



NCRI

National
Cancer
Research
Institute

NCRI Psychosocial Oncology & Survivorship Clinical Studies Group

Annual Report 2016-17



Partners in cancer research

NCRI Psychosocial Oncology & Survivorship CSG Annual Report 2016-17

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

Over the past 12 months, the Psychosocial Oncology & Survivorship (POS) CSG has revised its strategic objectives for the next five years and reviewed the Subgroup structure accordingly. In the coming 12 months, we will work hard to implement it. The Group continues to collaborate with site-specific CSGs, e.g. Sarcoma, Teenage & Young Adult (TYA) & Germ Cell Tumours (GCT) and Brain, which resulted in securing funding from Sarcoma UK and The Bone Cancer Trust. The POS CSG raised the profile of its work by hosting symposia at the NCRI Conference 2016, EONS/IPOS Conference 2016 and British Psychosocial Oncology Society (BPOS) 2017 Annual Conference. Due to the success of the collaboration with BPOS, the CSG has been invited to host a session at the BPOS 2018 Annual Conference.

A key challenge for the CSG is the lack of specific funding streams for psychosocial oncology and survivorship research. However, we continue to explore with individual funders whether funding opportunities exist for this type of research. Allocation of studies to the POS CSG portfolio continues to be problematic with few new studies added to our portfolio in the past year. This has significantly reduced the number of people recorded as being recruited to the POS portfolio. We will undertake a piece of work to review the allocation of studies relevant to the POS portfolio and develop criteria that can be used in future to make more appropriate allocations. It has become apparent that the profile of the POS CSG is lower than hoped with Subspecialty Leads (SSLs) responsible for promoting studies for both Supportive and Palliative Care and POS. Thus, a key priority for 2017-18 will be to establish closer working links with the SSLs in England and their relevant counterparts in the devolved nations.

Achievements

In past 12 months, the CSG has:

- Developed a new CSG strategy for 2017-22.
- Extended our collaborations with site specific CSGs leading to joint grant applications (Brain, Sarcoma and TYA & GCT).
- Successfully raised the profile of the work of the POS CSG by hosting two symposia at the NCRI Conference 2016, a joint EONS/IPOS session at the IPOS Conference 2016, as well as a very successful symposium at the British Psychosocial Oncology Society Annual Conference 2017.

2. Structure of the Group

The main CSG consists of 15 members from a variety of disciplinary backgrounds, two of whom are consumer members. The composition of the Group differs from site-specific CSGs in that most members are employed in the university sector rather than the NHS. We appointed Dr Jennifer Harrington and Dr Fiona Kennedy as trainees to the CSG, and over the past year they have joined the Understanding and Measuring Consequences of Cancer and its Treatment, and Lifestyle and Behavioural Change Subgroups respectively.

In the last year, Dr Richard Simcock, Professor Linda Sharp and Dr Abi Fisher joined the POS CSG. Dr Abi Fisher has taken over chairing the Lifestyle and Behaviour Change Subgroup, taking over from Dr Gill Hubbard who rotated off the CSG. Dr Gill Hubbard has made a significant contribution to the work of the CSG and her strong leadership was central to the success of the Lifestyle and Behaviour Change Subgroup. Professor Nick Hulbert-Williams rotated off the CSG having contributed significantly to the CSG through his leadership of the Psychosocial Interventions Subgroup and Professor Mary Wells has taken over leadership of this Subgroup.

3. CSG & Subgroup strategies

Main CSG

The strategic aim of the Group is to develop and undertake research that results in improved patient experience, as well as improved psychosocial and physical outcomes for people living with and beyond cancer (LWBC). We aim to expand the breadth of the portfolio over the next three to five years. The plan is to build on success in gaining charity funding for studies, to move to funding from national governmental organisations and international funders. This will permit us to conduct larger, multicentre studies that aim to produce definitive answers to research questions. We will need to ensure the portfolio of studies is cognisant of national fiscal constraints in health care delivery and so we will seek to explore and test cost effective interventions such as may be achieved via ehealth. This may offer opportunities to link with industry partners.

The strategy to meet this aim has three core components which also apply to all three Subgroups:

1. To work collectively as a team to develop research proposals and seek funding for projects. This will improve the quality of studies and thereby improve our chances of grant success.
2. To actively seek collaboration with tumour-specific CSGs. This will promote psychosocial oncology and survivorship research among a wider group of clinicians and foster joint working across CSGs.
3. To provide support and advise researchers working in this area. This will increase research capacity and quality.

Understanding and measuring consequences of cancer and its treatment Subgroup (Chair, Dr Lynn Calman)

The strategic aim of the Subgroup is to develop and conduct research to understand the experiences of people living with cancer, to identify the consequences of LWBC cancer (including psychosocial and/or physical consequences of treatment), whether shortly after treatment or in the longer term.

The Subgroup has a number of studies underway and is making good progress. Evaluation of Patient-Reported Outcomes Protocol Content and Reporting in UK Cancer Clinical Trials (EPiC) study (PI: Derek Kyte) – the study protocol (quantitative) has been published and the qualitative protocol is under review. A poster of progress to date was presented at the NCRI Conference 2016 and an oral presentation of preliminary findings was given at the POS CSG Symposium at the BPOS Annual Conference. The Prostate PROMS project (A Gavin and A Glazer) is recruiting well across the UK and the HORIZONS programme (L Calman) started recruiting in September 2016 and is currently recruiting above target. The BRIGHTLIGHT study (R Taylor) disseminated findings via improvisational theatre performance 'There is a Light' which toured the country.

The Subgroup applied for research funding from Sarcoma UK, Roy Castle Lung Cancer Foundation and Macmillan Cancer Support. We have been in consultation with the Lymphoma and Lung CSGs about potential projects.

Psychosocial Interventions Subgroup (Chair, Professor Mary Wells)

The aim of this Subgroup is to develop and test targeted psychosocial interventions to improve patient-centred outcomes. The Subgroup aims to work closely with the Understanding and measuring consequences of cancer and its treatment Subgroup in order to ensure that the outcomes we use to test psychosocial interventions are informed by their work and are relevant and meaningful. Recognising that interventions to address lifestyle and behaviour change will have 'psychosocial' components, the distinction between this Subgroup and the Lifestyle and Behavioural Change Subgroup can be articulated by the focus and target of the interventions we plan to develop and test. These aim to improve psychosocial and quality of life outcomes through the provision of psychosocial, emotional and informational support.

The Subgroup has recently applied to Macmillan Cancer Support for funding to undertake a digital health themed project to address fears of cancer recurrence (PI: Dr Laura Ashley). Several other projects, in which a number of Subgroup members are involved, are underway or in submission. These include a CSO funded Swallowing Intervention Package study, Sarcoma UK funded PROMS study, TAG CRUK funded knowledge and attitudes towards e-cigarettes study, Brain Tumour Charity, fatigue intervention for brain tumour survivors, among others.

Lifestyle and Behavioural Change Subgroup (Chair, Dr Abi Fisher)

The key strategic aims of this Subgroup are to develop and run conduct studies (trials, cohorts or qualitative studies) to explore the role of lifestyle behaviours (physical activity, diet, smoking, alcohol, sun safety) after cancer diagnosis, and conduct studies that explore how to embed appropriate health behaviour advice into the cancer care pathway.

The Subgroup received funding from Breast Cancer Now to conduct a feasibility study determining whether breast cancer patients would prefer to have a physical activity intervention in a clinical or community setting. Building on this, since travel was a key barrier for patients, the Subgroup received Chief Scientist Office funding to determine whether the intervention could be delivered remotely (via telephone). The manuscript(s) summarising the key findings will be submitted summer 2017 and a submission for a larger efficacy trial is in preparation.

In addition, a survey was conducted with stoma patients gathering their views on lifestyle intervention (manuscript accepted) and the Subgroup has received funding from Bowel & Cancer Research to develop and feasibility test a physical activity intervention for colorectal cancer patients with a stoma. These studies were led by the previous Chair, Gill Hubbard, and involved

multiple members of the Subgroup and external partners.

4. Task groups/Working parties

None have been convened by the POS CSG for this reporting year.

5. Patient recruitment summary for last 5 years

In the POS CSG portfolio, 9 trials closed to recruitment and 2 opened. The number of people recruited to the CSG's portfolio studies decreased substantially during 2015-2016. The number recruited to interventional studies, however, increased. Over the past 12-24 months, allocation of studies onto the Group's portfolio have diminished and studies the CSG have been successfully awarded have not been included (e.g. ACTIVE, S-PROM, SIPS, MENOS-4) but have been allocated to site-specific CSGs. This may account for the drop in participants recruited identified in Table 1. The Group will work with the NIHR Clinical Research Network (CRN) over the next 12 months in an attempt to rectify this and develop criteria to aid appropriate study allocation in future.

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	1197	155	1168	155	-	-
2013/2014	1360	306	1325	305	-	-
2014/2015	1919	310	1909	310	-	-
2015/2016	2649	374	2369	359	-	-
2016/2017	1095	541	713	496	-	-

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

Links to other groups

- Professor Watson is a Primary Care CSG member.
- Professor Wells is a Head & Neck CSG Survivorship Subgroup member.
- Dr Taylor is a TYA Health Services Research Subgroup member.
- Dr Armes and Ms Morris are Symptom Management Subgroup (Breast CSG) members.
- Professor Linda Sharp is a member of the Screening, Prevention & Early Diagnosis (SPED) Advisory Group.
- Dr Armes and Professor Watson are Supportive, Transfusion and Late Effects Working Party (Haem Onc CSG) members.
- Dr Calman is a Lung CSG member.
- Professor Beaver is a Gynae CSG member.
- Richard Simcock is Chair of the Expert Reference Group for Cancer in the Older Person, member of the Oversight Group at NHS England for Living with and Beyond Cancer and sits on the Steering Committee of the James Lind Alliance Priority Setting Partnership for Living with and Beyond Cancer.

International Links

- Professor Hulbert-Williams chairs the Research Committee of the International Psychosocial Oncology Society (IPOS).
- Professor Wells is Co-Chair of the Research Working Group of the European Oncology Nursing Society (EONS).
- Professor Wells and Dr Armes are members of the Expert Reference Group for JBI CONnECT+ Cancer Care Node.
- Professor Wells is a member of the Conference Management Committee International Society of Nurses in Cancer Care.
- Professor Wells was Chair of the Scientific Committee for EONS10 Conference in Dublin, October 2016.

7. Funding applications in last year

A substantial number of submissions were made during 2016-17; however, the outcome for most of these is as yet unknown. The funding opportunities for this type of research are more limited than for disease-specific clinical or biomedical/translational research, as we are not eligible to apply to certain funding streams (e.g. MRC, CRUK). In order to generate preliminary evidence needed for substantial applications to the NIHR and European Union, we have focused on submitting smaller applications to relevant cancer charities. Such an incremental approach has been successful previously and resulted in National Institute for Health Research (NIHR) and European Union funding (FP7 Framework) for both the eRAPID and eSMART studies respectively which are on the POS CSG portfolio. The Group has successfully collaborated with the Sarcoma and TYA & GCT CSG to gain funding to develop a sarcoma-specific patient-reported outcome measure.

Table 2 Funding submissions in the reporting year

Other committees			
Study	Committee & application type	CI	Outcome
Brain Tumours - Lifestyle Intervention and Fatigue Evaluation: A multi-centre feasibility randomised controlled trial *Collaboration with Brain CSG*	Brain Tumour Charity	A Rooney, Co-applicants: R Grant, A Chalmers, M Wells, H Bulbeck, C Hewitt, D Gillespie, G Anderson, C McBain	Successful
FRaMinG: Fatigue Review and Management in Glioma - a twin-centre feasibility study examining tailored, non-pharmacological interventions for fatigue	Brain Tumour Action	A Rooney, M Wells	Unsuccessful
Developing a supported self-management programme to improve quality-of-life in adult primary brain tumour survivors	Brain Tumour Charity	L Sharp	Successful
Novel approaches to understanding and treating fear of recurrence in breast cancer survivors	Breast Cancer Now	C Hirsch, Co-applicants: J Armes & E Banks	Unsuccessful
Symptom appraisal following treatment for primary	Breast	E Watson	Unsuccessful

breast cancer, and pathways to diagnosis of a recurrence or new primary cancer	Cancer Now		
Exploring the experiences of patients undergoing treatment and surviving with bone cancer *Collaboration with Sarcoma CSG and TYA & GCT CSGs*	Bone Cancer Research Trust	R Taylor, Co-applicants: M Wells, J Whelan, L Bennister, L Storey, C Gerrand, L Fern, R Windsor, J Woodford	Successful
Development and application of innovative survival methodologies: advancing understanding of the pathways between diagnostic route and cancer survival	Cancer Research UK	L Sharp	Pending
Energy Balance in Cancer Programme Renewal	Cancer Research UK	Co-applicants: A Fisher, R Beeken Collaborator: R Taylor	Pending
Pan London Joint Research Fellowship: health behaviour change in TYA cancer patients	Cancer Vanguard	A Fisher, G Pugh	Successful
EFFECT II Telephone-delivered physical activity intervention for people with breast cancer after surgery: A feasibility study	Chief Scientist's Office	PI: Gill Hubbard, Lifestyle and Behaviour Change Subgroup	Successful
Lifestyle intervention for people following major resection for rectal cancer and given a temporary stoma	Chief Scientist's Office Scotland	G Hubbard & Lifestyle Subgroup	Successful
Lifestyle & Long-Term Health in Teenage and Young Adult Cancer Survivors: A Pan-London Cohort	Children with Cancer	Abi Fisher, Co-applicant: R Taylor	Pending
Which survivors of childhood ALL are at increased risk of long-term neurocognitive deficits? Identifying biomarkers to inform prevention and rehabilitation	Children with Cancer	L Sharp	Unsuccessful
A sustainable European data-based network generating for optimal access to work, insurance and mortgage among adult cancer survivors	European Commission	EORTC Co-applicants: Newcastle University (L Sharp)	Unsuccessful
The SEA-CHANGE study: a pilot randomised controlled trial of the Self-management After Cancer of the Head And Neck Group intervention	Health Research Board Ireland	Gallagher Co-applicant: L Sharp	Successful
What influences cervical screening uptake in older women and how can screening programmes translate this knowledge into behaviour changing strategies? A CERVIVA-CervicalCheck co-production project	Health Research Board Ireland	O'Leary Co-applicant: L Sharp	Successful
Beating Fatigue: Realising potential through app development	Macmillan	E Ream Co-applicant: J Armes	Pending
CanWalk: community walking for people with advanced cancers, a multicentre randomised controlled trial	Macmillan	J Armes, Co-applicant: A Fisher	Unsuccessful
Fears of cancer recurrence: using digital	Macmillan	L Ashley,	Unsuccessful

technology to aid self-management *Collaboration with Psychosocial Interventions Subgroup*		Co-applicants: M Wells, E Watson, R Simcock, N Hulbert-Williams, L Storey, C Morris, H Plant, P Hall, B Swash, J Harrington, G Ozakinci	
Global use of online digital technology to improve the experience and psychosocial outcomes of young people living with cancer *Collaboration with TYA & GCT CSG*	Macmillan	G Hubbard, Co-applicants: N Hulbert-Williams, A Edgar	Pending
Improving patient-centred outcomes following a diagnosis of cancer: enhancing the role of primary care	Macmillan	E Watson	Pending
Recording oncology consultations using a health care app	Macmillan	K Beaver	Pending
Symptom appraisal following primary breast cancer: promoting timely presentation to health services with possible symptoms of recurrence	Macmillan	L Brindle, Co-applicant: E Watson	Pending
Systematic review of effectiveness and cost-effectiveness of digital supportive interventions for people with cancer that cannot be cured	Macmillan	AM Bagnall, L Ashley, P Hall, M Wells, C Hulme, M Bennett, I Lawrie	Successful at outline
Understanding and characterising supported self-management in the context of cancer which cannot be cured	Macmillan	L Calman, Co- applicant: C Foster	Pending
Maximising uptake of FIT-based colorectal cancer screening in Ireland: Developing an intervention prototype	National Screening Service Ireland	Clarke Co-applicant: L Sharp	Successful
How is cancer care best provided to patients in English prisons? Assessing the disease burden in the prison population, experiences of diagnosis and support, and of receiving and providing cancer care	NIHR HS&DR	E Davies, Co-applicants: R Taylor, J Armes	Pending
Trial of Optimal Personalised Care After Treatment – Gynaecological Cancer (TOPCAT-G)	NIHR HS&DR	Val Morrison, Co-applicant: K Beaver	Pending
A systematic review and economic evaluation of the effectiveness of alternative strategies to hospital based follow-up after treatment for cancer	NIHR HTA	K Beaver	Pending
Upper GI cancer patients' experiences of diagnosis and treatment pathways: informing review of cancer services across the North East and North Cumbria	North East and Cumbria Specialised Commissioni ng Hub, NHS England	Sowden Co-applicant: L Sharp	Successful
Assessing the acceptability and feasibility of a self-management support intervention for cancer patients due to start chemotherapy: A mixed methods feasibility study	Pan London Cancer Vanguard	H Plant, Co-applicant: J Armes	Pending
The young adult cancer patient journey	Pan London	W van der Graaf,	Pending

	Cancer Vanguard	Co-applicant: R Taylor	
Self-management in the context of advanced lung cancer *Collaboration with Lung CSG*	Roy Castle Lung Cancer Foundation	L Calman Co-applicants: C Foster & S Popat	Pending
Development of a sarcoma-specific patient-reported outcome measure *Collaboration with Sarcoma CSG and TYA & GCT CSG*	Sarcoma UK	R Taylor, Co-applicants: M Wells, J Whelan, L Bennister, L Storey, C Gerrand, L Fern, R Windsor, J Woodford	Successful
Exploring socio-demographic inequalities in the diagnosis of sarcoma, with a particular focus on deprivation	Sarcoma UK	Co-applicants: L Sharp, McNally	
Online information and support needs for young people with cancer *Collaboration with TYA & GCT CSG*	Teenage Cancer Trust	R Taylor, L Fern	Successful
There is a Light: BRIGHTLIGHT collaboration between and the CONTACT Youth Company *Collaboration with TYA & GCT CSG*	Wellcome Trust	B Lobel, Co-applicants: R Taylor, L Fern	Successful

8. Collaborative partnership studies with industry

The POS CSG does not have any collaborative partnerships with industry.

9. Impact of CSG activities

Portfolio research on cancer survivorship has made a significant impact on practice and policy. This research has inspired action to reorganise cancer services through the National Cancer Survivorship Initiative (NCSI). Increased awareness of the unmet needs of cancer survivors resulting from studies in secondary and primary care (Armes et al 2007; Harrison 2011) supported major health policy changes in the UK and informed the NCSI 2010 Vision and Department of Health's Improving Outcomes: A Strategy for Cancer (2011). Furthermore, evidence on the experiences of women living with metastatic breast cancer was widely cited by media and policymakers, for example the NCSI report published in March 2013. This research, funded by Breast Cancer Now, drew attention to this neglected group and, for the first time, illustrated how the disease unfolds from first diagnosis to death. This research also received attention in Parliament when Baroness Morgan referenced the study in the House of Lords in November 2011 during discussion of the Health and Social Care Bill, and was widely publicised in the media including the Daily Mail (circulation 1.8 million). Most importantly, this has led to the development of a movement in support of the 36,000 women living with secondary breast cancer in the UK.

10. Consumer involvement

Consumer input continues to be welcomed from the Group and it was clear from the outset that the different skillsets from our careers, in addition to our perspective as patients, help us lend an alternative approach or viewpoint in discussions. We continue to be valued as equal contributors and are integrated in the Group's work. The Group respect and welcome our contributions as co-

researchers and collaborators and the experience we bring as a result of our involvement in work across the UK, our earlier careers and our genuine interest in supporting all aspects of the work of the Group. We have played a full and active part into the future strategy of the CSG, attending planning days and providing feedback on the proposed direction of research.

Elsbeth Banks

I have served as a consumer member of the POS CSG since 2013, act as patient advisor on the Lifestyle and Behaviour Change Subgroup and a member of the NCRI Consumer Forum.

My scientific mentor on the CSG also chaired my subgroup which was an important means through which to develop and strengthen experience and input. This support offered by mentors and other colleagues has ensured that my contributions are both meaningful and effective. Positive working relationships have led to involvement in many activities both within and outwith NCRI, including co-chairing a session at NCRI Conference, regular requests to offer guidance on PPI involvement and invitations to be co-applicant/steering group/trial management group member across a broad range of clinical and academic trials. These include ACTwell, Effect, Macmillan HORIZONS, FoR, PROACT, APP-AFTER, Scotroc, Stratify and Systems 2.

The depth of my interest in the specific work of the CSG has led to the organisation and delivery of a two day event on the theme of Survivorship. While being invited by ICPV, (Independent Cancer Patients' Voice), to manage this, many of those who will attend are members of both the charity and NCRI groups. This participation will impact on knowledge, skills and understanding of current thinking and practice across the range of issues linked to aspects of LWBC. An excellent example of collaboration is that the majority of the speakers are themselves NCRI CSG and subgroup members.

Some of my other involvement that enhances, supports and results from my CSG work includes:

- Consumer member of clinical trials committees at the Beatson WOSCC (Clinical Trials Executive Committee), In-house Trials Advisory Board and sole independent member of Umbrella Trials Steering Committee.
- Trustee and active member of Independent Cancer Patients' Voice.
- Member of the ECMC PPI Strategy Group.
- Invited regularly to review and offer comment on documents such as study protocols, study proposals, funding applications and patient information for both clinical trials and intervention studies.
- Providing PPI input in a Scottish Cancer Innovation Challenge in PROMS/PREMS.
- Delivering PPI input on PROMs and PREMs as part of a Cross-Innovation Cancer Challenge in Scotland.
- Providing the patient/stakeholder component in a Research Impact MOOC at the University of Glasgow.

Carolyn Morris

I have been a consumer member of the POS CSG since 2012, act as patient advisor on its Interventions Subgroup and on the Breast CSG's Symptom Management Subgroup. I am also a member of NCRI Consumer Forum. My membership of the CSG comes to an end in June 2017.

I am closely involved with Galina Velikova's team at Leeds and with Irene Higginson and Gao Wei at Cicely Saunders Institute, Kings College London. I continue to play a key role in portfolio studies such as eRAPID, (with regular meetings of systemic therapies and radiotherapy work

streams), and GUIDE Care. A number of studies under this umbrella focus on variations in place of death. I am a co-applicant on recent grants in fear of recurrence, recording patient consultations and health-related quality of life in metastatic breast cancer.

Work I have led on patient responses to questions about research in England's National Cancer Experience Survey continues, with poster and oral presentations on variations in access at the NCRI Conference, NCRAS Conference and other conferences. I am a founding member and Trustee of Independent Cancer Patients' Voice. Much of this work complements my NCRI roles such as commenting on studies at outline and application stages and promoting the advocacy cause. My local involvements in Sussex are now rather low key as I have been stepping down from Clinical Senate and Partnership group activities. I remain in touch with patient and carer issues, not least through my own continuing treatment.

11. Open meetings/annual trials days/strategy days

The POS CSG held a successful Strategy Day in January 2017 and the revised strategy is available in Appendix 2.

The Group hosted two symposia at the NCRI Conference 2016 in Liverpool:

- 1) Delivering patient-centred cancer care: meeting the psychosocial needs of people living with and beyond cancer (Chair: Professor Nick Hulbert-Williams). Speakers included Professor Alex Mitchell, Professor Afaf Girgis and Dr Gozde Ozakinci.
- 2) The changing face of cancer follow-up: supported self-management (Co-chairs: Professor Claire Foster and Mrs Elspeth Banks). Speakers included Professors Dame Jessica Corner, Penny Schofield and Irma Verdonck.

Feedback indicated that there was a really good selection of speakers, highlighting issues of real concern to patients as highlighted by the following quote:

"Don't talk yourselves down. Most carers and probably most patients could tell you everything you have said today BUT we have neither the voice nor the authority to express it. By doing these studies, publishing the results and talking about them you are taking a huge burden from our shoulders. This changes our lives. You are astonishing people" (NCRI Conference patient participant).

The POS CSG also hosted a symposium at the BPOS Annual Conference 2017 in Oxford to raise the profile of its work and to showcase the research on the POS portfolio. Speakers included Professor Myra Hunter, Professor Mary Wells, Mr Richard Stephens, Dr Derek Kyte and Dr Abi Fisher. The feedback showed the session was well received with 85% rating it as excellent or very good as illustrated by the following quote: *"Really superb examples of the work being done"*. As a consequence, we have been invited to host a session at the 2018 BPOS Conference.

POS CSG members also participated in an International EONS/IPOS joint symposium at the IPOS conference in Dublin in October 2016. The session, entitled 'Psychosocial support in practice: Who cares?', was chaired by Professor Mary Wells and a lively panel discussion included Professor Claire Foster, Professor Nick Hulbert-Williams and Dr Jo Armes.

12. Priorities and challenges for the forthcoming year

Priorities

- Increase the number of large scale national CSG-initiated studies developed.
- Establish closer working relationship with Subspecialty Leads (SSLs) to raise the profile of the CSG and clinical trials units to enhance the quality of research applications.
- Review the allocation of studies to the POS CSG portfolio and develop criteria that can be used by the NIHR Clinical Research Network to make more appropriate allocations in the future.

Challenges

- Allocation of studies to the POS CSG portfolio continues to be extremely challenging and since the initiation of the new contract with the co-ordinating centre, few studies have been added to our portfolio. This has significantly reduced the number of people recruited to our portfolio studies.
- Funding for POS research continues to be limited and very competitive.
- SSLs tend to come from the field of supportive and palliative care and thus are less focussed on promoting the POS CSG portfolio studies. The challenge is to raise the profile of the Group with all SSLs to ensure greater uptake of POS CSG portfolio studies.

13. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

A – Main CSG Strategy

B – Understanding and measuring consequences of cancer and its treatment
Subgroup Strategy

C – Psychosocial Interventions Subgroup Strategy

D – Lifestyle and behavioural change Subgroup Strategy

Appendix 3 - Portfolio Maps

Appendix 4 - Publications in previous year

Appendix 5 - Major international presentations in previous year

Dr Jo Armes (Psychosocial Oncology & Survivorship CSG Chair)

Appendix 1

Membership of the Psychosocial Oncology & Survivorship CSG

Name	Specialism	Location
Professor Linda Sharp	Cancer Epidemiology	Newcastle
Dr Richard Simcock	Clinical Oncology	Brighton
Mrs Elspeth Banks	Consumer	Carlisle
Mrs Carolyn Morris	Consumer	Lewes
Professor Claire Foster	Health Psychology	Southampton
Dr Fiona Kennedy*	Health Psychology	Leeds
Professor Eila Watson	Health Services Research	Oxford
Dr Hilary Plant	Information Specialist/Psychotherapist	London
Dr Jennifer Harrington*	Medical Oncology	Cambridge
Dr Peter Hall	Medical Oncology/Health Economics	Edinburgh
Dr Joanne Reid	Nursing	Belfast
Dr Rachel Taylor	Nursing/Clinical Trials	London
Dr Jo Armes (Chair)	Nursing/Health Services Research	London
Professor Kinta Beaver	Nursing/Health Services Research	Preston
Dr Lynn Calman	Nursing/Health Services Research	Southampton
Professor Mary Wells	Nursing/Health Services Research	Stirling
Dr Abigail Fisher	Physiology/Exercise Science	London
Dr Lesley Storey	Psychology	Belfast
Mr Matthew Nankivell	Statistics	London

* denotes trainee member

Membership of the Subgroups

Lifestyle and Behavioural Change Subgroup		
Name	Specialism	Location
Mrs Elspeth Banks	Consumer	Carlisle
Dr Rebecca Beeken	Psychology	London
Dr Chloe Grimmett	Health Psychology	Southampton
Dr Gill Hubbard	Health Sociology	Inverness
Dr Gozde Ozakinci	Health Psychology	St Andrews
Dr Sarah Slater	Medical Oncology	Glasgow
Professor Robert Thomas	Medical Oncology	Cambridge
Dr Jackie Gracey	Physiotherapy	Ulster
Dr Abigail Fisher (Chair)	Physiology & Exercise Science	London
Dr Anna Campbell	Sport & Exercise Science	Edinburgh

Psychosocial Interventions Subgroup		
Name	Specialism	Location
Dr Richard Simcock	Clinical Oncology	Brighton
Ms Carolyn Morris	Consumer	Lewes
Dr Laura Ashley	Health Psychology	Leeds
Professor Nick Hulbert-Williams	Health Psychology	Chester
Dr Brooke Swash (associate member)	Health Psychology	Chester
Dr Gozde Ozakinci	Health Psychology	St Andrews
Professor Eila Watson	Health Services Research	Oxford
Dr Hilary Plant	Information Specialist/Psychotherapist	London
Dr Jenny Harrington*	Medical Oncology	Cambridge
Dr Peter Hall	Medical Oncology/Health Economics	Leeds
Professor Mary Wells (Chair)	Nursing/Health Services Research	Stirling
Dr Lesley Storey	Psychology	Belfast

Understanding and measuring consequences of cancer and its treatment Subgroup		
Name	Specialism	Location
Vacant	Consumer rep	
Dr Fiona Kennedy*	Health Psychology	Leeds
Dr Diana Greenfield	Nurse/Endocrinology	Sheffield
Dr Anna Gavin	Public Health/Cancer Epidemiology	Belfast
Dr Rachel Taylor	Nursing/Clinical Trials	London
Dr Jo Armes	Nursing/Health Services Research	London
Dr Lynn Calman (Chair)	Nursing/Health Services Research	Southampton
Dr Anne Lanceley	Nursing/Health Services Research	London
Professor Adam Glaser	Paediatric Oncology	Leeds
Dr Derek Kyte	Physiotherapy/Health Services Research	Birmingham
Mr Mike Horton	Psychology/Psychometrics	Leeds

*denotes trainee member

Appendix 2

CSG & Subgroup Strategies

A – Main CSG Strategy

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
1 CSG Structure & function	1. Write clear statement of CSG overall aims & objectives from which research priorities flow and to which the subgroup structure aligns	CSG chair & sub-group chairs to review research strategy annually	Clear remit and operational structure for main CSG and sub-groups CSG Chair & subgroup chairs hold quarterly TC to review progress	Chair & subgroup chairs Chair & sub-group chairs	30/6/17 Ongoing
	2. Ensure the CSG and sub-groups are working towards a shared vision and have clear remit and operational structure	To define objectives and expectations of subgroup members, including trainees	Sub group strategies align with CSG vision/strategy	Chair, subgroup chairs	31/8/17
	3. Redefine focus, membership and leadership of CSG & sub groups to align with revised strategic priorities	Review CSG & sub group membership & identify gaps in expertise. Recruit new members (taking account of geographical location and institutional affiliation)	Venn diagram of CSG & sub-group members (ie expertise, institution & region) Refreshed CSG & sub group membership	Chair, subgroup chairs, Chair, subgroup chairs in discussion with CSG members	June annually with each recruitment round June annually with each recruitment round
	4. Grow future capacity/capability	Allocate trainees a developmental project	Trainees feedback at end of programme	Chair, subgroup chairs & trainee mentors	At each recruitment round and 3 monthly review with mentor
	5. Positive working relationships between consumers and scientific mentors that support the	All consumers are allocated a mentor	Consumers actively engaged in work of CSG including co-applicants on grant application	Chair, subgroup chairs & mentors	At each recruitment round and 3 monthly review with mentor

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
	work of the CSG and its subgroups	CSG Chair to review mentorship arrangements annually to ensure consumers and their scientific mentors are aware of their responsibilities and have mechanisms for regular feedback.	Annual review undertaken with consumer and mentor	Chair	February 2018 and then annually
2a. Portfolio development (general)	1. To develop a programme of studies arising from the revised CSG research priorities	Sub groups to revise research strategy in line with CSG strategy	Submitted grant applications	Chair & sub group chairs	Ongoing
		Revise research strategy following publication of LWBC JLA	Revised strategy	All	After publication of LWBC JLA
	2. To map existing studies to revised strategic priorities, identifying gaps in portfolio which need to be addressed with new studies	To review & update portfolio maps, identifying studies on site-specific portfolios that should be co-badged.	Comprehensive & accurate portfolio map, with mechanism for updating on a regular basis	Trainees supported by all members of CSG	January 2018
			Clear list of gaps according to revised priorities	All	June 2018
	3. To increase number and range of collaborative studies with site-specific CSGs	Discuss with secretariat Mechanism for identifying potential to bolt on psychosocial questions to other CSG studies at an early stage	Clear mechanism for identifying studies in development in other CSGs	Chair & NCRI Secretariat	31/8/17

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
		Expand links with other CSGs/subgroups, identify members interested in POS	Link people advertised on CSG web page Set of materials illustrating work of POS to raise awareness & establish meaningful links with other stakeholders & groups	Nominated CSG member Nominated CSG members	30/9/17 31/12/17
	4. Promote recruitment to POS studies across the cancer networks to enhance equity of access to research studies	Review portfolio and identify gaps (e.g. tumour type, geographical, interventional studies) Review uptake of POS studies with SSLs	Annual plan developed to fill gaps Studies developed to meet gaps in access to research	Sub group chairs All	January 2018 Ongoing
	5. To monitor the NCRI portfolio to identify future gaps and trial concepts for discussion	Annual review of portfolio by CSG and subgroups	Studies developed to fill gaps	CSG	January 2018 and then annually
	6. Greater engagement with influencing funder's research priorities e.g. MCS, NIHR	Initiate discussions following publication of JLA for LWABC	Agree with NCRI mechanism for highlighting priorities to key funders	Chair	After publication of LWBC JLA
	7. To identify alternative funding streams	Review pharma industry funding streams Establish links with industry through ABPI	List of POS relevant funding streams & applications submitted	Nominated CSG members Chair	January 2018 31/8/17

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
	8. Identify scope and opportunities or including biomedical aspects to POS studies and vice versa	To design and deliver studies to embracing the concept of personalised psychosocial support – targeted to need	Links made with researchers in biomedical science who could work with POS	All	Ongoing
2b. Portfolio development (Subgroups specific)	1. Increase cross CSG & sub groups collaboration (less silo working)	Revise CSG meeting to facilitate greater cross group working	Revised meeting format	JA	June 2017
	2. Identify studies which cross-cut sub-groups	Encourage CSG & sub group members to participate in other CSG meetings as non-core members (travel not paid) – either in person or via telco/skype	Greater use of members skills according to need in grant applications	All	31/8/17
		Sub group chairs to distribute meeting agenda 6 weeks in advance to CSG and subgroup members	Distribution of agenda 6 weeks in advance to CSG and subgroup members	Sub group chairs	Ongoing
2c. Portfolio development (Crosscutting)	1. Identify leads within the CSG to link cross cutting CSGs and advisory groups	To identify link people for each cross-cutting CSG and advisory group from POS CSG and/or subgroups	Named links to CSGs (& survivorship subgroups) with clear terms of engagement	Chair	30/6/17
		To ensure POS members are aware of communications/progress	Regular agenda item for POS meetings and teleconferences	Chair	June 2017

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
		with cross-cutting CSGs and advisory groups			
2d. Portfolio development (Other CSGs)	1. Continue to promote work of POS CSG to other CSGs	To ensure there is good mutual understanding of POS research ambitions by other groups and continued consideration of POS CSG involvement in studies currently being planned	Write to CSGs to inform them of our new strategic priorities and what we have to offer, using newly developed POS materials to remind CSGs of our expertise	Chair	31/8/17
	2. To increase number and range of collaborative studies with site-specific CSGs	Explore opportunities to include bolt on studies to clinical trials in development	Bolt on studies added to clinical trials	All	Ongoing
	3. Explore opportunities to conduct secondary analysis on RCT or routine PROMS data	Discuss with secretariat and CTU leads process for identifying studies in development	Process for identifying studies in development	Chair & NCRI Secretariat	31/8/17
		Identify RCTs and other sources of secondary data that could inform POS strategic priorities	List of potential resources	MN	31/12/17
		Link with NHS Digital & NCRAS	Named person	MN	31/8/17
	4. Strengthen links with CTUs with expertise in POS research	Discuss with CTU leads	List of CTUs with which to work on trial development	Chair	September 2017
				MN	31/12/17

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
		Contact all CTUs			
3 Ensuring successful delivery of studies through integration with NIHR CRN:	1. To establish regular contact with CRN subspecialty leads	Develop clear mechanisms for POS researchers to make all appropriate links and contacts with SSLs & RDMs	Flowchart to guide steps in linking with CRNs, CTUs etc Materials available illustrating work of POS for distribution to relevant SSLs, RDMs	Nominated CSG members Nominated CSG members	30/11/17 30/11/17
	2. Ensure equity of access to POS research portfolio	Work with subspecialty leads		All	Ongoing
	3. To work with NIHR CC to ensure POS studies appropriately allocated to POS portfolio	Trainees to develop criteria for allocation	Clear criteria & mechanism for NIHR CC to allocate POS studies to CSG portfolio	Chair, subgroup chairs	31/1/18
	4. Develop timely mechanism for acting on studies that are experiencing problems with recruitment		All POS CSG members to send new strategy to their SSL by way of introduction	Nominated CSG members	31/1/18
	5. To strengthen links with devolved nations CRNs to ensure equity of access to research studies	Arrange meetings with devolved nations CRNs and ensure examples of current needs and challenges are shared	Clear mechanism developed Closer working relationships	Nominated CSG members	30/6/18
4. Strengthen UK and international working	1. Identify & establish links with national experts	To identify senior individuals and groups	Ongoing list of experts/potential	All	Ongoing

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
	<p>with key expertise lacking in the CSG</p> <p>2. To identify key links to national & international research organisations eg Macmillan, BPOS, EORTC, IPOS, ISOQOL, ESMO, ECCO, EONS</p>	<p>working in POS research who are not currently linked to the CSG</p> <p>To identify terms of reference and engagement with other research organisations (what do we need from them, what is the link for?)</p>	<p>collaborators to be held by NCRI Secretariat</p> <p>Ongoing list to be held by NCRI Secretariat</p>	All	Ongoing
5. Patient and Public Involvement	<p>1. Ensure PPI input is an area of strength in research activity and in funding applications.</p> <p>2. Consumers to be involved in research priority setting</p> <p>3. To articulate key benefits and contributions of PPI more clearly</p> <p>4. To identify training and support needs of PPI members</p>	<p>Ensure each subgroup has PPI representation, recruiting and replacing new members as needed</p> <p>Liaise with consumer forum when appropriate</p> <p>Identify examples from PPI reports that can be used in POS materials to illustrate PPI contribution</p> <p>Allocate scientific mentor in accordance with NCRI Guidelines</p>	<p>Research activity and funding applications have strong PPI input which is clearly defined in terms of timing of involvement and nature of involvement e.g. co-researcher, co-applicant, collaborator .</p> <p>Clearer articulation of consumer involvement in CSG annual report</p> <p>Consumer Representatives have a named mentor</p>	<p>All</p> <p>Consumer Representatives</p> <p>Consumer Representatives</p> <p>Chair & sub group chairs</p>	<p>Ongoing</p> <p>Ongoing</p> <p>June 2017</p> <p>Ongoing – reviewed annually in January</p>

CSG Principles	Strategic objective	Actions	Outcome Measures	CSG Lead	Dates
				Consumers & JA	
6. Raising awareness	1. To improve dissemination of studies	Ask NCRI to help us develop mechanism for highlighting when POS studies are published/cited so we can maintain up to date database of dissemination and impact	Process/mechanism for identifying publications in place	Chair & NCRI Secretariat	31/12/17
		Develop eNewsletter for dissemination to other CSGs SSLs, RDMs, POS researchers – to include new POS studies in set up, summary of results	eNewsletter distributed to other CSG's biannually	Nominated CSG member	31/7/17 then biannually in February and July
	2. Ensure POS research continues to be represented on NCRI conference programme	Plan, in advance, topics and speakers	Minimum of 1 CSG-led session at NCRI Conference 2018	Nominated CSG member (topic dependant)	By 31/7/17
		Liaise with NCRI events team to create mechanism for influencing NCRI planning committee	Mechanism in place	Nominated CSG member	31/7/17

BPOS = British Psychosocial Oncology Society NIHR CC = NIHR Co-ordinating Centre CLG = Consumer Liaison Group JLA = James Lind Alliance LWBC = Living with and beyond cancer
 NCRAS = National Cancer Registration Service NIHR = National Institute for Health Research MCS = Macmillan Cancer Support
 RDM = Research Development Managers SSL = Sub-Speciality Lead

B – Understanding and measuring consequences of cancer and its treatment

Aims

- Ensure high quality patient-centred outcome data is available to help patients LWBC make more informed decisions around their care and support.
- Inform health and care strategy through generation of robust patient-centred evidence.
- Influence research strategy and funding priorities to focus on patient-centred outcomes.

Objectives

- Promote the measurement of research outcomes that matter to people LWBC (patients and their support networks).
- Enhance understanding of the consequences of cancer treatment:
 - Providing information for current/future patients and their clinicians.
 - Informing patient choice and supporting shared decision-making.
 - Advising at a provider and population level to inform service development and policy change.
 - Advising the research community and industry to inform the development of novel interventions.
- Enhance understanding of how outcomes differ and what contributes to variation in patient-centered outcomes
 - Develop evidence for psychosocial risk stratification.

C – Psychosocial Interventions Subgroup Strategy

Our key strategic aim is to improve experiences of care, treatment and support in people affected by cancer by developing and facilitating intervention-based research.

Our key objective is to develop and test targeted psychosocial interventions to improve patient-centred outcomes.

This year we plan to strengthen links with other CSGs, particularly where psychosocial intervention research is less well established, e.g. Sarcoma. We also plan to focus on key policy and funder priorities, exploiting the expertise we have in primary care and economic evaluation, and to continue our work on Fears of Cancer Recurrence, with further submissions to funders on this topic.

D – Lifestyle and behavioural change Subgroup Strategy

The key strategic aims of this Subgroup are to develop and run conduct studies (trials, cohorts or qualitative studies), to explore the role of lifestyle behaviours (physical activity, diet, smoking, alcohol, sun safety) after cancer diagnosis and conduct studies that explore how to embed appropriate health behaviour advice into the cancer care pathway.

Aims

- Submit CRUK programme grant renewal (June 2017) which includes two members, A Fisher and R Beeken, with other Subgroup members on the steering committee (G Hubbard, C Grimmett).
- Draft and submit manuscript(s) from EFFECT (physical activity for breast cancer) Phases I and II and submit a proposal for a large efficacy trial building on EFFECT 1 and 2.
- Begin recruitment for the stoma study from September 2017.
- Submit a Subgroup WCRF proposal to establish a UK lifestyle and clinical outcome cohort of breast, prostate and colorectal cancer patients.

Appendix 3

Portfolio maps

NCRI portfolio maps							
Psychosocial Oncology and Survivorship							
Map A – All cancers, bladder, brain, breast, Children's cancer and leukaemia, colorectal							
Click ↓ below to reset map							
		All cancers	Bladder	Brain	Breast	Children's cancer and leukaemia	Colorectal
Instrument development	All						
		EORTC QL Cut/Of					
		eRAPID RCT in s					
		Generic EORTC Q					
					eSMART: Randomi	eSMART: Randomi	
Living with cancer	All						
		EORTC CAT Full Validation					
		Rehabilitation: Perceptions and					
Other	All						
		ACTION					
		CanACT					
		Fertility preservation					
Symptoms and side effects	All						
		PROACT					
		HORIZONS					
					FAST/Forward		
					HORIZONS		
Transition from active therapy	All						
		monitoring development &					

Filters Used:

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

■ Open Multi CSG
■ Open Single CSG Null

NCRI portfolio maps

Psychosocial Oncology and Survivorship

Map B – Gynaecological, haematology oncology, head and neck, lung, lymphoma, skin cancer

Click ↓ below to reset map

		Gynaecological	Haematology oncology	Head and neck	Lung	Lymphoma	Skin cancer
Instrument development	All						eSMART: Randomi
Living with cancer	All						
Other	All						
Symptoms and side effects	All	HORIZONS				HORIZONS	
Transition from active therapy	All	OvPSYCH 2					

Filters Used:

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

Open Multi CSG

Open Single CSG Null

NCRI portfolio maps

Psychosocial Oncology and Survivorship

Map C – Prostate, renal, sarcoma, teenage and young adult, testicular, upper gastro-intestinal

Click ↓ below to reset map

		Prostate	Renal	Sarcoma	Teenage and young adults	Testicular	Upper gastro-intestinal
Instrument development	All						
Living with cancer	All						
Other	All						ROCS
Symptoms and side effects	All						
Transition from active therapy	All						

Filters Used:

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

■ Open Multi CSG Null

Appendix 4

Publications in the reporting year

Study	Reference
ACTION	Rietjens, J, Dunleavy, LJ, Preston, NJ & Payne, SA 2016, 'Advance care planning – a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study' BMC Cancer, vol 16, 264. DOI: 10.1186/s12885-016-2298-x
ALLINEX	Horne B, Newsham A, Velikova G, Liebersbach S, Gilleece M, Wright P. Development and evaluation of a specifically designed website for haematopoietic stem cell transplant patients in Leeds. European Journal of Cancer Care. 2016;25(3):402-18
BRIGHTLIGHT	Taylor RM, Solanki A, Aslam N, Whelan JS, Fern LA. (2016) A participatory study of teenagers and young adults' views on access and participation in cancer research. European Journal of Oncology Nursing 20(1):156-164 doi.org/10.1016/j.ejon.2015.07.007
	Taylor RM, Fern LA, Aslam N, Whelan JS. (2016) Direct access to potential research participants for a cohort study using a confidentiality waiver included in UK National Health Service legal statutes. BMJ Open 6:e011847 doi:10.1136/bmjopen-2016-011847
	Vindrola-Padros C, Taylor RM, Lea S, Hooker L, Pearce S, Whelan J, Gibson F. (2016) How do young people, their families and staff describe specialized cancer care in England? Cancer Nursing 39(5): 358-366
	Taylor RM, Feltbower RG, Aslam N, Raine R, Whelan JS, Gibson F. (2016) A modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer. BMJ Open 6:e011361. doi:10.1136/bmjopen-2016-011361
	Walker E, Martins A, Aldiss S, Gibson F, Taylor RM. (2016) Psychosocial interventions for adolescents and young adults diagnosed with cancer during adolescence: a critical review. Journal of Adolescent and Young Adult Oncology 5(4): 310-321
Computerised adaptive testing for EORTC QLQ-C30	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). Health and Quality of Life Outcomes 2016, 14:72
CRIB	Hubbard G, O'Carroll R, Munro J, Mutrie N, Haw S, Mason H, Treweek S, The feasibility and acceptability of trial procedures for a pragmatic randomized controlled trial of a structured physical activity intervention for people diagnosed with

	colorectal cancer: Findings from a pilot trial of cardiac rehabilitation vs. usual care (no rehabilitation) with an embedded qualitative study, BMC Pilot and Feasibility Studies, 2016, 2:51
Creation of symptom based questionnaires	Sodergren, S. C., Copson, E., White, A., Efficace, F., Sprangers, M., Fitzsimmons, D. Johnson, C. D. (2016). Systematic Review of the Side Effects Associated With Anti-HER2-Targeted Therapies Used in the Treatment of Breast Cancer, on Behalf of the EORTC Quality of Life Group. Target Oncol, 11(3), 277-292. doi:10.1007/s11523-015-0409-2
CREW cohort study:	Foster, C., Haviland, J., Winter, J., Chivers-Seymour, K., Batehup, L., Calman, L., Corner, J.L., Din, A., Fenlon, D.R., May, C., Richardson, A., Smith, P. (2016) Pre-surgery depression and confidence to manage problems predict recovery trajectories of health and wellbeing in the first two years following colorectal cancer: results from the CREW cohort study. PLOS ONE, 11(5):e0155434. DOI: 10.1371/journal.pone.0155434
Development of a HRQOL questionnaire for cancer patients with cachexia	Wheelwright, S. J., Hopkinson, J. B., Darlington, A. S., Fitzsimmons, D. F., Fayers, P., Balstad, T. R., Johnson, C. D. (2017). Development of the EORTC QLQ-CAX24, A Questionnaire for Cancer Patients With Cachexia. J Pain Symptom Manage, 53(2), 232-242. doi:10.1016/j.jpainsymman.2016.09.010
Development of an EORTC disease or domain specific quality of life questionnaire (Phases I/II & III)	Brédart A, Beaudeau A, Young T, Moura De Albuquerque Melo H, Arraras JI, Friend L, Schmidt H, Tomaszewski KA, Bergenmar M, Anota A et al: The European organization for research and treatment of cancer — satisfaction with cancer care questionnaire: revision and extended application development. Psycho-Oncology 2016: 26(3): 400-404
	T, Kuljanic K, Tomaszewska IM et al: EORTC QLQ-COMU26: a questionnaire for the assessment of communication between patients and professionals. Phase III of the module development in ten countries. Supportive Care in Cancer 2016: doi: 10.1007/s00520-016-3536-0.
	Juan Ignacio Arraras, PhD; Lisa M. Wintner; Monika Sztankay; Krzysztof Tomaszewski; Dirk Hofmeister; Anna Costantini; Anne Bredart; Teresa Young; Karin Kuljanic; Iwona M. Tomaszewska; Meropi Kontogianni; Wei-Chu Chie; Dagmara Kullis; Eva Greimel. EORTC QLQ-COMU26: A questionnaire for the assessment of communication between patients and professionals. Phase III of the module development in ten countries. Support Care Cancer (2016).
ENDCAT	Beaver K, Williamson S, Sutton C, Hollingworth W, Gardner A, Allton B, Abdel-Aty M, Blackwood K, Burns S, Curwen D, Ghani R, Keating P, Murray S, Tomlinson A, Walker B, Willett M, Wood N, Martin-Hirsch P (2017).

	Comparing hospital and telephone follow-up for patients treated for Stage I endometrial cancer (ENDCAT Trial): a randomised, multicentre, non-inferiority trial. BJOG: An International Journal of Obstetrics and Gynaecology. Vol. 124 (1), pp. 150-160
Development of cut-off scores for symptom screening with the EORTC quality of life scales and evaluation of graphical presentation styles for quality of life results including these cut-offs	Giesinger JM, Kuijpers W, Young T, Tomaszewski KA, Friend E, Zabernigg A, Holzner B, Aaronson NK: Thresholds for clinical importance for four key domains of the EORTC QLQ-C30: physical functioning, emotional functioning, fatigue and pain. Health and Quality of Life Outcomes 2016, 14(1):1-8
EORTC SWB36 Validation Phase 4	Bella Vivat, Teresa Young, Julie Winstanley, Juan Arraras, Kath Black, Anne Brédart, Anna Costantini, Guo Jingbo, M. Elisa Irarrazaval, Kunihiro Kobayashi, Renske Kruizinga, Mariana Navarro, Sepideh Omidvari, Gudrun Elin Rohde, Samantha Serpentine, Nigel Spry, Hanneke van Laarhoven, Grace Yang. On behalf of the EORTC Quality of Life Group: The international phase 4 validation study of the EORTC QLQ-SWB32: a stand-alone measure of spiritual wellbeing (SWB) for people receiving palliative care for cancer. European Journal of Cancer Care (In press)
EORTC QL Questionnaire development phases I/II Thyroid	Singer S, Jordan S, Locati LD, Pinto M, Tomaszewska IM, Araújo C, Hammerlid E, Vidhubala E, Husson O, Kiyota N et al: The EORTC module for quality of life in patients with thyroid cancer: phase III. Endocrine-Related Cancer 2017, 24(4):197-207
	Tomaszewska IM, Araújo C, Hammerlid E, Vidhubala E, Husson O, Kiyota N et al: The EORTC module for quality of life in patients with thyroid cancer: phase III. Endocrine-Related Cancer 2017, 24(4):197-207.
EORTC QLQ-COMU26	Juan Ignacio Arraras, PhD; Lisa M. Wintner; Monika Sztankay; Krzysztof Tomaszewski; Dirk Hofmeister; Anna Costantini; Anne Bredart; Teresa Young; Karin Kuljanic; Iwona M. Tomaszewska; Meropi Kontogianni; Wei-Chu Chie; Dagmara Kullis; Eva Greimel. EORTC QLQ-COMU26: A questionnaire for the assessment of communication between patients and professionals. Phase III of the module development in ten countries. Support Care Cancer (2016).
EPiC	Ahmed K, Kyte D, Keeley T, Efficace F, Armes J, Brown JM, Calman L, Copland C, Gavin A, Glaser A, Greenfield DM, Lanceley A, Taylor R, Velikova G, Brundage M, Mercieca-Bebber R, King MT, Calvert M. (2016) Systematic evaluation of patient-reported outcome (PRO) protocol content and reporting in UK cancer clinical trials: the EPiC study protocol. BMJ Open 6:9 e012863 doi:10.1136/bmjopen-2016-012863

ePOCS feasibility study	Ashley L, Velikova G, Downing A, Morris E, Wright P. Health-related quality of life in cancer survivorship: predictive power of the Social Difficulties Inventory Psychooncology. Early view. Accepted for publication 4 January 2017. DOI: 10.1002/pon.4368
	Marti J, Hall PS, Hamilton P, Hulme CT, Jones H, Velikova G, Wright P. The economic burden of cancer in the UK: a study of survivors treated with curative intent. Psycho-Oncology. 2016;25(1):77-83.
	Hellstadius Y, Lagergren J, Zylstra J, Gossage J, Davies A, Hultman CM, Lagergren P, Wikman A. HRQL after Surgery for Upper Gastrointestinal Tumours: Prevalence and predictors of anxiety and depression among esophageal cancer patients prior to surgery. Dis Esophagus. 2016 Nov;29(8):1128-1134
eRAPID	Warrington L Holch P, Kenyon L, Hector C, Kozłowska K, Kenny AM, Ziegler L, Velikova G 2016 Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer (V: 24, #: 12, Pg: 5041-5048)
eSMART	Maguire, R., Fox, P.A., McCann, L., Miaskowski, C., Kotronoulas, G., Miller, M., Furlong, M., Ream, E., Armes, J., Patiraki, E., Gaiger, A., Berg, G.V., Flowerday, A., Donnan, P., McCrone, P., Apostolidis, K., Harris, J., Katsaragakis, S., Buick, A., & Kearney, N. The eSMART Study Protocol: A Randomised Controlled Trial to Evaluate Electronic Symptom Management Using the Advanced Symptom Management System (ASyMS) Remote Technology for Patients with Cancer. BMJ Open
	Fox, P., Darley, A., Furlong, E., Miaskowski, C., Patiraki, E., Armes, J., Ream, E., Papadopoulou, C., McCann, L., Kearney, N., Maguire, N. The assessment and management of chemotherapy-related toxicities in patients with breast cancer, colorectal cancer, and Hodgkin and non-Hodgkin lymphomas: a scoping review. European Journal of Oncology Nursing. doi: 10.1016/j.ejon.2016.12.008
	Miaskowski, C., Cooper, B.A., Aouizerat, B., Melisko, M., Chen, L.-M., Dunn, L., Hu, X., Kober, K.M., Mastick, J., Levine, J.D., Hammer, M., Wright, F., Harris, J., Armes, J., Furlong, E., Fox, P., Ream, E., Maguire, R., & Kearney, N. 2016 The symptom phenotype of oncology outpatients remains relatively stable from prior to through 1 week following chemotherapy. European Journal of Cancer Care doi:10.1111/ecc.12437
Lung Cancer Distress	Ellis J, Warden J, Molassiotis A, Mackereth P, Lloyd-Williams M, Bailey C, Burns K, Yorke J. Participation in a randomised controlled feasibility study of a complex intervention for the management of the Respiratory Symptom Distress Cluster in lung cancer: patient, carer and research staff views. Eur J Cancer Care (Engl). 2016 Jul 8. doi: 10.1111/ecc.12538.

	Tan JY, Yorke J, Harle A, Smith J, Blackhall F, Pilling M, Molassiotis A. Assessment of Breathlessness in Lung Cancer: Psychometric Properties of the Dyspnea-12 Questionnaire. J Pain Symptom Manage. 2017 Feb;53 (2):208-215.
Maintaining psychosocial wellbeing in advanced illness: what can we learn from patient's and carers' own coping strategies?	Walshe, C., Roberts, D., Appleton, L., Large, P., Calman, L., Lloyd-Williams, M., Grande, G. 2017 Coping Well with Advanced Cancer: A Longitudinal Qualitative Interview Study with Patients and Family Carers. PLOS ONE http://dx.doi.org/10.1371/journal.pone.0169071
Lifestyle in Multiple Myeloma	Smith, L., McCourt, O., Heinrich, M., Paton, B., Yong, K., Wardle, J., & Fisher, A. (2015). Multiple myeloma and physical activity: a scoping review. BMJ Open. doi:10.1136/bmjopen-2015-009576
	Heinrich, M., Fisher, A., Paton, B., McCourt, O., Beeken, R. J., Hackshaw, A, Yong, K. (2016). Lifestyle in Multiple Myeloma - a longitudinal cohort study protocol. BMC Cancer, 16, ARTN 387. doi:10.1186/s12885-016-2407
PROACT	S Catt, R Starkings, V Shilling, L Fallowfield. Patient-reported outcome measures of the impact of cancer on patients' everyday lives: a systematic review. Journal of Cancer Survivorship. Published online first 10 Nov 16. doi:10.1007/s11764-016-0580-1
	Shilling V, Matthews L, Jenkins J, Fallowfield L. Patient-reported outcome measures for cancer caregivers: a systematic review. 2016, 25(8):1859-1876
PROWESS	Tompkins, C., Scanlon, K., Scott, E. Ream E, Harding, S & Armes, J. 2016 Survivorship care and support following treatment for breast cancer: a multi-ethnic comparative qualitative study of women's experiences. BMC Health Services Research. 16(1) pp. 401., doi:10.1186/s12913-016-1625-x
SIPS	Wells, M. and King, E. (2017) Patient Adherence to Swallowing Exercises in Head and Neck Cancer. Current Opinion in Otolaryngology & Head & Neck Surgery (e-Pub Ahead of Print) Doi: 10.1097/M00.0000000000000356. https://www.ncbi.nlm.nih.gov/pubmed/28266944
Smoking Cessation	Wells M, Aitchison, Harris F, Ozakinci G, Radley A, Bauld L, Entwistle V, Munro A, Haw S, Culbard B & Williams B. Cancer Diagnosis as an opportunity for smoking cessation study https://bmccancer.biomedcentral.com/articles/10.1186/s12885-017-3344-z
When Cure is Not Likely	Ngwenya N, Kenton C, Taylor R, Whelan J. (in press) Experiences and preferences for end of life care for young adults with cancer and their informal carers: a narrative synthesis. Journal of Adolescent and Young Adult Oncology
YoDA BRCA	Grimmett, C., Brooks, C., Recio-Saucedo, A., Cutress, R., Copson, E., Evans, G., Gerty, S., Armstrong, A., Turner, L.,

	<p>Mason, S., Ahmed, M., Eccles, B., Eccles, D. & Foster, C. 2016. YoDA BRCA: views and experiences around genetic testing for young women with breast cancer: developing a decision aid. <i>Psycho-Oncology</i>, 25, 10-11.</p>
--	--

Appendix 5

Major international presentations in the reporting year

Study	Conference details
BRIGHTLIGHT: Do specialist cancer services for TYA add value?	Anazodo A, Fern L, Gupta S, Taylor R, White V, Smith A. What can we learn from cross country comparisons of cancer care for adolescents and young adults (AYAs) to improve cancer outcomes? Symposium presentation UICC World Cancer Congress, 4th November 2016, Paris France
	Lea S, Taylor R, Martins A, Fern L, Whelan J, Gibson F. 'It was like having a big sleepover with our chemo bags on': exploring the relationship between physical and social hospital environments. 1st Global AYA Cancer Congress 5th – 7th December 2016
	Taylor R, The BRIGHTLIGHT STUDY; Using patient reports and treatment data to evaluate the effectiveness of AYA services in the UK. UICC World Cancer Congress, 4th November 2016, Paris France
When Cure is Not Likely	Ngwenya N, Kenten C, Jones L, Gibson F, Pearce S, Stirling C, Taylor R, Whelan J. "Hospice Scares the Life Out of Me": Breaking Down Barriers to Communication with Young Adults with Terminal Cancer (oral presentation) 21st International Congress on Palliative Care, 18th – 21st October 2016, Montreal Canada
CREW	Foster C, et al. Implementing a New Programme of Follow Up after Treatment for Colorectal Cancer in the UK and The First Two Years after Colorectal Cancer Treatment: UK Colorectal Wellbeing (CREW) Cohort Study. International Conference on Cancer Nursing 4-7 September 2016. Hong Kong
Lung study	Calman L., et al. Investigating the feasibility of establishing a prospective cohort of lung cancer patients following radiotherapy with curative intent. World Conference on Lung Cancer 2016 Vienna
CanWalk	J Armes et al. CanWalk: A randomised feasibility trial of a walking intervention for people with recurrent or metastatic cancer. 18 th International Psycho Oncology Society Conference, Dublin.
eRAPID	Absolom K eRAPID: Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice A Randomised controlled trial in systemic cancer treatment. 18th International Psycho Oncology Society Congress (IPOS) Conference Dublin.
eSMART	Armes J. eSMART: Patients' and nurses' approach to mobile PROs. EU Parliament (Brussels), May 2016.
ePOCS	Wright P. et al Health-related quality of life in cancer survivorship: predictive power of the Social Difficulties

	Inventory. 18th International Psycho Oncology Society Congress (IPOS) Conference Dublin.
LIFESTYLE IN MULTIPLE MYELOMA	McCourt, O., Heinrich, M., Fisher, A., Paton, B., Beeken, R., Hackshaw, A, Yong, K. (2016). FATIGUE, QUALITY OF LIFE AND PHYSICAL FITNESS IN PATIENTS WITH MYELOMA. Presented at: 21st Congress of the European-Hematology-Association
	McCourt, O., Heinrich, M., Fisher, A., Paton, B., Beeken, R., Hackshaw, A, Yong, K. (2016). Use of an 'adapted Zelen' design in a randomised controlled trial of a physiotherapist-led exercise intervention in patients with myeloma. Presented at: the European Congress of the European Region of the World Confederation of Physical Therapy (ER-WCPT)
CRIB	Hubbard G, et al. Cardiac rehabilitation to increase physical activity among cancer patients: is it feasible and acceptable? International Society of Behavioural Medicine, Melbourne, Australia December 2016
Raising adolescent cancer awareness and cancer communication in families	Hubbard G, et al. International Society of Behavioural Medicine, Melbourne, Australia, December 2016