



**EXPERT
REFERENCE
GROUP**

Older people living with cancer

Designing the future health care workforce



More than two thirds of cancer diagnoses occur in people aged over 65 years.¹ However, compared to countries with similar health care systems, the outcomes for older people in the UK following a cancer diagnosis are worse in relation to experiences of care and treatment, quality of life and survival.

Achieving World-Class Cancer Outcomes – A Strategy For England 2015-2020 set out a welcome ambition to improve cancer outcomes, with a review of the cancer workforce recommended as an important activity to achieve this goal. The workforce across health and social care remains a critical component to the story of improving outcomes for older people. Following recent evidence showing trainee oncologists' confidence to treat older people is low, research has identified an over-reliance on age as a determining factor in decisions about treatment and a lack of skills and training specifically related to ageing within the healthcare workforce core curricula. In light of this, the Expert Reference Group for the Older Person with Cancer – established by Macmillan Cancer Support to bring together patients with health and care professionals to address poor outcomes in older people with cancer – commissioned a review of evidence, and found that the current workforce is not well prepared to meet the needs of older people living with cancer. As the population ages, the gap between what can be provided by the current workforce and what older people actually need is likely to grow. There is evidence that policy and practice is shifting to better reflect older people's needs, but system-wide effort is required to close this gap.

This report summarises the evidence review and sets out recommendations about what will be required of the future health and social care workforce to ensure that it can appropriately meet the needs of older people with cancer.





Why focus on older people?

Nearly two thirds of cancer diagnoses occur in the over 65s and one third in people aged 75 years and over, with over half of all cancer deaths occurring in people aged 75 and over.¹ As the greatest risk factor for cancer is age, the UK's ageing population will have a significant impact on cancer services. By 2040, the number of people aged over 65 with a malignant cancer is expected to treble.² Almost one quarter of all people aged 65+ years in the UK will be cancer survivors by 2040, up from one eighth in 2008.^{2,3} However, when compared with similar countries, the UK compares poorly on some outcomes for older people with cancer. For instance, the 2005-07 survival rates at one year and five years for colorectal cancer were 10-15% lower in the UK than Australia, Canada, and Sweden for people aged 65+ years.⁴ Other research consistently indicates that older people with cancer in the UK are more likely to present as an emergency and less likely to have surgery, radiotherapy or chemotherapy than younger people.¹ In addition, people aged over 65 use 68% of all UK hospital bed days and represent 80% of emergency readmissions.⁵

⋮ **Almost one quarter of all people aged 65+ years in the UK will be cancer survivors by 2040, up from one eighth in 2008**

Cancer symptoms are less likely to be definitive with increasing age, and so getting an accurate diagnosis for older cancer patients may take time and involve a number of specialists. Age-related changes to tumour biology, a lack of research on effective treatments for older people and an increased vulnerability to the side effects of treatment, mean more carefully tailored and closely monitored treatment plans are

required. Older people are more likely to have needs that extend beyond the cancer and its treatment, such as comorbidities, more complex social situations and an increased need for personal, as well as health care, support. For example, the number of carers over the age of 65 is increasing more rapidly than the general carer population, and so the likelihood of a cancer patient having caring responsibilities is higher with older age. Many cancer treatments hinder a person, and issues such as cognitive changes, pain, exhaustion, nutrition and reduced mobility all require additional support. Older people are at higher risk of longer-term adverse outcomes as consequence of treatment, and so careful attention is needed to optimise health and well-being throughout their cancer journey. In addition, in contrast to an overriding concern with survival at all costs and thus the pursuit of curative treatment as the only goal of seeking help from cancer services, older people value a range of outcomes which may go beyond the extension of life. Older people are particularly concerned about maintaining independence and the longer-term consequences of cancer treatment can impact upon this.⁷ The differences for older people mean that time and skill, full assessment and multi-professional input is crucial to enable professionals and the system to best support older people as individuals, tailoring support and delivering appropriate care that can best meet the needs of that person. In spite of these important differences that can accompany old age, evidence suggests that current UK pathways for cancer care do not serve older people with complex needs well, and that a focus on speed as the primary driver of care can result in rushed and sometimes inappropriate treatment decisions.^{5,6}



What do older people want from cancer services?

Type of cancer, geography, socioeconomic status, gender and ethnicity all play a role in shaping needs and outcomes, regardless of age. The needs and preferences of active older people in otherwise good health can be very different from those of people living with frailty and other health conditions.

Macmillan's research on older people's attitudes to cancer found that older people living with cancer are just as likely to feel positive about their health, age and life as older people living without cancer.⁷ Very few older people in the survey reported that they declined treatment.

The findings indicated that older people feel positive about their prospects following a cancer diagnosis and want access to available appropriate treatment and support. The research also indicated that maintaining independence is just as important as maintaining health for older people, whereas maintaining health is the primary concern for younger people with cancer.⁷ These preferences have important implications for the role of the current and future workforce, and echoes findings from other work that cancer services need to focus on the older person with cancer, not just on treating the cancer.⁵

Research into older people's experiences of cancer care indicate that older people can have worse experiences. Data from the National Cancer Patient Experience Survey indicates that people aged over 75 years are less likely to have access to a clinical nurse specialist or to have been given information on the side effects of treatment but conversely are more likely to report feeling involved in decisions about care.¹ Studies have also identified that older people have a high trust in health care professionals and that they are often conscious that professionals seem very busy and lacking in time.¹⁷

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How prepared is the current workforce?

A scoping review of existing research literature was conducted at the University of Southampton between May and June 2016 to answer the primary research question 'How prepared is the existing UK workforce to deliver high quality cancer care and treatment to older people?'.⁸


Findings were categorised into six different themes:

1 EDUCATION, TRAINING, DEVELOPMENT

The evidence indicates strongly that deficits exist across the workforce in terms of education and training in the assessment, management and treatment of older people with cancer.

In particular, medical and nursing education needs support to ensure curricula reflects the skills needed to care for an older population.^{6,16,21,24,25} For example, neither the current medical nor the clinical oncology curriculum have dedicated learning objectives related to older people. However, both curricula include specific learning objectives related to the management of adolescents.¹⁶

Training in older people's care for the existing workforce also needs to be implemented.^{6,16,26-28} There is a consistent call beyond cancer care, across a number of specialists including oncologists, care assistants, non-cancer specialists, nursing, and allied health professionals, for specific support to address the needs of older people.^{8,17,18,30,31}



The needs and preferences of active older people in otherwise good health can be very different from those of people living with frailty and other health conditions

Moreover, specific areas for training needs are also highlighted in the literature including:

- the assessment of older people,^{14,15}
- chemotherapy and treatment decision-making,^{17,19}
- communication skills,^{23,27}
- dementia and delirium,^{16,23,31}
- polypharmacy,¹⁶
- nutrition,¹⁴
- falls,¹⁴
- co-morbidities.^{14,16}

Across the literature, education and training to help the workforce care for older people with cancer appears to be an emerging priority. Looking internationally, education is one of the International Society of Geriatric Oncology's (SIOG) top priorities worldwide³² and the European Oncology Nursing Society has developed a curriculum focused on older people and cancer.³⁰ As well as this, the Association of Medical Oncologists has on its agenda the specific action of, 'training and Continuing Professional Development (CPD) to address the problems of older patients with cancer'.²²



2 PRACTICE AND TOOLS

This theme relates to the way in which current practice reflects the level of workforce readiness. If the evidence mentioned previously suggests that age affects the type of treatment offered, and that training and education are a problem, then this theme explores what is happening in practice and what resources and tools the workforce draw upon.

Three areas were identified in the literature:

- In practice, fewer diagnostic and staging procedures, and less treatment, is offered with advancing age.^{12 19 33-35}
- Older people's needs in some cases are not being met.^{14 36} In particular, older people are given less information on support, including financial support and benefits entitlement³⁴ and less information on treatment and side effects;¹ they are not referred appropriately onwards to support and voluntary organisations;^{14 37} there is a lack of practical and social support in place,⁶ and within general settings and nursing homes, staff are unable to meet their needs.³⁸
- Older people are underrepresented in clinical trials.¹¹

In particular, evidence suggested that the lack of a reliable assessment instrument hampers professionals' ability to treat and manage older people effectively.^{6 13 16 27 34 39} Approaches such as the Comprehensive Geriatric Assessment (CGA) are considered essential to enable the workforce to assess need and plan care accurately.^{6 13} Evidence points to new approaches to assessment being piloted and trialled^{20 22} and also describes some specific initiatives targeting delays in diagnosis and early presentation with older people.^{22 40}

3 SKILLS AND COMPETENCIES

There is evidence that health care professionals lack confidence, knowledge and skills in caring for older people with cancer.^{16 20 21 24}

For example, a survey of medical oncology trainees found that only 27.1% of the trainees were confident in assessing risk to make treatment recommendations for older patients compared with 81.4% feeling confident to treat younger patients.¹⁶ In particular, there is a lack of skills and knowledge about how to refer older patients on for support,^{6 14 18 37} how to manage and deal with older people's health issues, comorbidities and dementia,^{16 21} how to communicate effectively with older people,^{17 21} and how to discuss and deal with specific issues, for example, death and dying or sexual needs.^{31 41}

The evidence base is lacking to guide healthcare professionals in recommending effective and safe treatment to older people.^{10 16 20 42} This lack of knowledge ultimately impacts upon treatment decisions.^{13 16 19} Evidence suggests that the workforce requires experienced and skilled staff with strong interpersonal and communication skills³¹ who understand the aging processes.^{42 43}

Furthermore, it indicates that gerontological^a and oncology skills need integration^{42 44} and that knowledge must be shared between gerontologists and oncologists.^{45 46} Specifically, knowledge is needed on how to interpret and act on issues presented in the assessment of older people⁶ as well as more research, innovation and the development of specialist roles.²²

^a "Gerontology", "gerontological" or "gerontologist" refer to a wider, multiprofessional outlook on older people's care, and may include specialist input on older people's care and treatment from doctors, nurses, allied health professionals, social workers or others, whereas "geriatric", "geriatric medicine" or "geriatrician" are terms used to specifically refer to the medical specialty, that is doctors providing specialist medical input on older people's treatment and care.



4 CAPACITY AND ACCESS

Across the workforce pathway, issues of capacity and access are reported. Within secondary care, older people (+75) have less access to clinical nurse specialists (CNSs).^{1 27 37 47 48}

Specifically, it is reported that another 1,234 CNS posts are required (2010 data) and that there is a shortage of nurses with specialist experience in older people's care.⁴² Other areas of the workforce have capacity issues. Geriatricians (that is, doctors specialising in geriatric medicine) are in short supply,^{6 26 49-51} and there is pressure on the radiologist workforce, who are unable to meet demands.⁵²⁻⁵⁴ Further, as reported by the Association of Cancer Physicians, there is a need to grow the number of medical oncology consultants through increasing the number of trainees.²²

There is a shortage of nurses with specialist experience in older people's care



Within community and primary care settings, older people value continuity of care, especially those who live alone³⁶ but access to this is variable. Research suggests that there are particular issues in this area; support services are not in place in time¹⁸ and out of hours provision is patchy.⁴³ Gaps in community support mean that health care professionals may be less willing to offer intensive treatment.²⁰ Additionally, the workforce itself is aging; this is noticeable in district nursing^{43 46} and palliative care nursing.⁵⁵ Health care professionals can feel frustrated when they don't have the time and space to assess and meet older people's needs¹⁸ Some health professionals devalue work related to older people,^{9 10} often for financial reasons like comparatively low salaries, or because of lack of clarity in roles and lack of career prospects.⁵⁴ It is here that the inverse care law – that the availability of good medical care tends to vary inversely with the need for the population served – is demonstrated most starkly. The literature suggests that it is essential to examine capacity, skill mix and increase capacity across health and social care.^{43 46}





5 WORKFORCE ATTITUDES AND BELIEFS

Evidence suggests that the attitudes and beliefs of UK healthcare professionals can shape the care and treatment that older people with cancer receive.

There is some research to indicate that ageist attitudes do persist within the workforce and that age-related views can affect practice, decision making and treatment.⁹⁻²² However, other evidence points to a more positive picture. Professional bodies, including medical royal colleges and standard setting organisations are tackling age equality as a priority.^{14 19 22-24}



6 WORKING RELATIONSHIPS, TEAMS, AND SPECIFIC ROLES

Evidence suggests that multidisciplinary working is key to effective care for older people with cancer.^{13 16 21 28 56} However, coherent and joined up care is not always in place,³¹ and information and communication is cited as a weakness.^{6 19 28} There is a need for statutory and voluntary sectors to work together^{20 37} which includes the role of volunteers and carers as members of the wider workforce.^{40 41 46 57} The role of the nurse is often cited as crucial: as an advocate,³⁹ for information,³⁷ and specifically in terms of the clinical nurse specialist (CNS) role^{18 20} and the skills provided.^{48 56 58} In this way, the development of an oncology nursing workforce which is competent at meeting the growing needs of older people⁴² and the development of the nurse role^{17 44} is needed as well as senior nurse posts.⁵⁹

The role of the geriatrician liaison or an older people's care specialist in cancer care of older people also emerges as seminal.^{6 13 14 16 18 21 24 26 29 34 41 59} However, while the value of gerontology input is evidenced across this review, in the UK, oncology and older people's care specialists don't see each other's work as their business¹⁸ and formal gero-oncology roles and links are rarely resourced.^{24 49}

To move forward, and prepare the workforce for caring for older people with cancer, effective leadership is needed within professional organisations to establish models of joint working,^{18 22} drawing on international models and alliances²² and by delivering innovative change.^{22 42}

What is Macmillan Cancer Support doing?

The Cancer Services Coming of Age project, led by Macmillan Cancer Support in partnership with Age UK and the Department of Health identified the benefits of engaging geriatricians and other elderly care specialists in cancer care. It also highlighted that using the Comprehensive Geriatric Assessment (CGA) within cancer care may well contribute to the right cancer treatment decisions being made for older individuals and towards general quality of care.⁶ Macmillan Cancer Support has since convened a UK-wide 'Expert Reference Group for the Older Person with Cancer' (ERG) to inform, test and influence improvements in outcomes for older people with cancer. The ERG ensured that the needs of older people with cancer were incorporated into recommendations 41 and 42 of *Achieving World-Class Cancer Outcomes – A Strategy For England 2015-2020*, calling for specific action to improve care pathways and assessment for older people with cancer, and to increase investment into research to understand why outcomes remain poor for older people.

The ERG is now working to improve assessment and care planning for older people as part of Recommendation 41. As part of this work, an online survey was distributed to health care professionals to identify current assessment methods used for older people in UK cancer services and to identify current access to geriatricians and other relevant services.⁶⁰

Responses from 640 health care professionals reflected that structured screening and assessment instruments were not frequently used with older people, with most respondents reporting that they would not consider using many of the common validated tools in clinical practice.⁶⁰

In addition, only 14% of respondents often or always had geriatricians involved in the assessment of an older people in cancer services. Only 25% had urgent access to a geriatrician, 25% had urgent access to social workers, 27% to psychological support, 16% to old age psychiatry input and 17% to specialist nurses in older people. Although 15% reported some dedicated geriatrics services for cancer patients in place, many of these services were funded temporarily by charities. Seventy percent of respondents had interest in further developing services linking older patients in cancer services to geriatricians.⁶⁰

The Macmillan Older People's Taskforce brings together older people affected by cancer who are experts by experience to understand how outcomes can be improved for people of this age. The Taskforce surveyed 140 older people with experiences of living with cancer about their views on the workforce. The survey findings point to the importance to patients' experiences of professional training, communication skills (especially at the point of diagnosis) and the extent to which different professionals and specialties coordinated care. The findings from these different sources exploring older patients' experiences suggest significant variation in the skills and time that staff have to suitably involve and enable older people to have a say in their care and treatment, and that there is scope for improved team working.





The future workforce

Our review of the evidence strongly indicates that the current UK healthcare workforce is not adequately prepared to meet the challenges of an ageing population with cancer. A range of policies and practices are being introduced to help address this gap, but more must be done to ensure that the workforce of the future is fully equipped.

The points set out below define the desired parameters of the future workforce, pertinent to all aspects of the cancer journey from the first suspicion of cancer through to discharge from active treatment, rehabilitation, survivorship and end of life. While these parameters have developed from a focus on older people, they may well be relevant for everyone with cancer, for example, with people with complex health and social care needs at higher risk of poor experiences and outcomes if these are not met:

All staff^b are aware of the need to treat people with dignity and respect, and have the skills to enable people to participate as fully as possible in understanding and making decisions about their care and treatment regardless of their age, gender, diagnosis, beliefs or any other characteristic.

Staffing levels and skill mix enable full patient participation in decisions made, consultation with and support of family and friends, the delivery of care and treatment tailored to the requirements and preferences of that individual, and that meets the full range of needs that require attention in each episode of care.

Family members, friends, staff and volunteers supporting older people on their cancer journey have **access to support, clear information, advice, advocacy and respite** as appropriate to their identified needs.

All health care professionals^c involved in assessing and delivering care and treatment to older people with cancer **know about common age-related health issues** (e.g. falls, frailty, difficulties with mobility and daily living activities, incontinence, cognitive impairment including dementia, hearing impairment, poor vision, low mood, polypharmacy) as well as social challenges (social isolation, lack of care network, caregiving roles, poverty and challenges of transport links); and have the **skills to identify and address these issues**, for example: conduct an initial assessment, develop a care plan with the patient, refer to relevant community services and know when to consult specialists.

All cancer services have sufficient staff with the necessary skills to ensure that everyone aged 70+ years (or younger where potential issues can be anticipated) is assessed for comorbidities, other common age-related health issues and social challenges at an early stage in their cancer journey and that these results are then interpreted by staff qualified to identify people in greatest need of additional input and specialist referral. Resources need to shift to meet the demand of patients with greatest need who are continually let down, this means greater resource to be dedicated to older people and greater care coordination to address those needs with incentives for staff to do this. Pathways are in place to ensure that individuals with greatest need are seen and assessed in the patient's home when possible and an appropriate plan is implemented to address the issues identified. These assessments and resulting actions are ideally conducted by one or more members of an older people's specialist team but alternative pathways could include primary care physician support, falls services, audiology clinics and social care.

^b Includes registered health and social care professionals, and support workers.

^c Individuals with registration with a health care professional body e.g. doctors, registered nurses, physiotherapists.



Treatment and care plans are developed and evaluated in partnership with patients and with the benefit of continuing input from a team of specialists that reflects the complexity of individual need, the team membership adjusting as patient needs change over time. When individual needs are particularly complex, specialists in older people's care (doctors, nurses, allied health professionals) are routinely involved in supporting decision-making and coordinating treatment and care. Champions in cancer care for older people in individual trusts are supported to drive improvements in care and treatment.

All older people have access to a cancer clinical nurse specialist or other care navigator to coordinate the different facets of their care and treatment for cancer and, where relevant, for other conditions, to provide psychosocial support and information, including on sensitive and difficult topics, and to advocate for them and optimise their involvement throughout their cancer journey.

Services are organised and resourced to support continuity of care for individual patients, multi-professional working and learning, the involvement of specialists in older people's care and key staff regardless of setting. This could include physical co-location of specialists, joint clinics, virtual cancer multidisciplinary team (MDT) meetings and a redefinition of the purpose and membership of these meetings. Health care professionals have the authority to agree with individual patients with more complex needs an exemption from NHS Constitution pledges to achieve maximum waiting times on cancer. This should apply when the person's health and wider needs merit fuller assessment and/or management than is possible within the set timescale prior to cancer treatment commencing. This will help to ensure sufficient time is available to make optimal decisions about care and treatment. This exemption – based either on the patient choosing to or if delaying treatment is in the patient's best clinical interests – currently applies to the 18-week waiting time target from referral to consultant-led treatment.



What has to happen to build this workforce?

A multi-faceted, system-wide approach is required to equip the current workforce and adequately prepare the future workforce for an ageing cancer population. We outline below four key strategies to guide these developments.

1. Develop and implement an education and training framework for older people's care

A basic national education and training framework is required for nurses, allied health professionals and medical professionals working with older people, regardless of specialty. This framework would specifically address competencies in the areas outlined above. A good template would be the Health Education England Dementia Core Skills Education and Training Framework.⁶¹ Like the dementia framework, the older people's care framework should detail the essential values, skills and knowledge needed across health and social care, taking into account the required attributes for all staff through to staff with expertise in working with older people. The Northumbria University National Career Framework for nurses caring for older people with complex needs, currently being evaluated, could be the foundation for a framework across the workforce.⁶²

All pre-registration curricula for health care professionals training to work with adults should be developed and delivered with reference to this framework. Ongoing specialist curricula should ensure continued professional development in all areas of oncology, including surgery (particularly general and gynaecological) reflects the development of values, skills and knowledge related to older people with cancer, so that they are equipped to assess for, and address commonly occurring issues in this group. In addition to this general provision, the development and delivery of accredited gero-oncology education programmes will enhance the knowledge and skills base of the existing workforce, and underpin the development of specialist gero-oncology roles.

2. Ensure adequate staffing levels in current workforce

As noted earlier, patients with more complex needs require additional time and a wider group of professionals to ensure thorough assessment, appropriate patient and family involvement, and the development and delivery of a tailored plan of care. In addition, decisions that are made about staffing levels, skill mix, grade mix, and staff deployment should be based on the best available evidence and guidance for instance, the NICE guidance for safe staffing for nursing in adult inpatient wards.⁶³ However the numbers of available professionals in many of the relevant disciplines are inadequate to meet the needs of growing numbers of older people with cancer. Such disciplines include community nursing, older people's nursing, geriatric medicine, clinical oncology, palliative care, primary care, radiology, and the allied health professions. This issue needs active and evidence-based medium to long term workforce planning, in addition to the efforts being made by NHS employers to tackle immediate recruitment and retention issues. A national strategy is also required to address the low status attributed to health and social care work with older people, and to make visible the high levels of skill and knowledge required to deal with complex needs. The societal status of older people is shifting as more positive images of ageing become mainstream, but assumptions that working with older people is unskilled and unrewarding need actively addressing at a national level.



3. Support older people's pathway development with integrated care models

As cancer services develop their comprehensive care pathways for older people with cancer,⁴³ particular attention will need to be paid to planning a workforce able to deliver these service innovations. Previous research has highlighted the importance of close working between cancer teams and older people's care specialists, and the centrality of the nurse specialist role to a positive patient experience.⁶ It has also raised questions about the appropriateness of current models of multidisciplinary working and the primacy of time-based targets for all cases.⁵ There is sufficient evidence from the acute care part of the cancer journey to guide hospital-based service development and piloting, and there are examples of integrated working in some UK centres, where geriatric physicians (plus in some cases specialist older person's multidisciplinary teams) are working with cancer teams to undertake comprehensive geriatric assessment and take an active part in planning care and treatment. Such centres have included the Royal Berkshire NHS Foundation Trust, Nottingham University Hospitals NHS Trust and Guy's and St Thomas' NHS Foundation Trust. In addition, the shape of the workforce outside of hospital settings has received little attention and, if the proposed care pathway is to cover the whole of the cancer journey, there are many aspects of workforce as yet undefined, including who will navigate the whole pathway with the patient and what workforce resources are required to properly support people at home, during and following active treatment: e.g. primary care teams, palliative and end-of-life care, social care, rehabilitation, community nursing and voluntary organisations.

4. Build the evidence base to guide workforce

Evidence is required to guide the future development of the workforce. At present, we lack an overview of which workforce-based interventions are effective in improving older patients' experiences and outcomes. These interventions include skill mix/grade mix changes, integrated roles/service model innovation, skills substitution, training and development. The University of Southampton is conducting a systematic review for the ERG on the effectiveness of specific workforce-based interventions aimed at improving outcomes for older people living with cancer, due to report in early 2017, and this will form the basis of recommendations for building the workforce evidence base.



Moving forward

Cancer is a major health challenge for older people and the health care workforce has a critical role in maintaining optimal health and quality of life for older people and families through their cancer journey. This review has found that the cancer workforce is not currently prepared to meet this challenge and accommodate an expanding and ageing cancer population.

There are existing areas of practice where good progress has been made in adapting the workforce to an ageing population and it is important that these are identified, evaluated and shared more widely.

Following on from this review, a further systematic review of the evidence into workforce interventions and their effectiveness against a specific set of outcomes is planned.

These outcomes encompass what an older person with cancer might want from health care: living longer, good quality of life, rapid recovery, positive experience and safe care and the review findings will highlight the ways in which the health care workforce can be developed to support older people achieve these important goals.



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Contributors to the Expert Reference Group workstream on Workforce

Professor Jackie Bridges Professor of Older People's Care,
University of Southampton (Chair)

Lisa Barrott, Macmillan Acute Oncology Clinical Nurse Specialist,
Brighton and Sussex University Hospitals NHS Trust

Lorraine Burgess Macmillan Dementia Nurse Consultant,
Christie NHS Foundation Trust

Dr Lallita Carballo Joint Clinical Lead for Supportive Cancer Care
& Head of the Macmillan Support and Information Service,
UCH Macmillan Cancer Centre, University College London Hospitals
NHS Foundation Trust

Mr Kwok-Leung Cheung Clinical Associate Professor,
University of Nottingham; UK National Representative,
International Society of Geriatric Oncology

Dr Anthea Cree Clinical Oncology Registrar,
NHS Foundation Trust

Nicky Dann Nurse Specialist, COCOC team,
Royal Berkshire NHS Foundation Trust

June Davies National Cancer Rehabilitation Lead,
Macmillan Cancer Support

Dr Carole Farrell Nurse and AHP Research Fellow,
Christie NHS Foundation Trust

Dr Naomi Farrington Post-doctoral Research Fellow,
University of Southampton; Staff Nurse, University Hospitals
Southampton NHS Foundation Trust

Liz Fenton Nurse Advisor, Health Education England

Dr Mary Flatley Lead Nurse, St Joseph's Hospice, London

Professor Margot Gosney Professor of Elderly Care Medicine,
University of Reading; Honorary Consultant in Elderly Care Medicine,
Royal Berkshire NHS Foundation Trust; Deputy Postgraduate Dean
at Health Education England Thames Valley

Dr Berkin Hack National Medical Director's Clinical Fellow

Philippa Jones Macmillan Associate Acute Oncology Nurse Advisor,
NIHR Clinical Research Network: West Midlands Cancer Division

Andrew Jazaerli Senior Health Inequalities Manager,
Macmillan Cancer Support

Dr Tania Kalsi Consultant Physician in Geriatric Medicine,
Guys & St Thomas' NHS Foundation Trust

Grace Lucas Visiting Fellow, University of Southampton

Selina Mehra Patient Experience & Health Inequalities
Programmes Lead, Macmillan Cancer Support

Vicki Morris Professor of Medicine, University of Minnesota;
Staff Physician, Hematology/Oncology, Hennepin County Medical Center

Dr Charlotte Moss Consultant in Medical Oncology,
Brighton and Sussex University Hospitals NHS Trust

Dr David Plume GP GPwSI Palliative Care and Cancer,
Staff Grade PBCSPC, Macmillan GP Advisor (LASER Region),
Co-Course Director Red Whale (GP Update) Cancer Course

Dr Richard Simcock Clinical Oncologist,
Brighton and Sussex University Hospitals NHS Trust

Julie Wells Transforming Health

Professor Theresa Wiseman Clinical Chair of Applied Health in Cancer Care,
Strategic Lead for Health Services Research, The Royal Marsden NHS
Foundation Trust, Faculty of Health Sciences, University of Southampton

Ms Lynda Wyld Consultant Breast Surgeon,
Reader in Surgical Oncology, University of Sheffield

Expert Reference Group Older People's Taskforce

Judy Bayer

Alison Doyle

Jon Newman

Alan Quarterman

Lynne Wright

Supported by Fatimah Vali, Senior Engagement Officer,
Cancer Services Innovation, Macmillan Cancer Support

