nobody identified me as her full-time carer or, at this stage, pointed me in any direction for help and support.'

Patrick, who cared for his wife Pam

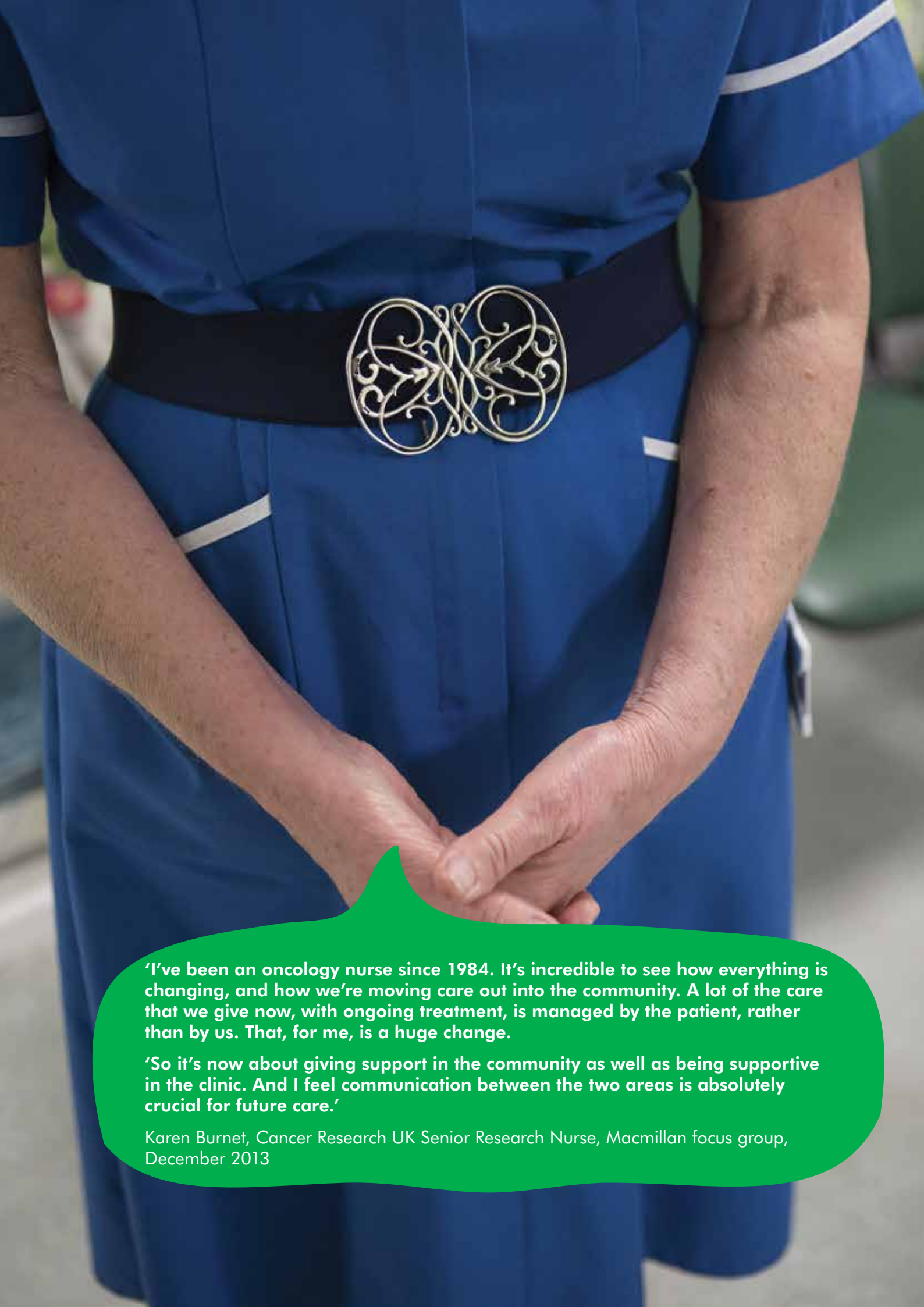
Volunteers

Volunteers, and the organisations that support them, play a vital role in supporting people with cancer and their carers, families and friends. From befriending services and support groups, to helping with practical tasks such as shopping, to performing a supportive role in a health setting, volunteers are an important part of the care and support network for someone with cancer.

In England, there are at least three million people regularly volunteering within the health and social care sector.³⁶ And in 2010–11, the voluntary sector in the country spent £2.9 billion from its own fundraising on adult social care and provided a further £6.2 billion of care that was commissioned mainly by local authorities.³⁷

Yet the crucial role played by volunteers is often undervalued in health and social care settings. This is despite volunteers often supporting integrated care for people with multiple needs, linking services and local communities, enhancing individual experiences of care and reaching groups who may be isolated or disconnected from services.³⁸

Governments and health and social care bodies across the UK need to do more to recognise the efforts of volunteers who help people affected by cancer, services and communities, and support them as members of the care team.



'I've been an oncology nurse since 1984. It's incredible to see how everything is changing, and how we're moving care out into the community. A lot of the care that we give now, with ongoing treatment, is managed by the patient, rather than by us. That, for me, is a huge change.'

'So it's now about giving support in the community as well as being supportive in the clinic. And I feel communication between the two areas is absolutely crucial for future care.'

Karen Burnet, Cancer Research UK Senior Research Nurse, Macmillan focus group, December 2013

6 Providing care in the community

As the number of people living with and beyond cancer grows, and their needs change, the demand for services delivered at home or closer to home is increasing. For many years, UK governments have aimed to provide better health and social care in the community.³⁹ Although there is still a long way to go, effective care in the community that matches that available in hospitals and empowers people to take more control of their own conditions is becoming an increasingly realistic prospect. A key factor in this progress is improved communication and technology.

There are a number of significant benefits to delivering care in the community, rather than in hospital. For example, it frees up hospital beds, which is especially important as demand for them is going to increase as the population continues to age. Currently, the UK has an average bed per population that is 40% lower than the average for nations belonging to the Organisation of Economic Co-operation and Development.⁴⁰ The cost of a person occupying a hospital bed for a day is around £250,⁴¹ plus a free bed means that someone who may need it more than a person who can be cared for in the community has access to it.

Care in the community takes a number of forms, including chemotherapy delivered at home, rehabilitation in community settings, blood and other monitoring tests in GP surgeries or local settings, and increased access to local services and support groups. It can be particularly important for people at the end of life, with 73% of people with cancer wanting to die at home with the right support;⁴² currently, only 30% actually do this.⁴³

The reality is that once older people and people at the end of life are admitted to hospital they are less likely to be discharged quickly.⁴⁴ This

'Chemotherapy delivered in community settings is well established in Australia and Canada. There's no reason that we can't do it on a large scale in the UK as well.'

Dr Ash Paul, Public Health Consultant, Hackney and City of London, Macmillan focus group, December 2013

can lead to the avoidable use of hospital beds, which when combined with poor communication around final wishes can also result in those at the end of life not being able to die in their place of choosing.

We need to examine the capacity and skill mix of the community workforce, and the changes that need to be made to meet increased demand for community based health and social care services. The number of qualified district nurses in England has fallen,⁴⁵ and the community workforce has an ageing profile,⁴⁶ which may cause problems as professionals who are currently practising begin to retire.

Another barrier to effective care in the community is the lack of care available 24 hours a day, seven days a week. In 2010, nearly half of primary care trusts (44%) did not provide a 24/7 nursing service for all patients. Where 24/7 care is not available, it is likely to lead to increased hospital admissions, putting increased strain on accident and emergency services. Furthermore, a 24/7 community care service can improve workflow, as 24/7 working avoids surges of work after the weekend and allows the workforce to manage their time more effectively.⁴⁸ However, it will be difficult to ensure 24/7 cover without growing and properly supporting the community workforce.



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7 Developing the right cancer care teams for the future

To meet the changing needs of people affected by cancer and deliver the highest standard of care and treatment, we need to develop an efficient, effective and flexible workforce that places people with cancer and their carers at the heart of decision making and service provision. For us to achieve this, we need to increase our understanding of the needs of people with cancer at every stage of the cancer pathway and begin to think differently about the way we deliver care and invest in services. In particular, we need to think more carefully about:

- the size and capacity of the cancer specialist workforce
- enhancing and improving roles and skills in the current cancer workforce
- increasing capacity and cancer awareness across the whole health and social care workforce
- engaging and supporting unsalaried but trained people to become members of cancer care teams, including individuals who self-manage their care, carers and volunteers
- facilitating better communication and team working, particularly at transition points of care.


Our next steps

Macmillan is committed to working with people affected by cancer, governments, health and social care bodies and third sector partners across the UK to develop and support a workforce that is fit for purpose and can rise to meet current and future challenges. We need to continue this important discussion to fully explore the best ways to deliver care for people with cancer and their carers, families and friends.

We can only do this with your input and support. Please get in touch with your thoughts, comments and questions.

GET IN TOUCH

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When people have cancer, they don't just worry about what will happen to their body, they worry about what will happen to their life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support people through. From help with money worries and advice about work, to someone who'll listen, we'll be there. We'll help people make the choices they need to take back control, so they can start to feel like themselves again.

Together, we are all Macmillan Cancer Support.

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**