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### Foreword



**Lynda Thomas,** Chief Executive, Macmillan Cancer Support

The number of people living with cancer in the UK is growing and, as treatments advance and survival rates increase, the disease is becoming more complex. Against this backdrop, the role of the workforce in supporting people with cancer – from diagnosis, through treatment and beyond – has never been more important.

At Macmillan, we hear every day from people living with cancer about the fantastic care they receive from both Macmillan professionals and wider health service staff in England, Scotland, Wales and Northern Ireland. But the task of providing the very best care to people living with cancer is becoming harder. Issues including staff shortages, growing workloads and an historic lack of long-term planning, all mean that staff providing cancer care are under unrelenting pressure. They are concerned about whether workforce pressures will impact on their ability to continue delivering high quality care for people with cancer. It is in this context that we present this report, which provides a snapshot of the views of staff providing cancer care in the NHS today.

Our research found that many staff are already concerned about the impact of current pressures on people with cancer. For instance, over 50% of GPs and nurses surveyed in the UK say that, given current pressures on the NHS workforce, they are not confident that the workforce is able to provide adequate care to cancer patients.<sup>1</sup> 44% of those surveyed said pressures meant patients were not always being treated as early as they should be.<sup>2</sup>



of GPs and nurses surveyed say that given current pressures on the NHS workforce, they are not confident that the workforce is able to provide adequate care to cancer patients.

Over a third of the GPs and nurses surveyed told us that existing workforce pressures mean some cancer patients are attending A&E because they can't get help elsewhere.<sup>3</sup> In addition, 31% of those surveyed reported that patients are not being supported to regain a good quality of life after treatment.<sup>4</sup> Addressing workforce pressures is a daunting task, however it is not impossible. It is vital if people with cancer are to get the highest quality care and support to live life with cancer. There is a wealth of experience, knowledge and skill within the NHS workforce which has the potential to transform how cancer care is delivered in future. As such, it is important that we listen to - and learn from - the staff who are not only delivering fantastic care, but are also at the forefront of designing services people with cancer use every day. It is only by understanding their concerns and frustrations, and by listening to their ideas for how to solve these issues that we can create a viable vision for the future cancer workforce across the UK which delivers for both staff and people with cancer.

Lucia H P

## **OVER A THIRD**

of GPs and nurses surveyed told us that existing workforce pressures mean some cancer patients are attending A&E because they can't get help elsewhere.





## Introduction and methodology

This report contains findings from a Macmillan and nfpSynergy survey of primary care professionals in the UK conducted during May and June 2017. Participants were asked to fill in an online survey, and responses were received from 154 GPs and 103 nurses.

We also conducted an online survey of 51 Macmillan GPs between 3 June and 24 July 2017, and an online survey of 62 Macmillan professionals between 23 May and 12 June 2017. In this report, references to 'GPs or nurses' refer to the nfpSynergy findings, while 'Macmillan GPs' or 'Macmillan professionals' refers to those surveyed directly by Macmillan.

**Macmillan GPs** are practising GPs who devote an average of one day per week to work with Macmillan and primary healthcare teams to make a recognisable improvement to cancer care across the UK. They are recognised locally as cancer clinical leads.

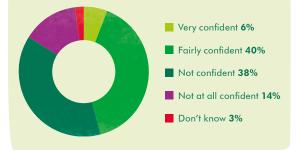
**Macmillan Professionals** work in a variety of roles supporting people with cancer. These roles include Allied Health Professionals (AHPs), Clinical Nurse Specialists (CNSs) and Information Professionals. Some posts are still funded by Macmillan, while others are now funded by the NHS.



## What professionals told us

We found that, given current pressures, there are significant concerns about whether the workforce can continue delivering high quality care to people with cancer. This was clear among GPs and nurses working in primary care, with over half of respondents reporting that they are not confident in the NHS' ability to provide adequate care for people with cancer.

Given the current pressures faced by the NHS workforce, how confident are you that the workforce is able to provide adequate care for cancer patients, many of whom are surviving longer but with poor health and disability following treatment?<sup>5</sup>



This finding was echoed amongst Macmillan professionals and Macmillan GPs. Of 101 respondents, over a third reported that they were 'extremely concerned' about the ability of the NHS to continue delivering high quality care to people with cancer.<sup>6</sup> When we asked what the biggest challenges facing the NHS were, the three most common answers from Macmillan professionals and Macmillan GPs were:<sup>7</sup>



#### **Increasing demand**



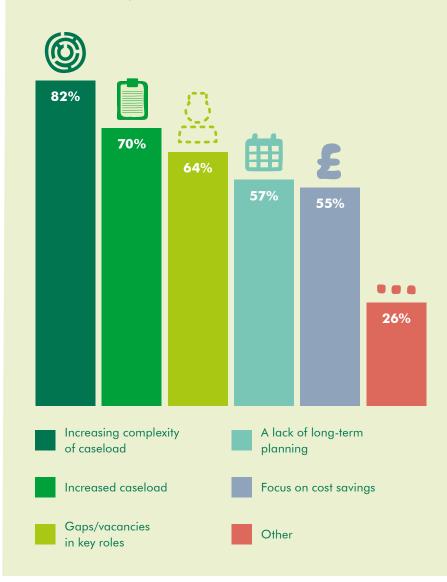
Funding



Workforce

## The biggest workforce issues

Which of the following workforce challenges, relating to cancer, are you aware of in your local health system?<sup>8</sup> Number of respondents: 107



We surveyed Macmillan professionals and Macmillan GPs to give us some more detail about the workforce challenges they are facing.

The most common workforce challenges reported by Macmillan professionals and Macmillan GPs were the increasing complexity of cancer, and increasing caseloads. Many professionals also reported gaps and vacancies in key roles as a challenge in their local area.

Nurses told us that they are under increasing pressure to do more and more with no extra staff. One nurse told us the service specification for her lung cancer team is supposed to be one CNS for every 80 new cases per year. However, she explained, 'My team currently has two CNSs for 249 cases diagnosed in 2015.'

Many professionals feel increasingly responsible for keeping services going for their patients, as one AHP explained: 'Patients' needs are increasingly complex; there are no succession plans in place in the organisation. When I am not at work – [on] annual leave [or on] sick leave [or] part-time hours – no one covers my caseload.'

The impact of rising vacancy rates is being keenly felt, with professionals reporting that any additional demands fall to them to resolve. For example, one nurse acknowledged, 'I end up being the key person in trying to manage all these issues without necessarily having knowledge or skills but learning as I go along.'

A key issue highlighted by respondents was that staff shortages mean that specialist skills are not being used efficiently. One nurse said that, 'Due to staffing levels on the wards in the acute trust I work in it can mean that my time is spent on carrying out tasks that others would normally do, chasing other healthcare professionals to speed up the discharge process, and the staff that are on the wards are too busy to attend training sessions.'

Issues around funding and cost-savings also emerged as key challenges. One nurse reported that she spends a 'significant amount of time sorting out paperwork' to 'ensure funding approvals and paperwork is in place for treatment' which 'limits clinical time'.

One nurse also spoke of the challenge of 'retaining staff in the NHS due to increasing workload, stress and lack of support'. One AHP highlighted the 'lack of training for skills and career progression'. Another nurse drew attention to 'staff shortages leading to poorly inducted new staff'.

'My role has changed dramatically – patients now have a variety of treatment options whereas before they had none. This is good news for patients who are living longer but it is hard to manage the increased workload and hard to explain to management the impact that this has on the team.' This is also an issue in primary care. One GP explained, '[Not only is there a] lack of GPs [and a] lack of practice nurses suitably trained and thus confident in managing patients with cancer, [there is also a] lack of district nursing service provision.'

'Extreme workload pressure, not enough time to deal with complex patients with multiple problems, leaving not enough time to spend with cancer patients, but also fear of missing early diagnosis because of these extreme pressures.' **GP**  GPs highlighted issues around access to diagnostics. They also emphasised their lack of time, describing the difficulties of having to manage complex patient concerns within 10 minute appointments, and they spoke of 'spiralling workloads'.

GPs also highlighted how problematic the gaps in key roles in primary and community care are becoming, particularly because cancer is increasingly a longterm condition. Some GPs called for better resource and suggested that primary care workforce development for cancer should be in line with other conditions such as asthma and diabetes.

The need for community and primary care health professionals to be trained to support people with cancer is keenly felt post-treatment. One GP explained that there needs to be 'more community/ practice nurses with a knowledge of cancer care so care can be provided more locally to the patients'. Another said, 'Increasing demands on primary care [are] leading to lack of time to spend with patients with complex needs.'

## The impact on professionals and people with cancer

We asked Macmillan professionals and Macmillan GPs to tell us how these challenges impact on staff treating and caring for people with cancer. They gave us their frank accounts of the realities they experience. A number of key themes emerged, including pressure and low morale, poor use of skills, lack of workforce planning and lack of time for service development. The increasing workloads and increasing complexity also impact on the quality of care professionals can offer people with cancer.

#### **Pressure and low morale**

Nurses, AHPs and GPs across the country told us that these workforce challenges make for stressful working environments and impact heavily on individual staff.

For example, one GP told us, 'There is a recurring theme of despair. The current workload pressures we are facing are unsustainable. GPs locally are retiring early and those left are at high risk of burnout. We are all trying our best to continue to deliver high quality care to our patients but this is becoming increasingly difficult, meaning an early cancer diagnosis is not always straightforward ... I fear the pressures GPs are currently working under will make this less likely to happen going forward.'

Some told us they are consistently working well above normal hours and many are becoming increasingly tired, anxious and burnt out. Professionals are considering leaving their roles as a result of feeling frustrated and demoralised, and they are experiencing reduced job satisfaction. One nurse explained, '[You] have to work harder and faster and there is a risk of taking on roles that you are not adequately prepared for.' '[There are] increased stress levels day to day ... there is a price to be paid if [I] take annual leave or study leave because [my] already full clinics will have more pressure put on them ... [I feel] responsibility, if patients haven't been seen or needed advice or support and [I was] not available, or overstretched and unable to fit them into [my] workload in a timely manner.'

Nurse

#### Poor use of skills, lack of workforce planning and lack of time for service development

Many respondents reported how specialist nurses are filling gaps for more generalist ward staff or carrying out administrative functions. One nurse explained, '[There is an] onus on nurse specialists to carry out a lot of admin which is inappropriate in a senior nursing role.'

Another told us, 'The ward staff rely on the specialist nurses to pick up generalist work as they are too stretched and not confident enough as they have not had the training.'

Professionals told us there is a lack of capacity to implement new ways of working and less space for innovation. One nurse reported, '[There is] no future planning for [the] nursing workforce [and] no desire by leads within [the] service to review pathways of care.'

'In a managerial role it is hard to make an impact on people's experience in primary and community care without investment in new ways of working.'

Nurse

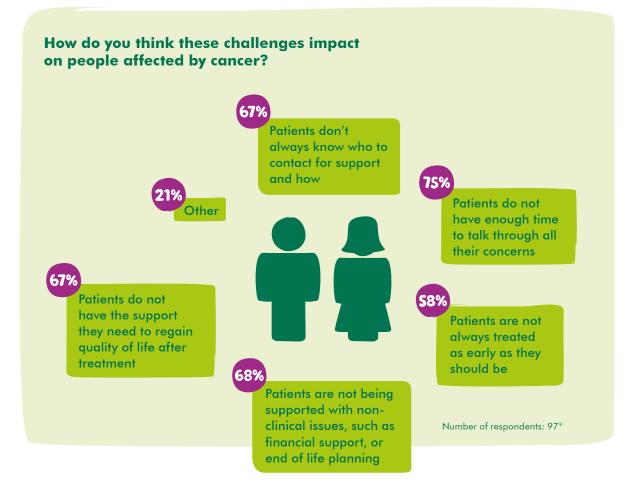
#### Increasing workloads and increasing complexity impact on quality of care

Professionals are concerned that these workforce challenges are now impacting on people living with cancer. Many felt they were letting their patients down and were worried about issues of variation in care. In some cases they also raised serious concerns about standards of care.

One GP explained, '[It] makes it very difficult to provide the standard of care cancer patients need and deserve.'

Another GP worried that, '[Cancer care staff are] over-worked – pressured into doing overtime so may make more mistakes.'

We surveyed Macmillan professionals and Macmillan GPs about the impact of workforce pressures on people with cancer, including following treatment (see graphic on page 13). The impact on patients most commonly selected by respondents was that of patients not having enough time to talk through all of their concerns. Many professionals said that patients are not being supported with non-clinical issues, such as financial support or end of life planning.



This echoed the findings of the research we carried out with non-Macmillan primary healthcare professionals. 31% of those surveyed by nfpSynergy reported that patients do not have the support they need to regain quality of life after treatment.<sup>10</sup> Over a third of respondents said that existing workforce pressures mean that some cancer patients are attending A&E because they can't get help elsewhere.<sup>11</sup> In addition to this, 44% of those surveyed said that pressures meant patients were not always being treated as early as they should be.<sup>12</sup>

'You feel you let people down. You can't fully support everybody.' Information professional

'[You] never feel as if you are able to do the best job you can.'

Nurse

Professionals are finding they must change how they support people with cancer as a result of the challenges they are facing. One nurse explained, '[It's] not physically possible to see all patients at diagnosis.' The problems are affecting every stage of the cancer pathway. Another nurse said, '[Care is] much more complex for patients. While our numbers in head and neck cancer are not huge, the input they need due to the extensive treatment or surgery means they need huge amounts of support.' Increased complexity means that many people with cancer will require more support, but the reality for many professionals is that they do not have sufficient time with individuals to deliver the highest quality care they want to provide.

'[I'm] frustrated as to why there are national guidelines and recommendations for best practice which are not being implemented. This affects patients care. [I] can't see every patient so some patients get a good assessment and support; others just get given a telephone number if anything at all.'

## Conclusion: how to address these challenges

While the workforce is evidently facing significant challenges, we were inspired by the drive of staff to provide solutions and improve services.

'I have worked for 25 years in the NHS and seen many changes. For the past 14 years I have worked in cancer care and feel privileged to share the journey with those that I meet. They confide in me and share their darkest thoughts and I am honoured to be able to offer them support and a way forward.' As one GP explained, '[Given that] the NHS in general and primary care faces huge pressures with demand and insufficient capacity and workforce, we have to be innovative and work smarter so that we can be proactive in meeting the needs of people living with cancer.'

In February 2017, Macmillan published a report, Thinking Differently: Macmillan's vision for the future cancer workforce, which included ways that the cancer workforce could be strengthened. We surveyed Macmillan professionals and Macmillan GPs about which of these was most important in addressing workforce challenges. The solution most commonly chosen by professionals was ensuring that workforce is a key consideration when looking at how to transform cancer services.

Nurse

# Ensure that workforce planning is a key driver of service redesign

Macmillan professionals overwhelmingly felt that workforce needed to be front and centre of any changes to services. Given the changing nature of cancer, this is perhaps unsurprising. The workforce was originally designed to treat cancer as an acute disease. As this changes, we need to ensure that the workforce is supported to continue delivering high quality care to people with cancer.

'[Focus on] workforce planning. [With] insufficient numbers in current roles [and] too few being trained [we] need to look at skill mix honestly [and] not just go for the cheaper options.'

GP

#### Improve skill mix and introduce new roles

Professionals were excited about opportunities to ensure that their time and skills were used most effectively. Many highlighted the importance of getting the right balance of skills across a cancer care team. It was felt that looking at where new roles might fit in was key because not only could they improve care but they could also take the pressure off specialist staff.

'I'm particularly keen to hear about how skill mix/new roles can improve the care of people living with cancer as employing more nurses/doctors is not a feasible option.'

Nurse

#### Improve career pathways to and through specialist roles

Education and training were strong themes, with many professionals highlighting the key role these play in retraining staff and ensuring the workforce has the necessary skills to support people with cancer throughout the pathway.

'All new roles that are introduced to the cancer workforce need to have a bespoke, extensive, continuing training programme so that staff are confident, competent and are retained.'

Macmillan Cancer Support Worker

## Enhance the skills and confidence of existing staff and communication between them

Communication was a key theme, both within cancer care teams, but also between primary and secondary care. It was felt that better communication could help combat fragmentation of care, save time, and ensure that people with cancer know where to get support.

'Clinical Nurse Specialist roles are very challenging and can be quite isolating as well. Working in a team committed to supporting each other is really important.'

Nurse

#### What next?

Although staff tell us they are stretched to breaking point, we know they work tirelessly to maintain excellent services and provide the highest levels of care for people with cancer.

These fantastic professionals deserve to be recognised and celebrated for all that they do, but they must be supported to be able to offer their patients the highest quality care. It is vital that governments and NHS bodies across the UK take a strategic and long-term approach to workforce planning which considers the impact of the changing needs of cancer patients on workforce design. In England, the Cancer Strategy recommended that Health Education England (HEE) should undertake a strategic review of the cancer workforce, including the development of a vision for the future shape and skills mix of the cancer workforce. Both HEE and the Department of Health have key roles in providing leadership, not only in ensuring that the review is delivered, but also that it is ambitious in considering what the future workforce should look like.

It is only through taking this long-term strategic approach that the NHS will be able to develop a sustainable approach to recruiting, training and retaining the cancer workforce we need to meet the future needs of people with cancer.

## Research methodology

This report contains findings from a Macmillan and nfpSynergy survey of primary care professionals in the UK conducted during May and June 2017. Responses were received from 154 GPs and 103 nurses. Participants were asked to fill in an online survey, which included a question on their confidence in the ability of the NHS to continue providing adequate care, and a question on the impact of workforce pressures on patients.

We also conducted an online survey, including a mixture of multiple choice and open-ended questions, of 51 Macmillan GPs between 3 June and 24 July 2017. Macmillan GPs are practising GPs who devote an average of one day per week to work with Macmillan and primary healthcare teams to make a recognisable improvement to cancer care across the UK. They are recognised locally as cancer clinical leads. By surveying this group, we were able to gain a primary care perspective on the workforce issues across local health systems. Of the 51 responses, 43 were from England, two were from Northern Ireland, two were from Scotland and four were from Wales.

We also conducted an online survey again including a mixture of multiple choice and open-ended questions of 62 Macmillan professionals between 23 May and 12 June 2017. Macmillan professionals work in a variety of roles supporting people with cancer. Some posts are still funded by Macmillan, while others are now funded by the NHS. We received responses from 35 nurses, 11 AHPs, eight information professionals and eight other roles including programme and project managers, care co-ordinators and support workers. We received 53 from England, three from Northern Ireland, three from Scotland, and three from Wales.

The questions asked to Macmillan GPs and Macmillan professionals were largely the same, with a few minor tweaks in language to ensure clarity for each audience. The questions asked were based on conversations with Macmillan professionals at the Macmillan Professionals Conference in November 2016. They covered many of the issues highlighted in our recent report, *Thinking Differently*.<sup>13</sup>

In this report, references to 'GPs or nurses' refer to the nfpSynergy findings, while 'Macmillan GPs' or 'Macmillan professionals' refers to those surveyed directly by Macmillan.

## Endnotes

- 1 nfpSynergy, Primary Healthcare Monitor, 2017
- 2 Ibid
- 3 Ibid
- 4 Ibid
- 5 Ibid
- 6 Analysis of the results of an online survey of Macmillan professionals conducted in May– June 2017 and an online survey of Macmillan GPs conducted in June–July 2017. In both surveys respondents were asked: 'Are you concerned about the ability of the NHS to continue to deliver high quality care to people with cancer?' Respondents were given five choices of answer ranging from 'not at all concerned' to 'extremely concerned'.
- 7 Qualitative analysis of the results of an online survey of Macmillan professionals conducted May–June 2017 and an online survey of Macmillan GPs conducted in June–July 2017. In both surveys respondents were asked: 'What, in your view, are the three biggest challenges facing the NHS as a whole?' Respondents were given three free text boxes to fill in and their responses were then coded.
- Analysis of the results of an online survey of 8 Macmillan professionals conducted in May-June 2017 and an online survey of Macmillan GPs conducted in June-July 2017. In both surveys respondents were asked: 'Which of the following workforce challenges, relating to cancer, are you aware of in your local health system?'. In both surveys, respondents were given the six options shown on the graph. They were able to select as many as apply. The only variation was that Macmillan GPs were given 'a lack of long-term workforce planning' as an option, whilst Macmillan professionals were given 'a lack of long term planning' as an option.

- 9 Analysis of the results of an online survey of Macmillan professionals conducted in May– June 2017 and an online survey of Macmillan GPs conducted in June–July 2017. In both surveys respondents were asked: 'How do you think these challenges impact on people affected by cancer?' Respondents were given the six options presented in the infographic to choose from and were able to select as many as apply.
- 10 nfpSynergy, Primary Healthcare Monitor, 2017
- 11 Ibid
- 12 Ibid
- 13 Macmillan Cancer Support, Thinking Differently: Macmillan's vision for the future cancer workforce, February 2017

# At Macmillan, we know how cancer can affect

At Macmillan, we know how cancer can atte everything. But you are still you.

We're here to help you get on with your life no matter what. We can give you the practical, emotional, and genuinely personal support you need to hold on to who you are and what's important to you.

We can be there for you during treatment, help with work and money worries and we'll always listen if you need to talk. We've helped millions of people through cancer and we can do the same for you. Life with cancer is still your life and we will help you live it.

From diagnosis, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk** 

Life with cancer is still life – we'll help you live it.

