Cancer Plan - Call for Evidence: Macmillan submission

Introduction

About Macmillan Cancer Support

Macmillan Cancer Support is one of the UK's leading charities for people living with cancer. We're here to do whatever it takes to help everyone with cancer live life as fully as they can.

We have unparalleled insight into the needs of people living with cancer in England. Each year we reach over a million people affected by cancer through our Macmillan professionals. We bring together local services, the NHS, people living with cancer and many other partners to ensure people living with cancer have the best joined-up care experience.

We play a key role in shaping the cancer workforce to meet the changing needs of people living with cancer. We pioneered the clinical nurse specialist (CNS) role and we fund nearly 12,000 Macmillan nurses, doctors, and other health and care professionals[3] and play an integral role in recruiting, training, deploying, developing and supporting cancer professionals.

With our significant reach into the health service, expertise across the cancer pathway and insight into the experiences of people living with cancer, Macmillan is uniquely placed to understand the challenges in the existing system, shape the long-term vision for cancer care in England and support this transformation.

Macmillan's response to the Cancer Plan Call for Evidence has been informed by:

- The responses of more than 130 people living with cancer, and over 1,000 campaigners who have told us what their specialist cancer nurse meant to their care needs
- More than 50 statements from cancer professionals on their priorities for the new Cancer Plan
- A focus group with professionals on their ambitions for and the barriers to transformation in cancer services

Summary: Our vision for cancer care by 2032

The 10-year Cancer Plan is a radical opportunity to transform outcomes for people living with cancer over the next decade, and beyond. For Macmillan this is about delivering world-leading cancer care that is equitable, harnesses innovation, and is personalised to the growing and complex needs of people living with cancer.

The next 10 years will see significant shifts in the cancer population in England. The number of people living with cancer is projected to rise to 3.3 million by 2030 - 70% of whom also manage other long-term conditions[1]. The volume and complexity of their needs will only increase over the next decade and so cancer care must change too.

Cancer care is personal. Everyone, regardless of who and where they are, deserves high quality care that helps them, as well as treating their cancer. At Macmillan we know not everyone gets the support that they need. To succeed in delivering world-leading cancer services, the new Cancer Plan must have a relentless focus on tackling

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[1] The burden of cancer and other long-term health conditions, Macmillan Cancer Support, April 2015

inequalities. Addressing disparities will be critical for improving people's experiences now and ensuring everyone can benefit from the services of the future.

Cancer treatment will also see impressive advancements over the next decade. Developments in genomics, personalised medicine and digital interventions have the potential to transform care for many people living with cancer. But without a skilled and supportive workforce, these advances will be out of reach for many people and may not deliver their true potential for those they do reach. The cancer workforce will be integral to realising the full ambitions of the new Cancer Plan – ensuring everyone can benefit from high-quality care, tailored to their needs.

To ensure that everyone with cancer can benefit from high quality care and support that is tailored to their holistic needs, Government and partners in health and care must:

1. Develop a robust understanding of inequalities across the cancer pathway to drive targeted interventions that improve access and experience for the most excluded groups.
2. Ensure that every patient receives their diagnosis, treatment for their cancer, and treatment for their wider needs within national waiting time limits and in a way that works for them. To deliver this, services must be equipped with the staff and funding they need to eliminate the backlog by 2023.
3. Ensure that at every stage of their cancer journey from diagnosis, through and following treatment, and at the end of life, people understand the benefits of personalised care and support planning (PCSP) and can access tailored support for their holistic needs. Government must provide greater accountability and systems must be scrutinised on their performance against proven personalised care interventions.
4. Build the cancer workforce of the future by addressing current shortages, retaining expertise, and investing in innovative workforce planning models so that everyone with cancer has the dedicated support of a team of professionals to help meet their needs and navigate around the system.
5. Ensure that everyone with cancer can benefit from the research and innovation being undertaken to build our future cancer care, through improving data collection and sharing, ensuring equitable access to clinical trials and improving public trust and understanding around innovations like genomics.

Priority 1 – Prevention

Macmillan estimates that the number of people living with cancer is set to rise to 3.3 million in England by 2030[2]. This rise will include people who are living longer with their condition, as well as those with a new diagnosis. The increase will put immense strain on a system already struggling.

Many risk factors for cancer are linked to the wider determinants of health[3] - the social, economic and environmental factors that are the root of many health inequalities. Prevention efforts must address the inequalities that sit behind disparities in cancer.

Whilst Macmillan's submission focusses on other areas of the pathway, we agree that prevention must be a key consideration for Government in developing the new Cancer

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[2] Calculating cancer prevalence. Macmillan Cancer Support.

[3] Health Equity in England: The Marmot Review 10 Years On, Michael Marmot, 2020

Plan. Macmillan are signatories on a cancer charity consensus statement issued by One Cancer Voice[4] which offers more specific recommendations on cancer prevention.

Priority 2 – Early diagnosis and inequalities

Our 10-year vision:

The knowledge gaps around health inequalities across the cancer pathway are addressed, with data being used to inform targeted interventions which improve access and experience for the most excluded groups.

Inequalities in diagnosis

The 2019 NHS Long Term Plan set out the welcome ambition for the proportion of cancers diagnosed at stage 1 and 2 to reach 75% by 2028[5]. In order to achieve this ambition inequalities must be addressed as a priority – cancers are detected later in many marginalised populations and this has a direct impact on people's outcomes and experiences of cancer care.

If the needs of marginalised groups are not prioritised there is a risk that inequalities in outcomes will widen. We know that:

- People from more deprived groups, minority ethnic groups and people with learning disabilities are more likely than comparable groups to be diagnosed at a later stage for certain cancers[6,7,8,9].
- People in the most deprived socioeconomic groups are less likely to have their cancers detected at screening and more likely to be diagnosed through an emergency presentation[10].
- People with learning disabilities are less likely to be screened for cervical, breast or bowel cancer than those without[11].
- Bisexual and lesbian women are up to 10 times less likely to have had cervical screening in the past three years than heterosexual women[12].
- People from Black and minority ethnic communities are more likely than their white counterparts to report visiting their GP three or more times before receiving a referral for a cancer diagnosis[13].
- Some communities report a lack of trust in health services, with one study showing that 78% of Black women did not believe that their health was equally protected by the NHS, compared to white people[14].

A commitment to innovation and scaling up proven interventions will be needed to tackle these barriers and generate the solutions needed. For example, there is evidence of where more innovative approaches to screening for certain cancers has had an

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[4] One Cancer Voice, Cancer charities consensus statement – cancer plan 2022-32, March 2022

[5] NHS Long Term Plan, NHS England, 2019

[6] Staging data in England, National Disease Registration Services, 2020

[7] A Mixed Picture: An Inquiry into Geographical Inequalities and Breast Cancer, APPG on Breast Cancer, 2018,

[8] Health Inequalities: Cancer, PHE

[9] Barclay, Socio-demographic variation in stage at diagnosis of breast, bladder, colon, endometrial, lung, melanoma, prostate, rectal, renal and ovarian cancer in England and its population impact, British Journal of Cancer, no. 124, p. 1320–1329, 2021

[10] Routes to Diagnosis, PHE, 2020

[11] Health and Care of People with Learning Disabilities, Experimental Statistics: 2018 to 2019 [PAS], NHS Digital

[12] Evidence to March 2010 on cancer inequalities in England, NCIN, 2010

[13] National Results Summary, NHS Cancer Patient Experience Survey, 2019

[14] The Black community and human rights, CVR insights, 2020

impact on inequalities. Research has found that locating screening facilities within a familiar community setting, such as a church or mosque, effectively promoted screening among Black and minority ethnic women[15]. Macmillan are also exploring new approaches to pharmacy-based triage, as well as home-based self-screening programmes which may reach communities who are not currently accessing screening.

Recommendations:

1. The Department of Health and Social Care (DHSC) must provide significant investment into research and innovation to understand what works when it comes to addressing inequalities in cancer diagnosis and treatment amongst different demographic groups. This should be used to generate and test new solutions. DHSC must also commit to scaling up proven interventions.
2. DHSC must support the development of better data collection around health inequalities. The data in cancer is poor and this may be concealing other inequalities. New methods for collecting and reporting data about different demographic groups should be explored.
3. Government must take steps to understand and address discrimination across the health and care system, as this can lead to later diagnosis, poorer treatment, and support. Local integrated care systems (ICSs) must also improve outreach to increase understanding of the different support needs in local communities.
4. DHSC must facilitate flexible approaches at ICS level to ensure that everyone is able to access screening, diagnostic, and treatment services in a way that works for them, continuously reviewing and developing these as more data into inequalities in cancer diagnosis and treatment becomes available.
5. Statutory bodies and wider stakeholders must work to earn the trust of groups where a deficit is identified. Lack of trust or fear of discrimination may discourage some groups from engaging with the system and sharing data.

Priority 3 – Diagnosis and Treatment

Our 10-year vision:

Everyone with cancer receives their diagnosis and treatment for their cancer, and the wider needs they experience as a result, within national waiting time limits.

Tackling the backlog

The pandemic has exacerbated pre-existing pressures on cancer services, creating backlogs of many thousands of people waiting for diagnosis and treatment. Data in January 2022 showed that more than 47,000 people are 'missing' a cancer diagnosis in the UK[16]. Tackling the treatment backlog as well as managing ongoing demand with significant workforce shortages means that services are now seeing unprecedented delays for people starting treatment. Performance on urgent referrals is also declining.[17] Macmillan's latest analysis estimates the NHS in England would still need to work at 110% capacity for further 16 months to catch up on missing cancer diagnoses and for 12

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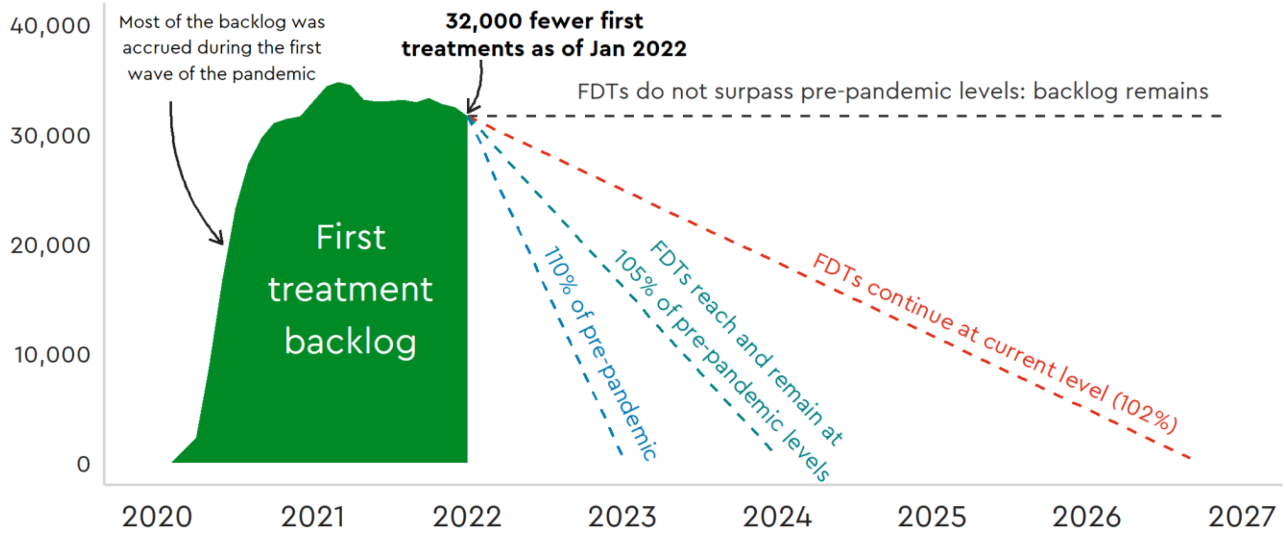
[15] Thomas, V. N., Saleem, T. & Abraham, R. (2005). Barriers to effective uptake of cancer screening among Black and minority ethnic groups. Int J Palliat Nurs

[16] January 2022 data showed that more than 47,000 people are 'missing' a cancer diagnosis in the UK (compared to January 2020). The total number of people starting cancer treatment in England since the start of the pandemic is still more than 31,000 lower than expected. Macmillan responds to January 2022's Cancer Waiting Times data for England, Macmillan Cancer Support, March 10 2022.

[17] Macmillan responds to January 2022's Cancer Waiting Times data for England, Macmillan Cancer Support, March 10 2022,

months to clear the cancer treatment backlog. We are concerned that the Elective Recovery Plan, published in February 2022, does not go far enough to address the current gaps in the cancer workforce.



Redressing the first cancer treatment backlog could take years

First definitive treatments (FDTs) must remain above pre-pandemic levels to reverse the damage caused by the pandemic

Source: Macmillan Cancer Support analysis of Cancer Waiting Times (NHS England)
'Backlog' is calculated as difference between reported and expected activity.
Expected activity is based on average activity reported across 2019.

Impact on outcomes and experiences

'Covid altered the care I received in a very negative way. The surgery was cancelled the week before. Told by phone I had to take hormone blockers instead. The tumour could be seen & had doubled in size & painful since I spotted it. I had to go & have clips put in, extra scans & x rays. Kept getting sent appointments for outpatients cancelling the previous one. The Government kept stating on TV that cancer care treatment/ surgery hadn't been affected!' **Person living with cancer**

The pandemic continues to affect people's cancer care and wider health. One in three people currently having cancer treatment tell us they are worried that delays to their treatment could affect their chance of survival. People with cancer from a minority ethnic background are twice as likely to feel that Covid-19 is affecting their health.[18]

Macmillan innovation **Prehabilitation and rehabilitation** can improve the quality of life of people with cancer by maximising the outcomes of their treatment and minimising the impact of symptoms such as fatigue, breathlessness and lymphoedema. Rehabilitation can benefit people from the point of diagnosis by helping them prepare for treatment ('prehabilitation') and after they are discharged. This approach has been

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[18] Macmillan Cancer Support/YouGov survey of 2,085 adults in the UK with a previous cancer diagnosis. Fieldwork was undertaken between 12th November to 2nd December 2021. The survey was carried out online. The figures have been weighted and are representative of UK people living with cancer (aged 18+).

shown to help people get well and stay well, as well as to build their empowerment and control by encouraging behavioural changes[19] [20]

Macmillan has pioneered work on prehabilitation, to help people access tailored nutrition and exercise support, which during the pandemic, helped people stay as healthy as possible, while waiting for delayed treatment[21]

Recommendations:

6. Services must be able to access the funding and resources they need to eliminate the backlog by 2023. This will include a properly funded workforce plan, ongoing access to independent sector capacity and waiting list initiatives.
7. ICSs and Cancer Alliances should prioritise investment in rehabilitation and prehabilitation programmes for people waiting for/undergoing cancer treatment.

Inequalities post-diagnosis

The Call for Evidence has focused heavily on inequalities before a diagnosis of cancer. It is vital that the Government looks beyond early diagnosis to address differences in access, outcomes and experiences which exist across the whole cancer pathway and should be treated with the same urgency.

We know that:

- Patients from socioeconomically deprived groups report more negative experiences at the point of diagnosis, such as not receiving adequate information on their diagnosis or test results[22].
- Patients from a minority ethnic background report poorer experiences of cancer services than white patients, including delays in diagnosis and referrals to hospital doctors; the provision of information; communication and interactions with healthcare professionals; and access to help and support[23].
- Patients from a minority ethnic background report a poorer experience of involvement in decisions regarding their treatment[24].
- There are significant differences in gay, lesbian, and bisexual patients' experiences of cancer care[25].

Recommendations 1-5, listed in the section on early diagnosis and inequalities, should be adopted across patient pathways to address these inequalities.

Digital interventions

The health service has moved rapidly to adopt digital interventions, including virtual consultations and apps like My Planned Care, both prior to and as a result of the Covid-

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[19] Macmillan Cancer Rehabilitation Pathways, Macmillan Cancer Support

[20] Prehabilitation for people with cancer, Macmillan Cancer Support, These benefits can be seen in as little as 2 weeks

[21] Cancer Prehabilitation and Rehabilitation program, Health Education England

[22] Lyratzopoulos, G., Abel, G. A., Brown, C. H., Rous, B. A., Vernon, S. A, Roland, M. & Greenberg, D. C. (2013). Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer. Ann Oncol, 24(3), 843-50.

[23] Cancer Patient Experience Survey, NHS England

[24] El Turabi, A., Abel, G.A., Roland, M. & Lyratzopolous, G. (2013). Variation in reported experience of involvement in cancer treatment decision making: evidence from National Cancer Patient Experience Survey. British Journal of Cancer. 109, 780-787.

[25] Hulbert-Williams, N. J., Plumpton, C. O., Flowers, P., McHugh, R., Neal, R. D., Semlyen, J. & Storey, L. (2017). The cancer care experiences of gay, lesbian and bisexual patients: A secondary analysis of data from the UK Cancer Patient Experience Survey. Eur J Cancer Care.

19 pandemic. This change has had many positive impacts on outcomes and experience of care, including for some members of marginalised communities.

Macmillan innovation: Macmillan has worked with digital cancer care providers to help improve access to treatments that have traditionally been delivered in an NHS setting at scale. This can potentially reduce costs in the wider national health economy and provide convenient access to interventions which we believe will have a material impact upon the lives of people living with cancer.

We have partnered with Careology, an award winning MedTech company, to improve access to, and use of, their app, which can help people living with cancer monitor and manage their health and help them to feel more in control of their care[26]. Macmillan have also developed similar partnerships with Onko Health and Big Health, which focus on the provision of digital prehabilitation and cognitive behavioural therapy for sleep problems and anxiety, respectively.

It is important to ensure that no-one is left behind by this transition to digital, potentially restricting their access to vital services and worsening inequalities. Digital exclusion, based on language barriers, lack of familiarity with technology and lack of access to appropriate technology, can mean marginalised populations being left out of advances in cancer care, or unable to access vital support in a format that works for them.

In 2021, Macmillan co-funded 'Unlocking the digital front door', a National Voices report[27], which highlighted the experiences of people from marginalised groups and those with high burdens of ill health who struggled to access services during the pandemic. The report put forward five principles for inclusive innovation to address the challenges of digital exclusion:

- Make inclusion the core principle, with the same levels of access, advice and outcomes offered to everyone regardless of channel
- Co-design services with people with lived experience, having a focus on those at risk of exclusion
- Offer supported choice and personalised care, adapting communications so that people can access care and information in a way that works for them
- Support staff to innovate, building a positive culture around testing new ways of working
- Know that health is wider than healthcare.

Recommendation:

8. DHSC should adopt inclusive principles to address digital exclusion, as set out in the report Unlocking the digital front door[28].

Priority 4 – Personalised care

Our 10-year vision:

By 2032 Macmillan wants everyone with cancer to be able to benefit from care and support that is tailored to their needs, along their cancer journey. This means that at every stage, from diagnosis, treatment, following treatment, treatable but not curable cancers and at end of life, people can access support for their holistic needs. This

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[26] Careology. Macmillan Cancer Support
[27] Unlocking the digital front door, National Voices, 2021
[28] Unlocking the digital front door, National Voices, 2021

requires systems to be held to account for their rollout of interventions that make a major difference to people's outcomes and experiences.

As positive as new technologies and innovation to improve diagnosis and treatment are, the varied, more complex needs people will increasingly have as a result, also need to be supported. The drive for innovation must extend to patients' experiences and wider holistic needs if we are to achieve the positive transformation people with cancer need. Macmillan is leading huge innovation to improve people's experience of care.

Cancer and its treatment affect every person differently and take their toll, not just on people's physical health but their emotional wellbeing, finances, family, social and work life. Taking a personalised approach empowers people living with cancer to be involved in the planning and delivery of their care around their specific needs, which can help improve their experience, health and wellbeing[29].

It is very welcome that personalised care, which is a vital part of cancer care, is a priority for the new Cancer Plan. However, we are concerned that a very generic approach to personalised care is increasingly being used in cancer to include the use of apps and social prescribing initiatives to meet the requirements of person-centred care[30].

Personalised care, as distinct from stratified follow-up, has a specific meaning in cancer care, as set out in the NHS Long-Term Plan, to encompass an assessment of each person's needs, followed up with a care plan connecting the person to information and support to meet those needs. Tools such as Holistic Needs Assessments (HNAs, which Macmillan recommends) are designed to help the person discuss any concerns they may have with an experienced professional and have been shown to improve patient outcomes[31].

Personalised care can also help to address inequalities, providing better reach into communities with the greatest need and taking more time to develop care pathways that best suit their needs[32].

Integrating personalised care at every point of the cancer pathway

'I haven't experienced much of a personal approach. I did get help from a specialist lung cancer nurse in the early days of diagnosis, and part of that was to fill out a form, a holistic needs questionnaire. But that never got looked at again, just filed away' **Person living with cancer**

'I was made to feel that I was a valued person' **Person living with cancer**

The NHS Long Term Plan committed that *'every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support'*[33].

Despite this commitment, Macmillan's evidence highlights that personalised care is still not routinely available for everyone with cancer, and that at three specific points of the cancer journey, people's personalised care needs are not being met:

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[29] Improving the cancer journey: providing holistic assessments of need and care planning in a local authority setting, Macmillan Cancer Support

[30] Health and Social Care Secretary speech on Health Reform, Rt Hon Sajid Javid MP, 8 March 2022

[31] Evaluation of the Macmillan Cancer Pathways Programme at Nottingham University Hospital NHS Trust - Final report –; Evaluation of the Macmillan Living with and Beyond Cancer Programme, South Yorkshire, Bassetlaw and North Derbyshire

[32] Health inequalities: time to talk, Macmillan Cancer Support, 2019

[33] NHS Long Term Plan, NHS England/Improvement, 2019

I) Living with and beyond cancer '

The after care has been very poor and pretty much there you go you just go off and get on with it' **Person living with cancer**

For many people, the physical and emotional effects of cancer, radiotherapy and other treatment can continue for years[34]. However, the follow-up support many require after treatment is too often missing or is not tailored to their needs[35]. The new NHS England/Improvement Quality of Life cancer metric is already showing that 18 months after diagnosis, people are experiencing unmet health needs as a result of their cancer, which disrupt their lives. Almost half (48%) of respondents had problems carrying out their usual activities (work, study, housework, family, or leisure activities) compared with around one in five of the general population[36].

Recommendation:

9. ICSs and Cancer Alliances must prioritise longer-term support for the consequences of cancer and its treatment. This includes implementing Government guidance, including investing in tools such as End of Treatment Summaries, Cancer Care Reviews, rehabilitation and prehabilitation and responding to patient-reported experience data showing unmet needs.[37][38].

II) Emotional and psychological needs of people with cancer

'Please address the funding of care for patients and family members' psychological & mental health needs. Funding clinical psychologists and psychological professions is hardly ever prioritised over physical health risks and needs urgently addressing with centralised funding to improve clinical outcomes and quality of life' **Professional**

People living with cancer tell us there are specific impacts of a cancer diagnosis/treatment that can impact mental health (for example, body image after treatment, Post Traumatic Stress Disorder, fear of cancer re-occurrence)[39]. Yet we know that for too many, a limited focus on psychosocial needs in cancer care means that support is often unavailable. Even where support is available, it is not always suitable for the individual's needs, and finding support is a difficult and exhausting experience for those affected. It is estimated that 18% of people recently diagnosed with or treated for cancer have unmet psychological needs. This means that they would benefit from an assessment and/or support but have not yet received any.[40]

Macmillan innovation: Macmillan has developed a model in London for providing integrated psychosocial support for cancer patients. Building upon the effectiveness of this model, we are investing in a series of test sites across other areas of the UK to test the principles of this model and see whether we can deliver the same outcomes for people living with cancer.

Recommendations:

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[34] Am I meant to be ok now? Macmillan Cancer Support, 2017

[35] Caught in the maze, Macmillan Cancer Support, 2021

[36] Cancer quality of life survey. NHS Digital. 2021

[37] COSD v9.0.1 Final Dataset - updated version, National Cancer Registry and Analysis Service, (replaced 18 October 2019)

[38] Quality and Outcomes Framework guidance for 2021/22, NHS England/BMA, 2021

[39] Prioritising needs. Macmillan Cancer Support Available on request.

[40] Understanding the needs of PLWC. Macmillan Cancer Support and Populus. Paper and online survey of 6,905 people across the UK who were recently treated for cancer or were diagnosed with cancer in the last 5 years. Fieldwork July-September 2019. Survey data has been weighted to be representative of the population invited to take part in the 2018 Cancer Patient Experience Survey in England (Cancer Registration data) in terms of age, gender and cancer type.

10. DHSC commissions further research to assess the potential lasting consequences of the pandemic on the mental health of people living with cancer and how services can be best supported to adjust to potentially increased demand.
11. Every Cancer Alliance should implement NICE guidance to ensure that people with cancer have access to an integrated psycho-oncology team, and all levels of psychological support[41]. Currently, access is variable across England.

III) People receiving end of life care

'The recognition of the risk of dying, communication about it [and] integration of palliative care remains patchy and inadequate. Palliative care improves quality of life, reduces cost, and in some cases prolongs life. It reduces complex bereavement and the impact of unnecessarily challenging situations for health professionals, patients and families alike. Please make this a priority' **Professional**

Although palliative and end of life care services are generic and are therefore wider than the scope of a cancer strategy, the effective integration of cancer and end of life pathways is critical to ensuring people dying of cancer receive the best possible support. This is particularly important in terms of addressing inequalities in access to good end of life care.

Inequalities persist until the end of life for many patients:

- The percentage of people with three or more emergency admissions in the last three months of life was higher in the most deprived areas and lower for White British people than all other ethnic groups[42].
- People who live in poverty and those from minority ethnic groups who have end of life care needs are less likely to access necessary care, more likely to die in hospital and more dissatisfied with the care they receive[43].

Early engagement with palliative care enhances the quality and continuity of care. There is usually more time for advance/anticipatory care planning while a person is well enough to engage with the process and their preferred place of care and death can be facilitated more often[44]. However, challenges such as the confidence, time and capacity of health and care professionals and poor access to integrated data/advance care planning systems have meant that too many people who are in their last 12 months of life are not being identified and having their needs met.[45]

Recommendations:

12. ICS's must prioritise provision for palliative and end of life care and ensure they are better integrated with cancer and workforce planning so that the non-specialist workforce is supported with skills, knowledge and specialist out of hours support, in line with the Long-Term Plan commitment to deliver high quality personalised end of life care for all. This is particularly important in community settings where demand is increasing.

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[41] Improving supportive and palliative care for adults with cancer National Institute for Clinical Excellence 2004

[42] Emergency admissions in the three months before death 2009 to 2018, PHE, The percentage of people with 3 or more emergency admissions in the last 3 months of life was also highest for people with an underlying cause of death of liver disease, COPD and cancer

[43] Equity in the provision of palliative and end of life care in the UK, Marie Curie, 2015

[44] At the Crossroads Macmillan Cancer Support, 2019

[45] At the Crossroads Macmillan Cancer Support, 2019

13. NHSE must increase investment in community end of life and specialist palliative care, as well as out-of-hours care to meet demand.

A 'whole system approach' to integrated personalised care

Overcoming these barriers and delivering joined up personalised care requires the collaboration of Cancer Alliances, trusts, primary, community and social care, and the voluntary and charity sector, together with each individual. Macmillan's evidence shows that where interventions work well, support is designed around the individual's holistic needs, provided by a range of health and care teams, and integrated across settings[46].

Personalised care also has the potential to reduce the costs spent on cancer care in the UK, for example, through reductions in emergency bed days, routine follow-up appointments, and reduced waiting times for people living with cancer[47].

Recommendations:

14. NHSE, ICSs and Cancer Alliances should implement national guidance enabling everyone with cancer to have a supportive conversation with a health professional - whether that's in hospital, a community setting or at home, that addresses their individual needs throughout their cancer journey and connects them to local statutory and voluntary support.
15. NHSE, ICS's and Cancer Alliances should raise awareness of how personalised care can benefit individuals with cancer through information campaigns, health professionals and targeted outreach work. Everyone with cancer should be able to have a supportive conversation, (see Recommendation 14) be able to access their care plan and know who they can contact with any questions about their symptoms, care, appointments, or concerns. This should be offered through supported self-management for patients with less complex needs.
16. NHS England should commission an economic evaluation of personalised care, to help identify possible cost savings, as well as other benefits (e.g. helping people back into work), so that system leaders understand the benefits that of personalised care for the individual and the system and invest in it.

Monitoring and accountability of integrated personalised care

'I didn't have the option of discussing how I might improve my wellbeing and work/life balance. When [I] mentioned to a CNS that I should have an immediate clinic chat at the first trust, she was too busy, and Dr did this as a tick box having told me the diagnosis. No follow up was arranged. Definitely not personalised!' **Person living with cancer**

The Call for Evidence states that approximately 83% of all cancer multidisciplinary teams have implemented PCSP based on HNAs, but it is unclear where this originates from. While we recognise that progress has been made on personalised care, this has not yet translated into everyone with cancer being able to access high quality support. For instance, the last full Cancer Patient Experience Survey (CPES) conducted in the same year as the Long-Term Plan was developed, shows that 38% people reported receiving a care plan[48].

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[46] Evaluation of Improving the Cancer Journey –Final report, Macmillan Cancer Support, Edinburgh Napier University, September 2020; Caught in the Maze, Macmillan 2021

[47] One to one support for cancer patients: a report prepared for DH, Frontier Economics, 2010

[48] National CPES report, Picker 2019

Macmillan's research and analysis consistently shows a high number of people with unmet needs that would benefit from better access to personalised support:

- Pre-pandemic figures show that 87% of people recently diagnosed with or treated for cancer in the UK report a concern about their physical health (including fatigue, pain and sleep problems). Of this group, 63% would like more support, although not all those who feel unsupported have sought help[49].
- 83% of people with cancer in the UK experience some kind of financial impact from their diagnosis, and for those affected, this reaches an average of £891 a month, on top of their usual expenditure[50].
- People from the most deprived areas are twice as likely to report unmet needs on emotional and practical support than higher income groups[51].

The Independent Cancer Taskforce which developed the 2015-20 Cancer Strategy also specified that the metrics to be reported and reviewed by Cancer Alliances should include CPES data, aftercare plans and further experience measures, together with waiting time and survival data[52].

Recommendations:

17. In order to improve performance on this critical area of cancer care, NHSE should regularly publish PCSP data alongside cancer performance data (e.g. waiting time and Quality of Life data) in a single public resource such as an improved version of CancerData.
18. Nationally NHSE and locally ICSs should be held to account more robustly for performance on PCSP, cancer patient experience, and Quality of Life data for example, by the Care Quality Commission (CQC) in its system and provider collaboration reviews.

Priority 5 – Workforce

Our 10-year vision:

We need to build a cancer workforce for now and for the future, so that everyone with cancer has the dedicated support of a team of professionals to help meet their needs and navigate around the system

Current pressures are impacting patient care

'All the staff are lovely and doing the best they can but…. there just aren't enough'
person living with cancer

Delivering on workforce is essential. Better access to development opportunities, and support for multi-disciplinary teams to work together differently will be critical to the future of the cancer workforce, but without an increase in the number of health and care professionals, the new Cancer Plan will set aims that are either unrealistic or unambitious.

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[49] For those who feel unsupported with their concerns related to their physical needs, 55% have not looked for any support. Macmillan Cancer Support and Populus. Paper and online survey of 6,905 people across the UK who were recently treated for cancer or were diagnosed with cancer in the last 5 years. Fieldwork July-September 2019. Survey data has been weighted to be representative of the population invited to take part in the 2018 Cancer Patient Experience Survey in England (Cancer Registration data) in terms of age, gender and cancer type

[50] Paying the price of cancer. Macmillan Cancer Support. December 2021.

[51] Health Inequalities: Time to talk. Macmillan Cancer Support. 2019.

[52] Achieving World Class Cancer Outcomes: Independent National Cancer Advisory Group 2015

Earlier diagnosis and better treatment mean that more people with cancer are living longer and with more complex health needs. 70% of people with cancer are also living with one or more long-term health condition and will often require additional support[53]. The discovery and ever rising cost of new treatments presents another dimension to this fast-changing cancer care environment.

The opportunity to invest in the workforce is now. It is critical that the NHS has an appropriately sized and skilled workforce to deliver high quality care for people living with cancer, including increasing numbers of people with treatable but not curable cancers.

Snapshot: impact of staffing shortages on patient care

Cancer patients who report being given the name of a specialist cancer nurse are more likely to describe better care experiences[54], but staff shortages are affecting the quality of the care they can provide for people with cancer.

In a 2017 Macmillan survey, **52% of GPs and nurses** did not feel confident that the workforce was able to provide adequate care for cancer patients[55]. They highlighted **increasing complexity of workload (82%)** and **increased caseload (70%)** as the two biggest challenges facing the cancer care system[56].

Macmillan's 2021 modelling shows the situation is set to get worse: if the number of specialist cancer nurses stays **at the current levels, we will be short of 3,371 nurses in England by 2030**[57].

Cancer Research UK has estimated that assuming no changes to current ways of working, demand for services will increase such that by 2027, the number of **radiologists, may need to grow by 70%**, the number of **gastroenterologists by 45%,** the number of **therapeutic radiographers by 80%** and the number of **oncologists may have to triple**[58].

Pressures have only been exacerbated by the Covid-19 pandemic. People left without sufficient specialist nursing support at diagnosis or treatment during the pandemic were more likely to report adverse outcomes, including serious mental health impacts and A&E admissions[59].

'Cancer nurses are everything to people with cancer, they are our hope, our best advisor, our best mentor and our best friend. Nurses are indispensable' **Person living with cancer**

On top of this, the specialist cancer nurse workforce is ageing and will be significantly affected by staff retirement over the next 5-10 years. Our 2017 census found that more than a third of cancer nurse specialists in England are aged 50 or over (37%, compared to 33% in 2014), rising to around one in two in certain parts of the country[60]. In February 2021, almost 30% of nurses and midwives in England (equivalent to 108,000 staff) said

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[53]. The burden of cancer and other long-term health conditions, Macmillan Cancer Support, 2015.

[54] Alessy SA, Lüchtenborg M, Rawlinson J, Baker M, Davies EA. Being assigned a clinical nurse specialist is associated with better experiences of cancer care: English population-based study using the linked National Cancer Patient Experience Survey and Cancer Registration Dataset, Eur J Cancer Care (Engl). 2021 Jul 26.

[55] From the frontline: workforce pressures in the NHS, Macmillan Cancer Support, 2017.

[56] From the frontline: workforce pressures in the NHS, Macmillan Cancer Support, 2017.

[57] Cancer nursing on the line, Macmillan Cancer Support, 2021.

[58] Securing A Cancer Workforce For The Best Outcomes. Cancer Research UK. 2018

[59] Cancer Nursing on the Line, Macmillan Cancer Support, 2021

[60] Cancer Workforce in England, Macmillan Cancer Support, 2017

they were more likely to leave the profession, compared to a year ago[61]. A more flexible approach to ensure staff retention is required to make the most of the experience of the workforce.

Recommendations:

19. In addition to Framework 15 and the recently commissioned long-term workforce strategy, NHSE and Health Education England (HEE) should urgently deliver a long-term fully costed cancer workforce plan. This must be based on realistic estimates of the workforce numbers, across all parts of the care pathway, that will be required to meet the needs of people living with cancer.
20. As part of this process the Government must ensure that a workforce assessment report is published, at least every two years, to address workforce numbers in addition to training and development needs.

Wellbeing and morale of staff

'We are all pretty exhausted and demoralised at the huge workload we have at present. I worry about making mistakes and missing things when working under such pressures- sometimes having 40-50 patient contact in a day' **GP**

During the pandemic, many health professionals have stepped up and given everything to ensure that patients were still able to access care and support. However, the redeployment of cancer professionals and high levels of staff absence led to a severely depleted workforce at risk of burnout[62]. Even before the pandemic, 39% of cancer nurses surveyed felt their current workload was unmanageable, whilst 44% said that the current workload was negatively affecting their morale[63]. Health professionals need to be supported to prevent further burnout and reduce the risks of negatively impacting the wellbeing and mental health of staff.

Developing the skills and expertise of health and care professionals

Career and development opportunities are hugely important to health and care professionals[64,65] and are a key to the NHS's ability to tackle current backlogs and rising demand.

'We are at a crisis point where a whole cohort/generation are about the leave/retire so we will be hit harder' **Professional**

Over three quarters (76%) of nurses responding to a Macmillan survey in England said that having more time for Continued Professional Development (CPD) would help them improve care for people living with cancer[66], yet many specialist cancer nurses currently experience barriers to undertaking training. The overwhelming majority (64%) cannot access protected time to undertake CPD, with one in five having to take annual leave. 43% said lack of funding was the main barrier to CPD, with one in five self-funding their CPD.

'[We need] investment in nurse specialists to support patients, reduce admissions, avoid delays in pathway, increase nurse led clinics. Investment in cancer support

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[61] Recover, Reward, Renew: A post-pandemic plan for the healthcare workforce, Institute for Public Policy Research, March 2021.

[62] 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.

[63] Voices from the frontline: challenges facing nurse specialists right now. Macmillan Cancer Support, 2019

[64] Cancer nursing on the line: why we need urgent investment across the UK, Macmillan Cancer Support, 2021

[65] Allied Health Professional Workforce Report, Macmillan cancer Support, 2018

[66] Cancer nursing on the line: why we need urgent investment across the UK, Macmillan Cancer Support, 2021

workers to assist with practicalities of cancer diagnosis & emotional support.' **Professional**

The lack of a clear, structured pathway from general adult nursing into specialist cancer nursing prevents many nurses specialising[67]. National arms-length bodies including CQC and HEE have recognised the scale of the problem. As recently as July 2021, CQC highlighted that 'cancer nurse specialists were overstretched'[68], but not enough has been done to tackle the crisis.

Recommendations:

21. NHSE, NHS Improvement and HEE must urgently boost the supply and retention of the general adult nursing workforce and (AHPs). This is not only necessary to meet current demands, but to also ensure that all nurses and AHPs have backfill for their clinical commitments to undertake Continued Professional Development (CPD); and to provide a pipeline for specialist roles.
22. HEE's budget must be protected and rise proportionally with NHSE budgets to ensure the continued development and expansion of the cancer workforce. HEE's budget has already been cut by 25% in real teams between 2013/14 and 2019/20[69].
23. NHSE, HEE, – alongside ICSs and Cancer Alliances – should be accountable for ensuring that nurses and AHPs across England have equal access to relevant CPD to end variation in access.
24. HEE should urgently implement a careers framework to support more nurses and AHPs to become specialist cancer nurses, including developing structured pathways from general adult nursing into specialist cancer nursing and a greater focus on cancer care in the undergraduate syllabus.

Creating a flexible workforce that can adapt to the changing healthcare environment

'We are missing opportunities for our dedicated 'untrained' staff, many of whom have years of experience and love their jobs but have nowhere to go/get no recognition for their contribution. Cancer treatment profiles are changing so we need to be thinking creatively about roles - pharmacy technicians for example, could do toxicity clinics in the community, alleviating some pressures on acute trusts' **Professional**

As well as boosting workforce numbers and ensuring health professionals have the right skills and training to deliver care and support for people living with cancer, it's also important that teams are set up to work in an efficient way.

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[67] Voices from the frontline: challenges facing nurse specialists right now. Macmillan Cancer Support, 2019

[68] Provider collaboration review: ensuring the provision of cancer services, Care Quality Commission, July 2021; Cancer Workforce Plan: Phase 1, Delivering the cancer strategy to 2021, Health Education England, 2017.

[69] Pressures on the NHS, IFS, 2021.

This requires relooking at the role of multidisciplinary teams. Previous Macmillan research has highlighted the importance of getting the right balance of skills across a cancer care team. Professionals felt that looking at where new roles might fit in was key to improving care, and also taking the pressure off specialist staff.

Skill mix innovation: Designing workplace roles around necessary functions rather than traditional job descriptions may allow recruitment from wider pools.

- Schemes to use **apprenticeships** rather than degree courses to train people to work within breast screening (Mammography Associate Apprenticeship) are an example of work role and recruitment flexibility[1]. This is a 12-month course developed by the National Breast Imaging Academy to produce Mammography Associates, qualified to work within the breast imaging workforce, thus improving capacity within the system and freeing up the time of the more highly qualified staff members.
- The increased use of **Physician Associates, support and link workers** has improved capacity, provided greater flexibility and career development opportunities.
- **AHPs** are key members of the cancer multidisciplinary teams. They have a vital role in managing complex needs and as part of a skill mix approach to workforce planning[1]. AHPs can provide a wide range of interventions as part of HNAs which improve patient care.

Recommendations:

25. NHSE should urgently address the future development and shape of the cancer workforce to encourage greater investment in support or link worker roles and AHP involvement throughout the pathway to ensure people living with cancer are supported to access all the relevant care and support.
26. Trusts should be encouraged to be more flexible in the use of the existing experienced workforce, for example increasing opportunities for flexible or part time working for those nurses near or at retirement age to ensure they can work with new or aspiring specialist adult cancer nurses before they leave the NHS.

Macmillan is keen to work further with Government and others to apply our insight into the needs of the cancer workforce to ensure the NHS is equipped to deliver high-quality care and good outcomes for cancer patients, both now and in the future. Our existing work has given us an understanding of how the experience of people with cancer is likely to change over the next 10 years and what this means for the workforce who will be supporting people with cancer. We are currently commissioning a significant research and modelling partnership which will model how changes to the healthcare pathway for people with cancer by the mid-2030s will impact on their experience and the implications of those changes for the healthcare workforce delivering care to them. We would welcome the opportunity to partner with Government to ensure that these findings can be embedded in the system and used to shape the future cancer workforce.

Macmillan's innovative workforce partnerships

- Cancer care coordinators are being recruited to a local primary care network to support people with cancer closer to home. This work will provide an opportunity to look at cancer care review, support and information, improved communication across all cancer setting and earlier diagnosis.
- A multi-level oncology pharmacy team is being put in place working across the one Cancer Alliance area and create a career pathway for cancer pharmacists.
- Macmillan, in partnership with HEE and others, are currently seeking to improve workforce training with the ACCEnD (Aspirant cancer education and career development framework) programme. This programme aims to provide guidance on the knowledge, skills and capabilities required by all nurses and AHPs who care for people affected by cancer in generalist and specialist cancer services and roles as part of multi-professional teams across the four UK nations. This includes developing a clear career development pathway, with tailored education, to develop professionals from at all stages of the career path; pre-registration, registered staff, enhanced, advanced and consultant practice, through to executive leadership.

Priority 6 – research, data and innovation

Our 10-year vision:
Everyone with cancer can benefit from the research and innovation being undertaken to build our future cancer care.

Rapid innovation is likely to transform cancer care over the next decade and the system will need to be prepared to adopt such innovations. This will require an appropriately trained and resourced cancer workforce, focused on delivering personalised care. In order to ensure that innovations address, rather than exacerbate inequalities, there will need to be improvements to routine data collection and sharing, as well as more equitable access to clinical trials.

Data collection

'*An NHS IT system that is linked and supports secure sharing of patient information would make a big difference*' **Cancer Commissioning Manager**

Research and innovation are key to healthcare improvement. The insights and data collected by the NHS can be used to improve diagnosis and disease management, whilst allowing national and local NHS leaders to evaluate innovations and utilise new models of care[70]. New digital tools can be developed, and new data interpreted so clinicians and managers can better collaborate and use their insights to improve care.

Recommendation:

27. The 10-year cancer plan must underpin the vital role that research, data and innovation will have to play in improving patient care. It must support this ambition with the appropriate funding and resources for staff to develop and

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[70] Untapped potential: Investing in health and care data analytics. Health Foundation, 2019

train in creating high quality research and data insights[71]. It must also invest in building patient trust around research and data collection.

Improving routine data collection across the pathway will also be vital to understanding existing inequalities, as well as allowing meaningful evaluation of initiatives intended to address them. Efforts to improve data collection will need to involve building trust with communities who may be reluctant to share their data, as well as ensuring that professionals see the value in data collection and are comfortable in asking for and recording sensitive information. Macmillan are currently working on a project to identify data gaps around cancer and inequalities and make recommendations for how these gaps can be filled.

As well as improved collection and analysis of data on clinical outcomes, there should be a focus on non-clinical outcomes such as quality of life and patient experience. Many more people may live years beyond initial diagnosis, requiring ongoing treatment and/or long term physical and emotional support.

Improving care for patients will require better understanding of patient experiences through a full Patient Reported Outcome Measure (PROM) survey. Research shows that the routine use of PROMs during a course of care can provide additional opportunities to inform clinicians and can improve the quality of life and overall survival of people living with cancer[72, 73, 74]. However, it is important that the latest evidence and research in relation to the use of PROMs is reviewed to ensure their most effective and appropriate uses[75].

More focus should also be given to improving the quality and completeness of PCSP data. Cancer Alliances and trusts must prioritise collection of this data and NHSE should improve data flows in the system and communication of this data, so that we have a better understanding of where PCSP interventions are happening (see Recommendation 17).

Data sharing

'My consultant was able to leave the consulting room in Manchester and view the scan which had been done in Macclesfield via the Internet. He made a few suggestions but said he had no need to see me again. I haven't seen him for about six years. Being able to access a patient's records [in this way] is clearly a valuable facility' **Person living with cancer**

The NHS needs to improve its data sharing capabilities. The health data landscape is complex, but the lack of data linkage across the NHS is a key barrier to improving data quality[76]. This includes the sharing of patient records, but the interoperability of data is also vital for personalised care and essential to improving Genomic Medicine Services.[77]

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[71] Untapped potential: Investing in health and care data analytics. Health Foundation, 2019

[72] Field J, Holmes MM, Newell D. PROMs data: can it be used to make decisions for individual patients? A narrative review. Patient Relat Outcome Meas. 2019;10:233-241

[73] Frédéric Fiteni, Cousin Christelle. Clinical Relevance of Routine Monitoring of Patient-reported Outcomes Versus Clinician-reported Outcomes in Oncology. 2019.

[74] Graupner C, Kimman ML, Mul S, et al. Patient outcomes, patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care: a systematic review. Support Care Cancer. 2021;29(2):573-593. doi:10.1007/s00520-020-05695-4

[75] Nic Giolla Easpaig B, Tran Y, Bierbaum M, et al. What are the attitudes of health professionals regarding patient reported outcome measures (PROMs) in oncology practice? A mixed-method synthesis of the qualitative evidence. BMC Health Serv Res. 2020;20(1):102. Published 2020 Feb 10. doi:10.1186/s12913-020-4939-7

[76]. How better use of data can help address key challenges facing the NHS. The Health Foundation, 2022.

[77] Genomics policy roundtable – discussion summary. AstraZeneca. 2021.

Linking data allows clinicians to access all relevant information about each patient, and omissions in the patient's records may impact on their care. This is also an issue in relation to end of life care, where advance care planning can enable healthcare professionals to identify and meet people's end of life wishes, via tools such as the Electronic Palliative Care Co-ordination Systems (EPaCCS). ICSs must have plans in place to develop an EPaCCS system or an equivalent tool for coordinating palliative care[78]. They need to show how they are considering the needs of end-of-life patients in wider plans for digitalisation and on data interoperability.

Any system being developed must work with all health and care providers, including private providers of care such as local 111 services or residential and care homes.

Recommendation:

28. NHS Digital should ensure the right systems are in place to enable effective data sharing to support the delivery of personalised care for people living with cancer. This should enable information to be easily shared between health and care settings and and also be accessed by the patient, professional teams and at all stages of the cancer pathway, including advance care planning to meet people's needs at end of life.

Access to clinical trials

Clinical trials are an important option for many patients, providing them access to novel treatments and increasing their clinical options in the process. Access to clinical trials is currently inequitable – older patients and those from minority ethnic groups with cancer are less likely to be placed on clinical trials. One study found the odds of being in a trial were 30% lower for a member of a minority ethnic group compared to a white cancer patient after adjusting for disease, age and gender[79].

Macmillan innovation: Access to clinical trials may depend on being treated in a teaching hospital or being health literate and self-advocating. Macmillan is in the early stages of exploring initiatives to improve equity in trial access for all people living with cancer, with a particular focus on the most marginalised populations in society. We are also working with the National Institute for Health Research and the NHS Race and Health Observatory to increase participation in clinical trials in minority ethnic communities.[80].

As we progress this work, we would be keen to share our insight with Government on best practice in making clinical trials more accessible for all cancer patients. We hope this will play a part in helping to tackle some of the disparities in experiences of cancer care and treatment among different groups we have previously discussed.

Genomics and personalised medicine

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[78] At the crossroads: How can the NHS Long Term Plan improve end of life care in England. Macmillan Cancer Support. 2019.

[79] Godden, Ambler, Pollock, Recruitment of minority ethnic groups into clinical cancer research trials to assess adherence to the principles of the Department of Health Research Governance Framework: national sources of data and general issues arising from a study in one hospital trust in England, J Med Ethics 2010 Jun;36(6):358-62. doi: 10.1136/jme.2009.033845

[80] Inclusive Britain: summary of recommendations and actions UK Government, March 2022

'We need more funding for new technology, such as AI/adaptive radiotherapy - to give our patients the best possible treatment we can. Centres in Europe are already way ahead of us, why should our patients be left behind?' **Senior Therapy Radiographer**

Successive Government plans have outlined a range of initiatives to scale up rapid diagnosis and treatment innovation, including the expansion of Community Diagnostic Centres, mobile diagnostics and technology, rollout of surveillance and liquid biopsies, the genomics programme and personalised medicines[81].

Genomics and personalised medicine have the potential to transform care for many people living with cancer. Knowledge about cancer, diagnostics and its treatment will be greatly enhanced with better genomic data as well as federated data that combines genomic datasets with other datasets, such as those from NHS and research to improve decisions about access to clinical trials and treatment.

This sort of data sharing will need to be supported by robust information governance systems, as well as communication and trust building with communities around new uses of data. Use of pharmacology and genomics (pharmacogenomics) will allow development of safe, effective treatments tailored to an individuals' genetic make-up. The Government published 'Genome UK: the future of healthcare' which outlines the UKs ambitions in this space, but more needs to be done to deliver on this.

The potential to improve people's ability to understand their risk of cancer and make very personalised decisions about treatment obviously has enormous potential. It also generates additional and more complex support needs which the workforce needs to be better equipped to meet.

Recommendations:

29. DHSC needs to provide investment and resource to successfully operationalise personalised medicine in England[82], including expanding the capacity of genomic laboratory hubs, a fully developed learning and development offer around genomics and personalised medicine for a range of professionals, and wider research on the impact and needs of the workforce regarding genomics and personalised medicines.
30. Statutory bodies must work to improve public trust and understanding of genomics. People with cancer should be partners in wider insight gathering to understand how genomics and personalised medicine can impact and benefit them, ensuring that any engagement captures a diverse range of views and experiences.

Macmillan looks forward to seeing the Cancer Plan that emerges from this Call for Evidence and to continued involvement in its development. We are happy to be contacted about any of the issues raised in this submission paper.

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[81] GENOME UK: The future of healthcare. HM Government. 2020.

[82] The operationalisation of Precision Medicine. Public Policy Projects. 2021.