

# PRIORITIES FOR THE NHS LONG-TERM PLAN

The number of people getting cancer in the UK is increasing: around one in every two people born after 1960 can now expect to be diagnosed with the disease at some point in their lifetime.<sup>1</sup> Improvements in diagnosing and treating cancer however, mean that more people are surviving, or living for longer with it, and there are now 2.5 million people across the UK living with or beyond cancer. Cancer prevalence specifically in England will increase from 1.6m in 2015 to 3.1m in 2030.<sup>2</sup> Particularly large increases are anticipated in the oldest age groups and in the number of long-term survivors.

Yet not all these people are living well. 70% of people with cancer are living with one or more serious health condition other than their cancer, often as a result of cancer and its treatment. This includes high blood pressure, chronic heart disease or mental health problems. Almost 30% of people with cancer have 3 or more long term conditions as well as cancer, which amounts to 600,000 people in England.<sup>3</sup>

Many experience physical, emotional and financial consequences of cancer and its treatment and this can remain the case for many years after treatment has ended.<sup>4</sup> Until recently, this wasn't well understood, but with the data available to the NHS it is now possible to understand cancer journeys in an unprecedented level of detail. Understanding the ongoing health and support needs of people living with cancer can help the NHS to provide care that is personal to the individual and risk stratify patients to ensure tailored help is provided where it is needed most. This makes sense for people living with cancer but it makes economic sense too.

**The NHS Long-Term Plan is a vital opportunity to ensure that as the population living with cancer in England grows, the diverse health and care needs of people are met and that the workforce that treats and cares for them is set up to meet this challenge. Other enablers need to be in place too, including wider access to treatments and technology.**

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This briefing outlines what Macmillan believes must be the three key priorities for the cancer part of the NHS Long-Term Plan:

- (1) **Personalized care for all** together with **improvements in patient experience**;
- (2) **Systematic action to tackle inequalities**; and
- (3) **A growing, skilled and agile workforce** that has the resource to deliver increasingly complex treatment and care.

We also briefly address two other priorities: (4) **continued improvements in diagnosis and treatment**; and (5) **widening access to digital and technology**. Further evidence and case examples of interventions are available as separate materials, should NHS England or other stakeholders wish to see them.

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<sup>1</sup> Macmillan estimate based on; Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 107: 1195-1202. (Scenario 1 presented here). Forman D, et al. Cancer prevalence in the UK: results from the EUROPREVAL Study. *Annals of Oncology*. 2003. 14: 648–654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency

<sup>2</sup> Estimates of prevalence are based on the method developed by Maddams J, Utley M and Møller H. 2012. *Projections of cancer prevalence in the United Kingdom, 2010–2040. British Journal of Cancer*. 2012; 107: 1195-1202. More up to date data has been used, and a slightly updated methodology, resulting in prevalence figures of around 1.6m in 2015 and 3.1m in 2030, for England only

<sup>3</sup> Macmillan Cancer Support. The burden of cancer and other long-term conditions. April 2015

[www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf](http://www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf). Research commissioned by Macmillan Cancer Support from Monitor Deloitte.

<sup>4</sup> Macmillan Cancer Support (2013) *Cured – but at what cost? Long-term consequences of cancer and its treatment*.

## Key Recommendations

In this paper, we call for a significant step-change in the personalized care available to people living with cancer. Furthermore, we call for care coordination to support individuals as treatment options and patient pathways become more complex. We also call for dramatic action to grow, sustain and skill the workforce needed to provide people with world-class treatment and care. Many of these recommendations will be relevant across the whole NHS long-term plan and not just the sections that specifically relate to cancer.

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| <b>(1) Personalized care for all</b>                       | <b>Trusts need to be given sustainable resources to embed personalised care and support interventions. This needs to start with Holistic Needs Assessments (HNAs), which from point of diagnosis should be available to all patients living with cancer.</b> HNAs should be electronic and shareable across systems.   |
|  | <b>Cancer services should be equipped to ensure every person living with cancer can benefit from</b> <ul style="list-style-type: none"> <li>○ <b>A conversation</b> and a <b>holistic needs assessment</b> that identifies cancer-related clinical – and – non-clinical needs</li> <li>○ <b>A treatment summary</b> and a personalised <b>care plan</b>, which then remain under review</li> <li>○ And support with <b>navigating</b> the health and care system if needed.</li> </ul> |
| <b>Improvements in patient experience</b>                  | <b>Everyone who is diagnosed with cancer should have</b> <ul style="list-style-type: none"> <li>○ <b>Their diagnosis written down in language that is easy to understand;</b></li> <li>○ <b>Adequate information on possible side effects of treatment;</b></li> <li>○ <b>Access to a named Clinical Nurse Specialist (CNS)</b> that they can reach throughout their treatment.</li> </ul>   |
| <b>Health and work</b>                                     | <b>Health care professionals should be encouraged to raise and discuss work with working-age patients</b> as this is an important first step in the process to provide better work-focused health support.   |
| <b>Stratified pathways</b>                                 | <b>There should be renewed action on the implementation of stratified pathways for breast, prostate and colorectal cancer patients</b> with a view to utilising learning to inform further rollout across other cancer types.  |
| <b>Advance care planning</b>                               | <b>Everyone approaching end of life should be offered the opportunity to have a personalised Advanced Care Planning Conversation.</b> Personalised care must work for people with all cancers and at every step on the patient pathway.  |
| <b>End of life care</b>                                    | <b>There is an urgent need for local plans to be developed and implemented, to ensure everybody - no matter where they live - receives good end of life care.</b> There should be continued efforts to roll out EPaCCS systems to digitise shared palliative and end of life care records.   |
| <b>Patient outcomes measures</b>                           | <b>Patient reported outcomes and experience should be prioritised as key indicators to benchmark health and care systems against,</b> alongside clinical outcomes.   |
| <b>(2) Systematic action to tackle health inequalities</b> | <b>Clear improvement measures to tackle health inequalities should be core to any plan on cancer,</b> identified so inequalities can be addressed across the whole patient pathway.  |

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|  | <b>Further consideration should be given to how deprivation and inequalities will be factored into funding formulas for healthcare provision</b> , and where appropriate, how these formulas can be more sensitively weighted to population need.  |
| <b>(3) A growing, skilled, agile workforce</b> | <b>There needs to be a costed plan to grow and sustain the health and care workforce based on projected demand and the gaps in supply that need to be filled</b> , not simply what is affordable today. Existing 2015-20 commitments, so for example that all people living with cancer should have access to a Clinical Nurse Specialist (CNS) or Support Worker, still need to be fulfilled.   |
| <b>Adult nursing</b>                           | <b>Specifically, there needs to be significant growth in general adult nursing to meet future demand.</b> HEE will need to work with NHS England to set out national policy initiatives that increase supply but also set out specific support that will be given to local providers and planners to implement change.   |
| <b>Student uptake</b>                          | <b>The long-term plan should consider next steps now nursing and allied health student bursaries have been removed.</b> There should be steps to encourage more undergraduate - and especially postgraduate - student uptake.  |
| <b>Training</b>                                | <b>It is essential there is a more effective mechanism for rolling out training around scientific, technological and medical developments</b> to ensure professionals can confidently administer, and talk to patients about, newer forms of personalised treatment and care.  |
| <b>Continuing Professional Development</b>     | Alongside initiatives to increase staff numbers, <b>there is an urgent need to improve the skills of the existing workforce through training opportunities and continuing professional development (CPD).</b>  |
| <b>(4) Other key recommendations</b>           | <ul style="list-style-type: none"> <li>○ <b>Continued improvements in diagnosis and treatment</b></li> </ul> <p><b>Macmillan believes rapid diagnostic and assessment pathways should be optimised across England.</b> Existing models of good practice need to be drawn on, <b>including GPs being able to directly access key investigative tests.</b></p> <p><b>While the 62-day waiting time-standard is a useful barometer of service capacity, particularly in relation to diagnostics, Macmillan does not believe it represents the most effective means of performance managing providers.</b></p> |
|  | <ul style="list-style-type: none"> <li>○ <b>Emotional and psychological support</b></li> </ul> <p><b>Health professionals who treat and care for people living with cancer should have training for levels one and two emotional support</b> as defined by NICE Guidelines.</p> <p>In common with people living with other long-term conditions, <b>people living with cancer should have clear pathways available to them to receive levels three and four emotional and psychological support if needed.</b></p>   |
|  | <ul style="list-style-type: none"> <li>○ <b>Quality of Life</b></li> </ul> <p>NHS England's commitment to developing a <b>world-leading Quality of Life Metric for people recovering from cancer</b> needs to be carried through to the long-term plan.</p>  |



# 1. Personalising care for all and improving patient experience

Progress in diagnosing and treating cancer means that a person diagnosed with cancer is now twice as likely to survive for at least 10 years than they were 40 years ago.<sup>5</sup> But sadly, many who survive cancer can then struggle with physical and mental health issues that affect their ability to live the life they want.

Current evidence and future trends indicate that cancer will become increasingly complex, with new treatments offering different treatment pathways, more people living with cancer and one or more long-term condition, and more people living with cancer that is treatable but not curable.

As personalised medicines and targeted treatment become more prevalent, there will be greater variation in cancer pathways. People living with cancer will have increasingly diverse needs. Some will have minimal needs for support, but a significant proportion will need health care services that can meet long-term consequences of cancer and its treatment. To respond, **the NHS Long-Term Plan needs to ensure individuals' unique needs can be identified and where care needs to be coordinated, it can be effectively joined-up.** The risk of fragmented care will need to be confronted head-on. A 'one size fits all' approach to supporting people won't work.

Access to personalised and integrated care is then vital – as is a positive patient experience.

## 1.1 The importance of personalised care

NHS England believes personalised follow up and support to help people live well with and beyond cancer is “one of the cornerstones to creating world class cancer services”.<sup>6</sup> It is key that progress made to date, stemming from the Cancer Strategy for England, continues. This includes Cancer Alliances' work to deliver stratified follow-up pathways, and interventions including Holistic Needs Assessments and Care Plans, to personalise care for patients across England by 2020/21. Such interventions not only deliver better care for patients, but enable early identification and diagnosis of side effects or consequences of treatment. Critically, personalised care and support needs to be available whatever stage of the patient pathway they are on.

We can make informed predictions based on current trends, but ultimately, we do not know what people's experience of living with cancer will look like in 10 years' time, in terms of new treatments and new technology. There are types of cancer, such as those that are incurable, that health and care systems are only beginning to adapt to. There will be more people with multi-morbidities. To build the foundations of a health system that by the end of the next decade is flexible enough to meet over 3 million people in England's cancer-related needs, Macmillan believes that the system should place a person's holistic needs at the heart of treatment and care. These needs should be regularly assessed and individuals should be at the heart of care planning, co-producing care plans with a professional.

## 1.2 Macmillan's approach to personalised care

NHS England is developing a comprehensive model for personalised care. Macmillan summarises our approach to personalised care, as follows:

- **A conversation**
- **A holistic needs assessment** that identifies cancer-related clinical and non-clinical needs
- **A treatment summary** and a personalised **care plan**, which remain under review
- And support with **navigating** the health and care system if needed.

<sup>5</sup> 40 year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: a population-based study. M Quaresma et al. The Lancet 2014; 385: 1206–1218

<sup>6</sup> Living With and Beyond Cancer – Baseline Activity, January – March 2017. NHS England (2018).

Each individual element is important but will only be truly impactful if delivered as a process to ensure that a person's cancer journey remains tailored to their individual needs.

Despite steady progress in some parts of England, elsewhere there is still a paucity of personalised care and support on offer to people living with cancer. This is reflected in the low proportions of people receiving a Holistic Needs Assessment or a care plan. A recent NHS England baselining survey looking at use of different Recovery Package interventions showed that an estimated 31% of patients had a Holistic Needs Assessment.<sup>7</sup>

Reflecting on another core intervention, only 35% of respondents to the Cancer Patient Experience Survey 2017 responded that they had a care plan.<sup>8</sup> A care plan has been defined as “a document that sets out your needs and goals for caring for your cancer [and] and agreement or plan between you and your health professional to help meet those goals”. The NHSE baselining survey suggests from its own analysis of trusts that only 15% of patients had a care plan, with the highest reported rate being 24% for breast cancer patients.<sup>9</sup>

As part of the long-term plan, **Trusts need to be given sustainable resources to embed personalised care and support interventions. This needs to start with Holistic Needs Assessments (HNAs), which should be available to all patients living with cancer.** Macmillan sees HNA's as the bedrock of personalised care so they should become 'business as usual', with faster progress made in ensuring everyone with cancer is given an HNA at diagnosis and at regular enough intervals throughout treatment and beyond to reflect that people's needs do not evolve in a linear fashion.

**HNAs should also be electronic, and shareable across systems.** Evidence suggests that Electronic Holistic Needs Assessments (eHNA) bring a range of benefits. They can be shared more easily across health and social care teams, with half of all care plans produced from eHNAs shared with other professionals (compared to 39% when using paper HNAs). 81% of patients who received an eHNA said they received support at the right time, compared with 69% who didn't recall completing any sort of HNA.<sup>10</sup>

### 1.3 Patient experience between diagnosis and treatment

Macmillan believes that for many people diagnosed with cancer, the point of diagnosis is too confusing.

73% of respondents to the most recent National Cancer Patient Experience Survey (NCPES) said that, when they were told they had cancer, they were given written information about the type of cancer they had, and that it was easy to understand<sup>11</sup>. Of the remainder, 10% said that they were given written information, but that it was difficult to understand; and 17% said that they were not given written information.<sup>12</sup> For the more than one quarter of people to be told they have cancer, who then receive information that is difficult to understand or simply don't have any written information at all, this is a situation that needs remedying. It is also concerning to note that only 56% of respondents to NCPES said that, before they started their treatment, they were 'definitely told' about any side effects of the treatment that could affect them in the future rather than straight away.<sup>13</sup>

**It is vital that everyone who is diagnosed with cancer should have their diagnosis written down in language that is easy to understand and that they are given adequate information on possible side effects of treatment. They should also have access to a named Clinical Nurse Specialist (CNS) that they can reach throughout their treatment.** If all of this occurs, this will reduce the likelihood that patients must recount their diagnosis to different people and it will provide

<sup>7</sup> Living With and Beyond Cancer – Baseline Activity, January – March 2017. NHS England (2018).

<sup>8</sup> National Cancer Patient Experience Survey 2017 National Results Summary.

<sup>9</sup> Living With and Beyond Cancer – Baseline Activity January – March 2017. NHS England (2018).

<sup>10</sup> Ipsos Mori EHNA Evaluation Tool

<sup>11</sup> National Cancer Patient Experience Survey 2017 National Results Summary

<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

patients with informed choices when presented with different treatment options. It can also alleviate some feelings of anxiety. The written diagnosis should be in an electronic form, where possible. Steps should be taken to integrate this with new digital initiatives, such as the new NHS app.

People with cancer should be supported to take as much control as they wish to over decisions about their care and treatment, co-producing the content in their care plan.

This includes making decisions around access to prehabilitation and rehabilitation, which can reduce post-treatment complications. Research has shown that effective prehabilitation measures have reduced median post-operative hospital stays from 14 to 11 days, a decline in post-operative pneumonia from 60% to 29% and a reduction in post-operative complications.<sup>14</sup> **Macmillan believes that prehabilitation is an integral part of the rehabilitation pathway. This means that a suitable workforce needs to be in place to meet individuals' diverse cancer-related needs including dietitians, physiotherapists and psychologists.**

#### 1.4 Emotional and psychological needs

A comprehensive model of personalised care needs to also support early identification of emotional and psychological needs. Even 10 years after a cancer diagnosis, 54% of people have at least one psychological issue.<sup>15</sup> This can include loss of confidence around changed appearance, depression, emotional distress caused by a loss of sexual function and loneliness and social isolation.

From our own recent [unpublished] analysis of 1,600 people with cancer, representative of the 2.5m UK cancer population, we know that nearly half (46%) of people living with cancer report having emotional support needs, with a third (33%) reporting they would like more support.<sup>16</sup> These needs can be recurrent. A large proportion of those living with cancer feel the emotional effects of cancer are most difficult to cope with. Despite this, 58% feel their emotional needs are not looked after as much as their physical needs.<sup>17</sup>

Studies have highlighted population groups that experience higher levels of emotional distress, including women, people with young children, people with co-morbidities and people from lower socio-economic backgrounds.<sup>18</sup> Critically, unmet emotional needs and poor mental health can impact on a person with cancer's physical health outcomes and could cost the NHS more financially. Some studies have shown that mortality rates are up to 39% higher in cancer patients with depression.<sup>19</sup> When people with a long term physical illness, such as cancer, also develop mental health problems, this can increase the cost of care by 45%.<sup>20</sup> There needs to be a concerted approach in the long-term plan, drawing together mental health and cancer services, so better outcomes can take place for patients with both cancer and mental health needs.

Ultimately, however, the goal must be to prevent and minimise ongoing psychological needs after a cancer diagnosis and treatment. **A key recommendation is that health professionals who treat and care for people living with cancer should have training for levels one and two emotional support** as defined by NICE Guidelines. In common with people living with other long-term conditions, **people living with cancer should have clear pathways available to them to receive levels three and four emotional and psychological support if needed.** Recent commissioning guidance by NHS London TCST (Transforming Cancer Services Team) and Macmillan has identified 12 specific recommendations for establishing sustainable pathways for whole-population

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<sup>14</sup> PREPARE programme. Imperial College Healthcare. 2016. Available from <https://www.imperial.nhs.uk/our-services/cancer-services/oesophago-gastric-cancer/prepare-programme>[Accessed June 2017]

<sup>15</sup> Age and Ageing, Volume 47, Issue 3, 1 May 2018, Pages 374–380, available at <https://doi.org/10.1093/ageing/afx201>

<sup>16</sup> Analysis from Macmillan has analysed a nationally representative sample of PLWC and assessed their needs that are most common, and most likely to be unmet

<sup>17</sup> Throwing light on the consequences of cancer and its treatment, 2013

<sup>18</sup> [https://www.macmillan.org.uk/images/Psychological-and-Emotional-Support\\_tcm9-283186.pdf](https://www.macmillan.org.uk/images/Psychological-and-Emotional-Support_tcm9-283186.pdf)

<sup>19</sup> Satin J et al. Depression as a predictor of disease progression and mortality in cancer patients. 2009. Cancer. Canada

<sup>20</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

cancer psychological care<sup>21</sup>, which should be considered as part of a body of evidence to examine components of a psychological support pathway that could be rolled out elsewhere.

### 1.5 Aftercare and stratifying patient pathways

If the NHS is to truly take a personalised approach to the delivery of treatment and care, there needs to be a specific focus on aftercare, adapting to new ways of working which can ensure that ongoing care and support needs are addressed in the most efficient manner.

Over 80% of people facing physical difficulties in the two years after treatment say they have not been fully supported to get their life back on track. Similarly, nine in ten people whose emotional wellbeing has been impacted in the two years after treatment feel they have not had enough support to deal with this.<sup>22</sup>

A common problem experienced by those who have finished their treatment is the lack of a clear route back into the system when and if it is necessary. Historic research showed how a quarter of people with cancer (26%) felt abandoned by the health system when no longer in hospital receiving treatment.<sup>23</sup> Traditional follow up does not account for the increasing complexity of people's needs and expectations. Research has indicated that there is a great demand on the system following the conclusion of cancer patients' treatment. Fifteen-months post diagnosis there is a significant increase in the number of emergency admissions, outpatient appointment, elective admissions and GP visits.<sup>24</sup> Broken down, this represents 60 per cent more accident and emergency (A&E) attendances, 97 per cent more emergency admissions, four times as many outpatient attendances and nearly six times more elective admissions than expected. A similar pattern was seen for GP visits, with cancer survivors having 50 per cent more contact with their GPs than expected 15 months after diagnosis.

The NHS spends more than £500 million a year on emergency inpatient care just for people diagnosed with one of the top four cancers and where they received a diagnosis within the past five years. Of this, more than £130 million is spent on emergency inpatient care for people who will mostly have finished their initial treatment but are not in the last year of life.<sup>25</sup> The sum will obviously be greater for all cancers combined. These are people who should be receiving appropriate long-term support to help prevent the need for emergency care.

However, despite such strong demand, there is a lack of clarity within the health system over which is the most appropriate care setting to handle the concerns and support needs of people post-treatment.

**Macmillan believes there is an urgent role for appropriate follow up pathways which can effectively support patients when they need it the most.** Some of these pathways have already started to get rolled out, but again, progress can be slow. The NHSE baselining survey relating to early 2017 implementation of Recovery Package interventions shows that half of Trusts that responded have criteria or protocols in place to assign breast cancer patients to supported self-managed follow-up, and a third had these protocols in place for colorectal and prostate cancer.<sup>26</sup>

Further, of those Trusts that had adopted Stratified Follow Up pathway criteria or protocols, on average, they were assigning 49% to 67% of patients to self-managed follow up. However, looking at the bigger picture, overall only 26% of breast cancer patients are stratified onto a supported self-management pathway. The proportion for prostate and colorectal cancers was significantly smaller.<sup>27</sup> **The NHS long-term plan must tackle variation and ensure consistent protocols on**

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<sup>21</sup> The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer. Transforming Cancer Services Team for London (May 2018).

<sup>22</sup> Macmillan/YouGov online survey of 2,067 people living with cancer in the UK. Fieldwork conducted 23 June – 6th July 2017

<sup>23</sup> Worried sick: The emotional impact of cancer. Research conducted for Macmillan Cancer Support by Opinion Leader Research (2006).

<sup>24</sup> The Nuffield Trust, The use of health and social care by people with cancer, May 2014

<sup>25</sup> Cancer Cash Crisis. Counting the cost of care beyond treatment. Macmillan Cancer Support (2015).

<sup>26</sup> Living With and Beyond Cancer – Baseline Activity, January – March 2017. NHS England (2018).

<sup>27</sup> Ibid.

**follow-up pathways.** This will lead to greater efficiencies, but it will also support patients to self-monitor and manage their health and wellbeing, where this is appropriate.

Evidence from pilots of stratifying follow up care [or aftercare] for breast cancer patients showed important change to key areas of service delivery. 92% of patients felt their appointments were the right length compared to 85% on a traditional follow up. There was a 20% increase in the number of patients who felt satisfied that their mammogram appointments had happened on time.<sup>28</sup>

Not only does the evidence suggest there is a vast amount of benefit to patients but also stratifying follow up care yields great results for the system. A large review of stratified pathways found that 53% of patients had not contacted their GP in the preceding 6 months with a concern about their cancer or treatment.<sup>29</sup>

In summary, research has shown that stratified follow up care has a role to play in enabling a shift towards care which can enhance patients' overall experience. This is reflected in the fact that there tends to be a reduction in the number of days spent in the cancer pathway and as such patients can be discharged earlier, helping to reduce feelings of anxiety. **We want to see further and renewed action on the implementation of stratified pathways for breast, prostate and colorectal cancer patients with a view to utilising evaluation learnings to inform further rollout across other cancer types.**

Reflecting on the role of primary care, the use of a cancer care review provides a structure of support for people on a stratified follow up pathway who will receive their follow up care within the community while also supporting healthcare professionals in the ongoing management and support of this cohort of patients. The value of cancer care reviews in primary care is well evidenced in a 2010 study of oncologists and primary care physicians (PCPs) in England which found that 60% of primary care physicians felt the cancer care review was useful for the patient.<sup>30</sup>

Macmillan has worked with all major IT providers to ensure templates to support these conversations are embedded within primary care IT systems. We acknowledge there can be a tendency for templates to have a strong biomedical basis but the templates we have developed encompass a holistic approach and have been widely welcomed by the primary care community as a framework for conversations.

Use of the Macmillan cancer care review template has been shown to foster active consultations between patient and primary care physician and has encouraged patients to be more open about discussing their needs and in doing so, play an active role in shaping the delivery of their care. This is reflected in the evaluation where 71 % of patients reported being 'very satisfied' with the process.<sup>31</sup> **We encourage GP practices to review how they carry out cancer care reviews so these can remain meaningful and act both as an aid to primary care professionals and to patients.**

## 1.6 Integrated and coordinated care

More people living with cancer and one or more other serious long-term conditions, combined with the fact the cancer population is an ageing population, means that people living with cancer will be navigating complex health and social care pathways. This will make it more likely that people living with cancer will need to interact with a multitude of services and teams across health and social care. **Macmillan believes that where support to secure other services is identified as a need in a HNA, people living with cancer should have access to a care navigator.**

A navigator can take the form of a link worker, a patient navigator or a support worker. It is important to emphasize a navigator role need not be cancer-specific, as many of these roles could get set up

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<sup>28</sup> Transforming cancer follow up, Northern Ireland, 2015

<sup>29</sup> The Adult Survivorship: Concept to Innovation project was mixed-methods, with 1300 questionnaire responses

<sup>30</sup> Watson EK, et al., *Views of primary care physicians and oncologists on cancer follow-up initiatives in primary care: an online survey*, 2010 <https://link.springer.com/article/10.1007/s11764-010-0117-y>.

<sup>31</sup> Macmillan Cancer Support, *Evaluation of Macmillan's Cancer Care Review Template*, available in PDF.



to support individuals with a range of long-term conditions. People living with cancer who have been assessed to have high levels of self-efficacy and an ability to self-manage might access a navigation function that is an online directory of services so digital options need to be available too.

The rationale for this access to a navigator role is that if people can easily access services that meet their holistic needs, there is a higher chance of adhering to treatment, keeping people out of acute settings where it is avoidable. If a person cannot easily access support, they are more likely to seek help through the easiest route, which is often expensive acute admissions.

Macmillan believes that there is not a single gold-standard approach to navigation. Good practice does exist, namely Macmillan's Improving the Cancer Journey (ICJ) model in Glasgow that has been evaluated to improve levels of concern, with levels of concern decreasing from an average standardised score of 7.15 (out of 10) to 3.85. The evaluation highlighted the navigation system of ICJ, with everything being 'in one place' as particularly appreciated by people during treatment.<sup>32</sup> Other options with regards navigation include social prescribing. In this model, GPs and primary care nurses refer patients to local services that are non-clinical; this could be befriending services or physical activity groups<sup>33</sup>. **Macmillan believes that social prescribing could be embedded more into primary and community care.**

Together with Imperial College Healthcare NHS Trust, Macmillan has been making improvements for people affected by cancer across North West London. One way we're doing this is through Macmillan Navigators. Expected outcomes include patients receiving a timely response to their queries and having a positive, seamless experience of accessing cancer services, support and information. Freeing up Clinical Nurse Specialists (CNS) to focus on appropriate patient support, clinical care and innovation is another key outcome. Evidence of impact so far are improved patient experience scores.<sup>34</sup>

As part of the long-term plan, **NHS England should work to identify where care navigation would be beneficial for people living with cancer, and work with partners to undertake more evaluation of different models.**

Integration can take place at many levels. There's a need for horizontal integration, as it's sometimes referred to, across different parts of the health and care system. The Macmillan/South Western Ambulance Service NHS Foundation Trust (SWASFT) support ambulance and urgent care services' capacity to deliver effective interventions – the right care at the right time in the right place. The project involves training and support for Trust staff attending cancer patients as well as service and system improvements. Fewer inappropriate emergency hospital admissions is one obvious benefit.

The population living with cancer is an ageing population so integration across health and social care will be key. We know that 55% of people living with cancer report fatigue and exhaustion, with just under a third (31%) reporting they would like more support. 33% report needs around completing practical tasks and mobility, with 22% reporting they would like more support.<sup>35</sup> The Social Care Green Paper, said to be forthcoming, will be a timely opportunity to address these needs.

Reflecting on another example of integration, Macmillan believes the health service has a key role to play integrating health care and work-related support. Professionals can help working age patients to understand the potential impact of their cancer and treatment on their working life and signpost or refer to specialist support. To do this, healthcare professionals need to have work-related conversations with patients at key stages of the cancer journey – for example, on diagnosis, during treatment and at end of treatment. They also need to be equipped to fully integrate a return

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<sup>32</sup> Improving The Cancer Journey Glasgow Joined up care and support for people with cancer. A Snowden, J Young, J Mabelis, S McDermott

<sup>33</sup> <https://www.kingsfund.org.uk/publications/social-prescribing>

<sup>34</sup> Better Connections and Navigation: Macmillan Cancer Navigator Service at Imperial College NHS Trust.

<sup>35</sup> Analysis from Macmillan has analysed a nationally representative sample of PLWC and assessed their needs that are most common, and most likely to be unmet

to work into assessment and care planning processes and to conduct high quality and individualised conversations about work, signposting to work support specialists where appropriate. Holistic Needs Assessments, again, have a role to play.

**Encouraging professionals to raise and discuss work with patients is an important first step in the process to provide better work-focused health support.** In addition, more investment is needed to increase the availability and accessibility of specialist support services – including occupational health (OH) and vocational rehabilitation (VR). This is to address the current lack of specialist work support services available to people with cancer and other long-term conditions.

### **1.7 The benefits of integrated care for patient experience**

The 2017 Cancer Patient Experience Survey highlights that cancer patients broadly have a positive experience of cancer care, however there remain some concerning issues, particularly for certain patient groups. For instance, as outlined above just 35% reported being given a care plan,<sup>36</sup> which is important in helping patients understand and feel more in control of their treatment and recovery. To address this, **the NHS Long-Term Plan must reflect that both patient reported outcomes and experience should be prioritised as key indicators to benchmark health and care systems against, alongside of course clinical outcomes.**

One of the most important factors in people's overall experience of cancer care is good administration and team-working among the professionals supporting and treating them. Analysis of more than 71,000 responses from the 2015 England Cancer Patient Experience Survey shows people living with cancer who are not happy with the administration of their care are typically around twice as likely to be unsatisfied overall.<sup>37</sup> The ability of NHS staff, such as GPs, hospital doctors and nurses, to work well together was also important. The study showed patients were twice as likely to say they were not satisfied with their overall care, if their cancer team failed to communicate with each other effectively. Involvement in decision-making and the patients' relatives having the correct information required to care for them at home was also strongly associated with patient satisfaction.<sup>38</sup> This just underlines once again how important it is to integrate care around an individual's needs, and use an electronic Holistic Needs Assessment to identify and define those needs, with actions then summarised and acted on through a personalised care plan. This also underscores why a support worker or navigator role can be so useful in coordinating care.

### **1.8 Quality of Life and patient reported outcomes**

Quality of life (QoL) is important to patients throughout their cancer journey, and methods of better understanding and improving QoL are necessary to drive improvements both in patient experience and outcomes. Patient reported outcomes (PROs) collected as part of clinical trials and in routine care are important for better understanding the effects of new treatments beyond their clinical benefit. This information is vital for ensuring that patients receive personalised care, that is tailored to their individual needs and goals throughout their cancer treatment and beyond. Collecting information about QoL will be increasingly important as we move to use more targeted treatments such as immunotherapy – the long-term consequences of which are yet to be fully understood.

Unfortunately, PRO results are often poorly reported in trial publications or may not be reported at all. Our review of 160 cancer trials found that while most consistently published data around survival or cancer progression, more than one in three (38%) failed to publish the PRO data they had collected. Macmillan Cancer Support, in partnership with the University of Birmingham, are working to support trial researchers to collect and publish high-quality PRO data for the benefit of all cancer patients. We want to see the long-term plan promote the importance of PRO data in helping people affected by cancer, and their care teams, to make more informed decisions about treatment.

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<sup>36</sup> Ibid.

<sup>37</sup> Gomez-Cano M, Lyraztopoulos 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.

<sup>38</sup> Ibid.

More immediately, **NHS England's commitment to developing a world-leading Quality of Life Metric for people recovering from cancer needs to be carried through to the long-term plan.** Whilst progress in implementation has been mixed, these recommendations from England's Cancer Strategy were welcome and **Macmillan strongly recommends continued effort in the roll out of the Quality of Life Metric.**

### 1.9 Personalised and integrated support at end of life

For those approaching the end of life, it is vital that health and care services work together to ensure high quality and personalised care. High quality care as defined in NICE Quality Standard 13 on End of life care for adults is holistic, personalised and coordinated.<sup>39</sup> Yet there are significant variations here which impact on patients and their families, and this must be addressed. For example, whilst 64% of people with cancer would prefer to die at home, less than a third (30%) currently do.<sup>40</sup> **Personalised care must work for people with all cancers, whatever stage they are on in the pathway, including through adequately-resourced and personalised end of life care services.**

Worryingly, much remains to be done if the government is going to meet its National Commitment to improve end of life care for everybody in England. There is a concerning lack of progress towards the delivery of the Commitment by 2020. Notably, the Commitment included personalised care plans for all.

A core component to the delivery of the 'National Commitment' was the focus and leadership on improving end of life care at both national and local levels. It was envisaged that end of life care would be most likely to improve when local commissioners and Health and Wellbeing Boards explicitly prioritised end of life care as a vital policy area when planning local strategies and priorities. Further, Delivering the Forward View 2016/2017 – 2020/2021 asked local systems to address how they plan to close the health and wellbeing gap, and include within their STP plans, plans for a 'radical upgrade' in patient choice and plans for how they would manage this, particularly at end of life. Disappointingly this urgent need for local areas to strategically plan for end of life care has not been recognised everywhere and avoidable variation in the care people receive at the end of their life remains.

When the End of Life Care Coalition – comprising six charities including Macmillan, analysed the draft plans for STPs in England, we found that 41% of them had no mention or little detail of how end of life care would be improved in their populations.<sup>41</sup> In addition to this, recent research of 152 regional Health and Wellbeing Boards showed that only half of the Health and Wellbeing strategies mentioned end of life care, few prioritised it and no strategies provided evidence for effective interventions at end of life.<sup>42</sup> When we know that people dying of cancer continue to receive variable care, it is clear **there is an urgent need for local plans to be developed and implemented, to ensure everybody receives good end of life care, no matter where they live.**

What we continue to see are too many people not being cared for or dying in their preferred setting. Macmillan knows that, all too often, people are dying in hospital when this is not their preferred place of death.<sup>43</sup> We estimate that every year 62,000 people die of cancer in hospital<sup>44</sup> despite the

<sup>39</sup> End of life care for adults Quality Standards (QS). NICE (last updated 2017).

<sup>40</sup> The Final Injustice. Variation in end of life care in England. Macmillan Cancer Support (December 2017).

<sup>41</sup> End of Life Care Coalition analysis, March 2017, <http://endoflifecampaign.org/wp-content/uploads/2017/10/STP-one-pager.pdf>

<sup>42</sup> Sleeman, K., Leniz, J., Higginson, I. and Bristowe, K. (2018). Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies. *Palliative Medicine*, p.026921631878633.

<sup>43</sup> YouGov Plc. (2017). Macmillan commissioned YouGov Plc. to survey UK adults with a cancer diagnosis. Total sample size was 2005 people with a previous cancer diagnosis, and 1878 people answered our questions relating to death and dying. Fieldwork was undertaken between 20 and 29 March 2017. The survey was carried out online. The figures have been weighted and are representative of the population of those living with cancer in the UK. YouGov Plc. (2017). Respondents were asked, 'If the right care and support was available in any of these locations, where would you prefer to spend your final days?'

<sup>44</sup> In 2015 in England and Wales, 37% of people aged over 28 days who died from cancer died in hospital (55,256 people), 30% died at home, 17% died in a hospice, 14% died in a care home and 2% died elsewhere. ONS, Deaths Registered in England and Wales in 2015 (Released November 2016, accessed April 2017) <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables/2015/drtables15.xls> ISD Scotland. Place of death for cancer. <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Place-of-Death/> (accessed April 2017). In 2015 in Scotland, 43% of people who died from cancer died in

majority (64%)<sup>45</sup> preferring to die at home with the right support. In some cases, hospital may be the right place for someone to die, but for many who want to die at home, or in a community setting, they might not be aware they have the chance to express preferences and choice about their care in their final days. Despite regular contact with health and social care professionals, people are often 'waiting for' professionals to start these conversations.

At Macmillan, we feel passionately about the need for public and professionals to have early Advance Care Planning (ACP) conversations as we know that ACP can enable and facilitate a 'good death'. In fact, when staff have a record of where someone would like to die, that person is almost twice as likely to die in the place of their choosing.<sup>46</sup> We know that commitments have been made by the NHS to promote planning ahead as an important part of person-centred health service. However, while more than three quarters (76%) of people living with cancer have thought about the fact they may die from their cancer,<sup>47</sup> worryingly only 8% of these people spoke to their healthcare team about the subject.<sup>48</sup> Further, the national clinical audits of case note reviews found that, though three quarters of deaths are expected, ACP discussions are recorded in fewer than half of the deaths registered.<sup>49</sup> There are still considerable barriers to ensuring ACP is well understood and undertaken by professionals and patients.

Many health and social care professionals who don't work in palliative care are unclear about who is responsible for ACP.<sup>50</sup> The impact of this uncertainty means professionals along the patient journey feel they do not hold the expertise or capacity to broach the topic of planning with patients. Alongside a misunderstanding about who is responsible for initiating ACP conversations, many professionals are concerned about documenting a preferred place of care, as in many cases, dying at home may not be realistic. Professionals worry that advance care plans may raise expectations among people with terminal diagnosis about the kind of support they may receive. This is a legitimate concern given the challenges health and social care services are facing across England. **However, everyone approaching end of life should be offered the opportunity to have a personalised Advanced Care Planning Conversation.** If the comprehensive model for personalised care is going to be properly embedded in all parts of England, it should also be embedded across all parts of the patient pathway, including at end of life.

## 1.10 Community-based palliative and end of life care

Access to community-based end of life care is a preference for many people at the end of their lives. Community-based end of life care means people can remain in their own homes, in hospices or in their existing care homes. They do so with the support of community nursing, palliative care, primary care, their local pharmacy, and occupational therapy.

An estimated 48,000 people in England experience poor care in the final three months of their lives<sup>51</sup>, plus more than 12,500 cancer patients spend the last two days of their lives without

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a hospital (6,983 people), 30% died at home, 19% died in a hospice and 8% died in a care home or elsewhere. Equivalent data not available for Northern Ireland. On this basis we estimate that more than 62,000 cancer deaths occur in hospital each year in the UK.

<sup>45</sup> YouGov Plc. (2017). Macmillan commissioned YouGov Plc. to survey UK adults with a cancer diagnosis. Total sample size was 2,005 people with a previous cancer diagnosis, and 1,878 people answered our questions relating to death and dying. Fieldwork was undertaken between 20 and 29 March 2017. The survey was carried out online. The figures have been weighted and are representative of the population of those living with cancer in the UK. Respondents were asked, 'If the right care and support was available in any of these locations, where would you prefer to spend your final days?'

<sup>46</sup> Macmillan analysis of Office for National Statistics, NHS England. (2015). National Survey of Bereaved People, 2014.

<sup>47</sup> Ibid.

<sup>48</sup> Ibid.

<sup>49</sup> Royal College of Physicians and Marie Curie Palliative Care Institute, End of Life Care Audit – Dying in Hospital, 2014 and End of Life Care Audit – Dying in Hospital National report for England 2016

<sup>50</sup> Macmillan Cancer Support, Missed Opportunities. Advance Care Planning Report. May 2018

[https://www.macmillan.org.uk/\\_images/missed-opportunities-end-of-life-advance-care-planning\\_tcm9-326204.pdf](https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf)

<sup>51</sup> Macmillan estimate of deaths between February 2015 and February 2016 based on Office for National Statistics. 2015. National Population Projections, 2014-based projections. <http://www.ons.gov.uk/ons/rel/npp/nationalpopulation-projections/2014-based-projections/index.html> (accessed January 2016); and 10% of the bereaved (all conditions) reporting that the overall, taking all services into account, they would rate the deceased care in the last three months of life as poor. Office for National Statistics. 2015. National Survey of Bereaved People (VOICES), 2014. <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-407293>

adequate pain relief.<sup>52</sup> Building on this, with an average of 22,000 (35%) of those who die each year from one of eight common types of cancer having five or more emergency visits in the last year of their life<sup>53</sup>, and more than 3000 (5%) of these patients having more than 10 emergency visits in their final 12 months<sup>54</sup>, Macmillan is concerned that we continue to see an enduring gap in the resources needed for community-based health and social care services. At optimal levels of provision, these would provide the necessary care to stop people from dying in pain, outside of their preferred place and unnecessarily visiting hospital in an emergency.

The North Manchester Macmillan Palliative Care Specialist Service (NMMPCCS) was introduced to develop a new model of consultant-led, community-based palliative care. This approach was adopted as part of the Macmillan Cancer Improvement Partnership (MCIP) to address significant issues in North Manchester's end of life care provision. The principles of the redesign were based on the Midhurst service, also supported by Macmillan.

NMMPCCS operates from a central 'hub' with links to the four community neighbourhoods in North Manchester. Underpinning the model are innovations including: an increased number of nurses and access to specialist therapy support; the introduction of an Assistant Practitioner role to support care delivery; a system of open referral for patients, carers and professionals with clinical triage of calls and referrals 8am-8pm, 7 days a week; a single point of access enhancing the 24-hour helpline; and the development of a volunteer model of support; and closer liaison with the spiritual care team. The multidisciplinary nature of the team, with doctors, plus access to counselling as well as nursing, means they can respond to a wide range of patient and carer needs in the community. As a result, the service can serve more patients with a diagnosis of cancer or other life limiting illnesses.

Outcomes from the pilot have meant the work of a palliative care coordinator led to the number of patients on the GP palliative care register increasing by 67% in 12 months. By the end of the pilot, 100% of patients had advance care plans in place. In 2015/2016, 82% of patients achieved their preferred place of death, compared to only 59% in 2014/2015. Finally, the service had a target of 20% or less of patients dying in hospital, which was consistently achieved during the pilot with an overall reduction to 13.1% of deaths occurring in hospital, compared to 20.9% prior to service redesign.<sup>55</sup>

Another key component to delivering end of life care is the ability to share a record of patient preferences, but we know the lack of digital system integration across health and care settings can be extremely detrimental to the delivery of personalised care at the end of life. We know that many people with cancer are unsure where their details are stored and how they are circulated. This was particularly the case for those who moved between Trusts to receive treatment and care.<sup>56</sup> The result of this is that people towards the end of their life are having to constantly repeat their wishes, as well as their symptoms to various health and social care staff.

There has been commitment at a national level through the 'National Commitment' that NHS England will ensure that shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS), will be rolled out across England to support the sharing of information and promote personalised care. Macmillan is disappointed that despite efforts

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<sup>52</sup> Office for national statistics, 2016. National Survey of Bereaved People 2015 (VOICES). 10% of all respondents disagreed or strongly disagreed that the cancer patient had sufficient pain relief in the last two days of life (Q35), among those who had pain (88.5%). Excludes those who are not sure.

<https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/nationalsurveyofbereavedpeoplevoices/2015/referencetablesvoices2015.xls>

Macmillan (June 2017) estimation of over 12,000 people each year calculated by applying 10% to England 2015 cancer mortality figures of 122,580 deaths (88.5% of the total of 138,509 deaths, to represent those who had pain relief). Office for National Statistics, 2016, Cancer Deaths registered in England and Wales in 2015

<https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/006211cancerdeathsregisteredinenglandandwales2015/cancerdeathsendlandandwalesseparately2015.xls>

<sup>53</sup> Macmillan Cancer Support/Public Health England. How many emergency hospital visits do cancer patients make towards the end of their life? June 2017. Poster presentation at the 2017 Cancer Data and Outcomes conference

<sup>54</sup> Ibid.

<sup>55</sup> The Final Injustice Variation in end of life care in England. Macmillan Cancer Support (2017).

<sup>56</sup> Macmillan Cancer Support, Missed Opportunities. Advance Care Planning Report. May 2018

[https://www.macmillan.org.uk/images/missed-opportunities-end-of-life-advance-care-planning\\_tcm9-326204.pdf](https://www.macmillan.org.uk/images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf)

to do this, progress has been slow, ultimately impacting on the ability for people at the end of life to have their preferences recorded. **An early priority on end of life care would be to continue supporting efforts to roll out EPaCCS systems to digitise shared palliative and end of life care records.**

There also needs to be a **tie-in between palliative care reviews in general practice, as provided through the Quality and Outcomes Framework (QOF) and effective planning on palliative and end of life care within the NHS long-term plan.** Macmillan recently responded to the review of the Quality and Outcomes Framework (QOF) to recommend an initial review should take place within one month of a patient being added to the palliative care register, not the three-months provided for within the QOF indicator (PC2) now.

### 1.11 Inequalities in end of life care

Something as fundamental as the quality of care a person receives in their dying months, or where they die, should not depend on where they live or the level of deprivation they experience. Unfortunately, recent Macmillan analysis on the impact of income deprivation on place of death for people dying of cancer found that the most deprived are more likely than the least deprived to die in hospital in England.<sup>57</sup> Beyond place of death, Macmillan knows that the level of deprivation also impacts on the number of emergency hospital admissions a cancer patient experiences in their last 12 months of life. In fact, people from the most deprived areas who die from cancer each year have 15,000 more emergency hospital visits in the final years of life compared with those from the least deprived areas.<sup>58</sup>

Macmillan funded research has also shown in the last six months of their lives, cancer patients from the most deprived areas, living with the four most common types of cancer, spend longer in hospital on average following an emergency admission.<sup>59</sup> If this was resolved for the most deprived patients dying from colorectal, breast, prostate and lung cancer alone, it could save the NHS £4.6m per year.<sup>60</sup>

Together, these findings on palliative and end of life care present a startling picture of the experiences of those from deprived backgrounds in their dying months. The NHS long-term plan needs to tackle head-on what appears to be lost momentum in delivering the National Commitment. Crucially, personalised end of life care provision must become the norm.



## 2. Systematic action on tackling health inequalities

The need for action on health inequalities cannot stop once a person is diagnosed with cancer: the NHS long-term plan needs to ensure that, once a person is diagnosed with cancer, there are not unjust and avoidable differences in the treatment they receive, their access to information and support, or their ongoing experiences of care.

Unfortunately, this is not currently the case. For example, despite being a well-known indicator of improved patient experience, access to Cancer Nurse Specialists varies across socio-demographic groups,<sup>61</sup> and in their final year of life, the section on end of life care above illustrated how people from more deprived areas with cancer are more likely to die in hospital and report poorer

<sup>57</sup> National Cancer Registration and Analysis Service, Public Health England and Macmillan Cancer Support. 2017. Cancer deaths by deprivation, place of death and emergency admission in last year of life. [www.ncin.org.uk/about\\_ncin/releases](http://www.ncin.org.uk/about_ncin/releases)

<sup>58</sup> Walsh, B. and Laudicella, M. (2017). Disparities In Cancer Care And Costs At The End Of Life: Evidence From England's National Health Service. *Health affairs (Project Hope)*, 36(7), pp. 1218–1226. doi:10.1377/hlthaff.2017.0167.

<sup>59</sup> Walsh, B. and Laudicella, M. (2017). Disparities In Cancer Care And Costs At The End Of Life: Evidence From England's National Health Service. *Health affairs (Project Hope)*, 36(7), pp. 1218–1226. doi:10.1377/hlthaff.2017.0167.

<sup>60</sup> Walsh, B. and Laudicella, M. (2017). Disparities In Cancer Care And Costs At The End Of Life: Evidence From England's National Health Service. *Health affairs (Project Hope)*, 36(7), pp. 1218–1226. doi:10.1377/hlthaff.2017.0167.

<sup>61</sup> Saunders CL, Abel GA, Lyratzopoulos G. Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English Cancer Patient Experience Survey. *Eur J Cancer Care (Engl)* 2015; 24(1): 85-98

experiences of care, and collectively have 15,000 more emergency admissions than those from less deprived backgrounds.<sup>62</sup>

This must be addressed, and as such **tackling health inequalities must be a key priority within the NHS long-term plan, with clear improvement measures to tackle inequalities identified across the whole patient pathway.**

The NHS long-term plan is an opportunity to take a wider, more holistic approach to tackling health inequalities. In truth, what is needed next is systematic action, across the NHS, but other public health, care and local government services too. A sustainable budget settlement across health, public health and social care, needs examining even though the £20bn announced increase will be targeted on NHS services.

A more holistic approach should be based on three core principles.

- **First, we must address inequalities in how health care resources are accessed and distributed.**
- Socio-economically deprived people have a wide range of social needs which impact their opportunity to have a patient experience [post-diagnosis] and quality of life comparable with less deprived patients. The point is that people from the most deprived communities often enter the health system with a wide range of needs that lower their opportunity to have a good patient experience. This can lead to higher use of acute care, emergency services and other health care resources after the point of diagnosis. **Second, therefore, the NHS should more fully realise its role in addressing this ‘inequality of opportunity’ from the point of diagnosis onwards.** It should first seek to recognise what these needs are, through early conversations and Holistic Needs Assessments and where practical, work in a place-based way through STPs/ICS's, and Cancer Alliances, to mitigate these.
- **Finally, third, health inequality policies must be specific; sustained over time; and targeted at tackling the inequality gap in and of itself.** In practice, it means introducing inequality-focused levers into NHS policies and practice. These should include explicit initiatives or mechanisms to ensure policies reach and engage the most deprived groups; and enhanced or accelerated service provision or funding is targeted where socio-economic inequality is more prevalent. Research into this ‘universal, but targeted’ approach has had highly promising outcomes<sup>63</sup>, and, given that population-wide cancer policies have struggled to reduce cancer inequalities in the past, has the potential for tangible impact.

## 2.1 Inequalities in survival

There is no good reason that treatment, or the time it takes to receive treatment, should vary according to socio-economic status. Yet this may be the case in practice. A recent study showed that difference in treatment given – particularly surgical treatment – may explain more inequalities in survival than previously thought, even when controlling for stage of diagnosis.<sup>64</sup> However, evidence on cancer treatment inequalities is somewhat inconclusive. **More regular data releases on the treatment people receive, and their wait times for that treatment - with demographic and deprivation splits - would increase accountability and provide a resource for interested researchers.**

## 2.2 Inequalities in patient experience

The 2017 Cancer Patient Experience Survey (CPES) confirmed that people from deprived backgrounds had worse experiences in terms of patient-staff communication, support and

<sup>62</sup> Macmillan Cancer Support, The Final Injustice: Variation in end of life care; December 2017

<sup>63</sup> For example, see: Egan, Matt et al. 2016. Proportionate universalism in practice? A quasi-experimental study (GoWell) of a UK neighbourhood renewal programme's impact on health inequalities; Benach, Joan et al. 2012. A new typology of policies to tackle health inequalities and scenarios of impact based on Rose's population approach; Bo Burstrom et al. 2017. Practising proportionate universalism – a study protocol of an extended postnatal home visiting programme in a disadvantaged area in Stockholm, Sweden; and <http://www.healthscotland.com/uploads/documents/24296-ProportionateUniversalismBriefing.pdf>

<sup>64</sup> See: <https://link.springer.com/article/10.1007/s10654-016-0155-5> <https://link.springer.com/article/10.1245%2Fs10434-013-2959-9> <http://journals.sagepub.com/doi/abs/10.1177/2051415815594976>

information. They reported lower support during and after treatment; lower proportions reported they felt that GPs and nurses did everything they could; and more people reported being given information they couldn't understand, including from their Cancer Nurse Specialist (CNS).<sup>65</sup> As NHS England have previously stated, improving training for staff in communicating with, informing and understanding people from deprived and seldom heard groups will be useful in addressing this variation.

**NHS England and HEE's work on a costed workforce strategy should be based on resourcing and implementing local workforce plans drawn up by Trusts and CCGs. Among other things, this could look at specific steps needed in areas that have both higher numbers of deprived patients and lower rates of Cancer Nurse Specialists per new patient.**

**Other recommended actions worth examining could include steps to actively support patients from the most deprived groups to access Holistic Needs Assessments and other personalised care and support interventions.** This could include uptake of Personal Health Budgets.

We agree Personal Health Budgets (PHBs), can support people with the lowest levels of confidence in managing their health – themselves more likely to come from deprived groups. However, this is contingent on fair and inclusive implementation, ensuring that people have the right information, advice and support to be able to make informed decisions about their care.

The most deprived patients may have lower 'activation' scores and require more support taking up or making use of PHBs. This might dis-incentivise them from being offered self-management tools. Inequalities may then worsen. The most deprived patient groups are more likely than less deprived patients to have severe concerns including financial worry and housing problems. Self-management may, then, add another priority or anxiety to an already long list. This could mean self-management and attempts at self-activation present more of a challenge than a step up for deprived patient groups. The long-term plan offers an opportunity to address these concerns, whilst embracing the potential of personalised care. **There could be an explicit target of equal access to, and satisfaction with, PHBs across the deprivation quintiles** (and other demographics) – in addition to any more general targets (i.e. the current target of 40,000 PHBs in 2018/2019 and 100,000 by the end of 2020/21).

### **2.3 Community hub models**

Other steps we would like to see taken as part of the long-term plan include greater out-reach to communities through primary and community care pathways, or 'integrated hubs', which serve as a single (accessible) point of access. This concept has been termed a community care pathway elsewhere – and has been shown to have popular appeal with patients who report feeling isolated.

As outlined in the section on personalised care above, "Improving the Cancer Journey" is a service available to all cancer patients within Glasgow. They undertake a needs assessment to assess their concerns at significant points in their cancer journey. They – and friends, families and carers affected by a cancer diagnosis – then receive dedicated support through their cancer journey. The main aim is to direct service provision based on need. A secondary aim is to improve engagement and incorporate users into the design and delivery of their care.

Evaluation has shown that the majority of service users were deprived. 61% came from the lowest deprivation quintile, and 77% from the bottom two quintiles. 54% had at least another health condition. The five most common were Arthritis, Diabetes, Chronic Obstructive Pulmonary Disease, Hypertension and ill Mental Health.<sup>66</sup>

The top concerns service users reported were money, housing, fatigue and getting around. Between March 2014-July 2016, 8117 referrals were made to relevant service providers. A follow-up

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<sup>65</sup> National Cancer Patient Experience Survey 2017 National Results Summary.

<sup>66</sup> Macmillan and Edinburgh Napier University. 2017. Evaluation of Glasgow Improving the Cancer Journey Programme.



survey of ICJ and non-ICJ users found users had a higher quality of life, social support and patient activation. **The long-term plan should build on this best practice. NHS England should work with partners to share learning on community hubs, so these can reach out to the most deprived and seldom heard patients, prevent crisis; and link patients into services and support they might otherwise experience barriers accessing.**

## 2.4 Funding formulas and adjusting for inequalities

Health inequalities remain one of the greatest challenges for the NHS. People from the most deprived communities' live shorter lives and experience almost two decades less good health than those from the most affluent communities.<sup>67</sup> There will need to be dramatic action to really make an impact.

Building on a recent NHSE Board paper, **NHS England should work with NHS Clinical Commissioners to further consider how deprivation and inequalities will be factored into funding formulas, and where appropriate, how these formulas can be more effectively weighted to population need.** The adjustment formula could be made more explicit in CCG allocations to ensure any additional funding can in fact get targeted at tackling inequalities.



## 3. A costed plan for a growing, skilled and sustainable workforce

The NHS workforce is widely reported to be under strain, and Macmillan's research shows that many staff are concerned about the impact of current pressures on people with cancer. For instance, over 50% of GPs and nurses surveyed in the UK said that, given current pressures on the NHS workforce, they are not confident it is able to provide adequate care to cancer patients.<sup>68</sup> This is desperately concerning and pressures across the care pathway must be alleviated.

The reasons behind this situation are varied and multifaceted, ranging from recruitment issues to increasing workloads. **A costed plan for a growing, appropriately skilled and sustainable workforce is vital if the NHS is to meet the needs of people with cancer.** This must be based on the projected increase in both overall volume of demand but also future complexity of new caseloads. For example, some estimates Macmillan has seen suggest that there needs to be a growth in the NHS general nursing workforce of at least 45% in aggregate over the next ten years to reflect both the need to 'catch up' and to ensure future delivery of key service priorities. The latest NHS Improvement figures reveal that 11.8% of nurse posts were not filled, a shortage of nearly 42,000,<sup>69</sup> underscoring how grave the situation is.

Further to ensuring sufficient numbers of health and care staff, a workforce plan must also drive the upskilling of the current workforce through continuing professional development (CPD). Cuts to CPD budgets need to be reversed. Reflecting on the challenges at Cancer Alliance-level, a 'skills mix' will also be essential, enabling colleagues to work with a range of competencies, but with those who reach advanced practice being able to work to their licence, at the top of their scale. A more effective mechanism for rolling out training around scientific, technological and medical developments also needs to be developed to ensure professionals can confidently administer newer forms of treatment and care.

A robust workforce plan must additionally seek to improve career pathways amongst the cancer workforce and support flexible ways of working to improve rates of retention. This could see greater use of 'return-to-practice' initiatives to ensure experienced members of staff come back to skilled roles. It also needs to reflect that cancer services will increasingly need to be networked into a wide range of allied health professionals to provide people with the range of support needed; and support worker and navigator roles, in linking patients into holistic health and care support.

<sup>67</sup> ONS. 2018. Health state life expectancies by national deprivation deciles, England and Wales: 2014-2016.

<sup>68</sup> From the Frontline. Workforce pressures in the NHS. Macmillan Cancer Support (September 2017).

<sup>69</sup> Performance of the NHS provider sector for the quarter ended 30 June 2018, NHS Improvement (September 2018).

### 3.1 Workforce supply

Macmillan's evidence shows the number of vacancy rates across cancer nurses means as many as one in seven chemotherapy nurse positions remain unfilled in some parts of England.<sup>70</sup> Macmillan professionals also tell us that specialist nurses are increasingly asked to cover shifts on wards where general staffing is under capacity. This use of specialist nursing skills is neither cost efficient nor does it deliver the best patient care.

There are also similar gaps in the workforce supporting people at the end of life. There is evidence of a projected increase in the number of people requiring specialist palliative care between 25-42%.<sup>71</sup> The Royal College of Nurses (RCN) has in the recent past issued an unprecedented warning that the role of District Nurses is 'critically endangered', which is extremely concerning as they are key coordinators for people's end of life care in the community.

The rising nursing shortfalls are also reflected in the wider nursing population nearing retirement age. Macmillan's evidence showed the proportion of specialist cancer nurses aged 50 or over has increased since 2014.<sup>72</sup> At the same time nurses appear to be retiring earlier. The average age of a nurse leaving the Nursing and Midwifery Council (NMC) register has reduced steadily from 55 years of age in 2013 to 51 in 2017,<sup>73</sup> emphasising the importance of succession plans, to secure future cancer /clinical nurse specialists (CNS) that a growing population will need.

Macmillan's census also shows there is significant regional variation across Cancer Alliances when looking at the ratio of whole time equivalent (WTE) specialist cancer nurses to newly diagnosed patients across cancer types. For example, this variation stretches from 62 to 203 new patients per nurse for lung cancer, and between 56 and 145 new patients per nurse for breast cancer.<sup>74</sup> Whilst we know some variation is to be expected, the level of variation is concerning and can negatively impact on patient care. Our census also revealed, that when compared to 2014, there is a greater proportion of nurses working in lower pay bands at Bands 5 and 6, and a lower proportion working at Band 7. Whilst we need to better understand why this has happened, our concern is that a trend of highly trained specialists taking on increasingly complex caseloads for lower pay is not only economically imprudent but also may exacerbate recruitment and retention problems in the cancer nursing workforce.

**Given the urgency around the current and predicted shortages in nursing staff, it is essential workforce planning is based on the projected increase in patient needs and not current affordability. In the next ten years, there needs to be significant growth in general adult nursing to meet future demand. Importantly, Health Education England (HEE) will need to work with NHS England to set out national policy initiatives that increase supply but also set out specific support that will be given to local providers and planners to implement change.**

**Existing 2015-20 commitments, so for example that all people with cancer should have access to a Clinical Nurse Specialist (CNS) or Support Worker, still need to be fulfilled.**

### 3.2 Wider health and care professionals

While pressures in the cancer workforce continue to grow, the long-term plan must of course address the wider workforce shortages that affect cancer treatment and care. The cancer care workforce represents only a portion of the professionals working across NHS and social care services who contribute to the care and support of people living with cancer. Recent data shows a

<sup>70</sup> Macmillan Cancer Support. Census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017 [https://www.macmillan.org.uk/\\_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017\\_tcm9-325727.pdf](https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf)

<sup>71</sup> Etkind S, Bone A, Gomes B, Lovell N, Evans C, Higginson I, Murtagh F. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine 2017; 15:102 (Data is for England and Wales).

<sup>72</sup> Macmillan Cancer Support. Census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017 [https://www.macmillan.org.uk/\\_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017\\_tcm9-325727.pdf](https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotherapy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf)

<sup>73</sup> The Nursing and Midwifery Council Register 2012/13 - 2016/17 <https://www.nmc.org.uk/globalassets/sitedocuments/other-publications/nmc-register-2013-2017.pdf>

<sup>74</sup> Macmillan Cancer Support. Census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017

30% rise in workload for clinical radiologists between 2012 and 2017,<sup>75</sup> and a shortage of therapeutic radiographers, with fewer students taking up the course, which could cause future delays in patients receiving treatment.<sup>76</sup> The need for community and primary care health professionals to be trained to support people with cancer is perhaps most acute post-treatment. But, within primary care, the number of GPs between March 2017 and March 2018 has decreased by 3%<sup>77</sup> and is insufficient to meet demand. In the community, nearly two-thirds of trusts that provide community services are worried or very worried about community services being able to maintain adequate staffing in 12 months' time.<sup>78</sup>

We must not underestimate the impact of shortages in general practice and community services as it will often be professionals working in these settings that encounter people at their key times of need: when people have suspected symptoms that require investigative tests and referral for treatment; and when their treatment has ended, but they transition into a period of recovery.

The number of advertised vacancy FTEs in England for Q4 2017/18 for Allied Health Professionals [AHPs] is 9,360.<sup>79</sup> Statistics from a Macmillan Survey with AHPs [to be published later in 2018] will highlight that the majority of AHP respondents felt more AHPs are needed to deal with the needs of people living with cancer, particularly dietitians and speech and languages therapists.<sup>80</sup> Patients benefit from interventions by AHPs from diagnosis through to end of life care. But our late 2018 survey will highlight this is not consistently delivered throughout the patient pathway - much of the support delivered by AHPs is primarily provided during palliative and end of life care. More AHP interventions could be provided earlier in the pathway including where people live with cancer – and can continue to be treated - but are incurable.

### **3.3 Recruitment, training and retention**

From 1 August 2017, new nursing, midwifery and most allied health students have not received NHS bursaries paid by HEE to support their living costs, instead receiving financial support through the standard student support system. Last year there was a 23% decline in nursing degree applications in England. New data on 2018 applicants show that this number has continued to fall, with applications down a further 13% since 2017<sup>81</sup>. HEE's draft workforce strategy (phase 2) outlines an additional 21,500 expansion of nurse training posts in the next five years to combat these shortfalls, but the issue of student finance presents a fundamental challenge to how these posts will be filled.

An announcement of a 25% increase in university nurse training places is an encouraging step, but it takes a minimum of 3 years to train a nurse, so increasing the number of UK training positions will only alleviate pressures in the long-term. With current shortages, the issue of nursing student attrition has never been more challenging, with new data showing an average attrition rate of 24% in the UK, showing little change over the last decade.<sup>82</sup>

### **The long-term plan should consider next steps now nursing and allied health student bursaries have been removed. There should be steps to encourage more undergraduate and**

<sup>75</sup> Royal College of Radiologists. UK Workforce Census 2017 Report.

[https://www.rcr.ac.uk/system/files/publication/field\\_publication\\_files/bfcr185\\_cr\\_census\\_2017.pdf](https://www.rcr.ac.uk/system/files/publication/field_publication_files/bfcr185_cr_census_2017.pdf)

<sup>76</sup> The Society of Radiographers. <https://www.sor.org/about-radiography/media-centre/press-releases/shortage-therapeutic-radiographers-will-have-critical-effect-if-decisive-action>

<sup>77</sup> NHS Digital. GP Primary Care Workforce. September 2015 to March 2018

<https://app.powerbi.com/view?r=eyJrjoiNzFmMzZTEtMmQ2Zi00NDdjLTlhNmYtMmQxMDI5MGE3YjQwliwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMlI5MmMjMiOjIj9&pageName=ReportSection1b8cc727338a02512894>

<sup>78</sup> NHS Providers. The State of the Provider Sector <http://nhsproviders.org/state-of-the-provider-sector-05-18>

<sup>79</sup> NHS Vacancy Statistics England - February 2015 - March 2018, Provisional Experimental Statistics: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-vacancies-survey/nhs-vacancy-statistics-england---february-2015---march-2018-provisional-experimental-statistics>. This is likely to be an under-representation of the real number of vacancies due to issues with the quality of the data. One of the problems is that the data is taken from NHS Jobs, the main recruitment website for the NHS, which uses one advert to show multiple vacancies or ongoing recruitment, so it tends to undercount the real number of vacancies.

<sup>80</sup> Macmillan Survey of Allied Health Professionals (AHPs). 2017. An online survey to better understand the make up of the AHP workforce. The following groups were included; n=247 Speech and Language Therapists, n=480 Occupational Therapists, n=401 Physiotherapists, n=646 Dietitians. All members of the relevant professional bodies representing the above professions across the UK were given an opportunity to fill in the survey. The results are based on the self-selecting respondents and cannot necessarily be generalised to the wider AHP workforce.

<sup>81</sup> UCAS Nursing applicants at the 15 January deadline (2018 cycle). [https://www.ucas.com/file/147216/download?token=wuwe\\_zbe](https://www.ucas.com/file/147216/download?token=wuwe_zbe)

<sup>82</sup> <https://www.health.org.uk/news/one-four-student-nurses-drop-out-their-degrees-graduation>

**especially postgraduate student uptake and to encourage universities to run long and shortened courses.** However, the number of university places will need to drastically increase to provide a sufficient workforce supply in the long-term. Reducing attrition and ensuring there is sufficient training is also integral to ensure a strategic approach to recruit and retain enough nurses to meet the needs of the growing population.

**Alongside initiatives to increase staff numbers, there is an urgent need to improve the skills of the existing workforce through training opportunities and continuing professional development (CPD).** Investing in the professional development of the workforce can significantly improve retention<sup>83</sup>, flexible employment and increase autonomy. The CPD funding cuts for nurses and AHPs is suspected to contribute to individuals leaving the professions. In the last two years, the CPD budget has reduced by £121 million.<sup>84</sup> HEE's draft workforce strategy – which was starting to show promise and must be carried through as part of the long-term plan - also suggests a national CNS training programme over the next five years. This programme will need to be costed and evaluated, and should be available for all generalist nurses to develop key communication skills and competencies. This would allow nurses to progress into senior and specialist cancer nurse roles and work at the top of their license.

As more people will be living with cancer and other long-term conditions, they will regularly interact with different parts of the health system. The multidisciplinary workforce needs to have a mix of appropriate skills and training to communicate with people living with cancer and manage their needs effectively. But, with rising pressures and staff shortages, nurses face limited opportunities for learning and development in these areas.

Our '*People Behind Cancer Care*' 2015 report on the experiences of patients and cancer care professionals highlighted that staff and patients alike recognise that quality of care is not solely measured by clinical outcomes. The report highlighted that effective communication is essential between clinicians and patients and amongst all staff, who should work as a team to provide the best possible care, regardless of their position within the NHS.<sup>85</sup>

As well as addressing clinical needs, the cancer workforce need to address the holistic needs of people living with cancer. **One approach would be to embed a clear training framework into the curricula for undergraduate general nursing, nursing associates, apprenticeships and other fast-track learning schemes. This ensures that there is a minimum level of training in key competencies such as communication skills to meet expectations of cancer patients.**

Developing the skills and training opportunities for generalist nurses is necessary to ensure specialist nurses can use their skills and expertise in their daily role. It is also important to develop clear career pathways for generalists into specialist roles to encourage better care and improve job satisfaction. Training and development through e-learning programmes such as Macmillan Explore<sup>86</sup> can help staff develop confidence in cancer specific knowledge and skills to support people living with cancer.

Training is also necessary in the wider workforce, including for GPs, AHPs, support workers and care navigators. **They should have the resource and support to take part in training and development, with sufficient resource to back-fill when they take part.** It is essential community staff like support workers can access training resources for key competencies to grow in confidence in their current position and progress in their career. Where professionals can provide support

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<sup>83</sup> Buchan J and Aiken L, Solving Nursing Shortages: a common priority. J Clin Nurs. 2018; 17:24 pp3262-3268 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2858425/#R14>

<sup>84</sup> House of Commons Health Committee, The Nursing Workforce. Second Report of Session 2017-19. 2018 <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/353/353.pdf>

<sup>85</sup> Macmillan Cancer Support. The People Behind Cancer Care.

[https://www.macmillan.org.uk/\\_images/Thepeoplebehindcancercare\\_tcm9-271112.pdf](https://www.macmillan.org.uk/_images/Thepeoplebehindcancercare_tcm9-271112.pdf).

<sup>86</sup> <https://learnzone.org.uk/courses/course.php?id=321>

across the care pathway, this works to the benefit of people with cancer. It also helps relieve some of the burden from a CNS, freeing up their time away from more administrative tasks.<sup>87</sup>

We support the use of schemes such as Retire and Return to encourage experienced members of staff to come back to skilled roles but on a part time or more flexible basis. While this addresses workforce shortages, it will still be insufficient to provide the size of the workforce we need given the scale of the overall problem.<sup>88</sup>

The strategic workforce plan also needs to help develop and improve career pathways into specialist roles and support flexible working to improve retention. For example, working as a triage system nurse, working flexible hours or alternatively, mentoring so retired nurses can guide younger trainees and newly qualified nurses. This may be the most cost-effective way to ensure the future health system has the staff it needs.

If the cancer workforce is to retain its staff, it is important that working conditions are improved and staff are valued. Not only is a positive staff experience key to retention, it is also linked to improving patient experience.<sup>89</sup> The current challenges of workforce shortages and an ageing population with increased risk of multi-morbidities makes for stressful working environments. This impacts heavily on individual staff, increasing their risk of early retirement and burnout, leaving those who are left to consistently work above normal working hours. As such, professionals are taking more sickness leave related to stress and are considering leaving their roles because of reduced job satisfaction, and feeling frustrated and demoralised.<sup>90</sup> We support new initiatives such as TalkHealthandCare and suggest these continue to get built on.

### 3.4 A skills mix

A skills mapping approach will help build a competency framework with the aim of standardising training and providing direction to cancer services as the demands of providing cancer care change. This should involve training to improve skills in key competencies and training in key cancer terminology and information support to address the holistic needs of person living with cancer. Not only will this be essential for career development and progression but it will also build a picture of skills needed in the workforce (rather than roles), hence providing a practical tool to help redesign the skill mix in teams and identify gaps in skills, contributing to better workforce planning and training mechanisms. **A 'skills mix' approach to workforce planning will in fact be essential, enabling colleagues in the workforce to work with a range of competencies, but with those who reach advanced practice being able to work to the top of their licence.**

### 3.5 Technological and medical advances and the impacts on the workforce

**It is essential there is a more effective mechanism for rolling out training around scientific, technological and medical developments to ensure professionals can confidently talk to patients about and administer newer forms of personalised treatment and care.** With continuing advancements in medical developments such as genomics and immunotherapy, up-to-date training is key to patient experience and outcomes. HEE's draft cancer workforce strategy (phase 2) suggests that undergraduate and post-graduate curricula will need to incorporate training in genomics, artificial intelligence and other advances to ensure sufficient training and understanding.

The workforce will need to adapt to provide timely and appropriate information around new developments in precision medicine. Healthcare professionals who are part of cancer patients' pathway may have to communicate the benefits and implications of genomics and more

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<sup>87</sup>Macmillan Cancer Support. From the Frontline. 2017 <https://www.macmillan.org.uk/assets/macmillan-workplacesurvey-reportmac16756.pdf>)

<sup>88</sup> Nuffield Trust response to Health Select Committee Inquiry into the Nursing Workforce.

<sup>89</sup> Macmillan Cancer Support. The People Behind Cancer Care. [https://www.macmillan.org.uk/images/Thepeoplebehindcancercare\\_tcm9-271112.pdf](https://www.macmillan.org.uk/images/Thepeoplebehindcancercare_tcm9-271112.pdf)

<sup>90</sup> House of Commons Health Committee, The Nursing Workforce. Second Report of Session 2017-19. 2018 <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/353/353.pdf>

personalised treatment solutions, as well as why patients may be eligible for some treatments but not others. This includes the potential side effects and long-term consequences. Increasing coverage around personalised medicines such as immunotherapy can lack necessary nuance and presents an additional challenge to meeting patient expectations. Furthermore, ethical issues such as consent and disclosure of information will have greater significance. The increased use of precision medicines will affect the general cancer workforce, not just specialists. Many healthcare professionals will not have used genomics in their work and may not understand its importance or the relevance of training and education. The current workforce will need upskilling and general education to understand and talk about immunotherapy, with training stratified depending on the professional's involvement in cancer care.

**The healthcare workforce should be well supported and trained to enable them to have informed conversations about the side effects and long-term consequences of treatment, particularly precision treatments such as immunotherapy.**

The side effects and long-term consequences of treatment may affect quality of life and impact people's ability to undertake activities they did prior to diagnosis. The 2017 England Cancer Patient Experience Survey reported that just 55% of participants across all cancers were told about any side effects of the treatment that could affect them in the future rather than straight away. The "mainstreaming" of precision treatments is likely to make conversations about side effects and the long-term consequences of treatment more challenging but no less important. Healthcare professionals should ensure that patients at risk of or experiencing long-term consequences are identified earlier and provided with timely and appropriate support. There should also be a good assessment of the information needs of the patient with regards to potential, long-term consequences of cancer and its treatment. Evidence suggests that excessive information can be a significant risk for later anxiety, depression and fear.

**It will be vital to educate the workforce to understand and effectively communicate the benefits and ethical implications of genomic medicine.** We welcome the work of HEE and the genomics education programme, and would like to see this built on to seamlessly integrate genomics into routine healthcare.

Finally, it's crucial that when NHS England commissions these technological advances, there is necessary and informed workforce planning, to ensure there is enough staff with the right learning to develop the specialist skills that can support new and innovative models of delivery. **It is essential there is a coherent nationwide approach to supporting the workforce to roll out new technologies, drugs and good practice to drive and deliver personalised care.**

### **3.6 Workforce planning and new ways of working**

New ways of working will be central to the sustainability of the workforce to meet the needs of people living with cancer. **Workforce planning needs to improve workforce productivity including the use of e-rostering tools to manage safe staff levels, efficient deployment of staff and drive greater employee engagement.** An effective e-roster empowers e-roster creators and senior staff to make informed decisions to ensure that the right staff will be in the right place at the right time, so that patients receive the care they need and trusts can better manage their workforce and their financial efficiency. Open and transparent e-rostering processes improve employee engagement and satisfaction, and are a key influence on retention.

In summary, ensuring that there is a variety of level of skills in multidisciplinary teams will meet the holistic needs of people living with cancer. This includes specialists, generalists, AHPs, support workers, and navigator roles all of whom need to work together across organisational boundaries – including social care. As such, there needs to be a strategic look at new ways of working, that do not look exclusively at the health service but also at organisations across the local health and care economy.

In the next two sections (4) **Continued improvements in diagnosis and treatment**; and (5) **Widening access to digital and technology**, we briefly highlight a small set of additional priorities for the NHS long-term plan. Further evidence and case examples of interventions are available on request.



## 4. Continued improvements in diagnosis and treatments

### 4.1 Routes to diagnosis

Early diagnosis can improve a person's chances of survival and a better quality of life.<sup>91</sup> However, the emphasis should also be on a good experience of diagnosis. The Cancer Patient Experience surveys show repeated visits to the GP for some cancers which can exacerbate anxiety. In principle, the route to cancer diagnosis should be short and safe, with rapid access to diagnostic tests, including for those with non-specific, vague symptoms.

Late diagnosis continues to be a problem and there is significant variation by cancer type. For example, in 2015, 44% of people with pancreatic cancer were diagnosed as an emergency compared with 22% of people across all cancers.<sup>92</sup> There are significant barriers to diagnosis including low symptom awareness among the public for certain cancers and suboptimal diagnostic pathways. Non-specific and vague symptoms present a huge challenge. GPs need tools to identify with greater probability people who present with complex symptoms that do not meet the criteria for urgent referral. Diagnostic pathways need to be flexible and optimised to ensure faster time to testing for those individuals. Moreover, quicker time to testing provides faster reassurance for those who do not have cancer in what can be a difficult and anxious period.

There are existing models for improving time to diagnosis for cancers with non-specific, vague symptoms. However, access is varied. Direct access to diagnostic tests for GPs and multi-diagnostic clinics (MDCs) are two approaches to optimising the diagnostic pathway that are proven to work in practice but where access varies.

Streamlined pathways can help limit the time patients spend being referred between GPs and consultants. This is especially important for those cancers with non-specific, vague symptoms that do not meet the referral criteria for urgent investigation and are therefore more likely to go undiagnosed for longer periods and/or diagnosed in emergency presentation. For example, between 2006-2015 just 1% of people affected by a brain tumour were referred via the two-week wait compared to 59% diagnosed through emergency presentation.<sup>93</sup>

There are examples of optimised pathways at the local level, which potentially can be scaled up and applied more widely. One of these is access for GPs to key investigative tests for suspected cancer, which remains varied and unequal despite a recommendation in the England Cancer Strategy that they be mandated by NHS England (NHSE) by the end of 2015. Research reports high levels of satisfaction with direct access among GPs and patients, with reduced time to referral.<sup>94</sup> Evidence also shows that it can reduce wait times, providing early reassurance.<sup>95</sup> Recent studies have shown that GP's direct access to diagnostics perform as well as consultant led diagnostics, and GP's overall estimation of the patient's risk of cancer at referral was associated with the probability of finding cancer.<sup>96</sup> **Macmillan believes diagnostic pathways should be optimised across**

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<sup>91</sup> [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis)

<sup>92</sup> [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis)

<sup>93</sup> [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis)

<sup>94</sup> <https://bjgp.org/content/early/2018/08/13/bjgp18X698561>

<sup>95</sup> [https://www.researchgate.net/publication/49670211\\_Impact\\_of\\_GP\\_direct-access\\_computerised\\_tomography\\_for\\_the\\_investigation\\_of\\_chronic\\_daily\\_headache](https://www.researchgate.net/publication/49670211_Impact_of_GP_direct-access_computerised_tomography_for_the_investigation_of_chronic_daily_headache)

<sup>96</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4445271/>

## **England, drawing on existing models of good practice including GPs being able to directly access key investigative tests.**

There is also evidence of programs operating effectively at the local level to raise awareness of symptoms or identify potential high-risk individuals for screening. Local initiatives can prove effective in increasing awareness among high risk groups. For example, Manchester's Lung Health Check Pilot aimed at finding high risk cases saw an increase in the numbers of those with lung cancer diagnosed at an earlier stage.<sup>97</sup> Campaigns developed locally to increase awareness of cancer are potentially better placed to understand local populations and reach at risk groups. These can be up-scaled along potential larger regional or national Public Health England campaigns.

### **4.2 Treatment options and implications for cancer care**

Greater understanding of tumours at the molecular level provides new opportunities for precision medicine, with a move toward treatment that is determined by the individual's tumour characteristics.

The Genomics Medicines Service has the potential to transform healthcare, helping patients gain access to targeted treatments that are specifically designed for their tumour type with better associated outcomes. Widespread use of genomics will also help direct patients to clinical trials, allowing access to novel treatments. However, if access to genomics is not equitable across the country there is a risk that existing health inequalities will be exacerbated, creating unwarranted variation in treatment across the country.

The "mainstreaming" of precision treatments will present more complex cases for clinicians. There is evidence that the multi-disciplinary team (MDT) model in its current format struggles to cope with the challenges of an ageing population and more complex case work.<sup>98</sup> The traditional model will need reform to cope with these challenges. Streamlined MDT models is one way in which to meet the new demands. At present, implementation of streamlined MDTs varies across the country. Learning from best practice and sharing knowledge across the NHS is central to further streamlining.

There is often not enough time in MDT meetings to discuss patients with complex needs. The wider uptake of precision treatments may increase the number of complex cases and further reduce time for discussion of patients at MDT. Meanwhile, MDT activity has increased but workforce capacity continues to be a problem. Consequently, almost half of all patient discussions last two minutes or less.<sup>99</sup>

MDT working needs to be optimised so that they operate more efficiently. The England Cancer Strategy made recommendations to streamline MDTs, which may be more appropriate for some cancers where pathways are well defined. However, this happens sporadically across England. There is currently no national guidance or protocols for streamlining MDTs, which would be valuable in increasing uptake of streamlined MDT protocols.

### **Good practice needs to be developed and shared across cancer services to ensure any streamlining of MDTs is efficient and effective and doesn't cause any inequity in patient outcomes.**

Individuals may wish to participate in a clinical trial to access a new treatment or make a contribution to future knowledge, and evidence suggests patients may do better in a clinical trial

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<sup>97</sup> [https://www.macmillan.org.uk/\\_images/lung-health-check-manchester-report\\_tcm9-309848.pdf](https://www.macmillan.org.uk/_images/lung-health-check-manchester-report_tcm9-309848.pdf)

<sup>98</sup>

[https://www.cancerresearchuk.org/sites/default/files/full\\_report\\_meeting\\_patients\\_needs\\_improving\\_the\\_effectiveness\\_of\\_multidisciplinary\\_team\\_meetings.pdf](https://www.cancerresearchuk.org/sites/default/files/full_report_meeting_patients_needs_improving_the_effectiveness_of_multidisciplinary_team_meetings.pdf)

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[https://www.cancerresearchuk.org/sites/default/files/full\\_report\\_meeting\\_patients\\_needs\\_improving\\_the\\_effectiveness\\_of\\_multidisciplinary\\_team\\_meetings.pdf](https://www.cancerresearchuk.org/sites/default/files/full_report_meeting_patients_needs_improving_the_effectiveness_of_multidisciplinary_team_meetings.pdf)



when compared to routine care.<sup>100</sup> We know that current access to research, including clinical trials, is poor with just 31% of respondents to the 2017 England Cancer Patient Experience Survey saying they had had a discussion about opportunities to participate in research.<sup>101</sup> Some centres are better at involving patients in trials than others. For example, the presence of a trial nurse at a MDT meeting is a factor which may affect recruitment, however this doesn't happen at every centre or there are too few trial nurses covering large areas and portfolios. The rapid development of precision medicines and use of biomarker segregation presents additional challenges and opportunities to the recruitment of patients for trial for the foreseeable future. For example, increasing research into rarer cancers means patients may be more difficult to find and with a smaller pool available to recruit from.

With people living with and beyond cancer growing and ageing there needs to be focus on preparing patients for how to cope with the long-term consequences of their condition and treatment to give them a better quality of life. These include physiological and social consequences and physical consequences.<sup>102</sup> Those affected will need to be supported with timely and appropriate information to enable them to access support. This includes children and teenagers affected by cancers. Around 76% of children live 10-years or more and around 80% of young people live at least five years following a cancer diagnosis, trends which are improving.<sup>103</sup> The potential late effects of cancer that emerge in adulthood can be mitigated or managed with timely and appropriate information.

There is a lack of data on the side effects and long-term consequences of treatment for cancer, limiting the predictions healthcare professionals can make about the long-term risks. Part of the problem is that data is not consistently or routinely collected and reported in patients' medical records around the consequences of treatment. This information can help to develop targeted treatments and advise patients on the potential long-term risks associated with their treatment. To enable people to seek help quickly to cope with side effects and long-term consequences of treatments there needs to be greater understanding of how people experience toxicities. Patients are in favour of more patient reported outcomes data to help give insight into what life will be like during and after treatment.<sup>104</sup> To make people aware of the side effects and long-term consequences of treatment and enable them to seek help, more evidence is needed on how people experience toxicity.

There are existing challenges around the extent to which patients can access information and support around the long-term consequences of treatment. As evidenced in the section above (1.3 on preparing for treatment) prehabilitation can improve physical outcomes. Further, prehabilitation supports improved quality of life, reduced complications, increased tolerance to treatments and reductions in length of stay. There is no explicit mention of prehabilitation in England focused cancer strategies, resulting in varied understanding and implementation of prehabilitation across the country. **Prehabilitation should be considered as an integral part of the rehabilitation pathway, and not as a standalone intervention.** Early work has commenced in developing UK wide principles and guidance for prehabilitation and these should be actively promoted.

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<sup>100</sup> <https://qualitysafety.bmj.com/content/14/3/175> and <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-015-1105-3> and [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>101</sup> <http://www.ncpes.co.uk/reports/2017-reports/national-reports-2>

<sup>102</sup> [https://www.macmillan.org.uk/documents/aboutus/newsroom/consequences\\_of\\_treatment\\_june2013.pdf](https://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf)

<sup>103</sup> <https://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers/survival#heading-Zero> and <https://www.cancerresearchuk.org/health-professional/cancer-statistics/young-people-cancers/survival#heading-One>

<sup>104</sup> <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0092-4>

### 4.3 Cancer wait standards

**There should be a review of current cancer wait times *for all cancers* to consider best options for benchmarking and performance managing cancer services.**

Cancer Wait Times are designed to monitor performance and improve standards on time to treatment. Macmillan supports the use of targets to monitor waiting times in principle. Historically, people with cancer faced long wait times contributing to poorer outcomes and worsening patient experience. The introduction of cancer wait time targets has enabled patients to be treated more quickly, reducing anxiety and worry.<sup>105</sup> However performance against the 62-day wait has failed in recent years, with significant variation among cancer types, and performance against the two-week wait has worsened in recent months.

Improving performance against waiting time standards is increasingly problematic for many providers. We know that complex case mixes mean that some cancers take longer to investigate or patients may choose to delay treatment. Furthermore, delayed access to diagnostic tests is exacerbated by a growing workforce deficit. Case mix is out of providers' control and as the diagnostic workforce is generalist, it needs a strategic approach.

The current target measuring the number of patients who start to receive first definitive treatment for cancer within 62-days of an urgent GP referral does not reflect these nuances. As a result, providers find meeting the target difficult and likely prioritise meeting those targets which are more achievable. **While the 62-day waiting time standard is a useful barometer of service capacity, particularly in relation to diagnostics, Macmillan does not believe it represents the most effective means of performance managing providers.**

### 4.4 Genomic medicine service

The development and roll-out of the genomic medicine service should be sufficiently resourced to ensure equitable access across the country and reduce the potential for exacerbating health inequalities.

The roll out of the service should include significant resources for meaningful patient engagement, including with seldom heard groups, to ensure that genomics is well understood and accessible to all. Further to this, NHSE should provide the necessary infrastructure to deliver the service, especially in trusts that are less well developed in terms of IT infrastructure.



## 5. Widening access to digital and technology

Rapid advances in technology are changing the way we access information and consequently how we access and interact with healthcare. Digital technology can impact all aspects of cancer care, including at the point of diagnosis, during treatment and post-treatment too. **Macmillan Cancer Support wants to see digital healthcare and technology that is affordable, usable and inclusive. Among other things, this should reduce the administrative burden on healthcare professionals (HCPs), freeing up more time for patient care.**

The advantages of digital technologies in improving healthcare are obvious – empowering patients to take a more pro-active role in their healthcare, streamlining work processes and enhancing the relationship between healthcare professionals and patients – but it also comes with a few challenges.

Delivering on digital health for all will enable the NHS to provide truly personalised, joined up care for patients - improving their experience and maximising the use of resources. But to deliver this

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<sup>105</sup> <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0201288>

vision, we first need to get the basics right first. Despite significant interest in digital health for many years, progress has been slow and results have been patchy and fragmented across the country.

## 5.1 Patient use of digital and technology

'Digitally excluded' groups risk being left behind if technology is not designed and introduced in a way that meets the diverse digital needs of the population. In the UK, around 5.3 million people say they have never been online, and 12.6 million don't have basic digital skills. This means 23% of the UK population are currently less able to benefit from advancements in digital health.<sup>106</sup> Evidence suggests that a cancer diagnosis can be a trigger to engage more heavily with digital health interventions, whether this is using the internet to understand a diagnosis or treatment, or more complex activities such as downloading and using apps to manage a long-term condition.<sup>107</sup> In these instances, guided use by a friend or family member is a common way of improving digital literacy, at least sufficiently to perform basic tasks to aid their cancer journey.

Health literacy is also an issue when designing digital technologies, especially offerings that aim to help patients understand their disease and make informed decisions. Levels of health literacy shows significant variation across the country, affecting a person's ability to access and understand information pertaining to their health.<sup>108</sup> Work by the Tinder Foundation has suggested that some patients find the information on the NHS Choices website too overwhelming.<sup>109</sup> When designing patient facing digital interventions, it is therefore vital to ensure that they are understandable and usable for all and help patients without confusing or concerning them – allowing for delivery of truly personalised care. Measures should also be taken to direct patients to viable sources of high quality information, reducing the chance of increasing anxiety based on a google search of their symptoms. This is also a significant problem for digital decision aids, where overwhelming numbers of options can paradoxically be detrimental to the process of choosing treatment options.<sup>110</sup> Significant patient engagement during the development of technologies and guided use when necessary are important to avoid creating technologies that worsen feelings of confusion and anxiety for patients at an already difficult time.

The current market for digital health tools and apps is a crowded place, and this can be confusing for some patients who may struggle to understand which digital intervention may be best for their needs. In 2015 a study by the IMS Institute for Health Informatics estimated there were as many as 165,000 health related apps – a number that is likely to have grown considerably in the past few years.<sup>111</sup> These apps serve a wide range of purposes including tailored guidance, accessing clinical records, group support and enabling communication with healthcare professionals. However, while the NHS Apps library is tasked with reviewing apps for their quality and effectiveness, a significant number of apps on the market remain that may have little or no benefit for patients. Methods of accessing health records also vary across the country depending on a patient's GP practice – such a fragmented and crowded system of digital solutions can only serve to confuse patients.

A robust system of appraising digital health technologies will be important in the future, not only to ensure that patients are accessing useful resources, but also to help guide developers while creating new interventions. The current assessment process for app developers, developed by PHE<sup>112</sup>, covers many key features of app development, including interoperability, data protection and evidence of co-creation or consultation with relevant target groups. These criteria should be widely communicated and adapted as needed to ensure app developers are creating products that are suitable for the NHS now and in the future. Despite challenges in ensuring the quality and usability of digital tools such as patient apps, when developed and used properly in consultation with their target audience, they have the potential to improve patient experience by helping provide joined up personalised care.

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<sup>106</sup> Nuffield Trust (2018) – [Why the NHS must tackle digital exclusion](#)

<sup>107</sup> Macmillan Cancer Support (2017) – *Patient needs in digital* (unpublished). Also see: Corbett, T, et al. (2017) [Understanding acceptability of and engagement with Web-based interventions aiming to improve quality of life in cancer survivors: A synthesis of current research](#). *Psycho-Oncology*. 2017; 1– 12.

<sup>108</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4370358/>

<sup>109</sup> Tinder Foundation (2015) – [Digital nation: Facts, stats and closing the gap](#)

<sup>110</sup> Chernev A, et al. (2015) - [Choice overload: A conceptual review and meta-analysis](#), *J Consum Psychol* 22 (2015) 333–358

<sup>111</sup> IMS Institute for Healthcare Informatics (2015) – [Patient adoption of mHealth](#)

<sup>112</sup> PHE (2017) - Health app developers: The assessment process

We support initiatives to activate patients through digital technology, **but all new digital systems should be built and monitored with consideration of their ability to create and exacerbate health inequalities.** It is important to acknowledge that digital pathways are not suitable for everyone, and multiple pathways need to be available to avoid increasing inequalities. Digital maturity varies across the population. A purely digital route to healthcare – and digital health technologies designed only for those with a high level of digital literacy - risks leaving people behind and perpetuating a possible increase in health inequalities.

Ensuring that processes are inclusive of everyone is an integral part of getting the basics right and improving patient experience. When technology is used successfully in an equitable way, older, less educated and more deprived people can benefit more from digital interventions than younger, more affluent groups<sup>113</sup> - potentially closing the gap between the groups with the best and worst outcomes. Consideration of health inequalities should be an integral part of developing any digital health technology, and the NHS should monitor uptake of new technologies to ensure they are used in an equitable fashion.

## 5.2 The potential for digital in patient self-management and care

Digital health technologies also have a large role to play in building a system that delivers truly personalised care for patients – improving outcomes and patient experience. Digital resources can offer a simple way for patients to access the information they need to manage their own conditions, and interact with the healthcare system in new ways – enhancing the patient-clinician relationship and allowing patients to stay out of hospital while maintaining a high level of care.

**Digital health technologies should work to empower patients to take a more active role in their healthcare and increase their involvement in decision making.** Patient facing technologies should aim to improve patient experience by increasing people’s ability to control and contribute to their care. For instance, being able to access and contribute to healthcare records and track appointments from referral into the system would save time spent on coordinating care for both patients and healthcare professionals. Such a system would also allow patients to share their data in line with their own needs – helping deliver joined-up care, tailored to the needs of the individual. Digital technology can also help patients in proactively looking after their health, altering behaviours and potentially preventing a further need for healthcare interventions.

A cancer diagnosis can act as a trigger for many people to engage more frequently with digital technology – whether that be through using the internet, downloading health apps or online forums. A key factor in enabling many people to do this is having a friend or family member who can help them learn to use a new technology or application. Guided use could introduce patients to new technologies so they can use them to coordinate and complement their care. Using this opportunity to increase the digital skills of patients beyond a single technology could also have knock-on benefits for their future interactions with healthcare. Alternatively, for those with limited access to technology or internet connectivity, providing facilities across the NHS estate and in community spaces where patients can access technology and receive guidance could be a successful way to reduce the potential for inequalities. We would welcome further research into this approach and the best ways of encouraging digital literacy amongst patients - investigating whether guided use would be best delivered by HCPs or in a community setting.

## 5.3 Patient data

**The NHS should continue to work with partners to communicate the importance of patient data and the measures in place to protect it.** While the NHS ranks highly as an organisation that people trust with their data<sup>114</sup>, it will be vital to continue to build public trust as health technology advances. Recent changes to data protection legislation, including GDPR, the new Data Protection Act and the roll-out of the National Data Opt-out have led to a potentially confusing landscape for both patients and the workforce. Communicating these changes in a clear and understandable way is vital for building trust in the system and avoiding repeats of past controversies such as care.data. We welcome the work of organisations like Understanding Patient Data and UseMyData, as well as NHS England’s communication

<sup>113</sup> Basch, E, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol*. 2016; 34(6): 557–565.

<sup>114</sup> Ipsos MORI (2018) - [New research finds data trust deficit with lessons for policymakers](#)

campaigns around the launch of GDPR and the National Data Opt-out, and would like to see a continued commitment to transparent communication around the storage and use of patient data.

A large part of the solution to all the above issues is an increase in meaningful engagement with patients during the development and implementation of digital solutions, and clear communication about the benefits of digital solutions. If we can invest in the basics to ensure that trusts can implement new technologies – patients can then play a huge role in creating the tools for a digital health system that works for them. **The NHS should require that digital health technologies for routine use are co-created with relevant stakeholders - such as patients and the workforce – to ensure their utility and accessibility for all.**

#### 5.4 Workforce use of digital and technology

The success of any digital health technology is heavily reliant on the willingness and ability of the workforce to use it in routine care. If new technologies are not well designed and implemented, they can be seen as an extra burden by some staff members. This in turn limits their use and prevents the widespread role out needed for improved patient outcomes and efficiency gains. In 2017 the Academy of Medical Royal Colleges set out its clinical requirements for information and digital technologies.<sup>115</sup> Overarching recommendations from this report included creating systems with easy and complaint free access to patient records across care boundaries that are intuitive to use and commensurate with routine use by non-permanent staff. This required that systems take less than an hour to learn to use safely and less than half a day to master. New technologies should be practical to use at the point of care without queueing or waiting. Developing such technologies requires engagement with the workforce, as highlighted by research from the King's Fund.

If designed and implemented properly, digital health solutions have the potential to improve patient care and free up time for healthcare professionals (HCPs) to spend with patients. This will not only allow for better person-centred care, but may also help relieve some of the current pressures on the workforce.

Rapid advances in technology also require the workforce to be responsive to change and learn new skills to deliver care in new ways. Training staff to use new systems in the context of an already overstretched NHS can be challenging, and failure to implement technology has often been attributed to systems not treating innovation as an adaptive, cultural change, rather than merely a technical one.<sup>116</sup> As technology becomes more commonplace in healthcare, the workforce will not only need to learn to use technology for their day to day work, but also to guide patients – often with low levels of digital literacy – to use technology as part of their own healthcare. A system of training and backfilling staff could be used to help free up time for learning these new skills in an already stretched workforce. Initiatives such as the NHS digital academy are already underway to improve the digital capabilities of the NHS workforce, but with the first cohort only having started in March 2018, we are still a long way from seeing significant impact.

Macmillan's work on the Review of Informed Choice for Cancer Registration highlighted that many HCPs do not feel comfortable talking about data flows and information governance<sup>117</sup> – key skills for guiding patients in their use of digital tools. Training will be needed to give all staff a basic working knowledge of digital health tools, with more specialised programmes developed for staff who need to be highly skilled in the use of digital health interventions. The basics of data governance and digital literacy will need to be included in the basic training of all new health care professionals, and programmes will need to be developed for long serving and returning staff.

Macmillan would like to see a system that can harness technological advances and innovation to benefit people living with cancer in the shifting landscape of healthcare delivery. For this to happen the long-term plan must create the conditions for full uptake of proven technologies. This will include upgrading outmoded technologies and digitising pathways across health and social care, while addressing the cultural shift and workforce development that will be needed to ensure that patients are fully informed and able to engage with digital technology in an informed and safe manner – allowing them to make better

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<sup>115</sup> Academy of Medical Royal Colleges (2017) – [Information and Digital Technologies Clinical Requirements 2020](#)

<sup>116</sup> [The Wachter Review \(2017\) - Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England](#)

<sup>117</sup> Macmillan Cancer Support and CRUK (2016) - [Improving awareness of the English cancer registry amongst patients, health professionals and the public](#)

choices about their own care.

***Digital technology should aim to enhance the workforce and not replace it.***

With current workforce pressures, well implemented technological solutions will allow healthcare professionals to spend more time looking after patients and less time with administrative and simple tasks. Technological changes will require the workforce to work differently, ensuring that digital interventions (e.g. teleconsultations) have sufficient staff resources to improve patient experience, while maintaining a sufficient workforce to deliver holistic patient centred care in more traditional settings. Any aim to use technology to save money by replacing staff may lead to a decrease in quality of care, and this should be a key consideration during the development and implementation of any new technology.

**HEE and the NHS need to ensure that staff are sufficiently trained to use new technologies and understand changes to information governance as they are rolled out across the system.**

Rapid advances in technology will require constant development of individual staff members and the wider skills mix of the workforce to ensure cancer services can keep pace with change. Core principles, such as information governance should be taught to all staff, starting during initial training, with regular updates to ensure all staff are up to date. This should include the skills needed to answer questions posed by patients and signpost them to relevant resources. Training resources will need to give all staff basic digital skills, with more advanced programmes being developed for more digitally focused roles. As technology using AI and machine learning are more widely adopted, training must also prepare HCPs for blended decision making, where the outcome is based on outputs from algorithms combined with human judgement. Investing in skills related to change management will also be important for helping embed new systems. We welcome the work of HEE and the Topol review to better understand the impact of technology on the future workforce and how we can prepare for it.

**Opportunities to develop AI solutions should be explored to help alleviate workforce pressures where possible.** As technology using AI and machine learning becomes more common place, the NHS should seek to capitalise on technologies that can alleviate workforce pressures and improve patient outcomes and experience. Any such technology must be rigorously tested and regulated to ensure that it is not detrimental to patient safety, and adheres to regulations around data protection. The use of AI to perform digital pathology tasks is a good example of how technology can be used to streamline time-consuming processes when used in tandem with experienced staff to validate results<sup>118</sup>.

## 5.5 Macmillan's contributions

Macmillan are increasingly funding research into digital technologies with the potential to improve patient experience, including explorations into the role of VR in helping patients deal with the consequences of treatment, and producing digital aids to help patients navigate their care across multiple sites.<sup>119</sup> Macmillan are also rolling out electronic versions of key interventions such as the Holistic Needs Assessment (HNA) a core component of the recovery package, which NHS England committed to rolling out more widely in the 2015-20 cancer strategy. The eHNA was developed to offer an electronic method of completing the HNA – this ensures that HNAs are consistent across the country, and allows for data to be collected and stored for groups of patients – identifying common unmet needs and helping inform service provision.

A survey in 2015 revealed that 96% of patients felt that completing and eHNA was easy or very easy, and 90% of HCPs felt that HNAs were important for the overall care of their patients.<sup>120</sup> Patients who completed an eHNA found it helpful and were more likely to receive support at the right time compared to patients who didn't fill out an eHNA. Importantly, 91% of HCPs felt that the aggregated data from eHNAs was useful or very useful.<sup>121</sup> The EHNA is a key example of how even simple electronic tools can improve the experiences of both patients and the workforce.

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<sup>118</sup> Acs B, Rimm DL. (2018) [Not Just Digital Pathology, Intelligent Digital Pathology](#). JAMA Oncol. 2018;4(3):403–404. doi:10.1001/jamaoncol.2017.5449

<sup>119</sup> [Living well with Oesophageal Cancer](#)

<sup>120</sup> Ipsos Mori 2015 - [Evaluation of the electronic Holistic Needs Assessment \(eHNA\)](#)

<sup>121</sup> Young J, Cund A, Renshaw M, Quigley A. [Improving the care of cancer patients : holistic needs assessment](#). Br J Nurs. 2015;24:2012–6.

With digital technology set to play an ever-increasing role in the delivery of healthcare, Macmillan will work to understand what patients and the workforce would like to see from advancements in technology, - developing solutions that improve patient care while alleviating workforce pressures and streamlining processes for health and social care systems. However, there remain key areas of work the NHS needs to take responsibility for so digital health and technology can truly work for all.



### **More information**

If you would like more information on the content of this written submission, please contact [NHSinfluencing18@macmillan.org.uk](mailto:NHSinfluencing18@macmillan.org.uk)