

**Written evidence submitted by Macmillan Survivorship Research group (MSRG), Health Sciences, University of Southampton (CSV0028)**

**Executive summary:**

In response to this call for evidence on cancer services by the Health and Social Care Committee we provide evidence and policy recommendations in relation to all three questions posed, focusing on how the Government can improve cancer outcomes in England.

We call for a **clear recognition** that psychosocial factors (such as quality of life, mental health, confidence to manage illness, social support) are key both to the health and wellbeing and improved outcomes for people living with cancer. This view is underpinned by our extensive research evidence presented in the submission. The Covid-19 pandemic has placed significant additional impact on the wellbeing of people living with and beyond cancer, which is likely to have negative impacts on long-term outcomes. Providing personalised and stratified care can help reduce psychosocial problems that affect cancer-related outcomes.

We recommend that the government should:

- Further develop delivery of personalised care and support to people living with and beyond cancer as outlined in the NHS Long Term Plan for cancer.
- Support an improved universal offer of psychosocial care to all cancer patients. To make these services world class and to improve outcomes, further investment in psychosocial services and research is required.
- Accelerate the roll out of the national quality of life metric to all cancer groups and to multiple points in the cancer pathway.
- Support the development of evidence-based ways to assess psychosocial wellbeing and tailor care to ensure cancer patients needs are identified and supported
- Take the opportunity when supporting the recovery of cancer services after the pandemic, to ensure that psychosocial services are recognised in this strategy.

**Response authors:**

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Claire Foster is Professor of Psychosocial Oncology, Director of the Macmillan Survivorship Research Group (MSRG) and leads the Cancer and Life Limiting Conditions Care Research Group in Health Sciences, University of Southampton. For the last 20 years Professor Foster has led a research programme that focuses on understanding the impact of cancer and its treatment on everyday lives and how equipped people feel to manage this; understanding the impact of a family history of cancer on people's lives; and developing and testing digital resources to support people affected by cancer to manage some of the consequences of treatment and make complex decisions about treatment or genetic testing. The programme includes large prospective cohort studies, qualitative studies, development and testing of complex interventions, evaluation of service transformation. The MSRG team works with people affected by cancer and life limiting conditions as research partners as well as clinical, academic and policy leaders to support the design, conduct and dissemination of the research to maximise impact.

This submission has been developed in collaboration with members of the MSRG:

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### **About the Macmillan Survivorship Research Group (MSRG):**

The MSRG, led by Prof Claire Foster at the University of Southampton, is delivering an internationally leading programme of research that provides a detailed understanding of the long-term impact of cancer and treatment on people living with and beyond cancer. We have established unique UK wide cohorts including patient-reported health-related outcomes, experiences and clinical data from diagnosis (prior to curative intent treatment) and over time. Our research has influenced the international survivorship agenda, shaped national and international policy, and transformed health services, improving the delivery of personalised care and self-management to the benefit of people diagnosed with cancer<sup>1</sup>. Our United Kingdom [UK] wide [cohort studies](#), which follow cancer patients over time from diagnosis for three to five years (e.g. CREW and HORIZONS) provide new insights into the long-term implications of cancer diagnosis and its treatment from patients' perspectives. Continued data collection during the pandemic has allowed us to track the impact of the Covid-19 pandemic on people living with and beyond cancer.

The views expressed in this submission are those of the Macmillan Survivorship Research Group, University of Southampton.

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<sup>1</sup> Foster, C., Calman, L., Richardson, A., Pimperton, H., & Nash, R. (2018). [Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice](#). *Journal of Cancer Policy*. <https://doi.org/10.1016/j.jcpo.2018.02.004>

## Why do cancer outcomes in England – in particular survival – still lag behind comparable countries internationally?

- 1.1. Reasons for international disparities of cancer outcomes are multifactorial and complex and include public health and prevention, early detection and access to diagnosis and treatment.
- 1.2. To improve cancer outcomes there needs to be a clear recognition that **psychosocial factors (such as quality of life, mental health, confidence to manage illness, social support) are key to improving or maintaining the health and wellbeing** of people living with and beyond cancer. These psychosocial factors are drivers for seeking help and support and managing problems and symptoms both before and after a cancer diagnosis. They can positively impact on:
  - Decision-making about treatment
  - Confidence to manage problems during and after treatment that can lead to improved engagement with treatment and wellbeing
  - Fitness for arduous cancer treatment that can improve survival
  - Early help seeking behaviours for side effects, symptoms or signs of disease progression/recurrence.
  - Self-management of cancer related problems and improvement of quality of life.
- 1.3. This view is underpinned by our extensive research evidence that has demonstrated that psychosocial factors from the point of diagnosis are as important as stage of disease in predicting health and wellbeing outcomes for people with cancer over the long term.

The NHS Long Term Plan for cancer clearly articulates the importance of delivering [personalised care support](#) to people living with and beyond cancer, recognising a person's holistic needs. The Plan also recommends that quality of life metrics should be used to track and respond to the long-term impact of cancer. Psychosocial issues are recognised globally as important for cancer survivorship with survivorship/living with and beyond cancer guidelines/initiatives developed in [Canada](#), [USA](#), [Australia](#), [Europe](#). We need to offer world class psychosocial support and services to provide comparable cancer care in the global context. The importance of the psychosocial and wellbeing outcomes of people living with and beyond cancer was recognised in UK policy with the establishment of the National Cancer Survivorship Initiative in 2010. This initiative was highlighted as a key commitment of the Cancer Reform Strategy in 2007 and was endorsed in 2011 in the Department of Health, Improving Outcomes Strategy for Cancer. Progress in this area has been made over the last 10 years but further investment in psychosocial services and research is required to improve outcomes of people living with and beyond cancer. The number of people living with cancer in the UK is growing. It has been estimated that by 2030, four million people in the UK will be living with cancer<sup>2</sup>: surviving cancer is not the end of the story. At least one in four of those living with cancer (currently around 500,000 people in the UK) face poor health or disability after cancer treatment<sup>3</sup>.

- 1.4. Psychosocial factors need to be assessed and attended to if cancer outcomes are to improve and include the following:

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<sup>2</sup> Maddams J, Utey M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer. 2012 Sep 25;107(7):1195-202. doi: 10.1038/bjc.2012.366. Epub 2012 Aug 14. PMID: 22892390; PMCID: PMC3461160.

<sup>3</sup> Macmillan Cancer Support (2013) Throwing light on the consequences of cancer, Macmillan Cancer Support, London

i) Self-efficacy (confidence to self-manage)

1.5. Our [research](#) has shown that cancer patients who are confident to manage the impact of cancer, treatment and its consequences are more likely to have good physical and mental health and wellbeing up to 5 years later ([CREW](#) and [HORIZONS](#)). Our research has also found that around 40% of patients had suboptimal levels of confidence to manage illness-related problems following curative intent cancer treatment<sup>4</sup>. Levels of confidence remain steady over time without intervention. However, confidence to manage can be improved with appropriate support. Identifying those with low confidence to manage and personalising care to support increased confidence as soon as possible after cancer diagnosis is likely to benefit health and wellbeing in the longer term and improve quality of survival.

ii) Fatigue

1.6. Confidence to manage symptoms associated with cancer and its treatment is a significant issue affecting outcomes in the long term. For example, our CREW cohort indicates that 37% of people have fatigue at 3 months and 20% at 5 years post diagnosis. Fatigue is a common and debilitating symptom following cancer treatment and, if unrecognised and untreated, is detrimental to long-term health and wellbeing. Our research has shown that cancer survivors often lack confidence to manage the impact of fatigue on their daily lives. Simple intervention, such as evidence based [RESTORE](#), can enhance confidence to manage the impact of fatigue.

iii) Mental Health

1.7. It is important to assess and manage appropriately mental health from the time of diagnosis. Our UK wide CREW cohort data demonstrates that 21% of participants reported depression soon after diagnosis and left untreated 15% reported depression up to 5 years later. People who reported clinically significant levels of depression pre-surgery had a higher risk of being depressed over follow-up and this was similar for highly anxious people. This may impact on health and wellbeing as poor recognition of depression and anxiety is associated with reduced quality of life and survival.<sup>5</sup>

iv) Comorbidities

1.8. People living with other health conditions that impact on daily life are likely to have worse health and wellbeing. Risk of cancer increases with age and older people are more likely to have other health conditions. Our CREW cohort found that 72% of people had at least one other health condition, 27% of whom said these other health conditions had a negative impact on daily living. At present, regular screening tools such as the [Holistic Needs Assessment](#), do not assess comorbidities. There is thus a need to identify those struggling to manage the impact of comorbid conditions so they can be supported to build confidence in managing comorbidities alongside cancer treatment and recovery.

1.9. Cancer and its treatment can have significant and varied consequences for everyday life including physical symptoms and late effects, psychological and social impact and uncertainty for the future which can disrupt everyday lives and undermine long recovery and health and

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<sup>4</sup> Grimmett C, Haviland J, Winter J, Calman L, Din A, Richardson A, Smith PWF, Foster C. Colorectal cancer patient's self-efficacy for managing illness-related problems in the first 2 years after diagnosis, results from the ColoRECTal Well-being (CREW) study. *J Cancer Surviv.* 2017 Oct;11(5):634-642. doi: 10.1007/s11764-017-0636-x. Epub 2017 Aug 19. PMID: 28822053; PMCID: PMC5602065.

<sup>5</sup> Pitman A, Suleman S, Hyde N, Hodgkiss A., Depression and anxiety in patients with cancer [2018] *BMJ* 361:k1415. DOI:10.1136/bmj.k1415

wellbeing outcomes. With appropriate support this disruption and uncertainty can be moderated and managed reducing the need for emergency admissions, building confidence to manage and improving quality of life (QoL). **Failing to support people living with and beyond cancer in managing cancer-related problems will limit the quality of their survival and negatively affect health and wellbeing outcomes.**

## 2) How will Covid-19 affect efforts to catch up to the best cancer outcomes internationally?

- 2.1. Our psychosocial research during the Covid-19 pandemic has revealed that there has been significant *additional* impact on the wellbeing of people living with and beyond cancer, this may have negative impacts on long term outcomes. During the pandemic access to psychosocial care was disrupted and became less flexible. New services and alternative means of providing support (e.g. virtual/telephone) were developed rapidly. For example, the SafeFit trial; a virtually delivered programme of exercise, nutrition and psychological support.<sup>6</sup> The need for such support was illustrated by the unprecedented speed of registration to this trial of 906 in 11 months. However, not all new programmes have been based on compelling evidence or been adequately evaluated. Consequently, the implications of these innovations remain unclear.<sup>7</sup> This risks the timely identification and support of patient identified need, potentially having a detrimental impact on long term outcomes.
- 2.2. It is the case that prior to the pandemic psychosocial care was not accessible to all cancer patients with some communities underserved or under-represented in services. Pre-pandemic there was already considerable room for improvement of these services. There is now an opportunity for psychosocial services to be improved over the coming months and years. The NHS Cancer Programme's [Covid Recovery Taskforce](#) has established a Task and Finish Group to undertake focused work to address the impact of the Covid-19 pandemic on psychosocial support for people affected by cancer. The findings of this group, due in autumn 2021, will be important to inform this inquiry. Our research is informing the recommendations for this Task and Finish Group.
- 2.3. Our research has clearly established that psychosocial need is now higher in people living with cancer due to the pandemic. Since Autumn 2020, we have been surveying and interviewing [HORIZONS](#) participants to find out about the needs and experiences of people being treated for and recovering from cancer during the pandemic. Based on the first 579 responses, key findings include:
  - 50% have needed someone else to take on tasks like food shopping or collecting medicine that they would normally do.
  - 37% who needed to make a GP appointment could not always do so.
  - 70% of those who had a phone or video call with a health care professional preferred face-to-face appointments. Interviews highlight some particular concerns about not having a face to face physical examination.
  - 95% felt the pandemic had caused at least some negative impact on their overall quality of life.

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<sup>6</sup> Grimmett C, Bates A, West M, et al SafeFit Trial: virtual clinics to deliver a multimodal intervention to improve psychological and physical well-being in people with cancer. Protocol of a COVID-19 targeted non-randomised phase III trial *BMJ Open* 2021;11:e048175. doi: 10.1136/bmjopen-2020-048175

<sup>7</sup> Archer, S., Holch, P., Armes, J., Calman, L., Foster, C., Gelcich, S., MacLennan, S., & Absolom, K. (2020). No turning back' Psycho-oncology in the time of COVID-19: Insights from a survey of UK professionals. *Psycho-Oncology*, 29(9), 1430-1435. <https://doi.org/10.1002/pon.5486>, accessed 31 August 2021.

- 50% reported at least one negative psychological impact caused by the pandemic, e.g. stress, feeling helpless, fear.
- There was a significant association with negative psychological impact in the following: people who remained at home at all times, those who had difficulty taking the measures they thought were necessary to protect themselves from Covid-19, people who had concerns about meeting financial commitments, those who felt the pandemic was having a negative overall effect on their quality of life.

2.4. Additional issues raised by HORIZONS survey respondents about the effect of the pandemic included:

- Delays/cancellations to follow up appointments.
- Concern about not having to face to face follow up appointments, meaning there could be no physical examination.
- Long delays (> 12 months) to reconstructive surgery for breast cancer patients.
- Lack of support at hospital appointments due to social distancing.
- The challenges of social isolation and how people respond to these challenges.
- Negative impact on mental health.

2.5. [ENABLE](#), a qualitative study of people living with advanced cancer during the pandemic has highlighted issues likely to resonate more widely with patients:

- People were experiencing more uncertainty and anxiety as a result of the pandemic.
- Not being able to see loved ones had a significant impact on patients' and carers' emotional well-being. People were increasingly using technology to stay in contact with family and friends.
- Not all participants had access to, or were able to use, technology for support.
- Patients and carers living with advanced cancer wished to maintain their independence, a sense of normality and control. This had been impeded by the pandemic. Participants had lost opportunities to do the things important to them to maintain psychological wellbeing, such as social activities voluntary work, clubs, classes and outdoor exercise.
- Some carers were experiencing a higher burden of care but had less access to practical, emotional and social support and respite from formal and informal sources.
- Participants had concerns about the longer-term impact of changes to aspects of their treatment during the pandemic like changes in frequency of treatment.

2.6. These data highlight the ongoing impact of the pandemic and the potential future implications for the long-term outcomes of patients and their carers. Covid has highlighted the importance of psychosocial wellbeing for the health of the UK population. In light of the data presented here, indicating the additional pressures cancer patients have experienced, Covid recovery presents an opportunity for psychosocial services and research to be accelerated to meet current and future need and to achieve world class cancer outcomes.

### **3) Will implementing the Long Term Plan for cancer improve cancer outcomes to the level of the best countries internationally?**

3.1 The NHS Long Term Plan for cancer clearly states that [Personalised Care and Support Planning should be offered to people living with and beyond cancer](#). Our data demonstrate that providing personalised and stratified care can help reduce psychosocial problems that affect cancer-related outcomes. Personalised care will improve outcomes for cancer patients, and our work shows that these approaches are [cost-effective and can improve quality of life](#). However, personalised psychosocial care needs investment, research and evaluation to ensure improved outcomes.

3.2 We would recommend this can be achieved through the following approaches:

- i) Identifying and supporting those with low self-efficacy
  - ⇒ Identifying those people with low confidence to manage the consequences of cancer and its treatment soon after diagnosis
  
- ii) Identifying and supporting those with depression
  - ⇒ Identifying people experiencing depression soon after diagnosis so that care and support can be tailored accordingly (*e.g.* support from the health care team; support from specialist services as required)
  
- iii) Tailoring care to ensure needs are identified and supported
  - ⇒ Delivering cancer services that are tailored to the needs of the individual is essential if long-term outcomes for people living with and beyond cancer are to be improved. However, there are significant challenges in realising the NHS Long Term Plan's ambitions for personalised care. These include: poor integration of primary, acute and community services; a lack of knowledge / skills for those delivering front-line services on personalised care; a lack of validated measures that specifically identify support needs for people with cancer at the point of diagnosis.

3.3 Our research demonstrates that personalised care should therefore attend to the following factors:

- The level of confidence a person has to manage their cancer-related problems and how active they are in their health and health care.
- Optimal deployment of resources to ensure adequate skill mix within a health care team and across primary / acute / community sectors to identify and support patient-identified need.
- Access to training and educational resources to up-skill clinical teams on cancer-related psychosocial needs and personalised care.
- The availability of tools / measures / resources to enable clinical teams to identify, assess and support cancer-related problems from the point of diagnosis.

3.4 The NHS Long Term Plan includes the introduction of a quality of life metric. Measuring quality of life for people living with and beyond cancer is an important step towards improving it. We recommend that confidence to manage cancer-related illness and symptoms, depression, and the extent of unmet need are included in this monitoring. These factors may change over time and are known to be important in recovery of quality of life after cancer treatment.

3.5 Personalised care, and the introduction of a quality of life metric, are key facets of the Long Term Plan aimed at improving both physical and wellbeing outcomes. Wellbeing, or quality of life, is a crucial cancer survivorship outcome. Implemented in full, these aspects of the Long Term Plan will benefit millions of people living with and beyond cancer and improve cancer outcomes in the UK.

#### **4) Conclusions:**

4.1. Psychosocial health and wellbeing are key to improving cancer outcomes. We have highlighted evidence in this submission to support this claim. We have also made recommendations that could improve psychosocial care and wellbeing of patients. These will have a long-term impact on the UK's outcomes in comparison to other countries.

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