

## Written evidence submitted by Macmillan Cancer Support (ECS0026)

**1.1** Macmillan Cancer Support is a registered charity providing information and support for people with cancer. There are around 3 million people currently living with cancer across the UK with 385,000 people receiving a cancer diagnosis every year.<sup>1</sup> The population of people living with cancer is projected to reach 4 million by 2030<sup>2</sup>. Macmillan plays a key role in supporting the NHS workforce. Over the past ten years Macmillan has invested £386 million in the NHS. Macmillan funds nearly 12,000 Macmillan nurses, doctors, and other health professionals.<sup>3</sup>

**1.2** Macmillan supports people with cancer throughout their cancer journey – we work on the range of topics that the Expert Panel has identified. For the purposes of this submission we have prioritised workforce and personalised cancer care issues.

### Government Commitment 1: Workforce

*The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021*

#### **Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?**

**1.3** Progress has been made around expanding some parts of the workforce. However, there are still chronic shortages in key roles, for example in diagnostic roles which result in unacceptable waits for patients. The Cancer Workforce Plan never delivered a detailed vision or actions setting out the growth and support required by the non-medical workforce caring for people with cancer.

#### **Specialist cancer workforce**

**1.4** The 2017 Cancer Workforce Plan<sup>4</sup> has supported much-needed increases in cancer posts. Phase 1 of the Plan committed that “We will support the expansion of Cancer Nurse Specialists so that every patient has access to a [Clinical Nurse Specialist] CNS or other support worker by 2021 by developing national competencies and a clear route into training, with a more detailed report on nursing and cancer in the light of new census data in spring 2018”. Macmillan provided Health Education England (HEE) with detailed figures from our 2017 Census of cancer, palliative and chemotherapy speciality nurses, and support workers in England<sup>5</sup>. However we note that a detailed report on cancer nursing/non-medical roles was never published.

**1.5** The NHS England (NHSE) commitment to provide 250 grants for specialist cancer nurse training and 100 grants for chemotherapy nurse training in the most recent NHS People Plan 2020/21 is a welcome step, and one of the few condition-specific commitments on nurse training. However this is not enough to fill the gaps in the cancer workforce. We need to facilitate and support people into specialist nursing posts where there are vacancies, but we also need a massive expansion in post numbers to meet patient need.

**1.6** Macmillan estimates that by 2030 the number of people living with cancer will reach 3.3 million in England<sup>6</sup>. Our research indicates that if the number of specialist cancer nurses stays at the current

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<sup>1</sup> Statistics fact sheet, Macmillan Cancer Support, 2021. [https://www.macmillan.org.uk/\\_images/cancer-statistics-factsheet\\_tcm9-260514.pdf](https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf)

<sup>2</sup> Calculating cancer prevalence. Macmillan Cancer Support. <https://www.macmillan.org.uk/about-us/what-we-do/evidence/using-cancerdata/calculating-cancer-prevalence.html>

<sup>3</sup> Macmillan annual report, Macmillan Cancer Support, 2018 [https://www.macmillan.org.uk/\\_images/macmillan-2018-annual-report-andaccounts\\_tcm9-354056.pdf](https://www.macmillan.org.uk/_images/macmillan-2018-annual-report-andaccounts_tcm9-354056.pdf)

<sup>4</sup> Cancer Workforce Plan, Health Education England 2017, <https://www.hee.nhs.uk/our-work/cancer-workforce-plan>

<sup>5</sup> Cancer workforce in England: A census of cancer, palliative and chemotherapy speciality nurses, and support workers in England in 2017, Macmillan Cancer Support, 2017 Cancer workforce in England, [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)

levels, we will be short of 3,371 nurses in England by 2030. We have calculated that a financial investment of £124 million will be needed to train the cancer nurses needed to fill this gap<sup>7</sup>.

**1.7** The impact of Covid-19 on staff working in cancer care has been significant. Some cancer professionals were re-deployed during the pandemic whilst others were required to take on new responsibilities. Interviews conducted by Macmillan in Summer 2020 indicated that a combination of staff needing to self-isolate or shield and being re-deployed meant the cancer workforce was severely depleted<sup>8</sup>. We are very concerned that this has resulted in higher levels of burnout and a less resilient workforce. In addition, the specialist cancer nurse population is ageing. Macmillan's 2017 workforce census data highlighted that 37% of specialist cancer nurses were over 50. This increased from 33% in the 2014 census and raises concerns that the system is not adequately preparing for the future<sup>9</sup>.

**1.8** Survey data indicates that working under such intense workloads and sustained pressures with mounting staffing gaps is pushing more than 50% of nurses to consider leaving the NHS<sup>10</sup>. NHSE and HEE must take urgent action to retain the cancer workforce and support overstretched professionals by boosting the supply and retention of the general adult nursing workforce. This is necessary to ensure all nurses have backfill for their clinical commitments to undertake continuing professional development (CPD) and ensure a pipeline for specialist nursing roles to double the number of cancer nurse specialists required by 2030. Pay and reward is an integral part of ensuring adequate workforce numbers. Pay for the cancer workforce must be fair and reflect their value and contribution.

**1.9** Ongoing access to training and professional development opportunities is vital to providing high quality care. Over three-quarters of cancer nurses in England (76%) have told us that having more time for Continued Professional Development (CPD) would help them improve care for people living with cancer<sup>11</sup>.

**1.10** Specialist cancer nurses and lead cancer nurses have reported three main barriers to accessing CPD – lack of protected time, lack of funding and lack of locally available courses.

**1.11** Even before the pandemic, Macmillan 2019 research, found only a third (36%) of specialist cancer nurses had protected study time to access and attend CPD training.

**1.12** One in five (22%) of CNSs had taken annual leave to undertake CPD<sup>12</sup>. Individual workload was the most significant reported barrier to professionals being able to take time to access and attend training, with over half (58%) agreeing this was the case. Without backfill for clinical commitments many nurses are unable or unwilling to undertake CPD. CNSs have been reporting workload pressures for a long time. In 2019 Macmillan found that 39% of specialist cancer nurses did not feel their current workload was manageable and 44% felt that their workload was negatively affecting their morale<sup>13</sup>.

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<sup>6</sup> Statistics Fact Sheet, Macmillan 2021

<sup>7</sup> Cancer nursing on the line, Macmillan Cancer Support, 2021. [https://www.macmillan.org.uk/\\_images/Forgotten-C-Nursing-Report\\_tcm9-360416.pdf](https://www.macmillan.org.uk/_images/Forgotten-C-Nursing-Report_tcm9-360416.pdf)

<sup>8</sup> Background interviews for Macmillan Cancer Support's submission to the Health and Social Care Select Committee Inquiry on Workforce burnout and resilience in the NHS and social care, June 2021. <https://committees.parliament.uk/publications/6158/documents/68766/default/>

<sup>9</sup> Cancer Workforce in England: Macmillan Cancer Support, 2018.

<sup>10</sup> Royal College of Nursing, January 2022, <https://www.nursingtimes.net/news/workforce/rcn-survey-suggests-half-of-nursing-staff-thinking-about-quitting-04-01-2022/>

<sup>11</sup> Voices from the Frontline, Macmillan Cancer Support, 2019 [https://www.macmillan.org.uk/\\_images/voices-from-the-frontline-september-2019\\_tcm9-355168.pdf](https://www.macmillan.org.uk/_images/voices-from-the-frontline-september-2019_tcm9-355168.pdf)

<sup>12</sup> [Voices from the Frontline](#), Macmillan Cancer Support, 2019

<sup>13</sup> [Voices from the Frontline](#), Macmillan Cancer Support, 2019

**1.13** Funding was also seen as a significant issue, with 43% of CNSs citing lack of funding as the main barrier to accessing CPD in the last 12 months. Funding from charitable or professional grants accounted for over half (54%) of the overall funding for CPD and one in five (22%) of CNSs had self-funded their CPD.

**1.14** A third of CNSs (33%) reported being unable to access CPD because of a lack of local courses.

### **Wider workforce**

**1.15** Specialist cancer nurses sit within a much larger team of professionals, all contributing to the delivery of high quality, personalised cancer care. Workforce funding and strategy must quantify and address gaps in this wider group of professionals to ensure that the right skills mix is available to deliver the best care to people living with cancer.

**1.16** GPs and primary care teams also play a big role in supporting people across the cancer pathway, including cancer management, follow up care after treatment and at end of life. This role is set to increase as the number of people living with cancer grows. People with cancer require coordinated and personalised care from their GPs, in collaboration with secondary care teams, to support their health needs. Easy access to primary care services is a key component of this, but these services are currently under significant pressure.

**1.17** The Government has made a welcome commitment to recruit 6,000 additional GPs by 2024, but it must urgently ramp up efforts to deliver on this promise (by its own admission this is not on track<sup>14</sup>) and further bolster our primary care workforce. This includes not just GPs, but also the wider primary care team who can offer vital support to people living with cancer, including nurses, link workers, and Allied Health Professionals such as dietitians, physiotherapists, and paramedics.

### **Was the commitment effectively funded (or resourced)?**

**1.18** The commitment was not effectively funded. HEE was allocated £46 million from the 2020/21 Comprehensive Spending Review (CSR) for cancer and diagnostics workforce education and training. Unspecified grants were also made available under the NHS People Plan for the recruitment and training of cancer nurse specialists and chemo nurses and diagnostics staff. However this was a one-off funding allocation. This is a long way from the recurring investment in recruiting and retaining the cancer workforce that Macmillan has called for, including planning for training an extra 3,371 specialist cancer nurses by 2030. We note that HEE's budget for NHS workforce recruitment, training and support has not been published as part of the 2021-24 CSR despite the CSR committing that: "The government will provide hundreds of millions of pounds in additional funding over the SR21 period to ensure a bigger and better trained NHS workforce"<sup>15</sup>.

**1.19** NHSE and HEE should urgently deliver a fully costed cancer workforce plan. This must be based on realistic estimates of the workforce numbers that will be required to meet the needs of people living with cancer and must be supported by long-term financial investment from the government.

**1.20** The Government is yet to confirm the funding allocation for the next three years, but once announced, it is unlikely to provide the foundation for the long-term planning and security required to meet transformational multi-year Long Term Plan commitments.

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<sup>14</sup> No 10 set to break promise of 6,000 more GPs in England, Sajid Javid says, The Guardian, 2 November 2021.

<https://www.theguardian.com/society/2021/nov/02/no-10-set-to-break-promise-of-6000-more-gps-in-england-sajid-javid-says>

<sup>15</sup> Autumn Budget and Spending Review 2021, HM Treasury 2021,

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1043689/Budget\\_AB2021\\_Web\\_Accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1043689/Budget_AB2021_Web_Accessible.pdf)

### **Did the commitment achieve a positive impact for patients?**

**1.21** People with cancer consistently report that they value the support of experienced, knowledgeable cancer professionals<sup>16</sup>. This support is integral to delivering high quality, personalised care which benefits people with cancer. For example, the 2018 Cancer Patient Experience Survey showed that 76% of respondents said that it had been ‘quite easy’ or ‘very easy’ to contact their CNS and 84% said that when they had important questions to ask their CNS, they had got answers they could understand all or more of the time<sup>17</sup>.

**1.22** However, as evidenced above, the workload issues facing cancer nurses and development needs of the non-clinical workforce has meant that this commitment hasn’t been as extensive as it could have been.

### **Was it an appropriate commitment?**

**1.23** The commitment has not secured the workforce needed to provide personalised care for everyone with cancer. Recruiting and retaining the right level of cancer and general workforce to meet the needs of the current and future needs of people with cancer requires detailed long-term planning and investment.

**1.24** In order to achieve this:

- The Government must commit to producing an independently verified assessment of health and social care workforce numbers every two years, as well as a projection of workforce supply and demand (based on projected health and care needs) in the following five, ten and 20 years. A commitment to do this should be incorporated into legislation as part of the Health and Care Bill.
- HEE and NHSE, alongside local Integrated Care Systems (ICSs) and Cancer Alliances, should be accountable for ensuring that cancer nurses across England have equal access to relevant CPD to end variation in access. Geographical location or lack of charitable funding should not be barriers to accessing CPD.
- There should be clear and supported professional development pathways for a nurse to become a CNS. HEE, NHSE, ICSs, and Cancer Alliances should work together to support this at local level. Local bodies should also undertake proactive workforce planning, which includes providing structured support programmes for the development of general adult nursing staff to gain insight and experience of cancer nursing.

### **Government Commitment 3: Living well with and beyond cancer**

*By 2021 where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.*

### **Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?**

**2.1** No – the deadline for this commitment has passed, without everyone with cancer being able to access personalised care.

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<sup>16</sup> One size doesn’t fit all, Macmillan Cancer Support, 2018 [https://www.macmillan.org.uk/images/one-size-doesnt-fit-all-report-web\\_tcm9-341625.pdf](https://www.macmillan.org.uk/images/one-size-doesnt-fit-all-report-web_tcm9-341625.pdf) Caught in the Maze, Macmillan Cancer Support, 2021, [https://www.macmillan.org.uk/images/caught-in-the-maze-report\\_tcm9-359697.pdf](https://www.macmillan.org.uk/images/caught-in-the-maze-report_tcm9-359697.pdf)

<sup>17</sup> Cancer Patient Experience Survey – National Results Summary Picker, 2019 [https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report\\_V1.pdf](https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf)

**2.2** This is a very difficult commitment to track performance on because it is evidenced by a combination of personalised care interventions and people’s reported experiences. The Cancer Outcomes and Services Dataset measures specific interventions (whether a person had an HNA, a care plan) but these are not fully reported and do not capture the totality of someone’s access to personalised care and how it benefitted them. NHSE estimates that 80% of multi-disciplinary teams are offering personalised care and support planning – the data supporting this is not published<sup>18</sup>.

**2.3** At local level, service delivery of the Long-Term Plan commitment depends on whether Cancer Alliances prioritise personalised care in their plans, which are not published. Inevitably during the last two years of the pandemic, NHSE has focussed on referral, diagnosis, and treatment pathways in its guidance to services. It is therefore been even more difficult to hold services to account around personalised care commitments over this period.

**2.4** The latest Cancer Patient Experience Survey (CPES) data is expected in Summer 2022 (Covid-19 pressures prevented a full CPES national report being conducted in 2020). Previous CPES results have consistently recorded the level of people saying they have been given a care plan at around 35%. In 2019, 38% said they had been given a care plan<sup>19</sup>.

**2.5** Macmillan survey data also shows high levels of unmet need amongst people with cancer. The pressures of the pandemic have added to people’s physical and emotional health needs, the strain on services and the workload of cancer professionals who are key to delivering personalised care. Our evidence shows:

- High levels of unmet psychosocial needs: Research commissioned by Macmillan in February 2021 showed that around 40% of people living with cancer said that the pandemic has affected their wellbeing. Of those individuals, 73% said the pandemic made them feel anxious and/or depressed. A minority of respondents accessed support for their mental health during the pandemic. Around 83% of people who self-identified as having anxiety and/or depression did not try to access support for their mental health from their cancer team. Around 40% of those that did, found it difficult<sup>20</sup>.
- Almost half of people Macmillan surveyed in July/August 2021 reported serious medical impacts (including ending up in A&E, being unsure about the side-effects of cancer treatment or if they were taking their medication correctly) as a result of missing out on the personal support of a cancer professional. 25% of people diagnosed with cancer in the UK in the past two years – including at least an estimated 75,000 people diagnosed since the start of the pandemic – have lacked specialist cancer nursing support during their diagnosis or treatment (meaning they didn’t get any support and would have liked to, or the support they got wasn’t enough)<sup>21</sup>.
- Serious ongoing health issues: the new NHSE Quality of Life cancer metric shows that people experience significant health and wellbeing needs for many months after diagnosis. For example, almost half (48%) of respondents had problems carrying out their usual activities (work, study, housework, family, or leisure activities) 18 months after their diagnosis, compared with around one in five of the general population. Significant numbers of people

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<sup>18</sup> Personalised care and improving quality of life outcomes <https://www.england.nhs.uk/cancer/living/>

<sup>19</sup> Cancer Patient Experience Survey – National Results Summary Picker, 2019

<sup>20</sup> Macmillan Cancer Support and YouGov. 2021. Ongoing impact of COVID-19 on people living with cancer. Online survey of YouGov online survey of 2,156 adults with a previous cancer diagnosis. Fieldwork 15th February - 5th March 2021. Survey data has been weighted to be representative of the UK adult population in terms of age, gender, and cancer type.

<sup>21</sup> Cancer Nursing on the Line, Macmillan Cancer Support, 2021

reported unmet needs at a level that may benefit from further health checks, including difficulty sleeping (26%), fatigue (13%) and constipation (10%)<sup>22</sup>.

**2.6** It is therefore vital not only that personalised care is offered to everyone with cancer, but that following a conversation about their needs with a health professional they are linked with support to meet their needs.

### **Was the commitment effectively funded (or resourced)?**

**2.7** It is difficult to establish if adequate funding has been made available for personalised cancer care. In 2019/20 NHSE published figures on Cancer Alliance allocations including for personalised care initiatives, however these figures have not been updated therefore it is difficult to understand what targeted funding has been allocated to Cancer Alliances to deliver personalised care and/or how much investment Cancer Alliances have dedicated to delivering this programme<sup>23</sup>.

**2.8** The other key resource constraint facing personalised care is the longstanding shortage of cancer professionals. Before the pandemic in 2019, primary care professionals reported that they felt that cancer patients did not have enough time to talk through all their concerns<sup>24</sup>. Our 2021 research highlights how staff shortages and emotional burnout exacerbated by Covid-19, affected the quality of patient care specialist cancer nurses were able to deliver<sup>25</sup>.

**2.9** Part of the challenge in assessing how far the personalised care commitment has been met, is the absence of any national published performance metric on personalised care. Cancer Alliances do not have to publish monthly data on personalised care and are not held to account for their performance, as is the case for Cancer Waiting Times data. There are specific measures which incentivise personalised care at particular points of the pathway - for example around the delivery of cancer care reviews in primary care. However, there is no system-wide incentive to collaborate as organisations to deliver personalised care for everyone with cancer across their cancer journey<sup>26</sup>. The 2015 Cancer Taskforce and subsequent 2015-21 Cancer Strategy stated that patient experience should be on a par with clinical outcomes and survival. The evidence does not point to this having been achieved.

**2.10** In order to achieve this:

- The cancer workforce gaps need to be addressed (as detailed in Section 1)
- A system-wide performance standard to measure the delivery of personalised care for everyone with cancer across their cancer journey should be developed. The evaluation for whether this has been met should include patient experience data and the performance data should be published.
- Personalised care should also be prioritised in national guidance to Cancer Alliances, together with funding to encourage Cancer Alliances to deliver this programme to a high standard.

### **Did the commitment achieve a positive impact for patients?**

**2.11** Patients regularly report the benefits of having dedicated professional support and tailored care planning on their experiences and outcomes<sup>27</sup>. Evidence shows that patients with a named CNS were

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<sup>22</sup> Cancer quality of life survey summary report: first data release October 2021, NHSE <https://www.england.nhs.uk/publication/cancer-quality-of-life-survey-summary-report-first-data-release-october-2021/>

<sup>23</sup> Funding and support for Cancer Alliances, NHSE <https://www.england.nhs.uk/cancer/cancer-alliances-improving-care-locally/nhs-england-support-and-funding-for-cancer-alliances/>

<sup>24</sup> One size doesn't fit all, 2018,

<sup>25</sup> Cancer nursing on the line, Macmillan Cancer Support, 2021 <https://www.macmillan.org.uk/about-us/what-we-do/we-make-change-happen/we-shape-policy/cancer-nursing-on-the-line.html>

<sup>26</sup> Caught in the maze, Macmillan Cancer Support 2021.

more likely to completely understand the explanation of what was wrong with them (74% of patients as opposed to 65% without) and to agree that they had definitely been involved in decisions about their care and treatment as much as they wanted to be (80% as opposed to 62% without)<sup>28</sup>.

**2.12** There remains a question about the impact that this commitment has made to everyone with cancer, including groups exposed to health inequalities, particularly low income, and socially deprived groups. These are people who could benefit significantly from personalised care e.g. people with the lowest incomes are twice as likely to report unmet needs on emotional and practical support than higher income groups<sup>29</sup>. Where personalised care interventions are targeted at marginalised communities there is evidence that they have a hugely beneficial impact<sup>30</sup>.

**For further information on this submission, please contact Clare Woodford**

**Feb 2022**

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<sup>27</sup> One size doesn't fit all, 2018 Macmillan Cancer Support,; Caught in the Maze, 2021, Macmillan

<sup>28</sup> Cancer Patient Experience Survey (CPES) 2019: National Results Summary, 2019

<sup>29</sup> Time to talk 2019, Macmillan, <https://www.macmillan.org.uk/assets/health-inequalities-paper-april-2019.pdf>

<sup>30</sup> Improving the Cancer Journey: More than the Sum of its Parts Edinburgh Napier University. 2018. [https://www.macmillan.org.uk/images/Glasgow-improving-cancer-journey-programme-full-evaluation-2017\\_tcm9-324593.pdf](https://www.macmillan.org.uk/images/Glasgow-improving-cancer-journey-programme-full-evaluation-2017_tcm9-324593.pdf)