ONE SIZE DOESN'T FIT ALL

Why we need to make cancer care in the NHS more personal

Katy, diagnosed with breast cancer in 2016

MACMILLAN CANCER SUPPORT

Contents

Foreword

Every year nearly 300,000 people in England receive a life changing diagnosis of cancer[i] and we know that in the coming years the number of people living with cancer in England will rise from 2,000,000 today to 3,400,000 by 2030[ii].

This rising need represents a significant challenge to the NHS – especially at a time of financial and workforce constraints, to provide everyone with the right care and support when it's needed, where it's needed.

Macmillan knows that behind every NHS statistic and newspaper headline there are many individuals with their own unique stories. In the year that we celebrate the NHS's milestone 70th birthday and that the NHS in England is tasked with developing a vision for the next decade, we want to put those stories at the heart of the debate: what is it like to be diagnosed with cancer in 2018? How well does the NHS support us when our needs are greatest? What should we celebrate and build on? What must we change? In this report, six people describe in depth, their experiences navigating the NHS through diagnosis and treatment for cancer, answering these questions. We also consider a range of national data to give the fullest picture possible of cancer care in England today.

Their stories give cause for optimism and hope. We heard that people felt their cancer treatment was a priority even though times were tough. We heard that even when staff were stretched, people valued their care, recognising a system doing the best it can.

But it is also clear that we can do better. We heard that sometimes the NHS struggles to make links between different services and health professionals. We heard that people don't always get the information they need or the help to work through what the information means for them.

Sadly, not everyone has someone they can talk to about how they feel and how to move forward with life as best as they can. We also heard that sometimes, the place that you receive care affects how you feel about it.

The Prime Minister has challenged the NHS to deliver survival rates which match the best in Europe, and it is right and essential that we ensure that people diagnosed with cancer in England today can be confident that is the case. But this is only part of the picture. **The story of cancer is changing and we must all rise to the challenge to ensure that everyone living with cancer, sometimes many years beyond diagnosis, has access to care and help that meets all their needs.**

Rapidly evolving advances in science and technology signal a future with many exciting possibilities for uniquely personalised treatments. But Macmillan knows that true personalised care is contingent on a full understanding of each individual's physical, mental, emotional and practical support needs, and critically, a health system which is agile and works seamlessly together to deliver care and support in an integrated way. This is one of Macmillan's key ambitions for the NHS – and alongside that ambition, we promise to work collaboratively in partnership to improve services for everyone living with cancer.

A note on this report

A cancer diagnosis means different things for different people. Care and support needs may be physical, practical, emotional or financial. Whilst this report touches on many of them, it focuses on people's experiences of treatment and care within the NHS.

Between June and July 2018, we carried out telephone interviews with six people affected by cancer from the Macmillan Case Study Library Database. This is a database of patients who have shared their story with us. These interviews focused on their experiences of a cancer diagnosis and treatment or having cared for someone with cancer in the NHS in the last four years. The interviews also touched on wider health services and their views on the future of the NHS.

This report reflects on the collection of these stories, which are presented in people's own words as much as possible. We are grateful to those who told us their stories.

To add context to these personal stories we also commissioned a 'temperature check' survey[iii] on people's experiences and perceptions with the NHS. In this report, we will be referring only to the 2,373 people who responded to our survey in England. We are also part of a syndicated study, the Primary Healthcare Monitor[iv] which gathers the opinions of General Practitioners (GPs) and nurses working in primary care regarding the NHS. Other data contained in this report is publicly available and was not commissioned by Macmillan.

Fran Woodard

> **'Having someone who could advise, support and explain everything, so you're getting the exact answers you need, rather than going away with only the information you're given. It would be better to be given reliable information first hand, rather than trying to find out for yourself. It would alleviate the anxiety and stresses of any uncertainties and questions. It would make people feel more comfortable and confident in moving forward with the illness and dealing with it, because there are so many forms and variations of cancer but everyone's case is unique.'**
>
> **Katy**

Katy, diagnosed with breast cancer in 2016 with family

Executive summary

2018 has seen the NHS celebrate its 70th anniversary, but as health and care services look to the future, the NHS long-term plan presents a timely opportunity to address issues facing people living with cancer. Our report highlights where progress still needs to be made and the challenges that still need confronting to deliver world-class cancer care.

People are anxious about the state of the NHS and cancer services and there is mixed confidence in what the future may hold.

- Only a third of people Macmillan has surveyed (32%)[v] feel the government is doing a good job in dealing with pressures on the NHS. The NHS Long-term plan presents an obvious and immediate opportunity to address those concerns.
- Only half (50%) feel that the cancer care delivered by the NHS in 2018 is world-class[vi] – and confidence dips even lower (43%)[vii] when we asked if people were confident that cancer care would be world-class in five years' time.
- 60% are not confident[viii] that the government is making adequate preparations for the number of people who will be living with cancer in the future. It's important that NHS plans on cancer address the full range of concerns people say they have, including improved support for patients at diagnosis and receiving treatment.

NHS services and health and care professionals are under pressure and struggling to provide the best care possible for an increasing number of patients. These pressures impact on timely access to care, care quality and patient experience.

- Most people (78%)[ix] feel that staff are doing a good job despite pressures on the NHS.
- However, around a quarter (24%) of the people we surveyed had experienced a problem with the NHS in the last three months[x]. The most common was waiting more than a week to get an appointment with a GP, with 30% of people who had tried to book an appointment in the last three months waiting more than a week[xi].
- The number of specialist cancer nurse roles has grown from around 3,100 in 2014 to just over 4,000 in 2017, which is positive news. However, there is considerable variation across England when looking at the ratio of specialist cancer nurses to newly diagnosed patients for different cancer types. There is also variation in vacancy rates across the country.

There have been years of policy initiatives designed to improve integration but the NHS is still struggling to connect care across services and professional boundaries.

- Coordinated care was identified by one in five (20%) people as being the most important factor in ensuring people living with cancer get the best possible care and support.
- Unfortunately, this was least positively reported on by people living with cancer, where 68% of people agree that health and care services were well coordinated in their experience[xii]. This means nearly one in three people are not getting an integrated service.

The provision of information and support for people at diagnosis and throughout treatment for cancer is inconsistent and failing to meet the needs of all people living with cancer.

- Around two in five (42%) people felt that people having the right information at the right time about diagnosis and treatment options was most critical. But we found inconsistencies in the availability of information and support, and our survey of primary healthcare professionals found that the majority (63%) felt that cancer patients don't always know how to get support.

Personalised care should meet the range of people's physical, mental, emotional and practical support needs. All too often non-clinical needs are not being addressed, resulting in prolonged and increased anxiety and poorer quality of life.

- Over half (52%) of the respondents to our survey of primary care professionals, felt that cancer patients do not have enough time to talk through all their concerns.

52%

of the respondents to our survey of primary care professionals, felt that **cancer patients do not have enough time to talk through all their concerns.**

'Spending a lot of time on your own, you learn a lot about yourself – about how strong you are as a person.'

Amrik, diagnosed with Hodgkin lymphoma in 2010

YOUR FEELINGS AND RELATIONSHIPS

Lurline, diagnosed with breast cancer in 2016

What should the NHS focus on in the future long-term plan?

The needs of people living with cancer are varied and complex but more could be done to help people live life as fully as they possibly can after a cancer diagnosis. Macmillan believes that the NHS in England should prioritise the following areas in developing the long-term plan:

The NHS long-term plan must be realistic about the level of future care needs. The health and care system will need to cope with increased absolute need (by 2030 we anticipate 3.4 million people will be living with a cancer diagnosis in England). But the system will also need to address increasingly complex care needs as people continue to live longer with complex, multiple comorbidities (the number of people alive five or more years from initial diagnosis is predicted to more than double to 2.2 million between 2010 and 2030). By 2040, older people will account for more than three quarters of people living with a diagnosis[xiii].

There should be a focus on non-clinical outcomes such as quality of life and patient experience as well as absolute health outcomes, recognising that many people may live years beyond initial diagnosis, sometimes with cancer that requires ongoing treatment and sometimes with long term physical and emotional consequences of cancer treatment.

Effective integration and coordination of services across and between health and social care settings is needed to ensure that treatment, care and support following a cancer diagnosis is seamless and person-centred. This requires systems and organisations to work well with each other at system level; and for all professionals to have core skills and competencies to deliver the right care and support.

Everyone should be given all the information and support they need on their cancer journey. This should be embedded within the system and commissioned to be available for all, from the point of diagnosis and throughout treatment and beyond. This should take the form of a holistic needs assessment addressing the range of physical, emotional and practical needs of the whole person; and a personalised care plan to address identified needs. A needs assessment should be revisited and care plans adjusted as people progress through and beyond treatment.

People living with cancer need help to navigate the system, so that they can access all the information and support available and be signposted and referred to other support services if appropriate, including support for unmet emotional and practical needs.

There needs to be an increase in cancer nurse specialists to meet the current and increasing future demand and complexity of need. This should include investment in educating and training new specialist nurses as well as urgent initiatives to encourage retention and return to practice of the existing workforce.

There should be an urgent focus on supporting the development of the existing workforce to be more flexible and responsive to meet the needs of people living with cancer. There should be investment in support or link worker roles to ensure people living with cancer are supported to access all the relevant care and support.

There needs to be more targeted action on health inequalities. Consistent access to diagnosis, treatment, care and support should be accessible to everyone regardless of their background or where they live.

Introduction

To assess the health of cancer services, we must also consider the current state of the wider health service, both to understand the pressures the service is under and the policy ambitions which have been driving change in the last decade.

NHS funding

Since 2010 the NHS has been in the grip of an unprecedented financial squeeze, with annual funding increases not keeping pace with the rising demand of a growing, ageing population with increasingly complex health needs. Independent experts agree that a 4% annual increase is required both to keep pace with this demand, and provide some additional investment for priorities such as cancer and service transformation[xiv]. The 3.4% average uplift announced in the summer of 2018, whilst a welcome respite for the NHS, will not alleviate all the pressures our services face. In addition, this funding will also have to cover increased pay for doctors, nurses and other NHS staff, as well as to help plug some of the debts that have accrued in recent years.

It is in this challenging financial climate that the NHS also must agree and deliver a future long-term plan for the NHS, setting out bold ambitions for care across the next ten years. We welcome that cancer services will be a key priority and measure of success for the government and the NHS in delivering these plans, and that early announcements suggest a strong focus on improving survival rates and early detection and intervention. But it is essential that we do not lose sight of the importance of supporting people to live the best life possible after a cancer diagnosis.

Integration

The Five Year Forward View[xv] was launched in 2014 to set out a new direction for the NHS. It contains ambitious plans to prioritise prevention and give local areas the mandate to develop new models for delivering integrated, person-centred care. As well as promising to give people greater control of their care, the plan also sets out ambitious plans to break down historical – and artificial - barriers between different types of care services. For example between hospitals and community or general practice settings, between health and social care services or between physical and mental healthcare. These ambitions are the right ones for people living with cancer. For the NHS to deliver on this challenging aim, organisations must work better together, and people accessing services will need suitable information and support to enable them to make informed decisions about their care, regardless of where they receive their care or which professional delivers it.

Personalised care

The Five Year Forward View has ‘personalised care’ at its core. Personalised care is care which is designed in collaboration with the person who needs it, or with someone who knows them well, so that it is tailored to meet individual needs.

The expansion of personalised care is important for the NHS in England. Moving away from operating through single disease pathways is crucial for people living with cancer, to ensure they are empowered to make decisions around their treatment, care and support that work best for them, and are supported to live as well as possible following a cancer diagnosis.

Lurline, diagnosed with breast cancer in 2016

Cancer services and NHS performance in 2017/18

Cancer waiting time targets

Current performance measurement of NHS services, for example by analysing waiting times targets, cannot paint the whole picture of what it feels like for individuals receiving treatment. It can, however, give an indication to the relative health of cancer services in England today. Performance measurement can also act as an early warning system to flag areas which may be a cause for concern or indicate problems in the wider health system.

Waiting times targets set out a range of standards by which the NHS seeks to ensure people receive timely diagnosis and treatment for their cancer[xvi]. Most recent statistics indicate both a continuation of trends which we have observed for a number of years and some potentially concerning new patterns, with some targets that the NHS has broadly met in recent years beginning to dip in performance.

There are a range of cancer waiting time targets in England, which measure different waits within the patient pathway, including two week waits to see a specialist for suspected cancer after urgent referral from a GP, and 31-day waits for first definitive treatment following a cancer diagnosis. Further, there are 62-day cancer waiting time targets focused on first definitive treatment getting underway following an urgent GP referral.

One cancer waiting time target that has been challenging for NHS Trusts to meet is the 62-day cancer standard. Delays with diagnosis can lead to breaches in the 62-day standard, although providers have been working with the support of NHS regulators, to recover performance. Longer waits also run the risk of increasing a person's anxiety when waiting with uncertainty for confirmation of their diagnosis. In June 2018, only 79% of patients in England started treatment within two months of being urgently referred by their GP with suspected cancer, against the target in England of 85%. This was an all-time low, and the 62-day target has now been breached every month for two and a half years in a row.

The NHS struggles to meet this target in part because of common delays at the start of the investigation and care pathway and a lack of diagnostic capacity, making it hard to make up lost time[xvii]. Focusing on this in greater detail, almost two thirds of NHS hospital trusts in England (65%) missed the 62-day target in June 2018. Around one in three trusts – 45 trusts – missed it by 10 percentage points or more[xviii].

In the 12 months to June 2018, over 27,000 people waited more than two months for treatment to start after an urgent GP referral, including over 10,700 people who waited for more than three months. In fact, since the target was first breached in January 2014, around 110,000 people have waited more than two months for treatment to start. This is a startling situation and one that despite the hard work of professionals, points to continued pressures diagnosing and then beginning treatment for individuals with cancer.

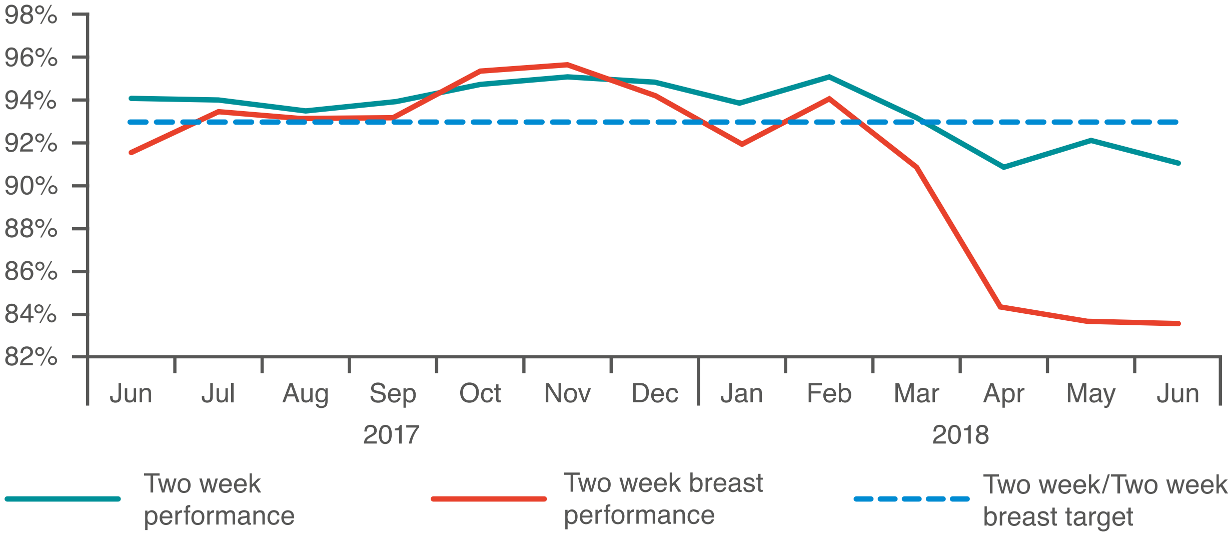
Elsewhere, there are concerning signs that performance against other cancer waiting time targets is also declining. The two week wait for urgent referral from a GP where individuals with suspected cancer need to see a specialist was also missed in June 2018 – the target is 95%, whereas only 91% of patients saw a specialist within two weeks of being urgently referred by their GP. This is the third month in a row that this target has been missed and this is the first time this target has ever been missed in consecutive months.

Similarly, there have been fluctuations in performance against the 90% target for patients receiving treatment within 62 days following referral from an NHS screening service. While performance has been relatively good, the target has been missed in five of six months up to June 2018, raising further concerns.

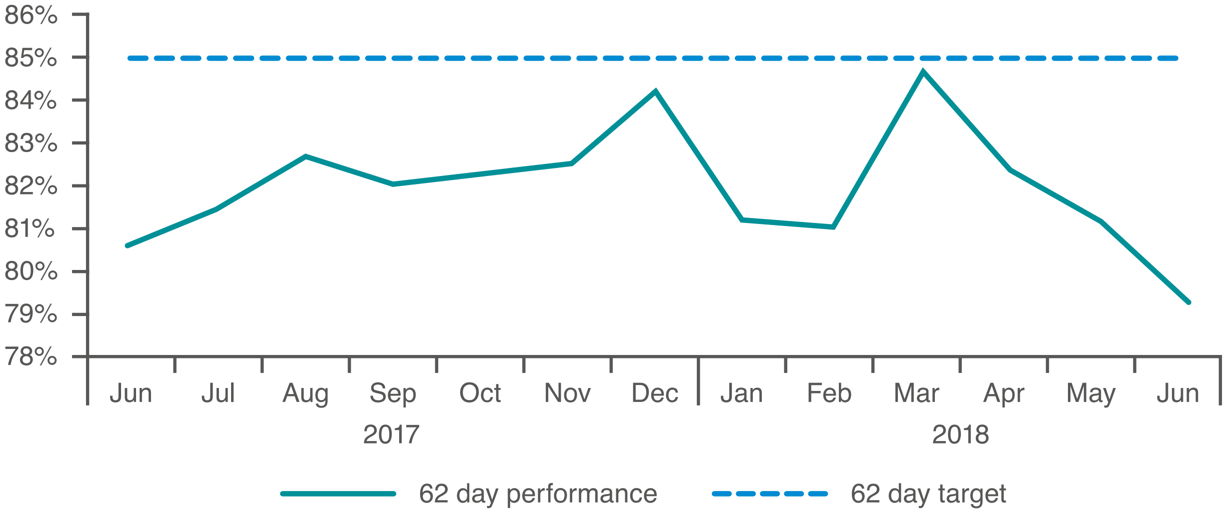
The charts opposite illustrate performance across key waiting time targets between June 2017 and June 2018.

While there may be multiple and complex reasons why a target is not met, they are indicators of the resilience of cancer services at a given point in time and the potential warning signs of more sustained difficulties to come. It is also important to remember that even if a performance target is met, there are people who are missed in receiving treatment. Each missed waiting time means people living with cancer had to wait longer for appointments or treatment. Longer waits can then affect clinical outcomes and raise people's anxieties and concerns.

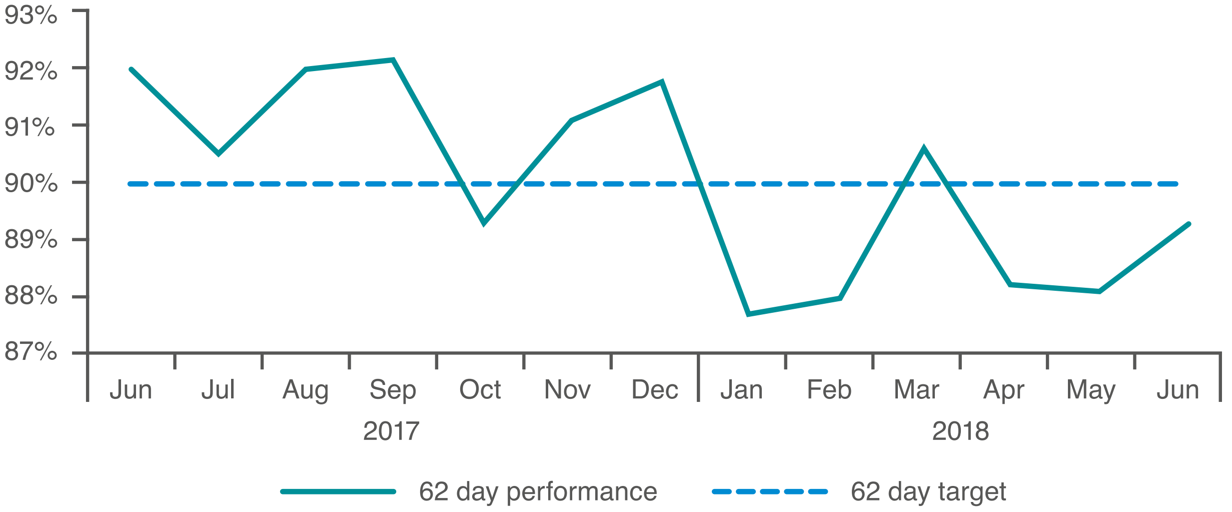
Two week wait: to see a specialist after urgent referral for suspected cancer (all cancers & breast symptoms)



Patients beginning first treatment within 62 days following an urgent GP referral for suspected cancer



Patients beginning first treatment within 62 days following referral from an NHS cancer screening service



NHS workforce

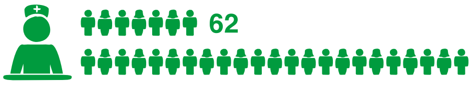
Like waiting time targets, the size and resilience of the NHS workforce can be another lens through which we assess whether the NHS has the capacity, to deliver the high-quality of care people living with cancer deserve. Macmillan's recent census of the cancer workforce in England gives a snapshot of the state of the current cancer care workforce, including cancer nurse specialists, chemotherapy nurses and support workers.

We found that the number of cancer nurse specialist roles has grown from around 3,100 in 2014 to just over 4,000 in 2017 which is positive news for people living with cancer[xix]. However, an increase in absolute numbers is only part of the picture. The growth of the workforce needs to be understood in the context of the increasing overall need and complexity of need of people living with cancer now and in the future.

Wider pressures on the NHS and social care are also impacting on the cancer workforce, as cancer nurse specialists may find themselves being called to plug general workforce gaps, taking them away from their specialist roles.

We also found that where you live, or the type of cancer you have, can impact on your access to key specialist health professionals. **There is considerable variation across England when looking at the ratio of specialist cancer nurses to newly diagnosed patients for different cancer types** (calculated based on whole time equivalent).

Lung cancer

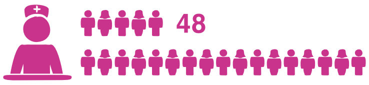


Varies between 62 and 203 new patients per nurse

Urological cancers

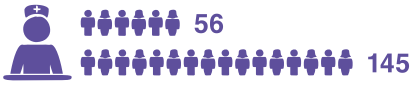
Varies between 87 and 251 new patients per nurse

Colorectal cancer



Varies between 48 and 150 new patients per nurse

Breast cancer



Varies between 56 and 145 new patients per nurse

There is also variation in vacancy rates across the country, with rates as high as 15 for every 100 filled roles for chemotherapy nurses in some Cancer Alliances[1].

Chemotherapy nurses

Highest vacancy rate

15
vacancies
per 100 filled roles

Lowest vacancy rate

0
vacancies
per 100 filled roles

Specialist cancer nurses

Highest vacancy rate

11
vacancies
per 100 filled roles

Lowest vacancy rate

1
vacancy
per 100 filled roles

This means people living with cancer in some parts of the country may not have access to the same level of specialist support as other areas.

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[1] Cancer Alliances bring together clinical and managerial leaders from different hospital trusts and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. These partnerships enable care to be more effectively planned across local cancer pathways.

Local Cancer Alliances set up their health services according to local need and to fit with the wider system in place, meaning that some variation is to be expected. However, variation in vacancy rates may impact patients' access to care and information and could have implications for workforce planning.

We know too that the proportion of Cancer Nurse Specialists (CNS) who are over 50 years old has risen from 33% to 37% since the last census in 2014, and that there is variation across the country in the age profile of the workforce.

33%
2014

37%
2017

CNS Age	2014	2017
Under 30	2%	4%
30–39	23%	22%
40–49	42%	37%
50–59	31%	34%
60 and over	2%	4%

This is concerning and highlights the need for urgent action to ensure plans are in place to train new health care professionals and keep the workforce sustainable in the long term.

People living with cancer often access treatment from non-cancer specific health services and health professionals across the NHS. Pressures on the wider NHS workforce are currently significant, with statistics for April 2018[xx] showing a decline in the number of nurses and GPs, despite rising patient need.

The Nursing and Midwifery Council, which regulates the nursing profession, have highlighted that at the end of March 2018 there were 495 fewer nurses and midwives on their register than at the end of March 2017[xxi] and it is believed there are 40,000 nursing vacancies in total[xxii]. The picture in nursing is concerning, posing fundamental challenges to continuity and coordination of care. But just as concerning are figures showing the increasing pressures on general practice. An annual vacancy survey of GPs found that 15.3% of positions are currently empty, an increase from 12.2% in the previous year[xxiii]. As our report will demonstrate, the care of people living with cancer is being impacted by these wider pressures across the NHS workforce.

Finally, trend data for medical and clinical oncologists and therapeutic radiographers shows that staff numbers in these three roles combined have grown by nearly 4% per year on average over the last three years. However, cancer incidence alone is increasing by 8% per year[xxiv] meaning that the workforce must continue to grow to meet increasing demand.

Patient experiences of the NHS

To better understand the issues people experience when they receive a cancer diagnosis and treatment in the NHS, we asked a number of individuals to tell their stories. We also analysed national data such as the Cancer Patient Experience Survey and Macmillan's own surveys of people who have had a cancer diagnosis, the wider public and the primary care workforce. Taking all of this information together, we can build a clear picture of what really matters to people when it comes to treatment and care; as well as understand how confident people are about cancer care both now and looking to the future.

In England, around 70,000 patients a year respond to a National Cancer Patient Experience Survey (NCPES), giving feedback about both practical and emotional aspects of their care. The results for 2017[xxv] tell us that on the whole, people rated their care highly with an average score of 8.8 out of 10[xxvi]. Of those who took part, 79% reported that they were as involved as they wanted to be in decisions about their care and treatment[xxvii] and 91% were given the name of a Clinical Nurse Specialist who would help them throughout their treatment[xxviii]. This is positive.

The people who shared their stories with Macmillan were also generally positive about their experiences and most felt that they were a priority to health professionals and the NHS, particularly oncology services.

42%

of patients surveyed felt that **having the right information at the right time** about diagnosis and treatment is most important if people are to get the best care.

Access to the right information and support

Macmillan knows that there is no one size fits all model when it comes to making sure everyone gets suitable information to understand and make choices about their cancer diagnosis and treatment. Some who shared their story told us they received information but were in too great a state of shock to understand what it meant; whilst others told us that they chose not to explore information further until they were ready. Conversely, others felt they would have valued more information, for example about what their diagnosis meant for them or the long term implications of their cancer.

In our Temperature Check survey, we asked people what they thought was most important to ensure people living with cancer got the best care and support. Around two in five[xxix] felt that people having the right information at the right time about diagnosis and treatment options was most critical (42%). People also identified support being most pressingly needed at the point of diagnosis (32%), when told that cancer cannot be cured (19%) and during treatment (20%).

People's experience of information and support varies: for example, the least and most deprived groups experienced significant disparities in access to information in the 2017 NCPES[xxx]. Patients from more deprived backgrounds also reported they experienced significantly lower levels of care and support from health and social care, both during[xxxi] and after treatment[xxxii]. For example, significantly fewer people in the most deprived group felt GPs and nurses did everything they could[xxxiii] and fewer people felt they got answers they could understand from their cancer nurse specialist[xxxiv]. Strikingly, more patients from a deprived background felt doctors and nurses talked in front of them as though they weren't there[xxxv].

The NCPES results confirm that whilst many people are happy with the information they receive and what it means for them, there is plenty of room for improvement. For example, only 73% of respondents said that they completely understood the explanation of what was wrong with them[xxxvi]. 80% of respondents said that the results of their tests were explained to them in a way they could completely understand[xxxvii]. This still leaves a sizable minority not feeling best prepared for what is to come.

There is also evidence of variation in the information given at different parts of the care pathway - whilst 83% of respondents with more than one treatment option said that before their cancer treatment started the options were explained to them completely[xxxviii], only 73% of respondents said that the possible side effects of treatment were definitely explained to them in a way they could understand[xxxix].

Having access to the right information and support to understand what it means should not be a game of chance but should be embedded within the health and care system.

Lurline, 55,

diagnosed with breast cancer in 2016

Lurline is a retired dental hygienist. In 2016 she was diagnosed with breast cancer.

My life has changed dramatically, physically, professionally and emotionally since having cancer and living with the side-effects. But I've gained a lot of positive things out of a dreadful and life changing experience.

The diagnosis was primary breast cancer grade two. I'm cancer free now and I've been clear since last April. However, I am living with some side-effects. I now have heart problems from when I started the Herceptin treatment. I'm also living with lymphoedema, and have a lot of joint pains.

In February 2016, I had an appointment for a routine mammogram screening. When I went to have the mammogram, the first thing the radiographer said to me was,

"Oh, have they told you they found something?"

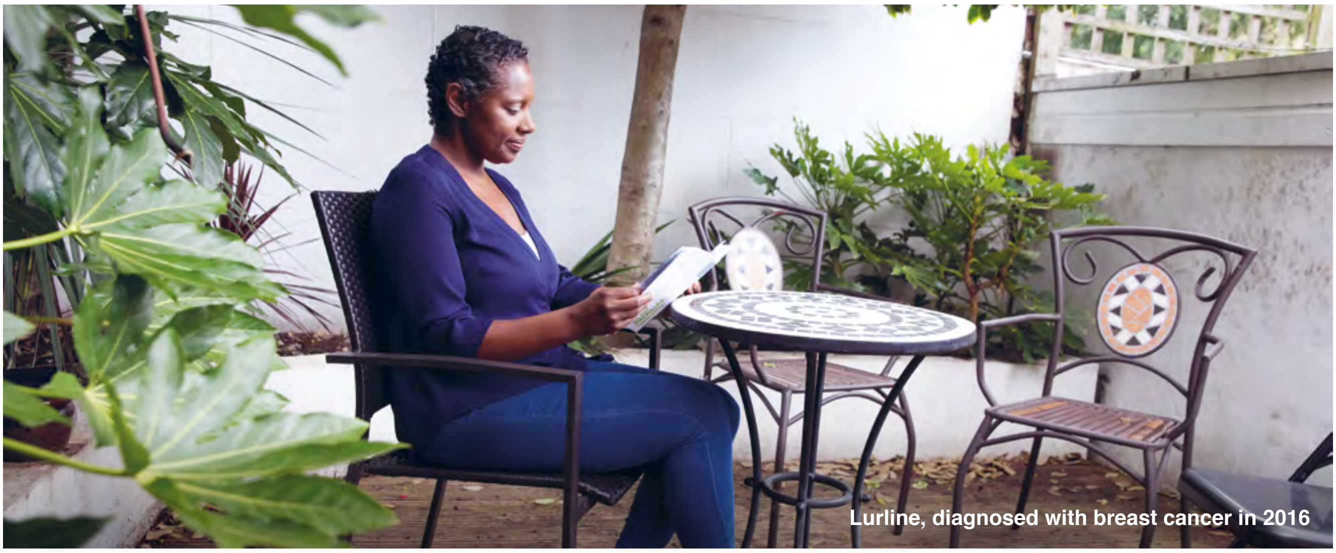
I was absolutely in shock, I wasn't prepared for that. I tried to maintain my calmness but inside I was in shock. I think she could see that and she realised she'd made a mistake in saying what she said.

I think professionals should be aware that patients come from different streams for their mammograms. Some are referred from their GP because they've found a lump, some because they know there is something there, but some of us, have been referred from a routine mammogram. If that was somebody else it might have shattered them, it wasn't the right time to say something like that.

After I had a biopsy I was referred to a nurse who was there to answer any questions.

She helped me map out a journey, so that I was aware of what was going to happen next.

That was very good and helpful, and she was very patient with me. She gave space for me to ask questions, as well as my husband. She asked him how he felt and going forward, how he could get help if the results showed a malignant tumour.



Lurline, diagnosed with breast cancer in 2016

Later, the surgeon explained everything from my diagnosis and the best treatment plan going forward. I think because I have a healthcare background and I understood everything quicker and easier, I didn't have a lot of questions to ask at that point.

My oncologist also explained everything to me using diagrams. I was given a huge folder with information and was introduced to my breast care nurse, who is invaluable and who you can contact whenever you need to. You're treated very well and there isn't a lack of information. Some may say it's too much information.

I was a bit nervous for my first chemotherapy session. To have the chemotherapy administered, I needed a PICC[2] line. I remember the nurse said the PICC line should have been organised before I had my first chemotherapy appointment, but unfortunately it wasn't for me. **I ended up having the chemotherapy go straight into my vein the first time. Because of this it was very painful, I had very sore hands and black lines in my arms for a long while afterwards. I think it was because they were short of specialist nurses who could do that procedure**, if there were more nurses I may have dealt with my first chemotherapy session better.

I saw staff were stressed because of their workload. They had a lot of patients to see and make sure that everybody was in the right place, at the right time, checking who needed to have what and when. Most of the time, I saw the same set of nurses but sometimes they would have temps or bank staff and nurses because of the shortages. I remember for one appointment a nurse couldn't find my notes and I had to wait over two hours before I could start my chemotherapy. The head nurse came to me to explain that a temp nurse had accidentally misplaced my file.

At the Macmillan centre, I accessed loads of leaflets and booklets, and they were on hand to explain anything. At the beginning of my diagnosis, I was quite proactive, I read everything that I was given. I remember at the Macmillan centre, they told me about the free prescription for five years, small things like that which I didn't know about before.

I could also choose appointment times that suited me for my radiotherapy and hopefully I'd be able to see the same set of professionals and patients again, so we built up a rapport over that time. Every day at that time I knew I was going to have my radiotherapy, so it was easy to plan the rest of my day.

I did get support from the chemo suite around my hair loss. A nurse wrote a request to the wig unit to find a wig that I could use because of my hair loss from the chemotherapy, but there wasn't much choice for ethnic minorities at all and I was told I had to go to a salon in the centre of London and try on my wig there. I just thought that was appalling. It's devastating when you lose your hair, I was going through chemotherapy, I was so weak and I had to travel into London which was not nice. For other patients of a different ethnicity, they had the choice and the comfort of having the wigs delivered to the hospital but that was not the case if you were an ethnic minority.

My experience at A&E was just different to my experience with the oncologist department. They didn't treat me with less care, but it's more about efficiency for them and dealing with the large numbers of patients coming in. I didn't feel there was a personal aspect to my care.

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[2] A peripherally inserted central catheter (PICC) line is a long, thin, flexible tube used to administer chemotherapy and other medicines.

Meeting all people's needs

Ensuring everyone has the opportunity to talk through and identify their needs and to complete a needs assessment is critical. This ensures people can be referred or signposted on to further tailored support, which can be absolutely critical, and yet the Primary Healthcare Monitor showed that the majority (63%) of professionals surveyed felt that cancer patients don't always know how to get support[xl].

This information and support should include practical help in understanding what treatment may mean for life at a later stage, perhaps long after an initial diagnosis or treatment. The 2017 NCPES results show, that whilst 67% of respondents said that they were offered practical advice and support in dealing with the side effects of their treatment[xli] initially, only 56% of people said that they were also told about any side effects of the treatment that could affect them in the future[xlii]. Being diagnosed with cancer and beginning treatment can be an overwhelming time and things can often move at speed. The NHS needs to ensure there is holistic support for people at diagnosis and throughout the care pathway, so that everyone is empowered to manage decisions about treatment and side effects and actions they can personally take to plan for the future as best as possible.

It is clear that there are too many gaps in the system in which people's support needs fail to be identified, with a number of people describing only coming across invaluable information or support services by chance or because they felt they had been incredibly 'proactive'. Nearly half (46%) of respondents to the Primary Healthcare Monitor felt that cancer patients are not being supported with non-clinical issues, such as financial support[xliii].

Ensuring everyone has access to someone who can help assess and work through what their needs might be from as soon as they are diagnosed would help address these gaps and help signpost people on to tailored support as soon as they need it.

A holistic needs assessment[3] and personal care plan[4] empower people by equipping them with the best available knowledge to make decisions and ensure that there is accountability within the system for making sure the identified needs are met. As our stories show, these needs are frequently not limited to medical treatment for cancer but support for a variety of practical and emotional needs, which if unmet, prevent people from living the best lives possible.

63% of primary care professionals felt that cancer patients don't always know **how to get support.**

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[3] A Holistic Needs Assessment (HNA) gives a person living with cancer the chance to think about their concerns and discuss possible solutions. These concerns cover areas such as physical, emotional, practical, financial and spiritual needs.

[4] A Personal Care Plan is part of a HNA, and may include ideas to help an individual manage their concerns. It will also include contact details for organisations or services that could help.

> ‘It felt like a team of oncologists, nurses, the medical team and the patient were working together. The two-way conversations and being very open to the patient wanting [help] in decision[-making]. It’s about making sure that what the patient wants is at the centre of it.
>
> The great thing about the NHS, is the nurses and the doctors who really care and remember you as a patient, it’s the recognition that patients are people who have feelings.
>
> My mum’s treatment was a very long rollercoaster. I think we are very lucky to have the NHS and the resources that she had available. I was proactive to look for what else might be available but I imagine people who aren’t didn’t have as much available to them as we may have.’
>
> **Maymay**

Maymay, carer for her mother who was diagnosed with ovarian cancer in 2017

Katy, 38, diagnosed with breast cancer in 2016

Katy is a teacher. She was diagnosed with triple negative breast cancer in August 2016.

In August 2016, I was diagnosed with triple negative breast cancer, four months after I gave birth to twin girls. I've had a lumpectomy, six rounds of chemotherapy and 18 rounds of radiotherapy. I am currently clear from cancer.

On that day I went for my biopsy, my husband and I had a feeling something was up. You could tell by how the professionals changed and more people stepped into the room. The breast surgeon, who would be doing the operation, gave me the results and there was a Macmillan breast care nurse there for support.

I was half expecting the diagnosis and half thought, "It will be okay". **We were given a lot of information and booklets to take away, go through and digest it all. It was a practical way to think about it, because the booklets gave ideas of questions that you might want to ask which was helpful. But in hindsight, I took a lot of information but it wasn't explained to me, I would have needed to find it myself and ask those questions.** It would have been helpful to have had someone sit with me and explain, "This is the type of cancer you've got, this is what that means". I was given a primary breast cancer folder of information and there's suggestions of activities to do, but most of it you have to seek out yourself. A nurse flicked through a few pages, but it was difficult for me to fit these into my routine when I had a new family.

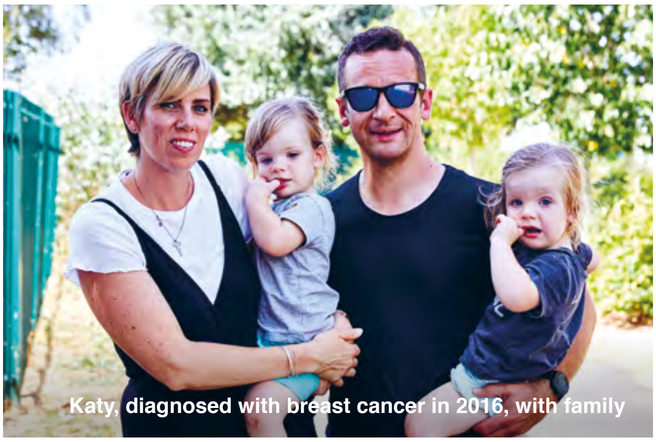
The treatment options were clear because the breast surgeon went through my next steps. But he was a bit in and out. **There's so many people that go through there, it was like, "On to the next one". That was an issue I had, the waiting time where it felt like they'd give you just enough information we needed to go away with and then move on to the next patient.**

Within a week, I had surgery which was one of the worst days for me. I was dropped off at 7:30am but I was the last operation of the day. I had the whole day to get very anxious, especially as I'd never been under general anaesthesia before. The staff were lovely and they really looked after me but I felt like a level of care was missing. It was a day surgery, and I couldn't stay in the hospital overnight because there were no beds for me. It felt like they were waiting for me to be well enough to go as soon as someone could pick me up and I felt I had to make myself feel as well as I could, so I could leave at the end of that day. When my husband came, they were shutting the door behind me. It felt strange and unnerving. **I didn't know what to expect when I went home. I was worried and scared if something would happen in the night. No-one talked to me about it. I did call the breast cancer nurses and they were great and helpful, but they are busy because they don't have enough staff.**

Between the surgery and chemotherapy, I had no contact with anyone. You were in limbo. In some respects, I thought I could enjoy my new children but on the other hand I was worried why I hadn't heard from anyone, what's happened, should I be worried? I was eventually told I would start chemotherapy in November, but I wasn't given a reason why I waited so long. It would have been nice to have a follow up after my surgery for my chemotherapy.

The nurses that administered the chemo gave me one-to-one care. Even though they were short-staffed, they always had time and made sure my guests and I were comfortable. They were really helpful explaining things. I had a PICC line for my treatment and I did all my care at home. My mum was shown or almost trained on how to do it and they were very thorough at explaining that.

It was a two-hour round trip to get to my radiotherapy, and the journey would add extra mental and physical stress onto the situation. But my priority was sorting out childcare, as the appointments were in the middle of the day. The radiotherapy was in an old hospital. It felt depressing, because you were shut in and it could get busy. But everyone was friendly and made me feel relaxed. I tended to see the same two nurses and I'd built up a relationship with them. It made the experience more positive and it was nice to have conversations away from cancer, and more about your personal life.


Katy, diagnosed with breast cancer in 2016, with family

I didn't use any other non-cancer services. I think because I didn't need them, I wasn't aware of them. They weren't brought to my attention and I wonder if I had suffered more and had complained about things, then I might have been told about them.

I had appointments with my oncologist regularly. Generally I was okay, but I'd be in a waiting room for three hours to see him for five minutes, and it felt like a real waste of everyone's time. The worst one for us was near New Years. We were waiting for what felt like an eternity as there just weren't enough doctors on duty. I waited all day to [hear], "I'm fine". It was a waste of time for my husband and I, and that we had to get someone to look after our children. I understand the oncologists must see you but perhaps general check-ups could be done in different way, like a telephone call? It would save their and everyone's time, and then they can see the people that they need to see and have the time and resources for them.

The staff are managing very heavy workloads, it's not their fault they're understaffed. It felt like a case of wanting you in and out because of the pressure of how many patients they had to see. Generally, I was okay but if I had any questions I couldn't ask them because I didn't want to waste their time. Instead I would go and try find it out myself. But if there was a drop-in session where you could just ask the things that you were worried about or a helpline, it might have been easier.

I never felt like anyone had a conversation with me about my situation and being a new mother, who could have directed me to the support I could have received. I'd tell people my story and they'd be a bit like "Wow, that's a lot". But I wasn't signposted to where I could get help or talk to someone if I needed to. There are leaflets but it's not the same as someone telling you. I had to use my own initiative or ask friends and other patients, sharing what they've been through.

> ‘I’ve had a great experience from everybody, great care, great response.’
>
> **Mohammad**

Mohammad, diagnosed with prostate cancer in 2014, with family

Emotional support

Our stories are a powerful testament to the depth of emotions experienced following a cancer diagnosis as well as the ways in which feelings and priorities can change over the course of treatment.

The emotional impact of a cancer diagnosis and treatment, and life beyond that, can impact on people differently. We heard that some people after the initial shock of diagnosis were able to tackle further challenges with positivity and adapt to new circumstances. Others felt the impact of their diagnosis at a later stage – being struck suddenly by the enormity of what cancer meant for their lives now and moving forward. No two experiences are the same, but what is fundamentally clear is that we must do more to support everyone's emotional needs throughout diagnosis and treatment.

A number of questions in the NCPES also highlight that clinical environments are unable to consistently provide the emotional support people need. For example, **only 53% of people in the 2017 survey said that, during their hospital visit, they definitely found someone on the hospital staff to talk to about their worries and fears**[xliv]. More needs to be done to understand why this is and how we can do better. But it may reflect, as with general practice, the general 'stretched' nature of many NHS services and the clinical and support staff who work within them.

It is worrying that whilst hospital based services do not appear to be able to offer all the necessary emotional support, this may not be picked up elsewhere either. **Over half (52%) of the Primary Healthcare Monitor respondents felt that cancer patients do not have enough time to talk through all their concerns**[xlv]. This raises real concerns about how and where this gap in support can be filled and highlights the importance of providing bespoke support across the care journey, to help people work through their needs and the best way to meet them.

Linda, 63,

diagnosed with bowel cancer in 2015

Linda is semi-retired and works for the family business. In 2015 she was diagnosed with colorectal cancer.

In November 2015, I was diagnosed with colorectal cancer. **I'm in remission and although I've had good support and treatment, I've been constantly fighting, constantly anxious and in a state of panic.**

My symptoms became worse in September, so I contacted my GP who fast-tracked me for a sigmoidoscopy, but as my daughter's wedding was approaching, I declined and went in November. When I had the procedure, it was obvious they'd found something as they were trying to shield me from what was on the screen and I could tell there was something seriously wrong. After it was done, I remember her saying, "I'm afraid we have found something sinister". She told me that before my appointment with the consultant I'd be bombarded with tests. **Then you were left in no man's land for the next two weeks. I remember thinking, "I don't know what to do".** So, I saw a doctor at my GP practice who since has become my regular GP and mentor through it all.

The first time I met my consultant, he said all the tests were inconclusive, but as it looked like a cancer, he was going to treat it as one. He had a surgery slot two days later and it all felt a little bit fast. I was given two options, a colostomy which was irreversible or an ileostomy which was reversible, but I didn't feel like I had all the information or time to decide. **The surgeon made it clear that it was my decision to make but I'm not a doctor, so how could I decide? It was difficult because I had this period from a preliminary diagnosis to a proper diagnosis and I was in limbo.**

As a family we made a chart of the pros and cons of each procedure and we decided on the colostomy. I told the consultant but he still wanted to try the ileostomy so I decided to leave it up to him and went into the procedure not really knowing what was going to happen.

The surgery failed and I needed emergency surgery the next day. It was only after this that the consultant said, “Oh by the way, it is cancer so I’ve passed you onto the oncology team”. But with no explanation of what the oncology team were actually going to do. I didn’t know what to say other than if I still had a future? The surgeon was a very kind gentleman, but he was always in a hurry, he’s always got one foot out of the door before he gets in. The nurse said that’s not how I should’ve been told about my diagnosis.

I just wish he explained things more to me with a bit more compassion. I think in anyone’s world, the word “cancer” is mind-blowing and you’ve got this romantic idea that when you’re told, you’re going to be surrounded by your family, but at the end of the day, I’ve got cancer, it was devastating.

It’s only dawned on me more recently, no-one’s ever sat down and explained my cancer to me - I’ve done research on my own and figured it out. I mentioned this to my daughter and she asked me if I wanted to know at the time? I can’t answer that question, you get onto this treadmill and you just go with the flow.

Unfortunately, the information doesn’t come to you, you’ve got to go out there and find it. It’s been a very lonely road. I’ve got to be on the ball every day for dealing with things that I shouldn’t have to deal with, instead of dealing with the issues that are there. I don’t think I’ve been offered much emotional support besides the colorectal nurses referring me to a clinical psychologist, otherwise, I’ve been given an occasional telephone number or a website to find information.

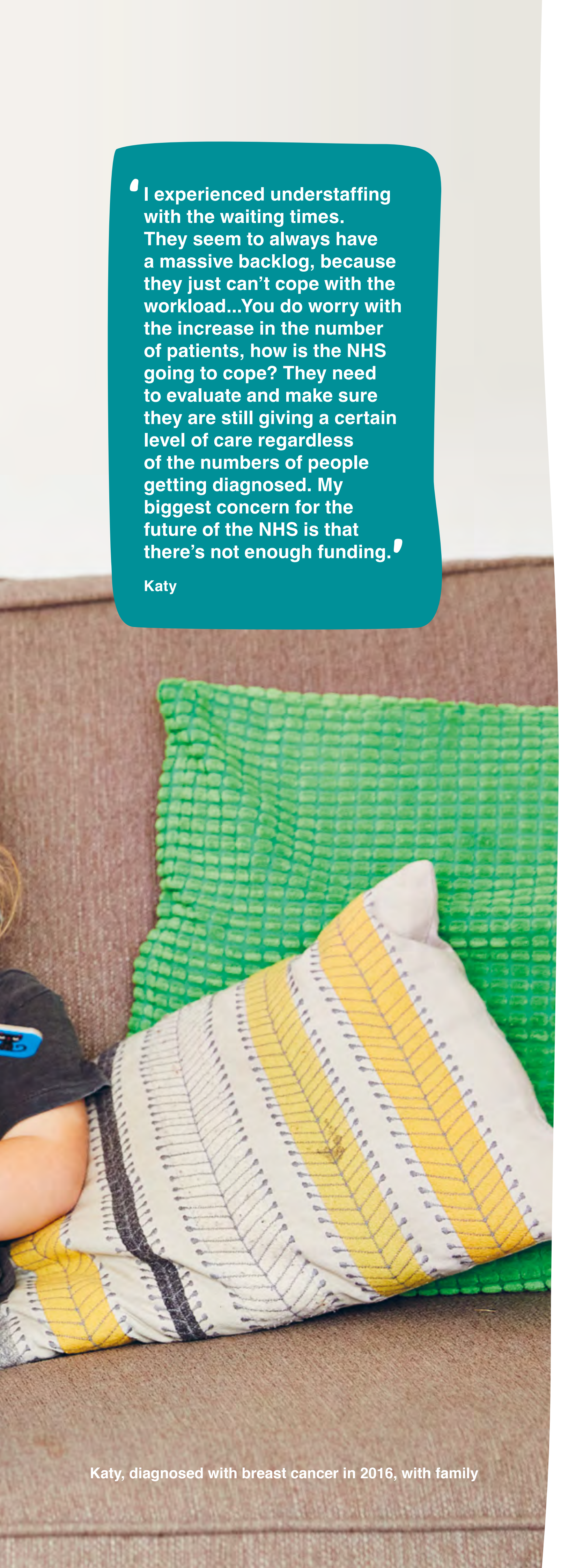
At one point, I had five different consultants at the hospital, where everyone was dealing with their situation but no-one was talking to each other. Once, my GP was on maternity leave I saw different doctors all the time, I sort of fell off the wagon. I had to get used to dealing with updating different professionals I see because there was a lack of coordination. I’ve got my faculties to sort these things out, but if I was a much older person or someone with dementia, I wouldn’t know what was happening. **When my regular GP returned, everything went back on track. You’ve got to think of a wheel and you and your GP are in the centre of it. All the spokes go out to different teams but your meeting point is not with each other, it is passed back to the GP.**

I just live in a permanent state of fear, I’ve never been able to relax and switch off from my diagnosis because it’s always there, in the back of your mind. Once you’ve had a cancer diagnosis, it never leaves you. There’s not a day goes by when you don’t think about it. It’s hard to move on with your life especially if you’ve issues going on.

Linda, diagnosed with bowel cancer in 2015, with family


My First Book of Things to Find
ANIMALS
ILLUSTRATED BY MAXINE DAVENPORT
My First Book of Things to Find
ANIMALS
ILLUSTRATED BY MAXINE DAVENPORT
THE RAINBOW

> ‘I experienced understaffing with the waiting times. They seem to always have a massive backlog, because they just can’t cope with the workload...You do worry with the increase in the number of patients, how is the NHS going to cope? They need to evaluate and make sure they are still giving a certain level of care regardless of the numbers of people getting diagnosed. My biggest concern for the future of the NHS is that there’s not enough funding.’
>
> **Katy**



Katy, diagnosed with breast cancer in 2016, with family

The impact of an overstretched NHS workforce and services

Throughout the stories we heard there was consistent praise for the NHS staff who provide treatment and care. Many placed great value and emphasis on their relationships with nursing staff, be that a cancer nurse specialist or a chemotherapy nurse. It was nurses, on the whole, who were singled out for helping to work through what a diagnosis or the next steps of treatment really meant and for taking the time to really listen.

However, nearly everybody reported that in at least some care settings both staff and services were overstretched. These impacts ranged from having to wait a long time for an appointment to feeling like better care may have been given if the staff had more time.

Sometimes very specific examples were given – for example not having a PICC line put in before a first session of chemotherapy, perhaps because there weren’t enough skilled staff at the right time to do so. But more generally, most people reported that interactions with NHS staff outside oncology services meant less personalised care from staff who appeared to have less time.

The NCPES results again underline why integration of care is so important and how various members of staff working together can impact on patient experience. Previous analysis of around 70,000 responses from the 2015 England Cancer Patient Experience Survey found that **patients who gave a below-average score for GPs, hospital doctors and nurses all working well together were, typically, almost three times less likely to be satisfied with their overall care**[xlvi].

Clint, 54,

diagnosed with oesophageal cancer in 2017

Clint is 54 and a self-employed photographer. In 2017, he was diagnosed with oesophageal cancer.

In June 2017, I was referred for an endoscopy test. The endoscopist and a senior nurse said, “I’m sorry to tell you, I’ve found a tumour in your oesophagus”. He explained that he’s had to put on the form that it was possibly cancer because I needed an urgent CT scan. The nurse said, “It’s amazing what we can do with modern drugs”. I thought, why are you telling me this, if it might not be cancer? My world caved in. It was a shock, that was the worst day, I just had to think, “Pull yourself together, you live on your own, you haven’t got a wife or any dependents, you’ve got to get through this on your own”.

After my consultant confirmed the diagnosis, I was just staring into the abyss thinking, “I’ve got cancer”. I got home, burst into tears and rung the head gastrointestinal nurse who was there. She explained they’re pretty confident that the cancer hadn’t spread and she went through the next steps and what I should expect, which I missed at the appointment earlier.

The two weeks waiting for those tests were difficult but three weeks after I was told my cancer was curable and all thoughts of negativity went out the window. I was given my treatment plan, chemotherapy, surgery and more chemo. The nurse gave me little booklets of information which I didn’t want to read but when I did, everything made sense. If they told me all the information when I was diagnosed, I would not have taken it all in. My head would have exploded with it all. They give you snippets when it’s relevant so you can get your head round it.

At chemotherapy, it was a production line, once a chair is empty, someone else comes, sits in it and starts. They gave me a card, which had what chemotherapy I was administered and I had access to a 24-hour triage line which I could call anytime.

The chemo nurses are wonderful and really clued up on cancer. I think they know more than the doctors, and I was very well informed.

On one occasion, my arm had been bleeding and was swollen after my PICC line was fitted and a nurse from the 24-hour triage told me to go to A&E. I was kept over the weekend with antibiotics and blood thinners, but it wasn't until Monday morning that the doctor had explained why I'd been kept in and what had been the problem.

On that Saturday morning, I saw the nurses were short staffed and rushed off their feet. The nurses were brilliant, two stayed behind after their shift to clean and change my PICC line. **The problem was there were too many patients and not enough nurses.** The oncology nurses have more time because they haven't got a ward full of patients. But at A&E, because of the nature of the beast, it's whichever nurse is free at the time.

Before my surgery, I saw my new consultant, who went through the operation bit by bit. But I had to tell him that I was on blood thinners and ask when my PICC line was to come out. My consultant was confused, the communication between the hospital departments just wasn't there. They need to bang their heads together and start talking to one another because I was doing the running around, even though I was ill.


Clint, diagnosed with oesophageal cancer in 2017

Coordinated care

Most of our stories showed that the NHS is still not delivering seamless care throughout cancer treatment and beyond. Whether this is people feeling like they needed a ‘phonebook’ of contacts to try and access the right support to deal with a pressing problem or people feeling like they know more about their cancer than the doctors they meet. Coordinated care was identified by one in five (20%) respondents to our NHS Temperature Check as being the most important factor in ensuring people living with cancer got the best possible care and support. However, this was also one of the areas of cancer care that was least positively reported on by people living with cancer with 68% of people agreeing that health and care services were well coordinated in their experience[xlvii]. **This means that nearly one in three people did not feel their care was well coordinated.**

It is important to recognise that people living with cancer require a range of services across primary, community and acute care. These all need to be responsive to individual needs, meaning not only do systems for sharing information and providing seamless care need to be in place, the entire workforce needs to have core competencies in order to deliver quality care for cancer patients.

The NCPES results confirm that there continues to be room for improvement in how well professionals (such as GPs, hospital doctors, hospital nurses, specialist nurses, and community nurses) work together to give the best possible care, with only 62% of respondents agreeing that professionals always worked well together[xlviii]. Recent research funded by Macmillan Cancer Support shows that patients who rate administration of care poorly were typically around twice as likely not to be satisfied with their overall experience of cancer care[xlix].

A care plan is meant to clearly set out each person’s needs and a plan to meet them and is one way to support coordinated care delivery. However, according to the findings of the NCPES, only around a third (35%) of people currently receive a care plan[l].

In addition, many of the people who shared their stories with Macmillan would have benefited from help in navigating the many NHS services they came into contact with. This could be a single point of contact who understands the system as well as each individual’s care needs; and can help people to access the right services in a timely manner, as well as help with issues ranging from booking appointments to signposting to further information.

20%

of patients identified **coordinated care** as the most important factor in ensuring people living with cancer got the **best possible care and support.**

Maymay, carer for her mother who was diagnosed with ovarian cancer in 2017, with family

> ‘Once we phoned the 24-hour triage line at 3am. They gave us advice and support, and were honest about not having a bed available. They advised that if we couldn’t wait to be seen, to go to A&E. As a cancer patient, you want to go to the cancer specialist, but if there was no bed, you’d have to find another way to get into the system.’

Maymay

Maymay, 37,

carer for her mother who was diagnosed with ovarian cancer in 2017

Maymay was a carer for her mother who was diagnosed with ovarian cancer in 2017.

My mum was diagnosed with stage 4 ovarian cancer in March 2017. I am her youngest of four daughters. She was diagnosed at 71 but her treatment made her immobile and lack confidence in her ability. I decided to work part-time and be her carer from May 2017, until she passed away in March 2018. I was also her primary carer as her first language is Cantonese, so I helped with translation.

Our GP is very clear about our family history and previous medical conditions, so he was quick to refer my mum to our local A&E. But it seemed to take 6-8 weeks for a proper diagnosis. A nurse and oncologist mentioned the possibility of cancer at different times but it still wasn't 100% confirmed. The waiting was very difficult, you just want to have either a 100% yes or no and a very clear treatment plan.

My mum's surgery was within two weeks of her diagnosis. There was a lot of preparation leading up to and after it. It felt like a team, her surgeon dealing with the medication, my sisters and I supporting as a carer, then her helping herself to exercise and start eating, it felt like a real recovery. With chemotherapy, you get a lot of information beforehand, but it never really prepares you. People describe the main side-effects, the hair loss, vomiting and fatigue, but there's lots of others which you aren't prepared for. It's a constant living with not knowing what's going to happen next, which makes cancer more of a lifestyle change.

The 24-hour triage phone line at the hospital really helped. We could talk to an oncology nurse for guidance and reassurance. It was a step between panicking at home by yourself and phoning 999.

The oncology team were dedicated to medical treatment and medical related issues. Sometimes I would ask questions about diet and other lifestyle areas, but it didn't feel like it was in their remit. Because I was her carer, I did a lot of research myself, especially from patient forums.

Maymay, carer for her mother who was diagnosed with ovarian cancer in 2017, with family

The hospital was fantastic, but the admin was slow in booking appointments, we had to chase and follow up. My mum's care felt very disconnected and separate. There were lots of different doctors and phone numbers so sometimes there would be miscommunications. I ended up with a phone book of different people and numbers and it took a while to understand who to contact for different situations and seeing who was available. Normally the GP would signpost us to A&E. It would have been joined up better if the oncology and treatment team were connected with the GP.

We felt we could only contact the oncology team about her treatment but our GP was more for day-to-day needs. But as a patient, you don't differentiate between what is oncology and your day-to-day basic.

Cancer can be a long-term condition, and the treatment is difficult, it takes months or years to treat and you end up having a two-sided relationship with the oncologist. An oncology team are used to managing chronic illnesses, pain and people living with cancer. They understand it's a lifestyle change so there's just more care and openness to a patient-doctor relationship and working together.

There was an evident difference with the staff from A&E. They have very different mannerisms in how they treat somebody with cancer. **From our experience, it was less of a team and more of diagnose, fix them up and get them out. At one point my mum wanted to be moved to the oncology hospital, because she felt the difference in how the staff were treating and caring for her.** During the last couple of days her health deteriorated very quickly. I kicked up a fuss and because of it she was transferred to an ICU ward immediately so that they could dedicate more attention and resources onto her. **It felt like they feared handling a cancer patient because of the complicated medical history. In a way, both you and the A&E doctors wanted you to be referred to the oncology hospital.**

We always had a cancer nurse specialist, who was very helpful but we always felt we wanted to speak to the oncologist. They were very busy and difficult to get hold of. A lot of times, we would see the registrar, but they also had less information. In some ways, the patient knew more about themselves than the registrar and that felt quite disconcerting, when you want somebody who you trust to tell you an answer.

My mum had a conversation around what her needs might be in the hospice through a support worker and a physiotherapist. The physiotherapist provided us with equipment, like a bath lift for when my mum was recovering from surgery, and equipment to build her confidence in going outside and exercising. We were also given a social worker but it took several months to come back with something.

The emotional needs weren't addressed even though her treatment was a rollercoaster of emotions. Even when my mum didn't have evidence of disease, she felt scared to enjoy life again because of the fear it could be snatched away at any moment.

I didn't really have any support as a carer, it was just a role I took on that's a whole different lifestyle and requires a lot of different skills and expertise. I felt like I had to have some basic medical or first aid knowledge. One time, we were surprised that it was expected of us to give my mum's injections at home. The nurses put a DVD player in front of us to watch and learn how to administer injections. I wasn't prepared for that, I can't give people injections and it's that kind of expertise or after-care that wasn't available. She always looked to me for support like that and I struggled with that.

Care outside oncology services

Our stories demonstrate clearly that when people undergoing treatment for cancer come into contact with other parts of the NHS which are not dedicated cancer services, notably general practice and urgent and acute services, often those services ‘feel a bit different’. Emergency services deal with life threatening and urgent care situations and will inevitably respond in very different ways to planned and elective care. However, it is clear that staff were under pressure from the high volume of patients and had less time to spend with patients and personalise care; and also, that sometimes they were less skilled in how they communicate with and meet the needs of people living with cancer.

Our NHS Temperature Check survey asked if people had experienced a problem with the NHS in the last three months. Around a quarter (24%) had[li]. The most common problem identified was 17% of total respondents had experienced more than a week’s wait to get an appointment with a GP. In fact, of those that tried to book an appointment in the last 3 months, 30% reported waiting more than a week[lii].

The 2017 NCPES also shows that care outside hospitals is an area where care could and should be better. For example, only 60% of people reported feeling that their GPs and general practice nurses definitely did everything they could to support them whilst they were having cancer treatment (a reduction of 1% from last year)[liii]. GPs are stretched, but for patients seeking support from their local GPs, this means they may not be getting the care they need.

The experience and views of health professionals working in primary care also reflect these pressures. When we asked this group if they were confident that the workforce is able to provide adequate care for cancer patients given current pressures on the NHS workforce, over half (56%) were not[liv].

Furthermore, not only do we know that general practice is under acute strain, impacting on patients’ ability to consistently access services in a timely manner, we also know some members of the primary care workforce do not feel equipped to provide all the necessary information for people living with cancer at various stages of their care pathway. For example, 24% did not feel adequately equipped to provide the information needed for people currently undergoing cancer treatment and 26% of primary care professionals felt this way with regards to providing information for people with advanced cancer. These figures rise to around a third of primary care professionals surveyed on people who have been diagnosed with cancer but not started treatment (33%) and those who have finished treatment and are recovering (35%). This presents a significant gap in information and support for people across their cancer journeys[lv].

There is an inevitable question around how in-depth any support provided to a cancer patient in a setting like A&E can be, but where patients learn they have a cancer diagnosis or need treatment in A&E, it can impact on their experience of care.

> **‘There was an evident difference with the staff from A&E... it was less of a team and more of diagnose, fix them up and get them out. At one point my mum wanted to be moved to the oncology hospital, because she felt the difference in how the staff were treating and caring for her.’**
>
> **Maymay**

Maymay, carer for her mother who was diagnosed with ovarian cancer in 2017

Life beyond treatment

Our stories show that the impact of cancer can live on long beyond diagnosis and an initial treatment plan, with people finding themselves coping with ongoing physical and emotional consequences for months and years after and in some cases, for the rest of their lives.

Our recent survey of primary care professionals found that a substantial minority (39%)[lvi] of this group of health professionals do not believe that cancer patients have the support they need to regain quality of life after treatment.

In 2017 Macmillan published *Am I meant to be ok now?* shining a light on peoples' experiences of life after cancer treatment[lvii]. We found that one in three people we spoke to reported struggling up to two years after the end of treatment with physical side effects such as breathlessness or difficulty eating; and two in five reported living with moderate or extreme pain or discomfort. Previous estimates have suggested chronic fatigue alone affects 350,000 people who have finished cancer treatment in England[lviii]. Overall, what we found for many people we spoke to was that there was a sense of being unprepared – and unsupported – for what happens next.

> **'The NHS needs to invest [and] adapt to meet the aftercare needs of cancer as more people end up living a lot longer with cancer. Not just physical needs but also for going back to work and the emotional aspects, like living with the diagnosis after you don't have it anymore.'**
>
> **Maymay**

Mohammad, 56,

diagnosed with prostate cancer in 2014

Mohammad is a retired heavy goods vehicle driver. In 2014, he was diagnosed with prostate cancer.

In 2014, my thigh had swollen up and my wife was telling me to go and get it checked at the GP. I was sent for a PSA[5] check for my prostate which was very high so I was referred to the oncologist. Two weeks later I was called back. In the room there were four or five people, the oncologist, the head nurse and some students. He just came out bluntly and said, “There’s no easy way of telling you, you’ve got prostate… you’ve got cancer”. “Okay, what does that mean? Can you operate, can you take it away?”. He said, “No, it’s gone too far ahead for us to operate but it’s nothing to worry about, we can treat you and control it, you’re not going to die from it”.

I didn’t think anything of it really until three or four months later. Then it hit me that I had cancer, it wasn’t right. I was in denial and didn’t want to accept it. I had talked to my wife and kids and they were all very supportive but I just needed someone to talk to that didn’t know me, wouldn’t judge me for what I am or who I am, just someone neutral.

At my diagnosis, they gave me leaflets and things which I picked up from the hospital. They’ve got a Macmillan office there with all the leaflets and booklets if you want the information. But do you really want to read about the illness that you have? I didn’t really want to. I think it took me about two years before I actually read into exactly what prostate cancer is.

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[5] Prostate Specific antigen (PSA) is a protein produced by normal cells in the prostate and also by prostate cancer cells.

My cancer specialist nurse stands out to me and is who I see most often. She works in the oncology department and she deals with all the cancer patients, so she knows what to look for. She gets feedback from me every month, I tell her if I've got a problem and if it's something she can't handle, she'll book an appointment to see the specialist, who'll send me for a bone scan, CT scan, X-ray or anything else. Then the results are fast tracked to her, sometimes in a day, and she'll check if everything is okay or tell me there's no need to worry about it. It's nice not having to wait, you're seen instantly and any concerns that you have, you can just talk to the person. For example, I went to see my nurse two months ago and I said, "This pain is expanding into my shoulders, my jaws have started hurting, my teeth have started hurting, I'm concerned". She went to the professors and the registrars and they sent me for a brain scan and X-ray straight away, and they just said, "No, you're just getting old, your teeth are moving about, it's nothing to do with the treatment that you're having".

My doctor doesn't really have time, he doesn't say much actually, just says, "Three months have gone by really quick". He gives my injection, puts a tape on it and off we go, "See you in three months". He never asks, "How are you getting on? Is there anything I can do for you?" I would like him to take a little bit more initiative towards asking me, "How are you feeling?"

At the hospital we have our own parking facility where we can just drive in, park up, go inside, have our blood test and see the doctors and nurses, it's such a great experience.

The words that keep ringing in my ears from my oncologist surgeon was that, "You're going to live with it". I began to understand those words, what they exactly mean, you're living with it… No-one provided me with any support or advice, they just said, "You're living with cancer, just carry on the normal life like you are". I thought, "Really? How can you just blank this out?"

Mohammad, diagnosed with prostate cancer in 2014, with family

Facing the future

In our Temperature Check public survey, we asked a number of questions to better understand how people feel about cancer services and the NHS generally. The results showed some anxieties and lack of confidence in what the future may hold. People were aware that the NHS is currently facing challenging times but only a third (32%)[lix] felt that the government is doing a good job in dealing with pressures on the NHS. Only half (50%) felt that the cancer care delivered by the NHS in 2018 is world-class[lx] – and confidence dips even lower (43%)[lxi] when we asked if people were confident that cancer care would be world-class in five years' time. People know that cancer will become more common in the future and yet 60% are not confident[lxii] that the government is making adequate preparations for the number of people who will be living with cancer in the future. The NHS long-term plan needs to be ambitious on cancer care so it can radically reset people's expectations for how they will be supported if they or a loved one is diagnosed with cancer.

However, in the face of these difficulties, most people (78%)[lxiii] feel that NHS staff are doing a good job supporting patients at this difficult time. This very much echoes the stories shared in this report.

Only

32%

of patients felt that the government is doing a good job dealing with pressures on the NHS.

> ‘I certainly was given priority as a cancer patient, whether that would be the situation now and what the situation is going to be in the future, I don’t know because more people are being diagnosed with cancer.’
>
> **Linda**

Linda, diagnosed with bowel cancer in 2015, with family

What should the NHS focus on in the future long-term plan?

Macmillan has developed seven principles which we believe should form the basis of the NHS's new long-term plan. For cancer care, we believe the plan must:

1. Strategically address the challenges facing the cancer workforce to deliver high-quality patient care for all.

2. Ensure the NHS can both meet existing commitments as well as transform cancer services for the future.

3. Take a long-term view to enable effective planning for changing demographics and deliver sustainable allocation of resources to meet future demands.

4. Look at how both health and social care can be sustainably funded to ensure one integrated health and care system.

5. Deliver personalised care to improve quality of life for people at diagnosis, but also those receiving treatment and beyond.

6. Harness technological advances and medical and scientific innovation to benefit people living with cancer in the shifting landscape of healthcare delivery.

7. Tackle health inequalities by reducing variation, ensuring equity in cancer care delivery and improving the cancer patient experience.

Macmillan supports early promises from the government that improving survival rates to match the best performing health systems in Europe will be central to future ambitions for cancer care. But we know too that the needs of people living with cancer, often for many years, are varied and complex and that too often more could be done to help people to live life as fully as they possibly can after a cancer diagnosis. The stories in this report, supported by the many others we have heard from people who have experienced a cancer diagnosis in recent years, give voice to the following areas as priorities for the government and the NHS if they are to deliver world-class, compassionate cancer services in the next ten years:

The NHS long-term plan must be realistic about the level of future care needs. The health and care system will have to address both increased absolute need (by 2030 we anticipate 3.4 million people will be living with a cancer diagnosis in England) but also increasingly complex care needs as people continue to live longer with complex, multiple comorbidities (the number of people alive five or more years from initial diagnosis is predicted to more than double to 2.2 million between 2010 and 2030). By 2040, older people will account for more than three quarters of people living with a diagnosis[lxiv].

There should be a focus on non-clinical outcomes such as quality of life and patient experience as well as absolute health outcomes, recognising that many people may live years beyond initial diagnosis, sometimes with cancer that requires ongoing treatment and sometimes with long-term physical and emotional consequences of cancer treatment.

Effective integration and coordination of services across and between health and social care settings is needed to ensure that treatment, care and support following a cancer diagnosis is seamless and person-centred. This requires systems and organisations to work well with each other at system level; and for all professionals to have core skills and competencies to deliver the right care and support. For example, communication between and within care settings, such as treatment summaries and electronic care records, should be improved.

Everyone should be given all the information they need about their cancer journey. This should be embedded within the system and commissioned to be available for all from the point of diagnosis and throughout treatment and beyond. This should take the form of a holistic needs assessment, addressing the range of physical, emotional and practical needs of the whole person. Following a needs assessment, everyone should have a personalised care plan and a subsequent plan of action to address identified needs within and outside direct NHS services. Needs assessments should be revisited and care plans adjusted as required as people progress through and beyond treatment.

People living with cancer need **help to navigate the system**, so that they can access all the information and support available and be signposted and referred to other support services if appropriate, including support for unmet emotional and psychological needs.

There needs to be an **increase in cancer nurse specialists** to meet current and increasing future demand and complexity of need. This should include investment in educating and training new specialist nurses as well as urgent initiatives to encourage retention and return to practice of the existing workforce. There should also be an urgent focus on **supporting the development of the existing workforce, across all grades, to be more flexible and responsive** to meet the needs of people living with cancer. There should be investment in support worker or link worker roles to ensure people living with cancer are supported to access all the relevant care and support.

There needs to be more targeted action on health inequalities. Consistent access to diagnosis, treatment, care and support should be accessible to everyone regardless of their background or where they live.

Conclusion

This report demonstrates that the NHS has much to be proud of and to celebrate. In the coming months, as the NHS in England develops ambitions for the next ten years, we hope the stories we have shared will help provide a catalyst to continue to develop world-class care for people living with cancer now and in the future.

References

i. 299,920 a year in England. 2001 - 2015 incidence figures from Office for National Statistics

ii. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated overall 2.5 million in 2015

iii. Macmillan Temperature Check. An online survey of 2828 adults aged 18 and over. Fieldwork conducted between 16th to 23rd July 2018. The figures have been weighted and are representative of the UK population for age, gender and region.

iv. Macmillan-nfpSynergy. Online survey of 254 Primary Healthcare Professionals. Fieldwork conducted 10th May to 2nd June 2018. Sample includes 75 GPs with CCG/CSU role, 78 GP's without CCG/CSU role, 50 community nurses, 51 Practice nurses.

v. Macmillan, Temperature Check. Based on a total sample of 1914 adults living in England. The Government is doing a good job in dealing with the current pressures on the NHS? 32% Either strongly agreed or agreed on a 5 point agree/ disagree scale.

vi. Macmillan, Temperature Check. Based on a total sample of 1914 adults living in England. Question: 'In your opinion is the cancer care delivered by the NHS world class' Yes=50%, No= 23% and Don't know=27%

vii. Macmillan, Temperature Check. Based on a sample of 1914 adults living in England who did not say that they had no experience of cancer. Question: 'Do you think that in 5 years' time that the cancer treatment offered by the NHS will be world class?' Yes=43%, No=23% and Don't know=34%

viii. Macmillan, Temperature Check; Based off a total sample of 2373 Adults based in England Question: The Government is not making the necessary preparations for the greater number of cancer patients there will be in the future - Some people have expressed the following opinions. To what extent do you agree/ disagree with the following statements? 5 point Agree/ disagree scale. 60% is a net of Agree Strongly 23% and Agree 37%

ix. Macmillan, Temperature Check; Based off a total sample of 2373 Adults based in England Question: NHS staff are currently doing a good job in supporting patients while there are pressures on the NHS (To what extent do you agree or disagree with the following) Question asked on a 5 point scale. 78% Net of Strongly agree 33% and Agree 44%.

x. Macmillan, Temperature check, Question asked 'Thinking about your experience with the NHS. Which of the following have you ever personally experienced?' Any problem included anyone who selected 'Had an appoint-ment cancelled or rescheduled by a hospital or GP practice' or 'Been denied access to a drug or other treatment' or 'Waited in A&E for more than four hours' or 'Had an operation cancelled or rescheduled by a hospital' or 'Been unable to leave hospital because of a lack of care and support at home', 'Had to wait for more than a week to get an appointment with a GP', Had another bad experience with the NHS (not one of the problems listed above). To qualify they had to select that the last time they experienced that problem was in the past 3 months.

xi. 1,284 respondents had tried to book an appointment in the last three months. Statistic relates to 30% of these respondents.

xii. Macmillan, Temperature Check Result based on 1391 in England. Excluded were those who said don't know or not sure. Question asked was 'From your experience of cancer, how would you rate the NHS on the following areas of cancer care?'. The question was rated on a 0-10 scale. Those who rated it 7-10 are counted as rating it as good.

xiii. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Older people refers to those aged 65 and over. Projections estimated a population of 1,070,000 people living with cancer more than five years after their diagnosis in 2010. This is projected to increase to 2,240,000 by 2030.

xiv. https://www.kingsfund.org.uk/publications/pm-letter-funding-settlement-nhs

xv. https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

xvi. Cancer Waiting Times are published by NHS England and are available from https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/.

xvii. Cancer waiting times: how has NHS performance changed over time? Nuffield Trust (January 2018). Accessed online: http://www.qualitywatch.org.uk/blog/cancer-waiting-times-how-has-nhs-performance-changed-over-time

xviii. Based on trusts seeing 5 or more cancer patients within that month's reporting period.

xix. Macmillan Cancer Support. Cancer Workforce in England: A census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017. Available from https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotheraphy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf [Accessed in August 2018] Note: The 2014 numbers do not include community nurse roles; in 2017 the data includes 17 WTE census specialist cancer nurse roles that may have been excluded from the 2014 census as they provide care in the community.

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xxi. Nursing and Midwifery Council. The NMC Register March 2018.

xxii. Figures from the Royal College of Nursing based on 2017 Freedom of Information data.

xxiii. https://www.telegraph.co.uk/science/2018/07/05/nearly-every-gp-surgery-missing-doctor-warns-royal-college-general/

xxiv. Cancer Research UK. Full Team Ahead: Understanding The UK Non-Surgical Cancer Treatments Workforce December 2017.

xxv. Quality Health. National Cancer Patient Experience Survey 2017. Available from http://www.ncpes.co.uk/reports/2017-reports/national-reports-2

xxvi. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 59 "Overall, how would you rate your care?". Score taken from the 66,563 people that responded to this question.

xxvii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 16 "Were you involved as much as you wanted to be in decisions about your care and treatment?". Score taken from the 66,183 people that responded to this question.

xxviii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 17 "Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?". Score taken from the 65,693 people that responded to this question.

xxix. Macmillan Temperature Check. In response to the question Which of the following is most important to ensure that people living with cancer get the best care and support from the NHS? Options included 'Making sure that everyone has a conversation about their individual needs', 'Making sure that everyone has access to a Specialist Nurse and/or key worker', 'Making sure people who need it can access social care', 'Making sure that people are given the right information at the right time about their diagnosis and treatment options', 'Making sure that all health and care services are coordinated', 'Don't know', 'Other [please state]' Base size: 1914 respondents based in England who did not say that they had no experience of cancer

xxx. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by Index of Multiple Deprivation (IMD) quintile. In response to question 5 "Beforehand, did you have all the information you needed about your test?" patients in quintile 1 provided an average score of 93.1% which was significantly lower than those in quintile 5 with an average score of 94.5%. Scores taken from the 58,017 people that responded to this question.

xxxi. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by IMD quintile. In response to question 50 “During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?” patients in quintile 1 provided an average score of 50.9% which was significantly lower than those in quintile 5 with an average score of 55.6%. Scores taken from the 34,034 people that responded to this question.

xxxii. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by IMD quintile. In response to question 51 “Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?” patients in quintile 1 provided an average score of 42.9% which was significantly lower than those in quintile 5 with an average score of 47.6%. Scores taken from the 20,512 people that responded to this question.

xxxiii. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by IMD quintile. In response to question 53 “Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?” patients in quintile 1 provided an average score of 56.9% which was significantly lower than those in quintile 5 with an average score of 61.3%. Scores taken from the 45,919 people that responded to this question.

xxxiv. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by IMD quintile. In response to question 19 “When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?” patients in quintile 1 provided an average score of 85.4% which was significantly lower than those in quintile 5 with an average score of 89.2%. Scores taken from the 51,130 people that responded to this question.

xxxv. Quality Health. National Cancer Patient Experience Survey 2017. Analysis by IMD quintile. In response to question 28 “Did groups of doctors and nurses talk in front of you as if you weren’t there?” patients in quintile 1 provided an average score of 77.9% which was significantly lower than those in quintile 5 with an average score of 82.5%. Scores taken from the 41,387 people that responded to this question.

xxxvi. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 10 “Did you understand the explanation of what was wrong with you?”. Score taken from the 68,067 people that responded to this question.

xxxvii. Macmillan-nfpSynergy -Primary Healthcare Monitor 2018. In response to the question; ‘In your experience, how are current NHS workforce pressures affecting cancer patients?’ 63% of the 254 Healthcare Professionals selected “cancer patients don’t always know how to get support’. For the different primary healthcare professionals: There are 75 GP- no CCG/CSU role=71%, 78 GP’s- with CCG/CSU role=59%, 50 Community Nurse=66%, 51 Practice nurses=55%.

xxxviii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 14 “Were you offered practical advice and support in dealing with the side effects of your treatment(s)?”. Score taken from the 65,162 people that responded to this question.

xxxix. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 15 “Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?” Score taken from the 61,563 people that responded to this question.

xl. Macmillan-nfpSynergy Primary Healthcare Monitor 2018. In response to the question; ‘In your experience, how are current NHS workforce pressures affecting cancer patients?’ 63% of the 254 Healthcare Professionals selected “cancer patients don’t always know how to get support’. For the different primary healthcare professionals: There are 75 GP- no CCG/CSU role=71%, 78 GP’s- with CCG/CSU role=59%, 50 Community Nurse=66%, 51 Practice nurses=55%.

xli. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 14 “Were you offered practical advice and support in dealing with the side effects of your treatment(s)?”. Score taken from the 65,162 people that responded to this question.

xlii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 15 “Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?” Score taken from the 61,563 people that responded to this question.

xliii. Macmillan-nfpSynergy Primary Healthcare Monitor 2018. 46% is the result for the total sample of 254 Healthcare Professionals. For the different primary healthcare professionals: There are 75 GP- no CCG/CSU role=49%, 78 GP- with CCG/CSU role=44%, 50 Community Nurse=48%, 51 Practice nurses=41%. The question was; ‘In your experience, how are current NHS workforce pressures affecting cancer patients?’

xliv. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 35 “During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?” Score taken from the 29,969 people that responded to this question.

xlv. Macmillan-nfpSynergy Primary Healthcare Monitor. 52% is the result for the total sample of 254 Healthcare Professionals. For the different primary healthcare professionals: 75 GP- no CCG/CSU role=58%, 78 GP- with CCG/CSU role=52%, 50 Community Nurse=54%, 51 Practice nurses=41%. The question was; ‘In your experience, how are current NHS workforce pressures affecting cancer patients?’

xlvi. Gomez-Cano M, Lyratzopoulos G, Abel G. Drivers of overall satisfaction with cancer care in England – analysis of the national Cancer Experience Survey. June 2017. Poster presentation at the 2017 Cancer Data and Outcomes conference. The finding relates to the 2015 survey and question 54 (Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care? Abstract available from https://www.phe-events.org.uk/hpa/frontend/reg/absViewDocumentFE.csp?documentID=13793.

xlvii. Macmillan, Temperature Check. Result based on 1391 in England. Excluded were those who said don’t know or not sure. Question asked was ‘From your experience of cancer, how would you rate the NHS on the following areas of cancer care?’. The question was rated on a 0-10 scale. Those who rated it 7-10 are counted as rating it as good.

xlviii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 56 “Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?” Score taken from the 67,751 people that responded to this question.

xlix. Gomez-Cano M, Lyratzopolous G, Abel G. Drivers of overall satisfaction with cancer care in England – analysis of the national Cancer Patient Experience Survey. June 2018. Poster presentation at the PHE Cancer Services, Data and Outcomes Conference, June 2018 the finding relates to the question ‘Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes / test results, etc.)?’ (Q56).

l. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 55 “Have you been given a care plan?” Score taken from the 52,421 people that responded to this question.

li. Macmillan, Temperature check. Question asked ‘Thinking about your experience with the NHS. Which of the following have you ever personally experienced?’ Any problem included anyone who selected ‘Had an appoint-ment cancelled or rescheduled by a hospital or GP practice’ or ‘Been denied access to a drug or other treatme-nt’ or ‘Waited in A&E for more than four hours’ or ‘Had an operation cancelled or rescheduled by a hospital’ or ‘Been unable to leave hospital because of a lack of care and support at home’, ‘Had to wait for more than a week to get an appointment with a GP’, Had another bad experience with the NHS (not one of the problems listed above). To qualify they had to select that the last time they experienced that problem was in the past 3 months.

lii. 1,284 respondents had tried to book an appointment in the last three months. Statistic relates to 30% of these respondents.

liii. Quality Health. National Cancer Patient Experience Survey 2017. National average score in response to question 53 “Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?” Score taken from the 45,919 people that responded to this question for 2017 was 60.4%. This was significantly lower than the score of 61.6% taken from the same question in the 2016 survey (from 49,113 responses).

liv. Macmillan-nfpSynergy Primary Healthcare Monitor 2018 56% result from the sample of 254 Healthcare Professionals (those responding either ‘Not confident’ or ‘Not at all confident’).. Sample comprised of 75 GP- no CCG/CSU role=55%, 78 GP- with CCG/CSU role=53%, 50 Community Nurse=58%, 51 Practice nurses=61%. ‘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?” Options: Very confident/ Fairly confident/ Not confident/ Not at all confident/ Don’t know.

lv. Macmillan-nfpSynergy- Primary Healthcare Monitor 2018 Total sample of 254 primary healthcare professionals. Comprising of 75 GP- no CCG/CSU role, 78 GP- with CCG/CSU role, 50 Community Nurse, 51 Practice nurses. Question: For each of the following conditions, please indicate the extent to which you feel adequately equipped to provide patients with the information they need. Options: Very well equipped/ Quite well equipped/ Not very well equipped/ Not at all equipped. Not equipped is a combination of Not at all well equipped & Not very well equipped.

lvi. Macmillan-nfpSynergy- Primary Healthcare Monitor 2018. In response to the question; ‘In your experience, how are current NHS workforce pressures affecting cancer patients?’ From a list of options 39% selected ‘Cancer patients do not have the support they need to regain quality of life after treatment’. For the different primary healthcare professionals: There are 75 GP- no CCG/CSU role=45%, 78 GP’s- with CCG/CSU role=45%, 50 Community Nurse=36%, 51 Practice nurses=25%.

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lix. Macmillan, Temperature Check. Based on a total sample of 1914 adults living in England. The Government is doing a good job in dealing with the current pressures on the NHS? 32% Either strongly agreed or agreed on a 5 point agree/ disagree scale

lx. Macmillan, Temperature Check. Based on a total sample of 1914 adults living in England. Question: ‘In your opinion is the cancer care delivered by the NHS world class’ Yes=50%, No= 23% and Don’t know=27%

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lxii. Macmillan, Temperature Check. Based off a total sample of 2373 Adults based in England Question: The Government is not making the necessary preparations for the greater number of cancer patients there will be in the future - Some people have expressed the following opinions. To what extent do you agree/ disagree with the following statements? 5 point Agree/ disagree scale. 60% is a net of Agree Strongly 23% and Agree 37%

lxiii. Macmillan, Temperature Check. Based off a total sample of 2373 Adults based in England Question: NHS staff are currently doing a good job in supporting patients while there are pressures on the NHS (To what extent do you agree or disagree with the following) Question asked on a 5 point scale. 78% Net of Strongly agree 33% and Agree 44%

lxiv. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Older people refers to those aged 65 and over. Projections estimated a population of 1,070,000 people living with cancer more than five years after their diagnosis in 2010. This is projected to increase to 2,240,000 by 2030.

Being told ‘you have cancer’ can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you’re still you. We get that. And, after over 100 years of helping people through cancer, we get what’s most important: that you’re treated as a person, not just a patient.

It’s why we’ll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We’re here to help you find your best way through from the moment of diagnosis, so you’re able to live life as fully as you can. **For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk**

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