



**NCRI**

National  
Cancer  
Research  
Institute

# **NCRI Supportive & Palliative Care Clinical Studies Group**

**Annual Report 2016-17**



Partners in cancer research





## **NCRI Supportive & Palliative Care CSG Annual Report 2016-17**

### **1. Executive Summary (including top 3 achievements in the year)**

2016-17 was the first year for the implementation of the Supportive & Palliative Care CSG's new strategy and Subgroup structure. It has been a year of growth and success, but also a major sadness. We learnt that Professor Ken Fearon, who was a leading international figure in the area of cancer cachexia research, passed away suddenly. Ken was at the height of his career, having served on the CSG and acted as mentor to many members of the Group. Our thoughts were with his family, including his widow Professor Marie Fallon, who is also a stalwart contributor to the CSG with her research in cancer-related pain.

The new Subgroup structure has largely worked out well, especially with respect to the already active Advanced Disease & End of Life Care Subgroup (Chair, Dr Matthew Maddocks) and the newly-formed Early Stage Disease & Acute Treatment Toxicities Subgroup (Chair, Professor Annie Young). Both of these held productive strategic and practical workshops during the year, making new alliances with researchers outside the CSG and are initiating new studies. The Survivors & Late Consequences Subgroup has suffered from losing its Chair, Dr Vaughan Keeley, by retirement during the year. There has thus been a hiatus in developing new strategic plans for this area, although the legacy of Dr Keeley's long involvement in the CSG means that the important lymphoedema and thrombosis strands of work will continue. Naturally, this Subgroup will also respond to the emerging NCRI Living With and Beyond Cancer (LWBC) initiative.

Our main achievements this year have been successful NIHR and other grant applications, an increase in the overall recruitment to portfolio trials, especially in terms of non-interventional studies, and a very impressive publication output. The main challenges remain the need to develop and secure funding for multi-centre interventional studies (including industry collaboration) but we are already seeing new studies in development coming through all of the Subgroups.

### **2. Structure of the Group**

During the reporting year, the CSG has undergone a moderate turnover of membership. We lost a longstanding and productive member, Professor Marie Fallon (palliative medicine), but gained three new members with a broad academic coverage: Dr Andrew Dickman (pharmacist), Dr Paula Mulvenna (clinical oncology) and Dr Anne-Marie Nelson (clinical trialist). We were also pleased to

recruit a new consumer member, Dr Jim Elliott, replacing Lesley Turner who served the Group very well for many years. In addition, three new colleagues have joined our Subgroups as non-core members: Dr Jason Boland, Dr Rebecca Hale and Dr Richard Wagland.

### **3. CSG & Subgroup strategies**

#### **Main CSG**

In 2015-16, the CSG adopted a new strategy to reflect its change of name in the previous year. Thus, we now span the entire duration of cancer from diagnosis, encompassing early curative and adjuvant treatments and the toxicities arising from these, advanced stage disease and end of life care, and long term survivors and late consequences of survivorship. These are the focus of research for the three new Subgroups, described below.

In 2016-17, instead of holding an Annual Trials meeting (as we had done very successfully for the first time in 2015), the CSG decided to focus its energies on fostering the research agendas for the three new Subgroups. Two of these, Early Stage Disease & Acute Treatment Toxicities and Advanced Disease & End of Life Care, have held strategic and study design workshops which are starting to produce results in terms of new studies. A particular success of these sessions was to bring in new active researchers from the UK who are not currently working within the CSG structure. Members of these workshops have gone on to hold their own study-specific teleconferences and face-to-face meetings, e.g. a multidisciplinary group which is working up a community-based study to answer a recent NICE research recommendation about anticipatory prescribing during the last days of life. Our discussions with oncologists, who are working in the burgeoning area of immunotherapies, has led us to work on a study design to capture and respond to the early and late toxicities associated with these new approaches.

Another growing area is our engagement with industry. During the past year, we have engaged with several pharmaceutical companies who have specifically approached us to help them design and carry out UK and international studies in a wide range of clinical settings, including cancer cachexia, chemotherapy-induced peripheral neuropathy, and chemotherapy-induced nausea and vomiting. Medical device companies are also working with our members, e.g. on a new subcutaneous needle for delivering injections and infusions.

#### **Early Stage Disease & Acute Treatment Toxicities Subgroup (Chair, Professor Annie Young)**

The Subgroup has developed a new stream of work focusing on the experience of patients in the early phase of disease and their treatments into survivorship. The Subgroup has 16 open studies, six of which are multi-centre (see Appendix 3). This has mainly been a developmental year, with two separate Subgroup face-to-face meetings forming proposals around the symptoms and complications of cancer and toxicities from the therapies used. We have also reached out to other CSGs to collaborate on specific supportive and palliative areas of care.

Each member of the Subgroup is responsible for the development of one new trial:

#### **Acute treatment toxicities**

- Chemotherapy-induced nausea and vomiting in multi-day chemotherapy regimens.
- Immunotherapy IO, Patient Experience and Quality of Life – initially to be taken through existing IO studies at Southampton University.
- 5-FU cardiotoxicity biomarkers.

- Prevention of Venous Thromboembolism (VTE).

### **Prehabilitation and rehabilitation for patients with early stage disease**

Having just completed PRO-REHAB for patients who have had treatment for adjuvant and advanced disease, we are working alongside the Supportive Care, Transfusion & Late Effects Subgroup (Haematological Oncology CSG) to design a PREHAB study (to follow on from PRE-EMPT) in patients with multiple myeloma undergoing autologous transplantation.

We look forward to the funding and implementation phase of these subgroup studies. Progress will be monitored and presented at the CSG's Annual Trial's meeting in the autumn of 2017.

### **Advanced Disease & End of Life Care (Chair, Dr Matthew Maddocks)**

Our remit is to stimulate and develop research concerned with people with advancing disease and towards the end of life. Priorities for the first year were three-fold: (1) symptoms of advancing disease including thrombosis, cord compression, anaemia, pain, lymphedema, fatigue and breathlessness; (2) issues near the end of life including prognostication, identification and management of dying and caregiver distress including through bereavement and (3) rehabilitation, which in advanced disease aims to optimise quality of life by increasing the time people can remain reasonably active and independent. Subgroup members have working links with, among others, the European Association of Palliative Care, Multinational Association of Supportive Care in Care, Society on Cachexia and Wasting Disorders and Association of Chartered Physiotherapists in Oncology & Palliative Care.

The current portfolio of 12+ studies offers a range spanning these priorities and funding has been secured for new studies in keeping with our strategy. This includes interventional work (e.g. ACTION and IMPACCT), large scale observational studies (e.g. C-CHANGE and PiPS2, both recruiting about 100 patients per month) and studies outside the hospital setting (e.g. Goal Attainment Scaling, recruiting across ten hospices approximately 30 patients per month). The Subgroup has enjoyed a successful year, with completion and on-going recruitment of existing studies. This includes three new HTA funded feasibility studies which hold promise for future definitive work. One of the challenges of end of life studies, in particular trials, has been the resource required to screen and identify patients, and offer interventions, many of which require face-to-face contact. Subgroup members are increasingly devising and delivering studies that are recruiting larger numbers of patients than previously, across many sites, and crucially are open to new sites joining. This includes pragmatic studies and flexible, resource-light studies that can be opened without demanding excessive staff time.

In the last year we have held two face-to-face meetings and further teleconferences to develop new studies within the Subgroup. Several Subgroup members are developing a study of anticipatory prescribing in end of life care. A half-day workshop was hosted to draft research questions, and take existing ideas forward together. Funds for a part-time fellowship to work on this area have been secured via an NIHR CLAHRC. Another study development meeting was held in November 2016, with members invited to attend and present an emerging study idea. Four ideas were presented, spanning rehabilitation, carer support and repurposing drugs and Subgroup members inputted and committed support to the work. Progress and development of these proposals will be reviewed in the CSG's Annual Trials meeting in September.

### **Survivors & Late Consequences Subgroup (Chair, Professor Sam Ahmedzai (interim))**

In this year, the development of this Subgroup was temporarily halted with the departure of its Chair, Dr Vaughan Keeley. We have been unable to appoint a replacement so far but that

position will be confirmed at the next CSG meeting in September 2016.

Before he stepped down, Dr Keeley was able to work on the Subgroup strategy and, crucially, took into account the NCRI's own Living With and Beyond Cancer (LWBC) initiative which was launched in 2016-17. Thus, the Subgroup's strategy is focussing on three key areas:

1. Lymphoedema arising as an early complication after cancer treatment, or as a late consequence of progressive disease.
2. Medical problems faced by longterm survivors, such as gastrointestinal malfunctioning after pelvic surgery and radiotherapy.
3. Aspects of exercise, nutrition and rehabilitation for longterm survivors to combat chronic problems such as persistent pain, fatigue and breathlessness.

We look forward to the new Subgroup Chair (to be announced at the Annual Trials meeting in the autumn of 2017) picking up from Dr Keeley's important start to develop streams of work with other site-specific CSGs and other national/international collaborators.

#### 4. Task groups/Working parties

The Supportive & Palliative Care CSG does not currently run its own task group or working party. However, for the past two years, two of our members (Professors Sam Ahmedzai and Annie Young) have actively collaborated on the Supportive Care, Transfusion & Late Effects Working Party led by Professor John Snowden in the Haematological Oncology CSG. A positive outcome of that work has been the development of an exercise study to improve rehabilitation following stem cell transplantation led by Professor Young.

#### 5. Patient recruitment summary for last 5 years

During 2016-17, the Supportive & Palliative Care CSG portfolio has seen eight trials close to recruitment and 26 new studies opened. The table shows that these led to a sharp rise in recruitment in non-interventional studies, both in cancer and non-cancer populations. This was balanced by a slight dip in patients recruited to interventional trials but overall, compared to 2015-16, we have seen a 41.6% increase in all participants and a 35.5% increase in cancer patients only.

Traditionally, palliative care studies have been largely observational and, if interventional, they have frequently followed the MRC complex intervention model and this has led to relatively small studies based in only one or a few centres. Our strategic move towards embracing supportive care research has shifted our emphasis more towards an oncology-based model of interventional studies. Our previously low rate of interventional trials is being actively addressed by the Subgroups which are working on new studies focusing on relatively simple interventions such as single drugs for a defined indication.

**Table 1 Summary of patient recruitment by Interventional/Non-interventional**

Year	All participants		Cancer patients only		% of cancer patients relative to incidence	
	Non-interventional	Interventional	Non-interventional	Interventional	Non-interventional	Interventional
2012/2013	570	399	303	399	-	-

2013/2014	1473	393	524	324	-	-
2014/2015	1336	498	1290	473	-	-
2015/2016	869	2261	706	2244	-	-
2016/2017	2510	1923	2250	1747	-	-

## 6. Links to other CSGs, international groups and network subspecialty leads

The Group continues to keep close links with many of the site-specific CSGs and nearly all of our members attend other CSG meetings as core or non-core members, or attend strategy days. Particularly successful collaborations of this kind have been with the Brain, Psychosocial & Survivorship Oncology (POS) and TYA & Germ Cell Tumours CSGs. Members of our CSG have contributed actively to the Supportive Care, Transfusion & Late Effects Working Party led by the Haematological Oncology CSG. We have also made a presentation to CTRad which has led to a study being developed on radiotherapy adverse effects. Our members contribute to international groups such as the European Association for Palliative Care (EAPC) Research Network, Multinational Association for Supportive Care in Cancer (MASCC) and EORTC Quality of Life Group.

We value the important contribution of the LCRN Subspecialty Leads (SSLs) in delivering NCRI-generated portfolio studies and we have extended our work with this group. Each year we work with the NIHR Cancer Cluster office in Leeds to host a meeting for all network SSLs who work on the supportive & palliative care and psychosocial & survivorship oncology portfolios, which this year included the Research Delivery Managers (RDMs) who are crucial to network delivery. In addition, one of our new members, Dr Christina Faull, has started a bi-monthly conference call and webinar series which is open to all SSLs. This is co-hosted by Julie Cunningham, RDM for Peninsula LCRN and who is also the nominated national lead RDM for our area of work. Thus, we are very well engaged with the teams that are delivering NCRI studies.

## 7. Funding applications in last year

2016-17 has been a modestly successful year for grant applications from the CSG. In terms of Group members who are co-applicants on national grants, we are well represented on key studies being funded by NIHR as well as charities.

**Table 2 Funding submissions in the reporting year**

<b>Other committees</b>			
<b>Study</b>	<b>Committee &amp; application type</b>	<b>CI</b>	<b>Outcome</b>
Managing Medicines at the end of life for patients being cared for and dying at home	NIHR Health Services and Delivery Research Programme	CI: Dr K Pollock; Co-applicant: Professor C Faull	Successful
Support for informal carers in the techniques of specialised care at home for patients with MND	Marie Curie	CI: Dr Eleanor Wilson; Co-applicant: Professor C Faull	Not successful
NOBLE-PAR: Noisy Breathing at Life's End: The impact of Purposeful, Anticipatory Reassurance on carer distress and the use of antimuscarinic drugs	NIHR HTA	CI: Dr M Poolman & Dr C Wilkinson; Co-applicant:	Successful

(NoBLE-PAR)		Professor C Faull	
HYDRANT-F	Marie Curie	Professor Annie Young	Not successful
PIPS -2	NIHR	Dr Paddy Stone	Successful
Nurses' decision-making about the delivery of skin care to patients with advanced cancer at the end of life: A vignette based study of a prototype decision making algorithm (Wales portfolio)	Pathway to portfolio Cwm Taf/Aneurin Bevan	Samuriwo R, Hopkinson J, Anstey S, Job C, Carson-Stevens A	Successful
REACT project: an investigation of the active components of a specialist home treatment intervention to prevent hospital admission of people with dementia in crisis in the community	NIHR RfPPB	Dr S Muthukrishnan and Professor J Hopkinson	Successful
Nurse decision-making about the delivery of skin care to patients with advanced cancer at the end of life: an exploratory study to develop a decision support algorithm	General Nursing Council grant	Samuriwo R, Anstey S, Job C, Hopkinson J	Successful
Co-feasibility study of a behavioural intervention to reduce fatigue in women undergoing radiotherapy for curable breast cancer (Wales portfolio)	Tenovus Innovation Grant	Urtier N, Hopkinson J, Gambling T, Radley L, Armes J, Barrett-Lee P, Johnson A, Smith A	Successful
An international field study for the reliability and validity of the EORTC cancer cachexia module (the EORTC QLQ-CAX24) and the EORTC QLQ-C30 for assessing quality of life in cancer patients with cachexia. The European Organization for Research and Treatment of Cancer Quality of Life Group	EORTC GRANT	Johnson C et al	Successful
Underserved and overlooked: Investigating the management of refusal of care in people with dementia admitted to hospital with an acute condition	NIHR	Featherstone K, Bridges J, Harden J, Harrison K, Hillman A, Tope R, Hopkinson J	Successful
An evidence synthesis of holistic services for refractory breathlessness in advanced malignant and non-malignant disease	NIHR Health Services & Delivery Research	Maddocks M, Gao W, Higginson IJ, Yi DH, Man WD, Farquhar M, Bajwah S, Booth S	Successful
E-Breathe: Actionable research tools for breathlessness management	The Health Foundation	Higginson I, Benalia A, Ellis-Smith A, Evans C, Gao W, Koffman J, Maddocks M	Successful
Understanding the social determinants of outcomes important to older people at the end of life: reducing social inequality in palliative care	The Dunhill Medical Trust	Davies J, Murtagh FEM, Maddocks M	Successful
Implementing a palliative Pain Management Programme (PMP) in a hospice setting	The Health Foundation / St Joseph's Hospice	Quilty C, Maddocks M, Fettes L	Successful
Living well at home using rehabilitation volunteers	Hospice UK / St Christopher's Hospice	Talbot-Rice H, Preston G, Maddocks M	Successful



Developing 'frailty fit' pulmonary rehabilitation services for people with chronic obstructive pulmonary disease	NIHR CDF	Maddocks M, Man WD, Higginson IJ, Lamb SE	Successful
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## 8. Collaborative partnership studies with industry

In the past there has been little collaboration with industry for this CSG. However, the new strategic drive to work upstream in the area of early stage disease and new therapies is opening up new possibilities. Thus, we are engaged in discussion and study planning with companies on topics such as medical interventions for chemotherapy-induced nausea and vomiting and chemotherapy-induced peripheral neuropathy. In advanced disease patients, we are working with industry partners on drug trials for pain, cancer cachexia and side-effects of palliative treatments such as opioid-induced constipation.

As well as the pharmaceutical industry, we have welcomed collaboration with medical device companies. One such liaison, led by new CSG member Dr Andrew Dickman, focuses on a new subcutaneous needle and pump which could make injections and infusions more reliable and acceptable for patients with advanced disease and particularly at the end of life.

## 9. Impact of CSG activities

The CSG is starting to make an impact on the care delivered by the NHS and also in the charitable hospice sector. Admittedly, in the past our portfolio focused especially on advanced disease and end of life, but there our studies in pain control, cachexia and fatigue have begun to influence clinical decision-making. Over recent years, we have also contributed to current therapy of breathlessness in cancer and also in patients with chronic lung disease; and the role of rehabilitation in helping patients maintain independence towards the end of life. Other examples of practice-changing studies have also arisen from our work in thrombosis and pulmonary embolism prevention and lymphoedema assessment and management.

## 10. Consumer involvement

The Group's consumer members attend the biannual meetings of the main Group and are actively involved in the Subgroups, sharing the work between them. In 2016, we took on a new consumer member, Dr Jim Elliott, who will replace Lesley Turner who is leaving us after many years of productive work. Jim joins Jean Gallagher who joined the Group in 2015-16.

Lesley Turner has been a co-applicant on a number of supportive care studies that are funded and in set up such as the YodaBRA trial which is currently developing an online interactive genetic testing decision aid for young women newly diagnosed with early stage breast cancer. She is also a member of the Trial Management Group for the MENOS4 trial which is a multicentre randomised controlled trial of a breast care nurse delivered cognitive behavioural therapy intervention to reduce the impact of hot flushes in women with breast cancer. She has helped design the protocol for PRIMETIME which is a trial aiming to selectively avoid radiotherapy in patients with a very low risk of breast cancer recurrence.

Lesley was a founder member of the Breast CSG Symptom Management Subgroup and provides a link between the Breast and the Supportive & Palliative Care CSGs. The Symptom Management Group is currently working on sexual issues following cancer treatment.

Lesley is also a member of the NIHR Cancer and Nutrition Infrastructure Collaboration, working with the World Cancer Research Fund and NCRF to provide a coordinated framework for future research into the areas of cancer and nutrition. She is the lead for one of the work streams and has presented at a number of meetings and events throughout the year. She has been an active member of the Southampton Trial Development Group working on a funding proposal involving physical activity and nutritional advice for Breast Cancer Patients undergoing adjuvant chemotherapy.

Lesley works closely with charities such as Breast Cancer Now and is a member of the Grant Committee of the Pfizer Catalyst Programme which is a new initiative allowing academic researchers access to research drugs from pharmaceutical companies. She recently helped review the expressions of interest for funding. She is also a member of the Breast Cancer Now Tissue Bank Advisory Council.

She has been awarded a number of bursaries to attend conferences such as the NCRF Liverpool Conference and the Early Diagnosis Research Conference which helps her to keep up to date and increase her knowledge.

She is a member of the Register of Chinese Herbal Medicine Research Ethics Committee, and recently approved a prospective observational study to standardise Chinese herbal medicine for oligomenorrhoea and amenorrhoea in Polycystic Ovary Syndrome.

## **11. Open meetings/annual trials days/strategy days**

After our highly successful first Clinical Trials Conference held in 2015 in Sheffield, the CSG decided to not hold a large conference again in 2016. Instead, we chose to work on our new strategy and subgroup structure by holding more focused strategic and study planning workshops during the year. These have been successful for the Early Stage Disease & Acute Treatment Toxicities subgroup and the Advanced Disease and End of Life subgroup. Unfortunately the Survivors and Late Consequences subgroup was not able to make progress owing to the retirement of its chair; however he and the CSG chair have contributed to the NCRF Living with and beyond cancer initiative led by Feng Li.

In 2017 we will again host a larger national Annual Clinical Trials meeting. This will be held in the Shard, London Bridge and will feature keynote speakers on the three strategic areas for the CSG, sessions on the subgroups, a review of new national initiatives and also a Dragon's Den.

## **12. Priorities and challenges for the forthcoming year**

### **Priorities**

Our priorities apply to all three Subgroups and may bring some Subgroups together to share expertise.

1. Work with other NCRF CSGs to initiate at least three multicentre interventional studies in the coming year: We plan to design and apply for funding for interventional studies in the areas of our three subgroups – early treatment-related toxicities, symptom management in advanced disease and end of life and overcoming medical problems in long-term survivors.
2. Work with NCRF cross-cutting CSGs and Advisory Groups to initiate at least one large multicentre observational study: We have been in discussion with groups such as CTRad,

Primary Care CSG and TYA & Germ Cell Tumours CSG. From these, we aim to choose, co-design and launch a multicentre study which will gather a large dataset of observational data, e.g. prevalence of key symptoms, use of selected but poorly researched drugs for symptom control, medical barriers (such as osteonecrosis) to rehabilitation for young people after childhood cancers. This will ultimately feed into a range of interventional studies in coming years.

3. Work with industry to develop and launch at least three commercial interventional trials: We have already started to work with industry partners and we aim to refine these projects into three specific interventional studies using new drugs/medical devices.

### **Challenges**

1. Widening the scope of funding opportunities for our supportive and palliative care studies: So far, we have used a relatively narrow range of national (NIHR) and charity funders for our trials. Through the NIHR Cancer Charities Summit which was held in April 2016, we plan to go to many more cancer charities to seek their support for new studies or to improve access to existing studies.
2. Overcoming barriers to delivery of portfolio studies in specific settings, especially hospices: The NIHR Cancer Charities Summit showed that many hospices, which could potentially be an important resource for study patient identification or recruitment, are currently not “research-ready”. Through our new collaboration with the LCRN SSLs, as well as the Cancer Cluster office in Leeds, we aim to open these doors.
3. Improving the recognition of our CSG studies on the NIHR portfolio: Historically many studies led by CSG core members or subgroup members have not been identifiable on the NIHR cancer portfolio, or been allocated to an incorrect CSG. This has proved to be discouraging to the CSG and a significant barrier to raising awareness of the Group’s true portfolio in the wider supportive and palliative care communities. We intend to review the whole cancer portfolio and those non-cancer portfolios relevant to our CSG, e.g. neurology and chronic lung disease, to correct the inappropriate allocations.

## **13. Appendices**

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

- A – Main CSG Strategy
- B – Rehabilitation Subgroup Strategy
- C – Gastrointestinal Subgroup Strategy
- D – Pain & Neuropathy Subgroup Strategy
- E – Vascular Subgroup Strategy

Appendix 3 - Portfolio Maps

Appendix 4 - Publications in previous year

Appendix 5 - Major international presentations in previous year

**Professor Sam H Ahmedzai (Supportive & Palliative Care CSG Chair)**

## Appendix 1

### Membership of the Supportive & Palliative Care CSG

Name	Specialism	Location
Dr Gillian Prue	Chronic Illnesses	Belfast
Dr Paula Mulvenna	Clinical Oncologist	Newcastle
Dr Andrew Dickman	Consultant Pharmacist	Liverpool
Dr Jim Elliott	Consumer	Newport
Mrs Jean Gallagher	Consumer	Yorkshire
Mrs Lesley Turner	Consumer	Southampton
Dr Sabine Best	Head of Research, Marie Curie	Leeds
Dr Teresa Young	Health Service Researcher	Middlesex
Dr Vicky Coyle	Medical Oncologist	Belfast
Dr Caroline Forde*	Medical Oncologist	Belfast
Dr Anthony Maraveyas	Medical Oncologist	Hull
Dr Dawn Storey	Medical Oncologist	Glasgow
Professor Jane Hopkinson	Nurse	Cardiff
Professor Annie Young	Nurse	Warwick
Professor Sam Ahmedzai (Chair)	Palliative Medicine	Sheffield
Dr Christina Faull	Palliative Medicine	Leicester
Dr Matthew Maddocks	Physiotherapist	London
Dr Annmarie Nelson	Scientific Director, Marie Curie Palliative Care Research Centre	Cardiff
Professor Gareth Griffiths	Statistician	Southampton

\* denotes trainee member

## Membership of the Subgroup

<b>Advanced Disease &amp; End of Life Care Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Dr Andrew Dickman	Consultant Pharmacist	Liverpool
Mrs Lesley Turner	Consumer	Southampton
Dr Vicky Coyle	Medical Oncologist	Belfast
Professor Jane Hopkinson	Nurse	Cardiff
Professor Sam Ahmedzai	Palliative Medicine	Sheffield
Dr Christina Faull	Palliative Medicine	Leicester
Dr Matthew Maddocks (Chair)	Physiotherapist	London
Dr Jason Boland **	Palliative Medicine	Hull

<b>Early Stage Disease &amp; Acute Treatment Toxicities Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Dr Gillian Prue	Chronic Illnesses	Belfast
Mrs Jean Gallagher	Consumer	Yorkshire
Dr Teresa Young	Health Service Researcher	Middlesex
Dr Vicky Coyle	Medical Oncologist	Belfast
Dr Caroline Forde*	Medical Oncologist	Belfast
Dr Anthony Maraveyas	Medical Oncologist	Hull
Dr Dawn Storey	Medical Oncologist	Glasgow
Professor Annie Young (Chair)	Nurse	Warwick
Dr Rebecca Hale **	Oncology and Haematology	Lothian
Professor Sam Ahmedzai	Palliative Medicine	Sheffield

<b>Survivors &amp; Late Consequences Subgroup</b>		
<b>Name</b>	<b>Specialism</b>	<b>Location</b>
Dr Gillian Prue	Chronic Illnesses	Belfast
Dr Jim Elliott	Consumer	Newport
Dr Teresa Young	Health Service Researcher	Middlesex
Dr Caroline Forde*	Medical Oncologist	Belfast
Dr Dawn Storey	Medical Oncologist	Glasgow
Dr Sara Faithful **	Nurse	Surrey
Professor Sam Ahmedzai (Interim Chair)	Palliative Medicine	Sheffield
Dr Richard Wagland **	Senior Research Fellow	Southampton

\*denotes trainee member

\*\*denotes non-core member

## Appendix 2

### CSG & Subgroup Strategies

#### A – Main CSG Strategy

Since 2015-16, the CSG's strategy has been to reflect the current scope of supportive and palliative care in cancer. Thus, we have three main areas of focus:

1. Problems facing patients with early stage disease and who are undergoing acute curative and adjuvant treatments: Some of the symptoms these patients experience arise from the cancer disease itself but the CSG will target those more adverse effects that arise from therapies such as surgery, radiotherapy, chemotherapy and biological treatments. An important new area is the growing number and range of toxicities from immunotherapies as these could ultimately reach a very large group of patients.
2. Symptoms and problems with functioning in patients with advanced, progressive disease and those who are at the end of life: Hitherto, the CSG has enjoyed a very good track record in trials of pain management, breathlessness, cachexia and fatigue. We will build on this but also expand to other key problems such as those identified by the recent NICE guideline on care of the dying adult (NG31, 2015). This highlighted recognising when a person is entering the last days of life, management of agitation and delirium, of noisy respiratory secretions and of anticipatory prescribing. In addition, we will focus on the largely unrecognised or ignored side-effects of traditional palliative medical treatments, e.g. opioid-induced constipation, immunomodulation and hyperalgesia.
3. Medical problems facing patients who are long-term survivors of cancer, or those living with cancer as a chronic illness: This is ultimately one of the greatest challenges as more people are living for longer after cancer treatment. We will focus on the medical barriers they face to rehabilitation to a "normal" lifestyle after treatment and especially on the clinical issues which arise as late consequences of anti-cancer treatments. These may be structural, e.g. loss of limbs or organs, functional, e.g. late GI malfunction after pelvic radiotherapy or lifestyle-related, e.g. nutrition and exercise programmes for survivors. Clearly, for this group we will work closely with the NCRI Living With and Beyond Cancer (LWBC) initiative and also with the Psychosocial Oncology and Survivorship CSG.

An important new aspect of our strategy is to incorporate fundamental biomedical questions wherever possible and to add research questions relating to mechanisms. We will therefore work with other CSGs and basic scientists to add translational aspects to our studies where relevant, e.g. biomarkers and genomics of symptom expression, pharmacogenetics of drug usage and adverse effects.

We also have a remit for researching the use of specific complementary therapies in order to increase their evidence base. We will continue to address this area which is important to patients but often overlooked by clinicians.

#### B – Early Stage Disease & Acute Toxicities Subgroup Strategy

Stemming from a needs assessment study of cancer patients who had been potentially cured (carried out some years ago by some of our CSG members), this new Subgroup is utilising the results as the foundation of our strategy. One third of people were found to have a moderate or severe unmet need arising from their cancer and in living their new "normal" lives. Research for people with early stage disease and research on treatment toxicities have markedly progressed since then, alongside the patient voice.

## **Strategic aims**

1. We aim to be the UK arm of MASCC (Multinational Association of Supportive Care in Cancer), the international group that many of our CSG members contribute to, and for the Subgroup to take our UK studies of toxicities of treatment globally.
2. Our priority strategic actions are to develop our own portfolio studies, e.g. patient experience of immunotherapy (IO), and to work with other CSGs in integrating the science of supportive care with mainstream oncological treatments. For example, in our venous thromboembolism (VTE) prevention and treatment studies, we are joining with international groups in identifying blood biomarkers of VTE, ultimately to predict risk of VTE or recurrence of VTE. We wish to incorporate translational elements into the majority of our toxicity studies.
3. The Subgroup strives to have two large portfolio studies recruiting by Q3 of 2018.

## **C – Advanced Disease & End of Life Care Subgroup Strategy**

1. Symptoms of advancing disease

Locally advancing and metastatic disease frequently lead to complications, e.g. thrombosis, cord compression, anaemia and symptoms, which impact adversely on quality of life, e.g. through pain, lymphedema, fatigue and breathlessness. Focussed basic and clinical research under this theme seeks to discover more effective ways to prevent, detect and treat these symptoms in the context of advanced disease.

The CSG has a strong history of research into pain, cachexia and breathlessness (for which there were previously dedicated Subgroups) and links forged through the CSG have continued to produce joined up research efforts, e.g. via the UK Breathlessness Research Interest Group. Open studies on the current portfolio cover symptom screening and detection, for example in interstitial lung disease, symptom management including new agents and approaches, e.g. the TVT trial which compares a two-step versus three-step approach to the use of opioids in the treatment of pain. We expect to continue developing studies for the key symptoms described above but to also extend our scope to examine the complications of long-term symptom management drugs and how these can be reduced/managed, as well as exploring late manifestations of symptoms deriving from new cancer treatments, e.g. immunotherapies or novel radiotherapy regimens. For this we recognise the importance of joint working with oncologists in relevant site-specific CSGs, as well as with the Early Stage Disease & Acute Treatment Toxicities Subgroup.

2. Issues towards the end of life

This theme focuses on complex symptoms and issues towards and at the end of life including the management of dying. Core values for palliative care include providing the best possible symptom management, supporting families through holistic care that extends to the family unit, and empowering patients facing the end of their life by ensuring excellent care is delivered where they wish to spend their last days.

Existing portfolio studies are examining hydration at the end of life, management of complex symptoms in frail older people, and management of chronic refractory symptoms, e.g. fatigue and breathlessness, both with pharmacological and non-pharmacological strategies. A study to discover clinical features and biomarkers for prognostication is supporting nationwide working, with around 40 sites contributing and around 1,000 participants recruited. We intend to develop new studies from within the CSG using this as an exemplar and will invite the CI to speak with the Subgroup. We encourage active investigators in the continued development of their programmes,



especially for research at the end of life, and we will invite active investigators into the Subgroup where they are identified.

### 3. Rehabilitation

Rehabilitation within supportive and palliative care helps people reach and maintain their optimal levels of physical, sensory, intellectual and social functioning, with minimum dependence on others. In advanced disease, rehabilitation aims to improve quality of life by increasing the time people can remain reasonably active and independent. Current CSG work relating to this theme includes studies on the use of acceptance commitment therapy to deduce psychological distress and improve health behaviours, on dysphagia management in the context of radiotherapy, and on the use of goal setting within hospice based rehabilitation services. The latter study has recruited >300 participants nationally over the last year. Newly opened studies include an RCT of a supportive care intervention (nutrition, exercise, anti-inflammatory medication) to manage cancer cachexia. This international study (sample size 250) includes blood sampling for a cachexia biobank and is open across multiple UK sites. We intend to develop new CSG studies where possible building on pilot work already completed by Subgroup members and with a design that facilitates multi-site working. The development of new studies will be aided by extending Subgroup members to rehabilitation leaders.

### **D – Survivors & Late Effects Subgroup Strategy**

Before he stepped down as Chair of the Subgroup, Dr Keeley was able to work on the Subgroup strategy and, crucially, took into account the NCRI Living With and Beyond Cancer (LWBC) initiative which was launched in 2016-17. Thus, the Subgroup's strategy is focussing on three key areas:

1. Lymphoedema arising as an early complication after cancer treatment, or as a late consequence of progressive disease.
2. Medical problems faced by longterm survivors such as gastrointestinal malfunctioning after pelvic surgery and radiotherapy.
3. Aspects of exercise, nutrition and rehabilitation for longterm survivors to combat chronic problems such as persistent pain, fatigue and breathlessness.



### Appendix 3

#### Portfolio maps

NCRI portfolio maps								
Supportive and Palliative Care								
Map A – Supportive and Palliative Care								
Click ↓ below to reset map								
		Gastro-intestinal	HSR of Supportive and Palliative Care	Pain and neuropathy	Rehabilitation/other	Respiratory	Vascular and thrombosis	
All	Presentation and acute treatments	IRON					POSNOG	
				ACUFOCIN				
			study of the effectiveness of the MENAC Trial				EZH/203 ETter Treatments for R	
			Int Scaling in Palliative					oid induced hyperglycaemia ing treatment for women ive Aspergillosis Study
			reported AEs in early phase 2WW v1		The PREeMPT study			
			experience data on acute			VERE Breathe : Versio		
			Continuing Bonds					
							HIDDEN study	
		Progressive disease and end of life					R'therapy+ BKM120	CE: At home Compression
					SarCaBon	ROCS		Lymphoedema
				ACTION CanACT				MEDI4736
				is in Palliative care Study	response to radiotherapy			
	Survivorship and late consequences						PLACE	
			ASCOT	PROSPER				
			CLASP		EPOP1			
			TION: A qualitative study		PACT (V1)	Cancer, Fertility and Me		
			ms in people with cancer		Tenovus Cancer Choirs			
	Translational		HORIZONS					
			CANDID		Lymphocyte prod.		MR Lymphangiography	

Filters Used:  
 Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All

- Open Multi CSG
- Null
- Suspended Single..
- Open Single CSG
- In Setup, Waiting ..

## Appendix 4

### Publications in the reporting year

Study	Reference
<b>EAGLE</b>	Taylor S, Demeyin W, Muls A, Ferguson C, Farnell DJ, Cohen D, Andreyev J, Green J, Smith L, Ahmedzai S, Pickett S, Nelson A, Staffurth J. Improving the well-being of men by Evaluating and Addressing the Gastrointestinal Late Effects (EAGLE) of radical treatment for prostate cancer: study protocol for a mixed-method implementation project <i>BMJ Open</i> , 2016 Oct 3;6(10).
	Taylor S, et al., The Three-item ALERT-B Questionnaire Provides a Validated Screening Tool to Detect Chronic Gastrointestinal Symptoms after Pelvic Radiotherapy in Cancer Survivors, <i>Clinical Oncology</i> (2016), <a href="http://dx.doi.org/10.1016/j.clon.2016.06.004">http://dx.doi.org/10.1016/j.clon.2016.06.004</a>
<b>CANOPY</b>	Cathy Sampson; Ben Hope-Gill; Nicholas Kim Harrison; Annmarie Nelson; Anthony Byrne (2016) The Care Needs of Patients with Idiopathic Pulmonary Fibrosis and their Carers (CaNoPy): results of a qualitative study. <i>BMC Pulmonary Medicine</i> PULM-D-15-00026R1
<b>BOLERO (Bladder)</b>	E Harrop, J Kelly, G Griffiths, A Casbard, A Nelson (2016) Why do patients decline surgical trials? Findings from a qualitative interview study embedded in the Cancer Research UK BOLERO trial (Bladder cancer: Open versus Laparoscopic or RObotic cystectomy) <i>BMC Trials</i> 17 (1), 35
<b>Phase III RCT BIS</b>	Farquhar MC, Prevost AT, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, Todd CJ, Booth S. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. <i>Trials</i> . 2016 Apr 4;17:185.
<b>AFTER</b>	Bowyer, A, Harrop, E, Finlay, I, Byrne, A., Snow, V, Nelson, A. (2016) Gaining an accurate reflection of the reality of palliative care through free text feedback: the AFTER study. <i>BMJ Supportive and Palliative Care</i>
<b>Emergency Department Attendance by Patients with Advanced Cancer</b>	Henson LA, Higginson IJ, Daveson BA, Ellis-Smith C, Koffman J, Morgan M, Gao W; BuildCARE.. 'I'll be in a safe place': a qualitative study of the decisions taken by people with advanced cancer to seek emergency department care. <i>BMJ Open</i> . 2016 Nov 2;6(11):e012134
<b>Factors associated with aggressive end of life cancer care</b>	Henson LA, Gomes B, Koffman J, Daveson BA, Higginson IJ, Gao W; BuildCARE. <i>Support Care Cancer</i> . 2016 Mar;24(3):1079-89
<b>Development of a preference-</b>	Dzingina M, Higginson IJ, McCrone P, Murtagh FE

<b>based outcome measure for Palliative Care</b>	Development of a Patient-Reported Palliative Care-Specific Health Classification System: The POS-E. Patient. 2017 Mar 7. doi: 10.1007/s40271-017-0224-1
<b>Funding models in palliative care: Lessons from international experience</b>	Groeneveld EI, Cassel JB, Bausewein C, Csikós Á, Krajnik M, Ryan K, Haugen DF, Eychmueller S, Gudat Keller H, Allan S, Hasselaar J, García-Baquero Merino T, Swetenham K, Piper K, Fürst CJ, Murtagh FE. Palliat Med. 2017 Apr;31(4):296-305
<b>Current state of the economics of palliative and end-of-life care: A clinical view</b>	May P, Morrison RS, Murtagh FE. Palliat Med. 2017 Apr;31(4):293-295
<b>IMPACT (EU FP7 – HEALTH 2010)</b>	Iliffe S, Davies N, Manthorpe J, Crome P, Ahmedzai SH, Vernooij-Dassen M, Engels Y. Improving palliative care in selected settings in England using quality indicators: a realist evaluation. BMC Palliat Care. 2016 Aug 2;15:69.
<b>QUARTZ</b>	Mulvenna P, Nankivell M, Barton R, Faivre-Finn C, Wilson P, McColl E, Moore B, Brisbane I, Ardron D, Holt T, Morgan S, Lee C, Waite K, Bayman N, Pugh C, Sydes B, Stephens R, Parmar MK, Langley RE. Dexamethasone and supportive care with or without whole brain radiotherapy in treating patients with non-small cell lung cancer with brain metastases unsuitable for resection or stereotactic radiotherapy (QUARTZ): results from a phase 3, non-inferiority, randomised trial. Lancet. 2016 Oct 22;388(10055):2004-2014.
<b>EPCCS (European Palliative Care Cancer Symptom study)</b>	Ekström M, Johnson MJ, Schiöler L, Kaasa S, Hjermstad MJ, Currow DC. Who experiences higher and increasing breathlessness in advanced cancer? The longitudinal EPCCS Study. Support Care Cancer. 2016 Sep;24(9):3803-11.
	Johnson MJ, Booth S, Currow DC, Lam LT, Phillips JL. A Mixed-Methods, Randomized, Controlled Feasibility Trial to Inform the Design of a Phase III Trial to Test the Effect of the Handheld Fan on Physical Activity and Carer Anxiety in Patients With Refractory Breathlessness. J Pain Symptom Manage. 2016 May;51(5):807-15.
<b>NMES in Severe COPD</b>	Maddocks M, Nolan C, Man WD, Polkey M, Hart N, Gao W, Rafferty GF, Moxham J, Higginson IJ. Neuromuscular electrical stimulation to improve exercise capacity in patients with severe COPD - Authors' reply. Lancet Respir Med. 2016 Apr;4(4):e16
	Maddocks M, Nolan CM, Man WD, Polkey MI, Hart N, Gao W, Rafferty GF, Moxham J, Higginson IJ. Neuromuscular electrical stimulation to improve exercise capacity in patients with severe COPD: a randomised double-blind, placebo-controlled trial. Lancet Respir Med. 2016 Jan;4(1):27-36.
	Currow DC, Abernethy AP, Allcroft P, Banzett RB, Bausewein C, Booth S, Carrieri-Kohlman V, Davidson P, Disler R, Donesky

	D, Dudgeon D, Ekstrom M, Farquhar M, Higginson I, Janssen D, Jensen D, Jolley C, Krajnik M, Laveneziana P, McDonald C, Maddocks M, Morelot-Panzini C, Moxham J, Mularski RA, Noble S, O'Donnell D, Parshall MB, Pattinson K, Phillips J, Ross J, Schwartzstein RM, Similowski T, Simon ST, Smith T, Wells A, Yates P, Yorke J, Johnson MJ. The need to research refractory breathlessness. <i>Eur Respir J.</i> 2016 Jan;47(1):342-3.
<b>NMES trial</b>	Murton AJ, Maddocks M, Stephens FB, Marimuthu K, England R, Wilcock A. Consequences of Late-Stage Non-Small-Cell Lung Cancer Cachexia on Muscle Metabolic Processes. <i>Clin Lung Cancer.</i> 2017 Jan;18(1):e1-e11
<b>Optimising palliative care for older people; phases 1b and 2 (OPTCare Elderly)</b>	Bone AE, Morgan M, Maddocks M, Sleeman KE, Wright J, Taherzadeh S, Ellis-Smith C, Higginson IJ, Evans CJ. Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders. <i>Age Ageing.</i> 2016 Nov;45(6):863-873
	Selman LE, Daveson BA, Smith M, Johnston B, Ryan K, Morrison RS, Pannell C, McQuillan R, de Wolf-Linder S, Pantilat SZ, Klass L, Meier D, Normand C, Higginson IJ. How empowering is hospital care for older people with advanced disease? Barriers and facilitators from a cross-national ethnography in England, Ireland and the USA. <i>Age Ageing.</i> 2016 Nov 3. [Epub ahead of print]
	Bone AE, Gao W, Gomes B, Sleeman KE, Maddocks M, Wright J, Yi D, Higginson IJ, Evans CJ; Factors Associated with Transition from Community Settings to Hospital as Place of Death for Adults Aged 75 and Older: A Population-Based Mortality Follow-Back Survey. <i>OPTCare Elderly. J Am Geriatr Soc.</i> 2016 Nov;64(11):2210-2217
<b>Rehabilitation in patients newly diagnosed with inoperable lung cancer</b>	Bayly J, Wilcock A, Higginson IJ, Maddocks M. Early Engagement in Physical Activity and Exercise Is Key in Managing Cancer Cachexia. <i>Oncology (Williston Park).</i> 2017 Jan 15;31(1)
<b>A palliative care intervention for people with dementia in care homes</b>	Gao W, Crosby V, Wilcock A, Burman R, Silber E, Hepgul N, Chaudhuri KR, Higginson IJ; OPTCARE Neuro trial. Psychometric Properties of a Generic, Patient-Centred Palliative Care Outcome Measure of Symptom Burden for People with Progressive Long Term Neurological Conditions. <i>PLoS One.</i> 2016 Oct 25;11(10):e0165379
<b>OXN3506</b>	Ahmedzai SH, Leppert W, Janecki M, Pakosz A, Lomax M, Duerr H, Hopp M. Long-term safety and efficacy of oxycodone/naloxone prolonged-release tablets in patients with moderate-to-severe chronic cancer pain. <i>Support Care Cancer.</i> 2015 Mar;23(3):823-30

<b>OIC-BOI</b>	Coyne KS, Sexton C, LoCasale RJ, King FR, Margolis MK, Ahmedzai SH. (Opioid-Induced Constipation-Burden of Illness study) Opioid-Induced Constipation among a Convenience Sample of Patients with Cancer Pain. <i>Front Oncol.</i> 2016 Jun 8;6:131
<b>Living with Advanced Myeloma</b>	High prevalence of cardiovascular and respiratory abnormalities in advanced, intensively treated (transplanted) myeloma: The case for 'late effects' screening and preventive strategies. Samuelson C, O'Toole L, Boland E, Greenfield D, Ezaydi Y, Ahmedzai SH, Snowden JA. <i>Hematology.</i> 2016 Jun;21(5):272-9
<b>select-d</b>	Annie Young, Jenny Thirlwall, Helen Hancocks, Catherine Hill, Neya Joshi, Andrea Marshall, Janet A Dunn, Oliver Chapman, Anticoagulation Therapy in SELECTeD Cancer Patients at Risk of Recurrence of Venous Thromboembolism, Poster 6-9 Nov 2016 NCRI 2016, Liverpool. Young AM. Stopping unnecessary deaths. <i>Nurs Stand.</i> 2017 31(19): 29
<b>PO-39</b>	Bozas G, Muazzam IA, Ilyas W, Maraveyas A. PO-39 - Primary thromboprophylaxis for ambulatory patients with advanced metastatic pancreatic cancer. A practical implementation of lessons from published experience. <i>Thromb Res.</i> 2016 Apr;140 Suppl 1:S191
<b>PO-27</b>	Adesanya MA, Maraveyas A, Madden LA. PO-27 - Thrombin generation in pancreatic cancer and multiple myeloma with use of calibrated automated thrombography. <i>Thromb Res.</i> 2016 Apr;140 Suppl 1:S186.
<b>ABC-02</b>	Bridgewater J, Lopes A, Palmer D, Cunningham D, Anthony A, Maraveyas A, Madhusudan S, Iveson T, Valle J, Wasan H. Quality of life, long-term survivors and long-term outcome from the ABC-02 study. <i>Br J Cancer.</i> 2016 Apr 26;114(9):965-71.
<b>CCMM</b>	van der Hulle T, den Exter PL, Planquette B, Meyer G, Soler S, Monreal M, Jiménez D, Portillo AK, O'Connell C, Liebman HA, Shteinberg M, Adir Y, Tiseo M, Bersanelli M, Abdel-Razek HN, Mansour AH, Donnelly OG, Radhakrishna G, Ramasamy S, Bozas G, Maraveyas A, Shinagare AB, Hatabu H, Nishino M, Huisman MV, Klok FA. Risk of recurrent venous thromboembolism and major hemorrhage in cancer-associated incidental pulmonary embolism among treated and untreated patients: a pooled analysis of 926 patients. <i>J Thromb Haemost.</i> 2016 Jan;14(1):105-13
	Latter S, Hopkinson J, Hughes J, Hughes J, Duke S, Anstey S, Bennett M, May C, Richardson A. (In revision) Supporting family caregivers to manage pain medication in cancer patients at end of life: a feasibility trial. <i>Palliative Medicine.</i>
	Boland JW, Pockley AG. Clinically relevant concentrations of opioids for in vitro studies. <i>J Opioid Manag.</i> 2016

	Sep/Oct;12(5):313-321.
	Obita GP, Boland EG, Currow DC, Johnson MJ, Boland JW. Somatostatin Analogues Compared With Placebo and Other Pharmacologic Agents in the Management of Symptoms of Inoperable Malignant Bowel Obstruction: A Systematic Review. <i>J Pain Symptom Manage.</i> 2016 Dec;52(6):901-919
	Boland JW, Bennett MI. Opioids do not influence metastasis in experimental animal cancer models. <i>Pain.</i> 2016 May;157(5):1173
	Latter S, Hopkinson J, Richardson A, Hughes JA, Lowson E, Edards D. (2016) How can we help family carers manage pain medicines for patients with advanced cancer? A systematic review of intervention studies. <i>BMJ Supportive &amp; Palliative Care.</i> 5: 1-13
	King M, Hopkinson J, Milton R (2016) Reflections of a team approach to involving people with dementia in research. <i>International Journal of Palliative Nursing.</i> 22(1): 372-377
<b>International validation of the EORTC QLQ-CAX24</b>	Wheelwright SJ, Hopkinson JB, Darlington A-S, Fitzsimmons DF, Fayers P, Balstad TR, Bredart A, Hammerlid E, Kaasa S, Nicolatou-Galitis O, Pinto M, Schmidt H, Solheim TS, Strasser F, Tomaszewska IM, Johnson CD, on behalf of the EORTC Quality of Life Group (In press) Development of the EORTC QLQ-CAX24, a questionnaire for cancer patients with cachexia. <i>Journal of Pain &amp; Symptom Management.</i> Oct 31. pii: S0885-3924(16)30765-5. doi: 10.1016/j.jpainsymman.2016.09.010. [Epub ahead of print]
	Maddocks M, Hopkinson J, Conibear J, Reeves A, Shaw C, Fearon KCH (2016) Practical multimodal care for cancer cachexia. <i>Current Opinion in Supportive and Palliative Care.</i> 10(4):298-305.
	Courtier N, Milton R, King A, Tope R, Morgan S, Hopkinson J. (2016) Cancer and dementia: an exploratory study of the experience of cancer treatment in people with dementia. <i>Psycho-Oncology.</i> 25(9):1079-84. doi: 10.1002/pon.4212. Epub 2016 Aug 9.
	Hopkinson J, Milton R, King M, Edwards D. (2016) People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review. <i>Cancer and dementia review. Psycho-Oncology.</i> 25(10):1137-1146. doi: 10.1002/pon.4185. Epub 2016 Jul 13.
<b>Computerised Adaptive Testing for EORTC QLQ-C30</b>	Gamper E-M, Petersen MA, Aaronson N, Costantini A, Giesinger JM, Holzner B, Kemmler G, Oberguggenberger A, Singer S, Young T et al: Development of an item bank for the EORTC Role Functioning Computer Adaptive Test (EORTC RF-CAT). <i>Health and Quality of Life Outcomes</i> 2016, 14:72
	Thamsborg L, Petersen M, Aaronson N, Chie W-C, Costantini

	A, Holzner B, Leeuw IV-d, Young T, Groenvold M: Development of a lack of appetite item bank for computer-adaptive testing (CAT). <i>Supportive Care in Cancer</i> 2015, 23(6):1541-1548
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<b>AMWELL-SL (Acupuncture/Moxibustion for wellbeing in lymphoedema)</b>	de Valois B, Asprey A, Young T. The Monkey on Your Shoulder: A Qualitative Study of Lymphoedema Patients; Attitudes to and Experiences of Acupuncture and Moxibustion. <i>Evidence-Based Complementary and Alternative Medicine</i> 2016, 2016:14 pages. <a href="http://dx.doi.org/10.1155/2016/4298420">http://dx.doi.org/10.1155/2016/4298420</a>
<b>MESALO</b>	Young AM, Arif AA. The use of scalp cooling for chemotherapy-induced hair loss <i>British Journal of Nursing</i> . 2016, 25(10), S22-27
<b>Limiting chemotherapy side effects by using moxa</b>	de Valois B, Young T, Glynne-Jones RG, Scarlett C, Staebler F: Limiting Chemotherapy Side Effects by Using Moxa. <i>European Journal of Oriental Medicine</i> 2016, 8(3):29-39
<b>PlosONE</b>	Pino M, Parry R, Land V, Faull C, Feathers L, Seymour J. (2016). Engaging terminally ill patients in end of life talk: How experienced palliative medicine doctors navigate the dilemma of promoting discussions about dying. <i>PlosONE</i> . DOI:10.1371/journal.pone.0156174.
	Parry, R., Pino, M., Faull, C. and Feathers, L. (2016). Acceptability and design of video-based research on healthcare communication: Evidence and recommendations. <i>Patient Education and Counseling</i> <a href="http://dx.doi.org/10.1016/j.pec.2016.03.013">http://dx.doi.org/10.1016/j.pec.2016.03.013</a>
	Dickman A, Bickerstaff M, Jackson R, Schneider J, Mason S, Ellershaw J. Identification of drug combinations administered by continuous subcutaneous infusion that require analysis for compatibility and stability. <i>BMC Palliat Care</i> . 2017 Mar 23;16(1):22.
<b>Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey</b>	Armes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, Palmer N, Ream E, Young A and Richardson A. <i>J Clin Oncol</i> . 2009 ;27(36):6172-9

## Appendix 5

### Major international presentations in the reporting year

Study	Conference details
<b>PRO-REHAB</b>	Joanne D. Fisher, Laura Vail, Andrea Marshall, Gill Furze, Ray Owen, Irene Singleton (posthumously), Annie Young, Holistic cancer rehabilitation: is this usual aftercare for people with cancer? ICCN 2017 Anaheim, California, United States
	Joanne D. Fisher, Laura Vail, Andrea Marshall, Gill Furze, Ray Owen, Irene Singleton (posthumously), Annie Young. What is the usual rehabilitation care pathway for people with cancer? MASCC / ISOO 2017 Washington, United States
	Joanne D. Fisher, Laura Vail, Gill Furze, Andrea Marshall, Irene Singleton, Ray Owen, Morna Woods, Annie Young. Mapping the evidence for cancer rehabilitation. ICCN 2016 Hong Kong
	Joanne D. Fisher, Claire Balmer, Gill Furze, Andrea Marshall, Ray Owen, Irene Singleton, Morna Woods, Annie Young. Pro-rehab (the development and pilot trial of two programmes of rehabilitation for cancer patients): developing a holistic approach to rehabilitation for cancer patients. MASCC / ISOO 2016 Adelaide, Australia
<b>select-d</b>	Annie Young, Jenny Phillips, Helen Hancocks, Catherine Hill, Neya Joshi, Andrea Marshall, Janet A Dunn, Oliver Chapman, Anticoagulation therapy in selected cancer patients at risk of recurrence of venous thromboembolism. Abstract (no poster) 8-10 Apr 2016, ICTHIC 2016. Bergamo, Italy
<b>Myeloma X</b>	Patient-Reported Outcomes (PRO) in the Setting of Relapsed Myeloma: The Influence of Treatment Strategies and Genetic Variants Predict Quality of Life and Pain Experience.
	Sam H Ahmedzai, John A Snowden, Angela Cox, David A Cairns, Cathy D Williams, Anna Hockaday, Jamie Cavenagh, Christopher Parrish, Kwee L Yong, Jim Cavet, Hannah Hunter, Jennifer Bird, John Ashcroft, Julia Brown, Curly Morris and Gordon Cook. 36 <sup>th</sup> World Congress of Int Soc Hematology/Brit Soc Haematol, Glasgow, April 2016
<b>OXN3506</b>	Sam H Ahmedzai, Oliver T. Löwenstein, Wojciech Leppert, Wolfram Kremers, Bjoern Bosse, Michael Hopp. SAFETY AND EFFICACY OF A HIGH DOSE OXYCODONE/NALOXONE PROLONGED RELEASE FORMULATION (OXN PR) TABLETS IN DAILY DOSES UP TO OXN180/90 mg IN CANCER PATIENTS. Int Assoc Study Pain, Yokohama 2016