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Submitted to Consultation on the Cancer Strategy for Northern Ireland 2021-2031
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Introduction

1 What is your name?

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3 Are you responding on behalf of an organisation?

Yes:
Yes

No:
No

4 What is your organisation?

Organisation:
Royal College of Occupational Therapists (with support of the Northern Ireland Regional occupational therapists working in Oncology and Palliative care and RCOT Specialist Section - Major Health Conditions)

Strategic Direction for Cancer Services in Northern Ireland

5 Do you agree that the proposals set out in the Cancer Strategy Consultation paper are the correct strategic priorities for Cancer services in Northern Ireland?

Strategic priorities:

The four strategic themes identified are reflective of the seven subgroups tasked to develop the draft strategy.

In an attempt to be user friendly and to provide clarity, we suggested that the recommendations are clearly numbered and placed with the relevant sections of the cancer strategy. The Cancer Recovery Plan should also be clearly linked within the cancer strategy in order to provide the clear and measurable targets that have been set for delivery and implementation.

Preventing Cancer

6 Do you agree that these recommendations will reduce the number of preventable cancers in NI? Please provide details for your answer.

Preventable Cancer :

The number of cancer cases diagnosed in Northern Ireland has doubled over the past 25 years and is projected to double by 2040. Large increases are predicted for many cancers with poor survival.

In order to achieve greater success in prevention we need to be able to measure progress. Recommendations 1-4 fall short. We require ambitious targets be set for at least the next five years with plans that detail meaningful action on prevention, especially on tobacco and obesity.

We support the need to raise public awareness and deliver regular, effective, targeted evidence-based ‘Be Cancer Aware’ campaigns and to develop measures to increase uptake of all cancer screening programmes. However, the opportunity for collaborative and multi-professional working should not be overlooked. In the overall delivery of health care services occupational therapists, and AHPs are in a prime position to support the public in raising their awareness and also in identifying and supporting individuals with potential health concerns. This has the potential also to support the overall aim to target those in hard to reach communities. A collaborative and multi-professional approach will be essential in the recovery of cancer referrals resulting from the knock-on impact of Covid and late presentation in the years going forward.

For those people with learning difficulties, mental health difficulties, dementia or those who are homeless it is often carers, support workers, family or other healthcare professionals who are best placed to notice signs and symptoms of cancer or be in the position to implement and support health promotion initiatives. These programmes need to take that into account and make provision for the ongoing need for training/advice and the role Oncology/Specialist Palliative care teams could play to ensure symptoms are not missed due to diagnostic overshadowing.

As is recognised, almost half of all cancers could be avoided, action must be taken in a coordinated manner by multiple partners and across many

settings. Occupational therapy practitioners look at all aspects of a person's life and areas of function to support optimal health. By promoting person-centred approaches to performing daily activities (occupations related to self-care, home management, and community participation), and adoption of healthy habits and routines, occupational therapy practitioners facilitate health across the lifespan.
We know from feedback from patients and health professionals that people who have been diagnosed with cancer would like more information, tailored to their individual needs on how to make lifestyle changes. The implementation of AHP led prehabilitation programmes will also provide a forum to address prevention at what is recognised as a "teachable moment".

Diagnosing and Treating Cancer

7 Do you agree that these recommendations will improve outcomes for people living with cancer? Please provide details for your answer.

Improved outcomes :

We welcome the recommendations for Northern Ireland to be in line with the National Screening Guidelines and support the introduction of centralised diagnostic hubs. It is recognised there will be significant challenges in meeting these demands. Building diagnostic capacity will require a variety of funding approaches for new equipment, workforce planning and training, as well as new models of diagnosis – it is important that there is a continued commitment to this and a push to fund initiatives that will have the greatest impact.
Work to develop the '28 days to diagnosis' standard is positive. It will be important to get a sense of what the baseline for this standard is, so that we can understand the scale of improvement needed.

Prehabilitation
Occupational Therapy welcomes the inclusion and recognition prehabilitation has within this document. However, we would request prehab is discussed after diagnosis and prior to any cancer treatment1. This is suggested in order to help to shift the current mind-set that prehab is purely prior to surgery2.
1 Ref - Macmillan (2019) Prehabilitation for People with Cancer. Available at: https:// Www.macmillan.org.uk > assets > prehabilitation-guidance-for-people-with-cancer
2https://www.nursingtimes.net/clinical-archive/cancer-clinical-archive/prehabilitation-to-improve-lung-cancer-outcomes-1-principles-and-benefits-20-09-2021/

We welcome the clear statements within recommendations 21 and 22, however we request clear measurable targets and agreed timeframes are set. The recognition of these services being led by Allied Health Professionals is also welcomed and it is agreed there is no planned, coordinated or commissioned prehabilitation service available in Northern Ireland. This strategy however fails to take account for the difficulties AHP would have in delivering these recommendations due to the shortfall in workforce. The Cancer Recovery plan refers to a scoping of existing prehabilitation resources, identifying gaps in existing resources and to formulate a plan to address gaps across tumour sites.

The Royal College of Occupational Therapists wish to raise concerns in regard to the set-up of prehabilitation services to date and the future plans as stated within the Cancer Recovery Plan. Within Northern Ireland, the occupational therapy profession has been at a disadvantage in the formation of many of these small ad hoc pilot projects. Often singular / limited multi professional groups have been involved in the setup, largely dependent on resources available. Some have been established through grants or temporary funding. Due to staffing levels and workload prioritisation occupational therapists have rarely been in a position to input to these unfunded pilot programmes, placing occupational therapy at a disadvantage when going forwards. RCOT is disappointed to see the Cancer Recovery 3 year Plan endorses the continuation of the development of ad hoc, inconsistent application of prehabilitation.

The Royal College calls for the opportunity within Northern Ireland to take stock of service provision to date and to reimagine the service provision that is required to meet our patients and service needs. From the outset we request services which are regionally agreed, cohesive, apply consistent application of prehabilitation and take into account equitable access to all health care professionals including occupational therapy

The endorsement of the 2017 Allied Health Professions (AHP) cancer and palliative care workforce scoping report3 is required in order for the implementation of prehabilitation, as there is insufficient AHP capacity to meet and deliver the current and projected needs of the population.

3. Department of Health (Northern Ireland) and Macmillan (2017) Specialist Allied Health professions (AHP) cancer and palliative care Workforce Scoping Report www.health-ni.gov.uk

Evidence is clear that by investing in prehabilitation the cost will be effective, but more important the experience and quality of life better for the service user.

Whilst RCOT welcomes these important recommendations and are aware of the potential benefits it will have for patients and services downstream, we cannot negate the need to ensure that the current existent AHP service delivery gaps and unmet needs are also recognised and addressed. There needs to be a clear focus across the continuum of care and for AHPs to be able to provide rehabilitation, living well with and beyond cancer, palliation end of life care and alongside these, early intervention. Without careful consideration of the needs of each AHP service we are at significant risk of creating further inequity and inconsistency across professions and trusts.
Evidenced based education also needs to be available to non-cancer specific AHP professionals who may be involved with those patients care outside of the cancer specialist units regarding their roles, expectations for provision of occupational therapy intervention, data collection and application of appropriate outcome measures and to be aware the impact this will have on patient outcomes.
In addition, we would ask for further consideration to be given to the wording on the following points:
• Pg 49 - While some ad hoc pathways, pilot initiatives and models are developing for some tumour groups there is minimal provision available for rehabilitation despite strong international evidence about the benefits and cost effectiveness. – This should read "prehabilitation".

Radiotherapy
As identified, radiotherapy is a vital component of the different treatment options available for cancer patients with approximately 50% of people with cancer receiving it as part of their primary treatment. With a growing complexity in treatment regimes and a focus on reducing numbers of fractions

delivered for patients, there also needs to be due consideration given to AHPs and their current capacity to be able to identify, assess and deliver AHP interventions in this shorter timeframe, to this complex patient cohort as early as possible within their pathway. However, given current waiting lists and staffing pressures we would welcome a workforce review of staffing capacity to ensure adequate resources are available and therapy can be provided in a timely, efficient and effective manner. Consideration to logistics of clinic space and environments also needs to be taken into consideration as often for AHPs this can be a barrier to being able to provide treatment in the appropriate timeframe due to lack of space at key specific times.

SACT

Recommendation 23 refers to the implementation in full of the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan by 2026. This section raises concern within the occupational therapy and other AHP workforce.

RCOT is very concerned that AHPs have not been included (with the exception of radiography) within the Oncology Transformation Project or the Oncology Haematology Stabilisation Plan. These reports not only address the necessary changes that are required in the delivery of SACT services but also address the impact of COVID and the identified 6% projected annual growth requirement in SACT services. Despite this projected increase in growth of cancer services overall, the workforce of AHPs has not been reviewed for oncology or haematology.

The opportunity for AHPs to inform and contribute to new service models has been denied, which has potential for a negative impact on patient care and outcomes. Whilst it is recognised AHPs are not responsible for the administration of SACT they are in the prime position to contribute to the multidimensional nature of assessment and put in place strategies and interventions that will support patients when considering SACT treatments. It is of concern that evidence based work being carried out Nationally and Internationally, which has the potential to transform outcomes has failed to be integrated into cancer services and the Cancer Strategy. (See response under 'Older people with Cancer' for proposals of the potential contribution AHPs can provide within New Models of Care).

New service models need to be developed and regional pathways to improve for access to equitable services for vulnerable groups,. such as frail elderly, dementia patients those with learning difficultiesor patients with mental health difficulties. AHP's need to be on board and included to inform these services. The use of holistic assessment and appropriate geriatric screening tools should identify those people in need of a more thorough assessment of frailty/mental capacity by Oncology/Specialist palliative care teams and will ensure appropriate treatment either curative or palliative is achieved. Similarly, to ensure equitable access to prehabilitation, rehabilitation and symptom management services delivered by the right people in the most appropriate setting. We support the development of regional specific pathways to guide and streamline processes and improve communication/decision making.

This work has also failed to recognise that changes in service delivery such as remote consultation and the devolvement of service in relation to SACT delivery, has a knock-on impact to patients and access to AHPs regionally. No consideration has been given to how these patents will access AHPs in outreach clinics, nor consideration given to AHP waiting times. It is inevitable that a plan requesting approximately 150 new posts will have an impact on AHP services. The expectation has been that AHP services will absorb the knock-on impact without an increase in staffing. This is no longer sustainable.

It is important to acknowledge that there are clear inconsistencies in service delivery not only between various AHP professionals but also across regional services and as a result service provision is often ad-hoc, lacks consistency and is not sustainable.

The Royal College and members in Northern Ireland wish to highlight the inequities that patients experience in regards to regional access to Specialist Occupational Therapists. To date there is no designated therapist for cancer patients within the South Eastern Cancer Unit and within the NWCC, occupational therapy has only been funded for the radiotherapy service. Non radiotherapy oncology cohorts of patients at both the inpatient and outpatient level and haematology services have not yet been funded.

In a recent pilot study conducted by occupational therapists on the unfunded Western Trust acute cancer unit a total of 329 occupational therapy referrals were received over a 12 month period (April 2020- March 2021), despite Covid 19. Of these referrals, 116 had a diagnosed haematological condition and 121 were oncology patients not on the radiotherapy pathway. Together these figures amounted to a total of 237 of the 329 referred patients overall who currently do not fit under current occupational therapy funding and staffing levels and outside of this pilot would not be eligible for occupational therapy service delivery. This will have a significant impact on patient experience, their functional outcomes, recovery, and quality of life and for inpatients, will increase length of stay. RCOT requests such inequities and failings in service provision be factored in within the 10 year cancer strategy, and ensuring a sufficient and reliable occupational therapy service can be provided regionally.

Metastatic Spinal Cord Compression

We welcome Recommendation 29 which refers to the development of a robust and coordinated 24/7 metastatic spinal cord compression service with rapid access to gold standard imaging and treatment. We would however request that the rehabilitation needs of these patients be given due recognition and resourced to ensure we are able to deliver on improved outcomes for this complex patient group that require specialist rehabilitation services.

AHPs and in particular occupational therapists, are often the first port of call when considering MSCC management and as such we would request that due consideration be given as part of the workforce planning to ensure we are in a position to respond effectively to this highly complex and specialist cohort of patients. We would also like to highlight the significant work that AHPs carried out in addressing the rehabilitation needs of patients suspected or diagnosed with MSCC. This resulted in the publication of GAIN Guidelines for the AHP Rehabilitation of Patients with MSCC for the acute and community sector. This work has been widely recognised and is often referenced, implemented and audited nationally. Unfortunately, it has failed to be recognised or integrated into the cancer services within Northern Ireland.

Guidelines for the Rehabilitation of Patients with Metastatic Spinal Cord Compression (MSCC) (rqia.org.uk)

bc5d1cc4-9eab-48db-a225-ebcf8dd35b09.pdf (rqia.org.uk)

Acute Oncology Services

We welcome recommendation 30 to develop a fully integrated equitable 7 day acute oncology service across all Trusts. We request however consideration be given to a whole team approach. Services as provided by occupational therapists allow a multidimensional nature for assessment and intervention and will have contributed to the overall aim of the acute oncology service. AHP services are often referred to on an ad hoc basis dependant

on availability. By exploring service reform and providing training and education in acute oncology, there is potential to enhance the accessibility and contribution occupational therapists' could provide to the acute oncology service. This will require workforce modelling to ensure equitable access to AHPs along the acute oncology pathway.

Cancer of Unknown Primary

Metastatic Cancer
We welcome recommendation 40 which aims to ensure that an effective Multi-Disciplinary Team meeting is held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease. RCOT would recommend the inclusion of AHPs as very important in the formation of these MDTs.
For many diagnosed with metastatic cancer this will ultimately be terminal. However now thanks to developments in SACT we are seeing people live for many years. However, they are often living with the side effects of cancer and treatment. Improved collaboration between oncology, AHPs and specialist palliative care services would result in these patients being referred earlier. Enabling them to access services earlier in their journey improved symptom management and quality of life. Cancer Centre and cancer unit outpatients currently availing of SACT treatments are rarely being identified or referred until much later in their journey and would have benefited from this input much sooner.

Haematological Cancers
We acknowledge there has been a 42% increase in haematology referrals and inpatient activity has increased by 120-130% between 2013 and 2016, we also note, a projected 30% of patients who will undergo CAR-T, however the subsequent increased demand for AHP intervention in line with this has not been reflected in the recommendations. The exclusion of AHP's in the Oncology-Haematology stabilisation plan will further disadvantage AHP's from being able to provide an adequate and essential service to this complex cohort of the cancer population and as such there will remain shortfalls and inconsistent funding for AHP services regionally if not redressed.

To date there has never been a Haematology AHP workforce review. Current staffing has resulted from oncology funding which has been detrimental to both oncology and haematology patients. We would welcome a robust workforce planning review to address the substandard and, in some cases, non-existent AHP regional service provision currently available. We would also request a clear plan including provision of education in order to respond to the projected increase in caseload and clinical skill mix required to deliver an optimal, equitable and timely AHP rehabilitation service for patients with haematological conditions across the entire cancer pathway for the future.

The occupational therapy profession is able to clearly identify the needs and demands for our professional input within this area. In an effort to reform existing service provision and to provide equity in overall cancer service provision including haematology, the occupational therapy department in the Northern Ireland Cancer Centre has provided dedicated occupational therapy staffing to haematology from the start of 2021. This has enabled attendance at ward meetings and subsequent screening of referrals by the occupational therapy service. This led to an increase in referral rate of 46 % (i.e., Nov-April 79 referrals & April-Sept 147 referrals).
During this period a service improvement initiative was also carried out to explore the Occupational Therapy needs stem cell transplant inpatients admitted to the haematology centre. These patients were not routinely referred for occupational therapy intervention prior to April 2021. From April 2021 to September 2021, 29 patients admitted for a stem cell transplant were screened by the occupational therapy service. Of these 29 patients screened:
• 72% of patients screening did indeed require occupational therapy intervention
• 59% patient required information /education on fatigue management
• 14% patients required onward referral for health and wellbeing support post discharge
• 14% patients received relaxation information /CD
• 17% patients required equipment provision / community occupational therapy follow up
Our occupational therapy members in Northern Ireland are able to further demonstrate the continued failings to provide essential and equitable services to our cancer and haematology patients. It has only been since the establishment of the radiotherapy cancer centre within the Western Trust that there has been any funding for occupational theray staff provided. This funding however was only commissioned for the provision of radiotherapy. In an effort to inform and highlight the deficits of what should be considered a necessary service occupational therapy carried out an inpatient pilot on the unfunded cancer specialist ward within the Western Trust. A total of 329 patients were referred in a 12-month period of which 116 of these had a haematological diagnosis requiring intensive occupational therapy input. Despite the importance occupational therapy plays in delivering interventions to haematology patients no consideration has been given to the lack of workforce.

It was the concern of a poorly funded / unfunded occupational therapy service and our awareness of patients' needs that compelled us to carry out these audits. It is unfortunate and of great concern that as a professional group and within a wider group of AHPs, we have been denied the opportunity to inform on our current position, the needs of patients and ability to provide a responsive service over the next several years.

Occupational therapy would also like to highlight that should plans go forwards for the development of CAR-T services in Northern Ireland, that the needs for AHPs need to be considered. It is referenced within the strategy that 30% of patients undergoing CAR-T will require ICU admission during their inpatient stay. In recognition of this, NICE guidelines (2009) for "Rehabilitation after critical illness in adults" recommend occupational therapy provide a structured comprehensive assessment to identify physical, sensory, cognitive or communication needs". The NSF for longterm conditions also advises that "staffing must be adequate both in terms of staff numbers and experience to deliver rehabilitation services, but when introduced early and intensive, rehabilitation has been proven to be cost-effective" (NSF, 2005) and provision of occupational therapy has been associated with improved function at hospital discharge, reduced ICU length of stay and reduced incidence of delirium (Pohlman et al 2010, Schweickert et al, 2009).
So, whilst we welcome the mention of a required multi-professional approach for safe management of these patients including AHP input there must be recognition that as currently stands, there is a complete deficit in occupational therapy funding for Haematology patients, which needs to be urgently addressed.

Older People with Cancer
We welcome Recommendation 36, which aims to ensure the development of appropriate pathways and services for older people with cancer, rarer cancers, teenage and young adults and people from seldom heard communities. Older people with cancer require specialist AHP input due to increased

frailty, co-morbidities and carer burden, we urge that AHPs are detailed within these pathways.
Occupational therapy considers new models of care are required in order to address the identified needs of these subgroups. To date, occupational therapists have not been consulted in any new models of care, but in an effort to demonstrate our potential contribution, highlighted the following factors as detailed within the cancer strategy:
• Cancer is a disease related to ageing and increases in incidence in older adults.
• The Cancer Research UK report "Advancing Care, Advancing Years: Improving cancer outcomes for an Ageing Population", highlights the complexity of the ageing population including increased co-morbidities, cognitive issues and social care needs. They call for significant consideration to be given in the development of cancer treatment and care plans.
• Age-related inequality is reported
• It is stated "methods currently used routinely to assess fitness for treatment are, arguably, not fit for purpose and lead to poor assessment of the needs of older people with cancer".
• In addition to the risk of under treatment in older people there is a risk of over treatment without the appropriate geriatric assessment screening tools to identify those older people in need of a more thorough assessment of frailty.
• Similar findings are reported for those living in socioeconomically deprived areas.

Whilst a recommendation is made for the development of appropriate pathways, RCOT would like to draw attention to the valuable contribution and the body of evidence that clearly demonstrates the vital work AHPs and in particular occupational therapists can provide. AHPs are experts in carrying out comprehensive assessment of frailty. We also recognise frailty as a dynamic condition, the course of which can be influenced. By occupational therapists addressing preventable and modifiable risk factors, such as functional impairment, nutritional compromise, cognitive impairment, social isolation, physical activity, falls and lifestyle modification we are able to transform outcomes.

Whilst the cancer strategy seeks to improve services and outcomes for older people and advocates for better integration with care of the elderly services, it must be stressed that frailty in cancer does not solely align to only those who are elderly.

Children and Young People
There is no mention of AHP services in this section at all and NICE guidelines recommend these are available to all children and young people with a cancer diagnosis. We welcome recognition of the need to further develop the AHP services. It is also of concern that despite the recognition of children's services within the cancer strategy, they have not been included within the cancer recovery package, which is for adult services only.

At present some AHP services have been appointed but there needs to be sustainable succession planning into this specialist area.

AHPs work across the whole spectrum of children with childhood and teenage cancers. By their nature these cancers are in real terms rare and small numbers. This can pose challenges in the breadth of skills required and the ability to access specialist training or evidence based or nationally pathways of care. Whilst RBHSC is the primary treatment centre in NI patients often access specialist medical services in other centres in UK or Ireland and there are challenges in the continuity of AHP provision and care.

AHPs lead on prehabilitaton and rehabilitation across all childhood cancer diagnosis including those children with brain and CNS tumours.
The development of an all-island provision of cancer services is welcomed but equity of AHP provision should be considered.

Paediatric AHPs have a contribution in the treatment of teenagers and young people up to the age of 16, but often beyond if episode of care is ongoing. AHPs have a significant role in the return to normal life and school at the end of treatment, promoting physical activity and healthy lifestyles, and promoting age-appropriate independence.

Current accommodation in RBHSC does not support the development of AHP services and limits the potential for rehabilitation in terms of treatment space and storage of specialist equipment. Dedicated facilities for AHP services supporting haematology and oncology patients would enhance care and patient journey.

AHPs in RBHSC are supported by those working in community in all regional trusts. Access to AHP services should be equitable across all regions. This is particularly true for palliative care when a community AHP response is often required on an immediate and response basis.

Teenage and Young Adults
It is recognised that the findings of ESMO highlights deficiencies in access to both specialist facilities and support from a wide range of health care professionals including specialist nurses, AHPs, social workers and psychologists. They advocate for a strengthened multidisciplinary approach.

In the recognition of these deficiencies, we would welcome an AHP workforce review and consideration be given to address these shortfalls in service provision where the requirement of specialist AHP services are required.

Learning Disabilities
For people with a learning disability (LD), symptoms are commonly missed due to diagnostic overshadowing. There should be training for generalist AHP staff in oncology, tailored to the assessment and management of needs of those with learning disabilities and a cancer diagnosis. MDT working needs to increase across oncology, learning disability and mental health teams. This will need time and training on both sides to manage care well. A survey of staff in NHSCT learning disability and primary care staff showed lack of knowledge on management and available services and supports on both sides. When palliative care was involved, staff reported a more positive experience for both patient and staff. Oncology/Spec primary care teams could act in a training/advisory role, however this is not available in acute or community Trusts to date.

It is noted, Scotland have a learning disability pathway for oncology/palliative care – Northern Ireland needs regional standardised pathways and services set up with appropriate time and training.

Clinical Trials / Clinical Research

Clinical Trials and research is vital for the continued development of cancer services. Expansion of trials and research to include the wider AHP team is key and should be addressed in order to fulfil the stated recommendations. Creation of new research and development posts for therapy radiographers and the wider AHP teams would enable a more MDT approach to the research environment.

Supporting people to live well and die well

8 Do you agree that these recommendations will deliver person centred care? Please provide details for your answer.

Supporting people to live well and die well:

The Recovery Package

We welcome recommendations, 42, 43 and 44 – We believe that personalised care, built around individualised care planning, must be central to any improvements in cancer services. However, if the Recovery Package is to be rolled out to all patients, it would be useful to see more detail on how the recommendation regarding the split in commissioning responsibilities is addressed, including the split within elements of common cancer pathways as well commissioning for rare cancers. We would like to see a clearer focus and central expectations for the commissioning of cancer services that allow for needs assessment, care planning and provision of support as highlighted within this strategy.

The Cancer recovery Plan highlights the importance of providing appropriate information, support, prehabilitation and rehabilitation services to improve reduce and manage any consequences of cancer and its treatment. However there has been no reflection of the ability to provide such services. We would like to see more detail on how patients will be supported in managing the side effects of cancer and its treatment. It is critical that plans are put in place, to make sure that tailored AHP support is commissioned and made integral to the cancer pathway.

The component section of Risk Stratification identifies the inclusion of all stages of cancer including those with a palliative prognosis. However, the elaborative section on risk stratified follow-up (pg 82-83) does not detail how this should look for palliative patients. Palliative patients are often a vulnerable group of patients requiring information on self-management and increased awareness of services & support, roles of teams, peer support. This continues to be an unmet need. AHPs play a key role within this, with occupational therapy providing advice on fatigue, relaxation, managing activity, energy conservation etc. However, we require the resources to do this.

A recent service improvement initiative carried out by an occupational therapy Team within a cancer centre, highlighted the valuable contribution occupational therapy makes when integrated early into the lung cancer patient pathway at the time of diagnosis. On review of occupational therapy assessments and intervention, they were able to report the high level of support required.
• 87% were no longer able to carry out meal preparation,
• 63% experienced a decline in ability to attend to personal care,
• 70% had difficulties with bathing/showering.
• 57% had difficulties with stairs,
• 50 % had difficulties with transfers.
Occupational therapists in their holistic assessment identified that 36% of patients lived alone, 22% lived with another elderly person, only 3% had a formalised care package. 73% were required to climb stairs in order to access their bedroom, and 38% to access a toilet. In their intervention they observed patients struggling to coming to terms with their diagnosis and its subsequent impact on function. Although many patients were initially hesitant to accept recommendations such as changes to the environment and accepting support, by the occupational therapist using advanced communication skills, demonstrating equipment and techniques, we observed patients became more receptive to our recommendations. As a result of our intervention 78% of patients accepted recommendations for equipment and support. Improvements in more comprehensive and timely referrals to community services were also facilitated by this work which ultimately resulted in improved QOL, for patients who would not have typically been seen. This service was initiated prior to Covid 19. The occupational therapy service has found that in light of the impact of Covid 19 they cannot remove this service, as they now find lung cancer patients are unfortunately presenting with more advanced disease with a high level of support needs. This work was presented at the British Thoracic Oncology Group Conference and was awarded runner up.

Support from Healthcare Professionals
We welcome the recognition for Recommendation 45: We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist (CNS) throughout the entire care pathway.
It is encouraging that access to a CNS for all patients has been declared a priority. The mechanisms of how to deliver a CNS workforce has been given due consideration within the cancer recovery plan. It provides a clear plan for implementation addressing, leadership, workforce including succession planning and education. However, RCOT would question why such clear recommendations have not been reflected within the AHP section.

It will be important to identify the skills and competences within the CNS role. Which could provide greater opportunities for multiprofessional working and open up some of these roles to other health care professional with the relevant skills and experience.
Occupational therapists core skills in holistic assessment of physical needs (including assessment of frailty), psychological, social, environmental and QOL, along with intervention and social prescribing, places them in a prime position to both deliver and optimise available supportive care services for the effective management of their condition. They have advanced communication skills in dealing with loss of function and supporting individuals in their adjustment to disability, which often requires then to help support individuals and their families in considering and balancing their options and aiding the decision making process.
In addition, we would ask for further consideration to be given to the highlighted diamond PG 84:
“There was no clinical nurse specialist within oncology”. This statement is misleading and not completely reflective of the current position overall. We recognise the shortfall, but this statement is subjective and is a reflection of one person. This is not all service users experience.

Support from Allied Health Professionals (AHPs)
We welcome the inclusion of Allied Health Professionals within the document, however we consider this section is not reflective and is extremely light in

detail of the 13 distinct unique disciplines. There is an understanding that not all 13 professions and their role can be explained. But whilst we welcome that creative therapies have been highlighted, it is imperative that similar weighting is given to the key AHPs including occupational therapy, that are integral to the care of the patient with Cancer. We would therefore request that paragraph 2 and 3 be removed within this section.
We request that review and consideration be given to the work as originally produced within the consultation group and was regionally agreed be reflected in this strategy.
The Northern Ireland regional occupational therapists working in oncology and palliative care, request that as part of AHPs group in NI the following statement is included within this document:

Allied Health Professionals (AHPs) are the third largest professional workforce in the NHS, with 13 distinct and unique disciplines. They are integral to the delivery of cancer care across the entire pathway. The AHP workforce is essential in diagnosing cancer, in the delivery of cancer treatment, supporting people through treatment, leading the delivery of prehabilitation and rehabilitation services and providing palliative and end of life care. The engagement of AHPs and their holistic approach will result in improved health, wellbeing and survivorship of patients and carers.

There is inadequate and inequitable access to AHPs throughout the entire cancer pathway. Failing to address the current and projected AHP needs of the cancer population will result in poor outcomes for patients.

During the co-production and consultation stage of drawing up this strategy the AHP groups clearly identified both in articulation and writing the regional AHP workforce deficits across the entire pathway. It is disappointing that no recognition of this deficit is reflected within the document or within the cancer recovery plan. RCOT recommends that equal consideration, review and plans be given to the AHP workforce as has been identified for other professional groups.

Within this section of Supporting People to Live and Die Well there is a clear failing to not include an AHP recommendation. We strongly propose the following AHP recommendation be considered:
“We will ensure that all patients, diagnosed with cancer have access to an AHP throughout the entire care pathway”.

We would suggest that a definition of AHPs and the 13 professions be placed into the appendix 3 glossary, such as-
AHP – Allied Health Profession – 13 unique professions
Art Therapist, Dietitian, Drama Therapist, Music Therapist, Occupational Therapist, Paramedic, Physiotherapist, Podiatrist, Prosthetists, Orthoptist, Orthotists, Radiographer and Speech and Language Therapist.

Psychological support:

We agree people with cancer and palliative disease need timely psychological support, we also feel it is important to highlight timely support for their loved ones/carers, as emotional and psychological burden can be very high for them.
Whilst we recognise the important role psychology has for those affected by cancer, we wish to highlight that occupational therapists are trained across physical and mental health. Occupational therapists resourced adequately and with had time/capacity to fully carry out their role, could include interventions such as anxiety management, mindfulness, behavioural activation, goal setting, and increasing independence/therapeutic activity which would improve psychological outcomes for patients and meet the Level 1 intervention need. This would mean psychologists would be less inundated with these and receive more appropriate referrals for the more appropriate complex psychological needs that present.

Supporting people to live well
It is well recognised that people with a cancer can be left with disabling, chronic long-term conditions, often struggling to get the right treatment and support, often assuming that the symptoms are the cost of a cure. It is also recognised that cancer can have a major impact on a person’s ability to work and while most wish to stay in or return to work, many do not receive the information, advice or rehabilitation support they need to help them do so.
To date there are no agreed pathways in place addressing the symptoms as discussed within the strategy. Treatment and care is often poorly managed, disjointed and uncoordinated. Currently services either do not exist or are not resourced to meet the growing demand. As a result, and we would suggest that alongside the requirement to coordinate a treatment approach to address this, there should be recognition of the role of AHP’s in management and in some cases prevention of many of these side-effects.

We would also strongly advocate for better integration of existing services. Examples of his could include the integration of services such as the Condition Management Programme and access to work into vocational rehabilitation services for cancer patients. Better collaboration between services such as occupational therapists in pain management teams should also be explored. The valuable role occupational therapists can have in managing pain is routinely not considered. This can include activity analysis, skill development, activity adaptation, problem solving, prioritisation, planning and pacing of activities to resolve imbalance of under/over activity, relaxation training, stress management and environmental assessment.
Adequate funding is required to ensure these interventions are, equitable and streamlined across the region for all patients with access to AHP’s as early as possible in their pathway. Further exploration of the role of AHP’s as non-medical prescribers
should be undertaken.
During Covid 19 there has been a significant shift to using digital technology in order to meet individuals needs for support and information. There continues to be an increased demand for virtual formats as new ways of working. Occupational therapists are involved in these collaborations such as the production of webinars, videos, telehealth, however this has and still requires the need to upskill staff, ensure the availability of IT resources and funding.

We welcome that there is a recognition that although there are commissioned Lymphoedema services in place, demand exceeds capacity and further wish it to be noted that in some services it is not a protected role which causes further delays in assessment and review. Investment should be made within AHP’s to increase number of Lymphoedema professionals trained and enable these professionals to access prescribers courses to ensure that these professionals can deliver as streamlined, efficient and effective a service as possible which will lead to better management and outcomes of the condition for patients.

As well as the invaluable role specialist palliative care clinicians will play in management of cancer pain , AHPs also play a key role in managing patients symptoms of chronic pain, breathlessness and fatigue and there is a need for greater recognition of this and opportunities for a collaborated approach to

AHP treatment alongside the pharmacological management.

Caring When Cancer Can't Be Cured
The working group decision was made not to use the terminology "palliative" but it is considered the title" supporting people to live well and die well" is not clear enough to describe the end phase.

Improving quality of life is a key focus for AHPs and timely identification, referral, triage and monitoring with a robust system for improved communication between disciplines and sectors would facilitate better symptom management, crisis management and A&E admissions.

Identification of palliative care needs
We need a mechanism of identification of palliative patients at the earliest possible stage and a pathway to integrate specialist palliative services and non-palliative service to ensure patients with palliative care needs are being offered support by the right professional at the right time. This needs to link seamlessly with the voluntary sector to reduce duplication and maximise patient experience, efficiency and effectiveness. We feel a transparent pathway and technologies will promote better communication. We would welcome regional streamlining of services.
There still continues to be a need for cultural change both within professional services and public awareness around end-of-life care. There should be promotion of the palliative care roles with the aim to involve services earlier in the pathway, which would enhance outcomes. The risk of promoting service however would place further strain on the existing small teams that exist or do not exist within each Trust.
We also call that in line with the evidence base that even those with noncurative cancers have equal access to prehabilitation supports to make their life as comfortable and maintained for as long as possible.

Access to palliative care keyworkers
This role very often sits with the district nurse. Whilst this is often very appropriate at the End of Life Care stage when they are instrumental in the care provided and co-ordinating services, when individuals are not so unwell, the district nurse often has less of a role. This is a time when it may be more appropriate for key worker role to be assigned to AHPs who will be monitoring those individuals who can be actively engaged within their services.

Access to generalist and specialist palliative care services
It is disappointing that little recognition has been given to the role of the existing MDT AHP community specialist palliative care teams. It is considered the term therapeutic and practical support services is insufficient and unclear. Specialist Palliative Care AHP teams can have significant impact, supporting patients with complex symptoms both cancer and non-cancer related, to remain in their preferred place of care by offering palliative rehabilitation; complex symptom management & education for patient, carers and professionals to improve quality of life . It is important to note that not all Trusts have Community Specialist Palliative Care AHP Teams and that limited investment has been made over the years despite the drive to support people in their own home to live and die well. However, it is acknowledged, that not all patients with a palliative care diagnosis have complex needs and are often very well supported by generalist services who have a high degree of clinical expertise. When considering Out of Hours support it needs to be recognised that there are not enough funded posts in primary care SPC AHP to provide spec AHP services 24/7, therefore Mon –Friday 9-5pm AHP service provision is all that can be offered on current staffing levels.

In the consideration of access to generalist and specialist palliative care we would highlight that greater exploration needs to occur in how to improve end of life care for patients within the acute hospital setting and care home residents and ensure the implementation of new ways of delivering effective end of life care within such settings. In order to achieve improvements in EOLC we need to ensure workforce planning delivers the right people with the right skills to support improved quality and greater choice in end-of-life care, in both hospital and out-of-hospital settings.
Advanced Care planning

The Royal College of Occupational Therapists agree that all patients should be supported to express what is important to them and make informed choices about their care at end of life. However, the reality of choice at the end of life is not always straightforward. Preferences change over time, often reflecting changing needs and circumstances. Every dying person needs to have ongoing opportunities to have these conversations. To support this process, all staff involved with dying people must be capable of having difficult conversations about death and dying, taking the time to listen carefully to what dying people and those important to them say, and provide opportunities for developing, reviewing and updating personalised care plans with dying people. Health and care providers delivering this care must ensure that staff have the time and space to achieve this. We welcome the current policy in development "Advance Care Planning" (ACP) that will support this, but again we strongly suggest that AHPs are recorded as key professionals in this Palliative and EOL journey.

In Northern Ireland, there remains a significant taboo around discussing death and dying. We recommend multi agency working to change culture. Regional education programme to equip health care professionals with support on care planning conversations is already established, however robust recording systems, a mechanism to share with all relevant professionals both for primary and secondary care and flexibility to change or amend the document needs to be created. It is also recognised that it is one thing to have staff trained in ACP but having staff who are confident and comfortable with having these conversations is not the same thing. There is a need for this training to be seen as applicable in oncology and not just palliative care – these things should be considered when well. Patients after a cancer diagnosis and treatment are in that teachable moment to consider their future needs and choices and plan ahead. This should be a public health approach and all professionals should be trained in this and resourced.

Pre-bereavement and bereavement support
It is encouraging to see bereavement services included as currently most bereavement support sits outside of trust palliative care services. Historically there has been limited investment in Trusts for pre-and post-bereavement services. There has been an over reliance on the voluntary sector e.g. hospices/cancer charities to fill the gap, as well as regional inequality, difficulty accessing services, waiting list etc.

Workforce planning
Workforce planning was completed previously and unfortunately little or no action was seen. We appreciate that post COVID19 the NHS will be compromised by financial constraints but would like to encourage staffing levels and skill sets appropriate to support safe working, and that are able to make the recommended improvements in service. We have learnt to work in different ways and use different technology, but palliative care needs to be person centred and where possible delivered in person. We require a workforce that is appropriately funded to deliver on the care that is proposed.

Workforce and service modelling needs to take account the review of Marie Curie in terms of projection of where people want to die in 2025-this will shift systemically from hospital to the person's own home. AHP workforce modelling within palliative care will need to reflect this.

Implementing the strategy

9 Do you agree that these recommendations will enable delivery of the 10 year strategy? Please provide details for your answer.

Implementing the strategy:

The recommendations should not be in the Appendix and more coherently linked to recommendations throughout the text. It would be great to see this set out like the recovery document with a plan or time targets. The plan on page 120 is difficult to read, Under the section "Supporting people to live well and die well", under the heading "We need to Ensure" there is a reference to psychological and practical support but nothing at the this stage specifically about prehabilitation / rehabilitation and symptom management delivered by specialist AHP's. We feel this needs to be clearer, especially as this will lead to workforce planning. We feel if this is not specific now there may be continued ambiguity about what services are needed and what will be commissioned.
It is crucial that AHPs are more robustly referenced in this 10-year strategy if the vision of improvement and equity is to be achieved.

We welcome the Cancer Recovery Plan and the cancer workforce reviews.These need to clearly reflect the crucial role of AHPs within the cancer journey and make clear commitments to ensuring that we have an AHP workforce and new models of delivery to obtain it.
Members welcome recommendation 58: We will set up a clinically led, managerially supported NI Cancer Programme with sufficient resources to oversee the implementation and delivery of the cancer strategy implementation plan. This will be data driven and will include commissioning of cancer services and further policy development. The Royal College of Occupational Therapists would like details on how will AHPs be represented on this programme. The Royal College recognises that much of the success of the strategy will be reliant on how well priorities and new initiatives are communicated to the service. We strongly recommend a radical upgrading of communication and engagement. There will be a need for the NI Cancer Programme Board and NICAN to consider and optimise other communication routes to ensure commissioners, providers, healthcare professionals and patients are able to play their part in driving change. We welcome that the Chief Allied Health professions Officer is on the Management Board at DOH to ensure that AHPS are equitably represented. We also would like to see AHPs represented as part of the Collective Leadership Model in Trusts.

To achieve success, we need to be able to measure progress. We would suggest that the proposals as stipulated within the Cancer Recovery Plan are clearly aligned and integrated into the Cancer Strategy.

Enhanced data analysis will ensure better service models are developed and implemented, will ensure robust evaluation of projects and enhance the strengthening of accountability and transparency that will drive improvements.

Workforce

On behalf of Allied Health Professions, the college wish to raise significant concern in regard to the statement made: Oncology services workforce planning and modelling was undertaken as part of the Oncology Services Transformation work in 2019. A blueprint was developed for a range of roles including nursing, pharmacy, Allied Health Professionals and doctors. (pg 110). This is an inaccurate statement, as it is not reflective of all AHP services, as only takes account of one AHP profession (Radiography).

The Royal College of Occupational Therapists welcomes the recognition of Allied Health Professionals having a key role across the cancer pathway including diagnostics, the provision of prehabilitation and rehabilitation services, providing palliative care and support for people at the end of life. We are however very concerned that no consideration was given in regard to the implementation of this strategy and the workforce needs of AHPs, indeed there was no commitment within the short AHP section. Without the workforce it will not be possible to implement the strategy. We ask that the occupational therapy and AHP workforce required is is identified and resourced to ensure the successful implementation of the strategy.

There has been several recommendations and references with this strategy for a workforce analysis. No recommendations within the strategy have been proposed for an Allied Health Professional workforce analysis. We welcome the current work in establishing workforce workstreams, however we would ask that AHPs are fully represented across the workstreams. In regards to recommendation 60 we request clarity: We will develop and implement a regional, multiprofessional workforce plan to ensure we have the appropriately skilled staff available to deliver cancer services for the future. This will be essential in order to deliver the cancer strategy. Clarity is required in the definition of "multiprofessional".

We would also call that there should be regional developments for AHPs – patients should have equitable services and pathways/programmes etc and not just pockets of services. Oncology and Specialist AHPs want to work together and not in silos but need time factored in to meet and work on developing pathways/services etc. Patient demand always takes precedent and development work is undervalued.

Education

We welcome Recommendation 61, 62 and 67, and fully endorse the need for multiprofessional education and training for all staff in all settings, inclusive of all professions. We would ask for clarity on who these professionals are, e.g., AHPs

We welcome the recognition and support for advanced communication skills training as have found there is a lack of ACS trainers in NI. NHSCT are short of trainers and have to fund the programme through the NI Hospice at a marked cost. At present the commissioned funding is for D/N in NHSCT only. We wish to stress that AHPs are dealing with delivering bad news/sensitive conversations – loss of function/facing dying/not able to return home etc, this training is essential in their skill development.

Education is important to support all staff both generalist and specialist to deliver services for patients with palliative care needs. Training needs to be

delivered by experts with high level of knowledge. However it is questioned who will deliver such training? A Regional Multiprofessional training programme needs to be developed and implemented. The need for commissioned education pathways for all professions –funding and time allocated to attend is also identified.

Additional comments

10 Please use the space below share any additional information you feel is relevant to this consultation. We are particularly interested in responses that relate (but not limited) to the EQIA and Rural Needs elements of this consultation.

Additional comments: