

Written evidence submitted by Prof Claire Foster, Dr Lynn Calman, Dr David Wright and Dr Chloe Grimmett (ECS0018)

Executive summary:

In response to the evidence call on cancer services by the Health and Social Care Committee Expert Panel, we provide evidence and recommendations on two policy areas: workforce and living well with and beyond cancer.

In the efforts to build the workforce for cancer services, we call for recognition of the important role clinical nurse specialists, cancer support workers and Allied Health Professionals have in providing personalised care. We also call for improved education for the workforce across primary and secondary care in cancer-related psychosocial needs and quality of life. Our research has identified that psychosocial factors (such as quality of life, mental health and confidence to manage illness) are as important as disease-stage in determining long-term health and wellbeing outcomes for people living with cancer. These factors are even more important for people with cancer during COVID-19, who have been affected by increased isolation, anxiety and uncertainty. Investment in workforce, education and psychosocial intervention development, delivery and evaluation is vital.

We recommend that the government should:

- Address workforce gaps that limit the delivery of personalised care for people with cancer, including Clinical Nurse Specialists, Allied Health Professionals and Cancer Support Workers
- Introduce boundary-spanning health professionals to integrate care between primary and secondary care services
- Support the delivery of training for clinical teams in personalised care and quality of life for people diagnosed with cancer
- Ensure the psychosocial needs of people diagnosed with cancer are routinely identified from the point of diagnosis and over time to inform their personalised care

Response authors:

[Professor Claire Foster](#), Director of the Macmillan Survivorship Research group (MSRG), Health Sciences, University of Southampton C.L.Foster@soton.ac.uk. Claire is Professor of Psychosocial Oncology and for the last 20 years, has led a research programme focusing 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
- developing and testing digital resources to support people affected by cancer to manage consequences of treatment and complex decision-making about treatment or genetic testing
- evaluating innovative models of workforce configuration and educational resources to deliver integrated personalised care.

Her research programme includes large prospective cohort studies, qualitative studies, the development and testing of complex interventions, and evaluations of service transformation. Her team works with people affected by cancer as research partners as well as clinical, academic, charity and policy leaders to support the design, conduct and dissemination of research to maximise impact.

[Dr Lynn Calman](#), Associate Professor, Deputy Director of Macmillan Survivorship Research Group, Health Sciences, University of Southampton L.Calman@soton.ac.uk. Lynn is a registered adult and mental health nurse with over 20 years of experience in Health Services Research. Her research focus is on:

- Understanding the impact of cancer and its treatment on everyday lives
- Supporting people to self-manage illness related problems
- Understanding the experiences of people living with advanced, incurable cancer

[Dr David Wright](#), Senior Research Fellow, Macmillan Survivorship Research Group, Health Sciences, University of Southampton D.Wright@soton.ac.uk. David leads the Evaluation Programme in the Macmillan Survivorship Research Group and has over 20 years' experience in health research and evaluations with particular interest in:

- Understanding the impact of cancer and its treatment on everyday lives
- Quality Improvement and service development in health care
- Evaluating innovative models of workforce configuration across primary, secondary and community sectors to deliver integrated personalised care.

[Dr Chloe Grimmer](#), Senior Research Fellow and National Institute of Health Research post-doctoral Fellow, Macmillan Survivorship Research Group, Health Sciences, University of Southampton C.Grimmett@soton.ac.uk. Chloe is a behavioural scientist leading a programme of work to support physical activity engagement and psychological wellbeing. She has 15 years' experience of developing and evaluating health promotion interventions with particular interest in:

- Understanding how best to support people with cancer to engage in physical activity in the long-term
- Designing and evaluating the impact of prehabilitation (optimising physical and psychological health prior to cancer treatments) interventions on cancer recovery
- Engaging with community organisations and professionals, including exercise specialists and counsellors to deliver health promoting interventions.

About the Macmillan Survivorship Research Group:

The Macmillan Survivorship Research Group, led by Prof Claire Foster at the University of Southampton, is delivering an internationally renowned programme of research providing a detailed understanding of the long-term impact of cancer and treatment on people living with and beyond cancer. We have established unique United Kingdom [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 support to the benefit of people diagnosed with cancer¹. Our [cohort studies](#) (e.g. CREW and HORIZONS) provide new insights into the long-term implications of cancer diagnosis and its treatment from patients' perspectives. Our evaluations programme is testing optimal means of assessing and supporting patient-identified need across primary and secondary care, including workforce development and education. Data collection during the pandemic has allowed us to track the impact of the COVID-19 pandemic on people living with and beyond cancer.

Recent publications from the Group:

¹ 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>

- Radcliffe E, Khan A, Wright D, et al. 'It feels it's wasting whatever time I've got left': A qualitative study of living with treatable but not curable cancer during the COVID-19 pandemic. *Palliat Med.* 2022 Jan;36(1):152-160. doi: 10.1177/02692163211049497
- Calman L, Turner J, Fenlon D, et al. Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoRECTal Wellbeing (CREW) study. *Colorectal Disease.* 2021. doi: 10.1111/codi.15949.
- 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
- Wright D, Gabbay J, Le May A. Determining the skills needed by frontline NHS staff to deliver quality improvement: findings from six case studies. *BMJ Qual Saf.* 2021. bmjqs-2021-013065. doi: 10.1136/bmjqs-2021-013065.
- Howell, D., Mayer, D. K., Fielding, R., Eicher, M., Verdonck-de Leeuw, I M., Johansen, C., Soto-Perez-de-Celis, E., Foster, C., Chan, R., Alfano, C. M., Hudson, S. V., Jefford, M., Lam, W, W, T., Loerzel, V., Pravettoni, G., Rammant, E., Schapira, L., Stein, K. D., Kocswara, B. Global Partners for Self-Management in Cancer, (2020) Management of cancer and health after the clinic visit: A call to action for self-management in cancer care, *JNCI: Journal of the National Cancer Institute*, , djaa083, DOI:10.1093/jnci/djaa083
- Frankland J, Wheelwright S, Permyakova NV, Wright D, Collaço N, Calman L, et al. Prevalence and predictors of poor sexual well-being over 5 years following treatment for colorectal cancer: results from the ColoRECTal Wellbeing (CREW) prospective longitudinal study. *BMJ Open.* 2020 Nov 12;10(11):e038953. doi: 10.1136/bmjopen-2020-038953.

Citation:

Foster C, Wright D, Grimmett, C, and Calman L. (2022) *A Response to: cancer services - a call for evidence from the Health and Social Care Committee's Expert Panel*

1. Workforce: The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021

1.1. Half the UK population will develop cancer, with half of those diagnosed likely to live at least 10 years. Improvements in diagnosis and treatment mean that cancer is increasingly seen as a long-term and not a life-limiting condition. While increases in cancer survival are to be celebrated, the long-term impact of living with and beyond cancer is significant and, if left unidentified and unsupported, can have a detrimental effect on health and well-being outcomes. There are also some cancer groups where survival remains poor and people are living with complex needs. These issues are recognised in the Cancer Workforce Plan and the NHS Long Term Plan.

1.2. There have been notable successes in delivering the Cancer Workforce Plan's ambitions with an increase in full time equivalent professions since 2016 in areas such as diagnostic radiography and clinical and medical oncology. However certain workforce gaps remain that limit the health service's wider ambition of improving patient outcomes through delivery of care that is responsive to need. The NHS Long Term Plan set the aspiration of personalised care becoming 'business as usual' across health and care systems. Specialist cancer nursing (CNS) and Allied Health Professionals teams are ideally placed to support this agenda but are currently under-utilised. CNSs and Cancer Support Workers are particularly effective in supporting:

- shared decision making
- personalised care and support planning
- enabling choice
- social prescribing and community-based support
- supported self-management

1.3. Our NHS England-funded evaluation of Cancer Support Worker (CSW) roles – [*Improving Access to Cancer Clinical Nurse Specialists and Key Workers*](#)² reported that patients and staff characterised high quality service provision as accessible, responsive, personalised, empowering, proactive, consistent and coordinated. The evaluation found that introducing CSWs into the specialist nursing team has a positive impact on access to assessment and care planning; community support services; practical and financial support; and health and wellbeing advice and support. Notable challenges exist however, including 'professional protectionism' between clinical roles; 'gatekeeping' of tasks by CNSs; professional isolation for CSWs; limited training resources (e.g. communication skills and psychological support); and infrastructural barriers (e.g. in informatics and communication). Fundamentally, a lack of capacity within the nursing team can act as a barrier to the consistent delivery of personalised care.

1.4. There is a need for an effective, integrated service for people living with cancer across primary and secondary care services. For the majority of people with cancer, most contact is outside of secondary care, in primary care – at home, work or in the community. The average general practice has 280 patients with cancer, nearly 200 of whom have one other long-term condition.³ Our ColoRECTal Wellbeing cohort study (CREW) identified several factors associated with poor

² Foster C, et c. *Improving Access to Cancer Clinical Nurse Specialists and Key Workers* (2019) University of Southampton and Wessex Cancer Alliance.

³ Yager, A. *Cancer as a long term condition* .:

<https://ipswichandeastsuffolkccg.nhs.uk/Portals/1/Content/Members%20Area/Training%20and%20education/GP%20training%20events/GP%20resource%20packs/GP%202021%20resources/Presentation%20Macmillan%202021%20CANCER%20as%20a%20LTC%20web.pdf>.

long-term cancer outcomes (e.g. depression, comorbid conditions limiting everyday life, low confidence to self-manage).^{4,5} Primary and community care teams are well placed to address many of these problems. However, our recent evaluation of 'boundary spanning' nursing roles working across primary and secondary care (*Cancer Nursing Across Boundaries*) identified significant barriers including:

- lack of communication between primary and secondary care professionals
- lack of an agreed model for person-centred, integrated care for people with cancer
- lack of cancer-specific training for primary healthcare professionals
- lack of understanding of chronic disease management alongside cancer for secondary healthcare professionals
- inability to access electronic systems across primary and secondary care
- logistical difficulties (e.g. lack of direct contact information)
- cancer care reviews viewed as a tick box exercise

The qualitative evaluation found that introducing boundary-spanning roles increased primary care knowledge, skills and confidence to manage cancer, and secondary care knowledge, skills and confidence to manage long-term conditions alongside cancer, providing enhanced support for people with cancer and complex needs/multi-morbidity.

1.5. A lack of clinically-relevant training and time to engage in educational activities is a barrier limiting the extent to which health professionals deliver personalised care. Specific educational gaps include the long-term implications of cancer and treatment, personalised care, rehabilitation and prehabilitation. Health Education England, Macmillan Cancer Support and others recognise this skills deficit, and various initiatives are in place to address this. PROsPer (Pre/Rehabilitation and Personalised Care) is an educational intervention for healthcare professionals, clinical leads and commissioners, funded by Health Education England (HEE) and delivered by Macmillan Cancer Support, and aims to address these educational gaps. The first modules went live in 2021 (<https://www.e-lfh.org.uk/programmes/prosper/>), with the remaining modules planned for delivery over 2022.

2. 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

2.1 The NHS Long Term Plan for cancer clearly articulates the importance of delivering [personalised care](#) 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. As stated in our previous submission to the Committee,⁶ psychosocial issues are recognised globally as important for cancer survivorship and the UK needs to offer world-class psychosocial support and services that are comparable with global cancer care. The

⁴ Foster, C., et al. Pre-surgery depression and confidence to manage problems predict recovery trajectories of health and wellbeing in the first two years following colorectal cancer: results from the CREW cohort study. *PLoS One*, 2016. 11(5): p. e0155434.

⁵ Cummings, A., et al., Comorbidities are associated with poorer quality of life and functioning and worse symptoms in the 5 years following colorectal cancer surgery: Results from the ColoRECTal Well-being (CREW) cohort study. *Psycho-oncology*, 2018. 27(10): p. 2427-2435.

⁶ Foster C. et al (2021) A Response to: cancer services - a call for evidence from the Health and Social Care Committee

importance of psychosocial and wellbeing outcomes was recognised in UK policy through the National Cancer Survivorship Initiative (established in 2010), the Cancer Reform Strategy (2007) and the Department of Health's Improving Outcomes Strategy for Cancer (2011). Significant progress has been made over the last 10 years, but more investment in psychosocial services and research is required to help people live well with and beyond cancer.

2.2 Our research identified the psychosocial factors that need to be attended to if cancer outcomes are to improve, including:

- Self-efficacy (confidence to self-manage): People 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](#)). Around 40% of patients had suboptimal levels of confidence to manage illness-related problems following curative intent cancer treatment.⁷ Levels of confidence remain steady over time without intervention. However, confidence to manage can be improved with appropriate support. Identifying and supporting those with low confidence to manage will benefit health and wellbeing in the long-term and improve quality of survival.
- Fatigue: our CREW cohort revealed that 37% experienced fatigue at 3 months and 20% at 5 years post diagnosis. Fatigue after cancer treatment is a common and debilitating symptom and, if unrecognised and untreated, is detrimental to long-term health and wellbeing. Cancer survivors often lack confidence to manage the impact of fatigue and resources, such as our evidence-based [RESTORE](#), can address this.
- Mental Health: It is important to assess and manage appropriately mental health from the time of diagnosis. Our CREW study found that 21% of participants reported depression soon after diagnosis and, left untreated, 15% reported depression up to 5 years later.⁸ People reporting clinically significant levels of depression pre-surgery had a higher risk of being depressed over follow-up. This may impact on health and wellbeing as poor recognition of depression and anxiety is associated with reduced quality of life and survival.
- Comorbidities: People living with other health conditions impacting 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.

2.3 Our research during the COVID-19 pandemic has revealed an additional impact on the wellbeing of people living with and beyond cancer, which may have greater negative impacts on long term outcomes. During the pandemic, access to psychosocial care has been disrupted and less flexible. New services and alternative means of providing support (*e.g.* virtual/telephone) were developed rapidly. The SafeFit trial, for example, is an evidence-based virtual programme of exercise, nutrition and psychological support delivered by cancer exercise specialists.⁹ Over 900

⁷ 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.

⁸ Calman L, Turner J, Fenlon D, et al. Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoRECTal Wellbeing (CREW) study. *Colorectal Disease.* 2021. doi: 10.1111/codi.15949.

people registered for the trial in 11 months, indicating the support for this initiative. Results of the impact on quality of life and psychological wellbeing will be available early 2023. Not all new programmes are evidence-based nor have been adequately evaluated. The implications of these innovations thus remain unclear, potentially limiting the delivery of personalised care and thus having a detrimental impact on long term outcomes.⁹ Before the pandemic, psychosocial care was not accessible to all cancer patients: there is thus an opportunity for such services to be 'Built Back Better', ensuring the needs of all those affected by cancer are fully met. Our research informed the recommendations of the NHS Cancer Programme's [Covid Recovery Taskforce](#) Task and Finish Group to address the impact of the pandemic on psychosocial support for people affected by cancer.

2.4 Our work has 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 907 responses, key findings include:

- 49% have needed someone else to take on tasks, such as food shopping or collecting medicine, that they would normally do.
- 41% who needed to make a GP appointment could not always do so.
- 71% 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.
- 94% felt the pandemic had caused at least some negative impact on their overall quality of life.
- 44% 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.

2.5 Additional issues raised by [HORIZONS](#) respondents about the effect of the pandemic included:

- Delays/cancellations to follow up appointments.
- Concern about not having face to face follow up appointments, meaning there could be no physical examination.
- Long delays (> 12 months) for 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.

2.6 [ENABLE](#), a qualitative study of people living with advanced cancer during the pandemic, highlighted issues that are likely to resonate more widely with cancer patients¹⁰:

⁹ 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.

¹⁰ Radcliffe E, Khan A, Wright D, et al. 'It feels it's wasting whatever time I've got left': A qualitative study of

- People have experienced more uncertainty and anxiety as a result of the pandemic.
- Not being able to see loved ones has had a significant impact on patients' and carers' emotional well-being. People have increasingly used technology to stay in contact with family and friends.
- Not all participants have had access to, or were able to use, technology for support.
- Patients and carers living with advanced cancer have wished to maintain their independence, a sense of normality and control. This has been impeded by the pandemic. Participants have 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 have experienced a higher burden of care but have had less access to practical, emotional and social support and respite from formal and informal sources.
- Participants have had concerns about the longer-term impact of changes to aspects of their treatment during the pandemic, such as changes in frequency of treatment.

2.7 Findings from our completed and ongoing evaluations of personalised care indicate that the 2021 ambition of every person diagnosed with cancer having access to personalised care has not been met. There is inconsistency in the understanding and delivery of personalised care across the primary and secondary care sectors. For example, *Cancer Nursing Across Boundaries*, and our evaluation of *Right by You Wessex* (an intervention involving the appointment of boundary spanning CNSs and CSWs, supported conversations, personalised care plans, information signposting and support service referrals), suggest that Cancer Care Reviews and needs assessments are undertaken in varied ways. For some, such assessments involved the use of tools such as the Holistic Needs Assessment, completed with the patient. For others, this is a 'tick box' exercise involving a short discussion with the patient.

3. Recommendations:

We would recommend the following to ensure the government's commitment to cancer services are met:

- Workforce gaps that limit the delivery of personalised care for people with cancer need to be addressed. This includes building the cancer care workforce including Clinical Nurse Specialists, Allied Health Professionals and Cancer Support Workers and ensuring they are integrated effectively in clinical teams. Their involvement will help improve patient health and wellbeing outcomes through the timely identification and support of patient-identified need.
- Boundary-spanning health professionals should be introduced to facilitate integrated care across primary and secondary care. Such professionals will help deliver joined-up care for people with cancer, skilling up primary care with cancer management, and improving the management of cancer as a long-term condition alongside comorbidities within hospitals.
- Clinical teams should undertake clinically relevant training to enable them to deliver personalised care and improve health and wellbeing outcomes, including quality of life for people living with and beyond cancer. This requires investment in educational resources and protected time for health professionals for professional development.
- The psychosocial needs of people diagnosed with cancer should be routinely identified from the point of diagnosis and over time. Identification of needs should include confidence to

living with treatable but not curable cancer during the COVID-19 pandemic. *Palliat Med.* 2022 Jan;36(1):152-160. doi: 10.1177/02692163211049497.

self-manage cancer/treatment related problems and concerns, mental health and impact of other conditions. Information from needs assessments should be used to inform the timely delivery of effective personalised care.

4. Conclusion:

Psychosocial health and wellbeing are key to improving cancer outcomes, particularly with the ongoing impact of COVID-19. Effective provision of psychosocial support requires a diverse, integrated primary and secondary care workforce, skilled in understanding and supporting the impact of cancer and its treatment on patients. It also requires early and regular identification of patient-identified need, investment in workforce education, and psychosocial intervention development, delivery and evaluation.

Jan 2022